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ENCYCLOPEDIA OF
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3RD EDITION

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Encyclopedia of Bioethics, 3rd edition

Stephen G. Post
Editor in Chief

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PREFACE

At the time of the first publication of the *Encyclopedia of Bioethics* in 1978, the then fledgling field of bioethics was neither well defined nor widely recognized. Warren Thomas Reich, then Senior Research Scholar in the Kennedy Institute of Ethics at Georgetown University, envisioned a major reference work that would contribute significantly to the establishment of bioethics as a field by integrating historical background, current issues, future implications, ethical theory, and comparative cultural and religious perspectives. Professor Reich became the editor in chief for the first edition, a four-volume set that, as he foresaw, was immediately acknowledged as a landmark reference work defining the field.

The 1978 edition received the American Library Association's 1979 Dartmouth Medal for outstanding reference work of the year, as well as widespread critical acclaim. The eminent bioethicist Daniel Callahan, writing for *Psychology Today* in March of 1979, entitled his stellar review of the *Encyclopedia* "From Abortion to Rejuvenation: A Summa of Medical Ethics." *Choice* declared the work "an outstanding achievement." *Social Science* described the work as "magnificent," and the *Hastings Center Report* acknowledged it as both "an astonishing achievement" and "a major event." Throughout the 1980s, as programs in bioethics and medical humanities proliferated in professional schools, undergraduate and graduate school curricula, "think tanks," and academic societies, the first edition of the *Encyclopedia* was considered the essential reference work in the field, and contributed significantly to intellectual vitality.

While the 1978 first edition will always be essential and fascinating reading for anyone interested in the history of bioethics, it was, by the late 1980s, in need of a revision. A reference work at the interface of biology, technology, healthcare and ethics becomes dated due to the fast pace of biotechnological development, changes in the healthcare delivery system, and the emergence of important new voices in a rapidly expanding field. Although in certain respects the modern bioethics movement began in the United States, it took root in many countries around the world during the 1980s, requiring the inclusion of scholarship from other nations and cultures in order to properly reflect worldwide growth. Professor Reich impressed all those working on the second edition with his remarkable grasp of the history of medical ethics, of the modern bioethics movement, of European thinkers, of religious ethics and moral philosophy, and of salient clinical issues.

The revised edition included various topic areas including: professional–patient relationship; public health; ethical theory; religious ethics; bioethics and the social sciences; healthcare; fertility and human reproduction; biomedical and behavioral research; history of medical ethics; mental health and behavioral issues; sexuality and gender; death and dying; genetics; population; organ and tissue transplantation and artificial organs; welfare and treatment of animals; environment; and codes, oaths, and other directives. All of these topics are retained and enhanced in the third edition.

The five-volume revised edition, which was carefully planned at editorial meetings in the spring and fall of 1990, was supported by both the National Endowment for the Humanities and the National Science Foundation, in addition to several private foundations and individual donors. The Joseph P. Kennedy, Jr. Foundation was a major funder of both the first and the revised editions. Published in 1995 by Macmillan Reference Division, it received the same high level of acclaim as the first edition.

Development of a Third Edition

Yet with the passing of the 1990s, the *Encyclopedia* again required a thorough revision and update. Warren Reich, professor *emeritus* at Georgetown and deeply engaged with a new project on the history of "care," decided not to prepare the third edition. He recommended Stephen Garrard Post—who had served as his associate editor in the preparation of the second edition—for the position of editor in chief of the third edition. Subsequently, Macmillan Reference, after consulting with Georgetown University (which had sponsored the first edition), offered the position of editor in chief to Post.

This invitation was accepted with the understanding that a third edition could only emerge from the already remarkable scope and framework of the revised edition, and would be much indebted to all those responsible for that extraordinary work, including the following area editors: Dan E. Beauchamp, Arthur L. Caplan, Christine K. Cassel, James F. Childress, Allen R. Dyer, John C. Fletcher, Stanley M. Hauerwas, Albert R. Jonsen, Patricia A. King, Loretta M. Kopelman, Ruth B. Purtillo, Holmes Rolston III, Robert M. Veatch, and Donald P. Warwick.

There are more than 110 new article titles in the third edition, and approximately the same number of new articles appearing under old titles. Thus, half of the third edition is entirely new, while half consists of deeply revised and updated articles from the earlier edition. There isn't a single article that was not thoroughly updated, even if only at the level of bibliographies. The least revision was needed in the topic areas of environmental ethics, population ethics, and the history of medical ethics. For all necessary revisions, we went back to the articles' original authors, whenever possible, and many accepted to undertake the revision work. In those cases where the original authors were not available, new authors were asked to complete the work. Both original and new authors are acknowledged and their contributions clearly identified in the bylines. A small but exceptional set of articles from the revised edition were designated by the editorial board as *classics,* and are retained in the third edition unchanged. These articles were selected because they were written by a distinguished contributor to the field and were still deemed definitive. For example, Daniel Callahan's article on "Bioethics" was retained as a classic, as was Reich's "Care: I: History of the Notion." Also included without revision are those articles under the title "Medical Ethics, History of," which do not pertain to the contemporary period. But all articles dealing with the contemporary period were significantly revised in order to be current with the many developments in bioethics over the past decade in countries and regions across the world.

EDITORIAL BOARD. The development of this third edition of the *Encyclopedia* was facilitated by a new editorial board consisting of area editors David Barnard, Dena S. Davis, Eric T. Juengst, Loretta M. Kopelman, Maxwell J. Mehlman, Kenneth F. Schaffner, Bonnie Steinbock, Leonard J. Weber, and Stuart J. Youngner. These editors were selected because their particular expertise—as philosophers, ethicists, healthcare professionals, and teachers—was needed to revise and expand those topic areas from the revised edition where new developments had been particularly rapid over the 1990s. The Editor in Chief and the Editorial Board were responsible for the intellectual planning of the third edition, including all decisions about contents and authorship, as well as for reviewing and approving all manuscripts. Mark Aulisio served as associate editor for ethical theory and clinical ethics.

CONSULTANTS. William Deal, Patricia Marshall, Carol C. Donley, Sana Loue, Robert H. Binstock, and Barbara J. Daly made significant contributions to the quality of the overall work as editorial consultants. Carrie Zoubol assisted with bibliographical updating.

The Appendix, found in volume five of the *Encyclopedia,* consists largely of an exhaustive collection of historical and contemporary codes and oaths across all the healthcare professions, as well as research ethics guidelines and regulations. The remarkable collection of primary documents in the revised edition was thoroughly updated by Kayhan Parsi of the Neiswanger Institute for Bioethics and Health Policy at the Stritch School of Medicine of Loyola University. This was a major task because there have been so many revisions of contemporary documents since the early 1990s, as well as the introduction of many new policy and ethical statements from a wide array of professional organizations. Carol C. Donley contributed an annotated bibliography on literature and medicine from the Center for Literature, Medicine, and the Healthcare Professions at Hiram College. Emily Peterson added an annotated bibliography on law and medicine. Doris M. Goldstein, Director of Library and Information Services at the Kennedy Institute of Ethics, Georgetown University, thoroughly updated the section on "Additional Resources in Bioethics," which she had prepared for the revised edition. Volume five is the fruit of much labor and will be a definitive resource for the field over the next decade.

Acknowledgments

The day-to-day work of preparing the third edition entailed close collaboration with the publisher's team in New York and Michigan. None of this work would have been possible without a publisher able to efficiently implement the intellectual plan. The Macmillan team commissioned all the articles, maintained contact with all authors, coordinated reviews, copy edited all manuscripts, checked revised manuscripts and bibliographies, and prepared all materials for production. In particular, Hélène G. Potter, Editor in Chief of Macmillan Reference USA, provided vision and managerial insight for the development of the third edition—as well as many thoughtful perspectives. Similarly, Monica M. Hubbard, Senior Editor with Macmillan Reference USA, provided excellent leadership in implementing all the operational aspects of the project. Before the revision project began in earnest, Elly Dickason, prior to her retirement from Macmillan Reference USA, provided her usual thoughtful guidance.

The Department of Bioethics, School of Medicine, Case Western Reserve University, provided a collegial environment for a number of those involved as editors, consultants, authors and reviewers. The School of Medicine has a long tradition of humanism in medicine that creates a welcome atmosphere for the *Encyclopedia.*

We wish to acknowledge support for both the revised and third editions from The Alton F. and Carrie S. Davis Fund of the Cleveland Foundation. In addition, the John Templeton Foundation provided Stephen Post with a generous grant in 2002 in support of a research institute on altruism and compassion, “The Institute for Research on Unlimited Love—Altruism, Compassion, Service,” which allowed him to devote additional editorial time to related themes in the third edition, especially as these pertain to the ongoing dialogue between science and religion.

STEPHEN G. POST
EDITOR IN CHIEF
SEPTEMBER 2, 2003

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INTRODUCTION

In the Introduction to the 1995 revised edition of the *Encyclopedia of Bioethics*, Warren Thomas Reich, Editor in Chief, defined bioethics as "*the systematic study of the moral dimensions—including moral vision, decisions, conduct, and policies—of the life sciences and health care, employing a variety of ethical methodologies in an interdisciplinary setting.*" This definition shapes the third edition, which continues the broad topical range of earlier editions.

The word *bioethics* was coined in the early 1970s by biologists in order to encourage public and professional reflection on two topics of urgency: (1) the responsibility to maintain the generative ecology of the planet, upon which life and human life depends; and (2) the future implications of rapid advances in the life sciences with regard to potential modifications of a malleable human nature. In his book entitled *Bioethics: Bridge to the Future,* published in 1971, Van Rensselaer Potter focused on evolutionary biology, a growing human ability to alter nature and human nature, and the implications of this power for our global future. Other life scientists at that time, such as Bentley Glass, Paul Berg, and Paul Ehrlich were among many similarly interested in spurring thought on the biological revolution with regard to eugenics, the engineering of new life forms, and population ethics. Bioethics, then, emerged from biologists who felt obliged to address the moral meaning of the biosphere, and to reflect on the remarkable implications of their discoveries and technological innovations.

Alongside of bioethics as an intellectual movement among life scientists there emerged the field of medical ethics, which was both old and new. It was old in the sense that physicians had reflected perennially on their professional duties from within the narrow confines of the guild. It was new in that now this reflection was occurring in open dialogue with theologians and philosophers, and attentive to widening public concerns in a time of civil rights and "the twilight of authority." The emerging discussion quickly included all the significant healthcare professions. Physicians focusing on medical ethics were in conversation with the accumulated wisdom of Catholic, Jewish, and Protestant reflection on medical ethics, as well as with moral philosophy. Many philosophers in this early period engaged in fruitful and mutually enriching dialogue with religious thinkers. Such dialogue not only contributed to the vitality of the field, but also reflected the dynamics of a liberal democracy in which citizens of all backgrounds and persuasions were, by the early 1970s, becoming awakened to the important moral questions surrounding developments in healthcare, medicine, research, and the professional–patient relationship.

Bioethics, as the tradition of the *Encyclopedia* defines it, developed then from these two central lineages, and includes both. The *Encyclopedia* integrates all aspects of healthcare and medical ethics, without losing sight of the wider context provided by the life scientists of the early 1970s, including their environmental and public health concerns.

The earlier editions of the *Encyclopedia* remain the key historical documents defining the field in its initial stages. Many elegantly written and authoritative articles included in these editions represent the thought of a generation of remarkable thinkers whose intellectual creativity, scholarly breadth, and openness to dialogue across traditions may never be surpassed. These thinkers were relatively free of any conventional literature of the field of "bioethics" as we would now be able to describe it; they were generally free from the internal status hierarchies and concerns with legitimization in academic medical centers that can sometimes limit creativity; they were almost entirely free from conflicts of interest, a serious concern in current bioethics, in response to which this third edition has required full disclosure from all authors.

Bioethics, Pluralism and Public Discourse

The tradition of the *Encyclopedia* makes an instructive contribution to the future of bioethics in the academy because it includes the full spectrum of voices addressing the questions of bioethics, consistent with diversity in the public square of liberal democracies. The academic field of bioethics, in order to remain both relevant and creative, is wise to include thoughtful representatives from this full spectrum.

As Alasdair MacIntyre has pointed out, every system of philosophical or religious ethics has its own foundational assumptions about human nature and the human good, its unique historical context and questions, and its inherent conceptual limits. Bioethics is therefore enhanced by dialogue between different traditions of thought, both secular and religious, reflecting the diversity of the public square. Such dialogue requires a set of core virtues—mutual respect, tolerance, civility, and an openness to modification of one's perspectives based on the clarification of empirical fact and the persuasiveness of others. These virtues pertain not only to discourse within the Western context, but to global discourse. Whether African, Asian, Middle Eastern, or Native American, religious perspectives and the philosophical systems that have emerged from them need to be respected and engaged. Secular or religious monism—the view that only one voice is valid—eliminates meaningful dialogue, inhibits full participation, and thwarts conceptual growth.

Even within the particularistic scope of contemporary Western moral philosophy, whether utilitarian, Kantian, or contractarian, there is a need for dialogue with equally useful schools of thought, such as Aristotelian reflection on the virtues and final causality, natural law thought on essential human goods and correlative moral obligations, existential concern with the emotional underpinnings of human action such as hope or "the will to power," phenomenological description of the transition from solipsism to the "discovery of the other as other," feminist reflection grounded in the experience of women, and many other Western philosophical traditions that raise significant and yet very distinctive questions. Depth discussion requires an appreciation for different systems of moral thought, each of which raises a unique set of questions that those inculcated in other systems may miss.

Secular monists hold that religious ethics should be privatized and excluded from bioethical and public discourse; that religion should be a purely internal affair, no more relevant to public discourse than one's culinary tastes; that religious voices result in a discordant mixture that means nothing. Public debate requires, it is said, common secular language; religious language constitutes bad taste. While it is true that religious voices can be "conversation-stoppers"—to use the philosopher Richard Rorty's pejorative term—secular voices can be just as easily so. A great many religious voices are respectful, diplomatic, and contributory to deeper levels of discourse on public issues; they are often conversation-starters rather than conversation-stoppers by virtue of raising unique questions of human nature and destiny. In a liberal and robust bioethics, an opinion is no more disqualified for being *religious* than for being atheistic, psychoanalytic, feminist, Marxist, or secular existentialist.

The *Encyclopedia of Bioethics* is unique because it has always included many voices and traditions in an effort to foster dialogue, prevent the narrowing of the field, and engage a wide international readership. This edition, like previous ones, embraces cross-cultural approaches, the full history of bioethics, comparative religious and philosophical ethics, and global perspectives. The articles on the history of medical ethics are exemplary efforts to highlight the degree to which our contemporary theories of ethics and bioethics evolve from particular social, cultural–religious, and historical contexts. Moreover, the historical articles on "the contemporary period" provide important information on developments such as population ethics in China, assisted suicide in the Netherlands, and brain death legislation in Japan.

Yet the array of materials presented is not intended to imply moral relativism, even as it conveys the substantial reality of ideational difference. Many articles, while balanced and expository, do highlight areas where those in search of a common morality can find respite. In the classical dialectic between the One and the Many, or between moral objectivism and moral relativism, there are some areas in which no agreement is either likely or necessary. There are other areas, however, such as the wrongness of genocide or the sexual abuse of children, where agreement is both expected and imperative. Most of us are partial relativists, which is also to say that we are partial objectivists. When an incompetent physician lies by claiming competence and as a result inflicts avoidable harm on a patient, or when a researcher refuses to halt a study despite the intolerable suffering of subjects as they perceive it, ethics is objective and we can speak with authority of a common morality. Yet in other areas, such as brain definitions of death or certain reproductive technologies, few would assume moral objectivism. There are also difficult disagreements as to whether we should attempt to significantly modify human nature itself through advanced biotechnology.

The third edition of the *Encyclopedia* was animated by the recognition that no other work presents bioethics in its fullness, both with regard to definition, methods, and contents. It is this fullness that makes the *Encyclopedia* of continuing international value in maintaining the open and expansive nature of the field.

New Points of Emphasis

The third edition includes a wide array of new titles ranging from "Bioterrorism," "Holocaust," and "Immigration, Ethical and Health Issues of," to "Artificial Nutrition and Hydration," "Cancer, Ethical Issues Related to Diagnosis and Treatment," "Dementia," "Dialysis, Kidney," "DNR—Do Not Resuscitate," and sets of articles under "Cloning" and "Pediatrics." Topic areas such as Reproduction and Fertility, Organ and Tissue Transplantation, Death and Dying, Ethical Theory, Law and Bioethics, Mental Health, Genetics, Religion and Ethics, and alike have been thoroughly redesigned, and are essentially new. As mentioned in the Preface, half of the third edition is entirely new, while half consists of deeply revised and updated articles from the earlier edition. There isn't a single article that was not thoroughly updated, even if only at the level of bibliographies, unless it is designated as *classic.*

Some new points of thematic emphasis in the third edition can be highlighted and commented on, although the revised edition was comprehensive with regard to general topic areas within the field of bioethics.

Posthumanism and Anti-Posthumanism

The reader will find new articles entitled "Transhumanism and Posthumanism," "Cybernetics," "Cloning," "Human Dignity," "Embryo and Fetus: III. Embryonic Stem Cell Research," "Enhancement Uses of Medical Technology," "Nanotechnology," and "Aging and the Aged: VI. Anti-Aging Interventions: Ethical and Social Issues." Collectively, these articles and others accentuate the question of what it means to be human.

Posthumanism (or sometimes "transhumanism") is a pure scientism that endorses fundamental alterations in human nature (see, e.g., <www.betterhumans.com>, <www.transhumanism.org>, <www.forsight.org>). Off with biological constraints! Transcend humanness by technology! The posthumanist embraces the eventual goal of decelerated and even arrested aging, but only as a small part of a larger vision to re-engineer human nature, and thereby to create biologically and technologically superior human beings that we humans today will design for tomorrow. As such, posthumans would no longer be humans. Genetics, nanotechnology, cloning, cybernetics, and computer technologies are all part of the posthuman vision, which even includes the idea of downloading of synaptic connections in the brain to form a computerized human mind freed of mortal flesh, and thereby immortalized. Posthumanists do not believe that biology is destiny, but rather something to be overcome, for there is, they argue, no "natural law," but only human malleability and morphological freedom. Their appeal lies in the fact that, within the boundaries of technology, humans have been reinventing themselves anyway through applied technologies for millennia. Science is moving so rapidly that serious conversation is required to distinguish salutary from destructive transformations.

Human nature as we know it is, for the posthumanist mind, a mere constraint to be overcome. To use Walt Whitman's language, theirs is a "Song of the Open Road." After all, it is argued, there was a time when the very idea of human beings trying to fly was deemed heretical hubris in the light of eternity—*sub specie aeternitatis.* Now are the posthumanists to be deemed the new heretics in the light of evolution—*sub specie evolutionis*? Or shall we set aside trepidation and with confidence rethink ourselves in the light of human creativity and so-called "superbiology?" Indeed, Francis Bacon, a founder of the scientific method, in his millennialist and utopian essay *The New Atlantis* (1627), set in motion a biological mandate for boldness that included both the making of new species or "chimeras," organ replacement, and the "Water of Paradise" that would allow the possibility to "indeed live very long."

One of the wiser minds of the last century, Hans Jonas (d. 1993), an intellectual inspiration for today's anti-posthumanists, articulated the ethical questions around human malleability with thoroughness. He asked how desirable would the potential power to slow or arrest aging be for the individual and for the species? Do we want to tamper with the delicate biological balance of death and procreation, and preempt the place of youth? Would the species gain or lose? Jonas, by merely raising these questions, meant to cast significant doubt on the anti-aging enterprise. In current discussion, debate grows over cybernetics, nanotechnology, genetic enhancement, reproductive cloning, therapeutic stem cell cloning, life span extension, and new forms of behavior control. For some, the ambitions of posthumanists to create a new posthuman who is no longer human are, it is argued, arrogant, pretentious, and lacking in fundamental appreciation for natural human dignity. And yet others see potential for progress in these developing technological powers.

Ours is an age that is seriously beginning to consider "transhuman" possibilities through biotechnological enhancements in human biological capacities such as lifespan, personality type, and intelligence. What will be the status of the altruistic generativity that Erik Erikson associated with old age as adventurous human beings begin to experiment with efforts to alter their lifespan? Will compassion be left behind in favor of the biotechnological pursuit of bigger muscles, prolongevity, happy dispositions, and unfading beauty? Or are the care and compassion that lie within us the "ultimate human enhancement"? Readers of the *Encyclopedia* are encouraged to reflect on such questions and draw their own conclusions.

Business Ethics in Healthcare

The reader of the third edition will find new articles with titles such as "Corporate Compliance," "Health Insurance," "Health Policy in the United States," "Health Services Management Ethics," "Healthcare Institutions," "Just Wages and Salaries," "Labor Unions in Healthcare," "Managed Care," "Medicaid," "Mergers and Acquisitions," "Organizational Ethics in Healthcare," "Private Ownership of Inventions," and "Profit and Commercialism."

This new feature of the *Encyclopedia* grew from the concern throughout the 1990s and beyond with the ways in which healthcare has become a business ruled by corporate executives and the bottom line of economic profit. While the nonprofit context of healthcare delivery is still significant, even there the freedom of the physician to focus on the best interests of the patient has been to varying degrees compromised by sometimes necessary cost cutting. Many professionals have struggled to retain the moral core of commitment to beneficence and the well-being of patients as even the time allowed for each patient visit has been dramatically contracted, compromising the time to establish an empathic and compassionate relationship. With the restructuring of healthcare along corporate lines, and with the emergence of for-profit healthcare systems answerable to stock holders and Wall Street forces, business ethics in healthcare becomes a significant addition to the *Encyclopedia.*

The article entitled "Conflict of Interest" raises a question of significance for the field of bioethics itself. Increasingly, especially in academic medical centers at major universities, bioethicists have themselves accepted lucrative financial benefits from pharmaceutical companies and biotech firms. While this does not mean that some bioethicists are no longer free to think for themselves about ethical issues, it does mean that they are subject to various pressures and should fully disclose any financial interests whatsoever that might influence their opinions. Of all fields, bioethics should remain untainted by financial conflict of interest, for its public credibility is always at risk.

Basic Approaches to Ethics

The *Encyclopedia* has, in its earlier editions, always been strong in providing the reader with background articles in ethical theory. The third edition enhances this aspect of the work with articles including "Conscience, Rights of," "Contractarianism and Bioethics," "Ethics Committees and Ethics Consultation," "Human Dignity," "Human Rights," "Moral Status," "Principlism," "Utilitarianism and Bioethics," and "Value and Healthcare," among others. In addition, new articles dealing with religious ethical approaches have been added, such as "Authority in Religious Traditions," "Christianity, Bioethics in," "Circumcision, Religious Aspects of," "Compassionate Love," "Jehovah's Witness Refusal of Blood Products," "Mormonism, Bioethics in," and related topics. Additional articles on anthropology and bioethics have also been developed.

Organization of the *Encyclopedia*

Entries are arranged alphabetically. Some *entries* are comprised of several *subentries.* For example,

Aging and the Aged
I. Theories of Aging and Life Extension
II. Life Expectancy and Life Span
III. Societal Aging
IV. Old Age
V. Anti-Aging Interventions: Ethical and Social Issues

The reader wishing to study ethical aspects of aging and anti-aging research would do well to read all five of these interlocking articles.

Cross-references are provided for each article. However, for a complete perspective on the thematic relationships between articles, please see the "Topical Outline" in the front of the first volume following the "List of Contributors."

The bibliographies following each article are an important resource. These were prepared by the authors, or otherwise updated with approval by the Editor in Chief. The bibliographies are necessarily selective rather than completely exhaustive due to the volume of significant new books and articles relevant to each article.

The lengthy collection of codes, oaths, and policies in the fifth volume is of great value. Readers will benefit from reviewing these contents as they pertain to a specific topic of interest. Various annotated bibliographies in law and medicine, literature and medicine, and in bioethics should also be consulted. The section on "Additional Resources in Bioethics" is especially important for its thoroughness and its international aspects, including current websites worldwide that are easily available to students.

A special effort has been made to keep these volumes free from technical jargon. The articles should be accessible to students at the high school, college, and graduate levels, as well as to interested lay readers. They are written in such a manner as to be authoritative for professionals wishing to gain a clear perspective on how ideas have evolved.

Bioethics, Civil Discourse, and a Common Humanity

Because the issues with which bioethics grapples are profoundly relevant to the future of nature, human nature, and healthcare, they are often contentious. Moreover, in the dialectic between moral objectivism and moral relativism, while many of these issues allow for plausible resolutions, there are others for which no resolutions emerge. Tolerance, civility, respect, and the willingness to seriously engage with the views of others who work out of different traditions, both secular and religious, are necessary virtues and habits of mind. Bioethics is inevitably subject to criticism by those who believe that answers to the many new questions brought on by the accelerating biological and healthcare revolutions are immediately and simply apparent. But what, after all, is a good ethicist, whether secular or religious, if not the person who asks an unsettling new question that no one else envisioned, and thereby prompts renewed debate as an alternative to superficiality.

While this *Encyclopedia* does not include biographies of bioethicists who were also moral leaders attempting to influence the world of science, healthcare, and public opinion, the list would be extensive and pluralistic. Many of the finest contributors to the field of bioethics are actively engaged in the service of needful constituencies, involved with voluntary associations, and otherwise engaged in practice. As appropriate, they move beyond the mere exposition of the essential inventory of existing thoughts on a topic, and argue persuasively for a normative viewpoint. Indeed, those who read these volumes will hopefully be motivated by a sense of responsibility and service, as well as by intellectual curiosity. For the purpose of liberal education and learning is not only the enhancement of knowledge, but also progress in benevolence, creative altruism, and commitment to a common humanity.

As Editor in Chief, I hope that readers of these volumes become better informed participants in a respectful public dialogue over a set of issues that increasingly must be understood and appreciated by all citizens of a liberal democracy. The gravity and significance of these bioethical issues for the future of our generative planet, of life itself, and of humankind might impress the reader so as to inspire purposeful educational and life pursuits.

STEPHEN G. POST
EDITOR IN CHIEF, THIRD EDITION
SEPTEMBER 2, 2003

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TOPICAL OUTLINE

The classification of articles that follows provides a thematic view of the Encyclopedia's contents, depicting overall coverage in various divisions of the field of bioethics. It is also intended to assist the user, whether researcher or browser, in locating articles broadly related to a given topic. Because the topic headings are not mutually exclusive, certain entries are listed more than once.

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A

ABORTION

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I. MEDICAL PERSPECTIVES

Medical information and perspectives on abortion are not just data untinged by values. Throughout history medical facts and moral values regarding abortion have been inextricably intertwined, and the current era is no exception.

People interested in the ethics of abortion turn to medicine and medical practitioners for the following sort of information and perspectives, which will be considered in this entry :

1. whether medical knowledge clarifies the moral status of the fetus as a human being;
2. whether medical information on abortion confirms it to be safe for the woman;
3. what the medical perspectives are on performing early versus late abortions, particularly in light of controversies regarding *partial birth abortion*;
4. what the public health and international perspectives are on abortion.

Medical Knowledge Regarding Status of the Fetus

However much information biomedical investigation may provide regarding pregnancy, fetal development, and abortion, it cannot provide a determination as to when human life begins. The answer to that question—which deals with the moral status of the fetus—is arrived at by a process that entwines medical facts with experiences, values, religious and philosophical beliefs and attitudes, perceptions of meaning, and moral argument. Such a process extends beyond the special competency of medicine. For example, medicine has never had the ability to establish when ensoulment—an ancient criterion involving the *infusion* of the soul into the body of the fetus, thus conferring moral status on the fetus—occurs. Similarly there is disagreement among some physicians over the moral status of the fetus and the permissibility of abortion.

There is some confusion about the definition of abortion. Spontaneous abortion, or what is commonly termed a miscarriage, refers to a spontaneous loss of a pregnancy before viability (at about twenty-four weeks of gestation). Losses after that point in a pregnancy are termed *preterm deliveries,* or, in the case of the delivery of a fetus who has already died, *stillbirths.* The terminology commonly used in relation to induced abortion is different. Here, viability is not the key point. Rather, any termination of a pregnancy by medical or surgical means is termed an abortion, regardless of the stage of the pregnancy.

Safety and Harm for the Woman

POSSIBLE PHYSICAL HARM. There is a close tie between medical information on the safety of abortion practices and ethical positions on abortion. For example, at a time when abortions were frequently harmful to women—such as when legal restrictions increased recourse to untrained practitioners—opponents of abortion appealed to information on the likelihood of medical harm to the woman and risks of future pregnancies as arguments against abortion (Kunins and Rosenfield).

As of 2003, induced abortions performed within the first twelve weeks of pregnancy are among the safest and simplest forms of surgery and, based on maternal mortality ratios (number of deaths per 100,000 live births), both first- and second-trimester abortions, when performed by properly trained personnel, in general are safer than carrying a pregnancy to term (Cates and Grimes). As a result, ethical arguments against abortion tend to be restricted to areas other than maternal safety. Nonetheless, some aspects of medical safety and harm—including possible complications and psychological sequelae—continue to be important for ethical discourse, especially since a basic tenet of medical ethics is to avoid harm.

The major immediate complications of induced abortion, listed in order of frequency, are infection, hemorrhage, uterine perforation, and anesthesia-related complications. Overall complication rates for legal first-trimester abortions are less than 0.5 deaths per 100,000 abortions performed (as compared to more than four per 100,000 in the early 1970s, before the U.S. Supreme Court decision *Roe v. Wade* [1973] permitted medically supervised abortions). Medical complications associated with induced abortion are directly related to gestational age and the type of procedure used to terminate the pregnancy. Most abortions (over 90%) done in the United States are performed within the first twelve weeks of pregnancy, when abortion is safest. More serious complications may occur in procedures done later in pregnancy.

ABORTION PROCEDURES. Information on abortion procedures often sheds light on questions of safety as well as on other aspects of abortion that are relevant to ethics. The most common early-trimester abortion procedure (done between seven and twelve weeks' gestation) is suction curettage, in which a thin plastic tube (canula) is inserted through the cervix and, by negative pressure vacuum, the contents of the uterus are aspirated. Usually, following the aspiration procedure, a curettage (using a sharp, spoon-shaped surgical instrument, a curette) is performed to ensure that all fetal tissue has been removed.

Complications of suction curettage procedures are rare, and even when they occur, are usually not serious. General anesthesia is considered by many to be an unnecessary additional risk, since local anesthesia, injected into the cervix, often is quite effective (Grimes et al.). A short course of prophylactic antibiotics is sometimes prescribed, although postabortion infection is uncommon with suction curettage. Because of its safety, suction curettage is performed most often in free-standing clinics or outpatient centers in hospitals.

At twelve to twenty weeks' gestation, the most common method used for abortion is dilation and evacuation (D&E), which uses specially designed forceps in conjunction with vacuum aspiration to facilitate the removal of the uterine contents. Prior to initiating the procedure, the cervix is dilated gradually over a number of hours using sponge-like materials that expand as they absorb local cervical fluids. Though still considered a minor surgical procedure, D&E is clearly more involved and invasive than suction curettage, and a trained and skilled clinician is essential. Although it is possible to use only local anesthesia for D&E, the procedure is considerably more uncomfortable than suction curettage, and general anesthesia is often used, making the procedure more risky. The D&E procedure can be performed in free-standing clinics, but often ambulatory surgical services in a hospital setting are chosen for the procedures performed later in pregnancy (after the fourteenth week) because emergency care can be quickly provided in case of a complication. Informed-consent procedures require that the various methods of abortion be discussed as well as the possible anesthesia alternatives.

The other abortion procedure used fairly commonly in the second trimester is instillation abortion, in which a solution instilled into the amniotic cavity through the abdomen via amniocentesis results in the death of the fetus and termination of the pregnancy. Uterine contractions signaling labor begin twelve to twenty-four hours later and culminate with the expulsion of the fetus. Anesthesia is not commonly used for instillation procedures. Discomfort varies widely among patients, usually in relation to the length of labor and the time before complete expulsion of the fetus and placenta. More serious complications can occur during instillation procedures, including inadvertent introduction of the solution into the mother's bloodstream, excessive bleeding at the time of expulsion of the fetus, or retention of placenta, and for this reason hospital admission is usually advised. Instillation procedures are used mainly for procedures beyond the twentieth week of gestation. All late-pregnancy abortion procedures carry significant risk if carried out by physicians not specially trained in the technique.

A promising alternative to surgical abortion for early first-trimester terminations of pregnancy is chemical abortion. For example, the antiprogestin drug RU-486 works by blocking progesterone production by the ovaries, an essential hormone in the early stages of pregnancy and in the implantation of the embryo. The drug is given within the first forty-nine days of a confirmed pregnancy and is used in conjunction with a prostaglandin, which produces uterine contractions and subsequent expulsion of the uterine contents. A follow-up visit is necessary eight to twelve days later to ensure that complete termination of the pregnancy has occurred.

On September 28, 2000, the U.S. Food and Drug Administration (FDA) approved RU–486 for use in the United States, and it has been distributed since the following November by Danco Laboratories, LLC under the brand name Mifeprex. According to the guidelines set forth by the FDA, it has been distributed only to physicians and is not available through pharmacies; furthermore, the FDA has approved a specific regimen for the use of RU–486. Three visits are necessary for this medical means of pregnancy termination: the first to make the diagnosis and to give the RU–486, the second, two days later, for the prostaglandin, and the third within two weeks for the final follow-up. In France, a fourth visit is required by law since a one-week delay between the diagnosis of pregnancy and the initiation of an abortion procedure is mandated.

As a result of the requirement for three visits (or four in France), because there may be a few days before the abortion occurs and as many as ten or more days of vaginal bleeding thereafter, and because it may be more expensive than surgical abortion, many women in France and the United States still prefer suction curettage as their method of choice (Kolata). However, there is anticipation that as awareness grows, many women will still prefer a medical means of abortion, not wishing to undergo surgery (albeit a minor procedure) or to be subjected to the harassment that may occur outside some clinic facilities.

Successful termination has been shown to occur in 97 percent of patients using the RU-486 regimen, with the remaining patients requiring suction curettage for complete removal of the products of conception. In comparison, for surgical procedures, less than 1 percent of patients require a second curettage because the procedure was incomplete. Most women develop strong cramping after taking the prostaglandin (because the drug induces uterine contractions) and usually have the abortion within a few hours after receiving prostaglandin. In France, RU-486 is therefore provided only through clinic facilities and in this setting, the abortion often occurs during the same four hours women remain in the clinic after taking the prostaglandin. However, some French physicians believe that a clinic setting is not essential. In the United States, specific requirements for facilities providing abortion vary from state to state. Federal guidelines, however, require only that RU-486 be prescribed by or under the supervision of a physician who can diagnose the duration of pregnancy accurately, diagnose an ectopic pregnancy, and either can provide surgical intervention in cases of incomplete abortion or who has made arrangements to provide such care through others.

While studies have demonstrated the safety and effectiveness of RU-486 as a *morning after* pill for use after unexpected midcycle intercourse (Ashok), preparations containing the same hormones as are found in oral contraceptive pills (estrogen and progestin or progestin alone) have been approved for this purpose. Furthermore, the copper-T intrauterine device (IUD) can be inserted up to five days after unprotected intercourse to prevent pregnancy. Both emergency contraceptive pills (ECPs) and the IUD are more readily available and remain the standard of care for postcoital contraception in the United States (American College of Obstetricians and Gynecologists [ACOG], 2001).

AVAILABILITY OF ABORTION PROVIDERS. The majority of abortion procedures in the United States are provided by obstetrician-gynecologists, with a small percentage performed by other providers such as family practice physicians, midwives, or nurse practitioners. There are serious concerns about the provision of abortion procedures in the future for several reasons. Although most obstetrician-gynecologists believe that women should have the right to choose to terminate a pregnancy, at the same time, most do not wish to perform abortions. As a result, approximately 84 percent of counties in the United States do not have an abortion facility, and the number rises to 94 percent outside metropolitan areas.

Many ob-gyn residency training programs do not offer abortion training routinely and as a result, many graduating residents have little or no training in this area. However, over the last decade there has been an increase in the number of residency programs providing training in abortion procedures. In 1996, the Accreditation Council for Graduate Medical Education required ob-gyn residency programs to include family planning and abortion training for its students, though abortion is generally still presented as an elective part of training. The impact of these requirements was demonstrated in a survey conducted by the National Abortion Federation (NAF). The investigators of the NAF report found that from 1992 to 1998, ob-gyn residency programs reporting routine first trimester abortion training increased almost fourfold, from 12 percent to 46 percent, and routine second trimester abortion training from 7 percent to 44 percent (Almeling et al.).

Finally, even where training has taken place, the increasing incidence of harassment and even violence (including the 1993 and 1994 murders of abortion providers in Florida) has resulted in more reluctance on the part of physicians to be involved in the provision of this service. In response to the escalating violence, Congress enacted the

Freedom of Access to Clinic Entrances Act, or *FACE,* in 1994. This statute established federal criminal penalties and civil remedies for violent, obstructionist, or damaging conduct affecting reproductive healthcare providers and recipients, and supplemented the penalties available under then-existing federal criminal statutes such as the Hobbs Act, the Travel Act, and federal arson and firearms statutes. Rising violence as well as the federal response highlight serious ethical questions as to the social responsibility of professionals in this field to make certain that this procedure is available to all patients.

POSSIBLY HARMFUL EFFECTS ON SUBSEQUENT PREGNANCIES. Questions have been raised about possible long-term harmful effects of induced abortion, especially for women who have had multiple abortions. Much of the concern centers on subsequent pregnancies, following one or more induced abortions. Medical evidence has consistently shown that a woman who has one properly performed induced abortion in the first trimester of pregnancy has the same chance of a normal outcome of a subsequent pregnancy as a woman who has never had an abortion. The evidence is less definitive for women who have had more than one induced abortion or an abortion with complications, although there is no reason to believe that additional abortion procedures, carried out by well-trained professionals, will have a long-term adverse effect. Overall, in terms of medical risk, abortion procedures, particularly those carried out in the first trimester of pregnancy, are among the safest of all surgical procedures.

PSYCHOLOGICAL EFFECTS. A much grayer area is that of the psychological consequences of induced abortion. It is difficult to generalize about the emotional responses of patients to pregnancy termination but, like physical complications, psychological complications may be related to the type of procedure and the gestational age at the time of termination, with earlier suction curettage theoretically leading to fewer psychological complications than later procedures. However, most studies in this area suffer from methodological problems, including a lack of consensus about symptoms, inadequate study design, and lack of adequate follow-up. Furthermore, the so-called postabortion syndrome does not meet the American Psychiatric Association's definition of trauma (Gold).

Despite the many problems with most investigations, "the studies are consistent in their findings of relatively rare instance of negative responses after abortion and of decreases in psychological distress after abortion compared to before abortion" (Adler et al., p. 42). Former U.S. Surgeon General C. Everett Koop, at the request of the White House, undertook a major assessment of the literature on this topic and concluded in a 1989 congressional hearing that "the data were insufficient … to support the premise that abortion does or does not produce a postabortion syndrome and that emotional problems resulting from abortion are minuscule from a public health perspective" (Human Resources and Intergovernmental Relations Subcommittee of the Committee on Governmental Operations, p. 14). Given Koop's personal opposition to abortion, the conclusions of his assessment are of particular importance.

Approximately 10 percent of induced abortions in the United States take place between twelve and twenty weeks of gestation, and less than 1 percent take place between twenty and twenty-four weeks. This means that more than 150,000 second-trimester procedures occur each year, a much larger number than in other developed nations where abortion is legal. Most would agree that decreases in the total numbers of abortions would be highly desirable, particularly decreases in second-trimester procedures.

The most common reasons for these later procedures, particularly among younger teens, are indecision about termination and failure to recognize (or denial of) pregnancy. A smaller percentage of these later abortions occur because of medical or genetic reasons, which theoretically may correlate with greater psychological distress. Although techniques such as nuchal translucency measurement with serum screening, chorionic villus sampling, and early amniocentesis have allowed earlier diagnosis, the results of more commonly used techniques of antenatal fetal diagnosis with midtrimester amniocentesis are generally not available until well into the second trimester.

Choosing to terminate a pregnancy is a serious decision that is rarely made lightly. In addition to complete information about abortion procedure options, counseling should be made available to women faced with a decision about an unplanned pregnancy.

Early Versus Late Abortions: Controversies in Medicine

Medical attitudes toward abortion have constantly been shaped by the medical profession's knowledge of and attitude toward the stage of development of the fetus, interacting with local cultural, religious, and legal ideas and beliefs. Together, these factors have had a significant impact on medical practice. Medical practitioners often have more difficulty with late abortions as compared to earlier ones, because the procedures are more difficult to perform in late abortions, because of the more advanced state of fetal development, and because of the political climate surrounding so-called *partial-birth abortion.*

Prior to the latter half of the nineteenth century, abortion was available in the United States under the doctrines of British common law that permitted termination of a pregnancy until the time of *quickening* (detection of fetal movement). However, medical knowledge available at that time made it difficult to confirm a pregnancy with certainty prior to quickening, for it was only this detection of fetal movement that confirmed the existence of a living human fetus. There is little in the historical literature that describes how physicians in that era actually felt about abortions, although based on the information discussed below, one can assume that there were concerns about abortion.

By the second half of the nineteenth century, as scientific knowledge grew, so did the realization that fetal development occurs on a continuum, suggesting that the fetus is a living entity before fetal movement is felt. Prompted by this new medical knowledge, physicians, particularly those who were members of the newly formed American Medical Association (AMA), began openly to oppose abortion and urged its criminalization as an immoral practice. As a basis for this change, the Hippocratic Oath was used to oppose abortion at any time during pregnancy.

The concept of the fetus as a human entity separate from the mother has long been the subject of ethical concern within the medical profession. The AMA's Principles of Medical Ethics permit physicians to perform abortions, provided they are done in accordance both with the law and with *good medical practice* (Council on Ethical and Judicial Affairs, Opinion 2.01). In general, for the last 100 years or more, and especially since the U.S. Supreme Court decision in *Roe v. Wade* greatly liberalized the legal permissibility of abortion, medical practitioners have tended to place the value of the life of the mother above that of the fetus and there has been general agreement that late abortion is permissible in those cases where medical judgment deems that the health of the mother is seriously compromised by a pregnancy.

However, just as *Roe v. Wade* allowed for some restrictions on abortions after fetal viability, so the medical profession has shown a reluctance to perform abortions later in pregnancy, even early in the second trimester. In addition to new ethical dilemmas over fetal and maternal rights, many medical professionals remain ambivalent about the morality of abortion, a conflict that is heightened both by increased technological sophistication in the field of perinatology and genetics and the current political climate.

Depending on the technology available to a physician and the condition of the individual fetus (gestational age and any developmental deformity), it is often possible, depending on the availability of neonatal intensive support, to save the lives of premature babies born at twenty-seven weeks gestation. Babies born at twenty-four to twenty-six weeks and earlier have survived with intensive neonatal intervention and support, though often with some degree of functional impairment. With abortions occasionally performed up to twenty-four weeks gestation, one can see the conflict within medicine: Fetuses that might be aborted by one group of physicians are aggressively supported as patients by another group.

Physicians who provide abortion services prefer to do early abortions, that is, up to twelve weeks, for several reasons. First, it is generally agreed that, though a fetus may exhibit primitive reflexes before twenty weeks gestation, there is no evidence that the brain and neurological system are developed enough even at twenty-four weeks for the fetus to experience pain. Second, as discussed earlier, second-trimester techniques that might appear to be more humane or to show more respect for the fetus generally entail more danger for the woman. Third, the physicians who are committed to offering abortion procedures are intent on offering the safest procedures for the woman and regard the benefit to the woman as superseding the goal of minimalization of harm to the fetus.

Most recently, the debate over partial birth abortion has presented significant challenges to physicians, other providers of abortion services, and proponents of a woman's right to choose to terminate a pregnancy. While legislation to ban this procedure has been proposed and debated in Congress, in several state legislatures, and finally in the Supreme Court, the vagueness of the definition of partial-birth abortion (which is not a term used by medical professionals), the failure to allow physicians to protect a woman's health after a fetus becomes viable, and the application of the ban before fetal viability has resulted in the failure of these bans to be constitutionally upheld (Annas, 1998).

In March 1995, the first Partial-Birth Abortion Ban Act was introduced in the U.S. Congress to make it a federal crime to perform "an abortion in which the person performing the abortion partially vaginally delivers a living fetus before killing the fetus and completing the delivery." In April 1996 President Clinton vetoed the bill because of its failure to include an exception allowing the procedure to prevent *serious, adverse health consequences to the mother* (Remarks on Returning without Approval to the House of Representatives Partial Birth Abortion Legislation, pp. 643–647); he vetoed a revised bill in October 1997 for the same reason (Message to the House of Representatives Returning without Approval Partial Birth Abortion Legislation, p. 1545).

Over the interim between the two bills, medical organizations took conflicting positions. In contrast with the AMA, which endorsed the federal bill, the ACOG executive board urged the president to veto the bill. The executive board understood the term partial birth abortion to describe a method members of the ACOG would understand as *intact dilation and extraction,* one method of terminating a pregnancy after sixteen weeks' gestation and specifically involving "1. deliberate dilation of the cervix, usually over a sequence of days; 2. instrumental conversion of the fetus to a footling breech; 3; breech extraction of the body excepting the head; and 4. partial evacuation of the intracranial contents of the living fetus to effect vaginal delivery of dead but otherwise intact fetus" (ACOG p. 2). While the committee could identify no specific circumstance where this method would be the only option to preserve the health of the woman, they stated that "only the doctor, in consultation with the patient, based upon the woman's particular circumstances can make this decision" (ACOG, 1997, p. 3).

Similar laws have since been passed in more than two dozen states and found unconstitutional; the most significant decision was issued by the Supreme Court in a challenge to Nebraska's Partial-Birth Abortion law in the case of *Stenberg v. Carhart* in 2000 (Annas, 2001). The case involved Dr. Leroy Carhart, a Nebraska physician who sued in federal court to have Nebraska's law declared unconstitutional because it endangered women's lives and was void because of its vagueness in that physicians could not know exactly what procedure was proscribed. Ultimately, the Supreme Court ruled on June 28, 2000, that the Nebraska law and all other laws banning partial birth abortion are unconstitutional. The majority opinion held that the law was unconstitutional for two reasons. First, it did not provide an exception to protect the health of the woman as required by *Roe v. Wade.* Second, the law imposed an undue burden (as proscribed in *Planned Parenthood v. Casey*) because it was written so broadly as to ban not only the rarely used dilation and extraction (D&X) procedures but also dilation and evacuation (D&E) so commonly used to terminate pregnancies even early in the second trimester. Ultimately, the *Stenberg* decision reinforced the important position that decisions regarding how abortions can most safely and satisfactorily be performed should be made by women and their physicians.

Public Health and International Perspectives

Abortion is widely available with varying restrictions throughout the industrialized world. In recent years, there also has been a trend toward liberalization of abortion laws in many developing countries, such as in India, where abortion has been legalized; and in Bangladesh, where an early first-trimester procedure called menstrual regulation (which is really an early suction curettage) has been officially sanctioned by the government even though abortion per se has not been legalized. Abortion laws are most restrictive in Latin America, sub-Saharan Africa, and Central Asia.

Many of the countries in these regions have high rates of maternal mortality, and complications of illegal abortions are one of its leading causes. According to the World Health Organization (WHO), as many as 100,000 or more maternal deaths occur each year as a result of complications of an unsafe, usually illegal abortion. Even in the United States, some illegal abortions continue to be performed in cases where women are without the resources to obtain a legal abortion. Although reliable incidence data are lacking as to the number of illegal abortions performed worldwide, there clearly is a strong demand for abortion, a demand that will probably always exist. As evidenced by the estimated number of women who undergo illegal abortion, most women who are determined to terminate a pregnancy will attempt to do so either by themselves or with assistance.

Consequently, the public-health concerns about the complications of unsafe abortion, coupled with the complex issues relating to the reproductive and autonomy rights of women versus the rights of the fetus, suggest the continuing importance that must be given by the field of bioethics to abortion, particularly to the question of whether and by what means abortion should be made available equally to all persons requesting it, regardless of national citizenship, ethnic or racial identity, or economic status.

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SEE ALSO: *Embryo and Fetus; Fertility Control; Reproductive Technologies;* and other *Abortion* subentries

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II. CONTEMPORARY ETHICAL AND LEGAL ASPECTS: A. ETHICAL PERSPECTIVES

Abortion is widely regarded as one of the most intractable problems in bioethics. It is certainly true that few issues in bioethics have inspired as much discussion, debate, and open conflict as abortion, in part because the abortion controversy, unlike many others in ethics, has not been limited to scholars and practitioners, but has been engaged on numerous fronts in the United States. Churches and religious organizations, political office holders and candidates, the courts, and the general public have all taken a stand on abortion. In the decades since the U.S. Supreme Court, in its historic 1973 *Roe v. Wade* decision, effectively legalized abortion through the second trimester of pregnancy, the conflict—political, legal, social, and ethical—has not abated.

Another reason for the intractability of the abortion issue is that the views held by critics and defenders of abortion often occupy extremes. At one extreme, abortion opponents defend an absolute prohibition on abortion, calling abortion nothing less than the murder of an innocent person. At the other extreme are those who defend a woman's absolute right to abortion on demand at any time during pregnancy. Both sides engage in rhetoric and hyperbole; abortion opponents call themselves "pro-life," implying that their opponents are anti-life, while abortion rights supporters call themselves "pro-choice," suggesting that anti-abortionists oppose personal freedom and choice. When the battle lines are largely ideological, as they are in the abortion conflict, there is little room for rational argument. The result is that rather than search for a middle ground, both sides of the conflict have simply dug their heels in deeper.

An additional source of difficulty in reaching agreement about abortion is that the anti-abortion movement in the United States has been led primarily by the Roman Catholic church and fundamentalist Protestants, who base their opposition to abortion on fundamental religious convictions. If it is impossible to argue rationally for or against such convictions, it is no less difficult to argue about an ethical position that is deeply rooted in them.

Finally, the abortion problem is unusually difficult because the fetus is significantly unlike other entities of moral concern, and because the relationship between a fetus and a pregnant woman is unique, in many ways, among human relationships. The moral status of the fetus is itself a highly contested matter, such that the general moral principles that can be appealed to in other areas of human conduct and conflict do not fit cleanly into the abortion picture. Additionally, because the status of the fetus is at issue, abortion can be as much a metaphysical problem as a moral one.

The contemporary moral controversy over abortion focuses on three central issues: the moral status of the embryo or fetus, which many ethicists contend hinges on the ontological status of embryonic and fetal life; the rights conflict between pregnant women and their fetuses; and consequentialist arguments that weigh the potential for harm to women as a result of restricting or abolishing abortion against the negative consequences of terminating fetal or embryonic life.

Ontological and Moral Status of the Fetus

The question of the ontological status of the fetus can be teased apart from the question of moral status, but in the abortion debate, fetal personhood and the possession of moral rights are often assumed to go hand in hand. The term *person,* however, is ambiguous, having a legal, a descriptive, and a normative sense. To be a legal person is simply to possess legal rights. In *Roe v. Wade* (1973), the Supreme Court held that fetuses are not persons as defined by the 14th Amendment of the Constitution, but declined to offer a positive thesis on personhood, acknowledging the difficulty of doing so. “We need not resolve the difficult question of when life begins. When those trained in the respective disciplines of medicine, philosophy, and theology are unable to arrive at any consensus, the judiciary, at this point in the development of man’s knowledge, is not in a position to speculate as to the answer” (*Roe v. Wade,* 1973). To say that something is a descriptive person is just to say that it satisfies certain criteria of personhood, such as species membership. The claim that a fetus is a person in this sense does nothing to justify the claim that killing a fetus is morally wrong unless the fetus also qualifies as a person in the normative sense. Being a person normatively speaking means being a bearer of moral rights, including the right to life. The crucial question of fetal or embryonic personhood, as it relates to abortion, then, is whether and when the genetically human, living entity resulting from the fertilization of an ovum by a spermatozoon is a normative person, a possessor of rights. There is, however, no more consensus on the proper criteria for personhood, and whether or not fetuses can satisfy these criteria, than there is on abortion.

At one extreme of the personhood debate is the position that personhood begins at fertilization, so even very early embryos, composed of only a few cells, are persons. At the other extreme is the view that personhood does not begin until birth or even later, and so no fetus, and perhaps no infant, qualifies as a person. Between the two extremes, there are a multitude of possibilities.

One approach to personhood is the developmental view, which denies that a bright line can be drawn at any particular point in natural development when the fetus acquires moral standing. The developmental view hinges on the continuity of fetal development, and the difficulty of non-arbitrarily picking out properties that qualify some fetuses, but not others, as persons. Since infants are generally regarded as persons with a right to life, and the difference between a late term fetus and a neonate—particularly in the case of viable premature infants—is merely a matter of location, it appears that in the continuous process of embryonic and fetal development, there is no non-arbitrary place to draw a line where personhood begins. This view is in line with the intuition, shared by many on both sides of the abortion conflict, that fetal life becomes increasingly important as gestation continues, but that it is impossible to say with certainty when, exactly, a fetus becomes a person. The inherent vagueness of the developmental view is an obstacle to translating it into practical moral guidelines or public policies, however.

The potentiality view advances conception or fertilization as the beginning of personhood because it is the fertilized ovum, not its constituent gametes, that is considered to have the potential to develop into a human being with full moral status. This can be criticized in two ways. First, it may be argued that even gametes do have the potential to become human persons. Second, as a number of critics of the potentiality criterion have observed, having the potential to become a person is not the same as being one, and it is being a person that confers moral status and rights.

As Judith Jarvis Thomson noted, “A newly fertilized ovum, a newly implanted clump of cells, is no more a person than an acorn is an oak tree” (Thomson, 1971, p. 199). In *Roe v. Wade,* the Court located fetal viability as a line of demarcation, the point after which the state may have a compelling interest in protecting fetal life. Although viability is not a specific moment in the continuum of fetal development, it occurs at approximately twenty-four to twenty-eight weeks gestation, when a number of other significant developmental markers have been achieved, and is the point at which, given proper support, a fetus can potentially survive outside the womb, independently of its mother. It has taken on significance as a convenient, relatively identifiable and verifiable turning point in fetal development, when personhood plausibly begins. Fetal viability is to some extent dependent on technology—premature neonates often need considerable medical support to survive. As technological advances in neonatal care occur, it is possible that the point at which a fetus is viable may change. Some critics of the viability standard claim that personhood ought not be contingent on external facts about the state of medical technology, and therefore cannot stand as a proper criterion for personhood.

As technology has provided a better understanding of the different stages of embryonic and fetal development, criteria such as implantation (when the conceptus becomes imbedded in the uterine lining), the appearance of external human form, and the presence of detectable brainwave activity have all been advanced as criteria for personhood and rights. Traditional criteria for fetal personhood include *animation,* when fetal movement first occurs, and *quickening,* the time at which a pregnant woman first feels fetal movement. Early Christian authors talked about *ensoulment,* the time at which the embryo or fetus is imbued with a soul.

Species membership, or genetic humanity, is the most lenient criterion for personhood, and the most easily verifiable. According to this definition of personhood, any entity conceived of human parents is a member of the human species, and is therefore a person. John T. Noonan, writing from a Catholic perspective, argues that the fetus acquires personhood at the moment of conception, when it receives from its parents the human genetic code (Noonan). The genetic humanity standard can be regarded as both too broad and too restrictive, however. It is too broad because it implies that any living entity with the human genetic code qualifies as a human life worthy of protection. Cancer cells, sperm, and ova all have a human genetic code, and on the least restrictive definition of genetic humanity, such cells would have a right to life, implying that if abortion is impermissible, then so is contraception and chemotherapy. Ethicists who advance a genetic humanity view generally exclude from personhood cells that lack the potential to become human beings, combining a genetic humanity standard with a potentiality principle. The genetic humanity standard can also be regarded as too restrictive because it excludes from the possibility of personhood all nonhuman beings, including some that may warrant the moral status of rights-bearers.

The philosopher Mary Anne Warren argues for a very strict psychological standard of personhood, defining a person as “a full-fledged member of the moral community” (Warren, 1973, p. 347). Genetic humanity alone isn’t sufficient for personhood, according to Warren, so not all human beings are members of the moral community. Warren proposes a set of cognitive criteria that, it is claimed, everyone can and does agree are central to the concept of personhood: consciousness, the developed capacity for reasoning and problem-solving, self-motivated activity, the capacity to communicate, and self-awareness. Beings that satisfy some or all of these criteria are people with a moral claim on us, whether they are human or not, for just as some human beings are not people, “there may well be people who are not human beings” (Warren, 1973, p. 348). Membership in the moral community requires the capacity for moral participation, in Warren’s view; it would be absurd to ascribe moral obligations and responsibilities to an entity that cannot satisfy any of the cognitive or psychological criteria for moral personhood, and it is equally absurd to ascribe full moral rights to such a being. It is obvious that no fetus can satisfy any of these criteria, and it is equally obvious, Warren argues, that anything that fails to satisfy any of these criteria cannot be a person. A fully developed fetus is no more like a person than a newborn guppy, and cannot have a right to life sufficient to override a woman’s right to have an abortion at any stage of pregnancy.

Critics were quick to point out that Warren’s standard of personhood could not be met by infants, nor many children and adults with serious cognitive deficits, and thus would problematically justify not only abortion, but infanticide and nonvoluntary euthanasia as well. Warren responded to such criticism by allowing that although a newborn infant is not a person with a right to life, and infanticide is not murder, there are other, utilitarian reasons for the impermissibility of infanticide. Infanticide is wrong for the same reason it is wrong to destroy great works of art or natural resources, because destroying these things deprives people of a great deal of pleasure. Moreover, most people value infants, even if their own parents do not, and would prefer that they not be destroyed. These considerations are not sufficient to override a pregnant woman’s right to freedom, happiness, and self-determination, nor her right to an abortion at any stage of pregnancy, Warren claims, but the moment of birth marks the point at which the infant’s continued life no longer violates any of its mother's rights, and is thus the point at which its mother no longer has the right to determine its fate. Birth is also morally significant "because it permits the establishment of direct social relationships between the infant and other members of society" (Warren, 1985, p. 6). Thus, although an infant may lack the intrinsic properties that ground a right to life, "its emergence into the social world makes it appropriate to treat it as if it had such a right" (Warren, 1989, p. 56).

While Warren has been accused of offering an ad hoc solution to the problem of infanticide, Michael Tooley argues that neither abortion nor infanticide is intrinsically wrong or undesirable, and indeed, "in the vast majority of cases in which infanticide is desirable … there is excellent reason to believe that infanticide is morally permissible" (Tooley, 1985, p. 14). Tooley's argument is that personhood requires nothing less than self-consciousness, and "An organism possesses a serious right to life only if it possesses the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity" (Tooley, 1972, p. 315). Tooley and Warren both explicitly reject the view that the mere potential to become a person gives the fetus any moral standing.

Philosopher Don Marquis attempts to resolve the personhood standoff by starting with an unproblematic assumption: It is seriously morally wrong to kill an adult human being. Marquis then identifies the natural property that adults have that makes killing them wrong. If the same property is found to belong to fetuses, Marquis argues, it must follow that abortion is also seriously morally wrong. Marquis concludes that what makes killing wrong is that murder deprives its victim of a life and future that is valuable. The victim of a murder is deprived of all the experiences, activities, projects, and enjoyments that would have constituted his or her future, deprived of all that he or she values, or would have come to value, in life. The loss of that valuable future, of what Marquis calls a "future like ours," is ultimately what makes killing wrong. It is also what makes abortion morally wrong, Marquis argues, because fetuses have futures of value. "The future of a standard fetus includes a set of experiences, projects, activities, and such which are identical with the futures of adult human beings and are identical with the futures of young children" (Marquis, p. 192).

Marquis's future-like-ours account implies that it is seriously wrong to kill any being with a future of value—it is non-speciesist in that it does not claim that only human life has value or worth. Rather, like some personhood theories, Marquis's theory leaves open the possibility that other species, if they share the property of having a valuable future, have the same right to life that a human being has, and that killing members of other species would therefore be seriously morally wrong. Marquis offers no account of what a future like ours must look like, or what shared properties of an adult human future make it valuable. This point has been a focus of attack for critics, like David Boonin (see below), Jeffrey Reiman, and Peter K. McInerney, who claim that fetuses do not, indeed cannot, have futures like ours.

Marquis's future-like-ours theory, in opposition to other pro-life accounts, is compatible with the permissibility of euthanasia because it is only the loss of a *valuable* future—not merely the loss of a life—that makes killing wrong. The future-like-ours theory also accounts for the basic intuition that it is seriously wrong to kill young children and infants, for it is presumed they have futures of value. Personhood theories that advance psychological criteria do not straightforwardly account for the intuition or belief that killing infants and children is morally wrong, and must make appeal to other principles, such as social utility, to account for its wrongness. Appeals to social utility, however, cannot explain the wrongness of killing those who are unwanted or unnecessary.

Marquis's critics point out that he fails to provide an argument for why a fetus that is incapable of valuing its own future should count as a being that can suffer a morally relevant loss of its future. The philosopher David Boonin develops an alternative future-like-ours theory that refutes the claim that every fetus has a right to life, and that abortion is in typical cases morally impermissible, on terms that critics of abortion, like Marquis, can and do accept. Boonin argues that a fetus acquires a right to life only at the point in fetal development when organized cortical brain activity is present. The "cortical criterion" is the only morally relevant criterion for moral standing and a right to life, Boonin argues, because organized cortical activity is what makes it possible to have a future like ours. "We have a future-like-ours only because we have a brain which will enable us to enjoy, in the future, the kinds of conscious experiences that make our lives distinctively valuable to us" (Boonin, p. 126). Boonin's theory, like Marquis's, identifies a natural property that fetuses possess that makes killing them morally wrong. But while Marquis's future-like-ours property broadly applies equally to all fetuses and embryos, Boonin's cortical criterion narrows the category of beings with a right to life to those with a developed capacity for conscious desires. "It is because these individuals currently have desires about their futures that our desires about how to behave are not the only ones that are morally relevant" (p. 73). Thus, Boonin's theory does not claim, as some personhood theories do, that no fetus ever has a right to life, but only that this right does not exist from the moment of conception, and he concludes that if, as Marquis proposes, depriving a fetus of a future like ours is the wrong-making feature of abortion, then "abortion in typical circumstances is permissible," because the typically aborted fetus lacks a future like ours (p. 129).

Marquis contends that a desire-based account of the wrongness of killing cannot explain why it is morally wrong to kill individuals who have no desire to live, such as suicidal teenagers, the sleeping, and the unconscious. Any theory in which having a valuable future depends upon actually desiring that one's life continue fails to adequately account for the basic intuition that killing beings who do not occurrently value their own futures is seriously morally wrong. The value of life, Marquis argues, is not secondary to our desire for it. If it were, a mere reordering of desires could make killing morally right. The fact that a fetus does not desire the continuation of its own life does not imply that its future has no value—its future is ultimately valuable to it because it will be valuable to it in the future.

Boonin proposes a modified future like ours principle that can account for the wrongness of killing in Marquis's counterexamples, however, because it does not depend on occurrent desiring. In Boonin's modified future-like-ours principle, *present ideal dispositional desires*—desires an individual would have, given perfect conditions such as rationality, consciousness, and ideal circumstances—account for that being having a valuable future (p. 73). It is only the possession of *actual* dispositional desires, however, and not the mere capacity for such desires in the future that has moral relevance, Boonin argues. Consequently, a preconscious fetus does not have the same moral standing, or the same right to life, as a conscious late term fetus, an infant, a child, or an adult. If Boonin's cortical criterion is accepted, the vast majority of abortions, which take place well before the point at which fetuses can form conscious desires, are morally permissible.

A looser cognitive criterion for personhood is adopted by Baruch Brody, who appeals to the symmetry between the development of a functioning brain as the beginning of fetal humanity and the cessation of brain function as the definition of death, or the end of humanity. That is, the property whose acquisition confers the right to life in the first place is the same property that, when permanently lost, entails the loss of a right to life. That property is the possession of a functioning brain. If the brain death theory is correct, Brody concludes, a fetus becomes a human being about six weeks after fertilization, when it has a functioning brain. After that point, abortions, except under unusual circumstances, are morally impermissible. Brody's is a significantly looser cognitive criterion than Boonin's "organized cortical activity" criterion because it makes fetal humanity dependent on the presence of early brain function which is not sufficiently organized to support consciousness. A difficulty for Brody's theory is that determining when brain death has occurred may be nearly as difficult as determining when personhood begins. Brain death has proved notoriously difficult to ascertain because detectable electrical activity can continue in a brain that has ceased meaningful functioning. One study shows that at least 20 percent of "brain dead" patients continued to exhibit electrical activity on electroencephalograms, some of it compatible with function (Truog, p. 161). The symmetry Brody appeals to is thus elusive—it may be no easier to define when personhood ends than it is to define when it begins.

Both proponents and opponents of abortion believe that settling the abortion controversy requires settling the question of personhood. While there is room for agreement in positions like Boonin's, Brody's, and even Marquis's, at either extreme standards of personhood like Noonan's and Warren's are incommensurable, leading some to question the utility of defining personhood as a route to resolving the abortion conflict. So long as the fetus's moral standing is believed to depend on fetal personhood, however, the question of personhood will not disappear from the abortion debate.

Rights Conflicts and Abortion

Most opposition to abortion is grounded in two assumptions: the first is the moral personhood and right to life of the fetus; the second assumption is that, in a conflict of rights, the right to life must trump a woman's right to privacy, choice, and bodily autonomy. Many pro-choice arguments ignore the second assumption—perhaps because it seems intuitively implausible that any other right could outweigh a right to life—and focus solely on the first assumption, either offering support for the claim that fetal personhood occurs substantially later in fetal development than conception, or arguing that the criteria for moral personhood can never be met by a fetus. Neither proposition is acceptable or defensible to abortion opponents for whom it is an article of faith that a fetus has a right to life. Thomson puts forth an argument that grants, for the sake of argument, fetal personhood from conception, but challenges the second pro-life assumption that the right to life always overrides other rights.

Thomson's argument employs an analogy that has engendered controversy among both defenders and critics of abortion. Imagine, Thomson writes, that you awake one morning to find yourself hooked up to the body of an unconscious violinist who is suffering a fatal kidney ailment. The Society of Music Lovers has kidnapped you and plugged this famous violinist into your circulatory system, so that your kidneys can be used to filter his blood. You are told that in nine months, the famous violinist will have recovered, and can be safely detached, but in the meantime, to unhook him from your body would kill him. The violinist is a person, and so he has a right to life. Your life is not endangered, but you must remain tethered to the violinist against your will for nine months, thus greatly diminishing your freedom. If his right to life guarantees him the use of your body for life support, then it is morally incumbent on you to provide it, regardless of the cost to your personal freedom. The implications for abortion are clear: the violinist is meant to be analogous to a fetus, and you and your kidneys are analogous to a pregnant woman providing life support to a fetus. If, Thomson argues, it is implausible that you are morally obligated to sustain the violinist's life at such a cost to your personal freedom, then it ought to be equally implausible that a fetus's right to life guarantees it the right to continued use of a woman's body (Thomson). Thus, the fetus's right to life doesn't make abortion morally impermissible, for "having a right to life does not guarantee having either a right to be given the use of or a right to be allowed continued use of another person's body—even if one needs it for life itself" (Thomson, p. 336).

If Thomson's analogy is accepted, there are serious grounds for questioning the assumption that abortion is morally impermissible if a fetus has a right to life. However, both opponents and proponents of the right to abortion have argued against the soundness of Thomson's analogy. Abortion critics claim that there is a deep, even grotesque disanalogy between a fetus and the violinist, and that Thomson fails to attend to the moral distinction between intentionally killing and letting die. Abortion, it is argued, intentionally kills a fetus, but detaching oneself from the violinist only allows the violinist to die from his kidney ailment, an act with a very different moral status than murder. Abortion proponents and opponents alike raise a responsibility objection to Thomson's argument, claiming that her conclusion only holds in cases where pregnancy results from an involuntary act. Warren criticizes Thomson's analogy on those grounds, arguing that it is too weak to provide a thorough defense of a right to abortion, allowing it only in cases of rape (Warren, 1973). Since the majority of unwanted pregnancies are not the result of rape, Thomson's argument would permit abortion in only a small fraction of unwanted pregnancies. Thomson acknowledges that her argument leaves open the possibility that there may be some cases in which the unborn person acquires, tacitly or by consent, a right to the use of the mother's body, and in which abortion would be an unjust killing. But this possibility does not force the conclusion that all abortions are unjust killings. "Except in such cases as the unborn person has a right to demand it … nobody is morally *required* to make large sacrifices, of health, of all other interests and concerns, of all other duties and commitments, for nine years, or even for nine months, in order to keep another person alive" (Thomson, p. 338).

It is difficult to consistently maintain the position that a fetus's right to life trumps all other rights or considerations. In cases where the life of a pregnant woman is endangered by pregnancy, only the most extreme opponents of abortion claim that because abortion is the intentional killing of an innocent person, it is still morally wrong and the mother must be allowed to die. More moderate opposition to abortion allows exceptions for the life or health of the mother, and also for cases where pregnancy results from rape or incest. There is a clear inconsistency in the rape and incest exception, however, since it makes the unborn fetus's right to life contingent on the actions of its father. Abortion opponents who grant exceptions in cases of rape and incest must, if they are consistent, explain why those fetuses have a different moral status, or less of a right to life, than other fetuses, or why the right to life loses its priority to a woman's rights in those cases.

Pro-choice feminist arguments charge that most discussions of abortion place undue emphasis on fetal rights and too little emphasis on the contexts in which decisions about abortion take place. Susan Sherwin argues that traditional, nonfeminist approaches to the abortion controversy are too simplistic, considering the permissibility of abortion in isolation from the social and sexual subordination of women, and the struggle of women for control over their bodies and reproduction. Nonfeminist arguments thus mistakenly claim that the moral status of abortion turns exclusively on the moral status of the fetus (Sherwin). The central moral feature of pregnancy, Sherwin argues, is that it takes place in women's bodies and profoundly affects their lives. Because fetuses have a unique physical status of dependence on particular women, they have a unique social status as well—the value of a fetus, Sherwin claims, is determined solely by the nature of its primary relationship to the woman who carries it, and "no absolute value attaches to fetuses apart from their relational status" (p. 111). The focus on the fetus as an independent, rights-bearing entity denies pregnant women their proper roles as independent moral agents who, alone, have "the responsibility and privilege of determining a fetus's specific social status and value" (p. 110).

Some pro-life feminists attempt to sidestep the rights controversy and argue instead that abortion is inconsistent with the goals and ideals of feminism, such as opposition to violence, and the promulgation of an ethic of caring, nurturing, and interconnectedness. Others, like Sidney Callahan, argue that feminist goals cannot be achieved in a society that permits abortion (Callahan). The exclusion of the unborn from the sphere of rights and protection, Callahan argues, is analogous to the exclusion of women in unjust, patriarchal systems where "lesser orders of human life are granted rights only when wanted, chosen, or invested with value by the powerful" (Callahan, p. 368). Moreover, to grant a right to abortion in the name of women's privacy or autonomy validates the view that pregnancy and child-rearing are the sole responsibility of individual women, relieving men and the community from any responsibility. Thus "women will never climb to equality and social empowerment over mounds of dead fetuses …" (Callahan, p. 371). To exercise moral autonomy, Callahan argues, requires responsiveness and responsibility not only to what is wanted or chosen, but to what is unwanted and unchosen as well. Callahan makes no exceptions for pregnancy due to rape, arguing that even the involuntarily pregnant woman has "a moral obligation to the now-existing, dependent fetus whether she explicitly consented to its existence or not" (Callahan, p. 370).

Margaret Olivia Little argues that the literature on abortion deeply undersells the moral complexity of abortion, focusing too much on a thin moral assessment of its permissibility. She proposes that what is needed in the moral discussion of abortion is an ethics of gestation that addresses questions of "what it means to play a role in *creating* a person, how to assess responsibilities that involve *sharing,* not just risking, one's body and life, what follows from the fact that the entity in question is or would be *one's child.*" (Little, p. 493). A more complex moral interpretation must move beyond questions of metaphysical and moral status and permissibility to consider abortion's "placement on the scales of *decency, respectfulness,* and *responsibility*" (Little, p. 492).

If fetuses are not persons, Little argues, they are nonetheless respect-worthy because they are burgeoning human lives, and abortion remains a serious matter because it involves the loss of something significant and valuable. Even if we allow that fetuses are persons, however, the important moral question is what positive duties and responsibilities, if any, pregnant women have to continue gestational assistance. Both liberal and conservative positions on the duties of parenthood assume that it is an all or nothing affair, and that pregnant women either have the same obligations and responsibilities to fetuses that they do to children, or that they owe nothing beyond general beneficence. But parenthood, Little claims, is more than a social role—it is, more crucially, a relationship that develops through time, interaction, and emotional intertwinement. Regardless of the view one takes on the personhood of fetuses, gestation uniquely changes the relationship a woman has to her self, bringing with it a new identity and an impending relationship with another that is not always welcome or sustainable. Thus, "assessing the moral status of abortion … is not just about assessing the contours of generic respect owed to burgeoning human life, it's about assessing the salience of *impending relationship*" (Little, p. 498).

The fetus's status becomes progressively weightier as pregnancy continues, Little suggests, but until the fetus is a person, there is a moral prerogative to decline parenthood and end pregnancy because it "so thoroughly changes what we might call one's fundamental practical identity …. As profound as the respect we should have for burgeoning human life, we should acknowledge moral prerogatives over identity-constituting commitments and enterprises as profound as motherhood" (Little, p. 498).

The Selective Abortion Controversy

The development of tests to prenatally diagnose genetic diseases and disorders has greatly outpaced the development of effective treatments and therapies. The Human Genome Project promises to accelerate the development of prenatal diagnostic tests. Through procedures like chorionic villus sampling (CVS), which can be performed at ten weeks gestation, and amniocentesis, available at fourteen to sixteen weeks, numerous genetic abnormalities in the fetus can be detected in utero. The tests are routinely administered to women at risk for fetal abnormalities, such as older mothers and those with a family history of genetic disorder. Ultrasound, which is routinely performed throughout most pregnancies, can detect a number of abnormalities as well, including neural tube defects that can result in severe physical and cognitive disability and death. In rare instances, fetal therapy, including surgery, can correct the problems, but the overwhelming majority of pregnant women whose fetuses are found to have abnormalities are currently faced with only two options: abort the defective fetus, or risk giving birth to a child that will potentially face a lifetime of disability and hardship. In cases where the fetus's condition will result in severe physical or mental impairment, or where it will lead to inevitable death and a short, painful life, only the most extreme opponents of abortion maintain that it is wrong to abort. Abortion moderates and supporters see those as clear cases where abortion is not only morally permissible, but in some situations, morally required. Less agreement exists regarding the abortion of fetuses with minor abnormalities, genetic predispositions to disease, and genetic diseases that are eventually lethal, but compatible with more or less normal life for many years.

Disabilities rights advocates oppose the routine administration of prenatal screening and the selective abortion of fetuses found to have abnormalities. Although many disabilities rights scholars are pro-choice, and defend a woman's right to choose abortion, they object to the use of selective abortion for fetal indications, which they argue discriminates against existing people with disabilities, and sends the message to those living with disabilities that they should never have been born. This so-called Expressivist Argument claims that selective abortion expresses discriminatory attitudes towards the disabled and undermines efforts to create a more just, inclusive society (Asch, 2000). The disability critique of abortion is novel because it is concerned only with the abortion of otherwise wanted fetuses that possess a single undesirable trait, a disability.

There is profound disagreement about the use of prenatal screening and selective abortion to select fetuses for gender, either for purposes of family "balancing" or because of personal or cultural preferences for children of a particular sex—typically male. Throughout many parts of Asia, where female infanticide was once common, it has been to some extent replaced by the use of ultrasound to prenatally determine the sex of a child, followed by selective abortion of female fetuses. Analysis of census data and predicted sex ratios shows that, by a conservative estimate, more than 100 million females are missing worldwide. In China alone, where selective abortion of females is illegal, it is estimated that there are 30 million missing females, about five percent of the national total; in India and Pakistan, the number exceeds 24 million (Kristof). The criminalization of female infanticide and abortion in China and India has done little to change the deeply ingrained cultural preferences that lead to the practices, and there is good reason to believe that in societies where male offspring are overwhelmingly preferred, missing females who are not aborted are the victims of infanticide, abandonment, or fatal neglect. For consequentialist reasons, many would regard abortion as preferable in those circumstances. Little observes that in cultures that openly discriminate against women and girls, giving birth to a daughter who will face rejection and disrespect can do violence to a woman's ideals of creating and parenthood: "A woman living in a country marked by poverty and gender apartheid wants to abort because she decides it would be *wrong* for her to bear a daughter whose life, like hers, would be filled with hardship" (Little, p. 499). In Western countries where gender equality is avowed, however, the use of abortion for sex selection leaves many abortion rights defenders uneasy with the prospect of justifying a morally serious practice done for reasons regarded as trivial or patently discriminatory.

There is growing controversy over the use of fertility treatments like in vitro fertilization (IVF) and superovulatory drugs, which pose a fairly high risk of multiple gestations and births. Numerous complications affecting both the pregnant woman and her offspring are associated with multiple pregnancies. The high cost and low success rate of fertility treatments contributes to the problem—with IVF, it is typical practice to implant more than the desired number of embryos in order to increase the odds of success; superovulatory drugs, which stimulate a woman's ovaries to produce dozens of ova, afford little control over the number that will ultimately be fertilized and implanted. It is more than a little ironic that the effort to assist couples in achieving pregnancy has led to an abortion controversy over the use of selective reduction, the practice of removing some fetuses in multiple pregnancies in order to increase the chances of a healthy pregnancy and birth for the remaining fetuses. Although the procedure is not without risks—miscarriage, fetal death, and disability are known complications of selective reduction—some commentators question whether in pregnancies with a large number of fetuses—more than two or three—there is a moral imperative to reduce in order to decrease the risks to the surviving offspring. In 1997, twenty-eight-year-old Bobbi McCaughey made history when she gave birth to seven live babies—born eight weeks premature—after using fertility drugs to stimulate ovulation. While the McCaughey septuplets were widely reported as a medical "miracle," some medical ethicists questioned the wisdom of the parents who, as devout Christians, refused the option of selective reduction, thus placing their offspring at increased risk for prematurity, low birth weight, cognitive and physical disability, and death (Steinbock, p. 377). In addition to serious ethical concerns about the risks of fertility treatments and multiple pregnancies, there are consequentialist and social justice concerns about the multimillion dollar cost of neonatal care associated with multiple births, and, in a climate of medical cost-cutting, the responsible use of limited healthcare dollars.

Partial Birth Abortion

Partial birth abortion is a nonmedical term coined by anti-abortionists to describe an abortion procedure known technically as intact dilation and extraction (D&X). D&X is used primarily in second trimester abortions, and the procedure involves partially delivering a living fetus into the birth canal, then collapsing the skull and completing delivery of a dead but otherwise intact fetus. In an *amici* brief to the Supreme Court, the American College of Obstetricians and Gynecologists noted that D&X involves substantially less risk of complication than other methods of abortion used during the same gestational period (*Stenberg v. Carhart,* 2000). Fewer than five percent of abortions performed in the United States occur in the second trimester, with the vast majority taking place in the first trimester, but when the D&X procedure was widely publicized by abortion opponents in the mid-1990s, it created immediate controversy. President Bill Clinton twice vetoed federal bills to ban partial birth abortions, but a number of state laws were passed prohibiting the procedure. A Nebraska statute that made the performance of D&X a felony was challenged in a case brought to the U.S. Supreme Court in *Stenberg v. Carhart* (2000). The Court held that the Nebraska statute violated the Constitution because it lacked any exemption for the preservation of the health of the mother, and because the law's vagueness imposed an undue burden on a woman's ability to choose the more common dilation and evacuation (D&E) abortion procedure, which sometimes involves partial delivery prior to fetal dismemberment. In striking down the Nebraska ban, the Court invalidated the nearly identical laws of thirty other states.

From a consistent pro-life perspective, there can be no moral difference between partial birth abortions and abortions performed using other methods. Because a second-term fetus more closely resembles an infant than does an embryo or very early fetus, publicizing graphic and often gruesome descriptions of the D&X procedure helped the pro-life cause politically, but aside from its inflammatory aspect, it contributed little to the abortion debate. Many pro-choice ethicists, however, regard later abortions of healthy fetuses as more morally serious than early abortions. When the moral permissibility of abortion depends on the criteria used to determine fetal moral status, there is an unsettled empirical question that becomes more urgent as pregnancy continues. In second trimester abortions, cognitive criteria for fetal personhood or rights, such as sentience or cortical activity, may, by conservative estimates, be satisfied, but it remains an open question whether certainty can be achieved in this substantial gray area of fetal development.

Consequentialism and Abortion

The abortion debate in the United States has almost exclusively focused on questions of rights, to the exclusion of all other considerations. A consequentialist approach that assesses the morality of abortion in light of its good and bad consequences has the potential to resolve the rights standoff, and a number of consequentialist considerations have bearing on the abortion debate. Abortion critics have long raised fears of a slippery slope, charging that permissiveness about abortion will inevitably lead to the devaluation of human life, and a "culture of death" in which attitudes about other forms of killing, such as infanticide and euthanasia, will become more permissive. The argument depends on the assumption that the killing of a fetus is regarded as just as serious as the killing of an infant, child, or adult, and that the permissibility of one entails the permissibility of all. The culture of death argument, like other slippery slope arguments, also makes an empirical claim that the evidence to date fails to support. Since abortion was legalized in the United States in 1973, there has been no slide toward permissiveness about other forms of killing. Only one state, Oregon, has legalized physician-assisted suicide, under strict regulation. In all other states that have considered physician-assisted suicide or euthanasia, voters have declined to endorse it. Neither is there evidence to suggest that the killing of newborns is more common in the United States than it was before abortion was legalized, but in parts of the world where infanticide has historically been an acceptable means of eliminating unwanted offspring, the availability of abortion has not increased the incidence of infanticide, but reduced it (Kristof).

The coat hanger has been a powerful symbol of the abortion rights movement, a reminder of the dangerous, sometimes deadly abortions women endured before *Roe v. Wade.* Proponents of abortion rights have substantial evidence to support the claim that legal prohibitions on abortion lead to the deaths of women through self-induced abortions or illegal, unsafe abortions performed by untrained providers. Legal abortion performed under safe and sanitary conditions is generally safer than pregnancy, but in countries where abortion is prohibited, or access is severely limited, the negative consequences of unsafe and self-induced abortions include serious complications such as sepsis, hemorrhage, genital and abdominal trauma, perforated uterus, gangrene, secondary infertility, permanent disability, and death (World Health Organization [WHO]). Treatment of complications from unsafe abortions places a serious strain on the medical infrastructure of developing countries, where a disproportionate share—up to 50 percent—of scarce hospital resources are expended treating abortion complications. Unsafe abortions thus compromise other maternity and emergency health services in poor countries where healthcare is already inadequately resourced (WHO). Statistics on abortion-related mortality are especially telling: In Paraguay, illegal abortions are responsible for an astonishing 23 out of every 100 deaths of young women (United Nations). In Romania, abortion-related deaths increased sharply after 1966, when the government restricted abortion. The maternal death rate rose from 20 per 100,000 live births in 1965 to 150 per 100,000 in 1983. Abortion-related deaths decreased by more than 50 percent in the year after abortion was again legalized in 1989 (WHO). Statistics on abortion-related mortality in the United States tell a very different story about safe, legal abortion: the death rate is 0.6 per 100,000 procedures, making it as safe as a penicillin injection (WHO).

Social Justice and Access to Abortion

Decades after *Roe v. Wade,* state and federal courts and legislatures continue to address the abortion issue, and government agencies have adopted numerous regulations that affect access and funding for abortion. The practical effect of much of this activity has been the erosion of abortion rights.

Women seeking abortions currently face difficulties that are not encountered in any other area of medical care. The consolidation of the healthcare industry has reduced the number of hospitals that perform abortion, and the majority of abortions in the early twenty-first century take place in free-standing clinics that are often besieged by anti-abortion protesters who block entry to clinics and harass patients. Abortion clinics have been bombed, and doctors who provide abortion murdered. This use or threat of violence by anti-abortion extremists has had a profound effect on access to safe abortion by contributing to a decline in the number of doctors willing to perform abortion. A 1997 study shows that the percentage of obstetrics-gynecology providers willing to perform abortions dropped from 42 to 33 percent between 1983 and 1995 (*Washington Post,* 1998). A 1998 study published by the National Abortion and Reproductive Rights Action League showed that 86 percent of U.S. counties—with nearly one-third of the female American population—had no abortion provider (Michelman).

In such an atmosphere, concerns about equality and social justice arise because limited access to abortion disproportionately affects poor women (Schulman). The deeply divisive moral controversy over abortion has engendered a secondary political conflict over who should pay for abortions. Federal restrictions limit Medicaid funding for abortions to those necessary to preserve a woman's life, or for pregnancies that result from rape and incest. At the same time, state and federal welfare reform initiatives have resulted in many women and children losing welfare benefits, putting a further strain on the ability of the poorest women to procure abortions that are available to financially better-off women, and compounding the economic injustice of a healthcare system already rife with inequalities. When access to safe abortion depends on the ability to pay, the right to abortion exists in principle, but not practice.

Equally problematic from the standpoint of justice are government policies that deny financial assistance to family-planning clinics that provide information to clients about abortion. The global gag rule imposed on international family planning groups—which sometimes provide the only healthcare available to poor women and their children in developing countries—prohibits those organizations from receiving funds from the U.S. government if they discuss abortion. It is incompatible with principles of justice and equality to deny women access to information about the option and availability of abortions if it means they will be denied healthcare services that are available to women who are wealthier or better educated.

Medical abortion, or the use of the abortion drug RU-486, also known as Mifeprex, was once viewed as a solution to the problem of limited or inconvenient access to surgical abortion, but it has not proven to be an option for most women in the United States. The drug has been widely used in Europe, and was approved by the Food and Drug Administration (FDA) in 2000 despite considerable protest by anti-abortion forces. But recent surveys show that only 6 percent of obstetrician-gynecologists and 1 percent of family doctors provide RU-486 to their patients. There are a number of reasons: RU-486 is expensive, it requires three visits to a doctor—which is particularly difficult for women who must travel substantial distances to see a provider—and it must also be administered early in pregnancy. FDA regulations also require that doctors who administer RU-486 be able to perform surgical abortion, or be affiliated with a hospital that can, which limits the number of doctors who can prescribe the drug (*Washington Post,* 2002).

Can the Abortion Conflict Be Resolved?

The reasons women choose abortion are as varied as the reasons they often choose not to abort. In countries where abortion is legal, and countries where it is not, millions of women make individual moral choices to end pregnancies. Some seek abortion after contraceptive failure, others because it is the only contraceptive option available to them; some choose to end their pregnancies for financial or emotional reasons, or for the well-being of their families; still others make the tragic decision to terminate a desired pregnancy because of an unwelcome prenatal diagnosis, or because their child is the wrong sex, or because their own health is in jeopardy. Regardless of what courts and politicians, ethicists and church leaders decide about abortion, there will always be unwanted pregnancies, and there will always be women willing to risk their lives and health to have abortions. Those are the facts of the matter.

The moral picture is characterized by far less clarity. Few reasonable people would argue that abortion is not a morally weighty issue, but just how serious it is, or is not, are questions that remain unsettled. Abortion may be an insoluble political problem in a pluralistic society where incommensurable moral and religious convictions hold sway and admit of little compromise. That does not necessarily make it an insoluble moral problem. All sides can agree that the stakes are high in abortion, and the difficulty of resolving the moral conflict should not be understated. Equally reasonable and thoughtful moral theories about abortion have produced greatly divergent conclusions. If none of these theories has yet proved immune to counterargument and criticism, if none has yet prompted a collective sigh of relief that the debate is at last over, they have all contributed to the unavoidable conclusion that the abortion controversy defies simplification, and, in its uniqueness, defies easy assimilation to familiar moral principles.

L. SYD M. JOHNSON

SEE ALSO: *Adoption; Autonomy; Conscience; Conscience, Rights of; Double Effect, Principle or Doctrine of; Embryo and Fetus; Genetic Testing and Screening: Reproductive Genetic Testing; Harm; Human Dignity; Infanticide; Life; Maternal-Fetal Relationship; Moral Status; Population Policies; Women, Historical and Cross-Cultural Perspectives;* and other *Abortion* subentries

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II. CONTEMPORARY ETHICAL AND LEGAL ASPECTS: B. LEGAL AND REGULATORY ISSUES

Most contemporary legal systems regulate the practice of induced abortion. Governments around the world regulate whether, when, why, and how the estimated 46 million annual abortions occur. In some countries, abortion is governed primarily by national laws; in others, abortion is governed mainly by state or regional laws. Belief that abortion is unsafe, irreligious, immoral, unjust, or genocidal has tended to push regulation in the direction of laws that expressly prohibit some or all abortions. Convictions that abortion can alleviate overpopulation, avert economic hardship, protect women's health, promote sex equality, or eliminate undesirable progeny have tended to produce laws that permit, guarantee, or even compel abortion. More than 75 percent of the world's population live in countries in which abortion is legal, even when the life of pregnant woman is not at stake (Center for Reproductive Law and Policy).

An international survey of existing law reveals four basic patterns or models of express abortion regulation:

1. a model of prohibition;
2. a model of permission;
3. a model of prescription; and
4. a model of privacy.

Under the model of prohibition, the laws of a jurisdiction punish most or all abortions as criminal offenses, as in Ireland, Nigeria, Brazil, and Indonesia. In these countries, abortions are banned other than to save the life of the mother. Under the model of permission, laws permit abortions that meet criteria and conditions established by government, as in Sweden, Germany, England, India, and Zambia. For example, in Sweden abortions are readily available, subject to the approval of a National Health Board. In Germany, women face counseling and waiting period requirements for otherwise permitted early abortions. In the United Kingdom excluding Ireland, abortion for health and disability reasons is lawful up to 24 weeks, but a woman must obtain the approval of two physicians. Under the model of prescription, laws specifically require or encourage the termination of pregnancies falling into certain specific categories, as in The People's Republic of China. Finally, under the model of privacy, laws restrain government from enactments that criminalize or severely restrict access to medically safe abortions, as in the United States and Canada. The model of privacy treats abortion decisions as substantially a matter of private choice rather than public law. In some countries using models of permission, prescription, and privacy, including the United States, China, France, the Russian Federation, and South Africa, women are not required by law to provide officials or physicians with a state-approved reason for routine legal abortions (Center for Reproductive Law and Policy). In Russia, whose per capita abortion rate was second in the world after Romania's in 2002, 60 percent of all pregnancies end in abortion.

Abortion law is subject to change from one era to the next. Countries under the sway of the model of prohibition in one generation have moved toward the models of permission or privacy in subsequent generations. For example, when the Supreme Court of the United States declared in *Roe v. Wade* (1973) that the nation's constitution bars statutes categorically criminalizing all abortions, it announced a national standard for state and federal law that ushered out the model of prohibition and ushered in the model of privacy. Abortion law can also change from liberal to restrictive and back again, in response to political developments and judicial interpretations of constitutional principle. Thus, Poland adopted more restrictive abortion laws after democratic elections in 1989; greatly liberalized its law in 1996; and then, in response to an adverse constitutional court ruling overturning the permissive 1996 law, quickly revised its law in 1997. Under a 1997 act of Parliament, Poland permits abortion to protect the pregnant woman's life or health, or to terminate pregnancies resulting from criminal acts or in cases of fetal abnormality.

The Model of Prohibition

The model of prohibition governs official abortion policy in many African, Latin American, South Asian, and Middle Eastern countries. For example, Brazil and Sri Lanka permit abortion only to save the life of the woman. Most jurisdictions in Europe and North America reject the model of prohibition, permitting abortion on request, where pregnancy results from rape or incest, or where the continuation of pregnancy threatens the physical, mental or social well-being of the woman or her fetus. Ireland, a largely Roman Catholic nation, is one of the few European countries whose laws continued to criminalize abortions either absolutely or subject to a strictly limited number of exceptions beyond the 1970s. Under a 1983 amendment to the Irish constitution, Irish law permits abortion only to save the life of the woman. Overturning a ruling that a teenage rape victim who credibly threatened suicide could not travel to England for an abortion, the Irish Supreme Court found in 1992 that abortion would be permissible “if it is established as a matter of probability that there is a real and substantial risk to the life as distinct from the health of the mother, which can only be avoided by the termination of her pregnancy.”

Jurisdictions whose laws reflect the model of prohibition often assert a strong religious or humanitarian policy interest in protecting what are thought to be the rights and interests of unborn children. However, other objectives have also prompted strict abortion prohibition. For example, during the nineteenth and twentieth centuries, abortion opponents in the United States cited the need to protect pregnant women from the medical and psychological risks of abortion. There can be no doubt that unskilled, unsanitary abortion procedures are a health risk, and that some women who obtain abortion services experience medical complications and emotional anguish. However, some lawyers and judges doubt that medical abortion performed during the first three months of pregnancy is less safe than pregnancy and childbirth (Tribe; Rhode). They similarly doubt that elective medical abortion poses a serious risk of psychological harm. Although one writer has concluded that “every woman pays a psychological price for abortion” (Reardon, p. 141), the American Psychological Association has concluded that serious emotional problems rarely result from abortion.

Countries whose populations have been ravaged by war and genocide have sometimes proscribed abortion in an effort to increase the birth rate. Strict abortion prohibition has had the additional, if only implicit, goal of reinforcing social roles. The cultural assumption that motherhood is the appropriate social role for women buttressed Joseph Stalin’s 1936 abortion prohibitions, enacted to furnish the former Soviet Union with “a new group of heroes” (Sachdev). The belief that bearing children is women’s natural destiny may lead some to assume that birth control and abortion are both immoral and unhealthful. After 1933, Adolf Hitler prohibited contraception and declared abortion a capital offense on the belief that birth control was unhealthful. On the other hand, abortion prohibitions adopted in Germany in 1943 aimed at the “vitality of the German people” and excluded from criminality abortions performed on “racially” undesirable women (Sachdev).

The reach of laws prohibiting abortion can be broad. Obtaining an abortion has been subject to criminal penalty in some instances, and so too has distributing abortion information. Provisions of the famous Comstock Law enacted by the Congress of the United States in 1873 —later rescinded—outlawed abortion-related implements and information as “obscene” and “immoral” (Garrow; Rhode). Offenders of the Comstock Law faced imprisonment with hard labor and monetary fines. Jurisdictions prohibiting abortion generally aim at the conduct of third-party abortion providers. However, some abortion statutes also criminalize pregnant women’s own conduct, making it a punishable offense to obtain or seek abortions from third parties. Legal systems rarely punish medical abortion as the full equivalent of felonious unjustified murder.

Criminalizing non-surgical and self-induced abortion poses special problems of detection and law enforcement. Pharmaceuticals approved for other purposes, like the cancer drug methotrexate, can be used to induce abortion. Self-induced abortion has often involved risky procedures, such as inserting knitting needles, wire coat hangers, or other foreign objects through the cervix. Many self-induced abortions are detected because they end tragically in medical and police emergencies. In 1989, a healthcare group in California promulgated a videotape demonstrating “menstrual extraction,” a nonmedical abortion technique trainers say women can learn to perform safely at home with the help of a friend. To the extent that they are workable, abortion procedures that can be performed without professional assistance fall beyond the practical reach of law.

Prohibitive abortion law requires lawmakers to define what counts as abortion, and therefore what is subject to criminal penalties. The surgical and medical procedures generally in use by physicians in licensed hospitals and clinics in Europe and the United States plainly qualify as abortion. However, certain forms of birth control not viewed as abortion could conceivably fall under the scope of strict abortion prohibitions. Popularly viewed as a form of contraception, the intrauterine device (IUD) may function as a kind of abortifacient, blocking implantation of a fertilized egg, rather than preventing ovulation or fertilization. Étienne-Émile Baulieu’s drug, RU-486, named for its French manufacturer, Roussel Uclaf, poses a related difficulty of definition. Described by French Minister of Health Claude Levin as “the moral property of women, not just the property of the drug company,” RU-486 (mifepristone) arrived on the European scene in the 1980s and in the United States in 2000. Unlike pharmaceutical contraceptives that prevent fertilization or ovulation, RU-486 acts to block the successful implantation of a fertilized egg. Rejecting the popular “abortion pill” label, Baulieu has suggested that RU-486 is neither contraception nor abortion but something new—“contragestation.” Still, it seems unlikely that a jurisdiction that strictly prohibits abortion would view “contragestation” as anything other than early abortion.

Abortion flourishes under regimes of prohibitive abortion law (Sachdev). In fact, about half of the estimated 46 million abortions that take place each year are illegal in the jurisdictions in which they occur. The criminal code of Bangladesh strictly prohibits most abortions, but physicians commonly induce abortion by performing a uterine evacuation procedure known as “menstrual regulation” on women who are many weeks pregnant. Prohibitive abortion laws commonly fall short of their stated goals and public expectations because governments are unwilling or unable to enforce the letter of the law. The prohibitive laws that governed abortion in the United States prior to *Roe v. Wade* were enacted to preserve unborn life and women’s physical and mental health (Garrow). It has been argued that the aim of fetal preservation was at least partly undermined by the large number of clandestine abortions performed, notwithstanding prohibitive laws (Tribe). Although most abortions were illegal in much of the United States prior to 1973, American women obtained an estimated 200,000 to 1.2 million abortions each year in the 1960s and early 1970s (Tietze, Forrest, and Henshaw), compared to about 1.5 million each year throughout the 1980s and early 1990s, and 1.3 million in 1997. David Reardon puts the number of abortions pre-*Roe* at merely 100,000 to 200,000 per year. The aim of preserving women’s health may have been frustrated under the regime of prohibition because clandestine abortions were commonplace but were not always performed by skilled practitioners in hygienic settings. This was especially true of the illegal abortions obtained by African-American women, who accounted for a disproportionate number of the victims of illegal procedures. (Twenty percent of the deaths related to pregnancy and childbirth in the United States in 1965 were attributed to illegal abortions.) Legalization of abortion probably resulted in a small-to-moderate increase in the number of abortions, but it appears to have greatly decreased the incidence of abortion-related infertility and death.

Model of Permission

The model of permission became the pervasive one around the world in the final quarter of the twentieth century. Under the model of permission, abortion is legally available, but only with the approval of government officials or officially-designated decision makers, such as administrative boards, committees, physicians, or judges. In some permission-model jurisdictions, officials grant permission pro forma in nearly every case. In Norway, prior to 1975 reforms that liberalized abortion, as many as 94 percent of the requests for abortions made to Abortion Boards were routinely granted (Olsnes). Official decision makers in permissive jurisdictions rely upon a handful of factors to determine which abortions to permit and which abortions to prohibit (Petersen; Glendon).

The stage of pregnancy is very frequently a factor. Officials called upon to implement legal norms or exercise discretion often permit “early” abortions and prohibit “late” ones. This no doubt helps to explain the statistic that 90 percent of reported abortions take place within the first three months of pregnancy. Another factor decision makers commonly consider is the woman’s medical or social status. Restrictive laws require that officials deny permission to abort for reasons other than medical hardship. Liberal laws often require that officials allow abortions because pregnancy or childbirth would involve social or economic hardship for the woman. In many jurisdictions, grounds for social hardship include rape, incest, or the age and marital status of the woman. The health or condition of the fetus can be a third factor in permitting or prohibiting abortion. The law may premise access to abortion on evidence that a child would be born with serious physical or mental abnormalities.

Genetic testing for the purpose of enabling parents to abort fetuses born with undesirable traits is already practiced in the United States. Healthcare providers in some states even face “wrongful life” and “wrongful birth” lawsuits for negligent failure to offer women information needed to prevent or abort an unwanted pregnancy. With advances in prenatal testing that enable detection of the sex of a fetus, it is possible for a pregnant woman to abort selectively unwanted male or female offspring. In some instances, abortion for sex selection may be tied to a desire to avoid giving birth to a child with a gender-related genetic disease. Jurisdictions that permit abortion without regard to reason presumably permit abortion for sex selection.

For most of the twentieth century, a number of countries governed abortion under highly bureaucratic versions of the model of permission (Sachdev). For a time in the eastern European countries of Hungary, Romania, Poland, and Bulgaria, abortion was lawful only if approved by a state board or committee. These countries reportedly permitted abortion in almost every case through the fourth month of pregnancy. Romania reverted to a prohibitive policy in 1966 in response to concerns about underpopulation and the health effects of multiple abortions. It prohibited most contraception and abortion for women who did not have at least four, and eventually five, children. Abortion prohibition was accompanied by a significant incidence of mortality related to illegal abortion. In the mid-1980s, 86 percent of the women in Romania who died as a consequence of pregnancy or childbirth died as a result of illegal abortions, compared with, for example, 29 percent in the former Soviet Union and 13 percent in Sri Lanka.

Other historical instances of the bureaucratic model of permission are the laws and administrative regulations in force in Denmark from 1939 to 1973, and in Sweden from 1939 to 1974. In Denmark, local and national committees consisting of teams of social workers, physicians, and psychiatrists evaluated the applications of women seeking legal abortions. Scandinavian officials on boards or committees charged with decision making typically assessed the impact of childbirth and child care on the mental or physical health of the woman, and the woman's living conditions. Israeli Ministry of Health regulations enacted in 1978 permitted hospitals and clinics to form committees consisting of two physicians and a social worker to decide whether to grant women's abortion requests. Although living conditions, such as other children and economic hardship, were initially an authorized basis for granting abortion requests, Israel amended the law in 1980 under pressure from religious groups and in response to concerns about a declining population rate.

At the beginning of the twenty-first century, a number of countries in Asia, South America, Europe, and North America make a woman's obtaining an abortion dependent upon the approval of one or more physicians, a judge, or one or both parents. Great Britain and countries whose abortion law was modeled on Great Britain's—Hong Kong, Zambia, and Australia—are examples of countries whose laws place decision making in the hands of physicians. The law of Great Britain was transformed over a great many centuries from a model of prohibition, to a model of permission, and even a model of privacy. Early English common law embodied the model of prohibition, at least for abortions taking place after the first few months of pregnancy. The common law proscribed abortion after *quickening,* about the fourth month of pregnancy, when fetal *animation* or *ensoulment* was deemed to have taken place. In 1861 the statutory abortion law of Great Britain defined as a felony any act intended to cause abortion, whether induced by the woman herself, if she were pregnant, or by others, whether or not she was in fact pregnant. The Abortion Act of 1967 abolished the nineteenth-century felony. The act's liberal provisions permit an abortion where any two medical practitioners certify in good faith that pregnancy "would involve risk to the life of the pregnant woman, or of injury to the physical or mental health of the pregnant woman or any existing children of her family, greater than if the pregnancy were terminated." Under this rule, qualifying for abortion poses no practical difficulty for women with the money to pay private physicians. As English law illustrates, the model of permission can have the distinct effect of empowering the medical and psychiatric professions to govern reproduction in accordance with their profession's internal standards of judgment.

Abortion is common in Australia, where abortion rights vary significantly from state to state and are governed both by common law and criminal statute. A liberalizing trend has been observed since the mid-1990s, when only South Australia and the Northern Territory had statutes specifically permitting some abortions. In 1998 controversy erupted over Australian abortion law, when two physicians were arrested in Western Australia for violating a moribund nineteenth-century criminal statute. The doctors had performed a consensual abortion in 1996 on a Maori woman who stored the aborted fetus in her refrigerator, planning to take it to New Zealand for burial in accordance with Maori traditions. Following reforms, early abortion is available virtually on demand in some Australian states, and is subject to enforced restrictions in others.

In India, the Medical Termination Pregnancy law enacted in 1971 permitted abortions that one or, if the woman is more than twelve weeks pregnant, two physicians certify. Grounds for certification are liberal. Abortion may be obtained to preclude a risk to the pregnant woman's mental or physical health, or a risk of the birth of a child with serious mental or physical abnormalities. No abortions after twenty weeks are legal under the law. A woman's mental health is considered at risk in cases of economic hardship and where pregnancy resulted from failed contraception. The 1975 Abortion and Sterilization Act made many abortions lawful in the Republic of South Africa, on the certification of two physicians that statutory requirements are met. The law required that where abortion was sought on grounds of risk to mental health, one of two certifying physicians be a psychiatrist willing to attest to danger of permanent mental harm. South Africa has subsequently liberalized its abortion law, making early abortion available on demand.

French law permits women to make their own judgments (early in pregnancy) about whether they are entitled to abortion on grounds of hardship. In this respect, French law resembles the federal law of the United States under *Roe v. Wade.* French regulations enacted in 1975 are representative of international responses to the judicial transformation of United States law with *Roe v. Wade* in 1973. Reflecting the aspirations of both the model of permission and the model of privacy, the French enactment begins with a declaration that the law guarantees respect for every human being from the beginning of life, and that this principle is to be sacrificed only in case of necessity and according to specific conditions. But the law authorizes any woman who is ten weeks pregnant or less to request a physician for an abortion if she believes pregnancy or childbirth will create hardship. Moreover, at any stage of pregnancy, right up to the moment of birth, abortion is lawful if two physicians, one of them from an official list, certify that continuation of pregnancy would put the woman's health gravely in peril, or that there is a strong possibility that the child would suffer from an incurable condition.

The French abortion law imposes numerous conditions on all abortions. Attending physicians must inform women of the medical risks of abortion and give them an official guide to the forms of assistance available to families, mothers, and children, and to relevant social service organizations. Women then must consult one of the listed social services. Women wishing to proceed with abortion must confirm their request in writing, after a one-week waiting period. Abortions must be performed by physicians in a public or recognized private hospital and must be reported to the regional health authorities. Hospitals must provide women who have obtained abortions with birth control information.

The model of privacy may best describe the overall aspiration of *Roe v. Wade.* However, the model of permission is arguably more descriptive of United States abortion law pertaining to unemancipated minors. The Supreme Court has taken the position that minors have a constitutional right to privacy and may terminate their pregnancies without parental consent, but that minors may not object on constitutional grounds to parental notification requirements and waiting periods. Individual justices on the Court have argued that requiring pregnant minors to notify family members of pregnancy and abortion, in effect, gives veto powers to third parties in a way that is inconsistent with the spirit of *Roe v. Wade.* Yet, a majority held in *Hodgson v. Minnesota* (1990) that states providing a "judicial by-pass procedure" may attempt to involve one or both parents in minors' abortion decision making by requiring minors or their physicians to contact parents in advance of abortion. In judicial bypass procedures, minors must be permitted to ask a judge to waive parental notification requirements. The judge is expected to waive the requirement if he or she determines that the minor is mature or that notification is not in the minor's best interests. Justices in the minority have objected that bypass procedures are unwarranted, since most minors notify parents or other responsible adults of pregnancy and abortion, and most minors seeking judicial waiver obtain it. In addition, the practical effect of mandatory notification is that some teens will delay abortion, increasing costs and medical risks. Some justices have argued that laws requiring parental involvement place minors with abusive parents or broken homes at a disadvantage and even at mortal risk.

Model of Prescription

Under the models of permission and privacy, a government permits some or all of the abortions women want. Under the model of prescription, a government compels or virtually compels women to obtain abortions the government wants. Far-reaching compulsory abortion laws have been rare in the modern world. In the West, policymakers frown upon official and unofficial policies of mandatory abortion for poor and mentally incompetent women. Although healthcare providers reportedly recommend abortion in some instances—for example, when a pregnant woman is addicted to cocaine or infected with the AIDS virus—the United States government does not officially recommend or mandate abortion for any class of pregnancy. Under a penal code adopted in 1979, Cuban law proscribes abortion performed without the permission of the woman.

In an effort to control overpopulation and protect its economy, China began adopting "planned birth" family-planning measures in 1953. These measures aggressively encourage abortion through a system of penalties and rewards. Under the Chinese constitution, both the government and individuals are responsible for the planned-birth policy. In 1974, couples were limited to two children. Since 1979 couples wishing to bear children have been authorized to have only one child, and then only after securing a government permit. To encourage compliance, abortion is offered at no cost and may entitle the woman to a two-week paid leave of absence; women who have an IUD inserted or a tubal ligation along with abortion may receive additional paid leave. The effect of the planned-birth policy on the abortion rate in China is not known in the West. However, female infanticide and abortion for sex selection are reported. Chinese families have reportedly resorted to infanticide and selective abortion to ensure that their one-child quota is filled by a child of the culturally preferred male sex.

Model of Privacy

Under the model of privacy, the law rarely compels abortion and permits all or virtually all abortions, as long as they are performed by medically qualified persons in clinics, hospitals, or other qualified facilities. Safety is a frequent goal of legal systems characterized by the model of privacy, although safety is not necessarily suggested by "privacy" nomenclature. The former Soviet Union adopted the model of privacy on safety and privacy grounds in 1920, more than a half century before the model came to dominate understandings of U.S. law. The goal of the Soviet decree legalizing any abortion performed by a physician in a state hospital was both to keep women safe from unskilled abortionists and to secure women's freedom and equality in work, education, and marriage. In 1936, the decree was rescinded in favor of a law prohibiting abortion other than to spare the life or health of the woman or prevent transmission of an inheritable disease. The shift back to the models of prohibition and permission seems to have been motivated by concern about declining birthrates, health effects of medical abortions, and diminished regard for marriage and childbearing. But in 1955, the Soviet law moved back toward the model of privacy, again to protect women from unskilled abortionists and to give women themselves an opportunity to decide whether to become mothers (Sachdev).

In Japan, abortion has been legal since the government passed Eugenic Protection Laws in 1948 to protect women's health and deter the birth of what were considered undesirable offspring. In practice, abortion is available to women in Japan upon request. The law does limit abortion, but the limitations are extremely liberal: Abortion is permitted when performed by designated physicians to avert mental and physical disease or abnormalities; when pregnancy results from violence; or when the woman's health would be impaired for physical or economic reasons. Functionally, one can view Japan as a model of privacy jurisdiction; yet women's autonomy and equality are not the express policy objectives of its liberal abortion law. Japan follows the model of permission insofar as laws restrict abortion and have not been designed specifically to promote autonomous, private decision making. For nearly thirty years after they had been approved for use in North America and Europe, low-dose birth control pills were banned in Japan out of concerns about safety. The end of the ban in 1999 could mean that abortion will no longer function as a major form of birth control in Japan.

In the United States, abortion policy since the early 1970s has been directed to women's rights. During the early 1970s, the United States and a number of other countries adopted laws approximating the model of privacy. The theory that during the first trimester abortion ought to be available without any restrictions gained popularity. In effect, this approach was adopted in the former East Germany in 1972, Denmark in 1973, Sweden in 1974, France in 1975, and Norway in 1978 (Sachdev; Olsnes). "Fetal viability," the point at which, in some of these countries, the interests of the woman cease to be accorded overriding weight, is variously fixed between twenty weeks and twenty-eight weeks. In Norway, under 1978 amendments to a 1975 law, a woman "shall herself make the final decision concerning termination of pregnancy provided that it is possible to perform the operation before the twelfth week of pregnancy has elapsed." After the twelfth week, abortion sought for a number of medical or social indications is available upon successful application to an "Abortion Board" (Olsnes).

In *Morgentaler et al. v. The Queen* (1988), the Supreme Court of Canada found by a margin of five to two that provisions of the Criminal Code infringed Section 7 of the Canadian Charter of Rights and Freedoms promising "life, liberty and security of the person." The Canadian justices argued that "personal security," and with it "bodily integrity," "human dignity," and "self-respect," were threatened by interference with reproductive choices (Morton). The Canadian legislature remains free to regulate abortion consistent with the *Morgentaler* decision. However, in 1990 a bill to restrict abortion access to women whose physicians certified a health-related need for the procedure failed. The government thereafter announced that it would not seek new abortion legislation.

In Canada, the United States, and other privacy-model jurisdictions, liberal abortion law permits autonomous choices about matters that profoundly affect women's bodies, lifestyles, and equality. However, it is generally recognized that laws that decriminalize and deregulate abortion do not guarantee that every woman who desires an abortion will get one. Abortion is costly, and may or may not be covered by the health insurance of women who have insurance. The U.S. Supreme Court has repeatedly held that state and federal governments may encourage childbirth over abortion by refusing to include abortion among Medicaid and other entitlements awarded the poor. As a consequence, public funding for abortion is not available as a matter of right; publicly funded civilian and military hospitals are not required to perform abortion services; and states may prohibit physicians employed by public hospitals from performing abortions.

Focus: The United States

The Constitution of the United States does not mention "abortion" by name. However, the Supreme Court has consistently held since *Roe v. Wade* (1973) and *Doe v. Bolton* (1973) that the due process clause of the Fourteenth Amendment guarantees American women a fundamental right to obtain medically safe abortions. States may not categorically ban abortion or unduly burden women's fundamental constitutional right to terminate pregnancy.

The state of Connecticut passed the first American legislation against abortion in 1821 (Garrow). At first, American law did not penalize early (pre-quickening) abortion. However, between 1827 and 1860, twenty states or territories passed statutes against abortion at all stages of pregnancy. By 1868, thirty-six states or territories had antiabortion statutes in place, enforcement of which was often lax. In 1965, all fifty states treated abortion and attempted abortion at all stages of pregnancy as felonies, subject to certain exceptions. In forty-six states and the District of Columbia, the relevant statutes explicitly permitted abortion to save the mother's life, while in two of the other four states a similar exception was recognized by the courts.

Between 1967 and early 1973, a dozen jurisdictions in the United States adopted somewhat permissive abortion laws patterned on the model legislation suggested in 1962 by the influential American Law Institute. These laws permitted abortion when performed by a licensed physician who determined that there was a substantial risk that pregnancy would seriously injure the physical or mental health of the mother; that the child would be born with grave physical or mental defect; or that the pregnancy resulted from rape or incest. Almost all of the other reforming jurisdictions nevertheless sought to strengthen the institutionalization of abortion practice by stipulating that an abortion would be lawful only if performed in an accredited hospital after approval by a committee established in the hospital for that purpose.

The decriminalization of abortion on the national level lagged behind the decriminalization of contraception. In 1965 the Supreme Court decided *Griswold v. Connecticut,* holding that states may not outlaw a married woman's use of birth control. The Court based its ruling on an unenumerated constitutional "right to privacy" implicit in the Bill of Rights and the Fourteenth Amendment. This same right to privacy was invoked in 1973 in *Roe v. Wade* to limit government interference with abortion. The right to privacy was, and is, controversial among lawyers and judges reluctant to recognize novel unenumerated rights. However, both the American Medical Association and the American College of Obstetricians and Gynecologists favored legalization of abortion. The immediate effect of *Roe v. Wade* and *Doe v. Bolton,* its simultaneously decided, lesser-known companion case, was to invalidate the laws regulating abortion in every state, except perhaps the already very permissive laws adopted in 1969 and 1970 in New York, Alaska, Hawaii, and Washington.

Roe and *Doe* established that:

1. no law can restrict the right of a woman to have a physician abort her pregnancy during the first three months, or first trimester, of her pregnancy;
2. during the second trimester, the abortion procedure may be regulated by law only to the extent that the regulation reasonably relates to the preservation and protection of maternal health;
3. at the point at which the fetus becomes "viable," a law may prohibit abortion, but only subject to an exception permitting abortion whenever necessary to protect the woman's life or health (including any aspects of her physical or mental health); and
4. no law may require that all abortions be performed in a hospital, or that abortions be approved by a hospital committee or by a second medical opinion, or that abortions be performed only on women resident in the state concerned.

The Court in *Roe* and *Doe* concluded that the Constitution does not accord legal personhood status to the fetus. Critics of this conclusion point out that the unborn are implicitly treated as legal persons in several other areas of the law. The unborn are taken into account in the allocation of property rights and the attribution of criminal and civil responsibility. For example, the unborn can inherit property. Negligently killing or injuring a fetus can give rise to civil liability for wrongful death, wrongful birth, battery, and other torts.

Roe made clear that women were not to be ascribed a right to exclusive control over their bodies during pregnancy. Yet the case signaled that the Constitution limits the role government may play in abortion decisions. In the first decade and a half after *Roe,* the Court struck down numerous state abortion restrictions. States unsuccessfully attempted to control abortion through advertising restrictions; zoning restrictions; record-keeping and reporting requirements; elaborate "informed consent" and physician-counseling requirements; mandatory waiting periods; bans on abortions for sex selection; the requirement of the presence of a second physician during the abortion procedure; the requirement that physicians employ methods of abortion calculated to save the lives of viable fetuses; the oversight requirement that physicians send all tissue removed during an abortion to a laboratory for analysis by a certified pathologist; the requirement that insurance companies offer at a lower cost insurance that does not cover most elective abortion; legislating a statewide information campaign to communicate an official state policy against abortion; legislating criminal sanctions for physicians who knowingly abort viable fetuses; and requirements that some or all abortions after the first trimester be performed in a hospital. However, the Supreme Court has repeatedly validated state and federal government policies that prefer childbirth to abortion by declining to pay for the abortions of poor women entitled to welfare benefits for prenatal care and childbirth (Solinger).

A major reaffirmation of *Roe, Thornburgh v. American College of Obstetricians and Gynecologists* (1986), held that states were not permitted to indirectly prohibit abortion by encumbering the decision to seek abortion with unnecessary regulations. A series of highly publicized Court decisions handed down since 1989 appear to permit more extensive regulation of first- and second-trimester abortions than *Roe* and *Doe* seemed to contemplate. *Webster v. Reproductive Services* (1989) permitted legislation requiring viability testing and limits on publicly funded physician care. The Court declined in *Webster* to decide the constitutionality of the declaration in the preamble of a Missouri statute that "[the] life of each human being begins at conception," and that "unborn children have protectable interests in life, health and well being" because the state had not yet sought to limit abortion by appeal to it. Encouraged by the *Webster* decision, several states and the territory of Guam sought between 1989 and 1992 to ban or discourage abortion through aggressive new regulation and enforcement. Anticipating that the Supreme Court would welcome an opportunity to overrule *Roe* in the 1990s, Guam enacted legislation prohibiting most abortion and its advocacy. A federal judge quickly declared Guam's law unenforceable under *Roe.*

In two 1990 cases critical of *Roe, Hodgson v. Minnesota* and *Ohio v. Akron Center for Reproductive Health,* the Court upheld parental notification requirements for minors. *Rust v. Sullivan* (1991) upheld a federal "gag rule" statute, subsequently eliminated by Congress, prohibiting abortion counseling by physicians in federally supported facilities. *Planned Parenthood v. Casey* (1992) affirmed *Roe v. Wade* as the law of the land and invalidated spousal notification. However, the case upheld a twenty-four-hour waiting period as part of a state's "informed consent" procedures. *Casey* shed the trimester framework of *Roe,* opening the door to regulation at any stage of pregnancy. *Casey* also announced a weaker standard of review in abortion cases that promised to permit more state regulation. Under *Roe,* abortion statutes were to be struck down if they did not further a "compelling" state interest. Under *Casey,* statutes "rationally related" to a "legitimate" state interest are to be upheld, assuming they do not "unduly burden" the abortion right.

Many Americans favor some restrictions on abortion, although a 2000 Gallup poll showed more than 80 percent of Americans approved some or all abortions. A national poll conducted in 1994 by Barna Research Groups showed that 78 percent of the adults surveyed approved the legalization of some (49%) or all (29%) abortions. In a 1994 survey conducted by Yankelovich Partners, Inc., 85 percent said a woman should be able to obtain an abortion no matter what the reason (46%) or in certain circumstances (39%). A CBS News/*New York Times* poll conducted in 1998 found that 61 percent of those surveyed favored legal abortion in the first trimester, 15 percent favored legal abortion also in the second trimester, and 7 percent favored legality in the third trimester. The same poll showed about 45 percent of those surveyed favored more restrictions on abortion, and 22 percent favored blanket prohibition.

The weakening of the standard of review in abortion cases after the *Casey* decision underscores that constitutional abortion law in the United States hovers uneasily between the models of permission and privacy. For this reason, it seems likely that the Supreme Court will be asked again and again to clarify the extent to which the state and federal government may restrict abortion rights. Proposed state and federal statutes such as the Partial Birth Abortion Ban Act of 2000 and the Born Alive Infant Protection Act of 2002 would extend legal protections to viable fetuses and curb certain abortion practices. Yet in *Stenberg v. Carhart* (2000), the Court declared unconstitutional a Nebraska statute outlawing so-called "partial birth" abortions. The Court reasoned that the broadly drafted statute lacked a constitutionally necessary exception for abortions to save the life of the mother, and could be construed to rule out *dilation and evacuation* as well as the more controversial *dilation and extraction* or *partial birth* procedure.

The U.S. Food and Drug Administration approved the controversial drug RU-486 (mifepristone) in 2000. The long awaited "abortion pill" has not become the elected method of abortion for a majority of American patients and providers. Notwithstanding the limited popularity of mifepristone as an abortifacient, state and federal lawmakers who oppose its use acted quickly but unsuccessfully to propose legislation outlawing the drug or limiting the types of physicians authorized to prescribe it. Because of *Roe v. Wade* and possible nonabortion uses of the medication, it is unlikely that blanket legislative bans on mifepristone would be found constitutional.

As long as they stand, *Roe v. Wade* and *Casey* will serve to provide a national abortion law standard for the United States. Since *Roe* in 1973, several attempts have been made in both houses of the U.S. Congress to undercut the judicial decision through legislation. One attempt, premised on the idea of "states' rights," involved legislation which, if adopted, would have established that no right to an abortion is secured by the Constitution and, therefore, that the fifty states are free to adopt restrictions on abortions. A second attempt, premised on "fetal personhood," would have expanded the definition of "person" under the due process and equal protection clauses of the Fifth and Fourteenth Amendments. The fetal personhood legislation would have declared that the right to personhood attaches from the moment of conception.

Supporters of *Roe* in Congress have attempted to legislate the holding of Roe through a federal statute. The Freedom of Choice Act was introduced into Congress several times after *Webster,* beginning in November 1989. Its passage by Congress would prohibit states from enacting restrictions on the right to abortion before fetal viability. A 1994 survey conducted by the Hickman-Brown Research Company found that 56 percent of those polled "strongly" or "somewhat" favored passage of a Freedom of Choice Act, while 38 percent somewhat or strongly opposed such a law. Initiatives to amend the federal constitution to include pro-life or pro-choice strictures have not advanced far beyond the drafting table. State statutes and state constitutions are an increasingly significant source of protection for abortion rights.

With *In re T.W.* (1989), the Florida Supreme Court invalidated that state's parental consent requirement, relying upon the state constitution. As a result of this decision, Florida recognized a fundamental abortion right independent of *Roe v. Wade.* A Maryland referendum endorsed by voters in 1992 similarly established state abortion rights not tied to the fate of *Roe v. Wade* in the Supreme Court.

The Implications of Abortion Law

The liberalization of abortion law establishes rights for women who wish to terminate their pregnancies. The full implications of those rights are unclear for

1. the use and disposal of fertilized eggs, embryos, and fetal remains;
2. the enforceability of surrogate mother and surrogate gestator contracts granting third parties a legal interest in a woman's pregnancy;
3. the criminalization of pregnant women's conduct;
4. the tort liability of healthcare providers for wrongful birth and wrongful life; and
5. organized protest at abortion facilities (Purdy).

One legal concern is whether women who elect to abort have a familial, proprietary, or other interest in routinely aborted embryos or fetuses. State statutes typically require that abortion providers dispose of fetal remains in the way physicians dispose of other excised tissues. Yet some effort has been made to treat abortion tissues and fetuses differently, either because of their possible commercial value for research into the treatment of diabetes, leukemia, Alzheimer's disease, and Parkinson's disease; or because of their possible value as deceased "children." In 1984 a federal judge in Louisiana held that a statute requiring abortion providers to present patients with the option of burial or cremation was an unconstitutional burden on freedom of choice. About 90 percent of all abortions performed in the United States, and in other countries, are performed during the first trimester. The court implied that women might be discouraged from first-trimester abortions on the mistaken belief that extracted tissue would resemble a baby. Another legal concern is whether aborted embryos and fetuses may be sold for research purposes. American courts and legislators are unlikely to permit outright sales of abortion tissues for research purposes. Indeed, federal agency policies adopted in the 1980s declared a moratorium on the use of abortion tissues derived from elective abortions partly out of concern that women might be encouraged to abort for gain. Signaling a change in policy, in 1993, Democratic President William Jefferson Clinton issued an executive order lifting the moratorium on fetal tissue research. President George W. Bush reversed this move, with his announcement of new federal restrictions on human embryo-derived stem cell research in 2001.

Hundreds of men and women have been parties to commercial surrogate motherhood contracts in recent decades. Commercial surrogacy agreements commonly obtain provisions in which the would-be surrogate mother or gestator undertakes that she will not obtain an abortion should she become pregnant as a result of the surrogacy transactions. In the celebrated 1988 *Baby M* case, MaryBeth Whitehead agreed in writing that she would "not abort the child once conceived" unless a physician determined it necessary to protect her health or "the child has been determined … to be physiologically abnormal." Although the Supreme Court of New Jersey refused to enforce the surrogacy contract in *Baby M,* other jurisdictions have not done so and face questions about the commercial alienability of constitutional abortion rights.

Another set of issues relates to the extent to which abortion rights may prevent government from intervening to enjoin or punish risky behavior by pregnant women who, for example, smoke cigarettes, consume alcohol, abuse drugs, and fail to heed medical advice. In a number of isolated cases in the United States, judges have jailed pregnant women they feared would abuse or neglect their fetuses. In *Ferguson v. City of Charleston* (2001), the United States Supreme Court struck down a program under which a hospital tested pregnant patients for illegal narcotics use without their informed consent and reported patients who refused prescribed rehabilitation to law enforcement authorities. A somewhat different concern is the legal implications of government intervention in the event that a pregnant woman refuses a blood transfusion needed to save her life, or a cesarean delivery physicians believe to be in the best medical interest of the unborn. Some view *Roe v. Wade* as holding by implication that women have a broad right to control—and even abuse—their own bodies without regard to fetal well-being. Yet a plausible counterview is that *Roe* does nothing more than immunize women from prosecution for early abortions, if they choose to have them.

Abortion is controversial in many countries. Violence aimed at abortion providers has occurred both in Canada and the United States. In May 1992 a bomb blast blamed on antiabortion radicals destroyed the Morgentaler abortion clinic in Toronto. Rare in Canada, dozens of abortion clinic bombings and fires have occurred in the United States. Antiabortion activists throughout the United States have demonstrated at abortion sites to focus attention on their concerns. Generally peaceful, these demonstrations have sometimes become blockades that interfere with the ability of patients and staff to utilize facilities where abortions are believed to take place. Demonstrators have sometimes resorted to harassment, noise nuisance, property damage, and murder. The shooting deaths of two Florida physicians outside abortion facilities in 1993 and 1994 dramatized the conflict between protesters and clinics. The United States Congress passed the Freedom of Access to Clinic Entrances Act of 1994 in an effort to assure freedom of access to reproduction services. The act makes acts of obstruction and interference at places providing reproductive services a federal offense punishable by fines and imprisonment.

The right to abortion has been held by some state courts to provide a rationale for permitting "wrongful birth" or "wrongful life" lawsuits. In wrongful birth actions, parents sue healthcare providers to recover from emotional distress and expenses connected with raising children with congenital abnormalities. In wrongful life actions, disabled offspring sue healthcare providers alleging that professional negligence caused their births into lives of pain, suffering, and extraordinary expenses. Citing *Roe v. Wade,* in *Berman v. Allan,* 80 N.J. 421, 404 A2D 8 (1979), the New Jersey Supreme Court allowed a wrongful life lawsuit for professional negligence to go forward against the obstetricians of a woman who alleged that she was not offered amniocentesis and, as a consequence, was denied an opportunity to exercise her legal right to abort a fetus affected by down's syndrome. Pennsylvania and several other states have refused to permit wrongful birth or wrongful life suits. Permissive jurisdictions stress the fairness of compelling negligent physicians to share the economic burdens borne by the families of the disabled. However, some policy makers believe such suits imply disrespect for the human life and for the right to life of disabled persons.

Abortion rights and free-speech rights clash in the context of conflicts over abortion clinic protests. Women have a legal right to seek abortion without highly offensive intrusion, physical assault, and violence. These rights come into play where, for example, protesters block access to clinics, or broadcast video of clinic patrons over the Internet or on public access television. But antiabortion protesters have a First Amendment right to freedom of speech, expression, and assembly. Citing the First Amendment in *Schenck v. Pro-Choice Network of Western N.Y.* (1997), the Supreme Court refused to uphold an injunction that created a "floating buffer zone" with a 15-foot radius around persons utilizing abortion facilities. Seeking to balance the rights of clinic users and protestors, in *Hill v. Colorado* (2000), the Court upheld a statute creating a narrow, 8-foot "bubble zone" around abortion clinics as a reasonable restriction of protestors' free speech. Following the murders of physicians who performed abortions, a federal appeals court in *Planned Parenthood of the Colom./Willamette, Inc. v. Am. Coalition of Life Activists* (2002) held that the federal Freedom of Access to Clinics Act's definition of a violent threat extended to the circulation by antiabortion activists of "guilty posters" targeting specific abortion providers. Some federal courts have been reluctant to enjoin abortion protestors accused of actual or threatened violence on the basis of state or federal statutes, such as the Ku Klux Klan Act, not clearly enacted for that purpose. In *National Organization for Women v. Scheidler* (1994), however, the Supreme Court determined that the federal Racketeer Influences and Corrupt Organizations (RICO) statute could apply to a coalition of antiabortion groups alleged to be members of a nationwide conspiracy to close abortion clinics. The alleged conspirators unsuccessfully argued that RICO applies only to conspiracies in which the alleged racketeers act for the sake of economic gain rather than out of religious, moral, or political conviction. The Court found that acts that did not generate income for alleged racketeers but that adversely affected businesses such as abortion clinics were potentially conspiratorial under the RICO statute. The victory for proabortion rights groups was undercut by a later Supreme Court decision, *Scheidler v. National Organization of Women* (2003), which held that antiabortion protesters interfering with the property right of lawful abortion did not amount to racketeering acts of extortion required by the RICO statute.

In sum, the practice of abortion raises numerous legal issues in the jurisdictions that permit it. Because so many oppose abortion on religious and moral grounds, abortion-related questions of legal policy will remain especially complex in the United States and other pluralistic societies. In addition, should reproductive technologies for creating, preserving, and terminating gametes and fetuses continue to proliferate, the number of legal concerns about reproductive rights and responsibilities is as likely to expand as to contract.

ANITA L. ALLEN (1995)
REVISED BY AUTHOR

SEE ALSO: *Adoption; Autonomy; Conscience; Conscience, Rights of; Double Effect, Principle or Doctrine of; Embryo and Fetus; Genetic Testing and Screening: Reproductive Genetic Testing; Harm; Human Dignity; Infanticide; Life; Maternal-Fetal Relationship; Moral Status; Population Policies; Women, Historical and Cross-Cultural Perspectives;* and other *Abortion* subentries

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III. RELIGIOUS TRADITIONS: A. JEWISH PERSPECTIVES

The Jewish discussion of abortion is a multi-vocal one that crosses several centuries of text and tradition. However, for a tradition in which much is in contention, the legal and ethical norms surrounding abortion are relatively less controversial. The tradition, in general, takes a clear middle path—allowing some abortions, in certain circumstances, for specific rational moral appeals. For Jews who are not close followers of Talmudic law, the cultural and economic realities of modernity affect religious practice, social justice and ethical norms, but these norms themselves have been shaped by this largely permissive tradition. In Jewish ethics, one considers both the whole of human activity and the whole of the community as well: Women as well as men are moral agents. This argument is primarily contained in the extensive debate and exegesis of the rabbinic literature, a discourse of contention and casuistic narrative ethics that both determines and discusses the 613 commanded acts named as *the mitzvot* by the Rabbis of the Talmudic period (200 B.C.E.–500 C.E.)

Jewish law has developed, in the 1,500 years since the redaction of the Talmud, by an ongoing series of *responsa* to questions about the legal code discussed in the Talmud, called *halacha.* Difficult cases of social crisis of all types are brought before arbiters and scholars who rule on the facts of the cases, on the methodological principles of logical argument, and on certain key principles of relationships in familial, ritual, civic, and commercial spheres. Each commentator is intellectually tied to those who came previously, and is confronted by changes in context: politics, cultural shifts, and scientific understandings that were not available to previous generations. Nowhere is this more evident than in the rapidly changing field of reproductive health.

Nearly all commentators would agree that it is clear that the concerns of the tradition are specific and protective of four principles:

1. to assure that women are not required to have children, since childbirth was seen in the Talmudic period as potentially life-threatening;
2. to assure that the temptation to immerse oneself in a life of study is avoided and that every man is married and in a family with children;
3. that sexuality after reproduction of two children—the required number—could be enjoyed without reproductive consequence; and
4. to allow both women and men to pursue, within limits, options for family planning based on a complex assessment of personal needs and social context.

The discursive method of Jewish ethical reasoning follows from close analysis of key texts—but it is never a history of unanimity—rather, it is a centuries-long argument with sharply disagreeing authorities making definitive and, in some cases, contradictory statements. A review of the development of the internal argument of the classic texts illustrates both the mutability of the tradition and the argumentative nature of the normative debate.

Abortion as such does not appear as an option for women in the Biblical text. There is only one direct reference to the interruption of a pregnancy, and it is a sort of collateral damage: when a woman is hurt as she stands near a fight.

> And if men strive, and hurt a woman with child, so that her fruit depart and yet no harm follows, he shall be surely punished, according as the woman's husband will lay upon him; and he shall pay as the judges determine. But if any harm follows, you shall give life for life.… (Exodus 21:22–23)
>
> The Biblical text assumes the following conditions:
>
> that the event described—an induced abortion—is an accidental occurrence;
>
> that it is not in woman's control, that the being lost is of value since it is, perhaps, the property of the husband;
>
> that the being that is *departed* is not a life in the way that the woman is a human life;
>
> that a crime of some sort has been committed, but that it is not a capital crime.

What is at stake is whether the woman herself is hurt—the child's loss is explicitly not the loss of a life.

Later texts then address the question of when an abortion is sought. Is this permitted without direct mention in the Biblical scripture? The response is found in the earliest sources of the Mishneh. Clearly seen as an emergency option, it was nevertheless clearly available under several circumstances.

Two later commentaries interpret the Bible text, and they do so with different types of arguments that allow abortion in some circumstances. The first argument follows the general line of thinking that the fetus is in some ways a danger to the woman, and can be aborted because of the more general rule of self defense: This becomes articulated as the argument called the *Rodef* (pursuer). This is evident in the following proof text:

> If a woman suffer hard labor in travail, the child must be cut up in her womb and brought out piecemeal, for her life takes precedence over its life; if its greater part has [already] come forth, it must not be touched, for the [claim of one] life can not supersede [that of another] life. (Mishneh 6)

Here the text assumes three things: Abortion is deliberate; the decision to abort is a conjoint one and somewhat in woman's hands (she is the sufferer, so it is her suffering that calls the question, and it must have something to do with her stated limits); and that all can agree that a *child* is in her womb, but not a child who counts as a *nefesh* (fully ensouled human person) until its head is out.

This first argument is further developed centuries later, by Maimonides:

> This, too, is a mitzvah: not to take pity on the life of a pursuer (*Rodef*). Therefore the Sages have ruled that when a woman has difficulty in giving birth one may cut up the child within her womb, either by drugs or by surgery, because he is like a pursuer seeking to kill her. Once his head has emerged he may not be touched for we do not set aside one life for another; this is the natural course of the world. (Maimonides 1:9)

Maimonides assumes three things: that the fetus is in fact a *nefesh;* that it is a *pursuing nefesh* (*Rodef*); and that a life must be at stake to allow the killing of the *Rodef.* The reason for the opinion of Maimonides here, namely, that the fetus is like a pursuer pursuing the mother in order to kill her, is that he believed that a fetus falls into the general law of *pikuah nefesh* (avoiding hazard to life) in the Torah since a fetus, too, is considered a *nefesh* and is not put aside for the life of others (*Hiddushei Rabbi Hayyim Soloveitchik to Mishneh Torah,* Hilkhot Rotze'ah 1:9). Ben Zion Uziel, in the early modern period, then extended this argument to include not just the mother's life, but her health.

> We learn in this matter that according to the doctors, the fetus will cause its mother deafness for the rest of her life, and there is no greater disgrace than that, for it will ruin the rest of her life, make her miserable all her … Therefore, it is my humble opinion that she should be permitted to abort her fetus through highly qualified doctors who will guarantee ahead of time that her life will be preserved.… (Ben Zion Uziel, *Mishpetei Uziel,* Hoshen Mishpat 3:46)

Finally, Rabbi Eliezer Waldenberg in the mid-twentieth century interprets the text to include protection of not just physical health, but mental health, allowing abortions in the case of a diagnosis of Tay Sachs in the child:

> One should permit … abortion as soon as it becomes evident without doubt from the test that, indeed, such a baby [Tay-Sachs baby] shall be born, even until the seventh month of her pregnancy … If, indeed, we may permit an abortion according to the Halacha because of *great need* and because of pain and suffering, it seems that this is the classic case for such permission. And it is irrelevant in what way the pain and suffering is expressed, whether it is physical or psychological. Indeed, psychological suffering is in many ways much greater than the suffering of the flesh. (Eliezer Waldenberg, *Responsa Tzitz Eliezer,* Part 13, no. 102)

A second line of argument is largely based on developmental moral status, a principle that gains ground via rabbinical medical science. All discharges from the body present a problem to be adjudicated by the rabbis, since persons with discharges need to participate in purification rituals before they can rejoin the larger community. Since examination of the contents of the womb after a miscarriage for the first forty days after conception did not seem to show a fetus, the rabbinic authorities deemed that during this period, the fetus had the status of *mere water.* Abortions during this period, went the reasoning, then could not be opposed.

A third line of justification develops in entirely another tractate of the Mishneh (Arakin) that abortion is permitted as a health procedure since a fetus is not an ensouled person. Not only are the first forty days of conception considered *like water* but even in the last trimester, the fetus has an lesser moral status—more akin to a part of a woman's body, than like a separate being.

> Gemara: But that is self-evident, for it is her body! It is necessary to teach it, for one might have assumed since Scripture says "according as the woman's husband shall lay upon him" that it [the woman's child] is the husband's property, of which he should not be deprived. Therefore, we are informed [that it is not so].… (Exodus)

This proof text is the introduction of an argument that the fetus is simply not a *nefesh* and therefore, is seen as a part of a women's body. A later authority, Rashi, assumes this is valid because the fetus is not a separate being until the head is born.

This argument continues in later *responsa* and it is clear that, even after birth, whether the child is fully independent, with it own, separate being and body, is still an issue: For some, the status of the infant remains uncertain for thirty days.

> Because when a child dies within thirty days (being then considered a stillborn and not mourned like a person who had died) it becomes evident only in retrospect that it was a stillborn (*nefel*) and that the period of its life was only a continuation of the vitality of its mother that remained in him. (Ben Zion Uziel 3:46)

In the post-Holocaust period, a new and contradictory tradition is developing as some commentators have voiced concern that an overly liberal abortion practice is inappropriate in the face of declining numbers of Jews, and urge a more strongly pro-natalist stand. As Moshe Tendler and Elliot Dorff argue, Jews are "a people are in deep demographic trouble. We lost one-third of our numbers during the Holocaust … the current Jewish reproductive rate among American Jews is between 1.6 and 1.7.… This social imperative has made propagation arguably the most important mitzvah of our time." While this position does not come from classic halachic sources, it has nevertheless, gained some ground in the contemporary period.

Religion for Jews is not a set of external institutional events visited on occasions of crisis or celebration—religion is a binding to a commanded life, in which every single daily act of practice and attention is a part of the being of the faithful person. It is the totality of life that Jewish belief is after—the inescapable call of the stranger, the constancy of the demand for justice in every interaction, and the mattering of minute details of daily life. The commanded life is a matrix of competing and complementary and contentious strands. There is both a temporal aspect to the matrix, in that interpretations are the result of more than 2,000 years of discourse, and an analytic aspect in that any act can be judged in a variety of ways. An act can be prohibited but unpunished, prohibited and punished, permitted but not approved of, permitted and accepted, obligatory but with many exceptions, or obligatory in all cases. Hence, much of our understanding about abortion comes not from these texts that describe variations and exceptions, but from the far broader range of normative texts that support a pronatalist family life.

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SEE ALSO: *Authority in Religious Traditions; Judaism, Bioethics in; Population Ethics: Religious Traditions, Jewish Perspectives;* and other *Abortion* subentries

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III. RELIGIOUS TRADITIONS: B. ROMAN CATHOLIC PERSPECTIVES

The following is a revision and update of the first edition entry “Abortion: Roman Catholic Perspectives” by John R. Connery. The Roman Catholic tradition has always treated abortion as a serious sin. Yet Catholic teaching on abortion has not always centered on the “right to life” of the individual fetus, nor has it always viewed all abortion as homicide. For several centuries, early abortion in particular was characterized more as a sexual sin than as killing, and was condemned as an interference in the natural outcome of the reproductive process, often assuming as its context an illicit sexual liaison.

The fact that Catholic views of the precise status of the fetus as human life have changed over time and that the church's position has a philosophical rather than a religious basis are key to late-twentieth-century church teaching on abortion. That teaching is that the fetus must be given the benefit of the doubt, and be treated as if it were a person from conception onward. This teaching is not stated as a sectarian religious proposition, but as a humanistic and philosophical truth to be recognized in civil laws guaranteeing appropriate protection to fetal life. Although exhortations to protect life in the womb have often been supported with religious allusions (for instance, to the will of the Creator or to the image of God in humanity), the duties to continue pregnancy and to sustain infants have been grounded primarily in the "natural law," understood as a shared human morality innate to all persons and knowable by reason.

In examining the foundations and development of the Catholic position, it is important to place modern teaching in the context of changing views of women's roles in family and society. Other factors influencing debates about Roman Catholicism and abortion are the relation of scientific knowledge about the beginnings of human life to the moral status of life; the relation among civil law, morality, and the church as an institutional actor; and contraception and population, especially in international perspective.

Historical Development

Although Catholic claims about abortion are not narrowly religious, certain biblical and early Christian characterizations of life in the womb no doubt have contributed to an ethos in which abortion is viewed negatively. The Hebrew Scriptures (Old Testament) did not treat the killing of a fetus as the killing of an infant (Exod. 21:22), although the Greek Septuagint translation of the Hebrew (early third century B.C.E.) adds a distinction between the formed and the unformed fetus, and presents abortion of the former as homicide. This distinction reflects the ancient Greek view (Aristotle) that the matter and form of any being must be mutually appropriate (the *hylomorphic theory*), and that the embryo or fetus could not have a human soul (*form*) until the body (*matter*) was sufficiently developed. Often quoting the Septuagint, patristic and medieval theologians maintained this distinction, which remained a key component of Roman Catholic discussion of abortion until at least the eighteenth century.

The Gospels do not address abortion explicitly, though the infancy narratives manifest interest in the importance of the individual before birth, at least in respect of God's will for him or her in the future (Matt. 1:18–25; Luke 1:5–45). In Paul's Letter to the Galatians (5:20) and in Revelation (9:21), condemnations of magical drugs (*pharmakeia*) associated with various forms of immorality, including promiscuity and lechery, may very likely extend to abortifacients. The connection is made clear in two early Christian texts, the Didache and the Epistle to Barnabas. "'You shall not kill. You shall not commit adultery. You shall not corrupt boys. You shall not fornicate. You shall not steal. You shall not make magic. You shall not practice medicine (*pharmakeia*). You shall not slay the child by abortions (*phthora*). You shall not kill what is generated. You shall not desire your neighbor's wife' (Didache 2.2)" (Noonan, p. 9).

Contraceptive and abortifacient drugs, as well as infanticide, were certainly used widely in the ancient world, not only to conceal sexual crimes but also to limit family size and conserve property. Early Christian authors such as Tertullian, Jerome, and Augustine in the Western church, and Clement of Alexandria, John Chrysostom, and Basil in the Eastern church, repudiated these practices. They did not, however, challenge their patriarchal social context, with its requirement that female sexuality serve the good of the family and its assumption that women seeking to avoid pregnancy were usually guilty of sexual infidelity. Local councils tended to support this stand. In 303 C.E., on the Iberian Peninsula, the Council of Elvira excluded from the church for the rest of her life any woman who had obtained an abortion after adultery. In 314, the Eastern church, at the Council of Ancyra (Ankara), reduced the period of penance to ten years, although it retained the lifetime ban for voluntary homicide. Such church laws made no distinction between the formed and the unformed fetus, but Tertullian, Jerome, and Augustine considered that the sin of abortion might not be homicide until after ensoulment. (The fetus was considered by many ancient writers to receive a soul only after the body had "formed," or reached an appropriate level of development, at about three months.)

Formation of the fetus became a consideration in assigning penance in private confession during the seventh century, but it was not universally recognized in church law until the decree *Sicut ex* of Innocent III in 1211. The decree dealt with irregularity, which could be incurred for homicide. An irregularity is a canonical impediment that bars a man from receiving or exercising holy orders. Irregularities are based on defects (such as mental or physical illness) or crimes (including attempted suicide, murder, and abortion). According to the decree, irregularity would not be incurred for abortion unless the fetus was animated. Since the time of animation was identified with formation, the decree implied that only abortion of the formed fetus was considered homicide. Following Aristotle, forty and ninety days were accepted as the time of animation for the male and the female fetus, respectively. Confusion arose, however, from a parallel tradition that extended the notion of homicide not only to the abortion of the unformed fetus but also to sterilization. Both traditions claimed a factual base, the one in the premise that the "man" is contained in miniature in the male seed, and the other in Aristotle's reported observation of aborted fetuses. During the Middle Ages, the distinction between formed and unformed was generally accepted, notably by Thomas Aquinas, and only the abortion of the formed fetus was classified as homicide, even in reference to sacramental penances. Earlier abortions were not murder, but they were still forbidden as serious sins because they interfered with the procreative outcome of sexual acts.

In the early fourteenth century, the Dominican John of Naples introduced an exception, subsequently accepted by several others: It would be permissible to abort the unformed fetus in order to save the life of the mother. Later theologians, particularly Thomas Sánchez (sixteenth century), used the argument of self-defense against an unjust aggressor (so characterizing the fetus) or the principle of totality (looking on the fetus as part of the mother). In 1588, Sixtus V reaffirmed a more rigid position, classifying even sterilization as homicide, and (in the decree Effraenatam) making excommunication a penalty of the universal church for the sin of abortion. A modification in 1591 again limited the provision to the case of the animated fetus, at either forty or ninety days. This legislation remained in effect until 1869, when Pius IX extended it to all direct abortion. Twenty years later, the Holy Office of the Vatican declared that neither craniotomy nor any other action to destroy the fetus directly would be permitted, even if without it both mother and child would die. Until that point, the exception to save maternal life had been debated by the theologians without receiving official condemnation. While theologians sought a balance of the value of the fetus with other values, especially the life of the mother, papal legislation moved toward a reinforcement of the abortion prohibition.

A moderating influence that continues today was exerted via the *principle of double effect.* This principle, pertaining to acts that have both good and evil effects, permits a moral distinction between direct and indirect abortion. Only direct abortions are absolutely prohibited in official Roman Catholic teaching. Indirect (permitted) abortions are those operations that have as their primary effect the saving of the mother's life, with the death of the fetus a foreseen but not directly intended secondary effect. The classic example is the removal of the cancerous uterus of a woman who is pregnant. In this case, the death of the fetus is neither in itself the desired outcome of the intervention, nor even willed and caused as the means by which the woman's life is saved. The removal of the cancer, not the fetus, heals. Double effect may also be applied to the removal of a fallopian tube in the case of an ectopic pregnancy. The premise behind the justification of indirect abortion is that while the direct killing of an innocent human being is immoral, the woman's life is at least equal in value to that of her unborn offspring, so that she has no duty to assume serious risk to her own life in order to sustain the child.

Contemporary Teaching

In his 1930 encyclical on marriage, *Casti connubii,* Pius XI affirmed the equal sacredness of mother and fetus, but condemned the destruction of the "innocent child" in the womb, who can in no way be considered an "unjust assailant." (The sticking point here, of continuing interest to moralists, is whether it is necessary to have an unjust intention to qualify as an unjust aggressor, or whether unintentionally posing an unjust danger to another is sufficient. Soldiers in war, for instance, may have noble personal intentions, yet validly be viewed by their opponents as unjust attackers.) The Second Vatican Council (*Gaudium et spes,* no. 51) referred to abortion and infanticide as "unspeakable crimes." The complex agenda of and challenges to current church teaching are well focused by the 1974 Vatican "Declaration on Abortion."

This document is a response to changed Western abortion laws, as well as to population measures in developing nations. Even as it resists these pressures, it adapts its message on abortion to cultural and legal contexts characterized by the emancipation of women and the need to control births. The document responds to the Western political value of free choice by asserting that "freedom of opinion" does not extend further than the rights of others, especially the right to life. It observes that while ensoulment has been debated historically, abortion has always been condemned. Most important, the document insists that human reason can and should recognize respect for human life as the most fundamental of all goods, and the condition of their realization. It sees modern science as confirming that human life begins with fertilization, though allowing that science can never definitively settle what is properly a philosophical question. Still, "it is objectively a grave sin to dare to risk murder" if there is doubt as to whether the fetus is fully a human person.

The "Declaration on Abortion" recognizes that pregnancy can pose serious burdens for the health and welfare of women, families, and children themselves. It advocates that individuals and nations exercise "responsible parenthood" by natural means of avoiding conception. It also exhorts "all those who are able to do so to lighten the burdens still crushing so many men and women, families and children, who are placed in situations to which in human terms there is no solution" (no. 23). It excludes abortion as an answer but also concludes that what is necessary "above all" is to "combat its causes" through "political action" (no. 26). The "Declaration" anticipates later efforts, notably by the U.S. episcopacy, to advocate moral consistency on killing, in that it contrasts growing protests against war and the death penalty with the social vindication of abortion. From the standpoint of both the Vatican and the U.S. bishops, the unborn should be included within a greater respect for life in general, and be protected by more stringent social limits on killing of all kinds.

Critical Debates

Among the debated questions regarding the Roman Catholic tradition on abortion are certainly the following. First, is it reasonable and scientifically sound to urge that the fetus be treated as a "person" from conception onward, especially if to do so will have dire consequences for the woman who bears it? While most Roman Catholic theologians assume a conservative attitude toward the value of prenatal life, not all accept that full value is present at the outset; rather, it increases in some developmental fashion, at least through the earlier stages. Several authors (Tauer; McCormick; Shannon and Wolter) have pointed to the time of implantation, at about fourteen days, as a "line" after which individuality appears more settled (the possibility of "twinning" being past) and the chance of survival greatly magnified (for a discussion, see Cahill).

Second, is the equality of women, and the substantive legal, social, and material support for women and families enjoined by the "Declaration," really as high on the practical pro-life agenda of Roman Catholicism as is the enactment of punitive sanctions for abortion? A deep skepticism about whether this is so gives the "abortion rights" cry of many feminists its immense symbolic value in the struggle for gender and sexual equality. While some Catholic feminists believe that sexual self-determination and effective birth control is a better way to ensure women's liberation than recourse to a form of killing, other Catholic feminists insist that the choice to terminate pregnancy must be available to women as long as a patriarchal church and society identify women's roles as reproductive and domestic in order to constrain women's moral agency and to exclude women from the range of social participation available to men.

Third, even granted that the fetus has significant value, can and should restrictive abortion laws be kept in place—or reenacted in nations that have moved toward liberalization? John Courtney Murray (ch. 7) distinguishes between law and morality. Morality in principle governs all human conduct, while law pertains to the "public order," the minimum moral requirements of healthy social functioning. Modern nations vary in the degree of restraint on abortion choice they see public order as requiring (see Glendon). Abortion policy debates, especially in more lenient systems like that of the United States, challenge Roman Catholicism to reshape the social consensus about the value of the unborn. Any legislation not backed by a consensus favoring enforcement will lead both to disrespect for the law and to the proliferation of unregulated extralegal alternatives. A precondition for a less permissive abortion consensus is the creation both of avenues other than "abortion rights" for the exercise of women's social and personal freedoms, and of social supports encouraging women and families to raise children.

A major point of debate within Roman Catholicism is the level of legal compromise acceptable to those who would accord the fetus more value than does the current consensus. Following the principle that law and morality are not coterminous, some argue that a policy that encourages early abortion and restricts it to "hard cases" (e.g., threat to life or health, rape, incest, serious birth defects) could command enough broad support to justify it as a practical advance in the limitation of abortion. Advocates of a more stringent position insist that the full weight of the church's moral authority be marshaled behind a policy that would outlaw abortion altogether.

Finally, can the church credibly defend its antiabortion position while disallowing the most effective forms of birth control? It is relevant to this question that many nations' aspirations to economic and cultural prosperity are plagued by limited freedom for women in marriage and family, and by increasing overpopulation. In the industrialized countries, the abortion controversy tends to focus on individual rights, either of the fetus or of the mother, with Roman Catholic proponents framing the issue in terms of a legally protectable right to life. In such nations, the church tends to address itself to the absolutization of private choice over what it sees as human life, and the trivialization of the abortion decision as it becomes a substitute for sexual responsibility and contraception.

However, the Roman Catholic church is an international organization, with a substantial or growing membership in, for example, Latin America, the Philippines, and Africa. In many nations, the question of women's freedom to combine family with public vocation as the context for the abortion debate is overshadowed by dire poverty; the inaccessibility of education, adequate employment, and healthcare; the ambiguous economic implications of a large family in rural, agricultural settings; and the radically disadvantaged position of girls and women within the family in some traditional cultures. Especially in the absence of ready access to contraception, abortion may appear to such women, to families, and even to government agencies to be a desperate but necessary means of controlling fertility. As the 1974 "Declaration on Abortion" indicates, the global Roman Catholic position on abortion must go beyond the condemnation of abortion as murder to address personal and social situations in which abortion appears as the only viable answer to deprivation or oppression.

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SEE ALSO: *Authority in Religious Traditions; Christianity, Bioethics in; Conscience, Rights of; Embryo and Fetus: Religious Perspectives; Feminism; Genetic Testing and Screening: Reproductive Genetic Testing; Human Dignity; Moral Status; Natural Law; Population Ethics: Religious Traditions, Roman Catholic Perspectives;* and other *Abortion* subentries

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III. RELIGIOUS TRADITIONS: C. PROTESTANT PERSPECTIVES

Reviews of the history of Protestant teaching on abortion focus most often upon specific comments regarding abortion in the writings of leaders of the various church reform movements in European Christianity beginning in the sixteenth century. Several of the most effectual Reformation leaders, including Martin Luther (1483–1546) and John Calvin (1509–1564), were powerful both in reconceiving church practice and in articulating reformulations of Christian theological and ethical teaching. Consequently, for many of their followers and spiritual heirs, their teaching has remained uniquely authoritative in discerning Protestant truth claims. The formal criteria for discerning Christian truth proposed by these reformers, however, is best characterized as privileging the role of Christian scripture (usually referred to by Protestants as the Old and New Testaments) in adjudicating doctrinal and moral disputes. This primacy of scripture as theological and moral norm also characterized the teaching of most other sixteenth-century reformers, including the theological leaders of the many Anabaptist movements.

Since the sixteenth century, all dissent from authoritative Roman Catholic teaching and practice, including newly emergent Christian movements, receives the label "Protestant." The rapidly growing Pentecostal movements in Latin America, indigenous Christian movements in Asia, and the African indigenous churches that have become numerically preponderant among Christians on that continent all fall under this rubric. As a result, extreme caution needs to be exercised in characterizing "Protestant" moral teaching in any contemporary moral dilemma. Even when interpreters are familiar with very diverse Protestant cultural traditions, those who identify themselves as Protestants interpret the meaning of conformity to scriptural norms in a wide variety of ways, and reveal wide differences in biblical "hermeneutics," or principles of interpretation, of sacred texts. The diversity of hermeneutical options available accounts in part for the complexity of Protestant voices on abortion today.

Before identifying contemporary Protestant hermeneutical diversity and therefore the range of existing contemporary Protestant viewpoints on abortion, it is important to clarify the cultural roots of Protestantism that shape them.

Early Protestant Views of Abortion

Martin Luther's and John Calvin's theological and moral reforms were shaped by their reconceptions of both the meaning of Christian life and Christian ritual practice. Neither could be said to have proposed shifts in the foundational notions of human nature embedded in late medieval Christianity. Traditional notions of human nature, including gender and human species reproduction, were not in dispute and did not shift at the time of the Reformation. What is notable among Protestant reformers is the paucity of comment on any questions about human sexuality and reproduction, including abortion. Martin Luther, a prolific preacher and writer, did not mention abortion at all. Had he done so, he likely would have presumed its moral wrongness because he was educated as an Augustinian monk and was learned in the available theological texts of the period, including especially *Sentences* by the twelfth-century theologian Peter Lombard, which contained collations of opinions on abortion by earlier theologians. The lists included the judgments of many who associated abortion with sexual immorality, especially with adultery, and condemned the practice.

John Calvin also knew this authoritative tradition that explicitly condemned abortion, as his commentaries on Genesis 38:10 make clear. His remarks on Exodus 21:22 further attest that he believed abortion to be wrong morally. Modern critical biblical exegetes agree that Exodus 22:21 is the only text in Christian scripture that explicitly refers to abortion, albeit to abortion that occurs because of injury to a pregnant woman. The issue in this passage was not elective abortion. Even so, Calvin used the occasion of comment on this text to make known his view that the fetus is already a person, a matter the text does not address.

On gender, sexuality, and reproduction, these reformers maintained continuity with earlier traditions. Both Luther and Calvin also followed what they took to be early Christian theological consensus, that divine ensoulment (i.e., the point of spiritual animation of human beings by God) of human life occurs at conception, though not all the Protestant theologians who followed them agreed. Modern conservative historical interpreters construe Calvin and Luther's views on this point as confirming their own current belief that Protestant teaching agrees with modern papal teaching, namely, that full human life occurs at conception. Caution needs to be exercised here, however. Although the majority of Protestant theologians followed the view that ensoulment occurred when the "seed" was planted in utero, their perspectives were not developed in relation to questions about human gestation. To argue that these views speak to the value of fetal life is misleading, since their opinions were developed as aspects of the theological debate about sin and salvation, and not in relation to modern embryological understanding. In any case, Protestant ritual practice suggests that commonsense norms were in fact applied to actual fetuses. Protestants, like Roman Catholics, did not practice baptism in relation to miscarriages or aborted fetuses.

Modern Protestant Views on Abortion

Specific comment on abortion is rare in most Reformation traditions until the twentieth century. Perhaps in deference to the lack of biblical discussion, most reformers considered matters regarding the morality of abortion, like matters governing all sexual and reproductive behavior, to be ordered by human rational discernment. They were issues of "natural morality" rather than of revealed truth. Despite emphasis on recovering the meaning of Christian biblical tradition, Lutherans, Calvinists, and Anglicans (post-Roman Church of England adherents) maintained the view, longstanding in western Christianity, that much moral knowledge, including the order of human sexuality and reproduction, falls within the purview of "natural" human knowledge, that is, they are matters for rational deliberation and discernment. Contrary to the trend of modern Protestant fundamentalist biblicism in discussions of abortion, most Protestant traditions tended to embrace a type of reasoning that accepted human rational (and therefore "scientific") data as relevant to these moral judgments on these issues. The Anabaptists were often exceptions methodologically, however. They sought guidance on moral issues exclusively from scripture without reference to other sources. However, Anabaptists also stressed freedom of conscience in deliberating moral dilemmas, and often resisted fixed ecclesiastical standards on questions such as abortion. Not surprisingly, contemporary Anabaptist heirs often oppose with great adamance state-prescribed policies making abortion illegal.

It is not too much to say that Protestantism possessed neither an explicitly developed tradition of moral reasoning about abortion nor any elaborated body of teaching on the ethics of so-called medical practice until well into the nineteenth century. Reproduction in Protestant communities, as in all premodern communities, was shaped by female cultural practice and midwifery until at least the very late nineteenth century. Contemporary cultural historians agree that nearly all female subcultures encouraged some means of fertility control, and that most took recourse to abortifacients (substances that induce abortions) in extreme cases. Such methods were primitive and dangerous, however, and documentation regarding the range and scope of their use is all but nonexistent. The fact that women, and not men, both comprised and knew the culture of reproduction probably limited public awareness in prevailing practices. Knowledge about available interventions in pregnancies may not have been widely shared, and such knowledge may have been quite rare among male theologians until the "medicalizing" of pregnancy and reproduction in the twentieth century. In the nineteenth century, male medical practitioners increasingly attempted to discredit midwifery, frequently on the grounds that midwives practiced abortion, but Protestant clergy in the United States showed great reluctance to support such efforts.

The major impact of the Reformation in shaping Protestant attitudes on abortion is rarely mentioned in traditional historiography. The most important influence of Protestantism in the abortion debate arose from the changes in spiritual practice initiated by Reformation Christianity; these changes in turn led to a powerful shift in how socialization into Christian faith took place. Initiation into Christianity moved from a locus in the church-based penitential system to the Christian family, which gradually became the basic social unit of Christian piety. Protestant spirituality was pervasively formed by this embrace of the family as the proper site for transmission of both faith and morals. The change engendered by the Reformation overturned celibacy not only as the proper norm for clerical life but also as the norm of optimal Christian piety. The Reformation movements made the sexually monogamous, procreation-centered family both the center of their basic community and their strongest metaphor for divine blessing. For Calvinists, explicitly from the outset, and for Lutherans, Anglicans, and Anabaptists more slowly, adherence to this form of social practice came to be taught as a Christian duty. Parents were to oversee their children's successful entrance into procreative-centered marriage literally as a mandate of faith.

This shift in the structure of Christian sociology, more than any change in explicit moral teaching, shaped subsequent moral sensibilities toward abortion among Protestants. This new emphasis on the sacerdotal character of the family reinforced the appeal of Protestant Christianity in traditionalist non-European cultures as well. Both ancient Hebraic and Jewish and pre-Protestant Christian sources had at times equated procreation and biological fertility or fruitfulness as signs of divine blessing, and such pronatalist sentiments had had some influence in earlier Christian attitudes toward abortion. However, the rise of Protestantism made such sensibilities powerful in European cultures and central to modern Christian moral sensibility about reproduction. This portended a deep suspicion regarding elective abortion when the practice became widespread and safe.

Many modern Protestants arrive at their judgments about the morality of abortion from a deep-seated sense that any pregnancy is intrinsically a sign of divine blessing and that to deny this is impious. So deep does the equation of fertility and divine blessing run in Protestant cultures that western Christianity itself has strongly reinforced traditional patriarchal norms that female "nature" is centered in and fulfilled only through maternity. Traditional Protestant cultures (those untouched by religious pluralism) tend to experience any weighing of questions about the status of fetal life as expressing a "secular" or "antireligious" mindset.

Despite the strong pronatalist disposition of traditional Protestant spirituality, however, critical historians have also noted a certain tension between Protestant teaching on abortion and Protestant pastoral practice. Even in traditionalist Protestant cultures, where moral and theological discourse is unequivocal in condemning abortion, pastoral practice is frequently far less censorious. Scattered evidence exists that Protestant priests, pastors, and elders often treated those who had abortions or administered them with a surprising degree of compassion or even leniency. There is no evidence that the practice of abortion was deemed "an unforgivable sin," as some ancient church canons insisted, or that abortion was equated with "murder" or "unjustified killing." Even among contemporary Protestant fundamentalists, historians have observed this tension between formal moral condemnation and more permissive ecclesiastical practice. Theological and moral condemnation notwithstanding, noncelibate clergy may be in touch with many of the concrete conditions and dilemmas of pregnancy and reproduction that shape women's lives. In any case, the general stance of Protestant traditionalism and of the newer, postmodernist biblical hermeneutics is toward a degree of pastoral compassion, even if abortion is starkly condemned at the formal level. All current available data suggest that the rate of recourse to abortion among women who are part of Christian communities that formally condemn abortion—Protestant traditionalist, Protestant fundamentalist, or Roman Catholic—is at least as great as it is among women who come from liberal Protestant and Jewish communities or who are nonpracticing with regard to religion.

The most typical contemporary Protestant attitude toward abortion remains a traditionalist, pronatalist negativity toward the practice, with a reluctant recognition that abortions do occur frequently, even within the Protestant communities of faith. Such cautious negativity is maintained without strong, elaborated moral justification, chiefly because the strong cultural ethos of the existing family-centered sociology of the Protestant churches gives this view such plausibility. Traditionalist consensus tends to break down, however, whenever Protestant communities are confronted with debates shaped by conflicts within the wider culture or from newly articulate dissent within these Protestant communities themselves. Such debate is now ongoing in all churches rooted in the continental Reformation. For the most part the debate reflects the divisions in biblical hermeneutics already mentioned.

Three newer hermeneutical positions appear in the abortion debate. First, there is a quite unprecedented biblical fundamentalist hermeneutic asserting itself in many Protestant cultural contexts. This new fundamentalism is developed particularly to resist change in issues involving gender, sexuality, family, and reproduction. On all of these issues, restoration of a premodern interpretation of sex/gender and the reproductive system is the primary goal. Human gender and sexual identity, this approach insists, are rooted in “nature” and in “divine decree” central to the presumed “biblical” message. Using both the language of natural law and tradition of the mandate of divine revelation as synonymous and as equally legitimated by scripture, the new fundamentalists contend that the essence of the biblical witness is the biological-religious “givenness” of male/female nature and the revealing of the proper “telos,” or end, of human sexuality. Abortion is unthinkable, a violation of all of the norms of faith and morals. This hermeneutic aims to make even the discussion of abortion taboo in Protestant theological and moral discourses, to make it literally unthinkable. This approach tends to drive from the field several generations of historical-critical study by Protestant theological liberals. Previously, liberal biblical scholarship had successfully persuaded interpreters of the Bible within mainline Protestantism that interpretation of scriptural texts had to be guided by awareness of different historical times and variations among cultures. Liberals recognized that biblical worldviews do not presuppose modern ideas about the origin and nature of the universe and its inhabitants. Such considerations undergirding previous Protestant biblical interpretation, once widely accepted, are often forgotten in the wake of the force of the new fundamentalist hermeneutic.

Second, although the new fundamentalism gains force in Protestant communities, most “oldline” Protestant denominations (rooted in Europe) remain informed by historical-critical methods of scriptural interpretation and continue to speak in a voice consistent with conclusions of the earlier liberal biblical hermeneutic. Broadly speaking, these churches acknowledge that biogenetic and other scientific knowledge must be given its due in deliberating the morality of abortion. Most concede that decisions to have abortions are justified in some cases and can be consistent with biblical faithfulness. This casts several major Protestant denominations on the side of the public policy debate that supports limited legality of abortions. Although several of the “old line” denominations have been strongly pressed by fundamentalists and traditionalists in their ranks to shift to antiabortion public-policy positions, Lutherans, Anglicans, Methodists, Presbyterians, and United Church of Christ denominations, among others, have maintained their public positions. Discussion of what may constitute “justifiable reasons” for choosing abortion is decidedly underdeveloped in such Protestant communions. A strong consensus prevails that supports abortions in cases of pregnancies due to sexual violence (rape and incest); in cases where the life or physical health of the mother is at stake; and, perhaps, in cases where prospective parents lack the spiritual and physical resources to rear an additional child. There are also important historical reasons why old-line liberal Protestant communities place a strong emphasis on “responsible parenthood,” but that story is outside the scope of this entry. This too is an important and largely unexamined chapter in understanding Protestant views on both family planning and abortion.

Finally, in nearly all contemporary Protestant communities/cultures, another hermeneutic for interpreting the Christian abortion tradition is emerging. It may be called a *liberationist* or even a *profeminist liberationist* principle of interpretation. Although it is still a decided minority position within formalized Protestant theological-moral discourse, this hermeneutic is influencing many, especially women. It calls upon Protestant theology and ethics to reformulate moral and religious judgments with special attention to concerns for women’s well-being and in recognition that Christian teaching on gender, sexuality, and reproduction is embedded in a wider system of social control of women’s lives. Acknowledging internal contradictions within scripture, a liberation hermeneutic refuses authority to culturally repressive male-supremacist readings of biblical texts and postscriptural theological interpretations. Like liberals, proponents of the emerging liberation hermeneutic represent a spectrum of convictions about what reasons might justify specific acts of abortion, but strongly concur that the Protestant Christian moral voice must actively advocate broad-based social change to enable women to shape their reproductive capacity. They contend that the moral evaluation of abortion must not be predicated on discourse that obscures women’s full standing as moral agents or that fails to include realism about the historical pressures surrounding biological reproduction in women's lives. Among Protestants, only Unitarian/Universalists have adopted such a hermeneutic officially.

The contesting voices characterized here are most visible and most intense within Protestant Christian communities in the United States. However, analogous dynamics are at work in Protestant communities in other areas of the globe, as they are within Roman Catholic, Orthodox, and other religious communities. The struggle over which hermeneutical voice shall prevail in Protestant teaching on abortion remains unresolved.

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SEE ALSO: *Christianity, Bioethics in; Embryo and Fetus: Religious Perspectives; Feminism; Genetic Testing and Screening, Reproductive Genetic Testing; Human Dignity; Moral Status; Population Ethics: Religious Traditions, Protestant Perspectives;* and other *Abortion* subentries

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III. RELIGIOUS TRADITIONS: D. ISLAMIC PERSPECTIVES

Since ancient times every human society has dealt with the issue of abortion. The way each treats the issue has depended on the way each views fundamental questions of individual and societal life, such as the meaning and sanctity of human life, sexuality and gender relations, the role of marriage and family, the meaning of human freedom, and the related issues of rights and responsibilities of the individual.

The Roles of Medicine and Law in the Islamic Debate on Abortion

Islam's response to abortion during the fourteen centuries of its existence has been documented mostly in the jurisprudential works of its doctors of law and the medical writings of its physicians. Islamic perspectives on abortion have been shaped directly by both its theology and its revealed law (*Shari'a*). Because of the centrality of the latter as a practical guide in the religious and spiritual life of Muslims, however, they depend heavily on the deliberations and ethico-legal decrees (*fatwās*) of experts whenever practical problems arise in society. The main practical role of theology is to provide the necessary spiritual and intellectual framework within which ethico-legal debates are pursued.

Since the Divine Law of Islam refuses to make a separation between law and ethics, the traditional Muslim jurist (*faqih*) is at once an ethicist and a legal expert. The physician's duty in matters concerning abortion is to provide medical advice and recommendations befitting each individual case, as Islamic law generally permits abortion on medical and health grounds up to a certain stage of pregnancy. Close collaboration between medicine and law in Islam has generated a well-developed branch of Islamic jurisprudence that deals with many biomedical issues, including contraception and abortion.

In all cases of abortion, the physician is an important witness. The idea of the testimony of a trustworthy physician is well known in Islam, since Islamic law puts great emphasis on the idea of a trustworthy witness, whom it always defines in terms of believing in God and having a good moral character. The close rapport between medicine and law in Islam is further strengthened by the fact that this religion has produced a sizeable number of jurists who either practiced medicine or at least possessed a sound general knowledge of the subject. Ibn Rushd (known by the Latin name Averröes, d. 1198), Ibn al-Nafīs (d. 1288), the discoverer of the minor circulation of the blood, Ibn Ḥazm (d. 1064), Fakhr al-Dīn Rāzī (d. 1209), and in more recent times, Ḥasan al-ʿAṭṭar al-Khalwatī (d. 1835), a rector of the prestigious al-Azhar University in Cairo, were some of the most famous jurists–medical practitioners. Al-Shāfiʿī (d. 820), the founder of one of the four Sunni schools of law, is credited in traditional sources with knowledge of medicine.

Conversely, there have been many Muslim physicians who were well versed with the philosophy of the Shariʿa and the ethical teachings of the Qur'an and *hadiths* (i.e., recorded sayings, behavior, and actions attributed to the Prophet, and in the case of the Shi'ite branch of Islam, also to the Imams, their foremost spiritual leaders), but who were never recognized as jurists in the technical sense of the term. The most famous of these was Ibn Sīnā (d. 1037). These physicians were generally knowledgeable in embryology. As scholars of natural philosophy, of which psychology is a part, many of these physicians also developed a comprehensive theory of the soul that includes a treatment of the problem of identifying the stage of pregnancy when the ensoulment of the body takes place in the womb. The connection between embryology and psychology is therefore of great practical interest to Islamic law.

At ensoulment a fetus attains the legal status of a human being, with all the rights accorded by the Shariʿa. Although Muslim jurists rely substantially on the Qur'an and prophetic medicine for their knowledge of embryology, they also demonstrate a positive attitude toward the scientific embryology of the philosopher–physicians, since they do not see any basic contradiction between the two sources.

The Theological Context

The abortion debate in Islam takes place in a particular religious environment created by the divinely revealed teachings of the religion. These teachings are accepted by Muslims as sacred and immutable and have remained unquestioned in the debate over the centuries. The most important of these teachings concerns the meaning and purpose of human life.

Islam teaches that human life is sacred because its origin is none other than God, who is the Sacred and the ultimate source of all that is sacred. Human beings are God's noblest creatures by virtue of the fact that he has breathed his spirit into every human body, male and female, at a certain stage of its embryological development. This breathing of the divine spirit into the human fetus is called its ensoulment; it confers on the human species the status of theomorphic beings. Islam shares with Judaism and Christianity the teaching that God has created humans in his own image.

Islam teaches that a human is not just a mind–body or soul–body entity that has come into existence through an entirely physical, historical, or evolutionary process. He or she is also a spirit whose reality transcends the physical space–time complex and even the realm of the mind. This spiritual substance present in each human individual, to which Muslim philosophers and scientists refer as the most excellent part of the rational soul and which has cognitive powers to the extent of being able to know itself, God, and the spiritual realm in general, is what distinguishes humans from the rest of earthly creatures.

The Qur'an refers more than once to the ensoulment of the human body, almost always in the context both of describing God's creation of Adam, the first ancestor of the human race, and of affirming the superiority of humans over the rest of creation, including the angels (for example, at 15:28–30). There is also a more specific reference to the ensoulment of the human fetus that is made as part of its description of the process of pregnancy and birth. The Qur'anic passage quoted perhaps most often in the abortion debate is, "We [i.e., God and his cosmic agents] have created man out of an extraction of clay [the origin of semen]; then we turn it into semen and settle it in a firm receptacle. We then turn semen into a clot [literally, something which clings] which we then fashion into a lump of chewed flesh. Then we fashion the chewed flesh into bones and we clothe the bones with intact flesh. Then we develop out of it another creature. So blessed be God, the best of creators" (23:12–14).

Both ancient and modern commentators on the Qur'an generally agree that the last stage in the formation of the human fetus as indicated by the phrase "develop out of it another creature" mentioned in this Qur'anic passage refers to the ensoulment of the fetus, resulting in its transformation from animal into human life. As to exactly when the ensoulment of the fetus takes place, the Qur'an does not provide any information. The prophetic hadiths contain a detailed periodization of each of the different stages of fetal growth mentioned in the Qur'an. In theology as in law, matters on which the Qur'an is either silent or held to be less explicit than the hadith, the latter takes a decisive role. Thus it is the testimony of the hadith concerning the ensoulment of the fetus that has proved decisive in the formulation of Islamic theological doctrine concerning abortion.

According to one hadith, organ differentiation in the fetus does not begin to take place until six weeks after the time of fertilization. According to another, an angel who is a divine agent of ensoulment of the fetus is sent to breathe a distinctively human soul into it after 120 days of conception have passed. In his commentary on the Qur'anic verse on human reproduction cited above, basing his views on hadiths as well as on the findings of physicians, Jalāl al-Dīn al-Suyutī (d. 1505), an encyclopedist and author of a popular work on prophetic medicine, declared, "All wise men are agreed that no soul is breathed in until after the fourth month" (Elgood, 1962, p. 240).

If God has given a theomorphic nature to human persons and has created them in the best of molds (Qur'an, 95:4), having unique faculties not enjoyed by creatures of other species, it is not without a noble purpose. According to the Qur'an, human beings have been created to know God and to be God's servants and representatives on Earth in accordance with his own wishes as revealed to all branches of the human family through his prophets and messengers. One of the six fundamental articles of the Islamic creed is belief in a future life—not in this world of sensual experience and mental images, but in another world whose space–time complex is entirely different from the one we presently experience.

In the Qur'anic view, human life does not end with death. In reality, death is only a passage between two parts of a continuous life, namely the present and the posthumous. How we fare in that future life depends on how we conduct ourselves in this present life. By leading a spiritually, ethically, and morally healthy life in this world, we will attain salvation and prosperity in the after-death life. The previously cited verse on human conception and birth is immediately preceded by a reference to life in paradise and immediately followed by a statement on the certainty of death and resurrection. Muslims understand from this and other verses that there is a grand divine scheme for humans that they have no right to disturb. On the contrary, they are to participate fully in this cosmic scheme as helpers of God in both their capacities as his servants and representatives.

Human reproduction, birth, and death are part of this grand divine scheme. Indeed, the Qur'anic view is that there is even a preconception phase of human existence. The Qur'an refers to a covenant between God and all the human souls in the spiritual world before the creation of this world. God addressed the souls collectively, asking them "Am I not your Lord?" Without hesitation they all bore witness to his Lordship, thus implying that God-consciousness is in the very nature of the human soul.

The general implication of the Islamic teachings on the meaning and purpose of life for reproduction and abortion is clear. Although reproduction is not explicitly commanded in the Qur'an, it does appear to be encouraged. A few hadiths are explicit in their encouragement of procreation. The most popular is the hadith that says that, on the Day of Resurrection, the Prophet would be proud of the numbers of his community compared with other communities and that he admonishes his followers to reproduce and increase in number.

One can say with certainty that the general religious climate that prevailed in Muslim societies throughout the ages even until modern times is one in which procreation is encouraged and abortion very much discouraged. Cyril Elgood observes that "in Islamic countries moral approval of the practice of abortion was not readily given" (Elgood, 1970) although procurement of abortion, of which there were many cases, was not necessarily considered a criminal act. When he further says that "it is almost universally recognized by civilized nations that abortion is to be practiced only on the rarest of occasions" (Elgood, 1970, p. 240), the majority of Muslims would make the spontaneous response that this is precisely the Islamic view of abortion.

If Islam encourages the propagation of the human species, then it also insists that every human life be given due protection. (Abortion, however, is not considered the ending of a human life unless ensoulment of the fetus has occurred.) One of the fundamental goals of Islamic law is the protection of human life. Islam takes a serious view of the taking of human lives (except in cases that have been legitimized by the Divine Law itself) and of all acts injurious to life. One of the five basic human rights enshrined in the Shariʿa is the protection by the state of every human life. The Qur'an asserts that "whosoever kills a [single] human for other than murder or other than the corruption of the earth [i.e., war], it is as though he has killed all humankind and whosoever has saved one human, it is as though he has saved all humankind" (5:35). The phrase "other than murder" in this verse refers to justifiable homicide, like self-defense and capital punishment as prescribed under the Islamic law of equality (*qisas*).

The Islamic view of marriage and sexuality also casts a long shadow on the abortion debate. Human reproduction should take place within the framework of the sacred institution of marriage. Islam describes marriage as "half of religion" and strongly condemns sexual relations outside of marriage. The main purpose of the institution of marriage is the preservation of the human species, although Islam also recognizes the spiritual, psychological, and socioeconomic functions of marriage. That there is indeed much more to marriage than just procreation or sexual fulfillment has been amply clarified by many classical Muslim thinkers.

One of the best treatises on the wisdom of marriage in all its dimensions was composed by the prominent jurist, theologian, and Sufi, al-Ghazzālī (d. 1111). This highly influential religious scholar and critic of Aristotelian philosophy defends the permissibility of married couples' practicing contraception on the ground of their need to secure a happy marriage. He goes so far as to hold that a man who fears that his wife's bearing children might affect her health or good looks, and that he might therefore begin to dislike her, should refrain from having children (Rahman). Al-Ghazzālī's view clearly suggests that procreation is not the sole purpose of marriage.

Islamic discussion of abortion is always related to the question of the rights and responsibilities of both the husband and the wife. One of the major issues in contemporary debate on abortion in the West concerns the rights of women to procure abortion. Islam answers the question not only by appealing to its theological doctrines on the meaning and scope of human rights and responsibilities, but also to its religious theory of conception based on revealed data and hadith teachings. The Qur'an stresses the idea that everything in the heavens and on earth belongs to God. Metaphysically speaking, humans do not own anything, not even their own bodies. It is God who has apportioned rights and responsibilities to males and females, husbands and wives, fathers and mothers. Men and women in Islam obtain their mutual rights through the arbitration of the Divine Law.

In general, Muslim jurists pay great attention to women's rights in the practice of contraception and the procurement of abortion. In the words of Basim F. Musallam, "One can speak of a classical Islamic opinion on contraception generally and consistently adopted in Islamic jurisprudence, regardless of school. This classical opinion was the sanction of coitus interruptus with a free woman provided she gave her permission" (Musallam). A "free woman" is a nonslave and married. Islamic jurisprudence treats coitus interruptus under three categories, namely (1) with a wife who is a free woman; (2) with a wife who is a slave of another party; and (3) with a man's own slave or concubine. All schools of Islamic law consider coitus interruptus permissible. The majority of them insist on the woman's consent only if she belongs to the first category, since Islamic law recognizes her basic rights to children and sexual fulfillment. No permission is needed from a slave woman. In the case of abortion, the Hanafis granted the pregnant woman the right to abort even without her husband's permission provided she has a valid reason in the eyes of the Shariʿa. (The Hanafis are followers of the Islamic school of law founded by the prominent jurist Abu Hanifah and are mainly found in Turkey and the Indian subcontinent.) The Qur'anic teaching that children are not created of the man's semen alone, but of both parents together, has a bearing also on Muslim discussion of the mutual rights of husband and wife in the permissibility of abortion.

Islamic Law and Abortion

The Islamic view of fetal development based on the Qur'an and hadith is central to the Muslim arguments on abortion. All Muslim jurists believe that the fetus becomes a human being after the fourth month of pregnancy. Consequently, abortion is prohibited after that stage (Musallam). However, the jurists differ in their views concerning the permissibility of abortion during the first four months of pregnancy, that is, the period prior to the ensoulment of the fetus.

Jurists of the Hanafi school of law allowed abortion to be performed at any time during the four-month period. A special document compiled by five hundred Hanafi *ulamā* (religious scholars) decrees that "the woman has the right to adopt some method of obtaining abortion if quickening of the fetus has not occurred, which happens after 120 days of conception" (Abedin, p. 121).

Most Maliki jurists, by contrast, prohibit abortion absolutely. Their main argument is that although the fetus does not become a human until after its ensoulment, one should not tamper with the natural process of conception once the semen has settled in the womb, since the semen is destined for ensoulment. A minority of Maliki jurists, however, allow abortion of a fetus up to forty days old. Other schools of Islamic jurisprudence, among both Sunnis and Shi'ites, agree with the Hanafis in their tolerance of abortion, although again they differ on the specifics.

It is important to emphasize the fact that there is a specific theological and ethico-legal context in which abortion has been permitted in Islam. Muslim jurists classify all human acts into five categories, namely (1) the obligatory (*wājib*), (2) the recommended (*mandūb*), (3) the allowable or the indifferent (*mubāh*), (4) the blameworthy or the discouraged (*makrūh*), and (5) the forbidden (*ḥarām*). Abortion, at the most liberal level, has been placed by jurists in the third category, that of the allowable. Jurists have deliberated on the special conditions under which abortion is permitted, apart from the biological factor of ensoulment. They have also discussed cases of criminal abortion and types of penalties to be imposed on convicted wrongdoers.

Muslim jurists permit abortion mostly on medical and health grounds. One of the valid reasons often mentioned is the presence of a nursing infant. It is feared that a new pregnancy would put an upper limit on lactation. The jurists believe that if the mother could not be replaced by a wet nurse, the infant would suffer, if not die.

Contemporary Muslim society is faced with the reality that the practice of abortion is on the rise. In a number of Muslim countries, many unwanted pregnancies result from illicit sexual relations as well as from rapes. There are also related issues of birth control or family planning as a national policy, easy access to modern contraceptives, and the challenge to traditional Islamic doctrines on abortion and contraception arising from advances in genetics and biomedical technology. A well-defined Islamic response to these contemporary challenges has not yet emerged, but interest in these subjects is gaining momentum. As contemporary Muslim intellectuals and religious scholars debate these problems, traditional sources on contraception and abortion will be of immense value.

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SEE ALSO: *Authority in Religious Traditions; Islam, Bioethics in; Medical Ethics, History of: Near and Middle East; Population Ethics: Religious Traditions, Islamic Perspectives;* and other *Abortion* subentries

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ABUSE, INTERPERSONAL

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I. Child Abuse
II. Abuse between Domestic Partners
III. Elder Abuse

I. CHILD ABUSE

Current pediatrics and social-work textbooks generally include chapters on child abuse that describe the epidemiology, clinical manifestations, differential diagnosis, and treatment of abused children. They usually discuss the legal requirement to notify state child-protection agencies of suspected abuse, and may describe the investigations such reports trigger. It is accepted by most pediatricians, social workers, and laymen that investigations may result in legal actions against parents and other responsible adults. Children may be removed from their homes. Parents may have their custodial rights terminated, and may face criminal charges. The entire process of diagnosis and intervention for child abuse is presented as both necessary and morally compelling.

Changing Attitudes on Child Abuse

However, within this seeming consensus of moral sentiment lies a mystery. Until the twentieth century, much of what we now consider to be child abuse was regarded as morally acceptable and legally permissible. In fact, people generally argued not only that it was permissible to oppress and punish children to the point of physical abuse, but also that such abuse was necessary for the children’s moral edification (Radbill). Thus, “Spare the rod and spoil the child.” Parents and teachers had absolute authority over children’s lives. They could, and did, physically and sexually abuse children with an impunity so complete that such acts were seldom recognized or acknowledged.

Our current approaches to child abuse reflect a radical change in our moral view of the family. Until the twentieth century, families were usually seen as small, autocratic moral universes. Parents (in most cases, fathers) could use children (and wives) as they saw fit. Children had no independent moral rights. The movement to recognize and prevent child abuse, and to punish abusers, reflects a partial empowerment of the child. Such a sea change in moral sentiment raises important questions about the timelessness of moral principles affecting the care of children. Either child abuse was always wrong but not recognized as wrong, suggesting that our moral sensitivities are improving over time, or child abuse became wrong only recently, suggesting that moral values are not timeless and immutable but transient and constantly evolving.

Whether moral principles, such as those designed to guide the care of children, have changed over time or whether people have gradually become more or less virtuous in the treatment of children will be debated elsewhere in this work. Currently, attempts to formulate standards for appropriate ethical and legal responses to child abuse can be seen as efforts to craft social and legal policies that reflect our views of how children should be cared for and reared. But parents and other caregivers receive conflicting messages from current social policies; whereas our society restricts child abuse, its institutions and laws condone other activities—such as sexual activity during early teenage years and exposure to violence in television, films, and daily life—that would have been regarded as morally problematic in societies of previous eras and are so regarded in non–U.S. societies in the early twenty-first century. From one perspective, these conflicting efforts can be seen as experiments in social policy; from another perspective, selective legal interventions in the area of child abuse are viewed as justified by the legal doctrine of *parens patriae.* In this doctrine the state claims an interest in protecting the lives and well-being of children, even if this means limiting parental autonomy and infringing on family privacy.

Nevertheless, physical and sexual abuse of children is still common; in most instances, abuse is never reported or discovered.

Defining Child Abuse

Definitions of abuse are notoriously variable, circular, or designed to leave room for interpretation on a case-by-case basis. In the United States, the Child Abuse Prevention and Treatment Act of 1974 (PL93–247) defines abuse and neglect as:

> the physical and mental injury, sexual abuse, negligent treatment or maltreatment of a child under the age of 18 by a person who is responsible for the child's welfare under circumstances which indicate that the child's health and welfare is harmed or threatened thereby.…

State definitions based on this law vary. Arguments about whether a particular act constitutes abuse under such a definition may focus on the nature of the act itself, whether the act caused harm, whether there was or should have been prior recognition that the act would cause harm, and whether the caretaker might have prevented the harm.

In both physical and sexual abuse, different individuals or communities distinguish acceptable from unacceptable behaviors using different criteria. In physical abuse, a distinction must be made between acceptable forms of discipline or punishment and abuse. As Kim Oates (1982) points out, definitions must specify whether abuse should be defined in terms of particular actions or particular effects. He describes two children who are pushed roughly to the ground by their fathers. One falls against a carpeted floor, the other hits a protruding cupboard door. The second sustains a skull fracture, the first is uninjured. If an act must cause harm to be abuse, then the second child was clearly abused, while the first may not have been. Acts that leave no physical marks are harder to classify as abuse, and it is generally harder to sustain criminal convictions or obtain civil sanctions in such cases, even though an unmarked child may sustain as much or more psychological harm as from actions that cause physical signs of abuse.

In sexual abuse, definitional problems also arise. Child sexual abuse is generally intrafamilial, and falls under the rubric of incest. While prohibitions against incest are universal, different cultures define incest to include, or exclude, different activities. "Parent-child nudity, communal sleeping arrangements, and tolerance for masturbation and peer sex play in children coexist with stringent incest taboos.… (M)others in many cultures use genital manipulation to soothe and pleasure infants. Some cultures prescribe the deflowering of pubertal girls by an adult male or by the father" (Goodwin, p. 33). Exotic cultural differences may be mirrored by different beliefs in our own culture. Some parents may sleep with their children, bathe with them, or take pictures of the children naked on the beach. In some jurisdictions, these activities may be defined as illegal or morally inappropriate.

Cultural or religious differences may also play a role in evaluating what constitutes medical neglect. Christian Scientists, for example, may claim that it is appropriate not to take their sick children to a doctor, while courts may determine that such behavior constitutes neglect. Some Native Americans believe that organ transplantation is prohibited, and so may refuse lifesustaining treatment for their children in liver failure. Similarly, Jehovah's Witnesses may, on the basis of their belief, seek to refuse consent for blood transfusions for their children, even if transfusions would preserve life. In situations like these, judgments must be made about the relative importance of respecting religious and cultural diversity, on the one hand, and protecting the interests of vulnerable children, on the other.

In addition to cultural differences in defining what behaviors are or are not permissible, serious moral problems arise when we attempt to determine whether, in any particular case, a behavior that is clearly not permissible in fact occurred. Court cases may turn on the rules governing the collecting and presentation of evidence. Even in adult rape cases, victims have difficulty convincing juries that they have been raped. Such difficulties are compounded in child-abuse cases, where young children often cannot testify convincingly on their own behalf.

In summary, both physical abuse and sexual abuse of children exist along a spectrum, from obvious cruelty and exploitation to grayer areas of corporal punishment or sexual game playing. The strong moral arguments against egregious abuse of children often lose strength as the definition of abuse expands along a spectrum including activities that may be considered morally praiseworthy, morally acceptable, morally forgivable, or immoral but noncriminal.

Reporting Child Abuse

Most laws are vague in defining the reporting requirements for child abuse. Generally, they require reporting if someone "has reasons to believe that a child has been subjected to abuse." Such laws do not attempt to quantify the degree of suspicion, the quality of the evidence, or the likelihood of abuse that must be present to compel a report. In the crafting of such laws, it seems that the goal was to protect people who report abuse by allowing broad latitude to individuals in defining what they mean by a "suspicion" of abuse. A utilitarian calculus seems to be at work—that it would be better to have reports made that prove to be groundless than to allow subtle cases of abuse to go unreported. Even with such vague and permissive requirements, evidence suggests that abuse is underreported rather than overreported.

There are a number of reasons why people might not report child abuse even though they believe it to be wrong. Child abuse may be ignored because people have difficulty defining and recognizing it (Besharov; Zellman, 1992). It may go undiscovered because adults who are aware that a child is being abused are reticent to get involved and do not report it (Dhooper et al.). Or professionals may feel reticent to threaten what they perceive as a therapeutic relationship with the adult or adults involved. When abuse is reported, health professionals and legal agencies need to weigh the relative risks and benefits of preserving the family against those of removing the child from it (Zellman, 1990).

Reticence to report suspected child abuse may be based on the sociology of healthcare delivery, on respect for confidentiality in the doctor-parent relationship, on unwillingness to stigmatize parents when there is doubt about the actual occurrence of abuse, or on a desire to preserve a therapeutic relationship or avoid the perception that professionals are enemies.

Pediatricians in private practice are paid by the parents or other adults responsible for the children to whom they provide care, and often develop long-term relationships with these adults and the children. In such situations, relationships must be based on mutual trust. Pediatricians may give adults the benefit of the doubt regarding injuries that may be associated with abuse. They may also be fearful that child-abuse reports will be bad for business. These factors may partially explain why reports of abuse are more likely to come from hospital emergency rooms than from private doctors' offices (Badger).

In addition to economic considerations, moral aspects of the doctor–parent (or other adult) relationship may impede reporting. Generally, doctors promise confidentiality, and the moral reasons for confidentiality are compelling. Adults must confide in doctors, and may need to tell them information that would be embarrassing or damaging were it known by others. However, this promise of confidentiality may conflict with a pediatrician's concern about the child's best interest. Although the law requires doctors to report suspected child abuse, reporting is quite sporadic and inconsistent (Dhooper et al.; Zellman, 1990; Oates). Studies of pediatricians reveal that older doctors are less likely to report child abuse than are younger doctors, and males are less likely to report it than females (Kean and Dukes). None of the studies that document inconsistent reporting disentangle the economic, moral, and legal considerations that lead doctors and other child-welfare professionals to report or not to report abuse.

Reticence to report may also result from a lack of faith in the efficacy of interventions. Many child-protection agencies are underfunded and understaffed. In times of tight budgets, they may not receive the highest legislative priority. As a result, they may be unable to provide counseling and supervision services to every child or family reported to them. In some states, child-protection agencies operate under court supervision because they have been found to neglect the children in their custody. While such agencies clearly provide excellent services to most children, highly publicized cases in which they have failed to provide adequate protection may lead to skepticism about the efficacy of reporting.

Risks and Benefits of Intervention

Because society only recently recognized the problem of child abuse, there has been little time to evaluate the effects of different responses to abuse. Three types of responses have been attempted: (1) those designed to prevent abuse; (2) those designed to deal with the psychological consequences of abuse; and (3) those designed to punish offenders.

Preventive programs are difficult to evaluate because of almost insurmountable ethical and methodological problems (Conte). Abuse is a hidden problem. Assessing whether heightened awareness of the problem leads to increased reporting or decreased occurrence would require intrusive evaluation and follow-up for enormous numbers of people (Reppucci and Haugaard; Fink and McCloskey). Generally, studies focus on surrogate outcome measures, such as "ability to discriminate safe from unsafe situations," rather than on actual decreases in the incidence of sexual abuse (Hazzard et al., p. 134).

Intervention for children who have suffered abuse requires a delicate balance between trying to protect the child, trying to help the parents, and trying to preserve the family. Parents who abuse children often have been abused themselves, and may have a higher incidence of psychiatric problems (Steele and Pollack). Many parents regret their actions, desire psychiatric help, and comply with treatment programs. However, 5 to 30 percent of abused children who stay in their family are subject to further episodes of abuse (Jellinek et al.). At present, there are no reliable indicators of which parents will continue to abuse their children and which are likely to respond to therapy. Furthermore, any data that might address this issue will necessarily be probabilistic. Thus, decisions about the value of such data in an individual case will incorporate normative values about the degree of risk appropriate for a particular child facing a particular custody decision.

Programs designed to punish child abusers are driven less by considerations of the risks and benefits of interventions and more by the dictates of the legal system. Evidence against alleged abusers seldom establishes guilt beyond a reasonable doubt. As a result, criminal prosecution is rare, and conviction even rarer (Peters). Furthermore, it is unclear whether stricter laws or harsher punishments decrease the incidence of child abuse. As in other areas of criminal law, the justification for criminal prosecution seems to derive more from a notion of punitive justice than from a calculation of the degree to which punishment of offenders deters potential future offenders. Debate about this issue must take place in the context of more general debates about the morality of incarceration or the potential for rehabilitation in any criminal situation.

Conclusion

An apparent consensus about child abuse masks profound disagreements about the proper boundaries of family privacy, the obligations of parents and health professionals, and governmental responsibility to oversee the care and nurturing of children. These disagreements are reflected in difficulties in defining child abuse, difficulties in enforcing compliance with mandatory reporting requirements, and difficulties in evaluating the effects of interventions. Thus, while the law requires that child abuse be reported if it is suspected, health professionals can create their own index of suspicion. Some providers may report ambiguous cases, while others rarely report suspected abuse at all.

Individuals who work with children must balance their legal and ethical obligations to children, to their parents or caretakers, and to society. Professionals who have a higher regard for familial privacy and parental authority may develop a stricter standard or a higher threshold for suspecting abuse, and thus may be less likely to report it. Professionals who believe more strongly in the independent rights of children may develop a lower threshold for suspecting abuse, and may thus be more likely to report it. Current legal and moral approaches, while theoretically compelling, are quite recent, and have not been thoroughly evaluated. The principle that children deserve protection and nurturance is generally accepted, but the means by which the principle is to be brought to fruition remain uncertain.

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SEE ALSO: *Children: History of Childhood; Circumcision, Female; Harm; Homicide; Social Work in Healthcare;* and other *Abuse, Interpersonal* subentries

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II. ABUSE BETWEEN DOMESTIC PARTNERS

Common sense suggests that abuse between domestic partners is "just plain wrong." Nonetheless, domestic violence began to be recognized as an ethical issue only because of the advocacy work of grassroots battered-women's movements and of feminist and liberationist movements in theology, ethics, and the social sciences. This entry defines domestic violence, explores some of the reasons it is difficult for women to escape abuse, and outlines some of the underlying social and ethical issues.

Definition of Domestic Violence and Its Broader Social Context

The term *domestic partners* implies some serious bond, such as marriage, a child in common, cohabitation, or financial ties. It also usually implies emotional and sexual connections between people who have chosen to be with each other. Emotional, legal, and material connections make it difficult to end the relationship once abuse occurs. Police officers, lawmakers, medical professionals, and the general public have found it difficult to acknowledge the prevalence of domestic violence or act to prevent it because of the voluntary, emotional nature of a relationship based in the private rather than the public sphere and because of patriarchal assumptions about women and marriage.

In any intimate relationship people may hurt each other, but abuse occurs when one person systematically hurts, threatens, rapes, manipulates, tries to kill, or kills the other, and when fear replaces trust and respect as the basis of the relationship. Physical violence, with the intent of one spouse to cause harm to the other, is the accepted definition of spouse abuse in all countries where spouse abuse has been studied (Gelles and Cornell). Consistent insults, criticism, disregard for one partner's needs, isolation, damage to property and pets, and withholding money, food, or other necessities are other ways abusers try to dominate and control the relationship. The overwhelming majority of spousal abuse throughout the world is by men against women (Gelles and Cornell; Levinson), suggesting the pervasive influence of patriarchal family and social structures on abuse.

It is hard to document the extent of domestic abuse for several reasons. First, until recently, very few countries have kept records of it—violence has to be reported to some authority in order to be recorded (Gelles and Cornell). Many countries lack the bureaucratic infrastructure to maintain centralized records about domestic violence even if they desired to do so. Second, domestic violence incidents are consistently underreported, because of the shame of the abused, the desire to protect the abuser, and the failure of many agencies where women seek help to ask for and record many kinds of evidence of abuse. Third, the information kept (e.g., percentage of police calls related to family disputes, homicide statistics, number of women served by shelters, percentage of people reporting violence in surveys) varies widely. Research about domestic abuse against women tends to lag behind research about child abuse. Most research studies have analyzed family violence in a single country, using approaches that provide no basis for cross-cultural comparison (Gelles and Cornell).

Domestic violence is an international problem. The World Bank reports that gender-based violence accounts for as much death and ill-health in women between the ages of fifteen and forty-four as cancer, and more death and ill-health than malaria and car accidents combined (Venis and Horton). The World Health Organization (WHO) initiated a multi-country study on women's health and domestic violence in 1997 in response to the recommendation of an Expert Consultation on violence against women and the Beijing Platform for Action. Its objectives are to obtain reliable estimates of the prevalence of different forms of violence against women, to document the consequences of domestic violence on women's reproductive health, mental health, injuries, and general use of health services; to identify and compare risk and protective factors for domestic violence; and to identify strategies and services used by battered women. Research began in seven countries in 1999 and is expected to continue through 2002 (World Health Organization Multi-Country Study on Women's Health and Domestic Violence, Progress Report).

In the United States on average each year from 1992 to 1996 approximately 8 in 1,000 women and 1 in 1,000 men age twelve or older were violently victimized by a current or former spouse, boyfriend, or girlfriend (Henderson, 2000). In 1995, 26 percent of all female murder victims were slain by their husbands or boyfriends (FBI, 1996).

Despite the lack of statistical information and survey data, awareness of domestic abuse is increasing. In 1993 the United Nations (UN) General Assembly adopted the Declaration on the Elimination of Violence against Women and established a Special Rapporteur on Violence Against Women (U.S. Department of State). The UN designated November 25 as an International Day for the Elimination of Violence against Women in 1999. The U.S. Department of State highlighted the problem of rampant discrimination against women for the first time in 1993 in its annual report on human rights abuses. Examples cited included physical abuse against women in all countries; "honor killings" for alleged adultery by wives, especially in South America; denial in many countries of political, civil, or legal rights in voting, marriage, travel, testifying in court, inheriting and owning property, and obtaining custody of children; forced prostitution and the refusal to recognize marital rape as a crime on several continents; genital mutilation in many African countries; sexual and economic exploitation of domestic servants in Southeast Asia; and dowry deaths (murder of a bride when her family cannot give her husband's family the expected dowry) in Bangladesh and India. The Violence Against Women Act of 1994 set federal guidelines for intervention, arrest, prosecution, and treatment of battered women in the United States.

The Psychological and Social Context of Domestic Abuse

The changes that occur in a battered woman's sense of self-esteem and competence are often more lasting and more damaging to the woman than the actual physical abuse. Battered women learn to pay attention to their partner's needs instead of their own in hopes of reducing the violence. They begin to distrust their own judgment and their own abilities to provide for themselves and their children (if they have children). They may eventually come to believe that they deserve the abuse they receive. When family, friends, religious leaders, police officers, and helping professionals disbelieve, blame, or trivialize battered women's experiences and do not respond to their appeals for help, women feel even more trapped and convinced that abuse is inevitable. Chances to escape abusive relationships or find a loving relationship begin to seem impossible (Moore).

Another psychological dynamic first described by Lenore E. Walker in her 1979 book, *The Battered Woman,* also helps to explain why it is so difficult for battered women to decide to leave an abusive relationship. Walker documented a three-part cycle of (1) a violent episode; (2) regret by the abuser, love, attention, reparation, and promises never to be abusive again (the "honeymoon period"); and (3) cessation of loving attention and a period of escalating tension between partners, leading to another violent episode. Battered women yearn for the honeymoon period of love and attention that reinforces their initial hopes for the relationship. Unfortunately, over time, the honeymoons become shorter and the severity and frequency of abuse increase, sometimes resulting in death. Walker also described the "learned helplessness syndrome," where women lose faith in their ability to act effectively because batterers respond so unpredictably and illogically to so many of their actions.

The emotional, psychological, and physical consequences of abuse must be understood in their larger context of sexism, patriarchy, and paternalistic dominance (Lerner). Gerda Lerner defined sexism as “the ideology of male supremacy, of male superiority, and of beliefs that support and sustain it” (Lerner, p. 240). Sexism undergirds patriarchy, “the institutionalization of male dominance over women and children in the family and the extension of male dominance over women in society in general” (Lerner, p. 239). A sociological study of domestic abuse in Scotland documented the connection between domestic violence and patriarchal marriage. The researchers concluded that the law, the church, economic opportunities, appeals to science or to “the natural order,” and social customs all promote women’s subordinate status in marriage. Women find their struggle to resist domination, including violence, within marriage labeled “wrong, immoral, and a violation of the respect and loyalty a wife is supposed to give her husband” (Dobash and Dobash, p. ix). A study of ninety small-scale societies found that economic inequality, inequality of domestic decision-making authority, and restrictions on women’s freedom to divorce were the strongest predictors of wife beating (Levinson). The major religious faiths have traditionally taught male superiority, the duty of women to obey men, and the sin of divorce even in the case of extreme abuse, which only exacerbates religious women’s difficulties in escaping abuse.

Women’s subordination is ostensibly mitigated by the unwritten contract for exchange of services in marriage, which Lerner called “paternalistic dominance”: Men are expected to provide economic support and protection from harm in exchange for obedience, sexual service, and unpaid domestic service, including care of dependent family members (Lerner). These expectations are built into marriage and divorce laws (Weitzman) and help define women’s roles, opportunities, and sense of self (Degler). The perception and public rhetoric that women’s subordination is “normal,” “necessary,” and even desirable for women may contradict women’s lived experiences. Yet without language and communities in which women may define their own experience, subordination often goes unchallenged.

In a 1990 article in the *Annual of the Society of Christian Ethics,* Karen Lebacqz offered a powerful analysis of the role conditioning of men and women that contributes to domestic abuse in marital and nonmarital relationships. She argued that “‘normal’ patterns of male–female sexual relating in U.S. culture are defined by patterns of male dominance over women,” so that women come to expect male domination and the possibility of violence in heterosexual relations (Lebacqz, p. 3). Many recent studies (Fortune; *Against Her Will*) find that women have often experienced undesired forced sexual relations with male acquaintances that neither women nor men considered to be rape. Male power over women is eroticized in mainstream media and pornography and comes to be perceived as sexually desirable, even when women know their experiences of abuse are not desirable (Lebacqz).

Expectations of male dominance in private heterosexual relations are reinforced by men’s greater access to economic, political, religious, and cultural power in public life. In a 1992 contribution to the *Annual of the Society of Christian Ethics,* Christine Firer Hinze analyzed how the creation and maintenance of distinct public and private realms tends to keep women dependent on male earning power and status. “A ‘feminized’ private realm confers indirect status and informal power in childbearing, homemaking, and other personalized nurturing, caretaking and consumption tasks … a separate, ‘masculinized’ public arena disperses public status and formal power in cultural, political, and economic matters” (Hinze, p. 283). Even within the public realm, women are most frequently employed in domestic service and in technical service and sales occupations with lower status and salaries than male-dominated occupations. In the United States, women of color are disproportionately represented in the lowest-paid positions in domestic service compared with white women (U.S. Department of Labor). Delores S. Williams, in her contribution to the 1994 book, *Violence against Women,* offered a nuanced analysis of violence in the United States against women of color. She insisted that the analytic context of violence against African-American women must include attention to three levels: (1) the national level, the history of national violence against African-American people; (2) the work level, including the violence African-American women experience working in the homes of white employers; and (3) the home level, violence experienced in their own homes. The differences between male and female access to power and between women of different ethnic groups become especially apparent when women who decide to leave abusive partners try to find adequate jobs, housing, medical care, child care, and education for their children.

Emerging Awareness of Domestic Violence as a Social and Clinical Problem

The understanding of the *paterfamilias* (male head of a household) with life and death control over wife (wives), children, slaves, and property is found in most every culture throughout the world: in ancient Greek and Roman society; in the Middle Eastern cultures represented in Christian, Jewish, and Muslim scriptures; and in Confucian understandings of the family, to name a few examples. Religious values have played an ambiguous role, sometimes perpetuating, sometimes condemning domestic abuse. For instance, trends in Christian history that attribute to women responsibility for the presence of evil in creation also sanctioned public torture and murder of women accused of being witches or heretics (Brown and Bohn; Fortune). Yet ideals in all religions, such as the intrinsic worth of all people in Christianity or of special obligations of husbands toward wives and vice versa in Christianity and Judaism, have also condemned domestic abuse. The emergence of religious and secular movements to prevent child abuse and violence against women could not occur until women and children began to be seen as individuals in their own right. In her 1999 book, *Wounds of the Spirit,* Traci West offered a model of how churches can support African-American women in their resistance to violence based on the obligation of congregations to be agents of healing in their families and communities.

The gradual shift in attention from silent acceptance of abuse to its recognition as a problem can be illustrated by examining the history of changing laws in the United States. Until the late nineteenth century, the assumptions underlying laws and social policy in the United States came from English common law, where the husband was considered the head of the house with absolute control over his wife and children. The term *rule of thumb* comes from a modification of English common law that gives husbands the right to beat wives "provided that he used a switch no bigger than his thumb" (Martin, p. 32). From 1874 until the 1970s, the prevailing U.S. court precedents held that although husbands do not have the legal right to chastise their wives, the courts should not interfere in domestic affairs except when permanent injury, malice, cruelty, or dangerous violence can be proven (Martin). In the 1970s, growing recognition of the severity of abuse against women, due largely to the "women's liberation movement," led most states to offer women legal protection against abuse by their husbands or by the fathers of their children. In many states, however, access to information about legal options, advocates to clarify procedures and support women, and affordable remedies are still hard to find.

The first battered women's shelters were established in the 1970s in England and the United States when women who had suffered abuse came to newly formed women's support groups asking for a place to stay (Schechter). In her 1992 book, *Trauma and Recovery,* Judith Lewis Herman described the interaction of consciousness-raising groups, increased public awareness, and changes in social policy and the treatment of female victims of rape and domestic violence by medical and psychological professionals in the United States, beginning in the 1970s. Public discussion of domestic violence gave its victims the language, the courage, and the end to isolation that enabled them to decide that abuse against them was wrong even when prevailing social norms had led them to accept abuse as normal and justifiable (Herman; Schechter; Russell).

"Why don't women just leave?" is a frequent query. Unlike children or the elderly, adult women are expected to be able to protect themselves, so women who "choose" to remain with an abuser are often blamed for their situation. Men and women are—in theory—peers in a relationship of mutual equality and need, although the reality of male privilege undermines genuine equality. The long-term effects of abuse by a chosen lover, the economic, social, and legal barriers faced by women living independently or with children, the fear of even greater violence or death for the woman or for other family members if she leaves, and the pressure on women to sustain intimate relationships with men reduce the options available to women who want abuse to end. These same factors also reduce battered women's ability to recognize and act on existing options. According to the National Clearinghouse on Domestic Violence, more than 79 percent of all violent attacks occur after a woman leaves her abuser.

Legislative Issues

Increasing awareness of the extent and severity of violence against women in the United States led to the passage of the federal Violence Against Women Act in 1994. This act made orders of protection enforceable, recommended mandatory arrest laws, and granted federal money for battered women's shelters and legal services. It also allowed battered women who were not legal residents to petition for immigration privileges without the help of their abusive spouse. Twenty-nine states recognize domestic violence as a factor in custody disputes, and "battered women's defense" is legally recognized under federal and state law. Mandatory arrest policies have become central to most states' strategies to protect women, punish offenders, deter future violence and convey the new social norm that battering is wrong (Sontag). Perhaps in partial response, the number of violent victimizations of women by an intimate partner declined from 1993 to 1996, from 1.1 million reported incidents to 840,000 incidents (Greenfield et al.).

Yet some people are beginning to question the effectiveness of mandatory arrest policies because they undermine women's right to self-determination, their complicity in the violence, and their ability to negotiate safety for themselves and their children without police intervention (Mills). Is a male-dominated and racially biased judicial system revictimizing women by forcing them to share intimate and often shameful accounts of their lives in front of court authorities and to subject the men they still love to a legal system whose racial and economic fairness they question? Mandatory arrest policies also disproportionately affect low-income batterers, perhaps because more affluent batterers and victims have more access to private lawyers, doctors, escape places, and treatment options before the police are called. In their 1997 report, *Preventing Crime,* Lawrence W. Sherman and colleagues found a correlation between men's social status and increased violence: Arrests seem to deter employed men but make unemployed men more violent. Advocates for battered women counter that though the laws are imperfect they are at present the best way to protect battered women and ensure that domestic violence is treated as the crime that it is.

Medical Care

Questions about the possibility of domestic violence should be part of all regular medical histories for all women in all settings where women come for medical care. Domestic violence affects women of all economic groups, educational levels, ethnic groups, religions, and ages. Routinely asking about violence and childhood sexual abuse may help abused women recognize that they are not alone and that help is available. Questions should be posed so that they do not impute blame to women. Women who are abused may well deny their abuse out of fear, shame, or distrust. This is far more likely when their partners accompany them to doctors' offices or emergency rooms: Women need to be asked about abuse when they are alone, or at least when their partners are not able to hear their responses. Information about resources for battered women should be prominently displayed and easily available for women to take without their asking.

Battered women who have left their abusers are also likely to return more than once before they are ready to leave permanently. This can be frustrating to medical professionals who treat a particular woman's injuries repeatedly and can lead them to blame the woman, who needs to take her own time to decide how she can live in safety. Accurate medical records, including clinical reasons for suspecting abuse, are essential evidence for women who may eventually press criminal or civil charges against their abusers. Suspicious bruises should be noted on medical charts for an accurate history and evidence for possible future use. No laws require reporting suspected abuse against women (whereas there are such laws for suspected child abuse), because women are not "dependent." Nonetheless, if medical professionals incorporate questions and information about domestic violence into their routine treatment of women, they will address some of the social barriers that keep battered women from finding safety.

Ignorance about domestic violence and childhood sexual abuse also plagues psychotherapists, psychiatrists, and clergy who do not understand the emotional or material barriers that make leaving difficult. Often, they either blame women for remaining in dangerous relationships or they consistently ignore signs of abuse and refuse to pay serious attention to women who talk about abuse. Couples therapy often tries to assign responsibility for problems equally to each partner in the relationship, which ignores the reality of violence and the fear of the abuser that makes abusive relationships inherently unequal. Attributing responsibility for the violence to the offender, and specific treatment for the batterer in individual therapy or groups, is essential if abuse is to end. Fear of retaliation by the abuser can also prevent counseling professionals from intervening in situations of domestic abuse.

Treatment resources for male abusers are still scarce. Most abusers deny they have a problem. Most batterers participate in treatment groups for batterers only when they are ordered to do so by a judicial authority. Inconsistent prosecution, enforcement, and sentencing often reinforce abusers' beliefs that their abuse is not a serious problem. Mandated treatment programs are often predominantly attended by low-income men, men on welfare, or men with prior criminal records. They are likely to conclude that learning to avoid arrest is more important than changing their abusive behaviors. Treatment programs take several different approaches: Some are primarily didactic (designed to teach), some use cognitive and behavioral approaches, and some include attention to a batterer's psychological history and psychodynamic issues and the circumstances of the abuse. There is no definitive study that has proved the effectiveness of any treatment approach (see Sherman et al.).

Conclusion

Ethical issues raised by abuse between domestic partners fall into categories of treatment and prevention. Treatment includes breaking the silence that surrounds domestic violence; holding abusers legally accountable for their actions and requiring them to cease their violence; listening to victims; helping victims recognize their strengths and believe they are worthy to live in safety; and helping victims navigate through social, economic, legal, and religious barriers to safety (NiCarthy). The balance between active intervention to keep women from being hurt or killed, and respecting their need to decide how and when to end an abusive relationship, is difficult to find.

Nuancing the caricature of completely violent man and wholly submissive victimized woman is also essential in prevention, treatment, and ethical analysis. Unpacking the complicated dynamics of love, anger, and violence in particular relationships may reduce incidences of violence in those relationships. Some men are battered by women, and abuse occurs in same-sex relationships. Yet it is vital to remember the context of unequal power within which men and women learn to love, fight, attack, and seek safety. No woman will be safe until social, political, and economic institutions ensure her access to the material resources she needs to support herself and her children.

Laws alone are not enough, in the United States or any other country, to prevent abuse. In Bangladesh, a nation with very strong laws against battering, violence against women continues to rise sharply (Venis and Horton). Prevention includes challenging the prevailing social norms of sexism and patriarchy, the cultural definitions of masculinity and femininity, and the assumption that violence is a legitimate way of resolving conflict between people or groups of people. Broad economic and educational empowerment of women is ultimately the only way to end violence against women.

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SEE ALSO: *Family and Family Medicine; Feminism; Harm; Human Rights; Sexual Ethics; Women, Historical and Cross-Cultural Perspectives;* and other *Abuse, Interpersonal* subentries

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INTERNET RESOURCE

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III. ELDER ABUSE

The phenomenon known as elder abuse first appeared in the British scientific literature in 1975 (Burston) to describe the physical abuse of an elderly dependent person by a caregiving family member. In the years that followed, the definition expanded to include acts of commission (physical, psychological, and financial abuse) and omission (neglect) that result in harm to a person sixty-five years (in some states, sixty years) or older by a relative or a person with whom the elder has a trusting relationship. Self-neglect and self-abuse typically are included under broad conceptualizations of elder abuse. They refer to neglectful or abusive behaviors of older persons directed at themselves that threaten their own health or safety.

Beginning in the mid-1980s the meaning attached to elder abuse expanded further to reflect a criminalization of the phenomenon. Accordingly, there evolved interest in such areas as sexual assault in later life, battered older women, and fraud and scams (e.g., Ramsey-Klawsnik; Harris; Tueth). Likewise, since the 1990s there has been a resurgence of attention given to elder abuse in institutions, particularly nursing facilities. Exposure of fires and inadequate care in these settings during the 1970s fueled the enactment of federal legislation to protect residents. Investigations of resident conditions led to the identification of additional institutional elder abuse forms, like violation of rights, thefts, and examples of covert abuse (e.g., Meddaugh; Payne and Kovic; Harris and Benson). Finally, international perspectives on elder abuse resulted in the United Nations (2002) World Assembly on Aging's delineation of still more abuse forms. Included among them are variations emanating out of social conditions in individual countries, like systemic abuse as well as political violence and armed conflict.

Throughout this thirty-year period of problem recognition and definition expansion, there has been concern about the lack of universally accepted definitions and forms of elder abuse evident in either research or state laws. The most notable attempts to standardize both are found in research conducted by Margaret Hudson and her associates (Hudson, 1991; Hudson and Carlson, 1999; Hudson et al., 2000). Using a national panel of elder abuse experts, Hudson developed a five-level elder abuse taxonomy with eleven related definitions. Subsequent work compared the experts' perceptions to public perceptions across cultures, the results suggesting differences between cultural groups in defining and responding to elder abuse. Other studies have yielded similar findings (Tatara, 1997, 1999). For example, Georgia Anetzberger, Jill Korbin, and Susan Tomita (1996) focused on four ethnic groups in Ohio and Washington and discovered that the worst thing family members could do to an elderly person was psychological neglect, according to European-American and Puerto Rican subjects, and psychological abuse, according to Japanese-American and African-American subjects. Only African Americans listed financial abuse or exploitation among the worst things. Moreover, response to elder abuse varied by ethnic group. European-Americans and African Americans typically would contact an agency serving elders, Japanese Americans would talk to family or friends, and Puerto Ricans would contact the proper authorities.

Policy Development

In the United States interest in elder abuse was sparked by testimony on battering of parents before a U.S. House of Representatives subcommittee investigating family violence in 1978. The growing numbers of elderly persons in society, the rising political power of the older population, and the existing state bureaucracies for delivering protective services lent legitimacy to making elder abuse a public issue. Despite the efforts of a few representatives to pass national legislation throughout the 1980s, no action was taken by the Congress. Nevertheless, federal agencies did incorporate elder abuse into their agendas, but not at the funding level of the U.S. Children's Bureau program for child abuse.

Without a national focus, a knowledge base, or model statutes, the states developed their own laws, definitions, and reporting procedures. Some used existing adult protective legislation; others, domestic violence acts. Still others passed specific elder abuse laws. By the late 1980s, each of the fifty states had a system in place for receiving reports and investigating, assessing, and monitoring cases. Four-fifths of the states adopted the child-abuse approach, making it mandatory for health and social-service professionals and others who work with older persons to report suspected cases of abuse and neglect, subject to a fine or imprisonment or both. In the other states, reporting is voluntary.

Despite the widespread enactment of mandatory reporting laws, most elder abuse is not reported to authorities charged with investigating the problem. It is estimated that only one in eight (or fewer) abuse situations are reported (Pillemer and Finkelhor; U.S. House Select Committee on Aging). Still, elder abuse reporting has increased over time. From 1986 to 1996 the number of reports nationwide grew 150 percent (i.e., 117,000 to 293,000). During this period reports of neglect and self-neglect increased; those of sexual abuse remained constant; and reports of physical, financial, and psychological abuse decreased (Tatara and Kuzmeskus).

Since the 1980s all states have made revisions to their protective or elder abuse laws, often to clarify definitions, increase penalties for perpetrators, or criminalize certain abuse types. Much recent policy activity seems centered at the federal level. This includes convening the first National Policy Summit on Elder Abuse in 2001. More than eighty individuals and agencies from across the country identified priority recommendations to address elder abuse at multiple levels of responsibility. Some of these recommendations are evident in the first comprehensive legislation to address elder abuse—the Elder Justice Act, introduced in the U.S. Senate in 2002. Among its many provisions, the Act seeks to create Offices of Elder Justice in the Departments of Health and Human Services and Justice, develop forensic capacity in abuse detection, establish safe havens and other programs for elderly victims, and increase efforts to address abuse in long-term care.

Theoretical Considerations

Early attempts to understand the nature of elder abuse were influenced by the child-abuse model. Victims were viewed as very dependent older women mistreated by well-meaning but overburdened adult daughters. Later findings suggested that spouse abuse might be a more useful framework for study, since the individuals involved were legally independent adults. To some health researchers, however, using the family violence paradigm, with its emphasis on harm, intentionality, and responsibility, was counterproductive, particularly in cases that involved elders with unmet needs (Phillips, 1986; Fulmer and O'Malley). They recommended that elder abuse be considered from the perspective of family caregiving. None of these interpretations are sufficient in and of themselves. Neither the child abuse nor the spouse abuse model takes into consideration the impact of the aging process, while the family caregiving theory cannot explain abusive situations in which the victim has no unmet physical needs. It has been suggested that the concept of elder abuse may be too complex to be encompassed in one unifying theoretical model (Stein).

Risk Factors and Characteristics

Although early studies were useful in documenting the existence of the problem and promoting state elder abuse policies, they were generally based on data collected from agency files, used small, unrepresentative samples, and lumped together the various types of abuse. Karl Pillemer (1986) sought to overcome some of these methodological weaknesses by interviewing victims directly, adding a nonabused comparison group, and limiting the investigation to physical abuse. His results showed that the abusers were much more likely than the comparison group of caregivers to have mental, emotional, and/or alcohol problems and to be dependent on the victims. Conversely, the abused elders were less functionally dependent than the control group in carrying out their activities of daily living. The families in which abuse occurred also tended to have fewer outside contacts and were less satisfied with them than were their nonabuse counterparts. Similar results have been reported by other researchers (Phillips, 1988; Bristowe and Collins; Anetzberger; Lachs et al., 1997).

A comparison of 328 cases by abuse type revealed three distinct profiles (Wolf et al.). Perpetrators of physical/psychological abuse were more likely than perpetrators of neglect to have a history of mental illness and alcohol abuse, and to be dependent on the victim for financial resources. The victims were apt to be in poor emotional health but relatively independent in the activities of daily living. In contrast, those cases involving neglect appeared to be very much related to the dependency needs of the victim. Neither psychological problems nor financial dependency was a significant factor in the lives of these perpetrators; instead, the victims were a source of stress. Financial abuse represented still another profile. The victims were generally widowed and had few social supports. The perpetrators had financial problems and histories of substance abuse. Rather than interpersonal pathology or victim dependency, the salient factor in explaining these cases was the desire for money.

Few studies have examined the consequences of elder abuse. Those that have suggest that the effects of abuse infliction may have physical, behavioral, psychological, or social dimensions. In particular, victims of elder abuse seem to experience higher levels of depression than non-victims (Pillemer and Prescott; Harris). Furthermore, they are three times as likely to die sooner (Lachs et al., 1998).

Prevalence and Incidence

Although knowledge about the extent of elder abuse is sorely needed to guide policy and planning activities, no national prevalence study has been conducted in the United States. Among localized studies, the best known used a methodology that had been validated in two national family violence surveys. Karl Pillemer and David Finkelhor (1988) surveyed 2,020 noninstitutionalized elders living in the metropolitan Boston area and found that 3.2 percent had experienced physical abuse, verbal aggression, and/or neglect in the period since they reached sixty-five years. Spouse abuse was more prevalent (58%) than abuse by adult children (24%), the proportion of victims was roughly equally divided between males and females, and economic status and age were not related to the risk of abuse. Using comparable methodologies, but typically including financial abuse among forms to be investigated, national prevalence studies in Canada, Great Britain, Finland, and the Netherlands found that between 4 and 6 percent of older people surveyed were elder abuse victims (Podnieks; Ogg and Bennett; Kivelä et al.; Comijs et al.).

In 1998 the National Center on Elder Abuse completed the first national incidence study on elder abuse in the United States. Using a representative sample of twenty counties in fifteen states, two data sources were examined to identify the number of unduplicated new cases of elder abuse in a single year. The data sources were reports to Adult Protective Services and reports from sentinels, namely, specially trained community agency personnel having frequent contact with older people. The results for 1996 suggested a national incidence rate of 551,011, with self-neglect and neglect comprising over two-thirds of all elder abuse reported.

Treatment and Ethical Issues

A number of potential conflicts face practitioners who are handling elder abuse cases. While tangible proof may be obtainable in situations involving physical and financial abuse, psychological abuse and neglect are far more difficult to verify. Symptoms of sexual abuse may elude the investigator who is not aware that old people can be so victimized. Cultural biases and lack of full knowledge about the circumstances involved in a case may lead a worker to conclude, falsely, that abuse has occurred. The instability of the mental and physical status of the victim and/or the perpetrator and the dynamics of their relationship may add to case uncertainty. The issue of competency can be particularly troublesome. There may be resistance on the part of the victim to undergo medical assessment, or of the perpetrator to allow it, or even of the medical profession to make a decision.

An individual who under the law is mandated to report a case of suspected abuse may hesitate because the details of the situation have not been fully documented. Whether the problem is civil or criminal may be unclear. Certainly, the unwillingness of the victim to press charges has been a major hindrance to intervention efforts. Even though the law may require an investigation, the older person may not wish to cooperate or to accept the services that are offered. This negative response brings the worker face to face with a dilemma: the interest of the state, professionals, and society in protecting vulnerable persons versus the individual's right to self-determination; in terms of ethical principles, the tension between autonomy and beneficence.

Conclusion

Advances in understanding the nature of elder abuse will necessitate examining the problem from many perspectives. Not only must distinctions be made among the various types of elder abuse, but more attention must be paid to differences based on gender, race, culture, relationships, and circumstances. The growing interest in the problem among social scientists and medical personnel all over the world is important. The results of their efforts should be very constructive in building the theoretical and empirical base for successful treatment and prevention programs.

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SEE ALSO: *Aging and the Aged: Old Age; Dementia; Harm; Long-Term Care;* and other *Abuse, Interpersonal* subentries

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ACCESS TO HEALTHCARE

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The question of access occupies a curious position in the complex ethos of healthcare. On the one hand, it would seem to be the most basic of all ethics issues, for if people do not have access to care, all the other problems that providers and ethicists worry about are more or less moot. If there were no patients, it would be impossible to provide healthcare, at least to human beings.

On the other hand, despite all the rights that have been addressed (and, in some cases, created) by modern bioethics—including, but not limited to, the right to refuse treatment, the right to informed consent, the right to protection as a human subject of research, and the right to die on one's own terms—no right of access to care has been formally established. It is not addressed in the Declaration of Independence. Its only association with the U.S. Constitution is the 1976 Supreme Court ruling in *Estelle v. Gamble,* which held that deliberate indifference to an inmate's serious illness or injury on the part of prison officials violates the Eighth Amendment prohibition against cruel and unusual punishment.

Access is not addressed in the Nuremberg Code or the Universal Declaration of Human Rights. Even the World Health Organization's (WHO) oft-cited definition of health, set out in the preamble to its constitution (1946), as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" does not specifically address the issue of access, although the same preamble states that "the extension to all peoples of the benefits of medical, psychological, and related knowledge is essential to the fullest attainment of health."

Perhaps the closest the United States has come to a formal policy statement is the language in the 1983 report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The commission concluded that "society has an ethical obligation to ensure equitable access to healthcare for all" and that "equitable access to care requires that all citizens be able to secure an adequate level of care without excessive burdens" (p. 4). Despite these recommendations, no policy initiatives were undertaken.

Yet, in both charitable tradition and public policy, there is a history of implicit acknowledgement that the sick and injured should be able to obtain the care they need. Most major religions have, to one degree or another, adopted the provision of care as a ministry, usually in the form of hospitals. Most developed nations (and some others) have formally committed themselves to access to care for most or all of their residents. Public funds support hospitals, nursing homes, clinics, and other sources of care, and in some nations (the United States and Australia being prominent examples), these funds are also used to subsidize insurance coverage, which is usually public but sometimes private.

In the United States, federal law requires that any person seeking care in a hospital emergency department must receive an examination and evaluation, and if the person is at grave risk of death or severe debility, or is a pregnant woman in labor, the hospital may not transfer that patient unless it is clinically necessary. Many states have similar laws. There are also civil penalties for providers who are perceived to have refused care if the need was dire (and sometimes, even if it was not). Furthermore, public opinion surveys conducted by a wide range of opinion research organizations have found that most Americans support universal access to needed care, even if definitions of what that means vary considerably.

In the twentieth century, the United States also passed laws providing public funding for many healthcare services for people sixty-five or older (Medicare); for some of the poor, including some pregnant women and young children and the disabled (Medicaid); and for other low-income children (State Children's Health Insurance Program). Many states have also enacted programs subsidizing the care of low-income individuals.

Philosophy Versus Practice

Despite both rhetoric and law, access to care is hardly universal in the United States. To be fair, access to care is undoubtedly compromised, to one degree or another, in every nation on earth, because of lack of facilities, difficult terrain, poor transportation, poverty, weather, and other factors. The United States is no exception.

However, at least three factors make the United States unique with regard to access. First, unlike those of other developed nations, its federal government has never made a political commitment to universal access. Second, the key to access, generally speaking, is insurance coverage—and with few exceptions, the provision and acquisition of insurance is voluntary on the part of employers and individuals. Third, there is no political or societal consensus that access to care should be a right.

The most obvious evidence of resultant access problems is that a significant portion of the population lacks coverage. As of 2001 (the last year for which complete data were available), 16 percent of non-elderly Americans were uninsured; that represents 40.9 million people (U.S. Bureau of the Census, 2002b). Among them were 8.5 million children younger than eighteen and 272,000 people over sixty-five. Furthermore, members of minority groups were far more likely to lack coverage: Although 13.6 percent of whites were uninsured, 19 percent of African Americans and 33.2 percent of Latinos were uninsured (U.S. Bureau of the Census, 2002a).

There were also significant variations in the rate of lack of coverage among states, ranging from 23.5 percent in Texas and 20.7 percent in New Mexico to 7.5 percent in Iowa and 7.7 percent in Rhode Island and Wisconsin (U.S. Bureau of the Census, 2002c).

It is often argued that coverage is not equivalent to care, and that although it might be less convenient and will likely consume more time, the uninsured are usually able to obtain care when they need it. Some proponents of this position cite the system of public hospitals, operated by counties and cities and occasionally by states and even the federal government; the legal obligation of non-public hospitals to treat the seriously ill and injured; and hundreds (if not thousands) of subsidized clinics, public and private. Millions of people receive care through these avenues every year.

However, the network of public hospitals has contracted in recent years, and often those that remain are severely stressed financially, leading to long waiting times and delays in preventive and nonemergency care. Voluntary and for-profit hospitals vary significantly in terms of how much free care they can and do provide, and many limit what they do beyond the requirements of law. And although clinics often provide excellent and timely primary care, they are unable to offer the technology and specialty care that are available in hospitals.

Seeking to explore the validity of the argument that coverage does not determine access, in 1999 the Institute of Medicine of the National Academy of Sciences undertook a study of the interrelationship of coverage, access, and health status; the results were released in May 2002. The report estimated that 18,000 or more people die prematurely each year because of lack of coverage and a resultant lack of care.

The report concluded, "As a society, we have tolerated substantial populations of uninsured persons as a residual of employment-based and public coverage since the introduction of Medicare and Medicaid more than three and a half decades ago. Regardless of whether this is by design or default, the consequences of our policy choices are becoming more apparent and cannot be ignored" (Institute of Medicine, p. 15–16). But the United States has demonstrated on many occasions that for the most part, it can and will ignore them, at least as a matter of policy. Indeed, even when there was widespread awareness of the coverage crisis on the part of policy makers in the late 1990s, as well as a federal budget surplus, they focused most of their efforts on improving access to care for members of health maintenance organizations—who were already insured.

The Ethics Issues

Policy decisions (or the lack thereof) do not occur in a vacuum; there are always guiding philosophies at work. And with regard to access, the philosophical and ethical issues are exceedingly complex. They include:

- Is there a right of access to care?
- To what should a person have access?
- Should there be a standard of merit or *deservedness*?
- Are two or more tiers of care acceptable?
- If there must be denial or harm, to whom should it apply?

RIGHT OF ACCESS. Virtually all of the rights that patients and families have been able to claim, at least in the early twenty-first century, are individual in nature and involve the protection and honoring of a single person's (or a single family's) decisions. The idea of a right of access to care involves a great deal more than that. In order for such a right to be acknowledged, it must be agreed to by patients, the general public, providers, and whoever will pay for the care that is provided. Furthermore, at least in healthcare, there do not appear to be many endemic, universally supported rights that have consequences as profound as those that a right to healthcare would entail. The sudden enfranchisement of more than 40 million people would have profound consequences for the healthcare system as a whole—and for the society as a whole, if public money were to fund that enfranchisement, as it likely would.

It is impossible to state unequivocally that rights exist unless they are acknowledged to exist and are honored in practice. Americans may have a right to "life, liberty, and the pursuit of happiness," but unless conditions are created that allow these rights to be real, they are only abstractions. Even a general religious and moral consensus that people should be able to obtain the care they need does not constitute a right, if that access is not present in fact. Thus, as a practical matter, there is little evidence that a general right of access to care exists. What can be stated is that a person at grave risk of immediate or imminent death, or a woman who is in the process of giving birth, has a right of access to care, because both a general consensus and the presence of law and penalties make it so. No overall right of access exists except as a moral desirability; if access is granted, it is largely a voluntary act.

TO WHAT SHOULD A PERSON HAVE ACCESS? The general abstraction of a right of access becomes more real when the question is what a person should have access to. The ethical standard here is usually thought to be necessity—that is, a person should be able to obtain the care that he or she needs. As for what constitutes necessity, there are certain broad agreements: Purely cosmetic surgery is hardly ever necessary, whereas treatment for a serious bullet wound is almost always necessary.

At that point, however, any further consensus evaporates, because the standard becomes almost totally subjective. Many services, from breast reduction (or enlargement) to chiropractic to acupuncture to preventive colonoscopy, are seen as necessary for one and as frills for another. Those who provide these services believe (or at least profess to believe) that they are necessary for good health; those who seek them believe the same. Those who pay for them (if they are not the patients) and those who do not seek them have a different opinion. The difficulties that the state of Oregon encountered when it sought (successfully) to reduce the scope of services covered by its Medicaid program attest to this.

Yet it is possible that an ethically acceptable consensus could be achieved in terms of what a person should have access to, if it fulfilled four requirements: First, that it would satisfy most people, which is necessary in a democracy; second, that those services deemed necessary were seen to be so by objective experts; third, that the people who were most likely to be affected were part of the decision making process; and fourth, that some form of exception was provided for in unusual cases (for example, even if organ transplants were limited to one for any patient, retransplantation might be allowed if the donor organ proved unusable or the operation had been bungled and if there were a reasonable possibility of success). The obstacles to such a consensus are largely financial and political in nature, and not ethical.

SHOULD THERE BE A STANDARD OF MERIT OR *DESERVEDNESS*? One of the most widespread means of allocating resources is on the basis of merit, one of six principles of social justice often used in healthcare (Fox, Swazey, and Cameron, 1984). This *meritarian* principle has been used in situations as widely varied as allocation of kidney dialysis machines when they were scarce to determination of eligibility for Medicaid to pricing of health insurance. It has been argued that access to care should be governed by the same principle, that is, those who do not work for a living by choice, or who practice poor health habits, or who live socially irresponsible lives, should not have access to care, or at least not the same access that more *deserving* individuals merit. Certainly this principle has been applied elsewhere in U.S. social policy and practice, notably in what is colloquially known as the welfare system.

The problem here is threefold. First, if the goal being pursued is universal access to some level of care, then the core of that goal is *universality.* Determining the eligibility for access of individuals on the basis of any criteria, no matter how persuasive, negates the primary principle. However repugnant some individuals are to society—convicted mass murderers (who, as mentioned earlier, have a legal right of access, however spottily honored), child molesters, terrorists, obese fast-food addicts, smokers—their inclusion is necessary if there is to be universality. On the other hand, if the system is allowed to be selective on the basis of meritarian criteria, history suggests that it is quite likely that the same people excluded under the old system would be excluded under the new, and that many of them would probably be poor, powerless, and nonwhite.

Second, what constitutes merit? In public policy debates, much is made of tax monies being used to subsidize those who are *undeserving* because they do not work. Yet leaving the work force in order to raise a child is considered perfectly acceptable if the family has the financial means. The association of racial and ethnic minorities with welfare (and because the two programs were tied until recently, with

Medicaid) led to a widespread stereotypic belief that nonwhites were less deserving of public largesse. In general, society condemns obesity, use of tobacco products, overuse of alcohol, use of illegal drugs, and lack of exercise. Yet exercise-induced injuries, stress from overwork, misuse of prescription drugs, and anorexia are all excused, and insurance will usually pay for treatment.

It is extremely difficult to establish an ethical standard that will be generally accepted when the criteria appear to be random, or, worse yet, when the criteria appear to follow a pattern of racial, gender, age, or income discrimination. Nonetheless, these patterns are evident in the making of other social policy, and thus can be expected in healthcare.

Third, because access to care appears to have a direct effect on longevity, the denial of care based on a person's current character and behavior may effectively deny the possibility of redemption, a concept that is important in most ethical thought. Were society to deny access to care on the basis of irresponsible behavior, millions of young people under the age of thirty would likely be barred. Were society to deny access to care on the basis of poor health habits, many people who changed their behaviors after a health scare would never have the opportunity to do so. And, however unfortunate it is that the criterion is used, there are those who were born into poverty who went on to become successful, who might not have lived long enough to change their lives if they had not had access (if they did). A standard that denies the possibility of redemption seems exceedingly harsh.

ARE TWO OR MORE TIERS OF CARE ACCEPTABLE? Part of the debate over access, and to what one should have access, is the question of whether one standard of care should be applied to all patients, or whether tiers of care should be allowed, largely determined on the basis of either income and location.

For example, should someone living in a remote part of Alaska expect the same access as someone living a block away from a renowned teaching hospital? More germane is the question of whether a person of significant means should be able to buy coverage or services that are not fiscally available to most others, or, conversely, whether someone who is unable to pay for coverage or care should receive the same services that others must pay for, directly or indirectly.

There are both philosophical and practical responses. The philosophical responses are sharply divided. On the one hand, those who believe that healthcare is a public common that belongs to everyone would argue that one standard must apply to all, in order to preserve both quality of care and equality of opportunity. As former U.S. Surgeon General David Satcher said in 1999, "Bioethical principles call for one standard of health for all Americans" (Friedman, p. 5). Indeed, the nation of Canada has gone to great lengths, in policy and practice, to ensure such a standard by refusing to allow private insurance to cover any service that is also covered by the national health program.

On the other hand, in a market-capital society such as the United States, having more money usually means that one can buy more or better—a larger house, a fancier car, gourmet food. That is part of the reason wealth is sought after. Why should this principle not extend to healthcare? If one wishes to purchase more lavish insurance, or more personal healthcare attention, or services that are not available to lower-income people, why should that be denied?

Both arguments have merit. Perhaps a middle ground can be found in a compromise and a reality. The compromise is that tiers of care may be allowed to exist as long as the bottom tier offers acceptable access, quality and outcomes—a criterion that the U.S. healthcare system has so far failed to meet. The reality is that tiers of care exist in every healthcare system on earth, including those of Canada and the United Kingdom, because of the existence of a private sector willing to fulfill the demands of those willing to pay more, and because of the existence of national and international air transportation.

The purest ethical standard would demand absolute equality of access, of opportunity, and of care. Yet no nation on earth has been able to achieve this. That is not to say that this standard should be abandoned, but rather that the measure should be how close a society comes to meeting that standard, and what the consequences are when it does not. Lack of access to *frill* healthcare services may not be harmful, clinically or ethically, especially in light of the dangers posed by hospital-induced infections, insufficient nurse staffing, and substandard care. Lack of access to desperately needed care, based on ability to pay, is not ethically acceptable. The problems, as is usual in ethics, lie in the gray area between these two extremes.

"Two tiers of healthcare services will by right exist: those provided as part of the minimal social guarantee to all and those provided in addition through the funds of those with an advantage in the social lottery who are interested in investing those resources in healthcare," argues H. Tristram Engelhardt (Engelhart, p. 69). Others would disagree, arguing that wealth should not be able to buy health when it is denied to others. But whether they exist by right, by policy, or by accident, tiers exist, and the ethical imperative is to protect those at the bottom, rather than engaging in a fruitless effort to constrain those at the top.

IF THERE MUST BE DENIAL OR HARM, TO WHOM SHOULD IT APPLY? With respect to this question, it is instructive to consider who is harmed or denied under the system in the early twenty-first century: the uninsured, especially the uninsured poor; patients with certain diagnoses such as AIDS; racial and ethnic minorities; the chronically ill; and, in some cases, the dying (whether in this case the harm comes from overtreatment or undertreatment). Traditionally in U.S. society, those with less power and money are more vulnerable, because being poor, powerless, or politically irrelevant is equivalent to failure, and, as Roger Evans has written, "While the lives of the uninsured are clearly worth less than those of the insured, their plight reflects the unwillingness of our sociopolitical system to reward failure" (Evans, p. 17). The question is whether such failure should be punished by denial of access to care.

There is a reason that so many other societies have made a commitment to universal access to care, no matter how imperfect their efforts to implement it. That commitment is rooted in a communitarian ideal, an ethics precept that states that everyone is involved in what is happening and everyone is equally vulnerable to the consequences. This is not based only on theoretical ideals—however appealing they might be—but also on practicality: If only some individuals are protected, then some individuals are at more risk than others, although one's level of risk can change very quickly indeed. If all are protected, either none are at risk, or else all are. The strength of purpose that such an arrangement engenders leads to a stronger commitment to access, because it affects everyone. As the late Joseph Cardinal Bernadin wrote, "It is best to situate the need for healthcare reform in the context of the common good—that combination of spiritual, temporal, and material conditions needed if each person is to have the opportunity for full human development" (Bernadin, p. 65).

Conclusion

As an ethics issue, access to care will continue to be challenging, not so much on its merits as in the inability of the United States to act on the challenge. Norman Daniels has written, "If the glaring inequalities in access in the United States are justifiable, it must be because acceptable general moral principles provide justification for them" (p. 4). No such principles provide that justification, at least when it comes to denial of all but the most critically needed care, which is often halfheartedly provided. Thus there is no moral or ethical justification for the continued denial of access to care, whether intended or not. In the absence of any ethical defense of this ongoing denial, the explanation must be found in a lack of political and social will—and in the failure to find a workable communitarian ideal in a highly individualistic society.

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SEE ALSO: *Healthcare Systems; Health Insurance; Health Policy in the United States; Hospital, Modern History of; Human Rights; Immigration, Ethical and Health Issues of; International Health; Justice; Medicaid; Medicare*

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ADDICTION AND DEPENDENCE

• • •

While addiction has been called a *victimless crime,* nothing could be further from the truth. Research consistently demonstrates that acts of violence against self and others, accidents, decreased productivity, health problems, and a number of other social ills have links to alcohol and drug abuse and addiction. Every day we read about, hear about, or know someone who is a victim of a crime caused by those who use or seek drugs. For some, it is tempting to ignore the ravages of addiction by rationalizing their lack of substance use. However, much like recent findings on secondhand smoke, researchers are identifying other deleterious secondhand effects of substance abuse and dependence. These events include dealing with noise from intoxicated partiers, assault from intoxicated persons, and encountering intoxicated drivers (Wechsler, Lee, Nelson et al.).

Few people disagree that substance abuse and dependence are destructive health behaviors, yet there seems to be a vast sea of confusion surrounding these behaviors. The facts are clear: Addiction to and dependence on tobacco, alcohol, illicit and legal drugs, and possibly biologically driven behaviors such as sex and eating, and social activities such as gambling, are widespread and very destructive.

Addiction has wide-ranging consequences. In 1998 over 500,000 full-time college students were unintentionally injured under the influence of alcohol and over 600,000 were hit or assaulted by another student who had been drinking (Hingson, et al.). Over 1,400 students died from unintentional alcohol injuries (Hingson, et al.), 42 percent of adolescents admitted to a trauma center tested positive for drugs or alcohol and 72 percent of adolescents who were victims of gunshot wounds tested positive for substance use (Madan, et al.). Young persons are not the only ones affected by drug and alcohol abuse. For example, almost half of patients over 65 years old who were treated at trauma centers tested positive for alcohol (Zautcke et al.).

As can be seen from the above data, drug and alcohol abuse puts an extreme burden on the healthcare system. Over the past eighteen years, persons admitted to level I trauma centers testing positive for alcohol has declined by about one-third. However, during this same period, the number of patients testing positive for cocaine has increased 212 percent and for opioids, 543 percent. (Soderstrom et al.)

Drug and alcohol abuse and dependence cut across all geographic, ethnic, and social boundaries although some groups have rates higher than other ethnic groups (National Household Survey on Drug Abuse, 2000). According to the Drug Enforcement Agency (DEA), the total sales of illicit drugs in the United States in 1993 amounted to $100 billion. This makes the sale of illicit drugs as large a business as a top ten company on the Fortune 500 list.

Despite concerted efforts at education and interdiction, drug use is still commonplace in the United States. For example, National Household Survey on Drug Abuse data indicate that 14 million Americans (6.3% of the population age twelve and older) used an illicit drug in the month prior to the survey. Marijuana was the most commonly used drug (4.8%). National rates for other drugs were as follows: cocaine (0.5%), hallucinogens (0.4%), and inhalants (0.3%). Approximately 130,000 Americans (0.1%) are heroin users. MDMA (Ecstasy) use between 1999 and 2000 increased by almost 25 percent to 6.4 million persons (National Household Survey on Drug Abuse, 2000). This statistic is particularly alarming given the propensity of Ecstasy to cause permanent brain damage in its users.

The business community is so concerned about substance abuse and dependence that pre-employment drug screening of prospective employees has become commonplace. The majority of Fortune 500 companies have some sort of drug-testing program. Drug testing is the norm in the U.S. armed forces, and many court cases in the early twenty-first century are examining if and when the government has the right to test its employees. In 2002 the U.S. Supreme Court, in *Board of Education of Independent School District No. 92 of Pottawatomie County et al. v. Earls et al.,* held that drug testing of students is a reasonable means of preventing and deterring drug use among school children and is not a violation of Fourth Amendment rights.

The death toll from health problems caused by smoking is staggering. A study published in the *Journal of the American Medical Association* (JAMA) in 2000, estimated that almost 400,000 Americans die each year from smoking related illnesses (Thun, et al.).

Beyond the health consequences for adults, smoking is a serious threat to young people on several levels. Despite widespread antismoking programs, 14.9 percent of teenagers smoke on a regular basis. Unfortunately, many youth perceive low risk of dangers from smoking and others start smoking tobacco cigarettes after smoking *safe* marijuana.

Smoking is not the only potential threat from addictive substances to young people. The National Household Survey on Drug Abuse estimates that 27.5 percent of twelve- to twenty-year- olds have used alcohol in the past month. The 2000 Household Survey found that 6.6 percent of the household population, ages twelve to seventeen, had used marijuana in the preceding month while 9.8 percent reported using some illicit drug during the same period.

Why would anyone engage in such behavior in the face of such obvious and dire consequences? What are the root causes of such behavior? Why is there any debate about drug use when the frightening consequences are known? Part of the answer comes from exploring the question of what addiction really means.

What Is Addiction?

The concept of addiction—whether to alcohol, cigarettes, heroin, or sexual behavior—is widely misunderstood. Although there is room for debate about the *levels* of addiction caused by different substances, and perhaps about the *rights* of people to use addictive substances, there is no debate about what constitutes addiction. Addictive disease is defined by compulsion, loss of control, and continued, repeated use despite adverse consequences. Even though a person knows what will happen, he or she will use the addictive substance again. Thus, addiction is a disease characterized by repetitive and destructive use of one or more substances, and stems from a biological vulnerability exposed or induced by environmental factors such as drug taking.

Until scientists learned how popular *recreational* drugs such as cocaine affected the brain, it was thought that addiction required a physical withdrawal syndrome. That is not necessarily true. While a mild withdrawal has been described, positive effects drive compulsive use of cocaine. This information has contributed to research that clearly indicates there is no valid distinction between physical and psychological addiction.

Anyone who uses any chemical in the way described above is suffering from addictive disease. Users are distinguished by the type of drug, genetic vulnerabilities, individual predisposition to addiction, and the setting in which the drug is used.

Addiction includes preoccupation with the acquisition of a drug. In general, when obtaining a drug plays a central role in a person's life, addiction is present or near. Many studies have shown that addicts rank finding and using their drug above work, family, religion, hunger, sex, and survival. Even when the high is no longer achieved, the drug and its use are paramount. Drug taking fools the brain, giving the user a false sense of accomplishment that is at odds with reality, to the point that denial is common.

Since drugs cause a chronic disease in an otherwise healthy person, staying clean, or straight, becomes a daily problem. Relapse, therefore, is another significant and expected part of addictive disease. It is common for addicts to have relatively long periods of abstinence intermingled with drug-use binges. Chemical addiction does not happen overnight. Addicts are not moral failures but victims of a disease.

If addiction is understood as defined above, it is easy to see why it can be called a process: Use leads to brain changes; tolerance leads to abuse, which leads to loss of control, chemical dependence, and addiction.

Who Becomes Addicted?

Who becomes addicted is a complex disease process that is best understood in a biopsychosocial model where biological, environmental, and social influences create this brain disease (Tsung et al.). While research in this area is ongoing, several findings are clear. First, genetics plays a powerful role in who becomes addicted and to what. For example, approximately 10 percent of the population has a preexisting biological, or genetic, predisposition to drug and alcohol dependency. This genetic relationship is supported by the higher concordance rates (likelihood of one twin having the condition if the other has) of substance dependence among identical twins (those who share the same genetic material), compared to fraternal twins (those with non-identical genetic material). Genetic factors underlie neurotransmitter receptor patterns in the brain that predispose a person to addiction (Rose et al.). Genetic factors are important in explaining why one person can have a drink and walk away and another person cannot stop drinking until he or she passes out.

Second, there is clearly a drug effect. That is, while all drugs impact upon similar reward properties of the brain, the pharmacological properties of some drugs are more addictive than others. Some substances such as cocaine or narcotics can cause addiction in almost anyone, regardless of genetic predisposition, if they are used frequently for a long enough time.

Third, environmental factors and drug use expectancies (i.e., motivation and intent) also play a role in the addiction process (Jang et al.). For example, rarely do cancer patients become addicts despite taking powerful doses of narcotic pain medication. Similarly, while an estimated 20 percent of American soldiers in Vietnam developed heroin addiction, 90 percent were able to give up heroin once they returned from Vietnam. An outcome rate much higher than typically seen among heroin users. Finally, as Russian physiologist Ivan Pavlov (1849–1936) proved, whether it is food and a bell or a drug and a bell, salivation is salivation. Drugs are powerful conditioners shaping behavior and responses.

Despite all of this evidence of addiction, the fields of psychiatry in particular and medicine in general have been slow to respond to the medical and societal challenges posed by addiction. Even the 2000 Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-R), the bible of psychiatric diagnosis, does not mention addiction, per se, but instead discusses dependence.

What Is Dependence?

What is meant by *dependence*? Is there a real distinction between dependence and addiction or is the difference only semantic? Examination of the DSM-IV-TR criteria for Substance Dependence reveals that the above criteria cited for addiction (e.g., compulsive use, loss of control, and continued use despite adverse consequences) are included in the Dependence criteria. However, the Substance Dependence criteria also include the additional factors of tolerance and withdrawal. Thus, traditional distinctions that viewed dependence as a stage below addiction, where the choice to continue taking drugs or alcohol or to continue certain behaviors can be stopped if the person really wants to stop, may be of reduced utility (Kleiman).

In any event, once a person's drug use progresses from abuse to dependence, the capacity for voluntary control is significantly reduced. The addicted brain becomes an impaired brain because the original drug free condition has been replaced by a drug present new normality. As drug policy expert Mark A. R. Kleiman explains, people act and make decisions differently when they are intoxicated than when they are sober. Making decisions such as having another round, Kleiman points out, may lead to further bad choices. The nature of the drug—to reduce inhibition when intoxicated—brings about *drugged choices*.

Is Addiction a Real Disease?

In addition to genetics, addiction as a disease is supported by the common signs and symptoms among the homeless and physician drug addicts. The target for drugs of abuse is the brain and changes in the neuroanatomy of the brain occur in all addicts and underlie the disease of addiction. Recent research in neuroscience has identified a specific area of the brain described as the *reward center*. This area of the brain makes essential survival behaviors such as eating, drinking and sex pleasurable, reinforcing, and thus likely to reoccur. It has become evident that virtually all drugs of abuse target this same area of the brain and result in neurotransmitter brain reward. The problem is that the neurotransmitter changes caused by these drugs far exceed those produced by the natural reinforcers. Animals will press a lever for a drug injection or a puff of cocaine. Once they learn that pressing the lever gives them cocaine, they press and press and press, frequently at the expense of eating, drinking, and ultimately their lives. Unfortunately, the same is true in humans where it is not uncommon to see addicts lose family, careers, and even their lives because of their addiction.

This same area has connections to the emotional areas of the brain (i.e., limbic system). Thus, drug use and addiction can be seen as a disease of brain reward with significant physical and psychological consequences. To truly understand the concept of addiction, one must look at issues of both positive and negative reinforcement. The pleasure effects of the drugs obviously result in positive reinforcement. However, continued drug use ultimately leads to changes in neurotransmitter levels and a host of negative states and emotions (e.g., depression, anxiety, fatigue, etc.). In these cases, continued use of the drug leads to a decrease in these unpleasant effects and results in what is called *negative reinforcement* (e.g., removal of unpleasant feelings) and the subsequent return to a *normal* (in this case, drugged brain) state. Research has led to a new understanding of addiction that is not based solely on withdrawal effects.

To understand this process in more detail let us examine the drug cocaine. Drugs like cocaine trick the limbic system by triggering the reward response through the release of neurotransmitters. Neurotransmitters are chemical messengers between nerve cells that are intricately involved in regulating moods. Cocaine use, for example, acutely leads to the increased availability of the neurotransmitter dopamine. Dopamine causes specific nerve cells to fire, and the result is endogenous brain reward or euphoria. Since cocaine uses brain systems normally reserved for species survival reward, the user feels as if he or she has just accomplished something important. The euphoria and brain reward produced by cocaine make the brain view the drug as a substance critical for survival. Hence the brain asks for more cocaine and excessive amounts of dopamine are released. Normally, any surplus dopamine released by the nerve cells is reabsorbed by them; however, cocaine interferes with this reabsorption. Finally, the brain's store of dopamine is depleted. With their supply of neurotransmitters depleted, cocaine users experience intense depression and cravings for more cocaine. In addition, the limbic system remembers cocaine's pleasurable response, a memory that can be triggered by talking about the drug, or smelling it, or even a visual stimulus such as talcum powder. It is believed that the action of drugs in a section of the brain called the nucleus accumbens is primarily responsible for the feelings of positive reinforcement that result from use of virtually all substances of abuse.

Other factors besides the pharmacological effects of drugs may lead to positive reinforcement. For example, drug use may enhance a person's social standing, encourage approval by drug-using friends, and convey a special status to the user. Recent research has shown that environmental factors can account for a considerable amount of the variance attributed to whether teens decide to use or abstain from alcohol (Rose et al.).

Given enough repetitions, drug and alcohol use become as entrenched as the desire for food, water, or sex. Furthermore, the dopamine pathways have many other influences, from the hypothalamus and hormones to the frontal lobe of the brain—the area responsible for judgment and insight. Not only do drugs cause the addict's brain to demand more drugs; the addict's ability to handle this demand rationally in the context of other everyday demands (such as work, family responsibilities, health and safety concerns) is distorted. Tormented by the acquired drive for the drug, memory of euphoria, and denial of obvious consequences, the addict becomes out of control.

Obviously, the complexity of the body and the brain means that no simple answer for the cause of addiction will be found. However, researchers are using sophisticated diagnostic examinations to uncover more information in an attempt to understand better the effects of drugs upon the brain. While it is doubtful that these procedures will provide a definitive, simple answer to the cause of addiction, the information gleaned from them may result in more effective treatment and prevention strategies.

What Is Tolerance?

Tolerance may occur when the brain environment redefines normal and resets that level of feeling due to continued drug use. If drugs are taken to seek pleasure, they develop a life of their own as the brain redefines normal to require their presence in expected quantities. In other words, it takes more and more just to feel normal.

Interestingly, the emphasis on drug reward in the addiction process paves the way for other conditions, such as eating disorders and even sexual or gambling disorders, to be considered addictions. Eating disorders, in particular, share common behavioral symptoms, biological reward pathways, high relapse rates, and treatment strategies with other forms of substance abuse. More research is necessary to establish the legitimate inclusion of sexual and gambling behaviors with other expressions of addiction.

Drug Triggers: The Brain Learns

Drug use provides a quick and powerful means of changing one's moods and sensations. In a cost-benefit analysis, the user seeks the immediately gratifying effects as a benefit that outweighs the long-term cost of drug use. Other users may be influenced by physical or psychological states such as depression, pain, or stress that may be temporarily relieved by drug consumption. Drug use is such a powerful reinforcer and shaper of behavior that drug paraphernalia and virtually all of the events associated with finding and using drugs become reinforcers.

A variety of nondrug factors, including psychological states such as depression or anxiety, and/or environmental factors (such as drug paraphernalia and drug-using locations or friends) can become so associated with drug taking that merely being depressed or seeing drug paraphernalia may trigger the urge to use drugs.

WITHDRAWAL. While significant evidence supports the role of dopamine in the reward process, the neuroanatomy of withdrawal is not as clearly defined. However, a wide variety of abused drugs, with apparently little in common pharmacologically, have common withdrawal effects in certain areas of the brain. Opiates, benzodiazepines, nicotine, and alcohol have all had their withdrawal symptoms treated effectively with clonidine, a medication that works in an area of the brain called the locus coeruleus.

Unlike opiate and alcohol withdrawal, symptoms of cocaine withdrawal are relatively mild and disappear relatively quickly. This dearth of withdrawal symptoms helps to explain the episodic pattern of use reported by many cocaine addicts: Periods of intense bingeing alternate with intervals of abstinence. The intense craving and high relapse rate associated with cocaine use appear to derive more from a desire to repeat a pleasurable experience than to avoid the discomfort of withdrawal.

In fact, for all drugs, reward may be more important than withdrawal in the persistence of addiction and relapse, in that successful treatment of withdrawal has not generally improved recovery.

TREATMENT IMPLICATIONS. The disease model of addiction is supported by the high degree of addiction that various substances of abuse cause and the likelihood that someone addicted to one drug often will be using more than one drug. This multiple addiction is a major factor and plays a significant role in the treatment of addiction. Treatment strategies aimed at eliminating one specific form of addiction, such as cocaine abuse, without addressing other mood-altering substances, have usually failed. The addict who abuses only one drug is very rare. The Epidemiologic Catchment Area study of over 20,000 respondents found that 16 percent of the general population experienced alcoholism at some point during their lifetime—with 30 percent of these alcoholics also abusing other drugs. Alcoholics were 3.9 times more likely than nonalcoholics to have comorbid drug abuse. Similarly, the rates of alcohol abuse among other drug addicts were high: 36 percent of cannabis addicts, 62 percent of amphetamine addicts, 67 percent of opiate addicts, and 84 percent of cocaine addicts were also alcoholics. These studies, combined with clinical observations regarding the concurrent use of multiple substances, suggest common biological determinants for all addiction (Miller and Gold).

The success of Alcoholics Anonymous, with its broad ban of all mood-altering substances, lends further support to the unified disease concept of addiction. Similarly, naltrexone, a medication known previously for its efficacy in helping opiate addicts to recover, has been used successfully to treat alcoholism, cocaine addiction, and eating disorders. Although naltrexone can block the effects only of opiates, it appears to be effective against other drugs of abuse primarily because of the involvement of the opiate system in reward. According to this theory, naltrexone's opiate inhibition makes other drug use less reinforcing and ultimately prevents full-blown relapse to drug use as the addict's body learns not to associate drug use with reward. However, even with the use of Alcoholics Anonymous and viable pharmacological therapies like naltrexone, addiction remains difficult to treat primarily because drug use is so intertwined with the biological reward system.

For an addict, drug use becomes an acquired drive state that permeates all aspects of life. Withdrawal from drug use activates separate neural pathways that cause withdrawal events to be perceived as life threatening, and the subsequent physiological and psychological reactions often lead to renewed drug consumption. The treatment research consensus is that time in treatment and/or abstinence is the greatest predictor of treatment success and may reflect the time required to reinstate predrug neural homeostasis, fading of memory of euphoria and conditioned cues, and the reemergence of endogenous reinforcement for work, friends, shelter, food, water, and sex.

Drug reinforcement is so powerful that even when it is eliminated by pharmacological blockade (e.g., naltrexone), humans quickly identify themselves as opiate available or unavailable and change their behavior without changing their attachment to the drug and its effects. Once pharmacological intervention is discontinued, the addict will often resume self-administration.

Moods and other mental states, such as drug craving and anxiety, can become conditioned stimuli that may lead to drug use. Clinicians have used relaxation training, in which patients are taught relaxation and breathing techniques, to use in the presence of drug-related stimuli or the mental states they would normally associate with the need to use drugs.

Clearly, relapse prevention and successful treatment of addiction require much more than the alleviation of withdrawal symptoms. It is well known that patients with higher pretreatment levels of social support, employment, and productivity have a better prognosis for successful response to initial treatment and long-term abstinence. Treatment outcomes for these patients may improve because they perceive the long-term cost of drug use (loss of family or job) as outweighing the short-term benefit of drug use. Educational efforts that stress the risks associated with drug abuse help individuals to avoid drug use. No pharmacological or nonpharmacological treatment strategy can match the success of prevention. Research has shown that treatment efforts and relapse prevention are especially effective in impaired professionals (i.e., healthcare and other professionals whose licenses are controlled by state agencies). It appears as though these individuals have access to necessary inpatient and residential care to reverse the patterns of this devastating disease. These programs use a carrot and stick approach and rely on abstinence verification through objective urinalysis testing. Lessons from treatment of these patients can be used to improve the treatment of all patients with addiction.

The disease model of addiction should not be used to excuse the addict's responsibility; abuse has to begin somewhere. The addict remains culpable for the initial decision to use the drug and for continuing to use it despite adverse consequences. Nevertheless, an understanding of addiction and the addiction process allows us to comprehend the existence of addiction as well as why abstinence in treatment is difficult to achieve.

Summary

All abuse-prone drugs are used, at least initially, for their positive effects and because the user believes the short-term benefits of this experience surpass the long-term costs. Once initiated, drug use permits access to the reinforcement reward system, which is believed to be anatomically distinct from the negative/withdrawal system in the brain. This positive reward system provides the user with an experience that the brain equates with profoundly important events like eating, drinking, and sex.

While studies have confirmed an encouraging decline in the number of illicit drug users, substance abuse continues to be a national problem. National Household Survey suggests that over 14 million Americans are users of illicit drugs (National Household Survey, 2000). Estimates of the presence of drugs like cocaine and opiates in trauma victims has increased several hundredfold from less than two decades before. Ecstasy use among adolescents jumped almost 25 percent between 1999 and 2000. In 2001, 5.2 percent of 8th graders, 8.0 percent of 10th graders, and 11.7 percent of high school seniors had used Ecstasy in their lifetimes (NIDA Infofax). Increased use has resulted in a dramatic increase in emergency room visits. According to data from the Substance Abuse and Mental Health Services Administration's Drug Abuse Warning Network, Ecstasy-related hospital emergency room incidents increased from 253 in 1994 to over 4,500 in 2000. The number of MDMA related deaths has also been increasing. (Goldberger and Gold).

Better news is increased understanding of the role that genetics and inheritance play in possible predisposition to addiction. And the best news of all is the widespread acceptance of the biological nature of drug addiction and the disease model, which brings hope to millions of people who think they are at fault because they cannot overcome their body's desires. The future will bring greater understanding of the biological pathways and, with that, cures for addiction and dependence.

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SEE ALSO: *Alcoholism; Freedom and Free Will; Harmful Substances, Legal Control of; Health and Disease: History of Concepts; Impaired Professionals; Maternal-Fetal Relationship; Organ Transplants; Smoking*

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ADOLESCENTS

SEE *Pediatrics, Adolescents*

ADOPTION

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Adoption is an institution as old as civilization. It may be defined as a social transaction through which a person belonging by birth to one family or kinship group acquires, through legal means, a new family or new kinship ties.

Historical Background

In its broadest sense, the term “adoption” may be used to describe the taking in, nurturing, and rearing of biologically unrelated children in need of protection and care. The terms “adoption” and “fostering” are used interchangeably in some countries, but in the United States adoption, in contrast to temporary foster arrangements, is a legal and permanent transaction.

Shaped by the laws and cultures of each society, adoption was seldom concerned primarily with rescuing abandoned children but rather with the transfer of a child or adult from one set of parents to another in order to ensure property rights or family continuity. Yet the perception of adoption has always wavered between the legal fiction that a child is reborn into the adoptive family and the folk belief that blood is thicker than water. The Egyptians and the Hebrews practiced adoption; the Old Testament chronicles the story of Moses, who was adopted by the daughter of the Pharaoh but later returned to his people and led them out of bondage.

Roman law, the foundation of institutionalized legal adoption, was concerned primarily with property and inheritance rights but permitted birth parents to reclaim their abandoned children if they paid expenses incurred by the adoptive parents (Boswell). The Code of Napoleon, enacted in 1804, which was the beginning of modern adoption legislation and is still a major influence in French and Latin American law, allowed adoptees to have knowledge of family background and the option to retain their original name.

The modern French government social security system provides for both "simple" (open) adoption and "complete" (closed) adoption.

English common law, the basis for U.S. law, stressed blood lineage and did not legalize stranger adoption, the total legal transfer of the child to nonrelatives, until 1926. Until then, a form of apprenticeship existed in which children lived with and worked under the master training them. Orphans were sent as indentured servants to the American colonies to help with the labor shortage. Economic considerations superseded any concern for the welfare of the individual child.

From the mid-nineteenth century until the beginning of the twentieth century, New York City street urchins were routinely rounded up and loaded into boxcars on "orphan trains" that carried them to "God-fearing" farm families in the West. There were no legal contracts or protections for the children who, once severed from their families, were regarded as orphans and forced into a life of domestic or manual labor thousands of miles away.

The transition from apprenticeship and indenture to present-day adoption was gradual in the United States, but by 1929 every state had some form of statutory adoption. Licensed adoption agencies established in the 1920s investigated prospective adoptive families to try to ensure the well-being of adopted children. Adoption records were open, but in the late 1930s a few states began to close them.

After World War II, U.S. adoption shifted its focus from the needs of homeless children to the desires of infertile couples to adopt healthy white newborns. Adoption became the means for the childless to create a family. As state after state closed their records, the adopted child's birth certificate was sealed and replaced with an amended document that named the adoptive parents as the birth parents. The original intent was to spare the child the stigma of illegitimacy, not to cut him or her off from the birth heritage. Over the years the rationale of protecting the confidentiality of the birth mother was added, but an even greater concern was the protection of the adoptive parents, who feared the birth parents might reappear to reclaim their biological, though no longer legal, child. By 2003 all but six states had sealed records.

Adoption Practice in the United States in the Mid- to Late Twentieth Century

The social upheavals of the 1960s and 1970s had a major impact on adoption practice. The legalization of abortion, along with the widespread use of contraceptives and the increased tendency of unmarried mothers to keep their children, led to a shortage of white, adoptable newborns. At the same time, there was a rise in infertility among couples who delayed having children.

The states regulate adoption practice; most states permit both independent and agency adoption. As the shortage of white, adoptable babies grew more acute, adoption became a commercial enterprise. Lawyers and "baby brokers" took over most infant adoptions from the agencies, frequently using newspaper advertisements to entice pregnant women and couples to give up their children with offers of money and other benefits.

Without regulation by the child-welfare field, there is little protection for the baby and both sets of parents. Prospective adopters may spend a great deal of money for medical, living, and legal costs only to have the pregnant woman change her mind and keep the baby or choose another family. Conversely, a birth mother who has been promised open communication with the adoptive parents and the child may find herself cut off once the adoption is finalized. Or the birth mother may break her promise to stay in touch with the family if she finds visits too difficult to continue. Safeguards for the baby are lacking when the investigation of the family by an agency occurs after the infant is already in the home and petition has been filed for legal adoption.

Special Needs and Biracial Adoption

In the 1990s adoption agencies, both private and public, focused primarily on finding families for "hard to place" children, a category that includes older children, sibling groups, disabled children, and biracial or minority-racial children. The U.S. Department of Human Services estimated in 1998 that 520,000 children lived in foster care in the United States, a sizable increase from 1992. About 110,000 children were reported to be legally free for adoption. Many child-welfare specialists believe that if sufficient effort were expended, homes could be found for them. Some states offer subsidies to families who are willing to adopt and raise disabled children. Single persons and gay and lesbian couples, not generally approved for newborn babies, are often considered acceptable for placement of children who otherwise might not find permanent homes. This remains a controversial issue in some parts of the United States, as a number of individuals and groups question the ability of these nontraditional adoptive parents to raise healthy, normal children.

In 1972 the National Association of Black Social Workers (NABSW) launched a campaign against allowing white families to adopt black or biracial children. The NABSW called this practice genocide. They maintained that, with enough effort and focus, black families could be found for these children. Proponents of interracial adoption argue that the benefits children gain from having permanent and loving homes outweigh the social and psychological difficulties they may face because of society's prejudice toward mixed-race families. Mental-health professionals generally agree that permanency, whether with legal adoption or long-term placement, is a paramount need for all children; they believe that growing up without roots and a stable home is a primary cause of lifelong problems. Many child advocates prefer that a child be placed with his or her extended family or within his or her community of race or religion, but accept the fact that biracial placement is preferable to no permanency as long as the families are sensitive to biracial issues and seek integrated communities in which to raise their children.

Adoption of Native American children is a related and equally controversial issue. Many Native Americans believe that adoption by Caucasians robs them of their children and robs the children of their native heritage. When Congress enacted the Indian Child Welfare Act of 1978, giving tribal courts exclusive jurisdiction over adoption proceedings involving Native American children, each tribe developed its own guidelines concerning the Native American lineage a child needed to qualify as a member. Children identified as members of a particular tribe must be placed for adoption with a family of that tribe.

Intercountry Adoption

The shortage of desirable adoptable babies in the United States has led many who wish to adopt to seek children in other countries. The first international adoptions generally involved Amerasian children, that is, those fathered by GIs in Japan during and after World War II, in Korea during and after the Korean War, and in Vietnam during the U.S. involvement there. These adoptions were first sponsored by church groups and then by licensed adoption agencies (Lifton, 1994).

Since the middle of the 1980s, international adoption has shifted from the rescue of war orphans to the legal or (in some cases) illegal trafficking of children. Most of the children are drawn from Korea, China, Russia, Eastern Europe, and Latin America because these countries have made the emigration of children more accessible. Human-rights organizations report that many children are taken away from their families without formal relinquishments (Mantaphon). Studies of intercountry adoptions suggest that children cut off from their own culture and transplanted into a totally foreign environment may be more vulnerable to emotional problems (Verhulst et al., 1990a, 1990b). Many have difficulty in attaching to their new family or feeling part of the community, where they may not find full acceptance because of racial differences.

The 1989 U.N. Convention on the Rights of the Child addressed the rights of the adopted child along with the rights of all children. According to the convention, each child has a right to receive a name, to acquire a nationality, and, as far as possible, to know and be cared for by his or her parents. A child placed outside of his or her family of origin has the right to maintain contact with his or her birth parents.

The Sealed-Record Controversy

For over half a century, closed adoption (i.e., with sealed records) was viewed by U.S. society as beneficial to everyone: The homeless child born out of wedlock was given a second chance in a new family, the infertile couple was able to become "real" parents, and the birth mother was free to go on with her life as if she had never had a child. Yet research conducted since the mid-1970s has consistently indicated that the secrecy in the closed-adoption system can often create lifelong psychological problems for everyone involved (Sorosky et al.).

Although adopted children comprise less than 5 percent of the population, the percentage of adopted children in mental-health facilities and residential treatment centers has been reported to be as high as 30 percent. Some researchers have found that adopted children score lower in academic achievement and social skills than the nonadopted, have a high incidence of learning disabilities, and display behavior characterized as impulsive, aggressive, and antisocial (Schecter et al.; Brodzinsky and Schecter; Brinich). Psychotherapists have postulated that an adopted child's perception of rejection and abandonment by the birth mother can cause low self-esteem. Ignorance of origins ("genealogical bewilderment") can lead a child to rebellion against the adoptive parents and society, and eventually to delinquency (Wellisch; Sants; Kirschner and Nagel).

Women who relinquish their infants often suffer a profound loss and experience lifelong difficulties. Like the child, they are encouraged by society to deny and repress the feelings that accompanied giving up their children for adoption. Some studies indicate that these women never forgive themselves. Some may feel they have no right to a happy marriage and other children, while others may try without success to have other children as replacements for the one that they relinquished (Deykin et al.; Millen and Roll).

The closed-adoption system also encourages adoptive parents to deny their grief at not being able to produce a child that will carry on their lineage. They are expected to conceal their unresolved conflicts over infertility as they pretend that adopting a child is the same as giving birth (Blum). Adoptive parents who are able to acknowledge the differences between an adoptive and birth family, instead of denying them, have been shown to have better communication and closer relationships with their children (Kirk).

The closed-adoption system tends to pit the right of the adopted child to know the identity of his or her birth parents against the right of the birth mother to confidentiality, and against the right of the adoptive parents to maintain exclusive parental roles. The National Council for Adoption (NCFA), a lobbying organization representing traditional adoption agencies, contends that sealed records protect the privacy of the birth mother, who was promised confidentiality (Caplan). A national birth-parent group, Concerned United Birth Parents (CUB), argues that the majority of birth mothers did not ask for confidentiality and in fact want to have knowledge of or some contact with the children they gave birth to. Until 1976, birth fathers had no rights, only responsibilities. At that time, the U.S. Supreme Court gave birth fathers equal right of consent with birth mothers in adoption arrangements.

Search and Reunion

One of the effects of the civil-rights movement of the 1960s was the emergence of an adoption-reform movement led by adult adoptees. Its rallying cry was that the civil rights of the adopted had been violated when their original birth records were sealed, denying them access to information available to nonadopted people. Adoption support groups have been established across the United States to provide emotional support, lobby for open records, and facilitate the search for birth parents.

Some states, rather than open their previously sealed adoption records, have established "reunion registries" that will connect adoptees with their birth parents if both register and indicate their mutual desire. In other jurisdictions, there is an intermediary system, in which the court, or an adoption agency is empowered to search for the birth mother if an adoptee requests a reunion. The birth mother retains the right of refusal of contact. Adopted activists believe that both registries and intermediaries violate their right to information and the ability to make direct contact with birth relatives.

More adopted women search for their birth parents than adopted men. The quest to find the birth mother is usually stronger than the need to locate the birth father. Adoptees tend to begin their search when they become aware of formerly repressed feelings that often surface at times of life transitions, such as impending marriage, parenthood, or death of adoptive parents (Sorosky et al.; Lifton, 1988).

The secrets inherent in the closed-adoption system make reunion difficult for both birth mother and adoptee. To return to each other is to return to their earlier traumas. The adoptee experiences grief, anger, and divided loyalties; the birth mother relives the unresolved sadness, guilt, and humiliation she felt at the time of pregnancy, birth, and relinquishment (Lifton, 1994).

No matter whom adoptees find—a loving, a withholding, or even a deceased parent—the opportunity to heal arises when they can integrate the past with the present. Adoptees' relationship to their adoptive parents is usually strengthened once they have resolved their identity issues. Reality replaces their fantasies, and they are able to recognize the important role of their adoptive parents (Gonyo and Watson; Sorosky et al.; Lifton, 1994). Birth parents also enter a healing process after reunion because they have the opportunity to explain to their child why they relinquished him or her and to forgive themselves and be forgiven (Gediman and Brown).

Some adoptees and birth parents develop close, ongoing kinship ties. Others maintain a more distant relationship that may involve little more than exchanging holiday cards. A few, after one or two meetings, close off contact. Whatever follows the reunion, however, the individuals involved have been able to take control of this important aspect of their lives.

Open versus Closed Adoption

Since the early 1980s there has been a trend toward openness in adoption. In the placement of older children, good adoption practice dictates providing each child with a "life book" that has information and photographs about their history. Often these children are encouraged to maintain contact with the previous foster mother and with relatives, such as grandparents, in the extended birth family.

In infant adoption, a birth mother may choose the parents for her baby, but completely open arrangements—where there is an ongoing relationship between birth and adoptive families—are still rare. Semi-open adoption is more usual. It may vary from little more than a single meeting between the birth mother and adoptive parents, with no disclosure of names or discussion of future contact, to annual exchanges of photographs and information and the promise of more contact when the child grows up (McRoy et al.). Professionals describe open-adoption arrangements as a process in which all parties move at their own pace over the years (Silber and Dorner).

Opponents of open adoption argue that it makes it difficult for the birth mother to accept that she has given up a child, that it hinders adoptive parents in forming secure ties with an infant, and that it deprives the child of a sense of permanence with the adoptive family (Caplan). Proponents of open adoption believe that birth mothers who take an active part in the placement process can resolve their guilt and grief about giving up their baby; that it obviates adoptive parents' fantasies about the child's background because they have facts; that it permits adopted children to know that their birth parents are real persons, not ghosts; and that they were not given up because there was something wrong with them (Silber and Dorner).

Court Battles between Birth Parents and Adoptive Parents

Since the mid-1980s the number of contested adoption cases has multiplied. Many have been brought by birth mothers (and increasingly by birth fathers) who feel that they did not receive proper counseling or enough time, or were coerced into signing relinquishment papers. When the birth mother seeks the return of the child, lawyers for the adoptive parents may delay action in order to prolong the child's presence in the adoptive home. The longer that period, the stronger the argument that it is in the best interests of the child to stay in the only home he or she has ever known. Adoptive-parent lobbies seek to limit the time that birth parents may have to revoke their consent or relinquishment. There is also a strong movement to develop uniform state laws that would limit the problems of interstate placements and decrease the legal conflicts of different jurisdictions.

Conclusion

The adoption field is betwixt and between stasis and change. The records remain sealed in most states, but the traditional closed system is gradually giving way to a more open one that allows birth parents and adoptive parents to meet and even maintain contact over the years for the sake of the child.

Adoption practice is no longer exclusively concerned with healthy white newborns. Adoptees include transracial and biracial children and older handicapped children with special needs. Standards for adoptive parents, once modeled on white, middle-class, heterosexual couples, have changed to include single parents, homosexual couples, and minority and biracial couples of any age.

Uniform state laws are necessary to regulate adoption practice, but there is much disagreement about the relative importance of birth-parent versus adoptive parent rights. The term "best interests of the child" has come to mean whatever people want it to mean. Prospective adoptive parents and birth parents find themselves in adversarial roles where their own best interests may conflict with the best interests of the child.

Adoption-reform activists believe it is in the best interests of the child to have adoption practice limited to nonprofit agencies and child-welfare specialists. They stress the need for adequate legal and psychological counseling for both birth parents and adoptive parents before and after the birth of the baby and especially before finalizing relinquishment plans.

Reformers would like to see adoption records unsealed so that adopted children can integrate their dual heritage and avoid many of the psychological problems that are caused by secrecy. They advocate a nationwide program that would promote sex education, pregnancy prevention, family preservation, and legally enforced open-adoption arrangements when relinquishment and placement are necessary.

POSTSCRIPT

Twenty-First Century Adoption Practices

During the late 1990s, laws erasing the secrecy and anonymity of the last century of adoption practice have been enacted in a number of states. Adopted adults are gaining access to their original birth certificates through legislative acts and voter referendums, despite the fact that there is still resistance to opening adoption records in most states. However, even in states where the records remain sealed, there has been an increase in reunions between birth parents and adoptees relinquished in infancy or childhood.

The Internet has revolutionized the adoption field. Searches for identifying information have become easier than in previous decades due to the nation's fascination with genealogy and the growth of databases on the Internet. Potential adopters and pregnant women considering relinquishment are also using the Internet to make contact. Families with special-needs children can turn to a variety of websites, help lines, chat rooms, and referral sources. There are also special websites on international adoption that lay out the unique problems one can encounter in the various countries where children are available.

The lucrative business of adoption in the marketplace continues to grow as attorneys, private agencies, and intermediaries use the Internet for networking in both domestic and international placements. International adoption is increasing as the number of adoptable healthy newborn Caucasian infants born in the United States decreases. Most women, married or single, choose to raise, rather than relinquish, their babies. Potential adoptive couples fear that even those women who initially choose to relinquish their babies will change their minds, or that the birth father will challenge the legality of the adoption. The publicity around and pain caused by contested adoptions has resulted in the introduction of new codes and procedures in many states to act as safeguards.

At the same time, open arrangements between birth and adoptive families in the United States are becoming the accepted practice with both infants and older children. The degree of openness varies and may be modified over the years, but all parties generally have identifying knowledge of each other. Agencies and other adoption practitioners can no longer offer guarantees of confidentiality or anonymity. In fact, many agencies offer post-adoption services in which they act as intermediaries in reunions, conduct support groups, and do counseling with all members of the triad.

By the beginning of the twenty-first century, private and public adoption agencies served different communities. The private agency or practitioner deals primarily with Caucasian infants born in the United States and with international adoptions of infants and toddlers. Public agencies, connected to the welfare system, place special-needs children. These children are usually older, part of a sibling group, non-Caucasian, racially mixed, or with medical or developmental problems. The federal government has enacted special programs, with financial incentives to local public agencies, to increase the numbers of children moving from foster home placement into permanent or adoptive homes. In both public and private agencies, there is greater acceptance of adoptions by single persons and gay and lesbian couples.

Those couples or individuals who prefer international adoption discover that the availability of children and the cost involved shifts from country to country, depending on political, economic, and legal issues. Regulations in the United States as well as in the country of the child's origin and in international umbrella agencies all contribute to the complicated procedures facing those applying to adopt. Nevertheless, a growing number of children are adopted through these routes. Those who choose international adoption to avoid the risk of legal challenges or interference from the birth parents overlook the psychological need of adopted children to know their heritage. Many young adults adopted from Asia, Europe, and South America have returned to seek their biological families in an attempt to resolve their ethnic, racial, and cultural identity.

Another revolutionary development in the adoption field is its connection with alternative reproductive techniques. Adult children who have learned they were conceived by donor insemination have organized a world wide movement, still small in number, to gain the right to have identifying information about their fathers. They refer to themselves as "in utero adoptees." Their initiative has brought about a growing acceptance of the right to access of identifying information in both egg and sperm donations. The American Adoption Congress recognizes donor offspring as adoptees, and advocates opening their records, as well as promoting future openness in all alternative family building methods. Embryo adoptions are being seriously considered as an alternative, due to the surplus of fertilized embryos no longer needed by couples. Rather than defrost and destroy them, a few agencies are encouraging donation of these embryos to infertile couples.

Researchers have not yet determined what the psychological effects will be on children born to parents to whom they are not genetically related when they learn of their high tech origins. One thing is certain: that they will ask the same question that legions of adoptees since Oedipus have struggled with: "Who Am I?"

ANNETTE BARAN
BETTY JEAN LIFTON (1995)
REVISED BY AUTHORS

SEE ALSO: *Abortion; Children: History of Childhood; Embryo and Fetus: Religious Perspectives; Infanticide; International Health; Natural Law; Sexism*

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ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING

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Advance directives are oral or written statements in which people declare their treatment preferences in the event that they lose decision-making capacity. Advance directives may allow patients to prevent unwanted and burdensome treatments when struck by terminal illness, permanent unconsciousness, or profound mental disability. Advance directives are only one part of a process known as advance care planning, in which patients, ideally in consultation with physicians and loved ones, plan in a thoughtful and reflective manner for medical care in the event of future incapacity.

This entry discusses the various types of advance directives along with the goals of and the ethical basis for advance care planning. It explores practical problems associated with advance care planning and concludes with discussions of how advance directives are used in clinical practice, and how decision makers ought to proceed in the absence of a clear advance directive.

Goals of Advance Care Planning

Advance care planning refers to any planning by patients for decision making in the event of future decisional incapacity. Although it could refer simply to signing a form in a lawyer's or doctor's office, ideally it creates an opportunity for patients to explore their own values, beliefs, and attitudes regarding quality of life and medical interventions, particularly as they think about the end of their lives. Patients may speak with loved ones, physicians, spiritual advisers, and others during the process. This reflective work can help patients make important decisions about issues that may come up even when they still have the capacity to make decisions. When a patient loses decision-making capacity, physicians and loved ones who have been involved in the advance care planning process may feel that they know the patient's goals and values better. This allows them to make medical decisions that are likely to be consistent with the patient's values and preferences.

Advance care planning accomplishes a variety of goals for patients and families. First, patients may use the process to clarify their own values and to consider how these affect their feelings about care at the end of life. Second, patients can learn more about what they can expect as they face the end of life and about various options for life-sustaining treatment and palliative care. Third, they can gain a sense of control over their medical care and their future, obtaining reassurance that they will die in a manner that is consistent with their preferences. Finally, patients may increase the probability that loved ones and healthcare providers will make decisions in accordance with their values and goals.

Advance care planning may serve other goals, not directly related to medical treatments. Patients may wish to relieve loved ones of the burden of decision making and to protect loved ones from having to watch a drawn-out dying process. Patients also may use the process to prepare themselves for death. Advance care planning may help one reflect more deeply about one's life—its meaning and its goals. Patients may reflect on relationships with loved ones, "unfinished business," and fears about future disability and loss of independence. In this way, advance care planning may improve patients' feelings of life completion and satisfaction with their treatment in their final days.

Many people engage in advance care planning through conversations with their lawyers or loved ones. Peter A. Singer and colleagues reported in 1998 that among the HIV patients that they had studied, many had engaged in serious discussions with loved ones but had not seen any reason to involve their doctors. Nevertheless, physicians, physician extenders, nurses, chaplains, and medical social workers can play an important role in assisting patients in advance care planning.

Healthcare providers have their own reasons for wanting to engage their patients in advance care planning. First, providers may use these discussions to reassure patients that their wishes will be respected. This can enhance a sense of trust. Second, providers may hope that advance directives will help to decrease conflict among family members and between family members and the healthcare team when the patient is seriously ill. Finally, they may hope that advance directives will assist them in making difficult decisions when the patient has lost decision-making capacity.

Advance care planning discussions vary depending on a patient's state of health. Patients who are in good health may benefit from selecting a healthcare proxy and thinking about whether there are any situations so intolerable that they would not want their lives prolonged. When patients are older or have more serious chronic illnesses, physicians may wish to begin a discussion that is broader in scope. Although many view advance care planning as an opportunity for patients to make known their "preferences" for treatment, many patients do not have well-formed treatment preferences. By careful exploration of patients' values, healthcare providers can help patients discover these preferences. Patients can be asked to talk about their goals for life, their fears about disability, their hopes for what the end of their life will look like, and their ideas about states worse than death. This expanded view of advance care planning allows people to think about their mortality and legacy. From such discussions, healthcare providers can help patients consider specifically whether there are certain treatments that they might wish to forgo, and to think about the circumstances under which they might forgo them.

When the patient's illness has progressed to its final stages, healthcare providers can use the groundwork from these earlier discussions to make specific plans about what is to be done when the inevitable worsening occurs. Among other things, the patient and the healthcare providers can decide the following: Should an ambulance be called? Should the patient come to the hospital? Which life-prolonging treatments should be employed and which should be forgone? Are there particular treatments aimed at symptomatic relief that should be employed?

Types of Advance Directives

Advance care planning may lead to written documentation of the patient's wishes. Although this documentation can take the form of a physician's note documenting a discussion, patients often complete written advance directives. These are particularly important in states with formal requirements about the level of evidence surrogates need to forgo treatments or in situations in which conflicts are likely.

There are two types of advance directives: proxy directives and instructional directives. Both proxy and instructional directives are invoked only if the patient has lost decision-making capacity. Proxy directives, often referred to as *durable powers of attorney for healthcare,* allow patients to specify a person or persons to make decisions. They are relatively easy for physicians and other healthcare providers to discuss with patients and are straightforward for patients to understand. Proxy directives, however, do not indicate the patient's wishes, preferences, or values, and used alone they do not provide any information to the decision makers about what treatments the patient might have wanted under the circumstances at hand.

Instructional directives attempt to fill this gap. These directives, often referred to as *living wills,* identify situations in which the patient would or would not want specified treatments. For example, a patient's directive might state that "if I am permanently unconscious or terminally ill, I would not want to undergo cardiopulmonary resuscitation." Documents vary in terms of the scenarios described and the specificity of the different treatments. Some documents use general terms such as "heroic measures" or "aggressive care," whereas others list the specific interventions in detail.

Instructional directives apply only under the circumstances specified in the document. If a patient has a directive relating to treatment in the event of permanent unconsciousness, the directive will not help in decision making if that patient has suffered a devastating stroke. Although advance directives often focus on situations in which the patient would want to forgo treatment, they sometimes state circumstances under which a patient would want aggressive treatment. Finally, on some forms, people have the opportunity to provide more comprehensive information about their values and goals in relation both to their lives generally and to medical care specifically.

Philosophical Issues

The ethical argument that advance directives should be honored is based on the principle of patient autonomy and is a logical extension of the doctrine of informed consent. Patients with decision-making capacity have the right to refuse treatment, even if the treatment would extend their lives. Advance directives are a means for patients to continue to exercise this right, even if they lose decision-making capacity, by making thoughtful and informed decisions in advance. This approach allows patients to direct that medical care be given in a way that they feel best reflects their values and goals. Because physicians generally feel that they have an ethical obligation to work to preserve life, advance directives most commonly give patients a way to tell physicians caring for them the circumstances under which they would not want to be kept alive. On the other hand, some patients might use advance directives to indicate that they would want life-sustaining treatment, even under conditions in which most patients would choose to decline these measures.

Advance directives also serve ethical principles other than autonomy, such as beneficence. Physicians often feel duty-bound to preserve life under almost all circumstances, regardless of quality, even if they are uncertain that this serves the patient's best interests. Encouraging a patient to engage in advance care planning is a means for a physician to safeguard the patient's best interests.

A number of objections to the use of advance directives have been proposed in the literature. In a 1991 article, Alan S. Brett argued that an advance directive form cannot possibly direct the care that is to be given in a real clinical situation. If a patient writes a very general form, stating, for example, that "if I have no reasonable chance of recovery, I direct that no life-sustaining treatment be used," decision makers will have to determine how much of a chance of recovery is "reasonable," how much of a recovery would be worth trying for, and what precisely are "life-sustaining" interventions. Even if one specifies a list of treatments to be forgone in a number of detailed scenarios, this, too, creates problems. First of all, no matter how specific the document, it is unlikely to capture the circumstances of a real clinical situation exactly. Also, patients might not truly understand the specific treatments that they are listing in the document, running the risk of erroneously requesting or forgoing a treatment.

This objection is sound as far as it applies to advance directive documents, and it illustrates the need for a rich advance care planning process. Documents are inherently limited for the reasons Brett suggested. While they provide some insight into the patient's wishes, they nearly always require interpretation. If, however, the patient had engaged in discussions with doctors and proxies about his values, beliefs, and wishes, then decision makers will be in a better position to interpret a document and to make medical decisions with the patient's values in mind.

A related objection is the concern that patients can never know what they would want under conditions that they have not experienced or that they may change their minds. There is certainly reason to be cautious in this matter. Nevertheless, advance directives apply when patients have lost decision-making capacity, often for what is anticipated to be an indefinite period of time. Because these patients can no longer express their preferences, the choice is either to listen to their previous wishes about the situation or to apply some standard external to the patient (the provider's opinion or some societal consensus). Given these alternatives, it would seem most respectful to patients to rely on their previously stated wishes to make treatment decisions, unless there is good reason to believe that the patient did not understand what was written in the directive. Patients also should be told that they may change their advance directive at any time.

In a 1989 article, Rebecca Dresser and John A. Robertson raised another objection regarding whether advance directives should determine the medical care of a patient who has become demented. They believe that when one becomes severely demented, that individual may, in a sense, become a new person, no longer having the thoughts, memories, attitudes, values, and beliefs of one's "former self," who wrote the advance directive.

Now, imagine a moderately demented patient who has pneumonia. Until she developed pneumonia, she had appeared content and comfortable, chatting socially with the staff even though she is unable to recognize anyone, has severe memory loss, and needs assistance with daily activities. This woman has an advance directive stating that if she ever became moderately demented, she would not want lifesaving antibiotics for pneumonia. When she wrote the directive, she said that she would find such a life intolerable. Dresser and Robertson contended that the advance directive would have no moral authority over the new person, who now has pneumonia. Instead of relying on the values and beliefs of a person who no longer exists, a decision should be made based on what is in the best interests of the demented person in her current state. If she appears content and able to enjoy life, Dresser and Robertson argued, she ought to be treated with the antibiotics.

There is significant controversy over what to do in this instance. Accepting Dresser and Robertson's argument would mean frustrating the desires of many people who would not want the final chapter of their lives to involve being kept alive in a demented state. After all, the demented individual is not treated as a new person in any other way. She continues to have ownership of the property that she acquired when she was healthier. She continues to be responsible for any debts that she incurred previously. When she dies, the will that she wrote when she was of sound mind will be operative.

Practical Problems with Advance Directives

There are practical barriers to the use of advance directives. Although this entry describes an ideal of advance care planning in which patients first consult with loved ones and physicians, and then document their wishes, most advance directives are not products of this sort of process. Patients often write advance directives when they create an estate will. They may leave the document in a safe-deposit box or with their lawyer. Occasionally, they will give it to a family member. All too often, they will not take it to their doctors. Advance directives created in this manner might not be available when needed for decision making. Because there has been no discussion with physicians about life goals and values and how medicine fits into these, the physicians are deprived of critical information that is needed in interpreting the advance directives. Patients, meanwhile, might have signed documents that they do not completely understand and that are not truly in keeping with their values. The same is true for documents created in the hospital in the midst of a medical crisis. To overcome this problem, physicians need to routinely ask their patients if they have advance directives.

Furthermore, advance directives may not be available when needed. They often do not accompany patients transferred to the hospital from a nursing home. Patients may not be under the care of their regular doctor when they are hospitalized, and the hospital staff may not know about the existence of an advance directive. In addition to the federal regulations requiring hospitals to ask about advance directives, electronic medical records and registries of advance directives may also help with this problem.

Another problem is that physicians are often reluctant to raise the subject with their patients. They may be under overwhelming time constraints. They may have never been trained to discuss this issue and are not sure how to introduce the topic. They may be worried that they will give patients the impression that they are "giving up" on them or that they think they will die soon. If they have focused in past discussions on interventions rather than patient values and goals, they may have found these discussions frustrating and unhelpful.

Time constraints are difficult to overcome. Physicians could dedicate visits to discussing advance directives; but insurance companies may not pay for such a visit, and many patients may not wish to make a separate trip to the doctor for this purpose. The use of booklets and other tools to introduce the concepts involved in advance care planning may help physicians efficiently use their time to answer specific questions patients may have and to guide patients through the process. Enlisting nurses and social workers to help patients with the advance care planning process may also help.

Although physicians are often worried that patients will be put off by a discussion about advance care plans, surveys show that most patients want to discuss these issues, early in the course of their disease, and that they think that the doctor should bring up the topic. Nevertheless, there will be some patients who are not ready to discuss advance directives. Healthcare providers must be sensitive to these patients. Advance care planning is a process that should be offered to patients, not forced upon them.

The root cause of much of physicians' reluctance stems from lack of training in how to have these discussions. With training, physicians can feel more comfortable having these discussions, can learn how to deal with patients' emotional responses, and can have effective discussions that the physician will find truly helpful in caring for patients.

Clinical Use of Advance Directives

Rarely do advance directives clearly dictate the care that should be given to a patient who lacks decision-making capacity. Generally, some interpretation of the document is required, a responsibility left to the named surrogate decision maker, other family members, and the healthcare team.

When a patient who has an advance directive lacks decision-making capacity and is seriously ill, the healthcare providers should discuss the situation with the named surrogate and other appropriate loved ones. Reviewing the advance directive, those involved should decide what they think the patient would have wanted under the current circumstances. People who are not used to working with advance directives often misunderstand them. For example, an advance directive may state that life-sustaining treatment should be forgone but mention only the scenario of permanent unconsciousness. If the patient under discussion has had a devastating stroke but is not permanently unconscious, the document itself may not provide much evidence of the patient's wishes. In this case, it will be necessary to proceed almost as if there were no advance directive. In such situations, prior discussions involving the patient, his loved ones, and physicians about the patient's values regarding prolongation of life would be extremely useful. For example, when the patient under discussion expressed the preference to forgo treatment in the case of permanent unconsciousness, he might have given reasons for this that can shed light on his likely preferences in the circumstances of the stroke.

Even when there seems to be an applicable advance directive, there may be disagreement among family members or between family members and the healthcare team regarding the patient's care. These disagreements can occur even when everyone agrees that the advance directive applies to the current circumstances. Loved ones may disagree with the content of the advance directive, believe that the patient changed her mind, or believe that the patient made an error. In these situations, it helps to focus the decision makers on what the patient would have wanted and why the advance directive was written in the first place. Healthcare providers should, however, listen carefully to evidence that the patient changed her mind. This is a realistic possibility, and patients do not always remember to destroy the advance directive or issue a written revocation.

Other times, disagreements may occur because of differing interpretations of the document. Loved ones or healthcare providers may disagree on the meaning of a "reasonable chance of recovery," for example. In this case as well, it is helpful to try to focus decision makers on what they think the patient would have wanted.

Although it is best to gain a consensus of all the interested parties, especially about forgoing life-sustaining treatment, ultimately a named proxy has the final decision. Healthcare providers who wish to override proxies based on a patient's written advance directive should be wary. It is not clear that all patients would want their proxy's or loved one's wishes overruled. Because people often write advance directives to relieve family members of the burden of decision making, the patient may not have wanted it followed if doing so would cause tremendous anguish. In a 1992 study, Ashwini Sehgal and colleagues found that over half of a group of dialysis patients thought their doctors or proxies should have at least some leeway to interpret their advance directive. Rather than taking unilateral actions against the wishes of proxies, healthcare providers might be best off consulting with the hospital ethics committee.

When no advance directive is present, decision making often proceeds in a similar fashion. Generally, the physician will initiate a discussion with those who seem closest to the patient to discuss the patient's medical situation. Physicians should then focus the family on discussing whether the patient had ever discussed similar situations and what he or she would want under the current situation. Some states have laws regarding who is the surrogate decision maker in the absence of a written durable power of attorney. In other cases, the healthcare providers should try to determine who was closest to the patient or may find it best to reach a consensus decision. Advance directives do not change this process much but are a mechanism for the patient to provide evidence about his own wishes.

Conclusion

Advance directives provide documentation of patients' wishes for medical care in the event of future incompetence. Healthcare providers can assist patients in developing useful advance directives through the process of advance care planning. The goals of advance care planning will be different for patients at different stages of life and health, but the aim in all cases is to help patients articulate health-related values in a manner that can assist decision makers when the patients can no longer speak for themselves. In this manner, patients' autonomy and uniqueness as individuals can be respected.

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SEE ALSO: *Autonomy; Beneficence; Cancer, Ethical Issues Related to Diagnosis and Treatment; Competence; Conscience, Rights of; Dementia; Death, Professional Education; DNR; Ethics Committees and Ethics Consultation; Informed Consent; Life Sustaining Treatment and Euthanasia; Medical Futility; Nursing Ethics; Pain and Suffering; Palliative Care and Hospice; Right to Die; Surrogate Decision-Making*

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ADVERTISING

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As the cost of healthcare becomes an increasing focus of attention, advertising becomes an increasing object of concern. At its best, advertising can provide information to help consumers make informed choices. Conversely, it can also inflate expectations, create demand, manipulate desire, transform wants into perceived needs, and increase the use and cost of healthcare services. In the not too distant past, healthcare was understood as medical care. The activities of physicians were regulated by standards of ethics that eschewed commercialism. Though there has always been an economic aspect (usually a fee) associated with the physician–patient encounter, the revolution in the financing of healthcare delivery is transforming the personal doctor–patient relationship into a socially complex interaction in which physicians are cast among a multitude of providers, and patients are transformed into consumers. The focus on the economics of healthcare underscores the commercial aspects of healthcare delivery both by physicians and other providers. Though physicians and not-for-profit institutions should be responsive to a service ethic, they compete in the same economic arena as for-profit organizations and often behave similarly. Furthermore, in some cases the patients are not the direct consumers; services may be purchased by employers, alliances, the state, or other contracting entities, whose interests may not entirely coincide with those of patients.

Advertising may be judged by the standards of business ethics: truthfulness, nondeceitfulness, nonexploitativeness, and profitability. But healthcare is not strictly a commodity to be sold effectively with profit to the public. The care of health is also a fundamental human endeavor binding the caregiver and the care-seeker in mutually reciprocal ways. Otto E. Guttentag, noting the essential human quality of healthcare, defined medicine as "the care of health of human beings by human beings." Lawrence J. Nelson and colleagues argued in a 1989 article that several key features distinguish caring for the sick from other commercial products: (1) Patients are in a distinctive position of vulnerability and dependency on those providing the services; (2) their own self and destiny—even life—are at stake in the encounter with the provider; and (3) the relationship with the provider may become an important aspect of the healing encounter. All of these elements suggest that there are special obligations incumbent on healthcare providers that go beyond the usual obligations of the seller to the buyer of most commodities.

Traditional prohibitions against advertising attempted to orient professionals to their service obligations by minimizing the commercialization of the encounter (Relman). According to the traditional view, physicians and other professionals should obtain business by developing a reputation for quality service, getting referrals from satisfied patients/clients or from others who know their work, not through any kind of self-promotion.

The major ethical issue in advertising in a market economy is truthfulness. If given adequate information, the consumer should make appropriate choices: what kind of healthcare, where, when, provided by whom, at what cost. A larger question concerns the justice of a market system of choice based on individual self-interest. Proponents view advertising in healthcare as a way to promote competition and thus reduce cost in a highly regulated industry. Opponents criticize advertising for inflating expectations and thus increasing cost. Others suggest that the quality of care has been lowered by making cost rather than quality the focus of allocation decisions (Rodning and Dacso).

The high cost of healthcare in the United States has prompted a search for ways of reducing both the cost of medical services and the percentage of gross national product devoted to healthcare without appreciably lowering quality of care. Advertising is located at the crossroads between cost and quality, between regulated markets with an emphasis on quality and free markets with an emphasis on cost and choice. Regulations that provide standards for training, licensure, specialty certification, and hospital accreditation have resulted in high-quality, but expensive, healthcare. Market solutions, such as encouraging advertising to promote competition, have been seen as a way of reducing cost.

Historical Background

Physicians participate in markets, but traditionally orient themselves by ethical standards that go beyond economic behavior.

THE ORIGINS OF PROFESSIONALISM. Modern professional organizations, defined by their codes of ethics and regulating themselves by ethical principles, take their origin from the Aesculapian societies of the fourth century B.C.E. and in particular from the oath of the Greek physician Hippocrates, which bound its members to ethical standards that did not apply to society as a whole. The Hippocratic oath emphasized the principle of patient benefit, placing the patient at the center of the physician's attention.

By the nineteenth century, when the British Medical Association (BMA) and the American Medical Association (AMA) were founded, the concept of a profession organized around explicit standards of ethics was well established. Prohibitions against advertising were among the first professional standards because treatments based on scientific knowledge distinguished physicians from their main competitors, itinerant nostrum salesmen promoting often dubious products with even more dubious promotional claims. Advertising was expressly prohibited as unprofessional and undignified in virtually all countries in which physicians had established their professional identity through professional associations such as the BMA and AMA, which were organized around a code of ethics (Havighurst; Dyer, 1985). Although the actual license to practice is granted and regulated by the state, the task of enforcing the ethics codes falls to the professional associations or the specialty societies.

THE ANTITRUST CHALLENGE TO THE PROFESSIONS. The professions have always maintained a delicate balance between altruism and economic self-interest (Jonsen, 1990). As the medical profession became more scientifically effective and better organized, it enjoyed regulations (licensure, specialty certification, and accreditation) that guaranteed a virtual monopoly on healthcare delivery. Healthcare became synonymous with medical care. Although the Sherman Antitrust Act of 1890 banned monopolies, the learned professions were considered exempt from the act, which applied only to businesses. Late in the twentieth century, however, the business aspects of medicine began receiving increased attention, and the learned professions exemption ended in 1975 with the U.S. Supreme Court's *Goldfarb v. Virginia State Bar* decision, in which Virginia lawyers were found liable to charges of price-fixing the fees charged for title searches. The *Goldfarb* decision heralded a flurry of antitrust activity in the professional arena, most notably the 1975 suit by the Federal Trade Commission (FTC) against the American Medical Association, holding that the AMA was in restraint of trade because its code of ethics prohibited advertising. The AMA Principles of Medical Ethics then in effect (1957 version) said simply, "[A physician] shall not solicit patients," meaning that a physician should not attempt to obtain patients by deception. The 1980 revision eliminated all reference to advertising. Nonetheless, in the 1982 case *Federal Trade Commission v. American Medical Association,* the U.S. Supreme Court decided in favor of the FTC, barring the AMA from making any reference to advertising and the solicitation of patients, and further prohibiting the AMA from "formulating, adopting and disseminating" any ethical guidelines without first obtaining "permission from and approval of the guidelines by the Federal Trade Commission."

The FTC suit hinged on the questions of cost, advertising, and the mercantile aspects of medical practice. The position of the FTC was that costs were high because doctors had a monopoly on healthcare delivery and could thus maintain artificially high costs for their own profit. If doctors were not prohibited from advertising, it was argued, prices would come down because patients could shop for the best prices. In other words, medicine could better be controlled if it were regulated as a business rather than as a profession (Pertschuk).

The Ethics and Goals of Advertising

Advertising serves two very distinct and divergent objectives: (1) dissemination of information, and (2) product differentiation, which economists define as public perception of differences between two products, even though such differences may not in fact exist.

Dissemination of information provides the facts on which rational consumers can make informed choices. In healthcare, information about the services provided, location, hours of service, fees charged, and languages spoken are examples of services that might be advertised. Arguments in favor of advertising in healthcare are based on an understanding of advertising as dissemination of information.

Advertising also serves to differentiate products, and the methods for doing so are more ethically problematic. How can the claim be made and justified that one product is better than another? The FTC requires that any claims of product differentiation be empirically measurable. For example, in order to claim that a particular mouthwash "kills germs on contact by millions," it is necessary to be able to count killed germs. Usually advertisers attempt to differentiate products not on the basis of objective criteria about the product but by manipulating unconscious wishes and fantasies (such as youth, power, beauty, sex, and affluence), associating the product with images of attractive people in beautiful surroundings. The consumer is left to feel tremendous anxiety about the possible consequences of making the wrong choice of detergent, antiperspirant, or health plan.

Though many physicians have shown reluctance (or an aversion) to advertising their services, healthcare institutions have readily accepted the imperative to advertise in an attempt to create markets, capture market share, and find niches in the marketplace. Notable in this regard is advertising directed at target populations, for example, women, cancer patients, and those needing psychiatric and substance abuse services.

Truth in advertising was the concern when the field of advertising itself attempted to follow the course of professionalism in the early part of the twentieth century. At issue were the values that distinguished professional advertisers from retail-space merchants. The American Marketing Association established university training programs and codes of ethics that promoted the scientific ideal of detachment and statistical analysis. The scientific vision of community and definition of people as consumers replaced the older, empathic, and value-laden world in which a merchant understood what customers (not consumers) wanted and needed based on living in the same community (Christians, Schultze, and Simms; Schultze).

Professional advertising is illustrative because medicine's traditions of professionalism are derived from an era in which physicians participated in the life of the community in which they practiced. Knowledge of the patient as a person, as well as the patient's life history and social situation, has traditionally been deemed essential to quality care. At issue in 2003 for medicine is whether it will be possible to preserve the values of personal care that characterized the ideals of an earlier era.

The Commodification and Commercialization of Medicine and Medical Technology

Some aspects of healthcare are unquestionably commercial. The pills that only a doctor can prescribe are things, and a price must be attached to their acquisition. Hospital overhead becomes part of healthcare costs. Physicians' services (either for procedures or for time spent with a patient) involve a commercial aspect, though they are not just commercial. The locus of ethical decision-making shifts as the mechanism for financing shifts. Whereas physicians once made decisions on behalf of patients or with patients (according to principles of beneficence or autonomy), decisions are being made by corporations on behalf of populations or in the interest of reducing costs to populations. As this happens marketing of goods and services becomes an investment opportunity, not necessarily in the interest of conserving resources, but in the interest of creating capital for investors.

Medicine and medical technologies are increasingly considered in economic terms as commodities. It is fashionable to think of healthcare as an "industry," and as such the activities of the players—doctors and patients, providers and consumers, hospitals and healthcare organizations, equipment manufacturers and pharmaceutical suppliers—are seen in terms of market value rather than values deriving from a personal healing encounter. Value becomes a matter of money rather than a matter of conscience. It is the job of a market economy to distribute goods and services, bringing together consumers and products. Markets may be trusted to be free (laissez-faire) to the extent they do not violate their own frame of reference. Markets must be valued and controlled on their own terms, such as in the admonition, *caveat emptor* (let the buyer beware). But when vast public resources are involved, public oversight is also required. Deceptive or coercive marketing practices cannot be tolerated and require regulatory restraints on market freedoms.

DIRECT-TO-CONSUMER MARKETING. The growing trend of direct-to-consumer marketing needs to be evaluated in terms of the integrity of the information provided and the nature of the appeals made. Informed consumers make good partners in the healing relationships. Advertisements whose message is "Ask your doctor if this pill is right for you" provide little or no information about the product being promoted. Hair loss, impotence (erectile dysfunction), unhappiness, and sleeplessness are all subjects to be discussed with physicians and for which pharmacologic remedies may be expected. Once the expectation is created, it may be harder for the physician to assess risks (such as addiction liability) or side effects versus benefits, especially if a drug company has already courted the physician with gifts ranging from pens and notepads (bearing the name of a drug) to dinners (where "information" about products is offered) to vacations in expensive resorts.

The traditional way of mediating such claims is through scientific research, published in peer-reviewed journals. Consumers have access via the Internet to all sorts of information that does not receive such academic scrutiny. In the United States, federal regulatory agencies, such as the Food and Drug Administration (FDA) and the FTC, are charged with evaluating the research on which such claims are made. Yet much of the research is performed or funded by product manufacturers, and results that are unfavorable to the product may be suppressed, resulting in a publication bias in which only positive results are published and leading to a false (unscientific, but commercially advantageous) impression of the efficacy of a particular product (Otto et al.). Expensive high-technology screening tests (such as computed tomography scans for heart disease and cancer) are similarly promoted as educational information directly to consumers even though these tests' lack of specificity (resulting in false positives and negatives) causes physicians to question their value (Lee and Brennan). The ethical standard for judging such advertisements would be the truthfulness of the claims made. But presenting such appeals as informational when they are in fact promotional is a manipulation of demand, especially when the research on which such claims are made is not presented or, even worse, when it is skewed (Wolfe).

Several dramatic examples bring into mind the ethical constraints that might be necessary on advertising designed to create markets. Cosmetic surgery to improve a person's subjective sense of one's own beauty, for example, is medical in a way that is different from reconstructive surgery to repair a face damaged by an accident, although both involve similar skills and may be performed by the same plastic surgeon. Similarly (in an economic sense) assisted reproductive technologies, such as in vitro fertilization, may like other medical treatments relieve the distress of a childless couple, although the availability of such services is based more on the ability to pay than on need. The assisted reproduction industry commodifies the product, a human pregnancy, in ways that are more ambiguous ethically than they are commercially (Macklin and White). Technologies such as assisted reproduction along with the emerging genetic technologies, as well as more established technologies such as safe abortion, intensive care, and organ transplantation, help one to imagine limits on commercialization, advertising, and marketing (Dyer, 1997). As Allen Verhey noted in a 1997 article, "There are some boundaries and limits to the sphere of the marketplace. We do not want a market in which body parts are profitable; we prohibit the sale of organs, even those of the dead. We do not want babies sold at auction. Some things are not to be commodified and commercialized" (p. 135).

Conclusion

It could be debated whether advertising that goes beyond dissemination of information is ever ethical, though it is an accepted feature of market economies. The ethical issue for advertising is whether advertising is truthful and whether there can be objectively measurable standards for judging the truthfulness of advertising claims. A more problematic concern is the way in which advertising plays upon people's unconscious wishes and fantasies: sex, greed, and the quest for power, status, and perfection. The scientific basis for advertising rests on the ability to identify and manipulate such longings and fears. When one speaks of "the market" or "market forces" or "demand," one is generally talking about human wants and wishes.

Key questions facing the ethics of advertising in healthcare include:

- What standards or regulations should be in place concerning the placement of advertisements?
- Is any appeal legitimate so long as it does not mislead, make false claims, or actually harm?
- Is the negative portrayal of women in, for example, the promotion of unhealthful products such as tobacco or alcohol so morally offensive as to persuade the government to extend the scope of regulation of what is permissible in advertising, such as limiting advertising to dissemination of information?
- Is the effectiveness of the psychology of persuasion sufficient to justify advertisements, or can some higher principle be brought to bear?

Perhaps advertising itself should be subjected to the first principle of Hippocratic ethics, *primum non nocere* (first do no harm). Or to echo the caveat of President Dwight D. Eisenhower about the "military-industrial complex," beware the medical-industrial complex. Advertising that promotes consumer choice by providing information is consistent with the ethical ideal to promote patient autonomy. Advertising that deceptively promotes the interest of the provider at the expense of the consumer could not be ethically condoned, especially when the consumer is a patient.

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SEE ALSO: *Harmful Substances, Legal Control of; Lifestyles and Public Health; Medicine, Profession of; Pharmaceutical Industry; Professional-Patient Relationship; Profit and Commercialism*

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AFRICAN RELIGIONS

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This entry presents a brief, general picture of Africa's traditional religious heritage, focusing on the major beliefs because these underlie the general attitudes of individuals and society and shape their worldview. Various terms are used to refer to the indigenous religious heritage, including African religion, African traditional religions, African indigenous religions, and African religious traditions. This entry makes use of the most current term, "African religion." It is clear that in such a vast continent, there are diversities of religious life and concepts, but there are also similarities that make it possible to give a general picture.

After a brief word on the origin of African religion, this entry considers it in terms of belief in God and other spiritual beings, mystical power, and the continuation of human life after death. It describes how human beings are seen to be at the center of the world, and traces the journey of individual life from birth to death and beyond. Moral and ethical values are shown to regulate people's relationships with one another, nature, and God. African peoples give health and related problems much attention, for both their physical and their spiritual welfare. Religions originating outside of Africa, together with the influences of "modern" life, also have an impact upon the traditional religious heritage.

Origin and Sources of African Religion

African Religion evolved gradually as people experienced different life situations, raising questions and reflecting on such mysteries of life as birth and death, joy and suffering, the forces of nature, and the purpose of life. Its history is bound up with the history of each people or tribe, and goes back to prehistoric times. Some elements distinguish it from Christianity and Islam, the other major religions of Africa, while other elements resemble them. African religion is practiced in the early twenty-first century mostly in the southern two-thirds of Africa, including Madagascar, where Christianity is statistically dominant. In the northern one-third, dominated by Islam, African religion exists beneath the surface, among indigenous peoples, despite their having been subjugated and dominated by Arab immigrants for many centuries.

African religion is found primarily in oral sources, including stories, myths, proverbs, prayers, ritual incantations, songs, names of people and places, and the specialized and carefully guarded knowledge of religious personages. Other sources are art and language; ceremonies and rituals; religious objects and places like shrines, altars, and ceremonial symbols; and magical objects and practices. It also emerges among Christians and Muslims in times of crisis like severe illness or death, disputes, political and sports competitions, examinations, and the search for employment. Since the nineteenth century these sources have increasingly been recorded in writing, and since the second half of the twentieth century, on film and on audiotapes and videotapes.

African religion spread to the western hemisphere through African peoples who were forcibly transplanted to the West Indies and the Americas by the slave trade. It settled there and survived in a mixture with Christianity, despite the influence of other cultures and environments. For example, the spirit possessions that abound among people of African descent in Brazil and the West Indies have their origins in Africa. Voodoo in the Caribbean and macumba in Brazil are remnants of African religion that have been modified to suit local practice. Some names of people in Jamaica, like Cudjoe, Acheampong, Kwaku, and Obi are originally African, but these are said to be disappearing. After careful study of the American scene, Gayraud Wilmore concludes that "an essential ingredient of Afro-American Christianity prior to the Civil War was the creative residuum of the African Religions," characterized by a spirituality of response to the reality of the spirit world and its reaction with objective reality (1983, p. 26).

Major Beliefs in African Religion

As an all-embracing worldview, African religion has a number of beliefs held in common by the community. Individuals cannot reject a particular belief, since beliefs are part and parcel of the wider community. The term "community" is used here to refer to a grouping of persons in a particular area who lead a fairly similar cultural life, within a given people or in a town.

BELIEF IN GOD. Belief in God is found among all African peoples. The Creator and Preserver of all things, God is invisible, but the ongoing work of creation points to God's existence and involvement in the world. There are no atheists in African traditional society; belief in God is part of the common knowledge of everyone, including children. There are no pictorial or other representations of God by African peoples. Oral appellations of God include Father, Mother, Parent, Friend, Savior, Protector, Giver of Children, Giver of Rain, the Shining One, the Kind One, and the Everlasting One. God is good, compassionate, just, and loving to all people. The overall picture of God is of one who is above gender classification, neither male nor female, since God is Spirit. To grasp some aspects of God, people find anthropomorphic concepts useful and, according to the situation, may speak of God in male or female terms for that purpose. Furthermore, many African languages do not distinguish gender grammatically. People express their belief in and awareness of God through prayers, invocations, sacrifices and offerings, praise songs, and dedication of children to God. In some areas priests and priestesses officiate at religious ceremonies, pray on behalf of their communities, and pass on the theological, philosophical, and practical knowledge of their religion. They are, or should be, morally upright. In Nigeria and Uganda, priestesses regard themselves as "married" (i.e., wholly dedicated) to God for a given period of time in their life, but later marry human husbands.

BELIEF IN OTHER SPIRITUAL BEINGS. There is widespread belief in the existence of other spiritual beings created by and subject to God. The spirits can be considered in two categories: those associated with nature and those that are remnants of human beings after death. Nature spirits are personifications of heavenly or earthly objects and phenomena: the stars, the sun, thunder, rain and storms, mountains, earthquakes, lakes, waterfalls, and caves.

Some communities, especially in West Africa, have "divinities," spirit functionaries prominent in the life of the community. This particularly reflects the political structure, with the queen or king at the top and various chieftains or ministers below. Some "divinities" are said to have assisted God in the ordering of the world; others, to be in charge of aspects of nature like the weather, earthquakes, and epidemics. But many African peoples do not have divinities in their cosmology.

Most of the human spirits are those of people who died more than five generations ago; the others are of persons who are remembered by name and known collectively as the "living dead," since they are regarded as part of the family. When they "appear" to the living, either directly or through a medium, they are recognized by name, and what they communicate, in the form of requests, instructions, or warnings, is taken very seriously by their families. However, the spirits of the departed generally have little or no place in the beliefs of nomadic peoples, probably because they do not remain for years on the land where they bury their dead.

Spirits of the unknown dead are sometimes called upon or otherwise used in divination and medical practice, but otherwise they have no personal family ties to the living. They are said to possess people or animals, and are often featured in folk stories in which they perform great feats, although sometimes they are depicted as stupid or as fearful of the living. Many stories are told about spirits, resulting in an integration of their world into the world of living human beings.

HUMANITY AT THE CENTER OF THE WORLD. African religion places humans at the center of the world. It is believed throughout Africa that God created human beings, and thousands of stories and myths visualize how this happened. According to some, humans were created at the end of the primal creation, formed from clay as husband and wife (or as two pairs), or created in heaven (sky) and lowered to the earth. Others say that husband and wife were created in a vessel, in water, or in the fruit of a tree. Creation stories relate that the original state of humanity was one of bliss, in which people were endowed with immortality, rejuvenation (if they became old), or resurrection (if they died). The earth was directly linked to heaven (the sky); God and humans lived close to each other, as a family. For various reasons these gifts were lost; death, disease, and suffering appeared, as well as the separation between heaven and earth, between God and humans. However, God did not abandon humans, but he endowed them with various abilities and knowledge, so that they could survive. Through sacrifices and prayers humans still have access to God at any time. Through prayers people praise and thank God, and solicit God's help in the fight against disease, suffering, danger, and death.

A strong feature of African cosmology is the recognition of the world as comprising two interlinked realities: the visible and the invisible, the physical and the spiritual. Both are bound together in a primordial unity. They interact, and Africans do not make a strong distinction between the two. This helps to explain African awareness of and insights into the spiritual realm, an awareness at both shallow and deep levels ranging from visions, dreams involving spiritual objects or beings or messages, contact with the living dead and spirits, and divination to concepts about and experiences of God.

The life journey of the individual is marked with rites, particularly at birth, initiation, marriage, and death. Birth and name-giving ceremonies express joy in the family and gratitude to God for the child. Children are the symbol and actualization of immortality; they counteract death with new life, and old age with rejuvenation. At adolescence, initiation ceremonies are performed, often followed by a period of seclusion for the initiated, during which they learn matters pertaining to adult life. Initiation ceremonies serve, among other things, to give the individual an identity as a member of the community to which he or she is thereby mystically bound. The most dramatic involve circumcision for boys and clitoridectomy for girls. The personal shedding of blood forges mystical links to the ground, to the land.

Marriage is a religious duty that, under normal circumstances, everyone is obliged or expected to fulfill. The bearing of children is the central part of marriage, and no efforts are spared to ensure that there are children in each marriage; otherwise, the couple fails to become a family. In effect the family never dies; only its members do. If, for example, the husband is impotent, his "brother" (in the wider sense of kinship ties) will (must) sleep with his wife so that she will bear him children. If the wife is barren, her husband will marry another wife, who will be expected to bear children for both wives. Polygamy is an accepted and respected form of marriage in about 15 percent of African families. Children knit the community into a vast network of relationships: brothers, sisters, cousins, parents, grandparents, uncles, aunts, and many distant relatives. The basic philosophy says "I am because we are, and since we are therefore I am."

Burial and funeral rites serve, among other things, to send the departed in peace to the spirit world, and to express condolences to the bereaved. Various symbols and acts speak of death and the continuation of life: normal activities are stopped for a day following a death or funeral; hair on the head is shaved; the house of the departed is closed or even abandoned; clothes of colors that symbolize bereavement (white, black, or red) are worn; the bodies of surviving members of the family are smeared with mud or white chalk; cattle are driven away from the homestead of the departed; people fast; and fires in the home are extinguished. Some societies bury a few personal belongings with the dead, such as spears, cooking pots, ornaments, money, and clothes. Among other groups the property of the deceased is distributed—by force if need be—among relatives or clan members.

LIFE AFTER DEATH. Belief in the continuation of life after death is held all over Africa. The next world is pictured as being like the present one, inhabited by spirits and located in thick forests, desert places, underground, or on mountains. There is neither reward for a good life on earth nor punishment for an evil life. The departed retain their human characteristics and the living dead are still part of their earthly families, to whom they appear in dreams, in waking, or through divination, particularly if there is a major family event.

The living show remembrance of the departed through such acts of affection as naming new children after them, taking care of their graves, and pouring libations of beer, wine, milk, or tea and placing bits of food on the floor, on the graves, or in a family altar. People who die without children are considered most unfortunate, since they have no descendants to "remember" them, something that the extended family only rarely does. In some societies people invoke departed members of the family, especially parents and grandparents, and ask them to relay their requests further, until they reach God. There is thus a unity and a line of communication between the living, the departed, and God. Harmony is necessary to maintain this unity in a healthy spiritual condition.

BELIEF IN MYSTICAL POWER. There is a deeply rooted belief in a mystical power or force in the universe that derives from God. This power is used in medical practice, divination, protecting people and property, predicting where to find lost articles, and foretelling the outcome of an undertaking. It is also employed in the practice of magic, sorcery, and witchcraft. Diviners, traditional doctors, and witches know better than others how to employ it. The belief in and practice of magic causes much fear in African life, which leads to accusations, quarrels, fights, and countermeasures in families and communities. The positive use of this mystical power is cherished and plays a major role in regulating ethical relations in the community and in supplying answers to questions about the causes of good luck and misfortune.

SACRED PLACES AND OBJECTS. Sacred places and objects—including mountains, caves, waterfalls, rocks, trees, rainmaking stones, and certain animals, as well as altars, sacrificial pots, masks, drums, and colors—are set aside for religious activities. Some places are kept as sanctuaries in which no human beings or animals may be killed, and where no trees may be felled. Some homesteads have family altars or graves that serve as sacred spots where prayers, offerings, and small sacrifices are made. Nature is often personalized in order that humans may communicate and live in harmony with it. If humans hurt nature, nature hurts them. Humans are the priests of nature, indeed of the universe; this is a sacred trust given to them by God, who endowed them with more abilities than other creatures on earth.

ETHICS AND MORALS. The ethics and morals of African religion are embedded in values, customs, traditional laws, and taboos. God is ultimately the giver of morality. Moral offenses include disrespect toward elderly people, sexual transgressions (incest, rape, intercourse with children, adultery, and homosexual intercourse), murder, stealing, robbery, telling lies, deliberately causing bodily harm, and the use of sorcery and witchcraft. Such acts are punished by making the offender and his or her family feel shame or ostracism, or pay a fine; sometimes the offender is beaten or stoned to death.

On the other hand, kindness, friendliness, truthfulness, politeness, generosity, hospitality, hard work, caring for elderly parents, respect for elderly people and the weak and retarded, and protection of children and women are virtues that earn praise and admiration in the community. Women are regarded and treated as full moral agents; they are also protected against maltreatment by men, since they are considered to be less able or equipped to defend themselves physically, especially when they are pregnant or aged. Society rewards the good and punishes the evil. The spirits of the living dead maintain interest in the morals of their descendants, and may punish offenders by causing failure in undertakings, sickness, and bad dreams as warnings or deterrents. God is ultimately watching over the moral life of the community, society, and humankind. From time to time, if moral order is severely broken, God may punish the wider society or give warnings through calamities, epidemics, drought, war, and famine.

The home and the community convey moral teaching, generally from the older to the younger members, through word and example. Initiation ceremonies (some of which may last several years) are the formal communal occasions for instilling moral values in young people. Stories, proverbs, and taboos are employed in the teaching of morals. Where the basic philosophy of life is “I am because we are,” it is extremely important that the two dimensions of “I am” and “We are” be carefully observed and maintained for the survival of all, through moral values. The individual is very much exposed to the community, and anonymity is virtually out of the question.

African religion affirms and celebrates life. Laughter is heard even in the most difficult situations. Communal festivals filled with rejoicing—laughter, eating, dancing, singing, and drumming—renew and strengthen community ties. Even sad occasions like funerals are communal events that bring many people together to share in mourning, and thus lighten the burden of bereavement.

Health and Medicine

Life in African communities is often a struggle against forces of destruction: illness, disease, accidents, childlessness, suffering, misfortune, spirit possession, quarrels, war, and death. Natural threats such as drought, earthquakes, epidemics, famines, and locust invasions affect the whole community. When these forces of destruction strike the individual or the family, people ask “who” has caused it to happen. Even if there are physical explanations of how an accident has occurred, or how a disease like malaria or AIDS is caused, human agents are believed to be behind it. These agents are said to use mystical power—magic, witchcraft, sorcery, the spell, the curse, or broken taboos—following quarrels, acting out of jealousy, hatred, greed, or evil intentions. Health is seen as a fundamentally ethical question pointing to relationships in the family, in the community, and between people and nature.

Medicine women and men (traditional doctors) are found in every village. Their work is highly appreciated and in constant demand. They undergo long training and apprenticeship to acquire knowledge of herbs, roots, fruits, shells, insects, and juices, especially of their medicinal properties. They learn to diagnose illnesses and complaints that affect not only human beings but also animals and fields. They use divination to communicate with the invisible world at the psychic level of consciousness. They perform healing rituals and invocations. Their “medicine” is directed not only against the disease or misfortune in question but also to the removal and prevention of its mystical cause, such as witchcraft. The human or spirit agent “behind” the problem is usually named, and part of the healing process involves coming to terms with the “diagnosed offender.” The process of diagnosis, cure, and preventive measures is often carried out in the presence of the family or community, which thus participates in the healing.

African society generally shows great care toward handicapped and retarded people. Part of this special treatment comes from the fear that if you mistreat or fail to help the handicapped, you or members of your family will become similarly handicapped. Likewise, the issue of abortion is partly undergirded by the fear that a major misfortune, such as the failure to bear more children, will befall the family of a woman who has an abortion. Furthermore, the high rate of infant mortality has probably contributed to the great value that people attach to children and their consequent abhorrence of abortion. There are extremely few written references to abortion, and in some societies a woman who has had one is killed by the community or a curse is placed on her. There are, however, areas where twins were traditionally considered to bring misfortune, and consequently one or both children would be killed for the protection of the community. On the other hand, in certain areas twins were (and still are) considered to be special people, bearers of blessings or extraordinary abilities, and even called “children of God.” Written information on so-called mercy killing is scanty, but suicide and homicide occur in many areas. From time to time the community is provoked beyond endurance and a mob kills by stoning, beating, or burning an offender, such as someone accused of stealing and robbery (nearly always men), practicing witchcraft (nearly always women), or committing sexual offenses like incest, intercourse with children, or rape (only men). In such cases the community undergoes a healing process, physically and ethically. The life and dignity of the community are thereby placed above the lives of individual members who do not maintain its values and order.

"Medicine" is also used to bring good fortune (health, success, loving relations, protection against danger). In their practice, traditional doctors hold that it is God who heals or brings about good results, and some of them regularly invoke God for healing and the welfare of the individuals and community. These doctors are upright, trustworthy, and respected members of their community, the symbols of its welfare and health. Through them, folk medical knowledge and practice have been passed on through many generations. Since modern or Western medicine and its wonders are too expensive for most Africans, the traditional doctors continue to respond to the health needs of many people, and complement or even replace the services of modern medicine. As in other spheres of religious life, women are very active in health matters and are believed to show deeper sensitivities than men, especially since they carry human life in their own bodies and are more attuned to the spiritual dimension of health. In many communities female traditional doctors outnumber their male counterparts, and nearly all mediums are women.

Conclusion

African religion has encountered other religions, notably Christianity and Islam, and other cultures, especially Western. Many of its adherents convert to Christianity or Islam. But conversion does not mean abandoning the world of traditional religiosity. On the contrary, many Christians derive rich spirituality from African religion. Translations of the Bible into some seven hundred African languages (as of 1992) use religious terms and concepts of African religion. But while it seems to find ways of surviving and of accommodating to contemporary life, there are changes in social, political, educational, technological, and scientific life for which it has not prepared itself.

In the nineteenth century African religion was studied almost exclusively by foreigners: missionaries, anthropologists, colonial rulers, and self-styled African experts. On the whole it was presented negatively, often interpreted falsely, and ridiculed by those with racist attitudes. However, since about the middle of the twentieth century, a more objective approach has gained ground not only in Africa but also in the New World, where peoples of African descent find in it a meaningful part of their heritage. The African religious heritage in North America provided the cultural, social, and spiritual setting for modeling Christianity among African Americans—for example, the place of the church as a focal point of community life, the dynamic worship tradition, and the assimilation of African cultural traits. In Latin America, especially in Brazil, African religion has blended firmly with Roman Catholicism, so much so that many people do not know where to draw the line (if need be). Some of the healing practices called *folk medicine* are traceable to those of traditional doctors in Africa. Gayraud Wilmore (1983), Roger Bastide (1978), and Leonard Barrett (1976), among others, have documented the survival and strong impact of African religion in the New World.

We are in a much better position to understand African religion academically at the beginning of the twenty-first century than at the beginning of the twentieth century. Just as it has survived since prehistoric times and has done so in new social and cultural environments across the oceans, we may presume that it will survive in new forms in the coming generations.

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SEE ALSO: *Circumcision; Islam, Bioethics in; Environmental Ethics; Medical Ethics, History of: Africa; Medicine, Anthropology of; Minorities as Research Subjects; Population Ethics: Religious Traditions, Islamic Perspectives*

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AGING AND THE AGED

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I. Theories of Aging and Life Extension
II. Life Expectancy and Life Span
III. Societal Aging
IV. Healthcare and Research Issues
V. Old Age
VI. Anti-Aging Interventions: Ethical and Social Issues

I. THEORIES OF AGING AND LIFE EXTENSION

> Theory without fact is fantasy, but fact without theory is chaos. C. O. Whitman (1894)

An old adage says that nothing is certain except death and taxes. That is true, but it does not say anything about four score being the absolute measure of a person's years. That is good because knowledge about the biology of aging is changing, and with it people's expectations of what they can do about it. This new knowledge and the likely uses people will make of it will challenge perceptions of what constitutes a full human life as well as force people to rethink the increasing ability to alter aging. However, it is necessary here to define what is being talked about. What exactly do people mean when they talk about aging and senescence, and what is known about how aging comes about?

One goal of the material that follows is to answer the first question briefly in modern biological terms. Another goal is to describe the current understanding of the biological mechanisms that underlie aging. The final goal is to review successful cases of longevity intervention in laboratory animals and discuss their implications for humans. More extensive details and references on these general topics can be found in Arking (1998), Masoro and Austad (2001), and the Science of Aging-Knowledge Environment website.

The twenty-first century is forecast to be "the century of biology." Not only has the genome of many organisms been sequenced, scientific understanding of the way in which a fertilized egg transforms itself into a complex multicellular organism has taken giant strides to the point where developmental biology in the twenty-first century is taught as a complex series of gene-environment interactions. An outcome of these investigations has been the realization that there are few truly different developmental mechanisms. Apparently disparate organisms such as flies and humans use the same basic mechanisms in somewhat different ways. The modular nature of living organisms makes it possible to translate findings obtained with one species (e.g., flies or worms) to another species (e.g., humans). However, the adult that arises from this developmental process goes on to age and senesce and die. Somehow the sophisticated interactions fail to keep working. This seems paradoxical. As the Nobel laureate Francois Jacob wrote, "It is truly amazing that a complex organism, formed through an extraordinarily intricate process of morphogenesis, should be unable to perform the much simpler task of merely maintaining what already exists" (1982, p. 50).

Jacob's paradox contains two different questions. The first is the longtime philosophical poser: Why do people age? The second is the mechanistic consideration: How do people age? In the terminology of Ernest Mayr, the first component addresses the nature of the ultimate processes and the second addresses the details of the proximate mechanisms. Therefore, the answer to Jacob's paradox must be bipartite because the understanding of the mechanistic processes of aging depends crucially on an understanding of the evolutionary rationale for aging.

Definition of Aging

Aging is not a single biological event but a process in which multiple biological events accumulate in different tissues over time. Despite the complexity of this process, a workable operational definition is that "aging is the time-independent series of cumulative, progressive, intrinsic, and deleterious (CPID) functional and structural changes that usually begin to manifest themselves at reproductive maturity and eventually culminate in death" (Arking, p. 12).

Although *senescence* often is used interchangably with *aging,* here it will be used to refer specifically to the changes that underlie the loss of biological function that are characteristic of aging. Studies at the cellular level have shown that the inability of cells to continue dividing in vitro is accompanied by substantial alterations in patterns of gene expression. These SAGE (i.e., senescence-associated gene expression) patterns are objective although complex indicators of a phenotype that differs from that of a normal (i.e., "young") cell primarily in its altered repertoire of expressed functions. It is the author's belief that the term *senescence* soon will gain a more precise meaning as these SAGE patterns are cataloged and those associated with a loss of function are identified. Tissue-specific manifestations of age-related disease, such as congestive heart failure, are being characterized in terms of their own particular SAGE patterns. Aging was defined above as being time-independent, for which there is strong theoretical support, but this has been demonstrated empirically in only a few instances (e.g., Finch). The existence of tissue-specific changes in SAGE patterns supports this concept by providing a mechanism by which functional loss can occur independently of time.

Aging thus should be viewed as being composed of a series of such patterns of gene expression, certain of which when induced by a variety of internal or external stimuli result in (or inhibit) a SAGE cascade, leading to the alteration of cellular and tissue functions. The large differences in life span between mice and humans, for example, can be ascribed in part to the greater efficiency of the cellular anticancer defenses in humans and thus their gene expression patterns, not to the circular observation that mouse cells live "faster" than do human cells. Also, the differences in life spans between individuals in one species, such as humans, can be ascribed to the genetic and contingent factors that collaborate to confer some extraordinary stability (in the case of centenarians) or instability (in the case of premature mortality) of their SAGE patterns. Time is, for a number of technical and conceptual reasons, a poor measure of age; and researchers will likely use SAGE patterns and other biomarkers of aging in the future. The candles on the physiologically correct (P.C.) birthday cakes of the future might be based on gene expression patterns.

The Ultimate Explanation: Evolutionary Considerations

"Nothing in biology makes sense except in the light of evolution." This statement by the well-known geneticist Theodosius Dobzhansky has been verified by the study of aging. The operation of natural selection means that some genetic variants of any population will be more successful (i.e., leave more copies of their genes in the next generation) than will other variants, and the first variant will be favored.

Most known populations are structured by age; that is, the population is composed of individuals of different age classes, each of which represent a different proportion of the population. The high mortality rates resulting from predation, illness, and accidents that are common among wild populations indicate that only a few, if any, individuals live long enough to show signs of aging and senescence. Thus, in any wild population there are many more young breeding adults than old adults, and in each generation the genetic contributions to the next generation come predominantly from young adults. One consequence of this age structure is that deleterious genetic variants that act late in life are not selected against because their carriers probably will have died from environmental hazards before they reach old age or will have survived, but as postreproductive adults. In either case they are invisible to the operations of natural selection. Another consequence is that long-lived genetic variants will not be selected because they are expressed only in those few surviving postreproductive individuals.

From an evolutionary point of view, the "name of the game is to play again"; that is, the whole point of being a reproductive adult is to pass copies of one's genes to the next generation. This is a game that no one can win but anyone can lose simply by not transmitting sufficient copies of his or her genes to the next generation. There is no evolutionary value (i.e., Darwinian fitness) in any trait, including extended longevity, if that trait does not materially assist one in playing the game. There is evolutionary value in living long enough to reproduce, but there usually is no increased fitness associated with living so long that an individual is postreproductive (see Rose for review and references).

However, because people live so long already, why are they not capable of reproducing and living indefinitely or at least much longer than they do now? The answer to this question involves energy. Organisms must channel and apportion their energies into reproductive activities as well as into the maintenance and repair of the soma. Although the energy cost of making an egg or sperm probably stays more or less constant over time and is therefore the same for both young and old, this is not the only energy cost incurred in reproduction. The energy costs of courtship, pregnancy, and child rearing are high and represent a significant investment of energy by an organism. In addition, some energy must be devoted to the repair and maintenance of the soma if an organism is to survive reproduction. It is reasonable to assume that even a well-fed organism has only a limited amount of energy available to it. Thus, the problem facing the organism is how best to allocate its finite metabolic energy to maximize both reproduction and repair.

A theoretical analysis by Kirkwood (1987) showed that increasing the amount of energy expended on somatic repair results in increased survivorship but decreased fecundity, and vice versa. A choice must be made. Reproduction requires less energy than does repair. Therefore, allocating sufficient energy to maximize somatic repair will reduce fecundity and thus decrease an organism's Darwinian fitness. In contrast, increasing fecundity will decrease the energy available for repair and thus probably result in shortened longevity. In most cases decreased fecundity over a longer life span yields fewer copies of an individual's genes in the next generation than does higher fecundity over a shorter lifetime. Thus, fitness is maximized at a repair level lower than that required for indefinite somatic repair. Hence, people die. It is easy to see how this theory came to be known as the disposable soma theory. This process is nothing more than the cost-benefit analysis most people make when faced with the decision whether to continue to invest their hard-earned money in repairs to the old car or invest it in purchasing a new car. At some point the cost of repairs exceeds the cost of purchase, and so the old car is junked and a new one is obtained.

Because modern humans have a very low and culturally controlled rate of reproduction, it is reasonable to question whether the disposable soma theory still applies to human beings. It does, for people evolved under its aegis and the control mechanisms of the body that set fitness and repair levels are not reversed by one or two centuries of nonheritable demographic change. This concept provides a plausible mechanism by which evolution can act and has made people what they are today. Shakespeare foresaw this relationship in Sonnet 12:

> When I do count the clock that tells the time,
> and see the brave day sunk in hideous night; …
> Then of thy beauty do I question make,
> That thou among the wastes of time must go, …
> And nothing 'gainst Time's scythe can make defence
> Save breed, to brave him when he takes thee hence.

Therefore, people age not because of a philosophically satisfying cosmic reason that requires senescence and death but simply because the body's energy allocations are such that failure to repair ensures that there is no reason not to age. This biological conclusion may seem dark:. Who, after all, wants to believe that his or her death serves no larger purpose? The major religions of the world are based on the opposite premise (but see Holliday). Some people, however, find it liberating. Jacob compared embryonic development to adult aging and saw a paradox. What biogerontologists see in the early twenty-first century is the fact that there is no evidence for the existence of a genetically based aging program. People do not have an organismal death program built into their genes. *Human beings are not required to age.* It follows that if people age only because there is no biological reason for them not to age, this clearly implies that people need not age (or at least not age so quickly) if they can supply their bodies with a relevant biological reason not to age. It is the business of biogerontologists, then, to provide those reasons (de Grey, 2002).

Penultimate Explanations: Mechanisms of Aging

How good are those reasons? The categorization of the reasons leads to the different mechanisms that are known to be involved in the aging process. There are several methods by which one can organize the different theories of aging. None of these systems is fully satisfactory, but the origins of the change and its level of action both appear to be reasonable and logical pegs from which to hang these descriptions. Here a dual classification scheme is employed in which one considers whether the theories suggest that their particular effects are exerted within all or most cells (intracellular theories) or whether they are exerted mostly on the structural components and/or regulatory mechanisms that link groups of different cells (intercellular theories). In addition, the following paragraphs will consider simultaneously whether the effects postulated by each theory are conjectured to take place accidentally (stochastic theories) or are the result of the hierarchical feedback cascades characteristic of the species (systemic theories). Table 1 lists fourteen major theories sorted out by this dual classification scheme, and Table 2 offers a very brief summary of each theory. The highlighted terms in both tables indicate those theories for which the empirical data support their playing a central and important role.

The experimental data also show that certain aging phenomena are observed in almost all species. For example, experimental organisms extend their life spans significantly if those organisms are maintained under a reduced food intake regime but under conditions that maintain good nutrition. This method, called caloric restriction (CR), has worked in almost all species tested. It also is generally accepted that longevity is inversely related to early adult fecundity or reproduction. Elevated resistance to oxidative stress is observed commonly in many longevity mutants.

Interestingly, all these phenomena appear to be interrelated. For example, experimental organisms maintained under CR conditions have higher levels of antioxidant defense system (ADS) activities and lower levels of fecundity compared with controls. In addition, the mild dwarfism noted in CR-raised animals also is observed in mutants screened for longevity. Finally, it has been demonstrated

TABLE 1

A Classification of Aging Theories

Level at Which Effect of Change Is Executed	Origin of the Change	
	Stochastic	Systemic
Intracellular	Altered Proteins Somatic Mutations DNA Damage and Repair Error Catastrophe Dysdifferentiation **Free Radicals** Waste Accumulation	Metabolic Theories **Genetic Theories** Selective Death
Intercellular	Cross-linkage Wear and Tear	**Neuroendocrine** Immunological

SOURCE: Arking, 1998, Tables 8.1 and 8.2.

that the stimuli used to extend longevity experimentally are not maximally effective (i.e., do not induce a delayed onset of senescence) unless those stimuli are capable of bringing about a particular type of metabolic reorganization and energy economy in the organism. Thus, metabolic profiles, caloric intake, growth, stress resistance, fecundity, and longevity are all empirically intertwined (see Arking et al., 2002a, or Tatar et al., 2003 for references).

This observation is important, for it demonstrates that the theories listed in Tables 1 and 2 are not the discrete entities presented there but involve different facets of the same process. What is needed are much wider and more inclusive theories of the biology of aging that emphasize the interactions between these different components. One such integrative theory addressing the relationships at the organismal level among metabolism, stress resistance, and longevity has been put forth by Arking et al. (2002a). Another integrative theory that addresses the relationships at the cellular level of the roles of DNA damage, cell division, genomic stability, and longevity was put forth by Guarente et al. (2001) and Hasty et al. (2003).

Perhaps the most successful integrative theory that has been propounded is that involving the insulinlike signaling system (ISS) (Braeckman et al.; Tatar et al.). Insulin is a protein hormone that plays a vital role in regulating a cell's response to glucose. Insulin and the subcellular signaling system associated with it are not unique to humans but are widespread in animals, being found even in species in which molecules different from but similar to insulin are used for this purpose. It is an example of the modular organization of living organisms.

This ISS is thought to play a major role in an organism's response to CR because decreasing the intake of calories has the effect of partially repressing the activity of the ISS. If one uses mutations to inactivate components of the ISS and thus bring about a genetically based repression of the ISS, one finds that the mutated flies and worms live long and express a delayed onset of senescence. The molecular basis for the apparent ability of the ISS to bring about a shift in the body's emphasis from growth to repair lies in the fact that the subcellular signaling system controlled by the insulin molecule eventually results in the activation or repression of two diametrically opposed sets of genes. One set includes the ADS genes discussed above, and the other set includes genes that bring about the rapid bodily growth and high reproductive rate of the organism. When the ISS is activated by high amounts of insulin in the blood (as a result of a high-calorie diet), the ADS genes are repressed and the pro-growth genes are activated. When the ISS is repressed because there are low amounts of insulin in the blood (as a result of caloric restriction), the ADS genes are activated and the growth genes are repressed. It seems that the ISS may be one of the body's conserved molecular switches that bring about the change in energy allocations and reproduction predicted by evolutionary theory.

Laboratory Interventions into the Aging Process

An obvious limitation of the laboratory record is that there are few human data: One cannot experiment on humans for both ethical and practical reasons. There are four species of multicellular animals that account for most of the recent research into longevity extension. Two of those "model systems," the mouse and the rat, are mammals commonly used in biomedical research. The other two are invertebrates beloved of geneticists: the fruit fly and the worm. Also, some laboratories focus on the use of *in vitro* cell cultures with which to investigate the biology of the individual cells of the mammalian organism. Modular organization and common descent ensures that the genes each of these organisms carries are homologous to the genes humans carry and often have similar if not identical functions. For example, some 62 percent of the genes that are recognized to cause human diseases are known to exist in flies and to give rise to similar disorders when mutated. By investigating these model organisms, human beings investigate themselves by proxy.

PATTERNS OF AGING. When people intervene in the aging process, how can they tell if they are successful? Obviously, by extending longevity, but it turns out that there are at least three different manners of extending longevity, and only one of them is likely to be useful (Arking et al., 2002b). Compared with their normal-lived controls, experimental animals can live long by (1) increasing their early survival

TABLE 2

An Overview of Some Theories of Aging

Theory	Major Theoretical Premise and Current Status
Altered Proteins	Time-dependent, post-translational change in molecule which brings about conformational change and alters enzyme activity. This affects cell's efficiency or nature of the extracellular matrix. Proven.
Somatic Mutation	Somatic mutations alter genetic information and decrease cell's efficiency to ubvital level. Disproven in a few cases, but the occurrence of age-related neoplasms at least is apparently due in part to somatic mutation.
DNA Damage and DNA Repair	Cell contains various mechanisms which repair constantly occurring DNA damage. The repair efficiency is positively correlated with life span and decreases with age. Proven but exact role not clear.
Error Catastrophe	Faulty transcriptional and/or translational processes decrease cell's efficiency to subvital level. Disproven but modern reformulation has empirical support.
Dysdifferentiation	Faulty gene activation-repression mechanisms result in cell's synthesizing unnecessary proteins and thus decreasing cell's efficiency to subvital level. Proven. Modern reformulation based on SAGE patterns is likely to be a conceptually powerful approach.
Free Radicals	Longevity is inversely proportional to extent of oxidative damage and directly proportional to antioxidant defense activity. Damage likely originates in mitochondria and spreads out from there. Proven. Appears to be widespread damage mechanism.
Waste Accumulation	Waste products of metabolism accumulate in cell and depress cell's efficiency to subvital level if not removed from cell or diluted by cell division. Possible but unlikely.
Post-translational Protein Changes	Time dependent chemical cross-linking of important macromolecules (e.g., collagen) impairs tissue function and decreases organism's efficiency to subvital level. Related to altered protein theory. Proven.
Wear and Tear	Ordinary insults and injuries of daily living accumulate and decrease organism's efficiency to subvital level. Proven in restricted examples (e.g., loss of teeth leading to starvation) but modern reformulations are part of other theories.
Metabolic Theories	Longevity is inversely proportional to metabolic rate. Disproven in orginal form but reformulated into a form of the free radical theory and that reformulation appears to be correct.
Genetic Theories	Changes in gene expression cause senescent changes in cells. Multiple mechanisms suggested. May be general or specific changes. May function at intracellular or intercellular level. Analysis of changes in gene expression may be a powerful tool with which to understand the progressive loss of function in a cell or organism. Proven.
Apoptosis	Programmed suicide of particular cells induced by extracellular signals. Proven. Failure to induce or repress apoptosis probably is responsible for a variety of diseases. Role in non-pathological aging changes not clear.
Phagocytosis	Senescent cells have particular membrane proteins which identify them and mark them for destruction by other cells such as macrophages. Proven but only in restricted cases.
Neuroendocrine	Failure of cells with specific integrative functions brings about homeostatic failure of the organism, leading to senescence and death. Proven for female reproductive aging and other specialized cases. Probably involved in many other cases. Exact role needs to be ascertained as a general case.
Immunological	Life span is dependent on types of particular immune system genes present, certain alleles extending and others shortening longevity. These genes are thought to regulate a wide variety of basic processes, including regulation of neuroendocrine system. Failure of these feedback mechanisms decrease organism's efficiency to subvital level. Probable.

SOURCE: Arking, 1998, Tables 8.1 and 8.2.

rate, (2) increasing their late survival rate, or (3) delaying the onset of senescence. The first two longevity patterns are conceptually interesting but have no practical application because neither affects the basic aging rate. The organisms age normally but seem to be somewhat more resistant to the various stresses that kill off their normal comrades. For example, exercising humans have a higher early and midlife survival and a lower level of morbidity. They age, however, in a normal fashion and show no real decrease in mortality later in life. Centenarians, in contrast, seem to have a higher late-life survival rate, but although they have a lower rate of morbidity and mortality, no one would mistake a centenarian for a middle-aged person. They have aged in a normal fashion but are simply a bit healthier than their normal fellows. Their health span is not affected, only their late-life mortality. These two extended longevity patterns are not useful clues to the attainment of people's longevity goals.

The most interesting alteration involves the third type: the delay in the onset of senescence. There are many examples of this pattern in animals but none in humans, yet this is the one people want. Figure 1 shows the survival curves of normal-lived and long-lived fruit flies created in the author's laboratory by means of artificial selection for increased longevity. It is clear that both the mean and maximum life span values are shifted to the right. If one assumes that the flies' health span covers the period of time from birth until 10 percent of the initial population has died, the low mortality and high survival characteristic of the first thirty days of the normal-lived animals' life span has been extended so that it now spans the first sixty days of the long-lived animals' life span. The health span has been doubled, but the senescent period occupies the same length of time (approximately thirty-five days) in both strains and thus represents a smaller proportion of the maximum life span in the long-lived flies.

These data demonstrate that the health span and the senescent span are two separate phases of the life span and that longevity extension through a doubling of the health span is possible. The fact that each of the model organisms can express this "delayed-onset extended-longevity phenotype" strongly suggests that the potential to double the health span is built into each species, including mammals. The task is not to introduce alien mechanisms into organisms but instead to discover how to activate the already existing longevity mechanisms effectively and safely. In this sense, what is being done is "natural."

What would be the outcome if this knowledge was applied to humans? If one projects a survival curve for contemporary U.S. females on the simplifying assumption that they would follow the same survival and mortality kinetics as do long-lived fruit flies, there would be no real decrease in survival (and therefore no increase in age-related mortality) until the age of about 102 years. The 82-year health span in this projected population is double that of the 40 years (i.e., 20 to 60 years) characteristic of contemporary normal-lived humans. If it is possible to understand the mechanisms in the fly that delay the onset of senescence and make them happen in humans, the goal will have been achieved.

Is it realistic to believe that the extension of longevity in laboratory organisms foretells a comparable achievement in humans? All the genes known to be involved in delaying the onset of senescence in the author's laboratory model systems are known to have homologues in humans. This implies that the relevant mechanisms are in place. In light of this fact, it seems reasonable to conclude that the failure to induce the delayed-senescence extended-longevity phenotype in humans represents a transient limitation of knowledge rather than a permanent limitation imposed by human biology. Thus, the question becomes one of understanding the biological mechanisms that regulate this pattern and deciphering the cellular signals that control its expression by the organism.

EXAMPLES OF PROVEN LABORATORY INTERVENTIONS. The delayed-senescence extended-longevity phenotype has been induced successfully in laboratory animals as a result of genetic interventions designed to decrease oxidative stress and/or alter the energy metabolism of the organism.

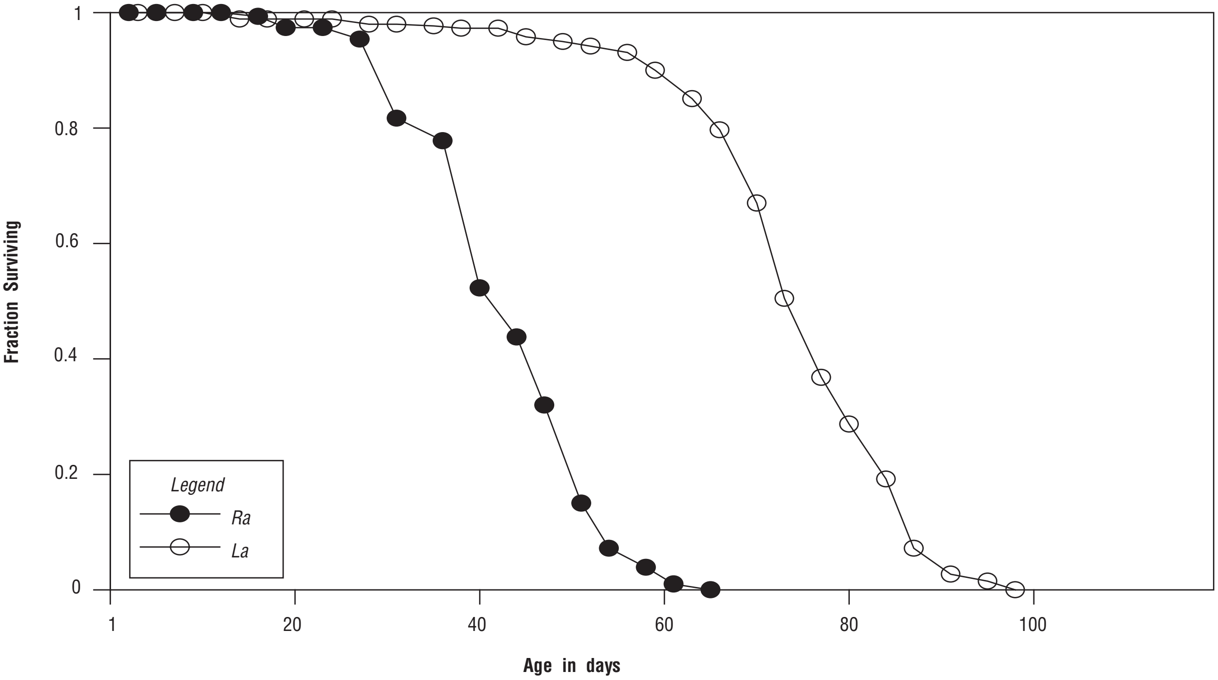
Decreasing oxidative stress. People need oxygen. Without it, human beings cannot generate enough energy to live and quickly die. However, the oxygen that keeps people alive is a double-edged sword, for it also can break down within the cell to yield highly chemically reactive molecules of various kinds that are termed collectively reactive oxygen species (ROS) or, less accurately, free radicals. These ROS chemically combine with any of the cell's components and transform them into oxygen-based damage products, a process referred to as oxidative stress. In lay terms, one might envision the cell undergoing something akin to self-perpetuating rusting.

Organisms have within them a very elaborate system with which to defend themselves against the depredations of oxidative stress. That system seems to be reasonably effective at getting rid of most (but not all) of the ROS molecules that are generated in young animals and thus keeping the level of oxidative stress to a low (but measurable) level. But even this low level of oxidative stress causes some damage, which accumulates. Eventually the failure to repair completely causes increasing inefficiencies in the body's ADS. This then allows the rate of oxidative stress and cell damage to increase at a compound rate, and the age-related loss of function soon

FIGURE 1

Survival of Control and Experimental Flies

SELECTED FOR LONG LIFE



Note: Survival curves of normal-lived control flies (Ra) and of the long-lived experimental flies (La) derived from them by artificial selection for extended longevity. Note the "health-span" portion of the life cycle is increased significantly in the La flies whereas the length of the "senescent span" is about the same in both strains.

SOURCE: Redrawn from Arking and Colleagues, 2002.

becomes apparent. This process is sped up in mutant flies and in worms and mice in which the ADS genes have been made inactive. In the laboratory such mutant organisms aged and died very quickly. The mice exhibit systemic failures similar to those observed in various age-related diseases.

It occurred to many investigators that perhaps one could extend an organism's health span by increasing the level of its ADS mechanisms. Genetic engineering techniques were used independently in several laboratories to introduce extra copies of certain ADS genes into otherwise normal flies. The flies then lived longer, displaying a delayed-senescence extended-longevity pattern (Parkes et al.). Equally interesting was the observation derived from the author's selection experiments, in which a normal-lived population gave rise eventually to long-lived descendants because only the longer-lived flies of each generation were bred. After some twenty-two generations the descendants had a much higher level of ADS activities, a lower level of oxidative damage, and a significantly delayed onset of senescence, as is shown in Figure 1. Other experiments showed that certain mutants in the nematode worms also up-regulate (i.e., turn on to a higher degree) certain ADS genes—the same ones that are operative in the fly—and the resulting worms also live long because of a delayed onset of senescence (Honda and Honda). The ISS-based interventions mentioned above bring about the delayed onset of senescence inevitably coupled with an enhanced resistance to oxidative stress and an altered metabolism; this finding may well identify an evolutionarily conserved regulatory mechanism (Tatar et al.).

Altering energy allocations. The first intervention known to delay the onset of senescence in mammals and increase the health span significantly was reported in 1934. Reducing the amount of calories in an animal's diet by about 40 percent while keeping the different nutrients at normal levels results in healthy and long-lived mice and rats (and flies and worms as well). These findings have been replicated literally hundreds of times and are probably the most robust experimental findings in the field. However, it has also been noted that these long-lived animals cannot withstand as much stress as can their normally fed littermates (Hopkins). Similar experiments are under way in primates such as macaque monkeys; although these long-term experiments are still in progress and thus incomplete, the available data suggest that a similar response may be happening in primates. The limited human data that are available lead to the same conclusion (Walford et al.).

CR radically changes an animal's metabolism and SAGE patterns so that the animal becomes a physiologically different organism than is its normally fed sib. Many, perhaps all, of these differences can be attributed to a shift in the animals' functions from growth and reproduction to repair, possibly as a result of altering the output signals of the ISS, as was described above.

Pharmaceutical Interventions into the Aging Process

The genetic manipulations used in the laboratory are not likely to be well received as therapeutic tools. Once the longevity extension mechanisms described above were identified, many scientists independently tried to develop pharmaceutical interventions by feeding various drugs suspected of regulating those two processes to their laboratory animals. Five of those experiments have shown signs of success. Although those independent experiments used different intervention strategies and administered different molecules to the laboratory animals, they all recorded significant increases in the animals' health span (comparable to those in Figure 1) and/or a significant extension of the animals' functional and mental abilities.

A recent experiment done by Kang et al. (2002) may serve as an example of this category of data. Those researchers fed a drug called 4-phenylbutyrate to fruit flies throughout all or part of their lives. This dietary pharmaceutical intervention resulted in a delayed onset of senescence in the treated flies, with survival curves similar to those shown in Figure 1. It turns out that this drug alters the manner in which DNA normally wraps itself around certain chromosomal proteins, in what appears to be an evolutionarily conserved manner (Hekimi and Guarente), and this alteration significantly changes the pattern of gene expression in the animal. Some genes are repressed, and others are enhanced. One of the genes most significantly enhanced is an ADS gene identical to that found to be highly effective in extending longevity in genetically engineered flies and worms. Thus, it is possible, although not yet proved, that this drug can bring about its longevity extension effects because it increases an animal's resistance to oxidative stress. Another interesting observation from this experiment is the fact that different strains of flies needed different drug doses to yield the same result. This implies the existence of genetically based individual differences in the response to drug-based longevity interventions. No reports are available regarding the existence of various side effects or trade-offs in any of these experiments.

Is a Complete Understanding of Aging Needed Before Intervening in the Process?

There are other mechanisms that the laboratory data suggest also may be involved in regulating the aging rate. Perhaps the most persuasive is the cell senescence/telomere theory. Except for stem cells, body cells either divide very rarely (i.e., nerve cells, muscle cells) or divide either continuously (i.e., blood cells, skin cells) or when stimulated (i.e., liver cells). Those cells that divide seem to have an upper limit on the number of divisions they can undergo. There is some evidence that the telomerase enzyme may play a still not quite understood role in regulating this process. The failure to maintain cell numbers in different tissues probably underlies some aspects of age-related loss of function. The operative part of the cell senescence theory may not be the actual number of divisions cells undergo but the probability that nondividing senescent cells alter their SAGE pattern from one that inhibits oxidative damage and permits division to one that permits oxidative damage and inhibits both cell repair and cell division. If this is the case, one could merge the cell senescence/telomerase theory, the oxidative damage theory, and the metabolic change theory into a single general aging theory based on harmful changes in gene expression that shift the cell from a "youthful" preventive stance to an "older" damage-permitting stance. Such a general theory of aging is reasonable although still under construction, and a persuasive data-based account of it can be found in Fossel.

However, the fact that researchers have accomplished successful interventions into the aging process in the absence of a complete understanding suggests that total comprehension is dispensable: It is desirable but not required. How can this be? The evolutionary considerations discussed above make clear that organisms usually are geared toward reproduction as opposed to repair. This means that any population of animals will contain very few, if any, individuals that are optimally configured for repair. Most, if not all, individuals will have one or more physiological processes that are less than optimal. Tweaking any one of them—oxidative stress resistance, metabolic change, for example—will have the effect of making that organism better in that one respect. Other physiological processes not directly affected by the intervention will show no change or a secondary and dependent change induced by the initial perturbation. The animal will have some measurable improvement in at least one of the several aging processes that operate in its body and as a result will age more slowly and live healthier and longer.

This is in effect what has been done with the flies, worms, and mice. The very specific interventions used appear to have brought about a global effect on the organism. The animals live longer despite the researchers' ignorance about exactly what kind of a control cascade brought this about.

An interesting implication comes out of this observation. The more complex an organism is, the greater the number it will possess of different regulatory and control processes that affect aging mechanisms. More complex organisms, which are organized in a hierarchical modular manner, should have more potential sites where intervention could take place. In principle, mammalian aging should be subject to alteration by more interventions than will work in flies and worms (see de Grey et al.). The greater role that cell division, for example, plays in mammalian aging relative to the invertebrates and the probable relationship between cell division and altered gene expression patterns bolster this point. However, having a greater number of potential drug targets is not an unmitigated blessing. The trade-off is that the mammalian interventions probably need to be very biologically specific in order to be effective. There have been interventions that work in flies and worms but so far have failed in mice, possibly because they were not specific enough to coax the mammalian regulatory systems into altering the organism's SAGE patterns. It is likely that deciphering these specificities will constitute much of the research necessary for the development of a successful mammalian pharmaceutical intervention.

The gap between the predicted and actual effects of extended longevity on human society is likely to be huge. All the writing in the world will not define the texture of that future society. Many people would not go forward without detailed knowledge of the consequences. In the twentieth century people faced the question of whether society should permit human flight. It is necessary to ask if people really wish the Wright brothers had failed (or, worse, that their success was suppressed) and that this was still a flightless society.

ROBERT ARKING

SEE ALSO: *Dementia; Genetic Engineering, Human; Health and Disease: History of the Concepts; Human Dignity; Justice; Long-Term Care; Medicare; Natural Law; Population Ethics; Transhumanism and Posthumanism;* and other *Aging and the Aged* subentries

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II. LIFE EXPECTANCY AND LIFE SPAN

In the United States in 1900, the average life expectancy (also referred to as longevity) of a newborn baby was 47.7 years—46.4 for males and 49.0 for females. By 1990 the average life expectancy increased to 75.4 years—78.8 for females and 72.0 for males. Why did life expectancy increase so rapidly in the twentieth century, and what are the prospects for increasing it further? Perhaps more important, has the overall health of the population improved or worsened during this transition, and what are the health consequences of further increases in life expectancy?

The measure of life expectancy at birth is a statistic that represents the expected duration of life for babies born during a given time period, usually one calendar year. Calculated from death rates observed at every age, it is based on the critical assumption that the age-specific risks of death observed during a given year will prevail for all babies born in that year, for the remainder of their lives. In contrast, life span is the theoretical upper limit to life that would be observed if everyone in the population adopted ideal lifestyles from birth to death and if external threats to life were eliminated. Some researchers believe that there is no biologically determined life span per se (Carey et al.), but rather a series of time-dependent physiological declines that may eventually be subject to modification.

Life expectancy in the developed nations increased rapidly during the twentieth century because of rapid declines in death rates (usually expressed as the number of deaths per 100,000 population over one year) at younger and middle ages. This transformation in death rates, which has occurred to some extent in every nation, is referred to as the epidemiologic transition (Omran). During this transition, death rates from infectious and parasitic diseases, which tend to kill at younger ages, decline rapidly and the saved population lives to older ages, at which they are exposed to aging-related disorders such as vascular diseases and cancer. Although a small fraction of the population has always survived to older ages, the epidemiologic transition allows over 90 percent of all babies born to survive past the age of sixty-five. The redistribution of death from younger and middle ages to older ages is a general characteristic of the epidemiologic transition, although varying degrees of decline in death rates are experienced by different nations and subgroups of populations within nations.

Mortality Transition Patterns

There are two interesting patterns in the epidemiologic transition of the United States. In 1900 the average life expectancy for women was 2.6 years greater than that of men. By 1990 this difference had increased to 6.8 years. Although the increasing gender gap in longevity is attributable to more rapid declines in death rates for women at every age and for most causes of death, it is unclear why the mortality transition of women has proceeded at a faster pace than that of men. The prevailing explanation for the widening gender gap in life expectancy in the twentieth century is a combination of lifestyle characteristics among men that make them more prone to vascular diseases and cancer, and, with extended longevity, the increased expression of genetic differences.

Another interesting pattern in the U.S. mortality transition is the difference observed in historical trends in longevity between blacks and whites. In the early part of the twentieth century, the expectation of life at birth was lower for blacks than for whites by about ten years because blacks had higher death rates than whites. The difference in death rates between blacks and whites is thought to be due to a combination of biological, social, and environmental factors, but scientific studies to date have not adequately determined the relative importance of these factors. In the later twentieth century the racial gap in longevity was reduced to seven years. This indicates that the mortality transition for blacks was faster than that of whites—particularly for black females. However, it is important to remember that because blacks had considerably higher mortality at most ages than whites early in the century, larger reductions in death rates were required for blacks to close the racial gap in longevity.

An interesting aspect of racial trends in longevity is that at older ages (i.e., at ages seventy and older), the death rates for blacks in 1995 were lower than those of whites. This is caused either by poor data quality, resulting in an underestimation of old-age mortality for blacks, or by selective survival, in which only the most robust segment of the black population survives to older ages. Also interesting is the trend since 1984 toward declining life expectancy for blacks, while life expectancy for the rest of the population continues to increase. This unexpected trend is a direct result of increasing death rates for blacks between the ages of fifteen and forty-four—a product of higher mortality from accidents, homicides, and AIDS.

Extending Life Expectancy

The prospect for increasing life expectancy further is a subject of intense scientific debate. Projections of life expectancy can have a significant influence on anticipated changes in social programs, such as Social Security and Medicare, that are influenced by the future size and health status of the older population. Some scientists have argued that life expectancy at birth for humans cannot practically exceed about eighty-five years (Olshansky et al., 1990). This conclusion is based on the facts that (1) survival up to and beyond the age of 110 is as rare in the early twenty-first century as it has always been; (2) the rapid increase in death rates from aging-related diseases that begins in the second decade of life has not changed in recorded history—instead, death rates have shifted down at comparable rates for most age groups; (3) the reduction in death rates required at every age to increase average life expectancy at birth to eighty-five years is extremely large—in fact, larger than what would occur with the elimination of cancer and heart disease; and (4) life expectancy has been shown to be a demographic statistic that becomes less sensitive to declining death rates as it approaches higher levels. Taken together, these facts point clearly to the difficulty in achieving the reduction in death rates required to increase life expectancy past eighty-five years.

Other researchers have argued that theoretically, average life expectancy at birth could reach 100 years (Manton et al.; Ahlburg and Vaupel). Several conditions are required for this to occur. Under one scenario, everyone in the population would have to adopt an “optimal” risk-factor profile, maintain their physical functioning throughout life, retain the risk-factor status of a thirty-year-old for the duration of life, and respond in the same beneficial way to a fixed regime of risk-factor modifications (Manton et al.). This means that everyone would have to eliminate behaviors such as smoking, drinking, and overeating, and somehow avoid the health problems, such as arthritis and sensory impairments, that now tend to compromise physical functioning in older ages.

In a second scenario, a life expectancy of 100 could be achieved if death rates declined by 2 percent at every age for every year for the next century (Ahlburg and Vaupel). Recent evidence indicates that mortality declines of this magnitude have been rare in the historical record of the United States (Olshansky and Carnes), and that such models lead to death rates that are inconsistent with evolutionary theories about the onset and progression of death rates from aging-related causes (Carnes and Olshansky). It is doubtful that either of these scenarios is practicably achievable, although they do represent laudable goals for healthcare planners.

Effects of Extended Life Expectancy on General Population

Observing historical trends in mortality, and anticipating future improvements, raises the question of how the overall health of the population is influenced by these trends. From a historical perspective, there is little doubt that the thirty-year increase in life expectancy in the twentieth century was a result of trading one set of diseases and causes of death for another. The epidemiologic transition allowed much larger proportions of each birth cohort to survive to older ages, something that had never before been experienced by the human population. There is little doubt this was a worthwhile trade. Now that the focus of modern medicine is to attack the causes of death that were traded for earlier in the century, we are faced with the same sort of question: What do we get in return for reducing the risk of death from vascular diseases and cancer? This is a particularly interesting question, since successful efforts to reduce the death rate from fatal diseases will produce much smaller gains in life expectancy than those achieved in the twentieth century, when primarily the younger population was saved from early death.

This question of how future declines in old-age mortality will influence the health status of the population is also an area of intense scientific debate. The debate is framed around what is generally referred to as the expansion versus compression of morbidity hypotheses. Those who follow the *compression-of-morbidity* hypothesis believe that improved lifestyles and advances in medical technology will postpone the onset of disease to older ages, thus compressing the period of disease and disability into a shorter time before death (Fries). With this hypothesis the critical assumption is that both fatal diseases, and nonfatal but highly disabling age-dependent diseases, will simultaneously be postponed and compressed against a biologically fixed and immutable upper limit to life.

The *expansion-of-morbidity* hypothesis, however, points out that factors that are known to reduce the risk of death from fatal diseases do not alter the age at onset or progression of the most debilitating diseases of old age, such as Alzheimer's disease and hearing and vision loss. Further reductions in old-age mortality from present levels are therefore hypothesized to allow much larger segments of the population to survive to the oldest ages (over eighty-five), where the risk of age-related disabling diseases is particularly high and currently immutable (Verbrugge; Olshansky et al., 1991). The empirical data used to test these competing hypotheses indicate that morbidity and disability may in fact be declining for those under the age of eighty-five, but after that age the risk of disability and its duration appear to be increasing. However, it is not yet possible to draw definitive conclusions about these hypotheses because of deficiencies in the available data.

Is it possible to extend the human life span beyond early twenty-first century practical limits and achieve an increase in the duration of healthy life among the older population? Answers to these questions may be found in work under way in molecular biology. Based on a current understanding of the process of senescence, extending the human life span would require slowing down the aging rate itself. There is no definitive evidence at this time to indicate that the life span of humans can be modified by any means. However, there is suggestive evidence to indicate that dietary restriction could postpone many of the physiological decrements associated with aging—including those associated with both fatal and nonfatal diseases of aging (Weindruch and Walford). Although it is not practical to expect that human experiments will be conducted on the longevity benefits associated with dietary restriction, or that enough people will actually restrict their diets to influence national statistics, research in this area may eventually reveal the underlying physiological mechanisms that link dietary restriction to increased longevity. In this way it may eventually become possible to imitate the effects of dietary restriction without actually altering diet.

Scientists debate these issues on scientific grounds, but there are important moral issues close to the surface in the discussions. For example, we know that a lower life expectancy observed among subgroups of the population is linked to poverty and minority status. If we are interested in preventing premature death, then social conditions may be a more direct target than efforts to manipulate the basic rate of aging. Also, the definition of "premature death" is no longer obvious, and raises questions about the value of length of life compared with quality of life when extreme longevity is also associated with the expression of frailty and disability.

Since societies do not have homogeneous views on these competing values, whose values should prevail? Further, societies almost always provide public support for infirm elderly people. How shall we value policies in the context of increasing life expectancy when many other social goods and needs are unfulfilled? This question is stated most clearly in the intergenerational equity debate. That is, should we be donating so much of our resources to the old when so many children live in poverty, when public schools are so needy? Some would argue that increasing longevity is a triumph of modern society, and if we work hard enough on prevention, we can eliminate old-age disability. But even for those who believe this is theoretically possible, it does not seem likely in the foreseeable future. Finally, the push toward increasing life expectancy raises fundamental resource-allocation questions for those concerned about the problems posed by global population growth. For example, it is inescapable that in the long run (i.e., beyond the middle of the twenty-first century), gains in longevity beyond those already expected will accelerate growth rates that, even at early twenty-first century rates of increase, will inevitably lead to a doubling of the size of the human population by the year 2050.

The Impact of Science on Life Expectancy

Population aging also has implications in the context of human evolution. Scientists in the field of evolution biology have hypothesized, in nonhuman species, a link between reproduction and the rate of senescence (Finch). Although it is unlikely that the physiological mechanisms regulating human reproduction will be altered intentionally to postpone senescence, it may eventually become possible to manipulate the genome to achieve the same effect. In fact, the mapping of the human genome may eventually reveal these and other aging-related genes that could be manipulated by methods being developed in molecular biology. There is reason to believe that breakthroughs in this area are forthcoming and that by controlling genes that influence diseases of aging, it may become possible to allow more people to survive longer and healthier than is currently the case. Just how much longer and healthier people can survive through manipulating the genome is the subject of intense debate. It may also become possible to achieve increases in longevity by introducing pharmaceuticals that alter the environment in which the genome operates. One example is the effort to introduce into the human diet natural and artificial antioxidants (i.e., substances that reduce the amount of damage caused by the presence of free radicals, products of normal metabolism implicated in the aging process). The result may be a general deceleration of the entire aging process.

If methods of increasing human longevity are realized by manipulating the genome or introducing pharmaceuticals, then a new set of questions will arise: How would such developments influence the age structure of the human population and the social and economic institutions that have been developed under the assumption that human longevity is limited? These may prove to be a much more difficult set of problems than those we face today.

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SEE ALSO: *Autonomy; Death; Future Generations, Reproductive Technologies and Obligations to; Harmful Substances, Legal Control of; Human Dignity; International Health; Justice; Life, Quality of; Natural Law; Population Ethics; Right to Die, Policy and Law;* and other *Aging and the Aged* subentries

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III. SOCIETAL AGING

A society is said to age when its number of older members increases relative to its number of younger members. The societies of the United States and of many other industrialized nations have been aging since at least 1800. In 1800 the demographic makeup of developed countries was similar to that of many Third World countries in the early 1990s, with roughly half the population under the age of sixteen and very few people living beyond age sixty. Since that time, increases in life expectancy, combined with declines in fertility rates, have dramatically increased the proportion of older persons in developed nations. By contrast, the age profile in many Third World countries is still heavily weighted toward younger age groups, even though the increase in actual numbers of old people is even greater in many developing countries than it is in the developed world. What future societies will regard as distinct about population aging in the twentieth and twenty-first centuries is the rapid pace at which it is occurring. Since 1900 the percentage of Americans sixty-five and over has become eleven times more numerous (from 3.1 million in 1900 to 35.0 million in 2000). The fastest growth has occurred among the oldest old. Thus, in 2000, the group aged sixty-five to eighty-four (18.4 million) was eight times larger than in 1900, but the seventy-five to eighty-four age group (12.4 million) was sixteen times larger, and those over the age of eight-five (4.2 million) were thirty-four times larger (Administration on Aging).

During the last century or more that population records have been kept, women's life expectancy has always exceeded men's (Cassel and Neugarten). Although at younger ages there are more men than women, by old age women far outnumber men (Cassel and Neugarten). In 2000 there were 143 women for every 100 men sixty-five and over. Sex-based disparities increase with age. The ratio of older women to older men ranges from a low of 117 to 100 for persons sixty-five to sixty-nine, to a high of 245 to 100 for those eighty-five and older (Administration on Aging). Although demographic predictions have sometimes been proven wrong by subsequent facts, demographers in the early twenty-first century predict this sex differential will increase until the year 2050, at which time it will level off; but before it does, there will be only 38.8 men per 100 women aged eighty-five and over.

Ethical Implications

The rapid increase in the number of older persons relative to younger ones carries important implications for society. In the area of healthcare, societal aging will increase costs and exert greater pressure to ration services. It will thus bring to the fore questions regarding a just distribution of healthcare between young and old. The population's aging will also alter the nature of health services by increasing the number of patients who have chronic and disabling conditions that are not life threatening. This, in turn, will change the face of bioethical debate, from a focus on acute life-and-death medical decisions made at a particular instant in time, to an emphasis on ongoing and often relatively mundane problems spanning many years. Finally, societal aging portends changes for family life. Already, the imbalance between young and old is placing strains on offspring who undertake care-giving responsibilities and is prompting questions about the scope and limits of filial duties. To the extent that family members play an increasing role in elder care, their role in healthcare decision making is a significant and vigorously debated question.

HEALTHCARE RATIONING. The aging of society will increase healthcare expenditures simply because persons over the age of sixty-five consume far more healthcare than other age groups do. In the United States, persons sixty-five and over account for roughly 12 percent of the population but utilize one-third of the country's total personal healthcare expenditures (exclusive of research costs). In an era of fiscal constraints, this makes the elderly an obvious target for healthcare rationing. The financial savings that would accrue if the elderly were disfranchised from various forms of healthcare is disproportionately high, because the elderly are more frequent utilizers of healthcare. According to one estimate, if those over the age of fifty-five were excluded from treatment for renal disease in the United States, 45 percent of the costs of the renal-disease program would be saved. In many other areas a large financial saving could be achieved through excluding elderly persons.

Arguments supporting age-based rationing and the shifting of scarce resources from old to young groups have been advanced by Daniel Callahan, Norman Daniels, Richard Lamm, and Samuel Preston, among others. Callahan, for example, proposes rationing publicly funded life-extending care based on old age. Such a proposal might be implemented once society comes to accept the idea that "government has a duty, based on our collective social obligation, to help people live out a natural life span, but not actively to help extend life beyond that point" (Callahan, p. 137). Both Lamm and Preston favor directing fewer resources to older age groups and more to younger persons as a necessary condition of meeting duties to younger and future generations. They maintain that unless society limits healthcare expenditures for the old, it will eventually impoverish health services and other social goods for the young. Finally, Daniels urges one to think about justice between the young and old from a first-person point of view. According to him, when we succeed in viewing our lives as a whole, rather than from a particular point in time, it will sometimes be prudent for us to prefer a healthcare plan that distributes fewer services to our old age in exchange for more services earlier in life.

Critics of age-based rationing object, for example, to the implications of age-based rationing for women (Jecker, 1991); to the violation that age-based rationing implies of the moral thrust of both Judaism and Christianity (Post); and to the message that age-based rationing conveys about the meaning and worth of the lives of aged persons (Murray). Finally, critics cast doubt on the prediction that age-based rationing would yield large financial savings in healthcare expenditures. They point out that the amount of money that would be saved by old age-based rationing would be negligible if these dollars were simply spent elsewhere in the healthcare system.

LONG-TERM CARE. In addition to increasing healthcare expenditures, societal aging will increase the number of disabled persons and the need for long-term care, including adult day care, in-home services, and care in resident facilities, convalescent homes, and intermediate and skilled nursing facilities. Several factors will contribute to a greater need for long-term care. First, the ratio of older women to older men is expected to increase, and older women experience a greater incidence of morbidity and disability than older men. Second, the population over age eighty-five constitutes the fastest-growing age group in the population, and this group is also the heaviest users of long-term care. More than 70 percent of those eighty-five and over require some kind of assistance with one or more activities of daily living. Finally, fewer offspring will be available to serve as informal caregivers for future generations of elderly persons. This is because individuals are having fewer children than previous generations did, and greater numbers of women are joining the paid labor force.

The growing need for long-term care raises social and policy questions concerning the just allocation of funds between acute hospital care and *low technology* supportive services for chronic disabling conditions. In addition, it alters the nature of clinical ethical cases by changing the sorts of decisions faced and the age, gender, and health profile of the affected population. According to Harry R. Moody, bioethical analysis has tended to emphasize a principle of individual autonomy and respect for persons' self-determination. Yet this principle begins to break down as the patient population becomes increasingly geriatric, increasingly dependent, and increasingly disabled. In this environment, it is argued, the ideals of human dignity and self-respect, ideals that are intimately linked to human relationship and community, will assume greater significance. Yet others suggest, to the contrary, that the values of autonomy and privacy must retain their central importance because such values are inextricably linked to assuring a good quality of life in old age.

FAMILY RELATIONSHIPS. The rapid aging of society will reshape relationships within the family as parent-child relationships extend over many more years and pose new challenges in later life. Although most agree that parents undertake special duties toward offspring, there are different opinions as to whether grown children have corresponding duties toward aging parents. For example, Jane English denies that adult offspring owe their parents anything by virtue of being their offspring. Instead, she defends the idea that "the duties of grown children are those of friends, and result from love between them and their parent, rather than being things owed in repayment for the parents' earlier sacrifices" (English, p. 147). Others object to special duties of any form, whether founded on friendship, filial status, citizenship, or other bases. The favoritism implied by special duties is sometimes considered logically or psychologically at odds with the ethical requirements of impartiality and equal respect for persons. Still others object, on justice grounds, to the disproportionate share of caregiving borne by women.

On the other side of this debate are those who defend special duties. Various underpinnings for adult children's responsibilities toward aging parents have been offered, including gratitude, reciprocity, and duties to the vulnerable.

Historical and Cultural Perspectives

An aging society, defined as a society in which the population of older individuals is increasing relative to the population of younger individuals, presupposes that individuals can be separated into meaningful categories of old and young. Although contemporary Western society tends to conceive of youth, adolescence, middle age, and old age as unique life stages with distinct sets of problems, this perspective is hardly universal. Indeed, present conceptions of the life course are a relatively recent phenomenon. Thomas Cole traces the metaphor of life's stages to the cities of northern Europe in the sixteenth and seventeenth centuries, where the current life-stage metaphor first emerged. Picturing life as a series of ordered stages represents the life course as in conformity with the order of the universe and makes it possible for every individual to "step outside of his own life experiences and view it as a whole" (Cole, p. 25).

Just as society's recognition of aging reflects historical and cultural traditions, so society's beliefs about the meaning and value of old age bespeak historical and cultural heritage. The social rank of elderly persons varies during different historical and culture periods, depending upon the perceived cost of supporting older age groups and the contribution they are thought to make (Amoss and Harrell). For example, the Akamba people of Africa believe that "the older a person becomes, the more intricately interwoven that person becomes in the lives of others, and the greater the damage done if that person is removed. At the same time, the older person has wisdom—a perspective on life that comes only with age—which is considered to be a particularly important social resource" (Kilner, p. 19). By contrast, U.S. society has traditionally valued "pragmatism, action, power, and the vigor of youth over contemplation, reflection, experience and the wisdom of age" (Butler, p. 243); hence, ageism (age discrimination) is especially evident in U.S. society.

Despite different cultural conceptions of aged persons and their role in society, anthropologists identify common biological and cultural features of aging. Thus, every known society has "a named category of people who are old—chronologically, physiologically, or generationally. In every case these people have different rights, duties, privileges, and burdens from those enjoyed or suffered by their juniors" (Amoss and Harrell, p. 3). This suggests that people in culturally distinct societies may face similar ethical questions concerning relationships among people of different ages.

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SEE ALSO: *Chronic Illness and Chronic Care; Future Generations, Reproductive Technologies and Obligations to; Healthcare Resources, Allocation of; Human Dignity; International Health; Justice; Life, Quality of; Long-Term Care; Natural Law; Population Ethics; Right to Die, Policy and Law; Women, Historical and Cross-Cultural Perspectives;* and other *Aging and the Aged* subentries

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IV. HEALTHCARE AND RESEARCH ISSUES

What is so different about the ethics of healthcare and research in older people that would render a general discussion of these topics insufficient? Basic principles, such as autonomy, beneficence, and justice, are no different and no less important because the individuals involved in healthcare or research are older. Many factors associated with aging, however, do alter substantially the facts of clinical and research encounters with older people.

Healthcare of Older People

The nature of illness in older people greatly influences the ethical issues in their healthcare. Older people have a higher burden of illness than younger people. On average, they are likely to have several chronic medical conditions, be on multiple medications, and have frequent encounters with the healthcare system, including more hospitalizations. Because older people are closer to the end of their life expectancy, they have a greater chance of being involved in situations where difficult healthcare decisions must be made. Decisions about the appropriate use of life-sustaining medical treatment for older patients are commonplace. These range from Do-Not-Resuscitate (DNR) orders, to decisions to discontinue dialysis, to decisions about withholding or withdrawing artificial nutrition and hydration. Many, if not most, deaths in healthcare institutions in the United States are preceded by explicit decisions to limit treatment. These treatment limitation decisions, more properly viewed as decisions to change to a palliative care plan from life-sustaining or death-delaying efforts, are generally more common in the care of older people.

While any individual may become incompetent during a critical illness, older people are at greater risk of impaired decision-making capacity because of either a transient delirium or a chronic dementing illness, such as Alzheimer's disease, which results in permanent cognitive impairment. Thus, older people are not only at risk of having end-of-life decisions made in the healthcare setting; they frequently are not capable of making those decisions themselves at the time required. In such situations, physicians routinely turn to the family of an older person to serve as a surrogate decision maker or proxy. Several studies of the treatment preferences of older patients and their potential proxies (spouses, children, and physicians), like that of Allison Seckler and her colleagues in 1991, have uncovered serious discord between the choices that would be made by patients and by their proxies. While this raises concerns about the validity of proxy decision making vis-à-vis its accuracy as a substituted judgment, one can argue that family members are still appropriate surrogates and that many older people care more about who makes decisions for them than about the exact decisions being made.

The foreseeability of both serious illness and the loss of competency for older people, as well as questions about proxy decision making, have created a strong interest in the use of advance directives in the care of older people. Advance directives include instructional documents, such as living wills, and proxy appointment documents, such as the durable power of attorney for healthcare. Interestingly, most of the empirical studies done on both proxy decision making and advance directives have focused on older people. Advance directives have received increasing attention in the United States with the 1991 enactment of the Patient Self-Determination Act, a federal law requiring healthcare institutions to educate patients about the availability and use of these instruments. While it is hoped that these efforts will increase the number of older people giving advance instructions for their healthcare, it remains to be seen if older people will execute advance directives in significant numbers, and if physicians will respect the preferences outlined in these documents. Data from the 1997 SUPPORT study cast doubt on the effectiveness of advance directives.

Because of its effects on the competency of older individuals, dementia occasions significant ethical dilemmas as discussed by Greg Sachs and Christine Cassel in their article on the subject. Dementia affects perhaps as high a proportion as 10.3 percent of individuals over age sixty-five and 47 percent of those over age eighty-five, and raises ethical concerns for several reasons. First, rather than presuming competence and working within the bounds of confidentiality, truth telling, and patient autonomy expected in the normal doctor-patient dyad, when the patient has dementia, the doctor-patient relationship is altered in a fundamental fashion. A physician caring for an older person with dementia must reassess decision-making capacity frequently, carefully evaluate what the patient says for useful information, weigh what can be shared with the patient, and rely on others for information and assistance in executing a care plan. Second, the progressive and irreversible nature of the most prevalent kinds of dementia alters the goals of medical care of the patient with dementia. While promising research on dementia continues, existing treatments provide only modest benefits and there are no therapies that will either arrest or cure progressive dementias. As with hospice care or rehabilitation medicine, many, including Nicholas Rango, argue that the medical care of a patient with dementia properly focuses on maximizing function, including socialization, palliation of symptoms, maintaining hygiene, and preserving dignity. Third, the family members of an older person with dementia are not only proxies for decision making, they also usually provide the bulk of their relative's daily care needs. The great burden of caregiving places family members at risk of depression and other illness, causing health professionals to consider the psychosocial needs of the family as well as the patient.

While only about 5 percent of people over the age of sixty-five are in a nursing home at any one time, in 1991 Peter Kemper and Christopher Murtaugh estimated that the lifetime risk of spending time in a nursing home in the United States is as high as 40 percent. Thus, many older people do receive medical care in a nursing home for some portion of their lives and it is the location of death for an increasing number of older Americans, as noted by Joan Teno in 2002. At least in the United States, nursing home care frequently has been cited more for its deficiencies: unwarranted mechanical restraint of residents, inattention to treatable conditions such as urinary incontinence, and inappropriate and excessive use of psychotropic medications. At least part of the problem of poor nursing home care has been the lack of continuity in medical care of older people once they enter a nursing home. A minority of physicians in the United States visits their older patients once the patients enter a nursing home (as few as 28% in one U.S. nationwide study), according to research by Janet Mitchell and Helene Hewes. Subspecialty care, including psychiatry, is even less available to older people residing in nursing homes. On a more positive note, in 1997 Catherine Hawes and her colleagues noted that changes in nursing home regulations do appear to be having beneficial effects on many aspects of the quality of nursing home care.

Problems with access to good medical care for nursing home residents are actually a subset of the larger problem of the level of expertise in the medical care of all older people. While geriatrics is an established specialty in the United Kingdom, a subspecialty certifying exam in geriatric medicine in the United States was offered for the first time only in 1988. Very few physicians enter fellowship programs that provide postresidency training in geriatric medicine. In his study of these programs, David Reuben contends that the shortage of fellowship-trained geriatricians remains a significant challenge despite changes made in the late 1990s to shorten the duration of training required for certification (Reuben).

Research on Older People

As with the relationship between healthcare of older people and healthcare in general, research involving older people emphasizes different ethical issues because of the history of research on older people and specific healthcare attributes of older populations. As geriatrics has been late in being recognized as a specialty in American medicine, so too has serious research on older people been a relatively recent phenomenon in the United States. The National Institute on Aging (NIA) was established within the National Institutes of Health (NIH) in 1974 to promote research on aging. That the creation of NIA was necessary is supported by the dearth of research on the problems of older people in earlier years. People over the age of sixty-five were frequently excluded from clinical studies, even from trials examining cancer, heart disease, diabetes, and hypertension, all conditions more prevalent in older populations. Older people have remained under represented in clinical trials even after investigators stopped employing arbitrary age cutoffs as documented in a 1999 study by Laura Hutchins and her fellow researchers.

While it is not clear why older people were excluded from research in the past, conducting research on older people is more difficult than working with younger subjects. Surveys have shown that older people tend to be less willing than younger people to become research subjects. As noted earlier, they are likely to have multiple medical conditions and to be taking several medications, factors that may cause them to be excluded from research projects that are trying to study single illnesses and the unadulterated effects of single medications. Because of these factors, older people also have a higher attrition rate, necessitating larger numbers of older subjects when the study begins in order to compensate for dropouts over time. Impairments in vision, hearing, or cognition may make efforts to obtain informed consent and enroll older subjects more time consuming and labor intensive. These factors together may make research on older people more expensive to complete. For all of the above reasons, it is clear that under representation of older people in clinical research will remain a persistent challenge. Specific, targeted initiatives from funding agencies and clinical trial consortia, however, can facilitate important studies with adequate numbers of older subjects.

Two additional attributes of older people that most affect research ethics were mentioned in discussing their healthcare: the prevalence of dementia and the frequent use of nursing homes. Dementing illnesses fundamentally change the investigator-subject relationship, as well as the doctor-patient relationship. Far less is known empirically about issues in the research setting, such as the ability of subjects with dementia to give informed consent, the reliability of proxies in giving consent for experiments, or the practices of investigators in safeguarding vulnerable, cognitively impaired subjects. The assessment of decision-making capacity for research consent, for example, is best characterized as a growing but still quite immature field. Serious concerns were raised by a 1991 study, conducted by John Warren and others, of relatives who gave proxy consent for their cognitively impaired older family members residing in nursing homes. Many of these proxies gave consent for a study on urinary catheters despite saying that they thought the older person would not have wanted to participate and that they themselves would not want to be in such a study.

Over the 1980s and 1990s, various organizations and authorities have published guidelines for research involving subjects with dementia. In the first decade of the twenty-first century, the National Bioethics Advisory Commission (NBAC) and state commissions in New York and Maryland weighed in on these issues. Most authorities endorse the practice of proxy consent, as long as the subject assents when the particular study commences. Some explicitly prohibit the participation of subjects with dementia if it is known that the older person would not have wanted to participate in a study. Others worry, however, that excessive safeguards may end up serving as barriers to research that might benefit people with dementia.

The ethics of research on older people in nursing homes also focuses on consent issues because of the high prevalence of dementia in nursing homes, but there are other ethical concerns as discussed in an article edited by Brian Hofland in *Gerontologist.* On the one hand, access to research may mean access to improved care and increased socialization for an older nursing home resident. On the other hand, limited freedom and the existence of less than optimal care in many nursing homes may create a coercive environment for enrolling subjects. Another concern is that although much nursing home research is conducted in large, academically affiliated, well-staffed nursing homes, these conditions do not exist in many nursing homes, raising the question of how much one can generalize the research findings to more typical nursing homes.

Finally, all of these research ethics issues regarding older people have been playing out on a background that changed significantly in the United States in the late 1990s. Articles in the *New York Times* and *Washington Post* have reported on the concerns about safety and research oversight, prompted by deaths of research subjects, which led to the temporary suspension of clinical research at many prestigious academic centers. Clinical research is under greater scrutiny. In addition, serious questions have been raised about the relationship between academic investigators and industry.

Additional Ethical Issues

Unfortunately, many of the issues that affect younger individuals with regard to access to healthcare and research do not disappear when people get older. While this is not a great concern in countries with a national health service or national health insurance, it remains a major issue in the United States. Many people, including a surprising number of older people, assume that Medicare, the federal health insurance program for older people, covers most healthcare needs. While Medicare pays a substantial portion of hospital and physician fees for acute care, it does not cover the cost of medications, many preventive services, and important items for older people such as eyeglasses and hearing aids; most important, Medicare pays for very few long-term care services. Older people who are poor, female, or minority, especially African Americans, are disproportionately affected by problems with access to care. In the United States, as noted by David Barton Smith, the difference between African Americans and whites in terms of access to hospitals and nursing homes narrowed from the 1960s to the 1980s. However, studies in the late 1980s and 1990s, such as that by Kenneth Goldberg and others, continued to uncover less utilization of aggressive and expensive treatments for cardiac disease, for example, in African Americans and women compared with white men, even when insurance status was taken into account.

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SEE ALSO: *Access to Healthcare; Dementia; Grief and Bereavement; Life Sustaining Treatment and Euthanasia; Long-Term Care; Medicaid; Medicare; Research, Human; Research Policy;* and other *Aging and the Aged* subentries

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V. OLD AGE

Every generation seems to yearn for some glorious era in a mythic past when older people were honored and suffered little from material deprivation, derision, or debility. In the late twentieth century, the aging society of the United States has many reasons to seek such comforting ideas about the experience of old age in Western history. Growing alarm about the "graying" of an unbalanced federal budget, concern about allocating expensive medical resources, fears of intergenerational conflict, anxiety about prolonged technological dying and medical indigence, all give a strikingly contemporary, secular resonance to the Psalmist's plea: "Do not cast me off in old age, when my strength fails me and my hairs are gray, forsake me not, O God."

Recent historical scholarship (Cole et al.) reveals no grand narrative, and certainly no "golden age," capable of unifying the diverse experiences of aging and old people in the past. Of all previously silenced groups, the elderly—"clothed as they were with official respect and buried, as they often were, in reality"—may prove the greatest challenge to historians (Stearns, p. 2). Despite the difficulty of generalizing about the historical experience of older people, we can follow the evolution of life in Western history. This entry will sketch these themes. It will also highlight research findings about aging and the life course in ancient, medieval, early modern, and modern Western societies and conclude with the problems posed by the end of modernity.

Every society creates symbols, images, and rituals that help people live meaningfully within the limits of human existence. Cultural meanings of aging and old age are linked to these symbolic forms. Western culture has traditionally relied on two archetypal images to represent the wholeness, unity, or meaning of human experience in time: the division of life into ages (or stages), and the metaphor of life as a journey. Classical antiquity first connected the ages of life and the journey of life, weaving them into its beliefs about the nature of human existence and the cosmos to which human life was intimately linked. In the Middle Ages, Christian writers adopted Greco-Roman ideas about the ages of life and conceived the journey of life as a sacred pilgrimage. Between the sixteenth and the twentieth centuries, secular, scientific, and individualistic tendencies steadily eroded ancient and medieval understandings that aging was a mysterious part of the eternal order of things. Instead it became an individual experience that was best explained scientifically and divorced from larger communal rituals and cosmic meanings. In the early twenty-first century, we are living through the search for ideals adequate to contemporary culture, in which the recovery of cosmic and collective sources of meaning may stimulate appreciation of the spiritual and moral aspects of aging without devaluing individual development (Cole).

All traditions that preceded the modern, scientific effort to master old age share an appreciation of its mystery and complexity. The resulting tendency to view old age as both a blessing and a curse is therefore prominent in Hebrew, Greco-Roman, and Christian writings, each with its own variation.

Ancient Societies

Ancient Hebrew religious literature contained an ambiguous vision of old age. It commanded the young to honor their parents and respect the old for their wisdom, yet it also described the old as "apelike … and childlike," loathed by their children and household (Isenberg, p. 149). Despite the special place Jewish biblical culture reserved for the old, the ancient Hebrews acknowledged that not all old people would be wise, nor would all children support their elders in time of need. The Book of Job specifically challenges the view that old age brings wisdom and asks why God grants long life to the wicked. Later rabbinic law translated the Biblical injunction to honor one's parents as requiring children to provide care, a task that belonged primarily to women.

Greco-Roman literature on old age shares three common themes: the "relationship between wisdom and age; the social and political authority of the elderly; and the care of the aged" (Falkner and de Luce, pp. 4–5). While the Greeks of the classical era generally portrayed old people more harshly than did the Romans, they also viewed old age as one of life's great mysteries. Plato considered virtue a possibility, rather than a necessary by-product, of old age. Aristotle saw middle age as the peak of human life and considered old men unfit for political office. Weakness and poor judgment rendered them objects of pity or scorn.

Greek representations of old age also revealed practical worries. In ancient Greece, a son's coming of age did not absolve him of legally enforced filial duties. Greek drama emphasized that every hero's death deprived his father of *threpteria,* or support in old age. "Sons formed the only pension plan available to the elderly" (Falkner and de Luce, p. 15). While care of older family members also fell to Roman children, the absolute power of the Roman *paterfamilias,* who retained authority over his children as long as he lived, intensified the fires of intergenerational conflict (Bertman). Roman comedy, which openly flaunted rules of respect for elders, mercilessly portrayed old men as weak fools or aging lovers as objects of ridicule.

The evidence on attitudes toward and conditions of older women in Greco-Roman antiquity is scanty yet suggestive. Greek idealization of young men and emphasis on female fertility weighed against cultural appreciation for older women. Yet, postmenopausal women of substance may have experienced unusual freedom in a male-dominated, hierarchical society. Despite the literary contempt that older Roman women received, those with the necessary resources and relations apparently achieved a measure of personal freedom after the constraints of spousal roles and motherhood were removed (Falkner and de Luce). Roman custom accorded respect and authority to aging women and expected sons to support their older mothers (Banner). Even prior to menopause, Roman women did not experience the same exclusion from education or power that Greek women suffered.

The ancients divided the cycle of human life into ages or stages, each corresponding to a generation, each possessing its own set of natural characteristics. Aristotle formalized this threefold division in the *Rhetoric.* Hippocrates' four physiologically determined ages was the most common scheme until the late Middle Ages, when Ptolemy's astrologically based system of seven ages was translated into the vernacular and eventually immortalized by Shakespeare's cynical Jaques:

> All the world's a stage,
> And all the men and women merely players.
> They have their exits and entrances;
> And one man in his time plays many parts,
> His acts being seven ages. (*As You Like It,*
> Act II, vii)

In *De Senectute* (On Old Age), Cicero identified the philosophical bedrock beneath these ages-of-life schemes, that is, the belief that despite the diversity of size, appearance, ability, and behavior that characterizes the different stages, the human life span constitutes a single natural order. "Life's racecourse is fixed," he wrote, "nature has only a single path and that path is run but once, and to each stage of existence has been allotted its appropriate quality" (cited in Burrow, p. 1).

Ancient writers such as Aristotle, Galen, Hippocrates, and Cicero also sought to explain the nature and causes of aging. Associating old age with "dryness" and "coldness," they saw aging as a process of diminution of vital heat or fluids.

Medieval Societies

In the Middle Ages, Christian writers took up these explanations and added a supernatural cause—the Fall of Man. According to Saint Augustine, sickness, aging, and death were unknown in the Garden of Eden; they entered the world after the sin of Adam (Post). While Christian theology considered aging a punishment for original sin, medieval writers also envisioned the journey of life as a sacred pilgrimage to God and eternal judgment. Thus Christian writers fashioned a vision encompassing both physical decline and the possibility of spiritual ascent (Cole).

For the period after the decline of the Roman Empire and the emergence of a decentralized feudal society in Europe, generalizations about the material conditions of older people become even more perilous. The practical experiences of growing old in the chaotic and often violent Middle Ages are difficult to isolate. Early wills reveal the practice of notarizing contracts by which middle-aged peasants agreed to maintain their parents. This was a sign that loss of property or physical vitality rendered older people vulnerable. Such negotiated retirement practices were apparently most common among urban artisans and merchants (Troyansky). To date, there is little evidence on the socioeconomic status of older women in the Middle Ages. While old women and widows were cruelly attacked in both high and popular culture, older widows of substance may have often maintained the authority of their late husbands, while poor, single women and widows became even more vulnerable.

Early Modern Society

Early modern Europe—the age of Montaigne and Shakespeare, of Petrarch and the revival of Ciceronian Stoicism, and later of the Protestant Reformation—was an age of widely disparate images of old age (Troyansky). It was also the period when quintessentially modern ideas and images of the human lifetime were born (Cole). During the Reformation, the traditionally circular representations of life's stages were recast iconographically into a rising and falling staircase, a visual map of the life course, complete with virtues and vices for each stage of life. This new iconography encouraged urban burghers to envision life as a career, a sequence of events over which individuals had some control. Long before longevity became a realistic expectation, Protestant writers and artists urged people to seek a long, orderly, and stable life. They wove together qualifications for salvation with requirements for longevity, thus drawing the cultural cognitive maps for the secular, institutionalized life course of the modern era.

Historians no longer identify the transition to modernity as the key to understanding changes in the lives of older people. In the shift from rural, communal, preindustrial to urban, individualist, industrial society, old people did not simply lose venerated positions of power or security and become scorned outcasts of the past (Stearns). While historians have spilled considerable ink debating the power and status of older people in North America since the colonial period, we still lack sufficient empirical data to justify strong generalizations (Achenbaum; Fischer; Haber).

It is clear, however, that the experience of growing old in modernizing Western societies was shaped by basic changes in the structure of the life course conceptualized not simply as an aggregate of individuals, but as "a pattern of rules ordering a key dimension of life" (Kohli, p. 271). Beginning in the late eighteenth century, shifts in demography and family life, as well as the growth of age-stratified systems of public rights and duties, forged the modern life course. Demographically, age at death was transformed from a pattern of relative randomness to one of predictability (Imhoff). Average life expectancy rose dramatically, especially after 1900. By the mid-twentieth century, death struck primarily in old age, and with much less variance than in the past. (The AIDS [acquired immunodeficiency syndrome] epidemic that began in the 1980s altered this trend.)

Meanwhile, the experience of a modern family cycle (including marriage, children, survival of both spouses to age fifty-five, "empty nest," and widowhood) became increasingly common and standardized (Hareven and Adams).

Modern Society

In the century roughly between 1870 and 1970, the social transition to adulthood (end of school, first job, first marriage) became more abrupt and uniform for a growing segment of the population. At the same time, the spread of universal, age-homogeneous public school and chronologically triggered public pension systems divided the life course into three "boxes": education, work, and retirement. In the modern life course, old age was transformed from a cultural category and a negotiated phase of work and family life into a separate, bureaucratically defined segment of the life course.

The rise of the welfare state facilitated the creation of old age as the capstone of the institutionalized life course. Following the example of Germany (in 1889) and other industrial democracies (e.g., Great Britain, 1908; Austria, 1909; France, 1910; the Netherlands, 1913), the United States instituted a national pension system in 1935 through its Social Security Act (Quadagno). In linking retirement benefits to a specific age, public pension systems provided the economic basis for a chronologically defined phase of life beyond gainful employment. During the middle third of the twentieth century, this "new" phase of life became a mass phenomenon. Increasing life expectancy, the dramatic growth of the elderly population, the spread of retirement benefits, the emergence (in 1965) of Medicare and Medicaid to help defray medical costs, a booming nursing-home industry, and the rise of gerontology as an area of scientific research and professional service transformed old age into the final stage of the institutionalized life course.

By the mid-1970s, increasing longevity, economic security, and medical care available to most older people testified to the success of welfare-state policies. Shortly thereafter, however, economic troubles, initially provoked by the 1973 oil crisis, helped undermine the political legitimacy of old age (Minkler). To a number of critics, an aging society threatened the welfare of other age groups. These critics, who focused on Social Security and Medicare, blamed the deteriorating condition of children and families on the graying of the federal budget, and raised questions of generational equity (Longman). Heightened awareness of an aging population blended silently with fears of nuclear holocaust, environmental deterioration, economic decline, social conflict, and cultural decadence.

Fears about the economic consequences of an aging society framed in terms of generational equity seemed especially troubling, because modern U.S. culture offered no convincing answers to questions of meaning or purpose in old age. During the long period between the Reformation and the modern welfare state, old age was removed from its ambiguous place in life's journey, rationalized, and redefined as a scientific problem. The triumph of mass longevity was not accompanied by culturally rich notions of what old age could or should mean for individuals or society. Instead, modern old age became a permanent threshold, marked by exit but devoid of entry into a world of shared ideals, a season without a purpose.

In the early twenty-first century, which coincides with the end of the modern era, we are living through a search for ideals and roles in later life—a search involving renewed concern about the moral and spiritual dimensions of growing old (Cole). The outcome of this search, which attempts to integrate the ancient value of submission to natural limits with the modern value of unlimited individual development, will influence the answers to many pressing ethical questions in our aging society (Moody).

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BIBLIOGRAPHY REVISED

SEE ALSO: *Autonomy; Death; Future Generations, Reproductive Technologies and Obligations to; Harmful Substances, Legal Control of; Human Dignity; International Health; Justice; Life, Quality of; Natural Law; Population Ethics; Right to Die, Policy and Law;* and other *Aging and the Aged* subentries

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VI. ANTI-AGING INTERVENTIONS: ETHICAL AND SOCIAL ISSUES

An estimated 2,500 physicians in the United States had established specialty practices devoted to "longevity medicine" by 2003, and the American Academy of Anti-Aging Medicine (A4M) boasted 11,000 members in that year. The goal of this clinical community is to extend the time their patients can live without the morbidities of the aging process; namely "memory loss, muscle loss, visual impairment, slowed gait and speech, wrinkling of the skin, hardening of the arteries, and all the other maladies we call aging" (Shelton). At the beginning of the twenty-first century, however, there was little the practitioners of anti-aging medicine could prescribe that had any scientific validation (Olshansky, Hayflick, and Carnes; Butler et al.). But the scientists who study the biology of human aging, known as *biogerontologists,* are slowly making headway, and a central research agenda for this community is to provide clinicians with the tools they require to make anti-aging medicine a reality (Kirkwood; Olshanksy and Carnes).

Biogerontologists pursue a wide array of scientific strategies, based on a variety of different theories about the biological process of aging. However, their research programs generally fall into one of three basic types, depending on their goals. The most conservative model is commonly described as seeking *compressed morbidity* (Fries). The goal of biogerontological research under this paradigm is to forestall the chronic ailments of old age so that humans will be able to live long, healthy, and vigorous lives within the limits of the maximum life span for the human species. Its approach, however, is to prevent age-associated maladies by intervening in the underlying aging processes that make people vulnerable to them, rather than attack them piecemeal (Kirkland). In this model, biogerontologists are actively seeking increases in the average human life expectancy, but not increases in the maximum human life span. The successful realization of this paradigm will result in a society with many more very old people playing active social roles right up until their death.

A second, more ambitious paradigm seeks to produce *decelerated aging.* Here, the research goal is to develop ways to slow the fundamental processes of aging to the extent that both average life expectancy and maximum life span are increased beyond the species' prior experience. Under this model, people would continue to move through the same stages of senescence (decline) as they age, but the process would take place against an elongated timescale, providing more years of vigorous life before the declines of old age. One prominent biogerontologist suggests, for example, that it may be possible to produce ninety-year-old individuals who are as healthy and active as today's fifty-year-olds, as well as to achieve a mean life expectancy of about 112 years for Caucasian American and Japanese women, with an "occasional outlier" reaching an age of about 140 years (Miller).

The most radical paradigm being subscribed to by biogerontologists is arrested aging. Here the hope is to develop the ability to continously reverse the processes of aging as they occur in adults, in order to maintain vitality and function indefinitely (Fossel; De Grey et al.). Some scientists envision that "negligible senescence" could be accomplished by finding ways of removing the damage inevitably caused by basic metabolic processes, and thereby attaining an indefinite postponement of aging. They expect that substantive progress toward this objective will be feasible by the second decade of the twenty-first century (De Grey et al.).

Should Scientists Attempt to Control Aging?

The fundamental philosophical and cultural challenge of anti-aging research is the blow that it could deal to aging's historical role as a constant in human affairs. If it is not necessary to assume the universality of aging in the ordering of society, new choices present themselves. From the point of view of the public good, is aging, as it is now known, a human experience to be encouraged or discouraged? Both biomedicine and American culture reinforce the inclination to interpret the biological changes that accompany human aging as losses that harm those who experience them (Cole and Gadow). Society in general and health professionals in particular have a fundamental obligation to do what they can to protect people from the harms to which they are vulnerable, whether those harms originate with terrorists, epidemic disease, the accumulated insults of the environment, or genes. Though not everyone would choose to avoid the "harms" of aging, should those who wish to use these interventions be discouraged from doing so?

It is clear that there is a powerful psychological dynamic at work behind the bioethical debates over anti-aging research. Against the mythic power of rejuvenation, almost any form of social and personal risks involved in pursing the mastery of aging fade away. This is because it has so often been rejuvenation—in the forms of resurrection, reincarnation, renewal, or rebirth—that defeat deterioration and death in human belief systems (Gruman).

Critics of anti-aging medicine suggest that cultural and medical assumptions about the biological changes of late adulthood might be different if society were not so pervasively influenced by the perspective of those who have not yet undergone them (Callahan, 1993). Perhaps, when seen from the other side, not all the changes that young adults view as the harmful losses of aging are harms at all. One familiar example of this is menopause—this loss of reproductive capacity, though fraught with physical and emotional turbulence, is one that many women come to celebrate as opening new opportunities and life pleasures (Martin; Logothetis). Similarly, in many societies the loss of physical strength and endurance that comes with aging allows the individual to relinquish responsibility for the labor of survival and move into an even more important role as an elder for his or her community (Moody, 1986).

Traditionally, even the health challenges of aging (e.g., failing senses, vulnerability to disease and accident) have been seen as contributing to the life experiences of older adults in a way that gives them a level of equanimity and insight difficult to achieve at earlier stages in life (Post). The psychologist Erik Erikson has looked to old age as a crucial source of generativity in the human life cycle, and the philosophers Daniel Callahan and Leon Kass have argued that growing old provides special opportunities for teaching, wisdom, and altruism. This does not mean that the major diseases that threaten human health in late adulthood are not a cause of concern, but it does suggest that attempting to intervene in the aging process itself, for all its attendant complaints, may be shortsighted and harmful because it would deny adults the wider benefits of growing old.

On the other hand, advocates of anti-aging medicine claim that, at best, this argument leads to the position that it would be wrong to deny people the right to "grow old gracefully" if they value the benefits of doing so (Stock). The physical burdens that accompany aging can be very serious, and modern society is not designed to optimize the role of the elderly. Given the social realities of aging in modern Western culture, many adults would consider the price of the late stages of human development high enough to warrant attempts to postpone and compress them as much as possible. Advocates of anti-aging research point out that respecting that human ability to project and pursue a life plan is at the heart of what it means to respect self-determination and personal autonomy.

Is There a Natural Life Cycle?

In reply, the critics of anti-aging medicine ask us to imagine our reactions to a hypothetical biomedical intervention that would interrupt the development of a child and extend childhood by delaying puberty (Hayflick). What is worrisome about that is not simply the psychological harm such a developmental distortion might produce. Nor is it just a matter of violating the child's rights to self-determination—those rights are not yet in full flower and it is their parents' role to protect, and to some extent define, the child's best interests. If interrupted, the child's bodily development is no longer progressing on its own schedule, nor is it being driven by the complex, automatic interplay of genes and their reactions to the environment. Such a disruption of the child's "developmental autonomy" alienates his or her life story from the temporal narrative that characterizes the human species.

Postponing the normal biological changes of aging, the critics argue, constitutes a similar disruption. Whether or not the biological changes of aging are beneficial or harmful, they are meaningful: They and their natural timing constitute part of the normal life cycle for human beings, and thus part of what it means to be human (Kass, 2001). Intentionally distorting that cycle alienates the elderly from the definitive human life story, and dehumanizes them in the process. In this view, adults should be taught to seek the meaning of the later stages of human development, and biomedical research should focus on making the experience of that part of life as healthy and pleasant as possible, but not interfere in its essential rhythm (Callahan, 2000).

Of course, arguing that the traditional human life cycle is normative for human beings requires a good bit of philosophical work if it is not be reduced to a statement of religious faith or accused of making a virtue of necessity (Overall). Just because human beings have always lived their lives within a traditional time frame is not necessarily a reason to continue doing so. In fact, the social and technological dimensions of the "typical human life story" have been rewritten continuously during human history, without diminishing the moral status of those people whose lives are made possible by that evolution (Gruman). Given this history of pushing back the natural limits of human life through science and technology, the burden of proof, the advocates argue, is on the critics to complete their philosophical project convincingly. Until then, theirs is one ideology among many, which autonomous adults (and researchers) in a free society should have the right to assess, adopt, or reject as they will.

The Limits of Medicine

Interestingly, one sector of medicine that is strongly wed to a naturalist ideology is biomedicine. Human health is usually understood by biomedicine not merely as the absence of diagnosable disease, but as functioning within a range that is typical for human beings of one's age and gender (Boorse). For functionalists in biomedicine, the statistically "normal" is morally normative; that is, it represents the state of health that is supposed to be the goal of research and the priority of practice. This is why biomedical professionals strive to draw a line between their work devoted to addressing health problems and the use of their work for cosmetic, aesthetic, athletic, or social enhancements (Juengst). The use of medical tools for enhancement might be tolerated in a free society, but to the extent that they do not address *bona fide* health needs, they should not be given a high priority by health professionals and researchers. On what side of this professional boundary line should human growth hormone (HGH) replacement fall? If there is nothing pathological about the aging process itself, critics argue, all the current efforts that health professionals are mounting to combat it seem wrong-headed and wasteful (Callahan, 2000).

From this perspective, it becomes crucial for the ethical debate over anti-aging research to answer the question of whether or not intervening in human aging is a legitimate form of healthcare. Part of the problem, of course, is the current limited knowledge of the fundamental causes and dynamics of the aging process. In this debate, the scientific contest between the theories of aging that rely on accumulated insults and those that look to genetics is crucial. If the aging process turns out to be a confluence of conditions that would individually be considered health problems, and that vary between individuals and across populations, it would be plausible to conceptualize the process as ultimately accidental, and thus to medicalize the causal cofactors as individual health problems (Caplan).

On the other hand, if aging is a natural and inevitable consequence of normal physiology, then the process itself is normal, and therefore healthy. This is a matter of scientific interpretation, but to the extent that cellular, metabolic, and organismic senescence is inherent in the human species, the less legitimate anti-aging research appears as a field of health science. This in itself does not mean that there is anything intrinsically wrong with anti-aging research, of course, any more than research into advanced tattoo techniques is wrong. It only means that anti-aging researchers must give up their claims to be promoting human health—and the measure of public support that mantle provides (Murphy).

It is unlikely that anti-aging researchers will be able to offer any intervention that could address the genetically programmed aspects of the aging process in the foreseeable future. Instead, partial interventions, such as HGH replacement, will be developed in response to genuine health concerns. Almost any intervention that would postpone specific milestones of normal aging would also help prevent the health problems common to those milestones. Would successful HGH replacement prolong the vitality of the musculature or prevent the onset of aged-related weakness? As long as these are two sides of the same coin, the anti-aging effects of such interventions will always be eclipsed by the medical obligation to prevent disease, effectively deciding the question of the intervention's appropriateness and the need for its development (Juengst). Against this conceptual backdrop, anti-aging researchers might insist, it would be better to embrace the anti-aging goals of the patients and researchers interested in these interventions, rather than foster increased off-label (unapproved) use of interventions without appropriate safety and efficacy testing. A well-regulated and thoughtful program of anti-aging research, they could argue, will ultimately do more to protect the public welfare than relegating the effort to the margins of biomedicine (Mehlman).

Fairness in Anti-Aging Medicine

Critics might reply that appeals to the public welfare change the terms of the debate once again. At the level of social policy, the dangers of the off-label use of medical interventions for anti-aging purposes dim in comparison to the injustices that might be facilitated if anti-aging interventions are treated as elective enhancements. Public attitudes toward the enhancement technologies already available suggest that the demand for truly effective anti-aging interventions will be so substantial that legal prohibition would simply produce a robust black market in these interventions. On the other hand, if the interventions are seen as "elective" or "cosmetic" enhancements, they are likely to be left to the market to distribute, according to the ability of consumers to pay.

If anti-aging interventions are, like other cosmetic uses of medical tools, available only to those who can afford them, society would see the disparities between the haves and the have nots exacerbated in a particularly insidious way. For example, if wealthier older adults can maintain their youthful features, they may come to have more interests in common with young adults than with the poor elderly population, and this may lead to a shift in political allegiances. If they were to continue to identify with their age cohort, a larger population of youthful elderly might benefit the interests of the aging elderly. If other interests realign allegiances, however, the poorer aging elderly could find themselves increasingly marginalized. If anti-aging medicine ultimately stigmatizes the aging process as a pathology of the poor, this political disadvantage could be compounded even further by social intolerance (Seltzer).

One alternative, of course, is for the government to play a role in financing and distributing these interventions. For candidates of equal age, should the previously treated or the untreated have the highest priority? For candidates of equal health status, should the chronologically younger or older take precedence? Finally, how should the benefits of these interventions be measured in order to determine the amount of public funds that should be spent on making them widely available?

These are critical public-policy questions that will have to be addressed as anti-aging interventions become available. On the other hand, they are not problems that should guide the progress of scientific work. In practice, medicine is not likely to police anti-aging interventions for social policy reasons unless it becomes clear that the social problems created by their availability as elective medical services are severe enough to compare with public health emergencies. According to some critics, such crises are not unforeseeable in a long-lived society (Hayflick). But until it is clearer that medicine should steer by social justice as well as patient welfare, the advocates argue complicity that with these social problems is not likely to stand in the way of anti-aging medicine.

Conclusion

The prospect of anti-aging interventions raises searching questions for individual families, biomedical professionals, and public policy. Most of the issues described here are questions that need to be addressed at all three levels, and they call for both social-scientific research and deep cultural reflection on the meaning of aging. Nevertheless, it not too early for anticipatory public discussions of these questions to begin.

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SEE ALSO: *Enhancement Uses of Medical Technology; Human Dignity; Transhumanism and Posthumanism;* and other *Aging and the Aged* subentries

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AGRICULTURE AND BIOTECHNOLOGY

• • •

Among approximately 80,000 types of plants that are known to be edible, only about 100 are cultivated intensively worldwide, and of that number fewer than 20, such as rice, maize, wheat, and rapeseed, provide 90 percent of food crops. This handful of species has been subjected to genetic manipulation for millennia so that even before the advent of gene splicing, they diverged dramatically in genotype and phenotype from their wild ancestors.

The Distinction between Conventional Breeding and Genetic Engineering

For thousands of years human beings have altered the genomes of all major crops radically and constantly to change growth and ripening characteristics, speed maturity, eliminate grain shattering, improve taste and reduce toxins, increase size, and even get rid of seeds, as in grapes and bananas. Pictures comparing the wild and cultivated types of any crop invite incredulity because the differences are so sweeping.

Crops that are very different from each other, such as Brussels sprouts, cabbage, cauliflower, and broccoli, derive from the same ancestral stock, whereas other crops, such as bread wheat and canola, are artifacts. Wheat used for bread was created when technologists about 4,000 years ago hybridized tetraploid durum wheat with an inedible goat grass. Canola (Canada oil) was fabricated in the twentieth century by Canadian biologists who assaulted and pummeled by heat, radiation, and other means the genome of an inedible rape (mustard) plant. They selected for mutations that eliminated toxic acids and smelly glucosinolates that had made the plentiful rapeseed oil unpalatable. Every cultivar has a story of genetic manipulation and hybridization that explains its stark differences from its wild ancestors. Some of those stories, such as those of kiwi fruit, strawberry, and tomato, suggest that one can make the agronomic equivalent of a silk purse out of a sow's ear.

To assess ethical objections to agricultural biotechnology one must distinguish concerns that apply to forced mutation, hybridization, and artificial selection generally from those that apply only to the changes—often small by comparison—associated with genetic manipulation (GM). Because conventional breeding techniques have become more sophisticated and in principle may be able to achieve (although more arduously) the same mutations that GM accomplishes easily, the boundary between old and new biotechnologies may be hard to draw. The principal difference may be this: GM performs "outcrosses" that take advantage of the apparent fact that all life has the same origin, whereas conventional techniques cross species that are more closely related or apply pressure to a genome to induce hoped-for changes.

Health Risks and Benefits of GM Food

Critics of GM food present three kinds of arguments to suggest that it may not be good to eat (Thompson, p. 76). First, GM foods may produce allergic reactions because known or unknown allergens could be introduced into products people believe are safe. The food industry should and does take this problem seriously; the liability issues alone are sobering. For example, because many people are allergic to peanuts, it would be risky to introduce into other crops genes that code for a protein unique to the peanut. The fact that GM foods should be tested or screened for allergens—and this may be true of all foods—seems incontrovertible.

Second, critics contend that GM foods are not more nutritious or tasty or otherwise better for the consumer than the foods that traditionally have been available (Kneen). This is largely correct. Although all kinds of crops that promise benefits to the consumer are said to be on the horizon, few have materialized; even the highly touted vitamin A–rich "golden" rice may not be better—or cheaper or more acceptable to target consumers—than simple vitamin pills. As things stand, the benefits of GM crops go principally to farmers; those benefits will be considered below. Time will tell whether GM foods will offer significant benefits to consumers.

Third, critics invoke the precautionary principle to argue that GM is novel and untested: How can one be sure it is safe? (Pence, ch. 5). Defenders of the technology answer that GM crops are hardly new; hybridization, including distant outcrossing, has been the basis of agriculture for millennia (Prakash). The genetic alterations GM achieves are more precise and therefore less extensive than are those associated with conventional breeding. There is no evidence that suggests that genetic material introduced into a plant from more distant relatives is more dangerous than that introduced from closer cousins. The food product, moreover, will not be any less safe because of the placement of a few nucleotides in its DNA. The oil from GM soy or canola, indeed, will not contain in principle any DNA or protein (there could be traces) and thus will be chemically identical to that from the non-GM plant, which is itself an artifact of conventional breeding. Those who study the extent to which genomes of plant crops have been manipulated over the millennia see no reason to think that twenty-first century techniques produce food that is inherently more dangerous (IFT).

Those who make this reply do not contend that forced mutation and artificial selection—whether by conventional methods of breeding, more advanced techniques of hybridization, or genetic recombination—are always or necessarily safe. Instead, they contend that the risks are the same across all these ways of re-creating plant genomes. Techniques of embryo rescue, mutation-forcing irradiation, and wide crosses that transformed varieties of nightshade into the tomato, for example, dwarf twenty-first century's molecular methods in scope and effect.

As expert panels typically find, "Crops modified by modern molecular and cellular methods pose risks no different from those modified by earlier genetic methods…"

(IFT, p. 23). Similary, a FAO/WHO (1991) report stated: "Biotechnology has a long history of use in food production and processing. It represents a continuum embracing both traditional breeding techniques and the latest techniques based on molecular biology. The newer biotechnological techniques, in particular, open up very great possibilities of rapidly improving the quantity and quality of food available. The use of these techniques does not result in food that is inherently less safe than that produced by conventional ones."

GM and the Farmer

Farmers eagerly adopt GM varieties, especially herbicide-resistant soybean and insect-resistant cotton and corn, for several economic reasons. Farmers like to rotate soy with corn, for example, because soy, a legume, nourishes the soil corn depletes. However, soy is sensitive to the residues of glyphosphate herbicide that control weeds in corn. A glyphosphate-tolerant (Roundup-Ready) soy allows rotation; an insect-resistant corn goes far toward eliminating that risk. As farmers produce a more predictable crop—and are able to plant more closely because they do not have to cultivate it—their harvests increase. This is a mixed blessing, however, because the resulting surpluses drive down prices. As the risks decrease, moreover, farms become a target for vertical integration by agribusiness.

In the developed world GM crops represent the latest turn in the technological treadmill, with the usual consequence: glut. According to the pure theory of the treadmill, as overproduction causes crop prices to fall, farmers adopt new technology to increase yields and lower cost. The early adopters of the new technology eke out a profit by underpricing the competition, thus driving farm prices down farther. Those who are late to adopt the technology go broke and sell their land to those who still operate, leading to ever-greater concentration in the industry. The survivors must adopt increasingly more efficient technology, and so the cycle continues (Cochrane, p. 429).

In the twenty-first century, although about 593,000 Americans identify farming as their principal occupation, most of those farmers produce less than $100,000 in annual sales; only about 172,000 farmers produce the bulk of American crops. Demographers expect these numbers to continue to fall; for every full-time farmer under age thirty-five, three are over sixty-five years old. The majority of the nation's crops, many experts predict, will in a few decades be fabricated by computer-run systems overseen by engineers and other technologists directing huge machines over a vast unpeopled landscape covered with grain (Berardi and Geisler). Whatever services are not automated will be provided by contract labor, as is presently with hogs and chickens.

Farming in the traditional sense may become a "cottage" industry like glassblowing, or there may be two different kinds of agriculture: one method utterly industrialized and efficient and the other a "craft" system responsive to aesthetic, cultural, landscape, and noneconomic concerns. Large corporations may integrate food production vertically by absorbing farms. Those companies also may make and market "craft" food products, as General Mills manufactures organic foods through its subsidiary, Cascadian Farms.

Critics protest with good reason that industrial farming by megacorporations—genetic manipulation of seed is only one aspect of the industrialization of agriculture—undermines the cultural, aesthetic, ethical, ecological, and landscape values and commitments that are associated with pastoralism or with the traditional farming of the agrarian past (Comstock). These critics contend that the products of industrial agriculture, even if they are technically safe, are so manipulated, artificial, and unnatural that they are inherently disgusting, distasteful, demoralizing, and repellent. Even if food safety is not the issue, one can argue that food is more than nourishment; it is part of a way of life and has symbolic and aesthetic value. GM undermines nature and, with it, the value of food.

These are credible criticisms, but there is a rub. The people who make these charges generally are unwilling to grow their own food. They expect other people, such as farmers, to do it for them. Farmers do the best they can against nearly impossible economic odds. They find that they cannot provide the variety, quality, and abundance of food people demand at anything close to the prices people pay unless they take advantage of the efficiencies offered by technology. Farmers will absorb the relatively higher costs of raising GM-free crops, however, if people are willing to pay a large enough premium for them. Just as members of religious communities—Jews who keep kosher, for example—pay a little more for food that meets their requirements, so too may people who prefer non-GM foods. Consumers should have an "exit" option with respect to GM foods; presumably, the market for "organic" food provides that option.

Labeling

Critics of GM foods may agree that they have to send a message not only through political advocacy but also through the consumer choices they make. For consumers to send a message through their choices, they must know which foods contain GM ingredients. No one questions the right of the consumer to make informed choices. Why not require that GM food be labeled to guide consumer choice?

Industry representatives offer three responses to this question. First, they observe that any manufacturer can state on a label or in advertising that its product is GM-free as long as this is true; indeed, the "organic" label implies as much. If the label does not say that a product is "GM-free" or "organic," the consumer can assume that it is not. The label "May Contain GM Ingredients," if stamped on food products, would add no information. In international forums U.S. representatives have appeared to be ready to accept this type of universal label or symbol. The label would underscore the fact that a product not labeled as being GM-free may contain at least some amount of an ingredient from a GM plant (USDS).

Second, to segregate commodity flows would be enormously costly. If a drop of soy oil from an engineered plant is mixed into a tank of oil—chemically identical to it—from conventional soy, would that taint the whole lot? How well would the tanker have to be cleaned to remove the taint? Those who observe religious restrictions have over the centuries worked out rules to determine, for example, how milk and meat are to be separated and how plates are to be washed. Are the resources available to segregate and trace through the entire food industry flows of commodities, such as canola oil, to segregate by source substances that are nearly indistinguishable chemically? No one objects if those who wish to observe aesthetic, ceremonial, or religious distinctions do so, but this must be done at their own expense. At present purveyors of "organic" food pay to assure its identity and history. Those who produce, sell, and buy ordinary products do not want the burden of that expense (IFT, pp. 124–136).

Third, so many methods of genetic manipulation enter into the production of food at so many levels—bacteria that produce enzymes that catalyze fermentation are genetically engineered but are not found in the cheese, for example—that it would be a nightmare to write regulations that determine what is or is not manipulated. By comparison, to set up rules to define "organic" food was an exercise as difficult as squaring the circle; in a literal, biological sense all food is organic. Virtually all foods are genetically manipulated as the products of artificial selection; to say which ones are not manipulated in a relevant sense is not easy. Worse, megacorporations design for the label; lawyers and engineers find ways to make the products of industrial processes comply with any set of regulations. This is the way the food industry works. This situation frustrates those who want to get food from Mother Nature rather than from Consolidated Agribusiness (Pollan).

Biotechnology and the Developing World

From a global perspective, increased production of food, however efficient, will not relieve the principal causes of famine and hunger, for these forces involve powerlessness, destitution, civil war, and oppression. The road to food security lies in making governments less corrupt, reducing ethnic and racial rivalries and hatreds, ending civil wars, improving education, providing employment, and halting gender discrimination. Food security is a function of social justice. With or without the latest advances in genetic engineering, a peaceful and just world could feed its people easily.

Farmers can and will plant and harvest as much as they can sell. As the economist Amartya Sen has written, "food output is being held back by a lack of effective demand in the marketplace" rather than by ecological constraints on production. In other words, food is not scarce but demand is because many people are too poor or powerless to purchase food even at the twenty-first century's historically low prices. As Gordon Conway of the Rockefeller Foundation points out, however, even if global production is ample, "there could still be nearly a billion people who lie outside the market and are chronically undernourished." Conway believes that agricultural biotechnology can benefit peasants who depend on local, subsistence farming. In Kenya, for example, scientists funded by Monsanto have developed a recombinant sweet potato that resists a devastating virus. Edible vaccines may be engineered into crops such as bananas. A rust-resistant cassava could make a huge difference in Africa. There is no general economic theory that shows why or how biotechnology can benefit people in developing countries. A long list of examples can be supplied, however, of the nearly miraculous potential of genetic engineering to relieve malnutrition and hunger on a crop-by-crop, problem-by-problem basis.

However, as an article in *Foreign Policy* observed, biotechnological innovations that create "substitutes for everything from vanilla to cocoa and coffee threaten to eliminate the livelihood of millions of Third World agricultural workers." Vanilla cultured in laboratories costs a fifth as much as vanilla extracted from beans and thus jeopardizes the livelihood of tens of thousands of vanilla farmers in Madagascar. A rapeseed (canola) engineered to express high levels of laurate, an ingredient in soaps and shampoos, allows growers in Canada to take markets away from producers of palm oil in developing countries. In general, genetic engineering of crops leads to biosubsititution, biorelocation, and bioreplication, enabling industrialized countries to produce the equivalent of traditionally tropical products and thus cease importing those commodities from developing countries. Developing nations by virtue of the same technology may flood world markets. The technological treadmill is poised to increase commodity surpluses, especially of commodities, such as cocoa and coffee, which sustain the developing world, and therefore, ironically, result in further impoverishment and further declines in demand. Rather than tending by its logic to make everyone better off, biotechnology may make wealthy countries more wealthy while taking from poor countries the monopoly on the few export commodities that once were exclusively theirs.

The Ecological Implications of Biotechnology

Critics contend that GM crops are likely to have deleterious environmental effects. For example, they will lead to greater pesticide resistance among weeds and insects because genetic material from GM organisms will drift into wild varieties; plant leaves and pollen that contain Bt or other insecticides will kill nontarget species; drought tolerance, salt tolerance, cold-hardiness, and other feats of genetic engineering will permit farms to expand into wild areas that formerly were not arable; and animals, particularly fish such as salmon, will hybridize with wild stocks, domesticating all of nature (Graziano). Nothing will evolve free of human influence.

Although all these concerns are credible, defenders of biotechnology respond that these objections are not specific to genetic engineering but apply to agriculture and aquaculture generally. Indeed, GM technologies may only increase slightly—or indeed decrease slightly—the relentless, total, and overwhelming impact of agriculture on the natural world. Even before the discovery of the structure of DNA, the entire midsection of the United States had been turned from prairie or savanna ecosystems to amber waves of grain. To restore the prairie, ecologists searched for native species in abandoned cemeteries and railroad rights-of-way. Modern agriculture roots out nature literally and figuratively and replaces it with monocultures that cover millions of acres. Nature is equally devastated whether those monocultures consist of conventional hybrids or GM plants.

Insecticides promote resistance whether they are sprayed on or bred into a plant. When they are sprayed from airplanes over large areas, these chemicals may kill nontarget species more extensively than they would if they were engineered into the leaves of crops. Weeds subjected to dousings of glyphosphate eventually must evolve to withstand the herbicide; the addition of herbicide resistance in crops may hasten this inevitable process somewhat. Crops that are the products of conventional breeding are no more "natural" than GM crops are; indeed, human-caused mutation and selection have just taken longer to achieve the desired properties. These conventional hybrids—both crops and animals, including fish—can intermingle their genes with wild types if and when wild types are found.

The effect of farming on nature can be seen best in Europe, where agriculture counts as "nature," with the alternative being urban or suburban development. Americans think of nature as wilderness, although the wilderness that remains is managed, designated wilderness—a kind of botanical garden maintained in national parks. To estimate the extent to which GM plants threaten nature, one must ask what "nature" is, whether it is more than the smile of the Cheshire cat. Environmental historians such as William Cronon state that agriculture and industry have transformed the landscape so thoroughly so many times over that it is hard to say what people are trying to protect. Also, the pressure of *Homo sapiens* on other organisms has directed their evolution for millennia; humans are the "keystone" species that structures the natural environment that people consider wild (McKibben).

Human Biotechnology

Many of the most controversial technologies bioethicists study in medicine—artificial fertilization and cloning are obvious examples—originated in the barnyard. The genetic manipulation of animals will be the proving ground for the genetic manipulation and enhancement of human beings. What may be most interesting in the ethical study of agricultural biotechnology, therefore, may lie in its effort to identify something "natural"—some essence, condition, history, or pedigree—that makes an animal characteristically itself and that can be lost as a result of genetic engineering. If this essence proves elusive in the agricultural context or if it turns out that everything physically possible is equally natural, by analogy, it may not be possible to identify any limits in the nature of humans (e.g., mortality) that people may not try to transcend. Human beings may be tempted, then, to improve human qualities through germ cell engineering just as they have improved the qualities of plants and animals.

The distinction between the "natural" and the "artificial" may not survive the advance of biotechnology because everything, including the human genome, may become both. This makes the human species responsible for everything, or it greatly diminishes the "given" or contingent in nature. The ability to manipulate the human genome—as people have manipulated the genomes, say, of salmon and chickens—for many technical reasons is a long way off. Indeed, it still may be considered science fiction. Someday human beings may cultivate themselves as they do other organisms. The idea that people eventually may apply to the human genome the same techniques by which they have changed crops and livestock could be the ultimate irony of agricultural biotechnology.

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SEE ALSO: *Animal Research; Animal Welfare and Rights; Cloning; Environmental Ethics; Environmental Policy and Law; Technology*

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AIDS

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I. Public Health Issues
II. Healthcare and Research Issues

I. PUBLIC HEALTH ISSUES

At the conclusion of *Plagues and People,* a magisterial account of epidemics and their impact on history, William McNeill asserts, "Infectious disease, which antedates the emergence of humankind, will last as long as humanity itself and will surely remain, as it has been hitherto, one of the fundamental parameters and determinants of human history" (McNeill, p. 291). In the mid-1970s, this observation seemed overdrawn, especially in relation to economically advanced societies, where chronic diseases had displaced infectious threats to communal well-being. Yet just five years later, McNeill's comment seemed prescient.

In June 1981, the first cases of what would ultimately be called acquired immunodeficiency syndrome (AIDS) were reported by the U. S. Centers for Disease Control

(CDC). Within three years of the first CDC report, human immunodeficiency virus (HIV), the viral agent responsible for AIDS, was identified. Although those who were infected could experience a long disease-free state—50 percent remained symptom-free for up to ten years—in the end the virus attacked the immune system, resulting in a series of ultimately fatal opportunistic disorders. By the beginning of the twenty-first century, it was estimated that approximately 900,000 Americans and more than 42 million people worldwide were infected. Although found on every continent, AIDS had made its most stunning impact on Africa. Projections by the World Health Organization (WHO) forecast a grim picture, with catastrophic spread of HIV in Asia and the former Soviet Union.

Exceptionalism and the Ethics of Testing, Reporting, and Partner Notification

In the early and mid-1980s, at the outset of the American encounter with AIDS, it was necessary to face a set of fundamental questions: Did the history of responses to lethal infectious diseases provide lessons about how best to contain the spread of HIV? Should the policies developed to control sexually transmitted diseases or other communicable conditions be applied to AIDS? If AIDS were not to be so treated, what would justify such differential policies?

To understand the importance of these questions, it is necessary to recall that conventional approaches to public health threats typically provided a warrant, when deemed appropriate, for mandating compulsory examination and screening, breaching the confidentiality of the clinical relationship by reporting to public health registries the names of those diagnosed with “dangerous diseases,” imposing treatment, and in the most extreme cases, confining persons through the power of quarantine. To be sure, many aspects of this public health tradition, forged at the outset of the twentieth century, had been modulated over the decades, in part because of changes in the patterns of morbidity and mortality.

Nevertheless, it was the specter of the historically coercive aspects of the public health tradition that most concerned proponents of civil liberties and advocates of gay rights and bioethics as they considered the potential direction of public health policy in the presence of AIDS, a disease that so disproportionately affected disfavored groups—gay men, drug users, the poor in minority communities. In place of the conventional approach to public health threats, there emerged an alternative view—broadly defined as exceptionalism (Bayer, 1991)—that took as its starting point the need to craft policies that were persuasive rather than coercive, which viewed the protection of the rights of those who were infected as integral rather than as antagonistic to the goals of disease prevention. For those who advanced this new perspective, privacy and confidentiality were to be accorded great importance. In all, the goal was to avoid measures and practices that might be counterproductive, which might “drive the epidemic underground” by inspiring fear and distrust rather than fostering engagement between public health officials and those most at risk. How the exceptionalist perspective with its commitment to noncoercive approaches to HIV affected policy is most clearly illustrated in the debates over HIV testing, reporting of HIV, and partner notification efforts.

HIV TESTING. From the moment of its introduction in 1985, the HIV test became the subject of intense debate. Fear that those identified as having HIV might be subject to discrimination and stigma; concern about how the diagnosis of HIV infection, in the absence of effective therapy, could produce unbearable psychological burdens; and a belief that testing had little to do with behavioral change led AIDS activists generally, and gay leaders specifically, to adopt a posture of hostility and/or skepticism regarding the test. On the other hand, many public health officials believed that the identification of infected persons could play a crucial role in fostering behavioral change. Out of their confrontations emerged a broad consensus that, except in a very few well-defined circumstances, people should be tested only with their informed, voluntary, and specific consent (Bayer, 1989).

Much of the early discussion of HIV testing occurred in the context of extreme therapeutic limits. And indeed in the epidemic’s early years the primary function of testing was as an adjunct to prevention efforts. By 1990, as a result of clinical developments—the belief that treatment with zidovudine (also known as azidothymidine, or AZT) could delay the onset of symptomatic AIDS and the recognition of the importance of primary prophylaxis against Pneumocystis carinii pneumonia—the medical significance of identifying those with early HIV disease had become clear. Consequently, the clinical and political context—involving a wide range of constituencies—of the debate about testing underwent a fundamental change (Bayer, Levine, and Wolf). Gay organizations began to urge homosexual and bisexual men to have their antibody status determined under confidential or anonymous conditions. Physicians pressed for AIDS to be incorporated into the medical mainstream and for the HIV-antibody test to be treated like other blood tests—that is, given with the presumed consent of the patient.

Pressure to shift the paradigm of testing away from the exacting standard of informed consent was especially pronounced in the case of pregnant women and newborns (Bayer, 1995). Diagnostic progress was to make it possible to determine whether HIV-positive newborns were truly infected soon after birth, and the improved prospects of clinical management were to make such determinations for infected infants appear all the more critical. So it is not surprising that pediatricians became increasingly impatient with the strict regimen of explicit and specific consent that surrounded the testing of newborns for HIV (Hegearty and Abrams)—all the more so because routine and unconsented testing of newborns for inborn errors of metabolism such as phenylketonuria was mandated in virtually every state and had provoked little ethical objection.

In 1994 a research study discovered that the administration of zidovudine during pregnancy could reduce the rate of maternal–fetal HIV transmission by two-thirds (to about 8%) (Connor, Sperling, and Gelber). In the aftermath of that finding, pressure mounted to ensure that infected women were identified early in pregnancy. In 1996 the American Medical Association's House of Delegates passed a resolution calling for mandatory testing of pregnant women (Shelton). Even the Institute of Medicine, which early in the epidemic had opposed testing policies that abrogated the privacy rights of pregnant women, was by the end of the 1990s to endorse routine testing on the basis of an informed right of refusal, a much less exacting standard than specific informed consent (Institute of Medicine).

In other contexts as well, the retreat from the exacting standard of specific informed consent with pretest counseling has taken the form of efforts to integrate HIV testing into clinical practice where standards of presumed consent prevail.

REPORTING OF HIV. A course similar to that which occurred with testing characterized the debate surrounding case reporting for HIV infection. Given the profound stigma that surrounded AIDS in the epidemic's first years, and the extent to which individuals with or at risk for HIV feared the social consequences of having their diagnoses made public, it is not surprising that confidentiality of AIDS-related information assumed great salience. From the pragmatic perspective of the public health officials, it was crucial to preserve confidentiality as a way of assuring that those at risk would come forward for testing and counseling (Institute of Medicine). Others objected on grounds of principle. Privacy was a value that should not be lightly set aside.

But however central were the claims of privacy and the duty to protect confidentiality, they were not absolutes. One of the conventionally accepted limits to those claims occurred when individuals with infectious diseases were reported by name to confidential public health registries. It was thus not surprising that despite concerns about privacy, little opposition existed in the epidemic's first years to making AIDS cases reportable by name (Bayer, 1989). The acceptance of AIDS case reporting requirements was facilitated by the well-established record of state health departments in protecting such records from unwarranted disclosure.

With the inception of HIV testing, however, debate emerged about whether the names of all infected persons, regardless of whether they had received an AIDS diagnosis, should be reported. Activists who accepted AIDS case reporting opposed HIV reporting because of heightened concerns about privacy, confidentiality, and discrimination. For them the potential public health benefits of reporting were too limited and the burden on those who would be the subject of reporting too great to justify an abrogation of privacy.

While many public health officials, especially those who came from states with large AIDS caseloads, opposed HIV reporting because of its potential effect on the willingness of people to seek testing and counseling, some public health officials did become strong advocates of such reporting. In their arguments in favor of such reporting, they sought to underscore the extent to which the public health benefits of HIV reporting would be similar to those that followed from more broadly conceived reporting requirements, such as those that applied to syphilis, tuberculosis, and AIDS itself (Vernon).

As therapeutic advances began to emerge in the late 1980s, and as the logic of distinguishing between HIV and AIDS became increasingly difficult to sustain, fissures began to appear in the relatively broad and solid alliance against named HIV reporting. At the end of November 1990, the CDC declared its support for HIV reporting, which it asserted could "enhance the ability of local, state and national agencies to project the level of required resources" for care and prevention services (CDC, 1990, p. 861). The House of Delegates of the American Medical Association also endorsed the reporting of names (Bayer, 1999).

Central to the argument for HIV name reporting was the assertion that AIDS case reporting captured an epidemic that was as much as a decade old and that an accurate picture of the incidence and prevalence of HIV infection—especially in light of the impact of treatment—required a surveillance system based on HIV case reporting.

At the end of 1999, in the face of lingering opposition from most AIDS activists, the CDC finally proposed that all states put in place an HIV reporting system. And while it left open the possibility of reliance on unique identifiers that met strict performance criteria, it was clear that the use of names was viewed as preferable (CDC, 1999). Remarkably, of those states that adopted HIV case surveillance after the publication of the CDC's recommendations, virtually all adopted coded systems. By 2002 only one state—Georgia—had not adopted some form of HIV reporting.

PARTNER NOTIFICATION. In the controversy over partner notification the limits of privacy were also encountered. What emerged as a source of contention in the first decade of the epidemic was the extent to which the protection of identifiable third parties who had been or were currently placed at risk for HIV by already infected individuals provided a warrant for public health interventions. This was not a new issue; it had been confronted in the context of psychiatry in the so-called *Tarasoff* doctrine (from the mid-1970s court case, *Tarasoff v. Regents of the University of California*), which held that physicians who knew that their patients were about to inflict serious harm on other identifiable individuals had a duty to act to warn or protect. While opinions differed about the wisdom of such efforts, there was little principled objection to breaching confidentiality under such circumstances.

Thus in the mid- to late 1980s, when many AIDS activists argued that the principle of confidentiality had to be inviolable, and when public health officials were loath to endorse legislative mandates requiring third party notification, many ethicists suggested that protection of unsuspecting sexual partners took precedence over privacy. In 1988 the American Medical Association's House of Delegates embraced the duty to warn.

Some states sought to meet the challenge of endangered third parties by enacting statutes that secured a "privilege to disclose." Under such laws physicians could, if they chose, breach confidentiality to warn unsuspecting individuals but would not be held liable if they failed to do so.

The depth of antagonism to public health interventions in matters of sexual intimacy was further demonstrated by the deep suspicion of contact tracing programs, under which public health officials would notify those who had been placed at risk without divulging the identity of the individual who had imposed the risk. Such efforts were typically voluntary and relied on the willingness of index patients to provide the names of their contacts.

Despite the four decades of experience with contact tracing, efforts to undertake such public health interventions in the context of AIDS met with fierce resistance in the first years of the epidemic. Opposition by gay leaders and civil liberties groups had a profound impact on the response of public health officials, especially in states with relatively large numbers of AIDS cases, where contact tracing efforts remained all but moribund (Bayer, 1989). In part the opposition was fueled by the fact that throughout most of the 1980s, no therapy could be offered to asymptomatic infected individuals. Thus, the role of contact tracing in the context of HIV infection differed radically from its role in the context of other sexually transmitted diseases. In the latter case, effective treatments could be offered to notified partners. Once cured, such individuals would no longer pose a threat of transmission. In the case of HIV, nothing could be offered other than information about possible exposure.

Public health officials saw in such information an opportunity to target efforts to foster behavioral changes among individuals still engaging in high-risk behavior—behavior that could place both the individual contacted and future partners at risk; for such officials, this was reason enough to undertake the process. For opponents of contact tracing, the very effort to reach out to such individuals represented a profound intrusion on privacy with little or no compensating benefit. The task of behavioral change, they asserted, could be achieved more effectively and efficiently through community-based HIV prevention efforts (Bayer and Toomey).

Early misapprehensions about the extent to which public health officials typically relied on overt coercion in the process of contact tracing, and the degree to which confidentiality might be compromised, had by the end of the 1980s all but vanished. With such concerns allayed, many gay leaders had come to recognize that partner notification, in fact, could be a "useful tool" in efforts to control AIDS (Schram). The debate began to shift to one centered on relative efficacy (APHA). That dispute was informed by questions that had already surfaced about the usefulness of contact tracing in the control of syphilis in populations where individuals had large numbers of sexual partners, many of whom were anonymous (Andrus et al.).

In short, by the early 1990s the exceptionalism of the first years of the AIDS epidemic began to fade and a process of normalization had set in.

Public Health and Clinical Research

The HIV epidemic provided the circumstances for the emergence of a broad and potent political movement that sought to reshape radically the conditions under which research was undertaken. Brought into question were the role of the randomized clinical trial, the importance of placebo controls, the centrality of academic research institutions, the dominance of scientists over subjects, the sharp distinction between research and therapy, and the protectionist ethos of *The Belmont Report* (the landmark formulation of research ethics published in 1979 by the U.S. National

Commission for the Protection of Human Subjects of Biomedical and Behavioral Research). Although scholars concerned with the methodological demands of sound research and ethicists committed to the protection of research subjects played a crucial role in the ensuing discussions, both as defenders of the received wisdom and as critics, the debate was largely driven by the articulate demands of those most threatened by AIDS (Epstein). Most prominent were groups such as the People with AIDS Coalition and ACT UP, organizations made up primarily of white, gay men. They were joined by community-based physicians who identified closely with the plight of their patients.

What was so stunning—disconcertingly so to some, exciting to others—was the rhythm of challenge and response. Rather than the careful exchange of academic arguments, there was the mobilization of disruptive and effective political protest. Most remarkable was the core demand. As Carol Levine noted in 1988, "The shortage of proven therapeutic alternatives for AIDS and the belief that trials are, in and of themselves, beneficial have led to the claim that people have a right *to be* research subjects. This is the exact opposite of the tradition started with Nuremberg—that people have a right *not to be* research subjects" (Levine, p. 172). That striking reversal resulted in a rejection of the model of research conducted at remote academic centers, with restrictive (protective) standards of access and strict adherence to the "gold standard" of the randomized clinical trial.

Having blurred the distinction between research and treatment—expressed forcefully through the slogan "A Drug Trial Is Health Care Too"—those insistent on radical reform sought to open wide the points of entry to new "therapeutic" agents both within and outside of clinical trials; they demanded that the paternalistic ethical warrant for the protection of the vulnerable from research be replaced by an ethical regime informed by respect for the autonomous choice of potential subjects who could weigh, for themselves, the potential risks and benefits of new treatments for HIV infection. Moreover, the revisionists demanded a basic reconceptualization of the relationship between researchers and subjects. In place of protocols imposed from above, they proposed a more egalitarian and democratic model in which negotiation would replace a scientific authority. Indeed, research "subjects" were now thought of as "participants." Furthermore, the role of the carefully controlled clinical trial as providing protection against the wide-scale use of drugs whose safety and efficacy had not been proven no longer commanded unquestioned respect (Bayer, 1990).

The new perspective did not go without challenge, of course. Some were concerned that the proposed regime would make all but impossible the conduct of research so crucial to the needs of those with HIV/AIDS ("Parallel Track," 1989), while others feared that desperate individuals would, in the absence of the now discredited (paternalistic) ethos, be subject to deception (Annas).

The AIDS-inspired challenge to the ethics of research was not restricted to issues within the United States. Just as the protective regime surrounding research in the United States was a product of a history of abuse, efforts to enunciate ethical standards for the conduct of research in Third World nations was shaped by a history of exploitation, a history characterized by investigations on the poor designed to serve the interests of the privileged. Central to those efforts was the belief that the ethical principles first encountered in industrialized nations had direct bearing on the norms that should govern research in very different settings (IJsselmuiden and Faden). Such universalism took as a given the need to assume that insights regarding cultural differences not serve as the basis for moral relativism.

Just as individual informed consent was the first principle of the ethics of research in advanced industrial nations, it was at the heart of the codes designed to guide research in the poorest nations. To preclude exploitation, international consensus also existed on the extent to which it was critical that research be responsive to the health needs and priorities of the community in which it is to be carried out (CIOMS). What would remain a matter of uncertainty, however, was whether the needs of the poorest and the requirement of responsiveness could justify research that would be unacceptable in the richest nations—whether the principle of universalism could accommodate research in Burundi that would be prohibited in Brooklyn.

That was the issue that would animate a furious international debate occasioned by the 1994 finding that AZT administered to infected women in the second and third trimesters and to their infants for six weeks could reduce by two-thirds the rate of mother-to-child HIV transmission (Connor, Sperling, and Gelber). Although superficially a conflict over a technical matter involving research design—the role of placebos—the dispute touched on the deepest questions of what ethical conduct meant in a world characterized by great inequalities and profound inequities.

Given the burden of pediatric AIDS in Africa and Asia, it was a matter of some urgency that trials begin to determine whether radically cheaper alternatives to the standard regimen could achieve at least some measure of reduced maternal–fetal HIV transmission. In June 1994 a special consultation of the World Health Organization (WHO) considered the challenge and called for the launching of studies to achieve that goal. The consultation made clear its conclusion that placebo-controlled trials—trials in which a comparison is made between an inert substance and the potentially active agent—"offer the best option for obtaining rapid and scientifically valid results."

There was no question that a placebo-controlled trial would have been considered unethical in the United States or any other advanced industrial nation. No trial that denied access to the effective standard, or to an intervention thought to hold the promise of being at least as effective as, if not more effective than, the prevailing standard of care, would have satisfied the requirements of ethical review. The question posed by the furious controversy that unfolded was whether it was ethical to conduct such a trial in a poor country. In 1997 the *New England Journal of Medicine* gave its answer unambiguously: "Only when there is no known effective treatment is it ethical to compare a potential new treatment with a placebo. When effective treatment exists, a placebo may not be used. Instead, subjects in the control group of the study must receive the best known treatment" (Angell, p. 847).

Given this premise, the *Journal* rejected as irrelevant the fact that healthcare available in most Third World countries provided nothing like healthcare available in industrialized countries. Citing for authority the Declaration of Helsinki—the international code of research ethics adapted by the World Medical Association in 1964—the editorial noted that control groups had to be provided with the best current therapy, not simply that which was available locally. "The shift in wording between 'best' and 'local' may be slight, but the implications are profound. Acceptance of this ethical relativism could result in widespread exploitation of vulnerable Third World populations for research programs that could not be carried out in the sponsor country" (Angell, p. 848).

Those who rejected the *Journal*'s viewpoint made clear that placebo-controlled trials were dictated by the urgency of the situation. Only placebo-controlled trials could provide "definitive," "clear," "firm" answers about which interventions worked, thus allowing governments to make "A sound judgment about the appropriateness and financial feasibility of providing the intervention" (Varmus and Satcher, p. 1004). The failure to employ a placebo would have made it difficult to clearly determine whether the affordable but less effective intervention was better than no intervention at all. In short, they concluded that placebos were crucial to policymakers required to make relatively costly decisions under conditions marked by profound poverty and scarce public health resources (Varmus and Satcher).

Paralleling the debates over maternal–fetal transmission of HIV were those that surfaced over the ethics of AIDS vaccine trials. In this case the focus was on those research participants who might become infected with HIV during a trial. On the one hand there were those who argued that such individuals be provided with optimal care—the retroviral therapy available in the developed countries. On the other hand there were those who asserted that care should reflect that which was consistent with what was available in the host nation (Bayer, 2000). So divisive was this controversy that the Joint United Nations Programme on HIV/AIDS (UNAIDS) could not come to an agreement on the appropriate ethical norm and indeed had to settle for a procedural rather than substantive solution, a solution that focused on how to reach acceptable agreement rather than one that put forth a standard to guide such deliberations (UNAIDS).

Thus were the issues joined. These controversies ultimately provoked an international effort to consider ethical standards of research in the Third World. The World Medical Association undertook a series of consultations on the revision of the Declaration of Helsinki; the Council for International Organizations of Medical Sciences (CIOMS) did so as well. Finally, within the United States, which funded much of the international research that had been subject to scrutiny, the National Bioethics Advisory Commission took up the issue of studies in poor nations.

Whereas those who saw in any effort to craft "flexible" standards that reflected the uniquely pressing context of international poverty and inequality the treacherous embrace of moral relativism, their opponents persisted in arguing that a failure to consider the context of investigation was a failure of moral understanding. Principles could be universal; their application could not be rigid. (Singer and Benatar; Benatar and Singer).

Securing Access to Care

In the first years of the epidemic there was little that medicine could offer those with HIV. Indeed, that was the context within which AIDS activists struggled to increase access to experimental trials. As the prospects for clinical intervention improved, first with the use of prophylactic treatment to prevent Pneumocystis carinii pneumonia and other opportunistic infections and then with AZT, the first widely prescribed antiretroviral agent, it was inevitable that the inequities of the U.S. healthcare system would be encountered.

Some who needed treatment had private insurance—although they frequently faced efforts on the part of their insurers to deny them coverage for their HIV-related conditions; those who were poor or who became impoverished because of their disease could qualify for Medicaid; but many remained unprotected (Green and Arno). To meet the needs of the latter group, special programs were developed. The federal government, through the Ryan White Comprehensive AIDS Resources Emergency Act of 1990, directed significant sums to localities to provide medical services. Among the initiatives under the act was the AIDS Drug Assistance Program (ADAP), designed to pay for AIDS-related medicines. Like the End Stage Renal Disease Program that assured access to dialysis and transplantation regardless of the ability to pay, these AIDS programs left untouched the basic patterns of medical inequality.

When the protease inhibitors emerged in the mid-1990s and combination antiretroviral therapy became the standard of care, the system was strained to the limits. Medication costs alone for those receiving care could range from $10,000 to $15,000 per year (Deeks et al.). A 1996 review of dramatically improved therapeutic prospects added the caveat that the new achievements were important "at least for those socioeconomically privileged" (Richman, p. 1887). ADAP experienced persistent shortfalls in funding. When that was the case, it was necessary to resort to a host of rationing strategies (Henry J. Kaiser Family Foundation). At one point, nearly half of the ADAP programs limited access to protease inhibitors (Carton).

The remarkable advances in therapeutics have provided a critical element in the argument that the exceptionalism of the epidemic's early years is no longer appropriate. It is therefore a remarkable paradox that the very same achievements have set the stage for challenging the exceptionalist programs that seek to ensure—however inadequately—access to those same treatments. These expressions of disquiet must be understood, at least in part, as a reflection of concern that the American AIDS epidemic may no longer be seen as immediately threatening, that the unique services for those with HIV would be vulnerable unless they were embedded in a broader system of a just healthcare system.

On an international plane the prospect of effective antiretroviral treatment would pose challenges vaster by many orders of magnitude. What justification was there for a system of pricing that made the cost of drugs beyond the reach of the desperate? Could markets ever respond to need where effective demand was nil? Could the monopoly confirmed by patent rights be compatible with a response dictated by claims of the dying? Was the treaty on intellectual property rights, incorporated into the World Trade Organization's international regime, a barrier to survival in context of the AIDS epidemic? What moral obligation did the wealthiest nations have to the poorest to provide the resources necessary to purchase the new lifesaving agents and build the medical infrastructure necessary for their appropriate administration? Was there any reason to believe that a global community that permitted millions to die each year from treatable and preventable diseases such as tuberculosis and malaria would respond differently in the face of AIDS?

AIDS activists ultimately seized on this issue and began an international campaign to confront the pharmaceutical industry. What might have seemed an utterly quixotic undertaking would ultimately, however, take on worldwide dimensions linking protesters in the United States, France, and South Africa (Berkman), institutional proponents of global health such as the World Health Organization, and a sympathetic public. By the end of the 1990s the pharmaceutical industry was placed on the defensive, perceived as protecting narrow self-interest when the lives of millions were at stake. Against the claims that high prices were necessary to fuel the engine of research, and that patent protections were crucial to spurring investments in drug investigations, those who sought to turn the terms of discourse asserted that urgency demanded that the barriers to drug access tumble.

Ultimately, under pressure from generic drug manufacturers, prices began to fall, and pharmaceutical firms began to accept the notion of differential or equity pricing.

As prices began to fall, it became ever more apparent that even if drugs were to be provided at cost, even if the principle of equity pricing were to guide sales, even if nations pursued the option of compulsory licensing and parallel imports, the cost of providing antiretroviral therapy was simply beyond the reach of the poorest and most HIV-burdened nations. And even if drugs could be paid for, the necessity of a medical infrastructure that could offer and monitor the use of drugs in a way that was attentive to the needs of individual patients and the risks to public health from drug resistance would require huge investments. This was the context within which a remarkable movement would take shape to create a massive funding effort to respond to the threat of AIDS.

The moral urgency of AIDS treatment was amplified by United Nations Secretary General Kofi Annan, who called for a global trust fund that would spend $7 to $10 billion a year over an extended period to face the threat to the world's poorest people. Most striking was his assertion that the care that had for so long eluded men, women, and children in the less-developed nations was a matter of moral right. Everyone who was infected should have access to medicine and medical care. That was a moral imperative. What was the unfortunate had become the unfair; inequality had become inequity (Bayer, 2002).

Conclusion

This discussion began with an analysis of ethical and policy issues that emerged in the United States as it confronted the AIDS epidemic. These issues were commonly addressed in other economically advanced nations bounded by the liberal tradition, even when the resolution of the controversies that surfaced took on divergent forms.

No ethical analysis of the challenges posed by AIDS will ever again be sufficient if it is restricted to the challenges faced in wealthy developed nations. Indeed, increasingly the analysis will need to be driven by the complexities of an epidemic in the world's poorest nations. Older concerns rooted in a focus on the need to protect the privacy rights of individuals will inevitably be overshadowed by new concerns about global equity.

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REVISED BY AUTHOR

SEE ALSO: *Confidentiality; Epidemics; Healthcare Resources, Allocation of; Homosexuality; Human Dignity; Human Rights; Life, Quality of; Public Health; Sexual Identity;* and other *AIDS* subentries

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II. HEALTHCARE AND RESEARCH ISSUES

The early ethical debates regarding the AIDS epidemic were largely driven by the concerns of the politically active, primarily white, homosexual or bisexual men in the United States in whom the disease was first identified. Because of severe discrimination against HIV/AIDS patients, early activists argued for special confidentiality protections for HIV information. Because infection at that time was almost always fatal, patients also demanded access to experimental treatments, which offered the only chance of survival. Over the 1980s and 1990s, however, the epidemic changed, as did many of the ethical issues.

The global impact of HIV/AIDS in the twenty-first century dominates ethical and policy debates. In late 2001 an estimated 40 million people worldwide were HIV infected, with approximately 5 million new infections and 3 million deaths that year. More than 95 percent of new infections are in developing countries. AIDS is the leading cause of death in sub-Saharan Africa and the fourth leading cause of death worldwide. Although Africa has been particularly hard hit by the AIDS epidemic, with about 70 percent of HIV-infected persons and new infections, the looming epidemic in other developing areas, particularly China and India, may surpass it. Failure of governments to acknowledge the threat of HIV may be exacerbating the epidemic.

In the United States, HIV/AIDS remains a serious public health problem. Spread primarily through sexual transmission and injection drug use, the epidemic in the United States increasingly affects poor people of color. In 2001 an estimated 800,000 to 900,000 people in the United States were HIV-infected, with over 300,000 diagnosed with AIDS. But as a result of the introduction of highly active antiretroviral therapy, as well as prevention and education efforts, the number of AIDS deaths in the United States has fallen dramatically.

This entry discusses ethical issues regarding HIV testing, confidentiality of HIV information, HIV infection in women and children, end-of-life issues for HIV-infected patients, and access to healthcare for HIV disease. This entry also discusses clinical research issues, with particular attention to international HIV research and HIV vaccine research.

Healthcare Issues

Fear and social stigma may be barriers to seeking HIV testing or care. In the United States, special procedures, protections, and programs have been developed to encourage testing and to provide care.

TRANSMISSION AND PREVENTION. HIV is transmitted by direct contact with bodily fluids that contain the virus. The major modes of transmission are sexual contact and injection drug use (through sharing needles and drug paraphernalia). HIV can also be transmitted from mother to infant during pregnancy or through breast-feeding. Prevention measures, such as safer sex education, condoms, needle exchange, and methadone maintenance, have proven effective at preventing HIV transmission.

Nevertheless, these prevention efforts often meet with strong resistance. Some object that providing condoms and discussing safer sex techniques inappropriately encourage sexual behaviors outside of heterosexual marriage. Similarly, some object that providing clean needles fosters illegal and harmful injection drug use. From a population perspective, however, such preventive measures reduce the incidence of a serious, often fatal illness. Empirical studies do not demonstrate an increase in high-risk behaviors after these preventive interventions.

HIV TESTING. Because of the sensitivity surrounding HIV, testing for the disease is treated differently from most other medical tests.

Special procedures for HIV testing. Because the physical risks are minimal, in the United States, blood tests typically do not require extensive informed-consent discussions, and consent often is implied rather than explicit. Early in the AIDS epidemic, however, HIV testing was recognized as different from other blood tests because it presented serious psychosocial risks, such as familial rejection, employment discrimination, and/or loss of healthcare, insurance, and housing. Moreover, because there was no proven treatment at that time, the benefits of early diagnosis to individual patients were uncertain. In recognition of these circumstances and to encourage voluntary testing, special procedures were adopted for obtaining consent for an HIV test, such as pretest counseling and specific informed consent. Special protections for confidentiality of HIV test results also were enacted. For the most part, these special requirements remain in effect. Numerous states require pretest counseling, and the majority of states require specific (often written) informed consent to HIV testing.

Availability of anonymous testing. Because of the serious stigma and potential psychosocial risks associated with HIV testing and to further encourage voluntary testing, most states offer anonymous HIV testing. At special, anonymous test sites, individuals are not required to provide their names or other identifying information. Upon testing, they are given a unique code to use to obtain results. People identified as HIV-infected at these sites are not reported to public health officials.

Exceptions to informed consent. States may permit HIV testing without informed consent under limited circumstances. For example, many states permit testing of patients without their permission after emergency response workers or healthcare workers are exposed to their blood or other fluids. Nevertheless, the patient's permission must be requested even though it is not required. In addition, some states permit the testing of prisoners and persons accused of sex crimes without their consent. Two states also require HIV testing of newborns, which indirectly reveals maternal HIV status.

Conventional versus rapid testing. Conventional HIV test results typically are not available for one to two weeks because initial positive tests must be confirmed with more sophisticated and accurate tests. In the United States, such testing is required to avoid mistakenly informing someone that they are HIV-infected based on a falsely positive test. However, this approach can be problematic when there is time urgency, such as when women first seek medical care when in labor and without a previous HIV test, or when people are unlikely to return for results, such as in clinics for sexually transmitted diseases. Effective interventions cannot be implemented without timely test results.

Rapid HIV tests are available that provide test results within hours of testing. Rapid testing is commonly used in developing countries. Because of the high prevalence of HIV in this setting, the risk of false positive results is lower than in the United States. In addition, several different rapid tests can be used to improve accuracy. In this setting, the benefits of identifying an infected individual using a rapid test are considered to outweigh the risks of false positive results.

CONFIDENTIALITY. Although medical information generally is considered confidential, there are additional requirements that apply to HIV-related information.

Protections. In the United States, physicians and healthcare organizations have ethical and legal obligations to preserve the confidentiality of all medical information. Because of the sensitivity of HIV-related information, many states in the United States have adopted laws that provide additional protection to HIV-related medical information. For example, many states require specific authorization from patients to disclose HIV-related information to third parties. Such protections are particularly important where stigma associated with HIV infection is high. Although the U.S. Supreme Court determined that HIV infection can be a disability under the Americans with Disabilities Act of 1990 (*Bragdon v. Abbott,* 1998), HIV-infected individuals still experience negative effects, such as ineligibility for certain governmental jobs (e.g., Peace Corps, foreign service, Job Corps, and the military) and limitations on international travel.

Exceptions. There are a number of exceptions to the legal and ethical rules of HIV-related confidentiality. First, healthcare providers in the United States have a duty to report AIDS cases and, in most states, HIV infections to public health authorities. The public health benefits of this reporting justify overriding the duty to maintain confidentiality. Reporting of AIDS cases includes the patient's name and other identifying information. Although reporting of HIV infections initially was not done by name, there has been a recent and controversial movement in the United States toward confidential name-based reporting of HIV infection. Supporters of name-based reporting argue that because antiretroviral therapies successfully delay progression to AIDS, the reporting of names is needed for more accurate epidemiological information. This information can be used for better planning and funding of HIV-related programs. Other proponents support name-based reporting because it would facilitate partner notification. Opponents of name-based reporting argue that it will deter testing and increase the risk of discrimination. Opponents contend that reporting of HIV infection can be effectively accomplished using codes, rather than names. Because of the potential psychosocial consequences associated with HIV infection, anonymous testing continues to be offered in states that require name-based reporting.

Second, healthcare providers may be permitted to inform an infected patient's sexual or drug-sharing partner of the patient's HIV infection. In some states, such as California, a healthcare provider must first inform the patient of the intended disclosure. Such a breach of confidentiality is justified on the grounds that it is the only means of preventing serious harm to an identifiable person and that the breach of confidentiality is minimized. Public health officials may also carry out partner notification. Although notification is typically conducted confidentially, it may inadvertently reveal the identity of the source patient.

Third, U.S. policy recommends that an expert panel review the cases of any HIV-infected healthcare workers who perform invasive procedures that might lead to transmission of HIV/AIDS. The panelists have to decide if an HIV-infected healthcare worker should be permitted to continue to perform such procedures, or if doing so would constitute too great a risk to the patients to be permitted. Additionally, the panel should decide if it is necessary to inform the healthcare worker's patients of any risk of infection, so that the patients can make an informed decision about whether they wish to continue in the healthcare worker's care. There is wide variation in state law and not all states require disclosure of HIV infection.

HIV INFECTION IN WOMEN AND CHILDREN. Worldwide, mother-to-child transmission is a major public health crisis. In parts of Africa, 45 percent of pregnant women are HIV-infected. Their children contract HIV in 25 to 45 percent of cases, resulting in some 540,000 perinatal cases annually. In the United States, the introduction of antiretroviral therapy has significantly reduced mother-to-child HIV transmission in the United States; by the early 2000s there were fewer than 300 perinatal HIV cases annually.

United States. To take advantage of the proven effectiveness of antiretroviral therapy for preventing perinatal HIV transmission, women must know that they are HIV-infected. U.S. policy strongly encourages HIV testing of all pregnant women, but at the same time U.S. policy embraces the state-based requirements for specific informed consent. Because many women are not offered and do not receive HIV testing during pregnancy, several consensus guidelines from professional societies have recommended that HIV testing should be made a routine part of prenatal care for all pregnant women. Notification that an HIV test will be performed, along with other prenatal blood tests, would be required, but specific consent to the HIV test would not. This proposal raises several concerns. First, women may not have enough information to know that they may refuse testing. Second, routine HIV testing in the prenatal context may undermine pretest counseling and informed consent for HIV testing in other clinical contexts. Third, because it forgoes certain opportunities for education and counseling, routine testing may undermine prevention efforts. Despite these concerns, the clear benefits of prenatal antiretroviral therapy in reducing the risk of mother-to-child HIV transmission may justify routine universal prenatal HIV testing.

Developing world. In developing countries, to date, the high cost of antiretroviral therapy to reduce the risk of mother-to-child HIV transmission has prevented the vast majority of women from receiving it. Even if antiretroviral therapy were to become affordable, the full protocol followed in the United States, which includes administration of antiretrovirals to the woman during the third trimester of pregnancy and during labor and delivery and administration to the infant after birth, may not be achievable because many women in the developing world do not receive prenatal care or deliver their babies in the hospital. Nevertheless, a single dose of nevirapine to the woman during labor and the infant after delivery has proven effective at significantly reducing mother–child HIV transmission. This simpler preventative regimen is more feasible, and some governments have committed to providing it.

Transmission from mother to child may also occur after birth through breast-feeding. A randomized clinical trial has shown that bottle-feeding instead of breast-feeding reduces the risk of transmission. Nevertheless, bottle-feeding is not a feasible option in many countries because of lack of access to clean water and cost. Moreover, some women may resist bottle-feeding, even if it were safe, because, unlike in the United States, breast-feeding is the norm in many developing countries and may play an important symbolic role in conveying social status to mothers. In such cultures, failure to breast-feed may indirectly reveal HIV status, which could subject women to risk of physical harm or loss of housing and support, particularly when there is a history of domestic violence. Women need to know about the steps they can take to reduce the risk of HIV transmission to their infants so that they can assess the risks and benefits in light of their own circumstances and make informed decisions.

END-OF-LIFE ISSUES. Early in the U.S. epidemic, before antiretroviral therapy was available, HIV infection often quickly progressed to a terminal illness. In many cases, AIDS patients were unable to make medical decisions for their care as a result of complications from their disease. There was uncertainty, however, as to who should serve as a patient's surrogate decision-maker. In the absence of a written advance directive from the patient, the law and physicians typically look to family members for surrogate decision-makers. But many homosexual men with AIDS were estranged from their family. These patients often would have preferred to give decision-making authority to committed partners or friends with whom the patient had discussed his wishes. Because the availability of highly active antiretroviral therapy has prolonged survival, end-of-life care in HIV infection has become a less prominent issue in the United States.

In the developing world, where antiretroviral therapy is generally not available, palliative care, which focuses on relief of suffering, is often the only tenable goal. Severe resource constraints may make it difficult to provide palliative measures such as opioids for pain control or dyspnea (difficult breathing). Under these circumstances, care may be limited to psychosocial support and helping patients make plans for such practical issues such as burial or child custody and support.

ACCESS TO HEALTHCARE FOR HIV DISEASE. Access to healthcare for HIV disease remains an important issue both domestically and internationally.

United States. In the United States, the average annual cost of care for an HIV-infected individual is between $10,000 and $15,000 annually. For those in the "advanced stages" of AIDS, the average annual cost of care is $34,000. In delving further into access to healthcare in the United States, it is necessary to discuss two areas: private coverage of HIV infection and coverage of HIV infection by public programs.

HIV-infected individuals may face several difficulties with private healthcare insurance. Most individuals in the United States with healthcare coverage receive it through their employers. Employers and insurers may seek to control the soaring cost of health insurance by limiting coverage for HIV infection. A 1990 federal appeals court case affirmed employers' "freedom to amend or eliminate employee benefits" in health insurance and allowed self-insured employers to reduce or eliminate benefits for any particular illness, even if all other medical conditions are covered (*McGann v. H & H Music Company,* 1991). A 2000 federal appeals court decision concluded that such limits do not violate the Americans with Disabilities Act (*Doe v. Mutual of Omaha Insurance Co.,* 2000). Those who do not receive healthcare coverage through their employers may find it impossible to obtain private coverage for their HIV infection because, if coverage for individual applicants with HIV infection is available at all, it is very expensive or provides limited coverage.

As their disease progresses, previously employed persons cease working and lose their employment-based health insurance. About half of HIV-infected adults and 90 percent of HIV-infected children receiving medical care are covered through publicly funded sources. There are several ways to receive such coverage. First, patients may be insured through Medicaid. To be eligible for Medicaid, patients must either have AIDS or HIV-related disability *and* meet (low) income eligibility requirements. Second, state AIDS drug assistance programs (ADAP), which are funded through the federal Ryan White Comprehensive AIDS Resources Emergency

(CARE) Act of 1990, make HIV medications available to low-income and uninsured persons. Because each state receives different funding and determines eligibility and benefits packages, Medicaid coverage and access to medications vary widely from state to state. In addition, because, unlike Medicaid, the drug assistance programs are not entitlement programs (i.e., programs in which all those who meet the eligibility criteria are entitled to receive the benefits), they are funded through annual appropriations, which may vary year to year. Finally, the CARE Act provides funding for HIV/AIDS services that are not covered by Medicaid or state or local government funds. Although the majority of the CARE Act funds are used for medical care (including the ADAP programs), they also provide funding for HIV/AIDS-related support services. These services include counseling, emergency housing assistance, training for clinicians who treat HIV-infected patients, and developing programs to improve treatment. States and other local governments receive CARE Act funds based, in part, on the prevalence of HIV/AIDS in their populations. Because of shifts in the epidemic and the effectiveness of antiretroviral therapies in delaying progression to AIDS, using AIDS cases to allocate funds may not accurately reflect the burden of HIV disease in the population. Reporting of HIV infection can provide essential information to ensure that funds are appropriately distributed to meet the needs of HIV-infected patients.

The shift to Medicaid and other public funding causes several problems. Because of low reimbursement levels, many physicians do not accept Medicaid patients. Thus, patients who lose private insurance may also lose access to care. As a result, emergency departments and public hospitals bear a greater burden of care. In addition, because of large budget deficits, many states and counties are finding it increasingly difficult to pay for such care.

Specific funding that provides for HIV care, but not for other fatal illnesses whose treatments are expensive, such as cancer, raises issues about equitable allocation of resources. AIDS activists exerted considerable political pressure to obtain this funding and to continue the programs supported by it. There are public policy reasons for providing special funding for HIV care. First, HIV is an infectious disease. Providing care and access to antiretroviral medications slows the progress of disease, which may decrease transmissibility and, therefore, help control the spread of the epidemic. In addition, because AIDS patients are categorically eligible for Medicaid and the overall cost of antiretroviral therapy is less than caring for a patient with AIDS, it may be more cost effective for the government to provide antiretroviral therapy to delay progression to AIDS.

Developing world. There have been many efforts to make HIV medications more available to the developing world by pressuring pharmaceutical manufacturers to reduce prices, permitting production of generic versions of effective therapies, and providing funds for drug purchases. Even though the annual cost of antiretroviral therapy has been reduced to between $500 and $1,350 for the developing world, this cost is beyond the means of many developing nations. In 2001 the United Nations secretary general, Kofi Annan, proposed a $7 billion to $10 billion fund to combat AIDS globally, although, as of 2003, funding has fallen well short of this goal. The obligation of developed nations to address the AIDS epidemic in the developing world can be justified on several grounds. First, compassion may motivate developed nations to help alleviate the suffering caused by the AIDS epidemic. Second, to the extent that good health and healthcare are basic human rights, nations who are able are obligated to contribute resources to guarantee these rights. Third, because the wealth (and health) disparities between the developed and developing world are largely a legacy of colonialism, the developed nations have an obligation to address those problems to which they contributed. Finally, it is in the self-interest of developed nations to assist the developing world. If the AIDS epidemic is not controlled in the developing world, the resulting economic and political instability will threaten the security of all nations.

Even if antiretroviral therapy can be made affordable, there are challenges in providing treatment in developing countries that have little healthcare infrastructure. Because failure to adhere to the treatment regimen may lead to drug resistance, it is important to develop treatment protocols that can be implemented effectively using existing infrastructure. Once-a-day regimens are being developed that could facilitate implementation of antiretroviral treatments in the developing world. Also being studied are programs for providing care when intensive laboratory monitoring is not available. To successfully maintain HIV treatment programs in the developing world, host-country personnel must be trained to provide and monitor the treatments.

Clinical Research Issues

Activists and the scope of the HIV epidemic forced society and scientists to reconsider fundamental questions about clinical trials of promising new therapies (Lo, 2000b).

WHAT IS THE GOAL OF THE CLINICAL TRIAL? To most scientists and to the U.S. Food and Drug Administration (FDA), the goal of clinical trials is to determine the safety and effectiveness of new drugs. Historically, clinical research has been considered dangerous for subjects. The HIV epidemic, however, caused many patients to consider clinical trials beneficial rather than risky, because they offer access to promising new treatments, closer medical follow-up, and more sophisticated laboratory monitoring than does standard care.

WHO SHOULD PARTICIPATE IN CLINICAL TRIALS? Historically, women, children, and people of color have been underrepresented in clinical trials. Usually, children are restricted from clinical trials to protect them from the risks of unproven therapies. Unlike adults, children cannot give informed consent. The rationale for excluding women of childbearing age, particularly women who are pregnant, is to protect their developing and future children from possible long-term side effects of unproven drugs. But restricting women and children from clinical trials also harms them. Unless they participate in clinical trials, the effectiveness and safety of therapies cannot be rigorously established. For example, the trials of the effect of zidovudine (also known as azidothymidine, or AZT) on mother-to-child transmission provided important information that has dramatically reduced perinatal HIV transmission. Without the participation of pregnant women in clinical trials, the effectiveness of antiretroviral therapy in preventing mother-to-child transmission of HIV would not be proven. What is more, there would be no evidence basis for enhanced public health measures and increased funding to prevent mother-to-child transmission. Similarly, the increased inclusion of minorities in trials has provided information on the efficacy and adverse effects in these populations. In addition, it is problematic to take away women's decision-making about research participation simply because they are pregnant.

INTERNATIONAL RESEARCH. Because of the great disparities of wealth between the developed and the developing world and a history of exploitation, research conducted in the developing world has been controversial. There are concerns that research that will never benefit the host country is being conducted in developing countries solely because costs are lower and the local ethical requirements are not as onerous as those in the sponsoring nation. Moreover, there are concerns that people will participate in research, regardless of the level of risk, because research participation represents the only opportunity to receive medical care. Nevertheless, unlike research associated with many other conditions, HIV-related research in developing countries typically does not involve privately sponsored trials of new drugs that are unlikely to become available to the host country. Rather, such research generally is publicly funded and designed to assess efficacy of affordable treatment regimens or behavioral interventions. Government involvement and sponsorship may result in research addressing health policy issues that are more salient to the host countries.

Controversy over perinatal trials. Placebo-controlled trials testing interventions to reduce perinatal HIV transmission conducted by U.S. researchers in Africa and Asia sparked extensive debate over research in developing countries. Relying on the World Medical Association's (WMA) Declaration of Helsinki (first adopted in 1964), which stated that "[i]n any medical study, every patient—including those of a control group, if any—should be assured the best proven diagnostic and therapeutic methods" (World Medical Association, 2000), some argued that the placebo-controlled trials were unethical because zidovudine was a proven effective treatment, even though it generally was not available in the countries in which the trials were taking place because of cost, poor health infrastructure, and lack of prenatal care. Others argued that such placebo-controlled trials can be ethically justified because they provide information that responds to local needs. A developing country needs to know whether a simpler, cheaper therapeutic regimen is superior to what is currently available in the country (generally no therapy) rather than whether a simpler, cheaper treatment is comparable to the best proven treatment, which the country cannot afford.

Appropriate comparison group. The controversy over the perinatal HIV transmission trials influenced the larger debate regarding international research, particularly as the WMA revised the Declaration of Helsinki in 2000. After considerable debate about the role of placebo-controlled trials, the final version reads: "[t]he benefits, risks, burdens and effectiveness of a new method should be tested against those of the best current prophylactic, diagnostic, and therapeutic methods. This does not exclude the use of placebo, or no treatment, in studies where no proven prophylactic, diagnostic or therapeutic methods exists" (World Medical Association, 2000). There is a growing recognition, however, that it may be ethically permissible to compare an inexpensive, simple regimen to a current practice of no therapy in developing countries when the regimen used in developed countries is not feasible. For example, the WMA issued a clarification after the 2000 revision of the Declaration of Helsinki that "a placebo-controlled trial may be ethically acceptable, even if proven therapy is available … where for compelling and scientifically sound methodological reasons its use is necessary to determine the efficacy or safety of a prophylactic, diagnostic or therapeutic method" (World Medical Association, 2001).

In its 2001 report, *Ethical and Policy Issues in International Research,* the U.S. National Bioethics Advisory Commission (NBAC) concluded that members of any control group should be provided with an established effective treatment, whether or not such treatment is available in the host country. NBAC also declared, however, that a placebo-controlled design may be permissible based on the health needs of the host country, but that such a design requires strong justification.

Post-trial access to treatment. There is general agreement that research in a developing country should not go forward unless there is a realistic chance that its inhabitants will gain access to the treatment after the trial. For example, HIV vaccine trials would be permissible in a developing country only if the vaccine candidate, if successful, would be made available within the host country. There is, however, disagreement regarding how far researchers' obligations extend toward assuring access and to whom the obligation is owed (i.e., trial participants only or others within the community or nation). NBAC points out that researchers are not in control of government policy and funding for clinical care. It therefore would be unfair to hold them responsible for ensuring post-trial access to therapies. NBAC suggests instead that researchers should be obligated only to make good faith efforts to make therapies available after completing a trial. Moreover, the successful results in a well-designed clinical trial may cause resources to become available to provide a new therapy, even though such resources were not available before the trial commenced.

Informed consent. U.S. federal regulations, the Declaration of Helsinki, and other international ethics guidelines all require individual consent for research participation. However, U.S. requirements regarding informed consent may present challenges for research in developing countries. Informed consent is often not the norm for clinical care in many developing nations. People may therefore be uncomfortable or even scared by being asked to provide consent. In addition, most people assume that the doctor is giving them something that is known to work. It may be difficult to overcome this presumption and to get them to appreciate the risks involved in participating in the research. In addition, women may be used to deferring decisions to husbands, fathers, or other family members. In some communities, it may not be possible to approach individuals without the community leader's permission. In such cases, although assent from the authority figure may be needed to approach people regarding the research, voluntary consent must be obtained from individual participants. Finally, in some communities, documentation of consent may be difficult because of illiteracy or because people fear that a signed document may be used against them. In such cases, it may be necessary to seek approval of the institutional review board to modify the documentation of consent to accommodate these local conditions.

Vulnerable participants. Vulnerability is particularly important in the context of HIV-related research. Those infected with HIV may be medically vulnerable from their infection. In addition, homosexuals, injection drug users, minorities, and women, who, for various reasons, may be at higher risk of HIV infection, are more likely to be socially and economically vulnerable because of historical attitudes and discrimination. This may be particularly true in the international setting, and the degree of vulnerability for these groups may vary from country to country. Accordingly, investigators conducting HIV-related research, especially internationally, must pay particular attention to vulnerability and take steps to protect potentially vulnerable research participants.

SPECIAL ISSUES IN HIV VACCINE RESEARCH. HIV vaccine trials present special ethical concerns. First, HIV vaccine trials must go forward with less preclinical evidence of efficacy than other interventions. This is because a good animal model does not exist, HIV is highly variable and undergoes rapid mutation, and there is little information about how to build protection against HIV. Nevertheless, because of the enormous suffering caused by HIV, such trials are ethically appropriate if there are credible scientific reasons to believe the candidate vaccine may be effective.

Second, vaccine trial participants may mistakenly believe that they will receive protection from the vaccine and, therefore, may increase risky behaviors. This issue is a particular concern because, unlike most vaccines, HIV vaccines are unlikely to confer full immunity. While researchers need outcomes (i.e., seroconversions—positive HIV tests in persons who previously tested negative for HIV) to evaluate the efficacy of the vaccine candidate, they also have an obligation to protect research participants. Accordingly, researchers must provide high-quality risk-reduction counseling and emphasize the uncertainty about the effectiveness of the candidate vaccine to all participants, even though, if such counseling were totally effective, the clinical trial would be undermined. To avoid this potential conflict, it may be necessary to have separate staff for the counseling and research aspects of the trial.

Finally, HIV vaccine trials pose unique risks to participants. Participants may be prevented from participating in future vaccine trials, and subsequently developed vaccines may be less effective for them. In addition, because participants may react positively to certain HIV antibody tests, they may be excluded from certain professions and activities, even if their seroconversion does not represent a true infection. Subjects may also face stigmatization from family or friends to whom they disclose information. Mere participation in some trials may identify the subject as someone at high risk of contracting HIV. Because of the high stakes if confidentiality is breached, researchers should take extra steps to protect the confidentiality of the information they collect in HIV vaccine trials.

Conclusion

In summary, the HIV epidemic has raised new ethical and policy dilemmas and has forced reconsideration of established guidelines and policies that apply to a much broader range of issues. In the future, controversies will likely continue to focus on addressing the global impact of HIV/AIDS and what justice requires in healthcare access and research.

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SEE ALSO: *Children: Healthcare and Research Issues; Confidentiality; Epidemics; Healthcare Resources, Allocation of; Homosexuality; Human Dignity; Human Rights; Life, Quality of; Public Health; Research Policy;* and other *AIDS* subentries

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ALCOHOL AND OTHER DRUGS IN A PUBLIC HEALTH CONTEXT

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Psychoactive drugs are substances that alter the mental state of humans after ingestion. There are a wide variety of those substances, both naturally occurring and synthesized, including tobacco, alcoholic beverages, coffee, tea, chocolate, and some spices, as well as substances that are legally available only through medical channels, such as benzodiazepides, cannabinols, opiates, and cocaine. Such substances often have other use values along with their psychoactive properties. Users may like the taste or the image of themselves that the use of those substances conveys. Substance use may be a medium of sociability (Partanen) or part of a religious ritual. Some substances have other useful properties; alcohol, for example, is a source of calories and is used as a solvent in many tinctures.

Psychoactive drugs differ in their metabolic pathways and mechanisms of action in the human body, the strength of their effects, and the states of mind and feelings they induce. However, the effects of drug use also are highly dependent on the pattern of use and on the set and setting, that is, the expectations of the user and of others who are present and the context of use (Zinberg). Although the psychoactive effect of tobacco may not register in the consciousness of a habituated cigarette smoker, in other circumstances the effect of tobacco use may be so strong that the user is rendered unconscious, as early Spanish observers reported in describing tobacco use among native South Americans (Robicsek).

Psychoactive substances frequently are valued by potential consumers well above the cost of production. On the one hand, this means that taxes on alcohol, tobacco, and other drugs have long been an important fiscal resource for the state. On the other hand, it means that there are substantial incentives for an illicit market to emerge in places where the sale of drugs is forbidden or stringently restricted.

A consideration of drugs in a public health context may start with an examination of general cultural patternings and understandings of drug use. This entry continues by discussing the major approaches to limiting harm from drug use. The entry concludes with a characterization of the major directions in the development of drug policies in the United States and other industrialized countries.

General Cultural Framings of Drug Abuse

Three social patternings of psychoactive drug use can be distinguished as prototypical: medicinal use, customary regular use, and intermittent use. In many traditional societies some drugs or formulations have been confined to medicinal use, that is, use under the supervision of a healer to alleviate mental or physical illness or distress. For several centuries after the technique for distilling alcoholic spirits had diffused from China through the Arab world to Europe, for instance, spirits-based drinks were regarded primarily as medicines (Wasson). This way of framing drug use has been routinized in the modern state through a prescription system, with physicians writing the prescriptions and pharmacists filling them. Drugs included in the prescription system usually are forbidden for nonmedicinal use.

When a drug becomes a regular accompaniment of everyday life, its psychoactivity often is muted and even unnoticed, as is often the case for a habitual cigarette smoker. Similarly, in southern European wine cultures wine is differentiated from intoxicating “alcohol”; wine drinkers are expected to maintain their original comportment after drinking. This may be called a pattern of *banalized use*: A potentially powerful psychoactive agent is domesticated into a mundane article of daily life that is available relatively freely in the consumer market.

Intermittent use—for instance, on sacred occasions, at festivals, or only on weekends—minimizes the buildup of tolerance to a drug. It is in the context of those patterns that the greatest attention is likely to be paid to a drug’s psychoactive properties. The drug may be understood by both the user and others as having taken control of the user’s behavior and thus to explain otherwise unexpected behavior, whether bad or good (see the “disinhibition hypothesis” in Pernanen; see also Room, 2001b). As in Robert Louis Stevenson’s fable of Jekyll and Hyde, normal self-control is expected to return when the effects of the drug wear off. In light of the power attributed to the substance, access to it may be limited: in traditional societies by sumptuary rules keyed to social differentiations and in industrial societies by other forms of market restriction.

In industrial societies a fourth pattern of use is commonly recognized for certain drugs: addicted or dependent use that is marked by regular use, often of large doses. Because the pattern of use of a particular drug is not defined in the society as banalized, addiction is defined as an individual failing rather than a social pattern. Although attention is paid to physical factors that sustain regular use, such as use to relieve withdrawal symptoms, most formulations of addiction focus on psychological aspects, including an apparent commitment to drug use to the exclusion of other activities and despite default in performing major social roles. An addiction concept thus also focuses on the loss of normal self-control, but the emphasis is not so much on the immediate effects of the drug as it is on a repeated or continuing pattern of an apparent inability to control or refrain from use despite the adverse consequences.

Addiction as a Modern Governing Image

The concept of addiction as an affliction of habituated drug users first arose in its modern form for alcohol as heavy drinking lost its banalized status in the United States and some other countries under the influence of the temperance movement of the nineteenth century (Levine; Valverde). Habitual drunkenness had been viewed since the Middle Ages as a subclass of gluttony; now abstinence from alcohol was singled out as a separate virtue and an important sign of the key virtue in a democracy of autonomous citizens: self-control. Along with other mental disorders, *chronic inebriety,* as alcohol addiction usually was termed, was reinterpreted as a disease suitable for medical intervention, although without losing all of its negative moral loading.

In nineteenth-century formulations addictiveness was seen as an inherent property of alcohol no matter who used it, and that perception justified efforts to prohibit its sale. By the late nineteenth century such addiction concepts were being applied also to opiates and other drugs, and this formulation has remained the governing image (Room, 2001a) for those drugs to the present day. However, as temperance became unpopular with the repeal of national alcohol prohibition in the United States in 1933, for alcohol the concept was reformulated to be a property of the individual “alcoholic,” who was mysteriously unable to drink like a normal drinker. This “disease concept of alcoholism” received its classic scholarly formulation by Jellinek (1952), although that author (1960) later retreated to a broader formulation of alcohol problems.

In popular thinking and often in official definitions addiction has remained a property of the drug for illicit drugs but of the person for alcohol (Christie and Bruun). The inherent addictiveness attributed to illicit drugs is the primary rationale for their prohibition. The extent of the anathema imposed in U.S. cultural politics by labeling a substance as addictive can be gauged from the unanimous testimony of cigarette company executives to the U.S. Congress in 1994 that they did not believe that cigarettes are addictive despite the evidence of their own corporate research (Hilts).

In recent years philosophers and cultural analysts have begun to question and rethink the meaning of addiction concepts (Szasz; Fingarette; Keane) and consider the implications for drug policy (Husak). In a related initiative economists have begun propounding and testing theories of *rational addiction* (Elster and Skog). By the early 2000s that critical thinking had had no discernible influence on the American political consensus in favor of an addiction-based policy for illicit drugs.

Approaches to Limiting the Problems from Drug Use

Most human societies have known of and used psychoactive drugs, and most also have made efforts to limit the use of one or more drugs, customarily if not legislatively. Historically, the main aim of those restrictions was to diminish threats to the social order or to increase the labor supply. Public health concerns sometimes were expressed in attempts to justify restrictions—for instance, in the efforts of James I of England to stem tobacco smoking (Austin)—but such concerns were rarely decisive. The restrictions on the spirits market adopted in Britain as a response to the extreme alcoholization of eighteenth-century London (depicted in Hogarth's famous print of "Gin Lane") are an early example of limits substantially motivated by concern about public health (Warner; Dillon). Only in recent decades have public health concerns become a major element in discussions of drug policies, although those concerns often are subordinated in the case of legal drugs to fiscal and economic considerations and in the case of illicit drugs to moral and lifestyle issues.

Health hazards from psychoactive drugs occur in two main ways: in connection with particular occasions of use and in connection with the patterning of use over time. Thus, an overdose from barbiturates, a traffic casualty from drunk driving, and an HIV infection from sharing a needle to inject heroin are all consequences associated with a particular occasion of use, whereas lung cancer from tobacco smoking, liver cirrhosis from alcohol use, and (by definition) addiction all reflect a history of heavy use (Room, 1985). As is discussed below, measures to prevent event-related problems often differ from and even conflict with measures to prevent cumulative, condition-related problems. For alcohol the ethical situation with regard to public health measures is complicated by the possibility of a protective effect of drinking on heart disease that must be balanced against the undoubted negative health effects (Room, 2001c; Rehm et al.).

Efforts to limit problems from drug use can be seen as oriented to controlling whether a drug is used at all; influencing the amount, context, and pattern of use; or preventing harmful consequences of use (Bruun; Moore and Gerstein).

PROHIBITING USE TO ALL OR SOME. Efforts to impose a general prohibition on the use of a drug for all the members of a society have a lengthy history, although those efforts frequently have failed (Austin). Perhaps the most sustained effort has been the prohibition on alcoholic beverages in Islamic societies. In general, religious taboos on drug use tend to have had more lasting effect than have state prohibitions. Prohibiting the sale or use of a drug that some might choose to use and enjoy involves a degree of intervention in the marketplace and in private behavior that is unusual in modern democratic states. If there are people who use a drug without problems, the prohibition on their use of that drug must be justified as benefiting others who would have or would cause problems if they used it. In societies with a strong tradition of individual liberties and consumer sovereignty discomfort with the use of this line of argument to support prohibition commonly is resolved by presumptions that users sooner or later will become addicted and that users without problems do not really exist.

A common form of prohibition of use in village and tribal societies has been sumptuary rules restricting use to particular status groups, most commonly the most powerful segments of the society. Depending on the culture, a variety of arguments are offered for the inability of lower-status groups to handle drug use appropriately. Because psychoactive drugs offer visions of an alternative reality (Stauffer) and may be associated with disinhibition, dominant groups may fear challenges to their power if subordinates have access to drugs (Morgan). The universalist ethic of modern states has made explicit sumptuary restrictions untenable, with the substantial exception of prohibitions on use by children. Even the provisions, still common in U.S. state laws, that the names of habitual drunkards be posted and that those listed be refused service of alcoholic drinks are largely unenforced because of their perceived interference with individual liberties.

A third form of modified prohibition of use that often is employed in modern societies is limitation to medicinal use. The individual's supply of such medications is controlled by state-licensed professionals who are backed up by a state system of market controls. National controls on psychopharmaceuticals are backed up by an unusual and elaborate international control structure (Bruun et al.; Room and Paglia). In principle, prescription and use of these drugs are limited to therapeutic purposes. For psychoactive drugs, which commonly are prescribed to relieve negative affective states or mental distress, the definition of therapeutic use often is quite wide, and a substantial proportion of the resources of the health system in industrial societies is absorbed in superintending the provision of psychoactive drugs.

Except for methadone as a remedy for heroin addiction and nicotine as a remedy for tobacco smoking, it generally is considered illegitimate to prescribe a drug to help a person maintain a habitual pattern of use without withdrawal or other distress. Use for pleasure or for the sake of the psychoactive experience is considered nontherapeutic, and so the functions of drugs that are considered psychopharmaceuticals always are described in terms of the relief of distress rather than the provision of pleasure. To some extent the medical prescription system in a modern state serves as a covert form of control by status differentiation, according to the prejudices of the prescriber; for instance, older and more respectable adults find it easier than do the younger and more disreputable to obtain a prescription for a psychopharmaceutical.

INFLUENCING THE PATTERN OF USE. An enormous variety of formal and informal strategies have been used to influence the amount, pattern, and context of the use of drugs. Among the potential aims of those strategies is the public health goal of reducing the prevalence of hazardous use.

Controlling availability. One class of such strategies attempts to reduce drug-related problems by controlling the market in drugs by means of taxes, general restrictions on availability, or user-specific restrictions (Room, 2000; Babor et al.). Public health considerations are one reason among several that governments tax legally available drugs such as alcohol and tobacco. Those taxes often constitute a substantial portion of the price to the consumer. Raising taxes does diminish levels of use among heavier as well as lighter users, although demand usually diminishes proportionately less than the increase in price; that is, demand is relatively inelastic. Thus, short of levels that create an opening for a substantial illicit market, raising taxes on drugs tends both to have positive public health effects and to increase government revenues.

Governments often also control the conditions of availability, particularly for alcohol. Through a system of retail licenses or a government monopoly of sales, limits are placed on the hours and conditions of sale. Changes in those limits sometimes have been found to affect patterns of consumption and of alcohol-related problems (Babor et al.). However, with the strengthening of the ideology of consumer sovereignty—legal goods should be readily available, with purchases limited only by the consumer's means—controls on availability tend to have been loosened in the contemporary period (Mäkelä et al.).

A generally stronger and more direct effect on hazardous alcohol consumption has been found to result from measures that ration or restrict the availability of alcohol for specific purchasers (Babor et al.). A general ration limit for all purchasers restricts heavy consumption or at least raises the effective price, but such measures strongly conflict with the ideology of consumer sovereignty and are thus politically impracticable nearly everywhere. As was noted above, proscriptions or limits on sales to named heavy users also have fallen out of favor because they are considered infringements on individual liberty.

Controlling the circumstances of use. Another class of strategies aims to deter drinking or drug use in particularly hazardous circumstances, usually through the use of criminal sanctions. The prototypical situation is driving after drinking. Because alcohol consumption impairs the ability to drive a vehicle, most countries treat driving with a blood-alcohol level above a set limit as a criminal offense, and enforcement of those laws often absorbs a substantial proportion of the criminal justice system's resources. Popular movements as well as policy makers have expended much energy, particularly in the United States and other Anglophone and Scandinavian countries, in seeking a redefinition of drunk driving as a serious crime rather than a "folk crime" (Gusfield). This type of situational limit or prohibition has been extended to other skill-related tasks and also has been applied to driving after using other psychoactive drugs, particularly illicit drugs. A related development has sought to eliminate illicit drug use in working populations and alcohol use in the workplace by means of random urine testing of workers, with job loss as the sanction (Zimmer and Jacobs).

The ethics of this measure, which was pushed strongly by the U.S. government in the 1980s, are controversial, particularly because the tests detect illicit drug use that has not necessarily affected work performance (Macdonald and Roman). Random blood-alcohol tests of drivers to deter drinking before driving also have proved controversial: They are effective, well accepted, and widely applied in Australia (Homel et al.; Peek-Asa); legally permissible but not intensively applied in the United States; and viewed as an impermissible infringement on individual liberty and privacy in many countries.

Education and persuasion about use. A third class of strategies seeks to educate people or persuade them not to engage in hazardous drug use. Because such strategies are seen as the least coercive, at least for those beyond school age, they are used very widely and commonly despite the frequent lack of clear evidence on their effectiveness (Paglia and Room). Education of schoolchildren about the hazards of drug use is very widespread, indeed nearly ubiquitous, in the United States. Most countries also have made at least a token effort at public information campaigns about the hazards of tobacco smoking, and poster and slogan campaigns against drinking before driving and illicit drug use are also widespread. Other public information campaigns on alcohol have promoted limits on drinking (e.g., suggestions of safe levels in Britain and Australia) or campaigned against drinking in various hazardous circumstances.

Often these public information campaigns compete for attention in a media environment saturated with advertising on behalf of use from tobacco or alcohol companies. In the last two decades of the twentieth century some governments imposed substantial restrictions on tobacco and, to a lesser extent, alcohol advertising, for example, banning advertisements on electronic media, and mandated warning labels in advertisements or on product packages. These restrictions often have precipitated court fights about the constitutional permissibility of restrictions on the freedom of "commercial speech."

REDUCING THE HARM FROM USE. The strategies considered above are directed primarily at influencing the fact or pattern of use. They thus fall into the category of either supply reduction or demand reduction, to use terminology commonly applied to the use of illicit drugs. Since the late 1980s substantial attention has been directed toward a third option: harm reduction, or strategies that reduce the problems associated with drug use without necessarily reducing drug use (O'Hare et al.; Heather et al.). Attention to this class of strategies has a somewhat longer history for alcohol (Room, 1975). Usually these strategies focus on the physical or social environment of drug use, seeking physical, temporal, or cultural insulation of the drug use from harm. Thus, needle exchanges are intended to remove the risk of HIV infection from injection drug use, and seat belts and air bags insulate drivers who drink and those around them from the possibility of becoming casualties.

The debate over harm reduction strategies for illicit drugs has raised classic ethical issues for public health. Some argue that insulating the behavior from harm will encourage and thus increase the prevalence of the undesirable behavior. A further consideration is the effectiveness of the insulation provided. Thus, efforts to provide a safer tobacco cigarette largely have been undercut by compensatory changes in puffing and inhaling by smokers. At an empirical level it seems that insulating drug use from harm does not necessarily increase the prevalence of drug use (Yoast et al.). Even if it did, an old public health tradition that is epitomized by the operation of venereal disease clinics would argue that reducing the immediate risk of harm has a higher ethical priority than affecting the prevalence of disapproved behaviors.

The Political Reality in the Early 2000s: Lopsided Policies

The United States and many other countries have experienced recurring "moral panics" in recent decades concerning illicit drug use and have invested substantial resources in efforts to prevent such use. These resources have been invested largely in two areas: a particular preventive strategy—interdicting the illicit market—and the provision of treatment. The first strategy has received the greatest investment of government resources. There was a substantial decrease in illicit drug use in North America in the late 1980s and early 1990s, but it was followed by a rise in the 1990s.

Governments often are blamed for these ebbs and flows, but they may have more to do with cyclical patterns in youth fashions and social mores. The illicit market remains strong, and drug-related imprisonments have helped propel the United States to having the highest rate of incarceration among industrial societies. Meanwhile, the highest rates of health and social harm come from legal drugs. For instance, the World Health Organization (WHO) estimates that 13.3 percent of the net disability and death (in disability-adjusted life-years) in the subregion consisting of the United States, Canada, and Cuba is attributable to tobacco, 7.8 percent to alcohol, and 2.6 percent to illicit drugs (Ezzati et al.), yet alcohol and tobacco have received a much lower priority. In government policy making on these licit substances public health considerations often have been subordinated to economic concerns. In recent years, for example, the United States has successfully attacked control structures and forced a greater availability of both alcohol and tobacco in other countries through lawsuits under the General Agreement on Tariffs and Trade (Ferris et al.).

A substantial emphasis on the treatment of addiction has accompanied the attention paid to prevention. However, in this mixed policy environment the role of treatment has been highly differentiated by the type of drug. To a large extent tobacco smoking has continued to be defined as a health problem rather than a social problem, with the emphasis on the health consequences of smoking rather than the physical dependence of smokers on tobacco. Thus, there has been very little public provision of treatment for smoking addiction; most of those who have quit have done it by themselves or by using nicotine substitutes.

At the other extreme the goals for an illicit drug treatment system have been highly ambitious: In theory, in the mid-1970s and again in the late 1980s, the United States aspired to provide treatment to every unincarcerated addict. Quite explicitly, treatment for illicit drug use has been seen as a form of social control, and a high degree of coercion has been taken for granted (Gerstein and Harwood). On occasion U.S. drug strategies have argued for the provision of treatment as a means to encourage courts to be tougher on those who choose not to accept it (Strategy Council on Drug Abuse), and drug treatment agencies have argued routinely for maintaining jail sentences for drug use in order to force users into treatment as an alternative.

In the case of alcohol there also has been substantial growth in treatment provision, and not only in the United States (Klingemann et al.). However, in the United States alcohol treatment until recently was only an adjunct of the criminal justice system, and it remains quite separate in many countries. The growth of alcohol treatment provision, it has been argued, accompanied and served as a "cultural alibi" for the dismantling of the alcohol control structure left behind by the temperance era (Mäkelä et al.). Although there is an increasing contradiction between the demands for sobriety in a technological environment and the increased market availability of alcohol, managing that contradiction is seen as a character test for the individual consumer, with treatment for alcoholism provided for those deemed to have failed the test.

These policy trends for alcohol and tobacco apply in broad terms to other industrial countries, although high-tax strategies have been applied more commonly outside the United States, particularly for tobacco. For illicit drugs the U.S. "drug war" ideology has been exerted internationally as well as at home (Traver and Gaylord). Through mechanisms such as the international narcotics control conventions and through active multilateral and bilateral diplomacy the United States has been relatively successful in maintaining and often strengthening legal prohibitions. Nevertheless, the international illicit market continues to grow. In debates about drug policies in the 1990s and early 2000s the practical relevance and the ethics of U.S. policies have been questioned increasingly by scholars (Bertram et al.; MacCoun and Reuter).

ROBIN ROOM (1995)
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SEE ALSO: *Addiction and Dependence; Alcoholism; Public Health; Smoking*

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ALCOHOLISM

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What are the benefits and problems that attend the use of alcoholic beverages? In what ways may drinking cause harm? Is the use of alcohol hazardous for all individuals or only for some? Who is at risk? Should an intoxicated person be held accountable for his or her actions while "under the influence"? How is excessive drinking like or unlike other self-injurious appetitive behaviors such as overeating, smoking, or other substance abuse? Should society limit or control the use of alcohol, and should it warn consumers of potential risks associated with drinking? Is alcoholism a disease, primarily a medical rather than a moral problem?

Opinion remains divided on many of these issues, reflecting the diversity of beliefs, practices, and emotions surrounding the use of beverage alcohol in various cultures. Historical and cross-cultural investigations indicate that prevailing cultural beliefs about alcohol and alcohol problems play an important role in determining moral attitudes. Research continues to generate new data about the biomedical and behavioral aspects of drinking. An informed consideration of the use of alcohol must attend simultaneously to the implications of new information and the influence of shifting values.

Alcohol: Blessing or Curse?

A product of natural fermentation, beverage alcohol, or ethanol, is perhaps the oldest known and most universally consumed psychoactive substance. Ancient peoples drank copious amounts of wine, beer, and other naturally fermented alcoholic beverages, praising their ability to lift the spirits, relieve fatigue, and enhance health. In many societies, alcohol was regarded as a divine gift and was incorporated into religious rituals. Early historical records indicate, however, that alcohol also brought problems. The Hebrew Bible, for example, tells how Noah embarrassed his sons by getting drunk (Gen. 9:20–24) and warns of calamity for "those who tarry long over wine" (Prov. 23:29–35).

Ambivalence toward alcohol use has persisted into modern times and is expressed cross-culturally in a wide diversity of attitudes, beliefs, and practices. The French, for example, regard wine as essential to their diet and lifestyle, and tend to view abstainers as deviant. Millions of Muslims, by contrast, forswear all alcohol as evil. Even within a particular society, attitudes may be heterogeneous and historically variable. Seventeenth-century colonial settlers in North America, for example, viewed drink as the Good Creature of God; three centuries later, the United States banned Demon Rum (Rorabaugh).

Empirical evidence suggests that the use of alcohol offers both modest benefits and significant hazards. In moderate amounts, alcohol is a mild relaxant that stimulates appetite and facilitates social interaction. Sociocultural norms play an important role in determining specific contexts in which drinking may normally occur and influence the experience and behavior of the drinker as well. Aside from alcohol's subjective benefits, there is evidence that moderate drinking may reduce the risk of coronary artery disease in some individuals (Klatsky).

Hazards of Alcohol Use

The potential social and economic costs of alcohol use to society can be staggering. In the United States alone, it is estimated that abuse of alcohol cost $136.3 billion in 1990 for alcohol-related diseases, accidents, lost productivity, and rehabilitation (Harwood et al.). Three aspects of alcohol use may present problems: drinking itself, acute intoxication, and chronic heavy drinking, commonly referred to as alcoholism.

Ethanol is a simple yet highly toxic molecule that is rapidly absorbed throughout the body and brain. While moderate consumption of alcohol (no more than two drinks per day) does not appear to pose significant health risks for most individuals, there are some populations for whom even moderate drinking may be ill-advised. Specifically, there is evidence that drinking by pregnant women may expose the fetus to serious risk of a number of permanent morphological and cognitive defects collectively known as fetal alcohol syndrome (FAS) (U.S. Department of Health and Human

Services). The relatively recent discovery of FAS (and its milder form, fetal alcohol effects [FAE]) has raised vexing ethical questions concerning the moral and legal culpability of women who drink during pregnancy. Acknowledging society's duty to warn consumers about this previously unrecognized hazard, the U.S. government passed legislation in 1988 that requires manufacturers, bottlers, and importers of alcoholic beverages to include a surgeon general's health warning on all containers.

Acute intoxication and chronic heavy use of alcohol pose the greatest hazards and raise the most pressing ethical concerns. Acute intoxication directly impairs a range of perceptual and motor functions, thereby increasing the risk of accidental injury and death by motor vehicle accidents, falls, slips, drownings, and other mishaps. The risk of serious accidental injury is greatly increased in modern technological societies, where alertness is required to safely operate heavy machinery and high-powered vehicles. In recent years, there has been a growing movement in many countries to reduce alcohol-related automobile injuries and fatalities through tougher laws and preventive education aimed at deterring drunk driving. The late twentieth-century legal consensus appears to be that while intoxication undoubtedly affects judgment and competence, the drunk driver should be held accountable for the decision to drive while impaired. Doubts about the ability of some individuals to make this choice when drinking is reflected in the enactment of new laws that hold bartenders, party hosts, and other servers of alcoholic beverages responsible for monitoring consumption and refusing drinks to inebriated individuals.

Intoxication may also lead to harm through its apparent ability to break down inhibitions on sexual and aggressive impulses in some individuals. In the United States, for example, alcohol intoxication has been strongly associated with assault, murder, rape, spousal violence, and other types of violence. It has not been established that intoxication itself is the direct cause of these outcomes, since in some societies drinking and intoxication are not commonly associated with such violence. Personality variables and culturally influenced expectations regarding intoxication may be important in mediating the relationship between alcohol and violence (Anglin).

In addition to the problems directly related to episodes of acute alcohol intoxication, there is widespread recognition of the harm caused by chronic excessive drinking, commonly referred to as alcoholism. At sufficient doses, the daily or frequent drinker may experience increased tolerance and, eventually, physiological dependence and withdrawal symptoms. Prolonged heavy drinking is implicated in a number of serious and potentially fatal health problems, including cirrhosis, pancreatitis, peptic ulcer, hypertension and cardiovascular disease, and various cancers. Moreover, both the central and the peripheral nervous systems are damaged by chronic alcohol abuse. In addition to well-known complications such as peripheral neuropathy, ataxia, and alcohol-related dementias, researchers have discovered more subtle cognitive deficits resulting from chronic alcoholism (Tarter et al.).

Epidemiological studies indicate that about one person in ten in the United States is a problem drinker. The persistence of excessive drinking in the face of adverse consequences is the primary criterion in the diagnosis of alcohol abuse; alcohol dependence is diagnosed if tolerance and withdrawal symptoms have developed. Sex, age, and ethnicity are significant variables in the distribution of problem drinking. Men are at least four times as likely to be diagnosed with alcohol dependence as women. D.W.I.-related accidents and fatalities are most frequent among the young. In some ethnic groups, such as Chinese Americans and Orthodox Jews, alcohol problems are rare, while in certain Native American tribes alcoholism is a leading cause of death.

Alcoholism is associated with an increased prevalence of psychiatric disorders, although symptoms of anxiety and depression may often abate following detoxification and a period of abstinence. Whether alcoholism is a cause or a consequence of other mental disorders continues to be debated. An important longitudinal study challenges the view that alcoholism is but a symptom of preexisting emotional problems with the finding that the mental health of nonalcoholics and future alcoholics does not differ significantly in childhood (Vaillant).

Is Alcoholism a Disease?

Beliefs about the cause or causes of alcoholism and the nature of drinking problems exert an important influence on public perceptions, institutional responses, and treatment and prevention, and shape the framework that guides ethical inquiry and response.

The disease concept of alcoholism, first articulated by Elvin M. Jellinek in the 1940s, was actively promoted by a loose coalition of reformers, service providers, and recovering alcoholics. Since then, it has become the official view of the American medical profession and the World Health Organization (WHO), and has gained wide acceptance among the public at large in the United States and many other Western countries. Proponents of the disease concept argue that alcoholism, like diabetes, essential hypertension, and coronary artery disease, is a biologically based disease precipitated by environmental factors and manifested in an irreversible pattern of compulsive, pathological drinking behavior in individuals who are constitutionally vulnerable. Central to the disease model is the belief that the alcoholic effectively loses control over his or her consumption of alcohol and can never safely drink again. The disease model also holds that alcoholism is a progressive disease that may be arrested by abstinence but never cured.

Although subsequent research has provided evidence of a genetic predisposition for some types of alcoholism (Goodwin), attempts to demonstrate empirically a biological basis for alcoholism have yielded inconclusive results. Whatever influence genetics and biology have in the pathogenesis of alcoholism, many authorities agree that psychosocial variables are of equal importance to the onset and course of drinking problems. The current consensus among researchers and scholars is that alcoholism is a complex biopsychosocial disorder in which multiple factors play a role.

Critics of the disease concept argue that empirical research has failed to support its basic tenets. Herbert Fingarette refers to the disease concept as a myth, asserting that "almost everything that the American public believes to be the scientific truth about alcoholism is false" (p. 1). Reviewing research, Fingarette challenges the following tenets of the disease concept of alcoholism: (1) irresistible craving and loss of control after the first drink; (2) inevitable progression; and (3) the impossibility of a return to controlled drinking. More specifically, he cites studies that show alcoholics do not always experience craving and retain a considerable degree of volition in their actual drinking behavior (Mello and Mendelson); epidemiological studies that suggest patterns of alcohol abuse are highly variable and may spontaneously remit without intervention (Cahalan and Room); and, finally, evidence that at least some alcoholics have successfully returned to more moderate drinking (Davies; Polich et al.).

Arguing that the disease concept is pseudoscientific, Fingarette and other critics (Peele, 1989) imply that by lending the legitimizing mantle of medical science to the disease concept—at least as it is currently formulated—proponents deprive the public of accurate information that forms the necessary basis for informed consent regarding treatment. Others (Vaillant), while conceding that alcoholism is not a disease in the strict medical sense, continue to defend the disease model; they argue that its value in destigmatizing alcoholism and legitimizing treatment outweighs issues of epistemological rigor.

The modern disease concept emerged and gained acceptance primarily in response to humanitarian concerns rather than on the basis of scientific evidence. Eager to undo the religious underpinnings and moralistic legacy of the American temperance movement and prohibition, advocates of the disease concept correctly perceived its ability to recast the alcoholic as sick rather than as morally deviant. If the alcoholic is unable to control self-destructive drinking because of an incurable illness, then he or she deserves compassion and treatment rather than blame. Paradoxically, the attempt to reconceive alcoholism in medical rather than moral terms can be seen as fulfilling a moral agenda, that is, a desire to help rather than condemn the problem drinker. This ethical stance can be seen, in turn, as part of a broader movement in modern society to destigmatize deviant behavior of all types by promoting understanding and compassionate intervention. Thus, much of the controversy surrounding the disease model arises out of a tacit conflict between scientific and moral agendas, a confounding of facts and values in society's response to alcohol.

Anthropology offers a possible semantic solution to the disease controversy by distinguishing between *illness* and *disease* (Chrisman). Whereas diseases are defined by objective scientific criteria, social anthropologists view illnesses as cultural constructions defined by subjective distress, loss of normal social functioning, and adoption of the sick role. Within these terms, alcoholism can be seen as a culturally defined illness or *folk disease* for which society has sanctioned the sick role and compassionate intervention.

The Role of Alcoholics Anonymous

Despite the widespread acceptance of the disease concept, the leading approach to overcoming alcoholism in the United States is, ironically, not a medical treatment but a self-help program based on principles of moral and spiritual renewal. Founded in 1935 by Bill Wilson, an alcoholic stockbroker, Alcoholics Anonymous (AA) borrowed many of its ideas from an evangelical Christian movement known as the Oxford Group. Though it embraces the disease concept as part of its holistic view of alcoholism as a threefold illness (physical, mental, and spiritual), AA's primary emphasis is on achieving sobriety through a process of moral-spiritual renewal as set forth in the Twelve Steps. Central to AA's approach is the alcoholic's decision to abstain from alcohol "one day at a time." Believing alcoholism to be a disease that may be arrested but never cured, AA views "recovery" as a lifelong process requiring constant vigilance and regular attendance at meetings where members "share their experience, strength, and hope." The Twelve Steps encourage AA's members to admit their faults, make amends to those they have hurt, and help other alcoholics achieve sobriety. Members are also encouraged to select sponsors, experienced AA members who are available for advice and support.

How effective is AA? AA's membership, estimated at 1.5 million worldwide (General Service Office), provides impressive evidence of its success in reaching problem drinkers. However, the overwhelming majority of alcoholics remain untreated. Of those who are exposed to AA, many drop out; those who remain may constitute a self-selected group receptive to its message and style. Moreover, because of the methodological difficulties of conducting research on a self-help group of anonymous individuals, few controlled studies exist on AA's effectiveness compared with other treatment approaches (Ogborne and Glaser). Nonetheless, AA has come to exercise a pervasive influence over both inpatient and outpatient treatment programs in the United States, where the primary goal is often to motivate the alcoholic to participate in AA.

Advocates of AA's approach to treatment have been accused of intolerance toward alternative approaches, especially behavior modification therapies that pursue the goal of controlled drinking rather than total abstinence. Despite evidence that not all problem drinking follows a progressive, deteriorating course and that some problem drinkers are able to return to more moderate patterns of consumption, controlled drinking advocates have been criticized as irresponsible for even suggesting an alternative to abstinence (Pendery et al.). AA's success presents a curious dilemma for researchers and clinicians: The very elements that may contribute to its effectiveness as a self-help group—simple beliefs, group loyalty and cohesiveness, and an emphasis on personal experience and testimony—leave it resistant to outside influence and to new information that appears to contradict its core assumptions (Galanter). The employment of large numbers of recovering alcoholics as counselors and administrators in alcohol treatment programs has further complicated the situation as personal loyalty to AA's "one disease, one treatment" approach has come into conflict with the more empirically based, eclectic approach of researchers and of clinicians trained in the mental-health professions. The difficulty of reconciling these two orientations finds expression in a growing trend toward *dual diagnosis* in which alcoholics are assigned an additional psychiatric diagnosis and treated with medication. Wary of all drugs as potentially addictive, many AA-based paraprofessionals have been uneasy with psychiatric diagnosis and medication; in turn, mental-health professionals have viewed alcoholism counselors as insufficiently aware of psychiatric disorders and treatments. Such tensions point to fundamental differences in the assumptive frameworks that each group brings to diagnosis and treatment.

The first of AA's Twelve Steps declares that the alcoholic is powerless over alcohol and must therefore surrender to a "higher power." Believing this to be a self-defeating prescription for helplessness and relapse in the face of a needlessly mystified "disease," Stanton Peele has argued for restoring an explicitly moral model of alcoholism and other addictions that emphasizes the alcoholic's ability rationally to choose sobriety and commit to new values (Peele, 1988). Advocates of AA's approach argue, however, that this is precisely what AA accomplishes: a daily commitment to abstinence and "a new way of life." That alcoholics may regain a sense of control by admitting powerlessness, they say, may simply reflect a spiritual paradox rather than a contradiction.

Medicalization of alcohol problems has yet to resolve the question of what causes alcoholism or to provide satisfactory solutions to the moral problems posed by the use and misuse of alcohol. Motivated by the desire to destigmatize alcoholism in order to promote compassionate treatment, the disease model still has not adequately disposed of the issue of personal responsibility. The drinker makes choices, but these choices are significantly influenced by biological, psychological, and sociocultural forces beyond conscious control. An important element of AA's success may be that it embraces both aspects of this duality: It holds that alcoholics do not choose their condition—they are subject to multiple systemic forces beyond their awareness—yet, with support, they can effectively assume responsibility for their problem and choose to abstain. Meaningful ethical inquiry must embrace both poles of this duality by recognizing the complex interplay of personal choice with the many factors that may influence or limit it.

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SEE ALSO: *Alcohol and Other Drugs in a Public Health Context; Addiction and Dependence; Behavior Modification Therapies; Freedom and Free Will; Genetics and Human Behavior; Harmful Substances, Legal Control of; Impaired Professionals; Maternal-Fetal Relationship; Mental Health Services; Smoking*

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ALTERNATIVE THERAPIES

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I. Social History
II. Ethical and Legal Issues

I. SOCIAL HISTORY

Healing is a profoundly cultural activity. The very act of labeling a disease and prescribing treatment expresses a healer's commitment to a particular set of assumptions about the nature and structure of reality. These assumptions not only help specify the agents thought to cause disease but also contain implicit understandings of what health optimally or normatively enables humans to do. Because rival medical systems typically subscribe to differing philosophical and cultural outlooks, the notion of orthodoxy pertains to medicine as surely as it does to religion or politics. What makes a therapy "orthodox" is its adherence to a belief system that, for intellectual and sociological reasons, informs the practice of the dominant members of a culture's medical delivery system. A therapy is therefore "unorthodox" to the extent that its diagnoses and treatments are not deemed legitimate by the dominant belief system.

The philosophical and professional differences that separate orthodox and unorthodox therapies give rise to complex ethical questions. How, for example, are we to understand medical "legitimacy," when this notion is the product of ever-changing philosophical, cultural, and social factors? What does it mean for a medical treatment to be unethical? Must it in some way bring about negative results, or is it unethical even if it is—such as vitamin placebo treatment—merely a harmless fraud? What constitutes a therapeutic benefit? Is it an improvement in physical, mental, or spiritual well-being?

First, the sheer diversity of alternative therapies hampers attempts to generalize about the kinds of ethical issues that unorthodox treatments present. There is an almost bewildering array of alternative therapies, ranging from chiropractic, osteopathy, and acupuncture, to shiatsu, herbal medicine, and religious faith healing. Further complicating this task is the fact that these alternative therapies find themselves labeled unorthodox for quite different reasons. Some, for example, are practiced by healers committed to an alternative belief system or worldview that grants reality to causal forces that differ greatly from those specified by medical orthodoxy. Such is the case with various "faith healing" traditions and New Age medical systems. Religious therapies such as these invoke an overtly metaphysical explanation of the causes of physical illness and depict human health in terms of adherence to specific spiritual or ethical outlooks on life.

Second, healing systems may become unorthodox when they employ therapies that, although predicated upon the consensus worldview, have not yet been validated or confirmed as efficacious by orthodox medical standards. Many of the treatments suggested for combating cancer or acquired immunodeficiency syndrome (AIDS) are considered unorthodox for this reason. Third, healers find themselves outside the medical mainstream when they provide services that are typically ignored or deemed of secondary importance by a culture's dominant medical practitioners. This has been the case, for example, with dentists in the nineteenth century, podiatrists in the early twentieth century, and midwives throughout most of modern history. The case of midwifery is instructive. While never as widespread in the United States as in other parts of the world, the use of midwives provided the only obstetrical assistance available to many women until early in the twentieth century. As obstetrics became a recognized medical specialty, primarily under the control of male physicians, hospitals equipped with surgical facilities supplanted the home as the normal site for giving birth. Increasingly the last resort of those who could not afford hospital births, midwifery generally fell into disrepute. Midwifery, then, became an "unorthodox" form of medical care not because it employed an alternative worldview or because it could not be validated as a treatment, but because the dominant providers of medical services decided that the home and the assistance of other women at childbirth were not of primary importance. Interestingly, midwifery has witnessed a modest resurgence in recent decades as part of a general cultural trend toward "natural" medicine and woman-centered healthcare. Nurse-midwives perform about 2 percent of all deliveries in the United States, and more than a dozen universities offer certification programs for midwives.

What alternative therapies have in common is economic, legal, and cultural disenfranchisement from the socially empowered institution of scientific medicine. Any attempt to reflect upon the ethical questions raised by these "alternative" approaches to healing requires sensitivity to the historical and philosophical roots of this disenfranchisement. "Regular" physicians coalesced into state and local medical societies during the nineteenth century, securing an institutional power base for what was to become medical orthodoxy in the United States. This emerging corps of physicians shared a more or less common approach to medical practice and were eventually able to "institutionalize" this approach through the influence they exerted over licensure laws enacted by state and federal governments, the accreditation of medical schools, and access to technologically equipped hospitals. The American Medical Association (AMA) (founded in 1847, but lacking strong organization and sufficient membership until the early twentieth century) eventually succeeded in organizing and promoting the interests of the nation's dominant medical practitioners on a national level.

Medical orthodoxy aligned itself with the worldview spawned by the Western scientific tradition. Its approach to therapeutic intervention has been firmly rooted in the evolving body of information that has emerged from advances in physiology, chemistry, and pharmacology. Accompanying this reliance upon the Western scientific tradition has been an implicit endorsement of a secularist and rationalist ontology (i.e., a worldview skeptical of claims concerning the supernatural or other unquantifiable influences). What has given scientific medicine its "public" character is its insistence that theories concerning the etiology and treatment of disease specify physical, as opposed to spiritual or metaphysical, causal forces. Its theories and strategies for therapeutic intervention are thus more susceptible to empirical verification, and disputes can at least potentially be resolved by an appeal to observable and quantifiable sets of data. This is also why scientific medicine found itself more amenable than many of its alternative counterparts to the economic and legal institutions of modern Western governments. Rejecting the "private" claims to truth made in religious arguments, Western democracies have required that all civic discourse be advanced according to rational and public grounds of argumentation.

To the extent that scientific medicine's academic and experimental foundations facilitate such "public" argumentation, it has largely merited its enfranchisement within the legal and economic institutions that make judgments about the allocation of medical resources. Any consideration of the ethical status of these judgments and their effect upon the practice of alternative medical systems must take into account the important role that such rational and public discourse has had in the development of Western culture.

Nineteenth-Century Alternative Medicine

THE THOMSONIAN SYSTEM. One of the first challenges to the orthodoxy of "regular physicians" occurred in the early 1800s. Samuel Thomson (1769–1843) was a poor New Hampshire farmer whose mother and wife had suffered from the bleedings and mercurial drugs forced upon them by regular physicians. Thomson believed that better treatments must be available, and he began studying the therapeutic value of herbs. He soon developed his own system of botanical medicine predicated upon the assumption that there is only one cause of disease, cold, and one cure, heat. Thomson believed that by restoring heat to his patients' systems, he could cure any ailment. Using botanics such as cayenne pepper, supplemented with steam baths, Thomson sought cures without the incessant bloodletting or mercurial drugs utilized by the era's orthodox physicians.

The Thomsonian system reached the height of its popularity in the 1820s and 1830s. Some estimate that its methods were employed in varying degrees by as many as a million Americans. One obvious reason for its appeal was that its treatments were generally more benign than the aggressive arsenal of bloodletting, alcohol, opium, mercury, arsenic, and strychnine that many regular physicians used to stimulate their patient's systems. Perhaps more important, Thomsonianism could be studied relatively inexpensively (although the official price for the right to use his methods was a substantial $20) and practiced by family members. During the days of medical professionalization in the United States, Thomsonianism strengthened the role of parents, and especially mothers, in caring for family members. Thomsonianism also fit nicely with the period's moral and religious climate, which urged individuals to take responsibility for their own moral and spiritual regeneration. It endeavored "to make every man his own physician" and encouraged individuals to take responsibility for restoring their rightful relationship to the divinely decreed laws of nature. Of lasting significance is the fact that Thomsonianism was the first system to take on the issue of licensing of medical practitioners, and to assert the public's right to free choice of healers. Thomsonians led the successful campaign to repeal medical licensing legislation in the mid-1800s and drew public attention to the somewhat predatory tactics with which orthodox physicians sought to restrict the right of would-be healers to practice whatever system they wanted.

HOMEOPATHY. A second form of sectarian medicine, homeopathy, emerged more or less concurrently with the public's gradual loss of enthusiasm for the Thomsonian system. The homeopathic system of medicine was the creation of the German physician Samuel Christian Hahnemann (1755–1843), who grew increasingly critical of the indiscriminate prescription of drugs by contemporary physicians. He coined the term *allopathic* to refer to orthodox medicine's alleged overreliance upon invasive therapeutic treatments (e.g., bloodletting, surgery, or the administration of strong pharmacological agents). In contrast to allopathic medicine, Hahnemann enunciated a medical theory that he thought relied more upon the body's natural powers to bring about recovery. The first principle of homeopathic medicine is "like cured by like." By this Hahnemann meant that physicians should treat symptoms by prescribing drugs that produce similar symptoms in a healthy individual. The second fundamental principle of homeopathic medicine is the doctrine of infinitesimals. It was Hahnemann's conviction that the greatest therapeutic benefit was to be achieved by administering diluted doses of a drug, sometimes only 1/1,000,000 of a gram. Although homeopathic physicians' use of infinitesimal doses undoubtedly negated any therapeutic value their drugs might have had, at least these small doses had the virtue of not assaulting the patient's recuperative powers. It is thus not surprising that many turned to homeopathy as a viable alternative to orthodox medicine.

Homeopathy spread quite rapidly in the United States. It was introduced by Hans Gram, who opened an office in New York after studying the homeopathic system in Europe. By 1835 a homeopathic college had been formed, and in 1844 the American Institute of Homeopathy was organized. Throughout the 1800s, 10 to 12 percent of the country's medical schools and medical school graduates were adherents to homeopathy. In contrast to Thomsonianism, which was practiced by nonprofessionals, homeopathic practitioners were educated professionals who often came from the ranks of regular physicians. Moreover, while those who received Thomsonian treatment tended to be rural and poor, there is evidence to suggest that homeopathy thrived among the urban upper and middle classes. This latter fact led to direct economic competition with the regular system and proved an important catalyst in the formation and success of the American Medical Association as economic motives joined with scientific ones to rally regular physicians in opposition to their irregular competitors. As the most popular of the century's alternative systems, homeopathy raised a number of important ethical questions. For example, could allopathic physicians consult with "unscientific" practitioners? (The AMA's original code of ethics included a consultation clause that prohibited such interactions.) Or should homeopathic physicians be allowed to practice in publicly supported hospitals or in the military? Even in the late twentieth century there was some debate about whether pharmacies should be required to stock homeopathic medicines.

HYDROPATHY AND DIETARY REGIMENS. In the mid-1840s another alternative therapy, hydropathy (water cure), began to attract a following in the United States. Based on the theories of Vincent Priessnitz of Austria, hydropathy was based on enhancing the body's inherent vitality and purity. Priessnitz believed that pure water could be used to flush out bodily impurities and stimulate the body's inherent tendencies toward health. Water-cure treatments emphasized drinking large amounts of water and applying water externally through baths, showers, or wrapping wet sheets around the body. Most American adherents of water cure advocated an eclectic approach to health based on the curative powers of fresh air, diet, sleep, exercise, and proper clothing. The philosophy of water cure also had a decidedly moral tone. As one anonymous American enthusiast put it, "We regard Man, in his primitive and natural condition as the perfect work of God, and consider his present degenerated physical state as only the natural and inevitable result of thousands of years of debauchery and excess, of constant and wilful perversions of his better nature, and the simple penalty of outraged physical law, which is just and more severe than any other" ("Water-Cure World," 1860).

Hydropathy thus equated disregard of the laws of healthful living with defiance of God's will. Systematic efforts to promote healthful living were not only the means to physical well-being but also the key to the spiritual renovation of Earth. The hydropathic cause naturally attracted many of the period's moral and religious reformers. William Alcott, Lucy Stone, Amelia Bloomer, Susan B. Anthony, and Horace Greeley visited major hydropathic retreat centers, where they circulated reformist agendas ranging from vegetarianism to utopian socialism. Critical of the alleged superiority of "official" medical authorities, advocates of hydropathy had a natural affinity with the feminist thought of the time. Hydropathy looked to nature, not credentialed male physicians, as the ultimate source of healing, and in so doing, it provided a vehicle for those seeking to redress what they thought were faulty notions of social and political authority.

Another nineteenth-century forebear of contemporary alternative therapy in the United States was Sylvester Graham (1794–1851), who combined conservative religious beliefs with zealous concern for health reform. An ordained Presbyterian minister and itinerant evangelist, Graham believed that human physical, moral, and spiritual well-being required scrupulous adherence to the natural order established by God. Graham admonished his followers that avoiding alcohol and the overstimulation of the sexual organs could help them maintain moral and physical health. His advice for a healthful diet included a coarse bread, later produced in the form of a cracker that still carries his name. Graham's dietary principles, widely circulated throughout the nineteenth century, served the cause of keeping the soul's "bodily temple" free from impurities.

Ellen White (1827–1915) occasionally visited a hydropathic resort in Dansville, New York, where she became a convert to Graham's dietary gospel. White thereafter had a series of mystical visions in which God revealed to her that he expected humans to follow the divinely given laws governing health and diet as faithfully as his moral laws. The Seventh-Day Adventist denomination founded by White has since then adopted Grahamite principles and a vegetarian diet as essential parts of purifying themselves in expectation of the Second Coming of Christ. Seventh-Day Adventists, one of the largest religious groups to originate in the United States, support a number of health sanatoriums and combine their evangelical religious faith with a strong emphasis on healthy dietary practices. This emphasis upon a healthful diet does not in and of itself constitute an alternative medical practice. Their dietary concerns are, however, closely connected with their belief in the efficacy of petitionary prayer.

The Rise of Mental Healing Practices

MESMERISM. The introduction of Franz Anton Mesmer's "science of animal magnetism," commonly known as mesmerism, in the 1830s and 1840s popularized a belief in the power of the unconscious mind to draw upon an invisible healing energy. Mesmer (1734–1815), a Viennese physician, believed that he had detected the existence of an almost ethereal fluid that permeates the universe. This fluid, called animal magnetism, flows continuously into, and is evenly distributed throughout, a healthy human body. If for any reason an individual's supply of animal magnetism is thrown out of equilibrium, one or more bodily organs will begin to falter. Mesmer proclaimed, "There is only one illness and one healing." The science of animal magnetism revolved around the identification of techniques for restoring a patient's inner receptivity to this mysterious, life-giving energy.

Mesmer held magnets in his hands and repeatedly passed them over the heads and bodies of his patients in an effort to induce the flow of animal magnetism into their systems. His followers later dispensed with the magnets, finding that verbal suggestions from the healer could induce patients into a trance, ostensibly heightening their receptivity to the influx of this metaphysical healing agent. Mesmerized patients claimed to feel prickly sensations running up and down their bodies that they attributed to the influx and movement of animal magnetism. Awaking from their sleeplike trance, they reported feeling refreshed, invigorated, and healed of such disorders as arthritis, nervousness, digestive problems, liver ailments, stammering, insomnia, and the abuse of coffee, tea, or alcohol. Some patients even claimed that the mesmerizing process enabled them to open up the mind's latent powers for telepathy, clairvoyance, and precognition. These claims contributed as much, or even more, to mesmerism's growing popularity than its reputation for healing.

A good many of those drawn to mesmerism were middle- and upper-class individuals who styled themselves progressive thinkers and were interested in uniting science and religion in a single philosophical account of human nature. Mesmerism struck them as an important step in this direction. The phenomena surrounding mesmeric trances were thought to provide empirical proof that each human is inwardly connected with higher, metaphysical planes of reality. Adherents of mesmerism believed that under certain conditions of psychological receptivity, humans are able to open themselves to an influx of energy or guidance from these higher realms. American mesmerists borrowed terminology from transcendentalism, spiritualism, and Theosophy to provide their middle-class reading audience with a new vocabulary for understanding the interconnection of their physical, mental, and spiritual natures.

MIND CURE AND CHRISTIAN SCIENCE. A popular philosophy known as the mind-cure or New Thought movement grew out of the mesmerists' healing practices. Mind-cure writers in the United States published books and pamphlets describing how thought controls the extent to which we are able to become inwardly receptive to spiritual energies. From Phineas P. Quimby and Warren Felt Evans in the late 1800s to Norman Vincent Peale, Norman Cousins, and Bernie Siegel in the late 1900s, Americans have displayed a remarkable enthusiasm for this "power of positive thinking" literature. The mind-cure movement gave rise to a novel form of religious piety based on the belief that the deeper powers of our mind control our access to a metaphysical power that can instantly help us to achieve peace of mind, improved health, and a never-ceasing flow of energy. The holistic health movement of the 1960s and 1970s relied heavily upon this cluster of metaphysical ideas.

Mesmerism was also instrumental in the formation of Christian Science. In 1862 Mary Baker Eddy, in great physical and emotional distress, arrived on the doorstep of the famous mesmerist healer Phineas P. Quimby. Quimby's treatments gradually cured her of her ailments; they also gave her a new outlook on life, based upon the principle that our thoughts determine whether we are inwardly open to, or closed off from, the creative activity of a spiritual energy (animal magnetism). Soon after Quimby's death, Eddy transformed his mesmerist teachings into the foundational principles of Christian Science. Her principal text, *Science and Health with Key to the Scriptures* (1875), reveals her intention to shift the science of mental healing away from the categories of mesmerism to those that bear more resemblance to Christian Scripture, albeit her own unique interpretation of it. The basic theological postulate of Christian Science is that God creates all that is, and all that God creates is good. Sickness, pain, and evil are not creations of God, and therefore they do not truly exist. They are simply the delusions produced in an erring, mortal mind that has lost a firm hold on the belief that only those things created by God have true existence. For Christian Scientists the universe is spiritual. What we call matter (e.g., bacteria, viruses, etc.) consequently does not really exist and therefore has no causal power. Christian Science healers, known as practitioners, help individuals to overcome their faulty thinking and to elevate their mental attitudes above the delusions of the senses. Healing occurs as the individual learns to function on a metaphysical, rather than a physical plane. Healings are understood not as miracles or faith healings but as the lawful consequence of exchanging false conceptions for true ones, which center solely on the higher laws of God's spiritual presence.

Both Christian Science and the "holistic health" philosophies that emerged from the mind-cure tradition teach that our thoughts control the degree to which we avail ourselves of the higher spiritual source from which health proceeds. As a consequence, illness or disease is understood as something the sufferer has brought upon himself or herself through failure to sustain a "correct" mental posture toward life. Any ethical analysis of these forms of alternative therapy must take seriously their built-in skepticism about whether a medical system really needs to attend to material causes of illness (bacteria, viruses, etc.). The issue is not quite so acute for holistic healing practices that teach that the mind can draw upon a higher energy capable of invigorating matter but do not teach that matter itself is unreal. In other words, most holistic health systems do not deny that there are physical and material causes of illness. They simply maintain that mental and spiritual factors are entailed in the etiology of most illnesses and must be taken into account in any comprehensive medical system. And thus, although they insist that a patient's mental outlook often is a significant factor in the creation and cure of illness, they do not espouse a medical theory that puts all the "blame" for illness or "credit" for recovery upon the patient.

Christian Science, by contrast, goes much further in challenging the empirical and rational foundations of Western science. By denying the ontological reality of matter, and hence the causal power of viruses or bacteria, Christian Science is clearly at philosophical loggerheads with both medical orthodoxy and the legal systems of most Western, democratic nations. For example, the Christian Scientists' belief system is opposed to immunization. The courts have understandably become concerned over the medical well-being of the children of Christian Science practitioners, as well as other students with whom they attend school; this has led to legal restrictions on the right of Christian Scientists to practice their form of religious healing. In 1990 the U.S. courts decided that two Christian Science parents were guilty of child neglect when their sole reliance on Christian Science methods was deemed responsible for their child's death (*Hodgeson v. Minnesota*). Such cases draw attention to the important ethical distinction between "private" religious belief and actions that have consequences in the "public" domain regulated by the legal system.

Christian Science healing practices, fundamentalist faith healing, and outright quackery have prompted strong responses from practitioners of orthodox medicine. The American Medical Association, emerging as a powerful national organization early in the twentieth century, set itself the task of prompting state and federal agencies to enact stricter licensing regulations. Its efforts to restrict medical practice to graduates of AMA-accredited medical schools surely furthered the cause of scientific medicine and protected the public from potentially harmful forms of quackery. It also tended, however, to force out of the medical marketplace those whose approaches to healing utilized a nonscientific worldview or whose medical services did not fit with dominant approaches to medical care.

Chiropractic and Osteopathic Medicine

Osteopathic and chiropractic medicine provide interesting examples of the fate of alternative philosophical, religious, and ethical interpretations of healing in an age dominated by scientific medicine. Osteopathic medicine emerged from the healing philosophy of Andrew Taylor Still (1828–1917). A former spiritualist and mesmeric healer, Still developed techniques for manipulating vertebrae along the spine in ways that he thought removed obstructions to the free flow of "the life-giving current" that promotes health throughout the body. Still explained the healing principles of osteopathy (a term derived from two Greek words meaning "suffering of the bones") in overtly metaphysical terms that described the origin and nature of "the life-giving current" ultimately responsible for human well-being. His followers largely discarded the occult-sounding dimensions of Still's philosophy and instead insisted that osteopathic medical education be grounded in anatomy and scientific physiology. Thus, although osteopaths originally relied only upon manual manipulations of the spine as a means of restoring health, they soon added surgery and eventually drug therapy to their medical practice.

By the 1950s, so few differences existed in the training or practice of osteopaths and M.D.s that their two national organizations agreed to cease the rivalry that had existed for several decades and to cooperate in such matters as access to hospitals, residency programs, and professional recognition. Having jettisoned the alternative worldview of its founder, osteopathy no longer bore any overt signs of unorthodoxy and finally found itself within the medical mainstream. Interestingly, during the 1960s many osteopaths were concerned about being absorbed into allopathic medicine and gave renewed focus to osteopathy's philosophical origins. Their commitment to osteopathy's historical concern with enhancing the body's natural powers for recuperation made them champions of holistic medicine long before the term *holistic* became commonplace among alternative healers. As of 1990, over 24,000 physicians practiced osteopathic medicine, collectively treating over 20 million patients per year.

The case of chiropractic medicine is more complex. Chiropractic originated in the work of Daniel David Palmer (1845–1913), a mesmerism-inspired magnetic healer in Iowa. Palmer, who knew of Still's osteopathic techniques, theorized that dislocations of the spine are able to block the free flow of the life force, which he called Innate (his nomenclature for animal magnetism). Palmer and his son, B. J. Palmer, explained that Innate is a part of the Divine Intelligence that fills the universe, bringing full physical health whenever it flows freely through the human body. Chiropractic medicine represents the Palmers' art and science of adjusting the spine in ways that remove obstructions to the free flow of Innate within the body.

Over the years, chiropractic physicians began downplaying the movement's metaphysical origins and emphasized its scientific approach to the treatment of musculoskeletal disorders. In this way, they minimized their theoretical unorthodoxy and identified an area of medical practice largely ignored by most medical doctors. Chiropractic physicians' sustained attention to this void in the "orthodox" medical system has earned them a viable niche in the medical marketplace; as of 1990, more than 19,000 chiropractic physicians were treating more than 3 million patients annually. Even though most medical insurance companies have come to recognize the medical functions performed by chiropractic medicine, M.D.s are still largely wary of chiropractic medicine because it has failed to elucidate an empirically validated theory that would substantiate its therapeutic claims. This professional tension provides a fascinating example of a continuing theme in the history of alternative medicine: the clash between orthodox medicine's rationalism (its insistence on an acceptable scientific explanation for all methods) and alternative medicine's pragmatism (discovery of therapies that produce results regardless of whether they are "proved" with rational theories).

Holistic, New Age, and Folk Medicine

During the last few decades of the twentieth century, the holistic healing movement led a surge of popular interest in therapies based on an explicitly religious, or quasi-religious, interpretation of the healing process. The precise meaning of the term *holistic medicine* varies among healing systems. Among its meanings are emphasis upon "natural" therapies, patient education and responsibility, prevention, and treating patients as "whole" people. Also common to holistic healing is the basic assumption that, as one handbook put it, "every human being is a unique, wholistic, interdependent relationship of body, mind, emotions, and spirit." The term *spirit,* alongside *body, mind,* and *emotions,* carries holistic healing beyond psychosomatic medical models; it also represents commitment to a belief in the interpenetration of physical and nonphysical spheres of causality. Even holistic healing's exhortations concerning reliance upon the body's own regenerative and reparative processes are typically laden with references to opening individuals up to the inflow of a divine healing energy. Persons who call themselves holistic health practitioners typically operate according to a worldview that is incompatible with the naturalistic framework of the modern Western scientific heritage.

One example of such a holistically oriented healing movement is Alcoholics Anonymous (AA), and its Twelve-Step program, which has influenced many other "self-regenerative" therapies. Founded in the 1930s, Alcoholics Anonymous has well over one million members, with about 35,000 groups meeting weekly in over ninety countries. The principal founder of the movement, Bill Wilson, was an alcoholic who became acutely aware of his inability to overcome his addiction. A mystical experience of "a great white light" convinced him that a loving Presence surrounds us and is capable of healing our broken inner lives. Wilson maintained that we need only to cease relying upon our own willpower and surrender to this Higher Power. Wilson was extremely wary of institutional religion, especially the moralism associated with biblical religion. From psychologists such as William James and Carl Jung, he pieced together a form of spirituality based upon opening the unconscious mind to a higher metaphysical reality. AA counsels its members that "in order to recover, they must acquire an immediate and overwhelming 'God-consciousness' followed at once by a vast change in feeling and outlook" (Alcoholics Anonymous, p. 569). AA's mystical, nonscriptural approach to personal regeneration sets its doctrines apart from most of America's religious establishment; its denunciation of both material and psychological/attitudinal factors in favor of an overtly spiritual view of healing sets its practices apart from the American medical and psychological establishments. But its open-minded and eclectic sense of the presence of spiritual forces in the determination of human well-being makes it one of the most powerful mediators of wholeness in America in the late twentieth century.

The various religious and healing groups that comprise the New Age movement endorse a holistic approach to health and medicine; they envision every human being as a unique combination of body, mind, emotions, and spirit. Central to New Age piety is the conviction that each person exists simultaneously in both the physical and the metaphysical (i.e., the astral and etheric) planes of reality. New Age therapies such as the use of crystals, therapeutic touch, and psychic healing seek to channel healing energies from higher metaphysical planes into the physical body. New Age crystal healing, for example, maintains that illness in the physical body is frequently caused by a disruption or disharmony of energies in what is called the *etheric body* (the portion of the self that extends into the astral and etheric planes). Healing consequently requires techniques to achieve harmony between the physical and subtle or etheric bodies. Crystals are thought to have unique properties that enable them to serve as receptors and capacitors of energies that emanate from the astral and etheric planes. Used properly, crystals are assumed to be capable of transmitting these energies in ways that bring the individual's physical, moral, and spiritual natures back into harmony. To this extent, New Age adherents do not reject the therapeutic efficacy of established medical science (though they do condemn what they perceive to be an overreliance on drugs and invasive surgical techniques) so much as its secularist and materialistic worldview, which fails to take into account our spiritual nature or potentials. Healing, for New Agers, is a by-product of the more fundamental goal of attaining an expanded spiritual awareness.

New Age healers are especially drawn to Eastern religious systems that involve entering into meditative states that heighten receptivity to the inflow of a higher spiritual energy, variously referred to as *ch'i, prana, kundalini,* animal magnetism, or divine white light. Yoga, t'ai chi ch'uan, Ayurvedic medicine, shiatsu, acupuncture, and various Eastern massage systems are studied for their advocacy of attitudes and lifestyles geared to the renovation of our moral and spiritual lives. Although each of these healing systems has its own philosophical basis and history, Americans tend to approach them with agendas left over from such nineteenth-century movements as mesmerism, spiritualism, and Theosophy. Even acupuncture, whose ability to alleviate pain and promote healing is more or less recognized—though poorly understood—by medical science, is embraced by many Americans not only for its obvious physical benefits but also for its connections with Eastern mystical philosophies.

A wide variety of folk and ethnic remedies exist alongside medical science. Botanical and herbal remedies, while ordinarily aimed at promoting health rather than curing illness, represent a noninvasive approach to physical well-being. Rural Pennsylvania Dutch still practice variations of *powwow,* an eclectic tradition using charms, prayers, and rituals, to prevent and cure disease. In the American Southwest, *curanderismo* still flourishes in Mexican-American communities, and recent immigration to the continental United States from the Caribbean has rekindled folk medicine practices (e.g., charms, herbs, incantations) peculiar to the African-American heritage. Immigration from Southeast Asia has brought Hindu and Buddhist medical practices like Ayurvedic medicine and prayers to the heavenly saints (bodhisattvas), who reward the faithful with their healing powers. Far East Asian immigrants have included dedicated practitioners of such religiomedical systems as t'ai chi ch'uan, shiatsu, and acupuncture. The continued presence of such folk or ethnic medical treatments may represent a form of preserving cultural identity, economic disenfranchisement from the nation's more expensive established medical system, or the seeds of a new era of genuine medical pluralism. In any case, both legal and economic attitudes toward alternative therapies must be philosophically and culturally nuanced.

The Challenge to Bioethics

Persons with life-threatening diseases who have not been helped by conventional treatments understandably become interested in pursuing alternative therapeutic strategies. The highly publicized debate over the effectiveness of laetrile for retarding cancer, for example, drew attention to the potential risks of the regulation of medicine by the U.S. Food and Drug Administration (FDA). At stake was the unresolved issue of whether a drug should be restricted only when it is known to cause harm or only when laboratory testing has failed to reveal measurable physical benefits. This debate continues in the controversy over various treatments for AIDS. Persons given a bleak prognosis by medical doctors seek immediate access to experimental drugs that have just entered the slow and laborious regulatory processes mandated by U.S. federal law. Although much has been done to try to speed up the evaluation of experimental AIDS-related treatments, a growing number of persons find themselves barred from access to innovative scientific treatment.

The central ethical question raised by alternative therapies is whether genuine medical treatment can be distinguished from various forms of quackery. Except for isolated instances in which individuals engage in deliberate medical fraud, quackery is difficult to identify or prove. Any reliable definition of therapeutic benefit requires being able to define the factors "known" to affect human well-being and what optimal health consists of. The practitioners of many forms of alternative medicine criticize the assumptions they believe underlie contemporary medical science. They argue that alternative therapies better understand human well-being and are cognizant of mental, moral, and spiritual factors that go well beyond the physiological considerations on which scientific medicine relies. To those who say that their practices or those who utilize them are "irrational," they respond that every therapy is rational insofar as its methods of treatment are logically entailed by its fundamental premises or its assumptions about the nature of disease.

Establishing criteria with which to mediate between competing medical systems is complicated by the fact that the plausibility of the beliefs or assumptions that underlie them are every bit as dependent on sociological factors as on intellectual "proofs." What we consider valid evidence, whom we consider expert authorities, and how we should go about separating relevant from irrelevant information turn not on objective, rational criteria but on the ways we were socialized into one belief system or another. Who, then, is in a position to decide what is an "irrational" medical choice? With what degree of confidence or philosophical integrity can orthodox physicians seek to dissuade persons from seeking alternative treatments? Do persons have a right to what seems to be an utterly ineffective therapy simply because it conforms to their personal belief system?

Alternative therapies may reasonably be expected to demonstrate their benefits to patients and to substantiate the claim that their distinctive healing practices directly cause these therapeutic results. Medical ethics is concerned with protecting persons from intended or inadvertent harm. Well-intentioned tolerance of alternative therapies should not preclude their undergoing rigorous scrutiny. Governmental agencies, healthcare facilities, and insurance companies are forced to allocate limited resources and to ensure the welfare of the general public. They must be prepared to make reasonable assessments of alternative medical systems that are based upon belief systems at considerable variance with modern Western science.

Because of the inherent threat that quackery poses to both personal and public well-being, ethical and policy-related judgments must exercise caution and strive for the unrelenting application of "public" (openly demonstrable and subject to empirical scrutiny) standards of evidence. The scientific study of psychosomatic interaction (e.g., of the role of psychological variables in the etiology of ulcers) promises to help practitioners of alternative therapies justify their practices in ways that are more amenable to these standards of evidence. Because psychosomatic medicine has expanded scientific appreciation of the roles nonmaterial factors play in the etiology of illness, alternative medicines have access to a set of medical categories that will potentially enable them to argue for the therapeutic efficacy of treatments that focus on such nonmaterial factors.

Cases involving patients' desire to be permitted to use drugs before they have received FDA approval testify to the conflict between private needs and the regulation of public well-being. Unlike alternative therapies that are based on different belief systems, unvalidated drug therapies are usually discussed using medically orthodox terms and logic. The ethical concerns here are more frequently about the speed with which regulatory agencies arrive at decisions on potentially lifesaving drugs or the possible collusion of powerful pharmaceutical companies with regulatory agencies to keep competitors from the marketplace. Perhaps the most important consideration in assessing unvalidated therapies is that contemporary medicine differs from its predecessors not because we have become more rational but because we have learned to use the controlled trial to determine the relative merits of competing medical treatments.

Medical systems that are labeled unorthodox because their concerns or treatments are at the periphery of mainstream medicine are reminders that dominant professional groups tend over time to employ predatory tactics to ensure their continued supremacy and keep potential competitors at a distance. These "medically peripheral" systems alert us to the fact that medical science has philosophical and institutional blinders that may close off, rather than open, innovative approaches to human health. The presence of alternative health professionals in the wider system of healthcare helps safeguard against the kinds of complacency and narrowness of vision that frequently creep into economically entrenched professions. By providing a range of services that address both curative and preventive issues typically neglected by allopathic physicians, many of these alternative therapies contribute to a comprehensive understanding of human health and well-being.

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SEE ALSO: *Healing; Health and Disease: Anthropological Perspectives; Medicine, Anthropology of; Medicine, Philosophy of; Medical Ethics, History of the Americas;* and other *Alternative Therapies* subentries

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II. ETHICAL AND LEGAL ISSUES

Alternative medicine covers a dizzyingly heterogeneous group of medical theories and practices. Alternatives range from the different forms of faith healing, Christian Science, and folk medicine to allegedly scientific systems like homeopathy, chiropractic, and visualization therapy. Also included under the term are acupuncture; herbalism; iridology; the traditional medicines of India, China, Japan, the Philippines, and indigenous peoples; holistic medicine; naturopathy (treatment using agents or elements found in nature); shamanism; yoga; radiesthesia (therapy based on detection of natural waves of force emanating from nature); color healing; aromatherapy; transcendental meditation; crystal therapy; thalassotherapy (treatment based on sea bathing, sea voyages, etc.); massage therapy; midwifery; and many others. Certain shared negative elements justify lumping together such diverse medical theories and practices. They include marginal social standing or fringe status; exclusion from mainline professional journals and public funding for research; exemption from mainline licensing requirements; and opposition to conventional medicine. The essential ethical and legal considerations raised by alternative medicine are veracity and nonmaleficence. Because false claims of healing efficiency can cause direct and indirect harm to patients, any such claims violate the essential ethical standards of all medical practice, whether alternative or conventional practice.

The Meaning of *Alternative* and *Conventional*

"Alternative" implies alternative to orthodox, regular, mainline, or conventional medicine. These latter adjectives refer to a medical theory, based on modern science, that began to emerge in the Renaissance with medical innovators such as Andreas Vesalius (1514–1564) and Paracelsus (1493–1541), and to scientifically validated medical therapies that blossomed in the twentieth century. If alternative medicine is characterized by an enormous variety of different medical theories and practices with little in common either conceptually or culturally, conventional medicine has the appearance of a single powerful system based on a narrowly conceived biology and focused primarily on the organic needs of sick people. Besides being scientific and materialistic, conventional medicine is also rationalistic: a system that relies on hard data, observation, controlled experimentation, logical argument, and a somewhat outdated view of causality. Alternative and conventional medicine actually help to define one another by contrast and opposition.

What is now classified as either *conventional* or *alternative* medicine was not always so designated. Formerly alternative medical theories and practices have moved into conventional standing; for example, the use of antioxidant vitamins and other dietary remedies for both prevention and therapy (Steinberg; Stampfer et al.; Rimm et al.). Formerly conventional medicine is in the alternative category; this includes most nineteenth-century therapies like baths, massage, and purgatives. Between the Renaissance beginnings of modern orthodoxy and its dominance in the twentieth century, conventional medicine was practiced by relatively few university-trained physicians. Most sick people during these centuries got along on remedies developed under older theories. Even university physicians used bleedings and purgings, sweating, and vomiting in addition to quinine and digitalis; not much separated scientific orthodoxy from nonscientific alternative practice when it came to therapeutic interventions. In the nineteenth and twentieth centuries, university-educated physicians established their own medical associations, adopted updated ethical standards, reformed their educational systems, proved that microorganisms cause infectious disease, developed vaccines to control them, employed technologies to improve both diagnosis and therapy, and finally gained legal status for their practice, along with monopolistic control of healthcare institutions. The line between a unified, socially supported, conventional medicine and separate, alternative medical practices became much more clearly drawn.

Differences between conventional and alternative medicine are accentuated by a continuing polemic. The term *alternative* is still used by conventional physicians as synonymous with quackery, falsehood, uselessness, and dishonesty. *Alternative* is frequently used to mean foreign or antiquated, or to emphasize the different cultural origins and ancient practices of alternative medicine. In literature favoring alternative therapies, conventional medicine is characterized by toxic and addictive drugs, high costs, aggressive procedures, impersonalness, unnecessary surgeries, economic monopoly, and iatrogenic (physician-induced) illnesses. For their part, orthodox critics create the impression that alternative medicines are products of prescientific cultures, but that conventional medicine is purely scientific and transcends historical and cultural influence.

What constitutes disease and illness, however, as well as how they are understood and treated by any medical system, is necessarily historical and cultural. Contemporary culture's medical–industrial complex, for example, has as much influence on mainline medicine as the military–industrial complex has on modern warfare. Indeed, the historical and cultural content of conventional and alternative medicines is an important consideration wherever legal and ethical issues are addressed. What is ethically right cannot simply be reduced to what is culturally dominant. Cultural dominance does not equate with ethical correctness; minority status or identification with another culture does not reduce to moral incorrectness. Only when cultural and historical factors are identified on both sides can ethical and legal questions about alternative medicine be clearly addressed. Then dialogue can be substituted for hostility and common ethical standards can be developed for both types of practice.

Conventional Allopathic Medicine: Justifying Its Preferred Status

Conventional medicine is known as *allopathy*. This term sets it apart from homeopathy, a nineteenth-century theory and practice that treated disease by administration of minute doses of a remedy that would, in healthy persons, produce the same symptoms as the disease being treated (*similis similibus curantur*). Allopathy, in contrast, is a system that counteracts disease by the use of remedies that produce effects different from those produced by the disease (*contraria contrariis curantur*). Allopathic medicine by definition combats, counteracts, and aggressively opposes specified disease entities. Today's conventional allopathic medicine has its own history and is the product of strong cultural influences. The allopathic approach, originating in ancient Greece with the Hippocratics, was reinforced in the nineteenth century by opposition to the homeopathic alternative. Another important historical influence was a high school teacher from Kentucky, Abraham Flexner, who wrote a book on U.S. medical practice that laid the foundations of what we call medical orthodoxy.

The Flexner Report, published in 1910, not only criticized medical education and practice in North America but also held up a model of ethical medicine grounded on hard laboratory science and universal laws. For Flexner, ethical medicine targeted disease objects rather than patient complaints, and like engineering was founded upon hard science. Under his influence, nineteenth-century German medicine came to be orthodox medicine in the United States, and a new medical school at Johns Hopkins University was held up as the model for the way orthodox medicine should be taught and practiced. Doctors William Welch (1850–1934), William Osler (1847–1919), William S. Halsted (1852–1922), and Howard Kelly (1858–1943) at

Johns Hopkins became the architects of mainline orthodoxy, and all four were products of German training (Ackerknecht). Because Flexner applied the images of war to medical practice, orthodox medicine became an aggressive, hands-on science. Engineering and military science shaped mainline medical attitudes and procedures, while biology, histology, embryology, anatomy, physiology, pathology, and bacteriology provided the substance of orthodox medical understanding. For Flexner all other approaches were both unscientific and unethical.

What over several centuries came to be orthodox medicine enjoys great power and prestige in so-called developed societies because it alone of the classic professions (law, medicine, ministry) wrapped itself in the mantle of hard science. Alternative medicine is alternative because it lacks that mantle. If alternative medicine is ethically suspect, it is because hard science became the ethical as well as the epistemological standard in twentieth-century culture. Being unscientific or deficiently scientific amounts to being irresponsible in medicine. All alternative medicines are not the same in this regard, but in general, alternative medicine's moral weakness can be traced to an absent or weak science.

Some alternative medicines claim to use "a different science." They adopt the stand that modern science is just another cultural variable or another historical belief system. Some defenders of alternative medicine argue that one cultural variable or belief system is as good as another. No rational grounds exist, they claim, to prefer one medical system to another or to assign to one a greater social and ethical standing. From the fact that mainline science is itself cultural and historical, radical advocates for alternative medicine make their basic argument for equal legal and ethical status. Patients, they insist, must be totally free to make their own choices about treatment. Their argument is strengthened by calling attention to the theoretical flaws in modern science.

Karl Popper's work, *The Logic of Scientific Discovery* (1939 German edition; 1959 English edition), on the concepts of verifiability and falsifiability undermined claims about what is proved in science. He argued that the best science can do is demonstrate what is false, not prove what it true. Later, Popper's claims about falsifiability were themselves shown to be flawed. Then Thomas Kuhn (*The Structure of Scientific Revolution,* 1962) showed how what he called a *paradigm* defines what counts as admissible evidence in science, and how these paradigms change. The foundations, then, on which modern medical orthodoxy bases its claims to ethical and social superiority are strongly influenced by cultural-historical factors.

Modern science and mathematics may have rational and conceptual flaws, but all flaws are not equal. Despite the flawed epistemological foundations of science and mathematics, they still can be used to build bridges that work and spacecrafts that arrive at their destinations. Modern medical science too has real explanatory power. The rigor of scientific explanation, however, is often absent in alternative medicines. Mainline scientific research is much more credible than unscientific and unsubstantiated claims. Admittedly, alternative medicines lack the government funding to carry out sound research, which is expensive, but many alternative medicines ignore research and have unrigorous standards for subjecting therapeutic claims to critical review. If a medicine is ethical and earns preferential social status because it bases its claims and practices on publicly confirmable evidence and continuing critical review, then orthodox scientific medicine warrants the ethical and legal priority it enjoys.

Some Alternative Medicines

CHRISTIAN SCIENCE. All alternative medicines do not have the same relationship to modern science. Christian Science is an alternative to conventional medicine in the most radical sense: denying the existence of matter as well as disease, illness, pain, and death. Mary Baker Eddy (1821–1910) was a sickly person who had a healing experience in 1866, which she understood as the discovery of Christian Science, a religion centered on healing and health. Her book *Science and Health: With Key to the Scriptures* (1875) is read at all Christian Science services along with the Bible, thereby continuing her healing ministry. It contains her metaphysical beliefs about disease, death, matter, spirit, and God, one famous synopsis of which is as follows:

> *Question.* What is the scientific statement of being?
>
> *Answer.* There is no life, truth, intelligence, nor substance in matter. All is infinite Mind and its infinite manifestation, for God is All-in-all. Spirit is immortal Truth; matter is mortal error. Spirit is the real and eternal; matter is the unreal and temporal. Spirit is God, and man is His image and likeness. Therefore man is not material; he is spiritual. (Eddy, p. 469)

Christian Science healing is not like the "miracle cures" of faith healers. Ministers who claim to heal acknowledge the existence of disease and evil, but Mary Baker Eddy did not. Her religion trains "practitioners," who devote their energies to healing in a different sense. They are called upon by believers just as non-Christian Scientists seek out physicians when they are ill. The practitioner talks to people on the phone, visits them at home, and heals by restoring patients to the spiritual plane of thinking that according to Christian Science is reality. Healing, then, is actually reeducation, in which the patient is brought to exchange mental errors and delusions for God's truth and God's reality, where evil, illness, disease, and death have no place.

Christian Science is a radical alternative because it is founded upon a worldview at odds with the theoretical base of conventional medicine. According to this metaphysical theory, disease, pain, sickness, and death only seem real because people believe them to be so, and practitioners heal by stripping away these false beliefs. Conventional doctors in this view are engaged in "un-Christian and sinful" activities; indeed, they live in an unreal world. And yet a certain civility characterizes the debate between orthodox medicine and Christian Science. The latter belief system may be too bizarre for most mainline physicians to take seriously. Christian Science apologists, however, tend to be middle-class and well educated, and they respond to objections with reasoned discourse.

This civility has been strained by several legal cases involving parents whose children died after being treated by Christian Science practitioners instead of by conventional physicians. Following the court decisions, calls were issued in the *Journal of the American Medical Association* and *New England Journal of Medicine* for stronger child-protection legislation and stronger penalties for "parents who use the pain and anguish of their children to demonstrate the strength of their belief in Christian Science." Conventional physicians warned against child-neglect legislation in Colorado, Texas, and Louisiana that provides religious exemptions for Christian Scientists. In some places Christian Science has become in effect the legal equivalent of conventional medicine. Mainline doctors object to this as well as to the fact that Christian Science practitioners have legal standing comparable to their own. Blue Cross and Blue Shield pay practitioners in some states, as do major insurance companies and Medicare. Practitioners may even sign certificates for sick leave and for disability payments. According to conventional physicians, this policy creates a double standard. Practitioners, they insist, should be required to meet much higher standards if they are to receive comparable medical responsibilities (and benefits).

In 1989 the parents of a seven-year-old girl were convicted of third-degree murder and child abuse in connection with her death from diabetes. A Sarasota, Florida, jury rejected the parents' claim that they had not sought medical treatment for their daughter because of Christian Science belief. This was the first case in the United States since 1967 in which Christian Scientists were held criminally responsible for relying on the practices of their faith alone to cure a child's illness.

In July 1990, a Boston jury convicted Christian Science parents of manslaughter because they relied on the services of practitioners rather than conventional medical care to treat their two-year-old son, who had died of bowel obstruction in 1986. The parents were sentenced to ten years' probation and ordered to take their other children for periodic medical checkups. This case aroused unusual interest because it took place in Boston, the headquarters of the Christian Science Church. Both cases reflect a pattern in U.S. courts, which have ruled that competent adults have a right to refuse treatment—even life-saving treatment—for themselves, but not for their children. The same response was made regarding Jehovah's Witness children whose parents refuse blood for them based on religious belief.

Official Christian Science response to these decisions has been reserved and moderate. In an official publication (First Church of Christ, Scientist), church officials recognize that the state has an interest in and a responsibility to protect children against abuse, including the possibility of their being used by parents to prove the strength of their faith. They acknowledge that the death of a child treated by practitioners alone is a tragedy, but counter with examples of thousands of children cured from certified illnesses by Christian Science practitioners and many deaths resulting from treatment with conventional medicine. They also recognize the distinction between unrestricted First Amendment freedom of belief, on the one hand, and restrictions on behavior or acting on belief, on the other. Still, church officials argue against any law that would radically restrict Christian Science treatment of children. Like advocates of alternative medicine generally, they argue for a right to unrestricted practice on the basis of the patient's right not to be interfered with in private matters. It would, however, be more ethically responsible for Christian Scientists to make explicit the childhood conditions where practitioners can cooperate with physicians, instead of forcing parents to make an either-or choice. This same solution could apply to other alternative practices; it would require increased communication and cooperation between conventional physicians and alternative practitioners.

Cases involving children put at risk because of parents' religious beliefs pose questions that can be addressed either by ethics or by law. In the language of ethics, these cases create a conflict between a negative individual right—not to be interfered with in private matters like religious belief and healthcare decisions—and a positive societal right or obligation: to protect vulnerable people. Put differently, they reflect a conflict between the principle of individual autonomy and the principle of justice. If the principle of autonomy is respected, justice is compromised, and vice versa.

In the history of Western ethics, individual rights and autonomy concerns are late arrivals—dating from the eighteenth-century Enlightenment period. Societal rights to protect life and the duties of citizens to obey societal norms are much older. Dilemmas involving the two types of ethics are worked out by emphasis on the importance of societal rights and justice, but restriction and limitation of their implementation by reference to individual rights and autonomy. Societal rights (justice) in effect are balanced with individual rights (autonomy), and the only justified degree of societal influence is that which is necessary to accomplish basic justice. In ethical language, the state has an interest not only in justice but in the protection of individual autonomy; therefore it has an interest in balancing the two goods. In legal language it is the balancing of negative constitutional rights—founded on the Bill of Rights (freedom of religion)—and a positive legal obligation of *parens patriae*. The particulars of the legal balancing are worked out through common law decisions in Anglo-Saxon systems. Statutory laws and policies that in effect deny a child access to effective treatment for serious illness can be considered both ethically and legally deficient.

LAETRILE. Alternative medicine is used by most patients for prevention and as an adjunct to conventional treatments. Alternative medicine, however, also flourishes where conventional medicine is weak, inattentive, or an outright failure. When conventional medicine has nothing more to offer and the patient faces death, many people look to alternatives. Cancer at certain stages of development provides a case in point. Because of devastating side effects associated with conventional cancer treatment (chemotherapy and radiation), alternative approaches are particularly attractive. Ten billion dollars is spent annually on unproven alternative cancer treatments, in many cases by affluent and well-educated patients. One such alternative that generated great public debate, court cases, and then finally involvement by the federal government was laetrile, a controversial drug derived from apricot pits and held up as the last hope for terminal cancer patients.

In the 1970s this drug, which had been around for decades, received wide publicity not only because of claims made about its effectiveness but also because the U.S. Food and Drug Administration (FDA) had banned its interstate shipment and sale. This created another conflict between an individual negative right not to be interfered with in choosing treatment and the positive social right to protect vulnerable people against exploitation. In 1979, the U.S. Supreme Court ruled that the FDA could legally inhibit the distribution of the drug, based on the agency's powers to establish "safe and effective" standards; this ruling validated the agency's positive social right. In *Rutherford v. United States* (1979), the Supreme Court remanded the case to the U.S. Tenth Circuit Court of Appeals for reconsideration of other arguments. The appeals court held that the FDA ban did not violate the individual negative right to privacy of cancer patients.

Responding to public pressure, the FDA on January 3, 1980, gave approval for the National Cancer Institute to initiate scientific trials to study laetrile. First, animal studies would be conducted, then stage-one toxicity trials on six human patients, and finally a clinical trial involving 200 to 300 advanced cancer patients who volunteered for the laetrile treatment. The studies were delayed by debate over the money and time required to test an allegedly ineffective drug and over who would perform the tests. Although some alternative practitioners were board certified in conventional medicine, most conventional physicians and scientists resisted involvement with an "alternative" therapy.

On April 30, 1981, the National Cancer Institute announced that it had found laetrile, or amygdalin, to be ineffective as a cancer treatment. The announcement was made at a meeting of the American Society of Clinical Oncology. Over half the patients given the alternative therapy had died and the rest had not responded to the treatment. Charles G. Moertel, director of cancer treatment at the Mayo Clinic, who gave the report, added that he hoped the study would end "the exploitation of desperate cancer patients" by doctors prescribing the drug in twenty-three states where its use was legal despite the FDA ban on interstate sale and shipment. (This apparent contradiction is rooted in the fact that federal regulations are often imperfectly coordinated with state statutes, which may allow the use of federally banned drugs.) Laetrile advocates claimed that the test was rigged and that a less than optimum form of laetrile was used. The contemporary debate over alternative therapies—especially for cancer—continues, although one hears little about laetrile (Cassileth et al.).

HOMEOPATHY. Homeopathy originated in Germany at the end of the 1700s in the work of Samuel Hahnemann. By the end of the next century, one in every seven physicians in the United States was a homeopath. The nineteenth- and twentieth-century successes of allopathic medicine considerably reduced the influence of homeopathy. As the limits of allopathic medicine have become better recognized, homeopathy has begun to make something of a comeback. About 1,500 homeopaths practice in the United States, and medical practitioners use homeopathy in Australia, the United Kingdom, Germany, India, Brazil, and Argentina.

Included under conventional allopathic practices are drug therapies in the process of scientific trial but not yet officially approved (unproven or nonvalidated therapies), and fully approved and scientifically validated drugs being used in novel ways (innovative therapies). Homeopathy uses its own special brand of unproven and innovative "drugs." Homeopathic medicines or remedies are available in many health and natural food stores in the United States. Because mainline pharmacy and professional pharmacists are strongly aligned with the allopathic system and conventional physicians, they have few incentives to become involved with homeopathic practices. Licensed conventional pharmacists would have little understanding of homeopathic preparations and little economic motivation to add these to their stock. Homeopathic pharmacists/practitioners prepare their own medications; a large part of the homeopathic doctors' work involves modifications (dilutions) of these remedies for each individual illness or patient.

If interest in alternative medicine continues, mainline drug stores may begin to carry some over-the-counter homeopathic remedies. Then, presumably, mainline pharmacists will learn about homeopathic background theories in order to explain these preparations to customers. Would doing so compromise the scientifically trained pharmacist's belief system because of the appearance of endorsement? Ordinarily not. Pharmacists as a group learn about natural remedies and understand the importance of patient belief in such products for therapeutic effectiveness. Pharmacists have their own professional code (American Pharmaceutical Association, 1981; see the Appendix) and standards of practice. These would be compromised only if an alternative therapy were known to be harmful.

VISUALIZATION THERAPIES. The biological sciences of orthodox medicine are materialistic (i.e., founded on physical realities and quantifiable data) and are ill-equipped to handle many of the problems listed as disease categories in psychiatry's diagnostic manual (American Psychiatric Association). A narrowly focused conventional psychiatry relies on chemical therapies and restricts practice to drug prescriptions and medication reviews. Beyond this narrow range of orthodoxy, psychological and social theories have added a broad assortment of nonchemical approaches to conventional practice—from classical psychoanalysis (through cognitive, behavioral, and group treatments) to visualization therapies.

Hypnosis, guided imagery, and biofeedback are all forms of visualization therapy often used in orthodox treatment centers. Practitioners may be conventional physicians, psychologists, social workers, or nurses. The conditions addressed by these techniques include everything from mental and emotional illness to immunological disorders, childhood hyperactivity, and cancer and senility. On the theoretical level, practitioners and advocates work to demonstrate just how the mind controls the brain and immune system (the mechanisms of psycho-neuro-immunology). The effect of biofeedback on psyche (stress reduction) and physiology (temperature, heart rate, blood pressure) is well documented. Advocates of visualization therapies argue that they can enhance the functioning of the immune system. Controversy about this last use of visualization therapies has centered on its scientific status. Whether it will be considered an alternative therapy or an extension of conventional medicine, in the sense that it broadens conventional medicine's positivistic base to include psyche, will depend on whether the visualization techniques can generate satisfactory scientific proof of effectiveness in this important area. Advocates of mainline medicine, such as Norman Cousins, Bernie Siegel, and Andrew Weil, testify to the need for a wider theoretical base for mainline practices, one that includes a place for the mind's influence on bodily healing (Cousins; Siegel; Weil).

CHIROPRACTIC. Chiropractic is probably the best-known alternative medicine in the United States. Practitioners call themselves doctors and complain bitterly about being excluded from mainline medical institutions. The effectiveness of manual manipulations, they insist, is based on scientific studies, but it is difficult for hands-on chiropractic manipulation to eliminate placebo effect and to satisfy double-blind requirements. Back pain could be called the chiropractic specialty, and orthopedic physicians the mainline competition. One double-blind scientific study of the effectiveness of chiropractic versus conventional treatment conducted in 1990 strongly favored chiropractic therapy (Meade et al.). Conventional physicians attacked the study's science, attempting to show that the statistics were unreliable because the study's method was not rigorous enough. Most chiropractors feel discomfort about requiring that any claim of effectiveness satisfy a double-blind requirement, because doing so would throw doubt upon many of their own scientific studies of effectiveness, which are statistical but not double-blind. Some chiropractic medical schools have their own research institutes and are continuously involved in effectiveness or outcome studies; one example is the ongoing research of the Palmer College of Chiropractic Graduate School in Davenport, Iowa. Despite extensive use of chiropractic in certain parts of the United States, serious dialogue and cooperation with mainline practitioners are limited.

Orthodox Public Health and Alternative Practices

No practice has been more orthodox since the nineteenth century than public-health medicine. When microscopic technologies aided in the discovery of bacterial causes of infectious diseases, public-health physicians began energetic application of laboratory science on behalf of societal health. Public-health physicians were laboratory science's strongest advocates. They insisted upon strict quantitive standards of proof for what they considered ethical medical practice. Only what could be shown quantitatively to be effective (e.g., vaccine) commanded their respect and endorsement. Laboratory science alone was the ground for real medicine. They used the police power associated with public health (health laws and their enforcement) to support the narrow positivistic foundation of conventional medicine. Medicine for them was narrowly focused on microbes and they tended to leave broader cultural and environmental issues out of consideration. We know that an adequate science does not leave ecology out of consideration, and it does not ignore sociocultural influences on behaviors that spread disease.

The new public-health practice requires "cultural competence," that is, an understanding of the culture of the people to whom public-health policies are applied. Ethnic ways, which include particular attitudes and practices related to health and disease, have to be taken into consideration in order to provide the most effective public-health services. Cooperation between conventional physicians and alternative practitioners, we know, may make the difference between compliance and noncompliance in minority populations.

The World Health Organization (WHO) has strongly advocated cooperation between conventional physicians and alternative practitioners because neither one is likely to disappear. In the United Kingdom in 1995, one in seven people visited alternative practitioners. In the Netherlands, a survey of 293 conventional generalists showed that many believe in the efficacy of certain alternative practices: manual therapy, yoga, acupuncture, hot baths, and homeopathy. In Germany, a distinction is made between scientifically supported alternatives such as naturopathy, which stimulates the body's own healing resources, and unscientifically based alternatives. The former are covered by some insurance policies and the state plan pays a subsidy to patients using them. In Norway, a group of conventional physicians and alternative practitioners are meeting to promote closer cooperation (Rankin-Box).

Because the use of alternative treatments continues to increase both in the United States and in Europe, new studies of alternative approaches have been initiated. In 1993, the National Institutes of Health (NIH) created an office of alternative medicine, where alternative approaches are tested; the public will be kept informed of research results. The U.S. Congress mandated the creation of this project and required that NIH spend two million dollars of its annual budget on it. An oversight committee includes both conventional physicians and alternative practice advocates. They have agreed that alternative practices will be evaluated with the same methods and standards as conventional therapies (outcome research, relative efficiency, double-blind where possible). This is an important development because ethical considerations of alternative practices have to start from reliable information about their effectiveness. This project has added ethical importance because the projects funded require cooperation and collaboration between alternative and conventional practitioners wherever possible.

Ethical Standards and Alternative Practice

Alternative medicine is governed by ethical obligations derived from what medical practitioners of any variety publicly profess and what societies have always required of them: to heal, to relieve pain, to restore function, and to comfort and accompany their dying, when patients are beyond treatment. In the Hippocratic tradition this basic ethical standard was encapsulated in the imperative "to help and not to harm." Early twenty-first century medical ethics talks about the same basic ethical obligation in terms of the principles of beneficence and nonmaleficence.

Alternative or conventional interventions that harm patients without providing offsetting benefits are unethical. Alternative treatments that are harmless may not violate either individual or social ethical standards—especially if patients have strong faith in them or if the illnesses for which they are used are self-limiting and conventional treatments are either expensive, have serious side effects, or have proven ineffective. When diseases being treated are more serious, however, harmlessness is not enough to satisfy individual and social ethical standards. If harmless alternative remedies prevent patients from seeking an effective treatment available from conventional medicine, then individual alternative practitioners would actually be preventing patients from being helped, and just social policy would require that such practice be curtailed. Although alternative remedies are most often adjuvant and complementary to mainline remedies, it remains important to respect the social and professional ethical requirement that treatment actually provide some benefit to patients. Patient benefit is a complicated concept that sometimes involves unquantifiable quality of life considerations, but patient benefit cannot be permitted to slip beyond empirical proof entirely. Societies have to make laws that use rigorous empirical standards for approval of treatment modalities. Anecdotal evidence of therapy effectiveness or claims of effectiveness dependent upon depth of commitment to an alternative belief system are not enough to satisfy basic individual and social medical ethical obligations.

Modern medical-ethical standards add another basic obligation derived from patient rights, that is, that the patient has the right to consent to treatment or to refuse consent. Alternative practitioners, like conventional doctors, are ethically obligated to provide patients with information relevant to their decisions and to protect patients against coercion, fraud, or manipulation. If patients are not competent, informed consent or refusal must be provided by surrogates—either family members or, in their absence, a guardian. Even decisions of competent patients, however, must meet professional standards, so that an irrational choice or insistence upon a treatment that is ineffective or futile or economically devastating might not—perhaps should not—be respected. The modern principle of patient autonomy must be balanced with the ageless principle of beneficence/nonmaleficence, which protects patients against irrational or incompetent decisions that involve harm without offsetting benefit. Care must be exercised, however, in judging irrationality so as not to confuse it with decisions based on value systems different from those of the treating physician or practitioner. Patients have their own values, and these cannot be set aside because they differ from what a scientifically focused specialist may think is organically best for a patient. True patient benefit requires consideration of both personal and scientific interests.

A competent adult may refuse an effective conventional treatment associated with real burden and choose instead an unproven or ineffective alternative therapy. Similar choices, made for children or for incompetent adults without advance directives, however, are neither ethically nor legally acceptable. Justice and autonomy, beneficence and nonmaleficence are broad, abstract ethical standards. Agreement about these standards in their abstract form is possible even in pluralistic and heterogeneous societies. But principles can come into conflict with one another. Respect for patient autonomy may mean not providing patient benefit or violating principles of justice and equality. When such conflict occurs, ethics at a more pragmatic level of discourse is required: concrete norms and rules that attempt to offer compromise, or to effect a balance between the conflicting principles. Working out the relationship between mainline conventional medicine and alternative practices involves just this form of concrete ethics. Appeal to abstract principles only in a situation of conflict between conventional and alternative medicine can turn an ethics discussion into an exchange of slogans. One important test of an ethics that addresses the relationship between alternative and conventional medicine is whether it encourages a needed dialogue between different practitioners and whether it can generate concrete norms and public policies to handle interaction between the two traditions (Eisenberg et al.).

Ethics has been intimately associated with mainline medicine since its beginning in Hippocratic times. Hippocratic physicians were distinguished from other healers not only by their emphasis on science but also by their commitment to patient benefit rather than to selfish goals. Medicine of any variety derives its ethics from obligations generated by a doctor-patient relationship in which a healer commits himself or herself to help someone in need by cure or pain relief or function restoration. Unselfishness and altruism are at the core of medicine's professional ethics. Truthfulness traditionally was not part of medical ethics, but recently it has been added in order to fulfill the obligations associated with patient autonomy. This essential and structural medical ethics is applicable to alternative and conventional medicine alike.

Mainline medicine obliges physicians to high ethical standards but has been weak in policing deviant members and sanctioning ethical failures. Alternative practitioners are not as well organized as conventional physicians, and some lack the strong ethical emphasis of the mainline tradition. Both face a daunting challenge: developing and maintaining the character traits without which concrete moral rules and abstract ethical principles are ineffective, in a new economic climate that encourages profit making more than altruism.

JAMES F. DRANE (1995)
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SEE ALSO: *Autonomy; Emotions; Healing; Healthcare Professionals, Legal Regulation of; Jehovah's Witness Refusal of Blood Products; Medicine, Philosophy of; Public Health Law;* and other *Alternative Therapies* subentries

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ANIMAL RESEARCH

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I. Historical Aspects
II. Philosophical Issues
III. Law and Policy

I. HISTORICAL ASPECTS

The historical background of the discussion of the ethics of animal experimentation will be examined by considering first the rise of medical research (physiology and pharmacology particularly), then the emergence and consolidation of opposition to research using live animals. Both developments were shaped, of course, by the capabilities and goals of science in every era, and were also powerfully influenced by the philosophical and religious environments within which science operated.

The History of Animal Experimentation

Vivisection—the cutting open of living animals to observe their inner structure and functioning—can be traced to Greek antiquity, but it was Galen (129–c. 210 C.E.), the most celebrated physician of the Roman Empire, who developed vivisection as a tool for methodical physiological investigation. By such procedures as ligation of the ureters to show they channeled urine from the kidneys to the bladder, and sectioning of the spinal cord at different levels to establish the relations between individual nerves and the body regions they served, Galen demonstrated the power of surgical interventions to produce a deeper understanding of bodily functions (Rupke).

During the early medieval period, animal experimentation fell into the same desuetude as other areas of scientific inquiry. To be sure, ancient scientific traditions were preserved and elaborated upon by Arabic scholars, but not until the late Middle Ages did an experimental spirit revive in the European world. Skepticism about the adequacy of ancient scientific ideas built to a head during the 1500s, culminating for the life sciences in the 1543 publication of *De Humani Corporis Fabrica* by Andreas Vesalius (1514–1564). The first anatomy text based on careful dissection of the human body, Vesalius's work sharply revised the long-accepted anatomical system of Galen (which had been derived entirely from animal dissections), and thus encouraged experimental reevaluation of Galenic theories of physiology as well.

The most significant correction of Galen's physiology was accomplished by the English physician William Harvey (1578–1657), whose demonstration of the circulatory movement of the blood through the body was based on observations of the contractions of the heart, ligation of the aorta and vena cava, and other vivisection procedures performed on more than eighty species. Harvey's *De Motu Cordis* (1628) heightened misgivings about the validity of other Galenic ideas and confirmed animal experimentation as an invaluable technique for physiological discovery. Vivisection became a commonplace scientific activity by the later 1600s; it was used over the next century and a half to investigate such varied phenomena as respiration, pancreatic secretion, and blood pressure (Rupke; Foster).

Yet as late as 1800, experimentation was still only one of several approaches to elucidating physiological processes. Drawing conclusions about function on the basis of structure—deducing physiology from anatomy—remained popular, as did *a priori* theorizing in accord with some physical or chemical model; experimentation might be employed in either of those cases, but only to substantiate the preestablished theory. That overly rationalistic orientation to physiology and medicine was already coming under attack, however, by the *philosophe*-physicians of the "Paris School." Their call for a medicine rooted in empiricism was answered most eagerly and effectively by Francois Magendie (1783–1855), who from 1805 through the 1820s used animal experimentation to clarify such questions as the mode of action of strychnine, the mechanism of emesis, and the functioning of the nervous system. Magendie insisted on analyzing function without being prejudiced by anatomical structure, and thereby established irrevocably the superiority of the experimental method for physiological inquiry. (Contemporaneously, researchers at French veterinary schools were also developing physiology along experimental instead of speculative lines). Magendie's pupil, Claude Bernard (1813–1878), utilized the experimental method even more successfully, discovering the vasomotor nerves, the glycogenic activity of the liver, the digestive role of pancreatic juice, and the mechanism of curare's effects on neuromuscular function. Bernard was equally significant for the philosophical analysis of the necessity of animal experimentation presented in his *Introduction a l'etude de la medecine experimentale* (1865). There he argued that it was unethical to experiment on human beings, no matter how beneficial the findings might prove for others, if the experiment could harm the subject to any extent whatever. Benefit to others did, on the other hand, justify experiments, including painful ones, on animals. The fact that many human lives could be saved by a relatively few animal deaths made the practice of vivisection a "right," he concluded, "entirely and absolutely" (p. 178). Bernard's analysis solidified the recognition of experimental research with animals as an essential practice for medical progress (Lesch; Rupke; Schiller).

At the same time, physiology and other experimental medical sciences were achieving the status of distinct, institutionalized professions. Historically, physiology had been pursued by physicians in whatever time they had left from treating patients or giving university lectures (and also, on occasion, by amateurs of means). The French had taken the lead in making physiology an independent discipline, yet it was in Germany that research physiology bloomed as a new professional field. The nineteenth-century reformation of universities in the German states, with its emphasis on research and the uncovering of new knowledge, led to the establishment of research institutes employing full-time physiologists, along with pharmacologists and other biological experimenters (Coleman and Holmes). The expectation that research would result in practical medical applications useful to humankind attracted both political and philanthropic support, and ultimately expectation was fulfilled with the flowering of medical microbiology and immunology in the 1880s. The germ theory was built upon laboratory experiments on thousands of animals; applications of the theory quickly made surgery far more effective and safe, and sharply refined programs for the prevention of epidemic disease. Louis Pasteur (1822–1895) discovered a vaccine for rabies in 1885 by infecting numerous dogs and rabbits with the disease, while the research leading to the introduction of diphtheria antitoxin in 1891 involved injecting guinea pigs, rats, and other species with diphtheria toxin. Such breakthroughs allowed experimental medicine to grow by feeding on itself, discovery generating support for more laboratories and scientists, leading to further discovery. By 1900, the German research ethos had established itself throughout the Western hemisphere, even in the United States (Fye). During the course of the twentieth century, moreover, the use of animals in research spread beyond the boundaries of physiology and pharmacology into areas such as psychology, the standardization of drug products, and toxicity testing of cosmetics and other consumer products. The "laboratory animal" has become a universal tool and symbol of medical progress and modern civilization.

The History of Opposition to Animal Experimentation

The laboratory animal also became, in the later years of the twentieth century, the chief object of attention of an aggressive animal rights movement (Plous). The movement's concentration on the immorality of animal experimentation seems odd on first consideration, since medical research, unlike other uses of animals as means to human ends (for food, clothing, sport, entertainment), has yielded unquestionable and inestimable benefits, and for animals as well as people. When examined historically, however, the focus on medical research becomes understandable, as it was the development of vivisection that most forcefully raised the question, "Do animals deserve the same moral consideration as humans?"

Initially, the answer was no. The rapid expansion of animal experimentation during the 1600s did provoke objections, but complaints were the exception, and were usually an experimenter's personal expression of revulsion rather than the product of a moral philosophy condemning cruel treatment of animals (anesthetics were not introduced into surgery, or research, until the mid-1800s). The absence of significant opposition to animal experimentation in the seventeenth century has often been attributed to the influence of the French philosopher and speculative physiologist René Descartes (1596–1650), who believed animals to be insensitive automata. Yet most experimenters recognized that animals did indeed feel pain; they simply did not regard the infliction of pain in experiments as cruelty. Physiologists accepted, with the rest of society, that humankind had been given dominion over animals to use as they saw fit. As scientists, furthermore, they considered experimentation the noblest of uses, since the unveiling of nature's design was a moral duty whose fulfillment deepened understanding of the Creator (Guerrini; Ritvo; Rupke). Animal research continues to the present to be justified on those two grounds, that it is a practical good—it benefits people; and an intellectual good—it enlarges understanding of the natural world.

Those justifications came under attack with increasing frequency during the second half of the eighteenth century. The humanitarian turn of mind engendered by the philosophical and religious emphases of the Enlightenment included a greatly heightened sensitivity to suffering that was readily extended beyond fellow humans to the higher animals. William Hogarth's print "The Four Stages of Cruelty" (1750–1751), for example, depicted the barbarous treatment of dogs and cats as the first stage of descent into savagery. The revolutionary's declaration of liberty, equality, and fraternity could likewise be interpreted as applicable to the animal creation. To be sure, the great majority of philosophers believed the exercise of natural rights required rational thought and speech, and thus could be granted only to humans. The Enlightenment's abhorrence of pain, however, made sentience a primary consideration for some thinkers. Jeremy Bentham (1748–1832) argued that animals' ability to feel and suffer earned them entrance to the sphere of moral consideration; less well-known writers even insisted that kind handling was a "right" to which animals were entitled. And although the most common criticisms of abuse were directed at the use of animals for food, labor, and sport, explicit attention was occasionally given to experimentation. Samuel Johnson (1709–1784), for one, not only denied that any practical benefits had come from animal research, he maintained that even if there had been a payoff, the gain was ill-gotten, tainted by the torture of innocent creatures. He repudiated obtaining knowledge through torment, in fact, as ultimately hurtful to society as well, for the callous treatment of animals would harden experimenters' hearts toward human suffering. Through assertions of the inutility, immorality, and corrupting influence of experimentation, philosophical argument overtook empathy as the basis of opposition to animal research (Passmore; Stevenson).

Philosophical argument matured into political action during the nineteenth century, hardening that triad of objections into the spearhead of an organized antivivisectionist movement. At first, the protesting of vivisection lacked an independent identity; rather it was subsumed under the broader animal welfare movement, largely because the country where animal protectionist sentiment was strongest—England—was the country where experimental physiology was weakest. Despite Harvey's example of two centuries earlier, English physiologists had come to rely primarily on dissection and anatomical reasoning rather than vivisection. There was too little animal experimentation at home to necessitate a distinct campaign; it seemed sufficient to fire occasional shells at less civilized scientists across the Channel.

By the 1850s, however, English physiologists realized that they had fallen behind their continental counterparts, and that animal experimentation was the key to catching up. Since ether and chloroform had been introduced as anesthetics in the 1840s, vivisection was far less harrowing, and it soon became as common in England as in Europe. Medical experimentation involved any number of species, but dogs and cats were especially common, and since the keeping of domestic pets had assumed an almost sacred place in genteel British culture during the first half of the century, vivisection could be horrifying even with anesthesia. (And not all researchers employed anesthetics, as the drugs sometimes interfered with the experiment.) Animal protectionists could thus still equate vivisection with cruelty, and this invasion of British soil by scientific barbarism incited a counterattack. The redoubtable Frances Power Cobbe (1822–1904) assumed generalship of the antivivisection forces, mobilizing them in 1875 into The Society for the Protection of Animals Liable to Vivisection—the first organization dedicated to overthrowing animal experimentation. Parliament, meanwhile, had appointed a Royal Commission to investigate charges of experimental cruelty, and though the Commission discovered no significant mistreatment of laboratory animals, it did recommend that vivisection be regulated by the state. The Cruelty to Animals Act of 1876 resulted, bringing experimenters and their laboratories into a system of registration and inspection, and requiring the administration of anesthesia (the 1876 Act was replaced in 1986 by the Animals [Scientific Procedures] Act) (French; Ritvo; Turner; Ryder, 1989).

Like so many pieces of legislation, the English Cruelty to Animals Act was a compromise that pleased neither side. Scientists regarded it as an insulting interference with their search for truth, antivivisectionists saw it as a skimpy fig leaf for scientists' arrogance. In truth, many proponents of animal welfare were placated by the requirement of anesthesia, but others noted the law permitted experiments without anesthetics if drugs would interfere with a potentially valuable study, insisted the inspection system was inadequate to insure anesthetics would be used in ordinary experiments, and declared that even when anesthesia was employed, the deprivation of freedom and life suffered by the animals was unacceptable cruelty. The 1876 law actually roused antivivisectionists to more vigorous opposition, because it struck them as official hypocrisy—it claimed to rescue animals from suffering when in fact it gave legal blessing to their confinement and killing.

Objections to animal experimentation now came to be broadcast more loudly than ever, and began to appear in other countries, including the United States, where Henry Bergh launched an antivivisection movement in the 1870s

(Rupke). The arguments raised against vivisection were not essentially new. As in the eighteenth century, the utility of vivisection experiments was denied, corruption of the experimenters' character was alleged, and, most important, the sacrificing of animals' lives for human comfort was condemned as fundamentally immoral. Ultimately, practical benefits from animal experiments were deemed irrelevant, as sinfully earned as if they had been derived from painful experiments on humans.

Yet it was the supposed utility of vivisection that gave experimentation overriding significance in the early formulation of a philosophy of animal rights. If one wished to extend animals the same rights as people, treating them as ends in themselves rather than as means to humans' ends, animal experimentation was the purest test case. The ends supposedly achieved by vivisection—saving human lives and relieving suffering—were clearly far worthier than the ends obtained by hunting, trapping, butchering, or other forms of animal slaughter. If the principle of equal rights for animals could be shown to obtain in the laboratory, it would necessarily obtain everywhere else. It was vitally important as well that experimentation was the one form of animal abuse practiced exclusively by educated and refined people, by an elite who should serve as models of civilized behavior for the rest of society. If scientists could not be made to recognize the moral claims of fellow creatures, what hope was there for educating drovers and butchers? The very nobility of the ends of medical research made (and makes) it the most attractive target for animal rights marksmen. Thus Henry Salt's 1892 treatise—*Animals' Rights Considered in Relation to Social Progress*—attacked every form of animal abuse, but singled out medical research as "the *ne plus ultra* of iniquity" (p. 102).

By 1900, however, the question of the utility of animal experimentation had blown up in the faces of antivivisectionists, for animal research was finally delivering its long-promised benefits. The newfound power over diphtheria, for so long the gruesome slayer of innocent children, was particularly important for eroding public empathy for innocent laboratory animals, and with the advent of the wonder drug era in the 1930s, criticism of animal experimentation effectively disappeared.

There followed several decades of dormancy, but during the last third of the twentieth century opposition to animal research underwent a dramatic resurgence. The extraordinary expansion of government funding of medical research in the post-World War II decades markedly increased the number of animals used in the laboratory; nearly 30 million warm-blooded animals were being used for research annually in the United States by 1980, and the number would reach an estimated 60 million by the early 1990s. During the 1970s and 1980s, furthermore, several instances of scandalous abuse of laboratory animals were brought to light (Fox; Finsen and Finsen). At the same time, studies demonstrating complex social interactions and the use of language within many species strengthened humans' feelings of kinship with higher animals, while heightened awareness of the endangerment of whole species by human activities fostered resentment of all forms of animal mistreatment (Wise; Clark). Finally, just as the political and religious trends of the late eighteenth century generated broad social sympathy for oppressed people, which was then extended to animals, so the late twentieth century's sensitivity to racial and sexual discrimination revived motivation to be just to all creatures; in 1975, the term *speciesism* was introduced to parallel racism and sexism (Ryder, 1975).

Within this environment, the ethics of animal experimentation became the subject of serious philosophical analysis. Particularly influential critiques were provided by Peter Singer, whose 1975 *Animal Liberation* presented a utilitarian argument against speciesism, and Tom Regan, who in 1983 advanced the case for animals' possession of inherent rights to liberty and life. By both analyses, animal research is a morally impermissible way of pursuing science (Singer; Regan). The philosophy of animal rights was translated into practical action by a number of organizations, most notably the Animal Liberation Front (ALF), founded in 1976, and People for the Ethical Treatment of Animals (PETA), established in 1980. The former group, as its name implies, has gone beyond the conventional activities of picketing laboratories and publicizing scientists' violations of animal rights principles, to the invasion of research facilities to free experimental animals and destroy property; estimates of the property damage caused by the ALF are in the millions of dollars (Finsen and Finsen; Petrinovich; Ryder, 1989).

The recent attacks on animal experimentation as unethical have, of course, provoked responses from the medical research community. For the most part, the reaction has been to bluntly assert the primacy of human interests over those of animals, and to emphasize the many medical advances that have come from animal research. There have also, however, been attempts to refute the animal rights position on its own terms, through strict philosophical analysis (Fox). Additionally, a great deal of consideration has been given to the "three Rs": reducing the numbers of animals used in experiments; refining procedures so as to lessen animals' discomfort; and replacing animals when possible with alternatives such as tissue cultures and mathematical models (Russell and Burch; Smyth; Rowan). Beginning in the late 1980s, in fact, several major producers of cosmetic products started abandoning animal testing; the publicity those companies have given to their action is a clear indication of continuing public uneasiness over the morality of animal experimentation (Welsh).

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SEE ALSO: *Cloning: Scientific Background; Harm; Hinduism, Bioethics in; Jainism, Bioethics in; Moral Status; Pain and Suffering; Veterinary Ethics; Xenotransplantation;* and other *Animal Research* subentries

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II. PHILOSOPHICAL ISSUES

Ethical problems related to research on nonhuman animals are grounded in the assertion that animals have conscious experiences and that their lives can go well or badly. Central to this issue is the belief that nonhuman animals can experience pain and other unpleasant or distressing mental states. The seventeenth-century philosopher René Descartes denied this (Regan and Singer), and one or two contemporary philosophers continue to deny it (Carruthers). On the whole, however, popular opinion and the overwhelming majority of contemporary scientists and philosophers agree that animals, especially vertebrate animals, can suffer (Smith and Boyd; DeGrazia, 1996, 2002). To take a contrary view, one must refute not just the experience of everyday owners of animal companions but also the increasing body of empirical evidence, both physiological and behavioral, suggesting close parallels between animal behavior and human behavior (Dawkins, 1980, 1993; Rollin; Griffin). Moreover, these behavioral parallels are supported by the known similarities among the nervous systems of all vertebrate animals and by the fact of common animal and human evolutionary origin (Rachels).

It is difficult to believe that despite all these similarities the nervous systems of human and nonhuman animals operate in radically different ways. Many codes regulating animal experimentation instruct regulating committees to assume that procedures that would cause pain in humans also will cause pain in vertebrate animals unless there is evidence to the contrary. From this point, therefore, the existence of animal suffering will be taken for granted.

Before considering the ethical questions that arise from the existence of animal suffering, however, it is necessary to provide some further information.

Nature and Extent of Animal Experimentation

Some governments provide detailed information on the number of animal experiments carried out each year. In the United Kingdom, for instance, the annual report on scientific procedures performed on living animals under the Animals (Scientific Procedures) Act 1986 for the year 2000 showed that 2.71 million animals were used in that year, a significant decrease from the 1980s, when the figure topped 5 million, although the decline appears to have leveled out. An estimated 12 million animals are used in the fifteen member nations of the European Union, which includes the United Kingdom. An incomplete Japanese survey published in 1988 reported a total in excess of 8 million. There are no accurate figures for the United States because the official figures compiled by the U.S. Department of Agriculture do not include rats, mice, and birds, the species used most commonly in research. In 1986 the U.S. Congress, Office of Technology Assessment, estimated that “at least 17 million to 22 million” animals are used in research annually (U.S. Congress, Office of Technology Assessment). Many think that this figure is very conservative, and several unofficial estimates indicate a higher figure. In addition to rats and mice, dogs, cats, primates, guinea pigs, and rabbits are used widely (Singer, 1990 [1975]; Orlans).

Opponents of animal experiments have focused on examples such as those discussed below (Singer, 1990 [1975]).

TOXICITY TESTING. From about 1950 until the late 1980s the standard method for assessing the toxicity of any product was the LD_{50} (lethal dose 50%) test. The object of this test is to find the dose level that will fatally poison 50 percent of a sample of animals. Often more than one species of animal is used. In the process of stepping up the dose until half the experimental animals die, all of them are likely to become ill, experiencing symptoms such as nausea, thirst, diarrhea, stomach cramps, and fever. The LD_{50} test was carried out routinely on most household products, including food colorings, household cleaners, shampoos, and cosmetics.

After campaigns against the test by the animal rights movement, most U.S. government agencies began to discourage the use of the classical LD_{50} test, and the Center for Laboratory Animal Welfare estimates that its use has fallen by as much as 90 percent (Center for Laboratory Animal Welfare). In 2000 the Organization for Economic Cooperation and Development announced that it was planning to delete the LD_{50} test from its testing guidelines in favor of three alternative methods. Nevertheless, the LD_{50} test still is used in some circumstances, and even if only 10 percent as many animals are subjected to it, that still amounts to hundreds of thousands of animals every year. The replacement for that test, the limit test, still uses animals but does not require doses sufficient to kill them. Instead, other signs of toxicity are used. In addition to undergoing toxicity testing, many products, especially cosmetics and shampoos, used to be placed in the eyes of conscious, unanesthetized rabbits in what is known as the Draize eye test, which was designed to assess the likelihood that a product would cause eye damage. In the late 1980s, after a decade of campaigning against that test, some leading cosmetic companies developed an alternative to the Draize test and stopped conducting tests on animals.

MILITARY TESTING. It is often difficult to find out exactly what happens to animals who undergo military experimentation, but in the United States, in experiments carried out in 1984, monkeys were trained with electric shock to run for hours on a treadmill and then were exposed to lethal doses of radiation to see how long the sick and dying animals could keep running (when they stopped, they received more electric shocks). At Brooks Air Force Base, in Texas, research that involves observation of the effect of radiation on the behavior of monkeys is, according to the most recent information available, still being funded. So too is research in which monkeys are trained to “fly” a device called a “primate equilibrium platform” which simulates some of the tasks that a pilot has to perform when flying a plane. They are then exposed to radiation, to see how this affects their ability to perform. This research was first carried out in the 1960s by Donald Barnes, a psychologist who later came to consider it cruel and pointless (Barnes). Nevertheless, the U.S. Department of Defense continues to fund the training of monkeys to operate the primate equilibrium platform before being exposed to "degradation in the functioning of the central nervous system."

PSYCHOLOGY EXPERIMENTS. In a psychology experiment performed at the University of Pennsylvania in 1968 dogs were placed in cages with wire floors that could be electrified. Subjected to repeated, inescapable electric shock, the dogs at first jumped, ran, attacked the cage, howled, defecated, and urinated, but the shocks continued until the dogs stopped attempting to escape. The experiment was designed to demonstrate the existence of a state known as "learned helplessness" in the belief that such research might throw light on some forms of depression in human beings. From 1984 to 1986 researchers at Temple University used rats in similar experiments with inescapable electric shock; at the same time researchers at the University of Tennessee at Martin were trying to apply inescapable electric shock to goldfish. Learned helplessness experiments on animals are continuing at various centers in the United States, including the University of Colorado at Boulder, where research of this kind has been carried out since 1993 (National Institutes of Health). Experiments in maternal deprivation in monkeys and other animals have been going on in American universities since the 1960s and are continuing. In research at the University of California, Davis, published in 2000, researchers carried out experiments over a five-year period to discover whether there are differences in the problem-solving abilities of monkeys reared with inanimate "surrogate mothers," as compared with the problem-solving abilities of monkeys reared by dogs (Capitanio and Mason).

STUDENT USE OF ANIMALS. Although it has been estimated that more than 5 million animals are used for dissection annually in the United States alone, there has been a move away from the use of living animals for practice surgery in medical schools. Only a minority of U.S. and Canadian medical schools still require the use of live animals, and in almost all those schools students may choose not to participate. In 2000 the Tufts University School of Veterinary Medicine became the first veterinary school in the United States to eliminate the use of healthy dogs for surgical training (Tufts). A number of valuable alternatives to the use of live animals in education have been developed (Smith and Boyd).

Guidelines and Codes

Many countries have national, legally enforceable guidelines, for the protection of animals in research. Among the more advanced are those developed by the Australian National Health and Medical Research Council and the Swedish regulations. Both require experiments to be approved by ethics committees. In Australia the ethics committee must include a lay member and, in addition, a person from an animal welfare organization (National Health and Medical Research Council). In Sweden the ethics committees consist of six scientists and six lay members and are chaired by a judge (European Science Foundation). Both the European Union and the Council of Europe have their own codes, dating from the mid-1980s. From the same period comes the most frequently cited international code, the International Guiding Principles for Biomedical Research Involving Animals developed by the Council for International Organizations of Medical Sciences (CIOMS). The CIOMS code is, however, much weaker than the relatively more advanced codes in specific countries, such as the European nations and Australia. Instead of mandatory review by committees that include lay members, for example, the CIOMS code allows "voluntary self-regulation by the biomedical community."

In Defense of Current Animal Experimentation

Defenders of animal experimentation emphasize the use of animals in medical experimentation, particularly in areas such as diabetes and hypertension research, where the use of animals is claimed to have led to important medical breakthroughs (Paton; U.S. Congress, Office of Technology Assessment). They assert that statistics on the large numbers of animals used can be misleading because a great deal of animal experimentation is of a relatively harmless nature, for example, running a rat through a maze with a reward of food as encouragement for good performance rather than an electric shock as punishment for poor performance. They argue that animal experimentation is the only way to advance basic knowledge of human anatomy and physiology and that it offers the best hope of finding cures for diseases such as cancer and AIDS. They also may point out that a considerable amount of animal experimentation is carried out in schools of veterinary medicine to find ways to treat diseases that affect animals. The majority of this work is concerned with farm animals, but some is directed toward companion animals and wild animals.

If experiments now being carried out inflict substantial suffering on animals, how can this practice be defended? The usual justification offered is that the suffering of animals is outweighed by the benefits to humans of discoveries that can be made only through the use of animals. Sometimes, however, it is said that the goal of increasing scientific knowledge is an overriding one and thus provides sufficient justification for whatever suffering might be inflicted on animals in the process of advancing toward that goal. Because this goal is not said to justify inflicting substantial suffering on nonconsenting human experimental subjects, however, further justification is needed to account for the alleged difference in moral status of human beings and other animals.

Behind such arguments lie a variety of philosophical positions. For instance, it may be said that, as related in Genesis 1:26, God has given human beings "dominion" over the other animals, to use them as we please. Combined with other theological notions, such as the idea that humans, alone of all animals, have immortal souls, this idea has been influential throughout the Christian world. But it can be turned the other way: As long ago as 1713 Alexander Pope argued against cruel experiments on the grounds that dominion requires us to play the role of the good shepherd, caring for our flock (Turner). More recently a number of Christians have suggested that the gift of dominion should be interpreted as one of "stewardship," which makes us responsible for the care of the nonhuman creation (Attfield; Linzey). It remains unclear, however, precisely what follows from this reinterpretation. In particular, does it imply that humans are not entitled to use animals in harmful experiments or only that there must be a strong reason for doing so?

It also has been said by writers as diverse as Thomas Aquinas and Immanuel Kant that animals are not "ends in themselves" or that they have no rights (Regan and Singer). In support of this idea it is alleged that the status of a being who is an "end in itself" or has rights belongs only to a being who is rational, is capable of autonomous action, or is a moral agent. This position attempts to equate the universe of moral agents—those *to whom* moral judgments or prescriptions can sensibly be addressed—with the universe of moral patients—those *about whom* it matters, morally, what people do. One possible justification for this equation would be a social contract model of ethics: We have a moral obligation to respect the rights or interests only of those who can reciprocate respect for their rights or interests (Gauthier; Carruthers). This position, however, does not provide any grounds for distinguishing between nonhuman animals, on the one hand, and infants and the profoundly intellectually disabled, on the other. It may be true that many people care more about members of their own species and hence wish to give infants and the intellectually disabled "courtesy status" as members of the moral community. But what if they do not? A social contract theory of morality, then, offers no footing for insisting on equal consideration for the interests of those human beings.

A second justification claims that all human beings form a moral community not because of an implicit contract but because of people's natural feelings for members of the human species. Those natural feelings, it is argued, resemble the natural affection of parents for their own children, which people take as a basis for the special moral obligation they think parents have to give preference to the interests of their own children over the greater interests of the children of strangers. The natural ties between members of a species should, the argument continues, serve as the basis for holding that humans have a greater obligation to other humans than they do to members of other species (Midgley; Gray, 1991a, 1991b).

If this argument were valid, it is not clear how much experimentation on animals it would justify because people do not think that parents are justified in causing serious harm to the children of strangers in order to benefit their own children. But is this argument valid? Understandably, those who use these arguments are silent about the obvious case that lies between the family and the species: preference for the interests of the members of one's own ethnic group or race over the greater interests of members of other ethnic groups or races. It would seem that if the argument works for both the narrower circle of the family and the wider sphere of the species, it also should work for the middle case. If we reject the extension from families to ethnic groups, the further extension to the whole of the human species looks very dubious (Singer, 1991).

A utilitarian defense of the current practice might be based on the idea that the benefits produced outweigh the harm done to the animals (Paton; U.S. Congress, Office of Technology Assessment). Prominent among the claimed benefits is a considerable extension of the human life span. The first question raised by this defense is how much animal experimentation has helped extend human longevity. In polemical debates dramatic claims often are made, but the consensus among those who have studied trends in human health from a historical point of view is that almost all of the increase in human longevity that has occurred over the last century has been due to improved sanitation, diet, and living conditions rather than to medical research of any kind, whether on animals or not (McKeown; McKinlay et al.).

It is possible to accept this verdict but to maintain that medical research, including research on animals, has benefited humans. For example, defenders of the value of animal research often point to the development of coronary artery bypass graft surgery as an achievement that was facilitated by research on animals. The contribution of this form of surgery to the prolongation of life is not clear, but the surgery is more effective than conventional medication in relieving angina, a painful condition that results from coronary artery disease (U.S. Congress, Office of Technology Assessment). Thus, it may contribute to a better quality of life rather than to a greater quantity of life. Against this it might be claimed that the funds spent on this research as well as on the surgery itself would have been more effective if they had been directed toward reducing the cause of the disease by promoting healthier diets and lifestyles. It also has been argued that misleading animal models sometimes have slowed the development of a cure for major diseases, such as polio (LaFollette and Shanks).

A second point in considering a genuinely utilitarian defense of current practice in animal research is that the classical utilitarian tradition has steadfastly required people to take *all* suffering—that of humans and that of nonhuman animals—into consideration. The leading nineteenth-century utilitarians—Jeremy Bentham, John Stuart Mill, and Henry Sidgwick—were unwavering on this point (Bentham; Mill; Sidgwick). Modern utilitarians who cast their views in terms of the satisfaction of preferences rather than in terms of pleasure and pain are equally comprehensive in the scope of their theories (Singer, 1993 [1979]; Hare). This makes it more difficult to claim that a genuinely utilitarian approach favors animal experimentation in general or as an institution. Nevertheless, some individual experiments—those which do not involve any or very much suffering for the animals and promise major benefits for humans or animals—may be defensible on utilitarian grounds.

Some seek to justify what researchers do to animals by appealing to a human-centered version of utilitarianism. In the extreme version of this view the conscious experiences of beings who are not members of our own species do not matter at all. In the more moderate version those experiences do matter, but they do not matter as much as the similar experiences of members of our own species. Both positions frankly endorse an ethic that is limited to, or biased toward, our own species. Once such an ethic is accepted, of course, the justification for animal experimentation becomes much easier. The difficulty of this position lies in defending such a *speciesist* ethic (see below).

Finally, defenders of current practice often accuse their opponents of a lack of consistency in objecting to the deaths of animals in laboratories while continuing to participate in the practice of rearing and killing animals for food. The rise of the animal rights movement in the 1980s has made this accusation less effective because most of those actively involved in that movement have been vegetarians as well as opponents of animal experimentation. In any case, the issue of whether animal experimentation is justified cannot be resolved by reference to the character of some individuals who object to animal experimentation.

Objections to Current Animal Experimentation

Critics of the current practice of experimenting on animals tend to fall into two groups: abolitionists and reformers. Abolitionists usually rely on the principle that the end does not justify the means. To inflict pain and death on an innocent being is, they maintain, always wrong. They point out that people do not think that the possibility of advancing scientific knowledge justifies taking healthy human beings and inflicting painful deaths on them; similarly, they say, the infliction of suffering on animals cannot be justified by reference to future benefits either for humans or for other animals (Ryder; Regan).

A weakness of the abolitionist position is that when the end is sufficiently important, most people think that otherwise unacceptable means are justifiable if there is no other way of achieving the end. People do not approve of telling lies, but most people accept the idea that politicians should tell lies to mislead the enemy when their country is fighting a war that they believe is right. Similarly, if the prospects of finding a cure for cancer depended on a single experiment, most people probably would think that the experiment should be carried out.

In response to objections along these lines, some abolitionists argue that although a single experiment, taken in isolation, may appear justifiable, the benefits of such experiments do not outweigh the suffering inflicted by the institution of animal experimentation as a whole. One also must take into account, these abolitionists would say, two other factors: First, a large (if uncertain) proportion of experiments are worthless; second, even if no pain or distress is caused by the experiments, experimental animals typically have been raised in conditions that constitute severe deprivation for beings of their species. The common laboratory rat, for instance, is a highly intelligent animal with a strong urge to explore new surroundings. Rats also like to get into small, dark spaces, yet in most laboratories they are kept in bare plastic buckets with a bit of sawdust at the bottom. Such treatment indicates the lack of consideration for the interests of animals that prevails in the world of animal experimentation, and abolitionists doubt that this will ever change as long as people continue to regard laboratory animals primarily as tools for research.

Reformers believe that a changed practice of experimenting on animals could be defensible. They demand that any benefits that are believed to be likely to arise from the experimentation should be sufficiently probable and sufficiently great to offset the costs to the animal subjects; they urge that every experiment should come under close and impartial scrutiny to determine whether this is the case.

Reformers point out that although during the 1980s and 1990s several countries (for example, Australia, Sweden, Switzerland, and the United Kingdom) developed legally obligatory systems of review based on an institutional ethics committee's review of proposals to carry out experiments on animals, experimenters usually are well represented on such committees, whereas animal welfare advocates either are not represented or are heavily outnumbered by experimenters. An impartial committee that weighed the cost to the animal in the same way that people would weigh a comparable cost to a human would, the reformers maintain, approve at most a small fraction of the experiments now performed. In other countries, such as the United States, institutional ethics committees exist but are not legally required for corporations or other institutions that do not receive federal funds, and their coverage of animal experimentation is incomplete. Moreover, in the United States these committees do not always have the authority to prevent experimenters from going ahead with painful experiments if the experimenters assert that alleviating the animals' pain would interfere with the purpose of the experiment (U.S. Congress, Office of Technology Assessment; Dresser; Smith and Boyd; Gavaghan; Orlans).

Among opponents of current practices of animal experimentation the line between reformers and abolitionists is not clear-cut because questions of long-term goals and short-term strategy intervene. A threefold division might be more appropriate: In the first category one could place those whose long-term goals do not extend beyond better regulation and control of animal experiments to eliminate the most painful and trivial experiments. In the next category would be those who have the long-term goal of abolishing all or virtually all animal experiments but who consider this an ideal rather than a realistic objective for the immediate future. This group therefore seeks reforms in the interim period, and its short-term goals do not differ significantly from those of members of the first category. The third category consists of those who aim at abolition and are not interested in advocating anything less.

Although members of these three categories disagree sharply among themselves, they all agree that the current situation is indefensible. They also agree on promoting the use of alternatives to animal experimentation. The use of such alternatives by cosmetic companies to replace the Draize eye test was mentioned above. Opponents of animal experimentation suggest that alternative methods would be developed more rapidly if they received more substantial government support (Ryder; Rowan; Balls).

The ethical stance of those in the first category, who seek only limited reforms, is often of a relatively conventional type: They can be thought of as following an "animal welfare" line rather than accepting an ethic of "animal rights" or "animal liberation." They accept the idea that animals may be used for human purposes but want safeguards to ensure that the purposes are serious ones and that no more suffering occurs than is necessary for the purpose to be realized. Those who take an animal rights or animal liberation stance want to narrow the ethical gulf that separates humans from other animals in regard to conventional morality. They thus raise a philosophically deep question with implications that go beyond experimentation, extending to the treatment of animals in general.

The Moral Status of Animals

In examining the case for current practices, this entry examined some attempts to justify in ethical terms the sharp distinction that is made currently between the treatment of members of the human species and the treatment of members of other species. The problems noted in this entry bedevil all attempts to make the boundary of the human species coincide with the boundary of human moral obligations. Although it is said frequently that humans are superior to other animals in such respects as rationality, self-awareness, the ability to communicate with others, and a sense of justice, human infants and humans with severe intellectual disabilities fall below many nonhuman animals on any objective test of abilities that could mark humans as superior to other animals. Yet surely these less capable human beings are also "ends in themselves," and it would not be legitimate to experiment on them in the ways in which people experiment on animals. For a contrary view that accepts the moral possibility of harmful experimentation on both nonhuman animals and humans at a similar mental level, see Frey.

Ryder, Singer, Regan, and other critics of current practices claim that respect for the interests of those humans and comparative neglect of the interests of members of other species with equal or superior capacities constitutes *speciesism,* a prejudice in favor of "our own kind" that is analogous to and no more justifiable than racism. This argument has been seen by many people as the most difficult for defenders of animal experimentation to counter, so much so that a leading philosopher has referred to it as a "won argument" (McGinn).

Certainly the view that species is in itself a reason for giving more weight to the interests of one being than to the interests of another is more often assumed than explicitly defended. Some writers who have claimed to be defending *speciesism* have in fact been defending a very different position: that the morally relevant differences between species—such as differences in mental capacities—entitle people to give more weight to the interests of members of the species with the superior mental capacities (Cohen; Leahy). If this argument were successful, it would not justify speciesism because the claim would not be that species in itself is a reason for giving more weight to the interests of one being than to those of another. The real reason would be the difference in mental capacities, which happens to coincide with the difference in species. However, in view of the overlap in mental capacities between some members of the species *Homo sapiens* and some members of other species, it is difficult to see how this argument can be used to defend current practices. In other contexts people insist on treating beings as moral individuals rather than lumping them together as members of a group; it is precisely those who practice racism and sexism who treat all members of a group in the same way (for instance, assuming that women cannot perform heavy physical labor as well as men can) without recognizing individual variation.

Defenders of animal experimentation sometimes have portrayed the animal rights position in an extreme form, for example, as implying that it is as wrong to kill a mosquito as it is to kill a normal human adult. This is, however, a caricature. Animal advocates do not claim that all animals have the *same* interests, only that interests are not to be given less consideration solely on the grounds of species. Thus, it is compatible with the animal liberation view to say that the interests of beings with different mental capacities vary and that these variations are morally significant (DeGrazia, 1996, 2002). If people are forced to choose between saving the life of a being who understands the meaning of death and wants to go on living and saving the life of a being who is not capable of having desires for the future because that being's mental capacities do not enable it to grasp that it is a "self," a mental entity existing over time, it is entirely justifiable to choose in favor of the being who wants to go on living. This is a choice that is based on mental capacity and not on species membership, as one can see by considering that the former being may be a chimpanzee and the latter being a human with profound brain damage (Singer, 1990 [1975]).

At least one scientist who experiments on animals has attempted to sweep aside such issues by denying that animal experimentation raises a moral issue at all. Robert J. White, whose work has involved keeping severed monkeys' heads alive and apparently conscious for as long as possible, has written that "the inclusion of lower animals in our ethical system is philosophically meaningless" (p. 507). Unfortunately, White does not explain why, to take only one example, the clear proposal of utilitarian writers—that pain as such is evil regardless of the species of the being that suffers it—is devoid of meaning. It may be difficult to compare the suffering of a human and that of, say, a rabbit, but sometimes rough comparisons can be made. It seems undeniable that to put into the eye of a rabbit a chemical that causes the eye to blister or become ulcerated is to do more harm to the rabbit than people would do to any number of human beings by denying them the possibility of using a new type of shampoo that could be marketed only if the chemical was tested in this way. When such rough comparisons can be made, the mere fact that rabbits are "lower animals" is no reason to give less weight to their suffering.

Seen in this light, the argument that restricting experiments on animals interferes with scientific freedom and medical progress appears less conclusive. People do not grant scientists the freedom to experiment at will on humans, although such experiments would do more to advance knowledge of human physiology and be more likely to find cures for diseases such as AIDS than would animal experiments. It would seem, therefore, to be incumbent on the defenders of experiments on animals to show that there is a relevant difference between all humans and other animals that justifies experiments on the latter but not on the former. Success at this task, however, still eludes defenders of animal experimentation.

Conclusion

Controversy over experiments on animals often has been polarized, and, especially in the United States, public exchanges between those who carry out animal experiments and those who oppose them often generate more heat than light. There has been a more serious discussion of the status of animals in philosophical journals and in books by philosophers, and it can be hoped that this level of discussion eventually will influence popular debate on the use of animals in research.

PETER SINGER (1995)
REVISED BY AUTHOR

SEE ALSO: *Animal Welfare and Rights: Ethical Perspectives on the Treatment and Status of Animals; Conscience, Rights of; Holocaust; Moral Status; Research Policy; Utilitarianism* *and Bioethics; Veterinary Ethics; Xenotransplantation;* and other *Animal Research* subentries

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III. LAW AND POLICY

This entry describes the laws and policies of the United States governing the care and use of animals in research, education, and testing; the history of these policies and laws since 1966; the issues addressed by these laws; and the lawsuits that have followed publication of regulations implementing these laws. Two federal laws govern the use of animals: the Health Research Extension Act of 1985 and the Animal Welfare Act, as amended. While all states have laws governing the care of animals, research usage is often exempted. Twenty states have simple facility licensure, and a few have only very general regulations governing research usage of animals. In reality, nearly all states defer to federal law in this area. A National Institutes of Health (NIH) document, *Public Health Service Policy on Humane Care and Use of Laboratory Animals,* which was revised in 2002, implements the Health Research Extension Act for all activities involving animals conducted or supported by the Public Health Service (PHS),while regulations implementing the Animal Welfare Act are in the *Code of Federal Regulations,* Title 9, Chapter 1, Subchapter A, Parts 1, 2, and 3 (known as animal welfare regulations). The PHS includes twelve health agencies within the U.S. Department of Health and Human Services (DHHS).

History of Public Health Service Policy

Regulations have been promulgated by the PHS since 1935, originally through one of its constituents, the National Institutes of Health (Whitney). NIH guidelines have provided direction and recommendations for caring for and using laboratory animals at NIH. Subsequently, a committee of laboratory scientists assembled by the Institute of Laboratory Animal Resources of the National Research Council (NRC) wrote the *Guide for the Care and Use of Laboratory Animals* (NRC guide). First published in 1963 and updated many times since, this work has become the standard guide in the field. The first policy based upon the 1963 NRC guide came from NIH in 1971. The PHS published its first policy on animal care in 1973, with revisions in 1973, 1979, 1986, 1996, and 2002. Each successive revision increased the specificity and level of responsibility of animal-care committees in the supervision of animal use.

At the outset of NIH policymaking in animal care and use in 1971, all institutions and organizations using warm-blooded animals for the purpose of research or other projects supported by NIH were required to give assurances that facilities for animals met "acceptable standards for the care, use, and treatment of such animals." This assurance could be met either by gaining accreditation through a professional laboratory-accrediting body (such as the Association for Assessment and Accreditation of Laboratory Animal Care International [AAALAC]) or by establishing a committee to evaluate the care and housing of animals used for NIH-sponsored activities. Institutions were also obligated to follow pertinent sections of the animal welfare regulations. In 1973, the NIH policy was replaced by the first of the PHS policies. Like the NIH policy preceding it, the first PHS policy required institutions either to be fully accredited or to have a standing institutional committee with a minimum of three members, including a veterinarian for those institutions using a "significant" number of animals. These committees were required to conduct periodic facility inspections, with the review of applications and proposals involving the use of animals considered optional.

The 1979 revision to the PHS policy required all institutions using animals, regardless of numbers used and accreditation status, to have a standing committee whose responsibility was oversight of the institution's animal-care program. In addition to the establishment of a committee of at least five members, including one veterinarian, the institution was obligated to establish a mechanism to review its facilities for warm-blooded animals for adherence to the principles contained in the NRC guide. The PHS policy recommended that AAALAC accreditation was the best means of satisfying this obligation, although periodic committee review of facilities and animals' care would suffice. Absent from the 1979 PHS policy was the requirement for review of individual proposals or projects, although review was encouraged. In 1986, however, the PHS policy was revised again, this time requiring the animal-care committees of institutions to take responsibility for specific organizational and supervisory duties in an effort to strengthen the system of institutional assurance.

History of Animal Welfare Regulations

A 1966 *Life* magazine feature titled "Concentration Camps for Dogs," along with other works published around this time, dramatized poor care and treatment of animals by some dealers who sold animals for biomedical research. This disclosure and the ensuing public outcry resulted in the introduction of twenty-nine bills in the U.S. Congress relating to the regulation of animal research. The bill that eventually became law was the Laboratory Animal Welfare Act of 1966 (LAWA; in 1970, after passage of the first amendments, the name was shortened to the Animal Welfare Act, or AWA). This act was limited to regulation of the sale and transportation of animals by dealers and the holding of animals by certain research facilities. Although the bill was passed, it was a compromise between far-reaching legislation and none at all; it did not apply to actual research usage of animals. The regulations implementing the LAWA specified that the housing facility provide shelter and protection from temperature extremes, that food and water be provided at least daily, and that cages be of a certain size and cleaned daily. These regulations also specified cage sizes and frequency of feeding and watering during transportation. Passage of amendments in 1970, 1976, 1985, and 1990 and of a law calling for the PHS policy extended federal regulations into areas covering the appropriate use and humane treatment of laboratory animals. The 1966 law regulated dogs, cats, hamsters, guinea pigs, rabbits and nonhuman primates. The 1970 amendment broadened it to include all warm-blooded animals, but regulations excluded birds, rats, and mice.

The 1970 amendments broadened the U.S. Department of Agriculture's (USDA) administrative responsibility to cover animal care throughout an animal's stay in research facilities, including the period during which research was being conducted. The 1976 amendments brought transportation carriers under the purview of the act, leading to more stringent standards for shipment of animals. The 1985 version of the AWA invested the USDA with responsibility for issuing and enforcing regulations regarding humane care, handling, and treatment of animals. Animals covered under the AWA include warm-blooded animals—such as dogs, cats, monkeys, guinea pigs, hamsters, rabbits, marine mammals, and normally wild animals—being used for research, testing, experimentation, exhibition purposes, or as a pet. Excluded from coverage are birds, rats, mice, and horses and other farm animals intended for use as food or fiber, or for use in improving animal nutrition, breeding, or management. The 1990 changes to the act added college-student work with animals to the list of areas over which a research institution has oversight responsibility.

Public Health Service Policy

PHS policy requires that each awardee institution provide a written assurance setting forth how that institution will comply with regulations. This assurance then forms the basis for the care and use of animals in research, education, and testing at that institution and is the basis for judging the adequacy of the institution's compliance with the policy. PHS policy calls for the establishment of a program for animal care and use, using the NRC guide as a basis for developing the program. Also required is the creation of an institutional animal care and use committee (IACUC), appointed by the chief executive officer of the institution. This committee must have at least five members, including at least one veterinarian experienced in laboratory animal science, one scientist, one layperson, and one person unaffiliated with the institution. PHS policy then charges this committee with oversight responsibility for: semiannual review of the program of animal care and use; semiannual inspection of facilities; review of research protocols, or proposals for the use of animals; investigation of all concerns raised by anyone regarding the humane use of animals at the institution; recommendations for personnel training; and suspension of activities deemed improper.

An institution's program for the care and use of laboratory animals encompasses institutional policies, laboratory-animal husbandry procedures, and veterinary care practices. Institutional policies address such personnel provisions as veterinary qualifications, procedures for safely handling hazardous agents, occupational health and personal hygiene including appropriate clothing and practices, and the prohibition of smoking and eating in animal rooms; special considerations are also addressed through policies, such as those concerning prolonged physical restraint of animals and multiple surgeries on a single animal. Laboratory-animal husbandry procedures include housing systems (size of cages and provision for social interaction among animals where appropriate); temperature, humidity, ventilation, lighting control, and cage and room sanitation schedules; and methods of animal identification and of clinical record keeping. Veterinary care practices include preventive-medicine strategies; methods for detecting and treating diseases; giving investigators advice about appropriate anesthesia, analgesia, and surgical and postoperative care; and methods of euthanasia.

Facility inspection covers not only visiting the physical plant but also assessing the health of the animals and reviewing portions of the institutional program for animal care. The physical plant should be properly constructed to house the species being used and to permit sterile surgery to be performed, if necessary.

PHS policy sets forth several criteria to be followed by the IACUC in reviewing protocols. These criteria go beyond mere care and housing guidelines. The care and use of animals in proposed research must be consistent with the NRC guide, unless acceptable scientific justification is provided for any deviation. The investigator must explain the rationale for using animals at all in the proposed research as well as the appropriateness of the species to be used, the number of animals, and their proposed use. PHS policy stipulates requirements for the use of sedatives, analgesics, and anesthetics if the proposed procedure might cause more than slight pain or distress; it also requires prompt euthanasia at the end of (or, when appropriate, during) a procedure for “animals that would otherwise suffer severe or chronic pain or distress that cannot be relieved” and imposes methods of euthanasia consistent with American Veterinary Medical Association (AVMA) guidelines. All personnel involved in the use of animals in research must be appropriately trained and qualified in the procedures to be employed in the experiment.

Each IACUC must have procedures for investigating concerns raised about the care and use of animals at the institution. In addition, the IACUC must ensure that the institution has a training program for both animal-care staff (people actually caring for the animals) and research staff; videotapes and training handbooks may be used to satisfy this requirement. The final charge—the power to suspend an improperly conducted activity—must come from an official of the institution such as the chief executive officer or the vice president. Without this official support, the IACUC cannot fulfill its duty to ensure compliance with PHS policy.

Several features of PHS policy are of special importance. While its legal force is restricted to awardee institutions, its scope includes all live vertebrates. It was the first U.S. law to call for a consideration of animal welfare during a procedure and to call for the establishment of a committee to review protocols for the appropriateness of design, the importance of knowledge sought (as set forth in the “U.S. Government Principles for the Utilization and Care of Vertebrate Animals Used in Testing, Research, and Training,” published in both the PHS policy and the NRC guide), and the competency of personnel. Thus, through PHS policy, committees have been created to review the use of animals in research, much like the committees that review the participation of humans in research.

Animal Welfare Regulations

Animal welfare regulations (AWRs) pertaining to the care and use of laboratory animals were extensively modified and rewritten following the 1985 amendments of the Animal Welfare Act to include provisions for an IACUC, for protocol review, and for more social interaction among the same species and between animals and their caretakers. These regulations are similar to PHS policy provisions because the secretary of the USDA was directed to consult with the secretary of the DHHS concerning the writing of regulations. In the AWRs, an IACUC committee with only slight differences from PHS policy is required (e.g., three members instead of five as a minimum, including an unaffiliated member and a veterinarian). The duties of the committee are very similar to the duties specified by PHS policy; instructions for reviewing protocols, however, are more detailed than those included in PHS policy. The AWRs require the investigator to search for alternatives to any procedure that may cause more than slight pain or distress and to assure that the proposed activity does not unnecessarily duplicate previous work. Several aspects of a personnel-training program are specified. In contrast to PHS policy, which requires institutions to develop an animal care and use program based upon the NRC guide, the AWRs have an extensive set of standards specifying the humane handling, care, treatment, and transport of various species of animals. The standards section of the regulations detail facility and operating standards, animal health and husbandry standards, and transportation standards for each regulated species. In addition, detailed specifications are given for marking dogs, cats, and other animals for the purpose of identification. In most, but not all, cases, the standards of the AWRs are the same as those of the PHS policy and, thus, are similar to the guidelines given in the NRC guide.

The AWA calls for the USDA to issue regulations in several areas. These regulations, which have engendered considerable public debate as well as the filing of a lawsuit, require exercise of dogs and the provision of a physical environment adequate to promote the psychological well-being of nonhuman primates. After considerable debate, the final regulations combined performance-based standards (standards that specify the desired outcome and leave the details of achieving that outcome to the regulated party) with design or engineering standards (standards that specify in measurable and objective terms how a particular outcome is to be achieved). It is the choice of performance-based standards that is especially controversial because plaintiffs in a lawsuit (see "Lawsuits" section below) alleged that they allow too much latitude for compliance by the regulated parties. It is generally true, however, that humane care and use of animals can be achieved under a variety of circumstances, making it difficult to use detailed engineering standards or specifications. For example, the regulations call for dry floors for most mammals. This can be accomplished by mopping the floor until dry, by wet-vacuuming the floor, by sloping the floor and letting water run off before placing an animal on the surface, and so on. Thus, there are a number of ways of achieving the desired goal, and it is the outcome itself that is specified rather than the steps needed to reach it. Critics of performance standards state that the goal often is not well described, leaving too much discretion to the regulated parties.

Another controversial aspect of the AWRs is that the regulatory definition of animal excludes birds, rats, and mice that have been bred for use in research; hence, these animals are not protected under the AWRs. The exclusion is a major one because more than 85 percent of animals used in research, education, and testing are rats, mice, and birds. The reason for the exclusion is to limit the scope and cost of annual USDA inspections; there are barely enough inspectors to review facilities and procedures involving larger vertebrate animals, whose use is thought to require more sensitivity and therefore more intense scrutiny. Adding rats, mice, and birds to the mandatory inspection list would exceed the capacity of the USDA, both because of the increased numbers of animals to be inspected and because there would be an increase in the number of registered research facilities requiring inspection. (A number of institutions use only rats and/or mice and therefore are not subject to inspection.) Because PHS policy defines *animal* as any vertebrate (with no exclusions), rats, mice, and birds are covered by PHS policy. In institutions not covered by PHS policy (e.g., industry and colleges not receiving PHS funds), the use of rats and mice remains largely unregulated, a glaring oversight unique to the United States (Orlans, 2000).

Protocol Review: Consideration of Pain and Distress and Numbers of Animals Used

Because both PHS policy and the AWRs explicitly require minimization of pain and distress of animals during research, there have been examinations of the implications and possible effectiveness of the IACUC consideration of these issues during protocol review (Dresser; Brody). Both regulations attempt to incorporate cost–benefit considerations, utilitarian theory, and some elements of a modified rights-based philosophy (Dresser). The success of PHS policy and the AWRs depends fundamentally upon the recognition that animals can experience pain and distress that can be alleviated (NRC, 1992). The USDA requires an annual report from all registered institutions that lists the numbers of animals used in research and testing, classified by the degree of pain and distress: (1) minimal, transient, or no pain or distress; (2) pain and distress relieved by anesthetics, analgesics, or tranquilizers; and (3) pain and distress not treated. A detailed statement on category 3 procedures is required, including scientific justification for withholding drugs. Another classification scheme, developed by the Scientists Center for Animal Welfare, lists six categories instead of three (Orlans, 1987). Many IACUCs use some classification scheme for pain and distress, reducing the number of animals used in research that fall into the higher categories of pain and distress by applying the "three Rs" (replacement, reduction, and refinement) of William M. S. Russell and Rex L. Burch, authors of a book first published in 1959 called *The Principles of Humane Experimental Technique.*

Some observers feel that IACUC review does not adequately reduce the number of animals used in research or the pain and distress of these animals. In a 1989 article, Mimi Brody suggested new legislation that would implement two oversight levels—first, a local committee; second, a national committee—to review uses of animals with "high ethical cost." Gary L. Francione argued in a 1990 article that open IACUC meetings, publicly announced and attended by interested members of the community, would improve the quality of protocol review. The two-committee approach has the disadvantage of delaying approval of certain types of research and has the potential for becoming excessively bureaucratic. The open-meetings approach presumes that the general public could comprehend the scientific details of the described procedures and would be able to judge the ethical and social justifications for the proposed procedure.

Lawsuits Concerning the Animal Welfare Regulations

As mentioned earlier, the definition of animals in the AWRs excludes birds, rats, and mice specifically bred for use in research. After parts 1 and 2 of the AWRs became final in 1989, the Animal Legal Defense Fund (ALDF) and the Humane Society of the United States (HSUS) filed a rulemaking petition with the USDA to amend the regulations to include rats, mice, and birds in the definition of animals. After the USDA denied the petition in 1990, the ALDF and the HSUS brought suit in federal court, seeking a declaratory judgment and an injunction preventing the USDA from excluding coverage of rats, mice, and birds. In 1992 the ALDF and the HSUS were granted summary judgment, and the USDA was ordered to reconsider its denial of plaintiffs' petition in light of the court's opinion holding the exclusion of rats, mice, and birds to be arbitrary and capricious (*Animal Legal Defense Fund v. Madigan,* 1992). The USDA appealed, and on May 20, 1994, the court of appeals vacated the district court's decision and directed the lower court to dismiss, holding that none of the petitioners had demonstrated both constitutional standing to sue and a statutory right to judicial review under the Administrative Procedure Act—leaving regulations, and presumably practice, to stand unchanged (*Animal Legal Defense Fund v. Espy,* 1994). In 1998, however, the Alternatives Research and Development Foundation filed a new suit to force the inclusion of rats, mice, and birds under AWA. The USDA settled the case (*Alternatives Research and Development Foundation v. Glickman*) in 2000, agreeing to inclusions. But the Farm Security and Rural Investment Act of 2002 blocked the settlement. This amendment permanently denied rats, mice, and birds legal protection under AWA.

The USDA regulations concerning requirements for exercise of dogs and for a physical environment adequate to promote the psychological well-being of nonhuman primates were published in February 1991. The ALDF and others sued, alleging that these regulations did not comply with the 1985 amendments of the AWA because they did not provide minimum standards for exercise of dogs and for adequate cage size and environmental enrichment for nonhuman primates as required by Congress. The district court granted plaintiffs' motion for summary judgment in February 1993 (*Animal Legal Defense Fund v. Secretary of Agriculture,* 1993). It was unclear at the time of this decision whether the federal government would appeal the decision, so the National Association for Biomedical Research (NABR) moved to intervene in the case to ensure an appeal. Although the NABR motion was originally denied, the denial was reversed by the court of appeals. The federal government subsequently decided to pursue an appeal, and the consolidated appeal was argued in May 1994. Two months later, the court of appeals vacated the district court's decision and directed the lower court to dismiss, concluding that the ALDF and the other appellees lacked standing to challenge USDA regulations (for the same reasons cited in the ALDF/HSUS case), again leaving policy unchanged.

Conclusion

Federal laws and policies regarding the use of animals in research, education, and testing have progressed rapidly from the first enunciation of principles for the care of laboratory animals in the early days of NIH and the first animal welfare laws passed in 1966. Early policy had limited effects on the use of animals because of the generally careful practice standards already in place as well as the lack of enforcement of the new policy. Several U.S. programs and institutions had their funding suspended in the early 1980s, with increased USDA inspections and subsequent violations at numerous institutions in the years that followed, all of which serve as a warning that all animal-care policies must be followed (Rozmiarek). The evolution of policies for animal care and use shows a trend toward increased responsibility for and supervision by IACUCs, with greater emphasis on the level of assurances institutions must give, on IACUC membership, on the process of protocol review, and on the committee's power in matters involving activities using animals. This has resulted in more scrutiny of the care and use of animals in scientific research. The regulations in effect are comprehensive and, if followed, result in excellent care for animals. The penalties for not adhering to the regulations are great enough to encourage compliance and will assure that the privilege of using animals in research is carried out in a humane and careful manner.

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SEE ALSO: *Animal Welfare and Rights; Law and Morality; Research Policy: Historical Aspects; Xenotransplantation;* and other *Animal Research* subentries

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ANIMAL WELFARE AND RIGHTS

• • •

I. Ethical Perspectives on the Treatment and Status of Animals
II. Vegetarianism
III. Wildlife Conservation and Management
IV. Pet and Companion Animals
V. Zoos and Zoological Parks
VI. Animals in Agriculture and Factory Farming

I. ETHICAL PERSPECTIVES ON THE TREATMENT AND STATUS OF ANIMALS

Normative ethical theory may be conceived as the systematic inquiry into the moral limits on human freedom. Philosophers and theologians throughout history and across cultures have offered different, often contradictory, answers to the central question of ethics thus conceived. Some have argued, for example, that the only justified limits on human freedom are those grounded in the rational self-interest of the agent, while others have maintained that the foundations of morality, and thus the basis of morally justified limitations on human freedom, are logically distinct from self-interest, though not from the dictates of reason. Still others have alleged that the foundations of morality have nothing to do with either reason or self-interest.

In view of the variety and conflicting nature of answers to the central question of normative ethics, it is hardly surprising that ethical theories sometimes offer strikingly different accounts of the moral status of those nonhuman animals we humans raise or hunt for food and clothing, use as beasts of burden, train to entertain us, and utilize as models for purposes of biomedical research. No philosopher or theologian has gone so far as to say that, from the moral point of view, there are no justified limits on what we may do to these animals. Even René Descartes, much celebrated for his theory that nonhuman animals are automata and thus incapable of feeling either pain or pleasure (Descartes, "Animals Are Machines," in Regan and Singer, 1976; 1989), is said to have treated his dog humanely. At a certain minimal level, then, all normative ethical theories speak with one voice. But at other levels, the differences are both real and deep.

Direct and Indirect Duties

These differences emerge clearly when we consider how competing theories answer two distinct but related questions. The first asks, What are the grounds for morally limiting human freedom when it comes to human interactions with nonhuman animals? The second asks, How extensive are these moral limits on human freedom? The former inquires as to why human freedom should be limited at all when our actions affect other animals; the latter challenges us to investigate how much our freedom should be limited. Of the two questions, the first is the more basic, for the reasons given in support of views about how much our freedom should be limited ultimately are based on views about why our freedom should be limited in the first place.

Two opposed possibilities present themselves as answers to the first, more basic question. One possibility holds that it is because of how animals themselves are affected or treated by human agents that we should limit our freedom. Viewed from this perspective, nonhuman animals are entitled to a certain kind of consideration or treatment. Because such views stress the idea that something is owed or is due directly to these animals, it is common to refer to them as "direct duty" views.

The second possibility, by contrast, locates the ground of moral constraint in some basis other than the animals. Viewed from this perspective, humans owe nothing to other animals, nor do these animals deserve any sort of treatment or consideration. Rather, human freedom should be limited because, for example, human cruelty to other animals will cause humans to treat one another cruelly. Because such views deny that we have duties directly to other animals, while recognizing that other factors should limit our freedom in our dealings with them, they are commonly referred to as "indirect duty" views.

All normative ethical theories, as they address the moral status of nonhuman animals, fall into one or the other of these two classes. That is, either they affirm that we have direct duties to nonhuman animals, or they deny that we have direct duties. Some of the major theoretical options within each class, as these have been developed by ethicists within the history of Western thought, will be considered in what follows.

Abolition, Reform, and Status Quo

As noted earlier, a second important question asks how much our freedom should be limited in our dealings with other animals. Three sorts of options may be distinguished: abolitionist, reformist, and status quo. An abolitionist position argues on behalf of ending human practices that routinely utilize nonhuman animals (for example, as a source of food or as models in scientific research). A reformist position accepts these institutions in principle but seeks in various ways to improve them in practice (for example, by enlarging the cages for animals used in research). A status quo position, unlike the abolitionist position, accepts these institutions in principle and, unlike the reformist position, does not recognize the need to improve them. Representative examples of each outlook and their logical relationship to competing normative ethical theories will be explained below.

While the heated, sometimes acrimonious, debate among partisans of abolition, reform, and the status quo captures the attention of the media, far less attention has been devoted to the critical assessment of the competing ethical philosophies, whether of the direct or indirect duty variety. This by itself suggests the degree to which the public debate over "animal rights," broadly conceived, has assumed the greater part of what is most in need of informed, critical reflection. For clearly, whether we should favor the goals of supporters of abolition, reform, or the status quo in practice depends on determining the most adequate account of how we should treat nonhuman animals in theory. It is to a consideration of some of the major options in ethical theory that this entry now turns.

Perfectionism

Aristotle (384–322 B.C.E.) presents the broad outlines of a moral theory that goes by the name "perfectionism." The cornerstone of this theory has a high degree of initial plausibility. Justice, it is claimed, consists in giving to individuals what they are due, and those individuals whose character is morally better (more "perfect") than the character of others prima facie deserve more of what is good in life than do other, less good people. Aristotle's accounts of what makes people morally better and of "the good of man" have helped shape much of Western moral theory. Concerning the latter first, Aristotle accepts the commonplace notion that the good we humans seek is happiness, but he argues that the true happiness we seek is not wealth, fame, or even pleasure in abundance but, rather, the possession and exercise of those virtues (those "excellences") that are uniquely human. Thus happiness, in his view, is characterized as "an activity of the soul in accordance with virtue." Those are happiest who optimally express their humanity in how they live and, in doing so, take pleasure in being the human beings they are.

As for the moral virtues (prudence, justice, courage, and temperance), Aristotle characterizes each as a mean between the extremes of excess and deficiency. A courageous person, for example, is neither foolhardy (an excess) nor cowardly (a deficiency); a courageous person has the right mix of the willingness to take risks and the fear of doing so. Among the intellectual virtues, a detached, contemplative wisdom, wherein one knows eternal truths and in this way shares in that knowledge possessed by the gods, is the highest. In the case of both the moral and the intellectual virtues, finally, the human capacity to reason plays a decisive role. For man is, in Aristotle's view, unique in being "a rational animal," and "the good of man" consists in actualizing, to the fullest extent possible, those unique potentialities that define what it is to be human. Thus, since those are happiest who optimally express their humanity in how they live, those are happiest who exercise their reason optimally.

Because it prescribes the distribution of what is good in life on the basis of one's possessing the favored virtues and, thus, on the basis of degrees of human perfection, perfectionism can—and in Aristotle's hands, does—sanction or require radically inegalitarian treatment of different individuals. In the case of nonhuman animals in particular, perfectionism provides no direct protection. Despite his teaching, in sharp contrast to Descartes's, that these animals share many of the same psychological capacities possessed by humans—including, for example, sensation and desire—Aristotle confidently denies that they share the capacity to reason. Moreover, because in his view the "lesser" exists to serve the interests or purposes of the "greater," Aristotle maintains that nonhuman animals exist for the purpose of advancing the good of human beings. He writes: "Other animals exist for the sake of man, the tame for use and food, the wild, if not all, at least the greater part of them, for food, and for the provision of clothing and various instruments" (Aristotle, "Animals and Slavery," in Regan and Singer, 1976, p. 110; 1989, p. 5). There is no implication here that Aristotle's teachings permit the wanton infliction of pain on nonhuman animals for no good reason. What is clear is that because he recognizes no greater purpose for nonhuman animals than to serve the interests of human beings, Aristotle can recognize only indirect duties in their case. Finally, while many of today's more controversial practices involving human utilization of nonhuman animals, such as factory farming and animal-to-human organ transplants, were unknown in his day, all the available evidence seems to indicate that Aristotle was well disposed to the status quo with respect to the relevant practices current while he was alive.

It is not only nonhuman animals, however, that exist for the sake of those who are more perfect. In general, women do not measure up to Aristotle's standards of "the good of man." "The male is by nature superior, and the female inferior," he writes, "and the one rules, and the other is ruled; this principle, of necessity, extends to all mankind" (ibid.). Moreover, some humans, whether male or female, lack the ability to grasp through reason those truths understood by the more virtuous among us; of such individuals Aristotle writes that they are "slave[s] by nature" (ibid.). And so it is that Aristotle affirms the obvious parallel, given the form perfectionism takes in his hands, between the moral status of human slaves and nonhuman animals: "The use made of slaves and of tame animals is not very different; for both with their bodies minister to the needs of life" (ibid.). Those humans who, because of their superior rationality, are morally more perfect are entitled to make use of those, whether human or not, who lack the virtues defining human perfection.

Few today will publicly embrace Aristotle's perfectionism. Not only does his view of women offend the emancipated gender egalitarianism of our time, but the comfortable elitism and classism that enable him to pronounce some humans "slaves by nature" will find no home among the most basic precepts of contemporary moral, political, and legal thought. The practical implications for humans of the fundamental principle of Aristotelian perfectionism—that those who are lacking in reason exist to serve the interests of those who are most virtuous—is morally offensive. It is one thing to affirm that those people who are more perfect than others prima facie deserve more of what is good in life; it is quite another to maintain that those who are less perfected exist for the sole purpose of ministering to the more virtuous. Moreover, since we cannot rationally defend the exploitation of some humans on the grounds that "by nature" they lack the potential to acquire the virtues possessed by those who exploit them, we cannot rationally defend human exploitation of nonhuman animals by offering an analogous defense—cannot, that is, rationally defend such exploitation by claiming that nonhuman animals "by nature" lack the potential to acquire uniquely human virtues.

Despotism and Stewardship

An alternative to Aristotle's philosophy is rooted in the biblical teaching that the God of Judaism and Christianity gives human beings dominion over nature in general and other animals in particular. As so often happens, however, there is more than one way to interpret the biblical message. Two ways in which human dominion can be understood—despotism and stewardship—will be sketched here.

Despotism teaches that nature in general and the other animals in particular are created by God for the sake of humans, and thus are ordained by the divine creator to serve such myriad human purposes as a source of food and clothing. Nothing within the natural order, save humans, has value in and of itself; what value the natural world possesses is entirely dependent on the extent to which it serves human interests. In this sense, human interests *are* the measure of all things, at least all things of value. Various biblical passages are cited to confirm the despotic reading, for example, "Then God said, 'Let us make man in our image, after our likeness; and let them have dominion over the fish of the sea, and over the birds of the air, and over the cattle … and over all the earth'" (Gen. 1:26).

Seen in this light, despotism's appeal to what God has ordained provides a reason for human supremacy over nonhuman animals that Aristotle's appeal to what is guaranteed "by nature" seems to lack, and it is a small step from acceptance of the despotic interpretation of human dominion to the conclusion that we owe nothing to nonhuman animals. Thus we find Saint Thomas Aquinas (ca. 1225–1274), for example, urging in words barely distinguishable from those of Aristotle except for their reference to God that it is by "Divine ordinance that the life of animals and plants is preserved not for themselves but for man" (Thomas Aquinas, "On Killing Living Things and the Duty to Love Irrational Creatures," in Regan and Singer, 1976, p. 119; 1989, p. 11). Mindful, moreover, that some biblical passages prohibit cruelty to nonhuman animals, Aquinas firmly places himself within the indirect duty tradition when he maintains that the import of such prohibitions is, for example, "to remove man's thoughts from being cruel to other men, and lest through being cruel to animals one become cruel to human beings" (Thomas Aquinas, "Differences between Rational and Other Creatures," in Regan and Singer, 1976, p. 59; 1989, p. 9).

To the extent that Saint Thomas's philosophy is rooted in the Scripture of the Christian tradition, those who stand outside this tradition are unlikely to be persuaded that God established in nature what nature was incapable of establishing by itself. Even granting biblical underpinnings to one's ethic, moreover, questions arise concerning the accuracy of the despotic interpretation of human dominion. While the Hebrew concept of *rada*, translated as "having dominion," often is interpreted to mean human despotism over the nonhuman world—an idea that, according to some early critics (White; McHarg), is the root cause of today's environmental crisis—a significantly different interpretation has been proposed by more recent thinkers (Barr; Linzey, 1987; McDaniel; Callicott, 1993).

For *rada* can be understood as the idea of human responsibility toward and care for a created order that is good independent of the human presence. According to this latter interpretation, commonly referred to as stewardship, humans are given the task of being as loving within the natural order as God was in creating the natural order in the first place. Humans, that is, are to be the loving caretakers of an independently good creation. Because, viewed from the stewardship perspective, the natural world in general, and those nonhuman animals with whom we share it in particular, are good apart from human interests, our duties with regard to these animals emerge as direct duties owed to them rather than indirect duties owed either to other humans or to their creator.

Although when thus interpreted all of creation is seen as having a kind of value that is independent of human interests, the value of nonhuman animals arguably is especially noteworthy. One might note, first, that these animals were created on the same day—the sixth—as were humans (Gen. 1:24–27); that in the original state of perfection, in Eden, humans did not eat other animals (Gen. 1:29); and that, in God's covenant with Noah after the flood (Gen. 9:8–12), animals (but not plants) are included. Using these images, one can argue that the choice we face today is *either* to continue to move further from the sort of relationship with the animals God hoped would prevail when the world was created *or* to make daily efforts to recapture that relationship—to journey back to Eden, as it were. Given this latter reading, the practical consequences of a stewardship interpretation of dominion would depart significantly from those favored by the status quo position, just as the goals one would hope to achieve would differ from those advanced by reformists. For if our righteous relationship with the other animals, in our capacities as their caretakers and protectors, is one of nonutilization (they are not to be eaten, not to be worn, etc.), then the stewardship interpretation of human dominion would seem to support an abolitionist ideal.

However these matters are to be settled, the biblical grounding of morality characteristic of both despotism and stewardship places these moral perspectives outside the mainstream of normative ethical theory, at least from the Enlightenment forward, where rigorous, imaginative attempts have been made to ground ethics independently of belief in God and the moral authority of the Bible. One such attempt is contractarianism.

Contractarianism

Among the most influential nontheological political and moral theories, contractarianism has a legacy that reaches at least as far back as Thomas Hobbes (1588–1679) and, among our contemporaries, includes such notable philosophers as John Rawls (1971) and Jan Narveson (1988). Like other theorists united by a common outlook, contractarians often disagree on many of the most fundamental points. It will not be possible to do justice to the rich fabric of disagreement that characterizes proponents of the theories under review.

As its name suggests, contractarianism conceives of morality as a kind of contract into which people (the "contractors") enter voluntarily. For contractarians, morality emerges as a set of mutually agreed upon and enforceable constraints on human freedom, constraints that each party to the contract rationally believes to be in his or her own self-interest. There is, then, according to contractarian theory, nothing that by its nature is morally right or wrong, just or unjust; rather, acts or institutions become right or wrong, just or unjust, as a result of the agreements reached by rational, self-interested contractors. In this sense, all of morality is conventional, and none is natural. Morality is created, not discovered, by human beings.

Both the self-interest that motivates and the rationality that guides the contractors are significant. We are not to imagine that people, as they deliberate about what limits on their freedom they will accept, are motivated by a natural sympathy for the misfortune of others or that they are willing altruistically to accept personal loss so that others might gain. Each contractor is motivated exclusively by his or her self-interest. The conception of individual self-interest each contractor has, moreover, is neither whimsical nor uninformed. Each person asks the same basic question: From the point of view of what is best for me, rationally considered, what limitations on my freedom would I be willing to accept? Morality, understood as rational, enforceable constraints on human freedom, arises when all the contractors jointly agree on the same constraints, not out of sympathy for others or because of altruistic motivations, but because each judges the outcome to be in his or her personal self-interest.

Two fundamentally opposed forms of contractarianism may be distinguished. The first permits the contractors to enter into their contractual deliberations equipped with the knowledge of who they are and what they want out of life, given their individual interests, talents, and hopes. This is the form of contractarianism favored by Hobbes and Narveson, for example. The second, favored by Rawls, requires that the contractors imagine that they lack such detailed knowledge of their individual psychology and circumstances, and instead deliberate about the terms of the contract from behind what Rawls calls "a veil of ignorance." Why Rawls would have recourse to this imaginative point of view will be explained momentarily. First, however, the implications of Hobbesian contractarianism for the treatment of nonhuman animals deserve attention.

Judged on the basis of the interests of these animals, the implications are not particularly salutary. In view of their inability to express these interests and to negotiate with others, nonhuman animals obviously are not to be counted among the potential contractors. Moreover, even while it is true that some things are in the interests of pigs and wolves, for example, the idea that these animals can have an informed understanding of what is in their rational self-interest has no clear meaning. Not surprisingly, therefore, what protection these animals are provided by Hobbesian contractarianism necessarily depends on what interests the human contractarians happen to have in them.

Narveson, for one, cheerfully indicates that this need not be very much (Narveson, "A Defense of Meat Eating," in Regan and Singer, 1989). Because many contractors have a special place in their hearts for companion animals ("pets"), these animals will be treated reasonably well, not because they are entitled to such treatment but because we owe it to their human friends not to upset them (these humans) gratuitously. In the case of most other nonhuman animals, however, including those slaughtered for food or used in research, Narveson finds no good reason to cease and desist. Clearly, then, given Hobbesian contractarianism, all our duties with respect to other animals are indirect duties owed to those human beings who help forge the contract. And just as clearly, considered from a political perspective, one finds little within this version of contractarianism that could mount an abolitionist or a far-reaching reformist approach to how other animals are treated; what one finds instead is a theory well disposed to the status quo while remaining open to modest reforms.

Critics of Hobbesian contractarianism have raised various objections (Regan, 1983). One concerns the possibility of arbitrary discrimination between people—for example, discrimination based on race. If we imagine that a large majority of potential contractors (say, 95%) are white, and the remainder black, then it is not obviously irrational for those who comprise the majority to exclude members of the minority from negotiating the contract; perhaps the majority might even agree to keep the minority in bondage, as chattel slaves, the better to advance the rational self-interests of those individuals comprising the majority. That such an arrangement would be unjust seems too obvious to need a supporting argument. And (for Hobbesian contractarianism) there's the rub. For since what is just and unjust is created by the agreements reached by the contractors, there is, within this form of contractarianism, no theoretical grounding for the evident injustice involved in excluding the minority from participating. The theory, that is, not only fails to illuminate why such discrimination is unjust, but it also seems to deprive us of the means even to raise this objection. If a moral theory is so fundamentally flawed when it comes to how human beings, given their differences in skin pigmentation, should be treated, it is unclear how it can be any nearer the truth when it comes to how nonhuman beings, given their species differences, should be treated.

Rawls's introduction of the veil of ignorance, mentioned earlier, can be interpreted as his attempt to preserve the spirit of Hobbesian contractarianism while departing importantly from the letter. Rawls invites would-be contractors to imagine themselves in what he calls the "original position," in which, because they deliberate from behind the veil of ignorance, they do not know when they will be born or where, whether they will be rich or poor, of exceptional intelligence or below average, male or female, Caucasian or non-Caucasian. The question now to be asked, by each of the contractors, is what limits on human freedom each would accept, in the face of such profound ignorance concerning such details.

The full scope of Rawls's answer need not concern us. Only two points are of particular importance here. The first concerns how Rawlsian contractarianism improves on Hobbesian contractarianism when it addresses the issue of discrimination based on race. Hobbesian contractors, as noted above, can have a self-interested reason for accepting such discrimination, given that they know they belong to a racial majority. Rawlsian contractors, in contrast, lack such a reason since, for all they know, they might be one of the minority. In this respect, Rawlsian contractarianism seems to represent a notable improvement over Hobbesian contractarianism.

Despite its apparent strengths in response to issues involving arbitrary discrimination, Rawls's account of the moral status of nonhuman animals seems to fail to live up to its own standards (VanDeVeer). While the imaginary contractors behind the veil of ignorance are denied detailed knowledge about their individual interests and circumstances, and thus do not know whether, say, they will be male or female, black or white, Rawls does permit them to know that they will be born as human beings. To allow knowledge of this detail, however, seems to prejudice the case against nonhuman animals from the start. Granted, rational, self-interested contractors, making choices from behind the veil of ignorance, will negotiate direct duties to human beings and indirect ones to nonhumans, if they know they will be born human. But this only shows that these contractors will discriminate against these animals if they are provided with an arbitrary reason for doing so. In short, neither Hobbesian nor Rawlsian contractarianism seems to offer a reasonable basis on which to ground the only duties each recognizes in the case of nonhuman animals: indirect duties.

Kantianism

A final example of an indirect duty view is provided by the great Prussian philosopher Immanuel Kant (1724–1804). In some respects Kant's moral philosophy regarding the treatment of nonhuman animals is an amalgam of Aristotle's and, stripped of its appeals to God, Aquinas's. In concert with both, Kant emphasizes rationality as the defining characteristic of being human and, echoing Saint Thomas, objects to cruelty to animals because of the deleterious effect this has on how humans are treated. "He who is cruel to animals," Kant writes, "becomes hard also in his dealings with men," whereas "tender feelings towards dumb animals develop humane feelings towards mankind" (Kant, "Duties in Regard to Animals," in Regan and Singer, 1976, p. 123; 1989, p. 24).

Despite these historical echoes, Kant's moral philosophy is in many ways highly original. Of particular note is his thesis that humanity exists as an "end in itself." Kant does not attempt to prove this thesis by appeal to some more basic principle; rather, it is set forth as a postulate in his system. In this capacity it places humans and other rational, autonomous beings in a unique moral category that distinguishes them, as "persons," from everything else that exists. Like Aristotle and Aquinas before him, Kant views the rest of the natural order as existing to serve human interests. In particular, animals, in his words, exist "merely as a means to an end. That end is man" (ibid.). Thus, whereas in Kant's view we are morally free to use other animals as we wish, subject only to the injunction to avoid cruelty, we are not morally free to treat human beings in a comparable fashion. Because humans exist as ends in themselves, we are never to treat them merely as means, Kant argues, which is what we would be doing if we treated them as we treat other animals (for example, if we raised humans as a food source). An abolitionist, a radical reformist, Kant is not. Provided only that we are not cruel in our treatment of nonhuman animals, we do nothing wrong when we treat them as we do.

A common objection against Kant's position is the argument from marginal cases (Regan, 1983; for criticism of this argument, see Narveson, 1977). All humans, Kant implies, exist as ends in themselves. To restrict this supreme moral value to humans among terrestrial creatures is not arbitrary, Kant believes, because humans, unlike the other animals, are unique in being rational and autonomous. However, not all humans are rational and autonomous. Those who are mentally enfeebled or deranged, for example, lack these capacities. Are these humans nevertheless ends in themselves? If Kant's answer is affirmative, then it is not the presence of rationality and autonomy that ground this supreme moral value; if, on the other hand, Kant's answer is negative, then it follows that these "marginal" human beings do not exist as ends in themselves, in which case it would seem that they, no less than other animals, may be treated as mere means. Because one assumes that this latter consequence would be seen by Kant to be morally grotesque, it seems fair to assume that he would want to avoid it; but he can do so, it seems, only by accepting the view that individuals who are neither rational nor autonomous nevertheless exist as ends in themselves, a view that undermines his confident assertion that nonhuman animals, deficient in reason and autonomy, exist "merely as means to an end," the end being "man."

Utilitarianism

The pioneering work of the nineteenth-century utilitarians Jeremy Bentham (1748–1832) and John Stuart Mill (1806–1873) represents a significant departure from the Aristotelian legacy we find in Kant's moral theory. Bentham, referring to nonhuman animals, writes, "The question is not, Can they *reason?* nor, Can they *talk?* but, Can they *suffer?*" (Bentham, "A Utilitarian View," in Regan and Singer, 1976, p. 130; 1989, p. 26). The possession of sentience (the capacity to experience pleasure and pain), not the possession of rationality, nor autonomy, nor linguistic competence, entitles any individual to direct moral consideration; and it is the possession of this particular capacity, in Bentham's and Mill's view, that creates in humans the direct duty not to cause nonhuman animals to suffer needlessly. We owe it to these animals themselves, not to those humans who might be affected by what we do, to take their (the nonhuman animals') pleasures and pains into account and, having done so, to ensure that we never make them suffer without good reason.

Both Bentham and Mill give a utilitarian interpretation of what such a good reason might be. Utilitarianism, roughly speaking, is the view that our duty is to perform that act that will bring about the best consequences for all those affected by the outcome. For value hedonists like Bentham and Mill, who recognize only one intrinsic good, pleasure, and only one intrinsic evil, pain, the best consequences will be those that include the greatest possible balance of pleasure over pain. A good reason for permitting animal suffering, then, is that such suffering is a necessary price to pay in bringing about the best consequences, all considered. How much of the spirit of reform, abolition, or the status quo happens to characterize individual utilitarians depends on how much animal suffering is judged to be necessary. Bentham opposes hunting, fishing, and the baiting of animals for sport, for example, while Mill's name is to be found among the earliest contributors to England's Royal Society for the Prevention of Cruelty to Animals. But neither Bentham nor Mill aligns himself with the cause of antivivisection, and both are lifelong meat eaters. So reformers they are, but abolitionists they are not. Even so, in their time, and given the broader social context in which they lived, they were seen by many of their contemporaries as radicals, if not extremists.

The degree to which utilitarians can differ over important practical matters is illustrated in our time by Peter Singer and R. G. Frey. Singer is justly famous for his seminal 1975 book, *Animal Liberation,* while Frey has written two books (1980, 1983) and many essays devoted to the issues under review. The two philosophers, while agreeing on some of the most fundamental points in ethical theory, disagree on many of the most important consequences each believes follow from the application of utilitarianism, including how nonhuman animals should be treated. For example, in *Animal Liberation* Singer advocates vegetarianism, on moral grounds; Frey disagrees, appealing to the same grounds in his *Rights, Killing, and Suffering: Moral Vegetarianism and Applied Ethics* (1983). It will be useful to explain how such profound disagreements can arise between partisans of the same moral philosophy.

By its very nature, utilitarianism is a forward-looking moral theory. The consequences of our actions, and the consequences alone, determine the morality of what we do. As such, utilitarians will reach opposing judgments about what is right and wrong if they have opposing views of what the consequences of a given act will be. In the case of vegetarianism in particular, utilitarians like Singer believe that, taking everyone's interests into account, and counting equal interests equally, the consequences that flow from abstaining from animal flesh will be better than if people continue to include animal flesh in their diets; Frey, however, believes that the consequences of a vegetarian diet are not sufficiently better so as to impose an obligation on us to become vegetarians. It is, then, factual disagreements over what the future might hold that underlie the type of moral disagreement separating Singer and Frey on the issue of vegetarianism.

Some critics of utilitarianism (e.g., Clark) argue that the apparently unresolvable impasse created by Singer's and Frey's application of utilitarian theory to the particular case of vegetarianism illustrates a major weakness in utilitarian theory in general. Because so much—indeed, because everything—depends on our ability to know what will happen in the future, and in view of the limitations of human knowledge in this regard, utilitarianism, these critics maintain, reduces moral judgment to guesswork about what might or might not occur.

Despite this problem, utilitarianism may seem to be a congenial theory for those who utilize nonhuman animals in animal model research. The most common justification of such research consists in appealing to the improvements in human health and longevity to which this research allegedly has led; and while researchers may recognize the need to look for alternatives to the animal model, lest these animals be used unnecessarily, it seems clear that the moral justification they offer is utilitarian. (For dissenting voices regarding the human benefits of such research, from the perspective of the history of medicine, see McKinlay and McKinlay; for epistemological concerns, see LaFollette and Shanks). Part of the enduring greatness of *Animal Liberation* lies in Singer's relentless documentation of how much of this research prima facie fails to meet the utilitarian standard favored by researchers themselves. No less important is the way Singer exposes a prejudice that he, following Richard Ryder (1975), denominates "speciesism," and that he characterizes as "an attitude of bias in favor of the interests of members of one's own species and against those of other species" (Singer, 1990, p. 6). Research scientists, Singer believes, frequently offer at best half a utilitarian justification of their work: Human interests are considered; those of nonhuman animals are not. To be consistent, the interests of both must be counted, and counted equitably. It is Singer's considered judgment that few researchers are consistent in this regard.

Frey, too, examines the lack of moral consistency among researchers ("Vivisection, Morals, and Medicine," in Regan and Singer, 1989). Given any reasonable view about the richness and variety of psychological life, it is unquestionably true, Frey believes, that the psychological life of nonhuman primates, or even that of a cat or a dog, is richer and more varied than the psychological life of some human beings (a child born with only the stem of the brain, for example). Thus, if the moral defense of animal model research is supposed to lie in the good results allegedly produced by using these animals, then a similar defense for utilizing marginal humans is at hand. To be consistent in their utilitarianism, therefore, Frey believes that researchers should be willing to conduct their studies on marginal humans—a finding researchers are unlikely to welcome. Frey is unperturbed, insisting that researchers cannot have it both ways, using utilitarian modes of thinking when they believe it justifies their practice of using other than human animals in their studies, only to discard utilitarianism when its implications for the selection of marginal humans as research subjects are made manifest.

Whatever form utilitarianism takes, one of the principal objections its advocates face centers on questions of justice (Lyons). What limits, if any, can utilitarianism recognize on how future good is to be obtained? The theory seems to imply that good ends justify whatever means are necessary to achieve them, including means that are flagrantly unjust. Classic examples include situations in which the judicial execution of the innocent is sanctioned on the grounds that others will be deterred from committing similar offenses. Here, critics concede, good consequences are brought into being, but the means used to secure them are reprehensible because they are unjust.

Utilitarians have replies to this and similar lines of criticism that go beyond the scope of the present entry (Brandt). Suffice it to say that among those philosophers who are not utilitarians, many dissociate themselves from utilitarianism because they believe that respect for the rights of the individual is a principle that should not be compromised in the name of achieving some greater good for others. Not surprisingly, perhaps, a position of this kind, one that prohibits the use of nonhuman animals in the name of advancing the general human welfare, has been advanced (Regan, 1983). Though not the only possible theory of animal rights (see, e.g., Rollin, 1981, 1989), this particular theory (the "rights view") can be seen as an attempt to blend certain features of utilitarianism and Kant's theory.

The Rights View

Kant, it will be recalled, recognizes only indirect duties to nonhuman animals; we humans are not to be cruel to animals, for example, not because we treat them wrongly by our cruel treatment but because cruelty to animals can lead people to be cruel to one another. By contrast, utilitarians from Bentham to Singer recognize direct duties to nonhuman animals; they believe that there are certain things we owe to these animals, apart from how humans will be effected. On this divisive issue the rights view sides with utilitarians against Kantians: Nonhuman animals are of direct moral significance; we have direct duties in their case.

In a second respect, however, the rights view sides with Kantians against utilitarians. Utilitarians believe that duty is determined by the comparative value of consequences; the right thing to do is what causes the best results. Kant and his followers take a decidedly different view: What is right does not depend on the value of consequences, it depends on the appropriate, respectful treatment of the individual—in particular, whether humans are treated as ends, not merely as means. In this regard, the rights view is cut from Kantian, not utilitarian, cloth. What is right depends not on the value of consequences but on the appropriate, respectful treatment of the individual, including individual nonhuman animals. Thus, the fundamental principle of the rights view (the respect principle) is Kantian in spirit: We are always to treat individuals who exist as ends in themselves (those who have "inherent value") with respect, which means, in part, that we are never to treat them merely as means.

One problem the rights view faces concerns which nonhuman animals possess value of this kind. Like other line-drawing issues ("Exactly how tall do you have to be to be tall?" "Exactly how old do you have to be to be old?"), this one has no precise resolution, in part because the criterion for drawing the line is imprecise. The criterion the rights view proposes is that of being the subject of a life, a criterion that specifies a set of psychological capacities (the capacities to desire, remember, act intentionally, and feel emotions, for example) as jointly sufficient. At least some nonhuman animals (e.g., mammals and birds) arguably possess these capacities, thus are subjects of a life, and thus, given the rights view, are to be treated as ends in themselves. (For criticism, see Frey, 1980).

Such a view, for obvious reasons, has massive political, social, and moral implications concerning how these animals ought to be treated. From an animal rights perspective of this kind, the abolition of human exploitation of these animals, whether on the farm, at the lab, or in the wild—not merely the reform of these practices, and certainly not approval of the status quo—is what duty requires.

Line-drawing issues aside, the rights view faces daunting challenges from other quarters. One concerns the idea of inherent value. Some critics (e.g., Sapontzis) allege that the idea is "mystifying," meaning that it lacks any clear meaning. Advocates of animal rights reply that the notion of inherent value is no less "mystifying" than Kant's idea of end in itself. As applied to human beings, Kant's idea of end in itself attempts to articulate the cherished belief that the value or worth of a human being is not reducible to instrumental value—not reducible, that is, to how useful a human being happens to be in forwarding the interests or purposes of other human beings. Neither John Doe nor Jane Doe, in Kant's view, exists as a mere resource relative to what other people want for themselves, and to treat the Does as if their value—their worth or dignity—consists merely in their resource or instrumental value for others is morally wrong. All that the rights view alleges, then, is that to be consistent, the same moral judgment must be made in those cases where nonhuman animals that are subjects of a life are treated in a similar fashion.

Another set of challenges alleges that the philosophy of animal rights, if acted upon, would lead to catastrophic consequences, either to human interests in particular or to the community of life in general. Concerning the former challenge, some critics argue that human health and longevity would be seriously harmed if, as the philosophy of animal rights requires, nonhuman animals ceased to be used as models of human disease (see C. R. Gallistel, "The Case for Unrestricted Research Using Animals," in Regan and Singer, 1989; and Cohen). Several responses seem apposite.

First, given the massive allocation of public monies that fund such research, it needs to be asked whether abandoning reliance on the whole-animal model really is contrary to what is in the collective best interests of human beings. Some (e.g., Sharpe) argue that customary reliance on this well-entrenched scientific methodology retards the development of alternative methodologies that would be more useful in understanding and curing major human diseases; in addition, these critics insist that humans would benefit more if the dominant focus of biomedical research were shifted away from curing disease to preventing it, a goal that is more efficiently advanced, these critics allege, by methodologies other than the use of the whole-animal model.

Second, recall one of the fundamental objections raised against utilitarianism: Just as one does not justify the violation of a human being's rights because doing so will benefit others, so one does not justify the violation of the rights of nonhuman animals on similar grounds. More generally, some gains others might obtain may be ill-gotten, and they are ill-gotten if the price of obtaining them involves the violation of another's rights. Thus, even if it is true that humans stand to lose some benefits if animal model research is abandoned, this by itself does not constitute a telling moral objection to the abolitionist implications of the philosophy of animal rights, assuming that these animals, like humans, have the right to be treated as ends in themselves.

Concerning the second line of criticism—the one alleging that acting on the philosophy of animal rights would have catastrophic implications for the community of life in general—the principal objection may be summarized as follows. Predatory animals obviously live off the death and flesh of their prey. Because prey animals have the right to be treated with respect, according to the rights view, critics (e.g., Callicott, 1980; Sagoff) allege that it follows that we should intervene to stop predatory animals in their natural depredations. However, if we were to do this, there would be no check on the balance that exists in nature between predators and preys; instead, the population of prey animals would explode, and this would have the effect of irreparably damaging the balance and sustainability of life forms within the larger life community.

Advocates of the philosophy of animal rights have a number of possible replies to the predation problem, the principal one of which is the following. Situations can and do arise where the right thing to do is to come to the assistance of another, whether the potential victim is a human or a nonhuman animal. However, in these situations the potential victim not only is at risk of serious injury but also is less than capable of mounting a defense. Thus, an elderly woman who is attacked by a psychotic killer, or a puppy who is being tormented by children, merits our intervention. But the predator–prey relationship seems to bear little resemblance to such cases. Most prey animals, most of the time, are perfectly capable of eluding their predators without anyone's assistance. Thus it would seem to be human arrogance, not informed responsibility, that would lead humans to believe that because animals in the wild have rights, we are duty bound to "police" nature. From an animal rights perspective, we have no general duty to intervene in predator–prey relations; that being so, the catastrophic environmental costs alleged to be implied by acting on the rights view seem to be more in the nature of fiction than of fact. (For a different response to the predation problem, see Sapontzis.)

Deep Ecology

Despite the significant differences separating the philosophy of animal rights and other, more traditional moral theories, such as Kant's, there are important similarities. For example, like Kant's theory, the philosophy of animal rights recognizes the noninstrumental value of the individual; and animal rights philosophy, as is true not only of Kant's theory but of utilitarianism as well, articulates an abstract, universal, and impartial fundamental moral principle—abstract because the respect principle enjoins us to treat others with respect, without regard to time, or place, or circumstance; universal because the respect principle applies to everyone capable of making moral decisions; and impartial because this principle does not favor some individuals (e.g., family members or companion animals) over others. Some contemporary moral philosophers find this approach to ethics archaic; among these critics, some of those who classify themselves as deep ecologists (see, in particular, Devall and Sessions) command a growing audience. (For a more systematic and in some ways different version of deep ecology, see Naess. For importantly different approaches to environmental ethics, see Taylor; Rolston; Callicott, 1980.)

Both traditional moral theories and the philosophy of animal rights are doubly to be faulted, according to Devall and Sessions—first, because these moral outlooks offer an overly intellectualized account of the moral life, and second, because they perpetuate the myth of the moral preeminence of the individual. Considering this latter charge first, Devall and Sessions argue that the concept of the isolated, atomistic individual, which arises out of the anthropocentric traditions of Western philosophy, is false to the facts of all life's embeddedness in the larger life community. People are not independent bits of mind existing by themselves; they are enmeshed in networks of relationships that bind them both to their evolutionary past and to their ecological present. Expressed another way, humans do not stand "above" or "apart from" nature; they stand "within" nature. And the natural world does not exist "for us," as a storehouse of renewable human resources (a view that is symptomatic of a "shallow" view of humanity's relationship to nature); we are inseparable from the natural environment (a view that indicates a "deeper" understanding of what it means to be human).

Thus, acceptance of the illusory concept of the isolated individual, existing outside the natural order, has done, and continues to do, incalculable damage to those who seek self-understanding. So long as we carry out this quest with a fundamentally flawed preconception of our place in the larger scheme of things, the longer we search, the less we will understand. As for the charge that traditional moral theories overintellectualize the moral life, Devall and Sessions argue that the moral life should be viewed as primarily experiential, not inferential, a life that is characterized by our coming to experience certain values in the concrete particularities of day-to-day life, rather than by apprehending abstract, universal, impartial moral principles by means of our rational powers.

Among those values to be found in the concrete particularities of day-to-day life, some involve other animals; and although deep ecologists have not written extensively on some of the most pressing practical issues, the general disdain these thinkers display toward reductionist science and industrial societies' technological domination of the natural world suggests that they would be strong reformists, at a minimum, in response to such practices as factory farming and animal model research. In the case of sport and recreational hunting, however, Devall and Sessions not only find nothing wrong, they applaud the practice. In pursuit of their prey, hunters tap into natural means whereby, through the act of killing, they can obtain greater self-understanding. Viewed in this light, Devall and Sessions seem to understand our duties with respect to animals as indirect duties limited by the overarching quest for self-knowledge. While, therefore, deep ecologists like Sessions and Devall can be counted upon to add their voices to those of reformists and abolitionists in some cases, they emerge as defenders of the status quo in others.

Ecofeminism

Ecofeminists, not just advocates of the rights view, are among those contemporary moral philosophers who differ significantly with deep ecologists. Like other isms, ecofeminism is not a monolithic position (see Adams; Diamond and Orenstein; Warren; Gaard); instead, it represents a number of defining tendencies, including in particular a principled stance that puts its advocates on the side of those who historically have been victims of oppression. For obvious reasons, women are pictured as among the oppressed, but the scope of ecofeminism's concern is not limited to women. The same ideology that sanctions oppression based on gender, ecofeminists maintain, also sanctions oppression based on race, class, and physical abilities, for example; moreover, beyond the boundaries of our species, this same ideology, ecofeminists believe, sanctions the oppression of nature in general and of nonhuman animals in particular.

In a number of fundamental ways, ecofeminism's diagnosis of the ideology of oppression resembles deep ecology's diagnosis of the deficiencies of traditional moral theory. As is true of the latter, ecofeminism challenges the myth of the isolated individual, existing apart from the world, and instead affirms the interconnectedness of all life. Moreover, no less than deep ecologists, ecofeminists abjure the overintellecutalization of the moral life characteristic of traditional moral theories, with their abstract, universal, and impartial fundamental principles. But whereas deep ecologists locate the fundamental cause of moral theory gone awry in anthropocentrism (human-centeredness), ecofeminists argue that it is androcentrism (male-centeredness) that is the real cause.

Nowhere is this difference clearer than in the case of sport or recreational hunting. Devall and Sessions celebrate the value of this practice as a means of bonding ever more closely with the natural world, of discovering "self in Self"; ecofeminists, by contrast, detect in the hunt the vestiges of patriarchy—the male's need to dominate and subdue (Kheel). More fundamentally, there is the lingering suspicion that deep ecologists continue to view the value of the natural world instrumentally, as a means to greater self-awareness and self-knowledge. In this respect, and despite appearances to the contrary, deep ecology does not represent a "paradigm shift" away from the anthropocentric worldview it aspires to replace.

Ecofeminists believe they offer a deeper account of the moral life than do deep ecologists, one that goes to the very foundations of Western moral theorizing. The idea of "the rights of the individual" is diagnosed as a symptom of patriarchal thought, rooted in the (male) myth of the isolated individual. Morally, a "paradigm shift" occurs when, in place of assertions of rights, we freely, lovingly choose to take care of and assume responsibility for those who are victims of oppression, both within and beyond the extended human family, other animals included. Writing for the growing number of ecofeminists, Josephine Donovan states:

> Natural rights and utilitarianism present impressive and useful arguments for the ethical treatment of animals. Yet, it is also possible—indeed, necessary—to ground that ethic in an emotional and spiritual conversation with nonhuman life forms. Out of a woman's relational culture of caring and attentive love [there] emerges the basis for a feminist ethic for the treatment of animals. We should not kill, eat, torture, and exploit animals because they do not want to be so treated, and we know that. If we listen, we can hear them. ("Animal Rights and Feminist Theory," in Gaard, p. 185)

Thus, whereas the grounds for practical action offered by ecofeminists differ fundamentally from those favored by the rights view, and despite the foundational gulf that separates these two theories, both philosophies arguably have the same abolitionist practical implications.

Conclusion

The "animal rights debate," broadly conceived, is more than a contest of wills representing professional, economic, and ethical concerns; it is also a divisive, enduring topic in normative ethical theory (Vance). Until comparatively recently, discussions of the moral status of nonhuman animals had all but disappeared from the work of moral philosophers. (For a historical overview, see Ryder, 1989.) Beginning in the 1970s (Godlovitch et al.; Singer, 1975; Linzey, 1976; Clark), however, we have witnessed a historically unprecedented outpouring of philosophical and theological interest in exploring the moral ties that bind humans to other animals, and there is every indication that this interest will intensify in the coming decades. The moral theories of philosophers are not the stuff of politics; still, the contributions philosophers make can help shape the political debate by clarifying the major theoretical options available to an informed public.

Principal among these options are those that have been canvassed here: perfectionism, despotism and stewardship, contractarianism, Kantianism, utilitarianism, the rights view, deep ecology, and ecofeminism. Doubtless other options will evolve as the discussion continues (Garner). Among these options, two in particular—utilitarianism and the rights view—have offered the most systematic accounts of those duties owed directly to nonhuman animals. It will be instructive, before concluding, to highlight some of the important practical differences, particularly as these pertain to animal model research, that flow from these competing philosophies.

Because utilitarianism is committed to reducing the total amount of suffering in the world, its proponents must be prepared to recognize the moral legitimacy of some research on nonhuman animals. Even Peter Singer, contemporary utilitarianism's most forceful critic of such research, has conceded this possibility (Singer, 1993). Moreover, utilitarians must be similarly well disposed to the activities of animal care and use committees (Singer has served as a member of such a committee), provided that these committees conscientiously work to eliminate unnecessary animal suffering. Legislative attempts to improve the well-being of animals, whether in laboratories or on the farm, find support among utilitarians. Viewed in these respects, utilitarianism offers a philosophical basis for those who would reform the ways in which nonhuman animals are utilized by humans; what it does not offer is a categorical condemnation of this utilization. For this reason utilitarianism is congenial to those individuals and groups working to advance animal welfare—who accept, that is, the morality of human utilization of nonhuman animals in principle but who seek to improve it, by making it more humane, in practice.

The rights view has a different perspective on such matters (Francione and Regan). This philosophy is opposed to human utilization of nonhuman animals in principle and seeks to end it in practice. Its practical implications are abolitionist, not reformist. Because those nonhuman animals who exist as ends in themselves are never to be treated merely as means, it is wrong to experiment on them in the name of advancing the well-being of others. Moreover, to the extent that animal care and use committees and reformist legislation help to perpetuate social acceptance of human exploitation of these animals, whether on the farm or in the laboratory, advocates of the rights view will—or, to be consistent, should—withhold their support. What animal rights advocates *can* consistently support are incremental steps that put an end to certain practices within the larger context of animal exploitation—for example, legislation that would prohibit the use of nonhuman animals in cosmetic testing and in drug addiction experiments, and the creation of policies that end compulsory vivisection and dissection in the classroom (Francione and Charlton). When, as can often happen, utilitarians deem such practices unjustified because they cause gratuitous animal suffering, these two conflicting normative ethical philosophies—utilitarianism and the rights view—can speak with one voice. And when this happens, their potential political power is greater than the sum of its parts.

No one can predict which of the tendencies examined above—reform, abolition, or the status quo—will prevail in the coming years. Some positions (e.g., the rights view and ecofeminism) call for fundamental social change; others (e.g., Aristotelian perfectionism and Kant's view) call for much less. To the extent that people act because of their beliefs, the future of how humans treat other animals depends on what we humans believe the latter to be and how we think they should be treated. Because what we should do in practice depends on understanding what we ought to do in principle, our ability to give an appropriate response to the practical issues constituting the animal rights debate, broadly conceived—from whether we ought to be vegetarians to whether we should continue to use nonhuman animals in biomedical research—depends on our ability to make an informed, rational choice among normative ethical theories. In this respect, while a fair consideration of such theories may not be the end-all, it can make some claim to being at least part of the begin-all of a commitment to seek understanding and truth in these troubled waters.

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SEE ALSO: *Animal Research and Rights; Endangered Species and Biodiversity; Environmental Ethics; Pain and Suffering; Veterinary Ethics;* and other *Animal Welfare and Rights* subentries

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II. VEGETARIANISM

Vegetarianism is traditionally defined as the practice of abstaining from eating animal flesh. Modern vegetarian societies, such as the Vegetarian Society of the United Kingdom, define the practice as abstaining from flesh, fish, and fowl, with or without the addition of dairy produce and eggs. Those who wholly or occasionally abstain from "red meat" but eat fish and/or poultry are described as "demi-" or "semi-" vegetarians. Veganism, or "pure" vegetarianism, is the practice of abstaining as completely as possible from all products and by-products of the slaughterhouse, including products derived from treatment deemed exploitative to animals. Vegans do not consume dairy produce or eggs and also exclude products such as honey on the grounds that animals are used and/or killed in producing such types of human nourishment. Most vegetarians do not wear slaughterhouse by-products such as leather, and vegans avoid wearing leather completely.

Health Vegetarians

As late as the 1950s, the unwritten consensus among health specialists and dieticians was that animal protein in some form is essential to maintain adequate human health. While this position has not been completely reversed, medical advice from official studies increasingly recommends low-animal-fat diets, some of which eschew animal protein completely. Studies suggest that vegetarians have lower rates of diet-related cancer (Chang-Claude et al.), especially colon and rectal cancer (Phillips; Willett et al.) and prostate cancer (Giovannucci et al.). Vegetarians experience lower mortality from coronary heart disease than nonvegetarians, possibly due to their lower serum cholesterol levels (Burr and Butland). One study has shown that mortality from cardiovascular disease among vegetarians was less than half that of the general population (Chang-Claude et al.; see also Snowdon et al., 1984). Vegetarians suffer less from hypertension (Armstrong et al.; Rouse et al.), obesity (Thorogood et al.), and diabetes (Snowdon and Phillips).

Interpretation of these and other studies has become a source of controversy, with advocates for each side citing evidence in their favor (Frey, 1983; Robbins). Increasingly, however, health specialists seem to favor vegetarian diets on medical grounds alone. According to present knowledge, a balanced vegetarian diet poses no health problems and offers some indisputable advantages.

"Green" Vegetarians

Green political parties in Europe (i.e., those parties committed to programs that give priority to ecological sustainability) increasingly advocate a vegetarian diet or, at least, reduced meat consumption for environmental reasons. For example, the policy of the Green Party of the United Kingdom "encourage[s] a reduction in consumption of animal produce and promote[s] the development and use of foods which are more healthy and humane" (Green Party, p. 15). They offer two arguments. The first is that if enough Westerners become vegetarians, worldwide food distribution will become more equitable. It is calculated that "if we all had a vegetarian diet and shared our food equally, the biosphere could support around six billion people; if 15 percent of our calories came from animal products (and again food were shared equally), the figure would come down to four billion people; if 25 percent of our calories came from animal products, then it would fall to three billion; and if 35 percent of our calories came from animal products, as in North America today, then it would fall to 2.5 billion" (Myers, discussed in Ticknell, p. 67). The second argument is that the present system of intensive farming, while cost-efficient, will prove inefficient in the long run in terms of energy and environmental costs (Porritt). Hence, Greens argue that the "expanding livestock industry contributes to … the destruction and pollution of the planet" by being "energy intensive rather than labour intensive" and contributes to "world starvation" (Green Party, p. 15).

Assessing these arguments is problematic. While intensive farming is energy inefficient and environmentally damaging—apart from concerns it raises about animal welfare—any measurement of food resources must take into account not only the quantity of food available but also the way in which complex systems of supply and demand militate against egalitarian food distribution. Again, while animal farming is not always an efficient use of food resources, it is not clear that the political will exists to adopt alternative economic policies. Those who are sympathetic to vegetarianism on environmental grounds believe that widespread and increasing vegetarianism can and will affect worldwide trade. Despite the evident increase in the number of vegetarians in the West, it is as yet unclear how far, if at all, such minorities will have lasting economic impact.

In response to the "Green" argument against vegetarianism, some environmental ethicists, while sympathetic to the view that modern industrial agriculture is environmentally damaging, hold that since nature is a predatory system, it is natural for humans as well as animals to consume sentient life forms. Frederick Ferré argues, "From the broadest biotic perspective, life is cannibalistic upon itself; an ecological ethic must begin with the affirmation of the nutrient cycle" (p. 392; see also Birch and Cobb). This view is reinforced by Holmes Rolston III, who states that "humans in their eating habits follow nature; they can and ought to do so." Rolston's argument is dependent upon a distinction between nature and culture: "Humans, then, can model their dietary habits on their ecosystems, but they cannot and should not model their interpersonal justice or charity on ecosystems" (p. 81).

Both arguments presuppose to some degree that what should be must be modeled on what is. Only faintly, if at all, do ethical considerations fundamentally apply to the human act of killing sentient animals even when it is unnecessary. Ferré and Rolston do not sufficiently consider that what is "given in nature" is as much a social construct as what may be presupposed in "human nature." No perception of nature is value-free. What we judge to be "given in nature" often turns out to be what we ourselves judge on other criteria should be the case. In sum, there is no ecological shortcut to avoiding the question of whether the human killing of sentient animals is a moral issue. Since not all ethicists, especially theological ethicists, are convinced that the natural order exists as God intended, arguments based on what is "natural" beg metaphysical questions about the justice of what is (see Linzey, 1987, 1994; Clark, 1994).

Ethical Vegetarians

Of three main arguments for vegetarianism on ethical grounds, the first is based on the value of animal life. Even if we grant animal life secondary or even minimal value, it is difficult to see how human taste preference alone can justify killing. In general, killing for food when it is not required for human health or survival fails the test of moral necessity. Consuming flesh when we could do otherwise is "empty gluttony" (Clark, 1977, p. 183). Some philosophers have argued that it is not justifiable to kill animals even painlessly, asserting that it is logically inconsistent to care whether animals suffer without also valuing animal life itself (Godlovitch).

Other philosophers perceive gradations of value. Ferré, for example, argues against the assertion that all beings with inherent value possess that value equally. "There is no reason to suppose that the quality and intensity of the mental life—and with it its value for itself—of an oyster is on a par with that of a pheasant; but there is likewise no reason to suppose that the quality and intensity of the mental life of the pheasant is on a par with that of a human child" (p. 396). Ferré argues that "there is no 'line.' … All living beings have some degree of inherent value … but different organisms call for different forms of respect" (pp. 397–398). But even if such gradations are admitted, the case of mammals, as distinct from plants, calls for greater ethical justification. We still need to know how the killing of animals—which are sentient beings with inherent value superior to that of plants—without strict necessity is compatible with appropriate "respect" for their lives. The logic of Ferré's position is inclusive. Even the killing of plants requires strong ethical justification.

The second argument derives from considerations of animal welfare. If animals should be spared unnecessary suffering, then eating meat should be avoided, since the rearing, transport, and slaughter of farm animals invariably—and in some cases, necessarily—involves suffering, sometimes of a severe and prolonged kind (see Singer; and Frey, 1983, in response). This argument gains credibility in light of modern farming methods and the recognized fallibility of slaughtering techniques (Harrison; Mason and Singer; Johnson).

Ferré accepts that many modern farming practices are cruel but argues that "moderate" meat eating is justifiable if "nearly painless methods" of slaughter are adhered to (p. 400). If such a goal were to be achieved, fundamental changes would be required at all levels of livestock management. Minimally, slaughtering techniques would have to be indisputably humane (i.e., render the animal instantaneously unconscious), slaughterhouses would have to be regularly inspected, and regulations would need to be enforced by law. Animals would need to be killed as close as possible to their point of origin to avoid suffering in transit. Handling of animals on farms would have to be subject to a new range of welfare criteria. Conscientious meat eaters could justify eating meat only in specific circumstances when all such conditions have been met. The current failure to secure humane farm management and slaughter renders "moderate" meat eating ethically problematic. While in theory this second argument justifies only provisional vegetarianism in most, perhaps all, circumstances as a protest against animal abuse, it is difficult to envisage a time when conditions will universally prevail so as to preclude animal suffering in agriculture.

The third argument appeals to notions of animal rights. Sentient beings, or beings that can be classed as "subjects of a life," have a right to live that is equal to, or analogous with, human beings' right to live. Vegetarianism, according to the rights view, is obligatory in principle, and entails the end of commercial animal agriculture in practice. However, even this animal right not to be harmed is viewed as "a prima facie, not an absolute right" (Regan, p. 330).

The precise implications of this argument are not always clear. Do animals have in each and every case an equal right with humans to life? To what extent may individual rights be overridden in particular crisis situations? Commercial nonanimal agriculture also depends to some degree upon the control of competing species. Some animal rightists defend a stricter definition of avoidability or necessity than others. For example, some would concede that meat eating may be justified in those limited situations were alternative resources are inadequate (Linzey, 1987).

Discussion has sometimes centered on the cultural survival of the Inuit peoples, for example, and the question of whether their cultural rights should override the rights of the animals they hunt for food and clothing. Some animal rightists would accept the legitimacy of a limited human-preference approach in such circumstances. George Woodcock maintains that there is not "a single responsible person in the animal rights movement who would object to the Indian or Inuit, where he can, following a partly subsistence life of hunting for food" (p. 5). Other animal rightists, however, would question whether cultural considerations should be paramount when considering the exploitation of animals. Both "moderate" and "strong" animal-rights positions would, however, concur with Woodcock's judgment that both indigenous peoples, as well as fur-bearing animals, "have always been the victims of the fur trade" (p. 5). The rights position may be described as the strong welfare position, more uncompromising in its insistence upon the correctness of not harming animals as a prima facie duty. The rights view may not always require absolute (as distinct from obligatory) vegetarianism, but it would contend that vegetarianism should be the ethical and social norm.

Religious Vegetarians

Two primary motifs, ascetic and mystical, have informed an ethico-religious awareness. Vegetarianism has an established place in some Indian religious traditions, especially Jainism and, to some degree, Buddhism and Hinduism. The ascetic motif, particularly within Jainism, is based on the doctrines of nonviolence and nonpossessiveness. The goals of the spiritual life are, among other things, the renunciation of aggressive and possessive urges and following the path of purification (Jaini).

While Christianity has not formally endorsed vegetarianism, some strands of its tradition have affirmed that abstaining from meat can have value as a spiritual discipline. Some religious orders—for example, the Benedictines—eschewed meat as part of their ascetic regime (Sorrell). Self-denial as part of striving toward moral perfection has sometimes formed the basis for vegetarian lifestyles (Tolstoy). Ascetic practices may involve a vegetarian diet as a conscientious ecological response to wasteful consumerism and affluence (Lappé).

Allied to asceticism has been a mystical appreciation of other creatures as valuable beyond human calculations of utility because of their divine creation. The origins of this outlook are clear in the early and medieval periods (Sorrell). Only in modern times has this viewpoint received systematic expression in notions of reverence for life or in life-centered ethics (Schweitzer; McDaniel; Linzey, 1994). Historical Christianity has not fostered these insights, mainly because of its continuing anthropocentric theology. However, theological affirmations that animals are humans' fellow creatures, whose life or spirit belongs to God—and that they are therefore worthy of respect—undergird an ethical impulse to minimize injury and harm to them. Because of the rights of their Creator, animals can be said to bear "theos-rights," or God-rights (Linzey, 1987, p. 68).

The "modern vegetarian movement"—in the sense of organized societies specifically founded to advance ethical or religious vegetarianism—can be traced to the emergence of humanitarian sensibility from the nineteenth century onward. The Bible Christian Church, founded in 1809 by an Anglican priest, William Cowherd, made vegetarianism compulsory among its members and heralded the later growth of specifically vegetarian societies in the United Kingdom and the United States. The Bible Christian Church found its inspiration in the biblical command, recorded in Genesis 1:29, to be herbivores. Later commands to eat flesh (for example, in Gen. 9:3) were understood as permission given to humankind only after the fall and the flood (for a discussion of Judaism and vegetarianism, see Schwartz).

The Bible is, however, ambivalent about meat eating. While carnivorousness may be construed as a divine concession to human sinfulness (Baker), almost all biblical writers accepted the practice as ethically justifiable. Moreover, Jesus Christ was not a "pure" vegetarian; the gospel accounts record that he ate fish. There were various sects advocating vegetarianism in early Jewish and Christian circles, but none of their practices became normative within Judaism or Christianity (Beckwith). Carnivorousness has seldom been theologically challenged within mainstream religious traditions and only comparatively recently has ethical vegetarianism emerged as a serious option. Some modern Jewish vegetarians (see, e.g., Kook) argue that abstaining from meat is one step toward realizing the biblical vision of universal peace as described by prophets such as Isaiah (11:6f). Some Christian theologians hold that contemporary vegetarianism constitutes a more Christlike response to the evil of animal exploitation (Linzey, 1994).

The best defense of meat eating is based not only on a denial that animals have rights (Frey, 1980, 1983; Leahy; Carruthers) but also a denial that they have any moral status. According to this view, the gastronomic pleasures humans experience by consuming flesh far outweigh the value of animal life and suffering. "By comparison with animals, our lives are of an incomparably greater texture and richness, and when we say of a dying man that he has led a rich, full life we allude to something incomparably beyond to what we would allude, were we to say the same of a dying chicken, cat or chimpanzee" (Frey, 1983, p. 110).

It is difficult to see how such a position can be sustained without putting at risk the moral status of some classes of humans, for example, the mentally handicapped, the comatose, or newborns. Furthermore, it follows from the denial of animal status that a species superior to humans—as some humans now regard themselves in relation to animals—would not be morally obligated to respect human lives and suffering. The hope that "our aliens' nobility will match the quality of their imagined mentality" (Ferré, p. 406) and that therefore they will spare us unnecessary suffering and death, sadly cannot be deduced from humans' own moral record in relation to sentient nonhumans.

What has given contemporary secular and theological arguments for vegetarianism their strength and cogency is the realization that meat is not generally essential for human health and well-being. Consuming meat may have been necessary at certain times in the past; it may sometimes be necessary in the present. But eating a balanced vegetarian diet carries with it no medical or nutritional handicap. And, more important, it respects the ethical injunction to avoid killing sentient beings whenever possible.

ANDREW LINZEY (1995)

SEE ALSO: *Harm; Hinduism, Bioethics in; Jainism, Bioethics in; Moral Status; Utilitarianism and Bioethics;* and other *Animal Welfare and Rights* subentries

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III. WILDLIFE CONSERVATION AND MANAGEMENT

Wildlife management may be thought a contradiction in terms. The logic of “wild” precludes “managed.” Wildlife lived for millions of years, unmanaged by humans. Part of what humans value in wildlife is animals that can look out for themselves. Wildlife that is managed is not wild; it is managed life. So there is logical difficulty in the idea. There is also ethical difficulty. Perhaps humans are not responsible for wildlife; wild lives are on their own. But then again, human activities affect wildlife quite adversely. Have we no duty to care for it, either because of what humans have at stake or because of what wildlife is in itself?

This entry outlines some main issues: the contemporary crisis of conserving historically evolved wildlife populations on rapidly developing human landscapes; ownership, control, management, and stewardship responsibilities for wildlife; conservation of endangered wildlife species; fishes and fisheries as managed wildlife populations; wildlife as game for hunting and trapping, including hunting as a conservation strategy; “hands-on” versus “hands-off” management; and feral animals. These are issues of management, but there are ethical questions at every point.

Wildlife and Human Populations: An Emerging Crisis

There are more species on Earth today than there have ever been in the 2.5-billion-year history of life. Estimates run from five to thirty million species; ten million is a typical figure. Most of the vertebrate wildlife and birds are known; most unknowns are in the invertebrate animal, insect, and plant species. During evolutionary history, there was no wildlife management; wildlife conservation takes care of itself if no humans intervene. On statistical average, more species have been produced than have become extinct; diversity has gradually increased.

Some five catastrophic extinctions have been followed by rather swift regeneration of the lost species. On landscapes that have grown colder or drier, species may become fewer. Some groups of species were more numerous in the past, such as dinosaurs in the Cretaceous period, or birds in the Pleistocene. Nevertheless, diversity is at an all-time high. In one sense, all biology is conservation biology (biology that conserves life), whether or not humans are involved.

There are many more humans on Earth today than ever, and the expansion of human habitat, coupled with pollution, hunting, and trade in wildlife, threatens populations of wild animals and their habitats. Humans now threaten the biological processes that have been creating and conserving life for billions of years. Hardly an American landscape has not been impoverished of its native fauna. The larger once-dominant animals—such as eagles, wolves, cougars, grizzly bears, wolverines, bison, otters, crocodiles—are especially depleted. The New World depletion in both hemispheres is a result of Europeans entering a relatively empty continent and engaging in explosive development over recent centuries. The Amerindians had coexisted with wildlife for ten to fifteen thousand years.

Long-settled continents do not escape the problem either. Humans have inhabited Africa since evolving there over a hundred thousand years ago. Only in the twentieth century, as contemporary nations grew rapidly, was African megafauna or avifauna seriously threatened. Wildlife in China, India, and Tibet, among the oldest settled areas in the world, was greatly depleted. The crisis is as serious in the Old World as in the New.

The crisis is now potentially more urgent than at any previous time in the history of the planet. This generates unprecedented responsibilities because humans previously did not have much effect on wildlife, which took care of itself; unprecedented demands for trade-offs between human values and the welfare of wildlife; and unprecedented implications because of its global and irreversible scale.

Wildlife conservation is now challenged to mix human values with wildlife values. Fortunately, wildlife is valuable to humans and, so far, can be included among the human values. Humans wish to hunt and fish; they enjoy watchable wildlife; wildlife art is the most popular American art form. If backyard bird feeding is included, almost one in four Americans spends some time bird-watching. Animals are chosen as state animals; sports teams and automobiles are named for animals. Many animals serve useful roles in ecosystems; hawks catch mice, birds control insect populations. Wildlife can indicate the health of an ecosystem. Unfortunately, many human values conflict with wildlife on landscapes, as shown by the massive depletion of wildlife. Here human interests seem contrary to wildlife’s flourishing. And what if wildlife is not valuable to humans? Have we some responsibilities for the values of wild things for what they are in themselves?

The Wildlife Society, the principal professional organization of management and conservation, affirms that “Wildlife, in its myriad forms, is basic to the maintenance of a human culture that provides quality living.” The society seeks “to develop and promote sound stewardship of wildlife resources and of the environments upon which wildlife and humans depend; to undertake an active role in preventing human-induced environmental degradation; to increase awareness and appreciation of wildlife values." It also urges "ethical restraints in the use of living natural resources."

Ownership, Control, Management, and Stewardship Responsibilities for Wildlife

According to long legal tradition in the United Kingdom, Canada, the United States, and many other nations, individual persons do not own vertebrate wildlife. Animals and birds do not belong to the landowner on whose property they are found. They move around, with dens and nests in particular places, but the larger animals and the birds can range over hundreds or thousands of square miles. They sometimes live on public land, sometimes on different tracts of private land. Continental European nations, by contrast, sometimes hold that property owners own wildlife resident on their lands.

In the Anglo-American tradition, landowners have the right to control access to their property; they control who, for instance, may hunt there. But the state determines whether and how much game may be taken. Permitted by the state, individuals can "take" wildlife—capture or kill it—at which point the animal enters their possession. State control of wildlife was long understood as state ownership, but wildlife paid no more attention to state lines than to local property boundaries; indeed, migratory birds resided in various nations. The U.S. federal government has often regulated wildlife, since much wildlife crosses state lines and much inhabits federal lands. In recent court decisions, the state ownership doctrine has been rejected as based on a flawed characterization of wildlife, which should be regulated like other natural resources considered commons, not so much owned as held in trust. State ownership of wildlife has been subsumed under the state and federal power to regulate all natural resources, an expanding public trust doctrine. Wildlife is a public good held in trust by the state for the benefit of the people (Bean).

The general idea is that there is a corporate responsibility for wildlife, a duty to persons concerning wildlife in which they have an interest, and a duty of individual persons to relate to wildlife, caring for it, tolerating it, perhaps hunting it, all within the context of a larger public interest and stewardship. Animal welfare was long subsumed under this rubric, since maintaining this public good required healthy wildlife populations. But animal welfare has increasingly become a concern in its own right, independent of human benefits. This is called the intrinsic value of wildlife, a value also held in trust. This concern becomes evident in concern for endangered species as well as in shifting attitudes toward hunting.

Conservation of Endangered Wildlife Species

The legal tradition arose with regard to individual animals, but protecting endangered species has increasingly figured in regulations covering both game and nongame species. State departments, once of "Game and Fish," have largely been renamed departments of "Wildlife"; though hunting and fishing remain a large part of their assignments, their interest in threatened wildlife has dramatically increased. If the government can regulate individual animals, by the same logic it can regulate species. In the fall of 1981, when black-footed ferrets were discovered on private ranches near Meeteetse, Wyoming, the ranchers were legally obligated to protect them. Furthermore, the federal government can designate critical habitat on private land.

Landowners ought not to shoot the bald eagles that fly over their property or cut the trees in which they nest. In compliance with the Endangered Species Act, in order to protect eighty bald eagle nesting sites, the Weyerhaeuser Company in the early 1980s set aside more than nine hundred acres in Washington and Oregon, representing over nine million dollars in unharvested timber. Lest it be supposed that the bald eagle, the national symbol, is a unique public good, Weyerhaeuser also, complying with the act, set aside 155 acres in southern states to protect 22 colonies of the endangered red-cockaded woodpecker. These woodpeckers prefer to nest in prime timber, eighty-year-old pine forests; loggers would rather cut these lands more often than that. Though these landowners cannot use the land as they once intended, costing them that opportunity, it does so lest they destroy, at the species level, eagles and woodpeckers that, though on their land, do not belong to them but are a common good.

The Endangered Species Act of 1973 is the most far-reaching wildlife statute adopted by any nation. The U.S. Fish and Wildlife Service is charged by the act to list both domestic and foreign wildlife species threatened with extinction. No government agency may undertake projects likely to jeopardize listed species, at home or abroad, except under authority of a high-level committee that has granted few exemptions. Jeopardizing species includes disrupting their habitat. Neither can persons take listed wildlife species on private lands. In evaluating whether to list a species, economic considerations may not be considered, a point of repeated contention but one that the U.S. Congress has reaffirmed several times. Importing species on the worldwide list into the United States is illegal except under specific conditions.

Generally this concern, enacted into legislation, reveals an increasing sense of human duty toward wildlife that comes to special focus when a species becomes endangered. Game managers who may once have thought of their responsibility as the production of an annual crop of game to shoot now see themselves as wildlife managers whose responsibility is to provide for a diverse native fauna on the landscape, both for the benefits such wildlife brings to humans and out of respect for what all species of wildlife, not just the game species, are in themselves.

Fish and Fisheries as Managed Wildlife Populations

Analogous changes have taken place with regard to fishes. Once, what one wanted was fish to catch; and fishing remains a popular recreation. But there is an increasing concern with native fish populations, including all species.

The native fish fauna of North America has been tampered with possibly as extensively as, and certainly more rapidly than, the fish on any other continent. Managers have introduced "game" and eliminated "trash" fish; humans have made dams and water developments for domestic, industrial, and agricultural uses; polluted; caused erosional sedimentation; and accidentally introduced parasites and diseases. Of the endangered fishes of the world, about 70 percent are in North America; 56 percent are receiving some degree of protection. The fishes in the United States have been as disturbed as any other wildlife, more so in the West than in the East, most of all in the Southwest. The Endangered Species Committee of the Desert Fishes Council identifies 164 fishes in North American deserts as endangered, vulnerable, rare, or warranting various degrees of concern.

Concern for these fishes has modified or stopped water development projects. On the Virgin River and its tributaries in Utah in 1980, for example, water authorities abandoned the Warner Valley project lest it jeopardize the woundfin, and built the Quail Creek project instead. Water release from dams may be adjusted in time and volume for the benefit of endangered fish and bird species (Minckley and Deacon).

Coming to focus again in endangered species legislation, what humans think they ought to manage for is shifting from game species to native fishery populations. There is an increasing sense of duty, represented in wildlife managers, to ensure the presence of fishes as an integral part of the wildlife community, not just for the human benefits involved but out of respect for what these fishes are in themselves, as well as for their roles in the riparian ecosystems.

Hunting and Trapping: Hunting as a Conservation Strategy

Wildlife management has traditionally meant game management. Hunting both for meat and for sport is an ancient practice. Humans evolved as omnivores; meat has been important in human nutrition, although it is quite possible for humans to be well nourished as vegetarians. The character of hunting has accentuated sport hunting in modern times; few hunters of the early twenty-first century are primarily meat hunters, although in most cases the carcass will be eaten. Most hunters have a code of ethics. They think it unethical to waste the meat. Hunters also seek a fair chase, a clean kill, minimal suffering, and respect for the animal; and hunters have long been among the most effective conservationists. Predators, especially wolves, were often eliminated as competitive hunters.

Since the mid-1960s, a strong antihunting movement has emerged, on the ground that shooting animals for sport is unethical, even if the hunter's ethic is observed. Such persons regard wildlife management for the purposes of maintaining hunting as morally wrong. A further problem is that much funding for wildlife conservation comes from hunting and fishing licenses, and if these activities are curtailed, alternative funding sources will have to be found. Hunters also argue that properly managed hunting can ensure conservation, since this activity makes wildlife valuable both to the hunter and to others who profit from the hunter's presence.

Such an argument is especially used for African wildlife. In Africa, although much hunting is legal, poaching has also been rampant, resulting in an international ban on skins, hides, horns, tusks, and other parts of various species. Wildlife managers may argue that whereas such bans may discourage poachers, they also prevent legal hunting, which can be quite profitable; this makes wildlife worthless to native peoples, who can neither hunt for food nor sell wildlife products. Even the products from culled animals (shot to reduce excess populations) cannot be sold. Ivory has been a case in point. Most world ivory trade has been made illegal, but some authorities argue that the sale of legal ivory could greatly benefit elephant conservation.

Trapping has been a traditional use of wildlife, largely for the pelts and hides made into mink coats, beaver hats, alligator-skin purses and shoes, and so on. Given available substitutes, many people object to such use of animals, on grounds that this trapping involves needless cruelty. Furs on fashion models simply flatter female vanities, somewhat as trophy animals mounted in sportmen's dens flatter male vanities. The leghold trap is especially objectionable to opponents of trapping. A counterargument is that a high value on animal skins, with effective management, can ensure conservation. Most of the world's crocodile species are endangered; crocodiles are dangerous and often frequent rivers where humans are present. Only if the crocodiles are of considerable value to local peoples are they likely to be tolerated and saved.

"Hands-On" versus "Hands-Off" Management

Although there is a growing consensus that humans have an urgent responsibility actively to conserve wildlife, many argue that the less wildlife is managed, the better. So far as wild animals are managed, their wildness is compromised-the paradox of wildlife management. The animals become artifacts, more like pets. This leads to a debate between "hands-on management," which favors active intervention, habitat enhancement, supplemental feeding, breeding, radio-collared monitoring, and so on, versus "hands-off management," which favors as little management as possible consistent with animal welfare.

From a medical point of view, there is contention whether veterinarians ought to treat wildlife diseases. Like all physicians, veterinarians seek good health. Colorado veterinarians treated a lungworm disease in bighorn sheep successfully. By contrast, when an epidemic of pinkeye ravaged the bighorn sheep of Yellowstone Park, authorities refused to let Wyoming veterinarians treat the disease. The welfare of the sheep, they said, required letting the disease take its course; disease-resistant sheep would survive and the genetic fitness of the herd would improve. Whether the disease is introduced by humans is a factor. The *Chlamydia* parasite producing pinkeye was not thought to be introduced; some said that the lungworm was introduced from domestic sheep, or at least that the sheep were weakened due to human disruptions, especially of their winter range. Although over half the Yellowstone herd perished by starvation and injury following partial blindness, the herd has recovered, although not yet to its former numbers.

Many argue that although hands-off management is an ideal for animals that inhabit extensive ranges, owing to development and human needs there remains insufficient habitat for hands-off management. With elephants in Africa, they say, only hands-on management is possible. Given the elephant's destructiveness and its tendencies to migrate, herds must be fenced, water holes provided, herds culled, and so on. This strikes a balance between responsibilities for elephants and for humans. A controversial case in the United States involved supplemental feeding for grizzly bears in Yellowstone Park, where, after such feeding went on for decades, park officials, preferring a wild bear over a managed bear, elected to risk letting the endangered species survive on its own.

Feral Animals

Feral animals are those introduced by humans, not native to landscapes, that have managed to survive on their own. Management of such animals is disputed, especially of mustangs and burros in the western United States. Although not now living in their native ecosystems, such animals may have been living wild for centuries. Management policy is typically to eliminate them, on grounds that they are not authentic wildlife, although the U.S. Congress has mandated preserving mustangs in some localities. Animal-welfare advocates have protested eliminating the mustangs and burros. Other cases involve feral hogs and goats. On San Clemente Island, off the coast of California, nearly thirty thousand goats were eliminated, about half of them shot, the other half captured and relocated with poor survival rates, in order to protect endangered species of plants, as well as to prevent further degradation of the island ecosystem. The goats had been left there by the Spanish in earlier centuries. The argument here is that we have a greater responsibility to native wildlife and plants than to feral species.

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SEE ALSO: *Environmental Ethics* and other *Animal Welfare and Rights* subentries

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IV. PET AND COMPANION ANIMALS

The term *companion animals* refers to those animals human beings keep for purposes of control, companionship, and comfort. The word *pet,* which suggests the indulgent use of animals (Shell), is being increasingly replaced by the term "companion animals." However, the term *pet animal* seems indispensable in conveying the relationship of intimacy between some humans and selected domesticated species.

The Emergence of Pet Keeping

The precise origins of pet keeping are obscure. There appear always to have been symbiotic relationships both between species and within species (see, for example, Kropotkin), although some argue that "almost alone among animals, humans domesticate and dwell with other animals" (Clark, 1982, p. 110). Keeping animals as companions may have been a by-product of both killing and domesticating them. Stephen Clark argues that "[p]eople who cared for their animals [kept for food] left more descendants than those who used them carelessly" and that "it 'paid' our ancestors to love what wasn't human" (1982, p. 111).

Some animals were undoubtedly kept for their own value as sources of fascination or as mediators of unusual benefits. For example, cats, although domesticated for a much briefer time than other species, have frequently been associated with the supernatural, as agents either of benign or malign forces (Clutton-Brock).

English society in the eighteenth and nineteenth centuries saw the emergence of widespread pet keeping, especially among the upper classes. Keith Thomas writes of how, as early as 1700, "symptoms of obsessive pet-keeping were in evidence," especially in the keeping of horses, cats, dogs, and pet birds (Thomas, 1983, p. 117). These species were clearly "privileged" in comparison with food animals, which were still reared and killed with hideous cruelty. Although the "idea of a pedigree did not originate in the nineteenth century," Harriet Ritvo shows how the notion of purity of species through selective breeding became widespread among the middle and upper classes, for whom particular companion animals were themselves indicators of social class and good breeding (Ritvo, 1986).

Since the nineteenth century, the phenomenon of pet keeping has increased not only among all English classes but also within European and U.S. societies. Although reliable estimates of animal populations are very difficult to obtain (partly because of nonexistent or unenforced licensing laws), one conservative estimate is that the total annual U.S. turnover in owned dogs in 1991 was 7.71 million, 4 million of which were handled by animal shelters and 2.1 million of which were euthanized (Patronek and Glickman). The current situation in the Western world of millions of animals being kept for purposes of companionship extends far beyond any reasonable interpretation of symbiosis and is historically without parallel.

Quite apart from the personal and psychological factors involved, one obvious reason accounts for this development. Pet owning has become an established part of consumer-oriented cultures in which animals are bought and sold like any other commodity. The pet industry itself, not to mention the allied supply (including veterinary) services, benefit directly or indirectly from the trade, management, and treatment of companion animals. In 1991, in the state of Washington alone, it is estimated that the number of dogs available from pet stores amounted to 11,442, and through breeders, 37,523 (Patronek and Glickman).

The Benefits of Pet Keeping

These may be classed under three broad headings:

PSYCHOLOGICAL BENEFITS TO HUMANS. It seems impossible to doubt that some human–animal bonds can contribute significantly to human flourishing. Relationships with pets seem to help prevent two sources of emotional disorder: deprivation and frustration. They enable nongenital physical contact, provide tactile comfort, improve self-esteem, enhance emotional security, boost personal prowess (as when a beautiful or socially appealing animal is owned), and engender loving relationships that are sometimes seemingly impossible with other humans (Ryder; Levinson; Fogle; see also Serpell).

Potential or actual benefits for pet owners specifically include lower blood pressure (Baun et al.), lower heart rates (DeShriver and Riddick; Wilson and Nettling), reduced anxiety (Wilson, 1991), and reduced depression (Bolin). However, Cindy Wilson argues that although "much has been made over the potential benefits of a pet," it is also true that a large amount of such research "remains anecdotal, nongeneralizable, and scientifically flawed" and that a new methodology should be based on assessable "quality of life measurements" (1994, pp. 4–8).

In the absence of large amounts of data based on objective evidence, interpretation of the psychological effects of pet keeping turns on whether interspecies relations are natural and commendable. Richard Ryder warns against the view that such interspecies relationships are "unnatural or cranky" (p. 5); but that accepted, it is still questionable to what extent legitimate psychological needs are met through pet keeping and whether these needs can or should be met through relationships with members of our own species.

BENEFITS TO HUMAN SOCIETY. It has long been thought that pet keeping can help sensitize children, even train them in attitudes of care and respect (Rothschild). One study goes so far as to claim that "companion animals are a vital part of the healthy emotional development of children" (Robin and Bensel, p. 174). Studies have also suggested that relationships with pets can contribute to the psychological and social well-being of adult humans, especially elderly people who live alone (Connell and Lago). Animal-assisted therapy is sometimes utilized for patients in psychiatric hospitals and for individuals with special needs, such as people with the human immunodeficiency virus (HIV) or aquired immunodeficiency syndrome (AIDS) (Gorczyca) and those suffering from chronic schizophrenia (Bauman et al.).

BENEFITS TO PET ANIMALS. The benefits of pet keeping to the animals themselves are difficult to quantify. Leaving aside the wider ethical question of whether animals should be domesticated at all, the impact on the individual pet depends on how well it is kept and to what degree its owners understand and meet its emotional and environmental needs. For example, although pet keeping can provide a stimulus to sensitize children, it can also conversely provide an opportunity for cruelty by abused or disturbed children or by children who lack parental supervision. Some commentators see something psychologically, even politically, perverse about indulging pet animals (see, for example, Shell), and, as discussed below, it is not clear that such indulgence is always beneficial to the animals' welfare.

The Disadvantages of Pet Keeping

Formidable ethical and welfare problems are associated with pet keeping (Carpenter et al.). These may be classified under three headings:

ABUSE. Recorded acts of cruelty against pets appear to be increasing in both the United States and the United Kingdom. Living in close proximity to animals, whatever the benefits to both parties, substantially increases the risk of abuse. Apart from deliberate acts of cruelty, even sadism, unsuitable environmental conditions can cause unacceptably high levels of stress for animals. Few owners fully understand the complex psychological and physiological needs of the animals they keep. Cruelty sometimes arises through ignorance and misunderstanding rather than deliberate neglect, especially when the subjects are exotic animals. Abuse or neglect does occur despite the many and various pet-care programs available.

OVERPOPULATION. Present high levels of pet populations inevitably mean death, and sometimes suffering, for other animals. In order to sustain high populations of species such as cats and dogs, for example, other species such as whales, kangaroos, and horses must be killed in order to feed them. Few pet animals of any size can be sustained without meat, though it appears that dogs can live well on an appropriately balanced vegetarian diet. The commercial production of pet food has also been criticized as a waste of resources. The average cost of feeding an eighty-pound dog has been estimated at $8,353 for its lifetime (Shell).

High pet populations also raise other problems for humans. These include possible health hazards, nuisance, and social control. Dogs can communicate diseases such as *Toxicara canis,* which can cause blindness in children. Fortunately, such cases are rare, but an awareness of this hazard in the United Kingdom has recently led to local councils outlawing dogs from public parks, particularly children's parks. Animal organizations, such as the United Kingdom's Royal Society for the Prevention of Cruelty to Animals (RSPCA), have argued the case for compulsory registration of dogs as a means of ensuring responsible ownership; so far, such schemes have operated only on a voluntary or local basis. In 1992, the Dangerous Dogs Act was introduced in the United Kingdom to deal with the threat posed by aggressive dogs after some distressing incidents in which children were attacked by uncontrolled dogs.

COMMERCIAL USAGE. Since domestic animals have almost everywhere only the legal status of property (Sandys-Winsch; Sweeney), the breeding and sale of pets is subject to few legal constraints, save principally that direct and "unnecessary" cruelty must be avoided. The view that pets are merely human property has inevitably led, as with other consumer items, to the refashioning of pets. Nonveterinary mutilation of pets (e.g., tail docking, ear cropping, declawing, and removal of a dog's larynx to prevent barking) is not uncommon, though in the United Kingdom the British Veterinary Association refuses to authorize all nonveterinary procedures; performance of such procedures can lead to revocation of a veterinarian's license. The RSPCA opposes all "selective breeding of animals which produces changes in bodily form and/or function," in addition to the commercial sale of puppies and kittens in pet shops (Royal Society for the Prevention of Cruelty to Animals, pp. 7–8).

Animal protectionists argue that the commercial trade in animals leads inevitably to overbreeding and the consequent abandonment and disposal of millions of unwanted animals. In the United Kingdom, the RSPCA estimates that it destroys on average about 1,000 unwanted dogs every week. In the United States, estimates vary from 2.1 million to 9.1 million per year for dogs alone (Patronek and Glickman). Such a wide discrepancy in the figures indicates, among other things, the difficulty in collecting uniform data from the estimated 1,800 to 3,000 animal shelters in the United States. Current widespread euthanasia suggests a prima facie disregard for the worth of pet animals (for a discussion of the ethical problems surrounding large-scale euthanasia, see Kay et al.).

Is Pet Keeping Immoral?

Despite the emergence of a strong animal-rights movement since the mid–1970s, the ethics of pet keeping is seldom questioned. The major works in animal ethics (Singer; Clark, 1977; Regan; Rodd) largely or entirely bypass this question, and only lone voices are raised in critical opposition (Linzey, 1976; Bryant). Animal-rights philosophy has evolved without offering any critical analysis of the pet trade, though some argue that abuse of pet animals is a "human breach of contract" (Rollin, p. 219). Since so many animal-rights thinkers oppose a purely utilitarian justification for animal exploitation, this omission is surely anomalous.

Part of the reason may be that, historically speaking, sensibility to animal suffering seems to have arisen as a necessary corollary to the practice of keeping pets (Thomas, 1983; Tester). The physical inclusion of animals into the human community seems to have signified a moral inclusiveness also. It may be no accident that the first country to found a society for the prevention of cruelty to animals—England—was also the country renowned for its love of pet animals. Moreover, one cannot but be struck by the way in which anecdotes about animal behavior, especially that of pet animals, have formed the basis for a whole string of pioneering humanitarian books appealing for greater kindness to animals and a fundamental recognition of their rights (see, for example, Youatt; Wood; Nicholson; Thomas, 1993; Lessing).

Yet questions must be asked about the ethical appropriateness of the psychological needs that pet animals apparently meet. Ryder accepts that some of these are "selfish" (p. 8). One early critique argued that "we need to distinguish between a kind of love which respects animals for what they are and allows them to pursue their own lives according to their own natural instincts, and another selfish form of love which seeks to condition animal lives in accordance with our own human desires." Pet keeping, it is argued, represents a "false anthropomorphism" in which we seek to "humanise" animals and "regard them as extensions of our own egos" (Linzey, 1976, p. 68). This view was subsequently modified on the grounds that "all loving is in practice a subtle blend of altruism and self-seeking," although "where the interests of animals are entirely subordinated to human emotional needs, we need to beware that we are not involved in a self-deceiving tyranny" (Linzey, 1987, p. 137). According to this perspective, at least some forms of pet keeping are wrong because they are insufficiently symbiotic and fail to recognize the right of animals to their own natural life.

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SEE ALSO: *Care; Compassionate Love; Environmental Ethics; Grief and Bereavement; Healing; Moral Status;* and other *Animal Welfare and Rights* subentries

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V. ZOOS AND ZOOLOGICAL PARKS

Wild animals have been displayed in captivity for millennia (Luoma). The first known large collections were assembled in Egypt around 2500 B.C.E. Early rulers displayed their exotic menageries, captured during campaigns or expeditions, for personal amusement and as symbols of wealth and political power. Romans later maintained menageries for bloody public spectacles, sending elephants, lions, bears, and other wildlife into battle in arenas throughout Europe. Urban zoos appeared in sixteenth-century Europe and North Africa; visitors ogled strange creatures captured on colonial adventures. In 1828, the first zoo dedicated to the scientific study of captive wildlife opened in London, and in 1889, the U.S. Congress established the National Zoo for the purpose of breeding native wildlife. As zoos continued to evolve in the twentieth century, they developed a broad mission that included research, conservation, education, and entertainment.

Zoos, aquariums, safari parks, and wildlife theme parks are popular worldwide. Approximately 400 professionally managed zoos exist in the world, in addition to thousands of roadside menageries and petting zoos (Chiszar et al.). Annual zoo attendance in the United States alone exceeds one hundred million (Nelson). According to studies conducted in the United States and Canada, one-third of the public has visited a zoo within the last twelve months, and 98 percent of adults have visited a zoo in their lifetimes (Nelson).

Despite their broad popularity, zoos are increasingly criticized on ethical grounds. As the public has grown more sensitive to animal-welfare and conservation issues, animal advocates have begun to question whether or not the benefits of zoos justify the incarceration of live, and often rare, wild animals. (Although the term *zoo* may refer to a broad range of animal facilities, for the purposes of this entry it will refer only to zoos and aquariums that meet at least minimum professional standards. These minimum standards are defined by the American Association for Zoological Parks and Aquariums [AAZPA] in the United States.)

The Ethics of Captivity

Many zoo opponents hold that wild animals should not be kept in captivity for human benefit. Dale Jamieson (1985) argues that animals taken from the wild are deprived of the opportunity to behave naturally. They are removed from their natural habitats, separated from family and social groups, and prevented from performing natural behaviors such as gathering food. Most important, the animals lose the freedom to pursue their own lives. Therefore, even under the best zoo conditions, Jamieson believes there exists a moral presumption against keeping animals in captivity.

Critics also focus on the possibility of physical or psychological suffering caused by captive conditions. Despite improvements in exhibit design, many animals remain confined in dirty, cramped, and isolated cages. Indoor facilities often lack fresh air and natural light, while outdoor enclosures may expose animals to extreme weather conditions to which they are not adapted. Without social or environmental stimulation, captive wildlife may become listless, self-abusive, or develop stereotypical behaviors such as the pacing often observed in big cats (Fox). When elephants or other potentially dangerous animals display aggression, zookeepers may respond with harsh discipline or physical restraints. The capture of animals in the wild, their transportation to zoos, and the handling required for veterinary care are other sources of stress.

Perhaps the most controversial source of potential suffering is the disposition of "surplus" animals. The zoo surplus includes aged adults and excess offspring of breeding programs. Animal activists assert that many surplus animals suffer inhumane treatment when zoos sell them to animal dealers who, in turn, sell them to research laboratories, private collectors, roadside menageries, and hunting parks (Clifton). An equally controversial disposal method is "culling," or mercy killing for management purposes. Critics decry this killing of healthy animals, especially when the surplus results from careless management. Animal advocates stress that zoos have a moral obligation to care for all zoo animals, regardless of their utility for breeding and other zoo goals.

Zoo advocates agree that culling is ethically problematic. However, they contend that responsible zoo directors manage breeding programs to avoid surpluses through contraception and segregation of sexes (Bostock). When contraception fails or a zoo's needs change, the director is expected to follow the AAZPA's code of ethics for distributing surplus animals to other qualified zoos or dealers. Euthanasia is seen as a last, though sometimes unavoidable, resort. To sustain viable captive populations of endangered species, zoo scientists must carefully balance age and sex ratios to maintain genetic diversity. Animals that are old, infertile, or genetically undesirable become surplus because zoos have limited space and financial resources. Zoo proponents defend culling these individuals as a necessary evil. Euthanasia and other disposal methods, proponents claim, allow zoos to conserve populations and species, although some individual animals must be sacrificed.

Animal welfare, according to zoo advocates, remains a high priority (Hutchins and Fascione). While recognizing that inferior enclosures still exist, they applaud the revolution in naturalistic exhibit design. At many zoos, for example, primates have been moved from isolated, tiled cells to family groupings in outdoor facsimiles of their native habitat. Tropical birds have flown from their cages into reproductions of rain forests. In addition, animal behaviorists are studying ways to stimulate animals' physical and mental activity, and veterinarians are investigating how to improve their nutrition and health. Through advances in captive breeding, zoos have also been able to reduce their demand for animals captured in the wild. Zoo advocates point proudly to these improvements, arguing that mortality and morbidity rates at zoos do not support claims that the animals are miserable (Chiszar et al.).

Furthermore, zoo proponents object to claims, such as Jamieson's, that captive animals suffer as humans would from the loss of liberty. Animals, they believe, may be happier in an enclosure free from predation and hunger than they are in the wild. Expecting animals to have the same needs and desires as humans do—an attitude called *anthropomorphism*—is viewed as a reflection of animal activists' sentimentality and biological ignorance (Robinson).

Justifications of Zoos

Another approach to the zoo debate is to examine the reasons for keeping animals in captivity. If the benefits of zoos are negligible, animal advocates contend, then keeping wildlife captive cannot be justified. However, if significant benefits can be shown, captivity for at least some animals might be defensible.

ENTERTAINMENT. Historically, the predominant function of zoos has been entertainment. Studies of zoo visitors show that most people continue to see these facilities as parklike settings for casual family socializing (Kellert). To zoo opponents, public amusement is a trivial reason for holding animals in confinement (Jamieson). Opponents especially attack circuslike events, such as sea lion shows, that use trained animals to draw large crowds. Similarly, zoos that import animals such as giant pandas to boost attendance and revenues have been condemned. Such events are seen as denigrating the animals by exploiting them as public spectacles.

Although zoo directors vaunt high attendance rates, many de-emphasize entertainment as a zoo goal (Luoma). Baby elephant rides and similar amusements are gradually disappearing as zoos try to develop a more serious image. However, zoo educators claim that entertainment is necessary to keep visitors interested in learning. Also, zoo administrators assert that animal shows, special events, and traveling exhibits are sometimes essential to raise the funds needed to pay for research and other zoo missions (Cohn).

RESEARCH. Few visitors are familiar with the scientific efforts of zoos. Although a handful of zoos sponsor field research, most studies are conducted on site by zoo staff or affiliated researchers. Common topics include animal behavior, nutrition, reproductive biology, genetics, and pathology (Hutchins and Fascione). Animal activists challenge both the quality and usefulness of this research (Jamieson). According to critics, the experimental design of most zoo research lacks scientific rigor, rarely qualifying for publication in peer-reviewed journals. In a nutrition study, for example, a small sample size or the absence of a control group may obscure study results. Some critics also say that much of the research is aimed at improving captive husbandry and exhibit design—unnecessary benefits if wildlife were not confined in the first place. Regardless of any benefits, some animal-rights advocates oppose all animal research. Tom Regan (1983) argues that the utility of research, whether to gain practical information of basic knowledge, is no justification for violating an individual animal's basic rights.

Zoo scientists reject the position that animal research is intrinsically wrong. They emphasize that most zoo research is noninvasive, nonterminal, and aimed at benefiting captive and wild populations (Hutchins). While acknowledging weaknesses in past studies, zoo proponents see a growing commitment to quality research at many institutions. Zoos are hiring research staff, cooperating with university faculties, and investing in major research facilities such as the U.S. National Zoo's 3,000-acre Conservation and Research Center. Much current research employs sophisticated, controversial techniques, such as embryo transfers, in efforts to improve captive breeding success. Although the experimental techniques may harm individual animals, zoo scientists contend that the long-term benefits for species conservation outweigh the costs to individual animals.

CONSERVATION. Animal advocates doubt that zoos can make a significant contribution to conservation (Fox). Although many recognize the biodiversity crisis, critics hold that zoos can do little to resolve the primary cause of extinction: habitat destruction. Nor can zoos protect more than an insignificant portion of the estimated five to thirty million species on the planet. Further, zoo conservation efforts are biased toward the charismatic large mammals preferred by zoo visitors, nearly ignoring disliked organisms such as bats and invertebrates (Kellert). When zoos do have success in maintaining a captive population, critics worry that the animals suffer from inbreeding and loss of natural behavioral characteristics. Are zoo animals and their wild relatives equivalent organisms? Could animals bred in zoos for generations be successfully reintroduced into the wild? If reintroduction is never possible, how long should the species be perpetuated in zoos? Extinction, to some zoo opponents, is more respectful of individual animals than endless confinement.

Yet conservation is viewed by many as the preeminent function of modern zoos. Zoo advocates liken the zoo to a crowded ark, struggling to accommodate as many threatened species as possible. Advocates remind critics that several organisms have already been saved from extinction by zoos, including the European bison and Mongolian wild horses (Tudge). Increasing resources are devoted to captive breeding through programs such as the AAZPA's Species Survival Plans (SSP) (Wiese and Hutchins). SSPs manage rare animal populations at zoos throughout the country, asking zoos to cooperate in breeding plans that promote genetic variability and demographic stability. SSP organizers hope that as such programs grow, world zoos will eventually be able to protect 500 to 900 endangered species (Luoma).

Zoos are also expanding efforts to reintroduce animals born in captivity to the wild, using some reintroduction projects to study techniques for managing small, isolated populations in the wild and to encourage habitat protection in developing countries. While they agree that zoos cannot directly save the majority of endangered species, zoo advocates proclaim that saving any species keeps options open for the future.

EDUCATION. The educational benefits of zoos are also viewed skeptically by animal advocates. Visitor studies indicate that relatively few people are interested in learning about animals or conservation, and there is little evidence that the zoo experience improves knowledge of biological facts or conservation issues (Kellert; Kellert and Dunlap). Given zoos' poor record of educational effectiveness, critics suggest that films, lectures, books, and nature centers may offer superior learning benefits without the ethical costs of confining wildlife. Most important, critics charge that zoos may be presenting harmful information and values (Sommer). Seeing rare animals in captivity, for example, may give visitors an inaccurate impression of human abilities to combat extinction. In addition, witnessing listless creatures in sterile cages may diminish respect for animals or concern for conservation.

Zoo advocates respond by describing the diversity of education programs and a growing commitment to educational progress (Chiszar et al.). Zoos attempt to teach casual visitors through signs, demonstrations, learning laboratories, and interactive computer technologies. Part of the revolution in exhibit design aims at enhancing learning by immersing visitors in natural environments. To extend their educational impact, zoos are developing curricula for primary and secondary students, holding workshops for teachers, visiting community centers, and organizing public lecture series. Michael Robinson (1989) promotes such changes as part of an educational revolution committed to teaching visitors about the interactions between wild animals, plants, and humans. Zoo proponents believe that, in our urbanized society, the zoo may be the only institution capable of demonstrating these vital links to the public.

Education, in fact, may offer zoos their best hope of effecting long-term, large-scale benefits (Kellert and Dunlap). If zoo educators could demonstrate positive program impacts, they could defuse criticisms and justify program expansion. Zoos should embark on a coordinated program of systematic educational evaluation and implement their findings through innovative programs dedicated to further progress. Given the wide popularity of zoos, it is doubtful that the ethical debate will result in their abolition. If zoos can learn how to teach the public scientific information and humane and conservation values, animal advocates, zoo proponents, and wildlife will all benefit.

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SEE ALSO: *Animal Research; Endangered Species and Biodiversity; Environmental Ethics; Veterinary Ethics;* and other *Animal Welfare and Rights* subentries

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VI. ANIMALS IN AGRICULTURE AND FACTORY FARMING

For almost all of human history, animal agriculture has involved human management of animals under living conditions for which the animals were biologically and evolutionarily adapted. Human intervention has consisted largely in ensuring the animals' health, nutrition, and reproduction by providing supplementary rations when forage was scarce, medical assistance, shelter from harsh elements, and so on. The symbiotic relationship between human and animal has been strongly reinforced by the cultural values of animal agricultural societies. To this day, for example, among ranchers in the American West, who are primarily traditional agriculturists and raise animals on open ranges, one finds a doctrine passed from generation to generation: "We take care of the animals, and the animals take care of us."

Factory Farming

Intensive agriculture, also known as confinement agriculture or factory farming, differs dramatically from traditional animal agriculture. The key notion behind confinement agriculture is the application of industrial methods to producing animals or animal products. This way of thinking about agriculture emerged in the middle of the twentieth century; before that, neither the technology nor the social conditions existed to make confinement agriculture possible. After World War II, various technological developments and changing social conditions combined to alter radically the face of animal agriculture, and to model farms on factories. At about the same time, departments of "animal husbandry" in agricultural universities began to change their names to departments of "animal science." Increasingly, agriculture became a business, not merely a way of life combined with a way of making a living.

The conditions that generated confinement or intensive agriculture are relatively clear. After World War II, increasing numbers of workers moved from rural, agricultural regions into urban localities, where wages were higher and economic opportunities were perceived to be greater. At the same time, urban centers grew, encroaching onto traditional farmland, so that rising land prices and higher taxes militated against keeping that land for agricultural use. Inevitably the land was developed. Thus fewer and fewer people were directly involved in production agriculture.

With less land and fewer workers (as of 1993, 1.7 percent of Americans were engaged in production agriculture), it was difficult to keep animals under far-ranging, open, extensive conditions. With fewer people caring for them, animals were brought into closer and closer confinement, both outdoor and indoor, so that effects of temperature, rain, snow, and so on could be minimized. Instead of depending on human labor, farmers began to rely on machinery to feed, clean, water, milk, collect eggs, and so forth. Animal agricultural operations became capital-intensive rather than labor-intensive.

Animals began to be crowded together in an attempt to get as many as possible into the expensive production unit. Laying hens, for example, are typically placed 5 to 6 birds in a 12-inch-by-18-inch cage, and up to 100,000 birds may be kept in one building. Broiler chickens are raised in huge open sheds at a density of approximately two birds per square foot. Beef cattle, traditionally raised on range grass, are moved for the latter portion of their lives into feedlots, where they are fed grain diets, thus producing both increased weight gain and an outlet for U.S. grain surplus. Hogs are increasingly raised in confinement buildings where they never see the light of day—buildings holding 500 to 1000 sows are not uncommon. Most notoriously, veal calves are raised in small crates in order to restrict movement and keep their flesh tender, and are also kept anemic or near-anemic to keep the meat "white."

Thus animals are forced into environments for which they are not biologically suited. Because the operations are so expensive, producers are motivated to crowd as many animals as possible into the systems, since profit per animal is small. Thus, even though it is well known that chickens will lay more eggs if given more space, it is more profitable to crowd as many birds as possible into cages, yielding fewer eggs per bird but more eggs for the operation as a whole. Such methods would be impossible without recent technology. In the absence of antibiotics and vaccines, the spread of disease would decimate the animals in weeks. Without growth promoters< the animals could not be processed quickly enough to be profitable—broiler chickens for instance, reach full growth in eight weeks. The rise of confinement agriculture has, according to its proponents, provided cheap and plentiful food. For example, the price of chicken has remained virtually the same for more than twenty years, even in the face of inflation. Advocates of intensive agriculture also argue that confinement provides animals with shelter from extremes of weather, protection from predators, and a consistent nutritional regimen.

Harms of Confinement

But there are hidden costs offsetting these benefits, the most important of which is the cost to the animals. The animals being produced in confinement are still essentially the animals that were genetically adapted to extensive conditions. Their fundamental biological interests are systematically violated in confinement. Thus animals that are built to move about are unable to do so. Social animals may be deprived of companionship. Air laden with dust and ammonia in confinement chicken, egg, and swine barns is execrable; in some swine operations, workers must wear respirators. Diets designed to maximize growth may lead to metabolic disease for some of the animals, even though this loss is balanced by economic gain in the other animals. In chicken and swine barns, unnatural floor surfaces such as wire and concrete slats may lead to leg, foot, and joint problems. With the advent of confinement agriculture, there has arisen a class of diseases, known as “production diseases,” that result from the systems of production. Since intensive systems have a low profit margin, they are often understaffed, and care of sick or injured animals is impossible for workers whose other duties stretch them to their limit.

As a result of such systematic violation of their physical and psychological (animal scientists prefer the word “behavioral”) needs, animals suffer psychologically as well as physically. Many animals in confinement show chronic signs of long- and short-term stress, which can lead to both disease and behavioral problems. Cannibalism among chickens increases in the absence of either space to flee or small enough numbers to establish a pecking order; to prevent cannibalism, producers “debeak” chickens with a hot blade and without anesthesia, sometimes producing chronic pain. Similarly, pigs are tail-docked to prevent tail-biting, a stress-induced result of confinement. Confined animals also show many bizarre, stereotypical behaviors that seem to result from the thwarting of natural inclinations and from boring, austere environments.

Confinement agriculture also exacts other social costs. In an industry requiring large amounts of capital, small operators cannot compete effectively, and large, well-capitalized corporations inevitably drive out small “family farmers.” Young people cannot afford to enter agriculture. Efficiency and productivity eclipse other values traditionally maintained in small farm communities, such as independence, self-sufficiency, and husbandry. Environmental problems such as waste disposal and water and energy consumption also arise from intensive agriculture. Lack of pasturing of animals contributes to soil erosion when land no longer used for pasture is tilled for grain. Drug residues in animal products may pose human health problems, and widespread use of antibiotics essentially breeds for resistant pathogens by eliminating microbes susceptible to the drugs. *Salmonella* and *Campylobacter* bacterial contamination are significant problems in chickens, turkeys, and eggs, since they can cause severe enteric disease in humans who consume these products.

Toward Reform

Agriculturists have recognized that the welfare of animals in confinement represents one of the three major challenges to agriculture in the next century, the other two being food safety and environmental concerns. When the British public became aware of factory farms in the 1960s as a result of Ruth Harrison’s pioneering book *Animal Machines,* the outcry generated a royal commission, the Brambell Commission, that was highly critical of confinement agriculture as violating the animals’ natures. In the face of confinement agriculture, European society is moving toward legal protection for farm animals. Laws in Britain, Denmark, Germany, and Switzerland have restricted certain aspects of confinement agriculture, and Sweden has essentially abolished such agriculture and guaranteed certain rights for farm animals, in a law that has been called a “bill of rights” for farm animals because it aims at protecting their fundamental interests. In the United States, public attention was first directed toward animals in research, and certain basic protections for such animals have been legally encoded in two federal laws passed in 1985. Public attention is beginning to focus on the treatment of farm animals as well as on the environmental consequences of confinement agriculture, and articles in agricultural journals show that agriculture is starting to pay more attention to these concerns.

Until very recently, U.S. confinement agriculturists (in contrast to their counterparts in Europe and Canada) tended to deny that there were any problems of animal welfare intrinsically related to confinement agriculture, and acknowledged only occasional “bad management.” This was further exacerbated by widespread skepticism in the scientific community about the existence and knowability of animal consciousness, pain, and suffering. Since the early 1990s, however, there have been indications that at least some parts of the industry and government are engaging such issues as animal deprivation, boredom, and inability to move in confinement, primarily by inaugurating research into improving animal welfare.

While it is unlikely that industrialized agriculture will ever revert to being fully or even largely extensive, it is possible to make intensive agriculture much more "animal-welfare friendly," and perhaps to change certain systems from full to partial confinement. For example, it is possible to raise swine profitably without keeping sows confined in small gestation crates for their entire lives. In addition, concern about sustainable agriculture may well result in a concerted social effort to return to less industrialized systems guided by husbandry. On the other hand, confinement agricultural systems are being introduced into Third World countries as a shortcut to rapid economic growth and as a way of adding animal products to the diets of these countries. This has generated a variety of ethical concerns, including fear of environmental despoliation, concern that successful indigenous agriculture will be lost, worries about importing Western health problems to these countries, and concern about proliferating animal suffering.

Growing Social Concern

Animal agriculture raises other animal welfare issues beyond confinement. Although cattle ranching is highly extensive and in fact presupposes a good fit between animal and environment, management techniques such as castration without anesthesia, hot-iron branding, and dehorning without anesthesia produce pain and suffering in these animals. Transportation of agricultural animals over long distances, for example to slaughter, is very stressful, and can cause disease and injury. Handling of farm animals by people ignorant of their behavior is an extremely widespread problem that creates high levels of stress and significant injury. Slaughter of food animals raises the issue of whether these animals can be provided with a death free of pain, suffering, and fear. This problem is particularly acute in the area of Jewish and Muslim religious slaughter, where preslaughter stunning has been considered incompatible with religious demands. Genetic engineering of farm animals for traits that are desirable to producers for reasons of efficiency and productivity may well exact costs in welfare from the animals' perspective. For example, swine and chickens engineered for greater size have suffered from a variety of diseases, including foot and leg problems. A cow engineered for double muscling was unable to stand on its own and required euthanasia. On the other hand, genetic engineering can also work to the benefit of farm animals, for example, by engineering for disease resistance.

Other branches of animal agriculture rear animals for uses other than food. Raising traditionally "wild" animals for various purposes has generated concerns about the well-being of these animals—pheasants for hunting, mink for fur, and deer for antler velvet (which is considered an aphrodisiac in the Orient) provide salient examples. Numerous welfare concerns have also been raised by the production of horses for human purposes—breakdown and injury in racehorses; injury in endurance horses (those used in long, grueling, competitive rides over difficult terrain); heat, water deprivation, and poor air for urban carriage horses. Indeed, no branch of animal agriculture is being ignored by growing social concern about animal welfare.

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ANTHROPOLOGY AND BIOETHICS

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In recent years a growing number of anthropologists have turned their attention to the discipline of biomedical ethics. Bioethics traces its origins as a distinct field to the styles of reasoning and reflection found within analytic philosophy and legal scholarship. In its early decades, work in bioethics relied heavily on principle-based analysis, an approach that often led to critiques of the moral dimensions of healthcare practice divorced from underlying social, cultural and political context. Often called the "empirical turn" in bioethics, social scientists utilizing diverse theoretical and methodological programs have questioned approaches to healthcare ethics that fail to account for context (Weisz; Hoffmaster, 2001; DeVries and Subedi; Brodwin, 2000).

Researchers in medical anthropology represent one arm of a strong, and growing, internal critique of bioethics. In addition to social science voices, this critique includes diverse perspectives within philosophy, such as feminist readings of core bioethics dilemmas and a resurgence of interest in the traditions of American pragmatism and casuistry. Even philosophers working within the Kantian tradition have called attention to bioethics' need to balance attention to "institutional and professional realities and diversities" with philosophical rigor (O'Neill, p. x). O'Neill questions the primacy of autonomy, to the exclusion of a focus on relationships of trust and trustworthiness, in contemporary bioethics discourse.

This entry explores how anthropologists working in the field of bioethics bridge the gap between conceptions of medical morality grounded in local worlds and the universal understandings espoused within the western philosophical tradition. Ongoing debates about relativism from the perspectives of anthropology and philosophy also are addressed with special attention paid to the implications of a "culturally informed" practice of bioethics. Culturally diverse understandings of the meaning and expression of personhood are highlighted in order to illustrate difficulties that emerge when one tries to judge certain practices as good or bad, appropriate or inappropriate. An anthropologically informed bioethics produces a fuller account of healthcare practices, an account that grounds ethical universals such as respect for persons in local moral worlds.

The body of empirical work reviewed below reveals the thinness of bioethics accounts that disregard social context and that celebrate a particular (often American) version of individual autonomy. Ethical analyses centered exclusively on individual actors create strong barriers to understanding the troubling conflicts that emerge in multicultural worlds, especially in the arena of social justice and human rights. A simplistic application of ethical universals to particular cases discounts the complexity of lived experience and real world dilemmas. In the same way, a naïve and unqualified acceptance of ethical relativism diminishes the potential of negotiating moral consensus across cultural boundaries. An anthropologically grounded framework for bioethics requires a solid recognition of the cultural assumptions that underlie our definition of the "good" in biomedicine. An anthropologically informed bioethics calls attention to the social, political and structural factors that affect the production of scientific and clinical knowledge and its application in the practice of global biomedicine.

Anthropological Approaches to Bioethics

Today the field of bioethics is uniquely multidisciplinary, indeed it is perhaps best understood as a cultural space in which scholars from many fields interact, joined together by topical interests. However, anthropologists and other social scientists did not play a significant role in the initial development of the field (Fox).

In his analysis of medical ethics, Lieban (pp. 221–222) suggests two key reasons why anthropologists have been absent. First, given the strong history of cultural relativism in anthropology, studies of health and illness conducted by anthropologists have generally avoided what might be construed as ethnocentric value judgments about other systems. Anthropological focus on documentation and description—as opposed to normative analysis—excludes questions about what is morally "right" or "wrong" about particular health practices.

Second, medical anthropologists have often worked in non-Western settings where the technological challenges provided by contemporary biomedicine are less salient. In addition, Marshall (1992) suggests that bioethicists—unlike anthropologists—have concentrated their attention on the individual rational actor as the primary unit of analysis. Although in recent years bioethics scholars have begun to acknowledge the importance of social milieu—for example the role of family—in constructing individual choice and shaping decision options, anthropologists, in part because of their traditional subjects, have generally theorized a more complex self, viewing the individual as firmly embedded within a broader social and cultural context. The notion of autonomy, or respect for persons, which many acknowledge has been over-celebrated in bioethics clinical discourse, presumes an individuated self, set apart from the collective experience of family or community, and triumphant over other critical values. These explanations, however, represent fairly superficial explanations for the lack of anthropological representation within or interest in bioethics. In fact, the unwillingness of anthropologists to engage with ethics (and for philosophers to reach out to social scientists generally) reflects deep seated disciplinary boundaries and conflicting epistemologies (Edel and Edel).

The concept of culture is rarely a starting point in ethics; by contrast, pioneering discussions of comparative medical ethics by anthropologists emphasized the importance of a cultural foundation for framing ethical issues in healthcare. For example, Kundstadter addressed ethical challenges associated with development projects in Third World communities, noting the relevance and importance of cultural context for understanding moral dilemmas surrounding health and illness beliefs and healing roles. Practices such as treatment of less than perfect newborns cannot be adequately understood, much less judged, without detailed local knowledge. Approximately a decade later, Fabrega and Lieban examined the potential of "ethnoethics" for cross-cultural studies of the moral dimensions of health practices. A key starting point is the recognition of variation in the issues that different societies define as morally relevant or problematic. The role of healer is also critical, including the nature of interactions between healers and their patients, interactions among healers themselves, and finally, interactions between practitioners and the larger society.

As engagement with scholars working in healthcare ethics increased, anthropologists have questioned the fundamental schema underlying bioethics, urging greater attention to the lived experience of human suffering and to the social dynamics of local context (Muller; Koenig, 1996; Kleinman, 1995, 1999; Marshall and Koenig, 1996, 2000). Cultural interpretation situates the moral dimensions of healthcare in local ethical practices and *local* notions of the good. This traditional anthropological orientation to ethics and morality is antithetical to the universalizing discourses of both basic science—which assumes that scientific principles and rules apply to human bodies in all times and places, and to the discourse of the philosophical traditions dominant in bioethics—which define a good ethical theory as one that can produce "objective" results that yield rational standards by which to judge actions, irrespective of their history or locality (Marshall and Koenig, 1996, 2000).

Medical anthropologist Arthur Kleinman (1995), in his critical analysis of the assumptions and theoretical foundations of bioethics, suggests that the new field is fundamentally ethnocentric, psychocentric, and medicocentric, and thus shares, rather than moves beyond, biomedicine's fundamental limitations. Kleinman argues that bioethics has failed to engage with the major non-Western moral traditions or to question the "orthodox sources of the self within the western philosophical tradition" (p. 1669). The medicocentrism inherent in bioethics constrains practitioner's ability to elicit a complex illness narrative despite the fact that bioethicists are charged with listening to patients and taking account of their perspective and preferences. Although Kleinman maintains optimism that bioethics may open up space in clinical practice for genuine moral reflection and debate, he remains concerned about the limitations of a bioethics devoid of attention to cultural locality: "In the end, then, ethics, once framed as models of moral reasoning championing the reflection and rational choice of autonomous individuals in quest of objective standards, risk irrelevance to the almost always uncertain circumstances and highly contextualized conditions of human experience" (1999, p. 72).

Anthropologists have the greatest potential to make significant contributions to the field of biomedical ethics in two domains: through studies of the cultural production of scientific and clinical knowledge and its translation into medical technology and healing practices, and, secondly, through analysis of the cultural construction of canons of medical morality, including the clinical practices of bioethics itself. Note that this contribution is not linked to the traditional role of anthropology in elucidating the cultural practices of exotic peoples. Ethnographic approaches to ethical questions help clarify the contextual features that are intrinsic to problematic moral issues that arise in medical and research settings throughout the world (Koenig, 1988, 1997; Hunt; Hogle; Rapp; Marshall and Koenig, 1996, 2001; Kleinman, Fox, and Brandt; Kaufman, 2000; Brodwin, 2000; Finkler; Farmer, 2003).

Anthropology and the Study of Biomedical Technology

A broad range of clinical issues and public health concerns have been addressed by anthropologists, including: end-of-life decision making, definitions of death, human organ and tissue transplantation therapies, disclosure of medical information, informed consent for medical treatment, reproductive technologies, genetic testing and screening, human rights, and treatment of human subjects in biomedical research. Scholars working at the boundary of anthropology and the field of science and technology studies have been central to evolving scholarship. A systematic review of the contributions of anthropologists to bioethics, and to our understanding of the moral dimensions of human suffering more generally, is beyond the scope of this review (see Marshall and Koenig 1996). Instead, several areas in which anthropologists have focused a cultural lens on moral problems in medicine are highlighted.

The development of new medical technologies has raised myriad questions at the intersection of culture, morality, and the production and application of scientific discovery (Lock, Young, and Cambrosio). New technologies in biomedicine challenge established meanings of personhood and provide fertile ground for a socially reimagined human body. Does social personhood begin with a fertilized egg, an embryo, at birth, or once the likely survival of an infant is established? How is life's end understood? Anthropological studies can reveal the ambiguous and contested boundaries between nature and culture, boundaries constantly challenged by scientific developments. Anthropological investigations of new reproductive technologies and genetics, in particular, illustrate how understandings of family are necessarily evolving, radically changing traditional notions of kinship and the cultural and biological creation and "production" of children (Ginsburg and Rapp; Lock; Becker; Finkler).

Rapp's intensive, multiyear ethnographic exploration of the use of amniocentesis for pre-natal diagnosis reveals the moral complexity of a seemingly straightforward technology. Ideally, pregnant women should make fully informed, voluntary decisions about undergoing the procedure and continuing a pregnancy if fetal anomalies are discovered. In the city of New York, where Rapp worked, the experience of testing, and the eventual decisions made, were fundamentally different for women of varying social class and ethnic background. The exercise of choice can only be understood in light of the social meanings attached to pre-natal testing. Rapp warns that a "new eugenics" is unlikely to be imposed by direct state power, but rather will be disguised under a rubric of individual choice.

Similarly, Press and Browner's 1998 study of the use of pre-natal maternal alpha fetoprotein blood testing (used to predict Down syndrome and other anomalies) illustrates the complex and culturally embedded issues surrounding women's refusal or acceptance of the procedure. Many women accepted the test believing it to be a positive way to assure the health of their baby, much like taking vitamins or other elements of routine prenatal care. In actual practice the only way to avoid the birth of an affected fetus is termination of the pregnancy, but U.S. abortion politics preclude a full and open discussion of the issues, leading to severely truncated communication in the clinic and misapprehension of the usefulness of the prenatal blood test.

Press, Fishman, and Koenig demonstrate how cultural context shapes our understanding of the meaning and practice of genetic testing for breast cancer risk, one of the first examples of a genetic test for a common adult-onset disease. Enhancing the decision-making capabilities of individual women is the most commonly suggested bioethical "solution" to the difficult dilemma of disclosing risk for cancer. Cultural analysis suggests two primary reasons for the limitations of this approach: the cultural construction of fear of breast cancer, which has been fueled in part by the predominance of a "risk" paradigm in contemporary biomedicine. The increasing elaboration and delineation of risk factors and risk numbers are in part intended to help women contend with their fear of breast cancer—fears that are inflamed by constant media attention in the form of health education campaigns. However, because there is no known cure nor foolproof prevention for breast cancer, risk designation brings with it recommendations for vigilant surveillance strategies and screening guidelines. Thus education about risks exacerbates women's fears of breast cancer, confounding decision making about genetic testing. The volatile combination of discourses of fear, risk, and surveillance has significant ethical and social consequences for women and their families.

The conceptual categories underlying our understanding of human identity and difference have been of particular concern to anthropology (Gaines; Lee, Mountain, and Koenig; Brodwin, 2002; Sankar and Cho). Is the species *homo sapiens* divided into biologically distinct races? With the advent of new knowledge about human genetic variation, as well as individualized therapies targeted to unique genetic signatures, this issue is of growing moral significance. Given profound health disparities across populations, how are we to tease out the interactions among culture, ethnicity, and most importantly, of race, in health research and clinical care? Ethnographic studies of the conduct of genetic research reveal how social categories of race inform all domains of biomedical practice. Locating disease etiology in an ethnic group's shared genetic ancestry—potentially excluding consideration of the relevant social determinants of health—may lead to group stigma as well as poor clinical outcomes.

New technologies—whether used for life-extending therapy, such as the mechanical ventilator, or diagnosis of death, such as functional brain imaging—may challenge settled understandings of the boundary between life and death (Lock). Liminal states, such as patients existing in persistent coma, are not "natural" entities, but are in fact created by new social arrangements, in this case long-term care centers dedicated to the management of those in persistent vegetative state (Kaufman, 2000). Bioethical debates about appropriate treatment for those suspended in such liminal states must take account of social forces. Anthropologists have been actively engaged in exploring the moral dimensions of changing definitions of death itself, calling attention to the powerful role that culture plays in shaping beliefs and practices for managing death and dying (Lock and Honde). Perhaps because of its potent emotional valence and symbolic salience, human organ and tissue transplantation has been studied extensively in many parts of the world. The moral questions fundamental to transplantation—whose organs should be replaced, whose may be "harvested," when is a donor "dead enough"—are deeply contingent, varying by beliefs about the location of the soul, the integrity of the physical body and the existence of an afterlife, beliefs which are negotiated within local economies and political arrangements (Lock; Ohnuki-Tierney; Sharp, 1995; Joralemon; Ikels; Hogle; Das; Gordon, E.).

A particular concern of social scientists has been the analysis of organs and their circulation, characterized initially as an elaborate system of nonmonetary gift exchange, glossed as giving the "gift of life." Sociologist Renee Fox, whose work shares many theoretical and methodological assumptions with that of anthropology, pioneered ethnographic work on transplantation. Later analysts have critiqued the status of human organs as a source of working capital for poor laborers in developing countries (Cohen), and have documented how a heart can create links of symbolic kinship between donor families and organ recipients (Sharp, 2001). Ethical quandaries stem from the commoditization of bodies that accompanies the marketing of human organs (Marshall and Daar). Most problematic is the exploitation of vulnerable individuals, especially when flows of organs go from poor nations to wealthy ones (Scheper-Hughes). Of interest is that fact that allowing individuals the right to sell their organs is justified using a neoliberal market language of rights, a discourse in many ways compatible with bioethics arguments that privilege individual choice and control of one's body. Joralemon documents the change in discourse about financial incentives for donation (from both living and cadaveric donors) since the origins of U.S. transplantation, showing the impact of a public relations campaign formulated to minimize public resistance to donation. Bioethics debates, in response to intense pressure to increase organ supply, have tipped from vehement opposition to any financial compensation for organs to a guarded approval (Joralemon).

Anthropological Analyses of Clinical Ethics and Research Ethics Practice

In the arena of end-of-life medical care, anthropological studies illustrate how decisions to forego technological interventions, such as intensive care, are socially negotiated (Slomka; Kaufman, 1998). Ethnographic findings allow a useful comparison with decision-making ideals based on abstract principles, providing a critique of models of care that evaluate the success of outcomes using a metric based solely on the exercise of patient choice. A review of the empirical literature suggests that the bioethics practices governing end-of-life care (a focus on self-determination, advance care planning, and explicit decisions to forgo life-sustaining treatment) are based on problematic and erroneous assumptions (Drought and Koenig). Studies of bioethics practices applied in culturally diverse clinical settings further illustrate the failure of efforts to enforce universal solutions on complex clinical problems. To fully engage with and respect a patient as a person, what is required is a nuanced understanding of each social environment (Frank et al.; Crawley et al.; Long, 2000; Koenig and Gates-Williams; Koenig and Davies). Anthropologists have also explored the ethical domain of truth-telling, demonstrating the significant impact of cultural difference on beliefs about disclosure of medical information, especially information relevant to diagnosis and prognosis of cancer and other life-threatening illness (Muller and Desmond; Gordon and Paci; Gordon and Daugherty; Orona, Koenig, Davis; Carrese and Rhodes; Kaufert; Long, 1999). Who decides which facts are truthful, whether that truth harms or helps, and who controls disclosure, are all culturally patterned.

Ethics consultation is a common and highly visible clinical application of bioethics. These services, common in U.S. hospitals, are carried out either by an expert consultant, an interdisciplinary ethics committee, or some combination of the two approaches; the goal is assistance with the identification of ethical quandaries and their resolution through bioethical analysis. Anthropological study of the actual practice of ethics consultation reveals the difficulty of simply "applying" bioethics theories in the clinic. A range of issues has been studied, including the nature of clinical disputes that are considered "ethical." In fact, consult requests often stem from non-ethical concerns, such as communication failure resulting from the social dynamics of complex hospital environments like intensive care units. Research has also examined actual decision-making processes by institutional ethics committees, power structures within organizational settings and their influence on consultation outcomes, and the potential for conflicts of interests when ethics consultants are institutional employees (Crigger; Orr et al.; Kelly et al.; Marshall, 2001a).

Voluntary informed consent is considered a universal ethical requirement for good clinical practice and for research with human subjects. However, anthropological studies reveal the ways in which the ideals of informed consent may be constrained in actual practice. The objectives of consent may be undermined by too great a reliance on a narrow conception of the exercise of personal autonomy—one excluding social relationships, by focus on consent as the articulation of a "legal" contract, rather than an ongoing process of communication, and by lack of attention to disparities in knowledge and power between professionals and lay people (Kaufert and O'Neill; Barnes et al.). Sankar demonstrates the critical value of classic observational methods by examining the actual practice of informed consent to research participation. Her analysis reveals how the informed consent process shares many characteristics with ritual; actual reflection and active decision making are not part of the dynamic. Rather, research participants offered informed consent had already made up their minds to participate in the study Sankar observed; going through the process of "consenting" the subject served primarily to inaugurate their participation in the research.

Cross-Cultural and International Concerns

Medical interactions, including discussions of consent, are mediated by language—and the use of interpreters—and cultural beliefs about health practices, decisional authority, and professional roles (Kaufert and Putsch; Marshall et al., 1998). These interactions are complex in any environment; cross-national research projects present particular challenges. Marshall (2001b) describes the profound influence of cultural context on informed consent to genetic epidemiological studies conducted in urban and rural settings in Nigeria. Her ethnographic work highlights the challenges of translating difficult scientific concepts in cross-cultural settings; the very idea of consent may be unknown in rural settings where participants are not literate and have little experience of research. Ideal notions of individual consent, as practiced in the United States or other resource rich countries, do not easily incorporate the significance of family and community relationships for the process of obtaining consent in diverse social environments across the world. In their work on community involvement in genetic research, Sharp and Foster outline potential strategies for representing the views of the larger community, suggesting that this may be an important component of the overall process of seeking and obtaining consent. Community consultation does not override an individual subject's right to decline or accept participation, and may serve to make individual consent more authentic. When working with international research teams, the role of the anthropologist is not simply to facilitate a particular study through in-depth knowledge of the local community, but rather to tailor the broad objectives of informed consent to fit local needs.

Issues of social justice in healthcare across the world—until recently neglected in traditional bioethics debates focused on individual choice and the dilemmas created by new technologies in resource-rich countries—are being addressed by anthropologists, particularly those working in the arena of public health (Levin and Fleischman). Anthropologists working in bioethics are deeply concerned about global health disparities, including class-based inequities in the United States (Levin and Schiller). Farmer (2003) levels a harsh critique against the narrow focus of bioethics, arguing strongly for greater attention to structural inequities that maintain health disparities in many areas of the world. The need for broadening the boundaries of bioethics beyond the confines of Western medicine and its limited attention to the political economy of social suffering is increasingly recognized by anthropologists engaged in discussions of global medical morality (Kleinman, Das, and Lock; Farmer, 1997; Kleinman, Fox, and Brandt; Das). Ethnography, which unifies the work of anthropologists, is more than a methodological orientation allowing fine-grained attention to local social and cultural processes. Rather, its theoretical foundation requires that the ethnographer draw connections between local suffering and global social and political processes.

Culture, Morality, and the Problem of Relativism

The landscape of bioethics—in particular the "bedside" practices of clinical ethics and research procedures—is informed by the intellectual and ideological orientations of the analytic philosophers who were key figures in shaping the development of the field. Much work in bioethics reinforces and sustains an Enlightenment preoccupation with the primacy of the individual, "rational" man. Although theoretically it need not, the field's emphasis on rational decision making and individual autonomy often diminishes the importance of the social realm in ethical analysis. Culture, like emotion, may be viewed as something tangential to the core human, something that might be stripped away to reveal a rational "universal" being underneath. And many bioethics procedures seem designed with that rational man in mind. Once practices such as advance care planning or informed consent are enshrined in law and regulation, it becomes increasingly difficult to tailor those procedures to fit local conditions, even though exactly that sort of tailoring may be required to fully observe an ethical principle such as respect for persons. This silencing of culture is confusing to most anthropologists, while the anthropologists' "failure" to appreciate the preeminence of universal ethical norms may lead philosophers to the false conclusion that all anthropologists are naïve relativists.

Identifying, defining, and evaluating the nature of morality has been difficult to achieve as a common area of inquiry for bioethicists and anthropologists. While there is general agreement among the disciplines that the forms and practices of morality are inherently social, the consensus ends there. As Hoffmaster observes, "According to the prevailing positivist approach in Anglo-American philosophy, morality consists of rules and principles, which because they are *normative,* can be articulated and defended only on the basis of rational arguments directed at what *ought* to be the case" (1990, p. 242). The potential for a meaningful dialogue with anthropologists and other empirical social scientists—who, according to the tenants of moral philosophy, work only at the level of "descriptive" ethics—is thwarted given the normative and metaethical focus of moral philosophy.

Anthropologists and philosophers have approached morality and cultural pluralism from two very distinct perspectives. The unique morality expressed in diverse cultural traditions is emphasized in the "cultural relativism" of anthropology. Thus, for anthropologists, morality is viewed as an entity, like other dimensions of culture, that can be empirically described (Geertz, 1989; Hatch). It is found in social space, not argued in textbooks. Anthropologists have engaged in prolonged debates about the theoretical and methodological utility of relativism as it relates to cultural context (Herskovits; Hatch; Fabrega; Spiro; Renteln; Shweder).

Indeed, relativism has been foundational in the development of anthropology. The claims of a "moderate" descriptive relativism might be stated as follows: "Because all standards are culturally constituted, there are no available transcultural standards by which different cultures might be judged on a scale of merit or worth" (Spiro, p. 260). Thus, the only normative judgment that might be possible is one that recognizes the equal worth of moral standards (and this holds for total cultures, single cultural systems such as religion, and specific cultural propositions). A normative claim based on this view is that because universally acceptable evaluative standards do not exist, judgments about cognition, behavior patterns, and emotions of different social groups must be relative to the variable standards of the cultures that produce them (e.g., all logic is ethno-logic or socio-logic). Epistemological relativism, the strongest form of descriptive relativism, is distinguished by its emphasis on the *particularist* theory of cultural determinism, which holds that because cultures are radically different from each other, each culture produces a unique and culturally particular set of human characteristics (Rosaldo). Epistemological relativism implies the basic incommensurability of moral standards across cultures since panhuman generalizations concerning culture are likely to be untrue; generalizations can only be true if confined to a specific group (Geertz, 1973).

The suggestion that it may be impossible to evaluate a moral system because it will always be relative to specific social traditions and historical contingencies is very problematic for many philosophers and bioethicists (Po-Wah, 2002). From the philosopher's vantage point, the sacredness and primacy of the moral sphere may be threatened by empirical descriptions of cultural variation regarding moral practices. At the heart of this debate is the presumed dichotomy of *fact* and *value.* As philosophers have asked: How can an empirical description of what "is" influence the formulation of statements about what "ought" to be? In *Against Relativism,* Macklin expresses the dominant position within Anglo-American philosophy:

> There is no denying that different cultures and historical eras exhibit a variety of moral beliefs and practices. The empirical facts revealed by anthropological research yield the descriptive thesis known as *cultural relativity.* But even if we grant that cultural relativity is an accurate description of the world's diversity, whether anything follows for normative ethics is an entirely different question. Do the facts of cultural relativity compel the conclusion that what is right or wrong can be determined only by the beliefs and practices within a particular culture or subculture? (1999, p. 4)

Macklin's (1998; 1999) argument for a strong version of anti-relativism is based upon her adherence to the idea that certain ethical principles are applicable cross-culturally. Macklin does allow that some bioethical practices might need to be compromised in culturally diverse settings. In traditional Navajo society words have enormous symbolic power; thus speaking openly about a poor prognosis is thought to actually bring on death, causing enormous difficulty for clinicians taught to disclose the truth while engaging in advance care planning or explaining the risks of clinical research (Carrese and Rhodes). In her consideration of a clinical compromise about how much information to disclose, a compromise designed to respect Navajo beliefs about the avoidance of discussing negative topics, Macklin (1999, p. 264) concedes that, "A degree of ethical relativism is undeniably present in the less-than-ideal version of informed consent, and it does admittedly constitute a 'lower' standard than that which is usually appropriate in today's medical practice." Although she acknowledges that in some cases it is appropriate to consider cultural difference in the application of ethical standards, Macklin justifies this not by recognizing that morality is culturally embedded, but instead, by noting that "flexibility" (in applying ethical rules) is "consistent with adherence to more fundamental ethical principles" (1999, p. 264).

A fear of unbridled relativism may underlie the deep seated ambivalence some bioethicists express when weighing the impact of cultural difference on beliefs about the moral. Rorty speaks directly to this concern, "Critics of moral relativism think that unless there is something absolute, something which shares God's implacable refusal to yield to human weakness, we have no reason to go on resisting evil" (p. xxxi).

The cultural relativism practiced by most anthropologists, however, is first and foremost a *methodological* position, a claim that each culture must be approached and judged initially on its own terms. The anthropologist makes every effort not to prejudge practices that are unfamiliar. Note that this methodological stance does not preclude eventual evaluation and judgment.

Relativism, Social Justice, and Human Rights

There is an inherent tension between the universalizing discourse of bioethics and the historical celebration of cultural relativism among anthropologists. These two approaches to understanding moral practices in relation to social justice and human rights appear to be antithetical, at least in their most extreme formulations. However, in recent years, scholars in anthropology and bioethics have begun to explore, once again, the possibility of identifying transcultural or universal dimensions of the social behaviors of human groups. For example, in his attempt to develop a qualified version of ethical relativism, Shweder identifies aspects of moral behavior that are universal and culturally prescribed. Profound differences may exist between the moral codes of different people, but according to Shweder, there is more than one moral code that can be rationally defended. Universal dimensions of morality—justice and fairness, for example—are *relatively* expressed through discretionary variables such as who is designated as the moral agent, or what behavior and beliefs are judged to be morally relevant.

Renteln characterizes relativism as a metaethical theory about the nature of moral perceptions. Renteln suggests that relativism is compatible with cross-cultural universals, which could indicate support for particular human rights. It is precisely in the arena of human rights that anthropologists and bioethicists share a common concern for fundamental abuses inflicted upon individuals and communities. What is especially troubling for proponents of human rights agendas is the reliance on relativism to justify social and political practices that condone and perpetuate the systematic oppression of individuals and groups based on their gender, ethnicity, religion or political affiliation. Macklin's (1999) treatise *Against Relativism* provides a good example of the philosophical arguments against a strong form of ethical relativism. Macklin repeatedly calls attention to the dangers of moving from empirical claims about cultural variability to moral justifications in the normative sphere. Baker offers a model for negotiating value differences relevant to science and health in a multicultural world. In his discussion of bioethics and notions of the "common good" as a foundation for international human rights, Thomasma brings us closer to a conception of human rights that acknowledges fundamental human values and, simultaneously, the importance of local context and cultural difference.

Anthropologists studying human rights abuses and structural inequalities clearly differentiate between the documentation of cultural patterns and normative judgments about them. Scheper-Hughes's recent work on the global trade in human organs, for example, strongly condemns the organ trade and the dehumanizing practices surrounding it. A culturally informed bioethics must take into account the impact of globalization on social justice, human rights, and public health disparities internationally (Kleinman, Das, and Lock; Das). Anthropologist and physician Paul Farmer, who has addressed a broad range of human rights issues in international health, is especially critical when the "culture argument" is employed to rationalize, excuse or vindicate suffering and structural violence:

> Concepts of cultural relativism, and even arguments to reinstate the dignity of different cultures and 'races,' have been easily assimilated by some of the very agencies that perpetuate extreme suffering. Abuses of cultural concepts are particularly insidious in discussions of suffering in general and of human rights more specifically: cultural difference is one of several forms of essentialism used to explain away assaults on dignity and suffering. (1997, p. 278)

In his work combating the HIV epidemic, Farmer has criticized the widely held notion that only AIDS *prevention* strategies—but not *treatment*—should be used in resource-poor countries. His successful use of anti-AIDS drugs in Haiti destroyed the rationalization that therapy would not be cost effective in certain cultural groups.

Conclusion: The Role of Anthropology

What, ultimately, will anthropology contribute to the field of bioethics, an increasingly important domain of inquiry in national and international discourses about culture, morality, and health? Whether the question is appropriate care for the dying, the donation and transplantation of human organs, the evaluation of new medical technologies, informed consent in scientific research, or national and international health disparities, the anthropological contribution will be to create carefully researched accounts of how the moral good is located in particular local worlds. Ethnographic methodologies make possible such accounts. Ethnography provides the tools for a robust description of the social dynamics of ordinary moral experience. The application of ethnography in bioethics promises to counter the prevailing policy discourse controlled by economics, decision analysis, and legal procedures, a discourse that often silences social suffering while at the same time providing the illusion of control to individuals (Kleinman, 1999, p. 89).

The paradox of relativism cannot be resolved. Instead, the work of medical anthropologists will enhance our understanding of the moral rendering and interpretation of health practices, scientific discovery, and the various uses and abuses of power in global biomedicine. A single set of universal principles or procedures will be inadequate. Bioethical approaches dominated by a simplistic application of respect for individual autonomy will fail not only in societies with a more nuanced view of the socially embedded nature of personhood, but in the West as well. In healthcare practice and in scientific research, procedures based on respectful negotiation among competing claims—measures informed by moral pragmatism—are most likely to avoid harm and contribute to the common good. Medical anthropologists have a vital role to play in furthering our understanding of the cultural construction of bioethics practices and their applications throughout the world.

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SEE ALSO: *Autonomy; Beneficence; Body; Circumcision; Confidentiality; Death: Anthropological Perspectives; Death, Definition and Determination of; Eugenics and Religious Law; Health and Disease; Human Nature; Informed Consent; Medical Ethics, History of; Mental Health; Mental Illness; Population Ethics*

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ARTIFICIAL HEARTS AND CARDIAC ASSIST DEVICES

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In 1964 the U.S. Congress budgeted $581,000 to establish an artificial heart program at the National Institutes of Health (NIH). This was the first large-scale effort by any nation to support systematic research into the development of an artificial heart. The effort to build a reliable, totally implantable artificial heart has yielded marginal results. But even though an effective device does not exist, the artificial heart has, since the 1960s, been at the center of a heated ethical, economic, and policy debate. The debate over the wisdom of building and testing an artificial heart has also served as a paradigm for debating the future of expensive technologies in the U.S. healthcare system.

Scientists and physicians in many countries have dreamed for centuries of curing fatal heart diseases by creating a mechanical substitute. Technological advances during the 1960s in engineering fields such as metallurgy, fluid dynamics, electronics, and computer modeling made some scientists think that it might be possible to actually construct such a device. The emergence of the kidney dialysis machine, which could mimic the functions of a human kidney, created a fundamental change in attitude in medicine about the feasibility of building an artificial heart. In the late twentieth century, the quest for the Totally Implantable Artificial Heart (TAH) was once again the catalyst for other technological advances; except for the TAH, the success of the artificial heart program to date is still up for debate.

The Total Artificial Heart

Constructing an artificial heart requires materials such as metals, ceramics, plastics, and polymers that are lightweight and durable. At the same time, these materials must be biologically inert. They must work synergistically with other body systems and not trigger attacks by the body's natural system of immune defenses that would lead to the disruption of the circulatory system and, ultimately, death. An artificial heart also requires sufficiently smooth surfaces so as not to disrupt blood flow through the heart or damage fragile blood cells. A TAH needs a power source that can maintain an efficient and steady stream of energy for long periods of time while being small enough to fit completely inside the body. Both the pump and the power source must be capable of responding to changes in position, temperature, and pressure associated with the needs of the person using the machine.

The decision to launch a program to build a totally implantable heart had its roots in a series of exploratory meetings held during the 1950s at the NIH (Shaw). Enthusiasm for undertaking the research accelerated in the 1960s as physicians and engineers began to build and successfully use the first heart-lung machines, external pumps that could be used to support blood circulation in the body. After a few hours, these machines damaged the blood cells (Zareba). Still, the heart-lung machine was a crude, partial artificial heart that inspired physicians to think that perhaps a permanent device was not beyond reach.

Moreover, as the U.S. space program began to enjoy success, optimism grew in both scientific and government circles about the feasibility of taking on large-scale technological challenges. Many in government were impressed with the productive results being secured in the space program and the military from centrally funded, programmatic research. U.S. physicians and biomedical scientists saw themselves as being able to overcome the many technical obstacles through hard work, directed budgets, and targeted programs. The space program had as its goal putting a man on the moon before the end of the 1960s. The artificial heart program launched at the NIH in 1964 set as its goal the testing of a total artificial heart in a human being by Valentine's Day, February 14, 1970 (Bernstein).

The goal of implanting an artificial heart by the end of the 1960s was not attained. A major hurdle was the development of an energy source capable of providing long-term power to an artificial heart—while fitting inside the body. Not only was progress slow but, during the time artificial heart researchers were trying to overcome the large number of technical challenges that confronted them, an alternative to the mechanical heart appeared: cardiac transplantation. Ironically, the rationale for recent clinical trials of artificial hearts is to find a replacement for the now common cadaveric heart transplant. The increased need for organs and a stable donation rate are the main reasons why there has been renewed interest in total artificial hearts.

While Denton Cooley did implant a crude mechanical heart in a human recipient at Baylor University College of Medicine in 1969, most of the device, including the power source, remained outside the body. He explicitly stated that his sole motive for using this primitive, untested device was the desperate hope that it might help an imminently dying patient live long enough for a donor heart to become available for transplant. According to Michael DeBakey, Cooley did not believe the device he implanted was a permanent replacement for his patient's heart.

This attempt to use an artificial heart as a *bridge* to keep a patient alive in the hope that a transplant could be done took place without the approval of Cooley's superiors or any government agency. The recipient, Haskell Karp, died shortly after the implant. Cooley's decision set off a storm of controversy within his medical center. Karp's wife later filed suit against Cooley for failure to obtain proper informed consent to the experiment. Texas courts held that since the procedure was experimental, there was no agreed-upon informed-consent standards that governed artificial heart implant surgery and dismissed the suit.

The power source for the TAH has been a persistent problem. Some researchers in the late 1960s believed that the problem of how to power a TAH could be solved by using a small, implantable capsule of plutonium. In 1972 a specially convened NIH panel, the Artificial Heart Assessment Panel, conducted the first governmental review of such technology. It concluded in 1973 that while the "advent of the totally implantable artificial heart" would be "an earth-shaking event," the use of atomic power to drive a mechanical heart posed unacceptable radiation-exposure risks to the public health (Artificial Heart Assessment Panel, 1973, p. 187). Current devices rely on access to external power and small batteries. More than thirty years after Cooley's first implant, battery technology still has proven to be a limit on how long a patient can safely remain on an artificial heart.

The Artificial Heart Goes Private

In 1976, Willem Kolff (a physician and the inventor of kidney dialysis and one of the first artificial hearts) and some of his Utah colleagues formed a private company, Kolff Medical Associates, to attract venture capital to support their research. In order to interest private investors, they had to create a marketing program for their mechanical heart. The decision to proceed with a private company constituted a first step into the emerging and often ethically controversial world of public-private partnerships intended to advance medical research.

After further testing and redesign of models previously tested in calves, Clifford Kwan-Gett, Willem Kolff, and later Robert Jarvik managed to use a Jarvik-7 to keep some animals alive for as long as eight months. In 1980, Kolff Medical Associates applied for permission from the institutional review board (IRB) of the University of Utah Medical Center to try the device on a human being. They also sought permission from the U.S. Food and Drug Administration (FDA), which, since 1976, had authority to regulate the testing and marketing of medical devices. While awaiting approval, members of the Utah artificial heart group traveled to Philadelphia and conducted a series of three practice implants of a Jarvik-7 heart on brain-dead patients at Temple University Medical Center. Permission from family members to use the cadavers was obtained by Jack Kolff, Willem Kolff's son, then a surgeon at Temple.

After many weeks of resubmissions and revisions, the IRB at Utah and the FDA granted approval to undertake a series of seven implants of a Jarvik-7 heart in human beings at the University of Utah. The subjects were to be patients with very severe, life-threatening congestive heart failure resulting from cardiomyopathy, a poorly understood condition that causes irreversible fatal damage to the muscle of the heart (Scherr et. al.). Kolff and Jarvik, who had renamed their company Symbion, selected a young surgeon, William DeVries, to perform the first implant in a human recipient.

The Experiment on Barney Clark

Barney B. Clark, a retired dentist who had been admitted to the University of Utah Medical Center on November 29, 1982, with cardiomyopathy, was deemed to be an ideal candidate for the first implant of the Jarvik heart (Fox and Swazey) as he was educated, enthusiastic, and had a very supportive family. He signed the eighteen-page consent form the night he was admitted to the hospital. When his heart began to fail on December 1, he was taken to the operating room, and after a nine-hour operation he became the first human being to receive an artificial heart intended as a permanent replacement for his own.

Jarvik and DeVries spent many hours speaking with the media about the operation, the device, and their patient's health status. In the days after the implant, the healthcare team made many optimistic pronouncements to the media about Clark's chances for survival. But Clark followed a very rocky course during the 112 days he lived with the Jarvik-7 device. He suffered a wide range of complications that required three additional surgical procedures. After a few weeks on the machine, his emotional and cognitive state deteriorated severely, and on more than one occasion, he asked that the artificial heart be turned off. This was not done. After his death, more than 1,300 people, including political figures, members of the governing council of the Latter-Day Saints (Mormon) Church, of which Clark was a member, many of his doctors, and media representatives from around the world attended his funeral in Seattle, Washington.

DeVries and the Utah group pronounced the Clark experiment a success. They had kept a man alive in the final stages of heart failure for well over three months. But the IRB at Utah, troubled by the many complications that had arisen during the experiment, asked for many changes and clarifications in the research protocol before giving DeVries permission to try another implant. Among other things, the Clark experiment raised questions about the adequacy of informed consent of potential recipients. Could those facing certain death really be said to choose? And were those conducting the research so enthusiastic and hopeful about its prospects that they could not provide a realistic picture of the risks and dangers inherent in the experiment (Fox and Swazey)?

Between 1984 and 1987, four more implants were done using artificial hearts as permanent replacements for the human heart. William J. Schroeder received his implant of a Jarvik heart on November 29, 1984, less than two months after the IRB at Humana-Audubon gave its approval. Schroeder initially did well on the heart, but within nineteen days he suffered a stroke. During the course of the next 620 days he spent on the device, he had three more strokes; the last brought about his death. The other recipients of total artificial hearts, two at Louisville, one in Sweden, and one in Arizona—all experienced similar difficulties and ultimately died. It became clear from these experiments that the Jarvik-7 was not suitable for use as a permanent replacement device.

In January of 1988 the new director of the National Heart, Lung, and Blood Institute, Claude Lenfant, decided to cancel the NIH program to build a total artificial heart. The recent experience with artificial hearts, he believed, clearly indicated that such devices could be best used to assist failing hearts or for temporary use until a transplant could be found. Lenfant argued that a totally implantable artificial heart was still at least ten years away and might well wind up benefiting a relatively small number of patients at great cost. The threat of shutting down research on the TAH created a whirlwind of political protest in Congress. Legislators from states such as Utah and Massachusetts, where heart research was being conducted, fought to block Lenfant's plan. By the end of 1988, $20 million had been awarded to four centers to continue this research.

In July of 1991, the National Academy of Sciences' Institute of Medicine issued a study in which they recommended continued federal funding for both Left-Ventricular Assist Devices (LVADs) and TAHs. They predicted that a reliable LVAD should become available in the late 1990s and a TAH by around 2005 (Institute of Medicine). Federal funding for research on both permanent and temporary artificial hearts continued.

In July of 2001 the first Totally Implantable Artificial Heart replaced Robert Tools's own heart. Abiomed, Inc., started the controversial clinical trial of the Abiomed artificial heart. The FDA has approved fifteen patient implants.

The Left-Ventricular Assist Device

The left chamber, or ventricle, of the human heart does the greatest share of the work of circulating blood throughout the body. Heart attacks and other forms of heart disease frequently damage this portion of the heart. An LVAD is a pump capable of supplementing the function of the left ventricle, thus allowing a weakened or damaged heart to support life. It does not require an implantable power source and its design can be simpler since it does not have to duplicate all the functions of a heart for prolonged periods of time.

In the United States the ventricular assist device is used primarily for three groups of patients: those who cannot be weaned from cardiopulmonary bypass after a cardiac procedure; those who have an acute heart attack that results in cardiogenic shock; and the largest group, those who have end-stage heart disease and need some support while waiting for a heart transplant. In several European countries the LVAD is used as destination therapy. This is prohibited in the United States because the FDA has only approved the device as a bridge to transplant.

Starting in 1973, the NIH spent approximately $10 million per year over the next decade and a half on research on LVADs for damaged hearts. The first implant of an LVAD in a patient who could not be weaned from bypass was done in August of 1966 (Goldstein et al.). In the ten days after surgery the patient's continued improvement allowed her to be successfully weaned from the pump (DeBakey). It was not, however, until the early 1990s that a number of universities and private companies in a wide variety of countries undertook formal clinical trials of LVADs. Currently LVADs are a relatively common treatment for patients who are candidates for heart transplantation.

Ethics and Mechanical Hearts and Cardiac Assist Devices

The history of artificial heart research and use raises many ethical issues. Among these there are several issues that are especially important. These issues are both specific to the artificial heart and also apply more generally to all forms of new and expensive high-technology healthcare.

The use of human subjects in a clinical trial is one of the most important dilemmas of artificial heart research. The existing protections for persons who participate in medical research are informed consent and review by local committees of scientists (IRBs) of research proposals. The history of artificial heart research has called into question the adequacy of both protections.

Patients asked to serve as subjects in the use of artificial hearts and during the development of LVADs are extremely vulnerable. They face certain death if the device is not implanted. In many cases their heart failure came about suddenly and unexpectedly, and in others the opportunity to receive a device is not introduced until the patient is facing imminent death. For many of the subjects, the complexities of the research and the rigorous post-implant monitoring of the device in the past have been extremely intimidating and continue to be. Moreover, subjects may hear the risks and benefits of participation only from researchers who themselves have a powerful interest in wanting their work to proceed. Those who sought subjects to receive artificial hearts in past trials did so as both clinician and researcher to the recipients of the device, generating a strong conflict of interest.

The threat of imminent death tends to coerce subjects to make particular choices; furthermore, those charged with reviewing requests to use artificial hearts have faced serious moral challenges. There has been a great deal of pressure associated with the race to be the first medical center to use a mechanical heart or to be the first to use one successfully. Considerable financial and publicity stakes are involved for the researcher, the institution, and any companies in which the institution or researcher might have an interest. Local IRBs usually do not have the requisite expertise or independence to evaluate exactly what sorts of criteria to use to govern subject selection, consent forms, or the methods for accumulating data on subjects over long periods of time. Because of limited time and resources, local IRBs often do not adequately monitor clinical trials over time, which provides little protection for research subjects.

Once it became clear in the 1980s that the devices then available could not safely support long-term heart function in human beings, enthusiasm for artificial hearts turned to their temporary use. Here, too, tough ethical questions must be confronted. If artificial hearts are to be used on a temporary basis, is it permissible to implant them without the explicit consent of a person who has undergone a sudden, unexpected heart failure? Which patients would constitute the best patient population for testing devices intended for temporary use only: those nearest death and thought to have the lowest risk for the greatest potential benefit, or those not quite as sick, who are most likely to recover if given a *respite* by an LVAD or temporary use of an artificial heart? It is not clear that those who are given artificial hearts or LVADs on a temporary basis understand what their rights are to turn off these devices. Nor is it clear, according to George Annas, that the use of these devices will contribute to an overall increase in the number of lives saved. When cadaver hearts are scarce, the use of artificial hearts or bridge devices as a prelude to transplant means only that the identity of those getting a chance at a transplant may change while the overall number of transplants done remains the same (Caplan). Many believe that assist devices will not save more lives since there are only a small number of cadaver hearts available for transplant. One must find the balance between simply extending life versus improving its quality and happiness.

The Societal Impact of the Artificial Heart

One of the obvious moral questions raised by research to develop an artificial heart is whether developing this device is the best way to spend limited research dollars in meeting the healthcare needs of Americans or of the world's population as a whole. Artificial heart research is expensive. The costs of doing the first TAH implants ran into the hundreds of thousands of dollars, and current research promises to be much more costly. Approximately 40,000 people die annually from heart disease so the life saving potential of the artificial heart appears significant, yet the development of expensive new medical technology raises ethical questions about where money should be allocated and what diseases should be the priority for research.

Many experts note that to develop, test, and manufacture a fully perfected artificial heart would probably cost billions of dollars. Those most likely to benefit from access to such a device would likely be those who could afford insurance to pay for mechanical hearts. The quest for a totally implantable artificial heart, as with many other new procedures, devices, and pharmaceuticals, brings to mind questions of equity and justice in asking all to bear the cost of research for a device that would only be available to some. Questions of fairness also exist in the decision to build a machine that may add years of life to those at the end of their life span, when tens of millions of persons around the globe die before reaching adolescence from diseases and injuries that can be prevented. Explicit debates about fairness have not been very much in evidence regarding how best to allocate resources to perfect new therapies in American healthcare policy. If the pursuit of a TAH is to continue, it would seem prudent to make considerations of fairness a more central part of the policy debate.

Finally, the development of the total artificial heart and the use of ventricular assist devices have gained popularity and are believed to be one solution to the problem of a limited number of donor hearts and an ever-increasing transplant waiting list. It is imperative as we seek new technology to replace organs that cease to function effectively that we continually ask, what are the acceptable limits of our drive for prolonging life through radical replacement technologies?

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SEE ALSO: *Biomedical Engineering; Cybernetics; Healthcare Resources, Allocation of; Informed Consent; Justice; Research, Human: Historical Aspects; Transhumanism and Posthumanism*

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ARTIFICIAL NUTRITION AND HYDRATION

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The ability to deliver nutrition and hydration artificially is a powerful tool; in many clinical settings patient weight, nitrogen balance, visceral protein markers, and other parameters are favorably affected. While it has been difficult to document impact on survival in many clinical settings, artificial nutrition and hydration have become an essential component of multidisciplinary care in acutely ill or injured patients.

The means for providing nutrition and fluids under these circumstances are twofold. One is parenteral nutrition, called total parenteral nutrition (TPN). Fluid and nutrients are administered intravenously, most often via a large central vein accessed by a catheter placed using a minor surgical or radiological procedure. The other is enteral nutrition, in which nutrients are artificially pumped into the stomach or small intestine through a transnasal tube or ostomy (gastrostomy, jejunostomy). While nutritional goals can often be met with either method, TPN is costly and subject to complications, particularly infection. Unless precluded by medical conditions, enteral feeding is most often chosen when non-oral feeding is to be initiated.

The benefits of generally short-term nutritional support can be significant. Not surprisingly, as a result of these experiences, chronic, indefinite use of enteral feeding has been proposed for patients who have permanently lost the ability to take in adequate calories. However, the benefits of long-term enteral feeding in many settings have, for the most part, not been defined in controlled clinical trials. While observational studies with case-control or cohort design have provided insight into this area, ultimately, a decision to live with enteral tube feedings when oral intake ability has been lost or impaired becomes an individual one and personal values can be a critical variable. Advanced dementia, terminal cancer, and catastrophic neurological injury are clinical circumstances in which this option is often considered.

In the past, when long-term artificial feeding was considered, surgical gastrostomy provided enteral access. This has been largely replaced by endoscopic gastrostomy that can be performed, if necessary, at the bedside. This technique does not require general anesthesia, has less associated morbidity, and can be performed for a fraction of the cost of that for surgical techniques. Endoscopic placement, or percutaneous endoscopic gastrostomy (PEG), was first reported by Michael Gauderer in pediatric patients. It has since been adapted to many clinical situations, involving patients of all ages who are unable to eat and are thought to need nutritional support. In the Medicare population alone, PEG procedures more than doubled from 1991 to 1999, numbering more than 160,000 annually.

Opposing Viewpoints

There are disagreements about the use of artificial nutrition and hydration (Lipman). One viewpoint favors enteral feeding in most situations in which the ability to eat and drink has been lost. After all, it is a relatively simple and straightforward process, and while there is some risk involved in providing access, it is relatively small. Many would argue that doing so is, in fact, an obligation, that food and water are basic human needs under all circumstances. They do not view feeding tubes as medical or life-sustaining therapy. Moreover, there is the concern that because food and water are often viewed as a good, withholding or withdrawing them will cause suffering, akin to the traditionally held concepts of starvation.

On the other hand, an alternative and competing concept is based on the view that this traditional position just described, while at first glance justified by the clinical circumstances, is one for which factual support is lacking. Further, there is evidence that in some clinical settings, particularly terminal conditions, artificial nutrition and hydration may actually be harmful and may add to the burden of suffering that medical providers are trying to minimize. This viewpoint also holds that in the setting of illness, forced administration of nutrition and hydration, provided artificially via alternative access to the digestive system using specially designed equipment, represents medical treatment. As such, it contrasts with oral ingestion of food and water, which provide nurture and comfort.

In view of these contrasting perspectives, it becomes necessary to consider the variables that impact on a decision about the use of artificial nutrition and hydration.

Experience in Specific Disorders

ADVANCED DEMENTIA. An extensive literature has evolved over the past several years addressing the long term use of artificial enteral feeding in patients with advanced dementia, including advanced Alzheimer's dementia, a terminal disorder. Survival is the variable most often measured. Thomas Finucane reviewed fifteen studies quantifying mortality after feeding tube placement in patients with neurogenic (including dementia) and mixed disorders. Nearly all of these studies failed to identify a survival benefit afforded by feeding tube placement. Moreover, up to 50 percent of advanced dementia patients may die within a month of PEG placement.

Finucane also reviewed available evidence about other outcome parameters: prevention of aspiration pneumonia, prevention of the consequences of malnutrition, prevention or improvement of decubitus ulcers, prevention of other infections, improvement of functional status, and improvement of patient comfort. In this review of the literature from 1966 through March 1999, there were no reports documenting improvement in any of these outcomes with tube feeding.

TERMINAL CANCER. The role of nutritional support as an adjunct to managing cancer patients, not just those with incurable disease, has long been a subject of discussion and opinion. Ten years ago, a review of the status of nutritional support in cancer patients concluded that with the possible exception of bone marrow transplantation, no benefit had been documented for any outcome parameter, including survival. In 1997 Samuel Klein summarized a conference sponsored by the National Institutes of Health (NIH) and two nutrition societies, which concluded that at least short-term enteral or parenteral support does not decrease mortality or complications in cancer patients receiving cancer therapy; no good trials of long-term support were available to analyze. The conference further noted that while one might expect nutritional support to improve quality of life, no data existed that demonstrated this. Although no trials have specifically addressed terminal cancer patients there is consensus that artificial nutrition would not be beneficial.

CATASTROPHIC NEUROLOGICAL INJURY. Supplemental nutrition is commonly provided in patients in the neurological intensive care unit, be it patients with stroke or head trauma with brain injury. Most such patients have altered consciousness and are unable to eat. Some stroke patients will have dysphagia as a manifestation of neurological injury, although many will eventually recover swallowing function. In the initial assessment of these patients, outcome cannot always be defined. Moreover, in young patients with head trauma, for example, families cannot easily accept the prospect of death or at best, permanent loss of cognitive function requiring indefinite custodial care. It is thus reasonable to implement artificial nutritional support during the acute care of patients with severe neurological injury. With failure of recovery, however, the decisions regarding long-term support, including enteral tube feedings, must at some point be confronted. At the very least, any benefits and adverse effects of continued support become items of discussion.

Devastating neurological injury from trauma or nontraumatic etiology (e.g., hypoxic encephalopathy, extensive cerebral hemorrhage or infarction) are a common cause of permanent vegetative state (PVS) in which patients may exhibit wakefulness but otherwise have no detectable awareness. These patients have been particularly visible in the public eye because of the Karen Ann Quinlan and Nancy Cruzan cases in which the courts have also played a role.

There are no trials of enteral tube feedings in patients with PVS. This disorder is different from advanced dementia, and terminal cancer in which supplemental nutrition is considered as an adjunct to management in dying patients but does not affect outcome. In PVS, it is clearly life sustaining treatment: Brain injury, this devastating, is lethal and it is only with artificial provision of nutrition and fluids, and in some cases other supportive interventions, that these patients continue to live. The mechanics of providing nutrition differ little, however, and because feeding may be indefinite, PEG is the route most often chosen.

Adverse Effects of Non-Oral Enteral Feeding

While placement of enteral feeding tubes is often taken for granted on a clinical hospital unit, complications are possible. These complications can be associated with placement itself, the mechanical effects of the tube once it has been placed, and the effects of the nutritional supplements themselves. Placement and mechanical complications, while unusual, include head and neck trauma (e.g., bleeding, infection, sinus perforation), inadvertent intubation of the tracheobronchial tree, esophagitis and esophageal stricture, and several issues related to dysfunction of these generally small caliber tubes. Many of these problems are not seen with gastrostomy or jejunostomy. However, the surgical or endoscopic procedures needed to place these tubes, while safe, have a small but measurable risk, primarily infection and, rarely, even death.

Regardless of delivery route, diarrhea and aspiration are the two most common problems that can occur when tube feeding is begun. In hospital patients, diarrhea and often incontinence occur in 25 percent of patients on general units and as many as 65 percent of patients in critical care units. The feeding solutions themselves are responsible for many of these cases. The problem is likely less in nursing homes and patients cared for at home. In most cases, instilling feeding solutions into the stomach, duodenum, or jejunum probably has little impact on the likelihood of aspiration, although reports are conflicting. Upper airway secretions are a more important variable in the risk for aspiration.

Sometimes adding to the suffering burden in dementia patients is the common need for restraints in patients with enteral feeding tubes. Restraining patients is often viewed as humiliating and demeaning, their dementia notwithstanding. In PVS patients, while pain and suffering are not experienced, indirect adverse effects such as incontinence and the requirement for diapers may jeopardize individual dignity.

Withholding Food and Water: The Patient Experience

Not surprisingly, there is little information that precisely defines the patient experience when food and water are withheld. Two aspects of this issue are worth noting, however. First, while a decision might be made to forego supplemental nutrition, oral intake will often continue. Examples are advanced dementia and terminal cancer. Either the patient will choose to eat or drink as desired, or family or providers will assist oral feeding; in this situation, a patient need is being met. The second aspect is the circumstance in which the dying patient makes a conscious decision not to eat or drink, or tube feedings are withdrawn in a patient with PVS. Are pain and suffering aggravated when food and water are withheld?

Independent of the healthcare setting, fasting does not cause physical suffering, although such individuals are presumably healthy and, in most cases, water is not withheld. Nonetheless, the prospect of going without food or water may be untenable for a healthy individual. However, in dying patients, anecdotal reports in the medical literature consistently note that they appear comfortable without food and water and even euphoria has been described. Further, urine volumes fall and respiratory and gastrointestinal secretions decrease, lessening cough, congestion, vomiting, and diarrhea. Robert McCann reported an experience with thirty-two dying cancer patients in a hospice-like setting. These patients were sufficiently aware to judge hunger and thirst, and were offered food and water as desired. Nearly two-thirds experienced neither hunger nor thirst; one-third had hunger only initially. Oral feeding as desired and/or mouth lubrication effectively met needs when they occurred and caregivers could focus on patient comfort.

The physiological basis for these effects is incompletely understood, but at least a few suggestions have been offered, based largely on both human and animal studies in which food and water are withheld. For example, accumulation of ketones, which accompanies fasting, may cause anorexia. Increased levels of salutary endogenous opioids have been found in the plasma and hypothalamus of laboratory rodents deprived of food and water. Metabolic changes that occur with dehydration can cause decreased awareness, obtundation, and coma; death follows naturally and without suffering.

There are no reports in PVS patients, but given the loss of awareness in this condition, pain and suffering are not likely to occur.

Perceptions about Artificial Feeding

Perceptions about enteral tube feedings vary, but in general, surveys of elderly patients show that the majority would not want artificial feeding were they to develop advanced dementia; these opinions were common in groups educated about the procedures involved and the adverse effects, in particular the possible need for restraint. Surveys of physicians generally support not placing feeding tubes when elderly patients, or those at end of life, are no longer eating; yet in reality feeding tubes appear to be used more often than such surveys would predict. Surrogates opt for feeding tubes more often than the patients would, but these decisions rely on an incomplete knowledge base of benefits and adverse effects.

A number of variables are likely at play in the outcome of tube feeding decisions. Historically the roots of artificial feeding are deep. For centuries, it was a foregone conclusion that food must be provided when patients were not eating. Supplemental nutrition has also been intrinsic to sound surgical management for over 100 years. Another major variable, as just noted, is poor understanding of benefits and risks. This deficit seems to be most evident in families and non-physician providers. Physician surveys suggest that these providers are knowledgeable but because tubes are placed anyway, other factors are likely at work. One is found in federal regulations for nursing homes, which require adequate nutrition for residents. However, this is not the only variable. Mildred Solomon surveyed physicians who reported acting "against their conscience" (Solomon, p. 16) in providing certain life-sustaining treatment. Others have cited a fear of litigation were a tube not to be placed. Christopher Callahan has suggested that practice patterns tend to dictate PEG placement when patients stop eating. Moreover, the underlying illness may serve as a distraction by occupying center stage such that the placement of a feeding tube is relegated to a lower priority. To completely educate patients and/or families is time consuming and it is simply easier for tube placement to be the default position when the question of supplemental nutrition arises. Often this proceeds without disclosure and hence without informed consent.

Legal Issues in Non-Oral Enteral Feeding

The controversy and concerns surrounding withholding nutrition and fluids in the clinical circumstances discussed herein have also extended to the courts. To the extent that death is predictable in a period of hours, days, or even weeks, these intellectual and emotional struggles are less intense. This is less likely to be the case in patients with terminal disorders in whom the timing of death is less certain or in PVS patients who might live for years with artificial feeding. As a result, disagreement has spilled over into the legal system. Subsequent judgments have provided legal support for the following concepts:

1. Artificial feeding is medical treatment, and can be viewed on a level with other life-sustaining interventions (mechanical ventilation, dialysis, antibiotics, etc.).
2. Competent patients may refuse life-sustaining treatment and this is a right also afforded to incompetent patients, particularly when there has been prior indication of this desire. State interests do not trump these rights.
3. Withholding and withdrawing life-sustaining treatment, including artificial feeding, are equal under the law. There is no requirement to continue a treatment once started if the proportionality of benefits and burdens is unfavorable.
4. Withholding or withdrawing life-sustaining treatment in a patient with terminal disease is neither killing nor euthanasia.

Obligations and Options in Artificial Nutrition and Hydration

A wealth of experience and a burgeoning literature, supported by sound ethical and legal principles, are questioning the appropriateness of artificial nutrition and hydration in clinical settings like the ones discussed here. (Among these are Finucane; Cillick; Lynn; Post; Slomka; Steinbrook; and Winter.) Yet many providers and laypersons are unaware, or because of personal views rooted in their own moral background, do not accept these concepts. It is important, therefore, to first educate patients and families to insure that knowledge and understanding are on an even par so that decision making may be shared. A second step is to define goals as one might with any treatment modality. Considerations include the patient's prognosis, and how feeding is expected to either positively or negatively affect the medical condition (benefits and burdens), taking into account expected life span, patient comfort, and, as applicable, any previously expressed wishes about use of life sustaining treatment. The availability of technology is coercive and constitutes a challenge to the physician; yet a recommendation to withhold or withdraw a useless, burdensome treatment can be a more caring act than any other. Nonetheless, in the event of uncertainty about prognosis, or with failure to reach a consensus, initiation of artificial feeding as a trial, for an agreed-upon time frame with defined goals, may be an appropriate option, which does not jeopardize the relationship between physician and the patient or surrogate. Decisions about continuation or withdrawal can then be made with more confidence.

Providing food for dying patients is much more likely rooted in the act of eating than in the provision of nutrition and fluid by an alternate route. While both options offer physiological benefits, oral feeding provides comfort and pleasure to the extent one wants to eat. It also respects autonomy in that one is left in control of oral intake. Assisting in this process is a nurturing act. Even thought artificial feeding may be rejected, assisted oral feeding should be considered an obligation rather than an option, as permitted by the clinical situation.

With disagreements about management that involves ethical issues for some, the institutional ethics committee can be helpful by shedding light on the pertinent issues and improving communication among the involved parties. This is a valuable resource when conflicts are looming, but also in providing support for providers and family in emotionally charged situations.

Summary and Conclusion

The symbolism associated with eating a meal, and wanting to provide nutrition when this is not possible, involves concepts that have been deeply ingrained in society for centuries. They traverse cultural boundaries. Technology affords society a relatively easy means of artificially providing food and fluids when oral intake diminishes or ceases. Thus, placing a feeding tube relieves the provider of liability concerns for not treating, and family or surrogates are relived of guilt for not feeding. Yet a tension exists. The idea of a seemingly simple way to provide food when a patient is not eating conflicts with the more ominous themes in the clinical settings considered herein of failing to benefit, adding to suffering, and using technology that may be dehumanizing and disrespectful.

Howard Brody has suggested that artificial nutrition and hydration in terminal illness may be "…a textbook case of disproportionate care, which patients may choose to forgo" (p. 740). A principlist analysis would likewise argue that both beneficence and autonomy might be in jeopardy if artificial nutrition and hydration are initiated in patients with terminal illness. Lastly, while the definition of medical futility is debatable, a physician is not obligated to provide treatment so judged; while sometimes considered an affront to autonomy, an element of paternalism may contribute to effective medical decision making, although physicians may hesitate to exercise it.

In many patients with advanced dementia, terminal cancer, and neurological devastation, artificial feeding is inappropriate. The ethical and legal basis for withholding this treatment discussed earlier is sound. While a morally pluralistic society will always generate different views because of competing value systems, the differences may not be as great as they might seem. While respecting these views, the goal of ethically sound decision making can realistically be achieved in most cases in a manner satisfactory to all.

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SEE ALSO: *Aging and the Aged; Autonomy; Chronic Illness and Chronic Care; Clinical Ethics; Dementia; DNR; Harm; Informed Consent; Judaism, Bioethics in; Long-Term Care; Technology; Surrogate Decision-Making*

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AUTHORITY IN RELIGIOUS TRADITIONS

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Religious authority is a complex and ever-contested issue. Historical studies of religion demonstrate that religions are always changing; nevertheless, most religions anchor themselves in the concept that there is an unchanging truth to which they are always loyal. Between this ideal of unchanging truth and the reality of historical contingency, issues of religious authority are played out. Some factions of a religious community push for change; others pull against the tide of new ideas, social practices, or technology. Balance or synthesis among these competing factions may be temporarily achieved, but changing circumstances will again challenge that consensus. Just as often, no consensus is possible and religious communities split, giving rise to new denominations and even to new religions. Thus, the existence of religious diversity is closely linked to conflicts about appropriate and reliable religious authority and the inability of religious communities to agree upon the same sources of authority.

Overview: Types of Religious Authority

Four major types of religious authority, usually combined in some way, are found in the world’s religions. In most cases, tradition itself is regarded as authoritative. Religions tend to appeal to a more remote past, the true tradition, especially when current authorities are being challenged. In only a few religions, however, is tradition regarded as the major source of authority. A second source of authority is the world of nature, used as a model for human behavior and often thought to set limits for humans. While some appeal to nature is common, again only a few religions regard it as the major religious authority.

Against that background of appeal to tradition or nature, texts, both oral and written, and often regarded as revealed, vie with people for the status of highest or final authority. The authority accorded to texts varies greatly, but they are always important, regarded as repositories of wisdom from ancient times, trustworthy because they represent sacred wisdom from long ago. According to many religions, the sacred text should always be more authoritative than any reader of that text; that is to say, the readers should submit to the authority of the text, not the other way around. However, the problem with texts is that they cannot function in an unmediated fashion, directly transmitting their contents. They have to be understood and made relevant for contemporary people by contemporary readers, which means that people interpreting the texts can have equal, or even greater, authority than the texts on which a religion bases itself, no matter what that religion may assert about the superior authority of texts. Other religions do not trust a text, by itself, to give clear guidance and rely more on learned or realized human beings who have experienced the text’s meaning for reliable authority. Thus, at least to scholars of religion, it is clear that the people who receive and interpret texts, are, in fact, the most important sources of religious authority, though few religions openly declare that to be the case.

Types of Religious Leaders

The types of people in whom religious authority is vested vary greatly and struggles among different claimants to religious authority often occur. Frequently, an educated, elite group claims authority by virtue of its training and credentials. In some cases, entry into that group depends on heredity and almost universally in traditional settings, women are barred from that group. Among the various types of religious leaders, these people often function as priests who perform rituals on behalf of the whole community and often they are conservative, rather than innovative or radical in religious matters.

Another elite group found in many religious traditions consists of charismatic leaders who often claim to have been chosen by the spirits for their vocation. Such leaders can have great authority among rank and file members of a religious community, and, because they owe their authority to unseen spiritual forces rather than to routine processes of education and licensing, they are difficult to control. But many religions expect leaders directly inspired by the spirits to be part of the mix of religious authorities and have an honored place for them. Such leaders can be avenues by which innovation comes into a tradition, or they may argue that a more traditional practice would be more pleasing to the spirits. They also may cause the development of new denominations or religions.

Especially in some Asian traditions, a sage or *guru* (teacher) who has personally experienced the truths taught by that religion is the highest religious authority. These leaders also are often innovators in their tradition because they have been thoroughly trained, authorized to lead by their own teachers, and are trusted to advise people on matters of spiritual disciplines such as meditation.

Finally, religious authority is always vested to some extent in the whole community. Those with authority may wish to lead the community in a certain direction, but find that their followers simply are not willing to be led in that direction. Who is more innovative and who is more conservative in these struggles also varies. Sometimes, religious leaders want to push their followers to accept new elements into the tradition, such as the ordination of women to clerical roles in twentieth-century Judaism and Christianity. In other cases, such as the frequent use of birth control by North American Roman Catholics, the ordinary members of the tradition defy the more conservative stances of religious authorities. But, in any case, however uneasy the consensus may be, religious communities and those who claim religious authority have to come to some common understandings. If that does not happen, the religious tradition would fall apart and become something else—either a purely secular community or a new religion.

When Authorities Clash

Clashes between religious authorities are common. One type of clash is that between completely different religions, for example, the contemporary hostility between Islam and Hinduism on the Indian subcontinent. In such cases, differences in worldview are so great that the only resolution is some accord permitting coexistence. A more common clash of religious authorities occurs within traditions, when some individuals argue very strongly for one way of practicing or interpreting the religion and another group argues just as strongly for a different method. Denominations within one religion or the formation of a new, closely related religion often are the result of disagreements between religious leaders, all of whom claim authority. In these cases, both leaders claim to revere that tradition's ultimate religious authority, but also claim that responsibility to care for and interpret that religion has fallen into the wrong hands. At least three major kinds of protest have arisen repeatedly.

First, individuals or groups protest that the wrong people have been put in authority or that they have too much power. The major division between the Sunni and Shi'ite branches within Islam arose from controversy over who was the legitimate successor to the Prophet Mohammed, meant to rule over a unified Islam. While the Protestant movement is complex, one major initial cause certainly was German Reformation leader Martin Luther's (1483–1546) defiance of papal authority. According to Luther, the pope had usurped the authority that should reside directly in the Bible and believers should form their faith directly on the Bible rather than relying on the decisions of a human intermediary. Luther's protests were only the first of many movements claiming to abandon various human institutions to return to the sacred text as ultimate and final authority. Today, numerous individuals and movements within Christianity claim to have found that unmediated text, but each claim is contested by another contender.

Second, individuals or groups often claim that those with formal authority have lost contact with the spiritual sources of the tradition and no longer can speak for the deity or interpret texts accurately. Claims of corruption on the part of established authorities are also common, found in every religion. Protestors often claim direct contact with the spiritual sources of the tradition, which they say is more authoritative than the mere rote learning or heredity power of those with formal authority. Usually they do not wish to form a separate group but long for a more vibrant, ecstatic spiritual experience within their tradition. Sometimes these movements can be incorporated into the larger tradition, as happened with many monastic movements in European Christianity and with many of the great Christian mystics. The Sufi movement within Islam also sought and provides more direct religious experience. The medieval mystical branch of Judaism, the Kabbalah, became quite popular, though it is not well-known or frequently practiced today. Some groups break away from their parent body, as did the English Quakers who believe that clergy are not necessary because deity can speak to anyone who waits in silence, only to become established groups themselves. Variations on this theme are infinite, as spirit-filled individuals and groups, dissatisfied with what they experience as dead and rigid ways of those with formal authority, refuse to remain silent.

Third, countless movements of social protest and reform have arisen when groups of believers claim that, while the religion dictates charity and concern for the poor and underprivileged, the religious authorities have sided with the rich and powerful. Many of the great reform movements of the nineteenth and twentieth centuries—abolition, the civil rights movement, feminism, war protest, environmental activism and anti-colonial movements—have been fueled in part by the inspiration that their religion authorizes social protestors to act against religious authorities who have lost their mandate because they ignored an important part of the sacred heritage.

The Predominance of Texts: Monotheistic Religions

Texts believed to be revealed are more definitive sources of authority in the three monotheistic religions than in other religions. Furthermore, the most serious disagreement among the monotheistic religions concerns which of them possesses the truly revealed, authoritative scripture. Judaism, Christianity, and Islam all claim to believe in a monotheistic deity and all three claim that the deity has spoken to humankind in trustworthy, definitive revealed scriptures. But each claims its scripture as the one reliable scripture, and predictably, as each of the three religions emerged into history, it claimed that its scriptures fulfilled and replaced previously recognized texts. Also predictably, those who did not follow the new revelation claimed it to be the work of misguided usurpers. Thus, Jews regard the Hebrew Bible, the oldest monotheistic scripture, as the valid revelation and do not recognize either the Christian New Testament or the Muslim Qur'an as revelations. Christians recognize the Hebrew Bible, virtually identical with what they call the Old Testament, as genuine revelation, but claim that their New Testament is the culmination and fulfillment of that scripture. However, they pay little attention to the Qur'an, which emerged later. Muslims, on the other hand, claim that both the Hebrew Bible and the New Testament were genuine messages from the deity, valid in their own time, but now made obsolete by their own final and definitive revelation.

Fundamental to claims of authority for these scriptures is the claim that revelation has now ceased; each of the three monotheistic religions in turn makes the claim that the deity said all it intends to say now that its scripture has been revealed and that humans can expect no further revealed messages. Thus each religion in turn has declared the canon to be closed.

Within each of the three monotheistic traditions, similar problems have developed in the process of living with a definitive, final revealed text that cannot be amended or changed. First, who determines that the canon is, indeed, closed? In the Muslim tradition, this issue was solved relatively easily. The entire Qur'an was revealed during the lifetime of the prophet Mohammed (570–632 C.E.) and Muslims of his own day and later times never questioned whether any other texts could be part of the Qur'an. But the issue was not so easily solved with the New Testament or the Hebrew Bible, in part because the idea of a definitive revealed scripture as the charter of the religious community was not yet well established.

By the beginning of the common era, the contents of the Hebrew Bible had been roughly agreed upon, though one class of literature, the Apocrypha, usually included in Roman Catholic Bibles but not in Protestant or Jewish Bibles, had an ambiguous status. Many new texts about Jesus and the meaning of his life were being circulated in the Roman Empire as Christianity began to form and to split from Judaism. Were they revealed scriptures? Many texts about Jesus did not make it into the New Testament canon as Christianity gradually defined its orthodoxy and rejected the texts of the defeated Christian groups. Bishops began to circulate lists of texts that they regarded as appropriate reading material for their congregations; they had a list in common sometime between the second and the fourth centuries C.E. that closed the New Testament canon. Christians also accepted the texts that had already become sacred to Jews, but they read them in Greek (or later in Latin), not in Hebrew. The Apocrypha circulated as part of the already established Greek translation, which is why Christians continued to regard it as scripture until the Reformation.

Jews experienced very chaotic times after the destruction of the Second Temple in 70 C.E., when they were dispersed to all parts of the Roman empire, and Christianity became dominant. In these conditions a group of rabbis regarded as religious authorities met to come to a firm decision about which texts were authoritative for Jews. They came to the conclusion that the Apocrypha should be set aside, leaving the Torah, the Prophets, and the Writings as the three parts of the Hebrew Bible.

One way or another, the authority of a specific text is established. All three monotheistic religions agree that life should be based on that text, that the text is the final arbiter of the deity's wishes and commands for human beings. But how is what the text really says determined, and who gets to make those determinations? These are the fundamental issues about religious authority in the monotheistic religions. Deeming the text authoritative does not solve the problem of which persons or institutions should determine the text's meaning or the text's solution to various unforeseen circumstances that inevitably arise.

This problem is solved by authorizing a specific group of people to determine the text's meaning. In all three monotheistic religions, these people must be well educated in the text and commentaries upon it because they should derive their interpretations from the text, not impose them upon the text. In time, commentaries become as important, if not more important than the root text, as each generation adds its layer of commentary, which becomes part of the whole authoritative tradition.

In Judaism and Islam, the revealed text is regarded above all as the guideline for daily life. Religious authority involves not only questions of belief or ethical behavior but also of diet, inheritance, marriage and divorce, testimony in court, and all the other myriad details that make up a whole society. The most respected scholars in the tradition are those who know the all-encompassing religious legal code and how to bring it to bear on any new situation that develops. The revealed text has often been compared to a constitution and the process of interpreting it to the development of constitutional law. This fact helps explain why the separation of religion and government is so difficult for many Muslim societies; there can be no real separation between religion and the affairs of daily life that governments oversee if the revealed sacred text is, in fact, a constitution setting forth a daily routine and way of life. Muslims and Jews usually regard this code for daily living as a great blessing rather than a burden. They say that having such matters as diet or family law predetermined by religious authority makes life simpler and less stressful.

Valid "constitutional law" that develops in this process is regarded as having equal authority with the original text. In Judaism, the *oral Torah* of the Mishnah and the Talmud, compiled in the early centuries of the common era, is regarded as having been contained, in a hidden way, in the written Torah, the first five books of the Hebrew Bible (which Christians call the Old Testament). It was the job of skilled, well educated rabbis to draw out those meanings, for often Jewish law as practiced in contemporary Orthodox Judaism goes well beyond the literal text of the written Torah. In a similar fashion, Muslims rely on the Hadith, the sayings of the prophet Mohammed that are not part of the Qur'an, to answer questions seemingly left unanswered by it. If more resources are needed, reasoning from the text is considered a valid source of authority in Islam. The fourth source of authority in Islam is the consensus of the whole community, a source of authority much less explicitly recognized in most other religions.

Christianity did not develop the same kind of overarching blueprint for daily living and so the same kind of detailed attention to the development of religious law did not occur. However, matters of theological doctrine drew the same intense scrutiny, the same creative reasoning to prove that doctrines most historians would regard as later developments really are present in the Biblical text itself. Early Christianity was very diverse and many different forms of Christianity competed for dominance, especially before the legalization of Christianity under the Emperor Constantine in 313 C.E. and the formation of the Nicene Creed in 325 C.E. With those events, a dominant form of Christianity, under the authority of the bishop of Rome (the popes) emerged.

Living Lineages of Oral Transmission: Asian and Indigenous Traditions

It is more common for accomplished religious practitioners to advise individuals and communities about what practices need to be followed and how to do that rather than to rely primarily on texts. Thus, religious authority is invested first in persons, who often use traditional texts extensively, but whose main basis for authority comes from their own realization of the meanings encoded in the texts. Another person, equally well versed in study of the texts, but lacking personal realization of their meaning, would not command the same prestige or be approached by others seeking religious guidance. In such religions, there is a well-established body of traditions, both textual and oral, but the canon of tradition and text is not closed; it is quite possible for contemporary teachers and their writings eventually to come to be as highly regarded as those of past leaders. Most important of all, the meaning of the text or tradition is regarded as locked and inaccessible to most ordinary people without the guidance of a teacher who has fathomed the meaning of the text.

In such traditions, the guarantor of authenticity rather than wholesale freelance creativity is the lineage of oral transmission. Locating reliable religious authority in a lineage of oral transmission depends upon two major premises. The first is that, because of the brittle, unreliable character of the written word, it can be rather dangerous and misleading for untutored individuals to try to rely directly on texts, particularly those that discuss advanced exercises in meditation and mystical experience. Such danger exists because the written word cannot fully capture or express the truths it tries to communicate. Instead, communication of the deeper meanings of a text or tradition depends on the oral instruction from someone who has already understood the text fully and can transmit it in an appropriate manner. A very different evaluation of the reliability and potency of written or memorized texts from that found in monotheistic religions drives this idea about reliable religious authority. However, protection from dangerous or misleading innovations is also needed so that the oral transmission does not become completely idiosyncratic. Such protection comes through insistence on lineage, the second major premise basic to a lineage of oral transmission as religious authority. Only those teachers who have been authorized to do so by their teachers can transmit the oral teachings, and it is believed that this lineage of transmission is unbroken from the current teacher back to the founder of the specific religious movement. Within that protective restriction of who can teach, it is believed that appropriate innovations will be introduced safely and as needed. In fact, in religions that rely upon a lineage of oral transmission for religious authority, innovations and new lineages occur frequently, often without opposition or divisiveness.

The clearest examples of investing religious authority in the authorized teacher are found in Vajrayana and Zen Buddhism, some lineages of Hinduism, and some indigenous religions. These religions value direct religious experience highly and mistrust anything else to satisfy the longings that drive people to religions in the first place.

Buddhism depends on the ineffable enlightenment experience of one man, Siddartha Gautama (563–483 B.C.E.), and his ability to teach his students to experience for themselves the peace and freedom he had found. What he experienced has never been put into words and most Buddhists would regard the attempt to do so as futile and unnecessary. However, he did teach methods to lead people toward their own enlightenment and others can teach these as well. The voluminous texts of the many denominations within Buddhism are primarily attempts to provide instruction on how to cross over from the confusion that Buddhists regard as the inevitable normal human condition to the freedom and peace that is the birthright of each human being.

Throughout Buddhist history, many types of Buddhism have evolved and some of these developments have included serious disagreement over the most reliable sources of authority. The major division in Buddhism is between the Theravadin Buddhists who prevail in Southeast Asia and the many forms of Mahayana Buddhism, which prevails in Tibet, China, Japan, and Korea. The name *Theravada* means *the way of the elders,* and this name indicates precisely what these Buddhists believe about themselves; they rely on the texts and traditions taught by the earliest generations of the Buddha's disciples and claim that Mahayana Buddhism is based on later, fraudulent ideas and practices that crept into Buddhism when some ignored the genuine oral transmissions. By contrast, Mahayanists claim that they possess oral transmissions going back to the historical Buddha, which were taught to only a few students during the Buddha's lifetime, but gradually were made more public (and written down) when conditions were appropriate. Among the many forms of Mahayana Buddhism, Vajrayana Buddhism of Tibet and Zen Buddhism (the Japanese name) of China, Japan, Korea, and Vietnam rely most heavily on a lineage of authorized teachers to communicate the core teachings and practices. In these forms of Buddhism, texts are sometimes ignored almost completely, so great is the mistrust of the written word and the emphasis on the student's direct personal experience as opposed to their competence in intellectual knowledge of philosophical traditions.

Hinduism is a much more complex and diverse religion than is Buddhism, and by no means do all forms of Hinduism rely on lineages of living teachers for authority. For some forms of Hinduism, tradition, as passed down in communal memory and in texts, to a lesser extent, is the final authority. However, forms of Hinduism more concerned with philosophy and meditation do rely on such living teachers and the transmission of their authority from generation to generation. Each teacher or group has its own history and dynamic and they are endlessly diverse. Summarizing them is impossible.

Indigenous traditions worldwide are also impossible to discuss in general. Among them, one important authority is a figure often referred to as a *shaman* in Western sources. It is believed that shamans gain their authority through direct encounter with the spirits. Who might become a shaman cannot be predicted and it is also widely believed that an individual who has been chosen to be a shaman cannot resist that call. Shamans do not usually learn much of their craft from other human teachers, but because of their ability to communicate between the human world and the spirit world, they are trusted authority figures in their communities. Usually, they function as advisors and healers, not lawgivers. Though shaman-like individuals can be found in many indigenous settings, some of the most famous and best known are found among groups of indigenous North and South Americans. One can also study shaman-like individuals in the religions of aboriginal Australia, but they are not characteristic of indigenous African religions. Formerly, they were common in the northernmost parts of Asia.

The Force of Tradition: Collective Memory as Religious Authority

Many religious communities are not especially oriented either to a sacred text or an authorized teacher. Instead, for them, what counts is what has always been done, what they believe their forbears always did, and what tradition dictates.

Tradition as the ultimate religious authority can be found in segments of the religions already discussed because convention has always had great appeal and force. However, in at least two major religions, large segments of Hinduism and the Confucian perspective, tradition and custom have been explicitly elevated to the highest rank of religious authority.

Hinduism is a modern European term for the religious behavior Europeans encountered in India, which is one reason why Hinduism as an overarching tradition is so difficult to summarize. For the vast majority of Hindus, tradition is the foundation of religious life, upon which other elements may be cast, but often tradition is the entire content of religious life. This is especially true for those segments of Hinduism not oriented to enlightenment and ultimate release but to doing one's duty well in this world—and this type of Hinduism is, at least theoretically, the bottom line for all Hindus, no matter what else they might add on to this foundation. For traditional Hindus, life is a vast complex of duties and relationships, all of them laid out in the *eternal dharma,* the law code that no one quite understands fully, that is contained in no single source, and that differs from person to person depending on one's caste and stage of life. Nevertheless, duty is absolute and cannot be avoided.

The mystery and complexity of understanding one's duty is discussed in many Hindu texts, including the national epic, the *Mahabharata* (The Great War). For starters, there is the complexity of the duty of caste and stage of life. India's controversial caste system was considered to be of ultimate authority in classical Hinduism, of cosmic or divine origins and not subject to human moral qualms about its effects on individuals and society. Part of one's required duty is to conform to the requirements of one's caste status, as determined by birth. Individual abilities and desires were meaningless against this bank of tradition. Furthermore, one should conform to the duties required by one's stage in life. It is not appropriate for young people to seek individual religious fulfillment; they must first fulfill their family and professional roles, as laid out by sex and caste. Countless authorities, from the Buddha to Mahatma Gandhi, have tried to modify or eliminate the caste system, but the force of tradition has always prevailed over them. Today, the caste system is illegal in India, and *affirmative action* that tries to elevate the status of the less privileged castes is deeply resented by many in the more privileged castes.

Rather than being the timeless traditions of ordinary believers, the Confucian system was the ruling ideology of the Chinese elite for most of Chinese history. Though many well known human authors, including Confucius (551–479 B.C.E.) and Mencius (372–289 B.C.E.), wrote texts that are regarded as foundational to the Confucian movement, the authors always claimed that they were not inventing anything but only urging return to the trustworthy customs of the ancients. These traditions turned on maintaining the proper hierarchical relationships between, among others, rulers and subjects, elder and younger family members, and husbands and wives. If each person truly fulfilled the duties appropriate to his or her role, harmony would prevail and society would prosper. However, in this hierarchical system, those with power had an obligation to be fair and generous, rather than to take advantage of their power. If they took advantage of their power, that would disturb cosmic harmony and warfare or poverty would result. An important part of the Confucian system is *Li,* the accumulated customs of civilized people which included everything from how to greet someone to how to use one's eating utensils. According to Confucian thought, having a custom or rule to govern every possible occasion led to social harmony and contentment.

The Ways of Nature as Religious Authority

Finally, for some religions, the natural world itself is the highest religious authority and the model upon which humans should base their lives.

A second religion indigenous to China—Daoism, whose founder is the legendary Lao Tzu (604 B.C.E., traditional birth date)—does not rely primarily on people or texts for authority, even though it is the source of the famous *Dao De Jing.* Rather, the Dao itself, the natural cosmic law that cannot be put into words but governs everything is the authority to which humans and everything else should submit and which they should imitate in every act of living. All human woe is said to derive from ignoring cosmic natural law and trying to impose human norms upon it. A wise person observes nature and trains until he or she can follow its ways in complete spontaneity, no matter where that may lead.

Finally, Shinto, the indigenous religion of Japan, is famous for not regarding texts as important. Ritual traditions and the cultivation of beauty are its primary means of expressing itself. Priests know how to perform the beautiful rituals and maintain beautiful temples, often located in places of great natural beauty, but they are not regarded as religious authorities or leaders either. Rather, the delightful natural world itself is of supreme value. It is the sacred source of all life and nothing human can compete with it for value.

This model of religion that orients itself more to the ways of the natural world than to texts or people is also common among indigenous religions around the world.

They commonly have a keen understanding of and appreciation for nature and regard the entire natural world as sacred, of ultimate value.

Religious Authority and Modern Thought

All traditional sources of religious authority are being challenged by modern thought, especially science, empirical history, and secular movements of social reform.

Religions respond to these developments in various ways, from significant internal changes accommodating modern thought to complete resistance.

In many ways, the religions most oriented to texts have had the most difficult time dealing with modern thought; the texts often contain science, history, and social systems that do not fit well with modernity and the texts are supposed to be eternally valid and binding. Many interpreters have found ways to combine the deepest insights of religious texts with modern thought by considering some aspects of the text to stem from its social context rather than divine revelation, and by regarding many stories in the text as metaphorical rather than literal truths. Others have refused to concede any aspect of traditional religious thought where it conflicts with modern science or history, with the result that fundamentalism is a dominant religious movement in the twenty-first century, especially in monotheistic religions.

The traditional religions of China have also been deeply affected by modern thought, largely in negative ways. The triumph of Communism deeply weakened the hold of both Confucian and Daoist thought on Chinese people. It also led to the severe repression of Buddhism in both Tibet and China.

Secularism or indifference to religion is also common in many parts of the modern world, especially Japan and Europe. Religion has become a minor ceremonial affair having little real authority for many people.

In other parts of the world, especially India and the Middle East, religion has become a major source of conflict as different religions claim that their texts and traditions give them alone control over land and sacred places. Both sides in the conflict claim the authority of their religious tradition and ignore similar claims by their opponents as illegitimate.

Conclusion

In every situation, religious authority will depend on a complex mix of tradition, views about nature, various types of religious leaders, and texts or oral traditions possessing varying levels of sanctity. Usually one or two of these sources of authority are dominant. Sometimes those sources of authority will try to push the religious community into new practices or understandings. Sometimes those sources of authority will try to conserve current practices and understandings in the face of intellectual or ethical challenges. Few generalizations regarding authority in religious traditions can be made with any reliability.

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SEE ALSO: *Autonomy; Coercion; Conscience; Conscience, Rights of; Responsibility; Trust*

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AUTOEXPERIMENTATION

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Autoexperimentation, which refers to the practice of intentionally utilizing oneself as an experimental subject, is not a rare event. Over the past four centuries, more than 135 examples have been documented, and the true incidence is undoubtedly much higher (Altman; Franklin and Sutherland). Although the preponderance of recorded autoexperimentation has been conducted in the name of biomedical research, investigators in the physical and social sciences have also engaged in this practice.

Autoexperimentation has long enjoyed a measure of romantic appeal in the scientific and popular tradition. “The experimenter,” wrote Sir George Pickering, “has one golden rule to guide him as to whether the experiment is justifiable. Is he prepared to submit himself to the procedure? If he is, and if the experiment is actually carried out on himself, then it is probably justifiable. If he is not, then the experiment should not be done” (p. 229). Henry K. Beecher suggested that any scientist wishing to engage in human experimentation ought to experiment on himself “as evidence of good faith.”

Despite a reputation for nobility of purpose, the practice of autoexperimentation has been the focus of substantial scientific and ethical debate. The scientific controversy concerns the methodological limitations of autoexperimentation and its capacity to yield useful data. The ethical debate is more complicated. Superficially, it concerns the extent to which autoexperimentation ought to be regulated. At its heart, however, lies a fundamental conflict between two opposing views of scientific research. The libertarian view advocates a relatively laissez-faire policy toward all forms of scientific inquiry, including autoexperimentation. The paternalistic view, in contrast, emphasizes the importance of protecting experimental subjects from risk, whether self-imposed or imposed by others. While this entry presents various perspectives on the issue, the author is opposed to autoexperimentation in most cases and will make clear why this view is plausible as the entry unfolds.

Neither the methodological nor the ethical aspects of this debate can be fully understood without examining the historical and cultural context in which autoexperimentation developed.

Historical Perspectives

One important factor in the history of autoexperimentation, upon which many investigators have remarked, is the existence of an extremely powerful and deeply rooted obligation to pursue scientific knowledge regardless of personal risk. A good example is John Hunter’s unfortunate experiment with venereal disease. Throughout the eighteenth century, physicians debated whether gonorrhea and syphilis were two separate entities or different manifestations of the same disease. Hunter, a prominent surgeon, anatomist, and fellow of the Royal Society, believed they were the same. In 1770, to prove the point, he inoculated his own penis with the fresh urethral discharge of a man with gonorrhea. When syphilitic chancres developed at the site of inoculation, Hunter erroneously concluded that his theory was correct. Even though he thought he had contracted gonorrhea, Hunter eventually died of syphilis (Franklin and Sutherland). It is clear, in retrospect, that the discharge most probably transmitted both diseases.

Closely related is the idea that the true scientist must always be prepared to engage in resolute acts of personal daring (including, though not necessarily limited to, autoexperimentation) to overcome impediments to research. There are two famous cases in point. In 1929, despite the direct prohibition of his department chief, Werner Forssmann surreptitiously passed an intravenous catheter into his own heart to prove the feasibility of cardiac catheterization in humans. He later shared the Nobel Prize for these experiments (Altman). The second case pertains to the thymidine experiments of Beppino Giovanella during the late 1970s. Thymidine had been shown to be a promising cancer drug in animals, but the U.S. Food and Drug administration (FDA) refused to authorize clinical trials on the grounds that its safety had not been established. Giovanella proceeded to ingest huge doses of thymidine, thereby proving its safety and overcoming the objections of the FDA (Franklin and Sutherland).

A third factor has to do with the problem of justifying human research before the safety of an experiment has been established. Experimenting on oneself or one's colleagues signals the conviction that the experiment is at least worthwhile, if not necessarily safe (see Beecher; Pickering; Bok). In 1997, the International Association of Physicians in AIDS Care (IAPAC) announced that many of its members had agreed to be subjects in trials of a live attenuated HIV-1 vaccine. Some AIDS researchers said the vaccine was too dangerous to be tested in people, but the head of the IAPAC initiative argued that 8,500 new HIV infections every day made further delay in testing vaccines unethical (McCarthy). As of March 1998, more than 270 physicians, healthcare professionals, and healthcare advocates had volunteered for the trials, which had not yet commenced in early 2003 (IAPAC).

A fourth factor derives from the observation that autoexperimentation is usually the best, and sometimes the only, way to ensure absolute adherence to an exacting research protocol. In 1962, for example, Victor Herbert undertook an investigation to explore a possible link between nutritional folic acid deficiency and megaloblastic anemia. To deplete the body of folic acid reserves, he subsisted for eighteen weeks upon an extraordinarily insipid and unpalatable diet (Altman). Herbert commented that the experiment would probably have failed had he not experimented upon himself.

Finally, autoexperimentation has often been fostered when it appeared that certain researchers, by virtue of special training and experience, might extract significantly more from an experiment by participating than by observing. Data obtained uniquely through autoexperimentation proved critical, for example, in the development of protective clothing for ultrahigh-altitude airplane ejection, in studies of extreme acceleration and deceleration, in investigations of decompression sickness, and in studies of human physiology in space (Gibson and Harrison; Dille; Franklin and Sutherland).

Criticisms of Autoexperimentation

Critics of autoexperimentation object to the practice on both methodological and ethical grounds.

METHODOLOGICAL ISSUES. The worth of an experiment depends upon its scientific merit, upon its permissibility from ethical and legal perspectives, and upon its advisability on other grounds. Before any experiment is carried out, each of these elements must be assessed. Autoexperimentation suffers from three major methodological problems. First, there is an inherent difficulty in observing oneself dispassionately. This difficulty often leads to the confusion of objective and subjective data. Second, it is virtually impossible to establish adequate controls, particularly because autoexperiments tend to involve serial observations of one individual. Third, it is very difficult to extract statistically valid information because of the typically very small numbers of subjects and experiments. As a general rule, the likelihood that useful data will result from experiments on very small groups is determined by the likelihood that the data would not be materially affected by iterations (repetitions of the experiment) on larger groups.

Because of these weaknesses, autoexperimentation rarely proves to be a wholly satisfactory experimental method. There may be two important exceptions, however: pilot studies to establish the feasibility of a procedure or the safety of a pharmacological agent in normal subjects; and studies in which the scientist consents to be treated as an ordinary research subject and to remain under the supervision of other investigators for the duration of the experiment. It is worth noting that the second exception complies with the provisions of the Declaration of Helsinki stipulating that "the responsibility for the human subject must always rest with a medically qualified person and never rest on the subject of the research" (World Medical Association, p. 3).

ETHICAL ISSUES. Autoexperimentation is clearly often heroic, but the basis for the alleged obligation to engage in this practice is less clear, for it is not clear that there are good moral reasons to encourage—let alone require—autoexperimentation. As discussed above, autoexperimentation is not always good science, for it may lack adequate controls and sufficient subjects to generate meaningful results. Therefore, autoexperimentation makes sense more as a potential condition to involving noninvestigator subjects in further testing than as a substitute for using such subjects. However, autoexperimentation may not be sufficient to establish that lay persons may appropriately participate in an experiment, for the investigator may be more risk-accepting than other subjects, or may not be medically representative of all potential subjects, or may not meet the physiological qualifications for subjects in that experiment. It is also unclear that autoexperimentation is necessary to establish that noninvestigators should participate in an experiment, for the processes of institutional ethics review and informed consent are probably better ways to determine whether that is appropriate. Of course, these points may not apply when the risks are exceptionally high and the need for the research exceptionally urgent.

To the extent there is an obligation for researchers to engage in autoexperimentation, that obligation does not always outweigh the problems with autoexperimentation. The fundamental issue is whether any of the precautions required to protect the subject in other forms of human experimentation may be legitimately suspended in the case of voluntary autoexperimentation.

The three basic arguments that have been brought to bear on this question are not easily reconciled: (1) Individuals are entitled to assume voluntarily risks they may never impose on others; (2) under proper circumstances, both self-sacrifice (martyrdom) or assumption of high risk for good reason (heroism) are universally lauded; and (3) societies have a vested interest in protecting the welfare of their members, and some degree of regulation in recognition of this interest is required or, at the very least, ought to be permissible.

Libertarians argue that the principle of autonomy grants scientists the right to engage voluntarily in risky behavior. On this basis, they refute the applicability of regulations for the protection of human subjects in autoexperimentation. Champions of a more paternalistic approach, in contrast, oppose unlimited risk taking in any experimental context because of the following concerns:

1. Many risks have been undertaken for unimportant goals;
2. Habitual risk takers might turn to autoexperimentation even when other, more desirable forms of investigation exist;
3. Investigator–subjects may be at greater risk than other potential subjects because curiosity, enthusiasm, and other intangible factors may induce them to ignore risks that would otherwise deter a prudent individual from participation (Bok);
4. Certain levels of risk are, or ought to be, beyond consent (Bok);
5. Investigators reckless with respect to their own safety are wont to become reckless in other aspects of their investigations;
6. The autonomy of investigator–subjects might be tainted by various levels of institutional or peer coercion, or even by self-imposed psychological pressures (Dagi and Dagi); and
7. Large-scale, unregulated autoexperimentation might subvert accepted guidelines for the protection of human subjects under other experimental conditions.

The apparent contradiction between concerns (3) and (4), on the one hand, and the respect and admiration traditionally accorded to martyrs and heroes in Western society on the other, is not easily reconciled.

Finally, because most scientific research is now done in teams, the simple model from earlier days of a lone researcher experimenting upon himself does not fit all current autoexperimentation. “Group autoexperimentation” can involve vulnerable subjects when junior investigators, students, or laboratory technicians participate as subjects. Some recent research ethics policies addressing autoexperimentation reflect concern for such investigator–subjects.

Policies and Regulations

While it is generally agreed that institutions are ultimately responsible for the regulation of all forms of experimentation carried out within their jurisdiction, there is no consensus regarding how—or even whether—autoexperimentation should be regulated. The Nuremberg Code tacitly encourages autoexperimentation through the provisions of Article 5: Perilous human experimentation is prohibited “except, perhaps, in those experiments where the experimental physicians also serve as subjects” (Germany [Territory Under Allied Occupation]). The World Medical Association’s Declaration of Helsinki does not address autoexperimentation directly, but does say that responsibility for the subject always rests with a “medically qualified person,” never on the subject (p. 15–16), and that, when the subject is in a dependent relationship with the researcher, informed consent should be obtained by a physician who is not engaged in the investigation and is “completely independent” of the relationship (p. 16). The U.S. National Institutes of Health promulgated a code for self-experimentation “to provide the same safeguards for physician–subjects as for the normal volunteer” (Altman). The Office for Protection of Research Risks of the U.S. Department of Health and Human Services has ruled that autoexperimentation is subject to the same regulations as other human research, including review by institutional review boards (IRB).

Some institutional ethics codes and policies now advise against or even prohibit autoexperimentation, even when it takes the form of “group” autoexperimentation, and involves residents, students, or employees. The *IRB Guidebook* issued by the Office for Human Research Protections of the U.S. Department of Health and Human Services suggests advertising for subjects, rather than recruiting students directly, and notes that some universities prohibit or severely restrict student participation. The research ethics policy of Massachusetts General Hospital is more stern: “Studies of volunteers in the investigator’s own department or who are the investigator’s students should be avoided and will usually be disapproved by the Human Research Committee because of the subtle coercive factors that could be present in even the most harmonious situations.” The University of Maryland Baltimore County requires IRB approval to enroll students and employees.

Conclusion

No act of autoexperimentation, no matter how worthy or well intentioned, should be sanctioned until three conditions are fulfilled: (1) The proposed experiment has been fully described; (2) potential sources of coercion influencing the experimenter have been investigated and excluded; and (3) the institutional and social consequences of the experiment have been thoroughly explored, particularly with respect to risks such as the appearance of condoning inconsistent standards for the protection of human subjects. In most cases, fulfillment of these conditions will result in autoexperimentation being held to the same standard of review as any other forms of human investigation. These conditions are expressly designed to protect both the experimenter–subject *and* the institution, in equal measure.

The decision-making process associated with autoexperimentation should, therefore, involve peer review, and it should accord with established criteria for determining the acceptability of experimental protocols. At the very least, judgments about the permissibility of autoexperimentation must weigh questions of risk, benefit, voluntariness, and scientific significance, as well as the more elusive issues comprehended by the term *institutional interests.* While the requirement for institutional review may induce some scientists to experiment on themselves outside the scientific mainstream, this effect is unlikely to prevail and, as a practical matter, is virtually impossible to repress.

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SEE ALSO: *Autonomy; Harm; Paternalism; Research, Human: Historical Aspects; Research, Unethical*

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AUTONOMY

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The concept of autonomy in moral philosophy and bioethics recognizes the human capacity for self-determination, and puts forward a principle that the autonomy of persons ought to be respected. At this level of generality, there is not much with which to take issue; a full account of autonomy must further define self-determination and state how and to what extent autonomy should be respected. Autonomy as a capacity of persons must be distinguished from autonomy as a property of actions and decisions, for a person with the capacity for autonomy may act nonautonomously on particular occasions, for example, a person who is coerced to do something. Autonomy as a fundamental value and a basic right is part of the moral and political theory of liberal individualism. According to this view, autonomous individuals are the ultimate source of value: The basis for an action, social practice, or government policy to be right or good is in the values, preferences, or choices of autonomous individuals. In social philosophy, individual autonomy as a basic value and a fundamental right is in tension with community values, such as caring for others, promoting the good of society, and preserving and enhancing the moral practices of society. In clinical bioethics, the right to autonomy of individual patients is in tension with healthcare professionals’ obligations to benefit patients. These conflicts will be examined in what follows.

Autonomy as Capacity

There are three elements to the psychological capacity of autonomy: agency, independence, and rationality. Agency is awareness of oneself as having desires and intentions and of acting on them. (Desire includes inclinations, aversions, wants, and similar terms.) When people have a desire for some state of affairs, they form an intention to do what they believe will bring about the desired state of affairs; further, they want their desire to determine their action (Benn; Haworth).

The capacity for agency distinguishes persons from inanimate objects and from nonhuman animals. Inanimate objects can be affected by objects and conditions external to them, as can persons, but unlike persons, inanimate objects cannot be said to act on desires. Nonhuman animals have desires, but there is no (noncontroversial) reason to believe that they have the capacity for self-consciousness that is manifest in having an awareness of desires and wanting them to be effective in action. Agency does not imply that persons are never influenced by external forces or that persons never act impulsively. It is an account of how persons are able to act and not how they always act.

Independence is the absence of influences that so control what a person does that it cannot be said that he or she wants to do it. This may seem a feature of an autonomous action rather than an element of psychological capacity. However, there are cases in which a person’s course of life is under constant threat of violence from others, and the person acts always to avoid harm: war, poverty, abusive relationships, police states. When the whole of a person’s beliefs, plans, self-image, and ways of relating to others are the result of unrelenting coercion and manipulation, then that person has little or no capacity for autonomy.

Autonomy also requires that persons have an adequate range of options. Coercion and manipulation limit options, but options are also limited by social and physical environments. If a person’s options are numerous and noncoerced but are trivial in relation to what is valued by the person, then there is no capacity for autonomy in a significant sense (Raz). This would be the case in a totalitarian, caste, or slave society where a combination of coercion and ideology suppress the aspirations and real options of a segment of the members of the society. A full account of the conception of autonomy must distinguish external influences that defeat autonomy from external influences that are consistent with being autonomous. The former includes coercion and manipulation, and the latter includes persuasion and the normal limitations of physical and social environments.

The third element of the capacity for autonomy is *means-end rationality,* or *rational decision making.* In addition to the self-consciousness of agency, the capacity for rational decision making requires a person: (1) whose beliefs are subject to standards of truth and evidence; (2) with ability to recognize commitments and to act on them; (3) who can construct and evaluate alternative decisions; (4) whose changes in beliefs and values can change decisions and actions; and (5) whose beliefs and values yield rankings of action commitments. Another way to understand rationality as an element of the capacity for autonomy is as the capacity for reflection on desires. A rational person can have a desire for or fear of something, such as a desire for food or a fear of surgery, and also have the wish that he or she not have that desire or not be moved by that fear (Dworkin, 1976, 1988; Childress). Persons who lack the psychological capacity for rational decision making are those who are severely mentally ill—paranoiacs, compulsive neurotics, schizophrenics, and psychopaths. Such persons have the capacity for agency, that is, they are aware of acting on their desires, but they fail to meet one or more of the above conditions. For example, a paranoid patient who persists in a delusion that the healthcare professionals are Martians attempting to capture him is unable to adjust beliefs and actions to a reality confirmed by evidence (Benn).

Principle of Respect for Autonomy

Principles that support autonomy can be directed at the everyday relationships and encounters between persons; at the constitution, laws, and regulations of a nation-state; and at the policies of institutions such as hospitals, insurance companies, schools, and corporations. What ought to be done to respect autonomy will not be the same at all these levels and will be a function of a broad social ideology.

The minimal content for a principle of respect for autonomy is that persons ought to have independence, that is, be free from coercion and other similar interferences. John Stuart Mill made this the main principle in *On Liberty* (1947): No one should interfere with the liberty of action of another except to prevent harm to others. This obligation not to coerce others is defensible as an obligation binding on individuals, private organizations, and governments. Mill defended his principle of liberty, not because he believed that there is a fundamental right to autonomy nor that autonomy is valuable in itself, but because the recognition of liberty is supported by the principle of utility. This principle is that an action or policy is right to the extent that it promotes the greater happiness for the greater number. However, securing negative liberty does not establish autonomy as fundamental in moral theory. Other philosophers have gone further than Mill in their defense of autonomy.

The most widely quoted principle of respect for autonomy is one of Immanuel Kant's versions of the categorical imperative: "Treat others and oneself, never merely as a means, but always at the same time as an end in himself" (p. 101). This is frequently expressed as treating others as persons, and its distinctive Kantian claim is that others should be treated as rational beings who have their own ends. A further explanation of this principle is that persons should be seen as having interests in two senses. First, interests in those things that are a benefit to nearly everyone, for example, being free of pain, not being killed, being saved from dying. A physician can treat a patient without that person's consent and still protect these interests. Second, autonomous persons "take an interest" in things, that is, have preferences, projects, and plans. Acting only with concern to serve interests in the first sense, as is sometimes alleged against uses of the principle of utility, is not sufficient for respecting another's autonomy; we must also discover and take into account the individual's values and objectives (Benn). For example, a physician may believe that a surgical procedure is an effective treatment to relieve the pain of a patient's ulcer, but the patient may have a greater aversion to the risks of surgery than the physician does, and would prefer a restricted diet and medication. To not solicit, or to ignore, the patient's preferences in this matter would not respect his or her autonomy.

Autonomy, Rights, and Liberty

The concept of rights presupposes that right-holders are beings who have the capacity for autonomy, who make choices and can use discretion to exercise a right or not. Basic liberties in a liberal democracy are protected by constitutional and other legal rights. The idea of a right has three elements: the right-holder (the person who has the right); the object of the right (the activity or thing that the right-holder has a right to); and the duty-bearer (the person or institution who must do what the right requires). Negative rights are rights not to be interfered with; for example, everyone has the right not to be given medical treatment without consent, and all healthcare providers must respect this right. Positive rights are rights that a person be provided with something—for example, the right of all senior citizens in the United States to Medicare payment for healthcare, a right that is binding on government agencies and healthcare providers.

Recognizing the negative right to autonomy imposes on everyone the obligation not to coerce or otherwise interfere with the action of another. This protection of autonomy is not as costly to social institutions as recognizing positive rights to autonomy. If there is a positive right to *X*, this means that someone is under an obligation to provide *X* to the right-holder(s). For example, if every citizen has a fundamental positive right to the best-quality medical care, then the state must provide full access to medical care to all citizens. While there cannot be a positive right to autonomy per se—for autonomy as capacity is not something that can simply be given to persons who do not have it—there can be rights to other things that are required for, or supportive of, autonomy. Among them are rights to a decent minimum of healthcare, education, a decent standard of living, political participation, freedom of inquiry and expression, and equal opportunity to compete for positions in society. These goods contribute to autonomy in two ways: First, they make possible the development of the capacity for autonomy; second, they make autonomy meaningful by establishing the personal and social powers and range of options for autonomously chosen projects and plans. Discrimination against minorities and women decreases their autonomy by explicitly excluding them from desirable positions in society and by implicitly agreeing to the limited range of options offered to minorities and women.

Autonomy as an Ideal

There is no sharp line separating accounts of autonomy as an ideal from autonomy as an actual capacity of persons. Autonomy can be described as a high level of self-determination that few persons will actually achieve, and yet it can still be regarded as a capacity for all persons, if it is believed that all persons under suitable conditions could acquire it and use it to direct their lives. Views that describe autonomy at a level that nearly all normal adult persons can and do exercise are views of autonomy as capacity, and views that describe it at a higher level are accounts of autonomy as an ideal.

Autonomy as an ideal will center on a person's use of the capacity for deliberation and reflection. The person who realizes the ideal of autonomy is, first, one who is consciously aware of having the capacity, someone who believes that he or she can use it to shape his or her life. Second, the autonomous person will make particular decisions with a sense of control—creating and evaluating options. That person will also reflect on how values, preferences, attitudes, and beliefs received in the socialization process function in his or her own decision making, examine the kind of person this makes him or her, consider alternatives, and make a commitment to accept or try to alter who he or she is. This is of course a matter of degree; like every virtue, it can be realized well and thoroughly or in some small measure. The ideal of autonomy does not require individuals to make conscious, deliberated decisions before every action. A person who has accepted a set of preferences, beliefs, and attitudes can respond without much thinking to common situations that fall into recognized patterns.

Autonomy of Actions

In a clinical setting, it is often important to determine whether a patient's decision regarding treatment, or the decision of a proxy in the case of an incompetent patient, is autonomous. A person who has the capacity for autonomy may, for a variety of reasons, not act autonomously on a particular occasion. Determining whether a particular action or decision is autonomous is a matter of how the three elements of the capacity for autonomy (agency, independence, and rationality) are involved in the process of deciding. The autonomy of actions is a matter of degree because independence and rationality are matters of degree, though agency is not.

Ruth Faden and her colleagues describe the three elements of autonomy as intentionality, freedom from controlling influence, and understanding. They point out that controlling influences and understanding can be seen on two independent continua. An action can be performed within the range of full understanding to full ignorance, and within the range of completely uncontrolled to completely controlled.

Bruce Miller views the autonomy of actions and decisions on four levels: (1) as free action (agency and independence); (2) as authenticity (the decision is consistent with what is known about the person's values, preferences, and plans); (3) as effective deliberation (rationality); and (4) as moral reflection (deliberation about one's values, preferences, and plans). The decision of a patient may be autonomous at one or more, but not all levels. For example, a patient who accepts a recommended treatment without reflecting much about the decision, acted autonomously at the level of free action, and perhaps authenticity, but not at the levels of rationality and moral reflection.

The legal concept of competence is closely related to the concept of autonomy. A competent person is one who has the capacity for autonomy, and a competent decision is one that is autonomously made.

David Jackson and Stuart Youngner present six cases of decision making in an intensive-care unit that "illustrate specific situations in which superficial preoccupation with the issues of patient autonomy and death with dignity could have led to inappropriate clinical and ethical decisions …" (p. 407). In one of the cases, a patient with multiple sclerosis appeared to autonomously refuse further lifesaving treatment following a suicide attempt. However, psychiatric evaluation showed that the patient had become depressed and withdrawn at the time his wife and sons began spending time with his mother-in-law who had been diagnosed with inoperable cancer.

Jay Katz has said that insufficient attention has been given to the unconscious and irrational motivations of behavior. It is not only patients' motivations that should be examined, but physicians' as well, for example, their denial of uncertainty. Whether a patient's decision to consent to or refuse treatment is autonomous depends on more than the patient's statement of decision and reasons. Physicians and patients must engage in conversations; physicians are obligated to facilitate patients' opportunities for reflection to prevent ill-considered decisions, and patients are obligated to participate in the process of thinking about their choices. The U.S. President's Commission (1982) echoes this view in its discussion of the importance of communication between patient and health professional to attain shared decision making based on mutual trust.

Privacy, Informed Consent, and Paternalism

Autonomy as a fundamental right is used to justify rights to privacy, confidentiality, refusal of treatment, informed consent, and a decent minimum of healthcare. The legal right to privacy has two components. The right to control information about oneself is protected in medicine as the patient's right to confidentiality of information gained by health professionals. The right not to be interfered with and to make one's own decisions is protected in medicine as a competent patient's right to refuse recommended treatment and as the obligation of health professionals to obtain a patient's informed consent to treatment. Informed consent requires that a patient be informed of a recommended treatment and of the options for treatment and their likely consequences, and that the patient give express permission for a treatment (often in writing). The right to autonomy also requires that patients be told the truth about their medical status and prognosis, that their questions be answered, and that they receive assistance from healthcare providers in making rational decisions. Meaningful exercise of the right to autonomy in living requires that individuals possess physical and psychological capacities within the normal, human range. So the positive right to autonomy supports a right to a level of healthcare that will return and maintain a person to the normal range of functioning. This includes acute care, for example, repair of a broken bone; chronic care, for example, treatment of diabetes or heart disease; and supportive care for permanent disability, for example, wheelchairs for paraplegics.

Paternalism in healthcare is treating a patient against his or her wishes on the grounds that the healthcare provider is professionally obligated to provide care that will benefit patients, and that the healthcare provider knows better than the patient what is good for the patient. When paternalism is justified, it overrides patient autonomy, at least partially. An example of justified paternalism could be when a physician does not accede to a patient's refusal of emergency treatment because the patient believes he or she will surely die.

Criticisms of Autonomy

Some authors (Clements and Sider; Callahan; Thomasma) have criticized the centrality of autonomy in medical decision making. Their argument states that the primary obligation of healthcare providers is to maintain and restore health. There are two aspects to this claim. First, if patient autonomy is given primacy over the obligations of health professionals, physicians and other providers may violate their obligation to maintain and restore the health of patients; for example, a patient may refuse a treatment that will save his or her life or prevent a serious illness. These conflicts between autonomy and patient benefit have often been decided by courts, usually in the form of a request by a terminally ill patient's family member, or other agent, that life-preserving treatments such as respirators be withdrawn, a request denied by physicians who cite their obligation to preserve life.

A second aspect of the criticism of autonomy recognizes the centrality of patients' values and wishes in cases of deciding whether to forgo life-preserving treatment for a terminally ill patient, but other sorts of medical-care decisions depend less on respecting patients' rights to autonomy and more on the value of restoring and maintaining the capacity for living a meaningful life. In this sort of case, autonomy is secondary to principles of beneficence, compassion, and caring.

Defenders of autonomy can make several replies to this critique. (1) Some of the attacks on autonomy wrongly assume that it is simply a principle of negative freedom, that is, the right not to be interfered with. (2) The claim of the centrality of patient autonomy in medicine does not imply that it is the only value. The principles of beneficence or nonmaleficence may, in some circumstances, justify paternalism. (3) Autonomy cannot be ignored in medical decision making. Knowing what will be most beneficial for a patient often requires input from the patient on values, objectives, and preferences. This is true not only in morally difficult situations that call for a decision about preserving the life of a terminally ill patient, but in less dramatic cases as well, for example, whether a patient should have surgery for a condition that causes minor discomfort and dysfunction but will not develop into something more threatening to health, or whether the patient should simply "live with" the condition. In cases of acute and severe injury or illness where there is clearly a best treatment that will almost certainly restore the patient to health, it can usually be safely assumed that whatever else the patient values, he or she will value the restoration of health, and hence, discussion of the relative value of options and their consequences is not required to respect the autonomy of the patient.

Criticisms of autonomy have also been launched from a broader, communitarian perspective (MacIntyre; Sandel; Callahan). Communitarians charge that the political theory of liberal individualism states that individuals are fully self-determining and that rights to autonomy are the primary or sole standard for individual behavior, institutional practices, and government policy. Communitarians object to liberal individualism on several grounds. First, the socialization process determines, or shapes, the values and preferences of individuals, hence, the idea of autonomously chosen values is factually incorrect. Second, an individual's actions, desires, and objectives are comprehensible only within the context of social conventions and institutions. For example, a person cannot report that he or she is thinking about depositing a check without the conventions of language and the institution of banking. Third, the view that an autonomous individual chooses his or her own values, preferences, and desires presupposes a self that does the choosing. This self will have to have a core of values with which to choose, in which case either there are values not autonomously chosen, or it is inexplicable how individuals come to have a set of values. Communitarians also claim that liberal individualism regards persons as separate from others in the sense that individuals have no obligations to others or society that are not voluntarily assumed, other than the obligation to respect the individual rights of others. A society that respects only the autonomy rights of all its members is not morally complete. A good society must recognize obligations to help others; its members must have virtues such as compassion, caring, and love, and they should recognize a commitment to society to maintain social practices and institutions that establish and promote these obligations and virtues (Callahan).

There may be theories of autonomy that are susceptible to these criticisms, but the fundamental value of autonomy can be defended without embracing such versions of liberal individualism (Sher; Taylor, 1985). The conceptions of autonomy presented above recognize that persons are social beings whose values and preferences are shaped by society and that the capacity for autonomy is itself socially determined. Being autonomous requires language and reason, and these abilities are not possible without socially given practices and standards. Reflecting on socially given values and preferences and either accepting them as one's own or changing them in some measure, which is a feature of autonomous persons, cannot be done unless there is a social environment that encourages autonomy. A free society makes autonomy possible.

However, a society in which no one does more or less than respect everyone else's liberal rights, in which there is no caring, love, or friendship and no neighborhood associations, political parties, or civic groups, is not one we would want, though it may be a liberal society (Gutmann). On the other hand, a society organized to promote civic virtues and obligations such as beneficence, caring, and compassion, but which does not recognize a right of individuals to be different, to make their own decisions about matters of importance to them or to find a style of life that makes them happy, is also not one we would want. Love and care can be stifling if they do not recognize an individual's own view of what his or her good is. Finally, a defensible theory of the nature and value of individual autonomy will fall between radical individualism and extreme collectivism. It must explain the obligations to create and maintain social and political institutions that support the exercise and flourishing of autonomy. It must explain how the exercise of autonomy depends upon the opportunity range and values given in the traditions and structure of society. It will also recognize other fundamental values and explain their place in decision making.

In the early period of contemporary medical ethics, much attention was on medical paternalism in cases of life-and-death decision making for terminally ill patients and on what can be called "medical opportunism" in research on human subjects. Critics of these practices brought the rights of patients and subjects to the forefront of medical ethics. In a climate of concern for allocation of healthcare resources and other issues of social policy, autonomy appears less frequently in medical ethics literature than do moral concepts such as justice, fairness, equality, economic efficiency, and cost-containment. This shift in issues should not lead to the view that autonomy has lost its importance in moral and social theory and in bioethics.

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SEE ALSO: *Beneficence; Coercion; Conscience; Ethics: Social and Political Theories; Freedom and Free Will; Human Dignity; Human Rights; Informed Consent; Justice; Professional-Patient Relationship; Research Policy: Subjects; Sexism*

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B

BEHAVIORISM

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I. History of Behavioral Psychology
II. Philosophical Issues

I. HISTORY OF BEHAVIORAL PSYCHOLOGY

The earliest human communities undoubtedly appreciated the systematic application of rewards and punishments as an effective means to control behavior. The domestication of animals throughout prehistory, and the numerous early historical references to the proficiency of animal trainers, further establish a form of behavioral psychology as the most venerable of the folk psychologies. Thus, if the term *behavioral psychology* is taken to mean only a set of techniques useful for the prediction and control of behavior, then its history is coeval with human history.

As it is generally understood, however, behavioral psychology is not merely a collection of methods for controlling behavior. It also represents a judgment on the nature of psychology itself—a position informed by identifiable traditions within philosophy and the philosophy of science, as well as by the larger scientific context within which psychology seeks a proper place.

Understood in this light, the subject has its origins in the first great age of modern science, the seventeenth century—the century of Francis Bacon, Johannes Kepler, Galileo, Thomas Hobbes, René Descartes, and Isaac Newton, to mention only some of the more celebrated figures. Setting aside the many and fundamental conceptual and scientific disagreements of this era, a coherent theme exists; namely, that an unprejudiced and objective inquiry into the operations of the natural world will yield lawful and useful knowledge. The older world of logical analysis, occult powers, hidden forces, revealed truths, and scriptural authority was now to be replaced by the more modest—but more solid—discoveries of direct experience. The knowable cosmos, from this perspective, is just the observable cosmos.

The two divisions of science most fully developed in the seventeenth century were mechanics and optics, and both of these served as models and metaphors for phenomena only poorly understood. The well-ordered Hobbesian state, the clockwork precision of the Newtonian heavens, and Descartes's stimulus-response psychology are all based upon the metaphor of the machine, as well as on the conviction that fuller explanations in these areas will be drawn from the science of mechanics. Descartes's (1596–1650) psychology of animal behavior, which he extended to include those aspects of human psychology not dependent upon language and abstract thought, is entirely mechanistic and behavioristic, even in the more modern senses of these terms. His explanations for all animal, and most human, behavior were grounded in what would now be called instinctual reflex mechanisms and acquired (but still reflexive) habits. The nervous system, in this view, is an elaborate input-output system organized in such a way that specific patterns of stimulation lead to organized and adaptive patterns of behavior. The tendency to focus on Descartes's famous dualistic solution to the mind–body problem, and his emphasis on the cognitive, rational, and linguistic uniqueness of human beings should not obscure the essentially behavioristic content of his overall psychology.

Criticized in Descartes's own time by Thomas Hobbes and Pierre Gassendi, among others, Cartesian psychology was stripped of its introspective features in the eighteenth century, where it survived within progressive circles as a primitive biological psychology. In British philosophy, David Hartley (1705–1757) stands out in the movement to adapt Newtonian and Cartesian mechanistic principles to the needs of an emerging mental science. His *Observations on Man* (1749) provides a richly argued and illustrated defense of a behavioristic psychology grounded in (Humean) associationistic principles operating within the sort of reflex framework advocated by Descartes. In France, Julien de La Mettrie's *L'Homme-machine* (1748) presented an uncompromisingly materialistic psychology, at once antispiritual, reductionistic, and behavioristic. The circle of French philosophes included stridently mechanistic theorists (e.g., Paul-Henri Dietrich, Baron d'Holbach), but also those with a radically environmentalistic orientation (e.g., Claude-Adrien Helvétius), who insisted that social and familial pressures were totally responsible for human psychological development.

As the philosophes and natural philosophers of the eighteenth century were assembling strong rhetorical arguments on behalf of a fully naturalistic psychology, the medical and scientific communities were broadening and deepening its empirical foundations. Robert Whytt's (1714–1766) pioneering studies of spinal reflexes are illustrative. These were accomplished while La Mettrie was offering little more than polemical defenses of psychological materialism. Whytt's research exemplified the steady, modest, and entirely experimental approach of scientists loyal to what they took to be the methods of Newton and Bacon. Early in the nineteenth century, programmatic research of this sort had unearthed the distinct sensory and motor functions of the spinal cord (the Bell-Magendie Law) and had put the mechanistic-behavioristic perspective on firm anatomical foundations. By the 1830s, Marshall Hall (1790–1857), in a tradition of Scottish medical science that includes Whytt and Charles Bell, would put the concept of "reflex function" at the very center of a nascent biological psychology that would influence the ultimate character of modern behaviorism.

It should be noted that it was during this same period (1750–1850) that the so-called animal model became accepted, and, in the early decades of the nineteenth century, a single laboratory might perform vivisection on *thousands* of animals, none of them anesthetized. Cartesianism, in still another sense, was the gray eminence here, fortifying the scientific community in the belief that nonhuman animals were merely a species of machinery. This perspective, shorn of its horrific surgical practices, would survive in the confident antimentalism of twentieth-century behaviorism.

By the middle of the eighteenth century, the medical clinic was also yielding an ever more coherent account of the causal efficacy of the nervous system in human sensory and behavioral functions. By the end of the century, and as a result of his own original and exhaustive studies (including postmortem examinations of exceptional as well as feeble and felonious persons) Franz Joseph Gall (1758–1828) would offer the "science" of phrenology as a developed and systematic psychology—a psychology grounded in the principle that all sensory, motor, affective, and cognitive functions are brought about by conditions in the brain and its numerous subsystems. Once again, the evidence all pointed to a quasi-mechanistic system, both complex and law-governed, functioning in such a manner as to adjust (or fail to adjust) behavior to the demands of the environment.

The Evolutionary Perspective

By the time Charles Darwin published *On the Origin of Species* (1859), the "Darwinian" perspective was already dominant in scientific and progressive circles. Adam Smith's *The Wealth of Nations* (1776), Jacques Turgot and his party of "physiocrats," and the writings of any number of philosophes point to a (more or less) settled Enlightenment position: The free movement of ideas, goods, and persons—constrained by no more than "natural" forces—produces an ever more refined, successful, and robust stock.

But Darwin's monumental contribution went beyond this general perspective and reached the level of a developed and richly integrative theory. Its implications for psychology were clear: As there is no sharp line dividing places along the broad evolutionary continuum that humanity shares with the balance of the animal economy, there is no reason to confine inquiries into complex psychological functions to the study of human beings.

Antecedents in Psychology

Darwin's evolutionary theory emphasized differences in degree, not in essence. Thus, the most complex human psychological attributes could, in principle, be examined in a more systematic fashion by studying their simpler, but kindred, manifestations in nonhuman animals. Studies of this sort, it was assumed, would establish psychology's own independent scientific status. As Herbert Spencer (1820–1903) declared:

> The claims of Psychology to rank as a distinct science … are not smaller but greater than those of any other science. If its phenomena are contemplated objectively, merely as nervo-muscular adjustments by which the higher organisms from moment to moment adapt their actions to environing coexistences and sequences, its degree of

> specialty, even then, entitles it to a separate place. (*Principles of Psychology,* p. 141)

In the patrimony of Darwin, and influenced chiefly by his *Descent of Man* (1871), specialists in animal psychology appeared before the end of the nineteenth century and made their own contributions toward a behavioral science. For all his anthropomorphic tendencies, George Romanes (1848–1894), in his *Animal Intelligence* (1882) and *Mental Evolution in Animals* (1883), put the study of animal behavior on the map of the new psychology. All that was needed to prepare this Darwinian psychology for adoption by the forthcoming generations of behaviorists was to strip it of just this anthropomorphism. C. Lloyd Morgan, in his *Introduction to Comparative Psychology* (1894), delivered his famous canon:

> In no case may we interpret an action as the outcome of the exercise of a higher psychic faculty, if it can be interpreted as the outcome of the exercise of one which stands lower in the psychological scale. (p. 53)

Thus, with this insistence on explanatory parsimony, did the "ism" in behaviorism begin to take shape.

It is customary, if misleading, to date the birth of experimental psychology with Wilhelm Wundt's founding of the discipline's first university laboratory at Leipzig in 1878–1879. Wundt (1832–1920) was perhaps the discipline's most prolific writer. His texts, which were wide-ranging and immensely influential at the time psychology departments were being formed in Europe, England, and the United States, emphasized experimental over ethological (naturalistic) modes of inquiry. But the reading of Wundt was rather selective. In his less-consulted multivolume *Völkerpsychologie* (best rendered as "anthropological psychology") he developed and defended the nonexperimental and essentially historical anthropological mission of psychology, drawing attention to the limits of reductionistic strategies and explanations. Even with this broadened perspective, Wundt remained loyal to the scientific views of his age, acquired in his medical education and as he assisted the great Hermann von Helmholtz. In these respects he was representative of an entire generation of thinkers committed to the scientific study of psychology and the abandonment of purely philosophical modes of analysis, wherever the scientific and experimental alternative was practicable.

In the Wundtian tradition, however, the subjects of scientific inquiry were taken to be mental processes and functions—those now generally dubbed *cognitive.* Moreover, although he did much to advance comparative psychology in his textbooks, the bulk of his theoretical writings, and all of the research undertaken in the Leipzig laboratory, focused on *human* psychology and the development of a *science of mental life.* To this extent, Wundtian psychology formed a path distinct from that so heavily trod by the neurophysiologists, anatomists, and clinicians, a path more readily associated with the introspective philosophical psychologists (e.g., John Locke and David Hume). Nor was it clear that Wundtian psychology had a place within the larger naturalistic context of Darwinian science.

Labels offer useful shortcuts, but they can be misleading. It may be said, with ample qualifications, that the Wundtian perspective, at least in the hands of his most influential students (e.g., Edward B. Titchener), was structuralist. Any number of passages and entire chapters in books by Wundt are devoted to the (hypothetical) constituents or components of thought. And, if *structuralism* (according to which the task facing a scientific psychology requires an analysis of the structure of consciousness) and *functionalism* (which focuses instead on the functions served by the behavior of animals or the functions of the nervous system itself) are to be understood in essentially dialectical terms, it is also the case that Wundt's major works are not beholden to the idiom of functionalism. But his attention to the workings of the nervous system, his attempts to provide a loosely evolutionary framework for both human and animal psychology, and his problem-centered cognitive psychology are all anticipations of the functionalist psychology so explicit in the works of William James (1842–1910).

What is relevant here in the tension (real or apparent) between structuralism and functionalism in the history of modern psychology is the claim later made by John B. Watson (1878–1958) that behaviorism was to replace both. In significant respects, it may be said to have replaced both by merging the two rather than by fully rejecting either. Structuralism, which was never a central feature of Wundt's own agenda for the discipline, has this much in common with behaviorism: It is a reductionistic theory or strategy, according to which complex and psychologically significant ensembles can be analyzed into more elementary components. Further, both posit that the only valid evidence is the observable and repeatable evidence gleaned by laboratory investigations. For all their differences, then, behaviorism and structuralism, in their mechanistic and reductive commitments, were faithful to that "religion of science" launched in the seventeenth century.

Functionalism, of course, is the immediate precursor to behaviorism and even a version of it, depending on how the term is to be understood. One account of it is defended by Alexander Bain (1818–1903), the founder of the journal *Mind* and intimate friend of John Stuart Mill. In *The Senses and the Intellect* (1855) and *The Emotions and the Will* (1859), Bain argued that the discipline of psychology was to be advanced by merging its issues and findings with the science of physiology in such a way as to ground psychological processes in the functions of the nervous system. Functionalism, in this sense, is a function-based psychology whose general laws are derived from neurophysiology. From still another (but quite compatible) perspective, such as that defended by William James, the question to ask of any psychological process or phenomenon is what *function* it serves in the larger context of the organism's (person's) overall and long-term interests. The psychological event is explained when the functions it serves are delineated. These, in the most general sense, are *adaptive* functions, rendering the organism more successful in its transactions with the environment. In the writings of William James, this orientation is tied to a *pragmatism* that anticipates the central tenets of modern behaviorism.

Modern Behavioral Psychology

The Nobel Prize–winning research of Ivan Pavlov (1849–1936) addressed gastric physiology and the chemistry of digestion. But in the process of studying the formation and secretion of digestive enzymes, Pavlov discovered that initially automatic or innate reflex mechanisms could be controlled externally by associating them with specific events in the environment. His theories of *classical conditioning* were grounded in neurophysiology and were intended to replace the mentalistic approach of traditional psychology. In this aim he was joined by the American psychologist John B. Watson, widely regarded as the father of behaviorism.

In his influential essay "Psychology as the Behaviorist Views It" (1913), and in his widely read and cited *Psychology from the Standpoint of a Behaviorist* (1919), Watson waged relentless war on introspective psychology, structuralism, "folk" psychology, and the entire tradition of philosophical speculation regarding the nature of human nature. He insisted that the only proper subject matter of any science is directly observable events, which for psychology means observable *behavior.* In tying his recommendations to a version of the Pavlovian theory, Watson failed to produce the sort of behavioral psychology compatible with the functionalistic and pragmatic bent already dominant in America. But his writing did much to put mentalistic psychologies on notice and promote a seemingly objective, scientific, and descriptive discipline, practical in its aims and stridently antimetaphysical.

This much of the Watsonian legacy was accepted by the most influential figure in the history of behavioral psychology, B. F. Skinner (1904–1991). In numerous books and articles, in scores of laboratory demonstrations, and through a veritable legion of students and coworkers, B. F. Skinner dominated psychology in the United States and, indeed, much of psychology around the world, for a quarter of a century. From 1950 until the 1970s, specialists in a wide variety of psychological employments came to regard themselves as "behavioral scientists," adopting the idiom and perspective of "Skinnerian" psychology and fashioning methods and measurements akin to those of the "Skinner box" and the cumulative recorder.

As early as 1938, in *The Behavior of Organisms,* Skinner had argued for the independence of *behavioral* science from physiology or other (even if somehow related) sciences. The facts of observed behavior, he insisted, remain what they are, no matter what the nervous system is found to be doing, no matter what the genetic composition of the organism proves to be, and no matter what theory is invented or adopted to account for these facts. Taking his lead from the research of Edward L. Thorndike (1874–1949), Skinner devoted himself to the study of *operant,* or *instrumental,* behavior—the behavior that is instrumental in securing positive reinforcers or in avoiding aversive stimulation. Unlike Pavlovian reflexes (or *respondents,* in Skinner's terminology), operant behaviors actually operate on and alter the animal's environment. Behavior that results in positive reinforcement (food, for example) becomes statistically more probable. Nonreinforced behavior—behavior that has no systematic effect on the environment—simply drops out. Thus, behavior within an environment containing reinforcing contingencies is not unlike the evolutionary arena itself. Those behaviors that result in more successful adaptations survive, while those that do not are extinguished.

As developed by Skinner, behavioral psychology is a descriptive, empirical science—more akin to engineering, perhaps, than to physics—and is able to identify the conditions under which behavior is rendered more or less probable. Useless to this enterprise are theories laden with hypothetical processes, hidden variables, or private "states." Perhaps the most concise philosophical defense of the perspective was provided by Gilbert Ryle in *The Concept of Mind* (1949), in which the Cartesian "ghost in the machine" was analytically exorcised, leaving in its wake a collection of psychological attributes uniquely specified by observable behavioral events and dispositions.

Skinner's version of behavioral psychology, though the most influential, is but one of several developed in the twentieth century. The main points of division among various schools or types are three: (1) the level of explanation to be attained by a behavioral psychology; (2) the room within such a psychology for nonobservable (mental) events and processes; (3) the proper place of such a psychology within the larger context of the natural (biological) sciences. On each of these points, major and self-proclaimed behaviorists have taken positions at variance with Skinner's.

Clark Hull (1884–1952), for example, adopted the nomological-deductive model of scientific explanation. According to the dominant version of the model, an event is explained when it is shown to be deducible from a general law, not unlike explanations in classical physics. He attempted to develop a formal theory of behavior based on a number of hypothetical constructs (e.g., "habit-strength") and intervening variables (e.g., fatigue-substances generated by muscular activity). Hullian behavioral psychology is characterized by pages of mathematical equations expressing such relationships as that between learning and practice, between strength of response and magnitude of reward, or between speed of response and hours of food-deprivation.

E. C. Tolman (1886–1959) defended a form of *cognitive*-behavioral psychology that grounded explanations of problem solving on the part of nonhuman animals in such notions as "cognitive maps." Rats, for example, who learn the various turns in a maze and are later placed on top of the maze box will run directly toward the goal rather than retracing the successful learned paths. What the rats have, in Tolman's theory, is a map or representation of the situation, and very different patterns of behavior can be arranged to achieve the same results.

Yet other behavioristic psychologists, notably Karl Lashley (1890–1958), retained their commitment to the study of observable behavior, while insisting that a science of behavior had to be fully integrated into the brain sciences, and had to make contact with the well-established cognitive dimensions of human and animal psychology. In this, the influences and criticisms of such Gestalt psychologists as Wolfgang Köhler (1887–1967) wrought changes on the behavioristic outlook—or otherwise rendered the outlook itself dubious.

Ethical Implications

From the first, the Darwinian, reductionistic, and positivistic character of behaviorism targeted it for criticism from expected (humanistic) quarters. Yet, unlike the value-neutral orientation of much of modern science, behaviorists have tended to defend their perspective on ethical grounds. Both Watson and Skinner were explicit in this regard. Skinner's *Beyond Freedom and Dignity* (1971), though dismissive of traditional moral theories and their supporting "folk" psychologies, contended nonetheless that a behaviorally engineered society would achieve the most precious of the ends envisaged by ethical theorists. His work inspired the formation of several small communities organized around principles of operant conditioning, with desired behavior brought about without the moral tags of "praise" and "blame." His work also provided the theoretical and technical foundations for various "behavior therapies" applied to disturbances ranging from bed-wetting to catatonic withdrawal. Considered ethically, these methods would seem to be neither more nor less coercive than those arising within other theoretical contexts and employed for the benefit of consenting patients.

In viewing human nature as part of nature at large, and as impelled by the same evolutionary pressures faced by the balance of the animal kingdom, behavioral psychology is neither more nor less humanistic than, say, psychoanalytic theory or, for that matter, the contemporary neurocognitive psychologies that have all but replaced behaviorism. Skinner rejected moral theories grounded in deontological or transcendental arguments, but accepted the proposition that complex societies require the imposition of constraints, and that coercive principles and practices must be justified in ways conducive to a flourishing and productive life within such societies.

It was clear by the end of the twentieth century that the central precepts and methodology of behaviorism would be steadily overtaken and replaced by what is generally referred to as *cognitive neuroscience.* Though the term is new, the perspective is not, for it has been the guiding perspective within physiological psychology at least since early in the nineteenth century. Rejected is the claim that the chief sources of behavioral control are external to the organism. Rather, what is assumed is the evolution of the nervous system as "pre-wired" (though not necessarily "hard-wired"); that is, it is able to perceive the environment selectively, to code or represent it in quasi-computational ways, and to do so by way of distinguishable "modular" processes in the brain.

If cognitive neuroscience has overtaken behaviorism within the theoretical and experimental domains, the complexities of mental and social life have rendered it suspect in the wider realms of thought and action. Life, as depicted by Watson and Skinner and otherwise implicit in the very language of behavioral psychology, matches up poorly with the life actually lived by most human beings and many other species. In ignoring or depreciating the richly social, self-moving, and self-conscious dimensions of life—and thus the irreducibly moral terms that rational beings must invoke to live together in a principled way—the architects and defenders of radical versions of behavioral psychology have more or less resigned from the domain of ethical discourse.

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SEE ALSO: *Autonomy; Behavior Modification Therapies; Coercion; Freedom and Free Will; Informed Consent; Mental Health Therapies; Mental Illness; Neuroethics; Patients' Rights, Mental Patients' Rights; Psychiatry, Abuses of; Psychoanalysis and Dynamic Therapies;* and other *Behaviorism* subentries

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II. PHILOSOPHICAL ISSUES

Behaviorism involves two basic views: (1) the proper subject matter of psychology is not consciousness but the behavior of persons and animals, and (2) the proper goal of psychology is the prediction and control of behavior through "stimulus control." There are many forms of behaviorism, and they evoke varied philosophical responses. Behaviorism arose out of frustration with older, introspective approaches to mind and consciousness that appeal to direct awareness of mental states and processes, and out also of the desire to turn psychology into a proper natural or physical science with an empirical methodology and subject matter.

Methodological and Metaphysical Behaviorism

Methodological behaviorism does not deny the existence of mind and consciousness. Rather, it holds merely that such things are causally ineffective and irrelevant in psychology. To be scientific, psychology must adopt an empirical, scientific methodology applied to the empirical, physical subject matter of observable human behavior.

Metaphysical behaviorism of the sort espoused by John B. Watson (1878–1958) and his followers makes a much stronger claim. It denies the existence of mind and consciousness and proposes that all mentalistic concepts be properly defined (or redefined) in terms of observable behavior. Watson maintained that behavior can be explained entirely in terms of stimulus and response, without the intervention of mental or conscious events and activities. For Watson, all behavior is environmentally derived and cannot be explained by appeals to heredity, instincts, the unconscious, human nature, or internal predispositions.

Some behaviorists recognize two different kinds of observable behavior: external behavior, which is sometimes characterized as overt, external, or molar (pertaining to the whole); and internal behavior, which is alternatively called covert, implicit, deep, or central behavior. If *thinking* is defined as "talking" or "speaking," an account must be given of what transpires when people are thinking silently "to themselves." The wife of a philosopher once complained that she could never tell whether he was working or loafing. Many psychological processes and activities seem, at times, to involve no external behavior. Behaviorists may either deny the reality of private events or affirm that they involve internal behaviors or processes. Thus, thinking becomes "motion in the head," as Thomas Hobbes (1588–1679) put it, or "sub-vocal speech," as Watson suggested.

Behaviorism is usually associated with some form of metaphysical materialism, of which there are many varieties (Foss). When internal behavior is identified with neurophysiological activity, behaviorism becomes *central-state materialism,* or *neuromaterialsim,* according to which the reality of mental states and processes is identical with that of physical states and processes in the brain and central nervous system. This theory identifies mental processes with electrical and chemical processes within the central nervous system ("motion in the head"). Modern brain-scanning devices give indirect sensory access to these neurophysiological motions and processes, though not to the mental processes that are supposedly embodied in them. Brain scans can picture structures and electrochemical changes within the brain, but an enormous and highly controversial conceptual leap, or explanation gap, exists when these are designated as thoughts, feelings, volitions, or emotions.

Taking both consciousness and neuroscience seriously need not involve mind–matter dualism, which affirms that matter but not mind has spatial properties. If, contrary to the

Cartesian tradition, people's thoughts, feelings, and volitions are spatially extended, then they can be located within specific regions of the brain. Whether psychological events are identical with or merely correlated with brain events is at present unknown.

This discussion, however, concentrates on the behaviorism of John B. Watson, B. F. Skinner, and those philosophers of language who focus on observable acts, or on dispositions to behave in observable ways. It raises questions about whether behaviorism is or is not incompatible with presuppositions that are commonplace in ethical theory and bioethics.

Logical or Linguistic Behaviorism

Many philosophers are attracted to behaviorism's original emphasis on observable external behavior, either for metaphysical or methodological reasons. Some want to escape from Cartesian mind–body dualism—from "the ghost in the machine," as Gilbert Ryle (1900–1976) put it—though this may be done without resorting to behaviorism. Members of the positivistic Vienna Circle, an influential group of scientifically oriented philosophers who flourished in Vienna from the early 1920s to the mid-1930s, wanted to avoid introspective methodology, and so do those influenced by them. They are attracted to the behavioristic methodology of theoretically redefining mentalistic language in terms of external, overt, publicly observable behavior because of its compatibility with the empiricist, or verification criterion, of meaning: that meaning consists exclusively in sensory reference.

Logical, or linguistic, positivism attempts to analyze or redefine the meanings of concepts and beliefs in terms of sensory reference and verifiability. Many recent and contemporary philosophers with a bent toward this form of positivism have tried to formulate in observable behavioral terms the meanings of psychological concepts such as thought, understanding, intelligence, doubt, imagination, and memory, as well as the classes and manifold subclasses of feelings, sensations, pleasures, pains, emotions, desires, and purposes.

Gilbert Ryle, a prominent British linguistic philosopher, was convinced that ordinary language is a behavioristic language, and that ordinary meanings of psychological terms are behavioral meanings. Without denying the existence of inner mental events, he believed that the ordinary meanings of mental concepts can be captured by reference to observable behaviors (or the dispositions to manifest them), without appeal to private or privileged access. Most philosophers and psychologists since Ryle, however, have believed that psychological concepts in ordinary language and "folk psychology" cannot be analyzed purely behaviorally without an important loss of significance. Many see this as a reason for abandoning familiar psychological terminology for a technically or theoretically constructed psychological vocabulary. Others have found self-awareness to be too evident and significant to be abandoned, believing that a purely behavioral outlook only fosters trivialities and ignores the obvious.

Although Ludwig Wittgenstein (1889–1951), a highly influential linguistic philosopher, did not deny the existence of consciousness and its contents, features of his philosophy of mind can be interpreted to support a behavioristic outlook. He argued convincingly against private languages and purely private experience, contending that human infants originally learn to use psychological concepts by reference to behavioral criteria in a social setting, and that these criteria are themselves integral aspects of the meaning of such concepts. Few philosophers today would deny this intimate connection between mental concepts and behavior. Nevertheless, "How do we learn mentalistic concepts?" and "To what do mentalistic concepts refer?" seem to be very different questions.

Some of Wittgenstein's interpreters subsequently dropped his conviction that psychological concepts point to something internal and mental, adopting only the view that the meanings or referents of psychological concepts consist entirely in behavioral criteria. Thus, the meaning of *pain* consists solely in pain behaviors such as screaming, crying, or moaning, and internal states do not need external criteria, for there are no internal states. Psychological concepts are identical in meaning with their external criteria, just as good Watsonian behaviorists contended.

Objections to Behaviorism

Behaviorism has been criticized from many philosophical and psychological perspectives, and developments in psychology often have a significant bearing on philosophical issues raised by behaviorism.

PSYCHOLOGICAL AND PHILOSOPHICAL DIFFICULTIES. The technical language that behaviorism aspired to generate was certainly not ordinary everyday language, for it never lost sight of consciousness, its complexity, and its manifold contents, purposes, and values. Since the middle of the twentieth century, more and more philosophers, psychologists, neuroscientists, and psychotherapists have acknowledged the centrality of consciousness for their own activities. Consciousness is now seen as being complex, ranging from minimal awareness devoid of conceptual representation, through symbolic awareness, to self-awareness, while a great deal of nonconscious data-processing occurs (Gazzaniga et al.).

Consciousness and immediate self-awareness are indispensable for people to understand their uniqueness and their personal, ethical, professional, and therapeutic relations with each another. Initially, behaviorists aspired to explain what people do on a simple Pavlovian stimulus–response model; but the terms *stimulus, response,* and *behavior* have been used quite loosely. Muscles, glands, and organs (and who knows what else) react to external (and, they confessed later, to internal) stimuli; and no conscious processing or activities intervene. This view, however, proved to be too simple, too ambiguous, and too devoid of comprehensiveness, to be true—which does not deny that valuable lessons can be learned from the study of behavior.

Gestalt psychologists recognized that empirical stimuli or data are processed internally and holistically, and that no simple stimulus–response theory could explain how humans perceive continuous motion from discontinuous and still motion-picture frames. Noam Chomsky argued effectively that psychological conditioning and associationist learning theory, according to which learning occurs solely through repeated exposures that form connecting links, are too weak to account for the genetically prestructured dispositions of human infants to learn human languages—and for the creative and rule-governed ways in which languages are employed. Abraham Maslow (1971) reported that having a child of his own made behavioristic views of conditioned associationist learning look so foolish that he could not stomach them anymore. To Maslow, the presence of conscious, creative processing of information in his own children was too obvious to be denied. Cognitive psychologists emphasized the indispensability of conscious cognitive or conceptual maps in understanding how people understand, anticipate the future, plan ahead, and act accordingly. According to evolutionary psychology, the evolutionary process has prepared and predisposed people to act, feel, think, and choose in certain ways; and conscious comprehension, insight, information processing, and problem solving have immense significance for purposive and voluntary activity, adaptation, and survival.

The teleological (consciously purposive) and the intentional (consciously focused on an object) features of much psychological discourse cannot be accounted for by a purely descriptive language that completely eliminates teleology, intentionality, and all "final causes." Purposive acts, like trying to persuade psychologists that behavior is the only proper subject matter of psychology, cannot be redescribed as nonpurposive behaviors without losing essential meaning. Denying the existence of consciousness, purpose, or intentionality is refuted by that very act, which is a conscious, purposive, and intentional event.

Behaviorists are asked why they adopt and espouse behaviorism, why they want psychology to be strictly sensory and empirical, and why they want to control the behavior of others. They repudiate conscious rationality, and with it the possibility of justifying any beliefs on rational or scientific grounds. To behavioralists, all that people are and do is a product of stimulus control, which means that behaviorists are behaviorists only because they have been conditioned to be, not because the preponderance of evidence supports the theory.

Stipulating that psychological processes and events are identical with behavioral processes and events is self-contradictory, some critics argue, for two different things cannot be metaphysically identical. Responding that the psychological and the behavioral are only one thing, not two, begs the question. Critics also suspect that the identity of the mental and the behavioral (or the mental and the neurophysiological in central-state materialism) is established by decree, not by observation or scientific method. Watsonian behaviorists solve the problem of other minds by stating that no problem exists because there are no minds at all, while for Skinner's behaviorism, minds do not matter.

First-person self-knowledge based on direct introspective experience has been a great obstacle to the acceptance of behaviorism. To be sure, introspection is not always reliable and is often confused; but direct self-awareness is often quite clear and trustworthy. Individuals are not always mistaken about what they think, how they feel, or what they select. Critics of behaviorism contend that individuals know many things about themselves before, not after, they receive overt expression. For example, authors solve many conceptual problems before they express their ideas in writing. There can be thought without speech (silent thought) and speech without thought (e.g., a parrot's speech). Most people can tell whether they are feeling well or ill before looking into the mirror in the morning or bouncing their countenances off the countenances of others. Further, one can deceive others about one's mental states and processes by playing public roles that do not match one's private self-awareness. A person might be in great pain and yet sit passively and unresponsively in a dentist's chair. Short- and long-range plans are made without a purpose being overtly expressed, and a person can change his or her mind about many things with no one ever knowing.

Nonbehaviorists are convinced that people frequently know many things about their psychological states and processes that are not identical with, and find no expression in, overt behavior. Further, attempts to establish the identity or correlation of mentalistic concepts with behaviors must rely initially upon the self-reports of individual experimental subjects, as well as upon ordinary language with its imbedded folk psychology. When the brain regions and events are examined through brain scanners, they are not labeled as "thinking," "remembering," "hearing," or "seeing a rainbow." Once the initial connections are made, an immense amount of information can be derived about the intimate associations of consciousness functions with brain regions and electrochemical activities through neuroimaging, electroencephalograms, brain stimulation, and studies of genetics, or brain disorders and injuries, as well as by experimenting on individual subjects, both animal and human (Gazzaniga et al.).

Behaviorism, Ethical Theory, and Bioethics

Other objections to behaviorism arise from its incompatibility with concepts and beliefs that are presupposed in most ethical theories, people's common moral life, and the practice of bioethics. This suggests a choice: either to give up behaviorism or abandon much that ethics takes with utmost seriousness, such as consciousness, pleasure and pain, agency or autonomy, freedom, and human dignity, just as Skinner advocated.

CONSCIOUSNESS. Ethics asks questions about right and wrong, and about good and evil. The notions of intrinsic goodness (that which is desirable or valuable in itself or for its own sake) and intrinsic evil (that which is undesirable and to be avoided for its own sake) are of central importance to ethical theory. In teleological theories of right and wrong, right acts result in intrinsic goodness, while wrong acts fail to do so or produce intrinsic evil. Doing good and avoiding or preventing evil are momentous moral duties even in deontological theories (except for Immanuel Kant's). Doing one's duty usually, if not always, involves understanding and acting in accord with moral ideals and rules—none of which even exist, according to metaphysical behaviorism. Ethicists may disagree about answers to questions like "What acts are right or wrong?" or "What things are good or evil?" There is, however, agreement that no moral obligations and no intrinsic good or evil would exist in a world without consciousness. Moral right and wrong and intrinsic good and evil exist only in and for conscious active beings.

Almost all the philosophers who have considered the question agree that ethics would have no point in a world devoid of conscious beings. Yet Watsonian metaphysical behaviorism gives us just such a world—one in which all behavior is caused by external or environmental stimuli and no behavior is caused by inner conscious mental states and processes. Skinner's radical behaviorism may allow that some activities are spontaneous rather than environmentally caused, but these behaviors are repeated only if their consequences are positively reinforcing. (He doesn't use the terms *pleasurable* or *enjoyable.*) When Skinner admits the existence of inner mental states and processes, he denies their causal efficacy in explaining behavior and providing reasons for action, as well as their relevance to the science of psychology. They are always the effects of stimuli, never the causes of behavior; they exist only epiphenomenally, that is, as ineffective appearances. Scientific psychology can disregard them, for scientifically knowing, controlling, and predicting behavior do not require them.

Some behaviorists retain the notion of consciousness and redefine it in purely behavioral terms—as overt wakeful behavior, for example, as opposed to sleep behavior. Most ethicists, however, are convinced that ethics is concerned with wakefulness itself, as directly experienced by conscious subjects, not merely with wakeful behavior and muscle jerks as experienced by external observers.

Medical professionals are concerned primarily with wakeful consciousness itself, not solely with its public or overt expressions. They often prescribe analgesics or other pain management strategies for suffering patients. During invasive medical procedures, general anesthesia is administered, not to circumvent external pain behaviors, but to prevent conscious pain. After a lapse of consciousness, a patient's return to awareness is eagerly awaited. Lost consciousness is the tragedy of comatose patients, while death involves the irreversible loss of embodied consciousness and its necessary physiological conditions. The seriousness of these medical interests seems to be quite incompatible with a concern only for overt behavior.

PLEASURES AND PAINS. Philosophical ethicists are keenly interested in consciously experienced pleasures and pains, and medical professionals give considerable attention to conscious pains, if not also to pleasures. Most ethicists believe that pointless pains (those that are not necessary for the achievement of goals knowingly and freely accepted) are to be avoided if possible; and most recognize that happiness, conceived of as a surplus of conscious pleasures over pains for extended periods of time, is one of the great goods of life (if not the only good, as hedonists maintain). Medical professionals accept the duties of relieving pain and not inflicting unnecessary conscious pain as serious professional obligations. Patients want relief from real pains, not merely the suppression or elimination of pain behaviors. *Pleasures* usually means "conscious inner qualities of feeling that persons or other sentient beings normally wish to cultivate and sustain for their own sake," and *pains* means "conscious inner qualities of feeling that persons or other sentient beings normally wish to avoid and eliminate for their own sake" (Edwards, pp. 74, 92–96).

Although pain behaviors are indispensable for describing or communicating inner sufferings to others, most ethicists and bioethicists do not believe that overt pain behaviors, completely divorced from conscious suffering, are intrinsically bad, or that they are duty bound to relieve and not induce pain behaviors as such. Reflex responses to pain stimuli may be evoked from irreversibly comatose patients with only brain-stem, but no upper-brain, functioning, yet no one believes that these patients are thereby subjected to intrinsic evil, or that moral duties are being violated or shirked. No one, not even behaviorists, really believes that happiness consists merely of overt expressions of pleasure. Neither pain behavior nor pleasure behavior is of significance to ethics unless they indicate inner conscious pains or pleasures themselves.

Skinner maintains that only positive and negative reinforcers, not conscious pleasures and pains, are relevant to a correct theory of good and evil. Good things are nothing but external positive reinforcers, and bad things are nothing more than external negative reinforcers. Secondarily, those stimuli, responses, or consequences that promote cultural survival may be good things, and those that threaten cultural survival may be evil things. The words *good* and *bad* may also be used to reinforce other behaviors, positively or negatively. Positive reinforcers are stimuli that strengthen the behaviors that produce them, and negative reinforcers are stimuli that reduce or terminate the behaviors that produce them. Just why some stimuli reinforce positively and others negatively is obscure for behaviorists. They cannot maintain that consciously experienced pleasures or pains are the mechanisms that induce or inhibit behaviors. According to Skinner, identifying values with reinforcers results in a purely descriptive, empirical, and scientific ethics that overcomes the "is-ought" gap that plagued traditional ethical theory.

A few philosophers accept Skinner's behaviorist ethics (Hocutt), but most are unconvinced. Most hold that G. E. Moore's "open question" ("Granted that *x* possesses some descriptive property, but is *x* good?") is not a senseless or self-answering question, not even when the *x* is a positive reinforcer. Skinner's position might avoid this objection, however, if construed as an answer to Moore's second question of ethics, "What things are good?" rather than to his first question, "What is the meaning of 'good'?"

Skinner's theory contains no purely empirical or descriptive method for resolving value conflicts. Suffering patients may beg stoic physicians for pain medication, who might refuse to give it because they believe that patients should be allowed, or even required, to suffer for their own good in order to strengthen their characters and powers of resolution. This value conflict is not eliminated by the behaviorist's explanation that these patients find pain-relieving behavior to be positively reinforcing, while the stoic physicians find it to be negatively reinforcing. Whether any other theory of the good can resolve value conflicts is another matter, but other theories generally do not claim to offer purely descriptive solutions to internal normative value problems. A behaviorist's recommendation to give pain medication because doing so has adaptation and survival value would be a prescriptive, not a descriptive, resolution.

Skinner often prescribes norms. He cannot resolve value disagreements about "good" and "ought" merely by describing what is positively reinforcing to individuals or to their communities of value, which are groups of individuals who find similar things to be reinforcing. The behaviorist's contention that psychology should be a strictly descriptive behavioral science does not describe the beliefs and practices of most professional psychologists and psychotherapists. It is a value prescription that, if analyzed in Skinner's own terms, means merely that he and the few psychologists who agree with him find it positively reinforcing to practice psychology behavioristically. Most psychologists and philosophers have not been so conditioned, and they cannot accept the narrow strictures that behaviorism places on psychological inquiry and practice. Skinner's program, which purports to eliminate purposes and prescriptive norms, can be advanced only purposively and as a prescriptive norm.

AGENCY, FREEDOM, AND DIGNITY. Most philosophical ethicists are rationally persuaded that moral obligation and responsibility presuppose internal, autonomous, rational agency, self-control, and choice, and that the denial of the existence or efficacy of informed conscious choice in bringing about moral action is fundamentally incompatible with morality. Ethicists may disagree about whether autonomous moral choice is compatible with rigid metaphysical determinism. Some maintain that autonomous moral choice must be creative and spontaneous, while others hold that conscious choice is sufficient for moral autonomy, even if it is strictly caused by a desire to do right (or wrong). However, ethicists seldom doubt that consciousness, agency, and self-control are essential for of morality.

Informed voluntary consent is a cardinal ethical principle in modern bioethics. This principle affirms that no diagnostic, therapeutic, or experimental medical procedures should be performed on patients unless they have consciously, knowingly, and voluntarily consented to them. The principle affirms that the rational agency or autonomy of patients—the capacity of conscious patients to make informed choices for themselves—is of paramount importance in the medical setting. When behaviorism affirms that all behaviors result from external or environmental stimuli, it denies the reality, or at least the efficacy, of inner mental processes and activities, including inner understanding and decisions.

Behaviorism affirms that people are controlled entirely by their environment, which includes other clever people trained to know how to condition them. People never control themselves or their circumstances through their conscious knowledge or efforts. Although stimulus controls can be self-administered, the "prediction and control of behavior" at which behaviorism aims is primarily meant for other people. But who controls the controllers? Where do they get, and how do they justify, the norms they impose on others by psychological manipulation?

Skinner sometimes writes as if inner conscious ideas, ideals, purposes, feelings, and choices simply do not exist (Blanshard and Skinner). At other times he makes an epiphenomenal (causally ineffective) place for inner activities like self-control, choice, agency, or autonomy. He recognizes that freedom of action is important because it allows individuals to avoid aversive or negatively reinforcing stimuli, but he can make no place for conscious moral agency.

In Skinner's view, human dignity consists of behaviors that cultivate the positive reinforcement of praise or credit from others for behaving well, or as others want them to behave. By contrast, most ethicists agree that human dignity involves conscious self-awareness, self-control, and rational persuasion. They abhor manipulative techniques that bypass these qualities, and they approve of educative and persuasive techniques that develop and appeal to them.

Escaping aversive stimuli and cultivating social credit have their proper place, but most moral philosophers would balk at Skinner's behavioral reduction of freedom and dignity to solicitous activity. Behavioral freedom means little without inner personal autonomy, and human dignity, however difficult to define, is something that persons constantly have as conscious persons; and it makes all people equals. Dignity is not just something that people possess during those rare moments when others credit them for behaving as they see fit.

Thus, behaviorism is incompatible with the ideal of informed voluntary consent as it functions in applied bioethics, as well as with many fundamental principles of ethics. In sum, it seems that one must give up either behaviorism or ethics and bioethics.

REM B. EDWARDS (1995)
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SEE ALSO: *Autonomy; Behavior Modification Therapies; Coercion; Freedom and Free Will; Human Nature; Informed Consent; Mental Health Therapies; Mental Illness; Neuroethics; Patients' Rights: Mental Patients' Rights; Psychiatry, Abuses of; Psychoanalysis and Dynamic Therapies;* and other *Behaviorism* subentries

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BEHAVIOR MODIFICATION THERAPIES

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Since the 1960s and 1970s, numerous developments have occurred in both the theory and the practice of behavior therapy. There has been a significant shift away from a reliance on models of classical and operant conditioning (derived largely from animal studies) as the theoretical basis for behavior therapy, and toward a more cognitive approach in both theory and practice. These two developments have “humanized” behavior therapy to a great extent. In addition, radical or metaphysical behaviorism has reemerged in a gradual, limited way as a basis for new therapeutic technologies and conceptual formulations. These changes imply a growing recognition by behavior therapists that human behavior is the result of a complex interaction of environmental, social, cognitive, genetic, physiological, and emotional factors (Fishman and Franks).

Criticisms of Early Behavior Therapy

Prior to 1970, behavior therapy was strongly criticized by proponents of other therapeutic schools (typically humanistic or psychodynamic) as being mechanistic and authoritarian. It was alleged, for example, that terms such as *behavior control* carried with them the implicit, and sometimes explicit, message that irrevocable and often involuntary behavioral changes could be induced by the selective application of conditioning techniques. The protestations of behavior therapists notwithstanding, psychosurgery, electroconvulsive therapy, and the enforced ingestion of psychotropic medications were lumped together with mainstream behavior therapy as further examples of this authoritarian approach to behavior change.

The behavior therapy of this era was also accused of attempting to impose therapy goals on unwilling or unaware clients, and of utilizing punishment and other aversion procedures to bring this about. Behavior therapists, it was believed, had the power to impose their wills upon a hapless society through a sinister manipulation of environmental responses to behavior in the form of carefully chosen rewards and punishments.

Finally, early behavior therapy was viewed by its most extreme critics as a nefarious attempt to maintain an unjust status quo, as an imposition of majority demands upon a socially deviant minority (e.g., prisoners, the developmentally disabled, chronic psychiatric patients) helpless to resist the behavioral juggernaut. Behavior therapists were viewed as willing agents of a ruling class unable to tolerate any deviation from the prevailing ethos.

While a small proportion of early behavior-therapy practice did reflect these values to some extent, most behavior therapists eschewed such methods of coercive behavior change, preferring a much more egalitarian approach to therapeutic goal setting and behavior change. Then, as now, most behavior-therapy techniques lacked the potency to bring about involuntary behavior change. Most behavior therapists, then as now, considered it unethical to “enforce” behavior changes against a client’s wishes, even when such changes appeared, from the therapist’s perspective, to carry with them potential client benefits. Regardless of theoretical basis, the “humanization” of behavior therapy referred to above has resulted in an increasing emphasis on teaching clients "self-control."

Cognitive Approaches in Behavior Therapy

In the early 1970s, behavior therapists began to explore the possibility of integrating cognition and self-guided behavior change (see Bandura, 1977; Beck; Lazarus; Mahoney). With the exception of those who espouse a radical perspective, most cognitive behavior therapists implicitly assume that human behavior is guided in part by an internal "self" that consists of cognitive structures called *schemas.* Schemas comprise learned patterns of information processing that guide both immediate behavior and general perceptions of the world. These perceptions, in turn, have a significant impact on affective states. Cognitively oriented behavior therapists believe that to change behavior one must change the schemas through which the environmental information is processed. By helping the client to alter maladaptive schemas, the therapist enables the client to engage in broader, more effective information processing, thereby producing changes in attributions that ultimately lead to changes in both behavior and affect.

Most cognitive approaches to behavior therapy still reflect a primarily linear, mechanistic view of behavior. For example, the rational emotive therapy (RET) of Albert Ellis (1962), one of the earliest attempts at integration of cognitive and behavioral approaches, affirms that emotional states occur as the result of an information-processing sequence in which an external event triggers a set of beliefs (a schema), which in turn triggers an emotional response. Thus, a rational emotive therapist would view the emotion of anger as being triggered by the patient's thoughts about the event to which the patient responded with anger, rather than by the event itself. In the view of RET, to paraphrase Shakespeare, nothing is good or bad but thinking makes it so.

Effective treatment enables the client to alter irrational beliefs that lead to negative emotional states or other maladaptive behaviors. This is accomplished by directly challenging irrational beliefs in a Socratic fashion and by devising behavioral exercises to assist the client in learning that irrational beliefs are, in fact, incorrect. For example, in order to combat irrational feelings of shame and self-consciousness, which are presumably based on an irrational fear of sanction or ridicule for particular types of behavior, a rational emotive therapist might assign a client to perform the behavioral exercise of boarding a commuter train and loudly announcing each stop to the other passengers. The objective is to demonstrate that such behavior, absurd and inappropriate though it may seem to the client, does not necessarily evoke public sanction or ridicule, and that, even if it does, such responses from others are not catastrophic.

In one form or another, this combination of restructured irrational beliefs and behavioral exercises is the hallmark of most cognitive approaches to behavior therapy. Albert Bandura's social learning theory (1977), for example, aims at altering specific cognitive structures called "self-efficacy expectations" through teaching clients new behavioral skills and helping these clients practice them both in the therapist's office and in the daily world. Self-efficacy is assumed to determine, in part, whether or not a given set of environmental contingencies will be responded to with a particular behavior by the client. Therapy consists, in part, of designing graded behavioral exercises leading to both new behavior and a revision of self-efficacy expectations. Accomplishing these goals is presumed to facilitate a change in client behavior in previously problematic situations.

Research has consistently demonstrated that, in spite of the heavy emphasis by many theorists on the "cognitive" component of cognitive-behavior therapy, the most effective means of promoting both cognitive and behavioral changes is through performance-based treatments; that is, by actively engaging in new behaviors that are incompatible with older, problematic ones (see Rachman and Wilson). Engaging in new behavior, under the guidance of a therapist, seems to be an effective approach to the treatment of a variety of emotional and behavioral disorders. For example, a client who suffers from a fear of cats might be encouraged, with the therapist's assistance, to engage in closer and closer contacts with cats, moving from merely approaching a cat to actually holding one, until the fear subsides.

Radical Behaviorist Approaches to Behavior Therapy

In contrast to cognitively oriented behavior therapists, radical behaviorists reject outright the concept of "self." They view cognition as simply a form of behavior that occurs in correlation to a person's responses to environmental contingencies, but not as a cause of those responses. All behavior is presumed to be "caused" by a relationship between external events (contingencies) and behavior. According to radical behavior therapists (e.g., Hayes, 1987, 1989; Kohlenberg and Tsai), people learn sets of "rules" that guide their behavior through the experience of being rewarded or punished for particular behaviors in specific situations. Rules, considered to be verbal representations of environmental contingencies (the relationship between behavior and reward or punishment), are largely determined by an individual's cultural and linguistic milieu and prior learning history. According to radical behaviorists, rules and the linguistic milieu constitute a context that forms the causal matrix within which behavior is produced. Emotional disorders result from rigid adherence to "rules" of behavior that do not apply in a particular context, or to misattributing the causes of one's behavior to emotions rather than environmental contingencies. Thus, rules themselves are potential causes of emotional or behavioral problems.

A similar situation can arise from responding to inappropriately formed environmental contingencies, usually those derived from the structure of the individual's language. These inappropriately formed contingencies reinforce aspects of a person's subjective experience (e.g., the association of emotions with events) in a way that leads the person concerned to misattribute behavior to emotions rather than to the external contingencies that, in the radical behaviorist view, actually cause behavior.

Radical behaviorist approaches to treatment place strong emphasis on the role of an individual's linguistic community and language structure in guiding behavior. Cognition per se is irrelevant, except to the degree that thought is a part of the client's use of language. Behavior change is brought about by teaching new linguistic structures that lead to less affective upset. This is accomplished by attempting to alter the way in which clients use language to form attributions about the causes and meanings of their emotional experience. Most often, this involves teaching clients that emotions are not experiences that can or should be avoided. Rather, they are to be viewed as natural accompaniments to the process of living. Clients are taught to accept and utilize in a positive fashion affective and other inner experiences that their linguistic community has taught them should be avoided or eliminated (e.g., anxiety). Clients are also shown how to alter the contexts (contingencies) that control their behavior. Curiously, radical behaviorist approaches to behavior therapy are in some ways philosophically more similar to psychoanalysis than they are to traditional behavior or cognitive-behavior therapy, in that clients are taught that negative emotions are a natural part of life and cannot be eliminated. Eschewing mechanistic, linear views, radical behavior therapists prefer to view behavior as the product of an interaction between person and context.

Although formally rejecting any direct consideration of cognition, radical behaviorist and cognitive approaches to behavior therapy are consistent in other ways. For example, radical behavior therapists view the person as an active influencer of an environment that, in turn, influences the person. This is similar to Bandura's notion of reciprocal determinism (1982), a key concept in social learning theory. In addition, both radical and cognitive-behavior therapists adopt as a treatment goal the empowerment of the client to control aspects of behavior or experience that are presumed to be at the root of his or her problems. While the pathways to change are different, direct attempts to alter thoughts and behavior by cognitively oriented behavior therapists and the alteration of environmental or personal contingencies by radical behavior therapists are predicated upon the same goal: enabling people to exert more control over the causes of the problems that brought them to treatment in the first place.

Therapist-Client Relationships in Behavior Therapy

From the beginning, most behavior therapists have been intensely concerned with the ethical aspects of the application of behavior therapy, the ethical implications of the relationship between therapist and client, and the role of each in treatment. In contrast to other psychotherapeutic approaches, behavior therapy is characterized by a heavy emphasis on the responsibility of the therapist for successful treatment outcome. In behavior therapy, failure to achieve treatment goals is presumed to be the result of therapist errors or environmental hazards beyond the therapist's control, rather than of client resistance. The therapist is viewed as an "expert" guide who brings to the situation a body of teachable knowledge. In collegial fashion, as a mutual collaborative process, the patient is shown how to use this knowledge to bring about desired change. In this view, therapeutic failures result from several sources of therapist error, particularly: (1) errors in selection of therapeutic goals due to inadequate assessment; (2) errors in the selection, teaching, or application of techniques; (3) failure to consider client values in the selection of therapeutic goals, or the placing of societal or therapist values above those of the client in the process of goal selection; and (4) variables beyond the therapist's control.

While early behavior therapists tended to neglect the importance of a workable therapeutic relationship with the client, as the field has evolved such issues have become increasingly important in behavior therapy (see Wilson and Evans). Most behavior therapists recognize that without a therapeutic relationship characterized by mutual respect, empathy, trust, and equality, the first three types of therapist error noted above cannot be avoided, and treatment is unlikely to be successful. An increasing emphasis on thought and feeling leads to recognition that an adequate therapeutic relationship is essential to assessment and treatment. Changes in thoughts and emotions can, in and of themselves, be appropriate outcomes of treatment, as can changes in overt behavior. These changes can be facilitated by the establishment of a good therapeutic relationship.

Ongoing Ethical Concerns in the Practice of Behavior Therapy

Ethical practice has been a priority among behavior therapists. Nonetheless, concerns continue to arise. Particularly in cases where, at least potentially, the application of a technique can inflict pain, or where clients are relatively powerless or are involuntarily the subject of treatment, areas of ethical concern still remain.

USE OF AVERSION PROCEDURES. The use of aversion procedures (the application of subjectively unpleasant stimulation contingent upon performance of an undesirable behavior) has been, and remains, a source of criticism of behavior therapists. Particularly when procedures such as low-level electric shocks are applied to clients who lack the ability to offer informed consent to the use of such procedures, behavior therapists face a dilemma in which the desirability of treatment outcome goals has to be weighed against the rights of the client. Even when aversion therapy seems to be the best, most rapid means of suppressing other, perhaps more injurious, behavior, such as self-destructive behaviors in clients suffering from pervasive developmental disorders, behavior therapists are ethically bound to attempt to reduce the target behavior through nonaversive means before considering an aversion procedure. Only when the target behavior has been conclusively shown to be impervious to other means should aversion therapy be used.

The use of aversion techniques with clients for whom rapid, permanent behavior change is not essential, or for whom there may be some question as to the desire or willingness to change, raises significant ethical concerns. The application of aversion procedures to clients in powerless positions, or where the goals of the agent of behavior change seem directly counter to those of the client, requires careful assessment of the interests of all involved parties, with extra weight perhaps being given to the client's right to be free from external influence over his or her behavior. Practices such as those reported to have occurred in the former Soviet Union, including the use of aversion procedures or drugs for the subjugation of prisoners and psychiatric patients, are clearly not in keeping with the ethical application of behavior therapy or any other form of therapy. When aversion procedures are used, clear guidelines need to be established. Review by an institutional ethics board in order to set up extensive safeguards of client rights has to precede treatment.

TOKEN ECONOMIES IN INSTITUTIONAL SETTINGS. Token economies are based on the notion that behavior can be changed by systematically rewarding desired behaviors contingent upon performance. Token economies set up a microeconomy in which desired behaviors are "rewarded" by contingent distribution of tokens, or "points," that can later be exchanged for rewards (often food or privileges). Early proponents of token economies in institutional settings frequently sought to enhance the effects of this process by withholding basic needs, which could be regained only by compliance with token-reinforced behavioral contingencies imposed by therapist fiat. This practice is now judged to be both legally and ethically unacceptable. Clients forced to reside in facilities where token economies are in effect are entitled to have basic needs for food, shelter, clothing, and social companionship met, regardless of ability to earn token reinforcers. As with the application of aversion procedures, the legitimate parameters of reinforcers need to be clearly spelled out, and the application of contingencies monitored, through continuing and independent peer review. It is the obligation of the therapist to develop effective reinforcers that are consistent with these values.

Token economies present another ethical and theoretical dilemma: the degree to which behavior changes effected through a token economy either will or should generalize to other settings in which the client may be placed in the future. Much research suggests that the sort of reinforcement contingencies that prevail in most token-economy programs do not characterize most naturally occurring reinforcers. When a client who has learned a new behavior under conditions of monitored and controlled reinforcement in a token economy moves to a setting in which different contingencies apply, there is substantial risk that the new behavior may disappear, leaving the client bereft of adequate, meaningful reinforcers.

The consequences for both the client and society of such a failure of generalization can be significant. For example, psychiatric patients who acquire workplace social skills in a consistent and regulated token-economy program and then enter a "real world" workplace where reinforcement is inconsistent may not be able to respond adequately to the new contingencies, and will therefore be unable to cope with the new setting, even though they functioned well under the token-economy conditions. This may lead to a financial inability to live independently, and even to homelessness and the need for welfare benefits that might not have been required had attention been paid to the generalization of token-economy-acquired skills to the outside world. This possibility makes it essential for behavior therapists to address the issues of generalization and maintenance of behavior change across various settings.

COMPUTER-ASSISTED AND ADMINISTERED THERAPY AND SELF-HELP BOOKS. Since the mid-1990s there has been an increasing interest among behavior and cognitive-behavior therapists in the development of computer-assisted and administered treatments, as well as in the dissemination of self-help books that detail, for the lay person, ways to cope with one's problems without the assistance of a therapist. This movement has been driven by the ready availability of computer technology and the Internet, and by a desire to bring the benefits of behavior therapy to people who might otherwise have limited access to therapists (such as those in remote rural areas).

The promulgation of treatments that involve minimal or no professional guidance, but rely instead upon the theories and techniques of behavior and cognitive-behavior therapies, as well as the claims made by these therapies in such a context, raises important ethical issues. Specifically, to what extent is a human therapist necessary to produce effective behavior change, and is it ethically responsible to promote these approaches in this way?

Many of these programs function by attempting to mimic the interaction between therapist and patient using decision tree programming that provide standardize computer responses to a variety of specific client input statements.

Researchers have also validated a number of computer-assisted and administered treatments using "virtual reality" and computer-assisted interviewing to treat panic disorder (Newman, Kenardy, Herman, and Taylor), anger (Timmons, Oehlert, Sumerall, Timmons, et al.), acrophobia (Vincelli), and problem drinking (Hester and Delaney). To the extent that these treatments have been found to be as effective as their human-delivered counterparts, they pose no more ethical concerns than do other behavioral therapies. However, there is a danger that untested approaches and methods will be used, possibly to the detriment of patients, and it is incumbent upon all behavior therapists to insure that computer or Internet-based treatments are subjected to thorough research testing prior to full dissemination.

Similar issues adhere to the publication of self-help books. As with computer- and Internet-based applications, it is incumbent upon the authors of these books to insure that they have reasonable research evidence for their efficacy.

Authors and users of both computer-assisted and administered applications of behavior therapy and self-help books need to be attentive to possible misapplication of these techniques, particularly by persons whose problems may be more complex and difficult than such approaches can address. Clear disclaimers and cautions to potential users with respect to the limitations of these approaches are necessary to insure their ethical dissemination and use. On the positive side, these approaches are entirely consistent with the traditional emphasis in behavior therapy on active client participation in treatment.

The Image of Behavior Therapy

As noted, the image of early behavior therapy among nonbehavioral professionals and the lay public was often extremely negative. Grossly inaccurate notions about the nature of behavior therapy were commonplace, and behavior therapy was lumped with such alien procedures as psychosurgery and Erhard Seminar Training. Such misconceptions are now infrequent. This is due largely to the incorporation of behavior therapy into the mental health mainstream, to increased sophistication and greater acceptance of behavior therapy by the general public, and, perhaps above all, to the concerted attempts of behavior therapists, both as individuals and as members of professional organizations, to correct these misconceptions and thereby improve the image of behavior therapy.

There is a continuing need to modify misconceptions through well-planned public education. Behavior therapists also need continuing educational training in the maintenance of good ethical practice. Measures of consumer satisfaction are the rule rather than the exception in both clinical research and treatment. Behavior therapists must increasingly think in terms of public relations and the necessity for keeping patients informed at all stages of the intervention process. For example, behavior therapists in private practice are beginning to make available written descriptions of the treatment procedures and policies for discussion and review before treatment begins (Franks).

Conclusion

Contemporary behavior therapy is characterized by an emphasis on client participation in therapeutic goal setting and a balancing of client rights (particularly when the client is relatively powerless) against societal needs, values, and expectations. Even in institutional settings the application of techniques is much less mechanistic and intrusive, and behavior therapists are trained to apply their techniques with stringent safeguards of client rights.

An increasing awareness of the roles of thoughts and feelings in the production and maintenance of behavior has led to behavior therapists' becoming more client-centered and humanistic in their approaches to behavior change. This awareness has also produced an increasing emphasis on teaching clients self-control techniques rather than "applying techniques to clients" without consideration of the active role the client should play in the process of changing behavior.

By virtue of the inclusion of cognitive and contextual variables in theory and application, contemporary behavior therapy is a considerably advanced over early behavior therapy, which was based largely on animal models of learning. Behavior therapy is unique among current psychotherapeutic schools in that practitioners rely on repeated, data-based, objective assessments of client behaviors, thoughts, and feelings to aid in the establishment of therapeutic goals and the continuous assessment of therapeutic progress. Contemporary behavior therapy is a diverse field in which theoretical progress and practice are based on demonstrable advances in scientific knowledge, rather than on the pronouncements of authorities or "gurus." Although not yet fully integrated into behavior-therapy practice, developments in basic psychology, human rule-governed behavior (Hayes), cognitive sciences, and computer science all hold promise for enhancing both treatment efficacy and sensitivity to ethical constraints. As practitioners of a discipline and through organizations such as the Association for Advancement of Behavior Therapy, behavior therapists are learning how to apply these rigorous standards to themselves and to their personal interactions with clients, colleagues, students, and society at large.

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SEE ALSO: *Autonomy; Behaviorism; Coercion; Freedom and Free Will; Informed Consent; Mental Health Therapies; Mental Illness; Neuroethics; Patients' Rights: Mental Patients' Rights; Psychiatry, Abuses of; Psychoanalysis and Dynamic Therapies*

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BENEFICENCE

• • •

Beneficence denotes the practice of good deeds. In contemporary ethics, the principle of beneficence usually signifies an obligation to benefit others or to seek their good. It is a principle of major importance in bioethics and has been prominent in the codes of physicians since antiquity.

Beneficence and Benevolence

Beneficence as a principle that guides decisions should be distinguished from the virtue that motivates actors. The

Oxford English Dictionary defines "beneficence" as "doing good, the manifestation of benevolence, or kindly feeling" (emphasis added). This definition bespeaks the etymology of both terms. *Beneficence* is derived from the Latin *bene* (well; from *bonus,* good) and *facere* (to do), whereas *benevolence* is rooted in *bene* and *volens* (a strong wish or intention) (Partridge). Philosophers who emphasize a more rationalist approach, calculated to guide principled choices, tend to endorse beneficence. Those who see ethics as primarily concerned with virtue, character, and the psychological dimensions of the moral life emphasize benevolence.

David Hume, for example, conceived of benevolence as one of the instincts originally implanted in human nature. Like Joseph Butler, Francis Hutcheson, Adam Smith, and other eighteenth-century English-speaking philosophers, Hume was not so much concerned with ethical problem solving as with describing the role and place of benevolence in the moral topography of human beings. Adam Smith used the term *beneficence,* but employed it to describe the virtue of goodwill, and saw it as a moral passion rather than a principle. Of concern to all these philosophers was a task set for them by Thomas Hobbes a century earlier.

Hobbes set the modern polemical context for discussions not only of beneficence and benevolence but also of ethics more generally. His moral philosophy was determinist, denying any capacity for choice based on values, and relativist, denying any independent reference for the terms good and evil: Liberty he saw as merely the ability to enact one's desires, not freedom to deliberate and choose. Good and evil simply denoted human appetites and aversions. "Will" was just another desire, not a distinctive moral capacity. Obviously such a philosophy was no place for beneficence as a principle of choice or benevolence as a motivation for the good of others. Ethics devolves into a deterministic egoism. Butler, Hutcheson, Hume, and Smith, in a variety of ways, took as their task a survey of the moral psyche, with special regard for the place of benevolence as something innate or natural to human life.

Unless Hobbes's egoistic portrait is correct, any well-rounded view of ethics will include ways of describing and evaluating both the motivational and character-laden aspects, and the decisional, action-oriented elements of ethics—that is, both benevolence and beneficence.

A principle of beneficence can be broadly or narrowly defined. William Frankena views beneficence as an inclusive principle involving elements of refraining from inflicting harm and preventing or removing evil, as well as an obligation actively to promote good. James Childress adopts Frankena's elements but reclassifies them according to two distinct principles: nonmaleficence, the obligation not to inflict harm; and beneficence, the obligations to prevent harm, to remove harm or evil, and positively to promote good. This refinement has the merit of following an intuitive division between refraining and active doing. It elucidates why refraining from harm is usually seen as a universal duty to others, while actively promoting good or helping others is typically seen as a less stringent obligation and often as resulting from specific role obligations (being a parent or a doctor) or contractual agreements. A broader-ranging sense of beneficence is, nevertheless, endorsed by some philosophers. For example, in *The Right and the Good,* W. D. Ross claimed that duties of beneficence are incurred because of "the mere fact that there are other human beings in the world whose condition we can make better …" (p. 21).

Relation to Utility

Beneficence has natural affinities with a principle of utility. Tom Beauchamp and James Childress, for example, claim that promoting good always involves a calculation of what harms might also be incurred. A principle of utility is a way to assess harms and benefits. In his *Utilitarianism,* John Stuart Mill asserted in 1863 that the measure of "good" by which all actions are to be judged is whether they promote the greatest happiness for the greatest number. Mill saw his principle of utility as a systematic expression of the teaching of Jesus, for example, as embodied in the "golden rule."

When defined through Mill's utility principle, beneficence becomes vulnerable to two criticisms frequently leveled at utilitarianism. The first is the problem of adequacy. A focus on beneficence as the promotion of happiness, to the exclusion of other kinds of goods and obligations, seems too narrow. People value things other than happiness, however broadly defined. Promoting the happiness of others can conflict with treating them fairly or respecting them as persons. The second problem is idealism. For Mill at least, utilitarianism presented a stringent requirement. "As between his own happiness and that of others utilitarianism requires him to be as strictly impartial as a disinterested and benevolent spectator" (1979, p. 16). To count the good of strangers equally with our own good, or that of our families or friends, seems saintly and perhaps impossible to achieve.

These problems have led some philosophers to question utilitarianism as a system but also to see beneficence as only one principle among others, and as usually (if not always) an imperfect or supererogatory duty. While some principle of utility is necessary to enact beneficence, it need not be Mill's rendition. A utility principle that recognized a variety of goods would at least moderate the force of the criticisms above.

Beneficence and Autonomy

How beneficence is put into practice depends on how it is modified by other principles. Especially important in this regard is respect for autonomy or self-determination. Another way to put this is to ask whose notion of *good* will be definitive. Respect for autonomy means that *good* will be defined by the recipient of the action rather than the agent. Beneficence not so defined leads to paternalism, in which the beneficent actor overrides or ignores the recipient's ideas of good and imposes his or her own. The history of medical ethics is largely (but not entirely) a history of paternalistic beneficence. In the mid-twentieth century, consistent challenges arose to beneficent paternalism through assertions of patient rights. Defenders of simple paternalism in healthcare relationships are now rare, and most ethicists would agree with Erich Loewy that paternalistic actions generally represent a "caricature" rather than a natural extension of beneficence.

Autonomy as a moral principle is historically rooted in freedom as a political principle, to which John Locke's *Second Treatise of Government* (1690) gave definitive expression. Freedom, Locke asserted, is not license "but a *liberty* to dispose, and order as he lists, his person, actions, possessions, and his whole property, within the allowance of those laws under which he is, and therein not to be subject to the arbitrary rule of another, but freely follow his own" (p. 32). The eighteenth-century monument to autonomy is the work of the German philosopher Immanuel Kant. Whereas Locke was concerned to protect individuals from the power of the state, Kant focused on freedom of the will. His "practical imperative" requires that others be treated as ends in themselves and never only as a means. For Kant this respect for the moral freedom of others was grounded in a recognition of their rational nature. In bioethics this raises the difficult issue of when and to what extent the rational capacities of patients are compromised and in which cases autonomy should give way to medical beneficence.

The grounds for limiting beneficence through respect for autonomy were most powerfully stated by John Stuart Mill. In *On Liberty* (first published in 1859) he cautioned against supposing that the principle of liberty necessitates a "selfish indifference." Indeed, he asserted, "there is need of a great increase of disinterested exertion to promote the good of others." But, he continued, "disinterested benevolence can find other instruments to persuade people to their good than whips and scourges, either of the literal or of the metaphorical sort" (p. 74).

While advocacy for autonomy as the preeminent principle of medical ethics was powerful during the 1970s and 1980s, there are still substantial voices for a beneficence-based theory. Edmund Pellegrino and David Thomasma argue that "medicine as a human activity is of necessity a form of beneficence" (p. 32). Rather than espousing the older traditions of paternalism, however, they argue for an enlarged beneficence, "beneficence-in-trust"—a non-rights-based approach that includes respect for autonomy but emphasizes a fiduciary grounding for doctor–patient encounters. This approach has an advantage over single-principle approaches that ground medical obligations in simple beneficence or simple autonomy, conceived as monolithic norms. Beneficence, unleavened by respect for autonomy, can lead to paternalism, while autonomy alone obviates trust and often deteriorates into indifference. Still the feasibility of trust depends upon shared values and goals, or at least stable role expectations between providers and patients. The greater the pluralism in a society, the less likely it is that the trust Pellegrino and Thomasma commend can be established.

Health Professional Codes

While beneficence is important to many philosophical and religious systems of ethics, it is central to the health professions. The Hippocratic Oath clearly states that the physician's actions are "for the benefit of the sick" (see Appendix for this and other codes and oaths). The Declaration of Geneva begins with a pledge to "consecrate" one's life to "the service of humanity." The 1980 "Principles" of the American Medical Association (AMA) opens with the declaration that these principles are established "primarily for the benefit of the patient." The International Code for Nurses devised in 1973 begins with a broad-ranging assertion of beneficence. The "fundamental" responsibility of the nurse, it states, is to promote and restore health, alleviate suffering, and prevent illness. While duties to specific persons are recognized, the obligation to perform beneficent actions is seen as universal, because the need for nursing services is universal.

The U.S. Code for Nurses of 1976 differs from all physician codes in recognizing that services not only should promote good but also should be guided by the values of those served. The first principle in this formulation asserts the "self-determination of clients." As noted above, self-determination, or autonomy, is frequently seen as a limiting factor in gauging the extent of beneficence, yet this factor is rarely mentioned in the ethical formulations of health professionals. For example, the practice of soliciting consent from patients was evident in medical practices in the United States in the eighteenth century. Yet these solicitations were not commensurate with today's notion of informed consent.

Consent was sought in the eighteenth century primarily to enhance therapy rather than to encourage independent decision making by patients (Faden et al.). Jay Katz presses this point by asserting that consent is largely "alien" to medical thinking, which prefers "custody" over "liberty."

Still, claims for the modern uniqueness of informed consent should be viewed with caution, especially when they tend to valorize an "autonomy model" over a "beneficence model" (Faden et al.). It would be anachronistic to believe that eighteenth-century physicians worked with the mid-twentieth-century concept of consent. Yet it is too sweeping and dualistic to believe that, by default, they were under the sway of a "beneficence model." Medical practices, or moral practices more generally, do not lend themselves to easy encapsulation into models, just as beneficence as a practice is not identical with the philosophical principle of beneficence.

While all versions of professional ethics agree that the acceptance of a patient or a client creates a specific obligation of beneficence, some codes go further and talk of a general duty to seek the public good in matters of health. Here the 1847 Code of the American Medical Association is notable. Chapter III of that code enumerates "Duties of the Profession to the Public." Among those listed are vigilance for the welfare of the community, counsel to the public on health matters, and advice about epidemics, contagion, and public hygiene. Twentieth-century medical codes tend to be more parsimonious in their interpretations of what beneficence entails.

Not even the more generous beneficence in the 1847 AMA Code, however, takes it to cover what Charles Fried calls "the duty to work for and comply with just institutions" (p. 129). Fried here follows and extends the thinking of Kant, who saw beneficence in terms of a duty of mutual aid. Such aid is required because all persons (including ourselves) will at some time need the help of others, so to neglect aiding others would be self-defeating. The societal and public policy implications of beneficence in healthcare are poorly worked out at present. The issues that require attention include general programs of prevention, medical assistance to specific groups (such as AIDS patients), and healthcare for the indigent and uninsured. Most proposals for a more equitable healthcare system in the United States build on notions of justice as an independent principle rather than deriving their justifications from an extension of duties of beneficence.

Limits

If beneficent duties are more than supererogatory, or optional, a persistent issue is how to discern their proper scope. Where do obligations to benefit others end? Are we morally required to give away all our surplus income and, beyond that, to chasten ourselves to more modest patterns of consumption? Are physicians obligated never to say "no" to patients so long as any thread of hope for improvement exists? Would beneficence require acceptance of higher taxes to fund universal health coverage, or does acting for my fellow citizens' good require me to die cheaply and forgo expensive treatments with low probability of benefit?

Beneficent duties may be limited in two ways. The first limiting force is duties to oneself. Self-respect, and an appropriate attention to one's own well-being, will of necessity restrict activities for the good of others, unless beneficence is given a preemptive place and is conflated with saintliness. Hume, for example, believed persons can be "too good," carrying "attention for others beyond the proper bounds," blunting a due sense of pride and the self-assertive virtues (p. 93). A second kind of limit involves our psychological capacity for identification of and sympathy with those who could use our help. The press of human suffering that could be alleviated by our actions is immense. To conceive of this larger and seemingly inexhaustible world of suffering as our charge would likely be debilitating. Jonathan Glover has suggested that a restricted but feasible beneficence may be the price we pay for our sanity. Limits to the duty to promote good restrict us, but also orient and direct our finite capacities. But perhaps the greater risk is that we will draw a circle around duties in a niggardly fashion, that our imagination will not be too large, risking paralysis, but too stingy and self-serving. It is this narrow and parochial tendency that concerns the advocates of a robust and extensive beneficence.

Relational Selves

The recent challenges to ethical theory from psychological studies of moral experience have profound implications for beneficence. In 1982 Carol Gilligan published her research on the moral development of women, titled *In a Different Voice.* She claimed that females tend to see moral problems in terms of relationships. They are prone to think of their choices in problem solving as issues of care and responsibility for those relationships. By contrast, males tend to see moral problems in terms of rules and principles, and are prone to think of their choices as logical adjudications. Women's moral orientations tend toward valuing and preserving ties among persons, while men's tend toward abstract thinking by an agent largely removed from and impartial to the parties involved. Gilligan's claim is not that there are precise gender types for moral experience but that the model of the moral self as an abstract, isolated, principled, and hierarchical thinker is insufficient.

Consider the case of Jake and Amy, two eleven-year-olds, who discuss the question “When responsibility to oneself and responsibility to others conflict, how should one choose?” (Gilligan, pp. 35ff.). While Jake adjudicates these responsibilities as if it were a problem of rule application, Amy’s response is pragmatic and assumes a relational self. Jake seeks fairness in the manner of a judge; Amy is concerned to see that others’ needs are met and relationships are nurtured. The point is not so much that Jake and Amy offer different answers but that they see different issues, and see themselves in different ways.

The implications for a principle of beneficence in bioethics, and in the ethical codes of health professionals, are substantial. Gilligan’s research directly challenges the adequacy of thinking of beneficence simply as a principle to be applied to cases, and recommends a notion of beneficence grounded in complex, relational understandings of the self. Hence, the issues of beneficence can no longer be formulated as if the agent were essentially solitary and could contemplate the scope of his or her duties from afar. The self is already, and essentially, immersed in a web of convivial responsibilities. The ethical formulations of most health professions exhibit precisely the hierarchical distancing and the assumption of optional relationships depicted in the “male” model. Attending to the second voice in moral experience would mean moving bioethics beyond an exhaustive reliance on applying beneficence, as a principle, to problem cases. It would also mean taking the ethical codes of health professionals beyond the contract model and into a recognition of a deeper and more integral bond between healers and the sick, and between health professionals and society.

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SEE ALSO: *Autonomy; Bioethics; Compassionate Love; Confidentiality; Ethics: Normative Ethical Theories; Justice; Paternalism; Professional-Patient Relationship*

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BIAS, RESEARCH

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In the behavioral sciences, the difficulties of studying complex, changing interactions among living beings led to investigations of possible sources of bias. For example, the gender, race, class, and even presence of a researcher during an interview have been shown to influence the responses of the interviewee (Oakley). Researchers sought to apply the scientific method to problems in the behavioral sciences, in an attempt to eliminate bias.

Like all scholars, scientists hold, either explicitly or implicitly, certain beliefs concerning their enterprise. Most scientists try to use what they assume to be the best information to collect data and draw theories to elucidate the laws and facts that will be constant, providing that experiments have been done correctly. But the individuals who make observations and create theories are people who live in a particular country at a certain time in a definable socioeconomic condition, and their situations and mentalities impinge on their discoveries. Aristotle "counted" fewer teeth in the mouths of women than in those of men—adding this dentitional inferiority to all the others he asserted characterized women (Arditti). Galen, having read the book of Genesis, "discovered" that men had one less rib on one side than women did (Webster and Webster). Neither is true, and both would be refuted easily by observation of what would appear by today's standards to be easily verifiable facts. Although they also could count, they took these to be "nonclassical cases" because what we take to be facts can vary depending upon the theory or paradigm—the specific problematics, concepts, theories, language, and methods—guiding the scientist.

Because most scientists, feminists, and philosophers of science recognize that no individual can live a life and be entirely neutral or value-free since science and values are both very important. To some, "objectivity is defined to mean independence from the value judgments of any particular individual" (Jaggar, p. 357). The paradigms themselves, however, also are far from value-free. The values of a culture, in the historical past and the present society, heavily influence the ordering of observable phenomena into a theory. The worldview of a particular society, time, and person limits the questions that can be asked, and thereby the answers that can be given. Therefore, the very acceptance of a particular paradigm that appears to cause a "scientific revolution" within a society may depend at least in part upon the congruence of that theory with the institutions and beliefs of the society (Kuhn).

Elizabeth Potter (2001) documented Boyle's choice of the mechanistic model to explain his Law of Gases both because it comported well with the data and because it supported the status quo of conservative religion and monarchy of the seventeenth century with regard to class and gender compared to the competing animistic model seen as more radical socially. Scholars suggest that Darwin's theory of natural selection was ultimately accepted by his contemporaries (whereas they did not accept similar theories as described by Alfred Russel Wallace and others) because Darwin emphasized the congruence between the values of his theory and those held by the upper classes of Victorian Britain (Rose and Rose). Social Darwinists used Darwin's theory to base the political and social rights to their wealth and power held by men and the upper classes in biological determinism. In this manner Darwin's data and theories reinforced the natural superiority of wealthy men, making his theories acceptable to the leaders of Victorian English society. Fausto-Sterling's research (1999) revealed how different societies at particular historical periods have also used varying biological and genetic data as determinants for the social construction of gender and race.

Not only what is accepted, but what and how we study, have normative features. Helen Longino (1990) has explored the extent to which methods employed by scientists can be objective, in the sense of not being related to individual values, and lead to repeatable, verifiable results while contributing to hypotheses or theories that are congruent with nonobjective institutions and ideologies such as gender, race, and class that are socially constructed in the society: "Background assumptions are the means by which contextual values and ideology are incorporated into scientific inquiry" (p. 216). For example, scientists may calculate rocket trajectories and produce bombs that efficiently destroy living beings without raising the ethical questions of whether the money and effort for this research to support the military could be better spent on other research questions that might be solved by using similar objective methods.

Unintended Research Bias

Given the high costs of sophisticated equipment, maintenance of laboratory animals and facilities, and salaries for qualified technicians and researchers, little behavioral or biomedical research is undertaken without governmental or foundation support. The choice of problems for study in medical research is substantially determined by a national agenda that defines what is worthy of study, that is, worth funding. As Marxist (Zimmerman et al.), African-American (Campbell, Denes, and Morrison), and feminist (Harding, 1998) critics of scientific research have pointed out, the scientific research undertaken in the United States reflects the societal bias toward the powerful, who are overwhelmingly white, middle/upper class, and male. Members of Congress and the individuals in the theoretical and decision-making positions within the medical and scientific establishments that set priorities and allocate funds for research exemplify these descriptors. The lack of diversity among Congressional and scientific leaders may allow unintentional, undetected flaws to bias the research in terms of what we study and how we study it. Some have characterized the diversion of scarce resources away from public health measures known to prevent diseases for the masses towards the multibillion dollar Human Genome Project as an example of placing the interests of the powerful above those of the general public, since gene therapy and designer genes are likely to benefit fewer, wealthier people.

Examples from research studies demonstrate that unintentional bias may be reflected in at least three stages of application of the scientific method: (1) choice and definition of problems to be studied; (2) methods and approaches used in data gathering, including whom we choose as subjects; and (3) theories and conclusions drawn from the data.

CHOICE AND DEFINITION OF PROBLEMS TO BE STUDIED. Many diseases that occur in both sexes have been studied in males only and/or used a male-as-norm approach. Cardiovascular diseases serve as a case in point. Research protocols for large scale studies (MRFIT; Grobbee et al.; Steering Committee of the Physicians' Health Study Group) of cardiovascular diseases failed to assess gender differences. Women were excluded from clinical trials of drugs, they said, because of the desire to protect women or fetuses (and fear of litigation) from possible teratogenic effects on fetuses. Exclusion of women from clinical drug trials was so pervasive that a meta-analysis surveying the literature from 1960 to 1991 on clinical trials of medications used to treat acute myocardial infarction found that women were included in less that 20 percent and the elderly in less than 40 percent of those studies (Gurwitz, Nananda, and Avorn).

Many of these studies, including the Physicians' Health Study, were flawed not only by the factors of gender and age but also by factors of race and class. Susceptibility to cardiovascular disease is known to be affected by lifestyle factors such as diet, exercise level, and stress, which are correlated with race and class. Since physicians in the United States are not representative of the overall male population with regard to lifestyle, the results may not be applicable to most men. The data from these studies should not have been generalized to the population as a whole. (Some argued they directed studies to the group that they care about most, namely, people like themselves.)

Designation of certain diseases as particular to one gender, race, or sexual orientation not only cultivates ignorance in the general public about transmission or frequency of the disease; it also results in research that does not adequately explore the parameters of the disease. Most of the funding for heart disease has been appropriated for research on predisposing factors for the disease (such as cholesterol level, lack of exercise, stress, smoking, and weight) using white, middle-aged middle-class males. Much less research has been directed towards elderly women, African-American women who have had several children, and other high-risk groups of women. Virtually no research has explored predisposing factors for these groups, who fall outside the disease definition established from the dominant perspective.

Recent data indicate that the initial designation of AIDS as a disease of male homosexuals, drug users, and Haitian immigrants not only has resulted in homophobic and racist stereotypes but also has particular implications for women of color. In 1981 the first official case of AIDS in a woman was reported to the Centers for Disease Control and Prevention (CDC). By 1991, $80 million had been spent since the inception of the Multicenter AIDS Cohort Study (MACS), designed to follow the natural history of HIV among gay and bisexual males (Faden, Kass, and McGraw). Although by 1988, the case reports for women were higher than the number for men in 1983, the year the MACS began (Chu, Buehler, and Berelman), it was not until the final quarter of 1994 that the first study on the natural history of HIV infection in women began. In 1998, the CDC reported that AIDS remains the leading cause of death among black females aged 25 to 44, and the second leading cause of death overall among those aged 25 to 44 (CDC, 1998). The majority of women diagnosed with AIDS are black or Hispanic.

These types of bias raise ethical issues. Healthcare practitioners treat the majority of the population, which consists of females, minorities, and the elderly, based on information gathered from clinical research in which women and minorities have not been included. Bias in research thus leads to further injustice in healthcare diagnosis and treatment. Understanding this bias led to changes in policies in the 1990s. Investigators now receiving federal money must give a compelling reason if their studies fail to include both men and women, young and old, as well as individuals of diverse races. Although this increases the cost of research, since the sample must be larger, cost alone does not stand as a compelling reason.

APPROACHES AND METHODS USED IN DATA GATHERING. Using the white, middle-aged, heterosexual male as the "basic experimental subject" not only ignores the fact that females may respond differently to the variable tested; it also may lead to less accurate models even for many men. For example, the standard dosage of certain medications is not only inappropriate for many women and the elderly, but also for most Asian men, because of their smaller body size and weight. Certain surgical procedures such as angioplasty and cardiac bypass result in higher death rates for women (Kelsey) and Asian men and may require modification for the same reason (Chinese Hospital Medical Staff; Manley et al.).

When women of color are used as experimental subjects, clinicians often hold stereotypical and racist views that limit accurate diagnosis. For example, numerous research studies have focused on sexually transmitted diseases in prostitutes in general (CDC, 1987; Cohen et al; Rosser, 1994) and African-American women as prostitutes in particular. Several studies have also revealed that practitioners recognize and report at higher rates crack-cocaine abuse in African-American women and alcohol abuse in American Indian women, compared to white women seeking prenatal care. An American Civil Liberties Union study revealed that in forty-seven out of fifty-three cases brought against women for drug use during pregnancy in which the race of the woman was identifiable, 80 percent were brought against women of color (Pattrow, p. 2).

Frequently it is difficult to determine whether these women are treated disrespectfully and unethically due to their gender or whether race and class are more significant variables. From the Tuskegee syphilis experiment (1932–1972), in which the effects of untreated syphilis were studied in 399 men over a period of 40 years (Jones), it is clear that men who are black and poor may not receive appropriate treatment or information about the experiment in which they are participating. Scholars (Clarke and Olesen) explore the extent to which gender, race, and class become complex, interlocking variables that may affect access to and quality of healthcare.

Using only a particular discipline's established methods may result in approaches that fail to reveal sufficient information about the problem being explored. This may be a difficulty for research surrounding medical problems particularly important to the elderly, women, men of color, and homosexual males. Pregnancy, childbirth, menstruation, menopause, lupus, sickle-cell disease, AIDS, and gerontology represent healthcare issues for which the methods of one discipline are clearly inadequate.

Methods that cross disciplinary boundaries or include combinations of methods traditionally used in separate fields may provide more appropriate approaches. For example, heart disease is caused not only by genetic and physiological factors but also by social/psychological factors such as smoking and stress. Jean Hamilton (1985) has called for interactive models that draw on both the social and the natural sciences to explain complex problems. Some of the biological solutions such as Depo-Provera or Norplant implants (Washburn) favored for addressing teen pregnancy in some African-American and American Indian populations will be less effective without accompanying strategies based upon research from the social and behavior sciences on raising self-esteem, increasing education, and dealing with underlying family dynamics. Stripped of the complex of social, economic, educational, and family dynamics issues that may contribute to teen pregnancy, Norplant implants and Depo-Provera may prevent a particular pregnancy. Without information about family planning, counseling to deal with family problems, and education and job skills, however, such approaches do not solve the basic problems causing the teen pregnancy.

THEORIES AND CONCLUSIONS DRAWN FROM THE DATA. Emphasis upon traditional disciplinary approaches that are quantitative and maintain the distance between observer and experimental subject supposedly removes the bias of the researcher. Ironically, to the extent that these "objective" approaches are synonymous with a particular approach to scientific phenomena, they may introduce bias. As a corrective to such bias to a science that is too narrow, Sandra Harding proposes the notion of "strong objectivity" which recognizes the cultural, social, and historical forces that shape the questions asked by scientists, their approaches, and the theories and conclusions drawn from their data (1993, 1998).

Theories may be presented in androcentric, ethnocentric, or class-biased language. An awareness of language should aid experimenters in avoiding the use of terms such as "tomboyism" (Money and Erhardt), "aggression," and "hysteria," which reflect assumptions about sex-appropriate behavior (Hamilton). Researchers should use evaluative terms such as "prostitute" with caution. Often the important fact for AIDS research is that a woman has multiple sex partners or is an IV drug user, rather than that she has received money for sex. The use of such terms as "prostitute" may induce bias by promoting the idea that women are vectors for transmission to men when, in fact, the men may have an equal or greater number of sex partners to whom they are transmitting the disease. Even more important, by emphasizing AIDS in "prostitutes," healthcare practitioners are able to distance themselves and their patients from the risk of AIDS. This may also lead to practitioners treating prostitutes as less than human and underdiagnosing AIDS in women who are not prostitutes. Focus on group characteristics such as "prostitute" or "poor, black, unmarried woman" repeats the initial mistake of identifying the disease by group rather than by behavioral risk.

Once a bias in terminology is exposed, the next step is to ask whether that terminology leads to a constraint or bias in the theory itself. Theories and conclusions drawn from medical research may be formulated to support the status quo of inequality for oppressed groups. Not surprisingly, the androcentric bias in research that has led to exclusion of women from the definitions and approaches to research problems may result in differences in management of disease and access to healthcare procedures based on gender. In a 1991 study in Massachusetts and Maryland, John Z. Ayanian and Arnold M. Epstein (1991) demonstrated that women were significantly less likely than men to undergo coronary angioplasty, angiography, or surgery when admitted to the hospital with a diagnosis of myocardial infarction, unstable or stable angina, chronic ischemic heart disease, or chest pain. This significant difference remained even when the variables of race, age, economic status, and other chronic diseases (such as diabetes and heart failure) were controlled. A similar study (Steingart et al.) revealed that women have angina before myocardial infarction as frequently and with more debilitating effects than men, yet they are referred for cardiac catheterization only half as often. Gender bias in cardiac research has therefore been translated into bias in management of disease, leading to inequitable treatment for life-threatening conditions in women. Women exhibited higher death rates from angioplasty (Kelsey et al.) and thrombolytic therapy (Wenger, Speroff, and Packard).

Recognizing the possibility of bias is the first step toward understanding the difference it makes and combating it. Perhaps white male researchers have been less likely to see flaws in and question biologically deterministic theories that provide scientific justification for their superior status in society because they gain social power and status from such theories. Researchers from outside the mainstream (women and people of color, for example) are much more likely to be critical of such theories because they lose power from those theories.

In order to eliminate bias and recognize the cultural, social, and historical forces impacting their research, the community of scientists needs to include individuals who serve as members on review panels and as leaders to review studies from backgrounds of as much variety and diversity as possible with regard to race, class, gender, and sexual orientation (Rosser, 2000). Only then is it less likely that the perspective of one group will bias research design, approaches, subjects, and interpretations. Since the scientific method itself is supposed to be "self-correcting," if results are continually tested and subject to critical review, these biases are likely to be exposed.

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SEE ALSO: *AIDS; Feminism; Genetic Discrimination; Metaphor and Analogy; Prisoners as Research Subjects; Privacy and Confidentiality in Research; Race and Racism; Research Policy; Sexism*

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BIOETHICS

• • •

"There is," says the biblical book of Ecclesiastes, "no new thing under the sun." Those words are worth pondering in light of the emergence of the field of bioethics since the 1950s and 1960s. From one perspective it is a wholly modern field, a child of the remarkable advances in the biomedical, environmental, and social sciences. Those advances have brought a new world of expanded scientific understanding and technological innovation, seeming to alter forever what can be done about the vulnerabilities of nature and of the human body and mind, and about saving, improving, and extending human lives. Yet from another perspective, the kinds of questions raised by these advances are among the oldest that human beings have asked themselves. They turn on the meaning of life and death, the bearing of pain and suffering, the right and power to control one's life, and our common duties to each other and to nature in the face of grave threats to our health and well-being. Bioethics represents a radical transformation of the older, more traditional domain of medical ethics; yet it is also true that, since the dawn of history, healers have been forced to wrestle with the human fear of illness and death, and with the limits imposed by human finitude.

It is wholly fitting that an encyclopedia of bioethics devote some of its space to defining and understanding the field that it would examine in both breadth and depth. Yet that is not an easy task with a field that is still evolving and whose borders are hazy. The word *bioethics,* of recent vintage, has come to denote not just a particular field of human inquiry—the intersection of ethics and the life sciences but also an academic discipline; a political force in medicine, biology, and environmental studies; and a cultural perspective of some consequence. Understood narrowly, bioethics is simply one more new field that has emerged in the face of great scientific and technological changes. Understood more broadly, however, it is a field that has spread into, and in many places has changed, other far older fields. It has reached into law and public policy; into literary, cultural, and historical studies; into the popular media; into the disciplines of philosophy, religion, and literature; and into the scientific fields of medicine, biology, ecology and environment, demography, and the social sciences.

The focus here will be on the broader meaning, place, and significance of bioethics. The aim will be to determine not only what the field means for specific ethical problems in the life sciences, but also what it has to say about the interaction of ethics and human life, and of science and human values. Bioethics is a field that ranges from the anguished private and individual dilemmas faced by physicians or other healthcare workers at the bedside of a dying patient, to the terrible public and societal choices faced by citizens and legislators as they try to devise equitable health or environmental policies. Its problems can be highly individual and personal—what should I do here and now?—and highly communal and political—what should we together do as citizens and fellow human beings?

While the primary focus of this entry will be on medicine and healthcare, the scope of bioethics—as the encyclopedia as a whole makes clear—has come to encompass a number of fields and disciplines broadly grouped under the rubric *the life sciences.* They encompass all those perspectives that seek to understand human nature and behavior, characteristically the domain of the social sciences, and the natural world that provides the habitat of human and animal life, primarily the population and environmental sciences. Yet it is the medical and biological sciences in which bioethics found its initial impetus, and in which it has seen the most intense activity. It thus seems appropriate to make that activity the center of attention here.

Historical Background

An understanding of the emergence of bioethics will help to capture the panoramic breadth and complexity of the field. The 1960s is a pertinent point of departure, even though there were portents of the new field and issues in earlier decades. That decade brought into confluence two important developments, one scientific and the other cultural. In biomedicine, the 1960s was an era of extraordinary technological progress. It saw the advent of kidney dialysis, organ transplantation, medically safe abortions, the contraceptive pill, prenatal diagnosis, the widespread use of intensive-care units and artificial respirators, a dramatic shift from death at home to death in hospitals or other institutions, and the first glimmerings of genetic engineering. Here was a truly remarkable array of technological developments, the palpable outcome of the great surge in basic biomedical research and application that followed World War II. At the same time, stimulated by Rachel Carson's book *Silent Spring,* there was a gradual awakening to the environmental hazards posed by the human appetite for economic progress and the domination of nature. Taken together, these developments posed a staggering range of difficult, and seemingly new, moral problems.

Bioethics as a field might not have emerged so strongly or insistently had it not been for parallel cultural developments. The decade was the spawning ground for a dazzling array of social and cultural reform efforts. It saw a rebirth, within the discipline of moral philosophy, of an interest in normative and applied ethics, both out of a dissatisfaction with the prevailing academic emphasis on theoretical issues and in response to cultural upheavals. It was the era of the civil-rights movement, which gave African Americans and other people of color new rights and possibilities. It was the era that saw the rebirth of feminism as a potent social movement, and the extension to women of rights often previously denied them. It was the era that saw a fresh surge of individualism—a by-product in many ways of postwar affluence and mobility—and the transformation of many traditional institutions, including the family, the churches, and the schools. It was an era that came to see the enormous possibilities the life sciences offer to combat disease, illness, and death—and no less to see science's possibilities for changing the way human beings could live their lives.

Some of these possibilities had been foreseen in the important book *Medicine and Morals,* written by Joseph Fletcher, an Episcopal theologian who eventually came to reject religious beliefs. He celebrated the power of modern medicine to liberate human beings from the iron grip of nature, putting instead in their hands the power to shape lives of their own choosing. This vision began to be lived out in the 1960s. That decade brought together the medical advances that seemed to foreshadow the eventual conquest of nature and the cultural changes that would empower newly liberated individuals to assume full control of their own destinies. There was in this development both great hope and ambition, and perhaps great hubris, the prideful belief that humans could radically transcend their natural condition.

The advances of the biomedical sciences and their technological application had three great outcomes that came clearly into full view by the 1960s. They transformed first many traditional ideas about the nature and domain of medicine, then the scope and meaning of human health, and, finally, cultural and societal views of what it means to live a human life. Medicine was transformed from a diagnostic and palliative discipline into a potent agent able to cure disease and effectively forestall death. Human "health" more and more encompassed the 1947 World Health Organization definition with its broad emphasis on health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." Traditional notions of the living of a life were changed by longer life expectancies, the control of procreation, and powerful pharmacological agents able to modify mood and thought.

The advent of bioethics can be seen as the principal social response to these great changes. If there was any single, overarching question, it might have been this: How were human beings wisely to confront the moral puzzles, perplexities, and challenges posed by the confluence of the great scientific and cultural changes? But this large question concealed an intimidating range of more specific issues. Who should have control over the newly emergent technologies? Who should have the right or privilege to make the crucial moral decisions? How could individuals be assisted in taking advantage of the new medical possibilities or, if need be, protected from being harmed by them? How could the fruits of the medical advances be most fairly distributed? What kind of character or human virtues would be most conducive to a wise use of the new technologies? What kind of institutions, or laws, or regulations would be needed to manage the coming changes in a moral fashion?

Facts and Values

It soon became evident that such questions required more than a casual response. Two important tasks emerged. One of them, logically the first, was to distinguish the domain of science from that of ethics and values. As a consequence of the triumphalist positivism that during the late nineteenth and the first half of the twentieth century had come to dominate the general understanding of science, matters of ethics and values had been all but banished from serious intellectual discussion. A sharp line could be drawn, it was widely believed, between scientific facts and moral values (MacIntyre, 1981b). The former were solid, authoritative, impersonally true, while the latter were understood to be "soft," relativistic, and highly, even idiosyncratically, personal. Moreover, doctors should make the moral decisions no less than the medical decisions; indeed, a good medical decision was tantamount to a good moral decision. The first task of bioethics, then, was to erase the supposedly clear line that could be drawn between facts and values, and then to challenge the belief that those well trained in science and medicine were as capable of making the moral decisions as the medical decisions.

The second important task was to find or develop the methodologies necessary to come to grips with the new moral problems. If there is no sharp line between facts and values, how should their relationship be understood? If there is a significant difference between making a medical (or scientific) decision and making a moral decision, how are those decisions different and what kinds of skills are needed to make the one or the other? Who has a right to make the different kinds of decisions? If it is neither sensible nor fair to think of moral and value matters as soft and capriciously personal, hardly more than a matter of taste, then how can rigor and objectivity be brought to bear on them?

As the scope and complexity of these two large tasks became more obvious, the field of bioethics began to emerge. From the first, there was a widespread recognition that the moral problems would have to be approached in an interdisciplinary way (Callahan, 1973). Philosophy and religion, long the characteristic arenas for moral insight, analysis, and traditions, should have an important place, as should the historical moral traditions and practices of medicine and biology. Ample room would also have to be made for the law and for the social and policy sciences. Moral problems have important legal, social, political, and policy implications; and moral choices would often be expressed through court decisions, legislative mandates, and assorted regulatory devices. Hardly less important was the problem of which moral decisions should be left to private choice and which required some public standards. While there was a strong trend to remove procreational choices from public scrutiny, and thus to move toward the legal use of contraception and abortion, environmental choices were being moved from private choice to governmental regulation. Debates of this kind require the participation of many disciplines.

While the importance of an interdisciplinary approach was early recognized, three other matters were more troublesome. First, what should be the scope of the field? The term *bioethics,* as it was first used by the biologist Van Rensselaer Potter, referred to a new field devoted to human survival and an improved quality of life, not necessarily or particularly medical in character. The term soon was used differently, however, particularly to distinguish it from the much older field of medical ethics. The latter had traditionally been marked by a heavy, almost exclusive emphasis on the moral obligations of physicians and on the doctor–patient relationship. Yet that emphasis, while still important, was not capacious enough to embrace the huge range of emerging issues and perspectives. *Bioethics* came to refer to the broad terrain of the moral problems of the life sciences, ordinarily taken to encompass medicine, biology, and some important aspects of the environmental, population, and social sciences. The traditional domain of medical ethics would be included within this array, accompanied now by many other topics and problems.

Second, if the new bioethics was to be interdisciplinary, how would it relate to the long-standing disciplines of moral theology and moral philosophy? While those disciplines are able to encompass some interdisciplinary perspectives, they also have their own methodologies, developed over the years to be tight and rigorous. For the most part, moreover, their methodologies are broad, aimed at moral problems in general, not just at biomedical issues. Can they, in their broad, abstract generality, do justice to the particularities of medical or environmental issues?

Another problem becomes apparent. An interdisciplinary field is not necessarily well served by a tight, narrow methodology. Its very purpose is to be open to different perspectives and the different methodologies of different disciplines. Does this mean, then, that although parts of bioethics might be rigorous—the philosophical parts taken by themselves or the legal parts—the field as a whole may be doomed to a pervasive vagueness, never as strong as a whole as its individual parts? This is a charge sometimes leveled against the field, and it has not been easy for its practitioners to find the right balance of breadth, complexity, and analytical rigor.

Varieties of Bioethics

As the field has developed, it has become clear that because of the range of diversity of bioethics issues, more than one methodology is needed; by the same token, no single discipline can claim a commanding role. At least four general areas of inquiry can be distinguished, even though in practice they often overlap and cannot clearly be separated.

THEORETICAL BIOETHICS. Theoretical bioethics deals with the intellectual foundations of the field. What are its moral roots and what ethical warrant can be found for the moral judgments made in the name of bioethics? Part of the debate turns on whether its foundations should be looked for within the practices and traditions of the life sciences, or whether they have philosophical or theological starting points. Philosophers and theologians have a central place in this enterprise, but draw strongly upon the history and practices of the life sciences to grasp the aims and developments of these fields.

CLINICAL ETHICS. Clinical ethics refers to the day-to-day moral decision making of those caring for patients. Because of that context, it typically focuses on the individual case, seeking to determine what is to be done here and now with a patient. Should a respirator be turned off? Is this patient competent to make a decision? Should the full truth be disclosed to a fearful cancer patient? Individual cases often give rise to great medical and moral uncertainty, and they evoke powerful emotions among those with a role in the decisions. Decision-making procedures, as well as the melding of theory and practice—what Aristotle called "practical reason"—come sharply into play. It is the concreteness of the judgment that is central here: What is to be done for this patient at this time? The experience of practicing physicians, other healthcare workers, and patients themselves takes a prominent place, yet on occasion can require a collaborative interplay with those trained more specifically in ethics.

REGULATORY AND POLICY BIOETHICS. The aim of regulatory and policy bioethics is to fashion legal or clinical rules and procedures designed to apply to types of cases or general practices; this area of bioethics does not focus on individual cases. The effort in the early 1970s to fashion a new legal definition of clinical death (from a heart-lung to a brain-death definition), the development of guidelines for the use of human subjects in medical research, and hospital rules for do-not-resuscitate (DNR) orders are examples of regulatory ethics. It can also encompass policies designed to allocate scarce healthcare resources or to protect the environment. Regulatory ethics ordinarily seeks laws, rules, policies, and regulations that will command a wide consensus, and its aim is practical rather than theoretical. The law and the policy sciences are highly important in this kind of bioethics work; but it also requires a rich, ongoing dialogue among those concerned with theoretical bioethics, on the one hand, and clinical ethics and political realities, on the other. Regulatory bioethics seeks legal and policy solutions to pressing societal problems that are ethically defensible and clinically sensible and feasible.

CULTURAL BIOETHICS. Cultural bioethics refers to the effort systematically to relate bioethics to the historical, ideological, cultural, and social context in which it is expressed. How do the trends within bioethics reflect the larger culture of which they are a part? What ideological leanings do the moral theories undergirding bioethics openly or implicitly manifest? A heavy emphasis on the moral principle of autonomy or self-determination can, for example, be said to display the political and ideological bias of culturally individualistic societies, notably the United States. Other nations—those in central and eastern Europe, for instance—give societal rather than individual concerns a more pronounced priority (Fox). Solidarity rather than autonomy would be their highest value.

The social sciences, as well as history and the humanities, have a central place in this interpretive effort (Marshall). If done well, the insights and analysis they provide can help everyone to a better understanding of the larger cultural and social dynamic that underlies the ethical problems. Those problems will usually have a social history that reflects the influence of the culture of which they are a part. Even the definition of what constitutes an ethical "problem" will show the force of cultural differences. Countries with strong paternalistic traditions may not consider it necessary to consult with patients about some kinds of decisions; they will not see the issue of patient choice or informed consent as a moral issue at all—yet they may have a far livelier dedication to equality of access to healthcare.

General Questions of Bioethics

While bioethics as a field may be understood in different ways and be enriched by different perspectives, at its heart lie some basic human questions. Three of them are paramount. What kind of a person ought I to be in order to live a moral life and to make good ethical decisions? What are my duties and obligations to other individuals whose life and well-being may be affected by my actions? What do I owe to the common good, or the public interest, in my life as a member of society? The first question bears on what is often called an ethic of virtue, whose focus is that of personal character and the shaping of those values and goals necessary to be a good and decent person. The second question recognizes that what we do can affect, for good or ill, the lives of others, and tries to understand how we should see our individual human relationships—what we ought to do for others and what we have a right to expect from them. The third question takes our social relationships a step further, recognizing that we are citizens of a nation and members of larger social and political communities. We are citizens and neighbors, sometimes acquaintances, and often people who will and must live together in relatively impersonal, but mutually interdependent, ways.

These are general questions of ethics that can be posed independently of the making of biomedical decisions. They can be asked of people in almost any moral situation or context. Here we encounter an important debate within bioethics. If one asks the general question "What kind of person ought I to be in order to make good moral decisions?" is this different from asking the same question with one change—that of making "good moral decisions in medicine"? One common view holds that a moral decision in medicine ought to be understood as the application of good moral thinking in general to the specific domain of medicine (Clouser). The fact that the decision has a medical component, it is argued, does not make it a different kind of moral problem altogether, but an application of more general moral values or principles. A dutiful doctor is simply a dutiful person who has refined his or her personal character to respond to and care for the sick. He or she is empathic to suffering, steadfast in devotion to patients, and zealous in seeking their welfare.

Another, somewhat older, more traditional view within medicine is that an ethical decision in medicine is different, precisely because the domain of medicine is different from other areas of human life and because medicine has its own, historically developed, moral approaches and traditions. At the least, it is argued, making a decision within medicine requires a detailed and sensitive appreciation of the characteristic practices of medicine and of the art of medicine, and of the unique features of sick and dying persons. Even more, it requires a recognition of some moral principles, such as *primum non nocere* (first, do no harm) and beneficence, that have a special salience in the doctor–patient relationship (Pellegrino and Thomasma). The argument is not that the ethical principles and virtues of medical practice find no counterpart elsewhere, or do not draw upon more general principles; it is their combination and context that give them their special bite.

The Foundations of Bioethics

There may not be a definitive resolution to the puzzle of whether bioethics should find its animating moral foundations within or outside medicine and biology. In any case, with time these two sources become mixed, and it seems clear that both can make valuable contributions (Brody, 1987). Perhaps more important is the problem of which moral theories or perspectives offer the most help in responding to moral issues and dilemmas.

Does an ethic of virtue or an ethic of duty offer the best point of departure? In approaching moral decisions, is it more important to have a certain kind of character, disposed to act in certain virtuous ways, or to have at hand moral principles that facilitate making wise or correct choices? The traditions of medicine, emphasizing the complexity and individuality of particular moral decisions at the bedside, have been prone to emphasize those virtues thought to be most important in physicians. They include dedication to the welfare of the patient and empathy for those in pain. Some philosophical traditions, by contrast, have placed the emphasis on *principlism*—the value of particular moral principles that help in the actual making of decisions (Childress; Beauchamp and Childress). These include the principle of respect for persons, and most notably respect for the autonomy of patients; the principle of beneficence, which emphasizes the pursuit of the good and the welfare of the patient; the principle of nonmaleficence, which looks to the avoidance of harm to the patient; and the principle of justice, which stresses treating persons fairly and equitably.

The advantage of principles of this kind is that, in varying ways and to different degrees, they can be used to protect patients against being harmed by medical practitioners and to identify the good of patients that decent medical and healthcare should serve. Yet how are such principles to be grounded, and how are we to determine which of the principles is more or less important when they conflict? Moral principles have typically been grounded in broad theories of ethics—utilitarianism, for example, which justifies acts as moral on the basis of the consequences of those acts (sometimes called consequentialism). Utilitarian approaches ask which consequences of a choice or an action or a policy would promote the best possible outcome. That outcome might be understood as maximizing the widest range of individual preferences, or promoting the greatest predominance of good over evil, or the greatest good of the greatest number. Just what one should judge as a "good" outcome is a source of debate within utilitarian theory, and a source of criticism of that theory. Such an approach to healthcare rationing, for instance, would look for the collective social benefit rather than advantages to individuals.

A competing theory, deontology, focuses on determining which choices most respect the worth and value of the individual, and particularly the fundamental rights of individuals. The question of our basic obligations to other individuals is central. From a deontological perspective, good consequences may on occasion have to be set aside to respect inalienable human rights. It would be wrong, for instance, to subject a human being to dangerous medical research without the person's consent even if the consequences of doing so might be to save the lives of many others. Our transcendent obligation is toward the potential research subject.

Not all debates about moral theory come down to struggles between utilitarianism and deontology, though that struggle has been central to much of the moral philosophy that influenced bioethics in its first decades. Other moral theories, such as that of Aristotle, stress neither principles nor consequences but see a combination of virtuous character and seasoned practical reason as the most likely source of good moral judgment. For that matter, a morality centering on principles raises the problems of the kind of theory necessary to ground those principles, and of how a determination of priorities is to be made when the principles conflict (Clouser and Gert). A respect for patient autonomy, stressing the right of competent patients to make their own choices, can conflict with the principle of beneficence if the choice to be made by the patient may actually be harmful. And autonomy can also conflict with the principle of nonmaleficence if the patient's choice would seem to require that the physician be the person who directly brings harm to the patient.

Another classical struggle turns on the dilemma that arises when respect for individual freedom of choice poses a threat to justice, particularly when an equitable distribution of resources requires limiting individual choice. Autonomy and justice are brought into direct conflict. Recent debates on healthcare rationing, or setting priorities, have made that tension prominent.

Even if principles—like autonomy and justice—are themselves helpful, their value declines sharply when they are pitted against each other. What are we supposed to do when one important moral principle conflicts with another? The approach to ethics through moral principles—often called *applied ethics*—has emphasized drawing those principles from still broader ethical theory, whose role it is to ground the principles. Moral analysis, then, works from the top down, from theory to principles to case application. An alternative way to understand the relationship between principles and their application, far more dialectical in its approach, is the method of *wide reflective equilibrium.* It espouses a constant movement back and forth between principles and human experience, letting each correct and tutor the other (Daniels).

Still another approach is that of casuistry, drawn from methods commonly used in the Middle Ages. In contrast with principlism, it works from the bottom up, focusing on the practical solving of moral problems by a careful analysis of individual cases (Jonsen and Toulmin). A casuistical strategy does not reject the use of principles but sees them as emerging over time, much like the common law that has emerged in the Anglo-American legal tradition. Moral principles derive from actual practices, refined by reflection and experience. Those principles are always open to further revision and reinterpretation in light of new cases. At the same time, a casuistical analysis makes prominent use of analogies, employing older cases to help solve newer ones. If, for instance, general agreement has been reached that it is morally acceptable to turn off the respirator of a dying patient, does this provide a good precedent for withdrawing artificially provided hydration and nutrition? Is the latter form of care morally equivalent to the former, so that the precedent of the former can serve to legitimate the latter? Those are the kinds of questions that a casuistical analysis would ask. At the same time, a casuistical analysis runs the risk of being too bound to past cases and precedents. It can seem to lack the capacity to signal the need for a change of moral direction (Arras).

Still another principle-oriented approach proposes a new social contract between medicine and society (Veatch).

Such a contract would be threefold. It comprises basic ethical principles for society as a whole, a contract between society and the medical profession about the latter's social role, and a contract between professionals and laypersons that spells out the rights and prerogatives of each. This strategy is designed both to place the ethics of medicine squarely within the ethical values of the larger society and to make sure that laypeople have sufficient choice and power to determine the kind of care they, and not paternalistic physicians, choose. Still another approach, more skeptical about finding any strong consensus on ethical foundations, stresses an ethic of secular pluralism and social peace, devising a minimal ethic for the community as a whole but allowing great play to the values and choices of different religious and value subcommunities (Engelhardt).

Contemporary feminist approaches to bioethics, like casuistry, reject the top-down rationalistic and deductivist model of an ethic of principles (Baier; Sherwin). They reject even more adamantly what is seen as the tendency of an ethic of principles to universalize and rationalize. Feminist ethics lays a far heavier emphasis on the context of moral decisions, on the human relationships of those caught in the web of moral problems, and on the importance of feeling and emotion in the making of moral decisions. Feminist approaches, rooted in ways of thinking about morality that long predate the feminist movement of recent decades, also reflect a communitarian bias, reacting against the individualism that has been associated with a principle-oriented approach. Feminist thinkers commonly argue that those who lack power and status in society are often well placed to see the biases even of those societies that pride themselves on equality. While feminism has gained considerable prominence in recent years, it is only one of a number of efforts to find fresh methods and strategies for ethical analysis and understanding. These include phenomenological analyses, narrative-based strategies, and hermeneutical, interpretive perspectives (Zaner; Brody, 1987).

How Important is Moral Theory?

There can be little doubt that the quest for the foundations of bioethics can be difficult and frustrating, no less so than the broader quest for the foundations of ethics in general (MacIntyre, 1981a). Yet how important for bioethics are moral theory and the quest for a grounding and comprehensive theory? Even the answers to that question are disputed. At one extreme are those who believe that bioethics as a discipline cannot expect intellectual respect, much less legitimately affect moral behavior, unless it can show itself to be grounded in solid theory justifying its proposed virtues, principles, and rules. At the other extreme are those who contend that—even if there is no consensus on theory—social, political, and legal agreement of a kind sufficient to allow reasonable moral decisions to be made and policy to be set can be achieved. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research of the early 1980s, and the National Commission for the Protection of Human Subjects in the mid-1970s, were able to achieve considerable agreement and gain general public and professional respect even though individual members disagreed profoundly on the underlying principles of the consensus. There is of course nothing new in that experience. The American tradition of freedom of religion, for instance, has been justified for very different reasons, both theological and secular—reasons that in principle are in fundamental conflict with each other, yet are serviceable for making policy acceptable to believers and nonbelievers alike.

What kind of authority can a field so full of theoretical and practical disputes have? Why should anyone take it seriously? All important fields, whether scientific or humanistic, argue about their foundations and their findings. Bioethics is hardly unique in that respect. In all fields, moreover, agreement can be achieved on many important practical points and principles even without theoretical consensus. Bridges can be built well even if theoretical physicists disagree about the ultimate nature of matter. But perhaps most important, one way or another, moral decisions will have to be made, and they will have to made whether they are well grounded in theory or not. People must do the best they can with the material at hand. Even in the absence of a full theory, better and worse choices can be made, and more or less adequate justification can be offered. As the field progresses, even the debates on theory can be refined, offering greater insight and guidance even if the theories are still disputable.

Where, then, lies the expertise and authority of bioethics (Noble)? It lies, in the end, in the plausible insight and persuasive rationality of those who can reflect thoughtfully and carefully on moral problems. The first task of bioethics—whether the issues are clinical, touching on the decisions that must be made by individuals, or policy-oriented, touching on the collective decisions of citizens, legislators, or administrators—is to help clarify what should be argued about. A closely related task will be to suggest how these issues should be argued so that sensible, moral decisions can be made. Finally, there will be the more advanced, difficult business of finding and justifying the deepest theories and principles. There can, and will, be contention and argument at each of these stages, and it well may appear at first that no resolution or agreement can be found. Endless, unresolved disagreement in fact rarely occurs in practice, and that is why, if one looks at bioethics over a period of decades, achieved agreement and greater depth can be found, signs of progress in the field. The almost complete acceptance of such concepts as *patient rights, informed consent,* and *brain death,* for instance—all at one time heatedly disputed concepts—shows clearly enough how progress in bioethics is and can be made.

Making Good Moral Decisions

Good individual decision making encompasses three elements: self-knowledge, knowledge of moral theories and traditions, and cultural perception. Self-knowledge is fundamental because feelings, motives, inclinations, and interests both enlighten and obscure moral understanding. In the end, individual selves, alone with their thoughts and private lives, must wrestle with moral problems. This sort of struggle often forces one to confront the kind of person one is, to face one's character and integrity and one's ability to transcend narrow self-interest to make good moral decisions. And once a decision is made, it must be acted upon. A decision of conscience blends moral judgment and the will to act upon that judgment (Callahan, 1991). A complementary kind of knowledge, not easy to achieve, is also needed. Even as individuals we are social creatures, reflecting the times in which we live, embodied in a particular society at a particular time. Our social embeddedness will shape the way we understand ourselves, the moral problems we encounter, and what we take to be plausible and feasible responses to them. Moral theory by itself is hardly likely to be able to give us all the ingredients needed for an informed, thoughtful moral judgment. Only if it is complemented by self-understanding and reflectiveness about the societal and cultural context of our decisions can moral theory be fleshed out sufficiently to be helpful and illuminating. Good moral judgment requires us to move back and forth among the necessary elements: the reflective self, the interpreted culture, and the contributions of moral theory. No one element is privileged; each has an indispensable part to play.

Yet something else is needed as well: a vision of the human good, both individual and collective. The biomedical, social, and environmental sciences produce apparently endless volumes of new knowledge about human nature and its social and natural setting. However, for that knowledge to be useful or meaningful, it must be seen in light of some notions of what constitutes the good of human life. What should human beings seek in their lives? What constitute good and worthy human ends? Proponents of the technological advances that emerge from the life sciences claim they can enhance human happiness and welfare. But that is likely to be possible only to the extent we have some decent idea of just what we need to bring us happiness and an enhanced welfare.

Bioethics must pay sustained attention to such issues. It cannot long and successfully attend only to questions of procedure, or legal rules and regulations, without asking as well about the ends and goals of human life and activity. Ethical principles, rules, and virtues are in part a function of different notions of what enhances human life. Implicitly or explicitly, a picture of human life provides the frame for different theories and moral strategies of bioethics. This picture should animate living a life of our own, in which we develop our own understanding of how we want to live our individual lives, given the vast array of medical and biological possibilities; living our life with other human beings, which calls up ideas of rights and obligations, bonds of interdependency, and the creation of a life in common; and living our life with the rest of nature, which has its own dynamics and ends but provides us with the nurturing and natural context of our human lives.

Is there such a thing as the human good, either individually or collectively? Is there something we can, in an environmental context, call the good of nature? There is no agreement on the answer to those questions; on the contrary, there is fundamental disagreement. Some would argue that ethics can proceed with a relatively thin notion of the human good, placing the emphasis on developing those moral perspectives that would make it most possible to live with our differences about the meaning and ends of life. Others stress the importance of the substantive issues and reflect some basic doubt about whether ethics can proceed very far, or have sufficient substance, without trying to gain some insight into, and agreement upon, those basic matters (Kass; Callahan, 1993). Those debates must continue.

The greatest power of the biomedical, social, and environmental sciences is their capacity to shape the way we as human beings understand ourselves and the world in which we live. At one level—the most apparent—they give us new choices and thus new moral dilemmas. At another level, however, they force us to confront established views of our human nature, and thus to ask what we should be seeking: What kind of people do we want to be? A choice about artificial reproduction, say surrogate motherhood, is surely a moral choice. But it is also a way into the question of how we should understand the place of procreation in our private lives and in society. To see that is to appreciate profound challenges to our understanding of sexual and familial roles and purposes. The boundaries of bioethics cannot readily be constrained. The expanding boundaries force us to take up larger and deeper problems, much as a small stone tossed into the water creates larger and larger ripples.

Summary

In its early days, contemporary bioethics was generally seen as an activity on the fringes of research and practice in the life sciences; it had no place within environmental analysis. The dominant view was that the life sciences were a strictly scientific endeavor, with questions of morality and values arising only now and then in the interstices. That view has gradually changed. The life sciences are increasingly understood as, at their core, no less a moral endeavor than a scientific one. Ethics lies at the very heart of the enterprise, if only because facts and values can no longer be clearly separated—any more than the ends of the life sciences can be separated from the means chosen to pursue them.

No less important, questions of the moral means and ends of the life sciences cannot be long distinguished from the moral means and ends of the cultures and societies that pursue and deploy them. Here, fundamental questions must be asked. First, what kind of medicine and healthcare, what kind of stance toward nature and our environment, do we need for the kind of society we want? Such a question presupposes that we have some end in view for our society, though that may not be all that clear. What is clear, however, is that it is almost impossible to think for long about bioethics without being forced to think even more broadly about the society in which it will exist and whose ends—for better or worse—it will serve.

The second question reverses the first: What kind of a society ought we to want in order that the life sciences will be encouraged and helped to make their best contribution to human welfare? The contribution bioethics makes will in great part be a function of the goals sought by the life sciences, and those in turn will be stimulated or formed by society's goals. The life sciences shape the way we think about our lives, and thus they increasingly provide some key ingredients in society's vision of itself and in the lives of the citizens who comprise society.

Understood in terms of these two broad questions, bioethics takes its place at the heart of the enterprise of the life sciences. Only a part of its work will bear on dealing with the daily moral dilemmas and ethical puzzles that are part of contemporary healthcare and environmental protection. A no less substantial part will be to help shape the social context in which those dilemmas and puzzles play themselves out. At its best, bioethics will move back and forth between the concreteness of necessary individual and policy decisions and the broad notions and dynamic of the human situation. It is still a new field, seeking to better define itself and to refine its methods. It has made a start in shaping its direction and possible contribution, but only a start.

DANIEL CALLAHAN (1995)

SEE ALSO: *Abortion; Animal Welfare and Rights; Bioethics Education; Clinical Ethics; Death, Definition and Determination of; Environmental Ethics; Ethics; Eugenics and Religious Law; Fertility Control; Genetic Testing and Screening; Health and Disease; Healthcare Resources; Informed Consent; Life, Quality of; Life Sustaining Treatment and Euthanasia; Medical Ethics, History of; Mental Health; Population Ethics; Reproductive Technologies*

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BIOETHICS: AFRICAN-AMERICAN PERSPECTIVES

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The type of healthcare delivery system used by a society says a great deal about what that society thinks of its most vulnerable citizens. African Americans in U.S. society have historically been treated unfairly in every dimension of group and individual life—subjected to segregated and inferior medical services, housing, employment, education, as well as racist environmental policies and practices. These are all factors that determine the collective and individual health of African Americans, which has been, and continues to be, worse than that of white people in the United States.

Until recently, mainstream bioethics paid little attention to the role of race, racism, and ethnicity in bioethical discourse. As opposed to specific issues like stem cell research, abortion, or end-of-life discussions, race plays a role in every ethical conundrum from violation of informed consent to allocation of organ donations. Notably, over the last few years, more bioethicists are devoting serious scholarship to the examination of race as a topic for debate.

An African-American perspective on bioethical issues brings to the table concerns that are important to the health and well-being of African Americans, concerns that are marginalized in mainstream bioethics. They include racial disparities in health status; racial disparities in access to healthcare and technologies; continued medical research abuses; and other factors contributing to poor health such as toxic dumping in communities of color, poor housing, dangerous jobs, and lack of adequate health insurance. African-American perspectives address a major principle: The health disparities of U.S. racial and ethnic groups are a fundamental bioethics issue.

Bioethics Perspective I: Health Disparities

What are health disparities and why are they ethical violations? Olivia Carter-Pokras and Claudia Baquet discuss a number of definitions that have emerged since 1985, when the U.S. Department of Health and Human Services issued the *Report of the Secretary's Task Force on Black and Minority Health.* The Task Force defines health disparities as excess mortality of minorities as compared to that of whites. Healthy People 2010, whose goal is to eliminate disparities, defines them as differences that occur by gender, race or ethnicity, education or income, disability, and residence in rural localities. The National Institutes of Health (NIH) defines disparities as differences in incidence, prevalence, mortality, and burden of disease (Carter-Pokras and Baquet).

According to reports from the Centers for Disease Control (CDC), African Americans have higher death rates than whites due to cancers, diabetes, cirrhosis, homicide, AIDS, and cardiovascular diseases. Maternal death is between three and four times higher for black women than for white women. More white women have breast cancer, but the death rate is higher in black women and is increasing.

The excessive rates of illness contribute to the higher mortality rate of African Americans; the National Vital Statistics Report puts life expectancy for white women at 80.0 years; 74.9 years for black women; 74.8 years for white men; and for black men it is 68.2 years (Arias).

Beginning with slavery and continuing throughout the twentieth century, a persistent and disturbing gap has characterized the health status of African Americans and whites. At emancipation public health officials predicted that freedom would lead to the extinction of the former slaves, who did, in fact suffer numerous health problems, including tuberculosis, malaria, excessive malnutrition, pellagra, and syphilis. The disparities continued throughout the twentieth century and into the beginning of the twenty-first.

A number of reports and policies established goals and recommendations to improve the alarming state of African Americans' health. With the launching of Medicare and Medicaid in 1966, the health of blacks improved, as did that of whites, but the health gap remained. In 1985 the previously mentioned Task Force made recommendations for reducing the disparities. In 1990 the American Medical Association (AMA) Council on Ethical and Judicial Affairs published an influential and much cited article on the disparities. In 1998 President Bill Clinton established the *Initiative to Eliminate Race and Ethnic Disparities* in health by 2020.

Despite some improvement over the years, the health gaps persevere and in some instances have gotten worse as the twenty-first century began. In 1970 infant mortality in blacks was twice that of whites; at the beginning of the twenty-first century, black infant mortality is still twice that of whites. In 1970 deaths due to asthma were about three times higher in blacks; at the beginning of the twenty-first century, deaths due to asthma have increased: They are now five times higher than in whites (Centers for Disease Control, 1996). Researchers Robert Levine and his colleagues report that the disparities have not improved since the end of World War II, despite decades of funding for health-related programs.

Some observers attribute the health gap to biology, suggesting that excess infant deaths and disproportionate incidences of lung cancer and breast cancer deaths are due to genetic differences. Others attribute the high rate of sickness and death to *irresponsible lifestyles.* According to this explanation, African-American women and men refuse or neglect to get timely cancer screenings until it is too late to curb the spread of the condition, or they prefer to smoke high-nicotine content cigarettes and drink high-alcohol content liquor that increase lung and liver disease (Moore, Williams, and Qualls). Still others attribute the disparity in health status to cultural attitudes and deficits that prevent health-seeking behaviors that take advantage of available health services; patient and family beliefs at variance with those of medical professionals; and negative attitudes toward healthcare providers. This explanation, for example, asserts that African Americans prefer dialysis to a kidney transplant (Ayanian et al.). In particular, many authors single out suspicion of the healthcare system as a barrier to seeking care. Indeed, many African Americans fear that they will become guinea pigs for unethical medical research (Thomas and Quinn; Dula).

Health researchers are beginning to acknowledge that health disparities do not merely reflect class, lifestyle choices, or genetics. They are also a result of current and accumulative racism and discrimination in U.S. society (Peterson et al.). Yet the word racism is grudgingly used even though it is a statistical fact that one's race often determines the quality and quantity of services, procedures, and healthcare that one receives. Health disparities must be understood as a bioethical issue if they result in more sickness and shorter life spans for African-American populations as compared to white populations. If these disparities are a result of racial discrimination, they ought to be ethically unacceptable in a just society.

Bioethics Perspective II: Race and Racism in Access to Healthcare

Differential treatment based on race or the group to which one belongs is an ethical problem because such treatment usually has a negative impact on life opportunities, education, and physical and mental well-being. African Americans have always been sicker and lived fewer years than whites; they have historically had—and continue to receive—different, unequal, and inferior access to healthcare. The prestigious Institute of Medicine's (IOM) March 2002 report evaluated over 100 studies focusing on health disparities published over the previous ten years. The IOM panel found that minorities who have the same income, education, medical conditions, and insurance as whites still receive poorer care than do the latter, showing that race is a significant variable in the health and healthcare of African Americans. Even though heart disease is a top killer of African Americans, whites get more aggressive treatment. Blacks with coronary heart disease are significantly less likely than whites to undergo bypass surgery, angioplasty, and a host of other services and procedures. Differential and racist treatment regarding kidney transplants, intensive care unit (ICU) treatment, and even the kind of information provided to pregnant women of different races have all been thoroughly documented.

Differential treatment is illustrated in government programs that provide health insurance for poor people on

Medicaid, elders insured by Medicare, and U.S. veterans. In these systems, no money is passed between patient and provider; thus, one assumes that patient enrollees in these three programs would be treated fairly, regardless of race. Studies of the distribution of services under all three programs show that blacks get a lower quality of care that whites. Under Medicare Managed Care, African Americans are less likely to receive breast cancer screening, diabetic eye examinations, beta-blockers for myocardial infarction, and mental health follow-up (Schneider, Zaslavsky, and Epstein). In Veterans Administration (VA) hospitals, black U.S. veterans get substantially fewer treatments for Acute Myocardial Infarction (AMI) than do white veterans and are less likely to undergo cardiac catheterization and to receive coronary bypass surgery (Peterson et al.). Medicaid too offers differential and substandard treatment to people of color. African-American children have a disproportional incidence of asthma; prevalence is twice that of whites, and death rates between 1980 and 1993 were four to six times higher (Centers for Disease Control, 1997; National Institute of Allergy and Infectious Diseases). Yet black and Latino children with worse asthma status are prescribed fewer preventive asthma medications than are white children within the same managed Medicaid plan (Lieu, Lozano, and Finkelstein).

Government programs also perpetuate disparities in health status and access to services in other ways. Due to federal medical criteria, African Americans receive proportionately fewer kidneys and they wait twice as long for them as whites. World-renowned transplant surgeon Thomas Starzl and his colleagues report that the national kidney allocation system inherently favors white patients because of the heavy emphasis placed on donor-recipient compatibility. They argue that antigen matching should not weigh so heavily in deciding who gets a kidney since differences in survival rates (the justification for current donor allocation) are negligible (Starzl, Aliasziw, and Gjertson).

Whether disproportional access to healthcare and services is intentional, it is clear that race is a factor in the delivery of healthcare in the United States. Although discussions of racism in healthcare and services have been prominent in other academic disciplines, it has been insufficiently explored in the area of bioethics. Differential treatment in access to healthcare is unassailably a bioethics issue.

Bioethics Perspective III: Informed Consent and Racism in Research

Informed consent in research is an ethical principle that has particular relevance to African Americans and similarly vulnerable populations. Throughout the history of this country, medical research has supported racist social institutions. The Tuskegee Syphilis Experiment (TSS) is the most egregious violation of informed consent against a specific group of people, but it certainly is not an isolated example. Enslaved women were used to conduct painful research on urine leaks into the vagina and black women were used to perfect Cesarean sections (Reverby). More recently, President Clinton's Advisory Committee on Human Radiation Experiments observed that in several studies, research subjects were disproportionately chosen from minority populations. Questions have also been raised about an early 1990s measles vaccine trial that involved mostly minority children in several inner cities (Marwick). All these studies are examples of research without consent.

Although blacks have been over-represented in unethical research, generally they have been excluded from ethically conducted research studies that might benefit future populations of African Americans. In an attempt to remedy this, the NIH Revitalization Act of 1993 mandated that women and minorities be included in federally funded research. However, during the ten years since the enactment, despite attempts at aggressive recruitment, researchers still have difficulty enrolling African Americans in clinical trials. Low participation is due to mistrust of the medical/scientific community because of real and perceived medical abuse; poor access to primary care physicians who make most referrals to trials; scarcity of minority health professionals who might facilitate enrollment; potential enrollees' lack of knowledge about clinical trials; and language and cultural barriers. The most significant factor that contributes to low participation in clinical trials is African American suspicion of the healthcare system. Until researchers understand the psychic, physical, and emotional damage done by racism in medicine and in the larger society, they will continue to have trouble recruiting African Americans for research. Despite possible benefits from research, an African-American perspective reminds one that research still offers a potent possibility for continued abuse.

Bioethics Perspective IV: Difference and Biology

One goal of the TSS was to show that the course of syphilis was different in blacks, suggesting biological differences between blacks and whites. Similarly, an underlying motive behind the enactment of the aforementioned NIH Revitalization initiative was that minorities and women sometimes respond differently from white men to the same drug, again suggesting the possibility of biological difference among races.

Belief in biological difference has long been used to justify different treatment in social arrangements. Aristotle said that from their birth, some people were set out for subjection and others to rule. Slaves were to be ruled by their masters, women by their husbands, and children by their parents. Difference has been used to establish authority and hierarchies; dominance and subordination; superiority and inferiority; the rulers and the ruled; us and them; good and evil; the beautiful and the ugly; and the civilized and the savage. Concepts of difference have been used to oppress, exploit, maintain the status quo, strip people of their rights, and prevent them from making decisions regarding their own well-being. For the most part these hierarchies in the United States have separated whites from nonwhites.

The construction of *difference* or *the other* was used as a rationale so that one group—the group in power—could do as they wished with another group. The political uses of difference led to slavery, colonialism, racism, classism, and sexism, as well as other atrocities and racist brutalities like lynching, rape, medical neglect, and research abuse. The construction of the other worked well for those in power; if people were biologically different—not quite human—they did not have to be treated as moral agents. This of course was part of the implicit justification for the TSS. The men were different (they were black), so they could be treated differently.

Scientists have long been fascinated with the possibility of genetic differences between blacks and whites and they continue to search for *black* genes that explain disproportionate susceptibility to breast and lung cancers, heart disease, violent behavior and intelligence deficits, poverty, and the relation between race and detrimental health effects of environmental pollution.

In the March 20, 2003, issue of the *New England Journal of Medicine,* two articles highlight the controversy surrounding race and disease susceptibility. On the one hand, Esteban Gonzalez Burchard and his colleagues argue that there are racial and ethnic differences in the causes and expressions of various diseases. Richard Cooper and his colleagues, on the other hand, see race as a social category, not biological, and think that doctors have been too quick to suggest genetics as the reason for the greater susceptibility of African Americans to certain diseases. As with the TSS, race is again explicitly linked to ideas of biological differences between racial and ethnic groups (Cooper, Kaufman, and Ward).

As the debate about biology and disease susceptibility continues, the TSS is a reminder of the hazards of research on race-based differences. Genetic explanations often neglect or gloss over the interactions of genes and the environment. It is important to remember that when blacks receive comparable treatment for lung cancer or breast cancer, their survival rate is comparable to that of whites (Bach, Schrag, and Brawley) and that when black VA patients receive the same treatment as whites, they also receive a survival advantage (Jha et al.).

Bioethics Perspective V: The Colorblindness of Bioethics

Bioethicists, in efforts to be colorblind, *white* out the experience of color as a bioethical issue, as well as the harmful effects of racism on health. A colorblind bioethics has the unfortunate potential of increasing health inequalities if it recognizes only the larger ethical issue in a policy or practice, and not also how that policy might affect less dominant populations. When ethicists ignore race, they remove racism and its effects on health from ethical debate. In a sense, a colorblind bioethics is misleading because it makes judgments based on incomplete information. Regrettably, race and racism are not high priority topics in bioethics.

The TSS is the paradigm case of the intersection of race, bioethics, and the healthcare system. In Macon County, Alabama, between 1932 and 1972, the U.S. Public Health Service conducted a study involving 399 African-American men and 200 controls to determine the course of untreated syphilis in the male Negro. During the study the men were told that they were being treated for bad blood. When the case came to public attention in 1972, a great deal of the bioethical discussion and debate centered around the lack of informed consent; deception and lying; the ethical and scientific benefits of research; the ethics of withholding treatment once penicillin became available; and the ethics of active intervention to prevent treatment. At the time of public disclosure of the study, there was little analysis of racism as a bioethics issue, even though the ethical violations clearly involved only black men and their families. The early failure to address the racism underlying the experiment illustrates the misguided colorblindness of bioethics.

Certainly mainstream bioethicists have done extremely valuable work from which society as a whole has benefited. Nonetheless white bioethicists have defined and shaped the field, deciding what is important. The interests, problems, and standpoints of those in power have obscured the unique concerns—race and racism in the healthcare system and in society at large—of African American and other people of color.

Happily, this is changing. More mainstream bioethicists are stepping outside their traditional role as white bioethicists, to consider race, racism, and white privilege as a valid bioethics concern. Bioethicist Catherine Myser—in an article dedicated to the late African-American bioethicist Marian Secundy—argues in the 2003 Spring issue of the *American Journal of Bioethics* that the cultural construction of bioethics in the United States has not sufficiently questioned the dominance and normativity of whiteness. The September–October 2001 issue of the *Hastings Center Report* also presented several articles on race and bioethics, including pieces by historian Susan Reverby and bioethicist Lawrence Gostin. Editor Greg Kaebnick comments on the movement of bioethicists to consider little talked about topics like race. Reverby revisits the TSS, and Gostin discusses the rights of pregnant women drawing on the late 1980s Medical University of South Carolina policy, which tested poor black pregnant women on Medicaid—without their consent—for drugs.

This entry has focused on some issues that make up a framework for African-American bioethcs: the ethics of health disparities, unequal access to healthcare based on race, and informed consent in research. Other framing issues include religion and suspicion of the healthcare system. Religion and spirituality play dominant roles in the lives of a majority of African Americans and is connected to social change. Any worldview that ignores this will fail to represent African-American reality. Also, any worldview that purports to represent African-American perspectives must take into account the widespread suspicion of the healthcare system. Suspicion has inhibited African Americans from participating in clinical trials for fear of being used as guinea pigs; it has led to false beliefs that the U.S government purposely infected the TSS men with syphilis; and it is responsible for the belief that the U.S. government is capable of genocide of the black population. Some think suspicion keeps African Americans from seeking timely care. The source of the suspicion resides in historically abusive treatment of African Americans at the hands of the healthcare system and the larger society. Annette Dula and Sara Goering's 1994 book *"It Just Ain't Fair": The Ethics of Health Care for African Americans* outlines additional considerations for African-American perspectives on bioethics.

When examined in this framework, from this perspective, every bioethics issues has a race/ethnicity element. For example, an African-American perspective challenges mainstream assumptions around end-of-life discussions. One mainstream assumption is that at the end of life, people will get unwanted healthcare that will compromise their dignity. Many African Americans believe the opposite; they are afraid that they will not get any treatment, let alone unwanted treatment, at the end of life. As a result they want all the care they can get at the end of life, even if it makes no sense. Given the lack of fair access to healthcare, the fear makes sense. Another assumption around end-of-life care is that people want to die with dignity. Mainstream bioethics associates dignity with quality of life. Most African Americans prefer quantity to quality of life, challenging the mainstream definition of dignity. Again this is reasonable since quantity of life for blacks has always been less than that for whites, and is often due to unfair practices of the healthcare system.

In a March 6, 2002, News Release, the Commonwealth Fund reported that African Americans are more likely than whites to experience difficulty communicating with physicians and to feel as if they were treated with disrespect when receiving healthcare. The doctor–patient relationship influences the quality of communication and health outcome. Doctor–patient communication is an important bioethics issue and has generated tomes of information. Just as African Americans have less access to healthcare, they also have fewer discussions with their physicians and their visits are less participatory. In many instances there is no meaningful communication because more blacks than whites lack a regular physician.

This discussion is meant not to vilify mainstream bioethics, but to show the need for a perspective and interpretation that focuses on bioethics issues that have a unique relevance for African-American populations.

ANNETTE DULA

SEE ALSO: *African Religions; Christianity, Bioethics in; Genetics and Racial Minorities; International Health; Islam, Bioethics in; Justice; Medical Ethics, History of Africa; Medicine, Anthropology of; Medicine, Sociology of; Minorities as Research Subjects; Organ Transplants, Sociocultural Aspects of; Race and Racism; Research, Multinational*

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BIOETHICS EDUCATION

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I. Medicine
II. Nursing
III. Secondary and Postsecondary Education
IV. Other Health Professions

I. MEDICINE

Education in medical ethics is as old as medical education itself. The Hippocratic school of medicine of fourth-century B.C.E. Greece is best remembered for the Hippocratic oath, which has provided moral guidance to students of medicine for more than two millennia.

For most of medicine’s history, efforts to inculcate ethical precepts relied on the apprenticeship model, through which medical students were guided in the simultaneous development of their knowledge, technical skill and judgment, and evolving sense of proper professional conduct (Bosk). Direct observation and emulation were the primary methods apprentices used to develop clinical judgment regarding right action.

In the second half of the twentieth century, however, the emerging field of biomedical ethics catalyzed a radical reexamination of the ways in which students learn to understand and manage ethical issues that arise in professional medical practice. Initially, this effort was led by nonphysician humanists—philosophers, theologians, and others—who developed interests in applied ethics and the medical humanities. In the early 1970s, medical schools, led by Penn State University, hired these humanists and began to offer first elective, then required, ethics courses for medical students. Rather than concentrating on the importance of mentorship and role modeling, these courses were rooted in a philosophical model, stressing ethical concepts such as autonomy and the importance of learning to apply ethical principles to discern the proper course of action. Lectures and seminars became the dominant method used to teach these cognitive skills. Unfortunately, with rare exceptions, the content of ethics training, particularly in the clinical years, has been either on the extreme ends of life or on technological innovations rather than on the day-to-day work of doctoring or justice-based concerns. Starting in the late 1990s, the difference in goals and methods between an apprenticeship model and a philosophical model of teaching medical ethics began to blur as programs focusing on professionalism arose. These programs concentrate more on physician character and offer the opportunity for medical ethics to focus more on the mundane ethical issues of doctoring.

The Growth of Medical Ethics Education

A series of empirical studies in the 1970s and 1980s documented the rapid growth of teaching programs. In a 1974 survey, 97 of 107 responding medical schools reported teaching medical ethics (Veatch and Solitto). Only six of these schools, however, reported a required exposure to medical ethics. In 1982 a majority of physicians reported that they had never received formal education in clinical ethics, and many felt inadequately prepared for common ethical problems in medicine (Pellegrino et al.). A 1985 study found that 84 percent of U.S. medical schools had some form of human values curricula during the first two years (Bickel). By 1989, 43 of 127 U.S. medical schools reported separate required courses in medical ethics (Miles et al.). In 2000, of the 125 American medical schools, 46 reported separate, required courses in medical ethics, 104 taught medical ethics as part of a required course, and 44 had separate electives in medical ethics; the numbers for teaching in medical humanities were 8, 87, and 51, respectively. The 2002 Association of American Medical Colleges (AAMC) graduation survey found that between 70 and 80 percent of students felt they had received adequate training in medical ethics.

It was not until the latter part of the 1980s that educators began to advocate explicit teaching in medical ethics during residency training. This is a critical formative period, because it is during their residency that physicians first acquire decision-making responsibilities, and thus can fully appreciate the relevance of medical ethics to patient care. In 1984 researchers found that residents in 40 percent of internal medicine residencies had no formal exposure to clinical ethics teaching (Povar and Keith). Two reports by the American Board of Internal Medicine and American Board of Pediatrics in the 1980s provided strong impetus to the development of teaching programs during the residency years. Since then, a growing number of other boards have issued recommendations regarding the teaching of medical ethics during residency. Moreover, residency requirements in medicine, surgery, pediatrics, and obstetrics-gynecology all require education in medical ethics, and the 2003 description of general competencies promulgated by the Accreditation Council for Graduate Medical Education (ACGME) requires that all residents “demonstrate a commitment to ethical principles pertaining to provision or withholding of clinical care, confidentiality of patient information, informed consent, and business practices” (ACGME website).

There was a long tradition of teaching medical deontology (study of moral obligation) in both Europe and Latin America, particularly in Catholic medical schools. But the 1980s saw in these countries, as in North America, a steady expansion of the number and scope of medical ethics programs. In Great Britain, the General Medical Council created a committee in 1984 to study the teaching of medical ethics in British medical schools and make recommendations. The resulting 1987 “Pond Report” recommended that the teaching of medical ethics be encouraged in medical school, but no specific guidelines were advocated (Institute of Medical Ethics). While initially little progress was made, a later study found that most medical schools included ethics education (Goldie).

A 1991 study in Canada found that fifteen of the sixteen Canadian medical schools provided medical ethics education and some sort of examination, with the number of required hours ranging from 10.5 to 45 (Baylis and Downie). Almost all of the schools used physicians as instructors and focused on specific ethical issues (e.g., euthanasia), as opposed to ethical theory or professional codes of ethics. The College of Family Physicians of Canada and the Royal College of Physician and Surgeons of Canada require ethics training, and there is increasing interest in continuing education in bioethics (McKneally and Singer).

In numerous other countries, medical schools have developed curricula in medical ethics. At Lagos University in Nigeria, two-day workshops were initiated in 1982 for fourth-year students, at which lawyers, doctors, and patients all participated in lectures and discussions of issues in medical ethics (Olukoya). In Australia, medical graduates are required to understand basic medical ethics principles, and in the early 2000s educators promulgated a core curriculum (Working Group).

During this period of rapid growth in formal medical ethics education, a wide variety of activities were subsumed under the general heading of "ethics programs." There was great variability in the establishment of explicit curricular goals, the identification and support of teaching faculty, the teaching methods that were employed, and the attempts (if any) at evaluation of educational success. Although a degree of consensus evolved for some areas, important areas of controversy remain.

Goals

Ambitious and diverse goals have been proposed for medical ethics education, including increased awareness of ethical issues; a cultivation of basic ethical commitments; more humane medical practice; tolerance of conflicting views; development of analytic skill in moral reasoning; enhanced intellectual development in ethics and the humanities; positive attitudes toward patients; less paternalism in clinical practice; higher professional conduct; and improved clinical decision making (Callahan; Miles et al.).

Despite this dauntingly heterogeneous list, a consensus has developed regarding some core objectives. First, the primary goal of clinical ethics education is to prepare physicians to deal effectively with ethical issues in clinical practice. Accomplishing this requires that students learn to: (1) recognize ethical issues as they arise in clinical care and identify hidden values and unacknowledged conflicts; (2) think clearly and critically about ethical issues in ways that lead to an ethically justifiable course of action; and (3) apply the practical skills needed to implement an ethically justifiable course of action. Each of these objectives in turn requires that the students possess specific knowledge, attitudes, and skills.

To recognize ethical issues as they appear in clinical care usually requires a positive attitude concerning the importance of the humanistic and value-laden aspects of medical care. For example, a physician's decision regarding chemotherapy for a woman with breast cancer involves the physician's awareness of the biomedical issues and of the morbidity and mortality of the disease, as well as of the patient's own views regarding continued life, her body image, and the morbidity of treatment. Recognizing the presence of an ethical issue also requires knowledge of the nature of common ethical issues and how they arise in clinical practice. Finally, proficiency in recognizing these issues requires students to learn certain behaviors. Highly motivated students who understand the importance of autonomy and recognize the ways in which patients' values are frequently ignored or overridden will still have difficulty incorporating respect for autonomy into care unless they become skilled in eliciting their patients' personal values, concerns, and goals.

A general consensus was also developed in the 1980s regarding most of the core content areas for medical ethics education. In the 1985 report of the DeCamp Conference (Culver et al.), leading physicians and ethicists proposed "basic curricular goals in medical ethics," stressing knowledge and ability as the primary targets of medical ethics education in medical schools. Among the seven items in the "minimal basic curriculum" are the ability to obtain a valid consent to treatment or a valid refusal of treatment, knowledge of how to proceed if a patient refuses treatment, and knowledge of the moral aspects of the care of patients with a poor prognosis, including patients who are terminally ill. Notably absent from this "core list," because of a lack of consensus, were issues related to financial aspects of medical care (including distributive justice and access to healthcare), doctor's societal obligations, and questions related to abortion. Interestingly, the U.K. and Australian consensus statements on core curricula are much broader and include both issues of resource distribution and physicians' role in society in their purview. (Whether this influences what is taught is unknown.) Building on these earlier reports, subsequent teaching programs increasingly stressed the importance of ensuring that educational goals are appropriate to students' specific level of training and future career choices. Courses for first- and second-year medical students, who have limited clinical experience, generally focused on developing an awareness of the complex moral issues that arise in contemporary medicine and on developing skill in moral reasoning. In contrast, teaching programs for physicians in subspecialty residency programs tended to focus on the specific issues that those physicians were already encountering in their fields of practice and the specific knowledge, attitudes, and skills needed to address those problems.

Attempts to teach medical ethics through "professionalism" began in the late 1990s. Professional organizations, such as the American Board of Internal Medicine and the ACGME, define professionalism in terms of virtues such as altruism, respect for others, honor, integrity, accountability, competence, and duty/advocacy. These statements typically stress physicians' public role in promoting health in terms of quality and access as much as they stress individual patient care (ABIM Foundation). Interesting the 2001 AAMC graduate medical student survey assessed professionalism separately from medical ethics, reflecting some confusion between the two content areas.

Methods

Given the diverse objectives of ethics education, it is no surprise that a variety of methods have been developed to help students develop the knowledge, attitudes, and skills needed to become proficient in dealing with ethical issues in clinical practice. Teaching methods have ranged from large group lectures providing conceptual and historical overviews of issues in medical ethics, to seminar room discussions of "paper cases," to participation in discussions of actual cases encountered during clinical rotations, to participation in ethics consultation programs, with each of these supplemented by readings and in some cases videotapes or films. During the clinical years and the years of residency training, there has been a slow but steady increase in the use of practical teaching exercises, with an emphasis on the communication skills deemed necessary for the identification and resolution of ethical problems. Achieving a thorough conceptual understanding of the doctrine of informed consent, for example, is increasingly understood to be of limited value if physicians are not able to explain information clearly to patients. More recently, end-of-life ethics education has been highlighted through the growth of palliative care education, both at the medical school level and during residency (EPERC).

By the early 1990s, there was widespread agreement that in almost all settings instruction should be primarily case-based, because using real or detailed hypothetical cases emphasizes the difference that clinical ethics can make in actual patient care. Moreover, there is some empirical literature supporting the use of case- or problem-based education in promoting students' knowledge of professional judgments regarding ethical issues. In addition, case discussions allow for integrating moral reasoning with the other tasks of patient care.

Some educators, however, have raised concerns about overreliance on the use of the case method in teaching medical ethics (Barnard; Kass). Case discussions typically emphasize problem solving and ethical dilemmas, and they may ignore essential issues of clinical ethics, such as what constitutes informed consent in routine office care. Critics point out that cases typically deal with either the beginning or end of life or an exotic use of technology. Issues of daily practice or resource allocation are typically ignored. In addition, by concentrating on what should be done in a specific case, participants often ignore the institutional or interpersonal factors that may have led to the problem. Analyzing the institutional factors that lead to family–physician conflict or how to treat families more respectfully in the intensive care unit may be more important in improving ethical care than teaching house staff about when it is ethically justifiable to override surrogate decision makers (Goold; Levine and Zuckerman, 1999, 2000). Institutional factors play an important and frequently overlooked role in influencing ethical decisions and behavior; discussion of institutional reforms may constitute an essential part of medical ethics education. Finally, while the cases presented often raise intellectually interesting ethical dilemmas, in practice, ethical conflicts are often attributable to communication problems.

In general, mirroring debates in moral philosophy, considerable disagreement remains about the importance of theory to ethical analysis. Tom L. Beauchamp and James F. Childress, authors of one of the most widely used texts in medical schools, emphasize the important role of the principles of respect for autonomy, nonmaleficence, beneficence, and justice, both as a framework for identifying moral issues and as a structure for moral justification. Others, such as K. Danner Clouser, argue against a primary stress on principles, for both theoretical and pedagogical reasons. In addition to intellectual concerns about the nature of proper moral justification, Clouser and others stress the importance of training students to attend to the highly specific biotechnical, psychological, and social complexities of individual cases in their moral reasoning, reporting that through a series of case discussions, students often arrive inductively at general precepts that they can then apply to other cases.

For different reasons, feminist theorists, virtue theorists, and casuists also have argued for less emphasis on theoretical principles. Rather than viewing cases as ways to illustrate principles, for example, casuists argue that they are the primary locus of moral meaning (Arras). Rather than using short, theoretically driven hypothetical cases, casuists encourage the use of real cases that illustrate the complexities and uncertainties of clinical practice. John D. Arras stated that these cases "display the sort of moral complexities and untidiness that demand the (nondeductive) weighing and balancing of competing moral considerations and the casuistical virtues of discernment and practical judgment (*phronesis*)" (p. 32). Feminists have argued for greater attention to social, economic, and political factors and their effect on the nature and dynamics of healthcare (Sherwin). Finally, according to Alisa L. Carse, virtue theorists and feminist theorists suggest that bioethical discussions should address questions such as 'What kind of person ought I be?' and 'What traits and capacities ought I to develop?' In an attempt to enhance students' moral imagination and empathy, and to stress the narrative aspects of medical ethics, educators include literature and film in teaching bioethics. These resources force students to critically reflect on the larger context and meaning of their work and, according to William T. Branch, to "conceptualize and generalize their behavioral changes into their mental structure of knowledge, skills and values" (p. 505).

Technological innovations also have spawned new approaches to teaching medical ethics. Computers and the Internet allow, for instance, attempts to combine ethics education with communication skills (an example is the MedEthEx Online website). Interactive DVDs dealing with difficult issues force the learner to confront challenges to their position in a structured manner. Telemedicine allows students at distant sites to interact in real time with faculty trained in medical ethics.

Most programs have adopted eclectic approaches to teaching medical ethics. In the preclinical years, a combination of lecture and small group case-based discussions predominate. Film and short stories are often used to promote self-reflection and discussion. In the clinical years, ethics education is usually structured as case-based small group discussions. Communication skills are often integrated with ethics education, and the focus of the discussion is practice-based.

The different programs, unfortunately, have some common limitations. First, as noted above, until very recently, the day-to-day life and behavior of physicians received little attention. The curricula are designed by faculty who are often unaware of the issues that students actually confront. (Student-run programs have focused more attention on issues that students are concerned about, such as "abuse" or being asked to violate their personal conscience.) Similarly, issues that are not directly applicable to patient care are discussed less frequently. Thus, for example, the medical-pharmaceutical-industrial complex and the ethical issues that it poses to both physicians and patients gets short shrift. Second, mirroring the lack of work in philosophy of medicine, there is little discussion of what it means to be a doctor in today's society. Third, the programs are, in general, cognitively physician-focused. Thus, despite the (re)inclusion of the humanities that has been taking place, students' ability to be empathic or to think creatively about ethical options may not be challenged. Attempts to integrate ethics, the humanities, and the social sciences in medical education may help with this situation.

Faculty and Program Development

As in other areas of medical education, the evolution of teaching in medical ethics has been heavily shaped by the availability (or, for many programs, the scarcity) of qualified faculty. Throughout the 1970s and early 1980s, a central debate involved the question of whether medical ethics teaching should be done primarily by physicians or by those trained in the humanities, such as philosophy or religious studies. Mark Siegler, for example, stressed the ways in which the knowledge and professional experience of clinicians was central to an understanding of the true complexities and realities of clinical-ethical problems and their possible solutions. He therefore urged that primary teaching responsibility should lie with the physician-ethicist. Respected clinical teachers who emphasize the importance of medical ethics can be important role models who can help shape students' ethical sensibilities. On the other hand, strong reasons for using nonphysicians to teach medical ethics have been offered. First, many important aspects of the identification, analysis, and resolution of ethical problems in medicine do not fall within a physician's own specialized training or expertise, but depend instead on the intellectual background and analytic skills of individuals trained in other disciplines. Second, involving nonphysicians in teaching medical ethics can help sensitize students to the importance of other viewpoints and improve physicians' ability to communicate with nonphysicians—two primary educational goals. This controversy regarding who should teach has largely been replaced by a consensus that a variety of disciplines have important and distinct contributions to make.

The limited number of trained faculty, more than disputes regarding the academic background of those faculty, restricted the growth of ethics education. Many programs depended on faculty who, despite an interest in medical ethics, had little formal background in the field. Over time, this problem has abated as the number of faculty with prior training in ethics has increased. Moreover, in part to address this shortcoming, both short courses and longer master's programs in medical ethics have been developed around the world. The growth of healthcare providers with graduate training in ethics reflects the degree to which medical ethics has become integrated in the culture of medical education.

In their attempts to develop ethics curricula, medical ethics faculty have encountered a number of other barriers, including financial and time constraints, students' attitudes toward medical ethics, and the lack of reinforcement by other faculty (Strong, Connelly, and Forrow). Ethics teaching programs occupy a tenuous position in most medical schools. Although the inclusion of ethics test questions in certifying exams has improved this situation a bit, ethics training is rarely viewed as central to the education of physicians in the way that the "basic sciences" and traditional biotechnical clinical training are.

Economic constraints are a limiting factor in ethics education. Ethics education, conducted in small groups, is very faculty intensive. Moreover, at the same time that ethics has become integrated into medical schools, funding for teaching programs has decreased. This has happened during a period in which physicians are under increasing pressure to generate income. Thus, trained faculties' availability for teaching may again become a rate-limiting factor in ethics education.

Evaluation

Evaluation, both of teaching programs themselves and of individual students, is still in flux. Most formal courses have included a pass–fail grading system based on class participation and written exercises, usually either papers or in-class essay examinations. These efforts convey to students the importance of medical ethics in the medical school (as has the addition of questions to the national boards and many of the specialty boards).

Efforts to develop formal and valid evaluation techniques have remained hampered, however, by uncertainty about what specific teaching goals are most important, about how best to measure whether any of those goals have in fact been accomplished, and about what is realistic to expect from ethics courses. (Similar constraints plague efforts to teach professionalism [Arnold].) Underlying the challenge of evaluating the impact of teaching medical ethics is a deeper debate regarding what teaching ethics does. Ethics as an academic discipline can be taught; one can evaluate a student's knowledge of ethical concepts and cognitive skills. Philosophers in undergraduate ethics courses have done this for centuries. Most attempts at evaluation in medical school have tried to measure this aspect of the ethics curriculum using essay or short-answer tests.

In arguing for the importance of formal ethics education, teachers of medical ethics typically have emphasized more ambitious goals, such as improving students' ability to address ethical issues in clinical practice or promoting humanistic qualities such as integrity. Efforts at evaluation, however, have not always distinguished among residents' attitudes, knowledge, or behavior. Moreover, there are numerous methodological problems, particularly in evaluating ethical behavior or character, problems that are compounded if one tries to determine whether improvements are attributable to formal ethics teaching. Some faculty involved in ethics programs question whether stricter standards of evaluation should be required of their curricula, arguing that courses in the traditional areas of anatomy, biochemistry, and physiology have rarely, if ever, been required to prove their ultimate effectiveness.

Attempts to develop innovative methods of evaluation have included measuring students' moral reasoning, evaluating students' behavior by nonphysicians (such as nurses or patients), and using formal tools such as the Objective Standardized Clinical Examination. These exercises have attempted to move beyond merely evaluating cognitive skills to analyzing students' actual behavior. Although these efforts show a great deal of promise as formative educational tools, few schools use these tools as summative evaluation methods. Limitations in their psychometric properties and the large number of raters needed for reliable ratings have limited their general use.

Conclusion

While formal teaching programs in medical ethics were practically nonexistent in 1970, by the early 1990s there was extraordinary diversity both in the United States and elsewhere in formal teaching activities from the undergraduate to the postgraduate level. Bioethics education in the early twenty-first century is an accepted part of education for students in almost all medical schools and for residents in many programs.

Nevertheless, despite this growth and an evolving consensus that began in the 1980s regarding some core goals and teaching methods, many questions remain only partially answered. What should the primary goals of such teaching be—analytic ability, behavioral skills, or actual practice? What is the relationship between professionalism and medical ethics? How should those goals vary according to the developmental stage of the health professional and according to the person's specific field of practice within medicine? How can (or should) the attention on ethical attention be expanded beyond conflicts at the beginning and end of life to the day-to-day activities of doctoring? Who are the most appropriate faculty members to lead teaching efforts in various settings? What teaching methods are most effective and efficient in accomplishing curricular goals in each of the various settings? Finally, what is the proper role of formal evaluation efforts, both of individual students and of overall teaching programs? What methods of evaluation are both valid and feasible?

The difficulty in finding answers to these questions ensures that designing and implementing effective medical ethics education will remain challenging well into the twenty-first century.

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SEE ALSO: *Casuistry; Conscience, Rights of; Literature and Bioethics; Medical Ethics, History of; Medicine, Anthropology of; Narrative; Nursing, Profession of; Professionalism and Professional Ethics;* and other *Bioethics Education* subentries

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II. NURSING

Ethics has received increased attention in nursing education programs; however, problems remain. This entry provides an overview of nursing ethics education in the United States and in other countries addressing both the advances made and the issues remaining.

Nursing Ethics Education in the United States

Nursing ethics has been incorporated to some degree in nursing education since the early twentieth century. In the early 1900s ethics was taught as a science necessary to the education of the competent nurse who put patient safety and welfare first (Robb). Ethics teaching, reflecting religious and military influences, focused on the character and ethics of the nurse, the virtues required of nurses (e.g., loyalty and obedience), the duties and obligations nurses owed physicians and the hospitals that employed them, and proper etiquette for nurses. Obligations that nurses have as citizens of the community to participate in public policy and political areas to achieve healthcare goals first emerged in the *Code of Ethics* proposed by the American Nurses' Association (2001) in 1926 and adopted in 1950, and in the nursing literature of the first half of the twentieth century (Goodrich; Densford and Everett; Fowler). These wider obligations of nurses as citizens continue to be a very minor theme in nursing ethics education.

Ethics as a distinct part of the nursing curriculum almost disappeared in the 1950s and 1960s, except in programs affiliated with religious traditions and institutions. The 1970s brought renewed attention to nursing ethics education, partly because of the resurgence of medical ethics and the appearance of bioethics in the professional and academic worlds. These were responses to challenges emerging from medical technologies, abuses in research, and changes in the healthcare environment, challenges for which no ready-made responses were available. Some nurse educators and philosophers recognized, however, that nurses faced ethical issues and challenges different from those faced by physicians, largely because of nurses' positions as employees rather than as independent professionals in healthcare organizations. The National Student Nurses' Association and the American Nurses' Association passed resolutions calling for more attention to ethics in nursing education programs.

A survey conducted to assess the status of ethics teaching in accredited baccalaureate and graduate nursing programs (Aroskar) disclosed that most schools offered limited opportunities for study of ethical aspects of nursing and that these opportunities were often integrated into other nursing courses. Only 7 percent of the programs required work in ethics or medical ethics. Codes of ethics such as the *Code for Nurses* (American Nurses' Association, 1976) were identified as priority content in ethics courses, followed by patients' rights and obligations. No nursing faculty had primary responsibilities for teaching ethics.

Beginning in the late 1970s and early 1980s, nursing ethics education that incorporates values clarification and a more philosophical, principled approach to ethical issues received increased attention in nursing programs. This continuing development, however, depends on administrative support, faculty priorities, interests, and expertise, and varies greatly from school to school. A few nursing programs have full-time faculty in teaching and research activities devoted to ethics in nursing. Usually these are schools with master's and doctoral programs in nursing that offer studies in ethics, bioethics, and philosophy as electives or as a minor field. Teaching resources such as textbooks and nursing journal articles on ethics have increased significantly. Since 1975, activities to enhance the teaching of ethics in nursing have been supported by the Joseph P. Kennedy, Jr., Foundation, the National Endowment for the Humanities, The Hastings Center, the Fund for the Improvement of Post Secondary Education (FIPSE), and other institutions. There are more than fifty-five academic bioethics centers in the United States offering undergraduate, graduate, or continuing education courses in bioethics. However, few have dedicated programs or joint appointments for nursing ethics education (National Reference Center for Bioethics Literature [NRCBL], 2002a).

Baccalaureate education provides the foundations for professional nursing practice that requires knowledge of ethical obligations of the profession and ethical decision-making skills for the practitioner. Not all baccalaureate nursing programs have required or elective courses in ethics. Ethics education is still not required for program accreditation. Where ethics is a required curriculum component, content may be offered through separate courses or modules (Payton); integrated throughout the curriculum in existing courses (Ryden et al.); or presented in some combination of separate courses and integrated into classroom and clinical experiences. New approaches focus on case discussion, writing portfolios, and web-based interaction to encourage application of core concepts to clinically encountered situations (Pinch and Graves; Sorrell et al). An overall goal is to develop morally accountable practitioners who have a clear conceptual framework and the skills for ethical decision making in practice (Cassells and Redman; Fry, 1989). Ethics education is required core content for master's education in nursing and for the preparation of advanced practice nurses (American Association of Colleges of Nursing, 1996; American Nurses' Association, 1996; Kenney).

Sara T. Fry identified four models of ethics teaching used in undergraduate and graduate nursing programs and clinical settings:

1. The *moral-concepts model* incorporates three general areas: historical foundations of the nursing ethic, including codes of ethics and medical versus nursing ethics; the value dimensions of nursing, such as advocacy, loyalty, and moral obligations; and the skills needed for ethical decision making.
2. The *moral-issues model* focuses on common moral problems in healthcare relationships, such as confidentiality and informed consent, and issues of moral concern in healthcare, such as abortion, termination of treatment, and allocation of healthcare resources. Course content includes historical and contemporary legal cases that illustrate the legal and ethical aspects of specific issues in patient care.
3. The *clinical-practice model,* developed by bioethicists and nurse ethicists, incorporates clinical conferences on moral issues in patient care usually specific to a clinical area, case-study presentations, and ethics rounds that focus on ethical issues pertaining to a patient's care rather than to a patient's clinical condition.
4. The *ethics-inquiry model,* found primarily at the graduate level, incorporates the forms of traditional philosophical inquiry such as descriptive, normative, and metaethics; explores diverse methods of ethical inquiry; and looks at the relationship of ethical inquiry to other forms of inquiry in science and nursing. Additional topics in ethics education include the role of the nurse as a moral agent; roles of gender and ethnicity in nursing ethics; major ethical theories and principles and their application in nursing practice; and the ethics of nursing research.

Since the early 1990s, caring as a foundation of nursing ethics has received a great deal of attention (Bishop and Scudder; Harbison). Curriculum change based upon theories of caring has been proposed and, in many places, implemented. However, strong critiques of theories of caring and the ethics of care persist and the success of these curricular changes has yet to be established.

The ethics of end-of-life care and pain management have also received much attention since the mid-1990s. Reviews of standard nursing texts found very little content related to pain management, end-of-life care, or the ethical issues at the end of life (Ferrell et al.). Concern over these shortcomings was mobilized into national projects to develop resources for teaching nurses the clinical skills needed for pain and symptom management as well as an understanding of the myriad ethical issues that arise in the provision of end-of-life care. The End-of-Life Nursing Education Collaboration Project (ELNEC) developed a standardized curriculum on end-of-life care and provided train-the-trainer programs for nursing school faculty, continuing education providers, and state boards of nursing across the country (American Association of Colleges of Nursing, 1996). The Toolkit for Nursing Excellence at End-of-Life Transitions (TNEEL) was provided free of charge to all nursing schools (Wells et al.). TNEEL is a computerized learning tool provided on CD-ROM that contains multimedia components such as audio, video, graphics, photographs, and animation to create an interactive program. Both of these projects contain specific ethics content as a prominent component of the suggested curricula.

Examples of specific outcome objectives for nursing ethics education include:

Identification of ethical dilemmas in the delivery of nursing care;

Identification of the components of an ethical decision-making framework;

Participation in ethical decision making in client care;

Leadership participation in ethics rounds and institutional ethics committees;

Analysis of impediments to the ethical practice of nursing;

Distinguishing the ethical elements of nursing practice from medical or technical elements; and

Analysis of nursing codes as they relate to client advocacy (NRCBL 2002b).

There are underlying tensions and ongoing debates in nursing ethics education. Argument continues over the question of whether nursing ethics does or should exist as a separate field of inquiry. Differences have arisen between those who teach ethics based on cognitive-moral-development theory and those who teach ethics based on moral philosophy and ethical theory. Evaluation of the effectiveness of ethics teaching has been a continuing challenge. Although research on ethics in nursing education has been expanding, it needs to be developed more systematically if it is to contribute to effective curriculum change (Silva and Sorrell). A shortage of adequately prepared faculty and overcrowded nursing curricula impede ethics teaching in nursing programs.

Nursing Ethics Education in Other Countries

The fact that nursing ethics education in the international arena varies so greatly reflects the state of nursing and nursing education, as well as the priority of healthcare problems and issues, in many different countries. The lack of systematic, international information about nursing ethics education creates problems in providing a general overview of the topic.

The International Council of Nursing (ICN), Geneva, in an effort to address the uneven development of nursing ethics education, has provided ethics education through publications, programs, and conferences. The ICN's code of ethics serves as the nursing code in many countries. The code was revised in 2000. Since these countries have different histories, cultures, and priorities, the question arises as to whether or not all countries have common ethical values and principles regarding nursing and nursing education. In addition, much of nursing ethics education in the United States focuses on the issues that arise from advanced medical technology, whereas the main issue in many other countries is primary healthcare. More recently, numerous countries have developed their own codes of ethics for nurses.

Since the early 1990s, ICN has scheduled a special interest group in nursing ethics at its major open international meetings. This has been very successful in identifying nurses around the world with this professional focus.

The Journal of Nursing Ethics, which began in 1994, provides an arena for information and research from an international perspective. In conjunction with the journal, the editors and editorial board members established an International Centre for Nursing Ethics at the University of Surrey, England, that provides a place for researchers and educators to visit or come for more extended work.

In the United Kingdom nursing education is well developed, and higher education has been available to nurses for many years. In some colleges or departments of nursing, ethics is either taught as a separate course or integrated into other courses. During recent decades, the Royal College of Nursing actively articulated nursing ethics. In addition, nurse educators and others have published numerous papers, research reports, and books focused on nursing ethics. A major British nursing journal includes an ethics column that deals with clinical ethical problems. The Center for Midwifery and Nursing Ethics in London publishes a newsletter, runs educational programs, and serves as a clearinghouse for ethics materials. In 1990, Swansea University, Wales, sponsored the first national conference on nursing ethics and nursing ethics education. Over the past several years, Swansea has also sponsored conferences on Nursing Philosophy and since 1999 has published a journal with this title that includes ethics articles (De Raeve).

In Canada, numerous conferences have focused on nursing ethics and ethics education. An annual conference to discuss philosophy and nursing touches on many ethical themes. Several schools of nursing have invited visiting professors to teach ethics and have prepared some Canadian nursing professors to teach this subject as well. Canada has revised its own nursing code of ethics in 2002.

The ethics committee of the Swiss Nursing Association wrote a code of ethics in the 1980s and has been instrumental in increasing nurses' awareness of the need for more systematic approaches to teaching ethics in nursing programs. The association includes in its annual conference papers on ethics in curriculum content and clinical practice. For some years, one nurse educator has taught courses in Switzerland and France on ethical issues in dying and death with a special focus on suffering.

Nurse educators in Finland have offered seminars around the country on nursing ethics. One nurse educator has published a book on the topic. Several nurse educators in Finland and other Nordic countries have conducted research on ethical questions and have participated in multinational research projects examining selected ethical issues.

The board of directors of the Center for Medical Ethics at the University of Oslo, Norway, consists of people from diverse health-related professions. It continues to work with nurse educators and nurse researchers in developing educational programs and research focused on ethical issues.

Universities in both Norway and Sweden have invited nurse educators from overseas to lecture on nursing ethics. The annual, week-long seminar held in Sweden for doctoral students in nursing, which has either a primary or secondary focus on nursing ethics, has been of special interest because of its potential impact on nursing education. Extensive research on the ethics of various clinical problems with elderly patients has been undertaken at the University of Umea, Sweden. In Stockholm, two nurse educators teach and conduct research in nursing ethics.

One nurse educator in Budapest developed an ethics course for nursing students and wrote a textbook to use in this education. Another nurse educator teaches an ethics class at the Academy of Medicine in Lublin, Poland. In the Baltic States and Eastern Europe, physicians often are the major or only faculty teaching in nursing schools. For example, Estonia has a shortage of nurses prepared to teach nursing. In this context, emphasis has been placed on the medical model and little, if any, ethics has been included because the teachers have had limited exposure to ethics content. Nursing leaders in Estonia and other countries with similar problems are developing alternatives to this situation.

Throughout Latin America, Colombia has been the most active in nursing ethics education. The National Association of Nursing Schools has an ethics committee working with schools of nursing, the Ministry of Health, and the Nursing Association to increase ethical content in nursing education. The ethics committee sponsors workshops on nursing ethics and has been involved in research projects on nursing ethics. Chile has a nurse who has dealt with ethical issues working in the national nursing association. Brazil nurse educators teach nursing ethics and conduct research on ethics topics. Increasingly, nurses, and colleagues in other professions, are developing collaborative activities in teaching and research in healthcare ethics. Some of these activities involve Spain.

Australian nursing education throughout the country has supported conferences, seminars, and consultation in nursing ethics. One nurse ethicist in Melbourne has taught in a nursing program and has published several books in the field. The Center for Human Bioethics in Melbourne, established in 1980, examined the state of nursing ethics in Australia and has continued to work with nurses seeking education in ethics. In Queensland, a professor in the university nursing department served as a member of the research ethics committee at her institution. Both Australian and New Zealand nurses contribute regularly to the nursing ethics literature.

Numerous nurse educators present papers at the ongoing World Congress on Law and Ethics which recently elected a Swedish nurse to its board. In Israel, Jewish ethics has been taught throughout the nursing curricula and several educators conduct research in healthcare ethics.

The High Institute of Nursing, University of Alexandria, Egypt, held a nursing ethics conference in 1993 on ethics in education and practice. More recently, the Aga Khan University College of Nursing, Pakistan, held a conference and invited a keynote paper on nursing ethics.

In Asia, the People's Republic of China has developed eleven bachelor of science in nursing programs. The curriculum has included an ethics course that combines Confucian and Maoist ethics. The political slogan "serve the people" translates in nursing into respect for patients as persons. One Hong Kong educator conducted extensive research focused on nursing ethics in China. Korean nursing has developed an interest in ethics that manifests the influences of Christian missionary work. At Japan's national and international nursing research conferences, nurses present papers on nursing ethics from a clinical and an educational perspective. The Japanese Association of Bioethics includes nurses as speakers and participants in its conferences. The Japanese Nursing Association has an ethics committee and increasingly, the many new colleges of nursing are developing research ethics committees.

This discussion reflects great differences and many activities in nursing ethics education on the international scene. The lack of teachers and resources to teach nursing ethics remains a serious problem in many countries. However, one of the most striking developments in nursing ethics education is the amount of international research being conducted. Collaboration among Europeans and among European, Asian, and North and South American nursing colleagues has increased and provides a rich source of data for teaching.

Conclusion

The last two decades of the twentieth century have seen a significant, worldwide resurgence and expansion of nursing ethics education activities and programs. These efforts have varied greatly. Many serious challenges remain for the twenty-first century, including a lack of formal ethics teaching in many programs, inadequate resources such as prepared nursing faculty to teach ethics, and the need for evaluation of the impact of existing nursing ethics education courses and programs on nursing practice.

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III. SECONDARY AND POSTSECONDARY EDUCATION

Since the early 1970s, there has been a marked increase in bioethical reflection within the secondary and postsecondary curricula. On the high school level there is a growing movement to incorporate questions concerning public policy and values into science teaching and to raise bioethical issues in social science classes. Many colleges and universities offer courses in bioethics that are popular with students bound for the health professions and with others simply interested in the topical issues raised in such courses. There has also been a proliferation of postgraduate programs offering advanced degrees or certificates in bioethics, which has become an autonomous and accredited discipline.

High School Level

It is a rare high school that offers its students a specialized course in bioethics. Bioethical reflection, however, may be embedded within the standard science offerings. To some degree this is an outcome of what has been called the "STS" movement—the acronym standing for "science, technology, and society." This movement reflects an attempt by U.S. secondary schools to include within the science curriculum the profound ethical and policy issues raised by developments in science and technology. This movement is not without its obstacles. For example, the training of science teachers, shaped by the traditional division of science from the humanities, has often placed little emphasis on developing teaching skills for ethical reflection. Nevertheless, the integrative movement has made inroads.

For example, bioethics issues may be raised in high school biology courses, during discussions of genetics, human and animal research, or environmental science. The treatment of such topics may be limited to brief case presentations or to discussions designed to help students with values clarification. There is a growing body of opinion, however, that such strategies can be insufficient; not all opinions are of equal value, and students need to develop the critical reasoning skills to evaluate their stances in the light of scientific evidence, material implications, and logical consistency. This approach, emphasizing the evaluation of ethical positions, may eventually prove most appealing to science educators for it dovetails well with aspects of the scientific method they are trying to transmit.

Bioethics teaching on the secondary level need not be restricted to the science curriculum. The High School Bioethics Curriculum Project of the Kennedy Institute of Ethics seeks to train and support teachers in using bioethical case studies in a wide range of courses, including those in social studies, civics, history, philosophy, and religion. The project has prepared curriculum units covering topics such as neonatal ethics, organ transplantation, human subjects research, and eugenics. High school teachers are introduced to these units through workshops and are assisted with ongoing curriculum development, networking, and resource identification.

College Level

On the college level, offerings in bioethics are a well-established feature. Certain institutions offer, or allow students to construct, an interdisciplinary major in bioethics. More common is a minor or concentration in bioethics, interdisciplinary in nature or offered through a philosophy, religion, or social-science-based department.

Though most colleges have neither major or minor, they are likely to offer one or more courses in bioethics. A typical course might use one of the standard textbooks of bioethics, either written from a unitary perspective or offering an edited collection of canonical "pro" and "con" articles on bioethical issues. The instructor may choose to supplement this with a collection of cases or to replace it with an assembled course packet of the instructor's choosing.

A number of didactic approaches may be used to help students become experientially involved with the topics. Most popular is the case analysis mode where students grapple with the dilemmas raised by actual or constructed cases. Class debates can provoke spirited dialogue, and a growing library of films and videotapes vividly portrays for students the human impact of these issues. Some professors may bring in, or team-teach with, healthcare professionals, or ask students to visit a healthcare setting as part of the course. Bioethics can lend itself well to a "service-learning" approach, where student service in healthcare-related fields can be used by the instructor as a way to make bioethical issues come alive.

Most bioethics textbooks and many instructors begin from a framework of ethical theories and principles that are then applied to specific issues, such as informed consent, abortion, and euthanasia. However, this "standard approach"—and indeed the "standard issues" of bioethics—have been criticized by professionals associated with fields such as phenomenology, pragmatism, hermeneutics, feminism, casuistry, virtue ethics, and narrative theory. Critics argue, for example, that to base ethical analysis on high-level theory may obscure the richness of particular cases and the complex modes of interpretation that real-life decision makers employ. Moreover, simply to stick to recognized "ethical quandaries" is to risk overlooking the sociopolitical biases and the metaphysics of self and body that have shaped contemporary Western medical systems in ethically significant ways.

Instructors may therefore choose to supplement the medical ethics textbook with other kinds of resources. For example, a brief selection from the seventeenth-century French mathematician and philosopher René Descartes might be used to reflect on the model of body-as-machine that has powerfully influenced the doctor–patient relationship. A literary work such as "The Death of Ivan Ilyich" (1886), by the Russian novelist and philosopher Leo Tolstoy, can render vivid and lucid the experience of illness, the significance of truth telling, and the dilemmas surrounding death and dying. A work of social critique, such as a feminist history of women and medicine, can raise issues concerning the power relations embodied in medical practice and disease categories. The growing diversity of methodologies used within professional bioethics can thus "filter down" to diversify the methods and materials used in college-level teaching.

Postgraduate Level

On the postgraduate level, a number of centers and universities around the country offer advanced degree programs specializing in bioethics. One popular model is the master's or Ph.D. program, often in philosophy, less frequently in religion, with a bioethics concentration. The program may include a series of courses focused on bioethical issues, some exposure to a clinical setting, and a thesis written on a topic relevant to bioethics. Such programs may attract individuals looking to pursue this field as a primary academic career. Alternatively, healthcare professionals may enter such programs, usually for the master's degree, in preparation for teaching and/or service on ethics committees, or out of personal interest. Then, too, certain programs are designed to offer joint degrees through collaborative arrangements, allowing students to complete a medical or a legal degree along with an M.A., M.P.H. (master of public health), or Ph.D. degree. While most degree programs focus on bioethics or medical ethics as such, others define themselves more broadly as teaching the medical humanities and thus may incorporate diverse disciplines such as history, sociology, anthropology, and literature.

In addition to degree programs, there are many options for those seeking more limited preparation in bioethics. A number of centers, for example, offer intensive courses in bioethics lasting from one to four weeks or involving sessions spread out over a longer period. There are continuing education courses and certificate programs in bioethics. Special bioethics fellowships are also available, often directed toward those already engaged in clinical practice.

Conclusion

Much of what this entry details concerning bioethics teaching on the high school, college, and postgraduate level has become available since 1978, when the first edition of the *Encyclopedia of Bioethics* appeared. Academic interest in bioethics has been growing apace. With the continued expansion of the healthcare industry, the constant development of new and troubling biomedical technologies, and the daily bioethics headlines in the popular press, it is likely that this interest will continue unabated.

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SEE ALSO: *Bioethics; Care; Casuistry; Ethics; Law and Bioethics; Literature and Bioethics; Narrative;* and other *Bioethics Education* subentries

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IV. OTHER HEALTH PROFESSIONS

Bioethics education in health professions other than medicine and nursing takes place both in professional schools and in continuing-education settings. The group to which *other health professions* refers is so diverse that no generalizations embrace all of the professions equally. Some major groups include therapists (e.g., occupational, recreational, respiratory, physical), technologists (e.g., radiologic, medical laboratory), physician assistants, pharmacists, dietitians, dentists, and medical social workers. This entry emphasizes major common themes that have emerged in the content and pedagogy of their educational offerings; it also describes common factors that have led to the introduction of bioethics teaching in these fields.

Common Themes in Content and Pedagogy

A set of guidelines for professional conduct has been one of the first types of documents produced when a new health field emerges. Up until the 1960s the documents often were called codes of ethics, but focused on dress codes and the importance of good manners and a cheerful disposition. They also emphasized the importance of keeping one's proper place in the bureaucracy, so that all documents except those for dentistry stressed deference to the physician's authority. Dedication to one's profession was considered essential. This list served as a foundation for teaching "ethics" to students in that field. The predictable result was that early ethics education was a presentation of a list of "dos and don'ts" that detailed a professional etiquette and morality punctuated by loyalty to one's group.

The educational emphasis has changed, as a result of changes in the focus of ethics documents and developments in the field of bioethics. There is also a growing consensus about the pedagogical methods that should be employed for bioethics education.

Late twentieth century codes of ethics reflect basic ethical principles and virtues relevant to professional practice. For instance, the Code of Ethics of the National Association of Social Workers is designed around the central notion of ethical responsibility. The American Academy of Physician Assistants followed the model of several others by delineating its major types of interactions and specifying principles for each. Many groups provide accompanying guides for professional conduct that attempt to elaborate behaviors consistent with those principles and virtues. For example, the American Dental Association includes "advisory opinions" for most of its principles, and the American Physical Therapy Association issues a separate guide detailing each of its eight principles. Faculty have adopted these documents as a basis for education, with the predictable result that there is less focus on simply indoctrinating students into behaviors and attitudes and more on urging them to think about the ethical principles and virtues that underpin professional roles and responsibilities.

The development of bioethics as a field also has influenced education in these fields. Teachers focus on basic bioethics theory and methods of ethical analysis. Students are taught to think critically, recognize ethical issues, and reflect on them. Character traits or virtues are not simply declared essential; rather, students are encouraged to understand the significance of behaviors and attitudes that express compassion, honesty, and integrity (to name some). Materials introduced from the social sciences highlight how ethnic, religious, age, sex, class, and other differences among individuals and groups influence situations in which bioethical problems arise. In short, the teaching of ethics has evolved to foster analysis of and reflection on practical issues.

There is a growing consensus about pedagogical methods that should be utilized to teach bioethics. Educational programs actively promote the integration of theoretical content with case examples. The case method is especially effective in allowing students readily to recognize key ethical issues as they arise in everyday practice and to grasp the relevance of bioethics to their chosen professions. A larger proportion of bioethics instruction is taking place in small group discussions during the clinical period of professional preparation, so that challenging cases can be highlighted in discussion. Some programs utilize real or simulated patients with the goal of integrating ethical aspects of a patient's situation into the diagnostic, treatment, and social aspects.

There is less consensus about who should teach bioethics. Some schools of thought favor a stronger emphasis on theory, so that persons formally trained in philosophical ethics or moral theology are thought to be ideal. Others argue that an understanding of the clinical peculiarities and "facts" is most important, so clinicians are favored, especially if they have taken advanced work (or even a short course) in bioethics. Another alternative is a teaching team composed of a bioethicist and clinician working together. Preferences for one or another of these approaches seem less profession-specific than idiosyncratic of particular regions or institutions. In spite of the differences of opinion, the debates revolve around the common goal of effectively integrating theoretical and practical dimensions of bioethics.

Common Factors Leading to the Necessity of Bioethics Education

At least three major factors have led to the need for bioethics teaching, with its focus on thoughtful deliberation about complex ethical issues.

The issue of professional autonomy in relation to physicians is the crucial distinguishing feature of bioethics education in the groups being discussed. Their predicament is shared with nurses, and nursing ethics has provided valuable insights into the dilemma that is created. Such groups must gain understanding of their peculiar situation: having moral authority without ultimate decision-making authority. In some states, groups such as physician assistants, physical therapists, and social workers have legal license to evaluate or practice independently. But this does not resolve the thorny questions of how to coordinate care for patients in a system largely centered on physician autonomy. The different levels of progress toward full professional status among the groups compound the issue.

A second factor distinguishing bioethics education for the groups under discussion is that many claim, as the rationale for their very existence, the mastery of a particular technology. Reliance on technology may drastically alter the complexion of the traditional health professional–patient relationship. First, technology may create a detrimental distance between health professionals and patients. Patients and health professionals alike may place unrealistic expectations on technologies to bring about "miracles," creating dissent and distrust when they fail to do so. And the high cost of many technologies may add undue burdens on patients and families.

Since the professional–patient relationship is at the heart of professional ethics, germane bioethics education is crucial so that health professionals can respond well to the larger human dilemmas created by technology. The types of technology the various professions employ will differ, but the generic challenges are similar for all. A list of "dos and don'ts" will not suffice. The concepts and methods of ethics are needed for thinking through and acting on technology-related challenges.

A third factor is the presence of inequities in healthcare. The tools of bioethics enable students to understand why inequities are morally unacceptable in the healthcare system. They also provide an opportunity to encourage reflection on how professionals can contribute to the advancement of just and fair policies.

Since bioethics education in the professions under discussion in this entry encourages critical thinking, considered action, and the exercise of ethically appropriate character traits, it will continue to be a powerful resource as new developments in healthcare and society give rise to ethical issues.

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SEE ALSO: *Bioethics; Dentistry; Literature and Bioethics; Narrative; Nursing Ethics; Nursing, Profession of; Nursing, Theories and Philosophy of; Pastoral Care and Healthcare Chaplaincy; Sexism; Teams, Healthcare; Women as Health Professionals;* and other *Bioethics Education* subentries

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BIOLOGY, PHILOSOPHY OF

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While it may seem that the philosophy of biology, a field known for its focus on metaphysical, epistemological, and conceptual issues in biology, is far removed from the concerns of bioethics, there is a trend in philosophy of biology towards descriptivism that paradoxically allows for significant bridges with the predominantly normative concerns of bioethics.

About the same time that bioethics was born (the 1960s), the field of philosophy of biology took its first steps. Initially, it looked a lot like the rest of philosophy of science, which often meant focusing on the kinds of concerns that had their roots in physics. David Hull, Michael Ruse (1973) and others created a field that was dominated by formal concerns in evolutionary biology, including the nature and structure of its theories. Questions for the field included the nature of any reductions from the theories of Mendelian and transmission genetics to molecular genetics, whether it was possible to axiomatize evolutionary theory, how to account for the apparent teleology of evolutionary explanations, whether species are classes or individuals, and what the units of selection are. Many of these topics have remained active sub-fields to the present day.

Over time, philosophy of biology came to include much richer and detailed involvement with both current biology and the history of biology. Many philosophers came to ground their philosophical insights in rich historical accounts of various periods in the history of biology or in contemporary debates of active concern to practicing biologists. This *naturalistic* turn occurred in many parts of philosophy of science, but seems to have been most acute in philosophy of biology, at least partly for institutional reasons, including the creation of the International Society for the History, Philosophy, and Social Studies of Biology (Callebaut).

Through these developments, the field still largely avoided normative issues and focused on evolutionary biology. Recently several attempts have been made to move the field to other parts of biology. There are a number of philosophers working on developmental biology and using it as an alternative for framing traditional issues (Oyama, Griffiths, and Gray). Kenneth Schaffner has made a notable and unusual attempt to discuss the more medical parts of biology. Paul Thagard has similarly attempted to use work in the biomedical sciences (attempts at explaining the causes of ulcers) to address general philosophical issues in the nature of explanation.

There are a number of topics within philosophy of biology that especially bear on issues within bioethics.

Biological Function

One of the central concepts in the more medical parts of biology, particularly physiology, is the concept of function. It is impossible to understand the way we classify organ systems without this concept. The function of the heart is to pump blood. Hence any blood pump is a heart—even if there are some structural differences between the hearts of different species or (as mechanical hearts demonstrate) differences in the material makeup of the heart. So, what makes something a heart is fundamentally its function or purpose. This poses a philosophical problem, because the concept of function is a teleological notion. The function of the heart is to pump blood is simply another way of saying that the heart is designed to pump blood. But, who is the designer? Prior to Darwin the answer would have been an appeal to God.

Philosophers have attempted to account for the apparent goal-directed nature of biological science in two different ways. One solution is to accept that functions are goal directed, but to appeal to natural selection. Rather than a conscious designer, natural selection *designed* the heart to pump blood. The etiological view of functions (sometimes called Wright functions) gives an explanation of why a function is there in historical terms. More precisely, “The function of X is Z means (a) X is there because it does Z and (b) Z is a consequence (or result) of X’s being there” (Wright, p. 139–168). To Larry Wright, “a heart beats *because* its beating pumps blood” (p. 40).

In contrast, in 1975 Robert Cummins rejected the goal-directed, historical approach to functions. What matters in thinking of functions is the contribution it makes to a whole system, the role that it plays in bringing about the performance of that system.

Early-twenty-first-century commentators have concluded that each approach captures a different notion of function. Where Larry Wright attempts to account for why a function is there (a function as opposed to an accident), Cummins explains what a function does, what it is good for (whether it is an accident or not). Continued debate over whether an etiological account can be developed in the Wright mode and how to overcome various problems continues (Cummins and Perlman).

The concept of function plays an especially important role in medicine since health and disease are often understood as normal (species typical) functioning or dysfunction respectively.

Concepts of Disease and Health

This is perhaps the most important area of research in philosophy of biology for bioethics. Arthur Caplan explains it as follows:

> It may strain credulity to believe that the analysis of concepts such as *health, disease,* or *normality* can shed light on the ethical and policy issues associated with the vast amounts of new knowledge being generated by the human genome project and related inquiries in biomedicine. However credulity must be strained. The focus of attention *qua* philosophy tends to be on who owns the genome or whether an insurance company can boot you off the rolls if you are at risk of succumbing to a costly disease. But this is not really where the ethical and philosophical action is with respect to the ongoing revolution in genetics. (p. 128)

There are two important distinctions that must be understood in the debates over concepts of disease. First, there is a distinction between ontological and nominalist concepts of disease. On the ontological (realist) view of disease, diseases are real entities that exist in the world. Nosologies represent a true classification of the world—they carve nature at the joints. The paradigm diseases on this view would be either discrete disease causing agents that are at the same time identified as the diseases themselves or as discrete lesions. Thus, poliovirus is not the cause of poliomyelitis, it *is* poliomyelitis.

In contrast, the nominalist about disease would appeal to the old saying, “there are no diseases, only sick people.” On this view, nosologies are merely conventional systems of classification. They may have a great deal of practical value, but they are not in any meaningful sense true descriptions of reality. In some cases we classify diseases based on the pathogen that causes the disease. In other cases we classify based on the signs and symptoms. In others we focus on the organ system that is damaged, regardless of the causes or the symptoms. Thus, the nominalist would use the current lack of unity in the organization of our taxonomy of diseases as support for the view that it is merely a conventional (and somewhat arbitrary) system. Realists would respond by appealing to the role of disease in medical science and point to similar problems with other taxonomic systems in science that are nonetheless regarded as capturing reality.

One of the arenas where this debate has been most heated has been over the issue of the status of the Diagnostic and Statistical Manual of Mental Disorders (DSM) in all of its versions. The fact that there are so many changes in the different versions of the DSM can be interpreted either as an indication that the classification scheme is merely a convention, or that the science of psychiatry is progressing (as any science does).

The second related distinction in debates over the concept of disease is over the role of values in the development of the nosologies. For the non-normativist, the starting point for understanding disease is to understand species typical functioning. Disease is malfunction of the organism, a failure to function as organisms are *designed* to do. To understand disease, one needs only to understand physiology. The concepts are the same in humans as in understanding disease in nonhuman organisms. Therefore, (non-scientific or epistemological) values play no role in the development of the classification and understanding of disease (Boorse).

In contrast, normativists believe that identifying a condition as a disease is a value-laden exercise. To say that a condition is a disease is to say something about what we value. Labeling something as a disease is a way of signaling the undesirability of the state. Normativists appeal to many examples that illustrate the way social values seem to permeate nosology. The early versions of the DSM identified homosexuality as a disease. The tendency of some slaves to attempt to escape was identified as a disease in the United States in the nineteenth century. Foot binding in Japan produces a condition that would be recognized as a disease in many parts of the world, but is seen as normal in Japan. Normativists deny that an account of disease solely in terms of species typical functioning can work. It is *normal* in some sense for humans to develop osteoarthritis in old age, normal for teeth to decay, normal to develop many ailments at advanced age. Yet medicine is committed to these things as disease. In fact age itself may be conceived of as both normal and a disease (Caplan et al.).

Finally, there is a dispute over the meaning of health. Non-normativists tend to think of health as the absence of disease. In that case, an organism is functioning within the normal parameters of its species at its age. In contrast there are those who adopt a much broader concept of health. On this view health is not the mere absence of disease, but is the full flourishing of a person in multiple dimensions, including psychological, economic, physical, and social well being. These different conceptions of health and disease lead to very different views about the obligations of medicine towards society, the scope of the medical field, and the nature of medical care.

What Counts as a Genetic Trait?

What does it mean to call something a *genetic* trait or disease? Clearly, at least part of that judgment rests on some kind of causal assessment. If a disease is genetic, then it is caused by one or more of an organism’s genes. Indeed, this seems to fit a more general concept of disease, in which the causal basis of disease is incorporated into our nosologies. As Richard Hull has explained:

> In its efforts to understand, control, and avoid disease, modern medicine has incorporated into the very identification of a disease the notion of the cause of the syndrome. This permits the individuation of similar syndromes with distinct causes into different diseases. (p. 61)

There is a fairly obvious problem with this as a way of distinguishing between genetic and epigenetic diseases. That is because there are genetic and nongenetic factors which are causally relevant to every trait, a fact recognized by virtually all commentators on the concept of genetic disease (see Gifford; Hull, 1979). So the real issue in deciding that something is a genetic disease, is whether the causal factors which are genetic are the most important causes. How do we decide whether genetic factors or environmental factors are more important in the production of various diseases? In response to the selection problem, a number of solutions have been proposed. These can be grouped into a few major categories.

One approach is to try to tease out a notion of genes as *direct* causes of disease. In 1990 Fred Gifford tried to capture this notion in one of his two definitions:

> …the trait must be the specific effect of some genetic cause, that the trait must be described or individuated in such a way that it is properly matched to what the gene causes specifically. (p. 329)

However, this approach seems hopeless in the face of the actual complexity of development. Quite simply, this definition probably does not identify any diseases or traits as genetic. As Kelly Smith argued in 1990, "genes do not directly cause anything of immediate phenotypic significance" (p. 338).

Perhaps the most obvious and promising approach to the selection problems is to try a statistical approach. A number of variants on this have been attempted.

> The first and central sense of *genetic* is this: a trait is genetic if genetic *differences* in a given population account for the phenotypic *differences* in the trait-variable amongst members of that population. (Gifford, p. 334)

This seems to exactly capture at least something important about society's concept of genetic disease. It can be put perhaps more precisely in terms of covariance. When some trait is identified as genetic, it can be argued that (in that population) the covariance of the trait with some genetic factor(s) is greater than the covariance of the trait with other (nongenetic) factors. This solves the selection problem neatly by allowing us to pick out which causal factors are irrelevant (the ones which are fixed) and highlight the important ones (the ones that *make the difference*). In one of the canonical examples of causality, one is inclined to say that the lighting of a match (under normal circumstances) was the cause of the fire, while the presence of oxygen (while a contributing causal factor) was not. In contrast, in an environment where fire was normally present and oxygen was not, one might well pick out the (unusual) presence of oxygen as the cause of a fire.

There are several advantages to this approach to the selection problem. First, it corresponds to the use of analysis of variance that is used by biologists to measure the causal contribution of hereditary and environmental factors in a population. Second, it is capable of clear explication. Third, it has at least some intuitive support. However, this account seems to conflict with common usage in cases where pathogens typically identified as *the* cause of disease are nearly ubiquitous (so that, for example, genetic factors may make the difference between which people exposed to the pathogen become ill).

In spite of its advantages, the statistical approach fails to capture all of the myriad uses of the concept of genetic disease. Another approach has been developed from the way the most important causal factor in an explanation is picked out.

Philosophers have claimed on quite general grounds that the most important cause is chosen in terms of the manipulability of the various factors. Whatever the general virtues of this approach, it is promising when it comes to medicine. In the natural sciences, it could be argued that there is a strong interest in prediction and explanation. In contrast it has been argued that the medical realm is more concerned with the prevention and treatment of disease than with explanation (Wulff; Engelhardt). Instrumentalist interests play a much more central role in medical practice than in science. Hence, the appropriate solution to the selection problem can be formulated in terms of manipulability. The most important cause is the one that is identified as the most easily manipulated to prevent or treat disease. A disease is genetic if it is genes that play this role and epigenetic if it is non-genetic factors that are most easily manipulated.

Like the statistical definition, the manipulability definition captures something important about our usage of the term. In addition it is often an implicit aspect of the justification for the extension of the concept of genetic disease to new cases. However there are some problems with this approach as well. The obvious problem seems to be that on this analysis, no disease could be classified as genetic. Many of the paradigm genetic diseases (phenylketonuria [PKU], cystic fibrosis [CF]) involve treatments that are not molecular. Indeed, in the case of PKU, the standard treatment involves a change in diet. At the same time the tests for PKU were developed before the actual mutation responsible for the disease had been identified. It is impossible to adhere to the manipulability definition and accept that PKU is a genetic disease. This seems to be a fatal flaw in the manipulability definition. In addition, it is not true that biomedical science is always instrumentally oriented. A great deal of effort is aimed not just at treating and preventing disease, but at understanding it. This may lead to a conflict over which causal factor is most important (the factor most easily manipulated for treating or preventing a disease may not be the most revealing for the purposes of understanding a disease).

It is worth noting that both the statistical approaches and the manipulability approaches seem to imply a relativity in the concept of genetic disease. In the case of the statistical notion, something will count as a genetic disease or not, depending on the population it is a part of. The manipulability definition implies that technological advances will affect what counts as a genetic disease as the *reach* of our technology is extended. Yet, this result seems to be incompatible with an ontological conception of disease. If diseases are real entities (and independent of values) then the solution to the selection problem should not depend on factors outside of the organism (Boorse). Thus the normativist or constructivist position on disease seems to be supported by these analyses (however inadequate they are as a general account).

Evolutionary Ethics

As philosophy has become more *naturalized,* it is unsurprising that philosophers (and especially philosophers of biology) would attempt to find a way to ground ethics in a biological account of human nature. Perhaps even more significantly, the development of sociobiology and its subsequent incarnation, evolutionary psychology, meant that biologists were looking to explain the origins of morality in an evolutionary account (Wilson; Farber; Wright, 1995). Michael Ruse has been perhaps the most influential voice on evolutionary ethics (1991, 1993).

Ruse argues that evolutionary theory offers *the* explanation of the origin of altruism and other moral sentiments. He follows the explanatory strategy of the sociobiologists (and evolutionary psychologists) by appealing to the apparent universality of cooperative behaviors and moral sentiments, combined with the obvious adaptive value that cooperative strategies represent. Indeed there are a number of game theoretic accounts to demonstrate the adaptive value of altruistic behavior in at least some circumstances (Smith, 1982).

Ruse then claims that the fact that evolution explains morality undermines moral realism. He offers two arguments. First, although human moral sentiments evolved, it is quite possible that an alternative set of sentiments could have produced the same effects. The contingency of evolution means that morality itself is contingent. Second, Ruse takes great care in dispelling any teleological interpretation of evolution. Evolution is a directionless process with no end or goal. Since morality is founded on a directionless process, it follows that realism towards ethics is undermined. Evolution is meaningless, and without value. Organisms that survived and adapted are not *better* in a normative sense. Hence there is no normative foundation for ethics.

Critics have attempted a number of strategies, including questioning the extent to which evolution can really account for morality (Lewontin), or denying the relevance of the facts of evolution to normative issues (Nagel). Other critics have argued that a fully naturalized ethics that accepts evolution as the foundation of morality is fully compatible with ethical realism (Maienschein and Ruse).

What Is Life?

A recently emerging research area at the intersection of philosophy of biology and bioethics is over the definition of life. This question has multiple dimensions. National Aeronautics and Space Administration (NASA) scientists wonder about the definition as they pursue research into the question of life on other planets. How will researchers know whether what they find is a living organism or a (nonliving) chemical reaction? Biologists interested in the origins of life similarly strive to understand the demarcation between the living and nonliving as they construct their models. Genomic scientists attempt to better understand gene function by trying to determine the minimal number of genes necessary for life—life's genetic essence. Public policy makers and scientists debate the moral significance of ex vivo fertilized egg cells and the stem cells that can be derived from them. Are the embryos living? Are they alive when they are frozen? Are the stem cells that can be derived from them living beings deserving of respect or are they research tools to be used to help people suffering from disease?

The process of development, from an early embryo to a fully differentiated and functioning organism is a long, complex process. Determining the moral status of that embryo at different stages of the process is a difficult task (Green). Prior to implantation, an embryo's undifferentiated blastomeres are each capable of creating separate and unique individuals (through twining). Other traits emerge later as the nervous system develops. At what point is there a (human) life? And is life (as opposed to, for instance, personhood) the right concept to be considering? And what is the status of the derived stem cells themselves? As Arthur Caplan and Glen McGee have argued, the problem of "What's in the dish?" remains one of the key concepts in this policy debate. At heart though, the issue turns on precisely the kinds of metaphysical and biological issues that philosophy of biology has been exploring for decades. Surprisingly few have weighed in (Maienschein) but more can be expected to do so in the future.

Debates about the origins of life have produced very different approaches to the meaning of life (Rizzotti). More reductionist accounts place a heavy emphasis on genetic features—the ability to replicate is key and the genes are seen as what make cells alive. In contrast, metabolists have long focused on the interactive elements of living things. Recent attempts to define the minimal genome represent the latest in the reductionist approach to defining life (Cho et al.).

Reductionism and Genetic Determinism

One of the themes that runs through much of the intersection of philosophy of biology and bioethics is the question of reductionism and its most criticized form, genetic determinism. To what extent is behavior and character dictated by genes? Popular images in magazines hype genes as the new Rosetta stone, the key to unlocking who and what people are (Nelkin and Lindee). Many biologists have defended the view that genes are the primary determinants of key traits (Hamer; Koshland).

Philosophically there are multiple meanings of reductionism that can be distinguished. There is theory reductionism in which theories at one level are explained by other theories that are seen as more *fundamental.* Recent philosophy of science has moved away from traditional views about theories, requiring alternative accounts of formal reductionism that looks at models and mechanisms (Sarkar). Reductionism can be epistemological in character—it can be about what provides the epistemological force to claims at different levels. So, for example, the force of rules in psychology could be dependent on the force of genetic rules that would explain the rules in psychology. Ontological reductionism would claim in one way or another that the only real entities are those at lower levels. Ultimately, the ideal reductionist picture would show the unity of science—behavioral accounts can be reduced to population genetics, population genetics can be reduced to molecular genetics, molecular genetics reduced to chemistry, and chemistry to physics. The only real entities are the entities posited by physics.

There have been many criticisms of reductionism (Sarkar; Moss; Kaplan; Lewontin; Keller; Kitcher). These have ranged from technical difficulties with reducing theories from biology to other levels (the only plausible laws in Mendelian genetics are not only false, transmission genetics is a measure of the degree of falsity of the law of independent assortment) to criticisms of specific *popular* reductions which purport to demonstrate the fundamental importance of genes as the determinants of human characteristics. Reductionism (especially the popular version) is largely a promissory note, one that the critics show is virtually impossible to pay off.

Conclusion

Philosophy of biology continues to grapple with conceptual issues that concern bioethicists. The meaning of disease, health, genetics, and even life are all issues that are full of import for normative concerns with how research should proceed, what sorts of science and medicine should be funded, and the moral status of different entities. The turn towards thick descriptions of biology and a growing interest in parts of biomedical science beyond evolution should fuel continued overlap between philosophy of biology and bioethics.

DAVID MAGNUS

SEE ALSO: *Body: Cultural and Religious Perspectives; Healing; Life; Medicine, Philosophy of; Natural Law; Science, Philosophy of*

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BIOMEDICAL ENGINEERING

• • •

Since the early 1960s biomedical engineering has transformed healthcare in industrialized countries, confronting healthcare professionals and the lay public with new problems, decisions, and possibilities. The need to understand those problems, decisions, and possibilities has contributed to the importance of bioethics in healthcare.

Biomedical Engineers and Biomedical Engineering

Biomedical engineers develop sophisticated quantitative methods of measurement and analysis for the diagnosis and treatment of health problems. Those methods typically draw on an understanding of various biomedical sciences, including normal and pathological physiology. For example, biomedical engineers use engineering methods to study the stresses and pressures in human joints so that they can develop replacements and study the mechanisms of cellular excitation and electrical propagation in tissue so that they can improve cardiac pacemakers. Their work includes the design, development, testing, and refinement of medical devices and procedures to prevent, diagnose, and treat trauma and disease. For example, biomedical engineers developed magnetic resonance imaging (MRI) not only as a new technique for noninvasive diagnosis but also to guide the treatment of tumors. Other biomedical engineers develop and oversee the manufacture, marketing, and maintenance of high-technology medical products.

In doing this work biomedical engineers collaborate with medical research investigators, healthcare providers, and other mechanical, electrical, chemical, aero/astro, and nuclear engineers. The collaborators often lack a biomedical background but may address special technical problems that arise in the design and development of medical products.

The devices that biomedical engineering makes possible vary from "smart" thermometers for home use to multimillion-dollar MRI equipment. Some biomedical devices come into direct contact with patients, becoming "the machine at the bedside" (Reiser and Anbar); other machines become part of the patient's body, such as cardiac defibrillators; these are new elements in the public's experience of healthcare.

Current Practices and Approaches

There are more than 3 million engineers in the United States, but engineering work is not well understood by the public, which often confuses the engineer who designs or develops a device with the technician who operates it or the skilled worker who assembles it. The most common, and mistaken, view of engineering in general and biomedical engineering in particular is that it entails only the application of science. This "applied science" model disregards the central place of design and synthetic or creative thinking.

Engineers invent, design, develop, and adapt devices, constructions, materials, and processes in response to human needs and wants. Their concern is the actual behavior of the objects and systems they study; that behavior results from many simultaneous influences, only some of which are the object of study in the natural sciences. Biomedical engineers, like other engineers, often enhance and extend the distinct body of knowledge known as engineering science.

In the early twenty-first century the dominant fields of engineering—mechanical, civil, electrical, computer, chemical, and materials—are based on the physical and mathematical-computer sciences. Biomedical engineering may draw on engineering knowledge from any of those fields to help solve health problems by using state-of-art technology. In being defined by an area of human concern—medicine—biomedical engineering is similar to another new field or area of engineering: environmental engineering.

Biomedical engineering has a somewhat different character within each of the established engineering fields. Electrical engineering informs the biomedical investigation of the bioelectric phenomena involved in nerve and muscle function and the designs of devices, such as pain-blocking stimulators and implanted electrodes, to aid hearing. Mechanical engineering illuminates problems in biomechanics, the large-scale and small-scale solid and fluid mechanics of the living body. Biomechanics leads to the production of devices such as artificial joints and has many of its applications in orthopedic surgery, physical therapy, rehabilitative medicine, and other empirical areas of healthcare. Advances in biomechanics include the investigation of cartilage at the cellular and subcellular levels and even at the molecular level.

Since the 1990s bioengineering as practiced by chemical engineers has been transformed by advances in molecular biology that have provided the theoretical and experimental basis for predicting how the human body will interact with nonhuman materials. It has produced major new tools, such as monoclonal antibodies. Therefore, molecular biology informs the design of devices in which there is dynamic exchange between human and nonhuman systems, for example, dialysis machines, heart-lung machines, artificial organs, and implants for the sustained delivery of medications. It also informs nondevice research areas such as therapeutic protein research and lends important techniques to tissue engineering: the use of engineering theory and methods to develop cell-based artificial organs. New skin for burn patients is the first of many therapies expected from tissue engineering.

Most biomedical engineers are employed outside healthcare facilities. However, a small percentage of biomedical engineers are "clinical engineers" who work in healthcare facilities and oversee the use, adaptation, integration, maintenance, and repair of an increasingly sophisticated array of devices. In rehabilitation technology, for example, "rehabilitation engineers" often collaborate in prescribing appropriate devices and designing unique devices for individuals.

Because cutting-edge technology often finds ready application in the development of military and medical devices, engineers who are attracted to such work may choose biomedical engineering as an alternative to military work. The desire to avoid military work may explain in part why the proportion of biomedical engineers in the United States who are women is high in comparison to the proportion in other engineering fields. The high proportion of women also may be due to women's interest in the helping professions, the relative openness of new fields to women, and the high rate of representation of women in the life sciences.

Collaborations between engineers and physicians in the United States highlight the cultural differences between those professions in this country. Although corporate management or "the market" may constrain engineering work, engineers thoroughly discuss and "brainstorm" how best to deal with all existing constraints. In contrast, physicians, especially surgeons and others who must make critical decisions quickly, are accustomed to unilateral decision making. Engineers often find the hierarchical organization and authoritarian practices of medicine perplexing and even counterproductive.

The naming of devices illustrates the dominance of medicine over engineering in collaborations on medical devices. Medical devices that are named for individuals (e.g., in orthopedic surgery the Harris hip and the Galante hip) bear the names of the physicians who collaborated on them or brought them into clinical use even when the design is largely the work of a single biomedical engineer. The influence of physicians on biomedical engineering in the United States is demonstrated further by the fact that the U.S. market for medical technologies, especially technologies used in healthcare facilities, is driven by physicians and the administrators of healthcare facilities. Even when U.S. physicians do not collaborate in design and development, their demands as major customers have a much greater effect on the design of biomedical engineering devices than do those of other health professionals. In contrast, in Sweden, where the healthcare system is government-sponsored, all the healthcare workers who are expected to use a device are involved in setting the requirements for the device to be designed or purchased.

Biomedical Engineering, Medical Technology, and Issues in Bioethics

One reason for the growing public interest in bioethics is the rapid change in healthcare practice that has resulted from biomedical innovation. The resulting technology has both desirable and undesirable effects as well as many effects that, although not clearly negative or positive, alter the responsibilities of professionals and laypersons in regard to birth and death, illness, and injury. As people confront new information and new possibilities, they are faced with difficult decisions that were unknown to previous generations. New biomedical technology forces people to become “moral pioneers” (Rapp).

There are several major categories of medical technology that have important implications for the definition of decisions and responsibilities. Medical information systems are computer-based systems that store patient information and assist in clinical problem solving. Rehabilitation devices are designed to give patients greater independence, comfort, and dignity. Drug delivery systems often alter patient participation in administering medications as well as affecting the safety, reliability, and efficacy with which medications are administered. Teaching devices enable students to learn and practice clinical skills, often reducing patient suffering and lessening guilt and stress among student-practitioners during clinical training. Finally, some technologies improve the use of healthcare technology. For example, assessment systems help clinicians match rehabilitation technology to an individual patient’s needs and abilities.

New technologies also change responsibilities by altering the healthcare labor force. Devices that require special skills to operate or for the interpretation of their output have created new healthcare occupations with new responsibilities. Other devices have reduced or eliminated the need for other kinds of work. Some devices, such as imaging technologies and therapeutic X rays, have tended to centralize care in large university or urban centers because of the expense or massiveness of the equipment or the requirements for its installation and maintenance (Reiser). For example, the powerful magnets used in magnetic resonance imaging require extensive shielding so that they do not affect metal objects in the vicinity. Other kinds of technology, such as information technology, have fostered decentralization by giving practitioners in less populated areas ready access to both specialized medical knowledge and patient information (Reiser).

New medical technology often makes healthcare more effective. However, some devices have become deeply entrenched in practice before their clinical value or lack of diagnostic clinical value has been established. This is illustrated by the electronic fetal heart monitor used during childbirth. After its introduction, this monitor was adopted quickly in hospital obstetrics units, but it was shown later not to improve birth outcome even for high-risk births (see Luthy et al.).

Medical technology has had a variety of profound effects on family-care as well as healthcare practice. For example, some people have criticized the intrusiveness of intensive-care technology in light of the relatively high frequency with which people die in intensive-care units. The unit isolates a critically ill patient from family members, making it impossible for them to care for and comfort the patient in his or her final hours and disrupting the grieving process.

Engineering innovations often change “standards of care” when the use of a particular device becomes required for care to qualify as competent. For example, a physician who does not order a diagnostic X ray in certain cases may be liable to charges of negligence.

Lasers, fiber-optic and endoscopic technology, and ultrasound irradiation have made some surgeries less invasive.

Other areas of surgery, especially invasive neonatal surgery, have grown dramatically as new devices for surgery and new intensive-care technology for postsurgical recovery have been introduced. The outcome of these surgeries is sometimes problematic. The U.S. Congress, Office of Technology Assessment, reported that largely as a result of such heroic interventions, there were 17,000 "technologically dependent" children chronically dependent on respirators, intravenous nutrition, and other medical devices for life support.

Bioethics has devoted much attention to effective but sometimes harrowing new therapies and means of life support. Diagnostic and monitoring devices have received less discussion. Diagnostic and monitoring technology often changes the character of medical decisions, along with their basis and the parties to them. For example, when a pregnancy can be terminated if prenatal testing shows an abnormality, a test, such as amniocentesis, which is done halfway through pregnancy, transforms the pregnancy into a "tentative pregnancy" even if the test results are normal (Rothman).

Some of the effects of technological devices and improvements are at least in part the responsibility of the engineers who design them. The engineering profession recognizes that engineers are responsible for both the safety and the performance of their products. The issue of safety in diagnostic, monitoring, and life-critical devices is especially prominent because a failure is often life-threatening. The scope of the biomedical engineer's responsibility for how devices are used has begun to be discussed widely among biomedical engineers only recently. That discussion has considered whether engineers bear some guilt for the suffering caused by the use of respirators in patients who have no hope of recovery (Lewis). This suggestion proposes a particularly stringent standard of professional responsibility for engineers because respirators perform their intended function very well and often enable people to resume active lives. However, when they are used on terminally ill patients, respirators may only prolong suffering for patients and families and use precious healthcare resources. This kind of misuse must be distinguished from, for example, the use of a device in a wet environment. Devices in the home or in a hospital frequently are used in areas that become wet, thus presenting the risk of electrocution. That risk is eliminated through the installation of groundfault-interrupt circuit breakers. There are no similar engineering measures to ensure that respirators are used only in patients who have some hope of recovery.

Because the basis of professional responsibility is the special knowledge that a professional possesses, professional responsibility must originate in the knowledge that enables a professional to recognize or remedy a particular class of ill effects and promote good ones. In recent years state and national legislation has strengthened the legal standing of patients' advance directives, such as living wills and healthcare proxy statements, about their care. Those measures have had some success in addressing problematic use of life-support technology. The engineers who design and develop medical technology have some responsibility to ensure that it furthers human welfare, but in a democracy all citizens bear some responsibility for government policies governing its use.

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SEE ALSO: *Artificial Hearts and Cardiac Assist Devises; Artificial Nutrition and Hydration; Cybernetics; Dialysis, Kidney; Human Dignity; Nanotechnology; Organ Transplants, Medical Overview of; Pharmaceutical Industry; Research Policy; Technology; Transhumanism and Posthumanism*

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BIOTERRORISM

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The issues associated with bioterrorism are as broad in their scope and as challenging in their complexity as any in bioethics. These issues engage the resources of basic sciences, history, political philosophy, sociology, healthcare administration, and public health, as well as clinical medicine. In some instances they present unique concerns, in others they are variations on more familiar bioethical problems. In providing a sound bioethical account of these problems this entry will presuppose that the terrorist threat in question is morally unjustifiable either because the cause it represents or the means used to advance this cause cannot be rationally defended.

Public Health and Civil Liberties

There is broad agreement that individual liberties of speech, movement, and personal privacy may be abrogated when they present an imminent risk of serious harm to other persons and when no other means of ameliorating this risk is available. This doctrine is familiar within the traditional domain of public health. An additional element presents itself when there is an intentional threat to public safety from persons or states that seek to advance a political agenda.

Whether the political element is in itself sufficient justification for permitting the state to have greater latitude in the abrogation of civil liberties than it would in a naturally occurring public health emergency is an issue that may be raised. One might argue that the intentionality of a terrorist act, expressed through a biological attack, is liable to sow panic in a fashion that differs from the psychological effects of a naturally occurring epidemic. Whether that is the case or not is an empirical matter, and whether it is sufficient justification for a more aggressive response is a matter of political philosophy.

It is clear that the tactics required to minimize the harms of a disease outbreak are not substantially altered by the cause of the contagion. In the case of highly contagious and dangerous diseases like smallpox, public health theory calls for the identification and isolation of primary cases and the creation of a ring around plausible secondary cases. This surveillance and containment strategy requires that all those exposed, and their immediate contacts, be vaccinated, isolated, and quarantined if they become ill. Treatment of all cases within that ring should be sufficient to control the epidemic.

Conceivably a disease might be more likely to appear simultaneously in several distant places as part of a terrorist conspiracy than it would as part of a natural event. There is disagreement among public health experts concerning the point at which a certain number of far-flung individual cases would constitute a dire emergency that would render the ring strategy inadequate.

Although bioethics has emphasized self-determination, the public health context presents demands that are incompatible with strict adherence to individual rights. Some have argued that, especially in an emergency, effective public health interventions may entail justifiable limitations on civil liberties that would at other times be unacceptable. Limitations on such rights as speech, privacy, and travel should not be excessive or arbitrary, and they must be rationally linked to protection of the public. They may be imposed no longer than required by the circumstances.

Not all agree that more stringent restrictions on civil liberties may be required by a bioterrorism event. Some oppose abrogating the right to refuse treatment and any requirement that doctors treat patients against their will. These critics also question the practicality and effectiveness of large-scale quarantine. All these actions tend to undermine the most important defense against panic, which is trust in government authority. Adequate and equitable healthcare for all would, under this view, go farther than draconian measures to build public trust and elicit cooperation in an emergency.

Resource Allocation in a Response to Bioterrorism

Standard accounts of a formal principle of justice require that similar cases be treated similarly. In an extreme event healthcare institutions may not have the capacity to absorb large numbers of patients that suddenly present themselves. An important problem is whether differential treatment is always morally wrong, or whether it can be justified in some instances.

The classic approach to sorting battlefield injuries is triage, a nineteenth-century French policy based on the strictly utilitarian principle of the greatest good for the greatest number. Depending on the particular model, triage utilizes three or five categories that range from *urgent* to *non-urgent* to *care not needed.* Although triage has become a familiar term in the civilian medical world, especially in busy emergency rooms, in its original military context the idea included a criterion of social merit, that the argument for care in any particular case turned on the potential for the individual to return to duty.

Under ordinary circumstances clinical triage differs from battlefield triage. In the former case the most seriously ill are not simply set aside. Rather, resources are made available through such ad hoc means as the temporary diversion of ambulances to other emergency rooms (Kipnis). Under extreme conditions these routine bypass procedures may not be feasible. A social worth criterion could be transferred to civilians if the circumstances were sufficiently dire that, for example, the very survival of the community was threatened. According to theologian Paul Ramsey, the comparative social worth of individuals can justifiably be measured in these highly defined circumstances.

First priority must be given to victims who can quickly be restored to functioning. They are needed to bury the dead to prevent epidemic. They can serve as amateur medics or nurses with a little instruction—as the triage officer directs the community's remaining medical resources to a middle group of the seriously but not-so-seriously injured majority. Among these, one could argue, a physician should first be treated (Ramsey).

A social worth criterion applied to extreme conditions appears to be incompatible with respect for each individual person, for the inevitably unsuccessful act of treating some is sacrificed in exchange for the potential survival of a valuable individual whose survival would in turn benefit the larger number. However, an argument can be made that the unequal treatment is justifiable precisely because one respects all of the others whose survival is made more likely because of the treatment of this one. Respect for all the others that might survive is respect for each of them as individuals, hence egalitarianism is preserved (Childress, 2003).

But not all who are possessed of critical skills may be required for the benefit of the community. Rather, only a few may be needed, therefore it would be unfair to guarantee all of these individuals a place at the head of the queue. Instead, to ensure that at least some of them survive without providing inappropriate advantages to all of them, essential workers may be entered into a weighted lottery in such a way that their selection is more likely, on average, than that of others (Childress, 2003).

As has been observed, the successful management of a bioterrorism event requires a high degree of public trust. Therefore, criteria for triage and resource allocation should be formulated as part of a public consensus process. Transparency in the development and application of resource allocation principles under extreme conditions should include their defense and readjustment in light of public reaction. Precedent can be found in the case of the allocation of organs (Childress, 1997). The articulation and adjustment of allocation principles must take place well in advance of the event itself.

The Obligations of Emergency Health Workers

Healthcare workers are often expected to undergo a degree of discomfort and inconvenience in executing their duties. This expectation is justified by the vulnerability of those under their care, a vulnerability grounded in illness and in the knowledge differential between doctor and patient. Similar role-related obligations apply to other professionals, such as attorneys or securities analysts, whose clientele is inherently vulnerable by virtue of social status or lack of relevant information. Perhaps because of the concreteness and intimacy of their work, no other professional group is held to as high a standard in this regard as are those in healthcare.

The degree to which healthcare workers must compromise their own well being for the sake of others is often unclear. The role-related duties of healthcare professionals imply at least a modest degree of self-sacrifice for the sake of others who are in need of their services. Ordinarily these sacrifices are limited to brief periods of discomfort or inconvenience, particularly embodied in the rigors of the medical residency. At the extreme, martyrdom and other supererogatory acts spell out the limits of these duties, but detailed guidance is lacking. Although emergency health workers have been designated as a special group with more extensive duties under circumstances that demand urgent attention, this designation is not informative about the boundaries of their obligations (World Medical Association, Pan American Health Organization).

One set of considerations has to do with the support emergency healthcare workers are given in executing their tasks. Professionals cannot be expected to perform their responsibilities in the absence of adequate materials, much less expose themselves to conditions that put them at risk. Governments must provide "an effective and centralized authority to coordinate public and private efforts." (World

Medical Association). In the context of terrorism the society under threat should also provide the material support required for emergency healthcare workers to do their job, particularly as there is an expectation that their personal welfare is at somewhat greater risk than that of other health professionals (Eckenwiler). The failure to provide suitable support is not an excuse for the healthcare worker to abandon his or her post. Rather it reflects the reciprocity that skilled professionals may fairly expect considering the physical and psychological stresses to which they are exposed.

Another consideration relevant to the question of the limits of emergency healthcare workers' duties is that of moral responsibilities to distant others, as compared to appropriate concerns for one's own welfare or that of significant persons in one's life. As the victims of catastrophe are less familiar to us, as they become more distant in space or culture, it may become more psychologically challenging to relate to their circumstances, especially if their plight competes with that of someone in greater geographic or social proximity.

A feature of the healthcare workers' morality that should, in principle, set them apart from the rest of society is that their circle of concern knows no distance. Yet it is worth asking if this presumption of universal concern, of impartiality, is always sound when it competes with more local concerns about one's own family, friends, and colleagues. Further, partiality is not a vice if it is conceived as one way in which human beings express their individuality through the uniqueness of their relationships (Eckenwiler). Healthcare professionals functioning in emergencies may not be expected and should not be required to subvert justifiable tendencies to place primary value on personal relationships when forced to allocate their caregiving under extreme conditions.

The Role of Private Sector Institutions

Many of the human and material resources that may be required in catastrophic circumstances are in the private sector, especially pharmaceutical manufacturers and managed care organizations. Nonpublic entities are generally agreed to have some responsibilities to the society that provides a stable framework for their business activities, responsibilities that must only increase in the event of social emergency. The contours of these corporate social responsibilities assume a special character in the context of bioterrorism.

Yet private industry cannot be expected or required to resolve all societal problems that are more appropriately considered the province of public entities, such as providing access to medication or healthcare for all. Rather, these private interests have a duty to participate in the public discourse that seeks the resolution of policy problems and to engage in business practices, such as fair pricing policies, that make solutions practicable. The rationale for this duty can be expressed in terms of the primary moral purpose of any business, to produce goods or services that contribute to the pursuit of the good life (DeRenzo).

Within this scheme drug companies can be said to have certain obligations with regard to the bioterror threat. For example, they are obligated to provide security to guard against any potential vulnerabilities in their production activities or storage arrangements. They should make positive efforts to help ensure that medications are available for the treatment of bioweapons injuries with a wide therapeutic range and based on different mechanisms, rather than simply produce medications similar to those already available. For cases wherein there is only one patented drug for a certain indication that is related to a bioterror threat, government may consider a *stop the clock* mechanism that permits at least temporarily lifting the patent so that production and distribution can be accelerated. (DeRenzo)

Managed care organizations (MCOs) have concentrated a large portion of the highly skilled healthcare work force in the private sector. Not limited to bioterrorism, this arrangement raises questions about the relationship between corporate responsibilities and threats to the public health. Controlling of costs while also providing excellent healthcare has proven to be a significant challenge to the industry, and quality improvement efforts have proven disappointing in resolving the cost-quality tension. Because public health agencies have limited resources, any severe public health problem would further tax the private healthcare system as MCOs would be obligated to provide care for victims even if they are not enrolled in some defined health or insurer plan (Mills and Werhane).

In one sense, as the burden of providing care for a potentially large patient population at risk from bioterrorism falls on MCOs—in the form of vaccination, treatment of victims and planning for attacks—the tension between cost and quality will become still more pronounced. In another sense, however, the requirements of physical survival in extreme circumstances render the cost issue moot, as the best possible care will simply have to be provided. From an economic standpoint the goods and services involved are *decommodified* or removed from the marketplace because market mechanisms are unable to deal with such conditions. Instead, MCOs should think of themselves as part of a wider system of healthcare, along with government agencies, the pharmaceutical industry and academia. Paradoxically, the threat of bioterrorism introduces a community perspective into privatized healthcare in a way that normal economic and political conditions do not (Mills and Werhane).

Research Ethics and National Security

The development of human research ethics, and of biomedical ethics itself, has been decisively influenced by experience with the involvement of human subjects in national security experiments. The signal event in this often dispiriting history was the exploitation of concentration camp prisoners in experiments under the cover of World War II, many sponsored by the Nazi German military apparatus. The culmination of the Nazi doctors' trial in 1947 was the creation of the Nuremberg Code, which set down rules for human subjects' research and is generally considered a landmark document in biomedical ethics (Moreno).

Subsequent policies regulating human experiments on biological, chemical and atomic warfare in the U.S. military during the cold war specifically referenced the Nuremberg Code. However, these policies were not always followed, in some instances because the activity in question was not considered to be a medical experiment but a training exercise. Secrecy has itself proven to be among the greatest single obstacles to developing consistently applied ethical standards in this area.

The populations that have been involved in national security research represent a wide range, from military personnel, conscientious objectors, and institutionalized persons including prisoners, mental patients and medical patients. Military personnel in particular occupy a complex role because they are expected to subject themselves to risks that would not be required of others, and must accept medical interventions that will preserve or reestablish their fitness for duty (Moreno). Certain basic ethical standards have been recommended, such as appropriate security clearance for all parties, including subjects, prior review by an institutional review board, an appeals process, informed consent, and record keeping (Advisory Committee on Human Radiation Experiments).

Like the other bioethical issues associated with bioterrorism, the development of ethical standards for the involvement of human beings in national security experiments requires the resources of several disciplines. Still more challenging, is the application of these standards, which requires a level of engagement with the political system that clearly identifies bioethics as a practical moral activity.

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SEE ALSO: *Coercion; Epidemics; Freedom and Free Will; Harm; Hazardous Wastes and Toxic Substances; Holocaust; Homicide; Immigration, Ethical and Health Issues of; Race and Racism; Warfare: Chemical and Biological Weapons*

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BODY

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I. Embodiment in the Phenomenological Tradition
II. Cultural and Religious Perspectives

I. EMBODIMENT IN THE PHENOMENOLOGICAL TRADITION

Philosophical and ethical issues are closely connected with medical and health professional self-understanding, knowledge, research, and practice. The human body occupies a central place in those contexts, but especially within medicine—certainly one of the sources for understanding the human body. In this entry, after a brief review of ideas about the body in the history of medicine, its place in philosophical thought since René Descartes is addressed. This history plays an important role in more recent philosophical reflections on human life, especially in writings directed to the experience of embodiment. After reviewing that history and the understanding of embodiment, some suggestions are made about the relationship between embodiment and the variety of ethical issues presented by medicine, biomedical research, and clinical practice. This discussion is unavoidably difficult, because both that history and the issues raised by efforts to explicate and understand embodiment are complex. Addressing those complexities, however briefly, will be helpful in delineating the specific concepts, terms, and methods used in the phenomenological tradition regarding embodiment.

From the earliest stirrings of human fetal life through old age, individuals are embodied. Whether their bodies are more or less healthy, or are sick, injured, compromised by congenital or genetic defects, or are such that they arouse social prejudice, individuals experience the surrounding world by means of a particular body. Being embodied, furthermore, means having a certain sexuality and thus experiencing the milieu in ways that both structure and are socially structured by that sexuality. Even slight reflection also shows that the human body has aesthetic, economic, political, and other dimensions specific to every cultural time: the body figures prominently in clothing styles, pornography, labor, torture, and the like. The experience of the body by oneself and others plays other important roles in broader terms: in the "body politic," for instance, or in the manufacture of automobiles, or in contexts such as physical examinations in the military.

Underlying all of these, however, is a striking phenomenon: regardless of the state of health, skin coloration, sexuality, or sociopolitical usages, one body is uniquely singled out for a person's experience as "mine," as that sole body through which anything else is experienced. While any full explication of embodiment must address each of these fascinating dimensions, the first question concerns that core sense of "mineness": How are we to understand that? It is to this that the present entry is devoted. First, however, an equally brief word is needed about the place of the body in medicine.

The Body in Medicine

Historically, physicians have sought to understand the body's structures (anatomy), functions (physiology), cellular makeup (biology, biochemistry), activating and regulatory mechanisms (neurology, immunology), the several organ systems and their connections (cardiac, pulmonary, renal, hepatic, etc.), and the variety of diseases, injuries, noxious environmental influences, and genetic and congenital conditions that govern the body's development and underlie personal life.

Even with this focus, however, historical medical views of the body have varied over time (Edelstein). For example, the "dogmatic" or "rational" view understood the human body as fundamentally causal in nature—events inside the body were thought to cause outer symptoms (a pathological understanding of the body and disease). By contrast, according to the "empiricist" and "skeptical" traditions, the body and the embodied person form an experiential, temporally developing "whole" in continuous and multiple interactions with the surrounding world (a holistic view). Physicians in later historical times who were convinced of the dogmatic, rational view literally looked inside the body—by dissection and vivisection—and understood its structures and functions. Those who held the empiricist view turned instead to history (the patient's history and the collective histories of other physicians) in treating diseases. These two basic, conflicting models have continued to have an important place in medical understanding (Leder; Zaner, 1988).

Although these views continue to be present in medicine, the rationalist tradition (emphasizing the body as a material, causally determined organic system) has been clearly dominant in more recent times. The first major steps in the historical development of a rationalist view of the human body were taken in the early fourteenth century by Mondino de' Luzzi and his student Guido da Vigevano (Singer). By far the most significant steps are found in the seminal work on anatomy by Andreas Vesalius (1514–1564) and later in the important discoveries in physiology by William Harvey (1578–1657), strongly endorsed by René Descartes and continued in the work of seventeenth- and eighteenth-century post-Cartesian physicians, such as Robert Boyle (1627–1691) and Friedrich Hoffmann (1660–1742) (King) and Jerome Gaub (1705–1780) (Rather).

In modern times, the body was first proposed as a fundamentally causally determined organic system by Giovanni Battista Morgagni (1682–1771) and Xavier Bichat (1771–1802). Before this time, even though abundant autopsy reports had been published, such recorded data had not offered any correlation between clinical and anatomical findings (King). With Morgagni and Bichat, however, this changed profoundly. The introduction of the "clinicopathological correlation" radically altered medical understanding. For the first time, what was found at autopsy was taken as "explaining" clinical symptoms observed while the patient was alive. Now disease took on a highly specific form—the "organic lesion" found inside the body—and was no longer associated with a more or less loosely collected set of clinically observed symptoms or patient reports (King; Zaner, 1988). Because this "correlation" fundamentally changed the way physicians understood disease, it has been called a "revolution" (Laín Entralgo) comparable to what Copernicus effected in astronomy when he proposed that instead of thinking that the sun moves around the earth, we should perceive it to be the other way around.

The marriage of clinical medicine to biological science, definitively begun in the nineteenth century, was consummated through the work of neurologists such as John Hughlings Jackson (1834–1911) and clinicians such as William Osler (1849–1919), and the educational reforms recommended by Abraham Flexner (1866–1959) in the early twentieth century. Medical thinking then incorporated the idea that the body is a complex system of physiologically interacting structures and mechanisms governed by multiply interrelated controls seated in the neurological system. Some physicians, appreciating that this complex organism (or set of organ systems) serves as the embodied person's means of expression and action, advocated a type of "medical dualism" or "epiphenomenalism"—there must be a place for the "person," whether thought of as a distinct entity or as a causal consequence of the body complex's functional stability across time.

The Body in Philosophy

While the history of philosophical and moral deliberations about human life is quite as sophisticated and colorful as medical history, the bulk of reflections have focused on *mind* (*person, self, subjectivity,* and related notions) (Zaner, 1980). With some notable exceptions, however, there has not been nearly as much reflection about *body* per se. In large part, a basically traditional view of these matters was assumed: that body and soul are distinct (or even separate) realities, and that what is essential in human life is to be found in the soul, not the body. The soul (mind, reason) is the pure and unchanging essence of the human; the body, on the other hand, is a baser sort of affair, belonging to the changeable, the temporal, and the corrupt. The soul, imprisoned within the corporeal, is subject to the body's peculiar "nature," its appetites and inclinations, but has its true destiny and nature elsewhere—a destiny it must pursue by becoming freed from its worldly, bodily prison.

There have been exceptions to this view of the human body. René Descartes (1596–1650), for example, argued that mind (*res cogitans*) and body (*res extensa*) are to be understood as "substances": mutually exclusive, self-subsistent, and ontologically distinct entities, neither of which requires the other to be or to be known. This familiar bifurcation of reality (dualism), often said to be at the basis of modern medicine and modern thought more generally (Cassell, 1991; Eccles), led Descartes to the view that mind and body "interact" in some manner, although specifying that the form of this interaction proved to be inordinately difficult and highly problematic (Leder).

Hardly satisfied with that, and challenged by Princess Elizabeth (daughter of the exiled king of Bohemia, living at the time in Holland), Descartes's reflections on the body show a surprising turn—one that has not been well appreciated. The mind, he thought, is not "in" the body in the way a boatman is "in" a boat—contingently or accidentally. Rather, the mind is "intimately" connected to the body, an "intimate union" that led him to the view that the human body is intrinsically complex and not at all the simple "extended substance" posited in his metaphysics (Zaner, 1988). As Descartes remarked to Princess Elizabeth, neither mathematics nor metaphysics is capable of apprehending this union. It can be known only in "daily conversation" and in clinical encounters—one might say that the union is essentially a matter of concrete experience (Descartes, 1967; Descartes, 1973; Lindeboom).

To be sure, from his early work in anatomy, Descartes had learned that the cadaver does indeed seem to be little more than such "extension." But from his earnest attempts to provide medical diagnosis, he knew full well that while it is alive, the body is far more than merely a material entity extended in space. For example, writing of the "dropsical patient" in his *Meditations* (Descartes, 1955), he took pains to point out that there are in fact *two* "natures": the one subject to the laws of nature, the other with its own specific characteristics that must be understood in quite different ways than the other (Kennington). Indeed, Neils Stenos (1638–1686), a younger physician contemporary of Descartes who specialized in the brain, contended that nature in the first sense was merely heuristic, a "manner of speaking" (*une pure dénomination* is Descartes's phrase), and should not be taken literally (Lindeboom). This intrinsic complexity of the body—as cadaver and as embodying the mind—did not attract the attention of many philosophers (or, for that matter, physicians) (Zaner, 1988).

Addressing the Cartesian idea of the "intimate union" of soul and body, Blaise Pascal (1623–1662) argued that one must be able to account for this intimacy. He noted with marked irony that if, like Descartes, one "composes all things of mind and body," surely that mixture would be intelligible—especially to one who so composes all things. Yet not only do we not understand the body, and even less the mind; least of all do we know "how a body could be united to a mind. This is the consummation of [our] difficulties, and yet it is [our] very being" (Pascal, pp. 27–28).

Benedict de Spinoza (1632–1677) thought that Descartes's bifurcation created insuperable difficulties for understanding how the mind could possibly be connected to the body, much less "intimately" connected. Like others at the time, Spinoza's argument is couched in metaphysical terms: he argued that what Descartes termed "substance" (mind and body) could only be "attributes" of the one and only substance, reality itself. Mind and body are essential to one another; the way in which they are "united," he concluded, then becomes comprehensible. The body is a mirror of the soul; mind, the idea of the body (Spinoza).

Understanding the body continued to preoccupy physicians but did not become a focal issue for philosophers until the early writings of Henri Bergson (1859–1941). Although he did not fully probe the matter, Bergson argued that the human body should be seen as the person's placement or locus in the world. What makes the body, a sui generis phenomenon, unlike any other worldly object is, he believed, that it is experienced as "mine," as "my center" of action and experience. While it is physical, it is not simply that; it is the "center" of experience, and thus the field of physical objects is spatially organized around it. In addition, the human body and its perceptual capacities are in the service of action. The body is fundamentally an actional center. It is that by means of which the embodied person is able to engage in actions in and on the field of objects. Spatial location and the familiar sensory qualities are thus always experienced within specific contexts of action: for the perceiver, "things" are "menacing," "helpful," "handy," "obstacles," and so on (Bergson). Correlated to the body as the center of action, physical things are organized as "poles of action" appearing only within specific activities directed toward them, as Jean Piaget (1896–1980) later emphasized. Because of these characteristics, the human body is a critical factor in the development of language and culture.

In the early days of the twentieth century, Max Scheler (1874–1928) devoted serious reflection to the "lived body" (*Leib*), in particular as regards the performance of "deeds" in moral conduct. Scheler's analysis suggests that both "ego" and the ego's "acts" are distinct from what he terms "lived bodiliness" (*Leiblichkeit*). At the same, lived bodiliness must be sharply distinguished from the "thing body" (*Körper*). Although Scheler does not mention it, this idea is a clear echo of the earlier Cartesian insight. The body that embodies the person ("my body") is uniquely singled out for, and experienced by, the person as "mine" (and in this sense is "intimately connected"). As the person's experiential "center," it is that by means of which the person is, as it were, worlded: in the midst of objects, people, language, culture, and so on. These points, which had also impressed Bergson, came to be regarded as fundamental to embodiment, and are crucial for understanding subsequent discussions.

Edmund Husserl (1859–1938) grappled with this phenomenon throughout his career. Its primary feature, he contended, is the experiential relationship of consciousness to its own embodying organism (Husserl, 1952). Granted that this organism (*Leibkörper*) is uniquely singled out (Husserl, 1956–1959), the problem of embodiment is to determine in what sense and in what ways it is actually experienced by the person as his or hers, since it is solely by means of that experience that it is at all possible for the person to experience worldly things (physical, biological, cultural).

What had so impressed and troubled Descartes—the "intimate union"—Husserl calls the experiential relationship to the "body-as-mine"; however, he did not appreciate Descartes's insight any more than had Bergson or Scheler. Descartes seems clearly to have recognized that while a person is alive, there is an "intimate union" between body and soul; yet how are we to understand this "union"—a connection that is all the more peculiar when death occurs and this "alive" body becomes a cadaver that seems no different in kind from any other material thing? Although apparently appreciating this puzzle, Descartes nevertheless obscured matters (as did many others after him) by trying to resolve the very different metaphysical question of the "mind–body" relation.

It is to the embodiment phenomenon that Gabriel Marcel's analysis of the fundamental opacity (the elemental "feeling" or, as he termed it, *Urgefühl*) at the heart of personal life—my body qua mine—is addressed (Marcel, 1940). It is here, too, that Maurice Merleau-Ponty locates the essential ambiguity intrinsic to the body itself (Merleau-Ponty). So "intimate" is this "union," both Marcel and Merleau-Ponty point out, that one is tempted to say, with Jean-Paul Sartre, "I am my body." "My body qua mine" is thus the paradigm of "belonging" or "having": the sense in which things belong to a person is ultimately derived from the ways in which the "own" body is experienced as belonging to the person. The latter is the condition for the former (Marcel, 1935). This existential source of "belonging" becomes apparent especially in instances where mental disturbances occur and the sense of "mineness" becomes severely compromised or remains seriously undeveloped (Bosch). A central issue then emerges: By virtue of what is this one animate organism uniquely singled out to exist in my experience as that whereby everything else in the world is experienced? Which specific processes are there without which this organism would cease to be experienced by me as mine, or which give it its sense as mine (Straus, 1958)?

The problem is exceedingly complex and subtle, and is by no means settled (Zaner, 1971, 1980). It is one of those regions where philosophy and medicine can productively learn from one another. Within philosophy, however, there seems at least some agreement that the animate organism becomes and remains an embodying organism solely to the extent that (1) it is not just a physical body but a genuinely animate organism, the sole "object" within which the person's own fields of sensation (that whereon sensations occur) belong; (2) it is the only object "in" which the person immediately "rules and governs," within and from each of its "organs" and the total organism itself; (3) it is that whereby the person's "I can" (walk, perceive, move, grasp, and the like) is most immediately realized and enacted; (4) it is that "by means of which" the person perceives and otherwise experiences the field of worldly objects (things, people, language, etc.) and thus is the person's access to the world and the focus of the world's (objects, people) actions on the person; and (5) it is not only that whereby the person experiences other things, but it is itself experienced by the person (in health and sickness, and these in specific individual ways)—that is, the person's embodying organism is reflexively related to itself (Husserl, 1956, 1959).

The Body in Medicine and Philosophy

It should of course be recognized that, given the uniqueness of each embodiment, individuals experience their bodies (and, correlatively, the surrounding world) in different ways, depending on initial biological endowments, native and cultivated abilities, activities that are available and/or encouraged, and others. Thus, a boy who from birth has been unable to walk experiences "I can" in quite different ways from a boy who has that ability. If the latter has an accident that renders him unable to walk, moreover, his inability is experienced quite differently from that of the former—indeed, while the one undergoes a "loss," the other may not, except perhaps in the indirect way of realizing that while others can walk, he has never been able to. One who is born blind experiences the surrounding world quite differently from one who goes blind due to an accident—while neither experiences a "visual world," the one has "to get used" to the absence of visual space while the other has never experienced anything else. Even in cases where an individual may from birth lack several bodily capabilities (such as Helen Keller), or loses them through illness or injury, the features suggested above still hold: the embodying organism is that whereby one experiences sensations, which most immediately embody wishes and movements, by means of which one perceives (in whatever ways), and through which other things are experienced. Moreover, there are many other meanings the human body acquires—social, political, economic, and others—that a more complete explication of embodiment must address—bodily abilities, stances, comportments, and movements (Buytendijk) that have their sense and place within the spheres of nature, culture, and history.

Embodiment is thus fundamentally connected with various levels and modalities of bodily actions, attitudes, stances, and movements (Buytendijk), personal striving or willing, and perceptual awareness of things (including the body itself). Wishing, desiring, noticing, attending, and the like are or can be actualized (embodied, enacted) by means of corporeal movements (kinesthetic flow patterns correlated with muscle activations) that are functionally correlated with the several perceptual fields and what appears in them (turning one's head and looking at …). Only to that extent can one sensibly say that this organism is "uniquely singled out" from the field of worldly objects as "mine." Involved in embodiment are processes of sensory "feeling"—coenesthetic (of inner body, e.g., of hunger), kinesthetic (of body motion), proprioceptive (of body stance or posture)—and elementary strivings (reaching, squinting, locomotion, etc.). Together, these contribute not only to the sensing of "this" organism as "belonging to me" but also to the forming of the surrounding field of objects as correlated to bodily feelings and movements, positions, and actions.

But it needs to be emphasized that there is quite another dimension to embodiment. Although surprisingly little attention has been devoted to it, it turns out to be quite essential. However tempting it is to say "I am my body" (when, for example, someone strikes me in the face, I say "Don't hit me!"), many cases in psychopathology literature (Binswanger), and situations in daily life, suggest that matters are more complicated. The relation between self and its embodying organism seems as much a matter of "otherness" as of "mineness." However intimate and profound the relation between the person and the person's body, it is equally true that a person experiences his or her body as strange and alien, in ways that can be understood (Leder).

I am my body; but in another sense I am not my body, or not simply that. This otherness is so profound that we inevitably feel forced to qualify the "am": it is not identity, equality, or inclusion. It is "mine," but this means that the person is in a way distanced from it, for otherwise there would be no sense to "belonging"; it would not be characterizable in any sense as "mine." So close is the union that a person's experience of his or her "own" body can be psychologically unnerving (its happy obedience that the person notices for the first time, or its hateful refusal to obey his or her wish to do something) (Binswanger). So intimate is it that the person has moments of genuinely feeling "at home" with it. Yet so other is it that there are times when the person treats the body as a mere thing that is other, obsessively stuffing it with food or otherwise mistreating it; or when it is encountered as "having a life of its own" to which the person must willy-nilly attend: like it or not, "my" hair grows and must be trimmed for certain purposes, "my" hands cleaned, "my" bowels moved, "my" cold cured, and so on (Zaner, 1980; Leder).

The person finds himself or herself embodied by an animate organism whose peculiar connections to the person (and the person to it) give embodiment its uniquely uncanny character. Nothing is so much "me-myself," yet nothing seems so strange; so deeply familiar (Who else could "I" be?) yet so oddly alien (Who, indeed, am "I"?). This experience is not indicative of an inability to make up one's mind but, rather, suggests the peculiarity of embodiment. What seems distinctive is this "mineness/otherness" (the most familiar yet the most alien) dialectic that is the core of human body-as-experienced (Engelhardt; Zaner, 1980).

In these terms, to speak of embodiment is to speak of something that "I" am and not something that can be placed over against me (*ob-jectum*) as an object. As embodied, "I" am in a clear sense a fundamental puzzle to myself—precisely what Pascal had appreciated with remarkable insight. What is expressed by "the problem of the body" is precisely the person's "being as embodied," that is, the fundamental sense of being human in the first place. The "self-body" (or "mind-body") problem is, therefore, a matter of experience: It is enacted at every moment in the ongoing life of the person. These considerations make it easier to appreciate that the human body is essentially expressive. It is that by means of which the person enacts and expresses feelings, desires, strivings, and so on (albeit in culturally and historically different manners) (Merleau-Ponty, 1945). This expressiveness signifies that embodiment is valorized, that is, deeply textured with a sense of worth (whether positive or negative, as the case may be). After all, what happens to it happens to me: the person, as that which "rules and governs," is at the same time subject to its conditions. What happens to the person's body, in still different terms, matters to the person whose body it is: The embodying organism lies at the root of the moral sense of inviolability of personhood—of the "privacy," "integrity," "consent," "respect," and "confidentiality" that play such profound roles in research ethics, bioethics, and clinical ethics. Nor does the fact that people can and do dissemble and deceive themselves and others—as in cases of factitious illness when a person is thought to "fake" symptoms (Ford)—belie the body's expressivity. Indeed, these are themselves expressive phenomena, however difficult it may be to discover and to interpret them (Hauerwas and Burrell).

This value character of the embodying organism also helps elucidate more fully why the continuing discussions of many bioethical issues—pregnancy, prenatal diagnosis, abortion, psychosurgery, withdrawal of life support, euthanasia—are so highly charged and deeply personal. On the other hand, the profound moral feelings evoked by certain medical practices (surgery, chemotherapy) and much biomedical experimentation (in particular the Human Genome Project) are understandable, as they are in effect ways of intervening or intruding into that most intimate and integral of spheres: the embodied person. The person is embodied, enacts himself or herself through that specific animate organism that is his or her own, and is thus expressive of that very person. Bodily schemata, attitudes, movements, actions, and perceptual abilities are all value modalities by which one enacts and expresses one's character, personality, habits, goals, moral beliefs—in short, by which the person is alive as such.

To view medical practice and biomedical research from the perspective of embodiment is to appreciate them as planned or potential interventions into the sphere of personal intimacy, whether this sphere be initial (as in infancy) or more developed. Whether or not such interventions are mainly directed to the body (medicine, surgery) or to the person's mental life or status (psychiatry, psychotherapy), they all unavoidably affect the individual. The person's life as a whole is necessarily affected by surgery no less than by psychotropic medication. Psyche and soma are inextricably bound together as constituents of an integral, contextual whole (Zaner, 1980). The expressive and valuative character of this whole, the embodied person, helps to explain why every medical intervention falls within the moral order. Recognizing this, of course, does not of itself settle any of the ethical issues present in research or clinical situations: when it is morally permissible to withdraw life support, for instance, or whether it is right to restrict a retarded person's ability to procreate. However any such issues may eventually be settled, the point here is that medicine is an inherently moral enterprise, in no small way due to the nature of embodiment and the interventional character of medicine (Cassell, 1973, 1991).

Clearly, the effort to settle the specific ethical issues associated with medical practice and biomedical research requires that the fundamentally ethical nature of any intervention be explicitly recognized and appreciated (Zaner, 1988). It can also be appreciated that the ethical issues associated with the medical profession (medical ethics) can be distinguished from those that arise in research (biomedical ethics) as well as from those that occur in clinical settings (clinical ethics). Each set of issues poses important and distinctive problems.

While embodiment has a place in each of these disciplines, perhaps it is more important in clinical ethics deliberations. Because embodiment is essentially individual, the tasks of identifying, discussing, and (one hopes) settling moral issues that arise in clinical situations require that the specific circumstances of each individual situation be determined. Personal integrity and respect for the unique person are not concerns somehow imported into clinical situations from the outside; they are, on the contrary, intrinsic to the very nature of biomedical research and clinical practice. It might be added that in problematic cases (interventions for an unconscious or incompetent patient, for instance), the decision to intervene in ways that do not or cannot include the patient's own perspective nevertheless requires other ethical grounds, and thus must be subject to critical ethical assessment. Other problematic situations—involving mental retardation, disabled infants, and so on—do not escape the necessity to respect the patient, though they do require special ways of taking it into account (e.g., consulting family or surrogate) along with the ethical issues involved in decision making (identifying and respecting the moral frameworks of each decision maker).

Medical and other health issues are not only inherently within the moral order but also context-specific. No bioethical or clinical ethics issue can be settled in the abstract. Every medical practice, no matter how apparently trivial, is value-laden to begin with, which means that it either explicitly or (most often) implicitly expresses some vision of what is, or is thought to be, morally good. The primary issue for ethics in clinical situations is to help primary decision makers make explicit what each believes to be most worthwhile, of greatest value, as this is found in ongoing clinical or research situations. Only subsequently does it become possible to make informed judgments about the particular context-specific practices and issues facing people in clinical or research contexts (Zaner, 1988).

How one can come to such truly informed judgments is an obvious problem, but it is not within the scope of this entry. It is, one hopes, enough to have delineated the philosophical and ethical dimensions of the human body—in particular, the phenomenon of embodiment, its expressive and value character, and consequently the ethical nature of medicine and biomedical research. What remains to be done is also clear: not only to find appropriate ways to incorporate these philosophical and ethical considerations into the teaching and practices of the health professions and the research community, but also to study the important aesthetic, political, sexual, and other dimensions of the body in social life more broadly.

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SEE ALSO: *Biology, Philosophy of; Feminism; Gender Identity; Human Dignity; Human Nature; Life; Women, Historical and Cross-Cultural Perspectives;* and other *Body* subentries

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II. CULTURAL AND RELIGIOUS PERSPECTIVES

Scholarly and popular thought alike have typically assumed that the human body is a fixed, material entity subject to the empirical rules of biological science. Such a body exists prior to the mutability and flux of cultural change and diversity, and is characterized by unchangeable inner necessities. Beginning with the historical work of Michel Foucault and Norbert Elias, the anthropology of Pierre Bourdieu, and phenomenological philosophers such as Maurice Merleau-Ponty, Hans Jonas, Max Scheler, and Gabriel Marcel, however, scholarship in the social sciences and humanities has begun to challenge this notion. Late twentieth-century commentators argue that the body can no longer be considered as a fact of nature, but is instead "an entirely problematic notion" (Vernant, p. 20); that "the body has a history" insofar as it behaves in new ways at particular historical moments (Bynum, 1989, p. 171); that the body should be understood not as a constant amidst flux but as an epitome of that flux (Frank); and that "the universalized natural body is the gold standard of hegemonic social discourse" (Haraway, 1990, p. 146).

This scholarly perspective—that the body has a history, and is not only a biological entity but also a cultural phenomenon—goes hand in hand with the increasing number and complexity of bioethical issues in contemporary society, many of which have strong religious overtones. Some decades ago the only such issue arose in cases where religious and biomedical priorities conflicted in the treatment of illness. Within the majority population, various groups such as Christian Scientists, some Pentecostal Christians, and members of small fundamentalist sects occasionally have created controversy by refusing medical treatment on the grounds that faith in medicine undermined faith in God, in other words, that since healing should occur only at the will and discretion of the deity, human medicine was presumptuous upon divine prerogative. This was especially problematic when young children suffered and were kept from medical treatment by their parents. In Native American communities it has been, and occasionally remains, the practice for ill people to seek biomedical treatment only after having exhausted the resources of their spiritually based traditional medical systems. This occasionally results in the discovery of serious illness such as cancer or tuberculosis at a very advanced stage, and creates a dilemma for healthcare personnel who are supportive of indigenous traditions yet concerned that their patients also receive timely biomedical treatment.

More recently, the number of bioethical issues with religious overtones has multiplied. The legality of and right of access by women to abortion have been defined not only as issues of civil rights and feminist politics, but also as religious and moral issues. Surrogate motherhood and donorship of sperm and eggs raise ethical dilemmas regarding the biological, legal, and spiritual connections between parent and child. There is also concern about the apparently godlike ability of biotechnology to determine the genetic makeup of the human species; some see this approaching with the increasing sophistication of genetic engineering and the massive Human Genome Project, which will catalogue all possible human genetic characteristics. At the other end of the life course, the problems of euthanasia, technological prolongation of vital functions by means of life-support machines, and physician-assisted death raise moral and spiritual questions about the prerogative to end the life of oneself or of another. Legal and ethical acceptance of the definition of death as "brain death" has particular significance in that the brain dead individual's other organs are still viable for transplantation to other persons. In the United States the bioethical dilemma is whether the brain-dead person can morally be considered dead until all other vital functions have ceased, or whether removing those organs constitutes killing the patient. In Japan an added dilemma is that a person's spiritual destiny as a deceased ancestor depends in part on maintaining an intact physical body.

Each of these issues has to do with religion, not only because religions often define them as within their moral purview, but also because at a more profound level, each taps a concern that is at the very core of religious thought and practice: the problem of what it means to be human. More precisely, the problem is the nature of human persons, of what it means to have and be a body, of life and death, and of the spiritual destiny of humankind. In the succeeding sections of this entry these issues are placed in the context of recent thought about the cultural and historical nature of the human body, about religious conceptualizations of the body, and about religious practices that focus on the body.

The Body as a Cultural Phenomenon

It has been suggested that in contemporary civilization the human body can no longer be considered a bounded entity, in part because of the destabilizing impact of "consumer culture" and its accompanying barrage of images. These images stimulate needs and desires, as well as the corresponding changes in the way the social space we inhabit is arranged with respect to physical objects and other people (Featherstone et al.). In this process, fixed "life-cycle" categories have become blurred into a more fluid "life course" in which one's look and feel may conflict with one's biological and chronological age; some people may even experience conflict between age-appropriate behavior and subjective experience. In addition, the goals of bodily self-care have changed from spiritual salvation, to enhanced health, and finally to a marketable self (Featherstone et al.; cf. Foucault; and Bordo). As Susan Bordo has observed, techniques of body care are not directed primarily toward weight loss, but toward formation of body boundaries to protect against the eruption of the "bulge," and serve the purposes of social mobility more than the affirmation of social position. Bodily discipline is no longer incompatible with hedonism but has become a means toward it, so that one not only exercises to look good, but also wants to look good while exercising. This stands in sharp contrast not only to early historical periods but to other societies such as that of Fiji where the cultivation of bodies is not regarded as an enhancement of a performing self but as a responsibility toward the community (Becker).

This transformation in the body as a cultural phenomenon has been related by Emily Martin (1992) to a global change in social organization. In her view the "Fordist body" structured by principles of centralized control and factory-based production is on the decline. It is being replaced by a body characteristic of late capitalism, a socioeconomic regime characterized by technological innovation, specificity, and rapid, flexible change. She sees these changes particularly vividly in the domains of reproductive biology, immunology, and sexuality, all of which are increasingly intense loci of bioethical debate.

With respect to immunology in particular, Donna Haraway (1991) understands the concept of the "immune system" as an icon of symbolic and material systematic "difference" in late capitalism. The concept of the immune system was developed in its present form as recently as the 1970s, and was made possible by a profound theoretical shift from focus on individual organisms to focus on cybernetic systems. The result has been the transformation of the body into a cybernetic body, one that for Haraway requires a "cyborg ethics and politics" that recognizes radical pluralism, the inevitability of multiple meanings and imperfect communication, and physical groundedness in a particular location.

This groundedness thus extends to biology itself. In addition to immunology, this is evident in recent feminist theory that eliminates "passivity" as an intrinsic characteristic of the female body and reworks the distinctions between sex and gender, female sexual pleasure, and the act of conception (Jacobus et al.; Bordo; Haraway, 1990). With biology no longer a monolithic objectivity, the body is transformed from object to agent (Haraway, 1991). The bioethical implications of the body as experiencing agent are evident in recent social science work on the experience of illness (Kleinman; Murphy), pain (Good et al.), and religious healing (Csordas, 1990, 1994). New disciplinary syntheses grounded in a paradigm of embodiment are emerging in disciplines such as anthropology (Csordas, 1990, 1994), sociology (Turner), and history (Berman).

Many of these new syntheses are predicated on a critique of tenacious conceptual dualities such as those between mind and body, subject and object, and sex and gender (Haraway, 1991; Frank; Ots; Csordas, 1990; Leder). Drew Leder, for example, begins his critique of Cartesian mind–body dualism with the observation that in everyday life our experience is characterized by the disappearance of our body from awareness. He contrasts this with a description of *dysappearance*, the vivid but unwanted consciousness of one's body in disease, distress, or dysfunction. He then argues that it is the very sense of disappearance, itself an essential characteristic of our bodily existence, that leads to the body's self-concealment, and thus to a mistaken notion of the immateriality of mind and thought. That such a notion is cultural is evident in the technological domain if one compares Western navigational techniques, which are based on intellectualist mathematical instruments and calculations, with traditional Polynesian navigation, which in contrast relied on concrete sensory information regarding clouds and light, wave patterns, star movement, and the behavior of birds (Leder). Leder further suggests that the Western tradition compounds the error by construing the body as a source of epistemological error, moral error, and mortality. In contrast, based on a phenomenological appreciation of unitary embodiment, he suggests the possibility of a new ethics of compassion, absorption, and communion.

The contemporary cultural transformation of the body can be conceived not only in terms of revising biological essentialism and collapsing conceptual dualities, but also in discerning an ambiguity in the boundaries of corporeality itself. Haraway points to the boundaries between animal and human, between animal/human and machine, and between the physical and nonphysical (Haraway, 1991). Michel Feher construes the boundary between human and animal or automaton (machine) at one end of a continuum whose opposite pole is defined by the boundary between human and deity. Cultural definitions of the boundary between human and divine can be significant given the circumstances of corporeal flux and bodily transformation sketched above. This is especially the case when the question goes beyond the distinction between natural and supernatural bodies, or between natural corporeality and divine incorporeality, to the question posed by Feher of the kind of body with which members of a culture endow themselves in order to come into relation with the kind of deity they posit to themselves (Feher). Thus, if the body is a cultural phenomenon in a way that makes its understanding essential to questions of bioethics, religion is an important domain of culture to address in understanding the body.

Religious Conceptualizations of the Body

Perhaps the most vivid example from the domain of religion that the body is a cultural phenomenon subject to cultural transformations is given in the classic work on New Caledonia by Maurice Leenhardt, the anthropologist and missionary. Leenhardt recounts his discovery of the impact of Christianity on the cosmocentric world of the New Caledonian Canaques via a conversation with an aged indigenous philosopher. Leenhardt suggested that the Europeans had introduced the notion of "spirit" to the indigenous way of thinking. His interlocutor contradicted him, pointed out that his people had "always acted in accord with the spirit. What you've brought us is the body" (Leenhardt, p. 164). In brief, the indigenous worldview held that the person was not individuated but was diffused with other persons and things in a unitary sociomythic domain:

> [The body] had no existence of its own, nor specific name to distinguish it. It was only a support. But henceforth the circumscription of the physical being is completed, making possible its objectification. The idea of a human body becomes explicit. This discovery leads forthwith to a discrimination between the body and the mythic world. (Leenhardt, p. 164)

There could be no more powerful evidence that the body is a cultural and historical phenomenon. Insofar as the objectification of the body has the consequences of individuation of the psychological self and the instantiation of dualism in the conceptualization of human being, it has implications for defining a very different regime of ethical relationships and responsibilities. This is not only a relative difference, but—as is clear in the missionary example of

Leenhardt—one that has consequences for relations between different cultures.

ANCIENT GREEK CONCEPTUALIZATIONS. There is much more to the cultural and historical variability of the human body, however. For the ancient Greeks, as described by Jean-Pierre Vernant, the distinction between the bodies of humans and the bodies of deities was not predicated on that between corporeality and incorporeality, but on the notion that the divine bodies were complete and human bodies incomplete. Furthermore, this distinction emphasized not bodily features or morphology, but the being's place on a continuum of value and foulness. Bodies were understood as mutable along these dimensions without losing their identity, and thus deities could be simultaneously very heavy and very light, moving over the earth without quite touching it while leaving exceedingly deep footprints (Vernant). The deities thus had bodies that were not bodies, but they had characteristics that never ruptured their continuity with human bodies, and which therefore defined human bodies by their very otherness. The existence of the deities guaranteed that in Greek culture qualities such as royalty and beauty were not abstract concepts or categories, since they were concretely embodied in beings like Zeus and Aphrodite (Vernant).

HINDU CONCEPTUALIZATIONS. In the Hindu worldview *atman,* "self," is understood not as soul in distinction to body, but as the center in relation to an existential periphery, or as whole in relation to parts (Malamud). The ritual act of sacrifice is personified and has a body, or in other words the body is both the model for and origin of sacrifice (Malamud). The individual bodies are inherently sexual and are portrayed as couples, or *mithuna.* The masculine is invariably singular and the feminine plural, as in the sun of day in relation to the multiple stars of night, or the singularity of act/mind/silence in relation to the multiplicity of speech. In contrast to the mutable but distinctly individual body of the Greek deities, Hindu ritual portrays a rich "combinatory of the sexes" that constitutes a way of mythically thinking with the body. The mithunas achieve cosmic engenderment (begetting) through diverse body operations including dismemberment, multiplication of body parts, replication of bodies, birth, coupling/copulation, merging/incorporation, transformation and transgendering, and the emission of body products/fluids (Malamud).

JEWISH AND CHRISTIAN CONCEPTUALIZATIONS. If, in Hinduism, engenderment is timeless and instantiated in the cosmos by the sacrificial act, in Judaism it is linear and instantiated in history by the act of procreation. Creation and engenderment are two moments of the same process, a "hiero-history" in which human generation does not imitate a divine process, but is that process (Mopsik). Whereas in the Christian perspective the biblical injunction for man and woman to "become one flesh" is understood to refer to the indissolubility of marriage, in the Jewish perspective it is understood as the production of a child, and the birth of Christ outside the historical chain of engenderments is the basis for the Pauline splitting of the spiritual and carnal individual (Mopsik). This view is elaborated further in the Jewish kabbalistic tradition's notion of the *sefirot,* the tengendered emanations of the Infinite that are represented as combining to form a body (Mopsik).

In sharp contrast to the Jewish kabbalistic elaboration of engenderment as life, the Christian gnostic tradition elaborates it as death (Mopsik). Gnosticism sees the corporeal form as the creation of monstrous demiurges or archons, foremost among whom is Ialdabaoth, the equivalent of Jehovah. The human condition is symbolized in the gnostic tale of the archons' rape of Eve, who escapes with her psychic body while her "shadow" or material body is defiled (Williams). The latter is a prison or garment, beastly because humans are created by beasts. Sexuality is an aspect of this beastliness, and hence cannot be part of an embodied sacred process, while the upright posture that distinguishes us from animals is attributed to a separate spark from the authentically spiritual Human (Williams).

From a more mainstream Christian perspective, the profound cultural implications of Feher's question of the kind of body people endow themselves with in order to come into relation with the sacred (Feher) can be seen by considering the Eucharist. That the consumption of bread and wine transubstantiated into the body and blood of Christ is essentially a form of ritual cannibalism is emphasized by the story of a miracle in which a priest who doubted the divine reality of the Eucharist was forced to experience the bloody flesh, so that he could come to appreciate God's graciousness in presenting it in the tamer appearance of bread and wine (Camporesi; see also Bynum, 1989). In earlier periods of Christianity the spiritual power of the Eucharist extended to the nourishment of the body, and this, not through ingestion but by means of its aroma (Camporesi). Unlike ordinary food, however, it does not become us, but we become it through its sanctifying power (Camporesi). Great anxiety was created among priests with regard to the immense responsibility of transforming something dead into something alive by the utterance of a few words, and among communicants because of the inclusion of such a sacred substance in such a profane terrain as the digestive tract—hence the importance of a fast before communion (Camporesi). Yet because the Eucharist was thought to release its grace only in the stomach, sick people who could not eat were excluded (Camporesi). When later the substantial bread was replaced by thin wafers, it became common to let the wafer melt in one's mouth. Well into the twentieth century, Catholics were taught that biting or chewing the Eucharist was an insult and injury to the deity that could result in divine retribution.

MEDIEVAL CONCEPTUALIZATIONS. Recent work on medieval Christian spirituality relates to the notion of the body as a cultural phenomenon. Caroline Walker Bynum (1989) has documented the prominence during the years 1200–1500 of a "somatic spirituality" that stands in contrast to gnostic rejection of the body, and that reflects a less dualist mentality than has heretofore been attributed to the thought of this period. In general, a great deal of concern with embodiment was evidenced in speculation about whether the final "resurrection of the body" might be a natural consequence of human nature rather than a discrete divine act to occur at the Last Judgment, and whether we will taste and smell heaven as well as see it.

The medieval body was defined less by its sexuality than by notions of fertility and decay, but the contrast between male and female was as important as that between body and soul. Somatic spirituality was especially evident among female mystics, who—in contrast to their more cerebral male counterparts' experience of stillness and silence—tended to blur the boundaries among the spiritual, psychological, bodily, and sexual by cultivating a sensualized relationship of human body with divine body. Bynum draws on the cultural-historical context to understand why the male-dominated ecclesiastical hierarchy allowed this female spirituality to flourish: evidence was needed against the contemporary dualist heresy of the Cathars; because they were denied education in Latin, they wrote in the less linear and more oral style of the vernacular; they were encouraged to act out maternal roles vis-à-vis Christ (1989).

In this context the relation between the genders took on remarkable properties. Although ideally a woman would die to defend her holy chastity, it was as likely for a holy man to be resurrected in order to complete a virtuous task. In other ways the genders were blurred, since it was thought that all had both genders within, and that men and women had identical organs with only their internal and external arrangements being different. Because of the powerful symbolic association of the female and the fleshly, while holy women sometimes experienced being the mother or lover of Christ, their nature often allowed them to mystically *become* the flesh of Christ. By the same reasoning, since body is equivalent to female, the incarnate Christ had a female nature, and the image of Christ as mother became a feature of medieval iconography (Bynum, 1989).

Religious Practices and the Body

FASTING. The cultural-historical transformation of the body is highlighted by comparison of fasting as a technique of the body in the medieval somatic spirituality with the phenomenon of anorexia nervosa in the late twentieth century. In a study of 261 holy women in Italy since the year 1200, Rudolf Bell distinguishes between contemporary anorexia nervosa and what he calls "holy anorexia." While the former is regarded as a syndrome of clinical pathology, in the latter, "the suppression of physical urges and basic feelings—fatigue, sexual drive, hunger, pain—frees the body to achieve heroic feats and the soul to commune with God" (p. 13). There are parallels between the two conditions and historical epochs. Bell suggests that the observation that the internal locus of evil as a corrupting force for women in the Middle Ages, in distinction to the external locus of sin as a response to external stimulus for men, corresponds to the Freudian model of anorexia nervosa as a food/sex oral fixation. In addition, in both, "the main theme is a struggle for control, for a sense of identity, competence, and effectiveness" (Hilde Bruch, quoted in Bell, p. 17). However, there is a critical difference, and "whether anorexia is holy or nervous depends on the culture in which a young woman strives to gain control of her life" (Bell, p. 20).

Bynum (1987) warns against the assumption that these are precisely the same phenomenon, given theological meaning in one epoch and psychiatric meaning in another. She points out that even medieval writers had more than one paradigm for explaining fasting—that it could be supernaturally caused, naturally caused, or feigned—and that there was a clear distinction between choosing to renounce food and the inability to eat. In both historical cases, the behavior "is learned from a culture that has complex and long-standing traditions about women, about bodies, and about food," including what kind of behaviors are in need of cure (p. 198). It is a profoundly cultural fact that in the patristic era miraculous fasting was attributed largely to men, while in the medieval period it was characteristic of women; likewise it is cultural that in the medieval period the illnesses of men were more likely thought of as needing to be cured, while those of women were to be endured. Furthermore, in the later Middle Ages fasting was associated with a wider array of miracles and practices of somatic spirituality, including subsistence on the Eucharist, stigmata, espousal rings, sweet-smelling bodies, bodily elongation, and incorruptibility. Some of the behavior of these women fits the pattern of nineteenth-century "hysteria," some is clearly the result of other illnesses, and some follows the thematic of control, altered body concept/perceptions, and euphoria. Yet one cannot be sure whether symptoms are associated with an inability to eat or are the result of freely chosen ascetic fasting. Finally, insofar as psychodynamic explanation can explain only individual cases, Bynum concludes that it is less helpful to know that contemporary labels can in some cases be applied to the medieval phenomenon than to account for cultural symbols that give meaning to the phenomenon, such as body, food, blood, suffering, generativity, or hunger (1987).

FAITH HEALING. Other contemporary religious practices equally require an appreciation of the body as a cultural phenomenon. How, for example, can we understand the imputed efficacy of "faith healing" among contemporary Christians? An understanding of the body as a cultural phenomenon suggests that ritual healing operates on a margin of disability that is present in many conditions. It is well known, for example, that some people who become "legally blind" are able to engage in a wide range of activities, while others retreat to a posture of near total disability and inactivity. Likewise, persons with chronic pain in a limb may be physically able to move that limb, but refrain from doing so for lack of sufficient motivation to make the risk of pain worthwhile. Disability is thus constituted as a habitual mode of engaging the world. The process of healing is an existential process of exploring this margin of disability, motivated by the conviction of divine power and the committed participant's desire to demonstrate it in himself or herself, as well as by the support of the other assembled devotees and their acclamation for a supplicant's testimony of healing. To be convinced of this interpretation one need only consider the hesitant, faltering steps of the supplicant who, at the healer's request, rises from a wheelchair and shuffles slowly up and down a church aisle; or the slowly unclenching fist of the sufferer of chronic arthritis whose hand is curled by affliction into a permanent fist. Ritual healing allows this by challenging the sensory commitment to a habitual posture, by removing inhibitions on the motor tendency toward static postural tone, and by modulating the somatic mode of attention, that is, a person's attention to his or her own bodily processes in relation to others.

Consider also the practice of "resting in the Spirit" or being "slain in the Spirit" among Charismatic and Pentecostal Christians as evidence for the kind of body with which people endow themselves in order to come into relation with the sacred. In this practice, which occurs primarily in healing services, a person is overcome with divine power, and falls into a semi-swoon characterized by tranquility and motor dissociation. Despite its popularity, or perhaps because of it, resting in the Spirit is a controversial phenomenon for Charismatics, and the heart of the issue is its authenticity. More specifically, critics challenge its authenticity while apologists argue for its beneficial effects in terms of healing and spiritual development. Both sides invoke the same biblical scenarios, such as Saul on the road to Damascus and the apostles confronted by the transfiguration of Jesus, and the same religious writers, including the ecstatic mystics Theresa of Avila and John of the Cross, and both sides draw opposing conclusions about whether these constitute examples of resting in the Spirit. They likewise draw opposing conclusions about the historical prototypes of healers known for similar practices, extending backward in time from Kathryn Kuhlman to Charles Finney, George Jeffreys, George Fox, John Wesley, and the fourteenth-century Dominican preacher John Tauler. To be sure, such analogies and precedents suggest that it would be possible to examine the varying meanings of religious falling or swooning across historical and cultural contexts. In the contemporary context, however, the ideological/theological/pastoral debate about authenticity is predicated on the recurrent, constitutive North American psychocultural themes of spontaneity and control, and on the Charismatic cultural definition of the tripartite person as a composite of body, mind, and spirit.

SPIRIT POSSESSION. The sacred swoon leads also to the complex issue of dissociation, common to discussions of "spirit possession." Spirits who inhabit people may be regarded either as malevolent, in which case they must be expelled or exorcised, or as benevolent, in which case becoming possessed is an act of worship and devotion. Possession of both types is widely reported in ethnological literature (Bourguignon), and is increasingly common in contemporary Western society. Not only is the negative, or demonic, variant reported among some varieties of Christian religions, but the positive variant of possession by deities is characteristic of rapidly growing African religions. These include religions based on the Yoruba tradition of Nigeria, such as *santeria, candomble,* and the related *vodun.* The Yoruba religion, in which the possessing deities are called *orixas,* is rapidly aspiring to membership in that select group of "world religions" that once included only so-called "civilized" faiths such as Christianity, Judaism, Islam, Hinduism, Buddhism, Taoism, and Confucianism. This cultural development requires a more sophisticated understanding of the possession phenomenon not as mental or cognitive dissociation but as physical and existential incarnation; not as a pathological hysterical amnesia to which the devotee becomes abandoned, but as a form of habitual body memory in which the deity's characteristics are enacted in a contemporary form of somatic spirituality.

ABORTION HEALING RITUALS. A final example of the interplay of religion and bioethics with respect to bodily practices pertains to the contemporary cultural debate over abortion. Among participants in the North American Christian religious movement known as the Charismatic Renewal, and in Japan as a facet of what are called the New Religions, healing rituals are conducted both for the removal of guilt presumed to be experienced by the woman, and for the fetus in order to establish its spiritual status. The American practice is largely a private one that takes place within the membership of a discrete religious movement within Christianity, and is a specific instance of the healing system elaborated within that movement. The Japanese practice has a relatively public profile not limited to a particular social group, and is an instance of a type of ritual common to a variety of forms of Buddhism.

In both societies the affective issue addressed by the ritual is guilt, but whereas in American culture this is guilt occurring as a function of sin, in Japan it is guilt as a function of necessity. For the Americans abortion is an un-Christian act, and both perpetrator and victim must be brought back ritually into the Christian moral and emotional universe; for the Japanese both the acceptance of abortion as necessary and the acknowledgment of guilt are circumscribed within the Buddhist moral and emotional universe. Both rites are intended to heal the distress experienced by the woman, but the etiology of the illness is somewhat differently construed in the two cases. For Charismatics any symptoms displayed by the woman are the result of the abortion as psychological trauma compounded by guilt, along with the more or less indirect effects of the restive fetal spirit "crying out" for love and comfort. In Japan such symptoms are attributed to vengeance and resentment on the part of the aborted fetal spirit that is the pained victim of an unnatural, albeit necessary, act. Finally, not only the etiology but the emotional work accomplished by the two rituals is construed differently. For the Charismatics, this is a work of forgiveness and of emotional "letting go." For the Japanese, in whose cultural context gratitude and guilt are not sharply differentiated, it is a work of thanks and apology to the fetus. Thus, "[t]here is no great need to determine precisely whether one is addressing a guilt-pre-supposing 'apology' to a fetus or merely expressing 'thanks' to it for having vacated its place in the body of a woman and having moved on, leaving her—and her family—relatively free of its physical presence" (LaFleur, p. 147).

Conclusion

The contemporary transformation of the human body and scholarly formulations of it, placed alongside the transformative power of religion in its task of defining what it means to be human, offers an important perspective on issues relevant to bioethics. These range from abortion to brain death, from fasting to resting in the Spirit, from consumer culture to dissociation, and bear on the relation between genders, between cultures, and between the poles of dualities such as mind and body. Such phenomena, and new ways of understanding them, will increasingly come to light with continuing elaboration of the body/culture/religion nexus.

THOMAS J. CSORDAS (1995)

SEE ALSO: *Anthropology and Bioethics; Buddhism, Bioethics in; Christianity, Bioethics in; Death; Embryo and Fetus; Healing; Judaism, Bioethics in; Medical Ethics, History of; Medicine, Art of; Native American Religions, Bioethics in; Sexual Ethics;* and other *Body* subentries

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BUDDHISM, BIOETHICS IN

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Buddhism originated in India around 500 B.C.E. In the early twenty-first century Buddhist traditions exist in South, Southeast, and East Asia, as well as Australia, Western and Eastern Europe, and North and South America. The diversity found in these traditions makes it impossible to speak of Buddhism in the singular or to assert an "official" Buddhist perspective. For the purpose of formulating an overview of Buddhist bioethics, however, Buddhist traditions can be categorized into two primary trajectories: Theravada and Mahayana. Theravada traditions are closely identified with the teachings of the historical Buddha, and include both early South Asian Buddhist traditions as well as contemporary South Asian traditions in Sri Lanka, Thailand, and Myanmar (formerly Burma). Mahayana traditions include some later forms of Indian Buddhism, Tibetan and other Himalayan-region Buddhisms (also referred to as Tibetan, Vajrayana, Tantric, and Esoteric Buddhism), and Central and East Asian Buddhist traditions. Both Theravada and Mahayana Buddhism are practiced in such places as Australia, Europe, and North and South America.

Historically, bioethics has been a field of inquiry primarily in Western cultures and thus centers on Western cultural assumptions and moral perspectives. Genetic engineering, cloning, and stem cell research—and the ethical dilemmas they engender—pivot on recent advances in biomedical technology and Western emphases on the value of medical progress. However, moral issues raised by biomedical technology are no longer confined to Western cultural contexts. Predominately Buddhist countries have begun to confront the ethical implications of biomedicine. Not surprisingly, Buddhist ethical perspectives stem from assumptions that are sometimes very different from Western views, and these concerns affect how Buddhists engage with bioethical issues.

Individuals from North American and European cultural backgrounds may be troubled at the specter of "playing God" in making ethical decisions. From a Buddhist perspective, however, emphasis is placed, for instance, on investigating how the Buddha's exemplary life and compassion might reveal satisfying solutions to problems never envisioned by past Buddhists. After outlining some fundamental Theravada and Mahayana Buddhist ideas, this entry considers ways that Buddhists might respond to bioethical dilemmas and which

Buddhist religious ideas could be invoked to make sense of diverse bioethical issues.

Theravada Buddhist Thought and Practice

Western interpretations of the Buddhist Dharma—Buddha's law or teaching—often treat it as a philosophy. Although it is possible to view the Dharma this way, Buddha emphasized the centrality of religious practice over philosophy and doctrines. Intellectual understandings merely point at what must ultimately be realized through experience. Buddha posited a religious path attainable through a rigorous tripartite practice of wisdom, morality, and meditation. These three were the foundations of the Noble Eightfold Path, Buddha's outline for how to live the religious life.

Theravada Buddhism focuses particular attention on the life of the historical Buddha (c. 563–483 B.C.E.). Buddha ("The Enlightened One") was a human being who, through assiduous spiritual practices, was able to comprehend the true nature of the universe. The realization of this transcendent wisdom is the achievement of *nirvana,* or enlightenment. Buddha, therefore, is a model for humanity, an example of what is possible by diligent practice of the Dharma.

The biography of the historical Buddha recounts the story of an entitled prince, Siddhartha Gautama of the Sakya clan, who is provided with material comforts and sensual pleasures by the king, his father. Wishing that his son will become a great leader, the king arranges for the prince to be sequestered in the palace, shielded from the pain and suffering that afflicts human beings. Over time, the prince—now grown and married with a young son—becomes curious about the world beyond the confines of the palace. Against his father's wishes, he ventures outside the palace walls on four separate occasions. Each time he encounters an aspect of human experience hitherto unknown to him. The four encounters—a sick person, an elderly person, a corpse, and a religious ascetic—result in the prince's realization of the fundamental suffering of human existence. The encounter with the ascetic prompts Prince Siddhartha's quest to attain an understanding of the world that would end suffering.

Prince Siddhartha subsequently decides to leave the palace and pursue the spiritual life of an ascetic renunciant. Single-minded in his resolve to attain spiritual liberation from the bonds of human existence by denying material needs, he nearly starves to death. As a result, he recognizes that liberation must lie somewhere between extreme hedonism and severe asceticism. He embarks on what becomes known as the Middle Path, a practice that allows sufficient bodily nourishment to carry out meditation and other spiritual practices. Through deep and persistent meditation he attains nirvana, thereby becoming Buddha. A reluctant teacher, he eventually accedes to the desire of others that he expound upon what he has learned. Thus begins Buddha's lifelong teaching of the Dharma.

Buddha's teaching centers on wisdom attained through enlightenment, a transcendent awareness of both the problem in the human condition and a means to its solution. This problem finds expression in the Three Marks of Existence, a description of the nature of life within the unenlightened world of *samsara* (the cycle of birth-death-rebirth). Individual status in the samsaric cycle is determined by actions (*karma*) and their moral consequences. Moral behavior leads to a higher spiritual rebirth, while immoral actions result in movement away from enlightenment. Buddha recognized that the samsaric world is fundamentally unsatisfactory and human beings eventually seek escape from it. According to the Three Marks, all existence is characterized by: (1) impermanence (*anitya*); (2) suffering (*duhkha*); and (3) absence of a permanent ground or essence (*anatman*).

Impermanence refers to the idea that all aspects of the samsaric world are in constant flux. While the world might appear to have stability and solidity, deeper scrutiny reveals that samsara is characterized by perpetual instability. Human beings mistake the temporary coming together of constituent elements (*dharma*s) for permanence. Thus, the world is best characterized not in terms of the atomistic existence of discrete enduring objects, but rather as a state of dependent origination, or interdependence—*pratitya-samutpada.* Samsaric entities—including human beings—exist as a result of cause and effect. Nothing has an intrinsic foundation or essence that gives rise to its own existence. *Samsara* itself is understood as constituted by conditioned reality, that is, arising from a series of causes and effects.

The second mark of existence is suffering. The Buddhist term *duhkha* refers to both physical and mental suffering—especially the latter. *Duhkha* signifies the anxiety and insecurity prompted by the impermanent, transitory nature of the human condition. Markers of impermanence include the cycle of birth, disease, old age, and death, as well as anticipation of the inevitable loss of happiness and other temporarily pleasant emotions. Buddha did not deny the reality of happiness, but simply noted that it too is fleeting and impermanent. Suffering results from ignorance of the true nature of the samsaric world as transitory, momentary, and subject to constant flux.

The third mark of existence, *anatman* (no-self), refers to the absence of a permanent self or eternal soul that persists after physical death. Human ignorance engenders a misperception of current identity or sense of self as an enduring, independent essence. This idea is illustrated in an

Indian Buddhist text that relates a dialogue between King Milinda and the monk Nagasena. In the *Simile of the Chariot,* Nagasena asserts that the self, like a chariot, has no essence. The King protests, so Nagasena describes the process of disassembling a chariot. Once the chariot has been reduced to a pile of parts, the King concedes that there is no essence of the chariot that persists. Like the chariot, human beings consist of constituent elements. These elements coalesce to form both animate and inanimate objects. Upon death, the *dharma*s disperse and re-form due to cause and effect, but no aspect of self, soul, or personality persists. Thus, *anatman* asserts that all existence is causally conditioned. The five aggregates of *dharma*s that constitute human beings are constantly arising and ceasing, but they do not produce a discrete, identifiable self or soul.

In accord with the worldview expressed by the Three Marks of Existence, Buddha taught that liberation from suffering may be attained though the Four Noble Truths:

1. All existence is suffering.
2. Suffering is caused by desire.
3. Cessation of desire results in the cessation of suffering.
4. The Eightfold Path leads to liberation (nirvana).

Like a medical analysis of the human condition, the Four Noble Truths mirror the steps of diagnosing a disease (suffering), understanding its cause (desire), identifying the cure for the disease (cessation of desire), and prescribing medicine that effects the cure (Eightfold Path). An outline of attitudes and actions necessary for spiritual advancement and enlightenment, the Eightfold Path offers a foundation for understanding Buddhist ethics in general and Theravada Buddhist bioethics in particular.

Buddha expounded the Eightfold Path as the mental and physical practices necessary to reach liberation from the samsaric world. The Eightfold Path consists of three components: wisdom (*prajna*): (1) right views and (2) right intention; morality (*sila*): (3) right speech, (4) right conduct, and (5) right livelihood; and concentration (*samadhi*): (6) right effort, (7) right mindfulness, and (8) right concentration.

Wisdom refers to the fundamental mental states necessary to practice Buddha's Dharma. Right views include knowledge and acceptance of the Four Noble Truths and other aspects of the Dharma. Right intention refers to cultivating qualities such as compassion, benevolence, and detachment from the fruits of actions, and a commitment to harm no living creatures.

Morality is conceptualized in terms of speech, conduct, and occupation. Right speech requires that Buddhists abstain from verbal abuses such as slander, lying, and gossip. Right conduct refers to the avoidance of actions that harm others, such as killing, stealing, and sexual impropriety. Right livelihood extends the ideal of moral actions and prohibits specific occupations. Thus, one must refrain from work that leads—either directly or indirectly—to harming other living beings.

Concentration entails mental practices aimed at purifying the mind of evil and other distracting thoughts, and gaining mastery of mental processes and feelings in order to engage in advanced meditation.

The practice of the Eightfold Path is neither linear nor sequential. Rather, all eight aspects must be cultivated simultaneously. Through self-effort these practices eventually effect a spiritual transformation from ignorance to a state of transcendent wisdom—*nirvana*. One who has cultivated of the Eightfold Path and achieved liberation is known as an *arhat* (holy one)—the model of Theravada Buddhist religiosity that all endeavor to follow.

Mahayana Buddhist Thought and Practice

Even a brief survey of Mahayana Buddhism, which arose less than 500 years after the historical Buddha's lifetime, strongly suggests that "Buddhist bioethics" cannot be approached in singular terms. Mahayana refashions Theravada perspectives through the concept of *sunyata* (emptiness), while adding a new soteriological possibility based on faith: birth in a Buddhist paradise as the goal of religious praxis. Thus, Mahayana Buddhism incorporates the ideal of enlightenment achieved through individual self-effort—Zen Buddhism is the most well-known exemplar of this—as well as potential for salvation through birth in a Buddhist paradise. Particularly noteworthy is the Western Paradise, or Pure Land, of Amitabha Buddha who vows to save all sentient beings that call on him for assistance. Further, anyone—monastic or layperson—could practice devotion to the "other power of Amitabha," emphasizing for the first time nonmonastic practice leading to salvation.

In contrast to Theravada emphasis on the arhat, Mahayana focuses on the figure of the *bodhisattva,* a concept that has two primary significances. First, meditation-based Mahayana centers on the bodhisattva vow, a pledge to follow the Buddha's Dharma in order to achieve enlightenment and to compassionately assist others in the same quest. Through meditation, the *bodhisattva* aims to perceive the reality of the universe—that all *dharma*s are empty of self-nature. The concept of emptiness (*sunyata*) asserts that all dualistic perceptions are misperceptions, and that *nirvana* and *samsara* are the same thing. Otherwise, a duality or opposition between the enlightened and the unenlightened is being expressed. The Mahayana goal is not to transcend *samsara,* but rather to understand—experientially—that dualities result from a mistaken view of nirvana as permanent and eternal, existing outside of *samsara.*

Second, in faith-based Mahayana, the term *bodhisattva* describes compassionate figures, like Avalokitesvara (Known in China as Guanyin and in Japan as Kannon), who have advanced along the path to enlightenment and gained great spiritual powers. They are called upon for assistance with both spiritual and material difficulties. Faith-based Mahayana recognizes that, for most lay Buddhists, following the Dharma is too difficult. In a degenerate age far removed from the teachings of the historical Buddha, the only hope for release from *samsara* is by calling—single-mindedly and with devotion—on those whose spiritual progress far exceeds our own. Devotions may be made to Amitabha Buddha for spiritual and material assistance in addition to the intervention of *bodhisattva*s.

Mahayana conceptions of the *bodhisattva* critique the Theravada *arhat* ideal, arguing that in an interdependent world individuals must assume responsibility not only for personal enlightenment, but also for assisting others in the quest. Thus, spiritual compassion becomes significant in Mahayana ethics in general, and in bioethics in particular.

Approaches to Buddhist Bioethics

Buddhist ethical perspectives, unlike some Western views, seldom characterize morality in absolute terms. For Buddhists, ethical behavior is a necessary component of successful adherence to the Dharma rather than an end in itself. Once enlightenment is attained, dualities expressed in ethical problems cease to exist. Action is judged not against an absolute moral standard (such as the Ten Commandments), but rather on the basis of its relative merit in leading toward or away from enlightenment. From an enlightened perspective, actions can no longer be characterized as moral or immoral. Rather, action (*karma*) has a neutral value, transcending moral distinctions. As such, ethics are important to the spiritual practice of human beings, but they have no larger significance.

Historically, Buddhist monastics and lay people have expressed ethical concern for the poor, the sick, and the elderly. Yet Buddhists differ in their approaches to bioethical dilemmas. In part, competing bioethical interpretations arise from Theravada and Mahayana distinctions. Further, as Buddhism has traveled across Asia and other parts of the world, diverse indigenous cultural traditions have informed Buddhist notions of morality. The divergent views of Buddhist practitioners and scholars of Buddhism add another dimension to understanding Buddhist bioethics. Finally, interpretive concerns arise when contemporary bioethical problems are evaluated using Buddhist texts composed centuries before the advent of current biomedical technologies. Despite these complexities, concepts such as nonharm (*ahimsa*) in Theravada and compassion (*karuna*) in Mahayana—though they do not posit an explicit bioethics—offer a way to measure the morality of bioethical issues.

Theravada Buddhist Bioethics

Precepts for both monastics and laypersons provide a starting point for investigating Theravada bioethics. Although the number of precepts and issues addressed differs depending on individual religious status, there is nevertheless a core set of values applied to all Theravada practitioners. Buddha's moral conduct serves as a behavioral model for those who wish to pursue *nirvana.*

The *sangha,* or monastic community, is bound by a code of moral conduct inscribed in monastic rules (*vinaya*) that were established to promote the rigorous mental and physical discipline required to achieve the Theravada religious goal. These detailed rules regulate monastic life and spiritual practice. The first five of the ten Theravada precepts, which apply to both monastics and laity, are:

1. abstention from causing injury to all living beings;
2. abstention from theft and cheating;
3. abstention from sexual misconduct;
4. abstention from lying and other forms of injurious speech; and
5. abstention from intoxication.

Of these five, injunctions against killing, lying, and sexual misconduct have specific relevance to Theravada bioethics. These precepts carry additional significance when coupled with other Theravada Buddhist concepts. For example, respect for life and non-injury to living beings (*ahimsa*) is linked to the idea of *pratitya-samutpada*, the interdependence of existence and consequentially the moral responsibility of all beings.

As noted above, Theravada Buddhist traditions assert that the universe is fundamentally impermanent. Given this assumption, Theravada ethics strongly advocate comforting the terminally ill rather than trying to extend life through any means available. The value of life is not commensurate with lifespan, and death is understood as an inevitable consequence of unenlightened existence in an ephemeral world. Attempts to postpone death are unnatural acts that suggest a morbid (and ignorant) fear of death and an ego-motivated attachment to life.

Theravada principles both inform and complicate responses to contemporary bioethical dilemmas. For example, in Thailand, Theravada Buddhism is intimately connected to all aspects of life. Abortion in Thailand is prohibited by legislation that makes exception only in circumstances such as danger to the mother's life, rape, or incest. Theravada precepts against killing and doing harm to others are used to justify this legislation. Thai Buddhists apply the precepts to the unborn because a fetus is considered a human being from conception, and often cite traditional Theravada texts that oppose abortion.

However, orthodox Buddhist views sometimes clash with the realities of contemporary life in Thailand. In fact, abortions are performed in Thailand (although illegally), and Thais advocate different interpretations of Theravada ethical principles to justify or deny the morality of abortion. While some Buddhists invoke the nonharm precept, others maintain that abortion—in cases such as pregnancy due to rape or incest—can contribute to positive karmic consequence if performed with selfless intention.

On the other hand, in situations where abortions might be morally justified—at least in the United States—this is not necessarily the case in Thailand. Malee Lerdmaleewong and Caroline Francis list reasons that Thais cite for seeking illegal abortions, including economic difficulties and the lack of adequate or effective contraception. Yet, when a Thai woman learns that her fetus is developing abnormally due to Down's syndrome or some other serious disease, abortions are rarely sought (Ratanakul, 1998). In such cases, women are reluctant to seek an abortion because they believe that the fetus's disease is the result of negative karmic consequence produced by both the mother and the fetus (in a prior existence). To abort the fetus would only increase the negative effect. (Ratanakul, 1998). Fear of detrimental karmic consequence, then, is a deterrent to having an abortion.

Mahayana Buddhist Bioethics

Mahayana Buddhist bioethics often center on the ideal of the bodhisattva. In devotional Mahayana, bodhisattvas such as Avalokitesvara embody compassion and the power to save those in material or spiritual distress—thus serving as ethical exemplars. In meditation-based Mahayana, emphasis is often placed on the ethical implications of a *bodhisattva*'s wisdom and experience of emptiness (*sunyata*). Despite positing different ethical ideals, the moral import of compassion and wisdom are interrelated in faith- and meditation-based Mahayana. Wisdom without compassion is no wisdom at all, and compassion without wisdom is potentially dangerous because action might originate in desire and attachment. Realization of compassion and wisdom results from actualizing attitudes and mental conditions—such as generosity, patience, and diligence—that are among the six perfections that bodhisattvas strive to achieve.

In part, the Mahayana bodhisattva ideal resulted in an increased emphasis on both monastic and lay concern for the spiritual and material well-being of others. Bodhisattvas enact the virtues of compassion and wisdom by striving to alleviate suffering and attending to the sick and elderly, among other selfless activities. When bodhisattvas declare the "thought of enlightenment" (*bodhicitta*), they vow not only to attain enlightenment, but also pledge to overcome defilements and to utilize compassion and wisdom to save all sentient beings.

For some Mahayana Buddhists, the imperative of compassionate action can override injunctions against harming others, lying, and other apparent violations of Buddhist morality. In essence, precepts may be broken in order to help others. This is possible because of the related notion of *upaya*—an expedient device. According to this important Mahayana concept, the historical Buddha used expedient means to expound the Dharma. That is, he presented his teachings in accord with variations in individual ability to comprehend his religious message. However, these alternate versions of the Dharma ultimately lead to the same truth. Similarly, *bodhisattva*s employ efficacious devices according to the needs of those who seek their aid. Japanese stories, for example, recount instances in which *bodhisattva*s assume the guise of a thief in order to be thrown in jail and thereby gain access to incarcerated individuals in need of spiritual solace. While this expedient device seems to transgress the precepts, the act is justified by virtue of compassion. In this and similar situations, the motivation for a behavior becomes central—a *bodhisattva* can only perform such actions if detached from any idea of self-benefit. As a being liberated from dualistic distinctions such as good and evil, the *bodhisattva* demonstrates action informed by the realization of *sunyata,* and the moral efficacy of integrating compassion and wisdom.

Bodhisattva virtues of compassion and wisdom impact Mahayana perspectives on bioethical issues such as abortion. For instance, in Japan, Buddhists do not officially condone abortion. Nevertheless, Japanese Buddhism generally tolerates abortion and sometimes plays a significant role in assuaging the negative karmic consequence that accrues from abortion.

In Japan, abortion is considered a *necessary sorrow* (LaFleur, 1990). That is, while never a moral good, sometimes abortion can be justified over carrying a child to term.

From a Japanese perspective, it is morally problematic and socially irresponsible to bring more children into the world than a family can support and nurture. In addition, Buddhist beliefs about rebirth characterize abortion as postponing the fetus's entry into the samsaric world. However, there are moral consequences to aborting the fetus. In order to try to rectify the negative karmic consequence that accrues from an abortion, Japanese Buddhist rituals, known as *mizuko kuyo,* are performed in order to speed the soul of the aborted fetus (*mizuko*) to a more positive rebirth. In addition, *mizuko kuyo* are intended to comfort aborted fetuses. Such rites also serve as a way for parents to repent sexual misconduct that results in unwanted pregnancy. Repentance helps alleviate the effects of immoral behavior, especially when admitted to a Buddha or *bodhisattva.*

Abortions are a common form of birth control in Japan and temples devoted to *mizuko kuyo* flourish to meet the spiritual needs of both mother and aborted fetus. The *bodhisattva jizo* (in sanskrit, *Ksitigarbha;* literally *Earth Womb*) is usually a focus of worship at these temples. Jizo is believed to aid sentient beings in their movement through the samsaric cycle and to protect deceased children as well as miscarried and aborted fetuses. Small statues of *jizo,* representing the fetus, are often dressed in children's clothing and presented with offerings of toys. Making offerings to *jizo* is a way to rectify negative karmic consequence of killing the fetus.

Buddhist Bioethics: Prospects

This entry has offered an overview of the relationship between Buddhist ideas and bioethical issues. The fundamental logic introduced concerning abortion, for example, also pertains to Buddhist discussions of other bioethical dilemmas. Most likely, ongoing Theravada and Mahayana debates over the morality of euthanasia or human cloning will also pivot on concepts of nonharm and compassion.

At least three areas remain for further study that will undoubtedly raise new and important questions about Buddhist bioethics. First, the Buddhist textual record that currently exists represents mostly the views of Buddhist males. What are the ethical perspectives, both past and present, of Buddhist women? Do Buddhist women have different views of bioethical issues than men? Second, as medical technology continues to impact traditionally Buddhist cultures, what new conflicts and challenges will emerge? Finally, in what ways will Western Buddhist (for instance, American Buddhist) syntheses of bioethical issues impact traditional Buddhist bioethics?

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SEE ALSO: *Authority in Religious Traditions; Compassionate Love; Death: Eastern Thought; Environmental Ethics: Overview; Ethics: Religion and Morality; Eugenics and Religious Law; Hinduism, Bioethics in; Medical Ethics, History of South and East Asia; Population Ethics: Religious Traditions, Buddhist Perspectives*

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CANCER, ETHICAL ISSUES RELATED TO DIAGNOSIS AND TREATMENT

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Significant advances in cancer control and prevention have emerged from the front lines of medicine since the 1970s. Sophisticated diagnostic modalities aid in the timely detection of the disease. The benefits of established treatments such as chemotherapy and radiation therapy have been maximized gradually but steadily, and the risks have been minimized. Major changes in other aspects of cancer care have followed. For example, oncology personnel today pay far more attention than did their predecessors to issues such as the frank disclosure of diagnoses and treatment options, long-term quality of life for cancer patients and their families, and ethically complex scenarios that range from gaining consent from incompetent adults to the participation of children in discussions and decision making about cancer clinical trials.

These and other developments also have created new problems and concerns for clinicians, ethicists, and other stakeholders in the struggle against cancer. These issues include complicated questions about the nature, quality, and outcomes of oncologist-patient communication and decision making. Is there a preferred way for an oncologist to disclose a diagnosis of cancer to patients and their families that is frank *and* compassionate, truthful *and* hopeful? Should children diagnosed with cancer participate in discussions and critical decisions about their disease and its treatment? Can one envisage a continued role for paternalism in contemporary cancer care, and how effective or realistic are the models proposed as alternatives? Are oncologists responding to the growing ethnic diversity of their patients? What sorts of opportunities and obstacles will confront oncologists as people with cancer organize and inform themselves through online advocacy groups, websites that promote "alternative" treatments, and other high-technology resources?

Cancer and the Oncologist's Ethical Duties: Some General Considerations

An oncologist's ethical responsibilities typically begin with a positive diagnosis of cancer, an event that triggers shock and anxiety in patients and their families. Cancer is associated by many people with disfigurement, dying, and death; therefore, the first ethical duty of an oncologist and his or her team is to convey the diagnosis in a way that balances the reality of the disease and its implications with the overall need to maintain optimism and hope. Whereas the obligation to be honest about the reality of cancer derives from the ethics of truth telling in cancer care and in medicine generally (see below), the duty to foster hope taps several sources (Kodish et al., p. 2974):

1. The poorly understood relationship between the mind and the body and the ability of the body to respond positively to a positive frame of mind.
2. The physician's responsibility to attend to the patient's psychological as well as physical welfare.
3. A need for humility on the physician's part in light of the limitations of her or his ability to predict the future for any individual patient.

How much hope should an oncologist foster in patients and their families? Researchers point out that the language of hope is a critical part of the culture of oncology in the United

States. It "articulates fundamental American notions about personhood, individual autonomy, and the power of thought (good and bad) to shape life course and bodily functioning" (Good et al., p. 61). Several factors have to be assessed in promoting hope in a specific case, including the type and stage of cancer, the patient's age, and the point of evolution in the disease and treatment at which the discussion occurs (Kodish et al., p. 2974). Cultural factors also may have to be considered. Cancer carries different connotations in different cultures and may require a discussion tailored to the degree of fatalism, fear, or "social death" that the disease inspires in different ethnic groups (Taylor; Good et al.; Gordon; Good).

From the reinforcement of hope flow other responsibilities: to time the disclosure of survival chances sensitively; to discuss the available treatment options and their respective risks and benefits fully; to discuss, among other rights, the patient's right to withdraw from a clinical trial if one is offered; to encourage patients and their families to ask questions; and to give honest answers to all the questions patients ask. Special attention has to be paid to clarifying key concepts in oncology such as the distinction between remission and cure. *Remission* means that there is no clinical or radiographic evidence of active tumor and often is accompanied by the hope of a cure. Unfortunately, relapse often occurs and brings a much more grave prognosis. Many oncologists and patients are reluctant to use the term *cure* because of the implied guarantee that there will be no relapse.

Care must be taken so that patients are neither overburdened with information nor underinformed. To strike this balance an oncologist initially should meet several times with a patient rather than only once and space the meetings to give the patient time to absorb sensitive or complicated information. Institutional review board–approved consent scripts and other written materials on cancer or cancer clinical trials may help literate patients understand their options and rights (Meade; Flores et al., p. 847).

These are some of the key ethical responsibilities that face oncologists in their daily encounters with patients. Many more exist and depend largely for their successful outcome on oncologists' ability to take into account the physical, emotional, and social needs of their patients. Some of those needs may be dictated by the ways in which cancer is conceptualized.

The Concept of Cancer: An Overview

Although the biological, epidemiological, and genetic origins and indicators of cancer are vitally important—they are the frontiers on which the disease is being battled—cancer is more than the sum of its physical parts. It is also a socially imagined disease that is collectively thought about, embellished, and reacted to in ways that mesh with a people's established social and cultural norms. In some African countries, for example, perceptions of cancer as a stealthy, insidious disease mesh with notions of malice and witchcraft (Bezwoda et al., p. 123; El-Ghazali, p. 101). In parts of Italy cancer poses the threat of social as well as physical disruption and death, a viewpoint that meshes with the importance Italians place on defining themselves and their worth in relationship to others (Gordon). In the United States, by contrast, "having" cancer sometimes is considered a personal failing and responsibility, a notion that clearly draws on deeply ingrained concepts of individuality and the individual's role in determining his or her destiny (Good et al.).

Ideas and perceptions about cancer are not, however, unchanging or static. Cancer was widely viewed in pre-nineteenth-century art and literature as a distinctly romantic disease. Susan Sontag has linked this view to evidence that for a long time cancer was confused with tuberculosis, a disease historically infused with a romantic mythology (Sontag). Gradually, however, after tuberculosis was identified in 1882 as being bacterial in origin, cancer developed a separate and far less romantic identity, characterized in Sontag's view by a highly deleterious and stigmatizing image that persists to this day.

In the United States the situation can be made worse by the punitive and often militaristic paradigm of the disease (Sontag, pp. 65–67; Payer). People with cancer are treated aggressively, sometimes without much concern for their quality of life, perhaps partly as a result of the way in which cancer treatment is framed as a "war" that should be "waged" with "weapons" such as chemotherapy and radiation therapy. Such language is widespread and public: Cancer research institutions have worked it into their mission statements, and high-profile cancer "survivors" such as Lance Armstrong use it to encourage others.

So detrimental do some scholars consider this metaphoric expression of cancer that they recommend a shift away from the use of metaphor to understand and define cancer and other diseases (such as AIDS). Writes Sontag: "The most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking" (p. 3). Metaphors can hurt, Sontag suggests; they are a rhetorical means by which diseases can acquire meanings that inflict additional pain and suffering on people with diseases such as cancer and AIDS.

Sontag's argument has to be considered in light of two other observations. First, cancer patients are rarely passive victims of the collective lore or mythology surrounding their disease. One cancer patient, in an advice column published online by the American Cancer Society, rejected the notion of cancer as a purely individual, unshakable disease: "I find myself more comfortable telling people, 'I was diagnosed with cancer' instead of saying, 'I have cancer.' On some deep level, I don't want to 'own' this illness." The writer goes on to offer the following advice to other cancer patients: "Choose language that suits you when you share your news. And keep in mind that there is no one 'right' way of doing this" (Murray).

Individually or as members of self-help organizations, cancer patients can and do actively oppose the aspects of their disease and its conception or management that they consider negative and unfair.

Second, metaphors do not only hurt or damage; they also may help patients cope with cancer. Studies show, for example, that cancer patients frequently draw on religion, nature, art, the military, and many other sources of imagery to help them visualize their diseases, treatments, and recoveries (Skelton; Tompkins and Lawley). Psychologists have reported considerable success working with the many different kinds of metaphors that cancer patients can adopt throughout the course of their disease (Tompkins and Lawley). Ethnographic evidence indicates that even oncologists and other specialists use metaphors to help them understand and confront cancer and "routinize" new technologies and treatments (Koenig; Simon; Skelton et al.).

"In the healing process the most important part of communication takes place at the metaphoric level," states the medical anthropologist Margaret Lock in Capra's *Uncommon Wisdom* (1989, p. 289). "Therefore, you have to have shared metaphors" (chapter 19). This may be especially true in the case of cancer because of the seriousness of the disease and the onus on patients and their caregivers to utilize the full range of resources—medical, social, and metaphoric—available to them in their joint effort against cancer.

The Doctor-Patient Relationship in Cancer Care: Four Models

The doctor–patient relationship has particular relevance in the context of cancer. Frequently life-threatening, clinically complex, and requiring sustained, repeated face-to-face interactions, cancer and its treatment raise the fundamental question of what exactly is involved when patients and clinicians enter into a "relationship." For months and perhaps years a cancer sufferer and his or her clinician or clinicians must meet, talk, listen to, and learn from one another in an atmosphere built on mutual trust, good communication and understanding, competency and compassion, and openness. Without these interpersonal characteristics the doctor–patient relationship is likely to be a rocky one, leading to possible patient and clinician dissatisfaction, mistrust, and a compromised quality of care.

The respective roles that patients and clinicians ideally should adopt, however, are not widely agreed on or easily implemented. Different models ranging from strict paternalism to complete patient autonomy have been suggested. Below, four of these models and their relevance to the cancer care setting are reviewed. Although paradigmatic in several important ways, these are not the only models that are relevant to cancer care. Variations on these models and other alternatives have been proposed (Ong et al.; Gattellari et al.).

THE PATERNALISTIC MODEL. Definable as the overriding or restricting of the rights or freedom of individuals for their own good, paternalism entails clinicians ensuring that patients receive the interventions that best promote their health and well-being regardless of the patients' preferences (Goldman). Although many scholars oppose strict paternalism, arguing that it is too coercive, some concede that paternalism has moral validity and limited practical relevance. Paternalism may be useful and necessary in emergency situations in which the time taken to discuss treatment options or obtain informed consent may harm the patient irreversibly (Emanuel and Emanuel, p. 73). Otherwise, strict paternalism rarely is advocated or considered tenable in the treatment of diseases such as cancer.

Nevertheless, patients and/or their families may at times express a desire for a paternalistic approach. In a large behavioral cancer study, for example, the authors audiotaped the parent of a young boy with leukemia in a discussion with an oncologist who was trying to explain the option of enrolling the child in a Phase III clinical trial. The parent interrupted the clinician and said, "Anything you gotta do to fix him! I don't care." The clinician persisted, saying she felt obligated to inform him about the clinical trial. She again was interrupted by the parent, who insisted: "You don't have to tell me all the lingo. Just fix him [the patient]!"

Clearly, a paternalistic approach in which the clinician calls all the shots may be preferred by some healthcare consumers. Other studies have highlighted similar preferences, finding that some cancer patients prefer to relinquish decision-making control in favor of a more passive or deferential role, a phenomenon that may be rooted in the inordinate trust some people place in their doctors or in prevalent cultural norms and values that discourage shared decision making and patient autonomy (Flores).

THE INFORMATIVE OR CONSUMER MODEL. Like all patients, cancer patients can be viewed as consumers, and their clinicians as providers of information and treatment. This model supports a view of the doctor–patient relationship as a neutral and transactional one in which the clinician furnishes, without trying to influence the patient, the facts relevant to the patient's diagnosis, prognosis, treatment options and their risks and benefits, and aspects of care. The goal of this approach is to empower the patient with as much information as possible so that the patient can make a fully informed, autonomous decision about treatment. Although this approach may prove beneficial to patient understanding and informed decision making, it also may lead to information overload and patient dissatisfaction. The burden of choice and decision making falls squarely on patients in this model, an outcome that not all cancer patients find desirable or helpful (Gattellari et al., p. 1867).

THE INTERPRETIVE MODEL. Also based on a view of the clinician as an information provider, the interpretive model suggests that clinicians furnish the facts and go several steps further to help the patient understand them and make a decision about treatment. The clinician may have to act as a counselor of sorts, supplying relevant information, elucidating the patient's values and preferences, and suggesting which treatment options best match the patient's values. An oncologist adopting this role, for example, might listen to a breast cancer patient, articulate the patient's values and then inform the patient that it is important for him or her to fight the cancer but that the treatment must leave the patient with a healthy self-image and quality time outside the hospital. Without recommending a particular course of action, the oncologist might suggest that the patient's values seem compatible with radiation therapy but not with chemotherapy because the former would do better at maximizing the patient's chance of survival while preserving the patient's breast.

Patient autonomy is conceived as self-understanding in this model; the patient "comes to know more clearly who he or she is and how the various medical options bear on his or her identity" (Emanuel and Emanuel, p. 69). Objections to this model include the possibility that clinicians may misinterpret the patient's values or impose their own values under the guise of articulating those of the patient.

THE DELIBERATIVE MODEL. From the standpoint of this model the clinician acts as the patient's teacher or friend, helping the patient *deliberate* on various aspects of the disease, prognosis, and treatment options. The clinician aims at most for moral persuasion, not coercion, and tries to engage the patient in a dialogue about what treatment is best in light of the patient's condition and health-related values. An oncologist adopting this role might begin by pointing out the facts, articulating the patient's values, and then balancing the options with the patient in a discussion of their risks and benefits and potential impact on the patient's life. This model supports an oncologist who goes on to recommend a particular course of action, suggesting, for example, that radiation therapy may be the best option because it offers maximal survival with minimal risk, disfigurement, and disruption of the patient's life (Emanuel and Emanuel, p. 71).

In contrast to the interpretive model and its emphasis on self-understanding, the deliberative model conceives of patient autonomy as "moral self-development" (Emanuel and Emanuel, p. 69). A major criticism of the deliberative model is that clinicians should not be entitled to act as moral teachers or guardians; their role is to heal without regard to a patient's personal values or morals. However, this criticism is subject to the counterargument that many people may not want or expect their clinicians to be simply mechanistic healers and may desire help—especially when faced with the prospect of cancer treatment—in developing a personal moral foundation for their long-term health and well-being.

In their classic work on the subject Thomas Szasz and M. H. Hollender make the point that the doctor–patient relationship is a relatively novel concept in modern medicine. Instead of fostering its relationship with patients as people, they argue, medicine has cared primarily about its relationship to such "things" as anatomic structures, cells, lesions, bacteria, and viruses (p. 278). Certainly this characterization rings true for oncology during the early and intermittent phases of the "war on cancer" (Proctor). Patients' rights, truth telling, and other ethical components of cancer care that are taken for granted today were not always high on the agenda in much of the twentieth century, when efforts were directed primarily toward developing a basic understanding of cancer and options for treating it. Before 1970 the paternalistic model was widely accepted, entitling oncologists to decide unilaterally what sorts of information and treatment their patients should get.

As different models of patient autonomy in cancer care are developed and debated by experts ranging from medical sociologists and anthropologists to oncologists and research nurses in oncology, the doctor–patient relationship in cancer care increasingly is undergoing scrutiny and refinement. Few experts still advocate the paternalistic model. The debate centers more on whether the model for cancer care should be informative, interpretive, or deliberative or should involve some combination of these models and their respective strengths. At the same time researchers across a spectrum of disciplines increasingly are consulting cancer patients and their communities for input on the merits or drawbacks of particular ways of gaining information, making decisions, adhering to drug regimens, and developing effective coping mechanisms for cancer. Such informant-based, empirical research will continue to play a vital role in understanding and developing the oncologist–patient relationship in ways that promote quality of care and quality of life for people with cancer.

Telling the Truth about Cancer and Its Treatment

In the United States attitudes toward truth telling in cancer care have changed markedly in the last few decades. In 1946 Charles Lund wrote that a patient diagnosed with cancer should not be told the "whole truth." He advised physicians to use a "loosely descriptive word" such as *cyst* or *lesion* in place of the word *cancer* and to give patients only "some rough idea" of the extent of treatment. That was sufficient information, Lund felt, on which to base a diagnostic discussion and consent to treatment. In the same vein, a 1961 survey reported that 90 percent of 219 Chicago doctors did not tell patients the truth about a diagnosis of cancer (Oken). Maintenance of hope, in contrast, was considered the single most important factor for physicians to take into account when discussing cancer with a patient. By contrast, 97 percent of physicians surveyed at the same Chicago institution in 1979 reported a preference for telling cancer patients the truth about their diagnoses, a dramatic reversal of earlier findings (Kodish et al., p. 2974). Since that time it has become widely accepted that patients should be told the truth about their diagnoses and prospects, although not all studies find that this happens in practice. Omission or concealment of the truth remains an issue in cancer care because of the traditional and cultural resonances of dread associated with the disease (Freedman, p. 572).

Studies reveal a number of benefits associated with an open, truthful approach to a patient's diagnosis of cancer, chances of survival, treatment options, and progress over time. Honest disclosures build trust and ameliorate conflict between clinicians and patients and their families. They satisfy legal and ethical norms of patient autonomy. Truthfulness also ultimately may help patients understand and cope with cancer. Nevertheless, a clinician should take into account several factors before initiating a frank discussion with a cancer patient.

Foremost among these factors is whether the patient has been diagnosed with cancer for the first time. Such patients may require a more sensitive approach than do relapsed patients or patients with long-standing symptoms, who generally will be less surprised and more prepared for a diagnosis of cancer. Also "the truth" must be balanced against the fact that a clinician can share openly with a patient only what is clinically knowable. The natural history of a particular cancer and the way a patient will respond cannot always be predicted at the time of diagnosis. This may add to a discussion an element of uncertainty that can make the truth appear murky and confusing as well as uncomfortable for patients. Finally, a frank approach to a cancer diagnosis may not be welcomed by all patients and their families. Comparative studies illustrate, for example, that the culture of oncology may vary from country to country. Cancer patients in parts of Italy, for example, fear that disclosure of the true nature and implications of their disease may lead to "social death" (Gordon). Similarly fearful, some Latino and Japanese immigrants in the United States consider American styles of disclosure and prognosis cruel and unnecessary (Good et al.).

In light of these and other contrasting cultural norms, oncologists practicing in diverse ethnic environments may need to approach their commitment to truth telling with special sensitivity and "cultural competence" (Flores). They may have to enlist the support of social workers, interpreters, and other appropriate support personnel to counteract the fear of social isolation and loss of hope that may strike some cancer patients harder than others.

Childhood Cancer and Its Ethical Challenges

Cancer kills more children than does any other disease. Recent data show that after unintentional injury, childhood cancer continues to be the most common cause of death for children ages one to nineteen years in the United States (Hoyert et al., p. 257). Beyond the impact on mortality, the disease burden of childhood cancer is very significant. The quality of life of an afflicted child and his or her family are affected profoundly. The time of a new diagnosis is a particularly difficult period, with parents reporting tremendous stress and emotional turmoil (Dahlquist et al., p. 111; Levi et al., p. 244).

Unlike most areas of clinical medicine, randomized clinical trials are the norm for pediatric oncology (Hirschfield et al., p. 256). Most often the "standard" therapy for a particular disease is determined by a previous study and then embedded in the randomized design of clinical trial along with one or more alternative regimens. Children in typical pediatric oncology randomized clinical trials may be assigned to the "standard" arm or to an "experimental" arm that is generally either more intensive (with hopes of improving the cure rate with tolerable toxicity) or less intensive (with hopes of maintaining the cure rate with less toxicity than the "standard" arm). If a parent or an older child declines study participation, the treating oncologist generally will elect to provide the “standard” therapy without collecting data for the research study.

Ethical issues in childhood cancer are complex and potentially difficult to resolve. Until recently children were compared to incompetent adults, for whom treatment-related decisions are made by a close family member. Ethicists now point out that this comparison fails to acknowledge a key distinction between children and incompetent adults: The former are different because in most cases their competency is still in a state of growth or evolution. In most prominent legal cases, by contrast, incompetent adults were never expected to regain competency (Truog et al., p. 1411). This places most children in a category different from that of incompetent adults, one that challenges doctors to preserve their future autonomy as opposed to the former autonomy that doctors strive to respect when offering multiple treatment options to incompetent adults. In light of this critical difference, how involved should children be in discussions and decision making about the treatment they will receive?

Answers to this question typically make use of the concept of “assent” for treatment, which first was proposed for pediatric patients in the 1970s by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (Truog et al., p. 1412). The commission proposed that children between ages seven and fourteen be asked for their assent to medical treatment, whereas older children would be presumed to have full decision-making capacity. The American Academy of Pediatrics sanctioned this approach in 1995, with its Committee on Bioethics adding that physicians should take the following steps to assure assent:

- Help the patient achieve a developmentally appropriate awareness of the nature of his or her condition.
- Tell the patient what he or she can expect with tests and treatments.
- Make a clinical assessment of the patient’s understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy).
- Solicit an expression of the patient’s willingness to accept the proposed care.

The last of these four requirements is perhaps the most controversial in the context of childhood cancer, in which the unwillingness of a child to accept treatment most likely would be considered insufficient grounds to forgo that treatment. For this reason the American Academy of Pediatrics is careful to account for situations in which children will receive a particular treatment despite their objection, noting that they should be told that and not be deceived (Truog et al., p. 1412). Although this approach helps ensure that children do not naively forgo treatments that could save their lives, it also raises questions about the sincerity of “assent” as a concept that is intended to foster patient autonomy. Also, achieving assent in practice may have unintended effects. Although more research is needed on the topic, at least one study of children with leukemia suggests that the consent process may be compromised when children and parents participate in the same discussions. With the oncologist typically focusing her or his comments and attention on the patient, the parents may ask fewer questions and display lower levels of understanding than do parents whose children are approached separately and who receive the undivided attention of their oncologists. These findings suggest an urgent need for further research on the practical compatibility of assent and parental permission.

Other Ethical Dilemmas in Pediatric Oncology

Parents sometimes express the wish that their children not know the diagnosis or severity of their disease. At one time this sentiment would have received support in most segments of the pediatric oncology community, in which the culture of nondisclosure widely included the notion that children had to be protected from the psychological trauma of finding out about cancer and their chances of survival (Truog et al.). However, evidence indicates that children cope remarkably well with the shock of a diagnosis such as cancer and may adjust better psychologically to their disease and its treatment if they are informed early (Slavin et al.; Truog et al., p. 1412). Oncologists may legitimately use such findings to convince reluctant or fearful parents of the importance of disclosing to their children the nature of their disease.

The refusal by some parents to consent to any kind of medical intervention for their child poses another dilemma for oncologists. Cancer is typically a life-threatening illness, and oncologists subsequently display a relatively low level of tolerance for parents who deny them permission to treat a child diagnosed with the disease. Court orders usually are obtained to override such parental decisions. The situation can become more complicated, however, when a parent’s decision not to treat a child biomedically is backed by a community whose values and life views differ dramatically from the mainstream, such as the ultraconservative segments of the Amish community in the Midwest. Careful negotiation aimed at building mutual trust and confidence may be required in such instances so that the best interest of the child and the community can be served.

Cancer and End-of-Life Care

In the past oncologists typically greeted with foreboding and mistrust the prospect of relinquishing treatment in favor of palliative, end-of-life support such as hospice care. That open opposition has been replaced in most cases with careful circumspection. Many oncologists recognize a threshold beyond which continued treatment does more harm than good even though they may struggle to unite that recognition with the Hippocratic imperative to heal. This threshold, however, may not always coincide with patient or family preferences.

An oncologist may be asked to taper off or stop treatment at a juncture where the oncologist foresees, with statistical and collegial support, that continued treatment is still likely to benefit the patient. In equally problematic situations the reverse may occur. Crawley and her colleagues cite as an example an African-American man with metastatic colon cancer who angrily rejected his physician's suggestion that they had reached a point where the interventions would be costly and would serve only to prolong the man's suffering (Crawley et al., pp. 673–675). The patient demanded that he receive every medical test and procedure available regardless of the cost. This insistence, the physician felt, was based on the man's inability to grasp the limitations of the technological options still available to him.

The provision of good end-of-life care for cancer patients frequently is complicated by disagreements, poor communication, and cultural differences. However, there are strategies that oncologists can adopt to alleviate end-of-life pain and suffering among their patients. Foremost is a willingness by a physician to probe beneath the surface for explanations of why patients and/or families may or may not desire an option such as hospice care. Investigating the case mentioned above further, Crawley et al. discovered that the physician, a European-American, consulted an African-American colleague for advice. As an ethnic "insider," the colleague was able to point out that African-Americans who have suffered discrimination may fear neglect if they do not insist on maximal care. The colleague also stated that many patients seek aggressive treatment because they value the sanctity of life, not because they misunderstand the limits of the technology available to them, as the patient's doctor had suspected (Crawley et al., p. 675). Enlightened by this and other information, the doctor met again with his patient and reopened the discussion with greater understanding about the patient, his cultural background, and his preferences.

A unique problem in end-of-life care arises when the physician's best-intentioned efforts appear to resemble physician-assisted suicide or euthanasia. The classic case involves the terminally ill patient whose death may be hastened by high doses of morphine. Discerning clinicians and ethicists usually can recognize whether a physician's goal in such cases is to relieve pain or respiratory distress—a fundamental clinical obligation in the eyes of many—or whether the objective is to hasten the patient's death, a goal that remains ethically controversial (Kodish et al., p. 2979).

The growing worldwide hospice movement provides an important avenue for improving end-of-life care for cancer patients. Hospice philosophy calls for providing patients and their families with medical, psychological, and spiritual support as they encounter terminal illness. The primary goal is palliation of symptoms and improvement of the quality of life. Antineoplastic therapy may be a part of hospice care, but cure of cancer is no longer attainable and the focus is on comfort. Although tension between the goals of cancer treatment and the goals of hospice care may arise, they need not be incompatible. Patients who develop a trusting relationship with an oncologist may feel abandoned if their care is transferred abruptly to a hospice team. For this reason oncologists should remain active in the care of patients with terminal cancer, using hospice services as an adjunct rather than a replacement for providing excellent care.

Cancer Care and the Future

Future developments in cancer care will be affected by advances in the clinical control and prevention of the disease. Ongoing genetic and molecular research promises not just more effective treatments for cancer but also less invasive procedures for patients, greater patient autonomy, and improved quality of life. Potential problems may include a compounding of concerns about informed consent for cancer clinical trials and genetic susceptibility testing, as well as more "macro" issues such as the inequitable distribution of cancer care resources in the United States and globally. Also, current trends suggest continued growth in "informal" cancer care resources ranging from online information networks to holistic alternatives to conventional cancer care. Many of these resources have the potential for linking together and empowering cancer patients but also of misinforming them or undermining the oncologist's authority and purpose through the exposure of patients to multiple, conflicting messages. Surveys and other kinds of behavioral research may be needed so that providers of cancer care may better grasp the pluralistic knowledge- and treatment-seeking tendencies of their patients and the way in which they affect physician-authority, treatment adherence, and other key clinical issues.

Finally, demographic trends at the beginning of the twenty-first century strongly suggest that cancer care will be provided amid growing ethnic and cultural diversity in the United States and elsewhere. Already many providers of cancer care feel the impact of this diversity through their daily struggles with language barriers, conflicting expectations, lack of treatment adherence, and other problems. Learning more about patients and their backgrounds provides an important way to address these and other problems. Clearly, however, it is unrealistic to expect caregivers to identify the countless cultural norms and behaviors that may affect their patients' preferences and decisions. An approach tailored to a particular institution's patient demographic is needed, and for this there are handbooks and other tools that may assist a cancer caregiver practicing in any region of the United States. Leading cancer care institutions also increasingly hire professional, culturally astute interpreters who can help oncologists and patients bridge the cultural and linguistic differences that may hinder effective communication and understanding. Conferences and workshops on "cultural competence" and "cultural sensitivity" increasingly are organized for researchers, ethicists, and caregivers to use in response to growing patient heterogeneity.

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SEE ALSO: *Alternative Therapies; Autonomy; Beneficence; Clinical Ethics; Double Effect, Principle or Doctrine of; Grief and Bereavement; Healing; Informed Consent; Life, Quality of: Quality of Life in Clinical Decisions; Life Sustaining Treatment and Euthanasia; Palliative Care and Hospice; Surrogate Decision-Making*

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CARE

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I. History of the Notion of Care
II. Historical Dimensions of an Ethic of Care in Healthcare
III. Contemporary Ethics of Care

I. HISTORY OF THE NOTION OF CARE

Prior to 1982 scarcely anyone spoke of an "ethic of care." The word "care" had never emerged as a major concept in the history of mainstream Western ethics—as compared, say, with the concepts of freedom, justice, and love. Yet, starting with the 1982 publication of a book by Carol Gilligan that spoke of a care perspective in women's moral development and throughout the 1980s and into the 1990s, an ethic of care emerged very rapidly, questioning earlier assumptions and setting new directions for bioethics. (These contemporary publications and discussions will be reviewed in the third subentry in this entry.) One characteristic of the literature on an ethic of care is that it has paid virtually no attention to the history of the notion of care prior to 1982. Yet one finds in this history a broad range of meanings and models that both illuminate and challenge the emerging ethic of care.

The "Cura" Tradition of Care: Ancient Rome

Ancient literary, mythological, and philosophical sources form the roots of the "Cura" tradition of care, named after a mythological figure. The background for this tradition is found in the ambiguity of the term *cura* (care) in the Latin literature of ancient Rome. The term had two fundamental but conflicting meanings. On the one hand, it meant worries, troubles, or anxieties, as when one says that a person is "burdened with cares." On the other hand, care meant providing for the welfare of another; aligned with this latter meaning was the positive connotation of care as attentive conscientiousness or devotion (Burdach).

A literary instance of the first meaning of care—the care that is so burdensome that it drags humans down—is found in the work of the Roman poet Virgil (70–19 B.C.E.), who placed the personified "vengeful Cares" (*ultrices Curae*) before the entrance to the underworld. The philosopher Seneca (4 B.C.E.—65 C.E.), by contrast, saw care not so much as a burdensome force that drags humans down as the power in humans that lifts them up and places them on a level with God. For Seneca, both humans and God have reasoning powers for achieving the good; in God, the good is perfected simply by his nature, but in humans, “the good is perfected by care (*cura*)”(pp. 443–444). In this Stoic view, care was the key to the process of becoming truly human. For Seneca, the word *care* meant *solicitude*; it also had connotations of attentiveness, conscientiousness, and devotion (Burdach; Seneca).

The struggle between the opposing meanings of care—care as burden and care as solicitude—as well as the radical importance of care to being human, were elements in an influential Greco-Roman myth called “Care,” found in a second-century Latin collection of myths edited by Hyginus (Hyginus; Grant). More than any other single source, this little-known myth, narrated below, has given shape to the idea of care in literature, philosophy, psychology, and ethics through the intervening centuries.

As Care (Cura) was crossing a river, she thoughtfully picked up some mud and began to fashion a human being. While she was pondering what she had done, Jupiter came along. (Jupiter was the founder of Olympian society, a society of the major gods and goddesses who inhabited Mount Olympus after most of the gods had already appeared.) Care asked him to give the spirit of life to the human being, and Jupiter readily granted this. Care wanted to name the human after herself, but Jupiter insisted that his name should be given to the human instead. While Care and Jupiter were arguing, Terra arose and said that the human being should be named after her, since she had given her own body. (Terra, or Earth, the original life force of the earth, guided Jupiter’s rise to power.) Finally, all three disputants accepted Saturn as judge. (Known for his devotion to fairness and equality, Saturn was the son of Terra and the father of Jupiter.) Saturn decided that Jupiter, who gave spirit to the human, would take back its soul after death; and since Terra had offered her body to the human, she should receive it back after death. But, said Saturn, “Since Care first fashioned the human being, let her have and hold it as long as it lives.” Finally, Jupiter said, “Let it be called *homo* (Latin for human being), since it seems to be made from *humus* (Latin for earth)” (see Grant; Shklar).

The meaning of the word *care* in this myth reflects the Stoic sense of an uplifting, attentive solicitude; it is in light of this positive side of care that we can understand the deeper meaning of the Myth of Care. Yet the word *care* is not without tension: The lifelong care of the human that would be undertaken by Cura entails both an earthly, bodily element that is pulled down to the ground (worry) and a spirit-element that strives upward to the divine (Burdach; Grant). The positive side of care dominates in this story, for the primordial role of Care is to hold the human together in wholeness while cherishing it.

It is significant that a myth communicates the meaning of care, for one of the major functions of myths is to offer ancient narratives that make it possible for people to understand the meaning of their experiences regarding the basic characteristics of human life (Doty; Frye). The Myth of Care conveys an understanding of how care is central to what it means to be human and to live out a human life. It also provides a genealogy of care in light of which to rethink the value of care in human life.

Myths of origins have often been used to question the established order, both divine and human, and to establish radical moral claims, including claims about power and the social order (Shklar). Although several prominent political philosophies that have shaped much of modern bioethics are based on myths of origin that emphasize adversarial struggles as the starting point for human societies, the Myth of Care offers a subversively different image of human society, with very different implications for ethics in general and bioethics in particular (Reich). Indeed, the Myth of Care presents an allegorical image of humankind in which the most notable characteristic of the origins, life, and destiny of humans is that they are cared for (cf. Grant). At the same time, this gentle myth also speaks about the roots of power. Modern psychology teaches us that those who are cared for from birth (which is the image conveyed in this myth) develop the nurturing power to care for self and others. Furthermore, the fact that the myth’s first human being is not named for the most powerful of the gods and goddesses, which would have been a symbol of being dominated by them, suggests that truly solicitous care protects humans from oppressive and manipulative power. The myth also suggests that humankind as a social totality is brought into the world and sustained by care. Since it binds humans together, care is the glue of society.

The Care of Souls Tradition

The moral meaning of care is not only shaped by narratives, it is also historically embedded in practices such as the care of souls (*cura animarum*). The care of souls refers to the care of troubled persons whose difficulties—whether spiritual, mental, or physical—are approached in the context of the pursuit of the religious goals of life or, in nonreligious contexts, the search for ultimate meanings (cf. Clebsch and Jaekle; Browning). The care of souls tradition—the explanations offered in its literature and the interpretation of its practices—sheds light on the origins and content of contemporary ideas about care.

The word *care* in the care of souls refers both to the tasks involved in the care of a person or group and to the inner experience of solicitude or carefulness concerning the object of one's care. In the framework of the first meaning of the word, the care of souls consists of helping acts that are directed principally toward "healing" and the means by which healing is brought about, for example, reconciliation (including penitential reconciliation for those who have sinned), sustaining (including compassionate consolation), and guiding (spiritual and moral guidance).

The selection of the term *care of souls* to designate these activities (the word *cura* in the term *care of souls* is frequently translated as "cure" of souls) reflects the historical emphasis on a comprehensive idea of healing in the care of souls tradition (McNeill; Clebsch and Jaekle). Socrates regarded himself as the physician or healer of the soul, as did other philosophers (McNeill); and Gregory of Nazianzus (362 C.E.) said all pastors are physicians of souls, "who must prescribe medicines, or cautery, or the knife"(McNeill, p. 108).

The word *soul* in the care of souls can have a variety of meanings, depending on the philosophical explanation chosen or the religious tradition in which the term is used. John McNeill calls the soul "the essence of human personality" (p. vii). It is spirit intertwined with the body without being a mere expression of bodily life. The soul is regarded as being susceptible to disorder and anguish, while being endowed with possibilities for well-being and blessedness. The care of souls, then, is the healing treatment of persons in those matters that reach beyond the requirements of physical life, in pursuit of the "health of personality" (p. vii). But the welfare of the soul was not isolated: Caring for the healing of the soul, mind, and body have often been integrated (May, 1982). Thus, when we speak of "the care of the whole person," we are speaking of something comparable to the ancient idea of the care of souls.

The care of souls conveys the primary message that there is invariably a hierarchy of values in what it is that humans choose to care about, and that among those values, care for the spiritual should be preeminent. Socrates exhorted his hearers in Plato's *Apology* "not to care for your bodies or for money above and beyond your souls and their welfare"; and in the *Phaedo* he argued that "the cultivation of the soul is the first concern"(McNeill, p. 20). Some scholars believe his exhortation greatly influenced the emergence of the idea of the care of the soul in ancient Greece and in Christianity (McNeill).

Another prominent feature of the care of souls has been the way in which it calls attention to the subjective experience of those who are suffering and their need for relief in the form of personal attention. In the Hebrew scriptures, the Psalmist speaks out of bitter anguish: "I looked … and beheld, but … no man cared for my soul" (Ps. 142:4–5; McNeill). The sufferer then appealed to the Lord to be his refuge in the land of the living. In the care of souls tradition, God, self, and other humans care for the troubled soul. The one who gives care must be very attentive to the needs of the individual sufferer. For example, Gregory the Great, renowned for his pastoral leadership in the Western church (590–604), taught that the guide of souls must be a compassionate neighbor to all, a shrewd observer, and watchful and discerning like the physician of the body (McNeill). But one problem remains constant: whether the sufferer will seek and/or accept care (McNeill).

The contrast between negative and positive care that one finds in Seneca and the Myth of Care was also presented by Jesus, who contrasted the heavy burdens (the "yoke") that many people bear—the worrisome cares of life—with relief or solicitous care (Matt. 11:28–30). He exhorted his followers not to be anxious about the necessities of life, but instead to trust that they would be cared for by the heavenly Father who knows their needs (Matt. 6:25–34; Davies).

The care of souls tradition produced three major bodies of literature that are of special historical interest to contemporary bioethics. First, casuistry arose within the context of the *cura animarum.* In contrast to the rigid ethics of the medieval penitential documents, in which priest-confessors were instructed on how to deal with various categories of sinners, casuistry had the objective of bringing the lives of ordinary people under the influence of religious and moral standards by emphasizing practical, case-based moral reasoning that avoided excessive abstractions and complications (McNeill).

Second, those who cared for souls cared for the sorrows and anxieties of individuals, partly by writing a body of so-called Consolation literature. For example, Seneca and Plutarch in the classical age and Cyprian and Ambrose in the third and fourth centuries C.E. composed Consolation literature, offering sympathy for the ills of life, suffering, and persecution (McNeill).

Third, in the fourteenth and fifteenth centuries, when the idea of death was so vivid, the care of souls tradition produced a vast *Ars moriendi* literature, commending the art of dying well (willingly and joyfully, rather than in despair) and how to help the dying person (Clebsch and Jaekle; McNeill).

Finally, care had the constantly changing function of sustaining souls through the pitfalls of the earthly pilgrimage of each period of history. For example, during the seventeenth and eighteenth centuries, sustaining the troubled soul became the dominant function of the care of souls. Because of the Enlightenment, hopes and human aspirations for this life ran very high, and pastoral sustenance attempted principally to keep believers mindful of their individual destinies beyond this life (Clebsch and Jaekle). This was precisely the environment in which care (*Sorge*) appeared in Goethe's *Faust.*

Goethe: A Romanticist Portrayal

The mythic idea of care made a major appearance in German literature in the eighteenth and early nineteenth centuries—a time when the meaning and relevance of myth were being rediscovered as never before—in the work of Johann Wolfgang von Goethe (1749–1832). Taking the Myth of Care from his teacher Johann Gottfried Herder (1744–1803)—specifically from Herder's poem titled "The Child of Care"—Goethe wove the major themes of that myth into his masterpiece, the dramatic poem *Faust* (Grant; Burdach).

Dr. Faust, passionately committed to the pursuit of reason and science, also wants to be care-free, that is, free of the disturbing anxieties of care that the pursuit of his goals would entail in working with ordinary human resources. He enters into a pact with Mephistopheles (the devil). In exchange for the knowledge and magical assistance of Mephistopheles, Faust agrees to be his slave; it is agreed at the outset that Faust may lose his soul to the devil in the process (Goethe, 1985).

In the final act of the drama, Faust has become powerful and wealthy, the ruler of a flourishing land that he has reclaimed from the sea. He discovers that the deceitful Mephistopheles, working under orders from Faust, has horribly destroyed by fire the last cottage destined for demolition in the reclamation project; consumed by the flames was a peaceful old couple to whom Faust had promised relocation. Appalled by the horrific consequences of his thoughtless order, Faust breaks with Mephistopheles and his magic. He wants to stand before Nature as the "mere" human being he had been before his pact with the devil. This internal change sets the stage for the struggle over Faust's character, and for the appearance of Care (Goethe, 1959; Burdach).

Care (*Sorge*), a gray hag calling herself the "eternally anxious companion" (*Ewig ängstlicher Geselle*), chides Faust for never having known her: "Have you never known Care?" (*Hast du die Sorge nie gekannt?*). She denounces the darkness and ambiguity of Faust's soul—and blinds him because he refuses to acknowledge her fully. The terrible power of the burdens of Sorge's care almost overwhelms Faust but fails to conquer his soul. Linked with Faust's profound horror over his own crime, Sorge's denunciation has the effect of bringing about Faust's turn from burdensome care to the uplifting solicitude of positive care. His "striving," which led him to ruthless acquisition, the oppressive manipulation of masses of people, and the destruction of the old couple, is transformed during his blindness into a genuine solicitude for his people (Jaeger, pp. 41–43). Faust's experience of a new and very satisfying solicitude (the greatest moment of his life) is represented by his vision of millions of free people living in comfort and freedom on an earth that has been reconciled with itself through human effort.

Goethe's Faustian narrative demonstrates that striving for one's own life goals while shutting out a sometimes worrisome and painful concern for people and institutions results in terrible external and internal harm. In the pursuit of one's destiny, a human cannot avoid care. One must first deal with the heavy side of care, rejecting its power to engulf and destroy, and then convert this care, which is the root of all human striving, into a positive, solicitous concern for people and institutions. For Goethe, care becomes conscientiousness and devotedness (Burdach). At the same time, care relates in a fundamental way to the human condition, for it may be the key to one's moral "salvation," as it was for Faust. In contrast to today's tendency to associate care exclusively with interpersonal devotion, Goethe works out the meaning of care in a political setting; the problem for Faust is whether he will show solicitous care as a ruler. As a result, Goethe's portrayal of care has important implications for political philosophy.

Kierkegaard and Heidegger: Existentialist and Phenomenological Approaches

KIERKEGAARD. Søren Kierkegaard (1813–1855), the Danish philosopher and religious thinker, was the first major philosopher to make significant use of the notion of care or concern, albeit in embryonic fashion. Intimately familiar with the *Sorge* of Goethe's *Faust* (Collins), Kierkegaard offered creative philosophical explanations of themes that had appeared both in the Myth of Care and in Goethe: that care is central to understanding human life and is the key to human authenticity. The extensive influence of Kierkegaard's idea of care or concern on subsequent thought can be seen in the context of his role as father of existentialism: It was Kierkegaard's idea of the "concerned thinker," pivotal for his own philosophy, that became the central theme of existentialist philosophy and theology (Bochenski).

Concern and care in Kierkegaard's philosophy. Kierkegaard introduced notions of concern, interest, and care to counteract what he considered the excessive objectivity of philosophy and theology as they were formulated in the early nineteenth century. To recover the sense and significance of individual human existence that he believed modern philosophy's abstract and universal categories had obliterated, Kierkegaard called attention to what he saw as the missing element of concern or care in the kind of philosophical reflection that those systems utilized (Copleston).

Kierkegaard distinguished between disinterested reflection, on the one hand, and consciousness, which entails interest or concern, on the other. Reflection, he argued, focuses on the objective or hypothetical; it is a merely disinterested process of classifying things in opposition to each other (e.g., the ideal and the real, soul and body); it has "no concern with, or interest in, the knower" (1958, p. 150), or with what happens to the individual person as a result of this kind of knowing.

Consciousness is inherently concerned both with the knower and with the collision of opposites that come to be known through reflection. Indeed, consciousness brings the merely objective elements of reflection into a real relationship with the knowing subject through care or concern (Kierkegaard, 1958). A personal (i.e., a concerned) relationship to truth is the basis of Kierkegaard's whole theory of knowledge (Croxall). For Kierkegaard the issue of concerned knowledge is a moral issue. To adopt the stance of the impersonally knowing subject rather than that of the concerned human being "as a refuge from the chaos and pain of life," he believes, "is cowardice and escapism" (Rudd, p. 28).

Kierkegaard also uses the notion of concern to express the nature of the human being and its moral choices. Humans are beings whose greatest interest or concern is in existing; concern or care is subjectively chosen as an intimate part of the individual's being (Kierkegaard, 1958; Stack). The individual gives form and direction to his or her life, and expresses his or her true self, not by being caught up in a large social system, but by exercising free choice and commitment (Kierkegaard, 1940; Copleston).

The fundamental question of ethics is: How shall I live? Objective reasoning plays a part in answering this question; but an ethical argument is valid only insofar as it articulates a concerned individual's search for meaning (Rudd). Thus, ethics starts with the individual. "As soon as I have to act, interest or concern is laid upon me, because I take responsibility on myself …" (Kierkegaard, 1958, pp. 116–117, 152–153). Without care or concern, action would not be possible: Concern is the impetus for the resolute moral action of the self-reflecting individual who acts with purpose (Stack). Always in the process of becoming, lacking the security of knowledge and facing contradiction, the human is constrained to mold his or her integrity through decision and action. One cannot do this without an "unrelieved and unceasing concern" for the passion and possibility of becoming oneself (Mackey, p. 71; Hannay).

Being burdened with cares; being cared for. Kierkegaard offers profound insights into the experience of being laden with cares and being cared for in writings that fall into the category of care of souls literature. He takes the traditional struggle between negative and positive care, previously discussed in the Myth of Care and in Goethe, in a new direction, by turning the subjective experience of worrisome care into reasons for caring for one's self and seeking the care of others.

In his writings on a biblical exhortation regarding human solicitude for material versus spiritual things (Matt. 6:19–34), Kierkegaard remarks that by contemplating the lilies of the field and the birds of heaven, who are not neglected, humans realize that even when they themselves are "outside all human care," neither are they neglected: They are still cared for by a caring God (1940, p. 16). Humans must work to fill their needs; but the human capacity to be weighted down by material care is a mark of perfection, for it also signals the human capacity to cast one's care from oneself, find consolers, accept their sympathy, and choose a caring God. On the other hand, humans can trap themselves into a care-ridden state of mind by worrying about future needs, being convinced they need total security against their anxieties, feeling an exaggerated sense of self-sufficiency, and comparing themselves unfavorably to others.

For Kierkegaard, a special kind of anxious care is created when, in the course of an illness, the question arises whether the sick person is confronting life renewing itself or the looming decay of death. The pathos of this question, which is more moving than the prospect of a terrifying death, can move the sick person to reduce his or her resistance to accepting consolation from others (1940). Finally, Kierkegaard remarks that caring for someone is not always a gentle art. When, for example, there is much that the sick person can do to improve his or her health, stern demands made by the authoritative doctor—sometimes even at the request of the patient—are the expression of concern for the anxious sick person.

HEIDEGGER. For Martin Heidegger (1889–1976), one of the most original and influential philosophers of the twentieth century, care was not just one concept among many; it was at the very center of his philosophical system of thought. Conceptually, Heidegger was strongly influenced by Kierkegaard's teachings on concern and care; yet there is a notable difference. Whereas Kierkegaard saw care or concern always in an individualized, subjective, and psychological fashion, Heidegger used the word at an abstract, ontological level to describe the basic structure of the human self. Although Heidegger insisted that he was not speaking of concrete and practical aspects of care, such as worry or nurturing, it can also be argued that his writings on care do have existential moral significance. He certainly developed some ideas that provide useful insights for a practical ethic of care (Stack).

Heidegger's starting point and lifelong interest was the philosophical question of being—in particular, the question of the meaning of being. He used the term *Dasein,* or "being-there," to represent the human experience of being in the world through participation and involvement (1973, 1985). Heidegger's interest was to show how care is the central idea for understanding the meaning of the *human self*, which is another word for *Dasein.* His philosophy explains how, at a deeper level than the psychological experience of care, care is what accounts for the unity, authenticity, and totality of the self, that is, of *Dasein.* Briefly, Heidegger claims that we are care, and care is what we call the human being (Gelven).

Heidegger explains the radical role of care by pointing to the tendency of the human self to turn away from its own authentic being to seek security in the crowd. It accommodates itself to what "they" think and forms its conduct in accordance with the expectations of public opinion. Care (*Sorge*) summons the self (*Dasein*) back from the feeling of insignificance and anxiety found in this flight from the self, and instead enables one to be one's own self, that is, to be authentic (Flynn; Martinez).

Heidegger also explains care in the context of openness to future possibilities. We are not simply "spectators for whom in principle, nothing would 'matter'" (Olafson, p. 104). To say that the self (*Dasein*) is care means that we understand and care about ourselves-in-the-world in terms of being connected with what we can and cannot do. Because of the connectedness brought about by care, it matters that we can act, and we must act to choose among our own possibilities (Olafson). In so doing, *Dasein* chooses itself; and the meaning of its existence unfolds in every resolute act. This is all implicit in care (Martinez).

For Heidegger, care has the double meaning of anxiety and solicitude—the same duality we found among the Romans—and these two meanings of care represent two conflicting, fundamental possibilities (1973). Anxious, worrisome care (*Sorge*) represents our struggle for survival and for favorable standing among our fellow human beings. It continually drives us to avoid the significance of our finitude, by immersing ourselves in conventionality and triviality, so as to "conceal from ourselves the question of the meaning of being, and in the process truncate our humanity as well" (Ogletree, p. 23). Yet care also bears the meaning of solicitude or "caring for" (*Fürsorge*): tending to, nurturing, caring for the Earth and for our fellow human beings as opposed to merely "taking care of" them. However, anxious care never totally dissolves: In the everyday world we cannot avoid the dual sense of care-as-anxiety and care-as-solicitude. Accepting the kinds of beings we are entails embracing a deep ambiguity in which we know that worrisome cares may drive us to escape and that solicitous care can open up all our possibilities for us (Ogletree).

Heidegger also contrasts *Besorgen* (taking care of, in the sense of supplying the needs of others) with *Fürsorge* (solicitous care). The human self (*Dasein*), which is essentially related to others, enters the world of others by way of care in two ways. On the one hand, we can take care of the "what" that needs to be done for the other, in a rather functional way. This sort of minimal taking care (*Besorgen*) requires few qualities—principally circumspection, so that the service is done correctly. Yet other humans are never merely things like equipment that need to be taken care of in this way; for they, too, are selves oriented to others. Hence they are not simply objects of service but of solicitude (*Fürsorge*). Solicitous care is guided by the subsidiary qualities of considerateness and forbearance. But Heidegger insists that when someone nurses the sick body as a mere social arrangement, that is, without considerateness, the nursing care should still be regarded as solicitude, albeit a deficient solicitude, and never as (mere) service-care (1973).

Heidegger also speaks of two extreme forms of solicitous care. Intending to show solicitous care, one can "jump in" and take over for the other, who then is dominated and dependent in the caring relationship. Doing what the other can do for himself or herself, the "solicitous" person is actually taking "care" away from the other. In contrast, Heidegger continues, there is a solicitous care that "jumps ahead" of the other, anticipating his or her potentiality—not in order to take away his or her "care" but to give it back. This kind of solicitude is authentic care, for it helps the other to know himself or herself in care, and to become free for care (Heidegger, 1973; Bishop and Scudder).

Heidegger's substantive development of the notion of care drew from and contributed to the "Cura" tradition of care. At the "high point" of his inquiry (Heidegger, 1973), Heidegger directly cited the Myth of Care as a primordial justification of his central claim that the human self (*Dasein*) has the stamp of care (Klonoski, p. 65). In spite of Heidegger's complexities, some writers are attempting to develop elements of an ethic of care from his insights; and some scholars, such as Anne Bishop and John Scudder, are utilizing Heidegger's ideas in their arguments regarding the moral practice of healthcare.

Rollo May and Erik Erikson: Psychological Developments

ROLLO MAY. Rollo May (1909–1994), a pioneer of the humanistic school of psychology, introduced to U.S. psychology the views of European existentialists. He made Heidegger's views on care more accessible to the average reader by pointing to their psychological and moral implications.

May's 1969 book *Love and Will* was written in a historical period in which, he argued, humans were experiencing a general malaise and depersonalization resulting in cynicism and apathy, which he regarded as "the psychological illnesses of our day" (p. 306). What the youth of the 1960s were fighting in their protests, May claimed, was the "creeping conviction that nothing matters …, that one can't do anything." The threat was apathy. Care "is a necessary antidote" to apathy, for care "is a state in which something does matter; care is the opposite of apathy." It is "the refusal to accept emptiness …, the stubborn assertion of the self to give content to our activities, routine as these activities may be" (p. 292). Care, regarded as the capacity to feel that something matters, is born in the same act as the infant: If the child is not cared for by its mother, it withers away both biologically and psychologically.

May was concerned that the idea of care would not be taken seriously if it were regarded as mere subjective sentiment. To counteract this attitude, he argued that care is objective. With care, "we are caught up in our experience of the objective thing or event we care about" and about which we must do something (1969, p. 291). Following Heidegger and citing the text of the Myth of Care, May holds that care constitutes the human as human: Care is "the basic constitutive phenomenon of human existence" (1969, p. 290). Drawing from these sources the idea that the human being is constituted in its human attitudes by care, May claimed: "When we do not care, we lose our being; and care is the way back to being." This has moral implications: "If I care about being, I will shepherd it with some attention paid to its welfare …" (May, 1969, p. 290).

We could not will or wish if we did not care to begin with; and if we do authentically care, we cannot help wishing or willing. Care makes possible the exercise of will and love; and it is also the source of conscience: "Conscience is the call of Care" (May, 1969, p. 290, quoting Heidegger). Care is a state composed of the recognition of a fellow human being, of the identification of one's self with the pain or joy of the other … and of "the awareness that we all stand on the base of a common humanity from which we all stem." Care of self psychologically precedes care of the other, for care gains its power from the sense of pain; but pain begins with one's own experience of it. "If we do not care for ourselves, we are hurt, burned, injured." And this is the source of identification with the pain of the other (May, 1969, p. 289).

According to May, care must be at the root of ethics, for the good life comes from what we care about. Ethics has its psychological base "in the capacities of the human being to transcend the concrete situation of the immediate self-oriented desire," and to live and make decisions "in terms of the welfare of the persons and groups upon whom his own fulfillment intimately depends" (1969, p. 268).

ERIK ERIKSON. Partly under the influence of Heidegger's philosophy, Erik Erikson (1902–1994) constructed a richly humanistic theory of psychosocial development in which care played a major role. Like May, Erikson made the idea of care more accessible to the average person; but he went far beyond all his predecessors by developing a fairly comprehensive psychological account of care that is relevant to many of the interests of contemporary ethics.

Based on his study of case histories and of life histories, Erikson developed a theory of psychosocial development in which the human life cycle has eight stages, each of them characterized by a developmental crisis or turning point. From the resolution of that crisis a "specific psychosocial strength" or a "basic virtue" emerges.

In the seventh stage, "adulthood," the developmental crisis is generativity versus self-absorption and stagnation. Generativity—"the concern with establishing and guiding the next generation" (Erikson, 1987, p. 607)—encompasses procreativity, productivity, and creativity. It entails the generation not only of new human beings but also of new products and new ideas, as well as a self-generation concerned with further personal development. Generativity struggles with a sense of self-absorption or stagnation, "the potential core pathology of this stage" that might manifest itself through regression to an obsessive need for pseudo-intimacy (Erikson, 1982, pp. 67–68; 1963, pp. 266–268). The virtue or "basic strength" that emerges from this crisis is care.

Adult caring is "the generational task of cultivating strength in the next generation" (Erikson, 1982, pp. 55, 67–68; 1963, p. 274; 1978, p. 22); that task may be parental, didactic, productive, or curative (1982). For Erikson, care is "the concrete concern for what has been generated by love, necessity, or accident"; it is "a widening commitment to take care of the persons, the products, and the ideas one has learned *to care for*" (1978, pp. 27–28).

The impetus to care has instinctual roots in the "impulse to 'cherish' and to 'caress' that which in its helplessness emits signals of despair" (Erikson, 1982, pp. 59–60). The infant's demeanor awakens in adults a strength that they need to have confirmed in the experience of care; conversely, maternal care enables the infant to trust rather than mistrust and to develop hope rather than a sense of abandonment (1987, p. 600).

The tasks of taking care of new generations must be given continuity by institutions such as extended households and divided labor (Erikson, 1987). "[A] man and a woman must [define] for themselves what and whom they have come to care for, what they care to do well, and how they plan to take care of what they have started and created" (1969, p. 395). Even if individuals choose not to have children, they have a relationship to "care for the creatures of this world" through participation in those institutions that safeguard and reinforce generative succession (1963, pp. 267–268). Some, like Gandhi, choose, as an expression of their care, to become "father and mother, brother and sister, son and daughter, to all creation …" (1969, 399). The task of taking care of the new generation also falls to organized human communities (1987); social and political leadership often entails giving direction to people's capacity to care (1969).

The framework for Erikson's ethic of care is one of dialectic dynamics, that is, it depends on a process of development and change through the conflict of two opposing forces; the moral task is to see to it that a new strength emerges. The negative aspect of adulthood (self-absorption) continues to interact dynamically with the positive aspects (generativity) throughout life (1963). Personal growth and the strength of care emerge from this conflict through an active adaptation that requires that one change the environment, including social mores and institutions, while making selective use of its opportunities (1978).

For Erikson, part of the ethics of care involves the struggle between the willingness to embrace persons or groups in one's generative concerns (a *sympathic* strength, which is the virtue of care) and the unwillingness to include specified persons or groups in one's generative concern (an *antipathic* inclination, which Erikson calls rejectivity). With rejectivity, "one does not care to care for" certain individuals or groups, or may even express hostility toward them (1982, p. 68). Because care must be selective, some rejectivity is unavoidable. "Ethics, law, and insight" must define the allowable extent of rejectivity in any given group. With the purpose of reducing rejectivity among humans, "religious and ideological belief systems must continue to advocate a more universal principle of care for specified wider units of communities" (1982, p. 69). Consequently, for Erikson, the ethics of care expresses itself in both "small but significant gestures" (1978, p. 15) and in global struggles against uncaring attitudes that contribute to the destruction of public and private morals.

Milton Mayeroff: A Personalist Vision

The 1971 book *On Caring* by American philosopher Milton Mayeroff (1925–1979) provides a detailed description and explanation of the experiences of caring and being cared for. Although he drew on several major themes from the history of the notion of care, he took the idea of care in new, personalist directions. Mayeroff's book is a philosophical essay that at the same time shares some of the characteristics of the care of souls tradition, inasmuch as Mayeroff's purpose was to show how care could help us understand and integrate our lives more effectively.

To care for another, according to Mayeroff, is to help the other grow, whether the other is a person, an idea, an ideal, a work of art, or a community; for example, the basic caring stance of a parent is to respect the child as striving to grow in his or her own right. Helping other persons to grow also entails encouraging and assisting them to care for something or someone other than themselves, as well as for themselves (1971).

The caring relationship is mutual: The parent feels needed by the child and helps him or her grow by responding to the child's need to grow; at the same time, the parent feels the child's growth as bound up with his or her own sense of well-being. Caring, Mayeroff says, is primarily a process, not a series of goal-oriented services. For example, if the psychotherapist regards treatment as a mere means to a future product (the cure), and the present process of therapeutic interaction is not taken seriously for its own sake, caring becomes impossible (1971).

According to Mayeroff, caring entails devotion, trust, patience, humility, honesty, knowing the other, respecting the primacy of the process, hope, and courage. Knowledge, for example, means being able to sense "from inside" what the other person or the self experiences and requires to grow. Devotion, which gives substance and a particular character to caring for a particular person, involves being "there" for the other courageously and with consistency. But caring does not entail "being with" the other constantly: That is a phase within the rhythm of caring, followed by a phase of relative detachment (1971).

Caring involves trusting the other to grow in his or her own time and way. There is a lack of trust when guarantees are required regarding the outcome of our caring, or when one cares "too much." One who "cares" too much is not showing excessive care for the other so much as deficient trust in the other's process of growing (Mayeroff, 1971).

In Mayeroff's vision, moral values are inherent in the process of caring and growth. When cared for, one grows by becoming more self-determining and by choosing one's own values and ideals grounded in one's own experience, instead of simply conforming to prevailing values. Mayeroff's moral approach to care is that of an ethic of response: He emphasizes the values and goods that are discovered in caring, and the fitting sort of human responsiveness to self and other that these engender. Care-related responsibilities and obligations—such as those that derive from devotion to one's children—arise more from internal sources related to character and relational commitments than from external rules (1971). When caring engages one's powers sufficiently, it has a way of ordering the other values and activities of life around itself, resulting in an integration of the self with the surrounding world.

The conviction that life has meaning corresponds with the feeling of being uniquely needed by something or someone and of being understood and cared for. Mayeroff concludes that the more deeply we understand the central role of caring in our own life, the more we realize it is central to the human condition (1971). Mayeroff's idea that care is central to the human condition reaches back through several philosophers to the Myth of Care, while his rich descriptions of the nature and effects of care set the stage for an ethic of care in the contemporary healthcare setting.

Parallel Concepts

SYMPATHY. The history of the ethics of sympathy provides useful insights for the developing notion and ethics of care. A number of philosophers writing between the end of the seventeenth century and the beginning of the twentieth—principally Joseph Butler (1692–1752), David Hume (1711–1776), Adam Smith (1723–1790), Arthur Schopenhauer (1788–1860), and Max Scheler (1874–1928)—developed an ethic of sympathy. Taken from the Greek word *sympatheia,* meaning "feeling with," sympathy referred to a "felt concern for other people's welfare" (Solomon, p. 552).

There are several reasons for considering some highlights of an ethic of sympathy in the context of this entry. First, there are some links between care and sympathy: Some of the authors who have developed the notion of care include sympathy, empathy, or compassion as elements of care, for example, Rollo May and Milton Mayeroff; yet sympathy differs from care, for care has a deeper role in human life, is broader than sympathy in its tasks, and entails a more committed role with other people and projects. Second, the ethics of sympathy offers sustained philosophical examination of issues that are of interest to the ethics of care, which has been subjected to relatively little systematic philosophical inquiry. In particular, an ethics of care has much to learn from an ethics of sympathy regarding its most distinctive formal feature: It is based on a fundamental human emotion that is viewed as the central feature of the moral life and the basis of an ethic—a fundamental characteristic that it shares with the ethics of sympathy.

Accordingly, there are questions significant for an ethic of care that could be examined in the context of the ethics of sympathy. For example, there is the question regarding justification for the use of a passion or emotion such as care as the starting point or central point in ethics. Joseph Butler, writing in the sympathy tradition, argued against the view of psychological egoism, which asserted that we cannot be motivated simply by a concern for others, for human psychology is such that we cannot help but act in our own interests when we act on emotion. Against this, Butler argued that passions and affections, which are "instances of our Maker's care and love," contribute to public as well as private good and naturally lead us to regulate our behavior. Benevolence for others and the self-love that prompts care of the self are distinct; they are not in conflict; and they are both governed by moral reflection or conscience. David Hume went much further: Passions, or moral emotions, are primary, for they alone move humans to action; reason must serve the passions by providing the means for achieving the ends that sentiment selects. Consequently, moral judgments, which are the motives moving us to action, must be based primarily on moral sentiments or feelings, not on reason (Hume, 1983; Raphael).

Another question is whether an altruistic virtue traditionally regarded as soft could have much effect on the ethics of the practice of medicine, which emphasizes principles and objectivity. A comparable issue arose particularly in the writings of John Gregory (1724–1773), a prominent Scottish physician-philosopher, who applied the ethics of "sympathy" and "humanity" (the paired terms were taken from David Hume) to the medical care of the sick. Gregory held that the chief moral quality "peculiarly required in the character of a physician" is humanity, namely "that sensibility of heart which makes us feel for the distresses of our fellow creatures, and which, of consequence, incites us in the most powerful manner to relieve them" (1817, p. 22). The moral quality paired with humanity is sympathy, which "produces an anxious attention to a thousand little circumstances that may tend to relieve the patient" and "naturally engages the affection and confidence of a patient, which, in many cases, is of the utmost consequence to his recovery" (1817, p. 22).

Gregory speaks of the development of a balanced skill of medical compassion in the clinician: Physicians who are truly compassionate, "by being daily conversant with scenes of distress, acquire in process of time that composure and firmness of mind so necessary in the practice of physic. They can feel whatever is amiable in pity, without suffering it to enervate or unman them" (1817, p. 23). In this way, Gregory closely tied the virtue of sympathy to the art of medicine and to medical benefit, while answering the objection that sympathy causes an emotional imbalance in the practitioner.

Not only does Gregory defend the role of the "soft" altruistic virtue in medicine; he pointedly identifies the core of the objection against them. Rejecting as "malignant and false" the view that compassion is associated with weakness, Gregory argues that rough manners are "frequently affected by men void of magnanimity and personal courage" in order to conceal their defects (1817, pp. 22–24). Men can gain from women both "humanity" and "sentiment," qualities that are at the very core of the moral life (1765).

ATTENTION. Attention (or heed or regard) has, for centuries, been one of the meanings of care; it remains an element of care today. To care for someone is to pay solicitous attention to him or her and to have a disposition of attentiveness. To take good (conscientious) care of a patient means to be attentive both to the needs of the patient and to the duties of proper care. The "attending physician" is one who has primary responsibility for the care of, and is ready for service to, the patient. Thus, the notion of attention is not only a concept parallel to care; it is an ingredient in care. The philosopher Gilbert Ryle says, "To care is to pay attention to something …" (p. 135).

The most significant and stimulating thinker on the topic of attention was Simone Weil (1909–1943), a French philosopher and mystic who makes attention the central image for ethics. Attention, she explains, is a negative effort consisting of suspending one's thought, leaving it detached, empty, and ready to receive the being one is looking at, "just as he is, in all his truth" (1977, p. 51).

Weil says that solving a philosophical problem (including one dealing with morality) requires a kind of caring contemplation: "clearly conceiving the insoluble problems in all their insolubility, … simply contemplating them, fixedly and tirelessly, … patiently waiting" (1970, p. 335). Being attentive is being open to illumination (Weil, 1978, p. 92); we should look at these problems "until the light suddenly dawns" (1952, p. 174). What we sometimes fail to see is what Weil perceives: that solving moral problems sometimes entails facing mystery. Thus, to discover what is causing a person's suffering and how to respond to it, the caring nurse may need to employ Weil's contemplative attention to all details; and even that exercise of attention is itself a caring act.

Attention offers a powerful approach to ethics. For example, Simone Weil thinks of equality and justice not as abstract concepts or principles that serve the well-ordered society; she conceives of them as virtues that can only be illuminated and developed through attentive knowledge. Thus, for Weil, equality is a certain kind of attention, "a way of looking at ourselves and others" (Teuber, p. 223). Respect for another person is not respect insofar as the other has a rational nature or is a person: Weil states bluntly that she could put out a man's eyes without touching his person or personality. Rather, we show respect for individuals in their concrete specificity: "There is something sacred in every man, but it is not his person [nor] the human personality. It is this man.… The whole of him. The arms, the eyes, the thoughts, everything …" (1981, p. 13). Respect for others is based more in compassion than in awe for personhood, and compassion does not depend on familiarity: We can and should foster compassion for individuals who are very different from ourselves (Teuber, p. 225).

Attention is also a key part of the practice of compassion. Weil explained that those who are suffering "have no need for anything in this world but people capable of giving them their attention." She contended that the capacity to give one's attention to a sufferer is a very rare and difficult thing; "it is almost a miracle; it is a miracle …" (Weil, 1977, p. 51).

Attention and the equality it discovers do not suffice for all problems in ethics: They do not in themselves define any principles for adjudicating conflicts; but they can and do convey certain attitudes and forms of conduct without which we would lose sight of the meaning and substance of our obligations and rights (Teuber, p. 228). In addition, Weil's sort of attention can show us duties we did not see before (Nelson, p. 13) and can instruct us in the skills required for caring.

Conclusion

In a variety of settings—mythological, religious, philosophical, psychological, theological, moral, and practical—the notion of care has developed throughout history, influencing moral orientations and behaviors. The tasks for the future will be to more fully understand the richness and complexity of the history of the idea of care, do justice to the texts that have imaginatively portrayed it and the thinkers who have made this idea central to their work, and enter into dialogue with them.

This history reveals, not a unified idea of care, but a family of notions of care. Yet it is a fairly closely related family, for the ideas of care are united by a few basic sentiments, some formative narratives whose influence stretches over time, and several recurring themes. Furthermore, in the history of the English word *care,* this single word serves a range of meanings but with a subtle coherence.

The meanings of the word *care* fall into four clusters. The basic meaning is associated with the origins of the word, which are found in the Middle High German word *kar* and more remotely in the Common Teutonic word *caru,* meaning "trouble" or "grief" (Simpson and Weiner, pp. 893–894). Correspondingly, the primary meaning of the word *care* is anxiety, anguish, or mental suffering. A second meaning of *care* is a basic concern for people, ideas, institutions, and the like—the idea that something matters to the one who is concerned. Two other meanings of care, sometimes in conflict, are found at a more practical level. One is a solicitous, responsible attention to tasks—taking care of the needs of people and one's own responsibilities; and the other is caring about, having a regard for, or showing attentive care for a person, for his or her growth, and so forth. In a sense, all the meanings of *care* share to some extent a basic element: One can scarcely be said to care about someone or something if one is not at least prepared to worry about him, her, or it. The truly caring health professional is one who worries about—is concerned about—his or her patients, especially the patients who cannot take care of themselves.

Several distinctive features stand out in this history of care. The metaphysical and religious dimensions of care appear forcefully and repeatedly in history, emphasizing that care is essential to understanding humans and the human condition. The history of care shows that, at one level, care is a precondition for the whole moral life. It also manifests various frameworks for an ethic of care, including evolutionary ethics, virtue ethics, an ethic of growth, an ethic of response, and duty ethics, yet one does not find a formal and systematic ethics of care in the sources examined.

Repeatedly in this history one encounters a dialectical element in which pairs of ideas of care struggle against each other: care as worry or anxiety versus care as solicitude; the care that enables growth versus the effort to care that robs a person of self-care; or taking technical care of the other versus caring about the other. There is much to learn from history about the dark side of care and how humans might deal with it.

A key historical puzzle is why the notion of care has not become better known and has not exerted more influence in ethics, in view of its highly significant, if somewhat limited, history. The answer lies, in part, in the fact that care has always been a minority tradition of thought and practice. As this survey exemplifies, care is a deeply engaging emotion/idea that has confronted and challenged rationalist, abstract, and impersonal systems of thought, with far-reaching social, political, ethical, and religious implications. In this sense, care has had a countercultural role.

More recently, care may be acquiring a "mainstream" importance, especially in the area of the ethics of healthcare. The following two entries will show how some elements in the history of the idea of care have become ingredients in an emerging ethic of care in the context of healthcare, while other historical elements have been overlooked.

All ethics assumes a vision of the human condition. The ethics of care rests on a vision of the capacity to care or be concerned about things, persons, a whole life-course, a society, one's self. The history certainly is not compatible with reducing care to caregiving. The Myth of Care suggestively offers a care-based genealogy of morals that is deeply ingrained in human psychology, anthropology, religion, and altruistic service. The philosophical and psychological developments in the idea of care have built on this basic vision of being well cared for. That the history of the idea of care also suggests many practical ideas—for example, the call and the limits of taking care of others; dealing with the negative side of care; and the intergenerational function of care—makes it all the more useful for a contemporary ethic of care.

WARREN THOMAS REICH (1995)

SEE ALSO: *Alternative Therapies; Beneficence; Chronic Illness and Chronic Care; Compassionate Love; Feminism; Human Dignity; Long-Term Care; Nursing Ethics; Obligation and Supererogation; Paternalism; Professional-Patient Relationship; Women, Historical and Cross-Cultural Perspectives;* and other *Care* subentries

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II. HISTORICAL DIMENSIONS OF AN ETHIC OF CARE IN HEALTHCARE

In the context of healthcare, the idea of care has two principal meanings: (1) taking care of the sick person, which emphasizes the delivery of technical care; and (2) caring for or caring about the sick person, which suggests a virtue of devotion or concern for the other as a person. At times these two aspects of care have been united; at other times they are in conflict.

Taking Care of: Competent, Technical Care

When speaking of the medical aspects of "taking care of" the patient, one often uses the language of taking good care, or receiving appropriate care. This practical vision of care can be viewed historically from the perspectives of medical competence and technical excellence. The Greek demigod Asklepios, because of his reputation for competence, became the "patron of human healers" (Jonsen). The virtue that motivated the physician of classical Greece was *philotechnia,* or love of the art (May, 1983; Laín Entralgo). In the Greek tradition, "the love of technical skill included not only an appreciation of the good which the application of that skill might achieve but also a kind of natural piety that recognized the limits of the art" (May, 1983, pp. 92–93). The ethic of competent care can also be called a Hippocratic ethic, after Hippocrates (c. 460–378 B.C.E.), the "father of medicine." One phrase in the Hippocratic oath—"I will act for the benefit of my patient according to my ability and judgment"—implies the imperative of the competent practice of the art of medicine (Jonsen). Under these historical influences, competence, "in the sense of a disciplined understanding of the science and skilled manipulation of the art [of medicine]," was regarded as the first virtue of medical care at least through the seventeenth century (Jonsen, p. 22).

In modern times, competence has become the essential and comprehensive virtue of medicine; medical practice and education came to emphasize ever-more-complete scientific knowledge and ever-more-competent clinical performance. This demanding standard of competence in turn fueled a drive toward biomedical excellence and deepened the sense of meaning and pleasure gained from practicing the art of medicine (May, 1983; Jonsen).

At the turn of the twentieth century, as medical competence focused more and more intently on the principles of pathophysiology and factual diagnostics, medical "care" came to be defined by objective data. Clinical and laboratory efforts to comprehend, apply, and evaluate medical data led physicians increasingly to divorce the disease from the patient, thus marginalizing personal care. The desire for liberation from the sometimes oppressive consequences of emotional involvement in "caring for" the person who is in critical condition may have contributed to this trend. As increased technical expertise raised expectations of what "taking care" should mean, legal and ethical requirements of "due care" spelled out the criteria for medical care, prompting clinicians to focus even more on the technical ideal of competence in "taking care of the sick" (Annas).

By the 1920s, competent care was becoming the moral meaning of "taking care of" the patient. Richard C. Cabot (1868–1939), a renowned professor at Harvard Medical School, articulated and championed this new ethic of competence. The humanistic virtue of "caring for" the patient was quickly pushed to the periphery of medicine, for that sort of care was viewed as bearing no apparent relation to the highly esteemed "hard data." This narrowing of the notion of care placed medical ethics in crisis (Jonsen).

Caring for the Sick Person

While "taking care of the patient" in competence had been pushing "caring for" the patient to the periphery of medical concerns, "caring for" the patient received a major impetus at Harvard during the 1920s. This section will consider what altruistic terms and virtues "caring for" replaced, why they had lost their meaning, an account of the onset of the term *caring for,* and its meaning in healthcare prior to 1982.

The moral term *caring for* was turned to at a time when the altruistic virtues that had shaped the care of the sick for centuries had lost much of their luster, particularly terms like hospitality, philanthropy, charity, love, and sympathy.

For example, hospitality, which meant the friendly and cordial taking in of strangers or travelers, had enormous influence as an altruistic virtue for healthcare; it was a model in rabbinic Judaism, early Christianity, and Islam (Exod. 23:9). Christianity had transformed hospitality from a private into a public virtue of mercy and beneficence that was often directed to the sick stranger (Bonet-Maury). Hospitality prompted establishment of travelers' inns, which evolved into hospices where healthcare was sometimes provided, and eventually to hospitals, especially in the Byzantine East but also eventually in the Latin West (Miller). But by the 1920s, this religious term had lost its force; even Christians no longer spoke of hospitality as a major public virtue motivating healthcare.

Philanthropy had, for centuries, been a dominant altruistic motive for "caring for" the sick in most religious traditions, but it has virtually disappeared from the moral sphere of healthcare. The ideal of philanthropy (from the Greek *philanthropos,* meaning humane or benevolent) encouraged a love of humankind that expressed itself in concrete deeds of service to others. Philanthropy, associated with the Christian ideal of charity, made it possible for the sick person to assume a preferential position in society (Sigerist) and motivated the establishment of hospitals starting in the fourth century in the East, until modern times in the West. The ideal of philanthropy also appeared strongly in the first code of medical ethics, adopted by the American

Medical Association in 1847. But by the 1920s, professional philanthropy, from which modern professionals had derived much of their authority and prestige, had lost much of its respect, and the significance of the word *philanthropy* had been reduced to its meaning of private (and to some extent, public) support of the arts, education, and research (May, 1983, 1986).

Sympathy and compassion have exerted a strong public influence on caring for the sick in times past, in particular by motivating the sensitivities of individual medical practitioners. Codes and oaths have exhorted health practitioners throughout the ages to care for the sick out of motives of compassion and sympathy. John Gregory (1724–1773) spoke of the sensibility of heart that makes us feel for the sick and arouses in us the desire to relieve their distresses. Use of the word *sympathy* to motivate personalized medical care appeared commonly right up to the 1920s and beyond. But the word *sympathy* lost its effectiveness as it often came to be regarded as the condescending manifestation of pity; the word *compassion* was looked on with some disfavor as it came to suggest too much identification with the suffering person.

In addition, there is an overarching reason why the previous caring virtues were discounted, leaving room for the new, secular term of care. In criticizing ecclesiastical institutions in the eighteenth century, Enlightenment thinkers denounced charity for the sick and philanthropic hospitals because these activities were tainted by the essentially self-centered gifts and legacies of pious people who sought to atone for their sins by acts of charity in support of the hospitals. Eighteenth-century rationalists emphasized that the poorly organized philanthropic hospitals of Christian Europe did little to help the sick get well; and some Enlightenment thinkers blamed the very concept of Christian charity for these abuses. Furthermore, Christian charity was regarded as too closely linked to dead traditions and blind superstitions to have a close relationship with science (Locke). The attempt by some philosophers in the eighteenth, nineteenth, and twentieth centuries to base an altruistic care of the sick on a secular notion of sympathy was, in part, a result of these developments.

By the 1920s, the secular term *care* had begun to replace the earlier altruistic terminology. By this time, the history of the idea of care had progressed to the point that the term was coming to be known for its moral implications. In addition, *care* had special appeal as a virtue for healthcare because the same word had—for centuries and in a variety of languages—been the descriptive term for "taking care of" sick people. It should be no surprise, then, that for a number of decades prior to 1982—when the idea of care began capturing widespread contemporary attention—there appeared a small body of literature in the clinical ethics of physicians and nurses as well as in religious medical ethics that focused attention on the moral meaning and practice of care, as well as on an ethic of care.

"Caring for" in Clinical Medical Ethics, 1920–1982

In championing the fast-developing technical art of medicine, Richard C. Cabot acknowledged and seemed to acquiesce in the fact that doctors and nurses were not caring for the whole patient: Their attention was "too strongly concentrated" on the difficult tasks of diagnosis and treatment, and "there is not enough attention left to go round" (Cabot, p. 16). He was certainly in favor of manifesting courtesy and patience with sick people; but under some conditions, he said, it is not advisable for the physician to care for anything but the patient's body; and when care for the whole person is desirable, others—medical students, social workers, and even ministerial students—can suitably offer that kind of care (Cabot). To carry out his purpose of designating surrogates who would "care for" the patient, Cabot was instrumental in establishing the professions of medical social work and clinical pastoral care.

The following year, Francis Peabody, a physician-professor colleague of Cabot at Harvard, offered the opposite point of view. "Caring for" the patient is essential to the practice of medicine, he argued; physicians must engage in this sort of care in order to achieve the goals inherent in medicine. His 1927 essay "The Care of the Patient" is one of the foundation stones of an ethic of care in twentieth-century medicine in the United States (Peabody).

Peabody acknowledged that the "enormous mass of scientific material" to which a young doctor must be exposed, the depersonalized aspects of modern hospital practice, and physicians' bias toward organic disease could jeopardize the personal aspects of the art of medicine. To remedy these problems, he urged the physician to form and be attentive to a personal relationship with the patient and with the patient's "environmental background." The treatment of a disease, which may be impersonal, "takes its proper place in the larger problem of the care of the patient" (p. 396), which "must be completely personal" (p. 389). His oft-quoted principle was: "One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient" (p. 401).

The physician must be attentive to particular circumstances of the patient, "not from the abstract point of view of the treatment of the disease, but from the concrete point of view of the care of the individual" (p. 398). Peabody was clearly attempting to exonerate the usefulness—indeed, the necessity—of care in the practice of good clinical medicine when he argued that neglect of careful attention to the true situation of the whole patient, including functional disorder, jeopardizes diagnosis, treatment, and effectiveness of care. Furthermore, the mere caring effort in the relationship with the patient, aside from drugs or other treatments, can help patients get well. This sort of care requires attentiveness and alertness to what kind of a person the patient is; sympathy for the patient's total situation; friendliness that elicits trust; and a consideration expressed in "little incidental" actions that assure the patient's comfort—which may require that the physician learn much from the nurse regarding practical care and comfort of the patient.

Following Peabody's clarion call for care in 1927, several physicians, writing in the 1960s and 1970s, advocated a caring perspective in professional attitudes, practices, and moral analysis in medicine. The starting point that convinced these writers of the need for "caring for" was the depersonalization of medical care in hospitals. Clinical care oriented to the disease in the body leads caretakers to allow technical considerations to dominate, avoid death at any cost, and ignore patients' preferences; this produces indignities for patients and suffering for caregivers (Benfield).

The concept of caring is defined in the literature of the 1960s and 1970s as implying a broader concern for the whole patient, or for the quality of the patient's life, rather than just for the patient's disease (Menninger; Benfield). Caring involves sympathy with the patient, which entails entering into or sharing the feelings of the patient. To prevent loss of objectivity and perspective, "compassionate detachment" (Blumgart, p. 451) is recommended, which is "to sense the patient's experience empathically without becoming so involved sympathetically that the physician's rational and effective clinical judgment is impaired by emotional involvement" (Menninger, p. 837).

Caring for the patient embraces both the science and art of medicine; both are oriented to the patient, and both should meet in the individual physician (Blumgart). A caring solicitude for the individual patient is integral and essential in the practice of clinical medicine (Tisdale); failure to practice caring medicine leads to incomplete or inaccurate diagnosis and ineffective treatment (Blumgart). On the other hand, patients manifest care-seeking behavior (Tisdale). Receiving the sought-for care can be crucial for the patient's "adaptation to various maladjustments, including illness" (Menninger, p. 836). The role of the physician and other healthcare providers in our society is one of a surrogate caregiver, who has the power to give attention to the ill and excuse them from the performance of everyday duties (Menninger).

There are several obstacles to caring in medicine. The demands of the scientific and technological aspects of medicine, combined with physicians' fascination with disease, achieve great progress for humankind but tend to block out compassionate attention to suffering and the particular needs of the ill individual who has the disease. In addition, patients and families are reluctant to communicate their feelings with health professionals, who are too busy monitoring the patient's physical condition to listen. Other factors that obstruct person-oriented caring are (1) lack of teamwork among healthcare providers, coupled with overemphasis on the physician's hierarchical authority; (2) caregivers' feelings of inadequacy due to lack of training in caring for critically ill or dying patients and their families; and (3) time pressures on health professionals (Blumgart; Benfield).

Acts of caring, some of which counteract the obstacles to caring, include: listening to patients with personal attentiveness, particularly as a history-taking technique that enables patients to relate their experiences in terms of their own values and concerns (Tisdale; Blumgart); being attentive to both the physical and the emotional components of illness (even though medical education and practice tend to focus on the physical—in fact, all medicine is psychosomatic, since the emotional and bodily factors always interact in every disease) (Blumgart; Menninger); and offering maximum understanding, freedom, and support to the individual patient (Tisdale).

Caring is also expressed through acting as companion to a bereaved family; solicitous communication regarding the nature of the illness and its expected course; sharing the patient's and family's responsibility and agony of deciding whether to continue care; relieving the patient of suffering from pointless dehumanizing treatment; and caring for caretakers who suffer the stress of the combined roles of technical caregiver and concerned caregiver (Benfield).

William Tisdale, writing in 1979, contended that modern medical ethics, with its concern for "the neon problems" of high controversy, is ill-adapted to account for an ethic of care. Because clinical caring pertains to the usual and the commonplace in medicine, it is more difficult to isolate and analyze. William Tisdale appealed for an inquiry into the unresolved and even the unrecognized problems inherent in basic clinical care and the problems inherent in care that are more demanding from an ethical perspective than the usual moral quandaries in medicine. In formal ethical terms, Tisdale saw clinical caring as characterized by the ideals of love and charity and as a form of duty beneficence, a duty to benefit others apart from special relationships and responsibilities. Making certain that expected benefits of a particular procedure outweigh the definite risks is a characteristic of caring for one's patients.

In the highly influential book published in 1970, *Patient as Person,* Paul Ramsey linked care with "covenant fidelity," which he saw as the appropriate norm for the relationship between physician and patient. Covenant fidelity always requires care, which is directed to the person of the patient. But at the end of life, when attempts to cure are no longer appropriate, one must always care even if one only cares—through keeping company and offering comfort—while permissibly withdrawing medical care.

Caring for the sick, the wounded, and the troubled has been characterized through the centuries by altruistic motives and virtues. By the 1920s, an interest had arisen in the virtue of care as the basic moral orientation to healthcare, based in feelings for the other. Practitioners felt that care could provide the grounding for the moral practice of healthcare and for mitigating some of the excesses of medical technique. Still, very little by way of a formal ethic had arisen.

Caring in Nursing Theory, Philosophy, and Ethics

It required the intellectual and moral energy of feminist perspectives on care in the 1980s to establish a noteworthy movement promoting an ethic of care that reached deep into the field of bioethics.

Nursing theorists, educators, and philosophers explored and applied a more extensive theory and ethic of care prior to 1982 than any other single group had. Their contributions differed considerably from those of physician-writers: The nursing theorists paid much more attention to the meaning and theories of nursing, examined the structures and functions of care, turned occasionally to philosophers who had explained the meaning of care (such as Martin Heidegger and Milton Mayeroff), developed the implications of care for nursing practices and skills, considered the status of caregivers, showed an interest in the historical links between nursing and maternal care, and proposed educational improvements to foster professional care.

The strongest impetus for an examination of the role of caring in nursing came from Madeleine Leininger, who has organized national conferences on caring and published on the topic (1981). Leininger was one of the pioneers who fostered the idea that caring is the essence of nursing and the unique focus of the profession. Leah Curtin went a step further when she claimed that the distinctiveness of nursing cannot be located in functions, but in "the moral art of nursing," in its primary moral conviction, by virtue of which nurses "are committed to care for, as well as to the care of, other human beings" (p. 26).

Nursing theorists offer a variety of definitions of care: for example, the explanation that caring in nursing is a process in which one shows "compassionate concern for the individual" (Gaut, in Leininger, 1981, p. 18). Leininger suggests this definition of professional nursing care: "those cognitively learned humanistic and scientific modes of helping or enabling an individual, family, or community to receive personalized services through specific culturally defined or ascribed modes of caring processes, techniques, and patterns to improve or maintain a favorably healthy condition for life or death" (1981, p. 9). This definition includes concepts of compassion, concern, nurturance, stress alleviation, comfort, and protection.

The precise historical origins of a concern for caring in nursing are unclear, but a number of authors trace them to the writings of Florence Nightingale. However, nurse theorists have relied not so much on a history of care in nursing as on the writings of social scientists and existentialists such as Buber, Erikson, and Rogers (Gaut, in Leininger, 1981).

Why did nursing theorists turn so strongly to the idea of care in the 1970s? Marilyn Ray explains that as nursing became increasingly technological, bureaucratic, managerial, and supervisory, nurses began experiencing a struggle relative to their central focus as a "direct caring profession" (Ray, in Leininger, 1981, p. 28). Barbara Carper (1979) answers the question by mentioning two factors that have had the effect of eroding care in health generally, not just in the experience of nurses: depersonalization of healthcare due to the fragmentation of specialized treatment, the subdivision of tasks, and highly institutionalized bureaucracy; and technological progress and technical expertise, which she saw as having the potential of overshadowing individuals, "reducing them to objects or abstractions" (p. 13). Within such a system, even when competent, scientifically based care is delivered, it "is often perceived by the client as lacking the 'personally experienced feeling of being cared for'" (p. 13, quoting Menninger, p. 837). This depersonalization of the individual entails the devaluing and loss of identity of the individual. She sees a compelling metaphor for the relationship of technology to care in the novel in which Dr. Frankenstein created a monster. Frankenstein's tragedy was not due to his scientific triumph over nature, but "his *failure to care* for what he had created. He was unable to recognize or experience the humanness of another's self" (Carper, p. 13).

Finally, even prior to the emergence of an ethic of care in other disciplines, nurses were already applying the idea of care both to nursing practice and to nursing ethics. For example, Carper argued that caring is the most essential ingredient in the curative process, because caring acts and decisions "make the crucial difference in effective curing consequences" (Carper, p. 14, quoting Leininger, 1977, p. 2). Anne J. Davis stimulated reflection on the relationship between caring and ethical principles in the context of taking care of the dying. She contrasted the compassionate meaning of care (to undergo with, to share solidarity with) with the technical terms *nursing care* or *medical care.* She argued that situations of serious illness and dying call for putting aside the instrumental meaning of caring and instead manifesting "the most demanding and deeply human aspect of caring: the expressive art of being fully present to another person" (p. 1). A caring attitude would incline the nurse not to turn away from the stranger's world of suffering, but to appreciate the other person's independent existence and enter into and share his or her pain as much as possible. Caring for the sufferer is an ethical obligation inherent in the health professional's role. But caring transcends role obligations: It acknowledges the vulnerable humanness of the other and reinforces the caring of the one who cares. Ethical principles are not at variance with care: They provide specific judgments in the context of caring for another person. A caring disposition inclines caregivers to respect the patient as an autonomous agent and to recognize the patient's considered value judgments, even if they go contrary to what the clinician expects.

The foregoing presents a few indications of the pioneering work in nursing care theory and ethics in the 1970s. As the following entry indicates, the ethics of nursing care expanded considerably after the notion of care came to be more widely acknowledged through the writings of women social scientists.

WARREN THOMAS REICH (1995)
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SEE ALSO: *Alternative Therapies; Beneficence; Chronic Illness and Chronic Care; Compassionate Love; Emotions; Feminism; Healing; Human Dignity; Long-Term Care; Medicine, Art of; Nursing Ethics; Obligation and Supererogation; Paternalism; Professional-Patient Relationship; Women, Historical and Cross-Cultural Perspectives;* and other *Care* subentries

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III. CONTEMPORARY ETHICS OF CARE

A major contemporary impetus to scholarly discussions of caring occurred with the 1982 publication of Carol Gilligan’s *In a Different Voice: Psychological Theory and Women’s Development.* Nursing theorists—and, to a lesser extent, physicians—were exploring moral dimensions of caring prior to the publication of Gilligan’s work; but her book led, for the first time in the history of the idea of care, to widespread efforts to develop a systematic philosophical ethic of care beyond the world of healthcare practitioners.

Contemporary Elements of an Ethic of Care

In a Different Voice begins by contrasting the primary moral orientation of boys and men with the primary orientation of girls and women. Gilligan proposes that females and males tend to employ different reasoning strategies and apply different moral themes and concepts when formulating and resolving moral problems. According to Gilligan’s analysis, females are more likely than males to perceive moral dilemmas primarily in terms of personal attachment versus detachment. From this perspective, which she dubs the *care perspective*, central concerns are to avoid deserting, hurting, alienating, isolating, or abandoning persons and to act in a manner that strengthens and protects attachments between persons. In this analysis, the moral universe of girls and women tends to be primarily “a world of relationships and psychological truths where an awareness of the connection between people gives rise to a recognition of responsibility for one another, a perception of the need for response” (p. 30). For example, Amy, an eleven-year-old girl whom Gilligan interviews in her book, describes herself in terms of her connection with other people: “I think that the world has a lot of problems, and I think that everybody should try to help somebody else in some way …” (Gilligan, p. 34).

By contrast, Gilligan argues that the primary moral orientation of men and boys tends to focus on moral concerns related to inequality versus equality of individuals. Rather than emphasizing the importance of sustaining personal relationships, this approach emphasizes abstract ideals of fairness and rights, and requires abiding by impartial principles of justice, autonomy, reciprocity, and respect for persons. Viewed from this perspective, which Gilligan refers to as the *justice perspective*, moral dilemmas are defined by hierarchical values and impersonal conflicts of claims. The moral agent, like the judge, is called upon to “abstract the moral debate from the interpersonal situation, finding in the logic of fairness an objective way to decide who will win the dispute” (p. 32). To illustrate justice reasoning, Gilligan describes the moral reasoning of Jake, an eleven-year-old boy interviewed for her book. Asked how he would resolve a conflict between responsibility to himself and other people Jake answers, “You go about one-fourth to the others and three-fourths to yourself,” and adds that “the most important thing in your decision should be yourself, don’t let yourself be guided totally by other people …” (p. 35–36). Gilligan concludes that Jake understands this moral dilemma as an abstract mathematical equation and perceives his responsibility for others as potentially interfering with his personal autonomy.

Gilligan, a developmental psychologist, argues that an ethic of care has been generally ignored in the past because girls and women have been excluded as subjects in the study of moral development. For example, accounts of moral maturation described by Lawrence Kohlberg (1981, 1984) and Jean Piaget were based entirely on studies and observations of boys and men. These male-based theories of moral psychology, when applied to girls and women, were interpreted as showing girls and women to be deficient in moral development. Gilligan identifies an ethic of care as a distinctive form of moral reasoning.

Implications for Ethics of Healthcare

The implications of Gilligan’s analysis for contemporary bioethics are the subject of ongoing discussion. First, an ethic of care may lead to positive changes in bioethical education, including placing greater emphasis on healthcare providers’ communication skills and emotional sensitivity, and on the effects that ethical issues have on relationships (Carse). To the extent that bioethicists with formal training in ethics are inclined to emphasize justice over care, it may be desirable to broaden their training to include an ethic of care (Self et al.).

In addition to producing changes in ethics education, a care orientation within bioethics arguably requires placing greater emphasis on beneficence as the healthcare provider's primary responsibility to the patient (Sharpe). Finally, an ethics emphasizing caring for others may produce substantive changes in the way we resolve moral problems. It may encourage resolutions of moral problems that give greater authority to family members in healthcare decision making (Hardwig, 1990, 1991; Jecker, 1990), or it may lead to paying greater attention to how various relationships are affected by moral decisions (Jecker, 1991).

One area within bioethics where an ethic of care has been studied in some detail is abortion. Gilligan found that women who face abortion decisions tend to frame moral issues in terms of a responsibility to care for and avoid hurting others. These women often base decisions about having an abortion on "a growing comprehension of the dynamics of social interaction … and a central insight, that self and others are interdependent" (p. 74). In other words, rather than conceptualizing abortion in terms of abstract values, such as *life,* or in terms of competing claims or rights, these women tend to see abortion as a problem of how best to care for and avoid harming the particular people and relationships affected by their choices. Considered in this light, the resolution of abortion requires taking stock of how any decision might affect not only the pregnant woman and fetus, but also the relationship between the pregnant woman and biological father, and relationships and persons within the wider family circle (Jecker, 1999). Arguably, an ethic of care illuminates the moral issues abortion raises better than an ethic of justice, because only an ethic of care portrays individuals as uniquely constituted by their connections to others (Gatens-Robinson).

In addition to these proposed changes, introducing a care orientation within bioethics may shed a negative light on more traditional forms of bioethical analysis (Carse). For example, Virginia Sharpe claims that a justice orientation has dominated bioethics in the past, and this has encouraged ethicists to treat provider–patient relationships as free exchanges between equals. She argues that this picture of the provider–patient relationship is seriously distorted. Rather than being equals in relationships with healthcare providers, patients typically experience diminished power and authority as a result of being physically and emotionally vulnerable and in need of the provider's help (Sharpe). Others charge that a justice orientation has traditionally prevailed within bioethics, resulting in too much focus on competition for power, status, and authority and too little focus on the human relationships at stake (Warren). For example, the autonomy–paternalism debate within bioethics concentrates on who has the authority to make treatment decisions. Similarly, when bioethicists emphasize impersonal ethical principles, such as autonomy, nonmaleficence, beneficence, and justice, the particular persons and relationships involved in ethical dilemmas can become incidental, rather than essential, to the crafting of moral responses.

Feminist versus Feminine Ethics

Gilligan's ongoing effort (Gilligan et al., 1988; Gilligan et al., 1989; Brown and Gilligan) to characterize the moral reasoning of girls and women in terms of care has occurred in tandem with important developments in feminist ethics. It is useful, however, to distinguish between the care ethic that Gilligan describes, which has been called a *feminine ethic,* and the development of *feminist ethics.* According to Susan Sherwin, the primary concern of feminine ethics is to describe the moral experiences and intuitions of women, pointing out how traditional approaches have neglected to include women's perspectives.

In addition to Carol Gilligan, both Nel Noddings and Sara Ruddick have made important contributions to feminine ethics. Whereas Gilligan emphasizes the unique form of moral reasoning that caring engenders, Noddings focuses on caring as a practical activity, stressing the interaction that occurs between persons giving and receiving care. From this perspective, she identifies two distinctive features of caring: *engrossment* and *motivational shift.* Engrossment refers to a receptive state in which the person caring is "receiving what is there as nearly as possible without assessment or evaluation"; motivational shift occurs when "my motive energy flows towards the other and perhaps … towards his ends" (Noddings, 1984, p. 33, 34). Critics of Noddings's approach raise the concern that her interpretation of caring may lead to exploitation (Houston) or complicity in the pursuit of evil ends (Card, 1990).

Unlike Gilligan and Noddings, Ruddick emphasizes *maternal thinking,* which she says develops out of the activity of assuming regular and substantial responsibility for small children. Although Ruddick acknowledges that the work of mothering falls under the more general category of *caring labor,* she argues that it cannot simply be combined with other forms of caring because each form of caring involves distinctive kinds of thinking arising from different activities (Ruddick). Ruddick delineates maternal thinking as a response to the small child's demands for preservation, growth, and acceptability. These demands elicit in the mothering person the responses of *preservative love, fostering growth, conscientiousness,* and *educative control,* which Ruddick identifies as the hallmarks of maternal thinking.

In contrast to feminine ethics, the primary concern of feminist ethics is to reject and end oppression against women. Susan Sherwin defines *feminist ethics* as "the name given to the various theories that help reveal the multiple, gender-specific patterns of harm that constitute women's oppression," together with the "diverse political movement to eliminate all such forms of oppression" (p. 13). By *oppression,* Sherwin means "a pattern of hardship that is based on dominance of one group by members of another. The dominance involved … is rooted in features that distinguish one group from another" and requires "exaggerating these features to ensure the dominant group's supremacy" (p. 24). Feminism aims, in this interpretation, to show that the suffering of individual women is related because it springs from common sources of injustice. According to Rosemarie Tong, feminist ethics is typically far more concerned than feminine ethics with making political changes and eliminating oppressive imbalances of power (1993).

In many respects, however, feminine and feminist ethics are interrelated. The careful study of women's lives and moral reasoning that feminine ethics undertakes can contribute substantially to dismantling habits of thought and practice that enable women's oppression to continue. Both feminine and feminist ethics share the goal of adding women's voices and perspectives to various fields of scholarly inquiry. Finally, as Ruddick notes, feminist ethics can lend important support to the ideals that feminine ethics upholds. For example, feminist ethics can help to ensure "women's economic and psychological ability to engage in mothering without undue sacrifice of physical health and nonmaternal projects" (p. 236).

Objections to an Ethic of Care

Since the publication of *In a Different Voice,* the proposal to develop a feminine ethic of care has met with a variety of concerns and objections. One set of concerns is that a feminine ethic of care may unwittingly undermine feminism. These concerns stem, in part, from a belief that the qualities in girls and women that feminine ethics esteems have developed within the context of a sexist culture. Thus, some suspect that women's competency at caring for and serving others is an outgrowth of their subordinate status within modern societies (Sherwin; Moody-Adams), and worry that emphasizing caring as a virtuous feminine quality may simply serve to keep women on the down side of power relationships (Holmes). Susan Moller Okin, for example, cautions that women are often socialized from a very early age into strict gender roles, involving caring for and serving others. This socialization radically limits their future prospects by diminishing women's capacity to choose alternative life plans. We should therefore reject traditional socialization, because it seriously violates the equality of persons basic to liberalism. Others urge women to aspire to assertiveness, rather than caring, in order to challenge conventional images of women as concerned with serving and pleasing others (Card, 1991). Feminist critics also warn that caring cannot function as an ethic that is complete unto itself. Observing that caring can "be exploited in the service of immoral ends" (Card, 1990, p. 106), Card insists on the need to balance caring with justice and other values. Exclusive attention to caring can also lead to overlooking "the lack of care of women for women" and may preclude "the possibility of our looking at anything but love and friendship in women's emotional responses to one another" (Spellman, p. 216). Finally, excessive focus on caring at the expense of other values can blind us to the critical assessment of the object of caring. As Warren Thomas Reich noted in 2001, care by itself can be easily manipulated, and does not offer tools for analyzing the moral importance of what we care about.

In response, defenders of feminine ethics distinguish between *distorted* and *undistorted* forms of caring (Tong, 1998). Distortions of caring include the exploitation, abuse, or neglect of careers. As Tong notes, just because caring can become distorted does not suffice to show that an ethic of care is inherently distorted. Nor does it establish that "every woman's caring actions should be contemptuously dismissed as yet another instance of women's *pathological masochism* or *passivity*"; instead care should be preserved and celebrated in its undistorted form: "rescued from the patriarchal structures that would misuse or abuse it" (Tong, 1998, p. 171).

A second family of concerns about a feminine ethic of care relates to the belief that caring for others can lead to neglect of self. The phenomenon of *burnout,* for example, refers to the situation of parents, nurses, family caregivers, or other individuals who become utterly exhausted by the physical and emotional demands associated with giving care. Especially when care is conceived to be an ethic that is sufficient unto itself, the tendency may be to continue caring at any cost. Attention to other values, such as respect for the rights of the one caring, may be necessary in order to preserve the integrity of the caregiver: Arguing along these lines, Nancy Jecker notes that "if women are seen as having the same possibility men have to create a plan of life that places central importance [in activities other than caregiving] …, then a duty … [to care] can potentially stand in the way of what a woman wants to do" (2002, p. 128). The idea here is that individuals presumably prefer to protect, as much as possible, their freedom to choose whether or not to devote themselves to caring (2002). Others suggest that in order to care for others—which is an inherently limited ability—one must first be cared for by other individuals, by communities, and by oneself (Reich, 1991).

A third group of objections to developing a feminine ethic of care holds that the concept of care is not helpful at the social and institutional level. This group of objections may acknowledge that an ethic of care serves well within the limited sphere of personal ethics, but finds care unhelpful outside of this sphere. One form this objection takes is to argue that an ethic of care cannot be formulated in terms of the general rights and principles that are necessary for designing public policies. Proponents of a care ethic sometimes acknowledge this limitation. Thus, Noddings states, "to care is to act not by fixed rule but by affection and regard" (1984, p. 24). Similarly, Patricia Benner and Judith Wrubel maintain that caring is always specific and relational; hence, there exist no "context-free lists of advice" on how to care (p. 3). They reject the idea of formulating ethical theories or rules about caring on the grounds that general guides cannot "capture the embodied, relational, configurational, skillful, meaningful, and contextual human issues" that are central to an ethic of care (p. 6). Despite this view, there exist historically important examples of using the vocabulary of general rights and principles to formulate an ethic of care. For example, the UN's *Universal Declaration of Human Rights* identifies "motherhood and childhood" as "entitled to special care and assistance," and that organization's *Declaration of the Rights of the Child* asserts general principles of caring for children, noting that children need "special safeguards and care" on the basis of their "physical and mental immaturity."

Another reason why care may be assumed unworkable at a social or institutional level is that historically, public and private spheres have been distinguished as separate moral domains (Elshtain). During the nineteenth century, for example, the doctrine of separate spheres held that the family constituted a private sphere in which a morality of love and self-sacrifice prevailed; this private domain was distinguished from the public life associated with business and politics, where impersonal norms and self-interested relationships reigned (Nicholson). To the extent that these historical attitudes continue to shape present thinking, they may lead to the mutual exclusivity of care-oriented and justice-oriented approaches. In response to this structural objection, some ethicists have argued that justice and care are compatible forms of moral reasoning (Jecker, 2002).

A final set of objections to a feminine ethic of care does not deny the importance of care, but rather argues that care is not properly interpreted as an ethic that expresses an exclusively feminine form of moral reasoning. Iddo Landau, for example, argues that the significant factors for preferring the use of care or justice ethics are, in fact, not masculinity or femininity, but factors such as education and economic class. Landau concludes that "Justice and care ethics should be seen as the ethics of certain economic classes and levels of education, not of men and women" (p. 57). Defenders of feminine ethics often meet this objection by claiming that their approach has been misunderstood. Thus advocates of feminine ethics may deny that care is an ethic that only women articulate, or an ethic that is valid only within the moral experience of women. According to Noddings, caring is an important ingredient within all human morality, and moral education should teach all people how and why to care. She concludes that "an ethical orientation that arises in female experience need not be confined to women"; to the contrary, "if only women adopt an ethic of caring the present conditions of women's oppression are indeed likely to be maintained" (1990, p. 171). Gilligan and Jane Attanucci also reject the idea that an ethic of care correlates strictly with gender, and instead report that most men and women can reason in accordance with both care and justice. Gilligan's research supports the more modest claim that care is gender-related. That is, although women and men can reason in terms of both care and justice, women are generally more likely to emphasize care while men generally emphasize justice. Thus she states that the so-called different voice she identifies is characterized "not by gender, but by theme," and cautions that its association with gender "is not absolute" and is not a generalization about either sex (p. 2).

Caring and Contemporary Nursing

Within healthcare, attention to caring is perhaps most evident within nursing. Emphasizing caring as a central value within nursing often provides a basis for arguing that nursing requires its own description, possesses its own phenomena, and retains its own method for clarification of its own concepts and their meanings, relationships, and context (Jameton; Fry, 1989a, 1989b; Watson; Swanson; Reverby, 1987a, 1987b). For example, Jean Watson holds that nurses should reject the impersonal, objective models that she says currently dominate ethics and choose instead an ethic that emphasizes caring.

Those who invoke caring in developing a theory of nursing ethics often assign caring a privileged or foundational role. For example, Sarah Fry posits caring as "a foundational, rather than a derivative, value among persons" (1989b, p. 20–21). She argues that other ethical values, such as personhood and human dignity, are an outgrowth of nurses's caring activity. Similarly, Benner and Wrubel argue for the primacy of caring on the grounds that skillful technique and scientific knowledge do not suffice to establish ethical nursing in the absence of a basic level of caring and attachment.

Like Fry, Kristen Swanson regards caring as central to nursing ethics. According to her analysis, caring requires acting in a way that preserves human dignity, restores humanity, and avoids reducing persons to the moral status of objects. Specifically, caring requires:

1. knowing, or striving to understand an event as it has meaning in the life of the other;
2. being with, which means being emotionally present to the other;
3. doing for, defined as doing for the other as he or she would do for himself or herself if that were possible;
4. enabling, or facilitating the other's passage through life transitions and unfamiliar events; and
5. maintaining belief, which refers to sustaining faith in the other's capacity to get through an event or transition and to face a future of fulfillment.

Susan Reverby finds caring to be a central ethic throughout nursing's history. Tracing the history of nursing to its domestic roots during the colonial era, when nursing took place within the family, Reverby argues that caring for the sick was originally a duty rather than a freely chosen vocation for women. Reverby suggests that nurses today possess "some deep understandings of the limited promise of equality and autonomy in a healthcare system. In an often implicit way, such nurses recognize that those who claim the autonomy of rights often run the risk of rejecting altruism and caring itself" (1987a, p. 10).

Some have challenged the proposal to consider care as a foundational or unique concept for nursing ethics. Invoking a Nietzchean method of analysis, John Paley rejects the idea that caring is the *core* of nursing on the ground that it bears a striking resemblance to a *slave morality* and thus deteriorates into *a celebration of weakness*. He urges nursing to aspire instead to *noble values,* including competence in the management of recovery and rehabilitation. Other approaches do not reject a care ethic outright, but question the attempt to regard an ethic of care as unique to nursing. Robert M. Veach, for example, suggests that care is essential to human relationships generally. Others hold that care itself is still too broad a concept to demarcate what is unique about ethics in nursing, and instead identify nursing with maternal practice, a specific kind of caring activity (Newton; O'Brien). For example, Patricia O'Brien defends the importance of nursing's maternal function by noting that historically the source of nurses' prestige has been the manner in which nurses blend home and hospital. That is, nursing's strength has come from nurses' skill at the traditionally female tasks of feeding, bathing, cleaning, coaching, and cajoling those in one's care. Just as mothers make a home, it is female nurses who have been able to make a home of the hospital, to personalize an increasingly impersonal environment.

Critics of the maternal paradigm for nursing fault this approach as casting women in traditional and stifling roles. Historically, for example, nurses were socialized into the healthcare field to know their place and were relegated to the bottom of the pyramid and taught not to ask questions (Murphy). Casting nursing practice in terms of mothering potentially reverses progress made in the late 1970s when nurses began to see themselves as shared-decision makers rather than handmaidens to physicians (Stein et al.).

A further objection to identifying ethical ideals of nursing with ethical ideals of mothering holds that nurses's proper function is to serve as patients's advocates, rather than as patients' parents. Gerald Winslow, for example, argues that advocacy of patients' autonomy, rather than paternalistic promotion of patient benefit, should guide nursing ethics.

Caring and Contemporary Medicine

Whereas nursing is often associated with a caring function, doctoring has traditionally been associated with a curing function. However, the tendency to associate caring exclusively with nursing is misleading for a variety of reasons (Jecker and Self). First, both doctors and nurses are engaged in caring for patients. In addition, assigning caring activities to nurses and curing activities to doctors is misleading because certain meanings of *curing* are actually derived from *caring.* Thus, the Latin definition of *cure* comes from the word *curare,* meaning "care, heed, concern; to do one's busy care, to give one's care or attention to some piece of work; or to apply one's self diligently"(Oxford English Dictionary).

Although there has been less explicit attention to an ethic of care in medicine than in nursing, caring for patients represents a central component of ethics in medicine. Caring is inextricably linked to the physician's obligation to relieve suffering, a goal that stretches back to antiquity (Cassell, 1982).

There are several more specific ways in which an ethic of care becomes manifest in the practice of medicine. First, caring is manifest in the activity of healing the patient. Whereas curing disease typically requires the physician to understand and deal with a physical disease process, healing requires that the physician also respond to the patient's subjective experience of illness (Cassell, 1989). For example, healing a patient who is suffering from a serious infection requires not only administering antibiotics to kill bacteria but also addressing the patient's feelings, questions, and concerns about his or her medical situation. In cases of serious illness where cure is not possible, caring for the patient may become the primary part of healing. For example, when patients are terminally ill and imminently dying, physicians' primary duty may become providing palliative and comfort care. Under these circumstances, healing emphasizes touch and communication, psychological and emotional support, and responding to the patient's specific feelings and concerns, which may include fear, loss of control, dependency, and acceptance or denial of death and final separation from loved ones.

Caring is also evident in what Albert Jonsen calls the "*Samaritan principle*: the duty to care for the needy sick, whether friend or enemy, even at cost to oneself" (p. 39). The tradition of Samaritanism dates to the early Christian era and the parable of the Good Samaritan described in the Gospel according to Luke; it persists during the modern, secular era as a central ethic for medicine. Jonsen argues that although the original Christian parable of the Samaritan refers to giving aid to a particular individual, the ethical tradition of Samaritanism within medicine bears relevance to entire groups of patients. So understood, Samaritanism underlies the physician's broader social duty to care for indigent persons. In contrast to the past, when physicians provided charity care for indigent persons without financial remuneration, universal health insurance is the norm in most developed countries. Therefore, in contemporary times physicians are generally compensated for their services through a private or government health insurance mechanism. In the United States, however, large numbers of patients continue to lack health insurance. A principle of Samaritanism continues to be evident in the legal and ethical requirement that U.S. physicians provide emergency treatment to any patient regardless of the patient's ability to pay for care. A stronger Samaritan ethic, mandating access to all forms of basic healthcare, would require, in the United States, successful implementation of healthcare reform.

A third way in which caring is manifest in the ethics of medicine is through the healing relationship of doctor and patient. Edmund Pellegrino and David Thomasma regard this relationship as one of inherent inequality because the patient is vulnerable, ill, and in need of the physician's skill. In light of the patient's diminished power, Pellegrino and Thomasma argue that the physician incurs a duty of beneficence, a duty requiring the physician to respond to the patient's needs and promote the patient's good. Other ethical values in medicine can presumably be derived from the physician's primary duty of beneficence. For example, according to Pellegrino and Thomasma, a duty to enhance patients' autonomy is based on the duty to benefit patients.

Some, Sharpe for example, have sought to identify the principle of beneficence that Pellegrino and Thomasma delineate with an ethic of care. However, beneficence and care differ in crucial respects. Whereas a principle of beneficence identifies promoting the patient's good as a requirement for right action, an ethic of care is a type of virtue ethic that is basically concerned about the affective orientation and moral commitment—that is, the concern—of the one who cares. For example, a physician may perform actions that promote a patient's good, and thus meet the requirement of beneficence, without caring about or feeling any commitment toward the patient. If this analysis is correct, then actions that fulfill the principle of beneficence do not necessarily fulfill standards associated with an ethic of care. An ethic of care suggests both a feeling response directed to the object of care and a commitment to ensuring that things go well for that person.

Despite the integral role that an ethic of caring plays in medicine, contemporary physicians sometimes neglect to offer adequate palliative and comfort measures to patients. This may stem from a failure to teach and nurture empathy in medical education (Spiro et al.) and from financial incentives that discourage spending time at patients's bedsides and getting to know patients as persons. In addition, physicians may overlook caring for patients when conflicts exist about the use of futile treatments (Schneiderman et al.). For example, members of the healthcare team may become distracted debating the appropriateness of high-technology interventions and neglect to care for patients's spiritual and emotional needs.

Conclusion

Although the development of theories of an ethic of care for healthcare is new, the idea of care has long presented a moral standard or ideal for healthcare. Although caring has been an abiding concern within nursing practice, within medicine care has sometimes been overshadowed by other ethical values and goals. The emergence of feminine ethics can play an important role in reemphasizing the value and importance of caring within medicine. However, the close association of care with gender and with the feminine voice may hinder efforts to develop a broader human understanding of care, such as the understanding of care that emerged earlier in human history.

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WARREN THOMAS REICH(1995)
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SEE ALSO: *Beneficence; Chronic Illness and Chronic Care; Compassionate Love; Emotions; Ethics: Normative Ethical Theories; Feminism; Healing; Human Dignity; Long-Term Care; Medicine, Art of; Narrative; Nursing Ethics; Obligation and Supererogation; Paternalism; Professional-Patient*

Relationship; Virtue and Character; Women, Historical and Cross-Cultural Perspectives; and other *Care* subentries

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CASUISTRY

• • •

Casuistry, a term derived from the Latin word meaning "event, occasion, occurrence" and in later Latin, "case," was coined in the seventeenth century to refer pejoratively to the practice described by contemporary Christian theologians as "cases of conscience" (*casus conscientiae*). Today the word might be defined as the method of analyzing and resolving instances of moral perplexity by interpreting general moral rules in light of particular circumstances. This entry will relate the origins and development of casuistry in Western culture, its decline, and its revival as a method of ethical analysis, particularly in bioethics.

Origins of Casuistry

The earliest discussions of morality in Western philosophy reveal the tension between general moral norms and particular decisions. The Sophists of fifth-century Greece maintained that since no universal truths could be affirmed in moral matters, right and wrong depended entirely on the circumstances: ethics consisted in the rhetorical ability to persuade persons about "opportune" action. Plato devoted his *Republic* to a vigorous refutation of this thesis, placing moral certitude only in universal moral truths: ethics consisted in transcending particularities and grasping permanent ideals from which right choice could be deduced. Aristotle proposed that in ethical deliberations, which deal with contingent matters, formal demonstration was not possible. Rather, plausible argument would support probable conclusions. Ethics belongs, he maintained, not in the realm of scientific knowledge but in the domain of practical wisdom (*phronesis*). *Phronesis* is a knowledge of particular facts and is the "object of perception rather than science" (*Nicomachean Ethics,* VI. viii. 1142a). Criticism, interpretation, and amplification of these theses constitutes much of the history of moral philosophy. The Aristotelian viewpoint, which places moral certitude in the domain of practical judgments about what ought to be done in the actual circumstances of a situation, is the remote philosophical ancestor of the casuistry that developed in Western culture.

The Roman philosopher and statesman Marcus Tullius Cicero (106–43 B.C.E.) designed an approach to moral problems that would powerfully influence the casuistic authors of the Middle Ages and Renaissance. Cicero, although a philosophical eclectic, inclined to Stoic thought in ethics. Drawing from the Stoics Panaetius and Posidonius and inspired by the Roman passion for practicality, he held that to be a virtuous person one must become "a good calculator of one's duty in the circumstances, so that by adding and subtracting considerations, we may see where our duty lies" (*On Duties,* I, 59). This adding and subtracting was done by offering and evaluating "probable reasons." The primary moral problem was the continual conflict between duty and utility, a conflict resolved only by examining the circumstances of cases. In his *On Duties,* Cicero proposed a number of cases, some drawn from the Stoic philosophers and others from Roman history. Each case, representing an apparently insoluble conflict between duty and utility, was then analyzed to show how, if circumstances were taken into account, one could discern one's moral duty. Cicero also espoused the Stoic doctrine of natural law and often referred to its overarching precepts in his analyses of cases; but the problem, he affirmed, was how these precepts were to be interpreted in context. *On Duties* remained one of the most studied texts of antiquity through the subsequent centuries. By its organization of material and its methods of reasoning, *On Duties* powerfully influenced the way in which morality was conceived and taught in the Western world, and thus sanctioned subsequent casuistry.

While moral discourse always moves between the broad generalizations of principle and the particular decisions made in specific circumstances, religions that are monotheistic and moral in nature face a particular problem in moving from the general to the particular. The three "religions of the Book"—Judaism, Christianity, and Islam—have in common a Scripture in which the word of God is recorded; that is, in which God speaks to believers in concrete and specific language. Also, the divine message contains imperatives that enjoin moral obligations, sometimes stated in broad terms and sometimes referring to specific forms of behavior. It becomes necessary for believers to understand how the broad general imperatives apply to the great variety of daily life, and to learn how specific commands expressed in the language and cultural setting of the past are to be followed in the circumstances of later times. Thus, each religion of the Book developed a moral teaching that begins with affirmations from the divine text, moves through traditional interpretations of that text by the saintly and the scholarly, and comes, finally, to the task of bringing text and interpretation to bear on particular circumstances of time and place. Each of these religions, then, has developed a casuistry or manner of working at the task of concrete application. The particular forms of Jewish and Islamic casuistry are discussed elsewhere; this entry will relate the development of casuistry in Western Christianity.

Christianity introduced a powerful and original morality into the Greco-Roman world. The thought of its founder, Jesus, both reflected the dedication of Jewish law to the sovereignty of God and refashioned it to include a demanding commitment to himself as Lord as well as self-sacrifice for one's neighbors, spelled out in strenuous, often paradoxical commands. His early disciples, seeking to follow these commands, preached an ascetic repudiation of "the ways of the world." This meant that the moderate virtues prized by the pagans among whom the early Christians lived were often deprecated and the vices of pagan life, which even pagan authors often criticized, were reviled. The morality of the Hebrew Scriptures and the Christian Gospels, which condemned many attitudes and practices common in pagan culture and demanded adherence to self-discipline and altruism, posed profound difficulties to believers. How were they to live in a world that held different values? How were the "hard commandments" of the Gospels to be carried out in daily life? These problems perplexed Paul of Tarsus, the most influential of Jesus' first followers, whose efforts to answer them, especially in his First Letter to the Corinthians, adumbrated the work of later Christian casuists. In addition, early Christian thinkers were suspicious of the philosophical thought of the Greco-Roman world. However, by the third century, many Christian scholars had come to accept that Christian belief and "pagan" philosophy were compatible in important respects. The authors of the patristic era (second to sixth centuries) reflected on Christian moral problems with the help of Plato, Aristotle, and Cicero. The framework of virtues, natural law, and practical reasoning elucidated in these and other pagan authors were modified and incorporated by Christian authors and teachers. They sought, as did their pagan mentors, to understand the nature of the moral life but were concerned, above all, with providing practical advice about how the faithful should live a Christian life in a non-Christian world. Many Christian authors used Cicero's *On Duties* as a model for treatises on morality: St. Ambrose of Milan (339–397), friend and teacher of the great St. Augustine, also titled a book *On Duties* and, closely following Cicero, attempted to refashion the latter's thoughts within the perspective of Christian faith.

Christian teaching does not merely require belief; it strongly stresses the importance of morally correct behavior. While killing, deception, and adultery are condemned as sins, and charity, self-denial, and honesty are commanded, inevitably questions arise about what sorts of behavior belong in these general categories. Early Christians were intensely aware that failure to follow the rigorous commandments of their faith separated them from God and from their fellow believers. The practice of confession of one's sins before the community of believers and the imposition of penance that would once again reconcile the sinner to God and to the community became common in the early centuries. By the eighth century, private confession to a priest, who had the ecclesiastical authority to absolve the repentant sinner from guilt, had been introduced. This practice of sacramental confession and penance enhanced the need for clear descriptions of the moral dimensions of various behaviors and of the ways in which various circumstances excused or aggravated the seriousness of those behaviors. From the eighth to the twelfth centuries, educators of the clergy produced penitential books that presented systematic catalogs of sinful and virtuous actions under various typical circumstances (e.g., the killing of another out of vengeance, in fear, in ignorance, etc.). The motives, the consequences, and the social status of the agent were important considerations in evaluating the responsibility and seriousness of behavior. Appropriate penances were assigned in view of the gravity of the sin.

These penitential volumes, the earliest examples of which came from the Irish and Welsh churches, became widespread throughout Europe. In the course of four centuries, their content became more elaborate and their format more systematic. The first were collections of crudely described cases with simple distinctions, elaborated with biblical or patristic quotations. Later examples incorporated advancing biblical and theological scholarship and, above all, the work of the canon lawyers who, since the rediscovery of Roman law in the eleventh century, had exercised increasing influence over the formulation of church law as it touched the organization and practices of Christian life. The work of Peter the Chanter (d. 1197), Alain of Lille (d. c. 1203), and Thomas Chobham (c.1200) were filled with well-described cases of moral perplexity, analyzed with reference to biblical texts, maxims from the fathers of the church, and the growing body of church law. These books were not only for the education of the parish priest but also to guide the ecclesiastical hierarchy in the formulation of policy and the making of judicial decisions. Some of these books were written for the instruction of the laity in making a proper confession and leading a good life.

During the twelfth through fourteenth centuries, great theological scholars such as Abelard, Peter Lombard, Albert the Great, Thomas Aquinas, Duns Scotus, and William of Ockham elaborated systematic treatises or *summas* in which they attempted to present the full range of Christian belief and to support it with rational argument. In doing so, they placed the questions of morality within larger frameworks of interpretation and justification, drawing heavily on philosophers of antiquity. These treatises did not discuss cases, as did the penitential literature, but created theoretical foundations for the discussion of cases. The relevance of scriptural admonitions, natural law, custom, and civil and canon law to moral decisions was explored in great depth; the relevance of principle, motive, and circumstances was carefully examined. These theologians, while not casuists, greatly influenced the next generations of casuists.

Casuistic Writings

Through the fourteenth and fifteenth centuries, many books of cases of conscience were published. The *Summa Angelica* (1480) and the *Summa Sylvestrina* (1516) were the most famous. However, these works were staid, unimaginative, and formalistic; many authors simply plagiarized from more celebrated authors. But casuistry properly speaking came into its own in the mid-sixteenth century. In 1556 a Spanish canonist, Martin Azpilcueta, published *A Handbook for Confessors and Penitents,* which revitalized the literature of cases of conscience. This book abandoned the practice of listing moral problems alphabetically and adopted a less frequently used device of organizing various sins under the Decalogue. This allowed for a more flexible and nuanced treatment and for comparison between various categories of moral behavior. Above all, it introduced the analysis of issues from the more clear and obvious to the more complex, a method that later casuists would exploit and that is described below as reasoning by paradigm and analogy.

Azpilcueta's style was widely copied. The Jesuit order, founded in 1534, was dedicated to the work of moral education and guidance of conscience, especially in sacramental confession. The Jesuits introduced Azpilcueta's approach into their own training of priests as ministers of the sacrament of penance. They published many volumes of cases of conscience. John Azor's *Moral Instruction* (1600) was the preeminent work. Jesuit casuistry was, in general, careful, scholarly, sensible, and practical. It was also comprehensive. While the general rubric of the Decalogue was used to organize materials, the duties of various occupations, the obligations of princes and bishops, and the moral dimensions of diplomacy, Jesuit casuistry also dealt with economics, warfare, and exploration. It has been suggested that the origins of modern economics, sociology, and political science lie in the work of the seventeenth-century casuists. Certainly, their advice was often sought by popes and kings in matters that we would today consider political or economic rather than moral. But in the seventeenth century, the moral questions on a king's or pope's conscience often concerned politics and finance.

The seventeenth-century casuists not only analyzed and resolved complex cases. They also elaborated speculative positions, writing treatises on topics such as justice, usually as prolegomena to their analyses of cases of government or trade. Among the central speculative questions was that of the degree of moral certitude required to act in good conscience, that is, how sure a person must be that a casuistic resolution of a moral problem is the correct one before acting upon it. A vigorous intellectual debate on this question took place in the last half of the seventeenth century between the Jesuits and their theological rivals, the Dominicans, and among the Jesuits themselves. From that debate, the position of the leading Jesuit theologians emerged as dominant. That position, *probabilism*, maintained that a person was entitled to act in good conscience if there were probable arguments in favor of the choice; probable arguments are those supported by solidly reasoned opinion and defended by respected authors. Probabilism, while defended with elegant argument and sanctioned by ecclesiastical authority, remained a contentious issue and led to the tarnishing of the casuists' reputation in the seventeenth century, since many critics accused them of being able to find any probable argument to justify their preferences.

The Jesuits were by no means the only authors of casuistry; many other Catholic theologians were so engaged. Anglican divines produced clear and sensible books of casuistry; and since most works of classical casuistry have not been translated from their original Latin, Anglican casuistical books offer the best access to casuistry for English readers (see Perkins). Lutherans were not well disposed toward casuistic analysis: Luther had cast into the flames the *Summa Angelica,* calling it "Summa Diabolica." Still, the Jesuits attained the reputation of being the premier casuists. Since they were deeply involved in the religious and secular politics of the era, they won enemies on every side and their casuistry appeared to many to serve their own interests rather than the good conscience of their penitents. In particular, the genius mathematician Blaise Pascal found distressing the Jesuits' opposition to Jansenism, a particularly rigoristic Catholic theology that he favored; and at the urging of other Jansenists, he set out to destroy the Jesuits' anti-Jansenist arguments.

Pascal's *Provincial Letters* (1656) was a brilliant and wittily written refutation of the Jesuit arguments against Jansenist theology and, in particular, of the casuistry that, he claimed, made a mockery of Christian moral beliefs. He gave numerous examples of Jesuit resolution of cases of conscience and found them tainted by a probabilism that bred moral laxity, intellectual sophistry, and disguised heresy. Despite the fact that Pascal took cases out of context and chose only those that suited his polemical purposes, his diatribe became immensely popular. At best, it can be said that his critique demolished not casuistry itself but the lax casuistry that was counted reprehensible even by the Jesuits whom he accused. It was not only Pascal's popular book that tarnished casuistry's reputation. Certain casuists, few of them Jesuits, did take the skill at case analysis to an extreme: Almost any argument could be presented plausibly and fine distinctions could be drawn to make, as Plato said of the Sophists, "the worse appear the better." Casuistry and sophistry became invidious synonyms, as did casuistry and Jesuitry. And casuistic argument, once quite liberal, became legalistic in tone and content, promoting a morality of observance rather than of conscience. Finally, casuistry was falling out of step with the prevailing intellectual progress. The interest in intellectual systems, seen in Isaac Newton, Gottfried Wilhelm Leibniz, Baruch Spinoza, and Hugo Grotius, made the casuists' interest in particular cases appear disorderly and without solid foundation. By the end of the seventeenth century, casuistry was discredited in the European intellectual world. The word *casuistry* was invented as a term of abuse (earlier the word *casista* was used merely to describe a scholar who presented cases of conscience). Bayle's *Dictionary* (1697) defined *casuistry* as the "art of quibbling with God." At the close of the eighteenth century, Kant, who was familiar with traditional casuistry as a way of teaching ethics, found the only interesting question to be how to transform the limited and probable maxims of moral discourse into categorical certitude.

Casuistic writing continued through the eighteenth and nineteenth centuries within the Roman Catholic tradition, particularly in the education of the clergy, but it was a desiccated casuistry, wary of innovative solutions and bound by ecclesiastical pronouncements on moral matters. The work of the French Jesuit J. Gury (1862) was representative of the fading tradition; a journal titled *The Casuist,* published for American Catholic clergy (1906–1917), shows the tradition at its nadir. Still, casuistry continued to serve the practice of sacramental penance for which it had been created. Outside this tradition, remnants of casuistry lingered in the teaching of ethics. The textbooks of the time included fragments of Aristotle and Cicero and many of the classical cases, loosely grouped around virtues and duties. In 1870, revolted by the untidy and incoherent presentations of these texts, Henry Sidgwick, professor of casuistical divinity at Cambridge University (he had his chair renamed "moral philosophy"), undertook to construct a systematic presentation of an ethical theory, utilitarianism, in which tenets were tightly argued, inconsistencies rectified, and opponents refuted. The progress of moral philosophy from Sidgwick's time until recently has been toward greater articulation of theory and away from analysis of cases of conscience.

The Practical Need for Casuistry

Casuistry then almost disappeared from the formal academic disciplines that study moral discourse. However, in the 1960s, a number of important moral questions began to trouble the American conscience, and moral philosophers were spurred to attend to the practical application of their discipline. The war in Vietnam required many to examine their consciences concerning support of and participation in what they felt was an immoral war. At the same time, the civil rights movement stimulated consciences concerning discrimination and racial injustice. The analytic moral philosophy current in academic circles had little advice to offer. Even the widely accepted and elaborate utilitarian theory seemed to lead to no firm conclusions.

The emerging interest in the ethics of medical and healthcare also opened vistas for a new casuistry. Medical care is about cases: the illness and the treatment of particular persons with particular diseases. Philosophers and theologians who engaged in this work had initially tried to bring the standard ethical theories to the analysis of medical problems, but they found themselves discussing cases, not theories, and felt the need for an approach that would stay closer to the particulars of the case under discussion than did the standard theories. Above all, they realized that cases were being discussed not merely to elucidate the meaning of concepts but also to arrive at a resolution: physicians, nurses, and patients were interested in what moral philosophy had abandoned: answers to practical moral perplexity. By the late 1970s, talk of "case method" had become common in bioethics. At the same time, ethical issues in business, government, and journalism seemed to call for study of individual cases rather than flights into ethical theory. Also, influential moral philosophers were beginning to criticize the dominance of moral theory in practical ethics and to call for approaches that were more concrete than speculative.

Albert Jonsen and Stephen Toulmin published *The Abuse of Casuistry* in 1988. Aware that many were interested in inventing a "case method" for ethics, they hoped to show that such a method had been invented long ago and that, although discredited and seemingly outmoded, classical casuistry had much to offer modern ethicists. Case method in ethics might be similar in many respects to the case method in Anglo-American common law, which had developed in parallel with classical casuistry. Both the common law, about which much research has been done, and casuistry, which has been invisible to the scholarly world for several centuries, need to be explored if a case method for ethics, of "morisprudence," is to be re-created. These authors attempted to restore casuistry to intellectual respectability. After a historical survey of the rise and fall of casuistry, they contrast it with current approaches to moral philosophy and define it as follows:

> [T]he analysis of moral issues, using procedures of reasoning based on paradigms and analogies, leading to the formulation of expert opinion about the existence and stringency of particular moral obligations, framed in terms of rules and maxims that are general but not universal or invariable, since they hold good with certainty only in the typical conditions of the agent and circumstances of the case. (p. 257)

Methodology

The term *methodology* may be too formal a word to describe how casuistry works. The casuists of the past left almost no formal description of their way of working; the casuists of the present, pressed by their critics based in moral philosophy, are still asking themselves questions about methodology. Still, certain characteristics of the casuistic approach can be noted. These characteristics appear to have their origins in the classical discipline of rhetoric rather than in philosophy as such. The historical casuists had, like all educated persons of their time, been educated thoroughly in rhetoric. Aristotle and Cicero, the authors from whom they learned rhetoric, also taught them ethics. Classical rhetoric was defined as having a moral purpose: the persuasion of persons toward right and just action. Indeed, the classical books of rhetoric, because they were so rich in comments about and examples of moral behavior, were often used as texts in ethics. In the centuries during which casuistry flourished, moral philosophy was not a clearly defined discipline. Thus, it is not surprising to find the historical casuists implicitly using the techniques of rhetoric in their analysis of cases of conscience. Both rhetoric and casuistry had morally correct attitudes and action as their ultimate goal.

Two characteristics of rhetorical technique are particularly important for casuistry: topics and the comparison of paradigm and analogy. Rhetoricians taught that discourse in general could be divided into a set of common ideas, such as "causality," "temporal sequence," and so on, which they called "topics." Each of these topics had sets of definitions and forms of argumentation that were invariant. Also, each special realm of discourse, such as discourse about politics, art, or economics, has its own set of "special topics," the features of the field that must be understood and discussed if an adequate argument is to be made about what should be done. A casuistic approach to an ethical problem, then, requires that the field of discourse be analyzed to designate the invariant features. For example, it has been suggested that the topics of clinical ethics are: (1) medical indications, (2) patient preferences, (3) quality of life, and (4) contextual features, such as costs of care and allocation of resources (Jonsen, Siegler, and Winslade). Each of these topics has certain definitions, maxims, and arguments that must be taken into account in discussion of any case. The particular circumstances of time, place, personal characteristics, various behaviors, and so on that are the details of any case are viewed in the light of these topics.

Once the particular case is described by its circumstances and topics, casuistical analysis seeks to place this case into a context of similar cases. The classical casuists were accustomed to line up cases of similar sorts, so that cases describing various sorts of homicide, for example, were aligned in order that the similarities and differences between cases would become clear. This enabled the casuist to see those cases in which the moral principles and maxims appeared to lead to an unambiguous resolution. Thus, the prohibition against killing another human being seemed most obviously to hold if the circumstances described a vicious, unprovoked attack on an unoffending person; the prohibition would allow an exception if the circumstances described a killing that resulted from that unoffending person's self-defense against a lethal attack. This technique of lining up cases, rather than seeing them in isolation, is the essence of casuistical analysis. It is called by some authors the technique of paradigm analogy: The paradigm case is the case in which circumstances allow moral maxims and principles to be seen as unambiguously relevant to the resolution of the case; the analogies are those cases in which particular circumstances justify exceptions and qualifications of the moral principles. A high degree of assurance, or moral certitude, pertains to the resolution of paradigm cases, while varying degrees of moral probability, or probabilism, attach to the resolution of analogous cases.

Finally, the resolution of each case depends on what Aristotle called *phronesis,* or moral wisdom: the perception of an experienced and prudent person that, in these circumstances and in light of these maxims, this is the best possible moral course. As one commentator on modern casuistry has written, "for casuistry, moral truth resides in the details … the meaning and scope of moral principles is determined contextually through the interpretation of factual situations in relation to paradigm cases" (Arras, p. 37).

Bioethics is the most prominent field in which casuistry is beginning to be reintroduced as a method for ethical analysis. This is not surprising, since a strong interest of bioethics is the clinical care of patients, and many cases that came to the early attention of bioethicists involved life-and-death decisions arising from the use of new medical technologies. Cases about whether life-supporting technologies should or should not be continued for particular patients lend themselves to casuistic analysis. The differing circumstances of individual patients, the topics (the significant categories into which a medical-ethical decision can be factored), and the maxims (such as "do no harm" or "respect the patient's informed choices") are each in their own way crucial to the resolution of any case. The placing of the case in a lineup of paradigm and analogy, from the most obvious—in which the patient is brain dead, or continued care is manifestly futile—to the problematic, in which diminished quality of life or unclear preferences are at issue, allows for discretionary judgment between cases (Jonsen). This sort of casuistry can also be applied to questions of healthcare policy, such as those surrounding the various programs proposed for allocation of resources, although relatively little of such analysis has been done.

Casuistry, then, keeps moral reflection close to cases. Neither classical nor modern casuistry repudiates principles: Casuistry is not merely another name for situationism or contextualism. Rather, principles are seen to be relevant to cases in varying degrees: In some cases, principles will rule unequivocally; in others, exceptions and qualifiers will be appropriate. Modern casuists dislike the description of casuistry as "applied ethics," since they explicitly repudiate the notion that an ethical theory must be elaborated and then "applied to" the circumstances of the case. Still, the relationship between cases and ethical theory is unclear and poses the principal speculative problem that casuists and moral philosophers must ponder, just as the historical casuists pondered the problem of the certitude of practical judgment. On the one hand, casuistry is not simply applied ethical theory; on the other, it is not simply immersion in the factual circumstances of cases, which would reduce it to situationism. Casuistry is not tied to any single theory of ethics but can be comfortable with selected elements of multiple theories. For example, a casuistic argument might draw on utilitarian, deontological, and contractual justifications in a single case. Also, the designation of topics and the selection of paradigms have theoretical presuppositions. Finally, the normative nature of principles and maxims, which must be clarified in order to specify the obligatory nature of casuistic resolutions, requires reference to theory. Casuistry, then, is not "theory free" but is rather, as one commentator has suggested, "theory modest" (Arras, p. 41). Theories, for contemporary casuistry, are not mutually exclusive, a priori foundations for practical ethical discourse but limited and complementary perspectives that illuminate practical judgment. Much work remains to be done on the relationship between theory and practical judgment. Still, as suits the style of casuistry through its history, it can grapple effectively with difficult cases even though all speculative and theoretical questions about its methods and presuppositions have not yet been answered.

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SEE ALSO: *Bioethics; Conscience; Conscience, Rights of; Ethics: Normative Ethical Theories; Narrative; Natural Law; Principlism; Responsibility*

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CHILDREN

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I. History of Childhood
II. Rights of Children
III. Healthcare and Research Issues
IV. Mental Health Issues

I. HISTORY OF CHILDHOOD

Childhood is a culturally determined social construct that might be thought of as a set of expectations for children. The principal dynamic in the history of childhood involves changes in these expectations. The history of childhood can be organized around three fundamental concepts: socialization, maturation, and modernization. Socialization is the process whereby a child incorporates the principal elements of the culture into which she or he is born. Maturation is the biological process of growing up. Modernization is the large-scale transformation of economies and societies—of European countries first, and then others. This process includes industrialization, urbanization, and the expansion of capitalistic systems of economic organization. The most dramatic changes in socialization and maturation of children come from the impact of modernization.

In traditional societies, socialization usually took place within families at a gradual pace and in informal ways. Sons learned the skills and practices of adult males by working alongside their fathers. Similarly, daughters worked and learned in close contact with their mothers. In the modern world, new agencies such as schools appeared and became part of the socialization process; and the process of maturation, formerly a natural process marked, perhaps, by rites of passage from youth to adulthood, now became the focus of serious social thought and practice. Put another way, maturation has been redefined in the modern age as a time of "identity crisis" for youth. In the modern age, youths have a greater range of choices for adult roles than did their ancestors.

The pioneering work in the history of childhood is *L'Enfant et la vie familiale sous l'ancien régime,* published by Philippe Ariès in 1960 (and translated into English as *Centuries of Childhood: A Social History of Family Life* [1962]). Ariès not only wrote one of the first modern scholarly treatments of the history of childhood, he also made the central point that childhood is socially constructed; that is, that ideas about and expectations for children are determined by social leaders and experts (advice-givers). Another early writer on the history of childhood, Lloyd deMause, in a work titled *The History of Childhood,* argued that "The further back in history one goes, the lower the level of child care and the more likely children are to be killed, abandoned, beaten, terrorized, and sexually abused" (p. 1). Professional historians have modified the views of Aries and deMause as they have developed deeper knowledge of the ways earlier societies regarded and treated children. The lasting importance of both scholars is that they founded the field of history of childhood and stimulated others to further investigations and revisions.

Childhood in the Ancient Western World

We know that childhood, a period of relative freedom from work, existed in the ancient world because children's play was depicted on Greek vases and Roman sarcophagi. There were several ancient treatises on the diseases of children and a recognition that children were to be treated differently from adults. Thus there was a tradition of childhood in the ancient world that saw children as passing through stages of growth, as being malleable, as being fragile, playful, and sometimes headstrong. This tradition saw children as individually different and in need of protection from abuse by adults. Ancient philosophers, particularly Plato and Aristotle, wrote about child-rearing practices and regarded children as a link to the future. Some children's toys have survived—dolls, small versions of weapons, and the like—and they point to adult agendas for future citizens. Epitaphs remind us that ancient parents mourned the death of their children.

The Greeks and Romans devoted special attention to children and child-rearing practices. Women were the child rearers, and a number of other adults worked with children: midwives, teachers, tutors, and physicians. Both Plato and Aristotle recognized five stages of childhood (expressed in modern terms):

1. Babyhood, from birth to about two years—that is, until the child is weaned and can talk;
2. The early preschool age, from two to three years or later—when the child is separating emotionally from the mother, becomes more active physically, and begins to play games alone;
3. Later preschool age, from ages three to seven—a stage when children become more active and more involved in social groups;
4. School-age children (up to puberty)—a time of intense competition, especially among boys; and
5. The stage between puberty and adulthood—which continues into the late teens or early twenties.

The last stage may have been brief or nonexistent for girls, who married at a relatively early age. In their broad outline, however, these stages closely resemble modern child-development theory.

Threats to Children in the Ancient World

Childhood in the ancient world had a darker side: some people practiced infanticide as a means of birth control or eugenics (French); some children were sold into slavery; and some of the little slaves were maimed so that they could be more pitiable beggars. Additionally, the use of wet nurses for the newborn was common and undoubtedly led to higher infant mortality rates. Wet nursing led to higher infant mortality because there was a greater possibility of disease, the wet nurse had less concern for the child than the mother did, and the amount of nourishment from the wet nurse might have been less. Infanticide was common, and such evidence as there is suggests that it was more common for female children than for male children to be killed by being abandoned and left to starve. A Roman law, for instance, said that all boy children and at least one girl born to a family had to be raised. In Sparta (from 700 to about 350 B.C.E.) infanticide was part of a program of eugenics whereby defective children were exposed. Illegitimate children were also disposed of through infanticide. Most children grew up in small nuclear families with one or two siblings. These small families were of concern to the Romans, who sought to increase the birth rate through incentives.

Childhood in Medieval and Early Modern Times

Very little is known about child-rearing practices and childhood in the early centuries of the Middle Ages because the historical sources for this period are very scattered and fragmentary. But it is known that children were valued. Among the Visigoths, for example, a male baby had a blood price (*wergild*) of one-tenth that of an adult male. As the child aged, the wergild increased. Female children had a blood price half that of male children, but adult women's wergild was five-sixths that of an adult male. There was some schooling in this period; scattered references attest to schools in palaces and monasteries, although the practice of taking in small boys as oblates by monastic orders was already declining. For much of the population the process of maturation involved a long apprenticeship with children working alongside adults and thereby learning adult roles and responsibilities.

Literary references suggest that adults treated young children in a kindly fashion but that they had little regard for young people in their teens. Laws set the age of criminal responsibility (when a child could be charged with a crime) at seven and the age of majority (when a person could make a binding contract) at eighteen or older. As in the ancient world, medieval parents clearly mourned the deaths of their children. Medieval commentaries on childhood saw three stages in place of the ancient world's five (again expressed in modern terms):

1. Infancy, up to the age of two;
2. The preschool period, from age two to age seven;
3. Puerility, from age seven to age fourteen.

There were texts that stressed the importance of breastfeeding (and by inference pointed to the dangers of wet nurses), but the use of wet nurses was common among the upper classes. An English bishop wrote of the importance of cradles (which would prevent infant deaths resulting from suffocation in the parental bed). Some children's toys—miniature figurines, for example—have survived from the period.

Infanticide was still common for female babies, but illegitimate children were sometimes added to the father's household. To counter the pattern of infant exposure and abandonment, orphanages appeared, the first being established in 787 at Milan. By the early fourteenth century, there were two hospitals in Florence that accepted foundlings, and in 1445 a separate foundling hospital, the Innocenti, was established. Other foundling hospitals appeared in Rome, Bologna, Pavia, and Paris by the end of the fifteenth century.

During the course of the Middle Ages, opportunities for schooling expanded from the limited possibilities offered by palaces, monasteries, or nunneries. Schools began to appear in the major cities of Europe; many of them, such as the grammar school at St. Paul's Cathedral in London, which was revived by John Colet early in the sixteenth century, were founded for the express purpose of training boys in business.

Most medieval children left home fairly early. Girls entered the work force at around age eight as servants, and boys typically were apprenticed to learn a trade. In effect these children traded their labor for their upkeep in their new households.

The death rate for children in the medieval world was extremely high—from 30 to 50 percent of children did not live to maturity. Besides disease, infanticide, and wet nursing, accidents claimed a great many children. There was little supervision of young children. Newborn children were swaddled (tightly wrapped with strips of cloth so that they could not move about or even move their limbs). Older siblings might provide some care, but most children were left alone; many of them suffered accidents, such as falling into an open fire, as a result.

European living patterns in the medieval and early modern period are comparable in some ways with traditional Japanese households. In traditional Japan the household was a residence as well as a legal, economic, affective, and ritual unit. In it children were regarded as treasures, although only one child would remain in the household as heir (the heir could be either male or female). The other children became apprentices or spouses or servants or remained in the household as dependents. The successor inherited all the assets of the household and was responsible for the continuity of the household and its reputation. The household was child-centered and stressed socialization into traditional roles. In recent times, as a result of the modernization of Japanese society, the process of socialization has changed. Japanese children do not remain in the traditional households, and younger families move to cities, where schools and other institutions have replaced the household as the primary agent of socialization because new occupations require different forms of preparation.

A similar transformation occurred in the Muslim Middle East. Ironically, it began with a reemphasis on the traditional household, which had been devalued by Westerners since the modern colonial period began in 1798. The family became a point for resistance to colonialism and strengthened paternal authority at a time when Western families were becoming more democratic. As the nations of the Middle East gained independence in the last half of the twentieth century, these traditional households began to give way before the process of modernization. And, as was the case in Japan and early modern Europe, schools and other institutions supplemented the family as agents of socialization.

Childhood in the Modern Western World

As modernization transformed western Europe and North America in the eighteenth and nineteenth centuries, a new and distinctive pattern of childhood emerged that was the result of a number of influences—economic changes such as the intensification of a market economy, a decline in family size, the rise of rationalism in public discourse, to name a few. In addition, several important European thinkers were midwives to this new form of childhood. John Locke helped to undermine the dominant Puritan conception of children as innately evil, that is, born in sin, when he published his *Essay Concerning Human Understanding* in 1690. In it he argued that ideas could come from experience and thus were not innate. In 1693 he issued *Some Thoughts Concerning Education,* in which he attacked the doctrine of infant depravity. Locke did not regard children as innately good; rather, he argued that they were morally neutral—blank tablets.

Another central figure was the French philosopher Jean-Jacques Rousseau, whose *Émile* (1762) was the story of a boy and his tutor. Rousseau argued that children should be reared more naturally, making use of their innate curiosity to motivate their learning. For Rousseau both nature and the child were innately good. Evil arose from the corruptions of civilization. One of Rousseau's followers who put his ideas into practice was Johann Heinrich Pestalozzi, who founded a school in Switzerland in 1799.

Yet another important figure in the emergence of the modern concept of childhood was the English novelist Charles Dickens, whose well-known child characters Oliver Twist, Charley Bates, Jack Dawkins, and the Artful Dodger personalized some of the tragic effects of the industrial revolution in England. Dickens vividly described the desperation of the urban working classes and the processes whereby homeless children had to fend for themselves. His writings, supported by the findings of royal commissions and by the work of social reformers, helped transform the social attitudes of the Western world. In 1848 the English established "Ragged Schools" for the children of the urban working classes. Later they created a system of universal public education with the Forster Education Act of 1870.

In the United States in the nineteenth century, Charles Loring Brace, a New York clergyman and reformer, founded the Children's Aid Society in 1853 to ship "surplus" urban children—whether orphaned or not—to rural areas. The Children's Aid Society also founded lodging houses for homeless newsboys and industrial schools for homeless girls of the streets. (It was hoped that by teaching the latter unfortunates a trade such as sewing, they might be rescued from prostitution.) Later in the nineteenth century another New York reformer, Elbridge Thomas Gerry, founded the Society for the Prevention of Cruelty to Children in 1875. Popularly known as "the Cruelty," the organization sought to reduce or eliminate the worst instances of child abuse and neglect.

While these reforms and the expansion of public schools sought to provide opportunities for the child victims of modern society, the problem of child labor proved more difficult to solve. In part this was because few people—and certainly not most parents or employers—regarded child labor as a problem. For one thing, children had always worked before the modern era. Only the sons and daughters of the privileged elite escaped labor during their childhood. In the preindustrial world most families, whether urban or rural, relied on the labor of their children. Children in that world were regarded as a renewable labor supply. They began doing simple chores as early as possible, and they continued to work throughout adulthood and into old age, as long as they were able. Children also functioned as safety nets for parents. As parents became too infirm to work, they relied on their offspring for food and shelter. This family labor system moved with families to industrial cities. Thus, in nineteenth- and twentieth-century factories children joined their parents on the shop floor, first as helpers and later as hands. Industries welcomed child labor because it guaranteed a steady supply of trained workers, and families depended on the income the children produced.

But modern society demanded more skills from its work force than the family labor system was able to deliver. As a result, families had to forgo the income from some of their children so that they could learn the skills necessary to obtain employment. At the same time, reformers began to define child labor as a social problem and to expand the availability of schools. By the 1920s, child labor was on the decline in the Western world as schools, child labor laws, and technological innovation finally reduced the supply of child laborers and the demand for them.

In the process of expanding schools and trying to reduce child abuse and to regulate child labor, Western society was redefining childhood. Childhood now became a special, protected status, a time during which biological maturation could run its course, and children could come to know the complexities of the modern world and find their places in it. Two other social developments were significant in this process of redefinition: the creation of the federal Children's Bureau and a federally funded program to reduce infant mortality in the United States. The Children's Bureau, established in 1912, was an outgrowth of the First White House Conference on Children, convened by President Theodore Roosevelt in 1909. At first it concentrated on the reduction of infant mortality, which led in 1921 to the passage of the Sheppard-Towner Act, a program of matching grants for states. The grants helped states set up programs of education and prenatal clinics. This program of prevention and education had the desired effect, but was killed by lobbying from the American Medical Association in 1929.

Other social advances in the nineteenth and twentieth centuries included the rise of pediatrics as a medical specialty and the rise of child psychologists, psychiatrists, and social workers. By the late twentieth century virtually all advanced industrial countries, including many outside the West, had made significant strides in reducing some of the threats to children's health and well-being.

Conclusion

The experiences of children in the recent past cannot be reduced to simple generalizations; there are too many variables. But it is obvious that region, economic health, and aspects such as race, class, and gender all have a major impact on children and childhood. Having noted these difficulties, some observations are possible. Abortion is more common in the industrialized world, whereas infant mortality is much lower. Children are less likely to become orphans in industrialized countries, to experience the death of a sibling, or to die before reaching adulthood. Children in industrialized countries will probably know their grandparents, and their parents may well have been divorced; many of them live in single-parent households, a sharp contrast to the extended households of traditional cultures.

Children in industrialized countries will spend more time in schools than children did in the medieval world, or than they do now where traditional cultures prevail. They will spend more time in groups with children of the same age. Their parents will have relied more heavily on experts, and they will probably have only a few siblings and perhaps a room of their own. They will have money of their own, and parts of the media will cater especially to them. They will also have a legal status that is clearly spelled out, although their status will vary from country to country. Of course even in industrialized countries poorer children will enjoy fewer privileges than the children of middle-class or elite parents.

In the twentieth century the improvements in children's lives in industrialized countries have been dramatic. In the United States, for example, in 1900 infant mortality was estimated to be more than 160 per 1,000 live births; by 1990 this rate had dropped to around 10 per 1,000. In Japan the rate was 5 per 1,000. Similar improvements occurred in access to schooling and literacy. In 1900 high school graduates in the United States constituted less than 4 percent of the seventeen-year-old population. By 1990 they represented approximately 75 percent. Similar evidence of significant improvement in children's health and education can be cited for most, if not all, industrialized nations.

In the modern world childhood has been extended, redefined, and supported by an array of experts and social institutions. Maturity, once a biological matter worth little notice, has become a complex process perhaps more social and psychological than physical in nature. Similarly, the process of socialization is now much more complex, reflecting, as always, the society into which children are to be socialized. In complex modern societies, the preparation necessary to become a productive adult is much longer and more intensive than formerly. In recognition of this, students now extend their schooling well into their twenties and even beyond. Maturation, modernization, and socialization as they have interacted have created an entirely new world of childhood.

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SEE ALSO: *Abuse, Interpersonal: Child Abuse; Adoption; Family and Family Medicine; Feminism; Infanticide; Infants, Public Policy and Legal Issues; Pediatrics, Adolescents; Research Policy: Subjects; Women, Historical and Cross-Cultural Perspectives;* and other *Children* subentries

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II. RIGHTS OF CHILDREN

Since about 1970, philosophical interest in the rights of children has grown substantially. This growth owes much to the social upheavals of the 1960s and 1970s, especially the civil rights and women's movements, both of which employed the rhetoric of rights. When the plights of children, homosexuals, and the disabled began to be highlighted, it was natural that advocates for these groups also used the rhetoric of rights.

The invocation of rights in connection with children, however, predated the 1960s. In 1959 the United Nations General Assembly (1960) adopted a ten-principle *Declaration of the Rights of the Child*, itself a descendant of one adopted by the League of Nations in 1924.

Why Rights?

Why do activists concerned with the lives of children attempt to protect children's interests by invoking the notion of rights? The key features of the rhetoric of basic rights are (1) that rights are entitlements, and (2) that they impose duties on others. To claim something as a fundamental right is to make the strongest kind of claim one can make; it is to claim that something is an entitlement, not a privilege—something it would be not merely inadvisable or regrettable, but wrong and unjust, to withhold. And, typically, if one person is the bearer of rights, some or all others are the bearers of obligations. In the case of basic rights, the responsibilities fall either on all others as individuals or on the government, which in the case of democracies means on individuals acting as representatives of the citizenry. This is easily seen in the cases of the rights of adults to free speech and to healthcare.

The rights to free speech and healthcare illustrate two broad classes of rights given a variety of names by theorists. These may be designated *option* rights and *welfare* rights respectively (Golding). The idea behind option rights is that there is a sphere of sovereignty within which the individual cannot be intruded upon by government, even for the greater good. This idea is at the heart of classical liberal theory. Option rights are rights to choose. For instance, although persons have the right to speak, they may remain silent if they wish. Welfare rights, on the other hand, are rights to direct provision of services, such as medical care, that meet a basic need.

Do both categories apply to children? The notion of option rights motivated children's rights activists who saw children as oppressed by adults. Psychologist Richard Farson stated, "Children, like adults, should have the right to decide the matters which affect them most directly. The issue of self-determination is at the heart of children's liberation" (p. 27). The authors of the United Nations *Declaration*, on the other hand, focused almost exclusively on welfare rights. For example:

> The child, for the full and harmonious development of his [*sic*] personality, needs love and understanding. He shall, wherever possible, grow up in the care and under the responsibility of his parents, and in any case in an atmosphere of affection and of moral and material security; a child of tender years shall not, save in exceptional circumstances, be separated from his mother. (United Nations, p. 113)

Although some children's advocates urge recognition of both option and welfare rights, the underlying rationales are quite different. While the rationale for according children option rights conceives of minor status itself as a disabling condition that ought to be removed, the rationale for welfare rights urges that various goods and services be provided to minors as minors.

Most sensible people would look askance at putting children, especially young children, on a par with adults, insofar as freedom to live as they wish is concerned. The notion of a protected sphere of autonomous decision making is closely linked to the presence of developed capacities for rational choice, capacities that usually are only potential in young children. It may well be that the development of autonomy is impeded when children are not permitted to exercise choices in their lives, but advocating that children be given some options is a far cry from asserting that children have the same rights as adults to live their lives as they please. Paternalism, the coercion of individuals for their own good, is odious only when those coerced are capable of exercising rational choice.

Why Not Rights?

Rights discourse does have some limitations in the context of advocacy for children. An initial difficulty lies in identifying universal rights while taking account of the limited resources and diverse values of particular societies. It may not be possible in some countries to fulfill the universal right to grow up in an atmosphere of material security, due to lack of resources. A second difficulty is that alleged welfare rights may be in tension with each other—for example, the right of a child to grow up in material security and the right to love and understanding.

A danger of rights discourse derives from the fact that, taken literally, respect of children's rights may permit substantial intrusion into parents' lives. For example, should government agents monitor parents to make sure they provide their children with the love and understanding they need? A less obvious danger derives from the fact that some of a child's most important needs, such as the need for love, cannot be coerced. If love fails, must the child be taken from the parent and given to another who is known to love the child? It is apparent that the struggle for children's rights may have the potential of making parents and children into adversaries.

Alternatives to Rights

Given children's vulnerability to abuse and neglect by immediate caregivers and by society at large, what ethical bases other than rights might serve to enhance children's welfare? Philosopher Onora O'Neill (1989) suggests that Immanuel Kant's notion of imperfect duty provides such a basis. An "imperfect" duty—the duty to contribute to charity is an illustration—differs from a "perfect" duty in the latitude allowed for fulfillment; toward whom and how much the duty requires is not specified. Thus, although we all have an obligation to help the next generation not only to survive but also to develop its capacities, we may meet this obligation in different ways—some as parents, some as professional caregivers, some as taxpaying citizens. The idea is attractive philosophically, but it admittedly lacks the precision, and hence the force, of the language of rights. Since the precise nature of the duty cannot be specified, it will be difficult to determine when people have or have not done enough to help needy children.

Another stream of ethical reasoning centers on character and virtue. So-called virtue ethics takes the focus away from whether particular acts are obligatory, permitted, or forbidden, and explores the notion of a good or virtuous person, a notion it alleges is fundamental. Proponents of virtue ethics would say, for example, that the idea of a virtuous or good mother cannot be reduced to that of a mother who performs or refrains from performing specific actions viewed as duties. A decided advantage of virtue ethics is that it encourages us to ask a key question: What legal and economic structures are conducive to "good parenting"? Virtuous parents, for example, take time to be with their children, especially when they are ill, but such virtuous actions will be more likely if employed parents enjoy legal protection against punitive actions by employers for their taking family leave.

Unlike the children's rights approach, which may pit parents against children, this approach does not put parents on the defensive. But virtue ethics also has theoretical difficulties, chief of which is defining character traits in ways that do justice to the diverse cultural ideals present in a heterogeneous population like that of the United States. Everyone will agree that virtuous parents, for example, need to teach their children to distinguish right from wrong, but may they use corporal punishment in the process? Here, consensus will break down. Another limitation of the approach is that virtue ethics has little to say about what precisely is owed to, or what ought to be done for, children whose primary caregivers have already failed them.

Care ethics, a variant of virtue ethics, is utterly antithetical to the Kantian emphasis on general principles and the development of rational agency. Deriving primarily from the work of feminist psychologists and philosophers, this approach takes close personal relationships, such as that between mother and child, as a model for all moral relations. Emphasis is placed on the need for compassion and empathy in the context of relationships to particular others in concrete settings, rather than on allegiance to abstract principles. Parents, for example, often succeed in meeting the needs of their children because they can empathize with them in particular situations; no abstract duty to care for one's children needs to be evoked. The ethic of care counters a philosophical focus on rationality as the defining essence of humanity.

Is care ethics sufficient to meet the needs of all children? For example, should affluent citizens provide funds for intensive professional care of babies born with drug addictions, babies they never will meet? If the answer to such a question is yes, then the notion of duty may provide a more secure basis for persuading people that such contributions are obligatory, since emotional identification with those one does not know is likely to be weak.

If both justice and care are regarded as virtues, then virtue ethics may have the potential to offer moral grounds for the protection and care of all children. Whether such a reconciliation of alternative approaches is possible remains an open question. If it is not possible, then philosophical ethics offers a number of lenses through which to view the status of children. As in the case of actual lenses, however, there may be no single lens that fits all purposes.

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SEE ALSO: *Abuse, Interpersonal: Child Abuse; Adoption; Feminism; Family and Family Medicine; Human Rights; Infanticide; Infants, Public Policy and Legal Issues; Justice; Natural Law; Pediatrics, Adolescents; Research Policy: Subjects;* and other *Children* subentries

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III. HEALTHCARE AND RESEARCH ISSUES

Access to good parenting, food, housing, and sanitation is the primary method for enhancing children's well-being and opportunities. The consensus that children also should have basic healthcare and social services grew throughout the twentieth century. Initially, advocates for better health and social care for impoverished, neglected, abused, and exploited children included those active in the women's rights movement, the newly recognized specialty of pediatrics, and the visiting home-health nursing programs. As the century progressed, lawyers and social scientists joined the reform movement, attacking the long-dominant views that children are the property of their parents or guardians and that the state has no authority to intervene even if children are abused or neglected.

Children gained rights to certain medical services and the right to be protected from abuse, poverty, neglect, and exploitation; adolescents gained liberties such as the right to consent to some kinds of treatments or services without parental approval or notification (Holder, 1985, 1989). Scientists helped transform children's programs through studies of children's growth, development, needs, experiences, illnesses, and perspectives, showing the importance of candor and respect for children's views. A distinctive feature of advocacy for improved health and social care for children can be summarized as follows: Others make most decisions for minors in terms of their personal care and the allocation of funds for children's programs.

Moral disputes about healthcare for children will be discussed under four headings: Who should make decisions for children? How should those decisions be made? When should children be enrolled as research subjects? How much of society's healthcare funds should be allocated to children's programs?

Basic Moral Values

Different solutions to these questions are evaluated herein in terms of basic moral values: Solutions are judged to be superior when they fairly promote children's well-being and opportunities to flourish and help children become empowered, self-fulfilled persons who can develop their potential. The United Nations *Declaration of the Rights of the Child* (United Nations General Assembly) endorsed these basic values, underscoring their wide acceptance.

These values received international support because most adults want to help children and recognize their responsibility to assist them. They also promote stability by helping address inequalities of the “natural lottery” (inequalities caused by nature, such as health status) and the “social lottery” (inequalities caused by social factors, such as wealth, schooling, and family). Children are not responsible for those inequalities, yet they affect whether children will thrive and flourish. Adequate healthcare and social services enhance children’s well-being and opportunities by treating diseases, in some cases returning children from the brink of death or permanent disability to full and healthy lives. These services also restore or maintain compromised function, avert or ameliorate suffering, and prevent disease or disabilities through interventions or counseling. Basic prevention, diagnosis, treatment, rehabilitation, and social services not only make children’s lives better, they provide society with healthier and more productive citizens.

The focus of this discussion is primarily on preadolescent children, who clearly are not responsible for their quality of life or its inequities and who need help in making prudent decisions.

Who Has the Authority to Decide for Children?

Adults are presumed competent and minors incompetent to consent to medical treatment or participation in research. Minors generally lack the capacity, maturity, foresight, and experience to make important choices for themselves and cannot determine which choices will promote their well-being or opportunities. In general, the younger and less experienced the child, the greater the presumption that he or she cannot participate competently in healthcare decisions but the trend is to include children as young as five years old. Many older children, especially adolescents, clearly overturn this presumption that they cannot participate.

SHARED DECISION MAKING. Ideally, important healthcare choices should represent a consensus among parents, doctors, nurses, and the child if he or she is mature enough and willing to participate. Together they find the option best suited to the child and the family (U.S. President’s Commission, 1982). In the final analysis, however, parents or guardians generally have legal and moral authority to make medical decisions for minor children.

PARENTS’ OR GUARDIANS’ AUTHORITY. Parents and guardians have the authority to make healthcare decisions for the same general reasons they can select their children’s religion and schooling. The philosophers Allen Buchanan and Dan Brock (1989) discuss several reasons for this policy. First, parents and guardians are generally most knowledgeable about and interested in their children and so are most likely to do the best job for them. Second, the family usually bears the consequences of the choices that are made for a child. Some choices and their consequences suit certain families better than others. Third, children learn values and standards within their families, and different values and standards may lead to different healthcare choices. Within limits it is important to honor the standards and values of families because it is primarily in the family structure that people in society learn values. Fourth, families need intimacy with minimal state intrusion. Thus, unless a child is placed at risk, there is reason to tolerate the choices that families make for their children and give families wide discretion in selecting children’s healthcare.

Parents or guardians maintain this authority as long as they promote the well-being and opportunities of those under their care and prevent, remove, or minimize harms to their minor children. Their authority can be contested, however (Rodham; Holder, 1985; Kopelman, 1997). Moral disputes over when to challenge parental authority to make healthcare decisions often center on practical and theoretical issues about when harms or dangers to children warrant interfering with parental authority and what restrictions on parental choice are needed to secure a child’s well-being.

Parents who abuse, neglect, or exploit their children may lose custody of them temporarily or permanently. Physical, sexual, or emotional abuse inflicted on children constitutes grounds for the loss of parental authority. In addition, parents who make imprudent or neglectful decisions may lose custody temporarily or permanently. For example, parents may lose custody temporarily if they endanger a child by declining standard antibiotic care to treat the child’s bacterial meningitis, preferring the use of herbal teas. Parents also may lose custody temporarily if they endanger a child by acting on certain beliefs. For example, Christian Scientists object to surgery and Jehovah’s Witnesses object to blood transfusions, yet courts can order either intervention if a child is endangered (Holder, 1985; Rodham; Kopelman, 1997). Because children cannot protect themselves, healthcare professionals, teachers, neighbors, and other members of the community have a duty to report suspected child abuse, neglect, or exploitation to state agencies for investigation. When parental acts or omissions pose an imminent danger to children, doctors, nurses, hospital administrators, and social workers have a moral and legal duty to seek a court order for proper care (Holder, 1985; Kopelman, 1997).

CHILDREN'S ASSENT AND CAPACITY Decisions about when to consult or inform children about their healthcare options usually are important for older children and those with serious illnesses in cases in which distinct choices result in different outcomes. Some, but not all, children want to understand the decisions about their healthcare and often have an opinion about their care (Buchanan and Brock; Holmes; Matthews). Moreover, adolescents do not always need parental consent to obtain services such as treatment for substance abuse, abortion, and contraception (Holder, 1985, 1989).

This trend toward informing or consulting children stems from several sources. First, it results from research about what children of different ages and stages of development can understand. Social-science research has found that many children understand a great deal about their diseases and even their imminent death (Bluebond-Langner). They sense when people are not truthful, and this can cause them to suffer by feeling isolated from discussions, decisions, and support (Bluebond-Langner; Matthews).

When children have capacity and are prepared appropriately, truthfulness usually has good consequences by promoting cooperation and enhancing trust in their caretakers. Truthfulness also can foster decision-making abilities and maturity. When children have life-threatening or chronic illnesses, it may be especially important to them to gain some control over their lives and some respect for their views. For those facing death, opportunities to become self-fulfilled and self-determining persons may be restricted to choices about how they will live their last months.

Second, this trend stems from an understanding that capacity is task-related. In assessing ability the question must be asked: Capacity for what? People are capable of doing some things and not others and thus may have the capacity to make some healthcare decisions but not others (Buchanan and Brock; Faden et al.; Kopelman, 1990; Matthews; U.S. President's Commission, 1982). An eleven-year-old child with cancer may understand a great deal about the illness because he or she has had experiences beyond those of most eleven-year-old children. Consequently, the child may be better able than most children of the same age to understand or participate in healthcare decisions.

Children are increasingly able to participate in healthcare decisions as they become better able to understand and reason about their options and life plans. Although young children cannot do this, some adolescents may be as capable as most adults in these respects (Holmes).

In recent literature *competent* and *incompetent* are used as legal categories. The presumption is that unless the courts decide otherwise, adults are legally competent and minors are not. In reality, many legally competent adults lack decision-making capacity and many older minors are as capable as most adults. For the purpose of healthcare, decision-making capacity concerns the individual's ability to understand and appreciate the information needed to make informed decisions, evaluate that information in terms of stable personal values, and be able to use and manipulate the information in a reasonable way (Applebaum and Roth; Buchanan and Brock; Kopelman, 1990). To decide whether minors have the capacity to participate in important healthcare decisions, adults should assess how well children can understand the information, deliberate, appreciate the situation, and make, defend, and communicate choices. In addition, it is important to determine whether a minor has reasonable and stable personal values. The more they have such abilities, the more they should participate.

Many authors favor a sliding scale to determine whether a person is capable of making medical decisions (Applebaum and Roth; Kopelman, 1990). The lower the probability and the magnitude of the risk of harm from the decision, the less the need to scrutinize the decision-making capacity of the person giving consent. However, the greater the probability and the risk of harm from the decision, the higher the level of scrutiny that the decision is rational. The reasoning of parents who refuse chemotherapy for a child with cancer, for example, has to be assessed very carefully.

How Should Decisions Be Guided?

There are four important standards for healthcare decision making:

1. The first standard—self-determination—applies primarily to the voluntary decisions of legally competent and informed adults who make their own choices about their well-being and opportunities as long as they do not harm or violate the rights of others. As minors become more mature, they should be accorded more self-determination, but their preferences need not be honored as are those of adults (Holder, 1985, 1989). An adolescent with cancer who insists that he or she would rather die than lose a leg needs help to understand that reaction. The degree of irreversibility and the severity of the consequences often determine whether a minor's preferences should be honored. Minors' choices generally become more morally binding on adults when minors show that they understand and appreciate the nature of the situation in relation to their life goals. Adult guidance is needed when minors cannot demonstrate that their choices enhance their well-being and opportunities.

2. Like some adults, older children may prepare advance directives about their healthcare choices if they become incapacitated. Although a minor's choice need not be honored in the same way as an adult's decision, it may be an important consideration or seem morally binding in some circumstances. Dying children may, for example, indicate that they wish to donate organs or plan their funerals. Parents may want to follow such instructions carefully out of respect to the child's wishes.
3. A third standard—substituted judgment—applies to someone who once was able to express preferences. In using this standard, people select the option they believe the person would choose if he or she were able. Families often know their relatives well enough to predict the choices their relatives would have made. Children, especially those with serious or chronic illnesses, also may express general preferences that should guide parental choices. One child who was very sick insisted that he did not want to be maintained in a persistent vegetative state (PVS) "like a zombie."
4. The best-interest standard applies to those who do not have the ability or authority to make decisions for themselves. This standard maintains that decision makers should try to identify a person's immediate and long-term interests and then determine whether the benefits of an intervention or procedure outweigh the burdens. This does not mean that they seek what is absolutely best, because that may be impossible (the best doctor cannot treat everyone), but that they seek the best among the available options. This standard permits complex judgments about what on balance is likely to be best for an individual in light of the available options (Buchanan and Brock; Kopelman, 1993, 1997). For example, the benefit of obtaining a long and healthy life would outweigh the burden of enduring intense pain for a short time. The best-interest standard, however, might be used by parents, doctors, and nurses to withhold or withdraw maximal life-support treatment from children who have intense and chronic pain, with no prospects of improvement or foreseeable pleasures, understanding, or capacities for interaction.

In some cases objectively or intersubjectively confirmable estimates about pain and a well-understood prognosis force parents and doctors to choose between preserving biological life and providing comfort. Some children live in considerable discomfort from the technologies that keep them alive, such as a gastrostomy (a tube through which food goes directly into the stomach), intravenous lines, ventilators (breathing machines), long stays in intensive-care units, and a tracheotomy (a hole in the throat that aids breathing).

One goal of medicine, which should be balanced against others, is to preserve and prolong biological life. Since ancient times this ideal has been understood to mean that one ought to prevent untimely death. However, a question remains regarding the best interests of a person whose life is continued by means of maximal treatment that is a burden to that person (U.S. President's Commission, 1983; Buchanan and Brock; Kopelman, 1993). In cases where doctors and others disagree about what is best, it is hard to apply the best-interest standard. In such situations and for the general reasons discussed above, which give parents wide discretion when doctors disagree about what is best, an established legal and moral consensus using the best-interest standard allows parents to choose from options advanced as best (Buchanan and Brock; Holder, 1985, 1989; U.S. President's Commission, 1982, 1983).

The best-interest standard was challenged by President Ronald Reagan (1986) and Surgeon General C. Everett Koop (1989), who believed that quality-of-life considerations were likely to be abused. Under their influence the federal government in 1984 amended its child-abuse laws and adopted the so-called Baby Doe guidelines ("Child Abuse and Neglect," 1985). These rules forbid withholding or withdrawing lifesaving care from a sick infant unless the child is dying or is in an irreversible coma or when treatment is both virtually futile in terms of survival and inhumane. To forgo lifesaving treatments it is not sufficient that the treatment be inhumane or gravely burdensome, as it would be in the Roman Catholic tradition. Suffering cannot be taken into account except when the child cannot survive even with maximal treatment (Kopelman, 1989a, 1993).

The Baby Doe rules are controversial because they radically restrict parental discretion and standard medical practice. In a 1988 survey U.S. neonatologists indicated that the use of this policy for judging when to withdraw or withhold care for infants would result in overtreatment, poor use of resources, and insufficient attention to suffering (Kopelman et al., 1988).

Defenders maintain that properly understood, the best-interest standard is a useful way to protect children and others who are incompetent (Kopelman, 1997). For example, the U.S. President's Commission states, "This is a very strict standard in that it excludes considerations of the negative effects of an impaired child's life on other persons, including parents, siblings and society" (U.S. President's Commission, 1983, p. 219).

Allen Buchanan and Dan Brock (1989) argue that quality-of-life assessments are not open to abuse if they are limited to judgments about what is best for the individual patient. The courts and others who reject such judgments made on behalf of incompetent people, they argue, do not distinguish two kinds of quality-of-life judgments. Quality of life judgments based on considerations of social worth try to weigh the interests or value of a person's life against the interests or value of other people's lives; they are comparative. In contrast, noncomparative quality of life judgments try to consider the value of the life to the person, comparing the value of living the individual's life to having no life at all. Although this comparison is difficult to make, it can be guided by choices made by competent adults who decide that there are worse things than death, including certain burdensome treatments to keep them alive. Buchanan and Brock (1989) hold that in applying the best-interest standard one should use noncomparative estimates, contemplating only the quality of life for that individual; a person's social value should not be part of the assessment. Noncomparative quality-of-life judgments, then, should be circumscribed very carefully and strictly. It is possible to reflect, for example, on whether most people would want to live such a life.

To some extent the effectiveness of the best-interest standard relies on the degree of social consensus about what is best for children and other persons who lack decision-making capacity. Consequently, it is hard to use in cases in which there is sustained disagreement, as there may be about when and how to use quality-of-life considerations. Arguably, one cannot avoid quality-of-life decisions entirely. For example, the Baby Doe regulations state that one need not provide maximal treatment to those who are permanently comatose, and that is a quality-of-life judgment. The debate also concerns what discretion should be given to parents, physicians, and other clinicians to select the best available option.

Kopelman (1997) has argued that some of the criticisms of the best-interest standard stem from confusing its different meanings. First, it is used as an ideal. For a child to receive a very scarce resource for a marginal benefit may be ideal yet unreasonable once one considers the claims and needs of others and the available resources. Nonetheless, it is important to consider what might be ideal for a child in framing what should be done in light of others' needs and the available resources. Ideals are also important in giving direction to people's efforts. The ideal of no children being abused or neglected gives direction to advocates for children.

Second, the best-interest standard is used in the sense of what is best given the options or what is best all things considered. For example, it may not be possible to give each child ideal healthcare, but it may be realistic to seek basic healthcare for all children. Another example is that some parents are not ideal guardians, but the state does not step in unless their children are endangered. If parents refuse lifesaving healthcare for children, the courts may remove custody from the parents temporarily or permanently; they then may use the best-interest standard to seek what is best for the child given the available options. They are not seeking what is ideal, because that may not be realistic, but what is best, all things considered, for the child given the available options.

Children as Research Subjects

Children are not responsible for their illnesses. The natural and social lotteries leave some children with diminished opportunities as a result of illness. Good health and social services may be essential to give these children a chance to flourish and develop their potential as self-fulfilled and self-determining persons. In addition, good healthcare helps children by preventing many illnesses and allows for early diagnosis and treatment. Good healthcare, however, is the product of study and research, and the problem is how research should be conducted to help children.

The ethical basis for research policy with children concerns promoting the same primary values that shape treatment decisions: enhancing well-being and opportunities. Because many children, like adults severely impaired with mental illness or retardation, lack the capacity to give informed consent, they are regarded as vulnerable research subjects. Like policy regarding treatment, research policy with children is shaped by different authority principles (who decides) and guidance principles (substantive directions about how decisions should be made). There is, however, an additional problem.

Pediatric research regulations and policy must deal with a dilemma: With too few protections, children selected as subjects may be exploited. If the regulations impose too many protections, however, it may become so difficult to conduct research that the knowledge base for making good decisions for children will erode. Different policy options try to solve this dilemma but do so differently:

1. The *surrogate* or *libertarian* solution allows the same sort of research with children as with other subjects if the parents consent. This solution may not offer adequate protection to children because it permits parents to enroll them in potentially harmful research even if it holds out no direct benefits to them. Parents' legal and moral authority presupposes the promotion of children's opportunities and well-being and the prevention, removal, or minimization of harms to them. Parents have no authority to enroll their children in potentially harmful research that hold out no benefits to them. Volunteering to put another person in harm's way may violate a guardian's protective role.

2. The *no consent–no research* or *Nuremberg* solution excludes children because children are not considered competent to give informed consent to being enrolled as research subjects. This view, expressed in the Nuremberg Code (Germany [Territory under Allied Occupation], 1947), seems too restrictive. It prohibits enrolling a child in a study even if the project could benefit the child directly. Moreover, to test the efficacy of treatments for distinctive groups, some members of those groups must be subjects. Competent, normal adults cannot serve as subjects in projects that test children's growth or maturity, drugs for premature infants, and treatments for children's life-threatening asthma.
3. The "risk-benefit" solution allows research with children if it benefits them directly or does not place them at unwarranted risk of harm, discomfort, or inconvenience. To balance the social utility of research with respect for and protection of children, this option stipulates that the greater the risk, the more rigorous and elaborate the procedural protection and consent requirements. Many countries, such as the United States, Canada, the United Kingdom, South Africa, Australia, and Norway, in addition to international organizations such as the World Health Organization in its *Declaration of Helsinki* and the Council for the International Organizations of Medical Science, favor this solution. Research should be approved by local boards known variously as institutional review boards (IRBs) ethical research committees (ERCS), or research ethics committees (RECs) and in some cases by federal boards as well. Approval is based on findings that subjects have been selected fairly and that the risks to them are minimized and reasonable in relation to the anticipated benefits of the study ("Protection of Human Subjects," 1993). Adequate provisions also must be made for the safety and confidentiality of subjects. Investigators must seek parents' informed consent. When possible, they also must obtain the child's assent, where assent means a positive agreement, not merely failure to refuse. Children's refusals are not binding when their parents and doctors judge that it is in their interests to participate, for example, in studies in which children may obtain a scarce resource to treat a deadly disease. This risk–benefit solution tries to determine whether the risks are proportional to the benefits for each individual and uses risk assessment to try to balance the social utility of encouraging studies that maintain respect for and protection of children's rights and welfare.

Using a likely harms-to-benefit calculation, U.S. regulations ("Protection of Human Subjects," 1993), as outlined below, specify four categories of research with children. As the risks increase, the regulations require increasingly more rigorous documentation of appropriate parental consent, children's assent, direct benefits to the child, or benefits to children with similar conditions. Local IRBs can approve studies only in the first three categories.

The first category of research permits research with no greater than a minimal risk provided that it makes adequate provisions for parental consent and children's assent. Many important studies are safe, such as asking children to perform simple and pleasant tasks. Using this category, investigators might gain approval to study at what ages preschool children can name colors, identify animals, and perform simple tasks such as stacking blocks on request.

The second category of research permits the approval of studies with greater than a minimal risk if (1) the risk is justified by the anticipated benefit to each subject; (2) the risks in relation to these benefits are at least as favorable to each subject as are the available alternatives; and (3) provisions are made for parental consent and the child's assent. This category permits a child to get an investigational drug that is available only in a research study. Moreover, because children have unique diseases and reactions, to study the safety and efficacy of many conventional, innovative, or investigational treatments for children, some children have to serve as subjects in controlled testing.

The third category of research permits research (1) with a minor increase over minimal risk that holds out no prospect of direct benefit to the individual subject; (2) in cases in which the study is like the child's actual or expected medical, dental, psychological, or educational situation; (3) in cases in which the study is likely to result in very important information about the child's disorder or condition; and (4) in cases in which provisions are made for parental consent and the child's assent. In using this category, investigators have been permitted to perform additional lumbar punctures on children with leukemia, who get them anyway, to help study that disease.

Research that cannot be approved under the first three categories may sometimes be approved if (1) it presents a reasonable opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of children; and (2) the study is approved by the secretary of the U.S. Department of Health and Human Services (DHHS) after consultation with a panel of experts about the value and ethics of the study and determination that adequate provisions have been made for public comment, parental consent, and the child's assent. In using this category investigators might gain approval to conduct studies to prevent or treat epidemics affecting children, such as the acquired immune deficiency syndrome (AIDS) epidemic, or a new infectious disease like the killers of the past (pneumonia, scarlet fever, diphtheria, and polio).

DIFFICULTIES. Unfortunately, the risk–benefit solution leaves key terms undefined or poorly defined, allowing different interpretations concerning when risks of harm are warranted and what constitutes a benefit (Freedman et al.; Kopelman, 2000, 2002; National Bioethics Advisory Commission [NBAC]). For example, consider the pivotal concepts of a "minimal risk" and a "minor increase over minimal risk." The federal rules state: "*Minimal risk* means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical and psychological examinations or tests" ("Protection of Human Subjects," 1993, section 102i). The first part of the definition focuses on everyday risks, and the second on routine examinations. (Interestingly, the National Bioethics Advisory Commision [2001] recommended dropping the second part of the definition in favor of the more permissive first part, whereas the Council for International Organizations of Medical Science [CIOMS] omits the first [Council for International Organizations of Medical Science, 2002].)

Kopelman has argued that this definition is morally and conceptually problematic, especially the part using "everyday risk": First, how should people establish thresholds for the probability and magnitude of harm used to identify everyday risks, and even if they solve this problem, why are everyday risks morally relevant for determining acceptable research risk? People's daily risks may include car accidents and terriorist attacks. Is it possible to know the nature, probability, and magnitude of these everyday hazards well enough that they could serve as a baseline to estimate morally acceptable research risks for children? It seems easier to determine that a study asking children to stack blocks is a morally acceptable, minimal-risk study than to estimate the nature, probability, and magnitude of whatever risks of harm people normally encounter.

Second, given the different hazards in different countries and communities, what locale or locales should be used to assess everyday risks in determining morally acceptable research? Some favor a relative standard by which minimal risk is judged against the background of the children's location, environment or condition. Others reject this "relativistic" standard in favor of an absolute standard, saying that all children should have the same standard; otherwise one reaches morally abhorrent conclusions such as that more risks can be taken with children in dangerous neighborhoods than with children in safe and affluent neighborhoods. Third, why should everyday risks of harm be regarded as morally relevant for determining that research risks are minimal when some everyday risks are great?

Fourth, if this is a useful and clear standard, why has there been sustained disagreement over whether common procedures should be viewed as having a minimal risk, a minor increase over minimal risk, or greater risk? Since the regulations appeared decades ago, there have been sustained and substantive differences among pediatric experts in both treatment and research settings about how to assess the risk of procedures such as venipuncture, arterial puncture, and gastric and intestinal intubation (Janofsky and Starfield). Investigators and others concluded that better standards of risk assessment in children's research had to be formulated (Janofsky and Starfield; Lascari; National Bioethics Advisory Commission; Kopelman, 2002).

In addition, the U.S. regulatory definition of minimal risk offers little guidance about how to assess psychosocial risks such as breach of confidentiality, stigmatization, labeling, and invasion of privacy. Risks are allegedly minimal if they are encountered ordinarily in daily life or during routine examinations. Doctors, nurses, and psychologists, however, "ordinarily encounter" many psychosocially sensitive discussions in routine examinations and testing, including those about family abuse, substance abuse, sexual preference, and diagnoses, any of which could affect how people are viewed or whether they will be able to get jobs or buy insurance. Moreover, psychosocial-risk assessment is an increasingly difficult problem. Some genetic and other testing has low physical risks, such as taking a drop of blood, but high psychosocial risks. For example, Huntington disease is a genetic condition that causes progressive dementia and loss of motor function typically when the person becomes an adult. A person known to have this condition could be denied a job or insurance or be stigmatized in the community. Thinking of risks of harm as merely physical ignores such profound psychosocial risks.

Moreover, there is no definition of "a minor increase over minimal risk," the upper limit of risk that many review boards can approve. The courts have begun to consider what risks of harm are permissible and may help standardize interpretations (Kopelman, 2002).

Even when it is agreed that the ethical basis for research policies with children is to promote their opportunities, well-being, fair treatment, and self-determination, it is difficult to articulate policies that balance the need to protect children and the need to gain knowledge. If research is not conducted with children as subjects, children may be denied the benefits of advances stemming from research and good information about which procedures or interventions promote health and prevent, treat, or diagnose disease. However, if children are enrolled as research subjects, vulnerable individuals who cannot give informed consent are being used.

Resource Allocation

Many children do not receive basic healthcare or social services. In some cases, countries that can afford to provide those services allocate insufficient funds for them. For example, the main health problems of children in the United States arise from failure to provide such basic care for children's allergies, asthma, dental pathology, hearing loss, vision impairment, and chronic disorders (Starfield; Newachecket et al.). Basic healthcare and social services promote children's well-being, enhancing their opportunities in fundamental ways and correcting some inequities caused by the natural and social lotteries. Children who are sick cannot compete as equals and thus lack equality of opportunity with other children. The more these conditions are easily correctable, as many of them are, the more unjust it is to leave children sick or disabled. Failure to provide children with basic healthcare and social services when a society has sufficient means is unjust on the basis of any of four important theories of justice: utilitarianism, egalitarianism, libertarianism, and contractarianism. This point of agreement among widely divergent positions serves as a powerful indictment and proof that as a matter of justice goods, services, and benefits should be redistributed more fairly to children to provide them with basic healthcare and social services.

Four theories of justice offer different guidance about how to allocate goods, services, and benefits. Proponents have used them to determine children's fair share of healthcare funding in relation to adults (intergenerational allocation) and ways to set priorities for funding within children's healthcare programs (intragenerational allocation). Each theory addresses what kinds of benefits, goods, and services should be provided to people as a matter of justice and how to choose from among programs when not all can be funded. Although there are many variations of these positions, each seeks a defensible standard to help make choices fairly.

UTILITARIANISM. Utilitarianism offers one solution to the problem of allocating healthcare justly between generations and among children's programs. In a well-known version, the philosopher John Stuart Mill (1863) argued that a just allocation provides the greatest good to the greatest number of people; the utility of following principles of justice is so great that these are among the most fundamental moral principles. People should not consider only the utility of isolated acts, Mill maintained, but also the rules of conduct that, if adopted and adhered to, maximize utility. Actions are right insofar as they fall under such a rule.

In their efforts to maximize utility for the greatest number in accordance with just rules, utilitarians seek to prevent or cure the most common illnesses, adopt programs that help many rather than few persons, and use funds where they will have the greatest impact for the most people. For example, utilitarians would resist funding expensive organ transplantations that help relatively few persons for a short time if those transplantations sidetracked programs that could help many people.

Some of the least expensive and most beneficial interventions are education about the benefits of exercise, a good diet, prevention of teenage pregnancy, and avoidance of alcohol, tobacco, and harmful drugs (U.S. Department of Health and Human Services). Relatively inexpensive interventions can aid in the treatment of many problems common in childhood, including vision impairment, hearing loss, dental pathology, allergies, and asthma, as well as the variety of chronic disorders that cause considerable functional impairment (Starfield; Newachecket et al.). Utilitarians favor providing such healthcare for children because it greatly increases their well-being and opportunities. It is socially useful and cost-effective because it can prevent costly illnesses and benefit the current generation of adults, who, when aged, will need support from a healthy, stable, and productive work force.

Utilitarians might even favor preferential consideration of children. Interventions that benefit both children and adults generally offer children the most years of benefit. Those added years increase the net good and thus could justify some preference toward children. For example, in some countries children receive dental care that is unavailable to adults because it has lifelong benefits and prevents costly future problems. Daniel Callahan (1987, 1990) believes that the young have a stronger claim to healthcare than the old and should be given priority; the healthcare system should see as its first task helping young people become old people and help older people become still older only if money is available. He argues, moreover, that medicine should give its highest priority to the relief of suffering rather than the conquest of death.

In choosing among children's programs for funding, defenders of utilitarianism assess the net benefit for the community of children. A utilitarian would favor funding routine care, mass screening, and prevention programs that help many children rather than the development of costly therapies that help few children. Consequently, utilitarians probably would resist using state funds to give otherwise normal short children growth hormone for many years, at a cost of many thousands of dollars a year, to increase minimally their adult height. Utilitarians, however, might permit private insurance or payment (in a multitiered healthcare system) for these and other services if it increased or did not diminish the net good.

Defenders of utilitarianism presuppose that it is possible to calculate what is best for the greatest number, but critics question that presumption (Brock). Moreover, critics state, whole groups could be excluded from beneficial healthcare for the sake of the common good, such as people with expensive or rare conditions and those with illnesses that are stigmatizing.

Utilitarians might respond that society would suffer from such exclusions, showing that this is not a good option even if one uses utilitarian calculations. This presupposes, however, that enough people would know about the exclusions and be distressed enough to alter the calculation. Sympathy for utilitarianism may depend on beliefs about whether it is possible to make utility calculations and whether a theory is acceptable if it permits people to exclude some groups for the common good regardless of the results of the utility calculation (see Brock). Defenders of rule utilitarianism, a version of utilitarianism that clarifies the role of rules in assessing utility, respond that, properly understood, utility prohibits unfair exclusions of individuals or groups; people adopt rights and justice principles because they are useful, and unjust exclusions undercut the utility of those rights and principles for all (Buchanan; Mill). Even if it is cost-effective or politically expedient to exclude a particular person or group, that exclusion undercuts something more important for all of us, namely, fair rules.

Utilitarians favor basic healthcare and social services for all children because of the utility to the children and to society. For example, suppose society could save a great deal of money by excluding certain children from healthcare services. Although this might save money in the short run, defenders of rule utilitarianism might argue that it is unjust because adapting and adhering to the rule that all should receive basic services are more useful in the long run than is excluding a few to save money. Accordingly, the rule that all children should receive basic care is vindicated because the rule is useful and making exceptions is less useful.

EGALITARIANISM. Egalitarianism is a theory of justice whose proponents attempt to solve allocation issues and intergenerational disputes by holding that access to the same benefits, goods, and services should be provided to everyone on the same basis. It is a principle of justice that requires society to try to make all people's objective net well-being or opportunities as equal as possible. Most people do not want dialysis because they do not have kidney disease, but people want access to dialysis if they should need it. Egalitarians, then, do not want exactly the same treatment for everyone as a condition of justice but want everyone to have access to the same goods, services, and benefits on the same footing.

Egalitarians look at outcomes of distribution schemes to determine whether distributions are fair. Accordingly, proponents of egalitarianism judge it to be unfair, for example, that adults over sixty-five can get diabetes and asthma treated free of charge in the United States but children cannot. Age might be a determinant in deciding who gets benefits, goods, and services, but only as one among other prognosticators of success. For example, people over eighty or under two years of age might be excluded from consideration for a certain type of surgery because they are unlikely to survive the procedure.

Defenders of egalitarianism hold that what is provided to one person should be available to all similarly situated persons. The advantages of good healthcare are such that in fairness they should be distributed on as equal a basis as possible. There should not be a multitiered system with one level of goods and services for the rich and another for the poor. If society allows some normal short children to have growth hormone for many years at a cost of thousands of dollars a year, all who are similarly situated should have access to similar services. For expensive or scarce resources, many egalitarians favor lotteries so that all those who are similarly situated have an equal opportunity and are recognized as having equal worth (Childress; Veatch). Consequently, if organs for transplantation can be provided only to some children, there should be a lottery among those who meet whatever standards are set. In this way people acknowledge the value of each person and the importance of fair access of all to scarce or costly benefits, goods, and services. One difficulty for egalitarians is that some people's needs are so great that they could consume most of the resources of a healthcare system. Robert Veatch (1986) tries to defend a commitment to those who are so disadvantaged that they could use unlimited resources while placing limits on their claims on other members of society.

In defending egalitarianism it is difficult to clarify what kind of equality is important. If it is *access* to the same benefits, goods, and services, age bias and discrimination could be introduced through preference for certain benefits, goods, and services. For example, treatment for prostatic hyperplasia and Alzheimer's disease helps only adults; other care helps adults much more than children, such as treatments for heart disease or lung cancer and treatments at the end of life. Some funding choices discriminate by excluding services equally and for all diseases afflicting people with stigmatizing conditions, such as sexually transmitted diseases. This parallels a problem of utilitarianism in which whole groups can be excluded if society decides, to save money, that none will have treatments for certain conditions.

If, however, equality is understood in terms of *outcomes* rather than access, age bias and discrimination also can be introduced through the method of collecting and presenting data (Starfield). In the United States, for example, data collection to determine the health of different populations focuses on life-threatening illnesses and death. Relatively few children have such morbidity or mortality in comparison to adults, giving the impression that children are generally healthy. This impression, however, is a consequence of how the data are collected. Most children's needs stem from problems that are not life-threatening illnesses but have a profound effect on health, such as dental problems, vision impairment, allergies, and asthma. Moreover, although the death rate of children in the United States is low compared with that of adults, it is the highest among equally affluent countries (Starfield). Looking at certain outcomes, then, promotes an unfair view of childhood health and morbidity. Programs based on such data can create unjust age bias against children. Thus, treating everyone as equals is problematic if the measures favor certain groups.

People's willingness to defend egalitarianism depends in part on whether they believe it is fair to restrict choices by insisting that no one can have healthcare that cannot be provided to all on the same basis. If people can squander their assets on entertainment and clothes, it seems unfair to insist that they cannot spend it on marginally beneficial, exotic, or expensive healthcare for their families. Some respond that rich people dread single-tiered systems because it means that they cannot have their usual advantages through money and forces them to live by the same rules as others. They argue that allocation of healthcare (especially in life-and-death situations) is too important to be left to unregulated personal choice and market forces. Some defenders of egalitarianism modify their view to permit people to use their discretionary resources as they wish.

LIBERTARIANISM. Libertarians generally agree that competent adults should not be forced to do anything by the state unless it prevents harm to third parties. Coercion is permissible to prevent theft, murder, physical abuse, and fraud; enforce contracts; and punish competent people for harming others (Buchanan). The best-known defender of this view, Robert Nozick (1974), follows the eighteenth-century philosopher John Locke in maintaining that people's right to their fairly obtained property is fundamental and determines the proper functions of the state and the moral interactions among individuals.

People are entitled to their holdings and may dispose of them as they wish, according to this view. They argue that the state should not redistribute people's wealth in accordance with a pattern of distribution that examines outcomes (such as utilitarianism and egalitarianism) or uses coercive measures to take people's holdings, and adults should be free to fashion social arrangements out of their ideas of compassion, justice, and solidarity (Engelhardt). People do not have a responsibility to be charitable, say libertarians, but acts of charity are praiseworthy and should be encouraged.

Libertarians hold that children's healthcare is the responsibility of their guardians, not the state. Market forces of supply and demand and choices about how to use their own money should shape the kind of healthcare people select for themselves and their children. If parents want to pay for special services such as growth hormones or repeated organ transplants, they should be permitted to do so. H. Tristram Engelhardt, Jr., argues that societies can decide morally who is entitled to healthcare of a certain kind within certain limitations. However, a society does not, for example, have "the moral authority to forbid consensual acts among agreeing adults, such as agreement to sell an organ" (Engelhardt, p. 10).

Sympathy for libertarianism depends on whether it is believed to offer enough protection for people, especially children and impoverished or incompetent adults. This view arguably benefits the wealthy and powerful; because most children are neither, it might create an age bias against children. Libertarians argue that competent adults should pay their own way, but when do people really do that? Typically, people's healthcare insurance gives them access to institutions heavily subsidized by public money. People who "pay their own way" may pay just a bit more for many more services. Those who cannot pay more are unfairly excluded. Libertarians might agree that separate institutions should be set up in which people truly pay their full share even if that would mean that few could afford such added care.

Libertarians usually favor special state protection for children, allowing the state to interfere with parents who endanger, neglect, or harm children. This can include providing children with a "safety net" of basic healthcare and social services. A system favoring special benefits based on redistribution of wealth for competent adults, however, is considered unjust. Hence, a system like that in the United States that provides many social and health benefits to competent and even wealthy adults but not to children, for example, in the allocation of healthcare benefits, goods, and services, would be viewed by libertarians as unjust.

CONTRACTARIANISM. Contractarians hold that distributions of social goods are fair when impartial people agree on the procedures used for distribution. The best-known defender of this position is John Rawls, who in *A Theory of Justice* (1971) and *Political Liberalism* (1993) contends that people form stable and just societies by building a consensus that merits endorsement by rational and informed people of goodwill.

This entails a commitment to three principles of justice. First, "each person is to have an equal right to the most extensive system of equal basic liberties compatible with a similar system compatible for all." Second, "offices and positions are to be open to all under conditions of equality of fair opportunity—persons with similar abilities and skills are to have equal access to offices and positions." Finally, "social and economic institutions are to be arranged so as to benefit maximally the worst off" (Rawls, 1971, p. 60). These principles are ordered lexically such that the first, the greatest equal-liberty principle, takes precedence over the others when they conflict and the second, the principle of fair equality of opportunity, takes precedence over the third, the difference principle. Nowhere is healthcare as a right mentioned specifically in Rawls's attempt to frame the basic structure of a just society. This is understandable because a society may not have enough healthcare goods, services, or benefits to distribute. In a society that does have such goods, services, and benefits, however, their fair distribution seems central to promoting fair equality of opportunity and benefits to the worst off.

Norman Daniels (1985), building on Rawls's work, argues that society should provide basic care to all but redistribute healthcare goods and services more favorably to children. The moral justification for giving children access to basic healthcare, argues Daniels, rests on a social commitment to what he and Rawls call "fair equality of opportunity" (or affirmative action). Healthcare needs are basic insofar as they promote fair equality of opportunity. Healthcare for children is especially important in relation to other social goods because diseases and disabilities inhibit children's capacity to use and develop their talents, thus curtailing their opportunities. For example, children cannot compete as equals if they are sick or cannot see or hear the teacher. Thus, a society committed to a fair equality of opportunity for children should provide adequate healthcare.

Daniels holds that to assess whose needs are greatest, people have to use objective ways of characterizing medical and social needs; the ranking of needs helps determine what is basic and who profits most from certain services. Using the difference principle, free, additional service might be provided to the poorest children to help level the playing field so that they could compete more effectively with those from more affluent homes. Unlike utilitarians, who would be guided by where money would have the greatest overall impact on the health of the greatest number of children, contractarians try to bring all children of similar talents to the same level of functioning so that they can compete as equals.

Contractarianism has certain difficulties. Some regard it as a method for arriving at ethical principles, not as an alternative to views such as utilitarianism, egalitarianism, and libertarianism (Veatch). Accordingly, those who think it generates a unique theory need to clarify how it has a distinct content. In addition, it is hard to specify what is meant by "people's normal opportunity ranges" or to decide how to apply fair equality of opportunity. This position seems to suggest (arguably similar to egalitarianism) the unsatisfactory consequence that people should fund treatments, however exotic and costly, that offer a chance for the most disadvantaged to improve their normal opportunity range irrespective of the needs of the many; gifted children could be denied opportunities to excel so that others could enhance their normal opportunity range or be brought to the level of well-being and opportunities of average children. Another problem is that contractarianism presupposes, like utilitarianism, that there is a fair and objective system for ranking medical and social needs and deciding who benefits most from services (Brock). It is unclear whether such a comprehensive and objective ranking is possible. Such "objective" choices about appropriate or useful programs might be mixed with social and personal biases. These problems, however, do not undermine the contractarians' commitment to the justice of equal opportunity for children, including the fairness of providing basic health and social care for children.

A PROPOSED CONSENSUS. Each of these theories of justice supports the claim that children are entitled to basic healthcare and social services to correct inequalities and promote their flourishing as free and self-determining people who can develop their potential. The fact that defenders of such divergent approaches agree on this entitlement reflects a consensus that children's distress ought to be relieved whether it is related to inadequate healthcare, poverty, abuse, neglect, malnutrition, or exploitation. A primary duty of a just society is to promote fairly its children's well-being and opportunities to become self-fulfilled persons through access to basic healthcare and social services and to address the inequities resulting from life's natural and social lotteries. Children living in low-income homes in the United States are two to three times as likely as children in high-income homes to be of low birth weight, get asthma and bacterial meningitis, have delayed immunizations, and suffer from lead poisoning. Poor children are also three to four times as likely as rich children to become seriously ill and get multiple illnesses when they become sick (Starfield).

The gap between the rich and the poor is increasing, and the rise of poverty is most rapid among children. Healthcare costs, driven higher by an aging population and increased demands for expensive technologies, will make it harder for societies to allocate costs justly. In addition, the AIDS epidemic has left many children sick, orphaned, or both, and many children live in the developing world, where resources that could help them are meager. Consequently, disputes involving intergenerational and intragenerational allocation from national and international funds are likely to continue as programs compete for funding. Because children depend on others to advocate for them, adults should continue to set aside their individual interests and consider children's well-being, needs, and opportunities as a matter of justice.

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SEE ALSO: *Autonomy; Coercion; Competence; Research, Human: Historical Aspects; Students as Research Subjects; Surrogate Decision-Making;* and other *Children* subentries

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IV. MENTAL HEALTH ISSUES

Conceptualizing a domain of “mental health and children” represents an advance in cultural and societal thinking. The various impediments to this view are well known among students of the history of childhood—at least in Western cultures. These include the concept of children as property, and the broader ignorance and denial of children’s affective and cognitive development.

More modern concepts of children and childhood provide a foundation for focusing on the mental health of children as a vital concern. One testament to this development is the passage in 1989 of the United Nations *Convention on the Rights of the Child*. The convention provides a view of children and childhood in which mental-health concerns are central, one that goes beyond the ideas contained in the 1959 *Declaration of the Rights of the Child*.

The convention makes it clear that mental-health issues (e.g., policies that facilitate prevention, and access to services, among others) are primary implications of children’s rights. Children, the convention asserts, are entitled to basic psychological resources. These include mandates to ensure family and social identity, empathic and stable care, protection from exploitation, and rehabilitative treatment when experiencing mental-health problems or being exposed to trauma, such as war and abuse.

This rights-focused orientation to the mental health of children reflects a growing appreciation for the scope, depth, range, and subtlety of children’s experience. Indeed, in the field of children’s mental health there has been a growing recognition and empirical exploration of the existence and characteristics of child variants and precedents of most major adult mental-health problems. Important examples are those of schizophrenia, post-traumatic stress disorder, and depression.

Schizophrenia

There is evidence that schizophrenia, one of the most devastating mental illnesses with a whole life prevalence rate of about 1 percent, is a developmental disorder, tracing its origin to abnormalities in brain development, which cause subtle and non-specific behavioral changes in childhood and later lead to full blown psychosis, usually in adolescence. Duration of untreated psychosis seems to be a significant predictor of poor outcome (Harrigan et al.), thus making early identification and treatment of first-episode schizophrenia especially important. However, because of the limited specificity and predictive value of the known risk factors for schizophrenia, treatment of asymptomatic subjects with psychotropic drugs is considered unwarranted from a clinical and ethical perspective (Heinssen et al.).

Childhood Experience of Trauma

Trauma—the overwhelming arousal and cognitive dislocation that results from experiencing horrible events—is an important field of study for those who seek to understand mental health in childhood. As with depression, it was once thought that children were incapable of experiencing genuine psychological trauma (Van der Kolk). But research and clinical experience since 1980 have established that trauma and post-traumatic stress disorder play significant roles in the mental health of children.

Children experience trauma in many settings: televised violence, community violence, domestic violence, war, and homelessness. All point to the need to develop a better understanding of the impact of trauma on childhood as part of a larger commitment to understand the mental health issues facing children.

Children may suffer from post-traumatic stress disorder as a consequence of their experiences at home, in school, or in the community. Symptoms in children include sleep disturbances, daydreaming, re-creating trauma in play, extreme startle responses, diminished expectations for the future, and even biochemical changes in their brains that impair social and academic behavior. Trauma can produce significant psychological problems that interfere with learning and appropriate social behavior in school and the family, the bedrocks for mental health in childhood.

The children least prepared to master trauma outside the home are those who experience psychological, physical, or sexual maltreatment at home. Hundreds of thousands of children face the mental health challenge of living with chronic community violence, whether it derives from war or domestic crime. Some 30 percent of the children living in high-crime neighborhoods of Chicago had witnessed a homicide by the time they were fifteen years old, and more than 70 percent had witnessed a serious assault (Garbarino et al.). In refugee camps around the world, children witness and are subject to violence and exploitation.

The experience of community violence takes place within a larger context of risk for these children. They are often poor; often live in families where the father is absent; often contend with their parents' depression or substance abuse; often are raised by parents with little education or few employment prospects; and often are exposed to domestic violence. This constellation of risk by itself creates enormous mental-health challenges for young children. For them, the trauma of community violence is often literally the straw that breaks the camel's back.

Depression in Children

Until the 1970s, many clinicians and scholars expressed doubt that children experience *genuine* depression. The common view held that children were incapable of experiencing full-blown depression. It is clear that children do experience depression, but do so and express it differently from adults (e.g., in offering less verbalization concerning mood and symptoms). With proper developmentally appropriate rewording, the same diagnostic criteria for major depression that are used in adults can apply to children. Depression becomes increasing common as the child grows and reaches a prevalence rate among adolescents that is comparable to that in adults. It is estimated that up to 9 percent of adolescents meet current criteria for major depressive disorder (MDD) and up to 25 percent had suffered from it by their late teens (Kessler et al.). While depression seems to equally affect boys and girls before puberty, female teenagers have a substantially higher rate of depression than their male peers. As in adults, in youth depression is a major risk factor for suicide, which in 2003 ranked third among the leading caused of death among adolescents.

Some children mask their depression by denying symptoms to avoid humiliation and embarrassment, to *protect* vulnerable adults who do not appear to be able to tolerate the child's sadness, or to avoid therapeutic intervention that children perceive adversely (e.g., a child may resist the idea of missing recreational activities to attend therapy or may not acknowledge symptoms of depression to avoid causing parental upset or even conflict).

More generally, one of the important breakthroughs in understanding the mental health of children has been the recognition that "what children can tell us depends upon what adults are prepared to hear." That is, children reveal their mental health status in ways that make sense to adults *if* the adults have the technical skill and psychological availability necessary to receive the child's messages. For adults to be responsive to the mental health issues facing children, they need to understand some basic features of child development, particularly the operation of risk and opportunity.

Risk Factors and Opportunities

Children face a variety of opportunities and risks for mental health and development because of their genetic makeup and because of the social environments they inhabit. Like in other areas of medicine, genetic and environmental factors act in concert in increasing or decreasing the risk for mental disorders. For instance, it has been determined that the risk for antisocial behavior was increased among maltreated boys who also had a genotype resulting in low levels of monoamine oxidase A (MAO), which is an enzyme involved in the metabolism of neurotransmitters (Caspi et al.). The importance of these findings rests on the fact that it was only the coexistence of maltreatment and low MAO expression genotype that conferred an increased risk, whereas either condition in isolation did not. Thus, environment can affect mental health through its impact on the genetically determined makeup of the child. In addition, specific environmental toxins can negatively impact the brain during development. For example, environmental lead poisoning of children may lead to mental retardation and/or behavioral problems. There are also many examples of positive impact of environment during development, such as proper education and non-abusive discipline, which can prevent the emergence of mental disorders even in the presence of an increased genetic risk for these conditions. The complex interaction of risk and protective factors, either environmental or genetic in nature, has profound implications for understanding the mental health of children. The *accumulation of risk factors* is especially important. For instance, the average IQ scores of four-year-old children were found to be related to the number of psychological and social risk factors present in their lives, including socioeconomic conditions as well as intrafamilial, psychosocial factors (Sameroff et al.). But this research reveals that the relationship is not simply additive. Average IQ for children with none, one, or two of the factors is above 115. With the addition of a third and then a fourth risk factor, the average IQ score drops precipitously to nearly eighty-five, with relatively little further decrement as there is further accumulation of five through eight risk factors. This is important because IQ plays an important role in resilience and coping. Thus, low IQ is a risk factor for children's mental health.

Windows of opportunity (opportunity that arises at particular points in development) for intervention on behalf of the mental health of children appear repeatedly across the life course. What may be a threat at one point may be harmless or even developmentally good for a child at another. Classic analysis of the impact of the Great Depression of the 1930s in the United States reveals that its mental health effects were felt most negatively by young children (Elder). However, some adolescents, particularly girls, benefited from the fact that paternal unemployment often meant special opportunities for enhanced responsibility and status in the family.

Opportunities for development include meaningful relationships in which children find material, emotional, and social encouragement compatible with their needs and capacities at a specific point in their developing lives. For each child, the exact combination of factors depends upon temperament, family resources, potential, skill, and the role of culture in defining the meaning and social significance of specific characteristics or behaviors, within some very broad guidelines of basic human needs that are renegotiated as development proceeds and situations change.

Participation of Children in Mental Health Research

Like in other areas of health, human research has shown to be the most efficient means of acquiring critical knowledge on how to prevent and treat mental illness among children. Direct participation of children in research is considered necessary as research in adults is neither fully relevant nor sufficient due to developmental differences. Thus, treatments of proven efficacy and safety in adults have been found to lack efficacy or to be toxic in children. Child participation in research is subject to special ethical requirements that are in addition to those common to all human research (Code of Federal Regulations). Based on the type of research activity, the concepts of *favorable risk/benefit ratio, minimal risk,* and *minor increase over minimal risk* are especially important in determining whether a particular study is ethically acceptable (Vitiello et al.).

Conclusions

The right to mental health is considered an integral part of children's basic rights. Recent years have seen major advances in understanding child development, especially with respect to the interface between neurobiological and psychosocial components and the interaction between genetic endowment and environment. Research on child mental health has emerged as an essential means of developing effective and safe mental health preventive and treatment interventions for children. Participation of children in research raises important ethical issues, thus making child mental health bioethics a particularly lively and rapidly developing area.

JAMES GARBARINO (1995)
REVISED BY BENEDETTO VITIELLO

SEE ALSO: *Abuse, Interpersonal: Child Abuse; Confidentiality; Emotions; Institutionalization and Deinstitutionalization; Mental Health; Mental Illness; Patients' Rights: Mental Patients' Rights;* and other *Children* subentries

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CHRISTIANITY, BIOETHICS IN

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As western culture moves ever deeper into the period characterized in the mid-twentieth century by historian Christopher Dawson as "secularized Christendom," the emerging interdisciplinary field that since 1970 has gone by the name *bioethics* can be understood only as a microcosm of the whole. In certain defining respects the impact of the Enlightenment of the eighteenth century was felt uniquely in the closing decades of the twentieth, in effects good and bad. The effacing of religious discourse from the public square, and the steady fragmentation of the professions under the reductionist pressures of economic and other social forces, show this delayed impact in contexts that have radically shaped the possibility of a bioethics rooted in the Christian vision of the western tradition. If religion is removed from the metaphor of public affairs, it is only in translation that the Christian worldview retains any opportunity to shape the public institutions of the culture. The predicament of Christianity in bioethics at the cusp of this third millennium C.E. lies precisely here. Yet at the same time, the subject matter of bioethics could hardly be of greater moment to those who hold the Christian view of the world.

The core question of which every bioethics issue is ultimately derivative is that of human nature. The vision of human beings defined by their creation in the image of God sets the Christian agenda, to be addressed within public and professional contexts in translation. As has been somewhat ruefully observed (Verhey and Lammers), the exercise of translation has itself led to the *marginalization* of religion. Stephen Lammers notes it at the micro level: The ubiquitous hospital ethics committees, often established under the tutelage of chaplains or other religiously-motivated professionals, immediately take their place in the secular institutional life and language of even religious hospitals. At the macro level, as the ebb tide of the sea of faith runs fast, it has become standard practice to translate Christian moral argument into secular language for public purposes. As a communications strategy in a changing culture, this is perhaps as inevitable as it is estimable. Yet the strangely invidious position in which it places the Christian religion has profound consequences for Christian engagement in bioethics. So it is worth exploring at more length the dynamics of bioethics on "Dover Beach" (Matthew Arnold's elegy on the collapse of the Victorian age of faith).

History of Bioethics

The half-century history of bioethics is emblematic of the relations of Christianity and the culture of the west. Arising as an interdisciplinary field in the aftermath of World War II, still in its old name of *medical ethics,* it focused the new ethical uncertainties of the generation of Joseph Fletcher. The promulgation of the *Declaration of Helsinki* by the World Medical Association (WMA) was intended to reassert Hippocratic medical values as the foundation for the reconstruction of medicine in light of the Nazi horrors revealed in the so-called "Doctors' Trial" at Nuremberg. Yet its supplanting of the Oath (a pagan document that was nonetheless powerfully theistic in orientation and had long sustained the theological ethics of the Western medical tradition) with a *Declaration* (that could of course be revised by vote, as it would be in response to liberal abortion) set the scene for the reconstruction of medical values on fresh, open-ended, terms. Powered by the continuing cultural weakness of the Christian religion and a succession of new scientific and technical achievements (and corresponding dilemmas) in medicine in the second half of the twentieth century, bioethics has emerged as the quintessentially ambiguous gift of the church to a culture struggling to free itself from the entailments of Christendom. The general failure of a *Christian bioethics* to take hold even within the churches and their educational and medical affiliates has led to a blending of religious and secular in a manner that, for all the good intentions of religious contributors, has tended to extinguish their distinctive character and give primacy to the secular debate and its categories. Thus the most prestigious American graduate program in bioethics is located at an institution of the Society of Jesus (Georgetown); yet its programmatic importance for the development of the discipline is focused in its advocacy of the *principlism* epitomized in Tom Beauchamp and James Childress's influential *Principles of Biomedical Ethics*, the embodiment of secular bioethics.

In Europe, by contrast, where the pattern of religious observance is in general substantially lower than in the United States, Christian participants in the bioethics community tend to be more distinctive in their approach, and in turn the community more accepting of religious perspectives. For example, the Roman Catholic university of Louvain (in the Netherlands) is overtly religious and theological in its approach; and the European Association of Centers of Medical Ethics, the major institutional network, includes a significant minority of explicitly Christian institutions, Catholic and Protestant. The explanation of this contrast lies in wider European–United States differentia, including assumptions about church–state issues and the public legitimacy of religious speech, and the more tradition-conscious nature of European debate, in which *medical ethics* remained for a generation the default term and bioethics was often noted as an Americanism; though the Council of Europe established in the 1980s an Ad Hoc Committee on Bioethics (CAHBI), its major fruit was the European Convention on Human Rights and *Biomedicine* (a favored European term). In parallel, in Europe the continuance of the idea of bioethics as an interdisciplinary field, in which theology is a legitimate participant, can be observed; this stands in marked contrast to the increasing specialized and reductionist approach to bioethics in the United States as a secularized quasi-discipline of its own.

The *magisterium* has given clear guidance to faithful Catholics on many of the questions of bioethics, but there has not emerged a major *school* of Roman Catholic writers within or even over against the bioethics community. By the same token, the substantial growth of conservative Protestantism in the United States during this period, despite its influential political stance on the question of abortion, has failed to initiate a commensurable intellectual movement in bioethics. The tendency of Protestant and Catholic participants has been to aggregate themselves to the secular bioethics mainstream, as they have played their own ironic part in the marginalization of the dominant tradition of western medical ethics (their own). Harder to explain is their failure to develop in parallel serious centers of intellectual gravity for their distinctive bioethics agendas, especially in the United States. This is more surprising in the case of the Roman Catholic church, possessed as it is of research universities and an extensive system of hospitals that have generally maintained stronger connections with their Catholic roots than their Protestant equivalents. As Albert R. Jonsen comments, even "theologically trained bioethicists … remain, in their bioethical analyses, outside the faith" (p. 58).

Christian Theology and Bioethics

From its beginnings, Christianity has displayed an interest in questions of health and healing that has verged on preoccupation. The gospels tell the story of one who went about *doing good* often in the form of miraculous interventions in the form of healings (throughout the Gospels) and, in certain cases, resurrections (e.g., Lazarus). In the ensuing story of the church the care and healing of the sick has had a special place, and medical missions have often been at the heart of the church's missionary thrust. In light of what is often taken to be a Christian focus on the life to come and the transitory nature of life in this world, this enduring theme of Christian service to health here and now may seem curious. Though Christian traditions have differed markedly in their approach to *miraculous* healing understood as a spiritual gift—denied absolutely by some, ignored by many, practiced as central to their faith within the Pentecostal and related traditions—the practical focus on medicine and nursing has led to the development of major hospital systems in the United States as well as mission hospitals in many centers of the developing world. Jesus's ministry focus on healing, evidence of miraculous healing in the early church, and the fact that much of the New Testament (Luke, Acts) was written by a physician, lie in a theological context that is not widely understood but sets the place of medicine at the heart of the Christian vision. Within orthodox Christian theology, explicated first and most fully in the Pauline corpus in the New Testament, the origins of human death and the disease that presages mortality are treated as fundamentally unnatural, the consequence of divine judgment on human sin (Romans 5). By the same token, among the benefits of the new order in Jesus Christ, who has stood in as representative and substitute and taken our death penalty as his own, will come not simply the resurrection but, specifically, the *redemption of the body* (Romans 8) as the final undoing of sin and its dire effects. This readily explains the focus on healing, as anticipatory of the final redemption; and the dramatic resurrections even of those who would *die again* like Lazarus. Whatever else these statements mean, they serve as object lessons in the faith that grant a sampling of the kingdom that is to come.

Behind these concerns lies the question that is emerging with increasing candor as the subject matter of contemporary bioethics conversation, the nature of human being. Within the Judeo-Christian tradition the answer has been unambiguous and, in the context of Western culture, profoundly influential. Human beings are constituted by their bearing the divine image (*imago Dei*), and from that fundamental fact flows their unique and inviolable dignity as persons. As the agenda in bioethics shifts from discussion of conditions under which human life may be taken (abortion, euthanasia, embryo experimentation, in the context of what we call here Bioethics 1) to our employment of the fresh manipulative powers that biotechnology is urging into our hands (cloning, inheritable genetic modifications, cybernetics—Bioethics 2), the relevance of this fundamental understanding grows markedly. Whether the churches and their theologian-ethicists will find it within themselves to rise to these immense challenges remains to be seen.

In light of the *imago Dei* question, and a historic commitment to the questions of sickness and healing, it is extraordinary that the distinctively Christian contribution to bioethics has, after an initial firm beginning, rapidly lapsed into a desultory state in which Christian and secular interpreters are generally indistinguishable; only a minority report offers trenchant engagement from within the "distinctive vision" of the Christian worldview. This is all the more surprising since the two most influential figures in the first generation of bioethics were theologians, who actually wrote explicitly theological ethics (from very different perspectives): Joseph Fletcher, whose innovative book *Morals and Medicine* (1954) framed the questions and sought radically fresh approaches in the 1950s, in effect seeking from the inside to subvert the Christian tradition at every key point and prepare the way for the post-Christian bioethics to come; and Paul Ramsay, whose work in the 1960s and 1970s set out a massive defense of Christian ethics even as he engaged the philosophy and emerging jurisprudence of his day.

As commentators have widely noted (Verhey and Lammers; Jonsen), the tendency has been for Christians writing in bioethics to be accommodated to the secular mainstream that since the waning of Ramsay's influence has set the tone for American bioethics. Across Catholic and Protestant thought alike we may note a spectrum of responses. At one end are writers who have essentially been absorbed by the categories and conclusions of the secular bioethics flow. In the center are others who while generally adopting the terminology of secular bioethics have sought to influence or restate it in terms that reflect Christian convictions; or, perhaps, to translate key components in the new bioethics into terms that are related to Christian theology. At the other end are those who take a classical approach from within the Christian tradition. While they sometimes use the public speech of secular bioethics, they are translating distinctively Christian ideas that are developed in explicit theological categories.

Throughout the second half of the twentieth century—from Joseph Fletcher on—much of the bioethics debate focused substantively on the question of the sanctity of human life (abortion, euthanasia, the use of human embryos in research, protocols for organ transplant, definition of death, scare resource allocation, and others), and procedurally on autonomy as the organizing principle of the new bioethics (centered on the role of the patient in decision making, and symbolized by the advanced directive and its culture of individualism in end-of-life choices). Indeed, the movement of bioethics has tended to be from substantive to procedural, and the bioethics literature is little focused on the rights and wrongs of such questions as abortion. The euthanasia debate, potentially of vast significance though on the sidelines of bioethics as a public policy concern, is encapsulated in the focus on *physician-assisted suicide,* which essentially turns substance into protocol. The sanctity of life, long the central feature of our civilization's medical values though seen by many in the bioethics community as perverse, is rarely a locus of bioethics debate; its central place in a Christian bioethics, stemming from the Judeo-Christian doctrine of the creation of human beings in the image of God, has had slight impact on the bioethics mainstream. Peter Singer's *speciesist* challenge—an upending of the *image Dei* that suggests it is as irrational and as unethical as racism—has evoked little Christian response.

The Future: Emergence of Bioethics 2

A similar spectrum of responses from those writing within the Christian tradition is already evident as the questions of Bioethics 2 begin to focus discussion. The advent of in vitro fertilization in the late 1970s heralded a developing agenda in which the focus would cease to be on the old clinical ethics with its dilemmas grouped around the sanctity of life and move to the new manipulative powers of biotechnology. However, one decisive difference is now evident. As a range of fundamentally new questions is raised for biomedicine and the human good, the Christian mind is one generation removed from the influence of Ramsey and still further from the older tradition of candid theological engagement with the earlier issues of bioethics. The prospect of cloning and germline genetic interventions, coupled with crucial policy issues focused in patent law, reveal the paucity of Christian resources since the fundamental questions of anthropology that are at stake in these debates have been comprehensively neglected by theologians and Christian bioethicists alike. C.S. Lewis's prophetic essay *The Abolition of Man* is widely quoted in the near-absence of more recent and more detailed theological reflection on what is widely agreed to be the most serious set of questions ever to have confronted the human race.

These unfolding questions raise the most profound concerns, both for the Christian understanding of human procreation and of human nature itself. The significance of such basic theological themes as the nexus of marriage/sexuality/family and the nature of human being itself are at stake, as the frontiers of the debate move from whether and when life may be taken to the logic of procreation-reproduction and the manipulative capacities of biotechnology to re-make human nature. It is for Christians an open question whether it is worse for life that is made in God's image to be taken, or for life to be made in an image of our own devising, in a wholly fresh assault on the sanctity and dignity of human being. There is no greater need than for fresh exploration of the significance of both the *imago Dei* and the incarnation of Jesus Christ for our human nature in light of the new, emerging powers of biotechnology and cybernetics. The challenge to Christian theology is both to articulate the distinctive implications of the Christian understanding of human nature for Christians themselves, and then, with equal vigor, to translate that understanding into public terms, drawing on the common language and values of our cultural tradition and engaging in arguments from natural law. Christian thinkers have so far shown little appetite for either of these tasks.

NIGEL M. DE S. CAMERON

SEE ALSO: *Abortion, Religious Traditions: Roman Catholic Perspectives; Abortion, Religious Traditions: Protestant Perspectives; Death: Western Religious Thought; Ethics: Religion and Morality; Eugenics and Religious Law: Christianity; Double Effect, Principle or Doctrine of; Medical Ethics, History of: Europe; Medical Ethics, History of: The Americas; Population Ethics, Religious Traditions: Roman Catholic Perspectives; Population Ethics, Religious Traditions: Protestant Perspectives; Population Ethics, Religious Traditions: Eastern Orthodox Perspectives*

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CHRONIC ILLNESS AND CHRONIC CARE

• • •

This entry traces the ethical topography and presents concepts entailed in chronic illness and chronic care. There is no authoritative definition of chronic illness or chronic care. However, a *consensus definition* for purposes of this entry can be found on the Public Broadcasting System (PBS) web site (Fred Friendly Seminars, 2001b), where chronic illness is defined as "a condition that lasts a year or longer, limits activity, and may require ongoing care." Some persons describe chronic as "illnesses or impairments that cannot be cured" (Institute for the Future, p. 260; Summer, p. 2). An incurable chronic condition can be manifest at birth, as in Down's syndrome.

Chronic illness is contrasted with acute episodes of illness or injury that will either result in death or will be treated and the person restored to *health.* Although chronic diseases differ from acute diseases, they can have acute episodes or flare-ups. Persons with chronic conditions may experience accidents or comorbidity in addition to their ongoing problem(s).

Paradoxically, as various public health measures, pharmacological agents, and other medical interventions become more effective in either preventing or curing diseases and postponing death, the number of persons with chronic conditions increases in both absolute and relative numbers. "Over the past century, the economically more developed countries of the world have gone through considerable change in their population structure and the types of diseases which afflict them—the so-called demographic and epidemiological transitions" (Harwood and Sayer, p. 1).

Care of a person with chronic illness should involve productive interactions between patients and providers; the latter may include medical and social support. Responsive providers and services are key in such care, as are the financial resources to enable the person to utilize them. Three elements seem to differentiate sound chronic *care,* at least in emphasis, from ordinary, good medical practice in general: continuity over time; management of any accompanying frailty and dependency; means to pay for the extraordinary costs of drugs, prosthetic devices, and care both in the home and in alternate living situations.

Three Related Concepts

PROGRESSIVE INTERMITTENT FRAILTY. Frailty can be seen as a condition at a given point in time and as a process over time. It denotes a condition in which a person has difficulty with activities of daily living and is vulnerable to various *assaults* upon his or her person both from within, (e.g., organ failure) or without (e.g., falls). Frailty, especially in the elderly, often continues over time in a progressive fashion with periods of remission and exacerbation until the person becomes substantially dependent and dies.

Persons who are frail may have difficulties with activities of daily living either on a temporary or an ongoing basis. Frailty often accompanies chronic illness, though not all chronically ill persons are frail. Some frailty results from general system(s) failure that is associated with age and the gradual molecular deterioration accompanying it; other frailty can be associated with a transitory illness or trauma.

DEPENDENCY. Dependency is a state in which a person requires the assistance of others. It may be temporary or permanent, intermittent or continuous. It may or may not be associated with chronic illness. Chronic illness, depending on severity, may or may not create a dependent state.

NATURAL DEATH AND DYING. All will die. Dying occurs in different modes. It may be caused by sudden organ failure or by disease or infection. A relatively new phenomenon is the increasing number of persons with serious chronic illness at the end of life. Certain patients function quite well for a time, with substantial decline in the last few weeks before death, typical of cancer. Others experience a less predictable course, with periods of disease exacerbation interspersed with periods of higher functionality, as in organ system failure of the heart or lung. Some go through a drawn-out course with early loss of function and incremental decrements in function and vigor over many months or years before death, characteristic of frailty and dementia (Lunney, Lynn, and Hogan; and Lynn).

As the trajectory toward death becomes more apparent, even if still somewhat unpredictable as to its exact time, specific medical, psychological, and spiritual interventions become central, emphasizing physical and emotional comfort rather than seeking to cure the underlying cause.

Seeking to Understand the Challenge

Given the lack of an agreed upon definition of chronic illness, it is difficult to estimate with any precision the aggregate numbers and costs. In addition to the confounding element of what to include as a chronic condition, each possible candidate has its own life course and associated costs. However, all agree there are large numbers of people with chronic illnesses. In fact, virtually all who die in old age will have one or more chronic conditions.

Having noted the imprecision of definitions and insurmountable difficulty of quantifying the extent and costs of chronic illness, some representative statements can contribute to an understanding of the dimensions of the problem:

- Almost one-half of the U.S. population of 276 million people in the year 2000 had a chronic condition in some form (Partnership for Solutions, 2001).
- In 2020, about 157 million people will live with chronic conditions, and about 81 million, more than half of these people, will have multiple chronic conditions (Partnership for Solutions 2002a, pp. 6–7).
- In one listing, thirty-seven conditions are characterized as chronic illnesses (Fred Friendly Seminars, 2001a). There may be more.
- Each chronic condition has its own etiology and course history and is experienced by a person unique in his or her personhood and cultural/social milieu.
- Each person has greater or less access to, or is in command of, a different array of help.
- Chronic conditions may be more or less debilitating at different parts of the course of the illness.
- About *60 million* people experience comorbidity, and more than *3 million* of these have five chronic conditions (Partnership for Solutions, 2001).
- Some chronic conditions can be ameliorated for long periods of time with medications and/or prosthetic devices; others may have a decided trajectory in which increasing, albeit sometimes periodic, disability requires hands-on assistance or a more supportive environment.
- The various treatment regimens for people with multiple chronic conditions can interact to diminish health and increase disability (Partnership for Solutions, 2002b).
- Some chronic conditions can render a person more vulnerable to disease or accidents.
- Not only do poor and disadvantaged people experience greater prevalence of chronic conditions, those who are unemployed, less educated, and uninsured suffer more from these conditions (Bethell, Lansky, and Fiorillo).

- According to a 1998 Medical Expenditure Panel Survey, 78 percent of healthcare dollars was spent on care of chronic conditions for noninstitutionalized persons, and approximately 58 percent of healthcare dollars was spent on the 21 percent of those suffering from more than one chronic condition (Partnership for Solutions 2002a, pp. 17 and 19).

Commonalities in Chronic Illness

The conceptual embrace of chronic illness has become so broad and varied that the utility in using this concept to inform policy may be compromised. However, all chronic conditions have common threads. Chronic conditions intrude upon the quality of life and life patterns of individuals. They not only alter the life of the persons closest to the afflicted individuals but many with whom these individuals come in contact on a daily basis, for example, employers, fellow employees, neighbors, and even strangers. Chronic illness sufferers need extra, even in some instances extraordinary, resources to ameliorate the effects of their illnesses, and this in turn generates costs to society either in the form of risk-sharing schemes such as insurance (public or private) or through welfare/charitable support.

Ethical Topography of Chronic Illness

Chronic illness occasions decisions that have an ethical component since it constitutes an interruption for a significant time in the life and life plan of an individual, and by extension, that of those who are closely associated with the individual. Furthermore, it constitutes a societal issue because of the *costs* involved.

DOMAINS. A chronic illness evokes responses with ethical implications in various domains. Each choice has implications for the well-being of the person with the chronic condition, those who are part of his or her primary social network, and the broader society.

THE INDIVIDUAL. While one must be cautious in blaming the victim, some, but by no means all, chronic illnesses have their origin in lifestyle choices. At the outset of ethical reflection, one must consider individual behavior not only because of a fundamental responsibility to self but also because of its consequences to others, both proximate and remote. For example, 80 percent to 90 percent of chronic obstructive pulmonary disease (COPD) cases are the result of long-term smoking (Ames). A substantial number of cases of human immunodeficiency virus (HIV) disease are caused directly or indirectly by unsafe sexual activity or needle sharing by drug abusers. Refusal to wear seat belts or helmets increases the risk of incurring catastrophic, debilitating injuries.

Regardless of the etiology of the chronic illness, the person suffering with it faces ethical choices that have an impact on his or her well-being, as well as that of other individuals and society in general. For example, one with chronic illness can be compliant with medical regimes or not, behave in a risky manner or not, and make treatment choices that can influence the quality and length of life and entail costs.

THE PERSON'S SOCIAL NETWORK. Depending on the severity of the illness and the moral/psychological bonds, the lives of family and psychologically significant others become a party to the disease. Each person impacted confronts ethical choices on how he or she will respond to the person in need.

Friends, neighbors, and even strangers are actors and reactors since physical proximity creates a moral field within which responses are evoked. Persons may or may not come to the assistance of others when that assistance is needed in a particular instance or over time. The need of the person, the relationship to *the other,* the inconvenience or costs (opportunity, monetary and psychological), and the availability of other assistance all enter into the ethical equation facing the potential helpers.

THE WORK ENVIRONMENT. Many persons with chronic conditions are employed or employable. While the Americans with Disabilities Act requires reasonable accommodations in the workplace, ethically based attitudes and interactions with co-workers will either enhance or detract from the well-being of persons with chronic conditions. For example, at one end of the spectrum are those co-workers who consistently respond with grace and enthusiasm from day to day. Their personal principles would propel them to risk their lives to help another co-worker in a wheelchair exit the building in an emergency. At the opposite end are those who frequently regard chronically ill co-workers with irritation or agitation; in an emergency situation, compromised co-workers with chronic conditions would not get their attention.

PRIVATE SECTOR POLICY. ***Insurance.*** Insurance in the private sector is driven mainly by marketplace forces and actors. It is also subject to both ethical considerations and to incentives and disincentives provided through public policy for taxation of employee benefits and for the regulation of insurance markets.

Insurance involves the sharing of risk. Paying a certain cost (premium) makes access to care affordable and possible for an expensive event that will occur in a group but not *to all* members of the group. Persons choose certainty over uncertainty and presumably pay premiums that they and their insurers hope will total considerably less than the costs associated with untoward events. However, when these events have already occurred or their imminent onset is highly probable (e.g., when a person over sixty-five pays his or her first premium), then insurance becomes a method of financing burdens that is unlikely to be profitable.

Insurers are economically motivated to exclude very sick and high-risk persons from coverage in order to lessen the cost of premiums and increase their corporate margins. Often they attempt to exclude persons with pre-existing conditions entirely, although this is more difficult to do under 2003 federal law. In lieu of such an option, actuarial considerations dictate a higher premium, which places a burden on all covered persons.

Faced with competitive pressures, major insurers are structuring boutique-type policies for healthcare, and to a lesser extent, long-term care, so that employers can offer lower premiums to presumably low-risk employees. This results in more costly options for those at higher risk. Some employers are moving toward a contribution to the individual for the purchase of insurance in the marketplace rather than offering an employer-sponsored plan. Presumably this will make the purchase of affordable insurance more difficult and costly for higher-risk persons. Such trends disadvantage chronically ill persons because they consign them to high-risk, high-cost pools.

A subset of ethical and public policy issues arises with chronic illnesses and conditions that have been associated with lifestyle choices, for instance, from motor vehicle accidents in which appropriate safety devices were not used (helmets or seat belts) and some AIDS patients. Should such persons be afforded benefits born by others because of their risky behaviors?

While these scenarios are the very stuff of free enterprise, they are not without ethical implications for insurers, group purchasers, and regulators.

Genetic testing. The field of genetics is in its infancy and holds promise in the prevention and treatment of all diseases, especially those that tend to be chronic. However, the knowledge gained by testing may identify the person as being at such risk of a particular chronic condition that he or she becomes *uninsurable* and, despite the absence of any indication of the disease, unemployable.

"At present the predictive value of most genetic tests is limited" (Anderlik and Rothstein, p. 425). These authors find scant evidence of discrimination to date on the basis of genetic testing in health insurance markets in the United States. This finding holds for states that do and those that do not regulate the use by insurers of genetic information. However, they note a particular problem for persons seeking long-term care insurance as genetic testing improves to permit discrimination among risks: *Medical underwriting* of long-term care insurance (in contrast to the provision of social insurance) could discriminate against persons with serious chronic disease because coverage is "directly tied to the provision of necessary health care" while the "premium structure … is based on mortality risk" (Anderlik and Rothstein, p. 425).

This potential for future discrimination as genetic testing is perfected is a concern in the insurance field, the popular press, and other countries. Dr. John W. Rowe, Chairman and CEO of Aetna, called for legislation and industry-wide guidelines to promote genetic testing and counseling with provisions for strict confidentiality. Furthermore, he advocated a prohibition of the use of genetic information to establish risk selection or classification (Aetna, Inc.). An editorial in *USA Today* on August 20, 2002, ends with "Medicine is giving people a chance to gaze into their futures—and maybe change them. But until their genetic secrets remain just that, the scientific breakthroughs could cause more problems than they solve" (*USA Today,* p. A.10). In 2001, the Human Genetics Commission of the British House of Commons "concluded that it was important to establish a clear and defensible regulatory system which not only balances the interests of insurers, insured persons, and the broader community but also enjoys the confidence of the public" and thus "decided to recommend to Government an immediate moratorium on the use by insurance companies of the results of genetic tests."

PUBLIC POLICY. The costs associated with chronic illness, the possible limitations of earning capacity, and the way others may treat those who have some limitation all make governmental action an important factor. Public policy affects not only access to needed services but continued participation in the life of the community for chronic illness sufferers.

Public policy emanates from the democratic process with its often messy and contentious elements. However, in many instances it finds justification, if not its origins, in widely held ethical perspectives. Among these public values are the convictions that people should not be denied opportunity because of particular characteristics and that the most vulnerable should have at least basic dignity.

Discrimination. Government has had a role in protecting the rights of individuals, especially those most at risk as evidenced in affirmation of voting rights, fair housing laws, and nondiscrimination in employment and public accommodations, as well as opportunities for participation for the disabled. While these result immediately from legislation and court decisions, they have foundation in a public ethic.

Income support. The costs often involved with chronic illness make governmental support a vital aspect for the well-being of those afflicted.

Based both on pragmatic and ethical considerations, the U.S. has enacted programs of social insurance requiring risk sharing and consequent creation of entitlement to meet basic needs in those areas in which people would be unable or unwilling to make prudent economic decisions about future need.

Social Security was enacted to assure a floor of income for those who cease to work because of age (1934) or disability (1956). It assures continued participation in the economy and offers support for those unable to work and their survivors. Social Security mandates equal contributions by employees and employers to a premium during employment in view of a possibility of unemployment. It offers a greater return to those who have modest employment earnings than to those who have been fortunate enough to have better earnings.

It has been United States policy since the 1930s that income in retirement should be considered to have three sources: Social Security, private pensions, and personal savings. There is growing evidence that income from these sources will be inadequate to meet basic living costs (including the costs of managing chronic illness) for most persons born between 1946 and 1964 who are living alone, and especially the oldest persons (Employee Benefit Research Institute [EBRI] Education and Research Fund and Milbank Memorial Fund; Dugas). The causes of this shortfall, which will be catastrophically expensive for society, include:

- structural problems in the private pension system;
- projected shortfalls in the Social Security Trust Fund that are tempting policy advocates to propose remedies that put individuals at higher risk;
- the difficulty most Americans have in both saving and maintaining their standard of living during their working years; and
- the periodic decline and routine volatility of the financial markets in which pension savings are invested.

Each of these causes raises ethical issues.

Financing and organizing care during acute episodes of illness. Most of the health insurance offered by government (Medicare and coverage of public employees most importantly) and the private sector (individual and group coverage) is derived historically from plans to cover infectious disease, injuries, pregnancy and childbirth, and episodes of chronic degenerative diseases requiring hospitalization and medical specialty services. Although this coverage has evolved gradually to include many services for managing chronic illness, payment is still driven mainly by diagnosis and is more generous for invasive procedures than for either counseling or outpatient drugs (Fox). As a result, most persons who experience progressive intermittent frailty (which means, in fact, most persons) are at high risk of receiving care that is discontinuous, fragmented, and inappropriate.

Financing and organizing long-term care. The United States has devised a vast system of long-term services based on the organizational concept of the nursing home and the financing assumption that individuals and families will pay for care with government serving as the payer of last resort. This system is a logical counterpart of a health insurance system created to respond to the most serious acute manifestations of disease. Nursing homes, the dominant institutions, are stripped down (or not so stripped down) hospitals in which persons wait, secure against injury but isolated from their community, until the next acute episode of illness returns them to the acute care health sector. Since waiting is deemed a residual activity, it is logical for individuals to pay for it out of income and savings unless (or until) they are too impoverished to do so. Then society (through Medicaid, Supplemental Security Income, and charity) pays the cost. This model for organizing and financing long-term care, like the health insurance model described in the previous paragraph, is deeply flawed: conceptually and financially, and many have argued, ethically. There is growing analysis and advocacy on behalf of alternative models for organizing and financing long-term care that take account of the inevitability of progressive intermittent frailty for most people and recognize the well-documented desire among Americans to spend as much of their later lives as possible in homelike, minimally restrictive settings (U.S. Department of Health and Human Services). One of these models is the Program for All-Inclusive Care of the Elderly (PACE). PACE is a risk-sharing system that provides for all acute, long-term care, and hospitalization needs of frail elderly participants in one program. Participants pay a capitated fee rather than fee for service with their Medicaid and Medicare entitlements. Most of the PACE participants can still live at home or in a community-based setting and are transported to the program's day health center one or more times a week for care of their medical and social needs.

To provide this "all-inclusive" care, the health center is staffed with an interdisciplinary team (Centers for Medicare & Medicaid Services, 2002). Another example allowing for various flexible state-designed alternative models is the Medicaid Home and Community Based Services (HCBS) 1915(c) Waivers Program. The U.S. government allows the states to provide HCBS waiver programs for certain segments of their Medicaid-eligible population. One segment is the elderly. Under an HCBS waiver program for care of the elderly, a state can ask the federal government for waivers of certain Medicaid requirements so that Medicaid benefits can be provided in the home or a community-based setting as well as in an institution (Centers for Medicare & Medicaid Services, 2003).

Research. Vast and increasing amounts are spent on research pertinent to chronic disease in the United States, primarily by the federal government, through the National Institutes of Health (NIH) and the Veterans Health Administration (VA), and by the pharmaceutical industry. The two most prominent objects of this research are the mechanisms of chronic disease and the development of drugs and devices to treat, cure, and manage them. Consumer and professional groups are prominent advocates of increased public research budgets for particular diseases, often with overt or covert support from the pharmaceutical industry and manufacturers of medical devices. However, enthusiasm for developing and testing new interventions distracts attention and resources that could be invested in new randomized controlled trials of existing interventions, research on head-to-head comparisons of competing treatments, and replacement of open or arbitrary drug formularies with preferred drug lists based on systematic reviews employing the methods of research synthesis. This hopeful and lucrative focus on new ways to prevent, cure, and manage disease has made it difficult for advocates of the rapidly developing science of research synthesis to make their case. This recently emerged area of research makes it possible to evaluate more confidently than ever before the effectiveness of health and social care interventions, including drugs, devices, diagnostic tools, and methods of organizing services (Chalmers et al.).

Social Solidarity and Concern for "The Other"

While individual autonomy is inherent in the notion of dignity, humans are social beings who inherit from the past, live in community in the present, and perceive themselves as having responsibility to the future. Humans are free to pursue their own goals as long as they do not interfere with others, a negative right. There is a generally recognized corollary that humans live in community with a positive obligation to contribute to the common good and share others' burdens. Personal responsibility is indicated not only for the sake of the person but because "no man is an island," and his or her well-being or disorder has social ramifications. Maintenance of health and function is significant not only to the individual but also to all who are part of his or her social network. Aristotle has been credited with teaching that a just society is one in which burdens are shared by equals equally and unequals unequally in accord with capacity and need.

The pluralistic nature of contemporary society makes it easier to identify when and where ethical issues occur than to apply universally accepted approaches to their solution. Yet, at least at the societal level, decisions have and will be made through the democratic process, largely driven by self-interest but often with appeals to a sense of fairness and decency. However, a recent study of policy makers' use of ethicists' advice concluded that persons who emphasize ethics "will always be disappointed by the politics of policy making in any countries that are fit to live in" (Fox and Klein). On the more personal level, however, such decisions are made, for better or worse, on a daily basis, either easing the burden of chronic illness or leaving the chronically ill person ever more isolated in his or her distress. Decisions of fairness and decency and those that ease the burden become ever more vital as the number of people affected by chronic illnesses increases in the first half of the twenty-first century.

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SEE ALSO: *Aging and the Aged; Care; Dementia; Disability; Healthcare Resources, Allocation of; Health Policy in the United States; Human Dignity; Justice; Life, Quality of; Long-Term Care; Managed Care; Medicaid; Trust*

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CIRCUMCISION, FEMALE

• • •

Female circumcision is the term used to identify the practice of removing healthy normal female genitalia by surgical operation. Because of the severity of the operation and its known harmful effects, the term *female genital mutilation* is now generally used. There are three increasingly severe types of this operation, and each makes orgasm impossible. Clitoridectomy, or sunna (Type 1), is the removal of the prepuce of the clitoris and the clitoris itself (Figure 1–1). When excited, the clitoris swells and becomes erect, and it is this excitement that causes female orgasms. Excision, or reduction (Type 2), is the removal of the prepuce, the clitoris, and the labia minora, leaving the majora intact. The labia minora produce secretions that lubricate the inner folds of the lips and prevent soreness when these lips rub against each other (Figure 1–2). Infibulation, or pharaonic circumcision (Type 3), is the removal of the prepuce, the clitoris, the labia minora and majora, and the suturing of the two sides of the vulva, leaving a very small opening for the passage of urine and menstrual blood (Figure 1–3). This type of circumcision is referred to as pharaonic probably because it is identified with circumcision methods of ancient Egypt under the pharaohs.

In a study of the various types of circumcision undergone by women in Sierra Leone (Koso-Thomas), it was found that 39.03 percent of the women had undergone Type 1, 59.85 percent, Type 2, and 1.12 percent, Type 3. In Somalia, 80 percent of the operations are Type 3 (El Dareer). The prevalence of circumcision in Africa ranges from 10 percent in Tanzania to 98 percent in Djibouti (Toubia).

The most common and basic procedure followed during circumcision is the traditional method. In this method, usually employed by circumcisers who have no medical training, the female is firmly held down on dry ground with her legs wide apart to expose the genitalia and the parts to be removed. In some cases, the genital part to be excised is held with a special hemostatic leaf before excision, or the candidates are made to lie near a cold flowing stream so the excised area can be bathed in chilled water to numb the pain. The implements used are often unsterilized razor blades, knives, scissors, broken bottles, or any other sharp implement. Some form of herbal dressing is applied to the raw wound after the operation. The same implement is used for successive operations without sterilization. When the operation is carried out in modern clinics, standard modern surgical practice is followed.

Origin of the Practice

We do not know with any precision when, why, and how female circumcision began. There is evidence that female circumcision and female genital surgery have been done in many parts of the world, although currently it is mainly done in different communities in parts of Africa, Asia, the Far East, Europe, and South America.

The early Romans, concerned about the consequences of sexual activity among female slaves, adopted the technique of slipping rings through their labia majora (Figure 1–4) to block access to the vagina. In the twelfth century C.E., Crusaders introduced the chastity belt in Europe for the same purpose; the belt prevented girls and women from engaging in unlawful or unsanctioned sex. This method caused little permanent physical damage to the individual. Genital surgery was permitted in North America and Europe in the late nineteenth century with the intention of curing nymphomania, masturbation, hysteria, depression, epilepsy, and insanity. There is no evidence that such surgery was associated with any ritualistic activity. Elsewhere, the surgery has historical links with either religious or ethnic rituals. It is believed that the ancient Egyptians and ancient Arabs practiced this form of surgery. Genital mutilation seems to have been transplanted to Latin America from Africa during the slave trade and may have taken root first in the central part of Brazil, where groups of West Africans were resettled after the abolition of the slave trade in the middle of the nineteenth century, and to eastern Mexico and Peru through migration. In Asia genital mutilation is found among Islamic religious groups in the Philippines, Malaysia, Pakistan, and Indonesia. Where the mutilation exists in the Middle East and Asia, it is strongly associated with Islam. Female genital mutilation is not practiced in all Islamic countries. Those societies known to practice it, namely, the United Arab Emirates, South Yemen, Oman, and Bahrain in the Middle East, and northern Egypt, Mauritania, Sudan, Somalia, Mali, and Nigeria in Africa, probably inherited it from pre-Islamic cultures.

Alleged Benefits of Female Circumcision

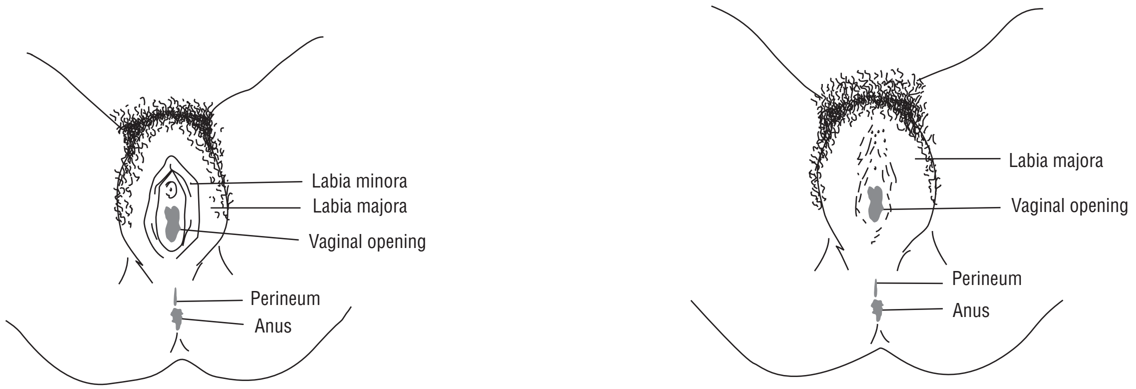
The modern defense of female circumcision allows us to reconstruct the ancient rules that governed moral action or behavior in polygamous communities. The defense enumerates a wide range of health-related and social benefits alleged to result from the practice:

1. maintenance of cleanliness;
2. maintenance of good health;
3. preservation of virginity;
4. enhancement of fertility;
5. prevention of stillbirths in women pregnant for the first time;
6. prevention of promiscuity;
7. increase of matrimonial opportunities;
8. pursuance of aesthetics;
9. improvement of male sexual performance and pleasure; and
10. promotion of social and political cohesion.

Cleanliness is regarded as a great virtue by women in countries where the practice is common. In some cultures, particularly in Africa, women are required to cleanse their genitalia with soap and water after urinating. Those who justify removing parts of the genitalia that produce secretions cite this preoccupation with the cleanliness of the genital organs. Some traditional circumcision societies claim that circumcised women are generally healthy and that the operation cures women suffering from problems resembling those identified in nontraditional societies as depression, melancholia, nymphomania, hysteria, insanity, epilepsy, and the social disorder of kleptomania. In situations where proof of virginity is essential for concluding a marriage transaction, circumcision is believed to be the guarantee against premarital sex. This guarantee benefits parents who are able to demand a high bridal price for their daughters. Marriage immediately after the transaction ceremony is common, and such marriages, involving pubertal girls, are usually followed by pregnancy within a very short time. Circumcised girls and women are regarded as having an advantage over the uncircumcised in marrying. Where female genital mutilation is an established custom, tradition

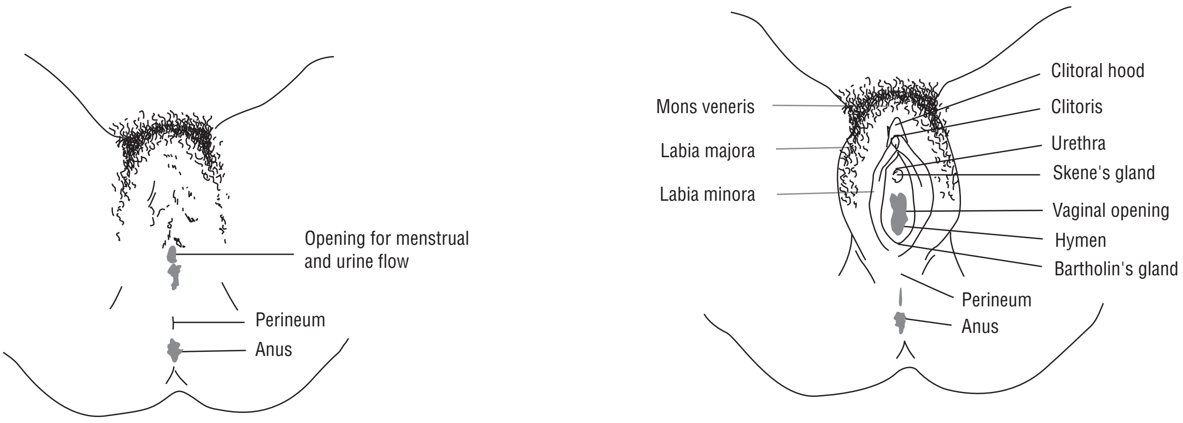
FIGURE 1

The Vulva


Labia minora
Labia majora
Vaginal opening
Perineum
Anus
Labia majora
Vaginal opening
Perineum
Anus

1-1 Vulva after clitoridectomy.

1-2 Vulva after excision.


Opening for menstrual and urine flow
Perineum
Anus
Mons veneris
Labia majora
Labia minora
Clitoral hood
Clitoris
Urethra
Skene's gland
Vaginal opening
Hymen
Bartholin's gland
Perineum
Anus

1-3 Vulva after infibulation.

1-4 Normal vulva before circumcision.

SOURCE: Author.

forbids men to marry uncircumcised girls; hence, circumcision of girls ensures they will be marriageable. Certain traditional communities, such as the Mossi of Burkina Faso and the Ibos of Nigeria, believe that a firstborn child or even subsequent babies will die if their heads touch a mother's clitoris during the birth process. The clitoris is therefore removed at the time of delivery if this has not already been done. Since female genital mutilation reduces or even eliminates sexual pleasure, the practice presumably eliminates the risk of female promiscuity. The justification of the practice to preserve chastity, eliminate promiscuity, foster or improve sexual relations with men, generate greater matrimonial opportunities, protect virginity, and increase fertility reflects the existence in traditional societies of strict controls on social behavior.

The belief that circumcision enhances beauty stems from the claim that the male prepuce or foreskin is removed mainly for aesthetic reasons, and that the clitoris, the female counterpart to the penis, should be removed for the same reason. If left intact, the clitoris is believed likely to grow to an embarrassing and uncomfortable size. In some patriarchal societies, female genital mutilation is also said to benefit the male by prolonging his sexual pleasure, since the clitoris is thought to increase male excitement during sexual intercourse with a female partner and may rush a man's orgasm. Of great importance to women in such cultures is the status circumcision bestows on the circumcised. It entitles them to positions of religious, political, and social leadership and responsibility.

The argument in favor of circumcision serves narrow social interests and does not achieve the goods desired or guaranteed. Failure to achieve these goods, moreover, is often blamed on the woman rather than the ritual. For example, maintaining cleanliness becomes an agonizing task. The hardened scar and stump that result from circumcision are unsightly, and they halt the flow of urine and menstrual blood through the normal channels. This obstruction causes unnecessary fluid retention and results in odors more disagreeable than those from the natural hormonal secretions that tradition teaches are degrading. Associating the death of babies at childbirth with clitoral contact is clearly refuted by the evidence that millions of healthy babies are born to uncircumcised mothers.

While the desire of organized society to maintain control over people's actions may be understandable, not all such control promotes their well-being or self-determination. Such rituals also cause harm to society by increasing morbidity and mortality levels. In addition, although these rites may promote social and political cohesion, they thwart the individual's freedom to determine what is right and in her best interests. Even women who learn that circumcision is an unsafe and harmful practice may feel pressure from society to agree to it for themselves or their children in order to marry or remain members of the group.

Harmful Effects of Female Circumcision or Female Genital Mutilation

The medical consequences of female genital mutilation are quite grave (El Dareer; Koso-Thomas). In Africa an estimated ninety million females are affected (Hosken). Three levels of health problems are associated with the practice. Immediate problems include pain, shock, hemorrhage, acute urinary retention, urinary infection, septicemia, blood poisoning, fever, tetanus, and death. Occasionally, force is applied to position candidates for the operation, and as a result, fractures of the clavicle, humerus, or femur have occurred. Intermediate complications include pelvic infection, painful menstrual periods, painful and difficult sexual intercourse, formation of cysts and abscesses, excessive growth of scar tissue, and the development of prolapse and fistulae. A fistula is an abnormal passage: a hole (opening) between the posterior urinary bladder wall and the vagina or a hole between the anterior rectal wall and the vagina. Late complications include accumulation of menstrual blood of many months or even years, primary infertility, painful clitoral tumors, recurrent urinary tract infections, and kidney or bladder stone formation. Obstetric complications such as third-degree perineal tear, resulting in anal incontinence and fissure formation, and prolonged and obstructed labor are also known to occur. Psychological problems of anxiety, frigidity, and depression, as a result of the physical inability to have a clitoral orgasm, may also develop.

Women who undergo circumcision suffer various degrees of emotional and mental distress depending on the nature of complications following their operation. Records show that 83 percent of all females undergoing circumcision are likely to be affected by some condition related to that surgical procedure requiring medical attention at some time during their lives. This level of health risk should be of concern to nations with a large proportion of circumcised women, because such women may never make the progress toward the economic and social development required of them.

Application of Modern Medical Practice to Female Genital Mutilation

Modern medicine has made impressive strides in investigating, preventing, and treating a wide range of ailments. Through its investigative approaches it has judged that unwarranted surgery is wrong. In the case of female genital mutilation, studies have found that certain of the resulting medical conditions are serious and can lead to complications and permanent health damage requiring both medical treatment and counseling (Koso-Thomas). Awareness of female genital mutilation's harmful effects has encouraged changes in how the operation is performed, changes that may include sterilization of equipment and dressings and administration of local anesthetic, antibiotics, and antitetanus injections prior to circumcision.

Ethical Aspects

Since some followers of Islam in Africa, the Far East, and the Middle East endorse circumcision, it has been widely identified as an Islamic rite. However, female genital mutilation is not practiced in Saudi Arabia, Algeria, Iran, Iraq, Libya, Morocco, or Tunisia. Many Islamic and Christian religious leaders have categorically denied that female circumcision or female genital mutilation is an injunction in the Qur'an or a "commandment" in the Bible. Since the foundations of the practice lie outside Islamic or Christian religious law, the origins of circumcision and its justification must lie in the moral, social, and religious structure and operation of societies practicing it. Individuals practicing it act within a system of rules that strictly regulate sexual behavior in society. Female genital mutilation generally thrives in communities with strictly enforced conventions and social rules.

With the knowledge of its harmful effects now common, no social system endorsing this kind of mutilation can be said to promote a favorable climate for a fulfilling life.

The attitudes of women toward circumcision depend on their experiences and level of education. Most women affected by the practice are unaware that circumcision is the cause of their health difficulties (Koso-Thomas). Once aware of this relationship, however, many women who have some education and training and who are exposed to a modern environment are better able to assess what is involved in circumcision actions and, on that basis, to make a reasoned judgment of its rightness or wrongness. Many such women have come to believe that the practice is unacceptable and have refused to allow their female children to go through the same traumatic experience. Many feminists and health professionals have openly displayed a higher regard for women's health than for tradition.

It has been shown, however, that some women who admit to suffering under the unexpected effects of the operation still feel obliged to support the practice. A study carried out to obtain opinions on circumcision involving 135 men and 120 women showed that 25 percent were shocked at what happened to them on their circumcision day, as it was not what they had expected (Koso-Thomas). The majority of them, either semi- or nonliterate, believed that they had done the right thing and planned to have their daughters circumcised. Those women who were not shocked by their experiences were also mainly illiterate and did not see why their daughters should not undergo circumcision. The attitude of men in the sample also varied according to their level of education. Illiterate men insisted that all women should be circumcised to keep them in their place, while the literate men argued that women should be given a choice as to whether or not to be circumcised. They felt that to deny women this choice was a violation of their human rights. It has also been found that circumcision is supported in most women's organizations, particularly political and social groups, since these groups reflect the feelings of the majority in the community.

Usually the decision to have a girl circumcised is made by the female elder members of the family/clan who insist on carrying out the procedure. An aura of secrecy, celebration, and pride surrounds the circumcision and encourages voluntarism on the part of recruits by making membership in the group seem more attractive. A few educated women, however, who have had access to modern medical assessment of their health as well as information on the dangers of the practice also support circumcision but advocate changes to reduce its health hazards. A few healthcare personnel have felt that medical intervention at the early stages of the operation might prevent the more serious health consequences of circumcision. Since circumcision cannot take place without health consequences, the position of these women and health practitioners is untenable.

Women who live in a traditional environment tend to judge their actions on the basis of traditional rules and principles of their society. There may be some misogynistic attitudes among such women, but the dominant force directing their actions comes from the society that demands, among other things, that this ritual be performed in order for them to qualify for marriage and social acceptance.

There are also attitudes inherent in African sexuality that not only permit circumcision but foster it. In most African cultures, sexuality is regarded as a gift to be used for the procreation of the human species, and any public or even private display of sex-related feeling or enjoyment is seen as debasing this gift. In some communities, only a token expression of the sexual self is permitted. The issue of sexual fulfillment is unimportant. Thus, controls over the sexual behavior of women are designed to curb female sexual desire and response and to encourage disregard for the sexual aspects of their lives. The removal of the organ or organs responsible for sexual stimulation is therefore taken as necessary for the fixation of certain values within the community and for ensuring the acceptance of rigid standards of sexual conduct. Thus, the underlying concern of those who defend the institution of female circumcision is that women's sexuality will be corrupted if women are allowed the freedom to control it or indeed to pursue the personal satisfaction of their sexual desire. Implicit in this argument is the major premise that it is immoral for a woman to act on her sexual desire. Women who still support the practice continue to promote injury with confirmed medical consequences. In this respect the role of the healthcare practitioner in the society is crucial and may lead to personal dilemmas that have to be resolved. Many feel anger against the executors and supporters of the ritual and sadness at the futility of the exercise and at the intransigence of traditional circumcising communities. Healthcare professionals presented with the choice of treating or not treating women who have chosen to be circumcised are often determined to rescue a life they see as poised on the brink of destruction. On the other hand, traditional circumcisers have no moral dilemmas about the practice. They believe that they have no choice in a matter which concerns the preservation of their cultural heritage. That heritage dictates how women must live, and to them, life should be one of happiness in subservience to the will of the people and in obedience to customary and religious laws.

OLAYINKA A. KOSO-THOMAS (1995)

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UPDATE

The United Nations International Children's Emergency Fund (UNICEF) estimates that "between 100 million and 130 million women suffered female genital mutilation or cutting as children" and that another 2 million are at risk each year (UNICEF). It calls on all nations to honor their commitments to eliminate those practices by 2010. The World Health Organization (WHO), UNICEF, and United Nations Population Fund (UPFPA) (WHO, 1997) issued a joint statement advocating a zero-tolerance view, but it has not been endorsed universally (WHO, 2000). The worldwide scrutiny of ancient practices in which some or all of women's genitals are removed, usually during infancy or childhood, stems from several movements that began in the 1980s.

Ongoing Disputes about Zero Tolerance

In the 1980s a growing number of activists in countries where these rites are popular tried to stop these practices or at least substitute less mutilating rites (nicking the labia or the foreskin around the clitoris) for the more mutilating forms, which were and in some cases still are practiced widely, especially in Africa, and some Middle Eastern countries. Those rites include Type 1 (removal of the prepuce with or without removal of all or some of the clitoris), Type 2 (removal of the entire clitoris and all or most of the labia minora), and Type 3, or pharaonic circumcision (removal of all of the clitoris and labia minora and parts of the labia majora) as well as the practice of infibulation (the wound to the vulva from the cutting is stitched closely, leaving a tiny opening so that the woman can pass urine and menstrual flow). Also included among those rites are scraping or cutting tissue at the vaginal opening or the vagina and placing corrosive substances into the vagina to induce bleeding or narrow or tighten it (WHO, 2000).

Prominent African activists, including Olayinka Koso-Thomas (author of the main entry above), Nahid Toubia, and Raquiya Abdalla, have long advocated stopping all forms of genital mutilation and cutting while retaining the cultural and religious rituals that educate and welcome girls into adulthood and the community. They favor "circumcision through words" and family-planning education that includes telling young males about the health hazards to women and asking them to make a vow not to require circumcision as a condition of marriage. Those changes might accommodate important religious, cultural, economic, community, and family considerations without harming girls.

Others argue that a more effective approach to zero tolerance would be to replace the mutilating rituals with removal of the foreskin around the clitoris or tiny nicks in the labia (Davis; El Dareer). This, they argue, might "wean" people away from the more extreme forms of genital mutilation. If there are no complications, the tiny nicks do not preclude sexual orgasm later in life. The chance of success with this tactic is more promising and realistic, they hold, than would be the case with an outright ban; people could maintain many of their traditions and rituals of welcome without causing as much harm, especially if the operations were done by doctors and nurses under sterile conditions. However, Nahid Toubia objects, stating that removal of the clitoral hood invariably causes considerable, even if unintended, harm to the clitoris because tissue from the clitoris is very likely to be taken.

Dena Davis expresses the concern that something other than zero tolerance could send the wrong message to immigrants:

> Because FGA [female genital alteration] in its most common forms around the world is mutilating and life threatening, it is reasonable to adopt a "zero tolerance" policy to make it absolutely clear to immigrants that this practice is never acceptable …

> further, an argument could be made that, once a "nick" is allowed, it would be difficult if not impossible for the state to make sure this did not become a loophole through which the worst elements of FGA would slide. As MGA [male genital alteration] is not anywhere close to as mutilating and threatening to life and health as are many forms of FGA, this argument would serve as a constitutionally valid distinction between the two practices. (p. 561)

In the end, however, Davis tries to justify a compromise for the sake of cultural sensitivity, legal consistency, and medical safety, arguing that procedures might be permitted that allow roughly the same harm done to girls as is done to boys in male circumcision: a minor nick in a girl's labia or clitoral hood.

Raquiya Abdalla, however, objects to equating female circumcision with male circumcision because their purposes differ and the degree of harm frequently is drastically different. For some people the best reason for drawing parallels between male and female genital cutting is to help abolish both practices. Even if the timetables do not coincide exactly, they hold, comparisons should not be used to allow some female circumcision in countries that permit male circumcision. Still others maintain that there are health benefits to male circumcision that justify distinguishing the two. Most agree, however, that it is unfortunate that the same word, *circumcision,* is used for the full range of practices, from trivial to mutilating. Removal of the clitoris is comparable to amputation of the penis rather than removal of the foreskin in men.

Findings about Morbidity and Mortality

In the 1980s some African clinician-activists from countries that practice those rites documented and brought to the world's attention the accompanying morbidity and mortality. Those pioneering medical studies include the ones conducted in the Sudan by Asma El Dareer (1982), in Sierra Leone by Olayinka Koso-Thomas (1987), and in Somalia by Raquiya Haji Dualeh Abdalla (1982). The death, infection, and disabilities associated with the rites are well established, challenging local beliefs that the rites promote health and well-being. For example, as Koso-Thomas (p. 10) pointed out, stable medical evidence discredits the belief that "death could result if, during delivery, the baby's head touches the clitoris," and Abdalla (p.16) pointed to the disutility of regional practices of putting "salt into the vagina after childbirth … [because this] induces the narrowing of the vagina—to restore the vagina to its former shape and size and make intercourse more pleasurable for the husbands." Some of those studies suggest that many women would prefer not to perform the rites if they were not necessary for the marriage of their daughters and that more younger women are having second thoughts about this cultural practice for their own daughters (Moschovis).

Other epidemiological studies have confirmed the morbidity and mortality associated with those rites and have demonstrated that they are still widespread in some regions. For example, Daphne Williams Ntiri (1993) found that in some African countries most young girls between infancy and ten years of age have received Type 3 circumcision from traditional practitioners who often used sharpened or hot stones, razors, or knives, frequently without anesthesia or antibiotics. The WHO estimates that worldwide about 80 percent of the rites involve excision of the clitoris and labia minora and that infibulation is done in about 15 percent of all cases (WHO, 2000). In some regions, such as Egypt, Guinea, Somalia, Eritrea, and Mali, national surveys indicate that 94 to 99 percent of women are circumcised (WHO, 2000, 2001).

Oppression of Women

Beginning in the 1980s, despite insistence by people within the culture about their good intentions, voices worldwide condemned the rites as brutal forms of oppression of women comparable to making men eunuchs (removal of the testes or external genitals). International organizations denounced the practices, including UNICEF, the International Federation of Gynecologists and Obstetricians, and WHO, along with the American Medical Association and many women's groups. They deny that this is just a cultural issue, arguing that the rites should be opposed with the same vigor as other violations of human rights (Schroder; Toubia). Pressure from human rights groups, for example, forced some governments to ban all registered health professionals from performing female cutting or infibulation and helped women find political asylum in other countries to avoid genital cutting.

Some countries are more willing to pass laws prohibiting the rites than to enforce those laws. UNICEF (2003) is troubled by governments' lack of will to confront those practices, educate their communities about the risks, and enforce existing laws that prohibit them. UNICEF promotes challenges to the beliefs, attitudes, and customs that support these rites and discrimination against uncircumcised women. Even in the United States, the United Kingdom, France, Canada, and other countries where female circumcision is viewed as child abuse, it is practiced in "back rooms" (Davis). UNICEF praised the European Parliament's launching of an initiative called "Stop FGM" in

December 2002. Whether or not the intent of the rites is to honor women, UNICEF and others regard them as "culturally sanctioned forms of women's oppression, male domination, and control of women's sexuality" (UNICEF, 2003).

Immigration

After 1980 waves of immigrants from North Africa and southern Arabia made the rites better known and widely condemned. Those immigrants came from regions where most women receive Type 2 and Type 3 forms of circumcision and moved to areas of the world where those rites are viewed as horrific and oppressive practices that put young girls at terrible risk of death and chronic disability. Consequently, families that seek female genital cutting in their adopted countries generally avoid the healthcare system, and the risks of nonmedical circumcision are assumed to be very high (Davis).

Cultural Sensitivity

The cultural clashes that have resulted from criticisms of female circumcision have centered on whether there is any justification for interfering with the deeply held practices of other cultures. Extreme ethical relativists state that there is no moral or epistemological basis for interfering with popular customs in other countries and that meddling constitutes cultural imperialism (Scheper-Hughes; Ginsberg; Shweder). This view, which once was popular among anthropologists and others, has been challenged on many sides (Kopelman, 1994, 1997).

First, shared goals and methods sometimes can be used to assess other cultures in a way that has moral and epistemological authority. For example, most people share the goal of seeking health for woman and infants and endorse similar methods of logic, science, and medical investigation. Medical research is respected in those communities and their own studies show that the rites cause pain, emotional trauma, infection, chronic disease, disability, and death. These shared goals and methods can be used to help reason with people about destructive cultural practices that involve not just female genital cutting but wars, pollution, and epidemics.

Second, criticism of these practices within those communities is growing (Moschovis), and as a result the depth of the commitment to the rites is changing. As the investigators who originally touched off the contemporary debate over female circumcision illustrate, cultures are not monolithic but contain passionate disagreements and may change rapidly. Moreover, most people do not live in only one culture but cross easily from one culture to another in their professions, religions, and ethnic groups. People who brought the practice of female genital cutting with them when they moved, for example, live in more than one culture. It no longer is possible to count or separate cultures sharply when world travel and communication are so easily available. Cultural, religious, professional, ethnic, and other groups overlap and have many variations within nation-states. To say that people belong to overlapping cultures or that people cannot distinguish precisely between or count cultures, however, undercuts extreme ethical relativism and its tenet that the only way to determine whether something is right is to see if it has cultural approval (Kopelman, 1994, 1997).

Third, cross-cultural criticism seems to be important and even obligatory when one considers cultures that engage in terrorism, war, torture, mass rape, infanticide, and slavery, and so people should be able to criticize female genital cutting on the same basis. Otherwise, people would be led to the very problematic view that any act is right if it has cultural approval even if it is a culturally endorsed act of war, oppression, enslavement, aggression, rape exploitation, racism, or torture. In this view the disapproval of other cultures is irrelevant in determining whether acts are right or wrong. Even if this version of ethical relativism is defended consistently, its plausibility is eroded by its conclusion that the disapproval of people in other cultures, even victims of war, oppression, enslavement, aggression, exploitation, rape, racism, or torture, is irrelevant in deciding what is wrong in the aggressor culture (Kopelman, 1994, 1997).

Consistency

Finally, scrutiny has revealed apparent contradictions in the beliefs and attitudes associated with the rites. For example, on the one hand people from those regions say that nothing is given up because women cannot enjoy sex, but on the other hand they say that the rites are needed to control women who mighty be sexually out of control without the surgeries (Kopelman, 1994, 1997). (This fear that girls will be sexually promiscuous is a frequently given reason for doing the surgery in the West, where girls and young women have considerable freedom compared with the situation in their original homelands.) Another apparent inconsistency concerns insistence that respect for cultural mores requires that deeply embedded cultural views about female genital cutting must be respected in the adopted countries even if this means violating the deeply embedded views of the dominant culture of the new land. It is inconsistent to insist that their deeply embedded views must be respected—but not those of other cultures. Finally, some say that there is no way to determine what is right when cultures disagree but also insist on transcultural universal normative principles such as "every culture counts for one," "preserve ancient cultures," and "when in Rome do as the Romans do."

Worldwide attention to female genital mutilation and cutting rituals since the 1980s has made those rites the center of controversy about practical and theoretical issues concerning human rights, ethical relativism, and the limits of tolerance of cultural diversity. Medical studies document the resultant morbidity, mortality, and disabilities and the resulting lack of sexual sensitivity and satisfaction for millions of women. Proposals by activists in those regions include stopping clinicians from participating in the rites and adopting and enforcing meaningful legislation, but many people believe that education about the harms of genital cutting and infibulation may be the most important way to stop the practices (El Dareer; Abdalla; Dirie and Lindmark; Toubia).

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SEE ALSO: *Anthropology and Bioethics; Body: Cultural and Religious Perspectives; Children: Rights of; Circumcision, Male; Circumcision, Religious Aspects of; Coercion; Feminism; Harm; Islam, Bioethics in; Judaism, Bioethics in; Medicine, Anthropology of; Sexual Behavior, Social Control of; Women, Historical and Cross-Cultural Perspectives*

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CIRCUMCISION, MALE

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Male circumcision entails the surgical removal of the foreskin that covers the glans of the penis. The relative simplicity of the surgical procedure itself belies the complexity of the conflicting values surrounding this minor operation. The primary ethical question is whether the pain, risks, and costs of routine neonatal circumcision are justified by the potential medical and social benefits to infants who undergo this procedure. Given the strong opposing opinions surrounding circumcision, there is some question as to whether children should undergo the procedure prior to an age when they can provide informed consent on their own behalf. Circumcision in adults is less common and will not be the focus of discussion here.

The Prevalence of Male Circumcision

Circumcision is the most common procedure performed on males in the United States—an estimated one million procedures are performed per year. Only about 20 percent of the procedures are performed for religious reasons; the majority are performed in newborns for medical, cultural, or aesthetic reasons. Estimates suggest that circumcision is performed on 60 to 90 percent of boys in the United States. Although observers have noted some variations by region and by cultural group in the use of this procedure, accurate rates for circumcision are not available (Wallerstein). The best documented rates of newborn circumcision in the United States come from a study of infants delivered in U.S. military hospitals (Wiswell, 1992). The rate of circumcision in 1971 was estimated to be 89 percent, falling to 70 percent in 1984, with a subsequent rise to 80 percent in 1990. These differences suggest that parents' decisions about circumcision are influenced by the ebb and flow of social debate over the procedure.

The high rate of nonritual circumcision places the United States in a unique position in the world. In regions where the majority of the world's population lives, including western Europe, the former Soviet Union, China, and Japan, male circumcision is not performed. In 1985, Edward Wallerstein provided the following estimates of circumcision rates: In Great Britain an estimated 1 percent of the male population is circumcised; in New Zealand the figure is about 10 percent; in Australia, 35 to 40 percent; and in Canada, 35 to 40 percent. Circumcision is performed commonly as a religious ritual by Jews, Muslims, many black Africans, and nonwhite Australians.

The History of Circumcision

The walls of Egyptian tombs depict male circumcision, so the practice is known to be at least 5,000 years old. The Jewish and Muslim traditions of circumcision have their origin in the Old Testament. Jews accept the practice as a sign of the covenant between God and Abraham. In Genesis 17:12, God instructs Abraham: "He that is eight days old shall be circumcised among you, every male throughout your generations." As a Jew, Jesus was circumcised, and the early Christian church debated the need for circumcision as a criterion for joining the Christian fellowship; it was decided that circumcision was not necessary for salvation. According to the apostle Paul, "For in Jesus Christ neither circumcision availeth nor uncircumcision; but faith which worketh by love" (Gal. 5:6). These religious traditions remain strong, although the health debate has led to a questioning of the religious practice by a few members of the Jewish community (Milos and Macris).

The practice of routine neonatal circumcision has been debated within the U.S. medical profession for over a century. Circumcision was initially advocated in the Victorian era as a measure that would reduce masturbation. Medical benefits from the procedure were first widely proposed in 1891 by P. C. Remondino, who claimed that circumcision prevented or cured a host of diseases, including alcoholism, epilepsy, asthma, and renal disease (Wallerstein). More scientific studies of the potential medical benefits of circumcision began to appear in the professional literature in the 1930s. Urologists observed an association between penile cancer and an intact foreskin (Schoen, 1992). During World War II, American troops stationed in the Pacific and in desert climates had problems with irritation and infection of the penis because of sand and the inability to maintain adequate hygiene. The military response was to circumcise many of the affected soldiers. However, the Japanese did not use circumcision despite their war experience in the same environments (Wallerstein).

Circumcision became popular, indeed almost universal, after the war. Rates remained high until the 1970s, when both the medical profession and the general public began to question the widespread use of the procedure for newborns. The American Academy of Pediatrics issued two separate statements, in 1971 and 1975, declaring that there were no valid medical indications for neonatal circumcision (Committee on Fetus and Newborn). Specific concerns were raised over the pain of the procedure and over potential complications in the face of questionable medical benefits. In 1985, the first in a series of papers was published that documented an increased risk of urinary tract infections in uncircumcised neonates (Wiswell et al., 1985). These reports came in association with an apparent increased risk of sexually transmitted disease, specifically the human immunodeficiency virus (HIV), in uncircumcised males (Schoen; Bailey). In 1989 the American Academy of Pediatrics issued a revised statement that concluded that there were both medical advantages and medical disadvantages to the procedure and that full information and informed consent were important for parents who were making this decision.

Medical and Ethical Issues

The basic ethical question regarding circumcision is whether it is justified to perform a surgical procedure on a healthy, unconsenting child to prevent the possibility of future disease. The primary ethical task is to balance the pain and potential complications with the potential benefits. In addition, there is a strong tradition of respecting parental wishes when their decisions are not clearly contrary to the welfare of the child. Although the full details of the risks and benefits are beyond the scope of this discussion, key issues will be outlined.

Proponents of circumcision claim several advantages for the procedure, including decreased incidence of urinary tract infections in infancy, decreased risk of penile cancer in adults, and decreased risk of sexually transmitted diseases (Wiswell, 1992; Wiswell et al., 1985). In addition, routine circumcision prevents occasional penile problems such as phimosis (a narrowing of the foreskin that prevents its retraction), balanitis (an infection of the head of the penis), and posthitis (an infection of the foreskin). Significant complications of the procedure are quite rare, occurring in less than 1 percent of circumcised neonates (Kaplan). Until the mid-1980s, circumcision was performed commonly without anesthesia. Current techniques permit the pain of circumcision to be reduced with a number of simple techniques. In contrast to female circumcision, the procedure has no significant effect on sexual function or pleasure (Collins et al.).

Social issues are a significant element in the debate. Many parents would like their sons to look like the majority of their peers, and many parents would like their sons to look like their fathers, the majority of whom are circumcised. Finally, parents who have grown up in a society of circumcised men may find a circumcised penis to be more aesthetically agreeable.

Those who question the value of the procedure counter that the case for reductions in urinary tract infections, cancer rates, and sexually transmitted diseases is not convincing, or that many of the same benefits may be achieved through better personal hygiene (Poland; Milos and Macris). While the procedure is generally safe, according to George Kaplan, there are risks of excessive bleeding, infection, removal of too much tissue, tissue damage and scarring, reactions to anesthetic agents, and retention of urine. It is also argued that the penile problems that may arise in uncircumcised males, such as phimosis or balanitis, can be prevented or effectively treated when they occur. Further, it is noted that pain-control measures are not consistently effective, carry their own risks, and are associated with some pain as well. Marilyn Milos and Donna Macris note that some have claimed that the foreskin provides a protective covering for the glans, making the uncircumcised penis more sensitive during sexual activity.

Since the 1960s, a cultural shift has placed a higher value on preserving the natural look. Uncircumcised males are common enough, the argument goes, that the appearance of an uncircumcised penis in a high school locker room will not be cause for embarrassment. Finally, it is claimed that a simple explanation from father to son will prevent a son's confusion about a different look to his penis.

Of all of the potential medical advantages of circumcision, the reduced risk of urinary tract infection in the infant is the best documented, and this is the benefit most likely to be experienced by the child (Wiswell, 1992; Schoen). Urinary tract infections in neonates are potentially serious infections that may be life-threatening and, if recurrent, may lead to the later development of renal insufficiency and hypertension. However, the risk of urinary tract infection in uncircumcised infants is still relatively small, occurring in approximately 1 to 4 percent of infants. Of those infected, only a small minority will suffer long-term kidney damage (Chessare). Further, it is estimated that eighty infants would need to be circumcised to prevent one urinary tract infection (Lerman and Liao).

Parents are thus left with a difficult decision. Circumcision might be delayed until the child is old enough to make his own choice, but this alternative obviates the primary medical advantage of decreasing the risk of urinary tract infection in infancy. In addition, performing the procedure beyond the newborn period may be associated with greater risks (Wiswell et al., 1993). Therefore, reliance on surrogate decision making by the parents for the newborn boy remains an ethically appropriate approach. With all of the current data in hand, many physicians and parents find themselves falling between the polar positions in this debate. The AAP drew the following conclusions in its 1999 policy statement on circumcision:

> Existing scientific evidence demonstrates potential medical benefits of newborn male circumcision; however, these data are not sufficient to recommend routine neonatal circumcision. In the case of circumcision, in which there are potential benefits and risks, yet the procedure is not essential to the child's current well-being, parents should determine what is in the best interest of the child. To make an informed choice, parents of all male infants should be given accurate and unbiased information and be provided the opportunity to

> discuss this decision. It is legitimate for parents to take into account cultural, religious, and ethnic traditions, in addition to the medical factors, when making this decision. Analgesia is safe and effective in reducing the procedural pain associated with circumcision; therefore, if a decision for circumcision is made, procedural analgesia should be provided.

For many parents the final decision will be made primarily on cultural and social grounds, with less weight placed on the potential health benefits or risks. Fortunately, there is some evidence that most adult men like the way they are, whether circumcised or not (Lee).

There has also been a vocal debate over the practice of female circumcision (AAP, 1998), which has led some to draws parallels between male and female procedures. While both procedures are performed primarily for cultural reasons, there are dissimilarities worthy of note. There are a few well-documented medical benefits to male circumcision and no long-term morbidities, unlike the female procedure. Further, male circumcision is not associated with sexual control and subjugation, cultural attitudes that are at the foundation of the tradition of female circumcision.

The social debate over the procedure in the United States is likely to continue. In this context, the responsibilities of both the physician and the parents are to make sure that all are fully informed about the benefits and risks of this procedure, and that the procedure, if elected, is performed in a competent and humane manner.

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REVISED BY AUTHOR

SEE ALSO: *Anthropology and Bioethics; Body: Cultural and Religious Perspectives; Children: Rights of; Circumcision, Female; Circumcision, Religious Aspects of; Coercion; Harm; Medicine, Anthropology of; Sexual Behavior, Social Control of*

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CIRCUMCISION, RELIGIOUS ASPECTS OF

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Throughout history different cultures have used genital alteration of males and females to express religious identity, inscribe social values, and enforce social norms of marriage, sexuality, and appropriate gender behavior. Societies differ greatly on whether they practice genital alteration on males and females, both, or neither, and on the stage of life at which procedures are done. Male circumcision, for example, is done on the eighth day of life by observant Jews, at around four or five years of age by Muslims in Turkey, and at puberty in some sub-Saharan African cultures.

Genital alteration became the subject of controversy toward the close of the twentieth century for a number of reasons. First, it is primarily performed on children and women, two groups perceived to be especially vulnerable. In the case of children, there is obvious lack of informed consent. Second, as immigrants from cultures that performed female genital alteration settled in Western countries, healthcare providers became aware of the procedures and of their negative effects on women's health. Third, a strong international feminist movement produced critics of the female procedures, both from within and without the indigenous cultures. Fourth, a century-long controversy in the United States over the health benefits of the male procedure began to move the practice away from routine recommendation of male circumcision. Fifth, a nascent *children's rights* movement began to question the ethics of performing surgery to excise healthy, normal tissue, with no proven medical benefit and, some argued, a diminution of sexual function.

The content of the controversy can be categorized into three parts. First, although there is no dispute over the lack of health benefit to females and the terrible impact of these surgeries on women's health, lively controversy exists over the negative and positive impact of male circumcision on males's health and sexual function.

Second, there is serious disagreement over appropriate language, reflecting the competing values in the debate. Male newborn genital alteration is almost always referred to as *circumcision,* a vaguely medical term that signals society's acceptance of this procedure. Conversely, the term *uncircumcised,* as opposed to *intact* or *natural,* signals the normative status of the circumcised male in American culture. When writers use circumcision to refer to the female procedure, there is often an outcry; opponents of the female procedure and defenders of the male procedure alike object to casting them in the same light. The term *female genital mutilation,* preferred by most opponents of the procedure and the term officially adopted by the World Health Organization (WHO), has its own problems. For one, as anthropologists Sandra D. Lane and Robert A. Rubinstein point out, "mutilation implies removal or destruction without medical necessity," which logically ought to refer to routine male circumcision as well (Lane and Rubinstein, p. 35). Further, the term ignores the meanings of female genital alteration in the cultures in which it is practiced, in which not to be circumcised is to look weird and disgusting. Finally, the term polarizes people rather than inviting discussion. *Cosmetic genital surgeries,* as a term for male and female procedures, has the advantage of inviting comparison with more widely accepted surgical interventions, such as breast augmentation, but the disadvantage of misleadingly implying a surgical environment, a far cry from the primitive conditions that attend most female genital surgeries. This entry uses the neutral terms *male and female genital alteration.*

Third, there is debate about whether genital alterations stem from *religion* or *culture,* with the explicit or implicit inference that the former commands more respect.

Male Genital Alteration

The origins of male genital alteration predate any religion now in existence. It is certain that ancient Egyptians practiced some form of adult male circumcision; there are many theories about how and why the practice made its way from Egyptian culture to the Israelites, who became the first people known to genitally alter infants.

According to the Hebrew Bible, Abraham was the first Israelite to be circumcised; performing the operation on himself at the age of ninety-nine. He then circumcised all the members of his household. The Biblical injunction reads: "Every male among you shall be circumcised. And ye shall be circumcised in the flesh of your foreskin, and it shall be a token of a covenant betwixt Me and you. And he that is eight days old shall be circumcised among you, every male throughout the generations" (Gen. 17: 11–12). Both of Abraham's sons were circumcised: Ishmael, the child of Abraham's servant Hagar, and Isaac, the son of Abraham's wife Sarah.

Male Genital Alteration in Judaism

While circumcision is the sign of belonging to the covenant, it does not confer Jewishness. Uncircumcised males can still be considered Jewish; Judaism does not practice female circumcision, but females are not thereby excluded from the covenant. In order for the religious obligation of circumcision to be fulfilled, the surgery must be set in the proper context, which includes the blessings, the correct procedure, the appropriate mindset, and the religiously mandated day of performance.

The Jewish ritual of male circumcision is called a *berit milah,* or a *bris.* It has two components: the cutting and the naming of the baby. The cutting is performed by a *mohel,* who may also be a physician. On the eighth day of the baby's life, the *mohel* comes to the home. The *berit milah* is a social occasion; friends and family are invited. Although there are many variations in how the ceremony is performed, the core ritual commonly begins with the lighting of a candle. One or two people have the honor of bringing the baby to the *throne of Elijah,* a special chair set aside for the male (often the baby's grandfather) who will hold the baby during the cutting. Traditionally, the mother remains in another room. After the ritual cutting, the baby is rediapered and allowed to nurse. The baby is given his Jewish name, and the *mohel* or rabbi, if one is present, recites blessings for the rapid healing of the baby and the continued recovery from childbirth of the mother. This is followed by a festive meal. The foreskin may be buried in the earth. In one custom, it is buried beneath a tree whose branches are later harvested to make the boy's wedding canopy.

Male Genital Alteration in Islam

In Islam male circumcision is performed for reasons of ritual cleanliness or purity; the term used is *fitra,* which implies both physical hygiene and inner purity. Cleanliness is required for prayer to be efficacious; the uncircumcised male faces the possibility that some trace of urine will remain under the foreskin and his prayers will be nullified. Circumcision is not mentioned in the Qur'an, but is part of the second source of Islamic law: *hadith* (the sayings and doings of the Prophet). Further, the obligation of circumcision can be inferred from the fact that Allah (God) told the Prophet Muhammed to follow the religion of Ibrahim (Abraham), and Ibrahim considered circumcision important enough to rectify his own uncircumcised state even at the advanced age of ninety-nine.

Depending upon the particular Islamic tradition and which scholars are most influential, male circumcision can be considered either obligatory or strongly recommended. The Prophet Muhammed recommended that circumcision be performed at an early age. In many Muslim cultures, the preferred time is on the seventh day after birth, and that is the common practice among North American Muslims.

Female Genital Alteration

It would be a mistake to assume an identity between Islam and female genital alteration. Saudi Arabia and Iran, two of the most conservative Muslim nations, abjure the practice, while non-Muslim minorities living in predominantly Islamic cultures sometimes embrace it. Further, traditional genital surgeries are performed in some non-Islamic African cultures. Nonetheless, the majority of people who practice some form of this custom identify with Islam, either as a religion or as a culture.

As is the case with male circumcision, the female procedure is not mentioned in the Qur'an, but claims for its legitimacy come from *hadith.* The use of the word *sunna* (meaning to follow the path of the Prophet) as the term signifying one form of the female procedure suggests that the practice is commendatory or virtuous. Similarly, the colloquial Arabic term for female circumcision is *tahara*¸ referring to a state of ritual purity. The *hadith* include a saying of the Prophet that ritual circumcisers should "not overdo it, because [the clitoris] is lucky for the woman and dear to the husband." This *hadith* (although considered somewhat weak in its authenticity) is used by some Muslims to argue against the more severe forms of female genital alteration (Winkel).

Religion and Culture Intertwined

The controversies over genital surgeries often include intense debates on the question of whether they are religiously or culturally inspired. In the United States, defining a practice as religious tends to surround it with an aura of heightened respect and protection not granted to those deemed *merely* cultural. However, it is often impossible to distinguish religious motivations from cultural ones.

Among all but the most traditional Jews, it is probably correct to say that the reasons for performing newborn circumcision are made up of religious elements, medical beliefs, and familial and communal motivations. In the United States, where approximately 80 percent of all males are circumcised, the practice of Jews is simply subsumed into the general norms. Although statistics are not available, it is generally believed that the majority of American Jews who have their newborn sons circumcised do not do so in a *berit milah.* Thus the circumcision does not fulfill the religious obligation, and will have to be repeated (in a nominal fashion) should the boy grow up to be a religious Jew. Other American Jews go through the religious ceremony, but do not partake of any other elements of Jewish religious or communal life. A high percentage of Jews genitally alter their sons in response to societal, community, or familial pressures, or simply so that a boy will look like his father. These reasons attest to the way in which male circumcision remains an important element of the communal *glue* that holds Jewish culture together, especially in tolerant America, where assimilation is feared more than anti-Semitism.

Some Jewish feminists have expressed criticism of *berit milah* because it surrounds the birth of a boy with more importance than that of a girl (although naming ceremonies for baby girls are becoming more common), and because it seems to imply a necessary connection between the male body and membership in the Jewish covenant. Miriam Pollack argues that the ritual cutting topples the mother from her rightful role as protector and nurturer of the baby, ignoring her biological instincts and “mother wisdom” (p. 171).

Female genital alteration is also practiced in response to a mix of religious, cultural, nationalist, and quasi-medical beliefs. A good example of this mix occurred in Egypt, where the proportion of genitally altered women is among the highest in the world. In 1994, at the International Conference on Population and Development in Cairo, a horrifying CNN film about female circumcision was shown, depicting the brutal cutting of a little girl. Members of Parliament responded with proposed legislation to criminalize the practice, but conservative religious authorities countered that female circumcision was an Islamic duty, and in integral component of Egyptian national identity. Other religious leaders claimed that female circumcision was a weak duty in Islam, at best, and that the issue should be decided by medical experts.

Anthropologists Lane and Rubinstein comment that, “Although it is not a practice of the majority of Muslims in the world, among those who do practice it female circumcision is nonetheless often considered to be legitimized by religion” (p. 34). Other reasons, often closely interwoven with religious ones, include the belief that without circumcision girls will *run wild,* become sexually active, and besmirch family honor (thus also flouting religious norms). The more extreme forms of genital alteration *guarantee* a daughter’s virginity until marriage. In cultures in which some form of alteration is the norm, parents worry that uncircumcised daughters will be unmarriageable.

Group identity and communal cohesiveness are other motivations for female genital alteration. As new national boundaries threaten to disrupt historical tribal dominance in particular geographic areas, a process accelerated by urbanization, genital alteration can be seen as a way of marking and strengthening distinct village and tribal identities. In fact, war and dislocation can stimulate people to defend and display their cultural identity by intensified adherence to the practice. In 1997 women in displaced persons camps in Sierra Leone celebrated the end of war and their imminent return to their homes by holding a series of circumcision rituals. “‘I decided to go to the bush and have this done now because I am a mature woman now,’ said Bateh Kindoh, a shy 16-year-old who sat with two other recent initiates to speak with a visitor. ‘We will go back to our villages soon, and I wanted to become part of the Bondo [women’s communal society] first. This is a happy time for us.’” (French, p. A4).

Male and female genital alteration has an abundance of layered meanings: religious, cultural, familial, and political. There are also economic incentives for professional circumcisers to continue to defend their practice. Any discussion of these practices must take these meanings into account.

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SEE ALSO: *Anthropology and Bioethics; Body: Cultural and Religious Perspectives; Children: Rights of; Circumcision, Female; Circumcision, Male; Coercion; Harm; Feminism; Islam, Bioethics in; Judaism, Bioethics in; Medicine, Anthropology of; Sexual Behavior, Social Control of*

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INTERNET RESOURCE

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CLIMATE CHANGE

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In recent years many environmental problems have come to public consciousness. Of all of these problems, global climate change could prove to be the most dramatic and least reversible. It could have profound implications for the health of humans and other beings.

A climate change is quite different from a change in the weather. While weather constantly changes, climate is relatively stable. One can discuss the North American climate during the last ice age, but when one talks about the cold and snow in Boulder, Colorado, yesterday, they are talking about the weather. Weather systems last from a few hours to a few weeks and range from about 10 to 10,000 horizontal kilometers in size. A climate regime may persist for millennia, with variability in temperature and precipitation being part of a stable climate system. The climate system involves complex interactions between the atmosphere, oceans, land surface, snow and ice cover, and the biosphere. Researchers are learning that human activity is also a part of the dynamic that affects climate.

The Discovery of Anthropogenic Climate Change

On June 23, 1988, a sweltering day in Washington, D.C., in the middle of a severe drought in the United States, James Hansen of the National Aeronautics and Space Administration (NASA) testified before the U.S. Senate Committee on Energy and Natural Resources. It was 99 percent probable, Hansen contended, that global warming had begun. His testimony, which was covered by media all over the world, appeared to many people to come from nowhere. But like most overnight sensations, speculation about climate change has a history.

In the eighteenth century Benjamin Franklin surmised that the hard winter of 1783 to 1784 was due to excessive dust in the air, either from the destruction of meteorites or from volcanic eruptions. Early in the nineteenth century the French mathematician Jean Baptiste Fourier (1768–1830) speculated that the atmosphere might function like the glass in a greenhouse, warming Earth's surface by preventing heat from escaping. In 1861 British physicist John Tyndall (1820–1893) showed that slight changes in the composition of the atmosphere could significantly raise Earth's temperature. The Swedish Nobel Prize winner Svante Arrhenius (1859–1927) theorized in 1896 that the use of fossil fuels would increase atmospheric carbon dioxide, thereby changing climate and affecting biological processes. He calculated that a doubling of atmospheric carbon dioxide would lead to an increase of four to six degrees centigrade in Earth's mean surface temperature. In the 1930s the British engineer George Callendar revived Arrhenius's ideas and asserted that global warming had already begun. Working in the United States, Gilbert Plass, Roger Revelle, and Hans Suess brought these ideas into the scientific mainstream in the 1950s. A very influential article by Revelle and Suess in 1957 asserted that because of the exponentially increasing use of fossil fuels, an experiment was in progress that could not have happened in the past and that could not be reproduced in the future. Their work led to the establishment of the Mauna Loa Observatory in Hawaii, which has been measuring carbon dioxide concentrations in the atmosphere since 1958.

The climate anomalies of 1972 and the global food shortages of 1972 to 1973 brought the possibility of climate change to the attention of a broader audience. Droughts in the Sahel region of Africa in the late 1960s and early 1970s had reminded people how dependent on climate humans remain. When drought also occurred in the Soviet Union in 1972, world grain prices doubled and global food shortages followed. During the same year, frost destroyed coffee plantations in Brazil, and changes in seawater temperatures (related to a climate anomaly called El Niño) had a severe impact on Peru's anchovy fisheries. U.S. Secretary of State Henry Kissinger raised the possibility of climate change in a 1974 speech to the United Nations.

The climate change scare of the early 1970s was a fear of cooling. From the 1940s through the 1960s, Earth's mean surface temperature had declined; there was concern that another ice age was beginning. The Central Intelligence Agency undertook a study of how such a cooling might affect agricultural production in the Soviet Union; and the same Senate committee that fifteen years later would hold hearings on global warming held hearings on global cooling.

Whether the fear was of a cooling or a warming, climate increasingly came to be viewed as a dynamic system that is vulnerable to human action. By the mid-1970s the possibility of climate change had been discovered.

The Current Scientific View

Throughout the late 1970s and 1980s, conferences and studies were instituted by a wide range of national and international organizations. The culmination of this activity was the 1990 report of the Intergovernmental Panel on Climate Change (IPCC). The process that led to the development of this report involved 170 scientists from 25 countries; 200 other scientists reviewed the results. The goal of the IPCC process was to determine the international scientific consensus about climate change. The conclusion was that if emissions of *greenhouse gases* (primarily carbon dioxide, methane, chlorofluorocarbons, and nitrous oxide) continue as usual, Earth's mean surface temperature could rise 0.2 to 0.5 degree centigrade per decade, with a likely warming of 1 degree centigrade by 2025, and 3 degrees centigrade by the end of the twenty-first century. This would be the greatest temperature change to have occurred on Earth for at least 10,000 years.

The eight warmest years in the historical record have occurred since the publication of the first IPCC report in 1990. This, combined with scientific advances in the understanding of climate and increasingly sophisticated climate models, has strengthened the case for anthropogenic climate change. This has been reflected in subsequent IPCC reports. The 1995 Second Assessment concluded that "[t]he balance of evidence suggests a discernible human influence on global climate" (p. 5). The Third Assessment, published in 2001, stated categorically that "[a]nthropogenic climate change will persist for many centuries," estimating that the Earth's global mean surface temperature will increase from 1.4 to 5.8°C from 1990 to 2100 (p.17).

Although some remain skeptical, one thing that is certain is that there is a *greenhouse effect.* According to climatologist Stephen Schneider, it is "one of the best, most well-established scientific theories in the atmospheric sciences" (Boyle and Ardill, p. 12). Were it not for the greenhouse effect, all of the planets of the solar system would be cold and lifeless. But as researchers have learned in other areas, such as medicine, too much of a good thing can be a bad thing.

The greenhouse effect occurs when a planetary atmosphere, due to its physical/chemical composition, permits solar radiation to heat the surface of the planet but traps some of the heat that would otherwise radiate back into space. The greenhouse effect explains, at least partially, the differences between conditions on the surfaces of Venus, Mars, and Earth. Venus has an extremely dense, carbon dioxide-rich atmosphere that traps so much heat that life is not possible on the surface of the planet. Mars has a very thin, carbon dioxide–poor atmosphere, and mid-latitude surface temperatures on Mars are about the same as those of Earth's polar winters. Earth is just right for evolving and sustaining life—at least for the moment.

Another fact about which researchers are certain is that human activity is affecting the chemical composition of Earth's atmosphere. From 1860 to 2000 there was an increase of about 34 percent in atmospheric carbon dioxide, more than half of that occurring since the 1960s. Other greenhouse gases have increased by even greater percentages during the same period. Concentrations of these gases have risen as a result of activities that are essential to economic growth and development, at least as they are presently conceived: fossil fuel combustion, deforestation, food-animal production, rice-paddy agriculture, and fertilizer use.

What is certain, then, is that the greenhouse effect exists, and that concentrations of greenhouse gases in the atmosphere are increasing. However, not all scientists agree about the likely effects of these increasing concentrations. There are extremely complicated and ill-understood feedbacks in the climate system. The effects of these feedbacks could be to stabilize climate even in the face of changes in the atmosphere, or to exaggerate the effects of climate change. Since these feedbacks are not well understood, the scientific community's prediction of a significant greenhouse warming is a cautious one.

The Effects of Climate Change

The image that many people have of a global warming is that all regions of Earth would be warmed equally, as if one turned up the thermostat in the global house. This image is quite misleading. The impacts of global warming would be very diverse. Some regions would warm while others would cool. Precipitation patterns would change, and extreme events (e.g., droughts and hurricanes) would become more frequent. While this much is clear, it is extremely difficult to say how particular regions would be affected. The predictions generally agree about the global effects of climate change but disagree to a great extent about its regional effects.

Impacts of climate change fall into three categories. First-order impacts involve physical changes such as rises in sea level, effects on biological systems and circulation of water and so on. A large number of species will become extinct and many ecosystems will fracture and disintegrate. Some of the most dramatic first-order effects of a global warming would be the inundation of island nations, such as the Maldives, Kiribati (Gilbert Islands), and the Marshall Islands. Egypt could lose 1 percent of its land due to flooding. Second-order impacts involve the direct social, economic, and health effects of first-order impacts. An example would be the economic, social, and cultural consequences of Egypt's loss of 1 percent of its land. The part of Egypt that would be threatened by a sea-level rise is the Nile delta, home to 48 million people and contributor of 15 percent of Egypt's GNP. Third-order impacts of climate change involve the indirect social and political responses to the first- and second-order effects. Third-order impacts might include massive emigration from affected regions such as the Nile delta, and international conflicts resulting from economic dislocations and changing patterns of resource use.

The impact of climate change on human health is an area of research that has been receiving a great deal of attention. In particular, there is concern that infectious diseases such as malaria and dengue fever will become more prevalent, along with water-borne diseases such as cholera. There are already 300 million clinically confirmed cases of malaria in the world, causing more than 1 million annual deaths. Infectious diseases are currently the largest source of mortality in the developing world, and until sometime in the twentieth century they were also the largest killer in most of the developed world. Increases in the prevalence of infectious disease could have devastating effects on the human population.

Until the late 1980s it was commonly said that all people would suffer from climate change. However it has become increasingly clear that climate change will involve winners and losers, and most experts believe that the rich countries will do better than the poor ones. Rich countries can build seawalls and dikes to protect coastal areas against rising sea levels. They can even gain economically by developing and exporting technologies that will help in adapting to climate change. Rich countries can pay more for food if climate change adversely affects agriculture. In general, their control of capital can be used to shield them from many effects of a changing climate. Poor countries do not have resources to protect themselves in these ways. Moreover, some poor countries (e.g., Bangladesh) already suffer enormously from extreme climatic events.

But even though it may generally be true that the rich would do better than the poor in adapting to climate change, there are still reasons for the rich to be concerned. Rich people are often more averse to risk than poor people, for they have more to lose. Moreover, if climate change occurs, there will be differential effects across both rich and poor countries. For example, according to some scenarios, agriculture in the U.S. Great Plains might dry up and blow away, while in some arid regions of Africa precipitation might increase.

Although the regional effects of global climate change are uncertain, it is clear that there will be winners and losers. When human action has consequences that benefit some and burden others, it becomes a matter for moral evaluation.

Risk and Insurance

Some commentators have tried to transform the ethical problems implicit in the possibility of climate change into problems of rational choice. One approach has been to think of the possibility of climate change as a risk, and the costs of emission reduction, mitigation, and adaptation as the premium paid for insurance against this risk. However tempting this approach may be, the insurance metaphor is misleading. An insurance company is able to set rational premiums because of actuarial tables that are based on the frequency with which compensable losses occur. But however strong the theoretical reasons are for thinking that climate change will occur, researchers have nothing like actuarial tables that tell them about the frequency of climate change when the atmosphere is loaded with greenhouse gases. Moreover, the idea that society is in a position to reasonably assess the potential damages of climate change is quite absurd. No one knows what all the economic and health effects of a greenhouse warming would be, much less how to attach meaningful economic values to the loss of many wild species and the destruction of societies and cultures. As a result, economists who work on climate change tend to focus on the more easily quantifiable costs of emissions reductions rather than on the damages that such investments might help society to avoid. While it is easy to talk about the importance of taking out insurance against the possibility of a greenhouse warming, at present there is no way to determine what it would be rational to pay for such insurance.

Finally, the insurance metaphor defers rather than evades the ethical questions. Even if one were able to determine a rational premium, the question of how the costs should be distributed would remain. Talk of purchasing insurance against the risk of a greenhouse warming does not free society from the hard ethical discussions.

Moral and Political Issues

Philosophers often distinguish duties of justice from other sorts of duties. For present purposes, however, one can think of climate change as posing questions of justice with respect to human contemporaries (intragenerational justice), descendants (intergenerational justice), and possibly nonhuman nature. Because climate change is by its very nature global in scope, the questions of justice that it provokes are international.

The rich countries of the world have loaded the atmosphere with the greenhouse gases that may already be changing climate. They have benefited from their actions by developing economically. While rich countries have gained the benefits, the deleterious effects of their emissions will be felt by everyone. If climate change-induced floods occur in Bangladesh, it will not be due to the actions of the Bangladeshis. They will not have caused the floods, nor will they have benefited from the past emissions of greenhouse gases that caused them.

In addition to these historical inequities in emissions, there are important differences in present emissions. A handful of industrial countries emit between one-half and three-quarters of all greenhouse gases. Yet at the United Nations-sponsored Conference on Environment and Development, held in Rio de Janeiro in June 1992, the rich countries were unwilling to agree to timetables and targets even for stabilizing their emissions, much less reducing them, mainly due to the intransigence of the United States. Finally at Kyoto in 1997 the nations of the world did agree to binding timetables and targets for emissions reductions, only to have the United States and Australia jump ship after doing everything they could to weaken the agreement.

Rich countries became rich in part by taking actions that are changing the global climate. This climate change may have devastating impacts on poor countries. What do the rich owe the poor as a consequence of their actions? This question arises against the background of an international system characterized by radical and increasing inequality. According to Sir Crispin Tickell, in 1880 the ratio of real per capita income between Europe, on the one hand, and India and China, on the other, was two to one; in 1965 it was forty to one; and in the 1990s it was seventy to one. Even on the most conservative assumptions, between 1820 and 1970 global inequality doubled (Dollar and Kraay). One way of making this inequality vivid is by considering these examples from the *Human Development Report 1998: Consumption for Human Development* (United Nations Development Programme, p. 29). In 1960, 20 percent of the world's people who lived in the richest countries had thirty times the income of the poorest 20 percent, and by 1995 eighty-two times as much income. The wealth of the fifteen richest people in the world exceeds the total GDP of sub-Saharan Africa. The assets of the eighty-four richest individuals in the world are greater than the GDP of China at the beginning of the twenty-first century. The 225 richest people in the world have combined wealth that is equal to the annual income of the poorest 47 percent of the world's population. In absolute terms, more than 1 billion people live on less than $1 per day, and nearly 3 billion live on less than $2 per day (World Bank).

Underlying these problems of inequality and poverty are an exploding population in some parts of the developing world and increasing overconsumption in the developed world. The United States, with 5 percent of the world's population, annually consumes 25 percent of the world's fossil fuels, 33 percent of its paper, 24 percent of its aluminum, and 13 percent of its fertilizer. A child born in 1994 in the United States will in his or her lifetime drive 700,000 miles, using 28,000 gallons of gasoline; produce 110,250 pounds of trash; eat 8,486 pounds of red meat; and consume enough electricity to burn 16,610 pounds of coal. Earth simply cannot support many Americans. The world population as of 2003 is more than 6.2 billion, and is increasing by 75 million per year. An optimistic scenario calls for world population to stabilize at more than 10 billion in the twenty-third century. Many observers expect population to grow far beyond that.

One way of trying to understand the joint impact of overconsumption and exploding population is to consider the following facts. Sweden is a country that enjoys one of the highest standards of living in the world, yet its per capita carbon dioxide emissions are little more than one-fourth of those of the United States. If Sweden's level of per capita emissions were to be established as an international ceiling, the United States would have to reduce its emissions by vastly more than anyone is willing to even consider. Yet, even given such painful reductions on the part of some countries, on this scenario world emissions would increase by more than one-third, reflecting the large populations of some less developed countries that consume very little energy.

Philosophical theorizing about international justice is underdeveloped, and very little work has been done on international environmental justice. The most influential philosophical theories of justice were formulated with an eye to what constitutes a just national distribution of private goods. Pattern theories such as that of John Rawls, and entitlement theories such as that of Robert Nozick, have received the most attention. Although one can speculate about what these theories might imply with respect to climate change, neither philosopher has had much to say about global justice, much less global environmental justice.

Rawls' principle of distributive justice is the "Difference Principle": Social and economic inequalities are to be attached to positions and offices that are open to all under conditions of fair equality of opportunity, and they are to be distributed to the greatest benefit of the least advantaged members of society. Whether one takes the subjects to be individuals or societies, it seems quite obvious that the global distribution of social and economic benefits is unjust according to this principle. Moreover, if one were to use the Difference Principle as a test for who should benefit from further releases of greenhouse gases and who should bear the costs of reduction, it seems equally clear that current policies would not satisfy this principle.

Nozick argues that the moral acceptability of a distribution depends entirely on how it came about. If the present distribution resulted from a just initial distribution through voluntary exchanges, then it is just, regardless of how unequal it may be. But given the global history of domination, imperialism, and exploitation, it seems clear that the present global distribution is unjust on Nozick's grounds. According to Nozick, any complete theory of justice must include a principle specifying how past injustices are to be rectified, but he has little to say about what such a principle may require.

Although it appears that both Rawls and Nozick are committed to the view that the current international order is unjust, neither deals specifically with this question or with the distribution of environmental benefits and burdens. Moreover, there are reasons for supposing that many environmental goods resist treatment as distributable benefits and burdens. The bad effects of climate change would include spillover effects suffered by some parties who had virtually no role in bringing them about. On reasonable human time scales, a stable climate is irreplaceable and irreversible. Furthermore, modeling aspects of the environment as distributable goods may be misleading and inappropriate. Such an approach neglects the fact that humans are situated in an environment that conditions and affects everything they do, and in part constitutes their identities.

While there is good reason for supposing that both historical and current patterns of greenhouse gas emissions are part of an unjust system of intragenerational relationships, philosophical theories of justice have not yet given the conceptual resources to address these issues in a detailed and meaningful way. More work needs to be done.

In addition to questions about intragenerational justice, global climate change poses moral questions about intergenerational justice. Those who come after us will live in a very different world than the one we inhabit in the early twenty-first century, due in part to actions that we are taking. Some who are influenced by utilitarian philosophers such as Henry Sidgwick may think that we owe just as much to future people as to present ones, since once they come to exist, they will be just as real as present people and will have the same moral status. On this view, the claims of future people should not be treated less seriously than those of present people simply because they are remote from us in time. But barring a complete collapse of Earth's human population, over the course of millennia there will be vastly more people in the future than exist now. If we take each future person as seriously as each present person, it would appear that the interests of the present would be swamped by virtue of the size of our future human population.

Other thinkers, impressed by an argument in Derek Parfit's 1984 book titled *Reasons and Persons*, may conclude that we have no obligations to future people (although this is not Parfit's conclusion). On this view, future people who feel disadvantaged would have no cause for complaint against us because their very existence would be contingent on actions that we have taken. If our present actions were other than they are, then different people would come to exist in the future. Thus, no future person can say that he or she would have been better off had we made different choices; for if we had made different choices, then that person would not have existed at all.

Many economists would grant that we have obligations to those who will follow us, but they would argue that these obligations are easily fulfilled. Suppose that, because in 2003 we act in such a way as to change the climate, our descendants living in 2103 incur damages valued at N dollars. In order for our climate change activities to be justified, we must profit enough from them to provide our descendants with N dollars when they come into existence. Because of the power of compound interest, small present benefits justify large future damages. If N dollars come due in a century and we can obtain a 5 percent return on our investments, our present benefit from climate-changing activities would have to be only $.0068N$ dollars (compounded monthly) in order for them to be justified. In other words, a present benefit of \$100,000 would justify inflicting a compensation of \$14.68 billion on those living a century hence.

There are many problems with such an approach. Even if we were able to compensate future people adequately in this way, they will have been deprived of the ability to make some significant choices. For example, they will not have been able to choose to preserve a stable climate regime, even if that implies a lower standard of living.

This approach also involves the ludicrous idea that we can attach meaningful economic values to the loss of many wild species, the destruction of societies and cultures, and the unknown health effects of significant climate change. There simply are no credible attempts to carry out a benefit-cost analysis of the warming of Earth's median surface temperature by 3 degrees centigrade. This is hardly surprising, since there is often a great deal of disagreement about such relatively simple questions as the short-term effects of a change in the marginal tax rate of a single country.

Peter Brown and Edith Brown Weiss have argued that we have a fiduciary trust to preserve Earth's natural and human heritage at a level at least as good as that we received. On this basis, Weiss argues that we should reduce greenhouse gas emissions, take steps to minimize the damage that results from climate change, and develop strategies to assist future generations in adapting to climate change. This is a sensible approach that has the virtue of squaring with many people's moral intuitions. It suggests that we have significant obligations to future people, but that they do not entirely swamp the interests of the present.

Unfortunately, the fiduciary view verges on the platitudinous. Among those who believe that the buildup of greenhouse gases poses a threat, not many would deny that we need to reduce emissions, minimize harms, and develop adaptation strategies. What people disagree about is how aggressively we should pursue these policies, what the proper mix of them is, and who should bear the burdens. The fiduciary approach stops short of trying to answer these hard questions.

Furthermore, if we take seriously the idea that each generation has an obligation to preserve Earth's natural and human heritage at a level at least as good as what was received, then we are immediately faced with questions about how to evaluate the goodness of our own heritage and various changes that we might make with respect to it. These are the sorts of questions that economists try to answer, using various techniques of benefit-cost analysis, such as interviewing people about their willingness to pay (or accept compensation) for environmental good, that ethicists typically find unsatisfactory.

In addition to the problems of human health and welfare that are likely to be caused by climate change, nonhuman nature will also be affected. Climate change is likely to be much too rapid for most plants and animals to adapt to or migrate from. Even when migration would in principle be possible, no migration routes will be available for most plants and animals in a densely populated and developed world.

In recent years a powerful literature has developed that argues humans have obligations to nonhuman nature. Some philosophers, such as Peter Singer, argue that our direct obligations end at the border of sentience; others, such as Holmes Rolston III, argue that we have obligations to virtually every element of the natural order. Whatever we may think about this dispute, only someone who believes that our obligations are exhausted by our duties to humanity can remain unmoved in the face of this anticipated destruction of nonhuman nature.

Indeed, even someone who believes that our obligations are only to humans may feel that massive destruction of nonhuman nature is morally appalling. Humans have preferences about what happens to nature, and insofar as nature's destruction is contrary to human preferences, this destruction can be morally condemned. Moreover, anyone can be morally appalled by the character of a culture that would so willingly destroy nature in order to preserve a way of life that is rooted in overconsumption. One might think of nature as being like a work of art. We may not think that works of art are the direct objects of moral concern, yet we may morally condemn those who would vandalize them—say by burning the contents of the Louvre in order to warm their houses by one or two extra degrees for a year or so.

Climate change poses serious threats to human health and welfare and raises questions about our global duties and our duties to nonhuman nature. As the concentration of greenhouse gases in the atmosphere continues to increase, the moral issue of climate change will grow in importance.

DALE JAMIESON (1995)
REVISED BY AUTHOR

SEE ALSO: *Agriculture and Biotechnology; Endangered Species and Biodiversity; Environmental Ethics; Environmental Health; Future Generations, Reproductive Technologies and Obligations to; Hazardous Wastes and Toxic Substances; Justice; Population Ethics; Sustainable Development*

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CLINICAL ETHICS

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I. Development, Role, and Methodologies
II. Clinical Ethics Consultation
III. Institutional Ethics Committees

I. DEVELOPMENT, ROLE, AND METHODOLOGIES

Formal efforts to address clinical ethics first developed in the United States and Canada, though similar efforts are clearly underway in western and central Europe and Japan. Indeed, interest in clinical ethics has spread to many areas of the world, including parts of Central and South America, eastern Europe, and parts of Africa. Though variously defined, clinical ethics involves the identification, analysis, and resolution of value conflicts or uncertainties that arise in the provision of healthcare in clinical settings (Fletcher and Boyle; Jonsen, Siegler, and Winslade). Clinical ethics activities include examination or formulation of relevant policies, ethics education, and ethics consultation to healthcare professionals, patients, families, surrogates, or organizations. Unlike some solely academic domains of the broader field of bioethics, clinical ethics must take into account the actual context in which clinical ethical issues arise because it aims to make contributions to clinical practice and to policy governing clinical practice. This context includes complex psychosocial, medical, legal, cultural, and political dimensions that have implications both for the types of ethical issues that arise and how those issues may be resolved (Aulisio, Arnold, and Youngner, 2000, 2003; May).

Traditionally, clinical ethics discussions tended to focus on issues related to informed consent, confidentiality and privacy, decision capacity or competence, decision making involving minors, resource allocation, and end-of-life care. Though these issues remain central to clinical ethics, the mid-1990s through early 2000s saw a growing recognition of the important relationship between clinical, organizational, and business ethics (Schyve et al.), along with the development of a number of new areas of concern, including physician-assisted suicide (Battin, Rhodes, and Silvers), palliative care (Barnard et al.), medical mistakes (Rubin and Zoloth; Institute of Medicine), ethics and genetics (Juengst), and even bioterrorism (Gostin).

The typical mechanism for addressing issues in clinical ethics in most healthcare institutions is an ethics committee. Ethics committees are present in most hospital settings in the United States and Canada, and increasingly in other settings, such as long-term care, as well. In some clinical settings, most often academic medical centers, ethics committees are part of a much larger clinical ethics program. Such programs are commonly staffed by full-time ethicists who are responsible for ethics education, service, and research.

Development

Renée C. Fox and David J. Rothman both argued that bioethics began in the 1960s as a social and intellectual movement. The earliest concerns of bioethics were focused on acute ethical problems in research settings. Influenced by the U.S. civil rights movement, bioethical inquiry also exposed weaknesses in institutional arrangements that no longer adequately protected research subjects or patients (Fletcher). From its origins to the present, the bioethics movement has had two arms: (1) an interdisciplinary dialogue, known as bioethics, that became a new academic subdiscipline in the larger field of ethics; and (2) an agenda for institutional and social change to prevent abuses and enhance the values that guide decision making concerning research subjects and patients. Social changes in research settings to protect human subjects preceded such changes in patient-care settings by almost a decade.

The 1960s saw a number of widely publicized and much debated cases that brought to the fore the value-laden nature of clinical practice and the difficult choices posed, in part, by rapid advances in medical technology (Jonsen, 2000). The invention of a plastic arteriovenous shunt by an American physician, Belding H. Scribner, in 1960 made possible chronic hemodialysis and, simultaneously, created a profound ethical dilemma because there were far more patients in need of chronic hemodialysis than the Seattle Artificial Kidney Center could accommodate. This dilemma led to the establishment of the Admissions and Policy Committee, later infamously referred to as the "Seattle God Committee," which employed "social worth criteria" to select candidates for dialysis. Throughout the decade, successes in organ transplantation created similar ethical dilemmas related to resource allocation. In 1967 South African surgeon Christiaan Barnard's successful transplantation of a beating heart from a patient with "irreversibly fatal brain damage" raised serious ethical questions about the definition of death. In response, a committee at Harvard Medical School, the following year, formulated a statement that defined "brain death" (Jonsen, 2000).

If the ethical dilemmas raised by chronic hemodialysis and organ transplantation remained a bit removed from the lives of ordinary people, the 1970s were dominated by cases that clearly resonated with the general populace. In the racially charged climate of the early 1970s, the *New York Times*' 1972 expose of the U.S. Public Health Service's forty-year Tuskegee Syphilis Study of the progression of untreated syphilis in African-American men powerfully demonstrated how social values, even disvalues such as racism, can dramatically affect "scientific" practice in clinical settings. The study, which ran from 1932 to 1972, enrolled 600 African-American men from Tuskegee, Alabama. All participants were told that they had "bad blood" and were in need of regular medical exams, including spinal taps. In exchange for these exams, participants were given transportation to and from the hospital, hot lunches, medical care, and free burial (upon the completion of an autopsy). Of the study participants, 200 did not have syphilis, while the other 400 were diagnosed with syphilis but were never told their diagnosis or treated for their disease (even after effective treatment became available) (Jonsen, 2000; Pence). In January 1973, less than a year after the Tuskegee expose, the value-laden nature of clinical practice was again thrust into the public eye when the U.S. Supreme Court handed down its landmark decision in *Roe v. Wade.* In setting off a decades-long struggle over the morality and legality of abortion, the case also introduced extramedical notions such as "personhood," "viability," and "privacy" into the public debate.

Despite the significance of Tuskegee and *Roe,* no single case captured the public imagination or shaped the development of clinical ethics more than the tragedy of Karen Ann Quinlan did (Pence). Quinlan was a twenty-one-year-old patient at St. Clare's Hospital in Denville, New Jersey. Having lapsed into a coma in April 1975 as a result of the combined effects of alcohol, Valium, and, possibly, Librium, she was dependent on a respirator (ventilator) and was eventually deemed to be in a *persistent vegetative state* (sometimes referred to as being *permanently unconscious*). In addition to the respirator, Quinlan was dependent on the technological administration of nutrition and hydration through the use of a nasogastric (NG) tube (one that delivers food and water to the stomach through the nose). After months of anguished deliberation, Quinlan's parents, Julia and Joseph Quinlan, in consultation with their parish priest, decided to remove her from the respirator and let her die. The Quinlan's decision, however, was opposed by hospital officials on the grounds that to remove the patient's respirator support in order to let her die was euthanasia—the moral and legal equivalent of murder (Pence).

Though New Jersey Supreme Court, in a 1976 ruling, ultimately supported the rights of the Quinlans to remove their daughter from the respirator, the tragedy of Karen Ann Quinlan had a dramatic impact on society and, in particular, on the rise of clinical ethics. Quinlan's dependence on a respirator and feeding tube came to symbolize, for many, "an oppressive medical technology, unnaturally prolonging dying" (Pence, p. 31). Once again, technological developments in medical science, this time the respirator and NG tube, had created new and difficult ethical dilemmas. Before the advent of respirators and feeding tubes, patients in Quinlan's situation simply died. There were no questions about "withholding" or "withdrawing" treatment, "active" or "passive" euthanasia, "ordinary" or "extraordinary" means, or who should be allowed to make life-and-death decisions and under what circumstances. If some people could not identify with chronic hemodialysis, organ transplantation, and the like, everyone could identify with the plight of Quinlan. Indeed, the New Jersey Supreme Court seemed to recognize this when it suggested that ethics committees be developed in hospitals so that future cases might be addressed before reaching the courts (*In re Quinlan,* 1976).

Not surprisingly, then, the 1970s saw the first clear growth of formal efforts in clinical ethics. Ethics committees began to be established in major hospitals. Scholars in bioethics increasingly taught new courses as faculty members of medical, nursing, and other professional schools. Bioethics scholars also served developing programs in the "medical humanities." In addition, some academic medical centers began to use bioethics and medical humanities scholars to offer ethics education and even ethics consultation in cases involving patients (Jonsen, 1980).

Throughout the 1980s difficult cases continued to spur the development of clinical ethics. In part because of the *Quinlan* case and a national debate on end-of-life decisions, 1980 saw the establishment of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, which in 1983 issued its groundbreaking report, *Deciding to Forego Life-Sustaining Treatment.* The 1980s also saw the debate about withholding/withdrawing life-sustaining treatment extend to neonatal intensive care medicine with a series of hotly debated "Baby Doe" cases involving impaired newborns. The cases of Nancy Cruzan (*Cruzan v. Director,* 1990) and Elizabeth Bouvia (*Bouvia v. Superior Court,* 1986) raised additional ethical issues concerning end-of-life decisions and adults: Is artificially administered nutrition and hydration medical treatment? What evidentiary standard should be satisfied in making end-of-life decisions for formerly competent, but now incompetent, adults? Who is authorized to set such a standard? Does a competent adult have a right to refuse nutrition and hydration? Finally, the emergence of the HIV/AIDS epidemic raised a host of ethical issues that surfaced throughout the 1980s, including, but not limited to, concerns about: confidentiality and privacy; health professionals' duties to treat HIV-infected patients and duties to disclose their own HIV/AIDS status; duties to warn at-risk third parties; patient duties to disclose HIV/AIDS status to health providers; and mandatory testing for health professionals and others.

During the 1980s, several postgraduate training programs, some textbooks, and one journal declared that they addressed *clinical ethics,* a term that had not been used in the earlier bioethics movement. The practice of ethics consultation began to be defined in the early to mid-1980s (Fletcher, Quist, and Jonsen), and ethics committees multiplied in clinical settings to protect shared decision making with patients and family members.

With the Patient Self-Determination Act of 1991 and the stipulation of the Joint Commission on Accreditation of Healthcare Organizations (1993) that member institutions must have a "mechanism" for "the consideration of ethical issues arising in the care of patients and to provide education to caregivers and patients on ethical issues in health care" (R.1.1.6.1, p. 9), the importance of formal efforts in clinical ethics was given expression through regulatory requirements in the United States. These rules intensified the need for competence and leadership in clinical ethics. Partly in response to this, the 1990s saw efforts by groups in Canada and the United States to address standards for ethics consultants and consultation. From the mid- to late 1990s physician-assisted suicide and palliative care captured much of the clinical ethics debate, and the rise of managed care pushed organizational ethical issues into the clinical domain.

There can be little doubt that clinical ethics is becoming an established subdiscipline of the broader field of bioethics. Highly multidisciplinary, clinical ethics is pursued by clinicians—physicians, nurses, social workers, and other health professionals—as well as by those with backgrounds in the humanities (including philosophy, theology, history, and literature), social sciences (including sociology, anthropology, and public health), and law. By 2001 there were at least forty-seven academic institutions offering graduate training programs (including certificate and fellowship programs) in bioethics or medical humanities; a number had clinical ethics components; and several were specifically devoted to clinical ethics (Aulisio and Rothenberg). Despite the rapid increase in graduate training programs in bioethics and medical humanities, the vast majority of the people offering clinical ethics services at healthcare institutions have little or no formal education and training in clinical ethics (Aulisio, Arnold, and Youngner, 2003). This suggests a continued need for educational and training programs tailored specifically to this group.

Role and Methodologies

Education and service (e.g., consultation and policy formation) are the foci of clinical ethics efforts in most healthcare institutions. Typically, a clinical ethics program in a healthcare institution, such as a large hospital, will provide staff and community education, policy critique and formulation, retrospective and prospective case review, and case consultation. The most active clinical ethics programs tend to be at academic medical centers that employ clinical ethicists. In the academic medical setting, clinical ethicists may be involved in teaching at all levels of health-professional education (preclinical, clinical, graduate, postgraduate, and continuing education). Some institutions with programs in clinical ethics offer advanced education and training through fellowship or degree programs. They may also have outreach efforts to assist in the formation of clinical ethics programs and the training of leaders for these programs.

Although education and service are central to any clinical ethics program, research can be an important component as well, particularly in an academic setting. Such research may include the type of conceptual and analytic work characteristic of humanities research (e.g., case analysis, conceptual clarification, normative assessment of particular clinical ethics issues) or the type of empirical research more characteristic of the social sciences (e.g., frequency occurrence of various ethical problems; the practical impact of various policies or practices; attitudes and beliefs of specific populations toward particular ethical issues; effectiveness of certain interventions designed to promote informed consent, protect privacy, and so forth) (Singer, Siegler, and Pellegrino). The increasingly vast clinical ethics literature is indicative of the dramatic growth in clinical ethics research since the 1980s.

Like clinical ethics itself, discussions of methodological issues in clinical ethics have evolved and developed over the years. As clinical ethics emerged, the prevailing approach to bioethical inquiry (Beauchamp and Childress) used systematic reflection on moral principles and their relevance for resolving ethical problems in biomedicine by weighing and balancing the claims of competing principles (an approach known as *principlism*). Although this mainstream approach achieved valuable work, criticisms pointed to three ways in which the approach needed to be strengthened: (1) more attention needed to be given to the nature of diseases and the clinical contexts in which clinicians and patients face ethical problems (Sider and Clements); (2) the criticism that principlism appeared to promote a hierarchical form of reasoning that deduced ethical resolutions for complex clinical problems from fixed moral principles and rules needed to be addressed (Jonsen and Toulmin); and (3) in addition to moral principles, more conceptual and methodological resources for ethical inquiry needed to be developed, because principlism appeared too vague and flexible to yield well-reasoned conclusions (Clouser and Gert).

In response to these perceived inadequacies in the forms of ethical inquiry, Glenn C. Graber and David C. Thomasma attempted to recast the theory and practice of medical ethics in terms of a “unitary ethical theory” founded in clinical medicine itself (Ackerman et al.). Their contribution, with strengths and weaknesses, was expertly reviewed in 1990 by Richard M. Zaner, a philosopher with significant clinical experience, who enriched the literature with narratives of illness and of the ethical conflicts over uses of high technology that are frequent in tertiary-care centers. Other contributors to the clinical ethics literature responded by drawing on the works of feminist (Gilligan; Noddings; Wolf; Tong) and theological (Hauerwas) writers who criticized bioethics for neglecting the ethical significance of specific clinical virtues, such as caring for persons in concrete human relationships.

Additional methodological resources for ethical inquiry appeared in the renewal of interest in casuistry, the art of ethical analysis that compares and contrasts relevantly similar cases (Jonsen and Toulmin; Brody, 1988; Arras). Clinical decision making is case-specific: It is directed at the care of a particular patient faced with a particular illness or injury. Each case has a history: what preceded the problems that needed medical attention, what needed to be done, and what was done to address the problems presented by the patient. Because it focuses on the ethics of clinical practice, clinical ethics strives for the richest possible descriptions of cases and their interpersonal dynamics and power differentials. In this vein, several anthologies of cases have appeared with well-informed clinical discussions (Pence; Crigger), including casebooks with cases drawn from ethics consultations (Kuczewski and Pinkus; Culver). Like the practice of clinical medicine, casuistry builds on the accumulated experience, both of the individual and of the professions, in dealing with a variety of cases. Comparing and contrasting related cases can reveal important ethical considerations that may not be apparent in isolated focus on a particular case.

Yet another response to critiques of earlier bioethics was to deepen and enrich the study of larger issues and themes in clinical practice, both by using cases and by drawing on knowledge available only through the intimacies of the clinician–patient encounter. Authors of such studies tend to be clinician-ethicists or ethicists who have adapted to the clinical setting sufficiently to share in such intimacies. Four examples among many are discussions of informed consent (Katz), life-and-death decision making (Brody, 1988), pain and suffering (Cassell), and the uses of power by clinicians (Brody, 1992). These studies draw on a variety of disciplines and experiential data obtained in clinical settings. As such, they encourage ethical scrutiny and reform of understandings and practices in the clinical encounters between patients and clinicians (Zaner). In this way, clinical ethics strengthens the conceptual underpinnings of bioethics with experiential data and helps motivate clinicians to reform their practices.

The continuing multidisciplinary growth in clinical ethics has, not surprisingly, created a great deal of methodological diversity in approaching clinical ethics issues. Methodological approaches characteristic of various health professions, the humanities, and the social sciences can be found in the literature (McGee; Charon and Montello; Kuczewski; Nelson; Bosk; Moreno). In practice, the approaches of different persons involved in clinical ethics efforts will, naturally, reflect, at least in part, their professional or disciplinary perspective. This is part of the great richness of clinical ethics.

In the face of this rich methodological diversity, clinical ethics, far from being fragmented, is held together by a profoundly practical aim: to make contributions to clinical practice and to policy governing clinical practice. To the extent that it is able to achieve this, clinical ethics must pay careful attention to and take into account certain features of the clinical context. As mentioned at the outset, these features include complex psychosocial, medical, legal, cultural, and political dimensions that have implications both for the types of ethical issues that arise and how these issues may be resolved (Society for Health and Human Values). For example, in the United States, the pluralistic societal context, the rights of individuals to live according to their values, and the value-laden nature of clinical practice make ethical conflict or uncertainty an inevitable feature of the clinical setting. Indeed, these features, in conjunction with advances in medical technology, arguably have created the need for formal efforts in clinical ethics. In the U.S. societal context, therefore, irrespective of the methodological approach employed by any particular person in working to address a given clinical ethics issue, the political rights of individuals must be taken into account if the approach is to make a contribution to actual clinical practice. Thus, in a very real sense, methodological approaches in clinical ethics and the theoretical commitments behind them are subordinated to the practical aim of this discipline.

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SEE ALSO: *Autonomy; Beneficence; Bioethics; Casuistry; Ethics: Normative Ethical Theories; Feminism; Informed Consent; Justice; Narrative; Nursing Ethics; Principlism; Virtue and Character;* and other *Clinical Ethics* subentries

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II. CLINICAL ETHICS CONSULTATION

The dictionary defines consulting as "providing professional or expert advice." A clinical ethics consultant is defined here as a person who upon request provides expert advice to identify, analyze, and help resolve ethical questions or dilemmas that arise in the care of patients. Although the ethics consultant also may provide ethics education and help formulate policy, the bedside role is central to the definition of an ethics consultant (Jonsen).

In the United States, clinical ethics consultation began in some academic medical centers in the late 1960s and early 1970s (La Puma and Schiedermayer), and was given great impetus by the development of hospital ethics committees in the late 1970s and 1980s. During this period the rapid growth of medical technology confronted critically ill patients, their families, and health professionals with difficult ethical choices. At the same time, the traditional authority of the physician was challenged not only by the patient-rights and consumer-rights movements, but also by changes in the way medical care was delivered in tertiary-care hospitals, where patients were often treated by teams consisting of physicians, nurses, social workers, medical technicians, and others. Decisions about forgoing life-sustaining treatment for incompetent adults or premature infants were being made in a legal vacuum often filled by the fears of civil and even criminal litigation. In this atmosphere there was considerable uncertainty about the optimum process for resolving difficult ethical decisions without resorting to the public arena of the courts.

In its 1976 Quinlan decision, the New Jersey Supreme Court tentatively suggested the use of ethics committees to assist persons who faced difficult end-of-life decisions. In the early 1980s, the federal "Baby Doe" regulations spurred hospitals to develop internal mechanisms for dealing with decision making for severely handicapped infants. In 1983 the U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research endorsed the notion of shared decision making between patients and physicians. It suggested consultation with an ethics committee as a possible means for resolving disputes that arose in the clinical setting, but noted that the efficacy of such consultation had not been demonstrated (U.S. President's Commission).

In 1985 the National Institutes of Health and the University of California at San Francisco cosponsored a conference in Bethesda, Maryland, for persons designated by their institutions as ethics consultants. The conference was attended by fifty-three invitees, and fifty additional persons expressed interest in attending a future meeting of this group (Fletcher, 1986). By 1987 the Society for Bioethics Consultation was formed for the support and continuing education of clinical ethics consultants. In 1992 the Joint Commission for the Accreditation of Health Care Organizations (JCAHO) published a requirement for healthcare institution accreditation that all healthcare institutions must have in place a mechanism for resolving disputes concerning end-of-life decisions.

Structures of Clinical Ethics Consultation

Clinical ethics case consultation is provided in several ways: by an ethics consultative group as a whole (such as an ethics committee), by a subgroup of the consultative group, or by individual consultants. Clinical ethics case consultation by a large group has the potential for having diffused accountability and being depersonalized, bureaucratic, insensitive, closed-ended, and removed from the clinical setting. But it has the advantage of providing multiple perspectives and opportunities for queries from persons of diverse backgrounds, and for correcting the potential for narrow or idiosyncratic views of an individual consultant.

In contrast, clinical ethics case consultation by an individual consultant is an open-ended process that can extend over a period of time, and permit ongoing discussion and pursuit of issues that require clarification. The individual consultant can decide what information is necessary and obtain it firsthand. Interviews with patients, families, and health professionals can be scheduled flexibly and conducted in private settings more conducive to diminishing apprehension, establishing trust, sharing information, and allowing the kind of give-and-take that is so important to exploring emotionally powerful and intensely personal issues. Furthermore, an individual ethics consultant is more visible and accountable than a committee (Agich and Youngner). For these reasons, many ethics consultative groups and healthcare professionals have found the individual clinical ethics consultant more effective than the committee. Many ethics consultative groups have created a middle ground that involves small teams who serve as an extension of the ethics consultation group or ethics committee.

Some see an advantage to a relationship between the ethics consultant and an ethics consultative group or committee because the large group regularly can review the individual consultant's activities. This arrangement provides peer review and quality assurance for the consultant as well as education for the larger group or committee. The ethics consultant or consultation team can ask the entire group to become involved in particularly controversial or complex cases.

The Role of the Clinical Ethics Consultant

Despite the growing interest in and practice of clinical ethics consultation, important questions remain about its purpose, requisite skills, methods, specific responsibilities, evaluation, and effect. Unlike traditional medical consultants, clinical ethics consultants are not subject to widely accepted standards and procedures for training, credentialing, maintaining accountability, charging fees, obtaining informed consent, or providing liability coverage (Purtilo; Agich).

While the role of the ethics consultant generally has been pragmatic, that is, to provide practical assistance with actual patient-care decisions (Cranford; Glover et al.; Siegler and Singer; Fletcher, 1986), there has been little consensus about how this role should be implemented. For example, although some see the ethics consultant, like the traditional medical consultant, as an expert who uses specific skills and knowledge to help "answer" ethical questions, exactly what constitutes the appropriate skills and knowledge base is a matter of debate. Does the expertise come from the wisdom of practical clinical experience (La Puma et al.), or is it derived from a knowledge of moral theory and ethical principles?

Others see the clinical ethics consultant's role not so much as an expert but as someone who facilitates decisions in a "community of reflective persons" (Glover et al., p. 24). This approach stresses the importance of involving all persons connected with the case—the patient, family members, physicians, nurses, medical students and residents, social workers, friends, and clergy. In this view, a shared decision-making process should extend beyond the physician–patient dyad so that a greater range of personal values and interests can be considered. This view is less compatible with the traditional model of medical consultation, which focuses more narrowly on the physician as decision maker.

Some commentators have worried that the individual ethics consultant, the ethics consultative group, or the ethics committee will act as moral "police" or "God Squad" (Siegler and Singer, p. 759), and erode the decision-making authority of the physician. Troyen Brennan has voiced a more subtle concern: that by turning increasingly to ethics consultants and ethics committees, we "run the risk of forcing the ethics of the caring relationship to the periphery of clinical practice as something that is best left to experts" (Brennan, p. 4). Furthermore, the role of the ethics consultant may be confused with other institutional roles, such as risk management, peer review, quality assurance, or resource allocation. Taking on these roles could create a conflict of interest for the ethics consultant.

Reasons for Ethics Consultation

Ethics consultations are requested for a variety of reasons that include prevention of litigation; mediation of disputes and resolution of conflicts between or among the patient, healthcare professional, and family; confirmation of or challenges to decisions already made; emotional support for difficult decisions; and identification of morally acceptable alternatives. For example, ethics consultation may be requested because physicians and family members disagree about how aggressively to treat a dying, incompetent cancer patient, or because there is difficulty interpreting a patient's living will. Ethics consultants may be called because there is disagreement about the acceptability of a family request to stop tube feeding an Alzheimer patient who refuses to eat. Requests for ethics consultation may come because nurses or house officers are concerned that competent patients are being left out of the decision-making process.

Goals of Ethics Consultation

There is disagreement about the appropriate goals of ethics consultation. John La Puma and E. Rush Priest have suggested that ethics consultations's primary goal should be "to effect ethical outcomes in particular cases and to teach physicians to construct their own frameworks for ethical decisions making" (La Puma and Priest, p. 17). Patient-rights advocates disagree. They argue that the primary goal of ethics consultation is the promotion of patient autonomy by encouraging shared decision making (Tulsky and Lo). John Fletcher takes a broader view. He identifies four goals of ethics consultation: (1) to protect and enhance shared decision making in the resolution of ethical problems; (2) to prevent poor outcomes; (3) to increase knowledge of clinical ethics; and (4) to increase knowledge of self and others through participation in resolving conflicts (Fletcher, 1992).

Contributions to the Practice of Ethics Consultation

While the general purpose of clinical ethics consultation is to help resolve ethical questions or dilemmas in patient care, persons who perform ethics consultation come from diverse professional backgrounds and do not share the same problem-solving methods or theoretical assumptions. This diversity has left its stamp on the way clinical ethics consultation is performed, and has profound implications not only for the practice of clinical ethics consultation but also for the training of its practitioners.

Despite this diversity, a common ground can be seen in the shared goal of identifying an ethically supportable solution to a clinical ethical question or dilemma, and in a recognition that the process of arriving at a solution requires knowledge of law, ethics, medicine, psychosocial issues, and at times, religion.

The legal tradition has influenced clinical ethics consultation by placing emphasis on rights and on formal mechanisms of decision making and arbitration, such as due process. The protection and nurturing of individual rights are central to this style (Wolf). Strict adherence to this style, however, may encourage adversarial rather than collaborative or nurturing relationships between patients and healthcare professionals (Agich and Youngner).

The medical tradition has contributed methods, assumptions, and traditions of clinical practice: a combination of technical knowledge and clinical experience (La Puma and Toulmin). Some argue that physicians are best suited to provide clinical ethics consultation because (1) their advice will be easily accepted by their medical colleagues, because they have clinical experience and speak the same language; and (2) only physicians can understand the ethos of physician-patient relationships. Critics caution that because they are "insiders," physicians may promote the values of medicine rather than those of their patients or the larger community. They argue that the ethics consultant should serve as a bridge between medical and other values, and cannot function properly from a position entirely within medicine (Glover et al.; Churchill).

Moral philosophy has offered three major approaches to clinical ethics consultation. The first is principle-based ethics, which argues that the answer to a given ethical question or dilemma may be discovered by applying the correct ethical theory (e.g., utilitarianism) or principle (e.g., autonomy) to the case. The second is virtue ethics, which emphasizes that the possession of certain virtues (e.g., honesty, loyalty, compassion) is essential to sound ethical decision making. The third is a case-based or casuistic ethic, which holds that by examining the particulars of a given case and comparing them with similar cases, a moral maxim that applies to the case can be discovered. An advantage of casuistry is that it sues a decision-making method already employed by clinicians (Jonsen and Toulmin). Casuistry relies upon teachable medical moral maxims that build upon experience. Because casuistry is not principle-based, it has been criticized as "situational," that is, pragmatically driven to solve individual problems without reference to a broader moral framework.

While principle-based clinical ethics reasoning has the advantage of providing a consistent moral reference point, its principles are necessarily abstract, often conflict with each other, and may create a rigid paradigm that is insensitive to differences in specific cases.

Theology and religion contribute to clinical ethics consultation by recognizing that specific religious positions may either facilitate the resolution of an ethical question or contribute to its intensity. For example, the Jehovah's Witness position on blood transfusions can create serious ethical dilemmas in the case of a Jehovah's Witness patient who is in urgent need of extensive, lifesaving surgery but refuses blood. One of the disadvantages of this perspective is that many physicians are suspicious of or even hostile to religious or theological interpretations of medical problems. However, insight into the religious morality of patients, family members, and healthcare professionals is useful in establishing communication and reaching understanding among physicians, patients, and family members.

Consultation liaison psychiatry and clinical psychology have influenced clinical ethics consultation by addressing dynamic and interpersonal elements of clinical ethics cases. This style involves using insight into the motivations and values of those involved in the ethics case to resolve conflicts among decision makers. The goal is to produce a consensus or compromise solution rather than to evoke rights language, ethical principles, or religious codes. A disadvantage of this approach is that a compromise solution is not always a just one. Its strength is that it skillfully manages confrontation and addresses the emotional needs of the participants.

Knowledge and Skills Needed for Ethics Consultation

While there is not unanimity about how rigorously schooled in specific academic disciplines or how proficient in specific skills the consultant should be, there is general agreement about the kind of skills, knowledge, and personal qualities ethics consultants require. These include knowledge of ethical language and ethical theory; skills of ethical analysis and reflective moral judgment; knowledge of clinical medicine (e.g., medical terminology, the natural history of disease and its treatment); knowledge of and familiarity with hospital structure, sociology, and politics; knowledge of and familiarity with the professional ethos of physicians and nurses; knowledge of the law and legal reasoning; knowledge of psychological and social theories of behavior; communication and teaching skills; personal qualities such as the ability to establish rapport, empathy, and compassion; and professional attributes such as dedication, ability to maintain confidentiality, and comfort with cultural and ethical diversity.

Access to Ethics Consultation

Who should be able to request an ethics consultation? The answer to this question has political as well as moral implications. On the one hand, if only physicians have access to ethics consultation, many important ethical issues may never be examined (Tulsky and Lo). On the other hand, permitting patients, families, and other health professionals to request ethics consultation, especially without the physician's concurrence, might discourage more direct communication, disrupt physician-patient relationships, or undermine physician authority. The last possibility would be most threatening to authoritarian-minded physicians and very likely would challenge the traditional power structure of many hospitals. This may explain the gap between the argument in the literature for the ideal—that patients, families, and nurses should be able to request an ethics consultation—and the impression that many institutions do not permit, and almost none actively encourage, patient, family, or other health professional requests for ethics consultation.

The ability to ask for consultation is only one question concerning patient and family access to and control over the consultation process. Other questions include whether the patient or family should have authority to (1) call a consultation when the physician refuses to do so; (2) be informed routinely when consultations are requested by physicians; (3) veto physician-initiated consultation requests; (4) participate in all ethics consultations if they wish; and (5) receive verbal or written information about the consultant's findings and recommendations. Some argue that an insistence on a rights-based approach to these questions would doom ethics consultation services to failure in modern hospitals because of political considerations (Agich and Youngner).

Standards and Evaluation

The fact that standards and methods for evaluating clinical ethics consultation are not established comes as no surprise. The infancy of clinical ethics consultation and the disagreement about its goals, as well as the diverse academic and professional backgrounds of its practitioners, account for this lack. Most studies to date have employed physician satisfaction and usage as outcome measures. By this standard, ethics consultations have been judged to be helpful. Critics have pointed out, however, that by not including patient and surrogate satisfaction and reactions of house staff and nurses, an incomplete and perhaps inaccurate picture of ethics consultation is painted (Tulsky and Lo). For example, "it would be hard to argue that it is desirable for an ethics consultant to reject the choices of a competent and informed patient, even if the attending physician expresses satisfaction with such a consultation" (Tulsky and Lo, p. 591). More objective measures like changes in physician behavior, reduction in use of limited resources (Kanoti et al.), and decreased litigation are attractive, but could confuse matters if these goals were achieved at the expense of more traditional values, such as patient autonomy and well-being.

Credentialing and Accreditation

As ethics consultation becomes more widespread and perceived as part of the standard of medical care, society will hold accountable its practitioners and the institutions that employ them. Individual institutions and national accrediting bodies, such as the Joint Commission for the Accreditation of Health Care Organizations, will undoubtedly become more concerned with setting standards for clinical ethics consultation: consultation through traditional professional methods, such as standardized education and training, accreditation of training programs, and credentialing of ethics consultants. This process will be a major challenge to an interdisciplinary field that has yet to agree on its goals and how to evaluate them.

Fees

By and large, ethics consultants have not charged patients or third-party payers for their services. This may be explained by at least two factors. First, the efficacy of ethics consultations has not been clearly demonstrated; and second, ethics consultations are called as frequently to assist health professionals as they are to help patients. Generally, ethics consultants have been paid by the institutions where they practice, either directly for their consultations or indirectly, as part of their overall responsibility in directing ethics programs or committees.

As our healthcare system becomes increasingly constrained by economic factors, healthcare institutions may find it more difficult to support clinical ethics consultation.

This will put pressure on ethics consultants to charge patients or third-party payers or to demonstrate that their activities save money by decreasing litigation or reducing resource consumption.

Conclusion

Clinical ethics consultation arose in the United States in the latter half of the twentieth century amid the moral and legal uncertainty spawned by the rapid expansion of choices produced by medical advances, the emergence of the tertiary-care medical center, and the individual-rights movement that challenged traditional authority structures. Although it holds great promise, clinical ethics consultation remains a nascent profession. Many of the theoretical and practical questions about its goals, training, evaluation, accountability, and support remain unanswered. Nonetheless, clinical ethics consultation is growing and even flourishing. As the U.S. health system evolves over the coming years, the role and place of clinical ethics consultation in the healthcare system certainly will be addressed.

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SEE ALSO: *Anthropology and Bioethics; Autonomy; Beneficence; Bioethics, African-American Perspectives; Care; Casuistry; Coercion; Compassionate Love; Competence; Confidentiality; Conscience, Rights of; Death; Ethics; Healthcare Resources, Allocation of; Informed Consent; Life, Quality of;* and other *Clinical Ethics* subentries

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III. INSTITUTIONAL ETHICS COMMITTEES

Ethics committees have played clinically relevant roles in U.S. healthcare contexts since the 1960s. At that time, some hospitals established committees to approve requests for abortion and sterilization and to allocate scarce dialysis machines. Universities and hospitals created human subjects committees to scrutinize research protocols and consent forms; in the 1970s, these committees became federally mandated institutional review boards (IRBs).

In the 1976 *Quinlan* case, in which parents won the authority to remove a ventilator from an incompetent adult child, the New Jersey Supreme Court recommended that hospitals establish ethics committees to confirm prognoses in cases involving withdrawal of life support. The 1982 "Baby Doe" ruling that allowed parents to withhold a life-saving operation from an infant with Down syndrome led to the establishment of infant-care review committees in cases of withholding or withdrawing life support from disabled newborns. In 1983, a report from the U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research encouraged the formation of hospital ethics committees to review cases that raised ethical dilemmas and to resolve ethical conflict.

By the mid-1980s, a movement had begun to establish institutional ethics committees in healthcare facilities, especially in hospitals. In 1982, only 1 percent of all U.S. hospitals had ethics committees; by 1987, over 60 percent did (Fleetwood et al.). Ethics committees were endorsed in this period by leading professional groups, including the American Medical Association, the American Hospital Association, the American Academy of Pediatrics, and the American Academy of Neurologists. Growth in the number of institutional ethics committees continued into the 1990s and spread to nursing homes and hospices (Glaser). It is likely that the number and influence of these committees will grow as the length of stay in hospitals continues to decline and more patient days are spent outside hospitals. Moreover, with the shift of many kinds of care to alternative sites, it is likely that other institutional ethics committees will develop and spread—in home-healthcare agencies and managed-care networks, for example. Hospital ethics committees remain, however, the most common institutional ethics committees and the most closely analyzed in bioethics literature.

There is a paucity of empirical studies of hospital ethics committees. Committees have a "grass-roots" character, reflecting a variety of local circumstances and personalities. These factors make it hard to generalize. Nevertheless, some typical features have emerged. One of these features is interdisciplinary composition. Generally, committees are composed of doctors, nurses, social workers, pastoral-care professionals, and philosophers or theologians trained in ethics. Committee members can also include administrators, hospital attorneys, and consumer or community representatives. Committees are sometimes authorized by the medical staff; sometimes by the hospital governing board; sometimes by the administration.

Functions of Ethics Committees

Committee functions vary but generally include one, two, or all three of the following. First, institutional ethics committees create a vehicle for education on ethical dimensions of patient care. Committees typically have dual efforts in this respect: education of the committee itself, through discussion of current bioethics literature, for example; and education of the medical staff and hospital employees, by organizing periodic lectures, panel discussions, and "ethics grand rounds."

Second, committees draft institutional policies on ethical questions. This may arise through committee initiative. For example, a hospital panel discussion may reveal the need for a new policy on withholding resuscitation from dying patients, and the ethics committee takes the lead by preparing a first draft. New policies or review of existing policies may also be requested from the ethics committee by the hospital administration, or other hospital committees may route drafts of proposed policies and revisions of existing policies to the committee for review and comment.

Third, many institutional ethics committees offer ethics consultations, prospectively or retrospectively, on difficult clinical cases, often those involving the withholding or withdrawal of life-support measures. This last function—ethics consultation, especially for ongoing cases—has been the main focus of discussion in the bioethics literature. Seven issues have dominated these discussions: questions of competence and authority; impact on the doctor-patient relationship; access to consultation; recordkeeping and charting; problems of evaluation; unsettled legal questions; and questions about the purpose or purposes of consultations.

COMPETENCE AND AUTHORITY. Some committees that offer consultation services, generally smaller committees, consult as a committee of the whole. Larger committees typically have a subcommittee that consults prospectively and reports to the committee as a whole for retrospective review of its work. Some committees offer consultation through a single ethics consultant who may be on the committee or have a formal relationship with it. Some critics have expressed concern that when committees consult, difficult ethical choices will be affected by compromise, hospital politics, professional rivalries, and conformism (Wikler). Concerns about competence have been raised when individuals provide consultations. Clinicians typically have few of the skills of trained ethicists and vice versa.

Continued spread of ethics committee consultation to more hospitals and nonhospital settings is indirect evidence that the challenges to competence and authority are being met successfully. Furthermore, most published concerns about the competence of committees or individuals are from the 1970s “first wave” of writing about institutional ethics committees, at a time when the idea of ethics consultation was new and controversial. The literature of the 1980s and 1990s displays a growing confidence about the concept of ethics consultation and more attention to resolving specific problems. Apparently, committees had learned to negotiate without conformism or loss of principle. Individuals have been acquiring the proper expertise: clinicians gaining the analytic techniques of ethicists, and ethicists learning to apply their analyses in clinically relevant ways.

Gender-related questions have not been raised directly in the bioethics literature on ethics committees. However, they are raised indirectly when the focus is on the role of nurses, given the fact that most nurses are women. Nurses have been excluded from some committees, could not access them for consultation, or have found their special ethical concerns omitted from consideration. In addition to the gender issue, this situation raises questions of professional status in relation to other healthcare providers. In some hospitals, these problems have been addressed by the formation of nursing ethics committees (Edwards and Haddad).

There has also been a suggestion in the literature that ethics committees, especially those that are or function as infant-care review committees, should include persons with disabilities on the committee (Mahowald). This step could help ensure that the quality of life of persons with disabilities is not undervalued in deliberations about treatment decisions.

DOCTOR-PATIENT RELATIONSHIP. Trust in the doctor-patient relationship is grounded in the doctor’s professional obligation to the patient. Some have expressed concern that ethics consultations will undermine that obligation and trust by limiting doctors’ authority to act for their patients or by encouraging abdication of the responsibility (Siegler). These concerns are addressed or attenuated by the fact that use of a committee’s consulting service is generally optional and its findings are advisory (Fost and Cranford). It should be admitted, however, that when an ethics consultation is sought and its findings are received, a de facto “burden of proof” may be imposed on those doctors who choose to reject or ignore the ethics committee’s advice. They will probably need to muster strong reasons for doing so.

ACCESS TO CONSULTATION. Who should have the authority to request an ethics consultation? Some committees use a medical model whereby only the attending physician can initiate a consultation; he or she alone joins in the deliberations and receives the advice. But many committees allow other physicians, nurses, other professionals, and the patient and family to initiate consultations.

There are two main reasons why ethics committees reject the medical model. First, ethical dilemmas in patient care, especially those surrounding withholding or withdrawing life support, are felt acutely by all professionals involved. Second, if the consulting process helps to delimit or set priorities for a patient’s options, the patient’s right of informed consent may require that he or she, or a surrogate, be able to participate in the consultation. There is no clear pattern for such participation in the literature. Some consulting teams interview competent patients; others do not. Some encourage the presence of patients or surrogates at consultations; others do not. While most committees that reject the medical model respond to patient requests for consultation, it is not clear generally whether objection by a patient or surrogate can prevent an ethics consultation or stop one that has been initiated by others.

RECORDKEEPING AND CHARTING. Some committees and consultants keep no records in order to ensure patient confidentiality and to prevent the use of committee deliberations in legal proceedings. Plainly, all institutional ethics committees must carefully adhere to the norms of medical confidentiality, but the prevailing wisdom is that ethics committees should keep good records and should enter their advice and reasons for it into the patient's active chart (Cranford et al.). Such procedures build trust in the committee, educate the medical and nursing staffs on ethical issues, and provide accountability for committee advice in what are often literally life-and-death decisions.

EVALUATION. The brief history of most ethics committees, the confidential status of what they do, and the ambiguity many of them experience about their roles, especially in consultation, have made it difficult to conduct comprehensive evaluation of their effectiveness. Moreover, there is no independent standard of right and wrong against which the advice of these committees can be measured. However, committees can be evaluated by reference to their own mission statements, by written assessments of those who request consultations, and by the informal measures of success as an interdisciplinary forum: enhanced institutional sensitivity to ethical issues and increased requests for consultation (Van Allen et al.).

Some ethics committees use very explicit regulations or ethical guidelines for consulting. These documents could provide norms for more focused evaluation of consultation. Hospitals in the Veterans Administration system, for example, employ detailed national protocols on withholding and withdrawing life support. Catholic hospitals make explicit use of ethical guidelines contained in the Ethical and Religious Directives for Catholic Health Facilities (Craig et al.).

UNSETTLED LEGAL QUESTIONS. A number of legal questions about ethics committees remain unsettled for want of legislation and court decisions. Can an ethics committee and/or its members be sued and held accountable in civil or criminal actions? Are the records of an ethics committee discoverable? If used in court, what weight should they be given (Wolf)? There is also a widely held, but undocumented, view that the availability of an ethics committee can lessen the likelihood of litigation because it provides a forum for resolving conflict and because it allows for thorough examination of ethical issues that frequently have significant legal components.

THE PURPOSE OR PURPOSES OF CONSULTATIONS. Several authors have argued that protection of patients' interests should be the single purpose of an institutional ethics committee's consultation (Hoffmann). But it is also clear that consultations often serve other purposes: to assist caregivers, to support patients' families, to negotiate compromise when disputes arise, to protect the hospital, to offer the correct or best moral advice. Sometimes these other purposes can conflict with the purpose of protecting the patients' best interests. Moreover, in some cases a patient's apparent best interest is incompatible with what the patient demands. Clear strategies for dealing with such conflicts have not yet emerged in the bioethics literature, but they are plainly needed.

Conclusion

Much remains to be done to sharpen the focus of the work of institutional ethics committees and to evaluate the strengths and weaknesses of various committee and consultation models. This area is one of social experimentation and will remain so into the foreseeable future. Nevertheless, in a very short time, ethics committees have contributed greatly to the general bioethics agenda of creating dialogue on ethics issues in healthcare. Most acute-care hospitals in the United States, and many other settings where chronically ill and dying patients receive care, have an established institutional vehicle for explicit, interdisciplinary discussion of difficult ethical issues.

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CLONING

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I. Scientific Background
II. Reproductive
III. Religious Perspectives

I. SCIENTIFIC BACKGROUND

The term *cloning* has many meanings. Scientific meanings are reasonably clear, although they have become more complex since technologies for reproducing mammals by cloning from nuclei of somatic cells were demonstrated by Keith H. Campbell and colleagues (1996) and Ian Wilmut and colleagues (1997), the latter resulting in Dolly, the first sheep cloned from an adult somatic cell. Since then, there has been an explosion of research in this area, and the terminology has sometimes been controversial. This entry will cover scientific aspects of both reproductive and therapeutic cloning.

Definitions

Etymologically, *clone* is derived from the Greek word *klon* (twig). The ancient Greeks already knew that planting a twig from a tree or bush generally resulted in a new organism very similar to the parent tree. Hundreds of species of plants routinely reproduce by cloning, both at the hand of mankind (e.g., potatoes, asparagus) and naturally (e.g., aspen trees). So, what does "reproduction by cloning" mean?

There are two main approaches to biological reproduction: sexual and asexual. In almost all cases, sexual reproduction involves the processes of meiosis and fertilization. Asexual reproduction does not include these processes. For example, seeds are products of meiosis and fertilization by pollen, and planting these embryos results in sexual reproduction. This is fundamentally different from cutting a potato into several pieces and planting them. Thus, cloning can be broadly defined as asexual reproduction.

There is plenty of asexual reproduction in animals, too. If one appropriately bisects a planarian (a flatworm) or various other invertebrates, two normal copies eventually result. The situation becomes less flexible with vertebrates, particularly with mammals. Nevertheless, even in mammals, asexual reproduction occurs when identical twins or triplets (or quadruplets, etc.) are produced. The duplication that occurs when one embryo produces two individuals is asexual reproduction, albeit superimposed on sexual reproduction. The production of identical multiple offspring is the norm in at least two species of armadillos, and probably in several other mammalian species.

Cloning can also be defined as transplantation of a nucleus from a cell (see Figure 1) into an ovum (technically, an oocyte, or egg). To understand this process, a few biological principles will be reviewed. The billions of cells in bodies of animals can be classified into two kinds: somatic cells and germ-line cells. The germ-line cells have an element of immortality; certain early embryonic cells divide to form a lineage of cells that divide to form gametes (sperm or oocytes), which, after fertilization, form embryos of the next generation, and so on *ad infinitum* unless the species becomes extinct. Except for gametes, all cells in the body are diploid, that is they have two similar copies of genetic material, one copy inherited from the sperm, and one copy from the egg. Whenever cells divide, they first duplicate the genetic material so that *each* resulting daughter cell remains diploid. However, the cells that will form sperm divide twice after duplicating their genetic material, resulting in four haploid (one copy of genetic material) sperm, rather than two diploid cells; similar divisions occur to form haploid eggs.

With this background, the basic principle of nuclear transplantation is simple enough. Instead of fertilizing the haploid oocyte with a haploid sperm, one removes the chromosomal genetic information from the oocyte and "fertilizes" it with a diploid cell (see Figure 2).

The first mammals produced via nuclear transplantation were derived from nuclei of cells of early embryos (around the sixteen-cell stage) in the 1980s by Steen M. Willadsen in Cambridge, England. With this approach, one makes a number of genetic copies of an embryo, not an animal. This, of course, changed with Dolly, whose "parent" was a somatic cell derived from differentiated adult mammary tissue. Thus, cloning via nuclear transplantation is fundamentally different when using nuclei from embryonic cells than when using nuclei from adult cells, in that there is considerable uncertainty about the phenotype (visible characteristics) that will result from the embryo, whereas there will be more information about what will result with a nucleus taken from an adult animal, or even a newborn.

Cloning is often defined very broadly as simply making a genetic copy (or copying an organism)—sometimes with the implications of making many copies. Sometimes *clone* is used as a noun to indicate a genetic copy.

How Identical are Clones with Each Other?

Clonal, or asexual, reproduction, in nature results in nearly genetically identical individuals. This includes two categories of genetic identity: between parent and offspring, and among offspring. However, for numerous traits, genetic identity does not result in phenotypic identity, either due to epigenetic effects or to environmental effects. The environmental effects are well known, particularly from human identical-twin studies. Epigenetic effects are defined as effects due to genes that vary from organism to organism due to random chance, and therefore, cannot ever be predicted exactly. Epigenetic effects are less well known than environmental effects, but can be huge for some traits, such as different coat-color patterns among clones or identical twins. There is no genetic instruction specifying the color of each individual hair in animals with hair of different colors, but only genetic instructions for the general pattern of hair color. These instructions provide general guidelines about how melanoblasts, which differentiate into cells termed melanocytes, migrate and invade hair follicles during fetal development, but not an instruction whether or not to invade an individual hair follicle. Melanocytes reside in hair follicles and add packets of melanin to color each hair as it grows. Numerous other epigenetic phenomena occur during embryonic and fetal development such as random X-chromosome inactivation in female mammals, different methylation (addition of a carbon atom plus 3 hydrogen atoms) patterns of cytosines (see below), and lengths of telomeres, which make up the ends of chromosomes.

There also is considerable variability in embryonic development due to chance effects. Richard C. Lewontin has described how these effects interact with genotype, and with epigenetic and environmental effects, in complex ways so as to generate considerable differences among clonal sets.

One other potential source of differences among animals cloned from genetically identical nuclei is cytoplasmic (see Figure 1) inheritance, illustrated most clearly by mitochondria. Mitochondria are small cytoplasmic bodies located in all cells (with hundreds per cell). They have numerous functions, including generation of energy for such life processes as muscular movement. Mitochondria have their own genetic information in the form of small, circular chromosomes. These almost always are inherited exclusively from mother via the oocyte. Different maternal lines have mitochondria of different genetic makeup, so it is the cytoplasm of the oocyte that determines the makeup of the mitochondrial genome, rather than the chromosomes in the nucleus. Thus, when cloning by nuclear transfer, the mitochondrial genetics will differ from clone to clone unless the oocytes are all derived from the same maternal line of females.

Another source of differences among clones is mutations in the DNA in nuclear chromosomes or mitochondria. DNA is composed of only four kinds of building blocks, known as adenine, thymine, guanine, and cytosine, or A, T, G, and C, respectively. The genetic makeup (DNA) of the nucleus of each mammalian diploid cell has around 12 billion of these building blocks, theoretically hooked together in precisely the same way when DNA is replicated, so that each daughter cell produced has the same genetic makeup, or order of the four building blocks as the "parent" cell that divided. As one might imagine, there is an occasional error when assembling 12 billion items in a specific sequence, and these errors are one source of mutations. Other causes of mutations include background radiation (with which we are constantly bombarded) and chemical reactions, such as peroxidation, which is a chemical process caused by oxygen that can be very detrimental.

The human body is loaded with antioxidants to prevent peroxidation, and its cells contain DNA proofreading and repair enzymes, but these are imperfect at preventing mutations. A common example of mutations is cancer cells, which no longer have true copies of the DNA of normal cells. Most mutations do not cause cancer or have any other noticeable effect, but some cause changes—such as blue rather than brown eyes. Differences among otherwise genetically identical clones due to mutations are usually minor, but nevertheless do occur frequently.

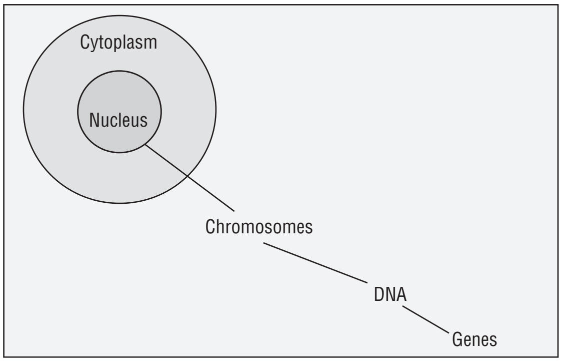
The "gold standard" for genetic identity of mammals is identical twins, triplets, etc. These at least start out with identical chromosomal and mitochondrial genetics and are gestated in the same environment. Even postnatally, identical twins usually grow up in a very similar environment. All man-made clones will be less identical than these, especially in phenotype. Since there are considerable differences between naturally occurring identical twins, such differences will also occur among manufactured clones, in addition to the other differences already discussed.

Procedures for Cloning Mammals

There are numerous procedures for cloning mammals, but two are the most common. The first concerns making identical copies of embryos from embryonic cells, and the second creates embryos (with identical nuclear DNA) from cells of embryos, fetuses, young animals, or adult cells.

FIGURE 1

The Arrangement of Genetic Units within Cells



Note: The functional genetic units, genes, are composed of DNA that is arranged linearly on chromosomes located in the nuclei of cells.

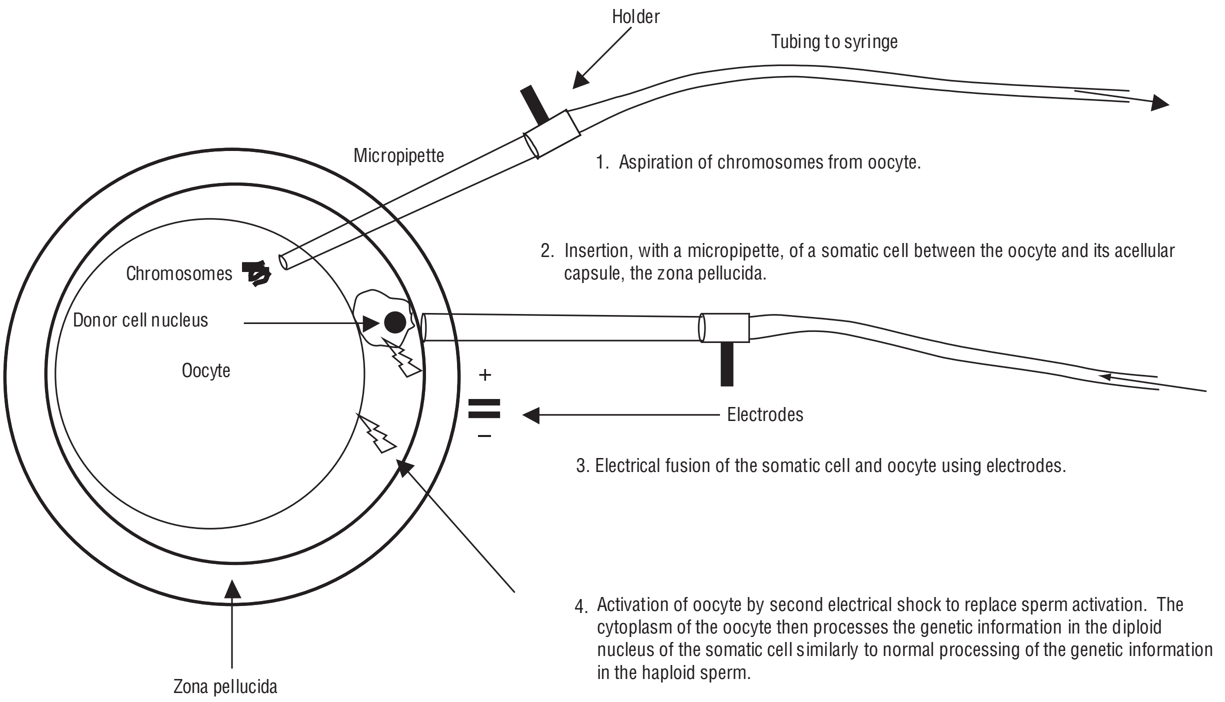
SOURCE: Author.

Conceptually, the simplest approach would be to separate the two cells of a two-cell embryo so that two identical organisms form. This has been done repeatedly in one way or another, even occasionally resulting in identical quadruplets when dividing a four-cell embryo four ways. Success rates are quite high when aiming at identical twins, but become very low when dividing embryos into quadruplets, the practical limit of the technique. For technical reasons, this approach is much more practical at later stages of embryonic development—at the 100-cell stage, for example), when embryos can be bisected. This latter approach has been used to produce thousands of identical twins (and occasionally triplets) commercially, primarily with cattle (as illustrated by Timothy Williams and colleagues [1984]).

Surprisingly, the main reason for splitting embryos to produce demi-embryos is not to produce sets of identical copies, but rather because splitting embryos augments the general technology of embryo transfer, which is designed to increase the reproductive rates of agricultural (and other) females, much like artificial insemination increases the reproduction of males. To illustrate, pregnancy rates for whole bovine embryos are around 65 percent, whereas pregnancy rates for half embryos are around 50 percent. Thus, because there are twice as many demi-embryos after the splitting process, the net pregnancy rate is frequently over 100 percent. Identical twins and triplets produced by these methods make excellent experimental subjects because genetic variation can be controlled, and sometimes they are produced mainly for these purposes.

FIGURE 2

Cloning by Cell Fusion


Holder
Tubing to syringe
Micropipette
1. Aspiration of chromosomes from oocyte.
Chromosomes
2. Insertion, with a micropipette, of a somatic cell between the oocyte and its acellular capsule, the zona pellucida.
Donor cell nucleus
Oocyte
+
−
Electrodes
3. Electrical fusion of the somatic cell and oocyte using electrodes.
4. Activation of oocyte by second electrical shock to replace sperm activation. The cytoplasm of the oocyte then processes the genetic information in the diploid nucleus of the somatic cell similarly to normal processing of the genetic information in the haploid sperm.
Zona pellucida

SOURCE: Author.

With nuclear transfer, the main principle is that the ovum, or oocyte is a minifactory designed to produce an embryo, which eventually develops into a term pregnancy. Half of the genetic instructions to make the conceptus normally come from the oocyte, and half from the sperm. With cloning, a complete set of genetic instructions is provided by the nucleus of one embryonic or somatic cell. Of course, those instructions originally were derived from the sperm and oocyte that resulted in the organism that provided the donor cell.

One problem is obtaining oocytes to use as recipients for the diploid nuclei. These cells, the largest in the body (about 1/200 inch in diameter), must be of the same species as the donor nucleus. Usually, they are aspirated from ovarian follicles (large blister-like, fluid-filled structures). In the case of farm animals, oocytes are often obtained from ovaries of slaughtered animals of unknown background. An alternative is to aspirate (remove by suction) oocytes through a large needle inserted into the ovaries in the body cavity of living animals—ultrasound is usually used to visualize the follicles so the needle can be guided into them after piercing the wall of the vagina. This method is used in women to obtain oocytes for routine in vitro fertilization. Oocytes from laboratory animals such as mice are usually obtained after the oocytes are ovulated (released from the follicles) naturally. The oocytes then are located in the part of the reproductive system called the oviduct, and the body cavity needs to be opened to get them out, either via surgery with anesthesia, or after euthanizing the animal.

After oocytes are obtained, they are cultured under specific conditions with specific chemicals until they have matured appropriately. The length of the maturation period may range from less than an hour to two days, depending on the species, the treatments, and the reproductive status of the animal providing the oocytes.

The next step is to remove or destroy the unwanted chromosomes of the oocyte. This usually is done by aspiration of this material with a micropipette (see Figure 2), although there are other options, such as destroying the chromosomes with a laser. Following this step comes transplantation of the nucleus. This can be done by removing the nucleus from the donor cell and injecting it into the cytoplasm of the oocyte. However, in the vast majority of cases the entire donor cell is simply fused with the oocyte using an electric pulse. This incorporates the nucleus into the oocyte, but it also mixes the cytoplasm of the two cells, which also mixes the mitochondria. This is usually not a problem because the oocyte has more than 100 times the volume of the cytoplasm of the donor cell, so the donor cytoplasm essentially gets diluted out.

When a sperm fertilizes an oocyte, it not only adds its 50 percent contribution of genetic material, it also activates, or turns on, the oocyte. Prior to fertilization the oocyte is a large, slowly dying cell. The sperm adds a specific enzyme that chemically activates the ovum, so it comes to life, starts using more energy, and, among other things, duplicates the genetic material in preparation for division to the two-cell stage. This activation function must be duplicated during the nuclear transplantation process for successful embryonic development. It is accomplished in a variety of ways, depending on the species and other details, such as the degree of maturity of the oocyte. A common approach is to apply a strong electrical shock.

The final step is to allow the cloned embryo to develop *in vitro,* eventually growing from the two-cell stage to a suitable stage for transferring the embryo back to the reproductive tract of a recipient. The length of this culture is usually a few days to a week, depending on the species.

Potential Applications of Cloning Nonhuman Animals

Aside from splitting embryos to produce more offspring, the main application of cloning to date has been to obtain basic biological information that can be applied in other areas. This will continue to be the main value of cloning for some time, and will result in information about causes of birth defects, aging, cancer, and other disease states.

One obvious application of cloning by nuclear transplantation and cell fusion is to make genetic copies of outstanding agricultural animals. As discussed earlier, a genetic copy does not equal a phenotypic copy, so this is not nearly as attractive as most people surmise. For example, the genetic contribution (heritability) to differences between cattle (within breeds) in milk production is on the order of 30 percent, while other factors, mainly environment and random chance, explain the other 70 percent. Thus, if one cloned a cow producing 3,000 gallons of milk annually, selected from a herd averaging 2,000 gallons of milk, on the average only 30 percent of the difference between the production of the individual cow and the herd would show up in the clone. A herd of such clones might average 2,300 gallons of milk, a substantial improvement over the 2,000 gallons average, but not even close to the 3,000 gallons produced by the animal being cloned. (This example is an oversimplification, for a variety of reasons—including interactions between genotype and environment [see Lewontin]—but the broad idea is correct.)

There is an even more serious problem with using cloning to increase production of milk (or meat, fiber, etc.), which is that it is not economically viable. The value of the extra milk produced by such a cow would be less than $1,000 during her lifetime, and she might eat more feed than other cows because more nutrients are required to make more milk, further decreasing her economic value. Costs of cloning in 2003 are in excess of $10,000 per cow, and while this likely will decrease markedly, it is unlikely that costs will approach economic viability in the foreseeable future. Thus, herds of cloned cows are not likely any time soon. The situation for meat production is even less favorable economically. If one did use this strategy, there would be hundreds of different donor cows cloned due to wanting different optimal genotypes for different environments (e.g. the optimal Vermont cow would be different from the optimal cow for Georgia) not to mention the individual preferences of farmers).

One agricultural application that does make sense is to make copies of genetically (as opposed to phenotypically) outstanding individuals. A good example is a bull whose daughters, on the average, have excellent milk production and are not prone to mammary gland infections. Such a bull might have thousands of daughters demonstrated to be superior to the average population. This bull obviously is essentially worthless phenotypically—copies will not produce any milk—but cloned copies of the bull will produce essentially identical sperm that can be used to produce more daughters by artificial insemination. For this example, one or two clones would likely produce all the semen that could be sold, so large numbers of copies are not needed. In fact, the main application in this context is insurance. Such bulls are extremely valuable, and having one or two copies makes good economic sense. More copies, however, are redundant and expensive to feed and maintain.

Another popular potential application of somatic-cell cloning concerns companion animals, particularly dogs and horses. Again, one will not get a phenotypic copy, so this only makes marginal sense. The resulting cloned animal will often have somewhat similar coat-color patterns and be roughly the same size, but it may have a very different personality, since this is largely influenced by environment. One does not recreate the same animal by cloning, simply a chromosomal genetic copy.

There are myriad experimental uses of cloning, particularly in making transgenic technology more useful. Cloning by nuclear transplantation is thus a powerful experimental tool.

Potential Applications of Human Cloning

In most cultures there would be huge ethical problems in making genetic copies of human beings—so-called reproductive cloning. Currently, this is ethically unacceptable because of the high incidence of congenital abnormalities in offspring derived from cloning by nuclear transfer. If there were no such problems—if cloned children would be as healthy as those produced naturally—one can concoct scenarios for which reproductive cloning might be ethically acceptable. The classic example is a couple whose baby dies within a day or two of birth due to an accident that also makes the mother incapable of reproducing due to damage to ovaries. One could theoretically take cells from the dead baby and clone them using a donated oocyte, which could then be transferred to the uterus (which is still functional) of the woman. The donor cells from the dead baby could also be frozen for later use, so timing would not be a problem.

Other (very improbable) scenarios could be envisioned that would make reproductive cloning ethically acceptable for most people. In any case, this technology for reproductive cloning of persons would likely work with a similar success rate as occurs in other species (extremely low, as of 2003). It is certainly possible that a century or more in the future this mode of reproduction will be used to some extent, and persons from that era may well consider our current collective thinking quaint. Since chromosomal genetic identity never results in phenotypic identity, one never recreates a person or animal, and even if phenotypic identity were possible, such individuals would still be individuals. Identical twins and triplets provide some guidance on potential problems. Such individuals usually lead fairly normal lives, and they are considerably more identical than manufactured clones will ever be.

Therapeutic Cloning

A second kind of cloning, therapeutic cloning, is intended to produce tissue and organ replacement parts. There are millions of people worldwide who suffer from debilitating diseases such as diabetes, heart disease, and cirrhosis of the liver. Similarly, millions suffer from accidents that severely damage tissues and organs, including burns, spinal cord damage, and crushed kidneys. In many of these cases, tissue or organ transplants will prolong life and greatly increase quality of life. There are two major problems with this approach: (1) There is a critical shortage of such tissues and organs, and (2) there is usually immunological incompatibility of donor and recipient, which requires immunosuppressive therapy that is debilitating and greatly increases the incidence of cancer.

A solution to this unfortunate situation is to use nuclei of somatic cells of the subject to make immunologically compatible tissues for replacement parts. This approach is not yet available for practical use, but likely will be developed in one form or another in the near future. What is envisioned is to take cells (e.g., from skin) of the person who needs the replacement tissue, and fuse them with donated oocytes from which original chromosomes are removed to form early embryos. Instead of transferring these to the uterus to form a fetus, they would be induced to develop into various tissues *in vitro*. No fetus would be formed, so there would be no brain, heart, leg, or face, but rather tissues that make up body parts. Quite a bit is known about how to induce the embryonic cells to make muscle, skin, or other tissues, but there is still much to be learned.

This approach likely cannot be used to produce a heart or a kidney, at least in the foreseeable future, but producing heart-muscle cells, nerve cells, pancreatic tissue, liver tissue, or skin does seem feasible. Liver, for example, has a remarkable regenerative capability, so only a small bit of liver may be needed—such as liver stem cells, which might regenerate a whole organ after transplantation. Producing pancreatic tissue to alleviate diabetes would likely be considerably simpler, while producing nerve cells to repair spinal cord damage would likely be more difficult.

It is possible that some tissues can be generated from adult stem cells, circumventing the need for cloning via embryos. However, the embryonic approach has several theoretical advantages—it is the way tissues develop naturally, for example—and it has some practical advantages as well. Furthermore, research into *in vitro* differentiation of tissue, much of which can be done in animal models with or without the cloning steps, will likely produce information that can eventually be used outside of the context of cloning to accomplish the numerous therapeutic objectives.

Characteristics of Cloned Animals and Related Ethical Consequences

If all goes well, a genetic copy of the animal being cloned is produced, but, again, one clone can vary considerably in phenotype from the donor for numerous traits. Unfortunately, natural reproduction does not go well in every case, and such problems are greatly exacerbated with cloning. In a 2002 summary of all available information on animals cloned from somatic cells (38 studies resulting in 335 subjects in 5 species), Jose B. Cibelli and colleagues found that 77 percent of the resulting animals were normal, while 23 percent were not. The normal subjects, though mostly adults, had not yet lived out their normal life spans, so additional problems (over and above those due to normal aging) could yet develop. Cloning from somatic cells has not resulted in monsters, but, in most cases, reasonably normal individuals.

However, 23 percent abnormalities, mostly neonatal death, is completely unacceptable ethically for producing children, and for most scientists working in this area that ends the ethical debate on human reproductive cloning. In the Cibelli survey it was noted that many of the animals produced represented the initial, or at least early, studies on cloning in respective laboratories, and that the incidence of abnormalities likely would decrease with more experience and improved techniques. This is already being borne out in the scientific literature, but it likely will be many years before the incidence of problems with somatic-cell cloning will decrease to acceptable levels for reproductive cloning of people. However, this ethical crutch will also likely disappear with time.

A complex ethical question is where to set the boundaries on acceptable levels of abnormalities. Interestingly, a 2002 study by Michèle Hansen and colleagues that looked at children produced via *in vitro* fertilization showed that congenital abnormalities were approximately double the 4 percent seen with natural reproduction. Most of these abnormalities were not extremely serious and could be circumvented or repaired. Nevertheless, the abnormalities were doubled, and some were serious. Thus, this ethical problem is already with us.

The question boils down to the right of people to reproduce given an increased risk of an abnormal child. Of course, these questions arise outside of the context of assisted reproductive technology, such as the increased risk of a child with Down's syndrome when older women reproduce. Modern science can minimize such suffering (e.g., by genotyping embryos before transfer back to the uterus, and eliminating those that will result in severely abnormal individuals). Another reality is that, in one sense or another, nearly all persons are abnormal. For example, essentially all humans have lethal or severely debilitating recessive alleles in their genetic makeup, which, if matched with another such allele in a gamete of a mate, will result in death of the conceptus or resulting child.

A frequent abnormality that occurs with cloning by nuclear transfer via embryonic or somatic donor cells is fetal overgrowth. It is not unusual for offspring to be 30 or 40 percent larger than normal at birth. In some studies, up to 30 percent of offspring have this condition, known as *large-offspring syndrome,* and some animals cloned from the same donor are large, some are normal, and some are small—which elegantly illustrates that identical chromosomal identity does not equal identical phenotype. Large-offspring syndrome is not a genetic trait, in that this problem is not transmitted to the next generation when the cloned animals reproduce naturally. Also, Michael Wilson and colleagues showed in 1995 that these excessively large neonates develop into only slightly larger adults. The scientific consensus is that large-offpsring syndrome can be summarized as a genetically normal fetus in an epigenetically abnormal placenta. That is, the placenta from cloned pregnancies is often abnormal, resulting in secondary problems in the fetus that largely correct themselves after birth. Unfortunately, with routine husbandry, the newborns often die because of being debilitated from gestating in an abnormal placenta. Fortunately, with a few days of intensive care starting at birth, such offspring survive reasonably well and develop normally, as shown by Frank B. Garry and colleagues in 1995.

As with human babies, animal offspring derived from *in vitro* fertilization or long-term *in vitro* culture of embryos have a much higher incidence of abnormalities than with normal reproduction, but a lower incidence than with cloning (see Kelley Tamashiro and colleagues). Clearly, some (but not all) *in vitro* manipulations, particularly when the *in vitro* period exceeds several days, lead to increased problems in resulting offspring. Thus, there is a baseline of problems with natural reproduction, which increases with the amount of *in vitro* manipulation (and reaches a higher level with somatic-cell cloning). It is likely that these problems will decrease or be circumvented with improved techniques, and also that the basic information obtained will be useful in decreasing birth defects and neonatal problems that occur with natural reproduction.

There are some special problems with a small percentage of pregnancies from somatic-cell cloning that are not just an increase in incidence of naturally occurring problems. In some cases, the immune system appears to be severely compromised, and there can be major problems with the heart, blood vessels, and kidneys that are extremely rare with normal reproduction. Furthermore, there is an unusual amount of embryonic death and fetal absorption or abortion with cloned pregnancies—over 80 percent embryonic and fetal attrition is not unusual (compared with around 30 percent with normal reproduction). Thus, the incidence of problem conceptuses is very high, and most of these die in early pregnancy. This is still another reason that, as practiced at the beginning of the twenty-first century, reproductive cloning should not be done with human embryos.

A final point is that cloning via nuclei from somatic cells is very inefficient, currently on the order of 2 percent success per oocyte. This is due to the multiplicative attrition (or success) of the various steps. For example, if there is 90 percent successful fusion of donor cell and oocyte, with 50 percent dividing into embryos suitable for transfer to recipients, 30 percent embryonic survival until pregnancy can be diagnosed, 20 percent of diagnosed pregnancies developing to term, and 85 percent surviving the neonatal period, the result is an overall success rate of around 2 percent. These are typical current values, and are one reason why the costs of cloning are so high. While success rates are improving, it will likely be some years until overall success even approaches 10 percent. For human reproductive cloning, dozens of women would need to be involved as donors of oocytes and recipients of embryos to produce even one baby—assuming the procedures worked as well as they do with animal models, which is unlikely. This illustrates another ethical issue, in that undue use of scarce and expensive medical resources would be required for clonal human reproduction.

Conclusion

The most important conclusions from this scientific overview are that, although cloning procedures for mammals are yielding huge amounts of important scientific information, current procedures are extremely inefficient and result in a high incidence of abnormalities in offspring. These problems severely limit immediate prospects for applications of cloning mammals due to both financial and ethical considerations. Furthermore, cloning does not and will not lead to reincarnation of an animal or person, but rather to a new individual with considerable phenotypic differences from the genetic donor.

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SEE ALSO: *Christianity, Bioethics in; Embryo and Fetus; Harm; Reproductive Technologies; Research Policy; Technology;* and other *Cloning* subentries

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II. REPRODUCTIVE

Reproductive cloning uses the technique of cloning to produce a child. Using technology to assist in "making babies" is nothing new. Artificial insemination has been available since the first part of the twentieth century. The first of many "test-tube babies" produced by *in vitro* fertilization (IVF) was born in England in 1978. Newer technologies include the injection of sperm directly into the egg and the use of frozen and donated eggs and embryos. In 1985 there were thirty fertility clinics in the United States alone, but by 2000 this number had grown to more than 350. More then 1 million couples in the United States seek fertility treatment each year, some of which includes the use of assisted reproductive technologies.

Only recently has producing a child through the technique of cloning become a real possibility. Since the birth of Dolly the sheep at the Roslin Institute near Edinburgh, Scotland in March, 1996, people have wondered whether it would also be possible to produce humans by this method. Dolly was a clone, a genetic copy, of a six-year-old ewe. Rather than coming into being by the joining of sperm and egg, Dolly was created by inserting the nucleus of a cell from the udder of this ewe into a sheep egg from which the nucleus had been removed. After being stimulated to grow, the egg was implanted into the uterus of another sheep from which Dolly was born. Because Dolly was a mammal like humans, people concluded that it might be possible to clone human beings as well. Moreover, Dolly was produced from a body or somatic cell of an adult sheep with already determined characteristics. Because the cells of an adult are already differentiated, have taken on specialized roles, scientists had previously assumed that cloning from such cells would not be possible. After Dolly, it seemed, it might be possible to produce an identical, though younger, twin of an already existing human being.

Reactions to this possibility varied widely. Some hailed it as another marvel of science that could benefit many. Others were horrified at the prospect that this seeming science fiction might become reality. Some thought of it as just another form of assisted reproductive technology, while others viewed it as something radically different. This overview of cloning for the purpose of reproduction will address the following questions:

What is reproductive cloning?
What are the present capabilities in the area of cloning?
What are the proposed uses of this type of cloning?
What are the ethical considerations and objections to it?
What are the public policy implications?

Cloning: Its Nature and Capabilities

The type of cloning described above is called somatic cell nuclear transfer (SCNT) because it transfers the nucleus of a somatic or body cell into an egg from which the nucleus has been removed. A different type of cloning is achieved through fission or cutting of an early embryo. Through this method it may be possible to make identical human twins or triplets from one embryo. These genetically identical embryos could then be stored for further tries at conception, thus saving a woman from undergoing repeated ovulation during fertility treatment. Here, however, the concentration will be on cloning through SCNT. Also, this entry treats only cloning for reproductive purposes, not what has come to be called research or therapeutic cloning. In the latter, the same process occurs but is not intended to lead to the birth of a child. Rather it is oriented, for example, to the study of the process of development or to the producing of stem cells that might be useful in therapies for Parkinson's, diabetes, and other diseases.

How close are we to being able to produce a human being through cloning? As of the beginning of 2003, to researchers' knowledge there have been no human beings produced through cloning. Clonaid, a company founded by a religious sect called the Raelians, has claimed to have produced five cloned babies. However, no DNA or other evidence has so far been provided to substantiate this. In November 2001, Advanced Cell Technology, a small biotech company in Worcester, Massachusetts, said it had succeeded in producing a human embryo through cloning. Scientists extracted human eggs from seven volunteer women and replaced the nuclei of these eggs with cells from an adult donor, some skin cells and some cumulus cells (the cells surrounding a maturing egg). While none of the eggs that used the skin began the cell division process, three of the eight eggs that were re-nucleated with cumulus cells began dividing. One developed to the two-cell stage, one to the four-cell stage, and the third to the six-cell stage, at which point it too died.

One can also judge something of the potential for human cloning from the progress of animal cloning. In just the past two decades a number of higher animals have been produced through cloning, including cows, sheep, goats, mice, pigs, rabbits, and a cat called CC for carbon copy or copy cat. Cloned animals themselves have produced offspring of their own in the natural way. Dolly had six seemingly normal lambs. Several generations of mice have also been produced through SCNT. Clones have been derived not only from udder cells, but also from cells from embryos and fetuses, and from mice tails and cumulus cells.

However, these experiments have been neither efficient nor safe. In the case of Dolly, 277 eggs were used to produce only one lamb. In March 1996, the Roslin Institute also produced two lambs from mature embryo cells, Megan and Morag. However, they were only two out of five who were born and survived in a project that used over 200 embryos. Alan Coleman, research director of PPL Therapeutics, the company that produced Dolly, reported having cloned five female pigs who were genetically modified to lack a gene that makes pig organs incompatible with the human immune system. However, here the success rate was again quite low. Scientists implanted 300 embryos, producing twenty-eight sows that gave birth to seven live piglets, only four of which survived. In another project involving rabbits, 371 eggs were implanted, using twenty-seven rabbits as foster mothers, but only six rabbits were born and only five of these survived to the state of weaning. CC, the cat mentioned above, was one of eighty-seven embryos implanted in eight surrogate mother cats, and was the only one of two resulting pregnancies that survived.

Cloned animals also have shown various abnormalities. In one study all twelve cloned mice died between one and two years of age. Six of the cloned mice had pneumonia, four had serious liver damage, and one had leukemia and lung cancer. On February 14, 2003, Dolly died. She was euthanized because she suffered from a lung disease that the owners feared would spread. At age five, Dolly had also been diagnosed with arthritis. Some suggest that this may be due to the fact that she was cloned from the cell of an already aged adult sheep. However, in late 2001 Advanced Cell Technology claimed to have cloned thirty cattle from skin cells, twenty-four of which were alive and healthy between one and four years later. Some say that the high failure rate and the prevalence of serious abnormalities in animals means that cloning humans is probably not possible. Others believe that with time the efficiency and safety of animal cloning will improve and then it may be possible to clone human beings as well.

Uses of Reproductive Cloning

What uses might there be, or what reasons might someone have, for producing a human being through cloning? What follows is a survey of a number of possible uses of this procedure, some of which are obviously more problematic than others. The ethical issues that have been or might be raised regarding the possible uses of reproductive cloning will then be discussed.

One of the probable primary uses, if cloning does become a reality, is for the treatment of fertility problems. For example, if the male or husband is sterile, or does not produce sperm, DNA from one of his cells could be inserted into a de-nucleated egg from the female or wife who would also bear the child. Both would then be contributing to the make up and birth of the child. Many have pointed out that there is a strong desire among people who want a child to have one that is biologically related to them. These parents also may wish to avoid the confusion that can result from the use of donor eggs or sperm. If the woman is infertile, another woman's egg could be used along with the DNA of the infertile woman or her husband or partner. Cloning might also be used to avoid genetic diseases.

Another possible use would be in the fertilization of a woman who wants to have children to whom she is related biologically, but who does not have a partner and does not wish to use donor sperm. The woman might be one who is single and who has not found a suitable partner, or who is divorced and still wants to have children. A cell from her body could be used. In this case the child would be a clone of the woman herself. Or in the case of a lesbian couple, a cell from the body of the other partner could be used. In this case both would have contributed to the make up of the child.

Someone might want to produce a child who is a clone of a much-loved spouse or child who has died. As noted below, while this would not bring back the loved one or duplicate them exactly, there would be some similarities and thus in a way the ability to keep some part of the person alive. One might even want to achieve a certain kind of immortality by cloning oneself. This would be similar in some way to living on through our children and their children.

Cloning could also be used to help ill family members. There have been cases in which parents have conceived a child in the hope that he or she could be a donor match for a sibling who had some serious disorder. A child who was the clone of such a sibling could also be a blood or bone marrow donor for the sibling. Although no one is suggesting that clones would be produced simply as the source of organs, some organ donation might not be objectionable.

Finally, cloned human beings could provide us with further information about the relationship between nature and nurture. A disabled person might want to show or see what he would have been like but for the disability, or someone might simply be curious to see how a clone of himself might grow to adulthood.

Ethical Objections and Arguments

Ethics judges or evaluates human choices and actions or policies as being, for example, good or bad, right or wrong, and just or unjust. Ethical or moral judgments (the terms being used synonymously here) require reasons that justify them. Many people have raised various ethical objections regarding human cloning. The arguments and the reasons given for them are summarized here as well as the responses of critics of the arguments. However, since what is presented is only a summary, it is not possible to give a full analysis of the kind of reasons that they exemplify and why these might or might not be well-grounded in generally-accepted values or in ethical theory.

It should also be noted at the outset that ethical evaluation is independent of social policy and law. Not everything that is morally bad or wrong ought to be illegal. It takes a separate set of reasons to conclude that because some instances of human cloning might be morally wrong that they should then also be illegal. Nevertheless many of our policies and laws do have ethical bases. First the ethical arguments will be treated and then finally some social policy issues related to them. Some suggestions regarding the relationship between these two domains will also be provided.

Playing God

One of the objections to human cloning most often raised is that it would be *Playing God.* While it is not always clear just what is meant by this, at least three or four overlapping versions of this objection can be delineated. One is that only God can and should create a human life. This role is specifically reserved to God, such that when humans who try to do it take on a role that is improper for them to play.

Those who hold this view might use religious reasons and sources to support it. However, while this looks like a religious position, it is not necessarily so. For example, it might mean that the coming into being of a new person is a creation, not a making or production. A creation is the bringing into being of something the outcome of which is not known in advance. The coming into being of a human being or person is also a said to be a mysterious thing and something in the face of which humankind should be in awe. When producing a human being, as in cloning, people become instead makers or manipulators of a product that they control and over which they have power. Rather, this argument continues, those who bring a child into the world should do so with an attitude of respect for something wondrous, the coming into existence of a totally unique and new being.

A third version of this objection stresses the significance of nature and the natural. In producing a human being through cloning, scientists act against human nature. In humans, as in all higher animals, reproduction is sexual, not asexual. Cloning, however, is asexual reproduction. Leon Kass is one of the strongest proponents of this view. He alleges that in cloning a human being people wrongly seek to escape the bounds and dictates of their own sexual nature.

A fourth and related version of the "don't play God" argument holds that attempting to clone a human being would demonstrate hubris, thinking we are wise enough to know the effects of one's acts when in fact that is not the case. It is similar to the warning that it is dangerous to "mess with mother nature." When dealing with human beings one should be particularly careful. Above all each person should avoid doing what unknowingly may turn out to be seriously harmful to the individuals produced and to future generations.

Just as there are various possible interpretations of this objection, there are various responses to, or criticisms of, it. On the point that by interfering in nature people take on a role that belongs only to God, the response is to ask how this is any different from other ways that man interferes with or changes nature. One example is medicine. Here science fights off natural threats, disease, and disability, for example, with inoculations, insulin, blood transfusions and prostheses. Others argue that God gave us brains to use and God is honored by that use, especially if it is for the benefit of humans and society. Human intelligence, the argument continues, is in fact a part of nature, so that in using it people do not actually oppose nature but follow it. Critics also point out that in using technology to assist reproduction, one does not necessarily lose a sense of awe in the face of the coming into being, though with human help, of a unique new being. Objectors may point out, however, that cloning does not create a unique new being, but a copy of one that already exists or has existed. This objection thus overlaps with a second major objection, namely, that cloning is a threat to individuality.

Threats to Individuality

Some people object to the very idea of cloning a human being because they believe that the person cloned would not be a unique individual. He or she would be the genetic copy of the person from whom the somatic cell was transferred. He or she would be the equivalent of an identical twin of this person, though years younger. Moreover, since dignity and worth is attached to a person's uniqueness as an individual, cloned individuals would lose something that is the basis of the special value each person should have. Some go so far as to claim that each person has in fact a right to a unique identity. Others point out the difficulties that clones would have in maintaining their individuality. People often have difficulty distinguishing identical twins from one another. Sometimes they dress alike and often they are expected to act alike. The implication is that they do not have the freedom or ability to develop their own individual personalities.

This objection is sometimes expressed as the view that a cloned human being would not have a soul, that he or she would be a hollow shell of a person. This version of the objection is probably based on a religious belief that only God should be allowed to create a human being and in doing so directly acts to place a soul in that person. Thus if through cloning man produces a human being, God is prevented from placing a soul in that person.

Again, criticisms of these objections vary with the interpretation. One response is to review the facts about identical twins. Identical twins are more like each other than a clone would be to the person who was cloned. This is because identical twins shared the same nuclear environment as well as the same uterus. This would not be the case with clones. They would have had different mitochondria. This is important because the mitochondrial genes in the cytoplasm surrounding the re-nucleated cell do play a role in development. Clones would have developed in different uteruses and they would be raised in different circumstances and environments. Studies of plants and animals give dramatic evidence of how great a difference the environment makes. For example, plants and some animals vary significantly in structure and characteristics depending on the altitude of the land in which they develop. The genotype does not fully determine the phenotype. CC, the cloned cat mentioned above, does not quite look like its mother, Rainbow, a calico tri-colored female. They have different coat patterns because genes are not the only factor that controls coat color. At one year CC also has a different personality from her mother, being much more playful and curious. Even in the science fiction stories of creation of groups of clones, for instance of Hitler in the movie, *The Boys from Brazil,* the creators try to duplicate the environment. While genes do matter, and thus there would be similarities between the clone and the person who was cloned, the two would not be identical. Furthermore, these critics note, even normally-produced children may look like one or both of their parents and this fact does not prevent them from being individuals.

On the matter of soul, critics wonder why could God not give each person, identical twin or clone, an individual soul. Consider when the soul is supposed to be implanted in an individual. Some medieval writers, for example, held that the soul appeared or was implanted in the fetus when it had developed sufficiently so that it was fit for a human soul. Previous to that point, some held, the developing fetus had a vegetable and then an animal soul. Aristotle held that the soul or psyche was simply the form of the being, that which gave it unity as a particular living being, whether it be a plant or animal or person. Like any living human being, a cloned human being would on this view be a distinct being and so would have a human psyche or soul.

A Right to an Open Future

Some have argued that cloning a human being is objectionable because the clone is expected to be like the person from whom he or she was cloned and thus would not be free to develop independently. Joel Feinberg has written about what he calls the "right to an open future" and Hans Jonas "the right to ignorance." The idea is that each person should be free to construct his or her own life and develop a unique self. However, a clone would be expected to use the person from whom he or she was cloned as a model. His or her future would already be given and known. Even if such expectations for the clone were not generally accepted, people would be hard pressed not to at least entertain such ideas. The argument also points out that an essential feature of having a child should include accepting whatever the child turns out to be. This would mean accepting the child as a unique being. Children are not objects to be controlled, nor to mold in a particular image. They have their own lives to lead. Parents may try to influence them and teach them while realizing that the children may decide to do or be different, which is their right as individual persons.

Critics of this argument may admit that there might be some inclination to have certain expectations for the clone. However, they argue, this undue influence is a possibility in the case of all parents and children, and not limited to clones. Parents decide on what schools to send their children and what sports or activities they will promote. The temptation or inclination may exist to unduly influence their children, but it is incumbent on parents to control the extent of that influence. The goal is to provide children with opportunities of various sorts from which the children themselves eventually choose. It is not cloning, these critics contend, that would cause a threat to an open future for a child, but the attitudes and character of parents and others.

Exploitation

Related to the previous objection is one that holds that cloned children or persons would tend to be exploited. If one looks at many of the reasons given for cloning a person, the objection goes, they tend to be cases in which the cloning is for the sake of others. For example, the cloned child could be a donor for someone else. We might make clones that are of a certain sort that could be used for doing menial work or fighting wars. We might want to clone certain valued individuals, stars of the screen or athletic arena. In all these cases the clone would not be valued for his or her own self nor respected as a unique person. He or she would be valued for what they can bring to others. German philosopher Immanuel Kant (1724–1804) is cited as the source of the moral principle that persons ought not simply be used but ought to be treated as ends in themselves.

Critics could agree with Kant, but still disagree that a cloned human being would be any more likely than anyone else to be used by others for their own purposes only. Just because a child was conceived to provide bone marrow for a sick sibling would not prevent her from also being loved for her own sake. Even a case in which a man would clone himself in order to see how such a being might grow could turn out to be a situation in which the clone would be much loved and respected for himself and his own unique characteristics. Furthermore, the idea that we would allow anyone to clone a whole group of individuals and imprison them while training them to be workers or soldiers is not living in the present world in which there are legal protections against such treatment of children or other individuals. So also, critics may contend, the possibility that some group might take over society and create a 'Brave New World' in which children were produced only through cloning is far-fetched and no more than fiction. So also is a world in which there would be widespread cloning of stars and pop idols. While eugenics as a social policy has not been unknown in modern history, it is highly unlikely in open societies. Moreover, cloning is not the only way that eugenics could be practiced, as is demonstrated by the existence of (little-used) sperm banks of Nobel prize winners.

Effect on Families

Some people believe that if human cloning were a reality, it would only add to the confusion already generated by the use of some other reproductive technologies. When donated eggs and surrogate mothers are used, the genetic parents are different from the gestational parents and the rearing parents, and conflicts have arisen regarding who the *real* parents are. Cloning, objectors contend, would be even more of a problem. It would add to this confusion the blurring of lines between generations. The mother's child could be her twin, or a twin of her own mother or father.

According to Leon Kass in "The Wisdom of Repugnance," this would lead to a confusion of kinship relations. In natural reproduction, two lineages come together to form one new being. "The child is the parents' own commingled being externalized and given a separate and persisting existence" (p. 30). Genetically, the cloned child has only one parent, the provider of the somatic cell. The child is literally the child of only one of a couple. What happens, then, to the traditional relationships with the members of the other side of the family, grandparents, aunts, and uncles? Or to the relationship of the husband to the child who is the twin of the mother or the wife to the child who is the twin of her husband? The answer, according to this objection, is that normal and natural human family relationships would be seriously eroded and harmed.

Critics of these arguments respond that, although there is a traditional type of family that in fact varies from culture to culture, there are also many different kinds of nontraditional families. Among these are single-parent households, adopted families, blended families, and lesbian and gay families. It is not the type of family that makes for a good loving household, the argument goes, but the amount of love and care that exists there. Children can learn new or different ways of relating to others. For example, just as stepparents can find ways of being valued parts of their stepchildren's lives, so also the parent who is not a genetic parent of a cloned child could adapt.

The *Yuck* Factor

The argument that gives this section its title goes something as follows: Sometimes one has a gut reaction to something regarded as abhorrent. One is offended by the very thought of it and cannot always give reasons for this reaction. Yet instinctively one knows that what is abhorred is wrong. Many people seem to react to human cloning in this way. Such emotional reactions can be described as an expression of a kind of knowledge, as a kind of moral intuition. They could even be viewed as expressions of a kind of deep wisdom. The very idea of someone making a copy of themselves or many copies of a famous star is simply bizarre, revolting, and repulsive, and these emotional reactions tell us that there is something very wrong with it, even if there is no full explanation for what that is.

Any adequate response to this argument would entail an analysis of how ethical reasoning works when it works well. Emotional reactions or moral intuitions may indeed play a role in moral reasoning. However, most philosophers would agree that adequate moral reasoning should not rely on intuition or emotion alone. Reflections about why one might rightly have such gut reactions are in order. People have been known to have negative gut reactions to things that in fact were not wrong—interracial marriage, for example. It is incumbent on those who assert that something is wrong, most philosophers believe, that they provide rational argument and well-supported reasons to justify these beliefs and emotional reactions.

Rights

Some of the arguments about human reproductive cloning have relied on the use of the language of rights for their conclusions. For example, as noted above, some have objected to cloning on grounds that people have a "right to an open future." In contrast, some argue that human cloning should be allowed because people have a "right to reproduce." And again, because cloning is such a risky process, some argue that it ought to be prohibited because children have a "right to be born healthy." Some attention should be given here, then, to what is meant by a right and why and whether we have certain rights, including these particular rights.

A right is generally understood to be a strong and legitimate claim that people can make to certain things. If the assertion is based on moral grounds, we refer to the right as a moral right, whether or not it is reinforced by law. It is a negative right or claim if it is a claim not to be interfered with. This is sometimes called a liberty right. Thus a right to freedom of speech would be classified primarily as a negative or liberty right, that is, a right not to be prevented from speaking out. But a positive right is a claim to be given certain things. Thus a right to healthcare would be classified as a right to be given certain forms of healthcare. Since rights are legitimate claims, there must be serious reasons or grounds given for their assertion. One view is that only persons have rights (not rocks or plants, while animals are a disputed case) for only persons are moral agents who can be held responsible for their actions. There are certain things that are essential in order for a person to function well as a human being, and these can be legitimately claimed as rights.

Given these clarifications about rights, which of the above mentioned claims might be legitimate claims and of what kind? Being able to produce a child of one's own might well be so important for a full human existence (with certain exceptions perhaps for celibates or others who serve higher or other causes) that one might well be said to have a legitimate claim or right to do so. It would first of all be classified as a negative or liberty right, in other words a right not to be prevented from producing children, and perhaps also producing them through cloning, at least when no one is harmed. Whether it is also so important that it could be considered a positive right such that society ought to provide the means or aids for those who are having trouble reproducing in the natural way due to infertility problems is another matter. While it may not at first seem reasonable to assert a right to reproduce in this or that way, it may make sense if one thinks of it as one thinks of eyeglasses or wheel chairs, namely as necessary aids to seeing and mobility, things that are essential for a satisfying human life and thus legitimate claims that people can make. A right to an open future could most reasonably be claimed as a negative right, namely a right not to be prevented from choosing a life for oneself. Things that would seriously interfere with this would then be morally problematic as threats to that right.

A right to be born healthy would most reasonably be thought of as a negative right. No one should deliberately do what will result in harm to a child, or do what poses an inordinate or undue risk to its life or health. It would be more problematic to claim that a being that does not exist in some requisite sense has a right to be given a life. However, if it is to have a life, then one might well argue that it should if possible have a life with decent chances for development and happiness. One might ground this in notions of equal opportunity and justice, that each person should have a fair chance to develop and to compete for access to life's goods. Given the risks that are associated with animal cloning, grave questions can be raised about human cloning in this regard.

Safety and Harms

Given the abnormalities so far associated with animal cloning, there is a high likelihood that similar risks would accompany human cloning, at least at present. As described above, animal clones are at a rather high risk for a short life and a life with various diseases and abnormalities. Some have argued that since the alternative for the cloned child is not to exist at all, one cannot claim that giving birth to a child with abnormalities harms that child. One could only say the child was harmed if it were brought into existence with such difficulties that its life with these conditions would be worse than having no life at all. However, others have questioned this sort of reasoning. They believe that it does make sense to say that doing what one knows will bring into existence a child whose life will be short and encumbered with serious ills is to harm that child. Since the harm is serious and the risk is high, they argue, one would be wrong to take it. However, this is not the same as arguing that the law ought to prevent people from taking such risks for others. This is discussed below.

Other harms to consider relate to the number of oocytes or human eggs that thus far must be used to achieve one cloning success. These eggs would presumably have to be obtained from women volunteers. Care would have to be taken that these donors are not coerced or simply used as egg providers. So also care would have to be taken, as in other cases, that women into whom the enucleated eggs were placed for gestation would not be harmed or unduly influenced into performing that service.

Some people have objected to human cloning on the grounds of possible harm to society. One argument is the possible threat human cloning might pose to genetic diversity. If the human gene pool were seriously restricted, we would be less able than otherwise to adapt or respond to environmental changes and threats. However, this would be a possible problem only if human cloning were widespread. Since the normal method of reproduction is so much more enjoyable and desired, this would be very unlikely.

Social Policy

Often, when the issue of human cloning is addressed, there is a confusion about whether what is being asserted is that human cloning is morally right or wrong or whether it ought to be legally permitted or prohibited. These two realms are distinct. In particular, not everything that is morally wrong ought to be legally prohibited. Many examples can be provided, such as spiteful thoughts about others. So also, where a particular case of cloning a human being might be morally objectionable, there may or may not be grounds for it to be legally prohibited. This is partially dependent on the relationship between the realms of morality and the law.

Although not all the views on this relationship can be analyzed here, the most generally accepted view is governed by what has been called the harm principle. This is the view that the law ought to restrict people's liberty only to prevent them from harming others. The purpose of law is not to see that people do the morally right thing or that they do not do what causes harm only to themselves (if they are adults), for example. On the basis of the harm principle, the possible harm done to those cloned would be particularly relevant. This is why the safety aspect of human cloning is particularly important with regard to what the law should do. Both the degree and certainty of the harm would be important. If the risk were high and the harm serious, there would be grounds to restrict the cloning of human beings by law, at least until it were safe.

One could also argue that people can be harmed by having their basic liberties restricted (where they are not harming others) or their privacy invaded. Those arguing for procreative liberties may also use this principle in support of their views. However, there would still remain a provision that their liberty or privacy could be restricted to protect others from being seriously harmed.

Some have argued in favor of allowing human cloning to proceed on grounds that science cannot and should not be legally regulated or restricted. However, this view would surely need to be tempered at least by the harm principle. Many laws and policies do restrict science on this ground, including food and drug safety regulations. Moreover, while technology has many benefits, it can also be misused. Concerns regarding the misuse and dangers of technology have probably given rise to objections to human cloning of the "Frankenstein" type. Some fear that the results of human cloning could not be controlled. Why cloning would be less controllable than other technology is an open question. But some argue that it is better to permit certain practices and technologies to develop and even to fund them with public money because of the increased publicity and monitoring that this provides.

At present there are no U.S. federal laws prohibiting human cloning, though a few states have passed such legislation, among them California, Louisiana, Michigan, and Rhode Island. Internationally a number of countries and international groups have banned the cloning of humans, including Great Britain, the European Union, and the General Assembly of the United Nations. In early 2003, the recommendations of the U.S. National Bioethics Advisory Commission in their 1997 Report are still being considered by the U.S. Congress as it addresses the issue of human cloning, both reproductive and research/therapeutic. A key recommendation of this report was that at present human reproductive cloning ought to be prohibited because of the safety issues. Congress may also consider the July 2002 recommendations of a divided Presidential Council on Bioethics for a four-year moratorium on both therapeutic and reproductive cloning. The Council rejected these terms in its report, opting instead for "cloning-for-biomedical-research" and "cloning-to-produce-children." However, there are also more general existing laws that could govern human cloning such as those protecting human research subjects, especially non-consenting subjects.

This summary of the issues surrounding human reproductive cloning has considered the nature of human cloning, its present capabilities, and some possible uses for it. It has focused on the ethical objections to cloning, responses to them, and has concluded with some discussion of the relation between ethics and public policy.

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SEE ALSO: *Christianity, Bioethics in; Embryo and Fetus; Genetic Engineering, Human; Harm; Human Dignity; Natural Law; Reproductive Technologies; Research Policy; Sikhism, Bioethics in; Technology; Transhumanism and Posthumanism; Utilitarianism and Bioethics;* and other *Cloning* subentries

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III. RELIGIOUS PERSPECTIVES

In its 1997 report on human cloning, the National Bioethics Advisory Commission (NBAC) paid significant attention to the views and concerns of the world's religious communities and their traditions. The NBAC recognized that various religions have supported critical and sustained reflection on issues relevant to assessing human cloning, including the relation of humanity to the natural world, the significance of marriage and procreation in human life, the status of the embryo, and others. For that reason, the NBAC commissioned a report, "Cloning Human Beings: Religious Perspectives on Human Cloning," and took testimony from distinguished scholars of various religious traditions. Drawing on the NBAC report, the testimony given before the commission, and other sources, this entry offers a thumbnail sketch of how four world religions understand the issues raised by reproductive human cloning, for the most part ignoring matters of "therapeutic cloning." Of particular interest are the issues of how cloned children are likely to be valued in contrast to children born of "natural" means; the relevance of parental motives; the possibility of cloning for the purposes of securing biological material for therapeutic use, for example, bone marrow for ill siblings; the issue of destroying embryos; and the notions of "playing God" and "cheating death."

Judaism

Many of Judaism's basic beliefs about humans and God are rooted in the Genesis account of creation. Jewish scholars generally agree that the Biblical account accommodates two views of creation, namely, creation as a completed act, and creation as a transformative process. These disparate views can dramatically influence the way one understands human cloning and the roles of God, humans, and technology in procreation.

Viewing creation as a completed event has led some Jewish ethicists to argue against human cloning on grounds that it violates the structure of nature and impinges on God's sovereignty. According to this line of thought, given that God created the structure of the world, who are humans to tamper with it? Further, the Genesis description of humans created in the image of God begs the question of how that likeness could be improved. From this perspective, human cloning is wrong in that it attempts to improve upon the divine creation that God has called both "good" and "very good." Further, cloning alters and transgresses God's ordained method of human sexual reproduction.

A related argument is that cloning is worrisome in that it fuels a kind of narcissistic fascination with the idea of escaping or cheating death. As such, cloning holds out the promise of rebirth, a second chance for the self to live a better, fuller life. Yet this promise is illusory, and so the quest to clone is a self-deceptive journey and one that distracts humans from pressing moral commitments here and now—for example, the pursuit of justice in healthcare.

The more generally accepted Jewish view suggests that human beings are partners with God in the ongoing act of creation. As such, humans are commissioned with a divine mandate both to steward and to improve the earth through their own creativity and knowledge. Humans thus become responsible, creative agents, cocreators with God, endowed with God-given duties to promote health and healing. Given that cloning may promote human well-being, it is, provisionally, an acceptable method of stewardship and improvement. In this view, humans do not usurp God's sovereignty in pursuing cloning because, if cloning changes the world for the better, this pursuit exercises their God-given freedom properly. Of course, the assumption that human cloning would actually improve the world is key to this view. Recognizing what a large assumption this is, Jewish scholars who endorse this view of creation also urge caution and recognize that cloning seems to possess inherent dangers for individuals, families, and cultures.

Jewish Biblical commentary traditionally recognizes two values with respect to human beings that are especially helpful in thinking about cloning: uniqueness and equality. Attending to these values may lead to important questions about cloning: Will human clones be more or less valuable than humans conceived through sexual reproduction? Are human clones more likely to be treated as commodities than humans conceived naturally?

Such concerns grow organically out of an understanding that humans are created in the image of God rather than as replications or images of an existing human. It is conceivable that human clones may be regarded as mere objects of production or genetically replaceable resources for our own uses and ends. That clones might be considered "made," may in some way devalue their existence. That clones may be replaceable may undermine their uniqueness. That clones may be used to breed genetic wonders may impinge upon the long-held value of human equality under God. That human cloning could jeopardize all of these values simultaneously and, in so doing, lead to a form of human slavery is a concern not taken lightly by Jewish thinkers.

While these cautions and concerns are taken seriously, Jewish thought also recognizes the transcendent character of the human person. Therefore, humans can never be fully controlled by human technology, will, or intervention. Furthermore, some Jewish scholars have argued that because cloning is a biologically natural process, whereby the clone would be born through a natural process of a human mother, cloning is an acceptable form of reproduction. It also follows that any cloned human being should be treated morally and legally as fully human. Indeed, there is rabbinic consensus that human clones would be fully human and have full moral status.

Finally, Jewish commentators have been concerned about public policy restrictions on cloning. Given the commitment of Jewish tradition to pursue scientific research for the betterment of humanity, many Jewish scholars have cautioned against restricting or prohibiting cloning as a matter of public policy. Also, because Jewish law does not grant full moral status to the embryo, Jewish scholars have not been among those advocating restriction on cloning because it will lead to the destruction of embryos.

Christianity

As with other religious traditions, Christian responses to cloning have been mixed. As early as the mid-1960s, Christian ethicists split sharply over whether cloning was "playing God." Supporting new biotechnologies, Joseph Fletcher famously claimed: "let's play God" (p. 126). Paul Ramsey's equally famous and oft-quoted response cautioned against advancing reproductive technologies: "Men ought not to play God before they learn to be men, and after they have learned to be men they will not play God" (p. 138). The contrast between such different Christian responses to interventions in reproduction continues into the twenty-first century. Some of the diversity in Christian responses to cloning is noted below.

PROTESTANTISM. Protestant Christianity shares a number of Judaism's intellectual and textual traditions. For example, some of the principal elements of the Protestant view of humanity are rooted in the biblical accounts of creation, taking seriously the *imago Dei* theme found in Genesis. Within the Protestant tradition, *imago Dei* is often discussed either in terms of "stewardship" or of "created cocreatorship," but unlike the Jewish thinking, the stewardship model understands creation as a completed process in which humans serve as God's appointed stewards overseeing a finished work, while the cocreatorship model sees creation itself as incomplete *creation continua,* a process in which humans are responsible to participate and improve. These two perspectives relate to human cloning when one asks whether cloning exceeds the limits of human createdness, and whether humans attempt to play God through the genetic manipulation of another human. Understood as stewards, humanity is restricted to conserving the created order. In this view, human cloning is problematic because it usurps God's role as creator; humans are not called to be creators but rather stewards of creation. By contrast, emphasizing the theme that humans are created cocreators tends to support the permissibility of cloning by highlighting the idea of creative freedom implied by this view of *imago Dei.*

In their analysis of human reproductive cloning, Protestant scholars also seriously consider the impact that asexual reproduction may have on the societal norms of marriage, childbearing, and how humans are likely to view and value human clones. Protestants often maintain a normative Biblical view of the child as a being conceived within marriage, a gift from God, and the result of a loving relationship between a man and a woman. Human cloning raises Protestant concerns regarding the disjunction of marriage and childbearing, and the fear that such a separation will have a lasting and adverse affect on children and society. As representatives in some Protestant denominations have argued, human cloning allows humans to sever the connection between human reproduction and the marital relationship, a separation considered harmful both to child and culture.

Protestants also fear cloning's potential to change how humans view children, namely from a "gift from God" to a "project." Some scholars distinguish between what is "begotten" and what is "made," arguing that begetting is consistent with human dignity in a way that manufacturing is not. Similarly, some Protestant traditions caution against cloning on grounds that it reduces humanity to raw material to be fashioned in human image rather than the image of God.

It is in this light that some Protestants consider both the parental motives for cloning and some of the possible benefits of reproductive cloning. Sympathetic to suffering and the human condition in a fallen world, Protestants remain skeptical of cloning humans for utilitarian purposes such as cloning to replace a young child killed in an accident or cloning to gain access to biological material. Each of these instances of cloning may violate Protestantism's commitment to the inherent and non-instrumental value of human beings.

Indeed, all of these themes are nicely illustrated in a resolution condemning cloning passed by the Southern Baptist Convention in June 2001. According to the resolution, because cloning involves the "wanton destruction" of human embryos; because it is contrary to the "biblical witness" that children are a gift from God and "not the result of asexual replication"; because cloning "does not meet the biblical standards for procreation in which children are begotten, not made"; and because cloning represents "a decisive step toward substituting human procreation with biological manufacturing of humans," cloning is morally abhorrent.

CATHOLICISM. Perhaps the most consistent and vocal opposition to human cloning has come from the Catholic Church. Magisterial (authoritative teaching) documents of the church have regularly and vigorously rejected cloning. For example, in *Donum Vitae,* an "Instruction" issued in 1987, the Vatican examined cloning in the context of other reproductive interventions made possible by the advent of *in vitro* fertilization and concluded that cloning was categorically wrong. *Donum Vitae* is typical of Catholic teaching on topics of bioethics in that it appeals both to beliefs that are shared primarily by the community of the faithful and also to basic human values and experiences that it takes to be common to all humanity. Thus, according to Catholic tradition, it makes sense to note reasons why cloning is morally wrong both in explicitly religious terms and in more secular terms.

An example of the former is Catholic teaching that life is a gift from God and that humans therefore have a responsibility to appreciate and safeguard the inestimable value of human life. According to the Catholic Church, the embryo should be treated as a person from the moment of conception. It follows that cloning is deeply troubling, for embryos will inevitably be destroyed when human beings are cloned. Cloning thus fails to respect the fact that life is a gift from God that should be treasured. Moreover, Catholic tradition emphasizes the fact that humans are created by God as a union of body and soul, and, for that reason, the human person cannot be treated merely as a complex biological system. Thus, to the degree that cloning defines the human person genetically (that is, largely in bodily terms), it is not consistent with a Catholic vision of the spiritual and bodily union of the person and is problematic. Indeed, according to the Vatican, cloning fails to respect the fact that there are limits on human dominance over nature. According to Catholic teaching, it is one thing for reproductive medicine to study human reproduction to assist society in the good that is procreation, it is another thing to dominate the process of procreation. Cloning crosses that line.

In addition to this religiously-grounded argument, Catholic teaching also appeals to the notion of common human experiences. Thus, for example, in her testimony before the NBAC, Lisa Sowle Cahill noted that although autonomy has become a, if not the, central value in contemporary debates in bioethics, Catholic teaching has always emphasized the importance of the common good in addition to individual liberty. With regard to cloning, therefore, Catholic tradition asks not merely whether this technology might benefit individuals, but whether it will benefit society in the long run. In answering this question, Catholic tradition focuses on the importance of family to social good. According to Catholic teaching, the biological connection between parents and children is a manifestation of the natural connection between sex, marriage, and procreation. In traditional language, natural law requires that sex and procreation go together. Thus cloning is wrong in that it violates natural law by separating sex and procreation. This conclusion, says the Church, should be clear even to those who do not share a commitment to natural law. Careful reflection on the importance of families, historically and cross-culturally, along with an examination of how cloning might fundamentally change the notion of family is enough to show that cloning is deeply worrisome.

Islam

Just as Jewish and Christian scholars have drawn on accounts of creation in thinking about cloning, so, too, have Muslim scholars. For example, Chapter 23, verses 12–14 in the Qur'an, the Muslim scripture, are frequently cited as relevant to a discussion of cloning. The passage reads: "We created man of an extraction of clay, then We set him, a drop in a safe lodging, then We created of the drop a clot, then We created of the clot a tissue, then We created of the tissue bones, then We covered the bones in flesh; thereafter We produced it as another creature. So blessed be God, the Best of creators!" Supporters of cloning have understood this passage to mean that because humans participate in the act of creation with God, humans may intervene creatively in nature to promote human welfare. Thus, to undertake cloning in an effort to promote human flourishing may be acceptable.

In summarizing the response of Islam to reproductive cloning, it is also important to stress three themes from the *Shari'a* (Islamic law) that regulate individual and social morality for Muslims. First, Islamic law places a high value on the importance of scientific knowledge. Scientific research reveals the complexity of God's creation and for that reason can be understood as a kind of worship of God. Second, Islamic tradition has emphasized the importance of heterosexual marriage and the family to social and communal good. Third, although the tradition has no definitive position on the moral status of the early embryo, there is a well-known hadith (saying of the Prophet) that an angel comes to breathe spirit into a fetus at six weeks.

With these fundamental commitments supporting Islamic reflections on cloning, a number of positions can and have been developed. Consistent with the Qur'anic emphasis on the pursuit of knowledge, scientific research into reproduction that has led to the possibility of cloning is entirely legitimate. Indeed, some verses of the Qur'an have been interpreted to support the claim that God's will is manifest in so-called artificial reproduction because unless God wills the creation of life, there would be no life. Thus, assuming that the knowledge gained by pursuing cloning would be used to benefit humanity and not instead misused, cloning may be supported.

Nevertheless, there are aspects of cloning that give scholars of Islam pause. For example, the fact that cloning allows for reproduction without heterosexual pairing is problematic, for the Qu'ran is understood to be quite explicit about this: "And of everything We have created pairs that you may be mindful" (51:49). Thus, just as Catholicism is concerned about the threat cloning may pose to the traditional family, so, too, is Islam. Given the importance Islam places on the notion of a family that is founded upon heterosexual union, cloning has seemed very problematic to some Muslim jurists.

Finally, Islam also shares the concern raised by other religious traditions that cloning will lead to the reduction of children to commodities. Given the emphasis in Islam on the notion of spiritual equality, cloning may be problematic if it leads us to value some humans more highly than others because they have, or are free of, certain genetic traits. If cloning will lead us to place a market value on human beings, it will be opposed by Islam. Moreover, given the tradition that the moral status of the fetus changes approximately six weeks after conception, cloning will be problematic to the degree that it results in a substantial loss of fetal life after this point in gestation.

Buddhism

In order to understand Buddhist responses to cloning, it is important to note that Buddhist teaching generally emphasizes the centrality of individual judgment and discretion informed by reflection on Buddhist texts and the opinion of respected teachers. Thus, on cloning as on other issues, it is difficult to speak of a Buddhist position.

Nevertheless, the tradition clearly emphasizes a number of values that are helpful in framing a Buddhist response to cloning. First, in Buddhism, human existence is particularly valuable because only human beings can achieve enlightenment and thereby escape perpetual rebirth. The birth of a human being is therefore important because it affords a sentient being the possibility of release from suffering. Reproductive cloning may be viewed positively from a Buddhist perspective because it appears to facilitate the process of rebirth and liberation. The fact that such cloning would involve asexual reproduction does not appear to be significant in Buddhist tradition, which clearly contains stories of other kinds of asexual generation.

In contrast to several Protestant, Catholic, and Islamic objections to human cloning, Buddhists do not argue that asexual reproduction and cloning are human attempts to play God, or that they in any way infringe upon God's sovereignty as creator. Nor do Buddhists fear that human cloning, through genetic manipulation, might deprive cloned individuals of their right to an open future. Buddhism rejects the kind of physical reductionism that such genetic determinism implies, and scholars have been careful to note that human cloning does not determine or control the life of another being. The Buddhist conception of human life maintains that while cloning does determine the genotype of an individual, one's genetic construction does not and cannot determine the complete life of the human being, usually thought to comprise the body, sensation, thought, dispositions, and consciousness.

Buddhism does look upon cloning with skepticism and caution for other reasons. The universal value shared by all Buddhist traditions remains ego-transcending thought and behavior. Egocentric conduct and its motives are considered great moral wrongs. Buddhism is likely to analyze the morality of human cloning in terms of the motives, intentions, and desires of those engaged in genetic engineering and cloning. Should the motives behind cloning in general, or cloning in a specific instance, be found to be purely self-centered or self-gratifying, then the practice would be immoral and contrary to Buddhist values. This point is nicely illustrated by the classic Buddhist narrative, the "Parable of the Mustard Seed." According to the parable, a mother who is grieving over the death of her child approaches the Buddha to ask that he bring her dead child back to life. The Buddha instructs the woman that she will be able to accomplish her goal if she prepares tea from mustard seeds that have come from a house not touched by death. Of course, the woman is unable to find such seeds, and that is indeed the point; all life is impermanent. In the face of this fact, the woman needs to reflect on her desires and attachments to things that are necessarily impermanent.

Given this parable, Buddhist tradition raises serious questions about the wisdom of one form of reproductive cloning, namely, cloning to replace a lost loved one. Such cloning might be acceptable if one can find a physician whose family has not been touched by death, but seeking to replace a loved one appears to interfere with a Buddhist commitment to seek enlightenment through freedom from bondage to the self and its attachments. The parable thus points to the significance of attending to the motives or desires for cloning in rendering a Buddhist assessment of the practice. Many of the reasons that have been advanced for reproductive cloning, for example, to resolve infertility, to replace a lost child, to replicate oneself, appear to be profoundly egocentric. As such, they would be morally problematic according to Buddhist teaching.

Nevertheless, scholars remain divided on this line of thinking. Some have argued that should cloning benefit the couple wishing for a child, and provided it does not cause pain or suffering, then such cloning should be supported. Others have noted, however, that even the least objectionable motivations for cloning, such as the desire to avoid passing down hereditary disease, remain egocentric and self-serving. In this view, the decision to clone instead of using donor cells or adopting a child in need of a family, for example, seems rooted in a desire to have a genetically related child and does not truly look to ease the suffering of another, but has a self-gratifying aim. Accordingly, the argument goes, virtually all rationales for reproductive cloning stem from this desire.

While the motivation behind cloning is of primary significance in assessing its moral value, there is some concern among Buddhists that the inevitable destruction of early human embryos in cloning's experimental phases and in the successful process itself runs contrary to Buddhism's objection to the taking of human life. Although as a non-sentient being the early embryo would not suffer, Buddhism does view the early embryo as a human being and, as previously noted, the human is highly valued for its role in one's attainment of nirvana and the release from suffering. Thus, destroying human life, however early or insentient, may violate one of Buddhism's highest values.

Conclusion

This survey of religious responses to cloning suggests that there is significant misunderstanding of how major religious traditions have reacted to the possibility of reproductive cloning, at least in the popular media. For example, when the story broke that the British House of Lords had legalized therapeutic cloning for the purpose of deriving stem cells in 2001, the Reuters news service described Parliament as "turning a deaf ear to religious leaders from across the spectrum who had urged them to oppose the measures." Reuters's characterization of religious leaders as uniformly opposed to cloning is fairly typical. The reality is quite different. As this survey attests, Judaism, Christianity, Islam, and Buddhism take subtly different positions on the status of the embryo, on the appropriate motives for even considering cloning, on the notion of "playing God" and manipulating nature, and other matters.

Add to this the fact that, within each tradition, there are disagreements about these matters and the picture becomes very complex. What can safely be said is that none of these traditions appears to embrace cloning as an unqualified good, and, with the exception of official Catholic teaching and that of some evangelical Protestant groups, none appears to condemn cloning as intrinsically and unqualifiedly wrong.

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SEE ALSO: *African Religions; Buddhism, Bioethics in; Christianity, Bioethics in; Daoism, Bioethics in; Islam, Bioethics in; Jainism, Bioethics in; Judaism, Bioethics in; Mormonism, Bioethics in; Native American Religions, Bioethics in; Reproductive Technologies; Transhumanism and Posthumanism;* and other *Cloning* subentries

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COERCION

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Is it ever acceptable for the government to coerce someone into receiving healthcare? Is it acceptable for healthcare professionals to do so? Equally important, if an individual is coerced to do something including, for example, consenting to treatment, does the coercion invalidate responsibility for the act? Are prisoners and other institutionalized persons able to freely decide whether to enroll as subjects in experiments, or should they be seen as coerced, and, if so, does that invalidate their consent? Is paying research subjects to participate in research acceptable, or is that practice coercive?

These questions are basic to many of the ethical dilemmas faced in healthcare and healthcare research. To answer them, it is necessary to answer a number of more general questions. What is coercion? Are coercive acts ever morally legitimate? If so, how can they be distinguished from illegitimate coercion? Are there types of coercive acts that are always illegitimate, or do their moral natures vary with the context in which they occur? This entry aims to answer these and other related questions. A clear definition of coercion is a mandatory first step.

What Is Coercion?

In their 4th edition of *Principles of Biomedical Ethics,* published in 1994, Tom L. Beauchamp and James F. Childress provided a definition of coercion that is consistent with common usage: "Coercion … occurs if and only if one person intentionally uses a credible and severe threat of harm or force to control another" (Beauchamp and Childress, p. 164). This definition has three critical elements: a person acting intentionally, a threat of harm, and an effort to control another. Perhaps the prototype of this image of coercion is the robber who approaches a victim and says, "Your money or your life." Note that the robber is not forcing the victim to hand over the money. The victim still has options, but the robber has manipulated the options in such a manner that most people would agree to hand over the money.

If Beauchamp and Childress's definition is correct, most constraints on freedom should not be thought of as coercion. In their definition only other people can coerce. Someone who lacks resources should not be thought of as being coerced by the lack of resources. The poor are not coerced into homelessness no matter how much their situation may be out of their control. A nation that lacks oil is not coerced into trading with a country that has oil simply because of its need. Similarly, an environment, such as a prison, cannot be thought to be coercive. Thus the regulatory restrictions on research with prisoners cannot be justified by limitations on coercion.

Similarly, threats are a fundamental feature of this definition; other pressures do not produce coercion. This position is controversial. In his 1986 volume, *Harm to Self,* Joel Feinberg, like Beauchamp and Childress, used the term *compulsion* rather than *coercion* to refer to the actual use of force, because compulsion reduces options and coercion only changes the attractiveness of the options. Michael D. Bayles, like others, however, did not consider this distinction important (Bayles).

Force is not the only type of pressure that is sometimes included in coercion. Positive pressures such as inducements and persuasion may be seen as "excessive." Many commentators on research ethics have suggested that excessive inducements may well constitute a form of coercion (Macklin; Levine; Ackerman; Dickert and Grady). For example, in his 1986 book, *Ethics and the Regulation of Clinical Research,* Robert J. Levine suggested that almost all bioethics support this view. The U.S. Food and Drug Administration's (FDA) information sheets require institutional review boards to ensure that payments not be "unduly influential" (FDA). Indeed, Neal Dickert and Christine Grady suggested in a 1999 article that whether or not a payment is unduly influential is largely determined by the strategy used to establish the amounts to be paid. Several others, including Beauchamp and Childress and Robert Nozick (1969), exclude positive incentives from the concept of coercion.

It should also follow from Beauchamp and Childress's definition that if the threatener has no intention of controlling the behavior of the other party, there is no coercion. Thus a physician who tells an individual seeking help for what might be a gunshot wound that he must report any gunshot wounds to the authorities is not coercing the potential patient, because there is no attempt to alter that person's behavior.

The question of coercion can be stated as follows: If *A* proposes to do something to *B*, what are the conditions that make the act coercive or not? Several commentators have suggested that the relevant question is whether the proposed act leaves *B* better off or worse off. If better off, it is a legitimate offer; if worse off, it is coercive (Zimmerman). Nevertheless, this does not entirely solve the problem. Consider a physician who tells a sick patient that she will provide treatment but only with the payment of $100 (or some other reasonable fee). This is an entirely reasonable offer and not coercive at all. If, however, the patient belongs to an HMO to which the physician belongs and which forbids this sort of co-pay, this "offer" might be coercive. Put more generally, whether an act is a legitimate offer or coercion depends on the right of the offerer to make the offer.

Such problems can be handled better by what Alan Wertheimer, in his 1987 book, *Coercion* called a "moralized theory" of coercion. Wertheimer objected to views suggesting that what is coercive can be determined simply by looking at the pressure applied to the individual. In his view, coercion is an inherently moralized judgment. One cannot determine whether or not an act is coercive except on the basis of understanding the normative context of the actions. Wertheimer argued that coercion judgments come down to whether the possible coercer has the right to make the proposal and whether the possible coercee has the obligation to resist it.

Coercion and Autonomy

The view in Western culture that coercion is a bad thing reflects a deep commitment to the principle of autonomy. Starting with the German philosopher Immanuel Kant (1724–1804) and his 1785 work, *Groundwork of the Metaphysics of Morals,* secular ethics has taken the respect for the autonomous actions of others as a primary point of orientation. In this context, coercion is wrong because it interferes with autonomy. Thus the nineteenth-century English philosopher and economist John Stuart Mill argued in *On Liberty* (1859) that there were inherent limitations on the power that the state or other authorities should exercise over individuals:

> [T]he sole end for which mankind are warranted, individually or collectively, in interfering with the

> liberty of action of any of their number, is self-protection.… the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. (Mill, p. 494)

Although this often quoted passage seems to prohibit many coercive actions that Western society accepts routinely today, it is worth noting that Mill made exceptions for children and for adults not of sound mind. His vision of autonomy is so rationalistic that there appears to be no basis for respecting the autonomy of those who are lacking in reasoning ability.

Is Coercion Always Wrong?

At least in the context of Western values, it is hard to defend coercive behaviors per se. Nonetheless, there are many examples of coercive behaviors that are generally accepted. Indeed, political scientists general acknowledge that the governmental monopoly on the use of force is a fundamental feature of civil order. The ability of the authorities to threaten the use of force seems essential. There are innumerable examples, both in and out of medicine, in which coercion is accepted. The courts routinely tell people who are thought to have a mental illness that they can either take their prescribed medicine or be involuntarily committed to a hospital. In this case, the courts are still consistent with Mill's viewpoint. But when parents are told that if they want their children to attend public schools, the children must have certain vaccinations, this appears to go beyond Mill's limits on coercion.

The viewpoint that coercion is sometimes justified is referred to as *paternalism.* Here the authority, be it the state or the medical professional, justifies the use of threats and force based on the best interests of the individual. Although few ethicists have expressly focused on justifying paternalism per se, there has been considerable discussion of the circumstances under which paternalism might be acceptable.

Feinberg (1971) distinguished between weak paternalism and strong paternalism. The former depends for its legitimacy on an individual's compromised ability to decide, based on, for example, the influence of psychotropic drugs, some forms of mental illness, severe acute pain, or acute neurological injuries. Strong paternalism, by contrast, justifies actions that are simply intended to benefit a competent rational individual who is, in the view of the paternalist, making the wrong decision. Strong paternalism may take the form of either restricting what is disclosed to an individual or simply overriding the person's autonomous choices.

Empirical Findings: The Example of Psychiatric Admission

Empirical data cannot resolve ethical issues, but experience in bioethics has shown that ethical issues often look quite different when they are embedded in complex situations. Likewise, empirical data can render problematic assumptions about the nature of the ethical decisions that occur in healthcare contexts.

There have not been very many efforts to study coercion in healthcare. The exception is psychiatric care. There has been considerable research into coercion in psychiatric admissions and in other aspects of psychiatric care that are mandated by courts or other legally constituted authorities. Precisely because such situations use the coercive power of the state and yet occur within the context of medical care, they have been of special interest to ethicists and policymakers. For this reason, research on coercion in psychiatry can also be helpful in understanding some of the general issues concerning coercion in healthcare.

Research on coercion in psychiatry was relatively unorganized until the MacArthur Foundation funded a series of studies in the 1990s. These studies contributed a number of important empirical findings, but their most important contribution was to create a measure of perceived coercion that has been widely adopted and that has allowed comparisons across international boundaries and among different types of psychiatric care. It is important to recognize, however, that this scale measures *perceived* coercion and that it is based on an understanding of coercion as a restriction on the ability to make decisions for oneself (Gardner et al., 1993).

Among its findings, the MacArthur group reported several that have important implications for understanding coercion in healthcare. First, there is surprising agreement among the participants in hospitalization decisions (patients, family, and clinicians) about what happened (Hoge et al., 1998; Lidz et al., 1998). The differences are in how the events are evaluated. Thus the different participants often disagreed about the level of coercion even when they agreed about the acts involved.

Perhaps the most surprising MacArthur finding was that being legally involuntarily committed is not necessarily perceived by patients as coercive. Indeed, almost a third of the people who were legally committed reported that they did not feel coerced. Conversely, more than 10 percent of those who were admitted "voluntarily" felt coerced (Hoge et al., 1997). These finding have been confirmed by other investigators (Nicholson, Ekenstam, and Norwood; Hiday et al.). Similar findings have been found in different countries (McKenna, Simpson, and Laidlaw), in involuntary outpatient treatment (Swartz et al.), and in drug treatment (Wild, Newton-Taylor, and Alletto).

Perhaps the most interesting of the MacArthur group's findings involved the issue of moralized versus nonmoralized concepts of coercion. In a 1993 study, Nancy S. Bennett and her colleagues examined the transcripts of interviews with admitted patients and noted that the patients' descriptions of their experiences with admission and their perceptions of coercion appeared to be substantially related to their perception of what came to be called procedural justice. This concept included the sense that patients had a chance to express their own thoughts on the hospitalization, that they were listened to, and that the motives of others involved in the hospitalization decision were benign (Bennett et al.). Subsequent follow-up studies, both from the MacArthur group (Lidz et al., 1995) and others (Hiday et al.), showed that both procedural justice and what the researchers called negative pressures (force and threats) were strongly related to perceived coercion but that "positive pressures" such as inducements were not.

Conclusion

Coercion may be defined in a purely behavioral manner as the use of a threat to control the behavior of another. Other thinkers have argued that coercion is inherently a moralized judgment that can be understood only in the normative context in which it is made. From this perspective, there can be no such thing as approved coercion. Indeed, coercion is almost universally condemned in the abstract, but there are many instances in which actions that fit behavioral definitions of coercion are approved. The empirical studies of coercion appear to support a view of coercion that involves both behavioral and moral components. There appears to be little empirical support, however, for the idea that offers or other inducements are experienced as coercive.

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SEE ALSO: *Authority in Religious Traditions; Autonomy; Behaviorism; Behavior Modification Therapies; Conscience; Conscience, Rights of; Ethics; Informed Consent; Paternalism; Psychosurgery, Medical and Historical Aspects of; Public Health*

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COMMERCIALISM IN SCIENTIFIC RESEARCH

• • •

Scientific research has never been entirely insulated from the incentives provided by the profit motive and the need to secure financial support. Scientists have always required funding, whether it be from personal funds, patrons, universities, or industry. Similarly, opportunities for scientific entrepreneurship have always existed. Since the early 1800s, however, scientific research has both required increasing amounts of capital investment and promised progressively greater financial returns. Consequently, scientists have been forced to rely on a broader range of funding sources and have become more willing to involve themselves in the financial implications of their work. This incremental “commercialization” of science has increased markedly since the early 1980s and poses challenges for both society and the research community.

Well into the early nineteenth century most scientists were indifferent to the commercial potential of their work and typically did not pursue large-scale or external financial support. Research then did not require huge expenditures, and many researchers believed that scientific research was the work of disinterested amateurs devoted to the pursuit of truth. In the mid- to late nineteenth century the development of the large-scale laboratory in Europe and ultimately in the United States increased the costs of research and foreshadowed the decline of the solitary, amateur researcher. At the same time, a variety of connections between industry and science developed. Many businesses employed their own scientists, but an increasing number established relationships with universities and employed academic scientists as consultants and researchers. While this trend continued in the early twentieth century, industry-sponsored research typically focused on applied-science projects. Basic research areas had yet to be viewed as fruitful areas of investment (Etzkowitz).

In the last half of the twentieth century, several developments enhanced the commercial aspects of science. The cost of basic science research continued to soar, requiring sophisticated equipment and resources, larger laboratories, and more staff. Basic research therefore has become increasingly dependent on financial support from either the government or the private sector. Scientific research, especially in the biomedical fields, promises to generate tremendous profits for those who control new discoveries. Moreover, the gap between basic and applied science has narrowed, so that discoveries can be translated into usable and profitable products with less energy and over a shorter span of time (Etzkowitz).

Commercialization, the Ideals of Science, and the Public Good

Despite the need for broad-based and generous funding and the right of scientists to reap rewards for their efforts and ingenuity, financial incentives may create conflicts of interest that can undermine and corrupt the ideal of disinterested scientific inquiry. A conflict of interest exists when any professional judgment or activity relating to a primary interest (e.g., intellectual honesty, validity, openness, or objectivity), equivalent to the scientific norms articulated by Robert K. Merton and others, may be influenced by secondary interests (e.g., financial gain, profit, position, or fame). The mere existence of a conflict of interest does not mean that unethical behavior has occurred; the scientist may honor the primary interests and refuse to be influenced by the secondary interests. Conflicts of interest instead signal cases in which the danger of unethical behavior is increased. In some cases the conflicts can be managed by restricting the secondary interests; in more extreme cases ethical outcomes can be assured only if the secondary interests are entirely removed (Thompson; Merton; Cournand).

Conflict of interest may exist at an individual or at an institutional level. For example, one primary interest of a university is to serve the public good. Financial incentives may induce researchers and institutions to behave in ways detrimental to society (Angell). For example, a scientist may forgo research on an important project in favor of another that is more profitable. Comprehensive ethical policies would ideally address both possible levels of conflict, though they require different forms of remedies.

Industry Investment in Academic Research

Private investment in university research may take a number of forms. Companies may offer universities large grants in exchange for patent rights to anticipated discoveries or establish lucrative consulting arrangements with faculty members who provide sponsoring corporations with priority access to valuable research. Faculty members sometimes own equity interests in biotechnology firms related to their work, or they may found their own corporations. And in what is so far a rare agreement, a corporation may provide an academic research institute generous payments in exchange for the right to market all the institution's discoveries. These secondary—financial—interests threaten to undermine the university's primary interests of advancing basic knowledge, promoting the open exchange of ideas, providing a source of expertise for society, and training future scientists (Etzkowitz; Ashford).

In 2003 Justin E. Bekelman, Yan Li, and Cary P. Gross provided a systematic review of the extent and nature of commercial influence on biomedical research. The researchers found that about one-fourth of biomedical scientists at academic institutions receive research funding from industry, while two-thirds of academic institutions hold equity interests in biotechnology firms. According to the survey findings, it is likely that such relationships bias scientific outcomes because published studies sponsored by industry are substantially more likely than nonindustry studies to reach conclusions favorable to the sale of the sponsors' products. Faculty sponsored by industry are more likely than other faculty to report that publication of their research results was delayed, and more than half of the firms surveyed reported that their contracts typically demand delays in publication of more than six months. Between 12 percent and 34 percent of investigators reported that they had tried to obtain and had been denied access to research results by industry sponsors.

If free exchange through traditional scholarly mediums of conferences and publications is blunted, scientists will be unable to examine and replicate experiments, and scientific progress may be endangered. Some contractual agreements with industries specifically require scientists to withhold submission of their findings to professional journals until the corporation has determined if the information warrants patent protection. After patent protection is secured, the findings can be released to the general scientific community. The propriety of these arrangements depends in part on the length and impact of the delay of release of scientifically important information and varies from contract to contract. It is possible that much of the research that is withheld from the scientific community as trade secrets has little intrinsic scientific value or applicability and is limited to information such as scientifically unimportant formulas for products, scientific instrument calibrations, or engineering tolerances (Snapper).

Commercial considerations can distort academic life in other respects. Researchers may be tempted to devote time earmarked for the university to their commercial projects and to use university resources, including graduate assistants and laboratory staff, for their own financial benefit. Graduate students are particularly vulnerable to the availability of funds; the entire course of their careers may be guided by the source of their mentors' grants (Porter 1992a; Blumenthal). The prospect of large infusions of money into a cash-starved university might make an institution less scrupulous when evaluating potential research projects. For example, an institutional review board (IRB) might be less likely to point out problematic aspects of an experimental study if they believe that the corporate sponsor will withdraw its funds and go elsewhere with the proposal. An existing or potential grant might influence a university's decision on the composition of its faculty, the structure of a department, and the granting of tenure (Nelkin and Nelson). Financial incentives have encouraged some university researchers to redirect their work toward projects that are more likely to yield financial rewards. Such a redirection of research might encourage researchers to value applied projects with clear commercial ends and patentable uses over basic science projects whose practical applications are uncertain. While society benefits from applied research, fundamental breakthroughs and scientific progress are predicated on a strong commitment to basic research.

Despite these caveats, private funding of university research serves as an effective and essential supplement to government funding. Some reports demonstrate that, in general, industry-funded scientists publish more, produce more patentable discoveries, and still manage to teach as much and to serve as many administrative roles as colleagues without corporate financial support (Blumenthal). Industrial subsidies allow universities to support a more talented and larger faculty and to improve their facilities. Therefore, some authors argue that the danger of increased commercial presence in universities must be weighed against the positive contributions made by industry funding (Blake).

Conflicts and Scientists' Social Duties

Professional researchers are the public's and policymakers' most important source of scientific expertise. Government agencies that evaluate biomedical proposals and projects must rely on scientists to analyze the safety and efficacy of research and products. Scientists also serve as reviewers for governmental grant applications and as authors, editors, and referees for professional publications. Conflicts of interest arise when industry, regulatory agencies, government committees, and editors all seek out the same individuals—a likely prospect when many of the most talented researchers have already-established commercial interests (Culliton).

Few scientists will purposely present biased conclusions, but researchers' commercial interests may influence their professional life in other respects. Scientists might be hesitant to participate in the evaluation of an industry with which they maintain a financial connection. Following a large oil spill on the California coast in the late 1960s, for example, government investigators found it difficult to recruit scientists willing to testify against the oil companies. Most qualified scientists had commercial ties to the industry (Kenney). When a medical journal sought independent reviewers to judge the quality of a research study showing the lack of benefits of a popular drug—a study whose publication the company manufacturing the drug was attempting to suppress on the grounds that the study was badly designed—the editors discovered that virtually all scientific experts in that field had existing financial ties to the company (Rennie). Corporations frequently employ researchers as consultants to determine if their facilities meet governmental health standards or if their new product induces disease. A researcher's desire to please the employer and to preserve the potential of future affiliations may influence the study design and methodology selected for the investigation. A study that monitors employee health for only a short time, for example, would be less likely to uncover an occupation-related disease with a long latency period. A corporation facing liability for a suspect drug would prefer its researchers to find that the product presented no danger and was not responsible for the maladies suffered by current users (Ashford; Porter, 1992a, 1992b).

Similarly, reviewers of grant applications may have commercial interests that unconsciously lead them to undervalue a potential competitor's proposal. Journal referees may denigrate articles or reports that threaten their commercial interests or their industry employer. A researcher with a consulting arrangement or an equity interest in a new development might tend toward findings that would laud the benefits of the innovation. In one egregious case, a researcher who owned over 500,000 shares of biomedical stock altered a study design to delay the release of negative findings until he could sell his holdings for a tremendous profit (American Medical Association). Physician-researchers with commercial interests in innovative treatments or research protocols bear additional responsibilities. A central tenet of medical professionalism holds that the welfare of the patient be placed before any benefit to the physician. If a physician-researcher is testing an experimental therapy, the patient must be protected from risks of undue harm from either the experimental drug itself or from withholding standard therapy. Physician-researchers with financial interests in their protocol might tend to recruit subjects aggressively, playing down the risks and exaggerating the benefits associated with the research. In a highly publicized case in which a young man died during experimental gene therapy, both the investigator and the university had financial interests in the biotechnology firm that planned to market the drug if it proved successful, and it was charged that substantial, known risks were not disclosed to the subject (2001).

During the 1990s a considerable change in pharmaceutical research funding occurred in the United States. Companies began to shift research grants away from universities and toward for-profit contract-research organizations (CROs). The CROs promised quicker research results and hence faster licensing of new drugs, compared to the more cumbersome, bureaucratic university system. Between 1991 and 1998, the portion of pharmaceutical industry research funds going to academic medical centers fell from 80 percent to 40 percent (2000). For-profit commercial IRBs sprang up to service the CROs, creating questions as to the adequacy of ethical review when both the IRB and the investigating organization had such strong financial incentives to speed the progress of research and to produce positive results (Lemmens and Freedman). As research funds were shifted to the private sector, university investigators had to compete more vigorously for the remaining funds, increasing the likelihood that both institutions and individuals would ignore serious conflicts of interest in their eagerness to secure funding.

Remedies and Safeguards

The integrity of individual researchers is clearly the most important guard against the malevolent potential of conflicts of interest. But honesty alone may sometimes be insufficient, as damage can occur from unconscious bias and error as well as from conscious falsification. While all conflicts of interest have the potential to undermine a scientist's or an institution's primary goals of truth, objectivity, and openness, all conflicts do not pose the same degree of danger or require the same response. The danger of a particular conflict of interest depends both on how likely the arrangement is to corrupt the scientist's professional duty and on how much damage that corruption is likely to cause. Larger financial payments, and longer and closer relationships between researchers and business, will typically pose greater dangers than small financial incentives and one-time contacts with corporations (Thompson). While supervisory and regulatory measures can usually be tailored to the degree of the risk, there may be some situations in which the danger of harm to scientific integrity and society is so high that no protective measure can remedy it.

Universities might limit the amount of support they accept from industry, limit the amount of time that faculty may devote to outside endeavors, or prohibit particularly suspicious arrangements. In addition, research institutes can require the disclosure of all commercial links and interests and establish prospective administrative review of all proposals for outside funding (Varrin and Kukich; AAMC, 1990). Disclosure rules not only assist university officials and peers in policing conflicts of interest but may also make researchers more scrupulous in evaluating the potential bias in their own work. Researchers sometimes end or eschew questionable relationships rather than disclose them to the academic community. Some have argued, however, that today's institutional policies tend to advocate, inappropriately, disclosure alone, treating it as if it were a panacea. A number of prestigious universities and organizations in the United States proposed stringent conflict of interest policies in the early 2000s (Kelch; Kassirer). Many focus on individual conflicts of interest to the exclusion of institutional-level conflicts. By contrast, a group of Canadian authors, stimulated by widely publicized cases in their country of egregious institutional violations of academic freedom, have proposed elements of a conflict of interest policy that offers remedies for both levels of conflict (Lewis et al.). A policy on institutional conflicts of interest proposed in 2002 by the Association of American Medical Colleges (AAMC) locates responsibility for policing potential conflicts of interest within each university, whereas the Canadian group suggested that an appellate process involving a national group independent of any one university would be desirable (Lewis et al.; AAMC 2002). After developing a policy considered one of the most stringent in the nation, Harvard Medical School came under pressure to loosen its requirements, lest some of its most prestigious researchers move elsewhere (Angell). Bioethics programs in universities are part of the research enterprise and, according to some, should have policies to prevent conflicts of interest. Concerns have been expressed about paid consulting relationships between bioethics faculty and industry (Brody et al.).

Government agencies and professional publications also institute policies to guard against conflicts of interest. The U.S. Food and Drug Administration and the National Institutes of Health require extensive disclosure of all advisers' commercial interests. Some professional journals demand that authors and reviewers disclose any commercial relationships that might be construed as creating conflicts of interest. According to this view, conflicts of interest should not automatically disqualify a reviewer or author, but the revelation will allow readers, editors, and administrators to scrutinize conclusions more carefully (Koshland). Other publications have adopted somewhat more stringent guidelines. The *New England Journal of Medicine,* for example, has required that authors disclose their financial conflicts, that its editors have no financial interest in any business related to clinical medicine, and that authors of review articles and editorials have no financial connection to their topics (Relman). The *Journal* was later forced to admit, however, that many of its authors of review articles had evaded these requirements (Angell, Utiger, and Wood). A few observers warn that excessive concern over conflicts of interest and safeguards may hinder scientific progress and undermine the scientific objectivity that they are designed to preserve. These writers claim that focusing reviewers' and readers' attention on potential outside influences instead of the content of the data, findings, and ideas generates a subjective skepticism unrelated to the objective merit of the work (Rothman). In 2001, however, the editors of thirteen major medical journals decided that the problem was serious enough to demand a unified and even more stringent disclosure policy (Davidoff et al.).

Some observers argue that the physician-researcher's commercial ties should be revealed to the patient-subject through the mechanism of informed consent and to the investigator's institution through a formal reporting mechanism (Finkel). Finally, IRBs can scrutinize protocols that promise great financial rewards for physician-investigators.

Patents and the Public Interest

Patenting is another commercially motivated practice that may create conflicts between the primary interests of good science and the secondary interests created by the profit motive. Patenting is based on the theory that innovators will be more likely to share their knowledge because they know that they will receive remuneration and credit and that entrepreneurs will be more willing to invest in the development of discoveries because they know that they have exclusive or protected access and will recoup their expenditures in profits. Patenting's skeptics, however, argue that the very nature of patenting undermines the traditional scientific norm of openness. Researchers may be tempted to withhold socially valuable information until they are certain that their pecuniary interests are protected by a patent (Kass; Wiener). Especially in the biomedical fields, a delay in the release of information can lead to postponed development and dissemination and the loss of lives. Others speculate that potentially patentable, lucrative discoveries will lead researchers away from less profitable yet socially important projects. Finally, some critics claim that entrepreneurs who purchase rights to a basic discovery often do not use or develop it in a socially responsible way. Furthermore, their monopoly advantage makes it impossible for the market to force them to distribute the breakthrough in an equitable and useful manner (Goldman).

The federal Bayh-Dole Act of 1980 provided the legal basis for universities to patent genetic and other biotechnology products and discoveries. When passed by Congress, the act seemed uncontroversial, because the public would benefit both from the quicker marketing of the fruits of new research and also from a lower tax burden as universities made more money from patents and licenses. In retrospect, some provisions of the act appear to have had undesirable consequences. Besides the dangers of turning so big a percentage of research funding over to corporate interests, some fear that the ease with which one can patent each separate step of a complex sequence needed to create genetic tests or therapies will actually pose a barrier to future advances, because the manufacture of any gene product may require negotiating license fees with the owners of dozens of patents (Nelkin and Andrews; Merz et al.).

The government can also provide patentlike incentives to encourage the development of products with marginal profitability that are intended to treat a small patient population or that are ineligible for normal patent protection—so-called orphan drugs. Orphan-drug programs might include research grants, investment tax credits, expedited approval processes, and exclusive licenses to produce and distribute the drug. Critics of orphan-drug programs argue that the policy excessively favors drug manufacturers, inflates the costs of lifesaving medications, and delays the development of lower-cost alternatives. Private corporations sometimes reap profits far in excess of their expectations and effort while effectively denying life-sustaining remedies to patients through monopoly pricing practices (Ackiron). Incentives are sometimes overgenerous, and corporations are able to enrich themselves on drugs that serve only a small number of patients and occasionally produce limited benefits (Wagner). It is important to scrutinize the incentive structure of the orphan-drug policy in an attempt to eliminate unnecessary windfall profits for drug manufacturers. Policymakers must balance the cost of the incentives, including monopoly pricing practices and tax abatements, against the benefits provided by the new drug (i.e., the number of people served and the efficacy of the remedy).

Marketable Products from Human Sources

Another challenging problem arises when an individual's body parts or cells are transformed into valuable commodities. In one such case, a patient's removed spleen contained unique cells that a physician-researcher cultured into a patented cell line. Should the patient have been apprised, as part of the informed-consent procedure, that the cells had potential commercial value? Fully informed consent would have allowed the patient to evaluate the physician's potential conflict of interests and choice of treatments more effectively. Because society and the law have typically been hesitant to "commodify" the body and do not allow the sale of organs, it might seem inappropriate to grant the patient a share of the profits based on the theory that the tissue is his or her "property." In contrast, the system appears to allow the biomedical entrepreneur to benefit from the sale of body parts. Developers of such innovative products might argue that the resulting cell line is not a body part but rather the result of their labor and ingenuity and that these efforts deserve to be rewarded and encouraged by traditional patents. Even granting this argument, it may be unjust to allow others to benefit from an innovation while the person upon whose existence the development rests receives nothing. Consequently, it seems fair and equitable that individuals receive some benefit from their unique physical characteristics that have been used to create great profits. The amount of remuneration could depend upon the nature of the informed-consent agreement, the degree to which the body tissue contribution was changed by the researcher before it was offered as a product, and the uniqueness of the physical material used (Murray).

Conclusion

It would be unrealistic to expect modern capital-intensive scientific research to thrive entirely without the support and influence of commercial interests and incentives. Similarly, it would be unwise and impractical to suggest that scientists who maintain commercial connections, and therefore have potential conflicts of interest, should disqualify themselves from all advisory duties. The trend toward adoption of explicit and stringent conflict of interest policies suggests a growing consensus that individuals, institutions, and professional groups have all been too tolerant in the past of ethically questionable but lucrative practices. It remains to be seen how effective these new policies will prove in policing the problem. The U.S. public, moreover, may be forced to reexamine the wisdom of allowing so great a percentage of the total research endeavor to be governed by private commercial interests.

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SEE ALSO: *Conflict of Interest; Corporate Compliance; Pharmaceutical Industry; Private Ownership of Inventions; Profit and Commercialism*

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COMMUNITARIANISM AND BIOETHICS

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In the 1990s, communitarian approaches to bioethics became increasingly common and explicit in the literature. This evolution was the result of the prominence of the communitarian philosophical critiques of liberalism that occurred in the 1980s, particularly works by Alasdair MacIntyre, Michael Sandel, Charles Taylor, and Michael Walzer.

Communitarianism is a neo-Aristotelian philosophy that focuses on the common good and is concerned with the relationship between the good person or good citizen and the good of the community or society. As would be expected, it has much in common with other neo-Aristotelian approaches, such as casuistry and virtue ethics. Communitarianism is both a critique of the dominant Western ideology of liberal individualism and an orientation to ethical problem solving.

Communitarians often argue that the notion of human nature and the concept of the self behind liberalism are insufficient to make possible a shared common understanding of values among members of society. Similarly, communitarians sometimes argue that liberal society is committed to neutrality toward all notions of the good life, and thereby cannot adequately address ethical issues. As a result, communitarians often stress an orientation toward ethical questions that relies on the establishment, or re-establishment, of a shared common understanding, a shared notion of the good life, or a shared notion of the self.

Only a few bioethicists have openly embraced the communitarian label in their writings (Emanuel; Brennan; Loewy; Nelson; Callahan, 1996; Kuczewski, 1997). However, much work in bioethics shares community-oriented assumptions—that healthcare is special and different from market commodities, for example (Daniels), and may be seen as a good that is part of the common good (even by those who do not embrace communitarianism in other spheres of distributive justice) (Jecker and Jonsen). Similarly, many writers take relationships as the starting point of their ethic, rather than the individual (Murray).

Furthermore, even if society tries to remain neutral toward visions of the good life, ethical issues arise within the context of healthcare and require that the public institutions that provide medical treatment and conduct biomedical research somehow address such ethical dilemmas. As a result, pragmatists such as Jonathan Moreno embrace communitarian strands of thought in an effort to resolve such questions through the production of consensus (e.g., the creation of shared common understandings) (Moreno).

Communitarian Critiques of Liberalism

Communitarian critiques of liberalism have an intuitive appeal, and the nature of the critiques determine the kind of solutions that communitarians seek. It is again important to note that these critiques were developed mainly in the philosophical and political-theory literature and then imported to bioethics, often in a compressed fashion. Two different, but related, starting points form the basis of the communitarian criticisms.

LOSS OF SHARED COMMON UNDERSTANDING. Some communitarians, most notably the philosopher Alasdair MacIntyre, claim that liberalism will always fail to settle ethical disagreements because of the loss of a shared common understanding, or of a shared view of the good life (MacIntyre, 1981). According to this view, ethical and moral concepts are only understandable within the framework of the traditions within which the concepts developed. Such traditions are marked by a shared vision of the good life. This vision is thought to contain a shared hierarchy of goods, and ethical disagreements are supposed to be resolved by reference to this hierarchy.

Such communitarians see the contemporary moral situation as dire. Because there is no shared vision of the good life within a liberal democratic society, they claim, there is no such thing as moral discourse. Although there may be the appearance of moral debate, such arguments tend to have a back-and-forth nature, mostly between rival conceptions that share few common assumptions. MacIntyre characterizes such discussions within our society as "shrill" and "interminable" (MacIntyre, 1981, pp. 8–12) The debates are shrill because, lacking the rational basis of a shared hierarchy of goods, rival conceptions can only advance their conclusions by the force of emotion. The debates are interminable because the force of emotion can produce no enduring consensus.

Societal discussion regarding bioethical issues is characterized as essentially being in bad faith. That is, bioethics must put forth public policy and some point to the developing of widespread consensus on several issues, but such consenses are said to be forced and sociological in nature (MacIntyre, 1984; 1990, pp. 226–227). For MacIntyre, the solution to the contemporary moral fragmentation is to build up from particular communities that share a vision of the good life, perhaps through sectarian universities, to the restoration of a shared common understanding of the good life (MacIntyre, pp. 220–223).

Similarly, a number of communitarians echo MacIntyre's criticism by highlighting the fact that liberal political theory embraces the *neutrality thesis* toward views of the good life. It is not that visions of the good life have mysteriously been lost from moral discourse. Rather they are, in principle, not allowed to form the basis of ethical quandaries or social policies (Larmore, 1987, pp. 42–55). The neutrality thesis can be illustrated by the suspicion with which religion is treated in the public sphere. Policy positions that are seen to emanate mainly from religious sentiments, sentiments that are expressions of a particular vision of the good life, are generally not considered viable options within public policy debates. Similarly, such positions, should they become the law of the land, can and are sometimes struck down by courts if they infringe on the liberty interests of the nonreligious.

Communitarians note that the state cannot remain neutral toward all elements of the good life. It is the role of the state to protect the life and liberty of its citizens and to foster opportunity among them (i.e., to foster the "pursuit of happiness"). Although safeguarding life, liberty, and the pursuit of happiness does not logically entail a vision of the good life, questions of what kind of life a society wishes to foster can be unavoidable in practice. Simply providing and mandating a specific minimum amount of such a value neutral commodity as education can be more conducive to some visions of the good life than to others. Given the inevitability of impacting on visions of the good life, communitarians often seek ways to produce consensus regarding the values to be fostered, or to create policy solutions that balance widely shared values.

LIBERALISM'S IMPOVERISHED VIEW OF THE PERSON. Communitarians can also begin by showing that liberal democracy is based on a certain view of human nature, and that this view is inadequate even for the purpose of establishing the moral aspirations that liberal democratic theorists hold dear.

Liberal theorists do not wish to set forth a vision of the good life. Nevertheless, thinkers such as John Rawls posit a view of what is essential to human nature. Rawls puts forward such a vision in order to provide support for the rationality of the choice of certain principles of justice to govern the basic institutions of society (Rawls, 1971, pp. 54–60). In other words, although no vision of the good life is essential to humans, *choosing* a vision of the good is what is essential to human beings. This self that is defined by choice and will, i.e., this *volitional self* is the justification for a view of society as fostering opportunity to pursue one's vision of the good life.

The communitarian critique of the volitional self points to the fact that this concept fails on its own terms. The political theorist Michael Sandel argues that this vision of human beings is too thin to actually justify the kind of contractarian liberalism that rests upon it. Liberalism typically includes a distributive or redistributive role for government to assist the least advantaged, an aspiration that is viewed as not justifiable when based on such a thin concept of the self. Justifying such an aspiration requires a view of human beings as deliberative and interrelational, not merely volitional and contractual. People are not static and fixed entities who mysteriously have a set vision of the good life that they pursue; they develop and refine values and preferences in social processes. As a result, political processes should be arranged to foster the deliberative capacities of citizens, not to count the preferences in a voting procedure (Emanuel, p. 232).

Liberalism includes a principle of sharing. John Rawls expresses this as the “difference principle” (Rawls, 1971, pp. 75–83). According to this principle, inequalities are allowed as long as they work to benefit the least advantaged. Because liberal theorists wish for a sharing principle to follow from the description of the volitional self, Rawls argues that citizens would choose this principle if they did not know which arbitrary advantages or disadvantages they would have by accident of birth or luck. This derivation of the difference principle follows deductively only if we assume that persons are highly risk-averse creatures and will go to great lengths to avoid being in the worst position, even if such an outcome would be unlikely. This is the position Rawls took in his early development of the “maximin principle” (Rawls, 1971, pp. 152–157).

One could also say that that the choice of the difference principle reflects the kind of choice that persons in a certain kind of historical community would make in virtue of their self-understanding. This is the position toward which Rawls moved in his later work. But, if reflection on the ideals of a community’s self-understanding can be the basis for ethics, ethics can be based on more contentful concepts of the self, such as the communitarian’s ideal of the self as deliberative and rational.

The Communitarian Concept of the Self

For the communitarian self, the pursuit and choice of the good life is a process that is interpretive and deliberative. Persons are born into, or thrown into, situations that contain fragments of traditions, values, customs, norms, and habits. However, these raw materials are continuously reinterpreted and reappropriated as circumstances evolve and change. Similarly, persons make choices, accumulate experience, and receive a variety of kinds of feedback. They modify, refine, or change their ends, or the means to those ends, based upon these life processes. In so doing, they come to know who they are. Being a “self” is therefore a process of self-discovery.

Being a person is also a process of mutual self-discovery (Kuczewski, 1997, pp. 51–56, 108–112). That is, a person not only makes his or her own plans and gathers feedback, but is also shaped by his or her response to, and participation in, the process of self-discovery of others. A person’s identity is thereby inseparable from the life of the communities and societies in which the person participates. Of course, this is not the mere alignment of the projects and values of the person with the community. The person’s identity is partially constituted by his or her community, even in the person’s rejection of the community’s values.

The essence of a person comes from the person’s participation in the process of mutual self-discovery. Thus, for the communitarian, the ultimate question is always how to foster the development of a person’s deliberative powers and create appropriate opportunities for exercising meaningful participation in communal deliberation. This heuristic applies to deliberation on levels of interpersonal encounters such as clinical decision making as well as societal decisions regarding the use of common resources.

Communitarian thought is obviously closely related to another neo-Aristotelian ethic, virtue theory. Communitarians hold that the concept of the person includes the notion of capacities that need to be developed to be a good citizen and good person. Virtue ethics takes the development of excellence of character as its end-point, its *telos.* That is, the virtuous person is what the community and social practices should aim to produce. There are few obvious points of tension between communitarianism and virtue ethics, and disputes would seem to be a matter of emphasis and tone. Communitarians are generally oriented to process, virtue theorists to outcome (i.e., character). But both emphasize the relationship and interdependence of the community and the deliberative capacities of its members.

The Methods of Communitarianism: Consensus from Fragmentation

Communitarianism is probably best characterized as a philosophy of public deliberation that tries to produce consensus on public matters—matters that include the topics typically considered in the field of bioethics. Of course, the important question is how to actually produce that consensus. Three general approaches predominate: the whole-tradition method, liberal communitarianism, and consensus in public judgment.

THE “WHOLE-TRADITION” METHOD: REVIVAL AND REVITALIZATION OF PARTICULAR TRADITIONS. The “whole tradition” method of communitarianism sees the fragmentation of values and traditions as an almost insurmountable problem. Communitarians such as the philosopher Alasdair MacIntyre and the Christian theologian Stanley Hauerwas view moral concepts as only intelligible within the traditions in which they originated. Moral traditions, therefore, contain concepts that are incommensurable with those of other traditions, and that are untranslatable because they only make sense within their respective traditions. As a result, moral method must take the form of reviving particular traditions.

MacIntyre proposes that moral discourse take the form of a competition among revitalized traditions. Each tradition would express itself through a university in which the tradition would express and develop its worldview across the disciplines. The ultimate test of a tradition is the degree to which it can create a comprehensive worldview that accounts for the facts of the contemporary world and can respond to new challenges and crises that arise. MacIntyre also holds open the possibility that one worldview may simply be developed that is comprehensive enough to encompass the truths and strengths of other traditions. He clearly believes that the Aristotelian-Thomistic tradition is the most promising in this regard (MacIntyre, 1990, p. 81).

The whole-tradition movement in communitarianism is the most radical and pessimistic form of communitarianism. It holds that there is (and can be) no genuine moral discourse in a pluralistic liberal society—and that the revival of whole traditions in toto is the only possible solution. Once such traditions are developed, people can choose among the views of the good life that are contained therein. The work required to bring this about is described by MacIntyre as being akin to the service that Saint Benedict and the monastic orders provided in keeping civilization alive during the medieval period.

LIBERAL COMMUNITARIANISM. Communal deliberation is intrinsic to communitarianism. So it is natural that some communitarians should propose that community members gather and deliberate to develop consensus. In bioethics, this approach is notably associated with the early work of Ezekiel J. Emanuel.

In his highly regarded book, *The Ends of Human Life: Medical Ethics in a Liberal Polity* (1991), Emanuel suggests that ethical decisions regarding medical care are best handled by the members of small cooperatives called Community Health Plans (CHPs). Members would have a choice of a variety of CHPs in their geographic area. In the early stages of the founding of the plan, members would articulate the fundamental value assumptions behind the plan. For instance, some CHPs could have a philosophy that is strongly geared toward preservation of biological life, while others might maximize palliative care options. Similarly, some might strongly favor choice in reproductive and contraceptive options, while others would promote religious approaches to family life. By organizing the CHPs according to nonnegotiable value choices, the CHP progresses easily beyond the shrill and interminable debates to the more subtle choices involved in developing a health plan.

In Emanuel's plan, each person would have a voucher that would be brought to the plan. As a result, the deliberation about values and coverage of treatments is also a resource-allocation process. Each member must think not only about his or her values in the abstract, but must consider how to balance the fiscal implications of those commitments against other values and potential needs. This discussion takes place within a communal dialogue among the approximately 10,000 members of the plan. In such a dialogue, a person comes to develop his or her deliberative capacities and refine and clarify his or her values.

The strength of such a proposal is that it embodies the virtues of a genuine deliberative democracy. Such a plan brings together the rights and responsibilities of each person, granting each the right to be true to his or her most fundamental value commitments, and to be self-determining in devising a health plan to meet those commitments. But, more importantly, it demands personal responsibility in accepting the allocation consequences of one's choices. One may choose to be part of a plan that explicitly provides a maximum amount of some services and minimizes other services, and one must live with the minimal services provided should he or she develop an illness that might benefit from a higher level of services. Because the plan respects the rights of each within a communal framework, it is sometimes called *liberal communitarianism.*

Of course, the proposal for CHPs suffers from the practical difficulties of any community-based initiative. Although our best selves may develop in a context of dialogue and deliberation, many persons will simply not wish to devote the time and energy needed to participate meaningfully. Emanuel acknowledges that the model of the New England town meeting (the model on which the CHP is based) usually becomes dominated by a small, highly participatory group in whom the silent majority comes to have confidence (Emanuel, pp. 231–232). However, if stable communal consensus can be developed in ways that do not require the direct participation of most citizens, such approaches may recommend themselves to communitarians.

CONSENSUS IN PUBLIC JUDGMENT. ***Proxy dialogue and balancing values.*** One of the striking facts concerning bioethics is that public debate has produced areas of stable consensus, most notably in the United States, concerning informed consent to treatment and the principles concerning end-of-life decision making. Similarly, some studies have suggested that the American people may, in general, be less fragmented in reference to their values than is usually thought to be the case. Contrary to the radical communitarians such as MacIntyre, there may be empirical reason to be optimistic that a society can achieve stable consensus on moral problems that occur within public and quasi-public institutions.

The public debate concerning informed consent and end-of-life decisions has not been one with a clearly identifiable locus, but has taken a variety of forms, including court decisions, state referenda, and the policy deliberations of institutions such as professional societies and accreditation agencies. The public has been informed in a variety of ways, including media coverage of court decisions, public education efforts when referenda are introduced, and portrayal of these issues in entertainment programming such as television medical dramas. Somehow, over time, a consensus has taken shape.

Consensus, in this context, has tended to mean a set of principles that are widely accepted. It does not mean unanimity, for a large pluralistic society will always include those who disagree. Similarly, the interpretation and application of the principles will constantly require refinement because of the wide variety of possible circumstances in which they may be needed. As a result, debate may seem to be ceaseless, but the object of the debates actually becomes more refined. For instance, the consensus on forgoing life-sustaining treatment includes a distinction between forgoing treatment and assisted suicide (though the state of Oregon does not adhere to this distinction in a substantive way). The consensus also holds that patients who have lost their decision-making capacity (i.e., they have been deemed "incompetent") have the same rights as other patients. While all U.S. states adhere to this general principle, the evidentiary standards regarding the incapacitated patient's prior wishes can differ substantially among states (Meisel, Snyder, and Quill). Although these are important disputes, they do not undermine the widely shared areas of agreement.

Of course, identifying that a society has achieved a stable consensus is not always a simple task. Public opinion polls can measure the public's views, but it is not always obvious when the data reflect a stable consensus. It is often the case that responses to poll questions reflect mere fleeting preferences. Although communitarianism is premised on the idea that people must come to discover their wishes, or how their values translate into preferences, how this happens on a grand scale is somewhat mysterious. However, some suggestions have been made.

First, a consensus is probably more stable if it is able to balance several competing values that are important to a society. For instance, the consensus on forgoing life-sustaining treatment has been relatively stable for more than a decade because it reflects the balancing of important values and considerations (Kuczewski, 2002). A patient's ability to participate in the decisions regarding his or her medical care, especially as one nears death, is fostered and balanced against the duty of society and the medical profession to protect patients, especially those who are vulnerable due to lack of decisional capacity. Policy proposals that tip the balance heavily in favor of patient self-determination, such as those for legalizing assisted suicide, have met with limited success. Similarly, proposals that eschew patient autonomy in favor of the physician's duty to do no harm, such as futility policies, continue to remain outside the consensus (Helft, Siegler, and Lantos).

Second, in situations in which the content of consensus gains widely shared acceptance without direct participation by the citizenry, some sort of "proxy dialogue" might have served as a substitute for direct participation (Yankelovich, 1999, p. 167). That is, representatives of various positions and interests might achieve recognition, and their interaction might forge a position that accommodates the major values at stake. By having the process play out publicly, the solution is internalized by much of the citizenry. Furthermore, consensus is semiperformative (Moreno, p. 52).

A consensus is furthered when an announcement is made that there is a consensus on certain points. People generally do not wish to overturn consensus for its own sake. Thus, when one announces consensus and proceeds to state the specific points, people will probably prefer to assent. This assent would seem more likely to be freely given if the citizens are able to recognize their values as being respected in the points of consensus. Dissent would seem more likely to follow if the consensus is ideological in the sense that it traces all its points to only one value or principle, rather than representing the array of values that are relevant to the issues under consideration. These values may be identified *a priori* by surveying the goods generally considered characteristic of a particular sphere of human activity (Walzer, pp. 6–10), or by empirical approaches that assess the values of the community involved.

Relationships, casuistry, and pragmatism. On the most pragmatic level, communitarians often approach ethical issues by beginning with the norms of the relationships involved, rather than the rights of the individual. In this way, communitarianism provides the foundational philosophical assumptions for the customary workings of popular methods in bioethics, such as casuistry, pragmatism, and the four-principles method. Bioethics, especially clinical bioethics, has often proceeded as if a number of persons have a stake in the outcome of the case, and that dialogue and negotiation leading to consensus are better than a simple assertion of one person's rights. These practices are more easily justified within a communitarian conception of the person as being essentially related to those around him or her than on the liberal conception of the individual. However, this does not necessarily result in a tyranny of the interests of the majority, as there may be spheres of being in which individual rights are more authoritative, and irreconcilable conflicts may have to be resolved in favor of certain individuals no matter in which sphere of endeavor it takes place.

Casuists such as Albert Jonsen and Stephen Toulmin assert that that the kinds of norms that predominate in various types of cases result from the nature of the relationships involved in the particular case under examination. Cases in which the relationships are intimate are more generally decided in favor of values such as beneficence and caring. In these kinds of cases the boundaries between persons are fluid, and looking out for the good of the other is often called for by the situation. In impersonal situations, in which persons are more likely to be strangers, solutions are more often found in the direction of autonomy and individual rights. Nevertheless, specific circumstances can render these generalizations inapplicable, and some spheres of interaction (e.g., healthcare) can embody elements of both an ethics of strangers and an ethics of intimacy. As a result, paradigm cases for each kind of bioethical issue must be sought and taxonomies of paradigms and variations established (Jonsen and Toulmin, pp. 291–292).

Similarly, the famed *four principles* approach, also known as principlism, takes the physician-patient relationship as the starting point of medical ethics (Beauchamp and Childress, pp. 12–13). Principlists argue that ethical problems arise when any of the four main obligations of physicians to patients (respect for autonomy, nonmaleficence, beneficence, and justice) come into conflict with another of the principles. The goal then becomes to resolve this conflict of principles. This method assumes that members of society share a common morality, and that it is interpretable within the confines of the healthcare system (Beauchamp and Childress, pp. 401–405). These same assumptions are shared by many communitarian bioethicists. However, communitarian philosophers have made advances on the static understanding of the moral principles of the principlists. For instance, Emanuel's communitarianism includes a theory of the physician-patient relationship. This relationship, in its highest expression, focuses on helping the patient to interpret and discover his or her health-related values and how they apply to the choices before the patient (Emanuel and Emanuel). In this framework, patient autonomy is an essential element, but in many situations it is seen as the outcome of an interpersonal process rather than as the starting point of the interaction. Others with communitarian leanings focus on familial relationships as the starting point of an ethic.

Thomas Murray, a sociologist by training, argues that bioethics will make more progress toward consensus on controversial issues by starting with a tapestry of relationships that are prized by persons in a society. He notes that familial relationships are often among those that give distinctiveness to life. By creating such a tapestry, and describing the goods fostered therein, he believes that some of the so-called unending debates in bioethics can be defused. For instance, Murray asserts that conclusions in the abortion debate often exceed the premises and are inconsistent with other practices of adherents of the conclusions. Murray believes that the strength of the conclusions is probably a derivative from perceived threats to valued relationships (Murray, pp.173–174).

James and Hilde Nelson have begun the work of developing an ethics of intimate relationships that takes familial relationships as the starting point. This kind of work exemplifies the nuances of contemporary communitarian bioethics in that it results in generalizations about specific spheres of relationships. Furthermore, the kinds of generalizations that are developed give moral weight to those whose interests are most affected by situations, rather than invoking individual rights.

Applications

Radical whole-tradition communitarianism results in the most radical prescriptions, since it nullifies all rights claims and counsels a return to separate communities to work out a shared ethic. As we have seen, most communitarians have far more subtle prescriptions for facilitating the kind of public deliberation that they seek.

There are few attempts in the literature by communitarians to directly deduce conclusions from communitarian premises. One might expect that communitarians will be more sympathetic to the common good in weighing solutions to ethical problems. It is true that some communitarians have favored aggressive approaches to organ procurement for transplantation (Nelson), mandatory rationing to resolve resource-allocation problems (Callahan, 1990), and public health concerns over individual privacy and choice (Etzioni). However, none of these positions are necessarily entailed by communitarian sympathies as one can easily argue that these same policies foster values the community should reject. As a result, communitarianism continues to be an approach to bioethics that is more about process than particular outcomes.

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SEE ALSO: *Consensus, Role and Authority of; Contractarianism and Bioethics; Feminism; Healthcare Resources, Allocation* *of; Human Nature; Justice; Law and Morality; Managed Care; Natural Law; Patients' Responsibilities; Public Health: Philosophy; Sustainable Development; Virtue and Character*

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COMPASSIONATE LOVE

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Compassionate love describes attitudes toward and service for others, motivated by a desire for the good of the other. It includes caring for, valuing, and respecting the person so loved. The combination of the two words "compassionate" and "love" highlights features in both words: this combination describes sympathy towards the other, in a way that is caring, respectful, and appropriately emotionally engaged, which leads to appropriate action in service of the other person. Compassionate love can operate through the relief of suffering, but also through acknowledging life's full possibilities and making space for each human being to reach his or her potential. Compassionate love encourages fullness of life in the other. By the early twenty-first century, compassionate love was also bolstered by scientific research and incorporated into a social science model. It provides a sound concept to guide action benefiting those who are in need, in various situations. Compassionate love is a valuable quality to bring to the care of those who are sick, and would be beneficial to include in treatment, care, and decision making.

Definitional Issues

Some of the most noble human actions are those that express compassionate love. A person acting with compassionate love perceives the suffering, needs, or potential of another, and chooses to act in ways that can better the condition of the other, placing the other's needs in higher priority. There are other moments when one sets aside selfish needs for those of others, when one expresses to others, by words or actions, that they are of value. This occurs in both professional and personal relationships. To contribute to a better understanding of the concept, some definitional points are helpful. Important features of compassionate love include:

(1) free choice;
(2) some degree of cognitive understanding of the situation;
(3) some understanding of self;
(4) fundamentally valuing the other;
(5) openness and receptivity; and
(6) a response of the heart (heart is here defined as "core," where emotions and cognition integrate).

The particular nature of individual personalities, social setting, cultural setting, genetic predisposition, and other factors limit the freedom of individuals. This makes up the substrate, the basic starting situation, in which individuals begin to act with compassionate love. This starting point is different for each person, and situations in which action takes place differ as well.

The full expression of compassionate love towards those who are ill relies on appropriate motive. Although helpful behaviors are good and useful, and can contribute to the well-being of another, motives focused more on the self than on the other can decrease the positive effect on the person being served, as well as on the moral growth of the individual giving the love. There are many attitudes that can diminish motives, such that they are less likely to result in compassionate love being fully expressed. These include a variety of possible needs or wants for the self: guilt, fear, needs for love and success, fears of failure, desire to claim the upper hand, reputation. Motives are usually mixed, but when self-centered needs predominate, compassionate love cannot be fully expressed.

Research Model

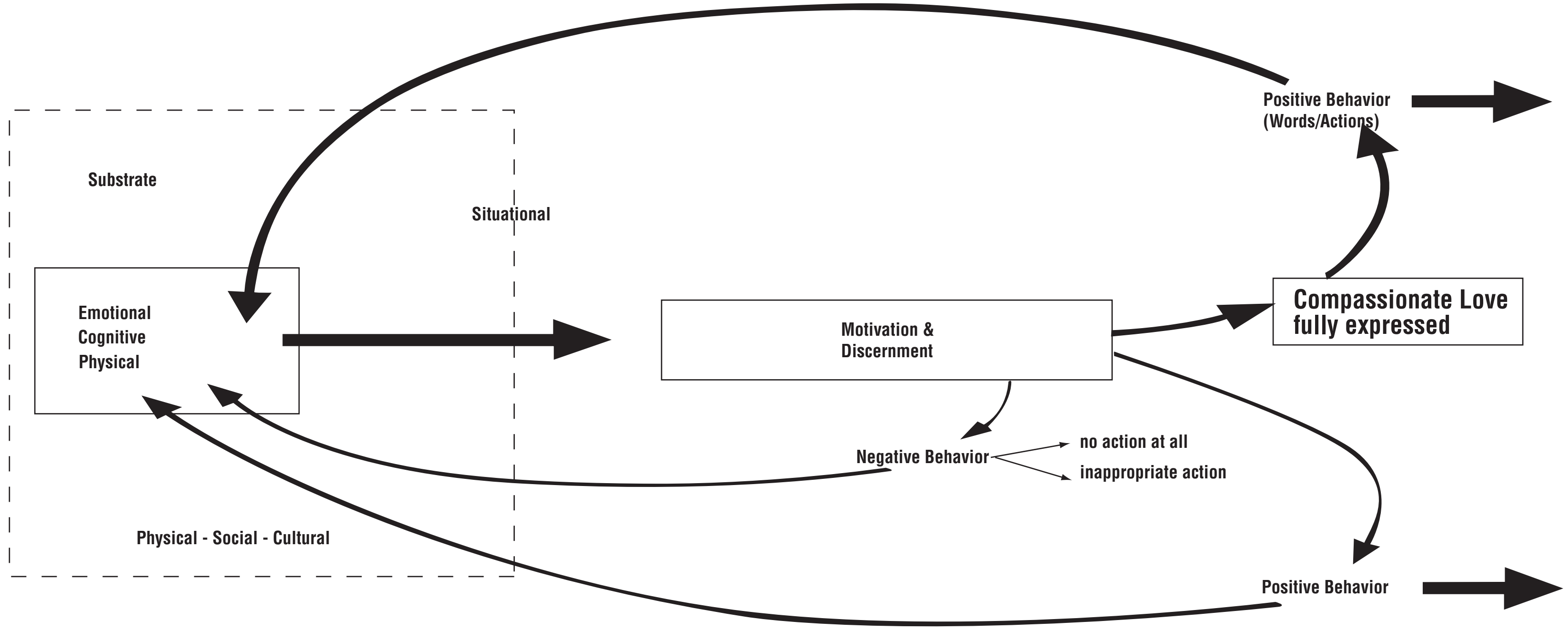
Research specifically on compassionate love is needed in order to determine how best to foster this quality in people's lives, and to assess the particular impact of this quality in the care of the sick. Results from research can help to give appropriate priority to this quality in the training of healthcare providers, and in the settings and circumstances provided for those who are sick. In order to do adequate research on compassionate love, it is important to clearly articulate the various essential components, the conditions that might foster and those that might impede its expression, and to develop methodologies for assessment. There are over fifty large research projects specifically gathering data on this topic, some in healthcare settings.

Figure 1 illustrates a research model that has shown promise in this area. It starts with the substrates discussed previously. Given those starting points, as one encounters a specific person in a specific situation, one must make a decision to act (shown centrally in the figure), and a motive drives that decision. Motive is particularly hard to research, but there are some ways to begin to investigate it, such as experimental models (especially those from economics and social psychology), implicit-explicit models, observational studies with multiple actions, insightful self-report, and neural imaging. When motives for self outweigh those for others, or there is an inappropriate action given the various factors to be considered, the result is frequently negative for the person being served. Good actions can also emerge from motives not full of compassionate love, such as the motive to look good in the eyes of others or to feel needed, but ultimately the feedback of repeating these kinds of behaviors on the moral development of the healthcare provider can be detrimental. It is also possible that the more self-centered, condescending, or less respectful motive is noticed by the sick person, and care is not as effective. These kinds of motives can also adversely affect discernment of appropriate care for the sick person.

In the center of the model is both motive and discernment. Compassionate love fully expressed is not just good intentions, but doing what is really good for the other. This kind of discernment occurs continually in healthcare settings. Short-term distress may be necessary to serve the longer-term interests of a sick person. Weighing the relative

FIGURE 1

Research Model for Expression of Compassionate Love


Positive Behavior
(Words/Actions)
Substrate
Situational
Emotional
Cognitive
Physical
Motivation &
Discernment
Compassionate Love
fully expressed
Negative Behavior
no action at all
inappropriate action
Physical - Social - Cultural
Positive Behavior

SOURCE: Underwood, 2002.

needs of others, including appropriate care for self, is also critical to good discernment leading to effective actions.

Revised "Professional Distance"

Compassionate love is not the same as romantic love, familial love, or affection, although it can accompany these other forms of love and blend with them. The professional in a healthcare setting needs to avoid becoming too attached to the patient, and compassionate love allows for this. In fact, one critical aspect of compassionate love is that it is not a "need love," the kind of love that focuses on the needs of the person giving love. In its focus on the needs of the other, compassionate love's non-attachment is very harmonious with the concept of "professional distance," but actually can be more satisfying to both the patient and healthcare provider: it enables an emotional component to be appropriately engaged, if that is called for in the specific setting.

Improving Well-Being and Health

In the United States and many other medical healthcare systems, a fee for service operating basis, or fee for time, results primarily in action from duty and obligation. However, there is leeway even within this operating system that provides opportunity to "go the extra mile for the patient," or engage in compassionate caring for the sick person.

Initial research has shown that empathy, valuing the patient, and giving the patient a sense that he or she is understood can be powerful factors in contributing to improvements in health outcomes, both through increases in adherence to regimens and more direct effects. Ongoing research is exploring whether increasing compassionate love on the part of the healthcare provider can improve patient outcomes.

It is generally acknowledged that there exists a placebo effect in medical treatments, such that placebos, usually inert substances, are included in most major clinical trials; the various constituents of this effect are currently unknown. Conditioning, optimism, improved self-efficacy, and natural regression to the mean are some of the most frequently cited mechanisms, but the role of the patient-provider relationship on outcomes is just beginning to be explored fully as a part of the placebo effect. Compassionate love is one of the components patients report as being important to them: being valued, feeling understood, feeling cared for, having a provider that goes beyond mere duty. This attitude of the healthcare provider can encourage the sick person to better adhere to medication regimes, and with a more positive attitude toward themselves, exert better efforts towards self-care and preventive measures. There may also be additional effects on health.

The therapeutic relationship is important for the person who is ill, as has long been asserted in psychotherapy. From the ill person's point of view, feeling valued, cared about, and understood is important, and this works synergistically with the actual treatment—even in treatment for physical illness. This kind of care also can contribute significantly to the well-being of the ill person in areas where health cannot be significantly improved, such as chronic progressive illness and end of life care. This is not a minor issue for healthcare in the twenty-first century context of a continually aging population, and extensive chronic diseases.

Effects on the Healthcare Provider or Administrator

As described in the model (Figure 1), various substrate factors affect the ability to give compassionate love. Supportive factors can be provided by the healthcare organizational structure, cultural setting, family, religious background, relationships, and others in the healthcare organization. Support from these sources helps to avoid the burnout problem that can occur when one's work focuses continually on those in need. Supportive elements can provide the strength needed to sustain those who care for others.

Outside of the work setting, social relationships, community involvement, family, and religious institutions encourage the healthcare provider's ability and desire to act with compassionate love. Many religions and particular social micro-cultures value this quality, and the nesting of the impetus to act within a religious or social context is useful, as it can provide an infrastructure and additional reinforcement for attitudes and actions.

One who gives compassionate love is also significantly affected by feedback from the one helped. When a good balance (see Figure 2) exists as decisions are made, and the motivation is well grounded, giving compassionate love fully can be satisfying and strengthening to the one who gives it. Feedback from patients can provide a real, positive input for this kind of work, and the ability to express this quality and engage the self more fully in care can be satisfying and add to one's own well-being. This can enable the healthcare provider or administrator to gain more joy from their job.

Compassionate Love within the Social Network

Social support can contribute positively to a person's health. Compassionate love is nested within social relationships, and it is not only the healthcare provider who improves health and quality of life, but also people within the sick person's social support network. This idea is central to providing healthcare systems and healthcare that value and nurture supportive relationships. Although material support in and of itself is important, scientific literature continually illustrates the value of emotional support. The concept of compassionate love as a contribution to quality of life and well-being can be particularly powerful, and in 2003 is being studied in a variety of social contexts, including a World Health Organization study of contributors to quality of life.

Both the giving and receiving of support can improve well-being and quality of life. Those who are sick generally do not want pity; they want others to help them and understand them and care about them, but also, unless totally incapacitated, they want to give to others, and want to feel of use. One study of pain patients conducted by Frank Keefe, Ph.D at Duke University, is examining the use of a "loving kindness meditation," a Buddhist-inspired practice that has patients dwell on compassionate love for themselves, close friends, those they have trouble with, and the whole world, to help those with pain experience less suffering. When sick people are enabled and encouraged to have good relationships with those around them, they can give to others within the constraints of their situation and this can be an additional positive outcome.

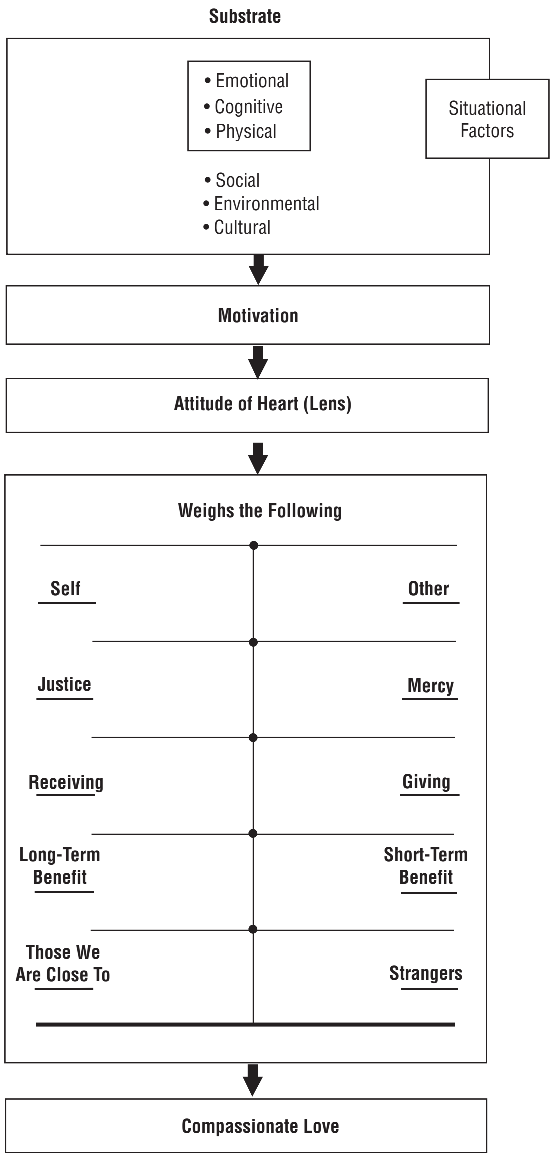
Making Healthcare Decisions

During a National Institutes of Health conference with the goal of setting a research agenda for end of life care in November of 2001, the physicians and nurses involved in care for patients and their families, the qualitative researchers, the economists, and those representing hospice and nursing homes identified a central theme: the importance of what the patient values, and what society values, as decisions needed to be made. Compassionate love, which includes valuing the other fully, action and attitude driven by other-centered motivations, and clear discernment as to the most caring action, can effectively guide healthcare decisions and policies. In a study of over four thousand people from various cultures and religions worldwide, conducted by the World Health Organization, and presented by Kate O'Connell at the International Quality of Life meeting in Amsterdam in November of 2001, it was found that issues of being loved, cared for, and accepted contribute significantly to overall qualtiy of life, over and above basic health indicators.

Compassionate love requires that decisions be considered through a lens that views the other as having significant value. Decision-making based in compassionate love also can include various more consciously-articulated ways of weighing competing factors (Figure 2). For example, the immediate desires of the patient may not be in the patient's long term interest, and therefore immediate relief of suffering is not always the most compassionately loving act. Decision-making that incorporates these qualities and complexities into the process can result in better decisions for both the cared-for and the caregiver. By including compassionate love in decision-making, the caregiver can better address the needs of the patient and enable a fuller expression of the humanity of the healthcare provider.

FIGURE 2

Balanced Decision-making



SOURCE: Underwood, 2002.

Conclusion

As a guide for action in healthcare settings, compassionate love can lift the care of the sick from a duty to be carried out to satisfying caring with joy. Attitudes toward and care for those who are ill are enriched by taking a respectful, caring, understanding approach that values each individual. The sick person can benefit substantially from this, and various social and behavioral sciences are contributing to a body of literature demonstrating how compassionate love positively affects health. Structural changes in healthcare environments and payment models need to adopt the value of compassionate love in order to improve care.

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SEE ALSO: *Buddhism, Bioethics in; Care; Emotions; Feminism; Hinduism, Bioethics in; Human Dignity; Human Nature; Medical Codes and Oaths; Narrative; Responsibility; Transhumanism and Posthumanism; Virtue and Character*

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COMPETENCE

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Competence is a necessary condition before a physician can accept a patient's treatment consent or refusal. Competence confers decision-making authority on those who are competent, while disenfranchising those who are not (Beauchamp). A determination of patient competence promotes respect for self-determination as well as patient participation in healthcare and other decision making. In most nonemergency situations, those who are legally competent may consent to or refuse healthcare. A patient maintained for years on outpatient hemodialysis, for example, may be allowed to terminate hemodialysis, resulting in death, if the patient decides that he or she can no longer tolerate the stress of the procedure (Neu and Kjellstrand). And based upon religious reasons, a Jehovah's Witness may even refuse a blood transfusion that would otherwise save his or her life. In contrast, the consent or refusal of those who are legally incompetent or clinically incapacitated need not be respected. A psychotic woman who refuses to have a cardiac pacemaker inserted because she believes that others could then monitor and control her activities would not be permitted to refuse this lifesustaining surgical procedure. Competence is usually not a relevant issue in healthcare emergencies, when treatment delay would be substantially harmful to the patient.

Competence and autonomy are often conflated, although their meanings are quite distinguishable (Beauchamp). Competence allows a person to exercise his or her autonomy. One must be autonomous to be competent, yet competent persons may act nonautonomously when, for example, compelled to do so by another person. Further, an autonomous person may act incompetently (e.g., a professional negligent at work).

This entry considers some of the issues in defining, determining, and assessing competence, as well as some of the applications of competence to the field of mental healthcare.

Definitions

Generically, "competence" means simply the ability to perform a particular task (Beauchamp), although it has often been used loosely in several senses. In healthcare contexts, competence is the capacity to make autonomous healthcare decisions (Morreim). In most accounts of competence, competence is specific to the task or issue, since a person may be able to perform one task but not another. Few people are globally competent or incompetent. Since one's abilities change over time, in either direction, competence is also specific to time. Abilities may also be a function of the conditions or the situation in which they are tested or the person who tests them.

Competencies, of course, relate to all areas of function (Grisso). While competence to consent to healthcare or research is of primary concern in the present context, issues are often raised about a person's ability to work, manage personal finances, make a contract, write a will, live independently, drive a car, marry and divorce, parent a child, or testify in court. In legal contexts, competence questions arise in civil actions as well as in criminal litigation (competence to stand trial, commit a crime, enter a plea, or be sentenced) (Bonnie). Legal competencies implicate past decision making (e.g., competence to write a will), present decision making (e.g., competence to stand trial), or future decision making (e.g., competence to manage one's financial affairs).

A person's competence may be questioned in more than one area. In the case of a mother with cancer and a psychotic depressive disorder who is separated from her husband, for example, questions may arise about her capacity to parent her children, manage her finances, and consent to medical or psychiatric care. If she were employed, questions may arise about her ability to function at work if she failed to meet deadlines or otherwise fulfill her job duties due to a medical or psychiatric disorder. Her or her husband's attorney may question her ability to consult with her attorney and participate in the divorce litigation.

This contextualized, decision-specific notion of competence may be contrasted with a more generalized conception that reflects the general legal and moral autonomy enjoyed by most adults in contemporary Western cultures (Wear). Many more adults are considered competent under the general conception than the task-specific one; therefore, establishing that a person is incompetent is more difficult under the former than the latter.

"Incompetence" has come to mean the loss in court of a person's legal right to function in some particular area. Such a narrow legal definition of competence or incompetence contrasts with the more common clinical use of incompetence according to which a person has a legal right to function but is unable to do so. Clinical and legal competence may not correspond. An elderly, demented person, for example, may have the legal right to drive a car or make his or her own healthcare decisions but may no longer be substantially able to do so. Similarly, an adolescent may not be legally competent to consent to healthcare but may be clinically or functionally able to do so.

The increasingly prevalent view is that individuals have various specific abilities or capacities as well as incapacities, each along a continuum. A person is considered incapacitated when the person is no longer able to perform that specific function and incompetent when a court has so ruled. Legally, there is a presumption of competence, which may be overcome when the court is presented with adequate evidence of incapacitation. In the clinical literature, however, competence refers either to an individual's capacities (a descriptive definition) or to whether that individual's particular capacities are sufficient to render legal decision-making authority to him or her (a threshold definition).

Finally, although competence usually refers to a person's abilities, it may also refer to his or her actions or behavior (Beauchamp). For example, a person of general competence may autonomously choose to act incompetently in a given situation (e.g., intentionally fail an examination).

Managing Incompetence

Because functional or decision-making capacities occur on a continuum and because a person's capacities can be expected to fluctuate over time, in most cases a clinician need not be resigned to accept a patient as permanently incapacitated. The clinician frequently has opportunities to enhance the person's functional or decision-making capacity. Hearing aids, eyeglasses, psychotropic medication, counseling and psychotherapy, and specific behavioral training in the area of incapacity are examples of remedial efforts that can be made to improve a person's capacity. When such efforts fail, disposition of those who are incapacitated is a complex matter and varies with the context in question. In a case where life-saving treatment may be needed, the clinician may have to obtain an adjudication of legal incompetence in order to treat an incompetent refusing patient.

Although competence is a necessary precondition to respecting patient choice, incompetence is not a sufficient condition to overriding it, contrary to much clinical and lay understanding. The clinician may wish to, and often should, respect a person's preferences even if the person is legally incompetent or functionally incapacitated. The clinician may ask a young boy with which parent he prefers to live following his parents' divorce; the clinician probably will ask an elderly, demented woman whom she prefers to manage her estate should the appointment of a legal guardian be authorized.

Before intervening over the person's objection, the clinician needs to specifically assess the risks, benefits, and alternatives; this includes an evaluation of the potential harms of a proposed intervention to the person. Overriding treatment refusals, whether by a healthcare professional, family member, or court, ethically and legally requires evidence that (1) such treatment would benefit the patient (the "best interests" test); (2) such treatment would have been the decision of the patient had he or she been able to make the decision (the "substituted judgment" test); or (3) the patient had provided some previous direction or instruction about the treatment in question ("expressed interest" test). The test of substitute decision making varies with the decision, the decision maker, and the legal jurisdiction. Use of the substituted-judgment or the expressed interest test, in contrast to the best-interests test, better respects the person's autonomy and self-determination.

Competence Criteria

There is no international clinical, legal, philosophical, or ethical consensus about competence criteria or standards, and many are in use. In other words, there is no agreement about the threshold of decision-making or functional capacity necessary to consider a person legally or morally competent. In a given case, there may be wide consensus among clinicians, legal professionals, and ethicists that a particular person is, or is not, competent in some respect; however, disagreement is likely in many cases. In part, this derives from the fact that competence determinations are not essentially factual, objective, or empirical matters but rather are value-laden judgments about the relative importance of autonomy and beneficence to the person, as assessed by the clinician or others. Competence is typically inferred from the person's behavior and thinking rather than observed directly, and evaluators may differ in their judgment of the person's competence. Such differences about the person's competence occur in part due to evaluators' varying perceptions of the person's values or of the person's rationality. Under the most common view, competence is not a fixed property of an individual applicable to all decisions and all potential risks; rather, competence is a context-dependent, decision-specific, interpersonal process (Buchanan and Brock; Drane).

Criteria for competence involve whether the person can make a choice, communicate that choice, understand relevant information about the choice and its alternatives, and rationally manipulate information about the choice and its alternatives (Appelbaum and Grisso). The person must be able to apply the relevant information about a prospective decision to his or her own case rather than in the abstract or as applied to someone else.

The influential U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research adopted a standard of capacity that requires (1) possession of a set of values and goals; (2) the ability to communicate and to understand information; and (3) the ability to reason and to deliberate about one's choices (U.S. President's Commission). This standard emphasizes the process of reasoning or decision making rather than the particular outcome of the decision. A competence standard that focuses upon the outcome of the decision can be faulted for granting greater priority to the values of the person assessing the patient's competence than to the values of the patient.

A similar definition of competence is offered by the Canadian province of Ontario: "Mentally competent means having the ability to understand the subject-matter in respect of which consent is requested and able to appreciate the consequences of giving or withholding consent" (Ontario Ministry of Health). This "appreciation" component, however, involves emotional rather than strictly cognitive considerations, and broadens the competence standard.

As noted by the U.S. President's Commission, assessment of the individual's current and previous personal values is an essential component of evaluating competence. Obtaining a values history for the individual provides critical information about the person's past major life decisions relevant to the present decision making. Judgments about a person's competence must be individualized according to his or her attitudes and values history rather than reflect only the person's knowledge, skills, and cognitive capacities.

It is unrealistic to expect that competence criteria are, or will remain, fixed over time. Competence criteria are likely to evolve as society seeks to resolve the conflict between the competing principles of respect for autonomy and concern for the person's well-being.

SLIDING SCALE OF COMPETENCE CRITERIA. The predominant approach to selecting competence criteria, at least with regard to competence to consent to healthcare, depends on the actual decision at issue. In this scheme, named the "sliding scale," the criteria for competence vary with the particular decision and its risks and benefits. As the risks of the proposed healthcare increase or as the benefits to the proposed healthcare decrease, more capacity is required for the patient to be considered competent to consent to the healthcare (Drane; Roth et al.). For example, it is less difficult to decide to consent to a course of conventional antibiotic medication for a urinary tract infection than a course of experimental chemotherapy for stomach cancer, and less capacity should be required to do so. Likewise, more capacity is required for the patient to be considered competent to refuse healthcare when its risks decrease or its benefits increase.

Although the sliding-scale approach to competence criteria is commonly used in healthcare decision making, some problems accompany its use. Given the strong bias of healthcare professionals—and society—in favor of treatment, one concern is that professionals will manipulate or selectively use those competence criteria that result in labeling competent someone who consents to healthcare, while labeling incompetent someone who refuses care. Another concern of the variable standard approach is that, counterintuitively, a patient could be considered competent to consent to a particular intervention but incompetent to refuse that same intervention (Buchanan and Brock). This may occur because refusing healthcare is more complicated than consenting to it, but here too a protreatment bias is evident.

Competence Assessments

Clinicians frequently make informal judgments about a patient's competence in their daily work; but some cases, such as treatment refusals or consents by questionably competent patients, necessitate formal, detailed assessments. Competence assessments should focus on the specific area of function in question. Assessments of global or general competence are unlikely to adequately respond to the presenting question. Among the procedural considerations in conducting competence assessments, the time and place of examination and the need for reexamination are especially important (Weiner and Wettstein). These assessments sometimes use written structured or formal assessment inventories of functioning, observational functional assessments (e.g., observing a patient grocery shopping and preparing a meal), psychological testing, or formal psychiatric interviews. History taking and collateral reports from third-party informants such as family, friends, and other healthcare personnel can be valuable additions to individual contact with the person being assessed. The examiner pays particular attention to eliciting information about the patient's decision-making history and the values he or she has placed on personal autonomy, healthcare, disability, and death. Consultations with colleagues or second opinions may also be helpful to the examiner in difficult cases. In general medical hospitals, competence assessments are conducted initially by nonpsychiatric physicians; if necessary, psychiatric consultants are called to assist in the evaluation.

Competence assessments raise many problematic clinical issues including denial of illness; subtle forms of incapacity; impact of elevated or depressed mood on decision-making capacity; fluctuating mental status (due to intermittent treatment compliance, the natural course of the disorder, or side effects of treatment); treatment refusals based on religious reasons; lack of information about the patient, including personal values and goals or history of treatment refusals; lack of formal staff training to do competence assessments; and disagreements among staff about the appropriate competence criteria or threshold. Typically, competence is not challenged, investigated, or formally assessed in clinical practice until a patient refuses treatment or is noncompliant with it.

Competence and Mental Healthcare

The presence of a mental disorder does not automatically negate the presumption of a person's competence. Although some severely mental ill persons are indeed incapacitated in many areas of their functioning, most mentally ill persons have only some discrete areas of decision-making incapacity, often confined to episodes of their illness. A paranoid delusional patient who denies that he is mentally ill, for example, may be unable to rationally decide whether or not to consent to antipsychotic medication while he is mentally ill but may have adequate decision-making ability to consent to treatment for diabetes and heart disease. In such a case, the content of the patient's paranoid delusions would be irrelevant to the patient's diabetes and heart disease, and the patient would not deny the fact of his medical illnesses. A patient in a manic episode may be unable to manage his finances because he will rapidly dissipate them, but his decision-making capacity will return as the episode ends. Subtle forms of decision-making incapacity can also arise from mildly altered mood states (depression, hopelessness, anxiety, euphoria), from cognitive dysfunction (impairment in memory or attention from head injury), or from personality traits (guilt, self-punishment, feelings of worthlessness).

COMPETENCE TO REFUSE PSYCHOTROPIC MEDICATION. In contrast to admission to a medical-surgical hospital, admission to a psychiatric hospital may be accomplished by voluntary or involuntary means. In either facility, however, there may be uncertainty about the patient's ability to consent to voluntary hospitalization. Patients who are demented or seriously depressed or psychotic often have difficulty understanding that they are ill, need treatment, or should be hospitalized. They may have difficulty comprehending the risks and benefits of treatment and hospitalization. Nevertheless, decisions about the person's ability to consent to voluntary hospitalization precede, and differ from, decisions about the person's ability, once hospitalized, to consent to treatment with medication.

Managing a person's refusal of psychotropic medication (e.g., antipsychotic or antidepressant medication), once he or she has been hospitalized, has been one of the most controversial issues in mental healthcare in recent years. Before the 1980s, many rejected the notion of a psychiatric patient's right to refuse medication, suggesting that the purpose of psychiatric hospitalization would be defeated if patients were permitted to refuse treatment with medication (Appelbaum, 1988). In part, the controversy about involuntary treatment of psychiatric inpatients with medication arose from the nature and effects of psychotropic medication. Psychotropic medications have been viewed somewhat inaccurately as powerful and dangerous substances whose use is akin to "mind control." Their risks, whether short-term dry mouth and constipation or long-term involuntary movement disorders, relative to their benefits, the treatment of the mental disorder, have been greatly exaggerated, at least by many attorneys and courts (Gutheil and Appelbaum).

Once patients enter psychiatric hospitals, especially on an involuntary basis by court order, they sometimes refuse recommended treatment with psychotropic medication, particularly antipsychotic medication. Patients refuse treatment based on problems in the physician-patient relationship, such as rebelliousness towards authority figures and reality-based side effects of medication (e.g., dry mouth, constipation, weight gain, restlessness), or most relevant in the present context, symptoms of the patient's illness, such as a delusional belief that the medication is poison. Decisions about hospitalizing a person involuntarily differ from those about medicating that person involuntarily once hospitalized; the former are largely a function of the person's future risk of violence to self or others due to a mental disorder, while the latter usually depend upon the person's ability to make decisions about accepting medication or his or her best interests. An involuntarily hospitalized patient, even one committed by a court, is not necessarily deemed unable to consent to medication. In most cases, a person who has been involuntarily hospitalized does not lose the legal right to object to or to refuse medication.

Voluntarily hospitalized patients who refuse medication for whatever reason may not be medicated involuntarily, except briefly in emergency situations. It is argued that patient autonomy regarding treatment refusal should be respected despite the consequences of continued illness, hospitalization, and incapacity. This legal right to refuse medication is based on the patient's right to free speech and thought, to freedom from bodily intrusion, the right to bodily integrity, a ban on cruel punishment, and the right to autonomy and self-determination.

Nevertheless, involuntarily hospitalized patients who refuse medication may sometimes be medicated involuntarily in nonemergency situations, as well as briefly in emergencies. Many states in the United States use a judicial model for these cases in which forced medication of involuntarily hospitalized patients may be accomplished only after a judicial hearing and court determination that the patient is incompetent to refuse the mediation because of the mental illness (Weiner and Wettstein). A substitute decision maker is sometimes appointed by the court to determine whether the patient should be compelled to take medication. This is the same procedure that would be followed if the physician sought involuntary surgery (e.g., amputation of a gangrenous extremity) on the patient. In contrast, in some U.S. states and in some Canadian provinces, the attending physician or a medical or administrative review panel decides whether or not to override the patient's refusal; the patient may then appeal the physician or panel's decision to involuntarily medicate to a court (Weiner and Wettstein; Ontario

Ministry of Health). In England, the Mental Health Act of 1983 permits the treating physician to authorize medication for up to three months to an incompetently refusing, involuntarily hospitalized patient (section 56); after that, a second physician opinion is needed to continue the involuntary treatment (section 58) (Appelbaum, 1985). In this nonjudicial model, the patient's decision-making capacity about medication as assessed by the attending physician may still be the most important factor in the disposition of the case. However, the U.S. Supreme Court has held that decision-making capacity is not relevant to determining whether prisoners should be medicated involuntarily with psychotropic drugs (*Washington v. Harper*).

According to empirical data about the right to refuse psychotropic medication, the judicial-review model, using a formal incompetence declaration, carries substantial fiscal costs, given the delays inherent in obtaining the required court hearing. It also involves prolonged periods of nontreatment pending the hearing, which often results in injuries to the patient, other patients, and staff (Ciccone et al.; Hoge et al.). Few courts ultimately grant the patient a right to refuse medication.

COMPETENCE FOR EXECUTION. According to U.S. law civil or criminal litigants must be legally competent before they can bring suit or have suit brought against them. In criminal law, defendants must be competent to stand trial, plead guilty, be sentenced, or be executed before those proceedings can occur.

Executing a person who is considered incompetent (i.e., "insane") at the time of execution, as opposed to at the time of the crime, has been ruled unconstitutional by the U.S. Supreme Court (*Ford* v. *Wainwright*). Execution in such cases offends humanity, has no deterrent value to others, and offers no retribution to the condemned person. The courts, however, have yet to articulate a competence standard by which to adjudicate a death-row inmate as incompetent (Winick).

The courts have not yet decided whether, once death-row inmates have been found incompetent, the state may involuntarily medicate them to restore competence and then execute them (*Louisiana* v. *Perry*). Such an eventuality places the treating psychiatrist, who ethically must not participate in an execution, in a difficult dilemma: Medicate the inmate to relieve suffering, which leads to the inmate's death, or do not medicate the inmate, which spares the inmate's life but fails to reduce suffering (Heilbrun et al.). Only automatic commutation of an incompetent death-row inmate to life in prison would definitively resolve the matter.

Conclusion

Whether in healthcare, financial, legal, or any other area of decision making, the stakes for both persons and professionals in competence definitions are substantial. Identifying and labeling someone as incompetent can be stigmatizing and deprives the person of self-determination. Legal and healthcare delivery systems are then confronted with, and disrupted by, the need for surrogate decision making for the incapacitated or incompetent person. On the other hand, failure to protect the incapacitated person from making erroneous and harmful decisions (e.g., refusing necessary medical care) may not honor the person's best interests. The question then is when and how to respect people's choices and maximize their decision-making autonomy while protecting them from their own harmful choices (Drane). In most cases in the healthcare system, clinicians agree that the person should, or should not, be considered competent, even if there is no universal consensus on how much rationality and understanding are sufficient for the person to be considered legally competent and granted authority to decide for him- or herself. Still, there are other cases in which judgments about the person's decision-making capacity are problematic, and clinicians, administrators, patients, families, and the courts become involved in emotionally charged disputes about how to manage the person's medical care. Such cases are unlikely to abate in the future as long as our society continues to value, and attempts to balance, autonomy and beneficence.

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SEE ALSO: *Advance Directives and Advance Care Planning; Aging and the Aged: Healthcare and Research Issues; Autonomy; Informed Consent; Law and Bioethics; Mental Illness; Patients' Rights; Pediatrics, Adolescents; Professional-Patient Relationship; Research Policy: Subjects; Responsibility; Sexism; Surrogate Decision-Making*

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CONFIDENTIALITY

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Confidentiality has its roots in the human practice of sharing and keeping secrets (Bok). For children, the desire to keep a secret is a manifestation of an emerging sense of self; the desire to share a secret stems from a need to retain or establish intimate relationships with others (Ekstein and Caruth). The willingness to share secrets presupposes an implicit trust or an explicit promise that they will be dept. Keeping and sharing secrets is a more complex social practice among adults. Some adults keep secrets simply to preserve their personal privacy; others may have something illegal or immoral to hide. Some persons do not reveal private thoughts, feelings, or behavior for fear of embarrassment, exploitation, stigmatization, or discrimination. Still others feel a need to disclose secrets to others to help resolve emotional conflicts or seek solutions to problems arising out of interpersonal relationships. The sharing and keeping of secrets among friends, for instance, creates a context in which ethical issues concerning promises, trust, loyalty, and interests of others may come into conflict. For example, I may promise a friend to keep a secret that she feels an urgent need to tell me. She trusts me not to tell anyone else about her revelation. Out of loyalty to my friend, I promise in advance to keep her secret. But I am thrown into a moral conflict when she unexpectedly discloses her impulse and plan to kill a family member who she believes is plotting against her. I realize that my obligations to keep my promise and preserve loyalty and trust conflict with a desire, if not a responsibility, to prevent my friend's harm to herself as well as serious harm to another. Do I preserve confidentiality or protect others? Similar ethical conflicts arise for health professionals and their clients or patients.

The following discussion clarifies the concept of confidentiality and the related ideas of privacy and privileged communication in healthcare settings. The rights of clients/patients and the responsibilities of health professionals to their clients, their professions, and society bring out key ethical issues. Legal regulations both protect and limit confidentiality, sometimes in ways that create ethical conflicts for clients as well as professionals. In healthcare contexts neither absolute protection nor total abandonment of confidentiality is plausible. Yet sometimes it is uncertain where boundaries should be drawn because legitimate interests come into conflict. Personal privacy, professional integrity, effective care, economic considerations, and public health and safety influence both general policies and specific practices concerning confidentiality.

Conceptual Analysis

Confidentiality is closely related to the broad concept of privacy and the narrower concept of privileged communications. All three concepts share the idea of limiting access of others in certain respects (Gavison; Allen). Privacy refers to limiting access of others to one's body or mind, such as through physical contact or disclosure of thoughts or feelings. The idea of limited access describes privacy in a neutral way. But privacy is closely linked to normative values. Privacy is usually thought to be good; it is something that individuals typically desire to preserve, protect, and control. Thus privacy and a right to privacy are sometimes not clearly distinguished. In law and ethics "privacy" usually refers to privacy rights as well as limited access. Thus, privacy in law is linked to freedom from intrusion by the state or third persons. It may designate a domain of personal decision, usually about important matters such as personal associations, abortion, or bodily integrity.

Confidentiality concerns the communication of private and personal information from one person to another where it is expected that the recipient of the information, such as a health professional, will not ordinarily disclose the confidential information to third persons. In other words, other persons, unless properly authorized, have limited access to confidential information. Confidentiality, like privacy, is valued because it protects individual preferences and rights.

Privileged communications are those confidential communications that the law protects against disclosure in legal settings. Once again, others have limited access to confidential information. A person who has disclosed private information to a spouse or certain professionals (doctor, lawyer, priest, psychotherapist) may restrict his or her testimony in a legal context, subject to certain exceptions (Smith-Bell and Winslade; Weiner and Wettstein).

Privacy and confidentiality are alike in that each stands as a polar opposite to the idea of "public": what is private and confidential is not public. Yet privacy and confidentiality are not the same. Privacy can refer to singular features of persons, such as privacy of thoughts, feelings, or fantasies. Confidentiality always refers to relational contexts involving two or more persons. Privacy can also refer to relational contexts, such as privacy of personal associations or private records. Thus, in this respect the concepts overlap. In many relational contexts the terms "privacy" and "confidentiality" are used interchangeably and sometimes loosely. Professional codes of ethics, for example, often use these terms in this way (Winslade and Ross).

It should be noted, however, that privacy and confidentiality are significantly different in one important respect. Relinquishing personal privacy is a precondition for establishing confidentiality. Confidentiality requires a relationship of at least two persons, one of whom exposes or discloses private data to the other. An expectation of confidentiality arises out of a special relationship between the parties created by their respective roles (doctor-patient, lawyer-client) or by an explicit promise. Confidentiality, as with its linguistic origins (*con* and *fides:* with fidelity), assumes a relationship based on trust or fidelity< Between strangers there is no expectation of trust. Privacy is given up because confidentiality is assured; unauthorized persons are excluded.

Yet confidentiality does not flow simply from the fact that personal or private information is divulged to another. If persons choose to announce their sexual preferences in street-corner speeches, in books, or on billboards, this information, though private in its origin, is not confidential. Confidentiality depends not only on the information, but also on the context of the disclosure as well as on the relationship between the discloser and the recipient of the information. Confidentiality applies to personal, sensitive, sometimes potentially harmful or embarrassing private information disclosed within the confines of a special relationship. It should be noted, however, that the disclosure of private information from client to professional is one-way, unlike other interpersonal confidentiality contexts (Winslade and Ross).

Rights of Patients/Clients

When clients enter into a healthcare relationship, they relinquish some personal privacy in permitting physical examinations, taking tests, or giving social and medical histories. Usually this information is documented in a medical record, often stored electronically and held by the health professional or an institution. In exchange for the loss of privacy, clients expect and are promised some degree of confidentiality. In general, all personal medical information is confidential unless the client requests disclosure to third parties or a specific exception permits or requires disclosure. For example, clients may request disclosure to obtain insurance coverage or permit disclosure to a scientific researcher. The law requires health professionals to report certain infectious diseases to public-health departments or to report suspected child abuse to appropriate agencies. Unilateral disclosure of otherwise confidential information to third parties by health professionals or institutions is unethical unless it is authorized by the client or by law.

In the United States and other Western societies, the values of privacy, confidentiality, and privileged communications are closely tied to the values of personal rights and self-determination. These rights include freedom from the intrusion of others into one's private life, thoughts, conduct, or relationships. Interest in protection of personal rights has grown in response to public and private surveillance of individuals through the use of data bases to collect, store, and transmit information about individuals (Flaherty). In the United States the ideas of privacy and confidentiality have generated much legal and philosophical scholarship, influenced important judicial decisions, and prompted federal and state legislation (Winslade and Ross). The legal doctrine and ethical ideal of informed consent in healthcare reinforces the importance of personal autonomy (Beauchamp and Childress). The right to informed consent, applied specifically to confidentiality, gives patients/clients the right to control disclosure of confidential information. Other countries with less individualistic traditions do not place such high ethical value on privacy or personal rights. Even persons in cultures where privacy is not a prominent value can be harmed, however, by revelations of personal information (Macklin).

Traditional ethical theories can be interpreted to provide additional support for the values of privacy and confidentiality. Deontology stresses the rights of persons and the duties of others to respect persons as ends in themselves, to respect especially their personal rights. To the extent that the social practices tied to privacy and confidentiality enhance the welfare of all, utilitarianism may also be invoked on behalf of individuals. Virtue theory advocates personal moral aspiration and achievement. Privacy and confidentiality provide a context and an opportunity for cultivation of virtues without outside interference.

Despite the value of privacy and confidentiality to individuals, however, other values—such as collective need for information or public health and safety—limit individual rights. Confidentiality conflicts often arise about information contained in medical records. Clients usually want information to remain confidential. Others—such as employers, insurers, family members, researchers, and litigants—exert pressure to limit confidentiality and to gain access to personal information. Health professionals are often pulled in both directions by their professional loyalty to patients/clients and their broader social responsibilities.

Responsibilities of Health Professionals

The responsibilities of health professionals, as articulated in codes of professional ethics, reinforce the value of confidentiality. For example, the Hippocratic oath states:

> What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about. (see Appendix)

Modern codes of professional ethics, like the Principles of Ethics of the American Medical Association, instruct physicians to "safeguard patient confidences within the constraints of the law" (see Appendix). Similarly, ethics codes for psychotherapists, nurses, and other allied health professionals make general, though not always coherent, reference to protection of professional-client confidentiality (Winslade and Ross). The American Psychiatric Association, however, has also issued detailed official Guidelines on Confidentiality pertaining to special situations, records, special settings, and the legal process (Committee on Confidentiality). The American Bar Association has offered a handbook, *AIDS/HIV and Confidentiality Model Policy and*

Procedures, that addresses the value of confidentiality, consent to disclosures, third-party access to information, and penalties for unauthorized disclosures (Rennert). The Council on Ethical and Judicial Affairs of the American Medical Association (1992) outlines the scope and value of confidentiality and addresses in detail confidentiality in the context of computerized medical records. These documents stress individual rights and specify professional responsibilities concerning confidentiality.

Despite the explicit attention given to confidentiality in oaths and codes, practical ethical problems arise, occasionally causing heated controversy. For instance, in 1991 an authorized biography of the deceased poet Anne Sexton relied in part upon audiotapes of psychotherapy sessions. One of Sexton's psychiatrists permitted the biographer to listen to some 300 hours of psychotherapy tapes. Prior to the publication of the biography, a front-page story in the *New York Times* about the disclosure of the tapes to the biographer generated a furious ethical debate. On the one hand, some critics believed that release of the tapes violated the deceased patient's privacy. Others pointed out the harm to surviving family members. Still others stressed the duty of the psychiatrist not to reveal anything about the content of therapy. Unless the therapist was required by law to release the information on the tapes, these critics argued, confidentiality should have been preserved. On the other hand, the psychiatrist claimed that his duty was primarily to protect his patient's interests—including her interest in self-revelation, in being understood, and in helping others. The psychiatrist believed that the patient, when competent, had specifically authorized him to use his own best judgment about what to do with the tapes. He also believed that he should cooperate with the request of the patient's literary executor—her daughter—to help make the biography accurate and complete. None of the relevant ethics codes sufficiently clarified or specifically addressed a case of this kind. Although charges were brought that the psychiatrist violated the code of ethics of the American Psychiatric Association, eventually a decision was reached that no ethics violation occurred. But a still-unsettled controversy swirls around these issues.

Professionals are often more aware of confidentiality issues than patients or clients. Professionals realize that privacy and confidentiality may give way to the institutional, governmental, and other third-party pressures for specific information about patients or clients. Health professionals desire to protect the integrity and special value of the professional-client relationship itself. Confidentiality is one basis of professionals' reciprocity with clients who reveal private information. (Other aspects of reciprocity include the clients' payment for the professionals' services in response to the professionals' expertise to meet the clients' needs.)

It should be emphasized that the primary justification for confidentiality is derived from the individual rights of clients and is supplemented by the responsibilities of professionals and the benefits of the healthcare relationship. This is why the client, rather than the health professional, determines what information is to remain confidential. Except where laws or other rules limit clients' rights to confidentiality, the client may not only request but require professionals to disclose otherwise confidential information. It is, after all, the client's private information that has been revealed to the professional.

Some recent critics, including feminist theorists, have questioned the adequacy of rights-based approaches. They argue that an ethics of care or caring must take account of a web of relationships, emotions, and values that include but go beyond individual rights. A care-based ethics stresses the interactive relationships, not only of patients and clinicians, but also families and society. Within the context of caring, humans—especially those who experience special suffering or discrimination—need more than just protection of their legal rights. In the specific context of privacy and confidentiality in medical genetics, for example, an ethics of care rather than rights may better explain the moral reasoning of geneticists (Wertz and Fletcher). This is discussed further in the later section on genetic and other medical screening.

Other critics think that the preservation of confidentiality should take priority over clients' and professionals' autonomy. This idea is based on the idea that total confidentiality is essential to protect both the integrity and the effectiveness of the professional-client relationship. No third parties should ever be permitted to penetrate the boundaries of a protected professional relationship. Neither the client nor the professional, according to this view, should be required or even permitted to disclose confidential information. Something close to this extreme position was considered but rejected by the California Supreme Court in *Lifshutz* (1970). Neither professional organizations nor their ethics codes endorse this idea, but it does highlight the importance that can be ascribed to confidentiality.

Even if the ideal of complete confidentiality cannot be justified in theory, it can sometimes be achieved in practice. A dyadic, exclusive relationship between client and health professional can sometimes fully preserve confidentiality. For example, a client establishes a relationship with a psychotherapist to explore the meaning of a significant personal loss. The client may not want others to know about the consultation. It is nobody else's business.

The therapist's office may have a separate entrance and exit to decrease the likelihood that clients will encounter each other. The therapist may answer personally all phone calls. The therapist may keep no client-specific records and take no notes. The client may pay cash, not file a claim for insurance coverage, explicitly request that all discussions be kept confidential, and take other precautions to prevent others from learning even that the relationship with the therapist exists at all. The client reveals his or her feelings, fantasies, thoughts, or dreams only to the therapist, who seeks to understand and help interpret their meaning only to the client.

If client confidentiality and professional secrecy were always as unambiguous as the foregoing scenario, there would be little more to say. However, professionals as well as clients have widely divergent attitudes, beliefs, expectations, and values concerning confidentiality (Wettstein). A few professionals espouse the absolute value of confidentiality in dyadic therapeutic relationships while many others acknowledge only its limited and relative value. Others lament the declining value of confidentiality while accepting the encroachment of legal, economic, public-health and safety, or research interests. A few others view confidentiality as an inflated value that some professionals or clients use as a shield to conceal fraud, malpractice, or even criminal activity.

Rather than a simple dyadic relationship, a more complex, polycentric model is necessary to capture the nuances of confidentiality in healthcare. Clients, health professionals, and third parties may have varying claims on ethical grounds to protection of or access to confidential information. Clients may waive their rights to confidentiality to obtain other benefits such as insurance coverage or employment. Professionals may discern a conflict between ethical obligations to their clients and legally required reports. Third parties may have a legitimate need to know otherwise confidential information to assess quality of healthcare services, uncover fraud, or determine appropriate allocations of healthcare resources. Loss of confidentiality may result not only from ethical, legal, or economic factors, but also because of client ignorance or misunderstanding, professional or institutional carelessness, or third-party overreaching. The interplay of those various factors can best be understood by examining in more detail selected problem areas where confidentiality comes into conflict with competing ethical and social interests.

AIDS

The acquired immunodeficiency syndrome (AIDS) epidemic brings with it a full range of confidentiality issues. Patients who think that they might be HIV-positive are reluctant to be tested for fear that disclosure of such sensitive information may cause them to lose employment or insurance coverage or may make them subject to other types of discrimination. Yet if they are not tested, the benefits of clinical care to diminish the damage of the disease are not available. Patients who know that they are HIV-positive may not want others to know of their status to prevent discrimination. But third parties, such as sexual partners, who are at risk of being infected with a lethal virus, have a legitimate interest in access to otherwise confidential information. If the infected person is unwilling to inform others who may be at risk of getting AIDS, health professionals may be permitted or even required to warn persons who have been or may be put at risk of being infected. Family members may want to know why their relative is sick; they may need to know if they become caretakers. But patients may not be willing to disclose their diagnosis. Healthcare workers want to know their patients' HIV status just as patients want to know if their caretakers are infected. Both desire to avoid becoming infected themselves. Those who are at risk of infection may have a justifiable need to know; others may not.

Confidentiality is not the only value at stake, but it does impose substantial burdens on others. For example, in institutional settings, confidentiality of personal information, such as a patient's diagnosis, must be protected by written policies and actual practices. In a recent court case in Maryland, a hospital failed to protect adequately a patient's medical record that included a diagnosis of AIDS. It is not sufficient to state a policy that access to medical records is limited. It is also necessary to have and implement policies that actually restrict physical access to the records (Brannigan). The hospital was negligent because it did not go far enough to limit physical access of unauthorized persons to the records.

Required Reporting

Legal rules that require health professionals to report child or elder abuse, infectious diseases, or gunshot wounds preempt many of the specific ethical conflicts between confidentiality and public health or safety. However, not all ethical issues are resolved by legal rules. For example, some child-abuse-reporting laws are overly broad; health professionals may fail to make mandated reports in part because of the value ascribed to client confidentiality. Other reporting laws are so narrow that protection of threatened victims is undermined by confidentiality rules and practices (Miller and Weinstock). Some commentators have pointed out, for example, the conflicts created by statutes that require the reporting of not only actual but also suspected child abusers. Some parents alleged to have abused their children have been required to undergo therapy; but to require them to admit abuse before conducting therapy conflicts with the constitutional privilege against self-incrimination.

Professionals, caught between the need for confidentiality in therapy and the legal demand for reporting abuse, sometimes underreport abuse; they protect therapeutic relationships at the risk of legal liability. Other professionals may overreport child abuse because of their concerns about legal liability, strained therapeutic relationships, vulnerability of potential victims, or uncertainty about the value of confidentiality. Some commentators have suggested that child-abuse statutes should be revised to be more specific and limited, requiring professionals to report only when their patients are victims of child abuse, but to give professionals greater discretion about whether to report abusers who are in treatment (Smith-Bell and Winslade).

Another ethical problem for health professionals that arises in connection with legally required disclosures of otherwise confidential information is what to tell clients prior to or near the outset of therapy. If clients are inadequately apprised about the limits of confidentiality, their trust in health professionals is damaged and their relationship may be ruptured. If clients are fully advised of the legal limits placed on confidentiality, they may withhold essential information, terminate therapy, or not even start it. A further problem is that professionals may not know precisely where legal lines have been drawn. For example, a therapist may know that notification must be made to authorities but may not know how much, if any, of the content of therapy must he disclosed.

Genetic and Other Medical Screening

Genetic and other types of medical screening by epidemiologists, physicians, employers, schools, and other public and private agencies give rise to situations in which confidentiality is threatened by a demand for personal medical information. Individuals who are screened want to control information about themselves to prevent stigma, loss of insurance or employment, or other forms of discrimination. Screeners desire access to such information to promote their interests in knowledge, scientific discovery, publication, or economic considerations as well as therapeutic purposes. Control over the information raises moral issues as well as practical problems. These values must be balanced against individuals' rights to preserve their informational privacy. Blood tests, family medical histories, personal medical histories, DNA assays, and data banking, for instance, all raise questions about confidentiality, access, and control of personal information (De Gorgey). Lack of consensus about ethical priorities, gaps in legal policies and remedies to individuals, and political uncertainty about jurisdiction and control over medical screening combine to create controversy. Protection of individual rights of privacy and confidentiality requires careful monitoring of the use of data banks to store information obtained by the Human Genome Project (Macklin).

Health professionals in genetics differ in their beliefs about the value of privacy and confidentiality. Considerable disagreement has been documented, for example, in an international study in nineteen countries of the attitudes of geneticists toward privacy and disclosure. These health professionals were asked to respond to vignettes concerning disclosure of false paternity; of a patient's genetic makeup to a spouse; to relatives at genetic risk; of ambiguous test results; and to institutional third parties, such as employers and insurers (Wertz and Fletcher). Some consensus as well as numerous differences were discovered among the geneticists' opinions about what disclosures are appropriate. Dorothy Wertz and John Fletcher also found that geneticists' reasoning was more likely to be based on the complex needs and relationships of the various parties rather than the rights of individuals. A care-based ethics approach poses a theoretical and practical alternative to a rights-based approach.

Legal Protections and Limitations

Legal protection of confidentiality in the United States has been sporadic and uneven. The 1974 Federal Privacy Act (P.L. 93–579) included some medical information and records; its passage signaled heightened congressional awareness of threats to privacy and confidentiality. The National Privacy Commission's report (U.S. Domestic Council, 1976) seemed to set the stage for further protective federal legislation. Several subsequent attempts to pass comprehensive federal laws to protect medical information failed; a patchwork of state statutes provides only limited protection of patients' confidentiality. The reason is that patients' interests in confidentiality are balanced against powerful interests of third parties, such as healthcare payers, governmental agencies, researchers, and law-enforcement agencies, who wish to have access to otherwise confidential medical information (Hendricks et al.).

Courts have been as hesitant as federal and state legislatures to provide stringent protection of patient confidentiality. The U. S. Supreme Court considered but rejected the idea that patients enjoy a constitutional right to "informational privacy" with regard to treatment records (*Whalen* v. *Roe*). This decision was rendered when the rhetoric of privacy was prominent in Supreme Court opinions; in the

1980s the right to privacy was restricted, and the rhetoric of privacy diminished. State courts, such as those in Florida and California, whose constitutions make explicit reference to a right to privacy, have been more inclined to protect confidentiality of medical information. But state laws provide infrequently enforced bureaucratic protections or opportunities for recovery of damages only after confidentiality has been violated. Even then, litigation is rare because patients are reluctant to further expose confidential matters, damages are difficult to prove, and awards are often limited by statute (Winslade).

In some settings, such as substance-abuse treatment programs, the federal government has established special rules to protect confidentiality. To encourage persons in need of treatment to enter substance-abuse programs, records are not disclosed to law-enforcement agencies that might otherwise seek to prosecute substance abusers. In sensitive human subject research, special "privacy certificates" can be obtained by researchers from the federal government to give added protection to confidential information. Similarly, coded and locked files, limited access even to authorized personnel, and other precautionary measures against leakage further enhance confidentiality (McCarthy and Porter).

Public concern about confidentiality surfaces periodically, especially concerning the potential evils of misuses of patient-identifiable information. For example, implications of the Human Genome Project and healthcare reform have most recently evoked anxiety about discrimination, violation of personal rights, and commerce in patient information. The potential for a new healthcare information infrastructure that relies heavily on computer technology to facilitate the flow of medical information dramatically increases the threat to confidentiality of medical records (Brannigan). Recent commentaries remind us that current legal policies are inadequate to protect individuals against unwarranted disclosure, to provide security for complex medical-information systems, and to preserve individuals' rights to consent and control the uses of personal medical information (Alpert; Gostin et al.).

A specific area of law that directly affects confidentiality concerns the obligations of psychotherapists whose potentially violent patients place other individuals at risk of harm. The California Supreme Court, in the case of *Tarasoff* v. *Regents of the University of California* (1974), ruled that psychotherapists of dangerous patients have a duty to use reasonable care to protect threatened victims from harm. To do so may require the disclosure of otherwise confidential patient information. In balancing public safety and confidentiality, the Court observed that "the protective privilege ends where the public peril begins."

In the *Tarasoff* case, a psychotherapist believed that his patient was potentially dangerous to a young woman who had rejected his interest in her. The patient was obsessed with her at the expense of his studies, his work, and his friends. When the patient talked of revenge and was thought to have a gun, the therapist sought to have his patient evaluated for involuntary hospitalization. But the police declined to bring the patient in for an assessment of his mental status. The patient, angry with his therapist, abruptly terminated treatment. A couple of months later the former patient killed the young woman. Her parents sued the therapists and their employer for failing to warn the victim or her family about the dangerous patient. Although this case was settled out of court without a trial, the reasonable-protection rule was articulated by the court for future cases.

Subsequently, a series of judicial decisions have elaborated the duty of psychotherapists to third parties. Some courts have restricted the duty to situations in which there is an imminent threat of serious violence toward an identifiable victim. Others have focused on the broader duty of health professionals to control the conduct of the dangerous patient. Still others have applied the *Tarasoff* standard even when the risk to others is neither serious nor specific. And a few courts have protected confidentiality rather than endorse the *Tarasoff* standard (Felthous).

The complexity of particular cases and the variability of judicial interpretations of facts and laws inevitably cause some uncertainty. In this context, as in many others, confidentiality is limited by other important values. For example, suppose a voluntary psychotic in-patient with no history of violence leaves the hospital against medical advice. He leaves behind some written notes that include violent fantasies about a family member. His therapist discovers the notes (which were left unsealed). Assume the therapist consults the patient, who demands confidentiality; but the therapist is concerned that the patient may be dangerous. The therapist must assess the probability of harm to the patient or the potential victim, consider alternatives to revealing confidential information, and decide what, if anything, to tell the patient, the threatened victim, or others. This delicate balancing inevitably occurs in contexts where information is incomplete, contextual nuances are elusive, and human behavior is notoriously difficult to predict. Nevertheless, decisions must be made and actions taken that will affect the scope of confidentiality as well as bring about other consequences.

Information about Limits of Confidentiality

When entering into a professional-client relationship, clients have a right to receive explicit information about the scope and limits of confidentiality. Most nonprofessionals assume that disclosures made in the context of healthcare are confidential (Weiss). Most clients are uninformed about the limits of confidentiality and pressures to reveal presumably confidential information to third parties. Some clients realize that there are legal and ethical restrictions on confidentiality in healthcare, but others learn of them only after an undesired disclosure (Siegler).

Clients for whom confidentiality is especially important may take steps to preserve it. For example, a medical patient who chooses to file an insurance claim may request the right to review all documents released to the insurance carrier. Or the patient may pay privately rather than file an insurance claim. Other clients may be less concerned with confidentiality. Clients have a responsibility to inform themselves about what expectations about confidentiality are reasonable; then they will not be surprised or dismayed because of false assumptions about confidentiality.

Professionals have a responsibility to inform themselves as well as their clients about legal, ethical, and practical aspects of confidentiality. For example, neither patients nor health professionals usually are familiar with the practices of insurance companies concerning redisclosure of confidential information. Patients often sign a blanket waiver of confidentiality in order to obtain insurance benefits. This information may then be sold by the insurer to the Medical Information Bureau, a clearinghouse to protect against insurance fraud. This goal is laudable, but the data-banking process may include erroneous information that is difficult to detect or correct. In addition, many other interests outside healthcare—such as employers, government agencies, educational institutions, and the media—may gain access to information contained in these data bases (Linowes; Alpert).

At the very least, professionals should ask their clients what they want to know about confidentiality. Some professionals prepare a disclosure statement to give each new client, that is, a document that outlines confidentiality practices the particular professional follows. Policies and procedures concerning written medical records might be given to each new client. Further conversation, including clients' questions and professionals' answers, can clarify details that written statements may not address. Because professionals, like their clients, may differ in their attitudes toward confidentiality, it is important that disclosures about confidentiality be particularized. For example, the values of a psychoanalyst in private practice who never publishes patient case reports significantly differs from those of a research-oriented psychoanalyst who tapes and transcribes every session and publishes detailed case reports. Each should fully inform clients about the nature of his or her practice (Stoller).

Professionals have an obligation to take precautionary measures to protect confidentiality even if their clients have not requested it. Professionals should assume that all client information (including the very existence of the professional-client relationship as well as personal and private information revealed is strictly personal and private information revealed) is strictly confidential unless the client has requested or waived disclosure or unless the law requires it. Professionals should advise their clients of required disclosures, inform them of waivers, explore with them the consequences of disclosing or not disclosing information, and examine the reasons for and against disclosure. But clients retain the authority to decide what voluntary disclosures are to be made to third parties (Winslade and Ross).

Professionals also have a special responsibility to protect confidential client information from leakage through lax office procedures, professional or personal gossip, or the inappropriate inquiries of unauthorized persons. This is particularly problematic in institutional settings, where many individuals may have routine access to patient information contained in medical records (Siegler). As computerization of medical records expands further and information storage, retrieval, and distribution technologies become more sophisticated, the need for professionals' vigilance increases.

Many third parties—government officials and agencies, insurance interests, employers, family members, researchers, and others—seek specific information about particular patients. Third parties should not assume, however, that mere interest gives them legitimate authority to have access to confidential information. Third parties have a responsibility to justify to patients and professionals their need for access to confidential information. In some instances, this may require only a routine inquiry and documentation, but in other situations, professionals may find it necessary to confirm that their patients have requested, waived, or forfeited their rights to confidentiality. Too often, professionals, especially in an institutional setting, capitulate to pressure to disclose more information than necessary to third parties. At the very least, third parties as well as professionals should notify patients when access is sought, how it will be used, and whether the information will be redisclosed to anyone else. If appropriate disclosures are made to patients before access to confidential information is granted to third parties, not only will confidentiality be better preserved, but patients will also be better served.

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SEE ALSO: *Autonomy; Beneficence; Genetic Testing and Screening: Predictive Genetic Testing; Healing; Healthcare Systems; Human Dignity; Human Rights; Paternalism; Pediatrics: Adolescents; Profession and Professional Ethics; Public Health Law*

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CONFLICT OF INTEREST

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In a conflict of interest, one's obligations to a particular person or group conflict with one's self-interest. A physician, for example, is ordinarily obligated to provide his or her patients with only the care that is reasonable and medically necessary, even if the physician may earn more money through unnecessary interventions. Conflicts of interest should be distinguished from conflicts of obligation, in which one's obligations to one person or group conflict with one's obligations to some other person or group. The latter need not necessarily involve any threat to the agent's own interests. For example, a physician is normally obligated to keep patients' medical problems confidential; however, when a patient poses a danger to others (by transmitting AIDS to a spouse, for example) the physician may have an obligation to protect that third party by violating the confidentiality that would otherwise be owed to the patient. In a healthcare context, conflicts of interest can arise for individual providers, such as physicians, dentists, nurses, or physical therapists, or for institutions, such as hospitals, health maintenance organizations (HMOs), insurers, or pharmaceutical companies.

Conflicts of interest can be found in any human endeavor; indeed, the clash between self-interest and altruism lies at the heart of morality. However, conflicts of interest in healthcare are especially serious because of the patient's vulnerability. Illness can impair a patient physically, emotionally, and rationally. To secure treatment, patients must expose physical and emotional intimacies normally reserved for loved ones, and they frequently face further risks from invasive diagnostic and therapeutic technologies. Patients usually have no choice but to submit to such exposure and risk, because typically they lack the knowledge and skill to identify and treat the illness or to ascertain whether care is being rendered appropriately. This vulnerability creates ample opportunities for providers to exploit patients for personal gain. Physicians or dentists might recommend costly, unnecessary care, or an insurer or an HMO might attempt to lure subscribers by promising more than it can deliver.

Accordingly, providers such as physicians and dentists are often regarded as fiduciaries, in both a moral and a legal sense. Fiduciaries hold beneficiaries' (the patients') interests in trust and are obligated to promote the latter's interests, even above their own hospitals, insurance companies and HMOs. Nursing and allied health professions are not ordinarily considered fiduciaries in the legal sense, but they do share a strong ethic of dedication to patients' interests.

For many years, a serious commitment to professionalism and an effacement of self-interest seemed sufficient to manage conflicts of interest. The traditional fee-for-service system admittedly encouraged unnecessary services, but prior to the mid-twentieth century providers had relatively few interventions to offer, beyond their own care and concern. As technologies emerged, a relative shortage of providers meant that each had more than enough to do. Furthermore, in the long-term relationships that characterized most healthcare, providers had to live with the consequences of their decisions, right alongside their patients. Exploitive or abusive practices thus carried strong disincentives.

Since about the mid-1960s, however, healthcare has become high cost and big business. Providers now face a plethora of conflicts of interest, ranging from the traditional but much-exacerbated conflicts implicit in fee-for-service to powerful pressures to cut the cost of care by doing less for patients.

Conflicts of Interest for Physicians

For physicians, conflicts of interest can arise in two distinct realms: the clinical setting, where medical care is primarily designed to help the patient, and the research setting, where physicians seek scientific knowledge that will only sometimes benefit the patient or research subject.

THE CLINICAL SETTING. In the clinical setting, a number of factors could encourage a physician to alter a patient's optimal care, whether it be to secure a personal gain or to avoid a loss. Conflicts can be posed by third-party payers, institutional healthcare providers, private industry, the legal system, and physician investment.

Third-party payers. Traditional fee-for-service reimbursement encourages physicians to deliver as many services as possible and, in a maneuver called "unbundling," to break down each service into as many separately billable small interventions as possible. Maximizing income may thus mean excessive care, which in turn threatens needless inconvenience, expense, and iatrogenic injury for patients.

Partly because fee-for-service is an inflationary reimbursement system, healthcare costs grew at an alarming rate from the mid-1960s through the early 1990s. In response, those who pay directly for healthcare—government, businesses, and insurers—placed powerful pressures on physicians to do less for their patients. Payers sometimes offered bonuses to physicians to discharge patients earlier than normal, and they often refused to pay for various tests and treatments unless they were performed in an outpatient setting. Through extensive *utilization review* (UR), many payers reimbursed only hospitalizations or medical interventions that met their criteria of medical necessity. Physicians therefore spent large amounts of time (usually uncompensated) justifying their plans of care to payers in order to secure reimbursement.

As a supplement, or sometimes an alternative, to such controls, many health plans instituted financial incentives. Capitation systems, for instance, attempt to save money by paying a single fee for a large unit of care, thereby creating an incentive to avoid rendering care beyond the budgeted fee. Medicare inaugurated its *diagnosis related group* (DRG) system in the early 1980s, paying hospitals a set amount for a specific episode of illness, based on such factors as the patient's diagnosis, age, and coexisting illnesses.

HMOs, in a broader capitation concept, began to provide all necessary healthcare for each subscriber in exchange for a single annual premium. In order to ensure that their physicians delivered services within the year's budget, most HMOs, in turn, applied downstream financial incentives to their physicians, often withholding 20 percent or more of the physician's salary or fees until the end of the year, when they would be paid (or not) depending on the HMO's financial health. HMOs also have commonly set aside a special fund for diagnostic tests, consultants, and hospitalization. Primary-care physicians, acting as gatekeepers whose permission is required for the patient to gain access to these services, would share any surplus funds (or debts) remaining at the end of the year. Other HMOs placed physicians under subcapitation systems in which the physician provided a range of services for a set fee per patient. These arrangements could make a substantial difference in a physician's year-end income, thereby providing a powerful incentive for physicians to economize on the level of care they provide or authorize for patients.

The mid-1990s saw a brief reprieve from healthcare cost inflation, which, combined with a booming economy and widespread horror stories about the abuses of managed care, prompted most health plans to scale back these cost controls and incentive arrangements. However, as healthcare costs began rising rapidly again in the early twenty-first century, health plans and providers again struggled to keep them in check through a variety of mechanisms.

Although these mechanisms have evolved, certain features have remained constant. Ultimately, all payment systems create conflicts of interest by creating an incentive to provide more of the services that are most profitably reimbursed, and less of those that generate less income. However, the challenge is markedly exacerbated in the healthcare setting. Every medical decision is a spending decision, yet payers ordinarily cannot control their costs by directly dictating what care the physician will and will not provide. To do so would be to practice medicine in the physician's stead. Rather, payers attempt to influence physicians, who control up to 80 percent of healthcare costs through their power of prescription and their professional influence over patients. That influence is almost always gained by placing physicians' personal interests in peril as they are rewarded or penalized for fiscally (im)prudent healthcare decisions.

Institutional providers. Institutional healthcare providers, such as hospitals and clinics, can establish incentives to encourage physicians to do more (or less), depending on the institution's economic status (proprietary or charitable) and the patient's financial status (well-insured or not). A for-profit walk-in clinic, for instance, makes its money through the tests and treatments its physician-employees order. Hence, high-profit physicians may be praised and invited to share profits, or even to own a share of the business, while low-profit physicians may receive administrative warnings or lose their jobs if they do not improve . In other cases, physicians and proprietary hospitals may enter into joint ventures to share both the profits and risks of running the facility.

Whether proprietary or charitable, all institutional providers need to contain costs. Monthly printouts comparing the costs of each physician's care may be shared with medical staff in an attempt to shame the high spenders into delivering more conservative care. And those whose patients consistently leave too many unpaid bills may lose their staff privileges in a strategy called *economic credentialing.*

Such incentives systematically place physicians in conflicts of interest. The potential loss of income, peer esteem, staff privileges, or even one's job creates powerful pressures to align one's judgment with the institution's interests, even at some cost to patients' interests.

Private industry. Many medical drugs and devices are sold only with the prescription of a licensed physician and, notwithstanding some notable exceptions, are often not readily advertised to the general public. Therefore, manufacturers' marketing typically targets physicians. Because physicians tend to be busy people with substantial incomes, pharmaceutical companies can go to great lengths to get their attention. Promotions over the years have included all-expense-paid trips to exotic locations, ostensibly to hear a lecture on a new product; cash payments to physicians who agree to read literature describing nonapproved uses of a drug; "frequent prescriber" programs that award frequent-flyer points with the physician's preferred airline for every prescription of the company's drug; lavish parties and tickets to entertainment events; costly gifts such as luggage and decorative arts; inexpensive gifts such as pens and notepads; and subsidies for local educational colloquiums and travel to professional meetings.

The conflicts of interest are obvious. Such gifts reward physicians for prescribing drugs and devices whether or not they are necessary, and whether or not that particular product choice is most appropriate and least costly for the patient. Acceptance of gifts can engender a sense of personal gratitude and indebtedness that can put corporate loyalty above patients' interests. Furthermore, patients ultimately bear the costs of such promotions and gifts, whether through higher costs of the drugs and devices, higher costs for health insurance, or by forgoing higher salaries or fringe benefits because their employers are paying higher insurance premiums.

Legal system. Parallel to the escalation of healthcare costs, both the frequency and cost of medical malpractice litigation have increased. Physicians fearful of lawsuits may order extra diagnostic tests and more potent therapies to ensure that no one can accuse them of missing a diagnosis or doing too little for their patients. The cost of such "defensive medicine" has been estimated at up to 15 percent of the total cost of physicians' services. When physicians order procedures that are not medically necessary in order to protect their actual or imagined legal interests, they expose patients to extra inconvenience and iatrogenesis—at the patient's expense and usually without the patient's knowledge. It is a clear conflict of interest.

Physician investment. In some cases physicians create their own conflicts of interest by investing in facilities to which they refer their patients. Examples include freestanding diagnostic imaging centers, home health services, clinical laboratories, and physical therapy services. Although such investments can enhance the availability and quality of healthcare facilities in a particular locale, the physician owners of such facilities nevertheless have an incentive to refer patients there, even when the care is unnecessary, costly, or of poor quality. In the 1990s a series of federal laws and administrative regulations forbade many, but not all, of these arrangements.

The conflicts embedded in investments are not limited to freestanding facilities. One study found that physicians who owned radiographic equipment in their own offices tended to use it four times more often (generating costs seven times higher) than physicians who referred patients to independent radiologists for those services.

THE RESEARCH SETTING. The research context sometimes involves testing new treatments on ill patients, but it can also involve healthy volunteers when researchers look for toxicities of the very newest drugs. In many instances there is no expectation that participation in research will benefit the patient at all, whether because the subject is a normal control subject, because many people in the study will receive a placebo instead of active medication, or because the patient is too hopelessly ill to benefit from any treatment. Whatever the research protocol, however, the physician must respect the research subject's rights and interests.

Physicians can enjoy many personal rewards for successful research. Private companies such as drug manufacturers commonly sponsor research, in some cases paying the physician-investigator a fixed fee of several thousand dollars per person enrolled. The sum is intended to cover the costs of each subject's participation in the study, but in fact can result in a considerable surplus of money pocketed by the investigator. The more patients one enters in a study, the higher one's rewards, and an overzealous recruiter may be tempted to understate the inconvenience, discomfort, or risk that research participation may present for the patient, or to compromise the integrity of the study by signing up patients who are not truly eligible for the protocol.

Research that is funded by the government or other nonprofit sources can mitigate some, but not all, of the conflicts of privately sponsored research. Physician researchers still have strong incentives to gain the prestige, larger laboratory, increased technical support, academic promotion, science awards, and institutional power that come with securing grants and producing publishable research. In addition, some research projects have paid finders' fees to those who recruit patients for studies. As a result, investigators have powerful incentives to recruit patients into studies without necessarily taking full account of the patients' best interests.

Physicians can also create their own conflicts of interest. Sometimes physicians invest in corporations that are sponsoring their research, or they may serve as the corporations' paid spokespersons when research is completed. They may earn money from producing a valuable commodity, such as a cell line, by using tissues that patients either knowingly or unwittingly donate (see *Moore v. Regents of the University of California*). In a few cases physicians performing for-profit scientific research have charged subjects a fee to participate. Although such entrepreneurial research is controversial, the conflicts embedded in for-profit research are not necessarily worse than those found throughout the high-pressure world of medical research.

Other Health Professionals

Whereas physicians and dentists often are private practitioners or independent contractors, nurses, physical therapists, dietitians, and allied health professionals usually are employees of hospitals, HMOs, clinics, home health services, or public health agencies. These professionals' conflicts of interest most often arise where their contractual duty to administer the therapies ordered by a physician or to follow established institutional rules clash with their own beliefs about what is best for a patient. Such health professionals may suffer personal retaliation if they violate institutional mandates in order to do what they deem best for the patient.

In these cases the problem begins with a conflict of obligation in which one's obligations to the institution do not match one's obligations to the patient. The conflict of interest arises as one faces a personal price, perhaps in the form of retaliation, for favoring the patient over the institution. Thus, though conflicts of obligation are not the same thing as conflicts of interest, in these cases they are connected. For example, in one instance a nurse was fired for informing a patient about alternative cancer treatments (the dismissal was later vacated on procedural grounds (see *Tuma v. Board of Nursing*). In another case a nurse was discharged for refusing to dialyse a patient for whom she believed the treatment was pointless and inhumane (see *Warthen v. Toms River Community Memorial Hospital*). Such clashes between administrative requirements and one's professional judgment are probably the greatest, though not the sole, source of conflicts for allied health professions.

Institutions

The interests of institutions and their administrators, like those of individual professionals, often mesh with patients' best interests. Ideally, in a competitive market where consumers seek quality and value for their dollars, a healthcare institution will prosper by serving patients well. However, such a happy match does not always occur, partly because ill patients are often not equipped to appraise and challenge the quality of their care, and because generous insurance policies insulate many patients from caring about the costs of care. Accordingly, the financial best interests of a hospital might prompt excessive charges, inadequate staffing and equipment, bloated advertising, or the premature "dumping" of uninsured patients into public institutions. Similarly, a pharmaceutical company may be financially rewarded for producing and marketing new drugs as early and as vigorously as possible, even if the drugs and their production methods are not as refined as they could be. As a result, some drugs may have more side effects, or cost more, than is necessary.

Managing Conflicts of Interest

The existence of a conflict of interest does not mean that a provider has done anything wrong, or has mistreated or will mistreat any patient. It means only that while there is a mandate to promote the patient's (or someone else's) best interest, there are self-interested reasons to do otherwise. To be tempted is not necessarily to succumb.

Providers cannot escape conflicts of interest. If they are paid according to how many services they provide, their interest is to provide more services, with the concomitant dangers of excessive interventions, costs, and risks of iatrogenesis. If they are paid according to how many patients they care for, their financial advantage lies in taking on too many patients. Physicians who are strictly on a salary have an adverse incentive to minimize their own labor, even if they cannot increase their income, by seeing fewer and less-needy patients.

Formal protections can help. Regulatory agencies, such as state boards of medicine, nursing, and dentistry and the Joint Commission on Accreditation of Healthcare Organizations, can establish standards of performance for individuals and institutions, and the legal system can redress individual cases where providers' self-interest injures patients. Fiduciary law, for example, requires a fiduciary in a conflict of interest to disclose that conflict fully to the beneficiary (here, the patient) and also empowers the latter to determine how the conflict should be resolved (see *Fulton National Bank v. Tate*). Patients thus can have common-law remedies for breach of fiduciary duty, lack of informed consent, and other causes.

Although regulation and litigation can thus provide important protections, they cannot supplant personal integrity. The prospective employee of an HMO, a hospital, or other institutional provider should check carefully into its incentive structure and refuse to join any organization that links financial consequences too closely to individual patient-care decisions. The physician in private practice can refuse to accept costly gifts from drug company representatives. Those who would invest in ancillary facilities within or outside of their offices can ensure that there is a genuine need for the facility, and they can empower their patients with information and freedom to make their own choices regarding their ancillary healthcare providers. Researchers can refrain from investing in corporations sponsoring their research, and they can work with other research-sponsoring institutions to minimize conflicts. Where private industry pays university-based physicians a large per-patient fee, for example, that fee can be put into a general fund to benefit the institution after research costs are paid. Nurses and allied health professionals can work individually or collectively for contract terms that protect their right to exercise professional integrity.

Institutions must ensure that they do not create inordinate conflicts of interest for the professionals they employ. HMOs, for instance, should refrain from instituting incentive systems that unduly influence individual patient-care decisions. They and other payers should likewise disclose to current and potential subscribers any such incentives or limits on care. Informed subscribers are better empowered to guard their own interests. Institutions can also ameliorate their conflicts by pursuing ongoing quality improvement as a way of promoting quality care while economizing on costs. A focus on the success that comes from long-term quality should replace any preoccupation with short-term profitability.

Conflicts of interest affect providers pervasively, powerfully, and personally. Where fiduciary duty once consisted mainly of refraining from vulgar exploitation, the obligation to place the patient's interests before one's own can no longer be an unlimited obligation. Providers must exercise great care to avoid conflicts where possible, and to uphold a strong fiduciary presumption to favor patients' interests over their own. However, they cannot be expected to commit professional self-sacrifice in what may be a futile unilateral attempt to battle economic forces beyond their control. Therefore, one of the most important and difficult moral challenges of medicine's new economics is to consider not just what providers owe their patients but also the limits of those obligations. As healthcare systems continue to evolve, one important remedy will be to provide patients with greater choice and control over the content of their healthcare benefits, and thereby with more power to make their own trade-offs between the cost and quality of care. This will alleviate at least some of the conflicts of interest that arise as providers attempt to make these trade-offs on their patients' behalf.

E. HAAVI MORREIM (1995)
REVISED BY AUTHOR

SEE ALSO: *Commercialism in Scientific Research; Divided Loyalties in Mental Healthcare; Healthcare Resources, Allocation of; Just Wages and Salaries; Managed Care; Maternal-Fetal Relationship; Nursing Ethics; Pharmaceutical Industry; Pharmaceutics, Issues in Prescribing; Profession and Professional Ethics; Surrogate Decision-Making; Whistleblowing in Healthcare*

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CONFUCIANISM, BIOETHICS IN

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Confucianism draws its name from the latinized honorific title of its founder, Kong Chiu or *Kong fuzi* (562–479 B.C.E.), an independent scholar and unsuccessful political advisor who believed moral self-cultivation and the practice of ritual were the cornerstones of an ideal society. Initially espoused by no more than a few dozen students, Confucius’s teachings—expanded and significantly elaborated over time—ultimately became the dominant sociopolitical ideology of much of East, Northeast, and Southeast Asia.

Other traditions, notably Mahayana Buddhism and Taoism, successfully rivaled Confucianism for state support over the centuries, but none—not even Maoist atheism in China—ever seriously threatened the Confucian tradition’s pervasive cultural dominance. Carried beyond its historical Asian boundaries by merchants, laborers, and refugees, Confucianism also maintains a strong hold on diasporic Chinese, Korean, Japanese, and South-Vietnamese populations the world over.

In considering the complexities of the Confucian tradition, the following must be borne in mind:

1. the tradition is not monolithic, that is, historical era, regional variation, and differential class appropriation inform Confucian practice;
2. the tradition does not exist in conceptual isolation, that is, within any given local culture at any particular historical moment, Confucianism has always been practiced by individuals as part of a constellation of personal practice, including Mahayana Buddhism and local folk religions;
3. although there is a sense of authority residing in the canonical texts and commentaries of the Confucian classics, there is no central governing body, no clergy, and no history of religious jurisprudence within the tradition to dictate orthodoxy or legislate orthopraxy;
4. there is neither a concept of evil nor an absolute dichotomy between right and wrong as understood in Western monotheisms; rather, it is ignorance, self-delusion, and a tendency to gratify selfish desires that pose the greatest obstacles to moral improvement;
5. Comparative discussion of certain contemporary topics, for example, human rights and abortion, is

complicated by the absence of notions of individual "rights"; in the Confucian view, humans are defined by their capacity to fulfill duties and responsibilities rather than by any sense of inherent possession of rights.

Origins of the Classical Tradition

Core concepts are found in brief statements attributed to the Master himself, recorded by others in the verses of the *Analects,* the *Great Learning,* and the *Doctrine of the Mean.* Modern scholars, notably E. Bruce Brooks and A. Taeko Brooks in their *The Original Analects,* have shown these texts to contain significant interpolations and emendations. As received tradition, however, the aphorisms ascribed to Confucius and his early followers continue to exert considerable authority. At the heart of Confucius's vision was the sense that an individual can become truly human only through a deliberate process of moral education. The cultivation of virtues and their expression in ritual forms yields a *gentleman* (or, in current terminology, a *perfected person*) who stands ready to fulfill the responsibilities of living in concert with others and of establishing a peaceful, just, and aesthetically pleasing society. Ritual without virtue is ornament without substance; virtue without ritual can lead to unbounded good intentions that may ultimately do harm.

Confucian society is built upon a set of five reciprocal relationships, each of which is characterized by particular virtues and specific responsibilities:

1. ruler-subject;
2. parent-child;
3. husband-wife;
4. older-younger (brothers); and
5. friends.

Confucius's primary concern was with the creation of a stable and prosperous state, but he understood that it was the family that would ultimately produce the individuals dedicated to establishing his ideal society. Of the five relationships, therefore, three are located within the family; of these, by far the most important is that between parent and child. For having given life, one's parents are owed an enduring debt of gratitude—an obligation that extends even beyond the temporal boundaries of this lifetime. The practice of filiality, or filial piety, is therefore the starting point for Confucian moral cultivation, and the family is the foremost focus of religious practice.

An individual's relationship with people outside the family is determined by interlocking considerations of age, social and educational position, gender, and degree of professional and personal connection—all of which determine relative seniority and significance, and thus the degree of deference and potential obligation owed. However, how one acts within the resulting relationship is far more flexible and less hierarchical than might be assumed. Much has been made in Western philosophical literature about the Golden Rule found in *Analects* 5:12 and 12:2, but Confucius himself indicated another *single thread* that bound his ethical teachings (*Analects* 4:15). Two strands comprise the single thread, namely, *chung* and *shu,* usually translated as *loyalty* and *reciprocity.* These terms refer to a dialectical process that requires that one first center oneself in the relationship at hand, clearly understanding its attendant responsibilities and privileges. One then imaginatively takes the other's position in the relationship. Then—and only then, from this enlarged and empathetic perspective—one acts, in full awareness of the consequences for the other of one's actions.

In the centuries after Confucius's death, new questions arose to challenge the tradition. A particularly vexatious problem was how to account for people's varying capacities to learn (or even to want to learn) to become truly human. The ensuing debate was ultimately settled in favor of the view espoused by Mengzi (also latinized as Mencius, 372–289 B.C.E.). According to Mengzi, all people possess the four seeds of humaneness, righteousness or duty, propriety, and wisdom. If nourished properly through environment and education, these seeds mature into the moral attitudes and ritual behavior of true humanity. It is worth noting, however, that extrapolation from this claim yields the conclusion that those who do not exhibit these seeds or their outgrowth are not entirely human—a conclusion with potentially troubling ramifications in discussions of capital punishment, euthanasia, and human rights.

The Han Synthesis

After China was united under the relatively stable administration of the Han dynasty in 206 B.C.E., training in Confucian principles was established as the basis for participation in the state's meritocracy. Over the course of the Han rule (through 221 C.E.), Confucianism's purview expanded beyond philosophical-political discussions of virtue and ritual to encompass cosmological theories derived from ancient divination forms, and from *yin-yang* and the so-called Five Elements systems. The goals were to discern macrocosmic and microcosmic correspondences and then to regulate human actions to ensure harmony with heaven and earth. Although many of the theories incorporated into this syncretic Confucian cosmology are frequently associated with Taoism, they are more accurately described as belonging to a pre-sectarian worldview that underlies all Chinese religio-philosophical traditions.

The hexagrams of the *I Ching* (*Book of Changes*) provided glimpses of the flow of natural processes, especially *qi,* the animating *breath* of the cosmos. The alternation of *yin* (darkness, passivity, decay, emotionality, and femininity) and *yang* (light, activity, growth, rationality, and masculinity) underscored notions of complementarity. The Five Elements (fire, water, wood, metal, and earth) explained a thing's inherent characteristics as well as its patterns of growth and decline. Elaborate correspondences were constructed among these classificatory systems, such that hours of the day, seasons of the year, foods and tastes, colors, sounds, organs of the body, stages of life, heavenly constellations, and virtually all human activities could be mapped and harmonized. A dislocation or inappropriate item in any one part of the schema would lead to disharmony and inauspiciousness elsewhere. In the political realm, disharmony breeds revolution; in the personal realm, disharmony breeds illness. The goal of Chinese medicine is to restore the natural balance of one's internal environment and to harmonize it with external environmental circumstances. This requires that a patient's food, medicines, and therapies be dictated not only by symptoms, but also by individual psychophysiology and local environmental factors such as season of the year. In the Confucian view, maintaining one's good health is dictated by filial responsibility, as one's parents should have no cause for worry.

Neo-Confucianism

After the collapse of the Han, China fragmented into several smaller kingdoms and parts of north China fell under non-Chinese rule. During the following centuries of disunion, the Confucian tradition was somewhat eclipsed by Taoist sectarian traditions and by the rise of Buddhism. Beginning in the Song dynasty (960–1279), a Confucian revitalization movement gathered momentum. Meditation, visualization, and other interior spiritual techniques were borrowed from Buddhism and Taoism, and traditional Confucian ethical concerns were now linked formally to a notion of the cosmos as inherently inclined toward moral good. Mengzi's view that human nature is essentially good was reaffirmed by the great Neo-Confucian, Zhu Xi (1130–1200). Together with the *Analects,* the *Great Learning,* and the *Doctrine of the Mean,* Zhu Xi promoted the *Mengzi* as comprising the Four Books, the basic course of education in Confucian ideology. Indeed it was Zhu Xi's editions of these and other classical Confucian texts that formed the basis for the imperial Chinese civil service examinations.

Zhu Xi further contributed to the development of Confucian practice through his preparation of detailed *jiaxun,* or family regulations. In addition to providing minute descriptions of ritual preparations, he admonished would-be filial sons and daughters-in-law to acquire medical knowledge adequate to the care of their parents (-in-law). Not only should they know how to prepare certain medicines, but they should also be able to select reputable physicians—practitioners who, in Zhu Xi's day, were viewed as little different from barbers and masseurs. Filial duty also entailed assumption of the primary burden of care. Down to the present, the sense that eldercare is the responsibility of the family remains deeply ingrained in Confucian societies, but with the decline of the extended family, reports of abandoned seniors are increasingly common.

New Confucianism

After the fall of the Qing dynasty in 1911, Confucianism was widely derided by Chinese intellectuals as a remnant of a feudal past that hindered China's rightful advancement into the modern world. Much of the blame for women's oppression, for example, was allocated to *Confucius and Sons,* and study of the canon was replaced by scientific and technical training. Nonetheless there were some scholars who believed that Confucianism, freed from its feudal origins and centuries of accreted (and erroneous) practice, could be rehabilitated. An international revitalization movement, known as *New Confucianism,* arose in the 1920s at Peking University under the intellectual leadership of Xiong Shili and continued to develop through the 1940s at New Asia College in Hong Kong under Tang Junyi. During the 1960s, the movement gained added momentum by the efforts of Mou Zongsan and Xu Fuguan at Tunghai University in Taiwan. These New Confucians asserted that the tradition holds spiritual resources sufficient to meet the challenges of industrialization, urbanization, and bureaucratization, and to combat the depersonalization of the modern world.

Contemporary New Confucians draw inspiration from Lee Sang-eun (South Korea), Okada Takehiko (Japan), and, especially, Tu Weiming at Harvard University. Following his teacher Mou Zongsan, Tu Weiming has championed Confucianism as a world religious tradition—its ideals and practices open not only to those of East- and Southeast-Asian ethnic background, but to anyone who shares its anthropocosmic vision. And there are many who do. Robert C. Neville, author of *Boston Confucianism,* is a prominent example of those who claim a dual religious orientation and who write persuasively on the significance of Confucian tradition for the West.

Women

There is nothing in the Confucian tradition inimical to women. Confucius had little to say about women other than, like uneducated men, they "were difficult to deal with" (*Analects* 17: 25). It was only later, with the Han dynasty grafting of cosmological speculation onto the tradition, that women became ineluctably identified with yin and its associated qualities in a negative way. Mengzi, for example, accepted the social mores of his day but did not see women as disposable or unworthy of regard:

> Chunyu Kuan asked, "In giving and receiving things, is it not the rule that men and women should not touch?"
>
> Mengzi repled, "That is the rule."
>
> "If my sister-in-law is drowning, then should I use my hand to save her?"
>
> "Anyone who wouldn't is a wolf. That men and women shouldn't touch in giving and receiving things is the rule; to use your hand to save your sister-in-law transcends rules." (4A17)

Yet it was Mengzi who underscored the filial necessity of producing an heir in order to ensure the care of elderly parents and the maintenance of ancestral veneration. He said, "There are three ways to be unfilial, and the greatest of these is to be without posterity" (4A26). In the premodern world, posterity meant a son or, preferably, sons. The resultant pressures on a woman were great. She was to bear children early and often; to continue bearing children until at least one son was born; and, in cases where she failed in this requirement or seemed likely to do so, to accept divorce or the introduction of concubines into the household.

The imperative to produce a son remains strong and has had a profound impact on the growth of certain reproductive technologies. The desire for male offspring, coupled with restrictive population control measures in China, and with trends toward smaller nuclear families in the industrialized nations of Japan, Taiwan, Korea, and Singapore, has led to increased use of sonograms for fetal sex determination, often followed by elective abortion if the fetus is female. Of course, to describe abortion as *elective* in this context is to gloss over the many pressures—economic, spousal and familial, societal—that may accompany the decision; use of the term here indicates only that the procedure is not medically necessary.

Abortion itself is condemned within the Confucian tradition as a mutilation of familial flesh. Buddhist notions of karma and the Buddhist prohibition against the taking of life compound the sense that a fetus should be protected. However, there is widespread ambiguity in the popular imagination about the ontological status of the fetus, as noted in studies of fetus-ghost appeasement rituals in Japan and Taiwan, conducted by William LaFleur, Helen Hardacre, and Marc Moskowitz. Most people believe the fetus to have a soul at conception, yet there is also the belief that this soul is not solidly anchored, meaning that it is extremely susceptible to fright—and flight—during the first 100 days of infancy. A soul that escapes its body in this way will likely make its way to another, but the specter of a free-floating vengeful spirit has fueled a lucrative fetal-ghost appeasement industry.

It must also be noted that nominally Confucian cultures have long embraced a pragmatic ethical relativism, sometimes attributed to Taoism, which seeks to maximize personal and familial benefit while avoiding inauspicious residual effects. In late-twentieth-century China, an alternative to abortion and female infanticide has emerged: After birth unwanted infant females are anonymously left at local orphanages or social welfare offices, or else they are quickly sold to baby brokers who then deliver them to state facilities. In this way, the state has found itself with a seemingly inexhaustible supply of a highly desirable commodity: infant girls for the international adoption market.

In some areas the male-female sex ratio of recorded live births is severely and increasingly skewed in favor of males. In Korea use of ultrasound screening to determine fetal sex is illegal but widely practiced. In China the overall male-female ratio of recorded births is between 117:100 and 120:100, whereas the average should be 105:100. In certain rural areas, the ratio rises to 144:100, the highest imbalance in the world. It is impossible to know with certainty the exact percentages of the *missing girls* who were aborted or were victims of infanticide, or the number of girls who were born and kept by their families but whose births were not recorded on official rosters. What is known is that decades of increasingly unbalanced male-female ratios have given rise to kidnappings, mail order marriages of children, and wholesale trafficking in women (Rosenthal, Eckholm).

Ownership of the Body

Of particular relevance to bioethics is the Confucian understanding of ownership of the body. Confucian tradition holds that one's body is not truly one's own; rather, it is held in custody for one's parents and ancestors. In a particularly gendered illustration of this notion, the historical records contain many examples of filial daughters and daughters-in-law who, charged with the care and feeding of parents and parents-in-law, cut flesh from their arms or legs in order to make nourishing broth in times of war or famine. In other circumstances, however, to harm or mutilate one's body might render it insufficient to its purpose of care for preceding generations. To a Confucian, therefore, preserving the integrity of the body is of great importance. This holds true even after death, for although the deceased becomes an ancestor him- or herself, he or she remains at the service of still earlier generations.

Here too, the complexity of Confucian interaction with other traditions becomes apparent: Internal organs are only valued for their functions, and thus the donation of a sample of bone marrow or of a single kidney would seem permissible. However, the general Confucian sense of the body remaining intact in order to serve one's family is compounded by the popular Buddhist notion that a body must be complete in order to move through its karmic destiny. For many people in Confucian cultures, therefore, the combination of these beliefs has precluded acceptance of organ donation and transplantation up until quite recently.

One organization that has been working to change this view is the Tzu Chi Buddhist Compassion Foundation, a lay organization that claims 4 million members worldwide. Founded in rural Taiwan in 1966 by Dharma Master Cheng Yen, a self-ordained nun, the Tzu Chi Foundation exhorts women to fulfill their traditional Confucian role of dutiful wife and mother—even as it promotes women's volunteer efforts outside the home, particularly in medical care and disaster relief. In 1994 Tzu Chi established a bone marrow registry, the third largest in the world in 2003. Tzu Chi encourages organ and tissue donation (and even body donation for the training of medical students) as examples of Buddhist compassion. Although these teachings are at odds with traditional Confucian-Buddhist attitudes toward the body, Master Cheng Yen emphasizes the interconnectedness of all beings and the importance of practicing compassion to save lives. At Tzu Chi hospitals, hospices, free clinics, and medical and nursing schools, healthcare workers are trained to view patients holistically and humanely, seeing them as teachers and as providers of opportunities to serve.

Current Directions of Contemporary Scholarship

For scholars *of* Confucianism, the implications of studying Confucianism as a world religion are that its texts and interpretive traditions are open to literary critical study; its history is scrutinized for gender, class, and other biases; its ideal figures are analyzed with historical, sociological, and psychological tools; and its entire ethos is set in a comparative framework. The profoundly transformative aspects of its humanistic project can be appreciated as overtly religious, and discussions of Confucian spirituality are increasingly common.

For scholars *in* the tradition, new questions abound. What is the Confucian response to environmental degradation? Can traditional relationships be recast to address new configurations of the nuclear family, for example, same-sex unions, one (female)-child households, or blended families? What is the nature of lateral relationships, that is, what is one's relationship to other members of a civil society? What is the Confucian perspective on various reproductive technologies, or on genetic screening? Such issues are fraught with ambiguity.

For people in cultural China, Korea, Japan, and Vietnam, Confucianism is perhaps best understood as providing a substratum of belief, complementing or complicating other beliefs and values, whether sectarian or secular. Although scholars can debate Confucian responses to any issue, a single Confucian judgment is probably impossible to construct. In the syncretic and diasporic world of Confucian cultures, a Korean Christian Confucian may hold one opinion, a Japanese Buddhist Confucian another, and a *Boston Confucian* may hold yet another view altogether.

VIVIAN-LEE NYITRAY

SEE ALSO: *Aging and the Aged: Old Age; Beneficence; Buddhism, Bioethics in; Daoism, Bioethics in; Death: Eastern Thought; Feminism; Medical Ethics, History of South and East Asia: China; Paternalism; Trust; Women, Historical and Cross-Cultural Perspectives*

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CONSCIENCE

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Matters of conscience arise with some frequency in bioethics. A health professional may cite considerations of conscience in declining to perform or participate in a certain procedure. A patient may refuse a particular treatment on grounds of conscience. And new or unanticipated circumstances may create conflicts of conscience for patients and health professionals alike. What do we mean by "conscience" in these and related contexts? Is conscience an internal moral sense sufficient for distinguishing right from wrong? Is the "voice" of conscience simply the echo of parental and social prohibitions? Or does conscience differ in important ways from either of these? How much weight should be given in ethical reflection to claims of conscience? To what extent and for what reasons should health professionals compromise personal convenience, institutional efficiency, or medical effectiveness in order to respect individual conscience, their own or their patients'?

Three Conceptions of Conscience

The idea of conscience has a long and complex history (D'Arcy, 1961; Mount). The word "conscience" derives from the Latin *conscientia,* introduced by Christian Scholastics. Most generally, it refers to conscious awareness of the moral quality of some past or contemplated action and the disposition to be so aware (conscientiousness). In what follows we consider three main conceptions: (1) conscience as an inner sense that distinguishes right acts from wrong; (2) conscience as the internalization of parental and social norms; and (3) conscience as the exercise and expression of a reflective sense of integrity.

MORAL SENSE. Conscience is sometimes conceived as an internal moral sense sufficient for distinguishing right from wrong. The reliability of this inner sense is usually attributed to its divine origin, its reflection of our true nature, or some combination of the two. There are, however, difficulties with this conception.

Consider, first, a variation of an argument developed by Plato in his *Euthyphro.* Is what makes an act right the fact that it is endorsed by one's conscience? Or does conscience recommend a certain course of conduct because it is right? If the former, the promptings of conscience appear to be arbitrary. Whatever is urged by a person's conscience would, in this view, be right. There would be no way to assess the deliverances of conscience or to compare the consciences of, say, Hitler and Mother Teresa. If, on the other hand, conscience directs us to perform certain acts because they are right, it cannot be the principal source of moral knowledge. We must, in this event, have prior, independent criteria of rightness and wrongness that allow us to distinguish those acts that should be recommended by conscience from those that should not—in which case conscience is not sufficient to guide conduct.

A related difficulty is the prevalence of conflicts of conscience, both within persons and between them. Such conflicts are especially pronounced in bioethics, where advances in knowledge and technology confront us with unprecedented, consequential choices ranging well beyond our ethical traditions. The limitations of conscience, if it is conceived as a sufficient guide to moral decision making, may not be so noticeable in static, homogenous, insular cultures and subcultures. But where new circumstances require members of pluralistic societies to come to some agreement on bioethical questions, appeals to an internal, self-validating sense of right and wrong are apt to generate more heat than light.

INTERNALIZED SOCIAL NORMS. The most plausible explanation for the limitations of conscience in resolving ethical conflicts is that the "voice" of conscience is simply the echo of social and parental admonitions impressed upon the developing psyches of young children (i.e., the Freudian superego). Whatever its psychological and developmental significance, conscience so conceived has little normative import. That we have certain moral compunctions as a result of our socialization does little to establish their validity. We are bound by the voice of conscience only if we can provide independent justification of its dictates. It is the adequacy of the justification, not the persistence of the voice, that carries moral authority. Conceived as internalized social norms, then, conscience plays no direct role in ethical deliberation.

SENSE OF INTEGRITY. "I couldn't live with myself if I were [or were not] to perform the abortion in these circumstances." "I can no longer participate in this treatment plan in good conscience." "How could I continue to think of myself as a Jehovah's Witness if I were to consent to the blood transfusion?" Each of these sentences expresses an appeal to conscience that is neither a deliverance of an internal moral sense nor an internalization of an external social norm. What is expressed in each case is the culmination of conscientious reflection about the relationship between a certain course of action and a particular conception of the self. So understood, appeals to conscience are closely connected to reflective concern with one's integrity. The focus is not so much on the objective or universal rightness or wrongness of a particular act as on the consequences for the self of one's performing it.

There is something absurd, Gilbert Ryle has observed, in saying "My conscience says that *you* ought to do this or ought not to have done that" (Ryle, p. 31). I may be troubled by your wrongdoing, but unless I have advised or assisted you, or culpably failed to prevent you from performing the act in question, my conscience will be clear. The same is not true, however, about those of my acts that I have determined, for one reason or another, were or would be morally wrong. Having judged a certain act to be wrong, an appeal to conscience stresses the added wrongness of my performing it. Appeals to conscience therefore presuppose a prior determination of the rightness or wrongness of an act (Childress, 1979). Moreover, one may or may not extend the standards one employs in making this assessment to others in similar situations. If, for example, the standards are universalizable principles of respect for persons, justice, or beneficence, one will maintain that anyone would do wrong in performing the act in question. But if one's standards are grounded in religious convictions, personal ideals, or a particular worldview and way of life, one may not hold everyone else to them. What is at stake in all such appeals is one's wholeness or integrity as a person.

Integrity

"It would be better for me," Socrates says in the *Gorgias,* "that my lyre or a chorus I directed should be out of tune and loud with discord, and that multitudes of men should disagree with me rather than that I, *being one,* should be out of harmony with myself and contradict me" (Arendt, 1971, p. 439). One cannot lead a good and meaningful life, Socrates suggests, unless the self is reasonably unified or integrated—unless, that is, one's words and deeds cohere with one's basic, identity-conferring, moral, religious, and philosophical convictions. Hence the importance of critical reflection on one's life as a whole. The words, deeds, and convictions of an unexamined life are unlikely to be sufficiently integrated to constitute a singular life—let alone one worth living.

Conscience should not, therefore, be conceived as a faculty or component of the self. It is, rather, the voice of one's self as a whole, understood temporally—as having a beginning, a middle, and an end—as well as at a particular moment. Operating retrospectively, what Christian tradition calls "judicial" conscience makes judgments about past conduct. Operating prospectively, what the same tradition calls "legislative" conscience anticipates whether a prospective utterance or course of action is likely to be at odds with one's most basic ethical convictions (D'Arcy, 1961). In each case, the signal that something is wrong—that one's integrity has been, is currently, or would be compromised—is an actual or anticipatory feeling of guilt, shame, or remorse.

Consider, in this connection, the words of Aleksandr N. Chikunov, a veteran of the 1968 Soviet invasion of Czechoslovakia, as he explains sharing his experience with young soldiers called to Moscow to suppress democratic reforms during the abortive coup of August 1991: "I entered Prague in 1968 and I still have an ill conscience about it. I was a soldier then, like these guys. We were also sent like they are now, to defend the achievements of socialism. Twenty-three years have passed, and I still have an ill conscience" (*New York Times,* August 20, 1991, p. A13). Here Chikunov draws upon the lessons of his "ill" judicial conscience to inform and alert the legislative consciences of the young soldiers. His motivation, it seems, is not only to spare them the pangs of an ill conscience but also to help heal his own (and thus to heal himself).

The authority and sanctions of conscience are, Mr. Chikunov suggests, self-imposed. No external source can create or directly relieve a troubled conscience. Nor may we easily rationalize or evade its judgments. "Other judges," as D'Arcy points out, "may be venal or partial or fallible; not so the verdict of conscience" (D'Arcy, 1961, p. 8). The oppressiveness of a guilty conscience is due in part to its identity with the self.

Conscience in Bioethics

Three factors contribute to the prevalence of appeals to conscience in bioethics: (1) bioethical decision making often involves our deepest identity-conferring convictions about the nature and meaning of creating, sustaining, and ending life; (2) healthcare professionals and patients and their families will occasionally have radically differing beliefs about such matters; and (3) the complexity of modern healthcare often requires agreement and cooperation on a single course of action.

CONFLICTS OF CONSCIENCE. Conflicts of conscience arise not only between individuals but also within them. Consider a physician whose patient, suffering greatly from the ravages of the last stages of a terminal illness, is also a longtime friend. The patient requests the physician to provide both the substance and the instruction for taking his own life. The physician finds herself torn. On the one hand, her conception of medicine and professional identity is incompatible with what appears to be physician-assisted suicide. On the other hand, the bonds of friendship and her natural sympathies strongly incline her to accede to her patient's request. The situation has, as a result, precipitated a crisis of conscience, and the physician must engage in what Charles Taylor has called "strong evaluation"—reflection about the self by the self in ways that engage and attempt to restructure one's deepest and most fundamental convictions (Taylor). Such reflection manifests an admirable concern for wholeness or integrity.

CONSCIENTIOUS REFUSAL. From Socrates to Sir Thomas More to Henry David Thoreau, individuals have appealed to conscience in refusing to comply with a wide range of legal or socially mandated directives. In some cases such noncompliance may be covert and evasive—for example, a physician's providing contraceptive information to married couples in Connecticut before that state's anticontraceptive law was declared unconstitutional (Childress, 1985). In most cases, however, health professionals and patients give reasons of conscience in openly seeking personal exemption from certain standard practices.

Physicians may appeal to conscience in refusing to do procedures that are both legal and performed by their colleagues. Consider an obstetrician's refusal to perform a legal abortion or a pediatrician's refusal to prescribe human growth hormone for short, but normal, children at the behest of their anxious parents. In each case the physician's decision may be based on moral convictions or personal ideals. The obstetrician need not believe that abortion ought to be illegal or that women who request, or physicians who perform, abortions are deeply immoral. The pediatrician may neither urge the legal prohibition of administering human growth hormone to short, but normal, children nor regard parents who request this treatment, or other pediatricians who administer it, as unethical. Both agree, however, that it would be a violation of conscience—a betrayal of their deepest personal convictions about life or the nature of medicine—if they were to perform the act in question.

Similarly, nurses appeal to conscience in seeking exemption from procedures or care plans that threaten their sense of integrity. For example, a nurse may conscientiously refuse to follow a physician's directive to remove medically administered hydration and nutrition from a patient in a persistent vegetative state. Regardless of the act's legality, the family's concurrence, and the physician's directive, given her deepest identity-conferring convictions about the nature and value of life, the nurse may be unable to carry out the action. Her reasoning, she might add, is not strong enough to condemn others who believe differently; but as for herself, she must refrain.

Patients, too, may appeal to conscience in refusing forms of medical treatment. When informed, mentally competent Jehovah's Witnesses refuse blood transfusions on religious grounds, they do not at the same time urge that blood transfusions be legally prohibited, nor do they condemn those who gratefully accept blood transfusions. What they want is not so much respect for the content of their particular convictions as much as respect for their consciences. The same is true of other patients who refuse or request certain forms of treatment on the basis of fundamental moral and religious convictions.

Respect for Conscience

Respect for conscience is a corollary of the principle of respect for persons. To respect another as a person is, insofar as possible, to respect the expression and exercise, if not the content, of a person's most fundamental convictions. A society's respect for individual conscience may extend not only to religious toleration but also, for example, to exempting conscripted pacifists from direct participation in war.

In the biomedical context, respect for conscience may be inconvenient, inefficient, or detrimental to medical outcomes. Still, it must always be taken seriously and often should prevail. In some cases, respect for conscience may be balanced with biomedical goals. At a certain level of abstraction, the purpose of healthcare is strikingly similar to that of protecting individual conscience. Although healthcare is usually focused on the body, emphasis on informed consent implies that the principal function of medicine is the health or wholeness of the patient as a person. Yet a person's sense of health or wholeness may also be threatened by what the former Soviet soldier, Aleksandr Chikunov, revealingly called an "ill" conscience. The values underlying appeals to conscience within the healthcare system are not, therefore, radically at odds with the values underlying medical and nursing care. In each case the aim is to preserve or restore personal wholeness. Insofar, then, as appeals to conscience and the healthcare system share a fundamental commitment to preserving and restoring personal wholeness or integrity, we ought in cases of conflict to seek some sort of balance or accommodation between them.

Health professionals who refuse, withdraw, or dissociate themselves from certain practices or procedures on grounds of conscience may well be among the more thoughtful and effective members of a healthcare team. Thus a healthcare institution intent on retaining such nurses and physicians has prudential as well as ethical grounds for accommodating their claims of conscience even at the cost of some inconvenience or expense. Respect for conscience requires going to greater lengths for patients, however, than it does for healthcare professionals. This is in part because an individual's role as a healthcare professional is voluntary in a way that being a patient is not. It is one thing, for example, to respect a Jehovah's Witness patient's conscientious refusal of a blood transfusion; it is quite another to respect the conscientious refusal of a physician who is a Jehovah's Witness to administer blood transfusions. An individual whose moral or religious convictions are incompatible with a common, essential type of healthcare has no business seeking a position in which such care is a routine expectation.

Problems and Limits

At least two important questions remain. First, how do we distinguish genuine claims of conscience from claims serving as smoke screens for laziness, cowardice, distaste for certain procedures, or dislike or prejudice toward certain patients? Second, given that a genuine act of conscience may be morally wrong, should individuals always (or always be permitted to) follow their conscience?

GENUINENESS. Understanding the nature and justification of conscientious refusal allows us to distinguish genuine from spurious or self-deceived appeals to conscience. In assessing the authenticity of such appeals we may, for example, inquire into (1) the underlying values and the extent to which they constitute a core component of the individual's identity; (2) the depth of the individual's reflective consideration of the issue; and (3) the likelihood that he or she will experience guilt, shame, or a loss of self-respect by performing the act in question. Such criteria have been employed with reasonable success by the U.S. Selective Service System in identifying those whose deep and long-standing moral convictions forbid direct participation in war. They can be used with similar success in identifying genuine appeals to conscience in the healthcare setting (Benjamin and Curtis).

CONSCIENTIOUS BUT WRONG. Conscience is not an infallible guide to conduct. Even those who attend carefully to matters of integrity and who critically examine their basic convictions may, at a later date, judge some of their conscientious acts as wrong. Should one, then, always follow one's conscience? If by "conscience" we mean the exercise and expression of good-faith efforts to integrate conduct with reflective ethical conviction, the answer is "yes." Following conscience is obligatory, even if one's act turns out to be wrong, because one is doing what one reflectively believes to be right. Conversely, deliberately acting contrary to conscience is blameworthy, even if one's act turns out to be right, because one is doing what one reflectively believes to be wrong.

We must therefore distinguish the character of an agent from the rightness of a particular act. That an act is required by conscience entails neither that it is right nor that others must endorse the agent's convictions or permit the act to occur. It is difficult, for example, to question the character of Jehovah's Witness parents when they conscientiously refuse to consent to a life-saving blood transfusion for a young child. Yet if we have good reasons for believing that withholding the transfusion would be seriously wrong, we may try to persuade the parents to consent and, if necessary, seek a court order mandating treatment. Distinguishing the conscientiousness of the parents from our judgment of the act, though not eliminating the difficult question of whether, and if so, how, to intervene, enables us to attend more adequately to its complexity.

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SEE ALSO: *Autonomy; Conscience, Rights of; Emotions; Ethics, Religion and Morality; Freedom and Free Will; Human Dignity; Human Nature; Principlism; Profession and Professional Ethics*

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CONSCIENCE, RIGHTS OF

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The phenomenon of a *right of conscience* arises only in a society that takes seriously the autonomy of individual persons. Philosopher James Childress has described appeals to conscience as "a person's consciousness of and reflection on his own acts in relation to his standards of judgment." (Childress, 1979) Rights of conscience are political rights that protect people's ability to do what they believe is morally best: they are political *autonomy rights.* Common scenarios for the exercise of a right of conscience in healthcare include seeking an exemption from mandatory vaccination and, for physicians, refusing to participate in morally controversial procedures like abortion.

Political Significance

To understand the political role of rights of conscience, it helps to think of the activities a person might engage in as falling into one of three political categories: (1) prohibited, (2) permitted, or (3) required. In Western societies, the vast majority of possible activities are permitted, meaning people may engage in that activity if they wish (it is not prohibited), but they do not have to engage in that activity (it is not required). A person may exercise autonomy, then, in deciding whether to engage in the activity. Likewise, some activities (e.g., murder, robbery) may be prohibited, and some activities (e.g., military service in times of war) may be required.

An autonomy right ensures that protected activities are not unduly prohibited or required. For example, one prominent autonomy right protects the practice of religion: the autonomy right of freedom of religion means that a person's religious practice cannot be unduly prohibited or required. This allows a person to practice religion, but also allows a person to decide not to practice a religion. Thus, the practice of religion is neither prohibited nor required, allowing a person to exercise autonomy in the practice of religion. Other examples of autonomy rights include freedom of speech (which protects against state prohibition of the expression of opinions, but does not require a person to express their opinion), freedom of assembly (which protects against state prohibition of people's ability to assemble), and, in the United States, the right to own firearms (which protects a person's ability to own a gun).

The Focus of Autonomy Rights

In Western societies, most political autonomy rights focus on ensuring that certain activities are not unduly prohibited (thus protecting a people's ability to engage in that activity if they should choose). This can be seen in the way such rights are normally phrased:

> Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof; or abridging the freedom of speech, or of the press; or the right of the people peaceably to assemble, and to petition the Government for a redress of grievances. (Bill of Rights, U.S. Constitution, Amendment I)

Rights of conscience, however, protect a person from mandatory participation in an activity if the activity in question threatens the fundamental values of an individual person. This focus can be seen in the way conscience clauses are typically phrased: "No person shall be required to …" In a clinical context, rights of conscience are exercised against a backdrop of a professional duty to treat a patient once a provider-patient relationship is established. Thus, rights of conscience claim an exemption to participation in activities that one would otherwise be expected to undertake. The most common example is a claim to be exempt from participation in abortion procedures.

Conditions of a Right of Conscience

The primary conditions necessary for the legitimate exercise of a right of conscience consist of: (1) the lack of harm posed to others by the exercise of a right of conscience; and (2) strength and sincerity of beliefs that are the basis for a claim of conscience. The exercise of a right of conscience does *not* require a demonstration of the truth of beliefs that are the basis of a right-of-conscience claim, as requiring the truth of a belief to be demonstrated would trivialize the right itself. The first of these conditions represents a straightforward balancing of the rights of individuals through recognition that autonomy rights must be restricted when significant harm is posed to others. Thus, for example, a right to freedom of speech does not include a right to shout "Fire!" in a crowded theater. Similarly, seeking an exemption from mandatory vaccination is restricted in circumstances of epidemic disease, where failure to be vaccinated could pose a threat of harm to others.

Such a balancing of autonomy rights and social harm was clearly recognized in the U.S. Supreme Court case of *Jacobson v. Massachusetts.* Henning Jacobson argued that he should not be forced to receive a vaccination during a smallpox epidemic because "compulsory vaccination is … hostile to the inherent right of every free man to care for his own body and health in such a way as to him seems best." The Supreme Court rejected this argument in the context of an epidemic, however, stating, "The liberty secured by the Constitution of the United States does not import an absolute right.… There are manifold restraints to which every person is necessarily subject for the common good" (*Jacobson v. Massachusetts*).

The second condition listed above is less commonly required for the exercise of an autonomy right. It requires that rights of conscience only be exercised on the basis of values that are central to one's life. As Childress describes it, "In appealing to conscience I indicate that I am trying to preserve a sense of myself, my wholeness or integrity … and that I cannot preserve these qualities if I submit to certain requirements of the state or society" (Childress, p. 327). To legitimately exercise a right of conscience, one must show that participation in the required activity would threaten values that play a central role in the way one has chosen to live.

Because the majority of people in Western societies are religious, and their religious convictions normally represent their most fundamental values, claims to rights of conscience most commonly arise in the context of religious convictions, though rights-of-conscience claims need not be based upon religion. The most prominent example is conscientious objection to participation in war. During the Vietnam War era, the U.S. Supreme Court ruled that a person may qualify for an exemption to participation in war if the person's opposition stems from "moral, ethical, or religious beliefs about what is right and wrong, and that these beliefs be held with strength of traditional religious convictions" (*Welsh v. U.S.*).

The type and significance of harm to others that might negate the ability to exercise a right of conscience, as well as the abstract notion of *strength of conviction* necessary to qualify for a right of conscience, represent the key points of contention in how to distinguish legitimate from illegitimate claims to a right of conscience. The most prominent debate in the literature concerns the consequences of recognizing rights of conscience relevant to access to abortion services. In some areas, conscientious refusal by physicians to participate in abortion services has limited access to abortion services, or made them unavailable. Use of this type of harm to negate rights of conscience, however, is met with substantial skepticism. The argument requires that the conscience of a woman seeking access to abortion takes precedence over that of a physician, and also assumes that a right to not be prohibited from having an abortion is tantamount to a right of access to abortion services. These issues remain at the center of this ongoing debate.

A second type of harm that is discussed in the literature consists of psychological and moral harms associated with the necessity of transfer of care from a provider a patient has chosen, due to that provider's refusal to participate in a particular treatment plan. The significance of this should not be overlooked: while transfer of care leaves a patient with continued access to care in the abstract, the patient may not feel as comfortable with the caregivers to whom he or she is transferred. Thus, one should only necessitate such a transfer if the values threatened are significant.

The Exercise of Rights

Recognition of the types of harms described above is closely tied to attempts to outline the scenarios in which a right of conscience should (and should not) be exercised. While it is desirable to recognize rights of conscience in matters of central moral importance to a person, rights of conscience should not be used, for example, to discriminate against a racial or ethnic group by refusing services to that group, or to undermine informed consent by pressuring a patient to agree to a treatment plan through threat of transfer of care. Conscience clauses that offer blanket protection and simply require transfer of care fail to address these concerns, so criteria to distinguish when a right of conscience is appropriately exercised become important.

Most of the literature recognizes that entering into a profession imposes some level of moral duty that may at times conflict with a person's own judgment. While it is important to recognize moral diversity within a profession, and thus allow for some cases of conscientious objection, it is also important to recognize the weight of professional obligations, such as respect for patient autonomy and informed consent. Because professional obligations to respect informed consent do carry moral weight, rights of conscience are, in general, more appropriately exercised over patient requests for services than over patient refusals, since objection to a patient's refusal fails to respect that patient's evaluation that the treatment does not offer desired benefits (this is a general guideline, however, and may admit of exceptions). So, for example, a physician's right of conscience (for refusal of services) is appropriately exercised over a patient's request for an abortion or for assistance in committing suicide (physician-assisted suicide). A right of conscience is not appropriately exercised, however, over a patient's refusal of a ventilator. Similarly, it is widely recognized that rights of conscience should not be exercised over simple disagreement with a patient's treatment choice. These general guidelines still leave a lot of gray area, however. For example, does a request by a Jehovah's Witness for surgery without blood products constitute a refusal of blood products or a request for a specific surgical procedure (one that does not involve the use of blood products)?

Professional obligations of nondiscrimination are also important in formulating criteria for the legitimate exercise of a right of conscience. The conscientious objection in question should not be based on *who* is to receive the treatment or procedure. Instead, conscientious refusal should be based on the *type* of treatment or procedure in question, rather than, for example, provision of this treatment or procedure to members of a particular racial or ethnic group. Here, too, the general guidelines leave room for debate; such as when an objection is based on the fact that a procedure is particularly dangerous for a certain segment of the population (e.g., organ transplant recipients, elderly patients).

Summary

While several points of debate continue to remain contentious, some general observations can be made concerning the appropriate exercise of a right of conscience. First, such rights should only be exercised if doing so does not pose a threat of significant harm to others. Second, the exercise of a right of conscience should be based upon values that play a central role in the life of the person claiming a right of conscience. Related to this, rights of conscience should not be exercised on the basis of simple disagreement about a treatment plan. Third, conscientious objection to patient requests will be, in general, more appropriate than objection to patient refusals. Finally, professional obligations to respect patient autonomy and to avoid discriminatory practices should be weighed against the exercise of a right of conscience. In this context, conscientious objection should be exercised only when based upon an objection to the *type* of activity in question.

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SEE ALSO: *Autonomy, Beneficence; Clinical Ethics; Conscience; Informed Consent; Surrogate Decision-Making; Warfare: Medicine and War; Whistleblowing in Healthcare*

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CONSENSUS, ROLE AND AUTHORITY OF

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Consensus plays a paradoxical role in bioethics: Although the weight of opinion is traditionally thought to have little or no merit in the resolution of moral problems, practical moral problems beg for a modus operandi that enables activity to proceed. Upon analysis, consensus also reveals a complex conceptual structure as well as a murky etiology in the history of ideas. Yet it seems difficult, if not impossible, to avoid the pursuit of consensus in the face of a morally troubling situation, however obscure the object of that pursuit might be. The impetus for a consensus is acute in a field like bioethics, which often expresses itself in such settings as clinical or research ethics committees (Moreno, 1988) and governmental policy commissions (Walters).

The History of Consensus

It is not easy to get clear on the idea of consensus, and particularly the idea of moral consensus. One reason is that relevant discussions in the history of philosophy do not always use those terms. For example, Plato’s political philosophy can be taken as a treatise on consensus, but he would understand a consensus (a Latin term, of course), as a common or shared opinion. Thus the findings of the jury in Socrates’s trial represent a shared opinion, and to Plato a deeply flawed one, that led to the death of his beloved teacher and seems to have inspired his elaboration and extension of Socratic philosophy in the *Republic.*

Literary and philosophical references to consensus seem first to have appeared with some frequency only since the nineteenth century. By then the political conception of consent of the governed had of course been subjected to close examination prior to the American and French revolutions and played a key role in those epochal events. Consensus might be regarded as the sociological cousin of political consent, not always as explicit in its manifestation nor as definitive, but nevertheless a key element in a well-functioning society. In contrast to the philosophical notion of consensus exemplified in social contract theories, sociological understandings of consensus emphasize acquiescence to extant norms.

For social scientists consensus emerged as an important category of analysis in the era of industrialization, as it helped account for the social harmony required of complex bureaucracies in the private and public sectors. Increasingly, societies in the process of pluralizing also had reason to be more aware of consensus as they encountered an unaccustomed diversity of basic values. By the late twentieth century consensus had become very nearly an end in itself among policy makers intent on finding common ground in postmodern societies rent by divisive issues, such as abortion.

Bioethics is certainly a result of this emerging process. In the early 1960s, when dialysis machines were developed to the point that they could extend life indefinitely but remained in short supply, the need to formulate an acceptable allocation arrangement was acute. Other matters of concern followed rapidly, including organ transplants, genetic engineering, human experimentation, and discontinuing life-sustaining treatment. In each case bioethics gained social standing through its participation in the formulation of a consensus. Conspicuous in its absence from this list is abortion, and it may be significant that this is the only one of these topics that was resolved almost solely in the legal system. Although the law is often an excellent instrument for consolidating a moral consensus, this is evidently not always the case.

The Paradox of Consensus in Bioethics

The emergence of consensus as a category of moral discourse flies in the face of some deeply held cultural assumptions, at least in the West. Plato's version of consensus as shared opinion was intimately related to his devastating critique of democracy as mob rule, a view that arguably required more than a millennium to overcome. His philosopher-kings knew the Good, they did not have a mere opinion about it. The great moral heroes of Western culture, from Moses to Jesus to St. Joan to Gandhi and Martin Luther King, Jr., embodied the Platonic ideal of the individual who knows the Good, confronting the mob, possessed only of an opinion.

Although one can hardly gainsay the salutary societal effects of moral heroism, the confidence it implies has its pitfalls. What American philosopher and educator John Dewey (1859–1952) so penetratingly labeled a quest for certainty characterizes much of subsequent thought, philosophical and scientific, as well as theological, all under the sway of Platonism. With the emergence of modernity, moral certainty in particular has been in tension with what another American philosopher, Charles Sander Peirce (1839–1914), called fallibilism: the doctrine that assertions must be revisable in light of further evidence, and that in the final analysis belief statements are certified as true by a community, not an individual. Fallibilism is the underlying philosophy of experimental science. Dewey especially argued that there is an experimental quality to the moral life, and that longstanding moral values have proven themselves over long experience and cross-culturally. On this view, the adaptation of values to new circumstances requires literal re-evaluation, much as scientific communities revise hypotheses in light of new evidence. In direct contrast to Platonism, this position valorizes community opinion, or consensus.

As bioethics both draws from traditional moral values and concerns itself with emerging and often quite novel problems, this tension between Platonic and Deweyan views of moral consensus underlies all bioethical discourse. It is perhaps especially well illustrated in the contrasting outcomes of two early bioethics debates. In the recombinant DNA controversy of the 1970s, the first generation of bioethicists allied with scientists to undermine theological critiques of science unleashed on unique human qualities (Evans). By contrast, at the same time bioethicists added their voices to those protesting the high degree of discretion permitted medical scientists in human experiments (Moreno, 2001).

Modes of Consensus

The moral paradox of consensus in bioethics may therefore work itself out in surprising ways, but on the whole, and especially when it engages in developing public policy, bioethics is largely a consensus-oriented field (Moreno, 1995). These consensus processes may occur in various contexts and may be more or less self-conscious. Patient management conferences often involve ethical issues that may not be acknowledged as such, in contrast to the more formal setting of an ethics committee. The most formalized and public context for moral consensus is the governmental ethics commission. Lying somewhere in between are ethics advisory boards for private entities.

Whatever the context, insofar as consensus is the preferred outcome it can be distinguished from compromise, in which the parties seek to defend and retain certain underlying principles though they may be willing to modify elements of their viewpoints that are less central (Benjamin). In a truly consensus-oriented situation the members of the group do not arrive with fixed positions but each appreciates a genuine puzzlement at the problem and the optimal solution. They then work together to find what seems to be the most ethically justifiable way to manage the problem. Although the common language refers to *seeking* and *achieving* consensus, these terms imply a static series of events while in fact consensus is more accurately described as a process through which a certain shared sense emerges.

Considering that the problems addressed in bioethics tend to be novel in at least some important ways and are often controversial, it may be surprising that consensus is ever realized. In this respect a focus on particular cases or rather highly specified issues can be critical. Frequently consensus characterizes a group discussion of a specific moral problem though the members of the same group may harbor substantial differences concerning general moral views. One may therefore contrast deep with superficial consensus, where the latter is not dependent on the former. Various moral systems may lead to the same conclusion in particular cases. Efforts to reach a deep consensus may even backfire if they fail and the group's solidarity is thereby undermined. The somewhat counter-intuitive conclusion is that, when consensus is the concern, superficial agreement is often quite adequate and efforts to resolve deeper differences should be approached with caution.

Because bioethics is a social institution that often expresses itself in appointed or self-appointed committees, panels, task forces, commissions or some other small group, an important question arises about the relation between that group and its stakeholders. Many ethics panels include members of the community, apparently in contrast to the experts who generally make up the majority of the group. The presence of community members is presumably intended to help ensure that the views of the wider society are represented. But the precise sense of representation at work here raises further questions. One way of modeling this activity is that of democratic deliberation, in which those actually engaged in the discourse are taken to be stand-ins for all those who do not have the resources or opportunity to immerse themselves in the issues at hand.

Consensus and Its Critics

The rapid growth of the bioethics profession and its close association with consensus processes expose it to the Platonic critique of shared opinion, particularly as these opinions are often received as a kind of moral expertise (Tong). The notion of expertise suggests that there is a certain body of information available to those who have certain training and experience, but not to others. If this information is taken to be at least partly factual in nature, then the consensus of moral experts must be limited to description rather than prescription. That is, on pain of violating the fact-value distinction, moral expertise can do no more than identify what is and has in fact been valued, not what ought to be valued.

Descriptive moral consensus is a form of social science, perhaps of survey research, that leaves little room for the dynamic public and professional discourse that characterizes bioethics. Without running afoul of the fact-value distinction, it appears that bioethicists must reconstruct their activity as a kind of social reform movement (Moreno, 1995). Their expertise lies not in the privileged status of their recommendations but in the arguments they put forward in support of these recommendations. Within these arguments is evidence drawn from many sources and principles derived from various sources, secular and theological, that are viewed as more or less authoritative.

Defenders of the role of consensus in bioethics, such as D. Micah Hester and Bruce Jennings, develop the notion of the individual as inherently a member of a community, so that values are embedded in social life. Rarely does any group speak with a single voice, however, and bioethicists themselves have diverse moral understandings regarding central moral issues. Even among these ethics experts there is often no common moral vision. In fact, it may be argued that this diversity is often ideological in nature, and therefore as suspect as any assertions about morality delivered by anyone with a partisan purpose (Engelhardt, 2002).

Similarly, no professional group can hope to speak for all moral viewpoints. Bioethicists have both adopted and helped articulate a certain ethical framework that valorizes individual self-determination. But many cultural subgroups, both in the developing world and within the developed world, do not accept the standard bioethical doctrines of truth telling and informed consent. Thus even if bioethicists as a professional class share some very broad consensus, they can hardly claim to speak for those groups that do not share their liberal sentiments with respect to individualism. Even a weak consensus seems hard to achieve across the board in a pluralistic society, and it is an impoverished morality that imposes self-determination on those who reject it (Trotter).

Yet a consensus among bioethical experts, however the latter term is defined, is not guaranteed to influence social policy. As Mark Kuczewski has pointed out, in the areas of foregoing life-sustaining treatment and the conduct of biomedical research, bioethicists have had extraordinary success in helping to develop a social consensus. But, as he notes, the same cannot be said for the questions concerning universal health insurance, even though many bioethicists are on record as supportive of such a program. This fact suggests that a bioethical consensus is perhaps not as weighty in public life as the critics of consensus may fear, nor as bioethicists may wish were the case.

Constraining Consensus

Considering both the moral hazards inherent in consensus and its practical inevitability in a field of ethics oriented toward practice and group decision making, careful attention must be given to the conditions under which consensus processes take place. As Kuczewski notes, in itself agreement among bioethicists means nothing. Acquiescence to expertise for its own sake would be an instance of the naturalistic fallacy, the derivation of a normative statement from a descriptive one. At the extreme, the widespread adoption of a collective bioethical soundbite that moves the public owing to its rhetoric would be emotivism in the guise of reflection.

What does count is the quality of arguments provided. These can and should be formulated, evaluated and revised by a community of bioethical inquirers. The environment must be one that fosters the exchange of reasoned views, further presupposing the peaceful resolution of moral controversy (Engelhardt, 1995). What emerges is a set of side constraints on moral consensus processes. Besides peaceable and reasoned argument there are also elements of democratic deliberation, such as a willingness to entertain unpopular points of view, mutual respect among the protagonists, and the assurance that the voices of all stakeholders have an opportunity to be heard. Strict attention must therefore be paid to the quality of the process. A self-critical consensus process should worry not about whether the outcome approximates an objectively right solution but whether the proceedings have satisfied the requirements of fairness and accuracy.

The Future of Consensus in Bioethics

If consensus is an intrinsic part of bioethics as a social institution, especially in its capacity as a forum for the development of institutional and public policy, then there will be a continuing need to examine the way consensus processes operate both within bioethics and in the larger society that incorporates the views offered by bioethicists. A field concerned with the construction of moral standards should not be ignorant of the ways its procedures and products may be distorted, whether intentionally or not. This conclusion argues not only for a degree of self-consciousness about bioethical discourse. It also commends the need to develop a sophisticated understanding about those social psychological and political processes that set bioethics apart from other forms of moral inquiry.

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SEE ALSO: *Authority in Religious Traditions; Autonomy; Clinical Ethics: Institutional Ethics Committees; Coercion; Communitarianism and Bioethics; Conscience, Rights of; Ethics: Social and Political Theories; Managed Care; Natural Law; Public Health Law; Trust*

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CONTRACTARIANISM AND BIOETHICS

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The idea of the social contract has been a central feature of Western moral and political thought since the seventeenth century. Theories that follow that tradition claim that the legitimate source of moral or political authority is mutual agreement. Contractarianism had widespread influence through the writings of Thomas Hobbes, Jean-Jacques Rousseau (1973 [1762]), Immanuel Kant (1965 [1797]), and John Locke (1960 [1706]) and has had a recent revival in the work of John Rawls (1971, 1993), David Gauthier (1986), and Thomas Scanlon (1998). Contemporary contractarians continue to drive discussions about topics such as the nature of democratic principles, the distribution of scarce resources in healthcare, the provision of public goods and services, the current generation's duties to future generations, and the current generation's obligation to preserve and protect the environment.

The Tenets of Contractarianism

Contractarianism includes a diverse family of theories that share a basic understanding about the nature of normative justification: When faced with questions such as the following—What is just? What is right? What should I do?—contractarianism seeks an answer rooted in agreement. The motivating force behind the contract approach is the idea that consent confers legitimacy on particular moral decisions, the policies and laws of a particular society, and the basic principles of a just society.

The metaphor of the social contract represents people's willingness to enter into a society or a system of moral rules for mutual benefit, agreeing to bind themselves to the rules that make cooperative life possible. The social contract sometimes is characterized as a general agreement to keep more specific agreements. This idea is rooted in a form of skepticism about competing sources of normative authority, such as theories about human nature, theories of natural law, perfectionist theories, virtue theory, and other theories that attempt to offer more objective or foundational support for the content of moral principles and theories of justice.

Within the family of theories contractarians tend to be divided over questions about how to characterize agreement and the mechanisms of choice. For example, does moral justification stem from actual historical agreement, or is it more appropriate to reason hypothetically about what people would have reason to agree to in certain ideal conditions? The former approach to moral questions traces moral justification to actual agreements. The latter approach reflects on the hypothetical agreements of imagined agents in idealized circumstances. Both variants posit a starting point or initial position from which people have historically or hypothetically emerged to contract with one another for the sake of mutual benefit. Both mechanisms make it possible to evaluate current conditions in society or current moral practices by reference to a more ideal historical or hypothetical situation. For the contractarian, social and political institutions are human conventions that are open to criticism, rejection, revision, and ultimately acceptance.

Both the actual and the hypothetical contractarian approaches to moral and political theory have played a central role in bioethics. People who are interested in carrying on the contractarian tradition within bioethics must contend with some of the problems inherited by the more general theory as it has been developed in moral and political philosophy. What follows is an overview of contractarian approaches to the special problems of bioethics, including consideration of the strengths and weaknesses of those approaches.

Contractarian Approaches to Bioethics

If morality and politics are understood as joint enterprises that are entered into for mutual advantage, as contractarians understand them, one can begin to see a natural affinity between bioethics and contract theory. The patient-physician relationship, the practice of informed consent, the use of advance directives, the conducting of medical and scientific research, the obligation to take care of the elderly, systems of medical insurance and national healthcare, and many other aspects of health policy are central issues in bioethical debates. In an important way contractarianism attempts to make health policy, scientific institutions, and individual practitioners answerable to the individuals they serve.

Howard Brody (1989) has drawn a parallel between the rise of contractarianism in political philosophy and the rise of contractarianism in medical ethics. Just as Enlightenment philosophers challenged the idea of the divine right of kings to rule over subjects without consent, bioethicists from the early 1960s through the 1970s challenged the idea of paternalism in medicine. If patients are viewed in the way Enlightenment philosophers viewed the citizens of a state—as being autonomous and worthy of respect—treating patients paternalistically—considering them as being ignorant and inherently dependent on physicians—violates patients' autonomy.

THE PATIENT-PHYSICIAN RELATIONSHIP. Robert Veatch (1991), one of the earliest proponents of contract theory in bioethics, posed the following question: What type of patient-physician relationship would the parties to that relationship rationally consent to, assuming they were placed in a starting position of equal power? The resulting contractual model allows for important differences in knowledge and decision-making capacities between a patient and a physician but requires that equal respect be given to the interests and goals of both parties. The model grants physicians control over technical decisions and grants patients control over the aspects of a decision that involve personal values. If a patient in renal failure is faced with the options of ongoing renal dialysis and kidney transplant surgery, it is the physician's responsibility to present the risks and benefits of those options and explain the relevant medical information. It is up to the patient to decide what degree of risk she or he is willing to accept with either option and weigh the options in light of his or her own values.

The contractual model of medical ethics views the patient-physician relationship as one of respectful communication and negotiation. The specific list of rights and duties is arrived at through the hypothetical contract mechanism. If physicians and patients were negotiating the terms of the patient-physician contract, what terms would all the interested parties include in the contract? Certain rights, such as the patient's right of self-determination, and certain corresponding duties, such as the physician's duty to disclose all the information needed by the patient to make a fully informed choice, would make up the content of the contractual model. Consistent with this model is the idea that a patient may willingly delegate his or her choices to a physician.

Norman Daniels (1981), following the political philosopher John Rawls (1971), relies on a Rawlsian model of the hypothetical social contract to construct a specific theory of healthcare needs. In the classic Rawlsian model it is imagined that a number of impartial observers are charged with the task of choosing basic principles of justice that will shape the constitution and laws of the society into which the observers will be born. These hypothetical agents do not know what place they will occupy within the society or even the generation to which they will belong. The thought is that the resulting principles of justice will be fairly chosen, unlike principles chosen by actual, biased, and self-interested parties in a real society. Rawls (1971) argues that rational agents in the original position will want to increase the amount of primary social goods available to them, consistent with an equal share of liberty. He assumes that such agents would be risk-aversive in a certain sense: They would not be willing to risk losing a certain basic amount of primary social goods in exchange for the possibility of seeking greater amounts of those primary goods.

HEALTHCARE NEEDS. Expanding on Rawls's general theory of justice, Daniels (1988) places healthcare goods under the principle of fair equality of opportunity, including healthcare needs among the primary needs of a society's members. One of the most interesting results of the theory as it is applied to health policy is the way in which Daniels attempts to solve the problem of age-group bias. In attempting to determine a just allocation of scarce health resources most real agents are deeply biased in favor of the scheme that will maximize the resources of their age group, heavily discounting the present over the future. If, however, people place themselves behind a Rawlsian veil of ignorance and imagine that they are blind to their particular generation, they will arrive at fair principles of healthcare distribution. The hope is that the resulting principles of resource allocation will ensure the well-being of all persons as they pass through various health institutions through the course of their lives. A healthcare system designed in accordance with the principle of equal opportunity will attempt to balance, for example, the need for services in critical care, preventive care, and long-term care. If the institutions at each stage are designed prudently, the hope is that all generations will benefit from the overall health system.

THE REQUIREMENT FOR PERMISSION. Against the Rawlsian contractrarian approach to bioethics, Tristram Engelhardt (1996) has offered a theory of bioethics rooted in the Kantian philosophical tradition, which relies centrally on the requirement of permission between persons. Engelhardt's approach to the specific problems of bioethics stems from deep skepticism about the possibility of achieving consensus about the substantive questions in morality and politics. He argues that all competing approaches to bioethics rely in some way on prior substantive assumptions about what is good or right. Such assumptions, he claims, cannot reasonably be made in a pluralistic world filled with competing ideas of justice and fairness, understandings of rationality, and visions of the good life.

Engelhardt offers an alternative model of bioethics that rests on a very minimal assumption salvaged from the Enlightenment project and the contractarian tradition. The basic assumption is that the only justifiable ground for dealing with moral controversies in a world of moral diversity is to appeal to actual agreement as the source of moral authority; any other appeal is illegitimate because it involves acceptance through force or coercion. To avoid imposing substantive moral views on those who are strangers to a group of people's views, Engelhardt urges people to appeal to consent as the mark of legitimate moral authority.

Rather than design a healthcare system that is based on the hypothetical agreement of hypothetical agents who must be assumed to have certain substantive views about what is just or good, Enghelhardt proposes that decisions about the allocation of health-resources be made directly by real parties to real agreements. In this model market mechanisms generally will guide decisions about the allocation of health resources on the national level, with the assumption that those who participate in the market implicitly if not explicitly consent to the practice and its outcomes.

Engelhardt leaves open the possibility that smaller groups and communities will agree to set up health institutions, such as private hospitals and long-term-care facilities, that are governed by more substantive goals of justice or visions of the good life. A Catholic hospital, for example, might have an internal policy against performing abortions and also might have a policy of offering a certain amount of charity care to indigent patients. In this model the relationship between the patient and the physician is characterized fundamentally in terms of permission and consent. Agreements between patients and their caregivers, such as those struck through the process of filling out advance directives, play a central role in ensuring that the minimal moral requirement of permission is secured. Similar to Veatch's account, the relationship between patient and physician is, in Engelhardt's model, understood as one of respectful negotiation between the different parties to the decision-making process.

Critiques of Contractarian Approaches to Bioethics

Several important criticisms have been lodged against contractarian approaches to bioethics. Those criticisms have a common theme: The moral relationships and contexts that characterize the healthcare and research settings are too complex and subtle to be understood solely in terms of a contract. The general concern is that contract theory is too minimal in its approach to the rich and complicated moral terrain of bioethics.

Critics have objected that the physician-patient relationship rarely begins with an agreement or involves explicit negotiating. More often the beginning of the relationship is characterized by surprise, stress, a lack of time, fear, hope, an imbalance of knowledge, and a great need for trust. It is not typically a calm encounter between equal partners in a negotiation. This objection speaks primarily against the actual-contract model offered by Engelhardt because the hypothetical model is attempting to ask what principles should guide this stressful, complex encounter, and these principles are chosen in a calmer hour by philosophers, bioethicists, and health-policy makers.

This objection can be extended to the hypothetical model, however, by pointing out the disparity between the ideal situation in which principles of bioethics are hypothetically chosen and the real world. If the disparity is significant, it is not clear what binding force hypothetically chosen principles should have in actual practice. A great deal depends on the content of the hypothetical situation of choice and the substantive principles of rationality that will guide choice. If too much is packed into the descriptions of the initial position, the resulting choice will be biased and arbitrary, exactly the pitfall the contract tradition was designed to avoid. If one provides no structure and content to the nature of rationality guiding choosers in the initial position, the resulting principles will be empty and meaningless. This is a serious problem for contract theory in general that has been inherited by those hoping to apply that model to bioethics.

The unique relationship between patient and physician, others have argued, is not best characterized by the economic-political metaphor of the contract because the contract model relies too narrowly on rights and permission and overlooks other important goals and duties, such as compassion and trust. From the perspective of virtue theory, for example, the contractarian model of bioethics fails to address important issues about the character of physicians and other healthcare workers. What does it mean to be a good physician or a good nurse? Certainly there is more to being a good health professional or a good researcher than making sure that one negotiates the permission of one's patients and research subjects thoroughly. William May (1996), for example, suggests that the religious idea of a covenant compared with the secular metaphor of the contract is better able to capture the rich sense of duty and obligation inherent in the physician-patient relationship.

What drives this objection is a deeper concern that the minimal moral requirements of the contract model will not encourage a lasting and dedicated relationship with patients but instead will encourage physicians to ask, "Has the consent form been signed?" Although beneficence and compassion are clearly compatible with contractarian requirements in bioethics, there is a sense in which such moral goals remain "optional" because they are not the central focus of the theory.

Along a similar line communitarians have argued that the contract model is too individualistic in its focus. Moral issues in bioethics, even in the narrower domain of medical ethics, involve complicated social systems, shared and unspoken understandings, deep-seated cultural beliefs, and common expectations. Explicit contracts account for only a small part of the moral dealings in this context. Especially in areas such as public health, many decisions are best made in terms of what is best for the community or what maximizes the overall health of the community over and above the desires and preferences of individuals. Sometimes the only way to stem the immediate threat of an infectious disease such as tuberculosis may require practices, such as reporting and quarantine, that infringe on principles of individual consent and permission.

A final objection to the contractarian model, especially as it is applied to bioethics, is that it is centrally a theory about persons, whereas bioethics involves important ethical issues about nonpersons or semipersons, including animals, embryos, fetuses, children, adults with serious mental deficits, brain-dead patients, and the dead. Some of the most interesting and challenging issues in bioethics involve subjects one does not easily imagine sitting at the negotiating table. Because the contract model focuses on what rational, conscious agents would choose, there is concern that the focus on rational agreement excludes the moral concerns of more vulnerable members of society.

A morality based on mutuality and rational consent certainly can deliver principles for addressing the needs of children, the mentally ill, and animals, but only insofar as the agents to the agreement deem those more vulnerable subjects worthy of consideration. Because moral duties and obligations emerge from mutual agreement, any duties that people have toward research animals, for example, could result only from the agreement of the human parties involved. The obligation is indirect: If animals and other vulnerable subjects are thought by human parties to an agreement to be worthy of care and respectful treatment, people will have indirect duties toward those animals. For some critics indirect consideration is too unstable a moral requirement, especially for subjects that cannot be parties to the agreement and are particularly susceptible to being overlooked in the moral calculus of rational consent.

Conclusion

Despite these objections the metaphor of the contract remains a powerful heuristic tool for reflecting on the existing conventions and practices of medicine and science. The lasting insight of contract theory is that the willingness of individuals, rather than force or rigid appeals to human nature, is a powerful legitimating force in morality and politics in a world where individuals disagree deeply about foundational moral issues. Thus, contract theory remains a particularly useful insight and starting point in the diverse field of contemporary bioethics.

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SEE ALSO: *Casuistry; Communitarianism and Bioethics; Consensus, Role of; Ethics; Freedom and Coercion; Obligation and Supererogation; Pragmatism; Principalism; Rights; Utilitarianism*

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CORPORATE COMPLIANCE

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The word compliance can be defined as the act of adhering to or conforming with a law, rule, demand, or request. In a business environment, conforming to the laws, regulations, rules and policies is the part of business operations often referred to as "corporate compliance." Corporate compliance involves keeping a watchful eye on an ever-changing legal and regulatory climate, and making the changes necessary for the business to continue operating in good standing within its industry, community, and customer base. In a broader sense, corporate compliance extends beyond mere legal and regulatory conformity into the realm of promoting organizational ethics and corporate integrity.

The roots of corporate compliance efforts are found in the government contracting scandals of the 1980s. During those years, the Department of Defense received extraordinary charges for commonplace equipment. Investigations led to criminal convictions and monetary settlements for a number of companies providing equipment and supplies under contract to the U.S. government. In response to these events, defense industry companies wishing to contract with the government were required to develop corporate compliance programs to prevent such abuses in the future. Shortly thereafter, the U.S. Sentencing Commission established Organizational Sentencing Guidelines that offered more lenient fines and penalties for corporate violators that created voluntary programs to prevent and remedy violations of law and regulation.

Leniency under the Sentencing Guidelines is calculated. Upon a finding of guilt, the court considers the company's compliance efforts. This is done through the use of a culpability scoring formula set forth in the Sentencing Guidelines and applied to corporate conduct. Documented evidence of compliance efforts such as monitoring, auditing, corrective actions, and system modifications or redesign to prevent future problem behavior reduces the culpability score or degree of "guiltiness." Fines and penalties are then assessed based upon this score.

Beyond the Sentencing Guidelines, indirect incentives exist for businesses to create compliance programs. A company's intolerance for wrongdoing, evidenced by corporate action taken consistent with its corporate compliance effort, can speak volumes to federal prosecutors conducting an investigation of alleged wrongdoing. Where prosecutors determine that a company has high standards of conduct demanding employee compliance with law and regulation, it may be inferred there was minimal or no criminal intent by the organization to commit a wrongful act. The absence or reduction of evidence of intent then translates into a lesser charge or citation, particularly in a case where intent is a critical element of the crime or offense. Corresponding to the reduced charge, the fines and level of penalty are less than would be associated if a more serious (in degree) offense were claimed.

Compliance programs may also impact civil enforcement fines or penalties. If a company is found liable for wrongdoing (rather than guilty as in a criminal action), the existence of a compliance program may reduce the risk of a full-scale government investigation of the company. Short of a civil trial seeking monetary recovery, the existence of an effective compliance program often prompts government agency auditors to find human error rather than conscious misconduct led to a failure to comply with a set of rules. In these instances, leniency can be granted in the form of more favorable repayment terms and interest rates, and reduced civil fines and penalties.

A well-developed, established compliance program also helps a company avoid the imposition of probation or a corporate integrity agreement (CIA). The CIA is a mandated type of compliance program where timeframes for achieving targeted performance are aggressively short. Components of a CIA include staff education on general and specific compliance issues, establishing specific policy and procedures to minimize recurrence of the misconduct, auditing, and monitoring activities. Quite often these mandatory compliance programs call for the use of outside consultants to support business operations and/or provide objective documentation of progress toward fulfillment of the terms set forth in the agreement. CIA implementation is often expensive. Aggressive deadlines for achieving compliance milestones, multiple compliance targets, complexity of compliance issues, and the use of government-approved outside agencies are factors influencing cost.

Healthcare Compliance

With the decade of the 1990s came a warning from the Office of the Inspector General (OIG) for the U.S. Department of Health and Human Services (HHS). The healthcare industry was not immune from prosecution and liability for fraudulent and abusive practices. OIG audits demonstrated that as much as 10 percent of U.S. government-funded healthcare expenditures were related to care that was not billed correctly, was not medically necessary, or was never delivered to the patient. There were additional concerns about the adequacy of care being delivered in the United States and concern about the reporting of health organization costs. Fraud and abuse are the terms often used in reference to these types of practices.

HHS and the OIG projected savings to be billions of dollars per year if concerted efforts were made to minimize such practices. Several initiatives were considered. One was a curative approach, whereby fraudulent or abusive practices would be investigated and prosecuted. Another was enlisting the voluntary aid of the healthcare industry to implement prevention programs. Given the magnitude of the problem, and the high cost of investigating and prosecuting fraud, the OIG determined that a cost-effective solution to minimize fraud and abuse was to emphasize prevention over law enforcement investigation and prosecution. With this thought, HHS and the OIG embraced the defense industry's compliance concept along with the Sentencing Guidelines and established the first government healthcare compliance guidance in 1997.

The initial guidance was written for laboratories. OIG compliance guidance is available for other care delivery settings such as hospitals, long-term care, home healthcare, hospice, physician offices, and support services such as medical coding and billing companies. On April 23, 2003, the OIG issued compliance program guidance for pharmaceutical manufacturers.

Early Healthcare Compliance Efforts

Initial OIG-written commentary for healthcare compliance programs focused on internal controls. Healthcare organizations were encouraged, for example, to develop protocols for insurance claim processing and billing, to properly use codes (e.g., diagnosis related group assignments for inpatient hospital service classification and payment), and to ensure patient freedom of choice. Hospital contracts with physicians that encouraged over-utilization of services prohibited by anti-kickback law were also high on the regulatory list of concerns. Yet other compliance efforts focused on provider or entity compliance with governmental and private insurer documentation guidelines, medical need for service, timely refunding of overpayments for services (e.g., refunding credit balanceS), and document retention and destruction policy.

By 2003, it was not unusual to find defined compliance departments within healthcare organizations. The actual name of the department may vary from simply the "corporate compliance department" to the "business practices office." In some organizations, corporate compliance, internal audit, and corporate ethics are combined or maintain close working relations. Independence of review and periodic reporting to senior company officials are two key aspects of any compliance function. Some compliance offices also have advisory committees to assist in various compliance endeavors. At least one organization is known to have a combined compliance and corporate ethics advisory committee. Consistent with the OIG guidance, compliance officers are instrumental in developing or assisting to develop comprehensive policy on OIG target areas, staff training, monitoring, and auditing.

Effective Healthcare Compliance Programs

Little has been published as to what constitutes an "effective" healthcare compliance program. The OIG initiative broadly encourages healthcare providers and entities to conduct business in a manner that conforms to federal and state law and regulations. Similarly, regulatory agency expectations of compliance initiatives vary with the size and complexity of the entity and monies available to fund compliance efforts. For example, a small family practice physician operating an office in a rural location is not expected to have the same size, scope, and sophistication in terms of a compliance program as a healthcare organization with 1,000 or more beds spread over multiple care delivery sites in a highly populated urban setting. Recent enforcement activities, however, demonstrate that staff compliance education and an entity's ongoing commitment to "following the rules" are key components to proving effectiveness, regardless of the entity's size and complexity. Ineffective programs may not provide the same leniency and opportunities as have been discussed above.

Development of an effective program includes ongoing review and revision of the program based on the emphasis found in the annual OIG work plan. A review of current and prior work plans reveals a continuing focus on payment, billing, and claims processing issues. The OIG also releases a number of publications and opinions throughout the year that advise healthcare providers and entities such as hospitals, home health agencies, extended care facilities, etc., on prevention, detection, and resolution methods for suspect practices. Other OIG publications and opinions clarify subject areas to better enable compliant conduct by health organizations.

Consistent with the expansion of regulatory agency focus, areas of compliance concern have expanded to include issues such as quality of care, maintaining patient privacy, eliminating healthcare errors, maintaining occupational safety, enhancing staff understanding of clinical and business ethics, and eliminating or minimizing conflicts of interest. Specialty areas of the law that were topics for compliance discussion in the early twenty-first century encompass employment law, environmental law, tax law, and intellectual property law. This broadened scope has prompted many organizations to revise and reprioritize compliance programs to incorporate standards of behavior that address organization expectations on existing as well as new focal areas.

Essential Elements of a Healthcare Compliance Program

Common elements of any healthcare compliance program incorporate the following:

1. designation of a high-level entity officer to lead the compliance program;
2. documented standards of behavior that are described in more detail in the entity's policies and procedures;
3. compliance training for staff with regular updates to maintain awareness;
4. establishment and maintenance of a readily available anonymous communication process for receiving complaints and concerns (i.e. telephone hotline, suggestion boxes);
5. procedures for protecting healthcare whistleblowers;
6. maintenance of a system for responding to complaints in a timely manner;
7. documented disciplinary action procedures for violations of law, regulation, or compliance policies of the entity;
8. planned auditing and monitoring activities to reveal areas where compliance issues exist, and to monitor correction actions for effectiveness;
9. defined investigation processes;
10. a procedure for initiating the entity's process improvement procedure to correct system process problems;
11. a process to address employment decisions for persons who are temporarily or permanently barred from participating in the care of patients who are beneficiaries of a federally-funded healthcare program.

Operating a Healthcare Compliance Program

Using OIG guidance materials, the compliance officer and compliance committee members develop and direct activities based on governmental and organizational identified areas of concern. The compliance officer should have direct access to both the chief executive officer and the governing board of the organization whenever necessary to ensure timely communication of pertinent issues.

It is important for the organization leadership to grant oversight authority to the compliance officer and committee members for monitoring, auditing, and corrective action activities of the corporate compliance program. Additionally, leadership should support the compliance officer's establishment of alternate methods of communicating with employees to encourage anonymous reporting of compliance issues. It is essential for employees to view the compliance officer as a non-threatening source of education and empowerment, a person they may seek out to resolve concerns without fear of discipline, retaliation, or retribution for reporting a concern.

Establishing a Corporate Culture of Compliance

An organization must be committed to compliance efforts in order for the program to be effective. Establishing written standards, policies, and procedures demonstrates acceptance by senior leadership and delineates behavioral expectations for all employees, governing body members, officers, management, physicians, contractors, and business associates of the organization. Beginning with a statement describing the organization's mission and vision (goals for the future), the organization guides conduct by defining a potential compliance issue along with the conduct standard and examples of appropriate behavior. An illustration of this concept:

- Mission statement: To provide excellent healthcare for our patients and the communities we serve.
- Vision statement: We are committed to the highest level of organizational and professional excellence and will serve others with respect for individual dignity.
- Performance Standards: Greet everyone with direct eye contact and a smile; At the end of an interaction, "ask is there anything else I can do for you?"; Provide information and give updates at specific intervals as promised.

It is important to write components of a compliance program at a reading level that the majority of staff can understand. It is also important to make the conduct requirements accessible to employees so they can be easily referenced. Since laws and regulations change and the OIG, HHS, professional review agencies, fiscal intermediaries, and carriers identify different areas of concern over time, compliance requirements must be updated to reflect behaviors required for the organization to remain in compliance.

A significant portion of the compliance officer and committee members' roles involve establishing and maintaining positive relationships with others in the organization. In maintaining a level of visibility and collegiality, the compliance officer is more likely to be in a position where opportunities for improvement can be identified and ethical behaviors can be positively reinforced. Likewise, visible, approachable committee members are likely to find less resistance to monitoring and auditing activities. Without these positive relationships, compliance activities may be impeded by efforts to thwart data access and collection for fear of poor audit results and the demand for time-consuming responsive action plans by management. While the compliance officer and committee members are often the most visible leaders of corporate compliance efforts, it remains important for organization leadership and management to mentor employees, encouraging responsible and ethical behavior in the workplace.

Strategies for Maintaining a Compliance Program with Limited Resources

The number of personnel assigned to the compliance department or to assist with compliance functions varies from organization to organization. The size of the compliance department and level of sophistication of the compliance program is not directly proportionate to organizational size and complexity. Given the limited size of many departments, a compliance officer must often utilize a variety of strategies to maintain the continuity of compliance program activities.

One strategy involves enlisting managers and supervisors of other departments to join in conducting and evaluating daily monitoring activities, and participate in development and implementation of solutions to issues raised. Compliance department staff or internal audit personnel may check on these efforts through quarterly or annual audits. If needed, in-depth analysis may be conducted by outside consultants.

Another strategy involves using work groups or task forces to assist with monitoring and auditing functions. The groups are formed from members of departments with specific but related functions (i.e. patient registration, patient accounts, collections, and coding). By doing this, members are exposed to the compliance program in action. Work group members engaged in program activities often become ambassadors and assist in enhancing the compliance culture within the organization.

Improved organizational performance can be a practical result from compliance work group efforts. Compliance initiatives may reduce payment collection times and rejections rates. Compliance initiatives may also resolve long-festering issues that impede work completion and flow. With the compliance officer acting as a mentor, information resource, and support person, multiple work groups may simultaneously be engaged in compliance activities, thus improving organizational compliance effectiveness in an efficient, thoughtful manner.

Providers Excluded from Federal Health Programs

Compliance initiatives must also implement steps to ensure practitioners and entities excluded from federal health program participation are not employed or used by the company. By partnering with numerous departments in an organization, a small compliance program can coordinate the monitoring of governmental databases to ensure excluded persons or entities rules are followed. If a monitoring process is ineffective, the organization is likely to realize a significant financial impact because federal programs such as Medicare, Medicaid, or Tri-Care will not reimburse services ordered or performed by these excluded providers.

The monitoring requires that the compliance officer or designee review the Health and Human Services Office of the OIG Excluded Provider database and the General Services Administration database at periodic intervals. The review process and subsequent response activities incorporate human resource, medical staff credentialing, materials management vendor selection, and contractor selection functions within the organization. Legal counsel must be included in these compliance activities to ensure that organization contracts incorporate provisions that impose an affirmative duty on contracting parties to communicate anticipated or actual government action that may result in the party becoming an excluded provider. Action in response to a finding of exclusion may involve, for example, contract termination, termination of employment, or loss of medical staff membership and privileges at the organization.

Corporate Compliance Programs and Organizational Ethics

Partnering within and among organization departments and functions appears consistent with OIG commentary on effective compliance plans. OIG writings suggest that organizations create and foster compliance efforts that conform to legal and regulatory directives as well as enhance the commitment to ethical clinical and business practices within the corporate culture. Though some similarities exist, ethicists caution that corporate compliance must be viewed as distinct from organizational ethics; each has a unique focus.

Corporate compliance programs focus on establishing a floor or minimum level of appropriate behavior for the organization in order for the organization to conform to legal and regulatory requirements for a given industry. The appropriate behaviors are communicated through the compliance program's conduct standards, policies, and procedures. In behaving appropriately, the organization avoids sanctions and maintains its reputation within the community.

Alternatively, organizational ethics focuses on the realm of behavior where no legal or regulatory requirements exist; where equal priorities compete and where individual values, interests, and beliefs differ to the extent that no "right" answer is readily available. In healthcare entities, organizational ethics faces the additional challenges of reconciling priorities often at the level of life and death seriousness. Individual, professional, and societal values and beliefs; competing interests among parties involved in a controversy; the rights of the patient, other individuals, and the organization must be considered in organizational ethics activities.

Unlike corporate compliance programs, organizational ethics is not a new concept in the business world. The curriculum in secondary education and beyond has included courses in business ethics and corporate responsibility, and coursework in these areas has existed for decades. There are, however, few healthcare industry examples of formal organizational ethics functions. Organizational ethics programs should not to be confused with clinical ethics functions.

Healthcare Clinical Ethics and Institutional Review Boards

In contrast with organizational ethics efforts, a number of healthcare organizations established clinical ethics programs within their organizations in the 1970s and 1980s. These efforts were often driven by the need to address ethical and legal dilemmas associated with patients or families seeking to terminate care or refuse care associated with the end of life, often in the absence of state law. In other cases, there was a need to address differing family and patient perspectives on what care should be given outside terminal illness settings. Even with greater clarity on the patient's right to refuse treatment, organizations still needed a defined, deliberate process to address the bioethical and legal issues associated with such decisions.

Another catalyst for establishing a clinical ethics program was the Federal Drug Administration requirement that called for creating an institutional review board (IRB) to protect the patient's rights in clinical research activities. For example, IRB members review research proposals to ensure the patient receives pertinent information about a study prior to agreeing to participate in it, and that adequate safeguards are in place to protect the patient.

Unscrupulous Activities Toll

In 2002, a number of U.S. corporations were fraught with business practice scandals. The "ripple effect" caused people across the country to watch helplessly as their retirement plans and stock portfolios withered after an international accounting firm and several major corporations ceased operations. Senior executive interest in the business practices of their industries and their organizations was heightened. A nationwide focus developed whereby corporations looked to ensure that their staff understood that compliance with industry-specific accepted business practices was an expectation. Likewise, staff were to conduct themselves in an ethically responsible manner in workplace activities.

It is clear that the federal and state governments were alarmed by these business scandals and the subsequent effects felt by the citizenry. Consequently, government began scrutinizing corporate business practices in an unprecedented manner. Thus, it may be prudent for all organizations, for-profit and nonprofit alike, to expand compliance programs to include an organizational ethics function as well.

Single Purpose

For one healthcare organization, the foregoing concerns coupled with a discussion of other real-life scenarios and case studies prompted senior leadership and the governing board to encourage the development of a coordinated approach to these issues. By expanding the scope of corporate compliance activities to incorporate organizational ethics and responsible business practices, the organization hopes to operate compliant with law, regulation, and ethical principles (Oakwood Healthcare Inc.). By 2003, a committee had been formed including compliance, ethics, finance, legal, religious, human resource, operations, and internal audit representatives. By appointing members with different perspectives, the committee provides a balanced approach to complex legal, regulatory, and ethical issues. Uniting ethics and compliance supports the effort to do the "right thing," and that, as many say, is the essence of ethics and compliance.

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SEE ALSO: *Conflict of Interest; Environmental Policy and Law; Genetic Engineering, Human; Healthcare Institutions; Healthcare Management Ethics; Hospital; Law and Bioethics; Managed Care; Medicaid; Whistleblowing in Healthcare*

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CYBERNETICS

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Cybernetics, in its purest definition, is the science of control and communication in the animal and the machine. The word was devised by Norbert Wiener in the 1940s and is derived from the Greek word *kybernetes*, meaning "steersman." In his book *The Human Use of Human Beings* (1950), Wiener wrote that "society can only be understood through a study of the messages and the communication facilities which belong to it; and that in the future development of these messages and communication facilities, messages between man and machines, between machines and man, and between machine and machine, are destined to play an ever-increasing part" (Wiener, p. 16). In 1957, W. Ross Ashby described the focus of this theory of machines as focusing not on what a thing is, but on what it does: "Cybernetics deals with all forms of behavior in so far as they are regular, or determinate, or reproducible. The materiality is irrelevant" (Ashby, p.1). Recognizing that there are significant similarities in biological and mechanical systems, subsequent researchers have pursued the ideal of merging biological and mechanical/electrical systems into what Manfred Clynes and Nathan Kline termed *cyborgs* or *cybernetic organisms.* In this sense, cybernetics has taken on the meaning of adding prostheses to the human or animal body to either replace lost function or augment biological activity.

Humans have long used tools to augment various functions, and for centuries have attached some of these tools to their bodies. Filled or artificial teeth, glasses and contact lenses, hearing aids, pacemakers, and artificial limbs are all examples of this phenomenon. By the late twentieth century, significant advances in the fields of neuroscience and computer technologies allowed the direct interface of animal or human nervous systems with electromechanical devices. Examples of this evolving field include the creation of neural-silicon junctions involving transistors and neurons to prepare neuronal circuits, the re-creation of visual images from signals transmitted in the optical pathways of a cat, the remote control of mechanical manipulator arms by implants inserted into the motor cortex of owl monkeys, and a remote control that can move rats over a directed path via implanted electrodes.

While the above are examples of direct internal interfaces between a nervous system and a cybernetic prosthesis, another approach to cybernetic augmentation is through the use of external or wearable computing devices. In this approach, prosthetic enhancement is achieved via miniaturization of traditional computing devices, interface mechanisms, and optical projection devices, and then seamlessly incorporating these devices into clothing, glasses, and jewelry. This form of cybernetic enhancement has moved from the academic to the commercial stage. Aside from allowing the user/wearer of such devices wireless access to the Internet and other databases on a continuous basis, they may also be used for *augmented reality,* which is the concept of supplementing traditional sensory input with augmented senses or new types of sensory data. Examples include retrograde vision (seeing to one's rear), distant or projected hearing, and infrared vision. Further visual input may be analyzed and correlated with other information such as Global Positioning System (GPS) location identification. Buildings and streets could be labeled, hours of business accessed, and people visually identified (with demographic information provided), with all of this information directly projected on the user's retina.

While these developments may sound like something out of a Star Trek episode, cybernetic technology has developed at a rapid pace, and will no doubt continue to be a growing field of investigation, therapeutic intervention, and commercial development. In June 2002, the National Science Foundation and the U.S. Department of Commerce issued a report recommending substantial U.S. government investment in the development of cybernetic technologies, with the specific goal of augmenting human performance. These technologies will be produced by the synergistic convergence of biotechnology, nanotechnology, information technology, cognitive science, and neurotechnology through a proposed Human Cognome Project.

Healing versus Augmentation

As has already been indicated, the mechanical or prosthetic manipulation of human beings is not a new idea or practice. In the past, however, such interventions have almost always been in the context of repair or replacement of absent, diseased, or disordered function. The goal of visual lenses is to restore vision to biological norms, not to augment or improve function beyond normal. Similarly, prosthetic limbs replace those congenitally absent, malformed, or traumatically severed or injured. Pacemakers replace the electrical pacing of heart contractions lost through injury, aging, or disease. In this context, new tools to restore sight to the blind, hearing to the deaf, and movement and normal function to the lame or paralyzed are tremendous advances fully in keeping with the traditional goals of medicine (healing, restoring, palliation, and prevention of injury). Yet humans also use telescopes, microscopes, night vision, and other means of augmenting visual function for specific purposes. The difference is that these tools are not permanent fixtures of the body. Wearable computing devices and implantable brain chips, however, are being produced and marketed to enhance the normal, not necessarily heal the afflicted. This raises a number of challenging ethical questions, including whether or not human augmentation should even be permitted, let alone pursued?

Before the question of whether augmentation should be permitted, promoted, or prohibited can be addressed, a more basic issue must be considered: Can a distinction between healing and augmentation be delineated? This question poses equal challenges to a variety of areas in addition to cybernetics, particularly the more immediate possibilities of genetic therapy or enhancement and pharmacotherapy for behavior control, mood enhancement, and cognitive enhancement.

The difficulty lies in trying to define a clear line of demarcation between a disease state and normal structure and function. It is sometimes easy to pick out extremes of phenotype, particularly if an underlying pathophysiological mechanism for the deviation can be demonstrated. Examples include hemophilia, congenital dwarfism, and impaired vision. Other situations raise difficulties, illustrating that many times the definition of disease or abnormality can be socially, rather than objectively or scientifically determined. How much deviation from ideal body weight is within the bounds of normal variation, and when does the deviation become pathologic? While anorexia nervosa and morbid obesity are clearly pathologic in that they can influence survival and other health issues, a significant number of individuals are on the edges of the norms, where the threshold of pathology is unclear.

A striking example of the cultural variation in the definition of disease is the response of many congenitally deaf individuals to the suggestion that they are afflicted and in need of therapy. Many deaf parents of deaf children have refused to allow their children to receive cochlear implants to correct the deafness because this would remove the children from the deaf community. At a 1997 conference of deaf individuals, 16 percent of the delegates were interested in prenatal diagnosis for deafness, but, of that group, 29 percent indicated that they would use these techniques to select for deafness in the child (see Middleton, et al.).

Cognitive and neurological function, the areas most impacted by cybernetics, are particularly fraught with difficulty, in part because certain deviations from the norm may impart certain functional advantages in addition to social or behavioral liabilities. For instance, while attention-deficit/hyperactivity disorder (ADHD) and autism are diseases, many of the individuals who have these conditions also manifest significant brilliance and creativity in mathematics, music, art, science and engineering. Both the positive and negative manifestations are part of the same disease entity, and what degree of negative manifestation requires treatment becomes subjective. The treatments employed may suppress the undesired manifestation, but they may also impair the desirable expressions. The situation becomes even more complex when these challenges are extended to a measure of cognitive function such as memory, mathematical calculation, musical ability or language processing. Who doesn't think of himself or herself as being deficient in cognitive abilities or able to benefit from enhancement of cognitive function?

In addition, necessary cognitive function may be very task or profession specific. Should individuals who would be considered cognitively normal be allowed to receive enhancing technologies to permit them to pursue a career otherwise beyond their intrinsic ability? And, as these technologies become available, should professions that demand high levels of cognitive excellence be allowed to require the use of enhancing technologies? Given that books and computers are forms of information exchange enhancement that are currently required for education in the professions, one could argue that the only thing that has changed is the intimacy of the enhancing method. Because, these technologies may intrinsically carry certain risks that are absent from current information technologies, however, many believe that such means should never be mandated, but only available by free choice. The reality, however, is that competition with peers will serve as a strong coercive force to pursue enhancement.

Safety Questions

The answers to these questions require the consideration of additional issues. At the most basic, cybernetic technologies, both implantable and wearable, must demonstrate physical, emotional, and cognitive safety. While physical safety will, in general, be the most easily addressed, there are still new challenges beyond those typically encountered by medical devices. Traditional medical-device safety issues include the risk of infection, local reaction, tissue injury, and involuntary or undesired neural or muscular stimulation. Current devices, however, tend to function in isolation in the specific local environment of the recipient body. Cybernetic devices, on the other hand, will often be connected to a shifting network environment, dependent upon software and the exchange of external information as well as hardware. As such, viral code could potentially disrupt function of the device, and possibly injure the user. Even wearable devices could potentially be turned into weapons, and so need to be strongly regulated, with proof of software and hardware safeguards against injury by rogue software agents.

The issues of emotional and cognitive safety will be more challenging to understand and regulate. In the era of the Internet there is a growing literature addressing problems with personality fragmentation, breakdown of direct personal interaction in favor of cyber relationships, increasing dissatisfaction with reality, addiction to cybersex and pornography, and other psychosocial concerns. These concerns can only increase when individuals are cybernetically connected most, if not all, of the time. The long-term consequences of virtual environments are unknown. The variability of involvement and susceptibility to dysfunctional utilization will vary tremendously between individuals, making generalized regulation difficult. However, some form of registered informed consent as to potential negative consequences, with mandatory, periodic, and long-term follow-up, may be helpful.

The Nature of Medicine

The issue of safety introduces yet another question: What sorts of individuals should be involved in implanting devices for internal cybernetic enhancements or for fitting wearable devices with optical interfaces? Because of the invasive nature of the implants, it would seem a logical requirement that physicians, particularly neurosurgeons, place these devices in humans. This certainly would be necessary for cybernetic devices of a therapeutic nature, but what about devices that are solely for enhancement purposes? Placing devices for nonmedical indications leads the physician into participating in interventions that are potentially harmful, have no therapeutic necessity, and thus are outside the traditional goals of medicine. A strong argument could be made that physicians should not participate in applying these technologies for other than therapeutic purposes. Yet few would want someone with less training than a neurosurgeon to invade their nervous system.

An analogy can be made to cosmetic surgery. Some ethicists, such as Franklin Miller and Howard Brody, contend that such interventions are outside the bounds of appropriate goals of medicine and should not be performed. Others counter that an individual should have the freedom to manipulate his or her own body, and, if a physician is willing to provide the service, restriction would be wrong and counter to the cherished goals of autonomy. Anders Sandberg takes the argument further, stating that each person has the fundamental right to pursue whatever means are available that might enhance or prolong life. The implications of this approach for medicine, however, are to change the profession from a group committed to healing (with a dominant ethos of beneficence in trust and nonmaleficence) to individuals skilled in surgical technique who are merely technicians providing whatever service may be requested.

Justice and Social Values

In the end, safety considerations may mandate that physicians and healthcare resources be used to implant cybernetic devices for nontherapeutic purposes, but justice may require that third-party healthcare dollars not be used to cover the costs of the devices or resources utilized. This raises concerns that access to enhancement technologies will be accessible only to those who already possess economic, educational, and technical advantages, further widening the gap between the haves and have-nots. As some members of society become incrementally enhanced and plugged in to cybernetic communities, these individuals will share less and less in common with the unenhanced, fragmenting society; potentially generating decreasingly compatible, or even competing, separate societies.

This is not necessarily a new phenomenon, for technologies have created boundaries between social groups in the past, the Amish and some Native Americans being notable examples. The difference is that the Amish have always wished to remain a distinct society, while some individuals who wish to reject personal enhancement may still desire participation in and access to the goods of the larger social structure. Deliberate efforts to maintain tolerance of individuals and groups who choose to forgo the use of certain technologies must be pursued if democratic-republican ideals are to be preserved, and inclusive means of communication must remain available to all members of society.

Cognitive cybernetic devices must also be equipped with reliable means of filtering incoming information, especially against information that might be designed for repetitive or subliminal influence. Privacy is a similar critical issue, and must be deliberately and prospectively defended in the cybernetic age. Technologies such as functional magnetic-resonance imaging are being proposed to sense, process, and interpret thought patterns. Not only is the accuracy of such technology a critical requirement, but the concept of invading the mind is at issue.

To Prohibit, Permit, or Pursue?

Cybernetics offers wonderful devises of healing for significant, age-old disabilities, and it can be welcomed when utilized in that context. It is likely that using such tools to enhance normal function will be possible, but great caution is needed, as well as a commitment to the preservation of privacy and justice. Rigorous safeguards for demonstrating the safety of cybernetics devices, and requirements for government approval and licensing, need to be set in place. The government, the academy, and industry should commit significant resources to the exploration of the ethical and social implications of these technologies, and to the development of appropriate analysis and preparation of guidelines for implementation.

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SEE ALSO: *Enhancement Uses of Medical Technology; Human Dignity; Human Nature; Nanotechnology; Technology; Transhumanism and Posthumanism*

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Encyclopedia of Bioethics, 3rd edition

Stephen G. Post
Editor in Chief

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DAOISM, BIOETHICS IN

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Daoism is an ancient and multifaceted element of traditional Chinese culture. Its origins and scope are debated by modern scholars, Chinese and Western alike. Most understand "Daoism" in terms of the naturalistic thought seen in ancient texts like those of Lao-tzu (the *Dao te ching*) and Chuang-tzu (see Lau, 1982; Graham, 1981). But to others, "Daoism" denotes primarily a religious tradition that emerged around the second century C.E. and has endured to the present (Seidel, 1990; Robinet, 1991, 1993). Specialists today generally employ a comprehensive approach, interpreting both of those elements as aspects of a broad and inclusive cultural tradition, interwoven both historically and thematically (Schipper).

Daoism may be characterized as a holistic worldview and ethos, including a variety of interrelated moral and religious values and practices. Daoism lacks any coherent conceptual structure, so there have never been any "Daoist positions" regarding ethics or any other issues. Yet, most segments of the tradition share certain assumptions and concerns. One is an assumption that human reality is ultimately grounded in deeper realities; humans are components of a cosmos, a harmonious universe in which all things are subtly but profoundly interrelated (Kirkland, 1993). Daoism is devoted to the pursuit of greater integration with the cosmos, in social as well as individual terms. Daoists vary widely in their understandings of how that integration is best expressed and pursued.

The first section of this entry outlines the elements of classical "Lao-Chuang" Daoism, and the history, teachings, and practices of the much-misunderstood "Daoist religion." The subsequent exploration of the Daoist moral life focuses upon (1) the ideals of refinement (*lien*) and "fostering life"; (2) the ideals of balance and harmony; and (3) the issue of death. Throughout, one should bear clearly in mind that many issues that are considered central in contemporary bioethical debate are completely alien to the traditional Daoist worldview. Daoists not only lacked the concepts of "good" and "evil," but they were simply never interested in arguments over "right or wrong" on any terms. One should thus beware assuming that contemporary issues could ever be translatable into Daoist terms.

The Daoist Heritage

CLASSICAL THEMES. In the ancient texts *Lao-tzu* and *Chuang-tzu,* integration with the cosmos is generally expressed in terms of returning to the natural rhythm or flow of life—to the Dao, an impersonal reality that constitutes simultaneously the source of the cosmos, the subtle structures of the cosmos in its pristine state, and the salutary natural forces that—in that pristine state—maintain all things in a natural and healthy alignment. In "Lao-Chuang" Daoism, all the world's problems are attributed to humanity's digression from the Dao, particularly to a loss of proper perspective upon the nature of reality. The goal of Lao-Chuang Daoism is to regain that perspective and thereby return to the original integration with the natural world and its constituent forces and processes. The eponymous Lao-Chuang texts are vague about the means to be employed in achieving that end. Later Lao-Chuang writings (e.g., in texts like the *Kuan-tzu* and *Huai-nan-tzu*) present a more detailed analysis of the human constitution, and suggest specific spiritual and physiological practices to reintegrate the individual and realign him or her with the natural forces of the cosmos (Roth). Suffice it to note that all such theory assumes none of the dichotomies of mindmatter or body/spirit that underlie much of Western medicine and moral theory. Moreover, it is a mistake to assume (as do most in twentieth-century Asia and the West) that Daoism was essentially individualistic: the basic Lao-Chuang writings (most notably the *Dao te ching*) often addressed broader problems of human society in both moral and political terms. The later Daoist tradition is generally an extension of the ideals and values seen in these earlier writings.

THE DAOIST RELIGIOUS TRADITION: NEW PERSPECTIVES. Until recently, virtually all educated people dismissed postclassical Daoism (often misnamed "popular Daoism") as a mass of disreputable superstitions created and perpetuated by the ignorant masses. Such was certainly not the case. The problem is that before the 1970s, few intellectuals, Chinese or Western, had any firsthand knowledge of later Daoism, in terms of either its modern practice or its historical tradition. As scholars began serious analysis of the Daoist texts preserved in the massive collection known as the *Dao-tsang,* and researched the roles that Daoism played in traditional Chinese history and society, they started to develop a far different perspective, though this new perspective has yet to reach the educated public.

Until the 1980s, religious Daoism was often said to have been focused on individual practices intended to confer longevity and/or physical immortality. The pursuit of physical longevity did exist in China from early times, but it is wrong to associate such pursuits with "religious Daoism."

Western scholars generally have placed emphasis on certain practices or crafts that they suppose have been particularly "Daoist," notably the quest for physical immortality, breath control, techniques of sexual union, herbalism, dietetics, and alchemy. In such a view, though, as in the question of doctrine in general, there is some ambiguity between what is specifically Daoist and what is simply Chinese (Strickman, pp. 1044–1045).

Extensive research has generally demonstrated that such practices have little or no intrinsic connection to the traditions of religious Daoism.

THE EVOLUTION OF THE DAOIST RELIGION. The Daoist religion has been compared to a river formed by the confluence of many streams. Its origins lie in the Han dynasty (206 B.C.E.–221 C.E.). During that period, Chinese intellectuals (like the Confucian theorist Tung Chung-shu) were seeking a comprehensive explanation for worldly events. From such roots, imperial advisers called *fang-shih* produced a series of sacred texts that culminated in the *T'ai-p'ing ching,* which is generally regarded as the first Daoist scripture. According to the *T'ai-p'ing ching,* ancient rulers had maintained an "ambience of Grand Tranquillity" (*t'ai-p'ing*) by observing *wu-wei* (nonaction)—a behavioral ideal of avoiding purposive action and trusting instead to the world's natural order (the Dao). When later rulers meddled with the world, the "Grand Tranquillity" was disrupted. Now, the scripture says, one must return to the Dao by looking within oneself. The text provides specific directions for pursuing union with the Dao, including moral injunctions and instructions for meditation, as well as recommendations for enhancing one's health and longevity through hygienic practices (such as breath control), medicine, acupuncture, and even music therapy. The focus of the *T'ai-p'ing ching* is thus upon providing the people with practical advice for reintegrating with the natural order (Kaltenmark).

In late Han times, the *T'ai-p'ing ching* helped inspire several social movements. One was led by Chang Dao-ling, who claimed to have received a divine mandate to replace the now-effete Han government with a new social order. Claiming the mantle of "Celestial Master," Chang and his heirs oversaw a religious organization in which male and female priests healed the sick by performing expiatory rituals. This organization, generally called "Celestial Master Daoism," was based on the idea that a healthy society depended upon the moral, physical, and spiritual health of all its members.

In the fourth century C.E., northern China was invaded by peoples from the northern steppes, and the leaders of the Celestial Master movement fled south. There they found a rich indigenous religious culture centered upon the pursuit of personal perfection through ritual activity. Unlike the Celestial Master tradition, the religion of southern China took little interest in ideals of a healthy society: its focus was almost exclusively upon the individual. Modern writers, Chinese and Western, have often mistakenly cited certain of its texts (like the *Pao-p'u-tzu* of the maverick Confucian Ko Hung) as representative of religious Daoism. In so doing, they have completely neglected the rich heritage of the *T'ai-p'ing ching* and most of the subsequent Daoist tradition.

The fourth century C.E. was a period of rich interaction among such diverse traditions, and there were two new developments, both of which occurred as the result of revelations from celestial beings. The first, known as the Shang-ch'ing (Supreme Purity) revelation, was received from angelic beings called "Perfected Ones" who dwelt in distant heavens of that name. The Perfected Ones revealed methods by which the diligent practitioner could ascend to their heavens, particularly visualizational meditation (Robinet, 1993). But Shang-ch'ing Daoism also subsumed the older southern pursuit of personal perfection through alchemy, a transformative spiritual process expressed in chemical terms. Alchemy, often misrepresented as a "typical" element of religious Daoism, actually arose quite independently, though it was embraced by certain Shang-ch'ing Daoists as a practice thought to elevate the aspirant's spiritual state for eventual ascent to the heavens (Strickmann). What the alchemical tradition shared with Daoism was a vital concern with self-perfection based on an assumption that the individual's being is a unified whole. For exceptional aspirants, alchemy provided secret knowledge that permitted control of the forces of the cosmos that inhere within the constitution of the individual. Outsiders often misunderstood the whole undertaking as a pursuit of physical longevity. But within Daoism, alchemy was actually a method of moral and spiritual self-refinement: through proper knowledge and action, one could pare away the grosser elements of one's being and eventually ascend to a higher plane of existence. Nonetheless, alchemy was, for most, a purely theoretical interest. The "average" Daoist practiced meditation and morality, and in later ages Daoists discarded the theory of "external alchemy" in favor of "inner alchemy"—a meditative pursuit of reunion with the Dao that employed the language of alchemy metaphorically.

The Shang-ch'ing revelations were immediately followed by a quite different set of revelations, known by the term *Ling-pao* (Numinous Treasure). *Ling-pao* Daoism is distinguished by (1) elements influenced by Mahayana Buddhism, and (2) a renewed concern with the human community. *Ling-pao* scriptures (such as the *Tu-jen ching,* "Scripture for Human Salvation") tell of a great cosmic deity—a personification of the Dao—who is concerned to save humanity. By ritual recitation of the scripture, one may participate in its salvific power. In the fifth century, the *Ling-pao* tradition was refocused by Lu Hsiu-ching, who reconfigured its ritual activities and formulated a new set of liturgies that continue to influence contemporary Daoist practice. A central liturgy is the *chiao,* a lengthy series of rituals that renew the local community by reintegrating it with the heavenly order. Other liturgies, called *chai,* had diverse aims. One was designed to prevent disease by expiating moral transgressions through communal confession. Another labored for the salvation of deceased ancestors. A third was intended to forestall natural disasters and reintegrate the sociopolitical order with the cosmos. Through these liturgies, Daoism incorporated ritual frameworks from all segments of society, from the imperial court to the local village, and unified them through the activity of priests (*Dao-shih*), some of whom were women (Kirkland, 1991a).

"Liturgical Daoism" soon became central to life at all levels of Chinese society. Admiring emperors sought to bolster their legitimacy by associating with Daoist masters, and by having them perform liturgies for the sake of state and society. During the T'ang dynasty (618–906 C.E.), cultural leaders in every field associated with such masters, and were deeply influenced by Daoist religious, artistic, and literary traditions. Prominent Daoists like Ssu-ma Ch'eng-chen not only maintained the liturgical tradition but also refined the meditative practices that had always been central to the Daoist spiritual life (Engelhardt, 1987). In addition, certain Daoists became known for their achievements as physicians. The social prominence of liturgical Daoism changed drastically during the twelfth and thirteenth centuries C.E., when China was again invaded by northern peoples. The foreign rulers often suspected religious organizations of fostering rebellious activities, so Chinese who sought social or political advancement began to dissociate themselves from such organizations. Hence, in late imperial China, liturgical Daoism became divorced from the elite segments of society, and endured primarily among the less affluent and less educated (Kirkland, 1992). The broadly based, ecumenical Daoist tradition of T'ang times dissipated, to be replaced by new, smaller sects. One of the earliest examples was Ch'ing-wei Daoism: founded by a young woman about 900, it introduced "thunder rites," by which a priest internalized the spiritual power of thunder to gain union with the Dao, then healed illnesses. In T'ien-hsin Daoism, founded by a twelfth-century scholar, priests healed mental illness by drawing spiritual power from stars. The most traditional of the new sects was T'ai-i Daoism, which stressed ritual healing and social responsibility, and was popular with some rulers, including the Mongol Khubilai Khan. None of those sects had much lasting influence. One that did endure was Cheng-i (Orthodox Unity) Daoism, which flourished under imperial patronage from the eleventh to eighteenth centuries and is still practiced in Taiwan. It preserves traditional liturgies, adding rituals for exorcism and personal protection. None of the new sects that arose during the "Daoist reformation" was in any way concerned with the pursuit of immortality. Rather, priests of all those sects ministered to the community by healing and performing other ritual services.

Modern Daoism has maintained the pursuit of individual self-perfection through meditation. Earlier Daoist meditation took a variety of forms. But from the eleventh century on, most Daoist meditation was couched in terms of "inner alchemy." Employing terminology from ancient Lao-Chuang texts, "inner alchemy" aims at self-perfection through cultivating "spirit" (*shen*) and "vital force" (*ch'i*) (Robinet, 1989).

These practices were embraced in Ch'üan-chen (Complete Perfection) Daoism, a monastic movement founded in the twelfth century. Ch'üan-chen institutions flourished into the twentieth century, as did some of its teachings on self-perfection through meditation.

The Ethical Dimensions of Daoism

Many accounts of Daoism lead one to question whether there is—or could be—such a thing as a Daoist ethic, suggesting quite incorrectly that Daoist values were intrinsically egocentric. In fact, all segments of the Daoist tradition fostered a personal ethic, and most segments taught a social ethic as well. At times, in fact, it is clear that Daoism assumed a universalistic ethic that extended not only to all humanity but also to the wider domain of all living things (Kirkland, 1986). These values were not borrowings from Confucianism or Buddhism, but a natural extension of fundamental elements of the Daoist worldview, rooted in the ancient heritage of the *Dao te ching* and the *T'ai-p'ing ching.* That worldview was interwoven with an ethos that encouraged individuals and groups to engage in activities intended to promote the healthy integration of the individual, society, nature, and cosmos.

THE MORAL LIFE: IDEALS OF REFINEMENT AND "FOSTERING LIFE." The Daoist view of personal identity and human values contrasts sharply with that of Confucianism. Confucians understand humans to be innately distinct from and superior to all other forms of life, because of humans' social inclinations and moral consciousness. Daoism, by contrast, locates the value of humanity not in what separates it from the rest of the natural world but in what humans share with the rest of the world. A constant if not universal goal of Daoism is to propel the individual's attention to ever higher and broader perspectives, to move as far as possible not only beyond the isolated concerns of the individual but also beyond the socioculturally defined concerns of the unreflective. The Daoist goal is not to ignore socioculturally defined concerns but to transcend them.

For that reason, despite all its insistence upon restoring harmony with the natural order, Daoism is not consistent with the activist tendencies of modern environmentalism. No Daoist of any persuasion ever embraced goal-directed action as a legitimate agency for solving problems. The *Dao te ching* in fact implies that, contrary to appearances, nature is ultimately more powerful than all human endeavor, and that if humans will refrain from taking any action, however well-intentioned, nature itself will inevitably rectify any problems.

Daoists insist that we must focus our concern upon ourselves, seeking (re)integration with the deeper realities of the cosmos through a process of personal refinement (*lien*). In some of Lao-Chuang Daoism, that process at times appears so rarefied that it involves no more than altered perceptions: one learns to reject conventional "truths" in pursuit of a deeper state of awareness. But most later Daoists understand the process of refinement as a more comprehensive undertaking, involving a transformation or sublimation of one's physical reality as well. Such "biospiritual" ideals are often couched in terms of the imperative of "fostering life" (*yang-sheng*). Some writers have identified *yang-sheng* with physiological practices designed to enhance individual health and prolong physical life. But in the Daoist context, at least, the term connotes much more:

> Indeed, the very idea of life or health, including as it does both physical and spiritual dimensions, evokes an archaic aura of religious meaning—that the fullness of life is supranormal by conventional standards—and symbolically is closely linked with a generalized Daoist notion of the mystic and religious, individual and social, salvational goal of reestablishing harmony with the cosmic life principle of the Dao. (Girardot, p. 1631)

Within the Daoist worldview, *yang-sheng* presupposed a personal ethic of moral and spiritual cultivation (Kirkland, 1991b). That ethic, moreover, assumed a dedication not only to the perfection of the individual self but also to reestablishment of a broader, universal harmony.

The term *yang* means "to foster, nourish, or care for." Thus the *Dao te ching* sometimes presents the Dao in imagery that suggests a loving parent who exerts no control, and oft-overlooked passages encourage altruistic attention to the needs and interests of others (Kirkland, 1986). In that context, *yang-sheng* can be interpreted as selfless concern with fostering others' lives as well as one's own.

> In fact, rather than being promoted by a Confucian sense of social service, hospitals, orphan care, and community quarantine procedures were linked to the activities of the Daoist and Buddhist monasteries during the Six Dynasties period.… The root of this concern for community healthcare would seem to be most strongly influenced by the Buddhist idea of universal compassion (*karuna*), but in Daoism this idea could be interpreted as an aspect of the selfless kindness and concern for human health extended to all persons in the practice of *wu-wei.* (Girardot, p. 1636)

Medieval Daoist literature abounds in stories of exemplary men and women who earned recognition—and, on occasion, the boon of immortality—by secretly performing compassionate acts, particularly for people and animals disdained by others (Kirkland, 1986; Cahill). Such values have sometimes been attributed to Buddhist influence, but they are actually rooted in elements of the ancient Daoist worldview. The Daoist ethos started with the individual, and redirected his or her attention to a broader life context: from body to spirit, from self to community, from humanity to nature. In addition, it presented the would-be Daoist with a moral responsibility to live for a purpose greater than oneself.

Daoist conceptions of history, humanity, and cosmos also undercut some of the paternalistic tendencies so common in other traditions, including Confucianism. Human lives are to mirror the operation of the Dao, which contrasts markedly with Western images of God as creator, father, ruler, or judge. The Dao is not an external authority, nor a being assumed to possess a moral right to control or intervene in the lives of others. Moreover, the *Dao te ching* commends "feminine" behaviors like yielding, as explicitly opposed to "masculine" behaviors of assertion, intervention, or control. There is thus little temptation for a Daoist to "play God," whether in medicine, government, or law.

THE MORAL LIFE: IDEALS OF BALANCE AND HARMONY. While Daoism did not create the ideals of balance and harmony, it embraced them to an extent unequaled by other traditions. A fundamental Daoist assumption, applicable to any facet of life, was that disorder is a result of imbalance, whether physical or spiritual, individual or social. Physical illness was generally understood as an indicator of what might be called a biospiritual imbalance within the individual. In many presentations of Chinese medicine, disease is explained as a result of a misalignment of *ch'i,* the natural life force (which eludes the distinction of "body" from "spirit"). In the minds of the peasantry, such misalignment was often understood as the result of moral misdeeds, and some Daoists who were anxious to involve the common people incorporated such ideas into their writings and practices. But in a broader theoretical context, the imbalances that result in disease might better be attributed to a kind of natural entropy. Ancient Chinese thought assumed that the present state of the world represents a degeneration from an earlier state of universal peace and harmony. The goal of life for Confucians and Daoists alike was to restore that original harmony. Certain Daoists took a profound interest in the problem of restoring the harmony of individuals through treating physical maladies (Girardot). But disease and healing were never understood in purely materialistic terms, and the goal of medicine was never simply the alleviation of physical suffering. Like healers in many traditional cultures, Daoists of most periods assumed that all physical symptoms remit when one restores the biospiritual integrity of the individual and reestablishes a state of balance and harmony with the deeper realities of life. Consequently, some Daoists worked to restore health through therapeutic ritual activity (Strickmann).

Restoring harmony, however, was never a purely individual matter, for the Daoist any more than for the Confucian. Just as a physical disorder was understood as resulting from a biospiritual imbalance within the individual, so sociopolitical disorder was generally understood as resulting from a biospiritual imbalance on a larger scale. Daoists and Confucians of classical times and the later imperial period felt a responsibility to rectify that imbalance, to play a managerial role in restoring *T'ai-p'ing,* "Grand Tranquillity." *T'ai-p'ing* connoted a well-ordered society, both in universal terms and in terms of the local community. But it was not merely a political concept:

> It was a state in which all the concentric spheres of the organic Chinese universe, which contained nature as well as society, were perfectly attuned, communicated with each other in a balanced rhythm of timeliness, and brought maximum fulfillment to each living being. (Seidel, 1987a, p. 251)

Daoist priests of all periods assumed a special responsibility to tend to the spiritual dimensions of upholding *T'ai-p'ing,* complementing the real and symbolic activities of the emperor and local magistrate. Until Mongol times, that understanding of the role of the Daoist priest was accepted at all levels of society, and emperors frequently relied upon Daoist priests to provide both advice and ritual support in keeping state and society in harmony with the cosmos.

The Daoist concern with balance and harmony extended to participation in religious activities. While the *Dao te ching* had commended "feminine" behavioral models, the early Daoist religious community offered participation to women, apparently on an equal basis with men. Though it is not clear how often women performed the same priestly functions as men, medieval texts describe women's spirituality in terms that make it only subtly distinguishable from that of men (Cahill; Kirkland, 1991a). The marginalization of liturgical Daoism after the twelfth century coincided with a more general diminution of opportunities for women throughout Chinese life, and from then on, few women appear in the Daoist tradition.

Daoist attitudes toward sexuality were quite vague. Daoists never articulated any specific sexual ethic. Aside from Confucian moralists, few Chinese regarded sexuality as morally problematic, and most regarded it as a valuable component of human life. Some Daoists took an interest in reproductive forces as the most readily accessible manifestation of the natural forces of the cosmos. The imagery of "inner alchemy" was sometimes applied to those forces, resulting in biospiritual practices aimed at total sublimation and concomitant personal perfection. Particularly in later centuries, some men and women focused their efforts at self-transformation upon the physical or metaphorical transformation of sexual forces. But once again, it is questionable whether such activities ought to be called specifically "Daoist," for they have little in common with the activities of any of the liturgical Daoist organizations.

DAOIST ATTITUDES TOWARD DEATH. One of the most intensely debated issues in modern discussions of Daoism is that of its attitude(s) toward death. The controversy stems from some interpreters' insistence that religious Daoists struggled to *avert* death, while the earlier Lao-Chuang Daoists had espoused an *acceptance* of death as a natural conclusion to the cycle of life. There is evidence to support that interpretation, but there are also passages in the *Dao te ching* and other Lao-Chuang texts that suggest the possibility of obviating death and the desirability of attaining a deathless state. A natural conclusion would be that "religious Daoism" focused upon those passages, and set about devising practical methods of attaining such a state. But while none can dispute the commonness of texts describing such methods, it is again questionable whether they can be considered representative of "religious Daoism." It should be noted that the most famous proponent of the pursuit of immortality—the fourth-century Ko Hung—actually repudiated the Daoist tradition. On the other hand, the architects of the Daoist liturgical tradition seldom even alluded to immortality as a desirable goal.

Daoists of all periods would be puzzled by the insistence of modern Western medicine that the prevention of human death transcends all other concerns. To Daoists, the reality of one's life extends far beyond the biological activity of one's body, and extending the latter *for its own sake* would hardly seem even desirable. The Daoist goal is always harmony with the deeper dimensions of life, and in those terms a medical model that defines "life" in strictly biological terms seems perverted.

In reality, Daoist attitudes toward death are hardly reducible to any clear, unequivocal proposition. But one may safely affirm that a pursuit of immortality for its own sake—that is, a search for some trick that would obviate the death event—was never a Daoist goal (Kirkland, 1991b). Rather, Daoists consistently pursued a state of spiritual perfection. Frequently, they expressed that state of perfection as a state that was not subject to death. Chinese literature (by no means specifically Daoist) is replete with stories of *hsien*—wondrous male and female beings who live outside the realm of ordinary life and death. Daoist writers sometimes employed such imagery to suggest the final fruits of spiritual development. Some writings suggest that rare individuals underwent a transformation that merely simulated death (Robinet, 1979). But one must beware mistaking metaphor for reality (Bokenkamp). When read carefully, most Daoist writings actually present a "postmortem immortality"; that is, a deathless state can indeed be achieved, but biological death remains a necessity (Strickmann; Seidel, 1987b). Daoist attitudes toward death thus remain a paradox.

Conclusion

Though some Daoist writings do present moral injunctions, Daoism never developed any real ethical code, for such an idea makes little sense in a Daoist context. For instance, since there was no divine Lawgiver, Daoists never developed an ethic conceived as obedience to divine authority. Daoists of various periods did accept the existence of divinities, and some Daoist writings incorporated popular concepts of a heavenly hierarchy that dispenses posthumous rewards and punishments. But acceptance of such beliefs was never considered mandatory, and most Daoist literature lacks such ideas.

Similarly, Daoists lacked the notion that the individual—or even the human species—is an independent locus of moral value. In fact, Lao-Chuang Daoism can easily be read as a concerted effort to disabuse humans of the absurd notions of self-importance that most people tacitly embrace as natural and normal. Hence, the very concept of "rights"—for individuals or groups, humans or animals—makes no sense in Daoist terms.

Daoism might appear to embody a virtue ethic. Indeed, the term te in the title of the *Dao te ching* is generally translated "virtue." But the Daoist perspective is quite distinct from the virtue ethic developed by Confucians like Mencius. Mencius clearly articulated virtues like *jen* (benevolence), and insisted that proper cultivation of such virtues would result in the perfection of individual, family, society, and state. Much of Daoism seems to suggest a similar model, with the substitution of *te* for *jen.* But though Mencius attributed human moral impulses to a natural inheritance from "Heaven," Lao-Chuang Daoists frequently criticized most Confucians as seeking answers to life's issues in terms that were excessively humanistic. Confucians often seem ambivalent concerning the relevance or even the existence of transhuman realities. And it was upon precisely such realities that Daoism centered itself.

To understand the moral dimensions of Daoism, one must understand the "vague and elusive" concept of the Dao—transcendent yet immanent, divine yet inherent in humanity and all of nature. Most important, since the Dao never acts by design, Lao-Chuang Daoists ridicule the notion that good could result from conscious evaluation of possible courses of action. Such deliberate "ethical reflection," they argue, blinds one to the natural course of action, which is the course that one follows when living spontaneously, without the arrogant and destructive imposition of rationality and intentionality. The ethical dimensions of Daoism are thus real but subtle. Since Daoists never embraced normative expressions of any kind, to perceive the ethical dimensions of Daoism, one must peer deeply and carefully into the entire tradition, extrapolating from a plethora of sources from different segments of a highly diverse tradition. In doing so, one forms the impression that to live a proper Daoist life is to live in such a way that one restores and maintains the world's holistic unity. The Daoist life involves dedication to a process of self-refinement, which is considered one's natural contribution to the health and well-being of both nature and society. In a sense, to be a Daoist is to accept personal responsibility for taking part in a universal healing, doing one's part to restore the health and wholeness of the individual, society, nature, and cosmos.

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SEE ALSO: *Buddhism, Bioethics in; Compassionate Love; Confucianism, Bioethics in; Death: Eastern Thought; Medical Ethics, History of South and East Asia: China; Population Ethics: Religious Traditions*

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DEATH

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I. Cultural Perspectives
II. Eastern Thought
III. Western Philosophical Thought
IV. Western Religious Thought
V. Death in the Western World
VI. Professional Education

I. CULTURAL PERSPECTIVES

What is death? How do we understand its meaning? Since death cannot be directly apprehended by straightforward scientific means, culture provides the key medium for comprehending the final boundary between our existence as living beings and the eventual end of that existence. Death is a fact of life, but awareness of mortality is a social, not a biological reality. Knowledge about death and its meaning and value is socially constructed. How should we account for profound differences across the world and throughout history? In some societies, elders choose to end their own life via exposure to the elements, to avoid being a burden to the wider community—the perhaps apocryphal Eskimo on an ice floe narrative—which provides a powerful image whether supported by the ethnographic evidence or not. Or mothers may withdraw their love and attention from an infant deemed unlikely to survive in an impoverished environment like the slums of northeastern Brazil.

In contemporary U.S. society, through a combination of technical prowess, institutional arrangements, and bioethics-governed procedures and practices, we elect to maintain the liminal—betwixt and between—existence of patients suffering from persistent coma, maintaining their biological lives in specialized ventilatory-care units. Others may decide to have their brains or bodies "cryopreserved" after the moment of physical, cardiopulmonary death, in response to internet advertisements. The native inhabitants of the Amazon, called the Wari, respect their dead, and assuage their grief, by engaging in ritual mortuary cannibalism. How might the profound range of cultural variability in organizing death inform bioethics debates about the morally right management of death and the end of life?

This entry examines the intersection of death, culture, and bioethics, taking the disciplinary perspective of anthropology, the field most associated with the analysis of culture. The scope is both broad, examining conceptually the ways in which the experience of death is culturally constructed within particular social and historical moments, and narrow, detailing the growing body of knowledge about the influence of an increasingly globalized biomedicine (and "the ethics" of that medicine, bioethics) on the experience of death and dying in multi-cultural societies (Kaufman; Conklin; Scheper-Hughes).

Intersections of Death, Culture and Bioethics

When *cultural* difference is considered, we generally think of differences among people from varied ethnic backgrounds in a diverse society, or of clashes emerging in the face of immigration or forced migration of populations. In homogenous societies, for example, when healers', patients', and broad social expectations about death are concordant, cultural difference may be transparent and cultural conflicts rare. In diverse societies, ethnic and cultural background influences all aspects of healthcare, nowhere more profoundly than when death is near. Even patients and families who appear well integrated into a diverse society such as the United States may draw heavily on the resources of cultural background (particularly spirituality) when experiencing and responding to death. When cultural gaps between families and healthcare providers are profound, accentuated by language barriers and varied experience shaped by social class, negotiating the difficult transitions on the path from life to death, always a daunting challenge, becomes even more difficult.

We argue that all domains of end-of-life care are shaped by culture, including:

the meaning ascribed to illness;
the actual language used to discuss sickness and death (including whether death may be openly acknowledged);
the symbolic value placed on an individual's life (and death);
the lived experience of pain and suffering;
the appropriate expression of pain;
the styles and background assumptions about family decision making;
the correct role for a healer to assume,
the care of the body after death, and
appropriate expressions of grief.

When the patient's family and healthcare providers do not share fundamental assumptions and goals, the challenges are daunting. Even with excellent and open communication—the foremost goal of culturally, and ethically, appropriate care—barriers remain. Differences in social class and religious background may further accentuate the profound challenge of defining and implementing "good" end-of-life care in healthcare systems serving increasingly diverse societies. The conceptual challenge for bioethics is defining the good in such situations, and making certain that recommendations for respecting cultural difference serve both pragmatic and principled goals (Sprio, McCrea Curnen, and Wandel).

When dealing with concepts as totalizing, but slippery as culture, and as seemingly precise as death, it is useful to begin by considering the definitions and basic concepts used by other disciplines.

Anthropological vs. Philosophical Approaches to Death

It is helpful to consider how taking an anthropological or cultural approach to the study of death differs from the approaches taken within philosophy, where the mystery of death has been a topic of debate and discussion for thousands of years. Philosophy has attempted to account for death conceptually, and more recently in terms of developing criteria for judging when death has occurred. Death is a state following upon the end of life; it is the absence of life. Death is a mystery, but is it more mysterious than other phenomena that we do not understand? Philosophers have tried to ask what death is, and in general have encountered serious definitional difficulties, stemming primarily from the problem of how one defines *life*.

A question of key philosophical interest was posed by the Epicurean philosophers, and most clearly articulated by Lucretius, who asked, "Is death bad for you?" His basic argument, that since the dead person no longer exists, death cannot be "bad" for the individual who dies, has been influential in the subsequent philosophical discourse on death. By contrast, cultural critiques begin with a set of *social* questions that move beyond the individual: How do different societies manage the existential fact that all members will eventually die, and the practical implications of the death of individuals, including the reintegration of survivors of a death? What role do healers and healing systems play, if any. Ethnographers, whether of tribal and hunter-gatherer societies or of a contemporary intensive care units, have a quite different task than the philosopher: describing the range of culturally patterned responses to the existential realities of eventual human frailty and death.

Death and the Birth of Bioethics

Death has been an essential focus of bioethics since the inception of the field nearly four decades ago (Jonsen). Dealing with the challenges of a dramatically changed biomedical landscape was, in fact, one of the main driving forces in the field's birth. One could argue that bioethics in its current form exists partly in relationship to its encounters with death, to birth pains peculiar to the unique cultural environment of the United States, where the field first crystallized into a new discipline. Following the successes of post-World War II clinical medicine, in particular the development of the mechanical ventilator, and its increasing use outside of its original site—in operating theaters and post-anesthesia recovery—the question arose: When is a patient beyond hope for a meaningful recovery and when is a patient whose heart and lungs are being continued by artificial means actually dead? (Veatch). The first heart transplant in 1968 added the complexity of figuring out when someone was "dead enough" for their organs to be harvested for transplant recipients.

A series of seminal legal cases, many receiving widespread attention, such as the cases of Baby Doe and Karen Ann Quinlan, revealed the fundamental ambiguities of medicine's power to combat death. Recognition of these ambiguities lead to the creation of a series of presidential commissions to debate and reflect on topics such as criteria for establishing brain death, and appropriate procedures for withholding or withdrawing potentially life-sustaining technologies.

Cultural analysis takes account of developments in technology but does not require a determinist position. The argument is *not* that new medical technologies transform cultural understandings of death in a straightforward, linear way. Rather, the meaning of any new medical procedure to forestall death will be developed and gain significance against a specific cultural background. Since understandings of technologies are inevitably culturally shaped, they are never *neutral* but their development is affected by the existing cultural milieu and once in use, cultural context affects how they are used. Thus, most researchers in science studies accept a view that the meanings of new medical technologies are *co-constructed,* rather than determined, they are in a way amalgams of social practices and technical objects; one must understand both in order to have the full picture. A totally implantable defibrillator to save patients from sudden death will not have a specific meaning in an environment where medicine's goal is to intervene in every death. Another society might question the use of certain procedures, such as resuscitation, in the situation of an expected death. The same dynamic affects "low tech" interventions like feeding tubes. Against the background of a long-standing cultural adage that "dying on an empty stomach" is a horrific fate, the surgically-implanted feeding tube will take on one sort of meaning. In another environment, where freedom from tubes and bodily interventions is highly valued, another outcome is likely. As the use of technologies intensifies, indeed, as patients begin to be defined as dying only after they have failed all readily available interventions, we might speak of death occurring in technological time (Muller and Koenig 1988).

Cultural Perspectives on Death

Exact definitions of culture are elusive, like the concept itself. At the most general level, culture is defined as those aspects of human activity that are socially rather than genetically transmitted. Thus culture is patterns of life passed among humans. Definitions are often so broad as to be meaningless, applying to every domain in society: religious beliefs, folk practices, language use, material objects, worldview, artistic expression, etc. According to pioneering anthropologist Robert Lowie, culture "is, indeed, the sole and exclusive subject-matter of ethnology [anthropology], as consciousness is the subject matter of psychology, life of biology, electricity as a branch of physics" (orig. 1917). "In explanatory importance and in generality of application it is comparable to such categories as gravity in physics, disease in medicine, evolution in biology," Alfred Kroeber and Clyde Kluckhohn wrote in 1952 (see Kuper for an overview).

With a category this broad, boundaries are difficult to delineate. Anthropologists have become critical of the application of the culture concept (Kuper). The work of Clifford Geertz moved the field of anthropology in the direction of interpretation, transforming culture from a passive noun to an active verb. "Man is an animal suspended in webs of significance he himself has spun; I take culture to be those webs, and the analysis of it to be, therefore, not an experimental science in search of law, but an interpretive one in search of meaning (p. 5)." In biomedicine the dangers of an essential view of culture are clear. We cannot simply *read* culture in patients facing death or indeed any clinical encounter, discerning their views, desires, and needs with false security based on knowledge that culture *A* holds view *B* about disclosing a terminal prognosis to a patient, and culture *C* holds view *D*.

The origins of the culture concept date back to the work of early post-Enlightenment folklorists, such as Herder, who made use of the concept to avoid the uniform, totalizing theories of human capabilities that were characteristic of the late eighteenth century. The modern concept of culture developed much later, partly in response to racist (and biological determinist) ideologies of the nineteenth century, most incorporating an evolutionary framework based on social Darwinism. The species *homo sapiens* was viewed as divided into separate sub-species or races, each with engrained, essential characteristics, a system that included a hierarchy of moral worth.

Philosophers maintain that a general problem with the culture concept is that it is often linked with a naïve relativism which precludes judgments about the unique cultural practices found around the world. Indeed, in some instances this criticism is warranted; attention to the diversity of cultures and the need to judge each on its own terms is central to the field. However such attention to cultural relativism at the empirical level does not necessarily lead to a stance of ethical relativism. Often practices dealing with death that were unsettling to Europeans, such as head hunting and cannibalism, were the focus of disproportionate attention, supporting efforts to justify and document a radically different "other" (Conklin).

The history of anthropological engagement with mortality dates back to the origins of the discipline, and is bound up with concerns about the origins of religion. Early theorists focused on small scale societies where magic, science, and religion are not separate cultural domains. For example the nineteenth century anthropologist Edward Tyler, who worked from an evolutionary paradigm of explanation, saw the origins of human society and culture in efforts to explain mortality, and in particular, in the recurrence of dreams and other visions about deceased close kin. The "savage philosopher" reflected on everyday experience and developed the notion of the soul. In *Magic, Science and Religion* Malinowski wrote,

> Of all sources of religion, the supreme and final crisis of life—death—is of the greatest importance. Death is the gateway to the other world in more than the most literal sense. According to most theories of early religion, a great deal, if not all, of religious inspiration has been derived from it.… Man has to live his life in the shadow of death, and he who clings to life and enjoys its fullness must dread the menace of its end. Death and its denial—immortality—have always formed, as they form today, the most poignant theme of man's forebodings. [Experience] at life's end condensed into one crisis which provokes a violent and complex outburst of religious manifestations. (p. 47)

Social theorists influential to the development of anthropology, such as Émile Durkheim, and later Robert Hertz, argued that all societies exert institutional controls to protect and preserve the lives of members, including rules governing appropriate and inappropriate killing. Many actions that appear to be individual choices, such as suicide or the expression of emotion during grieving, are actually socially patterned, as studies such as Durkheim's comparative analysis of suicide rates, one of the first uses of statistics in social science, illustrate (1951 [1897]). Hertz used cross cultural comparisons of mourning rituals to suggest that the human expression of grief can also be best understood as a *social fact,* particular to each society (1960 [1907]).

For reasons that have been the subject of extensive internal critique within anthropology (Rosaldo; Behar), until fairly recently the field concerned itself primarily with the rituals following death. This included ceremonies that focus on the disposal of the dead body and occur *after* cardiopulmonary death generally, although not always. This concern with ritual practices and symbolic meaning precluded a full engagement with the profound emotional significance of the process of dying, grief, and loss. Scholars focused on the recurrence throughout the world of death rituals that expressed fertility and rebirth (Bloch and Parry). The emphasis on sexuality, and the connection between sex and death, fit well with interpretations of ritual behavior that emphasized function. Death rituals serve the function of reintegration of society following a death, focusing on reproduction.

In some societies this symbolic link between death and regeneration is expressed explicitly; funerary practices incorporate the abandonment off usual standards of sexual propriety for a confined time period, or allow and encourage sexual relationships between categories of kin where such contact was generally excluded (Barley). These *rites de passage* seemed designed to guide the passage of humans through dangerous, liminal transitions, marking the boundary between life and death. Thus van Gennep (1960 [1909]) saw associations between funerals and other rites of transition, such as initiation ceremonies. In contemporary U.S. hospitals, the practices of bioethics developed in the last decades have become the *new* rituals guiding these transitions between life and death. A number of studies in anthropology (and medical sociology) examine contemporary death practices in biomedical settings, such as Bluebond-Langner's 1978 account of disclosure of a terminal diagnosis to children under treatment for leukemia, or Sudnow's 1967 account of dying in a public hospital. Christakis examines contemporary practices in foretelling death (1999). Other recent ethnographies chronicle the experience of death and extreme old age for specific populations, for example elderly Jewish immigrants (Myerhoff).

Defining the Boundary Between Life and Death

The concept of "social death" has been of considerable utility in describing the varied boundaries between life and death throughout the world. Nigel Barley, who has written an accessible account of the range of cultural practices surrounding death, describes his alarm and confusion when an African informant tells him casually that his wife "died" that morning, in the midst of a conversation asking him for a cigarette. In reality, she had been, in western terms "unconscious," but the Dowayo make no distinction, either linguistically or conceptually, between death-like states that are reversible (what we might call coma, persistent vegetative state or perhaps suspended animation) and that which continues permanently. This view of death provides a sharp contrast to biomedical definitions that assume irreversibility. (Although it is important to remember that even in the West, belief in resurrection calls the finality of death into question for many, and forms a core of religious belief.)

Studying ideas of death, of course, also reveals views on life and what it means to be human. The idea of social death is intimately tied up with notions of personhood, and who counts as a person within a society. Social death has utility in analyses at both ends of the human lifespan. Anthropologists have observed and documented societies in which full term infants are not considered fully alive, and thus members of the social group, until they have survived the first month of life (perhaps not by chance the period of highest vulnerability for a newborn) and received a name in a formal naming ceremony. Those who die before naming are not considered fully human—we might say that the social group does not recognize the infant' *personhood*—and thus do not warrant ritual attention, such as funerals or elaborate mourning rituals. Such practices are in sharp contrast with contemporary obstetrics practices in the first world, where developing fetuses are named and ultrasound images are exchanged prior to birth. Indeed, the very survival of extremely premature infants in neonatal intensive care units is best understood as an artifact of culture. In other societies specific kinds of birth—such as twins—or certain infants may be judged as incompatible with life, and thus viewed as already dead or infanticide may be allowed. In Bariba society (in Africa), certain infants are understood to be witches, and thus mothers are not allowed to grieve the loss because the infant is defined as not human (Sargent).

Social death is also a useful concept for describing practices near the end of life. In some societies, ritual mourning practices may begin before cardiopulmonary death occurs, since the ill or extremely aged person is viewed as meeting cultural criteria for social death. Or those who are very old may be viewed as almost dead. Many have argued that the warehousing of the elderly in sub-standard U.S. nursing homes constitutes a form of social death. In a series of pioneering ethnographic studies of hospital-based death in the U.S.—in the immediately "pre-bioethics" period—Glaser and Strauss conceive of the isolation of the dying as a form of social death (1965; 1968).

Arguably the most important example of social death in contemporary biomedicine is the notion of "brain death." A body maintained in a modern intensive care unit, pink, with heart beating and lungs inflating and deflating, appears to most observers as a living being. Yet a diagnosis of brain death results in that person's abrupt transition to a socially recognized state of death, and transforms the corpse into a container to house organs awaiting harvesting for another donor. A detailed analysis of the historical development of the concept of brain death, as well as a chronicle of contemporary brain death debates is found in Margaret Lock's 2002 *Twice Dead.* Lock uses a classic anthropological technique called the comparative method to reveal how culture shapes seemingly technical scientific and medical practices. The state of brain death appears to follow the straightforward application of a set of technical criteria about the functioning of the human brain. Lock tells the story of Japanese resistance to organ transplants that require the use of a brain dead patient. By contrasting Japan and the U.S., she reveals how the category of social death can only be understood in cultural context. In Japan, the core site or physical location of personhood is associated with the heart, not the brain. However, Lock makes it clear that the story is not simply about "traditional beliefs," rather many features of contemporary Japanese society—including distrust of the medical profession—play a role in widespread resistance to organ harvesting from brain dead donors.

New Rituals of Dying

For most in the wealthy, developed world the idea that death is an evil to be prevented at all cost, including the use of aggressive therapies like the totally implantable artificial heart, is commonplace. Buoyed by past successes, the arc of medical practice has extended to the moment of death, which increasingly is seen as a process to be stopped whenever possible. As new technologies became available, seeing a patient in cardiac arrest necessitated an action. Resuscitation, in reality attempts at resuscitation, became routinized and normalized at the moment of death (Timmermans). By the late 1960s dying within the sphere of biomedicine became defined as a problem in need of a solution.

The outcome of the many commissions, legal cases, and academic discussions described by Jonsen in the *Birth of Bioethics* (1998) is a set of novel, autonomy-based practices that seek to enhance the self-determination of the dying, and protect patients from the abuses of overzealous physicians "programmed" by their instrumental training to over treat, prolonging the dying process. These practices incude:

1. formal implementation of advance care planning (and execution of advance directives), institutionalized by law following the passage of the American "Patient Self-Determination Act" in 1991;
2. explicit discussion and decision making about the use of cardiopulmonary resuscitation, or DNR orders;
3. open discussion of diagnosis/prognosis and shared decision making about foregoing or withdrawing curative interventions; and
4. transition to "palliative care" or, in some cases, hospice.

Of course this ideal narrative is rarely followed. All of these practices required a commitment to open and full disclosure of information about death and detailed discussions about how one wishes to die, and assumed that the patient himself—and a gendered pronoun is used purposefully—was in full control of his destiny and fate. The model is gendered male by the focus on individual agency and control, as opposed to the inevitable interdependence of a dying person with her social environment.

What Differences Make a Difference?

Thus far, only broad cultural responses to death have been considered. With increased border crossing and south/north migrations throughout the world, how should we view and define difference in bioethics? Turning to contemporary biomedicine, considerable research documents the relevance of ethnic or cultural and religious differences in the experience of death and dying and in clinical approaches to end-of-life care. However, health researchers and clinicians generally do a poor job of making clear analytic distinctions among the key elements of difference, in answering the question, "What differences make a difference?" When we talk about *cultural* difference, do we mean a patient or family's voluntarily adopted and expressed *ethnic identity,* their nation of origin if recent immigrants, their *race* as assigned by a government enforcing discriminatory laws such as segregation or apartheid, or their adoption of specific health-related practices such as diet or use of medicinal herbs? In healthcare research there is considerable confusion in terminology, particularly with regard to the use of the term "race."

The lack of consistency in the use of terminology for concepts of race, ethnicity, ancestry, and culture is manifest in the wide variance in terms used to describe individual and group identities. Terms such as white, Caucasian, Anglo, and European are routinely used interchangeably to refer to certain groups, whereas black, colored, Negro, and African-American are used to refer to comparison groups. Also, white-black comparisons are straightforward in contrast to the confused use of terms such as Hispanic and Asian. Both of these labels, one based on linguistic criteria and the other on continental origin, lump together many populations of people reflecting enormous variability in factors related to health and medical care. The terms we use gloss over enormous diversity.

Debates in the biomedical literature focus on the appropriate use of terms such as race, ethnicity, and culture. Asking how race is relevant to bioethics, death, and end-of-life care is relevant, but caution is needed whenever the category of race is invoked. Much is "at stake" in how these categories of difference are utilized when conducting research or in designing programs to improve the care of patients, by way of enhancing the *cultural competence* of healthcare providers who must aid patients and families in decision making at the end of life. In particular, approaches to conceptualizing disease etiology or health outcomes may have moral significance if one naïvely assumes that culture predicts behavior in a precise way or that something essential or *inherent* in a certain population leads to poor health outcomes or barriers to healthcare access (Gunaratnam).

In the case of black-white differences in infant mortality or homicide rates, for example, how one thinks about causation, and the relative contribution of genes, environment, and social structure, may determine the type of intervention recommended. Meaningful genetic and biological differences do not always map clearly onto social categories of human difference, whether defined as race, ethnicity, or culture. American patients who self-identify as African American generally seek more aggressive care and are underrepresented in hospice services. If we talk about *racial* differences about preferences for palliative care services, what exactly do we mean? In the United States efforts to tease apart the independent contributions of *race* and socioeconomic status (SES) when analyzing healthcare outcomes may be daunting.

Although the dimensions of difference most relevant to end-of-life care are likely to be social or cultural, biological or genetic variation may also be germane. For example, the field of pharmacogenomics tracks individual and group differences in drug metabolizing enzymes to predict response to medications such as chemotherapy or pain medicines. Although classic understandings of human "races" do not parallel actual genetic variation at the molecular level, there may be frequency differences among socially defined populations relevant to pharmacogenomics. It has been known for decades that there is ethnic or cultural variation in the expression of pain or painful symptoms (Zbrowski; Garro); the degree of variation in the actual experience of pain—possibly modulated through the action of pain medicines—remains unexplored.

Immigration status is another key category of cultural difference. Recent immigrants provide challenges to the healthcare system, particularly in end-of-life care. In much of the world, the American ideal of open disclosure of information about diagnosis and prognosis is not the norm (Gordon and Paci; Die Trill and Kovalick). In fact, patients and families may experience the directness about diagnosis characteristic of U.S. healthcare as needlessly and aggressively brutal, violating norms espousing "protection" of the ill. Although children may be seen as more in need of protection than adults, much pediatric palliative care literature recommends openness, appropriate to an ill child's age, as preferable to concealment. U.S. bioethics procedures governing end-of-life care may seem unfathomable to those newly in this country, but it is perhaps the assumptions of bioethics that are culturally bound. As Die Trill and Kovalick note, "Those who argue that children always should be told the truth about having cancer must recognize that the truth is susceptible to many interpretations" (p. 203). Whether the dying person is a child or an adult, family members who object to sharing the full differential diagnosis with an ill child may be accused of being "in denial" about the severity of the patient's illness, their concerns "psychologized" rather than understood. Lastly, the experience of those immigrants who are refugees from political violence or war adds another dimension. The effects of multiple losses on family members—including the death of other children and adults in the family, one's country, one's entire history—are difficult to predict but clearly shape a family's response to the serious illness and threatened loss. Responses may appear to be overly stoic or overly emotional.

When considering societies with histories of deep racial divisions, it is especially important to separate analytically the concepts of culture, ethnicity, and race from the effects of social and economic status. Historically underserved populations may have special barriers to end-of-life care that have little to do with difficulties in communication and are not related to their identification with a certain set of ethnic traditions. Culturally specific values and beliefs often exist, but may not be of signal importance. In a ground-breaking study, an American physician documented the lack of availability of narcotic analgesics in minority communities such as Harlem (a low income, historically African American and Hispanic neighborhood in New York City); pharmacies simply did not carry the opiates that are "state-of-the-art" drugs for pain control (Morrison, Wallenstein, and Natale et al.). The American "drug wars," including the recent battles about the abuse of time-release opiates like oxycontin, are often fought in poor neighborhoods with limited access to legitimate employment. Patients from minority backgrounds may not receive adequate pain control if drugs are not prescribed because of fears of theft or abuse. When members of the healthcare team are hesitant to prescribe narcotics it may be a legitimate concern based on factual information about a particular family's drug history, or it may be the exercise of racial stereotyping. The end result is the same: patients may be denied needed pain relief.

The experience of people with sickle cell disease, whose pain is often undertreated because of concerns about drug abuse, is another example of stereotyping. Culture thus contributes to inadequate symptom management, but indirectly, through the actions of healthcare providers, not the essential cultural characteristics of a population. Research in a Los Angeles emergency department documented that Hispanic patients with injuries identical to whites were given less analgesic medication (Todd, Samaroo, and Hoffman). Do patients in such situations have different cultural values about analgesia? Can they exercise full autonomy when faced with decisions about foregoing or withdrawing life prolonging therapies? Surely not, without the assurance of adequate analgesia and palliative care.

Karla Holloway's *Passed On: African American Mourning Stories* (2002) vividly reveals how the unique history of Blacks in the U.S.—including the legacy of slavery, Jim Crow policies, and violent death, such as lynching—shape the experience of death for patients receiving care in hospitals that were segregated two generations ago. Clearly *difference* is relevant to bioethics; assuming that end-of-life procedures and practices have universal applicability is at best naïve and at worst harmful. In addition to the varieties of cultural and social class differences described here, other domains of difference that intersect with culture, such as gender, sexual orientation, disability, and religious background, must also be considered within bioethics (Parens).

Culture Matters: Bioethics, End-of-Life Care and Decision Making

In its report detailing needed changes in care of the dying, the Institute of Medicine has recommended attention to cultural diversity as a national policy objective (Field and Cassel). There is a growing literature based on empirical studies documenting the cultural dimensions of end-of-life care for patients and families. (For reviews see Kagawa-Singer and Blackhall; Koenig and Davies; Crawley, Marshall, and Koenig). Based on this literature, it is possible to identify the key domains of clinical significance in caring for patients from diverse ethnocultural backgrounds who are unlikely to survive.

In general, the cultural challenges of end-of-life care can be divided into two fundamental categories: those that do, and those that do not, violate the healthcare team's foundational cultural values, norms that may also be enforced by legal requirements in some societies. In the first category are cultural values or practices that call into question the biomedical goal of combating disease and extending life at all costs. A family who refused to allow a potentially curative limb amputation for a female child with osteosarcoma because of beliefs about the need to preserve bodily integrity, and a daughter's marriageability, would immediately create consternation for healthcare team members. By contrast, another family who wished to engage a spiritual healer to pray for a successful outcome to the same potentially life-saving surgery would *not* create a cultural crisis, since the family's goals could easily and effortlessly be incorporated into the clinicians' care plan.

Generally, issues such as care of the body after death do not provide a fundamental challenge to biomedical values and beliefs; thus customs prescribing particular approaches to post-death care are relatively easy to implement unless they violate laws governing disposal of the body. However, even in post-death care there may be situations that lead to cultural conflict, such as requests for autopsy or organ donation in situations where the wholeness of the body is highly valued. And the domain of grief counseling and bereavement care may or may not elicit conflict. For medical specialists focused on cure, less is "at stake" once a patient has died and can no longer be saved, but conflicts may still emerge over differing definitions of acceptable grieving practices.

Family Roles and Responsibilities in Shared Decision Making

Within the current conventions of bioethical decision making about end-of-life care for a competent adult patient, the decisions are left up to the individual; theoretically the family or broader community is not critical to the patient's choices. Autonomy is the primary value at play. In the case of children or the severely mentally incapacitated, where family members become surrogate decision makers, the situation is much more complex. A growing body of research documents how autonomy-focused bioethics practices may not adequately meet the needs of patients from diverse backgrounds. The value of respect for individual autonomy is not universal. Patients may express confusion and ambivalence when asked to participate in advance care planning about death (Frank, Blackhall, and Michel).

Disagreements about the goals of care, although rare, are emotionally difficult for all. In many cross-cultural situations, the Western view that individual patients will (and should) make decisions about care may be too narrow. In some societies a social unit beyond the nuclear family may also have considerable decision-making authority. Elders in an extended family or clan group may expect to be involved, and patients may desire this. Integrating extended family or kin groups into care in a Western hospital, hospice, or nursing home is hard but may be desirable. Gender may play a role as well. In traditional male-dominated societies, mothers may never have experienced the level of decision-making authority automatically granted to both parents in the United States. This may be a source of tension. Similarly, the evolving practice in pediatrics of requesting "assent" to care by older children, especially girls, may create tensions within the family.

A further dynamic may result from the ideal "shared decision-making" model. Tilden and colleagues have documented stress among family members involved in decisions to withhold treatment. The impact of family involvement in decisions to terminate treatment has not been studied extensively. Inexperienced clinicians or trainees may present decisions about limiting painful or aggressive procedures, sometimes an opening to a transition to palliative or hospice care, in an insensitive way, making it appear that the family decision makers must give "permission" for futile care to be withheld. Although the family's involvment in making decisions on behalf of their loved one is expected, few individuals, regardless of their cultural background, are able to do this easily. In fact, the resistance to giving up hope and explicitly limiting therapies found among families from diverse backgrounds may be appropriate. Models of care that do not require that curative therapies be abandoned in order to obtain excellent palliative services may ultimately lessen this problem. Patients or family members should never be told that care will be withheld; rather the focus should be on meeting the needs of the patient and family.

Varied Understandings of the Role of Health Professionals or Healers

Just as the appropriate role of parents or family members caring for a seriously ill person may vary, the families' expectation of the role played by health professionals may differ. In some societies, healers are expected to make a diagnosis almost magically, perhaps by feeling the pulse without asking any questions. Healers may exert considerable power and authority; they may expect and receive deferential behavior. Patients and families schooled in these traditions may be confused by the shared decision-making ideals of Western practice. They may lose confidence in physicians who do not appear to know unequivocally the correct course of action but instead ask for the patient's views.

In many societies the roles of healer and religious specialist intersect. "Each religious tradition has its own images and ideals of the doctor, in which the individual engaged in healing is defined as enacting some of the highest ideals of the tradition itself" (Barnes, Plotnikoff, Fox, and Pendleton). The healer's role at the end of life may be particularly meaningful, or it may be proscribed to take on the care of those not expected to survive, as in the Hippocratic tradition.

Families who have been denied access to healthcare providers may also question the trustworthiness of the "establishment" health system, worried that those in power do not have their best interest at heart. The disparities in morbidity and mortality across U.S. populations suggest that often African-American patients receive less intensive care. The irony is that research on end-of-life decision making in adults reveals that minority patients may actually desire more aggressive care near the end of life (Caralis, Davis, Wright, and Marcial; Tulsky, Cassileth, and Bennett).

Communication Barriers: The Need for Translation

Negotiation about the appropriateness of clinical services for patients nearing the end-of-life is a complex task when healthcare professionals, patients, and family members share fundamental goals and assumptions. By no means has a successful "formula" for such communication been established. When cultural barriers exist, particularly those created by language, the goal of open and effective communication is exceptionally difficult. Language translators may be available only intermittently, and are often poorly trained. In 2002, two hospitals in Brooklyn, New York, that routinely serve large numbers of Spanish-speaking patients were sued for failure to provide translation services, examples of a number of such legal actions dating back several decades.

The task of language translation in the arena of ethical decision making and end-of-life care is particularly complex. How does one translate a discussion about a "do not resuscitate" decision to a family with no previous experience of cardiopulmonary resuscitation (CPR), and no prior knowledge of the American bioethics tradition of requiring permission not to offer CPR, even to a patient who is actively dying an "expected" death, or may be frail because of extreme old age? What if the language characters representing resuscitation are interchangeable with those suggesting the religious concept of resurrection? Although it sounds odd from the perspective of Western, scientific understandings of death, who would not elect to have themselves or their dying loved one brought back to life if offered the choice in those words? How might medical interventions at the moment of death be understood among practitioners of Buddhism who believe that rituals spoken during the dying process guide the "soul" through dangerous spiritual territory and ultimately determine where and how a person will be reborn? How do you negotiate with a family about the location of death—home versus hospital—against a cultural background where speaking of an individual's death is thought to bring it about or where certain illnesses cannot be named? The use of family members as interpreters, which may be unavoidable, may make discussions such as these even more problematic. Family members may see their primary role as protecting others in the family from harm and thus "shield" them from information viewed as harmful. Such shielding is counter to bioethics norms of open disclosure.

Furthermore, models of professional translation, such as those employed in courtrooms where relationships are fundamentally adversarial rather than collaborative, assume that language interpreters should function as neutral "machines." Healthcare providers need to be aware that translation services such as those available by phone from AT&T may be based on legal models of interpretation. This stance ignores the interpreter's potential value in providing information about the family's cultural background, as well as providing language interpretation. When interpreters are engaged as full partners in providing care, they may aid in negotiations about difficult end-of-life dilemmas (Kaufert, Putsch, and Lavallee). When included as part of the healthcare team—for example, in programs where native speakers of commonly encountered languages are employed as bilingual medical assistants—interpreters can also serve the useful function of explaining the culture of biomedicine, and the seemingly peculiar assumptions of bioethics, to families.

Integration of Alternative and Complementary Medicine into Palliative Care

Patients and their families may be subject to strong pressures to utilize "ethnomedical" practices and procedures believed to be efficacious. Recent immigrants may utilize products obtained abroad or from Mexico and Central America. Practices vary widely, including acupuncture for pain, cupping or coining, dietary prohibitions based on "hot-cold" belief systems, Chinese herbal products, Ayurvedic patent medicines, and full-blown rituals including chanting and the sacrifice of animals. A skilled practitioner creates an open environment in which the patient, family, and perhaps a ritual specialist from the community may openly discuss the appropriate blending of biomedically sanctioned medicines and procedures with ethnomedical products. Although some patent medicines and food supplements are known to be harmful and may actually contain potent pharmaceuticals, the healthcare team is unlikely to obtain a full accounting of all treatments used for a particular dying patient unless a nonjudgmental attitude is maintained. This may be a challenge when a healthcare provider must compromise his or her own "ideal" care.

The need to integrate alternative and complementary medicine into palliative care is not limited to patients from particular ethnocultural communities. Research documents that a large percentage of Americans have utilized "alternative" medicine in the recent past (Eisenberg, Davis, Ettner et al.), with prayer being the most widely utilized practice (82 percent of Americans believe in the healing power of personal prayer) (Barnes, Plotnikoff, Fox, and Pendleton).

The Meaning of Pain and Suffering

End-of-life care has as a primary goal the relief of pain and suffering. Cultural difference is relevant to pain management in multiple ways. The effectiveness of symptom management may be lessened by economic barriers to medicines or special treatments. Cross-cultural research with adult patients has documented differences in the way people experience and express pain (Garro). What is considered acceptable way to express painful symptoms? Is stoicism rewarded? Are there gender differences in outward discussion of painful symptoms? Spirituality may have an impact on the meaning of suffering and hence on the management of symptoms. A study of infants and children with a rare genetic disease (recombinant 8 syndrome) in long-time Spanish-speaking residents of the American Southwest revealed the complexity of suffering. The experience of affected children in these devout Catholic families was thought to mirror Christ's suffering, providing meaning to an otherwise unexplainable tragedy (Blake).

Defining the Boundary of Life and Death

Biomedical definitions of death, including the concept of brain death, appear to be clear cut. However, when examined closely considerable ambiguity remains. Even among biomedical professionals one frequently hears confusion in language when speaking, say, about an organ donor who is technically brain dead, but may appear to be as "alive" as adjacent patients in an ICU. Linguistically, these brain-dead bodies experience a second "death" once organs are retrieved for transplantation and ventilatory support is removed (Lock). It is thus not surprising that patients and families can also become quite confused about states resembling death, including brain death, the persistent vegetative state, or coma (Kaufman).

Disputes arise when a patient meets the biomedical criteria for "brain death," but the family refuses to allow withdrawal of "life" support. In a masterful essay, Joseph Fins describes two clinical negotiations about withdrawing life support from children defined as brain dead (1998). In one case, the hospital team engages the family's orthodox rabbi and other religious authorities in a complex series of negotiations, respecting throughout the family's view that the patient is not truly dead and that only God can declare death. A more contentious case involves an African-American family who maintains a stance of mistrust toward the healthcare establishment in spite of every effort on the part of the clinical team. The family's past experience shaped its understanding of the team's intentions in spite of great effort to gain their trust. Disputes such as these are the "hard" cases, revealing cultural clashes that cannot be ameliorated simply by motivated clinicians, sensitivity, or excellent communication skills, although clearly those things may keep conflict to a minimum or may keep small cultural disputes from erupting into major pitched battles.

Work has focused on care of the body after death, particularly the question of autopsy, since in some societies the body is considered inviolable after death; its contents sacred and necessary for the individual's appropriate survival into the afterlife. These cultural practices were most fully-developed in Egyptian dynasties, where funeral practices and preparation for life after death—including mummification and building of elaborate tombs—consumed the society's symbolic attention and material resources. The acceptability of autopsy, or other uses of the body following death, is deeply sensitive to cultural and religious prohibitions. Knowledge about the acceptability of autopsy, or requests for organ donation in the case of acute trauma, cannot usually be guessed by "reading" a family's background.

Furthermore, different ethnocultural groups may have varied understandings of the nature, meaning, and importance of cognitive impairment in a patient. In a society where social relationships are a core value, esteemed more highly than individual achievement, disabilities that affect intellectual functioning but do not interfere with the ill person's role in the family may be more readily "accepted." By contrast, in some societies severely handicapped people may experience a form of social death, isolated from the broader community.

Acceptance of Hospice Philosophy

Utilization of hospice care programs is not identical across racialized U.S. populations. African Americans utilize hospice services at a lower rate than do European Americans. Home death is often considered an ideal within the hospice philosophy. A *good death* is often characterized as one that takes place at home, surrounded by family and/or friends, with pain and symptoms under control, spiritual needs identified and met, and following appropriate good-byes. Traditionally, this ideal good death required giving up curative interventions. At the moment in U.S. history, the 1970s, when hospice care became a viable alternative, aggressive end-of-life interventions were commonplace, and efforts to secure patient participation in decision making were not yet fully realized. Thus, the home became a refuge from the ravages of hospital death. Even though the strict implementation of a six-month prognosis requirement for hospice is changing, it remains difficult to predict the terminal or near-terminal phase of common illnesses, particularly cardiac, pulmonary, and metabolic conditions, in contrast with cancer. Acknowledging that death is near may be particularly difficult. Home death may not be valued in ethnocultural groups where it is considered inappropriate, dangerous, or polluting to be around the dead. Among traditional Navajo, the dying were removed from the Hogan dwelling through a special door to a separate shed-like room to avoid the catastrophe of a death occurring in the Hogan, which would then have to be destroyed. Burial practices were organized to make certain that ghosts could not find their way back to the Hogan, and family members did not touch the dead body. This task was relegated to outsiders. These issues remain salient for those practicing in the Indian Health Service. In some Chinese immigrant communities a death at home may affect the value of a particular property on resale.

Culture, Grief, and Mourning

Bioethics practices generally focus on decision making prior to death. Clinical interventions to aid the bereaved—increasingly seen as a critical component of services provided to patients and families—must take into account cultural differences. It is critical to acknowledge that Western ways of grieving and disposing of the body are not universally accepted as the *right* way. It is also likely that our theories of grief and mourning, including definitions of *normal,* are inappropriately based on Western behavioral norms. For example, a standard way in the West of dealing with grief is to talk-about one's experience, one's relationship with the deceased, one's feelings. But in some cultures, talking may disrupt hard-earned efforts to feel what is appropriate, and to disrupt those efforts may jeopardize one's health. In some cultures, talk is acceptable, but one must never mention the name of the deceased person. In other cultures, talk is acceptable as long as it doesn't focus on oneself. Even in the West, however, not everyone is open to talking. It is important not to label those who do not openly express their emotions as *pathological.* In fact, the concept of pathological grief is primarily a Western construction. A mother in the slums of Cairo, Egypt, locked for seven years in the depths of a deep depression over the death of a child is not behaving pathologically by the standards of her community (Wikan). There is enormous variation in what is considered appropriate behavior following death. The ideal among traditional Navajo is to express no emotion, while in tribal societies a death may be met with wild outpourings of grief, including self-mutilation (Barley). In contrast to clinical notions of pathological grief, in some Mediterranean societies widowhood was considered a permanent state of mourning, and mourning clothes were worn for years, if not decades. In a compelling book titled *Consuming Grief,* Conklin describes how native Amazonians assuage their grief by consuming the body of their dead kin (2001). A number of anthologies provide examples of the range of cross-cultural variation in post-death management (Counts and Counts; Metcalf and Huntington; Irish, Lundquist, and Jenkins Nelsen; Parkes, Laungani, and Pittu; Rosenblatt, Walsh, and Jackson).

The Need for Clinical Compromise: A Challenge for Bioethics

Respecting cultural difference may offer a profound challenge to healthcare practitioners' most fundamental values. In perhaps the best "text" explaining the cultural dynamics underlying the treatment of a critically ill patient, Anne Fadiman, in *The Sprit Catches You and You Fall Down* (1997), offers a detailed account of how the physicians caring for a young Hmong child with life-threatening, difficult-to-control epilepsy ultimately fail her because of their desire to offer her "state-of-the-art" care identical to that offered to any of their other patients. Through her detailed ethnographic account, Fadiman reveals how in this case the physician's quest for the "perfect" treatment was the proverbial "enemy of the good." The parents of the child, Lia Lee, were refugees from the American war in Southeast Asia, illiterate in their own language, with ideas about the cause of epilepsy and its appropriate treatment that were completely at odds with the views of the Western healthcare team. They were not, however, the only participants in the exchange shaped by cultural background and context. Fadiman's work documents the culture of biomedicine, explaining with great clarity how the physician's uncompromising dedication to perfection kept them from negotiating a treatment regimen acceptable to all.

Often in cross-cultural settings it is imperative to learn to compromise one's own clinical goals in order to meet the patient "halfway." Fadiman's book recounts the profound miscommunication between the pediatricians and family physicians involved in Lia's care, the Lee family, and the broader Hmong community. When her parents are unable to carry out a complex regimen of anti-epilepsy drugs, the child is turned over to the state's child protective services agency, provoking a profound and deepening spiral of tragedies. In the end, the physicians wish they had compromised their goals and prescribed a more simple medication schedule. Ironically, the parents' observation that the medicines were making Lia sick proved true in that one of the antiepileptic drugs contributed to an episode of profound sepsis that resulted in Lia's persistent vegetative state. A number of American medical schools assign this book as a required text in cultural sensitivity training. Its brilliance lies in revealing both sides of a complex equation: a Hmong enclave transported to semi-rural California and a group of elite, Western-trained physicians and healthcare practitioners caught up in a drama they cannot understand, not because the Lee family's cultural practices are so esoteric but because they fail to recognize how their own cultural assumptions and deeply held values limit their ability to help the ill child.

The Culture of Biomedicine and Biomedical Death Reflect Features of U.S. Society

National efforts to improve end-of-life care often include the notion that *cultural change* or promotion of *cultural readiness* is essential for reform efforts to be successful (Moskowitz and Nelson). Yet, what this cultural change would look like and what barriers to such change exist are rarely itemized. National public awareness campaigns such as "Last Acts" have used a variety of strategies to change the *culture of dying* in America, including working with the media. For example, one strategy has been to sponsor scriptwriting conferences to encourage widely viewed television programs, such as "ER," to include realistic stories about patients near the end of life. In fact, one episode focused on end-stage cystic fibrosis. Narratives created for television might convey the idea that a comfortable, pain-free death is possible and should be *demanded* by patients and families as an essential feature of a comprehensive healthcare system. The stories might convey the important lesson that physicians and other caregivers may forgo their most aggressive efforts at cure without abandoning patients.

Unfortunately, these efforts at promoting cultural change ignore a fundamental and problematic social fact—a profound cultural resistance to foregoing high technology interventions and giving up hope for recovery. narratives of hope and recovery compete with stories of patients abandoning efforts at cure after a valiant struggle with disease.

Research by Koenig and her team revealed that patients from minority backgrounds, in particular recent immigrants, seemed to lack a sense of the narrative structure of end-of-life care that English-speaking, middle-class European-American families understood more readily. In particular, the idea that patients and families would make an explicit choice to abandon curative therapy, followed by the "limiting" of aggressive interventions like intensive care and cardiopulmonary resuscitation, did not seem to be a story patients understood. Recent Chinese immigrant patients could not answer questions that presupposed a transition from curative to palliative goals; it was simply beyond their experience (Hern, Koenig, Moore, and Marshall). In their worldview, doctors do not *stop* treating patients. Efforts to change the culture through engagements with the media—encouraging op-ed pieces in newspapers, scriptwriting workshops, and so forth—may educate potential patients about existing approaches in palliative and hospice care.

One cultural barrier is particularly difficult to surmount. Before physicians can recommend palliative care and before patients and families agree to it, in our current system one must first accept the possibility that death is imminent or at least that one's likely survival is seriously limited. Eventually, current reform efforts to introduce palliative care early in a trajectory of disease or illness may decrease the need for patients or families to embrace their own death in order to make a clear transition between curative and palliative modalities of treatment. But it is unlikely that the tension caused by the need to balance conflicting goals will ever dissipate totally.

Even if one embraces the narrative of limiting aggressive treatment and adopting comfort care, including attention to spiritual and interpersonal goals, as a good idea "in principle" for those facing death, there still exists the radically difficult and jarring transition itself, the need to imagine you or your family member as now taking center stage in a particular EOL narrative. It is no longer theoretical but real. The resistance to seeing oneself (or a loved one) in this role is considerable and may prove insurmountable for many. A set of powerful cultural narratives operates to feed this resistance and encourage its perpetuation. Consider, as one example, the heroic narratives of successful research and triumphant cure that are much more often portrayed by the media than stories of failed therapy and excellent end-of-life care (Koenig). The content of public relations materials produced by medical centers and ads published by drug companies conveys powerful cultural metaphors that are directly counter to the mundane realities of palliative care, often focused on managing symptoms such as constipation. Hospital ads suggest that it is vital to "keep shopping" and eventually you will find the program offering the experimental or innovative therapy that will lead to cure. The heroic search for cure is celebrated in media accounts such as the film *Lorenzo's Oil* or news accounts of a family seeking gene therapy to cure their child's severe, life-limiting genetic illness (Canavan disease). A full analysis of the culture of dying in the United States must acknowledge these powerful counter images.

It is important to bear in mind that such stories and advertisements are features of a particular political economy of healthcare. Unlike providing palliative care, which does not generate an economic surplus for hospitals, administering chemotherapy generates profits even when the likelihood of its success is low or nonexistant. One recent study documents that curative chemotherapy is often given very close to the end of life, when its use may be futile (Emanuel et al.). This is not to suggest that individual physicians are primarily motivated by financial gain when they prescribe chemotherapy that they know has little chance of success. The full picture is a much more complex mix of faith in research, trust in therapeutic rituals as opposed to inaction, genuine prognostic uncertainty, and unwillingness to acknowledge the likely poor outcome of patients one knows well. But it is critical to acknowledge that the economic structure of U.S. healthcare for children creates few barriers for the use of advanced life-prolonging therapies such as chemotherapy or days in an intensive care unit, at least for those with insurance or access to government-funded programs. The most intensive services often generate the highest profits. By contrast, hospice and palliative care programs are often supported by philanthropy; providing excellent palliative care is at best revenue neutral and more often a money loser for medical centers. Thus, the political economy of healthcare supports what Daniel Callahan has called "technological brinkmanship," or the aggressive use of technology until the last possible moment, often leading to its overuse. Culture shapes the realities of care at many levels.

Conclusion: Bioethics, Culture, and Globalization

The experiences of death are culturally constructed within particular social and historical moments. An anthropological account of death takes into account the network of human relationships within which behaviors and practices associated with death and mourning are situated. A cultural analysis of the rituals and symbols evoked by death and dying also suggest the powerful role of social and economic conditions that necessarily define and constrain death experiences, including the treatment of bodies, burial practices, and reactions to grief. Viewed from a cultural perspective, death practices provide an important foundation for understanding the meaning of human suffering in response to loss.

Cultural analysis using ethnographic methods provides unique insights into the nature of bioethics practices that have become the new rituals of dying. These insights will be of increasing use in the context of a globalized biomedicine, which moves bioethics practices into multiple settings, often quite different from the social and historical context that shaped their development. When implemented in societies characterized by an increasing degree of cultural diversity, the limitations of these practices, and their cultural roots and sources, are revealed. Cultural analysis—particularly studies that highlight the response of ethnically different others to bioethics practices—is incomplete if not augmented by attention to the political economy of healthcare. Cultural variability does not *determine* ones views about death. Rather, we are all shaped by culture, and in turn contribute to dynamic change.

There is a naïve hope that cultural competency training will lead effortlessly to improved outcomes. It may under some circumstances, but significant cultural difference inevitably brings with it true conflicts that may not be resolved, even with ideal, open communication and mutual respect. In some situations, the distance between families and the healthcare team may be too profound to overcome in spite of considerable efforts by all. Anne Fadiman recounts a physician involved in the care of Lia Lee, who lamented that even if it had been possible to send the Lee family to medical school with an interpreter, the difference in world views separating a refugee Hmong family from mainstream Western pediatrics would remain insurmountable.

How one thinks about culture matters. A serious flaw in current cultural competency training in biomedical settings is a simplistic and unsophisticated account of culture itself. It is almost as if there is a belief that culture codes for—and predicts—behavior in the same way that DNA codes for a certain protein. Reductionist approaches to education in cultural difference will inevitably fail because, at best, they teach a few general clues that must be verified through interaction with a family and, at worst, they model an unsophisticated approach to culture that leads to simple stereotyping, thus doing more harm than good. Educational techniques and programs that emphasize an interpretive approach to understanding cultural difference are more likely to be successful.

If one accepts that analyzing the nature of ethical practice, and ultimately improving end-of-life care, is a fundamental goal of bioethics, then bioethics scholars must take account of culture in their work. Culture must be engaged at many levels, not just through a focus of *the other*. Ethnic and cultural difference in response to bioethics practices—the new end-of-life rituals—must be respected in a sophisticated manner, free of harmful stereotyping. But we must not stop there. Those working in bioethics must engage in a critical analysis of the culture of biomedical science and practice. And finally, they must be active students of the cultural assumptions underlying bioethics itself, interrogating the foundations of the field.

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SEE ALSO: *Aging and the Aged: Old Age; Anthropology and Bioethics; Autonomy; Body: Cultural and Religious Perspectives; Care; Grief and Bereavement; Harm; Holocaust; Human Dignity; Infanticide; Life; Life, Quality of; Life Sustaining Treatment and Euthanasia; Literature and Healthcare; Narrative; Palliative Care and Hospice; Pediatrics, Intensive Care in; Right to Die, Policy and Law; Suicide; and Virtue and Character; Warfare;* and other *Death* subentries

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II. EASTERN THOUGHT

Unlike other species, humans can reflect on death. One response to the mystery and fear humans associate with death is to create systems of religious meaning that give purpose to life in the face of death. A corollary of the fact that people can reflect on death is their realization that it is possible for them intentionally to end life. Religion constrains this possibility in the interest of human survival; only a few exceptions to the taboo against killing humans are allowed. Animals, by contrast, cannot decide to kill themselves and seldom kill members of their own species.

Concepts of death in Asian religions include two basic types: natural—for example, death by disease and old age; and unnatural—for example, death by an accident, by the intention of another person (homicide), or by one’s own intention. The latter, here called self-willed death, may be subdivided into three types: (1) suicide (self-willed death out of depression or passion, an irrational and private act); (2) heroic (self-willed death by warriors, and sometimes their wives, to avoid being killed or captured by an enemy, and therefore shamed; or to follow a leader in death because of loyalty); and (3) religious (self-willed death as a rational and public act sanctioned by a religion; for example, in cases of terminal illness or debilitating old age, or as a means to achieve heaven or enlightenment).

Hinduism

THE CONCEPT OF NATURAL DEATH. In no small measure, Vedic (Brahmanical) religion (1500–600 B.C.E.), its sequel now called Hinduism, and other Indian religions (Jainism and Buddhism) inherited views of death from the Indo-Europeans who came to India, probably from eastern Anatolia. Because life expectancy in the prehistoric world was about thirty years, on account of disease, natural calamities, and warfare, people turned to religion for help, performing rituals for health, physical security, longevity, or immortality.

A proto-Indo-European myth about death involved a primordial sacrifice in which Manu (literally Man), the first priest, sacrificed Yemo, his twin and the first king, to create the cosmos, including the realm of the dead. Located to the south, symbolizing warmth, the realm of the dead was described as a paradise where cold, suffering, labor, injustice, evil, darkness, aging, sickness, and death were unknown (Lincoln). According to one Indian version found in the *Rgveda* (10.13.4)—the earliest and most authoritative Hindu scripture—Manu sacrificed King Yama, who showed the path to where the forebears of old had gone: The *Rgveda* considered this place either the southern world or the highest region—a paradise with light, beauty, and joy. (In later texts, Yama was demoted to preside over a hell; the fetters that once bound him as the sacrificial victim for creation were now used by him to fetter sinners.) In another early Indian version, the Puruṣasūkta (*Ṛgveda,* 10.90), Man, the sacrificial victim, was bound, killed, and dismembered. His mind became the moon; his eye, the sun; his mouth, the fire; his breath, the wind; his feet, the earth. Henceforth, each sacrifice repeated the cosmogonic one, with animals representing the human victims of earlier Indo-European myths or rituals, to ensure the continued existence of the cosmos. A symbolic reenactment of the cosmogonic sacrifice occurred in the funeral ritual; according to *Ṛgveda* 10.16, different parts of a dead person went to various parts of the universe.

The Vedas prescribed a life of one hundred years, indicating a desire for longevity and natural death. For those who died a natural death, the funeral ritual (*śrāddha*) would be performed; this would provide them the status of ancestor, ensuring rebirth as a human or existence as a god (hence creating a double buffer against death as annihilation).

Drawing on their pastoral practice of seasonal migration, the Indo-Europeans referred to the dead as traveling along a pathway. In India, the Vedas also referred to the paths of the dead. The straight and easy one ascended to a luminous paradise where the gods lived; the tortuous and difficult one descended to a dark netherworld. By performing sacrifices and funerals, people gained access to the former (*Ṛgveda,* 10.2.3). The most common Indo-European image of the dead following a path involved crossing a river or ocean by means of a ferry guided by a ferryman, the personification of old age, to paradise (Lincoln). During their migrations into India, the Indo-Europeans conquered settlements at fords (*tīrtha*) to cross rivers. A popular Vedic myth alludes to this: The warrior god Indra killed the native serpent demon Vrtra, thus creating a passage from drought to water, barrenness to prosperity, death to survival, danger to security, darkness to light, and chaos to order (Young, 1980). Hence the Vedic notion of figuratively crossing over dangers to arrive happily on the other shore, to make a way through experience or suffering, and to penetrate the real or the true.

Some of these ideas prefigured a new worldview that led to a dramatic transformation of Vedic religion and the birth of two new religions (Jainism and Buddhism) around the sixth century B.C.E. This period witnessed a great increase in life expectancy. Seeing the miseries of frailty and old age, however, led many people to increasing anxiety over the end of life (Tilak). This gave rise to reflections on old age, the meaning and purpose of life, and ways to move beyond death. The path no longer led to another realm *within* the cosmos; it now crossed the cosmos (symbolized as the ocean of *saṁsāra,* characterized by the cycles of time, rebirth, finitude, suffering, and ignorance) to liberation.

One of the Vedic texts that elaborated on the ritual, the *Śatapatha Brāhmaṇa,* said the Vedic sacrifice was a boat; the priests, oars; and the patron, a passenger who would reach heaven if no error were made in performing the ritual (4.5.10). Sacrifice also became a way of overcoming death by moving beyond *saṁsāra,* the cycles of death and rebirth (2.3.3.7). A personification of death demanded what would happen to him. He was told by the other gods that he had dominion over the body but not over immortality, which would occur without him. In other words, the god of death controlled the process and time of dying, but he could not influence those who attained enlightenment because they were beyond the cycles of death and rebirth (10.4.3.1–9).

In the *Upaniṣads* (philosophical speculations said to reveal the supreme truth of the Vedas but, from a historical perspective, beginning the transformation of Vedic religion to Hinduism), this extracosmic liberation (*mokṣa*) was characterized by the realization of eternal consciousness, called Brahman. This could be achieved during life; at death the body would disappear forever. Or it could be achieved by a postmortem passage to a supreme heaven where there would be eternal life with a supreme God. Some Upaniṣadic texts spoke of sacrifice leading to the path of the forefathers (*pitṛyāna*) and thus to rebirth (indicating a demotion of the status of Vedic rituals), whereas others spoke of self-knowledge leading to the path of the gods (*devayāna*). Still others spoke of a passage to liberation made possible by religious discipline (*sādhana*) and the guidance of a teacher (guru) leading to supreme knowledge. This notion was expressed as a boat guided by a pilot, ferrying the individual across to the other shore. In *Kauśītaki Upanisad* 1.4, for example, the deceased proceeded to the river Vijará (literally, “apart from old age”, shaking off their good and bad deeds. Their good deeds were transferred to relatives for a better rebirth; their bad ones, to other people. Beyond deeds and dualities, the deceased approached the god Brahmá. Although the human body represented bondage, it also provided the only opportunity for liberation (an argument that was probably necessary to inspire humans to pursue a path to liberation in this life, because they might be reborn as plants or animals).

Closely associated with this development was the law of karma, according to which actions (karma) determined destiny. People were reborn higher or lower in the scale of beings (from high-caste people down to plants), depending on the quantity of good (*puṇya*) or bad (*pāpa*) karma they had accumulated. With an excess of good karma, they had a temporary vacation in a paradise; with an excess of bad karma, they descended to a hellish realm. But with an extraordinary religious effort (based on knowledge or devotion), they could negate the law of karma by removing the bondage of action and the perpetual cycles of rebirth. Despite the highly individualistic nature of this karma doctrine (people reap what they sow), some versions allowed the transfer of merit from an extraordinary person, or divine grace from a deity, in order to redirect destiny and ultimately achieve liberation.

After the sixth century B.C.E., the idea of crossing over, signified in the term *tīrtha,* became associated with various bodies of water; these were sacred places where people could cross over to a better rebirth, a vacation in a cosmic paradise (*svarga*), or liberation beyond the cosmos (*mokṣa*). To facilitate crossing over, they followed a religious path characterized by action (*karmayoga*), knowledge (*jñānayoga*), and devotion (*bhaktiyoga*); different schools order the three in different ways.

Even today, most Hindus want to die on the banks of the Ganges—believed to be the river of heaven, the nectar of immortality, a goddess, a mother, or even a physician, since this allows them to cross over to liberation. From all parts of India, the dying come to Banaras to live on its banks. They spend their final days in a hospice where spiritual help but no medicine is provided. Hearing the names of the gods chanted continually, they eat sacred *tulsī* leaves and drink Ganges water, focusing their thoughts exclusively on God. Śiva, Lord of Death, whispers the ferryboat mantra into their ears. After they die, their corpses are taken to the cremation ground, given a final bath in the Ganges, decked with garlands of flowers, and honored as a guest or deity. Then the last sacrifice (*antyeṣṭi*) is performed. The eldest son circumambulates the corpse counterclockwise (reversal symbolizing death) and lights the pyre. Relatives are silent, for wailing is inauspicious or even painful for the dead. Finally, the eldest son turns his back to the pyre, throws water over his shoulders to douse the embers, and leaves the pyre without looking back. For the next eleven days, during the performance of the *śrāddha* rituals, ideally at Banaras or another holy place, rice balls are offered to the dead; on the twelfth day, the departed soul reaches its destination (Eck). It is said that when people die in Banaras, their souls attain liberation—though the idea that transitional souls (*preta*) are transformed into ancestors (*pitr*) is also maintained, as are a host of other ideas about destiny.

If dying by the Ganges is impossible, dying at some other *tīrtha* in India may be a substitute, for the Ganges is said to be there, too, just as all rivers are said to be in the Ganges. And if even that is impossible, simply thinking about the Ganges at the moment of death may influence destiny. Casting the bones that remain after cremation into a *tīrtha* is also effective. Ascetics are buried, however, because they have given up their ś¿rauta fires (the locus of the Vedic rituals) and their sacrificial implements (Kane). Hindus perform the annual sraddha ceremonies for the dead (offering rice balls to three generations of male ancestors, pitṛs) at the Ganges or any other *tīrtha,* since this will either sustain the ancestors until rebirth as humans or allow them a long vacation as gods (*viśvadeva*) in heaven. In short, the Hindu tradition offers a number of safeguards against annihilation at death: rebirth, a visit to another realm, liberation. Individuals can influence destiny or others can help them by the transfer of merit. Gods, through their grace, also may influence an individual's destiny. There is always hope. The sting is taken out of death, for it is said that even mosquitoes are liberated in Banaras (Eck).

THE CONCEPT OF SELF-WILLED DEATH IN HINDUISM. According to the traditional law books, funeral rituals were not to be performed for those who died in unnatural ways. This may have been used as a deterrent against suicide; the Hindu tradition disapproved of suicide, which was defined as killing oneself because of depression, passion, or uncontrollable circumstance. But unnatural death was not always viewed negatively; death by violence (war, murder, or accident) was viewed as powerful, leading to heaven or deification. The type of unnatural death that has relevance for bioethics is the self-willed death, which is given religious sanction. During the late classical and medieval periods, Hinduism came to accept a rational decision either (1) to kill oneself as a way to destroy bad karma, create good karma, and thus attain heaven or liberation; or (2) if liberated in life, to remove the body. Such self-willed death (*iṣṭamṛtyu*), took many forms. People could walk without food or drink until they dropped dead (*mahāprasthāna*); bury themselves alive and meditate (*samādhimāraṇa*); abstain from food and wait in a seated posture for the approach of death (*prāyopaveśaṇa*); or jump into fire, over a cliff, into sacred water, or under the wheels of a temple cart. The terminally ill and the extremely old who were no longer able to perform their religious duties and rituals sometimes killed themselves by one of these methods. Such self-willed death was religiously permitted. *Sati* (a woman's self-immolation on the funeral pyre of her husband) was a variant of self-willed death that produced a surplus of merit that ensured heaven for both spouses. Despite efforts to prevent abuse, it appears that there was some, for by the tenth century, with the Kalivarjya Prohibitions, all forms of killing oneself—*except sati*—were prohibited (in theory though not in practice).

Some families continued to endorse *sati* because the alternative was lifelong support for widows or, as in Bengal, a share in the inheritance. After additional criticism by both Muslims and Christians in the following centuries, this practice virtually ended. The Indian Penal Code in 1860 made suicide and abetting suicide crimes; judges interpreted suicide as any form of self-willed death and used that interpretation to stop *sati* as well as other practices of self-willed death (Young, 1989). There have been isolated incidents since then, including the widely publicized case of Roop Kanwar in 1987. Almost 160 years after *sati* was declared culpable homicide, Roop Kanwar, an eighteen-year-old Rajasthani woman, performed *sati.* The government alleged that she was forced onto the pyre and pinned down with heavy firewood. This caused the Indian parliament to pass another law in December 1987 to check the practice. According to the new law, the death penalty is imposed for those who help carry out the ritual of *sati*; the woman who tries to perform *sati* may be sentenced to six months in jail; those who glorify *sati* may be given prison sentences up to seven years; and the government is empowered to dismantle memorials and temples related to *sati.* Accordingly, her brother-in-law, who lit the pyre, was charged with murder and twenty-two others received lesser charges.

IMPLICATIONS OF HINDU VIEWS OF DEATH FOR BIOETHICS. According to the *Caraka Saṁhitā* (a classical text on medicine with religious legitimation written about the first century B.C.E.), physicians were not to treat incurable diseases (a policy to establish the benefits of the fledgling science of medicine and to protect the physician's reputation as a healer). This refusal could provide traditional religious legitimation for modern withdrawal of treatment by physicians in cases of terminal disease.

Physicians also were not to reveal the possibility of impending death, unless there was a specific request, so that negative thoughts would not be imposed on the patient that might create bad karma and hasten death. Rather, the process of death should be peaceful and auspicious, because it was the prelude to rebirth or final liberation. The implication of this view for modern medicine is that pain relief provided by a physician might make the dying process peaceful and therefore auspicious in Hindu terms; however, the refusal to inform the patient about terminal illness unless directly asked would be against the modern concept of mandatory truth-telling by the physician and the patient's right to know the prognosis. But another view also existed in traditional Indian religions: a person's last thought influences destiny. In this case, the individual should know of impending death and should not allow anything to cloud the mind. The implication of this view for modern medicine is that pain relief should be given only to the extent that the person remains alert.

Finally, the long tradition of self-willed death, especially fasting to death, in cases of terminal illness or debilitating old age, can be used to give religious legitimation for refusal or withdrawal of treatment in modern India, for it accords with the voluntary and public nature of living wills requesting refusal or withdrawal of treatment and nutrition. Whether it will be used to invoke precedent for active euthanasia depends on the assessment of assistance and whether there had been a slippery slope in the practice of self-willed death. As for the first issue, the Hindu tradition was quite careful to insist on the voluntary nature of self-willed death, though once there was a public declaration and the person could not be discouraged from his or her decision, assistance was allowed, at least in the case of *sati.* For instance, priests were allowed to hold a woman down during her self-immolation if they had been convinced that the decision for *sati* had been her own. As for the second issue, the types of self-willed death and possibly their numbers increased over the centuries; since there was criticism of the practice internal to the religion by the tenth century, there was probably the perception of a slippery slope.

Jainism

THE CONCEPT OF NATURAL DEATH. Jainism is an Indian religion that developed about the sixth century B.C.E. The Jains speak of the twenty-four *tīrthaṅkaras,* such as their founder Mahāvīra, who are the makers of the path or causeway to liberation, enabling people to cross over *saṁsāra.* The Jain view of death is related to its view of liberation: Because karmas (actions) cause bondage in the cycles of existence (reincarnation), they should be eliminated by fasting and meditation leading to the realization of liberation, the radical autonomy of pure consciousness (*kaivalya*).

THE JAIN CONCEPT OF SELF-WILLED DEATH. According to tradition, Mahāvīra fasted to death. Henceforth, the ideal form of death for Jain monastics was a "final fast" to death known by different names—*bhaktapratyākhyāna, inginī, prāyopagamana, samādhi, pañcapada, sallekhanā, ārādhanā*—depending on variants in the practice such as whether there is the assistance of others, whether one dies meditating or chanting, whether the body is to be eliminated by emasculation after initiation, or whether death occurs after the attainment of wisdom (Settar, 1990). Jainism was the first Indian religion to legitimate self-willed death. Initially, the fast to death was to be done only by monastics late in life but before debilitating old age or terminal illness, so that they would be in full control of the meditative and fasting process. Some centuries later, however, the practice was extended to the Jain laity as a legitimate form of death in times of public crisis (natural calamities and military defeat) or personal crisis (debilitating old age and terminal illness).

IMPLICATIONS OF JAIN VIEWS OF DEATH FOR BIOETHICS. Although self-willed death is illegal in India, Jains are arguing for the decriminalization of suicide so that they can restore the traditional practice of fasting to death. They argue that this practice legitimates refusal or withdrawal of nutrition and life-support systems in modern medical contexts for the terminally ill. They also argue that prolongation of the dying process is immoral, because it increases suffering or depletes the resources of the family or community; thus the fast to death is a way to "permit oneself the honour of dying without undue prolongation of the process" (Bilimoria). But since the fast to death was also practiced traditionally in nonmedical contexts, it was not always a way to avoid the prolongation of dying; on the contrary, it was a way of hastening death by the cultural act of fasting when the body was not about to die of natural causes. Although the fast to death was generally understood to be voluntary and planned (and in a category distinct from both homicide and suicide), there were several exceptions. According to some, severely handicapped newborns were allowed to die (*bālamarana*) when permission was given by parents or a preceptor. In the *Bhāva Pāhuḍa Ṭīku, bālamarana* is classified as: "The death of the ignoramus, or a foolish process of meeting death … *Bāla* means childish, undeveloped, or yet-to-be-developed, premature and silly" (Settar, 1990, p. 15). It includes the death of infants and those who have an infantile knowledge—who are ignorant, who do not understand the moral codes, or who have a wrong notion of the faith and kill themselves by fire, smoke, poison, water, rope, suffocation, or jumping. While the original classification indicated simply a subdivision of natural death that would lead to rebirth, it seems that at some point in the tradition or perhaps in the modern period, the classification *bāla-marana* has been reinterpreted. Accordingly, Bilimoria (reporting on statements made by Jain informants) observes that

> in principle there appeared to be no reason why a child afflicted with or suffering from the kinds of conditions described earlier should not be given the terminal fast (*sallekhanā*). Parental permission would be required where there is contact, failing which a preceptor (for instance in an ashram) may be in a position to make a pronouncement. Consent of the recipient is not necessary (hence, a case of *nonvoluntary* terminal fast). One who has fallen in a state of unconsciousness, again, can be given the fast … even if the person had made no requests while she was conscious, though parents or kin would be consulted. It seemed evident that 'consent,' either of the individual or a proxy, or of the parent, does not seem to be a necessary condition for commending [a] final fast. This would seem to constitute a case of *involuntary sallekhanā*.… When … asked whether it would be acceptable to inject lethal poison to bring on the impending death, the response was that under extreme conditions where the pain and suffering is unendurable and not abating.… (p. 347)

It is argued by Jains that the history of fasting to death demonstrates that self-willed death need not lead to other forms of self-willed or other-willed death. While it is true that in the past there were a number of safeguards (permission of the head of the monastery, a formal public vow, established ascetic discipline, evidence of courage and will rather than cowardice) and the history of fasting to death was without any extreme abuse in India, there was still a change in the number of groups involved (from monastics to lay people) indicating extension or popularization of the practice. Moreover, the fact that Jainism was the first Indian religion to legitimate a form of self-willed death means that it set an example, which may have inspired legitimation of self-willed death without such careful safeguards by other Indian religions (Young, 1989). In other words, its indirect contribution to a slippery slope in Indian religions cannot be ruled out despite Jain disclaimers. When the Indian penal code made suicide illegal, fasting to death was included. Despite the fact that any form of self-willed death is still illegal in India, there are between six and ten reported Jain fasts to death annually (Bilimoria).

Buddhism

THE CONCEPT OF NATURAL DEATH. The imagery of crossing the ocean or river of *saṁsāra* to the other shore of enlightenment is used by Buddhists as well as Hindus. Theravāda (one of the main branches of Buddhism, which purportedly continues the early tradition and is still found in Sri Lanka, Burma, Thailand, Cambodia, and Vietnam) metaphorically considers the Buddha's teaching (*dhamma*) a boat and the individual its pilot. For instance, in Burma, a coin called "ferry fare" is placed in the mouth of a dead person (Spiro).

The Buddha thought often about the nature of death. According to Aśvaghosa's version of his life, the *Buddhacarita,* the future Buddha was surrounded by royal luxury as a youth, sealed off from the real world in a palace. When he finally ventured into the world, he was overwhelmed by his first sight of a sick person, an old person, and a dead person. These shocking revelations about dimensions of human existence beyond anything he had known so troubled him that he left his life of ease to become an ascetic and search for meaning. Later, on the verge of enlightenment, he recalled his own previous lives, meditated on the cycles of rebirth common to all creatures, and came to understand that all beings are propelled into repeated lives by ignorance and desire. The Buddha spent his life teaching others how to blow out (*nibbāna*) the flame of ignorance and desire by realizing that all beings are composite and impermanent (subject to suffering, decay, and death). In the final analysis, there was no "person" who died; there was only the process of dying. As narrated in the *Mahāparinibbāna Sutta,* written down about the first century B.C.E., the Buddha attained final release from his body (*parinibbāna*) at the age of eighty. After falling ill, he chose the time and place of his departure: Telling those present that all composite things must pass away and advising them to strive diligently for liberation, he meditated with complete equanimity and took his last breath.

Despite the Buddha's emphasis on liberation, subsequent generations of monks and nuns took precautions in case they were to be reborn. The *Mulāsarvāstivāda-vinaya* (a text composed at the end of the seventh century) describes the monastic funeral: A gong was sounded; the body was taken to the cremation ground and honored; verses on impermanence were recited; merit from this act was transferred to the deceased, suggesting extra insurance in case the monastic was to be reborn; ownership of property was transferred; and cremation was performed. Finally, Buddhist sacred monuments (*stūpa* or *caitya*) were worshipped by the living, who then took a sacred bath (Schopen). Laypeople tried to attain a better rebirth by practicing morality, accumulating merit, reflecting on the nature of suffering, and disengaging from activities during old age. They were helped by merit transferred to them through the religious activities of families and friends, especially during the dying process, the funeral, and subsequent ancestral rituals.

As in Hinduism, the moment of death was important, because the final thought influenced rebirth. Even today, according to the popular religion of Burma, relatives chant Buddhist texts or have monks chant the *paritta,* canonical verses for protection against danger, to calm those who are dying; good thoughts thus arise and lead them either to a better rebirth or to a heavenly reward (Spiro). In popular forms of Theravāda Buddhism, ideas of the soul often replace the doctrine of no soul (*anatta*). The soul, or ghost, lurks around the house for some days after death and must be ritually fed, placated, and induced to leave the world of the living. Death rituals, ideally involving food and gifts for the monks, not only eliminate the danger posed by a ghost but also allow for the transfer of merit to the dead person, as do rituals performed by relatives on the anniversaries of the death.

Mahāyāna (the other main branch of Buddhism, which originated in India but eventually became popular in Tibet, China, Korea, and Japan) also conceives of the teaching as a boat, but views the pilot as a *bodhisattva,* a salvific figure who refuses enlightenment until all sentient creatures are saved, graciously steering the boat across to the other shore. Nevertheless, Mahayana maintains that ultimately there is no boat, no pilot, and no shore, since all is nothingness (*śunyatā*).

In Tibet, monastics meditated on death and simulated the process of dying to attain enlightenment; they also protected themselves against a bad rebirth by certain funerary rituals. Laypeople focused mainly on rebirth and sought help to ensure a good destiny. A spiritual teacher performed the ritual *gzhan po wa,* by which a disciple went to a paradise. Or the *Tibetan Book of the Dead,* which describes the journey from the moment of death through an intermediate state to rebirth, was read to the deceased over a number of days. Each of the three stages, or *bardos,* offered an experience of past karma along with a vision of both peaceful and wrathful divine figures. These provided more opportunities to attain enlightenment (Buddhahood) or a better rebirth, even though each succeeding one was more difficult than the last. Only by recognizing that the deities were ultimately illusory, for all was emptiness (*śunyatā*), would one attain liberation. These beliefs and practices are still found in Tibetan communities.

In China, Mahayana views of death were reinterpreted in several ways: (1) The notion of heaven was modeled on both Daoist ideas of paradise and its images of Confucian kingdoms complete with palaces, courts, and bureaucracy; the notion of hell was based on Daoist hells and Confucian prisons. (2) Some Chinese argued that the existence of a soul was implied in the theory of reincarnation, in the storehouse of consciousness, or in the Buddhahood of all living creatures. (3) Transferring merit from monastics or relatives became extremely popular. Buddhist monks instituted the annual All Souls festival based on the story of Maudgalyāyana (Mu-lien), who rescued his mother from the lowest hell, as told in the *Ullambana Sūtra* of Central Asian origin (Smith). Food, clothing, and other gifts were offered to rescue seven generations of ancestors from their sufferings in various hells, and the story was reenacted at Chinese funerals (Berling). (4) Pure Land Buddhism, which became particularly popular in China, promoted, in some versions, an otherworldly paradise attained through faith in Amida (a savior whose grace allows people to be reborn in a paradise called the Land of Bliss until they reach *nirvāṇa*) and calling out his name at the moment of death. According to Pure Land philosophers, this paradise was not real, however, but a product of the mind. (5) Ch'an claimed that the Buddha nature was in all sentient beings, truth was near at hand, and Earth was the Lotus Land; enlightenment was the realization that nothing existed beyond the realm of *saṁsāra.* Consequently, death meant reabsorption into nature.

Just as Chinese Buddhism had absorbed Daoist ideas of death and native Confucian ancestor worship, so Japanese Buddhism assimilated, in turn, native Shintō views of death and ancestor worship. According to ancient Shintō, death was a curse; the corpse, polluting; and the spirit of the deceased, frightening. Buddhism contributed rituals to purify the spirits of the dead and transform them into gods: Spirits were deified thirty-three years after death and henceforth worshipped with the Shintō *kami* (entities with a spiritual function that inspire awe). In the seventh century, Empress Saimei ordered that the *Ullambana Sūtra* be taught in all the temples of the capital and that offerings be made on behalf of the spirits of the dead. The Japanese version of the All Souls festival, called Bon, dates from this time. The association of Buddhism with ancestor worship was reinforced in the anti-Christian edicts of the seventeenth century, which insisted on the formal affiliation of every Japanese household with a Buddhist temple and its death rituals (Smith).

Modern Japanese Buddhism has been primarily associated with death: In addition to funerals, there are seventh-day, monthly, hundredth-day, seventh-month, and annual rituals (Smith). Besides these, the collectivity of the spirits of the household dead is given daily offerings and honored at festival times. The Japanese hold conflicting opinions about where the spirits live: (1) Spirits may live peacefully in ancestor tablets on the altar in the home. (2) As depicted in Nō plays, those who suffered tragedy during life or died violently haunt their graves or former homes. (3) Spirits may have a continued existence as buddhas. Curiously, the dead are referred to as buddhas (*hotoke*). The Japanese misunderstood the term *nibbāna,* "to blow out" (in Japanese, *nehan*). Whereas in Indian Buddhism it expressed the metaphorical idea of blowing out the flames of desire in life and thereby achieving enlightenment, in Japanese Buddhism it was understood literally: People attained continued existence as buddhas when life was "blown out," a euphemism for death (Smith); this may have inspired self-willed death. (4) By chanting Amida's mantra (according to Hōnen) or having faith in him (according to Shinran), spirits enter paradise. (5) Spirits go to mountains such as Osore or Morinoyama with its Sōtō Zen and Jōdo-shin shrines. Many of these beliefs and rituals are dying out. The breakdown of the extended family due to mobility and urbanization has contributed to the lessening of interest in ancestor worship. Now, memory and prayers are for the immediate ancestors; tablets and altars, therefore, are becoming smaller (Smith).

BUDDHIST VIEWS OF SELF-WILLED DEATH. Despite his discussion of the body as the locus of suffering, the Buddha did not endorse self-willed death for everyone. He himself lived out his natural life span. An incident is recorded in the *Pārājika* (a text of the Pāli Canon, the scripture of Theravāda Buddhism) about how, when some monks became depressed in their meditation on the impurity of their bodies, a sham monk encouraged them—up to sixty in one day—to take their lives or be killed by him so that they could cross *samsāra* immediately. When he heard about this, the Buddha changed the form of meditation to a breathing exercise and declared that intentionally encouraging or assisting another person to die would lead to expulsion from the monastery. The Buddha also condemned, on the basis of nonviolence (*ahimsā*), any monk who told people to do away with their wretched lives. It is possible that the Buddha, known as the "good physician," allowed one exception to this general principle: From the accounts of the cases of Vakkali, Godhika, Channa, Assaji, Anāthapiṇḍika, and Dīghāvu, it seems that if people were experiencing unbearable pain in dying, they could kill themselves. There is some controversy over such an interpretation, however, for good palliative care had been offered and there were serious attempts to dissuade people from taking their lives. Moreover, neither the Buddha nor the monks gave explicit permission for these monastics and laypeople to take their lives, although the account implies that the act was condoned, perhaps because there were no options aside from physical force to restrain them.

According to an observation of I-Ching, a Chinese pilgrim who traveled to India (671–695), the practice of self-willed death was not popular among the Buddhists in India. Several centuries later, however, its popularity may have grown. In China, some Buddhist monks chose the time, place, and manner of death to bring its uncertainty under their control. It is possible that a story in the *Saddharmapuṇḍarīka* about how the *bodhisattva* Bhaisajyarāja, who was so dissatisfied with his worship that he set himself on fire, may have inspired the Chinese practice. But the fact that Chinese monks fasted to death in a yogic posture in underground pits (as in the Indian *samādhimāraṇa*), and after death their bodies were smoked, wrapped, lacquered, and installed in temples as objects of great veneration (Welch), suggests a different Indian Buddhist influence. This may have been combined with Daoist techniques to achieve immortality. Finally, it has been argued that self-willed death was popularized in China by a misunderstanding of Pure Land Buddhism, which suggested that people should kill themselves to reach the Pure Land more quickly. Shan-Tao's disciple, for example, jumped out of a tree to reach the Pure Land (Kato).

Some sects of Japanese Pure Land continued this idea. Kūya (903–972) and Ippen (1239–1289), both charismatic leaders among the masses, killed themselves by drowning in order to reach the Pure Land. Before his death Ippen instigated Nyudo to drown while meditating on Amida (a story illustrated on many scrolls). Ippen's death prompted six disciples to drown in sympathy. These examples were further popularized by a tradition of drowning to reach the Pure Land; ordinary people who lost their nerve would be hauled ashore by a rope attached around their waist (Becker). Devotees were told to "Delight in dying" and "Hasten your death" (Kato).

These Pure Land practices inspired more secular forms of self-willed death. There are over forty-five terms in Japanese to describe the various forms of self-willed death; for example, the tradition of parents killing first their children and then themselves to avoid further suffering; the tradition of abandoning old women in distant mountains; and the tradition of *joshi* or love-killing, also known as *oshinjuo* or *aitai-shi* (a death pact between two people, such as lovers who want to attain a happier realm) (Kato). Such practices (which also included death by fasting or fire), collectively called *shashinojo,* came under scrutiny by subsequent Pure Land leaders who argued that such acts of self-willed death were a denial of Amida's grace.

Some views held by Zen leaders may have been misinterpreted, inspiring self-willed death; Dogen, for example, says to throw away your "body-mind." Zen inspired the samurai warriors and helped them cultivate a stoicism to face death. In medieval Japan, *harakiri* or *seppuku* was practiced by warriors to expiate crimes, apologize for errors, escape disgrace, redeem friends, or express devotion to their master by following him in death. These forms of warrior self-willed death are similar to the forms of heroic death by warriors in India. Sometimes *seppuku* was assisted by a relative or friend. By the Tokugawa period (1603–1867), it involved an elaborate ceremony and, for the famous, burial in a Buddhist tomb.

The popularity of self-willed death in Japan may have been derived in part from ancient Shintō views of death. The lack of a definitive boundary between life and death led to a feeling of intimacy with death and a desire to take refuge in holistic being, understood as *kami* (nature). This Shintō idea was combined with the concept of the Dao (the transcendent and immanent reality of the universe, represented by vacuity or emptiness because of its being formless and imperceptible) or the concept of the Buddha as nothingness (*śunyatā*), pure consciousness, or nature. It was also combined with the Buddhist idea of life as suffering and transience, which could be escaped by attaining the Pure Land (Kato).

The Buddhist practice of self-willed death has acquired political significance in the modern period. Known as "falling down like cherry blossoms" or "dying with a smile" (Kato), this way of dying belonging to *bushido,* the way of the warriors, contributed to the psychology of the Japanese kamikaze pilots of World War II. In Vietnam, the monk Thich Quang Duc's selfimmolation in Saigon (1963) focused world attention on the plight of the Vietnamese under Ngo Dinh Diem's oppressive regime.

IMPLICATIONS OF BUDDHIST VIEWS OF DEATH FOR BIOETHICS. Assessments of the importance of Buddhist views of death for bioethics vary considerably, depending on whether Theravāda or Mahāyāna is the focus and what the commentator thinks about issues such as withdrawal of treatment and euthanasia. Pinit Ratanakul (1988) observes, for instance, that in Thailand the Buddhist principle of the sanctity of life is maintained and self-willed death is not condoned as a rule, even in cases of pain and suffering. Two reasons are given: (1) suffering is a way for bad karma to come to fruition rather than be transferred to the next life; and (2) a person who assists suicide or performs euthanasia will be affected by such an act, since it involves repugnance toward suffering and his or her own desire to eliminate that which arouses a disagreeable sensation. But one exception is allowed: self-willed death when incurably ill, in order to attain enlightenment. These comments suggest that Thailand has maintained a reluctance to endorse self-willed death, in line with its Theravāda tradition, but continues to acknowledge the precedent established by the cases of the terminally ill Vakkali, Godhika, Channa, and others reported in the Palī Canon.

Current Japanese views show a greater acceptance of euthanasia, which is to be predicted, given the history of self-willed death in Japanese Buddhism. It is striking that the modern word for euthanasia is *anraku-shi* (literally, "ease—pleasure—death"), also a name for the Pure Land, though now some Japanese prefer the term *songen-shi* (death with dignity). Carl B. Becker, a Western scholar who has discussed this topic with Japanese people, argues that the Buddha accepted or condoned "many" cases of suicide but gives only three examples. He also argues that Buddhists view death as a transition, not an end; therefore, it is the state of mind at the moment of death that is important, not whether the body lives or dies. Those who are not fruitful members of society should be able to die, according to his assessment of Japanese views. Once consciousness (which he takes as brain activity) has permanently dissociated itself from the body, there is no reason to maintain the body, "for the body deprived of its *skandhas* [the constituents of human existence] is not a person" (Becker, p. 554). In short, all that matters is clarity of mind at the moment of death. We must be careful in using Becker's analysis of the data. In point of fact, the Buddha was very reluctant to condone self-willed death if indeed he did so; it was only a few people who possibly killed themselves with the Buddha's blessing, because they were suffering from terminal illness and because they desired enlightenment. The other examples were simply threats. Becker also ignores the fact that the Buddha called the mere encouragement for others to perform self-willed death—or to provide the means—a deplorable act that would lead to expulsion from the monastery. One traditional commentator on the Parajita includes poison in the list of means. Because Buddhist monks were often physicians in ancient India, it is noteworthy that they were told not to perform abortions nor provide the means or even information to facilitate it; moreover, they must not help a family to kill a physically dependent member. This amounts to a strong position against physician-assisted suicide.

Shigeru Kato is much more cautious in his assessment of the Japanese practice of self-willed death and current Japanese interest in self-willed death, but for different reasons. After noting that some prominent Japanese jurists are advocating the legalization of euthanasia, he reflects on Japan's reputation of being "a kingdom of suicides" and relates the fact that it has the largest number of suicides among all Buddhist countries to its tendency to beautify suicide or absolve it of a sense of wrong. Kato argues that "Human beings have no right to manipulate arbitrarily and selfishly their 'own' lives, which are transiently borrowed and must be returned soon to the holistic Being" (p. 71). He opines that "We can never dismiss this religious holism as an outdated superstition; we must keep it as a brake against the drive toward euthanasia" (pp. 78–79). He also looks to the formation of a better hospice organization in Japan in the 1980s as a way of resolving the "euthanasia problem" through the practice of withdrawal of treatment combined with dialogue and religious and aesthetic care. In the final analysis, however, he is willing to entertain active euthanasia as the right to die "with dignity" and to consider the merits of each case.

Confucianism and Daoism

CONCEPTS OF NATURAL DEATH. Confucian concepts of death are closely associated with ancestor worship, which was practiced as early as the first historical dynasty, the Shang (ca. 1500–1045/1046 B.C.E.). Judging from the written record provided by inscriptions of oracles written on bones, the dead were consulted by means of divination, as if they were living. Everything needed for the next life was put in the tombs of the kings and nobles. Originally servants, entertainers, and others were buried with them. Later, pottery figures were substituted. (In modern times, paper effigies of servants are used.) The cult of the ancestors must also have been practiced by commoners, because it was considered an ancient and widespread practice by Confucius in the sixth century B.C.E.

The ancestor cult was based on rituals, or *li.* It assumed the continuity of life after death, communication between the living and the dead, the legitimacy of a social hierarchy, and a virtual deification of the ancestors. In his *Analects,* Confucius upheld the ancient practices, refusing to shorten the period of mourning (XVII.21). Nevertheless, he taught that the spirits should be kept at a distance, so as not to preoccupy the living (VII.20; XI.11). He also thought that mourning rituals should be moderate; they should express grief rather than fear (III.3). Four centuries later, details of the mourning rituals were described in the ritual text *Yi Li.* Now elaborate, they were to last for three years. During the first year, the eldest son (as chief mourner) had to wear sackcloth, live in a hut outside the home, wail periodically, and eat very little food. Over the next two years, the restrictions were gradually lifted. Even after life returned to normal, though, he reported family business to the ancestors. In Confucianism, as in other patrilineal traditions, the performance of funerary and ancestral rites by the eldest son has contributed to a preference for sons. As a result, female infanticide has sometimes been practiced unofficially.

The Chinese developed two other perspectives on death: a return to nature and physical immortality. The Daoist philosopher Chuang Tzu (365–290 B.C.E.) wrote that life and death were two aspects of the same reality, mere differences of form. Death was a natural and welcomed release from life, and was to be neither feared nor desired. Because individuals were reabsorbed into nature, both birth and death were as natural as the progression of the four seasons. Other Daoists were interested in alchemy, macrobiotic diets, exercises, fasting, and meditation. Besides desiring health, youth, and longevity, they wanted immortality. They had several views of the latter: the physical body would rise to heaven; the "real body," not the physical one in the tomb, would rise; the physical body would go to the Isles of the Blessed, said to be off the northeast coast of China; or the self would emerge from the body at death, like the butterfly from its cocoon, to wander freely about the universe or go to the realm of the immortals.

In Taiwan, the Chinese still practice ancestor worship. They believe that people are related to common ancestors and to each other by an elaborate kinship system in which status is symbolized by the length of time spent mourning and authority is passed through the eldest son. They also believe in two souls: the *hun,* living in a tablet at the shrine, and the *p'o,* living in the grave. Both souls may influence the living. Kin meet periodically in the ancestral temple for sacrifices to the *hun*; the latter are offered wine, food, rice, and first fruits in exchange for health, longevity, prosperity, offspring, virtue, and a peaceful death. They are also remembered by preserving extensive genealogical records and documents written by the deceased. Families visit graves to communicate with or pay respect to the *p'o* and thus ensure the *p'o*'s goodwill toward the living.

The Taiwanese euphemistically call death "longevity"; after fifty, a person begins to prepare for death by making "longevity clothes" in the Han style of the second century B.C.E., a coffin, and if possible, a tomb. At the time of death, the eldest son of the deceased person eats "longevity noodles" and puts on the "longevity clothes" inside out. Then he puts these garments on the corpse, whose personal name henceforth may not be spoken. Other family members don sackcloth, leave their hair uncombed, and wail periodically (Thompson). The *hun* is first given a temporary resting place in a paper sword, placed in front of the corpse to receive prayers. After processions to and from the grave, this sword is transferred to a home shrine where the son and relatives offer it food. Finally it is burned, and the spirit is thus transferred to a permanent tablet in the shrine. To keep the *p'o,* the body's orifices are plugged. The body is then rubbed with an elixir, placed in a coffin, and buried. Sometimes it is placed in a strong, watertight tomb to prevent decay. Coffins and graves are positioned according to exact rules for magical protection. If mistreated, the *p'o* causes trouble and threatens to become a ghost (*kuei*). Ritual specialists are then asked to inspect the grave, coffin, or bones to see why the p'o is unhappy (Berling). Daoist and Buddhist priests participate in the rituals of families who can afford them. For instance, priests hold services for seven weeks, during which they chant and pray for the soul to pass quickly through purgatory. Clearly, the Taiwanese try to ensure every advantage for the soul by incorporating practices from many religions.

In Taiwan, death remains associated with the ancestor cult. In the People's Republic of China, by contrast, there have been attempts to reform and even destroy ancestor worship. Communists have argued that traditional funeral rites and customs are remnants of the feudal economy and social structure; those lower in the clan hierarchy are exploited, and women, who cannot attend banquets in the ancestral temple, are excluded. Mourning clothes, moreover, waste cotton; wooden coffins waste timber; graves and tombs waste land; lavish funerals put families into debt; and beliefs in the afterlife instill superstition. Consequently, Communists have recommended the following: simple memorial services for the cadre, factory, village, or cooperative; the replacement of mourning clothes by arm bands; and the introduction of cremation (MacInnis).

CHINESE CONCEPTS OF SELF-WILLED DEATH. Some of these concepts have already been discussed in the section on Buddhism. But it is important to point out that there were practices of self-willed death in the warrior circles of China as well. In fact, it was the obligation, not only the privilege of warriors to practice self-willed death under certain circumstances. This tradition, which had once been found among the elite, became common among the lower classes when warriors began to be recruited from them in the late Chou Dynasty. Later, members of the Mohist school of philosophy, which had links with the lower-class warriors, maintained a tradition of absolute loyalty to their leader. In one incident, eighty-three disciples followed their leader in death (Fung Yu-lan, p. 83).

IMPLICATIONS OF CHINESE VIEWS OF SELF-WILLED DEATH FOR BIOETHICS. According to a report by Shi Da Pu (1991), euthanasia in China, once a taboo topic, has been discussed since the 1980s in the magazine *Medicine and Philosophy.* After the controversial case of the active euthanasia of a patient named Xia in 1986, which led to a court case being filed by her two daughters against their brother, who had authorized it, the topic was hotly debated in the media. It was also debated by the Chinese Dialectical Institute and Beijing Medical Ethics Academy, which concluded that active euthanasia was permissible for patients with no hope of cure. When the widow of former premier Zhou En-lai wrote that euthanasia was a "proper point of dialectical materialism" in need of discussion, there followed even more public debate. Some argued that it represented the height of civilization because it was a pure act of freedom; others, that it was "the result of the infection in the area of medicine from sick Western customs and morality … sharply against our socialist ethical values" (Shi Da Pu, p. 133). In 1988, a survey of 400 people (health professionals and nonprofessionals) showed that 80 percent were in favor of euthanasia. Both withdrawal of treatment and active euthanasia are being quietly practiced; though they are illegal, no one has been charged. Shi Da Pu concludes that most experts in China think that euthanasia should be regarded as part of the agenda of modernization, that the country should develop appropriate legislation to legalize it, and that the press should be enlisted to spread the dialectical materialist teaching about it.

Conclusion

Four major views of natural death emerge when Asian religions are compared: (1) the cosmic, (2) the existential, (3) the familial, and (4) the natural. Hinduism has focused on the cosmic dimension of death, though it has also included the familial in connection with ancestor worship and the existential because of its long interaction with Buddhism. Buddhist views of death are existential in philosophical texts and some monastic circles; cosmic in the popular religion of both Theravāda and Mahāyāna countries; and familial (in countries with traditions of ancestor worship). Chinese religions emphasize the familial aspect of death, though cosmic dimensions are derived from Buddhism and popular Daoism, along with natural ones from philosophical Daoism.

Some of the Asian religions legitimated self-willed death (and sometimes assistance) in certain circumstances—such as a way to attain heaven or enlightenment, or a way to cope with a crisis such as terminal disease or extreme old age—as an exception to natural death. Although there were attempts to distinguish such self-willed death and assistance from suicide and homicide, respectively, some of the religions decided that the practice had created problems over time.

Each religion has a tendency to assimilate many, often contradictory, views, as if these provide extra antidotes against death. When views are too this-worldly—for example, the desire to eliminate suffering or mundane problems—or too otherworldly—for example, promises of easy heaven or liberation by self-willed death—premature death may occur. People, it seems, need to balance respect for the body and transcendence of it in order to live with health and purpose, thereby doing justice to their full humanity.

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SEE ALSO: *Anthropology and Bioethics; Autonomy; Body: Cultural and Religious Perspectives; Buddhism, Bioethics in; Care; Compassionate Love; Confucianism, Bioethics in; Daoism, Bioethics in; Grief and Bereavement; Harm; Hinduism, Bioethics in; Holocaust; Human Dignity; Infanticide; Jainism, Bioethics in; Life; Life, Quality of; Life Sustaining Treatment and Euthanasia; Literature and Healthcare; Narrative; Paliative Care and Hospice; Pediatrics, Intensive Care in; Right to Die, Policy and Law; Sikhism, Bioethics in; Suicide; Virtue and Character; Warfare;* and other *Death* subentries

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III. WESTERN PHILOSOPHICAL THOUGHT

For both humankind generally and each living person individually, the recognition of the universality and inevitability of death is but the beginning of the problem of death. Indeed, recognizing death as the individual and collective fate of human beings, and of all living creatures, creates the problem of death: Why does it happen? What does it mean? Is death final? Is death a good thing or a bad thing? At least as often these questions emerge for us in their mirror image, still provoked by death: What is the meaning of life, its purpose? Can life be meaningful if it ends in death? What purposes could outlast the inevitability of my death?

Philosophers have struggled with a human fear of death. Recognizing the inevitability of death is very different from supposing death is final. At a very general level, philosophical reflections on death divide those who deny the finality of death and suppose there is ongoing, usually individual, self-consciousness after death, and those who regard bodily death as final, as the destruction of consciousness, but who offer consolation meant to assuage fear of the inevitability of personal extinction. A very few philosophers have found death to be inevitable, final, and horrible. What binds all together in a recognizably *Western* tradition are the analytically and argumentatively philosophical approaches each group takes and the exclusively human-centered character of their views.

Probably the single most persistent theme in Western philosophical reflection on death is the view that death is not the annihilation of the self but its transformation into another form of existence. The conviction that individual human beings survive death, perhaps eternally, has been very differently grounded and elaborated in the history of philosophy, but in some form has persisted and frequently dominated through antiquity, the long era of Christian theologizing, modernity, and into contemporary *postmodern* thinking. Considerably less attended to is the attempt to reconcile human beings to death's finality, to death as the end of individual human experiencing beyond which there exists no consciousness.

The Pre-Socratic Philosophers

The tension in Western philosophy between regarding death as transformation and thinking of death as final appears at the very outset of what is conventionally regarded as the beginning of Western philosophy, in the fragmentary remains of writing that have survived from thinkers in the early Greek colonies of Asia Minor, especially the Ionians. Anaximander (ca. 610–547 B.C.E.) and Heraclitus (ca. 533–475 B.C.E.) in particular were singularly impressed with the transitoriness of all things, as captured in the best-known corruption of a Heraclitean fragment, "One cannot step into the same river twice" (Kirk and Raven, fr. 217). The attempt to reconcile opposites—such as life and death—and to perceive the underlying unity, even harmony, in all of reality was preeminent for the pre-Socratics.

The very earliest surviving pre-Socratic fragment, from a book attributed to Anaximander, contains a passage that allows one to see both of the subsequent views about death—death as final and death as transitory—that have dominated Western thinking:

> And the source of coming-to-be for existing things is that into which destruction, too, happens, "according to necessity; for they pay penalty and retribution to each other for their injustice according to the assessment of Time." (Kirk and Raven, fr.112)

Jacques Choron, to whom all subsequent accounts of death in Western philosophy are indebted, reads this passage as evidence of how impressed Anaximander was with the terrible fact that things perish, but also as expressing the hope "that somewhere and somehow death shall have no dominion" (p. 35). Further, there is the suggestion that despite appearances, death is not annihilation: In the everlasting boundlessness (*aperion*), individual death is not meaningless, perhaps not even final.

In what is now southern Italy, Pythagoras (ca. 572–497 B.C.E.) struggled with these same realities, teaching that the soul suffered from embodiment, longed for release and reunion with the divine, possibly at death experienced transmigration into possibly other life forms, and could be purified in part through the process of rebirth. For the purification needed to overcome death and to be evermore united with the divine, it was most important to live a philosophical life, especially one that paid considerable attention to the contemplation of mathematical truth. This very abstract, highly intellectual element in Pythagoreanism distinguished it from the Orphic cults and Dionysian predecessors that so influenced it, and gave Pythagoreanism considerable appeal for Plato.

Continuity and change, constancy through flux, permanence and impermanence, death, extinction, and recurrence are the enduring concerns of pre-Socratic philosopher/scientists. If, as mathematician and philosopher Alfred North Whitehead (1861–1947) has suggested, the whole of Western philosophy is but a series of footnotes to Plato, it might equally be said that the history of Western philosophy on death is but a series of footnotes to Plato's predecessors.

Socrates, Plato, and Aristotle

What we know of Socrates's (ca. 470–399 B.C.E.) view of death is largely detached from a theoretical context replete with ontological and metaphysical doctrines. His views seem to be rooted in the immediacy of his experience and circumstances, at a time when he is first anticipating, then under, a death sentence. It is the example Socrates sets, more than the words that Plato (or Xenophon) reports him to have said, that have influenced generations of students.

Early in *Apology* (29Aff.), Socrates is tentative in his assertions about death, saying only that "To be afraid of death is only another form of thinking that one is wise when one is not; it is to think that one knows what one does not know." Later, having been sentenced to death, Socrates ventures that death is either dreamless sleep from which, it seems, we do not awaken (annihilation) or transport to a place where we might ever after commune with those who precede us in death. The first is not fearsome; the second is to be joyfully celebrated (41B–42A). Socrates's deepest and most influential conviction, however, may have been that "Nothing can harm a good man, either in life or after death" (41D).

Socrates's courage and equanimity in the face of a manifestly unjust death sentence is universally admired. But exactly why he was so compliant with injustice at the end of his life is a continuing mystery (Momeyer, 1982).

Less mysterious is how Socrates could go from the cautious and skeptical views on death expressed in *Apology* to the far more metaphysically burdened opinions of *Phaedo.* The accepted explanation here is that in *Phaedo,* written later than *Apology* and *Crito,* Socrates has been transformed into a spokesperson for Plato (ca. 428–348 B.C.E.). As such, *Phaedo* is best read as the most complete case that Plato makes for his views on the immortality of the soul, with only the final death scene bearing any likely resemblance to Socrates's actual words.

Plato's view of death is inseparable from his doctrine of the soul, his identification of the soul with personhood, and ultimately the theory of Forms. Curiously, Plato's arguments are directed more to establishing the immortality of the soul than to the logically prior task of showing that the soul is the person. Whether the soul is identical to the person is a matter of continuing controversy in bioethical debates over the definition of death and criteria for personhood.

In *Phaedo,* Plato reminds readers that knowledge is recollection and shows that the soul must have existed before birth and embodiment in order for us to know most of what we do know during life. While this does not show that the soul survives death, it is suggestive in that it implies the soul's independence from the body. Other arguments attempt to show that the soul is *simple,* that is, not composed of parts and hence not subject to dissolution; that the soul resembles immortal gods in ruling the body; and that since the essence of the soul is life, it cannot admit of its negation or opposite any more than fire can be cold. Similarly, Plato holds that since the soul is capable of apprehending the eternal and immutable Forms or Ideas, it must be of a similar nature, eternal and divine.

It is not clear how seriously Plato intends most of these arguments to be taken, nor how seriously he himself takes them. But at least two central Platonic views are relevant and seriously maintained. The first is the reality of ideas, a domain of pure, unchanging essences the apprehension of which, however imperfect, is as close to real knowledge as living human beings can get. Second, Plato's suspicion of the body—construed by much later followers to be outright disdain—and his longing to be free of its burdens are consistent throughout his work. In Plato's judgment, intellectual pursuits are the most noble, but these are consistently and constantly hindered by bodily appetites and bodily limitations of sensory experience. Hence the true philosopher aspires to death, we are assured in *Phaedo,* and lives to die, in the expectation that only the soul's liberation from embodiment will make possible the fullest attainment of knowledge.

Plato's premier student began his own philosophizing in *Eudemos,* espousing Platonic views on the immortality of the soul and how individual selves survive death. Soon, however, Aristotle (384–322 B.C.E.) departed substantially from his mentor, and in *De anima* sees the soul as almost entirely physical, the entelechy of the body. More than being physically inseparable from the body, Aristotle argues, the soul is logically inseparable, as vision is logically inseparable from the seeing eye. The closest Aristotle will allow us to come to immortality is in the same fashion other creatures experience it, in successive generations of progeny. (Aristotle, 1941).

Aristotle does allow for the possibility that part of the soul survives death, the part that distinguishes us from other animals: reason, our divine element. But Aristotle's writings on these matters are fraught with ambiguity, and it is not clear that he thinks there is any survival of individual personalities.

In any case, the strongest imperative for Aristotle is to live a life of reason, an important part of which requires one to overcome a natural fear of death through courage and virtue. It seems to be Aristotle's considered judgment that individual selves do not survive death, and no benign deity watches over us; yet life is still meaningful so long as we are awed by the beauty and order of nature, and meet life's misfortunes with courage and perseverance.

Aristotle's death in 322 B.C.E. brought an appropriate close to the Hellenic period of philosophizing and provided some of the central themes in reflections on death for the Hellenistic schools that followed. Chief among these were Epicureanism and Stoicism.

Hellenistic Schools: Epicureanism and Stoicism

Where death had been a distinctly secondary concern for Socratic thinking, it soon became a primary one for Hellenistic philosophers. For Epicurus, Lucretius, and Zeno, then Seneca, Epictetus, and Marcus Aurelius, discovering how to live life and confront death were the central tasks of philosophy.

Although Epicureans and Stoics differed on what they most valued in life, they equally valued attaining equanimity in the face of imminent death. Epicureans in particular saw no reason to fear death, believing that at death the soul, composed of the finest atoms, simply dissipated, so that there was nothing left to have experiences. Epicurus argued that one need not fear an unpleasant afterlife, for there was no afterlife; nor need one fear death as annihilation, for as soon as it occurred, one no longer existed to suffer anything. Epicurus's view is well captured in his memorable letter to Menoecus, in which he asserts:

> Death … is nothing to us, since so long as we exist, death is not with us; but when death comes, then we do not exist. It does not then concern either the living or the dead, since for the former it is not, and the latter are no more. (Epicurus, 1926, p. 85)

Epicurus may well be on strong ground in urging us to regard death as final and afterlife as nonexistent, for this claim at least is supportable by overwhelming empirical evidence: People die, and they do not return. His second assurance, however—that the living need not fear death because once it occurs, they no longer exist to experience it—is far more problematic.

Epicurus's argument seems to be the following: Only that which is experienced can be evil and fearful. But death is a condition in which nothing is experienced, for the subject of experience no longer exists. Hence, it is unreasonable to fear death.

The problematic assumption here is that only that which is experienced is harmful. Deception, betrayal, and ridicule behind one's back are all capable of doing great harm, though one may never be aware of them, know of the damage they do, or be able to mind the harm. Consequently, it is legitimate to argue, contrary to Epicurus, that death is a harm (even though not experienced) precisely because it is the irrevocable loss of opportunity, of the continued good of life. Death is the deprivation of life, and were one not dead, possibilities for satisfying experiences could be realized (cf. Nagel).

The Stoics pursued a rather different strategy than the Epicureans in attempting to accommodate people to their mortality. Though we have only the most minimal fragments from the early Stoics—Zeno of Citium (ca. 336–264 B.C.E.), Cleanthes of Assos (ca. 331–232 B.C.E.), and Chrysippus of Soli (ca. 280–206 B.C.E.)—it is clear that they were much influenced by Heraclitus and emphasized discoveries in logic and cosmology. In ethics, they were early natural-law theorists, urging the unity of physical and moral universes and the duty to live a life as orderly as the cosmos, always striving for *autarkeia* (autonomy) of the virtuous person. Socrates, especially during his trial and execution, was a model and inspiration for Stoics of all eras.

Most closely identified with Stoicism are the later Stoics of the first two centuries of the Christian era in imperial Rome. The most prominent of these were Seneca (ca. 4 B.C.E.–65 C.E.), Epictetus (ca. 50–130 C.E.), and Marcus Aurelius (121–180 C.E.). What bound these philosophers together was their commitment to virtue, understood as willing behavior in accord with reason (or nature) and unresisting resignation before what was uncontrollable.

The art of mastering the fear of death is not easily learned. Stoics recommend emulating great men [sic], virtuously living the life of a philosopher, and always remembering that living well is by far the most important thing. Reminders of the futility of fearing or resisting death are also prevalent in their writings. For all of its inevitability, death need not be our imposed fate before which impassibility is required. No philosopher more than Seneca recommended so enthusiastically and vigorously, nor practiced so decisively, taking control of death by choosing it in the form of suicide. In a remarkable letter he says the following:

> For mere living is not a good, but living well. Accordingly, the wise man will live as long as he ought, not as long as he can.… soon as there are many events in his life that give him trouble and disturb his peace of mind, he sets himself free.… It is not a question of dying earlier or later, but of dying well or ill. And dying well means escape from the danger of living ill.… Just as I shall select my ship as I am about to go on a voyage … so shall I choose my death when I am about to depart from life.… Every man ought to make his life acceptable to others besides himself, but his death to himself alone. The best form of death is one we like. (Seneca, 1970, Letter No. 70)

Seneca was not, in practice, so casual about self-killing as some of the above implies. Still, when Nero accused him of conspiring against the state, and ordered him to take his own life, Seneca is reported to have paused only long enough to remind his followers of the philosophical precepts they had striven to live by before slashing his wrists and bleeding to death.

The Long Transition to a Modern View of Death

In tracing our theme through Western philosophy—whether death is final or whether some notion of afterlife is envisioned—there is very little more to say about this between the time of Stoicism's greatest influence and the onset of a secular, scientific modern renaissance. For over 1,200 years Christian religious views held sway, and philosophy, dominated by theology, had little of substance and still less that was novel to say about death. Enormously important philosophical work was done during this long era, but little of it had much new to contribute to Western philosophical thought on death.

Western philosophical thought on death did not take a turn back to the secular until Francis Bacon (1561–1626) promoted an increasingly scientific methodology and worldview, and René Descartes (1596–1650) reordered the philosophical agenda. Both reflect on death with the aim of excising the fear of death (which in the late Middle Ages, overwhelmed by both plague and superstition, reached new heights). Bacon, however, does so by emphasizing the continuity of dying with living, such that once we learn to live fearlessly, we will be assured of dying fearlessly. Descartes chooses to assuage fears of death by the now more traditional route of arguing for the immortality of the soul.

And as is well known, Descartes's argument to this end relies upon a radical division of persons into different substances, body and soul, mysteriously and problematically united, which sets the stage for much subsequent philosophizing.

Most of modern philosophy pursues Cartesian themes, and the variety of responses is considerable. Rationalist philosophers have generally sought to salvage hopes of surviving death. (Benedict Spinoza [1632–1677] is a notable exception.) But the philosophers of the eighteenth century, and the empiricists they often looked to, came to regard doctrines of the immortality of the soul as *priestly lies.* French writer Voltaire (1694–1778), through Candide's misadventures in "The Best of All Possible Worlds," savagely ridicules Gottfried Wilhelm Leibniz's (1646–1716) faith in universal harmony, and other philosophers look back to the Epicureans and Stoics for inspiration on how to face the prospects of death as annihilation.

But it was David Hume (1711–1776) who most systematically and rigorously called into question doctrines of the soul's immortality. His attack is two-pronged: First he argues against the notion of substance, specifically the self as a substance, and second, he directs a series of arguments against the notion that some part of a person survives death. In his essay "On the Immortality of the Soul" (1777), Hume characterizes *substance* as a "wholly confused and imperfect notion," an "aggregate of particular qualities inhering in an unknown something" (p. 591). As for the self as a substance, he states in *A Treatise of Human Nature* (1739):

> There is no impression constant and invariable. Pain and pleasure, grief and joy, passions and sensations, succeed each other, and never all exist at the same time. It cannot therefore be from any of these impressions, or from any other, that the idea of self is derived; and consequently there is no such idea. (1978, bk. I, pt. 4, sec. 6)

Hume claims to be "insensible of *myself,*" for the self is "nothing but a bundle or collection of different perceptions which succeed each other with an inconceivable rapidity, and are in a perpetual flux and movement." All that binds perceptions together is memory and constancy, but it is futile to ask what it is that "has" memory or experiences constancy of conjoined perceptions (1978, bk. I, pt. 4, sec. 6).

Hume's more vigorous critique of immortality is reserved for benighted attempts to settle questions of fact by a priori metaphysical speculation, which is what is done by all doctrines of *immaterial substance* and all attempts to identify personhood with an immaterial *soul* substance that is individuated and survives the demise of the body. Placing his faith in the conviction that all natural processes have some point (if not purpose), Hume notes the universal fear of death and remarks that "Nature does nothing in vain, she would never give us a horror against an *impossible* event" (p. 598).

The only admissible arguments on such a question of fact as whether human beings survive death are those from experience, and these, Hume asserts, are "strong for the mortality of the soul." What possible argument could prove a "state of existence which no one ever saw and which in no way resembles any that ever was seen?" Body and mind grow together, age together, ail together, and, from all experience conveys to us, perish together. (p. 598).

Moral arguments that turn on a just Deity's desire to punish the wicked and reward the good fare no better than metaphysical ones when attempting to prove immortality. It would be a "barbarous deceit," "an injustice in nature," Hume asserts, to restrict "all our knowledge to the present life if there be another scene still waiting us of infinitely greater consequence." Still worse, it would be monstrous for a loving God to base a judgment of how each of us will spend eternity upon the all too finite experience of one human lifetime. (p. 593)

Notwithstanding that it was Immanuel Kant's (1724–1804) reading of Hume that woke him up from a comfortable immersion in conventional dogmas. Kant advanced his own version of a moral argument for the immortality of the human soul. Kant agrees with Hume that no argument from nature (i.e., experience) can demonstrate the immortality of a human soul, and he even concedes that *pure reason* is not up to the task. Nonetheless, Kant is firmly convinced that a compelling metaphysical/moral argument will do the job.

Kant apparently never doubted his belief in human immortality, and his argument to show the soul's immortality is both elegant in its simplicity and rich in the number of fundamental Kantian tenets that it incorporates or presupposes. Kant asserts in the *Critique of Practical Reason* (1788) that the most basic requirement of the moral law is the attainment of perfection. Such an achievement is not possible in a finite life, however. But the moral law can command only what it is possible for moral agents to do. Hence the necessity of an immortal soul so that moral agents will have the opportunity to do what they ought to do.

One of the more interesting features of Kant's *proof* is that it breaks with the long tradition that sees afterlife as occurring in paradise. In Kant's moral universe, there must still be pain and suffering in the hereafter, for these are inseparable features of the moral life. Further, doubt, uncertainty, and struggle for constant improvement must accompany our disembodied journey through eternity. The moral law would appear to be nearly as powerful as God.

The soundness of Kant's argument turns on the truth of at least the following Kantian doctrines: Objective reality must conform to the essential structure of the human mind; moral certainty is as sure a route to knowledge as the logical demonstrations of reason; moral perfection is required of all who would live a moral life; human beings exist, simultaneously, in two worlds, one phenomenal, the other noumenal. If any of these dogmas fail—and all have been extensively criticized—Kant's argument for the immortality of the human soul fails as well. Any number of philosophers after Kant, less enamored of metaphysical arguments, have turned his argument around and observed that if perfection is not possible in a human life span, the moral law cannot require perfection of human beings. Far from showing human immortality, Kant's insight into morality shows the limits of what a reasonable morality can demand of mortal creatures.

Toward Postmodernism

Variations on religious, usually Christian, views of death and immortality continued in the writings of eighteenth- and nineteenth-century philosophers, including most notably the idealism of Georg W. F. Hegel (1770–1831) and the atheistic pessimism of Arthur Schopenhauer (1788–1860). Not until a real break with modern thought occurred did genuinely novel views about the significance of death and the possibility of immortality arise. In the thought of Friedrich Nietzsche (1844–1900) many now find both the culmination of ancient and modern approaches to death and the transition to a postmodern worldview. And it is certainly true that in Nietzsche's various writings, one can find many different historically grounded and historically transcendent approaches to the problem of death.

While still a student, Nietzsche read Schopenhauer's *The World as Will and Idea*(1819). Profoundly moved and deeply disturbed, he sought escape from Schopenhauer's pessimism and atheism, and saw the task of philosophy as overcoming the former while taking responsibility for the latter (*Ecce Homo,* 1888). Physical pain and mental suffering were lifelong companions; staring into the abyss of despair and coping with the guilt of killing God, Nietzsche tried a number of different strategies for finding life worth continuing.

Through classical studies and art, Nietzsche supposed, one might escape the profound misery of existence (*The Birth of Tragedy,* 1872). The consolations of *beautiful dreams* soon faded, however, and Nietzsche turned to a detached, critical search for knowledge, and the "*interesting* illusion of science replaces the *beautiful* illusion of art" (Choron, p. 201).

Objective knowledge, or its semblance, proved unsatisfying as well, and Nietzsche then began to develop the idea of the *superman* as the disciplined Dionysian man capable of living a pain-filled life with full creativity. Truth is painful and, to all but the superman, unbearable. Above all, one must love fate (*amor fati*), which becomes possible with the Eternal Recurrence of the Same:

> Everything goes, everything returns; eternally rolls the wheel of existence. Everything dies, everything blossoms forth again; eternally runs the year of existence … All things return eternally and we ourselves have already been numberless times, and all things with us. (*Also Sprach Zarathustra,* 1891 quoted by Choron, p. 202)

At least Heraclitus's voice seems to recur here.

How such a view of the one life we have and the one death we experience, albeit endlessly repeated, solves the problem of death is not clear. Sometimes Nietzsche suggests that recognizing the Eternal Recurrence of the Same should lead us to passionately embrace and affirm life, to live with as much conviction and determination as we can muster, for life might otherwise be all the more miserable for its endless repetition. But Nietzsche, who attempted suicide three times, must have been terrified at the prospect of such recurrence. It is the ultimate test of the superman to love fate while recognizing precisely what fate has in store.

Contemporary Philosophy

The problem of death has not often been seen by contemporary philosophers as a choice between devising consolations for our finitude and demonstrations of our eternalness. For many, perhaps most philosophers early in the twenty-first century, the death of God is more than a century past, the grieving finished more than half a century ago. The problem of death, understood as the struggle to make life meaningful in an increasingly secular age plagued by the temptations of nihilism, continues. The little that philosophers in the present time have had to say about death—outside of chiefly moral concerns centering on choosing death—has tended to suppose death is final, not, in any form, to be survived.

German philosopher Martin Heidegger (1889–1976), once a student of Edmund Husserl (1859–1938), took as his project the application of phenomenological method to the fundamental question of metaphysics, the study of *Being-as-such.* To this philosophically most contentious enterprise in the twentieth century, Heidegger brought a particular concern for death. Since Heidegger is addressing the issue of why there is something rather than nothing, it is not nonexistence of Being that concerns him, but rather how individual beings—most particularly, individual self-conscious human beings (*Dasein*)—can possibly come to not exist.

Heidegger uses language in highly idiosyncratic ways, so when he talks about possibility and non-possibility and impossibility it is best to leave our conventional (and philosophical) understandings of these terms behind and attend to Heidegger's peculiar uses.

Understanding our own being at a deep level requires the attainment of wholeness and authenticity, which enables life to be lived with integrity and clear thinking. Nothing is more central to this quest than an appreciation of temporality and possibility, which provides insight into Being in general and Dasein in particular.

Dasein aspires to wholeness, but has future possibilities open to it only so long as it exists and can freely choose. But so long as Dasein exists and can make free choices, it cannot be whole. Death appears to us an end of Dasein and of possibility, but is it the attainment of wholeness? How can non-existence constitute completion?

Heidegger's resolution of these paradoxes involves an analysis of the unique way in which Dasein has possibilities and of how these are limited. Dasein's possibilities are ever limited by *the possibility of the impossibility of existing,* which in Heidegger's discourse is a synonym for death. Yet Heidegger maintains that his view of death leaves open the question of afterlife.

Death creates for Dasein its *ownmost possibility,* one that invites a uniquely free choice in response to mortality from each individual. The certainty of death is the ultimate realization of each Dasein, experienced alone and not shared by another. Attaining authenticity requires *Vorlaufen,* literally a *running forwards,* metaphorically, an ever self-conscious anticipation of death—a *being towards death*—that will free one from life's trivia and focus on using freedom to create an authentic self.

Jean Paul Sartre (1905–1980) in philosophy, and Carl Gustav Jung (1875–1961) in psychoanalytic theory, were both influenced by Heidegger's thinking. Jung developed Heidegger's notion of being towards death as a central focus of his psychoanalytic theory, and Sartre, along with French writers Simone de Beauvoir (1908–1986) and Albert Camus (1913–1960) articulated some of the most distinctive things to say about the problem of death in the twentieth century. Building on Nietzsche's alienation from convention, despair at the death of God, and attraction to nihilism, and struggling with revelations of the distinctly human capacity for genocide revealed during the Holocaust and the era of nuclear weaponry, existentialists have sought ways to affirm against all odds the meaningfulness of individual human existence. A good deal of the spirit of this distinctive approach to death is captured in de Beauvoir's unsettling judgment on the very difficult dying of her mother:

> There is no such thing as a natural death: nothing that happens to a man is ever natural, since his presence calls the world into question. All men must die: but for every man his death is an accident and, even if he knows it and consents to it, an unjustifiable violation. (p. 123)

Far from providing assurances of immortality or consolations designed to meet death with equanimity, existentialists recommend a rebellious, often angry response to the *cosmic injustice* that human beings die. Rebellion against or resistance toward death, however, is not recommended as a strategy for overcoming death; no illusions are allowed as to the inevitability and finality of death. Rather, for Camus especially, such resistance is recommended as an affirmation of one's decency, caring about life, and personal integrity. Nowhere is this better illustrated than in Camus's novel *The Plague,* an extended allegory about any number of evils, not the least of which is death itself. Dr. Bernard Rieux and his closest friend, Jean Tarrou, struggle mightily against the ravages of the plague in the seaside town of Oran in Algeria. In time, however, Tarrou succumbs to the plague, and Rieux reflects on what it means:

> Tarrou had lost the match, as he put it. But what had he, Rieux, won? No more than the experience of having known plague and remembering it, of having known friendship and remembering it, of knowing affection and being destined one day to remember it. So all a man could win in the conflict between plague and life was knowledge and memories. But Tarrou, perhaps, would have called that winning the match. (Camus, p. 262)

Afterword

Most Western philosophical views on death have been singularly human-centered, driven by the assumption of human uniqueness. Even atheistic existentialists, for whom God is displaced altogether from the universe, seem lost with no center, and substitute human beings and a kind of humanism as their moral center.

We have only just begun to explore the post-Darwinian implications of regarding human beings as a natural kind—as creatures like other creatures known to us, evolved from simpler life forms without conscious direction. The moral implications of such a change in worldview are getting considerable attention from philosophers at present—in reflections on ecology and the moral status of nonhuman animals, in more sympathetic treatments of rational suicide and euthanasia, in greater openness about the difficulties of dying—but the larger ontological and metaphysical consequences are infrequently addressed. If there is to be any substantial breakthrough in our philosophical thinking about death, it might well come only with the displacement of human self-centeredness, with seeing human beings as one among many natural kinds on a solitary planet in an ordinary solar system that is on the fringes of one of many billions of galaxies in an apparently infinitely expanding universe. Such a potentially revitalized naturalism need not imply that life is meaningless for solitary, mortal human beings, nor does it guarantee significant life, but it might suggest that our plight is not unique, not unshared by others, and not, finally, to be resolved (or dissolved) by exclusive self-centered speciesist concerns.

But maybe not. Even such a revitalized naturalism might prove to be but one more variation on one side of the recurrent debate between those who seek a satisfactory means to reconcile each of us to the finality of death, and those who, on the other hand, seek to sustain the hope that life does not end with death and that individual consciousness continues beyond the grave.

RICHARD W. MOMEYER (1995)
REVISED BY AUTHOR

SEE ALSO: *Anthropology and Bioethics; Autonomy; Body: Cultural and Religious Perspectives; Care; Grief and Bereavement; Harm; Holocaust; Human Dignity; Infanticide; Life; Life, Quality of; Life Sustaining Treatment and Euthanasia; Literature and Healthcare; Narrative; Palliative Care and Hospice; Pediatrics, Intensive Care in; Right to Die, Policy and Law; Suicide; Triage; Value and Valuation; Virtue and Character; Warfare;* and other *Death* subentries

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IV. WESTERN RELIGIOUS THOUGHT

Death in Biblical Thought

There is no "biblical view of death" as such. This lack of a single scriptural understanding of death is hardly surprising, given the fact that the Bible is sacred scripture for three world religions and that its contents were written and compiled over a period of a thousand years or more. But the history of literary and religious development embedded within the Bible itself does allow for a kind of "archaeology" of death in biblical thought. Though admittedly vastly oversimplified, the following narrative of the Bible's evolving views on death can be traced backward through their random branchings and read forward toward their studied convergences.

Put in its simplest terms, an ancient desert god named Yahweh came to be regarded not only as the national god of a holy nation, but ultimately as the one and only God of the universe. These momentous shifts in the biblical understanding of God were paralleled by remarkable changes in biblical views of death, beginning with the denial and concluding with the affirmation of individual postmortem existence.

THE HEBREW BIBLE. Hebrew religion emerged out of the tribal polytheisms of ancient Mesopotamia. The protagonists of Yahwism only gradually succeeded in establishing their deity as the national god of the various Semitic tribes that were finally welded together, during the latter half of the second millennium B.C.E., into the people known as the Israelites. A key weapon in their struggle to establish Yahweh's supremacy was the suppression of prevailing beliefs and practices dealing with death. In two very different responses to death, Mesopotamian culture had preserved primitive notions of life after death as a continuation of the life before death. On the one hand, mortuary cults affirmed a significant afterlife for the powerful and privileged who commanded the worship and fealty of the living. On the other hand, postmortem existence was limited to an awful underworld where the departed dead were shrouded in darkness and subsisted on clay. In either case, the realm of the dead was under the control of the gods of the underworld. For that reason, the champions of Yahwism denounced the polytheistic beliefs and practices of both the mortuary cults and the "house of dust."

Against the mortuary cults, the Yahwists presented a view of human nature and destiny that undercut all ancestor worship and necromancy. In the Yahwist creation myth, the protohuman couple was created from the soil and destined to return to the soil (Gen. 3:19). Human beings are material bodies animated by a life force (*nephesh* or *ruach*) residing in the breath or the blood. Death comes when the life force leaves the body and returns to Yahweh. Thus, a common fate awaits all persons upon death—master and slave, rich and poor, good and bad—all descend beneath the earth to the place of the dead called She'ol, where they continue a shadowy existence, but only for a brief period of time. This land of the dead was variously described as an awful pit shrouded in darkness or a walled city covered with dust. Although reminiscent of the Mesopotamian underworld, the Yahwist notion of She'ol excluded any divine ruler of the infernal regions. Neither a god of the underworld nor Yahweh himself was involved with the denizens of She'ol. Yahweh reigned supreme over the community of the living, meting out collective rewards and punishments only in the present life. In other words, mortality was accepted as a fact of life. Premature and violent deaths were feared as great evils and regarded as punishments for sin. As such, the untimely or agonizing death remained under the control of Yahweh (Isa. 45:7). But death at the end of a long and happy life was accepted, if not welcomed (Gen. 25:8; Job 5:26). What mattered were those things which survived the mortal individual: a good reputation (Prov. 10:7), male offspring (Isa. 56:3–5), the promised land (Gen. 48:21), and the God of Israel (Ps. 90).

Precisely this emphasis on present existence contributed to the eventual transformation of Yahwism. The naive assumption that Yahweh rewards the pious with prosperity and a long life while punishing the wicked with misfortune and a brief life was obviously contradicted by communal and individual experience. Especially the disasters that befell Israel between the eighth and the sixth centuries B.C.E. raised radical doubts about Yahweh's justice and omnipotence, because the entire social and religious order of Israel was disrupted and eventually destroyed.

This massive destruction evinced two distinctive responses. On the one hand, most of the great prophets of Israel responded to these dire circumstances by reaffirming collective retribution and promising collective restoration (Isa. 11:10–16; Ezek. 36:16–36). Some prophets moved beyond communal responsibility and punishment (Jer. 21:3), but their new emphasis on the individual only heightened the tension between divine power and justice in the face of innocent suffering (Job 10:2–9). On the other hand, an apocalyptic school of thought slowly emerged that anticipated a miraculous deliverance of the faithful living and dead at the end of time. Envisioned in this apocalyptic outlook was the final defeat of death itself, which had increasingly been personified as a destructive evil force. Thus, by the end of the second century B.C.E., two sharply contrasting views of death dominated the Hebraic worldview. The older notion that death marked the end of life remained the traditional view among those who came to be known as the Sadducees. The newer view that affirmed postmortem divine judgment and human resurrection flourished among such sectarian movements as the Pharisees and the Essenes. For these sectarians, the powers of death would eventually be overcome by the power of God.

THE INTERTESTAMENTAL LITERATURE. This sectarian transformation of the Hebraic view of death during the so-called intertestamental period was immense (ca. 200 B.C.E. to 50 C.E.). A number of disparate ideas were combined into a dramatically new eschatology. The Book of Daniel marked a watershed in Hebrew religious thought by promising Yahweh's final intervention in history to rescue his people from their enemies and to resurrect past generations from the dead to participate in this ultimate restoration. To be sure, this final restoration was limited to the nation of Israel. But, under the impact of speculative thought and foreign influences concerning life after death, the prospect of a final resurrection and judgment for all humankind appeared in the later apocalyptic literature, much of which is contained in the Apocrypha. In this apocalyptic literature, human consciousness and the life force were fused into an entity (*psyche* or *pneuma*) which, unlike the earlier conceptions of *nephesh* or *ruach*, survived the cessation of bodily functions in some spiritual fashion. She'ol was reconceived as a holding place for the dead until their ultimate fate was decided at a final judgment. More significantly, She'ol was divided into compartments reflecting the moral character of the dead, wherein rewards and punishments were already meted out in anticipation of the catastrophic end of the existing world order (Enoch 22:9–14). Thus, death held no terror for the righteous. In fact, death through martyrdom was seen as a seal of divine favor (2 Macc. 6:30–31) and even premature death from serious illness freed the righteous from further suffering (Wisd. of Sol. 4:11). Death was only a threat and curse to the wicked. Reminiscent of the older Yahwist traditions, the apocalyptic emphasis remained largely on the collective aspects of human destiny, for it is the nations that are arraigned for the final judgment (2 Ezd. 7:32–38). The postmortem survival of the individual became an affirmation of faith within certain Jewish circles only following the shattering of the Jewish state in 70 C.E.

THE NEW TESTAMENT. Primitive Christianity emerged out of Jewish apocalyptic expectations of the catastrophic end of the existing world order and the final judgment of the living and the dead. These apocalyptic expectations had been joined in the popular imagination with the older prophetic Messianic traditions in which a divinely appointed and endowed figure would crush the enemies and restore the glories of Israel. So far as the New Testament Gospels allow for historical reconstruction, the message of Jesus centered in the nearness of the Day of the Lord, when the chosen people of Yahweh would be vindicated before the nations of the world. Jesus called his compatriots to prepare themselves for the Coming Judgment through repentance and obedience to the written and oral Law of God. But, unlike the earlier nationalistic preoccupations of Jewish apocalypticism, this newer eschatology emphasized the eternal destiny of individuals in accordance with their moral achievements (Matt. 25:40–46). After his death and resurrection, the followers of Jesus identified him as the promised Messiah who would restore the righteous and judge the wicked. This same "Christianized" apocalyptic tradition informs the Revelation to John, which so profoundly influenced later Christian views of human death and destiny. Here the "end of the world" was described in elaborate detail as a cataclysmic establishment of the millennial reign of Christ and the saints on earth, after which the righteous are rewarded with eternal life and the wicked are punished with eternal death. Thus, the earliest Christian view of life after death was heavily influenced by, but not identical with, Jewish apocalypticism. Jesus was heralded by his early followers as their resurrected Lord who would shortly return in supernatural power and glory to preside over the Final Judgment of the living and the dead.

A somewhat different interpretation of the message and mission of Jesus was offered by Paul in his outreach to a Gentile audience. Paul regarded the death of Christ as a divinely planned event to rescue humankind from enslavement to the demonic powers of evil and death that ruled the world. Although influenced by apocalyptic thought, Paul's interpretation of a divine Savior's death and resurrection involved an eschatology very different from the apocalyptic scheme of things. No longer was obedience to the Twofold Law the basis on which the living and the dead would be judged; instead, faith in the crucified and risen Lord became the crucial factor. The ritual of baptism, which reenacted the death, burial, and resurrection of Christ, initiated believers into immortal life while still living in their material bodies. The baptized Christian, having become a new creation *in Christo,* had already passed from death to life. Thus, the imminent return of Christ and the end of the world held no fear for baptized believers, for their final judgment and destiny had already been settled.

With the Roman overthrow of the Jewish state in 70 C.E., the Mother Church of Jerusalem disappeared and eventually Pauline Christianity became the normative interpretation of Christ. Elements of the earlier apocalyptic eschatology were carried over into this form of faith. Christianity became a salvation religion centered in a Savior God who would shortly return to bring the existing world to a catastrophic end and to judge those who had oppressed the faithful. But the continuing delay of the second coming of Christ forced the Church to rethink its notions of eschatological fulfillment. The Church could no longer think of itself as an eschatological community awaiting the imminent return of their Lord. Rather, the Church developed a hierarchical structure and a sacramental system to shepherd believers through the perils and pitfalls of life from birth to death. Accordingly, Christ was reconceived as the heavenly mediator between God and humankind. Despite these doctrinal and ecclesiological developments, the apocalyptic vision of the catastrophic end of the world was retained, raising anew all sorts of problems about the status of the dead before the final day of resurrection and judgment. Over time, these problems were resolved in ever more vivid and complicated schemes of postmortem paradisal bliss for the saints and purgatorial torment for the sinners until the day of Final Judgment (Luke 16:19–26).

ETHICAL IMPLICATIONS. As noted above, the Bible is a diverse literature containing a variety of religious perspectives on death. Religious affirmation of the triumph of life over death is a common theme running through the whole of scripture, but how, where, and when this victory is won differs dramatically among biblical perspectives. For that reason, the Bible offers no consensus of direct guidelines on death and dying. Nevertheless some application of the biblical tradition to modern "end of life" ethical issues can be ventured.

1. Biblical views of death are greatly influenced by the wider cultural milieu. As human conditions and needs changed, so did prevailing religious beliefs and practices concerning death. Thus, the Bible itself seems to allow for changing definitions and responses to death in the light of new social conditions, scientific knowledge, and religious insights.

2. The biblical tradition's intimate connection between body and spirit is not only a mandate for medical care as treatment of the whole person but also grounds for regarding human life as more than biological functioning. While the Bible does not authoritatively establish when death occurs, it defines death as the separation of the spirit from the body. Thereby, the Bible provides indirect warrants for withholding or withdrawing extraordinary means of life support when the vital bond between body and spirit has been dissolved or destroyed.

3. The biblical tradition never accords absolute power or independent status to death. Death, whether viewed as a natural event or an evil force, is always subordinated to the power and purposes of God. While the Bible speaks of sin as both a cause and a consequence of death, even the death of the sinner remains under divine control and serves the divine will. God's sovereignty over death serves as a caution against simplistic religious warrants for directly or indirectly terminating the lives of the suffering.

4. Biblical support can be found both for death as a natural part of life and death as an evil power opposed to life. Those who regard death as an "enemy" that must be battled at all costs will find more support for their view in the New Testament. Those who see death as a "friend" that can be welcomed at the end of life will feel more kinship with the Hebrew Bible. But both Jewish and Christian scriptures regard untimely and violent deaths as evils to be avoided and enemies to be combatted by all legitimate means that do not compromise religious or moral duties. Of course, death by coercive martyrdom can be affirmed as a seal of great faith, and even premature death from debilitating illness can be welcomed by the believer as a deliverance from great suffering.

5. Taken as a whole, the Bible does not unambiguously affirm individual life after death. But where postmortem existence is affirmed in the Bible, the grounds are theological rather than anthropological. The individual's survival beyond death is a divine possibility rather than a human certainty. Immortal life is a "supernatural" endowment rather than a "natural" attribute. In other words, a belief in life after death is neither a given of human nature nor a constant of human culture. Thus, the idea of life after death cannot become an explicit warrant for public policies or ethical decisions regarding "end of life" issues in a pluralistic society.

Death in Systematic Religious Thought

The classical doctrines and rituals of Judaism and Christianity are no less complicated and diverse than their biblical backgrounds. Neither the Judaic nor the Christian tradition is monolithic. Both faiths have been developed over extended periods of time in response to changing historical circumstances and cultural influences. But these theological complexities can be simplified for purposes of comparing and contrasting their respective views of death. Just as there are elements of continuity and mutuality within the Hebrew Bible and the New Testament, so are there broad similarities between Judaism and Christianity in their traditional beliefs and practices regarding death.

POSTBIBLICAL JEWISH BELIEFS AND PRACTICES. A long and slow transformation took place from the completion of the Hebrew Bible (ca. 200 B.C.E.) to the completion of the Talmud (ca. 500 C.E.), during which time biblical Hebraism emerged as rabbinic Judaism. The Talmud brought together eight hundred years of rabbinic commentary on scripture that was broadly categorized as *halakhah* (law) and *haggadah* (story), the former describing the obligations, the latter explaining the meaning of God's covenant with Israel. This massive compendium of rabbinic thought explicated the scripture's "moralization" of life and death in vast and vivid detail. For example, heaven (*Gan Eden*) and hell (*Gehinnom*) were each divided into five separate chambers, reflecting different levels of eternal rewards for the righteous and punishments for the wicked. Similarly, the rabbis described 903 forms of death. The hardest way of dying is by asthma and the easiest, which is reserved for the righteous, is "like drawing a hair from milk." Death following five days of illness was considered ordinary. Death after four days or less indicated increasing degrees of divine reprimand. Those who died before fifty were "cut off," sixty years was "ripe age," and above seventy was "old age." Despite all this moralizing about death, comparatively few rabbis held that death as such was the wages of sin. Against those who taught that Adam's sin brought death into the world, the majority of rabbis taught that Adam's mortality was given with his creation. Death was an integral part of the good world that God created in the beginning. Thus, sin hastens death but does not cause it in the first place.

In other words, only the timing and manner of death are affected by moral conditions. Acts of benevolence and confessions of sins can delay the hour of death as surely as sins of impurity and injustice can speed it. But there is no avoiding death once the angel of death receives the order from God. Given God's permission to destroy, the angel of death makes no distinction between good and bad, but wields the sword against royalty and commoner, old and young, pious and pagan, animal and human alike. While both the wicked and the righteous must die, their deaths are as different as their lives. The wicked perish to pay for their sins while the righteous die to be freed from their sins. Death is a punishment for the sins of the wicked but an atonement for the sins of the righteous. Put another way, the righteous are still alive even though dead, while the wicked are already dead though still alive.

When death occurs, the soul leaves the body with a silent cry that echoes from one end of the world to the other. The soul's departure from the body is marked by the absence of breathing, heartbeat, and pulse. The slightest sign of movement is an indication that death has not yet occurred. Where the soul goes was a matter of considerable dispute among the rabbis. Some taught that the soul sleeps until the resurrection of the dead and the final judgment. Others believed that the soul passes into an interim state of consciousness and activity. But they all agreed that the body that remains must be treated with dignity and given a proper burial. Desecration of the body, such as mutilation or burial with missing body parts, is forbidden, and burial must be before nightfall if possible. Interment must be in the ground to fulfill the biblical mandate ("Dust you are and to dust you shall return") and to complete the atoning process ("May my death be an atonement for all my sins"). A speedy and simple burial also accorded with widespread popular beliefs that the soul is free to complete its journey to the other world only when the body has decomposed.

These beliefs about death were reflected in a number of customs and rituals surrounding the dying and mourning process. A dying person (*goses*) was given special consideration by loved ones who gave support and comfort during the last hours. The dying person was never to be left alone. Last wishes and spiritual advice were to be faithfully observed. When nearing the end, the dying were encouraged to make a confession such as the following: "I acknowledge unto Thee, O Lord my God, and God of my fathers, that both my cure and my death are in Thy hands. May it be Thy will to send me a perfect healing. Yet if my death be fully determined by Thee, I will in love accept it at Thy hand. O, may my death be an atonement for all my sins, iniquities, and transgressions of which I have been guilty against Thee." This confession was followed with the traditional Jewish affirmation of faith: "Hear, O Israel: The Lord is our God, the Lord is One" (Deut. 6:4).

When death had occurred, the eyes and mouth were closed by the eldest son or nearest relative. The arms were extended alongside the body, which was placed on the floor with the feet toward the door and covered by a sheet. A lighted candle was placed close to the head. Mirrors were turned to the wall or covered. Water in the death room was poured out, reflecting the ancient legend that the angel of death washes its bloody sword in nearby water. The windows of the death chamber were opened to allow the spirits to enter and depart. The dead body was never left alone, whether on weekdays or the Sabbath, until the funeral. Thus, the entire deathbed drama was structured to allow the dying to face the future realistically, yet within a reassuring framework of family and faith.

The theological and literary diversity of the talmudic period yielded two very different developments of the Jewish tradition during the Middle Ages (ca. 1100–1600). A mystical school emerged whose teachings concerning death and the afterlife went far beyond rabbinical Judaism. An emphasis on divine immanence and human transcendence lay at the heart of the *Kabbalah,* the most commonly used term for the esoteric teachings of medieval Judaism. Human life is the journey of the soul from God and back to God. During the interim period of life on earth and in the body, the soul must attain the "knowledge of the mysteries of the faith," which will purify and prepare it for its return to God. Since this esoteric knowledge is seldom learned in a single life, the soul transmigrates from one embodiment to another until all sins are purged and all duties fulfilled. In this mystical scheme of things, death is simply a threshold marking the passage from one life to another in the soul's ascent to God.

By contrast, a scholastic approach emerged, which codified talmudic beliefs and practices concerning death and dying. The greatest halakist of medieval Judaism was Rabbi Joseph Caro. His sixteenth-century work, *Shulhan Arukh,* became the authoritative code of Jewish law by synthesizing and reconciling the three giants of medieval *halakhah*—Isaac Alfasia, Moses Maimonides, and Asher B. Jehiel. Unlike Maimonides, who reinterpreted traditional Jewish teachings in Aristotelian terms, Caro did not subject Jewish law to speculative criticism. Rather, he brought order out of chaos by investigating each stage of development of every single law, finally arriving at a decisive interpretation and application of that law. His work has remained the indispensable guide to the development and interpretation of Jewish laws and customs for two millennia. Included in *Shulhan Arukh* are the detailed halakic rites and duties surrounding death, burial, and mourning observed throughout Orthodox Jewry to this day.

In the modern period, a variety of reform movements have modified many traditional Jewish beliefs and practices concerning death. Orthodox Jews have for the most part remained loyal to rabbinic eschatology, with its emphasis on the final resurrection, but they diverge on whether the resurrection awaits all humankind, the righteous of every age, or only the Jewish people. These otherworldly notions of Messianic redemption and divine judgment have largely faded into the background for Conservative Jewish thinkers. They interpret the Messianic Hope historically in terms of the restoration of the nation of Israel, and spiritually in terms of the immortality of the soul. References to the resurrection of the dead in Jewish rituals of death, burial, and mourning are retained, but the language of resurrection is assimilated to teachings about the immortality of the soul.

Reform Judaism has gone even further in rejecting doctrines of bodily resurrection and the Messianic Age. The "Pittsburgh Platform" of Reformed Judaism (1885) excluded all bodily notions of heaven and hell as abodes for everlasting punishment and reward. Indeed, some liberal Jewish thinkers have rejected the idea of individual immortality entirely, though they affirm the lasting value of each human life within the everlasting life of God. These reformulations of Jewish belief have also produced liberalizations in the areas of Jewish death, burial, and mourning rites. Curiously enough, this turn away from the otherworld and afterlife has fueled a profound concern for the salvation of humankind in the full reality of their historical existence. Thus, many Reformed Jews have returned full cycle to the essentially "humanistic" outlook of the great prophets of ancient Israel.

POSTBIBLICAL CHRISTIAN BELIEFS AND PRACTICES. The traditional Christian understanding of death developed largely in response to two challenges facing the Church at the close of the first century. Internally, the delay of the second coming of Christ forced Christian thinkers to deal with the state of the soul between death and resurrection. For the most part, primitive Christians believed that the dead slept until the Last Day, at which time they would be resurrected from the grave to receive their everlasting rewards or punishments. But, as this period of time lengthened, questions about the interim between individual death and universal judgment became ever more pressing. Externally, the pervasive view of death in Hellenistic religion and philosophy called for some theological response. The Greeks believed that the immortal soul is released from its bodily entrapment by death. This understanding of death was so widespread that some Christian assimilation of the soul's immortality and the body's inferiority was inevitable. Taken together over time, the delay of the return of Christ and the appropriation of Greek ideas of immortality fostered an elaborate system of Christian beliefs and practices concerning the active life of the soul during the period between one's death and the general resurrection at the end of the age. In time, this new eschatology displaced the apocalyptic vision of the Last Days, which vision survived for the most part in millenarian or chiliastic sects, who looked forward to the return of Christ and the establishment of the Kingdom of God on earth.

The church fathers adopted many of the categories of Greek philosophy but retained most of the substance of Pauline Christianity. They affirmed the immortality of the soul but rejected the ultimate separability of soul and body, along with all Hellenistic notions of reincarnation and immediate judgment. The soul is the vivifying principle and as such is incomplete without a body. Indeed, had Adam and Eve not sinned, humankind never would have experienced death. But all must suffer the separation of soul and body in death as punishment for their sins. Their souls, however, cannot perish because they are immortal. Therefore, these souls must eventually be reunited with "the dust of bodies long dead" (Augustine) in order to receive their final inheritance of everlasting salvation or eternal damnation. Surprisingly, there was little speculation among the church fathers about this interim between individual death and general resurrection. Since the soul is immaterial during this period, the dead could experience no sense of place or time, no awareness of comfort or pain, until the resurrection.

Given its finality, death thus became a decisive moment in the soul's destiny. The hour of death sealed the fate of the saved and damned alike. Those who died with their sins forgiven were destined for heaven's bliss. Those who died "while yet in their sins" were condemned to hell's agony. This emphasis on penance in relation to God's mercy and judgment fueled the more elaborate view of heaven, hell, and purgatory that characterized medieval Christianity. The materials for that view were already available in the earlier periods, but an adequate conceptual framework was lacking. The notion of a fire that cleanses the righteous and consumes the wicked at the final resurrection belonged to the earliest biblical traditions. Pushing this purgation of sins back from the final judgment into the interim period after death was encouraged by pietistic and penitential practices. Prayers to the saints and masses for the dead whose sins require expiation implied an active existence for souls following death and suggested a postmortem purgation of sins. But these implications were not fully worked out until the High Middle Ages (1200–1500).

Drawing on Aristotelian philosophy, Thomas Aquinas worked out an eschatology that combined an active spiritual afterlife with the traditional biblical notions of a general resurrection and last judgment. While the soul actualizes the body as its matter, it contains within itself to a degree all the perfections of physical and spiritual existence. Thus, the infliction of punishment or the bestowal of reward on the soul begins immediately after its separation from the body. But neither ultimate happiness nor ultimate misery is possible for a disembodied soul and, therefore, both must await the reunion of soul and body at the resurrection. Moreover, the soul that is ultimately rewarded must be entirely purified, either during or after this life. In other words, the existence of purgatory was a logical correlate of the immortal soul and the sacrament of penance, which requires contrition and satisfaction for all sins committed after baptism.

This thirteenth-century theological synthesis ineluctably shifted the emphasis to the individual's judgment at death rather than the universal judgment of humankind at the final resurrection of the dead. The Church's official view retained the two judgments, but in popular belief and practice they were in effect merged into one. People simply went to heaven, hell, or purgatory at the moment of death. Accordingly, the hour of death became overloaded with urgency. Dying in a state of grace meant eternal salvation, in a state of sin, eternal damnation, while dying with unconfessed sin required purgatorial cleansing. Thus, dying became more important than living. This focus on death was most obvious in the medieval *Ars moriendi* art of dying manuals that gave step-by-step advice to the dying and to the persons attending the dying to ensure a "good death." Of greater significance was the increasing importance of the sacrament of extreme unction, which was administered to the dying for all sins of sight, hearing, smell, speech, touch, and action. For those believers who died ill-prepared, there were masses for the dead and indulgences for the remission of sin for those in purgatory. In other words, a whole arsenal of beliefs and practices were mobilized against the terror of dying outside the state of grace.

What was developed in the thirteenth century as gifts of divine grace became in the fourteenth and fifteenth century marks of human folly. Or so the Protestant reformers claimed. Abuses surrounding the sacraments and indulgences for the dying were rife in the late medieval Church. These abuses were a precipitating cause of the sixteenth-century reform movements that swept both church and society. In point of fact, neither Luther nor Calvin broke with the fundamental worldview of medieval Christianity. Both challenged current beliefs and practices from within the medieval tradition. Thus, with regard to eschatology, the reformers retained the concept of the soul's immortality and eternal destiny. But they both undercut the entire penitential system with a different understanding of divine mercy and justice. The blood of Christ is the sole satisfaction for the sins of believers. Thus, medieval notions of a purgatorial state and a treasury of merits fell to the ground because these practices compromised the sole ground of salvation in Christ through faith. What remained for the reformers was an affirmation of the imperishable soul, which immediately enters its eternal reward or punishment upon separation from the body in death. The older idea of a general resurrection and judgment at the End of the Age was retained, but this last state of the soul only ratifies and perfects the fate of the saved and the damned at death.

In the modern world, mainline Catholic theologians have for the most part remained faithful to the position of Thomas Aquinas. The lurid images and frantic piety surrounding death and the afterlife in the Middle Ages have long since been rejected by educated Catholics. But the devout Catholic can still face the enemy of death armed with the traditional sacramental graces and doctrinal truths of life everlasting. To be sure, some contemporary Catholic theologians interpret these traditional beliefs and practices in symbolic rather than literal terms. For them, the experience of death is viewed as pilgrimage in faith rather than punishment for sin. Death is seen as "the law of human growth," whereby each stage of growth requires a tearing away from previous environments, which have become like so many prisons. In death, one's own body, like the mother's body at birth, is abandoned so that personal growth may continue. Alternatively, death allows the soul to enter into a new all-embracing unity. At death the soul is freed from the limitation of being related to one particular human body and becomes related to the whole universe. The pouring out of the self at death leads to a pan-cosmic level of personal and communal existence. But for the most part, contemporary Roman Catholics simply "look forward to the resurrection of the dead and the life of the world to come," in the words of the Nicene Creed.

Modern Protestant theologians have been even more innovative than their Catholic counterparts. To be sure, mainline Protestants have followed the guidelines laid down by the Reformers. They have combined an emphasis on postmortem rewards and punishments for the soul at death with some notion or another of a Final Consummation of the Age. But a growing freedom from ecclesiastical authority and biblical literalism allowed for a wide range of Protestant theological innovations. These new theologies were usually developed in response to the challenges of modern science and in partnership with one or another modern philosophy.

Beginning in the eighteenth century, the Christian faith was interpreted within such diverse philosophical frameworks as rationalism, romanticism, empiricism, existentialism, and process thought. Not surprisingly, each philosophical theology has dealt with the problem of death and the afterlife in its own distinctive way. These liberal theological experiments share certain convictions about life after death. They reject apocalyptic schemes of history and literalistic views of the afterlife. They empty the afterlife of all ideas of eternal torment, preferring instead to speak of either the total annihilation or eventual salvation of the wicked. But their concrete notions of eternal life run the gamut from the soul's immaterial existence in heaven to the self's authentic existence while on earth. Despite these wide-ranging theological reflections on death, most present-day Protestants hold to the idea of death as the soul's passage to its immortal destiny, either in eternal communion with or eternal separation from God and the people of God.

ETHICAL IMPLICATIONS. The long histories of Judaism and Christianity reveal disagreements within as well as differences between these religious traditions. And yet there are striking parallels between the ways they deal with death over the centuries. Of course, both traditions come out of the same Hebraic background and confront the same broad cultural challenges. But of greater importance is the fact that both traditions are preoccupied with the issue of theodicy. There must be some ultimate justification of the brute fact that the righteous suffer and die along with the wicked. The stubbornly moral character of the Judaic and Christian traditions militates against either indiscriminate immortality or universal annihilation. Thus, for all their differences, Judaism and Christianity are bound together by their efforts to reconcile ethics and eschatology. Not surprisingly, Judaism and Christianity respond in similar ways to a number of "end of life" ethical issues.

1. For the most part, Judaism and Christianity traditionally define death as the moment the spirit leaves the body. The accepted signs of the spirit's departure are the absence of breathing, heartbeat, and pulse. But there is nothing in these theological traditions that directly rules out more precise empirical signs of death, such as a flat brain wave. Most Christian theologians, and many Jewish thinkers, have accepted a brain-oriented definition of death, but some, especially within Orthodox Judaism, oppose such a definition, focusing instead on breathing as the definitive indicator of life. Some contemporary theologians are openly embracing higher-brain oriented definitions of death as modern equivalents of the departure of the spirit from the body.

2. Regardless of the etiology of death, the Jewish and Christian traditions regard death as an evil to be endured rather than a good to be embraced. Though death is inevitable, it is an event to be held at bay by every possible and honorable means that is not excessively burdensome or morally ambiguous. Therefore, most traditional Jews and Christians are categorically opposed to suicide and active euthanasia, or "mercy killing." Since martyrdom is not considered suicide, choosing death over life in service to one's faith or for the sake of others is allowable if it cannot be avoided in an honorable way.

3. Although all must die, not all deaths are the same in the Jewish and Christian traditions. Clearly, there are better and worse ways of dying. The best of deaths is the death of a person at peace with God who is "full of years," relatively free of pain, and surrounded by loved ones. The worst of deaths is to die "before your time," in rebellion against God, and alienated from family and friends. Recognition of these different ways of dying lends at least indirect religious sanctions to modern-day concerns about the "good death." There are no clear-cut religious obligations to prolong the dying process by extraordinarily burdensome means of life support. Indeed, the moral permissibility of withholding or withdrawing heroic means of life support from the terminally ill enjoys wide support among contemporary Jews and Christians alike, even though some Jewish scholars, particularly among the Orthodox, prefer to provide support, whenever possible, until the patient is moribund.

4. For both Jews and Christians, death is a reality that cannot be ignored or wished away. Whether death comes slowly or suddenly, the worst time to deal with death is after it happens. Believers should be prepared to deal with the heartache and havoc it brings before illness or tragedy strikes. We are ready to live only when we are prepared to die. While such preparation need not require the cultivated preoccupation with death of the medieval *Ars moriendi*, it should include a recognition of human mortality and an acceptance of human limits. In principle, such preparation might include the execution of advanced directives regarding terminal care.

5. Although the soul is infinitely more valuable than the body, the bodies of the dead deserve to be treated with care and love. For traditional Jews, such respect for the human body ordinarily excludes mutilation of the body, although sanctions against autopsies and dissection may yield to the superior value of protecting life or punishing crime. Some contemporary Jewish thinkers extend this overriding obligation to preserve life to the justification of organ harvesting for transplantation. Despite centuries of theological opposition, traditional Christians have reconciled themselves to the

legitimacy of anatomical dissection and organ harvesting in the interests of science and medicine, perhaps reflecting the Christian view that the resurrected body is a new creation of God. But more liberal Jews and Christians are untroubled by any of these postmortem procedures, provided they do not disgrace the corpse or disturb the family.

6. Both the Jewish and Christian emphasis on death is, in reality, the obverse of an even greater emphasis on life. At best, death serves as a motive for a creative and responsible life. At worst, death looms as a menace to a courageous and generous life. Either way, death lends an urgency to life that would be utterly lacking without it. Death enhances rather than cheapens the value of life.

7. For both Jews and Christians, there is hope that death does not have the final word in human experience. For many, death is a corridor that leads to a life free of sorrow, suffering, and separation. For others, death is powerless to cut off the faithful from the life of the community and the life of God. On either reckoning, death is incorporated as a meaningful stage in the life cycle. Both the Jewish and Christian traditions, strengthened by centuries of suffering and surviving, provide a variety of ways of affirming life in the face of death.

LONNIE D. KLIEVER (1995)
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SEE ALSO: *Anthropology and Bioethics; Authority in Religious Traditions; Autonomy; Body: Cultural and Religious Perspectives; Care; Christianity, Bioethics in; Compassionate Love; Grief and Bereavement; Harm; Holocaust; Human Dignity; Infanticide; Islam, Bioethics in; Judaism, Bioethics in; Life; Life, Quality of; Life Sustaining Treatment and Euthanasia; Literature and Healthcare; Narrative; Palliative Care and Hospice; Pediatrics, Intensive Care in; Right to Die, Policy and Law; Suicide; Triage; Value and Valuation; Virtue and Character; Warfare;* and other *Death* subentries

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V. DEATH IN THE WESTERN WORLD

This entry, by the late Talcott Parsons, is reprinted from the first edition. It is followed immediately by a Postscript, prepared by Victor Lidz for the purposes of updating the original entry.

That the death of every known human individual has been one of the central facts of life so long as there has been any human awareness of the human condition does not mean that, being so well known, it is not problematical. On the contrary, like history, it has needed to be redefined and newly analyzed, virtually with every generation. However, as has also been the case with history, with the advancement of knowledge later reinterpretations may have some advantages over earlier ones.

Some conceptualization, beyond common sense, of a human individual or “person” is necessary in order to understand the set of problems presented by death. Therefore, a few comments on this topic are in order before proceeding to a reflection on some of the more salient features of death as it has been understood in the Western world.

The Person and the Problematic of Death

The human individual has often been viewed in the Western world as a synthesized combination of a living organism and a “personality system” (an older terminology made the person a combination of “body” and “mind” or “soul”). It is in fact no more mystical to conceive of a personality analytically distinct from an organism than it is to conceive of a “culture” distinct from the human populations of organisms who are its bearers. The primary criterion of personality, as distinct from organism, is an organization in terms of symbols and their meaningful relations to each other and to persons.

Human individuals, in their organic aspect, come into being through a process of bisexual reproduction. They then go through a more or less well-defined "life course" and eventually die. That human individuals die as organisms is indisputable. If any biological proposition can be regarded as firmly established, it is that the mortality of individual organisms of a sexually reproducing species is completely normal. The death of individuals has a positive survival value for the species.

As Sigmund Freud said, organic death, while a many-faceted thing, is in one principal aspect the "return to the inorganic state." At this level the human organism is "made up" of inorganic materials but is organized in quite special ways. When that organization breaks down—and there is evidence that this is inevitable by reason of the aging process—the constituent elements are no longer part of the living organism but come to be assimilated to the inorganic environment. Still, even within such a perspective on the human individual as an organism, life goes on. The human individual does not stand alone but is part of an intergenerational chain of indefinite durability, the species. The individual organism dies, but if he or she reproduces, the line continues into future generations.

But the problematic of human death arises from the fact that the human individual is not only an organism but also a user of symbols who learns symbolic meanings, communicates with others and with himself or herself through them as media, and regulates his or her behavior, thought, and feelings in symbolic terms. The individual is an "actor" or a "personality." The human actor clearly is not born in the same sense in which an organism is. The personality or actor comes into being through a gradual and complicated process sometimes termed "socialization."

Furthermore, there is a parallel—in my judgment, something more than a mere analogy—between the continuity of the actor and that of the organism. Just as there is an intergenerational continuity on the organic side, so is there an intergenerational continuity on the personality or action side of the human individual. An individual personality is generated in symbiosis with a growing individual organism and, for all we know, dies with that organism. But the individual personality is embedded in transindividual action systems, both social and cultural. Thus the sociocultural matrix in which the individual personality is embedded is in an important sense the counterpart of the population-species matrix in which the individual organism is embedded. The individual personality dies, but the society and cultural system, of which in life he or she was a part, goes on.

But what happens when the personality dies? Is the death of a personality to be simply assimilated to the organic paradigm? It would seem that the answer is yes, for just as no personality in the human sense can be conceived as such to develop independently of a living organism, so no human personality can be conceived as such to survive the death of the same organism. Nevertheless, the personality or actor certainly influences what happens in the organism—as suicide and all sorts of psychic factors in illnesses and deaths bear witness. Thus, although most positivists and materialists would affirm that the death of the personality must be viewed strictly according to the organic paradigm, this answer to the problem of human death has not been accepted by the majority in most human societies and cultures. From such primitive peoples as the Australian aborigines to the most sophisticated of the world religions, beliefs in the existence of an individual "soul" have persisted, conceivably with a capacity both to antedate and to survive the individual organism or body. The persistence of that belief and the factors giving rise to it provide the framework for the problematic of death in the Western world.

Christian Orientations toward Death

Because the dominant religious influence in this history of the Western world has been that of Christianity, it is appropriate to outline the main Christian patterns of orientation toward death.

There is no doubt of the predominance of a duality of levels in the Christian paradigm of the human condition, the levels of the spiritual and the material, the eternal and the temporal. On the one hand, there is the material-temporal world, of which one religious symbol is the "dust" to which humankind is said to return at death. On the other hand, there is the spiritual world of "eternal life," which is the location of things divine, not human. The human person stands at the meeting of the two worlds, for he or she is, like the animals, made of "dust," but is also, unlike the animals, made in the image of God. This biblical notion of humanity, when linked to Greek philosophical thought, gave rise to the idea in Catholic Christianity that the divine image was centered in the human soul, which was conceived as in some sense an emanation from the spiritual world of eternal life. Thus arose the notion of the "immortal soul," which could survive the death of the organism, to be rejoined to a resurrected body. The hope of the resurrection, rooted in the Easter faith of the Christian community, was from the beginning a part of the Christian faith and provided another dimension behind the teaching on the immortality of the soul.

The Christian understanding of death as an event in which "life is changed, not taken away," in the words of the traditional requiem hymn, *Dies irae,* can be interpreted in terms of Marcel Mauss's paradigm of the gift and its reciprocation (Parsons, Fox, and Lidz). Seen in this way, the life of the individual is a gift from God, and like other gifts it creates expectations of reciprocation. Living "in the faith" is part of the reciprocation, but, more important to us, dying in the faith completes the cycle. The language of giving also permeates the transcendental level of symbolism in the Christian context. Thus, Mary, like any other woman, *gave* birth to Jesus, God also *gave* his only begotten Son for the redemption of humankind. Finally, Jesus, in the Crucifixion and thus the Eucharist, gave his blood for the same purpose. By the doctrine of reciprocation humankind assumes, it may be said, three principal obligations: to accept the human condition as ordained by the Divine Will, to live in the faith, and to die in the faith (with the hope of resurrection). If these conditions are fulfilled, "salvation," life eternal with God, will come about.

This basically was the paradigm of death in Catholic Christianity. Although the Reformation did collapse some elements in the Catholic paradigm of dualism between the eternal and the temporal, it did not fundamentally alter the meaning of death in societies shaped by the Christian faith. Still, the collapse of the Catholic paradigm did put great pressures on the received doctrine of salvation. The promise of a personal afterlife in heaven, especially if this were conceived to be eternal—which must be taken to mean altogether outside the framework of time—became increasingly difficult to accept. The doctrine of eternal punishment in some kind of hell has proved even more difficult to uphold.

The primary consequence of this collapsing was not, as it has often been interpreted, so much the secularization of the religious component of society as it was the sacralization of secular society, making it the forum for the religious life—notably, though by no means exclusively, through work in a "calling" (as Max Weber held).

Though John Calvin, in his doctrine of predestination, attempted to remove salvation from human control, his doctrine could not survive the cooling of the effervescence of the Reformation. Thus, all later versions of Protestantism accepted some version of the bearing of the individual's moral or attitudinal (faith) merit on salvation. Such control as there was, however, was no longer vested in an ecclesiastical organization but was left to the individual, thus immensely increasing religious and moral responsibility.

The concept of a higher level of reality, a supernatural world in which human persons survived after death, did not give way but became more and more difficult to visualize by simple extrapolation from this-worldly experience; the same problem occurred with the meaning of death as an event in which one gave life back to its Giver and in return was initiated into a new and eternal life. In addition to the changes in conceptualization set in motion by the Reformation, the rise of modern science, which by the eighteenth century had produced a philosophy of scientific materialism, posed an additional challenge to the Christian paradigm of death, manifesting itself primarily in a monism of the physical world. There was at that time little scientific analysis of the world of action, and there was accordingly a tendency to regard the physical universe as unchanging and hence eternal. Death, then, was simply the return to the inorganic state, which implied a complete negation of the conception of eternal life, since the physical, inorganic world was by definition the antithesis of life in any sense.

Contemporary Scientific Orientations

The subsequent development of science has modified, or at least brought into question, the monistic and materialistic paradigm generated by the early enthusiasm for a purely positivistic approach. For one thing, beginning in the nineteenth century and continuing into the twentieth, the sciences of organic life have matured, thanks largely to placing the conception of evolutionary change at the very center of biological thought. This resulted in the view, which has been already noted, that death is biologically normal for individual members of evolving species.

A second and more recent development has been the maturing of the sciences of action. Although these have historical roots in the humanistic tradition, they have only recently been differentiated from the humanistic trunk to become generalizing sciences, integrating within themselves the same conception of evolutionary change that has become the hallmark of the sciences of life.

The development of the action sciences has given rise, as already noted, to a viable conception of the human person as analytically distinct from the organism. At the same time these sciences, by inserting the person into an evolutionary sociocultural matrix analogous to the physico-organic species matrix within which the individual organism is embedded, have been able to create an intellectual framework within which the death of the personality can be understood to be as normal as the death of the organism.

Finally, the concept of evolutionary change has been extended from the life sciences (concerned with the organism) and the action sciences (concerned with the person-actor) to include the whole of empirical reality. And at the same time we have been made aware—principally by the ways in which Einstein's theory of relativity modified the previous assumptions of the absolute empirical "givenness" of physical nature in the Newtonian tradition—of the relative character of our human understanding of the human condition.

Thus there is now a serious questioning of absolutes, both in our search for absolutely universal laws of physical nature and in our quest for metaphysical absolutes in the philosophical wake of Christian theology.

The Kantian Impact and the Limits of Understanding

The developments in a contemporary scientific understanding of the human condition are both congruent with, and in part anticipated and influenced by, Immanuel Kant, whose work during the late eighteenth century was the decisive turning point away from both physical and metaphysical absolutism. Kant basically accepted the reality of the physical universe, as it is humanly known, but at the same time he relativized our knowledge of it to the categories of the understanding, which were not grounded in our direct experience of physical reality but in something transcending this. At the same time Kant equally relativized our conceptions of transcendental reality, whose existence he by no means denied, to something closer to the human condition. Indeed, it may be suggested that Kant substituted procedural conceptions of the absolute, whether physical or metaphysical, for substantive propositions.

While relativizing our knowledge both of the physical world, including the individual human organism, and of the metaphysical world, with its certitude about the immortality of the soul, Kant nonetheless insisted on a transcendental component in human understanding and explicitly included belief in personal immortality in the sense of eternal life.

With respect to the bearing of Kant's thought and its influence through subsequent culture on the problem of the meaning of death, I have already noted that he prepared the way, procedurally, for the development of the action sciences and their ability to account intellectually for the personality or actor experienced as one aspect of the human individual without the need to infer, of necessity, the existence of a spiritual soul existentially and not merely analytically distinct from the living organism. The action sciences, in a very real sense, attempt to provide a coherent account of human subjectivity, much as Kant attempted to do in his *Critique of Judgment,* without collapsing the difference of levels between the physical and what may be called the telic realm.

The framework provided by Kant's thought is indeed congenial to the scientific perspective on the normality of the death of a person, conceived as an actor whose coming into existence is in symbiosis with a growing individual organism and whose individual personality, while continuing into a new generation in the same sociocultural system, can be understood to die in symbiosis with the same organism. Nonetheless, if Kant was right in refusing to collapse the boundaries of the human condition into the one vis-à-vis the physical world, the meaning of human individual death can no more be exhausted by that of the involvement of the human individual in a sociocultural system of more comprehensive temporal duration than can the meaning of our sensory experience of empirical reality be exhausted by the impressions emanating from that external world, or even the theoretical ordering of those impressions.

If Kant's fundamental position is accepted, then his skepticism about absolutes must apply to both sides of the fundamental dichotomy. Modern biology certainly must be classed as knowledge of the empirical world in his sense, and the same is true of our scientific knowledge of human action. In his famous terminology, there is no demonstrable knowledge of the thing in itself in any scientific field.

In empirical terms organic death is completely normal. We have, and according to Kant we presumably can have, no knowledge of the survival of any organic entity after death, except through the processes of organic reproduction that enable the genetic heritage to survive. Kant, however, would equally deny that such survival can be excluded on empirical grounds. This has an obvious bearing on the Christian doctrine of the resurrection of the body. If that is meant in a literal biological sense (though this is by no means universally the way in which Christians understand it), then the inference is clearly that it can never be proved, but it can still be speculated about and can be a matter of faith, even though it cannot be the object of either philosophical or scientific demonstration.

The same seems to hold for the personality-action component of the human individual. Empirically, the action sciences can account for its coming-to-be and its demise without postulating its survival. But they cannot exclude the possibility of such survival. Thus the eternal life of the individual soul, although metaphysically unknowable, can, like resurrected bodies, be speculated about and believed in as a matter of faith.

Thus, included in the victims of Kant's skepticism or relativization is belief in the cognitive necessity of belief in the survival of human individuality after death as well as belief in the cognitive necessity of belief in the nonsurvival of human individuality after death. Kant's relativization of our knowledge, both empirical and metaphysical, both closed and opened doors. It did, of course, undermine the traditional specificities of received beliefs; but at the same time, and for the very same reason, it opened the door, by contrast to scientific materialism, not merely to one alternative to received Christian belief but to a multiplicity of them.

This leaves us with the position that the problem of the meaning of death in the Western tradition has, from a position of relative closure defined by the Christian syndrome, been “opened up” in its recent phase. There is above all a new freedom for individuals and sociocultural movements to try their hands at innovative definitions and conceptions. At the same time, the viability of their innovations is subject to the constraints of the human condition, both empirical and transcendental, noted by Kant.

The grounding of this door-opening process lies in Kant’s conception of freedom as the central feature of what he called “practical reason.” In essence, the human will, as he called it, can no more be bound by a set of metaphysical dogmas than a person’s active intellect can be bound by alleged inherent necessities of the empirical, relevant *Ding an sich.* This doctrine of freedom, among other things, opens the door to Western receptivity to other, notably Oriental, religious traditions. Thus, Buddhist tradition, on the whole by contrast with Christian, stresses not individuality except for this terrestrial life but, rather, the desirability of absorption, after death, into an impersonal, eternal matrix (as opposed to a personal eternal life). The recent vogue of Oriental religion in Western circles suggests that this possibility has become meaningful in the West.

The problem of the meaning of death in the West is now in what must appear to many to be a strangely unsatisfactory state. It seems to come down to the proposition that the meaning of death is that, in the human condition, it cannot have any “apodictically certain” meaning without abridgment of the essential human freedom of thought, experience, and imagination. Within limits, its meaning, as it is thought about, experienced for the case of others, and anticipated for oneself, must be autonomously interpreted. But this is not pure negativism or nihilism, because such openness is not the same as declaring death, and of course with it individual life, to be meaningless.

Conclusion

So far as Western society is concerned, I think the tolerability of this relatively open definition of the situation is associated with the activistic strain in our values, the attitude that human life is a challenging undertaking that in some respects may be treated as an adventure—by contrast with a view that treats human life as a matter of passively enduring an externally imposed fate. Even though Western religion has sometimes stressed humanity’s extreme dependency on God, and indeed the sinfulness of asserting independence, on the whole the activistic strain has been dominant. If this is the case, it seems that humans can face their deaths and those of others in the spirit that whatever this unknown future may portend, they can enter upon it with good courage.

Insofar as it is accessible to cognitive understanding at all, the problem of the meaning of death for individual human beings must be approached in the framework of the human condition as a whole. It must include both the relevant scientific understanding and understanding at philosophical levels, and must attempt to synthesize them. Finally it must, as clearly as possible, recognize and take account of the limits of both our scientific and our philosophical understanding.

We have contended that the development of modern science has so changed the picture as to require revision of many of the received features of Christian tradition, both Catholic and Protestant. This emergence of science took place in three great stages marked by the synthesis of physical science in the seventeenth century, that of biological science in the nineteenth, and that of the action sciences in the nineteenth to twentieth.

The most important generalizations seem to be the following. First, the human individual constitutes a unique symbiotic synthesis of two main components, a living organism and a living personality. Second, both components seem to be inherently limited in duration of life, and we have no knowledge that indicates their symbiosis can be in any radical sense dissociated. Third, the individualized entity is embedded in, and derives in some sense from, a transgenerational matrix that, seen in relation to individual mortality, has indefinite but not infinite durability.

From this point of view, death, or the limited temporal duration of the individual life course, must be regarded as one of the facts of life that is as inexorable as the need to eat and breathe in order to live. In this sense, death is completely normal, to the point that its denial must be regarded as pathological. Moreover, this normality includes the consideration that, from an evolutionary point of view, which we have contended is basic to all modern science, death must be regarded as having high survival value, organically at least to the species, actionwise to the future of the sociocultural system. These scientific considerations are not trivial, or conventional, or culture-bound but are fundamental.

There is a parallel set of considerations on the philosophical side. For purposes of elucidating this aspect of the problem complex, I have used Kant’s framework as presented in his three critiques. On the one hand, this orientation is critical in that it challenges the contention that absolute knowledge is demonstrable in any of the three aspects of human condition. Thus, any conception like that of the ontological essence of nature, the idea of God, or the notion of the eternal life of the human soul is categorized as *Ding an sich,* which in principle is not demonstrable by rational cognitive procedures.

At the same time, Kant insisted, and I follow him here, on the cognitive necessity of assuming a transcendental component, a set of categories in each of the three realms, that is not reducible to the status of humanly available inputs from either the empirical or the absolute telic references of the human condition. We have interpreted this to mean that human orientation must be relativized to the human condition, not treated as dogmatically fixed in the nature of things.

The consequence of this relativization that we have particularly emphasized is that it creates a new openness for orientations, which humans are free to exploit by speculation and to commit themselves in faith, but with reference to which they cannot claim what Kant called apodictic certainty.

If the account provided in the preceding sections is a correct appraisal of the situation in the Western world today, it is not surprising that there is a great deal of bafflement, anxiety, and downright confusion in contemporary attitudes and opinions in this area. Any consensus about the meaning of death in the Western world today seems far off, although the attitude reflected in this entry would seem to be the one most firmly established at philosophical levels and the level of rather abstract scientific theory.

A very brief discussion of three empirical points may help to mitigate the impression of extreme abstractness. First, though scientific evidence has established the fact of the inevitability of death with increasing clarity, this does not mean that the experience of death by human populations may not change with changing circumstances. Thus, we may distinguish between inevitable death and “adventitious” death, that is, deaths that are premature relative to the full lifespan, and in principle preventable by human action (Parsons and Lidz). Since about 1840, this latter category of deaths has decreased enormously. The proportion of persons in modern populations over sixty-five has thus increased greatly, as has the expectancy of life at birth. This clearly means that a greatly increased proportion of modern humans approximate to living out a full life course, rather than dying prematurely. Individuals living to “a ripe old age” will have experienced an inevitably larger number of deaths of persons who were important to them. These will be in decreasing number the deaths of persons younger than themselves, notably their own children, and increasingly deaths of their parents and whole ranges of persons of an older generation, such as teachers, senior occupational associates, and many public figures. Quite clearly these demographic changes will have a strong effect on the balance of experience and expectations, of the deaths of significant others, and of anticipation of one’s own death.

Second, one of the centrally important aspects of a process of change in orientation of the sort described should be the appearance of signs of the differentiation of attitudes and conceptions with regard to the meaning of the life cycle. There has already been such a process of differentiation, apparently not yet completed, with respect to both ends of the life cycle (Parsons, Fox, and Lidz). With respect to the beginning, of course, this centers on the controversy over the legitimacy of abortion and the beginning of life. And concomitant with this controversy has been an attempt at redefinition of death. So far the most important movement has been to draw a line within the organic sector between what has been called brain death, where irreversible changes have taken place, destroying the functioning of the central nervous system, and what has been called metabolic death, where, above all, the functions of heartbeat and respiration have ceased. The problem has been highlighted by the capacity of artificial measures to keep a person alive for long periods after the irreversible cessation of brain function. The main point of interest here is the connection of brain function with the personality level of individuality. An organism that continues to live at only the metabolic level may be said to be dead as an actor or person.

Third, and finally, a few remarks about the significance for our problem of Freud’s most mature theoretical statement need to be made. It was printed in the monograph published in English under the title *The Problem of Anxiety.* In this, his last major theoretical work, Freud rather drastically revised his previous views about the nature of anxiety. He focused on the expectation of the loss of an “object.” For Freud the relevant meaning of the term “object” was a human individual standing in an emotionally significant relation to the person of reference. To the growing child, of course, the parents became “lost objects” in the nature of the process of growing up, in that their significance for the growing child was inevitably “lost” at later ages. The ultimate loss of a concrete human person as object—of cathexis, Freud said—is the death of that person. To have “grown away” from one’s parents is one thing, but to experience their actual deaths is another. Freud’s account of the impact on him of the death of his father is a particularly relevant case in point.

Equally clearly, an individual’s own death, in anticipation, can be subsumed under the category of object loss, particularly in view of Freud’s theory of narcissism, by which he meant the individual’s cathexis of his or her own self as a love object. Anxiety, however, is not the actual experience of object loss, nor is it, according to Freud, the fear of it. It is an anticipatory orientation in which the actor’s own emotional security is particularly involved. It is a field of rather free play of fantasy as to what might be the consequences of an anticipated or merely possible event.

Given the hypothesis that, in our scientifically oriented civilization, there is widespread acceptance of death—meant as the antithesis of its denial—there is no reason why this should lead to a cessation or even substantial diminution of anxiety about death, both that of others and one's own. Indeed, in certain circumstances the levels of anxiety may be expected to increase rather than the reverse. The frequent assertions that our society is characterized by pervasive denial of death may often be interpreted as calling attention to pervasive anxieties about death, which is not the same thing. There can be no doubt that in most cases death is, in experience and in anticipation, a traumatic event. Fantasies, in such circumstances, are often characterized by strains of unrealism, but the prevalence of such phenomena does not constitute a distortion of the basic cultural framework within which we moderns orient ourselves to the meaning of death.

Indeed, the preceding illustrations serve to enhance the importance of clarification, at the theoretical and philosophical levels, to which the bulk of this entry has been devoted. This is essential if an intelligible approach is to be made to the understanding of such problems as shifts in attitudes toward various age groups in modern society, particularly the older groups, and the relatively sudden eruption of dissatisfaction with the traditional modes of conceptualizing the beginning and the termination of a human life, and with allegations about the pervasive denial of death, which is often interpreted as a kind of failure of "intestinal fortitude." However important the recent movements for increasing expression of emotional interests and the like, ours remains a culture to which its cognitive framework is of paramount significance.

TALCOTT PARSONS (1995)

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POSTSCRIPT

Talcott Parsons's entry "Death in the Western World" addresses the changing and conflicting orientations toward death in contemporary culture. Parsons sought to connect these orientations to broad cultural frameworks that have shaped Western civilization over hundreds of years. His effort was an extension of his previous writings on American orientations toward death and on more general patterns of Western civilization (Parsons and Lidz; Parsons; Parsons, Fox, and Lidz).

In the 1960s and 1970s, a number of authors argued that Americans "deny" death in a defensive manner (Mitford; Becker). They cited particular funeral and mourning customs as evidence, especially the preparing of remains to appear lifelike and peaceful for ritual viewing and the expectation that formal mourning need divert the family of a deceased person from other social obligations for only a brief time. Parsons, however, perceived that if there were a generalized denial of death, it would conflict with the pragmatic realism rooted in American culture since Puritan times.

Instrumental Activism

Parsons drew on German sociologist Max Weber's (1864–1920) characterization of the Puritan religious ethic as an "inner-worldly asceticism" that sought to engage the harsher realities of life to transform them into elements of the "kingdom of God on earth" (Weber, 1930). While agreeing with Weber's analysis, he preferred the term *instrumental activism* to characterize the basic values and worldview of American society. This term underscored that American civilization had secularized the Puritan emphasis on mastery over the given conditions of life and made it the ethical basis for a wide range of worldly social institutions. Thus, secular variants of the mastery ethic now guide the formation of institutions in science and technology, formally rational law and bureaucracy, the market system and entrepreneurship, and motives of personal self-discipline and improvement (Parsons). Highlighting consistency with this basic cultural theme, Parsons found not "denial" of death but mastery over its disrupting effects on personal and social life.

While death is inevitable, its social impact is meliorable. Parsons explored two respects in which this is true (Parsons and Lidz; Parsons, Fox, and Lidz). First, medical and public health technologies have reduced premature death and now typically enable members of society to use "God-given" talents to advance their vocations in good health over long lives. The demographic changes of the late nineteenth and twentieth centuries, and related efficiencies in the use of human talents, thus flowed from an effort to master death. Second, when individuals die, the resulting experiences of social loss can be controlled. Measures ranging from life insurance to retirement planning in business to estate planning in personal affairs to psychotherapy for grief and loss reduce harms ensuing from death (Zelizer, 1983). Similarly, American mourning customs emphasize austerely supporting the bereaved in overcoming grief and guilt, so they are able to return to their routine social obligations without long delay.

Parsons recognized that, despite sharing the values of "instrumental activism," Americans disagree over many matters related to death. Abortion, capital punishment, licensing of firearms, euthanasia, medical care for the terminally ill, and organ transplantation, for example, were matters of public controversy when Parsons wrote and remain so today. "Death in the Western World" attempts to explain why this particular domain of contemporary culture has been chronically ridden with controversy. Parsons sought an answer in the rationalism of the Enlightenment, focusing on its synthesis in the philosophy of Immanuel Kant (1724–1804).

Secular Rationalism

Kant epitomized the Enlightenment's elevation of Reason as a force of human betterment and a method of transforming culture (Cassirer). Ever since the Enlightenment, Reason has provided a principle for critique of traditional culture, social institutions, and customary practices. Over time, critique of the traditional has gradually given way to the articulation of new principles of legitimacy. Since the eighteenth century, the appeal to Reason has given rise to a secular moral culture as the primary ground of legitimation for the major institutional frameworks of modern society—for the institutional complexes that Weber characterized as having "rational-legal" legitimation (Weber, 1968; Lidz, 1979a, 1979b). Parsons epitomized this long and complex process of cultural change by focusing on Kant's writings and their long-term impact on the creation of new intellectual disciplines and moral-political ideologies.

In Parsons's view, Kant's critique of Newtonian physics became a model for assessing the intellectual legitimacy of new disciplines. It led to the opening of the domain of methodically developed and evaluated knowledge to new forms. Thus, from Kant's time to ours, there has been continuous growth in specialized scientific and scholarly disciplines. Kant's critiques of the human faculties of judgment and practical reason proved no less important, as they legitimated the voice of moral Reason and, as Parsons emphasized, undercut all claims to ultimate moral certainty. Ever since, Western civilization has been engulfed in ever-renewed moral and ideological controversies on almost every topic of social import. As Parsons expected, orientations toward death, given their irreducible significance to humanity, have been caught up in a range of the controversies.

Varying Worldviews

Across the Western world, one observes considerable variation in the adoption of principles of instrumental activism and secular rationalism. Parsons concentrated on a predominant American pattern, but one that many parts of Western civilization, including important groups in American society, have adopted only with qualifications. Catholic societies have generally shown more attachment to tradition, to historical continuity, and to sustaining community structures, and thus less activism in transforming traditional institutions and less individualism. Lutheran societies have given more emphasis to the inner moral cultivation of the individual and less to mastery of the outer world. Fundamentalist Protestantism has been less accepting of secular rationalism and has tended to maintain the emphasis of the Reformation on immediate mastery of morally problematic situations. Anglo-American versions of Enlightenment rationalism have been profoundly individualistic, while French rationalism has been more collectivistic, and German rationalism more focused on transcendental frames of judgment (Mead). In an article published in 2002, Hans Joas criticized Parsons's treatment of the gift of life as a basis of religious ethics in Western Christianity for having overlooked the continuing variation in worldviews. One may add that the variation in outlooks contributes importantly to contemporary controversies, sustaining the disagreements and adding to the anxiety over difficulties in resolving them.

Parsons's emphasis on Enlightenment rationalism as a foundation of modern intellectual disciplines and public moral discourse helps one to understand the nature of contemporary bioethics. Research on the history of bioethics shows that the field has emerged in the mold of an academic specialty that, although interdisciplinary, is dominated by philosophers (Messikomer, Fox, and Swazey). Philosophers trained in the field of ethics have successfully asserted the centrality of their expertise for resolving bioethical issues. Although the relevance of issues of life, death, illness, suffering, incapacity, and worry would seem to create a large role for theologians and religious philosophers in the field of bioethics, they have in fact been marginalized by the prestige of academic philosophy (Messikomer, Fox, and Swazey). Moreover, given the extent to which key innovations in biomedicine have been concentrated in the United States and that the issues created by such innovations have been suffused with the problematics of American moral discourse, the individualism and positivism of Anglo-American philosophy has predominated in bioethics internationally. This process has been further supported by the strategic role that American governmental regulations have assumed in the international structures of biomedical research, in particular regarding clinical trials for new medications and medical devices.

Recent Evolution of Cultural Conflicts

Although Parsons expected death-related matters to remain controversial, he could not foresee the recent evolution of cultural conflicts. The intense social criticism of funeral and mourning customs has subsided, though practices have changed little. How "life" and "living being" should be defined before birth and at the approach of death remain effervescent issues. Public debates over abortion not only have persisted but have grown in intensity, bitterness, and political importance. Issues of end-of-life care and the use of extreme measures to maintain life continue to figure in public discussion, often in connection with legal cases. Procedures once viewed as extreme, such as kidney, liver, and heart transplants, have become routine at many medical centers, but discussion continues around such issues as who should be treated—for example, whether persons with alcohol dependence should receive new livers or smokers new lungs, or whether HIV-positive patients qualify for organ transplants. The public attends with ever greater interest to advances in medicine, with new findings and procedures featured routinely on television and in newspapers. Coverage of heroic lifesaving procedures in particular resonates deeply in American moral culture, dramatizing shared beliefs in the unique value of each life. Themes of self-improvement pervade reports on the health food, antismoking, physical exercise, environmental, and even animal-rights movements.

Despite impressive institutions to master death, contemporary civilization remains acutely insecure over life (Fox and Swazey). The mass media's increasing attention to medicine, and especially to life-threatening conditions, has left the public less secure about health and more readily made anxious over environmental threats and even endemic conditions. The intensity of public fears over apparent "hot spots" of breast cancer in particular communities, over risks of anthrax infection following "terroristic" mailings of a small number of letters containing anthrax spores in the autumn of 2001, and over small risks of West Nile virus in the summer of 2002 are instances. In the context of anxiety over health, matters of personal habit and lifestyle, including diet, exercise, work schedules, and even sexual practices, are adjusted by many whenever new knowledge suggests possible effects on well-being or longevity. Parsons would have viewed such changes in personal habits as efforts to extend mastery over the conditions of life, including death.

In attending patients with highly cultivated medical insecurities, physicians have a limited fund of trust to draw upon, a situation that promotes the practice of "defensive medicine." When the lives of patients are genuinely at risk, pressures build to use the most advanced technologies and extreme measures to show that everything possible is being attempted. This is sometimes the case even when the chances of success are small and when the quality of the lives that may be extended will be quite limited. These tendencies persist while the public also worries over the rising aggregate costs of medical care and health insurance.

In the context of post-Enlightenment secular beliefs about human rights, Western societies have generally established a right of citizens to receive medical care. Different institutions have been established to secure this right, including government single-payer, publicly subsidized private, employer-paid, and combined health insurance systems. The United States stands out among Western nations for not having established universal healthcare or health insurance, although Medicare for the elderly and Medicaid for the poor cover many economically vulnerable citizens.

From the mid-1990s, U.S. national policy has engaged the issue of further democratization of access to medical care. The public has become aware that large sectors of the population lack medical insurance and, hence, access to healthcare independent of personal ability to pay for it. Although the desirability of providing better care to citizens of modest means and the poor is generally accepted, proposals about how to manage the costs while protecting the freedom of doctor–patient relationships are controversial. Proposals that appear to restrict the freedom of relationships between patients and practitioners, whether rights of patients to select their practitioners or the rights of practitioners to treat patients as they believe correct, are widely opposed. Moreover, new plans for cost containment have not directly confronted public sentiments favoring use of "heroic measures" and experimental procedures regardless of cost—sentiments that become especially forceful when physicians and family members face a patient's impending death. Eventual policy remains uncertain, but a system of national health insurance would extend "instrumental activism" in medicine by offering more secure protection from illness, suffering, and death for less affluent citizens.

Shaken Optimism about Modern Medicine

Parsons believed, along with many scientists in the 1960s and 1970s, that modern medicine verged on conquering all major infectious diseases, at least for societies with effective systems of sanitation and public health. The appearance in the 1980s of the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) has shaken such optimism. It has now become clear that humankind faces a major pandemic that, despite modern science and technology, will take scores of millions of lives globally (WHO). Twenty years of research has failed to produce an effective vaccine. New antiretroviral medications are extending the life and health of many patients with HIV/AIDS, but not all patients are helped, and how long the others will benefit remains unclear (IAPAC). In the meantime, many patients do not receive the new treatments because they have not been diagnosed, are not willing to face the consequences of an HIV/AIDS diagnosis, lack access to care or means of paying for treatment, or do not trust medical institutions to help them (Klitzman).

The costs of the new medications for HIV/AIDS are prohibitively high for most of the populations in non-Western nations, and an active controversy in the early 2000s concerned ways of making them available at reduced cost in African, Asian, and Latin American societies. Until there is an effective vaccine or a less expensive cure, prevention programs must play a prominent role in overall HIV/AIDS policy. In the United States, prevention programming still faces challenges in communicating effectively with sectors of the population most seriously at risk, in part because of political constraints on frank communication with adolescents and young adults regarding sexual practices and condom use and on laws affecting availability of sterile injection paraphernalia.

Western nations have had the public health resources to stabilize rates of HIV infections at low or moderate levels. According to World Health Organization (WHO) data from 2002, Thailand and Uganda had managed to reduce formerly high rates of infection. In a number of nations in sub-Saharan Africa, however, the continued rapid spread of HIV, as of 2003 affecting more than 28.5 million people, in some countries over 30 percent of adults in their reproductive years, is radically changing demographic structures and life-cycle patterns. In Parsons's terms, a major feature of the epidemic is that it afflicts mainly youths, young adults, and people in early middle age. People who become diseased and die are losing their most productive years. Their deaths represent unfulfilled lives, with future achievements, relationships, and experiences all lost. The economic impact on whole regions and nations is becoming immense, as is the burden of caring for children whose parents have died. WHO reported in 2002 that India, China, Burma, Indonesia, and perhaps Russia also had rapidly growing epidemics and were at risk of experiencing similar effects on regional if not national bases.

In Western societies, where HIV infection is concentrated in homosexual men, injection drug users, and, increasingly, women sex partners of injection drug users and of men who have sex with men (CDC), its transmission has often involved stigmatized behavior. HIV, with the ugly image of a wasting, disfiguring, and dementing disease, has added vastly to the burdens of prior stigmas. Many people with HIV disease have experienced intense feelings of guilt, shame, and self-blame as an added dimension of their suffering (Klitzman). Moreover, many have experienced great loss. In social circles where HIV has become common, many individuals still in early adulthood have lost many friends and associates, an otherwise rare experience in modern societies, given the generally thorough control of death before old age. Many are burdened by the "survivors' guilt" typical of people who live through disasters that have claimed the lives of many others (Erikson). They often find that any attempt at a spirited resumption of everyday activities is complicated by feelings that their futures are hopeless or meaningless without the individuals who have been lost. People not infected but aware of being at risk of infection may feel that they will inevitably become diseased—even that they are already "dead," although still walking around. Efforts to change personal conduct in order to avoid exposure to HIV may be complicated by beliefs that it is impossible to stay well or that it would be better to accompany friends in heroic suffering and death (Weitz). In some Western communities and in African and Asian nations, lassitude engendered by the HIV epidemic, through social loss, fear of death, and guilt, is causing immense social dislocation and will likely cause more in the future.

Conclusion

Parsons's entry highlighted the distinctive pattern of Western institutions relating to death. In comparative perspective, Parsons argued, the modern West has uniquely endeavored to "master" death. Such mastery has involved a range of institutions, including scientific medicine and public health services designed to protect life; insurance, retirement, and estate planning to manage the practical consequences of deaths; and mourning customs that emphasize recovery of survivors' abilities to perform ordinary social roles soon after the death of family members, friends, and associates. Some elements of these institutions remain closely tied to the "instrumental activism" of Western cultural values, while other elements, such as the techniques of scientific medicine or the actuarial tables and formulas of the insurance industry, have transcultural validity now that they have been developed. A matter for future investigation concerns the ways in which these universal elements will be institutionalized in sociocultural settings where they may be disconnected from Western value orientations. Scientific medicine is now practiced almost the world over, but in some non-Western societies it is generally reserved for patients from elite status groups, combined with traditional healing in ways that create different doctor and patient roles, or may be linked to personal relationships of political patronage (Kleinman; Scheper-Hughes). In these settings, the bioethical cultures that emerge in the future may prove to be very different from Western frameworks of the past several decades, not least because they will rest on different value orientations toward life and death. Comparative study of bioethical cultures may become a powerful way of building on, correcting, and refining the analysis developed by Parsons in his writings on Western orientations toward death.

VICTOR LIDZ (1995)
REVISED BY AUTHOR

SEE ALSO: *Autonomy; Body: Cultural and Religious Perspectives; Christianity, Bioethics in; Grief and Bereavement; Harm; Holocaust; Human Dignity; Infanticide; Islam, Bioethics in; Judaism, Bioethics in; Life; Life, Quality of; Life Sustaining Treatment and Euthanasia; Literature and Healthcare; Narrative; Palliative Care and Hospice; Pastoral Care and Healthcare Chaplaincy; Pediatrics, Intensive Care in; Right to Die, Policy and Law; Suicide; Triage;*

Value and Valuation; Virtue and Character; Warfare; and other *Death* subentries

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VI. PROFESSIONAL EDUCATION

Palliative care represents a new health professional discipline in the United States focused on the care of seriously ill and dying patients, although not necessarily just for patients at the end of their lives. There is widespread agreement that all facets of the end-of-life experience have been neglected in health professional education, including, but not limited to, pain and symptom management, communication skills, ethics, personal awareness and hospice care. Educational initiatives have emerged, especially within medicine and nursing, to address these deficiencies. This discussion will focus primarily on physician education within palliative care, although the discussion is directly applicable to other health professions.

Requirements for End-of-Life Physician Education in the United States

Until recently, few medical schools offered comprehensive training in end-of-life care. The training that existed was largely elective, in lecture format, and with limited patient contact. Although some U.S. medical schools developed dedicated palliative care courses or comprehensive curricula, this was the exception until very recently. The Liaison Committee on Medical Education (LCME), the accrediting authority for United States medical schools, mandated in 2000 that all medical schools provide instruction in end of life care, which may improve the situation.

Graduate physician education requirements for end-of-life training are also highly variable. Since 1997 the oversight educational committees for Geriatrics, Family Medicine, Internal Medicine, Neurology, General Surgery and Hematology/Oncology have added requirements for end-of-life training. In the realm of testing, the National Board of Medical Examiners started work in 1999 to review, re-write and expand end-of-life content on test questions administered to all medical students and interns.

Although there is no national requirement for physicians already in practice to attend continuing education courses in end-of-life care, the American Medical Association (AMA) has encouraged all its member physicians to participate in *Education for Physicians on End-of-life Care* (EPEC), a comprehensive training program. In addition, starting in 2000, the state of California began requiring that all applicants for a medical license successfully complete a medical curriculum that provides instruction in pain management and end-of-life care. As with the LCME requirement for medical schools, the exact criteria to determine what constitutes end of life instruction have not been defined.

Curriculum Guides for End-of-Life Physician Education

Several groups have worked to define the components of a comprehensive end-of-life and palliative care curriculum. Curriculum guidelines have been developed for Canadian medical schools and separate guidelines exist for medical student training in Great Britain and Ireland. Palliative care teaching objectives for U.S. physicians were first published in 1994. In 1997, a national consensus conference on U.S. undergraduate and graduate education was held, outlining curriculum features and opportunities for education across different educational venues (e.g. ambulatory care, inpatient care). Although each venue presented somewhat different aspects of end-of-life care education, there is broad similarity on the major educational domains (see Table 1). Finally, a consensus document was developed by participants from eleven U.S. medical schools working on an end of life curriculum project. This document outlines goals and objectives for medical student education along with a discussion of potential student assessment measures and curriculum implementation strategies.

The American Academy of Hospice and Palliative Medicine (AAHPM) developed a curriculum designed for medical educators and practicing physicians. This curriculum includes twenty-two modules, each containing a listing of learning objectives and core content for key domains in symptom control, communication, hospice care, and ethics. The AAHPM curriculum was originally designed for physicians working as hospice medical directors, but can easily be adapted for other levels of physician education. The EPEC project, designed for physicians in practice, contains a comprehensive palliative care curriculum including pain and symptom control, communication skills, ethics, and legal aspects of care. The most recent curriculum for medical oncologists and oncology trainees, developed in 2001 by the American Society of Clinical Oncology, includes twenty-nine modules covering symptom control, communication skills, and related aspects of palliative care. Curriculum standards for palliative care fellowships have been proposed by the American Board of Hospice and Palliative Medicine and the AAHPM. An extensive listing of peer-reviewed educational tools, curriculum guides, reference articles, and palliative care links are available at the End-of-Life Education Resource Center.

TABLE 1

Domains and Locations for Palliative Care Physician Education

Educational Domains

- Pain assessment and treatment
- Non-pain symptom assessment and treatment
- Ethical principles and legal aspects of end-of-life care
- Communication skills; Personal reflection
- Psychosocial Aspects of Death and Dying:
    Death as a life-cycle event
    Psychological aspects of care for patient/family
    Cultural and spiritual aspects of end-of-life care
    Suffering/Hope
    Patient/family counseling skills
- Working as part of an interdisciplinary team

Care Locations

- Hospital
- Hospice/ Palliative Care Consultation Service or Inpatient Unit
- Outpatient Clinic
- Home
- Residential Hospice
- Long-term care facility

SOURCE: Author.

In parallel to physician education, the nursing profession has been working to develop curriculum guidelines and materials for nursing education. Palliative care education content has been reviewed in nursing textbooks and two educational products have been developed for nursing education, *ELNEC* (end-of-life nursing education consortium) and *TNEEL* (the toolkit for nursing excellence at end-of-life transitions) (Ferrell et al.). In addition, a national consortium of nursing groups has come together to plan for institutional changes in nursing education and practice surrounding palliative care (Palliative Care).

Planning an End of Life Education Program

The first step in the design of any educational intervention is to conduct a needs assessment, to understand the gap between what is being taught and evaluated and the ideal. A variety of multidimensional palliative care needs assessments have been reported for different populations of learners.

Once the needs assessment has defined important domains for focused education, specific learning objectives can be developed. Objectives communicate to the learner what is expected of the educational encounter and form the basis for evaluating the impact of training. Learning objectives are broadly defined as those directed at attitudes, knowledge or skills. Given the pervasive and often negative attitudes, which shape caring for the dying, it is advisable to include a mixture of attitude, knowledge, and skill objectives in all training experiences. Thus, it is also desirable to include a mixture of teaching methods in each educational exercise. Addressing attitudes tends to be the most challenging feature of end-of-life education. It is a truism of medical education that attitudes can not be taught. Rather, a shift in attitudes requires the learner to feel safe and respected enough to give up one attitude (e.g. I am afraid to use opioids for fear of causing addiction) for another (e.g. opioids rarely lead to addiction, they are safe and improve quality of life). Providing information to address knowledge objectives can be done via lectures, self-study guides, journal articles, videotapes and audiotapes. Teaching directed at skill objectives requires the learner to practice and demonstrate a defined skill such as patient counseling, calculating equianalgesic doses or pronouncing death.

As with teaching methods, different assessment methods work best when appropriately matched to the learning objective. Attitudes are best assessed through personal interactions, directed questioning and surveys. Knowledge can be assessed via oral or written examinations and skills through direct observation, feedback from patients, or written problem solving (e.g. calculating opioid equianalgesic doses).

Awareness of adult learning principles is essential when developing an end-of-life educational encounter. These include keeping the experience *learner-centered,* with relevant information keyed to the learners *need to know,* and understanding that adult learners make choices about their participation (e.g. they leave the room if the information is not relevant to their needs).

Educational Issues for Specific End-of-Life Domains

PAIN EDUCATION. Pain must be controlled before physicians can assist patients with the myriad of physical, psychological, and spiritual problems at end-of-life. Yet, physicians frequently fail to apply accepted standards of care for acute or chronic pain management. Moreover, it is clear that despite a multitude of clinical guidelines, position papers, workshops, lectures, grand rounds, journal articles, and book chapters written about pain management, clinical practice is still far from ideal.

The primary reason that conventional education formats fail to translate into a change in clinical practice is that physicians harbor a host of attitudes about pain and pain management that inhibit the appropriate application of knowledge and skills. These attitudes fall into two broad categories. First are physician attitudes about pain that reflect societal views about the meaning of pain and pain treatment. Second are the fears and myths about opioid analgesics. These include fears of addiction, respiratory depression, and regulatory scrutiny, along with the secondary consequences of these fears—malpractice claims, professional sanctions, loss of practice privileges, and personal guilt about potential culpability for causing death.

In addition to attitudes, deficits in pain knowledge and skills are widespread. These include how to conduct a pain assessment, clinical pharmacology of analgesic medications, use of non-drug treatments, and skills in patient education and counseling. Educational techniques and results from various pain education programs have been reported; key findings from these include the following principles: pain education must include attention to attitudinal issues along with knowledge and skills; pain education must be longitudinal across all years of medical training; and pain education must be coupled to other elements of institutional change, such as quality monitoring, team building with non-physicians, development of routine assessment, and documentation and analgesic standards development.

ETHICS, LAW AND COMMUNICATION SKILLS EDUCATION. There is considerable content overlap between ethics and communication skills. For example, to effectively care for patients, trainees need to understand both the ethical and legal framework of advance directives *and* the communication skills necessary to discuss these with patients. Similarly, trainees need to understand the ethical and legal background to make decisions about treatment withdrawal *and* to acquire the skills to discuss these issues with patients and families.

There is a rich literature on educational methods and outcomes in ethics and communication skills education. Although ethics is generally considered a preclinical course in medical school, it is advisable that training in ethics be incorporated throughout medical school, residency, and fellowship training. As the level of professional responsibility increases with each year of training, such responsibility imposes demands on the trainee to make increasingly complex and ethically challenging decisions. Such decisions often strain the trainee's personal understanding of professionalism and altruism and thus merit dedicated time for self-reflection and mentoring. Although both ethics and communication skill training require attention to attitudes and knowledge deficits, communication skill training requires special and dedicated attention to the acquisition and demonstration of specific skills. Notably, trainees must be able to demonstrate their ability to give bad news and discuss treatment goals, treatment withdrawal, and issues surrounding hospice and palliative care empathetically and professionally.

CLINICAL TRAINING EXPERIENCES. Hospital-based palliative care teams are a valuable venue for clinical education in end-of-life care. Trainees, both physicians and nurses, can learn how to work within a multidisciplinary group and experience a collaborative process with the educational focus enlarged to include the physical, psychological, social, and spiritual dimensions of care. Since 1992 many medical schools and residency programs have established successful clinical experiences in hospice and palliative care at acute care hospitals, hospice residence facilities, and at home.

PERSONAL AWARENESS TRAINING. Very few health professionals have had formal training in how to deal with the emotions that arise when caring for patients with progressive fatal illness. Undergraduate course, residency, and fellowship directors have a number of options that can help trainees gain the needed personal awareness including support groups, family of origin group discussions, meaningful experiences discussion, personal awareness groups, literature in medicine discussion groups, and psychosocial morbidity and mortality conferences.

Future Directions

One important avenue to improve of end of life care is through health professional education. Much progress has been made since the early 1990s in defining curriculum content and establishing standards for education for medical students and primary care residencies. The most recent development in end of life education is the focus on training existing academic faculty and fellows in palliative care. Faculty development is needed if the established goals and standards in undergraduate and graduate palliative care education are to be met. Several courses have been developed in the United States, with the explicit goal of training academic faculty to become role models for end-of-life education. Fellowship training in palliative care is needed to prepare medical trainees for community or academic careers focused on care of the seriously ill and dying. In 2003 there are approximately twenty-five fellowship programs in the United States.

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SEE ALSO: *Care; Compassionate Love; Emotions; Life Sustaining Treatment and Euthanasia; Literature and Healthcare; Medical Education; Nursing, Theories and Philosophy of; Nursing Ethics; Palliative Care and Hospice; Suicide;* and other *Death* subentries

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DEATH, DEFINITION AND DETERMINATION OF

• • •

I. Criteria for Death
II. Legal Issues in Pronouncing Death
III. Philosophical and Theological Perspectives

I. CRITERIA FOR DEATH

Before the middle of the twentieth century there was no major dispute about the criteria for death. In the nineteenth century several isolated cases of premature burial from around the world raised some alarm, and safeguards (e.g., coffins equipped with alarms) were established to minimize the possibility of that practice. However, concern about the accuracy of diagnosing death largely abated by the turn of the twentieth century.

Beginning with the advent of more effective artificial respirators in the 1940s, major technological breakthroughs in modern medicine raised serious questions about the traditional ways of diagnosing death. Before the widespread use of respirators, defibrillators, intensive-care units, and cardiopulmonary resuscitation failures of cardiac, respiratory, and neurological functions were closely linked. When one system failed, the other two inevitably failed as well. However, respirators and other advanced life-support systems can sustain cardiac, respiratory, and other autonomic functions for prolonged periods even after neurological functions have ceased.

Terminology

With the advent of those new technologies neurological specialists became aware of certain new neurological syndromes, to which an array of confusing and inconsistent terms were applied.

Several landmark medical events stand out in the early days of the new neurologic syndromes. In 1959 the French first described the syndrome of brain death (*coma dépassé*) (Mollaret and Coulon), in 1968 a special committee of the Harvard Medical School formulated specific neurological criteria to diagnose brain death (“Definition of Irreversible Coma”), and in 1972 Bryan Jennett of Scotland and Fred Plum of the United States first used the term *persistent vegetative state,* or PVS (Jennett and Plum).

A variety of terms have been used to describe the medical syndrome of brain death: *cerebral death, coma dépassé,* and *irreversible coma.* Terms used as imprecise equivalents for the persistent vegetative state have included *apallic state, neocortical death, irreversible coma,* and *permanent unconsciousness* It also became necessary to distinguish the new neurological syndromes from common and well-accepted neurological conditions such as coma and dementia. Many newer terms, for example, *persistent vegetative state,* were used solely to describe the clinical condition. Others, such as the *apallic state* and *neocortical death,* were used in an attempt to correlate the loss of neurological functions with the underlying pathological changes in the brain.

As of 1994 there were two different legal/philosophical positions about what it means to be dead in terms of brain functions. Proponents of the whole-brain-oriented position consider a person dead if there is an irreversible loss of all the functions of the entire brain (brain death). Under the other position, which is not law in any jurisdiction in 2003, a person will be pronounced dead when there is an irreversible loss of higher brain functions (permanent unconsciousness).

Dilemmas surrounding these new syndromes, such as when it is appropriate to stop treatment and when death has occurred, have raised fundamental questions about the meaning of medical concepts such as consciousness, awareness, self-awareness, voluntary interactions with the environment, purposeful movement, pain, and psychological and physical suffering.

Neurological specialists are achieving a much greater understanding of these syndromes and their similarities and differences and are reaching a degree of consensus on terminology. However, they have not reached universal agreement on several major issues related primarily to the persistent vegetative state. A historical example illustrates how difficult it can be to reach consensus on terminology. The Harvard Committee ("Definition of Irreversible Coma,") equated irreversible coma with brain death, as did many neurological specialists in the 1970s. Others, equally knowledgeable and experienced, equated irreversible coma with the persistent vegetative state. Still others used the term in a much broader fashion to denote any form of permanent unconsciousness. Because this term has gathered so many different and contradictory meanings, the only reasonable alternative for neurological specialists was to drop it entirely.

Traditional Criteria

With all the controversy surrounding neurological criteria for death, the traditional criteria related to heartbeat and breathing have remained largely unchanged and undisputed except in the University of Pittsburgh Medical Center's program in which organs are taken from certain patients as soon as possible after expected cardiopulmonary death (Lynn). No major legal or ethical concerns have been raised about the traditional criteria for death. Medical organizations around the world have not felt it necessary to establish specific clinical criteria for the diagnosis of death that are based on the irreversible loss of cardiac and respiratory functions. The medical consultants to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research recommended that the clinical examination disclose at least the absence of consciousness, heartbeat, and respiratory effort and that irreversibility be established by persistent loss of these functions for an appropriate period of observation and trial of therapy ("Guidelines for the Determination of Death"). However, these consultants recommended no specific length of time for this period of observation.

Brain Death

The neurological syndrome of brain death has been accepted by the medical profession as a distinct clinical entity that experienced clinicians can diagnose with an extremely high degree of certainty and usually can distinguish easily from other neurological syndromes. Brain death is defined as the irreversible cessation of all the functions of the entire brain, including the brainstem. If the brain can be viewed simplistically as consisting of two parts—the cerebral hemispheres (higher centers) and the brainstem (lower centers)—brain death is defined as the destruction of the entire brain, both the cerebral hemispheres and the brainstem. In contrast, in the permanent vegetative state the cerebral hemispheres are damaged extensively and permanently but the brainstem is relatively intact (Cranford, 1988).

An understanding of the pathological sequence of events that leads to brain death is essential if one is to appreciate fully why brain death is a unique syndrome and why it can be differentiated readily from other neurological syndromes with a high degree of certainty. Although a variety of insults can cause the brain to die, head trauma, cardiorespiratory failure, and intracerebral hemorrhage are the most common causes. Regardless of the underlying cause, the pathological sequence is essentially the same in almost all cases. The acute massive insult to the brain causes brain swelling (cerebral edema). Because the brain is contained in an enclosed cavity, brain swelling gives rise to a massive increase in intracranial pressure. In brain death the increased intracranial pressure becomes so great that it exceeds the systolic blood pressure, thus causing a loss of blood flow to both the cerebral hemispheres and the brainstem. Whatever the primary cause of brain death, this end result of loss of blood flow results in the destruction of the entire brain. This sequence of events usually occurs within a matter of hours after the primary event, and so brain death can be diagnosed within a short period of time with an extraordinarily high degree of certainty.

The loss of both cerebral hemisphere and brainstem functions is usually clearly evident to an experienced clinician from the clinical bedside examination. The patient is in a coma, the deepest possible coma, a sleeplike state associated with a loss of all brainstem functions, such as pupillary reaction to light; gag, swallowing, and cough reflexes; eye movements in response to passive head turning (the oculocephalic response) and in response to cold caloric stimulation (oculovestibular response); and spontaneous respiratory efforts.

However, whereas respirations are completely dependent on the functioning of the brainstem, cardiac function can continue independent of brain destruction because the heart has an independent mechanism for spontaneously firing (semiautonomous functioning). With modern life-support systems continued cardiac and blood pressure functions can persist for hours, days, or even longer. Extremely rare cases of continued cardiovascular functions for over a year in the presence of the loss of all brain functions have been reported. The first cases of prolonged somatic survival in brain death usually occurred in the context of brain-dead pregnant women who were maintained on life-support systems for several months so that a viable fetus could be delivered (Wijdicks). However, the most extraordinary case of prolonged somatic survival of a patient with well-documented brain death involved a young adult age twenty-two who for eighteen years has been without any brain functions (Shewmon, 1998; Cranford, 1998; Shewmon, 2000).

In the 1970s and 1980s numerous medical organizations in the United States and around the world developed specific medical criteria for the diagnosis of brain death (Bernat). In the United States major criteria were published by Harvard University, the University of Minnesota, the National Institutes of Health, Cornell University, and the President's Commission. Major international criteria emerged from Sweden, Japan, the United Kingdom, and Canada. All those standards essentially agreed on three clinical findings: coma, apnea (loss of spontaneous respirations), and absence of brainstem reflexes.

The critical issue distinguishing these international criteria was not the clinical findings but how best to establish irreversibility. The United Kingdom, deemphasizing the use of laboratory studies such as electroencephalography, focused on the basic diagnosis as clinical and asserted that the best way to establish irreversibility was to preclude any reversible processes before making a final determination of brain death (Conference of Royal Colleges). Reversible processes that could mimic brain death include a variety of sedative medications and hypothermia (low body temperature, below 32.2° Centigrade). The British also recommended a period of observation of at least twelve hours. In contrast, the Swedish criteria focused less on the period of observation and more on the need for definitive laboratory studies to document a loss of blood flow to the brain, such as intracranial angiography.

In the United States the earlier standards emphasized the use of electroencephalography to establish electrocerebral silence (a loss of all electrical activity of the brain); more recent standards focused on establishing a loss of intracranial circulation by means of radioisotope angiography. The 1981 report of the medical consultants to the President's Commission, which became the definitive medical standard in the United States, recommended a period of observation of at least six hours combined with a confirmatory study, such as tests measuring intracranial circulation ("Guidelines for the Determination of Death"). If no confirmatory laboratory studies were performed, an observation period of at least twelve hours was suggested, assuming that all reversible causes of loss of brain functions had been excluded. In cases of damage to the brain caused by the lack of blood or oxygen (hypoxic-ischemic encephalopathy) the consultants recommended an observation period of at least twenty-four hours if confirmatory studies were not performed.

The diagnosis of brain death in newborns, infants, and children is often more difficult than is the diagnosis in adults. A major reason for this difficulty is that the usual pathological sequence of events in adults that leads to increased intracranial pressure and loss of all blood flow to the brain does not apply to newborns and infants because the cranial cavity in those patients has not yet closed completely. Thus, the mechanism for brain death in newborns and infants may be different from what it is in older children and adults.

To address this question a task force for the determination of brain death in children representing several neurological and pediatric specialty organizations in the United States developed specific diagnostic criteria for the younger age groups (Task Force for the Determination of Brain Death in Children). That task force stated that it would be extremely difficult to establish brain death in newborns less than seven days old. It recommended that in infants seven days to two months of age there should be two separate clinical examinations and two electroencephalograms separated by at least forty-eight hours; for infants two months to one year of age, two clinical examinations and two electroencephalograms separated by at least twenty-four hours; and for children over one year of age, criteria similar to those established for adults.

Beginning in the early 1990s, the University of Pittsburgh and a few other large transplants centers developed protocols for removing organs from patients whose hearts had stopped beating but who were not brain-dead (non-heartbeating organ donors, or NHBOD) (DeVita et al.). In cases of brain death and organ donation the patient is first pronounced dead after the medical diagnosis of brain death has been established, including a period of time to establish irreversibility. The patient then is transferred to the operating room for organ removal while life-support systems are continued. After the transplantable organs are removed, life-support systems are discontinued, but the cessation of heartbeat at this time has no clinical or legal significance. In cases of non-heartbeating organ donors, patients who are terminally ill or have sustained severe irreversible brain damage and are ventilator-dependent are transferred to the operating room, where the respirator is removed, with the resultant loss of heartbeat, usually within minutes. After two minutes of pulselessness, apnea, and unresponsiveness the patient is pronounced dead on the basis of cardiorespiratory criteria. Organ removal then occurs as expeditiously as possible before the organs incur ischemic damage from lack of perfusion. The entire process is carried out in the most humane and caring way possible, including full disclosure to the appropriate surrogate decision makers and the obtaining of their consent (Ethics Committee, American College of Critical Care Medicine). The success and limitations of this controversial procedure have been reported by some of the pioneering transplant centers.

Permanent Unconsciousness

The syndromes of permanent unconsciousness include two major types. The first is a permanent coma: an eyes-closed, sleeplike form of unarousable unconsciousness. The second is the permanent vegetative state: an eyes-open, wakeful form of unconsciousness (U.S. President's Commission for the Study of Ethical Problems). This entry takes no position on the ethical and legal issues involved in choosing between the whole-brain and higher-brain formulations of death but describes the neurological syndromes of permanent unconsciousness that would be considered the medical basis for the higher-brain formulation of death.

A permanent coma is an uncommon neurological syndrome because most patients with damage sufficient to cause brainstem impairment resulting in permanent coma die soon either naturally or because a decision is made to discontinue treatment as a result of the poor prognosis. Cases of prolonged (more than a few weeks) permanent coma do occur but are extremely uncommon.

The vegetative state has three major classes, depending on the temporal profile of the onset and the progression of the brain damage. The first form is the acute vegetative state. This occurs when the onset of brain damage is sudden and severe, such as with head trauma (traumatic vegetative state) or loss of blood flow to the brain caused by sudden cardiorespiratory insufficiencies (hypoxic-ischemic vegetative state). The second form is the degenerative, or metabolic, vegetative state, in which the brain damage begins gradually and progresses slowly over a period of months to years. In adults the most common form of the degenerative vegetative state is the final stage of Alzheimer's disease, whereas in children it is the final stage of a variety of degenerative and metabolic diseases of childhood. The third form is the congenital vegetative state secondary to a variety of severe congenital malformations of the brain that are present at birth, such as anencephaly.

The vegetative state is considered persistent when it is present longer than one month in the acute form and permanent when the condition becomes irreversible. The exact prevalence is unknown, but it is estimated that in the United States there are approximately 10,000 to 25,000 adults and 4,000 to 10,000 children in a vegetative state (Multi-Society Task Force on PVS). When it becomes permanent, this syndrome is the major neurological condition that is the prototype for the higher-brain formulation of death.

Vegetative State

The vegetative state is characterized by the loss of all higher brain functions, with relative sparing of brainstem functions. Because brainstem functions are still present, the arousal mechanisms contained in the brainstem are relatively intact and the patient therefore is not in a coma. The patient has sleep/wake cycles but at no time manifests any signs of consciousness, awareness, voluntary interaction with the environment, or purposeful movements. Thus, the patient can be awake but is always unaware: a mindless wakefulness.

Unlike brain death, in which the pathology and sequence of changes are relatively uniform regardless of the primary cause of the brain damage, the pathological changes in the vegetative state vary substantially with the cause of the unconsciousness. Although there are a variety of causes, the two most common causes of the acute form are head trauma and hypoxic-ischemic encephalopathy. In head trauma the major damage is due to shearing injuries to the subcortical white matter (the fiber tracts that connect the cell bodies of the cerebral cortex with the rest of the brain) of the cerebral hemispheres. With hypoxic-ischemic encephalopathy the primary damage is to the neurons in the cerebral cortex. These different patterns of brain damage are important for several reasons, among them the fact that the chances for recovery of neurological functions and the time necessary to establish irreversibility vary with the underlying cause.

For patients, both adults and children, in a hypoxic-ischemic vegetative state that lasts longer than three months the prognosis for recovery is uniformly dismal. The vast majority who recover and do well after a hypoxic-ischemic insult to the brain are those who have regained consciousness in the first three months. Among adults in a traumatic vegetative state the majority who do well usually will have regained consciousness within six months of the injury. The prognosis for the recovery of children in a traumatic vegetative state is slightly more favorable than that for adults (Council on Scientific Affairs and Council on Ethical and Judicial Affairs). However, in both children and adults a period of observation of at least twelve months may be appropriate before permanency is established (Multi-Society Task Force on PVS).

Although specific medical criteria for brain death have been established by numerous organizations around the world, no comparable criteria have been established for the diagnosis of the vegetative state. It is unlikely that any criteria as specific as those for brain death will be formulated in the near future because the diagnosis of the vegetative state is not nearly as precise and definitive. The determination of irreversibility in brain death usually takes hours and does not vary according to etiology, whereas it may take months to establish irreversibility in patients who are in the permanent vegetative state, and the time necessary to establish this irreversibility varies substantially with cause and age (Institute of Medical Ethics Working Party on the Ethics of Prolonging Life and Assisting Death).

Because all vegetative state patients are unconscious, they are unable to experience suffering of any kind, psychological or physical. These patients normally manifest periods of eyes opening and closing with accompanying sleep/wake cycles. They also may demonstrate a variety of facial expressions and eye movements that originate from the lower centers of the brain and do not indicate consciousness. They may appear at times to smile and grimace, but observation over prolonged periods reveals no evidence either of voluntary interaction with the environment or of self-awareness (Executive Board, American Academy of Neurology). Neuroimaging studies such as computerized axial tomography (CAT) and magnetic resonance imaging (MRI) may be helpful in establishing the severity and irreversibility of the brain damage. After several months in a vegetative state the brain begins to show progressive shrinkage (atrophy), primarily of the cerebral hemispheres. The loss of consciousness and the inability to experience suffering, which are established on the basis of clinical observations, have been supported by measuring the metabolism of glucose and oxygen at the level of the cerebral cortex by means of positron emission tomography (PET) scanning. These studies have shown a 50 to 60 percent decrease in cerebral cortical metabolism, a level consistent with unconsciousness and deep anesthesia (Levy et al.).

Long-term survival of vegetative state patients at all ages is reduced drastically compared with the normal population. Life expectancy in adult patients is generally about two to five years; the vast majority do not live longer than ten years. In elderly patients the prognosis for survival is even worse; many do not survive for more than a few months. Infants and children may survive longer than adults do, but probably not significantly longer. Some studies have shown the average life expectancy to be four years for infants up to two months of age and about seven years for children seven to eighteen years old (Ashwal et al.).

Cases of prolonged survival—longer than twenty years—have been reported but are rare. One patient, Elaine Esposito from Tarpon Springs, Florida, lived for 37 years and 111 days without regaining consciousness, from age six to age forty-three. Another patient, Rita Greene, a surgical nurse from Wheeling, West Virginia, who survived for 47 years, 100 days from age twenty-four to age seventy-one, is probably the longest survivor in a permanent vegetative state (“Woman Lived Since ’51 in Comalike State”). Considering the total estimated number of patients in a persistent vegetative state and the small number of well-documented cases of survival beyond fifteen years, the probability of an individual patient having such a prolonged survival is extremely low, probably less than 1 in 15,000 to 1 in 75,000 (Multi-Society Task Force on PVS).

It is more difficult to make the diagnosis of the vegetative state in newborns and infants. Generally, the diagnosis cannot be made below the age of three months except in the case of the condition of anencephaly. Anencephaly is the congenital malformation form of the permanent vegetative state (Stumpf et al.). This extensive and severe congenital malformation of the brain can be diagnosed with an extraordinarily high degree of certainty. At birth it is readily apparent by visual observation alone that the child has only rudimentary cerebral hemispheres and no skull except in the rear of the head. These children have variable degrees of brainstem functions but usually not enough functions to sustain life for any length of time. The vast majority are dead within two months, and most die within a few weeks.

The Locked-In Syndrome and the Minimally Conscious State

Brain death and the vegetative state should be contrasted with two other contemporary neurological syndromes of severe brain damage: the locked-in syndrome and the minimally conscious state. The locked-in syndrome, first named by Fred Plum and Jerome Posner in 1966, is characterized by a severe paralysis of the entire body, including the extremities and facial muscles, but with normal or nearly normal consciousness. This often results from a severe stroke to the brainstem that spares the cerebral hemispheres (in one sense the reverse of the vegetative state), and these patients often appear to be unconscious; however, a careful history and neurological examination uncover a high degree of cognitive functioning. Some physicians use this term to denote patients with any degree (e.g., mild to moderate) of disparity between paralysis and cognitive functioning. However, this term, when used properly, means a profound disparity between paralysis (severe) and consciousness (normal or nearly normal).

Unlike brain death, the vegetative state, and the locked-in syndrome, all of which are fairly well characterized and accepted by the medical profession, the term *minimally conscious state* is of relatively recent vintage, and its acceptance and potential usefulness as a distinct neurological syndrome are far from settled. Formally called the minimally responsive state, the minimally conscious state is defined as a condition of “severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated," in other words, a condition of severely to profoundly impaired cognitive functioning (Giacino et al.). This diagnosis is made by the demonstration on a reproducible or sustained basis of one or more of the following behaviors: following simple commands, gestural or verbal yes/no responses, intelligible verbalization, and purposeful behavior such as appropriate smiling or crying, pursuit eye movement, and sustained visual fixation. Even though the difference between being vegetative and thus completely unconscious and being "minimally" conscious may seem to be a subtle distinction and even though some have argued that being minimally conscious is a medical fate worse than being vegetative, the courts in recent landmark decisions and many healthcare professionals have treated these syndromes radically differently from a medical, ethical, and legal standpoint (Rich).

Conclusion

The criteria for diagnosing cardiorespiratory death and brain death have been well established and accepted by the medical profession. Even though there are differences in how physicians may apply these criteria in individual cases and even though the standards may vary somewhat in different countries, there are no major disputes about the medical diagnosis itself.

The syndromes of permanent unconsciousness, in contrast, are much more variable than are those of brain death. The three major forms of the vegetative state—acute, degenerative, and congenital—are substantially different in terms of causes, type of brain damage, and length of time necessary to establish irreversibility. Thus, the criteria for a higher-brain formulation of death are far more complex and uncertain than are those for the whole-brain formulation of death.

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SEE ALSO: *Body: Cultural and Religious Perspectives; Conscience, Rights of; Consensus, Role and Authority of; Judaism, Bioethics in; Life; Metaphor and Analogy; Organ and Tissue Procurement; Public Policy and Bioethics;* and other *Death, Definition and Determination of* subentries

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II. LEGAL ISSUES IN PRONOUNCING DEATH

The following is a revision and update of the first-edition entry "Death, Definition and Determination of, II. Legal Aspects of Pronouncing Death" by the same author.

The capability of biomedicine to sustain vital human functions artificially has created problems not only for medical practitioners but for the public and its legal institutions as well. In some cases, determining that people have died is no longer the relatively simple matter of ascertaining that their heart and lungs have stopped functioning. Mechanical respirators, electronic pacemakers, and drugs that stimulate functioning and affect blood pressure can create the appearance of circulation and respiration in what is otherwise a corpse. The general public first recognized the need to update public policy concerning when and how death could be declared when Christiaan Barnard performed the first human-to-human heart transplant in Cape Town, South Africa, on December 3, 1967. Beyond amazement at the technical feat, many people were astonished that a heart taken from a woman who had been declared dead conferred life on a man whose own heart had been removed.

Cardiac transplantation provides the most dramatic illustration of the need for clear standards to classify the outcomes of intensive medical support (e.g., respirators). But only a handful of the moribund, unconscious patients maintained through intensive support long after they formerly would have ceased living become organ donors (U.S. President's Commission). Sometimes such medical intervention is ended because it has succeeded in enabling the patient to recover; more often, it is terminated because the patient's bodily systems have collapsed so totally that circulation and respiration cannot be maintained. But for a significant number of patients, artificial support can be continued indefinitely with no prospect that consciousness will ever return. For some of this latter group of patients—especially those who can eventually be weaned from the respirator and require only nutrition and hydration by tube—the question arises whether to withdraw treatment and allow death to occur. But for others who have suffered great brain damage, the need arises to recognize that death has occurred and that further attempts to keep the patient alive are therefore no longer appropriate even before the point (usually within several weeks) when physiological processes in the body can usually no longer be maintained.

Beginning in the 1960s, the response of the medical profession was to develop new criteria, such as those articulated in 1968 by an ad hoc committee at Harvard Medical School. Experts in the United States tend to rely on certain clinical signs of the absence of any activity in the entire brain (Ad Hoc Committee); British neurologists focus on the loss of functioning in the brain stem, while doctors in certain European countries search for conditions for brain function, such as intracranial blood circulation (Van Till). Despite differences in technique, the medical profession arrived at a consensus that the total and irreversible absence of brain function is equivalent to the traditional cardiorespiratory indicators of death (Medical Consultants).

The story of the law's response to these new medical criteria can be divided into three parts. The first, largely played out in the late 1960s and the 1970s, concerned an issue of process—how ought society respond to the divergence between new medical precepts and practices, on the one hand, and the common understanding of the lay public of rules embodied in custom and law, on the other? (Anglo-American common law, for example, had traditionally defined death as the total cessation of all vital functions.) The second phase, from the 1970s through the 1980s, centered on the specific changes being made in the law. In the third period, which is still continuing, commentators (principally philosophers and a few physicians) have raised questions about the appropriateness of the legal standards that have been adopted and called for various changes in those standards.

Phase One: Framing Definitions

A MEDICAL MATTER? A number of routes were advanced for arriving at what was often termed a new definition of death that would encompass the neurological understanding of the phenomenon of death that emerged in the 1960s and has since been further refined. (The common shorthand phrase "definition of death" is misleading since "definition" suggests an explanation of a fact whereas the task at hand is specifying the significance of particular facts for the process of determining whether, and when, a person has died.) Early commentators proposed that the task should be left to physicians, because the subject is technical and because the law might set the definition prematurely, leading to conflicts with developments that will inevitably occur in medical techniques (Kennedy). Yet the belief that defining death is wholly a medical matter misapprehends the undertaking. At issue is not a biological understanding of the inherent nature of cells or organ systems but a social formulation of humanhood. It is largely through its declaration of the points at which life begins and ends that a society determines who is a full human being, with the resulting rights and responsibilities.

Since physicians have no special competence on the philosophical issue of the nature of human beings and no special authority to arrogate the choice among definitions to themselves, their role is properly one of elucidating the significance of various vital signs. By the 1970s, it became apparent that a new definition should be forthcoming, not simply to accommodate biomedical practitioners' wishes but as a result of perceived social need and of evidence that tests for brain function were as reliable as the traditional heart-lung tests.

JUDICIAL DECISIONS? If not physicians, then who should frame the definition? One answer was, "Let the courts decide." In the United States and other common-law countries, law is to be found not only on the statute books but in the rules enunciated by judges as they resolve disputes in individual civil and criminal cases. Facing a factual situation that does not fit comfortably within the existing legal rules, a court may choose to formulate a new rule in order to more accurately reflect current scientific understanding and social viewpoints.

Nonetheless, problems of principle and practicality emerged in placing primary reliance on the courts for a redefinition of death. Like the medical profession, the judiciary may be too narrowly based for the task. While the judiciary is an organ of the state with recognized authority in public matters, it still has no means for actively involving the public in its decision-making processes. Judge-made law has been most successful in factual settings embedded in well-defined social and economic practices, with the guidance of past decisions and commentary. Courts operate within a limited compass—the facts and contentions of a particular case—and with limited expertise; they have neither the staff nor the authority to investigate or to conduct hearings in order to explore such issues as public opinion or the scientific merits of competing "definitions." Consequently, a judge's decision may be merely a rubber-stamping of the opinions expressed by the medical experts who appeared in court. Moreover, testimony in an adversary proceeding is usually restricted to the "two sides" of a particular issue and may not fairly represent the spectrum of opinion held by authorities in the field.

Furthermore, in the U.S. cases in which parties first argued for a redefinition, the courts were unwilling to disturb the existing legal definition. Such deference to precedent is understandable, because people need to be able to rely on predictable legal rules in managing their affairs. As late as 1968, a California appellate tribunal, in a case involving an inheritorship issue, declined to redefine death in terms of brain functioning despite the admittedly anachronistic nature of an exclusively heart-lung definition (Cate and Capron).

The unfortunate consequences for physicians and patients of the unsettled state of the common-law definition of death in the 1970s is illustrated by several cases. In the first, *Tucker v. Lower,* which came to trial in Virginia in 1972, the brother of a man whose heart was taken in an early transplant operation sued the physicians, alleging that the operation was begun before the donor had died. The evidence showed that the donor's pulse, blood pressure, respiration, and other vital signs were normal but that he had been declared dead when the physicians decided these signs resulted solely from medical efforts and not from his own functioning, since his brain functions had ceased. At the start of the trial, the judge indicated that he would adhere to the traditional definition of death, but when charging the jury, he permitted them to find that death had occurred when the brain ceased functioning irreversibly. Although a verdict was returned for the defendants, the law was not clarified since the court did not explain its action.

The other two cases arose in California in 1974, when two transplant operations were performed using hearts removed from the victims of alleged crimes. The defendant in each case, charged with homicide, attempted to interpose the action of the surgeons in removing the victim's still-beating heart as a complete defense to the charge. One trial judge accepted this argument as being compelled by the existing definition of death, but his ruling was reversed on appeal, and both defendants were eventually convicted. This graphic illustration of legal confusion and uncertainty led California to join several other jurisdictions in the United States, Canada, and Australia that, beginning in 1970, followed a third route to redefining death, the adoption of a statutory definition.

STATUTORY STANDARDS? The legislative process allows a wider range of information to enter into the framing of standards for determining death, as well as offering an avenue for participation of the public. That is important because basic and perhaps controversial choices among alternative definitions must be made. Because they provide prospective guidance, statutory standards have the additional advantage of dispelling public and professional doubt, thereby reducing both the fear and the likelihood of cases against physicians for malpractice or homicide.

Not all countries have adopted legislation. In Great Britain, for example, the standards for determining death reside not in a statute but in medically promulgated codes of practice, which have been indirectly accepted in several judicial decisions (Kennedy and Grubb). Yet in the United States and among most commentators internationally, the first period in policymaking on a new definition of death produced wide agreement that an official response was necessary in light of the changes wrought by medical science, and that this response ought to be statutory.

Phase Two: The Contours of a Statute

By 1979 four model statutes had been proposed in the United States; in addition to those from the American Bar Association (ABA), the American Medical Association (AMA), and the National Conference of Commissioners of Uniform State Laws (NCCUSL), the most widely adopted was the Capron-Kass proposal, which grew out of the work of a research group at the Hastings Center (U.S. President's Commission, 1981). Ironically, the major barrier to legislation became the very multiplicity of proposals; though they were consistent in their aims, their sponsors tended to lobby for their own bills, which in turn produced apprehension among legislators over the possible importance of the bills' verbal differences. Accordingly, the President's Commission worked with the three major sponsors—the ABA, the AMA, and the NCCUSL—to draft a single model bill that could be proposed for adoption in all jurisdictions. The resulting statute—the Uniform Determination of Death Act (UDDA)—was proposed in 1981 and is law in more than half of U.S. jurisdictions, while virtually all the rest have some other, essentially similar statute. In four states the law derives from a decision by the highest court recognizing cessation of all functions of the brain as one means of determining death (Cate and Capron).

The UDDA provides that an individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards. This statute is guided by several principles. First, the phenomenon of interest to physicians, legislators, and the public alike is a human being's death, not the "death" of his or her cells, tissues, or organs. Indeed, one problem with the term "brain death" is that it wrongly suggests that an organ can die; organisms die, but organs cease functioning. Second, a statute on death will resolve the problem of whether to continue artificial support in only some of the cases of comatose patients. Additional guidance has been developed by courts and legislatures as well as by professional bodies concerning the cessation of treatment in patients who are alive by brain or heart-lung criteria, but for whom further treatment is considered (by the patients or by others) to be pointless or degrading. This question of "when to allow to die?" is distinct from "when to declare dead?"

Third, the merits of a legislative definition are judged by whether its purposes are properly defined and how well the legislation meets those purposes. In addition to its cultural and religious importance, a definition of death is needed to resolve a number of legal issues (besides deciding whether to terminate medical care or transplant organs) such as homicide, damages for the wrongful death of a person, property and wealth transmission, insurance, taxes, and marital status. While some commentators have argued that a single definition is inappropriate because different policy objectives might exist in different contexts, it has been generally agreed that a single definition of death is capable of being applied in a wide variety of contexts, as indeed was the traditional heart-lung definition. Having a single definition to be used for many purposes does not preclude relying on other events besides death as a trigger for some decisions. Most jurisdictions make provision, for example, for the distribution of property and the termination of marriage after a person has been absent without explanation for a period of years, even though a person "presumed dead" under such a law could not be treated as a corpse were he or she actually still alive (Capron).

Fourth, although dying is a process (since not all parts of the body cease functioning equally and synchronously), a line can and must be drawn between those who are alive and those who are dead (Kass). The ability of modern biomedicine to extend the functioning of various organ systems may have made knowing which side of the line a patient is on more problematic, but it has not erased the line. The line drawn by the UDDA is an arbitrary one in the sense that it results from human choice among a number of possibilities, but not in the sense of having no acceptable, articulated rationale.

Fifth, legislated standards must be uniform for all persons. It is, to say the least, unseemly for a person's wealth or potential social utility as an organ donor to affect the way in which the moment of his or her death is determined. One jurisdiction, in an attempt to accommodate religious and cultural diversity, has departed from the general objective of uniformity in the standards for determining death. In 1991, New Jersey adopted a statute that allows people whose religious beliefs would be violated by the use of whole-brain criteria to have their deaths declared solely on the traditional cardiorespiratory basis (New Jersey Commission).

Sixth, the UDDA was framed on the premise that it is often beneficial for the law to move incrementally, particularly when matters of basic cultural and ethical values are implicated. Thus, the statute provides a modern restatement of the traditional understanding of death that ties together the accepted cardiopulmonary standard with a new brain-based standard that measures the same phenomenon.

Finally, in making law in a highly technological area, care is needed that the definition be at once sufficiently precise to determine behavior in the manner desired by the public and yet not so specific that it is tied to the details of contemporary technology. The UDDA achieves this flexible precision by confining itself to the general standards by which death is to be determined. It leaves to the developing judgment of biomedical practitioners the establishment and application of appropriate criteria and specific tests for determining that the standards have been met. To provide a contemporary statement of "accepted medical standards," the U.S. President's Commission assembled a group of leading neurologists, neurosurgeons, pediatricians, anesthesiologists, and other authorities on determination of death (Medical Consultants). Their guidelines, which provide the basis for the clinical methodology used in most American institutions, have since been supplemented by special guidance regarding children (Task Force).

Phase Three: The Continuing Points of Debate

As a practical matter, the law nearly everywhere (most recently including Japan) (Akabayashi) recognizes that death may be diagnosed based upon the determination that the brain as a whole has ceased functioning. In the United States, this consensus is embodied in the UDDA, which has therefore become the focus of criticism from certain people—principally some philosophers, but also physicians and lawyers—who are not comfortable with this consensus. Their objections can be summarized in three challenges to the UDDA.

WHOLE-BRAIN VERSUS HIGHER-BRAIN DEATH. The strongest position against the UDDA is mounted by those who would substitute for its "whole brain" standard a "higher brain" standard. Many philosophers have argued that certain features of consciousness (or at least the potential for consciousness) are essential to being a person as distinct from merely a human being (Veatch; Zaner). The absence of consciousness and cognition—as occurs, for example, in patients in the permanent vegetative state (PVS)—thus results in the loss of personhood. A related argument rests on the ontological proposition that the meaning of being a person—that is, a particular individual—is to have a personal identity, which depends on continuity of personal history as well as on self-awareness. The permanent loss of consciousness destroys such identity and hence means the death of that person, even if the body persists.

Consideration of the implications of these theories for determination of death takes several forms. On a conceptual level, the specific characteristics deemed by philosophers to be essential for personhood have varied widely from John Locke's focus on self-awareness to Immanuel Kant's requirement of a capacity for rational moral agency (Lizza). Thus, while certain definitions would exclude only those who lack any capacity for self-knowledge, such as PVS (persistent vegetative state) patients, other conceptions would encompass senile or severely retarded patients who cannot synthesize experience or act on moral principles.

On a practical level, trying to base a definition of death on cessation of higher-brain functions creates at least two problems. The first is the absence of agreed-upon clinical tests for cessation of these functions. Although certain clinical conditions such as PVS that involve the loss of neocortical functioning when brainstem functions persist can be determined sufficiently reliably for prognostic purposes (such as when deciding that further treatment is no longer in the best interests of a dying patient), the greater complexity and uncertainty that remain prevent testing with the same degree of accuracy as with the whole-brain standards. The practical problems increase enormously if the higher-brain definition is grounded on loss of personhood or personal identity, because loss of such a characteristic is not associated with particular neurologic structures.

More fundamentally, patients who are found to have lost (or never to have had) personhood because they lack higher-brain functions, or because they no longer have the same personal identity, will still be breathing spontaneously if they do not also meet whole-brain standards such as those of the UDDA. While such entities may no longer be "persons," they are still living bodies as "living" is generally understood and commonly used. "Death can be applied directly only to biological organisms and not to persons" (Culver and Gert, p. 183). To regard a human being who lacks only cerebral functions as dead would lead either to burying spontaneously respiring bodies or to having first to take affirmative steps, such as those used in active euthanasia, to end breathing, circulation, and the like. Neither of these would comport with the practices or beliefs of most people despite widespread agreement that such bodies, especially those that have permanently lost consciousness, lack distinctive human characteristics and need not be sustained through further medical interventions. Perhaps for this reason, in proposing a statute that would base death on cessation of cerebral functions, Robert Veatch condones allowing persons, while still competent, or their next of kin to opt out of having their death determined on the higher-brain standard. No state has adopted a "conscience clause" of this type, and the New Jersey statute mentioned above does not endorse the higher-brain standard (Olick).

The major legal evaluation of the higher-brain standard has arisen in the context of infant organ transplantation because of several highly publicized attempts in the 1980s to transplant organs from anencephalic infants (babies born without a neocortex and with the tops of their skulls open, exposing the underlying tissue). In 1987–1988, Loma Linda Medical Center in California mounted a protocol (a formal plan for conducting research) to obtain more organs, particularly hearts, from this source. The protocol took two forms. At first, the anencephalic infants were placed on respirators shortly after birth; but such infants did not lose functions and die within the two-week period the physicians had set, based on historical experience that virtually all anencephalics expire within two weeks of birth. In the second phase of the protocol, the physicians delayed the use of life support until the infants had begun experiencing apnea (cessation of breathing). Yet by the time death could be diagnosed neurologically in these infants, the damage to other organs besides the brain was so great as to render the organs useless. No organs were transplanted under the Loma Linda protocol.

Proposals to modify either the determination of death or the organ-transplant statutes to permit the use of organs from anencephalic infants before they meet the general criteria for death have not been approved by any legislature, nor was the Florida Supreme Court persuaded to change the law in the only appellate case regarding anencephalic organ donation. In that case, the parents of a child prenatally diagnosed with anencephaly requested that she be regarded as dead from the moment of birth so that her organs could be donated without waiting for breathing and heartbeat to cease. The Florida statute limits brain-based determinations of death to patients on artificial support. Turning to the common law, the court held that it established the cardiopulmonary standard, and the court then declined to create a judicial standard of death for anencephalics in the absence of a "public necessity" for doing so or any medical consensus that such a step would be good public policy (T.A.C.P.).

Although the Loma Linda protocol for using anencephalic infants as organ sources attempted to comply with the general consensus on death determination, it also proved that the "slippery slope" is not merely a hypothetical possibility. While the program was ongoing and receiving a great deal of media attention, the neonatologist who ran the pediatric intensive-care unit where potential donors were cared for reported receiving offers from well-meaning physicians of infants with hydrocephalus, intraventricular hemorrhage, and severe congenital anomalies. These physicians found it difficult to accept Loma Linda's rejection of such infants, whom the referring physicians saw as comparable on relevant grounds to the anencephalic infants who had been accepted. Beyond the risk of error in diagnosing anencephaly, it is hard to draw a line at this one condition, since the salient criteria—absence of higher-brain function and limited life expectancy—apply to other persons as well. The criterion that really moves many people—namely, the gross physical deformity of anencephalic infants' skulls—is without moral significance. Thus, a decision to accept anencephaly as a basis for declaring death would imply acceptance of some perhaps undefined higher-brain standard for diagnosing any and all patients.

CHANGING CLINICAL CRITERIA. Some medical commentators have suggested that society should rethink brain death because studies of bodies determined to be dead on neurological grounds have shown results that fail to accord with the standard of "irreversible loss of all functions of the entire brain" (Truog and Fackler). Specifically, some of these patients still have hypothalamic-endocrine function, cerebral electrical activity, or responsiveness to the environment.

Although the technical aspects of these various findings differ, similar reasoning can be applied to assessing their meaning for the concept of brain death. For each, one must ask first, are such findings observed among patients diagnosed through cardiopulmonary as well as neurological means of diagnosing death? Second, are such findings inconsistent with the irreversible loss of integrative functioning of the organism? Finally, do such findings relate to functions that when lost do not return and are not replaceable?

If some patients diagnosed dead on heart-lung grounds also have hypothalamic-endocrine function, cerebral electrical activity, or environmental responses, then the presence of these findings in neurologically diagnosed patients would not be cause for concern that the clinical criteria for the latter groups are inaccurate, and no redefinition would be needed.

Plainly, in many dead bodies some activity (as opposed to full functions) remains temporarily within parts of the brain. The question then becomes whether the secretion of a particular hormone (such as arginine vasopressin, which stimulates the contraction of capillaries and arterioles) is so physiologically integrative that it must be irreversibly absent for death to be declared. Depending upon the answer, it might be appropriate to add to the tests performed in diagnosing death measurements of arginine vasopressin or other tests and procedures that have meaning and significance consistent with existing criteria.

Such a modest updating of the clinical criteria is all that is required by Truog and Fackler's data and is preferable to the alternative they favor, modifying the conceptual standards to permanent loss of the capacity for consciousness while leaving the existing criteria for the time being. Not only does this change fail to respond to their data that testing can evoke electrical activity in the brain stem, despite the absence of such activity in the neocortex (called electrocerebral silence); it also has all the problems of lack of general acceptability that attach to any standard that would result in declaring patients with spontaneous breathing and heartbeat dead because they are comatose (i.e., deeply unconscious).

THE MEANING OF IRREVERSIBILITY. The final challenge to the UDDA is less an attempt to refute its theory than it is a contradiction of the standards established by the statute and accompanying medical guidelines. Under a protocol developed at the University of Pittsburgh in 1992, patients who are dependent on life-support technology for continued vital functions and who desire to be organ donors are wheeled into the operating room and the life support disconnected, leading to cardiac arrest. After two minutes of asystole (lack of heartbeat), death is declared based upon the "irreversible cessation of circulatory and respiratory functions," at which point blood flow is artificially restored to the organs which are to be removed for transplantation (Youngner et al., 1993). Yet the failure to attempt to restore circulatory and respiratory functions in these patients shows that death had not occurred according to the existing criteria. The requirement of "irreversible cessation" must mean more than simply the physician "chose not to reverse." If no attempt is made to restore circulation and respiration before organs are removed it is not appropriate to make a diagnosis of death—merely a prognosis that death will occur if available means of resuscitation continue not to be used.

The reason for alternative standards for determining death is not because there are two kinds of death. On the contrary, there is one phenomenon that can be viewed through two windows, and the requirement of irreversibility ensures that what is seen is virtually the same thing through both. To replace "irreversible cessation of circulatory and respiratory functions" with "choose not to reverse" contradicts the underlying premise, because in the absence of the irreversibility there is no reason to suppose that brain functions have also permanently ceased.

A different, and more potent, challenge to the irreversibility requirement is posed by the prospect inherent in current research on human stem cells that some time in the future it may be possible to restore brain functions whose loss is at present beyond repair. Should such treatments become a clinical reality, the present standards for determining death will need to be reconsidered because the occurrence of death will in all cases turn on the decision whether or not to attempt repair.

Conclusion

The movement toward a modern legal formulation of the bases for pronouncing death has not been completed, and it is not clear that a complete consensus is possible (Younger, Arnold, and Shapiro, 1999). In some societies, that task may be left to the medical profession, since the problems faced in medical practice provide the impetus for change. Tradition as well as sound policy suggests, however, that the ground rules for decisions about individual patients should be established by public authorities. Whether the new legal definition of death emerges from the resolution of court cases or from the legislative process, it will be greatly influenced by opinion from the medical community. Recognition that the standards for determining death are matters of social and not merely professional concern only serves to underline the education of the public on this subject as an important ethical obligation of the profession.

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SEE ALSO: *Body: Cultural and Religious Perspectives; Consensus, Role and Authority of; Judaism, Bioethics in; Law and Bioethics; Law and Morality; Life; Metaphor and Analogy; Organ and Tissue Procurement; Public Policy and Bioethics;* and other *Death, Definition and Determination of* subentries

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III. PHILOSOPHICAL AND THEOLOGICAL PERSPECTIVES

The bioethics debate concerning the definition and criteria of human death emerged during the rise of organ transplantation in the 1960s, prompted by the advent of functional mechanical replacements for the heart, lungs, and brain stem, and by the ability to diagnose the pervasive brain destruction that is termed *brain death.* Previously, there had been no need to explore the conceptual or definitional basis of the established practice of declaring death or to consider additional criteria for determining death, since the irreversible cessation of either heart or lung function quickly led to the permanent loss of any other functioning considered a sign of life. New technologies and advances in resuscitation changed all this by permitting the dissociated functioning of the heart, lungs, and brain. In particular, society experienced the phenomenon of a mechanically sustained patient whose whole brain was said to be in a state of irreversible coma. And there were an increasing number of *vegetative* patients sustained by feeding tubes, whose bodies had been resuscitated to the status of spontaneously functioning organisms, but whose higher brains had permanently lost the capacity for consciousness. Such phenomena as these pressed a decision as to whether the irreversible loss of whole or higher-brain functioning should be considered the death of the individual, despite the continuation of respiration and heartbeat. With mounting pressure to increase the number of viable organs for transplant within the unquestioned constraint of the Dead Donor Rule which requires that the organ donor be dead before organ removal, the debate concerning whole-brain death arose.

The Beginnings of the Debate

The debate opened in 1968, when the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death (Harvard Committee) recommended an *updating* of the criteria for determining that a patient has died. The Harvard Committee put forth a set of clinical tests it claimed was sufficient to determine the death of the entire brain. It then recommended that whole-brain death be considered direct and sufficient evidence of the death of the patient. Thus arose the suggestion, which has become entrenched practice in the United States, that a binary standard be used for determining death: that in addition to the traditional heart and lung criteria still applicable in the vast majority of cases, a whole-brain death criterion be used to determine death for respirator-dependent, permanently unconscious patients.

This was the modest beginning of the so-called *definition-of-death* debate. Rather than having resolved over the last thirty-five years, this debate has evolved and intensified due to fascinating and complex constellations of philosophical, clinical, and policy disagreements. To best appreciate these disagreements, one must understand the definitional debate as one that has three logically distinct, yet interdependent levels: (1) the conceptual or definitional level; (2) the criteriological level; and (3) the medical diagnostic level. Let us look at each of the three levels in turn.

THE THREE LEVELS OF THE DEBATE. ***Level One: The conceptual or definitional level.*** At level one, the question is, What is human death? While some people think basic definitions such as this one are somehow written on the face of reality for our discernment, defining death is in fact a normative activity that draws on deeply held philosophical, religious, or cultural beliefs and values. The definition or concept of death reflects a human choice to count a particular loss as death. The level two and level three activities of deciding which physiological functions underlie that loss (i.e., choosing a criterion for determining death), and of specifying the medical tests for determining that the criterion is fulfilled, are medical/scientific activities. The conceptual question can be answered in a general, yet uninformative way by saying that human death is the irreversible loss of that which is essentially significant to the nature of the human being. No one will take issue with this definition, but it does not go far enough. There is still a need to decide what is essentially significant to the nature of the human being.

People differ radically in their views on the distinctive nature of the human being and its essentially significant characteristic(s). Because their fundamentally different perspectives on human nature flow from deeply rooted beliefs and values, the difficult policy question arises concerning the extent to which a principle of toleration should guide medical practice to honor the alternative definitions of human death that exist.

The discussion later in this section will show that the human being can be thought of as a wholly material or physical entity, as a physical/mental amalgam, or as an essentially spiritual (though temporarily embodied) being. The way the human is thought of will influence the view of what is essentially significant to the nature of the human being, and ground one's view about the functional loss that should be counted as human death. A metaphysical decision concerning the kind of being the human is, is the ultimate grounding for the normative choice of criteria for determining that an individual human being has died. There could be no more interesting or important a philosophical problem, then, than the problem of deciding: What is human death? Why? And, there could be no more interesting an ethical/policy problem than that of deciding whether and how to tolerate and enable a diversity of answers to these questions.

Level Two: The criteriological level. Based on the resolution of the ontological and normative questions at the conceptual level, a criterion for determining that an individual has died, reflecting the physiological function(s) considered necessary for life and sufficient for death, is specified. That is, the essentially significant human characteristic(s) delineated at the conceptual level is (are) located in (a) functional system(s) of the human organism. The traditional criteria center on heart and lung function, suggesting that the essentially significant characteristics are respiration and circulation. The whole-brain-death criterion is said by its proponents to focus on the integrated functioning of the organism as a whole. The higher-brain-death criterion centers on the irreversible absence of a capacity for consciousness.

Level Three: The diagnostic level. At this level are the medical diagnostic tests to determine that the functional failure identified as the criterion of death has in fact occurred. These tests are used by medical professionals to determine whether the criterion is met, and thus that death should be declared. As technological development proceeds, diagnostic sophistication increases. The Harvard Committee believed that the death of the entire brain could be clinically diagnosed using the tests it identified in its report, and recommended that the whole-brain-death criterion be used to determine death in cases of respirator dependency. However, it provided no conceptual argument (i.e., no answer to the level one question, What is human death?) to support the criterion and practice it recommended.

These three levels—conceptual, criteriological, and diagnostic—provide a crucial intellectual grid for following the complex definition-of-death debate since 1968. The debate encompasses all three levels. In any reading and reflection associated with this complex debate, it is essential to remember what level of the debate one is on, and what sort of expertise is required on the part of those party to the debate at that level. Further, any analysis and critical assessment of suggested criteria for determining death require that one attend to the important interconnections among tests, criteria, and concepts. Criteria without tests are useless in practice; criteria without concepts lack justification. It is the philosophical task of constructing an adequate concept or definition of human death that becomes central to a justified medical practice of declaring death. As Scot philosopher and historian David Hume (1711–1776) said centuries ago, “Concepts without percepts are blind.” At the beginning of the twenty-first century, a criterion for determining death without a philosophical analysis of what constitutes death is equally blind. All in all, there ought to be coherence among concept, criterion, and clinical tests. At least this is the way one would normally wish to operate. Among other things, the definition-of-death debate can be expressed as a debate among alternative formulations of death: the traditional cardio-pulmonary, whole-brain and higher-brain formulations.

The Traditional Cardio-Pulmonary Formulation

Initially, many objected to the whole-brain formulation because they saw it to be a change in our fundamental understanding of the human being, and a dramatic change from the essentially cardiac-centered concept and criterion for determining death (the traditional cardio-pulmonary criteria, which required the final stoppage of the heart). Several have called for a return to the use of the traditional criteria, consistent with an understanding of death as the irreversible loss of the integrative functioning of the organism as a whole. The claim has been that whether mechanically or spontaneously sustained, a beating heart signifies the ongoing integrated functioning of the organism as a whole, whether or not the patient is *brain-dead.* On this view, death has not occurred until the heart and lungs have irreversibly ceased to function. Some religious traditions adhere steadfastly to this concept of death, and consider the brain-death criterion an unacceptable basis on which to declare death.

The Whole-Brain-Death Formulation: Concept and Criterion

When the Harvard Committee recommended that a whole-brain-death criterion be used to determine death in respirator-dependent patients, thus creating an exception to the use of the traditional cardio-pulmonary criteria for a specific category of patients, controversy arose over whether the adoption of this criterion constituted a departure from the concept of death implicit in the use of the traditional cardio-pulmonary criteria for the determination of death.

Some saw the use of the brain-death criterion to be a blatantly utilitarian maneuver to increase the availability of transplantable organs. Some opposed it because it was inconsistent with their view of the human self and/or failed to protect and respect dying patients. While others agreed that the neurological focus represented an alternative understanding of the self, they saw the move to be eminently logical: What argument could one have with the notion that someone whose whole brain is dead, is dead? Others continued to affirm that life was essentially a heart-centered reality rather than a brain-centered reality: They saw the shift to a neurological focus on the human to be a discounting of the relevance of the spontaneous beating of the heart and the mechanically sustained functioning of the lungs. So, representatives of some cultures and faith traditions opposed the shift to the brain-death criterion, suggesting that it was a radically unacceptable way of understanding and determining the death of a human being.

The Harvard Committee report was a clinical recommendation, not a philosophical argument. It made recommendations at levels two and three (the criteriological and the diagnostic), and prompted but did not answer a number of level one definitional questions. What is death, such that either the traditional criteria or the whole-brain-death criterion may be used to determine its occurrence? Do the traditional criteria and the brain-death criterion presuppose the same definition of death? If not, should human death be *redefined* in response to technological change? It gave rise to a philosophical debate that is ongoing on the question, What is so essentially significant to the nature of a human being that its irreversible loss should be considered human death?

The literature has been replete with answers to this question, including the irreversible loss of the flow of vital fluids, the irreversible departure of the soul from the body, the irreversible loss of the capacity for bodily integration, the irreversible cessation of integrative unity (i.e., of the anti-entropic mutual interaction of all of the body's cells and tissues), the irreversible loss of the integrated functioning of the organism as a whole, and the irreversible loss of the capacity for consciousness or social interaction. Without such an account of what is essentially significant, the criterion used as a basis for determining death lacks an explicit foundation. However, the plurality of thoughtful answers to this fundamental conceptual question raises the issues of whether a consensus view can be fashioned, whether to tolerate diverse understandings of human death, and of how to assure societal stability concerning the determination of death.

While the Harvard Committee provided no philosophical defense of its position, adherents of the whole-brain formulation have continued to argue over the years that the traditional criteria and the whole-brain-death criterion share a common concept of death—the irreversible loss of the capacity for integrated functioning of the organism as a whole. Not everyone has agreed with this position, however. Some resist the adoption of the brain-death criterion for this reason, considering the shift to a new understanding of human death to be philosophically unjustifiable. However, others have welcomed the change: Reflecting on the contingency of the definition of death under circumstances of technological change, some have argued in favor of redefining death even further. In their view, the philosophical concept of death said to underlie the whole-brain-death criterion inadequately reflects the essentially significant characteristic of human existence: existence as an embodied consciousness. A more adequate concept of human death, they contend, would center on the permanent cessation of consciousness (requiring a higher-brain-death criterion), not on the permanent cessation of the integrated functioning of the organism. Advocates of the higher-brain formulation of death oppose the whole-brain formulation on the ground that the latter unjustifiably defers to the characteristics biological organisms have in common and ignores the relevance of the distinctively human characteristics associated with life as a person.

If the whole-brain formulation is essentially an organismically-based concept, and the higher-brain formulation is essentially a person-based concept, the controversy between whole- and higher-brain formulations suggests that in order to answer the question, What is human death? another layer of philosophical reflection is required. The central normative question concerning what is essentially significant to the nature of the human being requires a prior account of the nature of the human being. In philosophical terms, such an account of the nature of a being is referred to as an ontological account. One's view of the nature of the human being is informed by philosophical, theological and/or cultural perspectives on the nature of human existence, its essentially significant characteristics, and the nature of its boundary events. In the case of the human, there appear to be two logically distinct choices concerning the nature of the human being: one either sees it as one organism among others, for which meanings-in-common of life and death should be sought; or one sees the human being as distinctive among organisms for the purpose of characterizing its life and death, in ways we signify by the term *person.* In short we need to make and defend a decision concerning the way we look at the human—as organism or as person—for the purpose of determining what constitutes human death.

The Whole-Brain Formulation: Public Policy

In 1981 the whole-brain-death formulation originally advanced by the Harvard Committee was articulated in a major U.S. policy document. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research published its report, *Defining Death: A Report on the Medical, Legal, and Ethical Issues in the Determination of Death.* In this document, it provided a model law called the Uniform Determination of Death Act, to encourage the uniform adoption in each of the United States of the traditional criteria and the brain-death criterion as alternative approaches to declaring death. The supporting framework they offered for this recommendation was this: The concept of human death is the irreversible cessation of the integrated functioning of the organism as a whole. This, they claimed, is a function of the activity of the entire brain, not just a portion of the brain, and its occurrence can be measured, depending on the patient's circumstances, either by the traditional criteria or the brain-death criterion.

Questioning the Whole-Brain Formulation

The whole-brain formulation has been attacked at the conceptual level, and on the ground that the answers at each level collectively provide an incoherent account of concept, criterion and clinical tests for determining death. The President's Commission's concept or definition of death has been objected to by those who favor one centered on the essential features of a personal life, as well as by those who favor a circulatory concept and consider that only the irreversible cessation of circulation adequately signals death.

In addition, since 1981, clinical findings have confirmed that what has come to be called whole-brain death is not in fact synonymous with the death of the brain in all of its parts. There are instances of isolated continued functioning in the brain-dead brain. Those wishing to support the established consensus around the use of the brain-death criterion argue that such *residual functioning* in the brain-dead brain is insignificant to the determination of death. Specifically, then, they refuse to allow that these kinds of residual brain functioning have significance: (i) persistent cortical functioning as evidenced by electroencephalograph (EEG) activity, and in rare cases a sleep/wake pattern; (ii) ongoing brainstem functioning as evidenced by auditory or visual evoked potential recording; and (iii) preserved antidiuretic neurohormonal functioning. Such instances of residual functioning suggest that brain death, as customarily diagnosed, does not include the hypothalamus and the posterior pituitary. Most importantly, the third instance of residual functioning just cited actually plays an *integrative* role in the life of the organism as a whole. Hence, one of the residual functions fulfills the concept of life implicit in the definition of death underlying the whole-brain formulation.

So, the clinical tests used to establish the death of the entire brain have been shown to reflect a pervasive but nonetheless *partial* death of the brain only, opening wide the question, If brain death is to remain a reasonable basis upon which to declare death, which brain functions are so essentially significant that their irreversible loss should be counted as brain death? Why?

Both philosophically and clinically speaking, then, many feel that a rethinking of the U.S. societal adherence to the brain-death criterion is warranted. It rests on a contested understanding of what human death is, raising the issue of whether the brain-death criterion should be used to declare someone dead who holds philosophical/theological/cultural objections to it. It lacks coherence among its levels because (1) the brain-death criterion does not correlate with the irreversible loss of the integrated functioning of the organism as a whole; and (2) because the clinical tests for brain death fail to reflect the death of the entire brain. No important societally established practice can be imagined to be so highly problematic as this one.

The supporters of the whole-brain formulation have nonetheless stood their ground, claiming that the instances of residual cellular and subcellular activities occurring in the brain are irrelevant to the determination of the life/death status of the patient. In their view, the brain-death criterion should continue to be used, despite that it really reflects a pervasive albeit partial brain death.

The basic challenge to the whole-brain formulation has been that its defenders need to provide criteria for distinguishing between brain activity that is relevant and irrelevant for the purpose of determining death. Some have argued that the only bright line that could be drawn in this regard is between the brain functions essential for consciousness and those that are not; others have argued that the brain should be abandoned entirely as a locus for establishing that a human being has died. In point of fact then, advocates of the whole-brain formulation have embraced a partial-brain-death criterion but have failed to provide a non-question-begging, principled basis for it.

Another aspect of the whole-brain formulation that has been challenged concerns its reliance on the non-spontaneous function of the lungs to support the claim that the irreversible cessation of the integrated functioning of the organism as a whole has occurred. They claim that the integrated functioning continues, and that the manner of its support is irrelevant. Their point is that as long as the respirator is functioning, it seems something of a word game to say that the organism is not functioning as an integrated whole.

While in brain death the brain stem is no longer playing its linking role in the triangle of function along with lungs and heart, the respirator is standing in for the brain stem, just as it might if there were partial brain destruction in the area of the brain stem. If the patient were conscious, but just as dependent on the respirator in order to continue functioning as an organism, there would be no inclination to pronounce the patient dead. Hence, it would seem that even the brain-dead patient is exhibiting integrated organismic functioning until the respirator is turned off, the lungs stop, and the heart eventually stops beating. The phenomenon of a mechanically-sustained brain-dead pregnant woman producing a healthy newborn certainly seems to bear out their insight: Whatever the sort of organismic disintegration possessed in such a case, it seems most unfitting to call it death. Integrated organismic functioning is present in brain death, so if brain death *should be* considered the death of the human being, it is not because brain death signals the irreversible loss of the integrated functioning of the organism as a whole.

As this last point makes clear, the real reason so many people are inclined to agree that the brain-dead patient is dead has much more to do with the fact that the brain-dead patient is permanently unconscious than with the facts of brain stem destruction and respirator dependency. It is this loss of the self, the loss of consciousness and thus of embodiment as a self, that is for many of us a good reason to consider the brain-dead patient dead. This suggests that the concept of human death underlying people's willingness to adopt the brain-death criterion may have more to do with the loss of the capacity for embodied consciousness than with the loss of the capacity for integrated organismic functioning.

The Higher-Brain Formulation

Consistent with this insight, some contributors to the definition-of-death debate propose a higher-brain-death criterion for the determination of death, contending that this criterion presupposes a different and preferable view of what is essentially significant to the nature of the human being. They hold that consciousness, sometimes characterized as a capacity for social interaction, is the *sine qua non* of human existence, and that the criterion used to determine death should reflect this loss. In their view, requiring that the brain-death criterion be used when the patient is permanently unconscious is biologically reductionistic. That is, the brain-death criterion attaches primary significance to the functional connection of the brainstem, lungs and heart, and not the conscious capacity that that functioning supports. Unless the concept of human death reflects what is essentially significant to the nature of the human being as a person—conscious awareness—it fails to provide a community with an effective moral divide between the living and the dead.

Questioning the Higher-Brain Formulation

Critics of the higher-brain formulation object that the emphasis on consciousness and person-centered functions of the human being places us on a *slippery slope* that will eventually lead to a broadening of the definition of death to include those who are severely demented or only marginally or intermittently conscious. They argue further that the adoption of a higher-brain basis for determining death would require us to bury spontaneously respiring (and heart beating) *cadavers.*

These arguments have little to recommend them. First there is a bright and empirically demonstrable line between those who are in a permanent vegetative state (recall the cases of Karen Quinlan, Paul Brophy, Nancy Cruzan, and others) and those who retain the capacity for higher-brain functioning. The slippery slope worry that we would begin to declare conscious patients dead is unfounded. By contrast the slippery slope objection is telling in relation to the whole-brain-death criterion, which does not in fact measure the death of the brain in its entirety. Whole-brain-death adherents have failed to provide criteria for identifying some brain functions as residual and insignificant, so the opportunity for the unprincipled enlargement of the residual functioning category is ever present.

Finally, for aesthetic reasons as well as reasons of respect, society does not permit certain forms of treatment of the dead. There is no reason to think that a consciousness-based concept of death would lead to the abandonment of long-held understandings of the dignified and appropriate treatment of the body of the deceased person. One would not bury a spontaneously breathing body any more than one would bury a brain-dead body still attached to a respirator. A higher-brain advocate might argue that stopping residual heart and lung function would be as morally appropriate in the case of a permanently unconscious patient as the discontinuation of the ventilator is in the case of a brain-dead patient.

Questioning the Irreversibility of Death

Still laboring under the power of the Dead Donor Rule and a concern to increase the supply of transplantable organs, a 1990s effort to update the clinical tests associated with the cardiac-centered traditional criteria occurred. Several transplant centers began the practice, in the case of a dying patient who had consented in advance to be an organ donor and to forego both life-sustaining treatment and resuscitative efforts, of declaring death two minutes after the patient's last heartbeat, as the measure of the patient's irreversible loss of cardiopulmonary function. This approach to assessing the irreversible loss of cardiopulmonary function challenged people to accept a particular and unprecedented definition of *irreversibility* in relation to declaring patients dead. Both common understanding and the Uniform Determination of Death Act were understood to require irreversibility of functional loss in the stronger sense that the functional loss could in no way be recovered or restored.

If death is declared two minutes after the loss of cardiopulmonary function, when, conceivably, the heart could resume functioning on its own (auto-resuscitation) or resuscitation could successfully restart the heart, in what sense is the loss of function irreversible? It appears that irreversibility is only a function of a morally valid decision on the part of a patient or perhaps a surrogate to forego resuscitation. Is this change in the association of death with the irreversible loss of function ethically acceptable?

The interest in declaring death as close to the cessation of cardiopulmonary function as possible arises from the need to remove organs before warm ischemia destroys their viability for transplantation. But what sense of the concept of irreversibility should be required to assess a loss of critical function sufficient to ground a declaration of death? In the weak moral sense indicated above, two minutes after the last heartbeat when resuscitation has been refused? In the relatively stronger sense that auto-resuscitation of the heart has become physiologically impossible? Or in the strongest sense, that the heart cannot be restarted by any means?

While many hold the religious belief that the self survives the death of the body, the commonly held view is that the death of the body is a finished, non-reversible condition. The Uniform Determination of Death Act requires that the cessation of brain function be irreversible in the sense that all function throughout the entire brain is permanently absent, or it requires that cardiopulmonary function has ceased in the sense that the patient can never again exhibit respiration or heartbeat. Clearly, then, because it entails a novel understanding of the conceptual connections between death and irreversibility, the variation in the application of the cardiopulmonary criterion adopted by many transplant centers after 1992 requires philosophical justification.

In addition this new strategy for determining death raises interesting issues about the overall consistency of alternative approaches to determining death. It has always been the case that a patient declared brain-dead could not be declared dead using the traditional criteria, since the respirator was maintaining lung and heart functions. Those functions were effectively ruled out as signs of life. Yet after only two minutes of cardiac cessation, the patient is arguably not yet brain-dead, raising a question: Is the non-heart beating donor (NHBD) whose heart has stopped for two minutes but whose brain retains some functional capacity *really* dead? In order to be declared dead, should a patient be required to fulfill at least one but not necessarily all extant criteria and their associated clinical tests for the determination of death? Which way of being determined dead is more morally appropriate when surgery to procure organs is to be undertaken?

In sum, the definition-of-death debate goes on. The deep and disturbing irony in this debate surrounds the disagreement among ethicists as to whether the public should be informed about the degree of dissension on the conceptual, clinical, and policy issues central to the debate. Despite the rather stable practice in the United States of using the brain-death criterion to determine death, the definition-of-death debate is at loggerheads. The situation is such that, some have argued, parties to the debate should share none of this dissension with the public lest they disturb the acceptance of the brain-death criterion and the improved access to transplantable organs it allows over the traditional criteria for determining death. Others argue that every question in this debate, including the question of the kind of irreversibility that should ground the determination of deaths, is still an open question, and that the public should be informed and polled for its views. Yet others have suggested that one of the prime movers in the definitional debate, the Dead Donor Rule, should be rethought, and the practices of declaring death, discontinuing life-sustaining treatment, and removing organs for transplantation should be decided independently of one another.

Public Policy for a Diverse Society

The public policy issue in the definition-of-death debate arises because there are diverse, deeply held understandings concerning the nature of the human and human death. Because these views derive from fundamental philosophical, religious, or cultural perspectives, should people have any say in the concept and criteria for determining death that might be applied to them? If, for example, a person is aware that being declared dead under the brain-death criterion contradicts his or her religiously-based understanding of death, should that person be allowed to conscientiously object to the use of this criterion? Some argue that toleration in such matters is imperative because of the extraordinary damage done to persons by ignoring and disrespecting their foundational understandings. They claim that individuals should be allowed to use a conscience clause to express their wishes. Others claim that diversity on such a fundamental matter as the determination of when someone has died can only lead to social and legal instability. The next section explores the diverse philosophical perspectives that might be taken on human death. On this basis, the reader must decide on the importance and practicality of a conscience clause for those who disagree with the concept and criteria for determining death that have become established U.S. policy.

Philosophical and Theological Perspectives: Preliminaries

Human groups engage in different behaviors upon the death of one of their members. They do so because they have different understandings of the nature of the individual self and, consequently, of the death of the self. Yet every human society needs a way of determining when one of its members has died, when the quantum change in the self that both requires and justifies *death behaviors* has occurred, when the preparation of the bodily remainder of the individual for removal from the sphere of communal interaction both may and must begin.

This need for a line of demarcation between life and death suggests that for societal purposes, the death of an individual must be a determinable event. There has been debate, however, about whether death is an event or a process. Those engaged in this debate have appealed to the biological phenomena associated with the shutting down of a living organism. Some of them have argued that death is a discrete biological event; others, that it is a biological process. In fact, neither biological claim settles the philosophical question of whether death is an event or a process. Different communities decide whether to view the biological phenomena associated with death as an event or a process. For societal/cultural reasons, it is essential that some terminus be recognized.

Death is a biological process that poses a decisional dilemma because, arguably, the biological shutdown of the organism is not *complete* until putrefaction has occurred. Human communities have a need to decide when, in the course of the process of biological shutdown, the individual should be declared dead; they must decide which functions are so essentially significant to human life that their permanent cessation is death. For a variety of reasons, death has come to be associated with the permanent cessation of functions considered to be vital to the organism rather than with the end of all biological functioning in the organism. These vital functions play a pervasive and obvious role in the functioning of the organism as a whole, and so their use as lines of demarcation is reasonable. With their cessation, the most valued features of human life cease forever, and it is reasonable to regard that as the event of a person's death. Advances in medical technology, permitting the mechanical maintenance of cardiac and respiratory functions in the absence of consciousness, force us to evaluate the functions we have always associated with life, and to choose which of them are essentially significant to human life or so valuable to us that their permanent loss constitutes death. The ancient and (until the late-twentieth century) reasonable assumption has been that death is an irreversible condition, so it should not be declared until the essentially significant functions have irreversibly ceased.

In pretechnological cultures, humans undoubtedly drew on the functional commonalities between other animal species and themselves to decide that the flow of blood and breathing were essentially significant functions. When either of these functions stopped, no other *important* functions continued, and predictable changes to the body ensued. Since it was beyond human power to alter this course of events, the permanent cessation of heart and lung functioning became the criterion used to determine that someone had died.

This choice has clearly stood the test of time. Often referred to as the traditional cardio-pulmonary criteria, there is certainly no reason to impugn this choice for a society lacking the technological life-support interventions characteristic of modern medicine. But it is important to see that even in a pretechnological culture, the choice of the traditional cardiopulmonary criteria was a choice, an imposition of values on biological data. It was a choice based on a decision concerning significant function, that is, a decision concerning what is so essentially significant to the nature of the human being that its irreversible cessation constitutes human death. Such a decision is informed by fundamental beliefs and values that are philosophical/theological/cultural in nature.

If a technologically advanced culture is to update its criteria for declaring death, it must reach to the level that informs such a decision. Deciding the normative issue concerning the essentially significant characteristic of a human being is impossible without an ontological account of the nature of the human being. The assumptions and beliefs we hold on these matters form the combined philosophical/theological/cultural basis upon which we dissect the biological data and eventually bisect them into *life* and *death.*

Such assumptions and beliefs constitute the most fundamental understandings and function as the often unseen frame through which people view, assess, and manipulate reality. As a rule, this frame is inculcated through the broad range of processes that a social group uses to shape its members. The frame itself consists of assumptions and beliefs that are used to organize and interpret experience. They are deeply yet pragmatically held beliefs that may be adjusted, adapted, discarded, or transformed when they cause individual or social confusion, cease to be useful, or no longer make sense. Arguably, changes in the capacity to resuscitate and support the human body in the absence of consciousness have brought that society to such a point of non-sense. To respond fully to this crisis, people must consider the various philosophical and theological perspectives in their culture that inform thinking about human nature and death.

Representative Philosophical and Theological Perspectives

Death is the word we use to signify the end of life as we know it. As stated above, individuals and groups hold different understandings of the existence and the death of the self. These understandings are the background for the *nuts and bolts* medical decision that a person has died, when death should be declared, and what ought/ought not be done to and with the physical remains of the person who has died.

As individuals and as cultural groups, humans differ in their most basic assumptions and beliefs about human death. For some the death of the body marks the absolute end of the self; for others it is a transition to another form of existence for the continuously existing self. This transition may be to continued life in either a material or an immaterial form. Despite these differences, every human community needs a way of determining when one of its members has died, a necessary and sufficient condition for considering the body as the remainder of the individual that can now be treated in ways that would have been inappropriate or immoral before, and for preparing the body for removal from the communal setting. Different philosophical and theological perspectives on the nature of death, the individual self, and the death of the self will yield different choices of criteria for the determination of death, just as these differing perspectives yield very different death practices or death behaviors. To see why this is the case, various philosophical and theological views of death and the self must be reviewed.

In the Hebrew tradition of the Old Testament, death is considered a punishment for the sin of disobedience. It is an absolute punishment. This tradition does not hold a concept of an afterlife following the punishment of death. But it would be misleading to say that this tradition has no conception of immortality, since the communal setting of the individual's experience and life remains the arena of that person's identity and impact, even after the death of the body. Although the conscious life of the person ceases, the person lives on in the collective life, unless he or she lived badly. Thus, immortality is the community's conscious and unconscious memory of the person.

Another view, originating in Platonic philosophy and found in Christian and Orthodox Judaic thought, and in Islam and Hinduism, holds that death is not the cessation of conscious life. The conscious self, often referred to as the soul, survives in a new form, possibly in a new realm. The experience of the self after the death of the body depends on the moral quality of the person's life. The body is the soul's temporary housing, and the soul's journey is toward the good, or God, or existence as pure rational spirit without bodily distractions. Thus, death is the disconnection of the spiritual element of the self (mind, soul, spirit) from the physical or bodily aspect of the self.

Traditions believing in eternal life differ in their view of the soul and its relationship to the body. This has implications for the criteria that might be used to determine death, as well as for the appropriate treatment of the body after death. The soul is viewed by some as separate and capable of migrating or moving into different bodies as it journeys toward eternal life. The Christian tradition, by contrast, posits the self as an eternally existing entity created by God. The death of the body is just that—the person continues, with body transformed, either punished in hell for living badly or rewarded in heaven for having faith and living righteously. These diverse views have a common belief: Everyone survives death in some way. This may influence the understanding of what constitutes the death of the body as well as of what ought/ought not to be done to the body of the person who has died. For some traditions, certain bodily functions are indicative of life, whether or not those functions are mechanically supported, and damage to the body is damage to the self.

In contrast to these theological conceptions of death and the self, three philosophical perspectives, secular in that they hold materialist views of the self, figure in Western thought: the Epicurean, the Stoic, and the existential. A materialist view of the self considers the human to be an entirely physical or material entity, with no soul or immaterial aspect. The Epicurean view of the self holds that humans are fully material beings without souls. The goal of life is to live it well as it is and not to fear death since death is the end of experience, not something one experiences. Therefore, there is no eternal life for souls; the body dies and disintegrates back into the material nature from which it sprang. The death of the body marks the end of consciousness, and thus the death of the self. A materialist holding a view such as this could conclude that the cessation of consciousness itself should be considered death, whether or not the body continues to function in an integrated manner.

The Stoic view acknowledges death as the absolute end of the conscious self but directs persons to have courage about its inevitability and to resign to it creatively. This creative resignation is achieved by focusing on the inevitability of death in such a way that one treats every moment of life as a creative opportunity. The necessity of death becomes the active inspiration for the way one lives. Like the Epicurean view, the Stoic conception ties the self to the body; the end of the self to the death of the body. But it is the consciousness supported by the body that is the creative self.

In contrast existential thought believes that the absoluteness of death renders human life absurd and meaningless. The other materialist views of the self saw death as the occasion for meaning in life, not the denial that life has meaning. Rather than infusing meaning into life and inspiring a commitment to striving, existentialism holds that death demonstrates the absurdity of human striving. While individuals may pursue subjective goals and try to realize subjective values during their lives, there are no objective values in relation to which to orient one's striving, and so all striving is ultimately absurd. Since death is the end of the self, there is nothing to prepare for beyond the terms of physical existence and the consciousness it supports.

Without critiquing these theological and philosophical perspectives on death and the self, an inquiry into their diversity is relevant to a discussion of the debate in bioethics about the criteria for determining that a human being has died. The earlier demonstration that the criteria rest on a decision of functional significance, and that a decision of functional significance is philosophically/theologically informed, coupled with this demonstration of philosophical/theological diversity on the fundamental concepts of self and the death of the self, together show that criteria are acceptable only if they are seen to be consistent with an accepted philosophical/theological frame, and that what is acceptable in one frame may be unacceptable in another.

Further, while it might be the case that virtually every tradition has agreed on the appropriateness of the traditional heart and lung criteria for declaring death, they may do so for vastly different reasons deriving from their specific understanding of death and the self. There may be ways of reconciling virtually every ontological view to the use of the traditional criteria but not to the use of consciousness-centered criteria like the higher brain-death criterion, or even the brain-death criterion (which appears, to a tradition like Orthodox Judaism, to deny that the still-functioning body is indicative of life, even when the entire brain is dead).

Philosophical and theological commitments relate centrally to society's death practices, including conclusions concerning the acceptability of traditional, and whole-brain, and higher-brain formulations of death. How philosophically and theologically sophisticated has the bioethics debate on the definition of death been, over the years?

The Persistence of the Debate

Why do arguments concerning the definition and criteria of death persist? The debate has been intractable since 1968. One important reason is that the concepts of self and death that inform the various positions in the debate are based on fundamental beliefs and values that suggest that they will remain irreconcilably different. While it is true that persons holding different philosophical/theological/cultural premises may assent to the use of the same criteria for determining death, they may well do so for very different reasons. Because of this, it is reasonable to seek and adopt a broadly acceptable societal standard for the determination of death.

For example, the several materialist views of the self that were examined earlier suggest a consciousness-centered concept of self and death that further recommends a higher-brain formulation of death. But equally, the prevailing Judeo-Christian understandings of the self and death—that of death as the dissociation of consciousness from the body, the end of embodied consciousness—are also compatible with a higher-brain formulation of death.

Some traditions, like Orthodox Judaism, and certain Japanese and Native American perspectives, resist the use of the brain-death criterion because they understand death to be a complete stoppage of the vital functions of the body. The self is not departed until such stoppage has occurred. Such groups will be uncomfortable with the use of the brain-death criterion because it permits the determination of death while vital functions continue. This kind of philosophical/theological difference in perspective on the human self, intimately linked to a person's religious and cultural identity, raises serious questions about how a pluralistic culture should deal with deeply held differences in designing a policy for the determination of death.

Given that there are a finite number of possible perspectives on the human person and on human death, and given the rootedness of these perspectives in conscientiously held philosophical and religious views and cultural identities, public policy on the determination of death in a complex and diverse culture could well manage to service conscience through the addition of a conscience clause in a determination-of-death statute. Similar to and perhaps in conjunction with a living will, a person could execute a conscience-clause exclusion to the statute's implicit concept of death. For instance, an Orthodox Jew could direct that death be determined using the traditional criteria alone, and also indicate personal preferences concerning the use of life-sustaining treatment such as ventilator support in the situation of brain death.

The fact that a conscience clause would permit some to reject the use of the brain-death criterion need not hinder the law from specifying punishable harms against others on the basis of considerations additional to whether death was caused. The exotic life-sustaining technologies now available have already generated arguments concerning whether the person who causes someone to be brain-dead or the person who turns off the ventilator on that brain-dead patient causes the patient's death.

Life-sustaining technologies as well as the alternative concepts of death underscore the need for more precise legal classifications of punishable harms to persons. Such a classification should recognize permanent loss of consciousness as a harm punishable to the same extent as permanent stoppage of the heart and lungs.

The self can be thought of in a variety of ways: as an entirely material entity, as an essentially mental entity, and as a combined physical/mental duality. In contemporary language, the human being may be thought of as a physical organism, as an embodied consciousness (which we often call person), or as an amalgam of the two. As one examines the definition-of-death debate, one sees that fundamentally different ontological perspectives on the human have been taken.

Once such an ontological perspective on the human being has been chosen, a further decision as to what is essentially significant to the nature of the human being can be made. When a conclusion is reached as to which function is essentially significant to the human being, the potential exists for settling on the criterion (or criteria) for determining death. To the extent that these two steps of philosophical analysis support attention to the brain as the locus of the relevant human functions, views may divide on whether a whole-brain or a higher-brain formulation of death is adopted.

A complex entity that manifests its aliveness in a variety of ways has the potential to engender dispute about the ontological perspective that should be taken toward it, as well as about what is essentially significant to it. Hence, there may be no agreement on the definition of death that should be applied. Instead, the greatest achievement may be to articulate a policy on the determination of death that honors a plurality of philosophical/theological perspectives.

KAREN G. GERVAIS

SEE ALSO: *African Religions; Bioethics, African-American Perspectives; Buddhism, Bioethics in; Christianity, Bioethics in; Eastern Orthodox Christianity, Bioethics in; Embryo and Fetus: Religious Perspectives; Hinduism, Bioethics in; Infanticide; Islam, Bioethics in; Life Sustaining Treatment and Euthanasia; Moral Status; Right to Die, Policy and Law; Utilitarianism and Bioethics;* and other *Death, Definition and Determination of* subentries

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DEATH PENALTY

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Fewer and fewer crimes are punishable by death even in countries where execution is legal, and crimes that are widely considered to be extremely serious, such as murder, often lead to prison sentences rather than capital punishment. In 1991, offenses under the laws of over ninety countries carried a penalty of death. In eighty-five, execution was illegal or had ceased to be imposed. These included virtually all of the nations of western Europe, as well as Canada, Australia, Hungary, and Czechoslovakia. In the United States, in addition to military and federal jurisdictions, thirty-six states impose the death penalty. Not all of these states do so regularly, however; and in those where capital punishment has become routine, it is sometimes a relatively new development. From 1967 to 1977 there were no executions in the United States; between 1977 and 1992, there were 190, and over 2,500 people in 34 states were on death row. In a few countries in which the death penalty was still used in the 1980s—Brazil, Argentina, and Nepal—it had been reintroduced (in Brazil and Argentina by military governments) after a long period of abolition.

The reintroduction of capital punishment after centuries of decline has once again raised the question of the morality of execution. No code of law now prescribes death for the theft of fruit or salad, as Draco's code did in ancient Athens; and boiling to death is no longer a recognized punishment for murder by poisoning, as it was in England under the Tudors and Stuarts. Can a principle that explains why these developments are good also explain why it is good that some codes of law no longer prescribe death as punishment for murder? Or can a principle that condemns the death penalty for some crimes also support its imposition for others? These are live questions, for one of the arguments commonly presented against the death penalty turns on the suggestion that retaining it or reintroducing it is a case of being morally behind the times. According to this argument, standards of humane punishment have now risen to a point where killing a human being—even one who is guilty of a terrible crime—can only be understood as cruel, and therefore immoral. Such an argument is sometimes used to counter another that is perhaps even more familiar: that the death penalty is justified because of its power to deter people from violent crime. The argument from deterrence will be examined later.

The Argument from Cruelty

The language of this argument is sometimes taken from the Eighth Amendment of the U.S. Constitution ("Excessive bail shall not be required, nor excessive fines imposed, nor cruel and unusual punishments inflicted"); or from human-rights declarations that outlaw "cruel, inhuman or degrading" treatment or punishment. Thus, a brochure titled *When the State Kills,* issued by the British Section of Amnesty International (1990), contains the following passage under the heading "Cruel, Inhuman and Degrading": "International law states that torture or cruel, inhuman or degrading punishments can never be justified. The cruelty of the death penalty is self-evident."

Certain methods of execution are quite plausibly said to be so painful that any application of them must be cruel. Amnesty International cites the case of a Nigerian military governor who in July 1986 ordered successive volleys of bullets to be fired at convicted armed robbers. The shots would first be aimed at the ankles, to produce painful wounds, and only gradually would the firing squad shoot to kill. Other methods, believed by some authorities to be painless, can undoubtedly cause suffering when clumsily applied. According to eyewitness reports, the first death sentence carried out by use of the electric chair in the United States; in August 1890, was very painful. But these ill effects may not be typical. Certainly the electric chair was not introduced because it was thought to be painful; on the contrary, along with other methods of execution, such as the guillotine, it was thought to spare the convicted person suffering.

Execution by lethal injection is the latest in a series of supposedly humane methods of execution to be introduced. It is now being used in a number of states in the United States. Is this technique cruel? Perhaps not, if severe pain is the test of cruelty. Deliberate poisoning is normally cruel, and Amnesty International classifies the use of lethal injection as deliberate poisoning. But is it clear that poisoning in the form of lethal injection is always cruel? What if the injection is self-administered in a suicide or given at the request of someone who is dying in intense pain? If poisoning is always cruel, then it must be so in these cases. On the other hand, if it is not cruel in these cases, then it is not necessarily cruel in the case of execution. It is true that execution is usually not in line with the wishes of the convicted person, as it is when poison is administered to someone at his or her request. But that by itself cannot make execution cruel, unless virtually all punishment is cruel: Virtually all punishment is inflicted on people against their wishes. If it is not pain and not the unwillingness of the criminal to undergo it that makes lethal injection cruel, then what does? If nothing does—if lethal injection is sometimes painless and not cruel in other respects—then there may be principles that consistently explain why it is good for murderers, for example, to be punished with death (severe crimes deserve severe punishments); why it was bad for murderers to be put to death in the past by boiling (torture is wrong); and why it is not necessarily bad for murderers to be put to death today by lethal injection.

Arguments from Finality and Arbitrariness

Arguments against the death penalty sometimes emphasize its finality. There are several versions of the argument from finality, some religious, some secular. One religious version has to do with the way the death penalty removes all possibility of repentance or a saving change of heart on the part of the offender (Carpenter). Capital punishment writes off the offender in a way that, for example, imprisonment combined with education or religious instruction does not. It arguably refuses the offender the sort of love that Christianity enjoins, and it presumes to judge once and for all—a prerogative that may belong to God alone.

Secular arguments from finality are almost always combined with considerations about the fallibility of judicial institutions and doubt whether people who are accused of crimes are fully responsible agents. In some views, society contributes to the wrongdoing of criminals (Carpenter), so that they are not fully responsible and should not be punished. This argument shows sympathy for those who are accused of wrongdoing, but because it does not take wrongdoers as full-fledged agents it may not show them as much respect as apparently harsher arguments do. As for fallible judicial institutions, certain factors—such as prejudice against some accused people, and poor legal representation—can produce wrong or arbitrary verdicts and sentences; even conscientious judges and juries can be mistaken. When errors occur and the punishment is not death, something can be done to compensate the victims of miscarriages of justice. The compensation may never make up entirely for what is lost, but at least a partial restitution is possible; but where what is lost is the accused person's life, on the other hand, the possibility of compensation is ruled out. This argument is particularly forceful where evidence exists that certain groups (black males in the United States, Tibetans in China) are disproportionately represented among those receiving harsh sentences, including the death sentence (Amnesty International, 1991; Wolfgang and Reidel). In these cases, the possibility of an error with disastrous consequences starts to grow into something like a probability. What is more, the evidence of certain groups being disproportionately represented suggests that the law is not being applied justly. This adds to the argument that the death penalty should not be applied, for it suggests that people are fallible, the background conditions for the existence of justice are not being met, and consequently that some miscarriages of justice result from factors other than honest error.

Arguments from Side Effects

EFFECTS ON PROFESSIONALS. Executions are carried out by officials who are not always hardened to their task, and at times they rely on the services of medical people, who have sworn to preserve life. The burdens of those who officiate and serve in these ways; the suffering of those who are close to the convicted person; and the ill effects on society at large of public hangings, gassings, or electrocutions are sometimes thought to constitute an argument against capital punishment over and above the argument from cruelty to the offender.

The side effects on medical personnel have recently been brought into prominence in the United States by the use of lethal injection. The method involves intravenous injection of a lethal dose of barbiturate as well as a second drug, such as tubocurarine or succinylcholine, that produces paralysis and prevents breathing, leading to death by asphyxiation. Doctors have sometimes had to check that the veins of the convicted person were suitable for the needle used and, where death took longer than expected, to attend and give direction during the process of execution. In Oklahoma, which was the first state to adopt lethal injection as a method of execution, the medical director of the Department of Corrections is required to order the drugs to be injected; the physician in attendance during the execution itself has to inspect the intravenous line to the prisoner's arm and also pronounce him dead.

Of course, doctors have been in attendance at executions carried out by other methods, and some of the moral objections to their involvement are applicable no matter which method is used. What is different about intravenous injection, in the opinion of some writers (e.g., Curran and Cassells), is that it involves the direct application of biomedical knowledge for the taking of life. This practice is often said to be in violation of the Hippocratic Oath (Committee on Bioethical Issues of the Medical Society of the State of

New York); and many national and international medical associations oppose the involvement of doctors in the death penalty. The fear that nurses might assist at executions led the American Nurses Association in 1983 to declare it a "breach of the nursing code of ethical conduct to participate either directly or indirectly in legally authorized execution."

The conflict between providing medical services to further an execution and abiding by the Hippocratic Oath makes the moral problem facing doctors particularly sharp, but other professionals may face difficulties as well. Judges and lawyers may be caught up unwillingly or reluctantly in prosecutions that will lead to the imposition of the death sentence. They, too, have a reason for withdrawing their services if they are sincerely opposed to capital punishment; but if all the professionals with qualms acted upon them, the legal process, and the protections it extends to those accused of capital crimes, might be compromised as well (Bonnie). This argument probably understates the differences between legal and medical professionals: the latter recognize a duty of healing and of relieving pain; the former are committed to upholding the law and seeing that justice is done, which does not necessarily conflict with participation in a regime of execution.

EFFECTS ON PERSONS CLOSE TO THE CONDEMNED AND ON SOCIETY. In addition to the effects of the death penalty on involved professionals, the effects on persons close to condemned prisoners are sometimes cited in utilitarian arguments against the death penalty (Glover). These effects are undoubtedly unpleasant, but it is unclear whether they are to be traced to the existence of capital punishment or to the commission of the crimes classified as capital. As for the effects on society at large, they are harder to assess. Samuel Romilly, who campaigned successfully for a reduction in the very large number of capital offenses recognized in English law at the beginning of the 1800s, maintained that "cruel punishments have an inevitable tendency to produce cruelty in people." In fact, Romilly's success in law reform owed something to the benevolence of juries, who had consistently, and often against evidence, found accused people innocent of capital offenses as minor as shoplifting. Whoever was made cruel by the existence of cruel punishments, it was not ordinary English jurors. Judges avoided imposing the death penalty for minor crimes by transporting criminals to the colonies.

Deterrence

The death penalty has often been introduced to act as a strong deterrent against serious crime, and the deterrence argument is commonly used to justify reintroduction. In a British parliamentary debate on the reintroduction of capital punishment in May 1982, one legislator said, "The death penalty will act as a deterrent. A would-be murderer will think twice before taking a life if he knows that he may well forfeit his own in so doing" (Sorell, pp. 32–33). He went on to argue that the absence of the death penalty had been associated with a rise in the number of ordinary murders, and an increase in the rate of murder of police officers. But the evidence for its having the power to discourage, or for its having a greater such power than imprisonment, is inconclusive (Hood). Indeed, deterrence generally seems to depend on potential offenders expecting to be caught rather than on their judging the punishment for an offense to be severe (Walker). In the case of murder, the deterrent effect is particularly doubtful: Murder is often committed in a moment of high passion or by those who are mentally disturbed (Sorell). Either way, the serious consequences of the act are unlikely to register so as to make the agent hesitate. An American review of statistical studies concludes that the deterrent effect of capital punishment is definitely not a settled matter, and that the statistical methods necessary for reaching firm conclusions have yet to be devised (Klein et al.).

Incapacitation

A purpose of punishment that is more convincingly served by the death penalty is the incapacitation of offenders. The death penalty undoubtedly does incapacitate, but this is just another aspect of its finality, which has already been seen to be morally objectionable from some points of view. Again, for incapacitation to be a compelling general ground for the imposition of the death penalty—that is, a ground that justifies the imposition of the penalty in more than the occasional case—there has to be strong evidence that people who have the opportunity to repeat capital crimes frequently do so. Although killers sometimes kill again, it is not clear that they are *likely* to reoffend. Finally, life imprisonment without parole may be sufficiently incapacitating to make the death penalty unnecessary.

Retribution

Another argument in favor of the death penalty is based on the value of retribution. Here the idea is that the evil of a crime can be counterbalanced or canceled out by an appropriate punishment, and that in the case of the most serious crime, death can be the appropriate punishment because it is deserved. Appropriateness should be understood against the background of the thought that penal justice requires what Immanuel Kant called an "equality of crime and punishment." His examples show that he meant an act of punishment not identical to the crime but proportionate to its severity; Kant held that death was uniquely appropriate to the crime of murder. John Stuart Mill, in a famous speech in favor of capital punishment delivered in the British House of Commons in 1868, argued that only those guilty of aggravated murder—defined as brutal murder in the absence of all excusing conditions—deserved to be executed. Mill called the punishment "appropriate" to the crime and argued that it had a deterrent effect. He meant "appropriate" in view of the severity of the crime.

Retribution should not be confused with revenge. It is generally considered revenge, not retribution, when there is love or sympathy for the one who has suffered an injury; retribution requires a response even to injuries of people no one cares about. Its impersonality makes the injuries of the friendless have as much weight as the injuries of the popular. Again, revenge is still revenge when the retaliation is utterly out of proportion to the original injury, but the retributivist *lex talionis*—an eye for an eye—limits what can be done in return.

One question raised by the retributivist defense of capital punishment is how a punishment can counterbalance or cancel out an evil act. Retributivists sometimes refer in this connection to the ideal case in which the offender willingly undergoes a punishment as a sign of remorse and of wishing to be restored to a community from which he or she has been excluded due to a criminal act (Duff). In that case the punishment is supposed to counterbalance the crime. But it is unnecessary for retributivism to be committed to the idea that a punishment cancels out an offense. One can appeal instead, as Kant did, to a punishment's fitting an offense—being proportional in quality to the quality of the offense—and one can justify the imposition of punishment by reference to the following three considerations: (1) laws have to promise punishment if people who are not wholly rational and who are subject to strong impulses and temptations are to obey the laws, and promises must be kept; (2) offenders who are convicted of breaking laws in a just society can be understood to have been party to a social contract designed to protect people's freedom; and (3) threats of punishment in a just society are intended to prevent encroachments on freedom.

This is not a justification of capital punishment, until one specifies a crime that capital punishment uncontroversially fits. Murder is not always the right choice, since such factors as provocation, the numbers of people who die, and the quality of the intention can make some murders much more serious than others; while crimes other than murder—crimes in which, despite the criminal's best efforts, the victim survives—can be as bad as or worse than those in which death occurs. Aggravated murder is, as Mill maintained, a more plausible candidate for capital crime than is plain murder. But execution even for aggravated murder has something to be said against it: the danger of executing the innocent in error, and the suspicion—which goes to the heart of retributivism—that it is bad for pain or unpleasantness to be visited even on wrongdoers.

TOM SORELL (1995)
BIBLIOGRAPHY REVISED

SEE ALSO: *Conscience, Rights of; Human Rights; Justice; Medicine, Profession of; Nursing, Profession of; Prisoners, Healthcare Issues of; Prisoners as Research Subjects; Profession and Professional Ethics; Race and Racism; Warfare: Medicine and War; Women as Health Professionals*

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DEEP BRAIN STIMULATION

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Electrical stimulation of the brain is an important therapy for refractory neurological disorders such as drug resistant Parkinson's disease and severe tremor and has become an area of active clinical research in both neurology and psychiatry. Using a technique called *deep brain stimulation* (DBS), small electrical leads are placed into the brain using stereotactic localization. A special head frame is attached to the skull under local anesthesia, and electrodes are implanted using internal brain targets located with reference to anatomical landmarks determined by brain imaging techniques such as computed tomography (CT) or magnetic resonance imaging (MRI). This technique allows for the precise targeting of specific brain sites or nuclei. Insertion of electrodes can be done without damage to adjacent tissue. These electrodes are connected by a wire to a pacemaker implanted in the chest that generates electrical stimulation. Stimulation parameters can be modified by manipulation of the pacemaker.

Unlike ablative surgery that results in irreversible damage of brain tissue from the intentional destruction of targeted areas, the effects of DBS are reversible. The stimulator can be turned off, and the electrodes can generally be removed without any significant aftereffects. DBS differs from other methods that employ electrical stimulation of the central nervous system. Electroconvulsive therapy (ECT), primarily used to treat severe depression, stimulates the brain using electrodes placed on the scalp. Transcranial magnetic stimulation induces electrical currents in the brain using external magnetic coils. Electrical stimulation in the neck of the vagus nerve has been demonstrated to reduce epileptic seizures. Cortical stimulation of the brain is also employed as a treatment for chronic pain disorders (Greenberg).

Electrical stimulation of the brain is also used as a diagnostic tool in the treatment of epilepsy and as a means to localize specific brain areas in order to avoid injury during surgical procedures. Electrical stimulation has also been applied within the peripheral nervous system for neuroprosthethic applications such as reconstituting motor function in a paralyzed limb.

Historical Considerations

The modern history of electrical stimulation of the brain dates to the nineteenth century During this period the French surgeon and anthropologist Paul Broca (1824–1880) correlated speech with an area in the left hemisphere that is known as Broca's area, and the English neurologist John Hughlings Jackson hypothesized that electrical activity in the cortex could result in seizures. In tandem with these efforts to correlate cerebral structure and function, early neurophysiologists engaged in animal experimentation using electrical stimulation In 1870 the German neurologists Eduard Hitzig and Gustav Fritsch demonstrated motor activity in a dog following stimulation (Thomas and Young). In 1873 the Scottish neurologist David Ferrier induced contralateral seizures in a dog after unilateral hemispheric stimulation.

The first known electrical stimulation of the human brain was conducted by the American neurosurgeon Roberts Bartholow in Cincinnati, Ohio, in 1874 on a terminally ill woman with locally invasive basal cell carcinoma that had eroded her skull and left her brain exposed. Bartholow demonstrated that the dura mater covering the brain was insensate, that motor activity on one side of the body could be induced by stimulation of the opposite hemisphere, and that electrical stimulation of the brain could induce localized seizures and transient loss of consciousness when the amount of current was increased. The patient subsequently died from recurrent seizure activity. Contemporaries harshly criticized Bartholow on ethical grounds because of the fatal complications of the intervention, the uncertain nature of the patient's "consent," and the suffering that she experienced (Morgan).

Early electrical stimulation of the brain was used as a method of mapping cerebral cortical function, matching the site of stimulation of the brain's surface with the patient's response during operations under local anesthesia. Pioneering work was done by two American neurosurgeons: Harvey Cushing in the early twentieth century and Wilder Penfield, who later in the century used electrical stimulation in his study of epilepsy and the mapping of cognitive function. An important advance was the development in 1947 of stereotactic surgery, which enabled brain targets to be precisely located in three dimensions. With this technique, electrodes could now be inserted in the brain without the completion of a full craniotomy in which the entire skull needs to be opened (Gildenberg, 1990).

Robert G. Heath first described electrical stimulation for the control of chronic pain in his 1954 book, *Studies in Schizophrenia.* In the 1960s and 70s investigators demonstrated that deep stimulation of selected targets within the brain was demonstrated to relieve pain In 1985, the Swiss neurosurgeon, Jean Siegfried noted that stimulation of the thalamus for pain control could improve tremor in a patient with Parkinson's disease (Gildenberg, 1998).

The Psychosurgery Debate

Research involving electrical stimulation of the brain was closely linked to the broader debate over psychosurgery in the 1960s and 1970s (Fins, 2003). Commentators from that era worried about the use of electrical stimulation of the brain as a means of behavior control to address social problems such as crime and civic unrest. These concerns were prompted, in part, by the work of José M. R. Delgado who advanced the idea of "psychocivilizing society" using a brain implant that could be operated by remote control. Delgado came to international attention in 1965 when he stopped a charging bull in a bullring using a "stimoceiver" he had developed. Speculation was enhanced by popular novels such as Michael Crichton's *The Terminal Man* whose main character underwent electrical stimulation of the brain to treat violent behavior.

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, authorized by the National Research Act of 1974, was specifically ordered by the U.S. Congress to issue a report on psychosurgery (*National Research Act of 1974. U.S. Statutes at Large*). The National Commission, which issued its report in 1977, included electrical stimulation of the brain under its definition of psychosurgery, noting that "psychosurgery includes the implantation of electrodes, destruction or direct stimulation of the brain by any means" when its primary purpose was to "control, change, or affect any behavioral or emotional disturbance" (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research). The National Commission's definition of psychosurgery excluded brain surgery for the treatment of somatic disorders such as Parkinson's disease or epilepsy or for pain management.

Of the National Commission, the Behavioral Control Research Group of the Hastings Institute (Blatte), and the American Psychiatric Association's Task Force on Psychosurgery (Donnelly), none found reliable evidence that psychosurgery had been used for social control, for political purposes, or as an instrument for racist repression as had been alleged. Contrary to expectations of the day, the National Commission did not recommend that psychosurgical procedures be banned. Instead, it found sufficient evidence of efficacy of some psychosurgical procedures to endorse continued experimentation as long as strict regulatory guidelines and limitations were in place.

Although allegations of mind control were never substantiated, contemporary media reports about modern deep brain stimulation often allude to these earlier fears This misuse of historical analogy has the potential to distort current policy regarding the regulation of this novel technology (Fins, 2002).

Clinical Applications in Neuromodulation

The modern era of neuromodulation began in 1987 when the French neurosurgeon Alim Benabid noted improvements of parkinsonian tremor following stimulation of the thalamus (Speelman and Bosch). While engaged in mapping with electrodes prior to ablative surgery for Parkinson's disease, Benabid discovered that electrical stimulation of specific targets could modulate motor symptoms and tremor—a technique that came to be known as neuromodulation. These observations inspired him to develop the modern deep brain stimulator in use today (Fins and Schachter).

Deep brain stimulation is viewed as the standard of care for the treatment of refractory Parkinson's disease and is no longer investigational. In 1997 the U.S. Food and Drug Administration (FDA) approved use of the deep brain stimulator for refractory Parkinson's disease and essential tremor (Blank). DBS has been found effective in prospective, double-blind studies in patients with advanced Parkinson's disease (Deep-Brain Stimulation, 2001; Kumar et al.).

Complications can be related to the procedure, device, or stimulation, and they include hemorrhage, infection, seizures, and hardware-related complications. Such complications can necessitate revision or removal of the device at a rate per electrode year of 8.4 percent (Oh et al.). In one large series of patients, there were no fatalities or permanent severe neurological complications, although 6 percent of patients had some persistent neurological complication (Beric et al.).

In addition to being used to treat Parkinson's disease, neuromodulation using DBS has been used to treat chronic pain and manage epilepsy (Kopell and Rezai). Cortical mapping continues, with more electronic sophistication. Such mapping is being used to guide neurosurgical procedures; to prevent injuries to critical areas, such as those associated with speech or movement, during operations on the brain; and to precisely locate areas of the brain involved with epilepsy, occasionally by provoking seizures through stimulation (Feindel).

Investigational Applications

Research in deep brain stimulation is blurring the disciplinary boundaries between neurology and psychiatry. French investigators have discovered that DBS caused transient acute depression in a patient with Parkinson's disease whose motor function had improved markedly through DBS intervention (Bejjani et al.). Investigators are conducting clinical trials for the use of DBS for severe psychiatric illnesses such as obsessive–compulsive disorder using techniques pioneered in the treatment of movement disorders (Roth et al.; Rapoport and Inoff-Germain). Nicholas D. Schiff and colleagues have proposed the use of DBS for the modulation of consciousness after severe traumatic brain injury (Schiff, Plum, and Rezai).

Ethical Considerations

Deep brain stimulation raises special concerns because neuromodulation techniques deal with the direct stimulation of the brain. No other organ is so closely involved with concepts of mind or self, self-determination and consent.

POTENTIAL ALTERATION OF THE SELF. Interventions involving brain structure or function may result in alterations in cognition, memory, or emotions that may have a bearing on personhood. The potential of DBS to alter brain function may lead some to argue categorically against these interventions. This position would fail to appreciate that psychoactive drugs and cognitive rehabilitation alter brain states and that DBS can be used to restore brain functions that had themselves been altered by injury or disease.

The use of DBS as a potential agent of cognitive rehabilitation raises the question of whether helping a patient regain self-awareness is always an ethical good (Fins, 2000). Partial recovery of cognitive function could theoretically lead to greater awareness of impairment and increased suffering. These perceptions, which may also accompany improvement from more conventional rehabilitation, might be reversed with cessation of stimulation or be treated with antidepressant therapy.

THERAPEUTIC VERSUS INVESTIGATIONAL USE. Given the rapid development of this field, it is important to determine whether the application of deep brain stimulation to a particular disease is therapeutic or investigational. Historically, a treatment has moved from investigational use to therapeutic use when it is shown to relieve the symptoms it is intended to relieve with an acceptable degree of risk and when a significant proportion of physicians, especially those working in the field, are convinced that the intended outcome will appear without adverse long- or short-term effects that outweigh the benefits. This delineation between research and therapy has implications for the informed-consent process and the ability of surrogates to provide consent for DBS when a patient or subject lacks decision-making capacity. In the early twenty-first century DBS is recognized as therapeutic for the management of chronic pain, Parkinson's disease, and other movement disorders. It remains investigational for other indications.

Today, the use of a device such as the deep brain stimulator goes through several investigational stages before it is accepted as therapeutic. Formal mechanisms are in place to codify this transition. The FDA uses the investigational device exemption process to regulate devices that pose significant risk, such as the deep brain stimulator (Pritchard, Abel, and Karanian). FDA procedures, which supplement institutional review board (IRB) oversight of clinical trials, are designed to establish the safety and efficacy of devices and are required by law.

Once a device has been approved for use in humans, a clinical trial can proceed to assess the safety and efficacy of the device for a particular indication. Use of a device is deemed therapeutic when its safety and efficacy have been demonstrated in prospective trials, the most rigorous being ones that are double-blinded and randomized (a double-blinded study is one in which during the course of the study neither the subjects nor the conductors of the study know which subjects are in the active therapy or placebo group). Blinded studies can be conducted in the evaluation of DBS. Once the electrodes have been implanted, patients can be blinded to whether they are receiving stimulation, and their responses can be evaluated. Such methodological rigor is essential in the assessment of DBS because of the potential for a powerful placebo effect. The placebo effect has been shown to improve motor performance of patients with Parkinson's disease who were led to believe that they were being stimulated (Pollo et al.).

Demarcating the therapeutic use of DBS from the investigational may be difficult. For example, the use of an approved device does not, in itself, mean that an intervention is therapeutic. In these cases, the intent of the physician or clinical investigator may be important. Many would assert that if the physician's *intent* is to produce effects generally beneficial to the patient that have previously been demonstrated in similar cases, the intervention can be considered therapeutic. But when the investigator intends to use an approved device to increase knowledge of safety or efficacy for an approved indication or use the device at a new anatomical site or for a new indication, such interventions should be considered to be investigational and undergo review by an IRB.

Because investigational uses of DBS require more regulatory oversight, clinicians might be biased to classify borderline uses of DBS as therapeutic When it is unclear whether the use of DBS is therapeutic or investigational, clinicians should seek the guidance of their local IRB to mitigate this potential conflict of interest.

INFORMED CONSENT. The delineation of DBS as either therapeutic or investigational is also critical given ethical norms that govern informed consent. Given the ongoing investigational nature of many DBS procedures, potential candidates for stimulation need to be informed of whether the proposed procedure is therapeutic or experimental. Physicians who obtain consent from patients for therapeutic procedures should explain the risks, benefits, and alternatives so that the patient, or a surrogate authorized to consent for medical treatment, can provide consent.

Clinicians should seek to maintain the patient's voluntariness and ability to make an informed and reasonable decision about treatment with DBS. Those obtaining consent should appreciate that the chronic nature of the illness and desperation may lead a patient to consent to any treatment that promises symptomatic relief.

When individuals are approached for enrollment in an IRB-approved clinical trial, it is especially important to state the investigational nature of the intervention. Investigators should be careful to avoid the suggestion of a "therapeutic misconception" that falsely equates a clinical trial with safe and effective therapy (Applebaum et al.).

DBS RESEARCH IN THE DECISIONALLY INCAPACITATED. Individuals with severe psychiatric illness or head trauma, who may become candidates for enrollment in DBS clinical trials, may lack decision-making capacity. When these individuals are unable to engage in the informed-consent process, they are considered a vulnerable population and in need of special protections. While surrogates are generally allowed to consent to therapeutic procedures, their authority is more constrained when permission is sought for enrollment in a clinical trial unless they have been authorized through an advance directive for prospective research.

The National Bioethics Advisory Commission (NBAC), in its 1998 report, *Research Involving Persons with Mental*

Disorders That May Affect Decisionmaking Capacity, proposed guidelines to regulate the conduct of research on individuals who are unable to provide consent. While the NBAC recommendations were never enacted into law, they do point to the ethical complexity of neuromodulation research in several cases: when subjects lack decision-making capacity, when the research has yet to demonstrate the prospect of direct medical benefit, and when the research poses more than minimal risk.

BALANCING THE PROTECTION OF HUMAN SUBJECTS WITH ACCESS TO RESEARCH. When considering the balance between the protection of human subjects and access to neuromodulation research, it is important to ask whether current ethical norms deprive decisionally incapacitated individuals of interventions that have the potential to promote self-determination by restoring cognitive function (Fins, 2000). While the ethical principles of respect for persons, beneficence, and justice require that decisionally incapacitated subjects are protected from harm, these principles can also be invoked to affirm a fiduciary obligation to promote well-designed and potentially valuable research for this historically underserved population (Fins and Miller; Fins and Schiff). This justice claim becomes especially compelling as developments in neuromodulation demonstrate growing clinical potential (Fins, 2003).

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SEE ALSO: *Behaviorism; Behavior Modification Therapies; Electroconvulsive Therapy; Emotions; Freedom and Free Will; Informed Consent: Issues of Consent in Mental Healthcare; Neuroethics; Psychosurgery, Ethical Aspects of; Psychosurgery, Medical and Historical Aspects of; Research Policy: Risk and Vulnerable Groups; Technology*

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DEMENTIA

• • •

The syndrome of dementia is an irreversible decline in cognitive abilities that causes significant dysfunction. Like most syndromes, dementia can be caused by a number of diseases. In the nineteenth century, for example, a main cause of dementia was syphilis. As a result of dramatic increases in average human life expectancy, dementia is caused primarily by a number of neurological diseases associated with old age. Dementia is distinguished from *pseudo-dementia* because the latter is reversible—for example, depression, extreme stress, and infection can cause dementia but with treatment a return to a former cognitive state is likely (Oizilbash et al.). Dementia is also distinguished from *normal age-related memory loss,* which effects most people by about age seventy in the form of some slowing of cognitive skills and a deterioration in various aspects of memory. But *senior moments* of forgetfulness do not constitute dementia, which is a precipitous and disease-related decline resulting in remarkable disability. Since 1997, a degree of cognitive impairment that is greater than normal age-related decline but not yet diagnosable as dementia has been labeled *mild cognitive impairment* (MCI), with about one-third of those in this category *converting* to dementia each year. These cognitive conditions from normal age-related forgetfulness to dementia form a continuum. Specialized clinics that were once called Alzheimer's Centers are increasingly changing their name to Memory Disorders Centers in order to begin to treat patients at various points along the continuum prior to the onset of dementia.

Although dementia can have many causes, the primary cause of dementia in our aging societies is Alzheimer disease (AD). Approximately 60 percent of dementia in the American elderly and worldwide in industrialized nations is secondary to AD (U.S. General Accounting Office). This discussion will focus on so-called *Alzheimer's dementia* in order to illustrate ethical issues that pertain to all progressive dementias. One epidemiological study in the United States estimated that 47 percent of persons eighty-five years and older (the *old-old*) had probable AD, although this is a widely considered inflated (Evans et al). Epidemiologists differ in their estimates of late-life AD prevalence, but most studies agree roughly on the following: about 1 percent to 2 percent of older adults at age sixty have probable AD, and this percentage doubles every five years so that 3 percent are affected at age sixty-five, 6 percent at age seventy, 12 percent at age seventy-five, and 24 percent by age eighty. While some argue that those who live into their nineties without being affected by AD will usually never be affected by it, this is still speculative. According to a Swiss study, 10 percent of non-demented persons between the ages of eighty-five and eighty-eight become demented each year (Aevarsson). There are very few people in their late forties and early fifties who are diagnosed with AD. Without delaying or preventive interventions, the number of people with AD, in the United States alone, will increase to 14.3 million by 2050 (Evans et al). These numbers represent a new problem of major proportions and immense financial consequences for medicine, families, and society (Binstock et al).

There is a second very rare form of AD which is early onset that is clearly familial. About 3 percent of AD cases are caused by rare autosomal dominant (or causative) single gene mutations, of which three are clearly defined. In these cases of *familial* AD, symptoms usually occur in the early forties or mid- to late-thirties, and death occurs within five years of diagnosis, in contrast to the more typical seven to eight years for ordinary late-onset disease (Post and Whitehouse).

Various stage theories of disease progression have been developed. However, in clinical practice, professionals speak roughly of three stages. In *mild stage dementia,* the newly diagnosed patient has significant cognitive losses resulting in disorientation and dysfunction, and often displays affective flatness and possibly depression. In *moderate stage dementia,* the patient forgets that he or she forgets, thereby gaining relief from insight into losses. Some patients will at this point adjust well emotionally to a life lived largely in the pure present, although some long-term memories are still in place. The recognition of loved ones is usually still possible. However, as many as one-third of patients in the moderate stage will struggle with emotional and behavior problems, including agitation, combativeness, paranoia, hallucinations, wandering, and depression. A small percentage becomes sexually disinhibited. The *advanced stage of dementia* includes a loss of all or nearly all ability to communicate by speech, inability to recognize loved ones in most cases, loss of ambulation without assistance, incontinence of bowel and/or bladder, and some weight loss due to swallowing difficulties. The advanced stage is generally considered terminal, with death occurring on average within two years. AD, however, is heterogeneous in its manifestations, and defies simplistic staging. For example, while most people with advanced AD will have no obvious ability to recognize loved ones, this is not always the case. In late December 2000, for example, the daughter of a man recently deceased sent an e-mail note to the AD networks around the world:

> Hello Dear Friends: As many of you know, my father has been suffering from Alzheimer's disease for the past 4.5. years. It has been a long and often very hard road for him, for my mom, and for me too. However, as of 7 p.m. last night, my father no longer has to struggle with the disease that robbed him of every part of his being, except one. He never once stopped recognizing my mom and never, ever stopped reaching out to her and wanting to give her a kiss. No matter how many parts of his personality were lost, no matter how many hospital visits full of needles and catheters, no matter how many diapers, he always retained his kind, gentle sweetness and his European manners as a gentleman. In the end, things went very quickly for him. He simply closed his eyes and closed his mouth, indicating no more food or water.

The gentleman described above was in the advanced and therefore terminal stage of AD. Yet he retained the ability to recognize loved ones.

The Fundamental Moral Question: Do People with Dementia *Count*?

Despite the seriousness of dementia and the responsibilities it creates for caregivers, it is ethically important that the person with dementia not be judged by *hypercognitive* values (Post, 1995, 2000a). The self is not cognition alone, but is rather a complex entity with emotional and relational aspects that should be deemed morally significant and worthy of affirmation (Sabat). A bias against the deeply forgetful is especially pronounced in *personhood* theories of moral status in which persons are defined by the presence of a set of cognitive abilities (Kitwood). After discussion of the disparities in bioethical thinking about what constitutes a person, Stanley Rudman concludes, "It is clear that the emphasis on rationality easily leads to diminished concern for certain human beings such as infants, … and the senile, groups of people who have, under the influence of both Christian and humanistic considerations, been given special considerations" (Rudman, p. 47). Often, the personhood theorists couple their exclusionary rationalistic views with utilitarian ethical theories that are deeply incoherent with regard to life and death. As Rudman summarizes the concern, rationality is too severe a ground for moral standing, "allowing if not requiring the deaths of many individuals who may, in fact, continue to enjoy simple pleasures despite their lack of rationality …" (Rudman, p. 57). Of course, in the real world of families, love, and care, personhood theories have no practical significance.

The philosophical tendency to diminish the moral status or considerability of people with dementia is also related to a radical differentiation between the formerly intact or *then* self and the currently demented or *now* self. The reality is that until the very advanced and even terminal stage of AD, the person with dementia will usually have sporadically articulated memories of deeply meaningful events and relationships ensconced in long-term memory. It is wrong to bifurcate the self into then and now, as if continuities are not at least occasionally striking (Kitwood, Sabat). This is why it is essential that professional caregivers be aware of the person's life story, making up for losses by providing cues toward continuity in self-identity. Even in the advanced stage of dementia, as in the case presented at the outset of this entry, one finds varying degrees of emotional and relational expression, remnants of personality, and even meaningful nonverbal communication as in the reaching out for a hug.

The fitting moral response to people with dementia, according to western ethical thought as informed by Judaism and Christianity, is to enlarge our sense of human worth to counter an exclusionary emphasis on rationality, efficient use of time and energy, ability to control distracting impulses, thrift, economic success, self-reliance, self-control, *language advantage,* and the like. As Alasdair MacIntyre argues, too much has been made of the significance of language, for instance, obscuring the moral significance of species who lack linguistic abilities, or human beings who have lost such abilities (MacIntyre). It is possible to distinguish two fundamental views of persons with dementia. Those in the tradition of Stoic and Enlightenment rationalism have achieved much for universal human moral standing by emphasizing the spark of reason (*logos*) in us all; yet when this rationality dissipates, so does moral status. Those who take an alternative position see the Stoic heritage as an arrogant view in the sense that it makes the worth of a human being entirely dependent on rationality, and then gives too much power to the reasonable. This alternative view is generally associated with most Jewish and Christian thought, as well as that of other religious traditions in which the individual retains equal value regardless of cognitive decline. As the Protestant ethicist Reinhold Niebuhr wrote, "In Stoicism life beyond the narrow bonds of class, community, and race is affirmed because all life reveals a unifying divine principle. Since the principle is reason, the logic of Stoicism tends to include only the intelligent in the divine community. An aristocratic condescension, therefore, corrupts Stoic universalism." (p. 53). This rationalistic inclusivity lacks the deep universalism of other-regarding or unlimited love (Post, 2000a).

The perils of forgetfulness are especially evident in our culture of independence and economic productivity that so values intellect, memory, and self-control. AD is a quantifiable neurological atrophy that objectively assaults normal human functioning; on the other hand, as medical anthropologists's highlight, AD is also viewed within the context of socially constructed images of the human self and its fulfillment. A longitudinal study carried out in urban China, for example, by Charlotte Ikels, which was published in 1998, indicates that dementia does not evoke the same level of dread there as it does among Americans. Thus, the stigma associated with the mental incapacitation of dementia varies according to culture. Peter Singer, for example, is part of a *preference utilitarian* philosophical culture that happens to believe that those who do not project preferences into the future and implement them are not persons. According to Singer, those with memory impairment must then ultimately be devalued. While this devaluation is plausible for those human beings in the persistent vegetative state where the essentially human capacities—cognitive, emotional, relational, or aesthetic—no longer survive, people with dementia can experience many forms of gratification. The challenge is to work with remaining capacities. The first principle of care for persons with dementia is to reveal to them their value by providing attention and tenderness in love (Kitwood).

Enhancing Quality of Life

Emotional, relational, aesthetic, and symbolic well-being are possible to varying degrees in people with progressive dementia (Kitwood). Quality of life can be much enhanced by working with these aspects of the person. The aesthetic well-being available to people with AD is obvious to anyone who has watched art or music therapy sessions. In some cases, a person with advanced AD may still draw the same valued symbol, as though through art a sense of self is retained (Firlik).

A sense of purpose or meaning on the part of caregivers can enhance quality of life for the person with dementia. In an important study by Peter V. Rabinsand and his colleagues, thirty-two family caregivers of persons with AD and thirty caregivers of persons with cancer were compared cross-sectionally to determine whether the type of illness cared for affected the emotional state of the caregiver and to identity correlates of both undesirable and desirable emotional outcomes. While no prominent differences in negative or positive states were found between the two groups, correlates of negative and positive emotional status were identified. These include caregiver personality variables, number of social supports, and the feeling that one is supported by one's religious faith. Specifically, "emotional distress was predicted by self-reported low or absent religious faith" (Rabins et al., p. 335). Moreover, spirituality predicted positive emotional states in caregiving. Interestingly, the study suggests that it was "belief, rather than social contact, that was important" (Rabins et al., p. 332) Spirituality and religion are especially important to the quality of life of African-American caregivers, for whom it is shown to protect against depression (Picot et al.). Spirituality is also a means of coping with the diagnosis of AD for many affected individuals (Elliot).

In general, quality of life is a self-fulfilling prophesy. If those around the person with dementia see the glass as half empty and make no efforts to relate to the person in ways that enhance his or her experience, then quality of life is minimal. Steven R. Sabat, who has produced the definitive observer study of the experience of dementia, underscores the extent to which the dignity and value of the person with dementia can be maintained through affirmation and an existential perspective.

Specific Clinical Ethical Issues

Nearly every major issue in clinical ethics pertains to AD (Post, 2000b). The Alzheimer's Disease and Related Disorders Association issued an authoritative 2001 publication on ethics issues that covers truth in diagnosis, therapeutic goals, genetic testing, research ethics, respect for autonomy, driving and dementia, end-of-life care, assisted oral feeding and tube feeding, and suicide and assisted suicide. This work borrowed considerably from focus group work that led to the Fairhill Guidelines on Ethics of the Care of People with Alzheimer's Disease (Post and Whitehouse). The Fairhill Guidelines were also the acknowledged baseline for the Alzheimer Canada's national ethics guidelines entitled "Tough Issues" (Cohen et al). The most relevant work on ethics and AD emerges in a grounded way from the affected individuals, their families, and those who serve them in loyal care.

The Association recommends truthtelling in diagnosis because this allows the affected individual, while still competent, to make plans for the future with regard to finances, healthcare, and activities. Most clinicians in the United States and Canada do disclose the probable diagnosis of AD, even though it is only about 90 percent accurate and must be verified upon autopsy. This transition has been encouraged by the emergence of new treatments (Alzheimer's Disease Association).

Genetic testing is frowned on by the Association, except in the early-onset familial cases where a single gene mutation causes the disease. AD is the object of intense genetic analysis. It is a genetically heterogeneous disorder—to date, it is associated with three determinative or causal gene mutations (i.e., someone who has the mutation will definitely get the disease) and one susceptibility or risk gene. The three causal AD genes mutations (located on chromosomes 21, 14, and 1) were discovered in the 1990s. These are autosomal-dominant genes and pertain to early-onset familial forms of AD (usually manifesting between the early 40s and mid-50s) which, according to one estimate, account for possibly fewer than 3 percent of all cases. These families are usually well aware of their unique histories. Only in these relatively few unfortunate families is genetic prediction actually possible, for those who carry the mutation clearly know that the disease is an eventuality. Many people in these families do not wish to know their genetic status, although some do get tested. Currently, there is no clearly predictive test for ordinary late-onset AD that is associated with old age. There is one well-defined susceptibility gene, an apolipoprotein E $\in 4$ allele on chromosome 19 (apoE=protein; APOE=gene), which was discovered in 1993 and found to be associated with susceptibility to late-onset AD (after fifty-five years). A single $\in 4$ gene (found in about one-third of the general population) is not predictive of AD in asymptomatic individuals—it does not come close to foretelling disease, and many people with the gene will never have AD. Among those 2 percent of people with two of the $\in 4$ genes, AD does not necessary occur either (Post et al). Such susceptibility testing can be condoned in a research setting, but is not encouraged in clinical practice because it provides no reliable predictive information upon which to base decisions, it has no medical use, and it may result in discrimination in obtaining disability or long-term care insurance (Post et al., Alzheimer's Disease Association).

The Association's 2001 statement includes the important argument that disclosing the diagnosis early in the disease process allows the person to "be involved in communicating and planning for end-of-life decisions." Diagnostic truthtelling is the necessary beginning point for an ethics of *precedent autonomy* for those who wish to implement control over their futures through advance directives such as durable power of attorney for healthcare, which allows a trusted loved one to make any and all treatment decisions once the person with dementia becomes incompetent. This can effectively be coupled with a living will or some other specific indication of the agent's material wishes with regard to end-of-life care. Unless the person knows the probable diagnosis in a timely way while still competent to file such legal instruments, the risk of burdensome medical technologies is increased. Even in the absence of such legal forms, however, many technologically advanced countries will allow next of kin to decide against efforts to extend life in severe dysfunction. This is important because many patients suffer incapacitating cognitive decline long before having a diagnostic work up; those who are diagnosed early enough to exercise their autonomy can become quickly incapacitated.

The Association does not support mandatory reporting of a probable diagnosis of AD to the Department of Motor Vehicles. There are a number of reasons for this caution, one of which is patient confidentiality. Reporting requirements might discourage some persons from coming into the clinic for early diagnosis at a time early in the course of disease when drug treatments are most clearly indicated. Eventually all people with AD must stop driving when they are a serious risk to self or others. Family members must know that if a loved one drives too long and injures others, they may even be held financially liable and insurers may not be obliged to cover this liability. Ideally, a privilege is never limited without offering the person ways to fill in the gaps and diminish any sense of loss. An *all or nothing* approach can and should be avoided. Compromise and adjustments can be successfully implemented by those who are informed and caring, especially when the person with AD has insight into diminishing mental abilities and loss of competence. The affected person should retain a sense of freedom and self-control if possible (Alzheimer's Disease Association).

AD is on the leading edge of the debate over physician-assisted suicide (PAS) and euthanasia. The policies that emerge from this debate will have monumental significance for people with dementia, and for social attitudes toward the task of providing care when preemptive death is cheaper and easier. The Association affirms the right to dignity and life for every Alzheimer patient, and cannot condone suicide (Alzheimer's Disease Association).

The Association asserts that the refusal or withdrawal of any and all medical treatment is a moral and legal right for all competent Americans of age, and this right can be asserted by a family surrogate acting on the basis of either *substituted judgement* (what would the patient when competent have wanted) or *best interests* (what seems the most humane and least burdensome option in the present).

The Association concludes that AD *in its advanced stage should be defined as a terminal disease,* as roughly delineated by such features as the inability to recognize loves ones, to communicate by speech, to ambulate, or to maintain bowel and/or bladder control. When AD progresses to this stage, weight loss and swallowing difficulties will inevitably emerge. Death can be expected for most patients within a year or two, or even sooner, regardless of medical efforts. One useful consequence of viewing the advanced stage of AD as terminal is that family members will better appreciate the importance of palliative (pain medication) care as an alternative to medical treatments intended to extend the dying process. All efforts at life extension in this advanced stage create burdens and avoidable suffering for patients who could otherwise live out the remainder of their lives in greater comfort and peace. Cardiopulmonary resuscitation, dialysis, tube-feeding, and all other invasive technologies should be avoided. The use of antibiotics usually does not prolong survival, and comfort can be maintained without antibiotic use in patients experiencing infections. Physicians and other healthcare professionals should recommend this less burdensome and therefore more appropriate approach to family members, and to persons with dementia who are competent, ideally soon after initial diagnosis. Early discussions of a peaceful dying should occur between persons with dementia and their families, guided by information from healthcare professionals on the relative benefits of a palliative care approach (Alzheimer's Disease Association).

Avoiding hospitalization will also decrease the number of persons with advanced AD who receive tube-feeding, since many long-term care facilities send residents to hospitals for tube placement, after which they return to the facility. It should be remembered that the practice of long-term tube-feeding in persons with advanced dementia began only in the mid-1980s after the development of a new technique called percutaneous endoscopic gastrostomy (PEG). Before then, such persons were cared for through assisted oral feeding. In comparison with assisted oral feeding, however, long-term tube-feeding has no advantages, and a number of disadvantages (Alzheimer's Disease Association).

In closing this entry, attention will be directed in greater depth to three representative areas of special concern to family and professional caregivers: cognitive enhancing compounds, research risk, and tube feeding.

COGNITIVE ENHANCING COMPOUNDS. Persons with AD and their families greet the emergence of new compounds to mitigate the symptoms of dementia with great hope. These compounds, known as cholinesterase inhibitors, slightly elevate the amount of acetylcholine in the brain, slightly boosting communication between brain cells. In the earlier stages of the disease, while enough brain cells are still functional, these drugs can improve word finding, attentiveness to tasks, and recognition of others for a brief period in the range of six months to two years. Thus, some symptoms can be mitigated for a while, but these drugs have no impact on the underlying course of the disease, and neither reverse nor cure dementia. Some affected individuals, after taking any new compound whether artificial or natural, may exude a burst of renewed self-confidence in their cognitive capacities. But how much of this is due to the compound itself remains unclear. Presumably each person with AD is a part of some relational network that inevitably plays a role in the self-perception of cognitive improvement—indeed, self-perception is dependent on the perceptions of others and their need for a glimmer of hope as caregivers. Realistically, a medication may bring the self-perception of a renewed sense of mental clarity, as though *a fog has lifted,* yet none of the available cognitive enhancing compounds slow the progression of disease.

It is hard for professionals to know how to respond to the passion for the possible. Should unrealistic hopes be indulged for emotional reasons (Post, 1998, 2000b)? Should the money expended for new compounds of relatively marginal efficacy be spent on environmental and relational opportunities? Many clinicians caution both persons with AD and their family caregivers against thinking that the new compound is a miracle cure. Many still remain somewhat skeptical of studies of cognitive testing indicating significant but always minor benefit; no such studies take into account confounding factors such as the quality of relationships, environment, and emotional well-being. Nevertheless, reports of a *fog lifting* are interesting anecdotally. Are statements of future expectations so excessive among some desperate caregivers that hope is easily exploited by pharmaceutical profiteers? Medication needs to be placed within a full program of dementia care (including emotional, relational, and environmental interventions) so as not to be excessively relied on; family members should be respected when they desire to stop medication; even when medication is desired, families need to appreciate the limits of current compounds.

It is possible as well, that the anti-dementia compounds can, in those cases where they may have some capacity to give what is always at best a modest and fleeting cognitive boost,—fleeting because the underlying cognitive decline is intractable—be double-edged swords. While some slight cognitive improvements may occur, these may come at the cost of renewed insight into the disease process on the part of the affected individual, and of relational difficulties in the context of affected individuals and their caregivers. If the kindest point in the progression of AD is when the person with dementia forgets that he or she forgets, and is therefore able to get free of *insight* and related anxiety, then a little cognitive enhancement is not obviously a good thing for quality of life and quality of lives. Is it possible, then, to speak of *detrimental benefits?*

Decisions about these compounds are ethically and financially complex because their efficacy is quite limited, the affected individual remains on the inevitable downward trajectory of irreversible progressive dementia, and there may be nonchemical interventions focusing on emotional, relational, and spiritual well-being that are both cheaper and more effective. This is not to suggest that we should all be pharmacological Calvinists rather than pharmacological hedonists, but does anyone doubt that the pharmaceuticals wield a great deal of power across the spectrum of AD support groups? In the future, as compounds emerge that can actually alter the underlying progression of AD, affected individuals and caregivers will be faced with difficult tradeoffs between length of life and quality of life (Post, 1997, 2001a).

Research Risks

The *crucial* unanswered question in AD research is this: What should be the maximal or upper limit for permissible potential risks in any AD research, regardless of whether the research is characterized as potentially therapeutic for the subject or not? A secondary unanswered question is this: Should proxy consent be permitted in higher risk research, even when there is no potential therapeutic benefit for the participant, just as it is permitted when the research is considered potentially therapeutic? Without agreement on these fundamental questions, the upcoming treatments, promising both greater benefit and greater risk, will not expeditiously reach those in most need.

The Association's 2001 statement is as follows:

> (A) For minimal risk research all individuals should be allowed to enroll, even if there is no potential benefit to the individual. In the absence of an advance directive, proxy consent is acceptable.
>
> (B) For greater than minimal risk research *and* if there is a reasonable potential for benefit to the individual, the enrollment of all individuals with Alzheimer disease is allowable based on proxy consent. The proxy's consent can be based on either a research specific advance directive *or* the proxy's judgment of the individual's best interests.
>
> (C) For greater than minimal risk research *and* if there is *no* reasonable potential for benefit to the individual only those individuals who (1) are capable of giving their own informed consent, or (2) have executed a research specific advance directive are allowed to participate. In either case, a proxy must be available to monitor the individual's involvement in the research. (*Note*: this provision means that individuals who are not capable of making their own decisions about research participation and have not executed an advance directive or do not have a proxy to monitor their participation, cannot participate in this category of research.)

The Association's statement is laudable because of its endorsement of surrogate consent in all research of potential benefit to the subject, even if there is potentially a greater than minimal risk. Surrogate consent should always be based on accurate facts about the risks and potential benefits of the clinical research or trial, rather than on understatement of risks or burdens and exaggerated claims of benefit. Participants in all research should be protected from significant pain or discomfort. It is the responsibility of all investigators and surrogates to monitor the well-being of participants.

The Association indicates that surrogates must not allow their hopes for effective therapies to overtake their critical assessment of the facts, or to diminish the significance of participant expressions of dissent. Subject dissent or other expressions of agitation should be respected, although a surrogate can attempt reasonable levels of persuasion or assistance. People with dementia, for example, may initially refuse to have blood drawn or to take medication; once a family member helps calm the situation and explains things, they may change their minds. This kind of assistance is acceptable. Continued dissent, however, requires withdrawal of the participant from the study, even though surrogates would prefer to see the research participation continue.

At this point in time, the most important unresolved issue in dementia research is how much potential risk to those affected by AD should society allow? Research in AD is becoming increasingly physically invasive and biologically complex. Is there any maximal threshold of potential risk beyond which research should be disallowed? Furthermore, how can actual discomforts in research be properly monitored, and what degree of discomfort requires that research be halted? In general, research ethics has not addressed these issues, focusing instead on matters of subject and proxy consent.

END OF LIFE AND PEG TUBES. Gastrostomy tube feeding became common in the context of advanced dementia and in elderly patients more generally after 1981, secondary to the development of the PEG procedure. The PEG procedure was developed by Dr. Michael Gauderer and his colleagues at Rainbow Babies and Children's Hospital in Cleveland from 1979 to 1980 for use in young children with swallowing difficulties. The procedure required only local anesthesia, thus eliminating the significant surgical risk associated with general anesthesia and infection (Gauderer and Ponsky). Gauderer wrote two decades later that while PEG use has benefited countless patients, "in part because of its simplicity and low complication rate, this minimally invasive procedure also lends itself to over-utilization" (p. 879). Expressing moral concerns about the proliferation of the procedure, Gauderer indicates that as the third decade of PEG use begins to unfold, "much of our effort in the future needs to be directed toward ethical aspects …" (p. 882). PEG is being used more frequently even in those patients for whom these procedures were deemed too risky in the past.

For over a decade, researchers have underscored the burdens and risks of PEG tube-feeding in persons with advanced dementia. The mounting literature was well summarized by Finucane and his research colleagues, who found no published evidence that tube-feeding prevents aspiration pneumonia, prolongs survival, reduces risks of pressure sores or infections, improves function, or provides palliation in this population (Finucane, et al.; Gillick; Post, 2001b).

Families often perceive tube-feeding as preventing pneumonia or skin breakdown, and many assume that it extends survival. These perceptions are erroneous. The main benefit of PEG is that it makes life easier for the informal family caregiver who, for reason of competing duties or perhaps physical limitation, cannot find the time or energy to engage in assisted oral feedings. Yet PEG use is not really *easy,* because it has its technological complexities, and the recipient will usually have diarrhea. In some cases, physical restraints are used to keep a person from pulling on the several inches of tube that extend out of the abdomen. One wonders if assisted oral feeding is not easier after all. Regardless, purported technical ease and efficiency do not mean that these technologies should be applied. Should persons with advanced progressive dementia ever be provided with PEGs? In the general, assisted oral feeding and hospice are the better alternative to tube-feeding, although in practice there will be some cases in which the limited capacities of an informal family caregiver do justify tube-feeding as the ethically imperative alternative to starvation when the ability to swallow has begun to diminish. Ideally home health aides would make assisted oral feeding possible even in these cases, but this is not a priority in the healthcare system. Institutions, however, should uniformly provide assisted oral feeding as the desired alternative to tube-feeding, a measure that would profoundly obviate the overuse of this technology.

There will be many family caregivers who have no interest in PEG use and who feel that they are being loyal to their loved one's prior wishes. A physician should expect this response. A study included in-person interviews of eighty-four cognitively normal men and women aged sixty-five years and older from a variety of urban and suburban settings (including private homes, assisted-living apartments, transitional care facilities, and nursing homes). Three-fourths of the subjects would not want cardiopulmonary resuscitation, use of a respirator, or parenteral or enteral tube nutrition with the milder forms of dementia; 95 percent or more would not want any of these procedures with severe dementia (Gjerdingen et al.). These subjects were adequately informed of the burdens and benefits of such interventions.

Physicians and other healthcare professionals should recommend this less burdensome and therefore more appropriate approach to family members, and to persons with dementia who are competent, ideally soon after initial diagnosis. Early discussions of a peaceful dying should occur between persons with dementia and their families, guided by information from healthcare professionals on the relative benefits of a palliative care approach (Volicer and Hurley).

STEPHEN G. POST

SEE ALSO: *Abuse, Interpersonal: Elder Abuse; Advance Directives and Advance Care Planning; Aging and the Aged;*

Artificial Nutrition and Hydration; Autonomy; Beneficence; Care; Christianity, Bioethics in; Compassionate Love; Competence; Confidentiality; Genetic Testing and Screening; Grief and Bereavement; Human Dignity; Informed Consent; Judaism, Bioethics in; Life, Quality of; Life, Sanctity of; Long-Term Care; Medicaid; Medicare; Moral Status; Neuroethics; Palliative Care and Suffering; Research, Unethical; Right to Die, Policy and Law

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DENTISTRY

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Most dentists in the United States practice as independent entrepreneurs either individually or in small groups. Nevertheless, dental care generally is not viewed as an ordinary commodity in the marketplace. Instead, the vast majority of dentists and most people in the larger community think of dentistry as a profession. That is, they consider dental care to be a component of healthcare and consider dentists to be experts in the relevant knowledge and skills, committed individually and collectively as professionals to giving priority to their patients' well-being as they practice their expertise. Consequently, when a person becomes a dentist, he or she makes a commitment to the larger community and accepts the obligations and ethical standards of the dental profession. Those obligations and standards are the subject matter of the subdiscipline called dental ethics.

Ethical Dilemmas

Because dentists rarely make life-or-death decisions, some people are unaware that the professional obligations of dentists require careful study. Important human values are at stake in dental care: relieving and preventing intense pain as well as less intense pain and discomfort; preserving and restoring patients' oral function, on which both nutrition and speech depend; preserving and restoring patients' physical appearance; and preserving and restoring patients' control over their bodies. These matters are important, and as a result dentists who are committed to responding to them in accordance with ethical standards often face complex questions.

Ethical dilemmas such as the following are faced regularly by almost every dentist:

1. When examining a new patient, a dentist finds evidence of poor earlier dental work. What should the dentist say to the patient? Should the dentist contact the previous dentist to discuss the matter? Should the dentist contact the local dental society?
2. May a dentist ethically advertise that his or her practice will produce "happy smiles" as well as quality dental care, or is such advertising false or significantly misleading?
3. May a dentist tell a patient that the patient's teeth are unattractive with a view to recommending aesthetic treatment when the patient has not asked for an opinion and has indicated no displeasure with his or her appearance?
4. May a dentist ethically decline to treat a patient with a highly infectious disease? What obligations does the dentist have regarding the information that this patient is a carrier of infection?
5. How should a dentist deal with an adult patient who cannot participate fully in making decisions about about care? Do treatment considerations depend on the reason for that inability? What should a dentist do when the guardian of a minor or an incompetent adult patient refuses to approve the best kind of therapy?
6. What may a dentist do to obtain cooperative behavior from a young or developmentally disabled patient who needs dental care but is uncontrollable in the chair?
7. What obligations does a dentist have and to whom when that dentist learns that another dentist is substance-dependent in a manner that probably affects the care he or she is providing?

Issues and Themes in Dental Ethics

The specific requirements of a dentist's ethical commitments in any aspect of professional practice depend on the specific facts and circumstances of the situation. However, the principal categories of dentists' professional obligations can be surveyed under nine headings:

1. Who are dentistry's chief clients?
2. What is the ideal relationship between a dentist and a patient?
3. What are the central values of dental practice?
4. What are the norms of competence for dental practice?
5. What sacrifices is a dentist professionally committed to, and in what respects do obligations to the patient take priority over other morally relevant considerations?
6. What is the ideal relationship between dentists and coprofessionals?
7. What is the ideal relationship between dentists, both individually and collectively, and the larger community?

8. What should members of the dental profession do to make access to the profession's services available to all those who need them?
9. What are members of the dental profession obligated to do to preserve the integrity of their commitment to its professional values and educate others about them?

THE CHIEF CLIENT. For every profession there is a person or set of persons whose well-being the profession and its members are committed to serving. The patient in the dental chair is the most obvious chief client of a dentist, but dentists also have professional obligations to the patients in the waiting room and all their patients of record, to patients who present with emergency needs, and arguably to the entire larger community, especially in matters of public health. The relative weight of a dentist's obligations to each of these entities when those obligations come into conflict ordinarily is considered to favor the patient in the chair over the others, but comparative judgments of the respective degrees of need also must be made.

THE IDEAL RELATIONSHIP BETWEEN PROFESSIONAL AND PATIENT. What is the proper relationship between the dentist and the patient in the chair as they make judgments and choices about the patient's care? There are a number of different ways of conceiving this ideal relationship when it involves the dentist and a fully competent adult: with the dentist alone making the judgment that determines action, with the judgment resting with the patient alone, and with the judgment shared by both parties.

Since the late 1960s the accepted norm of dental practice in the United States has shifted toward the third type of relationship: shared judgment and shared choice regarding treatment. The legal doctrine of informed consent identifies a minimum standard of shared decision making for dentists and their patients, but it is important to ask whether informed consent fully expresses the ideal relationship between a dentist and a fully capable patient (Segal and Warner; Ozar, 1985; Hirsch and Gert; Ozar and Sokol, 2002).

What is the appropriate relationship between the dentist and a patient who cannot participate fully in treatment decisions? What is the dentist's proper role in this relationship? What is the role of the patient up to the limit of the patient's capacity to participate? What is the proper role of other parties?

In practice most dentists depend on choices made by the parents and guardians of such patients when they are available and when these choices do not involve significant harm to the patients' oral or general health. However, there is no clear consensus about how dentistry should proceed when these conditions are absent. The dental ethics literature has begun a careful discussion of the dentist's relationship with patients of diminished capacity or no capacity for decision making (Bogert and Creedon; Ozar and Sokol, 2002).

A HIERARCHY OF CENTRAL VALUES. Regardless of many professions' rhetoric on the subject, no profession can be expert in fostering the complete well-being of those it serves. There is instead a certain set of values that are the appropriate focus of each profession's particular expertise. These values can be called the central values of that profession. They determine and/or establish parameters for most aspects of a professional's judgments in practice. They are the criteria by which a person is judged to need professional assistance in the first place and by which that need is judged to have been met properly through the professional's intervention.

What, then, are the central values of dental practice, and if there is more than one, how are those central values ranked? One proposal is that the central values of the dental profession are, in the following order:

1. the patient's life and general health;
2. the patient's oral health, which is understood as appropriate and pain-free oral functioning;
3. the patient's autonomy—to the extent that the patient is capable of exercising it—over what happens to his or her body (including the patient's ranking of health, comfort, cost, aesthetic considerations, and other values);
4. preferred patterns of practice on the part of the dentist (including differing philosophies of dental practice);
5. aesthetic considerations from the point of view of skilled dental practice and from the point of view of patients' aesthetic values; and
6. considerations of efficiency, which may include considerations of cost, from the dentist's point of view. (Ozar and Sokol, 2002)

A particular dental intervention may achieve each of these values to a greater or lesser degree, and each value is more or less urgent for a particular patient. The ethical dentist takes the details of each situation into account and attempt to maximize dentistry's central values in accordance with their ranked priority in every encounter with every patient.

COMPETENCE. Every professional is obligated to acquire and maintain the expertise required to undertake his or her professional tasks. Every professional also is obligated to undertake only the tasks that are within his or her competence. Consequently, dentists must be constantly attentive to whether they have sufficient competence to make each specific diagnosis and perform each particular procedure for each patient in light of the clinical circumstances, especially when this involves something nonroutine.

Of necessity the dental community, not the community at large, determines the details of standards of competence because doing this requires dental expertise. However, the larger community is justified in demanding an explanation of the reasoning involved, especially regarding the trade-offs between quality of care and access to care that the setting of such standards inevitably involves.

SACRIFICE AND THE RELATIVE PRIORITY OF THE PATIENT'S WELL-BEING. Most sociologists who study professions and most of the literature of professions speak of "commitment to service" or "commitment to the public" as one of the characteristic features of a profession. Dentistry's self-descriptions are similar in this respect, but these expressions allow many different interpretations with different implications for practice. What sorts of sacrifices, for example, are dentists professionally committed to make for the sake of their patients? What sorts of risks to life and health, financial well-being, and reputation may a dentist be obligated to face?

The related question of the proper relationship between entrepreneurship and commitment to the patient, along with the sacrifice of self-interest this can involve, has been discussed in every age of the dental profession. The consensus is that especially in emergency situations, the patient's oral health and general health require significant sacrifices of personal convenience and financial interest on the part of a dentist. Since the arrival of HIV and AIDS, even more urgent implications of the obligation to give priority to the patient, including accepting an increased risk of infection, also have become part of this discussion.

RELATIONS WITH COPROFESSIONALS. Each profession has norms, usually largely implicit and unstated, concerning the proper relationship between the members of a profession. Should a dentist relate to other dentists as competitors in the marketplace, as cobeneficiaries in the monopoly their exclusive expertise gives them in the marketplace, or in some other way? What is the ideal relationship between dentists, and how is it connected with the fact that they are members of a profession, not only entrepreneurs in the same marketplace?

How should a dentist deal with another dentist's inferior work when its consequences are discovered in the mouth of a new or emergency patient or a patient referred for specialty care? The discovering dentist could inform the patient that bad work has been done or could hide that judgment from the patient. The discovering dentist could contact the dentist whose work had a bad outcome or possibly the local dental society. What is the proper balance between obligations to patients and obligations to one's fellow dentist? As in other professions obligations to the patient ordinarily take priority in dentistry, but this principle does not supply simple or automatic answers to the complexities of such situations.

There are also situations in which members of different professions are caring for the same patients. Many dentists, for example, work very closely with dental hygienists, whose professional skills and central professional values are closely related to but significantly distinct from those of dentists. In the best relationships those differences complement each other to the benefit of the patient, but in other situations the skills of the dental hygienist may be demeaned or the dental hygienist's status as a professional may be challenged. The ethical commitments of these professions imply an obligation to develop a working relationship that is conducive to mutual respect and focused on the well-being of the patient.

RELATIONS BETWEEN DENTISTS AND THE LARGER COMMUNITY. Every profession is involved in numerous relationships with the larger community and with important subgroups in it. Both the dental profession and individual dentists must monitor the quality of dental work and practice and report and address instances of inferior work and unethical practice. They also relate to the community as dental-health educators both through direct educational efforts and by monitoring the dependability and effectiveness of dental-care products offered to the public. Dentistry's relationships with the larger community also include developing proper standards for professional advertising. Dentists play an important role in public-health efforts, preserving public oral health, and addressing serious epidemic diseases such as HIV.

ACCESS TO THE PROFESSION'S SERVICES. Individual dentists and the dental profession as a whole have responsibilities in regard to access to dental care for people with unmet dental needs. Dentists also may be obligated to be educationally and politically active when policies are being made to determine how society will distribute its healthcare resources. Also, organized dentistry has an obligation to monitor access issues and use its resources to promote access for those whose dental needs are not being met.

INTEGRITY AND EDUCATION. A dentist who made no effort to influence patients to incorporate the central values of dental practice into their lives and educate them about how to do that would be falling short as a professional committed to these values. However, dentists influence and educate patients not only through their words and professional interventions at chairside but also by the way they live and act. Thus, there is a ninth category of questions to ask about dentists' professional obligations. What are dentists required to do and what might they be required to avoid to preserve the integrity of the values to which dentistry is committed and to educate others by living in a manner consonant with those values?

Organized Dentistry and Ethics

Ultimately, the content of a profession's obligations is the product of a dialogue between the profession and the larger community that entrusts the profession and its members with a high degree of autonomy in practice, including the power of self-regulation. In the case of dentistry this dialogue is often subtle and informal. Codes of ethics formulated by professional organizations such as the American Dental Association's *Principles of Ethics and Code of Professional Conduct* (American Dental Association, 2002) play an important role in articulating the most fundamental principles of dentistry's professional ethics within American society. However, such codes, like state dental-practice acts, can never articulate more than a small part of the content of a practicing profession's ethics. It therefore is incumbent on both individual dentists and organized groups of dentists to monitor this ongoing dialogue continuously and offer representative statements of its content as they are needed.

If the larger community had no part in this ongoing dialogue, its trust of the dental profession would make no sense. Nevertheless, the community exercises its role in the dialogue more often through passive tolerance than through active articulation. Therefore, the initiative ordinarily falls first to the members of the profession to articulate in word and action the current understanding of the profession's ethical commitments.

Although the dental profession includes every dentist who practices competently and ethically, those who speak for the profession most articulately and are heard the most widely are dentistry's professional organizations. Therefore, those organizations have a special responsibility to foster reflection on and contribute to discussion of dental ethics (Ozar and Sokol, 2002).

Some dental organizations, such as the American Dental Association (ADA), the American College of Dentists (ACD), and some specialty organizations, have contributed actively to the articulation of dentistry's professional standards. Particular issues have temporarily focused the profession's attention on dentistry's ethical commitments. This occurred when the ADA's Council on Dental Therapeutics first awarded its Seal of Approval to a commercial dentifrice (Dummett and Dummett) and when the ADA first issued a policy statement regarding dentists' obligation to treat HIV-positive patients (American Dental Association, 1991; Ozar, 1993).

Until the late 1970s most dental organizations fulfilled this responsibility chiefly through editorials and other hortatory articles in their journals and sometimes through a published code of conduct. Detailed, carefully reasoned discussions of ethical issues in which assumptions were explicit and alternative points of view were accounted for or that articulated the profession's ethics in more than broad generalities were few and far between. Even the published codes of conduct, significant as they have been as representative articulations of dentistry's professional commitments, have not exhausted the contents of dental ethics, much less effectively addressed new and specific issues as they have arisen.

Since the late 1970s, however, the level of interest in and sophisticated discussion of ethical issues within organized dentistry have increased steadily. Responding to newly significant ethical issues in a rapidly changing social climate, the ADA's Council on Ethics, Bylaws, and Judicial Affairs has regularly prepared, after considerable debate in print and other forums, a number of revisions and amendments of the ADA's *Principles of Ethics and Code of Professional Conduct* (2002). The ADA and its council also have sponsored national workshops and other educational programs on specific ethical issues facing the dental community.

The ACD sponsored several national workshops and a national grassroots educational program to train dentists in more sophisticated forms of reflection on ethical issues as well as national conferences, Ethics Summits I and II, in which representatives from every part of the oral healthcare community worked to develop common understandings of the ethical issues they face and respectful collaboration in dealing with them (American College of Dentists, 1998, 2000). Many other dental organizations have incorporated programs on dental ethics into their meetings and published scholarly and popular articles on those topics in their journals. A number of them also have made major revisions of their codes of ethics.

An organization specifically focused on dental ethics and its teaching, the Professional Ethics in Dentistry Network (PEDNET), was founded in 1982 by a group of dental school faculty members and has grown into a national organization with additional members in full-time practice as well as representatives from organized dentistry, dental hygiene, and the larger healthcare ethics community. The International Dental Ethics and Law Society (IDEALS) was established in 1999 to facilitate dialogue on dental ethics and law around the world.

The literature of dental ethics has grown significantly. In 1988 the *Journal of the American Dental Association* initiated a regular feature on dental ethics, "Ethics at Chairside," which moved in 1991 to *General Dentistry,* the journal of the American Academy of General Dentistry, and a similar series of ethics cases and commentary has appeared in the *Texas Dental Association Journal.* A peer-reviewed series, "Issues in Dental Ethics," supervised by the editorial board of PEDNET began publication in 2000, appearing as a special feature in each quarterly issue of the *Journal of the American College of Dentists.* Also since 2000, the dental journal *Quintessence* has published a series on ethical heroes in dentistry.

Dental Education

The changing climate of dental practice from the late 1970s into the 1980s and a heightened awareness of ethical issues throughout the dental profession in that period also brought about changes in dental schools. Until that time few dental schools had formal programs in dental ethics. Inspirational lectures by respected senior faculty members or local or national heroes were the standard fare (Odom). However, with prompting from the American Dental Education Association (ADEA), then called the American Association of Dental Schools, as well as the ACD, and the ADA, many dental schools began offering formal programs in dental ethics. They identified faculty members with an interest in dental ethics who began to develop curricular materials and network with the faculty in other institutions. For example, the University of Minnesota pioneered an innovative four-year curriculum in dental ethics in the early 1980s. With the founding of PEDNET, dental-ethics educators acquired a major resource for their teaching and a locus for scholarly discussions of issues in dental ethics at the national level both at annual meetings and at biennial workshops on teaching dental ethics.

During the 1990s, several new textbooks were published (Rule and Veatch; Weinstein; Ozar and Sokol, 1994, 2002) and additional educational programs and materials were developed for use in the classroom, in the clinic, and in continuing education programs. By the beginning of the new millennium, most dental schools had multiyear curricula in dental ethics in place (Zarkowski and Graham) and significant efforts were under way to integrate dental ethics education into the innovative patient-centered and problem-based-learning curricula that are the hallmark of contemporary dental school education.

Dentistry in the Twenty-First Century

As dentistry moves into the twenty-first century the focus on ethics will have to be even greater. Two of dentistry's greatest success stories of the twentieth century will yield two of its most important ethical challenges in the twenty-first.

Dentists deeply committed to preventive healthcare for the whole community lobbied successfully during the twentieth century for the fluoridation of water supplies. As a consequence most twenty-first-century dentists' patients will need much less restorative work to remedy the effects of caries than their predecessors' patients did. In these circumstances how will dentists maintain their practices fiscally and still remain true to their fundamental ethical commitments? For many patients and dentists the answer has been an increasing interest in aesthetic dentistry. However, there is a risk here. Too strong a shift in the focus of dental care in this direction could bring about a significant change in the community's view of dentistry, seeing it much more as a taste-driven commercial enterprise and much less as an expertise-grounded, value-based health profession.

The second success story concerns the tremendous advances made in dental research in recent decades. For example, the ways in which laser technology can be used in dental practice have multiplied at least tenfold since the early 1990s. However, these new technologies frequently require extensive training as well as new forms of theoretical understanding so that dentists can employ them safely and skillfully. Because so many patients are fascinated with new technologies, dentists, often fascinated themselves, feel strong pressure to purchase and employ them. The ethical standard of employing only those therapeutic techniques in which one is expert and that truly produce a marginal benefit for the patient compared with older technologies often is strained in these circumstances, and commercial pressures on dentists, both direct fiscal issues within their practices and the pressure of skillful marketing by manufacturers, enhance the challenge for twenty-first-century dentists to choose new technologies wisely and with their patients' best oral healthcare as the goal.

Further complicating both of these issues is the extent to which managed care has had an increased impact on oral healthcare since the early 1990s. More and more frequently dentists must negotiate with patients about treatments in circumstances in which a patient's insurance will pay only for the cheapest acceptable intervention and in which the patient has been poorly informed. The dentist or dental office staff frequently is the bearer of this bad news. Dealing with such situations in a way that preserves an appropriate dentist-patient relationship is often very challenging (Ozar, 2001).

Dentistry as a profession has always taken its professional ethics seriously. However, as a field of study and as a subdiscipline within the study of moral theory and professional ethics dental ethics is still a young field. Nevertheless, as reflection on ethical issues is taken more seriously and participated in more widely by practicing dentists and dental hygienists, dental school and dental hygiene faculty and students, and the leaders of organized dentistry, the dental profession's ethical standards and their implications for daily practice will be understood more clearly and creative dialogue about the ethical practice of dentistry will be more widespread and sophisticated.

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REVISED BY AUTHOR

SEE ALSO: *Conflict of Interest; Healthcare Resources; Informed Consent; Profession and Professional Ethics; Professional-Patient Relationship; Public Health; Trust*

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DIALYSIS, KIDNEY

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Two principal therapies exist for patients who develop irreversible kidney failure and require renal replacement therapy to survive: kidney dialysis and kidney transplantation. The topic of kidney transplantation is addressed elsewhere in the Encyclopedia. This entry discusses kidney dialysis.

The two main techniques for kidney dialysis are hemodialysis and peritoneal dialysis. In hemodialysis, blood is pumped from a patient's body by a dialysis machine to a dialyzer—a filter composed of thousands of thin plastic membranes that uses diffusion to remove waste products—and then returned to the body. The time a hemodialysis treatment takes varies with the patient's size and remaining kidney function; most patients are treated for three and one-half to four and one-half hours three times a week in a dialysis unit staffed by nurses and technicians. In peritoneal dialysis, a fluid containing dextrose and electrolytes is infused into the abdominal cavity; this fluid, working by osmosis and diffusion, draws waste products from the blood into the abdominal cavity and then is drained from the abdominal cavity and discarded. Most patients on peritoneal dialysis perform four procedures at home daily about six hours apart to drain out the fluid with the accumulated wastes and instill two to two and one-half liters of fresh fluid. This technique is called continuous ambulatory peritoneal dialysis (CAPD). An automated form of peritoneal dialysis at home, called continuous cycling peritoneal dialysis (CCPD), is also available.

Both hemodialysis and peritoneal dialysis require a means to enter the body, called an access. In hemodialysis, access to the blood is obtained by removing blood through needles inserted into surgically created conduits, called fistulas or synthetic grafts, from arteries to veins. In peritoneal dialysis, access to the abdominal cavity is obtained with a plastic catheter, which is surgically implanted into the abdominal wall with the tip of the catheter positioned in the abdominal cavity.

Dialysis is a benefit to patients with severe kidney failure because it removes metabolic waste products and excess fluid, electrolytes, and minerals that build up in the blood when the kidneys are not functioning normally. Without the removal of these substances, patients become very weak, short of breath, and lethargic and eventually die. While dialysis is lifesaving for these patients and some can return to their prior level of functioning, most do not, because they do not feel well. Despite dialysis and medications, patients may experience anemia, bone pain and weakness, hypertension, heart disease, strokes, infections or clotting of the dialysis access, and bleeding. In addition to these medical problems, dialysis may impose other burdens on dialysis patients and their families, including extra costs for medications and for transportation to the dialysis center, loss of time spent in the treatments and travel to the dialysis center, and loss of control over the patient and family schedule to accommodate dialysis treatments. For these reasons, renal transplantation is considered to be the preferable form of treatment for severe kidney-failure patients who are able to undergo this major surgical procedure.

Kidney dialysis predates other life-sustaining therapies. In 1945 in the Netherlands, Willem Kolff first used hemodialysis to save the life of a woman with acute renal failure. In subsequent years, Kolff and others improved hemodialysis, but it could not be provided to patients with chronic, irreversible renal failure, or what has been called end-stage renal disease (ESRD), until 1960, when Dr. Belding Scribner of Seattle, Washington, used plastic tubes to form a shunt that could be left in an artery and vein for repeated dialysis access.

By most standards, kidney dialysis can be considered a very successful life-sustaining treatment. In the United States alone, since the inception of the Medicare-funded ESRD program in 1973, well over 1 million patients have had their lives sustained by dialysis, and at least some of them have survived for longer than twenty-five years. This program has been costly, however; in 1999, for example, the cost of keeping ESRD patients alive in the United States exceeded 17 billion dollars. Because dialysis preceded many other modern life-sustaining medical technologies, and because initially there was a scarcity of resources to pay for it, many of the ethical concerns subsequently discussed for other modern medical technologies were initially debated regarding dialysis: patient-selection criteria, rationing, access to care, the just allocation of scarce resources, the right to die (by having dialysis withheld or withdrawn), end-of-life care, and conflicts of interest (in dialysis unit ownership). This entry examines a number of these concerns in the United States ESRD program and compares them with those in other countries.

Patient-Selection Criteria and Overt Rationing

The first ethical concern to arise for physicians was how to select patients for dialysis. In the early 1960s in the United

States, 10,000 people were estimated to be dying of renal failure every year, but there were not enough dialysis machines or trained physicians and nurses to treat these patients. Furthermore, the cost of treatment for one patient for one year, $15,000, was prohibitively expensive for most patients. Dialysis centers like the Seattle Artificial Kidney Center, founded in 1962, were able to treat only a small number of patients. It was therefore necessary to restrict the number of patients selected for dialysis; in other words, criteria had to be developed for the rationing of dialysis.

The problem of selecting patients had major ramifications because the patients denied access would die. The solution of the physicians of the Seattle dialysis center was to ask the county medical society to appoint a committee of seven laypersons to make the selection decisions for them from among persons they had identified as being medically appropriate. The doctors recognized that the selection decision went beyond medicine and would entail value judgments about who should have access to dialysis and be granted the privilege of continued life. Historian David Rothman says that their decision to have laypersons engaged in life-and-death decision making was the historic event that signaled the entrance of bioethics into medicine. Bioethics scholar Albert Jonsen believes that the field of bioethics emerged in response to these events in Seattle because they caused a nationwide controversy that stimulated the reflection of scholars regarding a radically new problem at the time, the allocation of scarce lifesaving resources.

The doctors regarded children and patients over the age of forty-five as medically unsuitable, but they gave the committee members no other guidelines with which to work. At first the committee members considered choosing patients by lottery, but they rejected this idea because they believed that difficult ethical decisions *could* be made about who should live and who should die. In the first few meetings, the committee members agreed on factors they would weigh in making their decisions: age and sex of the patient, marital status and number of dependents, income, net worth, emotional stability, educational background, occupation, and future potential. They also decided to limit potential candidates to residents of the state of Washington.

As the selection process evolved, a pattern emerged of the values the committee was using to reach its decisions. They weighed very heavily a person's character and contribution to society (Alexander).

Once public, the Seattle dialysis patient-selection process was subjected to harsh criticism. The committee was castigated for using middle-class American values and social-worth criteria to make decisions (Fox and Swazey). The selection process was felt to have been unfair and to have undermined American society's view of equality and the value of human life.

In 1972, lobbying efforts by nephrologists, patients, their families, and friends culminated in the passage by the U.S. Congress of Public Law 92–603 with Section 299I. This legislation classified patients with a diagnosis of ESRD as disabled, authorized Medicare entitlement for them, and provided the financial resources to pay for their dialysis. The only requirement for this entitlement was that the patients or their spouses or (if dependent children) parents were insured or entitled to monthly benefits under Social Security. The effect of this legislation was to virtually eliminate the need to ration dialysis.

When Congress passed this legislation, its members believed that money should not be an obstacle to providing lifesaving therapy (Rettig, 1976, 1991). Although the legislation stated that patients should be screened for *appropriateness* for dialysis and transplantation, the primary concern was to make dialysis available to those who needed it. Neither Congress nor physicians thought it necessary or proper for the government to determine patient-selection criteria.

By 1978, many U.S. physicians believed that it was morally unjustified to deny dialysis treatment to any patient with ESRD (Fox and Swazey). As a consequence, patients who would not previously have been accepted as dialysis candidates were started on treatment. A decade later, the first report of the U.S. Renal Data System documented the progressively greater acceptance rate of patients onto dialysis (U.S. Renal Data System), and subsequent reports have shown that the sharp rise in the number of dialysis patients could be explained in part by the inclusion of patients who had poor prognoses, especially the elderly and those with diabetic nephropathy (Hull and Parker). By 2000, of the new patients starting dialysis 48 percent were sixty-five years of age or older and 45 percent had diabetes as the cause of their ESRD.

Observers have raised concerns about the appropriateness of treating patients with a limited life expectancy and limited quality of life (Fox; Levinsky and Rettig). Specifically, questions have been raised about the appropriateness of providing dialysis to two groups of patients: those with a limited life expectancy despite the use of dialysis and those with severe neurological disease. The first group includes patients with kidney failure and other life-threatening illnesses, such as atherosclerotic cardiovascular disease, cancer, chronic pulmonary disease, and AIDS. The second group includes patients whose neurological disease renders them unable to relate to others, such as those in a persistent vegetative state or with severe dementia or cerebrovascular disease (Rettig and Levinsky).

The Institute of Medicine Committee for the Study of the Medicare End-Stage Renal Disease Program, which issued its report in 1991, acknowledged that the existence of the public entitlement for treatment of ESRD does not obligate physicians to treat all patients who have kidney failure with dialysis or transplantation (Levinsky and Rettig). For some kidney-failure patients, the burdens of dialysis may substantially outweigh the benefits; the provision of dialysis to these patients would violate the medical maxim: Be of benefit and do no harm. This committee recommended that guidelines be developed for identifying such patients and that the guidelines allow physicians discretion in assessing individual patients. Such guidelines might help nephrologists make decisions more uniformly, with greater ease, and in a way that promotes patient benefit and the appropriate use of dialysis resources. Subsequent studies have demonstrated that nephrologists differ on how they make decisions to start or stop dialysis for patients (Moss et al., 1993; Singer).

Access to Dialysis and the Just Allocation of Scarce Resources

The numbers of dialysis patients steadily grew each year, resulting in an ever increasing cost of the Medicare ESRD program. In the 1980s the United States experienced record-breaking budget deficits, and questions began to be raised about continued federal funding for the ESRD program. Observers wondered if the money was well spent or if more good could be done with the same resources for other patients (Moskop).

Critics of the ESRD program observed that it satisfied neither of the first principles of distributive justice: equality and utility. On neither a macro- nor a microallocation level did the ESRD program provide equality of access. On the macroallocation level, observers asked, as a matter of fairness and equality, why the federal government should provide almost total support for one group of patients with end-stage disease—those with ESRD—and deny such support to those whose failing organs happened to be hearts, lungs, or livers (Moskop; Rettig, 1991). On a microallocation level, only 93 percent of patients with ESRD have been eligible for Medicare ESRD benefits. The poor and ethnic minorities are thought to constitute most of the ineligible. The Institute of Medicine Committee for the Study of the Medicare End-Stage Renal Disease Program recommended that the U.S. Congress extend Medicare entitlement to all citizens and resident aliens with ESRD (Rettig and Levinsky).

From a utilitarian perspective, the ESRD program could not be argued to be maximizing the good for the greatest number. In the 1980s, more than 5 percent of the total Medicare budget was being spent on dialysis and transplant patients, who represented less than 0.2 percent of the active Medicare patient population. A similar disproportionate expense has continued into the twenty-first century. Furthermore, while in 2000 more than 40 million Americans were without basic health insurance, the cost to treat one ESRD patient on dialysis—of whom there were over 300,000—exceeded $50,000 per year. Despite the high cost, ESRD patient unadjusted one-year mortality approached 25 percent; for many, as Anita Dottes noted, life on dialysis was synonymous with physical incapacitation, dependency, chronic depression, and disrupted family functioning (Dottes).

Withholding and Withdrawing Dialysis

After cardiovascular diseases and infections, withdrawal from dialysis is the third most common cause of dialysis-patient death. In one large study, dialysis withdrawal accounted for 22 percent of deaths (Neu and Kjellstrand). Older patients and those with diabetes have been found to be most likely to stop dialysis. Over time, as the percentage of diabetic and older patients (those sixty-five or over) on dialysis increased, withdrawal from dialysis became more common. According to surveys of dialysis units performed in the 1990s, most dialysis units had withdrawn one or more patients from dialysis in the preceding year with the mean being three. (Moss et al., 1993).

Because of the increased frequency of decisions to withhold and withdraw dialysis in the 1980s and 1990s, the clinical practices of nephrologists in reaching these decisions with patients and families generated heightened interest. Discussions of the ethics and process of withholding or withdrawing dialysis became more frequent (Hastings Center, U.S. President's Commission). Two ethical justifications were given for withholding or withdrawing dialysis: the patient's right to refuse dialysis, which was based on the right of self-determination, and an unfavorable balance of benefits to burdens to the patient that continued life with dialysis would entail. Nephrologists and ethicists recommended that decisions to start or stop dialysis be made on a case-by-case basis, because individual patients evaluate benefits and burdens differently. They noted that such decisions should result from a process of shared decision making between the nephrologist and the patient with decision-making capacity. If the patient lacked decision-making capacity, the decisions should be made on the basis of the patient's expressed wishes (given either verbally or in a written advance directive) or, if these were unknown, the patient's best interests. They also advised that in such cases a surrogate be selected to participate with the physician in making decisions for the patient.

Questions were identified to help nephrologists evaluate a patient's request to stop dialysis. For example, why does the patient want to stop? Does the patient mean what he or she says and say what he or she means? Does the patient have decision-making capacity, or is his or her capacity altered by depression, encephalopathy, or another disorder? Are there any changes that can be made that might improve life on dialysis for the patient? How do the patient's family and close friends view his or her request? Would the patient be willing to continue on dialysis while factors responsible for the patient's request to stop are addressed?

If, after patient evaluation based on these questions, the patient still requested discontinuation of dialysis, nephrologists were counseled to honor the competent patient's request. In several studies, nine out of ten nephrologists indicated that they would stop dialysis at the request of a patient with decision-making capacity (Moss et al., 1993; Singer).

In half or more of the cases in which decisions have been made to withdraw dialysis, patients have lacked decision-making capacity. Nephrologists have expressed a willingness to stop dialysis of *irreversibly incompetent* patients who had clearly said they would not want dialysis in such a condition, but they have disagreed about stopping dialysis in patients without clear advance directives (Singer). In general, there has been a presumption in favor of continued dialysis for patients who cannot or have not expressed their wishes. The patient's right to forgo dialysis in certain situations has therefore usually been difficult to exercise.

The Patient Self-Determination Act, which applied to institutions participating in Medicare and Medicaid and which became effective December 1, 1991, was intended to educate healthcare professionals and patients about advance directives and to encourage patients to complete them. Although the ESRD program is almost entirely funded by Medicare, dialysis units were inadvertently left out of the act. Nonetheless, the completion of advance directives by dialysis patients has been specifically recommended for three reasons: (1) the elderly, who constitute roughly half of the dialysis population, are those who are most likely to withdraw or be withdrawn from dialysis; (2) dialysis patients have a significantly shortened life expectancy compared to non-renal patients; and (3) unless an advance directive to withhold cardiopulmonary resuscitation (CPR) is given, it will automatically be provided, and CPR rarely leads to extended survival in dialysis patients (Moss et al., 1992).

When patients lack decision-making capacity and have not completed advance directives, ethically complex issues may arise in the decision whether to start or stop dialysis. Many nephrologists have indicated that they would consult an ethics committee, if available, for assistance in making decisions in different cases (Moss et al., 1993). Ethics consultations are most frequently requested for decisions regarding the withholding or withdrawing of life-sustaining therapy such as dialysis.

By the end of the twentieth century, nephrologists recognized the need for a guideline on starting and stopping dialysis. Such a guideline, which would address appropriateness of patients for dialysis (patient-selection criteria), had been recommended by the Institute of Medicine Committee for the Study of the Medicare ESRD Program almost a decade earlier. In a 1997 survey of the American Society of Nephrology (ASN) and the Renal Physicians Association (RPA) leadership, the respondents gave the highest priority among twenty-four choices to the development of an evidence-based clinical practice guideline on starting and stopping dialysis. In the context of a changing patient population, the RPA and ASN leaderships believed that an evidence-based clinical practice guideline would assist patients, families, and the nephrology team in making difficult decisions about initiating, continuing, and stopping dialysis. The resultant clinical practice guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis,* was developed by a working group of physicians, nurses, social workers, patients, dialysis administrators, a bioethicist, and a health policy expert (RPA and ASN, 2000). The objectives for the guideline were to:

- Synthesize available research evidence on patients with acute renal failure and ESRD as a basis for making recommendations about withholding and withdrawing dialysis;
- Enhance understanding of the principles and processes useful for and involved in making decisions to withhold or withdraw dialysis;
- Promote ethically as well as medically sound decision-making in individual cases;
- Recommend tools that can be used to promote shared decision-making in the care of patients with acute renal failure or ESRD;
- Offer a publicly understandable and acceptable ethical framework for shared decision-making among healthcare providers, patients, and their families.

The guideline makes nine recommendations. These recommendations encourage the process of shared decision-making, the obtaining of informed consent or refusal for dialysis, estimating prognosis as part of informed dialysis decision-making, systematic approaches to conflict resolution, the use and honoring of advance directives, withholding or withdrawing dialysis for patients under certain circumstances, the use of time-limited trials to assist in reaching decisions about continuing or stopping dialysis, and the use of palliative care for ESRD patients who decide to forgo dialysis. By defining the appropriate use of dialysis and the process to be used in making dialysis decisions, this guideline should also prove to be very useful to ethics consultants when they are called to help resolve conflicts over starting or stopping dialysis (Moss).

End-of-Life Care

In the wake of public dissatisfaction with end-of-life care and efforts to legalize physician-assisted suicide in several states, physician groups, including the RPA and ASN, recognized their ethical responsibility to improve end-of-life care for their patients. In 1997 in a joint position statement on *Quality Care at the End of Life,* the RPA and the ASN urged nephrologists and others involved in the care of ESRD patients to obtain education and skills in palliative care. They noted that palliative care knowledge and skills were especially important for nephrologists because they treat ESRD patients who die from complications despite the continuation of dialysis or after withholding or withdrawing dialysis. For example, in 1999, 48,000 patients died from complications while continuing dialysis and 12,000 died after a decision to stop dialysis.

One issue unresolved in the 1997 position statement was whether cardiopulmonary resuscitation ought always to be provided if cardiac arrest were to occur while patients are receiving dialysis, even if individual dialysis patients preferred not to undergo it. Data suggested that as many as one-third of dialysis units performed cardiopulmonary resuscitation on all patients who arrested while on dialysis, including those who refused the procedure. The concerns driving the uniform resuscitation of dialysis patients were two: The cardiac arrest might be iatrogenic, i.e., due to a complication of the dialysis procedure; and other patients might be troubled if the dialysis team made no attempt at cardiopulmonary resuscitation.

In 1999 the Robert Wood Johnson Foundation convened a series of workgroups to evaluate how end-of-life care could be improved for special populations of patients. The Robert Wood Johnson Foundation included the ESRD population because they perceived a readiness to address end-of-life care issues among the healthcare professionals treating ESRD patients.

In its report the ESRD workgroup noted that

> most patients with end-stage renal disease, especially those who are not candidates for renal transplantation, have a significantly shortened life expectancy. In the United States, dialysis patients live about one-third as long as non-dialysis patients of the same age and gender. The unadjusted five-year probability of survival for all incident ESRD patients is only 39 percent; and for the 48 percent of incident ESRD patients who are 65 years of age or older, it is only 18 percent. Life expectancy is also shortened by comorbid conditions. 45 percent of new ESRD patients have diabetes, and many have other comorbid conditions including hypertension, congestive heart failure, ischemic heart disease, and peripheral vascular disease.… It is clear from the foregoing information that the care of ESRD patients requires expertise not only in the medical and technical aspects of maintaining patients on dialysis, but also in palliative care—encompassing pain and symptom management, advance care planning, and attention to ethical, psychosocial, and spiritual issues related to starting, continuing, withholding, and stopping dialysis. (p. 5)

The ESRD workgroup noted the following with regard to the unresolved issue of cardiopulmonary resuscitation in the dialysis unit: (1) research studies of cardiopulmonary resuscitation have indicated that the outcomes for ESRD patients are poor; (2) most dialysis patients express a preference for undergoing cardiopulmonary resuscitation, but over 90 percent believe that a dialysis patient's wish not to undergo cardiopulmonary resuscitation should be respected by dialysis unit personnel (Moss et al., 2001); and (3) it is necessary for nephrologists and other members of the renal team to educate dialysis patients about the likely outcome of cardiopulmonary resuscitation based on patients' particular medical conditions. They recommended that "dialysis units should adopt policies regarding cardiopulmonary resuscitation in the dialysis unit that respect patients' rights of self-determination, including the right to refuse cardiopulmonary resuscitation and to have a do-not-resuscitate order issued and honored" (Robert Wood Johnson Foundation, p. 10). The RPA and the ASN accepted this recommendation and revised their position statement on *Quality Care at the End of Life* in 2002 to include this and other recommendations of the ESRD workgroup.

The Effect of Reimbursement

Reimbursement has affected both dialysis techniques and quality of care provided to dialysis patients. In the 1980s cost was the federal policymakers' primary concern about the ESRD program, and federal reimbursement rates for dialysis were reduced twice. By 1989, the average reimbursement rate—adjusted for inflation—for freestanding dialysis units was 61 percent lower than it had been when the program began (Rettig and Levinsky).

When the U.S. Congress established the Medicare ESRD program, the highest estimate for cost of the program by 1977 was $250 million; the actual cost was approximately $1 billion (Fox and Swazey). At least two major reasons were held to be responsible for the higher cost: the increasing number of patients being started on dialysis, some of whom would have been *unthinkable* dialysis candidates ten years earlier, and the growth of in-center dialysis while the use of less costly home dialysis declined.

Despite inflation and increases in the costs of salaries, equipment, and supplies, there were only two modest increases in the Medicare reimbursement to dialysis providers in the 1990s. By the end of the twentieth century, the rate of reimbursement for dialysis by Medicare adjusted for inflation was only one-third of the amount in 1973. A longstanding historian of the ESRD program, Richard Rettig, observed, “No other part of Medicare has been subjected to this severe, even punitive, economic discipline” (2001, p. 16). Meanwhile, the incidence of ESRD in the United States had tripled compared to twenty years earlier. Almost 100,000 new patients were starting dialysis each year.

Conflicts of Interest

A conflict of interest occurs when there is a clash between a physician’s personal financial gain and the welfare of his or her patients. While a conflict of interest generally exists for all physicians who practice fee-for-service medicine, there is a potentially greater conflict of interest for physicians who share in the ownership of for-profit dialysis units in which they treat patients. Physicians who receive a share of the profits are financially rewarded for reducing costs. Although measures to reduce costs may simply lead to greater efficiency, they may also compromise patient welfare if they entail decreasing dialysis time; purchasing cheaper, possibly less effective dialyzers and dialysis machines; and hiring fewer registered nurses, social workers, and dietitians. In the past, for-profit dialysis companies were quite open about their policy of giving physicians a financial stake in their companies. Such companies flourished under the ESRD program (Kolata).

Physicians and dialysis units are paid on a per-patient and per-treatment basis, respectively, under the ESRD program, and the acceptance rate of patients to dialysis in the United States is higher than anywhere else in the world (Hull and Parker). This higher rate has been at least partly attributed to the acceptance on dialysis in the United States of a much greater number of patients with poor prognoses. Some have argued that this high acceptance rate was a sign that nephrologists and dialysis units were seeking to maximize their incomes, while others have commented that many physicians believed they were obligated to dialyze all patients with ESRD who wanted it (Fox).

In the 1990s, the concerns about conflicts of interest heightened. Two-thirds of ESRD patients were being dialyzed in for-profit units. Short dialysis times were found disproportionately in for-profit units and associated with increased mortality. Patients treated in for-profit dialysis units were noted to have a 20 percent higher mortality rate and a referral rate for renal transplantation 26 percent lower than that for not-for-profit units (Levinsky). The nephrologist who owned all or a share of a for-profit unit was confronted with a clear conflict of interest. In responding to financial pressures created by a dialysis reimbursement rate that failed to keep up with inflation and in instituting cost-cutting measures, he or she was believed to be treading a very fine line between maintaining adequate profit to keep the dialysis unit open and compromising patient care.

A decade earlier, nephrologist and *New England Journal of Medicine* editor Arnold Relman had anticipated the predicament nephrologist owners of dialysis units would face. He had warned that the private enterprise system—the so-called new medical-industrial complex—had a particularly striking effect on the practice of dialysis, and he urged physicians to separate themselves totally from any financial participation so as to maintain their integrity as professionals (Relman). Education of nephrologists about these issues, both in training and in continuing education courses, was advocated to help them to identify present and potential conflicts of interest and resolve them in a way that places patients’ interests first.

To hold dialysis units, both for-profit and non-profit, accountable for the quality of care they provide, the Medicare ESRD program through the eighteen ESRD Networks established quality indicators to measure the performance of individual dialysis units and all the dialysis units within a region. These measures monitor adequacy of dialysis, anemia management, vascular access placement, and standardized mortality ratios as well as other indicators.

Racial Disparities

Racial differences in access to effective medical procedures are known to be a problem in the United States. Black patients are less likely than white patients to undergo renal transplantation, coronary artery bypass surgery, and many other procedures. Despite the tendency to undertreatment in other areas, black patients are significantly overrepresented in the dialysis population, comprising 32 percent of all ESRD patients but only 13 percent of the United States population. There is also an overrepresentation of other racial and ethnic minority groups in the ESRD population. The increased susceptibility of nonwhite populations to ESRD has not been fully explained and probably represents a complex interaction of genetic, cultural, and environmental influences. Disparities in treatment for racial minority ESRD patients have been noted, including the following: (1) they are less likely to be referred for home dialysis and renal transplantation; (2) they are more likely to be underdialyzed; and (3) they are more likely to have less desirable synthetic grafts (shorter patency and more complications) rather than fistulas as permanent dialysis access. Nonetheless, blacks have better survival and quality of life compared to whites, and they are also less likely to withdraw from dialysis. The better outcomes despite less than optimal treatment present an opportunity to study and further improve ESRD care for minority patients.

International Perspective

Economics plays the leading role in determining the availability of dialysis in countries throughout the world. The countries with the largest numbers of patients on dialysis are among the richest: the United States, Japan, and Germany. The number of patients per million population treated with dialysis correlates highly with the gross national product per capita. Countries with a per capita gross national product of less than $3,000 per year treat a negligible number of patients with dialysis and transplantation. Approximately three-quarters of the world's population live in these poorer countries.

In parts of the world where dialysis technology and money for healthcare are limited, dialysis is severely rationed. Two sets of criteria have been used to select patients for dialysis. In India, China, Egypt, Libya, Tunisia, Algeria, Morocco, Kenya, and South Africa, money and political influence play an important role in deciding which patients will have access to dialysis and transplantation. In Eastern Europe, ESRD patients with primary renal disease who have a lower mortality and who are more likely to be rehabilitated tend to be selected (Kjellstrand and Dossetor).

Conclusion

Dialysis was one of the earliest life-sustaining treatments. Since its inception, dialysis has raised many ethical issues to be analyzed and resolved. In the 1960s the attempt to make difficult yet socially acceptable ethical decisions about patient-selection criteria and the rationing of dialysis failed because of the use of social worth criteria. The dialysis community and others learned from this experience. In the 1990s, prompted by the dramatic expansion of the ESRD program and a belief by many that not all patients on dialysis were appropriate for it, the renal professional societies succeeded in developing patient-selection criteria—based on likelihood of benefit and shared decision making—that have been widely endorsed. Other examples of analyzed and resolved ethical issues in dialysis that are broadly applicable are the ethical justifications for allowing patients to forgo dialysis, a life-sustaining treatment, and the development of an approach to hold providers accountable when there is a major and continuing conflict of interest.

Kidney dialysis has succeeded beyond all expectations in its ability to sustain life for hundreds of thousands of patients worldwide. Refinements in the technology have allowed patients who were previously considered not to be candidates for dialysis to experience several or more years of extended life. Its success brings with it three major challenges: how to finance the expensive treatments for a larger and larger number of patients; how to maintain the quality of dialysis care in the United States with the provision of dialysis increasingly being provided by for-profit dialysis corporations who have an inherent conflict of interest; and how to humanely care for an increasingly older, frail population with multiple medical problems and a significantly shortened life expectancy.

Because of the continuing challenges it poses, dialysis will likely continue to break new ground with regard to ethical analyses that will subsequently be helpful to other modern medical technologies.

ALVIN H. MOSS (1995)
REVISED BY AUTHOR

SEE ALSO: *Artificial Hearts and Cardiac Assist Devices; Biomedical Engineering; Body; Cybernetics; Healthcare Resources; Life, Quality of; Lifestyles and Public Health; Life Sustaining Treatment and Euthanasia; Medicaid; Organ and Tissue Procurement; Organ Transplants; Technology; Xenotransplantation*

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DISABILITY

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I. Ethical and Societal Perspectives
II. Legal Issues

I. ETHICAL AND SOCIETAL PERSPECTIVES

People who are physically or mentally disabled have many disadvantages. They may have an impairment, such as paralysis, blindness, or a psychiatric disorder, that reduces their ability to do things that nondisabled people do and may interfere with their fulfillment of socially valued roles. Also, disabled people often are subjected to various degrees of exclusion from the social and economic life of their communities. Political movements by disabled people to remove barriers and overcome discrimination, and protective legislation in several countries, have focused attention on the controversial concept of disability and on what constitutes just and compassionate behavior toward the disabled by individuals and institutions, including private employers, providers of public services, and schools. These ethical issues are pressing for all people because everyone can be disabled by trauma and because in societies in which life expectancy is long everyone may expect some impairments in old age.

This entry analyzes the concept of disability and its links to certain other concepts (impairment, handicap, health, and disease), explains the two competing explanatory models of disability, and surveys some of the ethical controversies that pertain to the nature of disability and the relationship between a disabled person and the rest of society.

Defining Disability: Conceptual Issues

The idea of disability and these related concepts are tricky to define. The conditions that often are referred to as disabilities are varied, including sensory losses, learning difficulties, chronic systemic illnesses and their effects (such as constant fatigue and pulmonary insufficiency), mental illnesses, lack of limbs, and lack of mobility. Do all these conditions have a common feature? Does every biological abnormality qualify as a disability? Does the availability of technological aids play a role in determining whether a bodily state is a disability? To what extent does being disabled depend on the environment in which a person lives? The very definition of disability is controversial; there is no single accepted definition.

The World Health Organization (WHO) of the United Nations offered the following definitions, which have been highly influential:

> *Impairment*: Any loss or abnormality of psychological, physiological, or anatomical structure or function.
>
> *Disability*: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
>
> *Handicap*: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors for that individual. (United Nations, 1983, quoted in Wendell)

Those definitions provide a good starting point but require fine-tuning. The distinction between impairments and disabilities is useful even though in some cases the distinction may be strained. The term *impairment* best captures a loss of or a defect in psychological, physiological, or anatomic features. Thus, paralysis of an arm muscle is an impairment, and inability to throw something is a disability brought about by that impairment, because it is a lack of the ability to perform an activity (throwing). Inability to throw a baseball is not an impairment or a disability; instead, in a person who would be expected to be able to throw a baseball it may be a handicap: a disadvantageous inability to perform a socially defined activity that is caused by an impairment and a disability.

Thus, not every impairment is disabling. An abnormal shape of the eyeball that prevents light from focusing properly on the lens is an impairment, but if the afflicted person can see perfectly well with glasses or contact lenses and carry out the same activities that other people can, that impairment is not disabling. One also can ask whether a disability is a handicap. Franklin Delano Roosevelt had a disability (he could not walk) that no doubt prevented him from fulfilling some social roles, but it did not prevent him from fulfilling the role of president of the United States, and so in that respect it was not a handicap.

Difficulties with the WHO Definitions

There are two main deficiencies in the definitions given above that should be remedied. First, they contain no account of what is normal or abnormal for human beings either in structure and function (as in the definition of impairment) or in the manner and range of performing an activity (as in the definition of disability). Second, only the definition of a handicap makes reference to disadvantage, yet intuitively, disadvantage, or at least inconvenience, is part of the concept of disability. Below are suggested improvements, although significant imperfections remain.

THE HUMANLY NORMAL AND ABNORMAL. An account of the type of abnormality necessary for the notion of impairment to be applicable is needed. What is normal human physiology, psychology, anatomic structure, and function? The topic is vast and controversial, and it is easy to go wrong.

A statistical account of normal structure and function would be misconceived. Even if all human beings were damaged in a nuclear accident, it would not be humanly normal to suffer from radiation sickness and sterility.

It is also not possible to define normal structure and function simply by listing all the body parts human beings are observed to have, what those parts are observed to do, and how they do it. This is not only because knowledge in this area is incomplete. If one simply observes human organisms, the list will include things frequently observed that never would count as normal. One would observe both sound and decayed teeth, both painful childbirth and painful urination, and both the beating of the heart and myocardial infarction (another thing the heart is seen to do), yet the second item in each pair is abnormal. The concept of a human organ and its function is inseparable from the concept of what is normal for human beings (an evaluative, teleological concept), and any definition of normality that refers to the functions of organs assumes the concept of the normal in the attempt to define it. (The biologist's concept of the function of an organ need not depend on cultural assumptions, however. It only presupposes the distinction between normal and abnormal.)

A partial account of the normal functions and abnormalities of body parts can be derived from an understanding of their role in the survival of the species. As Norman Daniels puts it (p. 28), the biomedical sciences, including evolutionary biology, provide an account of "the design of the organism" and "its fitness to meeting biological goals" relative to which a scientist can specify some normal and abnormal phenomena. However, the usual biological goal assumed in evolutionary theory—transmission of an organism's genes to the next generation—does not entail the abnormality of many intuitively abnormal conditions, such as the diseases of extreme old age.

Rather than abandon hope of a definition, though, it is possible to adopt the following crude and incomplete standard, which suffices for the issues surrounding impairment and disability and leaves the thorniest controversies aside. A state of a human being is an abnormality of the type that can make it an impairment only if the state is such that if all human beings had had it from the beginning of human prehistory and otherwise were as they in fact are now, the human species would have been significantly less likely to survive.

This is a necessary but not a sufficient condition of a state's being abnormal. That is, all abnormal traits are ones that probably would have precluded species survival, but not all states that would have precluded species survival are abnormal. States that are abnormal fulfill certain other conditions. There is no complete list of these conditions, but here are two of them.

The first requires a subsidiary definition. Some traits assist survival when they are present in some members of a population as long as other individuals have a different trait; however, if all individuals had the trait, the population could not survive. These can be called diversity-requiring traits. An obvious one is being male or female. Having some males has been indispensable to the species's survival over time, but if all individuals were male (from prehistory), the species would have died out long ago.

The other condition excludes from the definition characteristics that are universal in but are limited to human beings of a certain developmental stage. It is normal for newborn infants to be unable to walk, for example, even though if all human beings of all ages had always been unable to walk, the species would not have survived.

The definition of abnormality can be supplemented in light of this characterization. Thus, a state of a human being is an abnormality of the type relevant to impairment only if the state is such that if all human beings had had it from the beginning of human prehistory and otherwise were as they in fact are today, the human species would have been unlikely to survive. If the state (1) is of that kind, (2) is not a diversity-requiring trait, and (3) is not a trait that is characteristic of and limited to certain stages of human development, it is abnormal.

With this understanding of abnormality, one can say, with the WHO, that an impairment is any abnormal loss or other abnormality of psychological, physiological, or anatomic structure or function. This standard ensures that the abnormalities that qualify as impairments are ones that characteristically make a difference in living a human life, the typical life of the species, whether or not they cause a great loss for any specific individual in any particular set of circumstances. Thus, extreme myopia (nearsightedness or shortsightedness) is an impairment by this definition because if all human beings had had this characteristic since prehistory and otherwise had been the same as they are today, the human species would have been unlikely to survive. A hunter-gatherer society composed entirely of severely myopic people would be doomed. Yet severe myopia may not cause serious inconvenience to a person in a modern technological society.

IMPAIRMENT AND DISABILITY. The WHO definition of disability says nothing about disadvantage, whereas intuitively that seems to be part of the concept. People would not count it as a disability if someone were unable to perform an activity in the manner normal for human beings if it were an activity that that person, or perhaps everyone, had no interest in performing in that way. It is no disability to someone who has taken a vow of celibacy or has undergone voluntary surgical sterilization that that person is biologically infertile because it does not disadvantage that person even though it is an impairment.

Instead, one can define a disability as any impairment-caused disadvantageous restriction or lack of ability to perform an activity in the manner or within the range that is normal for a human being. The relevant notion of normality is the same one identified above: that manner and range of activity without which the human species as a whole would have been unlikely to survive. Thus, extreme myopia, although it is an impairment, is not a disability for someone who suffers no consequent disadvantage because she or he has glasses or contact lenses that enable her or him to see perfectly.

Some people argue that a disability need not be disadvantageous. Anita Silvers (1994) gives the example of the great violinist Izhak Perlman, who walks with great difficulty yet has had a life of magnificent artistic accomplishment. However, it is surely to Perlman's disadvantage to have difficulty walking, as Bonnie Steinbock (2000) notes. A particular condition may be disadvantageous even for someone who is fortunate overall.

In light of these definitions impairments may disable a person to different degrees or in different ways in different societies, depending not only on the technology available (as with severe myopia) but more generally on the modes of living prevalent in the person's society, for example, whether the society is literate, whether it is agrarian or industrial, and the forms of transportation available in it. People with impairments also may confront varied cultural obstacles. In a society in which those born with bodily defects are regarded as cursed by the gods, for example, people with congenital impairments may be shunned, barred from most vocations, and reduced to begging. For a less extreme example, in a society in which attendant care is available only to those who live in institutions people who need the help of an aide to dress or bathe must be institutionalized. Someone with the same impairment might live in his or her own home in a different society. Consequently, some have argued that disability is purely a social construct. The degree of disability may indeed vary greatly as a result of cultural factors, however, as defined here, the impairment that causes disability is not fundamentally social in nature.

Handicap

The difference between a handicap as defined by the WHO and a disability as it has been defined here is that handicap employs a different concept of normality. A handicap results from impairment or disability, but it is a disadvantage that results from the consequent inability to fulfill roles that are normal, where what is normal is determined by social and cultural factors. Some activities, such as walking and seeing, are normal for human beings regardless of cultural expectations. If one cannot perform them, one is disabled in that respect. Other activities are normal for people in a particular type of society but are not expected or needed in others. If a person cannot perform them, that person will be handicapped in one society but not in another. Reading and using a telephone are normal activities in some societies but not in others, and so the inability to perform them, for example, because one is dyslexic or deaf, is not culturally abnormal and thus is not a handicap.

However, humanly normal activities may not always be clearly distinguishable from culturally normal activities. Often people perform their normal human activities by carrying out certain social roles that are dictated by their cultural and physical environment. Susan Wendell (1996) points out that a woman with impaired vigor might be able to obtain drinking water in the way that is normal in western Canada (turning on a tap) but unable to obtain it in the way that is normal in rural Kenya (walking a long distance to a well twice daily). Consequently, the distinction between a disability and a handicap is not always sharp.

Disadvantages Resulting from Prejudice

People with disabilities tend to be looked down on, ignored, discriminated against, and otherwise badly treated. Sometimes they are denied education or medical care or excluded from employment. Sometimes they are institutionalized or sterilized against their will. Sometimes they are subjected to violence or other forms of abuse. Often, especially but not only in poor countries, their needs for food and shelter are not met. Many nondisabled individuals are uncomfortable in the presence of the disabled and therefore exclude them from social life. Thus, at times the attitudes of their fellow citizens bar disabled people from carrying out the social roles of students, employees, spouses, and parents, causing their handicaps.

Impairment, Disability, Disease, and Health

The concept of impairment is closely related to the concepts of disease and health. Health commonly is defined as the absence of disease. Chistopher Boorse (1977) defines disease as an impairment of or limitation on functional ability, identifying disease with impairment. (However, he gives a statistically based account of functional ability, which was rejected here.) Norman Daniels (1985) defines disease as a deviation from the natural functional organization of a typical member of the species. He says that in characterizing "natural functional organization," the biomedical sciences draw on evolutionary notions and "claims about the design of the species" (p. 28), yielding an account of what is humanly normal that is close to the account given here. Thus, disease and impairment are nearly equivalent. Impairment is a slightly wider category because it includes the absence of a structure, and this usually is not called a disease. An amputee may be healthy (free of disease), yet that person is impaired.

Disability has been defined as an impairment-caused disadvantageous restriction on the ability to perform normal human activities or to perform them within the normal range. Because diseases are a subset of impairments, many diseases are causes of disability provided that they impose a disadvantage on the persons who have them. Thus, an infection is both a disease and an impairment, and it may cause disability (temporary or permanent) by disadvantageously reducing the ability of an afflicted person to perform humanly normal activities. Nondisease impairments such as the absence of a limb also may cause disability.

Two Models of Disability

There are two opposing, dominant ways of conceiving of disability: the medical model and the minority group model; the latter sometimes is called the disability rights model. These are explanatory models for understanding how and why disabled people are disadvantaged and theories of the appropriate means to ameliorate those disadvantages. These two ways of representing disability influence their advocates' positions on several ethical issues.

THE MEDICAL MODEL. According to the medical model, a disabled person's lack of ability to perform normal human activities can be traced entirely to that person's impairment: the abnormalities in his or her psyche, physiology, or anatomy. A paraplegic cannot get from place to place because her legs are paralyzed; a blind person cannot read because he cannot see. Disability is a result of the state of a disabled person's body. Consequently, the best way to remove the disadvantage is to correct the impairment medically, by means of surgery, drugs, physical therapy, prosthetics, and the like. Proponents of the medical model advocate vigorous treatment to eliminate impairments, extensive research to find cures for impairments for which no treatment is available, and prevention of future impairments. Prevention should be achieved by increasing the use of existing safety devices (e.g., in automobiles), developing new ways to avoid disabling accidents and illnesses, and identifying and encouraging healthful behavior in pregnant women (such as good nutrition and not smoking) to prevent the birth of children with disabilities. Some people also support preventing the birth of affected infants by using prenatal screening and abortion of abnormal fetuses or using genetic engineering when possible.

Many corrective medical interventions are performed successfully to prevent or eliminate disability, but many impairments cannot be corrected. When medicine cannot restore normal structure or function, the extent of the incapacity may be reduced. However, in many cases this cannot be done, and the person remains impaired and disabled. The disadvantages that person experiences may be substantial. At this point the medical model has little to offer to enable a disabled person to overcome her or his disadvantage. Because the disadvantage is understood to arise from the impairment, if nothing can be done to remove the impairment, it follows that nothing can be done to overcome the disadvantage.

THE MINORITY GROUP MODEL. According to the minority group model, although disabled people have physical, sensory, or psychological impairments, the principal source of their disadvantage is not the impairments but the impact on those people of the socially created environment. Because people with impairments are few in number and lack power and influence, they make up a minority group that is not taken into account in the physical and organizational design of facilities and institutions. Consequently, they are excluded from many mainstream activities. Thus, disability and handicap are only to a small degree the result of impairments; the disadvantages they involve, which can range from inability to attend a nightclub to unemployment and poverty, are largely the result of a lack of social inclusion.

Whereas the medical model explains a paraplegic's disadvantage solely in terms of the fact that that person cannot walk, the minority group model explains it by reference to the fact that buildings and streets are built in such a way that a paraplegic cannot maneuver a wheelchair into them or through them and therefore cannot go where he or she needs to go to conduct business, acquire an education, perform a job, or engage in recreation. A paraplegic is disadvantaged because she or he cannot do those things. Anita Silvers (1995) points out that streets and buildings would be made wheelchair-accessible if the majority of people in the society moved about by means of wheelchairs. Silvers makes this statement to show that it is their minority status, not their impairment, that causes the disabled to be excluded from so much of ordinary social life.

In contrast to the medical model, the minority group model claims that a great deal can be done to overcome the disadvantage component of disability for those whose impairments are not medically correctable. Society should be altered to make it much more inclusive. To continue with the example of a person who cannot walk, buildings can be fitted with ramps and elevators, cities can provide buses and taxis with wheelchair lifts, and doorways can be widened, enabling a wheelchair user to lead an independent life that is fully integrated into the community. Thus, a wheelchair user would experience vastly less disadvantage as a result of changes in society rather than by means of medical intervention.

According to the minority group model, in nearly all societies there is rampant discrimination against the disabled. This is the case because the built environment, the chief means of information gathering, and many forms of activity are suitable only for nondisabled people. As an analogy one can imagine that unknown to the builders, a widely used building material gave off radiation that had no effect on most people but gave intolerable shocks to one small ethnic group. Members of that ethnic group thus could not enter many buildings, including places they urgently needed to go to do their banking, pay taxes, and so on. This clearly would be unfair, if unintentional, discrimination.

According to the minority group model, this is exactly the way things are. Barriers to the participation of the disabled are present both in the built environment and in cultural institutions. For example, proceedings in classrooms, courts, and legislatures are impenetrable to people with sensory impairments. According to the minority group view this state of affairs is unjust. It imposes terrible disadvantages on disabled people that could be alleviated, and because it is society that unfairly excludes the disabled, society should remediate the situation.

The tension between the more widely held medical model of disability and the minority group model helps shape some of the crucial ethical debates over the moral treatment of the disabled.

Ethical Issues

Two main categories of ethical issues pertain to disability: issues concerning the value of the lives of disabled people and issues that concern the rights disabled people have and the grounds on which they claim those rights.

THE VALUE OF THE LIVES OF DISABLED PEOPLE. The ethical issues in this category are those related to the withholding of life-prolonging medical treatment, euthanasia, physician-assisted suicide, prenatal screening and abortion of fetuses with likely birth defects, and genetic engineering to prevent impairments in future offspring. Of course, these are areas of great general ethical controversy that raise many other issues.

When nondisabled people hear descriptions of a person's impairments, especially ones that result from sudden trauma to a previously unimpaired individual, they often react by thinking, "I would not want to live like that." That is sometimes the reaction of a disabled individual to his or her own losses. Robert B. White (1975) reports that at one point after his disabling accident Dax Cowart summarized his attitude by saying, "I do not want to go on as a blind and crippled person." That type of reaction helps explain why many regard the lives of people with disabilities as not worth living. However, those who have had time to adjust to their disabilities or have always lived with them are usually very glad to be alive. Although some disabilities may deprive a person's life of value, this cannot be assumed, and such an assumption, which may be unconscious, could lead to grave wrongdoing by caregivers and the legal system.

Euthanasia, withholding of life-prolonging treatment, and physician-assisted suicide. The question whether an individual should be kept alive by medical means (for example, cardiopulmonary resuscitation) or allowed to die as the result of a disease or injury and the question whether a person's death should be brought about by his or her own agency or that of others often arise when a person is terminally ill. However, they also may arise when a person has an incurable disease or another medical condition but can be expected to live for a considerable amount of time if given fairly standard medical treatments and food and water. Justifications for withholding a standard form of life-prolonging treatment from such a person or for taking steps to bring about that person's death usually appeal to the fact that as a result of the person's wretched medical condition, life is not a good to him or her. This may be the case if the person is mentally competent and requests death (usually because the medical condition causes unbearable suffering) or if the person is in a persistent vegetative state and is unable to have experiences of any kind or is an infant too young to make decisions who faces a very bleak future.

The appeal to autonomy. The refusal of life-prolonging treatment by a mentally competent patient is justified by an appeal to individual autonomy. A patient has a moral right to refuse treatment; this is an aspect of the fundamental moral right to autonomy, including decision-making control over what happens to one's body. Some people doubt whether it is ever morally permissible for a person to exercise the right to refuse treatment for the sole purpose of hastening his or her own death. However, there is wide agreement that if a patient does refuse treatment for any reason, provided that that person is mentally competent and well informed about her or his condition and prospects, it is wrong for anyone else to force the treatment on that person against her or his will. To do so would be an act of assault.

It is far more controversial whether the right to autonomy includes the right to commit suicide (rather than only to refuse treatment), and whether once a competent patient has decided to end his or her life a physician or another person may rightly assist him or her in doing that or may deliberately end that person's life at his or her request. Some defend the legitimacy of suicide as a rational and autonomous act, at least in the face of great and irremediable suffering that deprives life of its value. Others object to it even in such cases on the grounds that suicide is incompatible with respect for life. Physicians sometimes are asked to provide help in dying, for example, by giving lethal doses of drugs. Some argue that in cases in which the patient's life is not a good to the patient assistance with suicide is legitimate and indeed is a compassionate act. Others condemn this practice either because they condemn all suicide and judge it wrong to assist in a wrongful act or because they deem assisting with suicide incompatible with the role of a physician. Finally, some regard active euthanasia as incompatible with respect for life, indeed as murder, even when the killing is requested by the person who is to be killed. Others argue that euthanasia is morally justified when it is fully voluntary and the person's life is not worth living.

The incurable conditions that sometimes cause people to refuse life-prolonging treatment or seek physician-assisted suicide (PAS) or euthanasia (or because of which treatment is refused or euthanasia is sought on people's behalf) are often impairments and/or disabilities or are, like pain and nausea, the causes of impairments and/or disabilities. Among them are such conditions as the extensive brain damage suffered by Nancy Cruzan and diseases (and impairments) such as bone cancer, which causes disability by producing such overwhelming pain that the person cannot engage in normal activities. Thinking of a person who wishes to die as being disabled, as nearly always is the case, may change one's thinking about the ethical issues involved.

For those who oppose all euthanasia and PAS no moral conundrum arises with respect to disabilities in these areas: All such acts are wrong. For proponents of euthanasia and PAS, however, disabilities introduce some special dilemmas.

Many advocates of euthanasia and PAS tend to think of the matter as follows: Disabling conditions such as cerebral palsy, paralysis, and the type of permanent respiratory insufficiency that requires daily use of a respirator are incurable and can deprive life of its value for the afflicted person. If that person is mentally competent and refuses a life-prolonging treatment, saying that he or she prefers to die, these conditions are sufficient reason for that person to do so, and of course the request should be honored because it represents an exercise of individual autonomy. Even the opponents of euthanasia and PAS agree that treatment should not be forced on a person who is competent. If a person requests PAS or euthanasia, these are also sufficient reasons for it to be administered by willing parties according to this view. People with disabilities who seek death by starvation or the removal of a respirator have been hailed as champions of individual autonomy who attempt to exercise their rights against the resistance of officious healthcare institutions.

TWO ARGUMENTS AGAINST THE AUTONOMY-BASED APPROACH. There are two important counterarguments to this way of looking at requests to die made by people with disabilities.

The first is Carol Gill's (1992) suicide-prevention argument. Gill notes that when a nondisabled person undergoes a life crisis and subsequently shows certain behavioral signs and expresses a wish to die, that person is diagnosed with depression and is given counseling. He or she is regarded as less than fully competent because of depression and suicidal ideation. Gill observes a widespread assumption among nondisabled people, including healthcare professionals, that life with a disability is not worth living. Because of this, she argues, when someone with a disability expresses a suicidal wish, it is not classified as a symptom of curable, temporary emotional pathology. Instead, healthcare professionals regard the wish to die as rational because of their revulsion at the thought of living with a disability. They overlook standard clinical signs of depression and may disregard the presence of life crises or disappointments that are not related to the disability, such as loss of employment and divorce. Consequently, instead of providing suicide-prevention services, they encourage withdrawal of life-prolonging treatment, euthanasia, or PAS. If suicide-prevention services were provided, the disabled person might see adequate reason to live regardless of the disability, for once the depression was treated, the person would find life worthwhile. Thus, to advocate a right to die for the disabled is, at least in some cases, not to promote individual autonomy in decisions about life and death but instead to deprive the disabled of the suicide-prevention services routinely offered to nondisabled persons, a form of invidious discrimination.

The second, and related, counterargument arises more directly from the minority group model of disability. There is evidence that in some cases disabled persons seek death not because they find their impairments unendurable but because they are trapped in a dehumanizing social setting. Larry McAfee, for example, became so frustrated with his confinement to a nursing facility that he obtained a legal ruling that his ventilator be disconnected. Disabilities activists helped McAfee obtain job training and arrange to live outside the nursing home; he then decided to continue to live. According to this argument, what makes life unbearable to such people is not their impairments but the social world that subjects them to physical confinement and denies them decision-making power over their lives. Many people who are fairly severely disabled can, with assistance, do what McAfee did. However, government aid programs often refuse to provide the needed services outside an institution or the person is stymied by an unresponsive bureaucracy or excluded from jobs or housing by physical barriers or human prejudices. Thus, the disabled person's misery is caused by the choices and policies of other people. The person may seek death as the only alternative to living without basic dignity. In this view the ethical solution is not to allow or assist in the person's death but to free the members of this minority group from the oppressive conditions under which they are forced to live by implementing policies that promote independent living.

EUTHANASIA OF NEWBORNS WITH IMPAIRMENTS. Because newborn infants cannot make informed decisions about whether to end their lives, those who grant that some euthanasia is legitimate usually argue that such decisions should be made for newborns on the basis of whether a child's life will be of value to the child. The witholding of life-prolonging treatment is treated in the same way because there is no possibility in this case of informed refusal of treatment by the patient. According to the minority group model, infants born with incurable impairments may be wrongly killed because caregivers and parents assume that their lives would be entirely unrewarding even though many people with similar disabilities lead satisfying lives.

PUBLIC POLICY. Even if euthanasia or PAS for some disabled individuals were morally justified and not a result of depression or exclusion from independent living, some authors predict that if those options were made legal and routinely available, many morally unacceptable acts would result. They cite the difficulties of judging the mental competence of suffering patients who request death. In busy or understaffed hospitals people could be put to death who did not really want to die or were not really able to make a decision about it. Those authors mention the further danger that death may be sought not for the benefit of the person who dies but for the benefit of family members overwhelmed by the responsibility of caring for or paying for the care of an incurable individual or for the benefit of insurance companies and publicly funded healthcare programs.

This position creates a conundrum: Is it acceptable to adopt a policy that denies euthanasia and PAS to some people who are morally entitled to it, resulting in their prolonged suffering, to prevent the wrongful killing of others from carelessness, poor administration, or evasion of the law? Some argue that disabled people would be particularly vulnerable to being put to death wrongly under a policy of legal euthanasia or PAS because of the tendency of nondisabled people to expect a life with disabilities to be much worse for a disabled person than it actually is, the corresponding tendency of healthcare professionals and others to overlook the needs for treatment and other services, and the costs of providing for the disabled person's needs. Any such policy must include rigorous safeguards to prevent abuses and errors, but no safeguards are foolproof.

ABNORMAL FETUSES, PRENATAL SCREENING, AND ABORTION. Testing during pregnancy for a variety of genetic and other congenital abnormalities is available in many places. Familiar examples are the test for Down's syndrome performed by means of amniocentesis or chorionic villus sampling and the blood test for the alpha-fetoprotein level to gauge the likelihood of neural tube defects. Most prospective parents seek prenatal tests with the intention of aborting the fetus or embryo if it is found to have an abnormality. The tests that exist or will exist in the near future are for types of impairments that can be fairly severe, although some exhibit a great range of severity, and tests cannot show how severely or mildly affected a child would be.

Those who regard abortion as wrong in every case or defensible only in very limited cases (e.g., to save the life of a pregnant woman) must regard abortions of impaired fetuses as immoral. Antiabortion arguments usually are based on the thesis that an unborn human being, no matter how primitive its stage of development, has a right not to be killed (and indeed to be kept alive) because it is human. If a human fetus has a right to life from conception onward by virtue of its human genome and if abortion is therefore wrong, abortion is just as wrong when a fetus is affected by spina bifida or another abnormality as it is when a fetus is normal. According to this view these fetuses are surely human, just as are adult disabled people. The most common antiabortion position holds that human fetuses are already full-fledged persons with moral rights. Thus, impaired fetuses are also persons with moral rights.

Those who argue that abortion is wrong because of a being's potential to become a person rather than as a result of its actual personhood may have some flexibility to justify exceptions for fetal abnormality. However, many abnormal fetuses have the potential to fulfill the fundamental criteria of personhood and thus could not rightly be aborted even according to the potentiality theory.

Therefore, an antiabortion position opposes nearly all abortions of impaired fetuses. Some general opponents of abortion try to defend an exception for fetal abnormalities, but it is difficult to make that position logically consistent.

Those who regard abortion as often permissible (those with a "prochoice" position) may hold a range of different views that are based on various ethical principles and countenance abortions at different stages of fetal development or for different purposes. Some regard only early abortion as acceptable, for example, before sentience; others think abortion is acceptable later in pregnancy. Some regard abortion for frivolous reasons as unacceptable, whereas others regard it as legitimate for almost any reason as long as other criteria are fulfilled. However, most defenses of abortion attribute to an embryo or early fetus a moral status below that of persons and for that reason see nothing wrong with an early abortion chosen because the prospective parents would find it burdensome to raise a child in their circumstances. The presence of an impairment in an embryo or young fetus would count as such circumstances for many couples or pregnant women. Therefore, on the whole, according to the prochoice position, early abortion of an abnormal fetus is morally acceptable.

Furthermore, if a prochoice stance is assumed, there are positive reasons for aborting an impaired embryo or fetus. If the child were born, it might experience significant suffering, and raising a disabled child can be a great strain on parents and siblings. Indeed, a good prospective parent tries to produce a normal child rather than a disabled child and to give it advantages whenever possible. Bonnie Steinbock (2000) argues that given the prochoice assumption, selective abortion is a method of disability prevention that is comparable to a pregnant woman's taking folic acid to prevent neural tube defects. It also may be argued that the birth of disabled children is best avoided on the grounds that it drains resources from the healthcare system because those children may require multiple surgeries and other costly interventions.

THE DISABILITY RIGHTS CRITIQUE OF SELECTIVE ABORTION. Some authors who adopt a generally prochoice stance, however, argue specifically that abortion in response to fetal impairments is wrong. This has been called the disability rights critique of selective abortion. It consists of several distinct arguments, two of which are given below.

The expressive argument. The expressive argument is used both to show that the choice to abort an impaired fetus is wrong and at times that the government should not sponsor prenatal screening services. In this view aborting a fetus solely because it would develop into a disabled child expresses rejection of the disabled and perhaps exhibits the attitude that such children are undesirable or should not be born or the belief that the lives of all disabled people are miserable and lack value.

To express such an attitude is morally wrong for several reasons. For one thing the attitude is both erroneous and unfair. Many disabled people have good lives, and respect for the equal human worth of all individuals is one of the bases of morality. Also, aborting impaired fetuses, it is claimed, perpetuates bias against the disabled, just as selective abortion of female fetuses in certain societies perpetuates bias against women. Also, communicating a message of contempt to disabled people demoralizes them. Public funding of prenatal screening programs that people will use for abortion decisions does particular emotional harm because it shows public contempt and announces that society cares more about eliminating disabled people from the population than about helping those who are already born.

The main counterargument to the expressive position is that people who choose to abort impaired fetuses do not have the feelings or beliefs they are accused of expressing. Instead, their decision may be motivated by perfectly legitimate attitudes. Parents undergo special hardships in raising a disabled child that may include providing arduous or costly care well into the child's adult years. The desire to avoid those hardships is not tantamount to distaste or contempt for disabled people and does not stem from a belief that those people are all wretched. In light of the prochoice assumption, in aborting an early-term fetus with an impairment prospective parents choose not to produce a child who probably will suffer more and have more limited opportunities than a normal child does. The attempt to avoid those outcomes is part of the legitimate effort to do well for their families.

It should be noted that regardless of the actual attitudes of the agent, an action can convey an unintended but hurtful symbolic message, particularly if it is done in a context of widespread discrimination. However, this must be balanced against the central interests of adults in exercising reproductive freedom and making choices that determine the nature of their family life.

The cultural differences/social construction arguments. The arguments in this category focus on society's contribution to the phenomenon of disability. According to the minority group model, mainstream society causes much of the disadvantage inherent in disability by excluding disabled people from its central activities. Disability is socially constructed in this view. The way to eliminate the disadvantages of the disabled, then, is not to eliminate impaired people from the population through prenatal screening and abortion but to restructure society so that the impaired are included in it.

In addition, it is claimed that certain groups of disabled people form a distinct culture that should be respected. Defect-based abortion threatens to destroy that culture. This sometimes is claimed with respect to the Deaf (deaf people who identify with Deaf Culture, with a language such as American Sign as its central component). If too few congenitally deaf children are born, they will not be able to perpetuate their community.

Counterarguments to these claims turn on the shared assumption that appropriately early abortion is generally legitimate because the fetus is not yet a person with rights. Selective abortion does not kill off members of a society or participants in a culture; it simply makes it the case that there will be fewer people eligible to join the culture in the next generation. That harm to the culture must be weighed against the disadvantages impaired children would suffer if they were born. Even if society were made more inclusive, significant disadvantages would remain.

Disability and Genetic Intervention

Developments in human genetics offer the prospect of correcting or preventing impairments by means of genetic intervention. Of course, this would eliminate only impairments that are genetically based; it is irrelevant to impairments with other causes.

One use of genetics—testing for genetic abnormalities followed by the abortion of affected fetuses—was addressed above. There are also other uses. One may screen prospective parents for deleterious genes, and the carriers may choose not to reproduce or to have children by using donor gametes or transplanted embryos. In the future one may be able to modify the somatic genome of an existing person to eliminate impairment or modify a person's germ-cell DNA (the genome of a person's eggs or sperm) to prevent disabling impairments in future generations.

Because no life is terminated in these procedures (not even that of an embryo), there is no ethical objection to them from the perspective of the right to life even among those opposed to abortion in general. The ethical concerns that arise for selective abortion against a prochoice background, however, also apply to genetic techniques that prevent the conception of impaired fetuses, although with less force. For example, choosing not to have children or to use someone else's gametes to avoid producing a disabled child might express an attitude that devalues the disabled, although merely using contraception would do that less forcefully than abortion does. Programs of gamete donation and embryo transfer and techniques for altering genes *in utero* also would reduce the size of the disabled population and the number of participants in subcultures composed of people with particular disabilities, just as abortion does.

However, techniques that "switch off" or replace deleterious genes in living people or in gametes or fetuses that will be allowed to develop have a special defense against such criticisms. First, it is hard to see what could be wrong with treating a gamete, fetus, or already-born individual to correct or prevent a disabling impairment. This would be like treating a child with antibiotics to keep an infection from causing blindness, which is surely legitimate; it is a form of healthcare. Second, individuals who were denied available interventions and went on to develop disabling impairments would have moral grounds for complaint. The claims of disabled people not to be incrementally marginalized by decreases in their numbers and not to be given a discouraging message must be weighed against the claims of other individuals to receive an intervention that spares them from grave disadvantages. To deny them this would be to make them bear a disproportionately steep cost to protect the sensibilities of others.

On the basis of either a liberal or a strictly egalitarian theory of distributive justice, Norman Daniels and others argue that citizens of an affluent industrialized society that spends heavily on healthcare have a right to a broad package of efficacious healthcare services (Daniels; Buchanan et al.). If genetic intervention in living individuals becomes a reliable form of healthcare (once it is beyond the experimental stage), it will become the type of treatment to which such citizens have a right, according to these theories (Buchanan et al.), and failure to provide it will be not only a failure of compassion but an injustice.

There are significant risks in altering the somatic-cell genes of a single individual because the biological processes involved are so complex and the environment may interact with the changed genome in unexpected ways. However, for the most part it is only the individual who is at risk. There is further risk in changing a person's germ-cell DNA so that the change is transmitted to all that person's descendants. The new genome may give rise to new impairments when it is combined with the genes of others during reproduction or in response to shifting environmental influences. Because the technology for those procedures does not exist yet, one can say only that the ethical legitimacy of germ-line intervention to prevent disability will depend on the range of risks involved in each particular procedure. Great caution here is morally obligatory.

EQUAL HUMAN RIGHTS. Western philosophers argue that all human beings, in spite of their many obvious differences in strength, intelligence, and so forth, have equal fundamental human rights. Equal human rights always are thought to include noninterference rights such as the right to autonomy or self-determination and the right to freedom. They often are thought to include rights to goods or services as well, such as the right to a minimum amount to eat or a basic education. Philosophers offer different grounds for these moral rights.

For Immanuel Kant (1996 [1797]) human beings have such rights because they possess reason, including the capacity for rational choice in regard to action. Many recent authors follow Kant in proposing as the basis for the possession of equal rights criteria that depend on the psychological properties of the rights holder: the being's conceptual capacities, its control of its behavior, its emotions, or its capacities for reciprocal social interaction.

Social contract theories such as that of John Rawls (1971) offer a different basis for equal rights for all human beings. Jeffrie Murphy, following Rawls, says that "an individual should be understood as having a right to x if and only if a law guaranteeing x to the individual would be chosen by rational agents in the original position" (p. 8). The original position is a hypothetical situation in which a group of rational agents comes together to agree unanimously to principles and practices to govern their community. Each participant is self-interested, may care deeply about some (but not all) of the others, and knows in general what can happen in human lives but is "behind the veil of ignorance"—does not know his or her future or what his or her role in society will be. Those to whom the items in question are guaranteed need not be rational.

RIGHTS OF THE MENTALLY DISABLED. According to theories that base rights on psychological features of the prospective right holder, mentally competent people with physical disabilities have the same fundamental human rights as other competent adults because they fulfill all the criteria that have been propounded as the bases of human rights. Inability to walk or see does not deprive people of rationality, the capacity for informed choice, or the ability to interact reciprocally with others. According to contractarians, those people also have rights equal to those of the nondisabled because people in the original position know that they themselves might become physically disabled and thus would agree to protect the disabled in their possession of many goods.

In the psychologically based theories, however, a problem arises for people with severe cognitive or emotional disabilities. As Lois Weinberg (1981) points out, these people will not develop the capacities frequently cited as the grounds for equal human rights, such as the capacity for rational choice (in the severely retarded) and the capacity to interact reciprocally with others (in the sociopath). According to these philosophical theories, such individuals do not have any fundamental human rights; but that is implausible. At the very least those with mental or psychological disabilities have the basic human right not to be physically abused, and some argue that they have human rights to minimal care and an appropriate education. Giving them those things is not merely an act of compassion but also one of justice, it is argued, and hence a matter of rights.

The contractarian approach fares better. Murphy (1984) argues that rational agents behind the veil of ignorance would agree to guarantee a certain level of security and training for the mentally disabled because they know that they might become mentally disabled or might have a much-loved mentally disabled child. They would not guarantee autonomy protections to the mentally disabled but would guarantee them rights to basic food, shelter, and freedom from abuse.

AUTONOMY/NONINTERFERENCE RIGHTS AND RIGHTS TO AID. Noninterference or autonomy rights are the rights of rational persons who are capable of deciding their destinies to be left alone to do that: rights not to have others deprive them of life, liberty, or legitimately owned property (Locke, 1975 [1699]). Even for contractarians the full range of these rights belongs only to rational decision-making creatures because of their capacity to guide their behavior through their choices.

Mentally normal people with other types of disabilities are rational choosers, and so there are no grounds to deny that they have noninterference/autonomy rights. It is unjust to coerce them in the making of important life decisions, for example, to subject them to forcible sterilization. Mentally disabled people, depending on the severity of their impairments, may not live up to the standard of rational decision making needed to qualify for noninterference/autonomy rights. Some ethicists think that therefore people whose mental disabilities are significant do not have the moral right to make their own decisions about medical treatment, life-skills training, and finances. Those decisions are rightly made for them and should be made in ways that serve their interests. Others defend some autonomy rights for the mentally disabled.

Apart from noninterference rights, various authors claim that the disabled have the right to have a great assortment of goods and services provided to them by the rest of society. This may include life aids (ventilators and wheelchairs), attendant care, special education or training, the rebuilding of public structures, and income support (for food and shelter and also for healthcare in countries where healthcare is not subsidized for all). It is controversial which, if any, of these things are owed to disabled people by right and on what conceptual basis.

RIGHTS TO THE MEANS OF INCLUSION. For Anita Silvers (1994) all persons, or perhaps all who are mentally competent, have equal rights to participate fully in society on the basis of their individual dignity and self-respect. If any are excluded, justice requires that the barriers to their participation be dismantled or bridged. Thus, equality rights are the grounds on which the disabled have a right to be provided with the means of inclusion. Barriers to full participation are conceived broadly: The lack of a teacher for the visually impaired might qualify as a barrier to a visually disabled child's full participation in her or his school. Thus, the removal of barriers consists not only in the alteration of physical structures but also in the creation of new structures or devices and the provision of trained personnel. The disabled have a right to these things solely because of their right to equal participation, which in this view is a right that everyone has. This equality right to devices and services that remove barriers does not include the right to income support, however, because people do not all equally have that right solely on the basis of their equal dignity and self-respect. Silvers (1995) argues that once disabled people are granted equal access, they will earn their own living. If a few severely disabled people have a right to subsistence support, that has a different and nonuniversal basis.

However, a contractarian view treats the right to the removal of barriers and the right to income support as being on a par. In a contractarian view both are based on the protections rational agents would agree to for their society when choosing behind the veil of ignorance.

Thus, Gregory Kavka (1992) argues on the basis of both Hobbesian and Rawlsian social-contract theory that in advanced societies people with significant disabilities have a right against society that it provide, where feasible, the accommodation, equipment, and training needed to permit the disabled to engage in the productive processes of their society and thus earn an income. The Rawlsian version of the argument says that people in the original position would agree to improve the lot of society's least-advantaged members and that the disabled are among the least advantaged because of the disadvantage inherent in their disabilities and the barriers and prejudices they face in society. The most effective way to better their lot is to give them access to self-respect, which in modern societies depends greatly on work and career identification. Income support will not provide the same basis of self-respect, and so it is not the best means to achieve this end. Thus, although Kavka argues for the subsidized removal of barriers to employment, if the provision of food and shelter were the most effective way to better the condition of the least well off, that is what he would defend. Murphy's argument, similarly appealing to the original position, defends the provision of food and shelter to the mentally disabled.

Vigorous counterarguments are made against these arguments that society should provide the disabled with the means of inclusion. Philosophers who reject Rawls's theory of distributive justice attack the relevant premises. A different sort of counterargument claims that it is too expensive to provide all the goods and services needed by the disabled. Although giving disabled people access to full social participation would enable many of them to earn a living and not depend on welfare payments, it is an economically inefficient solution, they say, because it would be cheaper to provide income support for all disabled people. Society could use the savings for other important purposes. This need not be a selfish argument; the savings could be used to provide free healthcare to the poor or to build better schools.

Various replies are offered to the efficiency objection. The basic structure of the argument is utilitarian, and it may be criticized on those grounds. The cheaper policy may increase the well-being of some elements in society, such as taxpayers and the nondisabled poor, but may yield a far lower level of well-being for the disabled than would inclusion, and no evidence is provided that the net well-being of all the persons affected will be higher with the less expensive policy. Alternatively, the argument may be rejected on grounds of justice: It may be less expensive to provide nothing but income support, but it is unjust to deny disabled people the bases of self-respect that come from inclusion in society.

Conclusion

This entry has investigated the concepts of disability, impairment, and handicap; defended partial definitions of those concepts; and related them to the concepts of disease and health. It has explained the two prevailing models for understanding disability: the medical model and the minority group model. Those conceptual analyses provided tools for surveying two groups of ethical issues pertaining to disability: issues regarding the value of the lives of the disabled and issues regarding the moral rights of disabled people. In the first category the entry examined permitting the disabled to choose death, abortion of impaired fetuses, and genetic intervention to prevent disabilities. In the second category the entry considered issues of whether the disabled have a right to various kinds of liberties and government assistance, and if so, on what grounds.

RACHEL COHON

SEE ALSO: *Adoption; Anthropology and Bioethics; Autonomy; Care; Christianity, Bioethics in; Chronic Illness and Chronic Care; Dementia; Eugenetics; Genetic Testing and Screening: Reproductive Genetic Testing; Human Dignity; Human Rights; Infanticide; Infants, Ethical Issues with; Judaism, Bioethics in; Life, Quality of; Long-Term Care; Mental Illness; Metaphor and Analogy; Moral Status; Pediatrics, Intensive Care in; Rehabilitation Medicine; Value and Valuation; Virtue and Character;* and other *Disability* subentries

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II. LEGAL ISSUES

Persons with disabilities daily face challenges beyond their individual disabilities. Social prejudice and physical barriers often pose far greater hindrances. Prejudice takes the form of the myths, stereotypes, and irrational fears that many people in society associate with impaired functioning. Barriers are those environmental factors, both physical and social, that limit the meaningful involvement of persons with disabilities in normal life activities (Herr, Gostin, and Koh). While a corpus of law has been developed in the United States to protect persons with disabilities, the passage of the Americans with Disabilities Act (ADA) of 1990 (42 U.S.C. 112101–12213 [Supp. II 1990]) marks the most important federal antidiscrimination legislation since the Civil Rights Act of 1964.

The Social Situation of Persons with Disabilities

The ADA was enacted in response to profound inequities and injustice for persons with disabilities (National Council on Disability). Americans with disabilities typically are poorer, less educated, less likely to be employed, and less likely to participate in social events than other groups in society. Social attitudes toward persons with disabilities add to their burdens. Persons with disabilities may be ignored, treated with pity or fear, adulated as *inspirations* for their efforts to overcome their disabilities, or expected to be as *normal* as possible. Moreover, Americans with disabilities have historically lacked a subculture from which to derive a collective strength, primarily due to the disparity of their disabilities and backgrounds. Disability interest groups, offshoots of civil rights groups, have filled this void in the last several decades (West).

Such prejudice and barriers raise a number of legal issues, most notably discrimination. In employment, in education, and in mobility, society often fails in its efforts to effectively accommodate persons with disabilities.

Legal Responses to Disability

Legal responses to disability range from application of constitutional theory to statutory initiatives. It would be comforting to believe that the U.S. Constitution provides meaningful protection to persons with disabilities. Sadly, the Constitution has little to offer persons with disabilities except in egregious cases. The Bill of Rights is applicable principally to government (*DeShaney v. Winnebago County Department of Social Services,* 1989). Since most forms of discrimination take place in the private sector, the Constitution is of limited applicability.

Even where state action can be demonstrated, the Supreme Court has not enunciated a coherent and compelling constitutional doctrine to protect persons with disabilities against discrimination. The Court, for example, has never found disability to be a *suspect classification,* and most government activities do not deprive persons with disabilities of a "fundamental freedom such as liberty" (*City of Cleburne, Texas v. Cleburne Living Center, Inc.,* 1985). Accordingly, the Court might be expected to uphold a state discriminatory action, provided the government could show a reasonable basis for its policy.

The Supreme Court, in one of its few constitutional decisions concerning discrimination against persons with disabilities, did suggest that it would not tolerate clear instances of prejudice or animus in government policies. In *City of Cleburne, Texas v. Cleburne Living Center*, the Court struck down a city zoning ordinance that excluded group homes for persons with mental retardation. The Court, in a particularly thorough search of the record, found no rational basis to believe that mentally retarded people would pose a special threat to the city's legitimate interest (Gostin, 1987).

A convincing constitutional argument could be made that persons with disabilities should have a high level of constitutional protection as is the case with racial minorities and women. Persons with disabilities have a similar history of exclusion and alienation by the wider society. They are often subject to discrimination on the basis of their status without regard to their abilities.

Much of the legal protection afforded to persons with disabilities is under federal and state law. Statutory initiatives in disability law fall into three general categories: (1) programs and services; (2) income maintenance; and (3) civil rights. Such statutes incrementally have sought the legislative goals of full participation and independence for persons with disabilities. While state laws vary in scope and effect, at the federal level three main acts shaped the corpus of disability law prior to enactment of the ADA.

The federal Rehabilitation Act (29 U.S.C. 791–794 [1988 and Supp. I 1989]), enacted in 1973, covers federally funded entities (and continues to cover all federal employees). Section 504 of this act (broadened by amendments in 1987) prohibits discrimination against otherwise qualified disabled persons in any federally funded program, executive agency, or the Postal Service. Sections 501 and 503 require affirmative action hiring plans in the federal government and certain large federal contractors.

The Individuals with Disabilities Education Act (IDEA) (42 U.S.C. 6000–-6081 [1975]; 20 U.S.C. 1400 *et seq.* [1991]), enacted in 1975 and amended in 1990, mandates a free and appropriate education for all children with disabilities, encouraging integration (*mainstreaming*) whenever possible.

The Fair Housing Amendments Act of 1988 (42 U.S.C. 3601–3619 [1988]) ensures that persons with disabilities are a protected class in housing discrimination cases, and mandates access requirements for new housing and adaptation requirements for existing housing to ensure that the housing needs of disabled persons are met. This act continues to cover housing discrimination in place of specific provisions in the ADA.

The Americans with Disabilities Act of 1990

While these initiatives were a start, they failed to address cohesively the needs and rights of persons with disabilities. The ADA is a strong response to the needs and rights of persons with disabilities, needs and rights articulated by the growing voice of disability interest groups in America. It offers a potentially important vehicle for safeguarding the rights of persons with disabilities, but the judiciary has been whittling away its protections over recent years (Gostin, 2002).

More specifically, as an outgrowth of civil rights law, the ADA serves as a legal tool because of its broad scope and unique ability to adopt the visions of both equality and special treatment. The ADA recognizes that a person's disabilities often have little to do with his or her inabilities. Often it is society's reactions to the person with disabilities or society's structural barriers that disable the person. The mandate of civil rights law is to destroy those negative reactions and dismantle those barriers in order to restore equal opportunity and full participation in daily life activities with dignity, not charity. The ADA strives to achieve this objective.

The act prohibits discrimination against qualified persons with disabilities in employment, public services, public accommodations, and telecommunications. The principal change in federal law is that the ADA applies to all covered entities, whether or not they receive federal funding. The impact of the ADA on public health departments and communicable-disease law (Gostin, 1991b) and on the healthcare system (Gostin and Beyer) is significant. It will also have a significant impact on other important areas of bioethics, including the duty to treat, the right to health-benefit coverage, and medical testing and examinations by employers (Parmet).

Although the specific titles of the ADA have slightly different provisions, a finding of discrimination is based on adverse treatment of a person (1) with a *disability* who is (2) *qualified* or who (3) would be qualified if *reasonable accommodations* or modifications were made available.

Disability is defined broadly to mean "a physical or mental impairment that substantially limits one or more of the major life activities," a record of such impairment, or being regarded as having such impairment (section 3). The definition of disability theoretically covers a wide range of medical conditions. The courts had construed the Rehabilitation Act to include a wide-range of disabilities that are both genetic (e.g., Down syndrome [*Bowen v. American Hospital Association*], muscular dystrophy [S. Rep. no. 116]); or cystic fibrosis [*Gerben v. Holsclaw*] and multifactorial (e.g., heart disease, schizophrenia, or arthritis [S. Rep. no. 116]). Disability was also construed to include diseases that are communicable (e.g., tuberculosis [*School Board of Nassau County, Florida v. Arline*], hepatitis [*New York State Association of Retarded Children v. Carey*], or syphilis); as well as those that are not (e.g., cerebral palsy [*Alexander v. Choate*], or diabetes [S. Rep. no. 116]). However, a person who is currently using illegal drugs is not considered disabled, but is covered once he or she has been successfully rehabilitated and is no longer using drugs (section 510). Similarly, a range of socially disapproved behavior disorders are excluded from protection, such as most gender-identity disorders, pedophilia, exhibitionism, voyeurism, compulsive gambling, kleptomania, pyromania, and psychoactive drug-use disorders (section 511).

Moreover, a person is disabled if he or she has a *record* of, or is *regarded* as, being disabled, even if there is no actual disability (*Southeastern Community College v. Davis*). A record indicates that a person has, for example, a history of disability, thus protecting persons who have recovered from a disability or disease, such as cancer survivors.

The term regarded includes individuals who do not have disabilities but are treated as if they did. This concept protects people who are discriminated against in the false belief that they are disabled. It would be inequitable for a defendant who intended to discriminate on the basis of disability to successfully raise the defense that the person claiming discrimination was not, in fact, disabled. This provision is particularly important for individuals who are perceived to have stigmatizing or disfiguring conditions such as HIV, leprosy, or severe burns (S. Rep. no. 116).

Although the ADA theoretically covers a wide range of persons with disabilities, the Supreme Court has been significantly narrowing its scope. The first Supreme Court opinion on the ADA was quite hopeful. In its decision in *Bragdon v. Abbott* (1998), the Court held that a person with purely asymptomatic HIV infection was *disabled* within the meaning of the Act.

The *Bragdon* decision makes it more likely that, in the future, the courts will find persons with asymptomatic HIV infection protected under the ADA. The question remains, however, whether other health conditions will satisfy the ADA's definition of disability. As explained above, courts deciding cases under the Rehabilitation Act did not view the definition of disability as a strict obstacle for plaintiffs. The issues did not turn on whether an individual *had* a disability, but rather on whether the disability was the *cause* of the adverse action, or on whether the action was *justified* because a person's disability rendered her unqualified for a job or ineligible for a service. The judicial approach in disability cases was similar to the approach when individuals claim discrimination based on their race or gender. When making decisions regarding race or gender discrimination, courts do not engage in searching inquiries into whether the individual is *really a woman,* or *really an African-American.* Rather, these cases are often lost because individuals are unable to prove they have been discriminated against *because* of their race or gender (Feldblum, 1996).

Nothing during passage of the ADA suggested that courts would adopt a narrow definition of disability. But the legal landscape has changed dramatically (D'Agostino). Courts deciding ADA cases have arrived at a restricted definition of disability through two principal methods. First, many courts analyze whether a plaintiff is substantially limited in the major life activity of working. Courts often conclude that the impairment is not sufficiently limiting because there is a range of jobs that the individual can still perform. This narrow view makes little sense because the ADA was designed to prohibit discrimination against people with disabilities who *can* work, but who are nonetheless discriminated against.

Even if an individual's claim that her impairment limits a major life activity *other* than working is accepted, there is a second method by which courts have restricted coverage under the ADA. Courts scrutinize whether the individual's impairment *substantially* limits a *major* life activity. In *Toyota Motor Manufacturing Kentucky v. Williams* (2002), the Supreme Court adopted a narrow construction of "major life activity." The Court found that a medical diagnosis of carpal tunnel syndrome was not sufficient to qualify a person as disabled; nor is evidence that the person cannot perform "isolated, unimportant, or particularly difficult manual tasks."

Courts have also restricted coverage under the ADA by asking whether the impairment of a major life activity is "substantial." The Supreme Court requires that the impairment be "considerable." For example, in *Albertsons v. Kirkinburg* (1999) the Supreme Court held that a person with monocular vision is not disabled because the condition is not serious enough to substantially restrict his life activities.

The Supreme Court not only requires a substantial limitation in a major life activity, but it also requires that corrective and mitigating measures be considered in determining whether an individual is disabled. In *Sutton v. United Airlines, Inc.* (1999) the Court held that severely myopic job applicants for airline pilot positions are not disabled because eyeglasses or contact lenses mitigate their impairment. Similarly, in *Murphy v. United Parcel Service, Inc.* (1999) the Court held that a driver with high blood pressure is not disabled because his condition could be mitigated with medication. The Court did not claim that individuals with myopia or high blood pressure are not qualified to be pilots or drivers. Rather, the Court held that since the plaintiffs were not disabled, their qualifications for the job were not even relevant considerations under the ADA. Thus, in an ironic twist, although the ADA's goal is to provide anti-discrimination protection to individuals who (perhaps because they are taking medication) are qualified for jobs and eligible for services, such individuals are denied protection precisely because their medical conditions are under control.

The third prong of the definition of disability—which protects individuals who are *regarded as* having a substantially limiting impairment—has been applied quite restrictively by courts. Indeed, the Supreme Court in *Sutton* suggested that the employer or service provider must actually believe the person is substantially limited in a major life activity before receiving protection against discrimination. Thus, a person fired due to irrational fear or prejudice will not receive protection under the ADA provided the employer does not think the individual has a substantial physical or mental limitation.

A person is *qualified* if he or she is capable of meeting the essential performance or eligibility criteria for the particular position, service, or benefit. Thus, a person with a disability is not protected unless he or she is otherwise qualified to hold the job or to receive the service or benefit.

Qualification standards can include a requirement that the person with a disability does "not pose a direct threat to the health or safety of others" (sections 103[b], 302 [b][3]). The *direct threat* standard means that persons can be excluded from jobs, public accommodations, or public services if necessary to prevent a *significant risk* to others (*School Board of Nassau County, Florida v. Arline,* 1987). The significant risk standard originally applied only to persons with infectious disease. However, it was extended by the House Judiciary Committee to all persons with disabilities (H.R. Conference Report no. 101–596).

In order to determine, for example, that a person with mental illness poses a significant risk to others, evidence of specific dangerous behavior must be presented. In the context of infectious diseases such as tuberculosis, the Supreme Court laid down four criteria to determine significant risk:

1. the mode of transmission;
2. the duration of infectiousness;
3. the probability of the risk;
4. the severity of the harm (*School Board of Nassau County, Florida v. Arline*).

The Supreme Court in *Chevron U.S.A. Inc. v. Echazabal* (2002), held that a person with a disability is not "qualified" if she poses a direct threat to herself. This is a form of paternalism that is not in the language of the ADA, but had been supported by the Equal Employment Opportunities Commission. Allowing an employer to balance the benefits and risks for an individual, rather than allotting that power to the individual, opens the door to unfair treatment whenever an employer has reason to believe that workplace conditions or activities may be harmful.

The ADA requires reasonable accommodations or modifications for otherwise qualified individuals (sections 102[b][5], 302[b][2][A][ii]). This requires adaptation of facilities to make them accessible, modification of equipment to make it usable, and job restructuring to provide more flexible schedules for persons who need medical treatment (section 101[9]). To accommodate otherwise qualified persons with infectious conditions, an entity might have to reduce or eliminate the risk of transmission. Employers, for example, might be required to provide infection control and training to reduce nosocomial (disease or condition acquired in the hospital) or blood-borne infections. An employer, however, is not forced to endure an undue hardship that would alter the fundamental nature of the business or would be disproportionately costly. The Eighth Circuit Court of Appeals, for example, held that a school for persons with mental retardation was not obliged to vaccinate employees in order reasonably to accommodate a student who was an active carrier of hepatitis B virus (*Kohl v. Woodhaven Learning Center,* 1989).

Conceptual Foundations of Disability Law

Conceptually, disability law follows two distinct traditions—equal treatment (based on civil rights law) and special treatment (based on social welfare law). The equal treatment perspective means that persons with disabilities should be treated as if their disabilities do not matter. Accordingly, the law mandates businesses, public accommodations, public services, transportation, and communications authorities not to discriminate. This concept of equal treatment is powerfully articulated in the law. At the same time disability law also requires special treatment. The law requires the aforementioned entities to adopt a concept of affirmative action that focuses on the person's disabilities, as well as on societal barriers to equal treatment (Feldblum, 1993). The ADA requires reasonable accommodations or modifications designed to enable or empower the person with disabilities to take his or her rightful place in society. The law, therefore, insists on special treatment when that is necessary to allow a person to perform a job, enter a public building, or receive public service. As the Supreme Court observed over two decades ago, "Sometimes the greatest discrimination can lie in treating things that are different as though they were exactly alike" (*Jenness, et al. v. Fortson*, p. 442).

Disability law, however, does not take either the equal treatment or the special treatment principle to its logical extension. With respect to equal treatment, the Supreme Court has dismantled the statute to such an extent that the ADA does not provide an effective remedy for many individuals with a disability. With respect to special treatment, the ADA does not allocate tax dollars to enable the person to participate equally in society, beyond use of government funds for *reasonable accommodations* in such areas as public transportation. Nor does it require covered entities to spend unlimited amounts to provide equal access and opportunities for persons with disabilities.

Conclusion: A New Vision

The ADA promised to revolutionize the way we view the law's protection and empowerment of persons with disabilities. No longer were we supposed to see persons with disabilities through the lens of charity, sympathy, or benign discretion. Now we were supposed to see persons with disabilities through the lens of civil rights law. Under civil rights law persons with disabilities should not have to not ask for societal favors. They should be able to demand an equal place in a society that has long been structured—physically and sociologically—by and for the able-bodied.

This promise and vision, however, have been sharply curtailed by the Supreme Court. It is no longer realistic to believe that persons with disabilities will receive the same kind of civil rights protection as, say, African Americans and women. For that to happen, Congress will have to amend the ADA to express the vision of true inclusion and protection against discrimination for all Americans with a disability.

LAWRENCE O. GOSTIN (1995)
REVISED BY AUTHOR

SEE ALSO: *Access to Healthcare; Genetic Discrimination; Human Rights; Informed Consent; Law and Bioethics; Medicaid; Patients' Rights; Right to Die; Utilitarianism and Bioethics;* and other *Disability* subentries

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DIVIDED LOYALTIES IN MENTAL HEALTHCARE

• • •

Physicians have traditionally understood their primarily loyalty as being to the patients they serve. This tradition goes back to at least to the time healers left behind their shamanistic roots, some twenty-five centuries ago. So important is this sacred commitment that it is enshrined in Hippocratic Oath, with which physicians and the public often identify the medical profession. The relationship between physician and patient is understood as a fiduciary relationship, meaning it is based on trust. Other healthcare professions—and indeed other professions—have modeled their self-understanding on this sort of promise to benefit those served.

Situations do arise in which physicians and other professionals experience divided loyalties—divided between allegiance to the patient and allegiance to some other interest. This has traditionally been spoken of as “the dual-agent (or double-agent) problem.” A physician or therapist is a dual agent, for example, if he or she owes an allegiance to an employer as well as the patient. In situations of divided loyalties the integrity of a physician’s judgment or action may be compromised. Classic examples of this occur when a physician (especially a psychiatrist) works for the military or for a state or federal institution, where confidences cannot be guaranteed. Increasingly, physicians and other providers find themselves asked to serve the broader interests of society; that is, the interests of populations rather than individuals. This is especially true for those working for large organizations, such as health maintenance organizations (HMOs), managed-care organizations, or nationalized health services. In these situations, the physician must recognize an obligation to society, making it more difficult to buffer the unique concern for each individual patient.

From the moral point of view, most dual-agent situations are best seen as cases of conflicting loyalties or clashing duties. The doctor must choose one duty over another (Macklin, 1982). Perhaps most problematic are situations in which the patient assumes (because of the weight of the professions’ patient-centered ethic) that the doctor is working for the patients’ best interest. A psychiatrist in a pre-arraignment examination might be able to elicit more information then a police interrogation simply by presenting a trusting demeanor. But if the message is not “I am here to help you,” then the purpose of the examination should be directly stated. An administrative evaluation in a student health service should clearly state, “You are being evaluated at the request of the dean, who will receive a report of my findings.” A health professional should not give the impression that everything a person says is confidential if that is not the case.

While cases in psychiatry and mental health have received the most attention, this attention has increased awareness of the problem of divided loyalties in virtually all areas of healthcare. A quick literature search for “divided loyalties” on the Internet returns results from the following specialties: nursing (Winslow; Dinc and Ulusoy; Chao; Tabik, 1996), ophthalmology (Addison), sports medicine (Sim), occupational medicine (Walsh), physical therapy (Lurie; Bruckner), military medicine (Howe; Camp; Pearn; Hines), transplant medicine (Bennett; Tabik, 1994), clinical researchers (Miller), aviation medicine (McCrary), infectious diseases, obstetrics (Plambeck), student health and those doing administrative evaluations and disability evaluations (Lomas and Berman), and house physicians and residents (Morris; La Puma), as well as psychiatrists, forensic psychiatrists and physicians, and child psychiatrists and pediatricians. Issues of privacy, especially the privacy of medical records, cut across all disciplines in the information age, as do issues of cost containment, reimbursement, and healthcare funding. While all these disciplines face situations of divided loyalties, perhaps nowhere is the conflict more dramatic than it is in nursing, where loyalties have undergone a transformation from loyalty to the individual physician for whom and with whom a nurse works, to the healthcare institution that employs the nurse, to patients more generally, and finally to the principles of medical ethics that inform the values of all professions.

Background and History

Divided-loyalty dilemmas have been most blatant in efforts at social control. Since mental healthcare often deals with deviance in behavior, its conceptions run parallel to society’s conceptions of social behavior, personal worth, and morality. Thus, in certain situations, there may be great pressure for mental-health professionals to label patients on the basis of social, ethical, or legal norms, and not on clearly established clinical or laboratory evidence of psychopathology.

Doctors are influenced in their activity and judgment by sociocultural context, by the ideology implicit in their professional training, and by the economic and organizational constraints of the setting in which they practice. Their practice involves multiple and, at times, competing professional roles with different social and ethical requirements, but often with no clear definition of boundaries (Mechanic). The practitioner must always ask the crucial question: Whom do I represent and whom do I serve? History is replete with cases showing that the patient is not always the primary one represented.

Extreme cases put the more mundane cases into perspective. Psychiatrists in the former Soviet Union (as well as in other Eastern European countries and in the People's Republic of China) have come under scrutiny for hospitalizing political dissidents and labeling them psychiatrically impaired (Bloch and Reddaway). Physicians in the military governments of Latin American have (perhaps under coercion themselves) cooperated with the torture of political prisoners, a situation that also occurred in South Africa during the period of apartheid. Nazi physicians conducted experiments in concentration camps that would have previously been unimaginable, giving rise to the safeguards of informed consent now required (Drob; Lifton, 1976, 1986). Nazi doctors acted completely contrary to their own moral and professional commitments, serving the ideology of the state and not their patients. These historic lessons make the need to examine divided loyalties all the more urgent.

The use of psychiatry as an instrument of social control had a long history in the former Soviet Union. Soviet authorities chose to have dissenters from official governmental policy labeled with mental illness designations such as schizophrenia, "sluggish schizophrenia," or paranoid development of the personality. The labeling of persons as mentally ill is an effective way to discredit their beliefs and actions, and to maintain control over those persons of whom a government disapproves.

Although the situation in the former Soviet Union was extreme, there have been examples in other societies in which psychiatry has been used (or abused) to stifle nonconformity, serving the interest of someone other than the patient. Notorious examples include the poet Ezra Pound and the actress Frances Farmer, both of whom where involuntarily hospitalized for political extremism (Arnold).

In cases of controversial religious movements, distressed families have sought help from mental health professionals to "rescue" and "deprogram" their children from such groups or cults. The mental health professional may be caught in a divided-loyalty dilemma between family values and religious liberties, possibly medicalizing religious conversions and then treating them as illnesses (Post). On the other hand, vulnerable young people may be particularly susceptible to coercive group pressure, and mental health professionals have traditionally acted in the "best interest of the child" for autonomous growth and development.

The question of divided loyalty can readily arise in matters of confidentiality. Mental health professionals cherish confidentiality as a prerequisite for psychotherapeutic work, but what is an appropriate limit to confidentiality when a patient reveals plans that might endanger others? This question came dramatically to public attention in 1974, when Tatiana Tarasoff, a college student, was murdered. Lawsuits were subsequently brought by the student's parents against the university, the campus police, and the psychotherapist who had failed to warn Tarasoff of threats made against her life by a fellow student (and patient of the therapist) who had fallen in love with her and whose love was unrequited. The therapist had alerted campus police to the danger his patient posed, but they arrested him, found him harmless, and released him.

The military is an organization whose needs and interests may compete with those of the patient. In the military, mental-health professionals are committed to serving society by supporting their commanders in carrying out military operations (Howe). The psychiatrist who returns a soldier to mental health may be returning him to a battlefield where he could be killed. Robert Jay Lifton highlights this ethical conflict by showing that the soldier's very sanity in seeking escape from the environment via a psychiatric judgment of instability renders him eligible for the continuing madness of killing and dying (a perfect example of Joseph Heller's "Catch-22"). Even in military situations, mental health professionals retain obligations to their profession. Further, their clinical effectiveness requires that they give high priority to the needs and interests of the military personnel they treat. In most cases, the mental health professional's ambiguous position in military medicine as a dual agent allows the person to believe that he or she is participating in both the care of patients and the public interest (Howe).

The prison system has also been the setting for a variety of divided-loyalty dilemmas. The professional may be called upon to evaluate an accused person's competency to stand trial. If treated, the person may become competent to stand trial, but left untreated the psychosis may prevent the person from participating in his or her own defense. In capital cases this can be a matter of life or death. How does a physician understand this obligation to the patient when providing treatment, particularly antipsychotic medication that may ultimately lead to conviction and death?

Conflicting obligations can easily arise in situations where doctors ask their own patients to participate in clinical research. While most doctors comply with their primary obligation to deliver the best possible care to their patients, the demands of adhering to a strict research design can create obligations that compete with those of giving good medical care. The research-oriented physician must maintain special ethical vigilance to assure that the patients' interest comes first, a vigilance that is reinforced by external review of research consent procedures.

Ethical Analysis and Resolution

A first step in resolving divided loyalties is to think of loyalty as an attachment or allegiance to a person or cause, and to see it as expressing a coherent meaning that unifies one's personal and professional conduct (Dwyer). Loyalties develop with the assumption of roles and relationships both inside and outside of professional practice. The professional's identity is connected with the primary role of restoring the patient to health. In approaching a divided-loyalty dilemma, it is necessary to articulate and reflect on the meaning of one's commitments in order to determine how these commitments ought to be ordered or reconciled in a particular case.

A basic principle of medical practice is that health professionals should be loyal to their patients and be advocates for them. This commitment does not always avoid conflict. For example, even when health professionals devote themselves exclusively to the good of the patient and show no allegiance to other persons or causes, conflicts may still arise between what the professional sees as good treatment and what the patient wants and sees as good treatment.

The roots of the confidentiality concept are essentially ethical and not legal, and from the earliest days of medical practice, respect for the patient's confidences has been considered an important part of the obligation owed by the physician to the patient. Communications told in secret and in trust have been guarded and respected. In a situation such as the Tarasoff case, however, while acknowledging the desirability of maintaining patients' confidences, one sees a strong competing ethical obligation. When a patient intends harm to another person, or when information is required for the adjudication of a dispute in court, physicians are faced with the claim that societal interests should take precedence. While absolute confidentiality is no longer the expectation, arguments for protecting and extending confidentiality, even in the face of competing demands, remain strong. The arguments usually rest on both ethical and utilitarian grounds and center on the moral good reflected in protecting private utterances. The arguments relate to the belief that confidentiality promotes desirable goals, such as encouraging potential patients to seek medical care and allowing patients to unburden themselves and provide all the information essential for the doctor to help them. In a healthcare system such as that in the United States, the practitioner's relationship to the patient is fiduciary—that is, he or she acts for the benefit of the patient. Can modifications be made that do not compromise the fiduciary relationship? Can the doctor–patient relationship be extended to support affirmative duties not only to the patient but also for the benefit of third parties? Ralph Slovenko, an attorney-psychologist, answers this question in the affirmative, stating that a psychiatrist's loyalty to the patient and responsibility for treating the professional relationship with respect and honor do not negate responsibilities to third parties, to the rest of the profession, to science, or to society. Slovenko goes on to say, however, that how these other duties are accepted, how the patient is kept informed, and how the patient is cared for when other duties are carried out can either introduce or help to avoid a divided-loyalty dilemma.

Joan Rinas and Sheila Clyne-Jackson recommend a forthright stance in preventing dual-agent dilemmas. They argue that the mental health professional has obligations to all parties with whom he or she has a relationship. These duties include notifying all parties of their rights, the professional's specific obligations to each party, potential and realistic conflicts that may arise, and limitations in knowledge and service. If, on exchange of this information, the mental health professional concludes that he or she is not the appropriate one to provide the requested service, the patient or the third party should be referred to a professional appropriate and qualified to perform the desired function. Participants in a Hastings Center symposium on double agentry made a similar set of recommendations for addressing divided-loyalty dilemmas (Steinfels and Levine).

The answer to what appears to be a divided-loyalty dilemma in court cases may rest on a particular type of disclosure. Where the psychiatrist is functioning as a friend of the court, the primary loyalty is not to the patient but to society as embodied in the judicial system. In such settings, the doctor–patient relationship does not exist in the traditional sense. Both doctor and patient must understand this from the outset. Divided-loyalty dilemmas are prevented when the psychiatrist advises all parties involved that the relevant materials they provide will be used in the court proceedings and that he or she is functioning as a consultant to the court (Goldzband).

Financial Considerations

Divided loyalties are becoming more prevalent due to efforts at cost containment and the rationing of health services. Society is demanding that healthcare costs be controlled. In response, careful protocols are being developed as to what services can be given, and for how long they can be given.

These cost-containment methods may interfere with what patients realistically need to remedy their health problems, and can therefore compromise the ethical principle of doctor as patient advocate. Ruth Macklin emphasizes that whether doctors cut costs voluntarily in treating their patients or are required to adhere to policies instituted by others, their ability to advocate vigorously for their patients' medical needs is weakened. When rationing becomes a factor in physicians' treatment decisions, such as which patients will be admitted to the hospital and for how long, physicians are forced into a divided-loyalty conflict. Further, the care obligation embraced by medical ethics cannot be accomplished without permitting a physician to strive for "a robust patient–physician relationship, patient well-being, and avoidance of harm" (Wolf, p. 38).

Conclusion

Conflicting responsibilities, contradictory goals, hidden scenarios, and unsigned contracts existing in the changing world of both the patient and the professional serve as reminders that ideal resolutions may be unattainable in many divided-loyalty dilemmas. Professionals must be very sensitive to the possibility that they may become double agents in the routines of their everyday practice with its many ambiguities and subtleties.

Further, review and examination of dual-agent issues should be a continuing obligation of mental health professionals, for that is one way to prevent these issues from disrupting the doctor-patient relationship. These are issues that often come before professional ethics committees, which keep them alive through education, codes, and professional discipline.

In cases of divided loyalties, physicians and other health professionals should give the patient their primary loyalty, and other allegiances should be subordinated to that of the patient. Where this is not possible, any conflicting allegiance should be explicitly disclosed. The goal of maintaining trust is essential for the therapeutic relationship, and anything that erodes that goal diminishes not only the therapy or the treatment, but also the therapist and the profession he or she represents.

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SEE ALSO: *Conflict of Interest; Profession and Professional Ethics; Professional-Patient Relationship; Psychiatry, Abuses of; Research, Unethical*

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DNA IDENTIFICATION

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In 1985, Alex J. Jeffries and his colleagues demonstrated that patterns of molecular markers in human DNA, or *DNA fingerprints,* could serve as uniquely identifying personal traits. This discovery was quickly applied by the criminal justice system, as way of definitively connecting suspects with blood, tissue, or semen from crime scenes. Shortly thereafter, governments at the state and national levels began authorizing the collection of DNA samples from individuals convicted of violent crimes who were considered at high risk for recidivism. By 1998, all fifty states in the United States had enacted such laws, and the U.S. Federal Bureau of Investigation (FBI) was able to launch a national electronic database of DNA profiles from convicted criminals for use in future cases (Hoyle). In the interim, the collection of DNA for personal identification purposes has already become mandatory within the military and has become a mainstay of civilian efforts to clarify the identities of children and kidnap victims, to investigate family lineages, and even to authenticate religious relics. On the horizon, lies the question that civil libertarians anticipate with dread: Why not store personally identifying genetic information on everyone as a matter of course, for the advances in public safety and personal security that can be gained thereby?

Photographs and traditional fingerprints have, of course, also been taken, collected, and used for all these same purposes in the past. But unlike photography and manual fingerprinting, collecting individually identifying DNA patterns (iDNAfication) does involve taking bits of people's bodies from them: nucleated cells and their complements of DNA molecules. For those concerned about the ethical and legal status of body tissues and an individual's ability to control what happens to him or her through use of that tissue, this corporeal side of iDNAfication raises an interesting challenge. Clearly, questions of personal privacy are involved. But unlike most other disputes over body tissues, the issues here are not primarily matters of personal sovereignty.

For example, unlike involuntary sterilization or forced surgeries, the central concern with mandatory iDNAfication does not seem to be the violation of a person's bodily integrity. Compared with the other infringements of personal freedom that legitimately accompany legal arrest, providing a saliva or cheek swab sample seems negligibly invasive (Schultz). Moreover, unlike the creation of marketable human cell lines or the commercialization of organ procurement, it is not the exploitation or misappropriation of the person's body for others's gain that is centrally troubling either. Manual fingerprints and photographs also exploit suspects's bodies in order to incriminate them, without raising special privacy concerns. Moreover, consider the fact that it does not matter to an identical twin whether a DNA sample under scrutiny actually comes from him or his sibling: To the extent that the genetic information it contains describes both their bodies, the privacy of each is endangered.

In fact, the major moral concern about iDNAfication has little to do with whether the DNA analyzed is a piece of the person being identified, the property of the person being identified, or even is forcibly extracted from the person being identified. In most iDNAfication contexts, these physical, proprietary, and decisional privacy considerations are beside the point. Rather, the important feature of iDNAfication is what the DNA analyzed can *disclose about* the person being identified. It is, in other words, individuals's informational privacy that is at stake in the prospect of widespread iDNAfication, and it is in those terms that the policy challenge of iDNAfication should be framed. What should society be allowed to learn about its citizens in the course of attempting to identify them?

Taking up this challenge means taking seriously the precedents set by society's use of photography and manual fingerprinting, since their primary impact on personal privacy also lies in the identifying information they record rather than the nature of their acquisition. If the collection of mandatory *mug shots* and fingerprint impressions are taken as benchmarks of social acceptance for at least some identification purposes, any iDNAfication methods that conveyed no more personal information than those techniques should also be socially acceptable, for at least the same range of purposes. Thus, where fingerprints of arrestees, inmates, employees and recruits are now taken legitimately, performing iDNAfication should also be justified, if its informational privacy risks were equivalent. Similarly, if society accepts the personal disclosures involved in using photographs on drivers's licenses and identification cards, it should be willing, in theory, to expose an equivalent range of genetic information in any legitimate forms of iDNAfication. One approach to the general challenge of iDNAfication, then, would be to ask the following question: If the ways in which photographs and manual fingerprints are used for legitimate identification purposes are accepted, under what circumstances, if any, might forms of iDNAfication meet the standard those practices set for the disclosure of personal information?

Personal Privacy Considerations

A number of personal privacy risks of iDNAfication have been described and anticipated in the design of some iDNAfication programs. Thus, for example, many have pointed out that if the DNA sequences used as the components of an iDNAfication profile are taken from the regions of the human genome that code for proteins, important biological information about their sources could be revealed, including information about their paternity, current health status, and potential health risks (U.S. Congress Office of Technology Assessment (OTA), National Academy of Sciences). Any risk of disclosing sensitive personal information of these sorts would clearly increase the intrusiveness of iDNAfication beyond that of traditional fingerprinting and photography. In addition, it could expose the person being described to the possibility of discrimination on the basis of a disclosed genotype (Bereano; DeGorgey; Scheck; Sankar) Fortunately, this is a privacy risk that can be almost entirely eliminated by two simple precautions: One need only avoid analyzing biologically informative DNA, and destroy the DNA samples upon analysis.

The first precaution can be accomplished by restricting the sections of DNA that are amplified, analyzed and utilized in the iDNAfication profile to the non-coding regions of DNA between our functional genes. By definition, markers selected from these regions will not disclose any biologically significant information. Rather, like fingerprints, they could merely provide a unique pattern to match in seeking to identify an unknown person. Even photographs are useful mainly as patterns to match, rather than for what they can independently tell us about the person pictured in them. Serendipitously, individual variation is also vastly more pronounced in this so called junk DNA (since mutations can accumulate in these sections without having any adverse effect on genomic function), making it more attractive for iDNAfication purposes on scientific grounds as well.

Thus, the FBI, in establishing standardized forensic iDNAfication markers for use by state laboratories contributing DNA profiles to the latter's National DNA Index System (NDIS), has focused on a set of thirteen loci from non-coding regions that contain series of repeated nucleotide sequences whose length is highly variable between individuals (Hoyle). The exclusive use of these markers in any iDNAfication program would forestall most genetic privacy concerns linked to the biological information content of the DNA profile itself.

The second important step to insuring the genetic privacy of iDNAfication is to destroy the physical samples of DNA once DNA profiles have been generated from them. As long as the DNA samples themselves are retained, the risk remains that they could be retested for their biological informational content. Thus, in its report on forensic DNA analysis, the National Academy of Sciences in 1990 recommended that even samples taken from convicted offenders be destroyed promptly upon analysis, and the FBI has designed its national iDNAfication collection as a databank, not a DNA bank, including only the electronic profiles of non-coding DNA markers (Murch and Budowle).

This second precaution has not been adopted by forensic laboratories at the state level, or by the military at the federal level. Most of these laboratories plan to bank their actual DNA samples indefinitely, on the grounds that the samples may need to be retested as new markers or testing technologies become standard (McEwen). The Department of Defense is storing dried blood samples from its recruits, for genotyping only in the event that the recruits later turn up missing in combat. This effectively undercuts the privacy protections afforded by using non-coding markers in the iDNAfication profile itself, and immediately elevates the privacy risk of any iDNAfication program well beyond that of ordinary fingerprinting. Even if, *contra* the National Academy of Sciences, this increased risk were tolerable for convicted offenders, it should not be for military recruits, government employees, or arrestees, since the potential intrusion goes well beyond what is required for identification.

Social Policy Considerations

Despite the initial hopes of early enthusiasts like English scientist Francis Galton (1822–1911), large collections of ordinary fingerprints have never been useful for much else besides individual identification. (Rabinow) The informational potential of the human genome, however, does require the designers of iDNAfication systems to consider in advance the range of uses they should accommodate. Even when a DNA profile collection is committed exclusively to use for personal identification purposes, several policy choices present themselves: (1) Should the system be designed to support any type of research involving the stored information? (2) Should the system be designed to aid in the identification of the sources of new DNA samples without clear matches in the database?, and (3) Should the system be designed to support electronic *dragnet* screening of the population in search of particular individuals? In the context of the expanding uses of iDNAfication, these choices raise some important social policy issues that go well beyond issues of personal privacy.

RESEARCH USES. Among the legislatively authorized uses of the existing iDNAfication databanks is their use for various kinds of research. For example, many state statutes, following the FBI's legislative guidelines, provide for the use of convicted offender iDNAfication data in research by state forensic scientists designed to improve iDNAfication techniques and protocols. Although the state statutes vary widely in the security procedures they mandate for containing this research within the crime laboratories and protecting the identities of the sample sources, if they were to implement the protections recommended by the FBI (Murch and Budowle) using such samples would raise few direct privacy issues. However, it is worth noting that to the extent that this research requires access to physical DNA samples, it provides the main impetus for retaining samples in state crime labs after the database profiles have been generated. This opens the door for other research uses of the collection. For example, Alabama allows the use of anonymous DNA samples from its convicted offender collection "to provide data relative to the causation, detection and prevention of disease or disability" and "to assist in other humanitarian endeavors including but not limited to educational research or medical research or development." (Alabama Laws [1994] 1st Spec Sess Act 94–100).

Alabama's generosity towards researchers is presumably premised on the view that the *anonymity* of the samples provides adequate protection of the sources's privacy, and frees the state from having to worry about the usual elements of biomedical research, like informed consent. But on the contrary, from the perspective of research ethics, these samples are not anonymous, nor even *anonymized,* since the iDNAfication database is itself the key to identifying the source of any given sample. Since that existing linkage makes it technically possible to benefit and harm the sample donors with the results of such research, all the usual biomedical research protections should apply (Clayton et. al.). In addition to these personal privacy issues, moreover, open-ended research on iDNAfication samples also poses broader questions of research justice. Collections of DNA samples from criminals or soldiers, for example, are likely to be perceived as particularly rich research resources by those interested in studying genetic factors involved in antisocial or aggressive behavior. Unfortunately, our social experience with such research has not been good (Marsh and Katz). Repeatedly, such studies have succumbed to ascertainment biases that ultimately mischaracterize—and stigmatize—groups of people that are disproportionately represented in the systems under study for social reasons. Two forms of injustice tend to flow from these results. First, genetic claims about individual research subjects, like those concerning XYY syndrome in the 1970s, become generalized to an entire class, simultaneously pathologizing behavior and stigmatizing bearers of the genetic trait. This has the effect of both undercutting personal responsibility and legitimizing draconian medical responses to the targeted behavior, like eugenic sterilization. Second, genetic studies tend to misdirect attention from the overwhelming social causes of the behaviors they purport to explain, by encouraging a determinism that suggests that efforts at social reform are ultimately futile. Where this misdirection reinforces existing social policy inequities, it is likely to have an even more pronounced effect (Wasserman).

PROFILING USES. The third kind of databank that is part of a comprehensive iDNAfication system (in addition to the identified DNA profile collection and the aggregate population polymorphism frequencies database) is an open case file: a collection of DNA profiles taken from crime scenes or battlefields or plane crash sites that come from as yet unidentified sources. Obviously, this collection needs to be comparable to the identified reference collection, which means the same markers should be used to compose the profiles in both. With these collections, however, investigators will be especially tempted to glean as much information as they can from their genetic analyses in their efforts to compose a profile of their missing sample source. One of the areas of highest interest has been in non-coding polymorphisms that would allow investigators to estimate the *ethnic affiliation* of a sample source (Shriver, et al.). These investigators call their markers *population specific alleles* (PSAs), and the ethnic populations they mark are, once again, just our traditional races: European-Americans, African-Americans, native Americans, and Asian Americans. Should these PSAs be included in or excluded from the panel of markers established for our universal, humanitarian iDNAfication system? Including them would allow the system to support an open case file that could take advantage of the additional information to narrow the search for sample sources. It would also, presumably, take the guesswork out of deciding which racial reference group to assess a particular sample against.

Of course, including PSAs in iDNAfication profiles would elevate the informational content of the profile beyond that of a traditional fingerprint, constituting more of an intrusion on privacy. Moreover, it would do so by reporting a particularly socially sensitive feature of the arrestee: their probable race. But photographs also can reveal race, and we sanction collecting them for identification purposes. How would this be different?

Photography is an illuminating analogy here. Photographs show only the superficial distinctions that we use socially to categorize a person's ethnic affiliation. They leave that categorization itself up to the observer, and make no claims about its merits. Thanks to our large-scale hybridization, in other words, *passing* for one race or another is still possible in mug shots. PSAs, on the other hand, are defined in terms of our society's racial categories, and purport to be able to *appropriately classify* even interethnic individuals into their true (ancestral) categories.

This has several implications. First, it means that genuine secrets might be revealed through PSA screening: for example, shifts in the social (racial) status of the arrestee or her ancestors that have nothing to do with their arrest, but which, if interpreted as normative, could cause psychological and social harm to the individuals and their families by upsetting their social identities. In that sense, PSAs are more threatening to privacy than photographs. Second, as the scientists's own hopes for appropriately classifying hybrids shows, it is hard not make the logical mistake of moving from the use of social categories to define the PSAs to then using PSAs to define our social categories. This mistake raises two important issues about the use of PSAs in iDNAfication schemes.

First, it risks exacerbating racism by reinventing in statistical and molecular terms the arbitrary social apparatus of the *blood quantum* and *the One Drop Rule*: Under PSA screening, one's proportional racial endowment could be quantified, and carrying the defining polymorphisms for any given race would warrant (statistically) *affiliating* one with it for official identification purposes, regardless of one's superficial social identity. In the wake of a program of iDNAfication in which thousands of American's would have their PSAs determined, this could have powerful social consequences. In fact, our bad experiences with other forms of *low tech* racial profiling in law enforcement has already led to court decisions prohibiting the practice as unconstitutional under the Equal Protection clause (Johnson).

The second danger in estimating ethnic affiliation through PSAs is the way it facilitates the reification of (fundamentally unjust) social categories as biological realities. If PSAs are not *genes for race,* they are at least differentially associated with the people we classify in particular races. Genetic association, however, in the public and scientific mind, often comes to imply causation that implies in turn the objective reality of the effect. In other words, if PSAs correlate with racially defined populations, they must be linked somehow with the defining genes of those populations, and if the racial populations have defining genes, races must be real and separable biological entities, not just social constructions. Our society has had recurrent experience with this kind of *hardening of the categories,* all of which has been detrimental to the least well off (Duster) because it fosters a particular form of social harm: the erosion of our sense of solidarity as a community and our empathy for members of other groups, leading to what one scholar has called social policies moral abandonment (Wasserman). Any widespread iDNAfication program that involved PSA-based ethnic affiliation estimations would run the real risk of exacerbating that harm, by fostering the public perception that PSA-based profiles revealed real racial assignments.

DRAGNET USES. Finally, there is a third set of choices about the range of use to which any arrestee iDNAfication system should be put. Given our commitment to the presumption of innocence, should such a system accommodate *sweep searches* of its stored profiles in the pursuit of a criminal suspect? Obviously, in addition to the precise identification of sample sources, the principal purpose of the existing convicted offender iDNAfication databanks in law enforcement is to aid in the identification of suspects by matching unidentified DNA samples from a crime scene with an identified profile in the collection. If in fact we kept the informational content of arrestee iDNAfication under the *pattern matching* standard of manual fingerprinting, could we really complain about police searches of arrestee iDNAfication databases for the same purpose?

On one hand, it is clear that some dragnet uses of iDNAfication would not be acceptable in the United States. Critics of current forensic iDNAfication programs often point to the 1987 British case in which every male resident in three Leicestershire villages was asked to voluntarily provide a DNA sample to the police in an (ultimately successful) effort to identify a murderer, as an cautionary sign of things to come (Wambaugh). However, given the coercive nature of such a request (police made house calls on those failing to appear for sampling), its effect of shifting the presumption of innocence to one of guilt, its lack of adequate probable cause, and the U.S. Supreme Court's rejection of similar uses of manual fingerprinting, it seems implausible that such a sampling practice would be constitutionally sanctioned in the United States.

However, what if the dragnet were only a matter of searching a database of DNA profiles previously collected by the state for the identification of arrestees? In supporting the existing convicted offender iDNAfication databases, the courts have argued that the public interest in prosecuting crime outweighs any presumption of innocence that criminals may have in future cases, thus justifying the reuse of their DNA fingerprints for forensic matching (*Jones v. Murray,* 1991). Moreover, we already store and reuse arrest photographs and manual fingerprints, even from those arrestees subsequently cleared of their charges, in attempting to identify suspects in future cases. Why should arrestee DNA fingerprints be handled differently?

Here is where the uniquely biological side of iDNAfication reenters the analysis, with its increased claims of physical privacy. U.S. courts have ruled that systematic analyses of tissue samples and body products (as opposed to photos and fingerprints) of suspects (as opposed to convicted criminals) are the sorts of searches that are protected by the Fourth Amendment, even when the samples are already in the state's hands. This suggests that, although one's arrest presumes enough probable cause to justify sampling for *identification* purposes, arrestees have not forfeited as much of their presumption of innocence and the physical privacy that attends it as convicted offenders have, whose samples can be searched at will by the state. If these decisions are accepted as precedents for iDNAfication, efforts to screen forensic DNA against a database of arrestee profiles from citizens who have no convictions would also have to pass the Fourth Amendment's tests, and show probable cause for each attempted match.

Moreover, if anything, the bar to dragnet searches of arrestee iDNAfication collections should be set higher than the bar to searching other tissue samples and body products, because DNA profile matching actually poses a greater risk to privacy than other forms of tissue typing. This is because, unlike both fingerprint and urinalysis screening, the process of matching a forensic sample against an iDNAfication database can reveal familial relationships as well as identities. Unlike fingerprints and photographs, in which the environmental vagaries of human development usually work to obscure any convincing evidence of kinship, DNA profiles can demonstrate those relationships in clear genetic terms.

Thus, when non-coding nuclear DNA markers are used to profile a forensic specimen, the siblings, parents, and children of the specimen source will all show partial matches with the specimen. Their appearance in an arrestee iDNAfication database will not make them direct suspects, because of the mismatching elements of the profile. But their matching elements can reveal that they are related to the suspect, and so will flag their family for further investigation by the police. Moreover, when mitochondrial DNA is used for genotyping, the resulting profiles will almost always be completely shared by the DNA source's mother and siblings, and by her mother and all her siblings as well: They are all essentially mitochondrial clones. In these cases, the appearance of family members in an arrestee database might even make them immediate suspects for investigation. In any case, the disclosure of the identities of a suspect's relatives is not something that fingerprint searches accomplish, which means that iDNAfication puts more personal information at risk. It therefore poses a greater threat to the privacy of both the arrestees and their kin. Moreover, experience from clinical DNA testing within families demonstrates that even in a supportive context, the disclosure of familial relationships can have tremendous psychosocial impact on family members (Juengst). To have those relationships disclosed publicly in the context of a criminal investigation only amplifies the risk that the impact will be negative on both the sample sources and their kin.

It is interesting to note in this regard that some states's convicted offender iDNAfication databanking statutes already include provisions mandating the expungement of a person's DNA profile, and the destruction of their samples, if their convictions are overturned or dismissed on appeal (McEwen and Reilly). The only circumstance in which that this happens with traditional fingerprints is in case of juvenile acquittals, where expungement is justified in terms of the burden of an early criminal record on the life prospects of the acquitted. This suggests that having one's DNA on file with the state is also recognized, at least in some states, to carry privacy risks to the individual that are unfair to impose on citizens cleared of criminal guilt, in the same way it is unfair to impose a criminal record on a reformed youth. But if that is true of those whose convictions are overturned, it should be equally true for those who are never convicted in the first place (Nelkin and Andews).

ERIC T. JUENGST

SEE ALSO: *Autonomy; Bioterrorism; Confidentiality; Conflict of Interest; Conscience, Rights of; Genetic Discrimination; Genetic Testing and Screening; Human Rights; Public Health; Warfare*

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DNR (DO NOT RESUSCITATE)

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In its most simple form, “DNR” is a physician’s order directing a clinician to withhold any efforts to resuscitate a patient in the event of a respiratory or cardiac arrest. The literal form, *do not resuscitate,* is more precisely worded as *do not attempt resuscitation.* While originally intended for hospitalized patients, the concept of withholding resuscitative efforts has since been extended to include patients in nursing homes, children with incurable genetic or progressive neurologic diseases, and terminally ill patients in the home or hospice setting.

More broadly, the DNR order has become a part of the ritual of death in American society. For the patient, a DNR order (or the absence of a DNR order) establishes how death will likely ensue. The introduction of DNR orders also marked a pivotal change in the practice of medicine, for it was the first order to direct the withholding of treatment. DNR orders are so commonplace and widely accepted in everyday practice that nearly all physicians and nurses have had some experience in determining whether to invoke or adhere to the order when it is written.

History

Although commonplace and widely accepted today, the development of the do-not-resuscitate order was, and remains, controversial on several fundamental issues at the intersection of medicine and ethics. As with artificial (mechanical) ventilation and artificial nutrition and hydration, the development of advanced cardiopulmonary resuscitation (CPR) techniques created decision points regarding treatment alternatives for both dying patients and their caretakers that had not previously been confronted.

Prior to 1960 there was little that physicians could do for a patient in the event of sudden cardiac arrest. In that year, surgeons at Johns Hopkins Medical Center reported a technique for closed-chest massage combined with “artificial respiration” and designed specifically for patients suffering anesthesia-induced cardiac arrest. This condition was especially conducive to closed-chest massage because it often occurred in otherwise healthy patients who needed only short-term circulatory support while the adverse effects of anesthesia were resolved. In the context for which it was designed—transient and easily reversible conditions in otherwise healthy individuals—the technique at first appeared miraculous for its effectiveness and simplicity. A 1960 article in the *Journal of the American Medical Association* stated: “Anyone, anywhere, can now initiate cardiac resuscitative procedures. All that is needed are two hands” (Kouwenhoven, Jude, and Knickerbocker, pp. 1064–1067).

Partly because of its simplicity, and partly because of uncertainty over who might benefit from the performance of CPR, it soon became the rule and not the exception that any hospitalized patient experiencing cardiac arrest underwent a trial of resuscitative efforts. These attempts often transiently restored physiologic stability, but too often also resulted in prolonged patient suffering. By the late 1960s, articles began appearing in the medical literature describing the agony that many terminally ill patients experienced from repeated resuscitations that only prolonged the dying process (see Symmers).

Soon a covert decision-making process evolved among clinicians regarding the resuscitation decision. When physicians and nurses responded to situations in which they believed that CPR would not be beneficial, they either refused to call a *code blue* or performed a less than full resuscitation attempt. New terms, such as *slow code* and *Hollywood code,* entered the vocabulary of the hospital culture as these partial or half-hearted resuscitation efforts became more pervasive.

Lacking an established mechanism for advanced decision making about resuscitation, some hospitals developed their own peculiar means of communicating who would not receive a full resuscitation attempt in the event of cardiopulmonary arrest. Decisions were concealed as purple dots on the medical record, written as cryptic initials in the patient's chart, or in some cases simply communicated as verbal orders passed on from shift to shift.

The absence of an open decision-making framework about resuscitation decisions was increasingly recognized as a significant problem in need of a solution. Unilateral decision making by clinicians in this context effectively circumvented the autonomy of the patient and prevented the full consideration of legitimate options by the involved parties prior to a crisis. From the patient's perspective, this covert decision making resulted in errors in both directions: some patients received a resuscitation attempt in circumstances where they did not desire it, while others did not receive a resuscitation attempt in circumstances where they would have desired it.

In 1976 the first hospital policies on orders not to resuscitate were published in the medical literature (see Rabkin). These policies mandated a formal process of advance planning with the patient or patient's surrogate on the decision of whether to attempt resuscitation, and also stipulated formal documentation of the rationale for this decision in the medical record. In 1974 the American Heart Association (AHA) became the first professional organization to propose that decisions not to resuscitate be formally documented in progress notes and communicated to the clinical staff. Moreover, the AHA position on DNR stated that "CPR is not indicated in certain situations, such as in cases of terminal irreversible illness where death is not unexpected" (American Heart Association).

Ethical Perspective

Parallel to the development of the DNR order in the medical community was the emergence of a broad societal consensus on patient's rights. The conceptual foundation of this consensus was the recognition that the wishes and values of the patient should have priority over those of medical professionals in most healthcare decisions.

An influential President's Commission further advocated that patients in cardiac arrest are presumed to have given consent to CPR (that is, a resuscitation attempt is favored in nearly all instances). By extension the commission argued that the context in which the presumption favoring CPR may be overridden must be explicit, and must be justified by being in accord with a patient's competent choice or by serving the incompetent patient's well-being (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research). Since that time nearly all states have adopted specific statues on the DNR order. The bioethics community, however, has not embraced this view without dissent.

The assumption that CPR is generally beneficial and should be withheld only by exception has been seriously challenged. CPR, the argument goes, is often not beneficial and was never intended to be the standard of care for all situations of cardiac arrest (four of the five patients in the original Johns Hopkins report experienced an unanticipated cardiac arrest in the setting of anesthesia). From this perspective, CPR, like any treatment, should only be offered to those patients for whom it is medically indicated—physicians are not ethically bound to seek consent to refrain from a procedure that is not medically indicated.

Few issues have been more contentious than whether a physician may determine, without patient or surrogate consent, that CPR is not indicated. Some hospitals have adopted a "don't ask, don't tell" approach to this question by allowing *unilateral* or *futility-based* DNR orders without asking or informing the patient of the decision. Still other policies employ a "don't ask, do tell" approach, where unilateral DNR orders can be written at the discretion of the attending physician, who then informs the patient or patient's family of the decision.

Attempts have been made within the medical profession to define *futile, nonbeneficial, inappropriate,* or *not indicated* in specific terms, such as lack of physiological effect or low likelihood of survival. The assumption underlying this approach is that physicians are best qualified to determine whether and when a medical therapy is indicated. Others advocate procedural resolution pathways, in the belief that it is not possible to achieve consensus on an accepted definition of what constitutes futile medical treatment. This approach assumes that end-of-life decisions inherently involve value-laden choices that people will not always agree on.

Who ultimately decides when a treatment is indicated? The original foundation of the consent process in medicine is the principle that permission is needed "to touch," even when the intent of the person who seeks "to touch" is solely to promote health and treat illness. Because the DNR order is an order not to touch—when that touch may be both highly invasive and life-preserving—only a properly informed patient can decide whether touching is wanted or not. This determination is ultimately a value judgment made by the patient, utilizing information as to efficacy (or futility) provided by the physician.

Conclusion

The introduction of the DNR order brought an open decision-making framework to the resuscitation decision, and also did much to put appropriate restraints on the universal application of cardiopulmonary resuscitation for the dying patient. Yet, DNR orders focus upon what will not be done for the patient, as opposed to what should be done for the patient. These deficiencies are being addressed through the palliative care movement, which recognizes that good care at the end of life depends much more on what therapies are provide than upon those that are not.

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SEE ALSO: *Advance Directives and Advance Care Planning; Aging and the Aged: Healthcare and Research Issues; Autonomy; Clinical Ethics: Clinical Ethics Consultation; Conscience, Rights of; Dementia; Human Dignity; Informed Consent; Pain and Suffering; Palliative Care and Hospice; Right to Die, Policy and Law; Surrogate Decision-Making; Technology: History of Medical Technology*

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DOUBLE EFFECT, PRINCIPLE OR DOCTRINE OF

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Originating in Roman Catholic scholastic moral philosophy, the Principle of Double Effect (hereafter referred to as the PDE or Double Effect) is still widely discussed in the bioethics literature on euthanasia, palliative care, physician assisted suicide, suicide and abortion (Barry; Quill, Lo et al.; Manfredi, Morrison et al.; Stempsey; Kamm, 1999; McIntosh; Shaw). It has also been applied to a range of other issues, including organ donation and transplantation (DuBois). Due in large part to these bioethics discussions, the PDE has been the subject of a resurgence of interest in moral and political philosophy generally. Double Effect has been debated in the philosophy of law as germane to discussions of, among other things, murder, self-defense, capital punishment, and suicide (Frey; Hart; Finnis, 1991, 1995; Aulisio, 1996). In social and political philosophy, it has been put forth as an important principle for rights theory (Quinn, 1989; Bole), and as a partial justification for affirmative action (Cooney). A traditional military ethics application of Double Effect, to distinguish between strategic and terror bombing, remains a subject of debate today as well (Bratman; Kamm, 2000). In addition, the PDE’s central distinction, intention/foresight, has been the subject of rigorous analysis in the philosophy of action (Robins; Bratman; Aulisio, 1995; Brand; Harman).

Double Effect is typically applied to conflict situations in which any action (or course of actions) will result in numerous effects, good and bad. Traditionally a four-part principle, contemporary versions of the PDE are usually formulated as two-part principles, along the following lines: An action with multiple effects, good and bad, is permissible if and only if (1) one is not committed to intending evil (bad effects) either as end or means, and (2) there is proportionate reason for bringing about the evil (bad effects). The first condition, a non-consequentialist intention condition, is lexically prior to the second. Most proponents of the PDE consider the second condition, the proportionate reason condition, to be consequentialist in nature while allowing for other considerations as well.

Paradigm Applications

In the Roman Catholic bioethics literature, the PDE has long been invoked to deal with cases of maternal-fetal conflict to distinguish between permissible interventions that may result in the death of the fetus and abortion, which is absolutely forbidden (Barry). Consider the following set of maternal-fetal conflict paradigm cases.

Paradigm 1: Therapeutic Hysterectomy. A thirty-three year old pregnant woman is diagnosed with a highly aggressive form of uterine cancer ten weeks into her pregnancy. The woman is a devout Roman Catholic, strongly opposed to abortion, and is under care at a Catholic hospital. If the woman were not pregnant, her doctors would recommend a therapeutic hysterectomy to prevent the spread of cancer.

Paradigm 2: Hypertensive Pregnancy. A thirty-nine year old woman is diagnosed with dangerously life threatening high blood pressure seventeen weeks into her pregnancy. The woman is a devout Roman Catholic, strongly opposed to abortion, and is under care at a Catholic hospital. An abortion would alleviate the hypertension and remove the threat to the woman's life.

Though it may come as a surprise to some, those familiar with the Roman Catholic double effect literature will know that the therapeutic hysterectomy proposed in the first case above has long been considered permissible by orthodox Roman Catholic moralists. Indeed, this is viewed as a paradigm instance of a *permissible* action under the PDE (Healy; Kelly; O'Donnell). On the traditional view, the physician's intended *end* would be *saving the life of the mother* by stopping the spread of cancer through her intended *means* of removing the cancerous uterus. Fetal death, on the traditional view, would properly be described as a foreseen but unintended (bad) side effect of the (good) act of saving the mother's life.

In contrast, the case of the hypertensive pregnancy has long been considered a paradigm instance of an action that fails the PDE. In particular, the abortion has traditionally been interpreted as the intended means to the good end of saving the life of the mother, thus failing the PDE's lexically prior intention condition (Healy; Kelly; O'Donnell).

The following scenarios illustrate another set of paradigm applications of the PDE, that is, to distinguish between palliative care and euthanasia:

Paradigm 3: Morphine Drip. David, a forty-nine year old HIV patient, is terminally ill and in constant pain. After much discussion with his partner, family, friends and care team, David has decided that he wants only comfort care. He is adamant that he be kept comfortable. David is placed on a morphine drip, which is then periodically adjusted to alleviate David's discomfort. David's physician knows that continued titration to alleviate David's discomfort runs the risk of hastening or even causing death given David's weakened state. David's physician continues to adjust the morphine drip to keep David comfortable.

Paradigm 4: Lethal Overdose. David, a forty-nine year old HIV patient, is terminally ill and in constant pain. After much discussion with his partner, family, friends and care team, David has decided that he no longer wants to go on living. After saying his good-byes to his partner, family, and friends, David asks his physician to give him a lethal injection of morphine. David's physician gives him a lethal overdose of morphine.

Traditionally, Paradigm 3, the Morphine Drip, has been considered permissible under the PDE, while Paradigm 4, the Lethal Overdose, has been considered impermissible. Why? In Paradigm 3, on the traditional view, David's physician's intended end is to alleviate David's pain. The intended means to this end is the administration of a palliative medication, morphine. Given David's excruciating pain and terminal illness, David's physician has proportionate reason to titrate to pain even though he knows this may hasten or even cause death. On the traditional view, should David die, his death is taken to be a foreseen, but unintended, side effect of the doctor's action (Healy; Kelly; O'Donnell).

In Paradigm 4, David's physician has the same end (i.e., to alleviate David's pain). His means, however, is to give David a lethal injection (i.e., to kill him). On the traditional view, Paradigm 4 is taken to fail the intention condition of the PDE because David's death, the bad effect, is intended by his physician as the means to alleviating David's pain. Paradigm 4 is, on the traditional view, a classic instance of mercy killing (Healy; Kelly; O'Donnell).

The application of the PDE to these, and other, types of cases has been challenged. These challenges generally fall into one of three categories: conceptual tenability, practical applicability, and moral significance. Since challenges to the conceptual tenability and practical applicability of the PDE are largely matters for the philosophy of action, they extend well beyond the scope of this entry. In the bioethics literature, challenges to the PDE have focused on its moral significance outside of the absolutist moral framework within which it emerged. In order to understand this type of challenge, however, it is important to consider the historical origins of the PDE.

Historical Origins

In its traditional form, the PDE has four conditions:

1. The act to be done must be good in itself or at least indifferent.
2. The good intended must not be obtained by means of the evil effect.
3. The evil effect must not be intended for itself, but only permitted.
4. There must be proportionately grave reason for permitting the evil effect. (Fagothey)

Most trace the origins of this traditional four-part PDE and its two-part contemporary successor to St. Thomas Aquinas's (1224–1274) discussion of killing in self-defense (Aquinas; Mangan). Aquinas notes that the Christian tradition had, until his time, almost universally forbidden killing in self-defense. This prohibition probably stemmed from a teaching of St. Augustine (354–430) in *De Libero* that Christians should not kill others to save themselves because bodily life is that which "they ought to despise" (I, 5 PL 32, 1228). In his justification of killing in self-defense, Aquinas invoked what later became the essential conditions of the PDE. He argued that:

> A single act may have two effects, of which only one is intended, while the other is incidental to that intention. *But the way in which a moral act is to be classified depends on what is intended,* not what goes beyond such an intention. Therefore, from the act of a person defending himself a twofold effect can follow: one, the saving of one's own life; the other the killing of the aggressor. (IIaIIae, q.64, a.7)

Implicit here is the crucial distinction upon which the PDE depends, namely intention/foresight. An act of self-defense is classified as such provided that it is the saving of oneself and not the killing of the aggressor that is intended. If the killing was intended (*intendere*), and not merely foreseen (*praeter intentionem*), then, for Aquinas, the act would properly be classified as homicide.

It would seem that both conditions one and three of the traditional PDE might be elicited from this passage. Condition three forbids the intending of an evil effect *for itself* (as an end). Yet if acts are to be classified according to what is intended, then a violation of condition three (intending the evil as an end) will also be a violation of condition one (the act will be classified as bad in itself). Furthermore, condition two, that the good intended not be obtained by means of the evil, though not explicitly stated, can be understood as a plausible explication of conditions one and three as one who intends an end may also be taken as intending the means to his or her end.

Not to have intended evil is a necessary, but not sufficient, condition of justified self-defense for Aquinas. In the same section he offers a second condition:

> An act that is properly motivated may, nevertheless, become vitiated if it is not *proportionate* to the end intended. And this is why somebody who uses more violence than is necessary to defend himself will be doing something wrong. (IIaIIae, q.64, a.7)

What became the fourth condition of the traditional PDE, the proportionality principle, can be elicited from this passage. Though it is not obvious from this passage, nor from the broader context of Aquinas's work, that proportionate is meant to refer to the measure of good and bad effects, later moralists interpreted the condition in this way.

Double Effect and Contemporary Bioethics

As noted at the outset, the contemporary bioethics literature generally treats Double Effect as a two-part principle. Interestingly, the two-part contemporary PDE, as the preceding discussion suggests, is closer to its Thomistic origins. Though its traditional applications to abortion, euthanasia, self-defense and suicide (particularly physician assisted suicide) continue to be discussed, the PDE has been applied to some novel contemporary bioethics cases, such as the separation of conjoined twins and the use of embryos in research, as well (Coughlan and Anscombe). The strong resurgence of interest in Double Effect in bioethics, however, is directly attributable to the rise of the palliative care movement (Cantor and Thomas; Cavanaugh; Quill, Lo et al.; Manfredi, Morrison et al.; Patterson and Hodges; Preston; Shorr; Gilbert and Kirkham; Sulmasy and Pellegrino; Hawryluck and Harvey; Nuccetelli and Seay; Sulmasy; Bernat; Luce and Alpers; Thorns). Indeed, the vast majority of contemporary bioethics discussion of Double Effect has centered its application to *terminal sedation* which, though controversial in some quarters, is usually little more than a logical extension of the morphine drip case considered above (Paradigm 3) (Krakauer, Penson et al.; Wein). A somewhat novel application of Double Effect in terminal sedation is illustrated by the following case.

Terminal Sedation: Agonal Breathing. Mrs. Jones, an eighty-two year old white female, is a vent dependent terminally ill cancer patient. She is conscious and deemed to have decision capacity upon psychiatric evaluation. Though her pain is well controlled, she requests to be removed from the ventilator. She also requests to first be sedated so that she will not have the experience of not being able to breathe once ventilator support is withdrawn.

The use of palliative medicine in the case of Mrs. Jones can plausibly be construed as satisfying the PDE. Here the use of palliative medicine is intended to alleviate the discomfort of agonal breathing and the attendant suffering of Mrs. Jones should she have to experience this. Critics have argued that invoking Double Effect in these types of cases is a thinly veiled attempt to avoid the charge of intentional killing (Quill, Dresser et al.; Kuhse). Such critics argue that, rather than invoking Double Effect as a rationalization for palliative care, it should be acknowledged that there are times when the intentional mercy killing (euthanasia) is appropriate, thus rendering Double Effect concerns irrelevant.

Double Effect and Moral Relevance: Curious Artifact or Bulwark?

Many critics of Double Effect and even some of its proponents have focused on its Roman Catholic origins, questioning its moral relevance outside of absolutist Roman Catholicism (Boyle 1991a, 1991b; Quill, Dresser et al.). Indeed, this is the most common challenge articulated in the bioethics literature. What, then, can be said of the moral relevance of the PDE outside of absolutist Roman Catholicism? Should bioethicists outside of Roman Catholic moral tradition view the PDE as little more than the curious invention of sectarian casuistry?

To understand this challenge, it is important to highlight the fact that the Roman Catholic moral tradition, in which the PDE emerged, absolutely prohibits certain types or classes of action, including active euthanasia, abortion, murder, and suicide (Boyle, 1991b). In such a tradition, the question of appropriate act description and classification is of paramount importance. The intention condition of the PDE helps to delimit what counts as falling into a given class of action (recall Aquinas's claim, cited above, that the way an act is to be classified depends on intention). Provided an act does not fall into one of the absolutely forbidden classes of action, one may then apply the proportionate reason condition to help determine the permissibility of bringing about the evil effect. Thus, the moral relevance of the PDE and, in particular, of the intention/foresight distinction, is easy to establish in the context of Roman Catholicism with its absolute prohibitions on certain types of acts.

The claim that Double Effect is morally relevant only within the context of absolutist Roman Catholicism is highly problematic. As discussed above, the most fundamental element of the PDE is a conceptual distinction between intention and foresight. Arguably, the normative significance of *any* conceptual distinction will depend on the normative framework within which the distinction is operative (Aulisio, 1996, 1997). The central distinction of PDE, intention/foresight, is embedded in ordinary language and common morality, and is arguably important for certain areas of Anglo-American law despite its emphasis on individual autonomy (e.g., law of attempts, distinction between murder one and manslaughter; etc.) (Aulisio, 1996). More importantly, any moral framework, absolutist or not, that incorporates deontic constraints, formulated in terms of intention, on consequentialist considerations may have use of the intention/foresight distinction (and, therefore, the PDE) (Nagel; Kagan; Quinn, 1993; Beauchamp; Kamm, 2001).

If the preceding discussion is on target, given the wide variety of moral frameworks that incorporate deontic constraints formulated in terms of intention, it seems likely that the PDE will continue to be relevant to a range of bioethics issues. This does not mean that proponents of the PDE can rest easily, however. Serious challenges to the PDE remain. Chief among these are challenges to the conceptual tenability and practical applicability of the intention/foresight distinction, and the need for an adequate theory of intention to address these challenges. Though interesting and important in their own right, it seems unlikely that these matters will inhibit continued vigorous bioethics debate concerning the application of the PDE to vexing cases.

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SEE ALSO: *Abortion, Religious Traditions: Roman Catholic Perspectives; Beneficence; Ethics: Religion and Morality; Life Sustaining Treatment and Euthanasia: Ethical Aspects of; Medical Ethics, History of Europe: Contemporary Period; Palliative Care and Hospice; Right to Die, Policy and Law; Triage*

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E

EASTERN ORTHODOX CHRISTIANITY, BIOETHICS IN

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The Eastern Orthodox church considers itself identical with the Church established by Jesus Christ and believes itself to be guided by the Holy Spirit, continuing that ecclesial reality into the present age as an organic historical, theological, liturgical continuity and unity with the apostolic Church of the first century. Historically, it sees itself as identical with the "One, Holy, Catholic, and Apostolic Church" that suffered the "Great Schism" in 1054 that led to the division of Christendom into Eastern and Western Christianity.

The Orthodox church is organized hierarchically, with an ordained clergy and bishops. A number of national and ethnic Orthodox churches, under the leadership of patriarchs, are united by tradition, doctrine, and spirit rather than by authority, although the Ecumenical Patriarch of Constantinople is accorded a primacy of honor. The church's identity is rooted in the experience of the Holy Spirit in all aspects of its life and in a doctrinal perspective that serves as a matrix for its ethical teachings (Ware; Pelikan). In the sphere of bioethics, this theological matrix forms a coherent source of values for bioethical decision making. At its center is the view that life is a gift of God that should be protected, transmitted, cultivated, cared for, fulfilled in God, and considered a sacred reality. Consequently, there is a high regard for the concerns usually identified with the field of bioethics.

Doctrine and Ethics

In Orthodox belief, the teaching of the church is found in the Old and New Testaments, the writings of the church fathers, and all aspects of the synodical, canonical, liturgical, and spiritual tradition of faith as lived, experienced, and reflected upon in the consciousness of the church, for which the general name "holy tradition" is used.

The Eastern Orthodox church understands ultimate reality to be the Holy Trinity, or God who is a triune unity of persons: the Father, source of the other two fully divine persons; the Son, forever born of the Father; and the Holy Spirit, forever proceeding from the Father. Thus, ultimate uncreated and uncontingent reality is a community of divine persons living in perpetual love and unity.

This divine reality created all else that exists, visible and invisible, as contingent reality. Human beings are created as a composite of body and spirit, as well as in the "image and likeness" of the Holy Trinity. "Image" refers to those characteristics that distinguish humanity from the rest of the created world: intelligence, creativity, the ability to love, self-determination, and moral perceptivity. "Likeness" refers to the potential open to such a creature to become "God-like." This potential for deification, or *theosis,* has been lost through the choice of human beings to separate themselves from communion with God and their fellow human beings; that is to say, sin is a part of the human condition. Though weakened and distorted, the "image" remains and differentiates human existence from the rest of creation.

The work of redemption and salvation is accomplished by God through the Son, the second person of the Holy Trinity who took on human nature (except for sin) in the person of Jesus Christ. He taught, healed, gave direction, and offered himself upon the cross for the sins of humanity, and conquered the powers of death, sin, and evil through his resurrection from the dead. This saving work, accomplished for all humanity and all creation, is appropriated by each human person through faith and baptism, and manifested in continuous acts of self-determination in communion with the Holy Spirit. This cooperation between the human and divine in the process of growth toward the fulfillment of God-likeness is referred to as synergy.

The locus for this appropriation is the Church—specifically, its sacramental and spiritual life. The sacraments, or "mysteries," use both material and spiritual elements, as does the life of spiritual discipline known as "struggle" and "asceticism" (*agona* and *askesis*). Both foster a communion of love between the Holy Trinity and the human being, among human beings, and between humans and the nonhuman creation, making possible continuous growth toward God-likeness, which is full human existence.

Though in this earthly life growth toward Godlikeness can be continuous, it is never completed. In the Eastern Orthodox worldview, the eternal Kingdom of God provides a transcendent referent for everything. The Kingdom is not only yet to come in the "last days," but is now a present reality through Christ's resurrection and the presence of the Holy Spirit. Within this spiritual reality, the goal of human life is understood to be an ongoing process of increasing communion with God, other persons, and creation. This forms the matrix for Orthodox Christian ethics and provides it with the materials and perspectives for articulating the "ought" dimensions of the church's teaching (Mantzaridis).

Among the more important aspects of these teachings for bioethics are (1) the supreme value of love for God and neighbor; (2) an understanding that sees nature fallen but also capable of providing basic norms for living through a foundational and elementary natural moral law; (3) the close relationship of material and spiritual dimensions of human existence and their appropriate relationship and integration; (4) the capacity for self-determination by human beings to make moral decisions and act on them; and (5) the criterion of movement toward God-likeness—all within a framework that is both this and other-world focused.

In practice, ethical norms are arrived at in holy tradition and by contemporary Orthodox ethicists by defining moral questions within this context of faith in a search for ethical guidelines that embody the good, the right, and the fitting (Harakas, 1983).

Bodily Health

Concern for the health of the body, though not central, has a significant place in Eastern Orthodox ethics (Harakas, 1986a). Orthodox Christian ethics calls for "a healthy mind and a healthy spirit with a healthy body." The body is neither merely an instrument nor simply a dwelling place of the spirit. It is a constituent part of human existence, and requires attention for the sake of the whole human being. Thus, in its sinful condition, the body can also be a source of destructive tendencies that need to be controlled and channeled. This is one of the works of asceticism, which seeks to place the body under control of the mind and the spirit. But asceticism is never understood as a dualistic condemnation of the body. As a good creation, under the direction of the proper values, the body is seen as worthy of nurturing care. Thus, everything that contributes to the well-being of the body should be practiced in proper measure, and whatever is harmful to the health of the body ought to be avoided. The Eastern Christian patristic tradition is consistent in this concern (Constantelos; Darling).

Practices that contribute to bodily health and well-being are ethically required. Adequate nourishment, proper exercise, and other good health habits are fitting and appropriate, while practices that harm the body are considered not simply unhealthful, but also immoral. Abuse of the body is morally inappropriate. Both body and mind are abused through overindulgence of alcohol and the use of narcotics for nontherapeutic purposes. Orthodox teaching holds that persons who might be attracted to these passions need to exercise their ethical powers in a form of ascetic practice to overcome their dependence upon them as part of their growth toward God-likeness.

Healing Illness

When illness occurs, Orthodox Christianity affirms an ethical duty to struggle against sickness, which if unaddressed can lead to death. The moral requirement to care for the health of the body indicates it is appropriate to use healing methods that will enhance health and maintain life. Two means are used concurrently: spiritual healing and different forms of medicine. The first is embodied in nearly all services of the church, in particular, the sacrament of healing, or holy unction. There is also a continuing tradition of multiple forms of prayer and saintly intercessions for the healing of body and soul.

The church does not see spiritual healing as exclusive nor as competitive with scientific medicine. In the fourth century, Saint John Chrysostom, one of the great church fathers, frequently referred to his need for medical attention and medications. In his letters to Olympias, he not only speaks of his own use of medications but advises others to use them as well. Saint Basil, another great fourth-century church father, underwent various forms of therapy for his illnesses. In fact, both of these church fathers had studied medicine. Basil offers a classic Christian appreciation of the physician and the medical profession:

> Truly, humanity is the concern of all of you who follow the profession of medicine. And it seems to me that he who would prefer your profession to all other life pursuits would make a proper choice, not straying from the right, if really the most precious of all things, life, is painful and undesirable unless it can be possessed with health. And your profession is the supply vein of health. (Epistle 189, To Eustathius, the Court Physician fourth century, p. 228)

Recent studies have highlighted the Eastern Orthodox church's concern with healing, both in its medical and spiritual dimensions. Orthodox monks established the hospital as a place of healing, a tradition maintained by Orthodox monasticism for almost a thousand years, until it was taken over by the medical establishment (Miller; Scarborough; Harakas, 1990).

Bioethical Concerns and Methods

Bioethics as a distinct discipline is only a few decades old, but some topics included in the discipline, such as abortion, have been addressed by the Christian tradition over the centuries. Many bioethical issues are new, however, and the Orthodox church's views concerning them have yet to be officially stated. The method contemporary Orthodox ethicists use to determine Eastern Orthodox perspectives on bioethical questions is the same as the general method used to make ethical decisions. The general doctrinal stance and ethos of the church form the larger context, delineating basic perspectives. The church requires further study, however, to assess the moral dimensions of newly created bioethical questions.

The ethicist concerned with bioethical questions then consults the tradition, which embodies the mind of the church: Scripture, patristic writings, decisions of the ecumenical councils and other synods, the received doctrinal teachings of the church, canon law, ascetical writings, monastic *typika* (constitutions of monastic establishments), liturgical texts and traditions, *exomologetaria* (penitential books), the exercises of *economia* (a process of judgment that allows for consideration of circumstances in a particular case, but without setting precedents for future normative decision making), and theological studies, for specific references that exhibit the mind of the church in concrete ethical situations. The "mind of the church" is understood as the consciousness of the people of God, together with the formulation of theological opinion, in conjunction with the decisions of the church in local, regional, and ecumenical synods, conceived and experienced as arising from the guidance of the Holy Spirit. It is a mindset, rather than a set of rules or propositions. The purpose of examining these sources is to determine whether these sources speak either directly, or indirectly, or by analogy, to new questions of bioethics. The historical contexts of these specific sources are kept in mind, and will serve to condition contemporary judgments.

Both general and specific applications can then be made and expressed as theological opinion on topics in bioethics. These views, however, are tentative, until the mind of the church specifically decides. Wherever this has already occurred, it will be noted below. Otherwise, what follows should be understood as thoughtfully considered theological opinion, subject to correction by the mind of the church (Harakas, 1980,1986b).

The Protection of Life

Orthodox thought holds that life is a gift from God, given to creation and to human beings as a trust to be preserved and protected. Just as the care for one's health is a moral duty for the individual, society's concern for public health is also a moral imperative. The first large division of concern is that existing life be protected. This can be expressed in a number of ethical positions characteristic of an Orthodox perspective.

The protection of life has been a value pursued throughout history by the church. During the early days of the rise and spread of Christianity, abortion was widely practiced in the Roman Empire. The Church, based on its respect for life, condemned this practice in its canon law as a form of murder. The Church considered abortion particularly heinous because of the defenseless and innocent condition of the victim (Kowalczyk). Of course, no moral stance is absolute. In Orthodox traditional teaching, however, abortion is nearly always judged to be wrong. There can be unusual circumstances, such as an ectopic pregnancy that threatens the life of the mother, that might be judged prudentially as calling for an abortion, but such situations are rare.

Historically related to the rejection of abortion was a condemnation of the exposure of infants, that is, their abandonment, a practice that caused their death or led to their exploitation by unscrupulous persons who profited from forcing children into prostitution or begging. These are severe examples of child abuse that unfortunately have continued into the modern age. Every such case, historic or contemporary, violates the moral requirement that adults care for children in a loving and supportive manner.

Modern Medical Technology and Ethics

The development of medical science and technology has raised many new issues, however. Studying these issues from within the mind of the church has produced a body of positions that are expressive of the church's commitment to the protection of life. Some of these follow.

ALLOCATION OF MEDICAL RESOURCES. A bioethical question that finds a response in the concern for the protection of life is the issue of the allocation of scarce medical resources. A healthcare system that fosters the widest possible distribution of healthcare opportunities is the most morally responsible, since it reflects the common human situation before God.

PROFESSIONAL-PATIENT RELATIONSHIPS. In the area of the relationships of providers and recipients of healthcare, the church affirms the existence of patients' rights and requires that the medical profession honor them. The full human dignity of every person under treatment should be among the controlling values of healthcare providers, manifested in their concern to maintain the patient's privacy, obtain informed consent for medical procedures, develop wholesome personal contacts between the patient and the medical team members, and treat the patient as a total human being rather than an object of medical procedures.

HUMAN EXPERIMENTATION. Because of the role it plays in the development of medical therapies and the possible cure of individual persons, human experimentation must be conducted and is morally justified by an appeal to the value of the protection of life. Wherever possible, however, such experimentation should fulfill the following minimal conditions: The patient should be informed of the risks involved and should accept participation in the experiment freely and without coercion, and the experiment should have potential benefit for the patient. Increased knowledge should be secondary to the welfare of the patient.

ORGAN TRANSPLANTATION. Protection of life finds intense application in the area of organ transplantation. This topic may serve as a somewhat more extensive example of Orthodox bioethical reflection. Organ transplantation was unknown in the ancient world. Some Orthodox Christians consider it wrong, a violation of the integrity of the body. Significant as this consideration is, it does not outweigh the value of concern for the welfare of the neighbor, especially since organs for transplants are generally donated by persons who are philanthropically motivated for the protection of life. The sale of organs is seen as commercializing human body parts and therefore unworthy, and is prohibited by a concern for the protection of life and its dignity.

There are two categories of potential donors: the living and the dead. Usually, the potential living donor of a duplicated organ is a relative. In such cases, concern for the well-being of the patient may place undue pressure upon the potential donor. No one has an absolute moral duty to give an organ. Healthcare professionals must respect the integrity of the potential donor as well as the potential recipient. Yet it is certainly an expression of God-likeness for a person to give an organ when motivated by caring concern and love for the potential recipient. Ethical consideration must be given to the physical and emotional consequences upon both donor and recipient and weighed in conjunction with all other factors. When these are generally positive, the option for organ donation by a living person has much to commend it.

In the case of donation of organs from the dead, some of the same considerations hold, while several new issues arise. Organs can be donated in anticipation of death. Some states, for example, encourage people to declare their donation of particular organs (liver, kidney, cornea) in conjunction with the issuance of auto licenses. There do not appear to be serious objections to this practice; many Orthodox consider it praiseworthy. When no expressed wish is known, permission of donation should be sought from relatives. Their refusal should be respected.

Persons may donate organs through bequests associated with their wills. This choice should be made known to responsible survivors before death. In 1989, for example, the Greek Orthodox Archbishop of Athens announced in the press that he had made provision for the donation of his eyes after his death.

BODY DONATION TO SCIENCE. Similarly connected with the protection of life is the issue of donating one's body to science. Much of the answer from an Orthodox Christian perspective has to do with what the representatives of science will do with it. Giving one's body to science means, in nearly all cases, that it will be used for the education of medical students. There has been a bias against this practice in many countries because at the same time that the personal identity of the body is destroyed, the body itself is treated without respect. The alternative to using donated bodies for medical education, however, is that medical students and young physicians will learn surgical skills on living patients. The concern for the protection of life could not, thus, totally disapprove of the practice of body donation. In principle, then, giving one's body for medical education cannot be ethically prohibited. But medical schools should strive to create an atmosphere of reverence and respect for the bodily remains of persons given for this purpose. In some medical schools, this already takes place; in most, it has not. Potential donors of their bodies should inquire about procedures and refuse to donate their bodies to schools that do not show adequate respect for the body. Usually this means making arrangements for ecclesial burial of the remains after their educational use.

THE AGED. The protection of life covers the whole life span. The Orthodox church has always had a special respect and appreciation for the aged. Industrial society, with its smaller, nuclear families, has tended to isolate the aged from the rest of society. The aging themselves ought not to accept such marginalization passively. They should continue to live active and fulfilling lives, with as much independence of movement and self-directed activity as possible. Spiritually, growth in the life of Christ continues to be important. Repentance, prayer, communion with God, service to others, and loving care for others are important in this and every age bracket.

Children and relatives should do everything possible to enhance the quality of life for their aging parents and relatives. But in cases of debilitating conditions and illnesses, it may be necessary to institutionalize them. Many Orthodox Christians feel that this is an abandonment of their moral responsibilities to their parents. If institutionalization is a way of abdicating one's responsibilities to parents for the sake of convenience, then it is wrong. However, it is often the best solution. Even when it is morally indicated, the important values remain; in a nursing home or outside of it, children still have the obligation to express love, care, and respect for their parents.

DEATH. Concern for the protection of life is also present at the end of life. Death should come of itself, without human intervention. God gives us life; God should be allowed to take it away. Proponents of so-called euthanasia hold that persons should be allowed and may even be obliged to end their earthly lives when "life is not worth living." In the church's judgment, this is a form of suicide, which the church condemns. If one does this to another person, it is a case of murder. Orthodox Christian ethics rejects euthanasia as morally wrong.

Modern medical practice has raised some related issues, however. The possibility that vital signs can be maintained artificially, even after death has occurred, raises the complex question of turning off "life-sustaining" machines after brain death is diagnosed. The tradition has never supported heroic intervention in situations where death is imminent and no further therapies exist. It has been Eastern Orthodox practice not only to allow a person to die but also to actively pray for it when, according to the best medical judgment available, a person is struggling to die. If a person is clinically dead but his or her vital organs are kept functioning by mechanical means, turning off the machines is not considered euthanasia. Until the determination of clinical death, both physician and family should seek to maintain the comfort of the patient. Spiritually, all should provide the dying person opportunities for repentance and reconciliation with God and with his or her fellows (Breck, 1989).

SUFFERING. In all serious medical situations, suffering should be relieved as much as possible; this is especially true for the Orthodox patient who has participated in the sacraments of Holy Confession and Holy Communion. Pain that cannot be relieved should be accepted in as redemptive a way as possible. For the church, a "good death" (in Greek, *euthanasia*) is one in which the human being accepts death with hope and confidence in God, in communion with him, as a member of his kingdom, and with a conscience that is at peace. Genuine humanity is achievable even on the deathbed.

The Transmission of Life

The Eastern Orthodox approach to marriage provides the context for discussing procreative and sexual issues. The church sees marriage as a sacramental dimension of human life, with ecclesial and interpersonal dimensions and purposes (Guroian). The Orthodox church sees both men and women as equal before God as human beings and as persons called to grow toward God-likeness. Both men and women are persons in their own right before God and may be endowed with many potentialities that ought to be developed as part of their human growth. Yet the special sacramental relationship of marriage, procreation, and child rearing gives to women, in the mind of the church, a special role. Accompanying it is the role of husband and father in constituting a marriage and creating a family. Most of the bioethical issues regarding the transmission of life arise out of this marital and familial perspective in Orthodox thought.

REPRODUCTIVE TECHNOLOGIES. Artificial insemination assists spouses to procreate when they cannot conceive through normal sexual intercourse. In such cases, the sperm of the husband is artificially introduced into the wife's childbearing organs. There are differences of opinion in the Orthodox church regarding this procedure. A major objection is that this is a totally unnatural practice. But since other "unnatural practices" such as cooking food, wearing clothes, using technical devices such as eye-glasses and hearing aids, and performing or undergoing surgery are considered morally acceptable, this argument loses much of its force.

More cogent is the argument that artificial insemination separates "baby-making" from "love-making," which is a way of emphasizing the unity of the spiritual and bodily dimensions of marriage. In the case of artificial insemination by husband (AIH), the personal, social, and spiritual context seems to indicate that AIH is morally acceptable. The opposite holds true when the semen of a donor is used (AID). The intrusion of a third party in providing the semen violates the psychosomatic unity of the marital couple.

The same pattern of ethical reflection applies to other procedures, such as artificial inovulation and in vitro fertilization. If the sperm and ovum come from the spouses themselves, and the wife bears the child to term, ethical objections to these procedures are lessened. Often, however, fertilized ova are discarded in the procedures. The majority of Orthodox consider this a form of abortion. Others hold that for abortion to take place, implantation in the womb must have previously occurred. Nevertheless, surrogate mothers, egg donation, and sperm donation from parties outside the marriage find no place in an ethical approach that places heavy emphasis on the wholeness and unity of the bodily and spiritual aspects of human life, and of the marital relationship in particular.

STERILIZATION. Where sterilization is intended to encourage promiscuous sexual living, Orthodox Christianity disapproves. A strong ethical case can be made for it when there are medical indications that a pregnancy would be life-threatening to the wife. An as yet unexplored ethical area is the case of almost all older, yet still fertile, married couples, for whom there is a significant likelihood that the children of their mature love would be bearers of serious genetic diseases.

GENETICS. Genetic counseling seeks to provide information to a couple before they conceive children so that potentially serious conditions in newborns can be foreknown. Genetic counseling is also related to genetic screening of population groups that might be carriers of particular genetic illnesses. Genetic screening refines and makes more accurate the earlier practices of the church and of society that sought to reduce the incidence of deformed and deficient children, through the restriction of marriages between persons closely related genetically.

As a procedure that would reduce the number of persons entering into marriages with dangerously high chances for the transmission of genetic illnesses, these procedures ought to be strongly encouraged. Premarital genetic screening of young people with Mediterranean backgrounds, where there is a relatively high incidence of thalessemia B and Tay-Sachs disease, might guide them in the selection of spouses. Once a child is conceived and growing in the womb, however, the church could not consider the termination of the pregnancy as anything other than abortion. An impaired child is still the image of God with a right to life (Harakas, 1982). Since the church strenuously opposes abortion, prenatal diagnostic information indicating the prospective birth of a genetically deformed child cannot justify ending the life of the baby in the womb. Instead, this information serves to prepare the parents to receive their child with the love, acceptance, and courage required to care for such an exceptional baby.

GENETIC ENGINEERING. Concern with genetic engineering as an aspect of the transmission of life provokes a conflicting reaction among Orthodox Christian ethicists. Some Orthodox ethicists value the potential therapeutic possibilities of genetic engineering. In this case, the treatment of the genome to correct deficiencies is looked at positively, as a form of medical therapy. Nevertheless, there is concern when these same techniques are thought of as means for eugenic goals. The potential for misuse and abuse make Orthodox Christian reactions very cautious (Breck, 1991).

Conclusion

The common denominator in all these issues is the high regard and concern of the church for human life as a gift of God. Eastern Orthodox Christianity takes a conservative approach to these issues, seeing in them a dimension of the holy and relating them to transcendent values and concerns. Only an intense respect for human life can curb the modern tendencies to destroy human life both before birth and as it approaches its end. The human person, from the very moment of conception and implantation in the womb, is dependent upon others for life and sustenance. It is in the community of the living—especially as it relates to the source of life, God in Trinity—that life is conceived, nurtured, developed, and fulfilled in communion with God. The trust that each person has in others for the continued well-being of his or her own life forms a basis for generalization. Eastern Orthodox ethics, consequently, functions with a pro-life bias that honors and respects the life of each person as a divine gift that requires protection, transmission, development, and enhancement.

STANLEY S. HARAKAS (1995)

SEE ALSO: *African Religions; Buddhism, Bioethics in; Christianity, Bioethics in; Daoism, Bioethics in; Eugenics and*

Religious Law; Islam, Bioethics in; Jainism, Bioethics in; Judaism, Bioethics in; Medical Ethics, History of: Europe; Mormonism, Bioethics in; Native American Religions, Bioethics in; Reproductive Technologies; Sikhism, Bioethics in; Transhumanism and Posthumanism

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ECONOMIC CONCEPTS IN HEALTHCARE

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Healthcare has always been an economic activity; people invest time and other resources in it, and they trade for it with each other. It is thus amenable to economic analysis—understanding the demand for it, its supply, its price, and their interrelationship. Economic analysis, of course, does not merely discern what the supply, demand, and price for healthcare in private or public markets are. It also attempts to understand why they are what they are: What behavior on the part of suppliers affects the demand for healthcare? How does a particular insurance framework affect supply and demand? And so on. Moreover, economic analysis is indispensable in the larger attempt to improve healthcare—to make it more efficient, for example, so that people can accomplish more with their investment in healthcare, or more in life generally with their resources.

The economics of healthcare, in fact, has grown into an established specialty within professional economics. Though virtually every good is in some sense an *economic good,* economists have been quick to notice some differences with healthcare. Final demand seems to be more supplier-created in the case of healthcare than it is with most goods; both the shape of health services and their price are very directly influenced by providers. Other forms of what economists call *market failure* occur in healthcare—for example, when people with a considerable demand for healthcare do not receive services because their high risk to insurers drives prices for even the most basic insurance to unaffordable levels.

As people have become increasingly concerned about rising cost, economic concepts have gained greater general currency in society's consideration of healthcare. Price is seldom *no object,* and the search for efficiency is vigorous. This entry on economic concepts in healthcare will:

1. Clarify the differences between two important forms of efficiency analysis in healthcare;
2. Articulate some of the difficulties in devising and using a common unit of health benefit;
3. Examine the monetary evaluation of one health benefit, life extension;

4. Focus on some of the fundamental moral difficulties that the demand for efficiency poses for clinical practice; and
5. Briefly explore the notions of *externality* and *public good* and their role in health policy.

Many other economic concepts apply to healthcare, but these are some that obviously raise ethical issues and are therefore most appropriate to include in this volume. Throughout, however, it will be important to keep in mind that economists, qua economists, usually think of their primary task as describing the world, not saying what it ought to be.

One should also note that although many economic concepts may appear to be more at home in capitalist than in centralized, collectivist, or socialist economies, they virtually always have a role to play in those other economies, too. For example, cost-effectiveness and cost-benefit analysis are used at least as much in socialist as in more capitalist healthcare systems. While the economic concepts developed here may not be ideology-free, they are hardly confined to free-market frameworks.

Cost-Effectiveness, Cost-Benefit, and Risk-Benefit Analysis

Efficiency involves the basic economic concept of *opportunity cost*: the value sacrificed by not pursuing alternatives that might have been pursued with the same resources. When the value of any alternative use is less than the value of the current service, the current one is efficient; when the value of some alternative is greater, the current service is inefficient. In thinking of the possible alternative uses, our sights can be set either narrowly or broadly. If we focus just on other options in healthcare, wondering whether we can get *more benefit* for our given healthcare dollars, or whether we can get the *same health benefit more cheaply,* we are engaged in cost-effectiveness analysis (CEA). If, on the other hand, we are comparing an investment in healthcare with *all the other things* we might have done with the same time, effort, and money, we are engaged in cost-benefit analysis (CBA). CEA asks whether the money spent on a particular program or course of treatment could produce healthier or longer lives if it were spent on other forms of care. CBA involves an even more difficult query: whether the money we spend on a particular portion of healthcare is *matched* by the benefit. We determine that by asking in turn whether, spent elsewhere, it could produce greater value of another sort, not just healthier or longer lives.

Both kinds of analysis are important. We want to get the most health and life for our investment in healthcare (CEA), but we also want neither to be so occupied with other investments that we ignore improvements in health that would be worth more to us, nor to pass up other things in life because we are investing too much in relatively unproductive healthcare (CBA). CEA is the less ambitious enterprise: We compare different healthcare services, detecting either final differences in expense to achieve the same health benefit or differences in some health benefit (for example, added years of life, and reductions in morbidity). That itself is a tall order, but it is less daunting than CBA. CBA is difficult, of course, because the advantages gained from such other investments often seem incommensurable with health and longevity. Improvements *within* healthcare, though, often seem terribly incommensurable, too: How do we really compare the values of non-life-extending hip replacement, for instance, and life-extending dialysis or transplants?

Formal, economic CBA puts into common *monetary* terms the various benefits of the endeavors in life that are being compared—a life saved with healthcare is seen to have a value, let us say, of $1 million. With the benefits thus monetarized, the conceptual package of resource trading is tied together; we are able to compare the benefits of healthcare and those of other endeavors with each other in the same terms (i.e., monetary ones). If benefits are assigned a monetary value, then, since costs have been stated from the beginning in monetary terms, we can ascertain straightforwardly whether the benefits are worth the costs. If, for example, it will likely take three $500,000 liver transplants to get one lifesaving success, and if a life saved has a monetary value of $1 million, then the transplants cost more than the life they save is worth. Whether we are achieving actual *value for money*—efficiency—now gets an explicit answer (though critics will doubt that we can ever sustain the judgment that a life saved has a monetary value of *only* $1 million).

Another, less formalized kind of analysis is *risk-benefit analysis*: One compares the probabilities of harm presented by a certain course of action with its likely benefits. If another procedure is likely to produce similar benefits with less risk, the latter is obviously preferable. It is not always clear, however, when one risk is *less* than another; the two may be risks of different things—one, say, of paralysis and the other of chronic pain. Moreover, one procedure may harbor lower risk but also promise fewer health benefits; again we are left with non-comparables. Unlike CEA, the beneficial effects in risk-benefit analysis are not all measured on a common scale, and unlike CBA, the benefits are not put in the same terms as the costs or risks.

We use the economic tools of CEA and CBA to discern potential improvements in efficiency. The existence of a potential efficiency improvement, however, does not by itself tell us that we should pursue it. Efficiency is only one goal; we might also need to consider the fairness of distributing goods and resources in the most efficient way. Economists, though, will be quick to note efficiency's especially great moral force in two sorts of circumstance: where the new, more efficient distribution is *Pareto superior* (someone gains, and no one loses), or where the gain to some is sufficient to allow them to compensate the *losers* back to their reference point and still retain some net benefit for themselves. If, for example, so many people gain from water fluoridation that they are better enough off even after being taxed to provide a really ample compensation fund for those who suffer some side effect, then all, even the *losers,* gain by fluoridation.

Health Benefit Units: Well-Years or Quality-Adjusted Life Years (QALYs)

CEA, unlike CBA, does not venture answers to the question of how much money to spend for a given health benefit. It does, however, attempt ambitious as well as modest comparisons within healthcare. What it needs to be able to do this is a common unit of health benefit. In some contexts this will quite naturally be present; suppose we are comparing the respective prolongations of life provided by bypass grafts and coronary *medical management* (drug therapy). The more difficult task for CEA comes in translating widely different health benefits into a common conceptual currency. The notion developed for this purpose goes by various labels: a *well-year,* a *quality-adjusted life year* (QALY, pronounced to rhyme with *holly*), or *health-state utility.* The essential idea is a unit that combines mortality with quality of life considerations—*a year of healthy life,* as one defender of QALYs puts it. We can then compare not only life-prolonging measures with each other but also measures that enhance quality with those that prolong life—hip replacements with kidney dialysis, for example. And then we can also track the health of a population, calculating changes in per capita *years of healthy life.*

Having available a unit that combines mortality and morbidity will be immensely useful if we are trying to maximize the *health benefit* of a given amount of resources invested in healthcare. Suppose dialysis patients' self-stated quality of life is 0.8 (where 0 is death and 1.0 is normal healthy life). They would gain 8.0 QALYs from ten years on $40,000-a-year dialysis, a cost-benefit ratio of $50,000 per QALY. Suppose hip replacements improve fifteen years of life from 0.9 quality ranking to 0.99. That will be a 1.35 QALY gain for the $10,000 operation, a cost of less than $7,500 per QALY. To achieve greater efficiency, we apparently should expand the use of hip replacements and look toward reducing dialysis.

A sizable literature of CEA has developed, not only studies of particular procedures but also discussions about the construction of common units of health benefit. Take the QALY. Questions abound. Whom does one ask to discern quality-of-life rankings for different sorts of health states—patients with the problems, or other citizens and subscribers who are less dominated by their desire to escape their immediate health need? What questions do we ask them? Those building the QALY and well-year frameworks have used *time trade-off* (how much shorter a life in good health would you still find preferable to a longer lifetime with the disability or distress you are ranking?), *standard gamble* (what risk of death would you accept in return for being assured that if you did survive, you would be entirely cured?), and several others. Whatever question people are asked, it should convey as accurately as possible what might be called the *QALY bargain*: their exposure to a greater risk of being allowed to die should they have an incurable, low-ranking condition, in return for a better chance of being helped to significant recovery or saved for prospectively normal health.

The moral argument for using some such common health benefit unit is more than just some narrow focus on aggregate economic efficiency per se. The major moral argument by many health economists for using both quality adjustment and longevity extension in a serious attempt to maximize the benefit that a plan or an entire healthcare system produces is that it is people themselves who implicitly quality-rank their own lives and thus consent to the allocation priorities that QALYs or well-years generate. Critics charge, however, that maximizing years of healthy life in our lifesaving policies systematically fails to respect the individual with an admittedly lower quality of life. To what interpersonal trade-offs have people consented, even when it might involve themselves? Suppose you yourself now prefer, as you did previously, a shorter, healthier life to a longer, less healthy one. You are now an accident victim who could survive, though paraplegic, while someone else could be saved for more complete recovery. Admittedly, you yourself prefer a life with recovery to one with paraplegia, and you would be willing to take a significant risk of dying from a therapy that promised significant recovery if it succeeded. You do not admit, though (and you never have admitted), that when life itself is on the line, a life with paraplegia is any less valuable to the person whose life it is than life without that disability. *Compared with death,* your paraplegic life could still be as valuable *to you* as anyone else's *better* life is *to* *them*—that is, you want to go on living as fervently as the nondisabled person does.

Some analysts, in attempting to incorporate points such as this and other ethical criticisms of QALYs, have emphasized a standard distinction in economics, that between individual utility and societal (or *social*) value. Individual utilities convey information about the welfare of an individual, while social values constitute preferences or evaluative claims about communities or relationships between persons. People hold social values, just as they also have preferences about their own lives. For example, they typically believe that those who are more severely ill should get a given healthcare service first before another who is not as severely ill, even if in either case the care produces equivalent improvement in those two persons' individual utilities. They also typically believe that even if the individual utility of a given number of years of life extension is arguably greater for someone in full health than it is for someone with a significant chronic illness, the value of saving either of their lives is equal. Using the *person trade-off* technique for eliciting such social values, some economists and policy analysts (Nord; Menzel et al) have argued for extending empirical value measurement to so-called *cost-value analysis* (CVA). Whether a model for health resource allocation developed along such lines will prove to be ethically superior to standard health economic analysis that focuses on individual utility units such as QALYs will undoubtedly be vigorously debated in the coming decade.

Common health benefit units will undoubtedly continue to be developed and used. Their contested character only indicates that the process of economic analysis into which they fit, systemwide CEA, is itself a morally contested vision for healthcare.

The Monetary Value of Life

CBA, in contrast to CEA, demands the assignment of monetary value to the benefits of a program or procedure. The health benefit whose monetarization has received the most explicit attention in the literature of CBA is life itself. Economic evaluation of life itself, as superficial and distorting as it may sound, is in one sense now an ordinary phenomenon. Now that a great number of effective but often costly means of preserving life are available, we inevitably and repeatedly pass up potential lifesaving measures for other good things, and money mediates those trade-offs. In CBA, however, one goes further and assigns a *particular* monetary value, or range of monetary values, to life. Is that value $200,000 or $2,000,000? Other questions abound. Is the monetary value of a relatively short remaining segment of life (a year, say) simply an arithmetic proportion of the whole life's value? If we assume that the length of different people's lives that remains to be saved or preserved is equal, is the economic value of their lives the same, or does it vary—for example, with income level, wealth, or future earning power? And if it does vary, should we still use those varying values or instead some common average in doing CBA of healthcare?

Independent of the debates on those questions, economists have developed two main models for translating empirical data into an economic value of life: discounted future earnings (DFE), also known as *human capital,* and willingness to pay (WTP). DFE looks at the future earnings forgone when a person dies. In the economy, those earnings are what is lost when a person dies, so that from the perspective of the *whole economy* (if we can speak of any such thing), it would be self-defeating not to save a life for $200,000 if the value of the person's earnings (after discounting the future figures back to present value) was more than that. While such DFE calculations continue to be used in some CBAs in healthcare, DFE has been largely surpassed in economists' work by WTP. In WTP the value of life is taken to be a direct function of people's willingness to use resources to increase their chances of survival. Suppose one annually demands an extra $500, and only $500 extra, to work in an occupation that runs an additional 1 in 1,000 risk of dying. Then according to WTP, $500,000 (1,000 × $500) is the monetary value one puts on one's life. Within the context of CBA, this would mean it would be inefficient to devote more than $500,000 per statistical life saved to healthcare that eliminates prospective risks of death.

In economic theory, WTP is generally regarded as the superior model; it captures the range of life's subjective, intangible values that DFE seems to ignore. Generally people spend money for reasons of subjective preference satisfaction quite independent of monetary return. That is, economic value incorporates consumption values, not just investment. Despite that firm basis in underlying economic theory, WTP has raised a host of objections. For one thing, questions arise similar to those that afflict DFE. Just as there are in DFEs, there are wide variations in willingness to pay—largely based on people's wealth and income. May those variations in value legitimately affect what is spent on lifesaving measures? If their effect is legitimate, is that only for services privately purchased, or also for those funded publicly? Defenders of WTP have articulated many responses to handle these and other critical questions, but the model may still seem suspicious. Any statement to the effect that "it was efficient not to save his life (now lost)—it was worth only $500,000" is not easily accepted. Consequently, despite its professional popularity, WTP has hardly gained widespread moral acceptance for actual use in health-policy.

The basic problem is simply that in the end the world is such a different place for a loser than it is for a winner. Suppose one refuses to pay more than $500 (when one could) for a CAT scan or magnetic resonance image (MRI) that one knows is likely to eliminate a 1-in-1,000 portion of the risk of dying from one's malady, and that then one later dies because of that decision. Of course one has in some sense consented to what happened, but one never thought anything remotely like "$500,000—no more—is the value of my life," the life that after the fact is irretrievably lost. The move that economists make in WTP to get from an initial trade-off between money and risk to the value of a real, irreplaceable life is puzzling. One critic has claimed that in principle only valuations of life made directly in the face of death are correct reflections of the actual economic value of life (Broome). And as another contributor to this discussion has noted, we do not know of anyone "who would honestly agree to accept any sum of money to enter a gamble in which, if at the first toss of a coin it came down heads, he would be summarily executed" (Mishan, p. 159–160). Some conclude from this that CBA can set no rational limit on what to spend to save a life because no particular finite amount of money is adequate to represent the real value of life.

Even if this point about the actual value of a life is correct, however, it may not render WTP estimates of the value of life irrelevant for use in health policy. In the context of setting policy about whether to include a certain service in our package of insurance, we cannot just assume that the later perspective of an individual immediately in the face of death is the correct one from which to make decisions. Such a perspective may be proper for the legal system to adopt in awarding compensation for wrongful death, for there we are trying to compensate people for losses actually incurred. But perhaps healthcare decisions ought to be made from an earlier perspective. In modern medical economies, after all, most people either subscribe to private insurance plans or are covered by public ones. Once insured, whether in private or public arrangements, subscribers and patients as well as providers find themselves with strong incentive to overuse care and underestimate opportunity costs. Why should we not address the problem of controlling the use of care in the face of these value-distorting incentives at the point in the decision process, *insuring,* where the major cost-expansion pressure starts? In the context of CBA for health policy, while it may not be necessary to claim that willingness to risk life shows us the *value of life,* willingness to risk may still be appropriate to use in any case. Perhaps what is important in decisions to invest resources in healthcare is only that what gets referred to as *the monetary value of the benefits* should be derived from people's decisions to bind themselves in advance to certain restrictions on the provision of care. The problem with WTP may then be narrower: Many of the *values of life* generated by WTP are not sufficiently close to the actual decisions of people to take risk by limiting their own investment in lifesaving. That would render any resulting CBAs that used them crude and ungrounded, but would not necessarily seal the fate generally of WTP-using CBA.

It is possible that as a formal method of analysis, CBA will never have great influence. Even if that is true, however, the larger enterprise of less formal CBA will remain an active and crucial dimension of the broader attempt to find the proper place of healthcare in our lives overall.

The Difficulties That Economic Concepts Pose for Clinical Practice

Suppose that economic efficiency analysis, whether of the CEA, CBA, or other less formalized sort, lays the groundwork for recommendations about the kind and amount of healthcare to use—fewer diagnostic MRIs in certain low-yield situations and very cautious introduction of new, expensive drugs, for example, and more hip replacements and much more assertive and widely diffused prenatal care. The former, service-reducing steps would not constitute the elimination of merely wasteful procedures that generate no net health benefit. They would constitute something much harder: *genuine rationing,* in which some patients did not get what for them would be optimal care. How does such rationing for efficiency relate to the ethical obligations of healthcare providers? The traditional (at least traditionally professed) ethic of physicians is one of loyalty to individual patients. Generally, in turn, that loyalty is interpreted to mean beneficence: doing whatever benefits a patient the most, within the limits of what the competent patient willingly accepts. If healthcare is to be rationed in order to control the resources it consumes, however, will the basic clinical ethic have to change? This potential clash between traditional ethical obligations and the economic and social demands of the *new medicine* in an age of scarcity is one of the central foci of ethical controversies in medicine as we enter the twenty-first century.

One can divide the potential views here into *incompatibilist* and *reconciliationist* camps: those who think that the demands of societywide (or at least large-group) efficiency cannot be reconciled with the ethical obligations of practitioners, and those who think they can be. The incompatibilists will end up in two different positions: (1) the "well, then, to hell with morality" view in which one is willing to pursue economic efficiency anyhow; and (2) the anti-efficiency stance that opposes rationing in the name of a morality of strict beneficence toward individual patients. Reconciliationist views will also come in distinctly different sorts. (1) Parties more distant from the patient than clinicians should make all rationing decisions, and clinicians should then ration only within pre-determined practice guidelines—the separation-of-roles position. (2) As a provider, one's proper loyalty to a patient, though not dominated by efficiency, is to the patient as a member of a just society; this then enables the clinician to ration with a clean conscience if based on considerations of fairness and justice (Brennan). (3) Patients are larger, autonomous persons; rationing can then be grounded in the consent of the prepatient subscriber to restrictions on his or her later care (Menzel, 1990). (Why would the patient consent?—to reserve resources for other, more value-producing activities in life.)

The strength of the incompatibilist views may seem to be that they call a spade a spade, but their abiding weakness is that they just dam up the conflict and create later, greater tensions. The reconciliationist views, on the other hand, deal constructively with the conflict and allow conscientious clinical medicine to find roots in a more cost-controlled, socially acceptable aggregate of healthcare. Their weakness may be the great difficulties they face in actual use. The separate-roles view requires extremely clear formulation of detailed care-rationing practice guidelines in abstraction from the medically relevant particulars of individual patients; by contrast, *bedside rationing* in which clinicians make substantive rationing decisions may be preferable and necessary (Ubel). The patient-in-a-just-society model requires a great degree of agreement on what constitutes a just society. And the prior-consent-of-patients solution requires not only accurate readings of what restrictions people are actually willing to bind themselves to beforehand but also a willingness of subscribers and citizens to think seriously about resource trade-offs beforehand and then abide honestly by the results even when that places them on the short end of rationing's stick.

Undoubtedly this discussion is not about to reach immediate resolution soon in societies that are enamored of ever-expanding healthcare technologies, pride themselves on respecting individual patients, and are determined to steward their resources wisely.

Externalities and Public Goods

Externalities and public goods play a prominent role in economics-informed discussions of public policy. Externalities are costs or benefits of a behavior not borne by or accruing to the actor, but by or to others. They pose a distinct problem for the achievement of efficiency in market economies. If I am making and selling an item whose production involves harms or burdens to others for which I do not have to pay, I will be able to price the product under its true cost and sell it more easily. The solution is to correct incentives by imposing a tax on the item equivalent to its external cost (or a subsidy equivalent to its external benefit). Even better, one could give the proceeds of that tax to the parties harmed by the item's use or production. Externalities, then, immediately propel us into public-policy decisions about taxes and subsidies.

Public goods also directly raise questions of public regulation and taxation. A *public good* in the economist's sense is one whose benefits accrue even to those who do not buy it. If you clean up your yard, I benefit from a somewhat better appearance on the block regardless of whether I clean up my own or help you clean up yours. Or if a large number of people contribute to an educational system in the community, I get some of the benefits of the more civilized culture and productive economy that result even if I never contribute anything. The benefit is thus public and nonexclusive: Once a certain mass of contributors is in place, it is difficult if not impossible to exclude from the benefits an individual who chooses not to contribute. Standard examples of public goods include many of the basic functions of the modern state (public safety, national defense, education, public health, and the reduction of pollution). Thus, public goods constitute a primary justification of the state's coercive power. If I contribute not a penny to a police force, for example, I will still receive most of its benefits; if not taxed, I can thus *free-ride* on others' willingness to fund public safety. The obvious solution is for the collective to tax me my fair share.

The use of both public goods and externalities is undoubtedly on the rise in discussions of healthcare. Note just two examples of the interesting contexts in which these concepts come up.

An example of externalities is the taxing of health-complicating products such as tobacco and alcohol. Smoking and excessive drinking undoubtedly increase certain costs to others—healthcare expenditures for smoking- and drinking-related diseases; lost work time; displeasure, sadness, and pain in dealing with others' destruction of their social and biological lives; and even direct loss of life (from passive smoking, drunk driving, etc.). These externalities provide part of the momentum behind the movement to increase taxes on tobacco and alcohol. Note, however, that the empirical picture can be much more complicated, and in the case of tobacco it certainly is. First-impression, informal cost analysis of smoking (and many published academic studies as well) leads us to think that smokers cost nonsmokers a great deal of money. That conclusion ignores, however, two hidden *savings* of smoking that accrue to others: Because smokers die earlier, and generally near the end of their earning years or shortly thereafter, they save others the pension payouts and the unrelated healthcare expenditures they would have incurred had they lived longer, without losing that saving through significantly reduced earnings. One leading study, in fact, concludes that all the costs that smokers impose on others, including losses from fires and the costs of the U.S. tobacco subsidies justify only a cigarette tax of $.37 per pack (Manning et al.). The typically higher taxes that actually obtain in most states cannot then be justified by any empirically well-grounded externalities argument, nor can the state governments' claims to settlements of hundreds of billions of dollars from tobacco companies (Viscusi). This is not the last word on the net external costs of smoking, but it illustrates the subtleties and hidden costs that increasingly sophisticated economic analysis reveals. Economic analysis may turn up equally surprising results in the future as we turn increasingly to prevention in the hope of controlling healthcare costs; prevention that saves healthcare expense in one respect may lose those gains as its longer-living beneficiaries draw more pension payouts and end up incurring higher aggregate costs of illness in their longer lives.

An example of public goods is sharing in the costs of a healthcare system that provides access to those who otherwise cannot pay. Suppose most people think a good society provides basic care to those who cannot afford it, and that they believe that the financial burdens of the medical misfortunes that people cannot have been expected to control by their own choices ought to be shared equally by well and ill. It is then possible to analyze the situation in the traditional and conservative terms of public goods and the prevention of free-riding. If a considerable amount of charity care is societally provided and access is thus improved, I gain both the security of knowing that I will be helped if I become poor or sick, and the satisfaction of knowing that I live in a society that does not neglect its poor and ill. If I do not contribute financially to make this more secure and arguably better society possible, I free-ride on the largess of others. This free-riding situation generates an essentially conservative justification for requiring people to pay into an insurance pool even when they think they are safe.

Many other interesting and controversial instances of the use of these and other economic concepts in the analysis of healthcare could be cited. Without being targeted accurately on identifiable pockets of market failure, tax breaks for health-insurance premiums would seem to create incentives for inefficient overinvestment in healthcare. If physicians significantly create demand for their own services, their incomes will need to be regulated either by the government or by market forces at work among health plans using salary or capitation payments (as distinct from fee for service) to compensate physicians. And so on and so forth. More generally, how to discern what constitutes efficiency in the investment of resources in healthcare, how to arrange incentives to stimulate efficient use of care, and how the achievement of efficiency is to be compared with the realization of other values central to the whole healthcare enterprise constitute the challenge that economic concepts bring to healthcare in the twenty-first century.

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SEE ALSO: *Healthcare Allocation; Healthcare Resources; Healthcare Systems; Health Insurance; International Health; Justice; Just Wages and Salaries; Managed Care; Medicaid; Medicare; Pharmaceutical Industry; Profit and Commercialism; Value and Valuation*

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ELECTROCONVULSIVE THERAPY

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Electroconvulsive therapy (ECT) is a highly efficacious treatment in psychiatry (Crowe, Abrams), and yet there is ethical controversy about its use. Some have claimed that ECT should be outlawed because it seriously impairs memory; others, that ECT is best viewed as a crude form of behavior control that psychiatrists frequently coerce patients to accept. Still others claim that, even if coercion is not employed, depressed patients are rarely, if ever, competent to give valid consent to the treatment (Breggin). The complaint is also sometimes voiced that ECT is given more frequently to women patients than to men. There is also ample evidence that, in earlier years, ECT was given in ways that are not used today: higher amounts of electrical current, and sometimes daily or several-times-daily treatments. Undoubtedly, this harmed some patients (Breggin). Probably because of concerns like these, one state, California, has passed legislation making it difficult for psychiatrists to employ ECT without satisfying many administrative regulations (California Welfare and Institutions Code). There also exist several activist groups that are opposed to all ECT and have even tried to criminalize the administration of ECT. Daniel Smith provides an excellent summary of these groups's arguments and activities in his 2001 article "Shock and Disbelief."

The nature of the treatment itself understandably frightens some persons, and there have been gruesome depictions of it in popular films and novels (Kesey). The notion of passing an electrical current through the brain, stimulating a cerebral seizure and causing unconsciousness, may seem forbidding, particularly in view of the fact that ECT's therapeutic mechanism of action remains largely unknown. There are, however, many effective treatments in medicine whose mechanisms are unknown, and there are probably many surgical treatments that would seem equally forbidding if they were observed by a layperson. In appraising the ethical legitimacy of ECT as a treatment, it is important to ask the same questions about ECT that are asked about any treatment: Of what does it consist, what is the likelihood that it will help, what kinds of harm can it cause; and how does its spectrum of benefits and harms compare with those of alternative plausible treatments?

ECT Treatment

There are several excellent reviews of the history, clinical indications, and likely harms and benefits of ECT (Abrams; American Psychiatric Association Task Force on Electroconvulsive Therapy (APA Task Force); Crowe; Ottosson). The essential feature of the treatment is the induction of a cerebral seizure (which is easily measured via concomitant electroencephalography) by means of electrodes attached to the scalp. Current is applied through the electrodes for a fraction of a second. The two electrodes may be attached to the right and left temples (bilateral ECT), inducing a seizure in both hemispheres of the brain, or to anterior and posterior placements on only one side (unilateral ECT), limiting the seizure to that side. Patients are premedicated with a muscle relaxant and anesthetized with a short-acting barbiturate general anesthetic. Patients remain unconscious after the treatment for about five minutes and are usually mildly confused for an hour or so after they awaken. They have no memory of the treatment itself. Treatments are usually given two or three times weekly for two to four weeks.

ECT was used originally as a treatment for schizophrenia on the basis of the now-discredited belief that epilepsy, which ECT was thought to mimic, and schizophrenia did not occur in the same persons. It is used chiefly with patients suffering from severe depression; most psychiatrists suggest its use to patients only when drug treatment and/or psychotherapy have not helped. ECT is also used occasionally with bipolar patients suffering from a life-threatening degree of manic excitement, or to schizophrenic patients suffering from a catatonic stupor, when these conditions do not improve with drug therapy.

Efficacy and Side Effects

The effectiveness of ECT in reversing severe depression seems beyond dispute (Abrams; Crowe; APA Task Force): Many large studies show a significant recovery from depression in 80 to 90 percent of patients who receive ECT, as compared with 50 to 60 percent of depressed patients who respond to antidepressant medication. Patients who do not respond to drugs show a high response rate to ECT: about 50 to 60 percent recover. No study comparing the differential effects of drugs and ECT has ever found that drugs have a greater therapeutic effect. ECT also works more quickly than drugs: Patients who improve typically begin to do so after about one week; drugs, if they work, typically take three to four weeks, sometimes longer, to have a significant effect. Many studies have shown that unilateral and bilateral ECT are equally effective treatments, although a minority have found unilateral ECT to be on average less effective. However unilateral ECT also causes, on average, less cognitive confusion during treatment and less residual memory impairment afterward.

Although ECT can cause death, it does so infrequently that it is difficult to reliably estimate a mortality rate. The largest modern report (Heshe and Roeder) studied 3,438 courses of treatment (22,210 ECTs), and only one death occurred. The APA Task Force estimates a death rate of 1 in 10,000 patients and 1 in 80,000 treatments. When ECT does cause death, it is usually cardiovascular in origin and is related to the use of a general barbiturate anesthesia.

The principal adverse effect of ECT on some patients is to cause one or another kind of memory impairment. Two of these kinds of memory impairment are limited. During the two to three weeks that treatments are given, memory and other cognitive functions are usually mildly to moderately impaired because of the ongoing seizures. Moreover in later years patients are often unable to recall many events that took place shortly before, during, and shortly after the two- to three-week course of treatment. Neither of these effects bothers most patients, as long as they understand ahead of time that they will occur.

The more important and controversial question is how often ECT causes an ongoing, permanent deficit in memory function (an anterograde amnesia). If and when it does, it is possible that the treatment has damaged parts of the brain underlying memory function. This has proven to be an elusive research problem, despite dozens of studies, many quite sophisticated, that have been carried out (Taylor et al., Abrams). Among the many methodological problems involved in doing this research (Strayhorn) is the fact that depression itself often causes cognitive impairment, including memory dysfunction. In fact studies of the effect of ECT on memory have repeatedly shown that the majority of patients actually report improved memory function after ECT, probably due to the diminution of their depression (APA Task Force).

A small minority of patients—the exact percentage seems unknown—do report mild, ongoing, permanent memory problems after ECT; nearly all of them rate the memory problem as annoying but not serious. However, when patients treated with ECT are compared with appropriate control groups, no deterioration in performance on objective tests of memory ability has ever been found. Nonetheless a very small number of patients, perhaps 1 to 2 percent, complain of serious ongoing memory problems. Memory complaints occur more frequently after bilateral than unilateral ECT, which has led many commentators to recommend that unilateral treatment generally be given, and that bilateral treatment be used only in serious conditions and after unilateral ECT has failed.

Ethical Issues

Is ECT so harmful that it should be outlawed? Very few persons maintain this position. ECT has an extremely small risk of causing death. It probably also has a small risk of causing chronic mild memory impairment, and a very small risk of causing chronic serious memory impairment. It is frequently used, however, in clinical settings where other treatments have failed and where the patient is suffering intensely and may be at risk of dying. Severe depression is a miserable and a serious illness: The three-year death rate in untreated or undertreated patients is about 10 percent, while in treated patients, it is about 2 percent (Avery and Winokur). Even if the risks of ECT were substantially greater than they are, it would still be rational in the clinical setting of severe depression for patients to consent to receiving ECT.

As with all other treatments in medicine, the possible harms and benefits of ECT should be explained to the patient during the consent process. The risk of death and of chronic memory dysfunction should be mentioned specifically. The APA Task Force also stipulates that a discussion should be included, during the consent process, "of the relative merits and risks of the different stimulus electrode placements and the specific choice that has been made for the patient. The patient's understanding of the data presented should be appraised, questions should be encouraged, and ample time for decision making should be allowed. Patients should be free to change their minds about receiving ECT, either before the treatments start or once they are under way" (pp. 5–6).

ECT is often suggested to patients only after other treatments have failed. However, although it has slight risks, ECT has several advantages over other treatments: It works more quickly, in a higher percentage of cases, and it does not have the annoying and, for some cardiac patients, possibly dangerous side effects of many antidepressant drugs. Following the general notion that part of an adequate valid consent process is to inform patients of any available rational treatment options (Gert et al.), a strong argument can be made that, from the outset of treatment, seriously depressed patients should be offered ECT as one therapeutic option (Culver et al.). The APA Task Force states: "As a major treatment in psychiatry with well-defined indications, ECT should not be reserved for use only as a *last resort.*"

Do psychiatrists often coerce patients into receiving ECT? This seems doubtful, but there are no data addressing this question. In the overwhelming majority of cases, psychiatrists should not force any treatment on a patient. Nonetheless there are very rare clinical situations in which it is ethically justified to give ECT to patients who refuse it (Group for the Advancement of Psychiatry): for example, patients in danger of dying from a severe depression that has not been responsive to other forms of treatment (Merskey). But this is a special instance of the general ethical issue of justified paternalistic treatment, and no special rules should apply to psychiatric patients or to ECT (Gert et al.).

There seems no reason to believe that the consent or the refusal depressed patients give to undergo ECT is not in most cases valid. If a patient is given adequate information about the treatment, if he or she understands and appreciates this information, and if the patient's choice is not forced, then the decision is valid and, in almost all cases, should be respected. Most psychiatrists would assert that the great majority of depressed patients are like the great majority of all patients: They feel bad, they would like to feel better, and if presented with information about available treatment options, they try to make a rational choice.

Is ECT disproportionally and unjustly given to women patients? There are no data that address this question, and it would be useful to obtain them. However, given the fact that women suffer from clinically significant depression two to three times more frequently than men (Willner), the critical question is not whether more women in total receive ECT, as would be expected, but whether ECT is given at a higher rate to women than to equally depressed men.

CHARLES M. CULVER (1995)
REVISED BY AUTHOR

SEE ALSO: *Behaviorism; Behavior Modification Therapies; Electrical Stimulation of the Brain; Emotions; Freedom and Free Will; Human Dignity; Informed Consent: Issues of Consent in Mental Healthcare; Mental Health Therapies; Mental Illness: Issues in Diagnosis; Neuroethics; Psychiatry, Abuses of; Psychosurgery, Ethical Aspects of; Psychosurgery, Medical and Historical Aspects of; Research Policy: Risk and Vulnerable Groups; Technology*

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EMBRYO AND FETUS

* * *

I. Development from Fertilization to Birth
II. Embryo Research
III. Stem Cell Research and Therapy
IV. Religious Perspectives

I. DEVELOPMENT FROM FERTILIZATION TO BIRTH

The ethical relevance of studying human development appears when one asks which stages of the human life cycle embody significant ethical concerns. Between birth and death, the human organism is a person, equipped with the full measure of basic human rights. This much is not really controversial, and the debate primarily concerns the prenatal phase of development. Do human rights accrue to the unborn all at once, for instance at fertilization? Do they instead arise in a gradual manner, based on the various progressive steps through which the prenatal human organism acquires significant person–like properties? Besides personal rights, are there other ethically–significant values and properties that would justify a respectful treatment of embryos and fetuses? An understanding of prenatal development is a necessary, albeit in no way sufficient, condition for addressing these issues successfully.

To understand the basic biology of any sexually reproducing organism, one needs to grasp the primary concept of the life cycle. The life cycle of humans includes fertilization, cleavage, gastrulation, organogenesis, fetal development, birth, child development and puberty, gametogenesis and again fertilization. It is through the germ–line that the life cycle persists from generation to generation. On the other hand, the somatic cells (which comprise all the cells of the fetus, child, and adult that are not directly involved in reproduction) belong to an inherently mortal entity, the human organism, whose fate is senescence and death. One turn of the life cycle defines one generation. Fertilization and birth define the beginning and end of the prenatal phase of development, which is comprised of two stages: embryonic and fetal.

The embryonic phase initiates with fertilization, the meeting of the male (sperm) and female (oocyte) gametes, giving rise to the zygote. At fertilization, a new, diploid genome arises from the combination of the two haploid genomes included in the gametes. The zygote divides several times (cleavage stage) to form a blastocyst. The cells of the blastocyst, called blastomeres, are separated into two parts: an outer layer, called the *trophoblast,* that eventually contributes to the placenta; and an inner cell mass that contributes to the future embryo. About six days after fertilization, the blastocyst attaches to the endometrium (the epithelial lining of the uterus). This marks the beginning of pregnancy and further development depends on intricate biochemical exchanges with the woman’s body. While the trophoblast invades the uterine wall, the inner cell mass undergoes further stepwise differentiation processes that lead to the formation of the embryonic epiblast (the precursor of the actual human individual) and several extraembryonic structures (Figure 1). The embryo then undergoes gastrulation, the process that starts with the formation of the *primitive streak.* This is the crucial developmental step, common to all animals but the most primitive invertebrates, by which the three basic germ layers of the embryo are formed. These are called ectoderm, mesoderm, and endoderm.

From the third to the eighth week, the process of organogenesis involves the differentiation of the three germ–layers into specific tissues and primordial organs. The earliest stage in organogenesis is called neurulation and starts when a specific area of ectoderm turns into the primordium of the nervous system. During organogenesis, many genes that are crucial to development are activated, and complex cell–to–cell signals insure the proper differentiation of various cell types, as well as the movement and migration of cells to their proper places in the developing embryo. For some cell types, this involves long–range navigation. For instance, the gamete precursors must travel from their initial position near the yolk sac to the primordial gonads.

At the end of the embryonic phase, many important organ systems are in place, at least in rudimentary form. The fetal phase is characterized by further differentiation and maturation of tissues and organs, as well as considerable growth, especially towards the end of pregnancy. In the late fetal phase, the nervous system undergoes an acceleration of synapse formation and maturation of the brain, which is increasingly sensitive to outside cues. This process continues well after birth.

Specific Developmental Stages in Detail

Especially in early development, specific developmental processes seem more meaningful than others in the ethical debate about the moral status of human prenatal life. These are described in more detail.

GAMETOGENESIS AND FERTILIZATION. The embryo is usually defined as coming into existence at fertilization and becoming a fetus when organogenesis is completed (eight weeks after fertilization). These borders are not sharply defined. The definition of an embryo thus cannot avoid being operational and context–dependent. The term *conceptus* is useful to denote any entity resulting from fertilization, when no reference to a more specific stage is intended. An additional complication results from the significant overlap between the final stages of female gametogenesis, fertilization, and initial cleavage.

Gametogenesis involves a special type of cell division called meiosis. When primordial germ cells (which are diploid—i.e., they have two complete sets of chromosomes) enter meiosis, their DNA is duplicated so that there are now four copies of each type of chromosome (a condition called tetraploidy). In the first meiotic division, there are genetic exchanges within each group of homologous chromosomes, which then separate into diploid daughter cells. In the second meiotic division, there is no further round of DNA duplication. Each chromosome in a pair is allotted to a separate daughter cell, now haploid. Each primordial germ cell thus gives rise to four daughter haploid cells.

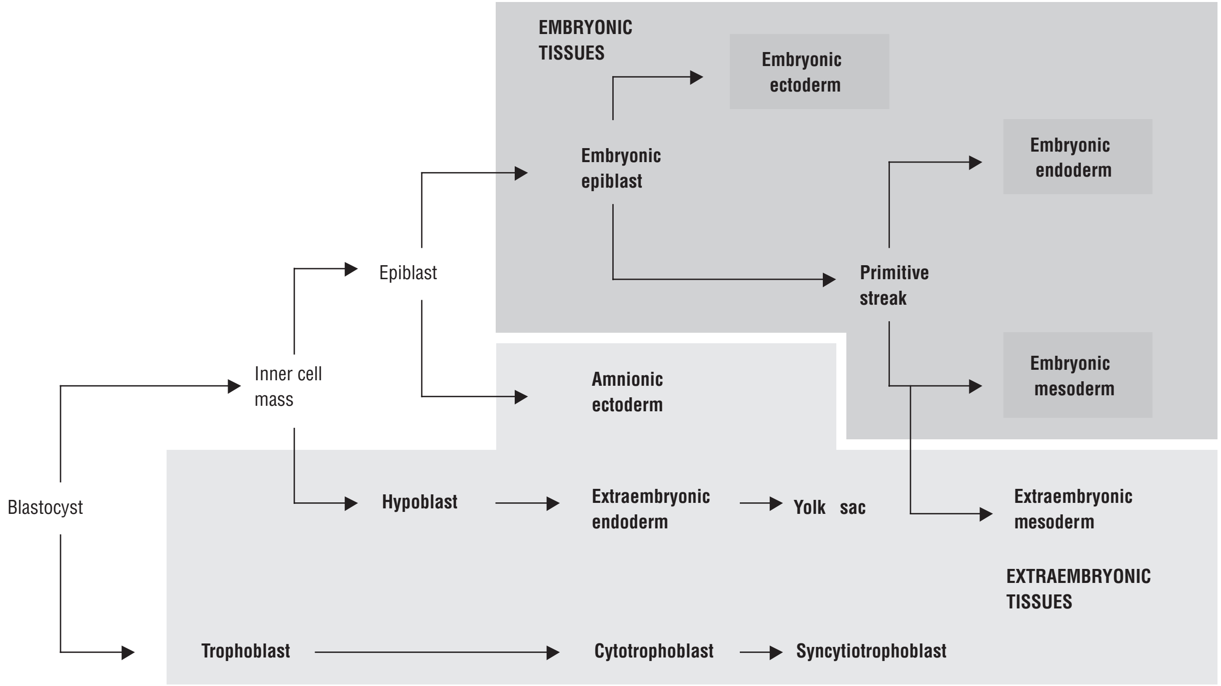
In the male, all four cells resulting from meiosis ultimately become functional spermatozoa. In contrast, in the female, only one of the daughter cells becomes an oocyte, the other three cells are discarded as polar bodies. In addition, female meiosis is not completed until after fertilization has occurred. During each ovarian cycle of the sexually mature female, one oocyte progresses partially through meiosis but is arrested in the middle of the second meiotic division at the time it is discharged from the mature ovarian follicle into the oviduct. If the oocyte is fertilized, meiosis is completed. Within the newly fertilized egg, the male and female pronuclei undergo a protracted migration towards each other, while DNA is duplicated within both. Thereafter, both nuclear envelopes disappear and the chromosomes derived from the male and female gamete are involved in the first cleavage division. Thus the first genuine diploid nucleus is observed at the two–cell stage only (30 hours after initial contact of sperm and oocyte). While fertilization usually occurs close to the ovary, the conceptus is gently nudged towards the uterus, a voyage lasting about five days.

Both through recombination of gene segments during the first meiotic division, and through random assortment of homologous chromosomes in gametes, genetic novelty is generated. In other words, gametes are genetically distinctive in relation to their diploid progenitors and do not simply reflect the genetic structure of their parent organism. In a sense, gametes are distinctive “individuals” in relation to the organism that produces them. Fertilization creates genetic novelty of a different sort, by combining two independent paternal genomes. The zygote is genetically distinctive because it represents the meeting of two independent parental lineages. Thus genetic novelty appears twice per turn of the human life cycle.

CLEAVAGE, PLURIPOTENTIALITY, AND TWINNING. During cleavage, the zygote divides into smaller embryonic cells. At the 16–cell stage, the embryo is called a morula and a first differentiation into two cell types is initiated. The trophoblast is the cell layer that will soon connect with the uterine wall, whereas the inner cell mass includes the cells of the later stage embryo. At the blastocyst stage, a central cavity (blastocoel) is formed. If a blastomere is removed from the inner cell

FIGURE 1

Derivation of Tissues in Human Embryos


EMBRYONIC TISSUES
Embryonic ectoderm
Embryonic epiblast
Embryonic endoderm
Epiblast
Primitive streak
Inner cell mass
Amnionic ectoderm
Embryonic mesoderm
Blastocyst
Hypoblast
Extraembryonic endoderm
Yolk sac
Extraembryonic mesoderm
EXTRAEMBRYONIC TISSUES
Trophoblast
Cytotrophoblast
Syncytiotrophoblast

SOURCE: Gilbert, 2000.

mass of a blastocyst (as, for instance, in preimplantation diagnosis), the blastocyst is still able to produce a complete late embryo and fetus. This illustrates a fundamental principle called regulation, or regulative development. Within the early embryo, cell fates are not definitely fixed but largely depend on interactions with neighboring cells, so that development adjusts to the presence or absence of specific environmental cues. The molecular basis and the genes responsible for these cues are increasingly well known.

At the blastocyst stage, the inner mass cells are pluripotent (i.e., they have developmental plasticity) and are able to participate in the formation of most cell types of the adult organism, as shown for instance by experiments with cultured immortalized blastomeres, called embryonic stem cells. Recent research does suggest that individual blastomeres acquire some degree of molecular specificity quite early. However, this inherent "bias" that tends to drive every blastomere towards a specific cellular fate can easily be overridden at this stage.

Around day 6, the blastocyst has hatched from the surrounding zona pellucida (the outer envelope of the ovum) and is ready for implantation. As it attaches to the endometrium, two distinctive layers appear in the inner cell mass. The ventral layer (hypoblast) contributes to the primitive yolk sac. The dorsal layer soon differentiates between the embryonic epiblast that will contribute to the embryo–to–be, and the amniotic ectoderm lining the newly appearing amniotic cavity (day 7–8). This two–layered structure is called the embryonic disk. All this happens as the blastocyst burrows deeper into the uterus wall and the trophoblast comes into close contact with maternal blood vessels. The trophoblast also produces human chorionic gonadotropin (hCG), which is the substance detected in pregnancy tests and is essential to the maintenance of pregnancy. Abnormal conceptuses are very common until that stage and are eliminated, usually without detectable signs of pregnancy. Inversely, fertilization occasionally results in a hydatidiform mole. This structure consists of trophoblastic tissue and therefore mimics the early events of pregnancy (hCG is produced), without their being any actual embryonic tissue present.

The term *pre–embryo* was often used to mark the embryonic stages described so far. This term is sometimes shunned in contemporary discourse, as it has been suspected to be a semantic trick to downgrade the standing of the very early embryo. Yet even writers like Richard A. McCormick belonging to the Catholic tradition, sets great store by the moral standing of the earliest forms of prenatal development, have expressed doubts about the validity of this suspicion (1991). More importantly, doing away with the term "pre–embryo" does not solve the two underlying conceptual problems that this term addresses. The first ensues from the cellular genealogy linking the zygote to the later stage embryo and fetus. Only a small part of the very early embryo is an actual precursor to the late embryo, fetus, and born child. Whatever terminology one wishes to use, no account of early development can avoid sentences such as this, written by Thomas W. Sadler in 2000, "[t]he inner cell mass gives rise to tissues of the *embryo proper*," or terms such as the *embryo–to–be*. This is an inescapable consequence of the fact that the late embryo includes only a small subset of all the cells that originate with the zygote and blastocyst (Figure 1 shows the complex genealogy of embryonic and extraembryonic tissues in human development). The second problem arises from the fact that the early embryo has a degree of freedom as regards its final numerical identity. Until about 12 days after fertilization, twinning can occur. In other words, until that stage, a single embryo still has the potential to divide in two embryos, ultimately developing into two separate persons. Therefore there is no intrinsic one–to–one relationship between the zygote and the late embryo, as there is between the late embryo, the fetus, and the born human.

GASTRULATION. Gastrulation begins with a wave of cellular movements that start at the tail end of the embryo and extend progressively forward. Future endoderm and mesoderm cells slip inside the embryonic disk through a groove called the primitive streak (day 14). The anterior end of the streak is called the node. Of the cells that migrate inside the streak, some form the endoderm and others will lie atop the endoderm and form the mesoderm. Finally, those cells that remain in their initial position on the surface of the embryonic disk become the ectoderm. Gastrulation sets the overall organization of the embryo in a definitive way. The main axes (anterior–posterior, left–right) are defined under the control of two central signaling centers: the node (which is the equivalent of the organizer discovered by embryologists working on frog and chick embryos) and the anterior visceral endoderm.

Recent data from molecular genetics have partially uncovered the molecular basis of axis determination. The determination of the anterior–posterior axis involves the HOX genes, a set of four gene complexes. Since HOX genes located at the "front end" of a HOX complex are expressed at the "front end" of the embryo, the arrangement of the various genes within each complex remarkably reflects the place at which they are expressed in the embryo along the anterior–posterior axis. The four HOX complexes thus provide four "genetic images" of the lengthwise arrangement of embryonic structures. The left–right asymmetry of the embryo (and thus of the future body plan) is thought to originate with specific cells in the node. In a way that is not fully understood, these cells induce a cascade of protein signals that is different on the left and right side of the embryo. This results in the synthesis of controlling factors that are laterally restricted. It is supposed that these controlling factors and other factors direct the development of asymmetric organs accordingly.

Through gastrulation, the embryo arises as a defined entity endowed with a much higher level of organic unity than at any stage before. The laying down of the head–to–tail axis and other defined spatial features, as well as the loss of pluripotentiality in many cell lineages, mark the beginning of a single individual human organism and thus provide one of the first important dimensions of the ontological continuity typical of the born human.

LATER DEVELOPMENTAL STEPS. In the initial step in organogenesis, the midline axial section of mesoderm—the notochord—instructs the overlying ectoderm to turn into the neural plaque. This structure soon wraps around to form the primitive neural tube, out of which the central nervous system will eventually grow. By the beginning of the fetal period (eighth week), the rudiments of the heart, blood and blood vessels, the major segments of the skeleton and associated muscle groups, the limbs, and many other structures are in place. It is noteworthy that although the primordial nervous system is one of the earliest organ systems to emerge in development, it takes the longest time to mature. Synaptogenesis (the formation of –contacts between nerve cells) starts on a grand scale only late in pregnancy and continues well after birth. This is important to keep in mind when interpreting early movements of the fetus, visualized more and more accurately by ultrasonography. These movements reflect the maturation of local neuromuscular structures and are not due to significant brain function, since there is no "brain" in the sense of the later, much more developed anatomic and functional structure called by that name. This is different later in pregnancy, when fetal movement is more reactive to the environment and when it becomes arguably legitimate to interpret it as "behavior," insofar as it reflects the increased functional capabilities of the central nervous system. Finally, the concept of *viability* basically reflects the ability of fetal lungs and kidneys to support extrauterine life, which is impossible before the twenty-second week.

As mentioned before, the differentiation and migration of early gametes also occurs during the embryonic phase. This separation of the germ cell lineage from all other cell lineages marks a bifurcation in the life cycle. Unlike somatic cells, gamete precursors have a chance of becoming gametes and participating in fertilization, thus contributing to the next generation. In a way, the germ cell lineage is eternal through successive turns of the life cycle, whereas the rest of the embryo, the sum total of somatic cells, is inherently mortal.

Extracorporeal Embryos

Science fiction fantasies about the artificial uterus notwithstanding, only the very first stages of human development can occur outside the female body. Since 1978, in vitro fertilization followed by embryo transfer has been a common treatment of fertility problems. The growth of ovarian follicles is stimulated by the administration of gonadotropins. Oocytes are then collected by laparoscopy and placed in an appropriate culture medium. Sperm is added and cleavage occurs in culture until the blastocyst is transferred in the uterus.

With in vitro fertilization, the early embryo became much more accessible to human intervention, and this has raised ethically perplexing possibilities. Interventional research on early embryos has become possible, raising the question of whether it is ethical to produce human embryos for research purposes, or whether research should be done, if at all, only on "spare" embryos. These occur when some embryos are no longer needed for fertility treatment, even though they resulted from in vitro fertilization performed with therapeutic intent. Additionally, progress in genetic testing techniques using very small amounts of DNA has made preimplantation diagnosis of genetic abnormalities possible. Single blastomeres are removed from in vitro blastocysts, their DNA amplified by polymerase chain reaction (PCR), and subjected to genetic tests with appropriate DNA probes. (Thanks to regulative development, the missing blastomere is soon compensated for.) In this way, embryos can be screened for certain genetic defects and only those free of defects chosen for embryo transfer. This procedure is sometimes suspected of being eugenic, and the controversy around it has led to it being outlawed in certain countries including Germany and Switzerland.

Developmental Steps and Moral Status

The biological processes around fertilization and early embryonic development are often accorded considerable relevance in ethical debates, making a detailed description of these processes necessary. This descriptive effort, however, is not based on the belief that "the facts speak for themselves." They emphatically do not. In fact, many ethical controversies about the ethics of in vitro fertilization, embryo research, therapeutic cloning, abortion and the like, are less about ethics in the strict sense as they are about expressing divergent interpretations of biology. The marshalling of biological fact to support apodictic statements of moral status involves many, usually unspoken, "bridge principles." These principles involve highly complex notions, such as unity, individuality, potentiality, and continuity. It is a common misconception that these theoretical concepts constitute stable, common–sense notions that are merely applied to biological entities and processes. In actuality, these concepts are themselves given new meanings and qualifications in the very process of using them to make sense of biological facts. Between the realm of ontological categories and the empirical domain of biology, there is a two–way street.

It is often said that "human life begins at fertilization." Strictly speaking, this statement is meaningless. Human life does not begin at any point of the human life cycle; it persists through successive generations. The ethically relevant question to ask is at what stage a human individual is first endowed with important ethical value and correlative rights against harm. The difficulty is that no particular step stands forth as a self–evident developmental marker, both because developmental events that appear as sharp discontinuities turn out to be protracted processes upon closer scrutiny (for instance, fertilization is a process, not an instantaneous event), and because the highlighting of one developmental process over another necessarily involves more or less plausible philosophical assumptions.

Three different concepts of individuality appear to be relevant:

- genomic individuality as established trough fertilization;
- numerical identity, defined once twinning is no longer possible;
- identity of the self, as sustained by a functional central nervous system.

Fertilization is important because it newly connects two parental lineages that were independent until then. The meeting of sperm and oocyte gives rise to a uniquely novel diploid genome that is not subject to further change. It will be the genome of the future person or persons arising from this particular fertilization. This fact is often misinterpreted according to a hylomorphic interpretation of the genome, where the latter becomes the formal cause of the future human being (Mauron). (Hylomorphism is the aristotelian and scholastic teaching that concrete objects, especially living things, result from a combination of form [morphê] and substance [hylê].) This interpretation suggests the notion that fertilization is the single crucial step, since the new genome appears at that point. This interpretation fails, not only because of the inherent conceptual problems of the hylomorphic view, but also because there exist biological facts such as twinning and genetic mosaicism that show that there is little connection between genomic individuality as such and personal identity. Monozygotic or identical twins are separate persons, even though they share "the same" genome, that originated from "the same" fertilization. This shows that genomic individuality does not provide any basis for the most essential property of personal identity, namely numerical identity through time. To be one and same person through changes in one's biography is an essential ingredient of any workable concept of the person, and the biological basis for this property does not originate before gastrulation. In fact, much of the organic singularity and coordinated functioning as one organism (rather than several potential organisms) is established only at that stage.

However, one may want a richer interpretation of this basic criterion of personal identity. Having a biography of one's own is not just being the same individual through time, but also experiencing a continuity of mental states, which is linked to an at least minimally–functioning central nervous system. In fact, nothing is more central to the modern conception of the self than the functional persistence of a central nervous system that provides the material substrate of an individual subjective biography. For this biographical, or subjective, identity, it is difficult to quote a definitive starting point. It is plausible to place it in late pregnancy, when the earliest possibility of a continuing self seems to be given, but there is no absolute certainty in this claim.

Conclusion

Ethical reasoning on this topic often shows a common pattern: one takes moral concepts that belong to uncontroversial persons (such as grown humans) and tries to apply them backwards to the fetus and embryo. However, importing intuitions pertaining to the ethics of personal rights and interests onto various forms of prenatal life is increasingly fraught with conceptual difficulties as one moves towards earlier stages. Indeed, the most perplexing problem in bridging human developmental biology and statements of moral standing is perhaps that traditional moral categories tend to be "all–or–none" concepts (either one is a person or not, and if so, one is equal in basic rights to all persons), whereas developmental biology shows mostly gradual change and tends to resolve what appear to be discrete borders into continuities. One obvious and popular answer to this quandary is to make ethical standing a gradually increasing property of the developing human organism. On the other hand, one may query the underlying assumption that there is a one–dimensional measure of ethical concern. Further reflection may benefit from a recognition that ethical concerns about human prenatal life are multidimensional, and sometimes qualitatively, not just quantitatively, different from the person–centered systems of ethical values and duties.

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SEE ALSO: *Abortion: Medical Perspectives; Alcoholism and Other Drugs in a Public Health Context; Cloning; Death, Definition and Determination of: Criteria for Death; Feminism; Infants; Infanticide; Maternal-Fetal Relationship; Moral Status; Reproductive Technologies: Ethical Issues;* and other *Embryo and Fetus* subentries

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II. EMBRYO RESEARCH

In previous editions of this encyclopedia, the topic of embryo research was included within the entry on fetal research. However, during the latter part of the twentieth century the issues arising from research involving in vitro fertilized embryos became sharply distinguished from issues in research with already-implanted fetuses. Moreover, new technologies such as the development of embryonic stem cells and the possibility of human cloning raised new ethical concerns in relation to research involving human embryos.

This entry will address the history of human embryo research, public policy on embryo research in the United States and internationally, moral considerations, particularly the debate on the moral status of the human embryo, and the relevance of ethical distinctions that have been proposed, such as the distinction between research use of surplus embryos versus embryos created specifically for research.

The Research Subject

Scientifically the product of conception is called an *embryo* until eight weeks of gestational age, when the name changes to *fetus.* However, contemporary discussions of embryo research customarily restrict the term embryo to the earliest stages of human development before implantation in the uterus occurs. This terminology is supported by the U.S. federal regulations on fetal research, which define the fetus as "the product of conception from implantation until delivery," thus excluding non-implanted embryos from the regulations (45 CFR 46.202).

In practical terms the embryo as subject of research is the embryo in the laboratory, generally the result of in vitro fertilization (IVF), but possibly developed by other means, for example, through flushing naturally-fertilized eggs from the fallopian tube, or through somatic cell nuclear transfer (SCNT) of a body cell into an enucleated egg, a type of cloning procedure.

A variety of terms has been proposed for the embryo as subject of research:

the *preembryo,*
the *preimplantation embryo,*
the *embryo ex utero,*
the *early embryo.*

In this entry the simple term *embryo* will be used, with the understanding that it refers to the embryo in the laboratory that has not undergone transfer to a woman. Some commentators maintain that only embryos resulting from fertilization of eggs by sperm are properly called embryos. This question will be addressed in later sections when it is relevant.

Early History of Embryo Research

Until the 1990s most research involving human embryos was directed toward improving the chances for pregnancy in laboratory-assisted conception. These investigations, in turn, were based on many years of research with animal models, where virtually all research in the United States has been supported with federal funding. It was hoped that procedures developed in animal studies could later be applied to human reproduction and embryology, especially to the understanding and alleviation of human infertility.

Attempts at laboratory fertilization of human oocytes (precursor eggs) showed some promise as early as 1944 in the work of American obstetrician-gynecologist John Rock and scientist Miriam Menkin. From that time until the birth of the first child conceived through IVF in 1978, various approaches were tried in order to achieve a pregnancy and live birth. The work of Robert Edwards, British reproductive endocrinologist, culminated in the birth of Louise Brown after he collaborated with Patrick Steptoe, an obstetrician who utilized laporoscopy for viewing and recovering a mature ovarian follicle containing an oocyte capable of fertilization.

According to embryologist Jonathan Van Blerkom, most current methods used in laboratory-based treatment of infertility have evolved from those used by Edwards and Steptoe and their predecessors. According to Van Blerkom, this work "established the basic science foundation of clinical IVF" (p. 9). Without these four decades of research on fertilizing oocytes, accompanied by study of the early cleavage and development of fertilized eggs or zygotes, the clinical practice of IVF, which is an almost universally accepted primary treatment for infertility, would not exist.

U.S. Funding and Regulation of Embryo Research

In 1975 the U.S. National Commission for the Protection of Human Subjects recommended guidelines for federal funding of research involving human fetuses, but stipulated that these guidelines did not cover research on IVF or on embryos resulting from IVF. It proposed that an Ethical Advisory Board be appointed to review such protocols, and this recommendation was incorporated into federal regulations. In 1978 an Ethics Advisory Board (EAB) was appointed to recommend a policy on federal funding for research involving IVF.

In its 1979 report the EAB concluded that research on IVF was ethically acceptable for federal funding under these conditions: that all federally funded research is directed toward establishing the safety and efficacy of IVF; all gametes used to develop embryos in research protocols are provided by married couples; and no embryos are preserved in the laboratory beyond fourteen days of development. The EAB's rationale was based on two main points. First, it would be irresponsible to offer clinical IVF without doing the studies necessary to insure its safety and efficacy. Second, given the high rate of embryo loss in natural procreation, a similar rate of loss could be tolerated for the goal of eventually achieving pregnancies and births.

The EAB did not distinguish between embryos created for research purposes and embryos remaining from infertility treatment. In fact, the board implied that at times it might be necessary to create embryos with no intent to transfer them to a woman. For the sake of safety, the results of new types of procedures would have to be studied in the laboratory before the procedures were offered clinically. It would be unethical to transfer to a woman the embryos resulting from unvalidated novel procedures.

The EAB report elicited an outpouring of letters opposing embryo research, and its recommendations were never implemented. When the EAB charter expired in 1980, a subsequent board was not appointed, thus leaving no body to review proposals for federal funding of IVF and embryo research. This situation effectively created a moratorium on federal funding in the United States, though it did not affect research that was privately funded.

Public Policy in Other Countries

It is not possible to review all legislation and policy recommendations throughout the world, but two early initiatives are of particular interest. They come from countries that share a common law tradition with the United States, Australia (Victoria), and the United Kingdom.

AUSTRALIA (VICTORIA). The earliest comprehensive legislation on reproductive technologies was enacted in the State of Victoria, Australia in 1984. The Infertility (Medical Procedures) Act addressed embryo research by prohibiting research that might damage the embryo or make it unfit for implantation. This prohibition appeared to outlaw any IVF or embryo research that was not directed toward benefiting each individual embryo.

In 1986 the review committee established by the act received a proposal for research on the microinjection of a single sperm into an egg. In their application the investigators suggested a novel approach for circumventing the prohibition on embryo research. They proposed to examine the egg after the sperm had penetrated it, but before the genetic contributions of the sperm and egg had fused at the stage known as syngamy. Arguing that fertilization was not completed until syngamy had occurred, researchers claimed that the law did not apply until the time of syngamy, thus giving them approximately twenty-two hours after sperm penetration for conducting their studies.

Since the review committee was uncertain as to whether the 1984 act allowed this interpretation, it recommended that the act be amended to clarify that research was permissible if it ended by the time of syngamy, even if the research destroyed the embryo's potential for implantation. The act was amended according to this recommendation in 1987.

UNITED KINGDOM. The issue of the regulation of reproductive technologies and embryo research was particularly pressing in the United Kingdom because of the publicity given to the birth of Louise Brown in England in 1978. The Warnock Committee was appointed to study the matter, and its 1984 report recommended national regulation of assisted reproduction. It also recommended that research on embryos resulting from IVF be permitted up to the fourteenth day after fertilization, under the jurisdiction of a licensing body.

Based on the Warnock Report, the Human Fertilisation and Embryology Act (HFE Act) of 1990 commissioned a standing body, the Human Fertilisation and Embryology Authority (HFEA), to develop standards for licensing clinical facilities and research protocols, and mechanisms for auditing and oversight. Initially research protocols were restricted to the study of infertility, the causes of congenital diseases, and the detection of gene or chromosome abnormalities in embryos.

Since its establishment in 1991 the HFEA has addressed new types of procedures and research through public consultation processes as well as the advice of experts. If a matter was beyond the scope of authority of the HFEA, it was referred to Parliament. In January 2001 Parliament extended the HFE Act to permit embryo research directed at increasing knowledge about treatments for serious diseases. This provision would allow the HFEA to issue licenses for research on embryonic stem cells, including stem cells derived from blastocysts resulting from somatic cell nuclear replacement (SCNR). However, the Pro-Life Alliance brought a challenge to this provision, arguing that the HFE Act applied only to embryos resulting from the fertilization of eggs by sperm. Despite a Court of Appeal ruling against the Pro-Life Alliance, in June 2002 the House of Lords agreed to hear a final appeal of the case. In March 2003 the House of Lords ruled that the HFE Act applied to all types of embryos, and hence the HFEA had authority over research with embryos created by nuclear transfer as well as embryos resulting from fertilization by sperm.

The U.S. Human Embryo Research Panel

After nearly twenty years of moratorium on federal funding of research involving IVF, the U.S. Congress in 1993 revoked the requirement of EAB review. Through the

National Institutes of Health (NIH) Revitalization Act of 1993, Congress explicitly permitted the NIH to fund research on assisted reproductive technologies with the goal of improving the understanding and treatment of infertility.

Since research on IVF includes the study of IVF-fertilized embryos, the research authorized by Congress included research involving human embryos. Recognizing the controversial issues raised by this research, NIH decided to conduct an examination of ethical issues before funding any research proposals. Consequently, the Director of NIH appointed the Human Embryo Research Panel (HERP) to provide advice and recommendations.

In developing its position and recommendations, the panel focused on two distinct sources of guidance: viewpoints on the moral status of the early human embryo, and ethical standards governing research involving human subjects. It considered a wide range of possible views on the moral status of the embryo, from the position that full human personhood is attained at fertilization, to the argument that personhood requires self-consciousness and is not attained until after birth. In the end, all nineteen members of the panel agreed to the following statement:

> Although the preimplantation embryo warrants serious moral consideration as a developing form of human life, it does not have the same moral status as an infant or child. (Human Embryo Research Panel, p. x)

This conclusion implied that the preimplantation embryo is not a full human subject and thus is not a fully protectable human being. As a result, some research that might be destructive to the embryo could be acceptable for federal funding. But the panel also asserted that the human embryo "warrants serious moral consideration," requiring that it be treated differently from mere human cells or animal embryos. The panel proposed restrictions on embryo research that would express such moral consideration, for example, that human embryos be used in research only as a last resort, that the number of embryos used be carefully limited, and that embryos not be allowed to develop longer than required by a specific research protocol, and in no case longer than fourteen days of development.

In applying the ethical standards governing research involving human subjects, panel members invoked the criteria used by Institutional Review Boards (IRBs) in approving research protocols. Donors of eggs, sperm, or embryos were to be informed of the specific goals, procedures, and risks of research projects. Risks to donors, particularly egg donors, were to be minimized. Eggs for research could be donated only by women who were undergoing diagnostic or therapeutic procedures where egg retrieval would present little additional risk.

The most controversial issue facing the panel was the question of whether human oocytes could be fertilized solely for research purposes. The panel decided to allow such fertilization only under very special circumstances, most particularly, if certain research by its very nature could not otherwise be conducted. For example, research on the laboratory maturation of human oocytes, which could eliminate the need for egg donors as well as infertile women to be subjected to high levels of hormonal stimulation, requires study as to whether such oocytes can be successfully fertilized.

The panel's limited acceptance of the fertilization of oocytes for research purposes aroused strong criticism, and President Bill Clinton immediately announced his opposition.

The Aftermath in the United States and Beyond

Despite President Clinton's directive that NIH not fund research involving the creation of embryos, most types of research on IVF and human embryos were still eligible for federal funding. However, in its next appropriations bill Congress reversed its previous stance and prohibited NIH from funding any research that might involve damaging or destroying human embryos. In 2003 this prohibition was still in effect.

During the 1990s scientific advances raised new questions regarding research with human embryos. In 1998 the first embryonic stem cell lines were developed from the inner cell mass of human blastocysts, and at the same time, similar stem cell lines were produced from the germ cell tissue of aborted fetuses. Deriving stem cells from blastocysts was clearly prohibited for federal funding. However, the derivation of stem cells from the tissue of aborted fetuses was eligible for federal funding under previous legislation (U.S. Public Law 103–43, Manier).

Another discovery was the successful cloning of a variety of nonhuman animals from adult cells, beginning with the cloning of the sheep Dolly in 1997. Research on human cloning arguably involves research on human embryos. These embryos are produced by transfer of somatic cell nuclei into enucleated oocytes, rather than through fertilization of eggs by sperm, yet their development and potential appear to be similar to those of fertilized eggs. Thus cloning research raises similar ethical questions.

The day after the announcement of the cloning of Dolly, President Clinton instructed the National Bioethics Advisory Commission (NBAC) to undertake a thorough review of the technology and to report within ninety days.

Given this short deadline, it is understandable that NBAC had to focus on issues specific to the cloning process. In particular, NBAC decided to “not revisit … the issues surrounding embryo research,” since the topic had “recently received careful attention by a National Institutes of Health panel, the Administration, and Congress” (Shapiro).

In contrast, when the President’s Council on Bioethics appointed by President George W. Bush issued its report on cloning in 2002, it called for a broader debate on the entire topic of human embryo research. The ten-member majority of the council wanted cloning discussed “in the proper context of embryo research in general and not just that of cloning” (p. 133). Both the majority and minority reports call attention to the fact that human embryo research of all types remains essentially unregulated in the private sector, with the minority noting that “it seems inappropriate to halt promising embryo research in one arena (cloned embryos) while it proceeds essentially unregulated in others” (p. 143).

In the United States, public policy at the national level is focused on what types of research are eligible for public funding. There is essentially no regulation of research in the private sector. This situation contrasts sharply with that of most other countries, where laws apply to all research, regardless of the funding source.

As of April 2003, Germany, Austria, and Ireland prohibit embryo research unless intended to benefit the individual embryo subject. Germany does allow some importation of established stem cell lines for research. France prohibits any embryo research that would harm the embryo. However, in January 2002 the French assembly passed a bill that, if enacted, would permit research using surplus embryos originally created for reproductive purposes. Sweden allows research on surplus embryos up to day fourteen, including research on deriving stem cell lines. Creating IVF embryos solely for research is prohibited, but creating embryos through nuclear transfer is not mentioned in Swedish law and thus has an uncertain legal status. The United Kingdom arguably has the most permissive policies on embryo research within the European Union. It explicitly sanctions the granting of licenses to create embryos, including cloned embryos, for specific research projects.

Because of the diverse views and policies of its member states, the European Union has taken an intermediate position, providing support for research on surplus embryos in countries where that is permitted, but discouraging the creation of embryos for research. In April 2003 the European parliament voted for a ban on cloning or otherwise creating embryos for stem cell research. However, this decision becomes law only if approved by all fifteen member states of the European Union.

In May 2002 the Assisted Human Reproduction Act was introduced into the Canadian Parliament. The act prohibits the creation of a human clone for any purpose. It also prohibits the creation of an IVF embryo for research purposes with the exception of “improving or providing instruction in assisted reproduction procedures.” In April 2003 the bill was in its third reading in the House of Commons.

In some non-Western countries, embryo research is proceeding with few restrictions. Chinese laboratories are forging ahead with cloning research to develop stem cells. Though Chinese scientists have been slow to publish their work, they may well be ahead of their Western counterparts (Leggett and Regalado). India has developed a number of internationally recognized stem cell lines, and scientists are developing additional lines. Dr. Firuza Parikh, Director of Reliance Life Sciences in Bombay, links their success to the absence of cultural and political opposition to embryo research (Lakshmi).

The Moral Status of the Early Embryo

In contrast to China and India, most Western countries are deeply divided over ethical issues related to embryo research. Does the embryo merit full protectability from the moment of fertilization, or does it gradually attain full protectability as it moves through a series of developmental stages? If fertilization is not the point of greatest moral significance, is there some later developmental marker beyond which embryo research ought not be conducted?

FERTILIZATION. Fertilization of egg by sperm marks the initiation of a new and unique genotype, that of a human being distinct from either of its progenitors. The zygote or fertilized egg not only contains the plan or blueprint for a new human being, but it has the potential within itself to develop into that human being.

Based on these facts, many would argue that the zygote is a full human being from the moment it comes into existence. This view would preclude any research that might be harmful or destructive to an embryo, unless intended to be therapeutic for that embryo or to improve its chances for implantation. This position has received able defense in contemporary terms by opponents of embryo research (McCarthy and Moraczewski).

It is possible to hold this position while acknowledging that fertilization is a process rather than an instantaneous event, and hence that the new human life begins only when the process of fertilization is completed. At least two possible candidates marking the completion of fertilization have been suggested. The first is the time of syngamy, when the chromosomes from the male and female gametes unite to form the genotype of the embryo. Since syngamy is not completed until about twenty-four hours after the sperm penetrates the egg, this view would allow some study of the early development of the embryo.

A second proposal maintains that the embryo does not begin its life as a new human being until the regulation of its development switches from oocyte genes to embryonic genes. In 1988 Peter Braude and colleagues showed that this occurs at the six- to eight-cell stage, approximately two days after penetration of egg by sperm. Arguably the embryo begins its own life distinct from that of the oocyte at the time that its own internal regulatory mechanism begins to function. This interpretation would allow investigation of questions such as why a large proportion of embryos are arrested in their development during the earliest cell divisions (Van Blerkom).

Such variant views of the process of fertilization do not counter the claim that the human being begins its life at fertilization. Rather, they provide differing interpretations as to what constitutes fertilization, under the assumption that the formation or activation of the unique genotype of the new organism is the crucial event.

IMPLANTATION. Implantation is the process by which the embryo imbeds itself in the uterine wall and begins to take nourishment from the woman, thus marking the beginning of pregnancy. It is at this time that the U.S. federal regulations define the product of conception as a fetus, and the research regulations begin to apply (45 CFR 46.201–207).

From a moral point of view, some have argued that the IVF embryo lacks the potential to develop into a human being as long as it is simply maintained in culture in the laboratory. Only those embryos that are transferred to women and that implant successfully acquire the potential for development. This type of argument has been utilized by politicians like U.S. Senator Orrin Hatch, who support some forms of embryo research while they take pro-life positions in relation to abortion. In his testimony to a Congressional subcommittee in July 2001, Hatch stated, “I believe that a human’s life begins in the womb, not in a petri dish or refrigerator.”

This view can be linked to a philosophic distinction between *possible* persons, entities that could possibly develop into persons if certain actions were taken with respect to them, and *potential* persons, entities that will develop into persons in the normal course of events unless something happens or is done to interrupt that development. The embryo in the laboratory or freezer is a possible person that might develop into a person if action were taken to transfer it to a uterus. The already-implanted embryo or fetus is a potential person that, under normal circumstances, will continue to develop into a person. Proponents of this distinction argue that while we may have a moral obligation not to interfere with the development of a potential person, we do not have a similar obligation to bring every possible person into existence (Singer and Dawson; Tauer 1997a).

PRIMITIVE STREAK. In the late twentieth century, scholars were faced with biological data about early embryonic development that led to new perspectives on the ontological and moral status of the early embryo. Particularly within the Catholic tradition, writers such as Norman Ford, John Mahoney, Richard McCormick, and Karl Rahner developed arguments questioning whether the zygote or early embryo is a full human being or human person. Their arguments appealed to the following points:

1. Twinning of the embryo is possible until implantation, and at least through the morula stage, several embryos may aggregate (recombine) to form one embryo. Thus the embryo lacks developmental individuation at this early stage. Philosophic arguments that rely on the continuity of personal identity and religious arguments based on ensoulment must deal with the phenomena of twinning and recombination, which occur naturally and can also be induced scientifically.
2. Until the blastocyst stage at approximately five days after fertilization, the cells of the embryo are totipotent or completely undifferentiated. Each cell has the capacity to differentiate into any of the cell or tissue types of the fetus, or more likely, not to become part of the fetus at all but rather to form placental and other extra-embryonic tissues. The early embryo is a collection of undifferentiated cells rather than an organized individual.
3. At approximately fourteen days after fertilization, the primitive streak appears, the groove along the midline of the embryonic disk that establishes in the embryo its cranio-caudal (head-to-tail) and left-right axes. The primitive streak marks the beginning of the differentiation of cells into the various tissues and organs of the human body, and thus initiates the development of the embryo proper (the cells that will become the fetus) as an organized, unified entity. The primitive streak is also the precursor of the neural system.
4. In normal procreation, during the period between fertilization and the completion of implantation a large proportion of embryos (generally estimated at over 50%) are discarded naturally. Karl Rahner argues that it is implausible that such a large number of human beings could come into existence

> and disappear without anyone's knowing about it. Others have argued that given nature's prodigality with human embryos, it ought to be morally acceptable to allow similar types of embryonic losses in research as part of the effort to achieve healthy pregnancies.

These sorts of arguments have been utilized in public policy debates since 1978, and the appearance of the primitive streak has come to be accepted internationally as a marker carrying moral significance. The prohibition of embryo research after fourteen days of development is almost universally accepted.

Opponents of embryo research have responded to claims that the early embryo is not yet a full human being. These commentators find arguments based on twinning and recombination, totipotency of cells, and embryo loss to be unpersuasive (Ashley; Ashley and Moraczewski; Mirkes). In its 2002 report on cloning, the majority members of the U.S. President's Council on Bioethics questioned the significance of the primitive streak as a moral marker, stating:

> Because the embryo's human and individual genetic identity is present from the start, nothing that happens later … —at fourteen days or any other time—is responsible for suddenly conferring a novel human individuality or identity. (p. 97)

GASTRULATION AND NEURULATION. Some persons regard the initiation of the neural system or the presence of brain activity to be the most significant marker for the beginning of the life of a human being. This view is based on the belief that the brain is the essential organ underlying our specifically human capacities. It also represents an effort to identify a criterion at the beginning of human life that is analogous to the criterion of whole-brain death marking the end of life. For those who regard the presence of sentience as a necessary condition for personhood, the neural system is significant since sentience is impossible in the absence of any neural structures.

While there is debate as to the stage at which brain activity first occurs, it is certain that there is no brain activity before fourteen days of gestational age. The emergence of the primitive streak marks the very beginning of the development of the nervous system. If the presence of neural structures is the significant criterion for the beginning of a human life, then it might be permissible to extend embryo research slightly beyond fourteen days of development.

Several possible cut-off points have been suggested. By the completion of *gastrulation* at about seventeen days, the three germ layers of the embryo are in place, with cells of each layer committed to forming tissues and organs of one of three types. Subsequent neural development leads to the beginning of *closure of the neural tube* around twenty-one days, with the primitive nervous system in place by the completion of *neurulation* around twenty-eight days.

However, given the widespread consensus that fourteen days of gestational age is a morally defensible boundary for embryo research, there has been limited discussion of extending research to a later embryonic stage.

Other Moral Considerations

Those who believe that the human embryo is a fully protectable human being have no choice but to oppose embryo research that could not ethically be performed on infants or children. But those who maintain that the early embryo is not yet a full human being, still have to determine how that embryo ought to be treated.

Some have proposed severely restrictive criteria for embryo research. Norman Ford, after providing painstaking arguments to support the conclusion that the embryo cannot be a human individual until fourteen days after fertilization, acknowledges that he could be wrong. In his view, the Catholic Church is right to insist on the principle that "human embryos should be treated as persons," even if they may not be (2001, p. 160). In other words, as long as there is any degree of uncertainty regarding the moral status of the embryo, it must be absolutely inviolate.

A more commonly held view is that the human embryo has an intermediate sort of moral status. While it is not a fully protectable human being, it is not merely cells or tissue. Proponents of this view are generally willing to permit some embryo research with restrictions that acknowledge that the embryo is nascent human life or a developing form of human life. Our ethical obligation toward the embryo is often characterized as *respect* or *profound respect.*

Proponents as well as opponents of embryo research have questioned the concept of respect as a guide for human embryo research. John Robertson, an advocate of scientific freedom with respect to embryo research, believes the notion of respect carries mainly symbolic significance. Hence its practical ramifications are vague, potentially allowing a wide range of types of research. Daniel Callahan, in an essay opposing most embryo research, wonders how one shows respect for a living being while intending to end its life and future potential, even if done for a good purpose such as research on infertility or disease.

In an effort to express respect for the special status of the human embryo, public policy bodies have stipulated conditions for embryo research that are considerably more restrictive than policies on research with human cells or animal embryos. For example, research must have important scientific or medical goals and may involve human embryos only when the research cannot be conducted in any other way. Research projects should be restricted to the smallest number of embryos that is feasible, and for the shortest possible time period. Careful records and security must be utilized to ensure that no embryos are diverted for unapproved purposes and that none are sold.

Bringing Embryos into Existence for Research

One of the most contentious issues in embryo ethics is the question of whether it is ever justifiable to bring human embryos into existence specifically for research purposes. Many would argue that research use of surplus embryos remaining after the completion of infertility treatment is ethically acceptable, since these embryos are destined to be destroyed in any case. At the same time, they may hold that the development of embryos for research purposes, so-called research embryos, is not morally justified.

The development of embryos for research purposes has been characterized as a novel practice that requires particular justification. Referring to embryos created through nuclear cell transfer, the President's Council on Bioethics in 2002 claimed that such research creation of embryos would constitute crossing a "major moral boundary" (p. 132). Yet decades of research on human IVF beginning in the 1930s required investigation of various methods of laboratory fertilization, followed by study of cleaving fertilized eggs to determine their normality before transfer to a woman was even considered (Soupart and Strong; Edwards and Steptoe).

Commentators agree that there is no ontological or intrinsic distinction between surplus embryos remaining after infertility treatment and research embryos developed specifically for study. Arguments that support a moral distinction must identify other morally relevant factors. The concept of respect is often invoked, as is the notion of *intent.*

Respect for the special status of the embryo seems to require that embryos be treated as entities of intrinsic value. When embryos are created purely for research purposes, they become instruments for purposes that have nothing to do with the embryos themselves. In Kantian terms, the embryos are used solely as means for the welfare of others rather than as ends in themselves. The practice of creating research embryos thus results in treating embryos as commodities, equivalent to mere cells or tissues.

In contrast, the intent to procreate justifies the development of embryos in the laboratory. Even when a large number of eggs is fertilized in an IVF procedure, each fertilized egg has an equal chance of being transferred to a woman and developing into a human being. Thus each zygote is equally respected for its procreative potential.

It is only because some of the embryos cannot be transferred (because of the decision of the progenitors, or because there simply are too many of them) that they become surplus embryos and are destined for destruction. It is arguably permissible to derive some good from the inevitable destruction of these embryos by using them in research. In doing so, one may be said to be choosing the *lesser evil.*

These arguments have been countered by a number of considerations.

It may be true that respect for the special status of the human embryo requires that it be treated differently from mere human tissue. But the concept of respect is vague and undetermined, so that a wide range of concrete interpretations is plausible. The claim that respect precludes all creation of research embryos gives heavy weight to one interpretation of the concept at the expense of any countervailing considerations. Research projects that include the development of embryos may promise significant benefits for relieving the suffering of living human beings. These benefits could outweigh a particular interpretation of respect.

While procreative intent may justify the creation of embryos in the laboratory, it is plausible that other sorts of purposes could provide equally valid justifications. The treatment of infertility, an elective medical procedure, may even hold lesser moral significance than the development of cures for life-threatening or significantly disabling diseases and trauma outcomes. Hence such goals may also justify the creation of embryos.

Moreover, surplus embryos do not appear purely by chance. Clinicians frequently make a decision to fertilize large numbers of eggs in order to optimize the chances of establishing a pregnancy. The initial intent is not to give every zygote the opportunity for implantation, but to achieve one or more pregnancies and births, as desired by the progenitors. A later decision to direct unused embryos to research cannot be justified by the principle of the lesser evil, since the existence of surplus embryos should have been anticipated. This situation was deliberately caused and could have been avoided. Thus it is invalid to invoke the principle of the lesser evil to justify use of surplus embryos in research, while maintaining that any creation of research embryos is prohibited.

Parthenogenesis

A potentially non-controversial process for developing morulas and blastocysts for research is the activation of oocytes without use of sperm or transfer of somatic cell nuclei. Such activation can be achieved through electrostimulation or chemicals in a process called parthenogenesis. The resulting cleaving eggs, called *parthenotes,* may develop much like normal embryos at least to the blastocyst stage. Although no human parthenotes have progressed this far, in February 2002 scientists announced that they had developed monkey parthenote blastocysts and established stable stem cell lines from them (Cibelli, et al.).

Scientists believe "there is a profound and intrinsic biological barrier that prevents mammalian parthenotes from developing to advanced fetal stages" (Human Embryo Research Panel, p. 20). On this assumption, parthenogenic morulas or blastocysts lack the intrinsic potential to become human beings. If this potential is a defining aspect of the human embryo and the basis for its special moral status, then human parthenotes are not human embryos and should not arouse the same sorts of moral concerns. Thus they may offer an attractive alternative for research.

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SEE ALSO: *Abortion: Medical Perspectives; Children: Healthcare and Research Issues; Cloning; Feminism; Fetal Research; Infants; Infanticide; Maternal-Fetal Relationship; Moral Status; Reproductive Technologies: Ethical Issues; Research Policy: Risk and Vulnerable Groups; Research, Unethical;* and other *Embryo and Fetus* subentries

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III. STEM CELL RESEARCH AND THERAPY

In this entry we review the ethical and legal issues that arise in the context of stem cell research and therapy. Stem cells have attracted both immense scientific interest and equal ethical and legal concern because of their capacity to “specialize” and become virtually any part of the organism into which they are introduced. Thus if introduced into the brain they become brain cells, if into the cardiovascular system they become cells of that type and so on. They also appear to be able to trigger cell regeneration and colonize damaged tissue effecting “repair” in situ. Thus if such cells are made compatible with the genome of a host using cloning techniques they could in principle repair and regenerate damaged tissue and halt or even cure many diseases. This holds out both great promise and causes great unease in equal measure. Here we examine both the scientific promise and the extent to which ethical and legal safeguards may be appropriate.

Ethical Issues

The ethical aspects of human stem cell research raise a wide variety of important and controversial issues. Many of these issues have to do with the different sources from which stem cells may be obtained. Stem cells are at present obtained from adults, umbilical cord blood, and fetal and embryonic tissue. Although there are widely differing views regarding the ethics of sourcing stem cells in these ways, there is general consensus that embryos are the best source of stem cells for therapeutic purposes—a consensus that may of course change as the science develops. If spare embryos or aborted fetuses may be used as sources for stem cells, there is a further question: Should embryos or fetuses be deliberately produced in order to be sources of stem cells, whether or not they are also intended to survive stem cell harvesting and grow into healthy adults?

The European Group on Ethics in Science and New Technologies, which advises the European Commission, has highlighted the women’s rights issues involved in stem cell research. It is particularly worth bearing in mind that women, as the most proximate sources of embryonic and fetal material and hence also of cord blood, may be under special pressures and indeed risks if these are to be the sources of stem cells.

The issue of free and informed consent, both of donors and recipients, raises special problems. Because embryos and fetuses can hardly consent to their role in sourcing stem cells, the question of who may give consent for the use of fetal or embryonic material is important, particularly because the usual basis for parental consent is hardly appropriate. This basis involves a judgment about what is in the best interests of the individual, and because, in most cases, the individual in question will not survive, the test is irrelevant (Harris, 2002a). Competent risk–benefit assessment is vital, and particular attention needs to be paid to appropriate ethical standards in the conduct of research on human subjects. Other issues concern the anonymity of the donors, the security and safety of cell banks, and the confidentiality and privacy of the genetic information and the tissue the banks contain. Finally, there are issues of remuneration for those taking part and of the transport and security of human tissue and genetic material and information across borders both within the European Union (EU) and worldwide. While these issues are important, they are well understood in biomedical ethics, and with the exception of the issue of consent, they do not raise special issues in connection with stem cell research and therapy (U.K. Human Genetics Commission).

Before considering the ethics of such use in detail, it is important to first explore the possible therapeutic and research uses of stem cells and also the imperatives for research and therapy.

WHY EMBRYONIC STEM CELLS? Embryonic stem cells were first grown in culture in February 1998 by James A. Thomson of the University of Wisconsin. In November of that year Thomson and his colleagues announced in the journal *Science* that such human embryonic stem cells formed a wide variety of recognizable tissues when transplanted into mice. Roger A. Pedersen, writing in 1999, noted potential applications of these stem cells:

> Research on embryonic stem cells will ultimately lead to techniques for generating cells that can be employed in therapies, not just for heart attacks, but for many conditions in which tissue is damaged.
>
> If it were possible to control the differentiation of human embryonic stem cells in culture the resulting cells could potentially help repair damage

> caused by congestive heart failure, Parkinson's disease, diabetes, and other afflictions. They could prove especially valuable for treating conditions affecting the heart and the islets of the pancreas, which retain few or no stem cells in an adult and so cannot renew themselves naturally.

Stem cells, then, might eventually enable us to grow tailor-made human organs. Furthermore, using cloning technology of the type that produced Dolly the sheep, these organs could be made individually compatible with their designated recipients. In addition to tailor-made organs or parts of organs, such as heart valves, it may be possible to use embryonic stem cells to colonize damaged parts of the body, including the brain, and to promote the repair and regrowth of damaged tissue. These possibilities have long been theoretically understood, but it is only now with the isolation of human embryonic stem cells that their benefits are being seriously considered.

Stem cells for therapy. It is difficult to estimate how many people might benefit from the products of stem cell research should it be permitted and prove fruitful. Most sources agree that the most proximate use of human embryonic stem cell therapy would for Parkinson's disease, a common neurological disease that has a disastrous effect on the quality of life of those afflicted with it. In the United Kingdom around 120,000 individuals have Parkinson's, and the Parkinson's Disease Foundation estimates that the disease affects between 1 million and 1.5 million Americans. Another source speculates that "the true prevalence of idiopathic Parkinson's disease in London may be around 200 per 100,000" (Schrag, Ben-Shlomo, and Quinn). Untold human misery and suffering could be stemmed if Parkinson's disease became treatable. If treatments become available for congestive heart failure and diabetes, for example, and if, as many believe, tailor-made transplant organs will eventually be possible, then literally millions of people worldwide will be treated using stem cell therapy.

When a possible new therapy holds out promise of dramatic cures, caution is of course advised, if only to dampen false hopes of an early treatment. For the sake of all those awaiting therapy, however, it is equally important to pursue the research that might lead to therapy with all vigor. To fail to do so would be to deny people who might benefit the possibility of therapy.

Immortality

Finally we should note the possibility of therapies that would extend life, perhaps even to the point at which humans might become in some sense "immortal." This, albeit futuristic dimension of stem cell research raises important issues that are worth serious consideration. Many scientists now believe that death is not inevitable that that the process whereby cells seem to be programmed to age and die is a contingent "accident" of human development which can in principle and perhaps in fact be reversed and part of that reversal may flow from the regenerative power of stem cells. Immortality has been discussed at length elsewhere but we should, before turning to the ethics of stem cell research and therapy note one important possible consequence of life extending procedures.

Human Evolution and Species Protection

Human Embryonic Stem Cell research in general, but the immortalizing properties of such research in particular raises another acute question. If we become substantially longer lived and healthier, and certainly if we transformed ourselves from "mortals" into "immortals" we would have changed our fundamental nature. One of the common defining characteristics of a human being is our mortality. Indeed in English we are "mortals"—persons; not "immortals" or Gods, demi-gods or devils. Is there then any moral reason to stay as we are simply because it is "as we are"? Is there something sacrosanct about the human life form? Do we have moral reasons against further evolution whether it is "natural" Darwinian evolution, or evolution determined by conscious choice?

One choice that may confront us is as to whether or not to attempt treatments that might enhance human functioning, so-called "enhancement therapies." For example it may be that because of their regenerative capacities stem cells inserted into the brain to repair damage might in a normal brain have the effect of enhancing brain function. Again it would be difficult if the therapies are proved safe in the case of brain damaged patients to resist requests for their use as enhancement therapies. What after all could be unethical about improving brain function? We don't consider it unethical to choose schools on the basis of their (admittedly doubtful) claims to achieve this, why would a more efficient method seem problematic?

We should not of course attempt to change human nature for the worse and we must be very sure that in making any modifications we would in fact be changing it for the better, and that we can do so safely, without unwanted side-effects. However if we could change the genome of human beings, say by adding a new manufactured and synthetic gene sequence which would protect us from most major diseases and allow us to live on average twenty five per cent longer with a healthy life throughout our allotted time, many would want to benefit from this. In high-income countries human beings now do live on average twenty five per cent longer than they did 100 years ago and this is usually cited as an unmitigated advantage of "progress." The point is sometimes made that so long as humans continued to be able to procreate after any modifications, which changed our nature, we would still be, in the biological sense, members of the same species. But, the point is not whether we remain members of the same species in some narrow biological sense but whether we have changed our nature and perhaps with it our conception of normal species functioning.

THE ETHICS OF STEM CELL RESEARCH. Stem cell research is of ethical significance for three major reasons:

1. It will for the foreseeable future involve the use and sacrifice of human embryos.
2. Because of the regenerative properties of stem cells, stem cell therapy may always be more than therapeutic—it may involve the enhancement of human functioning and indeed the extension of the human lifespan.
3. So-called therapeutic cloning, the use of cell nuclear replacement to make the stem cells clones of the genome of their intended recipient, involves the creation of cloned pluripotent (cells that have the power to become almost any part of the resulting organism—hence pluri-potent)and possibly totipotent cells (cells which have the power to become any part of the resulting organism including the whole organism), which some people find objectionable.

In other venues, John Harris has discussed in detail the ethics of genetic enhancement (Harris, 1992, 1998a) and the ethics of cloning (Harris, 1997, 1998b, 1999b). The focus of this entry, however, is on objections to the use of embryos and fetuses as sources of stem cells.

Because aborted fetuses and preimplantation embryos are currently the most promising sources of stem cells for research and therapeutic purposes, the recovery and use of stem cells for current practical purposes seems to turn crucially on the moral status of the embryo and the fetus. There have, however, been a number of developments that show promise for the recovery and use of adult stem cells. It was reported in 2002 that Catherine Verfaillie and her group at the University of Minnesota had successful isolated adult stem cells from bone marrow and that these seemed to have pluripotent properties (capable of development in many ways but not in all ways and not capable of becoming a new separate creature), like most human embryonic stem cells have. Simultaneously, *Nature Online* published a paper from Ron McKay at the U.S. National Institutes of Health showing the promise of embryo-derived cells in the treatment of Parkinson's disease.

Such findings indicate the importance of pursuing both lines of research in parallel. The dangers of abjuring embryo research in the hope that adult stem cells will be found to do the job adequately is highly dangerous and problematic for a number of reasons. First, it is not yet known whether adult cells will prove as good as embryonic cells for therapeutic purposes; there is simply much more accumulated data about and much more therapeutic promise for embryonic stem cells. Second, it might turn out that adult cells will be good for some therapeutic purposes and embryonic stem cells for others. Third, whereas scientists have already discovered that virtually any gene in embryonic stem cells can be modified or replaced, this has not yet been established to hold for adult stem cells. Finally, it would be an irresponsible gamble with human lives to back one source of cells rather than another and to make people wait and possibly die while what is still the less favored source of stem cells is further developed. This means that the ethics of embryonic stem cells is still a vital and pressing problem and cannot for the foreseeable future be bypassed by a concentration on adult stem cells.

RESOLVING THE ETHICS OF RECOVERING STEM CELLS FROM EMBRYOS. There are three more or less contentious ways of resolving the question of whether it is ethically permissible to use the embryo or the fetus as a source of material, including stem cells, for research and therapy. The three methods involve: (1) solving the vexing question of the moral status of the embryo; (2) invoking the principle of waste avoidance; and (3) showing that those who profess to accord full moral status to the embryo either cannot consistently do so or do not in fact believe (despite what they profess) that it has that status. Regarding the first of these, it is difficult to determine whether there will ever be sufficiently convincing arguments available for this question to be finally resolved in the sense of securing the agreement of all rational beings to a particular view of the matter (Harris, 1985, 1999a). Putting aside this contentious issue, then, the other two issues will be discussed below.

The principle of waste avoidance. This widely shared principle states that it is right to benefit people if we can, that it is wrong to harm them, and that faced with the opportunity to use resources for a beneficial purpose when the alternative is that those resources will be wasted, we have powerful moral reasons to avoid waste and do good instead.

That it is surely better to do something good than to do nothing good should be reemphasized. It is difficult to find arguments in support of the idea that it could be better (more ethical) to allow embryonic or fetal material to go to waste than to use it for some good purpose. It must, logically, be better to do something good than to do nothing good, just as it must be better to make good use of something than to allow it to be wasted.

It does not of course follow from this that it is ethical to create embryos specifically for the purposes of deriving stem cells from them. Nevertheless, in all circumstances in which "spare" embryos have been produced that cannot, or will not, be used for reproduction, because they have no chance of developing into normal adult human beings, it must be ethical to use such embryos as sources of stem cells or therapeutic material or for research purposes.

Does anyone really believe that embryos are moral persons? One way in which stem cell research and therapy using human embryos might be successfully defended is to draw a distinction between what people say and what they do, or rather to point out that there may be an inconsistency between the beliefs and values of people as revealed by their statements on the one hand and by the way they behave on the other. Although many people, including most so-called pro-life or right-to-life supporters, are prone to make encouraging noises about the moral importance of embryos, and even sometimes talk as if embryos have, and must be accorded, the same moral status as human adults, such people very seldom, if ever, behave as if they remotely believe any such thing. Taking for the moment as unproblematic the idea, made famous by the Greek philosopher Socrates (c. 470–399 B.C.E.), that "to know the good is to do the good," many pro-life advocates do not behave consistently with their professed beliefs about what is good. A few examples must suffice.

One would expect that those who give full moral status to the embryo, who regard it as a person, would both protect embryos with the same energy and conviction as they would their fellow adults and mourn an embryo's loss with equal solemnity and concern. This, however, they do not do. It is true that some extreme pro-life advocates in the United States have taken to murdering obstetricians who perform abortions, but those same individuals are almost always inconsistent in some or all of the following ways.

For every live birth, up to five embryos die in early miscarriages. Although this fact is widely known and represents massive carnage, pro-life groups have not been active in campaigning for medical research to stem the tide of this terrible slaughter. Equally well known is that, for the same reasons, the menstrual flow of sexually active women often contains embryos. Funeral rights are not usually routinely performed over sanitary towels, although they often contain embryos. In the case of spare embryos created by assisted reproductive technologies, there has not been the creation of a group of pro-life women offering their uteruses as homes for these surplus embryos. In his 1992 book, *Wonderwoman and Superman,* John Harris had to invent a fictitious quasi-religious order of women, "The Sisters of the Embryo," who would stand ready to offer a gestating uterus to receive unwanted embryos because (surprisingly given the large numbers of pro-life women available) there has never been such a movement. Indeed, anyone engaging in unprotected intercourse runs substantial risk of creating an embryo that must die, and yet few people think that this fact affords them a reason either to refrain from unprotected intercourse or to press for medical research to prevent this tragic waste of human life.

Finally, it is notorious that many pro-life supporters, including many Catholics, are prepared to permit abortions in exceptional circumstances, for example, to save the life of the mother or in the case of rape. In the former situation, however, the right course of action for those who believe the embryo has full moral status is to give equal chances to the embryo and the mother (perhaps by tossing a coin) in cases where one may survive but not both. In the case of rape, because the embryo is innocent of the crime and has therefore done nothing to compromise its moral status, the permitting of abortion by those who give full status to the embryo is simply incoherent (Richards).

These cases provide reasons for thinking that even if the views of those who believe the embryo to have the same moral status as normal adult human beings cannot be conclusively shown to be fallacious, it can at least be shown that these views are inconsistent with practice and that the "theory" is therefore not really believed by those who profess it or indeed that it is not actually compatible with the lives that human beings must, of necessity, lead.

Legal and Regulatory Issues

A draft United Nations (UN) convention to prohibit human reproductive cloning seeks to augment the advisory regulatory approach enshrined in the Universal Declaration on the Human Genome and Human Rights. The latter was developed by the United Nations Educational, Scientific and Cultural Organization (UNESCO), adopted unanimously by its 186 states on November 11, 1997, and adopted by the UN General Assembly on March 10, 1999 (via Resolution 53/152). Article 11 of the UNESCO Declaration states (in part): "Practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted." The limitations of this provision were revealed in a report by the director-general of UNESCO. The report concluded that "this prohibition concerns the reproductive cloning of human beings and should not be interpreted as prohibiting other applications of cloning" (UNESCO, 1999, p. 13).

The Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (1997; known as the Convention on Human Rights and Biomedicine), to which the United Kingdom is not a signatory, does provide some form of protection for the human embryo. Thus, Article 18(1) provides the following: "Where the law allows research on embryos in vitro, it shall ensure adequate protection of the embryo," and Article 18(2) states, "The creation of human embryos for research purposes is prohibited." Under Article 36, countries—such as the United Kingdom—that have a preexisting law may make a reservation to the convention based on that existing law. Those countries that have no preexisting law on the embryo and that sign the convention will be hindered or prohibited from sanctioning embryo research, unless they formally withdraw from the convention, pass the new permissive law, and then re-sign (as has happened with Finland and Greece).

In the United Kingdom, the appending of the Human Rights Act of 1998, which brought U.K. domestic law closer to the provisions of the Convention on Human Rights and Biomedicine, has provoked some commentators to focus on the provisions of Article 2 as having potentially significant effect on domestic abortion law and hence the status of the embryo in law. Article 2 stipulates the following: "Everyone's right to life shall be protected by law." Whether this will afford any greater degree of recognition to the fetus, let alone to the embryo, is unlikely.

No European consensus exists on abortion, (or, as Table 1 shows, on embryo research), and the European Commission and the European Court of Human Rights have been reluctant to pronounce substantively on whether the protection in Article 2 of the convention extends to the fetus. In the light of these differing laws, a state will have what is called under European human rights legislation a wide "margin of appreciation" with regard to the convention on the issue of abortion, and hence, it is thought, on the status of the embryo (Decision Reports of the European Commission of Human Rights, Application 17004/90 H v Norway 73 DR 155 (1992) E Com HR.).

The European Court of Human Rights has yet to rule on whether the term *everyone* includes a fetus. In *Open Door Counselling & Dublin Well Woman v. Ireland,* the European Commission had recognized the possibility that Article 2 might in certain circumstances offer protection to a fetus, but they took the point no further.

THE UNITED KINGDOM POSITION. Important distinctions must be drawn in the law's treatment of human cloning. The first distinction is between *reproductive cloning,* which is designed to result in the birth of a live human being genetically identical to another, and *therapeutic cloning,* in which an embryo is cloned for research purposes and will not be permitted to develop into a fetus or a live birth. The second essential distinction is that between two different cloning techniques: The first of these (when applied to *human* cloning) involves replacing the nucleus of an embryonic cell with a nucleus taken from another human embryonic or adult cell, and it is known as cell nuclear replacement (CNR).

The HFE Act of 1990. The Human Fertilisation and Embryology Act of 1990 (HFE Act) contains a clear prohibition on the first technique. Section 3(3)(d) states that a license granted under the act "cannot authorise … replacing a nucleus of a cell of an embryo with a nucleus taken from a cell of any person, embryo or subsequent development of an embryo." CNR, on the other hand, is not *expressly* prohibited by the act, nor is "embryo splitting," a process that can occur naturally at a very early stage of embryonic development, forming identical twins, but which can also be done in vitro to produce identical, cloned embryos. The form of CNR whereby the nucleus of an oocyte is replaced with a nucleus from an *adult* cell was beyond the bounds of scientific credibility when the 1990 legislation was being debated and drafted.

The legal status of CNR in the United Kingdom is, therefore, unclear. The regulatory framework of the HFE Act rests on a definition in section 1(1)(a), in which an embryo is defined as "a live human embryo where fertilisation is complete." This definition's emphasis on the process of fertilization (an emphasis repeated throughout the act) raises the possibility that embryos created by CNR fall outside the scope of the act and that accordingly their creation and use is unregulated. In their 1998 report, *Cloning Issues in Human Reproduction,* the Human Genetics Advisory Commission (HGAC) and the Human Fertilisation and Embryology Authority (HFEA) argued for a *purposive* rather than a *literal* interpretation of the definition. Through such an approach, organisms created by CNR would fall within the statutory definition of *embryo* on the basis that Parliament clearly intended to regulate the creation and use of embryos outside the human body, and that excluding organisms created by

TABLE 1

Legislation on Reproductive/Therapeutic Cloning, Embryo Research, and Stem Cell Research, 2003

Country	Reproductive Cloning Allowed	Therapeutic Cloning (SCNT*) Allowed	(General) Research on Embryos Allowed	Stem Cell Research on Spare Embryos Allowed	Legislative Source(s)
Argentina	No				Decree No. 200 of March 1997: A Prohibition of Human Cloning Research
Australia (federal)	No	No	Yes	Yes	Research Involving Human Embryos Act of 2002; Prohibition of Human Cloning Act of 2002 (Embryos created before April 5, 2002, may be used for stem cell embryo research; Subject to license)
Austria	No	Possibly	No	No	Reproductive Medicine Law of 1992 (Embryos may be created for (Cf. Import) reproductive purposes only)
Brazil			Yes	Yes	Law 8974/95, Normative Instruction by National Technical Committee of Biosecurity
Canada	No	No	Yes	Yes	CIHR Guidelines; Bill C-13, An Act Respecting Assisted Human Reproductive Technologies and Related Research (Surplus embryos only; Subject to license)
Costa Rica		No	No	No	Decree no. 24029-S. A Regulation on Assisted Reproduction, February 3, 1995
Denmark	No	No	No*	No	Act no. 460 of June 10, 1997, on Assisted Procreation *as interpreted by the Danish Council of Ethics
Finland			Yes		Medical Research Act no. 488, April 9. 1999
France	No	No	Yes	Yes	Projet de loi relatif á la bioéthique, tel qu'adopte par l'Assemblée nationale le 22 jan. 2002 (Subject to licence)
Germany	No	No	No	Yes	Embryo Protection Law of 1990; Stem Cell Act of 2002 (Imported stem cell lines created before January 1, 2002; Subject to licence)
Iceland	No	No	Yes	No	Ministry of Health and Social Security, Regulation No. 568/1997 on Artificial Fertilization
Ireland	No	No	No	No	Constitution of Ireland, Article 40, para. 3
Israel	No	Yes	Yes	Yes	Prohibition of Genetic Intervention Law (1999); (Five year moratorium); Bioethics Advisory Committee of the Israel Academy of Sciences and Humanities (Section 8—surplus embryos only)
Japan	No	Yes	Yes	Yes	The Law concerning Regulation Relating to Human Cloning Techniques and Other Similar Techniques (Article 3); The Guidelines for Derivation and Utilization of Human Embryonic Stem Cells (Surplus and created embryos; Subject to license)
Netherlands	No	Yes	Yes	Yes	Act Containing Rules Relating to the Use of Gametes and Embryos (Embryos Act), October 2001
Norway	No	No	No	No	Norwegian Law on Assisted Reproduction and Genetics, 1994
Peru	No	No	No	No	General Law No. 26842 of 9 July 1997 on Health
Russia	No				Law of Reproductive Human Cloning, April 19, 2002
Spain			Yes	Yes	Law no 42/1988 of 28 December 1988 on the Donation and Use of Human Embryos and Fetuses or Their Cells, Tissues, or Organs
Sweden		No	Yes		Law 115 of March 14, 1991, Act Concerning Measures for the Purposes of Research or Treatment in connection with Fertilized Human Oocytes, as interpreted by the Swedish Research Council's Guidelines for Research—Ethical Review of Human Stem Cell Research, December 4, 2001; Swedish Council on Medical Ethics, Statement of Opinion on Embryonic Stem Cell Research, January 17, 2000
Switzerland	No	No?	No	Yes/No?	Constitution fédérale de al Confédération suisse, 1999
United Kingdom	No	Yes	Yes	Yes	Human Reproductive Cloning Act of 2001 (extends to Northern Ireland); Human Fertilisation and Embryology Act of 1990 (Subject to license)
United States		Yes**	Yes**	Yes**	**No federal law to date; no federal funds for embryo research nor for creation of stem cell lines after August 9, 2001

SOURCE: Compiled from various sources by Authors.

CNR from the definition in the HFE Act would frustrate this legislative intention.

It is important here to immediately observe three things:

1. CNR is not specifically prohibited by the HFE Act.
2. The same is true of embryo splitting.
3. The HFEA gave careful consideration to embryo splitting as an additional possible form of infertility treatment in 1994, when its potential use at the two- or four-cell embryonic stage was discussed. After considering the social and ethical issues involved, the HFEA decided to ban embryo splitting as a possible fertility treatment. The HFEA, however, did not make a similar prohibition with respect to CNR research.

Is somatic CNR specifically covered by the wording of section 3(3)(d) of the HFE Act? And, as CNR does not involve fertilization, does section ("No person shall bring about the creation of an embryo … except in pursuance of a licence") 3(1) apply either? Is CNR regulated at all by the HFE Act? At least from a moral point of view, and taking what could be called a purposive or result-oriented approach, it may be possible to reconcile the CNR embryo with embryos created in vitro. From this, it would follow that there is no particular difficulty in accepting the view with which the HFEA works—that the creation of embryos through CNR is *already* brought within the scheme of the HFE Act by an extended interpretation of section 1.

Section 1(1)(a) reads in full: "In this Act, *except where otherwise stated* (a) embryo means a live human embryo where fertilisation is complete" (emphasis added). The emphasized words make it plain that the legislators could have provided otherwise for embryos created other than by in vitro fertilization to be included within the statute, but evidently they did not. To read the statute as providing for embryos created by CNR is to read it as providing that an embryo means a live human embryo where fertilization is complete, *unless the context otherwise requires.*

The* Quintavalle *case. In the early 2000s, a legal challenge by the Pro-Life Alliance, a U.K. lobbying group, tested the question of whether the HFE Act can be interpreted purposively to include organisms produced by CNR. In the High Court (*Regina [on the Application of Quintavalle] v. Secretary of State for Health,* 2001), the claimant submitted simply that an embryo that has not been produced by fertilization cannot be "an embryo where fertilization is complete" in terms of section 1(1)(a) of the HFE Act. The Secretary of State for Health argued for a purposive construction of this section, whereby the definition would be expanded to include embryos produced other than by fertilization. The judge decided that such a purposive approach would "involve an impermissible rewriting and extension of the definition" (*Quintavalle,* 2001, para. 62). In immediate response to this, the government introduced the Human Reproductive Cloning Act of 2001, under which it is an offense to place, in a woman, a human embryo that has been created by any method other than fertilization.

In the Court of Appeal (*Regina [on the Application of Quintavalle] v. Secretary of State for Health,* 2002), the Secretary of State continued to argue that section 1(1)(a) must be given a "strained" construction in order to give effect to the obvious intention of Parliament. The claimant disagreed that the intentions of Parliament with regard to CNR can be thought to have been clear when the technique was unheard of at the time the HFE Act was enacted. Furthermore, the claimant pointed out, had Parliament known of the CNR technique, they may well have decided to include it in the prohibition on cloning included in section 3(3)(d).

In upholding the appeal, the court placed particular emphasis on two considerations. First, it observed the dictum of Lord Wilberforce, in his dissenting judgment in the case of *Royal College of Nursing of the United Kingdom v. Department of Health and Social Security* (1981), that:

> Where a new state of affairs, or a fresh set of facts bearing on policy, comes into existence, the courts have to consider whether they fall within the Parliamentary intention. They may be held to do so, if they fall within the same genus of facts as those to which the expressed policy has been formulated. (*Royal College of Nursing,* p. 822)

The court decided, regarding "genus of facts," that the fact that an embryo was created by fertilization had not been a factor of particular relevance to the desirability of regulation when the HFE Act was envisaged, and that, furthermore, the embryo created by CNR is "morphologically and functionally indistinguishable" (*Quintavalle,* 2002, p. 639) from the embryo created by fertilization. The relevant point was taken to be the capacity to develop into a human being, which is shared by both.

The second point the court emphasized related to the policy of the HFE Act. Rejecting the argument that Parliament's intention was undiscoverable and that CNR, if possible at the time, may have been prohibited under s3(3)(d), the court decided that the rationale behind that prohibition was

> to prevent the production artificially of two or more genetically identical individuals. This policy would be put in jeopardy if the creation and use

> of embryos by cell nuclear replacement were unregulated. It would be furthered by making the production of embryos by cell nuclear replacement subject to the regulatory regime under the Act, for it is inconceivable that the licensing authority would permit such an embryo to be used for the purpose of reproduction. (*Quintavalle,* 2002, pp. 641–642)

In the final appeal to the House of Lords (*Regina [on the Application of Quintavalle] v. Secretary of State for Health* 2003), the decision of the Court of Appeal was unanimously sustained. In his leading judgment Lord Bingham upheld the Court of Appeal's endorsement of the dictum in *Royal College of Nursing,* saying that this "may now be treated as authoritative" (*Quintavalle,* 2003, para. 10). Indeed, following the House of Lords' judgment in *Quintavalle,* the passage in question can be regarded as enshrining a new rule of statutory interpretation.

The House of Lords' decision (and the Court of Appeal ruling that it upheld) is highly contestable, on several grounds. First, the clarity of the statutory language in section 1(1)(a) casts doubt on either court's freedom to use a purposive approach to interpreting it; moreover, the 2001 act prohibiting human reproductive cloning was in force when the appeal was considered, so the court's view that a purposive approach was necessary to prevent the production of genetically identical individuals is surprising. Second, embryos produced by the process prohibited in section 3(3)(d) would *also* be "morphologically and functionally indistinguishable," in the words of the Court of Appeal, from embryos produced by fertilization, just as are embryos produced by CNR, and yet Parliament adopted a different regulatory approach to *their* creation and use. This being so, the assumption that Parliament intended to treat all "morphologically and functionally indistinguishable" embryos alike seems mistaken. Finally, in its consideration of *genus,* the House of Lords seems to have replicated the Court of Appeal's erroneous conflation of the term's legal application (to facts) and its scientific sense.

The current research purposes specified in the HFE Act relate only to research that could be envisaged at that time. It is nevertheless difficult to argue that they were based on immutable moral criteria, and indeed the existence in the HFE Act of the power to broaden the research purposes in due course supports this view. Additional research purposes were in fact added by important new regulations that were enacted in 2001, as is discussed below. In all types of embryo research under consideration it has to be accepted that the embryo cannot itself receive any benefit. The embryo is used instrumentally—as a means to an end—and will be destroyed. This is, in any event, an inevitable outcome for all spare embryos whether donated for research under the currently allowed research purposes or no longer required for treatment. If the arguments of the Warnock Committee (established in 1982 by the U.K. government to report and advise on developments in human fertilization and embryology, in its report published in 1984), are accepted, the issue to be considered is one of balance: whether the research has the potential to lead to significant health benefits for others and whether the use of embryos at a very early stage of their development in such research is necessary to realize those benefits.

The post-*Quintavalle *situation. So far as CNR research within the United Kingdom is concerned, the legislation now draws a line at the point of implantation by prohibiting the placing in a woman of "a human embryo which has been created otherwise than by fertilisation." Until the Court of Appeal reversed the High Court decision, a decision confirmed by the House of Lords, it would not have been unlawful to do CNR work preparatory to implantation. After the reversal, however, research involving CNR embryos is lawful only when authorized by a license granted by the HFEA, and so long as the Human Reproductive Cloning Act remains in place it is inconceivable that the HFEA would license research directed at human reproductive cloning.

A license authorizing specific research under the HFE Act may be granted by the HFEA for a maximum period of three years. Any research license may be made subject to conditions imposed by HFEA and specified in the license, and any authority to bring about the creation of an embryo, keep or use an embryo, or mix human sperm with a hamster or other specified animal's egg may specify how those activities may be carried out. Each research protocol must be shown to relate, broadly, to one of the existing categories of research aim, and then again only if the authority is satisfied that the research is "necessary for the purposes of the research" (Schedule 2, para. 3[5]). These research aims are:

- Promoting advances in the treatment of infertility
- Increasing knowledge about the causes of congenital disease
- Increasing knowledge about the causes of miscarriage
- Developing more effective techniques of contraception
- Developing methods for detecting the presence of gene or chromosome abnormalities in embryos before implantation
- Increasing knowledge about the creation and development of embryos and enabling such knowledge to be applied

The Human Fertilisation and Embryology (Research Purposes) Regulations of 2001 extended these original purposes. These regulations provided for three further purposes for which research licenses may be authorized:

(a) increasing knowledge about the development of embryos;
(b) increasing knowledge about serious disease, or
(c) enabling any such knowledge to be applied in developing treatments for serious disease.

THE EUROPEAN DIMENSION. The Council of Europe's Convention on Human Rights and Biomedicine (1997), along with its Additional Protocol on the Prohibition of Cloning Human Beings (1998), which covers only *reproductive* human cloning, is an important document. Ten of the fifteen EU countries have now signed the convention, despite what some have seen as its (almost necessary) limitations.

The protocol makes what was implicit in the convention explicit by declaring that "[a]ny intervention seeking to create a human being genetically identical to another human being, whether living or dead, is prohibited" (Article 1[1]). Because "genetically identical" is defined as "sharing with another the same nuclear gene set" (Article 1[2]), somatic CNR is included within this prohibition. The term *human being* is not defined in the convention, and because *human being* is unlikely to be interpreted to include embryonic human life, some countries, in signing the convention and its protocol, have added their own interpretative statements. For example, the Netherlands, in doing so, stated that "[i]n relation to Article 1 of the Protocol, the Government of the Kingdom of the Netherlands declares that it interprets the term 'human beings' as referring exclusively to a human individual, i.e., a human being who has been born."

In its report titled "Ethical Aspects of Human Stem Cell Research and Use," however, the European Group on Ethics in Science and New Technologies advised that, at present, "the creation of embryos by somatic cell nuclear transfer ['therapeutic cloning'] for research on stem cell therapy would be premature" because there are alternative sources of human stem cells.

EXAMPLES OF OTHER JURISDICTIONS' LEGAL APPROACHES. In the United States, regulation of human cloning and embryo research has been undertaken or debated at both the national and state levels. At the federal level, there is a rigid separation between the public and private sectors. Little if any regulation applies to research involving the use of human embryos if it is funded by the private sector, although the U.S. Food and Drug Administration has asserted jurisdiction over reproductive cloning whenever safety issues are raised.

Federal attempts to regulate cloning have the support of President George W. Bush, who, on April 10, 2002, called on the U.S. Senate to endorse the Human Cloning Prohibition Act, which would ban all human cloning in the United States, including the cloning of embryos for research. This bill was nearly identical to the bipartisan legislation that passed the U.S. House of Representatives by more than a 100-vote margin in 2001.

This announcement supplemented the one issued on August 9, 2001, regarding stem cell research. In the latter, Bush resolved that federal funding of research using the more than sixty existing stem cell lines from genetically diverse populations around the world that have already been derived would be permitted, but that he would not sanction or encourage the destruction of additional human embryos. Henceforth, federal funds could be used only for research on existing stem cell lines that were derived: (1) with the informed consent of the donors; (2) from excess embryos created solely for reproductive purposes; and (3) without any financial inducements to the donors. In order to ensure that federal funds are used to support only stem cell research that is scientifically sound, legal, and ethical, the U.S. National Institutes of Health was charged with examining the derivation of all existing stem cell lines and creating a registry of those lines that satisfy these criteria. A further result was that federal funds cannot be used for: (1) the derivation or use of stem cell lines derived from newly destroyed embryos; (2) the creation of any human embryos for research purposes; or (3) the cloning of human embryos for any purpose.

In Canada, a similar approach was taken in February 2002. In Australia, the Research Involving Embryos and Prohibition of Human Cloning Act of 2002 was introduced into Federal Parliament in June 2002. There are three main elements to the bill: a ban on human cloning, a ban on certain other practices relating to reproductive technologies, and a system of regulatory oversight for the use of excess embryos created through assisted reproductive technologies that would otherwise have been destroyed. The legislation would establish a system of licensing, administered by the National Health and Medical Research Council.

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SEE ALSO: *Abortion: Medical Perspectives; Cloning; Feminism; Fetal Research; Human Dignity; Infants; Infanticide;*

Maternal-Fetal Relationship; Moral Status; Reproductive Technologies: Ethical Issues; Research Policy: Risk and Vulnerable Groups; Research, Unethical; Transhumanism and Posthumanism; and other *Embryo and Fetus* subentries

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IV. RELIGIOUS PERSPECTIVES

Even for those who are not actively religious, nascent human life evokes awe and a sense of being in the presence of primal powers of creation. In the procreation of all species, from plants to domestic pets, religious consciousness often senses the divine at play in the natural. In human procreation in particular, human beings not only observe but also participate in that power, and by conceiving and giving birth humans play a small but profoundly personal role in creation.

There is little wonder, then, that for millennia, religious texts have spoken of human procreation with tones of wonder. In the Hebrew Scriptures, Psalm 139 reads in part:

> For thou didst form my inward parts,
> thou didst knit me together in my mother's womb.
> I praise thee, for thou art fearful and wonderful.
> Wonderful are thy works!
> Thou knowest me right well;
> my frame was not hidden from thee,
> when I was being made in secret,
> intricately wrought in the depths of the earth.
> Thy eyes beheld my unformed substance … (Psalms 139:13–16a)

In ancient Hebrew thought, procreation is the realm of divine prerogative. The protracted struggle for monotheism is in part a rejection of the idea, probably widespread in the ancient world, that fertility is itself divine. Hebrew monotheism could not tolerate lesser gods, such as fertility. In the name of one God, the prophets insisted that though mysterious, fertility is one of many processes of nature entirely under God's control. Various forms of polytheism in the ancient world saw these processes as deities in themselves, often female, and the success of monotheism is in some respects a desacralization and a defeminization of these processes. But such a desacralization goes only so far. For the ancient Hebrew monotheist, the one supreme God is intimately and personally present in these processes, making them anything but merely natural.

From Creation to Procreation

As an arena of divine presence, nascent life must be held in respect, for if it is God's work, its development must not be thwarted nor its condition questioned. According to the prophet Isaiah, God declares:

> Woe to you who strive with your Maker,
> earthen vessels with the potter!
> Does the clay say to the one who fashions it, "What are you making"?
> or "Your work has no handles"?
> Woe to anyone who says to a father, "What are you begetting?"
> Or to a woman, "With what are you in labor?" (Isa. 45:9–10)

Because procreation is the work of God, it is unseemly to question how or when it occurs, much less speculate about God's competence in making humankind.

Ancient biblical culture is also characterized by the command to propagate (Genesis 1:28) and thus by a strongly reinforced desire for children. In addition to any innate yearning or social pressure for offspring, the infertile in biblical culture no doubt feared being seen as disobedient, and several biblical stories contain impassioned pleas for children. The most notably such plea is that of postmenopausal Sarah, the wife of Abraham, who according to the story subsequently gives birth to Isaac from whom all Israel descends. That God can cause this to happen against nature is taken as evidence of God's supremacy over nature.

In view of the involvement of God in procreation and of the command to populate the earth, it is somewhat surprising that Hebrew Scripture says little or nothing about the moral status of human life in utero. Exodus, chapter 21, discusses the legal consequences that follow from an accidental miscarriage: "When men strive together, and hurt a woman with child, so that there is a miscarriage, and yet no harm follows, the one who hurt her shall be fined, according as the woman's husband shall lay upon him; and he shall pay as the judges determine. If any harm follows, then you shall give life for life …" (Exod. 21: 22–23).

While the text leaves much unsaid, it does prescribe different penalties for causing a miscarriage (a fine) and for causing the women's death (a capital offense), suggesting that these are offenses of a substantially different magnitude. Strictly speaking the scope here is limited to miscarriage or unintentional abortion, so its applicability to an intended abortion is subject to debate.

Early Judaism

In Judaism at the beginning of the common era, this text was interpreted in various ways. In most interpretations, developing life was not generally regarded as possessing the legal status of a person, but abortion was nonetheless opposed, in part because of its interference with creation, in part because it violated the command to reproduce, and in part because it deprived the family (in particular the father) of something of value in the birth of another child. Generally speaking, Judaism objected to the widespread acceptance of abortion (and even of infanticide) in the ancient world, even if it did not see abortion as a highly serious offense.

In the translation of this Hebrew text into Greek, a significant mistranslation occurred. Where the original says "no harm," the translators substituted "no form," thereby introducing into religious debate the distinction between the unformed and the formed fetus. The widely influential Jewish scholar Philo (c. 20 B.C.E.–c. 50 C.E.), for instance, distinguished between formed and unformed fetus, and early Christianity picked up this distinction.

Christian Origins

The New Testament itself takes no position on abortion or on the status of embryonic or fetal life, although some scholars feel that negative references to *pharmakeia* in several passages specifically refer to abortifacient drugs and not to medicine generally. As in Judaism, the core Scriptures of Christianity ignore the moral questions of fetal life and of abortion. But to say that because the New Testament does not address abortion, it says nothing *theological* about fetal life, is wrong. Two of the four Gospels (Matthew and Luke) devote substantial attention to the miraculous conception not just of Jesus but also of his forerunner, John the Baptist. According to the story, John's mother Elizabeth is too old to conceive, but in keeping with a tradition that goes back to Sarah, she conceives because of God's involvement and for the sake of God's purposes. Mary, the mother of Jesus, is Elizabeth's cousin, and in the story of the "virgin birth" (or more precisely the "virginal conception") the tradition of miraculous conceptions reaches its culmination. God is so immediately involved in the details of this human conception that a human sperm is replaced by a miracle. The virgin birth is often the subject of theological puzzlement by scholars but is widely, if only sentimentally, affirmed by many ordinary Christians to this day. One must not underestimate the significance of this tradition in forming Christian attitudes toward embryonic and fetal life.

Not unexpectedly, therefore, as Christianity developed and distinguished itself from Judaism, it opposed abortion more strongly than Judaism or than the teachings of the New Testament itself. In some early post–New Testament writings, abortion is equated with murder. For instance, an early writing known as the *Didache* comments on abortion by listing it among the commandments: "You shall not commit murder … you shall not murder a child by abortion nor kill that which is born" (2:2). This text not only prohibits abortion, but, by identifying it with murder, also implies that fetal life is fully human or personal. Another early text, the *Letter of Barnabas,* uses essentially the same terms: "Thou shalt not kill the fetus by an abortion or commit infanticide" (19:5). These texts, critically important in shaping the early Christian conscience, expressed agreement in considering abortion as murder and as elevating its prohibition to the status of commandment. Furthermore, the claim that God is fully present in the human life of Jesus, even in utero, at once divided Christian from Jew and drove the Christian to a new consciousness of the value of nascent life.

Form and Soul

Even so, early Christian writers often retained the distinction between the formed and unformed fetus, implying that the unformed fetus possesses a lesser status than one that is fully formed. One of the first Latin Christian theologians, Tertullian, who lived around 200 C.E., opposed abortion but implied in his writings that there is a distinction of significance between the formed and unformed embryo. In chapter 37 of his treatise *On the Soul,* Tertullian wrote: "The embryo therefore becomes a human being in the womb from the moment that its form is completed."

One way to defend the distinction between formed and unformed is to hold that the human soul is added to the developing fetus when it attains a recognizably human shape. The metaphysics of the fourth century B.C.E. Greek philosopher Aristotle, which links soul and form, was often used here for support. Thus, what begins as an empirical question—does the fetus have a human shape?—becomes entwined with a religious and metaphysical question of whether the fetus has a soul, and at what stage this is so. The joining of the soul to the developing organism, a process called ensoulment, thus became a subject of intense religious debate among Christian theologians.

This debate was never resolved and in fact quickly became entangled in conflicting Christian views of the human soul, its origin, and the nature of its relationship to the human body, all set against the backdrop of competing philosophical options. In this regard Tertullian held a view peculiar among Christians that the soul is not a spiritual but a material substance and is transmitted sexually rather than created by God. Most other theologians of the early church saw the soul as a spiritual substance. In contrast, however, to philosophical views that accepted a dualism of soul and body, Christian theologians generally agreed that body and soul, though metaphysically distinct, are functionally inseparable. In death, the soul is not freed from the body, as the Greek philosopher Plato (c. 428–c. 347 B.C.E.) contended, but awaits the resurrection of the body in order that both soul and body might be transformed together into a glorified mode of immortal existence. Speculation about ensoulment, therefore, was always grounded on this insistence on the unity of soul with body.

Unity of Soul and Body

The widely influential Gregory of Nyssa (c. 335–c. 394), for instance, held so strongly to the unity of soul and body that he could not imagine the body developing at all without the soul being present. In a work called *On the Making of Man,* Gregory wrote: "As man is one, the being consisting of soul and body, we are to suppose that the beginning of his existence is one, common to both parts so that it is not true to say either that the soul exists before the body, or that the body exists without the soul, but that there is one beginning of both" (chap. 29). According to Gregory, at every stage of human development, from inception to resurrection, body and soul function as one.

In the same work, Gregory elaborates on the development of the soul with the body:

> For as the body proceeds from a very small original to the perfect state, so also the operation of the soul, growing in correspondence with the subject, gains and increases with it. For at its first formation there comes first of all its power of growth and nutriment alone, as though it were some root buried in the ground; for the limited nature of the recipient does not admit of more; then, as the plant comes forth to the light and shows its shoot to the sun, the gift of sensibility blossoms in addition, but when at last it is ripened and has grown up to its proper height, the power of reason begins to shine forth like a fruit, not appearing in its whole vigour all at once, but by care increasing with the perfection of the instrument, bearing always as much fruit as the powers of the subject allow. (chap. 29)

In Gregory's view, there is no moment or process of ensoulment subsequent to conception. Existence and ensoulment are one.

Augustine's Options

As Gregory of Nyssa profoundly influenced the development of Greek Christianity and thus of the subsequent Orthodox Churches, so Augustine (354–430) deeply shaped Western or Latin Christianity, which at the Reformation (beginning about 1520) became Catholicism and Protestantism. Augustine, whose influence can scarcely be exaggerated, accepted the distinction between the formed and unformed fetus. In addition he tended to be more dualistic in his thinking, and he therefore accepted greater discontinuity between soul and body than did Gregory or other Eastern theologians.

Although Augustine was not generally indecisive on theological and moral matters, he remained undecided throughout his life on the question of the origin of the human soul and the way it is joined with the human body. One possibility (called *creationism*) is that God creates the soul at around the time of conception or somewhat later and joins it to the developing body. By allowing separate origins for the soul and the body, this view makes possible the idea that for a time, the body develops without a human soul being present, something Gregory flatly rejected. The other possibility that Augustine considered (called *traducianism*) is that soul and body come into existence together, that is to say, at conception, when both are transmitted together from one generation to the next. Tertullian accepted traducianism, and perhaps for that reason, other Western theologians see it as degrading the soul by making it material rather than spiritual in substance.

Both Augustine's indecision and his speculations remain influential in Western Christianity. Concerning the pastoral question of whether the results of miscarriage or abortion will share in the general human destiny of immortality, Augustine wrote in the *Enchiridion:*

> … with respect to the resurrection of the body … comes the question about abortive fetuses, which are indeed "born" in the mother's womb, but are never so that they could be "reborn." For, if we say that there is a resurrection for them, then we can agree that at least as much is true of fetuses that are fully formed. But, with regard to undeveloped fetuses, who would not more readily think that they perish, like seeds that did not germinate? (23:84–85)

Here Augustine accepts the distinction between formed and unformed and uses it in the ultimate theological context—the question of what is human in the resurrection. He also uses it to clarify his opposition to abortion. For him, destroying the formed fetus is murder, whereas destroying the unformed fetus is a lesser offense.

When it comes to the deeper theoretical question of the beginning of human life, Augustine admits his uncertainty in the *Enchiridion:*

> On this score, a corollary question may be most carefully discussed by the most learned men, and still I do not know that any man can answer it, namely: When does a human being begin to live in the womb? Is there some form of hidden life, not yet apparent in the motions of a living thing? To

> deny, for example, that those fetuses ever lived at all which are cut away limb by limb and cast out of the wombs of pregnant women, lest the mothers die also if the fetuses were left there dead, would seem much too rash. (23:86)

The Development of Catholic Thought

In time creationism, with its dualistic tendencies, became the majority view in the Western or Latin church, and it was often combined with the idea that the soul was not joined to the body until formation. The reintroduction of Aristotle into Western thought brought new subtleties to the discussion. Thomas Aquinas, whose integration of Aristotle into Christian theology in the thirteenth century was at first controversial but was subsequently seen as authoritative for Catholics, combined creationism with the view that the soul undergoes transition. At its beginning, the embryo does not have a human soul, merely the kind of soul common to all forms of life and responsible for growth and development. Only when fetal development advances to a stage that resembles human form is it possible for the human soul to be present. The human or intellectual soul is immaterial and must be created by God, who joins it to the developing fetus. At that moment of ensoulment, the fetus becomes human or attains hominization, and its moral claim to life is absolute.

Thomas's position is dependent upon an empirical observation of Aristotle, who concluded that the human soul is present at forty days after conception for males and ninety for females. Because the soul was thought to animate the body, "quickening," or the feeling of fetal movement, was taken as a sign that ensoulment had occurred. Until 1869, the Catholic Church recognized a distinction between the ensouled and the unensouled fetus, insisting on a higher penalty for the destruction of the former.

Into the Modern Era

Protestantism, which in its various forms became separate from the Catholic Church in the sixteenth century, tended to take a more strict view against abortion than the Catholics, opposite to the modern situation. This is perhaps because of the Protestant return to early church standards and its rejection of much of the previous thousand years of church tradition, particularly in philosophical theology. Early followers of Martin Luther and John Calvin (leaders of the Reformation) held views that resembled those of Gregory of Nyssa more than those of Thomas Aquinas. In time, however, theological and philosophical considerations reentered Protestant discussion, along with both an encounter with new scientific discoveries in biology and embryology and a general tendency in Protestantism to accommodate contemporary culture whenever reasonably possible. As a result, by the twentieth century, Protestantism was largely tolerant of abortion even while discouraging its members from obtaining one for less than urgent reasons.

During this same period, Catholic teaching moved in the opposite direction. Scientific discoveries (and in some cases, misinterpretation of data, such as the view that the earliest embryo is fully shaped like a tiny human being) led Catholic theologians to challenge their own previous view of delayed hominization and to propose in its place a new theory of immediate hominization. This idea gained popularity after 1700, until, in 1869, Catholic canon law removed the distinction between the ensouled and the unensouled fetus, thereby implying but not asserting that immediate hominization is the correct view. The key point, however, is that the abortion of an unformed fetus is to be regarded as the moral equivalent of the abortion of a formed fetus, and therefore abortion is murder at any stage. With this development, Catholic moral teaching became absolute, whereas Catholic theology remained somewhat open to various perspectives on the metaphysical status of the embryo. As a result, Catholic morals and theology developed somewhat independently, based in part on the claim that moral certainty does not require doctrinal clarity.

Current Catholic Teaching

In 1987 the Catholic Church provided guidance on reproductive medicine and embryo research in *Donum vitae* (Respect for human life). *Donum vitae* poses and then answers a key question: "how could a human individual not be a human person? The Magisterium has not expressly committed itself to an affirmation of a philosophical nature, but it constantly reaffirms the moral condemnation of any kind of procured abortion" (Congregation for the Doctrine of the Faith, 1987, part I, no. 1). In other words, immediate hominization is not affirmed doctrinally but its implications are fully asserted morally, not just for abortion some weeks into a pregnancy but in regard to the embryo at the earliest moment. *Donum vitae* insists:

> The human being must be respected—as a person—from the very first instant of his existence.… Thus the fruit of human generation, from the first moment of its existence, that is to say from the moment the zygote has formed, demands the unconditional respect that is morally due to the human being in his bodily and spiritual totality. The human being is to be respected and treated as a person from the moment of conception; and therefore from that same moment his rights as a person must be recognized, among which in the first place

> is the inviolable right of every innocent human being to life. (Congregation for the Doctrine of the Faith, 1987, part I, no. 1)

Again asserting moral certainty while avoiding doctrinal conclusiveness, the Catholic Church in 1974 issued its *Declaration on Procured Abortion,* which states: "This declaration expressly leaves aside the question of the moment when the spiritual soul is infused. There is not a unanimous tradition on this point and authors are as yet in disagreement" (Sacred Congregation, p. 13). This statement almost invites debate on dogma while shutting the door to reconsideration of moral teaching.

Dogma and Debate

The discussion of the theology of nascent human life has been vigorous among Catholic scholars and some Protestants. Recent scientific discoveries in genetics and embryology have been considered in the debate, particularly relating to whether the human embryo prior to about fourteen days can be said to be an individual. There is general agreement, according to a 1984 article by Carol A. Tauer, that "the stage of individual has been seen as a morally relevant marker because it appears that only individuals can be wrongfully killed or otherwise injured" (p. 5).

While genetics and embryology support the idea that the newly conceived embryo is a genetically unique human life, three other biological considerations have been raised to argue against the idea that the early embryo is an individual: The embryo might divide into two (twinning); an embryo might join with another genetically unique embryo to form a chimera, which then continues to develop as one human individual; and as many as 75 percent of all human conceptions fail to survive. In a 1990 article, Thomas A. Shannon and Allan B. Wolter argued that "something human and individual is not a human person until he or she is a human individual, that is, not until after the process of individual is completed. Neither the zygote nor the blastocyst is an ontological individual, even though it is genetically unique and distinct from the parents" (p. 613).

A related question is whether the embryo, which lacks most human qualities, nonetheless typically anticipates their development and thus must be said to possess them potentially, or to have potentiality. If so, does that potentiality confer a status to the embryo as one who must be regarded morally as already possessing what is only its potential? Furthermore, if the embryo is out of the body (and thus unable to actualize its potential), does it possess a lower status? Or if the embryo is somehow biologically incapable of developing, either because of a natural or technologically induced impairment, does it likewise lack whatever value potentiality confers? These questions remain open.

Given that Catholic theologians hold various views on the individuation or personhood of the embryo, how can Catholic moral certainty be possible? Much depends, of course, on the conclusion one draws from the variety of views. One might conclude that when various views are held, one should err on the side of caution, give the embryo the benefit of any doubt, and treat it as if it were a human person. Others conclude that in light of the evidence, it cannot be a human person and that therefore, aside from the authority of the church, there is no obligation to treat it as such.

Protestant Perspectives

Protestants, in the late-twentieth century, were generally supportive of the right of women to choose an abortion, even though they adopted a cautious approach of limiting to the most serious reasons the circumstances under which this right could be exercised. For instance, the Presbyterian Church (U.S.A.), in a 2000 publication, outlined a position similar to that of other traditional denominations:

> The considered decision of a woman to terminate a pregnancy can be a morally acceptable, though certainly not the only or required, decision. Possible justifying circumstances would include medical indications of severe physical or mental deformity, conception as a result of rape or incest, or conditions under which the physical or mental health of either woman or child would be gravely threatened. (p. 431)

This is not to suggest that the members of these denominations are in strong agreement with the official position, and in fact there is some reason to believe that support for these positions is eroding. In addition, the character of Protestantism has been changing in the United States, with the rapid growth of evangelical, independent, and charismatic churches that often criticize traditional denominations for being too accommodating to secular culture on matters such as abortion. As a result, even those who fully support the right of women to choose an abortion as a matter of public policy are recognizing that at the same time, they must acknowledge the moral value of what is lost. Furthermore, some African-American Christians are suspicious of abortion for the additional reason that it appears to them to be a way to limit their numbers.

Prominent Protestants have also stood in opposition to abortion. Karl Barth, often seen as the most important Protestant theologian of the twentieth century, objected to abortion, while Stanley Hauerwas, perhaps the most influential Protestant theologian in the United States at the beginning of the twenty-first century, is also critical of abortion along with other accommodations to modern culture.

Whether tolerating abortion under limited circumstances or condemning it in almost all cases, contemporary Protestants tend to agree among themselves that questions of ensoulment are too dualistic for Christian faith, at least in its Biblical roots. They see human life, as a whole and from beginning to end, as a gift of God that we dare not refuse lest we reject our own humanity. In some respects the views of recent Protestants have more in common with those of Gregory of Nyssa than with recent Catholic debate, and thus Protestants agree with Orthodox theologian John Breck's assessment that Orthodoxy would "take issue with the Catholic Church's doctrine of ensoulment, at least as it has been expressed in Aristotelian and Thomistic terms … [as] dualistic to Orthodox ears" (p. 140). While Orthodoxy has no doubt about when the unitary gift of human life begins (that is, at conception), Protestants by virtue of their institutional structure and communal ethos will surely continue to disagree, some siding with Orthodoxy and practically with Catholicism, others siding with Judaism and Islam.

Special notice should be paid to the perspective of the Church of Jesus Christ of Latter Day Saints, commonly known as the Mormons. While dependent in many ways upon the views of Christianity and Judaism, and sharing scriptures with these traditions, Mormonism develops a somewhat distinct view. Mormons have tended to be restrictive if not prohibitive on abortion, although not necessarily seeing it as murder. Furthermore, as Lester E. Bush observes, Mormonism does not hold to a dogma on the embryo or the fetus, but tends to see each human person or soul as the dynamic interplay between the biological and the spiritual. Somewhere in the process of fetal development, usually at quickening or at birth but not at conception, spirit is present and thus the developing life is a person deserving absolute protection. Given the size of the Latter Day Saints, these views have considerable political significance in the United States.

Judaism, Islam, and Buddhism

Judaism is generally tolerant of the public policy of choice in abortion but teaches that abortion should be chosen only for compelling reasons. It does not regard abortion as murder, however, and it is open to the prospect of using human embryos in research and therapy because it regards the embryo outside the body as having no legal standing. In fact, even in the body, the embryo's status for the first forty days, according to the Talmud, is "as if it were simply water" (Dorff, 2002). As a result, Judaism is supportive not just of in vitro fertilization but of more recent developments such as preimplantation genetic diagnosis.

Islam bases its understanding of developing human life on the section in the Koran (23:12–16) that describes human creation as beginning with a tiny drop from which the larger and more complex structure of the fetus is fashioned by God the creator, who breathes life into what is formed. Islam thus sees each human life as created by God through a developmental process. Islamic scholars sometimes distinguish between the ensouled and the unensouled fetus, often arriving at the end of the fourth month as the point in fetal development when abortion is no longer permissible for any reason.

Other Islamic scholars argue that recent scientific discoveries demonstrate that the embryo is alive from the earliest moment and thus deserves full protection, but the more common and traditional view is to accord legal status as a person only after the form is recognizable and movement is voluntary. When it comes to the use of genetic or reproductive technology, Islam is guided primarily by the general context in which the technology is applied rather than by the technology considered abstractly. If reproductive technology serves the goal of health within the context of marriage, it is permitted; if not, it is rejected.

Detailed theological and moral discussion of topics such as abortion, the beginning of life, and embryo research is far more characteristic of the Western monotheisms (particularly Christianity) than of the other great religions. In Buddhism, however, rich conceptual and practical traditions have made it possible for some countries such as Japan to address abortion without the divisiveness characteristic of the West. The first of the Five Precepts of Buddhism is the prohibition against taking life, including embryonic life. While there is some traditional debate in Buddhism about when reincarnate life is present in the developing fetus, for the most part Buddhists agree that abortion is always wrong. At the same time, what is wrong is also sometimes necessary, but that does not make the act less wrong or the loss less tragic. On the one hand, there is the moral teaching, quoted by James Hughes as follows: "It is the woman carrying the fetus, and no one else, who must in the end make this most difficult decision and live with it for the rest of her life. As Buddhists, we can only encourage her to make a decision that is both thoughtful and compassionate" (Hughes, p. 191). But on the other hand, in Japan in particular, fetal loss of any sort is mourned and observed with ritual and remembrance (*mizuko*) far more than in the Christian West. Similar traditions are found in Thailand and Vietnam. Far from legitimizing abortion through religious sanction, these rituals help to maintain the Buddhist prohibition against taking even fetal life even in a social context that occasionally requires just this act.

New Technologies

Religious ideas about nascent human life were developed long before modern science opened up the fields of genetics or embryology and prior to technology making the embryo an object of manipulation. These new developments bear on religious understandings, and religious perspectives are likewise brought to bear in assessing the legitimacy of various technological options, such as in vitro fertilization, prenatal genetic testing, preimplantation genetic diagnosis, cloning, and embryonic stem cells.

The responses of various religious traditions to these developments are largely outgrowths of classic positions and thus predictable. Catholic teaching objects to any attempt to move procreation outside its natural context and thus opposes in vitro fertilization. Because of its uncompromising objection to abortion, *Donum vitae* objects to prenatal genetic diagnosis unless limited to healing the individual: "But this diagnosis is gravely opposed to the moral law when it is done with the thought of possibly inducing an abortion" (part I, no. 2). Judaism, Islam, and Protestantism generally permit in vitro procedures and also allow, with practical reservations, prenatal genetic diagnosis.

Preimplantation genetic diagnosis, which involves in vitro fertilization followed by a genetic test of the embryos to determine the most healthy for implantation, is likewise rejected by Catholic teaching but accepted by others, although the cost factor raises religious concerns for social justice.

Cloned Embryos

Reproductive cloning is widely condemned by religious institutions and by nearly all religious scholars, but use of the cloning technique (somatic cell nuclear transfer) to create embryos for research purposes is permitted under some religious grounds while being strongly condemned under others. Catholic teaching clearly forbids any form of embryo research that destroys the embryo, cloned or otherwise. According to the Pontifical Academy for Life, "The ablation of the inner cell mass (ICM) of the blastocyst, which critically and irremediably damages the human embryo, curtailing its development, is a gravely immoral act and consequently is gravely illicit."

In similar terms, the conservative Protestant Southern Baptist Convention, at its national meeting in 1999, stated: "[we] reaffirm our vigorous opposition to the destruction of innocent human life, including the destruction of human embryos." The opposite position, however, is taken by the Presbyterian Church (U.S.A.), which declared in 2001: "With careful regulation, we affirm the use of human stem cell tissue for research that may result in the restoring of health to those suffering from serious illness. We affirm our support for stem cell research, recognizing that this research moves to a new and challenging frontier."

On this, the Presbyterian position (shared by some other similar denominations) is substantially indistinguishable from that of Judaism. An example of the latter is found in a joint statement offered by the heads of the various branches of Judaism in the United States. This statement begins by stressing the God-given human role in mending the creation: "The Torah commands us to treat and cure the ill and to defeat disease wherever possible; to do this is to be the Creator's partner in safeguarding the created" (Union of Orthodox Jewish Congregations of America and the Rabbinical Council of America, 2002). To this end, humans are permitted to use human embryos in research, for "our tradition states that an embryo in vitro does not enjoy the full status of human-hood and its attendant protections. Thus, if cloning technology research advances our ability to heal humans with greater success, it ought to be pursued since it does not require or encourage the destruction of life in the process" (Union of Orthodox Jewish Congregations of America and the Rabbinical Council of America, 2002). Reproductive cloning, however, is opposed, and therefore careful oversight of research must be in place.

At the beginning of the twenty-first century, it appears possible to create human embryos by nuclear transfer, embryo splitting, or by a process usually called parthenogenesis by which researchers induce an egg to start dividing like an embryo without fertilization. In each of these processes, something like an embryo comes into existence without fertilization or conception in the usual sense. If an embryo strictly speaking is the result of conception, then these entities are not embryos. One cannot imagine, however, that those who hold passionately to the slogan that "life begins at conception" will not modify their rhetoric to say that life begins at conception or anything that replaces conception.

A deeper issue is whether these entities, even if implanted, have the biological potential to develop into a human life. In some cases, probably most, it will turn out that they lack this potential. If so, will they be seen as embryo-like but as sub-embryos, morally speaking? Surely, some out of religious conviction will defend their status as "one of us" or as fully human. In time, however, technology may find even more ways to create entities that function in some ways like embryos but in other ways fail as their biological equivalent, and so religious, moral, and policy distinctions are inevitable.

Conclusion

Far from being relics of a prescientific era, the religions today, even in their disagreements, serve to focus both our awe at the mysteries of our humanity and our anxieties about our future. Religious traditions, which are anything but changeless, will probably continue to adapt to our changing knowledge of ourselves and our growing powers to modify our nature. In so doing, through doctrinal argument and moral warning, they will perhaps shed some light on our biological origins and on our technological destiny.

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SEE ALSO: *African Religions; Bioethics, African-American Perspectives; Buddhism, Bioethics in; Christianity, Bioethics in; Daoism, Bioethics in; Eugenics and Religious Law; Islam, Bioethics in; Jainism, Bioethics in; Judaism, Bioethics in; Medical Ethics, History of Europe; Mormonism, Bioethics in; Native American Religions, Bioethics in; Reproductive Technologies; Sikhism, Bioethics in; Transhumanism and Posthumanism;* and other *Embryo and Fetus* subentries

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EMOTIONS

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In bioethics, as in ethics more generally, there is much debate about the significance of emotions in an account of moral character. Intuitively speaking, emotions are important because as moral beings we care not only about how we act but also about how we feel—what our moods are, as well as our attitudes and affects. Within the practice of healthcare, the emotions of compassion and empathy seem to have a particularly important place in a full description of decent and ethical treatment of a patient. The general point is not that emotion is internal and action external, because both action and emotion have exterior moments that point to deeper interior states, commonly thought of as character. Rather, emotions are important as modes of sensitivity that record what is morally salient and that then communicate those concerns to self and others. Thus, to grieve, pity, show empathy, or love is to focus on an aspect of self or other and to grasp information to which purer cognition or thought may not have access. Generally put, different emotions are sensitive to different kinds of salience. In the case of grief, what is salient is that humans suffer and face loss; in the case of pity, that they sometimes fail through blameless ignorance, duress, sickness, or accident; in the case of empathy, that they need the expressed support and union of others who can understand and identify with them; and in the case of love that they find certain individuals attractive and worthy of their time and attention.

In relations in which caring for others is definitive, emotional sensitivity plays a powerful role. In choosing physicians, for example, people tend to value medical skill and ability deeply, but value character and judgment as well. And part of what people look for in character and judgment is not just reliable and principled action but also a certain range of emotional responsiveness. Medical care ministered without human gesture may simply not be received in the same way as that conveyed through compassion and empathy. A physician’s sensitivity to a patient’s needs, worries, and fears is often also relevant to diagnosis, just as the physician’s communication of emotions may be relevant to how a patient confronts illness and recovery. As in any relationship, emotional interaction is part of the exchange. In more intimate friendships, we hope that loved ones will be able to respond to our joy and suffering in more than merely intellectual ways and that they will communicate feelings through spontaneous affect and gesture as well as more deliberate action.

What Are Emotions?

In general terms, then, emotional sensitivity is a moral feature of personal interaction. But what are emotions? It is useful to first review some alternative views.

The first is the commonsense view in which emotion is thought to be an irreducible quality of feeling or sensation. It may be caused by physical states, but the emotion itself is the sensation we feel when we are in that state. It is a felt affect, a distinctive feeling, but not something dependent upon thought content or appraisals of situations. This view quickly appears faulty, however, when one realizes that on this view emotions become no more than private states—sensations such as itches and tickles that have little to do with what the emotions are about and how a person construes or represents those affairs.

A second view, associated with the American psychologist and philosopher William James and Danish physiologist Carl Lange is that emotions are an awareness of bodily changes in the musculature and viscera. We are afraid because we tremble or flee, not the other way around; likewise, we are angry because of the knots in our stomachs. This view, though rather counterintuitive, nonetheless captures the idea that emotions, more than other mental states, seem to have conspicuous physiological and kinesthetic components. These often dominate children’s and adults’ reports of their emotional experiences. They dominate the literary world, too. Consider in this vein the lines of the Greek poet Sappho composed around 600 B.C.E.:

When I see you, my voice fails,
my tongue is paralyzed,
a fiery fever runs through my whole body
my eyes are swimming,
and can see nothing
my ears are filled with a throbbing din
I am shivering all over …

Literary history, social convention, and perhaps evolution conspire to tell us this is love. But even here it is not hard to imagine that what is described could be dread or awe or perhaps, mystical inspiration. Even well-honed physiological feelings do not easily identify specific emotions. An awareness of our skin tingling or our chest constricting or our readiness to flee or fight do not specify just what emotion we are feeling. Many distinct emotions share these features, and without contextual clues and thoughts that dwell on those clues, we are in the dark about what we are experiencing (Schacter and Singer). The chief burden of the work of the American physiologist Walter B. Cannon was to show that many physiological affects are virtually identical across manifestly different states. While more current research suggests a tighter fit between specific emotions and specific autonomic system responses (such as skin temperature and heart rate), visceral responses such as these nevertheless have slow response times, too slow to determine what emotion one is actually feeling at a given time (LeDoux). So Cannon's general insight about the indeterminacy of the "feel" of an emotion still holds, though for different reasons than the ones he offered.

A third view with some kinship to the James-Lange view holds that emotions are felt action tendencies (Arnold). They are modes of readiness to act or, in the different idiom of psychoanalysis, discharge impulses. Supporting this view is the tendency of people to describe emotions in terms of dispositions to concrete behavior, for example, "I felt like hitting him," "I could have exploded," "I wanted to spit," and "I wanted to be alone with him, wrapped in his embrace." Nevertheless, the action tendency view seems at best a partial account of emotion. The basic issue here is not that some emotions such as apathy, inhibition, and depression seem to lack activation modes—while others are more a matter of the rich movement of thought so well depicted, for example, in Henry James's novels. It is rather that emotions are about something (internal or external) that people represent in thought. As such, emotions have propositional or cognitive content. They are identified by that content, by what we dwell on, whether fleetingly or with concentrated attention.

According to a fourth and most plausible view, emotions are constituted by appraisals or cognitive evaluations. (This is the view the fourth-century B.C.E. Greek philosopher Aristotle developed in the *Rhetoric,* and a view the Stoics put forth in more radical form. It is the clear favorite of most philosophers of the late twentieth and early twenty-first centuries—for a sampling, see de Sousa, 1987; Stocker; Goldie; Nussbaum, 2001. It is also the reigning view in cognitive psychology—see Lazarus; Oatley; Frijda; Scherer, and for an important criticism, see Zajonc.) Such an account need not exclude other features of emotion, such as awareness of physiological and behavioral responses or a particular phenomenological feel. But these, when present, are dependent on the appraisals of circumstances that capture what the emotion is about. Moreover, it is compatible with this view that emotions have complex neuropsychological structures that can be investigated by science.

To be more precise, an appraisal, on this view, is a belief or evaluation about the goodness or badness of some perceived or imagined event. Anger requires an evaluation that one has been unjustly slighted by another, fear that there is present harm or danger, grief that something valuable has been lost, love that one values a person as supremely important in one's life. On the Aristotelian view, the evaluation is experienced with pleasure or pain, and in some, but not all, cases with a reactive desire, not unlike the earlier mentioned action tendency. According to Aristotle, "Anger is a desire [*orexis*] accompanied by pain toward the revenge of what one regards as a slight toward oneself or one's friends that is unwarranted" (*Rhetoric,* 1378a30–32).

The appraisals constitutive of emotions can be weaker than strict beliefs (P. Greenspan). Thus, many of the thoughts that ground emotions are not judgments to which we would give assent, but are rather thoughts, perceptions, imaginings, and construals (*phantasiai,* Aristotle would say) that we dwell on in compelling ways, though without concern about "objective truth." Familiar sorts of examples illustrate the point. Juan may fear spiders, even though he knows that most spiders he is likely to encounter are harmless; or Clarissa may know that Joe is a no-good lover for her, but she still finds herself yearning for him. In these cases emotions have thought contents or appraisals, though ones that are at odds with more circumspect judgment. They are mental states that seem to lag behind what a person is ready to grasp through belief.

On an Aristotelian view, appraisals constitutive of emotions have a qualitative flavor—a feeling of pleasure or pain. The flavor may be intense or mild, present to consciousness or hidden somewhere as background noise. So, for example, a patient reflecting on her illness may have fears that all may not turn out well, even though she never feels any strong or noticeable tension when she focuses on that thought. Some emotions may be felt as a mix of both pleasure and pain. Even a quick "flash" of emotion, such as a "twinge" of envy, can seem to oscillate quickly from one affective pole to another, from pain at another's good fortune to pleasure at being in a position to slight that person.

Aristotle suggests that many emotions have a motivational aspect, that is, they involve a reason or motive for action. Again, recognition of the diversity and variety of emotions is crucial here. Some emotions, such as calmness, confidence, and equanimity do not in an obvious way involve desires for action. In contrast, anger often involves a desire for revenge, just as envy seems to involve a desire to thwart others from having various goods. These sorts of desires can go on to constitute a motive or reason for full-fledged action, although often we train ourselves not to act, and not to take as a motive for action all our impulses and desires. In some cases, we act out our emotions only in our minds, as when out of anger, we slay the object of our anger in our fantasy life. Here impulses and urgings are present, but they are not taken up as reasons for action.

At yet other times we do externally act out our emotions but in a way in which that emotion still seems to fall short of constituting a full-fledged reason or motive for action. In anger, we sometimes act impulsively, slamming doors and storming out of rooms. This is a venting, a way of letting out tension, not a strategy for sweet revenge. Defiling a photograph of an ex-lover comes closer to the mark, for here at least there is symbolic aim. Nevertheless, these cases of anger do not really aim at effective revenge. They are reactive more than purposeful. And yet, they seem to be voluntary. They are certainly not the involuntary responses of the viscera. Like stroking a patient's brow or tousling a child's hair, emotion motivates the action. These two actions are likely done out of compassion and affection. But it seems strained, at least in some of these cases, to say that one does these actions in order to show compassion or affection—which is the common pattern a demand for reasons often takes. The gesture just expresses compassion or affection. The explanation stops there. It is not like drinking in order to slake thirst, in which drinking strategically promotes that end (Hursthouse).

Emotions and the Brain

In recent years neurophysiologists have turned to an analysis of emotions and the underlying brain structures of specific emotions and emotional pathologies. Two of the leading researchers in this field are Joseph E. LeDoux and Antonio R. Damasio.

In his 1996 book, *The Emotional Brain,* LeDoux makes three central points. First, he contends that emotions form a two-track response system. One track involves the "low road," or fast route where information travels directly from the thalamus, a subcortical "relay station" in the brain that mediates between external stimuli and specialized parts of the brain that process information, to the amygdala, a small region in the forebrain which generates the behavioral, autonomic and endocrine responses which make up an emotional reaction. The other track involves a "high road," or slow route where information takes a detour through the cortex, the more recently evolved part of the brain which supports higher cognitive functioning, including thinking, reasoning and consciousness. The first, subcortical pathway is a primitive survival mechanism, fast but "quick and dirty" and often filled with errors. It is the basis of the human fear response not only to snakes but also to slimy, bent sticks that look like snakes. The second cortical pathway is slower, but more precise, correcting for errors in overreaction and adding the advantages of conscious judgment and more fine-tuned discernment. The very slowness that makes it a poor defense mechanism suits it well for leisurely appraisal.

LeDoux notes, secondly, that memories of emotional situations are laid down by a two-track memory system. One system involves implicit or procedural memory, another explicit or declarative memory. So LeDoux asks us to imagine being in a horrific car accident, in which the horn gets stuck on. Later, when you hear a horn your body may automatically have a conditioned fear response—you break out in sweats, have a fast heartbeat, and so on. Procedural memory is at work, bringing information directly from the auditory system to the amygdala and opening the floodgates of emotional arousal. But in hearing the horn you also may remember the accident, consciously remembering the intersection where it happened, who was with you at the time, where you were headed, and so on. The two kinds of memories are of the same event, though one is emotion drenched, the other, cool and calm. Research by Larry R. Squire and Daniel Schacter, among others, suggests that the two memory systems are physically housed in different parts of the brain, though the memories, in normal cases, are "seamlessly fused" as one conscious, unified experience of the moment. The fusion results in memories that are "emotional." In those moments when we have arousal without declarative memory, we may experience intense emotions without knowing why. (This may be one explanation of the notion of "objectless" emotions.) Conversely, declarative memories without the emotional arousal of implicit memory may be experienced as emotionally flat.

In his third point, LeDoux focuses on our primitive fear response, suggesting that the brain system responsible for this mechanism can bypass higher, cognitive brain systems. But this leaves to the side questions about more complex, socially constructed emotions, such as indignation, compassion, pity, or shame. Do they operate solely through the high road, or do they have low-road counterparts, which they routinely correct and educate? Again, are memories of feeling compassion or indignation marked by a two-tier system—the fusion of an awareness of a present arousal with a conscious evaluation of the situation that invoked arousal? These sorts of questions raise a more general concern about how to generalize from LeDoux's important study of the fear defense mechanism to the wide array of emotions that characterize people's waking and dreaming lives.

In his 1994 book, *Descartes' Error,* Damasio argues that a wide range of emotional behavior is not primarily subcortical but is a function of the frontal lobe of the brain, typically associated with reasoning and decision making. Indeed, Damasio's research suggests that the prefrontal cortex is involved in both emotional arousal and rational decision making and that the emotion centers and the reasoning centers in the frontal lobe are intimately related. Damasio begins his account with the famous case of Phineas Gage, a mid-nineteenth-century railroad worker whose frontal lobe was pierced by an iron tamping rod in an accident that occurred while Gage was blasting stone to make way for a straight rail track. To the surprise of his doctors at the time, Gage's severe brain injury (the rod exited the front of his brain and landed more than a hundred feet away) affected not just his reasoning capacities, but his emotional character as well. A calm and polite man prior to the injury, Gage became irreverent and foul mouthed, obstinate and capricious, and full of plans quickly hatched and soon abandoned. A similar pattern had been repeated in others with prefrontal lobe damage. While patients were able to generate emotional responses that travel subcortical, "low-road" paths ("primary emotions," as Damasio calls them), they could not generate "secondary emotions" that require evaluation of stimuli (LeDoux's "high-road" emotional responses). On the basis of a series of related experiments, Damasio concludes that prefrontally damaged patients are unable to have normal, automatic emotional responses. Though they may understand abstractly the emotional significance of some stimuli (such as the punitive side of the risky moves they repeatedly make), they fail to correct their strategies, Damasio argues, because they seem unable to pair that understanding with a mechanism to reenact, in this case, a negative emotional response. They lack what Damasio calls a "somatic marker" mechanism that stamps the appraisal with its appropriate emotional flavor.

Both LeDoux's and Damasio's work shed important light on the interdependence of emotion and reason in emotional behavior—LeDoux through his notion of "high-road" emotional pathways that stand ready to correct "quick and dirty" subcortical responses, Damasio through his analysis of prefrontal responses that embody pairings between representations of situations and appropriate emotional dispositions.

Control and Responsibility

Emotions are reactive responses. But in what sense are we human beings able to choose their emotional responses? How, if at all, can the will intervene in emotional behavior?

Aristotle is once again helpful here. Both action and emotion, he holds, are subject to choice in the following sense. We choose to develop a state of character that stabilizes certain dispositions toward action and emotion. Accordingly, how one feels (and acts) may be less a matter of choice at the moment than the indirect effect of choice over time. In the case of emotion, especially, there are few shortcuts. For unlike action, emotion does not seem to engage choice (or will) in each episode. At a given moment, we may simply not be able to will to feel a certain way however skilled we are at posing appropriate emotional, facial expressions, such as a polite smile or a look of interest.

Common parlance includes many expressions presuming that emotions are "up to us" in various ways. We exhort ourselves and others by such phrases as "pull yourself together," "snap out of it," "put on a good face," "lighten up," "be cheerful," "think positive," and "keep a stiff upper lip." In many of these cases, what the person is being implored to do is to take on the semblance of an emotion with the hope that it might "take hold" and rub off on the person's inner state. Practice as if you believe and you will believe. Or, as de Sousa put it, "earnest pretense is the royal road to sincere faith" (de Sousa, 1988, p. 324; also see Ekman; and Tomkins on posed expressions and facial feedback mechanisms). Similarly, we can sometimes fuel the flames of a sincerely felt emotion by allowing it bodily expression. To weep may intensify our grief or make us more conscious of its presence. The James-Lange theory, and its notion of proprioceptive feedback from the expression of emotion, may be in the background here. There are other sorts of actions a person might take that are not a matter of body language or putting on a new face. A person may try to talk herself out of love, but discover that only when she changes locales do the old ways begin to lose their grip. Other times, it is more trial by fire: staying put and exposing herself to what is painful in order to become inured. The latter process involves desensitization.

Sometimes changing one's mood may be more a matter of mental or perceptual strategy. It may be a matter of bringing oneself to focus on different objects and thoughts—trying to see things under a new gestalt or recomposing the scene. Exhortation and persuasion play an important role here. A patient depressed by the possibility of relapse might be reminded of the favorable statistics and the steady progress she has made to date. Seeing things in a new light, with new emphases and stresses, helps to allay the fear. In a different vein, anger at a child may subside when one focuses less on minor annoyances and more on admirable traits. One may work on a more forgiving attitude in general by choosing to play down others' perceived faults or foibles. In certain cases, experiencing emotions is a matter of giving inner assent—of allowing oneself to feel angry or giving the green light to a new interest or love. It is as if something grabs hold, and then it is our turn to have some influence.

Mental training can of course follow a more methodical and introspective model. An individual can learn to take more careful note of the onset of certain emotions and of the movement of mind from one perceived object of importance to another. So Buddhists speak of a watchful mindfulness, an intensification of consciousness such that through awareness and knowledge, one comes to be more in charge (Thera).

There are other methods of effecting emotional change that depend upon so-called "deep" psychology. In psychoanalysis the recapitulation of patterns of emotional response through transference onto an analyst is intended to be a way of seeing at a detached level. The patient relives an emotional experience at the same time as he watches and interprets it. This is the putative advantage of an empathetic, clinical setting: A patient can come to see an emotional pattern in a detached way, free from judgment and accusation and from the crippling emotions that those stances often involve. In some cases, a patient tries to relieve the pain of present disabling emotions, such as anger, anxiety, or shame by coming to see their roots in primitive conflicts and frustrations that may have long been repressed. The goal is not to remove the patient from the vulnerabilities of emotion, but rather to make possible a way of experiencing emotions, including shame and anger, that is less crippling and self-destructive.

More Radical Extirpation or Removal of Emotions

Because emotions are valued as modes of attention, motivation, communication, and knowledge, we tend to put up with their messiness while at the same time attempting their reform. But there are venerable traditions in which moderating emotions through transformation and education is viewed as an inadequate therapy and an inadequate way of training moral character and agency. The Stoic view, which influenced later Kantian views and bears rough similarities to certain Eastern traditions, argues that the surges and delusions of emotion warrant their extirpation. Investment in objects and events we cannot control is the source of our suffering, and modification of our beliefs about these values is the source of our cure. In Stoic theory, virtue comes to be rooted in reason alone, for it is reason alone that is most appropriate to our nature and under our true dominion.

The attraction of the Stoic view rests in its powerful description of the anguish of the engaged emotional life. Many emotions (though not all) lead to attachment, but objects of attachment are never perfectly stable. Abandonment, separation, failure, and loss are the constant costs of love, effort, and friendship. The more tightly we cling to our investments, the more dependent we become upon what is uncontrolled and outside our own mastery. Self-reproach and persecution are often responses to lack of control. In our relations with others, the same clinginess of emotions can lead to stepping beyond what is appropriate, just as it can lead to exclusionary preferences and partialities. Provincialism can grow out of stubborn preference for what is familiar and comfortable according to class lines or other restrictive values.

This is a reasonable portrait of some moments of the life lived through emotion. Detachment and watchful awareness directed toward the emotions are important therapeutic stances in such a life. In addition, detachment and watchful awareness should be directed toward reason itself and its own tendencies toward egoism and imperious control. This is clearly at odds with Stoic practice though more in line with Eastern practices such as Buddhism. But it is difficult to see how a thoroughgoing rejection of the emotions can be compatible with what is a human life. Emotions, for all their selectivity, intensity, and stirring, enable us, through those very vulnerabilities, to attend, see, know, and experience in a way that pure cognition cannot. Some of that way of knowing and being known anguishes beyond words. Poetry and literature can only begin to express the reality. But even if at times unruled by reason's measure, emotion must not, on that account, be an outlawed feature of human life. Nor must it be an outlawed feature of morality. How we care for others, and what we notice and reveal, depends greatly on the subtlety, fineness, and often deep truth of our emotional readings of the world.

Conclusion

From the above, it should be clear that emotions play an expanded role within bioethics and within the moral practices of healthcare professionals. Emotional sensitivity is important for discerning the complexity of situations and for appreciating the competing needs and interests of various parties. A simple matter of noticing a patient's distress or displeasure, perhaps by attending to her facial expressions and bodily gestures, could figure importantly in assessing a case. But by the same token, it is important to communicate emotions and not just record those of others. Conveying compassion to a patient can be a significant part of therapeutic treatment and, in general, be an important part of establishing a relationship in which medical counsel can be trusted and followed. Again, emotions figure in deliberation of choices. Compassion toward a patient can ground a reason for telling a patient the true nature of her condition in a tone that respects the patient's fragile, emotional state. The relevant choice a caretaker faces may not be whether to withhold or not withhold the truth, but rather how to tell the truth in a way that respects both a patient's autonomy and feelings. It is here that healthcare providers' own feelings of compassion and sympathy can importantly ground the specific choices she makes. Finally, healthcare providers, as morally responsible agents, need to have ready access to their own emotions, so that emotions help rather than hinder effective care. In cases, for example, in which fears and prejudice cloud more circumspect judgment, healthcare providers must recognize such fears and prejudice as emotional impediments standing in the way of delivering quality care. In general, a reflective stance toward one's own emotions becomes an important part of caring for others.

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SEE ALSO: *Care; Compassionate Love; Conscience; Grief and Bereavement; Life, Quality of; Narrative; Pain and Suffering; Psychoanalysis and Dynamic Therapies; Women, Historical and Cross-Cultural Perspectives*

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EMPIRICAL METHODS IN BIOETHICS

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The period since 1970 has seen the development and maturation of the field of bioethics into a major area of scholarly inquiry. Scholarship in bioethics has traditionally relied on the discipline of moral philosophy and has taken a normative or prescriptive stance. However, bioethics is primarily a field of *practical* and *applied* study as well as a theoretical one. As such, to be relevant and useful to the providers and consumers of healthcare, bioethics must address questions and recommend solutions in the real world. Empirically-based studies provide an understanding of public and professional attitudes, practices, and the implications and intersections of practice and policy. These studies can provide information about the level at which purported problems actually exist and can be described and quantified. Similarly, they can measure the success or failure of public policies designed to help solve bioethics problems.

Employing the qualitative and quantitative methodologies of the social sciences and public health, bioethics scholars, often in collaboration with clinicians and scientists, have shed light on important bioethics questions such as:

- Patient and family preferences for treatment at the end of life;
- Nature and quality of communication between patients and physicians;
- Attitudes and understanding of informed consent by investigators and research subjects;
- Competency and the robustness of individual's stated wishes about end of life treatment;
- Why policy and legislative initiatives have failed to increase consent rates to organ donation;
- Impact of new genetic information on individuals, families, and society;
- Equity in allocation of scarce resources such as dialysis and organ transplantation;
- Disparities in the provision of care to ethnic minorities.

Research Methods

The methods used by researchers engaged in the empirical study of bioethics range from the quantitative to the qualitative, and often combine the two to provide a richer description of phenomenon and to answer research questions. Empirical research methods of all types comprise those that can be used to describe valid and reliable inquiries into phenomenon, including human behavior. Quantitative methods are used to answer hypotheses or to provide generalizable descriptions of populations and the incidence and prevalence of behaviors and problems within a population. Traditional quantitative methods in the social sciences include controlled experiments to compare the effects of an intervention on a sample population and measurement of subject characteristics. These measurements can include characterizing attitudes, behaviors, or physical characteristics. They are distinguished by the use of measurement tools that can provide reliable and replicable descriptions, usually in the form of numeric signifiers. Examples of such measurements are the use of psychometric tools to measure cognitive traits (e.g., anxiety, coping style, depression) and attitudes (trust in the healthcare system, fatalism). Psychometric techniques can also be sued to the measurement of physical traits such as health status (using measurements like the SF–36 or activities of daily living). Most of these measurements take place within structured interviews (either interviewer-administered or self-administered) in which the responses of subjects are strictly prescribed. The phrasing of questions is regimented and the respondent is provided with what are called forced choice responses in which information is produced as standardized coded information. Aside from obtaining information directly from subjects, another major source of quantitative data is secondary sources, such as administrative databases (such as the Medicare database) and medical records. The advantages of quantitative methods are that they enable collection of data from large sample sizes in standardized ways that permit comparisons across various populations and time periods. They also allow for controlled interventions or controlled introduction of conditions to subjects. These methods have allowed the documentation of racial and gender disparities in the provision of healthcare services.

Bioethics researchers have generally used qualitative methods in the generation of hypotheses rather than in the testing of hypotheses. Deduction characterizes qualitative methods, whereas induction characterizes research using quantitative methods. Qualitative methods permit detailed, and sometimes more accurate, observation of behaviors and contribute to the understanding of underlying social and cultural characteristics associated with specific patterns of behaviors. Moreover, qualitative methods allow discovery of subjects' perspectives rather than imposing a pre-existing framework. Qualitative methods can allow researchers to access areas of investigation not amenable to quantitative research, and to explore areas that have been little researched in the past. For example, how infertile couples have experienced new reproductive technologies and how they have incorporated traditional understandings of parenthood into their conceptual models of the rights and obligations of parents.

Qualitative methods include a variety of techniques. Subject interviews that incorporate wholly or partly open-ended questions are commonly used. These allow respondents to provide answers to questions in their own words, and allow interviewers to probe or follow up on information provided by respondents. More formative interviewing, in which the interviewer uses a guide to begin discussion about the research topic but does not structure the questions that follow, can also be used. In this type of interview, the subject creates a narrative and engages in a dialogue with the interviewer that informs the researcher about the topic under investigation. A similar technique, the focus group, uses six to twelve informants gathered to discuss a particular issue. For example, a study of the social and ethical consequences of genetic testing for Huntington's Disease might gather individuals from families affected by Huntington's Disease to discuss their attitudes, preferences, and intentions about genetic testing.

Qualitative methods can also include direct observation of healthcare situations and populations. For example, studies of informed consent to clinical trials have included directly observing and audio- or videotaping the consent conversation. Conversations can be examined as narratives and themes explored, or behaviors can be coded to extract quantitative data. For example, a trained observer can use 0, 1 coding to measure whether certain behaviors (e.g., explaining that trial participation is voluntary) occur or not. Participant observation—in which the observer actually participates in and observes the daily activities of a setting of interest (for example, observing a primary care setting to understand how or when advance directives are discussed with elderly patients)—can also generate a variety of data types. Personal diaries in which individuals are asked to keep records of activities and behaviors are another technique.

Historically, social sciences researchers have strictly divided themselves into researchers using quantitative methods (i.e., psychologists) or qualitative methods (i.e., anthropologists). However, in recent years there has been a blurring of these distinctions and an increasing enthusiasm for multimethod research. Whereas qualitative research begins by acknowledging that there is a range of different ways of making sense of the world, and approaches its subject matter in a naturalistic, interpretive way, quantitative research overlays hypothesized paradigms on the research phenomena of interest and collects data that can help determine the distributions of characteristics and behaviors in populations and settings. For example, quantitative studies have established how frequently dying patients are treated with futile therapies, but have not been especially successful in explaining why.

Conclusion

Ultimately, scholarship in bioethics can benefit from the methodologies of both the humanities and the empirical sciences. Normative bioethics provides a framework and guideposts for suggesting how healthcare services ought to be delivered, and what the fiduciary responsibilities of clinicians to patients are. However, normative bioethics is unable to describe and explain how these play out in real life. Moreover, the value placed in the principles of bioethics and the use made of these principals by actors in healthcare settings can only be illuminated using empirical methods. In the final analysis, the best empirical research in bioethics will always be based on a sophisticated understanding of the historical, philosophical, and cultural contexts of the delivery and consumption of healthcare services. Similarly, philosophical debate can often be enriched by an awareness of empirical data.

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SEE ALSO: *Anthropology and Bioethics; Medicine, Anthropology of; Medicine, Sociology of; Organ Transplants, Sociocultural Aspects of; Public Health: Methods; Public Policy and Bioethics; Research Ethics Committees; Research Methodology; Research Policy; Research, Unethical*

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ENDANGERED SPECIES AND BIODIVERSITY

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Although projections vary, reliable estimates are that about 20 percent of Earth's species may be lost within a few decades, if present trends go unreversed. These losses will be about evenly distributed through major groups of plants and animals in both developed and developing nations, with special concerns over tropical forests (Ehrlich and Ehrlich; Wilson).

The United Nations at the 1992 Earth Summit in Rio de Janeiro launched the Convention on Biological Diversity, signed by 153 nations that are "concerned that biological diversity is being significantly reduced by certain human activities" and who are "conscious of the intrinsic value of biological diversity and of the ecological, genetic, social, economic, scientific, educational, cultural, recreational and aesthetic values of biological diversity," and "conscious also of the importance of biological diversity for evolution and for maintaining life sustaining systems of the biosphere" (United Nations, Preamble).

The U.S. Congress has lamented the lack of "adequate concern [for] and conservation [of]" species, and has sought to protect species through the Endangered Species Act, as well as through the Convention on International Trade in Endangered Species (U.S. Congress, Sec. 2(a) (1)). About five hundred species, subspecies, and varieties of fauna have been lost since 1600 in what is now the continental United States. The natural rate would have been about ten (Opler). In Hawaii, of sixty-eight species of birds unique to the islands, forty-one are extinct or virtually so. Half of the twenty-two hundred native plants are endangered or threatened. A candidate list for all states contains over two thousand taxa (species and significant subspecies and forms) considered to be endangered, threatened, or of concern, three categories used to rank degree of jeopardy (U.S. Fish and Wildlife Service). Human-caused extinctions threaten to approach and even exceed the catastrophic extinction rates of the geological past.

Even where species are not endangered, almost all inhabited lands are impoverished of their native fauna and flora, owing to development, loss of habitat, hunting, collection, trade in fauna and flora, toxic pollutants, introduction of exotic species, and other disturbances produced by humans. Sustainable biodiversity, the use of biotic resources so as to leave them unimpaired for future generations, is an increasing concern. Another concern is the loss of wetlands, permanently or periodically flooded or wet areas, which at the end of the twentieth century in many areas are less than 10 percent of their original area. There is hardly a forest, grassland, or desert system in the developed world that is not impoverished of its once-native fauna and flora. Old-growth or pristine forests have been cut rapidly, as have tropical rain forests. Island ecosystems, often with species peculiar to that location and found nowhere else, are particularly at risk.

In the conservation of endangered species and biodiversity, bioethics in principle and in practice involves an unprecedented mix of science and conscience, especially since the species and ecosystem levels seldom figured in earlier ethical deliberations. A rationale for saving species that centers on their worth to persons is anthropocentric; a rationale that includes their intrinsic and ecosystemic values, in addition to or independently of persons, is naturalistic.

On an anthropocentric account, the duties involved are to persons; there are no duties to endangered species, though duties may concern species. Persons have a strong duty of nonmaleficence—not to harm others—and a weaker, though important, duty of beneficence—to help others. Many endangered species—which ones we may not now know—are expected to have agricultural, industrial, and medical benefits. They may be of scientific value, serve as indicators of ecosystem health, or provide genetic breeding stock for improvement of cultivated plants. Humans ought to conserve their global resources, a matter of prudence and enlightened self-interest in general, but a matter of moral concern when some persons threaten the benefits of these resources for other persons. Nonrenewable resources may have to be mined and consumed, but biological resources can be perennially renewable.

A developing concern between the species-rich, often underdeveloped countries and the developed countries, which are frequently responsible in part for environmental degradation, is who should bear the costs of saving species relative to benefits gained. Historically, native plant species, seeds, and germ plasm have been considered not to be owned by any nation. Developing nations are claiming ownership by the country of origin, arguing that these resources cannot be used by those in other nations without negotiating compensation. At the same time, developing nations claim that their biological resources are being conserved for the benefit of other nations, and that the developed nations ought to pay developing nations not only for new conservation measures put into effect there but also for the lost opportunity costs of development in such conserved areas.

The Convention on Biological Diversity states: “States have sovereign rights over their own biological resources” (United Nations, Preamble) and continues, “Recognizing the sovereign rights of States over their natural resources, the authority to determine access to genetic resources rests with the national governments and is subject to national legislation” (Art. 15). Nevertheless, the problem of reconciling biodiversity as a common heritage of humankind with biodiversity as a national resource remains unresolved. States may control access to biodiversity, but this does not imply ownership. The United States refused to sign the Convention over questions of ownership, both of the wild biodiversity and of beneficial technology derived from it.

On the harm side, the loss of a few species may have no evident results now, but the loss of many species imperils the resilience and stability of the ecosystems on which humans depend. The danger increases with subtractions from the ecosystem, a slippery slope into serious troubles. Many species that have no direct value to humans are part of the biodiversity that keeps ecosystems healthy. On the benefits side again, there are less tangible benefits. Species that are too rare to play roles in ecosystems can have recreational and aesthetic value—even, for many persons, religious value. Species can be curiosities. They can be clues to understanding natural history. Destroying species is like tearing pages out of an unread book, written in a language humans hardly know how to read, about the place where they live. Humans need insight into the full text of natural history.

Such anthropic reasons are pragmatic and impressive. They are also moral, since persons are benefited or hurt. But can all duties concerning species be analyzed as duties to persons? Many endangered species have no resource value, nor are they particularly important for the other reasons given above. Are there worthless species? As curiosities and relics of the past, perhaps all species can be given an umbrella protection by saying that humans ought to preserve an environment adequate to match their capacity to wonder. Nature is a kind of wonderland. But this introduces the question of whether preserving resources for wonder is not better seen as preserving a remarkable natural history that has objective worth—an evolutionary process that has spontaneously assembled millions of species. A naturalistic account values species and speciation directly.

A further rationale is that humans of decent character will refrain from needless destruction of all kinds, including destruction of any species. Such a prohibition seems to depend, however, on some value in the species as such, for there need be no prohibition against destroying a valueless thing. The deeper problem with the anthropocentric rationale is that its justifications are less than fully moral, fundamentally exploitive, and self-serving, even if subtly so. This is not true intraspecifically among humans, when out of a sense of duty an individual defers to the values of other persons. But it is true interspecifically, since *Homo sapiens* treats all other species as resources. Ethics has always involved partners with entwined destinies. But ethics has never been very convincing when pleaded as enlightened self-interest (that one ought always to do what is in one’s intelligent self-interest), including class self-interest, even though in practice altruistic ethics often needs to be reinforced by self-interest. To value all other species only in terms of human interests is rather like a nation’s arguing all its foreign policy in terms of national self-interest. Neither seems to be completely moral.

It is safe to say that in the decades ahead, the quality of life will decline in proportion to the loss of biotic diversity, though it is often thought that one must sacrifice that diversity to improve human life. So there is a sense in which humans will not be losers if we save endangered species. Humans who protect endangered species will, if and when they change their value priorities, be better persons for their admiring respect for other forms of life. But this should not obscure the fact that humans can be short-term losers. Sometimes we do have to make genuine sacrifices, at least in terms of what we presently value, to preserve species. If, for instance, Americans wish to save the spotted owl, they will have to pay higher prices for timber and accept some job losses and relocations.

Dealing with a problem correctly requires an appropriate way of thinking about it. On the scale of evolutionary time, humans appear late and suddenly. Even later and more suddenly they increase the extinction rate dramatically. What is offensive in such conduct is not merely the loss of resources but also the maelstrom of killing and insensitivity to forms of life. What is required is not prudence but principled responsibility to the biospheric Earth.

There are problems at two levels when considering duties to species; one is about facts (a scientific issue), and one is about values (an ethical issue). First, what sort of biological entity is a species? Indeed, do species exist at all? No one doubts that individual organisms exist, but species can have a more controversial factual reality. Taxonomists regularly revise species designations and routinely put after a species the name of the "author" who, they say, "erected" the taxon. If a species is only a category or class, boundary lines may be arbitrarily drawn, and the species is nothing more than a convenient grouping of its members, an artifact of taxonomists. Some natural properties are used—reproductive structures, bones, teeth. But which properties are selected and where the lines are drawn vary with taxonomists.

If this approach is pressed, species can become a conventional concept, a mapping device, that is only theoretical, something like the lines of longitude and latitude. Sometimes endangered species designations have altered when taxonomists have decided to lump or split previous groupings. To whatever degree species are artifacts of taxonomists, duties to save them seem unconvincing. No one proposes duties to genera, families, orders, phyla; biologists concede that these do not exist in nature.

On a more realist account, a biological species is not just a class; it is a living historical form (Latin *species,* a natural kind), propagated in individual organisms, that flows dynamically over generations. Species are dynamic natural kinds, historically particular lineages. A species is a coherent, ongoing form of life expressed in organisms, encoded in gene flow, and shaped by the environment. In this sense, species are objectively there as living processes in the evolutionary ecosystem—found, not made, by taxonomists. The claim that there are specific forms of life historically maintained in their environments over time does not seem arbitrary but, rather, as certain as anything else we believe about the empirical world, even though at times scientists revise the theories and taxa with which they map these forms.

Species are not so much like lines of latitude and longitude as like mountains and rivers, phenomena objectively there to be mapped. The edges of such natural kinds will sometimes be fuzzy, to some extent discretionary. We can expect that one species will slide into another over evolutionary time. But it does not follow from the fact that speciation is sometimes in progress that species are merely made up, instead of found as evolutionary lines articulated into diverse forms, each with its more or less distinct integrity, breeding population, gene pool, and role in its ecosystem (Rojas).

Having recognized what a species is, the next question is why species ought to be protected. The naturalistic answer is that humans ought to respect these dynamic life forms preserved in historical lines, vital informational processes that persist genetically over millions of years, overleaping short-lived individuals. It is not *form* (species) as mere morphology, but the *formative* (speciating) process that humans ought to preserve, although the process cannot be preserved without its products. Endangered "species" is a convenient and realistic way of tagging this process, but protection can be interpreted (as the Endangered Species Act permits) in terms of subspecies, variety, or other taxa or categories that point out the diverse forms of life.

A consideration of species is both revealing and challenging because it offers a biologically based counterexample to the focus on individuals—typically sentient and usually persons—so characteristic in Western ethics. In an evolutionary ecosystem, it is not mere individuality that counts; the species is also significant because it is a dynamic life form maintained over time by an informed genetic flow. The individual represents (re-presents) a species in each new generation. It is a token of a type, and the type is more important than the token. A biological identity—a kind of value—is here defended. The dignity resides in the dynamic form; the individual inherits this, exemplifies it, and passes it on.

A species lacks moral agency, reflective self-awareness, sentience, and organic individuality. Some have been tempted to say that species-level processes cannot count morally. But each ongoing species defends a form of life, and these diverse species are, on the whole, good kinds. Such speciation has achieved all the planetary richness of life. All ethicists say that in *Homo sapiens* one species has appeared that not only exists but also ought to exist. A naturalistic ethic refuses to say this exclusively of a late-coming, highly developed form, and extends this duty more broadly to the other species—though not with equal intensity over them all, in view of varied levels of evolutionary achievement. Only the human species contains moral agents, but conscience ought not to be used to exempt every other form of life from consideration, with the resulting paradox that the sole moral species acts only in its collective self-interest toward all the rest.

Extinction shuts down the generative processes. The wrong that humans are doing, or allowing to happen through carelessness, is stopping the historical gene flow on which the vitality of life is based, and which, viewed at another level, is the same as the flow of natural kinds. Every extinction is an incremental decay in this stopping of life. Every extinction is a kind of superkilling. It kills forms (species) beyond individuals. It kills "essences" beyond "existences," the "soul" as well as the "body." It kills collectively, not just distributively. We do not merely lament the loss of potential human information; we lament the loss of biological information, present independently of instrumental human uses of it. A shutdown of the life stream on Earth is the most destructive event possible. Each human-caused extinction edges us further in this direction; already the rate may be catastrophic.

A consideration of species strains any ethic fixed on individual organisms, much less on sentience or persons. But the result can be biologically sounder, though it revises what was formerly thought to be logically permissible or ethically binding. When ethics is informed by this kind of biology, it is appropriate to attach duty dynamically to the specific form of life. The species line is the more fundamental living system, the whole of which individual organisms are the essential parts. The species, too, has its integrity, its individuality; and it is more important to protect this than to protect individual integrity. The appropriate survival unit is the appropriate level of moral concern.

A species is what it is inseparably from the environmental niche into which it fits. Particular species may not be essential in the sense that the ecosystem can survive the loss of individual species without adverse effect. But habitats are essential to species, and an endangered species typically means an endangered habitat. Species play lesser or greater roles in their habitats. This leads to an enlarged concern for the preservation of species in the system. It is not merely *what* they are, but *where* they are that one must value correctly. This limits the otherwise important role that zoos and botanical gardens can play in the conservation of species. They can provide research, a refuge for species, breeding programs, aid for public education, and so forth, but they cannot simulate the ongoing dynamism of gene flow over time under the selection pressures in a wild ecosystem. They amputate the species from its habitat.

Extinction is a quite natural event, but there are important theoretical and practical differences between natural and anthropogenic (human-caused) extinctions. Artificial extinction, caused by human encroachments, is radically different from natural extinction. Relevant differences make the two as morally distinct as death by natural causes is from murder. Though harmful to a species, extinction in nature is seldom an evil in the system. It is, rather, the key to tomorrow. The species is employed in, but abandoned to, the larger historical evolution of life. There are replacements. Such extinction is normal turnover in ongoing speciation.

Anthropogenic extinction differs from evolutionary extinction in that hundreds of thousands of species will perish because of culturally altered environments that are radically different from the spontaneous environments in which such species are naturally selected and in which they sometimes go extinct. In natural extinction, nature takes away life when it has become unfit in habitat, or when the habitat alters, and typically supplies other life in its place. Artificial extinction shuts down tomorrow, because it shuts down speciation. Natural extinction typically occurs with transformation, either of the extinct line or of related or competing lines. Artificial extinction is without issue. One opens doors; the other closes them. In artificial extinctions, humans generate and regenerate nothing; they only dead-end these lines.

Through evolutionary time nature has provided new species at a net higher rate than the extinction rate; hence the accumulated global diversity. There have been infrequent catastrophic extinction events, anomalies in the record, each succeeded by a recovery of previous diversity. Although natural events, these extinctions so deviate from the normal trends that many paleontologists look for causes external to the evolutionary ecosystem—supernovas or collisions with asteroids. Typically, however, the biological processes that characterize Earth are both prolific and have considerable powers of recovery after catastrophe. Uninterrupted by accident, or even interrupted so, they steadily increase the numbers of species.

An ethicist has to be circumspect. An argument may commit what logicians call the genetic fallacy in supposing that present value depends upon origins. Species judged today to have intrinsic value may have arisen anciently and anomalously from a valueless context, akin to the way in which life arose mysteriously from nonliving materials. But in an ecosystem, what a thing is differentiates poorly from the generating and sustaining matrix. The individual and the species have their value inevitably in the context of the forces that beget them. There is something awesome about an Earth that begins with zero and runs up toward five to ten million species in several billion years, setbacks notwithstanding.

Several billion years' worth of creative toil, several million species of teeming life, have been handed over to the care of the late-coming species in which mind has flowered and morals have emerged. On the humanistic account, such species ought to be saved for their benefits to humans. On the naturalistic account, the sole moral species has a duty to do something less self-interested than count all the products of an evolutionary ecosystem as human resources; rather, this host of species has a claim to care in its own right. There is something Newtonian, not yet Einsteinian, as well as something morally naive, about living in a reference frame where one species takes itself as absolute and values everything else relative to its utility.

In addition to the deeper ethical principles at issue in conservation of species, questions of pragmatic strategy arise. One strategy proposed when there are limited resources is to sort jeopardized species into three groups: those that are probably going extinct even if we try hard to save them, those that will probably survive without our help, and those that will probably go extinct unless we intervene. This strategy is called triage. An alternative, or complementary, strategy is to focus more on endangered ecosystems than on single species, an approach that may result both in more effective management and in more efficient use of resources. Another strategy discourages claiming biodiversity as a national resource while thinking of conservation in other nations in terms of foreign policy, for if biodiversity is the common heritage of humankind, all nations share duties to protect it.

HOLMES ROLSTON III (1995)
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SEE ALSO: *Animal Welfare and Rights: Ethical Perspectives on the Treatment and Status of Animals; Environmental Ethics; Environmental Policy and Law; Hazardous Wastes and Toxic Substances; Native American Religions; Sustainable Development*

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ENHANCEMENT USES OF MEDICAL TECHNOLOGY

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In bioethics, one frequently encounters the belief that there is an important moral distinction between using biomedical tools and products to combat human disease and attempting to use them to "enhance" human traits. Thus, people argue that using biosynthetic human growth hormone to treat an inborn growth-hormone deficiency is praiseworthy, but that the use of the same product to increase the height of a short but hormonally normal child is not (Daniels, 1992). Similarly, while the use of human gene-transfer techniques to treat disease enjoys widespread support from secular and religious moral authorities, a line is usually drawn at using the same protocols to attempt to improve upon otherwise healthy traits (Anderson; Baird).

Even those unwilling to condemn the enhancement uses of biomedicine outright generally concur that ethics demands that therapeutic applications of these tools be given priority for research and development (Walters and Palmer). As a result, this distinction has been enshrined in policies at both professional and governmental levels, and it continues to inform much of the public discussion of new biomedical advances (Parens, 1998). The distinction is explicated in several different ways, however, which have different merits as moral boundary markers for medical research and practice. In fact, it often seems in danger of evaporating entirely under conceptual critiques even before the question of its moral merits is entertained.

Professional Domain Approaches

One approach to the enhancement/treatment distinction is to define it in terms of the accepted limits of professional medical practice. Under this view, *treatments* are any interventions that physicians and their patients agree are useful and proper, while *enhancements* are simply interventions that are considered to fall beyond a physician's professional purview. Thus, physician-prescribed physical therapy to improve muscle strength would be considered legitimate medical treatment, while weight lifting under a coach's supervision to achieve a particular physique would be considered an enhancement. This view resonates well with a number of contemporary social-scientific critiques of biomedicine, which suggest that medicine has no natural domain of practice beyond that which it negotiates with society (Good). It also provides a simple normative lesson for professionals concerned about their obligations in specific cases. Given medicine's fundamentally patient-centered ethos, one takes one's cues from the patient's value system, and thus negotiates toward interventions that can help achieve the patient's vision of human flourishing (Engelhardt).

Unfortunately, these same features also deny this approach the ability to be of help to those attempting to use the treatment/enhancement distinction in order to regulate biomedical research. Some argue that medicine's lack of an essential domain of practice means that a coherent distinction between medical and nonmedical services can never be drawn in the first place (Davis). Others accept the distinction between treating and enhancing, but question traditional values of medicine by arguing that privileging treatment over enhancement is itself wrong (Silvers). Still others argue that, for psychological and economic reasons, a professional medical line between treatment and enhancement will be impossible to maintain in practice (Gardner). To the extent that useful "upper-boundary" concepts are required at the policy level—for societies making healthcare research allocation decisions, for example—this impotence is an important weakness.

The Normalcy Approach

Fortunately, another approach to interpreting the treatment/enhancement distinction is framed explicitly as a policy tool for separating legitimate healthcare needs from luxury services. The most developed exposition of this view is Sabin and Daniel's endorsement of what they call the "normal function" standard for determining the limits of "medically necessary" (and therefore socially underwritten) health services (p. 13). Sabin and Daniels argue that an appropriate boundary between medically necessary treatments and optional enhancements can be drawn by thinking about how to provide medical services fairly within a population. Following Daniels' earlier work, they construe healthcare as one of society's means for preserving equality of opportunity for its citizens, and they define "healthcare needs" as those services that allow individuals to enjoy the portion of the society's "normal opportunity range" to which their full array of skills and talents would give them access. This is done by restoring or improving the patient's abilities to the range of functional capacities typical for members of his or her reference class (e.g., age and gender) within the human species. Any interventions that would expand an individual's range of functional capacities beyond the range typical for his or her reference class would be deemed a medically unnecessary enhancement. Others have used similar understandings of human malady to help explicate a distinction between "negative" (e.g., therapeutic) and "positive" (e.g., enhancing) human genetic engineering (Berger and Gert).

The advantage of the normal-function approach is that it provides one relatively unified goal for healthcare, toward which the burdens and benefits of various interventions can be relatively objectively titrated (measured against one another), balanced, and integrated. The normal-function approach comes close to accurately reconstructing the rationale behind many actual "line drawing" judgments by healthcare coverage plans and professional societies (Brock et al.). Unfortunately, this approach also faces conceptual challenges in an important way. The first serious problem is that of prevention. While efforts at generic "health promotion" straddle the border of biomedicine, efforts to prevent the manifestation of specific maladies in individuals are always accepted as legitimate parts of biomedicine, and thus are automatically located on the treatment side of the enhancement boundary. On the other hand, one of the ways one can prevent a disease is to strengthen the body's ability to resist it long before any diagnosable problem appears. These forms of prevention attempt to elevate bodily functions above the normal range for the individual (and in some cases the species), and to that extent seem to slide into enhancement (Juengst). If human gene–transfer protocols like these are acceptable as forms of preventive medicine, how can it be claimed that healthcare practitioners should be "drawing the line" at enhancement?

Disease-Based Approaches

Probably the most common rejoinder to the problem of prevention is to distinquish the problems to which prevention efforts respond. Treatments are interventions that address the health problems created by diseases and disabilities ("maladies" in the helpful language of Clouser, Culver, and Gert). Enhancements, on the other hand, are interventions aimed at healthy systems and normal traits. Thus, prescribing biosynthetic growth hormone to rectify a diagnosable growth-hormone deficiency is legitimate treatment, while prescribing it for patients with normal growth-hormone levels would be an attempt at "positive genetic engineering," or enhancement (Berger and Gert). Thus, to justify an intervention as appropriate medicine means to be able to identify a pathological problem in the patient. If no medically recognizable malady can be diagnosed, the intervention cannot be "medically necessary," and is thus suspect as an enhancement.

This interpretation has the advantages of being simple, intuitively appealing, and consistent with a good bit of biomedical behavior. Maladies are both objectively observable phenomena and the traditional target of medical intervention. They can be discovered through diagnosis, and it will be clear when one has gone beyond medicine when no pathology can be identified (Juengst). This interpretation is used by professionals working at the boundary, like cosmetic surgeons, to justify their services in terms of relieving "diagnosable" psychological suffering rather than satisfying the aesthetic tastes of their clients (Morgan), and it is also used when insurance companies insist on being provided with a diagnosis before providing coverage for surgery.

However, this interpretation does also face at least two major difficulties. The first problem that any disease-based interpretation of the enhancement boundary faces is, of course, biomedicine's infamous nosological elasticity. It is not that hard to coin new maladies for the purposes of justifying the use of enhancement interventions. By interpreting the boundary of medicine in terms of maladies, this approach puts the power for drawing that boundary squarely in the profession's hands, with the corresponding potential for abuse.

The more important problem, however, is that no matter where the line is drawn, most biotechnological interventions that could become problematic as enhancement interventions would not have to cross that line in order to be developed and approved for clinical use, because they will also have legitimate therapeutic applications. In fact, most biosynthetic biologicals and gene-transfer protocols with potential for enhancement uses will first emerge as therapeutic agents. General cognitive-enhancement interventions, for example, are likely to be approved for use only in patients with neurological diseases (Whitehouse et al.). However, to the extent that they are in high demand by individuals who are merely suffering the effects of normal aging, the risk of unapproved, or "off-label," uses of these products will be high (Mehlman). This last point is critical for policy purposes, because it suggests that the real challenge to regulation in this area may not be the development of enhancement interventions or "enhancement research," but downstream off-label uses of gene therapies for nonmedical enhancement purposes. The policy problem then becomes controlling access and use of the technologies, not their research and development. This presents another set of challenges for the law, since the novelty of enhancement technologies will make it difficult for judges and juries to ascertain the reasonableness of physician behavior (Mehlman).

These realities have pressed those who would use the treatment/enhancement distinction for policy purposes to articulate the moral dangers of genetic enhancement more clearly. After all, personal improvement is praised in many spheres of human endeavor, and biomedical interventions such as cosmetic surgery are well accepted, at lease in American society, as means to achieving personal improvement goals.

The Moral Dangers of Enhancement

There are two lines of thought that have emerged from this work. The first focuses on the idea that biomedical enhancements are a form of social cheating. In this view, taking the biomedical shortcut erodes the specific social practices that make the analogous human achievement valuable in the first place. Thus, some argue that it defeats the purpose of the contest for the marathon runner to gain endurance chemically rather than through training, and it misses the point of meditation if one can gain Nirvana through psychosurgery. In both cases, the value of the improvements lie in the achievements they reward as well as the benefits they bring. The achievements (successful training or disciplined meditation) add value to the improvements because they are understood to be admirable social practices in themselves. Wherever a biomedical intervention is used to bypass an admirable social practice, then, the improvement's social value (the value of a runner's physical endurance or a mystic's visions) is weakened accordingly. To preserve the value of the social practices considered to be "enhancing," it may be in society's interest to impose a means-based limit on biomedical enhancement efforts.

Interpreting enhancement interventions as those that short-circuit admirable human practices has special utility for policy analysis. To the extent that biomedical shortcuts allow specific accomplishments to be divorced from the admirable practices they were designed to signal, the social value of those accomplishments will be undermined. Not only will the intrinsic value be diminished for everyone that takes the shortcut, but the resulting disparity between the enhanced and unenhanced will call the fairness of the whole game—be it educational, recreational, or professional—into question. If the extrinsic value of being causally responsible for certain accomplishments is high enough (like professional sports salaries), the intrinsic value of the admirable practices that a particular institution was designed to foster may start to be called into question (Murray). For institutions interested in continuing to foster the social values for which they have traditionally been the guardians, a choice will have to be made. Either they must redesign the game (of education, sports, etc.) to find new ways to evaluate excellence in the admirable practices that are not affected by available enhancements, or they must prohibit the use of the enhancing shortcuts. Which route an institution should take depends on the possibility and practicality of taking either, because ethically they are equivalent.

Unfortunately, some of the social games people can play (and cheat at) do not turn on participants' achievements at all, but on traits over which individuals have little control, such as stature, shape, and skin color. The social games of stigmatization, discrimination, and exclusion use these traits in the same manner that other practices use achievements: as intrinsically valuable keys to extrinsic goods. It is becoming increasingly possible to seek biomedical help in changing these traits in order to short-circuit these games as well. The biomedical interventions involved, such as skin lighteners or stature increasers, are enhancements because they serve to improve the recipient's social standing, but only by perpetuating the social bias that inspired their use. When *enhancement* is understood in this way, it warns of still another set of moral concerns.

What makes the provision of human growth hormone to a short child a morally suspicious enhancement is not the absence of a diagnosable disease or the "species atypical " hormone level that would result—it is the intent to improve the child's social status by changing the child, rather than by changing her social environment, that is questionable (White). Such enhancement interventions are almost always wrong-headed, because the source of the social status they seek to improve is, by definition, the social group and not the individual. Attempting to improve that status in the individual amounts to a moral mistake akin to "blaming the victim": it misattributes causality, is ultimately futile, and can have harmful consequences. This is the interpretation of enhancement that seems to be at work when people argue that to use Ritalin to induce cooperative behavior in the classroom inappropriately "medicalizes" a social problem. In such cases, the critics dispute the assumption that the human need in question is one that is created by, and quenchable through, the human body, asserting instead that both its source and solution really lie in quite a different sphere of human experience.

This interpretation of the enhancement concept is useful to those interested in the ethics of personal improvement because it warns of a number of moral pitfalls beyond the baseline considerations that the enhancement/treatment distinction provides. Attempting to improve social status by changing the individual risks being self-defeating (by inflating expectations), futile (if the individual's comparative gains are neutralized by the enhancement's availability to the whole social group), unfair (if the whole group does not have access to the enhancement), or complicit with unjust social prejudices (by forcing people into a range of variation dictated by biases that favor one group over others). For those faced with decisions about whether to attempt to enhance themselves or their children through gene transfer, this way of understanding enhancement is much more illuminating than attempts to distinquishing it from medical treatment, because it points to the real values at stake. Ideally, gene transfer should not make an existing social problem worse, even if exacerbating injustice would further one's own interests.

On the other hand, protecting these values is difficult in a pluralistic society, because it means developing ways to police individuals' complicity with suspect social norms (Little). Under the historical shadow of state-sponsored eugenics programs, the U.S. government is unlikely to promulgate lists of acceptable and unacceptable enhancements, even if the intent of the lists are to protect the interests of those who are unenhanced.

Policy Implications

Clearly, all of the ways of understanding enhancement as a moral concept reviewed here have limitations. However, all these interpretations do seem to be alive and well and mixed together in the literature on the topic. It is not possible to cleanly assign the different interpretations of enhancement to different spheres of ethical analysis. But there do seem to be some rough correlations that might be made. Thus, the interpretations that contrast enhancement interventions with treatments seem most useful where it is the limits of medicine's expertise that are at issue. Whether medicine's boundary is defined in terms of concepts of disease, or in sociological terms as the scope of medical practice, or in terms of some theory of the human norm, this interpretation at least provides tools to draw that boundary. Moreover, all other considerations being equal, the line that it draws is the boundary of medical obligation, not the boundary of medical tolerance. Using this tool, enhancement interventions such as cosmetic surgery can still be permissable for physicians to perform, but it is also permissable to deny them to patients.

This has important implications for social policymaking about healthcare coverage, to the extent that society relies on medicine's sense of the medically necessary to define the limits of its obligations to underwrite care. Again, all other considerations being equal, this interpretation of the concept suggests that few enhancement interventions should be actively prohibited by society or foregone by individuals, even when they are not underwritten as a part of healthcare, since there is nothing intrinsically wrong with seeking self-improvements beyond good health.

In contrast, the interpretations of enhancement that focus on the misuse of biomedical tools in efforts at self-improvement seem the most relevant to issues of personal, rather than professional, ethics. Concerns about the authenticity of particular accomplishments are moral challenges to the individual, but find little purchase in the professional ethics of biomedicine, with its focus on the physical safety and efficacy of its tools. The primary policy implications of this interpretation are for the social institutions charged with fostering particular admirable practices, for enhancement interventions that offer biomedical shortcuts to achievement force reassessments of the values these institutions stand for, as well as the practices designed to foster them.

Finally, at the other end of the spectrum, enhancement interventions that seem to commit the moral mistake of trying to address social problems through the bodies of the potentially oppressed do seem to mark a stronger set of moral boundaries for all concerned. For biomedicine, this concept marks an epistemic limit beyond which medical approaches to problem solving are not only unnecessary, but conceptually wrong-headed. For individuals, parents, and society, these kinds of enhancement interventions risk either backfiring (by exacerbating the social problems they are intended to address) or being futile (if they merely result in a shift of the normal range for a given social trait).

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SEE ALSO: *Aging and the Aged: Anti-Aging Interventions; Genetic Engineering, Human; Human Dignity; Human Nature; Responsibility; Technology; Transhumanism and Posthumanism*

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ENVIRONMENTAL ETHICS

• • •

I. Overview
II. Deep Ecology
III. Land Ethics
IV. Ecofeminism

I. OVERVIEW

The magnitude and urgency of contemporary environmental problems—collectively known as the environmental crisis—form the mandate for environmental ethics: a reexamination of the human attitudes and values that influence individual behavior and government policy toward nature. The principal approaches to environmental ethics are "anthropocentrism," or the human-centered approach; "biocentrism," or the life-centered approach; and "ecocentrism," or the ecosystem-centered approach. Variously related to these main currents of environmental ethics are "ecofeminism" and "deep ecology." Moral "pluralism" in environmental ethics urges that we endorse all of these approaches and employ any one of them as circumstances necessitate.

Anthropocentrism

An anthropocentric environmental ethic grants moral standing exclusively to human beings and considers nonhuman natural entities and nature as a whole to be only a means for human ends. In one sense, any human outlook is necessarily anthropocentric, since we can apprehend the world only through our own senses and conceptual categories. Accordingly, some advocates of anthropocentric environmental ethics have tried to preempt further debate by arguing that a non-anthropocentric environmental ethic is therefore an oxymoron. But the question at issue is not, "Can we apprehend nature from a nonhuman point of view?" Of course we cannot. The question is, rather, "Should we extend moral consideration to nonhuman natural entities or nature as a whole?" And that question, of course, is entirely open.

In the mainstream of the Western cultural tradition, only human beings have been treated morally. Thus—at least for those working in that tradition—anthropocentrism is the most conservative approach to environmental ethics. Nevertheless, anthropocentric environmental ethicists have had to assume a more reactive than proactive posture and devote considerable effort to defending traditional Western moral philosophy against calls by bolder thinkers to widen the purview of ethics to encompass nonhuman natural entities and nature as a whole.

John Passmore and Kristin Shrader-Frechette were among the first to advocate a strictly anthropocentric approach to environmental ethics. Shrader-Frechette finds it “difficult to think of an action which would do irreparable harm to the environment or ecosystem, but which would not also threaten human well-being” (Shrader-Frechette, p. 17). Since many of the anthropocentric ethics in the Western canon censure behavior that threatens human well-being (utilitarianism, most directly), she argues that there is therefore no need to develop a newfangled non-anthropocentric environmental ethic.

Some of the damage that people have done to the environment certainly does threaten human well-being. Global warming and the depletion of the ozone layer are notorious examples. But it is easy to think of other instances of environmental vandalism that do not materially threaten human well-being. David Ehrenfeld asks us to contemplate the probable demise of the endangered Houston toad, a victim of urban sprawl, that “has no demonstrated or conjectural resource value to man” (p. 650). But, as Ehrenfeld points out, the Houston toad is not unique in this respect. Thousands of other species in harm’s way are nondescript “non-resources.”

To morally censure the extinction of such species and other kinds of environmental destruction that do not materially threaten human well-being, must we abandon anthropocentrism? Amplifying the work of Mark Sagoff (1988) and Eugene C. Hargrove (1989), Bryan Norton (1987), the leading contemporary apologist for anthropocentric environmental ethics, argues that we should enlarge our conception of human well-being instead. In addition to goods (energy, foods, medicines, raw materials for manufacture) and services (crop pollination, oxygen replenishment, water purification), an undegraded natural environment contributes to human well-being in important psychological, spiritual, and scientific ways. Scenery unmarred by strip mines or clear cuts and undimmed by dirty air is important to human aesthetic satisfaction. Clean air and water, open spaces and green belts, complex and diverse landscapes, national parks and wilderness playgrounds are important human “amenities.” Experiencing the solitude of wilderness and the otherness of wild things is an important aspect of human religious experience. Even if no one will be materially worse off after the extinction of “non-resource” species before science has a chance to discover and study them, important subject matter for pure, disinterested human knowledge will nevertheless have been irredeemably lost. Norton also suggests that contact with and care for the integrity of the natural environment can also be “transformative”; it can make better people of us.

Additionally, Norton argues that we should, as a matter of intergenerational justice, ensure that future human beings will be able to enjoy bountiful natural resources, a whole and functioning ecosystem, the full spectrum of environmental amenities, and the opportunity to partake of the psycho-spiritual experiences afforded by nature and to explore ecology and taxonomy intellectually. If we make our conception of human well-being both wide and long, he thinks that we may ground an adequate and effective environmental ethic without sailing off into the unfamiliar and treacherous waters of non-anthropocentrism.

The principal reason Norton offers for preferring an anthropocentic approach to environmental ethics is pragmatic. Anthropocentrism and non-anthropocentrism, he argues, support the same environmental policies. Norton (1991) calls this practical equivalence of anthropocentrism and non-anthropocentrism the “convergence hypothesis.” Why then advocate non-anthropocentrism? Most people, including most environmentalists, he claims, accept the familiar and venerable idea that human beings are ends-in-themselves deserving moral standing. On the other hand, the suggestion that all living beings (and species and ecosystems) ought to be granted a similar status is unfamiliar and controversial. If we rest environmental ethics on as broad and firm a foundation as possible, we can best ensure its rapid implementation. Indeed, Norton suggests that the vigorous philosophical effort to develop non-anthropocentric approaches to environmental ethics has actually done the beleaguered environment a disservice. The environmental movement, as a result, has been divided over purely intellectual issues that have little if any practical import.

Norton’s empirical claim that most people and even most environmentalists are anthropocentrists is supported only anecdotally. But opinion polls and the outcome of political contests suggest that most people probably have narrower allegiances—to self-interest, to institutional interests, to class interests, or to national interests—than to present and future collective or general human interests, very broadly construed. On the other hand, a growing minority of environmentalists seem to doubt the philosophical foundations of anthropocentrism. Are human beings really created in the image of God—the idea upon which anthropocentrism in Western religious ethics is founded? Are we uniquely self-conscious, rational, autonomous (some of the foundations of anthropocentrism in Western moral philosophy)? Must every being possess such characteristics to qualify for moral treatment? One may agree with the convergence hypothesis—that practical environmental goals are as well served by anthropocentric as by non-anthropocentric environmental ethics—but disagree that anthropocentrism is philosophically defensible. Hence, the question of the philosophical merits—the truth, as it were, of anthropocentrism—remains open.

Norton's convergence hypothesis, furthermore, overlooks an important difference between the way anthropocentric and non-anthropocentric environmental ethics support the same environmental policies. Suppose, as non-anthropocentrists variously argue, that the environment is "intrinsically" as well as "instrumentally" valuable—that is, that the environment is valuable for its own sake as well as for all the benefits, tangible and intangible, that it provides human beings. Warwick Fox decisively argues that such a supposition would shift the burden of proof from those who would disinterestedly preserve the environment to those who would destroy it for personal gain:

> If the nonhuman world is only considered to be instrumentally valuable then people are permitted to use and otherwise interfere with it for whatever reasons they wish.… If anyone objects to such interference then, within this framework of reference, the onus is clearly on the person who objects to justify why it is *more useful* to humans to leave that aspect of the nonhuman world alone. If, however, the nonhuman world is considered intrinsically valuable then the onus shifts to the person who would want to interfere with it to justify why they should be allowed to do so; anyone who wants to interfere with any entity that is intrinsically valuable is morally obliged to be able to offer *sufficient justification* for their actions. (Fox, 1993, p. 101)

Norton, for example, might object to lumber companies cutting down redwood forests because the remaining redwood forests are of greater benefit to present and future human generations as amenities than as raw material for decks and hot tubs. But to preserve the remaining redwood forests, Norton would have to persuade a court to issue an injunction preventing lumber companies from harvesting redwoods, based on the assertion that the trees, while living, are more useful to human beings as psycho-spiritual and transformative resources than cut down and sawed up as consumptive resources. If, on the other hand, the trees were regarded as being intrinsically valuable, then a lumber company would have to make a case in court that the utility of redwood forests as raw material is so enormous as to justify their destruction. Thus, although Norton may be correct in claiming that a long and wide anthropocentric environmental ethic supports the same policies as non-anthropocentric environmental ethics—in the case at hand, the policy of preserving redwood forests—he cannot correctly claim that it would do so as forcefully.

Biocentrism

At first, theories of environmental ethics that morally enfranchise both individual living beings and natural wholes, such as species and ecosystems, were called "biocentric." Then, Paul W. Taylor (1986) commandeered the term to characterize his militantly individualistic theory of environmental ethics. Not only in deference to Taylor's influence and authority, but in deference to the literal sense of the term ("life-centered"), "biocentrism" in this discussion refers to theories of environmental ethics that morally enfranchise living beings only. Since species and ecosystems are not, per se, living beings, a biocentric theory would not accord them any moral standing.

Although animal welfare ethics and environmental ethics are by no means the same, biocentrism is launched from a platform provided by animal welfare ethics. Both attempt to extend our basic anthropocentric ethics—which, generally speaking, prohibit harming human "others" or violating their rights—to a more inclusive class of individuals: animal welfare ethics to various kinds of animals, biocentric environmental ethics to all living beings.

Peter Singer and Tom Regan, the principal architects of contemporary animal welfare ethics, exposed anthropocentric ethics to a dilemma. If the criterion for moral standing is pitched high enough to exclude all nonhuman beings, it will also exclude some human beings; but if it is pitched low enough to include all human beings, it will also include a large and diverse group of nonhuman animals.

An anthropocentrist may follow such philosophers as René Descartes and Immanuel Kant and proffer some highly esteemed and peculiarly human capacity—such as the capacity to reason, to speak, or to be a moral agent—as the qualification a being must possess to deserve ethical consideration. However, if practice is to be consistent with theory, anthropocentrism, so justified, should permit people who cannot reason or speak or who are not morally accountable for their behavior—human infants, the severely retarded, and the abjectly senile, for example—to be treated in the same ways that it permits animals to be treated: used as experimental subjects in painful biomedical research, hunted for sport, slaughtered and processed into dog food, and so on. To obviate these repugnant implications, Singer (1975) suggests that we follow Jeremy Bentham, the founder of utilitarian ethics, and settle upon sentience, the capacity to experience pleasure and pain, as a less hypocritical—and arguably a more relevant—qualification for moral consideration. That standard would secure the ethical standing of the so-called marginal cases, since irrational, unintelligent, or irresponsible people are all capable of experiencing pleasure and pain. But it would open membership in the moral community to all other sentient beings as well. If, as Bentham asserted, pleasure is good and pain is evil, and if, as Bentham also asserted, we should try to maximize the one and minimize the other irrespective of who experiences them, then animal pleasure and pain should count equally with human pleasure and pain in all our moral deliberations.

Singer vigorously advocates vegetarianism. Ironically, however, Singer's Benthamic animal welfare ethic is powerless to censure raising animals in comfort and slaughtering them painlessly to satisfy human dietary preferences. Indeed, one might even deduce from Singer's premises that people have a positive moral obligation to eat meat, provided that the animals bred for human consumption experience a greater balance of pleasure over pain during their short lives. For if everyone became a vegetarian, many fewer cows, pigs, chickens, and other domestic animals would be kept and thus many fewer animals would have the opportunity, for a brief time, to pursue happiness.

Recognizing these (and other) inadequacies of Singer's theory in relation to the moral problems of the treatment of animals, Tom Regan (1983) advocates a "rights approach." He argues that some individual animals have "inherent value" because they are, like ourselves, not only sentient but "subjects of a life"—beings that are self-conscious, experience desire and frustration, and that anticipate future states of consciousness—that from their point of view can be better or worse. Inherent value, in turn, may be the grounds for basic moral rights.

Neither Singer's nor Regan's prototype of animal welfare ethics will also serve as environmental ethics. For one thing, neither provides moral standing for plants and all the many animals that may be neither sentient nor, more restrictively still, subjects of a life—let alone for the atmosphere and oceans, species and ecosystems. Moreover, concern for animal welfare, on the one hand, and concern for the larger environment, on the other, often lead to contradictory indications in practice and policy. Examples follow: Advocates of animal liberation and rights frequently oppose the extermination of feral animals competing with native wildlife and degrading plant communities on the public ranges; they characteristically demand an end to hunting and trapping, whether environmentally benign or necessary; and they may prefer to let endangered plant species become extinct, rather than save them by killing sentient or subject-of-a-life animal pests.

On the other hand, animal welfare ethics and environmental ethics lead to convergent indications on other points of practice and policy. Both should resolutely oppose "factory farming": animal welfare ethics because of the enormous amount of animal suffering and killing involved; environmental ethics because of the enormous amount of water used and soil eroded in meat production. Both should staunchly support the preservation of wildlife habitat: animal welfare ethics because nature reserves provide habitat for sentient subjects; environmental ethics because many other forms of life, rare and endangered species, and the health and integrity of ecosystems are accommodated as well.

Despite the differences, animal welfare ethics may be regarded as "on the way to becoming" full-fledged environmental ethics, according to Regan (1983, p. 187). Animal welfare ethicists went the first leg of the philosophical journey by plausibly lowering the qualifying attribute for moral consideration. Albert Schweitzer (1989), Kenneth Goodpaster (1978), Robin Attfield (1983), and Paul Taylor (1986) variously suggest pitching it lower still—from being sentient to being alive.

Schweitzer, writing long before the efflorescence of contemporary animal welfare and environmental ethics literature, appears to ground his "reverence for life" ethic in the voluntarism of Arthur Schopenhauer:

> Just as in my own will-to-live there is a yearning for more life … so the same obtains in all the will-to-live around me, equally whether it can express itself to my comprehension or whether it remains unvoiced.
>
> Ethics consists in this, that I experience the necessity of practising the same reverence for life toward all will-to-live, as toward my own. (Schweitzer, 1989, pp. 32–33)

Contemporary biocentrism appears to have been inspired by Joel Feinberg's observations about the moral importance of interests and the range of entities to which interests may be attributed. The foundational role of the concept of "conation" (an often unconscious striving, reified by Schopenhauer as the "will-to-live") in Feinberg's characterization of interests unifies contemporary Anglo-American biocentric environmental ethics with Schweitzer's version. According to Feinberg:

> A mere thing, however valuable to others, has no good of its own … [because] mere things have no conative life: no conscious wishes, desires, and hopes; or urges or impulses; or unconscious drives, aims, and goals; or latent tendencies, directions of growth, and natural fulfillments. Interests must be compounded somehow out of conations; hence

> mere things have no interests, *A fortiori,* they have no interests to be protected by legal or moral rules. Without interests a creature can have no "good" of its own the achievement of which can be its due. Mere things are not loci of value in their own right, but rather their value consists entirely in their being objects of other beings' interests. (Feinberg, pp. 49–50)

The clear implication of this passage is that the "insuperable line," as Bentham called the boundary separating beings who qualify for moral consideration from those who do not, falls between living beings and nonliving things, not between sentient animals and insentient animals and plants. Why? Because even plants have "unconscious drives, aims, and goals; or latent tendencies, directions of growth, and natural fulfillments." Feinberg, nevertheless, goes on to deny that plants have interests of their own. His reasons for doing so, however, appear to be less clear and decisive than his derivation of interests from conations and his argument that beings who have interests deserve moral consideration.

Kenneth Goodpaster (1978) argues that all living beings, plants as well as animals, have interests. And he argues, appealing to Feinberg as an authority, that beings who have interests deserve "moral considerability"—a term that Goodpaster uses to indicate precisely the ethical status of moral patients (those on the receiving end of an action), as distinct from moral agents (those who commit an act). Goodpaster agrees with Singer that their sentience is a sufficient condition for extending moral considerability to animals, but he disagrees that it is a necessary one, because sentience evolved to serve something more fundamental—life: "Biologically, it appears that sentience is an adaptive characteristic of living organisms that provides them with a better capacity to anticipate, and so avoid, threats to life.… [T]he capacities to suffer and enjoy are ancillary to something more important, rather than tickets to considerability in their own right" (p. 316).

Goodpaster's life-principle ethic is modest. All living beings are morally considerable, but all may not be of equal moral "significance." He leaves open the question of how much weight we should give to a plant's interests when they conflict with a sentient creature's or with our own. Paul Taylor (1986) has struck a much stronger and bolder stance and argued that all living beings are of equal "inherent worth."

Taylor bases a living being's inherent worth on the fact that it has a good of its own, quite independent of our anthropocentric instrumental valuation of it and quite independent of whether the organism is sentient or cares. Light, warmth, water, and rich soil are good for a sprig of poison ivy, though poison ivy may not be good for us. Unlike machines and other purposeful artifacts that we design to serve our own ends, organisms are ends-in-themselves. Most generally, they strive to reach a state of maturity and to reproduce. Therefore, just as we insist that others not interfere with our own striving and thriving, so, Taylor urges, expressly patterning his reasoning on Kant's, we should respect the striving and thriving of all other "teleological centers of life." Kant argued that we should respect, as individuals-in-themselves, all rational, autonomous beings equally. And Taylor argues that we should respect equally all living beings because they too are ends-in-themselves.

Because biocentrism is concerned exclusively with biological individuals, not biological wholes, it is an approach to environmental ethics that seems at once so restrictive that it would be impossible to practice, and an approach that has scant relevance to the set of problems constituting the environmental crisis. How can we do anything at all, if, before we act, we are obliged to consider the interests of each and every living being that we might affect? Why should we feel compelled to do so for the sake of the environment? Environmental concern focuses primarily on the spasm of abrupt massive species extinction and the loss of biodiversity generally, on rapid global warming and the erosion of stratospheric ozone, on soil erosion, water pollution, and the like; not on the welfare of individual grubs, bugs, and shrubs.

Schweitzer and Goodpaster frankly acknowledge the difficulty in practicing biocentrism. Schweitzer writes, "It remains a painful enigma how I am to live by the rule of reverence for life in a world ruled by creative will which is at the same time destructive will" (1989, p. 35). And Goodpaster writes:

> The clearest and most decisive refutation of the principle of respect for life is that one cannot *live* according to it, nor is there any indication in nature that we were intended to. We must eat, experiment to gain knowledge, protect ourselves from predation.… To take seriously the criterion being defended, all these things must be seen as somehow morally wrong. (p. 310)

Both reasonably suggest that we can at least respect the interests of other living beings when they do not conflict with our own. According to Goodpaster, biocentrism is not suicidal. It requires only that we use living beings considerately and sensitively. Schweitzer thinks that biocentrism permits us to injure or destroy other forms of life, but only when doing so is necessary and unavoidable.

Taylor's egalitarianism renders the practicability problem of biocentrism virtually insurmountable (Wenz). Starting with any individual's right to self-defense, he rationalizes our annihilating disease organisms with medicines and goes on from there to defend our killing and eating other living beings to feed ourselves. But the satisfaction of any "nonbasic" human interest, according to Taylor, must be forgone if it violates the basic interests of another teleological center of life. So it would seem that strict adherence to biocentric egalitarianism would require one to live a life of sacrifice that would make a monk's life appear opulent.

Writing before the advent of the environmental crisis, Schweitzer was not intending to address its problems. He seems genuinely concerned, rather, with the welfare of individual living beings. Thus, it would be unfair and anachronistic to criticize his reverence-for-life ethic for being largely irrelevant to the set of problems constituting the environmental crisis. Taylor, on the other hand, represents his biocentric ethic as an environmental ethic. And he is clearly aware that contemporary environmental concerns focus on such things as species loss and ecosystem deterioration. But he remains antagonistic to the holistic environmental ethics crafted in response to such concerns. He prefers to think of the extinction of species and destruction of ecosystems in anthropocentric, rather than in biocentric or ecocentric terms. Goodpaster, on the other hand, invokes "concern felt by most person about 'the environment'" as a reason for trying to extend moral considerability to all living beings (p. 309). He seems, moreover, to be aware that to actually reach the concern felt by most persons about the environment, biocentrism would have to "admit of application to … systems of entities heretofore unimagined as claimants on our moral attention (such as the biosystem itself)" (p. 310). Having once mentioned systems of entities, however, Goodpaster lavishes all his attention on individual living beings and has nothing at all to say about how biocentrism might actually admit of application to species, ecosystems, and the biosphere as a whole.

Biocentrism may be not only irrelevant to actual environmental concerns, it could aggravate them. Biocentrism can lead its proponents to a revulsion toward nature—giving an ironic twist to Taylor's title, *Respect for Nature*—because nature seems as indifferent to the welfare of individual living beings as it is fecund. Schweitzer, for example, comments that

> the great struggle for survival by which nature is maintained is a strange contradiction within itself. Creatures live at the expense of other creatures. Nature permits the most horrible cruelties.… Nature looks beautiful and marvelous when you view it from the outside. But when you read its pages like a book, it is horrible. (1969, p. 120)

Ecocentrism

Though the term "ecocentrism" is a contradiction of the phrase "ecosystem-centered," ecocentrism would provide moral considerability for a spectrum of nonindividual environmental entities, including the biosphere as a totality, species, land, water, and air, as well as ecosystems. The various ecologically informed holistic environmental ethics that may appropriately be called ecocentric are less closely related, theoretically, than either the anthropocentric or biocentric families of environmental ethics.

Lawrence E. Johnson has attempted to generate an environmental ethic that reaches species and ecosystems by a further extension of the biocentric approach. He does this not by making the criterion for moral considerability more inclusive but by attributing interests to species and ecosystems. Extensively developing the line of thought that Feinberg (1974) tentatively and ambiguously initiated, Johnson concludes that we should "give *due* respect to all the interests of all beings that have interests, in proportion to their interests" (p. 118). As this, his summary moral principle, suggests, Johnson follows Goodpaster in allowing that all interests are not equal and thus that all interested beings, though morally considerable, are not of equal moral significance. Johnson, however, provides no principle or method for hierarchically ordering interests and the beings who possess them; nor does he provide an ethical procedure for adjudicating conflicts of interest between people, animals, and plants, and, more difficult still, between all such individuals and environmental wholes.

In arguing that species have interests, Johnson exploits the fact that some biologists and philosophers of biology regard species not as classes of organisms but as spatially and temporally protracted individuals. To plausibly assign them interests, in other words, Johnson assimilates species to individual organisms. During the first quarter of the twentieth century, ecosystems (though then they were not so denominated) were represented in ecology as supraorganisms. Johnson adopts this characterization of ecosystems, as doing so allows him to attribute interests to ecosystems by assimilating them to individual organisms, just as in the case of species. Finally, Johnson points out that James Lovelock (1979) has suggested that the Earth as a whole is an integrated living being (named Gaia); if so, it (she) too may have interests and thus may be morally considerable. Adopting nonstandard, obsolete, or highly controversial scientific models of species, ecosystems, and the biosphere is the price Johnson pays to purchase moral considerability for these natural wholes. His attempt to add an ecocentric dimension to his essentially biocentric approach to environmental ethics is thus seriously compromised.

Holmes Rolston's ecocentric environmental ethic, like Johnson's, is launched from a biocentric platform. Rolston (1988) endorses the central tenet of biocentrism that each living being has a good of its own and that having a good of its own is the ground of a being's intrinsic value. And upon the existence of intrinsic value in nature he founds our duties to the natural world in all its aspects.

Rolston's biocentrism, in sharp contrast to Taylor's, is inegalitarian. Rolston finds more intrinsic value in beings that sense their own good, that feel hurt when harmed, than in those that lack consciousness. And Rolston finds the most intrinsic value of all in normal adult human beings because we are rational and fully self-conscious as well as conative and sentient.

Rolston avoids the scientifically suspect route that Johnson takes to enfranchise ethically such environmental wholes as species and ecosystems. Rolston argues instead that since the most basic telos of a teleological center of life is to be "good of its kind" and to reproduce its species, then its kind or species is its primary good. Species per se do not have a good of their own, but as the most basic good of beings that do have a good of their own, they too can be said to possess intrinsic value. The myriad natural kinds or species, however, evolved not in isolation but in a complex matrix of relationships—that is, in ecosystems. Thus, though not themselves teleological centers of life, either, some intrinsic value rubs off on ecosystems in Rolston's theory of environmental ethics. Rolston coins a special term, "systemic value," to characterize the value of ecosystems.

Systemic value does not seem to be entirely parallel, logically or conceptually speaking, to intrinsic value in Rolston's theory of environmental ethics. Rather, it seems that a necessary condition for the existence of the things that he believes do have intrinsic value—beings with a good of their own and the goods (their kinds or species) that such beings strive to actualize and perpetuate—is the existence of their natural contexts or matrices. Like the moon that shines by a borrowed light, systemic value seems to be a kind of reflected intrinsic value. Rolston finds a similar sort of derivative intrinsic value, "projective value," in elemental and organic evolutionary processes going all the way back to the Big Bang, since such processes eventually produced (or "projected") living beings with goods of their own.

Rolston's theory of environmental ethics hierarchically orders intrinsically valuable individuals in a familiar and conventional way. Human beings are at the pinnacle of the value hierarchy, followed by the higher animals, and so on, pretty much as in the Great Chain of Being envisioned by many Western philosophers of yore. Rolston is prepared to invoke his hierarchical arrangement of intrinsically valuable kinds of beings to resolve biocentric moral conundrums. For example, he expressly argues that it is morally permissible for people to kill and eat animals and for animals to kill and eat plants. Though such a hierarchical ordering of intrinsically valuable beings jibes with tradition and uncultivated common sense, it may not always jibe with, and hence may not adequately justify, our considered environmental priorities. Most environmentalists, faced with the hard choice of saving a sensitive, subjective dog or an unconscious, merely conative thousand-year-old redwood tree, would probably opt for the tree—and not only because redwoods are becoming rare. Pressed for good reasons for making this choice, Rolston might answer that an environmentally ethical agent is perfectly free, in reaching a decision to give priority to the redwood over the dog, to add to their intrinsic value the way standing redwoods are valued anthropocentrically and the way they serve the systemic value of ecosystems. The ethical agent can legitimately add the redwood's economic value to its systematic value, intrinsic value, aesthetic value, or religious value. How the intrinsic value of species and the systemic value of ecosystems fits into Rolston's value hierarchy is not entirely clear. Is a plant species more or less intrinsically valuable than a specimen of *Homo sapiens*, or than a specimen of *Ovis aries* (domestic sheep)?

According to Regan (1981) the very possibility of an environmental ethic turns on constructing a plausible theory of intrinsic (or "inherent") value in nature. He argues that anthropocentric environmental ethics are "management ethics," ethics for the "use" of the environment, not environmental ethics proper. Regan sets clear and stringent conditions for such value: first, it must be strictly objective, independent of any valuing consciousness; second, it must attend some property or set of properties that natural entities possess; and third, it must be normative, it must command ethical respect or moral considerability.

Rolston's basing a being's intrinsic value on its having a good of its own seems to meet the first two of these conditions, but possibly not the third. Before consciousness evolved, living beings had goods of their own; they could be harmed if not hurt; they had interests, whether they cared or not. The move, however, from the hardly disputable fact that living beings objectively possess goods of their own to the assertion that they have objective intrinsic value may turn on an ambiguity in the meaning of "good."

The word "good" has a teleological as well as a normative sense. All living beings have goods of their own in the teleological sense. They have, in other words, ends that were not imposed upon them—as the goods or ends of machines and other artifacts are—by beings other than themselves. But it is still possible to ask if such teleological goods generate normative goods. At this point in the argument, the smallpox and AIDS viruses are usually invoked as examples of organisms that have goods of their own in the teleological sense of the term, but organisms that one would be loath to say are good in the normative sense of the term.

However this particular conceptual issue may be resolved, another, moral general one casts a very large and dark shadow on Rolston's claim of finding objective intrinsic value in nature. While Rolston is very careful not to buck prevailing scientific opinion on the sort of reality possessed by species, ecosystems, and evolutionary processes, his argument that intrinsic value exists objectively in nature does buck more general assumption of modern science. From the modern scientific point of view, nature is value-free. Goodness and badness, like beauty and ugliness, are in the eye of the beholder. According to this entrenched dogma of modern science, there can be no valuees without valuers. Nothing under the sun—no rational self-conscious person, no sentient animal, no vegetable, no mineral—has value of any kind, either as a means or an end, unless it is valued by some valuing subject.

The crisp objective/subjective distinction in modern science, however, has been undermined by the Heisenberg Uncertainty Principle in quantum physics, as the observation of subatomic entities unavoidably affects their state of being. Therefore, the modern scientific worldview has become problematic. Seizing upon this circumstance, J. Baird Callicott (1989), among others, has broached a value theory for environmental ethics that is neither subjective nor objective. Just as experimental physicists actualize the potential of an electron to be at a particular place by observing it, so, Callicott suggests, the potential value of an entity, both instrumental and intrinsic, is actualized by a valuer appreciating it.

Although it may eventually give way to a postmodern scientific worldview, the modern scientific worldview continues to reign supreme. The "land ethic" sketched by Aldo Leopold (1949) has been the moral inspiration of the nonanthropocentric wing of the contemporary popular environmental movement, in part because Leopold respects the subjectivity of value required by the modern scientific world view without at the same time reducing nature to natural resources.

Callicott (1987) claims that Leopold's ecocentric environmental ethic may be traced to the eighteenth-century moral philosophy of David Hume and Adam Smith, who think that feelings lie at the foundations of value judgments. While feelings fall on the subjective side of the great subject/object divide, Hume and Smith also point out that our feelings may be altruistic or other-oriented as well as selfish. Hence we may value others for their own sakes, as ends-in-themselves. Further, Hume and Smith note that in addition to sympathy for others, respectively, we also experience a "public affection" and, accordingly, value the "interests of society even on their own account."

In *The Descent of Man,* Charles Darwin (1874) adopted the moral psychology of Hume and Smith and argued that the "moral sentiments" evolved among human beings in conjunction with the evolution of society, growing in compass and refinement along with the growth and refinement of human communities. He also developed the incipient holism of Hume and Smith, flatly stating that primeval ethical affections centered on the tribe not its individual members.

Leopold, building directly on Darwin's theory of the origin and evolution of ethics, points out that ecology represents human beings to be members not only of multiple human communities but also of the "biotic community." Hence, "the land ethic simply enlarges the boundaries of the community to include soils, waters, plants, and animals, or collectively: the land.… It implies respect for … fellow members and also respect for the community as such" (Leopold, p. 204).

Animal welfare ethicists and biocentrists claim that Leopold's ecocentrism is tantamount to "environmental fascism." Leopold wrote—and his exponents affirm—that "a thing is right when it tends to preserve the integrity, stability, and beauty of the biotic community [and] wrong when it tends otherwise" (pp. 224–225). If this is true, then not only would it be right deliberately to kill deer and burn bushes for the good of the biotic community, it would also be right to undertake draconian measures to reduce human overpopulation—the underlying cause, according to conventional environmental wisdom, of all environmental ills.

Providing for the possibility of moral consideration of wholes, however, does not necessarily disenfranchise individuals. The land ethic is holistic as well as (not instead of) individualistic, although in the case of the biotic community and its nonhuman members holistic concerns may eclipse individualistic ones. Nor does the land ethic replace or cancel previous socially generated human-oriented duties—to family and family members, to neighbors and neighborhood, to all human beings and humanity. Human social evolution consists of a series of additions rather than replacements. The moral sphere, growing in circumference with each stage of social development, does not expand like a balloon—leaving no trace of its previous boundaries. It adds, rather, new rings, new "accretions," as Leopold called each emergent social-ethical community. The discovery of the biotic community simply adds several new outer orbits of membership and attendant obligation. Our more intimate social bonds and their attendant obligations remain intact. Thus we may weigh and balance our more recently discovered duties to the biotic community and its members with our more venerable and insistent social obligations in ways that are entirely familiar, reasonable, and humane.

Ecofeminism

The term "ecofeminism" is a contraction of the phrase "ecological feminism," which may be understood as an analysis of environmental issues and concerns from a feminist point of view and, vice versa, as an enrichment and complication of feminism with insights drawn from ecology. Ecofeminism is both an approach to environmental ethics and an alternative feminism.

An axiom of ecofeminism is that, both historically and globally, men have dominated women and "man" has dominated nature. Further, many male-centered, culture-defining texts, such as the epics of Homer and Hesiod, the works of the ancient philosophers, and so forth, have associated women with nature and personified the Earth and nature generally as female (Griffin). The domination of women and nature appears to stem from a single source: patriarchy (literally, father-rule). Criticize and overcome patriarchy, the principal ideological force responsible for the domination of women, and one will at the same time have criticized and overcome the principal ideological force responsible for the degradation and destruction of nature. According to Marti Kheel, "for deep ecologists, it is the anthropocentric worldview that is foremost to blame.… Ecofeminists, on the other hand, argue that it is the androcentric worldview that deserves the primary blame" for the environmental crisis (p. 129).

Some environmentalists suspect such an analysis to be a thinly disguised ploy to divert the energies of the environmental movement into the feminist movement. Deep ecologist Warwick Fox (1989), for example, argues that a feminist environmental ethic focused on abolishing patriarchy is too self-serving, simplistic, and facile to be taken seriously as a panacea for environmental ills. Other movements, he points out, can make, and have made, the same implausible claim: If we only abolish the ideology of racism, capitalism, imperialism, and so on, then we will usher in the millennium and all will be right with the world, natural as well as social.

Karen J. Warren (1990) does not follow Kheel and blame the domination and subordination of nature by "man" on the domination and subordination of women by men. Rather, she argues, both forms of "oppression" are "twin" expressions of hierarchically ordered "value dualisms" reinforced with a "logic of domination." Critiques of anthropocentrism and androcentrism are mutually illuminating and complementary. A person opposed to the one ought to be opposed to the other—because subordination, domination, and oppression are wrong, whether of women by men or of nature by "man." Environmentalists should also be feminists and feminists, environmentalists. Ecofeminism is the union of the two.

An ecofeminist approach seeks to correct an alleged "male bias" in environmental ethical theory—a selection of concepts and methodology that ignores, discounts, or denigrates women's issues, concerns, and experience. Alison M. Jagger has suggested that modern Western ethics, "Enlightenment moral theory," is thoroughly male-biased since it portrays moral agents as being "disembodied, asocial, autonomous, unified, rational, and essentially similar to all other" agents (p. 367). In short, it abstracts, generalizes, universalizes. Intimately associated with this "Cartesian" moral psychology are such commonplaces of modern Western ethics as universal application of abstract principles and rules, impartiality, objectivity, rights, and the victory of synoptic and dispassionate reason over myopic and prejudicial feelings. Warren argues, accordingly, that "ecofeminism … involves a shift *from* a conception of ethics as primarily a matter of rights, rules, or principles predetermined and applied in specific cases to entities viewed as competitors in the contest of moral standing, *to* a conception of ethics as growing out of … defining relationships … and community" (pp. 141–142). She notes further that "ecofeminism makes a central place for [the more feminine, less male] values of care, friendship, trust, and appropriate reciprocity—values that presuppose that our relationships to others are central to our understanding of who we are" (p. 143).

It is surprising that ecofeminists have not warmly endorsed the Aldo Leopold land ethic, which grounds morality in such sentiments as love, sympathy, and fellow-feeling. The *locus classicus* for an environmental ethic growing out of "defining relationships" and "community" is found in Leopold's *A Sand County Almanac* (1949). Marti Kheel, however, castigates Leopold's land ethic, arguing that it epitomizes male bias. Leopold endorses hunting, historically a predominantly male activity, as a means not only of ecological management but also of experiencing our defining relationships with nature and cultivating a "love and respect" for "things natural, wild, and free."

Deep Ecology

Just as there are Democrats (with a capital "D," members of one of the two major political parties in the United States) and democrats (with a lower-case "d," persons, irrespective of party affiliation, who agree with Winston Churchill that democracy is the worst form of government except for all the others), so there are Deep Ecologists (with a capital "D" and "E") and deep ecologists (with a lower-case "d" and "e"). The latter, such as Aldo Leopold, think that ecology has profound philosophical implications that it transforms our understanding of the world in which we live and what it means to be a human being. Deep Ecologists, on the other hand, endorse the eight-point "platform" of Deep Ecology that Arne Naess co-authored with George Sessions (Devall and Sessions). Moreover, they downplay the importance of environmental *ethics*, and advocate "Self-[with a capital 'S'] realization," instead. In short, deep ecology is a philosophical orientation; Deep Ecology is an ideology.

Ethics per se, Deep Ecologists allege, assumes "social atomism," a conception of each individual self as externally related to all other selves and to unselfconscious nature (Fox, 1990). Therefore, Deep Ecologists suppose that an ethical act on the part of an atomic moral agent involves grudgingly considering the interests of other morally considerable beings equally and impartially with his or her own. But for people actually and consistently to behave ethically—as thus characterized—is as rare as it is noble. Therefore, even if environmental ethics could be broadly infused, environmental destruction and degradation would be little abated.

However, the metaphysical implications of ecology undermine the social atomism upon which ethics is supposedly premised. We human beings are internally, not externally, related to one another and to non-human natural entities and nature as a whole. "Others" cannot be cleanly and neatly distinguished from ourselves. Our relationships, natural as well as social, with "them" are mutually defining. We are embedded in communities, biotic as well as human. If we could only realize that the environing world is ultimately indistinguishable from ourselves, then we could enlist the powerful and reliable motive of self-interest in the effort to reverse environmental degradation and destruction (Naess).

The process of Deep Ecological Self-realization is experiential as well as intellectual. Through practice as well as study, we should cultivate a palpable sense of identification with the world. Nature-protecting behavior will flow from experiential identification with nature. Warwick Fox (1990) has suggested that Deep Ecology should actually be renamed "transpersonal ecology," since, as in transpersonal psychology, the goal of Self-(with a capital "S") realization involves self-(with a lower-case "s") transcendence.

Deep Ecology's suspicions about the efficacy of environmental ethics seems to be based upon a narrow characterization of ethics that excludes sentiment-based communitarian ethics like the Leopold land ethic and its ecofeminist correspondents. Ecofeminists have also sharply criticized Deep Ecology because it seems to "totalize" and "colonize" the "other" (Cheney; Plumwood). With the important exception of Naess, Deep Ecologists either explicitly or implicitly claim that the integrated, systemic ecological world view is true and regard other ways of constructing nature and the relationship of people to nature to be false. A cornerstone of feminism is openness to the experience of women, experience that is quite varied. The experience of all or even of most women may not jibe well with Deep Ecological Self-realization. Hence the Deep Ecologists' often doctrinaire assertions about how the world is really and truly organized and how we *ought* to experience it are anathema to most ecofeminists.

Pluralism

The term "pluralism" in ethics characterizes two things equally well.

What we might call "social pluralism" is the view that diverse and often mutually inconsistent ethical outlooks should be respected and that there may not be any single moral principle or set of principles, however basic, that all moral agents must acknowledge. Human rights, for example, may be widely acknowledged in the West, but not in other parts of the world; hence, from a social pluralist's point of view, for Western governments to try to impose standards of human rights upon non-Western societies is inappropriate.

Personal pluralism, on the other hand, is the view that a single moral agent may endorse a variety of different moral principles, some of which may be mutually inconsistent, and employ one or another in different morally charged situations. For example, in resolving ethical questions about diet, a personal pluralist might apply Singer's principle that one should not cause sentient beings unnecessary suffering and therefore decide not to eat factory-farmed meat. In resolving ethical questions about abortion, he or she might apply Schweitzer's reverence-for-life principle and vote for an anti-abortion candidate for public office. And, in resolving ethical questions about species conservation, the same person might embrace Leopold's principle that one should preserve the integrity, stability, and beauty of the biotic community and help save an endemic plant species by shooting the feral goats or pigs threatening it.

Social pluralism appears attractive because it seems to imply inclusiveness and tolerance. In extremis, however, social pluralism is vulnerable to the same sort of criticism that ethical relativism, in extremis, has attracted. A social pluralist recognizes no universal ethical values or principles, he or she has no means of ethically challenging any one else's sincerely held moral beliefs. Further, if there are no universal ethical values or principles upon which to base agreement, then radical and intractable differences of moral outlook are irreconcilable. How then can they be resolved except by coercion?

Personal pluralism arose in environmental ethics because finding a single moral principle that could guide our actions in respect to other people, animals, plants, species, ecosystems, the atmosphere, the oceans, and the biosphere proved difficult (Stone). Moreover, our inherently rich and complicated moral lives may be distorted if reduced to a single master principle of action and we are frequently misled if we try rigorously to follow one (Brennan). According to Mary Midgley (1992), we may read the history of Western ethical theory, from Plato and Aristotle to Singer and Leopold, not as a series of formulations of and justifications for competing master principles of action, but as a series of illuminating insights into human ethical experience that can deepen our moral reflection and help us to make wise practical choices.

Proponents and critics alike of personal pluralism have noted some obvious problems. An agent who has a variety of principles and their theoretical justifications at the ready, with no faithful commitment to any of them required, may be tempted to choose the most convenient or self-serving. But all ethics, whether pluralistic or unitary, assume good will on the part of moral agents. A more difficult problem is how to select which principle to apply when more than one is relevant at some moment of decision, and when those that are relevant indicate different and incompatible courses of action. But to demand an algorithmic solution to this problem is to beg the question against personal pluralism.

Moral principles, however, do not exist in an intellectual vacuum (Callicott, 1990). They are often derived from and are always associated with a complex of supporting ideas—usually an ethical theory, which is in turn supported by a moral philosophy. In choosing to act upon a moral principle, a personal moral pluralist thus also endorses—whether consciously or not—the ethical theory and ultimately the moral philosophy supporting it. But the ethical theories and moral philosophies supporting such popular principles as the Christian golden rule, the Aristotelian golden mean, the Kantian categorical imperative, the utilitarian greatest-happiness principle, and so on, offer radically different visions of nature and human nature. Are we morally autonomous rational ends-in-ourselves for whom nature exists only as means, as Kant argues; or are we vessels of pleasure and pain, equal in this morally relevant respect to all other sentient animals, as Singer holds? How can we be both at once?

Communitarianism

A communitarian moral philosophy might provide a coherent sense of self and world without compromising the richness and complexity of our moral lives or attempting to derive all ethical actions from a single principle. Suppose that ethics, as Darwin argued, is correlative to society; that at this stage of human social evolution, we are simultaneously members of many communities or societies, including families, neighborhoods, towns or cities, nation-states, the global human community, the mixed human-domestic animal community, and the biotic community; and that a spectrum of different and not always compatible duties and obligations grow out of our various social relationships—for example, to provide our children with affection, to watch our neighbors' houses when they are away on vacation, to donate old clothes to the Salvation Army, to pay our taxes, to relieve world hunger, to boycott factory-farmed meat, and to help preserve biodiversity.

Right and wrong behavior in respect to family and family members, humanity and human beings, the biotic community and wild animals and plants, grows out of the very different kinds of communal relationships that we bear in these very different cases. Hence what is right in the context of one kind of community (feeding domestic animals, who are members of the "mixed community," for example) may be wrong in another (feeding wild animals, who are members of the biotic community). A multiplicity of community-generated principles guides our actions, but this multiplicity is united and coordinated by a single general understanding of how our various duties arise and to whom they apply. A coherent moral outlook like this certainly does not automatically determine the best course of action when one's multiple duties conflict. But one can at least hope rationally to decide, in circumstances of hard choice, which of several relevant but conflicting duties is the most pressing because they can all be expressed in comparable and commensurable terms.

J. BAIRD CALLICOTT (1995)
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SEE ALSO: *Animal Welfare and Rights; Environmental Health; Environmental Policy and Law; Population Ethics;* and other *Environmental Ethics* subentries

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II. DEEP ECOLOGY

Deep ecology is a comprehensive worldview of humans in harmony with nature, an "ecosophy" ("ecowisdom") that responds to ecological crisis. It is also a movement to translate this worldview into radical societal reform. Supporters of the deep ecology movement contrast their position with "shallow" reform movements, holding that every living being has intrinsic or inherent value that gives it the right to flourish, independent of its usefulness for humans. All life is interrelated, and living things, humans included, depend on the support of others. For supporters of deep ecology, who tend to oppose the degradation of nature except to satisfy vital needs, the long-range integrity and health of the ecosystems of Earth are of fundamental ethical importance.

The ecological crisis has deep roots in misguided, anthropocentric attitudes about the dominion of humans on Earth. These exploitative, consumptive attitudes, according to the position of deep ecology, cannot be overcome without significant social changes, including changes in the lifestyles of those who live in the rich countries. Such changes can emerge only from a philosophical or religious basis that nurtures a sense of personal responsibility, not simply to persons living now but also to future human generations as well as fauna and flora. The current human population is already too large in many countries; further human population increases will lower the quality of life for both humans and nonhuman forms of life. A smaller human population is desirable and can be achieved by reduced birthrates over several centuries.

The position of the deep ecology movement can be illuminated by contrasting it with the position of so-called shallow ecology. The shallow position considers it unnecessary or even counterproductive to take up philosophical or religious questions to solve the ecological crisis. Its supporters argue that reforms of existing practices are needed, but reforms of basic principles are unnecessary. Those who advocate the shallow position do not find intrinsic value in nonhuman life forms, nor do they find the consumptive economic system problematic. Humans ought to exploit nature, though prudently. High standards of living are not objectionable, and can be raised even further by concentrating on investment in science and technology. Attempts should be made to bring less-developed nations up to this standard.

The deep ecology movement's historic forebears include Henry David Thoreau and John Muir. Aldo Leopold and Rachel Carson, also of the United States, are more recent pivotal figures. In 1962 Carson's book *Silent Spring* set off an ecological alarm. Starting with practical issues related to pesticides, Carson probed the philosophical assumptions underlying this attack on pests that stood in the way of human progress. In Europe such ecological concerns joined with the peace and social justice movements to create the first wave of the "green movement." Australians also became involved. In eastern Europe, ecologists were judged hostile to state-sponsored industrial development, and were banned. In the Third World, long-term ecological sustainability often had to take second place to short-term economic survival.

The deep ecology movement argues for ecological sustainability, human development that conserves the richness and diversity of life forms on Earth. This position, often said to be biocentric (centered on life) rather than anthropocentric (centered on human life only), includes what Leopold called "the land": the whole community of life on the landscape—rivers, mountains, canyons, forests, grasslands, and estuaries. Reforestation, for example, does not mean large tree plantations, producing timber and fiber for humans. Such plantations, which lack the biodiversity, complexity, health, and integrity of spontaneous natural ecosystems, are not genuine biological communities.

Those who advocate deep ecology and the more shallow reformers must learn to cooperate. Some strengths of each approach can be combined; some weakness of each, offset. The former sometimes become lost in utopian visions of a "green world"; the latter may be too absorbed in ad hoc, short-range solutions. The former can press for, and practice, more modest standards of living and support higher prices for nonvital products. Those who are less "deep" can be more pragmatic, willing to respond to what is currently politically realizable reform. Through such cooperation the supporters of both movements may help avoid crises likely to occur if ecologically responsible policies are forced too soon and too fast on populations that are not prepared for them. The deep premises of argumentation add to the utilitarian arguments, which are shallow in relation to philosophical and religious premises, needing more depth of analysis of the problem.

The discussions surrounding deep ecology have implications for the medical area of bioethics as well. "Rich life, simple means," an aphorism of the deep ecology movement, suggests for medical bioethics a strengthening of preventive medicine and a reduced reliance on technically advanced treatments, especially if they require large investments of resources and energy. Medical bioethics can learn from ecological bioethics the need for a moral vision that can reorder its priorities.

ARNE NAESS (1995)

SEE ALSO: *Animal Welfare and Rights; Endangered Species and Biodiversity; Future Generations, Obligations to; Jainism, Bioethics in; Native American Religion, Bioethics in; Population Ethics; Population Policies; Value and Valuation; Xenotransplantation* and other *Environmental Ethics* subentries

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III. LAND ETHICS

After graduating from the Yale Forest School, Aldo Leopold (1887–1948) joined the U.S. Forest Service in 1909 and served for fifteen years. He resigned to pursue his interest in wildlife ecology and management; in 1933 he was named Professor of Game Management and inaugurated a doctoral program in the subject at the University of Wisconsin. Over the course of his multifaceted career, Leopold came to believe that human harmony with nature could be achieved only if, in addition to governmental management and regulation, private citizens (and property owners in particular) acquired a "land ethic." Such an ethic would make ecosystems and their parts direct beneficiaries of human morality: "A land ethic changes the role of Homo sapiens from conqueror of the land community to plain member and citizen of it. It implies respect for his fellow-members, and also respect for the community as such" (Leopold, 1949, p. 204).

Leopold is routinely called a modern American "prophet." *A Sand County Almanac,* his slender book of literary and philosophical essays, has become the "bible" of the contemporary environmental movement in the United States. And his land ethic is the environmental ethic of choice among most American environmentalists and conservationists, both amateur and professional. It rests upon secular scientific, not sectarian or supernatural religious, foundations. It is less rigidly doctrinaire than deep ecology's eight-point ethical "platform." Unlike ecofeminism, it focuses directly on the human-nature relationship, unrefracted by the alleged historical oppression of women by men. And, in sharp contrast to Western ethical paradigms, it has a holistic dimension that can ground environmental policy and law respecting endangered species and biodiversity.

In the foreword to *A Sand County Almanac,* Leopold (1949, pp. viii–ix) identifies the central eco-axiological theme: "That land is a community is the basic concept of ecology, but that land is to be loved and respected is an extension of ethics. That land yields a cultural harvest is a fact long known, but latterly often forgotten. These essays attempt to weld these three concepts." Its forty-odd essays document two decades of Leopold's reflective intimacy with the natural world; they span the North American continent from Mexico to Canada and from the Southwest to the Midwest; and they range in style from pastoral vignettes to didactic sermonettes. Part One introduces the basic ecological concept of a biotic community (or ecosystem) personally and experientially through artful seasonal sketches of Leopold's beloved 120 acres of Wisconsin River bottomland. The regional sketches of Part Two develop the community concept in ecology more intellectually, generally, and abstractly. The prescriptive essays of Part Three frankly and forcefully explore the ethical and aesthetic implications of the community concept in ecology. The final essay, "The Land Ethic," is the book's philosophical climax and consummation.

The Biological Paradigm

Though liberally educated, Leopold was primarily a student of biology, not of philosophy. Hence his thinking about ethics was influenced more by Charles Darwin than by Immanuel Kant and Jeremy Bentham, the fountainheads of the two major modern paradigms in ethics—deontology and utilitarianism, respectively—both of which proceed somewhat as follows: I demand that others dutifully respect my rights (in the deontological tradition) or take full account of how the consequences of their actions affect my interests (in the utilitarian). To defend that demand, I identify a characteristic I possess that arguably justifies my claim to moral rights or to consideration of my interests. According to Kant, it is rationality; according to Bentham, sentience. If I am to be consistent in my moral reasoning, then I must acknowledge that those who possess the same morally enfranchising property are entitled to the same regard from me as I demand of them. In short, the prevailing modern paradigms reach the moral standing of others starting from one's claim against others of one's own moral standing.

In sharp contrast, the biological paradigm, the paradigm in which Leopold works, starts with altruism, not egoism. Human beings are bonded to their fellows through sympathetic feelings and what David Hume and Adam Smith call the moral sentiments. The prehuman ancestors of Homo sapiens, whose survival and reproductive success greatly depended upon communal living, sympathy, and the other moral sentiments, were strengthened by natural selection and ever more broadly cast through social expansion. With the evolution of the powers of speech and reflection, forms of behavior that accorded with altruistic and social sensibilities were articulated in codes of conduct. As clans merged into tribes, tribes into nations, and so on, such codes were extended to each emergent social whole and its members. Leopold (1949, p. 202) comments that "Ethics, so far studied only by philosophers, is actually a process in ecological evolution." And he alludes to natural selection when he defines an ethic from a biological point of view "as a limitation on freedom of action in the struggle for existence." That he built directly and self-consciously upon this scenario of ethics arising out of community membership, which Darwin had fully articulated in the Descent of Man, therefore, seems certain. To the evolutionary foundation laid by Darwin, Leopold adds crucial material from ecology—the "community concept," especially—in order to erect his land ethic.

In Leopold's (1949, p. 203) own words: "All ethics so far evolved rest upon a single premise: that the individual is a member of a community of interdependent parts." That is Darwin's account of the origin and development of ethics in a nutshell. Ecology "simply enlarges the boundaries of the community to include soils, waters, plants, and animals, or collectively: the land" (p. 204). When this novel ecological insight is added to Darwin's classic evolutionary account of ethics, Leopold believes that the land ethic follows. Therefore, he writes, "A thing is right when it tends to preserve the integrity, stability, and beauty of the biotic community. It is wrong when it tends otherwise" (pp. 224–225).

Most contemporary environmental philosophers follow another path to an environmental ethic. They work well within either deontology or utilitarianism, and proceed to extend ethical standing to nonhuman beings by lowering the qualifications for moral rights or for consideration of interests. "Animal liberation" follows from Bentham's first principles virtually without modification, if we acknowledge that most animals are sentient. And "animal rights" follows from Kant's first principles if we acknowledge that while few, if any, animals may be rational, many have sufficiently robust mental capacities to support claims of rights on their behalf. Of course, animal welfare ethics are not the same as environmental ethics. But, taking the next step along these parallel paths, other philosophers have variously argued that all things having interests, broadly construed, or goods of their own—that is, all living beings—deserve, if not rights, then either dutiful respect (according to the deontologists) or moral consideration (according to the utilitarians).

From Facts to Values

To most moral philosophers, the biological paradigm seems to be more a scientific theory about ethics than a normative theory of ethics. And Leopold's facile move from an ecological "is" (that Homo sapiens is a plain member and citizen of the biotic community) to an environmental "ought" (that therefore we ought to preserve the integrity, stability, and beauty of the biotic community) seems to commit the naturalistic fallacy—the fallacy (named by G. E. Moore, but attributed to David Hume) of deducing prescriptive statements about our moral obligations and ethical values exclusively from descriptive statements about the way things in fact are.

The two major modern philosophical paradigms, on the other hand, seem strained to the breaking point when one attempts to extend rights or entitlements to an entire species or to whole ecosystems, let alone "soils and waters." The Leopold land ethic, grounded in feeling and community, better accords with the holistic focus of contemporary environmental concerns. Environmentalists and conservationists are not too concerned about the well-being of individual grubs, bugs, and shrubs. They are concerned, rather, about what pollution is doing to Earth's atmosphere, fresh waters, and oceans; about what fragmentation is doing to ecosystems; about endangered species and biological diversity.

Contemporary environmental philosophers thus face a theoretical dilemma. Cling to the modern paradigm and remain out of phase with the more holistic character of genuine environmental concerns, or give up the intellectual security and familiarity of the modern paradigm, follow Leopold's application of the biological paradigm to environmental concerns, and work to solve the daunting problem of deriving environmental ethical values from facts about human moral psychology, evolutionary biology, and ecology.

Ironically, Hume himself may provide the key to bridging the lacuna between "is" and "ought," fact and value, and thus clear the way for environmental philosophers to embrace the biological paradigm of ethical theory that the land ethic extends. "Reason," our tool for determining facts, according to Hume (1960, p. 469), "in a strict and philosophical sense can have influence on conduct only after two ways: either when it excites a passion [such as the love and respect that Leopold identifies with ethics] by informing us of the existence of something which is a proper object of it; or when it discovers the connexion of causes and effects, so as to afford us means of exerting any passion." Dispassionate, descriptive evolutionary biology, a product of what Hume calls "reason," has discovered that human beings and other extant forms of life are descended from common ancestors. Evolutionary biology thus discloses a previously unknown fact: that we are literally kin to "our fellow-voyagers … in the odyssey of evolution," as Leopold (1949, p. 109) characterizes them. The discovery of the fact excites the passions—love and respect—we feel for our kin. Equally dispassionate and descriptive ecological biology has discovered the existence of the biotic community, of which we are no less members than of our various human communities. And the discovery of that fact excites the passions—loyalty and patriotism in this case—that we feel for the social wholes to which we belong. Thus may we move from facts to values, from "ises" to "oughts," in the land ethic, after a manner, according to Hume, that is so strict and philosophical.

J. BAIRD CALLICOT (1995)

SEE ALSO: *Animal Welfare and Rights; Endangered Species and Biodiversity; Environmental Health; Environmental Policy and Law; Life; Virtue and Character;* and other *Environmental Ethics* subentries

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IV. ECOFEMINISM

"Environmental ethics" refers to a wide range of normative positions, from traditional Western, utilitarian, rights- and justice-based ethics to nontraditional and non-Western ethics. Feminist concerns in environmental ethics span this broad range of positions. However, one feminist position is distinctive: ecological feminism.

"Ecofeminism" is expressly committed to making visible the nature and significance of connections between the treatment of women and the treatment of nonhuman nature, or "women-nature connections." Ecofeminism claims that understanding women-nature connections is essential to any adequate feminism or environmental ethic.

Varieties of Ecofeminism

Just as there is not one feminism, so there is not one ecofeminism. "Ecofeminism" is a term that refers collectively to various environmental perspectives with roots in different feminisms: liberal feminism, traditional Marxist feminism, radical feminism, socialist feminism, and Third World feminism. These roots give rise to different, sometimes competing, ecofeminist positions on the nature and resolution of contemporary environmental problems. What makes them ecofeminist is their explicit focus on "women-nature connections."

Consider the range of women-nature connections explored by ecofeminism (see Warren, 1993). Some ecofeminists discuss *historical* connections: for example, the role rationalism has played in Western philosophy and science in justifying the inferiorization of what is associated with female nature (Plumwood). They argue that to the extent that either the concept or the ascription of reason historically has been applied only to (some) human males, rationalism has been male-gender-biased. The male-gender bias arises from the mistaken assumption that women (and, typically, men of color) are incapable of the impartial, objective, abstract, universalizable reason by virtue of which rational men are both distinguished from and superior to nonrational "nature" (see Warren, 1989). These ecofeminists argue that philosophical conceptions of the human self, ethics, and culture that rely on Western historical conceptions of reason will thereby be male-gender biased (see Warren, 1989).

Some ecofeminists discuss *conceptual* women-nature connections: for example, the way women and nature have been conceived as inferior to male-identified reason and culture. Many ecofeminists claim that the twin dominations of women and nature grow out of and reflect oppressive ways of thinking. These are characterized at least minimally by value dualisms (mind/body, reason/emotion, man/woman, culture/nature), value hierarchies (assigning greater status, value, or prestige to what is "up" in "up-down" hierarchies), conceptions of power as power of "ups" over "downs," conceptions of privilege that systematically favor the "ups," and a logic of domination (the assumption that superiority justifies subordination) (Warren, 1990). On this view, oppressive patriarchal conceptual frameworks sanction behaviors that maintain the domination of women and nature.

Ecofeminists discuss *empirical* women-nature connections: for example, Third World women as managers of domestic households, primary gatherers of food and fuel (typically wood), and collectors and distributors of water (see Warren, 1992). These women must walk further for fuel and suffer greater exposure to contaminated water; in Western countries, poor women, men, and children of color face increased health risks associated with radioactive waste and hazardous waste incinerators (Warren, 1992; Commission for Racial Justice, 1987). Development policies and practices do not recognize the distinct gendered division of labor experienced by Third World women, or the gender, race, and class factors that contribute, even if unconsciously and unintentionally, to the subordination of women and people of color cross-culturally.

Ecofeminists also are interested in *epistemological* and *methodological* women-nature connections. At least 80 percent of the farmers in Africa are women, and women grow about 60 percent of the world's food (see Warren, 1992). A study in Sierra Leone showed that while local men could name an average of eight products of nearby bushes and trees, local women could identify thirty-one (see Warren, 1992). Such data suggest that women often have "indigenous technical knowledge" (ITK) or farming and forestry due to their gendered-role responsibilities in these areas (see Warren, 1992). Consequently, issues of epistemology and methodology in framing environmental ethics, policy, and decision making must ask not simply "What is known?" but "Who has the requisite knowledge and expertise?" According to ecofeminism, what women know as household managers of domestic economies, forests, and agriculture is important to the development of environmental ethics.

Symbolic associations between women and nature appear in art, literature, religion, and philosophy. This is especially evident in the sexist, naturist, and ageist language used to describe women and nonhuman nature. Women are characterized frequently as cows, sows, foxes, chicks, bitches, beavers, dogs, mares, dingbats, old bats, pussycats, birdbrains, harebrains, and serpents. They are pets, dolls, babes, childlike, whiny, "domesticated creatures." Nature is raped, mastered, mined, penetrated, domesticated, manipulated, conquered, and controlled by "the man of science." Virgin timber is felled, cut down; land that lies fallow is barren and useless (not "impotent" and "sterile"). (Similarly, men of color are disproportionately described in the subordinating language of the "downs" as animals, studs, dicks, weasels, wolves, unruly and dangerous "savages" driven by "animalistic instinct"; as docile, wimpy, sissy, childish, or childlike, and not fully rational; as childlike, simple [nonrational] "slaves" who need the guidance and protection of the paternalistic master, the "up.") In a patriarchal context, whatever is woman-, animal-, nature-, or even child-identified has historically been inferior ("down") to what is man-, male-, human-, adult-, or culture-identified. Thus language that feminizes animals and nature, animalizes and naturalizes women (and some men), or describes women, nature, and some men as domesticated pets or children, serves to reflect and reinforce their inferiorization.

What, then, about the allegedly positive connotations of "Mother Nature" or "Mother Earth"? Ecofeminists disagree about whether such female-gendered language truly liberates or merely reinforces harmful gender stereotypes (see Roach). However, all ecofeminists agree that within a patriarchal context, where gendered language has functioned historically to elevate that which is associated with men and male culture, its uncritical continued use in the prefeminist present is problematic.

Finally, there are *political* ("*praxis*") women-nature connections. The term "ecofeminism," coined by Françoise d'Eaubonne in 1974, has always referred to grass-roots activism by local women interested in bringing together feminist environmental concerns. Whether it is the Chipko women in India, who are attempting to save trees from commercial fiber producers by hugging the trees, or Native American women, who are protesting the dumping of uranium mining residue on their lands, or the thousands of women from various cultures who gathered to develop strategies for policy and community organizing to combat water pollution, soil erosion, deforestation, and desertification at planning sessions, conferences, and seminars in conjunction with the Earth Summit in Rio de Janeiro in 1992, ecofeminism has always been grounded in grass-roots, local community political organizing (see Lahar). Properly understood, then, ecofeminist ethics is largely a theoretical response to such grass-roots political concerns involving women's lives globally.

Contributions of Ecofeminism

One might summarize ecofeminism's contributions to environmental ethics as threefold: First, ecofeminism challenges male-gender bias wherever and whenever it occurs. Second, ecofeminism offers a corrective lens to oppressive male-gender bias by self-consciously attempting to develop environmental analyses and positions that are not male-gender-biased. Third, ecofeminism offers a transformative perspective in environmental ethics, one that builds on but goes beyond both feminisms that do not have an adequate environmental component and environmental ethics that does not have a distinctly feminist component.

Ecofeminism does this by using a feminist lens to form different insights about women-nature connections; those environmental ethics that do not include (eco)feminist insights are viewed by ecofeminists as either antifeminist or nonfeminist. Nonfeminist environmental ethics, unlike antifeminist environmental ethics, is not ipso facto male-biased; its claims and conclusions might be quite compatible with and supportive of ecofeminist ethics. What an explicitly (eco)feminist environmental ethic does is overtly challenge androcentric (male-centered) bias in the way environmental ethics is conceived and practiced. For this reason, many ecofeminists criticize other environmental ethics (e.g., deep ecology, traditional Western ethics) for either their androcentric bias or their inattention (however inadvertent or unintentional) to important historical and empirical data about women-nature connections. Ecofeminists insist that within the intellectual traditions of the past few thousand years and at least of Western cultures, anthropocentrism (human-centeredness) has functioned historically as androcentrism (male-centeredness); failure to see this results in a gender blindness that is harmful to the framing of an environmental ethic or philosophy.

Similarly, ecofeminist conceptual concerns challenge the dominant notions of reason, knowledge, and objectivity, as well as the dominant notions of the human self that underlie them, that have been a mainstay of Western philosophical and environmental ethics. What ecofeminists seek is the development of different, nonoppressive notions of each that change or expand how the notions of reason, knowledge, objectivity, and the human self are conceived. In this vein, many ecofeminists challenge the extension of rights by animal-rights ethics to some nonhuman animals because those rights are based on historically intact, unrevised (and hence problematic) notions of the human self as moral agent (claimant, right holder, interest carrier) separate from and superior to lower plant and inorganic life.

Ecofeminist epistemological concerns raise related issues about the underrepresentation of women's voices in environmental ethics. Such concerns prompt ecofeminists to criticize, for example, land ethicists for their apparent lack of interest in gender issues. Ecofeminist concerns about gendered language and nature symbols (e.g., Mother Earth) challenge those environmental ethics (e.g., stewardship ethics) that uncritically adopt or perpetuate gender-exclusive or gender-problematic language and symbol systems (see Adams). Ecofeminist political concerns about unequal distributions of power and privilege in maintaining systems of domination (e.g., domination over women and nature) challenge any environmental ethic uncorrected by feminism to pay more attention to power and privilege in discussions of environmental ethics (see Warren, 1990).

Concluding Remarks

In conclusion, ecofeminist ethics is a self-consciously feminist-biased ethics insofar as it consciously, intentionally, and explicitly adopts a feminist perspective as the organizing lens through which any environmental ethic is constructed. Despite their critics (see Biehl; Fox), ecofeminists argue that in contemporary patriarchal society, the label "feminist" *does* add something important to the nature and description of environmental ethics; in a nonpatriarchal context, "feminist" concerns may well be unnecessary and the label "feminist" may drop away (see Warren, 1990). But for now, ecofeminist ethics reminds us that in contemporary patriarchal culture, there are important ways in which the domination of nature and the domination of women are linked, and that failure to acknowledge such links perpetuates the mistaken view that feminism does not contribute anything significant to any environmental or biocentric ethics.

KAREN J. WARREN (1995)
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SEE ALSO: *Care: Contemporary Ethics of Care; Endangered Species and Biodiversity; Environmental Health; Environmental Policy and Law; Ethics: Normative Ethical Theories; Feminism; Hazardous Wastes and Toxic Substances; Women, Historical and Cross-Cultural Perspectives;* and other *Environmental Ethics* subentries

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ENVIRONMENTAL HEALTH

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Environmental health is “the segment of public health that is concerned with assessing, understanding, and controlling the impacts of people on their environment and the impacts of the environment on them” (Moeller, p. 1). The importance of environmental health has received increasing attention since the early 1990s as the connections between health and environment have come to be better understood and environmental challenges to health have become more pronounced.

Environmental health problems arise from poor air quality, lack of clean water, unhygienic living conditions, dangerous workplaces, unsafe food, careless disposal and treatment of wastes, and toxic pollution. A number of longer-range and more globally dispersed problems also pose significant challenges to health, including global climate change, depletion of the ozone layer, acid rain, nitrogen loading, loss of biodiversity, deforestation, loss of topsoil, increased pressure on resources as a result of changing patterns of consumption, and a rapid increase in the human population (McMichael, 2001; McCally, 2002).

The Global Environmental Health Picture

Although health around the world improved on average over the last half century—due mainly to improvements in environmental health fundamentals such as access to clean water, nutritious food, and adequate sanitation, alongside public health basics such as prenatal care and immunizations—it is likely that these gains will be lost if the environmental foundation for health continues to deteriorate. Billions of people already suffer from the effects of degraded environments: At the beginning of the twenty-first century fully one-third of the global burden of disease was attributed to environmental factors (Murray and Lopez).

Lack of clean water for drinking, inadequate sanitation, and lack of hygiene affect a third to a half of the world’s population and are responsible for 7 percent of all death and disease globally. Chemical agents, particularly in the form of air pollution, are considered major causative factors in increased rates of bronchitis, heart disease, and cancer. The incidence of asthma is mushrooming. Certain forms of cancer are on the rise. The health of people around the world is diminished by exposure to toxic substances such as lead, mercury, arsenic, cadmium, and dioxins. As local and global ecosystems show increasing signs of stress, human health is likely to become far less stable and far more difficult to maintain. Children are hit especially hard by environmental health problems: The World Health Organization estimates that environmental hazards kill at least 3 million children under age five each year (United Nations Environment Programme).

There is a broad international consensus that the earth’s ecosystems are under considerable strain, and global environmental decline will be the defining public health context in the twenty-first century (McMichael, 2001). According to an international report, the overall health of the earth’s natural systems declined by 37 percent in the 1990s (World Wildlife Fund), fueled largely by population growth combined with unsustainable levels of consumption and production, which have increased in aggregate even more quickly than have human numbers.

Environmental Health in the United States

Concern with environmental health in the United States has long focused almost exclusively on the problem of toxic pollution, and concern about toxins has shaped the American regulatory, legislative, and philosophical approach to environmental health. Since the publication of *Silent Spring* (Carson) the country has been alerted to the mortal danger of exposing human beings and other life-forms to many products and by-products of an industrialized lifestyle. Although the negative effects of environmental pollution on human health cannot be denied, the existence and magnitude of danger associated with particular processes and products remain controversial.

One reason for the controversy is that powerful interests typically have a stake in denying that their industries create health hazards. Nuclear industries deny that low-level radiation causes cancer. Cigarette manufacturers deny a causal link between passive smoking and cancer. Manufacturers of asbestos products take a similar stand about asbestos, as do manufacturers of agricultural pesticides in regard to their products.

A second reason for the continued controversy is that because causal connections between human health and environmental pollution are inherently difficult to establish, the affected industries can hire competent scientists to dispute claims of environmental hazards to human health. In general, three types of evidence can be used to show that an environmental constituent is a health hazard, but none can establish that connection beyond dispute (Luoma).

First, nonhuman animals can be exposed to a suspected health hazard and the effect can be observed. This cannot prove anything conclusively about human exposure because human beings are biochemically different from nonhuman animals. Also, to establish a connection quickly and at minimal cost, nonhuman animals often are exposed to doses much larger than those to which human beings are expected to be exposed. The effect of a small dose on human beings cannot be established conclusively from evidence about the effects of much larger doses on nonhuman animals.

A second method of investigation is to expose human beings over short periods to mild doses of materials suspected of causing serious health problems when exposure is considerably greater or more prolonged. The problem here is that some substances may be so toxic that it would violate human rights to expose people deliberately even to mild doses. Other substances, in contrast, may not have a deleterious effect at low levels of exposure but may be toxic at higher concentrations or over longer periods. In these cases public health hazards may be underestimated or missed entirely.

Third, in epidemiological studies a substance is tested by comparing the rate of disease in one population with that in another in an attempt to correlate differences between the two populations' rates of disease with differences in their rates of exposure. However, it is difficult to establish in that way a connection between a specific suspected toxin and illness or death because under normal conditions people are exposed constantly to many suspected toxins of various strengths for varying periods. It therefore is difficult to isolate the effect of any single substance. Also, the effect of exposure, if there is one, is often weak. In a small population, for example, few additional cancers can be expected to result from exposure to low-level radiation. In addition, the cancer effect is long delayed and spread out in the population over a forty-year period, making it difficult to detect at any specific time (Stewart). Finally, radiation exposure and cancer exist in the human population in any case, and so it is impossible to determine that any given cancer is caused by exposure to low-level radiation or that the low-level radiation in question is related, for example, to a nuclear industry (Stewart).

Basically the same considerations apply when the issue is the effect of exposure to passive smoking, asbestos, or agricultural pesticides. Thus, controversies can continue for decades. Nevertheless, the weight of evidence supports the claim that the exposure of human beings to chemicals and other products and by-products of industrial civilization is often harmful to human health.

The Problem of Toxins in the United States

"Since the 1950s, age-standardized cancer incidence rates in the U.S. have increased by 43.5 percent" (Epstein, 1992, p. 233). Death from cancer has increased at a similar rate. The best attempts to isolate the causes of cancer have resulted in the conclusion that environmental factors account for 60 to 90 percent of cancers. The rest are attributable to inherited tendencies and internal biochemical malfunctions (Epstein, 1987).

Studies have shown cancer effects from doses of radiation that previously were thought to be safe. In one study a distinguishing fact about children who died of cancer before age ten compared with both those who died of other causes and those who survived to age ten is that the cancer victims' mothers received on average twice as many X rays while pregnant (Stewart). Another study showed a strong statistical association between a father's exposure to external radiation while working at a nuclear-waste reprocessing plant before a child was conceived and that child's chance of contracting leukemia (Gardner).

Radiation is not the only risk factor for cancer: Pesticides and other chemicals are implicated as well. A study showed that the mammary adipose tissue of women with breast cancer contained significantly more residues of chemicals associated with pesticides than did the mammary tissue of women with nonmalignant tumors (Falck et al.). Another study revealed that among white male scientists and engineers those who were members of the American Chemical Society had significantly more deaths from leukemia and lymphatic cancer (Arnetz et al.). A study of men from Iowa and Minnesota showed a link between elevated environmental chemical exposures that resulted from living near a factory and two types of cancer: non-Hodgkin's lymphoma and leukemia (Linos et al.). Non-Hodgkin's lymphoma also has been linked to the use of certain pesticides (Weber). Foundry workers in Denmark who were exposed to elevated levels of silica dust, metallic fumes, carbon monoxide, and several organic chemicals had markedly elevated rates of lung cancer (Sherson et al.). Occupational exposure to asbestos is considered responsible for 8,000 to 12,000 deaths each year in the United States (Rauber).

Typically, years intervene between exposure to environmental contaminants and an associated cancer or death. However, in some cases the connection between environmental pollution and human mortality is more direct. The "U.S. Office of Technology Assessment estimates that the mix of sulphates and particulates in ambient air may cause 50,000 premature deaths in the United States each year—about 2 percent of annual mortality" (Postel, 1986, p. 34). Toxic chemicals released into the air in 1988 were estimated by the U.S. Environmental Protection Agency (EPA) to cause "up to 3,000 cases of fatal cancer yearly as well as birth defects, lung disease, nervous system disorders, liver damage, and other health problems" (U.S. General Accounting Office, p. 8). When all types and sources of air pollution are considered, the American Lung Association puts the toll at 120,000 premature deaths per year (French).

There is increasing evidence that indoor air is often a health hazard. Radon in homes is believed to be a leading cause of cancer. The "sick building" syndrome is also a concern; it is the phenomenon of buildings inducing illnesses of various sorts in a large percentage of the people who spend considerable amounts of time in them. For example, chemicals in materials used to build and decorate the Dupage County Judicial and Office Facility in Wheaton, Illinois, were considered responsible for a variety of employee illnesses. As a result, a nearly new building was evacuated temporarily.

Scientists have been concerned particularly about exposure to heavy metals such as lead and mercury. Although exposure to lead has been reduced greatly, pockets of the population still are exposed to lead in peeling household paint, and everyone is exposed to lead in outdoor air pollution and food. The health effects of lead are well documented and include serious and irreversible impairment of children's neurobehavioral development (Brooks et al.). Mercury contamination also has been of particular concern. As with lead, the health effects of mercury are relatively well understood, largely because of several large-scale exposures, including the Minimata Bay disaster, in which a whole Japanese village was poisoned after eating mercury-laced fish. Methylmercury is absorbed readily by fish in polluted aquatic environments. When humans eat contaminated fish, the methylmercury is absorbed readily into the bloodstream and tissues. Mercury can cause tremors, dementia, and congenital neurological deformities (Brooks et al.).

Beginning in the 1990s, concern has intensified about a group of chemicals called persistent organic pollutants (POPs). Those chemicals include the polychlorinated biphenyls (PCBs); pesticides such as DDT, chlordane, aldrin, and heptachlor; and industrial by-products such as dioxins. POPs are fat-soluble and accumulate in the fatty tissues of animals, where they persist for long periods. Research suggests that POPs are "endocrine disruptors": They mimic hormones and may play a significant and largely unacknowledged role in altering reproduction and development. Endocrine disruptors have long concerned wildlife biologists, who believe that declines in avian and amphibian populations are linked to POPs in the environment (Colborn, Dumanoski, and Myers). The way in which these chemicals affect humans is unknown, although some research has connected exposure to POPs with diminished sperm quality and quantity, impaired sexual function, increased testicular cancer, hypospadias, and cryptorchidism (Solomon and Schettler).

Environmental Racism

The risks of contracting environmentally influenced diseases and deaths are not distributed evenly across the population in the United States. Geographically, the people at greatest risk are those who live near sources of industrial pollution such as factories and certain types of mines and those who live near deposits of toxic waste. For example, it seems that a geometrically increasing cancer rate for people in some communities in Cape Cod, Massachusetts, is due to toxic deposits from the nearby Otis Air Force Base (Hallowell). By 1989, 14,401 sites of toxic contamination had been noted in 1,579 military installations around the United States (Renner). When cancer rates are plotted on a map of the nation, the places that show the highest rates are areas of industrial production such as Chicago, Detroit, northern New Jersey, and the lower Mississippi valley.

There is also a disparate impact on minority communities that is referred to as environmental racism. “Three out of every five African Americans and Hispanics live in a neighborhood with a hazardous waste site, and … race is the most significant variable in differentiating communities with such sites from the communities without them” (Steinhart, p. 18). “Probably the greatest concentration of hazardous-waste sites in the United States is on the predominantly black and Hispanic South Side of Chicago” (Russell, p. 25). With 28 million pounds of toxics poured into that area annually, the U.S. Environmental Protection Agency (EPA) estimates that the risk of cancer is 100 to 1,000 times the normal risk (Lavelle). According to the federal Centers for Disease Control, “lead poisoning endangers the health of nearly 8 million inner-city, largely black and Hispanic children” all over the United States (Russell, p. 24). Rural minority groups suffer disproportionately as well: “2 million tons of radioactive uranium tailings have been dumped on Native American lands; reproductive organ cancer among Navajo teenagers is seventeen times the national average” (Russell, p. 24).

Environmental racism is international as well as domestic. Toxic waste from industrial countries has been deposited in Africa (Jacobson). Some corporations in industrial countries continue to manufacture pesticides that are considered too dangerous for use in their own countries. Those pesticides are sold to farmers in the Third World, resulting in 10,000 to 40,000 poisonings per year (Postel, 1988). The Bhopal accident, in which 2,000 people were poisoned by a chemical leak from a factory in India, highlights the fact that environmental safeguards in the Third World are sometimes inadequate. The company that owns the factory is based in the United States, where it maintains higher standards of safety in its factories.

The Legal Structure

According to traditional Anglo-American jurisprudence, when one person injures another person, the injured party can sue in court to recover damages. The legal rules governing those proceedings constitute the law of torts. This body of law is largely unhelpful, however, when injuries are due to most forms of environmental pollution because it is difficult to prove that a harm such as a case of cancer resulted from a particular emission of radioactivity or a certain dumping of toxic waste. Also, it would be inefficient for each injured party to sue individually, as was done traditionally, when the activity in question is alleged to affect many people, possibly thousands. Finally, tort actions can take place only after harm is done, and it is preferable to use the law to avoid harms when possible. Thus, the major role of government in the area of environmental health lies in the regulatory process.

In 1970 the National Environmental Policy Act was signed into law to “fulfill the responsibilities of each generation as trustee of the environment for succeeding generations.” The EPA, which was established soon afterward, required that most federally funded projects be accompanied by an environmental impact statement so that the deleterious effects of those projects could be recognized and possibly ameliorated. Subsequent legislation has given the EPA the authority, for example, to regulate processes that pollute the air and water (the Clean Air Act and the Clean Water Act); locate, authorize, and fund the cleanup of hazardous wastes (the Resource Conservation and Recovery Act, which established the Superfund); and control the use of pesticides (the Federal Insecticide, Fungicide, and Rodenticide Act). States have their own EPAs that perform similar functions.

The U.S. EPA is not the only agency with the responsibility to oversee activities that can affect environmental health. The U.S. Department of Energy (DOE) oversees the disposal of nuclear waste, the U.S. Department of Agriculture (USDA) helps determine consumer exposure to pesticide residues in food, and the U.S. Department of Labor protects the health of workers through the Occupational Safety and Health Administration (OSHA). In addition, most states have administrative agencies with similar responsibilities for intrastate activities.

Because Congress has authorized those agencies and the many subagencies through which they operate to protect the public, courts are reluctant to intervene, making private lawsuits particularly difficult. If an agency is operating within its congressional mandate and arguably is doing its job in a reasonable fashion, the courts usually will protect both the agency and those in compliance with its standards from private lawsuits seeking compensation for environmentally related illnesses. Thus, the protection of environmental health depends much more directly on the actions of those agencies than on the concerns of private citizens and their elected representatives.

Enforcement Problems

As was noted above, the protection of human health from environmental contamination in the United States is largely the responsibility of the EPA and other federal and state agencies. Unfortunately, the performance of those agencies is sometimes disappointing. The EPA's regulation of pesticides exemplifies the general problem. The EPA regulates pesticides under the Federal Insecticide, Fungicide, and Rodenticide Act. The general public is exposed to pesticides primarily through residues in food and contamination of the groundwater that serves as a major source of drinking water. The EPA recognized in 1988 that "forty-six pesticides … contaminate groundwater solely as a result of normal agricultural use" (Fultz, p. 3). However, a registered chemical can remain in use for up to fifteen years after it is discovered in groundwater before a decision is made about its continued use. An example is atrazine, a pesticide that is in widespread agricultural use (Fultz). For pesticides that already have been found to be toxic, the EPA has not lowered acceptable exposure through residues in food in light of additional exposure through drinking water.

Not all pesticides in widespread use are registered with the EPA, resulting in the continued exposure of the public through food and water to pesticides that have not been tested for their "potential to cause birth defects, cancer, and other chronic health effects" (Fultz, p. 5). Exemption from the registration requirement is given in so-called emergencies for one year at a time, but some exemptions have been granted for more than a decade, during which time people have been exposed to pesticides of unknown toxicity (Guerrero, 1991b). Also, the EPA continues to emphasize the control of point sources of water pollution such as factories and municipal sewer systems instead of nonpoint sources such as agricultural runoff despite evidence that nonpoint sources pose a greater water pollution problem (Guerrero, 1991b). This may be due to the fact that the USDA promotes the use of many pesticides to increase crop yields even though those chemicals constitute health hazards.

Unfortunately, the EPA's inadequate protection of public health from the dangers of pesticides is typical. Similar stories can be told about surface-water pollution, hazardous waste management and cleanup, enforcement of the Clean Air Act, and U.S. Department of Energy (DOE) decisions about the disposal of nuclear waste: "The National Research Council estimated that only 2 percent of at least 60,000 chemicals that are used widely have been comprehensively studied for toxic effects" (Ziem and Davidoff, p. 88).

In addition to poor funding, a general reason for inadequate protection is that agencies tend to establish such close ties to the industries they are charged with regulating that they identify with industry perspectives and needs. An agency's capture by industry results partly from industry offers of future high-paying employment to regulatory personnel who are "reasonable." Another factor may be pressure on an agency by the legislators who are responsible for approving its budget. Those legislators may depend on the regulated industry for campaign contributions (Sanjour).

Conscientious federal employees who try to regulate effectively are relegated to tasks that have little impact. Employees who blow the whistle on an agency's failure to do its job must go before the presidentially appointed Merit System Protection Board, which may be more interested in protecting the president and "the system" than in protecting the whistle-blower (Sanjour).

There is also the appearance of racism in the EPA's enforcement efforts: "Penalties under hazardous waste laws at sites having the greatest white population were about 500 percent higher than penalties at sites with the greatest minority population" (Lavelle, p. S2). This disparity can be accounted for only by race, not by income. There is a similar disparity of 46 percent in penalties concerning nontoxic waste, air pollution, and water pollution. It takes 20 percent longer for toxic waste sites in minority areas to be placed on the priority list for cleanup, and the cleanup in minority areas is more likely than that in white areas to consist only of containment of the waste rather than treatment that removes its toxicity.

Environmental racism also appears to affect government regulation of international trade. For example, pesticides banned in the United States because of their toxicity to human beings can be manufactured and then sold abroad. Some return as residues on imported food.

Decisional Frameworks

How should decisions about environmental health be made? Advocates of free trade and free markets suggest that market mechanisms can protect public health adequately. However, from the perspective of firms competing for customers, environmental protection seldom makes sense. A manufacturer's plastic toys, for example, seldom are more attractive to customers because the water and air used in its manufacturing processes were purified before being released into the environment. Similarly, catalytic converters on automobiles add to cost but do not improve cars in most customers' eyes. Without government mandates requiring all the producers in an industry to protect the environment, the cost of such protection impairs the competitiveness, or reduces the profits, of conscientious firms that act alone. Thus, the free market discourages the protection of environmental health in the absence of government-mandated regulations such as those administered by OSHA and the EPA.

The EPA and other government agencies have been faulted for their failure to oppose the market-driven activities of private enterprise with sufficient vigor. Three kinds of reforms may be ameliorative. First, agency personnel could be barred for five years from employment, directly or indirectly, by companies that their agency regulates. This would encourage greater independence of agency personnel from the perspectives of regulated companies. Second, campaign finance reform could help diminish the influence of financial interests on the regulatory process. Third, whistleblowers could be given special job and financial protection (Sanjour).

What decisional framework should those agencies employ? Some libertarians, who stress the importance of individual rights, maintain that any environmental pollution that may harm anyone should be disallowed. The government should “enjoin anyone from injecting pollutants into the air, and thereby invading the rights of persons and property. Period” (Rothbard, p. 5). However, this purist approach seems unrealistic because it would disallow, for example, most manufacturing and almost all uses of fossil fuels, including use in automobiles. Polluting the environment in ways that are potentially harmful to human health is too ingrained in industrial ways of life to be eliminated entirely.

Pointing to the benefits of industrialization—air-conditioning in the summer, heating in the winter, rapid transportation, and sophisticated medical interventions—some people maintain that pollution should be allowed until the risks to people outweigh the benefits. According to this view, government agencies such as the EPA should use risk-benefit analysis to determine permissible kinds and levels of pollution (Ruckelshaus).

Critics maintain, however, that risk-benefit analysis favors continued pollution over health-related concerns. First, current levels of pollution often are assumed to be acceptable and are used as precedents for future decisions. Second, whereas the benefits of current pollution practices are assumed, risks must be proved scientifically, a task that is difficult. Third, risk-benefit analysis depends largely on subjective judgments of “experts” whose opinions may reflect employers’ interests (Winner).

Some people suggest avoiding subjectivity by using cost-benefit analysis (CBA), in which all the costs and benefits of proposed pollution-controlling regulations are expressed in monetary terms. The alternative with the highest net benefit should be chosen. Costly health hazards thus would be taken into account. The EPA usually allows environmental impact statements to employ CBA, and the Nuclear Regulatory Commission uses CBA regularly.

However, there are many problems with CBA. First, the costs and benefits associated with the length and quality of human life, which are affected by environmental health, cannot be translated reliably into monetary terms. Second, subjectivism remains because there is great uncertainty in projections of health hazards (Shrader-Frechette). Third, by employing money as its standard, CBA takes into account views and desires only insofar as they are expressed in monetary terms. The opportunity for that expression is proportional to the money at people’s disposal. Using CBA, then, agencies would give protection to people not equally but in proportion to their wealth or income. In regard to the actions of government agencies CBA denies equal protection of the law. Fourth, using normal economic techniques, CBA discounts the future, making a present cost or benefit larger than an otherwise equivalent but future cost or benefit. This biases public policy toward the short term. If the duty to avoid or minimize harming people is based on human rights, harming future generations is morally equivalent to harming contemporaries. CBA discounts the lives and well-being of future generations (Wenz).

Alternative Frameworks

Instead of CBA, the following are possible rules of thumb. First, the burden of proof should be reversed from that employed in risk-benefit analysis. Before a potentially harmful addition is made to the environment, its safety should be demonstrated. At the beginning of the twenty-first century, for example, potentially carcinogenic pesticides can be used widely for ten to fifteen years before investigations are completed. Products are withdrawn then only if they are demonstrated to harm public health. The burden to demonstrate its safety should be on those who want to expose people to a new chemical.

Second, the people at greatest risk should be given the greatest voice in decisions about creating or using potentially hazardous substances (Shrader-Frechette). For example, corporate officials and owners interested in manufacturing processes that create toxic wastes would retain a significant voice in regulatory decisions if they could and would store the wastes near themselves and their families.

Third, through subsidies the government should encourage sustainable agriculture, integrated pest management, mass transit, energy conservation, and other practices and products that reduce the introduction of health hazards into the environment.

Fourth, when the indirect costs of a product can be calculated reliably, those costs should over time be added as a tax to the consumer price of that product. For example, the price of gasoline should reflect the costs associated with the deleterious health effects of smog. Only then will consumers be guided by accurate information about how much a product actually costs them. Such information generally improves the results of reliance on market mechanisms.

Fifth, agencies should discourage practices that hide the existence or severity of environmental health problems. Storage of nuclear wastes underground so that the continuing health hazard is not noticed and the war on cancer that lulls people into thinking a cure is near lead the public to underestimate its jeopardy. This should be avoided in part because an informed public is central to addressing problems of pollution. In the absence of an objective formula for balancing alleged benefits against alleged harms to determine the acceptability of pollution, an informed public must be the ultimate judge of government decisions related to environmental health.

PETER S. WENZ (1995)
REVISED BY JESSICA PIERCE

SEE ALSO: *Environmental Ethics; Environmental Policy and Law; Future Generations, Reproductive Technologies and Obligations to; Hazardous Wastes and Toxic Substances; Occupational Safety and Health; Public Health; Sustainable Development*

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ENVIRONMENTAL POLICY AND LAW

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Among the many purposes of environmental law, two stand out: the protection of personal and property rights and the preservation of places. Laws controlling pollution serve primarily the first goal; they constrain the risks people can impose on others. Statutes that pursue the second purpose seek to preserve national forests, landscapes, and landmarks; to protect historical districts; to maintain biodiversity; and to defend the integrity of ecological systems, such as rivers and wetlands.

These two sorts of statutes emerge from two foundational traditions in the political culture of the United States, the first of which draws on the values of property and autonomy; the second, on those of community and diversity. The first tradition, which is associated with libertarianism and individualism, would protect each person from involuntary risks and harms. The second tradition, which is associated with Madisonian republicanism, suggests that Americans may use the representative and participatory processes of democracy to ask and answer moral questions about the goals of a good society. Americans, most of whom are immigrants or descended from immigrants, find in the natural environment a common heritage—a res publica—that unites them as a nation. Environmental laws, then, may regard shared nature as having a cultural shape, form, or value we are responsible to maintain for its own sake and for future generations.

Pollution-control law may be understood in ethical rather than economic terms insofar as it protects the separateness and inviolability of persons rather than satisfies their interests or preferences. Land-use law preserves the ecological and historical character but not necessarily the economic product of landscapes. Environmental law thus responds to intrinsic values, namely, the autonomy of persons and the integrity of places.

This entry provides a brief account of the three stages—aspiration, recrimination, and collaboration—that characterize the historical development of environmental law in the United States since the passage of the National Environmental Policy Act of 1969. It then describes some of the normative and conceptual problems that are most likely to affect the future of environmental policy.

Aspiration: 1980–1990

During the 1970s, when politicians discovered that being in favor of the environment won votes, Congress enacted, among other statutes, the Clean Air Act of 1970, the Occupational Safety and Health Act of 1970 (OSHA), the Endangered Species Act (CAA) of 1972, the Safe Drinking Water Act of 1974, the Toxic Substances Control Act of 1976, and the Resource Conservation and Recovery Act of 1976. These laws were aspirational—one might say, demagogic—because they set lofty but often vague and unrealistic goals, calling, for example, for *safe* thresholds for pollutants for which no such thresholds exist. The Ocean Dumping Act of 1972 prohibited ocean dumping—but did not say where the wastes should go instead. The Clean Water Act of 1972 required the restoration and maintenance of the "chemical, physical, and biological integrity of the Nation's waters." There is still no agreement on what these words mean.

The rhetorical objectives of laws enacted during the 1970s, which are strong enough to warm the heart of the most ardent environmentalist, soon became fictions as deadlines passed, violations were not monitored or prosecuted, and the agencies fought uphill political and legal battles to make whatever gains they could, given their limited resources. On those rare occasions when the regulatory agencies threatened to enforce a statute to its full extent, Congress could be counted on to weaken it. In 1973, when a court ordered the Environmental Protection Agency (EPA) to bring California into compliance with the Clean Air Act, for example, administrator William Ruckelshaus responded with gasoline rationing, since nothing less draconian would do the job. Congress intervened by extending deadline after deadline; they, too, passed unmet.

Some might regard the aspirational and draconian goals of environmental statutes as cynical: By promising environmentalists the moon, these statutes provided scant direction about how to solve conflicts on earth. OSHA requires the workplace to be as safe from hazards as *feasible,* but the government has regulated only about one hazardous substance per year. The Fish and Wildlife Service avoided drastic effects in applying the Endangered Species Act by failing to list species and by approving inadequate plans to protect those that were listed. This was often as much as was politically possible given the opposition of those who would rather "shoot, shovel, and shut up" than to dedicate their property to zoological ideals. The draconian wording of the statutes at least gave agencies a strong legal foothold when they could muster the political will to act.

The late and unlamented Delaney Clause of the Food, Drug and Cosmetic Act prohibited in prepared food any trace of a pesticide that can be shown to induce cancer when administered in massive doses to laboratory animals. It was rarely enforced. New methods of detection showed that every box, bottle, or can of food contains a trace of some carcinogen, so defined. Rather than close down the food industry, officials used dodges, such as a *de minimis* risk exemption, to skirt the law. Political factors—a congressional or presidential election, for example—did wonders in softening regulations in key districts; industry and other interest groups, moreover, knew how to use campaign contributions and their friends in Congress to chasten agency zeal in applying the law.

Retrospective Liability and Criminalization: 1980–1989

By 1981 environmental regulation had reached an impasse. Congress had announced the good news that the environment would be pollution-free and that the nation would preserve its scenic wonders and biological resources. Regulatory agencies then had to announce the bad news: what it would cost and who would have to pay for it. Many who bore the costs blamed the messenger; EPA and other agencies came under fire for policies that required great outlays to achieve sometimes minor improvements. When President Ronald Reagan announced a program of regulatory rescission and appointed Anne Gorsuch at EPA and James Watt at the Department of the Interior, it seemed that the goals of the 1970s would be abandoned, in view of the ideological commitments and managerial styles of these appointees.

By 1981 however, the constituency of the environmental movement had changed. At first enlisting primarily upper-middle class, well-educated suburbanites, environmentalism had become a populism, including lower-middle-class Americans in the heartland who resented the effects of global markets on their communities. Social-science surveys showed overwhelming support among all economic and social groups for the strictest regulation, regardless of cost. Because of the strength of environmentalism among his own supporters, President Reagan found himself obliged to replace the head of the EPA and the secretary of the interior, and to accept a new barrage of environmental statutes that appealed to a populist not to a technocratic constituency.

During the 1980s, Congress intensified top-down *command-and-control* regulation by enacting, for example, the Comprehensive Environmental Response, Compensation, and Liability Act of 1980, which makes the buyer of a contaminated property liable for the entire cleanup even though it did not contribute to the contamination. Other statutes—such as the Resource Conservation and Recovery Act Amendments of 1984, the Superfund Amendments and Reauthorization Act of 1986, and the Oil Pollution Act of 1990—likewise addressed not just present hazards but also the remediation of past ones. Some of these statutes included criminal penalties or made polluters jointly and severally liable for the entire cost of a cleanup, regardless of fault. Thus, any company whose name appeared on a manifest at a poorly operated waste dump might find itself legally liable to pay the entire cost of a gold-plated remediation.

Laws of this kind take a moralistic or retributivist approach, associated with populist crusades, in regulating pollution. In response, industries backed away from investments entirely, for example, where they were most needed in inner city neighborhoods, or they hired lawyers to avoid or spread liability rather than engineers to clean up or prevent pollution. It took about a dozen years for industry to deal with Superfund in some way other than litigation; eventually, public officials and industry lawyers learned to paper transactions needed to get some decontamination. EPA and state agencies began to allow industries to develop polluted properties—so-called *brownfields*—without incurring open-ended liabilities for perfect cleanups. EPA began to experiment with case-by-case negotiation to turn confrontation into compromise. Half way measures—often enshrined in consent decrees, supplemental environmental provisions, prospective purchaser agreements, habitat conservation plans, negotiated rulemakings, and many other instruments—kept the perfect environment the laws envisioned from becoming an implacable enemy of the good environment that patient case-by-case conflict-resolution could achieve.

The Contractual State

With the Clinton administration, the ethos of environment policy changed again. Large-scale polluters, such as smelters and refineries, had largely been controlled, but small sources, such as automobiles, trucks, lawn mowers, bakeries, cleaners, gas stations, and other modest businesses cumulatively added massively to pollution problems. Global threats, such as climate change, habitat loss, and fisheries depletion, implicated the average consumer, for example, those who drive gas-guzzling cars. Programs to *reinvent regulation* proposed to bring into the public sector innovations—such as information sharing, technology benchmarking, incentives, systems-thinking, and collaborative engagement—that had been introduced successfully in private enterprise.

EPA established several *banking, offset,* and *pollution trading* regimes that allowed firms to avail themselves of the cheapest ways to reduce pollution and gave them incentives to develop more efficient control technologies. Markets for trading pollution allowances, which capped total emissions at reduced levels, lowered lead and, especially, sulfur dioxide emissions, which were halved in a decade. Environmentalists could purchase and thus retire emission *allowances,* which sold at surprisingly low prices. EPA through Project XL engaged corporations in collaborative and negotiated rulemaking. Federal and state agencies also inspired decentralized community and individual action by providing information; for example, EPA's Green Lights program encouraged a transition from energy-intensive incandescent bulbs to far more efficient compact fluorescent ones. Similarly, toxic release inventories, eco-labeling, right-to-know regulations, and environmental certification programs illustrate other ways information can initiate local, decentralized improvements.

With the greater and easier availability of information, individuals and firms have begun to internalize environmental norms. Frustration with agency inaction, moreover, has led citizen and industry groups to try to collaborate to resolve their conflicts. Successful habitat conservation plans—the most famous concerns the desert tortoise—emerged from *civil society,* that is, from negotiation among concerned groups. Environmentalists and ranchers, usually at each other's throats, joined to petition the government to establish a market in tradable grazing rights that environmentalists can retire by buying them from ranchers. Officials have initiated successful stakeholder negotiations as well, for example, to protect visibility in the Grand Canyon, although agency intransigence and turf-mindedness—the Forest Service has opposed stakeholder governance of national forests, as in Quincy, California—can also undermine collaborative agreements.

In trying to decentralize decision making through collaboration, negotiation, information, incentive-formation, and so on, regulatory agencies have gotten ahead of legislation. Since 1990, Congress has enacted no major new environmental regulatory statutes nor significantly amended old ones. Since 1970, only two environmental statutes—the Right-to-Know Act of 1986 and the SO_2 trading program in 1990 CAA Amendments—depart from the standard top-down, command-and-control, one-size-fits-all approach. The trend toward more reflexive, adaptive, and collaborative approaches to conflict-resolution remains tenuous and vulnerable, since it lacks a statutory basis.

Economic Theory and the Environment

In the 1970s, economists described pollution and other environmental concerns as economic problems—external costs of production—that arise because markets fail to internalize in the prices of goods the costs of all the resources they consume. It soon became obvious, however, that public officials were no better able than private actors to gather and process the information needed to set *optimal* levels of pollution. Since the government confronts the same or greater information and bargaining costs as private parties, it is no more able than they to determine what people are willing to pay (or to accept) to gain or allow various outcomes. The government has confronted prohibitive costs when it has sought to measure the environmental losses caused by an episode of pollution—and defend those measurements.

In the early 1990s, for example, the government spent $30 million to commission experts to assess the damages associated with the discharge of DDT and PCBs into the Los Angeles Harbor. Tens of millions of dollars have funded Contingent Valuation (CV) studies of the non-use value of various environmental goods, such as the losses associated with the EXXON *Valdez* oil spill. EXXON commissioned Nobel laureates and other economists to debunk that study. Economists, like lawyers, take sides; economic estimates and valuations themselves become goods people are willing to pay for. No CV study, however expensive, has ever stood up as credible evidence in litigation.

Chastened by the transaction and information costs that bedevil official efforts to “get the prices right” or second-guess market outcomes, economists have turned to recommending ways that the government can create voluntary arrangements, such as markets in tradable rights and allowances, stakeholder negotiations, and governance committees, as ways to get to consensual and in that sense optimal outcomes. The question “what is the efficient allocation?” has given way to the question “what is the appropriate institution?” for governing resources such as watersheds and forests. When the government agency itself tries to govern, it becomes the object of *rent-seeking,* for example, zero-sum jockeying by opposing interest groups, which hire their own lawyers, economists, toxicologists, ecologists, and other experts. When these interest groups deal directly with each other by trading rights or by collaborating on decisions, they immensely reduce the transaction and information costs that tend otherwise to stymie environmental progress.

A Look Ahead

For thirty years, Congress and the executive branch have engaged in what psychologists call enabling behavior. Like an alcoholic and his or her spouse, Congress and the executive agencies may quarrel, but at a deeper level they have been in league with each other. By letting deadlines pass, accepting *reasonable progress* in lieu of compliance, substituting *reduced risk* for statutory *zero risk* standards, and otherwise failing to enforce legislation, agencies such as EPA spared Congress the unpleasantness of making hard choices and allowed it to parade itself as the defender of nature, personal rights, purity, and so on. Congress in turn gave the agencies autonomy—the ability to work the law as they liked—within the tolerance of the courts.

In the spirit of the civil rights movement, environmentalists enforced landmark legislation by confrontation and litigation, primarily by suing EPA and other agencies for evading draconian statutes, such as the Delaney Clause. In 1992, the Ninth Circuit Court held that the EPA exceeded its statutory authority by allowing a *de minimis* risk standard in conflict with the language of the Delaney Clause. (*Les v. Riley,*1992). The decision implied that food must be absolutely free of chemical additives, including pesticide residues, as the law requires, even if as a result no food could be produced or sold in the United States.

Congress responded by repealing the Delaney Clause and enacting a more flexible policy, the Food Quality Protection Act of 1996, in its place. This result whet the appetite of industry groups who hoped that if environmentalists prevailed in other suits, Congress might be forced to repeal other aspirational statutes. Industry lawyers began to argue that the CAA, for example, taken literally, prohibited all air pollution—and thus nearly all economic activity—or, if, taken in any other way, delegated the entire burden of lawmaking to executive agencies and derivatively to the courts. This would involve an unconstitutional delegation of legislative authority to other branches of government.

When in 1997, EPA tightened the air quality standards for particulate matter and ozone, the D.C. Circuit Court, in *American Trucking Association v. Whitman* (1999), in response to an industry legal challenge, remanded the regulation to EPA on the grounds that neither the statute nor EPA’s interpretation of it provided an *intelligible principle* necessary to channel the authority Congress delegated to the executive agencies. In reviewing this decision in 2001, the Supreme Court refused to declare the CAA unconstitutional on the grounds that it delegated the tough tradeoffs—and thus legislative authority—to the agencies. The Court and others recognized, however, that EPA has yet to determine a stopping point for regulation, that is, a point at which emissions are safe enough.

Some commentators argue that EPA should regulate emissions to the *knee of the curve,* referring to a graph in which the x-axis represents pollution reduction and the y-axis represents cost. The idea is that the government should require firms to reduce pollution to the point at which the costs of controlling the *next* unit increase exponentially or go asymptotic. In addition, agencies can encourage new technologies that may push the knee of the curve ever farther out along the pollution-control or the x-axis.

Other commentators argue that the most efficient controls on big sources of pollution are mostly in place, and it is small polluters, indeed, individual households, that hold the key to reducing pollution by becoming more energy-efficient. The reluctance of Americans to replace incandescent with fluorescent bulbs, to drive cars with greater fuel economy, to install better thermostats, windows, insulation, and so on, indicates the extent of the problem. Throughout the 1970s and 1980s, Americans blamed others—particularly large corporations—for their environmental woes, but it is apparent that the behavior of individuals has to change. The motto of the environmental movement has become more and more pertinent since cartoonist Walt Kelly's Pogo coined it: "We have met the enemy, and he is us."

The International Perspective

The other motto, "Think globally; act locally," recognizes that environmental problems have important global dimensions, particularly because carbon dioxide and other *greenhouse* gasses threaten to cause climate change. To some extent the international community has dealt successfully with environmental threats; for example, the Montreal Protocol, an international accord signed in 1987, initiated controls on the production of chemicals that damage stratospheric ozone. And conventions aimed at preserving endangered species and controlling the harvest of common resources—whales, for example—have long exerted influence on the international community.

To an even greater extent, however, international environmental conventions and the institutions—called *regimes*—set up to implement them meet many of the same problems of enforcement that are familiar in domestic contexts. Many of the conventions—such as those that ban pollution in the North Sea—are hortatory or idealistic. Politicians enact these protocols under pressure from the *green* movement, but because of the very great costs involved, they make slow progress in enforcing them. Nongovernmental organizations take the lead in litigating, harassing, and otherwise reminding officials of their responsibilities under the protocols they signed.

In 1997, industrialized nations, including Japan, the United States, and members of the European Union, promised at Kyoto that by 2012 they would cut to significantly less than 1990 levels, and permanently limit their production of, CO_2 and other greenhouse gases. Developing countries such as China, India, Indonesia, and Malaysia, believing that the welfare of their people depends more on the growth of their economies than on the stability of the atmosphere, refused to join the effort to lower emissions. These countries, because of rapid economic and population growth, are likely to surpass the industrialized nations in their greenhouse emissions within about fifteen years, and will by themselves emit more than enough greenhouse gases to destabilize the atmosphere. Partly for this reason, but also because of the costs involved, the U.S. Senate said that it would never ratify the climate treaty unless developing nations commit to *substantial participation.* President George W. Bush later brushed off the Kyoto Treaty entirely.

Environmental organizations have begun to turn their attention to international problems, particularly global climate change. Little has been said, however, about exactly how the United States should lower its emissions—whether by converting from coal-fired to nuclear energy, for example. Ethical debate has centered on a U.S. proposal to allow nations to sell credits for their *excess* reductions to other nations, who would then count them toward meeting their own targets. The United States, for example, might assist Russia to convert inefficient coal-burning electric utilities to cleaner and more efficient gas-fired power plants. The Russians would receive the new technology at little or no cost, and the United States would be able to take credit for the reduction in emissions from the Russian plants. It costs a lot less to achieve a 50 percent reduction from the dirtiest industries in Russia or India than a 10 percent reduction in industries that are already technologically advanced.

Critics have condemned pollution-trading because it "turns pollution into a commodity to be bought and sold," and thereby "removes the moral stigma that is properly associated with it" (Sandel). Yet CO_2, unlike toxic agents or carcinogens, should not be stigmatized. Under a safe global cap—let us say, the levels accepted at Kyoto—CO_2 emissions are not harmful or objectionable. If wealthy countries buy allowances by providing poorer countries with more efficient technologies, moreover, this does not necessarily indicate disrespect or arrogance, but might be looked at as partnership, if wealthy countries do not use less efficient technology at home than they subsidize abroad.

Some commentators have proposed a general requirement that ties CO_2 emissions to economic product, with the idea that wealthy countries can get credit for helping others reach the carbon-efficiency per dollar economic output achieved by the most efficient economies. The ethical impasse that stymies carbon *trading* strategies lies in finding a fair principle on which to distribute initial allowances—namely, whether to *grandfather* present levels or establish per-capita quotas. A global cap on greenhouse gases, in other words, must be translated into an initial set of permits nations can use or trade. This problem has proven intractable. As economist Tom Schelling has said, “Global emissions trading is an elegant idea, but I cannot seriously envision national representatives sitting down to divide up rights in perpetuity worth a trillion dollars” (Passell).

The greatest threat to the global environment remains war—especially in view of the proliferation of nuclear weapons. Environmental protocols, regimes, and conventions, when successful, bring nations closer together and teach them to cooperate with and to trust each other. Insofar as environmental protection encourages a sustainable peace, it will lay the surest foundation for environmental protection and sustainable development.

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SEE ALSO: *Endangered Species and Biodiversity; Environmental Ethics; Environmental Health*

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EPIDEMICS

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Epidemics may be defined as concentrated outbursts of infectious or noninfectious disease, often with unusually high mortality, affecting relatively large numbers of people within fairly narrow limits of time and space. They probably emerged in human populations with the “Neolithic Revolution,” roughly eight to ten thousand years ago, as humans began to domesticate animals, practice agriculture, and settle into towns and villages, with a corresponding increase in the density of population. This entry will cover the history of epidemics with particular reference to their implications for bioethics, beginning with a survey of ancient and medieval times, moving on to responses to epidemics before the nineteenth century, then examining in more detail the impact of cholera and the bacteriological revolution. It will conclude with a discussion of the epidemiological transition and its aftermath, the emergence of new epidemics in the late twentieth century, and the ethical implications of the data surveyed. The focus will be mainly but not exclusively on Europe and North America, where historical source material is richest, and scholarly and scientific studies are most numerous.

Ancient and Medieval Times

Hippocratic texts indicate the presence of tuberculosis, malaria, and influenza in the population of ancient Greece, and the historian Thucydides provides the first full description of a major plague, the precise nature of which remains uncertain, in Athens (430–429 B.C.E.), in his history of the

Peloponnesian War. The increase in trade brought about by the growth of the Roman Empire facilitated the transmission of disease, and there were massive epidemics in the Mediterranean (165–180 C.E. and 211–266 C.E.). The "plague of Justinian" (542–547 C.E.), which was said to have killed ten thousand people per day in Constantinople, is the first recorded appearance of bubonic plague (McNeill). In Europe and Asia, diseases such as measles and smallpox gradually became endemic, affecting virtually all parts of the population on a regular basis, with occasional epidemic outbursts. Periodic epidemics of bubonic plague continued, most seriously in the fourteenth century, when perhaps as much as one-third of Europe's population perished.

When Europeans arrived in the Americas, from 1492 on, they brought many of these diseases to native American populations for the first time, with devastating effects. The importation of African slaves introduced malaria and yellow fever by the seventeenth century (Kiple, 1984). The merging of the disease pools of the Old and New Worlds was completed by what appeared to be the transmission of syphilis to Europe from the Americas at the end of the fifteenth century, though the subject remains disputed by historians, some arguing that it was a recurrence or mutation of a disease that already existed on the Continent (Crosby).

Responses to Epidemics before the Nineteenth Century

The ancient Greeks and Romans commonly, though not universally, believed that epidemics were brought into human communities from outside. Thucydides, for example, described the plague that struck Athens during the Peloponnesian War as having arrived by sea. This belief was the basis of official reactions to epidemics in medieval Europe. Following the closure of the port at Venice to all shipping for thirty days as the plague threatened in 1346, regulations imposed in Marseilles in 1384, and in other ports thereafter, prescribed the biblical period of isolation for a "quarantine" (forty days) outside the harbor for any ship thought to have called previously at a place infected with the plague. In 1423 the Venetians set up a hospital where plague victims were isolated, and by 1485 the city had a sanitary authority armed with wide-ranging powers during epidemics. In some epidemics, as in the Great Plague of London in 1665, victims were compulsorily isolated in their own houses, which were marked with a red cross to warn the healthy not to enter. Compulsory screening was not an issue before the late nineteenth century, however, because diseases were recognized as such only after the onset of obvious symptoms, and the concept of the asymptomatic carrier did not exist. In addition to these measures, the authorities in many medieval towns, working on the theory that epidemics were spread through the contamination of the atmosphere, ordered the fumigation of the streets to try to clear the air. Doctors and priests were expected to attend to the sick; and those who fled, as many did, are strongly criticized in the chronicles of these events.

Popular reactions to epidemics included not only flight from infected areas and evasion of public health measures, but also attacks on already marginalized and stigmatized minorities. As bubonic plague spread in Europe in 1348–1349, for example, rumors that the Jews were poisoning water supplies led to widespread pogroms. Over nine hundred Jews were massacred in the German city of Erfurt alone (Vasold). Such actions reflected a general feeling, reinforced by the church, that plagues were visited upon humankind by a wrathful Deity angered by immorality, irreligion, and the toleration of infidels. A prominent part in these persecutions was played by the flagellants, lay religious orders whose self-flagellating processions were intended to divert divine retribution from the rest of the population. Jews were scapegoated because they were not part of the Christian community. Drawing upon a lengthy tradition of Christian anti-Semitism, which blamed the Jews for the killing of Christ, the people of medieval Europe regarded Jews at such times as little better than the agents of Satan (Delumeau).

State, popular, religious, and medical responses such as these remained essentially constant well into the nineteenth century. The medical understanding of plague continued throughout this period to draw heavily on humoral theories, so that therapy centered on bloodletting and similar treatments designed to restore the humoral balance in the patient's body. They were of limited effectiveness in combating bubonic plague, which was spread by flea-infested rats. The isolation and hospitalization of victims also therefore did little to prevent the spread of plague. Nevertheless, the disease gradually retreated from western Europe, for reasons that are still imperfectly understood. The introduction of more effective quarantines with the emergence of the strong state in the seventeenth and eighteenth centuries was almost certainly one of these reasons, however, and helped prevent the recurrence of epidemics in the seventeenth and eighteenth centuries (Vasold).

State intervention also played a role in reducing the impact of smallpox, the other major killer disease of the age after bubonic plague. Its spread was first reduced by inoculation, before compulsory programs of cowpox vaccination brought about a dramatic reduction in the impact of the disease in nineteenth-century Europe. Despite the imperfections of these new methods, which sometimes included accidentally spreading the disease, vaccination programs in particular may be regarded as the first major achievement of the "medical policing" favored by eighteenth-century absolutist monarchies such as Prussia. Police methods that paid scant attention to the liberties of the subjects were used to combat the spread of epidemics. They included the use of troops to seal off infected districts, quarantines by land and sea, and the compulsory isolation of individual victims. Most of these measures had little effect, however, either because of lack of medical knowledge or because poor communications and lack of police and military manpower prevented them from being applied comprehensively (Rosen).

The Impact of Cholera

These theories and practices were brought into question above all by the arrival in Europe and North America of Asiatic cholera. The growth of the British Empire, especially in India, improved communications and trade, and facilitated the spread of cholera from its base in the Ganges delta to other parts of Asia and to the Middle East. Reaching Europe by the end of the 1820s, the disease was spread further by unsanitary and overcrowded living conditions in the rapidly growing towns and cities of the new industrial era. At particular moments of political conflict, above all in the European revolutions of 1830 and 1848, the Austro-Prussian War of 1866, and the Franco-Prussian War of 1870–1871, it was carried rapidly across the continent by troop movements and the mass flight of affected civilian populations (Evans, 1988).

Cholera epidemics affected the United States in 1832, 1849, and 1866, on each occasion arriving from Europe in the aftermath of a major conflict. State, popular, and medical responses in 1830–1832 were unchanged from earlier reactions to epidemics. Quarantine regulations were imposed, military cordons established, victims isolated, hospitals prepared. In Prussia, the breaching of such regulations was made punishable by death. But the opposition that such measures aroused among increasingly powerful industrial and trading interests, and the feeling among many liberals that the policing of disease involved unwarranted interference with the liberty of the individual, forced the state to retreat from combating cholera by the time of the next epidemic, in the late 1840s. In addition, medical theories of contagion were brought into disrepute by the failure of quarantine and isolation to stop the spread of the disease in Europe. Until the 1880s, many doctors thought that cholera was caused by a "miasma" or vapor rising from the ground under certain climatic circumstances. It could be prevented by cleaning up the cities so as to prevent the source of infection from getting into the soil (Evans, 1987). This was a contributory factor in the spread of sanitary reform in Europe and the United States during this period. But its importance should not be overestimated. Boards of health established in American cities in the midst of the cholera epidemics of 1832 and 1849 were short-lived and of limited effectiveness, and even in 1866 the more determined official responses had less to do with the impact of cholera than with the changed political climate (Rosenberg).

The fact that cholera affected the poorest sectors of society most profoundly was the result above all of structural factors such as unsanitary and overcrowded living conditions, unhygienic water supplies, and ineffective methods of waste disposal. But state and public responses to epidemics in the nineteenth century, at least in the decades after the initial impact of cholera, were primarily voluntaristic. Religious and secular commentators blamed cholera on the alleged immorality, drunkenness, sexual excess, idleness, and lack of moral fiber of the victims. Fast days were held in eleven New England states in 1832, in the belief that piety would divert God's avenging hand. Once again, the socially marginal groups of industrial society, from vagrants and the unemployed to prostitutes and beggars—or, in the United States in 1866, the newly emancipated slaves and the newly arrived Irish immigrants—were blamed (Rosenberg).

The rise of the medical profession, with well-regulated training and a code of ethics, ensured that doctors were more consistently active in treating victims of epidemics in the nineteenth century than they had been in previous times. Partly as a result, there were popular attacks on the medical profession in Europe during the epidemic of 1830–1832. Angry crowds accused doctors of poisoning the poor in order to be able to reduce the burden of support they imposed on the state or, in Britain, in order to provide fresh bodies for the anatomy schools (Durey). As late as 1892, doctors and state officials were being killed in cholera riots in Russia (Frieden). There were also disturbances in the United States, where a hospital was burned down in Pittsburgh and a quarantine hospital on Staten Island, in New York City, was destroyed by rioters fearing the spread of yellow fever. However, in most of Europe, public disturbances caused by epidemics had largely ceased by the middle of the nineteenth century. Fear of disorder was another reason for the state's withdrawal from policing measures (Evans, 1988). In Europe, too, religious responses to epidemics had become less important by the end of the century as religious observance declined. In 1892, however, as cholera once more threatened America's shores, it fed nativist prejudice and led to the introduction of harsh new restrictions on immigration.

The Bacteriological Revolution

Cholera was only the most dramatic of a number of infectious diseases that took advantage of urbanization, poor hygiene, overcrowding, and improved communications in the nineteenth century (Bardet et al.). Typhus, typhoid, diphtheria, yellow fever, tuberculosis, malaria, and syphilis continued to have a major impact, and even smallpox returned on a large scale during the Franco-Prussian War of 1870–1871. Treatment continued to be ineffective. But the rapid development of microscope technology in the last quarter of the century enabled medical science to discover the causative agents of many infectious diseases in humans and animals. Building on the achievements of Louis Pasteur, Robert Koch identified the tubercle bacillus in 1882 and the cholera bacillus in 1884. These discoveries marked the triumph of bacteriology and completed the swing of medical opinion back from belief in “miasmas” as causes of epidemics toward a contagionist point of view.

From the 1880s, states once more imposed quarantine and isolation, backed by preventive disinfection. The greater effectiveness of state controls, compared with the earlier part of the century, was combined with the more precise focus on eliminating bacterial organisms. Once the role of victims’ excretions in contaminating water supplies with the cholera bacillus became known, it was possible to take preventive action by ensuring hygienic water supplies and safe waste disposal. By the outbreak of World War I in 1914, the role of the human body louse in spreading typhus, and that of the mosquito in transmitting malaria and yellow fever, had been identified. Mosquito control programs were launched by the U.S. Army in Cuba following the Spanish-American War of 1898, and subsequently in the Panama Canal Zone, in order to reduce the incidence of yellow fever cases to an acceptable level. Regular delousing reduced typhus among armies on the western front in Europe during World War I. The Japanese army prevented casualties from typhoid and smallpox by a campaign of systematic vaccination during the war with Russia in 1904–1905 (McNeill; Cartwright).

The bacteriological revolution thus inaugurated an age of sharply increased state controls over the spread of disease. Laws were introduced in many countries making the reporting of infectious diseases compulsory. The growth of a comprehensive, state-backed system of medical care, working through medical officers, medical insurance plans, and the like, made comprehensive reporting easier. Hospital building programs in the second half of the nineteenth century facilitated the isolation of victims in hygienic conditions where they could be prevented from spreading the disease. The greater prestige of the medical profession in most industrialized countries by the late nineteenth and early twentieth century ensured that doctors were no longer attacked, and that the necessity of compulsory reporting and isolation was widely accepted by the public. However, a bacteriological understanding of disease causation also involved a narrowing of focus, in which increased emphasis was placed on the compulsory reporting of cases, followed by their isolation, at the expense of broader measures of public health and environmental improvement (Porter).

The Epidemiological Transition

Lower death rates from diseases such as cholera, typhoid, and tuberculosis were only partially the consequence of bacteriologically inspired state preventive measures, and the disease burden from acute infectious disease began to decline rapidly. The provision of clean, properly filtered water supplies and effective sewage systems reflected growing municipal pride and the middle-class desire for cleanliness. It made epidemics such as the outbreak of cholera that killed over eight thousand people in Hamburg, Germany, in little over six weeks in the autumn of 1892 increasingly rare. Just as important were improvements in personal hygiene, which again reflected general social trends as well as the growing “medicalization” of society in western Europe and the United States. Such developments reinforced the stigmatization of poor and oppressed minorities as carriers of infection, since they were now blamed for ignoring official exhortations to maintain high standards of cleanliness, even though their living conditions and personal circumstances frequently made it difficult for them to do so. Particular attention was focused on working-class women, who were held responsible by official and medical opinion for any lack of hygiene in the home (Evans, 1987).

The development of tuberculin by Koch in 1890 made possible the compulsory screening of populations even for asymptomatic tuberculosis. This was increasingly implemented after 1900, in conjunction with the forcible removal of carriers to sanatoria, although this was more effective in isolating people than in curing them. Educational measures also helped reduce the spread of the disease. The development and compulsory administration in many countries of a preventive vaccine against tuberculosis from the 1920s aroused resistance among the medical community, not least because by creating a positive tuberculin reaction in noncarriers, it made it impossible to detect those who truly had the disease, except where symptoms were obvious. These measures had some effect in reducing the impact of the disease. However, although the precise causes of the retreat of tuberculosis remain a matter of controversy among historians, the long-term decline of the disease from the middle of the nineteenth century was probably more the result of improvements in housing, hygiene, environmental sanitation, and living standards than of direct medical intervention. The introduction of antibiotics such as streptomycin after World War II proved effective in reducing to insignificant levels mortality from a disease that had been the most frequent cause of death or disability among Americans aged fifteen to forty-five (Dubos and Dubos).

Similarly, official responses to syphilis centered, especially in Europe, on the forcible confinement of prostitutes to state-licensed brothels or locked hospital wards, where they were subjected to compulsory medical examination. Before World War I, New York, California, and other states had introduced compulsory reporting of cases of venereal disease, and official concern for the health of U.S. troops led to the jailing of prostitutes. Measures such as these had no discernible effect on infection rates, which rose sharply during the war. They also represented a serious restriction on the civil liberties of an already stigmatized group of women, while the men who were their customers, and equally active in the sexual transmission of disease, were regarded as irresponsible at worst, and were not subjected to similar measures. The development of Salvarsan (arsphenamine) by Paul Ehrlich in 1910 introduced the possibility of an effective treatment for syphilis. But here again there was resistance, both within the medical community and from outside, from those who considered that an increase in sexual promiscuity would be a result. This view became even more widespread following the use of penicillin on a large scale during World War II (Brandt).

Epidemics of the Late Twentieth Century

In the West, epidemic infectious disease was regarded by the second half of the twentieth century as indicating an uncivilized state of mind, and was ascribed above all to nonwhite populations in parts of the world outside Europe and North America. This reflected structural inequalities in the world economy, as the great infections became increasingly concentrated in the poor countries of the Third World. By the middle of the twentieth century, however, rapidly increasing life expectancy was bringing rapid growth of noninfectious cardiac diseases, cancer, and other chronic conditions that posed new epidemic threats to an aging population in the affluent West. Under increasing pressure from the medical profession, the state responded not only with education initiatives but also with punitive measures directed toward habits, such as cigarette smoking, that were thought to make such conditions more likely. The arsenal of sanctions governments employed included punitive taxation on tobacco and the banning of smoking, under threat of fines and imprisonment, in a growing number of public places. Increasingly, institutions in the private sector also adopted these policies. They raised the question of how far state and nonstate institutions could go in forcing people to abandon pleasures that were demonstrably harmful to their own health. At the same time, they contrasted strongly with the reluctance of many states and companies to admit responsibility for cancer epidemics caused by factors such as nuclear weapons testing, the proximity of nuclear power stations to human populations, or the lack of proper precautions in dealing with radioactivity in industrial production.

In the 1980s, the identification of a new epidemic, known as acquired immune deficiency syndrome (AIDS), once more raised the ethical problems faced by state and society, and by the medical profession, in the past. Lack of medical knowledge of the syndrome and the danger of infection from contact with blood or other body fluids, posed the question of whether the medical profession had a duty to treat AIDS sufferers in the absence of any cure. The evidence of the overwhelming majority of past epidemics, for which there was also no known cure, seems to be, however, that medical treatment, even in the Middle Ages, could alleviate suffering under some circumstances, and was therefore a duty of the practitioner. In a condition that could prove rapidly fatal, the ethics of prolonged tests of a drug such as AZT, in which control groups were given placebos, was contested by AIDS sufferers anxious to try anything that might possibly cure the condition, or at least slow its progress.

If this was a relatively novel ethical problem, then the question of compulsory public-health measures was a very old one. Like the sufferers in many previous epidemics, AIDS victims tended to come from already stigmatized social groups: gays, drug abusers and prostitutes, Haitians and Africans. The ability to screen these high-risk groups for the presence of the causative agent, the HIV retrovirus, even at the asymptomatic stage, raised the possibility of compulsory screening measures, quarantine, and isolation. On the other hand, individuals publicly identified as HIV-positive generally found it difficult or impossible to stay employed, to obtain life or health insurance, or to avoid eviction from their homes. In the absence of adequate supportive measures, public-health intervention reinforces existing discrimination against these groups, as in many past epidemics.

An alternative state response has consisted of neglect, on the assumption that AIDS is unlikely to affect the heterosexual, non-drug-abusing, nonpromiscuous majority of the voting public. It is noticeable that, generally, politicians have invested resources in public education and other preventive measures only when they have believed that the majority population is at risk. These problems have been raised again by the recent resurgence of tuberculosis in Western countries, among the HIV-positive but also among the poor and the homeless. Drug-resistant strains of the disease have become common, and the transient, jobless, and destitute have neither the means nor the stability of life-style to complete the lengthy course of drugs that is necessary to effect a cure. The compulsory isolation of victims and their forcible subjection to a course of treatment is not a satisfactory long-term solution to the problem, since reinfection is likely upon release, unless the social and personal circumstances of the affected groups undergo a dramatic improvement.

Conclusion: Ethical Implications

The history of epidemics suggests that society's responses have usually included scapegoating marginal and already stigmatized groups and the restriction of their civil rights. From the Jews massacred during the Black Death in medieval Europe, through the beggars and vagrants blamed for the spread of cholera in the nineteenth century, to the prostitutes arrested for allegedly infecting troops with syphilis during World War I, and the minorities whose life-styles were widely regarded as responsible for the spread of AIDS in the 1980s and 1990s, such groups have frequently been subjected to social ostracism and official hostility in times of epidemic disease. Frequently, though not invariably, they have been the very people who have suffered most severely from the disease they were accused of spreading. Doctors have sometimes been reluctant to treat them; the state has often responded with punitive measures.

At no time have public-health measures to combat epidemics been politically uncontested. Nineteenth-century feminists, for example, campaigned vigorously against the state's restriction of the civil liberties of prostitutes in the name of disease control. The fact that their male customers were left free to spread sexually transmitted diseases unhampered by the attentions of the state implied an official endorsement of different standards of morality for men and for women, and it was this major structural element of the social value system that the feminists were seeking to change. Without such change, not only was medical intervention ethically indefensible, but there would never be any likelihood of effective control of sexually transmitted diseases. Similarly, many nineteenth-century epidemics, such as cholera or tuberculosis, were spread by poor nutrition, overcrowded housing, and inadequate sanitation. Social reformers therefore regarded major improvements in these areas as more important than direct medical intervention through measures such as compulsory hospitalization.

Epidemics are frequently caused by social and political upheavals. In the past, movements of large masses of troops and civilians across Europe, from the Crusades to the Crimean War, brought epidemics in their wake. In the early 1990s, a major cholera epidemic broke out in Peru as the result of the flight of thousands of peasants from their mountain settlements, driven out by the pitiless armed conflict between the army and the "Shining Path" guerrillas, to the narrow coastal strip, where they lived in makeshift shantytowns with no sanitation. Economic crisis and the dismantling of welfare measures for the homeless, the mentally disturbed, and the destitute in many Western countries in the 1980s contributed to a massive increase in the transient population on the streets of the great cities. Discrimination against AIDS sufferers by landlords and employers has added to this problem. By the early 1990s there were an estimated ninety thousand homeless on the streets of New York City, half of whom were HIV-positive and several thousand of whom were suffering from tuberculosis. Any long-term solution to these epidemics must be more than merely medical, as must any explanation of their occurrence. Public-health measures are thus inevitably political in their implications, since they can be considered and administered only with reference to the wider social and cultural context within which the disease they seek to prevent or control has originated.

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SEE ALSO: *AIDS; Bioethics, African-American Perspectives; Bioterrorism; Care; Communitarianism and Bioethics; Human Rights; Literature and Healthcare; Medical Ethics, History of Europe; Narrative; Public Health, History; Public Health, Philosophy; Sexual Behavior, Social Control of*

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ETHICS

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I. Task of Ethics
II. Moral Epistemology
III. Normative Ethical Theories
IV. Social and Political Theories
V. Religion and Morality

I. TASK OF ETHICS

Ethics as a philosophical or theoretical discipline is concerned with tasks that concern ordinary, reflective individuals. Since its origins in classical and preclassical times, it has sought to understand how human beings should act and what kind of life is best for people. When Socrates and Plato dealt with such questions, they presupposed or at the very least hoped that they could be answered in "timeless" fashion, that is, with answers that were not dependent on the culture and circumstances of the answerer, but represented universally valid, rational conclusions.

In fact, however, the history of philosophical or theoretical ethics is intimately related to the ethical views and practices prevalent in various societies over the millennia. Although philosophers have usually sought to answer ethical questions without regard to (and sometimes in defiance of) some of the standards and traditions prevalent around them, the history of ethics as a philosophical discipline bears interesting connections to what has happened in given philosophers' societies and the world at large. Perhaps the clearest example of this lies in the influence of Christianity on the history of theoretical ethics.

Philosophical/theoretical ethics, of course, has had its own influence on Christianity, for example, Aristotle's influence on the philosophy of Thomas Aquinas and on the views and practices of the church. Nonetheless, to compare the character of the pre-Christian ethics of Socrates, Plato, Aristotle, the Stoics, the Epicureans, and other schools of ancient ethical thought with the kinds of ethics that have flourished in the academy since Christianity became a dominant social force is to recognize that larger social and historical currents play significant roles in the sphere of philosophical ethics.

Socrates, Plato, and Aristotle, for example, do not discuss kindness or compassion, moral guilt, or the virtue of self-denial, or selflessness. Christianity helped to bring these notions to the attention of philosophy and to make philosophers think that issues framed in terms of them were central to their task. By the same token, a late-twentieth-century revival of interest in ancient approaches to ethics may reflect the diminishing force and domination of Christian thinking in the contemporary world.

But if the concepts that ethics focuses on can change so profoundly, one may well wonder whether a single discipline of ethics can be said to persist across the ages, or even whether such a thing as "the task" of philosophical ethics can be said to endure. Socrates, and later Plato, were perhaps the first philosophers to make a self-conscious attempt to answer general ethical questions on the basis of reason and argument rather than convention and tradition. But was the task they accepted really the same as that of contemporary ethics? This issue needs to be addressed before the task of ethics can be described.

Despite the fact that the concepts and problems of physics have varied over the last few centuries, it is still possible to speak of the history of a single discipline called physics. Moreover, we might say that the task of physics has been and remains that of developing physical concepts for the explanation and description of physical phenomena. Something similar can be said about theoretical ethics. Over the millennia, thoughtful people and philosophers have asked what kind of life is best for the individual and how one ought to behave in regard to other individuals and society as a whole. Although different concepts have been proposed to assist in the task of answering these questions, the questions themselves have retained an identity substantial enough to allow one to speak of the task of philosophical ethics without doing an injustice to the history of ethics.

The History of Ethical Theories

There has been a good deal less variation in philosophical concepts between those Plato employed and those we employ than there has been in regard to physical concepts within the field of physics. Concepts in philosophical ethics are the instruments with which philosophers address perennial ethical questions, and the distinctive contribution of any given theoretical approach to ethics resides in how (and how well) it integrates such concepts into an overall ethical view.

The concepts of ethics fall into two main categories. The first category comprises notions having to do with morality, virtue, rationality, and other ideals or standards of conduct and motivation; the second, notions pertaining to human good or well-being and the "good life" generally. Notice that morality is only one part, albeit a major one, of the first category. Claims and ideals concerning how it is rational for us to behave are not necessarily "moral" within our rather narrow modern understanding of that notion. Prudence and far-sightedness, for example, are rational, but their absence is not usually regarded as any kind of moral fault; and since these traits are also usually regarded as virtues, it seems we have room for virtues that are not specifically moral virtues. In addition, questions about human well-being and about what kind of life is best to have are less clearly questions of morality, narrowly conceived, than of ethics regarded as an encompassing philosophical discipline. The two categories mentioned above basically divide the concepts of ethics understood in this broad sense, and all major, substantive ethical theories attempt to say something about how these two classes of concepts relate to one another. Since modern views employ concepts and ask specific questions that are more familiar to contemporary readers, these views will be discussed first.

DEONTOLOGY. Modern deontology treats moral obligations as requirements that bind us to act, in large measure, independent of the effects our actions may have on our own good or well-being, and to a substantial extent, even independent of the effects of our actions on the well-being of others. The categorical imperative of Immanuel Kant (1724–1804), in one of its main formulations, tells us that we may not use or mistreat other people as a means either to our own happiness or to that of other people, and various forms of moral intuitionism make similar claims (1964). Intuitionists typically differ from Kant in holding that there are several independent, fundamental moral requirements (e.g., to keep promises, not to harm others, to tell the truth). But they agree with Kant that moral obligation is not just a matter of good consequences for an individual agent or for sentient beings generally. Thus even though deontologists such as Kant and, in the twentieth century, W. D. Ross, have definite views about human well-being, they do not think of moral goodness and moral obligation as rooted in facts about human well-being (or the well-being of sentient beings generally); and here a comparison with Judeo-Christian religious thought seems not inappropriate.

The Ten Commandments are not a product of rational philosophy; they have their source in religious tradition and/or divine command. They do, however, represent a kind of answer to the question about how one should behave toward others; that is, they ask the question that philosophical ethics attempts to answer. Moreover, the way the Ten Commandments answer this question is somewhat analogous to the way moral principles are conceived by deontologists such as Kant and the intuitionists.

In religious thinking, the Ten Commandments are not morally binding through some connection to the well-being or happiness of individuals or even the larger community; they are binding because God has commanded them, and deontology seeks to substitute for the idea of a deity, the idea of requirements given by reason itself or of binding obligations perceivable by moral insight. The deontologist typically holds that one's own well-being and that of others are taken into account and given some weight by the set of binding moral requirements, but that these are not the only considerations that affect what we ought to do generally or on particular occasions. For deontologists, the end does not always justify the means, and certain kinds of actions—torture, betrayal, injustice—are wrong for reasons having little to do with good or desirable consequences.

CONSEQUENTIALISM. The contrast here is with so-called consequentialists, for whom all moral obligation and virtue are to be understood in terms of good or desirable consequences. Typically, this has meant framing some conception of human or sentient good or well-being and claiming that all morality is derivative from or understandable in terms such as "good" or "well-being." Thus Jeremy Bentham, Henry Sidgwick (1981), and other utilitarian consequentialists regard pleasure or the satisfaction of desire as the sole, intrinsic human good, and pain or dissatisfaction as the sole, intrinsic evil or ill, and they conceive our moral obligations as grounded entirely in considerations of pleasure and pain. The idea that one should always act to secure the greatest good of the greatest number is simply a way of saying that whether an act is right or wrong depends solely on whether its overall and long-term consequences for human (or sentient) well-being are at least as good as those of any alternative act available to a given agent. And since classical utilitarianism conceives human good or well-being in terms of pleasure or satisfaction, it holds that the rightness of an action always depends on whether it produces, overall and in the long run, as great a net balance of pleasure over pain as could have been produced by performing any of its alternatives.

This utilitarian moral standard is rather demanding, because it says that anything less than the maximization of overall human good or pleasure is wrong, and that means that if I fail to sacrifice my own comfort or career when doing so would allow me to do more overall good for humanity, then I act wrongly. But apart from the fact of how much it demands—there is nothing, after all, in the Ten Commandments or in the obligations defended by deontologists that requires such extreme sacrifice—what is most distinctive about utilitarianism is its claim that moral right and wrong (and moral good and evil) are totally, not merely partially, concerned with producing desirable results. The end, indeed, does justify the means, according to utilitarianism, and thus one might even be justified in killing, say, one innocent person in order to preserve the lives of two others.

Most deontologists would regard this as the most implausible, vulnerable feature of utilitarian and other consequentialist moral conceptions. But the utilitarian can point out that if you do not make human or sentient happiness the touchstone of all morality, but rely instead on certain "given" intuitions about what morally must or must not be done, you have given yourself a formula for preserving all the moral prejudices that have come down to us from the past. We require, Bentham argued, some external standard by which not only the state of individuals and society, but also all our inherited moral beliefs and intuitions can be properly evaluated. Bentham claimed that judging everything in terms of pleasure and pain can enable us to accomplish this goal. Historically, utilitarianism was conceived and used as a reformist moral and political doctrine, and that is one of its main strengths. If overall human happiness is the measure of moral requirement and moral goodness, then aristocratic privilege and the political disenfranchisement of all but the landed and wealthy are clearly open to attack, and Bentham and his "radical" allied did, in fact, make use of utilitarian ideas as a basis for making reforms in the British political and legal system.

But not all the reformist notions and energies lie on the side of consequentialism. The version of Kant's categorical imperative that speaks of never treating people merely as means, but always (also) as ends in themselves, was based on the idea of the fundamental dignity and worth of all human beings. Such a notion is clearly capable of being used—and, in fact, has been used—in reformist fashion to defend political and civil rights.

The debate between deontology and consequentialism has remained fundamentally important in philosophical ethics. Although there are other forms of consequentialism besides utilitarianism and other forms of deontology besides Kantian ethics, the main issue and choice has been widely regarded as lying between utilitarianism and Kant. This may be partly explained by the interest contemporary ethics has shown in understanding ethical and political issues as fundamentally interrelated; for both utilitarianism and Kantianism can claim to be "on the side of the angels" in regard to the large questions of social-political choice and reform that have exercised us in the modern period and may well continue to do so.

In the ancient world, the philosophical interest in ethics was also connected to larger political and social issues; both Plato (ca. 430–347 B.C.E.) and Aristotle sought to embed their ideas about personal morality within a larger picture of how society or the state should operate. Moreover, Plato was a radical and a reformer, though the *Republic* takes a direction precisely opposite to that of both utilitarianism and Kantianism. Plato was deeply distrustful of democratic politics and of the moral and political capacities of most human beings. His *Republic* (1974) advocates the rule of philosophers who have been specially trained to understand the nature of "the Good" over all those who have not attained such mystic/intellectual insight. Nor does Aristotle defend democracy. In somewhat milder form, he prefers the rule of virtuous individuals over those who lack—and lack the basic capacity for—virtue. If the ancient world contains any roots of democratic thinking, they lie in Stoicism, which emphasized the brotherhood of man (which seems to leave women out of account), but also spoke of the divine spark in every individual (including women). (Kant took the idea that all human beings have dignity, rather than mere price, from the Stoic Seneca [4 B.C.E.–C.E. 65].)

VIRTUE ETHICS. All schools of ancient ethics defended one or another form of "virtue ethics." That is, they typically conceived what was admirable about individuals in terms of traits of character, rather than in terms of individual obedience to some set of moral or ethical rules or requirements. Ancient ethics was also predominantly eudaimonistic. *Eudaimonia* is the ancient Greek word for being fortunate or doing well in life, and eudaimonism is the view that our first concern in ethics is with the nature and conditions of human happiness/well-being and in particular our own happiness/well-being. This does not mean that all ancient ethics was egoistic, if by that term one refers to views according to which the moral or rational agent should always aim at his or her own (greatest) good or well-being. Aristotle is a clear example of an ethical thinker whose fundamental orientation is eudaimonistic, but who is far from advocating that people should always aim at their own self-interest.

For Aristotle, the question to begin with in ethics is the question of what is good for human beings. But Aristotle argues that human good or happiness largely consists in being actively virtuous, thus tying what is desirable in life to what is admirable in life in a rather distinctive way. For Aristotle, the virtuous individual will often aim at the good of others and/or at certain noble ideals, rather than seek to advance his or her own well-being, so egoism is no part of Aristotelianism.

But certainly most interpreters have regarded the Epicureans as having a basically egoistic doctrine. Epicureanism resembled utilitarianism in treating pleasure and the absence of pain as the sole conditions of human well-being. Rather than urge us to seek the greatest good of the greatest number, however, the Epicureans argued that virtue consisted in seeking one's own greatest pleasure/absence of pain. (Given certain pessimistic assumptions, the Epicureans thought this was best accomplished by minimizing one's desires and simplifying one's life.)

Although there are some notable modern egoists (e.g., Hobbes, Spinoza, and Nietzsche), most recent moral philosophers have assumed that there are fundamental, rational reasons for being concerned with something other than one's own well-being. Moreover, the eudaimonistic assumption that questions about individual happiness or well-being are the first concern of ethics has, in modern times, given way to a more basic emphasis on questions like, "How ought I to act?" and "What obligations have I?" The Jewish and Christian religious traditions seem to have made some difference here. In both traditions, God's commandments are supposed to have force for one independent of any question of one's own well-being (assuming that one is to obey because God has commanded, and not just because one fears divine punishment). For most Christians, moreover, Jesus sacrificing himself for our redemption places a totally non-egoistic motive at the pinnacle of the Christian vision of morality. So the notions that one should always be concerned with one's own well-being, and that ethics is chiefly about how one is to conceive and attain a good life, are both profoundly challenged by any moral philosophy that takes Judaism or Christianity, understood in the above fashion, seriously.

Recent Developments

Twentieth-century philosophical ethics bears the imprint of much of the history of the discipline, and many of the more current, prominent approaches to the subject represent developments of historically important views. But earlier in the twentieth century, ethics, at least in Britain and in the United States, veered away from its past in the direction of what has come to be called metaethics. The move toward metaethics and away from traditional ethical theory resulted, in part, from the influence of a school of philosophy called logical positivism. The positivists held up experimentally verifiable science as the paradigm of cognitively meaningful discourse and claimed that any statement that was not empirically confirmable or mathematically demonstrable lacked real content. Since it is difficult to see how moral principles can be experimentally verified or mathematically proved, many positivist ethicists began to think of ethical claims as cognitively meaningless and refused to advance substantive moral views, turning instead to the analysis of ethical terms and ethical claims. Issues about the meaning of moral terms have a long history in philosophical ethics, but the idea that these metaethical tasks were the main task of philosophical ethics gained a prevalence in the early years of the twentieth century that it had never previously had.

In the latter half of the twentieth century, substantive or normative ethics (that is, ethics making real value judgments rather than simply analyzing such judgments) once again came to the fore and tended to displace metaethics as the center of interest in ethics. In particular, there was a resurgence of interest in Kantian ethics and utilitarianism, followed by a renewal of interest in the kind of virtue ethics that dominated the philosophical landscape of ancient philosophy.

The revival and further development of Kantian ethics received its principal impetus from John Rawls and younger philosophers influenced by him. Rawls's principal work, *A Theory of Justice* (1971) represents a sustained attack on utilitarianism and seeks to base its own positive conception of morality and social justice on an understanding of Kant's ethics that bypasses the controversial metaphysical assumptions Kant was thought to have made about absolute human freedom and rationality. Other Kantian ethicists (Christine Korsgaard, Onora O'Neill, and Barbara Herman), however, have sought to be somewhat truer to the historical Kant while developing Kant's doctrines in directions fruitful for contemporary ethical theorizing.

Meanwhile, the utilitarians responded to Rawls's critique with reinvigorated forms of their doctrine, and, in particular, Derek Parfit's Reasons and Persons (1984) seeks to advance the utilitarian tradition of ethical theory within a philosophical perspective that fully takes into account the insights of the Rawlsian approach.

Finally, virtue ethics has been undergoing a considerable revival. In a 1958 article, Elizabeth Anscombe argued that notions like moral obligation are bankrupt without the assumption of God (or someone else) as a lawgiver, whereas concepts of character excellence or virtue and of human flourishing can arise, without such assumptions, from within a properly conceived moral psychology. This challenge was taken up by philosophers interested in exploring the possibility that the notions of good character and motivation and of living well may be primary in ethics, with notions like right, wrong, and obligation taking a secondary or derivative place or perhaps even dropping out altogether. Such virtue ethics does not, however, abandon ethics' traditional task of telling us how to live, since, in fact, ideals of good character and motivation can naturally lead to views about how it is best to treat others and to promote our own character and happiness. Rather, the newer virtue ethics sought to learn from the virtue ethics of the ancient world, especially of Plato, Aristotle, and the Stoics, while making those lessons relevant to a climate of ethical theory that incorporates what has been learned in the long interval since ancient times.

More recently, however, a radical kind of virtue ethics without precedent in the ancient world has developed out of feminist thought and in the wake of Carol Gilligan's groundbreaking *In a Different Voice* (1982). Gilligan argued that men tend to conceive of morality in terms of rights, justice, and autonomy, whereas women more frequently think of morality in terms of caring, responsibility, and interrelation with others. And at about the same time as Gilligan wrote, Nel Noddings in *Caring: A Feminine Approach to Ethics and Moral Education* (1984) articulated and defended the idea of a feminine morality centered on caring.

The ideal of caring Noddings has in mind is particularistic: It is not the universally directed benevolence of the sort utilitarianism sometimes appeals to, but rather caring for certain particular people (e.g., one's friends and family) that she treats as the morally highest and best motivation. Actions then count as good or bad, better or worse, to the extent that they exhibit this kind of caring. Clearly, Nodding's view offers a potential answer to the traditional question of how one should live, but since the answer seems to be based on fundamental assumptions about what sorts of inner motivation are morally good or bad, it is a form of virtue ethics. Of course, her view can be stated in terms of the principle "Be caring and act caringly." But if we focus on conforming to the principle instead of on the needs of the individuals we care about, we risk falling short of what the principle itself recommends. It is the state or process of sensitive caring, rather than attention to principle, that generates what Noddings would take to be satisfying answers to moral questions and appropriate responses to particular situations.

Enriched by such feminine/feminist possibilities, ethical theory has been actively and fertilely involved with the perennial task(s) of ethics. But because few of the traditional questions have been answered to the satisfaction of all philosophers, one may well wonder whether philosophy will ever be able fully to answer those questions or even whether philosophers have, over the centuries, made real or sufficient progress in dealing with them. But it is also possible to attack the tradition(s) of philosophical ethics in a more radical fashion.

Modern Challenges to Philosophical Ethics

Some modern intellectual and social traditions have questioned the notion that ethics can validly function as a distinct sphere of rational inquiry. One example of such questioning was the widespread view, earlier in the twentieth century, that ethics should confine itself to the metaethical analysis of concepts and epistemological issues (and possibly to the sociological description of the differing ethical mores of different times and places) rather than continue in its traditional role of advocating substantive ethical views. (Metaethics has undergone something of a revival, but largely in a form regarded as compatible with substantive ethical theorizing.)

Historically, various forms of religion and religious philosophy have also posed a challenge to the autonomy and validity of traditional ethics. The claims of faith and religious authority can readily be seen as overriding the kind of rational understanding that typifies traditional philosophical inquiry. Thus, Thomas Aquinas believed strongly in the importance of the ethical issues raised by Aristotle and in Aristotle's rational techniques of argument and analysis; but he also permitted his Christian faith to shape his response to Aristotle and did not fundamentally question the superiority of faith to reason. He believed, however, that reason and philosophy could accommodate and be accommodated to faith and religious authority.

EXISTENTIALISM. But more radical religionists have questioned the importance of reason and have even prided themselves in flying in the face of reason. Religious views that stress our dependent, finite, sinful creatureliness can lead one to view philosophical ethics as a rather limited and even perverse way to understand the problems of the human condition. In modern times this religion-inspired critique of ethics and the philosophical received a distinctive existentialist expression in the writings of Blaise Pascal (1966) and Søren Kierkegaard (1960, 1983).

It is very difficult to give a completely adequate characterization of existentialism as a philosophical movement or tendency of thought. It cuts across the distinction between theism and atheism, and some of the most prominent existentialists have, in fact, been atheists. But the earlier theistic existentialism that one finds in Pascal and, more fully developed, in Kierkegaard is principally concerned with attacking rationalistic Western philosophy and defending a more emotional and individualistic approach to life and thought. Plato and Aristotle, for example, sought rationally to circumscribe the human condition by treating "man" as by his very essence a "rational animal" and prescribing a way of life for human beings that acknowledged and totally incorporated the ideal of being rational. But for Pascal, the heart has reasons that reason cannot know, and Kierkegaard regarded certain kinds of rationally absurd religious faith and love as higher and more important than anything that could be circumscribed and understood in rational, ethical, or philosophical terms.

The atheistic Nietzsche (1844–1900) also attacked philosophical ethics and rational philosophy generally by attempting to deflate their pretensions to being rational. Nietzsche saw human life as characterized by a "will to power," that is, a desire for power over other individuals and for individual achievement, and in *The Genealogy of Morals* (1956) he argued that Judeo–Christian ethics, as well as philosophical views that reflect the influence of such ethics, are based in debilitating and poisonous emotions rather than having their source in rational thought or enlightened desire. What comes naturally to man is, he thought, an aristocratic morality that is comfortable with power and harsh in regard to failure, and the idea that the meek and self-sacrificing represents the highest form of human being he took to be the frustrated and angry response of those who have failed to attain power, but are unwilling to admit even to themselves how they really feel.

Nietzsche clearly expressed an antipathy to the whole tradition of philosophical ethics, and even if he did defend an iconoclastic ethics "of the superman," his writings point the way to an attitude like that of the more recent existentialist Jean-Paul Sartre (1905–1980). In his *Being and Nothingness* (1956), Sartre argued that all ethics is based in error and illusion, and he attempted instead to describe the human condition in nonjudgmental, nonmoral terms. Sartre argued that human beings are radically free in their choice of actions and values, and he claimed that all value judgments, because they purport to tell us what we really have to do, involve a misunderstanding, which he called "bad faith," of just how free we actually are. At the end of his book, Sartre proposed to write a future book on ethics, but also set out, in compelling fashion, the reasons for thinking that any future ethics is likely to fall into error and illusion about the character of human freedom. Here, as in *Being and Time* of Martin Heidegger (1889–1976) which had a decisive influence on Sartre's existentialism, the existentialist philosopher is essentially critical of the role ethical thinking plays in philosophy and in life generally and says, in effect, that if we face the truth about our own radical freedom, we must stop doing ethics. Ethics may think of itself as a rational enterprise, but for Sartre, it was mainly a form of self-deception.

MARXISM. Existentialism has had a great influence on Western culture, but Marxism has probably had a much greater influence, and Karl Marx's writings (*Capital and the German Ideology*), like those of some of the existentialists, attempt to accustom us to the idea of taking ethics less seriously than practitioners of philosophical ethics have tended to do. According to Marx (1818–1883) (and Friedrich Engels), philosophical ethics and philosophy generally are best understood as expressions of certain class interests, as ideological tools of class warfare, rather than as independently and timelessly valid methods of inquiry into questions that can be settled objectively and rationally.

For example, intellectual, philosophical defenses of property rights can be seen as expressing and asserting bourgeois class interests against a resentful and increasingly powerful proletariat. All philosophy, according to such a view, is merely the expression of underlying economic forces and struggles. A truly liberated view of human history requires us to stop moralizing and start understanding and harnessing the processes of history, using the tools of Marx's own "scientific socialism." While Marx believed that a "really human morality" might emerge under communism, philosophical ethics is seen more as a hindrance than as a means to enlightened understanding of human society.

PSYCHOANALYSIS. In addition, psychoanalysis, as a movement and style of thought, has often been taken to argue against traditional ethics as an objective discipline with a valid intellectual task of its own. The psychoanalytic account of moral conscience threatens to undercut traditional ethical views and traditional views of ethics by making our own ethical intuitions and feelings seem illusory. In a manner partly anticipated by Nietzsche, Sigmund Freud's original formulation of psychoanalytic theory (e.g. in The Interpretation of Dreams and Introductory Lectures on Psychoanalysis) treat conscience and guilt as forms of aggression directed by the individual against himself (Freud). (Freud [1856–1939] tended to focus on the development of conscience in males.) Rather than attack parental figures he feared, the individual psychologically incorporates the morality of these seemingly threatening figures. If conscience is a function of hatred against one or more parental figures, then its true nature is often obscured to those who have conscience. According to classic psychoanalysis, the very factors that make us redirect aggression in such a fashion also make it difficult consciously to acknowledge that conscience has such a source.

If moral thought has this dynamic, then much of moral life and moral philosophy is self-deluded. However, for some more recent psychoanalysts, not all forms of ethical thinking are illusory. Followers of the British psychoanalyst Melanie Klein (1975) have said that various ethical ideals can and do appeal to us and guide our behavior, once "persecutory guilt" of the kind based in aggression redirected against the self is dissolved through normal maturation or through psychotherapy. Moreover, the analyst Erik Erikson (1964) gave a developmental account of basic human virtues that has clear, ethical significance.

In the end, perhaps it should not be surprising that many attempts to undermine ethics eventually reintroduce something like familiar ethical notions and problems. We have to live with one another, and the problems of making life together possible and, if possible, beneficial are problems that will not and cannot go away. Even if a given society and generation has settled on a particular solution to the problems of living together, new historical developments can make these solutions come unstuck, or at least force people to reconsider their appropriateness. And even if different societies and cultures have different moral standards, it is possible to overestimate the differences. For example, however much aggression societies may allow toward outsiders and enemies, no society has a moral code that permits people, at will, to kill members of that society. Moreover, the very fact of moral differences among different societies indicates a need for cooperative and practical ethical thinking that will enable people either to resolve or live with the differences.

APPLIED ETHICS. This is a point where the need for applied ethics most clearly comes into view. Whether it is in medicine, science, biotechnology, business, or the law, people have to come together to solve problems, and ethics or ethical thinking can play a role in generating cooperative solutions. If existentialism, religion, Marxism, and psychoanalysis all in varying degrees question the need for philosophical ethics, the practical problems of contemporary life seem to indicate some new ways and to highlight some old ways in which philosophical ethics has validity and value.

The explosive development of new knowledge and techniques in medicine and biology has made bioethics one of the central areas of practical, moral concern. And those seeking to solve moral problems in this area naturally appeal to philosophical ethics. To take just one controversial area, the question of euthanasia engages the ideas and energies of different ethical theories in different ways and often with differing results. Thus, the Kantian may focus on issues concerning the autonomy of the dying patient and the right to life, whereas utilitarians will stress issues about the quality of life and the effects of certain decisions on families and society as a whole, and defenders of an ethics of caring will perhaps see less significance in larger social consequences and focus on how a medical decision will affect those most intimately and immediately affected by it.

Applied ethics in our contemporary sense is not new: Socrates' discussion of the duty of obedience to unjust laws in the Crito and Henry David Thoreau's of civil disobedience are only two of countless historical instances of what we would call applied ethics. Today, we think, civilization is more complicated and our problems are more complex. Still, in facing those problems, bioethicists, business ethicists, and other applied ethicists typically look to philosophical ethics, to substantive theories like utilitarianism and virtue ethics and Kantianism, and to the criticisms each makes of the others, for some enlightenment on practical issues.

MICHAEL A. SLOTE (1995)

SEE ALSO: *Autonomy; Cancer, Ethical Issues Related to Diagnosis and Treatment; Care; Coercion; Communitarianism and Bioethics; Dementia; Emotions; Feminism; Justice; Life; Principalism; Virtue and Character;* and other *Ethics* subentries

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II. MORAL EPISTEMOLOGY

Moral epistemology is the systematic and critical study of morality as a body of knowledge. It is concerned with such issues as how or whether moral claims can be rationally justified, whether there are objective moral facts, whether moral statements strictly admit of truth or falsity, and whether moral claims are universally valid or relative to historically particular belief systems, conceptual schemes, social practices, or cultures.

The subdiscipline of moral epistemology is hardly a recent arrival on the philosophical scene. Plato's *Republic,* Aristotle's *Nicomachean Ethics*, Hume's *Treatise on Human Nature*, Kant's *Critique of Practical Reason*, and Hegel's *Phenomenology of Spirit* all grapple with moral-epistemological themes and issues. However, the lion's share of explicit, self-conscious reflection on moral-epistemological problems has taken place in the twentieth century, reflecting Western philosophy's more general preoccupation with the problem of knowledge since the time of Kant. This entry describes and critically evaluates some of the major options in moral epistemology taken during that period.

Intuitionism

When one describes a person as "good," or when one says of an action that it is "the right thing to do" under the circumstances, is one pointing out an objective feature of the person or action, or is one expressing one's own subjective reaction? Is one stating something that could be either true or false? Is one making a claim that could be supported by reasons or evidence, and that would warrant the assent of any rational human being? Or is one merely giving voice to one's own attitudes or feelings? Much of the contemporary debate in moral epistemology turns on the answer to these questions.

Intuitionists, chief among whom were G. E. Moore and W. D. Ross, insist that moral terms such as "good" and "right" name objective properties, refer to real aspects of real things, events, activities, and persons, and claim that we have access to these properties by a form of direct insight or perception. Because of this, moral statements are genuine propositions capable of being assigned a truth value of "true" or "false." To use a technical, philosophical term, morality is "cognitive." Intuitionists, while drawing an analogy between sensory intuition and moral intuition, also generally insist that moral intuition is different in kind from sense perception. While sense perception acquaints us with objective facts, moral intuition acquaints us with equally objective values.

According to G. E. Moore's *Principia Ethica* (1903), "good" is a simple, unanalyzable concept. Like the property concept "yellow," "good" cannot be defined except by pointing out instances of the concept, which enables one to grasp its unitary meaning. Unlike "yellow," which denotes a property intuited by our ordinary sensory apparatus, "good" names a nonnatural property, which, despite the fact that it is not empirically given, is nonetheless just as objective and real as is the property "yellow." W. D. Ross, in *The Right and the Good*, expands Moore's table of simple, objective moral properties to include "duty," or "rightness," and the degrees of rightness that attach to conflicting prima facie duties in different circumstances.

Intuitionists like Moore do not deny that there is moral knowledge; in fact, they affirm it emphatically. But for both Moore and Ross, our knowledge of what is ultimately good or right is not inferred or deduced but immediately given; we do not need to define, rationalize, or justify it. Thus a physician, deciding to remove an irreversibly brain-dead patient from a respirator, might give reasons for her decision by citing the beneficial consequences (e.g., an end to the patient's fruitless suffering) that might be achieved, or by insisting that the duty to preserve life is trumped by the higher duty to preserve a patient's dignity. But as to why these consequences are good, or why these putative duties are duties, the intuitionist physician can rightfully appeal only to her perception of the basic quality of goodness or rightness in them. Look and you too shall see.

The very immediacy of moral knowledge poses a serious problem for the intuitionist, namely, how moral argument and moral disagreement are possible. According to Moore, one either "sees" that something is good or one doesn't, and if one doesn't, there's little to be done except to look again. But what if two or more competent moral agents persistently "see" different values in the same circumstances? Who is "seeing" what is really there, and who is "seeing" a moral illusion? The intuitionist faces the difficulty of accounting for genuine moral disagreement—disagreement not about the empirical, factual issues of how to bring about the greatest good or do one's duty, but the evaluative issue of what sorts of things are genuine, intrinsic goods or actual obligations. This faculty of moral intuition is therefore curious. It is supposed to yield insight into objective properties of things, outcomes, deeds, and institutions, yet it lacks any public criterion against which claims like "X is good" or "Y is the morally right thing to do" might be checked and rationally validated.

Emotivism

A number of thinkers influenced by logical positivism, most notably A. J. Ayer and Charles L. Stevenson, rejected intuitionism and with it the conviction that moral discourse was objective and cognitive. The resulting theory, emotivism, denied that "good" or "right" named any sort of objective, intuitable property. Rather, to say of something that it is "good" or "evil," "right" or "wrong," is to express a subjective attitude or emotional response toward it. For example, the proposition, "You ought not to have lied to that patient," asserts nothing more than "you lied to that patient"; the "ought" merely notes an attitude of disapproval on the part of the speaker. Emotivists emphasize the imperative quality of moral utterance. To say lying is wrong is, in effect, to issue the command, "Do not lie." To place ethical discourse in a recognizable context, the effort on the part of agents is to influence the behavior of others and to persuade them to adopt different beliefs. If emotivists like Ayer and Stevenson are right about the meaning of moral statements, the demand to account for "moral knowledge" is senseless, since all moral discourse is inherently noncognitive, nonrational, and subjective.

Perhaps this is an acceptable price to pay to make the phenomenon of moral disagreement intelligible. An intuitionist would be vexed by disagreements such as the following:

(1a) Active, involuntary euthanasia is morally acceptable under certain conditions, versus
(1b) Active, involuntary euthanasia is always immoral, under any and all conditions.

Yet what for the intuitionist is an epistemological dilemma, for the emotivist is not a dilemma at all. The proponent of (1a) is "commending" the permissibility of involuntary, active euthanasia under certain conditions rather than asserting a true-or- false proposition; she is expressing a "pro-attitude" toward (1a), and trying to persuade others to do so as well. The proponent of (1b) is doing precisely the same thing, expressing an "anti-attitude." The disagreement is one of subjective attitude and feeling and does not concern anything objective; there is no deep, moral truth under dispute.

But perhaps it might be premature to claim that the ability to make sense of moral disagreement thereby vindicates emotivism. One serious difficulty with emotivism is that it narrows the human significance of moral discourse by flatly denying that whenever one makes a moral claim, one places oneself in the position of having to back up that claim by citing what one takes to be good reasons in its behalf.

Universal Prescriptivism

Universal prescriptivism is a compromise between emotivism and the commonsense conviction that morality is a rational enterprise. Its chief exponent, R. M. Hare, argues in *The Language of Morals* (1952) that moral imperatives carry certain inexorable rational constraints. If I make the moral judgment, "Active, involuntary euthanasia is wrong," I am in effect declaring that one ought not to perform active, involuntary euthanasia on someone, and thus commanding, "Do not perform active, involuntary euthanasia," where the ought command is issued to anyone in the relevant situation, including me, the speaker. So while moral judgments have an imperative or prescriptive component—like Moore, Hare rejects naturalism—they exhibit a universality that binds the speaker's deeds to her claims, and enables the speaker to use reason to draw further moral conclusions on the basis of prescriptions that function as premises in deductive arguments.

In affirming the role of deductive reason in ethics, Hare's universal prescriptivism challenges the emotivist's assumption that only indicative premises are beyond suspicion in valid argumentation. For surely the following argument is a valid deduction:

(2a) I ought not to lie to my patients and thus intentionally mislead them.
(2b) My patient Bill asked me to tell him about his medical condition.
(2c) I ought not to lie to Bill about his condition.

All its premises are meaningful, and since the major premise is prescriptive, the taboo against deducing an "ought" from an "is" is not violated. Furthermore, (2a) itself could be justified by being a valid conclusion drawn from more general prescriptions:

(2d) I ought not to be unjust.
(2e) To lie to one's patients and thus intentionally mislead them is unjust.
(2f) I ought not to lie to my patients and thus intentionally mislead them.

However, there cannot be an infinite hierarchy of such deductions. For the prescriptivist, one's ultimate prescriptive or evaluative premises are chosen rather than deduced: One cannot ground one's moral convictions in premises more basic. The foundations for moral reasoning cannot themselves have a foundation; they reflect one's basic stance or attitude toward persons and things. No "ought" can be derived from an "is." One's moral first principles, being prescriptions, cannot be rooted in indicative soil.

This might lead one to wonder whether universal prescriptivism is more a refinement of emotivism than a genuine advance on it. It seems to push the point where ethical discourse is a matter of attitude and criterionless choice back to the most general evaluation the agent wishes to make. For example, substitute the following premise for (2a) above:

(2a1) I ought not to lie to my patients and thus intentionally mislead them *unless* I have ample reason to judge that doing so will confer some psychological or medical benefit to them.

If a physician were to judge that some such benefit were to be obtained from intentional deception, then the conclusion that one may intentionally deceive a patient will follow, in direct contradiction to (2c) and (2f). Given the initial moral orientation, certain principles for action are validated, but the original moral orientation cannot itself be validated; it can only be accepted, endorsed, chosen. Since this nonrational, inaugural choice provides the basis for all subsequent moral reasoning, the content of an agent's morality appears to be ultimately arbitrary, even if it is not arbitrary in all its detail.

Hare disagrees. In *Freedom and Reason* (1963) he argues that universal prescriptivism sets limits on the kinds of fundamental moral choices an agent can make. Consider the following:

(3a) Certain people ought to be persecuted because, and only because, their skin is black.

If moral imperatives using "ought" are, as Hare claims, universal prescriptions, then the agent uttering these words is, or ought to be, committing himself to the proposition that if his skin were black he, too, ought to be persecuted. It is clear that few individuals who make such assertions, apart from those Hare dubs "fanatics," would assent to the latter claim. Yet it is entailed by the universal prescription (3a); hence, the morality of any agent who asserts (3a) and refuses to extend it to cover himself is, for that very reason, rationally inadequate.

Of course, there is no possibility of genuine argument with a genuine "fanatic": The fanatic's assertion of ultimate principles or fundamental commitments, however odious or bizarre they may be, can only be met with counterassertion and not counterreasoning. Hare seems willing to accept this lack of logical resources against fanaticism. Nevertheless it seems reasonable to ask universal prescriptivists such as Hare whether, by cutting off rational argument at fundamental principles, they are granting too much to fanatics by ruling out any way in which their convictions can be criticized, rather than their unpleasant characters. The fanatic may be vile and depraved, but by universal prescriptivist standards, he is not necessarily defective in reason.

Naturalism

Intuitionists, emotivists, and prescriptivists all agree that "facts" are distinct from "values"—that an "ought" cannot be deduced from an "is." G. E. Moore coined the term, "the naturalistic fallacy," to describe the frequent attempts on the part of philosophers to define "the good" by deducing it from some matter of fact about human beings and their desires. A number of philosophers have challenged this no-ought-from-an-is doctrine by providing counterexamples to it, in effect denying that the naturalistic fallacy is a fallacy.

Philippa Foot (1959), for example, has cited "rude" and "courageous" as concepts whose evaluative meaning cannot be pried from their descriptive meaning. The criteria for identifying someone as "rude" or "courageous" are factual. If someone fits a given description, one has warrant for saying that he or she is rude or courageous; thus, the proposition "She is rude/courageous" is cognitive. But to describe someone as rude is to evaluate that person negatively. Consider the absurdity of saying: "You're rude, cowardly, and abusive, but that isn't meant as a put-down." So, according to Foot, valid moral arguments can draw evaluative conclusions from factual premises.

Peter Geach (1956) makes an analogous point in his analyses of "good." To say that a thing is good is to say something concerning the kind of thing it is. "Good" does not mean precisely the same thing in the following sentences: "That car is good"; "that watch is a good watch"; and "Mohandas Gandhi was good." To say of each one of these that it is good is to employ criteria determined by the kind of thing being evaluated. But this is to say, again against the emotivist and the prescriptivist, that the criteria that fix the meaning of evaluative terms such as "good" are not ultimately matters of choice, but rather matters of fact. To know a good watch, one needs to know what a watch is and what it is for; to know a good person, one, likewise, must know what a human being is and those ends at which humans aim in their actions.

Finally, John Searle (1964) accuses noncognitivists of harboring an arbitrarily constricted notion of what constitutes a "fact." Human institutions are part of what is the case, and these "institutional facts" can appear in descriptive premises in valid deductive arguments that generate evaluative conclusions. For example, to acknowledge the institution of promising is to grant that under certain circumstances, when one utters the words, "I promise to do X," one places oneself under an obligation to do X, and therefore is obliged to do X, and therefore one ought to do X. Because institutional facts are determined by the rules guiding the aims and actions of participants, one can deduce values from them.

Naturalists sketch a picture of moral language in which moral concepts are understood by deriving them from nonmoral, "naturalistic" ones, upon which moral knowledge rests. A robust naturalism in bioethics, then, would show no qualms about defining "the good" or "the right" in a medical context by appealing to certain key facts about human beings (e.g., their pain, dignity, mortality, etc.) and about the social and institutional setting for these facts.

At this point, however, the prescriptivist can offer a rebuttal that is difficult to answer on the naturalist's own terms without begging an important question. The prescriptivist concedes that moral language necessarily has a factual or descriptive component, but insists that it also makes ineliminable reference to the agent's desires, aims, and wishes. These can be more or less rational depending on whether their satisfaction interferes with or complements other sets of desires, aims, and wishes, but no desire can be judged rational or irrational per se. These basic desires and attitudes might differ from person to person; there is no escaping the fundamental choice behind all evaluations and prescriptions. So when the naturalist claims to have deduced an "ought" from an "is," either the major premise harbors an implicit prescription (e.g., "One ought to honor institutions like promise-keeping") or the argument is not a strict deduction.

Naturalists might reply that the "natural" premises to which they appeal and that ground moral judgment and description are rooted not in the desires or aims of individuals but in general facts about human nature of which it is the philosopher's job to remind us. For example, Aristotle understood *eudaimonia,* or "human flourishing," to be the good for a human being, because it was a result of acting in accord with one's rational human nature; Thomas Aquinas defined the good in terms of human creatures' reestablishing a right relation to God; and John Stuart Mill's psychological theories stand behind his definition of the good as pleasure seeking and pain avoidance. Aristotle, Thomas Aquinas, and Mill all pursued ethics in the context of what might be called "philosophical anthropology." Yet this simply elevates the naturalist's dispute with the prescriptivist to a higher level of abstraction. The prescriptivist could deny that there is any fact of the matter that might constrain the choice between philosophical anthropologies, while the naturalist could just as adamantly insist upon it. Thus naturalism might provide a coherent, consistent alternative to prescriptivism, but only by accepting philosophical stalemate at a higher level.

Rationalism

One possible avenue around the prescriptivist/naturalist impasse would be to repudiate the naturalistic fallacy, yet insist that moral principles are justified by examining the nature of rationality itself. This sort of moral epistemology owes much to Kant. A number of notable philosophers, inspired by Kant yet eager to avoid his dubious treatment of the self, have endeavored to ground moral knowledge in the reflective exercise of reason by actual human agents.

The most ambitious of these attempts is clearly that of Alan Gewirth, who in *Reason and Morality* tries to prove the fundamental principle of morality by analyzing the bare concept of rational agency. Every rational agent, Gewirth argues, must presuppose certain generic goods—namely, freedom and a degree of well-being—that make the exercise of his or her agency possible. If the agent must claim these generic goods as necessary, he or she must also claim them as rights. But since these goods flow from the generic features of agency, he or she must also concede that all other agents must claim them as rights, and that there is a corresponding obligation to acknowledge and respect them. Hence, the Principle of Generic Consistency (PGC)—"Act in accord with the generic rights of your recipients as well as yourself" (1978, p. 135)—is the fundamental, categorical principle of morality, from which all other concrete moral norms and precepts can be derived, and which can be denied only on pain of logical self-contradiction.

Many of Gewirth's critics (e.g., Nielsen; MacIntyre, 1984; Arrington) have questioned a crucial move in his dialectical "proof" of the PGC: Acknowledging that there exist necessary goods of rational agency need not entail recognizing them as one's rights. If these critics are correct, Gewirth's foundational moral principle is not necessarily true. If it is only contingently true, Gewirth's claim to a proof of the one fundamental principle of morality has not been vindicated.

In contrast to Gewirth's "hard" rationalism, other moral rationalists adopt a "soft" rationalism that proceeds not from unassailable premises about rational agency, but from contingent truths about what all rational agents would, in fact, choose under ideal conditions. For example, John Rawls, in *A Theory of Justice* (1971), maintains that in a hypothetical "original position," where the specific identities, desires, and advantages of rational agents are deliberately obscured behind a perspective of impartiality—a "veil of ignorance"—rational agreement would be secured regarding two specific principles of justice, equal liberty and equal distribution of goods, except in those cases where an unequal distribution of goods would work to the benefit of the worst-off social group.

"Soft" rationalism proceeds from assumptions about the rational choices individuals would make in imagined, empirical situations; thus it lends itself well to concrete application in such fields as legal, business, and medical ethics. For example, Robert M. Veatch, in *A Theory of Medical Ethics* (1981), argues that the responsibilities of medical professionals are set in an implicit "triple contract" involving those professionals, their patients, and society at large; specifically, medical rights and obligations are fixed by determining what sorts of agreements would be rational for all three interested parties to agree upon.

There are serious difficulties with these "soft" forms of moral rationalism. Rawls's "original position" suggests that individuals could and should be able to abstract themselves from their specific, contingent identities when formulating and justifying the principles of justice. But, as Michael Sandel (1982) and Charles Taylor (1985) have argued, this project faces formidable epistemological difficulties. It presupposes that "the self" is prior to its ends, that one's identity as a pure, rational chooser is separable from and more basic than one's identity as, say, an American, a Christian, a physician, and so on—and that it can and must draw upon rational resources that are neutral with respect to the ends and desires connected with these identities. Yet it is questionable whether such an "unencumbered" self would have any rational resources upon which to draw or any concrete intentions upon which to act; whether, indeed, the contracting chooser in the "original position" could ever be more than a philosophical fiction. Thus it seems as if moral rationalism—if it is to remain on epistemologically solid ground—must compromise its purity by admitting that the contingencies of time, place, and personal identity do make at least some difference in determining which choices and which sets of moral beliefs will be accepted as rational.

Realism and Antirealism

Another way to get around the prescriptivist/naturalist standoff would be to insist with the naturalist that there are objective moral truths, but to question whether such truths can be deduced from more basic facts concerning human nature or human institutions. On this "realist" account of moral knowledge (so called because it affirms objective moral realities independent of the knowing subject), moral discourse is less a matter of reason than of careful perception and insight, of developing the capacity to discriminate moral facts and to describe them accurately and adequately. To the extent that moral knowledge rests on "seeing" moral properties, moral realism suggests Moore's intuitionism. Yet, unlike Moore, moral realists claim no special faculty of moral intuition, insist that moral properties are observable in precisely the same way as are empirical properties, and hold that moral judgments and observations are fallible and revisable.

This renewed form of moral realism has been advanced by a number of British philosophers (Platts; McDowell, 1979; Lovibond) influenced by Donald Davidson's theory of meaning and Ludwig Wittgenstein's critique of reductionism in the philosophy of language. From Davidson they have borrowed the idea that to know what any sentence means is to be able to specify the conditions under which it is true. From Wittgenstein they have taken the conviction that there is no way to establish a ground for language that is independent of and cognitively superior to actual language in use. Taken together, these Davidsonian and Wittgensteinian commonplaces work to deflate all forms of noncognitivism.

The noncognitivist needs to rely on a contrast between two kinds of utterances—those that carry truth values and those that do not—and thus insists on two kinds of "meaning" and two kinds of discourse. One kind of discourse can accurately represent facts (usually assumed to be science), and the other does not represent facts, but expresses attitudes and imposes those attitudes on a world plastic enough to accept them (art, poetry, morality). But since determining the meaning of any linguistic statement is inseparable from determining whether that which it asserts is true or false, the noncognitivist cannot plausibly draw the required contrast between first-rate, fact-picturing discourse and second-rate, value-projecting discourse. To know what any expression means is to know what would make it true, and this ability neither demands nor supports any assumptions about the superior cognitive reliability of any one form of discourse (scientific) over any other (commonsense, literary, or moral).

The moral realist argues that there are moral facts just as there are scientific facts, and does not expect moral facts to be reducible to or deducible from any other kind of fact. Moral properties are "supervenient" upon nonmoral properties. One discerns a moral property by enumerating a number of nonmoral properties standing in relation to each other, from which the moral property "emerges" without being strictly entailed by them. "Supervenience" becomes clearer when one turns from examining "thin," abstract moral concepts ("good," "right," "duty") to "thick" moral concepts (concrete, specific concepts, like "courage," "loyalty," or "mercifulness"). To know, for example, that a physician's treatment of an end-stage cancer patient with larger than usual doses of painkillers was merciful involves knowing a great number of facts concerning cancer, pain, the special needs of the terminally ill in general and of this patient in particular, and so on. While one does not infer the moral property of being merciful from these nonmoral facts, the property is a function of them; one perceives the moral fact that this act is merciful in and through perceiving the aforementioned nonmoral facts.

"Seeing" the moral facts in the associated nonmoral facts is a complex skill, demanding discipline, practice, and attentiveness to matters of minute detail. For the moral realist, becoming a morally competent bioethicist is largely a matter of acquiring and honing a certain sensibility, akin to that of understanding a work of art or literature, whereby one comes to notice the moral goods and obligations in the context of medical practice, and to disclose and explicate them in descriptive speech.

A number of moral epistemologists (e.g., Mackie) have complained that the realists' account of supervenience is incoherent. If the supervenient moral properties of a person change (for example, if someone ceases to be courageous or just), it is necessary that other, nonmoral properties also have changed (fleeing from every danger; ceasing to give others their due). Yet if that person possesses all the nonmoral dispositions associated with a moral property (steadfastness in the face of danger; a consistent willingness to keep promises), it cannot be inferred that he or she necessarily possesses the associated moral properties (the person might not be courageous or just, "despite appearances"). Supervenience is supposedly a logical relation between properties, yet because it cannot be interpreted as a form of inference, it becomes an inexplicable fact.

John Mackie subscribes to a form of moral antirealism or "projectivism" that allows for cognitive expressions in moral discourse—that is, the truth or falsity of moral beliefs, the validity or invalidity of moral arguments—yet understands them in an equivocal sense, as a disguised, second-level reflection upon first-level moral judgments and attitudes. The moral idiom forces us to speak as if there were moral facts, but such "facts" are ultimately projections of our attitudes. To insist that moral judgments are more than expressions of attitude would be to reintroduce supervenience, with all its difficulties. Moral antirealists would not exactly deny, then, that moral knowledge is a result of coming to "see things" and describe them in a certain way; they would, however, deny that such descriptions bear more than an instrumental function. The physician who "sees" that a particular act toward a patient is merciful is indeed "seeing" something, but that something is a function of the physician's subjective attitude projected outward toward the patient.

This may not be cause for genuine worry on the realist's part. He or she could, of course, stand firm and endorse the reality of objective moral facts—the instantiation of "thick," descriptive moral properties such as "courage," "patience," and "mercifulness"—in the face of the logically peculiar notion of supervenience. Perhaps supervenience is an inexplicable logical and epistemological fact. So what? Supervenience is a feature of ordinary moral discursive practice, one that morally competent speakers can handle without much trouble. The difficulties that antirealist moral epistemologists claim to have uncovered are more a matter of their a priori prejudices (perhaps their epistemological "scientism") than their discovery of a defect in moral language and moral practice.

The realist, like Wittgenstein, confidently affirms that ordinary moral language is in good working order as it is. The antirealist, of course, can reply that such "folk" moral philosophy is untidy, plagued with logical ambiguities and desperately in need of philosophical reinterpretation. Thus the clashes between moral realists and moral antirealists recapitulate the earlier standoff between prescriptivists and naturalists. What is at issue is not whether values can be derived from facts, but whether it even makes sense to speak of emergent "moral facts" alongside nonmoral ones.

Against Epistemology

Virtually all the various schools of moral epistemology considered seem to employ an ahistorical approach to moral discourse, argument, and judgment. Both prescriptivists and naturalists confidently speak of "*the* language of morals," presupposing that "morality" has a singular essence lurking under all the various "moralities" of human history. Their dispute only concerns what this "essence" might be. Rationalists, realists, and antirealists also claim their particular moral epistemologies for morality per se, as opposed to the morality characteristic of a particular time, place, or community; these epistemologies are seen as perennial options for anyone who wishes to think about ethics.

The assumption that "epistemology" studies the invariant universal structures of human knowledge, entitling it to "legislate" over all knowledge claims, has been the target of sustained philosophical attack in the latter half of the twentieth century by Ludwig Wittgenstein, Martin Heidegger, and John Dewey, among others. Richard Rorty's landmark *Philosophy and the Mirror of Nature* (1979) was one of the first works to point out the affinities between the projects of Wittgenstein, Heidegger, and Dewey. Rorty showed that all three undermined the pretense of "epistemologically oriented philosophy" to have attained a timeless, ahistorical, necessary vantage point in its judgments about knowledge by pointing out, in different ways, how knowledge claims are situated and justified in shared practical and social contexts and are unintelligible apart from such contexts. From Rorty's perspective, the different approaches of moral epistemologists are less important than their common goal of discovering the foundations of moral reason and showing how these foundations might (or might not) be "justified" to any rational person. But Rorty insists that the epistemological assumptions undergirding their "common goals" are baseless. Among those assumptions are the idea that there are moral truths available to human rationality as such, or that "morality," like "knowledge" and "being," is a concept with a unique, stable core meaning. Rorty's Wittgensteinian, Heideggerian, and Deweyan case against foundationalist philosophy thus makes a new, antifoundationalist and self-consciously historical approach to moral knowledge all the more appealing.

Relativism and the Feminist Critique of Objectivity

Antifoundationalism in moral philosophy has taken a number of different forms. One of them, relativism, has once again emerged as a serious option in moral epistemology. The doctrine associated with the ancient Sophists—that objectivity, truth, and knowledge are matters of adhering to sociocultural convention rather than of attaining insight into nature—has been revived and expressed in more sophisticated ways by Gilbert Harman (1975), Bernard Williams (1985), Joseph Margolis (1991), and David Wong (1984). Wong, for example, maintains that the concept of "an adequate moral system" is relative to particular places and times: There is no single, universally valid moral system available, even as an unattainable ideal. Within each extant system, there are resources available for evaluating and criticizing rival systems binding on all who share its standpoint. Wong is neither a subjectivist nor a noncognitivist. There is, however, no standpoint outside all such systems from which judgment could be passed upon each of them indifferently. For Wong, the collapse of epistemological foundationalism, and the acknowledgment that our "moral systems" are not the deliverances of pure, universal human reason but are products of historical contingencies, supports a form of relativism that is less concerned about specific judgments of right or wrong than with the assessment of moral systems or cultures on the widest scale.

Many critics of contemporary relativism have argued that it retains most of the self-referential inconsistencies that plagued its earlier incarnations. Can the relativist maintain that the relativistic thesis is "true" or "reasonable" without begging the question? (See Putnam.) Other critics argue that the historical contingency of moral beliefs and their lack of necessary epistemic foundations does not imply relativism, since it does not preclude the possibility of one moral system being more rationally adequate than its competitors (see Stout).

Yet this response elicits a further question: Whose conception of "rationality" is being employed when someone judges a moral system superior or inferior? Several important feminist philosophers have responded to this question by noting that, generally, the "rationality" employed and championed by moral philosophers has been "rationality" as understood and defined by men, who are ideologically biased by their place in a patriarchal social system and who tend to exclude the experiences and judgments of women (Tong; Code; Tuana). The idea that reason and objectivity could be "gendered" concepts has led some feminists to conclude that men and women evince different kinds of moral knowing, and to champion a feminine "ethic of care" as against a masculine "ethic of principles" (Gilligan), just as it has led others to reject those very "feminine virtues" as yet another aspect of women's oppression by men (Bartky; Puka). Whatever the ultimate outcome of these debates, contemporary feminism has done much to reinforce the antifoundationalist and historicist critique of "objectivity" and "rationality" as universal, unproblematic features of human thought and discourse. But does that critique undermine the idea of "moral knowledge" as such?

Historicism, Virtue, and Tradition

One systematic moral philosopher who disagrees with that sentiment, and who has used the insights of historicism and antifoundationalism in rethinking and recovering a workable notion of "moral knowledge," is Alasdair MacIntyre. *After Virtue* (1984) begins by noting both the interminable and arbitrary character of contemporary moral arguments and the vehemence with which they are conducted, and asks what might account for the powerlessness of contemporary moral philosophy to resolve moral conflict and secure agreement. MacIntyre attempts to answer this question by pursuing a historical inquiry into the succession of moral theories and the social contexts in which they arose. MacIntyre maintains that the intractability of moral disagreement is one aspect of the "emotivist culture" of late modernity that provides no solid basis for making shared, rational moral judgments and thus renders the idea of genuine moral knowledge unintelligible.

Most modern moral theory and practice has dispensed with the Aristotelian idea of a human *telos,* an "end" proper to human beings as such. Modern social and political orders have ceased to define their mission as that of articulating a shared vision of the good life and communally pursuing it, since it is assumed that there is no good-defining end to seek. Then what can moderns claim to "know" when they make ethical assertions, decisions, and judgments? MacIntyre dubs the standard modern response to this question "the Enlightenment project": the task of finding the universal rules or standards that guide conduct yet swing free from any substantive conception of a good life, and are justifiable by appealing to rationality.

All attempts to fulfill the ambitions of the Enlightenment project have failed, according to MacIntyre, by their own standards of success. Kantians, Utilitarians, Humeans, Intuitionists, and so on, all presuppose that there is something universally known or grasped (the Categorical Imperative, the principle of utility, the sentiment of benevolence, the self-validating property of goodness or rightness) that provides an adequate ground for moral judgment and action. Upon closer inspection, however, both the prescriptive force and the specific content of such moral foundations seem arbitrary and local rather than necessary and universal.

If this is so, the epistemological universalism of the Enlightenment project functions as a mask, concealing the manipulative, will-driven ambitions of its disciples under guise of the objectivity of universal principle. Friedrich Nietzsche thus stands as both the fruition and the ruin of the Enlightenment project. His achievement is to have revealed that behind the rhetoric of objective, universal rational foundations, the morality of the modern West is yet another arbitrary upsurge of "will to power," and its impending collapse is testament to its own timid denial of this hard truth.

While MacIntyre insists that Nietzsche is certainly right about modern moral theory and practice, he has not thereby shown that all morality falls victim to the same disease. If the history of moral beliefs and moral theories can reveal the bankruptcy of the Enlightenment project and the moral nihilism of Nietzsche's "genealogical" critique of morality, it can also show how the moral philosophies they displaced can succeed where they themselves failed. MacIntyre contends that contemporary Aristotelians can draw upon epistemological resources that both Enlightenment rationalists and Nietzschean skeptics lack.

First, Aristotelians begin thinking about morality with a systematic conception of the virtues, a set of character traits that enable human agents to perfect their natures and thus realize, however imperfectly, their ultimate end. Duties and obligations—what one ought to do—begin to make sense only against the background of belief about what one ought to be. Since virtue is intrinsically connected to a conception of well-being or human flourishing shared by members of a moral community, one can establish a sound, rational motive for being moral, without reducing what one ought to prefer or desire, in light of one's true end, to what one empirically happens to prefer or desire.

Second, by understanding moral behavior as action that proceeds from a character perfected by these virtues, one eliminates the need for thinking of morality as exclusively, or even primarily, a matter of conscientious rule-following. Hence one evades the difficulty afflicting most forms of moral rationalism, that of specifying substantial moral principles, rather than empty generalities, to putatively compel the rational assent of anyone whosoever. For Aristotelians, as MacIntyre understands them, there is no moral knowledge apart from moral education and training, education not so much in assimilating precepts and norms, but in acquiring the skilled moral wisdom (*phronesis*) to express the proper responses and sentiments in the proper way at the proper times.

Finally, Aristotelianism, for MacIntyre, can make sense of the ways in which traditions of rational inquiry and communal practice can sustain a conception of the virtues while subjecting it to both internal scrutiny and external challenge. Most moral epistemologists make the false assumption that morality names a universal phenomenon rooted in universal human reason. If MacIntyre is right, there is no morality except as rooted in particular communities with their own particular traditions concerning the nature of the virtues and their role in promoting human well-being. This might seem to lend comfort to those moral and political conservatives who take reason and tradition to be polar opposites, and who denigrate the former and deify the latter. Yet only by participating in the common life and practices of a tradition can we come to recognize moral reasons as reasons. By dialectically examining and testing these reasons against those of rival traditions of thought and practice, we can confirm or deny their adequacy and provisionally justify our confidence in them. Traditions are the primary bearers of moral reasons; the internal evolution of traditions and the conflicts between alternative traditions indicates the way in which moral knowledge is embodied in time and history, and how moral knowers can yet transcend historical limitations.

Conclusion

The virtue-centered historicism exemplified by MacIntyre might seem, at first, to be yet another item on the menu of moral epistemologies, yet another intellectual position for ethicists to choose and then defend. But it would be a mistake to view it in this way. Moral epistemology, as a historicist like MacIntyre conceives of it, differs from moral epistemology as most moral epistemologists have conceived of it. MacIntyre denies the ability to transcend all traditional allegiances and to spell out the conditions for moral knowledge in general and as such. As MacIntyre suggests, the moral system it would be rational to adopt depends on who one is and how one understands oneself; there is no moral system that is rational without qualification (1988). This is certainly not to suggest a radical moral relativism, since one's initial loyalties, convictions, and self-understandings are precisely what are to be tested by inquiry and comparative criticism. One must begin inquiring somewhere, however, and the only available starting points are within the assumptions and ways of life of the specific traditions one happens to inhabit.

Thus, for historicists like MacIntyre, Rorty, Stanley Hauerwas, and Jeffrey Stout, moral epistemology can no more escape the gravitational pull of human practice and human history than can any other form of inquiry. Since they cannot be detached from the changing, finite traditions that give them rational legitimacy, it may be more accurate to speak of moral epistemologies in the plural rather than a singular moral epistemology.

The implications of historicism for bioethics are, if anything, even more profound. Since claims to moral knowledge are always made within specific traditions of thought and practice, the claims made by bioethicists about informed consent, active and passive euthanasia, paternalism and autonomy will inevitably reflect these particular traditions and will preclude appeal to any neutral ground transcending these traditions to bioethics as such. "Bioethics as such," like "rationality as such," is a post-Enlightenment fiction. Each moral tradition—whether Christian, Jewish, Islamic, or secular—will provide resources for bioethical reflection, but the individual bioethicist cannot escape reflecting and theorizing as a member of his or her tradition, as opposed to being a disengaged, impersonal spectator on "universal values." From the vantage point of historicism, bioethical inquiry and debate need to be reconfigured as conflict among and reconciliation between these traditions, which give moral thought and action their lease on life.

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SEE ALSO: *Authority in Religious Traditions; Autonomy; Care; Communitarianism and Bioethics; Conscience; Conscience, Rights of; Consensus, Role and Authority of; Feminism; Medicine, Art of; Natural Law; Principalism; Profession and Professional Ethics; Utilitarianism; Virtue and Character;* and other *Ethics* subentries

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III. NORMATIVE ETHICAL THEORIES

The concept of normative ethics was invented early in the twentieth century to stand in contrast to the concept of metaethics. In ethical theories prior to the twentieth century, it is impossible to discern any sharp distinction between what have come to be called metaethics and normative ethics. In the first half of the twentieth century, however, this distinction began to structure ethics as an intellectual discipline and it continues to be influential at the end of the twentieth century even though crucial theoretical supports for it have disappeared.

Normative ethics was regarded as that branch of ethical inquiry that considered general ethical questions whose answers had some relatively direct bearing on practice. The answers had to be general rather than particular in order to distinguish normative ethics from casuistry; they had to have a bearing on practice in order to distinguish normative ethics from metaethics. Casuistry was understood in its classical sense as the study of particular cases, while metaethics was understood originally as the inquiry into the semantics of ethical language.

G. E. Moore's classic proposal for the structure of ethics distinguished three key questions: (1) What particular things are good? (2) What kinds of things are good? and (3) What is the meaning of "good"? The first question is the central question of casuistry, while the second question falls within normative ethics, and the third, within metaethics (although Moore used neither the term "metaethics" or "normative ethics" in his early work). Normative ethics as a field of inquiry, then, is positioned somewhat precariously between the detail of casuistry and the abstractness of metaethics.

The character of normative ethics was also strongly influenced in the first half of the twentieth century by the almost universal acceptance of the principle of moral neutrality. This principle, accepted by virtually all mainstream Anglo-American moral philosophers from the 1930s to the 1960s, asserted that the results of metaethical investigations were logically independent of normative ethics. When coupled with the original understanding of metaethics as an account of the meaning of key ethical terms, it implied that such semantic investigations were logically irrelevant to inquiries about how to live. Under the influence of this principle, normative ethics was largely abandoned by Anglo-American moral philosophers in favor of a single-minded pursuit of metaethical inquiry. And since the metaethical views most in favor during this period were various forms of noncognitivism (e.g., emotivism and prescriptivism), it was regularly asserted that normative ethics should be relegated to preachers, novelists, and other nonphilosophers. The widely accepted noncognitivist views held that there was no cognitive content to normative ethical judgments since these judgments were primarily expressions of attitudes (as emotivists held) or primarily expressions of prescriptions (as prescriptivists held). But if normative judgments had no cognitive content—if, that is, they were primarily the expression of noncognitive attitudes or imperatives—then it was unclear why moral philosophers should be concerned with examining them. Normative ethics was regarded as largely a matter of exhortation and was removed from the standard repertoire of strictly philosophical concerns.

This sharp distinction between metaethical and normative inquiry, however, together with the relegation of normative ethics to nonphilosophical inquiry, was too unstable to last. Philosophers increasingly recognized that the principle of moral neutrality was not a theoretically neutral presupposition of ethical inquiry but rather drew a considerable amount of its support from the prevailing noncognitivist view. When these noncognitivist views were severely challenged in the late 1950s and 1960s (by, among others, Philippa Foot, Kurt Baier, Stephen Toulmin, and Alan Gewirth), the sharp distinction between metaethics and normative ethics was blunted; this opened the way to a resurgence of interest in normative ethics, expressed by new attempts to reformulate and to defend classical ethical views. Although a complete historical explanation of the remarkably sudden return of philosophers in the 1960s and 1970s to the classical questions of normative theory will no doubt be extremely complex, the decline of noncognitivism and the concomitant rejection of a sharp distinction between normative ethics and metaethics surely contributed to it. Classical Kantian theory was developed in a creative and persuasive manner by John Rawls and his student, Thomas Nagel, along with Alan Donagan, Alan Gewirth, and others. Utilitarianism received new attention from, among others, Richard Hare and his students Derek Parfit and Peter Singer. The classical Aristotelian/Thomist view was reformulated and defended by Elizabeth Anscombe, Peter Geach, Alasdair MacIntyre, and like-minded moral philosophers.

What was revived under the label "normative ethics," however, was not identical to what had previously been neglected by moral philosophers as normative ethics. The watershed in ethical theory in the 1960s changed not only the interests of moral philosophers but also changed their conception of their discipline. The task of metaethics was expanded from the narrow one of clarifying the semantics of ethical terms to a much broader investigation of the whole range of metaphysical, epistemological, and semantic questions associated with ethical inquiry. Metaethics came to be concerned not only with questions about the meaning of ethical terms and judgments, but also with metaphysical questions about the nature of ethical properties and epistemological questions about how claims to ethical knowledge are to be appraised. Normative ethics in turn came to be understood as that pole of ethical theory that stood closest to practice. Whereas previously the distinction that most clearly structured ethical inquiry was the distinction between metaethics and normative ethics, the crucial distinction increasingly came to be that between ethical theory and applied ethics.

Ethical theory was distinguished from applied ethics by being both more general and more abstract, and also by being less driven by a concern that its results would have some immediate consequences for action or policy. Within ethical theory, however, elements coexisted that, according to earlier views, would have been sharply distinguished as metaethical and normative. Ethical theory inquired into the epistemological and metaphysical features of ethics as well as into the most general truths about how we should live. Also, the new conception of ethical theory held that these two kinds of inquiry were continuous; it was not possible to pursue either kind without attending to its implications for the other. Ethical theory had become a seamless web with areas of greater or less practical relevance, roughly corresponding to those areas earlier distinguished as the normative and the metaethical.

One consequence of these complex historical developments is that it has become much more difficult to give a precise characterization of normative ethics than it would have been at an earlier time. Nevertheless, certain common assumptions about the nature of normative ethics, as well as a widely shared taxonomy of the varieties of normative theory, have persisted through these developments in the concept of normative ethics. The common assumptions include the claim that the central task of normative ethics is to define and to defend an adequate theory for guiding conduct. The received taxonomy divides normative theories into three basic types: virtue theories, *deontological* theories, and *consequentialist* theories. The following section will examine these three types of normative theory with the aim of exploring their distinctive features.

Types of Normative Theory

The basis for distinguishing the three types of normative theory lies in three universal features of human actions. This recourse to the features of actions should not be surprising, since the aim of normative theory is to guide action. Every human action involves (1) an agent who performs (2) some action that has (3) particular consequences. These three features may be set out as follows:

P	⟶	+ + + + + + +
Agent	Action	Consequences

If Jones tells a lie to Smith that causes Smith to miss his train, then Jones is the agent, his telling a lie is the action, and Smith's missing the train is one of the consequences of the action. Difficulties arise, of course, in many cases in determining whether someone is an agent in a particular case (e.g., if Jones is insane when he shoots the president, is he really the agent of any action?); or the nature of the particular action performed (e.g., if Jones is cutting down a tree, believing reasonably that he is the only one in the forest, but Smith wanders by and the tree falls on him, causing his death, does a killing take place or merely a death?); or what the consequences of a particular action may be (e.g., if Jones tells Smith "Take the stuff," but Smith understands him to say "Take the snuff," with the consequence that he takes the snuff and due to a hitherto undiscovered allergy becomes ill, is his illness a consequence of Jones's action in saying "Take the stuff"?). These are difficult questions, of course, and they have been much discussed in contemporary action theory in philosophy. In the typical case of human action, however, agent, action, and consequences can be identified, and the typical case provides the basis for the widely shared taxonomy of normative theories.

Ethical or broadly evaluative judgments can also be classified using a taxonomy drawing on these features of human action. Some ethical judgments are primarily evaluations of agents, such as "Jones is a compassionate doctor" or "Smith is a conscientious nurse." In these cases the object evaluated is a particular person, and he or she is evaluated as a possible or actual agent of an action. Some other ethical judgments are primarily about actions in the narrow sense, such as "Jones has a duty to tell the patient the truth about the diagnosis" or "The direct killing of the innocent is always wrong." In these cases, the primary object of ethical evaluation is an action—the thing done or to be done. This action may be characterized either as required ("X must be done") or as permitted ("X would be right to do") or as forbidden ("A would be wrong to do"). More concrete characterizations of actions are also possible, such as "X was a vicious action" or "X was a heroic action." In all of the cases, however, the action is the primary object of evaluation.

A third class of ethical judgments is primarily about states of affairs or objects that are neither agents nor actions, such as "Health is more important than money" or "Human suffering is a terrible thing." Ethical judgments like these do not, directly at least, evaluate either agents or actions. However, the objects evaluated in them, may be, and frequently are, the possible consequences of actions. Thus, this last class of judgments can also be matched to one of the three basic features of human action.

Normative theories may have any of three basic structures, and the differences among these structures are determined by which of the three kinds of practical judgments is taken as basic by a particular theory. *Virtue* theories take judgments of agents or persons as most basic; *deontological* theories take judgments of actions as most basic; and *consequentialist* theories take judgments of the possible consequences of an action as more basic. The sense in which a theory takes a judgment of a certain kind as most basic will become clear in the discussion of each type of theory.

VIRTUE THEORIES. Normative theories that regard judgments of agents or of character as most basic are called virtue theories because of the central role played in them by the notion of a virtue. In the context of these theories, a virtue is understood as a state of a thing "in virtue of which" it performs well or appropriately. In this broad understanding of virtue not only human beings possess virtues but also certain inanimate objects—a virtue of a knife, for example, will be a sharp blade. Indeed, anything that can be said to have a function or role attached to it because of the kind of thing it is may be said to possess virtues, at least potentially.

A virtue theory takes judgments of character or of agents as basic in that it regards the fundamental task of normative theory as depicting an ideal of human character. The ethical task of each person, correspondingly, is to become a person who has certain dispositions to respond in a characteristic way to situations in the world. Differences among persons may be of quite different kinds. Some people are shorter or fatter than others, some more or less intelligent, some better or worse at particular tasks, and some more courageous, just, or honest than others. These differences can be classified in various ways: physical versus mental differences, differences in ability versus differences in performance, and so on. Those features of human beings on which virtue theories concentrate in depicting the ideal human being are states of character. Such theories typically issue in a list of virtues for human beings. These virtues are states of character that human beings must possess if they are to be successful as human beings.

Typically, a virtue theory has three goals:

1. to develop and to defend some conception of the ideal person
2. to develop and to defend some list of virtues necessary for being a person of that type
3. to defend some view of how persons can come to possess the appropriate virtues.

Virtually all ancient moral philosophers developed normative ethical theories of this sort. The ethical theories of Plato and Aristotle, in particular, provide models of this kind of normative ethical theory. As a consequence, the particular disputes that occurred among ancient philosophers centered on questions that one would expect to arise within a virtue perspective. What are human virtues? How are they acquired? Are they essentially states of knowledge? Can one know that a certain trait of character is a virtue without possessing it? Is it possible to have one, or a few, of the virtues without possessing all of them? Are all human virtues of the same type or are there fundamentally different kinds? Are human virtues a matter of nature or of convention? And, most important of all, what is the correct list of moral virtues? Much of the discussion of ethics in ancient Greece centered on a particular short list of virtues—justice, temperance, courage, and wisdom—that came to be called the *cardinal virtues.* After the introduction of Christianity into Europe, these four virtues were joined by faith, hope, and charity—the so-called *Christian virtues*—to form the seven virtues; these, together with the seven deadly vices, dominated medieval thinking about ethics.

One can also see how questions of human character are basic according to virtue theories by seeing how questions about (1) which actions one ought to perform and (2) which consequences one ought to bring about are subordinated to questions of human character. For a virtue theory the question "Which actions ought one to perform?" receives the response "Those actions that would be performed by a perfectly virtuous agent." Similarly, those states of affairs one is required to bring about in the world as a consequence of one's actions are those states of affairs valued by a perfectly virtuous person. Of course, particular actions may also be required by one's particular virtues. For example, someone who possesses the virtue of honesty may be required by the virtue itself to tell the truth in certain cases. Or someone may be required to pursue certain consequences by certain virtues. For example, an agent who has the virtue of benevolence may be required to pursue the happiness or well-being of others. But these requirements are derivative from the virtues, and the fundamental ethical question thus remains a question about the correct set of virtues for human beings.

DEONTOLOGICAL THEORIES. Deontological normative theories take moral judgments of action as basic, and they regard the fundamental ethical task for persons as one of doing the right thing—or, perhaps more commonly, of avoiding doing the wrong thing. While virtue theories guide action by producing a picture of ideal human character and a list of virtues constitutive of that character, deontological theories characteristically guide action with a set of moral principles or moral rules. These rules may refer to particular circumstances and have the following form:

> Actions of type T are never (always) to be performed in circumstance C.

Or, they may be absolute in that they forbid certain actions in all circumstances and have the following form:

> Actions of type T′ are never to be performed.

The essential task of a deontological theory, then, is twofold:

1. to formulate and to defend a particular set of moral rules
2. to develop and to defend some method of determining what to do when the relevant moral rules come into conflict.

One must qualify, however, the claim that deontological theories make rules fundamental in ethics. What is fundamental, in fact, are actions themselves and their moral properties. This emphasis on actions can take either of two forms: A normative theory may guide action by requiring agents to perform certain kinds of action that can be specified by a rule or other general action guide. Alternatively, one might regard normative theories as requiring particular actions that in their "particularity" elude specification by a rule. This difference has led some moral philosophers to distinguish two forms of deontological normative theories: *rule deontological theories,* which guide action in the first manner, and *act deontological theories,* which guide action in the second. Virtually all influential deontological theories, however, have taken a rule form and, for this reason, this discussion will continue to emphasize the centrality of rules.

Just as a virtue theory subordinates judgments of actions and consequences in a characteristic way, a deontological theory subordinates judgments of character and consequence. The state of character ethically most important in a deontological view is *conscientiousness*—that state of character that disposes persons to follow rules punctiliously, whatever the temptations may be to make an exception in a particular case. Conscientiousness does not have value in itself, but it has value derivatively because it is the most important state of character for ensuring that persons follow rules and, hence, that they do what is right. In a similar way, the consequences of actions that deontologists are most concerned with are the consequences of particular rule-followings. Not all of an agent's practical life, however, need be reduced to rule-following. An agent may have certain personal ideals or particular projects that exist apart from moral rules. These personal ideals or personal projects may be pursued, according to the deontologist, but their pursuit is permitted only if it does not violate the moral rules. Moral rules define the limits of practical pursuits and projects. They are the moral framework within which nonmoral matters can go on. And this is the sense in which moral rules with their emphasis on judgments of actions are basic, according to the deontological view.

Just as virtue theory has its historical roots in the moral philosophy of ancient Greece, deontological theories have affinities with legalistic modes of thought characteristic of Judaic and later Roman thought. The Decalogue (Ten Commandments), although it functions in a religious context, provides a model of a set of rules of conduct that are basic in much the same way rules function in a deontological theory. One is required to follow the rules in the Decalogue because they are the commandments of God, and reasons can be given why it is appropriate to do what God tells one to do. When a deontological theory is deployed in a secular context, however, this reason for rule-following is necessarily absent. Nor can deontologists require that rules be followed because doing so is necessary to become persons of a certain sort or because doing so is necessary to bring about certain consequences. If they took the first route, their view would become a *virtue* theory; if they took the second route it would become a *consequentialist* theory. For a view to be genuinely deontological, it must claim that an agent's fundamental ethical task is to perform certain actions and that the value of this task cannot be dependent on the value of either virtues or consequences.

The most profound attempt to defend this view was anticipated in ancient moral philosophy by the Stoics and was developed in its most persuasive form by the modern German philosopher Immanuel Kant. The Stoics claimed that moral rules are expressions in the human realm of laws of nature and that rational creatures are required to follow these rules because, as creatures, they are parts of nature and, as such, obligated to bring their action in line with natural forces. Human beings differ from other objects of nature by possessing both freedom and reason. Since they are free, they may act against nature; since they have reason, however, they can understand natural laws and choose to bring their action in line with such forces. Kant's view agrees with the Stoic view in broad outline, but he develops the notions of freedom and reason far beyond the Stoic view. Kant's ultimate answer to questions about how we discover the correct set of moral rules is that only by following the dictates of reason can we be genuinely free.

CONSEQUENTIALIST THEORIES. Consequentialist normative theories take judgments of the value of the consequences of actions as most basic. According to these theories, one's crucial ethical task is to act so that one will bring about as much as possible of whatever the theory designates as most valuable. If a particular consequentialist theory designates, for example, that pleasure is the only thing valuable in itself, then one should act so as to bring about as much pleasure as possible. The goals of a consequentialist theory itself are threefold:

1. to specify and to defend some thing or list of things that are good in themselves
2. to provide some technique for measuring and comparing quantities of these intrinsically good things
3. to defend some practical policy for those cases where one is unable to determine which of a number of alternative actions will maximize the good thing or things.

Like deontological theories, consequentialist theories can be divided into act and rule varieties. *Act consequentialism* requires agents to perform the particular action that in a particular situation is most likely to maximize good consequences. *Rule consequentialism* requires agents to follow those moral rules the observance of which will maximize good consequences. The difference between these two forms of consequentialism, however, is not as straightforward as it may at first seem. It is particularly difficult to precisely characterize rule consequentialism. Is the agent supposed to follow those rules that, if followed by everyone, would maximize good consequences, or rather those rules that will maximize goodness, regardless of how other agents act? There are a number of similar difficulties in characterizing rule consequentialism, and these difficulties have led some moral philosophers to deny that there is a genuine distinction here at all. They have argued, indeed, that when any form of rule consequentialism is rigorously characterized it will be found to degenerate into a form of act consequentialism.

For consequentialists, the distinction between instrumentally good things and *intrinsically* good things is also of special importance. Instrumentally good things are good only insofar as they play some role in bringing about intrinsically good things. If, in a particular case, something that is ordinarily instrumentally good does not stand in the appropriate relation to an intrinsically good object, then its goodness evaporates. Its goodness is merely dependent. Intrinsically good things, on the contrary, are good not because of any relation in which they may stand to other things. Their goodness is independent because it is constituted by the kind of thing the good thing is. Thus, a particular consequentialist theory may hold that only pleasure is intrinsically good, but that other things, including types of action and states of character, are instrumentally good. The virtue of honesty, for example, might be regarded as instrumentally good by such a theory since honesty is likely to contribute to maximizing human happiness. Even if honesty is typically instrumentally good, however, situations may arise in which one could maximize pleasure by acting deviously rather than honestly. In such cases, a consequentialist theory (complications about rule versions of the theory aside) would hold that one should perform the devious action. According to this view, there is nothing about honesty in itself that is good.

Consequentialist theories find their fullest expression in modern thought, especially in the thought of the British utilitarians Jeremy Bentham, John Stuart Mill, and Henry Sidgwick. Drawing on earlier work in the British empiricist tradition, the classic utilitarians claimed that the only intrinsically good thing is human happiness, which they understood as constituted by pleasure and the absence of pain. The utilitarian maxim, "Act always in such a way as to promote the greatest happiness to the greatest number," has been the paradigmatic consequentialist moral principle and has inspired many more recent consequentialists.

There was much disagreement among classical utilitarians, however, about the details of their view. Can pleasures be distinguished qualitatively as well as quantitatively? What role should rules and virtues play within the practical thought of a utilitarian? How can the flavor of the absolute prohibitions associated with justice and the inviolability of the person be preserved within a utilitarian framework? These questions, along with other similar ones, were answered differently by different utilitarians. They were at one, however, in aspiring to formulate and defend a particular version of consequentialism.

The distinction above between the instrumentally and intrinsically good makes it possible to specify more clearly what a consequentialist theory is and to overcome certain difficulties of definition that may creep in. If a consequentialist theory is characterized as one that specifies some object, state of affairs, or property that should be maximized, one might ask whether the object or state of affairs referred to in this definition might be either a state of character or the performance of certain actions. If so, then the distinctions between a consequentialist theory, on the one hand, and a deontological theory or a virtue theory, on the other, seems to be in jeopardy. If the intrinsically valuable things specified by a consequentialist theory can include actions or states of character, then virtue theories and deontological theories would seem to be mere species of consequentialism, distinguished from other forms of consequentialism by the type of thing they specify as intrinsically valuable. Virtue theories would be consequentialist theories that specify states of character as intrinsically valuable; deontological theories would be consequentialist theories that specify the performance of certain actions as valuable. If deontological and virtue theories are merely varieties of consequentialism, however, there are not three basic structures but rather one basic structure with a number of varieties.

One might deal with this difficulty by defining a consequentialist theory as one that specifies what is intrinsically good but includes neither states of affairs nor actions, but this seems arbitrary. In addition, although this solution no longer allows that deontological theories and virtue theories are varieties of consequentialism, it does not make it possible to understand how these three types of theory exhibit different structures. One can see that there are different structures here, however, by looking more closely at the differences among these theories. Suppose that a particular consequentialist theory specifies certain virtues as the only intrinsically valuable things. Suppose, more specifically, that a particular consequentialist theory, C, specifies that the virtue of justice is the only intrinsically valuable thing. One can also suppose that a virtue theory, V, specifies the good for human beings such that it is constituted solely by the virtue of justice. Are these two theories practically equivalent? If virtue theories are a mere variety of consequentialism, they should be. If they are not, then virtue theories are not a mere variety of consequentialist theory.

One can see that these two theories are not practically equivalent by considering the practical requirements each imposes on an agent. C requires that an agent act in such a way that he or she will maximize the number of just persons. Since consequentialist theories require that agents maximize whatever is intrinsically valuable, and since the only intrinsically valuable thing according to C is the virtue of justice, agents are required by this theory to maximize justice. V, however, need not have this consequence. What V requires of an agent is that he or she develop those virtues that are constitutive of being a good human being. V requires, then, merely that an agent develop justice. There is nothing in V itself that requires an agent to try to bring about justness in others. A virtue theory more complicated than V may include a virtue—perhaps benevolence—that requires agents to promote the well-being of others as well as themselves.

But this requirement to maximize the number of people who possess virtues is not a requirement derived from the nature of a virtue theory itself. It can be derived only from some particular virtue that may—or may not—be a component of a particular virtue theory.

One can arrive at this same point by considering an agent who finds herself in a situation where she can maximize the number of just persons only by becoming herself unjust. In order to make others just, she must become unjust. One example of such a case might be a politician who believes that the best way to make the citizens of her country just is to acquire political power and to exercise it in ways that only she can succeed in doing. Also, suppose she knows that only by renouncing justice herself, by being prepared to act unjustly, can she acquire political power. Thus it is only by becoming unjust that she can most efficiently make others just.

What do C and V have to say to this agent? It is clear that C would approve the renunciation of justice on her part if that would maximize the number of persons who possess justice. The loss of this particular agent's own justice to the sum of justice in the world is more than offset by the gain in the number of persons who are just. The sacrifice is worth it. But what would V require? It is equally clear that V does not require the agent to sacrifice her own justice. Virtue theories hold that an agent's own character plays a special role in his or her practical thinking that it does not play in a consequentialist theory. A virtue theory gives agents reasons to act because it is supposed that each person wants to be a flourishing and fulfilled human being. An agent's own life and character then will have a certain primacy according to a virtue theory. Virtues are not just intrinsically valuable things that should be inculcated in as many agents as possible. They are states of character that each agent must acquire in order to succeed as a human being. Thus, V will not necessarily require that this agent become unjust even if this would maximize the amount of justice in the world.

Similar conclusions follow with regard to a comparison between consequentialist theories and deontological theories. Consider a particular consequentialist teleological theory, C', that specifies that the only intrinsically valuable things are acts of truth-telling, and a particular deontological theory, D, that specifies that the only moral rule is one that enjoins truth-telling in all cases. Are these two theories practically equivalent? Again it is useful to consider a case in which maximizing a particular good requires the renunciation of it by an agent. Suppose that an agent finds himself in a situation in which he can most efficiently produce the maximum ratio of truth-tellings to lyings by himself telling a lie. Perhaps he has discovered that, by telling others that whenever they tell a lie their life is shortened by three weeks, he can most efficiently promote truth-telling. But he also knows that this is a lie. What should he do?

It seems clear that C' would require him to act in whatever way will maximize the number of truth-tellings, and, if this requires him to lie, so be it. Although his lie may be intrinsically bad, its badness will be more than outweighed by the intrinsically good states of affairs it brings about. The person who accepts D, however, believes that there is a moral rule enjoining everyone always to tell the truth. This rule gives him a reason to act, because he is committed to doing the right thing. He is not committed primarily to bringing about as many right or dutiful actions as possible; rather, he is committed to doing the right thing. Just as a virtue theory holds that an agent stands in a more intimate relation to his own character than he does to the characters of other persons, a deontological theory holds that an agent stands in a more intimate relation to his own actions than he does to the actions of others. The action of an agent who follows a moral rule will have a different moral significance for a deontologist than the action of an agent who brings it about that someone else follows a moral rule. For a deontologist, it is not as important that there be rule-followings as that he or she follow moral rules. D need not then require, or even permit, that the agent tell a lie if this is necessary to maximize truth-telling, and hence C' and D, like C and V, are not practically equivalent. If they are not practically equivalent, however, then deontological normative theories, like virtue theories, are not mere varieties of consequentialism.

Deeper Differences among Normative Theories

This comparison of virtue, deontological, and consequentialist normative theories suggests that the differences among them are deeper than might at first appear. Indeed it suggests that while they certainly differ with regard to which of the three kinds of practical judgments they take as most basic, there are other, and more fundamental, differences among them. To accept one of these normative theories is to accept a particular attitude toward the relation of an agent to his or her character and actions. If one adopts a virtue theory, one's own character comes to have an especially important place in one's practical thinking. It is of the first importance that one become a person of a certain sort. This view need not imply, as it may seem to, that one is committed to an egoistic or selfish life. One may be guided by a virtue theory to pursue a life dominated by generosity and concern for others. One may, indeed, strive to become completely selfless in the sense of always putting the needs of others ahead of one's own needs. But even if this is one's goal, it is also true that one's own character forms the primary focus of one's practical life. The apparent combination here of concern for self and concern for others may appear paradoxical, but it is surely not incoherent. Some of the greatest moral heroes—for example, Gandhi, Jesus, and Albert Schweitzer—seem to have combined these two concerns in their lives.

In a similar way, if one adopts a deontological theory, one's own actions come to play an especially important role in one's practical thinking. It makes a difference to one that one's actions are wrong. It is more important practically to an agent that he or she has told a lie than that a lie has been told. In cases where one's telling a single lie will prevent three others from telling lies, one will not decide what to do by simple arithmetic. Of course, a deontologist will not expect that others will have the same concern for her lie as she will have for it. She may recognize that for someone else, his telling a lie will have a different practical significance for him than *her* telling a lie will have for him. And just as she may not be prepared to tell one lie to prevent him from telling two, she will not expect him to tell one lie to prevent her from telling two. Indeed, she will recognize that from his point of view, his telling one lie is worse in an important sense than her telling two, just as from her point of view her telling one lie is worse than his telling two.

The special significance given to one's actions by a deontological theory need not imply that a deontologist is egoistic or, in the ordinary sense of the term, self-centered. In this way the deontologist is in a situation similar to that of the virtue theorist. The particular moral rules that one is required to follow may give the needs and interests of others parity with one's own, or, more likely, they may require one to put others ahead of oneself. What they cannot require is that one take up a particular attitude toward the rules themselves. The rules cannot, as it were, define their own condition of application—nor can they specify how they relate to one's faculty of practical decision making at the deepest level.

To a consequentialist, giving this special significance to one's character or one's actions may seem confused and possibly morally corrupt. Of course, consequentialists may be concerned with questions of character, but character cannot be their central normative focus. According to consequentialism, what is of primary ethical importance is that the amount of the intrinsically valuable be maximized. Determining the most effective means for maximization involves straightforward questions of efficiency. These questions may be neither simple nor easily answered, but structurally they are straightforward: Which of the possible courses of action will most likely maximize the amount of goodness in the world? In canvassing the possible means to this end, the consequentialist requires an agent to throw his own character and actions into the same category with other possible means. The kind of character one should develop depends upon the kind of character that will contribute most to the relevant goal. The actions one should perform depend similarly on consequentialist goals. For a consequentialist, one must put a certain distance between oneself—considered as the agent who must make practical choices—and one's own character and actions. One's character and actions have the same role in one's practical thinking as would any other possible means—one's wealth, for example, or influence—that are in a more usual sense external. More important, one's own character and actions have no more special role in practical thinking than do the character and actions of others. All are regarded as possible means to maximize intrinsically good things, and one's own actions and character may have special significance only insofar as they may be more easily—because more directly—manipulated by oneself.

One might think, however, that one feature of the agent's character cannot be treated as a mere means, even by a consequentialist. For any consequentialist theory, it will surely be important that persons have those states of character that dispose them to pursue or to favor intrinsically good things. It might be argued that this state of character cannot be treated by the theory as a mere means. But this argument underestimates the resources within consequentialism for distancing an agent from his or her character. Suppose an agent holds a consequentialist normative theory, C", according to which the only intrinsically good things are states of human pleasure. Suppose also that this agent has a character such that he is disposed always to act in ways he believes will maximize human pleasure. This argument suggests that this agent will not be prepared to sacrifice for the goal of maximal pleasure his own disposition to pursue this goal. But why should this be the case? One might think that a case could never arise in which an agent could contribute most to maximizing pleasure by changing his character to that of someone unconcerned with maximizing pleasure. But this view is surely wrong. Suppose the agent discovers an empirical law according to which human pleasure is maximized only if agents are disposed not to pursue human pleasure but to pursue knowledge. But if this is true—and it is surely possibly true—the agent should act to change as many persons' characters as possible from pleasure-seeking to knowledge-seeking characters. Nor is there any reason why, on consequentialist grounds, this agent should make an exception in his or her own case. So even those features of human character that lead an agent to pursue the maximization of intrinsically good things are not given a special place by consequentialists. Every feature of the character of an agent may be regarded as a possible means to the maximization of the relevant goal.

This feature of consequentialist theories was first emphasized by Henry Sidgwick, the greatest of modern utilitarians. Sidgwick was convinced that if the utilitarian goal of human happiness was to be maximized, then it was necessary that most persons not be utilitarians. Indeed, he thought that what was probably required was that most persons hold deontological views and have their character shaped in accordance with such views. He proposed then, for utilitarian reasons, that utilitarianism be propagated as an esoteric view, and that only a few of the most able and intelligent members of society have their characters shaped in accord with it. These bearers of the esoteric view, in turn, would mold the characters of those less able and enlightened in accord with a deontological perspective. Had Sidgwick's enlightened few become convinced that maximal human happiness required that they, too, acquire "deontological characters," simple consistency would have required them to change their own characters appropriately. In this way, consequentialism might require that agents strive to bring about a world in which no one, not even oneself, has the kind of character that would dispose one to strive at the most basic practical level for consequentialist goods.

Justifying Normative Theories

The question of how, if at all, one can rationally choose among these three normative theories is a question taken up under the topic of moral epistemology. It is important to note here, however, that these normative theories emerge in Western thought as components in comprehensive philosophical theories developed by Plato, Aristotle, Aquinas, Kant, Mill, and other major philosophers. They are embedded in rich and complex worldviews in ways that make it difficult to discuss them in isolation from their theoretical and historical settings.

The tendency within contemporary ethical theory is to discuss the merits of these views in purely ethical terms and to ignore to a large extent their larger theoretical settings. Thus, consequentialism is frequently attacked because it is alleged to countenance the judicial punishment of the innocent if that is required for achieving some good end. In arguments like this one, the alleged ethical implications of a normative theory are appealed to in order to evaluate the theory. Similarly, deontologists may be criticized for holding that certain actions are morally forbidden even if performing them in a particular case might prevent an enormous tragedy. It is now a matter of record that these arguments have been unsuccessful in producing agreement within normative ethics. Nevertheless, the same slightly tired arguments continue to be made.

The lesson from the history of these views would seem to be, however, that if any of them is to be adequately defended, or successfully criticized, its theoretical setting must be taken into account. Each of these theories has complex relations with particular philosophical accounts of rationality, explanation, nature, intention, the law, the passions, and other topics of central philosophical interest. A more adequate account of them, if possible here, would have to take these theoretical entanglements into account. Certainly any serious attempt to choose rationally among them would have to locate them in this larger theoretical setting.

Normative Ethics and Practice

The raison d'être for normative ethics, as we have seen, is to guide action, and the theories explored above have been developed with such guidance in mind. There is general disagreement, however, about exactly how these normative theories are to relate to the resolution of particular normative problems. It is not easy to demonstrate how the debate between consequentialists and deontologists is related to more concrete disagreements about physician-assisted suicide or recombinant DNA research. Part of the difficulty arises from the fact that each of the three normative theories embodies a particular conception of how it relates to concrete normative problems. There is no theory-independent criterion of how normative theories are to guide action, since each theory embodies a view about its own application. In this way normative theories double back on themselves with regard to their action-guiding function.

An illustration of this doubling-back phenomenon is found in current debates about the relation of virtue theories to practice. Virtue theories are frequently criticized because they do not yield concrete action guides in the way that consequentialist and deontological theories appear to do. The moral advice to "Be just" lacks the action-guiding bite of either a moral rule that requires an agent to perform certain actions or a consequentialist conception that specifies some good to be maximized. But this objection fails to take account of the distinctive way in which virtue theories purport to guide action. A central claim of virtue theories is that the action-guiding function of a normative theory is not to resolve concrete puzzles about action. Edmond Pincoffs, a leading contemporary virtue theorist, coined the useful term "quandary ethics" precisely to designate what virtue theories are against: a conception of normative ethics as guiding action by giving a particular solution to quandaries about action. If one supposes that the only way in which a normative theory can guide action is by resolving particular moral quandaries, then one is unlikely to take virtue theories seriously.

Virtue theories offer, however, an alternative account of the action-guiding function of normative theories. They claim that an adequate normative theory will prescribe something like a training program to make agents ethically "fit." This program may not specify exactly how one is to act in particular cases, because these decisions are best left to the prudential decisions of a "morally fit" agent in the concrete decison-making situation. Thus, virtue theories double back on themselves and specify how they are to relate to practice. Both deontological and consequentialist theories also contain such self-referential accounts of their own application.

An important implication of this doubling-back phenomenon is that one cannot assess the adequacy of normative theories by invoking a well-defined criterion for "successful" action-guiding without begging the question. To have such a well-defined criterion is already to have taken a position on some of the fundamental questions in normative ethics.

This difficulty is actually even more serious than this first point suggests. It is not just that each of the three normative theories embodies a well-defined criterion of how normative theory should relate to practice. Also, there are a number of different models of how general ethical thinking should relate to concrete practice. Some of these models have loose affinities with some of the normative theories, but there is not a fixed or necessary connection between them. Indeed, the conflicts among the normative theories cut across, in complex ways, the conflicts among these models for relating normative theory to practice. A representative collection of these models would include: (1) deductivism, (2) dialectical models, (3) principlism, (4) casuistical models, and (5) situation ethics. These models have been for the most part badly defined in the current literature, and the differences among them and their relations to traditional normative theories tend to be matters of dispute.

DEDUCTIVISM. The deductivist model regards the action-guiding function of ethical theory to be the development of highly abstract and general first principles that, together with some factual description of a particular morally problematic situation, will entail concrete action guides. According to this model, moral principles developed and defended within normative ethical theory will play the role of premises in deductive arguments for ethical judgments about particular cases. This model of application is particularly attractive to some deontologists and consequentialists. It is related to more general accounts of justification in contemporary epistemology that suggest that all justification must come from some set of foundational claims in the area in question. It also makes large demands on the justificatory resources of a normative theory, since all of the justification for the principles must come from the theory itself. There is no "bottom up" justification from particular moral beliefs to general principles, as will be found in some of the other models.

DIALECTICAL MODELS. Partly because of worries about the foundationalist character of deductivism, some moral theorists understand the relation between normative theory and practice in a dialectical way. Instead of supposing that justification is exclusively "top down," they suppose that there is dialectical interplay between the principles in a normative theory and particular moral judgments. Normative principles may be modified if they fail to fit our deeply held particular moral beliefs, just as our particular beliefs may be modified in order to fit principles. Whether agents modify principles or particular judgments will depend upon their degree of commitment to each and to the other beliefs they might hold. Just as the deductivist model has affinities with foundationalist theories in epistemology, the dialectical model is inspired by coherentist epistemological theories, which suggest that justification in general is to be understood as a function of how large sets of propositions "hang together" or cohere. The most influential form of the dialectical model is John Rawls's "method of reflective equilibrium," which he uses to support his deontological normative theory.

PRINCIPLISM. Some philosophers have wanted to downplay the importance of normative theory for resolving concrete ethical problems. They emphasize, for example, that consequentialist and deontological normative theories in most cases mandate the same actions, and that it is only in exceptional cases that differences seem to emerge. And they add that the exceptional cases are likely to be so difficult to resolve that both consequentialists and deontologists disagree among themselves about what normative theory requires. They conclude that general ethical reflection should focus on what they call "middle-level" principles, that is, not the most general principles in any normative theory but those that are likely to be acceptable to adherents of different normative theories. They hope that agreement may be easier to achieve in practical matters if the premises for practical arguments are not sought at the deepest level of normative theory. This model has been especially influential in bioethics and has been developed and defended by Tom Beauchamp and James Childress (1989). The middle-level principles they propose are labeled autonomy, beneficence, nonmaleficence, and justice. Their claim is that these principles, when suitably refined, are likely to be acceptable to both rule consequentialists and deontologists.

CASUISTICAL MODEL. Some philosophers have understood genuinely practical and action-guiding thinking in a way that makes it even more remote from the disputes among the classical normative theories. They propose that the appropriate model for practical reflection is found in the case-based approach popular in late medieval and early modern moral thought. According to this approach, ethical reflection should focus on certain paradigm cases of morally good action or morally bad action. Arguments from these paradigm cases to more problematic cases may be made by exploring similarities and differences between the two. This approach rejects attempts to formulate the goodness or badness of paradigm cases in abstract and general principles, and emphasizes analogical as opposed to deductive reasoning. Albert Jonsen and Stephen Toulmin (1988) have been the leading advocates of this model in recent normative ethics.

SITUATION ETHICS. Some might suggest that situation ethics is not so much a model for practical thinking as a rejection of any model. It claims that one should approach the resolution of particular moral problems by eschewing all general action guides in favor of concentrated attention to the details of the particular situation. In some of its versions it may look a bit like the casuistical model; but in its most radical formulations it would mandate that even paradigm cases should play no central role in particular reflection because they could deflect the agent's attention from the particular features of the case under consideration. Among contemporary thinkers, Joseph Fletcher has been the most prominent advocate of this view, although his early commitment to situation ethics developed later into a more general commitment to consequentialism. In his formulation of situation ethics, he suggests that reflection on particular cases should be guided by the general principle, "Do the loving thing!" However, he is insistent that this principle does not play the role of a premise in any deductive practical argument.

These five models represent different ways of thinking about how ethical reflection might be brought to bear on particular moral problems. They range from deductivism, in which successful ethical reflection requires premises drawn from an adequate normative theory, to situation ethics, which eschews any dependence on normative theory. The other three theories occupy the middle ground between these two extremes. In contemporary ethics there is no consensus on which of these models is most adequate. Each has its defenders and its critics, and there is a lively discussion in the contemporary literature about their respective merits.

When this disagreement about the correct approach to concrete ethical reflection is added to the disagreement among classical normative theories, it is easy to see why contemporary applied ethics involves conflicts of such depth and complexity. One is confronted not only with competing normative theories, but also with competing conceptions of how such theories would relate to concrete ethical problems. These two different levels of disagreement indeed tend to reinforce one another, since particular disagreements at each level tend to be tied to particular disagreements at the other.

Normative Theories and Bioethics

The revival of normative ethics in the 1960s was associated with a general renewed interest, across Western culture, in applied ethics and especially in bioethics. Rational reflection on the difficult ethical issues associated with the expanded technological resources of the biological sciences demanded a theoretical structure of some richness, and the classical normative theories provided that structure.

The conflicts between deontological and consequentialist theories have been particularly salient in discussions within bioethics. Indeed, some general discussions of bioethics and many popular textbooks treat these two options as if they are the only possible theoretical perspectives. Part of the explanation for this is surely that so many of the ethical problems in medical practice, as well as in the biological sciences more generally, involve questions about whether actions that are generally regarded as morally problematic can be justified in cases where they appear to promise great benefits. Examples of this kind of conflict are plentiful in contemporary bioethics: Can information obtained by a physician in a doctor-patient encounter be revealed to a third party without the patient's consent, if doing so will prevent some great harm? Can physicians lie to their patients in cases where doing so will increase the effectiveness of therapy and decrease the chances of severe depression? Can physicians override the religious objections of patients to certain therapies when it is clear that these therapies will provide important benefits to the patients?

Moral difficulties like these have been at the center of contemporary discussions in bioethics from its inception. They lend themselves to an analysis that regards them as embodying a general conflict between the thought that some actions (e.g., revealing confidential information, lying, or paternalistic interference) are simply not to be done and the thought that one should be prepared to do whatever is necessary so that things go as well as they can. This conflict in turn seems very close to the fundamental issues at stake between the deontologist and the consequentialist.

Until recent years, virtue theories have been conspicuously absent from most discussions of bioethics. The renewed interest in these approaches is associated with their revival within moral philosophy generally. But there are also features of contemporary bioethics that explain the attention they receive. First, a kind of impasse has developed between consequentialist and deontological approaches to some bioethical problems, and bioethicists have turned to virtue theories with the hope that they can avoid this impasse. Second, there is a new interest in questions about the character of the various agents (e.g., physicians, nurses, researchers, and technicians) who work in settings where bioethical issues arise. This interest in character is partially a reflection of impatience with "quandary ethics." It also, however, grows out of the search for new models of moral education. Molding and shaping character has seemed to many a more attractive goal for moral education than the goal of inculcating rules. Shaping character indeed seems especially important in bioethics, where change is endemic and rules become outdated quickly.

Finally, virtue theories seem to be attracting more attention within bioethics because of the strong analogies between the notion of health and overall biological fitness, on the one hand, and, on the other, the more general notion of human flourishing that lies at the heart of virtue theories. For those who think that bioethical issues are best approached by getting clear on the goals of the biomedical sciences, this analogy is likely to lead them to take virtue theories seriously.

In spite of the recent revival of virtue ethics both within bioethics and within moral philosophy more generally, however, the dominant argumentative strategies in bioethics continue to be drawn from the deontological and consequentialist traditions. Nevertheless, each of the three traditions is now represented in the contemporary bioethical discussion by competent and enthusiastic advocates, and it seems certain that the central problems within bioethics will continue to be discussed in terms contributed by these normative traditions.

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SEE ALSO: *Care; Casuistry; Communitarianism and Bioethics; Contractarianism and Bioethics; Double Effect, Principle or Doctrine of; Emotions; Obligation and Supererogation; Human Rights; Natural Law; Principalism; Utilitarianism; Virtue and Character;* and other *Ethics* subentries

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IV. SOCIAL AND POLITICAL THEORIES

Every social and political theory is entangled with ethics. The great political philosopher Jean-Jacques Rousseau proclaimed that the person who would separate politics from ethics will fail to understand both. Despite the efforts of practitioners of “value-free social science,” the concepts and categories with which political theorists work—order, freedom, authority, legitimacy, justice—are part and parcel of competing ethical frameworks. It is very difficult to talk about justice without talking about fairness. What is fair is an ethical question that cannot be adjudicated without some reference to what is good for human beings or what kind of good human beings may strive to attain. Terms that circulate within ordinary discourse, such as “fairness” and “freedom,” are also central themes within social and political thinking. The implication for bioethics is straightforward. No matter how strenuously the bioethicist may hope to isolate his or her perspective from metaphysical, ontological, epistemological, and civic imperatives, social and political theory frames and penetrates all bioethical considerations.

The human sciences cannot be value-free. In Charles Taylor’s words, “they are moral sciences in a more radical sense than the eighteenth century understood” (p. 51). There are, according to Taylor, inescapable epistemological arguments for what might be called an interpretive approach to the human sciences, for human beings are self-defining animals. These self-definitions, in turn, take place within a context that shapes our understanding of self and other as well as our appreciation of human possibilities and the need for constraint. We are caught in conceptual webs. It is the task of social and political theory to make more explicit the nature of the frameworks within which we think and act, and hence, the context within which bioethical imperatives make themselves felt, whether as advances in human freedom, triumphs of human control, or dangerous new forms of oppression. Based on an interpretive approach to political theory, this entry will demonstrate why political theory must be normative and will go on to rehearse contemporary debates in social and political theory using the public/private distinction and the women’s movement as illustrative examples.

Why Social and Political Theory Must be Normative

Terms of ordinary discourse serve as a conceptual prism through which we view different human relationships, activities, and forms of life. Most of the time we take such terms for granted. We are all shaped by ways of life that are built upon basic notions and rules. Political theorists concern themselves with the ways in which a society’s constitutive understandings either nourish or deplete human capacities for purposive activity. It is, therefore, one task of the political theorist to examine critically the resources of ordinary language, revealing latent meanings, nuances, and shades of interpretation others may have missed or ignored. When we examine our basic assumptions, we enhance our ability to sift out the most important issues (Elshtain, 1981).

Society’s understanding of the terms “public” and “private,” for example, are always defined and understood in relationship to each other. One version of private means “not open to the public,” and public, by contrast, is “of or pertaining to the whole, done or made in behalf of the community as a whole.” In part these contrasts derive from the Latin origin of “public,” *pubes,* the age of maturity when signs of puberty begin to appear: Then and only then does the child enter, or become qualified for, public activity. Similarly, *publicus* is that which belongs to, or pertains to, “the public,” the people. But there is another meaning: public as open to scrutiny; private as that not subjected to the persistent gaze of publicity. The protection of privacy is necessary, or so defenders of constitutional democracy have long insisted, in order to prevent government from becoming all-intrusive, as well as to preserve the possibility of different sorts of relationships—both mother and citizen, friend and official.

Our involvement in one of a number of competing ethical or normative perspectives is inescapable. It is influenced by what we take to be the appropriate relationship between public and private life, for this also defines our understanding of what politics should or should not attempt to define, regulate, or even control. There is widespread disagreement over the respective meaning of public and private within societies. Brian Fay sees the public and the private as part of a cluster of "basic notions" that serve to structure and give coherence to all known ways of life. The boundaries between the public and the private help to create a moral environment for individuals, singly and in groups; to dictate norms of appropriate or worthy action; and to establish barriers to action, particularly in areas such as the taking of human life, regulation of sexual relations, promulgation of familial duties and obligations, and the arena of political responsibility. Public and private are embedded within a dense web of meanings and intimations and are linked to other basic notions: nature and culture, male and female, and each society's "understanding of the meaning and role of work; its views of nature; … its concepts of agency; its ideas about authority, the community, the family; its notion of sex; its beliefs about God and death and so on" (p. 78). The content, meaning, and range of public and private vary within each society and turn on whether the virtues of political life or the values of private life are rich and vital or have been drained, singly or together, of their normative significance.

The social and political theorist recognizes that no idea or concept is an island unto itself. Basic notions comprise a society's intersubjectively shared realm. "Intersubjectivity" is a rather elusive term referring to shared ideas, symbols, and concepts that reverberate within a society and help to constitute a way of life. The philosopher Ludwig Wittgenstein claims that when we first "begin to believe anything, what we believe is not a single proposition, it is a whole system of propositions. (Light dawns gradually over the whole.)" (p. 21e). Similarly, when we use a concept, particularly one of the bedrock notions integral to a way of life, we do not do so as a discrete piece of "linguistic behavior" but with reference to other concepts, contrasts, and terms of comparison.

As with the concepts of public and private, there are no neatly defined and universally accepted limits on the boundaries of politics. Politics, too, is essentially contested. An essentially contested concept is internally complex or makes reference to several dimensions, which are, in turn, linked to other concepts. Such a concept is also open-textured, in that the rules of its application are relatively flexible, and it is appraisive or normative. For example, one political theorist might claim that a given social situation is unjust. Another might argue that to label the situation unjust only inflames matters, because he or she believes that certain underlying cherished social institutions and relations should not be tampered with or eliminated in the interest of attaining a political or ideological goal. In another example, the feminist political theorist who believes that being born female in and of itself constitutes an injustice on the "biological" level may want to eliminate all sex differences and a public/private distinction as well, for she will see in distinctions themselves a ploy to oppress women (Firestone). Other feminist thinkers may find this view reprehensible, as it deepens rather than challenges societal devaluation of female bodies and a woman's central role in reproduction. This latter group sees injustice in inequalities that are socially and politically, not biologically, constituted. The point is not to eliminate a public/private distinction but to push for parity in male and female participation in both realms.

Boundary shifts in our understanding of "the political" and hence, of what is public and what is private, have taken place throughout the history of Western life and thought. Minimally, a political perspective requires that some activity called politics be differentiated from other activities. If all conceptual boundaries are blurred and all distinctions between public and private are eliminated, no politics can, by definition, exist (Elshtain, 1981). The relatively open-textured quality of politics means that innovative and revolutionary thinkers are often those who declare politics to exist where politics was not thought to exist before. Should their reclassifications remain over time, the meaning of politics—indeed of human life itself—may be transformed. Altered social conditions may also provoke a reassessment of old, and a recognition of new, "political" realities. Sheldon Wolin observes, "The concepts and categories of a political philosophy may be likened to a net that is cast out to capture political phenomena, which are then drawn in and sorted in a way that seems meaningful and relevant to the particular thinker" (p. 21). Thus each social and political theorist must be clear about what rules he or she is employing to sort the catch and to what ends and purposes.

Bioethical Issues in the Concepts of Public and Private

In the history of Western political thought, public and private imperatives, concepts, and symbols have been ordered in a number of ways, including the demand that the private world be integrated fully within the public arena; the insistence that the public realm be "privatized," with politics controlled by the standards, ideals, and purposes emerging from a particular vision of the private sphere; or, finally, a continued differentiation or bifurcation between the two spheres. Bioethics is deeply implicated in each of these broad, general theoretical tendencies that often touch on the private and the public, as in a case, for example, where a couple decides to conceive a child through artificial insemination by donor (AID). What happens to a society's view of the family and intergenerational ties if more couples resort to artificial insemination? What is the effect on the psychosocial development of donor children? What are the responsibilities, if any, of the donor father beyond the point of sperm donation for a fee? Do contractual agreements suffice to "cover" not just the legal but also the ethical implications of such agreements? Does society have a legitimate interest in such "private" choices, given the potential social consequences of private arrangements? Should such procedures be covered by health insurance, whether public or private?

Questions such as these pitch us into the world of social and political theory and the ways particular ideals are deeded to us. Thus, the social-contract liberal endorses a different cluster of human goods than the virtue theorist or the communitarian. Political and social theory yield ethical debates about these competing ideals of human existence. Moral rules—and whether they are to be endorsed or overridden—are inescapable in debating human existence and the human imperative to create meaning. "Public" and "private" and the relations of politics to each exist as loci of human activity, moral reflections, social and historic relations, the creation of meaning, and the construction of identity.

The ways in which our understanding of public, private, and politics plays itself out at present is dauntingly complex. Contemporary society is marked by moral conflicts. These conflicts have deep historical roots and are reflected in our institutions, practices, laws, norms, and values. For example, the continuing abortion debate in the United States taps strongly held, powerfully experienced moral and political imperatives. These imperatives are linked to concerns and images evoking what sort of people we are and what we aspire to be. The abortion debate will not "go away" because it is a debate about matters of life and death, freedom and obligation, and rights and duties.

Perhaps the intractability of many of the debates surrounding bioethics can best be understood as flowing from a central recognition that language itself has become a preoccupation for theorists and ethicists because of our growing concern for establishing norms, limits, and meanings in the absence of a shared ethical consensus. A persistent theme of contemporary social and political theory is that language helps to constitute social reality and frames available forms of action. We are all participants in a language community and hence share in a project of theoretical and moral self-understanding, definition, and redefinition. Our values, embedded in language, are not icing on the cake of social reasoning but are instead part of a densely articulated web of social, historical, and cultural meanings, traditions, rules, beliefs, norms, actions, and visions. A way of life, constituted in and through language, is a complex whole. One cannot separate attitudes toward surrogacy contracts, in vitro fertilization (IVF), use of fetal tissue for medical experimentation, sex selection as a basis for abortion, or genetic engineering to eliminate forms of genetically inherited "imperfection," from other features of a culture. These bioethical dilemmas do not take place in isolation but emerge from within a culture and thus engage in the wider contests over meaning that culture generates.

Contemporary Debates in Social and Political Theory

Current debate in social and political theory has focused on the question of whether to buttress or to challenge the liberal consensus that came to prevail in modern Western industrial societies. These broad, competing schools of thought are known as liberalism, civic republicanism, and communitarianism. A social movement informed by one or more of these traditions will exhibit conflicting tendencies and posit incompatible claims.

Liberalism comes in many different forms. Some liberal thinkers stress the individual and his or her rights, often downplaying notions of duty or obligation to a wider social whole. They assume, optimistically, that each individual's pursuit of self-interest will result in "good" for the society as a whole. Those whose analyses begin with the free-standing individual as the point of reference and the "good" of that individual as their normative ideal are often called individualists. In the nineteenth century, this standard of individualism was most cogently articulated by John Stuart Mill in his classic work, *On Liberty* (1859).

By contrast, communitarians begin not with the autonomous individual but with a social context out of which individuals emerge. They argue that the pursuit of individual self-interest is more likely to yield a fragmented society than a "good" and fair one. Communitarians insist that rights, while vital, are not the individual's alone. Instead, individual rights necessarily flow from rights recognized by others within a community of a particular sort in which responsibilities are also cherished, nourished, and required of individuals (Bellah et al.).

FEMINISM. The contemporary women's movement and the way in which it reflects, deepens, and extends features of these traditions illustrate the range of social and political debate. There is no single ethics or moral theory of feminism. Liberalism, with its vibrant individualist strand, has been attractive to feminist thinkers. The language of rights is a potent weapon against traditional obligations, particularly those of family duty or any social status declared "natural" on the basis of ascriptive characteristics. To be free and equal to men became a central aim of feminist reform. The political strategy that followed was one of inclusion. Since women, as well as men, are rational beings, it followed that women as well as men are bearers of inalienable rights. It followed further that there was no valid ground for discrimination against women as women. Leading proponents of women's suffrage in Britain and the United States undermined arguments that justified legal inequality on the basis of sex differences. Such feminists, including the leading American suffragists Susan B. Anthony and Elizabeth Cady Stanton, claimed that denying a group of persons basic rights on the grounds of difference could not be justified unless it could be shown that the difference was relevant to the distinction being made. Whatever differences might exist between the sexes, none, in this view, justified legal inequality and the denial of the rights and privileges of citizenship.

Few early feminists pushed this version of liberal individualist universalism to its most radical conclusion of arguing that there were no bases for exclusion of adult human beings from legal equality and citizenship. Nineteenth-century proponents of women's suffrage were also heirs to a civic-republican tradition that stressed the need for social order and shared values, emphasized civic education, and pressed the importance of having a propertied stake in society. Demands for the inclusion of women often did not extend to all women. Some women, and men, would be excluded by criteria of literacy, property ownership, disability or, in the United States, race. Thus liberal feminism often incorporated the civic-republican insistence on citizenship as a robust, civically demanding, and limited privilege rather than a legalistic and universalistic standing.

At times, feminist theory turned liberal egalitarianism on its head by arguing in favor of women's civic equality on grounds of difference, an argument that might be called neo-Aristotelianism. Ronald Beiner writes,

> The basic conception of neo-Aristotelianism is that moral reason consists not in a set of moral principles, apprehended and defined through procedures of detached rationality, but in the concrete embodiment of certain human capacities in a moral subject who knows those capacities to be constitutive of a consummately desirable life. (p. 75)

Thus greater female political participation was promoted in terms of women's moral supremacy or characteristic forms of virtue. These appeals arose from and spoke to women's social location as mothers, using motherhood as a claim to citizenship, public identity, and civic virtue (Kraditor). To individualist, rights-based feminists, however, the emphasis on maternal virtue as a form of civic virtue was a trap, for they were, and are, convinced that only liberalism, with its more individualistic construal of the human subject, permits women's equality and standing.

The diverse history of feminism forms the basis for current feminist discourse and debate. These debates are rife with ethical imperatives and moral implications. Varieties of liberal, socialist, Marxist, and utopian feminism abound. Sexuality and sexual identity have become highly charged arenas of political redefinition. Some feminists see women as universal victims, some as a transhistorical sex class, others as oppressed "nature." A minority want separation from "male-dominated" society. Others want full integration into that society, hence its transformation toward liberal equality. Others insist that the feminist agenda will not be completed until "women's virtues," correctly understood, triumph. Feminism, too, is an essentially contested concept.

Divisions among feminists over such volatile matters as AIDS, IVF, surrogate embryo transfer, surrogate motherhood, sex selection—the entire menu of real or potential techniques for manipulating, controlling, and altering human reproduction—are strikingly manifest. One broad general tendency in feminist theory might be called noninterventionist. Noninterventionists see reproductive technologies as a strengthening of arrogant human control over nature and thus over women as part of the "nature" that is to be controlled. Alternatively, the prointerventionist stance foresees technological elimination of males and females themselves. Prointerventionists celebrate developments that promise control over nature.

The prointerventionists, who welcome and applaud any and all techniques that further sever biological reproduction from the social identity of maternity, are heavily indebted to a stance best called ultraliberalism. This theory is driven by a vision of the self that exists apart from any social order. This view of the self, in turn, is tied to one version of rights theory that considers human beings as self-sufficient, promoting a view of society that sees itself organized around contractual agreements between individuals.

THE SOCIAL-CONTRACT MODEL. The contract model has its historical roots in seventeenth-century social-contract theory, and it incorporates a view of society constituted by individuals for the fulfillment of individual ends, with social goods as aggregates of private goods. Critics claim that this vision of self and society ignores aspects of community life, such as reciprocal obligation and mutual interdependence, thereby eroding the bases of authority in family and polity alike.

The pervasiveness of the individualist position is further evident in the prointerventionist stance on bioethical innovations in the area of reproduction. In this view, new reproductive technologies present no problem as long as they can be wrested from male control (Donchin). Women, having been oppressed by "nature," can overthrow those shackles by seizing the "freedom" offered by technologies that promise deliverance from biological "tyranny." Strong prointerventionists go so far as to envisage forms of biological engineering that would make possible the following: "One woman could inseminate another, so that men and nonparturitive women could lactate and so that fertilized ova could be transplanted into women's or even into men's bodies" (Jaggar, p. 132). The standard of evaluation concerning these technologies is self-sufficiency and control, paving the way for invasive techniques that break women's links to biology, birth, and nurturance, the vestiges of our animal origins and patriarchal control.

The prointerventionist position owes a great deal to Simone de Beauvoir's feminist classic, *The Second Sex*. Beauvoir argues that the woman's body does not "make sense" because women are "the victim of the species." The female, simply by being born female, suffers an alienation grounded in her biological capacity to bear a child. Women are invaded by the fetus, which Beauvoir describes as a "tenant" and a parasite upon the mother. Men, by contrast, are imbued with a sense of virile domination that extends to reproductive life. The life of the male is "transcended" in the sperm. Beauvoir's negative appraisal of the female body extends even to the claim that a woman's breasts are "mammary glands" that "play no role in woman's individual economy: they can be excised at any time of life" (p. 24). If to this general repudiation of female embodiment one adds strong individualism, the prointerventionist stand becomes clearer.

Opposed to the radical prointerventionist stance is the noninterventionist voice associated with feminism in a less individualist, more communitarian frame. The noninterventionists ponder the nature of the many choices the new reproductive technology offers. They wonder whether amniocentesis is really a free choice or merely a coercive procedure with only one "correct" outcome: to abort if the fetus is defective. They speculate whether new reproductive technologies are an imposition upon women who see themselves as failures if they cannot become pregnant. Furthermore, noninterventionists reassess the values identified with mothering and encourage the growth and triumph of values they consider to be strongly, if not exclusively, female. They insist that technological progress is never neutral, stressing that "progress" requiring the invasion and manipulation of women's bodies must always be scrutinized critically and may need to be rejected.

Strong noninterventionists claim that women want nothing to do with new reproductive technologies. In the words of one, "The so-called new technology does not bring us and our children any kind of qualitative or quantitative improvement in our lives, it solves none of our basic problems, it will advance even more the exploitation and humiliation of women; therefore we do not need it" (Mies, p. 559). As with the prointerventionist posture, there are noninterventionists who maintain a critical stance but do not condemn all reproductive technologies outright. Moderate prointerventionists support some but not all of the technological possibilities presented by contemporary reproductive science.

These differences played themselves out in the quandaries confronted by feminists with the Baby M surrogacy-motherhood case, a situation in which biological motherhood and social parenting were severed—as feminists, especially strong individualist feminists, had long claimed they could or should be (*Baby M, In re,* 1988). It was also a case in which everyone presumably freely agreed to a contract. Baby M was born to Mary Beth Whitehead, who had contracted with a couple, the Sterns, to be artificially inseminated with Mr. Stern's sperm. She was to relinquish the baby on birth for $10,000. Ultimately, she could not give the baby up and refused the money. The Sterns sued on breach of contract grounds.

Although liberal feminism emphasizes contractarian imperatives, many liberal feminists, including such popular leaders of the women's movement as the liberal Betty Friedan, saw in the initial denial of any claim by Mary Beth Whitehead, the natural mother, to her child, "an utter denial of the personhood of women—the complete dehumanization of women. It is an important human rights case. To put it at the level of contract law is to dehumanize women and the human bond between mother and child" (Barron). Friedan implies an ethical limitation to freedom of choice and contract.

Clearly, feminist debates concerning reproductive technology and surrogacy inexorably lead feminists back into discussions of men, women, children, families, and the wider community. Once again we see that bioethical capabilities and possibilities cannot be severed from wider cultural and social surroundings, including our understanding of the human person and his or her private and public needs, identities, and commitments. One broad frame, the social contract, has been noted; it either assumes or promotes the image of the self-sufficient self and goods as the properties of individuals.

THE SOCIAL-COMPACT MODEL. A second model of social theory, that of the social compact, or social covenant, offers a more rooted and historical picture of human beings than that of the social contract. Compact, or covenant, theory does not recognize primacy of rights and individual choice as the self-evident starting point. The compact self is a historical being who acknowledges that he or she has a "variety of debts, inheritance, rightful expectations, and obligations" and that these "constitute the given of my life, the moral starting point" (MacIntyre). Modern uprootedness is construed as a problem in the social compact. To be cut off from a wider community as well as from the past, as required by strong individualist modes, is to deform present relationships. The argument here is not that the compact self is totally defined by particular ties and identities, but that without a beginning that recognizes our essential sociality, there is no beginning at all.

The world endorsed in the social-compact model is in tension with the dominant individualist mindset. For this reason, individualists sometimes claim that communitarians, who endorse a social-compact idea, express little more than nostalgia for a simpler past. But the compact defenders argue, in turn, that the past presents itself as the living embodiment of vital traditional conflicts. The social compact makes room for rebellion against one's particular place as one way to forge an identity with reference to that place. But there is little space in the compact frame for social revolt to take a form that excises all social ties and relations if the individual "freely chooses" to do so, a possibility the contractarian must admit. It follows that the familial base of the social compact is opaque to the standpoint of contract theory, given its individualist foundation. This difference about the family, the social institution that first introduces the child into the world, is the focus of political theory debates that bear important implications for bioethics.

The Family as a Theoretical Battleground

Given their individualist starting point, contractarians tend to devalue women's traditional roles and identities as mothers and familial beings. Proponents of the social-compact model, by contrast, understand women's contributions as wives, mothers, and social benefactors as vital to the creation and sustenance of life itself and, beyond that, of any possibility for a "good life." The compact theorist argues that community requires that an important segment or significant number of its members be devoted to the task of caring for the young, the vulnerable, and the elderly. Historically, the work of care has been seen by ethicists, political theorists, and political leaders, including many prominent women, as the mission of women. They worry that in a world of individualism, an ethic of care will be repudiated or replaced by modes of intervention less tied to concrete knowledge and concern of those being cared for (Ruddick; Tronto). They also advocate a reevaluation of families that gives conceptual weight to the "private realm" by showing that this sphere is central to social and political life. They insist that our understanding of justice must include a notion of what it means to be a caring society and to honor the work of care.

The compact theorist regrets the lack of a descriptive vocabulary that aptly and richly conveys what we mean when we talk about families and what makes caring commitments different from contractual agreements. The intergenerational family, for example, necessarily constitutes human beings in a particular web of relationships in a given time and place. Stanley Hauerwas, for example, claims that, "Set out in the world with no family, without a story of and for the self, we will simply be captured by the reigning ideologies of the day." We do not choose our relatives—they are given—and as a result, Hauerwas continues, we know what it means to have a history. Yet we continue to require a language to "help us articulate the experience of the family and the loyalty it represents.… Such a language must clearly denote our character as historical beings and how our moral lives are based in particular loyalties and relations. If we are to learn to care for others, we must first learn to care for those we find ourselves joined to by accident of birth."

Political theorists have grappled with the issue of the family's relationship to the larger society from the beginning: Where does the family fit in relation to the polity? In his work *Republic,* Plato eliminates the family for his ideal city. The ruler-philosophers he calls Guardians must take "the dispositions of human beings as though they were a tablet … which, in the first place, they would wipe clean." Women must be held "in common." A powerful, all-encompassing bond between individuals and the state must be achieved such that all social and political conflict disappears, and the state comes to resemble a "single person," a fused, organic entity. All private loyalties and purposes must be eliminated.

Plato constructs a meritocracy that requires that all considerations of sex, race, age, class, family ties, tradition, and history be stripped away in order to fit people into their appropriate social slots, performing only that function to which each is suited. Children below the ruler class can be shunted upward or downward at the will of the Guardians, for they are so much raw material to be turned into instruments of social "good." A system of eugenics is devised for the Guardians. Children are removed from mothers at birth and placed in a child ghetto, tended to by those best suited for the job. No private loyalties of any kind are allowed to emerge: Homes and sexual attachments, devotion to friends, and dedication to individual or group aims militate against single-minded devotion to the city. Particular ties are a great evil. Only those that bind the individual to the state are good.

No doubt the modern reader finds this rather extreme. Many contemporary theorists contend that Plato constructed his utopia in an ironic mode. Whether Plato meant it or not, his vision is instructive, for it helps us to think about the relation of the family to wider civic loyalties and obligations. Plato aspired to "rational self-sufficiency." He would make the lives of human beings immune to the fragility of messy existence. The idea of self-sufficiency was one of mastery in which the male citizen was imbued with a "mythology of autochthony that persistently, and paradoxically, suppressed the biological role of the female and therefore the family in the continuity of the city" (Nussbaum).

Moral conflicts, for Plato, suggest irrationalism. If one cannot be loyal both to families and to the city, loyalty to one must be made to conform to the other. For Plato, then, "Our ordinary humanity is a source of confusion rather than of insight … [and] the philosopher alone judges the right criterion or from the appropriate standpoint" (Nussbaum). Hence the plan of *Republic,* which aims to purify and to control human relations and emotions. Later strong rationalists and individualists take a similar tack: They hold that all relationships that are not totally voluntary, rationalistic, and contractual are irrational and suspect. Because the family is the ultimate example of embedded particularity, ideal justice and order will be attained only when "the slate has been wiped clean" and human beings are no longer limited by familial obligations.

Yet a genuinely pluralist civic order would seem to require diversity on the level of families as well as other institutions which, in turn, promote and give rise to many stories and visions of virtue. This suggests the following questions for social and political theory: In what ways is the family issue also a civic issue with weighty public consequences? What is the relationship between democratic theory and practice and intergenerational family ties and commitments? Do we have a stake in sustaining some models of adults in relation to children compared to others? What do families, composed of parents and children, do that no other social institution can? How does current political rhetoric support family obligations and relations?

Equality among citizens was assumed from the beginning by liberals and democrats; indeed, the citizen was, by definition, equal to any other citizen. Not everyone, of course, could be a citizen. At different times and to different ends and purposes, women, slaves, and the propertyless were excluded. But these exclusions were slowly dropped. Whether the purview of some or all adults in a given society, liberal and democratic citizenship required the creation of persons with qualities of mind and spirit necessary for civic participation. This creation of citizens was seen as neither simple nor automatic by early liberal theorists, leading many to insist upon a structure of education in "the sentiments." This education should usher into a moral autonomy that stresses self-chosen obligations, thereby casting further suspicion upon all relations, practices, and loyalties deemed unchosen, involuntary, or natural.

Within such accounts of civic authority, the family emerged as a problem. For one does not enter a family through free consent; one is born into the world unwilled and unchosen by oneself, beginning life as a helpless and dependent infant. Before reaching "the age of consent," one is a child, not a citizen. This vexed liberal and democratic theorists, some of whom believed, at least abstractly, that the completion of the democratic ideal required bringing all of social life under the sway of a single democratic authority principle.

COMMUNITARIAN VERSUS INDIVIDUALIST VIEWS OF FAMILY: MILL AND TOCQUEVILLE. In his tract *The Subjection of Women,* John Stuart Mill argued that his contemporaries, male and female alike, were tainted by the atavisms of family life with its illegitimate, or unchosen, male authority, and its illegitimate, or manipulative and irrational, female quests for private power (1970). He believed that the family can become a school in the virtues of freedom only when parents live together without power on one side and obedience on the other. Power, for Mill, is repugnant: True liberty must reign in all spheres. But what about the children? Mill's children emerge as blank slates on which parents must encode the lessons of obedience and the responsibilities of freedom. Stripped of undemocratic authority and privilege, the parental union serves as a model of democratic probity (Krouse).

Mill's paean to liberal individualism is an interesting contrast to Alexis de Tocqueville's observations of family life in nineteenth-century America, a society already showing the effects of the extension of democratic norms and the breakdown of patriarchal and Puritan norms and practices. Fathers in Tocqueville's America were at once stern and forgiving, strong and flexible. They listened to their children and humored them. They educated as well as demanded obedience, promulgating a new ethic of child rearing. Like the new democratic father, the American political leader did not demand that citizens bow or stand transfixed in awe. The leader was owed respect and, if he urged a course of action upon his fellow citizens following proper consultation and procedural requirements, they had a patriotic duty to follow.

Tocqueville's discerning eye perceived changing public and private relationships in a liberal, democratic society. Although great care was taken "to trace two clearly distinct lines of action for the two sexes," women, in their domestic sphere, "nowhere occupied a loftier position of honor and importance," Tocqueville claimed. The mother's familial role was enhanced in her civic vocation as the chief inculcator of democratic values in her offspring. Commenting in a civic-republican vein, Tocqueville notes, "No free communities ever existed without morals and, as I observed …, morals are the work of women."

Clearly, Tocqueville rests in the social-covenant or communitarian camp; Mill, in the social-contract or individualist domain. In contrast to Mill, Tocqueville insisted that the father's authority in a liberal society was neither absolute nor arbitrary. In contrast to the patriarchal authoritarian family where the parent not only has a "natural right" but acquires a "political right" to command his children, in a democratic family the right and authority of parents is a natural right alone. This natural authority presents no problem for democratic practices as Tocqueville construed democracy, in contrast to Mill. Indeed, the fact that the "right to command" is natural, not political, signifies its special and temporary nature: Once the child is self-governing, the right dissolves. In this way, natural, legitimate paternal authority and maternal moral education reinforce a political order that values flexibility, freedom, and the absence of absolute rule, but requires order and stability as well.

Popular columnists and "child experts" in Tocqueville's America emphasized kindness and love as the preferred technique of child nurture. Obedience was still seen as necessary—to parents, elders, God, government, and the conscience. But the child was no longer construed as a depraved, sin-ridden, stiff-necked creature who needed harsh, unyielding instruction and reproof. A more benign view of the child's nature emerged as notions of infant depravity faded. The problem of discipline grew more, rather than less, complex. Parents were enjoined to get obedience without corporal punishment and rigid methods, using affection, issuing their commands in gentle but firm voices, insisting quietly on their authority lest contempt and chaos reign in the domestic sphere (Elshtain, 1990).

FAMILY AUTHORITY AND THE STATE. In Tocqueville's image of the democratic family, children were seen both as ends and as means to a well-ordered family and polity. A widespread moral consensus reigned in the America of that era, a kind of Protestant civic religion. When this consensus began to erode under the force of rapid social change (and there are analogues to the American story in all modern democracies), certainties surrounding familial life and authority as a secure locus for the creation of democratic citizens were shaken as well. Tocqueville suggested that familial authority, though apparently at odds with the governing presumptions of democratic authority, is nonetheless part of the constitutive background required for the survival and flourishing of democracy.

Family relations, so this politico-ethical argument goes, could not exist without family authority. These relations and responsibilities, in turn, remain the best way to create human beings with a developed capacity to give ethical allegiance to the principles of democratic society. Because democratic citizenship relies on the self-limiting freedom of responsible adults, a mode of child rearing that builds on basic trust, loyalty, and a sense of commitment is necessary. Family authority structures the relationship between adult providers, nurturers, educators, and disciplinarians, and dependent children, who slowly acquire capacities for independence. Modern parental authority is shared by mother and father.

What makes family authority distinctive is its sense of stewardship: the recognition that parents undertake continuing obligations and responsibilities. Certainly in the modern West, given the long period of childhood and adolescence we honor and recognize, parenting is an ongoing task. The authority of the parent is special, limited, and particular. Parental authority, like any form of authority, may be abused, but unless it exists, the activity of parenting itself is impossible. The authority of parents is implicated in moral education required for the creation of a democratic political morality. The intense loyalties, obligations, and moral imperatives nurtured in families may clash with the requirements of public authority, for example, when young men refuse to serve in a war they claim is unjust because war runs counter to the religious beliefs of their families. This, too, is vital for democracy. Keeping alive a potential locus for revolt, for particularity, for difference, sustains democracy in the long run. It is no coincidence, this argument concludes, that all twentieth-century totalitarian orders aimed to destroy the family as a locus of identity and meaning apart from the state. Totalitarian politics strives to require that individuals identify only with the state rather than with specific others, including family and friends.

Family authority within a democratic, pluralistic order, however, does not exist in a direct homologous relation to the principles of civil society. To establish an identity between public and private lives and purposes would weaken, not strengthen, democratic life overall. For children need particular, intense relations with specific adult others in order to learn to make choices as adults. The child confronted prematurely with the "right to choose" is likely to be less capable of choosing later on. To become a being capable of posing alternatives, one requires a sure and certain place from which to start. In Mary Midgley's words: "Children … have to live *now* in a particular culture; they must take some attitude to the nearest things right away." The social form best suited to provide children with a trusting, determinate sense of place and ultimately a "self" is a family in which parents provide ongoing care, protection, and concern.

The stance of the democratic political and social theorist toward family authority resists easy characterization. It involves a rejection of any ideal of political and familial life that absorbs all social relations under a single authority principle. Families are not democratic polities. The family helps to hold intact the respective goods and ends of exclusive relations and arrangements. Any further erosion of that ethical life embodied in the family bodes ill for democracy. For this reason, theorists representing the communitarian or social-covenant perspective are often among the most severe critics of contemporary consumerism, violence in streets and the media, the decline of public education, the rise in numbers of children being raised without fathers, and so on. They insist, against their critics, that a defense of the family—by which they mean a normative ideal of mothers and fathers in relation to children and to a wider community—can help to sustain a variety of ethical and social commitments, including providing a strong example of adults working together to create a home. Because democracy itself turns on a generalized notion of the fraternal bond between citizens (male and female), it is vital for children to have early experiences of trust and mutuality. The child who emerges from such a family is more likely to be capable of acting in the world as a complex moral being, one part of, yet somewhat detached from, the immediacy of his or her own concerns and desires.

Toward an Ethical Polity

All political and social theorists, whatever their particular philosophic frameworks and normative commitments, agree that social and political theories always embody some ideal of a preferred way of life. Although a handful of postmodern or deconstructive contemporary theorists disdain all normative standards, most social and political thinkers insist that no way of life can persist without a widely shared cluster of basic notions. Those who locate ethical concerns at the heart of their theories hope for a world in which private and public lives bearing their own intrinsic purpose are allowed to flourish. A richly complex private sphere requires freedom from some all-encompassing public imperative for survival. But in order for the private sphere to flourish, the public world itself must nurture and sustain a set of ethical imperatives, including a commitment to preserve, protect, and defend human beings in their capacities as private persons, and to allow men and women alike to partake in the good of the public sphere with participatory equality (Elshtain, 1981). Such an ideal seeks to keep alive rather than to eliminate tension between diverse spheres and competing ideals and purposes. There is always a danger that a too strong and overweening polity will overwhelm the individual, as well as a peril that life in a polity confronted with a continuing crisis of legitimacy may decivilize both those who oppose it and those who would defend it.

The prevailing image of the person in an ethical polity is that of a human being with a capacity for self-reflection. Such persons can tolerate the tension between public and private imperatives. They can distinguish between those conditions, events, or states of affairs that are part of a shared human condition—grief, loss through death, natural disasters, and decay of the flesh—and those humanly made injustices that can be remedied. Above all, human beings within the ethical polity never presume that ambivalence and conflict will one day end, for they have come to understand that ambivalence and conflict are the wellspring of a life lived reflectively. A clear notion of what ideals and obligations are required to animate an authentic public life, an ethical polity, must be adumbrated: authority, freedom, public law, civic virtue, the ideal of the citizen, all those beliefs, habits, and qualities that are integral to a political order.

Much of the richest theorizing of democratic civil society since 1980 has come from citizens of countries who were subjected for forty years or more to authoritarian, even totalitarian regimes. They pose alternatives both to collectivism and to individualism by urging that the associations of civil society be recognized as subjects in their own right. They call for a genuinely pluralist law to recognize and sustain this associative principle as a way to overcome excessive privatization, on the one hand, and overweening state control, on the other. Solidarity theorist Adam Michnik insists that democracy

> entails a vision of tolerance, and understanding of the importance of cultural traditions, and the realization that cherished human values can conflict with each other.… The essence of democracy

> as I understand it is freedom—the freedom which belongs to citizens endowed with a conscience. So understood, freedom implies pluralism, which is essential because conflict is a constant factor within a democratic social order. (p. 198)

Michnik insists that the genuine democrat always struggles with his or her own tradition, eschewing the hopelessly heroic and individualist notion of going it alone. Michnik positions himself against contemporary tendencies to see any defense of tradition as necessarily "conservative"; indeed, he criticizes all rigidly ideological thinking that severs every political and ethical concern between right and left, proclaiming that "a world devoid of tradition would be nonsensical and anarchic. The human world should be constructed from a permanent conflict between conservatism and contestation; if either is absent from a society, pluralism is destroyed" (p. 199).

A second vital political-ethical voice is that of Vaclav Havel, a playwright, dissident, political theorist, and, in the years following the "tender revolution" of 1989, the president of a then-united Czechoslovakia. In his essay, "Politics and Conscience," he writes:

> We must trust the voice of our conscience more than that of all abstract speculations and not invent other responsibilities than the one to which the voice calls us. We must not be ashamed that we are capable of love, friendship, solidarity, sympathy and tolerance, but just the opposite: we must see these fundamental dimensions of our humanity free from their "private" exile and accept them as the only genuine starting point of meaningful human community. (pp. 153–154)

To this end, he favors what he calls "anti-political politics," defined not as the technology of power and manipulation, of cybernetic rule over humans or as the art of the useful, but politics as one of the ways of seeking and achieving meaningful lives, of protecting them and serving them. "I favor politics as practical morality, as service to the truth, as essentially human and humanly measured care for our fellow humans. It is, I presume, an approach which, in this world, is extremely impractical and difficult to apply in daily life. Still, I know no better alternative" (p. 155). This is the voice of an ethical polity. Were this voice to prevail, the way in which our ethical dilemmas are adjudicated, including those emerging from bioethics, would be rich and complex enough to enable us to see the public and civic consequences of our private choices, even as it would guard against severe intrusion into intimate life from the outside.

Ethical dilemmas are inescapably political and political questions are unavoidably ethical. Bioethical matters can never be insulated from politics, nor should they be. But the way in which such matters are addressed will very much turn on the social or political theories to which the ethicist, the medical practitioner, the patient or consumer, and the wider, interested community are indebted.

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SEE ALSO: *Coercion; Consensus, Role and Authority of; Communitarianism and Bioethics; Contractarianism and Bioethics; Human Rights; Justice; Medicine, Sociology of; Natural Law; Paternalism;* and other *Ethics* subentries

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V. RELIGION AND MORALITY

In the minds of many people, religion and morality are closely connected. Even in secular discussions of ethics, law, and medicine, the presumption remains strong that religious beliefs are an important source of moral guidance, and that religious authorities have a significant influence in shaping attitudes toward biomedical research, new technologies, and medical interventions at the beginning and end of life. Both those who hold religious beliefs and those who do not expect that such beliefs will make a significant difference in the moral lives of their adherents.

When this commonplace assumption about the connection between religion and morality is subjected to examination, however, problems emerge. Although moral virtues and behaviors characteristic of Christian love or Buddhist compassion may be clearly associated with a specific religion, the human possibilities they describe are often familiar and admired, even among those who do not share the religious beliefs. Persons outside of a community of faith may display its characteristic virtues, and those who reject a particular religion may realize its moral ideals better than most of its adherents. For example, Christian writers often turn to Gandhi as the modern model of the love that Jesus preached, while Gandhi valued the life of Jesus as an example of the harmlessness he sought to encourage. This recognition of specific moral virtues in persons outside the community of belief in which those virtues are defined and taught is so common today as to be unremarkable, but it challenges the assumption that specific moral beliefs and practices can be tied to specific religious commitments.

The assumption that religion and morality are somehow related thus gives way to questions about exactly what forms this relationship may take and how it is understood. What claims are persons making when they relate a moral judgment to a religious belief, and how are we to understand the similar judgments that others make on nonreligious grounds? How will these different moral and religious orientations relate to the findings of the biomedical sciences? How should the providers of medical services relate to the diversity of these religious and moral orientations in a complex, pluralistic society?

Types of Relationships

A first step toward answering these questions is to identify the variety of relationships between religion and morality that are found in the world's moral and religious traditions (Little and Twiss). In general, religion is an authoritative source of moral norms and a primary motivation for conformity to moral requirements. Significant variations on this general idea do, however, exist. Is religion the only source of the moral norms, or may those norms, or some of them, be discovered or created in other ways? Is the authoritative source the will of a divine lawgiver, or an intrinsic goodness in the nature of things themselves? Is the motive for moral action a religious love of the good for its own sake, or the hope for an ultimate compensation for the hardships that moral behavior sometimes requires?

Answers to these questions differ, both among different religious traditions and among different schools of thought within a single tradition. The major monotheistic traditions—Judaism, Christianity, and Islam—often represent key moral norms as direct commands of God. In the religions that originated in India—Hinduism, Jainism, and Buddhism—by contrast, the central concept is *karma,* a cosmic moral order that fixes inescapable consequences for any action (Green). Protestant Christianity has often stressed the word of God, the direct divine command that is independent of any human knowledge or wisdom, while Roman Catholic moral theology has relied more on the concept of "natural law," a moral order established by God, but knowable by human reason and apparent in the workings of the natural order (Gustafson).

While it would be possible to explore the relationships between religion and morality by surveying major religious traditions individually, that approach would quickly become a volume unto itself, and it would still do scant justice to the nuances and variety within each tradition. For present purposes, we must limit consideration to a typology of relationships that can be observed in a number of traditions, especially as these traditions come into contact with one another and with the forces of modern technological change. Examples of each type can be identified in a variety of religious traditions, but readers who seek a comprehensive understanding of morality in, for instance, Buddhism or Islam will need to consult other sources, some of which are identified in the bibliography for this entry.

The wide variety of possible relationships between religion and morality may be organized in three prominent types that have received most serious attention from modern scholars: (1) cosmic unity, in which moral obligations derive from a natural or metaphysical order that is understood in religious terms; (2) logical independence, in which moral norms, despite their historical connections to religion, do not depend directly on religion for their validity, and in which religious values must be sharply distinguished from judgments of moral worth; and (3) cultural interdependence, in which neither religion nor morality can be understood apart from the communities in which they have developed and in which their practices have become intertwined.

This typology is derived from modern Western scholarship and reflects particularly the development of religion in modern, secular societies. Each of the types, however, has roots in earlier developments in Western theology and philosophy, and most have parallels in other, non-Western religious and cultural communities. While the emphasis in what follows will be on the modern West, much will be relevant to modern and modernizing cultures in other parts of the world, and analogies to the relationship between religion and morality in other cultural settings may illuminate both those settings and the West's.

COSMIC UNITY. Many cultures have conceived moral and natural orders as an undifferentiated unity. The rewards and punishments associated with moral action are as much a part of reality as the forces of wind and water or the patterns of growth and development observed in plants and animals. To put the matter another way, both the observable patterns of nature and the system of moral requirements are part of a larger order that encompasses all reality, seen and unseen. This unity, expressed both in myths and poetry and in speculative metaphysics, comes into question as science and philosophy develop, but it remains a powerful influence, even in modern, secular societies.

Sometimes, the power that requires moral conduct is thought of in impersonal terms, as a force to be reckoned with by humans and by more powerful beings as well. Early Greek philosophers and poets understood justice (*dikê*) in these terms. Justice keeps gods and humans from exceeding their limits, and those who ignore justice risk disaster for the whole community (Adkins). In ancient China, *dao* was a pervasive force that both regulated the order of natural events and set the standard for human conduct (Girardot). Similar concepts appear in other traditions.

In the Hebrew scriptures, the ultimate power is a personal God who is not subject to higher forces, but who addresses human beings in terms of moral commandments (Deut. 5:1–21). This God is also the creator of the natural forces with which humans must reckon. A somewhat later strand of the tradition represents wisdom (*hokmah*) as the pervasive, unifying power by which God both shapes the material world and directs the conduct of good persons (Prov. 8:1–31).

These early conceptions of a moral order inherent in the order of things often gave way to an understanding of laws and obligations as purely human creations, having power only so far as they are enforced. The development of these skeptical ideas often coincided with the breakdown of traditional social patterns, or with the discovery of other peoples and cultures who lived by quite different rules. Both Greek and Roman philosophers, however, retained the notion that some requirements are not conventional, but natural. However much Greece and Persia otherwise may have differed, some moral requirements remained the same in both places (Aristotle).

This idea provided theologians with the basis for a concept of "natural law," through which God's commandments could be known by all rational persons. Thus, the same minimal requirements of morality apply to everyone, whether or not they share the same ideas about God. Both Judaism and Islam developed philosophical systems that transmitted the Hellenistic notion of natural law to the Christian West, and for a brief time in the Middle Ages, teachers in all three traditions could debate the relationship between God's will and the created order in a shared philosophical framework (Jacobs). In medieval Christian theology, natural law related all rational beings to God. Natural law was seen to be the way a finite, rational being participates in the eternal law by which God orders the universe.

The ever-present possibility of elevating a particular aspect of nature to the level of equality with God led, however, to widespread suspicion of natural law ideas among moral and religious reformers. The main line of development in Jewish ethics centered on observance of a code of law based on scripture and rabbinic interpretation, rather than on a rationalist moral philosophy (Lichtenstein). In Islam, the philosophical movement evolved in a more mystical direction, focused on the identity of the human spirit with the spiritual character of all reality, rather than on the moral requirements of a natural order (Rahman). In Western Christianity, the Protestant Reformation challenged all forms of religious legalism, including the precepts of natural law.

During the seventeenth century, however, a new group of legal and political theorists seized upon the concept of natural law as the key to understanding the relationships between nations as well as persons. While the religious significance of the natural law was not necessarily rejected, it was the universality of the obligation, not its divine origin, that attracted these jurists to the idea. In both legal and theological treatments of natural law, however, these highly articulated systems of moral thought share with the earliest myths of cosmic unity the notion that some moral requirements are inescapable because they are part of the structure of reality itself. Since World War II, renewed interest in theories of natural law as a starting point for an international recognition of basic human rights testifies to the continuing significance of this way of relating moral requirements to religious beliefs about the origin and end of the world in which the moral life is lived (Maritain).

The idea of a comprehensive order that encompasses both moral and religious requirements thus appears both in the most ancient religious traditions and in modern Western theories of natural law. Although reformers in many theistic traditions have sought to restore religious morality to a direct dependence on the will of God, the underlying idea that what God wills is also supported by the natural order that God has created never entirely disappears, even when the human ability to know God's will through the natural order is contested.

LOGICAL INDEPENDENCE. The fact that religion and morality are closely related in the history of Western thought does not, of itself, establish that their connection is important for contemporary moral decisions. The historical relationships might be viewed as accidental or contingent, subject to change without altering the basic requirements of morality. The links between religion and morality might even be points of confusion that obscure important features of both religious and moral truths. For some thinkers, then, it is important to establish the distinction between religious and moral evaluations, even though these may be commonly confused in practice, or integrally related in some more comprehensive system of ideas. Failure to make the distinction between religion and morality runs the risk of subordinating both to prevailing cultural practices, which may themselves be morally questionable.

By the eighteenth century, European philosophers had begun to advance theories about the historical development of religion that were not based on the history presented in the Bible. Religion could thus be given a "natural history," as opposed to the sacred history revealed in scripture. David Hume's "The Natural History of Religion" postulated a primitive connection between fear of the awesome power of natural forces and dread of punishment for moral transgressions. Such fear may continue to serve as a useful inducement to moral conformity, but it leads only to confusion if the source of the moral imperatives is sought in a supernatural power. Against those who worried that a distinction between religion and morality would lead to a decline in moral standards, Hume argued that a sound logical connection between moral requirements and the public good was the only secure basis for morality. A utilitarian calculation of the line of conduct that will produce the largest social benefits is the final source of moral norms, and respect for that public good is the only secure ground of moral motivation.

In addition to the possibility that the connection between religion and morality is simply a residue of primitive superstitions, philosophers noted another point that seemed not only to distinguish religion from morality, but also to give a logical priority to morality. Religious traditions frequently praise a divine center and origin of moral goodness, or point to the lives of exemplary religious figures as examples to be followed. To recognize that goodness seems, however, to require a moral judgment that precedes the religious assent. We can only praise God or emulate the saints for moral goodness if we have an idea of what is morally good, by which we measure even these supreme examples. "Even the Holy One of the gospel," wrote Immanuel Kant, "must first be compared with our ideal of moral perfection before we can recognize him as such" (p. 76).

Clearly, whether one begins with Hume's "natural history" of religion or Kant's rational foundation for moral judgments, morality and religion cannot be simply identical. The Christian natural law tradition used reason to discern God's will in the order of the created world. In Kant and Hume, reason formulates its requirements independently, on the basis of social utility or of logical necessity. The resulting standard of morality is then applied to religion, which may or may not measure up.

This separation of moral requirements from religious belief does not, however, imply that religion has no connection to morality. Many who accepted a rational morality, the requirements of which did not depend on faith, continued to value religion as a motive for the moral life. Love of a God who is perfect in goodness, and reverence for saints who have upheld the requirements of morality in the face of severe temptations, provide powerful motives for people to live up to moral expectations in more ordinary circumstances. Indeed, Kant argued that some conception of God is ultimately required to make sense of the sacrifices that all moral action requires of us. The logical independence of morality from religion does not require that religion be abandoned, but it does require that moral actions be undertaken precisely because we are convinced that they are morally right, and not because we believe that God commands us to do them.

These philosophical developments coincided with important historical changes in European religious life. By the end of the seventeenth century, the normative requirement of religious conformity was rapidly being replaced by practices of religious toleration and, eventually, by a civic commitment to religious freedom. The logical separation of religion from morality became a sociological necessity as well, if citizens who were no longer united in their religious beliefs were to acknowledge moral obligations to one another. In the United States, especially, the idea developed that a variety of quite different religious beliefs could support a common moral consensus (Frost). Because morality and religion are independent, diversity of religious beliefs need not lead to moral conflict, and moral order does not require religious agreement.

In other cases, where the break with traditional forms of religious and social life was sharper, or where the conflict between religious groups was more intense, public moral expectations were reformulated in nonreligious terms. Where cooperation between religion and government proved difficult, or where the moral consensus between different religious groups was obviously lacking, the concept of a "secular state" provided the necessary basis for social unity. A secular state not only refuses to privilege one or another religious perspective among its people, it resolutely excludes religious considerations from the formation of policy and regulations. Religion and religious morality become private considerations, subject to regulation for the public good.

This understanding first emerges clearly in the French Revolution, but the idea of a secular state has also provided hope for civil unity for many twentieth-century leaders in countries deeply divided by religious strife or torn by controversy over modernizations that undermine traditional forms of religious life. In the United States, where the prevailing model has been the religious consensus on moral expectations, elements of the secular state concept have nonetheless been invoked to curb sectarian religious practices that differ sharply from those of the majority, or to exclude religious arguments from controversial questions of policy. Judicial limitation of a parent's power to withhold medical care from children on religious grounds and political arguments that Roman Catholic opposition to abortion violates the constitutional separation of church and state are two instances in which the apparent lack of religious consensus has prompted arguments for policies of a secular state.

The logical separation of morality from religion, then, provides an important intellectual starting point for the ordering of societies divided by religious differences or seeking to modernize in the face of opposition by traditional religious groups. The distinction between religion and morality does not, by itself, prescribe a role for religion in public life. Religion may be one element in a powerful moral consensus that differs from the religious morality of a traditional society, or it may be virtually excluded from influence by a secular state that defines public morality in terms of a utilitarian calculation of the public good.

CULTURAL INTERDEPENDENCE. Although the logical separation of morality from religion is a premise for much of Western European and North American thought in ethics, law, politics, and even theology, its relevance to other points in history and other parts of the world is less clear. The modern Western distinction between religion and morality is missing from many highly developed religious and cultural systems, which assign duties to persons on the basis of their position in society without obvious distinctions between what modern Westerners differentiate into moral requirements, common courtesy, religious obligations, and patriotic duties.

This is most clear in the traditional societies of India, China, and Japan. Hinduism recognizes few duties that correspond to the universal moral obligations of modern Western ethics. Specific persons owe duties to specific others, based on the place each occupies in a social, moral, and religious hierarchy, so that traditional Hinduism can hardly exist outside of the social system in which it originates. In China, a Confucian system of philosophical morality was tied to the details of the education and duties of an elite corps of governing intellectuals, while in Japan, the traditional religion of the people centered on the cults of specific ancestors and the spirits of specific places. Hinduism and, to a certain extent, Confucianism demonstrated in the nineteenth century that they could be reinterpreted in more universal philosophical terms, but the reconstruction of State Shinto in Japan during the same time period suggests that the unitary system of religion, state, and morals can also be adapted to the demands of modernizing societies (Hardacre).

While the interdependence of religion and culture is most clearly seen in these highly developed national traditions, the missionary religions that have moved across large parts of the world also illustrate this interdependence, precisely in their adaptability to very different cultural settings. Christianity presents very different appearances in Moscow and in Dallas. Buddhism in Tokyo is distinctively Japanese, as it is distinctively Thai in Bangkok. The same might be said for Islam in Cairo and in Kuala Lumpur. Nor are these variations simply the result of a constant teaching consciously applied to different situations. Religious traditions develop by interacting with the economic life and productive systems by which their adherents meet their material needs, as well as by the inner logic of their spiritual teachings. The modern sociological study of religion rests on this awareness of the nonreligious forces that operate on religious communities and the unintended consequences that religious beliefs have in the world of economic life (Weber).

Those who view religion from this perspective identify important changes that religions undergo in modern, technological societies. The institutions of religion no longer occupy the central positions of power and authority they once held. Wider knowledge of the world and more exposure to other cultures lead to an awareness of other religions beside one's own. These changes mark what sociologists call secularization, but the interactions of religion and culture are no less real in that context than they were when religion had a more dominant position.

Secularization may reduce the power of religions institutions and leaders, but it does not produce a neutral culture free of religious influences. A "secular" society is shaped in part by the historical interactions between the religion and culture that have shaped the particular place in which the society now exists. A modern economy influenced by a Confucian past differs significantly from one that has developed out of European Protestantism. The process of secularization, therefore, does not provide a neutral, universal standpoint from which to settle questions of morality and policy.

Since the 1970s, social scientists, philosophers, and theologians have widely accepted this contextualization of their work and have sought to explore its implications for their systematic thought (Stout). What was believed to be universal and rational is now widely seen to be particular. Notions of objectivity, tables of individual rights and duties—even, perhaps, the idea of rationality itself—are shaped by particular cultural starting points.

Where supposed neutrality and rational authority have been used to suppress religious conflict, the continuing influence of religion on culture sometimes results in violent rejection of the secular state and its institutions. Fundamentalist movements throughout the Islamic world and among Hindus in India reject modern secular culture as an alien Western imposition and reassert an identity of religion, morality, and culture. In the United States and elsewhere, renewed interest in the religions of indigenous peoples includes a rediscovery of their distinctive understandings of health and healing, which link religion, morality, and medicine in ways unfamiliar to modern medical science (Sullivan).

The implications of this reassertion of the cultural integrity of religion and morality are, however, variously construed by authors reflecting on modern pluralistic societies. One view suggests that the loss of community and the rise of social disorder is a direct result of the attempt to exclude from public discussion the religious values that are the only available foundation for morality. The social achievements that people in the United States most prize, including their individual rights and political freedoms, are simply the fruit of the Christian moral traditions that gave rise to them. If we hope to continue to enjoy them, we must restore those moral traditions in which they originate to a central role in shaping the life of society (Neuhaus).

Another point of view suggests, by contrast, that the public life of a pluralistic society can no longer provide a forum for genuine moral convictions, which always have a particular religious basis. If we seek to develop persons of moral character, we must do it within religious communities that have a distinctive identity. It may then be possible to translate some of these religious values into public policy through political action, but it will not be possible to offer a public argument for the values at stake. They can only be understood in a community where the way of life in which they originate is cherished and enacted (Hauerwas).

An understanding of the cultural interdependence of religion and morality thus calls into question both the cosmic order that sustains religion's requirements everywhere and the universal, rational morality that is characteristic of modern understandings of the independence of morality from religion. In this emphasis on cultural specificity that is sometimes called "postmodern," everything depends on the relationship between religion and morality in a particular place and time. Those who hold this view agree on the importance of the interaction of morality and religion. They differ over whether this interaction should take the form of cultural hegemony by a particular religious tradition, in order to provide the necessary foundation for public order, or should be practiced in small communities of shared faith, who venture into politics and public policy only for limited purposes and confine their virtues to their separated life.

Implications for Bioethics

Perhaps the most striking result of this survey is the diversity of relationships between religion and morality that are held in different religious traditions and, indeed, within the same religious tradition, in different historical and cultural settings. In a pluralistic society, where researchers often work in global networks and medical-care providers deal with patients and families from many communities, many different understandings of morality and religion will impinge on their work, raising new issues in bioethics.

Questions of patient autonomy and appropriate respect for the human subjects of biomedical research become even more difficult when the parties have not only different religious beliefs about the nature of the human being, but also different understandings of how these beliefs appropriately relate to moral decisions that doctor and patient, researcher and subject, primary parties and review committees must make together. Conflicts may arise, for example, when medical personnel appeal for decisions on clinical or scientific grounds to patients and families whose beliefs do not admit nonreligious reasons for decisive personal choices. It is important in the first instance simply to be aware of this diversity of moral and religious perspectives and alert to their relevance to professional choices. Even specialists who are well trained in bioethics often uncritically accept the viewpoint that morality is logically independent of religion, because that is the position of the moral philosophy that has provided much of the theoretical framework for contemporary bioethics. Without awareness of the other possibilities this entry has surveyed, significant moral issues may be overlooked until they become the subject of public controversy or undermine the relationship of trust between medical-care providers and patients.

Investigations of the cultural interdependence of religion and morality may make us aware of serious moral claims. What a patient believes about ritual purity or about the fate of the soul after death deserves more than just respectful interest. It may determine what it means to treat that patient as a free person with an inherent dignity. In any case, the cultural specificity of all moral and religious perspectives should also alert us to the limitations of the claims of biomedical science.

Cultural interdependence opens up possibilities for serious conflicts between cultural perspectives in medical and scientific institutions. Often, research and clinical personnel do not share the commitments of universities or hospitals that have religious sponsorship. An ethical commitment to scientific objectivity or clinical autonomy, which is easy to sustain when religion and morality are believed to be logically distinct, may come into conflict with the view that sustaining a distinctive religious culture within the institution is the only way to sustain it as a moral community. Alternatively, religious views that stress the importance of distinctive moral communities may withdraw from the more complex, pluralistic world of the medical center or research institute, thus eliminating a possibly important mediating influence between the narrowly focused aims of medical practice and the values of ordinary Jews, Catholics, Muslims, or Baptists who happen for the moment to be patients in a medical facility.

The increasing cultural complexity of biomedical science and its institutions prompts the search for a core of morality that would provide the basis for policy decisions, without requiring unanimity on the religious reasons for those moral requirements. Logical independence of this common morality from particular religious commitments seems to be required, whether the morality is to be founded on a universal moral logic or, less ambitiously, on the necessary requirements of medical practice. Although the idea of a completely neutral, secular medical ethics may no longer be plausible, a standard of "secular arguments" for policy choices seems to some observers to solve the problem of moral and religious difference. By insisting that arguments for or against specific policy choices must be made for reasons accessible to all parties in the debate, we eliminate public choices based on specific religious convictions. Arguments for or against a program of acquired immunodeficiency syndrome (AIDS) education and prevention on ground of its effect on community health are acceptable. Arguments for or against it on grounds that it conforms to the requirements of a specific religious teaching are not.

While the standard of "secular arguments" or "publicly accessible reasons" is appealing, it presupposes a very large area of public moral consensus. Although some such consensus does exist, its scope is unclear, and there is no guarantee that it is actually broad enough to resolve the difficult bioethical issues that divide society today. In short, it may be that a strictly defined "secular argument" will be insufficient to yield a determinate solution to the problems, that some appeal to the religious convictions or other private views of the participants will be necessary if we are to settle the questions at all (Greenawalt).

Efforts to define an independent system of morality, in which bioethical issues could be resolved without reference to the diversity of religious moral positions, are thus subject to a variety of problems. The issues range from attacks on the supposed neutrality and objectivity of secular scientific inquiry, to the criticism that if it should achieve this neutrality, it would be unable to provide determinate solutions to policy questions that have been posed to medicine and science.

Another possibility, however, is to accept the unity of religious and moral discourse and ask whether biomedical science and clinical practice might participate in it. Physicians and other providers of medical services have ideas about human flourishing based on long experience with patients and clients. Scientific research may confirm or disprove widespread convictions about the best means to achieve and sustain a good life, and it may provide new evidence of causal links between choices and outcomes. Discussion of the human good typically takes quite different forms from the highly structured discourse of the biomedical sciences, but those sciences clearly do have a contribution to make to it.

Beliefs that hold that there is a cosmic unity of religion and morality, a single reality in which religious and moral truths make sense together, offer the clearest opportunities for biomedical participation. This openness is most apparent in contemporary formulations of natural law theory, which explicitly make use of biomedical knowledge as part of the determination of what is natural and what the conditions for human flourishing are. Even where religious traditions have not developed systematic statements, however, their narratives and rituals make implicit claims about the constraints that the world imposes on human life, and about what human beings must do to live well within those limits (Lovin and Reynolds).

Where these myths, narratives, hymns, and rites are taken to be rivals to a scientific account of reality, there will inevitably be conflicts between the biomedical sciences the religious ideas about morality. But religious discourse is never simply an objective account of the way things are. It is always also an orientation of human life within that world of facts, and the physician's or the medical researcher's account of those facts may have a place in that orientation. Such an understanding neither separates religion from morality, nor links them both to a specific cultural system, but regards morality as an orientation of human life within a reality that is susceptible both to scientific examination and to the imaginative and liberating comprehension that religion offers.

Those who seek to join a discussion of the human good in which both religious wisdom and scientific discovery have a place must acknowledge that there are other views, religious and scientific, that will reject that collaboration. A moral realism that links religion, science, and morality may provide the best framework for biomedical researchers and clinicians to explain the ethical implications of their work in terms that many religious traditions can accept.

ROBIN W. LOVIN (1995)

SEE ALSO: *African Religions; Bioethics, African-American Perspectives; Buddhism, Bioethics in; Christianity, Bioethics in; Daoism, Bioethics in; Eugenics and Religious Law; Islam, Bioethics in; Jainism, Bioethics in; Judaism, Bioethics in; Medical Ethics, History of Europe; Mormonism, Bioethics in; Native American Religions, Bioethics in; Reproductive*

Technologies; Sikhism, Bioethics in; Transhumanism and Posthumanism; and other *Ethics* subentries

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ETHICS COMMITTEES AND ETHICS CONSULTATION

• • •

The dominant mechanism for dealing with clinical ethics problems in healthcare at the beginning of the twenty-first century is the ethics committee. Present in various capacities since the 1960s, ethics committees in their contemporary form emerged in the late 1970s and 1980s in response to the growing need for a formal means to address ethical issues in clinical settings (Fost and Cranford). Early ethics committees were typically staffed by physicians and convened on an *ad hoc* basis. Indeed, in the period immediately following *In re Quinlan* (1976), ethics committees functioned largely as prognosis committees for difficult end-of-life cases in acute care settings. A 1983 study indicated that only about 1 percent of all U.S. hospitals had ethics committees, a figure that is consistent with this very limited function (Youngner, Jackson, Coulton, et al.). As awareness of the value-laden nature of clinical decision making grew, so did the role and number of ethics committees. Just four years later, a 1987 study suggested the presence of ethics committees in over 60 percent of U.S. hospitals (Fleetwood, Arnold, and Baron). In 1998–1999, the University of Pennsylvania Ethics Committee Research Group (ECRG) conducted the most comprehensive study of ethics committees to date and found that approximately 93 percent of U.S. hospitals have ethics committees (McGee, Caplan, Sanogle, et al.). Around the same time, an Agency for Healthcare Research and Quality (AHRQ) study of ethics consultation in U.S. hospitals, a standard function of ethics committees today, found ethics consultation services in all U.S. hospitals with 400 beds or more, all federal hospitals, and all hospitals that are members of the Council of Teaching Hospitals (Fox). Though there has been no systematic study of the presence of ethics committees outside of hospital settings, it should be noted that ethics committees are present in many other healthcare settings, such as long term care, hospice, and even home care.

Contemporary ethics committees are usually standing committees with multidisciplinary representation, including medicine, nursing, social work, law, pastoral care, healthcare administration, and various specialty areas (McGee, et al.). The primary functions of contemporary ethics committees are ethics education, policy formation and review, and ethics consultation, in decreasing order of time commitment (McGee, et al.).

Education

In re Quinlan gave impetus to the development of early ethics committees. Since, as mentioned above, these committees were largely staffed by physicians and primarily concerned with prognosis issues in end-of-life situations, the educational needs of ethics committee members were rather narrowly focused. Encouraged, among others, by a President's Commission (1983), professional societies such as the American Medical Association (1985), and accrediting bodies such as the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO, 1992), ethics committees evolved to become the primary mechanism through which clinical ethics issues are formally addressed. Educational efforts of a thriving ethics committee should include self education, education of health professionals and staff, and community outreach. Of these, self education is critical as it is an important precondition of both sound policy formation and review and ethics consultation. Consistent with this, the 1999 ECRG study indicated "self education" as the single activity to which ethics committees devoted the highest percentage of time (McGee, et al.).

Though physicians and nurses make up the largest majority of ethics committee membership, most ethics committees are multidisciplinary with members from social work, pastoral care, legal, and administration, among others (McGee, et al.). This broad spectrum of health professionals brings valuable experience and perspective in dealing with clinical ethical issues, which are inevitably complex and multilayered. The vast majority of ethics committee members, however, have no formal education or training in clinical ethics; thus self education is an important ethics committee activity (Fox; McGee, et al.). Indeed, in the 1999 ECRG study mentioned above, half of all ethics committee chairs reported "feeling inadequately prepared to address" the issues they face (McGee, et al.). This is not surprising, given that ethics committees face an array of complex clinical ethics issues, including informed consent and refusal of treatment, decision capacity or competence, confidentiality and privacy, minors and decision making, and a host of issues related to end of life decision making. To deal with these and other clinical ethics issues, ethics committees need to have a sustained self-education program.

Ethics committees have used a variety of means to meet this need. Ethics committees at academic medical centers, for example, often have members who are bioethics faculty at their respective centers or departments who are able to offer (or arrange for) ethics education for the committee. Some ethics committees that are part of large integrated systems may have access to system-supported centers or departments of clinical ethics that themselves offer ethics education for committee members. A notable example of this is the Veterans Health Administration (VHA), which has established a National Center for Ethics in Health Care, in part to assist in meeting the educational needs of ethics committee members throughout the VHA network (Glover and Nelson). Ethics committees without access to these types of resources might identify one or two members willing to do formal education and training in clinical ethics through the completion of a clinical bioethics degree, fellowship, or certificate program. Other ethics committees avail themselves of sustained continuing ethics education offered through regional ethics networks such as the University of Pittsburgh's Consortium Ethics Program (Pinkus), the Midwest Ethics Committee Network of the Medical College of Wisconsin (Kuczewski), or the West Virginia Network of Ethics Committees (Moss). These efforts foster partnerships to bring the bioethics resources often present in primarily academic settings to serve the broader healthcare community (Glover and Nelson).

Policy Formation and Review

A second important function of ethics committees is policy formation and review. The type and number of policies that are formulated or reviewed by the ethics committee will vary depending on the nature of the institution, and the authority and responsibility of the ethics committee. For example, a medical-staff-level ethics committee at a major academic medical center may have input on a large number of ethics-related policies. In addition to any policy governing the ethics committee itself, these might include policies governing informed consent, end-of-life decisions (e.g., advance directive and life-sustaining treatment policies), brain death, organ donation and transplant, disclosure of medical mistakes, and so forth. Indeed, the policy formation and review function of ethics committees has developed to the point where a number of "model policy" manuals are available as resources for ethics committees that may be struggling to establish themselves (Aspen Health and Administration Development Group). In addition to these more traditional ethics policy areas, ethics committees are increasingly being asked to give input on organizational ethics issues, especially when these issues may have an impact on patient care (Schyve, Emanuel, Winslade, et al.). The JCAHO ethics standards, for example, extend to organizational ethics issues (e.g., marketing, billing, financial incentives for clinicians, and so forth) and explicitly acknowledge the interdependence of patient rights and organizational ethics (see JCAHO, 2002).

Ethics Consultation

Ethics consultation, perhaps the best known and most discussed function of ethics committees, commands only about 20 percent of ethics committee effort, with the average number of consults ranging from twelve to twenty-three per year (McGee, et al.). Though variously defined, ethics consultation is "… a service provided by an individual or a group to help patients, families, surrogates, healthcare providers, or other involved parties address uncertainty or conflict regarding value-laden issues that emerge in healthcare" (American Society for Bioethics and Humanities, p. 3). Clinical ethics consultation focuses on ethical issues that arise in specific clinical cases and on policy consultation regarding patient care issues. As noted above, partly due to the rise of managed care in the United States, the 1990s brought a growing awareness of the important relationship between clinical and organizational ethics, thereby raising the visibility of organizational ethics consultation. The mid- to late-1990s also saw the first national level effort in the United States to set voluntary standards for ethics consultation when the American Society for Bioethics and Humanities (ASBH) released its report *Core Competencies for Health Care Ethics Consultation.* The report was the result of a two year effort by a national task force on standards for bioethics consultation which functioned as a consensus panel.

The prevalence of ethics consultation is hard to gauge. Ellen Fox's AHRQ supported study of ethics consultation in U.S. hospitals found that approximately 81percent of all U.S. hospitals have an ethics consultation service of some kind; ethics consultation services were found to be present in 100 percent of hospitals with 400 beds or more, federal hospitals, or hospitals that are members of the Council of Teaching (Fox). The same study estimated that each year in U.S. hospitals, approximately 35,000 individuals are involved in performing over 15,000 ethics consultations. The predominant model for ethics consultation is a small team approach (68%), as opposed to a full committee (23%) or an individual consultant (9%). Of those doing ethics consultation, 36 percent are physicians, 30 percent are nurses, 11 percent are social workers, 10 percent are chaplains, and 10 are administrators, while less than 1 percent are philosophers or theologians. Only 5 percent of those doing ethics consultation were reported to have completed a fellowship or degree program in bioethics or to have had any formal education or training for ethics consultation other than direct supervision (Fox).

From its inception in the late 1960s and early 1970s through the present, ethics consultation has raised a number of controversial questions (LaPuma and Schiedermayer; Singer, Pellegrino, and Siegler; Fletcher, Quist, and Jonsen). Some of these questions are directly attributable, no doubt, to the fact that ethics consultation emerged in part to address highly-charged and conflicted issues such as withholding or withdrawing life-sustaining treatment (see also *In re Quinlin*). Other questions, however, are endemic to the practice of ethics consultation. These include both practical and theoretical questions such as: What types of issues are involved in ethics consultation? Is ethics consultation best done by individuals, teams or committees? What is an appropriate approach to ethics consultation? What types of skills and knowledge are important for doing ethics consultation? Should those doing ethics consultation be required to be certified or accredited in some way? How might ethics consultation be evaluated?

In order to see the controversial and complex nature of these questions, it will be helpful to consider a case that is fairly representative of the types of cases that are brought to ethics consultation services, the Case of Mr. Jones:

> Mr. Jones, an 82 year old man, came to the ER with a gangrenous leg. He had fallen in his apartment and was unable to contact family or friends. Mr. Jones was discovered by his niece, his closest living relative, two days later. Mr. Jones, who was otherwise healthy, needed to have his leg amputated in order to save his life (without amputation he was likely to die from septicemia). Mr. Jones adamantly refused amputation and expressed a deep desire to die "in one piece." Mr. Jones' niece was devastated by his refusal of amputation and wanted the healthcare team to save her uncle's life. Mr. Jones' niece felt responsible for his condition since she was supposed to check-in on him everyday, but she had missed a day due to illness. Members of the healthcare team were split over whether Mr. Jones' refusal of treatment should be honored. The attending physician believed that the team had a moral obligation to go ahead with amputation since it was a "straightforward, relatively low risk, procedure that could save Mr. Jones' life." He argued that the procedure was

> "ordinary," not "extraordinary," and therefore obligatory. He emphatically stated "I became a doctor to save life, not to watch people die because they are afraid!" Other members of the healthcare team, especially several nurses, thought Mr. Jones' wishes should be respected. Some worried, however, that Mr. Jones might be depressed and was trying to kill himself by refusing amputation. An ethics consultation was called to resolve the conflict. (Aulisio, 1999, p. 211)

TYPES OF ISSUES. Clinical ethics consultation typically involves any of a range of clinical ethics issues, including informed consent, decision capacity, surrogate decision making, confidentiality and privacy, and a variety of issues surrounding end of life care (ASBH). The best current data suggests that a number of different types of cases are brought to ethics consultation and that these cases themselves may involve a variety of issues. For example, the ECRG study by McGee, et al. lists research trials, new technologies, patient autonomy and competency, cost containment, distribution of goods, improving communications, clinician competency, and end-of-life decision making as among the most common issues raised in ethics consultation. Among these, the largest percentage by far fall into three categories: patient autonomy and competence (38%±25%); improving communications (35%±26%); and end of life (7%±21%).

The case of Mr. Jones, however, illustrates well how a single case can (and often does) raise multiple issues, and the problem of categorizing cases. The case surely raises questions about patient autonomy and competence, as some members of the healthcare team fear that Mr. Jones may be depressed and "trying to kill himself" by refusing amputation. The case also raises questions about end-of-life decision making: Should Mr. Jones, even if competent and well informed, be allowed to refuse a life saving intervention? What is an appropriate role for family members or loved ones in end-of-life (or other) decisions? When are health professionals obliged to accede to patient wishes? Are health professionals ever permitted to override patient wishes or refuse to participate in certain patient decisions? Lastly, the case might just as easily be categorized as an "improving communications" case. Mr. Jones, for example, may simply not understand that he will die without the amputation due to septicemia, because he is confused by technical medical terminology or because he mistook probabilistic language as uncertainty on the part of his doctors.

In addition to the multiple issues that might be raised in a single case, the actual practice of ethics consultation differs from mere case analysis in important ways. As the 1998 ASBH report states, "The actual cases that give rise to these questions frequently also have complex interpersonal and affective features, such as guilt over a loved one's sickness or impending death, disagreement among healthcare providers, possible conflicts of interest, or distrust of the medical system. Increasingly, ethical issues regarding clinical care are raised or complicated by organizational factors" (ASBH, p. 3).

Even from a distance, one can discern these features in the case of Mr. Jones. His niece's feeling of guilt is a powerful factor in the case, as are divisions among members of the healthcare team. These factors are compounded by the time pressures of a real case, i.e., that a decision must be made and soon.

INDIVIDUALS, TEAMS, OR COMMITTEES. Though nearly always conducted under the auspices of an ethics committee, ethics consultation may be done by individual consultants, small groups or teams, or a full ethics committee. Which of these models is best is a matter of some controversy (Rushton, Youngner, and Skeel). Consultation by ethics committee was the dominant model following the *Quinlan* case and the rise of ethics committees in general. If ethics consultations are rare and called only in crisis situations, consultation by a full committee may be practical; however, the more active the consult service the more cumbersome full committee consults will be. Full committee consults also tend to be more formal and adversarial (Rushton, et al.). In contrast, consultation by an individual ethics consultant, though possibly present in a few U.S. healthcare institutions as early as the late 1960s or early 1970s, grew in popularity through the early 1990s at least in part as an alternative to full committee consults. Criticized by some as anti-democratic, the individual consultant model, though efficient, is impractical for many institutions because of the knowledge, skill and time demands it places on one person (Rushton, et al.). A small ethics consult team that functions as an extension of the ethics committee is probably the best model for most institutions. Not surprisingly, in U.S. hospitals today, as noted above, the predominant model for ethics consultation is a small team (Fox).

APPROACHES TO ETHICS CONSULTATION. A number of different approaches to ethics consultation can be found in the literature (Agich; ASBH; Rubin and Zoloth-Dorfman; Zaner). These range from those focused primarily on conflict resolution through facilitation or negotiation, to those that emphasize consensus building, to more directive approaches aimed at guiding participants to the morally "right" solution. One of the challenges for proponents of ethics consultation over the years has been to carve out a role for it that is consistent with societal values. In the United States, this means creating a model of ethics consultation that is consistent with the defining characteristic of a liberal society: that no particular set of substantive moral values should be politically privileged. For example, in the case of Mr. Jones, all involved parties have a right to their moral views and those moral views are widely divergent. Indeed, it is arguably the convergence of these features with the complex and value-laden nature of medical decision making that creates the need for ethics consultation in contemporary clinical settings (Aulisio, 2003).

In the case of Mr. Jones, the intersection of these factors leads to a value conflict that raises a question regarding the role of ethics consultation. Whether or not it is “right” to amputate Mr. Jones’s leg depends, in part, on the individual set of values through which the decision is assessed. Mr. Jones’s niece and the attending physician think that the morally right course is to amputate Mr. Jones’s leg, but for different reasons. Mr. Jones, because he values “dying whole,” considers the morally right course to be one that allows him to keep his bodily integrity, even if it ultimately leads to his death. According to the case vignette, “an ethics consultation was called to resolve the conflict,” but how should the conflict be resolved? The ethics consultants themselves will bring their own moral values to the case. Should they help resolve the case based on whether their moral values are more in line with those of the doctor, nurse, niece, or patient? Do they get to play the role of the moral sage, adjudicating on who is morally right—that is, who has the correct values? What is the role of ethics consultation in such a case?

The most strident critics of ethics consultation have made much of this problem, claiming that ethics consultation is at odds with democratic values (Ross; Scofield). Democratic values alone, however, would leave ethics consultation susceptible to a tyranny of the majority, in which the morally appropriate course might be determined, for example, by a vote. The deeper question is whether there is an appropriate role for ethics consultation that is consistent with the rights of individuals to live by their values (that is, consistent with a liberal society) (May). The 1998 ASBH report recognized the importance of societal context in informing a proper role for ethics consultation when it stated that:

> … societal values frame the context in which ethics consultation occurs and, therefore, shape the appropriate role for ethics consultation in contemporary healthcare settings. Individuals, for example, do not give up the right to live by their own moral values when they become patients or take up the practice of healthcare. These rights set boundaries that must be respected in ethics consultation, and they often suggest who has decision-making authority in different types of cases. Discussions of these boundaries, not surprisingly, comprise a large portion of the bioethics literature (e.g., explorations of informed consent, autonomy, confidentiality, privacy, resource allocation, and conscientious objection). Indeed, helping to identify the implications of these rights and who has decision-making authority in particular cases is an important role for healthcare ethics consultation in our society (p. 4).

Though a full characterization of any approach to ethics consultation is well beyond the scope of this entry, it should be noted that the ASBH report does go on to endorse what it terms an “ethics facilitation” approach to ethics consultation that is intended to be consistent with the societal context described above. “Ethics facilitation,” according to the report, aims at “identifying and analyzing the nature of the value uncertainty” that underlies the request for consultation and “facilitating the building of consensus” among involved parties (pp. 6–7). This approach is contrasted with what the report terms “pure facilitation” and “authoritarian” approaches to ethics consultation, which risk running afoul of appropriate boundaries for ethics consultation and displacing those with legitimate decision-making authority. The “ethics facilitation” approach aims at consensus building but in deference to the decision-making authority of involved parties. Indeed, when a consensus cannot be reached, the report recommends that

> … the proper course of action can sometimes be determined by answering the question “Who should be allowed to make the decision?” Societal values often indicate who should be allowed to make the decision in the absence of consensus. As several of the cases above underscore, the right of a competent and well informed patient to refuse treatment typically establishes decision-making authority even if some family members or healthcare providers disagree with the decision. Similarly, the right of conscientious objection typically gives a healthcare provider the authority to refuse to participate in a procedure that would seriously violate his or her conscience even if a patient and/or family wants the provider to participate (p. 8).

It is important to note that, at a general level, the ethics facilitation approach as characterized in the ASBH report is far more concerned with who has the right to decide than with who is right, and with building a consensus that respects legitimate decision-making authority. In the case of

Mr. Jones, this would require establishing whether he is competent and well informed. If so, his moral and political right to accept or refuse treatment is firm and, thus, any consensus will have to respect his decision-making authority (this does not preclude compromises or even a change of heart on his part). It is also important to highlight the general nature of the ethics facilitation approach and its potential compatibility with many different consult models and methodologies. Attempts to offer normative characterizations of ethics consultation, with their attendant methodological questions, will undoubtedly continue to receive attention in the coming years.

SKILLS AND KNOWLEDGE. Just as there is some disagreement about broad approaches to ethics consultation and more particular methodological issues regarding how ethics consultations should be done, there is also some disagreement about the skills and knowledge required to do ethics consultations. Some emphasize the importance of a strong clinical background such as medicine or nursing, while others emphasizes the importance of formal education and training in ethics, or, more commonly, bioethics (LaPuma and Schiedermayer; Baylis). Despite the disagreements in emphasis, there are some broad areas of agreement regarding core skills and knowledge for ethics consultation. The ASBH Task Force tried to capture these in its 1998 report, *Core Competencies for Ethics Consultation.*

The 1998 ASBH report articulated the broad skill areas as including interpersonal, process, and ethical assessment. Ethical assessment skills are those involved in identifying and analyzing the ethical issues that arise in specific clinical cases. This might include the ability to distinguish the ethical from other (e.g., legal, medical, psychiatric) dimensions of the case, identify relevant values, clarify key concepts, and justify a range of morally acceptable options given the contextual features of the case. Certain types of process skills, such as the ability to facilitate meetings and build consensus, are likewise central to helping to resolve ethical conflicts in actual cases. Finally, certain types of interpersonal skills are critical to nearly every aspect of ethics consultation. For example, the ability to listen well and to communicate interest, respect, support, and empathy to involved parties will be important throughout the consult process.

With respect to important knowledge areas for those doing ethics consultation, the 1998 ASBH report emphasized the importance of advanced knowledge in three areas as they relate to ethics consultation: moral reasoning and ethical theory; bioethical issues and concepts; and local healthcare institution's relevant policies. The report identified six additional areas in which those doing ethics consultation should have basic knowledge: clinical context, relevant health law; knowledge of local healthcare institution, beliefs and perspectives of patient and staff population, relevant codes of ethics and professional conduct, and guidelines of accrediting organizations.

It is important to underscore that the skill and knowledge can be distributed across a small team or even a full committee, depending on the model for ethics consultation employed. As noted above, over 90 percent of U.S. hospitals employ a team or committee approach, while less than 10 percent employ an individual consultant. The "core competency" recommendations are fair less onerous when considered against this backdrop. Individual ethics consultants, however, may need to supplement their professional backgrounds in order to satisfy these recommendations. This is discussed in the ASBH report and elsewhere (Baylis).

Conclusion

There are, of course, a plethora of other issues that must be addressed as ethics committees and ethics consultation continue to evolve and develop. These include questions concerning how their activities might be evaluated, legal liability for committees and consultants, and the ever-present question of whether committees or consultants should be certified or accredited in some form. Some of the data considered above, however, suggest a more immediate and pressing concern. Recall that contemporary ethics committees are usually standing committees with multidisciplinary representation, including medicine, nursing, social work, law, pastoral care, healthcare administration, and various specialty areas, and that half of all ethics committee chairs reported "feeling inadequately prepared to address" the issues they face (McGee, et al.). Even more concerning, recall that only 5 percent of those doing ethics consultation were reported to have completed a fellowship or degree program in bioethics, or to have had any formal education or training for ethics consultation other than direct supervision (Fox). Perhaps the single biggest challenge in the immediate future, then, will be helping to ensure that ethics committee members and ethics consultants have adequate education and training to carry out the important work that is entrusted to them.

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SEE ALSO: *Casuistry; Clinical Ethics; Consensus, Role and Authority of; Healthcare Institutions; Hospital, Modern*

History of the; Long-Term Care; Managed Care; Organizational Ethics in Healthcare; Surrogate Decision-Making

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EUGENICS

• • •

I. Historical Aspects
II. Ethical Issues

I. HISTORICAL ASPECTS

The word “eugenics” was coined in 1883 by the English scientist Francis Galton, a cousin of Charles Darwin and a pioneer in the mathematical treatment of biological inheritance. Galton took the word from a Greek root meaning “good in birth” or “noble in heredity.” He intended the term to denote the “science” of improving human stock by giving the “more suitable races or strains of blood a better chance of prevailing speedily over the less suitable” (Kevles, p. ix).

The idea of eugenics dated back at least to Plato, and discussion of actually achieving human biological melioration had been boosted by the Enlightenment. In Galton’s day, the science of genetics had not yet emerged: Gregor Mendel’s 1865 paper, the foundation of that discipline, was not only unappreciated but also generally unnoticed by the scientific community. Nevertheless, Darwin’s theory of evolution taught that species did change as a result of natural selection, and it was well known that through artificial selection farmers and flower fanciers could obtain permanent breeds of animals and plants strong in particular characters. Galton thus supposed that the human race could be similarly improved—that through eugenics, human beings could take charge of their own evolution.

The idea of human biological improvement was slow to gather public support, but after the turn of the twentieth century, eugenics movements emerged in many countries. Eugenicists everywhere shared Galton’s understanding that people might be improved in two complementary ways—to use Galton’s language, by getting rid of the “undesirables” and by multiplying the “desirables” (Kevles, p. 3). They spoke of “positive” and “negative” eugenics. Positive eugenics aimed to foster greater representation in a society of people whom eugenicists considered socially valuable. Negative eugenics sought to encourage the socially unworthy to breed less or, better yet, not at all.

How positive or negative ends were to be achieved depended heavily on which theory of human biology people brought to the eugenics movement. Many eugenicists, particularly in the United States, Britain, and Germany, believed that human beings were determined almost entirely by their germ plasm, which was passed from one generation to the next and overwhelmed environmental influences in shaping human development. Their belief was reinforced by the rediscovery, in 1900, of Mendel’s theory that the biological makeup of organisms was determined by certain “factors,” which were later identified with genes and were held to account for a wide array of human traits, both physical and behavioral, “good” as well as “bad.”

In the first third of the twentieth century, eugenics drew the support of a number of leading biologists, not only in the United States and western Europe but also in the Soviet Union, Latin America, and elsewhere. Many of these biologists came to the creed from the practice of evolutionary biology, which they extrapolated to the Galtonian idea of taking charge of human evolution. One of the most influential was Charles B. Davenport, the head of the Station for Experimental Evolution, a part of the Carnegie Institution of Washington and located at Cold Spring Harbor, New York, where Davenport established the Eugenics Record Office. Other eugenic enthusiasts included, in the United States, the biologists Raymond Pearl, Herbert S. Jennings, Edwin Grant Conklin, William E. Castle, Edward M. East, and Herman Muller; in Britain, F. A. E. Crew, Ronald A. Fisher, and J. B. S. Haldane; and in Germany, Fritz Lenz, who held the chair of racial hygiene in Munich, and Otmar von Verschuer.

Some eugenicists, notably in France, assumed that biological organisms, including human beings, were formed primarily by their environments, physical as well as cultural. Like the early-nineteenth-century biologist Jean Baptiste Lamarck, they contended that environmental influences might even reconfigure hereditary material. Environmentalists were mainly interested in positive eugenics, contending that more attention to factors such as nutrition, medical care, education, and clean play would, by improving the young, better the human race. Some urged that the improvement should begin when children were in the womb, through sound prenatal care. The pregnant mother should avoid toxic substances, such as alcohol. She might even expose herself, for the sake of her fetus, to cultural enrichment, such as fine plays and concerts.

Individuals with good genes were assumed to be easily recognizable from their intelligence and character. Those with bad genes had to be ferreted out. For the purpose of identifying such genes, in the early twentieth century eugenics gave rise to the fist programs of research in human heredity, which were pursued in both state-supported and private laboratories established to develop eugenically useful knowledge. The Eugenics Record Office at Cold Spring Harbor was typical of these institutions; so were the Galton Laboratory for National Eugenics at University College (London), whose first director was the statistician and population biologist Karl Pearson, and the Kaiser Wilhelm Institute for Anthropology, Human Heredity, and Eugenics in Berlin, which was directed by the anthropologist Eugen Fischer. Staff at or affiliated with these laboratories gathered information bearing on human heredity by examining medical records or conducting extended family studies. Often they relied on field workers to construct trait pedigrees in selected populations—say, the residents of a rural community—on the basis of interviews and the examination of genealogical records. An important feature of German eugenic science was the study of twins.

However, social prejudices as well as dreams pervaded eugenic research, just as they did all of eugenics. Eugenic studies claimed to reveal that criminality, prostitution, and mental deficiency (which was commonly termed "feeblemindedness") were the products of bad genes. They concluded that socially desirable traits were associated with the "races" of northern Europe, especially the Nordic "race," and that undesirable ones were identified with those of eastern and southern Europe.

Eugenics entailed as many meanings as did terms such as "social adequacy" and "character." Indeed, eugenics mirrored a broad range of social attitudes, many of them centered on the role in society of women, since they were indispensable to the bearing of children. On the one hand, positive eugenicists of all stripes argued against the use of birth control or entrance into the work force of middle-class women, on grounds that any decline in their devotion to reproductive duties would lead to "race suicide." On the other hand, social radicals appealed to eugenics to justify the sexual emancipation of women. They contended that if contraception were freely available, women could pursue sexual pleasure with whomever they wished, without regard to whether a male partner was eugenically promising as a father. If and when a woman decided to become pregnant, then her choice of the father could focus on the production of a high-quality child. Sex for pleasure would thus be divorced from sex for eugenic reproduction.

In practice, little was done for positive eugenics, though eugenic claims did figure in the advent of family-allowance policies in Britain and Germany during the 1930s, and positive eugenic themes were certainly implied in the "Fitter Family" competitions that were a standard feature of eugenic programs held at state fairs in America during the 1920s. In the interest of negative eugenics, germ-plasm determinists insisted that "socially inadequate" people should be discouraged or prevented from reproducing themselves by urging or compelling them to undergo sterilization. They also argued for laws restricting marriage and immigration to their countries, in order to keep out genetically undesirable people.

In the United States, eugenicists helped obtain passage of the Immigration Act of 1924, which sharply reduced eastern and southern European immigration to the United States. By the late 1920s, some two dozen American states had enacted eugenic sterilization laws. The laws were declared constitutional in the 1927 U.S. Supreme Court decision of *Buck v. Bell,* in which Justice Oliver Wendell Holmes delivered the opinion that three generations of imbeciles are enough. The leading state in this endeavor was California, which as of 1933 had subjected more people to eugenic sterilization than had all other states of the union combined (Kevles).

At the time, a number of biologists, sociologists, anthropologists, and others increasingly criticized eugenic doctrines, contending that social deviancy is primarily the product of a disadvantageous social environment—notably, for example, of poverty and illiteracy—rather than of genes, and that apparent racial differences were not biological but cultural, the product of ethnicity rather than of germ plasm. In 1930, in the papal encyclical *Casti connubii,* the Roman Catholic church officially opposed eugenics, along with birth control. By the 1930s, a coalition of critics had helped bring a halt in most countries to the attempts of eugenicists to gain significant social and political influence. An exception to this tendency was Germany, where eugenics reached its apogee of power during the Nazi regime. Hundreds of thousands of people were sterilized for negative eugenic reasons and scientific authority joined with social hatred to send millions of the "racially unfit" to the gas chambers. Verschuer trained doctors for the SS in the intricacies of racial hygiene, and he analyzed data and specimens obtained in the concentration camps. In the years after World War II, eugenics became a dirty word.

In the 1930s, attempts to sanitize eugenics had been made by various British and American biologists. They wanted to maintain Galton's idea of human biological improvement while rejecting the social prejudice that had pervaded the conception. They realized that sound eugenics would have to rest on a solid science of human genetics, one that scrupulously rejected social bias and weighed the respective roles of biology and environment, of nature and nurture, in the making of the human animal. They succeeded in laying the foundation for such a science of human genetics, and that field made great strides in the following decades.

The advances in human genetics boosted the new field of genetic counseling, which provided prospective parents with advice about what their risk might be of bearing a child with a genetic disorder. In the 1950s, the early years of such counseling, some geneticists had sought to turn the practice to eugenic advantage—to reduce the incidence of genetic disease in the population, and by extension to reduce the frequency of deleterious genes in what population geneticists were coming to call the human gene pool. To that end, some claimed that it was the counselor's duty not simply to inform a couple about the possible genetic outcome of their union but also to instruct them whether to bear children at all. By the end of the 1950s, however, the informal standards of practice in genetic counseling were strongly against eugenically oriented advice—that is, advice aimed at the welfare of the gene pool rather than of the family. The standards had it that no counselor had the right to tell a couple not to have a child, even for the sake of the couple's welfare.

At first, genetic counseling could draw only on family histories and could tell parents nothing more than the odds that they might conceive a child with a recessive or dominant disease or abnormality. Since the 1960s, as the result of amniocentesis and advances in human biochemical and chromosomal genetics, genetic counseling has become coupled to technical analyses that can identify whether a prospective parent actually carries a deleterious gene and can determine prenatally whether a fetus truly suffers from a selection of genetic and chromosomal diseases or disorders. If the fetus is found to be at such a disadvantage, the parents have the option to abort—at least in countries where abortion is legal, which in 1993 included the United States, Great Britain, and France.

Reproductive selection on a genetic basis—by screening of parents, abortion of fetuses, or both—has found support among liberal religious groups, secular ethicists, and many feminists. They regard it as enlarging women's freedom to control their lives and as contributing to family well-being. However, reproductive selection has been contested by the Roman Catholic church and fundamentalist Protestants, mainly because of their opposition to abortion for any reason. Some feminists have interpreted such selection as yet another among several recent innovations in reproductive technology—for example, in vitro fertilization—that threaten to reduce women to mere reproductive machines in a patriarchal social order. Others have pointed to the heavy emotional and familial burdens placed upon women by prenatal diagnosis that reveals a fetus with a genetic disease or disorder. Genetic selection also has raised apprehensions among some members of minority groups and among disabled persons that it will lead to a revival of negative eugenics that may affect them disproportionately. Handicapped people and their advocates have attacked the attitude that a newly conceived child with a genetic affliction merits abortion, calling it a stigmatization of the living who have the ailment and the expression of a eugenics mentality (Stanworth; Rothman, 1986, 1989; Duster; Cowan).

The Human Genome Project

These fears have been exacerbated by the Human Genome Project, the multinational effort, begun in the late 1980s, to obtain the sequence of all the DNA in the human genome. Once the complete sequence is obtained, it will in principle be easy to identify individuals with deleterious genes of a physical (or presumptively antisocial) type, and the state may intervene in reproductive behavior so as to discourage the transmission of these genes in the population. Such a policy could work special injury upon certain minority groups—for example, people of African origin, since the recessive gene for sickle-cell anemia occurs among them with comparatively high frequency. It could also threaten the disabled, since the only "therapy" currently available for most genetic or chromosomal diseases or disorders is abortion, and since identifying such fetuses as candidates for the procedure stigmatizes people who have been born with the handicap. In 1988, China's Gansu Province adopted a eugenic law that would—so the authorities said—improve population quality by banning the marriages of mentally retarded people unless they first submit to sterilization. Such laws have been adopted in other provinces and in 1991 were endorsed by Prime Minister Li Peng.

Negative eugenic intentions appeared to lie behind a July 1988 proposal from the European Commission for the creation of a human genome project in the European Community. Called a health measure, the proposal was entitled "Predictive Medicine: Human Genome Analysis." Its rationale rested on a simple syllogism—that many diseases result from interactions of genes and environment; that it would be impossible to remove all the environmental culprits from society; and that, hence, individuals could be better defended against disease by identifying their genetic predispositions to fall ill. According to the summary of the proposal: "Predictive Medicine seeks to protect individuals from the kinds of illnesses to which they are genetically most vulnerable and, where appropriate, to prevent the transmission of the genetic susceptibilities to the next generation." In the view of the European Commission, the genome proposal would make Europe more competitive—indirectly, by helping to slow the rate of increase in health expenditures; directly, by strengthening its scientific and technological base (Commission of the European Community).

Economics may well prove to be a powerful incentive to a new negative eugenics. In the United States, the more that healthcare becomes a public responsibility, paid for through the tax system, and the more expensive this care becomes, the greater the possibility that taxpayers will rebel against paying for the care of those whose genetic makeup dooms them to severe disease or disability. Even in countries with national health systems, public officials might feel pressure to encourage, or even to compel, people not to bring genetically affected children into the world—not for the sake of the gene pool but in the interest of keeping public health costs down.

However, a number of factors are likely to offset a broad-based revival of negative eugenics. Eugenics profits from authoritarianism—indeed, almost requires it. The institutions of political democracy may not have been robust enough to resist altogether the violations of civil liberties characteristic of the early eugenics movement, but they did contest them effectively in many places. The British government refused to pass eugenic sterilization laws. So did many American states; and where they were enacted, they were often unenforced. Awareness of the barbarities and cruelties of state-sponsored eugenics in the past has tended to set most geneticists and the public at large against such programs. Moreover, persons with handicaps or diseases are politically empowered, as are minority groups, to a degree that they were not in the early twentieth century. They may not be sufficiently empowered to counter all quasi-eugenic threats to themselves, but they are politically positioned, with allies in the media, the medical profession, and elsewhere, including the Roman Catholic church, to block or at least to hinder eugenic proposals that might affect them.

The European Commission's proposal for a human genome project provoked the emergence of an antieugenic coalition in the European Parliament that was led by Benedikt Härlin, a member of the West German Green Party. The Greens had helped impose severe restrictions on biotechnology in West Germany and raised objections to human genome research on grounds that it might lead to a recrudescence of Nazi biological policies. Guided by Härlin, the European Parliament's Committee on Energy, Research and Technology raised a red flag against the genome project as an enterprise in preventive medicine. It reminded the European Community that in the past, eugenic ideas had led to "horrific consequences" and declared that "clear pointers to eugenic tendencies and goals" inhered in the intention of protecting people from contracting and transmitting genetic diseases or conditions. The application of human genetic information for such purposes would almost always involve decisions—fundamentally eugenic ones— about what are "normal and abnormal, acceptable and unacceptable, viable and non-viable forms of the genetic make-up of individual human beings before and after birth." The Härlin Report also warned that the new biological and reproductive technologies could make for a "modern test tube eugenics," a eugenics all the more insidious because it could disguise more easily than its cruder ancestors "an even more radical and totalitarian form of 'biopolitics'" (European Parliament, Committee on Energy, Research, and Technology, pp. 23–28).

The Härlin Report urged thirty-eight amendments to the European Commission's proposal, including the complete excision of the phrase "predictive medicine" from the text. As a result of the report, which won support not only from German Greens but also from conservatives on both sides of the English Channel, including German Catholics, the European Commission produced a modified proposal that accepted the thrust of the amendments and even the language of a number of them. The new proposal called for a three-year program of human genome analysis as such, without regard to predictive medicine, and committed the European Community in a variety of ways—most notably, by prohibiting human germ line research and genetic intervention with human embryos—to avoid eugenic practices, prevent ethical missteps, and protect individual rights and privacy. It also promised to keep the European Parliament and the public fully informed via annual reports on the moral and legal basis of human genome research. Formally adopted in June 1990, the European Community's human genome program will cost 15 million ECU (about $17 million) over three years, with some one million ECU devoted to ethical studies (Kevles and Hood).

In the United States, apprehensions of the ethical dangers in the Human Genome Project found expression in the Congress across the political spectrum—from liberals who had long been concerned about governmental intrusion into private genetic matters to conservatives who worried that the Human Genome Project might foster increased practice of prenatal diagnosis and abortion. Among the Americans most sensitive to the eugenic hazards and the ethical challenges inherent in the project were a number of its leading scientific enthusiasts, particularly James D. Watson, the first head of the National Center for Human Genome Research, who considered it both appropriate and imperative that the American genome program stimulate study and debate about its social, ethical, and legal implications. In 1988, Watson announced that such activities would be eligible for roughly 3 percent of the National Center's budget. He told a 1989 scientific conference on the genome: "We have to be aware of the really terrible past of eugenics, where incomplete knowledge was used in a very cavalier and rather awful way, both here in the United States and in Germany. We have to reassure people that their own DNA is private and that no one else can get at it" (Kevles and Hood, pp. 34–35).

Human Genetics in a Market Economy

Despite the specter of eugenics that some see in the Human Genome Project, many observers hold that its near-term ethical challenges lie neither in private forays into human genetic improvement nor in some state-mandated program of eugenics. They lie in the grit of what the project will produce in abundance: genetic information. These challenges center on the control, diffusion, and use of that information within the context of a market economy.

The advance of human genetics and biotechnology has created the capacity for a kind of individual eugenics—families deciding what kinds of children they wish to have. At the moment, the kinds they can choose are those without certain disabilities or diseases, such as Down syndrome or Tay-Sachs disease. Although most parents would now probably prefer just a healthy baby, in the future they might be tempted by the opportunity—for example, via genetic analysis of embryos—to have improved babies, children who are likely to be more intelligent or more athletic or better-looking (whatever such terms might mean). People may well pursue such possibilities, given the interest that some parents have shown in choosing the sex of their child or that others have shown in the administration of growth hormone to offspring they think will grow up too short. In sum, a kind of private eugenics could arise from consumer demand.

Many commentators have noted that the torrent of new human genetic information will undoubtedly pose challenges to social fairness and equity. They have emphasized that employers may seek to deny jobs to applicants with a susceptibility—or an alleged susceptibility—to disorders such as manic depression or illnesses arising from features of the workplace. For example, around 1970, it came to be feared that people with sickle-cell trait—that is, who possess one of the recessive genes for the disease—might suffer the sickling of their red-blood cells in the reduced-oxygen environment of high altitudes. Such people were unjustly prohibited from entering the Air Force Academy, were restricted to ground jobs by several major commercial air carriers, and often were charged higher premiums by insurance companies. Life and medical insurance companies may well wish to know the genomic signatures of their clients, their profile of risk for disease and death. Even national health systems might choose to ration the provision of care on the basis of genetic propensity for disease, especially to families at risk for bearing diseased children (U.S. Congress, Office of Technology Assessment; Kevles).

In response to these threatening prospects, many analysts have contended that individual genomic information should be protected as strictly private. However, legal and insurance analysts have pointed out that insurance, and insurance premiums, depend on assessments of risk. If a client has a high genetic medical risk that is not reflected in the premium charged, then that person receives a high payout at low cost to himself or herself but at high cost to the company. The problem would be compounded if the person knows the risk—while the company does not—and purchases a large amount of insurance. In either case, the company would have to pass its increased costs to other policyholders, which is to say that high-risk policyholders would be taxing low-risk ones. Thus, insisting on a right to privacy in genetic information could well lead—at least under the largely private system of insurance that now prevails in the United States—to inequitable consequences.

American legislatures have already begun to focus on the genuine social, ethical, and policy issues that the Human Genome Project raises, particularly those concerning the use of private human genetic information. In the fall of 1991, a U.S. House of Representatives subcommittee held hearings on the challenge that such information posed to insurability. About the same time, the California state legislature passed a bill banning employers, health service agencies and disability insurers from withholding jobs or protection simply because a person is a carrier of a single gene associated with disability. Although California Governor Pete Wilson vetoed the bill, it was a harbinger of the type of public policy initiatives that the genome project no doubt will increasingly call forth. The Human Genome Project, like most of human and medical genetics, is less likely to foster a drive for a new eugenics than it is to pose vexing challenges to public policy and private practices for the control and use of human genetic information.

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SEE ALSO: *Eugenics and Religious Law; Genetics and Human Behavior; Genetics and Human Self-Understanding; Genetics and Racial Minorities; Holocaust; Human Nature; Judaism, Bioethics in; Minorities as Research Subjects; Race and Racism;* and other *Eugenics* subentries

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II. ETHICAL ISSUES

To what extent are there continuities, parallels, and trajectories between past eugenic ideas and practices, and current and pending developments with genetic testing and screening, prospective gene therapies, and the increasing utilization of sperm banks and egg donations? To begin to answer these questions, it is imperative to distinguish between state-sanctioned eugenic programs on the one hand, and private, individualized, *personal* decisions that are socially patterned, on the other. In the former case eugenic goals are usually explicitly articulated, and thus easy to identify, examine, and oppose or support. In the latter the eugenic implications are often unarticulated and subterranean—only exposed by a review of statistical patterns of what are otherwise perceived as individual choices. In matters of public policy and market choices, emphasis upon individual intent can camouflage the collective eugenic force of personal decision-making.

One heuristically useful attempt to distinguish between different kinds of contemporary eugenic forms can be found in Philip Kitcher's *The Lives to Come* (1996). Kitcher makes a distinction between *laissez-faire eugenics,* a hands-off approach that presumes that everyone will make their own *individual choices*—and a *utopian eugenics,* where as a matter of public policy there is an attempt to make available to all sectors of a society the information and technology to make those choices. While no public policy can ever deliver such information and technology evenly across all sectors, this provides an analytic device for assessing the degree of success of such an attempted distribution. The major difficulty surfaces with an empirical problem generated by the molecular genetic revolution itself, the fracture of the public health consensus of what constitutes *the public good.* Allen Buchanan and his associates, in *From Chance to Choice* (2000), argue that an assessment of the consequences for the general public good are vital to a discussion of the treatment/enhancement distinction. Before 1960 it was possible to achieve consensus that the public good was well-served by an elimination or mitigation of such diseases as smallpox, cholera, tuberculosis, yellow fever, typhoid, and sexually transmitted diseases. However, with the discovery that genetic disorders are located in risk populations that do not place the general population at risk, a new set of issues and new kinds of eugenic concerns have been generated regarding who has control over genetic screening and testing.

While it is true that individuals make choices, they do so in a social and economic context that can be demonstrably coercive. While relatively obvious when looking at other societies, it is less understood when examining one's own—substantially obscured because individual choice is deeply embedded in the taken-for-granted assumptions about decision-making. For example, long before the advent of prenatal detection technologies, preference for a male child in India and China was so great that a notable fraction of the population practiced infanticide of newborn females. While sex selection does not qualify as a eugenic strategy (unless the purpose is to prevent a gender-linked disorder), the practice in India and China does illustrate how and why a focus on individual choice can obscure the dramatically collective aspect of socially patterned individual choices.

Once technologies for prenatal determination of sex became available, the quest for *disclosure* of the sex of the fetus took a momentous turn for public policy in India. In 1971 India passed the Medical Termination of Pregnancy Act, which stipulates that a woman can be given an abortion only if there is a life-threatening situation, or grave injury to her physical or mental health. Amniocentesis use began in India in 1974, but there were early reports that the test was being used less to detect birth defects than to determine the sex of the fetus. In August 1994 the Indian Parliament passed a new law that stiffened the penalties for screening the fetus to determine the sex. However, there was a large loophole in the law that made it practically unenforceable—and the practice has continued at such a high rate that in 1994 *New York Times* reported that Haryana, a populous northern state, had an astonishingly low sex ratio of 874 females to every 1,000 males.

Individual Decision and Unexamined Group Patterns

It should be clear from the above examples of sex selection preferences in India that what appear to be individual familial choices may often be better understood as empirical social patterns reflective of the social and cultural hegemony. For example, in early 1994, *Nature* published "China's Misconception of Eugenics," an article that portrayed the Chinese government's policy of trying to prohibit couples with certain diseases from procreating as having a distinctively distasteful eugenic quality. While the article was forthright in denouncing the use of state power as the vehicle for discouraging procreation, it implied that a personalistic and individualistic decision to interrupt a pregnancy. Health Minister for China, Chen Minzhang, announced the plan to enforce a new law that would not only prohibit screening of the fetus for sex determination, but also ban marriages for people "diagnosed with diseases that may totally or partially deprive the victim of the ability to live independently, that are highly possible to recur in generations to come and that are medically considered inappropriate for reproduction"—as reported in the *New York Times* on November 14, 1993 in an article titled "China to Ban Sex-Screening of Fetuses."

The logical and empirical extension of the technology can be made explicit: Once it is possible to determine in time for the termination of a pregnancy whether the fetus has a condition that is regarded as a defect, who is entitled to make the decision about carrying to full term, or aborting? As noted, this should not be seen as a simple binary matter of voluntarism versus state power. There is considerable evidence to support the observation that what are characterized as personal or individual decisions in Western societies are upon closer inspection (just as with sex selection in India) actually very remarkably socially patterned.

In an influential treatise on reproductive choice titled *Children of Choice,* John Robertson acknowledged that social and economic constraints such as access to employment, housing and child care might play a role in the decision to have a child. However, the overarching theme, to which he returns again and again, is that reproduction "is first and foremost an individual interest" (p. 22). Because this is not reducible to an either/or formulation, it should be clearer why a continuum is a better analytic device for arraying an understanding of strategies and options—from individual choice to embedded but powerful social pressures (stigma and ridicule)—and from economic pressures (fear of loss of health insurance, or even of inability to obtain such insurance), and only then to the coercive power of the state to penalize.

When framed as individual choice, debate about a reproductive choice is set into the arena of individual rights: to have a child or not, then to have a male or female child, to have a child with Down Syndrome, cleft palate, or to choose to produce a clone. Such discussions of individual rights are typically de-contextualized from systemic concerns such as affordability. But amniocentesis is a relatively expensive procedure for the poor. The state often provides assistance to women seeking amniocentesis. In the 1980s California's Department of Maternal and Child Health noted with alarm that primarily wealthier women were getting state support for amniocentesis. Mindful of the state's eugenic history, officials embarked upon a program to try to get poorer women to accept the service. However, because the poor tend to have their children at an early age, this has become moot as a visible issue in the eugenics debate.

Continuity and Persistence of Eugenic Thought and Goals

During a time of rapid social change in which there are disruptions of the established order and the attendant challenges to authority and tradition, there is a special appeal of genetic explanations and eugenic solutions to the most privileged strata of society. The power of the state to control its population can be awesome, and thus when the state puts forward eugenic programs in a post-holocaust world, critics are well prepared to react with revulsion. The government of Singapore came under fire during the 1990s for its program to reward middle-class and wealthy families for having more children, while actively discouraging the poor from having large families. Far less attention has been given to the fact that 30,000 babies have been produced by sperm banks and egg donations in the United Kingdom alone, from people who are literally choosing what they consider to be *better human stock* (Maranto; Hill).

The industrial revolution and rapid urbanization wreaked havoc with traditional life and traditional social roles in both nineteenth-century Europe and the United States. Extended kinship systems that had been valued as an economic advantage on farmlands were often inverted and became economic liabilities when those families were forced off the land and moved to the teeming cities. Unemployment, homelessness, mental illness and a host of other social problems seemed to especially victimize the poor, whose visibility if not sheer numbers dominated the public sphere of urban life.

Cholera, yellow fever, typhoid, and tuberculosis were the scourge of city dwellers, and once again, the poor were the most likely victims. But as Sylvia Tesh noted in *Hidden Arguments* (1988), the poor were also the most likely to be blamed for causing the problems, typically characterized as living in unclean conditions. Hygiene came first as both an explanation for the better fortunes of the privileged and middle classes, and later—as a challenge to the poor.

As the wealthier families began to have fewer children, and to have the resources to hire the poor as servants to help them *clean up*—some observers began to notice what they thought was a disturbing pattern. The more well-to-do members of society were procreating less, while the poor were still having very large families. The dark Malthusian prediction about a population explosion took a particularly elitist turn. If people are to learn anything from the past, it is imperative to have a more complete understanding of the appeal and popularity of eugenics and why it was compelling to the full range of thinkers of all political persuasions at the beginning of the twentieth century. Very much like its sister concept *hygiene*—there was a strong association between cleanliness and order, progress and eugenics.

Just as hygiene was seen as the normal value of cleanliness to which all should aspire, eugenics was widely accepted and actively promoted by the major public figures of the period. University presidents, medical doctors, judges, academic scholars, writers, intellectuals, political figures on both the left and right of the political spectrum—all espoused the idea that the betterment of humankind would result from the practices and techniques that would prevent the procreation of *imbeciles* and *mental retards* and *criminals* and *prostitutes* and *homosexuals* and *alcoholics* and *gamblers.*

Contemporary Echoes of a Eugenic Past: The Genetic Screen

Genetic screening is one of the outgrowths of health screening for a number of public health problems, most notably tuberculosis. But unlike tuberculosis, genetic disorders tend to cluster in populations in which there have been centuries of in-breeding, because of cultural endogamy rules (who can marry whom), and/or because of long-term geographical residence of a population in which there has not been much physical mobility. In both circumstances, genes that cause diseases cluster in these populations, making those who are part of those populations at greater risk. Examples include cystic fibrosis, a disease affecting the lung's ability to accumulate liquids, primarily affecting persons of North-European descent; beta-thalassemia, a blood disease affecting persons living in the Mediterranean area; and sickle-cell anemia, a blood disorder primarily affecting persons with ancestors from West Africa, and in some areas of the Mediterranean.

In the last two decades of the twentieth century, many states began to offer postnatal genetic screening of all newborns. If the screen detects a high level of a particular chemical (alpha-feta protein) on the first go-round, the woman is offered a second test to determine if the fetus is likely to have anencephaly, which can produce a serious neural tube defect. In the most literal sense, to *screen* something means to prevent that something from getting past the screen. Thus, whether explicitly or implicitly, the institutionalization of genetic screening programs contains a strong residue of the old image of *cleaning* or *purifying* the gene pool. The social aspect of the eugenic implication is disguised by its being offered to individual women, or individual families. Thus the specter of state-sponsored screening of a particular group is diffused and obscured. However, as noted above, since genetic diseases tend to cluster in certain ethnic and racial groupings, individual decision-making (imposed or presumed) cannot mitigate the fact of systematically different outcomes for different groups.

Getting rid of *bad babies* with *genetic defects* is only half of the eugenic equation. There is also the idea of a positive eugenics, in which there is the active recruitment of some to procreate and selectively breed to increase some human trait or characteristic that is considered positive. Singapore actively encourages and rewards its wealthy and middle-class citizens to have more children. That is the group-approach to positive eugenics. On the individual level, contemporary residues of eugenic thinking can be seen in the emergence and increasing use of sperm banks with sperm donated by medical students, athletes, and Nobel laureates; the much higher cost of ova from young women from exclusive private colleges; and the exorbitant pricing of the ova from supermodels, which are offered on a website. Given a choice, there is evidence that some people will try to add a bit of height to their offspring with a growth hormone. Each of these developments indicates a lingering of a eugenic past.

Population/Group Taxonomy and the Relevance to Debates on Germ Line Intervention

The current discussions and debates about whether we should engage or support research that might alter the germ line rarely address the systematically eugenic potential that is a possible outcome. Germline is the term used to describe genetic changes that would influence inheritance across the generations, and is distinguished from genetic interventions that alter only the particular person undergoing gene therapy. Because bioethicists do not tend to formulate ethical concerns along dimensions of group stratification or access to political power on the part of *groups of individuals,* the discussion about the ethics of germ line intervention for group differentiation and social stratification is rare. An increased understanding of human genetics will enable the sorting of groups at higher and lower risk for certain diseases even more systematically than what was noted above.

If technology permitted entry into the germ line to eliminate either cystic fibrosis or sickle-cell anemia in an individual, that individual (or parent or guardian acting in behalf of that individual) might well make the individual choice. But a different order of ethical concern surfaces if one thinks about this more at the social and political level and less at the individual level. Zuni Indians are more likely to have cystic fibrosis than are persons of European ancestry, albeit a different mutation for cystic fibrosis than *Caucasians.* Yet the genetic test for cystic fibrosis is aimed at the Delta F508, the mutation most likely to be found in those of North-European ancestry. Quite simply, this is because genetic disease research is most likely to be aimed at those diseases that have the most politically powerful constituencies and/or for which there is a strong profit motive in the biotechnology industry. With more research dollars going into the Delta F508, than into the mutation which appears more frequently among the Zuni, individual Caucasians may come to believe that they are making an individual decision about altering the familial germ line. Stepping back to another level of analysis, social, political, and economic engines are driving molecular biology down certain research corridors of a particular group's genetic disorder and not others, and these have little to do with individual choice at the user end.

Parallel Massive Social Displacements: Late-Ninteenth and Late-Twentieth Centuries

Just as the twin shifts from agrarian to industrial and rural to urban dominated the shifting social demography of the late-nineteenth century in Europe and the United States, so the shift from industrial to service (or tertiary) and from urban to suburban dominated shifting social demography of the late-twentieth century. The United States has been in the vanguard of this development, and the massive economic displacement of African-American urban youth is the context for a renewed conception of biological thinking about social issues. At the beginning of the twenty-first century, the United States is heading down a subtly parallel road entertaining the connection between genes and social outcomes. This is being played out on a stage with converging preoccupations and tangled webs that interlace youth unemployment, crime and violence, race, and genetic explanations.

There is direct link between de-industrialization, youth unemployment, and ethnic or racial or immigrant minority status in the United States. In 1954 black and white youth unemployment rates in the United States were equal, with blacks actually having a slightly higher rate of employment in the age group from 16 to 19. By 1982 the black unemployment rate had nearly quadrupled in this age group, while the white rate had increased only marginally (Kasarda). Just as unemployment rates among African-American youth were skyrocketing during these three decades, so were their incarceration rates. This provides the context in which to review and interpret the clear pattern of the recent historical evolution of general prison incarceration rates by race. In the last half of the twentieth century, the incarceration rate of African Americans in relation to whites has gone up in a striking manner. In 1933 blacks were incarcerated at a rate approximately three times that of whites. By 1970 it was six times; and in 1995 it was seven times that of whites.

Genetic studies of criminality have a heavy dependency on incarcerated populations. Thus, for example, one of the more controversial issues in the *genetics* of crime is whether males with the extra Y chromosome, or XYY males, are more likely to be found in prisons than are XY males. The first major study suggesting a genetic link came from Edinburgh, Scotland. In 1965 Patricia Jacobs and her colleagues reported that while all of the 197 males in this account of prison hospital inmates were described as *dangerously violent,* seven had the XYY karotype. These seven males constituted about 3.5 per cent of the total. But since it was estimated that only about 1.3 per cent of all males has the XYY chromosomal make-up, the authors posited that the extra Y significantly increased one's chances of being incarcerated. Ever since a controversy has raged as to the meaning of these findings and the methodology that produced them. The claim for a genetic link to crime is based entirely upon studies of incarcerated populations.

Yet, incarceration rates are a function of a full range of criminal justice decisions, a fact which research has long shown to be a function of social, economic and political factors (Cole; Mauer; Miller; Currie). At the beginning of the twenty-first century, forensic sciences are attempting to use DNA markers to identify *ethnic affiliation estimations* of suspects in criminal investigations (Lowe et al.; Shriver et al.). Just as health and hygiene were the vanguard for the late-nineteenth century screen for the *unfit,* so the genetic screen was first a health screen. However, the shift in use and focus to forensic science has already begun. The national DNA database, CODIS (acronym for COmbined DNA Identification System) contained, as of January 2000, genetic profiles of 210,000 convicts. It is coordinated by the Federal Bureau of Investigation (FBI), and all fifty states contribute to the databank.

The states are the primary venues for the prosecution of violations of the criminal law, and their autonomy has generated considerable variation in the use of DNA databanks and storage. Even as late as the mid-1980s, most states were only collecting DNA samples from sexual offenders. The times have changed quite rapidly.There has been active change in the inter-linking of state databases, and states are uploading an average of 3,000 offender profiles every month. Computer technology is increasingly efficient and extraordinarily fast, and it requires only 500 microseconds to search a database of 100,000 profiles.

As the United States increases the numbers of profiles in the national database, there will be researchers proposing to provide genetic profiles of specific offender populations. Twenty states authorize the use of databanks for research on forensic techniques. Based on the statutory language in several of those states, this could easily mean assaying genes or loci that contain predictive information (Kimmelman). The program of research for CODIS is increasing exponentially on an annual basis, and this data base is sitting there waiting to be tapped by researchers looking for *violence genes*—as evidenced by the spate of national interest over the monoamine oxidase A (MAOA) gene. In the latter part of 2002, Caspi and his associates published an article in *Science* that cemented the relationship between behavioral and molecular genetics. The authors claimed to have produced findings that a functional polymorphism in the MAOA gene affects the impact of early childhood maltreatment on the development of antisocial and violent behavior. The policy implications of the research were strongly suggested in the conclusions, and re-ignite an old debate about the prospects and dangers of early identification of children who are thought to be at risk for violent or antisocial behavior. As in the earlier forms of eugenics, early identification always carries with it the appendage of both treatment and prevention.

Conclusion

Eugenic thought, practice, and advocacy are best understood as existing along a continuum with degrees of activity. It is therefore misleading and obscuring the complexity of the range of reproductive options to suggest that either a society does or does not have eugenic practices. Most significantly the social setting in which eugenics flourishes or declines is as important as the knowledge base in genetics and biology. The oft cited post-World War II defeat of eugenic thought is actually therefore better framed as its mitigation, its submersion, muting, or transmogrification. These changes came about more because of the defeat of the Nazis, and less because of advances in scientific knowledge of the genetics of race. As early as the 1930s, German and U.S. scientists had conclusive evidence that the ABO blood system did not track along racial or ethnic lines, but this knowledge did not inhibit some of the most vicious racist eugenic practices ever promulgated and perpetrated.

The social and economic setting in the technologically developed part of the world since the mid-1980s is propitious for a strong resurgence of eugenic thinking and advocacy, similar in degree to the social transformations of early-twentieth century Europe and the United States. The decline of the welfare state, the increasing gap between rich and poor, and the erosion of safety nets for the poorest members of a society have set the stage. This is accompanied by transnational migrations of laborers in the increasingly global labor markets of major post-industrial nations. The entry and consignment of these workers to the bottom quartile of the economic order, with the highest rates of poverty, disease, and recorded crime and violence will fuel the re-insurgence of attempts to explain their behavior. The new forms of eugenic insurgency will be disguised, muted, and made more palpable as: (a) the neutral requirements of forensic techniques of ethnic estimation; (b) the convergence of molecular and behavioral genetics in explanations of violent and antisocial behavior; and (c) the over-arching framework of individual choice regarding reproductive options, whether to prevent the birth of a child with a genetic defect, or in the use of new technologies to enhance the prospect of the fetus for competitive advantage.

TROY DUSTER

SEE ALSO: *Eugenics and Religious Law; Genetic Engineering, Human; Genetics and Human Self-Understanding; Genetics and Racial Minorities; Harm; Holocaust; Human Nature; Judaism, Bioethics in; Minorities as Research Subjects; Race and Racism;* and other *Eugenics* subentries

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EUGENICS AND RELIGIOUS LAW

• • •

I. Judaism
II. Christianity
III. Islam
IV. Hinduism and Buddhism

I. JUDAISM

The laws against incest and consanguinity in the Old Testament would seem to have a rationale in eugenics, although this is never specified in the biblical text. The traditional commentators, too, advert only to the natural repugnance against incest. In the Talmudic discussion as well as in the legal codes, the subject is treated as a sexual offense, involving a breach of morality rather than a eugenic error. (The Talmud is the repository of rabbinic exposition of biblical law and teaching, spanning more than five centuries. The legal codes are based on the Talmud and on subsequent development of the law, such as in Responsa, formal opinions rendered by rabbinic authorities in response to new case-law inquiries.)

Even bastardy is a moral rather than a eugenic category. The *mamzer* (in Jewish law, the product of an adulterous or incestuous liaison, not of a relationship between two persons who are not married to one another) is not legally ill-born; his or her status is compromised only legally and socially, rendered so in punitive or deterrent judgment against parents not free to have entered the relationship. But no difference obtains between the *mamzer* born of adultery—even a technical adultery, such as when the document of divorce for the mother's previous marriage was impugned—and the *mamzer* born of incest. Hence, no eugenic motive can be assigned here.

A man "maimed in his privy parts" bears the same legal disabilities as the *mamzer.* Thus, a man of "crushed testicles or severed member" is excluded from "the congregation of the Lord" (Deut. 23:2). This verse is interpreted to mean only that he may not enter into conjugal union with an Israelite woman. Thus, the castrated male is under the ban because the act of castration is forbidden. But one "maimed in his privy parts" as a result of a birth defect or disease, as opposed to one castrated by his own or another's deliberate assault, is free of this disability. The legal situations were thus analogized: "Just as the *mamzer* is the result of human misdeeds, so only the castrated one who is such as a result of human misdeeds is to be banned." Since that distinction is made in both cases, and since the banned *mamzer* and the castrated are permitted to marry, for example, another *mamzer* or a proselyte, it must be concluded that moral outrage and punitive judgment rather than eugenic considerations are operative.

Eugenics, in the sense of choosing a marriage partner with the well-being of progeny in mind, is more clearly present in Talmudic counsel and legislation. A man is counseled to choose a wife prudently, and guidance is offered in doing so in accordance with the intellectual and moral virtues of the prospective bride. And since, we are told, a son, for example, normally takes after his mother's brothers, a man should regard the maternal uncles in making his decision (Bava Batra, 110a). A hidden physical blemish in a spouse is grounds for invalidating a marriage, unless the other spouse can be presumed to have known of it in advance.

Heredity as a eugenic principle takes its legal model from rulings with respect to circumcision. A male infant whose two brothers died possibly as a result of this operation may not be circumcised. He is deemed to have inherited the illness (probably hemophilia) that proved fatal to his two brothers. The Talmud goes on to say that an infant whose two maternal cousins showed that weakness may not be circumcised either. That is, statistical evidence yielded by two sons from the same mother can also be reflected in two sisters of that mother (Yevamot, 64b). Coming from Talmudic times (before 500 C.E.), this is a remarkably early recognition that hemophilia is transmitted through maternal lineage—in itself a significant eugenic discovery.

The statistical evidence or the presumption of adverse hereditary factors in a third family member, when those factors are seen to exist in two others, thus becomes the basis of Talmudic laws of eugenics. With modern laboratory means to determine the presence of these factors, the principle of course operates even sooner, without waiting for statistical evidence in two members. The Talmud rules that one may not marry into a family of epileptics or lepers (Yevamot, 64b) or—by extension—a family in which tuberculosis or any similar disease appears in multiple members. This may be the first eugenic edict in any social or religious system.

The pure "heredity" underlying this recommendation is not unanimously agreed upon. While one view in the Talmud attributes the transmission of characteristics in the pre-Mendelian age to heredity, another view sees it as "bad luck." In a Responsum where the questioner considered abortion because the mother was epileptic, the rabbi responded that the latter of the two views stated above may be the right one, and that fear of bad luck is an inadequate warrant for abortion (Feldman, 1968).

In an earlier context, the Mishnah (the foundation layer of the Talmud) speaks of the faculties that a father bequeaths to his son: "looks, strength, riches, and length of years" (Eduyot, II, 9). Here, too, the commentaries align themselves on both sides: one sees the bequeathing of faculties as a natural hereditary process, the other sees them as divine reward for the father's virtues.

Two other Talmudic ideas with eugenic motifs are reflected in current practice. In the interests of fulfilling the injunction to "love one's wife as much as himself and honor her more than himself," a man is advised to seek his sister's daughter as a bride; his care for her will be the more tender due to his affection for his own sister. Yet in the thirteenth century, Rabbi Judah the Pious left a testamentary charge to his children and grandchildren that became a source of guidance to others on the level of precedent for subsequent Jewish law. In this famous testament, he advises against marriage with a niece because it may have adverse genetic results. Modern rabbinic authorities dismiss such fears as unjustified unless they are medically warranted.

A second point is a Talmudic notion that eugenic factors operate in intercourse during pregnancy. Conjugal relations, we are told, should be avoided during the first trimester as "injurious to the embryo"; but they are encouraged during the final trimester as desirable for both mother and fetus, for then the child is born "well-formed and of strong vitality" (Niddah, 31a). A medieval Jewish authority makes the matter a point of pride in comparative culture: the Talmud recommends coitus during the final trimester, whereas the Greek and Arab scholars say it is harmful. Do not listen to them, he says (Responsa Bar Sheshet, no. 447). Nonetheless, the Talmud prohibits the marriage of a pregnant or nursing widow or divorcee. In the case of a pregnant woman, the second husband, it is suggested, may be less considerate of a fetus fathered by another man and may inadvertently damage it through abdominal pressure during intercourse (Yevamot, 36a). In the nursing situation, the new father may fail to take the necessary steps to supplement the diet of his stepchild (it is assumed that a pregnancy diminishes the mother's milk). And a pregnant woman who feels an urgent physical or psychological need for food during the Yom Kippur fast is to be fed for the sake of her fetus's welfare as well as her own (Yoma, 82a).

More a matter of preaching than of law is the notion that defective children can be the result of immoral or inconsiderate modes of intercourse—an idea expounded but ultimately rejected by the Talmud (Nedarim, 20a). Yet in more modern times, the Hasidim (pietistic Jewish groups with a mystical orientation) maintain that spiritual consequences of the act are indeed possible; that if a man has pure and lofty thoughts during or preparatory to cohabitation, he can succeed in transmitting to the child of either sex an especially lofty soul. Hence dynastic succession of leadership, presuming the inheritance of that loftier soul, as opposed to democratic selection, obtains among Hasidic groups.

A study of biblical and Talmudic sources written by Max Grunwald in 1930, cited by Immanuel Jakobovits, discerns a broad eugenic motif. Grunwald writes that Judaism

> quite consciously strives for the promotion of the quantity of progeny by the compulsion of matrimony, the insistence on early marriage, the sexual purity of the marital partners and the harmony of their ages and characters, the dissolubility of unhappy unions, the regulation of conjugal intercourse, the high esteem of maternity, the stress on parental responsibility, the protection of the embryo, etc. To be sure, there can be no question here of a compulsory public control over the health conditions of the marriage candidates, but that would positively be in line with the principles of Jewish eugenics: the pursuit after the most numerous and physically, mentally, and morally sound natural increase of the people, without thinking of an exclusive race protection. (p. 154)

Although abortion is warranted primarily for maternal rather than fetal indications, screening of would-be parents for actual or potential defective genes, such as in Tay-Sachs disease, would, like premarital blood tests, be much in keeping with the Jewish traditional eugenic concern. Such genetic screening is, in fact, facilitated by a unique computerized system under the auspices of the New York-based Dor Yesharim (Generation of Upright [Descendants], from Psalms 112:2). Young men and women diagnosed as Tay-Sachs carriers are identified by code number. When marriage is contemplated, the couple is alerted to the fact that both are carriers, with one chance in four of a homozygous fetus, so that marriage plans may be reconsidered. Besides Tay-Sachs, which is fatal to the child by about age five, nonfatal disabilities have been added to Dor Yesharim's data base.

Although surrogate parenting and artificial insemination create social and family problems, the conceptional procedures that make them possible are in and of themselves acceptable when natural means are ineffective. In vitro fertilization, to assist in a conception that might otherwise be thwarted by blocked fallopian tubes or by sperm inadequacy, has been accorded full moral and legal sanction. Genetic engineering that alters the germ line has been ruled out by Jewish ethicists, but gene therapy, removing or correcting defective genes, would be a proper extension of the mandate to heal. The newly announced technology for cloning embryos has been greeted with more caution than hope—hope for improved procreational prospects for couples otherwise limited to one or no progeny, but caution against creating multiple embryos deprived of their distinctiveness as individuals. Safeguards are called for against the dangers of genetic mutation, or of political or profit-motive "baby farming" that could result from abuse of broader eugenic techniques.

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SEE ALSO: *Eugenics; Genetic Discrimination; Genetic Engineering, Human; Genetic Testing and Screening; Human Dignity; Judaism, Bioethics in; Medical Ethics, History of Near and Middle East: Israel; Population Ethics, Religious Traditions: Jewish;* and other *Eugenics and Religious Law* subentries

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II. CHRISTIANITY

The following is a revision and update of the first edition entry "Eugenics and Religious Law: Christian Religious Laws" by the same author. Portions of the first edition entry appear in the revised version.

Christian religious laws historically comprehend a large spectrum of rules to guide individual conduct and social relationships among the baptized. The laws most likely to have eugenic significance are the canons prohibiting the marriage of relatives. These regulations also form the basis for the modern civil law prohibitions against the marriage of relatives in both the Continental legal systems and the Anglo-Saxon statutory scheme. Though the principal justification given for such prohibitions in Christian law has been ethical and social, there is substantial evidence that they also may reflect considerations classified as eugenic in contemporary scientific research.

The ecclesiastical regulations that forbid marriage between persons closely related by consanguinity are among the most ancient canons of the Christian tradition. Penalties attached to the violation of religious exogamic laws have varied historically in their severity, as, indeed, have the ways of measuring the degrees of kinship and defining within which degrees the crime of incest shall be punished. But the core of the tradition of canon law remains constant and reflects an extreme reluctance to accept the marriages of close relatives as humanly or religiously feasible.

For Roman Catholics all marriages within the direct line of blood relationship, that is, between an ancestor and a descendant by parentage, and within the collateral line to the fourth degree, that is, to third cousins, are forbidden (*Code of Canon Law,* 1983, canon 1091). The definition of marriages within four degrees of relationship as incestuous dates to the Fourth Lateran Council in 1215 (c. 50). In the Greek Orthodox tradition, marriage in the direct line and in the collateral line to the sixth or seventh degree by the Roman method of computation is prohibited in canon 54 of the Synod in Trullo, 691/692 (Hefele). All Oriental Christians forbid marriages in the direct line; Armenians, Jacobites, and Copts prohibit it in the collateral line to the fourth degree, Melkites to the sixth degree, Serbs and Chaldeans to the third degree, and Ethiopians without distinction. Among Protestant reformers the restrictions of the medieval canon law were accepted by some, such as Phillip Melanchthon and Martin Chemnitz (Kemnitz); only the Old Testament regulations of Leviticus 18:6–18 by others, such as Martin Bucer and, perhaps, Martin Luther; and only the closest ties of direct parental relationship by still others, such as John Wycliffe. In the Anglican community, The Book of Common Prayer contains a table drawn up by Archbishop Matthew Parker based on Leviticus in naming relatives incapable of marriage (Wheatly). Most Protestant churches today follow the prohibitions of civil law regarding incest and kinship marriage (Acte for Kynges Succession; Acte for Succession of Imperyall Crowne; Concerning Precontracte and Degrees).

The sources of and commentaries upon the Christian laws record debate about the extent of the prohibition, the possibility of dispensation within certain close degrees of kinship, and the related question of the divine or natural law origin of the laws (e.g., Burchard of Worms, *Decretum,* bk. 7, “De Incesto”; Burchard of Worms, *Collection in 74 titulis* 65.281–284). They reveal, however, only the most sketchy discussion of the foundations of the regulations themselves.

The classical reasons given for the prohibition of consanguineous marriages are ethical and social. The first reason was called the *respectus parentelae,* namely, that such marriages would undermine the respect due to parents and consequently to all those who are closely related (Aquinas, 1948, *Summa theologiae* II–II, 154, 9). Second, they constitute a moral danger to family life arising from the possibility of early moral corruption of the young dwelling within the same household in which marriage could be allowed (ibid.; Sánchez 1605, 7.52.12, 7.53). Third, the prohibition of consanguineous marriages prevents the disruption of the family by sexual competition and forces the multiplication of friendships and the spread of charity (Augustine). These three reasons seem to have been sufficient to justify the laws, so that most scholars did not go beyond them to seek a further justification. Adhémar Esmein, for example, said the laws arose out of an instinctive repulsion for incest and were not reflective of any known adverse physical consequences. Some modern authors speculate that the reason for strict enforcement of prohibitions against incestuous marriages was to force the breakup of landed family estates (Duby).

It is only in comparatively modern times that an explicitly eugenic reason for the prohibition has received scientific attention. Writing in 1673, Samuel Dugard noted: “There is a *judgment* which is said often to accompany these Marriages, and that is *Want of Children* and a *Barrennesse*” (p. 53). “The Children are weak, it may be; grow crooked, or, what is worse, do not prove well; presently, Sir, it shall be said what better could be expected? an unlawfull Wedlock must have an unprosperous successe” (p. 51). Ambrosius J. Stapf’s *Theologia moralis* in 1827 alluded to this possibility (p. 359). A fuller treatment is found in Dominic Le Noir’s 1873 edition of St. Alphonsus’s *Theologia moralis.* Edward Westermarck in 1889 and Eduard Laurent in 1895 spoke at length of a physiological justification of the canons to prevent indiscriminate inbreeding and the risk of a high incidence of deleterious genetic effects. Franz Wernz, in 1928 (n. 352 [70]), writing from a comprehensive knowledge of the canonical tradition, said the ancient writers also knew of the undesirable effects of excessive inbreeding. He noted reasons derived from contemporary medical science in the writings of Gratian (early twelfth century) (C.xx “Anglis permittitur, ut in quarta vel in quinta generatione cognibitur,”

c. 20, c. 35, q. 2), Pope Innocent III (1161–1216) (Schroeder), and Thomas Aquinas (*Commentum in libros IV Sententiarum,* dist. 40 and 41, q. 1, art. 4). Since the late nineteenth century nearly all commentators on the canonical rules speak of eugenic objections to marriages of blood relatives.

It is possible to find in the ancient ecclesiastical commentators an awareness of a eugenic foundation to the prohibition expressed in primitive and undifferentiated modes of speech. For example, a persistent belief was kept alive among theologians and canonists that children of incestuous relationships will die or will be greatly debilitated, or that the familial line will be cursed with sterility. Benedict the Levite (850?) wrote of these marriages: "From these are usually born the blind, the deaf, hunchbacks, the mentally defective, and others afflicted with loathsome infirmities" (*Capitularum collectio*). Furthermore, in the explanations of the name of the impediment (i.e., the impediment of consanguinity), if one traces their origins through medieval glossography to the *Etymologies* of Isidore of Seville (560?–636), there appears an awareness of a physiological factor in the blood bond of close relatives that must be weakened before marriage can be contracted safely.

The antecedents of the Christian canons in the Mosaic law (Lev. 18:6–18) and the Roman law (Burge) were taken as expressions of natural law by the canonists and were continued in the barbarian codes (*Pactum legis salicae* 13.11; *Leges visigothae* 4.1.1–7; *Codex Euriciani* 2). In his *Ecclesiastical History* (I, 27), where the Venerable Bede (673–735) notes these laws, he records a quotation from a letter of Pope Gregory I to Augustine of Canterbury, written in 601 (*Responsa Gregorii*). The reason given by Gregory for forbidding marriages of close relatives is, "We have learned from experience that from such a marriage offspring cannot grow up." This letter and this reason not only are later picked up and cited by Gratian ("Anglis permittatur," c. 2, c. 35, q. 5) and Thomas Aquinas (*Summa theologiae suppl.* 54, 3), but may be found in virtually all the canonical collections of the early Middle Ages. Though comment on this passage is rare, comment was, perhaps, unnecessary. The passage from Gregory seems clearly to say that experience teaches that children from forbidden consanguineous marriages are affected or unable to grow up. There is thought to be a physiological consequence to incest. In the light of this it seems probable that the labored argumentation over the question of how close the relationship must be for marriage to be forbidden by natural law must have been conducted in some awareness of a popular belief in the biological consequences of such unions. The fear of genetic anomalies or biological debilitation from indiscriminate inbreeding may not be perfectly articulated. It is difficult to imagine, however, that warning of some physiological dangers to offspring may not have been intended in the frequent citation of Pope Gregory to sustain the severity of the prohibition.

Tomás Sánchez (1605), who wrote the greatest of the canonical commentaries on marriage, says that the most suasive ground for forbidding incestuous unions is that there is a sharing of the blood among close relatives and that the physical image of a progenitor (*imago, complexio, effigies, mores, virtus paterna*) passes to offspring, so that the blood must be weakened through successive generations before marriage should be contracted (7.50; 7.51.1–2). Thus, preventing marriages of close relatives to protect the offspring by allowing several generations to pass before procreation can be called a measure of eugenic foresight, however simple the scientific awareness to support it may have been.

In summary, a eugenic foundation to Christian religious laws forbidding the marriage of close relatives is clearly articulated and commented upon by modern scholars from the late eighteenth and nineteenth centuries. Evidence of this kind of awareness may be discovered earlier in the canonical sources, however, going back at least to the seventh century. It would seem consistent with the eugenic connotation of those laws rooted in antiquity, together with a Christian sense of responsibility for offspring that partly motivated them, to consider further eugenic restrictions on marriage in Christian communities today, in light of contemporary knowledge of genetics.

WILLIAM W. BASSETT (1995)

SEE ALSO: *Christianity, Bioethics in; Eugenics; Genetic Discrimination; Genetic Engineering, Human; Genetic Testing and Screening; Human Dignity; Human Rights; Population Ethics, Religious Traditions: Protestant Perspectives; Population Ethics, Religious Traditions: Roman Catholic Perspectives;* and other *Eugenics and Religious Law* subentries

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III. ISLAM

The idea of eugenics is not well developed in the Islamic world. Both Islamic law and tradition generally condemn abortion, which is permitted only if the mother’s life is endangered, so there is no genetic counseling that would lead to abortion. Both religious law and tradition do include references to a man’s choosing an appropriate wife, but these concerns have been interpreted as moral and social, rather than eugenic.

Islamic religious-moral law, the Shari’a, deals with questions concerning laws of incest and consanguinity from the perspective of moral and social relationships rather than eugenic concerns. The general counsel of the Qur’an and the Prophetic traditions regarding marriage is promulgated in the laws that require a Muslim to marry within the community of believers. A Muslim is better than a non-Muslim as a spouse. “A woman may be married for four reasons: for her property, her status, her beauty, and her religion; so try to get one who is religious” (Muslim, tradition 3457). There is no law to suggest choosing a marriage partner with the intention of improving the progeny through the control of hereditary factors. With slight variations among the Sunni and Shiite schools, the law specifies that a woman may not marry a man who is not equal to her. The earliest ruling to require equality in matters of piety and freedom from physical defects detrimental to marriage is found among the Malikis (see al-Juzayri, for variations among the four schools of Sunni law).

In the Qur’an the main source for marriage law is book 4, verse 23. This prohibits marriage between persons closely related by blood, but this ban reflects ethical and social, rather than eugenic, considerations. Thus in Muslim jurisprudence a man and a woman may be forbidden to marry either because of blood relationship (e.g., a man may not marry his mother or either of his grandmothers, etc.) or relationships established through marriage (e.g., he may not marry the mother or grandmothers of his wife, etc.). Moreover, there are women whom a man may marry singly, but not be married to at the same time (e.g., two sisters, a woman and the sister of her mother or father). This latter prohibition seems to be more for psychological than for eugenic reasons.

Evidence that the Qur’an (or Shari’a) considers nurture, or the environment, to have impact on a child perhaps comparable to that of nature, or genetic inheritance, comes from the Book of Marriage, which prohibits marriage not only between a man and the woman who gave birth to him but also between a man and the foster mother who breastfed him at least a certain number of times.

The ruling seems to indicate similar consequences for foster relations established through suckling: “What is unlawful because of blood relations, is also unlawful because of corresponding foster suckling relations” (al-Bukhari, tradition 46; al-E’Amili, 7/281, tradition 2). In establishing unmarriageability, a foster mother who suckles an infant is regarded exactly as the infant’s real mother.

There is further evidence of the Islamic tradition’s lack of interest in eugenics. Islam abolished one of the four types of marriages among Arabs, the one described in Arab tradition in terms that may reflect eugenic concerns. The tradition says:

> The second type [of marriage] was that a man would say to his wife after she had become clean from her period, “Send for so-and-so [whose nobility is well established] and have sexual relations with him.” Her husband would then keep away from her and would not touch her at all till her pregnancy became evident from that man with whom she was sleeping. After the pregnancy was established her husband would sleep with her if he wished. However, he allowed his wife to sleep with that person being desirous of the nobility of the

> child (*najabat al-walad*). Such marriage was called "marriage seeking advancement" (*nikah al-istibda'*). (al-Bukhari, 1986, sec. 37)

Islam, which insisted that faith in God was the main source of all human nobility, was uninterested in this practice, traditional in the Arab tribal culture, for the improvement of the human race through the control of hereditary factors.

Other traditions counsel the believers to choose a partner for breeding (*al-nutaf*) "bravery among the people of Khurasan" [in Iran], sexual potency among the Berber [in North Africa], and "generosity and envy among the Arabs" (al-ʿAmili, 7/29, tradition #6). The Islamic traditions (hadith literature) do reflect explicit knowledge of eugenics in choosing a marriage partner. The source of these eugenic considerations seems to be the Irano-Semitic culture, in which such interests were commonplace. Although these traditions were never used as authoritative precedents for legislation in the Shari'a, they express the popular piety connected with marital relations. For example, the Prophet is quoted saying, "Anyone wishing to follow my tradition should know that among my traditions is marriage. Seek children [through it].… Protect your children from the milk of the prostitute and the insane among women, because milk makes inroads [in the character of a child]" (al-ʿAmili, 1969, 7/4, tradition 6). Moreover, in the case of a person drinking wine, the Prophet regarded it permissible to annul the marriage contract, especially, if the person was alcoholic (literally, "sick" with alcohol) (al-ʿAmili). There also existed a warning against marrying fatuous individuals because their offspring would be a loss. However, it was acceptable to marry them for sexual reasons, as long as one did not seek children through such a union. These traditions reveal the concern about hereditary factors in the progeny.

Other traditions encourage marriages within one's own collateral line, to first cousins. The Prophet, who belonged to the Hashimite clan, at one time looked at the children of ʿAli and Ja'far, two brothers and his paternal cousins by relation, and said, "Our daughters for our sons, and our sons for our daughters" (al-ʿAmili, 7/49, tradition 7). This encouragement is contradicted by other traditions that recommend exogamous marriage and even intermarriage between Arab and non-Arab, and between a free person and a slave. There does not seem to be any awareness in these early traditions of deleterious genetic effects from excessive inbreeding. However, since 1970 there has been a growing debate among traditional Muslim jurists over the authenticity of the tradition that encourages endogamy indiscriminately. Certain injurious hereditary conditions have been detected in the fourth and fifth generations of some tribes in Muslim societies where endogamy is the norm.

Muslim traditions also speak about the negative impact on the fetus of "improper" modes of intercourse rejected by the Qur'an. Yet it was believed that special prayer when one intends to have intercourse with his wife keeps the devil away from what God has ordained to be created. The pure state of the parents' minds and bodies can be transmitted to the child through the invocation of the Divine Name before intercourse. In light of belief in the divine purpose and decree in the creation of offspring ("It is God who brought you forth from your mothers' wombs," Qur'an 16:78), either born with birth defects or normal, there does not seem to be any indication to support genetic diagnosis or screening that would justify abortion, which Islam permits primarily to safeguard the mother's health.

ABDULAZIZ SACHEDINA (1995)

SEE ALSO: *Abortion, Religious Traditions: Islamic Perspectives; Eugenics; Genetic Discrimination; Genetic Engineering, Human; Genetic Testing and Screening; Human Dignity; Islam, Bioethics in; Judaism, Bioethics in; Population Ethics, Religious Traditions: Islamic Perspectives;* and other *Eugenics and Religious Law* subentries

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IV. HINDUISM AND BUDDHISM

Because reproduction is one of the most important concerns of human life, most religions concern themselves with the regulation of sexual activity, marriage, and production of children. Hinduism and Buddhism also guide their followers in these matters, but in ways very different both from each other and from Western religions.

Eugenics might be defined as controlling human reproduction to modify or benefit the species. Prior to the present innovation of genetic engineering, eugenics meant restrictions on who could reproduce and with which partner. The recent development of methods of altering the human genome has opened a new area of ethical discussion: the propriety of voluntarily altering the human genome. Eugenics has also been used to excuse genocide, but this aspect will not be discussed here since nothing in Hinduism or Buddhism allows rationalization of genocide.

Although Hinduism and Buddhism have highly developed ethical philosophies, neither religion produces set positions on such contemporary matters as eugenics, nor is it likely that they will, given the nature and organization of the two religions. In both religions, ethics are developed by the individual or the social community; there is no official body that produces ethical statements. Hence there are no official Hindu or Buddhist positions on issues that were not envisioned when their scriptures were composed over 2,000 years ago. However, both religions have ethical ideas or methods that can be applied to modern problems.

Hinduism has its beginnings in the two millennia before the Common Era; the historical Buddha, Shakyamuni, died about 500 B.C.E. In those remote times there were no concepts akin to those of modern genetics and hence there could be no ethical discussions of genetic manipulation. Rather than a single scripture analogous to the Judeo-Christian Bible or the Koran, Hinduism and Buddhism have vast collections of diverse canonical texts that have appeared over millennia. Hinduism does have several authoritative legal texts, the most important of which, *The Laws of Manu,* was composed from about 200 B.C.E. to 200 C.E. These texts codify religious law (*dharma*) but are not regarded as the only legal or ethical authority. Buddhist texts are concerned with spiritual development and give only very general precepts for regulation of lay life. However, it is possible to develop Hindu or Buddhist positions on eugenics.

Hinduism and Buddhism both arose in India and share many common beliefs, such as the doctrine of *karma* (discussed below), yet the differences between the two religions must not be underestimated. Generally speaking, Hinduism is a legalistic religion and pays great attention to regulating life in the world. Buddhism sees worldly life as secondary in importance; attainment of release from suffering in this or subsequent existences is its central concern.

Reproduction in Hindu Religious Law

Although Hinduism recognizes a final stage of life in which the individual is released from domestic and social obligations in order to be able to pursue enlightenment (*moksha*), in the earlier, householder stage, detailed rules define acceptable behavior. Among the most important are those that regulate reproduction. The intent of these rules is to maintain the hereditary caste distinctions. Here Hinduism's outlook is very similar to that of nineteenth- and early twentieth-century Western eugenics, which proposed controlling reproduction to prevent what were considered undesirable unions. Although the specific rules for regulating marriage and reproduction were different from those proposed by Western eugenics, the spirit is the same: to protect the human species from degeneration due to unsuitable matches. Hinduism does not define suitability for marriage according to scientific understanding of genetics, but by caste membership, which is hereditary, and by physical traits, which are correlated with astrology. Traditionally, prospective brides were inspected undressed and an elaborate system of body divination existed for interpreting body markings, particularly on erogenous areas. Manu states, "A man should not marry a girl who is a redhead or has an extra limb or is sickly or has not body hair or … is too sallow … He should marry a woman who does not lack any part of her body … whose body hair and hair on the head is fine …" (Manu, p. 44). There are also rules for selecting the sex of children (males are conceived on even-numbered nights) and in all cases, the social class of husband and wife must match.

These procedures amount to methods of selecting marriage partners according to biological suitability, although the biological traits selected for concern may not seem very appropriate today. Marriage is discouraged if partners are not biologically and astrologically suited. In India, marriages have been and still are arranged by parents on the basis of social, economic, and reproductive suitability. Romantic interest is at best a very secondary consideration. The entire basis of marriage in Hinduism is eugenic, but the factors felt to predispose favorably to suitable offspring are quite different from modern Western ones. Marriage in Hinduism exists to ensure offspring and perpetuate family distinction and caste separation. These laws were intended to regulate reproduction rather than sexuality. Sexual liaison outside of marriage and across caste, though not approved of, was not considered wrong so long as no offspring resulted.

Hinduism does not contemplate elimination of inferior castes, but simply limitation of physical contact between them and higher ones. The higher castes must preserve their purity, but all castes are necessary and have their place in the cosmos (Danielou). This contrasts with the extreme, modern racism, in which one group, which considers itself superior, aims at the elimination of others. There is no idea of altering the genetic or social situation of humanity as a whole. On the contrary, marriage rules attempt to maintain the status quo. Their rationale is not to improve the human species but to prevent its degeneration.

In general, Hinduism has not been opposed to attempts to control reproduction. Female infanticide has been extensively practiced in India. An innovation is the use of ultrasound machines by entrepreneurs; at village marketplaces a pregnant woman can find out whether she is carrying a boy or girl, with abortion elected in the instance of the latter. A similar practice exists in China. Although the practice of female infanticide can be explained in economic terms (a girl's parents must provide a dowry if she is to be married), it represents a practice of controlling reproductive outcome for family or social goals. Infanticide has not been viewed with the same opprobrium as in the West, although it is certainly not fair to imply that the Hindu religion condones such acts.

The Indian concept of karma, which is fundamental to all its philosophical and religious systems, has some similarities to modern genetics. It is a law of moral cause and effect. The literal meaning of karma is action, and the theory holds that one's present state is the result of personal and collective actions in this and previous lives. Actions, like genes, have effects that persist across lifetimes. Much of each individual's present circumstances are the result of previous actions carried across generations. Karma and scientific genetics seek to account for the human experience that the past tends to repeat itself in the present. Both offer an explanation of how an individual comes to have certain traits.

Buddhism and Human Reproduction

Buddhism, which abolishes the caste system, has no concern with the suitability of marriages. Indeed, its monastic nature has made Buddhism generally uninterested in family life and reproduction. Throughout Buddhist history, clergy were forbidden to solemnize marriages; this was seen as inappropriate involvement in worldly affairs. (Wedding ceremonies officiated by Buddhist monks are a recent innovation.) Nor does Buddhism have an elaborate ethical code for regulation of lay behavior. Throughout most of its 2,500-year history, Buddhism has been monastic; lay life was not considered conducive for progress toward enlightenment. However, the sangha, the order of monks and nuns, did try to inculcate simple moral understanding in the laity.

In the Theravada form of Buddhism, which most closely resembles early Buddhism, the laity is taught the Five Precepts, which call on the Buddhist to avoid (1) unnecessary killing, (2) taking what is not given, (3) sexual misconduct, (4) harmful speech, and (5) use of intoxicants. Although Buddhist teachers will offer their particular interpretations of these principles, detailed rules are not given in any canonical text. Sexual misconduct, for example, is rarely defined and there is no position on contraception. Nor are there specific rules on suitability of marriage or sexual partners. The first precept might be interpreted as discouraging abortion; however, termination of pregnancy is not absolutely forbidden, though it is considered highly undesirable. Buddhism would see the ideal situation as one in which the partners are mindful of the consequences of their actions and avoid a situation in which abortion is a consideration. If carried out, abortion should use a method that minimizes any suffering. (For Buddhist analyses of the abortion issue see Taniguchi, 1987, and Redmond, 1991.) In Japan, where abortion is used as a method of family planning, Buddhist monks are involved in practices that women use to atone for abortion.

In contrast to the religious law of Judaism, Christianity, and Islam, the Buddhist precepts are very general, expressing morality in spirit rather than letter. Nothing in the five lay precepts can be construed to oppose genetic manipulation, provided that it is not harmful. Buddhism does not try to regulate lay behavior by detailed codes of laws, but rather by teaching *sati,* "mindfulness" and *ahimsa,* "harmlessness." The ultimate value in Buddhism is not living in accordance with a code of religious laws but being aware of the effects of one's actions so as to minimize harm. In general, a Buddhist would be concerned that genetic knowledge not be used in a way that causes suffering, but would not be opposed in principle to the acquisition or application of such knowledge. Buddhism places its highest value on knowledge, which it sees as the sole vehicle for enlightenment and release from suffering. Ignorance, not sin or disobedience, is the case of a human's unhappy state. Hence, Buddhism may be seen as favoring the acquisition and use of genetic knowledge, provided that it is applied in ways that help, rather than harm, living beings. Changing the genetic code so as to eliminate a disease in the offspring would be quite acceptable so long as it was carried out skillfully, that is, not harmfully. Partner selection for genetic or ethnic reasons is not supported by Buddhism, which abolished the Hindu caste system. However, such selection would not be ethically improper if it did not cause suffering to those involved.

Cosmology and Eugenics

There are two commonly held contemporary Western positions about eugenics that Hinduism and Buddhism see rather differently from most Western ethicists. One position is that since the world and everything in it, including human beings, are held to be created by God according to a divine plan, then altering the human genome is altering the very basis of God's creation, which is impermissible. Thus the Vatican's statement on reproductive technology holds that "no biologist or doctor can reasonably claim, by virtue of his scientific competence, to be able to decide on people's origin or destiny" (Vatican, Congregation for the Doctrine of the Faith, 1992, p. 84). A similar but secular argument holds that we should not alter nature. Although altering nature may not be inherently wrong, pragmatically such alterations are much more likely to do harm than good. The only safe course is stringently to restrict novel technologies such as genetic engineering.

Neither Hinduism nor Buddhism conceives of a creator God whose divine plan might be altered by genetic manipulation. (Although Brahma is considered the creator in Hinduism, the metaphysics of creation are quite different. Creation occurs from moment to moment and not according to a perfect plan.) Far from seeing the world as divine or perfect, both religions regard the world as inevitably a place of suffering. The fundamental virtue in both Hinduism and Buddhism is practicing *ahimsa,* or harmlessness, which means to avoid making living beings suffer. For example, the environment should not be harmed because living creatures are dependent on it. Since the universe was not created by divine plan, altering it is not considered a repudiation of God. In this context genetic manipulation is perfectly acceptable.

As to the second argument, that humans cannot handle their power over the genome, neither Hinduism nor Buddhism can be held to have a clear position on this. Evil is the result, respectively, of delusion, *moha,* or ignorance, *avidya.* Ethical ignorance is simply an aspect of more general spiritual ignorance, which clouds perception of the true nature of existence. However, Buddhism and Hinduism conceive of ethical ignorance somewhat differently. In Hinduism, it is necessary to be aware of the complex laws, or dharma, regulating human behavior. In Buddhism, ignorance is lack of awareness of the law of cause and effect, for example, of knowing how one's actions will affect oneself and others (Taniguchi, 1994). Mindfulness shows that an action harmful to another will cause suffering just as it would if done to oneself. A unique moral insight of Buddhism is that ethical behavior requires factual knowledge (Redmond, 1989)—for example, what effects behavior will have on others—as well as knowledge of ethical precepts. The way to this knowledge is through self-cultivation such as meditation, study of religious texts, and, especially, the influence of a teacher. Ethical behavior results from personal moral development rather than detailed moral legislation.

Karma and Eugenics

The concept of karma can be interpreted, or sometimes misinterpreted, so that it appears to oppose eugenics. Karma holds that misfortunes in this life are due to harmful actions in a former life (although there are also social sources of unfavorable karma). By this interpretation, if a child is born with a genetic disorder, then the misfortune is due to previous voluntary actions that harmed others and hence is deserved. Furthermore, this karma must be worked off; the suffering must be endured to expiate the previous wrongdoing. If the suffering is prevented, it will simply occur later. Thus, if a fetus with Down syndrome is aborted, the same individual will simply be reincarnated later with a similar affliction.

The idea that suffering should not be relieved, because karmically deserved, is widespread in India and Buddhist countries and is sometimes articulated by Buddhist teachers in the West. It is a misunderstanding of the Buddha's teaching, which was concerned to explain the way of release from suffering. Although Buddhism teaches compassion, some Buddhists, in common with some followers of other religions, find interpretations that rationalize evasion of the ethical obligation to be kind to others. It is not consistent with Buddhist teachings on compassion to refrain from relieving another's suffering on the grounds that it is due to the operation of karma.

Buddhism, although not opposed to eugenics if it is skillfully applied, does not require it. In contrast to Hinduism, it does not establish rules regarding reproductive behavior. Some contemporary Buddhists believe that each individual has his or her tasks in life and that, although these might be different for someone with a birth defect, others should not assume that such a life is therefore less worthy. This has affinities with the idea that we should not interfere with nature because we may not fully understand the effects of what we do.

Hinduism, then, requires a form of eugenics, and Buddhism is essentially neutral on eugenics as such, but would be greatly concerned to ensure that eugenic practice decreased suffering rather than increasing it. Neither religion sees eugenics as in itself improper, but both concern themselves with how it is carried out. However, Hinduism and Buddhism produce no set positions, and individual Hindus and Buddhists may have views different from those summarized here.

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SEE ALSO: *Buddhism, Bioethics in; Hinduism, Bioethics in; Medical Ethics, History of South and East Asia; Population*

Ethics, Religious Traditions: Buddhist Perspectives; Population Ethics, Religious Traditions: Hindu Perspectives; and other *Eugenics and Religious Law* subentries

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EXPERT TESTIMONY

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Courts frequently look to the testimony of expert medical witnesses to assist them in the search for legal truth. In addition to Egyptian and Biblical references to forensic medicine, physicians in Greece and Rome functioned as expert witnesses. A physician testifying at the inquest into Julius Caesar's death stated that he found twenty-three stab wounds on the corpse but only one wound, a wound in the throat, that could have caused death. The Institutes of Justinian (529–533 C.E.) and the codices of Charles V, the Lex Bambergensis (1507), also made provisions for expert medical testimony (Landé; Clements and Ciccone). In the United States, physicians are called on to testify as expert witnesses in a variety of civil and criminal matters. The civil issues range from workers' compensation to child custody, from physical and emotional damages to malpractice. The issues in criminal cases range from cause of death to competence to stand trial, from deoxyribonucleic acid (DNA) typing to the insanity defense. This entry traces how a physician becomes involved as a medical expert witness, what the requirements of the role are, and the ethical issues that may arise.

Courts of law distinguish between fact witnesses and expert witnesses. Fact witnesses may be required to testify if they have some direct knowledge about the issue before the court, but may not express opinions. Expert witnesses have knowledge that goes beyond that of the ordinary citizen and agree to undertake the role of expert witness and are permitted to express opinions.

The difference between a "fact" and an "opinion" is the degree of concreteness of the description, or the difference in the "nearness or remoteness of inference" (McCormick, p. 26). The courts and the public receive expert testimony with both admiration and suspicion. There is appreciation for the clarity provided, but fear that experts may control the legal outcome. This fear may be accentuated in a democratic society that mistrusts those with special knowledge. In 1986, the American Medical Association (AMA) took the position that "as a citizen and as a professional with special training and experience, the physician has an ethical obligation to assist in the administration of justice" (Council on Ethical and Judicial Affairs of the AMA, p. 138). The participation of the medical expert may be justified on the basis that a meaningful concept of justice requires empirical data on the function of the human organism in health and disease—data that the medical expert can provide (Ciccone and Clements).

The Expert-Witness Role

Expert-witness testimony in an adversarial legal system may lead to a battle of the experts, a battle that may be avoided if the court appoints an expert approved by both sides of a legal action. There are different models for the expert-witness role. In the first model, the court-appointed or "impartial expert" witness model, the expert witness is still subjected to cross-examination, yet has the implied endorsement of the court—the court would not hire an unqualified expert. However, the view that such an expert witness is neutral is a fallacy (American Academy of Orthopedic Surgeons) because the expert is necessarily an advocate for his or her opinion. In the second, the objective "expert-model," the expert is hired by or appointed to one party, but the expert's role is limited to a comprehensive examination of the evidence and formulation of an opinion, if possible. In the third, the "consultant" model, the expert functions as a consultant to the attorney. The expert provides an accurate statement of the examination conducted, the findings of the examination, and the opinion and reasoning used to arrive at the opinion, and provides assistance with trial strategy and cross-examination (Appelbaum). The ethical hazard of this model is that the expert may identify with the attorney's position and become an advocate.

In each model, the medical expert is expected to provide a clinical evaluation and a review of the applicable data in light of the legal question posed and in the spirit of honesty and striving for objectivity—the expert's ethical and professional obligation. This includes a thorough, fair, and impartial review and should not exclude any relevant information in order to create a view favoring either the plaintiff or the defendant (American Academy of Psychiatry and the Law). The treating physician, whom the court may compel to testify as a fact witness regarding contact with a patient, is frequently sought to provide expert-witness testimony. The legal system assumes that the treating doctor is more credible than a nontreating doctor. The treating physician has a specific therapeutic focus—the patient's health—that may not allow service as an expert witness. The treating physician may encounter a conflict of interest (e.g., maintaining the patient's confidentiality versus providing the court with information).

When taking on the functions and obligations of the expert-medical-witness role, the treating physician may, out of loyalty to the patient's best interests, act as an advocate for the patient. This distorts the obligation of the expert witness. On the other hand, if the treating doctor's expert testimony does not have the effect of adequately supporting the patient's position, the doctor-patient relationship may deteriorate as a result. Hence, the role of physician as advocate for the patient may be inconsistent with the role of physician as expert witness and pose the ethical issue of conflict of role obligation. This conflict should be avoided. When this is not possible, self-awareness of the possible conflict and awareness by the court of the conflict may minimize its effects.

The Ethics of Being a Medical Expert Witness

Medical professionals who undertake the role of expert witness are generally expected to have an unrestricted license to practice medicine, to be knowledgeable and experienced in the area in which they are functioning as a medical expert, and to have knowledge of the legal system. At the initial contact by the court or an attorney, the expert clarifies the question being asked and explores the relevant information about the case. The discussion of the question also permits the expert to be explicit about limitations of the evaluation he or she can offer. The expert witness must know the law that is relevant to the forensic question in the jurisdiction in which the expert may testify. The court or the attorney can provide the applicable statutes. Professional values require such obligations. In addition, legal consequences involving criminal and civil verdicts with ensuing penalties require this standard of obligation.

Medical experts can expect cooperation from the court or attorney in obtaining all the relevant legal, social, and medical documents. Medical experts should obtain consultations from others when there are important areas outside of the expert's knowledge. The medical expert must also be aware that the attorney may have a hidden agenda—understanding the hidden agenda may influence the expert's decision to accept or refuse the case. For example, when the evidence is not strong, is the prosecuting attorney's raising the question of competence to stand trial (CST) a way to keep the individual from being released? Is the defense attorney's request for an evaluation of CST a way to prolong the legal process so that prosecution witnesses may become difficult to locate, thereby weakening the district attorney's case? These are ethical questions the legal system must address, but medical experts who work with the legal system have a clinical obligation to avoid abuse of their role.

The individual who agrees to function as an expert witness is entitled to an expert witness fee, the terms of which should be clear and explicit at the time that the work is started. It is unethical for expert witnesses to make their fees contingent on the outcome of trials. In fact, there are advantages to the expert working with a retainer fee, against which the work of the forensic expert may be charged: (1) it diminishes whatever influence the examiner's concern for payment has on the quality of the work, and (2) if asked on cross-examination if the experts are being paid for their opinions, the experts are able to respond that in fact they were paid on a retainer basis for their time. Such arrangements avoid the ethical problem of experts being seen as "hired guns."

The informed consent of the individual to undergo a forensic medical evaluation should be obtained whenever possible. This includes a description of the purpose of the evaluation, the limits to confidentiality that may exist, and to whom a report will be made. The doctor-patient relationship includes, as one of its ethical requirements, the qualified obligation that the physician maintain confidentiality. The examinations conducted by the medical expert witness are usually outside the scope of the doctor-patient relationship; however, the bioethical obligations remain, and the physician must be aware of the bioethical obligation not to harm the individual unnecessarily by gratuitous disclosure of information. The disclosure of information must conform with the requirements of the law and the explanation made to the individual examined. In a legal context, the medical expert is bound not by rules of medical confidentiality, but by the rules of confidentiality that the legal circumstances require. It is expected that the medical expert witness will be aware of and abide by the specific rules of confidentiality applicable to work with the legal system. Informing the examinee may not be sufficient protection because the physician can create a relationship in which the examinee forgets the warning (Diamond). There are circumstances in medical-legal evaluations where consent is not required. The individual is then informed that the evaluation is legally required. However, if the individual chooses not to participate, the refusal will be included in any report or testimony.

Admission of Expert Testimony

The role of the expert witness is based on education, training, and experience that gives the expert knowledge in a particular discipline. The United States Supreme Court in *Daubert* v. *Merrell Dow Pharmaceuticals* (1993) described the limits of expert scientific testimony and endorsed the *Federal Rules of Evidence* (United States) that had broadened the admissibility of scientific testimony to include theories that were not widely held. The *Daubert* decision rejected the restrictive standard that permitted the judge to exclude expert testimony that the judge found was not "sufficiently established to have gained general acceptance in the particular field to which it belongs" (*Frye* v. *United States*, 1923). However, the U.S. Supreme Court also put limits on "the admissibility of purportedly scientific evidence" by requiring the trial judge to determine whether the reasoning or methodology underlying the testimony is scientifically valid and whether that reasoning or methodology properly can be applied to the facts in issue (*Daubert* v. *Merrell Dow Pharmaceuticals*, p. 2796). This gatekeeping function of the judge on expert scientific testimony may lead to judges who appoint their own experts to examine the experts put forward by opposing parties in the litigation.

Ethics and Medical Expert Testimony

The medical expert may be required to testify in perhaps one of ten cases that the expert is called upon to evaluate. It is this public role that causes the most discomfort and is the most sensationalized of all the expert's functions. The medical expert witness usually engages in this work as a part of a larger clinical practice. While some experts have given up clinical work, this is rare. Medical experts who have not actively engaged in their discipline or who have given it up may find their credibility questioned in court. Medical experts have the ethical obligation to inform the court or attorney hiring them of the status of their clinical practice. Prior to entering the courtroom, experts assist the attorney as well as they can "but only within the requirement of medical ethics" (Stone, p. 27). Each of the three models carries the ethical obligation that the expert be honest and, even when assisting an attorney, not become an advocate. The medical expert who is called to testify should require full and complete preparation from the attorney. Preparation for testimony, which almost always includes at least one pretrial conference between attorney and expert, is essential to adequate work in the courtroom.

In court, medical expert witnesses are not advocates for either side in the litigation, but may advocate their opinion. The most effective role of the expert witness is that of teacher—that is, one who elucidates the nature of the evaluations and the reasoning used to arrive at his or her opinions. The expert should present credentials without exaggeration. The expert should be prepared to present specific perspectives or bias and identify value components that are always present in interpretations of the data. If the issue before the court presents an ethical dilemma for the expert, whether as a result of personal belief or from concerns about societal harm that his or her opinion may cause, the expert has the obligation to avoid involvement in such cases. The requirement of truthfulness on the part of the medical expert witness requires that relevant information not be kept secret (Rappeport). In addition, there are limitations that occur in medical examinations, and these limitations of reviewed materials (e.g., completeness of the examination or knowledge of that area of medicine) may require the expert to qualify an opinion or, at times, to decline to provide an opinion to a particular question.

The attorney who retained the medical expert will call and question the expert with direct examination. This usually begins with eliciting the expert's credentials; the questions present the expert's education, training, experience, and other information that chronicle the achievements of the expert to the court. Using the *Daubert* directives, the judge may rule to exclude the expert. Medical-expert witnesses are expected to present their testimony—avoiding jargon—with sufficient clarity so that those lacking expertise can understand the findings and follow the reasoning. The attorney who has retained the expert can be expected to emphasize his or her ability and the brilliance of the conclusions. The cross-examining attorney, both in speech and gesture, will often attempt to convey to the court that the expert witness lacks credibility and that his or her conclusions are worthless.

The expert may be presented a hypothetical question, which is a conflation of assumptions and proven facts into an organized account of a situation. The hypothetical question calls for expert witnesses to assume the information in the question to be fact. Then experts are asked if they have an opinion derived from those facts and, if they do, to state that opinion. The hypothetical question is used because there is a dispute about the facts, and the hypothetical question allows the court to hear the expert's opinion without deciding if the facts in evidence are true.

The expert witness has rights in the courtroom and may ask the judge to clarify when material that is asked for is privileged. The expert witness may ask for clarification of a question or refuse to answer questions the expert does not understand. Experts may and should say that they do not have a response to the question, if in fact they do not have one. Experts, when asked a yes or no question, can ask the judge whether the answer can be qualified. If on cross-examination this is not permitted, on subsequent redirect examination the attorney who retained the expert may ask for further clarification. The expert has a right to complete an answer and should protest if interrupted. Expert witnesses, as contrasted with fact witnesses, may refresh their recollections using written notes and records.

The courtroom, the most visible portion of the adversarial system with its "battle of the experts," is viewed by some critics as a three-ring circus. Even when expert witnesses agree substantially, small differences may be exaggerated by an attorney and held up as proof that the entire discipline has nothing to offer the courts. If expert witnesses are expected to provide absolute certainty, the witnesses will inevitably be clowns in the courtroom. However, the opinion of the expert witness, as with a medical diagnosis, is a probability statement and as such, is the best conclusion given the analysis of the data. This conclusion may certainly be open to question. Although the credibility of the expert witness is important, the courtroom belongs to the attorneys. The weight given to the testimony of the expert is markedly influenced by the courtroom skill of the attorneys involved. Do the faults of the legal system outweigh its benefits and is there an alternative, superior system for arriving at legal verdicts? This is a question better considered in an analysis of the adversarial system.

At a trial, the ultimate issue is the question about which the jury or judge must arrive at a verdict (e.g., did the defendant's negligence cause the injury to the plaintiff?). It has been suggested that the medical expert respond only to questions about the medical condition and avoid responding to the ultimate issue, which some have called either a leap in logic (American Psychiatric Association [APA] Statement on the Insanity Defense) or the application of medical reality to a legal procedure. It is contended that the ultimate issue is an issue of social and moral policy and, therefore, is beyond the province of scientific inquiry. While there are circumstances when the information does not permit the medical expert to arrive at an opinion, the fact that the question has been framed in a legal context may make it appropriate for the expert to express an opinion. This opinion need not usurp the role of the trier of fact.

Conclusion

Much of society's ambivalence toward expert witnesses is derived from society's unrealistic hopes and fears of expert witnesses. The hope that the expert will have secret skills, which provide special access to absolute truth, imbues the expert role with unrealistic authority and certainty. This expectation of expert witnesses is not consistent with the reality of scientific expertise that allows for probable conclusions. The fear that the expert will take over the legal process and subvert justice is also exaggerated. The legal system has rules of procedure that limit the influence of the expert witness. Functioning within the boundaries of science and governed by ethical guidelines, experts are not oracles whose conclusions are not open to question, but witnesses who can provide the legal system with useful information.

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SEE ALSO: *Confidentiality; Conflict of Interest; DNA Identification; Law and Bioethics, Law and Morality; Malpractice, Medical*

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FAMILY AND FAMILY MEDICINE

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Families have played a most important role in the history of medicine, tending the sick when doctors were unavailable or unavailing. Medicine and the family, the two ancient and in some respects rival systems of care for the very vulnerable, are each in part shaped by the other and rely upon the other for certain kinds of help. When illness or injury exhausts a family's capacity for care, the family looks to professional medicine for the necessary facilities and expertise; in turn, technological advances in medicine have driven the healthcare system to depend on families for what can be enormous sacrifices of time, money, caring labor, and even spare body parts on behalf of its patients. Recent developments in medicine have not only expanded the options for forming families—for example, through in vitro fertilization and contract pregnancy—but they have also had an impact on familial demographics: artificial means of birth control have helped reduce family size, while improvements in healthcare have extended longevity, though they have not eradicated the ills of old age.

Yet the most profound impact of contemporary medicine on the family may not be so much a function of new technologies as of new social practices. A characteristic of the social arrangement of healthcare in the twentieth century was the professionalization of care and the concomitant migration of care provision from home to hospital. If trends in the 1990s hold true, however, the twenty-first century may see a reversal of that process, with greater amounts of care—requiring greater skill, and more intensive investment of time, energy, and emotion—moving back into family contexts.

Bioethics has a rather checkered record of engagement with moral issues that arise where families and medicine meet. While new reproductive technologies have been the focus of bioethical attention from the start, the proper role of family interests in healthcare decision making has been addressed only by relatively few workers in the area, and bioethics has, as of yet, taken little notice of the moral questions involved in the "hospital to home" shift. The lack of attention to issues apart from those suggested by reproductive technologies is curious, both because of the practical exigencies involved (family members, for example, are and will continue to be much more influential than formal advance directives in making healthcare choices for the incompetent), and because the conceptual and moral questions involved in understanding the special character of these intimate associations are very challenging. What constitutes a family? How do various forms of family relationship translate into moral duties and prerogatives? What does "justice" mean in such contexts, and how should justice within families relate to broader concerns about justice in the allocation of healthcare resources in society?

With the turn of the twenty-first century, however, bioethicists have shown a greater willingness to take up these questions, and to consider in particular that the role of family members in the care of ill relatives may be morally more complex than simply that of serving as conduits of information about the treatment preferences of patients too ill to express them on their own. The pioneering work of scholars such as John Hardwig has helped to instigate broader bioethical reflection on how healthcare choices can affect the well being of other family members, and has pressed in particular the question whether the impact of patient care on families gives them a legitimate stake in the treatment decision-making process. While the notion that the interests of families should be considered along with patient interests in choosing among treatment options remains highly controversial among bioethicists, there is some evidence that healthcare providers are more receptive to this idea than are theorists. A 2003 study by Hardart and Truog reports that many physicians regard the interests of family members as pertinent to healthcare decision making, even in the absence of specific patient acknowledgement of those interests. A sizable minority went further, regarding family interests as of equal significance to those of patients. If these results are representative, then bioethicists will have a strong incentive to consider the role of families more carefully then they have yet done, and to address in particular the burdens on families that do not emerge primarily from clinical decision making, but rather from policies on the part of hospitals and insurers that send patients home "quicker and sicker."

There is other evidence that healthcare providers have been more sympathetic than bioethicists to the role that families play in the lives of so many patients. *Family medicine* or *family practice* is a distinct primary care specialty within medicine, but there is no comparably entrenched specialty within bioethics and little bioethical attention has been paid to family medicine's particular focus and problems. In addition to its treatment of the family from perspectives pertinent to bioethics, then, this entry also contains a brief discussion of the ethical dimensions of family medicine.

Families: Myth and History

The development of a mature "bioethics of the family" is significantly complicated by controversies concerning the nature and importance of this much-vaunted, much-maligned social institution. The dramatic shifts in the demographics of American families have rendered them suspect, as have public debates that underscore the family's role in sustaining practices hostile to women's interests and that identify families or *family values* as a particular focus of conservative political perspectives. Families have come to seem so fragile, their configurations so arbitrary compared with what they once were, and their value so contested, that offering them a special role in bioethical deliberation may seem a dubious enterprise.

Yet neither hostility nor sentimentality does justice to the moral character of these complex and puzzling entities. Nor is the notion that families are particularly unstable in today's world altogether accurate. American families have always been somewhat fragile and subject to rapid reconfigurations. African- and European-American families in the Chesapeake colonies of Virginia and Maryland, to take only one instance, were so vulnerable to malaria and other fatal illnesses that it was not at all unusual for an adult, whether slave or free, to bury three or even four spouses, or for half-orphaned children to be reared by relatives other than the surviving parent. In the matrilineal Iroquois societies of that same period, divorce was quite common. It is true that middle-class families gained a certain solidity when they underwent a shift around 1800 to a sentimental, child-centered model of domestic life, but this was achieved through an arguably unjust gendered division of labor, in which the middle-class father was increasingly absent from home and the mother's work was narrowed principally to unpaid domestic tasks. For many poor young nineteenth-century mothers—whether black, Latina, Irish, or east European—this arrangement was not an option, and the long hours spent working outside the home left the care of their children a somewhat haphazard business. Death in childbed and other premature deaths once threatened the family's integrity as much as the divorce rate, which has risen by a steady 3 percent in every decade since the Civil War, does now. In short, there is good reason to think that stress, turmoil, and identity crises have long been a feature of American families.

The "Culture of Divorce"

The long history of family fragility notwithstanding, however, sophisticated scholarship now identifies divorce as a source of instability particularly threatening to children's well being. Sociological and ethnographic studies appearing since the mid-1990s suggest that the fate of the "family of origin" is of systematic and enduring importance to many central features of children's lives, and that the damage ensuing from divorce has a strong tendency to reach well into adulthood, at least in contemporary American culture. Judith S. Wallerstein, Julia M. Lewis, and Sandra Blakeslee argue in *The Unexpected Legacy of Divorce* (2000) that divorce impairs children's ability to consolidate their identities as mature adults and to form their own enduring intimate relations, in a way that is apparently different and seemingly graver than other forms of familial disruption and reconfiguration. Some of this damage would seem to be a function of features that often attend divorce: the subsequent inability of parents to provide reliable, timely, and well-directed care, the tendency of noncustodial parents—particularly fathers—to attenuate or even abandon their connections to their children, economic losses leading to a reduced ability of custodial parents to spend time with children, and so forth. Some damage, however, apparently is attributable to divorce itself. Even when parents divorce relatively amicably, maintain continual and substantial engagement in their children's lives, do not require their children to "take care of them" emotionally in inappropriate ways, and are able to support their children's fiscal and emotional needs without interruption, children undergo losses in their expectations and abilities concerning the maintenance of their own long-term intimate relationships, and seem to suffer a measurable delay in their movement into adulthood. These decrements seem to be of a different and more severe character than the harms that affect children who have grown up in families where the parents were continually unhappy but did not divorce.

While many questions remain to be answered—for example, why these harms seem to be more pernicious in the United States than in, say, Scandinavia; and whether divorces in which care is taken to protect the children are worse on the whole than other ways in which families have come unglued throughout history—recent social scientific studies make it difficult to regard divorce as a feature of contemporary life that children can simply get over.

These results may have implications for bioethics as well as for healthcare practice and policy. Is the process of transferring ever more intensive forms of care from hospital to home made more morally suspect by the possibility that children with divorce in their pasts will be less willing to provide such attention with the consistency and quality required for good health outcomes? Is the role of family members as presumptive proxy decision makers cast under a cloud? Is the apparent willingness of many physicians and at least some bioethicists to recognize family interests as relevant to medical choices rendered more problematic by these data? And, given the emotionally complex, internally contested, and structurally protean character of people's affiliative and kinship patterns, what counts as a family anymore, anyway?

Defining *Family*

A measure both of the importance of families to our lives and of our ambivalence about them is that any discussion of the topic quickly elicits a demand for an explicit statement of what is meant by *family.* The most useful such account is perhaps a normative one, which identifies features of special moral significance in the clear paradigm cases. Those features can then be used to determine what counts as a family in the less clear cases. Ludwig Wittgenstein's notion of family resemblances may be pressed into service here: any social configuration that incorporates at least most of the morally significant features of, say, marital and parent-child relationships can be thought of as a family for purposes pertinent to healthcare. These features include longstanding, committed relationships; blood ties; emotional intimacy; shared histories; and shared projects that produce solidarity among family members. Other crucial features identify functions: families forge the selves of their youngest members and help maintain the selves of adults. Further, familial relationships go beyond the contractual and the voluntary; in them people incur responsibilities not of their own choosing.

Relationships within families will take on greater or lesser bioethical significance, depending on the familial question under consideration. If treatment decisions for a badly damaged neonate are at issue, *family* means the mother and father; if the issue at hand is pedigree testing for a genetic disorder, *family* means blood kinship; if the issue is determining the appropriate caregiver for a person with progressive dementia, *family* may mean spouse or child.

Family and the Law

Discussions in family law echo the question of how we are to define families. While there was for many years no basis in common law for family members to make treatment decisions for incompetent adults, for example, a number of court decisions in the 1980s as well as various legislative actions gave families explicit decisional authority in twenty states. By the turn of the century, thirty-five states plus the District of Columbia recognized the authority of family members to make many significant healthcare decisions, should their relatives become incompetent, without having an explicit advance directive. This legal trend makes it all the more necessary to know just who is entitled to count as family. A strictly biological definition does not capture what seems socially significant about single parenting, adoptive parenting, step-parenting, or contract pregnancy. The legal notion of marriage skips over *kith*—long-standing, committed relationships resembling kinship that might give, say, a neighbor or housemate moral authority to speak on behalf of a patient who is too ill to make treatment decisions. The law also fails to recognize gay and lesbian relationships, though these are often more significant than blood ties to the people within them. On the other hand, functionalist definitions of families require courts to determine whether a particular relationship closely enough approximates an accepted norm of *family* to count as one. This involves inquiry into such areas as sexual activity, management of finances, and degree of exclusivity and commitment—a profound intrusion into personal privacy.

When one compares the body of family law against the body of law dealing with, for example, commercial transactions, family law seems distinctly underdeveloped and lacking in detail. The reason for this, Lee Teitelbaum argues in

"Intergenerational Responsibility and Family Obligation: On Sharing," is that families, incorporating "diffuse, particularistic, and collective values and relations," tend to reflect a wide-ranging set of circumstances and goals, while law is better suited to consider individuals as abstracted from these particulars in public settings that can be assimilated into a formal, rational scheme (Teitelbaum, p. 789). There is a further problem. In "Bioethics and the Family," Carl Schneider points out that in the last few decades family law has increasingly eschewed moral discourse. The temptation is understandable: the problems within families are complex and often "reduce to unresolvable disputes over unverifiable beliefs" (Schneider, p. 822). But by avoiding the language of morality, family law has stripped itself of conceptual notions that might help resolve such bioethical perplexities as contract pregnancy and the family's role in decision making for incapacitated patients.

Challenges to an Ethics of Strangers

Bioethics, however, need not lie down with the law. Because it can achieve a high degree of particularity, it is better suited than the law to use a working definition of families that identifies morally relevant features and notes family resemblances (so to speak) among various small-scale human groups that include some such features. Roughly speaking, two approaches have been used to incorporate what is morally valuable about families into bioethics.

The first approach assumes the moral framework characteristic of the Enlightenment, with its stress on the impartial and the universalizable. Within this tradition, Nancy Rhoden has criticized the suspicion of the motives and interests of family members that has opened family decisions concerning nontreatment of incapacitated relatives to court review. Arguing in "Litigating Life and Death" (1988) that because family members "are in the best position to reproduce the preferences of an incompetent patient," Rhoden concludes that the burden of proof should be on the physician rather than the family to convince a court of law that an unwise decision has been made. Using the same moral framework but setting it in service of a more radical departure from current practice, Hardwig (1990) has attacked the exclusionary bias of the doctor-patient relationship, insisting that the interests of all those with a stake in a medical decision, not just the patient's, be honored impartially.

At the same time, the so-called personal turn in ethics explored by Bernard Williams, Lawrence Blum, Jeffrey Blustein, Margaret Urban Walker, and others has challenged the orthodox assumption that ethics has primarily to do with right conduct among strangers—an ethics that favors no one and whose dictates are universalizable. The personal turn might be said to have begun with Williams's germinal observation in "Persons, Character, and Morality" (1981) that impartialist dictates, if followed scrupulously, leave insufficient room for moral agents to pursue their own individual interests, desires, and projects—all the substance, in fact, that gives life its meaning, yet such meaning is what motivates one to go on. The task of Williams and others has been to construct moral accounts that honor the particular and the personal, but do so in a nonarbitrary way. Feminist ethical theory has devoted much attention to this task (see Hanen and Nielsen; Kittay and Meyers; Mahowald; Nussbaum; Walker).

In bioethics, one can see the direct impact of the personal turn in the writings of Ferdinand Schoeman. He has argued that a Kantian ethics for strangers, which insists that medical decisions for an incompetent person can be made only in accordance with what is in that person's best interests, provides an inadequate basis for understanding the parent-child relationship. That relationship, because it is intimate, permits parents to compromise the child's interests so as to promote the family's goals and purposes. Parents could, for example, permit a child to donate bone marrow to save a sibling's life, even though donating the marrow is not in the child's medical interests. In Schoeman's view, then, the family is seen as an entity with an integrity of its own that is greater than the sum total of the interests of its members (Schoeman, 1980, 1985).

Rhoden's attempt to vindicate the decisional authority of families and Hardwig's challenge to the patient-centered focus of conventional bioethics use the relatively straightforward strategy of applying impartialist standards to a context—the doctor-patient relationship—where they have not been applied before. Both writers are concerned with decision making, and more particularly with the locus of the decision. By contrast, the personal turn in bioethics, which is concerned with a more fine-grained understanding of the structures of interpersonal relationships and their importance for human action, is less well developed. But attention to the personal suggests certain moral features of family life that might be used to construct an ethics of the family.

Some Elements of an Ethics of the Family

Social critics from Plato through Shulamith Firestone have argued that the distinctive features of the family constitute moral liabilities, and that families ought to be altered or abolished. In *A Theory of Justice* (1971), John Rawls notes quite explicitly that the family is always a problem for egalitarian social theory. A more sympathetic approach would portray those features as morally valuable, but whatever one's basic stance toward families, they do possess features that require moral attention and analysis.

One rather marked characteristic of families is their tendency to favor their own over outsiders. A central question is whether this sort of bias can be adequately understood inside a universalizable, impersonal framework. For example, can the favoritism parents show their children be justified insofar, and only insofar, as it increases the overall utility? James Rachels has argued for a position he calls "partial bias," which allows the expression of particular regard for children (and presumably for one's intimates in general) in those cases where their needs are in conflict with similarly serious needs of others, but not otherwise. This approach, he suggests, allows the special goods of intimacy to flourish within the context of appropriate regard for the needs of all, impartially considered. It is, however, questionable whether a truly disinterested regard for the needs of others, in a world where resources are massively maldistributed, would leave any appreciable room for special regard for the needs of one's own, particularly for people living in affluence. But even if some measure of special attention to loved ones could be made consistent with general impartialist norms, unless family members favor their own to at least a slightly greater degree than impartialist considerations mandate, it would seem they express only an ersatz partiality, not true loyalty, love, or commitment. To feel the force of this point, consider the intuitive response to a father who, when his only daughter thanks him affectionately for taking her to a baseball game, tells her, "Oh, I would have had to do the same for any child of mine."

Rather than attempt, as Rachels does, to assimilate personal loyalty into an impartialist framework, a promising strategy might be to put less emphasis on individual integrity and the separateness of individuals, and attend a little more to the connections among individuals. A careful attention to these interconnections offers a basis for just dealings with others that takes account of the difference between strangers and intimates.

A second notable feature of families is that not all of its relationships fit comfortably under what has come to be modern ethics' most favored image of relationship: the contract. Children notoriously "didn't ask to be born," and no one chooses one's blood relations. This fact has important implications for any theory that bases duties solely on consent; indeed, families are perhaps the most plausible counterexample to such theories. It is sometimes claimed that parental duties toward children arise from the parents' having tacitly consented to the child's existence, first, by agreeing to have sexual intercourse and second, by choosing not to abort the fetus. But this analysis entails that where intercourse was forced or good-faith efforts at contraception failed, and where abortion is for ethical, logistical, or economic reasons not an option, the parents are off the moral hook. Many will be reluctant to pay this dearly to retain the contract as the model of obligation. Ordinarily, responsibilities can arise from causal as well as contractual relationships. A proximate causal role in putting another in danger, for example, obligates one to stand ready to provide aid. This thought leads Hilde Lindemann Nelson and James Lindemann Nelson to suggest, in their 1995 work *The Patient in the Family,* that parental responsibility may stem from the fact that parents caused the child's existence and not from their having contracted for the child. In fact it can be maintained that intimate living as such creates expectations and other vulnerabilities, which, as Robert E. Goodin has argued, carry with them certain prima facie noncontractual duties (Goodin). Such an analysis would embrace family members other than parents in a web of moral but nonconsensual relationship.

A third feature of the ethics that typifies families is a less individualistic image of persons than is customary in impersonal ethics. Actions are often assessed in terms of their impact on the family overall, and there is a certain amount of collective responsibility for family members' well-being. A family of immigrants might, for example, devote its resources to settling other relatives in the new country, an enterprise that requires individual family members to subsume their own projects and goals to the familial one. While the communitarian feature of family ethics has often lent itself to abuse as repeated sacrifices are demanded of certain family members (particularly women) in service of an agenda set by its dominant members, it is also true that a family cannot function if its members are altogether unwilling to pull in common. An ethics of the family, in contrast to standard ethical theories, will concern itself with interests that are essentially held in common, as well as with individual interests.

A fourth distinguishing feature of what might emerge as an ethics of the family is that it is particularistic. Leo Tolstoy notwithstanding, happy families are not all alike. There are myriad differences among and within them—as there are, for that matter, among unhappy ones. Because familial relationships are not only intimate but also of long standing, family members can come to know each other in rich, particular detail and from a highly specific standpoint. This means that the principles governing their behavior toward one another can be fine-tuned to a pitch of precision that is impossible in other contexts such as law, where individual differences are perforce flattened out. What Iris Murdoch has called loving attention and Martha Nussbaum calls fine awareness would likely play an important role in any ethics of intimacy, whether among friends or within families. Attention to the particulars is what allows people involved in intimate relationships to focus on who they are together. This self-awareness, guided by general moral ideas such as justice, permits intimates to arrive at ethical decisions that are highly sensitive to circumstances and persons; the ethical work can be done "close up." Further, as these ethical deliberations become a part of the history of the relationship, their results can be used to guide future decisions that will be just as sensitive to the particulars.

Implications for Medicine

The primary health specialty of family medicine, or family practice, distinguishes itself by focusing on the healthcare needs of people from cradle to grave, and by explicitly acknowledging the ways in which illness or traumas that individuals confront resonate through the families of which they are a part. More than any other medical specialty, family practitioners have espoused the view that "the patient is the family," and they are typically trained to understand various family systems theories to gain a systematic perspective on how families can both suffer from, and contribute to, the ailments with which patients present. These skills and this orientation naturally lend themselves to dealing with ethical issues that involve patients and their families. While family practice physicians do not as a group dissent from the orthodox medical ethics doctrine that the interests of the patient always trump any inconsistent interests that individual relatives or the family as a whole might have, their interest in the family as an integral part of understanding both illness and caring can contribute to more nuanced and thoughtful ways of appreciating and ameliorating tensions between patient and family interests, as well as ways of supporting family contributions to the care of their relatives.

When a patient is incompetent to decide about his or her own medical treatment, or when competence is intermittent, physicians turn to the family for help, since families are presumed to know best what the patient would want and also to care about the patient's interests. Families are instructed to make their decision on the basis of what the patient would want—the "substituted judgment" standard established in the 1976 *In re Quinlan* case. If the patient was never competent, the family is expected to decide on the basis of what is best for her or him—the "best interests" standard. Tightly focused on the patient, either standard is open to challenge.

Linda L. Emanuel and Ezekiel J. Emanuel observe that the substituted judgment standard has been challenged on both theoretical and empirical grounds. An important theoretical objection is that reconstructing what a patient would want in highly specific circumstances from a general knowledge of the person's values requires a tremendous imaginative effort that may be beyond most people, while the empirical objections are that patients do not in fact discuss their preferences with family members, that family members are not good at assessing a patient's quality of life, and that proxies' selections are not much better than random chance in predicting patients' preferences for life-sustaining interventions. As Patricia White points out, people often do not know what they themselves would want if seriously ill.

The best interests standard is open to the objection that it cannot be seen as a patient's exercise, by proxy, of his or her right to refuse or consent to treatment, but instead gives the family power to exercise its own authority over the incompetent patient—something our society is reluctant to do because of the fear of abuse. While there are certainly instances of familial abuse of patients, one might question whether we ought to base social policy on the assumption that abuse is the possibility most to be feared. Yet if this objection to the best interests standard is unpersuasive, there is another that may be more convincing: the standard is not suitable to families because they are not, typically, a group of people each simply seeking to maximize his or her own self-interest. There is a collective character to family life that is not easily accommodated by the notion of individual best interests, and so the best interests standard is a code of conscience that from the family's point of view is distinctly second best. In fact, the standard is invoked primarily in adversarial situations where the family's solidarity has broken down, as in child custody disputes.

An ethics of the family might suggest that what family members owe each other is not the best, understood abstractly. If it were, parents would have a duty to find better parents for their children than they are themselves. Rather, what is owed is the good that inheres in this particular set of relationships. If this is right, then at the sickbed it is less important that a brother, lover, or daughter-in-law should correctly decide what is best for an incompetent patient than that the decision be made by this particular person, the one who stands as close to the patient as possible and so serves the patient as an extended self. Here, as well as where the patient is competent, decision making that recognizes morally salient features of family life might set the needs and desires of the patient into careful balance against the family's resources for care, bringing a nuanced understanding of all the relevant particulars to bear on the decision.

What, if anything, do adult children owe their frail elderly parents? Theories affirming a duty of reciprocity argue that parents gave their children life and cared for them when they needed care; in return, children owe their parents care when they are in need. The difficulty with such theories (held by Aristotle and Aquinas, and more recently by the Victorian jurist William Blackstone) is that they do not seem to recognize that parents have a duty to provide their children a decent minimum of goods and services. If parents are merely discharging their own obligations, it is hard to see why the child need respond with anything more than thanks. Following this line of reasoning, neither Jane English nor Norman Daniels can defend a duty of adult children to care for their parents. The child, not having contracted for the parental sacrifices made on his or her behalf, has no duty to reciprocate, since sacrifices that have not been requested require no return. A third view, shared by Blustein and Joel Feinberg, distinguishes between duties of indebtedness and duties of gratitude, and concludes that duties of gratitude are owed even for those actions that are included in the parents' own duties (Blustein, 1982; Feinberg). To discharge this duty of gratitude, children must help their parents when help is needed. And a fourth theory, developed by Nelson and Nelson (1992; 1995), bases a duty to parents in the parents' own moral duties, holding that the parental duty consists in part in encumbering the child with a loving relationship that in the child's maturity will be mutual. Once that mutuality is achieved, the mature relationship in turn generates the duty to care for parents in need.

Whatever the source of duties to frail elderly parents, the content of those duties is not easy to ascertain. If postindustrial societies do not set limits on the amount of increasingly costly medical care they offer the old as they leave this life, they may impoverish the young. Within a family, this dilemma might be played out in terms of nursing-home care for a grandparent versus a child's college fund. In "Moral Particularity" (1987), Walker has described such a decision as an opportunity for defining oneself morally, ratifying or breaking from a past course of action as one sets the course of one's future. Families, too, might be capable of strong moral self-definition of this kind.

Medical solutions to infertility are genetic solutions; there is an attempt to establish a genetic tie between the child and at least one parent. In a *genetic* contract pregnancy (in which the birth mother's egg is used to produce a child for people who have paid her to have the baby on their behalf), the importance of the maternal genes is played down, but the paternal genes—those of the contracting father—are considered crucial. In the far less common arrangement whereby the birth mother is hired to carry to term an embryo formed in vitro by the contracting couple's egg and sperm (this is called gestational contract pregnancy), the maternal genes regain their standard social meaning; the woman who is genetically linked to the child is regarded as its mother. By contrast, in artificial insemination by donor, the paternal genes are seen to carry no social responsibility for the child. The model for all this is one of consumer choice, in which the infertile parties are at liberty to decide for themselves what weight to give genetic ties.

This model raises important questions about the moral significance of being a parent. If those who contribute genetically to a child can be said to cause that particular child to exist, and if an ethics of the family adopts a causal rather than a contractual model of responsibility, then the child's genetic parents would seem to have a prima facie obligation to remain in the child's life in an ongoing way. Even if they delegate much of their responsibility for rearing the child, it does not follow that they may put themselves totally out of power to keep the child from harm. Thus lesbian or gay couples, for example, might have a duty to foster a loving bond between the child and the biological parent of the opposite gender.

Medicine invites a consumer-choice approach not only in the matter of genetic ties but also in the matter of genetic screening. While it is reasonable to protect one's family by trying to avoid giving birth to a child with a serious genetic defect, the choices made possible by genetic screening can be a burden as well as a benefit. An important mechanism for drawing new members into the family—the pregnant woman's continual process of making friends with her fetus—is distorted and interrupted by amniocentesis, endoscopy, chorionic villus sampling, ultrasound, alpha-fetoprotein assays. Such screening, along with the new possibility of fetal surgery, prompts the question, not when the fetus becomes a person, but how and when the fetus joins the family. As Stanley Hauerwas and William Ruddick ask, when is a fetus a child? (Hauerwas; W. Ruddick, 1989). At what point in the process of family creation ought the pregnant woman to make specific sacrifices on the fetus's behalf, and to what extent should these sacrifices be socially imposed?

A major function of the family is the care of its sick and vulnerable members. Because the United States has not acknowledged a basic responsibility to provide a minimum of healthcare for all its citizens, and because healthcare institutions are greatly concerned to minimize their own costs, the burden of providing that care has fallen disproportionately on families—and within families, on women. The difficulty in achieving gender justice with respect to healthcare is not conceptual but political: how can we reconfigure our society—and our families—to eliminate the bias that sees unpaid care as a natural task for women?

A further allocation issue concerns the range of the family's care. To whom is it owed, and when is it discretionary? What about adult siblings? Cousins? Grandparents? A child's partner? Need and the person's role in the family's history are both relevant considerations, as are the family's resources. If, after all, familial caregiving is exhausted, no further care will be forthcoming. What limits may the family set on the care it owes to its own? What limits may the family set on individual members' sacrifices? More particularly, in light of the fact that women assume a greatly disproportionate amount of the burden of care, what steps should be taken both within families and in the larger society to achieve gender justice? An ethics of the family might offer guidance through the concept of familial integrity, understood as the particular way in which a given family strives to sustain a fruitful tension between intimacy and autonomy, and the way it engages in its characteristic projects and activities. Family integrity cannot, perhaps, be preserved at any price, but it is important to recognize that families as well as individuals can be destroyed unless justice forbids it.

Implementing an Ethics of the Family

Just as medical care is ethically inadequate when the focus is on the organ to be treated rather than on the person in whom the organ resides, so it is likely to be inadequate when no notice is taken of the families in which patients reside. An ethics that treats people as if they were unconnected and self-centered is not up to the task of promoting either justice or human flourishing. Primary care physicians—not only practitioners of family medicine but also pediatricians and internists—are often adept at seeing beyond the patient to the nest of relationships within which that patient lives. They, like nurses and social workers, although hampered by institutional pressures that push families into the background, tend to be attuned to these relationships even when they cannot give a formal moral account of them. That account has been slow in coming; the values of families remain much more diffuse and implicit than the well-articulated values of medicine. But the relationship between the two systems of care is beginning to receive systematic exploration.

As discussions continue regarding what that relationship should be in the twenty-first century, it may be concluded that taking families seriously requires major institutional changes. Hospitals might need to be restructured so that patients are not so estranged from their families; hospital ethics committees might have to take on a mediator's role for disputes among family members concerning patient care; the moral significance of families might have to be better reflected in case law; the conditions under which care is delivered will certainly have to be more hospitable to an ongoing relationship between patients and those who care for them; there will have to be a greater acknowledgment that families—the original providers of primary care—are as essential a source of healthcare as medicine is. The practical difficulties in implementing an ethics of the family as it relates to healthcare, while daunting, are surely counterbalanced by the importance of the enterprise to the larger task of bioethics: thinking well and carefully about the concrete human realities—our differences, our similarities, our particularities, our intimacies—that have a direct bearing on health, whether within a medical or a familial setting.

HILDE LINDEMANN NELSON
JAMES LINDEMANN NELSON (1995)
REVISED BY AUTHORS

SEE ALSO: *Abortion; Abuse, Interpersonal; Adoption; Aging and the Aged; Care; Children; Cloning: Reproductive; Confidentiality; Dementia; Environmental Ethics: Ecofeminism; Fertility Control; Future Generations, Reproductive Technologies and Obligations to; Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Grief and Bereavement; Infants; Long-Term Care; Maternal-Fetal Relationship; Natural Law; Organ and Tissue Procurement: Ethical and Legal Issues Regarding Living Donors; Population Ethics; Psychiatry, Abuses of; Reproductive Technologies; Sexual Ethics*

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FEMINISM

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As a social and political movement with a long, intermittent history, feminism has repeatedly come into being, generated change, and subsided into oblivion. As an eclectic body of theory, feminism entered the academy in the early 1970s as a part of the women’s studies movement, where its contribution to scholarship in the arts, social sciences, and humanities has perhaps been particularly significant. Despite the variety of its political positions, social commitments, and theoretical vantage points, feminism’s common concern is with the social pattern, widespread across cultures and history, whereby power and entitlements are distributed asymmetrically to favor men over women. This asymmetry has been given many names, including the subjugation of women, sexism, male dominance, patriarchy, systemic misogyny, phallocracy, and the oppression of women. A number of feminist theorists simply call it gender, and that usage will be adopted here.

The concept of gender rests on the assumption that there are two sexes, male and female. The cultural meanings assigned to those sexes through complex social processes establish a power relation in which masculinity predominates over femininity, and the things associated with masculinity predominate over their feminine counterparts. The term *gender* refers to this power relation, which operates through society’s institutions and practices by conferring the control of resources and the right to social goods on men while relegating women to subordinate positions in service of men’s interests and concerns. But because gender always works in a complicated interconnection with other abusive power systems such as race, ethnicity, sexual orientation, class, age, and disability, some women enjoy more power than some men. By the same token, these other power systems produce greater amounts of privilege for some women than for others.

One of the characteristic features of gendered power relations is androcentrism: the (usually unstated) view that man is the point of reference for what is normal for humans. According to the logic of androcentrism, if man is the yardstick or measure for being human, then women, not being men, must be defective humans. Furthermore, because androcentrism presumes that men are the point around which everything else revolves, the feminist insistence that women too are full–fledged human beings is just as much about men as everything else is—it is a threat to masculinity, or an attempt to usurp men’s rightful place in the natural order of things.

Racism and discrimination against gays and lesbians employ the same sort of logic: the white race and heterosexuality are the norm for human beings, so anything other than the norm must be defective—not just statistically but morally abnormal. From this it follows that the demand to de–center the dominant group (or, to use another spatial metaphor, to dismantle the hierarchy that puts the dominant group on top) must be seen as a threat to the group—a threat to “the Southern way of life” or to “the family as we know it.” Looking at the demand in this way keeps the focus on the dominant group, so that it, rather than unjust treatment of the subgroup, remains the center of attention.

Criticism and Construction

As a political movement, feminism has sought to undermine or overthrow the social mechanisms through which gender operates to oppress women. Because gender identity cannot be understood or even perceived outside its complicated interaction with other abusive power systems, feminists resist those as well. A feminist politics is not only a politics of resistance, however. It is also a politics of construction. It seeks to build a more just society—one that is as good for all kinds of women as it is for all kinds of men. So, for example, "first-wave" U.S. feminists such as Elizabeth Cady Stanton, Sojourner Truth, and Lucretia Mott worked for the right of women to own property, not to be enslaved, and to vote.

As a field of scholarship, feminism likewise pursues two goals. The first is criticism. Feminists have uncovered and opposed gender bias in the humanities, social sciences, natural sciences, the arts, and professions such as law and medicine. Sandra Harding, for example, has criticized the view, widely shared by scientists themselves, that science is value–free. She argues that scientific knowledge is produced largely by men who command significant amounts of social prestige, and that the perspective of these men is necessarily colored by assumptions and values arising from the kinds of activities in which they engage. As science leaves this perspective unexamined, it assumes an objectivity that it does not in fact possess.

What Donna Haraway has dubbed the "god trick"—the ideal of a perspectiveless and timeless view from nowhere that purports to secure objectivity—strikes many feminists as both politically suspect and impossible to achieve. Feminist epistemologists such as Lorraine Code and Helen Longino argue that greater objectivity is attained by taking careful and rigorous account of knowers' social locations than by ignoring the effects of power on what kinds of knowledge is legitimated, whose knowledge is considered authoritative, and which knowers are ignored or excluded as a result.

As well as questioning sexist understandings of objectivity, feminists have criticized the gender bias that inheres in other key theoretical concepts and indeed in mainstream theories themselves. But like political feminism, academic feminism does more than criticize—it also constructs. Feminist economists, for example, have not rested content with condemning the masculine bias inherent in the individualism and competition of much economic theory; they have constructed economic models that begin from the fact of human dependency and connection. Feminist historians have not only pointed to the gender gaps created by their profession's focus on military campaigns and other male–dominated activity in the public sphere, but have used women's diaries, letters, and other writings to construct histories of women and of domestic life. Feminist constructions in philosophy include a shift from mainstream epistemology's preoccupation with necessary and sufficient conditions for knowledge, to the theoretical importance of the social location of the knower. Equally significant has been the construction of feminist moral theory, particularly the ethics of care and feminist responsibility ethics.

Feminist Epistemology

While on its face there seems to be something paradoxical about feminist criticisms of reason, given that the forms of argumentation on which these criticisms depend are themselves a part of what is under attack, the burgeoning literature on this topic may be understood, not as a repudiation of reason *tout court,* but as a dissatisfaction with a particular picture of reason. This picture, which underlies much of contemporary nonfeminist ethics as well as other areas of mainstream philosophy, is that of a pure, universal reason, abstracted from historical and social contexts, operating dispassionately and objectively to produce true propositions. Feminists fault this picture as much for what it excludes as for what it portrays.

For one thing, the picture excludes the emotions, rather than acknowledging that feelings such as empathy, resentment, or anger play a useful role in reasoning—especially moral reasoning. The picture in particular excludes what people care about, rather than acknowledging that what they care about can itself be a reason for thinking or acting the way they do. It excludes trust, rather than acknowledging that trust is what keeps one's reasoning from becoming paranoid. And it excludes narrative or figurative modes of reasoning, rather than acknowledging that people often use stories and images to make sense of the world.

One important strategy for feminist epistemologists, then, has been to identify the tension between the explicit content of philosophical arguments, which appears gender–neutral, and the models, metaphors, and imagery underlying these arguments, which covertly favor the experiences and preoccupations of privileged men. A second important strategy has been to question the tradition that divorces reason from other human attributes. Many feminists have emphasized the role of the emotions in rational reflection, while others have emphasized the point that human reasoners are embodied, and that the social constructions surrounding differences in embodiment count among the conditions that make knowledge possible. Still others have emphasized the essentially social nature of human existence, arguing that knowledge is not "in the head" of solitary reasoners, but rather is produced and imparted in communities of knowers, and that abusive power systems operate in these communities to discredit unjustifiably certain kinds of reasoning while authorizing others.

Borrowing from Marxist analysis, in the 1980s feminist standpoint theorists such as Nancy Hartsock and Patricia Hill Collins drew an analogy between women in gendered societies and workers in capitalist societies. They contended that just as the false presuppositions that sustain the ideology of capitalism are most visible from the hard–won perspective of the worker who has participated in consciousness–raising and political engagement, so too the false presuppositions that sustain the ideology of gender are best seen from the standpoint of those who have had to acquire detailed, self–reflective knowledge of the gender system simply in order to be able to function within it. Feminist standpoint theorists are less interested in claiming a single, unified standpoint that is representative of all women, however, than in taking seriously the knowledge that informs women's practices—whether domestic, emotional, intellectual, or professional.

Ethics of Care

One such practice is that of giving care. In the United States, but also in many other societies, women do far more unpaid, hands–on caregiving than men—they change the diapers, wash the dishes, clean the bathrooms, take the dog to the vet, feed and dress the children, take care of sick or disabled family members, and provide long–term care for elderly relatives. Even when married women have full–time jobs, they still almost invariably do the vast majority of the housework, childcare, and elder care. Nearly 75 percent of unpaid elder care is done by women, and after a divorce or in cases where the parents never married, 75 percent of dependent children live with and are cared for by their mothers rather than their fathers—a figure that approaches 100 percent when the children are infants or toddlers. Paid caregivers are mostly women, as well. Almost 96 percent of professional nurses are women, and the percentage of women providing daycare for children is close to 99 percent. In Canada, women do 80 percent of all caregiving, both paid and unpaid.

The Harvard psychologist Carol Gilligan, taking seriously the idea that women's experience of caregiving produces its own kind of moral reasoning, questioned whether the scale of moral maturity developed by her colleague, Lawrence Kohlberg, was as universally applicable as he supposed. At the first stage of Kohlberg's scale, morality is conceived of as a system of punishment and obedience. At Stage Two, it is motivated by personal reward. At Stage Three, it is taken to be a matter of helping and pleasing other people. At Stage Four it is understood as a set of rules for maintaining the social order. Those who reach Stage Five can sum up those social rules in a principle such as "the greatest good for the greatest number," while those at Stage Six are able to think of morality in terms of self–chosen universal principles of justice. Not everyone, claimed Kohlberg, reaches the more advanced stages of moral maturity.

Gilligan, noting that men consistently scored higher on the Kohlberg scale than women, questioned the reliability of the scale rather than accept its implication that women tend to be less morally mature than men. She claimed that many of the girls and women in her own developmental studies simply reasoned about moral matters "in a different voice." Instead of talking about rights and rules, they were using the language of relationships and connection. Rather than reasoning abstractly, their thinking was contextual and concrete. She called this a "care" orientation toward morality, and opposed it to the "justice" orientation displayed at stages Four, Five, and Six on Kohlberg's scale. Gilligan was careful not to say that the "different voice" is the voice of all women across cultures and through time, any more than the voice of justice is the voice of all men. She did, however, argue that gender shapes the experience of men and women differently, and that gendered experience—particularly the experience of living in a society that expects girls and women to perform vast amounts of caring labor—produces "different modes of moral understanding."

Nel Noddings, Virginia Held, Sara Ruddick, Joan Tronto, and Eva Kittay are among the most prominent of the feminist theorists who have used Gilligan's moral psychology to construct an ethics of care. They have examined caregiving for the moral understandings internal to the practice, offering accounts of not only what it is to care well, but also of the social and political framework in which this practice takes place. While care theorists have by no means created a unified account, it is nevertheless possible to identify three characteristic features of the ethics on which most, but not all, care theorists agree:

1. a caring relationship;
2. engagement with another's will; and
3. particularism.

Caring well both requires and is an expression of a caring relationship. The caregiver must care about the person she cares for, not only to keep the caregiving from becoming impersonal, cold, or self–serving, but because caring is a value in itself. To care in this sense is to feel concern for one's charge (Kittay's term for the person receiving the care). But while caring engages the emotions, the word does not refer solely to a cluster of feelings. As Held points out, it is also a moral term. It is a good thing to care about others; a bad thing not to care. Because it is a moral term, it can be used to guide how and when to act on one's feelings, as well as to evaluate specific instances of caregiving.

On the view of a number of care ethicists, the caring relationship requires engagement with another's will—the caregiver must treat her charge not simply as an object of her care, but as someone with wants, intentions, and desires of his own. Noddings calls on caregivers to practice what she calls engrossment, which consists of such close attention to the feelings, needs, ideas, or wants of their charges that the caregivers' own will is displaced. Other care ethicists emphasize the importance of self–knowledge, lest the caregiver confuse her own will with the will of her charge.

Caring well also requires the caregiver to pay attention to the particulars of a caring relationship rather than being guided by abstractly formulated rules or principles. It is by being closely attentive to this particular person, who needs this particular kind of care, in these specific circumstances, rather than by reflecting on general moral precepts, that morally admirable care is given. This is not to say that caregivers ought never to engage in abstract thinking. But the point is to remain within the caring relationship, which requires attention to the person for whom one cares rather than attention to moral abstractions.

A number of feminist ethicists have argued (repeatedly) that each of the three central features of the ethics of care reinforces the stereotype of the self–effacing wife and mother, prescribing courses of action and ways of thinking that are bad for women. In particular, the critics have identified three dangers. First, if the caregiver cares about the person she cares for, her feelings will not permit her to leave her charge's needs unmet, which poses the danger of exploitation. Second, the caregiver might become so engrossed in the needs and wants of her charge that she gives up her own sense of right and wrong, thereby losing her integrity. And third, if the caregiver attends closely to the particular needs and circumstances of her charge, her field of vision cannot accommodate the broader concerns of social justice.

Kittay's solution to the problem of exploitation is to call for financial, economic, and logistical support for caregivers. She argues that if one begins from the fact of human dependency instead of from the assumption that "all men are created equal," then caring for those who need it can be seen as one of the requirements of justice—as can support for those who provide this care. Diemut Bubeck has a different solution. Her idea, modeled on military service, is that men and women alike could spend some period of their lives in a "caring service" whose mission would be to provide respite care for unpaid dependency workers.

As for the problem of integrity, one solution is to build self–care into the ethics of care so that it does not become an ethics of self–erasure. However, if the caregiver's only motive for taking care of herself is that she can then better care for her charge, she stands in danger of losing herself altogether. Cheshire Calhoun's 1995 account of integrity provides a different solution. She argues that integrity is not only the personal virtue of holding fast to the moral values that are central to one's self–conception, but also a social virtue, exercised by reliably standing for one's own best moral judgments to other people. If integrity involves being the kind of person others can depend on, it cannot be threatened by caring well. Indeed, for the caregiver to do what she knows to be wrong would count as defective care, because it would mean that her charge could not rely on her.

In response to the claim that the ethics of care is too focused on the personal and the particular to attend to issues of social justice, Tronto proposes to redraw the boundary that political theorists and others have marked between morality and politics. As caregiving is a practice embedded in social life, she claims, it has to be understood in a political context and not just a moral one. A politics of care that complements the ethics of care would, in Tronto's view, recognize and support the caring labor on which every society depends. Such a politics would shift the goals of social policy from preserving autonomy to fostering interdependence; from promoting interests to meeting needs. It would value citizens even when they cannot fend for themselves.

Responsibility Ethics

The ethics of care is based on a morally crucial relationship between people that has too often been ignored or dismissed by nonfeminist ethicists, but relationships other than those involving care are also morally important, and they too give rise to responsibilities. Nor are relationships the only source of the moral demands made on people. For these reasons, several feminist ethicists have gone beyond care to develop an ethics of responsibility.

Margaret Urban Walker is less interested in the abstract questions that philosophers have traditionally raised about the conditions under which someone is morally responsible (Was he free to act otherwise? Did she form the proper intention?) than in examining how practices of responsibility operate within actual moral communities. People hold one another to their promises, excuse them, demand an explanation, give them a standing ovation, let them stew in their own juice, award them the Nobel Prize, and sentence them to death by lethal injection. In these and other ways responsibility is assigned, accepted, taken, deflected, redirected, and renegotiated.

How one is expected to participate in society's practices of responsibility depends just as much on one's gender, class, age, ethnicity, and race as it does on one's own achievements. Who gets to do what to whom is largely determined by the social power that is distributed according to these demographics, as is the matter of who must account to whom. And just as social position influences whether and to what extent one may take, assign, or avoid responsibility, so too it plays a role in determining who may set or change the rules that govern when, how, and by whom this may be done.

As Walker points out, however, the system is rigged. The social forces that allow some people to take responsibility for the things that are pleasant or rewarding, while imposing on other people the kinds of responsibility that keep them from attaining many of the good things in life, are the same forces that hide the fact that this is going on. Some of these forces naturalize the uneven distribution of responsibility, concealing the coercion that sustains the arrangement by representing it as natural—as when women are said to have a maternal instinct that qualifies them to care for children while men do not. Other forces normalize the unfairness, focusing so much attention on the norms or standards for fulfilling a particular responsibility that the question of why a particular kind of person must assume the responsibility is completely hidden from view. Incessantly barraging women with the norms for looking attractive, for example, is a wonderful way of concealing the unfairness of requiring them to take far more responsibility for their appearance than men.

Practices of responsibility look forward as well as backward. In *The Unnatural Lottery,* Claudia Card points out that people who have suffered from unfair distributions of responsibility can do more than make backward–looking assignments of blame for past wrongs. A woman who has been raped, for example, can adopt a forward–looking stance that allows her to take responsibility for what happened to her—not in the sense of blaming herself, but in the sense of refusing to be a victim. She can be responsible for rebuilding her life at the same time as she holds her attacker responsible for his deed.

Normally, adults are expected to know the moral rules and to be aware of the standards by which other people judge them. That is part of what it means to be a morally competent person. But in "Responsibility and Reproach," Calhoun observes that morally competent people can lose their competence in abnormal moral contexts, such as the one that feminists take themselves to inhabit. If, for instance, the normal moral context allows men to deflect responsibility for changing their babies' diapers, then even a well–meaning man is unlikely to see the sexism behind his assumption that when he does change a diaper, he is doing something nice rather than doing merely what he ought. As he is behaving irreproachably according to the standards of the moral context he inhabits, it hardly seems fair to blame him. One could, after all, excuse him for the same reason one excuses young children's wrongdoing—that he is not responsible for his attitude because he has not yet learned the moral rules that govern the abnormal moral context feminists occupy. But Calhoun thinks he should be held responsible anyway. When feminists reproach people who engage in sexist behavior, she argues, they teach them that what they are doing is wrong, motivate them to change their behavior, and show them respect rather than treating them like children. This is one way in which feminists can take responsibility (in Card's sense) for sexism.

The ethics of care and responsibility ethics display some common themes. Both reject the idea that persons are essentially self–sufficient and unconnected, insisting instead that selves are always nested in webs of relationship. Both emphasize the differences among people rather than making abstract generalizations about human nature. Both use gender as a central category of analysis. Both use the language of responsibilities rather than rights or duties. And both begin from careful examinations of actual, real–time personal interactions. This on–the–ground quality is highly characteristic of feminist ethics—it is a way of avoiding the mistake of theorizing from too limited a set of examples.

Feminist Bioethics

In Canada and the United States, the bioethics movement and second–wave feminism both began in the late 1960s, but the two discourses had little to say to one another for the better part of two decades. It was not until 1989 that the U.S. journal of feminist philosophy, *Hypatia,* published two special issues devoted to feminism and medical ethics. The few essays by feminists published up to that time in the premier U.S. journal in bioethics, the *Hastings Center Report,* dealt solely with ethical issues surrounding women's reproductive systems.

All that has changed. The 1990s saw a steady stream of conferences, monographs, anthologies, and essays in learned journals that examine bioethical issues through a feminist lens. Susan Sherwin's *No Longer Patient: Feminist Ethics & Health Care* appeared in 1992, as did *Feminist Perspectives in Medical Ethics,* edited by Helen Bequaert Holmes and Laura M. Purdy. The International Network on Feminist Approaches to Bioethics, begun in 1993 by Holmes and Anne Donchin, has some 300 members worldwide and has sponsored several conferences on feminist bioethics, in conjunction with the International Association of Bioethics. In 1995, the prestigious Kennedy Institute of Ethics devoted its Advanced Bioethics Course to feminist perspectives on bioethics, and the plenary lectures of that course were then published in a special issue of the *Kennedy Institute of Ethics Journal.* In 1996, the *Journal of Clinical Ethics* published special sections in each of its four issues on feminism and bioethics. That same year saw the publication of an anthology edited by Susan M. Wolf, *Feminism and Bioethics: Beyond Reproduction.* In 1998, the *Journal of Medicine and Philosophy* devoted an entire issue to the feminist ethic of care. Anne Donchin and Laura M. Purdy's anthology, *Embodying Bioethics: Feminist Advances,* appeared in 1999. In 2001, the journal *Bioethics* published an issue devoted to feminist bioethics. Textbooks and readers in bioethics routinely include essays written by feminists.

Feminist bioethics largely consists of criticism directed at practices surrounding the care of women's bodies, and in particular, the parts of women's bodies that mark them as different from men. There has been an ongoing focus on women's reproductive practices, in the form of arguments in defense of abortion, debates about the wisdom of various methods of assisted reproduction, arguments against sustaining postmortem pregnancies, ethical analyses of various sorts of maternal–fetal conflicts, concern about HIV testing of newborns and pregnant women, pleas for better prenatal care for pregnant women, debates about the use and abuse of the birth control implant Norplant, arguments for and against amniocentesis and other genetic testing of fetuses, and discussions about hormone replacement therapy for postmenopausal women. And when feminist bioethicists have moved "beyond reproduction," as Susan M. Wolf puts it, they have tended to criticize practices of healthcare for women—weighing in, for example, on the debates over the medical management of breast cancer, arguing that tying healthcare insurance to employment disadvantages elderly women, or protesting the injustice of a healthcare delivery system that devotes a disproportionate amount of high–tech care, such as arterial angioplasty and organ transplantation, to men. While this criticism can be seen as a political and moral protest against the sexism that permeates the healthcare system, it has been argued that the preoccupation with women's bodies, and especially women's reproductive health, tends to reinforce the androcentric view that men are normal but women, being abnormal, require special accommodations both within healthcare and within bioethics.

Not all of feminist bioethical criticism focuses on women's (reproductive) health. Mary Mahowald has, for example, used standpoint theory to criticize healthcare providers who systematically discount their patients' knowledge about their illness and treatment. Virginia Warren has pointed out that medicine's preoccupation with crisis issues diverts attention from what may be called housekeeping issues, which are perceived as women's work and are on that account not valued. Susan M. Wolf has argued that gendered differences in medical treatment, suicidal behavior, healthcare insurance, and social expectations about self–sacrifice offer a reason to suppose that legalizing physician–assisted suicide would further oppress women. A number of feminists have criticized the cost–cutting measures resulting in shorter hospital stays that unfairly exploit the gendered division of labor within families, where, compared to men, women do vastly disproportionate amounts of caregiving, even if this means that they are restricted to part–time employment or give up their jobs altogether.

Feminist bioethicists' constructions have consisted mainly of reconceptualizing problems in areas of healthcare practice and policy ranging from postmenopausal motherhood to home healthcare, and then offering solutions based on those reconceptualizations. With the major exception of the work of some feminist bioethicists on the ethic of care, however, constructions in theory have been almost nonexistent. Much more could be done both to expand the ethic of care so that it furnishes conceptual tools for social and political analysis, and to use the practice of medicine itself to enrich ethical theory. That so little of this work has been done is not surprising, not only because feminist bioethics is a very young discourse but also because bioethics in general has failed to produce much distinctive theory, contenting itself with the pragmatic strategy of agreeing on middle–level ethical principles where it can, and scavenging from the standing political and moral theories when it must. Feminist bioethicists, however, do not have the luxury of that sort of pragmatism, because it is the business of feminism to be deeply suspicious of the standing political and moral theories, on the grounds that they are shot through with gender bias and so cannot be regarded as trustworthy. Many feminists argue that their task is to construct new theory rather than to refine theories that leave everything exactly as it was.

Why ought feminists theorize about ethical issues arising from biomedical practice? Why, that is, should there be a feminist bioethics at all? One answer is that medicine ought to be of particular concern to feminists because it is one of the hegemonic discourses of our time, commanding enormous amounts of social prestige and authority. Because it is so powerful that no other discourse except, possibly, that of international capitalism competes with it, it interacts with gender at many levels and in many different ways. Feminists continue to criticize that interaction, but they also wish to learn from it. By studying how power, in the guise of gender, circulates through the healthcare system, they contribute to the body of normative theory that might guide this socially valuable institution in the direction of greater justice.

HILDE LINDEMANN NELSON

SEE ALSO: *Abortion; Abuse, Interpersonal: Abuse between Domestic Partners; Adoption; Aging and the Aged: Old Age;*

Authority in Religious Traditions; Autonomy; Body: Cultural and Religious Perspectives; Care; Children: Rights of Children; Circumcision, Female Circumcision; Coercion; Compassionate Love; Embryo and Fetus; Environmental Ethics: Ecofeminism; Fertility Control; Gender Identity; Maternal-Fetal Relationship; Psychiatry, Abuses of; Reproductive Technologies; Research Policy: Subjects; Sexual Ethics; Sexism; Women as Health Professionals

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FERTILITY CONTROL

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I. Medical Aspects
II. Social and Ethical Issues
III. Legal and Regulatory Issues

I. MEDICAL ASPECTS

The ability of individuals to regulate their own childbearing represents one of the great medical advances of the twentieth century. As a result of demographic trends, which indicate an earlier onset of sexual activity and smaller family size, a woman may spend as long as thirty-five years purposefully avoiding pregnancy. An array of contraceptive methods is necessary to provide individuals with options that are most appropriate to their lifestyle, motivation, desire for effectiveness and convenience, and acceptance of medical risk. Two fundamental trends have affected contraceptive practice since 1960: the development of safe, continuous, and highly effective hormonal contraception, and more recently, an increased awareness of the role of barrier contraceptives for the dual purposes of pregnancy prevention and protection against sexually transmitted infections.

Currently available contraceptive methods include permanent methods that cause sterility—such as vasectomy in men and tubal occlusion in women—and reversible methods. Reversible methods include oral contraceptives (OCs); subdermal implants (Norplant®); progestin injections (depotmedroxyprogesterone acetate; DMPA; Depo-Provera®); intrauterine devices (IUDs); barrier methods (male and female condoms, diaphragm, cervical cap, and spermicidal products); and "natural" methods such as celibacy, periodic abstinence (natural family-planning and fertility-awareness methods), and withdrawal.

General Considerations

It is unreasonable to assume that there is an ideal contraceptive method for each couple; more commonly, couples alternate among various methods over time. A number of general considerations can help to guide an individual (or couple) in the selection of an appropriate contraceptive method.

FREQUENCY OF SEXUAL INTERCOURSE. Couples who have frequent intercourse (arbitrarily defined as more than two to three episodes of intercourse per week) should consider the more continuous, non-coitusrelated methods of contraception: OCs, IUDs, implants, injectables, or if childbearing is completed, permanent sterilization. For less sexually active couples (those who have intercourse less than once per week), an episodic method, such as a barrier contraceptive, would provide protection without exposure to method-related risks at other times.

NUMBER OF SEXUAL PARTNERS. Individuals who have multiple sexual partners, or whose partners have other partners, should be advised to consider one or more barrier methods, with the dual purposes of protection against sexually transmitted infections (STIs) and prevention of pregnancy. For couples who desire an optimal degree of pregnancy prevention, a combined approach of a barrier method plus a highly effective contraceptive will compensate for the relatively high pregnancy rate associated with barrier methods. Additionally, women in this category should not wear an IUD, as the risk of pelvic inflammatory disease (PID) and tubal infertility in IUD wearers is increased significantly in women with multiple sexual partners. For couples who are involved in a mutually monogamous relationship, no method of reversible contraception, including the IUD, increases the risk of PID or tubal infertility.

USER ACCEPTABILITY. Personal attitudes regarding the acceptability of certain methods may influence the success of use. These include religious beliefs, which may preclude the use of "mechanical" and hormonal contraceptives; tolerance of "nuisance" side effects, such as breast changes and vaginal bleeding; willingness to touch the genitals (of self or partner); and aesthetic concerns, such as tolerance of the "messiness" of spermicidal creams and jellies.

MOTIVATION AND SELF-DISCIPLINE. The degree of motivation to avoid pregnancy has a strong impact upon the successful use of contraceptives. Women who contracept to *delay* pregnancy have a higher failure rate than those who are intent on pregnancy prevention. Self-discipline also must be assessed, as women who are highly motivated may do well with intercourse-related (barrier) methods, while individuals who are poorly motivated should choose continuous non-intercourse-related methods such as OCs, IUDs, implantable or injectable methods, or sterilization.

ACCESS TO MEDICAL CARE. Because of the risk of medical complications, certain methods should be used only on the condition of reasonable access to medical care. This concern centers mainly on IUDs and to a lesser extent, hormonal methods. Users of barrier methods, natural methods, and those who have been successfully surgically sterilized have a negligible risk of life-threatening method-related complications.

EFFECTIVENESS. Desire for high effectiveness versus willingness to accept a degree of risk of failure is a primary concern for many contraceptors. Those who insist upon a high degree of efficacy are best advised to use a combination OC (discussed below), an IUD, an implantable or injectable method, or sterilization. Alternatively, for individuals who will accept a higher method failure rate, coupled with an understanding that such failures will result in a choice between delivery and abortion, less effective methods, including barriers and natural methods, may be used.

SAFETY. Medical safety is a major concern for most contraceptors, and concerns regarding health risks are a major reason for discontinuation of use. Paradoxically, adolescents are more likely to avoid or prematurely discontinue contraceptives for fear of adverse health effects, yet they comprise the age group least likely to experience them. The risks associated with contraceptive use are dependent on the following four variables, with an example of each:

1. Age. The risk of arterial complications (adverse effect on the heart and blood vessels, e.g., heart attack) of OCs is age-related; this risk is greatly compounded by cigarette smoking.
2. Underlying medical conditions. Women with underlying cardiovascular risk factors (e.g., hypertension, glucose intolerance, hyperlipidemia, cigarette use) are more likely to experience myocardial infarction (heart attack) while using OCs.
3. Sexual behaviors. A pattern of multiple sexual partners increases the risk of STIs. In particular, IUD wearers would have a greater risk of PID resulting in primary tubal infertility (fallopian tubes blocked by scar tissue).
4. Method-specific risk. Complications are intrinsic to the method, regardless of age, health, and sexual behaviors. Examples include the risk of hepatic adenomas (liver tumors that are noncancerous but that may hemorrhage) in OC users; and pelvic actinomycosis (infection) in long-term IUD users.

A key component of contraceptive efficacy and safety resides in the quality and clarity of instruction and counseling given to the user. Initial instruction should include a description of the methods of contraception currently available, their relative effectiveness, the advantages and disadvantages of each method, and, if appropriate, a comparison of short- and long-term costs. Once a method has been chosen, instruction should center on method-specific advice, such as information regarding method use and danger signals that should be reported to the provider. If the individual will be learning the use of a relatively complex method, or one with an increased likelihood of side effects, it is prudent to provide a simple backup contraceptive method, such as condoms, should the user decide to abandon the initial method. Method-specific counseling should be supplemented with a written fact sheet or other instructional material at a reading and comprehension level appropriate to the individual. Finally, the user should be encouraged to telephone or visit the office of the provider, as necessary, for further advice or modification of contraceptive use.

Oral Contraceptives

The oral contraceptive (OC) is the method of reversible contraception used most widely in the United States. Two types are available: combination OCs, which contain fixed (monophasic) or variable (multiphasic) doses of synthetic estrogen and progestin, and progestin-only pills (POPs, mini pills). OCs primarily prevent pregnancy by preventing ovulation (release of an egg from the ovary). The estrogen and progestin in the pill exert negative feedback on the hypothalamus (the part of the brain that controls hormone production by the pituitary gland) to suppress the release of the hormone GnRH, which in turn decreases secretion of the pituitary hormones LH and FSH, preventing ovulation.

OCs also thicken cervical mucus, which promotes an environment hostile to sperm and alters the endometrium (the lining of the uterus), so that implantation of an embryo is unlikely to occur even if an egg "breaks through" (is released) and is then fertilized. The failure rate of combined oral contraceptives when used correctly and consistently is 0.1 pregnancies per one hundred women per year. In typical use, the failure rate is three pregnancies per one hundred women per year.

Research continues on a male birth control pill. The initial study, announced in 1996, showed that the pill lowered sperm counts significantly with few, if any, side effects. This contraceptive is composed of a progestin and testostrone.

BENEFICIAL EFFECTS OF OCS. Prevention of pregnancy: When used correctly, OCs are highly effective in preventing pregnancy. This includes ectopic pregnancies (those that implant outside the uterus), thus preventing an important cause of maternal morbidity and mortality. There is no increase in the rate of spontaneous abortion or fetal anomalies in former users of OCs, and no long-term reduction in fertility has been demonstrated.

Prevention of acute salpingitis (also called pelvic inflammatory disease, or PID): Even when controlled for sexual behavior and for the coincident use of barrier contraceptives, studies have shown that OC users have a decreased risk of acute salpingitis. It also appears that cases of salpingitis are less severe in OC users overall when compared to controls. Paradoxically, OC users seem to have a higher rate of chlamydial endocervicitis (an STI, with inflammation of the cervix, which may or may not progress to PID).

Prevention of genital tract cancers: Data from the Centers for Disease Control and Prevention's (CDCP) Cancer and Steroid Hormone (CASH) study show a 50 percent reduction in risk for the development of both endometrial and ovarian cancer. Past use of OCs appears to bestow this protective effect for as long as fifteen years after the user has discontinued OC use. The relationship of OCs and cervical dysplasia (abnormal cells of the cervix that, if not monitored, sometimes progress to cancer) and carcinoma is somewhat more complex because of confounding biases, but overall, OC use neither causes nor protects against cervical neoplasia (abnormal tissue formation).

Relief of menstrual symptoms: OCs provide excellent therapy for primary dysmenorrhea ("normal" painful or difficult menstruation that is not related to a disease) because they suppress the endometrium (the lining of the uterus). Consequently, the endometrium does not produce as much prostaglandin, the substance that produces cramping of the uterus. There is a more variable effect on premenstrual syndrome, in that while many women have a decrease in symptoms, others have no change, and a small percentage have worsening symptoms. Because of shorter and lighter menses, the incidence of iron deficiency anemia is reduced by 65 percent. There is also a reduced risk of toxic shock syndrome.

Reduced risk of benign breast disease: OC users have a significant reduction in the incidence of benign (noncancerous) breast conditions, including fibroadenoma and fibrocystic change.

Prevention and treatment of functional ovarian cysts: As a result of the pharmacologic suppression of GnRH release and consequent blunting of pituitary gonadotrophin release, women who use OCs are less likely to develop functional ovarian cysts than women who do not use hormonal contraception. This effect appears to be dose-related, and users of low-dose OC products have less protection than those using stronger formulations. If OCs are given in an attempt to suppress an existing ovarian cyst, it is necessary to utilize a relatively strong product (e.g., Ovral) in order to achieve an effective degree of hypothalamic/pituitary suppression.

Other beneficial effects: For reasons that are unclear, OC users also have a lower incidence of rheumatoid arthritis and peptic ulcer disease.

ADVERSE EFFECTS OF OCS. The most common OC-related side effects are relatively minor. However, the patient may perceive them as major, and this may result in OC discontinuation and subsequent pregnancy. Effective management of minor or "nuisance" OC side effects consists mainly of patient education, and occasionally, medical intervention. Side effects include nausea, weight gain, spotting or breakthrough bleeding between menstrual periods, failure to have a menstrual period during the seven days off OCs, new onset or exacerbation of headaches, and chloasma (darkening of facial skin). Complications, while rare on low-dose combined oral contraceptives, can be serious.

Vascular complications: While initial studies indicated a direct relationship between estrogen dose and an increased risk of deep vein thrombosis (clotting) and pulmonary thromboembolism, more recent studies with low-estrogen-dose products have demonstrated only a minimally elevated attributable risk of these complications. For this reason, OC products containing thirty-five mcg of estrogen or less should be used routinely. In early studies of unselected women using relatively high-dose products, OC users also demonstrated an increased risk of myocardial infarction and stroke in comparison to controls. As a result of exclusion of women with major cardiovascular risk factors and a progressive trend toward the use of lower-dose products, OC users as a group no longer have an elevated attributable risk of OC-induced morbidity or mortality from arterial disease.

Hypertension: The estrogen and progestin components of OCs act in concert to occasionally cause the development of blood-pressure elevation in a small number of OC users. Hypertension is reversible with discontinuation of OCs.

Carbohydrate intolerance: The progestin component of OCs is known to cause peripheral glucose resistance and consequent elevation of insulin levels. In most cases, these effects are minor and are not clinically significant. If a diabetic woman is started on OCs, frequent blood glucose monitoring is necessary initially, as insulin requirements may change. OCs should not be given to diabetics who have clinically manifested vascular or kidney disease or to those with such cardiovascular risk factors as smoking, hypertension, hyperlipidemia (elevated fatty substances in the blood), or age over forty.

Breast cancer: The relationship between OC use and breast cancer has been studied extensively since the mid-1970s. In aggregate, the studies show that the relative risk of breast cancer in a present or former OC user is 1.0, implying neither protection nor increased risk. This relationship was present with a number of subgroups, including women who had initiated OCs at an early age, those who used OCs for longer than ten years, women with a history of benign breast disease, and those with a positive family history. However, a number of studies performed in the early 1980s demonstrated a possible association between OC use and breast cancer in other subgroups. The only thread of consistency in these studies was to show a small increase in the risk of breast cancer for recent OC users who developed breast cancer at an age younger than thirty-five. In that there seems to be a small reduction in breast cancers in past OC users older than thirty-five, it has been hypothesized that OCs, like pregnancy and exposure to other hormonal contraceptives, may be a weak breast cancer promoter, and that OCs may hasten the growth of a tumor already in existence.

DMPA

On October 29, 1992, the U.S. Food and Drug Administration (FDA) approved contraceptive labeling for depot-medroxyprogesterone (DMPA); commonly known by its trade name, Depo-Provera. This culminated a twenty-year effort to make a long-acting injectable contraceptive available to American women. Based upon the findings of extensive clinical research done outside the United States over a decade, the FDA determined that while some concerns remained, DMPA was considered to be as safe as other hormonal contraceptives already on the market.

DMPA's mechanism of action is quite similar to that of all other hormonal methods of contraception: inhibition of ovulation; thickening of cervical mucus, which makes sperm penetration through the cervical mucus more difficult; and induction of endometrial atrophy, which prevents implantation in the highly unlikely event of fertilization. The chemical structure of DMPA is much closer to that of natural progesterone than that of the 19-nortestosterone progestins used in oral contraceptives and Norplant. This may account for the fact that DMPA users have little, if any, change in a number of metabolic parameters over time. In particular, there is no change in clotting factors, globulin levels, or glucose metabolism in DMPA users when compared to pretreatment levels. The slight decrease in total cholesterol levels seen in DMPA users is the result of a minor drop in high-density lipoprotein, the "good" cholesterol, although neither change is clinically significant. Interestingly, DMPA positively affects the central nervous system, causing the seizure threshold to increase, thus making seizures less likely in women with seizure disorders (e.g., epilepsy). Estrogen levels in DMPA users remain at early follicular phase levels, and while other menopausal symptoms do not occur, there is a possibility that some DMPA users may lose a small amount of bone mass over time.

With DMPA there are 0.3 failures per one hundred women during the first year of typical use. This high efficacy is due both to DMPA's efficiency in inhibiting ovulation and the fact that it is a relatively "user friendly" method of contraception. The long interval between injections, a two-week grace period for injections given beyond twelve weeks, and the absence of need for any user or partner intervention at intercourse all contribute to DMPA's high effectiveness.

DMPA is given as a deep intramuscular injection into the deltoid (upper arm) or buttocks every twelve weeks. Since administration most optimally is provided with a 11/2 inch needle, most DMPA users, particularly thin women, will prefer the buttocks site. The initial injection of 150 mg of DMPA must be given within the first five days after the onset of menses, unless the woman has effectively been using the pill or has an IUD, in which case the first injection can be given any time during the month. Subsequent 150-mg injections are given at twelve-week intervals, although pregnancy is highly unlikely during the following two-week grace period. If fourteen weeks or more have elapsed since the last DMPA injection, a negative highly sensitive urine pregnancy test must be documented before the next injection is given.

The ideal candidate for DMPA is a woman who is seeking continuous contraception; wants long-term birth spacing; desires a method that is neither coitus-dependent nor requires daily motivation; or who cannot use, or chooses not to use, a barrier method, an IUD, or an estrogen-containing method. It may be particularly appropriate for women who cannot use OCs because of a history of thrombophlebitis, hypertension, heavy smoking, or other cardiovascular risk factors. Women with sickle-cell anemia or seizure disorders actually may experience an improvement in their medical condition. DMPA is an excellent method for postpartum and post-abortal women and can be initiated immediately after completion of the pregnancy. Postpartum women who are lactating (nursing) should not be given DMPA until lactation has been established, usually one to two weeks after delivery. Women who desire a high degree of confidentiality in contraceptive use are attracted to DMPA because it does not require the personal possession of medications or devices, nor does it leave marks of administration or current use.

DMPA has few contraindications: active thrombophlebitis; undiagnosed abnormal genital bleeding; known or suspected pregnancy; active liver disease; a history of benign or malignant liver tumors; known or suspected carcinoma of the breast; and sensitivity (allergy) to the medication. Special conditions requiring more detailed medical evaluation and follow-up include a history of heart attack or stroke; diabetes mellitus; current migraine headaches; a history of severe endogenous depression; and chronic hypertension.

Menstrual changes are universal in women using DMPA and include episodes of irregular bleeding and spotting (lasting seven days or more during the first months of use) and amenorrhea (no menses). Sixty percent of women using DMPA for one year report amenorrhea, and the percentage increases with progressively longer use. Menstrual changes are the most frequent cause for dissatisfaction and discontinuation among women using DMPA, and appropriate patient education and selection and supportive follow-up measures can markedly reduce patient discontent. Medical intervention for irregular or heavy bleeding rarely is necessary, and anemia is uncommon. While counseling and reassurance are initial measures, medical therapy consisting of low-dose oral estrogen for one to three weeks may give temporary respite from bleeding. Women persistently dissatisfied may be better served by discontinuing this method and seeking alternative types of contraception rather than by repetitive medical or surgical intervention. In cases of heavy vaginal bleeding, gynecologic evaluation to rule out such unrelated conditions as vaginitis, cervicitis, or cervical lesions should be performed.

Another group of side effects that occur fairly frequently among DMPA users are pregnancy symptoms such as nausea, breast tenderness, abdominal bloating, and tiredness. While these symptoms are prevalent in the first few months of DMPA use, persistence is uncommon and they rarely are cause for discontinuation.

Weight gain occurs in two-thirds of DMPA users owing to the drug's anabolic effect and its resultant impact on appetite. On average, DMPA users gain four pounds per year for each of the first two years of use. Women concerned or dissatisfied with weight gain should be counseled that it may be controlled with adequate exercise and moderate dietary restriction. Many women notice weight stabilization or improvement with time. If these measures fail and weight gain becomes problematic, DMPA discontinuation may become necessary.

Headache is a relatively common complaint in DMPA users, although not all headaches are necessarily related to the hormone in the drug. If the headaches are mild and without neurologic changes, treatment may be attempted with oral analgesics.

After a 150-mg injection of DMPA, the mean interval until return of ovulation is four to six months. Conception usually is delayed in former DMPA users when compared with women discontinuing oral contraceptives or IUDs. The median time to pregnancy following the last injection is nine to ten months, and studies have shown that almost 70 percent of former DMPA users conceive within the first twelve months following discontinuation, and over 90 percent conceive by twenty-four months, a rate comparable to that of oral contraceptive users. Nulliparous women (those who have never given birth to a child) and those using DMPA for many years experience the same return of fertility as other women studied.

Recent medical studies have addressed other safety issues regarding DMPA use. A large study conducted by the World Health Organization (WHO) showed that in aggregate, there is no overall increased risk of breast, cervical, or ovarian cancers in users of DMPA. DMPA users have a reduction in endometrial cancer for as long as ten years after discontinuation of the method. While there was evidence of a weak association between DMPA use and breast cancer in the subgroup of women under thirty-five who had used the drug within the previous four years, most experts feel that this represents a very weak promoter effect at a level similar to OC use. A single study showed a 7 percent reduction in bone density in premenopausal DMPA users compared to controls, but it is not clear whether this is a true biologic effect caused by low estrogen levels or due to selection bias.

Until more work is done in this area, some believe that it is prudent to screen potential DMPA users for osteoporosis risk factors and to provide additional counseling or evaluation for those with multiple risk factors.

Norplant

Norplant is a sustained-release contraceptive system that acts continuously for five years. It consists of six silicone rubber capsules, each the length and diameter of a matchstick, which are surgically implanted under the skin of the upper arm. The synthetic progestin Levonorgestrel, a hormone found in many oral contraceptives, is slowly released into the bloodstream, resulting in a constant hormone level. The contraceptive effect of Norplant is due primarily to inhibition of ovulation, although secondary mechanisms include thickening of cervical mucus, and formation of an atrophic endometrium. Although 20 percent of Norplant users ovulate in year one and up to 50 percent ovulate by year five of use, studies suggest that when ovulation does occur, it is defective and the ovum is not subject to fertilization. The cumulative pregnancy rate of Norplant users is 3.8 pregnancies per one hundred women over five years; the first-year failure rate is only 0.09 per hundred women per year. Ectopic (tubal) pregnancies are reduced by two-thirds in comparison to noncontracepting women, although should Norplant fail, there is a greater conditional probability (proportionate risk) that the pregnancy will be located in the fallopian tube rather than in the uterus.

Studies that have evaluated the metabolic effects of Norplant have found minimal impact. There is no effect on cholesterol or lipoprotein metabolism, glucose metabolism, or propensity to blood clotting. Norplant is an appropriate method of contraception for women who desire long-term contraception, who have completed childbearing but do not desire permanent sterilization and have had problems with other methods of contraception (including combined OCs), and for postpartum women, whether nursing or not.

The technique of insertion of Norplant involves anesthetizing the skin with local anesthetic and creation of a four-millimeter incision, followed by placement of a twelve-gauge trochar to insert the capsules in a fan-shaped pattern. The procedure takes less than ten minutes and is well tolerated by most women. The method should be inserted within five days of the onset of the menses and provides a contraceptive effect within twenty-four hours. More problematic is Norplant removal, which requires substantially more skill and takes between fifteen and forty minutes. The ease of removal is related to a number of factors, including the correctness of the initial Norplant insertion, the amount of fibrous tissue that has developed around the capsules, and the skill of the clinician.

The most prevalent adverse effect of Norplant is the unpredictability and irregularity of menstrual cycles, especially in the first year of use. Cycles may be shorter or longer than usual and associated with more or less bleeding; there may be bleeding between cycles, or no bleeding at all. Although there is no *cure* for irregular bleeding patterns, short-term palliation of the problem can be achieved by the use of low-dose oral estrogen therapy (e.g., ethinyl estradiol 20 mcg orally per day for two to three weeks). Other side effects include mild weight gain, headaches, hair loss, and new onset or exacerbation of depression.

Intrauterine Devices (IUDs)

Although the IUD is used by only 1 to 2 percent of contracepting women in the United States, it is one of the most widely used methods worldwide. A popular method in the United States in the 1970s, IUD use dropped precipitously as a result of the high rate of pelvic infection and consequent tubal infertility experienced by women who used the Dalkon Shield IUD, which was removed from the market for this reason. Mainly because of business concerns related to the risk of product liability suits, manufacturers of most other IUDs voluntarily withdrew their devices over the next decade. The two IUDs currently available in the United States include a progesterone-releasing T-shaped IUD (Progestasert®), which must be exchanged yearly, and a copper-bearing T-shaped device called the Cu-T-380-A (ParaGard®), which exerts its contraceptive effect for eight years.

The IUD's mechanism of action is still a matter of conjecture. In copper IUDs, it is likely that copper ions released by the device have a toxic effect on sperm, rendering them incapable of fertilizing an ovum. Progesterone-releasing IUDs probably exert their contraceptive effect by converting the endometrium to a chronically atrophic state, preventing implantation of the zygote (fertilized egg). IUDs are known to be a relatively effective contraceptive, with failure rates in the range of 0.6 to 2.0 pregnancies per one hundred women per year. While many clinicians assume that the IUD increases a woman's risk of experiencing an ectopic (tubal) pregnancy, studies clearly show that users of progesterone-bearing IUDs have no increased risk of ectopic pregnancy when compared to nonusers of contraception, while users of copper IUDs experience profound protection.

Women best suited for the use of an intrauterine device are those who desire continuous contraception; who want long-term birth spacing or have completed their families but do not want to be sterilized; who require very high contraceptive efficacy; who desire a method that neither is coitus-dependent nor requires daily motivation; and who cannot use or choose not to use a barrier method or a hormonal method of contraception. IUD insertion and removal are simple office procedures that may result in temporary uterine cramping, but rarely require the use of local anesthesia or analgesia.

IUD use may result in relatively minor side effects such as heavy menstrual periods or cramping (less so with the progesterone-releasing type) and increased vaginal discharge. The relationship between IUD use and pelvic infection and consequent infertility has been studied in great detail. Early studies demonstrated that the major risk associations were recent insertion (within twenty days) and the type of IUD used (the Dalkon Shield bestowing the greatest risk). More recent studies have suggested that an IUD wearer's sexual behavior is the single most relevant risk factor for pelvic infection; a woman in a mutually monogamous sexual relationship has no increased risk of pelvic infection or tubal infertility ("blocked" or scarred tubes from PID) compared to the sexually active woman who uses no method. Conversely, women who have multiple concurrent sexual partners, or those who themselves are monogamous, but whose male partner has other sexual partners, appear to be at increased risk of IUD-associated pelvic infection.

In light of these considerations, contraindications to IUD use include the following:

- pelvic inflammatory disease within the past twelve months or recurrent PID (more than one episode in the past two years);
- post-abortal or postpartum endometritis or septic abortion in the past three months;
- known or suspected untreated endocervical gonorrhea, chlamydia, or mucopurulent cervicitis;
- undiagnosed abnormal vaginal bleeding;
- pregnancy or suspicion of pregnancy;
- history of impaired fertility in a woman who desires future pregnancy;
- known or suspected uterine or cervical malignancy;
- small uterine cavity;
- history of pelvic actinomycosis infection (not asymptomatic presence of the organism);
- known or suspected allergy to copper or, for copper IUD only, a history of Wilson's Disease (an inability to metabolize copper).

While young age may be associated with certain risky sexual behaviors, young age alone is not an absolute contraindication to IUD use. Correspondingly, a history of previous childbearing should not be an absolute prerequisite for IUD use. If a young woman is involved in a long-term mutually monogamous relationship and has no other risk factors, she may be considered a candidate for an IUD.

Barrier Methods

Barrier methods include mechanical barriers such as male and female condoms, the female diaphragm and cervical cap, and chemical barriers such as spermicidal products. Nonprescription barrier contraceptives are an important contraceptive option because of their wide availability, relative ease of use, and acceptably high efficacy when used correctly and consistently. While the contraceptive efficacies of the various barrier methods when used alone are comparable to each other (typically about twenty pregnancies per one hundred women per year), their use in combination adds significantly to their effectiveness. In addition, male latex condoms and female vaginal sheaths, when used consistently and correctly, provide a high degree of protection against both the acquisition and the transmission of a number of sexually transmitted pathogens, including gonorrhea, chlamydia, syphilis, and some viral pathogens, including hepatitis B virus and HIV (human immunodeficiency virus), the virus that causes AIDS (acquired immunodeficiency syndrome). Spermicidal products, in addition to their contraceptive effect, have in vitro microbicidal properties and appear to provide some protection against gonorrhea and chlamydia. Nonprescription barrier contraceptives include male latex and animal membrane condoms; female polyurethane vaginal sheaths; the contraceptive sponge; and spermicidal films, foams, jellies, creams, and suppositories. Contraindications include allergy to latex rubber (in the case of male condoms, diaphragm, or cervical cap), a history of significant skin irritation with acute or chronic exposure to spermicides, and inability to understand instructions for use.

The contraceptive diaphragm is a dome-shaped latex device that serves as a mechanical barrier against the cervix and also holds a spermicidal preparation in place within the vagina. The diaphragm is one of the oldest barrier methods of the modern era, and has retained its popularity because of its nonhormonal nature, ease of use, and reasonable efficacy. It may be an appropriate method of contraception for women who prefer an intercourse-related nonhormonal method of contraception; desire a barrier method that can provide continuous protection over twenty-four hours; and feel that the diaphragm is less noticeable during intercourse than other barrier methods. The diaphragm should fit comfortably with the anterior (front) rim tucked behind the pubic bone in front and the posterior (back) rim seated deep in the vagina and behind the cervix, so that the cervix is covered by the dome of the diaphragm. The largest, most comfortable diaphragm that fits well should be chosen. Use of a backup method of contraception until the return visit, or until the patient is sure that the diaphragm is staying in place during intercourse, should be advised.

No attempt should be made to use the diaphragm if the woman cannot be fitted with the device due to physical characteristics of the vagina, cervix, or uterus that interfere with proper placement, or if the proper size diaphragm is not available. Other contraindications include a recent history of frequent lower urinary tract infections (e.g., cystitis), especially if associated with prior diaphragm use; less than three months since cervical surgery; less than two weeks since mid-trimester abortion or less than six weeks postpartum (after delivery of a child); allergy to rubber or to all spermicides; inability to understand instructions for use; and inability to insert, remove, and care for the device correctly.

The cervical cap is a thimble-shaped latex device that fits over the cervix and stays in place by mild suction. When used with a spermicide, it is a reliable barrier method of contraception that can be used continuously for up to forty-eight hours. In use in European countries since the 1930s, it was approved by the FDA for contraceptive use in the United States in 1988. The efficacy of the cervical cap in preventing pregnancy is similar to that of the diaphragm in nulliparous women, although the failure rate of the cap is greater in parous women.

The Prentif Cavity Rim Cervical Cap® is the only cap currently approved by the FDA. It is available in four sizes: 22-, 25-, 28-, and 31-mm internal diameter. Because cervix size may vary considerably, these sizes fit approximately 70–75 percent of women. The cap may be an appropriate choice for women who have experienced frequent urinary tract infections, especially if they occurred in association with the contraceptive diaphragm. Because there is less pressure on the urethra and bladder, the cap may be more comfortable than a diaphragm and less likely to predispose the user to a lower urinary tract infection.

Natural Methods

The most effective methods of fertility control are those in which sexual intercourse is avoided entirely. Abstinence is defined as a limited period of time in which intercourse is avoided, while celibacy refers to a lifestyle decision in which an individual chooses to avoid intercourse for a longer time interval, which may be lifelong in some cases.

Fertility awareness methods are those in which sexually active individuals avoid unprotected intercourse during the "fertile period," which is defined as the time in each cycle that ovulation is estimated to occur. Since the ovum survives for about 48 hours after ovulation and sperm can survive in the fallopian tubes for up to five days, the length of the fertile period is about seven days in most women. Couples who practice the fertility awareness method use a barrier method of contraception with intercourse during the fertile period and no method for the remainder of the cycle. In the "natural family planning" technique, a variant of fertility awareness, intercourse is avoided entirely during the fertile period and mechanical contraceptive methods are not used at any time in the cycle. The latter approach generally is endorsed by religious groups who object to the use of other birth-control methods, which they consider to be "artificial" in nature.

Four techniques, which can be used alone or in combination, are used to estimate the fertile period.

- The *calendar* method, in which previous menstrual cycling patterns are charted and from which future ovulatory patterns may be predicted. This method is comparatively inaccurate, as factors such as stress or illness can affect the time of ovulation and thereby shorten or lengthen a given cycle. In addition, many women have such variable cycle lengths that the estimated duration of the fertile period can be as long as two weeks.
- The *basal body charting* or *temperature* method, which is based upon the fact that a woman's basal temperature will increase by 0.5° to 1.0°F twelve to twenty-four hours after ovulation and will remain elevated until the next menstrual period. Women using this method are expected to check their temperature each morning upon arising until the temperature rise has been confirmed. Once two days have passed after the temperature rise, the fertile period is considered to be completed, and unprotected intercourse can resume until the next menstrual period.
- The *cervical mucus* method, also called the "Billings" or "ovulation" method, which relies upon the fact that a woman's cervical mucus becomes copious and watery in the few days before ovulation. The presence of characteristic mucus at the vaginal opening is a sign of impending ovulation and, hence, defines the existence of the fertile period.
- The *sympto-thermal* method uses a combination of two or more of the above techniques. The use of the cervical mucus to signal the beginning of the fertile period and the basal

body temperature rise to predict its completion is the most accurate of the fertility awareness methods.

The effectiveness of the fertility awareness methods depends upon the couple's consistency of use and ability to avoid unprotected intercourse during the fertile period. When practiced correctly and consistently, the sympto-thermal method has a failure rate as low as two failures per one hundred women per year, while for the typical use failure rate for all methods of periodic abstinence is twenty pregnancies per one hundred women per year.

Sterilization

Voluntary surgical sterilization (VSS) is the most prevalent form of contraception in the United States; 60 percent of those surgically sterilized are women who have had tubal ligation, and 40 percent are men with vasectomies. Most couples who choose surgical sterilization have completed their families, although for some individuals this choice is prompted by an inability or unwillingness to use reversible methods of birth control. Criteria once used to determine the appropriateness of sterilization based on age and parity (number of children born) are no longer appropriate, and a woman's considered, informed decision should be respected by the provider, regardless of her age, parity, and social circumstances.

TUBAL LIGATION. The most important point to be made in counseling a woman regarding tubal ligation is that the procedure must be considered permanent and should be performed only when she is sure that she desires no further children. Alternative (reversible) methods of birth control should be discussed to ensure that these methods have not been rejected on the basis of misunderstanding or other biases. Other important aspects of counseling include a description of the surgical risks of tubal ligation, failure rates, and a comparison to the various methods of sterilization available, including vasectomy for the woman's partner. If consent cannot be obtained from a severely mentally disabled woman, a legal guardian may provide consent in some cases.

Both the federal government and individual states have regulations regarding minimum age requirements and waiting periods from the time of written consent until the date that the operation may be performed if federal or state funding is to be used. For this reason, women who plan to undergo postpartum tubal ligation should receive counseling and consent before thirty-four weeks gestation.

The surgical approach to tubal ligation is primarily dependent upon whether the procedure is performed in the postpartum period, or longer than six weeks after delivery, in which case it is considered to be an interval tubal ligation. In a postpartum tubal ligation, a minilaparotomy performed within four to twenty-four hours of delivery is the preferred approach subsequent to a vaginal delivery. After receiving a regional or general anesthetic, a three-centimeter curvilinear or vertical incision is made immediately under the umbilicus. Once the peritoneal cavity has been entered, either the operator's finger can be used to sweep each tube into the incision or each tube can be grasped under direct vision. In either case, positive identification of the tube can be made by visualizing the fringelike portion at the abdominal end of each tube and by demonstrating that the nearby round ligament is uninvolved. After completion of the tubal occlusion, each excised tubal fragment must be sent for histological confirmation. In a woman delivered by cesarean section, any of the three techniques described below can be performed after repair of the uterine incision has been completed.

A number of techniques are available when there is direct access to the fallopian tubes via minilaparotomy or cesarean section. They include the following methods:

- modified Pomeroy method, in which two ligatures (sutures, "ties") are placed in the midportion of each of the tubes and then the pieces of tube between the ligatures are removed. The closed ends retract, leaving a gap between the closed-off tubal segments.
- Irving method, whereby the tubal stump nearest the uterus is tucked into a tunnel made in the myometrium (muscular structure) of the large upper part of the uterus.
- Uchida method, which involves excision of a five-centimeter segment of tube, followed by burying the tubal stump farthest from the uterus within the mesosalpinx (the free margin of the upper part of the broad ligament).

While the failure rates of the Irving and Uchida techniques are exceedingly low (less than 1/1,000) in comparison to the Pomeroy method (1/250), the former take longer to perform and therefore are relegated to special cases.

Interval tubal ligation may be performed with a laparoscope (a narrow lighted tube) via a low minilaparotomy incision (a small horizontal incision, 2–5 cm long, just above the pubic hairline), the former being much more prevalent in the United States. Laparoscopic approaches ("band-aid" surgery) include either open or closed laparoscopy, and both one- and two-puncture instruments (laparoscopes) are available. While a large majority of laparoscopic tubal ligations are performed under general anesthesia, there is a growing trend to perform these procedures under local anesthesia, thereby reducing cost and avoiding the risk of general anesthetic complications, which is the most common cause of tubal ligation deaths. If local anesthesia is used, the tubes must be bathed in a long-acting local anesthetic, then banded or clipped, rather than electrocoagulated (coagulation or clotting of tissue using a high-frequency electric current).

Minilaparotomy for interval tubal ligation is performed via a three-centimeter low horizontal incision. Because of the difficulty entailed in working through a small incision, the procedure is facilitated by using a uterine elevator, an instrument placed in the vagina to lift the uterus. The procedure may be performed with general, regional, or local anesthesia. Minilaparotomy is contraindicated when the patient is obese, has an enlarged or immobile uterus, or when adnexal disease (in the areas adjacent to the uterus, e.g., ovaries and tubes) such as endometriosis is suspected. Nonetheless, minilaparotomy can be a safer, simpler, and less expensive procedure than laparoscopy, which requires more technical equipment and endoscopy experience.

If minilaparotomy is chosen, any of the occlusion techniques outlined above for postpartum tubal ligation may be used. In addition, spring-loaded tubal clips are available that can be easily applied through a minilaparotomy incision. With the laparoscopic approach, three methods of tubal occlusion are available:

- Electrocautery, with a coagulation or "blend" current, used at two or three sites along the mid-fallopian tube. Either unipolar or bipolar cautery may be used; while bipolar cautery is safer (since it is less prone to cause bowel burns), it takes longer and has a higher failure rate. Unipolar electrocautery is faster and more effective, but there is a risk of sparking between the electrode and the bowel, resulting in an unrecognized injury. Fallopian tubes occluded by electrocautery may be quite difficult to reanastomose (reconnect, in the event the woman changes her mind and wants to try to achieve pregnancy) because of extensive scarring.
- Silastic (silicone rubber) rings may be applied with a forceps-type applicator to a loop of mid-portion fallopian tube. This approach avoids the risk of electrical injury to the bowel and preserves much larger segments of healthy ends of the severed fallopian tube should later reversal be considered.
- Spring-loaded clips may be placed at a single site in the middle of the tube and can be used with double-puncture laparoscopy or at minilaparotomy.

The provider must explain that with tubal interruption alone, no organ is removed; tubal sterilization merely prevents conception. The operation is not "desexing" and will not reduce libido, vary the woman's menses, or alter her appearance. There is usually no adverse change in sexual function following tubal sterilization; on the contrary, many women who feared pregnancy before the operation report increased satisfaction in sexual intercourse and are pleased with the operative result. However, 2 to 5 percent report less frequent orgasm and a similar percentage have delayed regret that the procedure was performed.

Only hypophysectomy (excision of the pituitary gland), bilateral oophorectomy (removal of both ovaries), and ovarian damage by radiation are certain methods of sterilization. Abdominal and tubal pregnancies have occurred (rarely) even after total hysterectomy (removal of the uterus). Oophorectomy and sterilization by radiation are usually followed within four weeks by vasomotor reactions (symptoms associated with menopause such as "hot flashes") and a gradual diminution in libido or sexual satisfaction during the next six months.

VASECTOMY. Sterilization of the man by vasectomy is both less dangerous and less expensive than tubal ligation, as it is routinely performed as an office procedure under local anesthesia. Through one or two small incisions in the scrotum, the vas deferens (the tube or duct that carries sperm) is isolated and occluded and usually a small segment of each vas is removed. Neither physiologic impotence nor changes in libido result from the procedure. Sterility cannot be assumed until postoperative ejaculates are found to be completely free of sperm. Failure of the vasectomy, as manifested by pregnancy in a partner, occurs in 0.1 percent of patients. Medical risks of vasectomy include hematoma (blood clot or bruise) formation, epididymitis (congestion or inflammation of the epididymis, the coiled tubular structure where sperm cells mature), spontaneous recanalization of the vas (reconnection of the ends with restored patency) (incidence of less than 1%), and the development of a spermatocele (cystic nodule containing sperm). Atrophy of the testes very rarely results from ligation of excessive vasculature (blood supply). Vasectomy often is reversible—up to 90 percent in some reports—but requires expensive microsurgery and special skill with no guarantee of success. Pregnancy results in only about 60 percent of cases after reversal; factors that influence success include (but are not limited to) the surgeon's skill, the type of procedure used, and time interval since vasectomy.

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II. SOCIAL AND ETHICAL ISSUES

The status of contraception, sterilization and abortion services in the United States has always been linked to the various social and political movements that have been engaged with issues of women’s role in society, reproduction and sexuality. Different groups have advocated for and against family planning for different reasons and with different levels of success. While issues pertaining to reproductive control have always caused some degree of social conflict, this has been especially true since the 1970s when the abortion debate intensified and spilled over to other reproductive health services. The emergence of HIV and rising rates of other sexually-transmitted diseases have also contributed to the controversy surrounding fertility control in the United States and abroad as the new millennium dawns.

This entry begins with a discussion of fertility control in a historical context. One must be aware of this history in order to understand the current ethical debate and controversies surrounding family planning and abortion. The article then continues with discussions of the social, political, religious and moral perspectives. Although the circumstances may change, the issues surrounding fertility control will always be with us and will remain among the most unresolved in bioethics.

Historical Context

It is often said that if we are unaware of our history, we are doomed to repeat the mistakes of the past. Mistakes and dilemmas regarding birth control are particularly apparent when looked at from the perspectives of the women involved, rather than as a success of technology developed by the great men of medicine.

Advocates for birth control generally intended it to be an option for all women, regardless of race or class. The reality, however, was often that poor, otherwise unempowered women, often from minority backgrounds, were most in need of such advocacy, education and access to contraception. Upper-class women had greater access to information and methods of contraception through their private physicians and other social contacts. They could also pay for whatever was available at the time. They voluntarily reduced the number of children they had. The well-intentioned, beneficent efforts on the part of advocates for women and for birth control to improve access for poor minority women and empower them often had the effect of targeting these women for efforts to reduce the numbers of children they had. The ability of a woman to choose the number of children she had and when she had them might allow her to control other aspects of her life and family and to improve the quality of life for herself and others. It could also come dangerously close, on a population basis, to achieving the desires of eugenicists to reduce the numbers of poor minority, or otherwise undesirable people, in the population. One example of this tension is that involving immigrant Irish and Eastern European women in the late nineteenth century. There was a real concern on the part of eugenicists that the immigrant population was growing and reproducing while educated, upper class American women were successfully reducing the size of their families. Eugenicists may have wanted to control the fertility of immigrant women in order to maintain population proportions, especially those of the “desirable” component of the population. On the other hand, early advocates for birth control might have wanted to improve access to birth control in order to empower these women to control their own destinies to a certain extent. Promoting the autonomy of women and acting beneficently on their behalf, in this case, comes dangerously close to the less ethically acceptable motivation of the eugenicists.

The history of the birth control movement in this country over the past 125 years provides clear examples of the tensions which have always existed between empowering women to control their fertility and promoting limitations on fertility for the disadvantaged. Several important developments in the history of the American birth control movement have been chosen to illustrate these tensions and provide a context within which to analyze contemporary social, ethical and political issues (Powderly).

CONTRACEPTION IN LATE NINETEENTH CENTURY AMERICA. Victorian beliefs regarding sexuality accepted promiscuity as a fact of life for men who were either not expected to or were unable to control their sexual urges. Women, on the other hand, were expected to control or even deny their sexuality (Gordon, 1981). Prostitutes were a common and accepted solution to this dichotomy. Despite the view that female sexuality was viewed as inextricably linked to reproduction, contraception was widely practiced among all social classes. The methods of contraception varied by class, however, due to cost and availability. The upper classes were more likely to use relatively expensive methods of contraception such as condoms, spermicides, and douches. They might also have had access to diaphragms and cervical caps smuggled in from Europe at a high cost. Withdrawal and rhythm were often the only methods available to the poor. At a time when menstrual cycles were only partially understood, pregnancies often resulted. Abortion, often self-induced and always dangerous, was resorted to frequently. It is estimated that one out of every five to six pregnancies in America ended with an abortion by the 1850s (Chesler). Mortality from septic abortions was extremely high. In 1888, it was estimated as being fifteen times greater than maternal mortality (LaSorte, Powderly).

During this era, American feminists supported the concept of "voluntary motherhood" (Gordon, 1981). Far from empowering women and providing them with sexual freedom, however, voluntary motherhood sustained traditional family roles for women. Limitation of family size enhanced their ability to fulfill their societal roles as wives and mothers according to this view. These feminists were joined by moral reformers who were concerned about excessive breeding among the lower classes. Immigrants were particular targets of this concern. Focusing efforts toward reduction of fertility on the lower class and members of minority groups has strong historical roots in the late nineteenth century (Powderly).

Although contraception was widely practiced in private and abortion was accepted as a necessity when it failed, many were not willing to risk expressing support for them in public or admitting to their use. This Victorian reluctance influenced public policy. Abortion was declared illegal for the first time in the United States in 1830. A majority of states had declared it so by 1870 (LaSorte). A great legal blow was dealt to contraception in 1873 with the passage of the statute that came to be known as the Comstock law. This federal statute made it illegal to transport obscene materials through the mail. Contraceptive devices such as condoms and diaphragms as well as literature were confiscated under this law, which was in effect until 1936. It lost its power in a case in which Margaret Sanger established the right of doctors and other qualified professionals to use the mail for such distribution. Contraceptives themselves remained in the obscenity statutes until 1971 (Wardell, Powderly).

MARGARET SANGER AND THE AMERICAN BIRTH CONTROL MOVEMENT. Perhaps no name is more associated with birth control, family planning, and reproductive freedom for women than Margaret Sanger's. Sanger was born in 1879, the middle child in an Irish immigrant family with eleven children. She was impressed at a young age with the effect of frequent pregnancies on her mother, who suffered from tuberculosis and died at the age of fifty. Her mother's frequent pregnancies and their ultimate role in her early death angered Sanger. She went on to play a strong role in the birth control movement in the United States and abroad until her death in 1966. While her decision to devote her life to the promotion of access to birth control for all women was influenced by many factors, her own family background and experience certainly played an important role.

Sanger was trained as a nurse, although she left her training program early to marry William Sanger. Because of prohibitions against married nursing students in this era, she could not remain in the program once she married. She would remain conflicted throughout her life between her obligations to her family and the demands of her passionate cause—access to birth control for all women. This is a conflict that remains for many working mothers today in an era where there is often no choice.

Margaret Sanger's experience as a visiting nurse and midwife on New York City's Lower East Side provided the stimulus for her crusade. She often cited the case of Sadie Sachs, a twenty-eight year old Jewish immigrant and mother of three who was married to a truck driver named Jake. Unable to deal with another pregnancy and an additional child, Mrs. Sachs nearly died from a self-induced abortion. Sanger nursed her for weeks and listened to her pleas for reliable contraception. It is likely that Sanger offered her personal experiences with condoms and coitus interruptus, the common methods readily available at the time. Mrs. Sachs knew another pregnancy would kill her. The only advice her physician could offer her was to "tell Jake to sleep on the roof." If only these immigrant men could control their sexuality, there wouldn't be so many problems! There was no better or more constructive advice available to her. Three months later, Mrs. Sachs died of septicemia after another self-induced abortion. Her husband was distraught and her children left motherless. Margaret Sanger called it "the dawn of a new day in my life … I knew I could not go back merely to keeping people alive.…" (Chesler; Wardell; Sanger, 1931, 1938; Powderly).

Early in her crusade, Margaret Sanger used her connections to the Socialist Party to promote her cause. She published a column entitled: "What Every Girl Should Know" in *The Call,* a New York Socialist daily, in 1912 and 1913. The columns elicited a range of responses and were ultimately challenged by Anthony Comstock. Early in 1913, one of the columns was entitled "What Every Girl Should Know—Nothing; by order of the U.S. Post Office" and was followed by a blank space. Several weeks later the censored column appeared (Chesler; Sanger, 1938). Birth control was not to become a priority issue for the Socialists, however. It couldn't compete with suffrage and labor issues. Sanger was disillusioned and disappointed that birth control was not viewed by her comrades as a priority issue for women.

In 1914, Sanger abandoned her own failing marriage and devoted herself to the development of *The Woman Rebel,* a magazine for working women that would cover issues of sexuality and contraception. She was indicted under the Comstock laws for sending the first issue of this magazine through the mail. While awaiting trial, she wrote *Family Limitation,* a practical pamphlet on birth control methods. The world was about to go to war and Sanger's arrest and cause were not receiving as much publicity as she had hoped for. She decided to flee the country and her children and go to Europe until she could command more visibility. While she continued her research on contraceptive methods, her husband, still a supporter, went to jail for dispensing one of her pamphlets. Sanger returned to heightened publicity for her cause and the charges against her were ultimately dropped (Chesler; Powderly).

Sanger began a cross-country speaking tour to promote the importance of knowledge for women regarding sexuality and birth control. While she promoted access to birth control for all women, she focused primarily on the poor. Sanger believed that uncontrolled fertility and large families were inextricably linked to poverty. Her efforts to empower poor women, however, would be viewed by some as racist and by others as having eugenic propensities. While many eugenicists supported the ideas of limiting population growth, particularly among those they viewed as undesirable (e.g. the poor, immigrants, those with mental problems or disabilities), they were greatly troubled by the idea that the upper classes would use birth control and the lower classes would continue to breed.

Margaret Sanger brought birth control directly to the poor women of Brooklyn on October 16, 1916, when she opened a free-standing clinic in Brownsville. Immigrant women from many cultures lined up with their baby carriages to learn how to prevent future pregnancies. In the few weeks the clinic was open, 464 women were provided with sex education and contraceptive information (Chesler; Powderly). The clinic was raided by the New York City Vice Squad and Sanger and her sister, Ethel Byrne, the clinic's nurse, were jailed. The trial produced an important legal victory for birth control. The New York State Court of Appeals interpreted the law to allow for prescription of contraceptives by physicians not only to prevent or cure venereal disease—an interpretation largely applied to men—but also for any health reason. This opened the door for physicians to prescribe contraceptives for women. It also produced another dramatic effect, however. Birth control from that point on was a physician-dominated enterprise. While Margaret Sanger's Brownsville clinic brought contraception to the community level and to poor women, it did so at a price. Nurses, and to a large extent, women, were not to control the provision of contraceptives. This is a legacy that lingers today. In populations with limited access to physicians, it is a clear disadvantage (Chesler; Powderly).

The compromises struck with the medical community are evident in Margaret Sanger's interactions with Robert Latou Dickinson. Dr. Dickinson, a Brooklyn gynecologist, was a champion of studies of female sexuality, fertility and contraception. While he was not a strong supporter of contraception early in his career, he became one of its strongest supporters and was on the Board of Planned Parenthood at the time of his death in 1950 at the age of eighty-nine. Dickinson and Sanger fought for the right to contraceptives, but he viewed her techniques as propogandist. He sought initially to evaluate the effectiveness of contraceptive counseling and techniques, using more traditional scientific methods. Influential in his field, Dickinson used his platform as president of the American Gynecological Society to promote professional interest in birth control. He set up a committee on maternal health at the prestigious New York Academy of Medicine to promote contraceptive research. He found, however, that without Sanger's "propoganda" he had trouble recruiting patients. While he had access to the medical establishment, she had access to the women who would be the subjects of the research and the users of contraceptives. Dickinson also, ultimately, sought Sanger's assistance in securing diaphragms for his own patients. He had been unable to acquire enough diaphragms through legal channels. Sanger had been smuggling them into the country, sometimes in "Three-in-One oil boxes." She had married the millionaire head of the Three-in-One oil company and used his fortune and resources to promote her cause (Wardell; Powderly). Sanger and Dickinson often disagreed vehemently on strategy, but also cooperated to achieve their mutually desired goals. Dickinson ultimately joined Sanger's Birth Control Clinical Research Bureau's advisory board. Together, they assured that birth control would be available to American women. It was, however, to be a male-dominated enterprise constructed on the medical model (Powderly).

STERILIZATION. Tubal sterilization was first proposed in the early nineteenth century for effective long-term contraception in women undergoing operative deliveries (C-sections). The first reported tubal sterilization was performed in 1880 (Lungren; Siegler and Grunebaum). While technology had evolved enough to attempt these procedures, it is important to recognize that they were still quite risky. A paper delivered at the Brooklyn Gynecological Society in 1891 reviewed the sixty-eight sections that had been performed in the United States from 1882–1891. The Brooklyn maternal mortality rate of 33 1/3 percent compared favorably with the national mortality rate of 40 percent (Powderly). Surely, if a woman survived one section, avoidance of another would be an important consideration. Many of the early tubal ligations were recommended to protect the life or health of the woman.

In the early twentieth century, however, eugenics was a dominant reason for tubal sterilization, particularly involuntary sterilization. Compulsory sterilization began to be recommended for individuals with hereditary disease, the "feeble-minded" (i.e. the insane and demented) and the mentally retarded. There were also racial overtones, as undesirable characteristics were perceived to occur more often in Negroes, Orientals, and the foreign-born. In addition, there were some moves to sterilize habitual criminals—a move that some promote to this day for repeat sex offenders. While recommendations for habitual criminals dealt largely with men, efforts to control hereditary and mental illnesses were most often directed at women (Reilly; Powderly). Efforts to "train" female inhabitants of mental institutions gave way to a priority to keep them from reproducing. The view that deviance was hereditary was supported in large part by studies of two families—the Jukes and the Kallikaks.

Richard Dudgale, a social reformer, studied 709 people over five generations in a family he called the "Jukes." Although Dugdale believed both heredity and environment were to blame for the propensity of the Jukes for crime, intemperance and prostitution, he gave real credence to heredity (Dugdale). He estimated that their care had cost society well over a million dollars. In 1912, Henry Goddard added to the belief that deviance was hereditary with his publication of *The Kallikak Family.* Goddard had been studing feeble-mindedness when he discovered the family, which he traced back over six generations. The progenitor had produced both a legitimate and an illegitimate line. The legitimate line produced upstanding citizens, while the illegitimate line produced large families with a disproportionate number of feeble-minded individuals (Reilly; Powderly).

Already concerned with the effects of immigration on population demographics, eugenicists were given superb ammunition with these two studies. The eugenics movement also received financial support from some of the country's most prominent philanthropists. Even Theodore Roosevelt supported the movement, urging Americans to avoid "racial suicide"—the upper classes must not be outnumbered in their progeny by immigrants and the lower class.

The nation's first involuntary sterilization law was passed in 1907 and 14 states had laws allowing involuntary sterilization by 1914. The effect of the laws varied. From 1907 to 1921, there were 3233 documented sterilizations performed under state laws. These sterilizations were seen by many within the mental hygiene movement as beneficial to society and, at the very least, as not harmful to the individual (Reilly). While there was much popular and professional support, eugenic sterilization was still controversial. Some statutes were drafted with more concern regarding constitutional constraints and more care about guardians'consent. Ultimately, however, the Supreme Court provided a boost for involuntary sterilization with its decision in *Buck v. Bell* in 1927. Oliver Wendell Holmes wrote: "It is better for all the world, if instead of waiting to execute degenerative offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind." Sterilization programs were active through the 1940s and 1950s and not influenced by reaction to the Nazi sterilization programs (Reilly; Powderly; Lombardo). Eugenic sterilization virtually disappeared, however, in the 1960s in an era of awareness of patients' rights and the need for society to protect the vulnerable.

BIRTH CONTROL AND THE MODERN ERA. The 1960s and 1970s saw great technological advances in birth control, albeit all dependent on women. The development and approval of oral contraceptives, after controversial research on women in the third world, finally provided a highly effective form of contraception that was not associated with individual sex acts. Intrauterine devices (IUDs) also became popular choices for women and couples who wanted to control their fertility. Although IUDs would later become less available because of legal challenges related to side effects of the Dalkon Shield, they remained a method of choice for many women. By the end of the twentieth century, contraceptive rings and patches and long-acting contraceptives like Norplant, in addition to safer doses of oral contraceptives, would provide many accessible and affordable options for fertility control. The reduction in the use of barrier contraceptives, however, would increase concern about transmission of sexually transmitted diseases, including HIV.

In addition to technological advances, there were legal and policy victories for birth control. A significant victory in this regard occurred in New York City in 1957 when Dr. Louis M. Hellman fitted a severely diabetic postpartum woman with a diaphragm in violation of the policies of the commissioner of hospitals. The media had been notified in advance and the resulting coverage precipitated a policy change that allowed women to receive contraceptive counseling and devices in municipal hospitals in New York City (Hellman). Dr. Hellman went on to serve as deputy assistant secretary for population affairs in the Department of Health, Education and Welfare under President Nixon. He oversaw the Title X family planning initiatives that provided family planning services to five million women who desired them but could not afford them (Powderly).

The Supreme Court declared contraception a constitutional right for married couples in 1965 in the case of *Griswold v. Connecticut.* The Comstock laws were finally repealed in 1971 and the Supreme Court guaranteed a woman's right to abortion in *Roe v. Wade* in 1973. Women were now entitled to access to contraceptives and abortion services. This, however, did not ensure that they would have access. Some women did not have access to Title X funded services and could not afford contraceptives. Barriers to health care in general often extended to family planning services. For others, partners or spouses prohibited the use of desired contraceptives. Cultural and religious beliefs and prohibitions may also prove problematic. In addition, the fight against legalized abortion rages on and has escalated to violent outbursts that threaten the providers and users of abortion services. Coercion and social pressure may also result in women who do not desire contraception being forced to use them (Powderly).

Social and Political Issues

Numerous social and political issues have influenced fertility control in the modern world.

INTEREST GROUPS AND FAMILY PLANNING. ***Providers of Family Planning Services.*** Family planning services in the United States are offered by both private and public agencies. Public providers of family planning services at the local level include public health clinics in hospitals or neighborhood health centers, school-based clinics, Medicaid managed-care organizations and hospital-based clinics. At the county, state, regional and national levels, various arms of government are involved with the setting of policy for these publicly supported clinics and in devising formulas to disburse funding. The major conduit for public funding of family planning services is Title X of the Public Health Act of 1970. Title X has never allowed funding for abortion services, however.

In the private sector, abortion and family planning services are offered both by for-profit and not-for-profit clinics, managed care organizations and by private physicians. The not-for-profit Planned Parenthood Federation of America, Inc., with affiliates across the country, continues to be one of the most important providers of family planning services in the private sector.

In theory, the public and private components of the family planning delivery system share similar goals: the dissemination of contraceptive services and education under a public health model, which includes the prevention of HIV infection and other sexually transmitted diseases as well as services specifically rendered to control fertility. The relationship between the public and private components is quite complicated and intertwined, however. Family planning services, like other publicly provided social services in the United States, are typically delivered through a system that relies at least partly on private agencies, or "subcontractors," rather than directly by the government itself.

In addition, family planning became intensely politicized in the United States after the election of Ronald Reagan in 1980. Since then, the agendas of public and private providers of family planning services have often been at odds. Difficulties with Title X-funded programs illustrate these contradictions. A significant proportion of Title X-funded services in many communities across the country is provided by Planned Parenthood, which is also a prime target of those who are politically conservative because of the organization's visibility as an abortion provider. Political appointees within the Department of Health and Human Services, which oversees Title X and related services, have, at times, been aligned with political groups committed to the defunding of this program, because of some conservatives' opposition to family planning programs. The number of publicly funded family planning programs and clinics across the country has declined; this decline reflects the bitter ideological wrangling over the concept of publicly funded family planning (Ettinger, 1992; Scott).

In 2002, nearly five million women received health care services at family planning clinics funded by Title X. They were predominantly young, poor, uninsured, and had never had a child. Seventy-one percent of women using Title X-funded clinics are 20 years of age or older and 63 percent are white. Sixty-five percent have incomes at or below the federal poverty level. It is estimated that these clinics are the only source of family planning services for more than 80 percent of the women they serve (AGI, 2002a; Kaeser et al; Planned Parenthood).

The Women's Movement. Since the re-emergence of a visible women's movement in the United States in the late 1960s, various groups associated with the movement have been forceful advocates for family planning and abortion services. The new feminists have demonstrated a keen interest in issues of reproductive rights and sexuality (Joffe, 1986). The campaign to make abortion legal and accessible was a major focus of the feminist movement in the 1960s. During the 1980s, when a woman's right to a legal and safe abortion was threatened, women's organizations played a highly visible role in pro-choice activities, working closely with such organizations as Planned Parenthood and the National Abortion Rights Action League.

With respect to other reproductive issues, however, the relation of sectors of the women's movement to its abortion allies has been more complex. At times, the responses of some feminist health activists to prevailing contraceptive practices and new contraceptive innovations have conflicted with sometime allies, such as Planned Parenthood. These activists, for example, raised doubts early on about the safety of oral contraceptives, objected to testing new contraceptive technologies on women in developing nations and, more recently, voiced reservations about the likely social abuses of Norplant, a long-acting, implantable contraceptive device (Seaman; Gordon, 1976; Moskowitz and Jennings).

The Pro-Family Movement. Beginning in the 1970s, a movement of sexual conservatism—the "pro-family" movement—became a significant presence in family planning politics (Petchesky; McKeegan). This movement's main concern has been the breakdown of sexual morality in contemporary society, as evidenced by high rates of abortion, adolescent pregnancy, out-of-wedlock births, and sexually-transmitted diseases. For sexual conservatives, widely available family planning services—especially those supported by public funds—represent a temptation to break with traditional morality (Marshner). Though the pro-family movement is most visible in anti-abortion activity, its interests and interventions extend to a broad range of reproductive and sexual matters—contraceptive services, sex education, adolescent pregnancy prevention efforts, and HIV prevention (Joffe, 1986; Nathanson).

Family planning services for adolescents have been a major focal point of pro-family activity (Joffe, 1993). Conservative activists have persuaded legislators in a number of states to adopt parental notification and consent rules for teenagers seeking abortions, and have sought regulations that would include parental notification policies for federally funded clinics providing contraceptive services.

The "gag-rule" controversy, which has spanned the presidencies of Ronald Reagan through George W. Bush, is further illustration of the efforts of conservatives to link attacks on abortion to those on family planning. Originally written as an administrative guideline during the Reagan administration, the gag rule forbade employees in Title X-funded family planning clinics to provide counseling about abortion options, even when women asked for such information. For many within the healthcare community and the public at large, this ruling raised concerns about free speech for health professionals. In the space of several years, the gag rule was upheld by the Supreme Court, overturned by congressional legislation, and promptly vetoed by George H.W. Bush, under intense pressure from conservatives. In one of his first acts after taking office in 1993, Bill Clinton abolished the gag rule, under similar pressure from the pro-choice and family planning communities. On his first day in office, George W. Bush restored the Reagan–era gag rule for international family planning programs. This is a pattern that is likely to continue, illustrating the strong relationship between politics and women's health issues, especially those involving fertility control (Planned Parenthood; RowBoat).

Welfare Conservatives. In contrast to the pro-family movement, whose defining issue is the breakdown of sexual morality and traditional families, "welfare conservatives" are concerned about the rising welfare costs resulting from adolescent pregnancies, illegitimate births and failure of fathers to make child support payments. Welfare conservatives have made a number of policy proposals that either mandate use of contraception as a condition of receiving welfare or other financial incentives for such contraceptive use, that penalize recipients financially for having additional children and that forbid adolescent mothers from receiving welfare assistance directly, providing instead that the grant go to their parents or guardians (Nathanson; Peirce).

The contraceptive implant, Norplant, introduced in the United States in 1990, quickly became implicated in a number of policies advocated by welfare conservatives. Once inserted, the implant prevents pregnancy for up to five years. Both the insertion and the removal, however, must be done by a trained health professional. After the insertion, no further "user compliance" is required, making this a far more effective contraceptive device than other birth control methods. Within eighteen months of the introduction into the United States of this new method, virtually all states approved the public funding of Norplant insertion for welfare recipients. The potential for coercion is evident. There have been instances where judges have required Norplant use as a condition of probation or child custody for women convicted on drug-related charges or of child abuse (Forrest and Kaeser). Provision of access to Norplant for adolescents has also raised ethical concerns (Moskowitz and Jennings). In addition, lack of access to providers trained to remove the implant may restrict choice for some women.

SERVICES TO POTENTIALLY VULNERABLE POPULATIONS. ***Minority Communities.*** Minority communities in the United States have long had a wary relationship with family planning advocates and services. The previously cited historical links between the founders of the birth control movement, such as Margaret Sanger, and those in the eugenics movement with an avowedly racist ideology created a lasting sense of distrust in minority communities as to the intentions of some within the family planning movement (Chesler; Gordon, 1976). Such distrust reached a height in the late 1960s and early 1970s when many of the Title X clinics appeared to be targeted specifically at African-Americans, leading some African-American leaders to accuse family planners of "genocidal" intentions (Littlewood). More recently, some community leaders—most notably, black clergy—have joined forces with the pro-family movement, arguing against such measures as condom distribution in inner-city high schools and offering Norplant to adolescent mothers (Moskowitz and Jennings).

At the same time, the rates of premarital sexual activity, sexually-transmitted diseases, adolescent pregnancy and abortion have been disproportionately higher for minorities than for others. Thus, there is a need for culturally-sensitive family planning and abortion services, and many minority organizations argue forcefully for their retention and expansion.

Adolescents. In the early 1990s, adolescents were entitled to receive low-cost or free confidential contraceptive services at Title X sites. Adolescents, as a group, did not receive any public funds for abortion. The field of adolescent medicine recognizes the need to provide education and family planning services to sexually active adolescents (American Academy of Pediatrics, 1999). The rising rates of sexual activity among adolescents, particularly young adolescents, has increased concern within the family planning community about adolescent pregnancy and this group's vulnerability to HIV and other sexually-transmitted diseases (Alan Guttmacher Institute, 1991). In the 1980s, a major response to both these issues was the establishment of school-based clinics on the theory that while few teens would make their way to a free-standing clinic, clinics located within the school would reach a much larger public. Programs were also established for pregnant adolescents and those with children to try to keep them in school. Predictably, such school-based programs were controversial from the start, strongly opposed by conservatives and just as strongly advocated by health professionals and public health advocates (Kirby et al; Moskowitz and Jennings).

A number of school districts, particularly those in large urban areas, began distributing condoms to students in response to the HIV epidemic. There has been massive controversy here as well, with many parent and church groups opposing such efforts. Generally speaking, however, HIV-related interventions in schools seem to be more acceptable to the public and to educators than specific efforts for pregnancy prevention. A national study of sex education in U.S. schools in the late 1980s found far more attention paid to HIV and sexually-transmitted diseases than to family planning education (Forrest and Silverman). While most would advocate abstinence for adolescents, particularly young ones, the alarming rate of unprotected sexual activity in this age group warrants realistic education and confidential access to safe, appropriate family planning services.

In October of 1998, there was an attempt to pass legislation restricting minor's access to family planning services. The proposed amendment would have mandated that parents of dependent adolescents be notified before their children received contraceptives from Title X-funded clinics (Congressional Record). Supporters of parental consent feel that available, confidential family planning services encourage sexual activity in adolescents and undermine parental authority. However, research has demonstrated that confidentiality is crucial to teens' willingness to seek services related to sexuality (American Academy of Pediatrics, 1999; Reddy et al; Planned Parenthood). Moreover, Planned Parenthood states that the fact that the average teen does not visit a family planning clinic until 14 months after she has become sexually active provides clear evidence that clinics do not encourage sexual activity. Requiring parental consent may not deter adolescents from having sex, but it could keep them from seeking reproductive health care in a timely fashion or at all. This could contribute to an increased rate of pregnancies as well as sexually transmitted diseases (AGI, 2000; Planned Parenthood). While the 1998 amendment was not passed, there is an ongoing attempt by political conservatives to fight access to family planning services for adolescents and even punish them for having sex. In a recent NYC case, a group of eighth graders who skipped school to attend a party where they allegedly had sex were forced to submit to pregnancy and other gynecological testing and to provide the results before they could return to school. A suit has been filed on their behalf by the New York Civil Liberties Union (Williams).

Services to the Disabled. Case law in the United States generally recognizes that developmentally disabled individuals have the same fundamental rights regarding procreative choice as those who are not disabled. There are, however, difficulties in implementing family planning services for disabled persons. The issue of informed consent for mentally disabled individuals is particularly relevant and remains ethically problematic. Is the individual capable of giving informed consent, and if not, who is the appropriate surrogate empowered to make such decisions (Stavis).

In spite of legal decisions supporting provision of such services, relatively few disabled persons are served in Title X clinics (Moore and Lieber). Few clinic staffs have received the specialized training necessary to work effectively with this population. In addition, many caretakers, particularly parents, have difficulty dealing with sexuality in this population and are reluctant to ensure that these individuals receive such services. In addition, disabled individuals and caretakers are often not aware of the entitlement of the disabled to family planning services, which implies a need for more outreach to this population.

In light of the compulsory sterilization programs of the past, the major ethical conflict regarding sterilization today is balancing the rights of a mentally retarded or mentally disabled person to sexual freedom with a protection of their best interests regarding childbearing. Many writings deal with the sterilization of the mentally retarded who are somewhat incapacitated or even totally incapable of giving informed consent (Macklin and Gaylin). The Committee on Ethics of the American College of Obstetricians and Gynecologists has issued a statement on "Sterilization of Women Who Are Mentally Handicapped," which urges all possible attempts to communicate with the person involved on whatever level is possible. Even in cases where it is clear that the individual has no ability to comprehend a pregnancy and childbirth and may be harmed by the experience, it is difficult to obtain a court order for sterilization because of the history of abuses. Perhaps it is more beneficent to take the middle ground in these cases. While routine sterilization of a mentally impaired individual without her consent is clearly wrong, restricting the sexual expression of a profoundly impaired individual who cannot comprehend her sexuality, much less pregnancy or coitus-related conception, is also not justified. In carefully considered circumstances, advocates for the patient may conclude that sterilization is in the patient's best interest. The decision should be made by an appropriate surrogate or proxy, based on the best interests of the patient after considering alternative methods of dealing with the situation. The prominence of this issue in the Senate confirmation hearings of Dr. Henry Foster as Surgeon General in the Clinton administration illustrates the importance of this issue and the lack of societal consensus (Powderly, 1996).

Religious and Moral Issues

Most people today, along with philosophical ethicists, religious ethicists and organized religions, generally accept the morality of contraception within marriage, often appealing to the need for family planning. While recognizing a link between marital sexuality and procreation, many concede that marital sexuality also has other significant purposes such as expressing and enhancing the love union of the partners and thereby the good of the marriage. Unlimited procreation, or at times any procreation, could be harmful to one of the spouses, the marriage itself, the good of already existing children or the needs of the broader society. Judgments about the ethical use of contraception outside of marriage depends upon one's understanding of the morality of extramarital sexual activity. As a matter of fact, many unmarried people today are sexually active. Indeed, the majority of adolescents in the United States have had sexual intercourse by the time they are nineteen years old (Demetriou and Kaplan; American Academy of Pediatrics).

Many feminists emphasize reproductive rights, freedom, control of one's body and autonomy to support their stand that women have the right to make contraceptive decisions in all cases (Harrison). Although society at large in the United States no longer condemns all extramarital sexuality as immoral and irresponsible, the mainstream churches and religions still generally maintain the immorality of sexual relations outside marriage (Lebacqz). The use of condoms enters into the discussion of extramarital sexuality not only because of the desire to prevent procreation, but also because condoms can help to prevent the transmission of HIV and other sexually-transmitted diseases. If one believes that extramarital sexual relations are morally responsible, then the use of contraception to prevent unwanted procreation is morally acceptable.

No perfect contraception exists, but most ethical reasoning sees no significant moral differences among the various means, provided they are not harmful to the individuals who use them or others. One could justify contraception on the basis of an absolute autonomy, giving the individual control over her body and the right to make all decisions concerning it, but most justifications of family planning, which by definition concerns more than the individual, avoid such a radical individual autonomy. The official teaching of the Roman Catholic church constitutes the strongest and the primary contemporary moral opposition to the use of contraception.

The widespread moral acceptance of contraception has taken place well within the twentieth century. Individuals do not make moral judgments in the abstract. As indicated previously, a number of significant social factors have influenced the acceptance of contraceptive practices. These include the increased life expectancy of all human beings, the massive improvements in infant and child health resulting in more survival, the realities and pressures of an increasingly urban and industrialized society, the changing role and function of women in society, the wider and more accurate understanding of the physiology of human reproduction, the recognition of the population explosion and the need to limit population, and the development of accessible, effective methods of contraception.

The Christian religions have played a significant role in ethical views on contraception in the West. The ancient world of both East and West knew the reality of contraception either by avoiding insemination of the female or by using potions or magic. In the Greco-Roman world, some philosophers and physicians apparently accepted attempts at contraception. On the other hand, the Roman Empire tended to encourage childbearing. Some influential philosophers insisted that procreation constituted the only purpose of sexual intercourse and thus, logically condemned contraception. The Hebrew scriptures contain no law condemning contraception.

The Christian approach to contraception also developed in a context in which contraception was associated with prostitution and extramarital sexuality, which Christians strongly opposed. In addition, early potions used for contraception (and some modern methods such as IUDs) could not clearly be differentiated from abortifacients and abortion was even less tolerable than contraception. The Christian condemnation of contraception followed from its understanding of human sexuality and the belief that the purpose of sexuality was procreation. Some medieval theologians and their successors, however, including Thomas Aquinas, maintained that procreation was not the only lawful purpose for sexuality, at least within marriage. The church, for example, accepted the marital sexuality of the sterile and those no longer able to procreate. The procreation of offspring also included the responsibility for the well-being and education of the children—some would extend this to justify not having so many children that you could not care for the pre-existing ones. However, the condemnation of contraception remained, with emphasis on its violation of the order of nature calling for the depositing of the male seed in the vagina of the female. This nature-based rationale also served as the basis for the condemnation of sodomy, oral and anal sex, and masturbation. This view is closely related to the Hebrew prohibition on "spilling" seed.

Although some Protestant laypersons were involved in the Anglo-Saxon countries, the Christian churches remained firm in their condemnation of artificial contraception, as distinguished from abstinence, well into the twentieth century. The Church of England became the first Christian church to accept officially the morality of artificial contraception for spouses. In 1930, the Lambeth Conference, by a vote of 193 to 67, adopted a resolution recognizing a moral obligation to limit or avoid parenthood and proposing complete abstinence as the primary and most obvious way while also accepting other methods (Fagley).

The Committee on Marriage and Home of the U.S. Federal Council of Churches issued an influential statement in 1931 in which the majority of its members accepted the careful and restrained use of contraception by spouses. Subsequently, the major Protestant churches and the most significant Protestant theological ethicists accepted contraception as a way to ensure responsible parenthood. The proponents of change pointed to aspects in the Christian tradition supporting such a move. Christians had gradually come to recognize the loving or unitive aspect of marital sexuality in addition to the procreative aspect. The procreative aspect itself included not only the procreation but also the education of offspring. This called for the good health of the parents. Protestantism justified the use of contraception as a way for spouses to realize responsible parenthood (Fagley).

Roman Catholic official teachings continue to steadfastly oppose artificial contraception, even within marriage. Some Catholic theologians have advocated the use of the infertile period for sexual intercourse, or the rhythm method. In 1951, Pope Pius XII taught that serious medical, eugenic, economic and social indications justified the use of the sterile periods even on a permanent basis. Unfortunately, the rhythm method often proves to be a rather ineffective method of contraception. This can have devastating consequences, especially if there are serious medical contraindications to pregnancy. Pope John XXIII and Pope Paul VI established a commission to study the question. The majority of the commission favored changing the teaching to allow for artificial contraception, but Pope Paul VI and Pope John Paul II have reiterated an absolute condemnation of artificial contraception. In *Humanae Vitae,* Paul VI states that the natural law "teaches that each and every marriage act must remain open to the transmission of life" and refers to "the inseparable connection, willed by God and unable to be broken by man on his own initiative, between the two meanings of the conjugal act: the unitive and the procreative meaning" (Paul VI). In practice, the vast majority of Catholic couples use contraception (Curran). The Catholic Church's continued prohibition of any method of artificial contraception is especially problematic in poor, overpopulated developing countries with large Catholic populations. In such countries, uncurtailed childbearing can have dire consequences for women and children.

The Catholic Church also opposes voluntary sterilization for contraceptive purposes. As far as therapeutic sterilization is concerned, the principle of double effect is generally applied. Therapeutic sterilization is that done for the good or health of the individual and not primarily for contraceptive purposes. Direct sterilization is that which aims at making procreation impossible either as a means or as an end and is always considered wrong. Indirect sterilization aims directly at the health or good of the individual and the actual procreative effect is secondary. Thus, a cancerous uterus can be removed, but hysterectomy to prevent harm to the pregnant woman would be considered direct and morally wrong (Boyle).

The fact that there is little or no discussion of punitive sterilization in the more recent literature hints at a consensus against the practice. However, Francis Hurth, a conservative Roman Catholic theologian in the 1930s, proposed limited cases in which punitive sterilization might be justified. Pope Pius XI went out of his way not to directly condemn punitive sterilization. This is interesting in light of the absolute prohibition on sterilization for contraceptive purposes in women desperate to limit the size of their families. Proponents of punitive sterilization maintain that if the state can inflict capital punishment for certain crimes, it can also inflict the lesser punishment of sterilization in limited, appropriate cases. Critics reply that punitive sterilization does not achieve the purposes of punishment and does not even inhibit future sex crimes (McCarthy). Punitive sterilization is virtually unsupported (Mason).

Other religious bodies today generally support artificial contraception in the context of responsible parenthood. The Eastern Orthodox church accepts responsible contraception while condemning abortion and infanticide. The multiple purposes of marriage, the lack of any definitive statement against contraception by the church, a synergistic cooperation between God and humans, and the need for responsible parenthood serve as the basis for the responsible use of contraception within marriage (Harakas; Zaphiris).

Orthodox Judaism gives a limited acceptance to some forms of contraception. Jewish law puts the duty of procreation on the male, and this obligation militates against the use of condoms or coitus interruptus. In this view, the most acceptable contraception is that which interferes the least with the natural sex act (Rosner). Conservative and Reform Judaism fully accept and endorse contraception provided it is not harmful to the parties involved.

Islam accepts contraception if it does not entail the radical separation of procreation from marriage. All forms of contraception are acceptable provided they are not harmful and do not involve abortion. Justification for contraception in Islam rests on reports that the Prophet Muhammad did not forbid the contraceptive practices of some of his companions (Hathout).

Ancient Hindu medicine and Hindu tradition did not contemplate contraception, but did sanction means to enhance contraception. In time, medical texts began to address contraception by advising a few oral preparations to prevent conception. When India embarked on a national family planning program after its independence in 1947, the discussions accepted the morality of contraception, but the main focus was the relative population size of the higher and lower castes (Desai).

Contemporary popular morality—the behavior and values of ordinary people—as well as contemporary philosophy, theological ethics, and religious bodies (with the major exception of the Roman Catholicism), accept the morality of contraception for spouses in practicing responsible parenthood. General agreement exists that on the microlevel of the family, the decision about contraception should be made by the spouses themselves in the light of their own health, the good of their marriage, the education and formation of their children, and population and environmental needs, both local and global (Curran). In fact, with the exception of those who are politically conservative and/or pro-family, most accept the right to fertility control even for those who are unmarried.

International Population Control

The highly politicized nature of family planning in the United States has had major implications for the developing world. In response to pressures by conservatives, the emphasis of U.S. population programs abroad shifted heavily to programs promoting natural family planning rather than the more reliable methods of artificial contraception. Most notably, the "Mexico City policy" adopted by the Reagan administration in 1984 stipulated that no U.S. aid would go to any international organizations that supported abortion, even if the U.S. funds were separated and used only for nonabortion services. The Mexico City policy was overturned in the early days of the Clinton administration in 1993, thus renewing a commitment on the part of the United States to international family planning efforts after a period of marked decline. The policy again became an issue in the administration of George W. Bush who withheld $34 million in funding for birth control, maternal and child health care and HIV prevention from the United Nations Population Fund in 2002 (Rosenberg; Planned Parenthood; UNFPA Funding Act, 2003). The loss of U.S. funding has a grave impact on UNFPA programs and the people they serve. UNFPA estimated that the $34 million loss would lead to two million unwanted pregnancies, 800,000 induced abortions, 4,700 maternal deaths, and 77,000 infant and child deaths. Restoration of U.S. funding would also save lives through HIV prevention campaigns. The $34 million would provide one-third of the annual needs for mass HIV prevention information campaigns aimed at behavior change. It would also cover the cost of 13 per cent of the condoms needed worldwide to prevent sexually transmitted infections, including HIV. President Bush also reversed the U.S. position in support of the 1994 global agreement that affirmed the right of all couples and individuals to determine freely and responsibly the number and spacing of their children and to have the information and means to do so (United Nations; RowBoat). Walking a political tightrope, he then announced major programs to deal with HIV infection abroad.

Family planning issues are an increasingly high priority for many developing nations. Concerns about the ability to feed rapidly growing populations, the dramatic spread of HIV infection and AIDS in the Third World, especially in parts of Africa, Asia, and Eastern Europe, and the large number of deaths that occur each year from illegal abortions create constituencies for family planning services within these countries. There are, of course, also often significant religious and cultural objections.

The rise of indigenous women's movements in the developing world has also served as a particularly important stimulus for additional family planning services which must be provided in a culturally sensitive manner (Bruce; Dixon-Mueller). The International Women's Health Coalition has been one of the most successful international population groups in terms of its ability to work closely with local, grass roots women's organizations in the design and delivery of family planning programs.

Current and Future Controversies

The future of accessible family planning services in the United States and abroad is unclear. During the administration of Bill Clinton, the influence of political conservatives in public policy debates about family planning was greatly diminished. Clinton's appointments to key health policy positions of individuals strongly committed to family planning, especially in the area of adolescent pregnancy prevention, sharply reversed the trends of the Reagan-Bush era. Ideological battles were temporarily muted, but they will never entirely disappear because of a change in presidential administration. At the state and local levels, many of the bitter struggles over the public provision of reproductive health services continued. Bill Clinton attempted to reform health care in general and largely failed. The election of George W. Bush signaled an immediate return to the ideologically conservative policies of his father.

The abortion issue remains among the most politically explosive and unresolved issues in bioethics. Provision of abortion services has endangered funding for other family planning services and endangered the lives of providers and consumers alike. Concerns of political conservatives and anti-abortion groups have affected policy debates as diverse as end of life decision-making in New York State and Federal regulation of embryonic stem cell research. In August of 2002, George Bush revealed his decision on stem cell research. Had it not been for the terrorist attacks that occurred shortly thereafter, stem cells might have been the defining issue of his presidency. Bush allowed future work with stem cell lines already produced, but his policy did not allow for the development of additional cell lines. By sitting on the fence, Bush did not satisfy either side in the debate. Anti-abortion forces were not happy that the existing cell lines, obtained from aborted fetuses, would still be used. Those in favor of stem cell research did not think that the existing cell lines would be adequate to study the possible benefits of stem cells for those with diseases such as Parkinson's Disease, Alzheimer's Disease, and diabetes.

The historical context is important for the current ethical and policy debates related to fertility control. Efforts to empower all women, including poor women of color, must be balanced with a keen sense of the abuses evident in the history of the birth control movement. Racism and eugenic concerns have been consistent issues in debates about controlling fertility, and our targeted educational programs and initiatives must be sensitive to community concerns. Empowering women to make their own reproductive choices is a praiseworthy goal, but it is not a desirable one for some.

KATHLEEN E. POWDERLY

SEE ALSO: *Abortion; AIDS: Public Health Issues; Autonomy; Coercion; Conscience, Rights of; Embryo and Fetus; Eugenics; Family and Family Medicine; Genetic Testing and Screening: Reproductive Genetic Screening; Infanticide; International Health; Law and Morality; Maternal-Fetal Relationship; Natural Law; Population Ethics: Religious Traditions;* and other *Fertility Control* subentries

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III. LEGAL AND REGULATORY ISSUES

The ability to control fertility depends on available technology, moral and religious acceptability, and legal permissibility or the threat of sanction. The major fertility-control mechanisms are contraception and sterilization and, when neither is used or the chosen method fails, abortion. The mechanical and physiological characteristics of each method determine the ease and comfort of individual use, the likelihood of success, and the potential for coercion.

In many cultures men view children as proof of virility and power. They see attempts by women to limit or terminate pregnancy as an attack on male authority and reproductive potential, which in many societies equals wealth. For many women a desire to limit pregnancy must often be pursued furtively, with fear of violence and retaliation. Biology and the threat to a woman's independence, health status, and well-being make the control of fertility primarily a woman's concern. A woman's ability to limit and control her fertility may be a necessary precondition for equality and personal economic status.

Because they affect relationships between the sexes, population growth, and a woman's status, contraception, sterilization, and abortion are and have been problematic for many societies. Secular societies committed to individual rights and liberties are less likely to intervene in reproductive decisions. But all societies to some degree attempt to influence individual reproductive choices.

History of Contraception Use and Control

GENERAL. Various societies have interceded for centuries in the free use of contraception, largely for moral and/or religious reasons. Classical Islam permitted the use of birth control and even early abortion (Fathalla et al.). Biblical Judaism, based on interpretations of the story of Onan in Genesis 38: 8–10, condemned *coitus interruptus* and the use of male condoms. Christianity gradually evolved a doctrine, based on biblical references, interpretations of natural law, and the writings of Saint Augustine (354–430), that prohibited use of all contraceptive devices (St. John-Stevas). Widespread, class-linked knowledge of contraceptive practices was effectively withheld from most of the population following the condemnation of birth control by philosopher and religious Thomas Aquinas (1224 [or 1225]–1274] in the mid-thirteenth century (Fathalla et al.). As religion formed part of the basis for modern secular law, control of fertility became a subject of legal attention and regulation.

Abortion, as a method of fertility control, has always been especially controversial. Despite its morally and legally complex past and its tendentious present, there is evidence today that abortion remains a favored method of birth control for many women, both as a preferred method of fertility control and as a backup to failed contraception. An estimated 46 million abortions are performed worldwide each year (Alan Guttmacher Institute). Unintended pregnancy is the leading cause of abortion. Approximately 150 million married women want to stop having children but are not using contraception (World Health Organization [WHO]). In the United States, where contraception is readily available, 49 percent of pregnancies are unintended (Henshaw). The United States Center for Disease Control (CDC) reported 884, 273 legal induced abortions in 1998, a ratio of 264 abortions per 1,000 live births.

While contraception and abortion address the prevention or termination of any specific pregnancy, sterilization terminates individual fecundity. With the development of modern, comparatively safe, and effective means of sterilization (vasectomy, or surgical excision of the duct carrying sperm from the testicles; and salpingectomy, or surgical removal of one or both fallopian tubes), individuals can choose, by means of one medical intervention, to detach sexual intercourse from reproductive consequences. If chosen by individuals, these simple and almost always irreversible interventions extend autonomy; if imposed by the state, they can become instruments of repression.

Whether contraception, sterilization, and abortion should be permitted, prohibited, or coerced by government has generated intense controversy in countries as different as the United States, Romania, India, Ireland, and China. In each country, legislators, judges, individuals, and special-interest lobbies have struggled to affect how citizens will think about their options for controlling fertility, how the individual decision-making process will be informed and supervised, how access to contraception, abortion, and sterilization will be ensured or precluded, and whether coercion will be encouraged, permitted, or prohibited (Weston; Thomas).

Both female and male condoms have been available for centuries. Roman women attempted to use goat bladders (Fathalla et al.), and some African women hollowed out okra pods (Robertson). A picture of a penile sheath is recorded as early as 1350 B.C.E., although male condoms did not come into general use in Europe until 1671 and became reliable only with the vulcanization of rubber in 1843 (Robertson). Monitoring and prohibiting use of birth-control devices such as condoms are difficult because of the inherently private nature of their use. Manufacture, distribution, sale, and advertising are more easily regulated and prohibited.

Despite the long history and the private nature of fertility control, various legal and theological systems have attempted prohibition. The early Christian (Roman Catholic and Protestant) argument against contraception, influential as the model for legal regulation, holds that God's purpose for sex is conservation of the species, which is frustrated when people have intercourse for nonprocreative purposes (St. John-Stevas). The Catholic Church first proscribed contraception in canon law in 1140 (St. John-Stevas). While not all religions have been as resistant to the idea of contraception as the Catholic Church, contraceptive use has traditionally been considered an appropriate area for moral guidance and proscription and not until the beginning of the twentieth century did significant numbers of Protestant theologians provide moral approval (Larson).

Religious regulation has been selective. Some forms of birth control were interdicted, while others were and have remained relatively unnoticed. In addition prolonged lactation, postpartum abstinence, delayed marriage, celibacy, and to some extent infanticide, are all techniques of fertility management that have been and continue to be used.

U.S. HISTORY. Puritan theology dominated the early American colonists. The Puritans considered sex-related matters part of the devil's province, to be shunned and ignored, and they tolerated little open discussion (Robertson). In the 1830s some popular literature on contraception, such as Robert Dale Owen's *Moral Physiology,* began to be generally available (Robertson, Reed). Not until 1873 did law begin regulating distribution of contraceptives in the United States. The Comstock Act ("An Act for the Suppression of Trade in, and Circulation of, Obscene Literature and Articles of Immoral Use") equated contraception with obscenity and made it a federal offense to use the postal service for transporting obscene materials, defined to include contraceptive and abortion information and equipment. The act also banned importation and interstate transportation of such items (Sloan). After the act's passage, many states adopted their own regulations on the sale, advertising, and display of contraceptive devices.

Margaret Sanger, a nurse affected by her work in poor communities where morbidity (the incidence of disease) and mortality from abortion was high, was a vociferous advocate for birth control (Reed; *People v. Sanger,* 1918). She founded a monthly magazine, *The Woman Rebel,* for which she was arrested and indicted under the Comstock Act. She fled to Europe and returned in 1916 to establish the first American birth-control clinic in Brooklyn, a borough of New York City (Chessler). In 1918 she was convicted and sentenced to thirty days in the workhouse under New York State's Comstock law. Years later a physician in one of Margaret Sanger's clinics who had ordered a package of contraceptives through the mail was charged with violating the Tariff Act of 1930, a statute based on the Comstock Act that prohibited importation of "any article whatever for the prevention of conception or for causing unlawful abortion." On appeal the federal circuit court for the second circuit held that the act did not apply when the article imported was not intended for an immoral purpose. Judge Augustus Hand declared that the Tariff Act was part of a "continuous scheme to suppress immoral articles and obscene literature," and refused to find proper medical use of a contraceptive by a licensed physician to be immoral or obscene (*U.S. v. One Package …,* p. 739). Though the court did not invalidate the statute, its interpretation limited the sweeping definition of morality and obscenity that had previously held sway.

Statutes modeled after the Comstock Act continued to exist, however, until 1965, when the U.S. Supreme Court in the case of *Griswold v. Connecticut* invalidated a Connecticut statute prohibiting the use of contraceptives. The Court held, citing prior cases that had created a zone of privacy protecting certain personal behaviors, that these penumbral rights of "privacy and repose," based on several fundamental constitutional guarantees, protected the use of contraceptives by married persons (*Griswold v. Connecticut,* p. 481). *Griswold* was followed by *Eisenstadt v. Baird* (1972), extending this reasoning to nonmarried individuals. The statute that was invalidated in *Eisenstadt* prohibited single persons from obtaining contraceptives to prevent pregnancy, and permitted contraceptives only on a physician's prescription for the purpose of disease prevention. The statute was held to violate the equal protection clause of the Fourteenth Amendment:

> [W]hatever the rights of the individual to access to contraceptives may be, the rights must be the same for the unmarried and the married alike.… If the right of privacy means anything, it is the right of the individual, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child. (*Eisenstadt v. Baird,* p. 452–453)

Minors gradually attained access to contraceptive advice and devices. In 1977, in the case of *Carey v. Population Services International,* the U.S. Supreme Court invalidated a New York State statute that had banned the sale or distribution of contraceptives to persons below the age of sixteen and had prohibited the advertising or display of contraceptives by any person, including a pharmacist. In 1983 the Supreme Court struck down a federal statute prohibiting unsolicited advertisements of contraceptives (*Bolger v. Young Drug Products Corp.*). In addition, under Title X of the Public Health Services Act and Title XIX of the Social Security Act, receipt of federal funds prohibits a requirement of parental consent for services and requires confidentiality. Efforts to require parental notification under these acts have been held unconstitutional (*Jane Does 1 through 4 v. State of Utah Dept. of Health, Planned Parenthood Association of Utah v. Dandoy*), and federally funded clinics provide a full range of advice and service for fertility control for adults and minors.

New Contraceptive Technologies

A revolution in birth control techniques has created new possibilities for individual choice and new dangers of coercive action by legislatures, bureaucrats, and judges. Additional dangers arise from inadequate new-product testing and from lack of information or misinformation about risks and benefits of use. Female condoms, levonorgestrel (Norplant), and Depo-Provera are increasingly available to women for contraception.

The female condom or vaginal pouch was approved by the U.S. Food and Drug Administration (FDA) in 1993. The device, developed and marketed by Wisconsin Pharmaceuticals, consists of a polyurethane sheath secured inside the vagina by a small metal ring and outside by a large metal ring. It is the only barrier contraceptive that is under the control of a woman, an increasingly important factor for women seeking to protect themselves from sexually transmitted diseases and human immunodeficiency virus (HIV) infection when their partners refuse or neglect to use condoms. The device was approved by the FDA despite concerns that it was not proved as effective as the male condom for prevention of pregnancy or prevention of transmission of infection.

Norplant, approved by the FDA in 1990, is a long-term implantable contraceptive comprised of six capsules that gradually release progestin, thereby providing effective contraception for five years. A two-capsule version provides protection for three years. Norplant, like other contraceptive devices, is morally neutral; it may enhance the range of individual choice or, because of its long-acting nature, lend itself to coercive action by others. It permits a woman to protect herself without conscious attention to contraception but makes her dependent on medical intervention for removal, a dependency many women resent.

Norplant suppresses ovulation, and changes the female physiology to discourage pregnancy. For women who choose this contraceptive technique, it offers 100 percent compliance and effectiveness without the need to attend to individual acts of intercourse or to daily medications. There are some side effects and contraindications for use, including the possibilities of weight gain, headaches, and a general feeling of malaise. Implantation and removal remain expensive in the United States, costing between $500 and $750 (Planned Parenthood).

The only way to stop the contraceptive effect of the device is to have it surgically removed. Removal is more complicated than insertion and more than one session may be required to remove all the capsules; removal may also be painful. Norplant provides either long-acting contraception or time-limited sterilization (Mertus and Heller; Arthur).

Norplant presents an easy potential for coercive use by judges and legislatures. Problematic uses include requiring Norplant as a condition of parole following a conviction for child abuse, and paying women on welfare for consenting to initial and continued placement of the contraceptive. The first is clearly coercive. The second is potentially coercive depending on the context of a woman's poverty. Various state legislatures have considered statutes that would pay women receiving welfare to use Norplant or mandate its use by women convicted of child neglect and drug use, or both (Mertus and Heller; American Medical Association Board of Trustees [AMA]).

Judicial or legislative imposition of Norplant may violate a woman's constitutionally protected rights to choose how to manage reproduction and to choose whether or not to consent to or refuse medical care (*Cruzan v. Director, Missouri Department of Health*). Any long-acting male contraceptive would implicate these same rights. In addition, because long-acting contraception amounts to temporary sterilization, it raises the specter of eugenics—policies that are often directed at people of color, the poor, the retarded, the mentally ill, and other persons designated by those in power as undesirable. Norplant offers effective contraception when chosen voluntarily by a woman informed of the risks and benefits, and a potential for tyranny when imposed by judges or legislatures.

Regulation of Contraceptive Technologies

In addition to enhancing individual choice and restricting abuse, regulation of new technologies must ensure access and quality control. The development of new technologies is regulated formally by the approval process of the FDA, and informally by compensation awards under tort law for harm caused by defective products.

The FDA regulates the development of new drugs and contraceptive devices under the Federal Food, Drug and Cosmetic Act of 1938. Under this law, a company interested in marketing new contraceptive drugs or devices must submit data, including results from various tests for safety, effectiveness, and dosage, as part of an extensive approval process. In addition to approving new drugs and devices, the FDA reviews labeling and assesses data in a postmarketing surveillance program. The FDA approval process has been criticized as expensive, time consuming, and a barrier to new techniques. It has also been praised for protecting consumers from the harm of untested substances.

The FDA approval process is not the sole factor dictating whether a reproductive technology reaches U.S. consumers, however. The American tort system is designed to compensate those injured, deter the marketing of dangerous and defective products, and resolve disputes between the injured person and the manufacturer.

A person may recover damages for dangerous or defective products, including contraceptive devices, if either negligence or a strict liability is established. Negligence requires proof that the manufacturer was at fault. However, sometimes the fault of a large company is difficult to establish, and therefore the interests of justice dictate that a victim should be allowed to recover damages without proving specific fault. According to the strict products-liability principle, if a product is sold in a defective condition, and is unreasonably dangerous to the consumer, there is liability regardless of the care taken, that is, regardless of negligence in any individual case. Strict liability may make manufacturers apprehensive about putting new contraceptive products on the market.

This is the case especially since the litigation experience of the A. H. Robins Company, developer and marketer of the Dalkon Shield, an intrauterine contraceptive device. In a series of court cases in the early 1980s, this device was proved to cause pelvic inflammatory disease, infertility, birth defects, perforated uterus, and spontaneous abortion. In a series of jury verdicts throughout the United States, A. H. Robins was forced to pay compensatory damages and punitive damages because plaintiffs proved that the company had understood the dangers of the device, withheld this knowledge from prospective users, and misrepresented the nature and safety of the device (Mintz). Despite this experience, cases brought by women seeking recovery for harm from contraceptive devices have usually found the manufacturer liable only under theories of negligence—for example, negligent failure to comply with the duty of care, negligent failure to warn of risks, or fraudulent misrepresentation (*Hilliard v. A. H. Robins Co., Tetuan v. A. H. Robins Co.*). In fact, even those courts purporting to apply strict liability seem to be applying a theory of negligent failure to warn under the rhetoric of strict liability (Henderson and Twerski; Fox and Traynor).

How tort law is interpreted is in a state of flux. Some judges and juries appear to view manufacturers as *deep pockets* (Reilly) and to see tort law as a vehicle for providing social insurance for injury victims. Many critics of large jury awards argue that the size of jury awards often bears no relationship to actual economic loss or to pain and suffering, and that awards of punitive damages are arbitrary and unfair. Supporters of the present pattern of trial awards argue that claims of a law crisis in this area are exaggerated because of manufacturers's dislike for how the law determines their liability (Fox and Traynor). However as long as manufacturers fear they will have to pay large financial penalties to women who suffer the consequences of their new products, many may be reluctant to market new products, a trend that may limit women's access to new contraceptive technologies.

Postcontraception, the *morning-after* pill, is widely dispensed on college campuses after unprotected intercourse and in emergency rooms for rape victims; it promises to be another barrier to unwanted pregnancy. The process generally entails two treatments of oral contraceptives within seventy-two hours of intercourse and is thought to prevent pregnancy either by blocking fertilization or by blocking implantation of the fertilized egg. An antihormone (mifepristone) product called RU-486, discussed in the following section, has also shown promise as a morning-after pill.

Abortion

This article will not survey the legal history and the current status of abortion law and regulation. This discussion will be limited to RU-486 which, while functioning as an abortion inducer, is thought of by many users as similar to oral contraceptives.

RU-486 is a steroid analogue that, when used with prostaglandin (PG), is able to induce menses within eight weeks of the last menstrual period. It has been called a *menstrual regulator* in an attempt to distinguish it from contraceptives and abortion inducers, although to theologians the physiological function is clearly that of an abortion inducer. It was approved for use in France in 1988. Limited trials in the United States began in 1994. Shortly after its introduction in France, the manufacturer, Roussel Uclaf, attempted to halt distribution for fear of anti-abortion protests. The French government, a one-third owner of the company, ordered continued manufacture and distribution (Banwell and Paxman).

Whether RU-486/PG will become readily available will depend on each nation's interpretation of relevant abortion laws and regulations. If abortion "is defined to include techniques that operate before implantation is complete, RU-486/PG will be regulated by abortion law. If not, RU-486/PG might be considered similar to a contraceptive and could be made more widely available. This distinction is particularly important because abortion legislation generally imposes criminal penalties" (Banwell and Paxman, p. 1400).

While France considers RU-486/PG an abortion inducer, Germany, New Zealand, and Liberia use a definition of pregnancy in their abortion statutes providing that pregnancy begins only after complete implantation. In these countries, RU-486/PG and any other menses-inducing technique is regulated as a form of contraception. In countries with strict abortion laws in which pregnancy is defined as beginning with fertilization, even early use of RU-486/PG might be barred (Banwell and Paxman).

Many countries in Latin America and Africa have restrictive abortion statutes that require proof of pregnancy. Statutes that require proof of pregnancy will be difficult to use as a barrier to RU-486/PG. Other national statutes criminalize the intent to abort whether or not the woman is pregnant. In these countries, many of which are former French colonies, the widespread use of RU-486/PG is effectively precluded. In societies governed by Islamic law, where pregnancy may be terminated until quickening—when fetal movement is felt—RU-486/PG would likely be acceptable (Banwell and Paxman).

Sterilization

Sterilization is a particularly useful technique for men and women who are certain that they have fulfilled their reproductive agenda. For these individuals sterilization provides an uncomplicated and generally certain method of limiting fertility. Whereas sterilization done competently is 100 percent effective, cases have claimed damages for children conceived as the result of incomplete sterilizations.

The key legal issues in sterilization involve the need to ensure that the choice is made by a competent adult who has chosen voluntarily; the need to decide for some persons, almost always women, who are clearly incapable of deciding for themselves; and the need to prevent notions of eugenics from dictating sterilization policy and practice. Sterilization, because it requires only one medical intervention, has been particularly susceptible to government abuse.

Women or men who choose sterilization must be counseled about the risks and benefits of the intervention itself and about the very slim chances for reversal if permanent infertility is no longer desired. Some localities have regulations requiring a waiting period between a request for sterilization and the actual procedure. Others preclude caregivers from soliciting consent for sterilization from women during the birthing process. Both restrictions offer protection against coercion, especially for low-income women and women of color who have been historically at risk for nonconsensual sterilization.

Sterilization has been used by physicians and by state and federal governments since the turn of the century (Mertus and Heller), in order to limit the reproduction of low-income women and women of color. It has also been used as a method of eugenics "to weed out traits or characteristics that are held to be undesirable. Further, sterilization was simultaneously discouraged among affluent white women" (Mertus and Heller, p. 377).

The history of involuntary sterilization of incompetent and developmentally disabled individuals in the first half of the twentieth century is a history of "wholesale violations of constitutional rights carried out with the approval of the highest judicial tribunals." Eugenic sterilization—the attempt to rid the collective gene pool of hereditary mental and physical defects—was the result of the "enthusiastic application of Mendelian genetics" to population policy (*In re Conservatorship of Valerie N.,* p. 148).

In the early-twentieth century, thousands of young women and men were sterilized as the result of decisions by the directors of mental institutions or prisons in which they were housed, or by decisions of their conservators or guardians. The impulse to control the reproductive capacity of these people was fueled by the dual fears that children would perpetuate their parents's mental or physical *deformity* and would be a drain on state coffers. But there is another basis, never articulated as such in legislation or by the courts, and that is a general revulsion at the concept of mentally *defective* persons acting sexually. Indeed a 1913 California statute granted authority to *asexualize* committed mental patients and developmentally disabled persons prior to their release from state institutions (*In re Conservatorship of Valerie N.*). Sexuality, as well as reproductive capacity, was at issue.

By the second decade of the twentieth century, twenty-two states had eugenic sterilization statutes. Between 1907 and 1921, 3,233 sterilizations were performed, of which California was responsible for 2,558. By 1927 California had performed over 5,000 sterilizations, four times as many as had been performed by any national government worldwide. By 1960 approximately 60,000 persons had been subjected to compulsory sterilization in the United States, with nearly 20,000 in California (Mertus and Heller).

In 1927 the U.S. Supreme Court upheld a Virginia statute permitting the sterilization of the *mental defectives* (*Buck v. Bell*). The Court based its decision on two lines of reasoning: that if rendered unable to procreate, the person might more easily become self-supporting; and that society can choose to protect itself from further dissemination of defective genes. Justice Oliver Wendell Holmes wrote, "The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes.… Three generations of imbeciles are enough" (*Buck v. Bell,* p. 207).

Buck v. Bell, though never overruled, has been severely limited by later decisions. In 1942 the U.S. Supreme Court invalidated the Oklahoma Habitual Criminal Sterilization Act, which ordered the sterilization of anyone convicted of three crimes involving *moral turpitude;* however, the contested law excepted certain white-collar crimes. In *Skinner v. Oklahoma* (1942), declaring the Sterilization Act unconstitutional on equal-protection grounds, the Court ruled that procreation is a basic civil right that can be abridged only by showing compelling state interest. The Court referred to the right to marriage and procreation as a basic liberty and as one of the basic civil rights. The Court's reluctance to approve the Oklahoma statute appears to reflect apprehension that sterilization could be used oppressively.

The second half of the twentieth century has witnessed a revulsion against nonconsensual sterilization, based on the revelations of Nazi abuses and the emergence of various rights movements in the United States—civil, women's, welfare, mentally ill, the disabled, and prisoners. Sociological and medical research regarding the nature of mental illness and developmental disability also enlightened the public regarding the ability of developmentally disabled and mentally ill persons to lead constructive, competent, loving lives as partners and parents.

Beginning in the 1950s, numerous states repealed legislation permitting eugenic sterilization for institutionalized persons or limited the powers of conservators and guardians to procure individual sterilization. Yet in many states these statutes are still law. This has led to the ironic position, in many states, that no one can consent for the incapable, thus denying them access to sterilization even when sterilization is the only or arguably the best contraceptive solution—and even when it is required to protect health or life itself.

Arguments regarding sterilization for incompetent persons pit advocates of reproductive choice for the disabled against those who argue that the right to *bear or beget* a child includes the right to choose reproduction, contraception, or sterilization. Federal (*Hathaway v. Worcester City Hospital, Ruby v. Massey*) and state courts (*In re Moe*; *In re Grady*; *In re A. W.*) have generally held that developmentally disabled persons have fundamental privacy and liberty interests in making decisions about procreation and that these interests require sterilization to be an option for fertility control. Some state courts, however, have refused to authorize sterilization of an incompetent person unless the state legislature has specifically authorized the decision and specified a process (*Hudson v. Hudson, In re Eberhardy*). The U.S. Supreme Court has yet to examine the issue, but prior cases would seem to support a right of access to sterilization for incompetent persons.

Cases claiming rights of protection from sterilization most often involve consent for severely disabled young women for whom menstruation and pregnancy would be painful, provoking, upsetting, or possibly life-threatening (for example, one woman for whom the sight of her own blood caused a pattern of severe self-mutilation [*In re P. S.*]). In most states, courts appoint an independent guardian to protect the interests of the person and then base their decision on the standard of *best interest* (*In re P.S., In re Hayes*) or substituted judgment (*In re Moe, In re Grady*).

The dangers of forced sterilizations are apparent outside the realm of prisoners, developmentally disabled, and incompetent individuals, largely where issues of race and class are present. The indigent, who are often persons of color, have been particularly subject to sterilization abuses by public officials and collaborating physicians. Numerous cases have been documented of coerced sterilization of Native Americans (Kelly), Latinos (particularly those who spoke little or no English), and African Americans (*Relf v. Weinberger,* 1977). In response to one egregious incident (*Relf v. Weinberger*), the district court examined the practice of physicians at federally funded clinics who were using sterilization to limit the reproduction of African-American teenagers. The court invalidated federal regulations that permitted involuntary, coerced sterilization, including sterilization of minors or persons incapable of providing consent. The court further held that such sterilizations could not be funded under the Social Security Act or the Public Health Service Act. The court found that minors and other incompetents had undergone federally funded sterilization and that an indefinite number of poor people had been improperly coerced into accepting sterilization operations under the threat that various federally supported welfare benefits would be withdrawn unless they submitted.

Local statutes and federal regulations have further limited the use of sterilization. In New York City, for example, statutes passed in 1985 require completion of a complicated informed-consent process and a thirty-day waiting period before sterilization is permitted (New York City Charter and Administrative Code §17–401 et seq.). Federal regulations also prescribe special informed consent procedures and waiting periods for federally funded sterilizations (Code of Federal Regulations 1993b, 1993c).

Much current law attempts to protect vulnerable women and limit potential abuse by emphasizing voluntary, informed consent and limiting sterilizations to which individual, capable consent is not given. Even where there is no specific legislation to that effect, compulsory sterilization has become rare; those states that have retained compulsory sterilization statutes on the books have, for the most part, let them slip into disuse (Haavik and Menninger).

Discussion of eugenics as appropriate public policy for the protection of future generations has largely been discredited because of the Nazis's horrendous abuse of the concept, because of scientific and societal disaffection with eugenic theories, and because of increasing respect for those with developmental and other disabilities. Nonetheless eugenics is not yet dead. Increasing knowledge about genetics and new reproductive technologies such as in vitro fertilization, artificial insemination, and surrogate motherhood, may allow people to selectively create babies of *higher quality,* and may renew the specter of eugenics, albeit in a new light (Neuhaus).

An ethical policy controlling reproduction must offer a range of contraceptive services to women and men and simultaneously protect adults with reproductive potential from state coercion. New technologies offer increased protection from unwanted pregnancy and increased potential for overriding individual preferences.

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SEE ALSO: *Abortion; AIDS: Public Health Issues; Autonomy; Coercion; Conscience, Rights of; Embryo and Fetus; Eugenics; Family and Family Medicine; Genetic Testing and Screening: Reproductive Genetic Screening; Infanticide; International Health; Law and Bioethics; Law and Morality; Maternal-Fetal Relationship; Natural Law; Population Ethics: Religious Traditions;* and other *Fertility Control* subentries

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FETAL RESEARCH

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All of the research discussed in this entry involves women and men, as well as human embryos and fetuses. When implantation is a necessary condition for the research, as in the case of most fetal research, the fetus is implanted in the uterus of a woman. For all of the research considered in the entry, the oocytes (eggs) of at least one woman are required; in cases involving in vitro fertilization (IVF), the oocyte retrieval process can be onerous for the woman involved. In addition, sperm from at least one man are required for fertilization. Finally when research is conducted on the developing fetus, interventions also directly impact and take place through the body of the pregnant woman. For reasons of brevity, this entry focuses primary attention on the developing human embryo and fetus. However recognition of the inextricable connection between the fetus or embryo and the woman and man who provide the gametes that give rise to it or to the woman in whom gestation occurs is critical to ethical discourse, and is explicity discussed where possible.

Four major types of research will be analyzed in this entry:

1. research on preimplantation embryos;
2. research on unimplanted embryos and fetuses beyond the fourteenth day of development;
3. research on implanted embryos and fetuses; and
4. research on aborted, live embryos and fetuses.

The topic of research on living tissue derived from fetal remains is discussed in a separate entry.

Preimplantation Embryo Research

The human preimplantation embryo can be defined as the developing organism from the time of fertilization to approximately the fourteenth day after fertilization, assuming a normal rate of development. The major preimplantation stages in human and other mammalian embryos are usually distinguished by such names as zygote, morula, and blastocyst. By the end of fourteen days the early human embryo has, except in rare cases, lost the capacity to divide into two individuals; it has also begun to exhibit a longitudinal axis that forms the template for the spinal column, an axis called the primitive streak (McLaren; Dawson, 1990a).

Preimplantation embryo research generally requires the associated procedure of IVF (although it would in principle be possible to retrieve an early embryo by flushing it from the uterus of a woman following in vivo fertilization of an ovum). Thus the question of research on preimplantation embryos did not arise until IVF techniques had been developed and validated, first in laboratory animals, then in humans. In 1959 M. C. Chang of the Worcester Foundation in Massachusetts was the first scientist to demonstrate unambiguously the fertilization of nonhuman mammalian oocytes in vitro. Chang's success was followed in 1969 by the first confirmed report of IVF with human gametes by three British researchers (Edwards et al.). Only nine years later the first human birth after IVF—the infant's name was Louise Brown—was reported by members of the same British research team (Steptoe and Edwards).

Given that IVF is required for preimplantation embryo research, the risks to the woman of ovarian stimulation and oocyte retrieval are relevant to the discussion. Ovarian stimulation with injectable gonadotropins has been associated in some studies with an increased risk of ovarian tumors (Harris et al.), though the association is controversial. In addition gonadotropins are associated with a risk of ovarian hyperstimulation syndrome, which is associated with ovarian enlargement, massive fluid and electrolyte imbalances, renal insufficiency, and in rare cases thromoembolism and death.

There are two major contexts for research on preimplantation embryos. The first is one in which the transfer of the embryo into the uterus of a woman (or perhaps, in the future, into a device that can support full-term fetal development) is planned. In the second context, no embryo transfer is envisioned and, accordingly, the death of the embryo or later fetus at a stage before viability is intended. These two research contexts raise somewhat different ethical issues.

RESEARCH FOLLOWED BY EMBRYO TRANSFER. In the years preceding the birth of Louise Brown in 1978, researchers devoted substantial attention to improving the prospects for successful IVF and embryo transfer. This research focused on methods for maturing oocytes, facilitating fertilization, and culturing or cryopreserving early embryos (Biggers). During the 1990s, researchers continued this type of research. New methods for assisting fertilization have been devised, including the drilling of a small hole in the outer shell of an oocyte or the injection of a sperm directly into an oocyte, a process known as intracytoplasmic sperm injection (ICSI) (Van Steirteghem). Similarly researchers have developed methods for removing one or two cells from an eight- or sixteen-cell embryo in order to perform preimplantation diagnosis of genetic or chromosomal abnormalities (Edwards, 1993). These techniques are performed so that only embryos without genetic abnormalities are transferred to the uterus, while affected embryos are discarded. In the twenty-first century, one can anticipate research that attempts to prevent the later development of a genetic disease (for example, cystic fibrosis) by treating an individual at the embryonic stage of life. If successful this kind of disease prevention by means of gene modification would be likely to affect all of the cells of the person, including his or her reproductive cells (Wivel and Walters).

The ethical issues that arise with preimplantation embryo research when embryo transfer is planned are at least analogous to those that arise with fetal research in anticipation of birth, with research on infants, and with research on children. That is, one attempts to perform a careful analysis of the probable benefits and harms of the research to the individual and to others; one seeks an appropriate decision maker, usually a genetic parent or a guardian, who can represent the best interests of the potential research subject; and one looks for a disinterested mechanism for prior ethical review of the proposed research. This kind of embryo research, in which the research procedures are often designated *therapeutic* or *beneficial,* is generally approved by commentators on the ethics of such research, even if they diverge widely in their attitudes toward IVF, the moral status of preimplantation embryos, and abortion (see, e.g., Ramsey, 1970; Catholic Church; Singer et al.).

RESEARCH NOT FOLLOWED BY EMBRYO TRANSFER. Research in this context may be proposed for a variety of reasons. The goal of the research may be to assess the safety and efficacy of clinical practices, for example, IVF or the use of contraceptive vaccines. Alternatively the goal may be epidemiological, for example, to estimate the frequency of chromosomal abnormalities in early human embryos. Another goal that has gained significant national and international attention is the use of embryos for the creation of stem cells (Thompson et al.). Stem cells are a unique type of cell that have the potential to mature into cells of a particular type (e.g., heart, blood, muscle, or brain cells). This versatility has been thought to hold significant scientific and therapeutic promise for treatment of such diseases as Alzheimer's, heart disease or kidney failure; furthermore, these cells may be essential to understanding early stages of human development. Finally in other cases research on embryos may have little reference to clinical medicine or human pathology. That is, research with preimplantation embryos may be much more basic, seeking to compare early development in various species of mammals or to explore the limits of embryo fusion or hybrid creation among different species.

Two distinct ethical questions have received primary attention in the international bioethics debate about preimplantation embryo research without embryo transfer. The first question is: Is research on such embryos morally permissible if it is not intended to benefit the embryos themselves? If the answer to the first question is negative, the second question is irrelevant. However, if the answer to the first question is affirmative, there remains a second question: Is it morally permissible to fertilize human oocytes for the sole purpose of performing research on the resulting embryos and in the absence of any intention to transfer the embryos for further development?

In their responses to the first question, proponents of nonbeneficial (to the embryos) research procedures adduce several arguments. First the research may produce benefits, either for clinical practice or in terms of basic knowledge, that are not attainable by any other means (U.S. Department of Health, Education and Welfare [HEW]; Warnock; Ethics Committee of the American Fertility Society; Robertson; National Bioethics Advisory Committee [NBAC]). One variant of this argument asserts that it is morally irresponsible to introduce new techniques (for example, cryopreservation of embryos) into clinical practice without first performing extensive laboratory studies of the technique (International Society of Law and Technology [ISLAT] Working Group).

Second, proponents of preimplantation embryo research note that the biological individuality of the embryo is not firmly established until approximately fourteen (or perhaps twenty-one) days after fertilization. Before that time twinning can occur, or two embryos can fuse into a single new embryo called a chimera (Hellegers; Dawson, 1987; Grobstein). If developmental individuality does not occur until after the preimplantation stage, research proponents argue, the preimplantation embryo is not protectable as a unique human being.

Third, proponents of research cite the apparently high embryo loss rate that occurs in natural human reproduction. The most reliable estimates are that approximately 50 percent of the human eggs that are fertilized either fail to develop or die within two weeks after fertilization occurs (Chard). To this factual evidence is added the metaphysical assertion that entities with such a high rate of natural death within two weeks of coming into being cannot be morally significant at this early stage of their existence. Proponents of embryo research may acknowledge that adult persons have some moral obligations toward early embryos, but these obligations are viewed as relatively weak and are thought to be outweighed by, for example, substantial clinical benefits to many future patients (NBAC).

Opponents of preimplantation embryo research have replies to these arguments and adduce other arguments of their own. In response to the first argument of proponents, the opponents assert that the end of desirable clinical consequences does not justify the means of performing research that seriously damages or destroys the embryo. To the consequential argument of proponents, conservatives may counterpose a consequential argument of their own, namely, that negative consequences will result from research on early embryos. For example researchers may become desensitized to the value of human life, or bizarre human-nonhuman hybrids may be produced in the laboratory (Catholic Church, Dawson, 1990b).

The second and third arguments of the proponents are viewed as mere descriptions of natural phenomena that carry no particular moral weight. Twinning, recombination, and embryo loss, if they occur naturally and are beyond human control, are in this view no more morally relevant than other natural evils like earthquakes or volcanic eruptions. For their part, opponents put forward two additional arguments. First, the genotype of a new individual is firmly established at the time when the pronuclei from the sperm cell and the ovum fuse. This fusion, sometimes called syngamy, occurs at the conclusion of fertilization. Thus from a genetic standpoint, a new individual exists from syngamy forward. Second, opponents of preimplantation embryo research often adduce the potentiality argument: that the early embryo contains within itself all of the genetic instructions necessary for the development of a fetus, an infant, and an adult, provided only that the embryo is placed in an environment that will nurture its further development. Therefore the person that the early embryo may one day become should be respected in an anticipatory way even at the early stages of development, when it lacks many of the characteristics of persons in the full sense.

Proponents of research do not deny that a new genotype is established at the time of fertilization. They simply point to other factual considerations that are in their view more relevant to moral judgments about the acceptability of embryo research. In response to the potentiality argument, research proponents note that a single sperm cell and a single oocyte have the potential to become an embryo, yet opponents of embryo research do not accord special moral status to reproductive cells. Further only a few cells of the preimplantation embryo develop into the embryo proper;

the rest become the placenta, the amniotic sac, and the chorionic villi (McLaren). Finally with the advent of cloning technology (the creation of an embryo from a single somatic cell), a single somatic (i.e., skin, breast, or other) cell theoretically has the potential to become an embryo, and it would be impossible to accord special moral status to every somatic cell in a human's body. In other words potentiality is a continuous notion, or a matter of degree, not an all-or-nothing concept (Singer and Dawson).

Among proponents of research on preimplantation embryos there is a division of opinion on the second question noted above—whether the creation of human embryos specifically for research purposes is morally permissible. Proponents of the conservative answer to this question argue that only embryos left over from the clinical practice of IVF and embryo transfer should be used in research (Steinbock). Such embryos might include those selected out when the number of embryos available for transfer exceeds a number that is considered safe for the woman (between two and five, depending on patient age and other prognostic factors (American Society for Reproductive Medicine [ASRM]). Leftover or surplus embryos might also become available in the context of cryopreservation, if a couple completes its desired family size or if both genetic parents die in an accident while some embryos remain in frozen storage.

The principal argument of conservatives on the deliberate-creation question is a Kantian argument against using early human embryos merely as means. In the opinion of conservatives, creating embryos with the prior intent of destroying them at an early stage of development is incompatible with the respect that should be accorded to human embryos. Conservatives can accept the use of leftover embryos for research because there was at least at one time an intention to transfer the preimplantation embryos to the uterus of a woman, where they could develop into viable fetuses. In their view the research use of such *spare* embryos is a morally acceptable alternative to donation or discard (Steinbock). The primary argument of those who do not object to creating embryos for research is a composite. Proponents of this view argue, first, that our moral obligations to early human embryos are relatively weak. Further proponents of the liberal view note that good research design may require either a larger number of embryos than the clinical context can provide or unselected embryos rather than those that have been rejected for embryo transfer, perhaps because they are malformed or slow in developing (Ethics Committee of the American Fertility Society). Indeed while estimates are that approximately 400,000 cryopreserved embryos are in storage, only 2.8 percent of these are available for research (Hoffman et al.).

PRACTICE VS. ETHICS. In the 1990s international practice and ethical opinion regarding human embryo research diverged sharply. One polar position in practice was that of the United Kingdom, where research on preimplantation embryos was conducted in numerous laboratories under the supervision of voluntary and (later) statutory licensing authorities (United Kingdom, 1992). At the other pole was Germany, which prohibited the fertilization of ova for the practice of research, as well as any research that was likely to destroy or damage the embryo. In the United States, embryo research was legal though practically limited due to a legislative prohibition of federal funding for: (1) any research involving the creation of a human embryo for research purposes; or (2) any research in which a human embryo is destroyed, discarded, or knowingly subjected to risk of injury or death. This prohibition has been implemented yearly through a provision included in Congressional appropriations for the Department of Health and Human Services (DHHS) since 1996 (P.L. 107–116 [2002]).

Ethics advisory bodies have been far from unanimous in their evaluations of research involving preimplantation embryos. The earliest report on this topic, produced by the Ethics Advisory Board in 1979 for HEW, judged embryo research to be ethically acceptable if it was designed primarily to "assess the safety and efficacy of embryo transfer" (p. 106). During the 1980s and early 1990s, there emerged three general positions among such advisory bodies. Several Australian committees rejected the idea of any human embryo research. A few Australian committees and most of the committees based in continental Europe approved embryo research but rejected the deliberate creation of embryos for research purposes. In the Netherlands, the United Kingdom, Canada, and the United States, advisory committees tended to approve both human embryo research and the creation of embryos for research (Walters; National Institutes of Health [NIH]).

In the late 1990s and early 2000s, reports of stem cell derivation from human embryos (Thompson et al.) prompted reexamination of ethics and policy regarding embryo research (Green). International practice and ethical positions remain polarized. In 1999 the NBAC issued a report and recommendations that federal agencies should fund research on embryos left over after IVF for derivation of stem cells but not research involving embryos created solely for research purposes. Despite this recommendation, in 2001, the Bush administration decided to allow federal funding only for research on existing cell lines. In contrast the Human Fertilisation and Embryology Authority (HFEA) in the United Kingdom has continued to permit and license human embryo research and the creation of embryos for research but with enhanced guidelines specific to the derivation and use of stem cells.

Research on Unimplanted Embryos and Fetuses Beyond the Fourteenth Day of Development

The developing human organism is technically called an embryo during the first eight weeks following fertilization. It is called a fetus for the remainder of its development. In this section, prolonged in vitro culture of embryos and fetuses will be evaluated.

Prolonged embryo culture has been undertaken in several species of nonhuman mammals, especially rats and mice. In the early years of research, embryos at various stages of development were removed (or *explanted*) from the uteri of pregnant females and sustained in various kinds of laboratory devices that delivered oxygen and nutrients (New). More recently unimplanted mouse and cattle embryos have been sustained in culture to developmental stages more complex than those attained by preimplantation human embryos (Chen and Hsu; Thomas and Seidel).

As of 2003 no researchers are proposing to perform studies of either of these types with human embryos. The explantation mode of research will probably not be undertaken in humans because of the risks to the pregnant woman and because the need is questionable. However sustained culture of human embryos after IVF would in principle be possible. It is not clear whether the current lack of proposals to culture embryos in vitro beyond fourteen days is based on technical, ethical, or financial (given the bans on funding for embryo research) considerations. The longest well-documented periods for human embryo culture are eight days and thirteen days (Fishel et al.). Possible rationales for extending embryo culture beyond fourteen days could include studying differentiation, the anatomy and physiology of the embryo, the implantation process, or the effect of drugs or radiation on the developing embryo (Karp; Edwards, 1989; Sass).

There has been relatively little ethical discussion of embryo research beyond fourteen days. Most advisory committees have simply accepted the fourteen-day limit without extensive discussion. In the case of the Warnock Committee report from the United Kingdom, this limit was said to be appropriate because it correlates with the appearance of the primitive streak in the embryo (Warnock, 1984). The primitive streak is the first indication of the embryo's body axis, the last opportunity for twinning to occur, and a point before sentience is attained. Several commentators have suggested that the justification for the fourteen-day limit is relatively weak and have proposed extending the limit for in vitro human embryo research to approximately twenty-eight days (Edwards, 1989; Kuhse and Singer).

If embryo culture methods improve sufficiently, it may one day be possible to sustain either a nonhuman or a human embryo and fetus in vitro for an extended period, or even through an entire gestation. The technological support system that sustains such development will probably be called an artificial placenta. If prolonged embryo culture is employed with human embryos and fetuses, decisions will be required about whether to sustain development to the point of viability. At some point a transition will undoubtedly be made from laboratory research designed to test the technical feasibility of long-term culture to an actual attempt to produce a human child by means of ectogenesis (extrauterine development) (Kass; Fletcher; Karp; Walters).

Research on Implanted Embryos and Fetuses

The ethical questions that surround research on implanted embryos and on implanted fetuses are virtually identical, except for the different stages of development involved. This continuity in biological development and similarity in ethical analysis is so striking that both the U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (U.S. Commission for the Protection of Human Subjects) and the British Polkinghorne Committee employed the term *fetus* to refer to the developing entity from the time of implantation through the whole of gestation. In the following discussion the word fetus and its derivatives will be employed to refer to the embryo or fetus from the time of implantation in the uterus of a woman through the point at which physical separation from the woman occurs.

As in the case of preimplantation embryo research, one can distinguish two major contexts for fetal research. The first is one in which further development and delivery of an infant are anticipated. The second context is one in which induced abortion is either planned or in progress.

FETAL RESEARCH IN ANTICIPATION OF BIRTH. Many of the ethical issues involved in fetal research conducted at any stage of gestation in anticipation of birth closely parallel the ethical issues in research on newborns. The main reason for the close parallel is that the further development of the fetus or newborn into an adult person is planned. No research procedure that is likely to threaten the life or damage the health of a future person would be either proposed or carried out by responsible scientists. For this reason research not intended to benefit a particular fetus (in anticipation of birth) or a particular newborn is generally constrained by the no-risk or minimal-risk rule (U. S. Commission for the Protection of Human Subjects, Polkinghorne). That is, the research must be judged to pose either no risk at all (as in certain observational studies) or only minimal risk to the potential subject. For research intended to benefit a particular fetus or newborn, a careful weighing and balancing of likely benefits and harms to the subject is required (Polkinghorne; 45 C.F.R. 46.204).

The major difference between neonatal research and fetal research in anticipation of birth is that the fetus is contained within the pregnant woman's body, and any research intervention will require physical contact with, or at least physical proximity to, the pregnant woman. Thus fetal research inevitably and simultaneously affects a pregnant woman. For this reason it requires a careful weighing and balancing of the risks to her, as well as her informed consent.

Just as fetal research inevitably affects a pregnant woman, research on pregnant women inevitably affects the fetus. In the 1990s some commentators noted that a tendency to focus on fetal well-being resulted in the exclusion of women from clinical trials and in a paucity of information about the impact of medications and interventions on pregnant women or fetuses (Institute of Medicine). Their recommendations included presumed eligibility of pregnant women for participation in clinical studies, whether or not direct fetal benefit is anticipated. In the United States the revised Code of Federal Regulations accounts for the connectedness of the woman and fetus and modifies the minimal risk standard in that it allows for greater than minimal risk research in which the risk to the fetus is caused solely by interventions or procedures that hold out the prospect of direct benefit for the woman *or* the fetus (45 C.F.R. 46.204).

Many clinical procedures that are now routinely employed in obstetrical practice were first tested on pregnant women and fetuses in anticipation of birth. One early therapy was the use of exchange transfusions to overcome Rh incompatibility between a pregnant woman and her fetus. The worldwide epidemic of HIV infection and AIDS provided the context for important research affecting fetuses in the 1990s. In one groundbreaking randomized clinical trial, the antiviral drug azidothymidine (AZT) was administered to HIV-infected pregnant women in an effort prevent the transmission of infection to their fetuses, and was found to reduce the risk of vertical transmission by 66 percent (Sperling et al.).

One of the problems associated with early HIV research was that the impact of interventions to prevent maternal to child transmission was only measured with respect to fetal well-being; outcomes affecting pregnant women were not measured (Faden et al.). In the late 1990s the tendency to focus on fetal outcomes while ignoring those of women gained greater attention as one of several ethical issues surrounding experimental techniques now known as maternal-fetal surgery.

While surgical therapies for prenatally diagnosed lethal conditions have been investigated since the early 1980s, this type of fetal research gained considerable attention in the late 1990s and early 2000s due to several ethical issues associated reports on the use of maternal-fetal surgery to correct fetal myelomeningocele (Lyerly et al.). Myelomeningocele is a condition involving incomplete closure of the spinal cord during fetal development and may be associated with bowel and bladder dysfunction, weakness or paralysis of the lower extremities, and cognitive difficulties. Investigators hypothesized that some of the neurologic damage associated with myelomeningocele occurred in utero due to exposure of the spinal cord to amniotic fluid, and thus that closure of the defect prior to birth would be associated with fewer adverse consequences in the neonate. Therefore, surgical closure of the spinal cord defect before birth, involving an operation on the pregnant woman and fetus, has been attempted and has raised many clinical and ethical issues.

One issue raised was whether it was appropriate to perform interventions associated with greater than minimal maternal and fetal risks in order to correct a non-lethal fetal anomaly. Previously the risks of maternal-fetal surgery had been justified in part because their aim was to correct otherwise lethal fetal anomalies, such as severe urinary tract obstruction, hydrocephalus, and congenital diaphragmatic hernia. Myelomeningocele, on the other hand, is an anomaly that is compatible with a normal life. A related concern was that willingness to perform this procedure reinforced discriminatory attitudes toward individuals with disabilities, like those with spina bifida (Myelomeningocele). Another concern raised was the failure to collect data on outcomes related to women, even though the techniques involved experimental surgery on both women and fetuses. Commentators emphasized that both the woman and fetus needed to be considered research subjects. Other concerns included the tendency to view these procedures as *innovative therapy* rather than *research,* and the adequacy of the informed consent process in pregnant women with a potentially sick fetus. As techniques to diagnose and potentially treat prenatally diagnosed conditions improve, the ethical issues surrounding maternal-fetal surgery for myelomeningocele will continue to be relevant to the conduct of fetal research in anticipation of birth.

FETAL RESEARCH IN ANTICIPATION OF OR DURING INDUCED ABORTION. Fetal research conducted before or during induced abortion could have various aims. One possible goal would be to develop better techniques for prenatal diagnosis, for example, by means of fetoscopy or chorionic villi sampling. Another possible goal would be to study whether drugs, viruses, vaccines, or radioisotopes cross the placental barrier between pregnant woman and fetus. A third aim of such studies could be to develop techniques for induced abortion that are safer for pregnant women or more humane in the termination of fetal life. Fourth, during abortion by hysterotomy (a seldom-used procedure similar to a cesarean section), fetal physiology can be studied after the fetus has been removed from the uterus of the pregnant woman and before the umbilical cord has been severed (Walters, 1975).

Commentators on the ethics of fetal research in anticipation of induced abortion have always been aware that a pregnant woman who intends to terminate her pregnancy can change her decision about abortion even after a research procedure has been performed. In addition in rare cases an attempt at induced abortion results in a live birth. Thus except in the case of research procedures performed during the abortion procedure itself, the distinction between a fetus-to-be-aborted and a fetus-to-be-born is statistical rather than metaphysical. One study performed for the U.S. Commission for the Protection of Human Subjects in the 1970s estimated the change-of-decision rate between a visit to an abortion facility and the scheduled time of termination to be in the range of 1–2 percent (Bracken).

The possibility that a pregnant woman may change her decision to undergo induced abortion after a research intervention sets an outer limit on the types of interventions that prudent researchers would be willing to perform. For example it would be useful to know at what stages of pregnancy alcohol, drugs, or viral infections are most likely to produce malformations in human fetuses; however, in the view of most commentators on the ethics of fetal research, such studies ought not to be performed in humans. In the words of the Peel Committee report, “In our view it is unethical for a medical practitioner to administer drugs or carry out any procedures on the mother with the deliberate intent of ascertaining the harm that these might do to the fetus, notwithstanding that arrangements may have been made to terminate the pregnancy and even if the mother is willing to give her consent to such an experiment” (United Kingdom, 1972, p. 6).

Even if research likely to cause serious damage to the fetus is ethically proscribed, there are at least two different ethical standards that can be adopted with respect to fetal research in anticipation of or during induced abortion. The first standard asks for equal treatment of the fetus-to-be-born and the fetus-to-be aborted. In brief this standard requires either that one should perform research procedures on fetuses-to-be-born concurrently with performing the same procedures on fetuses-to-be-aborted, or at least that one should be *willing* to perform the same procedure on both groups of fetuses. In practice this standard would be virtually equivalent to the no-risk or minimal-risk rule discussed in connection with fetal research in anticipation of birth (McCormick; Walters, 1975; Ramsey, 1975; Polkinghorne).

An alternative standard would reject the equal-treatment requirement. What is proposed instead is a kind of case-by-case approach to fetal research (U.S. Commission for the Protection of Human Subjects; Fletcher and Ryan). For example if the primary risk of a research procedure like chorionic villi sampling is that it will cause abortion in a small percentage of pregnant women, then it can be argued that research on this diagnostic procedure should be performed on women who plan to undergo induced abortion. If the research procedure itself is unlikely to injure the fetus, then the major remaining risk is that the abortion that the pregnant woman planned to have induced in the future would instead occur spontaneously. The major ethical questions remaining in a case of this kind have to do with the timing of abortion: Is a later rather than an earlier induced abortion less respectful of the developing fetus? Does a later abortion entail greater risks to the physical and mental health of the pregnant woman?

An important dimension of the fetal research discussion is the possibility that research procedures will cause pain to the fetus (Steinbock). One of the difficulties in coming to terms with this issue is that the word *pain* probably has different meanings at different developmental stages. The anatomical basis for simple spinal reflexes seems to be present in human embryos at about 7.5 weeks post fertilization. Between the ninth and twelfth weeks of development, the fetal brain stem begins to function as a rudimentary information processor. However only at twenty-two to twenty-three weeks of gestation is the cerebral neocortex connected to the other parts of the brain (Flower). Presumably the fetal capacity to perceive pain would differ at each of these three steps, but it is difficult to know precisely to what extent painful stimuli would be felt or remembered.

Research on Aborted, Live Embryos and Fetuses

There are major conceptual difficulties involved in describing a previously implanted entity that is expelled or removed alive from a pregnant woman's body (or removed alive from attachment to an artificial placenta). One candidate term is *abortus;* another is *fetus ex utero* or *embryo or fetus outside the uterus.* Adjectives applied to such entities include *previable* or *nonviable* and *viable.* A *viable fetus outside the uterus* is in fact a newborn infant, albeit one that may be seriously premature. In addition the notion of viability is elastic, sometimes seeming to mean the gestational age, weight, or length at which the smallest known infant has survived, at other times seeming to mean the stage at which a stipulated percentage of infants survive, given the assistance of technological means of life support.

Three circumstances can be envisioned in which the question of research on formerly implanted, living embryos or fetuses could arise. First, the surgical removal of an ectopic pregnancy could provide a still-living embryo or fetus. Second, a spontaneous miscarriage could result in the delivery of a live embryo or fetus. Third, an already implanted embryo or fetus could be aborted by means that make it either possible or likely that an intact, living embryo or fetus will result from the abortion procedure.

There is no clear consensus on the ethical justifiability of research on living human embryos or fetuses outside the uterus. In the United Kingdom, two official reports reflect a clear trend in a more conservative direction. In 1972 the Peel Committee affirmed the scientific value of research on clearly previable fetuses outside the uterus and permitted many kinds of research on such fetuses (United Kingdom, 1972). However the Polkinghorne Committee report of 1989 expressly rejected the position of the Peel Committee, arguing that the only morally relevant distinction was between living and dead fetuses, not the distinction between previable and viable fetuses (Polkinghorne). In the United States the U.S. Commission for the Protection of Human Subjects allowed no significant procedural changes in the abortion procedure solely for research purposes and restricted what could be done with the live, delivered embryo or fetus to intrusions that would not alter the duration of its life. Recommendation 1100 by the Parliamentary Assembly of the Council of Europe (1989) also discussed "the use of human embryos and fetuses in scientific research." Its recommendation clearly reflected the ambivalence of ethical opinion on research involving live embryos or fetuses outside the uterus. After stating that "Experiments on living embryos or foetuses, whether viable or not, shall be prohibited," the recommendation continued as follows: "None the less, where a state authorises certain experiments on nonviable foetuses or embryos only, these experiments may be undertaken in accordance with the terms of this recommendation and subject to prior authorisation from the health or scientific authorities or, where applicable, the national multidisciplinary body" (Council of Europe, p. 6).

Conclusion

Since 1978 the ethical discussion of research involving implanted fetuses and live, aborted fetuses has matured, but it has proceeded largely along the lines established in the 1970s. In contrast the success of clinical IVF has given new impetus to the ethical debate about research on preimplantation embryos. In the future it is at least possible that new methods for sustained embryo and fetal culture in vitro will give rise to additional ethical challenges.

LEROY WALTERS (1995)
REVISED BY ANNE DRAPKIN LYERLY

SEE ALSO: *Cloning: Reproductive; Embryo and Fetus: Embryo Research; Embryo and Fetus: Embryonic Stem Cell Research; Maternal-Fetal Relationship; Research Policy; Research, Unethical*

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FETUS

SEE *Embryo and Fetus*

FREEDOM AND FREE WILL

• • •

Freedom is widely regarded as a highly desirable component of human personalities, interpersonal relations, and social and governmental arrangements. Despite multiple meanings, the main types of freedom can be defined and distinguished.

Types of Freedom

Diverse freedoms contrast with different types of restrictions, limitations, or restraints that negate them. Some freedom-inhibiting conditions are internal to persons, some external, some negative, some positive. Joel Feinberg (1980) developed a useful four-way typology of constraints: external positive, external negative, internal positive, and internal negative. Examples of these, respectively, are lack of money, being handcuffed, fear, and weakness. In the free will controversy, freedom of action equates with external freedom, both positive and negative, while freedom of will is a variety of internal freedom.

POSITIVE EXTERNAL FREEDOM. Positive external freedom is having the external means to achieve our ends and fulfill our desires or interests. These means are positive conditions in our environment such as money to pay our way, schools open to all, or accessible medical resources and personnel. A pregnant woman who desires an abortion but lacks the money to pay for it has insufficient positive external freedom. Whether society should pay for contraception services and abortions for the poor, thereby enhancing their positive freedom, is highly controversial (Edwards, 1997). Patients in great pain who desire analgesic medication may or may not have compassionate doctors who will prescribe adequate means to pain relief; if denied such means by uncaring, inattentive, or intimidated doctors, these patients lack external freedom.

NEGATIVE EXTERNAL FREEDOM. Negative external freedom is the absence of external pressures, constraints, or restraints that inhibit or prevent us from doing what we want or choose to do. Many negative conditions interfere significantly with freedom of action. We are negatively free externally when unencumbered by such restraints as chains, shackles, walls, and jails, and/or by such constraints as laws, institutional prohibitions, threats, intimidations, and coercive or covert pressures from others. Absence of external encumbrances usually correlates very directly with increased options for choice and action.

Many types of positive external freedom are widely recognized and cherished. Some of the most important are political freedoms or rights guaranteed by government. The Bill of Rights to the U.S. Constitution identifies and affirms such varieties of external freedom of action as freedom of religion, freedom of speech, freedom of the press, freedom to assemble peaceably, and freedom to petition government for redress of grievances. Other amendments guarantee the freedom to participate in political processes on an equal basis. These constitutionally guaranteed forms of freedom of action declare that government, other institutions, and specific individuals may not interfere with a person's choice of religion, with people expressing their thoughts, or with people communicating their beliefs, knowledge, and ideas through the press and other media. All of these kinds of freedom of action are both permitted and limited by our laws; none is absolute without qualification. All are highly desirable whether or not humans have free will and would be so even in a totally deterministic universe.

Historically, many classes of individuals were externally unfree in a great variety of undesirable ways. The fullest enjoyment of external freedom in the United States was once limited to competent, landowning, white males, whereas severe restrictions were imposed on the freedom of action of females, slaves, nonwhites, minors, mentally disturbed persons, the landless, homosexuals, and other disfavored groups such as animals. Gradually, as prejudices waned, usually after prolonged and bitter struggles, both the scope and types of freedom were extended to victims of unjust discrimination; but the process has not yet come to an end.

External social and governmental restrictions on freedom of action are not always undesirable. We are not and should not be free to do many things that would be harmful to the person and/or property of others or, more controversially, even to ourselves. Some external legal, moral, and social restraints on freedom of action are perfectly legitimate. When freedom of action conflicts with more legitimate goals and values, it must yield to their superiority.

External freedom of action is extremely valuable, but it is not sufficient for freedom in its fullest sense. Other kinds of freedom internal to persons are also highly desirable.

POSITIVE INTERNAL FREEDOM. Positive internal freedom consists of the effective presence of internal factors that contribute to people fulfilling their goals, desires, and interests; being self-reliant and self-directed—their own masters; and being in control of their own lives and destinies. These are elements of personality such as knowing who we are, our circumstances, the alternatives among which we must select, and the norms and facts relevant for making informed decisions; the ability to think, deliberate, and reason about our ends or goals, to prioritize and harmonize them, and to recognize effective means to achieve them; conscience, a moral sense of right and wrong; feelings, emotions, motives, desires, purposes, interests, and affections; and the ability to make our own choices for ourselves and to identify with our own purposes and projects, and the inner resources for acting as we will to act.

Occasionally freedom is said to consist of valuing and actualizing certain inner processes and states above all others. Saint Augustine (354–430), the early Christian church father, identified true freedom with complete conformity to the will of God; and the Stoics and the seventeenth-century Dutch philosopher Benedict Spinoza identified it with being rational and controlling or suppressing one's emotions.

Positive internal freedom may include free will, but most of its components would be highly desirable even in the absence of free will. Being positively free is what most bioethicists mean by being autonomous, or rationally autonomous, though whether this includes free will is not always clear. Respecting the rational autonomy of patients is a matter of valuing their positive internal freedom and acting accordingly.

NEGATIVE INTERNAL FREEDOM. Negative internal freedom is the absence of internal psychological or physiological obstructions that inhibit the proper functioning of the constituents of positive internal freedom—the absence of factors that inhibit knowing, deliberating, feeling, preferring, valuing, discerning right from wrong, self-control, making our own choices for ourselves, and acting effectively. Exercise of positive freedom is inhibited by such internal conditions as being overwhelmed by unconscious processes or motives, or by psychoses, neuroses, compulsions, addictions, or other nonvoluntary character defects and disorders. Genetic and neuromuscular conditions involving pain, weakness, disability, or hyperactivity may also undermine negative internal freedom.

Many conditions that undermine negative internal freedom have external causes, some medical in nature, some not. Negative internal freedom is absent in individuals who are temporarily stupefied by alcohol or by recreational or poorly administered psychotropic drugs, and in those who are more permanently impaired by brain damage, retardation, or a degenerative disease. People may also lose or lack independence if their capacities and options are reduced by lobotomies, psychosurgery, hypnosis, behavior modification, brainwashing, indoctrination, or massive ignorance. When used skillfully with the informed voluntary consent of patients, psychotherapy can increase human freedom, not decrease it. The Austrian neurologist Sigmund Freud (1856–1939) thought that the major purpose of psychoanalysis is to increase the freedom of otherwise freedom-impaired patients.

All four types of freedom have significant worth for human beings with or without free will and may be classified as intrinsic goods, valuable for their own sakes; as indispensable extrinsic goods, valuable as essential means to other human ends; or as both at once; but we can make such judgments justifiably only if we are sufficiently enlightened, fair-minded, and free!

Because healthy bodies and selves are our most directly efficient instruments, and because so many conditions that interfere with freedom are medical in nature, physicians and other healthcare professionals are uniquely positioned by their knowledge and power to enhance human freedom.

Free Will, Obligation, Responsibility, and Related Concepts

The concept of free will is inextricably bound up with many related but elusive concepts such as duty or obligation, responsibility, blameworthiness, and praiseworthiness.

THE FREE WILL POSITION. Defenders of free will insist that freedom in the most inclusive and desirable sense is something more than mere external freedom of action; it is a fundamental type of positive internal freedom. Free will involves more than a mere internal capacity for making choices, for choices may be either free or unfree. Free choices are informed and intentional as well as creative, originative, or "contracausal." Choices are not free if they are completely determined by ignorance or by preexisting desires, habits, beliefs, or by other psychological, physiological, genetic, social, or environmental conditions. When choices are so determined, we lack the power to choose otherwise and are inevitably destined to make exactly the choices we make and do exactly the things that we do. Representative defenders of free will include the fourteenth-century English philosopher William of Ockham, the eighteenth-century Scottish philosopher Thomas Reid, and such contemporary figures as C. A. Campbell, Roderick Chisholm, Rem B. Edwards, and Robert Kane.

Defenders regard free will as essential to human worth and dignity, partly because of its inherent value and partly because it is interwoven inextricably with other indispensable moral and legal concepts and practices such as obligation, responsibility, blameworthiness, and praiseworthiness.

Being *obligated*—having duties, whether moral, prudential, or whatever—is possible only if we have free will, genuinely open alternatives, and the ability to choose and act otherwise, defenders claim. Obligation presupposes being able to choose freely and act dutifully. Ought implies can, and cannot implies not obligated. In a deterministic universe devoid of free will, those who choose to do their duty can and must do so; oddly, those who do not cannot, and thus never have or had any duties at all. Actually, because neither ever encounters open alternatives or could ever choose or act otherwise, no one ever has any duties of any kind, for all persons are rigidly determined to choose and act exactly as they do.

Similarly, being *responsible* for our choices and the actions that issue from them just means that we understand the genuinely open alternatives before us, that we desire or intend some of them, and that our final decisions originate with us, rather than being programmed into us by heredity, our physical or social environment, fate, God, or any kind of external causes, however near or remote. These things may influence us, but they cannot completely determine us if we are to be responsible for what we decide and do.

The free will position also insists that blame and punishment as well as praise and reward are inextricably linked to being responsible. When we do wrong and are *blameworthy,* we may be justly blamed or punished only if we are responsible for our decision to do wrong, and only if we do it knowingly and intentionally, it originates with us, and it could have been otherwise—that is, only if it is informed, intentional, and free. And when we do what is right and are *praiseworthy,* we may be justly praised and rewarded only if we responsibly, knowingly, intentionally, creatively, and freely decide to do so. Blameworthiness cannot be defined simply as susceptibility to blame or punishment; nor can praiseworthiness be defined simply as susceptibility to praise or reward. The susceptibility must be just or appropriate, free will advocates insist; and this condition is satisfied only when we choose responsibly, that is, originatively or freely, knowingly, and intentionally and have the power to choose otherwise from genuinely open alternatives. If our choices do not originate with us, if they are programmed into us and we are predetermined to make only and exactly the choices that we make, then our programmers, but not we ourselves, are responsible for our decisions, and we cannot justly be held responsible or subjected to blame, punishment, praise, or reward.

Free will champions usually affirm *indirect* as well as the *direct* responsibility. We are indirectly responsible for our choices and actions, even when they are completely determined by our present character and strongest inclinations, as long as that character and those inclinations were significantly shaped by choices and efforts that we made earlier in life. Advocates of free will and self-creative responsibility typically do not hold that all our responsible choices are directly free or originative. Determinists are right that most of our present choices are completely determined by our existing dispositions and interests; but if we actively participated in forming them by earlier self-creative choices and efforts of will, then we are indirectly responsible for the choices and actions that issue from our self-established character.

HARD AND SOFT DETERMINISM. In his influential 1884 article, "The Dilemma of Determinism," the American psychologist and philosopher William James (1842–1910) distinguished between hard and soft determinism. *Hard determinists* usually accept every feature of the free will position except causal indefiniteness. They agree that a free will would be an originative or self-creative will, and that being obligated and responsible just means knowingly, intentionally, and originatively making right or wrong choices that could have been otherwise. Social practices involving obligation, blame/punishment, and praise/reward are just and justified only if we are free and responsible. Nevertheless, determinism is true and all our choices are caused or determined by antecedent conditions; none could be otherwise. Because we are not free and responsible, we are never justified in holding anyone obligated or responsible for anything. We can never justly blame or punish wrongdoers or praise and reward those who do right. Representative hard determinists include Spinoza; the English clergyman and chemist Joseph Priestley; the young Benjamin Franklin; the eighteenth-century American statesman and philosopher, who later recanted this position; and Paul Edwards.

Some hard determinists acknowledge that our established practices of being morally obligated as well as blaming, punishing, praising, and rewarding are so valuable morally and socially, so indispensable for the very existence of a livable community, that the illusion of free will should be sustained in order to perpetuate them (Smilansky, 2000). Others insist that hard determinists may legitimately abandon blame and punishment but retain obligation, praise, and reward. Without deluding anyone, hard determinists can approve, commend, encourage, praise, and reward right actions, even if they are not strictly obligatory. Such activities become integral parts of causal processes calculated to bring about decent social orders (Wolf, 1980, 1990; Pereboom, 1995, 2001).

Soft determinists do not embrace these drastic conclusions. They hold that causal determinism is perfectly compatible with human obligation and responsibility and the moral and social practices normally associated with them. Representative soft determinists include the seventeenth-century English philosopher Thomas Hobbes, the eighteenth-century American clergyman and theologian Jonathan Edwards, the eighteenth-century Scottish philosopher and historian David Hume, the nineteenth-century English philosopher and economist John Stuart Mill, and more recent figures such as Harry G. Frankfurt, Daniel Dennett, and Kai Nielsen.

COMPATIBILISM. Soft determinists are compatibilists who attack almost every element of the free will position and reject the free will view that causal determinism is incompatible with human freedom, obligation, responsibility, and just susceptibility to blame/punishment or praise/reward.

Compatibilists hold that freedom of action combined with inner conditions that do not presuppose causal indeterminism are quite sufficient for human obligation and responsibility—that free will is not needed in the first place. If we are free to do what we knowingly and intentionally most want to do, then we are responsible for doing it, and we can have moral and other kinds of obligation. Compatibilists attack the free will meaning of the term *responsible* and redefine the concept.

For the free will position, being responsible for making choices and the actions that flow from them means:

(1) Recognizing and understanding the alternatives, which are genuinely open metaphysically.
(2) Intending to or being motivated or predisposed to choose one or more of these alternatives without their being completely predetermined by our desire(s), dispositions, or anything else.
(3) Deliberating about the alternatives.
(4) Knowing that some alternatives are good or right, some bad or wrong, and perhaps some indifferent.
(5) Originating the choices and efforts that we make.
(6) Having the power to choose otherwise.

Compatibilistic soft determinists omit the self-originative features of this definition. For them, being responsible just means:

(1) Recognizing and understanding the alternatives, which need not be metaphysically open.
(2) Intending or being more strongly motivated or predisposed to choose one alternative over the

others, especially when these belong to our deep rational selves.

(3) Deliberating about the alternatives.

(4) Knowing that some alternatives are good or right, some bad or wrong, and perhaps some indifferent.

Origination, open alternatives, and the ability to choose otherwise are irrelevant; so, free will is irrelevant. Determinism is compatible with holding people under obligation and regarding them as responsible for what they choose and do. But is this compatibilistic redefinition of the term responsible acceptable? Can we really escape the deep-rooted intuition that we are not responsible for any choices and efforts that are programmed into us from beyond?

Objections and Responses

Past and present debates incorporate many objections to free will with corresponding replies.

CHOICE AND CHANCE. Free will itself is not compatible with having duties and being responsible because free choices are by definition uncaused and indeterministic, which means that they are mere uncontrolled chance events or accidents.

But, say free willists, chance events do not satisfy many conditions that define responsible free choices. They do not involve deliberation, knowledge of alternatives or of right and wrong, desires, dispositions and intentions, or the subjective experience of selecting or trying. When free choices are made, these conditions bring about inclinations without necessitating a particular choice. These conditions are the very essence of self-control and self-causation, not of chance.

UBIQUITOUS CAUSATION. Because all events have causes, free choices and all effort-makings have causes. There are no exceptions to deterministic causation.

Free will defenders respond that the very concept of causation is ambiguous, not clear and distinct. Free originative choices can be uncaused or "contracausal" in one sense, yet caused in another. Free choices have *necessary causal conditions* such as knowledge, desires, and (if moral) a sense of right and wrong; in their absence, free choices cannot occur. But these are not *sufficient causal conditions* in whose presence only one outcome must occur. Only with respect to sufficient causal conditions are free choices uncaused. With respect to necessary conditions, they are caused. The philosophical options are more complex than simple *indeterminism,* which denies the relevance of all causal considerations to free choice, versus *determinism,* which affirms the rigid causal determination of all choices. Partisans of free will may adopt *libertarianism,* which affirms that existing causal conditions limit but do not necessitate choices that cannot occur in their absence.

Some proponents of free will claim that self-creative choices are made by an enduring substantive self that is exempt from normal event-causation (Chisholm; O'Connor). Others hold that choices are made by events within that stream of consciousness that constitutes personal selfhood (Edwards, 1969; Kane, 1985, 1996, 2002). Still others claim that agency causation is not so radically different from event causation (Clarke).

CAUSATION BY STRONGEST MOTIVES. Experience shows that all our choices are determined by the strongest desires or sets of cooperating desires belonging to our settled character.

In response, free willists argue that experience actually shows that effort-making and self-creative choosing occur only when character, dispositions, and desires are in conflict and prevailing inclinations are not settled in advance—only when given motives are not sufficiently powerful to resolve motivational conflict. Free choices function to resolve conflicting motives when none are sufficiently powerful themselves to overcome their competitors. Sometimes choice boosts an inclination that is in conflict with others and makes it the strongest. Usually our choices are completely determined by our strongest inclinations, but even then we are indirectly responsible for them if our earlier choices and efforts helped to create them.

THE ABILITY TO CHOOSE OTHERWISE. Being able to choose otherwise is merely hypothetical, not categorical or absolute. Even on deterministic grounds, we can choose or could have chosen otherwise *if* our desires, dispositions, character, or other conditions are or were otherwise. This is quite sufficient for responsible choice.

On the contrary, free willists respond, hypothetical conditions are still incompatible with the deep and ineradicable intuition that we are responsible only if our choices and efforts originate with us; if they originate in heredity and/or environment, these, not we, are responsible for them and the actions that issue from them. Complete determination is incompatible with individual responsibility, blameworthiness, and praiseworthiness.

THE SCIENTIFIC WORLDVIEW. Free will is incompatible with what natural science tells us about the universe and about ourselves.

Free willists reply that Newtonian science had no place for free will because it regarded everything, including human choices, as completely determined and absolutely predictable, given existing facts and natural laws; but this worldview is now obsolete. Quantum physics recognizes indeterminateness and unpredictability within the depths of nature, including human brains. Random quantum events are themselves not within our control, admittedly, but they make room for creative self-control, just as Newtonian physics excluded it. On a more macroscopic level, modern brain scans reveal indeterminate, unresolved conflicts within and between different regions of the brain that are resolved when "executive control" is exercised (Posner and DiGirolamo).

Objections and replies to problems of free will are almost inexhaustible, and every response seems to generate another round of objections and responses. Free will and philosophical issues relating to it have been debated for over 2,000 years and will be, perhaps, for thousands more.

REM B. EDWARDS

SEE ALSO: *Autonomy; Authority in Religious Traditions; Behavior Control; Behaviorism; Behavior Modification Therapies; Coercion; Conscience; Conscience, Rights of; Human Dignity; Insanity and the Insanity Defense; Institutionalization and Deinstitutionalization; Mentally Disabled and Mentally Ill Persons; Neuroethics; Patients' Rights; Psychiatry, Abuses of*

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FUTURE GENERATIONS, REPRODUCTIVE TECHNOLOGIES AND OBLIGATIONS TO

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Since the early 1960s, scholars have struggled to define the nature and content of our obligations, if any, to future persons. These discussions began in the fields of environmental ethics and population policy and have had their most robust recent expression in the debate over risky reproductive technologies. This entry reviews the issues as they arise in decisions about reproduction, especially decisions involving reproductive technology.

The threshold issue is whether living persons have any duty to consider the welfare of future people. If that question is answered in the affirmative, then the content of the duty needs to be defined. The fact that reproductive conduct is existence inducing, however, greatly complicates the effort to determine exactly when a risky reproductive decision threatens the welfare of future persons.

Duties to Future Persons

Duties not to harm persons seem to presuppose their existence (Narveson). Yet, the future children whose interests are threatened by today’s decisions do not exist and may never exist. Because their existence is entirely contingent, skeptics question whether it is coherent to talk of a duty to these “potential” people.

Until the middle of the twentieth century, courts in the United States agreed. Since then, however, nearly all courts have abandoned that view, concluding as most bioethicists do, that duties can run to future people who are foreseeably endangered by our actions (Buchanan et al.).

Moral philosopher David Heyd, in his 1992 book, *Genethics,* argued that an exception must be made for people who control whether or not a future person exists. He contended that creators, such as parents making reproductive decisions or scientists deciding whether to clone a human, cannot have obligations to future persons whose very existence they control. Although he conceded that we ordinarily do owe duties to future persons, he contended that this duty does not extend to persons whose existence we determine. Thus, a baby food manufacturer has an obligation not to harm babies who are born after its pureed peas are canned, but parents or scientists cloning humans have no obligation to future persons whose very existence they control. “There are no moral constraints,” he argued, “in genesis decisions” (Heyd, p. 16).

Heyd’s argument has central implications for the law and ethics of reproductive behavior. Heyd seems to assume that the right to deny existence includes the freedom to create people without accountability. This would excuse parents and fertility clinics from any obligation to consider the welfare of the children whom they are trying to create.

Heyd’s view, however, does not appear to be widely shared. For example, in her 1998 book, *Child versus Childmaker,* Melinda A. Roberts noted that Heyd’s view “implies that my neighbor’s future child, but not my own, has a claim to my good behavior” (p. 20). Using his analysis, a homeowner who breaks a glass bottle in the backyard may have a duty to the neighbor’s future children to pick up the glass, but not to the homeowner’s own future children. That conclusion is difficult to defend persuasively. Heyd’s theory assumes that the power to create a person implies the absence of any obligation to use that power responsibly. In his view, childbearing is inherently a selfish choice. Yet, this assumption is certainly not self-evident and it conflicts with commonplace expectations of responsible parenting.

Perhaps the key issue in the debate over the duty to future persons is whether a duty can be owed to a “person” who does not yet exist and may never exist. So characterized, the duty appears to be owed to preconception phantoms. Advocates of the duty contend, however, that the obligation being asserted is better understood as a conditional obligation that ripens only if and when an actual person is harmed (Peters, 1999). Whereas it may not be sensible to talk of duties to people who may never exist (“potential people”), it is sensible to talk of a duty to the people who do come to exist in the future (“future people”). Thus, the baby food manufacturer’s duty runs only to actual, living people who consume its baby food. At that moment, the potential harmfulness of the earlier negligence crystallizes.

Harm to Future Persons

Many different theories have been offered to identify the circumstances in which reproductive behavior can cause harm to future persons. Each theory identifies a different vantage point from which to understand the interests of future persons. Collectively, they provide a useful set of tools for evaluating the impact of a novel reproductive technology.

At the outset, the inquiry into harmfulness requires a definition of what it means to harm someone. Under conventional analysis, harmful conduct is conduct that makes a person worse off than he otherwise would have been (Fishkin). Lawyers call this a "but for" test because it asks whether the victim would have avoided injury but for the conduct in dispute. Although this test can sometimes be applied to reproductive behavior without any novel difficulties, its application is often complicated by the fact that the injuries believed to be harmful could not have been avoided except by preventing the child from being born at all. A child conceived by cloning, for example, owes his life to this technology. When a disputed act is existence inducing, the only alternative to life with the disability caused by the existence-inducing technology is no life at all. If the conventional test for harmfulness is used, then the disability-causing technology is not harmful unless life with the disability is worse than the alternative—never existing at all. This comparison does pose special problems.

The remainder of this entry begins by exploring the simplest cases—those in which the traditional test of harmfulness seems most apt. The entry then examines the application of this test to injuries that are inextricably associated with life itself and reviews some alternatives that have been suggested to the comparison between life and nonexistence. Finally, it examines the dilemma posed when parents or clinics have a choice between two alternative paths to reproduction, one of which is safer than another.

Ordinary Harm

The easiest cases to analyze do not require a comparison between life and nonexistence. This is true whenever the behavior that caused the injury was not essential to the birth of the child. Consider, for example, the negligent repair of a fertile woman's uterus. A child who is subsequently born prematurely because of this carelessness has suffered injuries that could have been prevented if more care had been taken. Measuring the extent of her harm, therefore, does not require a comparison between life with her injuries and never existing at all. Instead, it requires only a comparison between life with her injuries and life without them.

In the context of reproductive technology, this kind of harm can occur both in routine settings and in exotic ones. Injuries caused by a fertility clinic's failure to properly store its frozen embryos are a straightforward example of this kind of ordinary, avoidable harm. Ordinary harm, however, can also occur in settings typically assumed to trigger the nonexistence comparison, such as multiple cloning or multiple embryo transfer. In a 1996 article, Roberts pointed out that any emotional injuries associated with being one of many identical clones can be avoided by cloning only one person from each source. That single child will consequently be better off than he would have been if additional identical siblings had been cloned.

Injuries caused by germ-line genetic engineering can also be understood in this way. A child who suffers injuries from the genetic engineering of her embryo need not have suffered these injuries if the embryo had been implanted without first manipulating its genes. Of course, she also would not enjoy the benefits, if any, conferred by the manipulation. Thus, she has been harmed by the manipulation if, but only if, it did more harm than good. Answering this question does not require a comparison between life and nonexistence.

The most interesting interpretive debate regarding the applicability of ordinary harm analysis to reproductive behavior involves parents who say that they will not conceive at all if they are not able to use a risky reproductive technique. Consider the case of a fertile couple who could conceive naturally but choose instead to employ a surrogate because the genetic mother fears the risks of childbirth, as occurred in the notorious case of "Baby M" (*In the Matter of Baby M,* 1988). If the parents would not have conceived at all had they been prevented from employing a surrogate, then their child's only alternative to surrogacy was nonexistence. For this reason, scholars such as John A. Robertson believe that no harm is done to this child by use of a surrogate unless the child suffers harms so serious that its life is worse than not existing at all.

The same surprising conclusion arises in other reproductive settings. Assume, for example, that parents can honestly contend that they will not have any children at all if they are not permitted to use a risky reproductive technique such as germ-line genetic engineering. If their claim is correct, then their future child's only alternative to the risks associated with germ-line genetic manipulation is not existing at all.

Roberts rejects the conclusion that no harm has been done in these cases. She has persuasively argued that children such as these are harmed whenever people could have prevented their injuries and chose not to do so (Roberts, 1996, 1998). From her perspective, the fertile couple's choice is a harmful one if it exposes the child to extra unnecessary risks. That the parents preferred not to avoid those risks does not make the choice any less harmful to the child. That child could have been born without his injuries.

Roberts's analysis squares with our intuitions. Surprisingly, however, it is less consistent than Robertson's is with the but-for test of causation. What matters under this test is what *would* have happened had the technology been banned, not what *could* have happened. If surrogacy had been prohibited, for example, the child would not have been born. The test does not take into account the fact that the same embryo could have been implanted in the genetic mother.

Nevertheless, the but-for test is only a starting point for the analysis of causation. Both philosophers and courts have recognized its occasional deficiencies and have fashioned a number of exceptions to ensure that the attribution of causation comports with common sense. Roberts's case for yet another exception is quite credible. Taken to its logical conclusion, conventional harm analysis would excuse even the intentional infliction of harm on future children, as long as being able to inflict it was essential to the procreative intent of the would-be parents. Thus, deaf parents who genetically engineer their children to be deaf cause no harm if this is the only way in which they are willing to have children. This makes no sense. The very intention that makes their conduct culpable also insulates it from moral responsibility.

In ordinary settings, the plaintiff's inability to satisfy the but-for test implies that the plaintiff would have been no better off if the defendant had behaved more responsibly. In the special context of existence-inducing conduct, however, the failure to satisfy the traditional but-for test of causation does not have this meaning. Nonexistence was not the child's only alternative to life with her injuries. Instead, the defendant could have prevented the child's injuries. The mere fact that the parents preferred not to do so seems an insufficient basis for concluding that no harm has been done by their choice.

To recap, reproduction decision making sometimes threatens future children with ordinary harm. Analyzing the harmfulness of these decisions is straightforward except when parents claim that they would not have conceived at all if not permitted to reproduce in a dangerous manner. In such cases, one can either treat the choice as harmless unless the injuries are so serious that life itself is harmful (a threshold that is the subject of the next section) or else replace the inquiry into what would have happened with an inquiry into what could have happened.

Life as a Harm

Sometimes, the underlying objection to a risky form of reproductive conduct is not that safer alternatives were foregone, but that the conduct in question is simply too dangerous to use, even as a last resort. Imagine, for example, an infertile couple who have been unable to conceive despite undergoing several cycles of in vitro fertilization (IVF) in which three embryos were implanted each cycle. For this couple, implanting a higher number of embryos may be the only feasible way to conceive. Yet, doing so greatly increases the risk of a dangerous multiple pregnancy and, with it, the risk of serious injury. Not using the higher number of embryos would reduce this risk—not by allowing the children to be born without injury but by preventing their birth. If the only alternative to the use of a risky reproductive technology is not having children at all, then no harm is done to the children under the but-for test unless life with the anticipated disabilities is worse than never existing at all. Thus, no harm is done unless life is worse than nonexistence.

The idea that life itself can be harmful has been very controversial, even though the nonexistence comparison is actually just a special application of the but-for test. Indeed, most American courts have concluded that the notion of a harmful life offends public policy because it suggests that life with a disability is less valuable than life without it and because it is logically incoherent. For these reasons and others, most courts in the United States have refused to allow lawsuits claiming that a child was harmed by birth with a serious disability. Most scholars and a few courts, however, disagree. Although evaluating the harmfulness of life itself does involve some conceptual puzzles, these puzzles seem soluble.

Because "it is necessary to be in order to be better off," critics believe that it is logically incoherent to say that someone could "be" better off if they had never been born (Feinberg). A related objection is that humans know nothing about nonexistence and, thus, cannot compare it to life. One judge put his concerns this way: "Ultimately, the infant's complaint is that he would be better off not to have been born. Man, who knows nothing of death or nothingness, cannot possibly know whether that is so.… To recognize a right not to be born is to enter an area in which no one can find his way" (*Gleitman v. Cosgrove*). Many scholars, however, argue that reference to nonexistence is not necessary to determine whether life with a catastrophic disability is harmful. Instead, the benefits of life can be balanced against the burdens. A life in which the burdens exceed the benefits can reasonably be characterized as harmful. Fortunately, injuries this serious are rare. The birth defects most commonly offered as examples are Lesch-Nyhan syndrome and Tay-Sachs disease.

Critics also contend that treating life itself as harmful is a repudiation of the value of human life and a threat to the welfare of living people with disabilities (*Blake v. Cruz*). Others believe, however, that respect for future persons dictates that they be spared these terrible injuries (*Turpin v. Sortini*). They also note that preventing the birth of a person with a disability is not inconsistent with vigorously protecting the welfare of people who are born with disabilities. Finally, they note that our comfort with decisions to refuse death-prolonging care reflects our recognition that life is not always a blessing (Peters, 1989).

Courts commonly offer one additional reason for rejecting wrongful life cases. They doubt that any harm ascertained using the nonexistence comparison can be rationally translated into money damages. Whether or not this is correct, it is not a reason for refusing to apply the nonexistence comparison in settings where money damages are not an issue. The difficulty of calculating damages for the injuries suffered by a cloned child, for example, may be a plausible argument for denying the child a civil action for compensatory damages, but it is not an argument against prohibiting cloning until it is more safe to perform.

In fact, outside of the courts, the most common objection to the nonexistence comparison is not that it is unmanageable or too readily assumes that life is not worth living, but that it is underprotective, that is, it dictates restraint only when the risks are truly catastrophic. The critics can be loosely sorted into two groups. The first group contends that the nonexistence comparison sets the threshold too high. They prefer a more demanding threshold such as a minimally decent quality of life or a probability of harm no greater than the risks associated with natural conception. Critics in the second group believe that reproductive conduct is harmful to future children, regardless of the absolute severity of the injuries, whenever parents or providers choose a risky route when a safer one is available.

The debate over a more demanding threshold was led at one time by scholars who felt that it was unethical to expose future children to the unknown risks associated with a new reproductive technology (Ramsey). They contended that it was unethical to impose this risk without the child's consent. The consent objection has lost emphasis in recent years, perhaps because parents have the same moral authority to consent to these risks on behalf of their future children as they have to consent to risky new treatments for their living children.

Although the consent objection has largely disappeared, it is still common to see discussions of reproductive conduct that measure the safety of a new technology against the risks of natural conception (Green). Despite the intuitive appeal of the comparison to natural conception, however, this benchmark is vulnerable to several objections when it is applied to treatments of last resort. First, the current level of risk for natural conception is not *natural* at all, but the product of modern medical technology. Thus, the current level of risk is merely a historical coincidence. Second, though matching this level of risk may be desirable, it is not obvious why parents who face greater risks, but who have no safer alternatives, are acting unethically. The only alternative for their children is not existing at all. Finally, using the average risks of natural conception as a baseline, which means treating a riskier than average procedure as immoral, even if the injuries associated with the procedure do not prevent the affected children from having fulfilling lives. This is counterintuitive. For these reasons, no consensus in support of routine comparisons to natural conception has emerged.

Another school of ethicists offers a very different threshold for deciding when reproduction violates our obligations to future persons. Starting at least with the nineteenth-century English philosopher and economist John Stuart Mill, philosophers have argued that we owe our children a minimally decent quality of life (Cohen, 1996, 1997; Steinbock and McClamrock). Support for this benchmark is found not only in the ethics literature but also in the daily decisions that prospective parents make to avoid the birth of children with serious birth defects, through either preventive sterilization or prenatal screening and abortion. Support of the idea of a minimal quality of life is also found in the regulatory stance of the U.S. Food and Drug Administration (FDA). Unquestionably, the FDA would deny approval for an effective fertility drug that caused significant birth defects, even if those injuries were not so catastrophic as to make life itself harmful.

Given its intuitive appeal, it is surprisingly difficult to explain why the goal of a minimally decent quality of life should be obligatory and not merely aspirational. Although it may be useful after birth as a measure of the support obligations that parents and society owe to their living children, this benchmark seems less apt as a determinant of reproductive obligations. Its advocates have yet to explain convincingly why it is wrong to create a child whose life—despite being considered to be below the quality of life threshold—will, on balance, be beneficial. Thus, some respected scholars reject it (Robertson; Roberts, 1998).

Nevertheless, the persistence of the minimally decent life standard and its relatively broad support suggest that it is driven by an important intuition. Thus far, the best attempts to identify the source of this intuition turn on the distinction between death and nonexistence (Cohen, 1996; Kamm; Peters, 1989). Because death is a fate faced by actual persons, it seems more tragic than never existing at all. And because we view life as precious, we are hesitant to conclude that a living person's suffering is so profound that death would be better. This skews our burden–benefit calculus in favor of life.

Decisions regarding whether or not to reproduce are materially different. Although a decision not to reproduce does mean that a potential future person will never come to exist, it does not lead to the death of a living person. As a result, we may feel comfortable imposing a more demanding test for preconception decisions than we would impose for the discontinuation of life support. Injuries that are not so catastrophic that death would be a blessing may, nonetheless, be so serious that it would be better never to have had the child at all. According to this view, one can rationally decide to treat disabled babies aggressively while simultaneously concluding that it would be better not to conceive more children who will suffer from these injuries. Using this distinction, the FDA's decisions make sense. If this insight is persuasive, then any application of the nonexistence comparison that overlooks this distinction threatens to underprotect future children.

To summarize, the mere fact that a reproductive technology is more risky than natural conception does not mean that its use violates our obligation to future children. However, technologies that cause injuries so serious that life is not worth having do cause harm and, thus, require justification. When policymakers ask whether the risks of a reproductive practice are so serious that nonexistence would be better, they need to remember that preconception decisions do not lead to the death of a living person and, therefore, a more demanding minimal threshold can be imposed than would be appropriate after birth.

Avoiding Injury by Substituting a Different Child

Even if the but-for test is applied in a way that recognizes that life itself is sometimes harmful, the test remains vulnerable to the criticism that it overlooks an important and quite different category of harmful conduct. This category is composed of decisions to engage in risky reproductive behavior when a safer alternative is available. In this category of cases, parents and clinics can minimize future suffering by taking the safer route. Thus, for example, sperm banks can materially improve the health of the babies that they help to create by screening their sperm donors for transmissible illnesses.

Yet, the but-for test of harm cannot explain why a choice not to screen sperm is harmful. That is because screening would result in the birth of different children. Whenever the choice between two reproductive alternatives would result in the birth of different children, the but-for test dictates that the harmfulness of the choice be determined by asking whether the child who is born would have been better off not existing at all. That is because choosing the safer route would not have made this child better off. Instead, this child would not have existed, and a different child would have been born. As a result, the options for the injured child were life with a disability or no life at all. If the injuries suffered are serious, but not so serious that never existing would be better, then no harm has been done to children created by the sperm bank. Even a clinic's failure to screen for HIV infection may not meet this threshold (Robertson).

This conclusion defies common sense. Because it focuses exclusively on the magnitude of the injury to a specific child, rather than on the presence or absence of safer alternatives, conventional analysis overlooks the harm caused when injuries could be avoided by substituting one future child for another. The harmfulness of a decision not to avoid injury by substitution lies not in the absolute magnitude of the threatened harm, but in the decision to take a risky route when a safer one was available. The but-for test cannot explain the harmfulness of these choices because choices such as these do not make a specific child worse off than she otherwise would have been. Instead, they substitute a different child. Yet, conventional analysis overlooks the fact that substituting improves the collective welfare of the class of future children.

Proponents of a duty to choose the child who will suffer least concede that tort compensation for the injured children will not be appropriate unless the injuries meet the wrongful life threshold (Peters, 1999). That is because these children could not have been born without their injuries. Their only options were life as it is and nonexistence. As a consequence, only those whose lives are worse than nonexistence have been individually harmed. Yet, taking avoidable risks can harm the welfare of the class of future children, even though there are no individual victims. Cumulatively, responsible decisions improve the welfare of future children as a class by substituting healthier children and, thus, reduce the suffering experienced by these children.

Giving content to our obligations to future persons in this manner was first discussed at length by Derek Parfit in his 1984 book, *Reasons and Persons.* Since then, others have applied the idea to reproductive technology (Brock; Peters, 1989). Parfit offered the example of a woman who is advised by her doctor not to become pregnant until she recovers from a temporary illness that causes moderate birth defects. Under the but-for test, she does no harm by refusing to wait, because waiting would change the identity of the resulting children. Parfit called this counterintuitive result the "nonidentity problem." To cure this gap in our understanding of harmful conduct, Parfit proposed a principle that he called *Q* that obliged parents and providers to have the child who will suffer least.

A primary obligation to avoid unnecessary suffering is intuitively appealing. It also seems consistent with the moral reasoning of John Rawls, outlined in his 1971 book, *A Theory of Justice.* Presumably, people acting under a veil of ignorance about their own circumstances, as according to Rawls, would agree that parents should try to have the children who will suffer least. This principle is also consistent with the utilitarian emphasis on beneficence because it calls for decisions that will maximize the welfare of the resulting children. When we are able to avoid injuries by substituting one child for another, we should do so unless doing so will threaten even more important interests.

This principle has surprisingly broad application to reproductive decision making. Parents deciding which embryo to transplant as part of an IVF procedure are making a choice that would be governed by this principle. Infertile patients deciding whether to clone a genetically related child or use donated embryos are making a similar choice, as are couples deciding whether to use donated sperm or to accept the risks associated with intracytoplasmic sperm injection (ICSI). ICSI is a treatment for male infertility that involves injecting a woman's egg with her partner's sperm. It poses extra risk because it bypasses the natural process for willing defective sperm.

The duty to choose the safest route to conception also provides an alternative way of resolving the debate, described briefly above, between Robertson and Roberts over the significance of reproductive alternatives that parents have available to them but decline to use. If avoiding injuries by substitution is better than declining to do so, then the disinterest of prospective parents in the safer option is not relevant to the assessment of harmfulness.

Concerns

One consequence of offering a more robust understanding of the interests of future children, like the theory of avoidability by substitution, is to expand the number of cases in which the interests of future children conflict with the interests of prospective couples, both fertile and infertile. Prospective parents have a liberty interest in making their own decisions free from governmental restriction. Critics charge that a broad conception of our obligations to future children will impose upon prospective parents an unwanted duty to undergo prenatal screening and to abort if tests are positive (Robertson). The enriched conception of the interests of future children described here does have broad implications, which apply to both artificial and natural conception.

While it is true that a broad conception will increase the number of cases in which we will appreciate that the children's interests conflict with parental liberty, rejecting that conception will not eliminate the conflicts—it will only reduce them. In either event, a model for reconciling these competing interests will need to be developed. The strength of the notion of avoidability by substitution is that it helps us to appreciate potential conflicts that are overlooked entirely by conventional analysis. The significance of this new methodology is not that it requires intervention in every case, but that it requires justification in cases overlooked by more conventional notions of harm.

A second concern expressed about avoidability by substitution is that it characterizes conduct as harmful in circumstances in which no specific person has been harmed. For some philosophers, this is a serious problem (Roberts, 1998). One critic called it merely a "norm against offending persons who are troubled by gratuitous suffering" (Robertson, 1997, p. 76). Advocates claim, however, that it is genuinely person-affecting insofar as it reduces unnecessary human suffering (Brock).

Finally, proponents of avoidability by substitution have struggled to find a method for handling "different number" cases. Different number cases arise when the use of a risky reproductive method (such as cloning or the use of fertility drugs at a dosage associated with multiple pregnancies) will result in a different number of children than would have been produced using a safer alternative (such as natural conception or lower doses of the fertility drug). Moral philosophers have discovered that startling paradoxes plague the effort to compare the welfare of groups of different sizes. A tentative solution has been offered that combines average utility and total utility into a combined index that can be used to compare the moral implications of different number reproductive choices (Hurka). This proposal, however, has not yet been thoroughly tested.

The debate over avoidability by substitution is far from resolved. While avoidability by substitution seems to provide a useful explanation consistent with our intuitions, it raises problems that make it unattractive to some ethicists. Even if it is persuasive, it must be supplemented by the nonexistence comparison in cases in which prospective parents want to engage in a risky reproductive practice for which no safer alternative exists, such as postmenopausal pregnancy.

Conclusion

Reproductive behavior can be harmful to future children in three ways. First, reproductive practices can sometimes cause ordinary harm. These are injuries that could have been avoided if more care had been used, such as injuries caused by failure to store frozen embryos properly. Second, reproductive technology can result in a harmful life when the child who is born has a life that is not worth having. Finally, the interests of future children are harmed when the birth of an injured child could have been avoided by changes in conduct resulting in the birth of a different, healthier child. This kind of harm is avoidable by substitution. Clinics performing artificial insemination, for example, can prevent needless suffering by screening out high-risk donors. Responsible efforts to protect future children from harm should aim at minimizing each of the three types of harm to the extent that is consistent with parental procreative liberty.

PHILIP J. PETERS, JR.

SEE ALSO: *Aging and the Aged: Anti-Aging Interventions; Children; Environmental Ethics; Environmental Health; Hazardous Wastes and Toxic Substances; Maternal-Fetal Relationship; Population Ethics; Sustainable Development; Technology*

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GENDER IDENTITY

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The term *gender* has a long history, with Greek roots signifying "birth, race, and family" and Latin roots signifying "birth, race, and kind." The psychologist John Money was among the first to use the term to refer to a person's felt identity as male or female, as distinguished from that person's biological sex traits (Money). The term also is used to refer to a person's nature or identity as male or female and to social aspects of sex such as the cultural roles of men and women.

Various biological traits distinguish male from female, but males and females are not distinct in categorical ways and the boundary between male and female is fluid rather than fixed: Human beings can exhibit atypical traits or intersexed conditions (Fausto-Sterling). Rather than having an XX or XY sex chromosome complement, for example, some people have an XXY or XYY complement. In some cases an individual may be born with only a single X chromosome. Some humans have indeterminate genitalia or both testicular and ovarian tissue. In regard to social roles male and female traits can overlap as well.

Gender Assignment of Newborns and Children

The sex of a newborn child is of keen interest to the parents, but some children are born with ambiguous genitalia, having both testicular and ovarian tissue, or genetic syndromes that confound a simple designation as male or female. The term *gender assignment* refers to practices that are used to discern and impose a gender identity on a newborn child. Suzanne J. Kessler has described how cultural ideals of sex influence the practice of gender assignment. She showed that some physicians have made decisions about gender assignment in accordance with the size and expected function of a child's genitalia rather than in accordance with more complex hormonal and genetic assessments (Kessler, 1990; 1998). If a male child was likely to have a very small penis, for example, some physicians and parents used surgery to assign a female identity to that child. Advocates of this kind of intervention argue that a secure gender identity depends on having appropriate sexual genitalia.

The gender assignment of John/Joan has received a great deal of attention (Colapinto, 1997). In 1966 a physician burned the penis of boy beyond repair during a circumcision that involved an electrocautery needle. Fearful of what the boy's life would be like, his parents took him Johns Hopkins University for evaluation. The psychologist John Money proposed gender reassignment from male to female on the assumption that the loss of the penis was so damaging that it would be better for the child to be raised as female; he also believed that gender identity can be shaped after birth. With the consent of the parents, in 1967 physicians removed the boy's testicles at the age of 22 months, repositioned the urethra, and induced a preliminary vaginal cleft. The parents selected a girl's name and began to treat and raise the child as female (Colapinto, 2000).

From 1972 on Money reported the child's gender assignment as successful. He said that the case showed that gender identity is plastic and can be shaped during early childhood. One's sense of self as male or female is not, he held, determined by anatomy, genetics, or prenatal history. Health practitioners translated that evidence into practice guidelines and encouraged gender interventions. One advocate said that the possibility of female sex assignment with genetic males “must be considered whenever the severity of the genital abnormality is such that it is likely to be extremely difficult or impossible to correct for normal adult functioning” (Baker, p. 266).

In fact, the gender reassignment of this child failed. The child consistently rejected female identification and exhibited male-typical interests and behaviors. Eventually the child refused further interventions, and at that point the family told the child the truth. The fourteen-year-old immediately reclaimed a male identity, adopted a male name, started male hormone treatments, underwent breast removal, and eventually was treated with phalloplasty, the construction of a penis. None of those events were reported in the professional literature until 1997. Thirty years passed between the beginning of this experiment and its publicly described failure (Diamond and Sigmundson).

Some commentators believe that that failure provides evidence that gender assignments do not work, but that conclusion is not fully supported by the evidence. Gender assignment in children has not been well studied, but even if this case failed spectacularly, other interventions might succeed. It also should be noted that the intervention made sense at the time of an unsettled debate about the extent to which gender identity can be influenced after birth. The unfortunate outcome has rightly forced broad reconsideration of gender assignment practices. Various commentators have noted that gender assignment can reinforce dubious notions such as the view that a person cannot be male unless he has a large and intact penis and that it is better for a child to grow up as a sterile female than as a male with a very small or damaged penis.

Some commentators have argued that gender assignment violates children’s autonomy (Dreger, 1999). That argument is not convincing because newborns and very young children lack the cognitive powers that justify respect for people’s choices. More convincing are worries that early gender interventions are not effective or work to the advantage of anxious parents, not to the benefit of the children. Concerns of this kind suggest that gender assignment in the case of ambiguous genitalia or intersex conditions at the very least should not be treated as inherently shameful or as a social emergency.

Physicians should propose gender interventions to parents only after a rigorous evaluation of the risks and benefits. Among other things, practitioners should advise parents that some individuals live happily with atypical genitalia or intersex conditions and that gender assignment can be carried out later on if that is desired by the child (Dreger, 1998). Parents need support as they think through decisions about gender interventions with their children, and this support should include nonpathologized images of intersex people. In the 1990s the Intersex Society of North America began its education and advocacy efforts to improve options for intersex people and their healthcare providers, and this group explicitly rejects a pathological view of intersexuality.

Gender Identity Disorders

Some people assert a gender identity that is at odds with their anatomy and genetic traits. The American Psychiatric Association (APA) treats some of those people as suffering from gender identity disorder (GID). GID sometimes is called gender dysphoria, and it occurs in children, adolescents, and adults. According to the APA, people with this disorder are characterized by a “strong and persistent cross-gender indentification” (American Psychiatric Association, 2000, p. 581).

This preoccupation is said to pass into the pathological when there is strong and persistent cross-gender identification and clinically significant distress or impairment in social, occupation, or other important areas of function. The diagnosis is not applied to persons with cross-gender identification who have intersex conditions. To some extent *gender identity disorder* replaces what previously has been treated as *transsexualism,* a term that came into use in the 1940s. Although some commentators still use that term, *transgenderism* and *cross-gendered identities* have come into common use.

The prevalence of cross-gender identities has been poorly studied. There have been no studies of prevalence in the United States, although there have been some studies in smaller countries. According to those studies, cross-gender identities occur in 1 in 30,000 adult males and 1 in 30,000 adult females (American Psychiatric Association, 2000). There are various theories about why some people come to have cross-gender identities, although no single theory is accepted as conclusive. Researchers have explored prenatal hormonal exposure, birth order, genetics, brain structure, and various psychological and social learning theories (Green and Blanchard; Devor). Whatever the origins of cross-gender identification are, there is a general pattern of development: People have a sense of dissatisfaction with their sex characteristics and assigned gender, conclude that that dissatisfaction would be alleviated by change and therefore pursue varying degrees of reassignment (Devor).

Adults with cross-gender identities differ in regard to expectations from medicine and how far they want to conform their bodies to a particular gender (McCloskey).

Not everyone wants to assume every male or female trait. Transgendered men may elect to have testosterone treatment, excision of the breasts and genitals, reduction in thyroid cartilage to minimize the Adam's apple, and the construction of a vagina. Transgendered women may elect to have estrogen treatment, electrolysis of unwanted hair, and the construction of male genitalia. However, some transgendered people continue to value aspects of their originally assigned sex and want to keep them even as they add other transfomations. Also, not all instances of cross-dressing or atypical gender expression represent cross-gender identities. Some men and women cross-dress for sexual reasons; this phenomenon is known in psychiatry as transvestism. In these instances there is no discordance between one's biological traits and one's desired gender identity. The issue here is gender expression rather than identity.

There are no specific clinical or psychological tests to diagnose cross-gendered identities; the diagnosis is made on the basis of the case presentation. Moreover, there are no pharmaceutical or surgical treatments for this condition. Generally, behavioral or psychosocial treatments are used to orient a person to a gender identity; no hormonal or pharmacological treatments are known. Some studies have shown that cross-gender identification can be reduced in children through a variety of psychological and social interventions (Green). Advocates of treatment with children focus their interventions on helping children become content with their birth sex. They counsel, for example, that "young children should be taught that sex is irreversible" (Green and Blanchard, p. 1658).

Some practitioners justify therapy for children to alleviate the distress associated with cross-gender identities and behaviors and prevent the emergence of a homosexual orientation in adolescence and adulthood (Rosen et al.). Critics have contested both of those goals. In 1996 the Human Rights Commission of the City and County of San Francisco condemned the use of the diagnosis of GID. According to that group, the diagnosis of GID in children is used to screen for homosexuality and stigmatize gender nonconformity. Others have defended the use of the diagnosis and therapy: "Whether or not someone else agrees, parents have the legal right to bring a child for therapy to modify behavior they disapprove of and with the goal of preventing a later behavior of which they disapprove" (Green and Blanchard, p. 1659). Those commentators compare this option to parents' rights with respect to their children's education, religion, and diet.

Parents have a prima facie right to choose on behalf of their children, but that right is tempered by the moral right of children to be protected from undue risk and useless treatments. For reasons of beneficence parents should not use therapies that bring more harm than good to their children. Medical ethics also recognizes that maturing adolescents deserve a degree of choice in regard to birth control practices, psychiatric treatment, and involvement in research even when those choices conflict with parental wishes. Gender therapies for maturing adolescents require much stronger justifications than do those undertaken with much younger children.

Harry Benjamin holds a central place in the scientific study of transsexualism or transgenderism. Benjamin was a German national who immigrated to the United States and published *The Transsexual Phenomenon* in 1966. In that book he offered the first comprehensive treatment guide for transsexuals. In late 1970s a group of healthcare professionals codified his approach in the Harry Benjamin Standards of Care. Among other things, those rules require that people who seek gender interventions:

1. obtain a diagnosis of gender disorder;
2. begin a relationship with a therapist;
3. receive hormone therapy;
4. live as cross-dressed for a sustained period; and
5. after therapists authorize it, receive desired surgical interventions (Harry Benjamin International Gender Dysphoria Association).

These standards are observed widely in professional relationships with transgendered people. However, some commentators believe that the standards are paternalistic in the sense that they represent a degree of control over medical interventions that is not required elsewhere, for example, in cosmetic surgeries.

Transgender therapy has important implications for a person's social and legal status. The physician and tennis player Renee Richards, formerly Richard, gained the right to play in women's professional tennis as a transgendered woman (Richards). Other transgendered men and women have not been as successful in finding accommodation in society and the law. Individuals who undergo transgender therapy often face legal difficulties insofar as they may violate laws regarding cross-dressing and the use of public washrooms. Those people are sometimes restricted in their right to marry and have children. Prison housing also raises special problems because transgendered persons are especially vulnerable to mistreatment and violence. Some jurisdictions have adopted laws that prohibit discrimination against people having or being perceived as having a self-image or identity not traditionally associated with one's biological sex. Most jurisdictions have no such laws.

The Ethics of Transgender Interventions

Insofar as male-to-female transgenderism is more common than its opposite, some critics have seen in transgender therapy the extension of male privilege. Janice Raymond has argued that male-to-female transgenderism trivializes women because it treats femaleness as a trait that men may adopt as they wish. She characterizes female-to-male transgenderism as an attempt to bypass constraints on female participation in a male-dominated society (Raymond). Raymond would not ban transgender therapy, but she believes that a greater social emancipation of women would eliminate the reasons for seeking it. By contrast, other commentators believe that the origins of cross-gendered identities are ultimately beside the point: Those commentators think that the proper focus of interest in these identities is not prevention and treatment but social accommodation so that people may live in whatever modes of sex or gender expression they find desirable (Devor).

Some commentators object to gender interventions for adults on the grounds that medical interventions violate the natural law principle of bodily integrity. However, other commentators working within the same tradition have defended medical interventions on the grounds that they protect psychic health (Springer). It is also possible to argue on utilitarian grounds that if psychiatry has no meaningful treatment for cross-gendered identities, gender interventions can help people achieve happiness. Even commentators who defend a pathological interpretation of cross-gender identities agree that “the most reliable conclusion is that the overwhelming majority of post-operative transsexuals are content with their decision to undergo sex reassignment” (Green and Blanchard, p. 1660). Utilitarian ethics not only advocates the greatest happiness for the greatest number of people, as in the philosopher John Stuart Mill’s formulation, it also asserts the liberty principle, a principle of noninterference with individual pursuits insofar as they do not harm others. A case can be made that atypical gender choices do not intrude on the rights of others any more than atypical religious or political views do.

Defending atypical gender identities and expression in adults does not of course establish what priority gender interventions should have in a health-care system. Some critics argue that too little research has been done on ways to improve the surgical needs of transgendered people (Devor). Some people have found that private insurers and government health programs are unwilling to pay for interventions because the interventions are voluntary and do not cure an underlying disorder. Other commentators have argued that gender interventions meet an important psychic need, that they work, and that their limitations can be overcome through better selection standards (Gordon). Those commentators therefore argue that private insurers and the government should pay for gender therapies.

Gender, Identity, and Gender Expression

One of the striking aspects of recent medical history is the way in which affected parties have worked to mitigate injurious or harmful medical practices. For example, women’s advocacy groups have helped reshape health-care practices that worked against the interests of women. Men and women with homosexual orientations have worked to change the medical perception of homosexuality as pathological (Bayer). People with AIDS have forced a reconsideration of problematic language and representations used to describe them (Treichler). In a similar way people with cross-gender identities and intersex conditions have challenged the assumptions behind diagnoses and treatments related to gender.

In 1993, participants at the International Conference on Transgender Law and Employment Policy issued the first version of the International Bill of Gender Rights. Among other things, that bill asserts the right of all people to self-definition in regard to gender and the right of free gender expression. It also asserts the right of people to control their bodies in regard to chemical, cosmetic, and surgical interventions as well as the right to receive competent and professional medical care. It also rejects the pathological interpretation of gender: “[I]ndividuals shall not be subject to psychiatric diagnosis or treatment as mentally disordered or diseased solely on the basis of a self-defined gender identity or the expression thereof” (International Conference). In the long run it is a goal of gender activists to move society away from the treatment and prevention of GID and toward acceptance of a much broader range of gender expression.

Gender activism generally rejects the idea that only people with a particular biological endowment may participate in masculinity or femininity. This approach is part of a larger critique of gender roles that are constructed from opposed conceptions of male and female (MacKenzie; Feinberg). A number of commentators point out that some societies have successfully incorporated more diffuse notions of gender identity and gender roles; Native American tribes are commonly cited examples (Williams; Jacobs, Thomas, and Lang).

This critique raises questions about whether gender assignment in children and the category of GID serve social rather than medical purposes. The APA has attempted to divest itself of responsibility for the enforcement of moral or political values: "Neither deviant behavior, e.g., political, religious, or sexual, nor conflicts that are primarily between the individual and society are mental disorders unless the deviance or conflicts is a symptom of a dysfunction in the person" that generates persistent stress, disability, or significant risk of suffering, death, pain, disability, or loss of freedom (American Psychiatric Association, 1987, p. xxii). Some commentators believe that the stress suffered by children, adolescents, and adults with cross-gender identities is primarily social in nature and thus is primarily a social problem, not an issue to be addressed through diagnosis and treatment.

Some commentators wonder whether medicine will continue to identify cross-gender identifications as pathological or whether another view will prevail. Certainly, attention to the views and counsel of the people under discussion and resistance to easy slippage between biology and culture will help medicine and ethics serve human beings as the people they are rather than as the people society would have them be.

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SEE ALSO: *Body: Cultural and Religious Perspectives; Homosexuality; Life, Quality of; Paternalism; Psychiatry, Abuses of; Psychoanalysis and Dynamic Therapies*

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GENETIC COUNSELING, ETHICAL ISSUES IN

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Genetic counseling is a complex communication process that takes place between a genetic counselor and one or more counselees, also called clients. It may involve a single encounter lasting thirty to sixty minutes or multiple encounters over months or years. The type and duration of the encounter is determined by the nature of the condition that led to the encounter. This includes whether the condition under discussion is genetic or nongenetic, the mode of inheritance, and the severity of the disorder, including its prognosis. Therapeutic and reproductive implications play a significant role as well as the counselor's evaluation of the effectiveness of the counseling encounter.

Effective and helpful genetic counseling should be guided by several ethical principles and human values judged by most workers in the field to be of vital importance (Wertz et al.). These include autonomy; beneficence and nonmaleficence; confidentiality; veracity and truth-telling; and informed consent. It is also crucial that varied cultural and ethnic factors be taken into account. The professional code of ethics for genetic counselors should also be considered (Palmer).

Since genetic counseling usually occurs in medical settings such as clinics, medical centers, or private offices, the ethical values that prevail in medical and nursing practice should also play a role in genetic counseling. These principles or values influence different aspects of the counseling process to different degrees. Their influence may also vary according to the cultural background, ethnicity, or religious beliefs of the counselees and their families. The latter factors should receive serious attention, since cultural, religious, or ethnic differences can profoundly influence the relative weight given to one value or principle over another. This is especially true when counseling involves individuals from other countries (Wertz et al.). Counselees from the so-called Third World may cherish religious tenets and ethical values drastically different from those of the Jewish and Christian faiths that inform so much of Western medical ethics (Fisher).

Autonomy and Nondirectiveness

A major facet of the counseling process, and one important goal of a successful counseling process, is a course of action (or inaction) that is determined according to the best available evidence. Genetic counselors generally agree that this decision should be made by the counselee, and that it should be made freely and without coercion (Fraser, 1974; Ad Hoc Committee on Genetic Counseling). Counselors want to avoid, to the extent possible, being accused of "playing god" and to resist any temptation to practice eugenics, the process of manipulating genes in order to "improve" genetic makeup. The manipulation is accomplished by directing the counselees about what reproductive decisions they should or should not make. This is inappropriate because respect for autonomy should be a predominant ethical value guiding the counseling process and its outcome. This is the clear consensus of genetic counselors from all over the world (U.S. President's Commission; Wertz and Fletcher).

If counselees are to make autonomous decisions, they must be fully informed about the disorder in question, free of coercion, aware of all the possible choices, and have access to any facilities and/or services to implement their decision. In its purest sense and with only rare exceptions, the nature of the decision is not an issue as long as the counselee has decided that such a decision is in her or his best interest. In this model of counseling the counselor makes every effort to be "nondirective," that is, to refrain as much as possible from providing any suggestion directly or indirectly to the counselee as to what decision she or he should make (Fraser, 1974, 1979; Hsia). No counselor can be totally unbiased and without any interest in the decision that is made. However, the aim in counseling is to create "an accepting psychologic climate" and thereby the possibility of a nondirective relationship (Antley).

An ethical dilemma may arise for the counselor if the counselee wants to make a decision that will have what the counselor strongly feels are mostly negative consequences. For example, a man and a woman are both affected by a serious homozygous recessive disorder (e.g., sickle-cell anemia) and are advised that all their children will be similarly affected. After being counseled, and with full knowledge of the genetic consequences, they decide to have their own biological children. This kind of decision is called dysgenic by some, because it has the potential of resulting in an increase in the number of deleterious genes in the next generation. This will be true if the couple has more than two children and they in turn live to reproduce in an environment where these genes have no selective advantage. Some counselors feel that the counselor may be justified in not honoring the principle of nondirectiveness because the net reproductive effect is likely to produce more harm than benefit (Yarborough et al.). It further results in a situation in which children who are destined to live a life of pain and suffering are knowingly brought into the world. Furthermore, there is the possibility of genetic harm to this population if this practice becomes more common. These harms must be balanced against the benefit to these parents of having their own biological children, even if these children are much more likely to suffer or to die an early death.

The counselor who feels that the principle of nondirectiveness ought not be violated under any circumstances should at least explore with the counselees the psychosocial and emotional reasons that led them to this decision. The counselor should assist them in a careful and deliberate examination of the benefits and harms that may effect them and their offspring (Kessler). Strong arguments have been advanced suggesting that by applying the principle of beneficence, the counselor is justified in attempting to persuade counselees to reconsider their decisions in certain cases without violating the rule of nondirectiveness (Yarborough et al.).

Beneficence/Nonmaleficence: Whose Needs Come First?

When the counselee is trying to balance the benefits and harms of a particular decision against one another, there may be a tendency to emphasize the benefits over the harms. In some cases, the benefit or beneficence for the counselee(s) may mean maleficence or harm for the child. If parents who know they will have a child with a serious genetically determined disease decide to go ahead because they believe they have a "right to bear children," they may benefit in having their own biological children. At the same time they might not be judged "responsible parents" because they may not have given serious enough consideration to the suffering and discomfort their offspring will suffer. Even if this factor has been considered, the parents may justify their decision on the religious grounds that they are merely following the dictates of a higher power, leaving it to God to determine whether or not they have children.

In some cases it may be difficult for counselor and counselee to agree on what constitutes a benefit and what a harm, since such determinations are often rather subjective, governed primarily by the counselee's values. For example, abortion of an affected fetus might be considered a benefit to some and harmful to others, depending on whose needs are considered primary. Providing information that there is a high probability that a counselee at risk to inherit a serious genetically determined disease of late onset has in fact inherited it might seem a beneficent act by some who value knowledge of any sort, and a maleficent or harmful act by others who value information only when it leads to the prevention or correction of harm. In the tension between these contrasting ethical principles, medical ethical tradition suggests that nonmaleficence should be weighted more heavily than beneficence in cases where they are in conflict. This position is consistent with the maxim of *primum non nocere,* first do no harm (Beauchamp and Childress), since providing information without clear benefit has the potential for causing social and emotional harm.

Veracity and Truth-telling in Genetic Counseling

A major part of the genetic counseling process is the exchange of information about the medical and family history provided by the counselee and comprehensive genetic and medical information about the disease in question provided by the counselor (Fraser, 1974; Hsia). The counselee needs accurate information, including the correct diagnosis, in order to choose a beneficial course of action. Truth-telling is an essential ingredient of the relationship between genetic counselors and counselees. Part of the trust that exists between them is based on this virtue. As a consequence, the genetic counselor should provide truthful, accurate, and complete information to the counselee concerning the genetic disorder being considered.

On some occasions the genetic counselor might have very good reasons for violating this important trust. Failure to tell the truth will most often involve withholding information rather than lying. But the counselor bears the burden of justifying failure to tell the whole truth. This is the case even if the counselor is keeping back some information until a time when it may be more readily received, that is, when the counselee is judged to be better prepared to accept negative information and its attendant consequences. Some reasons that might be given for holding back information include:

1. The information, if transmitted, is likely to cause permanent damage to the self-image of the counselee or result in a serious or severe emotional reaction. This is the case when a female is found to have an XY sex chromosomal constitution rather than the normal XX sex chromosomes.
2. Refraining from transmitting the information will not have a significant effect on the options open to the counselee or her or his family nor will it compromise any therapy the counselee or the family should receive.

3. The counselee has a history of serious depression and the information, if fully given, has a good chance of exacerbating the depression with a significant risk of suicide.
4. The information reveals evidence that the putative father in a family is not the biological father of a particular child; if this information is provided, it is likely to lead to the breakup of the family and the child will no longer have a father.
5. A young man or woman has been found to be a presymptomatic carrier of a late-onset, autosomal (related to chromosomes that are common to both sexes), dominant condition and does not want a fiance to be told because it is feared she or he might break off the relationship.

The latter two cases, in which information is withheld from third parties, raise the question of the counselor's obligation or "duty to warn" others who might be affected by the presence of the genetic condition in a spouse or significant other. For some counselors, the "right to know" or the "duty to warn" provides strong justification for telling the whole truth at all times during the counseling process, regardless of the potential consequences. At the same time, a minority of counselees feel they have a right "not to know." These people would rather not be told about a serious genetic condition of late onset, especially if there is no effective therapy or other maneuver that will forestall its onset or significantly reduce its symptoms. If counselees do not wish to know about their incurable condition, the information may nevertheless have to be placed in the medical record so that future health-care givers will be alert to the counselee's status. The information can also be provided if counselees should change their minds. In general, genetic counselors will withhold information only where there is a strong likelihood for serious harm to the family or to the self-image or status of the individual (Wertz et al.).

Confidentiality and the Control of Genetic Information

Medical genetics is more concerned with the family than almost any other medical subspecialty. As part of the evaluation of a clinically significant genetic disorder, the genetic counselor is required to collect detailed family data and record it in the form of a *pedigree.* This enables the counselor and the medical geneticist to determine whether there is a pattern of occurrence in the family consistent with control by a single gene of major effect (often referred to as a "Mendelian" gene). The pedigree may also provide information that may indicate the presence of inherited chromosomal structural rearrangements called translocations. More often than not, the pedigree information is insufficient to make this determination. But when it does demonstrate the presence of an inherited defect, this knowledge can have serious, even grave, implications for the other genetically related members of the family. This is especially true when one is dealing with conditions that demonstrate autosomal or X-linked dominant or X-linked recessive modes of inheritance, because inheritance of a single mutant gene on an X or non-X chromosome can cause the full-blown clinical disorder.

Under the medical model that governs medical geneticists and genetic counseling, the counselee has the status of a patient. All information relative to his or her case is covered by the guarantee of privacy and confidentiality that is required of health professionals (Beauchamp and Childress). The medical geneticist or genetic counselor should get permission from the counselee to contact other family members to inform them that they are at risk for a serious genetically determined disorder. In general, this is not a problem; most counselees readily consent to having their relatives contacted or are willing to do this themselves. But in at least two instances the genetic counselor may face an ethical dilemma concerning the release of information to third parties.

1. The disorder is *not* treatable and can be diagnosed by prenatal diagnosis, so a couple at risk could theoretically avoid the birth of an affected child; or individuals at risk for this might wish to take special predictive tests and use the knowledge to get their affairs in order or in other ways to alter their life situation.
2. The disorder is treatable and can be cured or can have the symptoms and any complications significantly reduced by safe and readily available therapy; or the expression of the disorder can be prevented if it is detected before the symptoms have appeared.

The obligation to maintain confidentiality of patient records and genetic information obtained in a medical setting is not absolute and may be breached when there is adequate justification. The exceptions may be invoked only if there are extenuating or overriding personal or social circumstances. The State of Texas statute on confidentiality, for example, allows confidential information to be disclosed if there is the probability of imminent physical injury to the patient or others (Andrews). In the case of genetic disorders, the most compelling argument for breaching confidentiality besides those instances where it is required by law is the protection of third parties from harm (Andrews). In ethical terms this is sometimes cited as "the duty or obligation to warn" when there is a clear or imminent danger.

In the cases shown above, there would appear to be clear justification for breaching confidentiality in the second case but not in the first. In the first example, useful information might be provided to third parties, but there is no evidence of harm because the condition identified is not treatable. In the second example, the fact that there is a treatment or a method of preventing the condition means that failure to warn would result in harm to a third party. Since the burden of justification would be on the genetic counselor to show that the harm, however, conceived, is correctable or preventable, it makes sense not to breach confidentiality in instances where the potential harm is not clearly defined. The U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research regarding confidentiality provided four conditions under which the requirements of confidentiality can be overridden and genetic information released to relatives or their physicians (1983).

Revealing genetic information, especially in cases of presymptomatic diagnosis, has other important implications for the counselee's eligibility for health insurance and possibly for life insurance. Depending on the condition involved, such information if revealed can also affect employability and opportunities for promotion. There is always a significant risk that sensitive information, if released, may find its way to individuals or agencies that might harm the counselee in the future.

Informed Consent in Genetic Counseling

Since a major component of genetic counseling is communication of information, and since the counselee is encouraged to make her or his own decision, problems or conflicts with informed consent are unusual. Informed consent is especially relevant in the counseling process when a procedure may result in potentially harmful or ambiguous outcomes, for example:

1. in connection with prenatal diagnosis, when the counselee or woman who is to undergo the test needs to understand its risks, benefits, errors, and limitations;
2. as a prelude to presymptomatic testing for a serious disorder without available treatment or methods of prevention, where a positive result can have profound implications for the individual's future life;
3. in connection with participation in a research protocol in which there may be questions about the future use of data or tissue or blood (especially DNA) in future studies or in the search for other genetic markers.

Ethnic and Cultural Influences

The population of the United States and many other industrialized nations is becoming more diverse. It is estimated that by the year 2010 nearly one-third of the population of the United States will be made up of minorities. Genetic counseling that promotes individual autonomy and is consistent with the ethical values discussed here will require that counselors be aware of and responsive to a wide and growing range of ethnic and cultural variations among those who are now and will be seeking genetic counseling (Fisher). Conflicts are almost certain to arise when the values and decisions of the ethnically and/or culturally different counselees conflict with those of the counselors and the Western values derived from Jewish and Christian sources that in general govern the decision-making process. The value systems that have been used traditionally in counseling will probably have to be applied in significantly different ways if the process and outcome of counseling is to be helpful and effective.

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SEE ALSO: *Access to Healthcare; Autonomy; Beneficence; Confidentiality; Eugenics; Family and Family Medicine; Genetic Counseling, Practice of; Genetic Testing and Screening; Health Insurance; Professional-Patient Relationship; Responsibility*

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GENETIC COUNSELING, PRACTICE OF

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Genetic counseling is a relatively new medical counseling service that aims to help those affected by genetic conditions or who face increased genetic risk. Clients seek this service asking questions about why a condition occurred, the chances that it may occur again in the future, and how they may be helped to cope with the uncertainty, risk, or prognosis of a diagnosis. Genetic counseling is often provided by a team of genetics providers (medical geneticists, master's level genetic counselors, and genetic nurses) in a specialty clinic within a hospital, university medical center, or in a community outpatient setting. Attention is paid to the medical, informational, and emotional needs of clients and their family members related to genetic conditions or birth defects.

History

Genetic counseling began in the United States in the 1930s when the academic discipline of genetics emerged and Mendelian principles of single gene inheritance could be applied to human conditions. The first *practitioners* were academic geneticists who were approached by individuals with concerns about their own family history. In the 1940s the field of human genetics was established, followed by medical specialization in genetics that focused on the diagnosis and natural history of genetic conditions. Shortly thereafter in the 1970s, the profession of genetic counseling was established in the United States. Practitioners earn a master's degree and are trained in both human genetics and psychological counseling skills. As of 2002 there were estimated to be over 2,000 genetic counselors practicing in the United States and Canada. Genetic counselors are credentialed by the American Board of Genetic Counseling to uphold practice standards. These professionals work with medical geneticists and obstetricians to provide education and counseling related to risk or diagnosis of a genetic condition or congenital anomaly.

Definition

Genetic counseling makes genetic information available to clients and facilitates their use of that information. Genetic information is important to understanding the cause of conditions, making informed choices, and adapting to genetic risk. The range of information provided includes the medical diagnosis, the inheritance pattern, the risk of recurrence, medical management or surveillance, prognosis, schooling needs, support groups, financial issues, and reproductive options. Since clients often seek services around significant life events or crises, the information is often highly sensitive, such as predicting the health of future children, the likelihood of a late onset condition, or the loss of an affected child. Discussion of genetic conditions or risks may therefore elicit feelings of lowered self-esteem, guilt, shame, loss, and blame for parents of affected children. Overall addressing the cognitive, affective, and behavioral aspects of clients' responses to the information are central components to genetic counseling. A practice definition states that:

> Genetic counseling is a dynamic psychoeducational process centered on genetic information. Within a therapeutic relationship established between providers and clients, clients are helped to personalize technical and probabilistic genetic information, to promote self-determination, and to enhance their ability to adapt over time. The overarching goal is to facilitate clients' ability to use genetic information in a personally meaningful way that minimizes psychological distress and increases personal control. (Biesecker and Peters, p. 195)

Settings and Practice Goals

There are a variety of different settings for genetic counseling, including reproductive, pediatric/adult, and common disease clinics. Each one embodies a different set of aims. In the reproductive setting, the focus is primarily on decision making. Most often clients seen in a prenatal genetics clinic seek to understand their age-related risks for having a child with a chromosomal abnormality, such as Down syndrome. Increasingly they may also be seen in follow-up to an abnormal screening test that implicates higher chances for having a child with a birth defect or chromosomal disorder. These clients most often have no family history of the disorder(s) in question and are helped to understand what the conditions are, their likelihood for occurrence, and the options for managing or terminating the pregnancy. The goal is to promote client self-determination in exercising choice about the use of prenatal tests. Reproductive genetic counseling aims to deliver personalized genetic information to the client in a useful way; to explore the meaning of the information with the client in light of personal values and beliefs; to promote the clients' preferences for reproductive options with consideration of alternatives, consequences, and barriers; and to prepare the client for adapting to the outcomes of the choice(s) (Biesecker). When an abnormality is detected, there are few options for treating the condition and couples face painful decisions about whether or not to abort a desired pregnancy. Genetic counseling is particularly important when couples face such irreversible life-altering decisions.

In the pediatric and adult genetics setting, the goal is to facilitate client understanding and adaptation to a condition. In this setting clients often have a child or other relative who is affected with a genetic condition that they seek to better understand as part of their adaptation to (often unexpected) circumstances. Obtaining an accurate diagnosis of the condition by a medical geneticist is an essential component. Medical information provided to clients includes a description of the condition and its potential long-term consequences. The aims of genetic counseling in the pediatric or adult genetics setting are to discuss client understanding of cause as it relates to a scientific (genetic) explanation and the client's interpretation, to explore the role of personal beliefs in adaptation, and to promote feelings of personal control and mastery over the condition (Biesecker). Genetic counseling helps clients to cognitively integrate genetic information into their personal beliefs and frame of reference in a manner that is personally useful to them. Referrals are often made to support groups or to other parents with similarly affected children. School referrals for attention to special learning needs for the child may also be made. Parents often require a great deal of follow-up medical, educational, and support services for their child and themselves.

In the common disease setting, such as cancer genetics, cardiovascular genetics, or neurogenetics clinics, most often adults seek to understand their own risk for disease. The goal is to maintain the health of at-risk individuals. Specific aims are to increase accurate risk perception, to facilitate adaptation to genetic risk, to promote health-enhancing behaviors, and to prevent disease (Biesecker). Predictive genetic testing may be offered as part of the effort to refine risk more precisely and as a basis for making screening or prevention recommendations. Yet decisions about predictive testing are highly personal due to the lack of empirical evidence to guide practitioners in making medical recommendations based on test results. In many cases genetic testing offers risk estimates but little else. Clients' decisions about undergoing predictive testing often lie with the meaning the test result would have for adapting to living at risk. Increasingly such testing will also be used to manage risk by offering targeted interventions for those identified to be at increased genetic risk, but this is rarely the case.

Cancer genetics services have been established in response to the research and commercial availability of predictive testing for cancer risk. Tests have been developed for breast and ovarian cancer risk, colorectal cancer risk and for certain rare cancer syndromes. While medical recommendations are made for tested individuals found to be at increased risk, there remains a paucity of empirical evidence to support the majority of these recommendations. With time more precise risk estimations will be made using testing, targeted interventions will be known to be effective, and reduction in morbidity and mortality will be achieved. In the meantime, however, the imprecise nature of cancer genetics testing necessitates informed consent and emphasizes the importance of pre-test education and counseling in the common disease setting.

Non-Directiveness

Genetic counseling is often described as *non-directive,* meaning that clients are helped to make personal decisions without undue influence by the counselor. This practice principle emerged from reproductive genetic counseling where couples face decisions about having children or continuing an affected pregnancy. It remains an important ethical principle for guiding clients through their reproductive choices. Clients are helped to make personally relevant and informed choices for themselves. Nonetheless non-directiveness is difficult to achieve since counselors have personal and professional biases and experiences that may be inadvertently expressed in how information is presented or emphasized in genetic counseling. While counselors may not intend to guide client decisions, it is reasonable to assume that genetic counseling influences them. Yet the majority of clients are capable of making their own decisions and can benefit from prenatal counseling by exploring their own beliefs, attitudes, and values related to their ability to parent a child affected with a particular condition. Genetic counseling that is client-centered focuses on meeting the needs of clients by working within the context of their sociocultural beliefs and lived experience. Even if a genetic counselor explicitly expresses her own beliefs during reproductive counseling, it is unlikely that a client will simply adopt them. However there are situations where conflicts in promoting personal reproductive choice do exist.

When a prenatal genetic counselor is employed by a commercial laboratory or prenatal testing center, there is more likely to be a potential conflict of interest. If the testing center promotes prenatal tests rather than promoting the choice of testing, then the counseling may emphasize the benefits of testing over the risks. There might be more frequent assumptions on behalf of the counselor that if the client was referred for prenatal testing, that the client is going to undergo testing rather than insuring that each client makes an informed and personal decision whether or not to undergo optional prenatal tests. Further, if the counselor's salary depends upon a certain number of tests being conducted, there is likely to be an even greater chance for persuasive prenatal genetic counseling.

In genetic counseling settings other than reproductive, non-directiveness has little relevance. In the common disease setting, for instance, making screening recommendations to promote health intends to be directive. Applying the notion of non-directiveness to genetic counseling in general has lead to a great deal of confusion in the literature (Kessler). In addition to directive health-related recommendations, communication in genetic counseling is often directive. Offering advice or making referrals may be also be construed as directive. The adoption of non-directiveness as a central tenet of genetic counseling has limited the use of (directive) therapeutic interventions that may be helpful to clients. Genetic counseling may be practiced in a more hesitant manner if counselors fear directing their clients' decisions when fully engaging with them may be more productive. Issues related to non-directiveness continue to be actively debated in the professional literature.

Client-Centered Practice

Interpretation and use of genetic information by clients depends somewhat on their personality traits and characteristics. Clients come from a variety of sociodemographic and ethnocultural backgrounds that shape their beliefs, values, and available resources. Clients also may belong to affected families who have experience with a condition under discussion. Others may not have had experience with it. These variables shape client needs, attitudes, and priorities. Genetic counseling necessitates assessment of these variables in order to tailor the information and counseling to meet client needs. A couple with two children affected with cystic fibrosis that faces a decision about prenatal testing with a subsequent pregnancy is expert on the disorder and its impact on the family. A couple who is found to be at increased risk for having a child with cystic fibrosis based on carrier screening with no family history of the condition may have little idea of what having an affected child may mean for the child or themselves. Genetic counseling would differ in meeting the needs of these clients, even though at face value, each involves a fetus at 25 percent risk for being affected with the same condition, cystic fibrosis.

Since genetic conditions affect families, there may also be differences in how relatives view or use genetic information. Genetic counselors working with various family members have obligations to protect the privacy of individual clients and to support different decisions made within the same family. The offer to undergo predictive genetic testing, for instance, may result in some individuals who are interested and others who are not. Yet test results for one relative may reveal the at-risk status of another. So protecting personal testing decisions within families can be challenging. Genetic counseling aims to help relatives anticipate such consequences prior to undergoing testing. Rarely family members may choose not to reveal risk of a genetic condition to relatives. In this circumstance, genetic counselors may be persuasive in encouraging clients to notify their relatives so that each at-risk person may be informed and equipped to make his or her own decision about whether or not to undergo genetic testing. There is debate about the duty of genetics providers to warn at-risk relatives in situations where family members choose otherwise.

As more genetic discoveries emerge and genetics medicine moves into an era in which diagnoses are refined by genetic information, more tests are developed, and treatments tailored, all healthcare providers will need to understand some aspects of medical genetics. Nurses, primary care physicians, and even social workers and psychologists will be faced with helping clients to make decisions about using new genetic technologies. This sea change suggests a significant need for professional genetics education to prepare a variety of healthcare providers to care for clients in the future. Genetic counselors are important providers for helping to train others. In the meantime, it is important that clients who encounter new genetic technologies have access to appropriately trained and certified genetics providers. As genetic testing is increasingly utilized as a tool for medical management and not merely as a means to obtain risk information, there is likely to be less psychological turmoil for clients in making decisions about undergoing testing. However carrier testing or pre-symptomatic testing for serious, late-onset disorders without medical treatment will continue to elicit strong thoughts and feelings from clients. Certain genetic testing will continue to need to be accompanied by psychoeducational genetic counseling provided by well-trained clinicians to facilitate personal decision making. As the number and background of professionals involved in genetic testing expands, there is a greater potential threat to well-informed decision making. The maintenance of a high training and practice standard for genetic counseling is a priority in anticipating some of the consequences of the diffusion and proliferation of genetic testing.

Genetic counseling has evolved rapidly in its short history from the reproductive arena to pediatric and adult genetics clinics and more recently into common disease clinics. With this expansion, its goals have become more diverse and specific to the setting. As genetics medicine further emerges and new genetic tests are introduced, promoting informed choice about use of genetic tests will continue to necessitate pre-test genetic education and counseling. Ethical controversies related to duty to warn relatives, risks to the confidentiality of genetic information, and conflicts of interest related to commercial incentives for testing will expand and policies and even legislative protections will emerge.

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SEE ALSO: *Autonomy; Beneficence; Confidentiality; Eugenics; Family and Family Medicine; Genetic Counseling, Ethical Issues in; Genetic Discrimination; Genetic Testing and Screening; Professional-Patient Relationship*

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GENETIC DISCRIMINATION

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Genetic discrimination is the term commonly assigned to actions taken against or negative attitudes toward a person based on that person's possession of variations in the genome, or variations in the genome of his or her biological relatives. A component of stigmatization, genetic discrimination differentiates social treatment based on assumptions about the value of information suggested by a particular genetic configuration in predicting present and future health status (Condit, Parrott, and O'Grady). The details of one's genome are typically available through genetic tests (Burke). The nature of genetics is such that information derived from one person's genetic composition may implicate or be attributed to the biological siblings and/or descendants of that person. Genetic discrimination illustrates the danger of a misinterpretation—or oversimplification—of information suggested by some genes. Fear of genetic discrimination is often cited as a reason for avoidance of genetic testing services (Rothenberg and Terry).

Empirical evidence of genetic discrimination in contemporary society is somewhat slight (Nowlan). Early reports of genetic discrimination by adoption agencies have not been repeated (American Society of Human Genetics). Nevertheless, fears of genetic discrimination by employers and insurance companies continue to influence decisions regarding submission to genetic testing and participation in certain forms of genetic research. The result may negatively influence individuals' health (Rothenberg and Terry). Efforts to address genetic discrimination include legislation, industry self-restraint, and private action, each controversial for what it suggests about the ability to prevent forms of discrimination.

Genetic Information

Some variations in the genome have demonstrated value in predicting the health status of a person. Where a disease is monogenic, like Huntington's disease, its onset is foretold by the presence or absence of a mutation in a single gene (Guttmacher and Collins). The presence and location of single nucleotide polymorphisms (each commonly referred to as a "SNP," pronounced "snip"), may inform decisions in drug therapy by predicting an ability to metabolize a drug or a risk of toxicity (Guttmacher and Collins; Syvanen). In other instances, an enzyme or protein may yield similar information. Efforts to map the human genome with greater specificity, as well as efforts in pharmacogenomics, rely upon comparisons of the patterns of genetic variation in large numbers of people.

Media coverage and other efforts to relate complex concepts in genetics to a lay audience have revealed a tendency to oversimplify the relationship between one's genome and one's destiny. Specifically, the predictive value of genetic information is often overstated. Behavioral genetics, for example, remains in its infancy; few genetic mutations or polymorphisms are thought predictive of intelligence or cognitive ability. With the exception of monogenic diseases, which are relatively rare, the predictive relationship between the genome and disease is compromised by the relative lack of knowledge about the influence of environmental factors. The wide range of more common diseases is a function of interactions between the genome and such factors as diet, climate, and physical activity. Finally, a gap typically exists between knowledge of the discovery of a causal relationship attributable to a particular genetic variation and knowledge of a treatment for the condition at issue.

The result of this oversimplification is genetic determinism (Rothstein, 1999), alternatively termed "genetic reductionism" (Lee, Mountain, and Koenig) or "genetic essentialism" (Nelkin). The terms describe the phenomenon through which the importance of genetic factors is emphasized at the relative expense of environmental and social factors. Together, determinism and discrimination are elements of stigmatization (Condit, et al.). As explained by Celeste M. Condit, Roxanne L. Parrott, and Beth O'Grady in their 2000 article, discriminatory attitudes about genetics get much of their stigmatizing impact from excessively deterministic attitudes about genetics.

Insurance

Discrimination might manifest in several ways. The use of genetic information by insurers figures prominently in assessments of public attitudes and fears about genetic research and medicine. Theoretically, genetic tests obviate the need for the family medical history common in medical underwriting practices. Relatively few instances of discrimination by an insurance company have been reported, whether because discrimination is difficult to recognize or prove, or because the practice is not prevalent (Rothenberg and Terry).

Within the context of life insurance, the question is whether companies should either require genetic testing or have access to the results of genetic tests documented in medical records in deciding whether to underwrite a policy.

Insurance is characterized by a commercial transaction in which the company pays a benefit upon the death of the policyholder in exchange for a premium proportional to the mortality risk assumed by the insurance company (Cook; Nowlan). The fear is that a life insurer would decline to underwrite a policy for a person or family of persons who possess genetic variations that suggests early death. Insurance companies wish to avoid financial harm caused by adverse selection. Adverse selection results when persons who believe they are at a lower risk of illness or early death choose to purchase less insurance or leave the market, while persons who believe they are at higher risk purchase greater amounts of insurance. Ultimately, the money paid in premiums by persons of lower risk is no longer sufficient to cover the expense incurred by insuring persons of higher risk.

Medical underwriting is not as common in the context of medical or health insurance as compared to life insurance (Nowlan). Countries with a national health service extend resources to nearly all citizens without regard to health status; medical underwriting becomes relevant only in the small market for private health insurance. Nevertheless, fears are particularly pronounced in the United Kingdom, where—contrary to other countries, including the United States—life insurance is a requisite to the purchase of a home or other real estate (Cook).

The private health insurance market is much more prominent in the United States than in other countries, but is made available primarily through group plans subsidized by the employer in a voluntary arrangement (Rothstein, 2000). Medical underwriting is a greater possibility in the relatively small market of private individual policies, which can be very expensive.

Employment

Initial fears suggested that employers who had access to genetic information would refuse to hire persons with inherited characteristics that suggested greater use of health resources by either the employee or family members. Employers would try to control expenses on healthcare and perhaps absenteeism by pricing premiums in accordance with health status of the employee. Recent legislation in the United States prohibits employers from charging employees of higher risk a higher premium (*Health Insurance Portability and Accountability Act of 1996 (HIPAA)*). Cases of genetic discrimination primarily involve an employer's attempt to require genetic testing or access to the results of genetic tests already included as medical records as a prerequisite or condition of employment. While state and federal statutes regulate the employer's use of results from genetic testing, other statutes that impose upon the employer a duty to ensure worker safety partially restore access to such medical information (Rothstein).

Eugenics

The eugenics movement and other misguided attempts to translate science into government policy provide support for contemporary fears of stigmatization. Proponents of eugenics, a dominant scientific philosophy from the late nineteenth century through the mid-twentieth century, sought to improve the quality of the human race through social policy based on flawed theories about heritable characteristics (Galton and Galton). Agents of the government dissuaded persons perceived as mentally deficient or possessing an inherently criminal nature from reproducing, sometimes through laws mandating sterilization of groups of persons (Markel). Eugenic principles were consistent with social classification policies implemented in support of Nazi Germany, and contributed to the mass exterminations of persons.

With regard to the issue of *race,* many who cite concerns of genetic discrimination emphasize the dangers attendant to the racialization of disease or conflating social categories with genetic variations (Lee, et al.). Despite evidence that patterns of genetic variation are greater within racialized groups than between them, resistance to historical patterns of classifying persons by race is neither easy nor simple.

The association of disease with an identifiable human population is a dangerous and often unintended consequence of technology. In the later years of the twentieth century, efforts in the United States to implement policies to help persons afflicted with sickle-cell disease, a heritable disease, proved disastrous. A push for early diagnosis and treatment yielded several state laws that mandated screening African Americans for the disease. The years following the passage of these laws were marked by an increase in acts of discrimination by government, insurers, and employers against persons afflicted with the disease, as well as against persons who were merely carriers of the trait (Markel). The disease became associated with African-Americans in a way that illustrated the dangers and improvidence of conflating *race* with a particular genetic composition. The foregoing demonstrates the perils of premature and perhaps shortsighted policymaking.

At the beginning of the twenty-first century, there were reports of discord within the Jewish community regarding genetic testing (Schwartz, Rothenberg, Joseph, et al.). Following the identification of mutations in BRCA1 and BRCA2 that are associated with a higher risk of breast or ovarian cancer, many supported testing as critical to prevention and treatment of women who carry the mutation, while others discouraged participation based on fear of stigmatization (American College of Medical Genetics). This reaction against genetic testing was based in part on a controversial history of research on Tay-Sachs disease. The knowledge gap between the ability to predict a condition and the ability to treat it created uncertainty and the opportunity for misinterpretation of existing information.

Fear vs. Fact

Some have observed that the greatest danger with respect to genetic discrimination stems from unsubstantiated fears of discrimination. Several studies document the effect of anxiety about the possibility of genetic discrimination on participation in genetic testing or screening procedures (Geer, Ropka, Cohn, et al.). Exaggerating the size of the problem promotes genetic determinism and feeds fears that inhibit participation in research and therapy.

The literature identifying the factors motivating an individual to participate in tests that yield genetic information useful in determining susceptibility to disease or illness reveal several themes. The desire to help a relative is commonly cited as a motivating factor (Applebaum-Shapiro, Peters, O'Connell, et al.). The relative paucity of empirical data as to the prevalence of discrimination does not influence public attitudes regarding a willingness to participate or fears of discrimination or stigmatization (Hall and Rich).

An individual's wish to avoid negative treatment based on deterministic attitudes can manifest in several ways. An individual may refuse to be tested for a particular trait even if necessary for diagnostic purposes. Alternatively, the person may opt to test anonymously or to pay for the test without filing an insurance claim—even if the test is covered—in an attempt to keep such information from the employer or medical insurer. For example, in the first years after the significance of the BRCA1 and BRCA2 mutations was announced and a predictive test made available, there emerged anecdotes in which persons took steps to conceal information from becoming a part of their medical records (Schwartz, et al.).

Social Policy

The power of the fear of genetic discrimination to direct behavior is central to debates regarding the need for curbs on such discrimination through social policy (Greely). The degree of restriction is often related to the degree of harm threatening economic and other values. In the United Kingdom, the strong relationship between life insurance, home ownership, and the effect of perceptions of danger on the national economy prompted a national investigation (Cook). At least partially to avoid more restrictive measures, the British life insurance industry declared a voluntary, qualified moratorium on policies. Some have suggested that industry self-restraint is preferable to overreaching or imprecise legislation (Nowlan). Critics contend that industry self-restraint can not serve as a sufficient deterrent to actions that could otherwise yield economic benefit.

Legislation plays a relatively more prominent role in policies regulating genetic discrimination in the United States. Absent a single, uniform statute at the federal level, the laws of individual states address genetic discrimination. The actions of employers and other entities are also subject to provisions within federal statutes that regulate the workplace and the marketplace (Pagnattaro). Legislation passed in the 1990s regulates the dissemination of medical records that could contain the results of genetic tests (*HIPAA*). Such regulation reflects the heightened value afforded privacy and confidentiality, particularly within the United States, in an era of advanced medical and informational technology.

Several scholars have criticized the use of legislation prohibiting genetic discrimination as premature and unnecessary government interference in a free market system (Epstein). Citing flaws in the legislative approaches to discrimination in other contexts, these scholars question the fairness of protecting the concealment of information that may have legitimate value. Others emphasize the absence of evidence of genetic discrimination by health or life insurance companies (Nowlan). To enact legislation on the basis of a problem that exists primarily through anecdotes, critics argue, is to validate fears that are unsubstantiated (Nowlan).

Still others praise legislation prohibiting genetic discrimination as an effective means of allaying the fears of the public (Greely). Legislation is a vehicle for establishing a shared consensus on the values underlying the matter. The cost of "symbolic" legislation, however, remains a matter for debate (Hellman).

Conclusion

More important than the prohibition of the actual behavior is the need to allay the concerns of persons acting on the basis of such fears. This is the challenge facing those who would shape public policy on the use of genetic information. Deterministic attitudes underlie fears of discrimination, as well as the actual discriminating conduct. The ability to surmise from one person's genetic information details about another will influence traditional notions of autonomy and even self-determination. The idea that stigmatization might follow from participation in genetic testing or other research is an obstacle to the optimization of the benefits in health and resources that are increasingly available through advances in genetic technology.

PHYLLIS GRIFFIN EPPS

SEE ALSO: *Access to Healthcare; DNA Identification; Eugenics; Genetic Counseling, Ethical Issues in; Genetics and Human Self-Understanding; Human Dignity; Human Rights; Justice; Patients' Rights; Population Ethics; Race and Racism*

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GENETIC ENGINEERING, HUMAN

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The development of recombinant DNA techniques in the 1970s enabled scientists to create genetically engineered organisms. In 1975 molecular biologists and geneticists held a conference in Asilomar, California, to discuss the biosafety issues relating to the new technology as well as policies for regulation and oversight. In 1978 fertility specialists used in vitro fertilization (IVF) techniques to assist a British couple in conceiving Louise Brown, the world's first "test tube" baby. In the early 1980s researchers began using embryo-splitting technologies to produce desirable livestock clones for agriculture. By the end of the decade universities and biotechnology companies were manufacturing and patenting transgenic mice for use in drug testing and medical research.

During the course of those events many people expressed concern that these discoveries and innovations eventually would lead to human genetic engineering (HGE). In early discussions of HGE (circa 1965–1980) scientists, journalists, and scholars conjured up the familiar allegories of Mary Shelly's *Frankenstein* and Aldous Huxley's *Brave New World* to question the wisdom of pursuing the new technologies (Gaylin; Boone). Science fiction novels such as *Mutant 59* and *The Boys from Brazil* depicted the disastrous effects of genetic engineering experiments gone awry. The biotechnology critic Jeremy Rifkin (1983) warned of the Faustian bargain of genetic engineering and the dangers of meddling with nature. Theologians such as Paul Ramsey (1970) and bioethicists such as Leon Kass (1972) spoke about the dangers of "playing God" and disrupting family relationships. However, scientists, such as Joshua Lederberg (1966) and James Watson (1971) and philosophers such as Jonathan Glover (1984) and Joseph Fletcher (1965) embraced the possibilities of using HGE to advance scientific and social goals.

Two Key Distinctions and Four Basic Categories

While the public debate continued, scientists, clinicians, and scholars began to envision potential medical uses of HGE as they developed a framework for justifying the application of gene transfer technologies to human beings. Two key distinctions defined this framework: the somatic versus germline distinction and the therapy versus enhancement distinction (Walters; Anderson, 1985, 1989). Those distinctions implied four types of HGE:

Somatic gene therapy (SGT)
Somatic genetic enhancement (SGE)
Germline gene therapy (GLGT)
Germline genetic enhancement (GLGE)

Anderson (1989) and others argued that SGT could be justified on the grounds that it was morally similar to other types of medical treatments, such as pharmaceutical therapy and surgery. The goal of SGT is to transfer genes into human somatic cells to enable those cells to produce functional proteins in the appropriate quantities at the appropriate time. In 1990 the first SGT clinical trial involved an attempt to transfer normal adenosine deaminase (ADA) genes into patients with ADA deficiency, a disease of the imnune system caused by mutations that prevent the patient from producing sufficient quantities of ADA (Walters and Palmer). Because SGT targets somatic cells, it probably will not transmit genetic changes to future generations as a result of the fact that genetic inheritance in human beings occurs through germ cells. However, there is a slight chance that an SGT protocol will result in an accidental gene transfer to germ cells, and that chance increases as one performs the experiment earlier in human development. For example, SGT administered to a developing fetus entails a significant risk of accidental gene transfer to germ cells (Zanjani and Anderson).

The goal of GLGT, in contrast, is to transfer genes into human germ cells to prevent the development of a genetic disease in a child who has not yet been born. A GLGT protocol for ADA deficiency would attempt to transfer normal genes into the parents' gametes or a zygote so that the progeny would have the correct gene and therefore would not develop the disease. Because GLGT targets germ cells, it is likely to transmit genetic changes to future generations; therefore, it poses far greater risks than does SGT. According to many authors and organizations, SGT can be morally justified but GLGT cannot because it is too risky. Thus, many clinician-scientists who saw the promise of SGT attempted to draw a firm moral boundary between SGT and GLGT.

After the first SGT experiments began, many writers made the case for crossing the line between somatic therapy and germline therapy (Zimmerman; Berger and Gert; Munson and Davis). Those writers argued that some germline interventions are morally justifiable because they promote medical goals such as disease prevention and the relief of suffering. Most of the approximately 5,000 known genetic diseases cause disabilities, premature death, and suffering. Although couples often can use nongenetic methods such as prenatal genetic testing and preimplantation genetic testing to give birth to children without genetic diseases, for some diseases germline therapy offers the only hope of producing a healthy child who is genetically related to the couple. For example, if a male and a female are both homozygous for a recessive genetic disease such as cystic fibrosis (CF), the only way they can produce a healthy child is to use gene transfer techniques to create embryos with normal genes (Resnik and Langer).

Therapy versus Enhancement

Many of the writers, clinicians, and scientists who defended genetic therapy also had moral qualms about genetic enhancement. In genetic enhancement the goal of the intervention is not to treat or prevent a disease but to achieve another result, such as increased height, intelligence, disease resistance, or musical ability. Thus, according to many authors, there is a moral distinction between genetic therapy, which is morally acceptable, and genetic enhancement, which is morally unacceptable or questionable (Suzuki and Knudtson; Anderson, 1989; Berger and Gert). Until society achieves a moral consensus on genetic enhancement, HGE protocols should not attempt to enhance human beings genetically.

By making these two fundamental distinctions, SGT proponents were able to obtain public approval of and funding for SGT experiments and dispel some of the fears associated with HGE. Under this twofold classification, SGT experiments were ethical and should be conducted but others types of HGE experiments were unethical or at least ethically questionable and should not be conducted.

Whereas the somatic versus germline distinction has stood the test of time, the therapy versus enhancement distinction has been criticized (Juengst, 1997; Stock and Campbell; Parens; Resnik, 2000a). Some critics of the second distinction argue that many genetic *enhancements* would be morally acceptable. For example, some day it may be possible to transfer disease-resistance genes to human beings. If childhood immunizations, which enhance the human immune system in order to prevent disease, are morally acceptable, what is wrong with *genetic immunizations*? It also may be possible some day to manipulate genes that affect the aging process. If nongenetic means of prolonging life such as organ transplants are morally acceptable, what is wrong with genetic means of prolonging life?

Other critics question the cogency of the distinction because it is founded on the concepts of health and disease (Parens). Therapy is an intervention designed to treat or prevent disease; enhancement is an intervention that serves another purpose. However, how should one define health and disease? Several decades of reflection on these concepts have not solved the problem (Caplan). According to an influential approach, disease is an objective concept that is defined as a deviation from normal human functioning that causes suffering and places limitations on a person’ s range of opportunities (Boorse; Buchanan et al.).

For example, CF is a disease because patients with CF do not breath normally. As a result, they have a variety of symptoms, such as shortness of breath and a persistent cough, which cause suffering and interfere with physical activity. CF patients also usually die many years before the normal human life span of seventy-plus years. Thus, a genetic intervention designed to treat or prevent CF is therapeutic.

However, this approach has some well-known problems and limitations. First, social and cultural factors play an important role in delineating the normal range of values that define disease. For example, dyslexia is recognized as a disease in developed nations because it interferes with reading, but it does not cause that problem in a nonliterate society. An adult in the United States who is shorter than four feet tall is regarded as having a disease—dwarfism—but the same adult living in an African pygmy tribe would be regarded as normal. Modern psychiatrists recognize depression as a mental illness, but it was regarded as a lifestyle or bad mood a hundred years ago.

Second, social and political values affect the range of opportunities in society and therefore have an impact on diseases; societies choose who will be disabled (Buchanan et al. 2000). For example, if a person has an allergy to cigarette smoke, he or she would have a difficult time breathing in a society in which smoking is permitted in public places. That person may become disabled, and his or her condition therefore would be a disease. However, that person would not have those difficulties is a society that bans smoking in public. The allergy would not prevent that person from working or participating in public activities. He or she therefore would not be disabled and would not have a disease.

Third, health usually is not defined as merely the opposite of disease. According to an influential definition of health, “Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (World Health Organization [WHO]). This definition implies that some enhancements of human functioning are necessary to promote health because health is understood not only as the absence of disease but as an ideal state of functioning and flourishing. Thus, immunizations that enhance the immune system promote health, as do exercise regimens that enhance human musculature and endurance.

As a result of these and other problems with the therapy versus enhancement distinction, several authors have argued that it does not mark any absolute moral or metaphysical boundaries. One cannot equate *therapy* with *morally acceptable* or *morally required,* and one cannot equate *enhancement* with *morally unacceptable* or *morally forbidden.* To determine the moral justifiability of a genetic intervention in a particular case, one must assess that intervention in light of the relevant facts as well as moral values and principles such as autonomy, beneficence, and justice (Resnik and Langer). Some writers who criticize the distinction nevertheless maintain that it may be useful in setting an agenda for policy discussions or for raising moral warning flags (Buchanan et al.).

Inheritable Genetic Modifications

In the early debates about germline interventions most writers viewed GLGT and GLGE as methods for transferring genes to human germs cells such as sperm, ova, and zygotes or to human germ tissues such as the testes and ovaries. A human germline intervention would be similar to a genetic engineering experiment in a mammal in that it would attempt to transfer a gene into the DNA in the chromosomes in the cell nucleus. Writers on both sides of the GLGT debate agreed that random gene insertion would be an extremely risky procedure and that targeted gene replacement (TGR) would pose the fewest risks to progeny (Resnik, Steinkraus, and Langer).

Several important scientific and technical developments in the 1990s challenged this way of thinking about genetic interventions in the germline. In 1997 the experiment that produced Dolly, the world's first cloned sheep, demonstrated that nuclear transfer (NT) techniques could be applied to human beings (Pence). In this procedure one removes the nucleus from a zygote and transfers a nucleus from another egg or a somatic cell to the enucleated egg. The resulting embryo has a donor nucleus combined with the cytoplasm of the recipient. An NT procedure, like a GLGT procedure, produces inheritable genetic changes. However, an NT procedure does not attempt to modify human chromosomes. Since the early 1990s scientists and scholars around the world have had a vigorous debate about the ethical and social issues of human cloning (Kristol and Cohen). Several European countries, including Germany and France, have outlawed all human cloning. At the time of this writing the United States was considering a ban on human cloning, although no bill has been signed into law.

While the world was debating the ethics of NT, researchers conducted a more modest form of genetic manipulation in human beings: ooplasm transfer (OT). OT already has resulted in over thirty live births (Barritt et al.). In OT one infuses ooplasm (the cytoplasm from an egg) into a zygote. The resulting embryo has its original nucleus and a modified ooplasm containing ooplasm from the donor egg. OT also produces inheritable genetic changes because it modifies DNA that resides in the mitochondria: mitochondrial DNA (mtDNA). Because the mitochondria facilitate many important metabolic processes in cells, mtDNA plays an important role in cellular metabolism. Some metabolic disorders are caused by mutations in mtDNA. Less than 1 percent of human DNA consists of mtDNA; the majority of human DNA, nuclear DNA (nDNA), resides in the nucleus.

Although OT experiments and NT experiments do not appear to be as risky as experiments that manipulate human chromosomes, they are not risk-free because they can result in a mismatch between nDNA and mtDNA known as hetereoplasmy, which can affect the expression of both nDNA and mtDNA (Resnik and Langer; Templeton).

Artificial chromosomes pose an additional challenge to the earlier paradigm because they would not modify the chromosomes but would carry genes on a separate structure that would be segregated from the chromosomes (Stock and Campbell). One reason for developing artificial chromosomes is to avoid tampering with existing chromosomes. However, because an artificial chromosome could carry dozens of genes, it would transmit genetic changes to future generations.

As these developments unfolded, scholars discussed ethical and policy issues related to NT, OT, and artificial chromosomes (McGee; Bonnickson; Pence; Robertson, 1998; Stock and Campbell; Parens and Juengst; Davis). Some writers suggested that it would be useful to develop a typology for different interventions in the human germline to allow a distinction between various techniques, procedures, and methods (Richter and Baccheta; Resnik and Langer). For example, some techniques, such as TGR, attempt to modify the nDNA in human chromosomes. Other procedures, such as OT, attempt to change the composition of mtDNA. One could classify these procedures according to the degree of risk they entail, with OT being *low-risk* and TGR being *high-risk* (Resnik and Langer).

In light of the scientific, technical, and philosophical developments that occurred after the early discussions of germline interventions, in 2001 a working group convened by the American Association for the Advancement of Science proposed that people use the term *inheritable genetic modification* (IGM) instead of GLGT or GLGE because it provides a more accurate description of the techniques and methods that have been the subject of so much debate. According to the working group, IGM refers to "the technologies, techniques, and interventions that are capable of modifying the set of genes that a subject has available to transmit to his or her offspring" (Frankel and Chapman, p. 12). Under that definition, TGR, OT, NT, and the use of artificial chromosomes all would be classified as types of IGM. IGM could include methods that are used to treat or prevent diseases as well as methods intended to enhance human traits.

Arguments for and against IGM

There is not sufficient space in this entry for an in-depth discussion of the arguments for and against applying IGM procedures to human beings, and so the entry will provide only a quick summary of those arguments (for further discussion, see Resnik, Steinkraus, and Langer; Walters and Palmer; President' s Commission; Holtug).

ARGUMENTS FOR IGM. The following arguments have been made in favor of IGM.

1. IGM can benefit patients by preventing genetic diseases as well as the disability, pain, and suffering associated with those diseases (Zimmerman; Berger and Gert; Munson and Davis). IGM also can benefit patients who will enjoy the effects of enhancements of health, longevity, intelligence, and so on (Stock and Campbell; Glover; Silver).
2. IGM can benefit parents by enabling them to have healthy children who are genetically related to the parents (Zimmerman; Robertson, 1994).
3. IGM can benefit society by reducing the social and economic burdens of genetic disease. Society also can benefit from IGM if enhancements of human traits increase human knowledge, productivity, performance, aesthetic experience, and other social goals (Harris; Silver).
4. IGM can benefit the human gene pool by enabling society to promote "good" genes and weed out "bad" genes. For a critique of this argument, see Suzuki and Knudtson (1989).
5. Parents have a right to use IGM to prevent genetic diseases and promote the overall health and well-being of their children (Robertson, 1994).

ARGUMENTS AGAINST IGM. The following arguments have been made against IGM.

1. IGM can cause biological harms to patients that result from genetic defects caused by IGM procedures, such as underproduction or overproduction of important proteins, the production of a protein at the wrong time, and the production of nonfunctional proteins. Although some procedures, such as OT, are safer than other procedures, such as TGR, IGM entails many risks that scientists do not understand fully (Resnik and Langer). IGM also could cause psychological harms to patients, who may view themselves as products of their parents' desires or as mere commodities (Kass, 1985; Andrews).
2. IGM could cause harm to a mother who carries a genetically modified child. For example, IGM might carry an increased risk of preeclampsia or complications during labor and delivery.
3. IGM could harm future generations. Because some genetic defects may not manifest themselves until the second or third generation, it may be difficult to estimate the potential harm to future generations (Suzuki and Knudson).
4. IGM could harm the gene pool by reducing genetic diversity, which is important for the survival of the human species (Suzuki and Knudston). For a critique, see Resnik (2000b).
5. IGM could cause harms to society, such as the increased social and economic burden of caring for patients with genetic defects caused by IGM, increased discrimination and bias against racial and ethnic groups and people with disabilities, the breakdown of the traditional family and traditional methods of reproduction, the loss of respect for the value of human life as a result of treating children as commodities, and the loss of human diversity (Kass, 1985; Kitcher; Kimbrell; Parens and Asch; Andrews, 2000).
6. IGM could waste health-care resources that could be better spent elsewhere (Juengst, 1991).
7. IGM could violate the rights of children, including the right not to be harmed, the right to an open future, and the right not be the subject of an experiment (Kimbrell; Andrews, 2000; Davis; McGee; Kass, 1985; Resnik, Steinkraus, and Langer).
8. IGM subverts natural reproduction and the natural human form (Rifkin; Kass, 1985). See Resnik, Steinkraus, and Langer (1999) for a discussion of this argument.
9. IGM is a form of "playing God" because people do not have the wisdom or the authority to design themselves (Rifkin; Kimbrell; Ramsey). See Peters (1997) for a critique of this view.
10. IGM is the vain pursuit of human perfection (Kass, 1985). See McGee (1997) for a critique of this view.
11. IGM is nothing more than a modern version of the eugenics movement (Kevles). It will repeat all the errors of the Social Darwinists and the Nazis (Kass, 1985). See Buchanan et al. (2000) and Kitcher (1997) for a discussion of this view.
12. IGM will cause social injustice by increasing the gap between the genetic "haves" and the genetic "have-nots." See Buchanan et al. (2000) and Mehlman and Botkin (1998) for further discussion of this argument.

Policy History

Many governments, regulatory agencies, and international bodies have taken a dim view of IGM. In the United States the National Institutes of Health (NIH) formed the

Recombinant DNA Advisory Committee (RAC) in 1975 to regulate and oversee recombinant DNA experiments supported by NIH funds. The RAC has the authority to regulate NIH-sponsored human gene therapy experiments, including IGM experiments. The RAC will not consider proposals for germline alterations because those procedures do not involve attempts to treat individual patients but instead involve attempts to change the genes passed on to future generations (Recombinant DNA Advisory Committee 1995).

The U.S. Food and Drug Administration (FDA) has the authority to regulate human experiments supported by private funds in the United States. The FDA sets ethical standards for human experimentation related to the development of new drugs, biologics, and medical devices. If a company wants to obtain approval of and market an item governed by the FDA, that company must submit data to the FDA that conform to its ethical guidelines. The FDA has stated that it has the authority to regulate human gene therapy as well as human cloning (U.S. Food and Drug Administration 2002a, 2002b). Although the FDA has not published a statement about its authority to regulate IGM, it would appear to have the authority to regulate any IGM procedures that involve new biologics, which could include human embryos. However, an important loophole in the FDA's regulatory authority is the fact that the agency does not have the authority to regulate assisted reproduction per se; it can only regulate drugs, biologics, and medical devices used in assisted reproduction. There are no federal laws and few state laws pertaining to assisted reproduction (Annas). It is possible that fertility clinics could perform IGM procedures such as OT or even cloning without any government regulation or oversight unless new legislation is enacted (Frankel and Chapman).

Outside the United States the Council for the Organization of Medical Sciences (CIOMS), the World Health Organization (WHO), and the United Nations Educational, Scientific, and Cultural Organization (UNESCO) have stated that the safety and efficacy of germline therapy must be evaluated thoroughly before any procedure takes place (CIOMS, WHO, and UNESCO). The International Bioethics Committee (IBC), sponsored by UNESCO, issued a report on human gene therapy that opposed germline manipulation at present as well as all forms of genetic enhancement (International Bioethics Committee). A group of advisers to the European Commission issued a report in 1993 that concluded that germline gene therapy is not ethically acceptable at the present time (Group of Advisors). Several countries, including Denmark and Germany, have banned germline gene therapy (National Bioethics Advisory Committee).

In the United Kingdom the Human Fertilization and Embryology Authority (HFEA) regulates and oversees IVF and infertility clinics. In 1998 the Human Genetics Advisory Commission (HGAC) and HFEA released a consultation paper opposing germline manipulation as well as cloning for reproductive purposes (Human Genetics Advisory Commission/Human Fertilization and Embryology Authority).

Professional societies also have not embraced IGM. The Council for Responsible Genetics (CRG), a genetics watchdog group, has opposed human germline engineering since the 1990s (Council for Responsible Genetics). The American Medical Association (AMA) does not oppose germline gene therapy, but it holds that genetic interventions should be limited to SGT for the present time. The AMA endorses genetic therapy but opposes genetic enhancement (American Medical Association). The American Society for Reproduction Medicine (ASRM) has not taken an official position on IGM but has called for a moratorium on NT until ethical and safety issues can be resolved (American Society for Reproduction Medicine).

Conclusion

It is likely that societies will debate the ethical and legal aspects of IGM for many years. The field of biotechnology is advancing so rapidly that interventions that were merely conceivable at the end of the twentieth century are fast becoming a practical reality. It is to be hoped that people will develop effective and well-balanced laws and policies pertaining to IGM before the first genetically engineered baby is born.

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SEE ALSO: *Aging and the Aged: Anti-Aging Interventions; Enhancement Uses of Medical Technology; Genetics and Human Behavior; Health and Disease: History of the Concepts; Human Nature; Medicine, Philosophy of; Neuroethics; Transhumanism and Posthumanism*

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GENETICS AND ENVIRONMENT IN HUMAN HEALTH

• • •

All living things interact with multiple environments, both physical and biological. With regard to the flourishing of plants and animals, environmental features such as temperature, humidity, sunlight, and altitude often set boundaries crucial to development. Biological interactions between living things frequently are another major factor in growth and survival, for example, where parasites and predators cause illness or injure plants and animals. So it is with human health and flourishing as well, where environmental hazards and infectious diseases account for the vast majority of illnesses resulting in death.

The publication of Rachel Carson's *Silent Spring* (1962) and the subsequent emergence of a worldwide environmental movement has raised social awareness of the dangers to human health posed by industrial chemicals. Of the several million chemicals listed by the American Chemical Society, about 75,000 are used as pesticides, cosmetics, pharmaceuticals, food additives, or industrial agents. Most new chemicals must be tested for potential toxicity to humans and other living things before they can be approved for sale. In the United States, the Food and Drug Administration (FDA) requires extensive animal and clinical testing of new drugs, vaccines, and approved drugs proposed for new uses, as well as animal testing for food additives and cosmetics. Under various pesticide laws, including the Toxic Substances Control Act of 1976, the U.S. Environmental Protection Agency (EPA) also requires toxicity testing of new chemicals before they are brought to market. In addition, the Occupational Safety and Health Administration, Consumer Product Safety Commission, Department of Agriculture, Department of Transportation, and their state and local counterparts, each have additional responsibilities regarding the control of chemical agents.

These regulatory policies have done much to improve environmental quality and protect humans from industrial hazards. Nonetheless, individuals do not bear the burdens of environmental risk equally and vary remarkably in their responses to chemical exposures and pharmaceuticals. Such variation may reflect differences in sex, age, nutrition, lifestyle decisions to smoke cigarettes or drink alcoholic beverages, recreational exposures to similar chemicals, concurrent occupational exposures, and use of protective gear or medicines. In addition, variation in individual response may reflect inherited differences in a person's ability to metabolize specific chemicals, thus affecting individual risks of disease and other adverse effects.

The products of the Human Genome Project are allowing new investigations of these inherited differences that appear to make some individuals more vulnerable to specific environmental exposures or more susceptible to environmentally-induced diseases. The study of these inherited differences and their potential influence on individual response to environmental agents is the subject of the field of ecogenetics.

Ecogenetics: Individual Variation in Susceptibility to Environmental and Chemical Agents

Ecogenetics examines how genes and environmental factors interact with each other to affect human health and disease. Genes are sequences of DNA in humans' twenty-three pairs of chromosomes in each nucleated cell. Genes specify the sequence of proteins, which are the main effector molecules of cells, serving as enzymes (catalysts), structural molecules (like collagen), antibodies to fight off infections, and binders of oxygen or xenobiotics (including pharmaceuticals or chemicals in the environment). Environmental factors include social and familial environment, intrauterine environment, cigarette smoking, alcohol, other substance abuse, stress, and exposures to chemical, physical, and biological agents. Some environmental exposures such as ultraviolet light, X rays, and certain industrial chemicals cause damage to DNA (genetic mutations), which alter gene function as well as the structure and function of the protein specified by that gene. Although many such mutations appear to be of little consequence, some may lead to disease.

There are many examples of gene-environment interactions combining to affect human health. Body weight and obesity, for example, appear to be the result of food intake, energy expenditure, and various genetic determinants. For infectious diseases such as malaria and tuberculosis, genetic features appear to affect both individual susceptibility and the severity of the illness. Another example is response to pharmaceutical products, where some drugs with limited side effects (at usual doses in most individuals) may cause severe problems for persons with genes associated with decreased capacity to metabolize the drug. Without exposure to the drug, however, these genetic variants may be innocuous. For example, cytochrome P450 enzymes form a family of dozens of related enzymes with distinct and overlapping characteristics. One specific P450 enzyme, debrisoquine 4-hydroxylase, has been associated with marked variation in the metabolism of more than thirty drugs.

Biochemical and molecular techniques are being used to develop new genetic markers of host susceptibility to environmental and chemical agents. To cause poor health, many chemicals must be activated by enzymes to intermediates that attack DNA (as appears to be the case in many environmentally-induced cancers and birth defects). Other enzyme systems detoxify potentially toxic compounds, and variation in the genes that specify the sequence of enzymes involved in these biotransformation steps can result in people with similar exposures having very different disease risks.

An example of this type of gene-environment interaction affecting health outcomes is deficiency in the enzyme glutathione S-transferase (GST), which is believed to be an important predisposing factor in the development of some environmentally-induced cancers. About 45 percent of persons of European ancestry lack detectable activity of a particular form of GST. Several studies examining GST levels in lung tissue suggest that GST-deficient smokers are at higher risk of developing lung cancer, presumably because this enzyme detoxifies carcinogenic chemicals. Thus, GST-normal smokers are partially protected against lung cancer. In addition, high GST activity is an important protective factor against liver cancer resulting from exposure to aflatoxin (a toxin from fungi that grow on peanuts and corn).

An additional example of this type of ecogenetic phenomenon is provided by variation in the liver enzyme N-acetyl transferase (NAT), which has been associated with marked differences in blood levels of several drugs, including the anti-tuberculosis drug isoniazid (at standard doses). Roughly 50 percent of individuals of European or African ancestry have the slow acetylator phenotype (the form of the gene and enzyme with lower metabolic activity) associated with higher levels of still-active drug and a propensity to adverse effects. The same detoxification mechanism metabolizes several other chemicals, including the human bladder carcinogens beta-naphthylamine, benzidine, and 4-aminobiphenyl—all former mainstays of the dyestuff industry worldwide. People who are slow acetylators are at higher risk for bladder cancer, as expected from the hypothesis that they would be less able to detoxify these potent carcinogens by acetylation to inactive products. DNA probes are available to assay this kind of genetic variation in peripheral blood cells, rather than having to administer a test drug and measure metabolites in urine.

Gene-environment interactions also can be seen in many other kinds of diseases, not just cancers. For example, the common organophosphorus pesticide, parathion, is converted to its toxic intermediate, paraoxon, by the P450 system and then inactivated by a circulating plasma enzyme, paraoxonase. About half of individuals of European descent have low paraoxonase activity. For similar exposures, people with lower activity of this enzyme are likely to be at higher risk for neurologic toxicity and take longer to recover. High blood cholesterol levels are related both to diet and to inherited variation in several genes affecting the proteins that carry fat (lipoproteins) and their cell receptors. Cholesterol- and fat-reducing diets and drugs can reduce coronary heart disease deaths and heart attacks; however, responses to diet and drugs appear to differ among people with different genetic causes of high levels of fat components in the blood. Chronic anemias due to iron deficiency are a major health problem throughout the world. Although iron can be supplied inexpensively by fortification of flour, a small percentage of individuals carry genes (for types of anemia called thalassemias or for an iron metabolism disorder known as hemochromatosis) that cause these individuals to absorb iron excessively. These people might be injured by additional dietary intake of iron.

Integrating Genetic and Environmental Information in Clinical Research

The risks posed by exposure to chemical and environmental agents are related to the level of exposure, the intrinsic potency of the agent, and the susceptibility of the person exposed. In general, the highest exposures are in patients receiving potent drugs or radiation as medical treatments and in workers manufacturing or cleaning up chemicals in various operations. Therefore, it is logical and efficient to investigate potential risks to human health in patients and in workers with known exposures to specific agents. Studies of risks to the general population from contamination of groundwater or from air pollution, consumer products, or hazardous waste sites are far more difficult to conduct because the levels of exposure are typically much lower and thus the likelihood of identifying adverse effects is significantly reduced. In addition, although chemical exposures may cause immediate toxicity to the skin, eyes, lungs, heart, liver, nervous system, reproductive organs, or other target sites in the body, some effects may be unrecognized at first, including mutations in specific genes that may eventually lead to cancer or birth defects. Repeated exposures at relatively low doses also may have cumulative toxic effects that are difficult to identify. The challenge of establishing that impairment of brain function can result from lead exposure, for example, illustrates the difficulty of assessing the role of chronic, low-level environmental exposures in disease.

These considerations highlight the importance of ecogenetic research combining careful exposure-assessment studies with investigations of genetic influences on disease. Such a multidisciplinary approach is being explored in a coordinated manner through the Environmental Genome Project (EGP), a research initiative supported by the National Institute of Environmental Health Sciences, a component of the National Institutes of Health. The goals of the EGP are to: (1) identify some of the more common genetic differences between individuals that appear to affect response to environmental hazards; (2) conduct epidemiological studies investigating the role of gene-environment interactions in the development of common diseases like asthma, cancer, and heart disease; and (3) promote the use of information regarding gene-environment interactions in public health initiatives.

The EGP will develop in several stages. In the first phase of the project, experts will identify a set of approximately 500 genes that appear to play a role in the development of environmentally-induced diseases. These will include xenobiotic metabolism and detoxification genes, DNA repair genes, signal transduction genes, and genes involved in oxidative processes. Having identified a set of genes that appear to be involved in environmental response, the second phase of the project will catalogue common genetic differences in these genes—differences that may affect the functioning of the associated enzymes. Finally, in the third phase of the EGP, researchers will study the biological implications of these genetic differences using functional assays and population-based studies of gene-environment interactions. Organizers of the project expect that the first two phases of the EGP will be completed in late 2004. The third phase of the project will require significantly more time to complete, however, and will involve numerous epidemiological studies conducted over the next ten to twenty years.

Since many of the genes believed to play an important role in how humans respond to environmental hazards appear to affect health only in the presence of specific environmental exposures, deciphering the relationships that exist between genetic variants and individual response has the potential to improve public health significantly. Identifying those persons most at risk, for example, and encouraging them to avoid those environmental hazards to which they are most susceptible, may help prevent or delay disease onset in large segments of the population without pharmacological interventions. In addition, projects like the EGP might eventually lead to:

1. more accurate estimates of disease risks;
2. targeted disease-prevention strategies or medical-monitoring programs to detect disease earlier;

3. pharmaceutical products with fewer adverse effects; and
4. a better understanding of biological mechanisms of disease.

A great deal of work will need to be done to elucidate specific genetic risk profiles for environmentally-induced diseases as we move into the era of genetic medicine. In the meantime, both the population-wide approach that emphasizes environmental measures and the genetic approach that aims to identify individuals at increased risk are likely to be advocated. It is certainly prudent, for example, that everyone follow a diet that avoids excess fat, cholesterol, and salt. At the same time, genetic tests may soon be able to identify those persons at highest risk of developing coronary heart disease and high blood pressure. Taken together, these two strategies may provide a powerful approach to encouraging individuals to change their diets and lifestyles in ways that promote good health.

Ethical Issues in Ecogenetics

Although ecogenetics is still in its infancy as a scientific field, a number of important ethical considerations can be anticipated and should be addressed before genetic tests are used to screen individuals or populations for inherited susceptibilities to chemical or environmental agents. For example, long before the development of molecular genetics, J.B.S. Haldane suggested in *Heredity and Politics* (1938) that it might be reasonable to exclude persons who are susceptible to potter's bronchitis (a common problem among British potters at the time) from work in that occupation. Since workplace exclusion, stigmatization, and discrimination can result from knowledge of genetic risk factors for disease, studies of gene-environment interactions raise a number of ethical and social issues of great importance.

How one defines the extent of an individual's risk, for example, is an issue deserving of attention. Susceptibility to one kind of chemical may not predict susceptibility to chemicals with unrelated metabolism or structure. Thus, no one should be branded as "hypersusceptible" to chemical exposures on the basis of being identified as vulnerable to a specific environmental hazard or chemical. Since much confusion often surrounds the interpretation of genetic information, with laypersons frequently overstating the predictive value of a test, educational programs that aim to improve public understanding of ecogenetic tests will be critical to the long-term success of this new field.

Another issue that will be important to clarify for the general public is that, even after a genetic risk factor has been identified and is well characterized, the cause of disease in a specific individual often will be unclear. The well-recognized interaction of cigarette smoking with workplace asbestos exposure in causing lung cancer reveals some of the scientific uncertainties and ethical problems associated with assignments of disease causation in individual cases. The mere fact that a person has a gene that predisposes him or her to a specific disease—and then goes on to develop that disease—does not establish that the genetic susceptibility was the cause of the disease. Other genetic or environmental factors, for example, may have contributed substantially to the outcome.

Another ethical consideration is that since genetic differences sometimes occur with markedly different frequencies across racial or ethnic groups, targeted genetic testing programs could place disproportional burdens on members of some racial or ethnic groups. Related to this is the problem of group stigmatization, where social disadvantage results from the general association of a susceptibility gene with a particular racial or ethnic group.

Although tests for genetic predispositions to chemical and environmental agents could lead to targeted preventive approaches and improved assessments of individual risk, it is important that the future availability of such techniques does not diminish the commitment to eliminate hazardous environmental exposures. For example, the ability to identify genetic sensitivities to toxins in the workplace may inadvertently shift the focus of risk-management efforts away from the improvement of unhealthy environmental conditions if employers find it less costly to dismiss genetically sensitive workers than to eliminate workplace hazards.

In addition, the potential *geneticization* of environmental disease may inappropriately place unreasonable expectations on those persons with known genetic sensitivities. Individuals known to be particularly susceptible to the harmful effects of a particular chemical agent, for example, may face social pressures to remove themselves from those environments in which that chemical is found (e.g., to move to a different neighborhood or change jobs). Ironically, if we are successful in reducing environmental exposures to levels sufficient to protect most of the population, genetic differences between individuals will account for a larger proportion of the remaining risk among those exposed. This possibility could foster more deterministic attitudes regarding the significance of genetic information, for example, resulting in research funding being diverted from traditional preventive strategies for improving public health to approaches stressing genetic causes of disease.

Lastly, while genetic markers of susceptibility are being developed for use in healthcare settings, it is important to be mindful of the possibility that information about gene-environment interactions may be used in other contexts before those associations are well validated. In this regard, a recent Equal Employment Opportunity Commission (EEOC) claim brought forth against the Burlington Northern Santa Fe Railroad Company illustrates the potential for not-yet-validated associations to be used inappropriately. The EEOC dispute in question involved the railroad company testing workers for an alleged genetic predisposition to carpel tunnel syndrome. Although the extent to which the gene in question may be a predisposing factor in the development of carpel tunnel syndrome is largely unknown, that did not prevent the company from attempting to use this information in their efforts to avoid responsibility for workers' compensation claims. Whether other employers will adopt similar practices based on new ecogenetic information is a matter to watch carefully in the coming years.

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REVISED BY RICHARD R. SHARP

SEE ALSO: *Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Genetic Discrimination; Genetics and Human Self-Understanding; Genetic Testing and Screening; Health and Disease; Health Insurance*

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GENETICS AND HUMAN BEHAVIOR

• • •

I. Scientific and Research Issues
II. Philosophical and Ethical Issues

I. SCIENTIFIC AND RESEARCH ISSUES

Interest in the possible effects of genetic inheritance on human behavior is a perennial one, with its modern roots dating back the writings of Sir Francis Galton in the late nineteenth century. The issue is often framed as a debate over "nature versus nurture." After the "rediscovery" of the work of Gregor Mendel (1822–1884) in the twentieth century, the issue came to be couched in terms of genes versus environments and their respective influences on the organism, while more recently the talk has been of DNA and its role in relation to other causal factors. Themes revolving around genetics and environment are especially contentious when behavioral and mental traits (and disorders) are brought into the picture. This has been the case for views about the self and responsibility, as well as in society in general, where the specter of eugenics is quickly raised. According to the Nobel Laureate Thorsten Wiesel, "Perhaps most disturbing to our sense of being free individuals, capable to a large degree of shaping our character and our minds, is the idea that our behavior, mental abilities, and mental health can be determined or destroyed by a segment of DNA." The inflammatory appearance in 1994 of *The Bell Curve* by social scientists Richard Herrnstein and Charles Murray, which argued IQ is substantially inherited and may differ among races for genetic reasons, represents a major example of this social contentiousness. Another highly fractious example revolved around the University of Maryland's project on genetics and criminal behavior, and especially the September 1995 conference. The conference was strongly criticized by groups opposed to any inquiries into genetics and crime, and some of these groups' representatives invaded the conference and had to be escorted away by the authorities (Wasserman and Wachbroit).

The academic discipline that studies the effect of genetics on human behavior is termed *behavior genetics* or *behavioral genetics.* In addition to studying humans, this discipline has a long history of examining the behaviors of simpler organisms, including the round worm (*C. elegans*), the fruit fly, (*Drosophila*), and the common mouse (*Mus*), as well as dogs, primates, and many other organisms. The organized discipline began to coalesce from a wide variety of disciplines in the 1960s with the appearance of the first textbook in the subject, *Human Genetics* by John Fuller and Robert Thompson. The disciplines contributing to behavioral (and psychiatric) genetics included biology (including genetics), psychology, statistics, zoology, medicine, and psychiatry. Especially significant was the psychology of *individual differences,* which perhaps provided the main themes of the new subject (see psychiatric geneticist Irving Gottesman's 2003 article for a brief but excellent historical introduction and references).

In the realm of behavioral disorders and genetics, the years since 1970 have seen a shift from the view of psychiatric disorders being primarily environmental (due to poor parenting, for example) to the contemporary view that amalgamates both genetic and what are called *nonshared* environmental influences as major causal determinants of mental disorders. This has not been a shift without controversy, and it reflects broader shifts in psychosocial studies of the contributions of nature and nurture (Reiss and Neiderhiser). Further, though psychology has paid increasing attention to behavioral genetics, cultural anthropology and sociology have been strongly resistant to any genetic approaches (Rowe and Jacobson).

Major Methods of Studying Genetic Influences

Traditional genetics, of the type investigated by Mendel and his followers, was able to identify genes that had large effects and often displayed typical patterns, such as those involving dominant, recessive, or sex-linked traits. Genes that affect human behaviors and exhibit such patterns are well-known, including Huntington's disease (caused by an autosomal dominant mutation) and phenylketonuria, or PKU (a recessive mutation). Symptoms of Huntington's disease's include degeneration of the nervous system, usually beginning in middle age and resulting in death. In this devastating disease, there is usually a gradual loss of intellectual ability and emotional control. The genetic pattern is that of a condition caused by a rare, single, dominant gene. Since affected people have one copy of the dominant disease gene and one copy of a recessive gene (for a "normal" nervous system), half of their offspring develop the disease. Huntington's never skips a generation. Since the gene is dominant, the person who inherits it will manifest the disease (if he or she lives long enough). If one full sibling has the condition, there is a fifty-fifty chance that any other sibling will also get the disease.

In contrast to dominant conditions, recessive conditions show a very different pattern of occurrence. *Recessive* means that both copies of the gene must be of the same form (the same allele) in order to show the condition. Two parents, neither of whom shows a trait, can have a child affected by a recessive trait (this happens if both parents are carriers of one copy of the recessive allele—the child thus has two copies, one from each parent, and manifests the condition). Recessive traits can skip generations because parents and their offspring can carry one copy of the recessive gene and not display the associated trait. In the population there are many recessive genes that cause various abnormal conditions. Each particular recessive allele may be rare, but since there are many of them, their combined impact on a population can be substantial.

Among humans, a classic example of recessive inheritance is the condition of phenylketonuria (PKU). Individuals with PKU usually are severely mentally impaired. Most never learn to talk; many have seizures and display temper tantrums. PKU is a form of severe mental retardation that is both genetic and treatable. It is genetic in that it is caused by a recessive genetic allele. Without two copies of that particular allele, a person will not develop the set of symptoms, including mental impairment, that is characteristic of PKU. However, scientific knowledge has led to a treatment. It was discovered that the recessive PKU gene prevents the normal metabolism of a substance that is common in food, making many normal foods toxic to the individual with two PKU alleles. A special diet that is low in the offending substance can prevent or minimize the nervous system damage that leads to the profound intellectual disabilities of untreated PKU individuals.

The example of PKU demonstrates that inherited (genetic) conditions can be treated—that knowledge of specific causation can result in effective treatment. This is an extremely important point both ethically and philosophically, because it is often misunderstood and misinterpreted.

Well over one hundred different genes are known for which relatively rare recessive alleles cause conditions that include severe mental impairment among their symptoms. The rapidly developing knowledge of basic genetic chemistry, from molecular genetics to biotechnology and the Human Genome Project, which produced a mapping of some 30,000 human genes early in the twenty-first century on April 15, 2003, holds out the hope that many more of these devastating genetic conditions may soon be treatable. As part of the Human Genome Project, genes for Huntington's disease and PKU have been identified and sequenced, though as yet no new therapies have been developed for these disorders.

In spite of these clear scientific successes related to Mendelian genetic-pattern disorders, many human traits—including normal traits, as well as somatic, behavioral, and psychiatric disorders—have *not* exhibited clear Mendelian patterns of inheritance. For those traits, an extension of Mendel's work to quantitative traits that was first developed by Sir Ronald Fisher, has been used extensively. Beginning in the 1990s, an additional, more molecular, set of techniques was developed to examine possible influences of genetics on human behavior. These two broad approaches to studying the influences of nature and nurture in psychiatry are termed *quantitative* (or *epidemiological*) and *molecular*. A brief summary of the two approaches is presented here, including some examples of their results and their problems (an overview of them can be found in Neiderhiser and in Schaffner [2001], and a systematic analysis is presented in *Behavioral Genetics* by Plomin et al.).

QUANTITATIVE METHODS. Quantitative, or epidemiological, methods are utilized to distinguish genetic and environmental contributions to quantitative traits or features of an organism, as well as to assess correlations and interactions between genetic and environmental factors that account for differences between individuals. These methods do not examine individual genes, but report on proportions of differences in traits due to heredity or environment, or to their interactions, broadly conceived. The methods include family, twin, and adoption studies. Adoption studies examine genetically related individuals in different familial environments, and thus can *prima facie* disentangle contributions of nature and nurture. Twin studies compare identical and fraternal twins, both within the same familial environment and (in adoption studies) in different familial circumstances.

Twin studies have been used extensively in psychiatry to indicate whether a disorder is genetic or environmentally influenced, and to what extent. Twin studies make several assumptions to analyze gathered data, including that the familial environment is the same for twins raised together but different for twins raised apart, an assumption called the *equal environments assumption.* Though critics of genetic influence often question this assumption empirical studies have confirmed it (Kendler et al.). The example of schizophrenia may help make some twin results clearer. Employing what are termed *concordance studies* of twins, Gottesman and his associates have reported over many years that the risk of developing schizophrenia if a twin or sibling has been diagnosed with the condition is about 45 percent for monozygotic (MZ) twins, 17 percent for dizygotic (DZ) twins, and 9 percent for siblings (Gottesman and Erlenmeyer-Kimling). This concordance pattern supports what is called a non-Mendelian polygenic (many genes) quantitative trait etiology for schizophrenia with a major environmental effect (> 50%), i.e., more than half of the differences in liability to schizophrenia among individuals is due to environmental factors. Twin studies can also be used to estimate the heritability of a trait or a disorder, which for schizophrenia is about 80 percent. *Heritability* is a technical term, one that is often confusing even to experts, and one which only loosely points toward the existence of underlying genetic factors influencing a trait. Investigators note that "it does *not* describe the quantitative contribution of genes to … any … phenotype of interest; it describes the quantitative contribution of genes to *interindividual differences* in a phenotype studied in a particular population" (Benjamin et al., p. 334). If there are no interindividual differences in a trait, then the heritability of that trait is zero—leading to the paradoxical result that the heritability of a human having a brain is virtually zero. Heritability is also conditional on the environment in which the population is studied, and the heritability value can significantly change if the environment changes.

Keeping these caveats in mind, heritability estimates for many major psychiatric disorders appear to be in the 70 to 80 percent range, and personality studies indicate heritabilities of about 30 to 60 percent for traits such as emotional stability and extraversion, suggesting that these differences among humans are importantly genetically influenced. But even with a heritability of schizophrenia of about 80 percent, it is also wise to keep in mind that approximately 63 percent of all persons suffering from schizophrenia will have *neither first- nor second-degree* relatives diagnosed with schizophrenia, reinforcing the complex genetic-environmental patterns found in this disorder.

Twin studies were also the basis of a distinction between *shared* and *nonshared* environments. The meaning of environment in quantitative genetics is extremely broad, denoting everything that is not genetic (thus environment would include *in utero* effects). The shared environment comprises all the nongenetic factors that cause family members to be similar, and the nonshared environment is what makes family members different. Remarkably, quantitative genetics studies of normal personality factors, as well as of mental disorders, indicate that of all environmental factors, it is the *nonshared* ones that have the major effect. A meta-analysis of forty-three studies undertaken by psychologists Eric Turkheimer and Mary Waldron in 2000 indicated that though the nonshared environment is responsible for 50 percent of the total variation of behavioral outcomes, *identified and measured nonshared environmental factors* accounted for only 2 percent of the total variance. Turkheimer infers that these nonshared differences are nonsystematic and largely accidental, and thus have been, and will continue to be, very difficult to study (Turkheimer, 2000). This possibility had been considered in 1987 by Robert Plomin and Denise Daniels but dismissed as a "gloomy prospect"—though it looks more plausible.

Epidemiological investigations have also identified two important features of how genetic and environmental contributions work together. The first, genotype-environment *correlation* (GṡE), represents possible effects of an individual's genetics on the environment (e.g., via that individual's evoking different responses or selecting environments). Such effects were found for both normal and pathological traits in the large Nonshared Environmental Adolescent Development (NEAD) study, described in detail in the 2000 book *The Relationship Code,* written by David Reiss and colleagues. Secondly, different genotypes have different sensitivities to environments, collectively called genotype×environmental *interaction* (G×E). Differential sensitivity is important in many genetic disorders, including the neurodevelopmental models of schizophrenia genetics and in a recent study on the cycle of violence in maltreated children (discussed later).

MOLECULAR METHODS. Classical quantitative or epidemiological studies can indicate the genetic contributions to psychiatric disorders at the population level, but they do not identify any specific genes or how genes might contribute (patho)physiologically to behavioral outcomes. According to psychiatric geneticist Peter McGuffin and his colleagues, "quantitative approaches can no longer be seen as ends in themselves," and the field must move to the study of specific genes, assisted by the completed draft versions of the human genome sequence (McGuffin et al., p. 1232). In point of fact, a review of the recent literature indicates that most research in behavioral genetics, and especially in psychiatric genetics, has taken a "molecular turn."

It is widely acknowledged that most genes playing etiological and/or pathophysiological roles in human behaviors, as well as in psychiatric disorders, will *not* be single locus genes of large effect following Mendelian patterns of the Huntington's and PKU type discussed earlier. The neurogeneticist Steven Hyman notes that mental disorders will typically be heterogeneous and have multiple contributing genes, and likely have different sets of overlapping genes affecting them. Mental disorders will thus be what are called *complex traits,* technically defined as conforming to *non*-Mendelian inheritance patterns.

There are two general methods that are widely used by molecular behavioral and molecular psychiatric geneticists in their search for genes related to mental disorders: (1) linkage analysis, and (2) alleleic association. Linkage analysis is the traditional approach to gene identification, but it only works well when genes have reasonably large effects, which does not appear to be the case in normal human behavior or in psychiatry. Allelic association studies are more sensitive, but they require "candidate genes" to examine familial data. An influential 1996 paper by statisticians Neil Risch and Kethleen Merikangas urged this strategy.

Studies in schizophrenia are again illustrative of these approaches, as are the Alzheimer's disease genetic studies reviewed later. Though there was an erroneous 1988 report of an autosomal dominant gene for schizophrenia on chromosome 5 that is seen as a false positive, evidence has been accumulating for genes or gene regions of small effect related to schizophrenia on many chromosomes, including 1q, 2, 3p, 5q, 6p, 8p, 11q, 13q, 20p, and 22q (Harrison and

Owen). Replication difficulties with these results in different populations of schizophrenics and their families have been a recurring problem, however.

Environmental Research and the Envirome

It is clear from epidemiological studies that more than half the variance of typical behavioral traits, as well as half of the liability for psychiatric disorders (including schizophrenia), is environmental. This has fueled major searches for various environmental causes. In schizophrenia, this work has been reviewed by Ming Tsuang and his colleagues, who note that the major environmental risk factors in schizophrenia are due to the nonshared environment. These include problems in pregnancy (e.g., pre-eclampsia) and obstetric complications, urban birth, winter birth, and maternal communicational deviance. Thus far, *identified* predisposing environmental factors have small values in comparison with genetic risk factors. Using a term coined in 1995 by James C. Anthony, Tsuang et al. have proposed that the entire *envirome* needs to be searched for extragenetic causes of disorders, including schizophrenia. These factors are believed to affect susceptible genotypes, involving G×E interactions.

Though evidence for susceptibility genes for major mental disorders continues to accumulate, there has been no strongly replicated result that might be used in diagnosis or in early detection and prevention interventions. Of all the *psychiatric* disorders that have been investigated to date by genetic strategies, only Alzheimer's disease (AD) provides both a classical Mendelian etiological picture and complex trait patterns, and thus can function as a concrete prototype for psychiatric genetics and for research on genetic influences on human behavior in general. There are three Mendelian forms of early-onset AD, due to dominant mutations in genes APP, PS1, and PS2. The strongly replicated APOE4 locus associated with late-onset Alzheimer's disease (LOAD), in contrast, is a *susceptibility gene,* neither necessary nor sufficient for the disease. The APOE4 and APOE2/3 alleleic forms also interact with other genes and with the environment. APOE alleles 2 and 3 appear to protect individuals with the APP mutation (Roses). Other susceptibility genes for LOAD continue to be investigated. a possible locus on chromosome 12 has been identified, and one was reported in 2000 on chromosome 9 (Pericak-Vance et al.; Roses).

Cognitive Abilities and Intelligence

Though there are more data about the inheritance of intelligence than about any other complex behavioral characteristic of humans, the word *intelligence* is viewed even by the proponents of IQ testing as misleading because it has too many different meanings. IQ researchers seem to prefer to use the expression "general cognitive ability," represented by the letter *g* (Jensen; Plomin, DeFries, et al., 2001). The notion of substantial genetic influences on individual variation in *g* or "intelligence" remains controversial even after almost a century of investigation.

Most investigators in behavioral genetics view the level of intellectual functioning (abstract reasoning, ability to perform complex cognitive tasks, score on tests of general intelligence, IQ) as a strongly heritable trait. In 1963, psychologists Nikki Erlenmeyer-Kimling and Lissy Jarvik summarized the literature dealing with correlations between the measured intelligence of various relatives. After eliminating studies based on specialized samples or employing unusual tests or statistics, they reviewed eighty-one investigations. Included were data from eight countries on four continents spanning more than two generations and containing over 30,000 correlational pairings. The overview that emerged from that mass of data was unequivocal. Intelligence appeared to be a quantitative polygenic trait; that is, a trait influenced by many genes, as are such physical characteristics as height and weight.

The results did not suggest that environmental factors were unimportant, but that genetic variation was quite important. The less sensitive trait of height (or weight) can be used to illustrate this distinction. It is well known that an individual's height can be influenced by nutrition, and inadequate diets during development can result in reduced height. The average height of whole populations has changed along with changes in public health and nutrition. Yet at the same time, individual differences in height (or weight) among the members of a population are strongly influenced by heredity. In general, taller people tend to have taller children across the population as a whole, and the relative height of different people is strongly influenced by their genes. This also appears to be the case with intelligence. The Erlenmeyer-Kimling and Jarvik survey data suggest that about 70 percent of the variation among individuals in measured intelligence is due to genetic differences. The remaining 30 percent of the variation is due to unspecified (and still unknown) environmental effects.

Two decades later, in 1981, Thomas Bouchard and Matt McGue at the University of Minnesota also compiled a summary of the world literature on intelligence correlations between relatives. They summarized 111 studies, 59 of which had been reported during the seventeen years since the Erlenmeyer-Kimling and Jarvik review. Bouchard and McGue summarized 526 familial correlations from 113,942 pairings. The general picture remained the same, with roughly 70 percent of normal-range variation attributable to genetic differences and about 30 percent due to environmental effects.

However, researchers examining the behavioral genetics of cognitive ability estimate the heritability of *g* (or IQ) as substantially lower, about 30 to 35 percent. Statisticians Bernie Devlin, Michael Daniels, and Kathryn Roeder argue that the much of the difference between the high and low heritabilities can be accounted for by a substantial maternal environmental component. As in the height and weight example above, there is also a substantial general environmental component that increased IQ scores by about 30 points between 1950 and 2000. This is known as the Flynn effect (see Flynn).

Robert Plomin and colleagues have attempted to identify specific genes or gene regions, also known as quantitative trait loci (QTLs), that influence IQ. Though there has been one publication reporting an IQ-related gene (see Plomin, Hill, et al.), replication has not yet been forthcoming.

Much is known about the genetics of mental retardation and learning disabilities. The most common single causes of severe general learning disabilities are chromosomal anomalies (having too many or too few copies of one of the many genes that occur together on a chromosome). These genes may reside on additional chromosomes, for example trisomy 21 (an extra chromosome 21, or three instead of the normal two) is the cause of Down's syndrome, and the "fragile X" condition may by itself account for most, if not all, of the excess of males among people with severe learning disabilities (Plomin, DeFries, et al., 2001). A large number of rare single-gene mutations, many of them recessive, induce metabolic abnormalities that severely affect nervous system function and thus lead to mental retardation. Because the specific alleles involved are individually rare and recessive, such metabolic abnormalities can cause learning-disabled individuals to appear sporadically in otherwise unaffected families. The new field of molecular genetic technology holds a promise of future therapeutic regimens for many learning disabilities.

Personality Studies

Dimensions of personality tend to be familial (Benjamin et al.). Modern studies of twins and adoptees suggest that for adults, some major dimensions are influenced by differences in family environments, while some are not. For the dimension of extroversion, which encompasses such tendencies as sociability and impulsivity, genetic factors account for about 30 to 60 percent of the variation among adults, with about 50 percent of the variation being environmental in origin. But, surprisingly, none of the variation among adults appears to be related to environmental differences within families.

For neuroticism, which taps such traits as anxiousness (a characteristic state of anxiety), emotional instability, and anxious arousability (a tendency to react with anxiety to events), about 40 percent of the adult variation appears to be caused by genetic differences, and again none of the variation is from environmental differences that are shared by members of the same family. In contrast, social desirability, which measures a tendency to answer questions in socially approved ways and to want to appear accepted by and acceptable to society, does not show evidence of genetic causation. Essentially all of the measurable variation in social desirability appears to be environmental, with about 20 percent due to family environment.

Some authors, including Robert Plomin and colleagues, the authors of *Behavioral Genetics* (2001), suggest that because extroversion and neuroticism are general factors involved in many other personality scales or dimensions, most of the others also show moderate genetic variation. For example, a twin study involving eleven personality scales found genetic influence of various degrees for them all (Tellegen et al.). On average, across the eleven personality scales, 54 percent of the variation was attributable to genetic differences among the people, and 46 percent to environmental differences.

Tendencies toward affective (mood) disorders, including psychotic depression and bipolar disorder type I (manic depression), also are clearly influenced by genetics. A lack of familial co-occurrence has established the separateness of schizophrenia from the affective psychoses. Unipolar depression and bipolar affective disorder do co-occur, and there may be a genetically influenced major depressive syndrome distinct from manic depression. The affective disorders probably include a diversity of genetic conditions.

Other Traits

Although data are sparse for many traits, modern studies are revealing genetic involvement in many conditions of importance to society. Plomin and colleagues point out that, for males, the best single predictor of alcoholism is alcoholism in a first-degree biological relative. Alcoholism clearly runs in biological families. Severe alcoholism affects about 5 percent of males in the general population, but among male relatives of alcoholics the incidence is about 25 percent. The incidence remains about the same for adopted-away sons of male alcoholics. However, biological children of nonalcoholics are not at increased risk for alcoholism when raised by alcoholic adoptive parents.

Behavioral and psychiatric geneticists have studied genetic influence on antisocial behavior and adult criminality. Studies tend to report that shared environment is more important as a cause in juveniles and that genetics plays more of a role in adults (Lyons et al.). These studies have been extremely contentious, however (Wasserman and Wachbroit). Since the early 1990s several molecular studies of genetics and violence have also emerged, two of which are cited here. In 1993 Hans Brünner and his group reported on a Dutch family with a missing gene on the X chromosome which governed the monoamine oxidase A (MAOA) enzyme, an enzyme that metabolizes some key neurotransmitters (Brünner et al.). The Dutch families' males exhibited an unusual number of antisocial behaviors of varied sorts (assaults, rape, arson, etc.). Males, lacking a second X chromosome, were more vulnerable to the effects of this mutation. The mutation was subsequently determined to be extremely rare, and behavioral geneticists largely lost interest in the MAOA gene. In August 2002, however, a major study involving about 1000 New Zealand families found that a less severe MAOA gene mutation had a significant effect on males' display of antisocial behaviors, including their being convicted for violent offenses (Caspi et al.). But the antisocial behaviors only appeared in those subjects (in as much as 85% of them) who had experienced abuse during childhood, indicating an important G × E interaction effect of gene with environment. This carefully designed study is yet to be replicated, but it has received widespread attention.

Both twin and adoption studies that indicate obesity is highly heritable, probably about 70 percent (Grilo and Pogue-Geile). In addition, a large adoption study of obesity among adults found that family environment by itself had no apparent effect—in adulthood, the body mass index of the adoptees showed a strong relationship to that of their biological parents, but there was no relationship between weight classification of adoptive parents and the adoptees. The relation between biological parent and adoptee weight extended across the spectrum, from very thin to very obese. Once again, cumulative effects of the rearing home environment were not important determinants of individual differences among adults (Stunkard et al.).

Philosophical and Theoretical Perspectives

Biologists, psychologists, and philosophers have engaged in high-level theorizing about the effects of genes on traits in general and on human behavior in particular. Perhaps the most vigorous and ongoing discussion has been generated by a variety of papers and books that can be loosely characterized as a "developmentalist challenge" to the separability of genetic and environmental contributions to an organism's features (Schaffner, 1998). Over the years, the biologist Richard Lewontin's views have been particularly influential in this regard. Similar views critical of an overemphasis of genetic influence on traits have been articulated by several other scholars (see *Cycles of Contingency* [2001], by Susan Oyama, Paul Griffiths, and Russell Gray, which presents a number of contributions to "developmental systems theory" [DST]). Thus far, DST has largely been directed at critiquing DNA priority in molecular developmental and evolutionary claims, and at recommending more epigenetic-driven research. It is conceivable that as DST develops further, it will be applied more specifically to the relation of nature and nurture in a number of psychiatric disorders.

Integrated Approaches

Some recent articles suggest that research integrating quantitative and molecular approaches with neuroscientific strategies will be the most fruitful way to provide a framework for genetic and environmental effects on organisms. Reiss and Neiderhiser recommend an "integrated" approach. In their 1991 book *Schizophrenia Genesis*, Irving Gottesman and Dorothea Wolfgram envision the future promise of neuroscience programs to assist progress in schizophrenia. The increasingly important neurodevelopmental perspective approach to schizophrenia has been championed by Tsuang and colleagues and implemented in recent papers from the Pittsburgh group (Mirnics et al.). In addition, a series of ethical issues have arisen in neuroscience that mirror many of those first generated by behavioral genetics, including issues of reduction, determinism, and responsibility. A new term, *neuroethics,* has been coined to describe these issues (Marcus).

The completion of the draft mapping of the human genome has led to a realization that the next stage of inquiry into examining human behavioral traits, and both somatic and mental disorders, will need to be very complex, involving functional genomics, proteomics (the study of proteins and their effects) (Pandey and Mann), and enviromics (Anthony). These will be difficult and complex projects that will also need to attend carefully to developmental issues, since most human diseases, including psychiatric disorders, probably represent the culmination of "lifelong interactions between our genome and the environment" (Peltonen and McKusick, p. 1228). Animal models will be helpful here, as will new technologies using DNA genetic chips, also known as *microarrays.*

Conclusion

There are diverse methodological approaches to studying the effects of genetics on human behavior and in relation to psychiatric disorders. The working out of the partitioning of genetic and environmental causes and their interactions at multiple levels of aggregation in complex systems, as humans are, will require many research programs extending over many years, hopefully producing a number of useful interim results such as those discussed above. These results, however, will not silence the continuing debates over the roles that genes and environments play in the complex choreography of organism development and behaviors.

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SEE ALSO: *Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Genetic Engineering, Human; Genetics and Environment in Human Health; Genetics and Human Self-Understanding; Genetics and Racial Minorities; Genetics and the Law; Human Dignity; Human Nature; Privacy and Confidentiality in Research;* and other *Genetics and Human Behavior* subentries

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II. PHILOSOPHICAL AND ETHICAL ISSUES

Behavioral genetics has been a focus of intense controversy both within and outside the field almost from its inception. Much of the controversy within the field involves conceptual and methodological issues such as the question: Do twin studies yield the most scientifically reliable conclusions about the degree to which genes shape behavior? Rather than address those issues, this entry examines some of the social and ethical issues that may arise as a result of what researchers in behavioral genetics claim to know regarding the role of genes in shaping human behavior. Special attention is given to what may be referred to as the promise or the threat of eugenics, depending on one’s philosophic perspective, as that relates to developments in the field.

Historical Background

Eugenics is characterized by the devising of interventions aimed at improving the quality of the human genome. Those interventions can be either social behavioral or molecular. In *The Republic* Plato recommended using the power of the state to arrange marriages of the best with the best. A practical problem with that approach is that it is a very crude and haphazard way to improve the human genome. Philosophical and scientific thinking for roughly the next 2,000 years was locked into Platonic and Aristotelian premises, specifically the belief that the *nature* or *essence* of each living thing is eternal and immutable. However, the emergence of evolutionary theory from the work of Charles Darwin radically undermined that premise.

The *immutable* natures of all plants and animals in fact have been changing constantly (or perishing) in response to environmental forces over millions of years. In the nineteenth century emerging agricultural sciences showed was that such change need not be left to slow and chaotic natural forces; instead, the tools of science could be used to effect deliberately changes that suited various human needs. Darwin’s cousin Sir Francis Galton took the next logical step and suggested that deliberate reproductive control could be applied to human beings as well. In 1883 he started using the term *eugenics* to describe those efforts.

In the early part of the twentieth century the eugenics movement was endorsed by many prominent scientists, intellectuals, and political leaders (Kevles), including Charles Eliot, the president of Harvard University. Still, the tools available for eugenic purposes remained crude and ethically problematic. It is one thing, morally speaking, to create social practices that would encourage the marriage of the best with the best; it is quite another to use the coercive powers of the state to sterilize individuals who are judged unfit to reproduce “their kind.”

In the early twentieth century enthusiasm for eugenics might be said to have reached a peak in 1927 with the U.S.

Supreme Court decision *Buck v. Bell.* Oliver Wendell Holmes there upheld the constitutionality of state sterilization laws with the ringing words "Three generations of imbeciles is enough!" The rise of Nazism and the appropriation by the Nazis of the rhetoric of eugenics to justify their atrocities resulted in a tarnishing of the eugenics movement in the middle part of the century. To this day those unsavory connotations remain attached to the term *eugenics.*

The second half of the twentieth century saw the discovery of the DNA molecule by Francis Crick and James Watson, followed by the very rapid development of genetics as a science and the dissemination of genetic insights and techniques into other areas of science, such as behavioral genetics in psychology. That effort culminated in the mapping of the entire human genome, beginning in the 1990s to April 2003. One consequence of those scientific successes is that eugenics has regained a considerable degree of scientific and moral legitimacy.

A primary reason for the renewed legitimacy is the fact that molecular biology offers the promise of tools that can achieve with great precision whatever eugenic goals *we* might embrace. Furthermore, the emphasis by advocates of the *new eugenics* is on the voluntary use of those tools by individuals as opposed to their forcible imposition by the state. In addition, the emphasis of advocates for eugenics is not on improving the quality of *the* human genome. Instead, that emphasis is individually therapeutic, as in traditional medicine. The dominant goal is to improve the lifetime welfare of future possible children who otherwise would be faced with genetic deficiencies that would compromise the length and quality of their lives. However, there are critics of all forms of eugenics, whether new or old, whether aimed at eliminating debilitating medical conditions or enhancing desirable human traits such as intelligence (Rifkin; Kass).

Eugenics: Some Broad Moral and Political Issues

Who should be the *we* that would have the moral authority to determine eugenic goals? Should this be part of the authority and responsibility of the state, or should such decisions be left to autonomous individuals? If people chose to invest that authority in a liberal democratic state, would careful adherence to legitimate democratic processes be sufficient to guarantee the moral legitimacy of the eugenic policies that emerged from those processes? If conscientious adherence to such democratic processes were insufficient, what extrapolitical norms could justifiably be invoked for purposes of assessing those processes and policies critically? What would be the source of the moral authority of those norms?

Alternatively, if the coercive powers of the state were judged to be problematic, especially with regard to intimate and personal matters such as the genetic endowment of children, eugenic goals could be left to the choices of individuals and the private organizations that would provide the means necessary for achieving those goals, such as genetic testing and alternative means of reproduction. This would be what Philip Kitcher refers to critically as "laissez faire eugenics." If such eugenic outcomes were both privatized and uncoerced, would that guarantee the moral and political legitimacy of those outcomes? Troy Duster thinks not. Or would a state be correctly judged to be irresponsible for allowing any and all voluntary eugenic decisions to happen in an entirely unregulated fashion primarily because the best interests of future children would be at risk?

These questions are raised in the context of a liberal, pluralistic, secular, tolerant democratic state that seeks to maximize the scope of individual liberty as long as that liberty is not used to threaten the equally valuable rights and liberties of others or undermine important public interests. This type of state recognizes that there are many reasonable visions of what it means to live a good life and that consequently a state must refrain from using its coercive powers to impose a preferred vision of a good life on those who would not choose it for themselves (Rawls). It is a state that will not allow sectarian religious preferences to shape public policy, especially if a policy is needed to guide intimate life decisions. Thus, critical religious appeals to the language of "playing God" will have little legitimacy as rational support for public policies that might be aimed at outlawing "private eugenic efforts" by parents to shape the genetic endowment of their children (Peters; Evans).

Eugenics: Some Policy Issues

A state that did nothing to regulate any of the medical technologies that might be used to shape or choose the genetic endowment of future children might be regarded as irresponsible. After all, one version of the argument might go, how can a compassionate and responsible society allow children to be born with serious medical disorders, such as cystic fibrosis or Tay-Sachs disease, that would very adversely affect the length and quality of their lives when that society has the technology to prevent such harm? Alternatively, how can a compassionate and responsible society allow genetic and medical researchers to experiment with alterations in the genetic endowments of embryos if there is any risk of significant harm to the children who eventually would be born?

Both of these questions suggest a necessary and legitimate role for the state in regulating the development and use of technologies that have a eugenic purpose. However, that leaves unspecified the norms that justifiably could be invoked in a liberal pluralistic society for purposes of shaping both the content and the purpose of those policies. For example, should a compassionate and responsible society use tax monies to underwrite basic research aimed at providing the capacity to shape the genetic endowment of future children? This society already spends billions of public dollars each year through the National Institutes of Health to address an enormous range of human health problems, many of which have genetic roots. Alternatively, the genetic research that people imagine necessarily would involve the destruction of numerous embryos that were only a few days old. That would violate the deep moral convictions of many people in the society who are concerned about protecting all human life from the moment of conception. Are their concerns sufficient to take such public funding off the table?

If the destruction of embryos is a legitimate societal concern, less offensive policy options are available for achieving eugenic goals. There could be public funding for eugenic education. This could take many forms, but the general idea is that future parents would know what options were available to them for shaping naturally or technologically the genetic endowment of their children. A society could encourage widespread and complex genetic testing long before marriage by underwriting the cost of that testing so that individuals would be motivated to refrain from having children altogether, refrain from having children with partners who were genetic mismatches, or refrain from reproducing except through the use of an alternative reproductive technology.

Utopian Eugenics

The policy options cited above would come under the rubric of *utopian eugenics,* a phrase introduced by Philip Kitcher. That phrase is intended to suggest the desirability of a society pursuing a range of eugenic goals within the constraints of a liberal pluralistic political framework. Broad public genetic education and public support for access to genetic testing would increase the capacity of individuals to make autonomous eugenic choices regarding their own children in the light of their deepest values. Such public support also would demonstrate responsible but noncoercive regard for the well-being of future children who otherwise would be vulnerable to the profoundly harmful vagaries of the genetic lottery.

The word *harm* merits special emphasis in understanding the thrust of utopian eugenics. Kitcher and others are morally and politically comfortable with eugenic policies aimed at giving parents tools for preventing substantial genetic harm to their future children. However, many people (Parens) are less comfortable with eugenic interventions aimed at enhancing the genetic endowment of future children. This raises two questions, one moral and the other conceptual: Is there a significant moral difference between genetic interventions aimed at minimizing genetic harm and genetic interventions aimed at enhancing traits? Can a sharp conceptual distinction be drawn between what are called genetic harms and what are called genetic enhancements? These questions are discussed and analyzed thoroughly, along with their practical implications, by Allen Buchanan and coauthors.

Behavioral Genetics and Eugenics: Distinctive Moral Concerns

The questions raised above might be characterized as generic questions about eugenics. The examples used have all been about physical diseases with strong genetic links. However, the actual history of the eugenics movement has largely involved what today would be labeled behavioral genetics. That is, what those advocates wanted eliminated from the human gene pool were genes associated with being feeble-minded, lazy, alcoholic, violent, inclined to criminality, and so on. This raises a host of other moral and political and philosophic issues that are much more perplexing than the issues listed above.

If an individual has a gene variant that will result in affliction with cystic fibrosis or Huntington's disease or an early-onset form of Alzheimer's disease, such disease processes are seen to be accidental afflictions of that individual's body. Those diseases do not alter people's fundamental nature as persons, as rational moral agents. However, if an individual is feeble-minded (or a genius), alcoholic, or inclined to criminality as a result of his or her genetic endowment, this seems to be integral to his or her nature as a person, as a choice-making creature. It also raises the troubling question of whether individuals with such genetic endowments can be held accountable for the behaviors that seem to flow from those endowments. The argument, stated very crudely, would be that people do not hold individuals responsible for having cystic fibrosis; consequently, those individuals should not be held responsible for their criminal behavior if that behavior is just another product of their genetic endowment.

Other troubling social consequences may be associated with behavioral genetics. Genes seem to "travel" in clusters: Family resemblances are a common social phenomenon. Those resemblances also show up among members of ethnic and racial groups. None of these observations are intrinsically troubling. However, if a particular racial or ethnic group is perceived socially to have many members who are less intelligent, more violent, more prone to engage in criminal activity, and so on, and if those undesirable traits are believed to be genetically rooted, those social groups as a whole will be vulnerable to serious social stigmatization.

The practical argument is obvious: If members of *that group* cannot benefit from social investments in education, why waste resources on *them.* In this way the worst social prejudices can be given scientific and political legitimacy as well as insulation from moral criticism. That is, if individuals in the disfavored group are denied various social opportunities, those denials can be justified morally on the grounds that those individuals are genetically incapable of taking advantage of those opportunities. This issue has been the focus of a political firestorm that initially was generated by Arthur Jensen and then reignited by Charles Murray and Richard Herrnstein.

Behavioral Genetics: Key Elements of the Science

Moral judgments about personal responsibility for behavior or social discrimination must take into account relevant well-established scientific facts. Thus, it would be morally wrong to hold an individual who is completely in the grip of psychotic delusions responsible for his or her behavior in the same way one does with a person with normal rational capacities and moral sensibilities. At least two popular beliefs associated with genetics represent a gross distortion of the actual science and an equally gross distortion of related moral judgments.

The first belief is that people's fate is in their genes, that the genetic endowment of an individual is a *future diary* of that individual. In other words, people's behavior is at least very strongly determined by their genes. The second belief is that for any biological fact about people there is a *gene for* that biological fact. Thus, if scientists look hard enough, they eventually will find a *gene for* depression, a high IQ, aggression, criminality, being gay, and so on. A headline from *Time* magazine (Lemonick) is illustrative: "The Search for a Murder Gene."

What is referred to colloquially as *the* Huntington's gene would reinforce both of these popular misconceptions. That is, if an individual has inherited this gene, it is almost 100 percent certain that that person will have the disease (although there is considerable variation in the age at onset and the intensity of the disorder). That person is fated in a very strong sense. No personal behavior and no environmental variables can alter that fate. However, this picture of genetic determinism seems to have an extremely limited range of application. No human behavior of even minimal complexity seems to be genetically controlled in that simple a fashion (Ehrlich and Feldman; Beckwith and Alper; Ridley; Schaffner).

This entry does not address the philosophic issues and arguments associated with the free will–determinism debate or the debates in the philosophy of mind about whether mental events are nothing more than mechanistic brain states. However, a review of core scientific propositions that would be endorsed by a wide range of behavioral geneticists and a linking of those propositions with core scientific propositions in the neurocognitive sciences probably would provide a better basis for identifying and addressing related moral and political issues such as the question of the possibility of moral responsibility.

The Nature of Human Nature

Steven Pinker is the author of a provocative book titled *The Blank Slate: The Modern Denial of Human Nature.* There are three "myths" he intended to undermine in that book: (1) the belief that human beings are born as blank slates (from the philosopher John Locke) that are shaped completely by experience, (2) the belief in the ghost in the machine (from the philosopher Renée Descartes), which holds that the mind is a nonphysical entity that is connected mysteriously to people's physical bodies, and (3) the belief (from the philosopher Jean-Jacques Rousseau) that human beings are born as "noble savages," that they are born morally innocent and corrupted later by social institutions. Pinker contends that none of these beliefs can be supported by contemporary science.

Pinker argues that human beings have a nature at birth, that what is referred to as the mind is really the human brain, that the architecture of the brain is the product of eons of evolutionary development, that very complex interactions among many genes (as well as complex environmental factors) are ultimately responsible for that brain architecture, and that the detailed architecture of the brain varies from one individual to another as a result of the genetic variation and environmental influences that distinguish individuals. This genetic variation among individuals includes both cognitive and emotional differences.

Pinker is comfortable with the idea that from birth some individuals are more shy or more outgoing than others, more happy or more depressed, more inclined to be socially conformist or to engage in antisocial behavior, more inclined to be forgiving or to erupt in anger, and so on. For Pinker the same thing is true with respect to the display of intellectual abilities. He sees all these behavioral predispositions as ultimately being rooted in the genetic endowment of each individual; this is why he rejects the notion that humans at birth are noble savages or blank slates.

Some people consider the picture Pinker has painted excessively deterministic and mechanistic, both eviscerating any basis for moral responsibility for human behavior and reinforcing deep social prejudices against certain racial and ethnic groups. However, that conclusion is not warranted. What Pinker writes (p. 48) and what generally would be endorsed by behavioral geneticists is the following: "Most psychological traits are the product of many genes with small effects that are modulated by the presence of other genes, rather than the product of a single gene with a large effect that shows up come what may." He goes on to note that the effects of most genes are probabilistic and that the environment often modulates the effects of particular genes in complex ways. This is why identical twins do not live identical lives.

Behavioral Genetics and Eugenics: Contemporary Ethical Concerns

In 2002 in Great Britain the Nuffield Council on Bioethics addressed these issues and reached essentially the same conclusions. That is, the council sees no reason why research in behavioral genetics necessarily yields a fatalistic picture of human life in general or an undermining of the human capacity for moral judgment and moral responsibility. The genetic endowment of individuals establishes a range of behavioral options and predispositions related to personality, but the precise way in which those predispositions manifest themselves in a particular individual is a complex product of environmental chance and the deliberative capacities of that individual.

Those deliberative capacities can be influenced for better or worse by the formal and informal social learning opportunities offered in particular social contexts. For example, an individual may have a genetic endowment that predisposes him or her to react depressively to a range of disappointments and frustrations. However, an individual who is reflectively aware of those behavioral predispositions as a result of diligent parenting, sensitive friends, or personal reading may adopt a range of psychological and behavioral strategies that minimize the potentially damaging results of those depressive feelings. Alternatively, that reflective awareness might suggest taking medications aimed at altering the brain chemistry that sustains those feelings of depression. In either case what is illustrated is a responsible reaction to what might be described as innate features of one's personality. Kay Jamison's struggle with depression, as recounted in *An Unquiet Mind* (1995), is illustrative of these points.

If the picture sketched here is roughly correct and if the work of behavioral geneticists does not undermine people's capacity to be responsible moral agents, are any other moral issues raised by this research? The work of the Nuffield Council (2002) is helpful in responding to this question. The council points to two large concerns that potentially raise moral issues: medicalization and eugenics.

The term *medicalization* typically is used to express a specific criticism: that what once was regarded as a normal behavior or bodily state now is regarded as abnormal because there are medical interventions that give people control over that behavior or state. Some people are *just shy*. This is a fact about some individuals that is accepted routinely. However, if antidepressants such as Paxil can alleviate such behavioral dispositions and allow individuals to be more sociable (per social expectations), such individuals may no longer be accepted as shy persons. Instead, they may be *diagnosed* as shy and advised (expected) to seek appropriate medical help.

There is no simple response to this issue. One legitimate fear is that the range of social tolerance for personality types and traits will be narrowed excessively to the detriment of such individuals. That is, those individuals may be subjected to excessive social scrutiny and social pressure to conform to a narrow range of socially acceptable behavior. This seems contrary to the core values of a liberal society. However, in other cases medicalization of behavior that once was regarded as normal may be beneficial to both individual and social welfare. Attention deficit hyperactivity disorder (ADHD) illustrates this point. Children who are identified as having ADHD benefit greatly from drugs such as Ritalin. The practical moral problem is that the behavioral and diagnostic boundaries of this disorder are fuzzy and controversial, and this can lead to morally troubling problems of overdiagnosis and underdiagnosis.

The other concern raised by the Nuffield Council is the eugenics issue. Dean Hamer and coworkers announced in 1993 the discovery of "the gay gene." Hamer later retracted that claim, recognizing that the basis for the sexual orientation of individuals is much more complex than the workings of a single gene. However, his original claim helped establish in the public mind that there soon may be a genetic test for "being gay" that would allow potential parents in the future to use preimplantation genetic diagnosis (PGD) to weed out gay embryos. Similar beliefs suggest that in the future it will be possible to pick out or create through germline genetic engineering smarter or happier or nonviolent or nonalcoholic embryos. This refers back to the eugenics issues that were raised earlier in this entry.

Those issues may be addressed more thoughtfully by recalling a key scientific claim about behavioral genetics. These types of behavioral phenomena are only indirectly the product of very complex interactions among many genes as well as environmental factors, all of which are very poorly understood. Nobody knows which genes, in what way, to what degree, and at what point in development yield the neural capacities that establish a range of intellectual abilities. This is true whether one's concerns are with happiness, aggressiveness, schizophrenia, or addiction (Hamer; Beckwith and Alper). Furthermore, if society's legitimate social goals include shaping human behavior in various ways, there also are available as tools a very large range of social practices and medical interventions.

Behavioral Genetics and Eugenics: Some Ethical Guidelines

The Nuffield Council on Bioethics) has suggested several criteria for assessing from a moral point of view eugenic interventions aimed at improving behavioral outcomes: effectiveness, safety, reversibility, and choice.

If researchers discover genes associated with intelligence, it is likely that any one of those genes will have only very small and uncertain effects on the intellectual potential of an embryo. Consequently, embryonic genetic intervention to improve intelligence appears to be an ineffective approach. IQ scores as measured by standardized tests increased twenty to thirty points during the twentieth century. Clearly, that improvement did not result from radical genetic changes.

Safety must be a critical moral consideration, especially if the individuals whose behavior is to be affected do not have the capacity to give consent, as would be true for children and embryos. Giving Paxil to a moderately shy child may be morally objectionable when researchers are not certain of the long-term effects of that drug and the behavior to be altered is only moderately dysfunctional. Gene therapy would be problematic on this criterion for children or adults because there has been little success and some serious bad outcomes. The risks of gene therapy may be reasonable if individuals are faced with a life-threatening disorder, but that is not the case when the goal is behavioral alteration.

Reversibility is the third criterion the Nuffield Council emphasizes. It is difficult to imagine that anyone would want to be less intelligent, less happy, vulnerable to addiction, or more prone to violence. However, if researchers engage in behaviorally oriented genetic alterations, they may overshoot the mark: An individual could end up experiencing feelings of happiness in socially inappropriate situations.

The Nuffield Council notes that physicians are very reluctant to do genetic testing of children for medical disorders to which a child might be vulnerable as an adult and for which there is no medical intervention. The council recommends similar reticence if genetic tests related to what might be described as presymptomatic personality disorders were developed.

For example, a child might seem as happy as any other child in the neighborhood, but parental concerns about a family history of depression might motivate them to pursue genetic testing of that child for depression. That testing would yield no obvious good for the child but could put the child at risk for stigmatization or a maladaptive response from the parents. In addition, such nonsymptomatic nontherapeutic genetic testing represents a violation of the privacy rights and autonomy rights of that child. Also, assuming that the test identified a genetic pattern associated with depression in the child's family, everything known today would suggest that this represented no more than increased susceptibility for that disorder, not certainty that it would express itself or that its expression would be severe.

There are considerations of justice and the protection of fair equality of opportunity that are relevant to this discussion. Some writers (Silver) fear that differences in wealth will permit the rich to purchase a superior genetic endowment, especially with regard to valued behavioral traits, for their children, establishing permanently superior genetic castes. However, this is a plausible concern only extremely far into the future, if ever.

Still, there are relevant considerations of justice in the present that are related to improving the genetic endowment of future children (Fleck). Genetic testing in vitro of eight-cell embryos, or preimplantation genetic diagnosis, permits the selection of embryos that are free of certain serious genetic defects. However, this intervention costs about $40,000 per successful pregnancy. It seems reasonable to ask whether such interventions should be publicly funded as a matter of social justice and perhaps as a matter of genetic social responsibility as well.

Conclusions

Relative to scientific understanding and technical capacities in the field of behavioral genetics, fears of behavioral eugenics are exaggerated. People have very little capacity, using the tools of molecular biology, to alter with confidence the genetic endowments of future children.

No emerging knowledge in the fields of behavioral genetics and developmental biology or the neurosciences would justify concluding in a global fashion that human beings can no longer be held morally responsible for their behavior because their behavior has been determined in a mechanistic fashion by their genes (Wasserman).

However, as knowledge of the behavioral sciences becomes more refined and certain, society will be forced to make increasingly nuanced judgments about the capacity for responsible moral action by individuals whose genetic endowment includes significant susceptibility to aggression or depression or other socially or medically deviant behaviors. That is, society will have no right to advance global assertions of moral responsibility by all individuals in all circumstances. In some circumstances moral or legal responsibility for specific actions will be diminished or eviscerated as a result of biological facts beyond the control of the individual.

A liberal society should accord substantial respect for the procreative liberty of potential parents, including their right to determine the genetic endowments of their future children. However, a responsible liberal society will take seriously its obligations to protect those children from embryonic behavioral genetic experimentation that would threaten their future capacities for autonomy or the future interests generally valued by all human beings. No simple moral algorithm can indicate how such balances should be struck in making public policy.

RICHARD A. SHWEDER (1995)
REVISED BY LEONARD M. FLECK

SEE ALSO: *Autonomy; Freedom and Free Will; Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Genetic Engineering, Human; Genetics and Environment in Human Health; Genetics and Human Self-Understanding; Genetics and Racial Minorities; Genetics and the Law; Human Dignity; Human Nature; Privacy and Confidentiality in Research;* and other *Genetics and Human Behavior* subentries

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GENETICS AND HUMAN SELF-UNDERSTANDING

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Genetics on the simplest level is the name of a class of problems of organic chemistry: how to name and describe the structure and function of the DNA that forms the core structure within the nucleus of all living cells. The particles of the molecule are arranged in a structure called the double helix, and this doubled form traces the function of the molecule and the transmission of data between generations of organisms as each is copied for replication. Scientists have come to understand and believe that genes, the smallest unit within that molecular system, direct chemical reactions that create larger proteins that drive the processes necessary for cell growth and cell death. Much remains to be discovered about *how* this occurs, but *that* it occurs—that proteins direct biological processes, and that they in turn are directed by genetic or epigenetic activity—is largely a settled question.

Why then, does the idea of genetics excite such controversy? The problem lies in what one makes of this genetic narrative, and how the epistemic task of genetics implies fundamental ontological and moral assumptions. Hence, the meaning of *genetics* is only partially addressed as a problem of scientific definitions. It also queries some of the most profound of issues in philosophy (such as the meaning of identity), social theory (such as the meaning of justice), and theology (such as the balance between imaginative human actions and proper human duties).

Genetics as Science and as Ontology: A Simultaneous Debate in Bioethics

Bioethics as a field grew contemporaneously and concordantly with genetics; bioethics began with speculation about the meaning of gene research (Jonson). Nothing has concerned the field of bioethics, a field largely marked by concern for the unknowable and speculative future implications of activities in the biological sciences and medicine, more profoundly than genetics. Genetics is a metaphor and a medical hope. It is at once a final cure for diseases, a prophecy for illness and for abilities, and perhaps a harbinger of troubling injustice when used as definitive of moral status. Genetic knowledge in the late twentieth century became the central way to make meaning of the single most contentious and heavily freighted problem in human self understanding, that of origins and kinship and the way that birth circumstance was or was not determinate of fate. As philosophy and theology has much to say about kinship, fate, and family, bioethics has much to say about genetic knowledge of the same issues.

There is long history of moral advice directed toward genetic science, stressing the profound dangers attendant upon the kind of knowledge that genetics presents. Genetic knowledge represents a powerful and new understanding of how basic biological processes can be expected to unfold relative to older systems of human understanding as presented in religious or moral traditions, and genetic knowledge can be destabilizing to these systems. Since the relationship between present states of being and the unknown future had, up until the late nineteenth century, been in the purview of magic, philosophy, or religion, the unease surrounding genetic knowledge is understandable—fate, behavior, and character are powerful grounds of contention in any case. Yet by the first years of the twenty-first century, the relationship between the science of genetics and the critique of this science began to be shaped by its own dynamics as well. Genetic knowledge itself began to stand in for modern scientific knowledge, for scientism, and for instrumentality. Bioethicists found a belief in genetic causation vexing, perhaps reductionist; this critique became a stable feature of the literature of bioethics. It was a hallmark of the debate: Researchers would describe new discoveries in genetic science, and bioethicists would describe the attendant dangers. This can be illustrated well in the first (1995) edition of the *Encyclopedia of Bioethics,* in which researchers (Whitney, Anderson and Friedman) delineate, with clear enthusiasm, the emerging science of the mapping of the human genome—at that point just begun as a project, and philosophers, (Flew, Shweder, Juengst and Walters) raise the specter of Nazis, insurance company misuse of information, “playing God,” and making “designer babies.”

Nearly a decade has passed since that edition, five decades from the first discoveries that lead to modern DNA research (Watson, Crick, 1953, Franklin) and three decades from the Asilomar conference on recombinant genetic methodology, in which ethical issues took center stage in genetic research (Soll and Singer, 1973.).

Despite dramatic changes in the scientific knowledge base over the last several decades of the twentieth century, and despite an emerging praxis of medical and agricultural genetics, many of the identical concerns about hubris and post-human futures are persistently raised in bioethical discussions of genetics, and little of the original choreography of the debate has altered. Why this might be the case, and why bioethicists might find genetic knowledge to be fraught with a particular sort of meaning, is the subject of this article.

Knowing and Meaning to Know

Genetic knowing long has implied a moral sense, a way in which we could come to know, utterly, and with certainty, our human selves. Thus genetic testing becomes the first issue of concern, and remains one of the most troubling ones. Genetic testing is where the process of differentiation begins, and is the most direct and immediate way that genetic knowledge inserts into the particular and individual lives of most members of society. Genetic testing leads to application as soon as it leaves the realm of the laboratory, and its rationale is only evident in application. If humans are constituted in particular and tangible physical ways, and if one comes to understand particular facts as expressing the very truth of one's being (things like gender, or size, or impulse regulation), then knowing more precisely or more clearly who one is implies that one might know more precisely what to do. One might, through knowing who one is more exactly, know the scope of possible actions. This could produce knowledge about how to live morally, how to construct the artifice of social order with compassion, wisdom, and insight. Further, the self might well be altered as humans alter other species. If humans can alter our species in the way that we can alter other parts of the natural world once thought immutable, the question emerges: how can we do so in a just and thoughtful manner?

One can argue at this juncture that it has always been the case that all science involves this sort of venture of self generation, and many have noted that genetic knowledge is a matter of more facts amassed, as opposed to a greater interpretive power (Jonson). In this argument, genetic knowledge is not unlike the new understanding of gametes that took place in the middle of the 1800s, a form of understanding of human reproduction that implicated theology as well as science. The shift from Aristotelian notions of the beginning of life to theories first developed when lenses could be ground and microscopes constructed allowed a democracy of meanings to be attached to reproduction. Large shifts in understanding occurred throughout the seventeenth, eighteenth, and nineteenth centuries. Darwinian explanations marked ontological revolutions as well as epistemic ones, disrupting and destabilizing fixed philosophical, social, and theological ways of understanding nature and moral location.

Maynard Olson argues that the understanding and interpretation of the double helix is another such leap in self understanding, and a prelude to even more potentially destabilizing—or potentially liberating—ways of organizing human societies. If humans' sense of ourselves as both free and freely choosing rests on a detachment from our bodily selves, it will be likely come to be seen as mistaken. We are, in this genomic age, as much shaped by this understanding of ourselves as genetically capacitated as we are by the understanding of ourselves as having souls and psyches.

Assembling Knowledge

Genetics suggests a set of ideas about the nature, goal, and purpose of human life. It suggests, then, a definition of the self relative to the human location in the phenomenological universe. Like all science, genetic science suggests a method—not only a set of facts, but a way of ordering, framing, and using the facts. Genetics—with the goal of understanding a large and complex phenomena, organism, or mechanism—seems to demand understanding, defining, and naming all the parts of the thing, knowing the smallest discreet part of the whole, and knowing how the activities of each part connect. Hence, the task is to define the parts list and the function of each part, as a way of describing the activities of the phenomena. What genetic science threatens are not only the ideal forms, but the relationships and activities of phenomena in the actual, moving, and existing world.

The search for atoms and wave particles in physics parallels the search for genes and chromosomes in biology. Genetics functions on the basic idea that pieces of the whole need to be fully understood, and that a reconstruction of both the structure and functional pathways of each event within the whole is critical to the organizing principle itself: Parts determine the whole. Further, like all knowledge, the fulcrum of genetics lies against the notion that naming and defining creates being and allows for possession: Names determine relationships. To name a thing is to define its identity, and hence to identify it as a thing that can be owned, exchanged, used, bought, and sold.

Finally, like all knowledge, genetics is also about power and control (of the unknowable future, of the unknowable body, and of the unknowable other). Genetics understands itself by disassembly, through the knowing and naming activity, done primarily by mapping in the lab and testing in the clinic. It is a critical Hellenistic notion that making is knowing and in the creation of a "working parts list" and a "manual," one can know the essence of the thing (Peters, 2002). The idea that having a parts list then assumes assembly is both what is intriguing and troubling about the meaning of genetics (Fleishacker). At the beginning of the twenty-first century, the hopes for the next logical stage—reassembly—were merely theoretical, yet the prospect of manufacture seems inevitable and troubling to many critics.

The result of such reassembly—a commodity without human connection, named as a clone or as a designer baby—haunts the field, and this specter transforms the debates about genetic testing into something far larger. It becomes a debate in which knowing *which one am I?* becomes a kind of knowing *who could I be?* In this scenario, if one creates an object rather than a human person, one could have an unjust power over the production. Hence, genetic knowledge, testing, and even basic research stands in for the clinical results of the research at its farthest reach. Meaning and mythos overcome actual science, as ethicists and society look at the next stage. The sense of the power behind the discourse has driven both the enthusiasts of genetic science and the catastrophists.

The concerns about the meaning of genetic knowledge center around five topical areas: issues of identity; issues of relationships and kinship; issues of health/illness, ability/disability; and issues of justice. Identity is at the core of reflections on human meaning. Of all the answers to this question of identity, it is perhaps the emerging research and applications of genetic information that offer a definitive response. After the human genome has been fully charted, it will be possible to answer the identity question with a set of mathematical coordinates, an identity bar code that would be distinctly individual. Genetics is, among many other things, a way to name and to describe the processes that make one distinctive and particular. An understanding of how DNA shapes the self unfolds within older contextual ideas about identity. In the words of many that describe the genetic mapping projects, knowing and naming can help us “crack the code of Life,” or “tell us who we are and why we behave the way we do,” or “explain our traits.” The genetic explanation—not the reductionist causality of one gene making one behavior—allows an understanding that genes, proteins, and the environment complexly and intricately signal one another and hence “write” the narrative of human action. If genes and proteins and signals allow for differing levels of biological products in our bodies, and if we react with pleasure, anxiety, or disease to these products, then the horizon of possibilities against which all action is taken is in part suggested by the limits of our creaturely, molecular selves.

The idea that inheritable characteristics determine family ties is an old notion, but the idea that membership in a class of people is similarly determined is an idea that gained ground only in the eighteenth century, when colonial expansion raised the problem of inclusion of others into categories of science. Membership, and hence moral status and social privilege, became linked not to narratives of place, dress, or speech, but rather to something more tangible: the phenotype of persons. This physicality of how one knew what was valid, the linking of truth with the observation of physical facticity, transformed both the science and the polity of modernity.

Identity is paradoxical for Americans. It is a country premised on the idea that who you were does not matter; who your parents were was not the determinant factor in this new land. For many, the radical change in heritage would be the interruption of centuries of closed familial possibilities, and the possibilities of shifting identity that urban and industrial concentrations required. Yet the mutable, spontaneous and creative re-imagining of the self has collided with another narrative, that of a deeply pre-organized and highly structured internal code, a code which, for better or for worse, is passed between generations. Hence, Americans hold two things in tension—that we are free of all previous and unchosen commitments, and that we are increasingly to be understood as having our fate scripted into our very cells.

The Remembrance of History

Paradoxically, what grounds concerns about the speculative future of science is the past—what is called “the shadow of history” (Juengst). Given the emergence of bioethics directly after the trials of the Nazi doctors at Nuremberg, it is not surprising that there is hardly any account of modern genetics that does not begin with a detailed account of the classic tragic and paradigmatic slippery slope of bioethics—the passage of Germany’s most imminent scientists from physiologic metrics, to behavioral genetics, to eugenics, mass murder, and torture based on Aryan racial science. The death camps of the Shoah were particularly horrific in their painstaking record on the “science experiments” on the imprisoned Jewish, gypsy, and homosexual subjects, conducted under the rubric of exploring the question of human difference understood as racialized genetic difference.

In the United States, most intellectuals of the Progressive Era held the assumption that breeding was linked to human behavior in the straightforward way that it was linked to animal behavior. Few doubted Francis Galton’s extrapolation of Darwin’s understanding of hereditary traits, and the widespread acceptance of physical and mental characteristics as hereditary—and thus subject to social engineering—was a feature of arguments from sources as disparate as American socialists and industrialist Henry Ford (Kevles and Hood). The measuring and mapping of the human body was driven by a need to account for conditions of vast social difference, emerging class distinctions made newly apparent by the industrial revolution and colonialism, and to justify such social inequalities with seemingly natural and logical categories (Duster; Gilman). Marking the physical differences between individuals and groups implied a ranking of worth and of deviance; it further implied that danger could be logically eliminated from a world cleansed and purified.

Genetics understood as eugenics could be used as the justifying modern ideology both to encourage "good" (i.e., healthy, large, white, socially obedient, Aryan) births, and to eliminate "sickly" or "weak" (mentally or physically disabled) births and people. While it is clear that the ideas of inheritance, family resemblance, and hereditary have ancient textual and historical power, this marriage of science and tradition clearly amplified the ideology. Hence, fears of the widespread misuse of genetics and its linkage to a "science out of control" were largely formulated in the period 1845 to 1945. This period, and the eugenic sterilizations that peaked in the 1920s and 1930s in the American context (finally ending only in 1973 with *Valerie N. v. State of California*), delineates the concern: since genetics was code for the worst excesses of state discrimination, is not the past inevitable prologue?

Issues of Justice

The idea of difference implies hierarchy. Genetic testing is conducted to find and define the metric of difference from an agreed-upon norm. Critics of genetic testing raise two problems: first, that the idea of testing can be used unfairly as a basis for allocation of scarce goods, such as admission to competitive institutions or privileged social locations (jobs, professional schools, university); second, the very idea of a norm is an invalid one, and one that creates and reifies social hierarchies that destabilize democracy.

One new bioethical argument has been raised by disability advocates. They argue that genetic tests are an imperfect way of understanding humanity. Genetic testing, which notes allelic variation, can point to difference but is not sensitive to how the differences will express in any one human body, nor any one human circumstance or exposure. Further, genetic testing can alert one to differences but cannot alter the genome of the person tested. Used in the context of a prenatal test, each parent must decide if the pregnancy should proceed or if the different genetic code and its attendant disease will create a child with a disability so profound that such a child would be better off having never lived. Then, argue advocates for the disabled, if such a child's life is considered too burdensome, will such a judgment be fatally linked to disabled persons already born? Since at this point only the person and not the genetic disease can be eliminated, will this have implications for the moral status of the disabled community?

A second troubling aspect of a widening use of genetic knowledge lies at the other end of the possible curve of genetic endowment and the notion of the normal. If researchers could intervene to alter disease-causing genes, might science not go further to enhance traits labeled as desirable? Justice issues arise not only in the classic distributive sense—wealthy individuals and classes of individuals will have a unique access to the first uses of enhancements—but also in the deeper sense that genetic science might disrupt the social compact by introducing such different abilities.

The final issue of justice asks a different genre of question: Will increased genetic knowledge and use of genetic information and interpretation allow for healthcare that is more or less just? There are at least two possible responses. First, as noted above, enhancement or differential access to genetics could deepen differences, particularly if such changes are heritable, allowing a persistent benefit across multiple generations. But the very quality of genetics that allows for wide applicability may well mean that genetic methods could be both widely available and less beholden. Chronic conditions that could be cured would mean that certain types of drug therapies would not be needed. Justice, argue Alan Buchanan, Daniel Brock, and Norman Daniels (2000), becomes a matter of making just choices rather than adjudicating and adjusting the unfairness of a genetic lottery. Many critical aspects of the problem of justice are not different in meaning from other types of sophisticated, highly technological medical interventions such as organ transplants, chemotherapy, or implantable cardioversion devices, which allow for similarly vast differences between persons, countries, and healthcare system membership. Genetic medicine can seem to be paradoxically more unjust precisely because it has the potential to become far more widespread in application, and because of its heritable character.

Issues of Relationships and Kinship

Linked to the issue of identity are the issues of family, kinship, and citizenship. Increasingly, genetic identity is used as a way of describing these sorts of relationships. Families in earlier historical periods defined the boundaries of love and relationship. With each new genetic advance from in vitro fertilization to cloning, the question is raised about whether bonds of love and family would be severed, and in some extreme accounts, the question of whether both genders would be needed at all, as genetic materials that carry identity could be disaggregated and reassembled at will, without regard to family bonds.

Genetic science made significant progress in the years around the turn of the twenty-first century. The Human Genome Project, which provoked concern in many bioethicists, had been largely completed by 2003, and many more genetic tests are available and even commonplace in prediagnostic use. Further, the field of population genetics has emerged as a new force in medicine, anthropology, and popular culture via genealogy. Genes and genetic testing have become a feature not only of the clinical world, but of the world in which families search for roots to their past history. The search for roots has long been a part of establishing authenticity, and in the twentieth century this search for roots became a popular staple of fiction and culture, with genetic testing kits to find ancestry available through the Internet. For many groups, searches for genealogy were linked to the larger project in which cultures that had been destroyed or threatened were remembered and preserved. Such endeavors are not without scientific grounding: genetic science has noted for years that predictable mutation rates allow for dating when populations reached bottlenecks, encountered plagues, etc. The Y chromosome is slow to change, and single nucleotide polymorphisms (SNPs) can be noted and interpreted and used as markers in human populations. Since each male inherits one Y chromosome from his father, the Y SNP model haplotypes can be and have been used to trace genetic origins.

Specific populations that have attempted to confirm their narratives of origin with genetic testing include the Melungians and the Lemba.

The Melungians are a group of related families in loosely-linked communities in the mountains of Appalachia, called a *tri-racial isolate* by social scientists of the 1930s who wrote the first ethnographic studies to describe them. The Melungians, though, have embraced an origin story that they are really lost Turkish sailors; they have enlisted the resources of the University of Virginia's genetics department to further these claims, and are supported by the Turkish government.

The South African tribe of Bantus called the Lemba, like other tribes in Africa, has claimed ownership of a narrative of Jewish heritage. The Lemba observe a practice curiously distinct from surrounding Muslim or African native traditions: they observe Sabbath, they have menstrual rituals, and they have a particular priestly caste—the Bubas—that hold significantly more leadership. In the case of the Lemba, DNA mapping tests have been preformed, and the distinctive Cohen haplotype occurs in the same frequency as it does in Ashkenazi Jewish populations; this is very suggestive of a valid claim of Jewish origin.

The question raised by these cases involves the idea of identity: After the genetic tests are completed, will the facts of genetics trump the narratives of inclusion? Will the genetic information disrupt the story and weaken the claim of inclusion, or will it strengthen it?

Identity and Authenticity

This new use of genetic testing has raised a series of intriguing questions. If genetics is what makes one a "real" Native American or a "real" Jew, then is the DNA self the authentic self? Increasingly, DNA testing does establish criminal identity, parentage, and paternity. At stake in this discourse is how one defines and creates identity. In reflecting on this problem, the work of Charles Taylor is useful. Taylor notes that modernity threatens an authentic sense of identity in several ways.

For Taylor, the sense of self is diminished by "three malaises." First is an increasing individualism, the idea that the conscience and the consciousness of the self is shaped by our attachment to freedom understood as autonomy from hierarchy, order, and authority. The self is understood less as a person within a social structure but far more narrowly, and this may well "flatten and narrow our lives, making them poorer in meaning, and less concerned with others or society." Genetic knowledge, in this view, portends an ever greater threat in this direction—it is not just the individual person but her *genes* that seem to direct the will. Taylor's second malaise is the cluster of fears about the use of instrumental reason, technology, and efficiency as both explanatory and justifying. For Taylor, who understands the usefulness and libratory possibility of technology, the critique is still important; he argues that devices, technological solutions, and a cost-benefit strategy will also "flatten" the moral self. Taylor's final concern is that a focus on the value of an atomized self, in a technological world driven primarily by instrumental reason, produces a world with less active citizenship and a diminished moral sense. If one understands that the condition of the world is such that it stands in need of healing and repair, and that medical genetics might well play a critical role in understanding and addressing many disease states, then one can turn to Taylor: "We are embodied agents, living in dialogical conditions, inhabiting time in a specially human way, that is making sense of our lives as a story that connects the past from which we have come to our future projects. That means if we are to properly treat a human being, we have to respect this embodied, dialogical, temporal nature" (p. 106).

For Taylor, the struggle to find the meaning of the authentic self is never fully completed or realized. He is not thinking here primarily of the problem of phenome to genome, but his model allows reflection on a similar set of issues.

Genetic identity is vexed by a concern that science is leading toward a post-evolutionary state, understood by bioinformatics professor Pierre Baldi as the result of an evolution and relationality that could be entirely planned on our collective behalf. If genetic codes and hence knowledge of the gene-protein-phenotype relationship is finite, it all potentially can be known. "[S]ooner rather than later we will know all the letters and genes in the human genomes, all the protein families, as well as their structures and functions … in many ways we are reaching the end of our evolutionary odyssey … All the things that have been created and molded by evolution stand a chance of being seriously challenged" (Baldi, 2003). Baldi's thoughtful optimism may be premature, as others have argued for a more iterative ethics, one that worries step-by-step about the actual thing one can do in science, rather than the problems created by a speculative future scenario (Olsen). Yet meaning is made through one's sense of journey and direction as much as by one's attention to the drama. One understands and makes meaning of genetic knowledge through attention to the past, and to the future, as well as to the present.

Philosopher Bernard Williams considers the novel by Nigel Dennis called *Cards of Identity,* in which "an organization, called the 'Identity Club' engages in making people over, giving them a new past and a new character—a new identity." Williams notes that the key feature in the process was the choice of a new name. For Williams, what matters for identity is the relationship between the many, or the type, and the one, or the particular. Existence can be discontinuous, and identity is not to be confused with role. One's role or social identity is constructed, always shared: "[I]ndeed it is particularly important that it is shared and an insistence on such an identity, (say, Native American) is an insistence on the way that it is shared, by 'social processes'." Williams argues that such an identity, if embraced, is "an aid to living." Here, Williams notes that social identity is understood to be causative: "thought to explain or underlie a lot of the individual's activities, emotions, reactions and in general, life. And such an identity, particularly, if chosen is a search for a sort of a homecoming." Williams argues:

> It is also typical of such identities that they are not just analogous to the classifications of nature, but closely related to nature … they seek to affirm and *origin*.… it is typical in such cases that they have some sense that they are not just opting for one group among others, but … finding something that was there; or coming home—one kind of obedience to Nietzsche's splendid instruction "become what you are." In such a case, what I have come to lies outside my will, something that is given, although I must choose to take it up. (p. 10)

Identity is political, and it is, for Williams, linked to the project of the Enlightenment itself—a project of understanding and discovery of what was there all the time.

Life in the Imagined Future

Can one, with the human genome mapped, the "parts list" on ready file—not only for humans, but for an increasing range of our favorite or feared animals, plants, and viruses—go beyond the familiar critiques? What does genetic knowledge mean for us now, that we in fact have lived through the calamitous times so feared by critics in the 1990s? What does it mean to think genetically? Is it different than how a philosopher would think in 1955, 1925, 1825, or 1155? What part of this is knowing that human genes make a series of proteins that control pathways of more protein-protein chemical reactions, allowing this author to create and the reader to read these words and allowing them to be seen and stored by other proteins in the neurons? Does it become merely another metaphor, akin to, for example, the culturally ubiquitous metaphor of the body that is formed of clay by a Master Potter's hand? Or does, it, as was predicted in 1995, "make us rethink many of our moral concepts and theories."

In part, moral concepts and theories have been revised with the acquisition of genetic knowledge. Parents and physicians are willing to understand and act on behalf of an embryo on the basis of genetic information alone: they terminate, complete, or choose a particular pregnancy based on prenatal genetic diagnosis. Courts and police find completely credible the notion that samples of DNA at a crime scene can prove that a particular suspect was there and use this to arrest and convict one person, or to free others.

But remarkably, given the level of concern, moral concepts appear to be remarkably resilient. While it is true that new reproductive techniques did change the variety of ways that pregnancies could be begun, the years around the turn of the twenty-first century also saw significant increases in adoption, including interracial and international adoptions, and the evidence that genetic material mattered more than other familial bonds was conflicted. Some of the advanced reproductive technology stressed genetic ties, but others (as in the use of surrogate eggs from young women implanted in older women, or the use of sperm banks) stressed gestational or non-genetic bonds as increasingly important. The last half of the twentieth century was notable both for a deepening sense of ourselves as driven by genetic coding, and for a deepening sense of fundamentalist religious fervor, spirituality, and attention to alternative medicine—quite an unexpected paradox. Genetic rhetoric in the period just after the mapping of the human genome, rather than accentuating perceived racialized divisions, steadily and officially proclaimed our unity as a remarkably coherent human species with highly conserved genetic similarities to other organisms. It has became commonplace to understand that genetic codes matter a great deal, at the same time that it has become commonplace to add that the complexities of environment and epigenetic factors, chaos theory, and randomness also play significant roles.

Conclusion

History, even very recent history, can be held to up to the prognostic ability of bioethicists who reflect on the future and predict its course. How has bioethics as a field done, in this way, against the unfolding of the knowledge only speculated about in the 1990s? To be sure, few if any of the predicted catastrophic or euphoric scenarios have occurred in any empirical way.

Is it prudent to have concerns about the potential consequences of genetic knowledge? To be sure. It has been fears and not faith that have driven the thoughtful design of many of bioethical regulations. Fearsome events may well await us, but the trends have not been in that direction, as a review of the world since the 1990s teaches. To the contrary, the importance of families has not waned, nor have kindred and kind been neglected. Children, as families have chosen to have fewer children overall, remain highly valued, and the bond between generations seems entirely unaffected at least by genetic testing, although there has been increased vigilance in all matters genetic. A deeper sense of faith in the ethical and moral integrity of research and in the core duties of medical science may well be in order.

By 2003, there were new laws, and far more robust ones, that protect privacy and insurance misuse; there also existed national oversight bodies in most industrialized countries, and bodies at the international, national, state, and non-governmental organization (NGO) levels, to regulate or at least publicly examine genetic policies and techniques. Bioethics centers and ethics debate in general flourished at the beginning of the twenty-first century, despite new and pivotal research in genetics taking center stage in many science policy debates. The President of the United States, George W. Bush, made human embryonic stem cells the subject of his first public address, and the U.S. Congress debated the science and ethics of genetic policies, especially cloning and genetic modification. The ethical discourse about meaning and agency moved from the academic margins to the center of the debate. Decades after James Watson, Francis Crick, Rosalind Franklin, and Linus Pauling moved the chemistry that enabled the basic theory of genetics towards the modern intellectual project of genetic sequencing, and decades after computational and structural biology coalesced this sequence into a credible account of how human persons develop, few would claim a victory for an unreflective position in the debates about the influence of nature versus nurture.

The human genome, our *nature,* is clearly understood as responsive and interactive with the environment, adaptive yet constrained. Few can credibly deny the reality of the genetic-protein explanation of the physical world. It is, for now, the best account of the phenomenological terrain, and it is the text and tool that facilitates the exploration of the details and the variable of our human selves. Will we reach unbreachable ethical boundaries in this terrain? Will the "moral harm" that might exist become too dangerous to contemplate, and will the existence of moral harms outweigh moral duties to simply know and name as much about the world as we can? Are there horizons beyond which we cannot venture, and entities we ought not to know, mysteries that allow humanity to exist? Or have we a human duty to our human curiosity? Can one argue for a duty to heal and in the pursuit of the goal of healing, allow for all knowledge, and all pursuit, no matter where it might lead? Such worrisome questions remain, despite both increased regulatory efforts and a series of gravely sobering and stochastic human events. An article such as this can only hope to highlight competing moral appeals as they emerge in the literature of bioethics and in the literature of science—it cannot hope to solve the quandaries, and humility in prognostication about our genetic future, for good or for ill, would be a wise and prudent path. Genetic knowledge places us in a position of unprecedented choices—not yet about our final telos, but in a very real way, in a position to understand both the gravity and the temptations of the road we travel there.

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GENETICS AND RACIAL MINORITIES

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Advances in genetic research such as the completion of the Human Genome Project (HGP) have significant implications for the health of members of racial minority groups. Research on human genetic variation is anticipated to increase biomedical understanding of disease etiology and affect social and cultural meanings of race. In this entry the ethical implications of genetic research for the health of members of racial minorities are discussed. Racial minorities are defined as groups that historically have been identified by race and as a result have limited access to resources and opportunities. This entry discusses the implications of advances in human genetics for the understanding of race and ethnicity and the impact of racial categories on research into human genetic variation. It addresses the effect of these implications on the national priority to decrease health disparities among racial groups in the United States. Discussion topics include genetic determinism and reification of race, the protection of research participants and informed consent, and the distribution of benefits from human genetic research and its implication for justice in regard to the health and well-being of members of racial minorities.

Human Migration, Genetic Diversity, and Race

Since its genesis in the sixteenth century, the concept of *race* as a biological *kind* has been a focal point of debate (Boxill). Controversy over the use of the term has emerged in regard to the values that have been attached to groups identified by race and the characteristics that have been attributed to them. Throughout the twentieth century scholars consistently challenged the validity of biological differences between populations that were linked to race. Scientific research consistently has revealed that more genetic variation exists within than between populations (Lewontin). Despite this finding, race has become increasingly salient in understanding disparities in the health status of population groups and continues to be an important factor in both biomedical research and clinical medicine.

Central to arguments over race is a lack of agreement on its definition. In a manner that often is implicit, biomedical researchers and clinicians use a potpourri of surrogate concepts, including skin color, hair type, national origin, and citizenship, to identify race. This situation is complicated by the common practice of relying on self-reports, which often are based on factors that have little to do with biology. In addition, racial categories change over time and tend to be context-dependent, as is illustrated by the history of U.S. Census racial and ethnic categories (Lee et al.). Since the insertion of the term *race* into scientific discourse, the definition of race has been a moving target, and this has contributed to confusion about its meaning and implications for biomedical research and clinical care.

In 1996 the American Association of Physical Anthropologists issued a statement that included the following assertion: "Pure races, in the sense of genetically homogenous populations, do not exist in the human species today, nor is there any evidence that they have ever existed in the past." Although it acknowledges that differences between individuals exist, the statement emphasizes that those differences are the result of hereditary factors and the effects of natural and social environments. Genetic differences between populations result from the effect of the history of human migration and reproduction and consist of a gradient of varying frequencies of all inherited traits, including those that are environmentally malleable.

Critical to comprehending human genetic variation is an understanding of the meaning of population genetic structure, which is best understood as the pattern of genetic differences among genomes, the full sets of human genes found in the nucleus of each cell. These genes are arranged linearly on chromosomes and consist of strings of chemical units called nucleotides (Weiss). The genome interacts with the environment to produce phenotypes, or all observable traits of individual appearance and behavior. Patterns within the genome vary across a species, depending on the history of mating within that species. The patterns or genetic frequencies of human populations have been affected by mutation, migration, natural selection, and random genetic drift to varying extents. These forces have resulted in the genetic variation that exists among human populations. Genetic differences between global populations do not map neatly onto the racial categories that have emerged through sociohistorical processes. Instead, race, defined by discrete group boundaries, serves as a poor proxy for the continuum of human genetic variation.

Racial Categorization in Human Genetic Variation Research

The completion of the HGP has resulted in new and well-funded themes of scientific inquiry in medicine. A central goal of human genetic research is identifying the genetic and environmental causes of human disease. Recent advances such as high-throughput genomic sequencing technology have increased the efficiency of large-scale rapid genotyping and ushered in a new era of genetic epidemiological research. This research has focused on the identification of single-nucleotide polymorphisms (SNPs). As was discussed briefly above, the genome is specified by the four nucleotide "letters" A (adenine), C (cytosine), T (thymine), and G (guanine) that form patterns. SNP variation occurs when a single nucleotide, such as an A, replaces one of the other three nucleotide letters: C, G, or T. SNPs are believed to be associated with individual differences in susceptibility to disease; environmental insults such as bacteria, viruses, toxins, and chemicals; and drugs and other therapies.

The search for these genetic clues has led to efforts to map SNPs and use that information to identify the multiple genes associated with complex diseases such as cancer, diabetes, vascular disease, and some forms of mental illness. For most SNPs, all populations have all the possible genotypes for a SNP, but populations may differ in regard to the frequencies of individuals with each of the different genotypes.

Although the location of SNPs is believed to hold the key to identifying the genetic basis for the onset of disease and influencing responses to drug therapeutics, it has been posited that SNPs do not travel independently. Instead, SNPs are located in what has been identified as blocks of alleles that are inherited as units. The patterns of the SNP alleles in those blocks are called haplotypes. Studies show that most SNPs are in haplotype blocks that have been transmitted for many generations without recombination. Because each block has only a few common haplotypes, identifying haplotypes eliminates much of the tedious work of attempting to find single SNPs that are correlated meaningfully with disease. In effect, the task of locating frequently elusive needles in the enormous haystack of the human genome has been mitigated by the knowledge that these needles, or SNPs, tend to be located in groups. It is expected that the 10 million common SNPs will be reduced to 200,00 to 300,000 tag SNPs that will signal the location of regions that affect disease more readily through genome scans.

To create a genetic test that will screen for a disease in which the disease-causing gene already has been identified, scientists collect blood samples from a group of individuals affected by the disease and analyze their DNA for SNP patterns. Next, researchers compare those patterns to patterns obtained by analyzing the DNA from a group of individuals not affected by the disease. This type of comparison, which is called a disease gene association study, can detect differences between the SNP patterns of the two groups, indicating which pattern most likely is associated with the disease-causing gene. Eventually, SNP profiles that are characteristic of a variety of diseases will be established. As part of that effort an increasing amount of research has called for the DNA sampling of individuals identified with specific racial minority populations. The collection of DNA samples has resulted in the racial categorization of genetic material stored in governmental and commercial genetic databases.

Scientific Racism and Eugenics: Cautionary Tales

In considering the ethical implications of race in human genetics research, it is prudent to review the lessons learned from the history of scientific racism in medicine. In the United States and abroad scientific racism has resulted in the exploitation of racially identified populations in the name of scientific and medical progress. Although science often has been portrayed as *value-free,* scientific theories have been used to support beliefs in the inferiority of racialized populations. Historically, race began as a biological taxonomy by which humans were categorized according to phenotypic differences such as skin color and facial features and by supposed personality traits. Despite general rejection of such definitions, scientific research is at times compromised by a priori assumptions that build on notions of race as biology.

The term *eugenics,* which was coined by Francis Galton early in the twentieth century, has been incorporated into various state-sponsored programs around the world (Galton). The most notorious of those programs was guided by the German program of *Rassenhygiene,* or "racial hygiene," that led ultimately to the Holocaust. In the early 1900s the eugenics program was promoted through scientific organizations such as the Society for Racial Hygiene and the Kaiser Wilhelm Institute for Anthropology, Human Genetics and Eugenics. Later, when incorporated into Nazi ideology after the rise of Adolph Hitler, the racial hygiene program led to a broad spectrum of egregious scientific experimentation and the eventual extermination of millions of Jews, Gypsies, homosexuals, and other individuals deemed undesirable by the Third Reich (Weigmann).

During that period of state-sponsored racism, other nations, such as Great Britain, Norway, and France, were adopting their own brands of eugenics policies. Eugenics gave scientific authority to social fears and lent respectability to racial doctrines. Powered by the prestige of science, it was coupled with modernizing national projects that promoted claims of social order as objective statements grounded in the laws of nature (Dikotter). Unfortunately, history provides several examples of how the marriage of scientific racism and national political agendas has led to the unfair treatment of socially and politically vulnerable racial minorities. In South America, for example, eugenic policies have been the key to a national revival in which indigenous concerns over racially diverse and socially disparate societies have led to race-based initiatives to regulate human reproduction. Brazil and Argentina have experienced the use of science in the name of forging "superior and cosmic national races" (Stepans).

Perhaps the longest single study involving the exploitation of human subjects in medical research was the Tuskegee Syphilis Study conducted by the U.S. Public Health Service. The study, which was called the Tuskegee Study of Untreated Syphilis in the Negro Male, began in 1932 and did not end until 1972. The study involved the recruitment of over 300 black men with syphilis who were told by researchers that they were being treated for "bad blood," a local term used to describe several ailments, including syphilis, anemia, and fatigue (Jones). Those men did not receive proper treatment even after penicillin became available as an effective therapy in 1943. In exchange for taking part in the study, the men received free medical examinations, free meals, and burial insurance. The Tuskegee Study caused a public outcry that led the assistant secretary for health and scientific affairs to appoint an Ad Hoc Advisory Panel that concluded that the Tuskegee Study was "ethically unjustified" (Brandt). It is a "powerful metaphor that has come to symbolize racism in medicine" (Gamble) and a cautionary tale about the vulnerability of racial minorities in biomedical research.

Ethical Issues of Identifying Race in Genetics

The development of genomic research technologies has the potential for a dramatic enhancement of biomedical prevention and treatment of disease. Efforts to identify genetic mutations associated with disease may yield significant findings that uncover important clues to the onset of common diseases. Critical to these endeavors is a growing need to understand human genetic variation. In the absence of cost-effective ubiquitous genotyping technology, researchers have tended to favor population-based sampling. Strategies of using racially identified populations in the mapping of genetic markers, however, should be viewed with due consideration of the potential ethical implications of such research. Of particular concern are the potential for stigmatization and discrimination, informed consent, and distributive justice.

REIFICATION OF RACE: STIGMATIZATION AND DISCRIMINATION. Historically, race, genetics, and disease have been linked inextricably, producing a calculus of risk. Sometimes these associations are accurate, and sometimes they reflect underlying social prejudice. One risk in medical research is that any racial or ethnic identifiers used in human genetic variation research will come to be reified as biological constructs, fostering a genetic essentialism. This essentialism could obscure the fluid nature of the *boundaries* between groups and the common genetic variation within all groups.

An example is sickle-cell anemia, an autosomal recessive disease that is caused by a point mutation in the hemoglobin beta gene (HBB). It is a condition that has been racialized as a "black disease" in the United States. However, closer scrutiny reveals that the incidence of sickle-cell anemia is associated with zones of high malaria incidence, because carriers of that gene have some degree of protection against malaria. The condition is the result of human migration and the interaction of genes with the environment. Its emergence as a racial disease is an artifact of U.S. history. If the source of slaves to the Americas had been Mediterranean regions, where the incidence of the disease is also appreciably high, rather than from Africa, sickle-cell disease might have become known as a southern European disease. The reification of race results in such conflations.

Stigma and discrimination are potentially harmful consequences that are associated with the reification of race and genetic essentialism, particularly if curative measures are not available. Insurance companies and managed-care organizations in particular have an economic stake in controlling the potential costs of "high-risk" clients (Knoppers). In addition, social prejudice could arise in the identification of correlations between genes and disease. Race may be treated as an independent variable in the calculus of risk and result in real social harms for individuals in regard to the anticipation that they will fall ill.

INFORMED CONSENT: PROTECTING POPULATIONS. Harm from race-based genetic research may extend beyond the individuals at risk for a particular disease if targeted genetic testing implicates socially identifiable groups. Increasing attention to the ethical implications of research on human genetic variation has resulted in a shift of emphasis from individuals to "groups." The question of who should "consent" to genomic research demands a discussion of who are the potential victims of research-related harms (Kass and Sugarman). Although the informed consent process focuses on individual participants in scientific studies, risks stemming from population-based research may affect those who are not direct participants but are implicated by their identification with particular groups (Wilcox et al.; Faden and Beauchamp).

Acknowledgment of such harms has fueled a growing debate over whether individuals alone are sufficient to consent to research participation or whether others who subscribe to or are ascribed membership in a racial group also should participate in this process as potential victims of research (Greely). Several scholars and policy makers have advocated "community consultation," arguing that internal review boards (IRBs) should implement new mechanisms that supplement individual consent with group permission (Weijer; Foster and Sharp; Clayton). Others have countered that giving groups the moral authority to bestow informed consent is conceptually flawed and logistically confusing (Juengst). In dispute are the assumptions that (1) there is a singular, self-evident social body that represents a particular individual human subject, (2) that social body has the moral authority to *speak* for all the members of a particular group, and (3) consultation with that social body absolves researchers of responsibility for prospective harms.

Population-based DNA sampling and the identification of racial minorities in research on human genetic variation have broadened the debate over informed consent. At issue are the responsibilities of researchers and clinicians for preventing future harms associated with knowledge that links race, disease, and genes and the need for the participation of research populations in the scientific process.

DISTRIBUTIVE JUSTICE: THE PROMISE OF PERSONALIZED MEDICINE. The decision to identify race in human genetic research may have important ramifications for the establishment of research priorities that could have implications for helping exacerbate or ameliorate health disparities between groups. An example of such research is the field of pharmacogenomics. It is well recognized that most drug therapies exhibit wide variability among individuals in terms of efficacy and toxicity. It has been estimated that over 100,000 patients die and 2.2 million are injured annually by adverse drug reactions (Lazarou et al.). For many medications differences in reactions are due in part to SNPs in gene-coding drug-metabolizing enzymes, drug transporters, and/or drug targets. The ultimate goal of such research is to develop "individualized" drug therapy that will reduce adverse side effects and provide cost-effective medicines (March et al.)

The adoption of pharmcogenomics has serious implications for the practice of clinical medicine. The population-based approach to the marketing of healthcare products raises the possibility that drug development will build on and strengthen notions of racial difference. Furthermore, *racial thinking* may have ramifications for the perceived beneficiaries of pharmacogenomics research in that racially identified consumer groups may unduly dictate the scientific development of therapeutics. This may lead to a racial segmentation of the market in which drugs are directed at groups in a way that will increase the economic health of the companies investing in therapeutics.

In the unlikely event that genotyping becomes so common that patients are able to identify themselves in terms of the multitude of SNPs involved in disease gene associations and drug metabolism, human genetic variation research will continue to use racially identified populations. Genetic research offers the potential for significant progress toward the mitigation of health disparities between populations in the United States. However, history serves as an important reminder that every leap in scientific advancement must be tempered by careful consideration of its ethical implications.

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SEE ALSO: *Bioethics, African-American Perspectives; Eugenics; Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Genetic Engineering, Human; Genetics and Environment in Human Health; Genetics and Human Self-Understanding; Genetics and Racial Minorities; Genetics and the Law; Harm; Health Insurance; Holocaust; Human*

Dignity; Human Nature; Minorities and Research Subjects; Privacy and Confidentiality in Research; Race and Racism

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GENETIC TESTING AND SCREENING

• • •

I. Reproductive Genetic Testing
II. Newborn Genetic Screening
III. Population Screening
IV. Public Health Context
V. Predictive Genetic Testing
VI. Pediatric Genetic Testing

I. REPRODUCTIVE GENETIC TESTING

Reproductive genetic testing comprises a set of techniques for sample collection and analysis, the aims of which are to detect fetal anomaly. This article will describe the most important of these techniques and consider their bioethical aspects. This will include both those reproductive genetic technologies that are used in established pregnancies and preimplantation genetic diagnosis, performed before the establishment of a uterine pregnancy.

Methods for Obtaining Samples for Prenatal Diagnosis

Amniocentesis is frequently used synonymously with the term *prenatal testing*. Amniocentesis is in fact merely a technique for removal, via a needle puncture of the uterus, of amniotic fluid from the sac which surrounds the fetus during pregnancy. This fluid contains fetal cells on which analyses can be performed. The usefulness of amniocentesis is tightly linked to expanding knowledge about genetics, the development of techniques of fetal analysis, and changing legal and social norms.

In 1955, it was first demonstrated that fluid could be removed from the amniotic sac, that fetal cells could then be cultured, and that the total number of chromosomes—including the sex chromosomes—could be ascertained—a process called karyotyping. The first use of karyotyping was to identify male fetuses of women who carried serious genetic conditions on their X chromosome. However, this was initially of limited usefulness as no information other than fetal sex was obtainable, the safety of the procedure needed further investigation, and pregnancy termination for fetal anomaly was not legal.

The later finding that a karyotype showing three rather than two copies of a chromosome (trisomy 21) was indicative of Down syndrome presented the possibility of much broader use for amniocentesis. Not only was Down syndrome an important cause of mental retardation, it was also predicted by a pregnant woman's increasing age rather than by her genetic history. When, in the mid-1970s, a large study demonstrated the safety of amniocentesis (NICHD National Registry for Amniocentesis Study Group) at approximately the same time that the Supreme Court decision in *Roe v. Wade* made abortion legal in the United States, the way was opened to the population-based use of this technique for women of advanced maternal age.

Serious maternal complications from amniocentesis are rare; the primary medical risk of amniocentesis is fetal loss from the procedure. For this reason, the age, at which amniocentesis is routinely offered, is driven by an equation that looks for equipoise between the risk of procedure-related miscarriage and the age-related risk of Down syndrome. It is worth noting that one can infer from this equation an equivalence between the negative outcome of a fetal death and birth of a child with a disability, an equivalence which, as discussed below, would be contested from various positions critical of prenatal testing. Nevertheless, as rates of procedure-related miscarriage have decreased—due primarily to the use of real-time ultrasound to guide the needle—the age at which women are routinely offered amniocentesis has also decreased. At the beginning of the twenty-first century, it is standard of care to offer amniocentesis to women over age thirty-five.

Although amniocentesis is most closely associated with trisomy 21, any chromosomal abnormality can be detected through karyotyping, and the sample of fluid obtained can be used to diagnose any fetal anomaly for which a cytogenetic, biochemical, or DNA test has been developed (e.g., Tay-Sachs, sickle cell anemia, Huntington's disease).

EARLY AMNIOCENTESIS AND CHORIONIC VILLUS SAMPLING. Amniocentesis is performed in the middle of the second trimester of pregnancy. By this time, pregnant women have often experienced *quickening* (perceived fetal movement) and the fetus is nearing the age of viability. These factors have led to a search for earlier modes of fetal sample collection, including first trimester ("early") amniocentesis and chorionic villus sampling (CVS).

Although there was initial enthusiasm for early amniocentesis performed in the eleventh through thirteenth weeks of pregnancy, recent data suggest that this procedure may pose significantly greater fetal risks than traditional amniocentesis, including high rates of pregnancy loss and risk of fetal malformations (e.g., club foot) (Bianchi, 2000). In addition, early amniocentesis is more technically difficult and thus more often will fail to obtain a fluid sample adequate for cell culture. Enthusiasm for the procedure has waned, although it is possible that future solutions to these problems will revitalize interest.

Rather, it is CVS that appears likely to become the procedure of choice for earlier fetal sample collection. The chorionic villi are precursors of the placenta and have proved a good source of fetal tissue. CVS can be performed safely as early as the tenth week of pregnancy, either transabdominally or transvaginally; the risks have been found to compare well with second trimester amniocentesis (Bianchi, 2000). In addition, the waiting period for results following CVS is shorter than in amniocentesis—three to eight rather than ten to fourteen days. Since there is considerable documented anxiety for parents waiting for prenatal test results, this represents a significant advantage.

MATERNAL SERUM FETAL CELL RECOVERY. Both CVS and amniocentesis are invasive techniques. They share disadvantages of potential fetal harm and are relatively costly to perform. Thus, there continues to be interest in finding a non-invasive, less expensive technique that could be used to gather a fetal sample early in pregnancy. There is only one such technique on the horizon in 2003—maternal serum fetal cell recovery.

It is known that a small number of fetal cells are sloughed off and cross into maternal blood circulation. After isolation from a maternal blood draw, these cells can then be used for any desired fetal analysis. However, fetal cells are numerically rare in maternal blood and their identification and isolation is difficult. In addition, the type of cell most amenable to detection and isolation is not ideal for chromosomal analysis (Holzgreve and Hahn). Nevertheless, work on this technique progresses and a prospective multicenter trial of this technique as a screen for chromosomal anomalies began in the mid-1990s (Bianchi, 2002). Early results were promising for chromosome analysis, but the future goal of fetal cell recovery remains broader than this: To be able to perform not only analysis of chromosomal abnormalities, but to capture the larger number of fetal cells needed for DNA techniques. This goal holds the promise of genetic analysis for any disorder of interest.

Screening Tests and Diagnostic Tests

The above techniques are used for diagnosis in high-risk women. But almost all pregnant women are offered a variety of other prenatal screening tests.

Although the distinction quickly becomes complicated, in its simplest form, screening tests are offered to a population of apparently healthy persons in order to find those few at increased risk. Ideally, screening tests are easy and inexpensive to perform and interpret, and do not entail risk for the person screened. Screening tests have high rates of initial positive results and thus a large percentage of people who have positive screening tests will prove not to have the screened-for problem on follow-up diagnostic testing.

In contrast, diagnostic tests are offered to individuals known to be at increased risk of a condition in order to answer the question, “Does this person have this disease?” Diagnostic tests are generally more complicated and expensive to perform and interpret, and may entail risk. They are expected to have higher standards of sensitivity and specificity: to do a much better job at identifying all and only cases of the disorder.

The screening and diagnostic testing regimens typically offered to pregnant woman and couples at the beginning of the twenty-first century are presented in Table 1. Each begins by asking a question that assigns the woman to a risk level. It is important to realize that each screening test has its own percentage of initial positive results; thus, each additional screen raises the risk for any individual woman of getting an initial positive result at some time during pregnancy. In addition, these tests are not all done at the same time in pregnancy. For example, an African-American woman, less than thirty-five years old, would be offered carrier testing for sickle cell disease in her first trimester and would also be offered multiple marker screening in her second trimester.

MSAFP and Multiple Marker Screening

While amniocentesis for Down syndrome is perhaps better known, the test which truly revolutionized prenatal diagnosis was maternal serum alpha fetoprotein (MSAFP) screening, which became the first screening test offered to all pregnant women solely for the purpose of discovering risk for a fetal anomaly.

MSAFP screening was developed to detect neural tube defects (NTDs) in the fetus. NTDs comprise a set of defects involving the development of the brain and spine and leading to varying degrees of physical and cognitive impairment, some of which are incompatible with life; they are among the most common of serious birth defects. Finding fetal NTDs is complicated by the fact that over 90 percent occur to women at no known risk, making it necessary to offer testing to the entire population of pregnant women to detect any reasonable percentage of fetal NTDs.

Alpha fetoprotein is a substance produced by the developing fetus and present in maternal blood during pregnancy. In the early 1970’s, it was found that higher than normal levels of MSAFP correlated with increased risk of fetal NTDs. This suggested the possibility of an inexpensive, minimally invasive, screening modality for NTDs (Brock, Bolton, and Monaghan).

In the 1980’s, researchers linked lower than normal levels of MSAFP to Down syndrome and other chromosomal abnormalities, thus expanding the utility of the test (Merkatz, Nitowsky, Macri, et al.). Early pilot projects demonstrating the feasibility of MSAFP testing increased enthusiasm for it as a prenatal screening test, and the screening became firmly established as standard of care in the United States when an American College of Obstetrics and Gynecology “Legal Alert” warned obstetrical providers that failure to offer the test might leave them open to liability in the case of a baby born with a detectable anomaly (ACOG, 1985).

However, one concern about using MSAFP to detect Down syndrome was that it had much lower sensitivity and specificity for chromosomal abnormalities that it did for NTDs. When it was found that the addition of other biochemical markers improved the ability of the screen to predict Down syndrome, these quickly became added to the analysis. Most providers perform multiple marker screening, with a *triple marker* screen including human chorionic gonadotrophin and unconjugated estriol being the most common. Since all these analytes are gathered from the same

TABLE 1

Current Screening Practices

Screening question	Answer	Next Step	Next Step	Next Step
What is your age?	>35	Referral for amniocentesis/CVS		
Is there any genetic disorder in your family?	Yes	Referral for carrirer testing **or** amniocentesis/CVS *(Depending on characteristics of the disorder and the mode of genetic transmission)*		
What is the race/ethnicity/country of origin of woman (and partner)?	African-American	Offered sickle cell carrier testing	If both partners are carriers, referral for amniocentesis/CVS	
	Ashkenazi-Jewish	Offered Tay-Sachs (and possibly an Ashkenazi-Jewish panel, including, e.g. Canavan disease) carrier testing	If both partners are carriers, referral for amniocentesis/CVS	
	Southeast Asian, Greek Southern Italian	Standard blood work-up looking for anemia may be used to suggest need for a next step	Offered alpha or beta thalassemia carrier testing	If both partners are carriers, referral for amniocentesis/CVS
	European-American	Offered cystic fibrosis carrier testing; some places may make this offer to ALL pregnant women	If both partners are carriers, referral for amniocentesis/CVS	
Are you beginning prenatal care <16 weeks of pregnancy	Yes	Offered multiple marker screening	If result is positive HIGH, referred for ultrasound If result is positive LOW, referred for amniocentesis	If result is inconclusive, referred for amniocentesis
		Suggested one-age screening protocol		
Are you beginning prenatal care in the first trimester?	Yes	Offered PAPP-A screening, adjusted by maternal age, and ultrasound to assess fetal nuchal translucency	If joint results are positive, referred for amniocentesis	

SOURCE: Author.

blood sample, the test has not changed from the point of view of the pregnant woman.

One important aspect of multiple marker screening is that it cannot be done until the fifteenth week of pregnancy, and most women are screened at sixteen weeks and above. This means that diagnostic work-up for a positive test is done toward the end of the second trimester, and a woman who wanted to terminate a pregnancy based on the results of a diagnostic test would be facing a late second trimester termination.

Suggestions for a One-Age Screening Protocol

Since the 1970s, maternal age has been used as a screen for offering amniocentesis to pregnant women, with biochemical screening offered to younger women since the late 1980s. However, there is debate about these guidelines (see, for example, Rosen, Kedar, Amiel, et al.; Haddow, Palomaki, Knight, et al.; Pauker and Pauker; Egan, Benn, Borgida, et al.; Dommergues, Audibert, Benattar, et al.). This controversy seems to be based largely on the trend toward women bearing children at later ages (from 1974 to 1997, the United States has seen a 2.7-fold increase in live births among women ages 35–49) (Egan, et al.). This age increase means a dramatic increase in the number of amniocenteses performed, with concomitant procedure-related losses and economic costs.

The most radical suggestion for changing the routine is to screen women of all ages in an identical manner (see last row of Table 1). The most promising of such approaches include ultrasound measurement of the thickness of subcutaneous edema in the neck of the fetus (fetal nuchal translucency) combined with new types of serum marker screening (e.g., PAPP-A). When these techniques are performed in the first trimester of pregnancy, and the results are combined with the risk based on maternal age alone, this regimen is believed to have an 80 to 90 percent detection rate for trisomy 21 and other chromosomal abnormalities (Nicolaides, Heath, and Liao). Although fetal nuchal translucency screening has not been accepted as standard of care, the American College of Obstetrics and Gynecologists stated at the end of the twentieth century that it shows promise (1999).

The advantages of a single screening modality for women of all ages are that it would decrease the number of amniocenteses in older women and, with these more sensitive screening modalities, also increase the detection rate in younger women. (In terms of raw numbers, younger women have the greatest number of affected pregnancies.) Several sets of modeling data suggest that with this approach the overall detection rate would improve and the fetal loss rates would decrease (Rosen, Kedar, Amiel, et al.; Haddow, Palomaki, Knight, et al.; Dommergues, Audibert, Benattar, et al.). The disadvantage, however, would be that, since amniocentesis has a virtual 100 percent sensitivity, some fetuses with Down syndrome that would have been detected through universal screening of women over thirty-five would be missed, and some women over thirty-five would bear a child with Down syndrome who would not otherwise have done so. The ethical, and political, debates concern the fact that a medical service that was accepted as a right for pregnant women of a certain age would be withheld from those same women unless they had demonstrated risk. This may well appear to be an unacceptable form of sudden healthcare rationing to older pregnant women.

It is also worth noting that none of these one-age screening models refer to the detection of neural tube defects, but rather appear to exist in a separate universe of consideration and calculation. Thus, they would not solve the problem of multiple screenings and multiple chances for initial positive results and concomitant anxiety.

Prenatal Screening and the Experience of Pregnancy

The advent of MSAFP screening transformed the experience of pregnancy for the *low risk* woman—that is, the great majority of pregnancies. As is clear from Table 1, it is possible for a woman to go through a period of waiting for results of one test only to then begin all over again with testing for another condition. For example, a thirty-year old Southeast Asian woman might have a standard blood workup that revealed anemia, be offered thalassemia carrier testing along with her partner, and, when both proved to be carriers, be offered CVS; she might have a negative result and then, some weeks later, be offered multiple marker screening and receive a positive result; she might then choose to undergo amniocentesis. All of this could produce a healthy baby and a disastrously upsetting and expensive pregnancy. There appear to be no empirical data on the frequency of such experiences. However, variations on this theme are frequently reported by obstetric providers.

General Ethical Issues in Prenatal Diagnosis

In addition to the issues involved in one mode of screening or another, there are overarching ethical issues that concern the entire project of prenatal diagnosis. These involve contestations over the meaning, experience, and implications of these tests. Specifically, there is a lack of clarity about the centrality of pregnancy termination to an offer of prenatal testing; whether testing resolves or creates maternal anxiety; and the relationship of individual reproductive choices to societal effect. This latter includes the effects of prenatal testing on those with disability and, more broadly, the relationship between prenatal screening programs and eugenics. Related to the latter is a question about the effectiveness of individual autonomous choice as a safeguard against eugenic abuses related to prenatal testing. All these issues affect and are affected by the lack of a mechanism for rational deliberative decision-making in the United States about why and which prenatal tests are developed and offered.

PRENATAL TESTING AND ABORTION DECISION MAKING. The performance of any medical test is predicated on a hypothesis of benefit which defines the way in which the results of the test will lead to actions that help prevent disease or ameliorate its burden. Implicitly, the person whose disease burden is being ameliorated is the person being tested. Although it is everyone's hope that identification of a fetus with a particular condition will lead to prevention or cure of that disease, this is very rarely true today and the only way to prevent the fetus being born with the condition is through termination of the pregnancy.

Religious objections. From the viewpoint of conservative religious positions that object to abortion under all circumstances, the link of prenatal testing and abortion is clear, and offering women this choice is deeply objectionable.

Cost benefit literature. There is another body of literature in which the centrality of abortion decision making to prenatal testing is quite clear—literature that assesses the effectiveness of testing programs by comparing the economic costs of prenatal testing to economic savings. The costs include such items as sample collection, analysis, and results communication; savings include monies not spent on medical care for children who would have been born with disability but instead are not born. One of the major variables in the equation is the minimum number of women who need to choose termination in order for the screening program to be cost-effective, assuming that not all women who test positive will go on to end the pregnancy. Thus, the calculation both acknowledges the autonomous choice involved in prenatal screening programs in the United States and the need for those autonomous choices to lean, in sum, in the direction of pregnancy termination.

However, most literature that discusses the benefits of prenatal testing talks about the reassurance provided about the health of the fetus for the large majority of women—those who test negative—and the chance for women or couples who choose not to terminate to prepare emotionally for the birth of child with a disability. Generally stated last is the enhancement of *reproductive choice* in the case of a positive test result.

REASSURANCE AND ANXIETY. The issue of reassurance and, conversely, anxiety in relation to prenatal testing has received considerable attention. Women themselves often cite *reassurance* as a benefit of testing. Much empirical research has focused on the issue of anxiety for that group of women who receive an initial positive result. These data suggest that women's anxiety is raised following a positive result but that, in general, this anxiety is relieved by a negative result. Data suggest that for some women, however, the anxiety persists, along with difficulty believing their fetus is healthy.

Some feminist critics also suggest an irony in which the reassurance provided by testing may be necessary, in great part, due to anxiety raised by the testing itself. In general, these critics claim that the expansion of prenatal testing has radically changed the experience of pregnancy and that while the number of fetal anomalies has, of course, not increased, the perception of risk among pregnant women has increased greatly.

INFORMATION PROVISION. Another aspect of prenatal testing, sometimes cited by theoretical literature and pregnant women as an advantage for those unwilling to terminate a pregnancy, is the opportunity to have time to prepare emotionally for the birth of a child with a disability. However, there are no empirical data demonstrating that advance preparation actually has an effect on adjustment to the birth of a child with a disability. In addition, the majority of women who receive positive results do terminate their pregnancies. Data suggest that close to 90 percent of women terminate following a diagnosis of a chromosomal disorder such as trisomy 21; the rate of termination for NTDs is more variable, reflecting the greater variation in the severity of the detected anomaly (Cragan, Roberts, Edmonds, et al.).

Thus, the most obvious advantage of prenatal testing must remain the ability to terminate a pregnancy which would result in a child with a disability. This suggests that the bifurcated conversation in the United States about prenatal testing—in which cost effectiveness calculations make assumptions which are omitted or contradicted in the clinical literature and most patient education materials—may make it difficult to have a societal conversation about the larger effects of prenatal testing on society.

The Effects of Individual Reproductive Choices on Society

In addition to advantageous or deleterious effects on individual women and couples, concerns exist about the effects of prenatal testing on society.

THE DISABILITY CRITIQUE. The most forceful critique of prenatal testing is that made by disability theorists (Parens and Asch). Their most straightforward claim is that prenatal testing represents "search and destroy" missions against those who would be born with disability and is, simply, a eugenic program. A more subtle disability critique states that the choice to abort an otherwise desired fetus on the basis of one trait or characteristic sends the message that the lives of those with disability are not valuable and that the disability makes the child unacceptable (Asch and Geller); this has been termed the *expressivist argument.* Objections to the expressivist argument share a skepticism about the ability of individual acts to constitute a message. Objections to the disability critique in general often point to the increasing societal protections of individuals with disability that have co-occurred with the growth of prenatal testing.

THE LIMITS OF AUTONOMY. The argument that prenatal testing is not eugenic and not disvaluing of living individuals with disability rests largely on the way that testing programs protect the autonomy of women's or couple's decisions in regard to the use of testing and test results. A central ethical issue, therefore, concerns the actuality and the limits of such autonomy. Specifically: Are women or couples making autonomous decisions in regard to prenatal testing? Can the aggregate effect of autonomous choices be eugenic? And, if they can, how problematic is this?

Are prenatal testing decisions truly autonomous? Individual autonomy is a foundational principle in Western bioethics, and there is virtually universal agreement that women and/or couples should make informed decisions about the use of testing and should not be coerced into pregnancy terminations following a positive prenatal test. The disagreement that exists, therefore, is about the possibility and actuality of such autonomy.

On a narrow level, there is concern that women do not understand the implications of an offer of prenatal testing; this has led to attempts to improve the informed consent process. Yet empirical research suggests that such attempts are only partly successful in the prenatal testing arena, as is true of informed consent in general. Empirical data suggest that, especially *low risk* women who are offered prenatal testing in a context of routine prenatal care, are likely to conflate prenatal testing for fetal anomalies with tests which can directly benefit themselves and their fetus (Press and Browner). It is possible that this misunderstanding is enabled by healthcare providers who are likely to find greater liability risk in the woman who refuses testing and has a baby born with a disability than one who does not fully understand the implications of prenatal screening and participates regardless; it may also reflect a reluctance on the part of both providers and pregnant women to discuss pregnancy termination. Some critics suggest, however, that some women would not have started down the prenatal testing path if they had truly understood the implications in terms of pregnancy termination; they argue that this may represent a compromise of their autonomy.

A broader concern is that the very existence of large-scale prenatal testing compromises the possibility of individual autonomous decision making. Feminist critics, among others, point out that prenatal screening has become routinized, with an offer of some sort of prenatal screening standard of care for all pregnant women. These critics assert that in this setting, not being screened, while a possible choice, becomes a marked one that requires justification to one's healthcare providers and one's peers. Concern has also been expressed that mothers who decide to forgo testing and give birth to a child with a disability will be blamed by society and even, perhaps, denied healthcare insurance for the child. There is little empirical support at this time for these latter claims.

Can the aggregate impact of autonomous choices be eugenic? Even if each choice to use prenatal testing and terminate a pregnancy is informed and autonomous, the net effect might be considered eugenic. And, in fact, there are those who do not consider this to be problematic. Thus, for example, some public health statements clearly cite the measure of success of screening for neural tube defects as the lowering of the number of children born with these defects. Some bioethicists also suggest that eugenics, premised on individual, autonomous choices, is not necessarily bad.

How Are Decisions About Prenatal Test Offers Made?

These positions would seem to require a clear social consensus of what changes in the gene pool would be *eu*-genic. Yet, at the turn of the twenty-first century there exists no body in the United States, as there is in other countries, that decides on the available panel of prenatal tests. Nor is there a forum for public discussion of this issue. Some tests stumble into becoming standard of care due to medico-legal concerns (e.g., MSAFP testing). At other times, decisions are made on an ad hoc bases. Thus, a strongly perceived need by obstetric providers for guidance about cystic fibrosis (CF) screening led to the convening of an National Institutes of Health (NIH) Consensus Development Conference. This group recommended the routine offer of CF carrier screening in pregnancy, but concerns that physicians were not prepared for this change in practice led to the creation of an ad hoc panel charged with creating recommended protocols for implementation (National Institutes of Health Consensus Development Conference). The existence of the panel has not calmed concerns that physicians are not ready to meet the challenge of offering a new population-based test.

As genes for Mendelian disorders and those that confer susceptibility to more common disorders are found in increasing numbers, the lack of any orderly process from gene discovery to test development and then to making that test available to the public becomes increasingly problematic. At this point, healthcare providers are the de facto gatekeepers, relying on recommendations from professional organizations, actions of insurance payers, patient demand, and their own consciences in making decisions about what tests to offer. As genetic knowledge increases, this will become an ever more pressing societal problem.

Preimplantation Genetic Diagnosis

If prenatal testing is about which children will not be born, preimplantation genetic diagnosis (PGD) can be said to be about which children will be born.

PGD began as an alternative to prenatal testing for fertile couples known to be at high risk of genetic disease. It comprises a series of highly technical steps. The scenario involves inducing superovulation in the woman to increase the number of eggs in one reproductive cycle, the harvesting of those eggs, and the creation of six to eight embryos by in-vitro fertilization (IVF). In the most common protocol, the resulting embryos are allowed to develop until they reach the eight- to twelve-cell stage, and then one or two cells are removed from each embryo for genetic analysis. Those embryos that carry the genetic defect are discarded. Depending on the number of unaffected embryos, some or all are implanted. Which embryos are chosen and what happens to those that remain are issues of ethical contention.

Many issues raised by PGD are outside the scope of this article. However, two issues raised by PGD are also directly related to dilemmas discussed in the context of prenatal diagnosis: First, what is abortion? Second, how does one decide which babies will be born, and with what traits and/or diseases?

WHAT IS ABORTION? One of the advantages commonly cited for PGD is that it avoids the problem of abortion. This assumes a definition of abortion as the interruption of an established pregnancy. However, abortion can also be defined as "the arrested development of an embryo at a more or less early stage" (from the *Random House Dictionary of the English Language*), a definition which would include the discarding of embryos, affected or unaffected, within PGD. It would also appear that those individuals (and points of view) most uncomfortable with abortion in the prenatal setting would be most likely to endorse this broader definition of abortion and thus be unlikely to see PGD as a solution to the abortion issue.

WHICH BABIES WILL BE BORN? PGD involves an issue not raised by prenatal diagnosis—more embryos are produced by PGD than can be used. The existence of these "excess embryos" demands that criteria be found on which to predicate decisions about which children should be born. Although, in practical terms, these decisions are often made on the basis of simply finding sufficient unaffected embryos for implantation, the possibility of deciding which embryos to implant has provoked considerable discussion. For example, is it appropriate to base a decision about which of two unaffected embryos to implant based on the preference of the parents for a child of one sex rather than the other?

Some of the discussion of how to choose embryos for implantation has a proscriptive edge, such as the view that to bring to birth a child with any impairment, however slight, if it could have been avoided, is to harm the child; more categorical is the view that procreative beneficence demands the selection of the "best" children. The logical extreme of this latter position is suggested by the view that "the question is not which individuals have worthwhile lives, but which of two possible worlds would be better: a world where disabled individuals are brought to birth or a world where non-disabled individuals are brought to birth" (Bennett, p. 468).

Much of this sort of discussion belies a belief in the ability of genetic analysis to do things that are neither currently possible nor likely to be so in the future—for example, to isolate the embryo that will become the most intelligent child. Nevertheless, these openly eugenic views, which are not found in the literature on prenatal testing, would appear to be premised on the belief that abortion is not involved in PGD and that the choice involves a more acceptable *selection for* rather than *selection against.* However, such an assumption would likely not satisfy those who have the most concerns about abortion. And for those critics (see, for example, the feminist and disability critiques) whose concerns do not involve abortion, this discussion around PGD lays bare the eugenic thrust they see in all prenatal testing.

Conclusion

Discussions of both prenatal testing and preimplantation genetic diagnosis appear to assume that the continuing march of reproductive technology is inevitable. It is possible that the overriding issue in all of reproductive genetics is whether society will see the development and use of these techniques as matter for democratic deliberation and decision, or whether the implementation of new technologies will continue in the established piecemeal fashion, and ethical discussion will continue to be reactive.

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SEE ALSO: *Abortion; Cloning: Reproductive; Disability; Embryo and Fetus; Eugenics; Eugenics and Religious Law; Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Genetic Discrimination; Maternal-Fetal Relationship; Mistakes, Medical; Moral Status; Reproductive Technologies; Value and Valuation;* and other *Genetic Testing and Screening* subentries

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II. NEWBORN GENETIC SCREENING

Throughout the United States, and in many other countries around the world, newborns are tested within the first few days to weeks of life for a varying array of metabolic disorders. Until recently, newborns were typically screened for only a handful of disorders, but recent technological advances and new knowledge about genetics have led to pressure for greatly expanded screening. At first glance, newborn screening might seem unremarkable. Much of medical practice is devoted to the early detection of disease to allow the delivery of effective interventions, and new developments are often received enthusiastically. But newborn screening programs have several features that individually and collectively pose particular ethical challenges.

All U.S. states require that newborns be screened, either prior to discharge or, if delivered outside a healthcare facility, within the first two to three days of life (AAP). Maryland, Wyoming, and, for some but not all tests, Georgia and Massachusetts require that parents give their permission for screening, though many states do permit parents to refuse screening (generally for religious reasons). This option may be difficult to exercise in practice, however, since few states require that parents even be told that screening is occurring, much less that they have a right to refuse. Thus, one of more remarkable aspects of newborn screening is that parents are not even nominally part of the decision-making process for their new infants (AAP; Paul; Clayton).

Those who argue against either notifying parents or seeking their permission reason that all children should be screened, and it would thus be a waste of money and effort to talk with parents (Cunningham). Proponents of mandatory screening argue that most parents would agree to screening, but that they might be unduly worried if they knew about the test (Cunningham). They assert further that parents who refuse would be harming their own children. These arguments raise two separate issues: (1) the justifiability of excluding parents, and (2) the characteristics of newborn screening programs (and the disorders they seek).

The Role of Parents

The role of parents in making healthcare decisions for their infants is addressed elsewhere in this encyclopedia. In general, parents are presumed to have a role to play in such decisions, which can be overridden only to avert serious harm. But clinicians cannot decide not to talk with parents simply because they think it would take too much time, would make parents worry, or that it would be a waste of effort because parents usually agree to the clinician's recommendations anyway.

These principles suggest to the advocates of seeking parental permission that parents cannot justifiably be denied the opportunity to be informed about and participate in decisions about newborn screening. Most parents agree to screening, and informed parents are more likely to ensure that screening is performed, as well as to obtain any follow-up that may be required (Andrews). Even if parents refuse screening, it is unlikely that their children will come to harm, for the disorders sought in these programs are very rare.

Newborn Screening Programs

Universal newborn screening was first adopted for phenylketonuria (PKU), an inherited metabolic disorder that causes severe mental retardation unless treatment is started in the first few weeks of life (NAS). Children with this disease have few symptoms early on, but the metabolic abnormality can be detected in the first few days of life by testing either the urine or the blood. Thus, several factors converged to support the idea of early detection:

- The disease has a devastating outcome
- Treatment is highly effective in averting this outcome, but only if it is started early
- Affected children cannot be detected on the basis of symptoms in time to start effective treatment
- Screening reliably detects most affected children (NAS)

When clinicians were slow to adopt these tests in their clinical practice, in part because they were uncertain about the efficacy of treatment, advocates went to their legislators to get them to enact laws requiring PKU screening (AAP; Clayton; NAS).

In the two decades that followed the enactment of these initial laws, the diseases that were added to the testing panels generally had similar characteristics. Congenital hypothyroidism requires early treatment to prevent severe retardation, and it frequently is not detected clinically during the newborn period. The risk of overwhelming bacterial infection faced by young children with sickle-cell disease can be greatly reduced by giving prophylactic penicillin. Children with galactosemia are often critically ill by the time the condition is detected on the basis of their symptoms, an outcome that can be averted by using a formula that does not contain lactose (milk sugar). Typically, programs were expanded to these and other disorders in response to a combination of mounting medical evidence and political pressure by families and clinicians.

Pressure to expand the number of disorders being screened for expanded dramatically during the 1990s, largely as a result of the development of tandem mass spectrometry ("MS/MS") (AAP). This technology permits the detection of a large number of metabolic abnormalities on a single specimen of blood. Unfortunately, no treatment exists for many of the disorders detectable by MS/MS, which raises issues of whether to test for these abnormalities, and of what to tell families whose children may have one of the untreatable diseases.

Until recently, most state statutes focused on identifying affected children. Most state programs tried to ensure that these children were directed to appropriate sources of care, but few actually ensured the availability of needed medications and diets. Since children do not have universal access to healthcare, some children received no treatment, and some parents suffered job lock. Increasingly, states, practitioners, and clinicians have begun to work together to develop systems to ensure the delivery of care for these children (AAP), a laudable goal which is threatened by the increasing pressure to privatize newborn screening.

The Problem of False Positives

Screening tests are assessed according to their sensitivity (the percentage of affected individuals detected) and their specificity (the percentage of unaffected individuals who are correctly excluded from further testing). The actual number of people who receive inaccurate initial screening results depends in large part on the frequency of the disease in the population. The more common the disease, the more likely it is that a person who receives a positive (abnormal) test result will actually be affected. (The rhetoric of screening and testing is confusing in that "positive" test results almost always mean that something is wrong.) As the disease becomes less frequent, the proportion of initial results that turn out to be "false positives" increases. Suppose a disease has an incidence of 1 in 10,000 and a population of 100,000 people is tested with a screening test that has a sensitivity of 90 percent (so that 9 out of 10 affected people will test positive) and a specificity of 99 percent (so that 99 out of 100 unaffected people will test negative). The results overall would be as follows:

	Test positive	**Test negative**
Affected	9 "true positive"	1 "false negative"
Unaffected	999 "false positive"	98,991 "true negative"

Put another way, for every person who was truly affected (and tested positive), 100 people who did not have the disease would also (falsely) test positive. In addition, nine people who did have the disease would test negative. While most people who get false positive test results are ultimately reassured by further testing, some may continue to be worried. Affected children who are missed in these programs may face substantial delays in diagnosis if clinicians reason that the child could not have the disorder because it would have been identified in the newborn period.

The disorders sought in newborn screening programs typically are quite rare, usually having frequencies in the 1-in-5,000 to 1-in-15,000 range. Some of the diseases that are being added being to newborn screening panels are as rare as 1 in 100,000. Without denying the benefits that can come to affected children who are detected in these programs, it is important to acknowledge the possible harms that may befall the many children who inevitably receive falsely abnormal results. The newborn period is a particularly vulnerable time. Parents are just beginning to know and bond with their infants. Bad news, even if incorrect, can interfere with the formation of this central relationship and lead parents to view their new infants as medically fragile. One study revealed that almost 10 percent of parents whose infants received initial false-positive screening results for cystic fibrosis were still worried a year later that their children were affected or otherwise sickly.

Thus, the trend has been to increase the disorders for which newborns are screened, including some for which the benefits of early invention are unclear or may be absent, all the while causing a growing number of infants to receive false-positive test results, which will cause some of them harm.

The Implications of These Disorders

Most of the disorders sought by newborn screening are inherited, usually as autosomal recessive disorders. If parents have a child with one of these diseases, they have a one in four chance in each subsequent pregnancy of having another affected child. Children with such a disease can have affected children themselves if they have children with partners who have one or two copies of the same mutated gene. Some screening protocols, such as those for sickle-cell disease and cystic fibrosis, also detect carriers (children who have a single copy of a mutated gene). While these children do not have the disease, the presence of a mutated gene signals an increased risk of having a truly affected child, both for them and for their parents. From an ethical perspective, it seems obvious that parents should be told about all of these implications, but this sort of communication often does not occur.

One of the more difficult ethical questions is whether parents should be encouraged to alter their future reproductive plans in order to decrease the costs of disease to society. The general consensus is that decisions about having children are to be made by the prospective parents according to their own values, and that genetic counseling is to be nondirective (Andrews, Fullerton, Holtzman, et al.).

Another complex issue is whether decreasing the number of affected children born, whether as a result of state intervention or even of independent decisions by prospective parents, should be seen as an additional goal or benefit of newborn screening. Some governmental officials have made this argument, even calculating the decreased healthcare expenditures that follow from the birth of fewer affected children in their efforts to calculate the cost efficacy of newborn screening (Cunningham). Others, including advocates of disability rights and opponents of prenatal diagnosis, find these arguments distasteful and potentially coercive (Asch).

Unintended Consequences

Untreated women with PKU are profoundly retarded and rarely have children. As a result of the successful implementation of newborn screening and treatment for PKU, however, many affected females are now in their reproductive years, have intelligence in the normal range, and can and do become pregnant. Unless these women adhere to the highly restrictive and burdensome PKU diet prior to conception and throughout their pregnancy, their children will be born with severe brain injury.

These children typically do not have PKU themselves because their fathers are not likely to be carriers since those mutations are not common. The injuries they suffer during pregnancy result instead from the high levels of phenylalanine that exist in their mothers' blood when they eat a normal diet, levels which are particularly toxic to the developing brain. The irony then is that improving the lives of women with PKU creates a high level of risk to the children they may bear. Clearly, these women need to be educated about the importance of adhering to the proper diet prior to and during pregnancy. The ethical dilemma is whether it is ever appropriate, and if so, how, to bring pressure to bear to lead these women to either follow this onerous diet or avoid childbearing altogether (Robertson and Schulman).

Newborn Screening Samples as DNA Databanks

Birth is the only time of life when the government collects blood from virtually everyone. Some states discard these samples within a few months after birth, while others retain them indefinitely. In the past it was not possible to extract much information from these samples because most metabolites deteriorate quickly, but recent advances, particularly in DNA testing, have created new possibilities. Newborn samples can be used for DNA identification, for further investigation when a child subsequently becomes sick, or for research, for which they may be particularly attractive as a true population sample. However, all these uses are secondary to the purpose for which they were initially collected—to detect children with diseases that urgently require treatment.

The appropriateness of using these samples for these other purposes raises many of the questions that attend any use of stored tissue samples for research, including: (1) whether it is necessary to ask the donor (or in this case the parent) for permission; (2) when, if ever, it is appropriate to inform individuals of their personal results; and (3) what sort of review needs to occur before these samples can be used. The fact that these samples are typically obtained without parental knowledge or permission makes these issues that much more urgent, particularly in a society that is so deeply concerned about issues of genetic privacy. It would be rather ironic if a system of universal DNA identification were developed as a by-product of newborn screening rather than as a result of an explicit policy decision.

Conclusion

The particular ethical issues posed by newborn screening arise because these programs are required and run by the government, typically do not involve parents in decision making, often implicate reproductive decision making, and can provide samples for a growing number of secondary uses. These unique factors suggest that parents should have a greater role to play in these programs, and that these programs should remain narrowly focused on detecting diseases for which treatment is urgently needed to avert serious sequelae.

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SEE ALSO: *Cloning: Reproductive; Disability; Embryo and Fetus; Eugenics; Eugenics and Religious Law; Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Genetic Discrimination; Genetics and Human Self-Understanding; Infants; Informed Consent; Maternal-Fetal Relationship; Mistakes, Medical; Moral Status; Reproductive Technologies; Value and Valuation;* and other *Genetic Testing and Screening* subentries

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III. POPULATION SCREENING

One of the sequelae of the Human Genome Project has been a resurgence of interest in using clinical genetic testing tools at the population level to promote public health goals (Khoury, 1996; Coughlin). This resurgence raises a number of bioethical issues for public health policy-makers and the health professionals involved in delivering genetic services: questions about the limits of public health authority in this domain, the justice of population-based genetic interventions, the social costs of such screening, and the ethical allegiances of the clinicians involved. In this entry, these issues will be reviewed through the lens of one problem that seems to animate all the rest: the problem of defining *prevention* for the purposes of a *public health genetics.*

Background

Mass genetic screening programs have a relatively long history amongst modern genetic services, starting with the screening of newborns for prophylactic therapy against metabolic disorders in the 1960s and continuing into adult carrier testing programs for recessive genetic diseases such as Tay-Sachs (Kaback; Blitzer and McDowell), sickle cell disease (Bowman; Duster), and the thalassemias (Angastiniotis, Kyriakidou, Hadjiminas) in specific at-risk populations in the 1970s. The early adult screening programs shared two features that warranted, and garnered, significant attention within bioethics and health policy (National Academy of Sciences; President's Commission). First, they targeted specific socially-defined populations, which raised issues of group-specific stigmatization and discrimination (Kenan and Schmidt; Markel). Second, the information about carrier status the screens provided was primarily useful for reproductive rather than therapeutic decision-making, raising issues of parental autonomy, paternalism and procreative choice (Juengst, 1988; Thompson et. al).

The 1980s witnessed a second wave of adult genetic screening programs, aimed at detecting pregnant women at risk for delivering children with genetic birth defects and chromosomal abnormalities (Cunningham and Kizer; Haddow, Palomaki, Knight). These programs are intended to have universal application within populations, and have been routinized into the obstetrical care of pregnant women in many countries, raising issues of voluntariness and informed consent (Press and Browner; Marteau). They have also provoked an outspoken reaction from the community of people with disabilities, who argue that such programs work against attempts to reform social attitudes about disability (Parens and Asch).

Today, these three *traditional* forms of population genetic screening—newborn screening, risk-group carrier testing, and pregnancy screening—continue to make up the vast bulk of population genetic screening activities that are funded and evaluated as state public health initiatives. At the same time, the disease targets of these screening efforts have changed, as public health programs see rationales for shifting specific tests from one form of testing to another. Thus, many states have added sickle cell testing to their universal newborn screening panels (Olney), and calls have been made for universal screening of pregnant women for maternal PKU (Kaye, et. al) and fetal hemoglobinopathies (Cuckle). Moreover, genetic tests originally reserved for clinical use in families at risk for diseases such as cystic fibrosis or fragile-X syndrome have also begun to be used as population screens, both as part of newborn screening panels and prenatal testing programs (Caskey; Cuckle). In all such shifts, the tests have moved in the direction of earlier and more universal screening.

The new wave of interest in *public health genetics* generated by advances in genomic science focuses on tests that would have universal application within multi-ethnic populations, like pregnancy testing, but, like newborn screening, would measure the tested individuals' personal risk for disease, with an eye toward prophylactic action. Moreover, in addition to screening for signs of rare *genetic diseases,* like all the traditional forms of screening, the emphasis is on the detection of molecular markers that confer statistically increased risks for more complex, and more common, chronic diseases of adulthood, like coronary artery disease, cancer, or diabetes (Khoury, Burke, Thompson).

The discussion of using these new tests as public health tools has been dominated by questions of feasibility and utility (Omenn, Holtzman). As one review concludes:

> Several issues must be addressed, however, before such tests can be recommended for population-based prevention programs. These issues include the adequacy of the scientific evidence, the balance of risks and benefits, the need for counseling and informed consent, and the costs and resources required. Ongoing assessment of the screening program and quality assurance of laboratory testing are also needed. (Burke et al., p. 201)

These concerns mirror those expressed in the literature on using predictive genetic risk assessments as a part of medical care in clinical settings (Geller, et. al.). The use of these same tests as population screening tools would place them in the larger context of the existing population genetic screening programs, however, and it is in that context that they become most bioethically challenging. As these tests become integrated into the shifting mix of existing *population-based prevention programs,* they expose fundamental questions about the goals of the enterprise that have not been so apparent in the past. What should population-based genetic screening strive to accomplish, and by what criteria should one measure success?

Phenotypic and Genotypic Prevention

The ubiquitous answer to these questions in the literature of public health genetics is *the prevention of disease,* a classic public health goal. This goal is operationalized as the reduction over time in measures of the morbidity and mortality caused by the target disease within the screened population. To flesh out the kinds of interventions that should be counted in those measures, most authors appeal to the public health field's traditional lexically-ordered scheme of primary, secondary and tertiary *levels of prevention,* and attempt to categorize population genetic screening tests accordingly. Thus, for example, one public health guidance document states:

> Primary prevention genetic services are services intended to prevent a birth defect, genetic disorder, or disease before it occurs. Genetic counseling is a form of primary prevention. Genetic counseling provides couples with information about their pregnancy, and reproductive risks and pregnancy options. Secondary prevention genetic services are services intended to prevent the unfavorable sequelae of an existing disorder or genotype. Newborn screening is a classic example of secondary prevention. Tertiary prevention genetic services are services aimed at ameliorating the unfavorable consequences of existing disorders, through enabling services such as parent-to-parent support and empowerment. (Kaye et al.)

Using this scheme provides a logic for shifting tests into the newborn, prenatal and preconception stages, because traditionally "primary prevention" has been considered the ultimate goal of public health interventions.

Unfortunately, this scheme also introduces an important equivocation into public health discourse between two different ways in which genetic screening might be thought to be *preventive*: genetic screening as a technique for preventing the expression of a genetic disease in an individual and genetic screening as a technique for preventing the intergenerational transmission of disease genes. For convenience, the first kind of prevention may be called *phenotypic prevention,* since its goal is to prevent the manifestation of a particular clinical phenotype. Similarly, the second sort of prevention may be called *genotypic prevention,* (or *genoprevention*) because its goal is to prevent the birth of people with particular genotypes. Equivocating between these two senses of prevention in discussions of population screening results in the attribution of genotypic preventive goals to public health genetics. That, in turn, generates the deeper questions of public authority, social justice, and professional allegiance that animate bioethical concern in this area.

Phenotypic Prevention

The dominant rhetoric of contemporary public health genetics stresses phenotypic forms of prevention as the primary goal of population genetic screening (Coughlin). This is not surprising. Phenotypic prevention is a straightforward medical pursuit that few would criticize: it is designed to further the health interests of individual patients by allowing them to avoid foreseeable medical problems. Almost all public health efforts outside of population genetic screening employ this concept of prevention, and even within public health genetics there are typical phenotypic prevention efforts at each of the three *levels of prevention* (Holtzman).

The concept of phenotypic prevention rests on several assumptions, however, which are worth unpacking. First, phenotypic prevention assumes that there are people who survive the intervention to benefit from having their foreseeable health problems forestalled. Thus, for example, proposals to *prevent* occupational disease by firing all susceptible employees instead of cleaning up the workplace seem inherently wrong-headed. Second, it assumes that diseases are best defined at the level of the actual health problems that they occasion for individual people, rather than in terms of their preclinical etiology. Otherwise, preclinical interventions like dietary changes would be directly curative, not prophylactic. Third, it assumes that diseases are distinct from the people they burden, so that it becomes appropriate to use metaphors of external defense to describe the beneficiaries, as *vulnerable* to *attack* by disease without the *protection* of prevention.

Along with these assumptions, the concept of phenotypic prevention enjoys a high degree of moral authority as an imperative for medicine and society. In fact, the promise of phenotypic preventive measures to "protect the helpless from harm" has been compelling enough in our society to allow both primary and secondary forms of phenotypic prevention to become established in effectively mandatory programs as a matter of public policy (President's Commission).

Of course, if primary prevention is the prevention of the onset of a genetic disease in an at-risk patient, then most of the preconception, preimplantation, and prenatal genetic screening interventions usually classified as *primary prevention strategies* cannot, in fact, qualify for that status. Neither pre-implantation embryo screening nor selective termination can serve to prevent the onset of a heritable disease in affected patients. At most, they are capable of preventing cases of a disease within a family (or a population), by allowing parents (or a society) to avoid the birth of at-risk individuals.

This conceptual confusion does lead to some cognitive dissonance in the literature. The Centers for Disease Control and Prevention, for example, illustrates the concept of *primary prevention* in genetics by listing "medical and community-based interventions focused on carrier detection and premarital counseling as ell as on prenatal diagnosis and pregnancy termination," but then adds the confusing parenthetical remark that "(This last may not be considered primary prevention)" (Khoury et al., 1997, p. 1718). It is also telling that one can find carrier screening, intrauterine diagnosis and selective termination classified in the literature as an example of primary prevention (Kaye, et. al.), secondary prevention (Wertz, Fletcher, and Berg), and even tertiary prevention (Porter)! Clearer thinkers: Holtzman (1989) sets carrier screening, amniocentesis and selective termination outside of preventive medicine's traditional trichotomy, by labeling them as a form of genetic disease *avoidance.* Similarly, the editor of the journal Community Genetics declares that:

> Calling termination of pregnancy after prenatal diagnosis "prevention" is a perversion of terminology. I suggest that we should use the term "reproductive choice." By analogy with prevention, one might define different levels of reproductive choice. Primary reproductive choice would then consist of actions to avoid conception of affected offspring, while secondary reproductive choice would bar implantation or birth of affected embryos and fetuses. (ten Kate, p. 87)

In fact, when they incorporate reproductive genetic screening programs into their menu of preventive interventions, public health geneticists have been forced to slip between two very different senses of *prevention.* They have conflated screening to prevent the phenotypic expression of a genotype in a particular patient (*phenotypic prevention*) with screening to prevent the birth of individuals with a particular genotype (*genotypic prevention*). These two visions of screening reflect quite distinct concepts of disease prevention, with different histories within healthcare, different philosophical assumptions, and different degrees of moral authority.

Genotypic Prevention

Genotypic prevention is a pursuit that is much more controversial than phenotypic prevention. That is understandable, for several reasons:

First, it is often hard to know what ends genotypic preventive measures are intended to serve. Genotypic preventive measures are usually described as a way of furthering the procreative interests of prospective parents, by allowing them to avoid the birth of individuals with foreseeable health problems (like AID following adult carrier testing for cystic fibrosis mutations, or selective termination following intrauterine diagnosis of Down's syndrome).

At the same time, these same interventions are often evaluated in terms of the economic and public health interests of society, according to their ability to reduce the incidence of genetic disease in a population. Thus, the famous "success stories" of genetic screening (like the Mediterranean carrier screening programs for beta-thalassemia, or Tay-Sachs screening in the Ashkenazi-American population) most often counted as successful in terms of these societal criteria (Rao, et. al.; Blitzer and McDowell). In those stories, in fact, the commitment to channeling screening efforts through the individual's voluntary reproductive choices is itself portrayed as simply a savvy strategy for achieving the profession's underlying goal of reducing society's healthcare costs (Caskey; Palomaki; Chappele, et. al.).

Secondly, whether geno-prevention is pursued in the cause of family planning or the public health (or both), it must make two sets of related assumptions. First, it assumes that the diseases it prevents are best understood at the level of the genotype, rather than through the pathophysiology of their expression, just as AIDS is understood in terms of its causal HIV infection rather than the infection's clinical sequelae. Understanding genetic disease through the lens of the germ theory in this way means that the language of "molecular disease," and "DNA-based diagnosis" seems apt, and it makes sense to contrast preventing the vertical transmission of pathogenic disease genes with palliative or symptomatic interventions like low phenylalanine diets.

Second, proponents of geno-preventive efforts must assume important personal (or social) value judgments about the burden of the cases of disease being prevented. Genes are not, like germs, external infectious agents that can be kept (or cleaned) out of a living person's body. Instead, genotypic prevention has to involve avoiding the birth of individuals conceived with the pathological genotype. The beneficiaries of such an intervention cannot be the individuals whose births are avoided: if the genotypic transmission has been successfully prevented, there can be no such individuals.

That means that to justify geno-prevention someone (parents or society) must make the judgment that the burden of coping with cases of a disease outweighs any other value that individuals with a given genotype might bring to a family or community, and warrants action to exclude individuals with those mutations from the lives of the wild type.

Finally, genotypic prevention already has a bad track record as a social and professional goal. Genotypic prevention has been accepted before as a societal imperative, on the coat-tails of the public health movement's successes with the primary prevention of infectious disease (Allen). The "Eugenics Movement" of the first half of the twentieth century is remembered primarily for the discriminatory immigration restrictions and coercive sterilization laws it produced (Reilly), and the ease with which it was appropriated to support genocide (Muller-Hill). The horrific consequences of ranking genotypic preventive goals over individual interests still effectively undermine any claims to moral authority it might make.

Unfortunately, as its controversial features already suggest, to the extent that population genetic screening becomes associated with a professional allegiance to genotypic prevention, it inherits all the history, assumptions and moral liability of that concept, and the prospects for a well-reasoned public assessment of its merits dim considerably.

Against this background, the professional confusion over the true goals of contemporary genotypic prevention services and the fact that all geno-preventive services require the judgment that some genotypes are predictably burdensome enough to others to outweigh any other potential their bearers might have, makes it easy for critics of new approaches to genotypic prevention to remind the public of the excesses of the historical eugenics movement, and label any new efforts accordingly, with powerful political effect (Hubbard).

Moreover, inviting external political challenges is not the only trouble that endorsing genotypic prevention would create for public health genetics. it would also create substantive philosophical tensions within the field which could threaten the ethical integrity of the field. Since genotypic prevention is also unnecessary as a rationale genetic screening and counseling services, some argue that it is time for public health authorities to explicitly eschew this old eugenic legacy as a professional goal.

Ethical and Social Implications

As a professional ethical matter, accepting genotypic prevention as a proper goal of public health genetics has chilling implications. Expanding the geneticist's preventive goals of genetic medicine to include reducing the incidence of pathological genotypes broadens their responsibilities beyond their presenting patients to the next generation's aggregate population. Since the latter will always be a bigger group, its preventive health needs will always be greater by at least some scores (e.g., disease care costs), and therefore, for some, more compelling. This makes it very easy for genetic medicine to elevate what began as a serendipitous "by-product" of its services—the reduction of disease burden and cost to society—to a central position within its mission, without even noticing when it does so.

Again, such criteria do have a long history in applied human genetics, as basic ingredients in the various programs of "negative eugenics" this century has witnessed. They even continue to be explicitly used by some genetic services programs seeking to justify their public support in economic terms (Chappele, et al; Cuckle). As a result, there is no need to guess at the internal dangers that adopting such ideals would pose for the professional ethics of genetic medicine: the experiment has already been conducted. Experience shows that there are at least four important hazards for the profession:

1. First, the field would have to decide where within the spectrum of human genetic variation to define the pathological genotypes it would seek to prevent (Juengst, 1988). Most of the proponents of preventive genetic screening programs skirt this problem by stipulating that they are only talking about "severe congenital abnormalities" that produce "serious handicaps." (Cuckle). These caveats address this line-drawing problem in a time-honored way, by appealing to common sense notions of severity. In doing so, the proponents of geno-preventive germ-line intervention are following the footsteps of authors like Dr. Nathan Fasten, when he wrote in 1935 that:

> Here one must pause to comment that it is difficult to define clearly the standards of desirability or the standards of perfection in the human family. Even so, most normal persons would agree that the hopeless cases of physical and mental defectives, those that are incapable of care for themselves, particularly where it is certain that such defects are the results of hereditary factors, are no asset to society and should be eliminated as quickly as possible. (p. 354)

So far, Dr. Fasten appears to be anticipating the modern argument. However, Dr. Fasten's own list of what "most normal persons" should include in the class of "hopeless cases" is telling:

> Here are included the feeble-minded, the insane, the paupers, the confirmed criminals, and the grave sex offenders. This group, in general, is a tremendous burden on society. Genetic evidence has been accumulating to reveal that most of these defects are due to heredity. Social workers also

> have discovered that from this stock the largest percentage of the dependent individuals originate. Geneticists and social workers, therefore, believe that nothing but good can come from efforts in the direction of the rapid elimination of this branch of society. (p. 355)

Of course, it would be unfair and anachronistic to insinuate that the contemporary advocates of genetic screening subscribe to eugenic ideologies like Fasten's: they clearly do not. The point in resurrecting him is simply to illustrate that it is often hard to know, in the thick of things, how much one's professional assessments of pathology are influenced by larger cultural ideologies and social values.

If genetic medicine is to prevent its practitioners from being lured away into other social agendas, it still must address the challenge of defining its domain. As the intensity of the debates over the prenatal sex selection as a professional practice already demonstrates (Warren), drawing these boundaries will involve just as difficult a set of value judgments as attempts to use genetic technologies to *enhance* specific human traits. As Dr. Fasten reminds us, without more operational definitions, rhetorical appeals to "severity" and the intuitions of the "reasonable person" will not help brighten any of the lines that will need to be drawn across the spectrum of human traits as genetic medicine's power matures.

2. Moreover, it is increasingly clear that preventing the birth of a particular "pathological" genotype will not always mean preventing a clinical health problem. The more we learn about human genetics at the molecular level, the more complicated the story becomes. One increasingly prominent feature of that story over the last few years has been the deterioration of the theory of specific causation within genetics (Strohman). Not only are most health problems "polygenic" to some degree, but even the traditional "single gene disorders" are turning out to be molecularly heterogeneous (Holtzman). As the number and variety of different specific mutations that can all cause the same disease increases, so does the challenge of detecting and correcting them all in a patient. Worse yet, the causal complexity works in both ways: even the paradigmatic examples of clean Mendelian "singe gene" disorders, like "recessive" cystic fibrosis and "dominant" Huntington's disease are turning out to be multifactoral enough that carrying one of their (multiple) pathognomic genotypes no longer guarantees that one will experience a problematic clinical syndrome (cf. Tsui; Benjamin).

In other words, genotypes are not turning out to function very well as germs. The complexity of their expression as health problems undermines the confidence with which a clinician can predict the occurrence of severe health problems from a DNA diagnosis. Since genotypic prevention is conceptually committed to a deterministic etiology of specific causation, geno-preventive measures risk making (and acting on) both false negative and false positive prognoses. This means that they also risk intervening unnecessarily in cases that the environmental forces of expression and penetrance would have naturally mitigated.

3. Thirdly, as a consequence of its deterministic assumptions, genotypic prevention cannot help stigmatizing genotypes, and (since they are inseparable) the people whom they mark, as undesirable or pathological in themselves (Markel, Parens, and Asch). This kind of reductionism, reducing personal identities to disvalued health problems and disvalued health problems to one stigmatizing sign, is at the root of much of the social discrimination that people with disabilities must already overcome (Fine and Asch). To have public health authorities endorse genotypic prevention as a goal can only exacerbate these challenges, because it provides a medical sanction for exclusionary attitudes.(Saxton; Kaplan; Faden). The concern is that, if a given genotype carries such a disvalue for health professionals, it would not seem unreasonable for the public to chastise those who avoid screening as "irresponsible reproducers" and hold them accountable for their recklessness by denying them opportunities or services, like medical care for affected offspring (Thompson, et. al).

4. Finally, the ways in which genotypic preventive goals tend to overshadow individual interests also endangers the therapeutic relationship within genetic medicine. To the extent that genetic services programs are evaluated in terms of their success to reducing the incidence of particular genotypes, genetic service providers will inevitably have an stake in seeing that their clients make the "right" reproductive decisions: i.e., decisions not to bear children at risk for genetic disease. This is a pressure that is already creating tension within medical genetics, as the field attempts to accommodate itself to healthcare delivery systems that are managed with societal healthcare costs in mind. For example, there has been a lively debate in the British medical literature about how genetic services should interpret the societal expectation that they will "pay their own way" within the national health budget (Chappelle; Clarke). Genotypic prevention, in other words, imports a professional goal that encourages practitioners to influence the reproductive decisions their clients make, despite their professed respect for the reproductive autonomy of those they serve.

Fortunately, all of these professional ethical risks—the subordination of professional integrity to social ideology, the inappropriate reliance on simplistic science, the professional disvaluing of human minorities, and the willingness to invade the sphere of reproductive privacy on behalf of society's economic interests—are dangers which human geneticists have succumbed to and overcome before (Kevles; Allen). Moreover, they are also the dangers in response to which the contemporary *client-centered* professional ethic of medical genetics has largely been shaped. In contemplating the future of germ-line gene therapy, it may be helpful to recall how this existing moral tradition handles the question of genotypic prevention, and consider its relevance for public health genetics. Doing so shows that genotypic prevention is not only a dangerous goal for genetic medicine to espouse, it is also completely unnecessary.

The Existing Tradition

One of the reasons it is easy to slip between the phenotypic and genotypic senses of *prevention* in discussing genetic medicine's goals is that the desire to bear children free from specific genetic diseases can and often does provide a rationale for prospective parents' interest in the specialty's services. But that does not pose a professional ethical problem for clinical geneticists: whether the intervention is genetic counseling, adult carrier screening, intrauterine diagnosis, preimplantation screening, providers of genetic services can help parents achieve their geno-preventive goal in good conscience, because it falls within the sphere of reproductive choices which parents are free to make in a tolerant society. Even the sharpest critics of genotypic prevention as a professional and public policy will agree that individual decisions about these interventions are inseparable enough from core personal values and beliefs to warrant the same respect we give to other fundamental freedoms (of religion, for example)(Saxton; Fine and Asch).

However, it is not necessary to conflate the *patients'* goals with the *professional* goals of genetic medicine in order to display respect for reproductive autonomy. In doing so, advocates of increased screening blur a distinction that clinical geneticists providing more traditional genetic service have worked hard to clarify: the distinction between the profession's mission in providing its services and the personal interests of their clients (Botkin).

Clinical geneticists argue that their professional goals in offering reproductive genetic testing and counseling services have little to do with the content of the autonomous reproductive choices that their clients make. Their mission is to treat a special class of reproductive health problems their clients face as prospective parents: *the reproductive planning problems posed by their risk of having a child with a genetic disease* (NSGC; Bartels). The advocates of this ethos assert that "the fundamental value of genetic screening and counseling is their ability to enhance the opportunities for individuals to obtain information about their personal health and child-bearing risks and to make autonomous and noncoerced choices based on that information," not the elimination of genetic disease (President's Commission). From this perspective, the geneticists' goals are not so much "preventive" as directly therapeutic: the reproductive planning problems they address are already fulminant when their clients engage their services, and their treatment consists of giving them the information, counseling, and options they need to address their problems in terms of their own values and beliefs (Kessler).

This approach to defining the mission of reproductive clinical genetics has several important features for our purposes. The first is its emphasis on the practitioner's primary professional obligations to his or her presenting clients—usually prospective parents—rather than with the next generation. Thus, practitioners are warned that:

> Counselors may find themselves pulled by an allegiance to the unborn child—whose well-being is, after all, the ultimate object of their concern as well as the motivating interest of the parents. As understandable as this concern may be, in the end it must give way to the duty owed to the counselee—the parents (Capron, p. 334).

Secondly, since in practice *reproductive health* largely boils down to the ability to fulfill one's procreative ambitions, the geneticists' treatment goals can only really be accomplished within the context of their patients' own life plans and beliefs. Because the content and consequences of the reproductive decisions that the geneticist helps facilitate reflect personal moral judgments made within the sphere of the patients' procreative liberty, they are understood to be beyond the geneticists' professional domain of concern. As a consequence, geneticists are expected to be strictly *nondirective* in the counseling they provide, and to help their clients to make their own value judgments about the relative burden of the disease their children may inherit. The practical result of this orientation is a strongly client-centered ethos that, historically, anticipated the rise of *patient autonomy* in the ethics of other medical specialties by twenty years.

In part, this tradition has historical roots in the reaction of postwar medical geneticists to the excesses of their eugenic predecessors. However, it also reflects an important strategy for dealing with the predictive and moral uncertainties of the reproductive decisions that geneticists' help their clients make (Juengst, 1989). The tradition is often inaccurately accused of prescribing "value-neutrality" and criticized accordingly (Caplan), but it would be more accurate to label it as "value-sensitive," since it instructs clinical geneticists to discern and work with their clients' values, rather than be blind to them.

The consequence of this client-centered, non-directive ethos is that genetic medicine has no need to adopt geno-preventive goals in order to explain or justify the interventions it performs on behalf of its clients. In fact, it is free to repudiate "public policy intended to change the genetic makeup of the populations" (Council of Regional Genetics Networks), and thereby to distance itself from the liabilities that the geno-preventive concept brings to the profession. One recent statement of this ethos is worth citing at length, because of the ways it clearly displays its roots in the field's concern with the hazards of espousing geno-preventive goals for their services:

> Reproductive genetic services must ultimately serve personal—not public—interests, in improving the overall reproductive lives of women. Whatever societal gains might be realized through the eugenic use of reproductive genetic services should be heavily outweighed by the personal needs of women and their families. The ideals of self-determination in family matters and respect for individual differences, ideal that lie behind the client-centered view of reproductive genetic services, are jeopardized whenever the primary goal of these services becomes the prevention of the birth of individuals with a disorder or a disability. To the extent that voluntary reproductive genetic services are evaluated even indirectly in eugenic terms, societal pressures have the potential to threaten the important interests of individual women and their families. (Thomson et al., p. 1161)

Of course, there are still plenty of ethical tensions within this model of genetic medicine (e.g. cf. Bartels). For example, as more can be done to address the phenotypic problems associated with fetal genotypes identified through genetic testing, it becomes harder to interpret prenatal testing as solely aimed at addressing a parental reproductive health problem. In these cases, the fetus emerges as a *presenting patient* for the medical geneticist, with its own claims to professional allegiance. Similarly, to the extent to which the profession fails to distinquish between their commitment to a non-directive counseling style and their professional obligation to establish the limits of their services, concerns about a laissez faire, commercialized, "consumer eugenics" will remain. Genetic medicine also has to grapple with the fact that, unless the profession is willing to use genotypic preventive measures of success, it may find its reproductive testing and counseling services excluded from cost-conscious healthcare coverage plans as relative luxuries.

Moreover, despite its prominence in the rhetoric of the field, it is also true that this client-centered ethos does not command universal allegiance amongst human geneticists: in fact, 59% of geneticists surveyed do still endorse the "reduction in the number of carriers of genetic disorders" as a professional goal for their field (Wertz and Fletcher). Nevertheless, on the whole, rejecting genotypic prevention in favor of focusing on the interests of the presenting patient serves its advocates well in clinical genetics. By keeping the specialty's loyalties with the particular patients at hand, and its professional prescriptions within the context of those patients' own values and goals, it inoculates the field against infection by the dangerous agendas of negative eugenics.

The bad news for proponents of population genetic screening, of course, is that returning to the client-centered ethos of medical genetics does mean that they will have to forego their appeals to genotypic prevention in making their case. Whether or not genetic screening has any promise for "purifying the human gene pool" should remain totally irrelevant to its acceptance as a public health tool. Given the political, professional and social dangers of going down the eugenic road, any short-term benefits of doing so could carry a very heavy price for all concerned.

Conclusion

Genetic medicine is quickly leaving the stage in its history when it only has information and solace to provide its patients. As it becomes increasingly incorporated into public health, it will be important not to forget the moral tradition that sustains it. Affirming the traditional commitment of geneticists to the physical health and reproductive autonomy of their clients and patients means relinquishing genotypic prevention as a formal goal for the profession. In contemporary political argot, public health genetics should continue to be an empowering, not an exclusionary science: it should continue to be about helping living people address their individual health problems, and not about protecting the *gene pool* or society from those people, as some form of expensive pollution. Speaking clearly about the place of *prevention* in public health genetics is one way the pioneers of the new era can reaffirm this fundamental conviction.

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SEE ALSO: *Coercion; Eugenics; Eugenics and Religious Law; Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Genetic Discrimination; Genetics and Human Self-Understanding; Informed Consent; Justice; Public Health*

Law; Value and Valuation; and other *Genetic Testing and Screening* subentries

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IV. PUBLIC HEALTH CONTEXT

Genetic testing and screening programs have long been part of public health programs in the United States. For decades public health authorities have recommended the screening of newborns for specific genetic (and nongenetic) conditions through genetic tests that use blood samples from infants. Neonatal genetic testing and screening increasingly are becoming part of public health practice in the modern genetic revolution. Genetic testing and screening in the delivery of health services and for occupational purposes (Shulte and DeBord) are becoming more common despite legal impediments.

The proliferation of genetic testing and screening in the interests of protecting public health may help improve health outcomes on a population basis, but it simultaneously raises significant legal, social, and ethical concerns. When should genetic tests be allowed without informed consent? Should genetic screening be allowed for every condition for which a reliable and accurate test is available? When should genetic screening programs be mandatory (required) or voluntary (optional)? How can public health authorities or others acquire, use, or disclose sensitive genetic test results? These and other ethical issues are discussed in this entry in the context of the classic debate between individual rights and the goal of protecting the public's health.

Genetic Testing and Screening: Similarities and Distinctions

Though often used interchangeably, genetic testing and screening are different concepts. *Genetic testing* refers to medical procedures that determine the presence or absence of a genetic disease, condition, or marker in individual patients (Gostin). Genetic tests involve an examination of chromosomes, DNA molecules, or gene products (such as proteins) to find evidence of certain mutated sequences.

Genetic tests can (1) confirm a diagnosis for a symptomatic individual, (2) assist with presymptomatic diagnosis (e.g., Huntington's disease) or assessment of the risk of development of adult-onset disorders (e.g., Alzheimer's disease), (3) identify carriers of one copy of a gene for a disease in which two copies are needed for the disease to be expressed, and (4) aid in prenatal diagnosis and newborn screening. Hundreds of genetic tests are available to predict diseases in individuals and the population (Secretary's Advisory Committee on Genetic Testing [SAGCT]). Many others are being developed.

Despite their great potential, technical limitations to genetic tests can inhibit the prediction of disease in individuals. A genetic test may not be able to identify every mutation of a gene (which can have mutations in several places along its base pairs) and thus may not indicate an abnormality. Different mutations in a gene have different effects. The cystic fibrosis gene, for instance, has 800 potential mutations with varied effects on health (SACGT). In addition, genetic tests do not measure the complex interactions between genes and environment that contribute to the onset of almost all diseases. As a result, a genetic test is limited in its ability to gauge an individual's susceptibility to causes of mortality such as heart disease accurately.

Screening entails the systematic application of a test to a defined population (Gostin). *Genetic screening* refers to programs designed to identify persons in a subpopulation whose genotypes suggest that they or their offspring are at higher risk for a genetic disease or condition. In many cases this requires the administration of genetic tests, as defined above. Thus, whereas genetic tests are used to reveal specific propensities among individuals, genetic screening programs help identify rates of genetic diseases or conditions among subpopulations and sometimes can uncover previously unknown or unrecognized conditions. The nature and scope of genetic screening programs vary. Some screening programs are mandatory: Persons must participate in a screening program unless they opt out (where allowed) for religious, philosophical, or other reasons. Most screening programs, however, are voluntary. Persons may choose to participate (opt in) but do not have to.

There are many examples of genetic screening for public health purposes. Women may be screened for genetically related breast cancers. Persons may participate in prenatal genetic screening programs to determine genetic disorders in embryos before implantation. Obstetricians may advise pregnant women in higher-risk groups about specific genetic tests. Fetal karyotyping, for example, can suggest an increased likelihood of carrying a fetus with Down's syndrome among older women. Screenings for conditions such as Tay-Sachs disease and cystic fibrosis are available. Perhaps the most prominent example of genetic screening among a subpopulation is the long-standing public health practice of screening newborns for genetic conditions. Most states require the screening of infants for treatable genetic disorders, particularly phenylketonuria (PKU), subject to refusal on religious or philosophical grounds (New York State Task Force on Life and the Law). Some statutes deem newborn screening voluntary, although in practice it almost always is done in the interest of protecting an infant's health.

Genetics and Public Health

Genetic testing and screening further public health goals of preventing and treating diseases in the population in many ways. Because many diseases and conditions result from interaction among genes, behavior, and environment, understanding the role genes play in contributing to diseases clarifies the ways in which environmental and behavioral influences may lead to the onset of diseases. With this knowledge public health professionals can shape their assessment, policy development, and assurance techniques more effectively. Public health professionals can promote the use of genetic tests and services when inexpensive and effective treatments are available to advance the collective health of the population. An example mentioned involves newborn screening programs, which are expanding in scope as new genetic causes and treatments of disorders are discovered.

Genetic testing and screening for multifactoral conditions such as cancer may allow susceptible persons to change their behaviors and environment, thus improving public health. Public health officials may be best equipped to conduct population research to evaluate the clinical validity and utility of genetic testing and screening. Also, those officials can play a substantial role in the dissemination of information to medical professionals and the public about the role of genetics in health (Gostin, Hodge, and Calvo).

The use of genetic tests and screening for public health purposes, however, can be problematic. Genetic tests that have high rates of inaccuracy can lead to low predictive values when they are incorporated into a genetic screening program. Significant numbers of tests results that are false positive (healthy persons are wrongly determined to be affected by a genetic disease or condition) and false negative (persons who are affected go undetected) can follow. Experience with genetic screening for sickle-cell anemia among African-Americans in the 1970s demonstrated the potential discrimination that may follow a public health screening program (New York State Task Force on Life and the Law). Beyond obvious individual harms, genetic screening programs that are not scientifically sound or justifiable on societal grounds have little utility in public health. With limited resources for preventive public health measures, genetic screening programs that produce small yields (the number of newly recognized cases derived from the screening) as a result of inaccurate testing or other failures can compromise public health goals. Stated simply, poorly administered or poorly designed genetic screening programs that use inaccurate tests or insufficiently target at-risk populations negatively affect individuals and result in minimal or no improvement in public health.

Ethical Concerns

Ethical issues pervade any public health strategy involving genetic tests or screening. This section examines some of the key ethical issues concerning individual informed consent, the design and application of genetic screening and testing, and privacy and discrimination. These and other issues are explored in the context of the sometimes divergent views of public health and individual ethical theories discussed below.

BIOETHICS AND PUBLIC HEALTH ETHICS. Ethical questions arising from genetic testing and screening in the context of public health require an understanding of the differing perspectives of individual and public health ethics. Principles of bioethics largely have an individualistic focus. Persons as individuals are entitled to autonomy, are owed fair and equitable treatment, and must not be harmed intentionally. These rights inhere in each person and, consequently, are owed to each person. Principles of public health ethics do not abandon this individualistic approach. Protection of individual rights is critical in public health practice that increasingly stresses an ethic of voluntarism.

In contrast, public health is focused on the health of communities. Protecting the health of communities sometimes may require individuals to act or contribute to the larger community goals. For example, screening infants for genetic diseases requires parents to allow their children's blood to be tested. The resulting infringement on individual autonomy and decision making under this scenario may be minimal, but the impact on public health can be extraordinary. Public health authorities suggest that this infringement is completely justifiable under a public health ethical framework that envisions individuals as members of society with certain communal goals.

Many bioethicists often perceive a conflict between individual ethical rights and duties and public health ethics. Public health programs and efforts seemingly interfere with individual decision making, bodily integrity, and other protected interests. Ideally, public health programs incorporate the ethical rights of individuals to promote individual participation, which is essential to accomplishing many communal health goals. Sometimes it is not possible to respect the ethical interests of individuals and accomplish legitimate public health goals. For example, it is problematic to allow persons to deny public health authorities access to their diagnoses of genetic disease, which the authorities need to conduct effective surveillance. The individual's claim of a breach of privacy rights under principles of autonomy could trump the community's goal of monitoring disease among the population. Public health ethics suggests that persons participate in public health measures even when some infringement of their individual rights may follow. This analysis provides an appropriate framework for considering the ethical issues discussed below.

INDIVIDUAL INFORMED CONSENT. Principles of autonomy strongly support the individual's right to informed consent before genetic testing or screening. Many law and policy makers, particularly at the state level, have passed legislation or created administrative regulations in the last decade that require specific, written informed consent (sometimes including genetic counseling). Before the administration of a test patients are entitled to explanations of the nature and scope of the information to be gathered, the meaning of positive test results, the underlying disease or condition, and any risks involved in the testing or activities that follow a positive result. Through advance informed consent it is hoped that patients can weigh the benefits of genetic testing against the risks. However, problems in understanding the complexities of genetic science and uncertainties in the meaning of positive test results can limit the value of informed consent (Press and Clayton).

Should genetic tests ever be allowed without informed consent? Public health officials may justify mandatory newborn screening programs without parental consent by reference to utilitarianism and corresponding legal principles that authorize the state to protect children. However, at least in regard to autonomous individuals, there is little justification to mandate genetic testing or screening without informed consent.

WHEN SHOULD GENETIC SCREENING BE PERFORMED? Although genetic screening may be enhanced through the use of accurate tests, there are other key considerations, including determining (1) the at-risk population to be targeted for screening, (2) the method or methods of screening, whether mandatory (required) or voluntary (optional), (3) the persons who have access to the screening program (Lin-Fu and Lloyd-Puryear), (4) whether there is an effective and affordable treatment for the condition being screened, (5) the corresponding benefits to individuals of screening in cases in which treatment is lacking, and (6) whether the screening program is well tailored to accomplish the underlying public health goals.

Each of these criteria underlying the implementation of a genetic screening program is critical. If the screening program targets too large a group and is thus over-inclusive, persons may unjustifiably be asked or required to participate without any individual or public health benefit. If the screening is mandatory, individual autonomy can be breached unfairly. In cases in which persons lack access to testing services, they are unfairly left out of a public health program designed to improve communal health. If there is no effective treatment for a genetic condition, is there a valid reason to screen anyone for it? Many public health officials would suggest that there is not.

PRIVACY AND DISCRIMINATION. Many persons view their genetic information as highly sensitive and take affirmative measures to protect the privacy of that information. According to Georgetown University's Health Privacy Project (2001), over 15 percent of people engage in privacy-protective behaviors (e.g., withholding information, providing inaccurate information, doctor hopping, or avoiding care) to shield themselves from misuse of their health information. Individuals are concerned about the privacy of their genetic data because breaches can lead to invidious discrimination against an individual or group (Hodge and Harris) by insurers, employers, government agencies, and other societal members. Health, life, and disability insurers may attempt to use genetic test results to limit or deny coverage. Employers may reject applicants for positions or advancement on the basis of their genetic flaws (Gostin, Hodge, and Calvo).

Complicating the privacy claims of individuals, however, are the legitimate claims of others who have a right to know about another person's genetic profile. Spouses, offspring, and close family members may claim a right to obtain knowledge of an individual's genetic test results. State courts in Florida and New Jersey have suggested that healthcare workers may be obligated to share the results of genetic tests with blood relatives of their patients in certain circumstances. Right-to-know claims may further principles of beneficence but can impinge on the privacy rights of individuals participating in public health genetic screening programs.

GENETIC EXCEPTIONALISM. Individual privacy and antidiscrimination concerns relating to genetic testing have led many states to adopt genetic-specific privacy and antidiscrimination laws that are intended to protect persons from wrongful acquisition, use, or disclosure of individually identifiable genetic data. These laws treat genetic information differently from other medical or personally identifiable information and typically establish heightened protections (Gostin and Hodge). Within the context of public health uses of genetic testing or screening programs the trend toward genetic exceptionalism presents its own ethical and practical concerns.

Genetic exceptionalism suggests that genetic information is unique. Many people believe that genetic information is different from other health data for several reasons. Foremost among those reasons is its predictive nature. Unlike most other medical records, which describe an individual's past or current health condition, genetic tests can identify (with varying degrees of confidence) the increased risk of future disease in otherwise healthy individuals. Other qualities add to the perception that genetic information is different. It remains largely stable throughout life. Genetic footprints are remarkably identifiable. Genetic conditions are inherited, and this means that genetic information necessarily reveals information about an individual's current family members and future offspring. Finally, although genetic tests are limited in their capabilities, genetic information can transcend health status to reveal predispositions and personal characteristics (Gostin, Hodge, and Calvo).

There are drawbacks to treating genetic information differently. Strict protection of autonomy, privacy, and equal treatment of people with genetic conditions may threaten the accomplishment of communal goods, including public health surveillance. As scientists discover more medical conditions that are gene-based, it will become increasingly difficult to distinguish genetic data from other medical data. Genetic information is part of the continuum of an individual's medical record and cannot be separated from those data easily. Some privacy advocates argue that genetic information is more sensitive than other health information because it can provide significantly more personal information about an individual's existing and future medical conditions. However, *nongenetic* electronic health records also may provide many personal details. Electronic health records include private demographic, financial, and family history information as well as a patient's social, behavioral, and environmental factors (Gostin and Hodge).

Genetic-specific statutes may be considered unfair because they treat people who are facing the same social risks differently on the basis of the biological cause of their otherwise identical health conditions. Why, for example, should medical information about a woman who has developed breast cancer of genetic origin (e.g., BRACA 1 or 2) be given greater protection than information about a woman who has developed breast cancer because of environmental or behavioral factors such as smoking (Rothstein)?

On a practical level, treating genetic diseases as distinct from other medical diseases or conditions may enhance the stigma of genetic testing and screening programs even as lawmakers attempt to remove their stigmatizing effects. This can create public fears and misapprehension about genetics that may discourage individuals from seeking testing or participating in screening programs and may thwart future scientific progress.

Conclusion

The public health benefits of genetic testing and screening support their existing and future uses in the population, yet the underlying risks to individuals and populations require caution and awareness. Ethical issues related to the administration of testing and screening with informed consent, the privacy rights of individuals, and concerns about discrimination cannot be resolved easily. Balancing individual rights with the community's interests in promoting public health requires an understanding of the sometimes divergent positions of bioethics and public health ethics. Exceptionalizing protection of individual rights that are based on distinctions of genetic tests or information from other health data is difficult. Ultimately, choices about the use of genetic tests and the administration of genetic screening in the population must be made collectively in the interests of promoting improvements in public health.

JAMES G. HODGE, JR.

SEE ALSO: *AIDS; Autonomy; Confidentiality; Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Holocaust; Informed Consent; Public Health; Public Health Law; Public Policy and Bioethics; Race and Racism; Utilitarianism;* and other *Genetic Testing and Screening* subentries

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INTERNET RESOURCES

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V. PREDICTIVE GENETIC TESTING

In June 2000 international leaders of the Human Genome Project (HGP) confirmed that the rough draft of the human genome had been completed a year ahead of schedule. In February 2001 special issues of *Science* and *Nature* published the working draft sequence and analysis. A complete, high-quality DNA reference sequence was announced in April 2003, two years earlier than the originally projected completion date. Although a major goal of the HGP is to provide tools to treat, cure, and ultimately prevent genetic disease, the immediate outcome has been a surge in the number of genetic tests that can be used to determine an individual's risk for developing an ever-increasing number of genetic diseases.

The ability to provide currently healthy individuals with DNA-based risk assessments for diseases that will manifest in the future, especially in the absence of effective treatment for those diseases, presents challenges for those at risk, health professionals, and society. This entry explores some of those challenges, concentrating on tests that can detect mutations associated with adult-onset disorders.

Available Tests

The beginning of the era of genetic prediction can be dated to 1983, when Huntington's disease (HD) became the first disease to be mapped to a previously unknown genetic location through the use of restriction enzymes that cleave deoxyribonucleic acid (DNA) at sequence-specific sites (Gusella et al.). Huntington's disease is a late-onset autosomal dominant neuropsychiatric disorder. The child of an affected parent has a 50 percent chance of inheriting the genetic mutation that causes HD. Disease onset usually occurs in the fourth decade of life and is marked by a movement disorder, alterations in mood, and cognitive decline. There is no treatment or cure.

Inherited variations of these DNA sequences, which also are known as restriction fragment length polymorphisms (RFLPs), can be used as genetic markers to map diseases on chromosomes and to trace the inheritance of diseases in families. The discovery of these markers represented a significant advance in HD research. Not only did the markers provide a possible clue for finding the HD gene and understanding the mechanism by which the gene causes brain cells to die, this discovery meant that predictive testing for some individuals at risk for HD was possible through the use of a technique called linkage. Linkage testing requires the collection and analysis of blood samples from affected and elderly unaffected relatives of the at-risk individual who asks for testing to trace the pattern of inheritance of the HD gene in a specific family. Linkage testing is labor-intensive and expensive and can result in erroneous conclusions caused by incorrectly attributed paternity, misdiagnosis, and the distance between the gene and the markers used for testing. The discovery of the HD gene in 1993 (Huntington's Disease Collaborative Research Group) made testing more accurate, less expensive, faster, and possible for every person at risk for HD.

Since that time new discoveries in molecular genetics have shifted the focus from relatively rare single-gene disorders such as HD to common adult-onset disorders that cause substantial morbidity and mortality. Examples include the identification of mutations in the BRCA1 and BRCA2 genes as causes of susceptibility to breast and ovarian cancers (Miki et al.; Wooster et al.), the discovery of multiple genetic mutations associated with the risk of colorectal cancer (Laken et al.; Lynch and Lynch), the reported association between the APOE e4 allele and late-onset Alzheimer disease (Strittmatter et al.), associations between factor V Leiden and thromboembolic disease (Hille et al.; Ridker et al.; Simioni et al.), and the identification of the HFE gene for hereditary hemochromatosis (Beutler et al.; Edwards et al.). In the second decade of the twenty-first century it has been predicted that genetic tests will be available for diabetes, asthma, dyslexia, attention deficit hyperactivity disorder, obesity, and schizophrenia. These discoveries point to the potential use of genetic tests for population screening in adult populations and an increasing role in public health for genetic testing.

Evaluating New Tests

The National Institutes of Health–Department of Education–Department of Energy (NIH–DOE) Task Force on Genetic Testing stated in 1998 that any proposed initiation of population-based genetic screening requires careful attention to the parameters of both analytical and clinical validity. For DNA-based tests analytical validity requires establishing that a test will be positive when a particular sequence is present (analytical sensitivity) and establishing the probability that that test will be negative when the sequence is absent (analytical specificity). Clinical validity involves establishing measures of clinical performance, including the probability that the test will be positive in people with the disease (clinical sensitivity), the probability that the test will be negative in people without the disease (clinical specificity), and the positive and negative predictive value (PV) of the test. The positive PV is the probability that people with a positive test eventually will get the disease. The negative PV is the probability that people with negative test results will not get the disease.

Two features of most of the genetic diseases discussed as candidates for population-wide screening also affect the clinical validity of any test designed to screen for those diseases. The first is heterogeneity, or the fact that the same genetic disease may result from the presence of any of several different variants of the same gene (an example would be cystic fibrosis, with over 900 mutations found in the CF gene) or of different genes (such as the genes for breast cancer BRCA1 and BRCA2). The second is penetrance, the probability that disease will appear when the disease-related genotype is present. Both heterogeneity and penetrance may differ in different populations, causing difficulties in the interpretation of test results. The final Report of the Task Force on Genetic Testing stated that "clinical use of a genetic test must be based on evidence that the gene being examined is associated with the disease in question, that the test itself has analytical and clinical validity, and that the test results will be useful to the people being tested" (Task Force on Genetic Testing).

From a public health perspective the value of implementing these tests on a population-wide basis will depend to a large extent on whether early treatment of diseases discovered through screening improves the prognosis (Burke et al.). That can be determined only through randomized clinical trials, an expensive process for the array of tests likely to be developed in the near future. However, experience with hormone replacement therapy (HRT) for healthy postmenopausal women in which HRT was found to cause more health problems than a placebo (Writing Group for the Women's Health Initiative Investigators) and a widely used knee surgery technique for osteoarthritis that was found to be ineffective (Moseley et al.) suggests that such trials may be a necessary component of any proposed large-scale screening effort.

Critics of this approach say that the prospective studies necessary to gather this type of information can take years. If widespread use of a test is withheld until the positive predictive value is determined fully and the risks and benefits of testing are known clearly, manufacturers and laboratories could be inhibited from developing tests, and consequently, people will be denied the benefits of being tested. Even without an effective treatment these benefits might include a reduction in uncertainty, the ability to avoid the conception or birth of a child carrying the disease-causing mutation, escape from frequent monitoring for signs of disease or prophylactic surgery, and freedom from concerns about employment or insurance discrimination.

In the absence of a consensus on the public health benefits of widespread screening, tests continue to be developed and in some cases marketed directly to physicians and consumers. For example, in June 2002 Myriad Genetics, based in Salt Lake City, Utah, announced that it would market genetic tests for familial cancers to the general public despite the fact that those tests were appropriate only for a very small percentage of the population. This practice has been the subject of some controversy (Holtzman and Watson), especially in cases in which predictive tests have become available without adequate assessment of their positive predictive value or benefits and risks. Without this information it is difficult for providers or consumers to make thoughtful and fully informed decisions about whether to offer or to use the tests. In another case a test based on the association of the APOE e4 allele with late-onset Alzheimer's disease was marketed directly to physicians just months after the first paper about that association was published. The genetics community decried this development, asserting that the actual interpretation of those associational data for any single individual could not be determined and that any test result based on it would be misleading if not worthless. The public outcry was so great that the test was withdrawn from the market in a matter of months.

The Testing Process

Requests for testing can arise from a variety of circumstances and for a number of reasons. For example, although genetic test results can be used to guide individual healthcare and reproductive decisions, genetic testing often is sought to fulfill familial, domestic, or vocational responsibilities (Burgess and d'Agincourt-Canning). For this reason healthcare professionals must be adept at presenting and discussing the potential ramifications of testing in light of the at-risk individual's reason for requesting testing. Genetics practice also calls for pretest and posttest counseling and formal informed consent procedures to ensure that people deciding whether to undergo genetic testing are informed about the risks and potential harms, benefits, and limitations of the test, as well as alternatives and treatment options (National Advisory Council for Human Genome Research; Holtzman and Watson).

At the beginning of the twenty-first century, the volume of genetic testing was not great and the vast majority of testing occurred in genetic centers or in consultation with highly trained geneticists and genetics counselors. As the number of tests increases, the demand for testing may outstrip the capacity of genetics-trained individuals to respond. This scenario suggests that it is likely that more and more testing decisions will be made by physicians with little formal training or experience in genetics. Some question the ability of physicians to perform this function and continue to recommend referrals to health professionals with specific training in genetics to ensure proper counseling, informed consent, and correct interpretation of test results (Giardello et al.).

A related issue is the fear that physicians will be more likely to take a directive approach to decisions about testing. This approach is antithetical to the concept of the value-neutral nondirective counseling that is a main tenet of all genetic counseling. Historically, this commitment to nondirective counseling can be understood as a moral stance designed to disassociate modern genetics from the eugenics movements of the first half of the twentieth century, which often advocated forced sterilization for individuals deemed to be genetically abnormal (Paul).

Philosophically, nondirective counseling also reflects the centrality of respect for autonomy (the right to self-determination or self-governance) in modern bioethics. Because decisions about genetic testing often involve reproduction and/or an individual's most personal desires and fears, the genetics community has adopted the view that the role of the genetics professional is to help an individual make a decision about testing that is consistent with that person's most strongly held values. Genetic counselors in training are taught specifically not to let their own opinions and attitudes influence the information that is given to people or recommendations for a course of action.

The Decision to Be Tested

The process of genetic testing can challenge traditional concepts of autonomy and privacy. The desire to be tested on the part of one individual can place pressure on other family members if their cooperation is required for the test to be done. In testing for familial cancers, for example, it is often necessary for a family member who is already affected to be tested first to identify the specific disease-associated mutation in the family. If the affected family member refuses to cooperate, that refusal can frustrate the desire of other family members to learn about their risk. This need to identify an index case also makes it difficult for an individual who wishes to be tested to keep that decision private.

Some authors have advanced the concept of *relational responsibility* as playing a key role in decisions regarding testing (Burgess and d'Agincourt-Canning). This ethical concept emphasizes that decisions about genetic testing occur within complex social relationships that are embedded in and shaped by notions of responsibility to specific others. Thus, although testing guidelines often emphasize that the decision whether to undergo genetic testing should be solely that of the individual for his or her own purposes and free from coercion by a spouse or another family member, research suggests that in reality people often make decisions about testing on the basis of the wishes and desires of others, primarily close family members, about whom they care deeply. Rosamund Rhodes has taken the notion of relational responsibility further, arguing that individuals have a moral duty to pursue genetic information about themselves, especially in cases in which that information has ramifications for others, such as spouses or children (Rhodes).

Ordering Tests

Once the decision has been made to pursue testing, tests for relatively common disorders usually are obtained from commercial laboratories (GeneTest). Blood is drawn and mailed to the laboratory, and the test results are conveyed back to the healthcare professional who ordered the test. That person then has the responsibility of conveying the results, usually in person, to the individual who has been tested. Genetic tests for rare disorders sometimes are available only from laboratories in academic medical centers that have a particular interest in the disease in question. Those laboratories may not have satisfied the ongoing quality and proficiency assessments required of commercial laboratories, thus raising questions about the reliability of testing obtained from this source.

Sharing Genetic Information

When a test has been performed and a result has been obtained, other considerations come into play. Perhaps the most vexing is whether and when a person has a moral duty to share genetic information. Genetic test results for a specific individual also reveal information about that person's relatives. Parents and children share half their genes, as do siblings. If a woman learns that she carries a gene associated with breast cancer, does she have a responsibility to share that information with her sister? Many writers agree that that responsibility exists, with Dorothy Wertz and colleagues suggesting that at the level of the person genetic information, although individual, should "be shared among family members" as a form of shared familial property (Wertz et al.). Indeed, most people, once they are aware of the implications of genetic information for other family members, willingly share the information with those for whom it is especially relevant.

However, what if a woman with a breast cancer mutation does not wish to share that information? May her physician breach her confidentiality and warn her sister? Several groups have addressed this issue in depth (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research; Andrews et al.). Guidelines published by the American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure in 1998 state that the legal and ethical norm of patient confidentiality should be respected, with breaches of confidentiality permitted only in exceptional cases. Those exceptions are (1) when attempts to encourage disclosure by the patient have failed, when the harm is highly likely to occur and is serious and foreseeable, when the at-risk relative or relatives are identifiable, and when the disease is preventable/treatable or medically accepted standards indicate that early monitoring will reduce the genetic risk and (2) when the harm that may result from failure to disclose outweighs the harm that may result from disclosure (Knoppers et al.). At least one author has argued that knowledge about the risk for conceiving a child with a deleterious gene does not pose the type of serious, imminent harm that generally would require disclosure (Andrews).

In regard to the issue of disclosure Ruth Macklin suggests the institution of a patient "Miranda" warning so that before genetic testing occurs, a patient would be warned about the circumstances that would result in the disclosure of genetic information to other family members regardless of the patient's intentions to disclose (Macklin).

Two court decisions appear to indicate an increasing trend toward disclosure. In *Pate v. Threkel,* Florida, 1995, a physician was held to a duty to warn patients of the familial implications of a genetic disease. In *Safer v. Estate of Pack,* New Jersey, 1996, the court held that a physician has a duty to warn relatives known to be at risk for a genetic disorder regardless of potential conflicts between the duty to warn and the obligations of confidentiality. The courts have not yet addressed a physician's obligation to disclose information concerning individuals whose occupations may place the lives of others in danger, such as pilots and air traffic controllers.

The completion of the Human Genome Project will result in a proliferation of genetic tests for a wide variety of disorders. Some public health advocates argue for a broader role for population-based testing, whereas critics believe that further work needs to be done to understand the value of testing on a widespread basis. Concerns exist about the ability of consumers and physicians to make informed decisions about whether to use genetic tests and are exacerbated by a growing trend on the part of commercial laboratories to market the tests directly to consumers. Once a test has been ordered and the results have been obtained, questions remain about the duties of both individuals and healthcare professionals regarding disclosure of test results.

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SEE ALSO: *Autonomy; Cancer, Ethical Issues Related to Diagnosis and Treatment; Children: Mental Health Issues; Dementia; Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Genetic Discrimination; Genetics and Human Self-Understanding; Health Insurance; Informed Consent;* and other *Genetic Testing and Screening* subentries

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VI. PEDIATRIC GENETIC TESTING

DNA-based clinical testing is available for over 900 genetic diseases, and research-based testing is offered for hundreds of others. Such testing can aid in making diagnoses, assessing recurrence risks, and providing accurate prognoses. Often genetic testing is initiated prior to the onset of symptoms. This type of testing is known as pre-symptomatic or predictive genetic testing, and is typically offered for adult-onset diseases such as Huntington's chorea or certain types of cancer. Huntington's chorea, or Huntington's disease, is a progressive, fatal, neurological condition that affects movements and memory. Individuals who carry the gene for Huntington's disease usually begin showing symptoms around age 40, though this can vary dramatically between individuals and families. The types of cancer that can be associated with inherited DNA mutations include breast cancer, ovarian cancer, and certain types of colon cancer.

Though DNA-based clinical testing has become a part of routine management for numerous diseases, it presents a unique set of circumstances that separate it from other types of testing. Since a number of genetic mutations are inherited from parents, testing either children or parents will often reveal increased risk for other family members. In the cases of autosomal dominant conditions such as Huntington's disease or Hereditary Breast and Ovarian Cancer syndrome, an affected parent has a 50 percent chance of passing on the defective gene to his or her child.

There are a number of ethical issues associated with the use of pre-symptomatic testing for adult-onset disorders. One important area of discussion focuses on whether genetic testing for these diseases should be initiated in children. Several professional organizations, including the American Academy of Pediatrics and the American Society for Human Genetics, have formal positions stating that children under the age of eighteen years should not undergo genetic testing for adult-onset disorders. The American Society for Human Genetics states: "if medical or psychological benefits of a genetic test will not accrue until adulthood, as in the case of … adult-onset diseases, genetic testing generally should be deferred" (American College of Medical Genetics, pp. 1233–1241), and the World Federation of Neurology Research Group on Huntington's Chorea explicitly recommends not testing any minors.

These policies are driven by the argument that since these are adult-onset disorders for which there is no treatment or medical intervention during childhood, there is no medical benefit to testing. Additionally, children are unable to understand the complexities involved in the testing and therefore cannot provide informed consent. Testing these children, then, potentially could be seen as harmful, as it takes away their right not to know their genetic status.

Proponents of genetic testing in children argue that there are situations when the benefits of testing, either medical or emotional, outweigh the potential harms. This article will explore these arguments in detail, and present a proposal for appropriate use for predictive tests in children.

Pre-symptomatic genetic testing for adult-onset disorders typically involves a detailed informed consent process. This process can include discussions of the natural course of the disease, prognosis, risks to other family members, and treatment options. Some informed consent processes, such as the one outlined by the Huntington's Disease Society of

America, require a psychiatric assessment to determine how test results will be viewed, and what potential reactions might occur. This process can be lengthy and challenging for an adult, and would not be possible for a child. The question, then, is raised as to whether parents can consent for the pre-symptomatic genetic testing for children.

Medical decision making for adults is largely guided by respect for persons and autonomy, whereas in pediatrics it is guided by beneficence. With regards to adult medicine, medical decisions made by competent adults who have undergone an appropriate informed consent process are typically respected. In a pediatric setting, the parents traditionally have had the responsibility of medical decision making, where a competent adult is challenged to make decisions not for his or her own care, but for the child's. This is based on the assumptions that parents are typically interested in maintaining their children's best interests and safety; parents are in a position to know what those best interests are by virtue of knowing their children better than anyone else; parents usually must deal with the financial, emotional, and practical aspects of such decisions; and Western society typically has strived to maintain privacy and parental control within a family unit whenever possible. In other words, the autonomy of parents traditionally is respected as long as it supports the benefit of the child; the challenge then becomes balancing the rights of the children with the rights of parents.

Can Predictive Genetic Testing be Harmful?

There are some situations where the desires of the parent, regardless of how well meaning, may not be in the best interest of the child. In the case of pre-symptomatic genetic testing, a parent often has a need to know what the genetic status of a child is, but that information may or may not be beneficial to the child, and even could be harmful. The purpose of an informed consent process for pre-symptomatic testing is to enable individuals to make decisions about whether they want this information, and to consider how it might affect how they live their lives. A child who has undergone genetic testing will never have the option not to know the results of that information. A positive test result in a child may result in potentially serious psychosocial affects on relationships, family, school performance, and self-concept. This is particularly true if the child has watched a great deal of suffering on the part of the parent. A negative test result can lead to survivor guilt or feelings of being ostracized from affected family members. Many adults choose not to undergo testing due to the psychological burden of incorporating a test result into their lives and futures, and opponents of predictive genetic testing in children feel that children should be offered that same freedom from knowledge.

Personal experience can also interfere with a child's ability to understand the complexities of a positive result, or the reassurance of a negative result. For example, a positive DNA test for the genes associated with Breast and Ovarian Cancer syndrome confers a lifetime risk of developing breast or ovarian cancer of approximately 50 to 80 percent, not 100 percent. Conversely, a negative test result for this child reveals that her risk of breast cancer is not zero, but rather that of the general population, which is approximately 10 percent. A child who has watched her mother die from breast cancer may view this positive result as a prediction of her future and a death sentence, instead of indicating an increased risk. This is a heavy burden to place on a child who is already struggling with the loss of a parent.

The nature of genetic material presents an additional challenge to testing individuals of any age, but these issues can be magnified when dealing with children. By definition, genetic testing often reveals information about other family members, and healthcare providers should consider prior to testing how that information will be addressed. Specifically, genetic testing can reveal cases of non-paternity that can have an adverse affect on the relationship between parent and child.

Can Predictive Genetic Testing be Beneficial?

There are potential benefits to pre-symptomatic genetic testing in children. From a parental standpoint, knowing the genetic status can help parents plan financially and emotionally for their child's future. A positive result may mean long-term care issues that can be offset by advanced financial planning. A parent who is afflicted with a genetic disease may seek comfort in knowing that he or she did not pass on the defective gene to a child, even if symptoms of that disease are years away. In the cases of Huntington's disease and certain types of cancer, an affected parent may not survive long enough for their child to reach adulthood, meaning the parent may die not knowing if their child will suffer a similar fate.

The child herself may be comforted by a negative result. There is a strong argument for the emotional benefit of being able to tell a child who is afraid of the disease of a parent that he or she is unlikely to develop the same disease. This is particularly true in an adolescent, who may have been able to identify his or her own risk through research, even if this information was never discussed at home or with a medical practitioner.

In addition, there are potential medical benefits to be considered. In the case of familial adenomatous polyposis (FAP), a familial colon cancer syndrome, colon cancer has been reported in children as young as ten years of age. Approximately 75 percent of those individuals carrying a DNA mutation associated with FAP will develop precancerous polyps before age twenty. In families where this disease has been identified, children of affected parents have a 50 percent chance of having inherited the mutation. For these children, a positive test result would mean a much more rigorous medical course, involving annual colonoscopies to monitor the development of polyps, and most likely a prophylactic colectomy in the future, both measures that could save lives. A negative test result would spare these children from such invasive screening, and reveal their lifetime risk of colon cancer to be that of the general population.

Though it is generally understood that children do not possess the competence to make medical decisions, the situation is less clear for adolescents. Obviously there is no perfect age that competence can be assumed, nor is there a minimum age at which it can be specified as absent. There are adolescents who are capable of engaging in the informed consent process and making medical decisions for themselves. One would hope that, when possible, the decisions of the parent would encompass conversation with the child or adolescent and involve the minor to whatever degree is appropriate for maturity, interest, and responsibility.

The Rule of Earliest Onset

One proposal for determining the appropriate use of predictive tests is the "rule of earliest onset." Simply put, the rule states that "genetic testing should be permitted no earlier than the age of first possible onset of disease" (Kodish, p. 391). This guideline allows for the possibility that medical benefit may outweigh potential harms. Employing this basic rule provides several advantages. First, predictive testing is limited to those children for whom there is a potential medical benefit. Though this does not eliminate the possibility that decisions to test will be fueled by additional motivations, it ensures that benefit to the child will be present. Secondly, by delaying testing until an age when symptoms may occur, one maximizes the likelihood that the now older child can participate in the decision-making process. Finally, it is a family-specific guideline for testing that accounts for variation in the age of onset. For example, even though the majority of Huntington's disease occurs in adults, approximately 10 percent of cases are juvenile. In these families, the disease is typically transmitted through a father whose own disease had an earlier than expected presentation. If predictive testing for a child is being considered, and the history reveals that in this particular family the father is the affected individual and his symptoms developed in his twenties, then the rule of earliest onset for this family would suggest testing an adolescent.

Conclusions

Predictive genetic testing in a pediatric setting is complicated by the complexity of the information, the fact that testing decisions are being made by someone other than the person being tested, and the potential impact of the test results. Traditionally it has been thought that predictive genetic testing should not be offered to children under the age of eighteen, and many professional policies have been developed in support of this.

These policies are based on the assumption that "medical or psychological benefits of a genetic test will not accrue until adulthood." This article has discussed situations where there is arguably either a medical or emotional benefit to the child that would warrant testing, and presented a proposal for the use of predictive genetic testing in pediatrics.

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SEE ALSO: *Disability; Eugenics; Eugenics and Religious Law; Genetic Counseling, Ethical Issues in; Genetic Counseling, Practice of; Genetic Discrimination; Genetics and Human Self-Understanding; Infanticide; Infants; Pediatrics;* and other *Genetic Testing and Screening* subentries

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GRIEF AND BEREAVEMENT

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The term *grief* can be defined as a type of stress reaction, a highly personal and subjective response that an individual makes to a real, perceived, or anticipated loss. Grief reactions may occur in any loss situation, whether the loss is physical or tangible, such as a death, significant injury, or loss of property; or symbolic and intangible such as the loss of a dream. The intensity of grief will vary, depending on many variables such as the meaning of a loss to the individual experiencing it. It should be recognized that loss does not inevitably create grief. Some individuals may be so disassociated from the loss object that they experience little or no grief, or their response may be characterized by intense denial.

This definition of acute grief distinguishes it from other terms such as *bereavement* or *mourning*. Bereavement refers to an objective state of loss. If one experiences a loss, one is bereaved. Bereavement refers to the fact of loss, whereas grief is the subjective response to that state of loss. Mourning has had two interrelated meanings within the field. On one hand, it has been used to describe the intrapsychic process through which a grieving individual gradually adapts to the loss, a process that has also been referred to as “grieving” or “grief work.” The term has also been used to refer to the social aspect of grief, the norms and patterned behaviors and rituals through which an individual is recognized as bereaved and socially expresses grief. For example, in the United States, wearing black, sending flowers, and attending funerals are common illustrations of appropriate mourning behaviors.

Paradigms of Grief

Grief was first empirically described in 1944 by Eric Lindemann, a psychiatrist who studied survivors of the Coconut Grove Fire, a 1942 Boston fire that swept through a nightclub, killing many. Lindemann described grief as a syndrome that was “remarkably uniform” and included a common range of physical symptoms, such as tightness of throat, shortness of breath, and other pain, as well as emotional and other responses. It should be recognized that Lindemann’s research was based on a sample of primarily young survivors of sudden and traumatic loss.

This medical model of grief was continued most clearly in the work of George Engel (1961). Engel believed that grief could be described as a disease, one having a clear onset in a circumstance of loss; a predictable course that includes an initial state of shock; a developing awareness of loss characterized by physical, affective, cognitive, psychological, and behavioral symptoms; and a prolonged period of gradual recovery, with the possibility that this recovery may be complicated by other variables. He noted that other disease processes also are influenced by psychological and social variables. Even the fact that grief is universal and rarely requires treatment, Engel argued, is not unlike other diseases. Engel also noted that whether or not a disease requires medical treatment or is even recognized as a disease is a social convention. Epilepsy, alcoholism, and many forms of mental illness are recognized as diseases but were not at other times in human history or in other cultures.

Another paradigm that attempts to offer insight into the nature of acute grief is the psychological trauma model. This model, based on the work of the Austrian neurologist Sigmund Freud (1917), views grief as a response to the psychological trauma brought on by the loss of a love object. Acute grief is a normal defense against the trauma of loss. To Freud, grief is a crisis, but one that will likely improve over time and that generally does not require psychiatric intervention.

Perhaps one of the more influential models to account for acute grief is the attachment model developed by John Bowlby (1980). This approach emphasizes that attachment, or bonding, is a functional survival mechanism, an instinct found in many of the higher animals. Given the prolonged periods of infancy and dependency, attachment is necessary for the survival of the species. When the object of that attachment is missing, certain behaviors arise that are instinctual responses to that loss. These behaviors, including crying, searching, and clinging, were seen by Bowlby as biologically based responses that seek to restore the lost bond and maintain the attachment. When these bonds are permanently severed, as in death, these behaviors continue until the bond is divested of emotional meaning and significance. These behaviors also serve a secondary purpose. By expressing distress, they engage the care, support, and protection of the larger social unit. This psychobiological model sees grief as a natural, instinctual response to a loss, a response that continues until the bond is restored or the grieving person detaches and divests of the bond.

These early approaches continue to influence understandings of grief, though more contemporary models emphasize that grief is a natural response to major transitions in life and that bonds between the grieving individual and the lost object continue, albeit in different forms, after the loss (Klass, Silverman, and Nickman). In addition, more recent approaches emphasize that a significant loss may shatter assumptions, causing grieving individuals to reconstruct their sense of self, their spirituality, and their relationship to others and the world at large. While this may be a painful process, it also may be a catalyst for growth.

Manifestations of Grief

Individuals can experience acute grief in varied ways. Physical reactions are common. These includes a range of physical responses such as headaches, other aches and pains, tightness, dizziness, exhaustion, menstrual irregularities, sexual impotency, breathlessness, tremors and shakes, and oversensitivity to noise.

Bereaved individuals, particularly widows, do have a higher rate of mortality in the first year of loss (Osterweis, Solomon, and Green). There may be many reasons for this—the stress of bereavement, the change in lifestyle that accompanies a loss, and the fact that many chronic diseases have lifestyle factors that can be shared by both partners. It is important that a physician monitor any physical responses to loss.

There are affective manifestations of grief as well. Individuals may experience a range of emotions such as anger, guilt, helplessness, sadness, shock, numbing, yearning, jealousy, and self-blame. Some bereaved persons experience a sense of relief or even a feeling of emancipation. This, however, can be followed by a sense of guilt. As in any emotional crisis, even contradictory feelings, such as sadness and relief, can be experienced simultaneously.

There can be cognitive manifestations of grief. Included here is a sense of depersonalization in which nothing seems real. There can be a sense of disbelief and confusion, an inability to concentrate or focus. Bereaved individuals can be preoccupied with images or memories of the loss. These cognitive manifestations can affect functioning at work, school, or home. Many persons also report experiences in which they dream of the deceased or have a sense of the person's presence, even sense-based experiences of the other.

Grief has spiritual manifestations. Individuals may struggle to find meaning and to reestablish a sense of identity and order in their world. They may be angry at God or struggle with their faith.

Behavioral manifestations of grief can also vary. These behavioral manifestations can include crying, withdrawal, avoiding or seeking reminders of the loss, searching behaviors, over activity, and changes in relationships with others.

The reactions of persons to loss are highly individual and influenced by a number of factors. These include the unique meaning of the loss, the strength and nature of the attachment, the circumstances surrounding the loss such as the presence of other crises, reactions and experiences of earlier loss, the temperament and adaptive abilities of the individual, the presence and support of family and other informal and formal support systems, cultural and spiritual beliefs and practices, and general health and lifestyle practices of the grieving individuals.

The Course of Grief

There have been a number of approaches to understanding the process or course of acute grief. Earlier approaches tended to see grief as proceeding in stages or phases. Colin Murray Parkes (1972), for example, described four stages of grief: shock, angry pining, depression and despair, and detachment. Recent approaches have emphasized that grief does not follow a predictable and linear course, stressing instead that it often proceeds in a roller-coaster-like pattern, full of ups and downs, times when the grief reactions are more or less intense. Some of these more intense periods are predictable—holidays, anniversaries, or other significant days—but other times may have no recognizable trigger.

More recent approaches have emphasized that grief involves a series of tasks or processes. J. William Worden

(1992) described four tasks to grief: recognizing the reality of the loss, dealing with expressed and latent feelings, living in a world without the deceased, and relocating the deceased in one's life. Therese A. Rando (1993) suggested that grieving individuals need to complete six "R" processes: recognize the loss, react to the separation, recollect and reexperience the deceased and the relationship, relinquish the old attachments to the deceased and the old assumptive world, readjust to the new world without forgetting the old, and reinvest. (While the language of both Worden and Rando is specific to death-related loss, their models can be adapted to other losses as well.) These and other similar models reaffirm the very individual nature of grief, acknowledging that these tasks or processes are not necessarily linear and that any given individual may have difficulty with one or more processes or tasks.

The critical point to remember is that the course of grief is not linear. Nor is there any inherent timetable to grief. Grief reactions can persist for considerable time, gradually losing intensity after the first few years. Recent research as well emphasizes that one does not "get over the loss." Rather, over time, the pain lessens, and the grief becomes less disabling as individuals function at levels comparable to (and sometimes better than) preloss levels. Bonds and attachments to the lost object continue, however, and periods of intense grief can occur years after the loss (Klass, Silverman, and Nickman). For example, the birth of a grandchild can trigger an experience of grief in a widow who wished to share this event with her deceased spouse.

Help and Grief

Persons experiencing acute grief can help themselves in a number of ways. Because grief is a form of stress, lifestyle management including adequate sleep and diet, as well as other techniques for stress reduction, can be helpful. Bibliotherapy or the use of self-help books can often validate or normalize grief reactions, suggest ways of adaptation, and offer hope. Self-help and support groups can offer similar assistance as well as social support from others who have experienced loss. Others may benefit from counselors, particularly if their health suffers or their grief becomes highly disabling, impairing functioning at work, school, or home, or if they harbor destructive thoughts toward self or others. Parkes (1980) particularly stressed the value of grief counseling when other support is not forthcoming.

Pharmacological interventions also may be helpful particularly when the grief is disabling, that is, severely compromising the individual's health or ability to function. Such interventions should be focused on particular conditions, such as anxiety or depression, that are precipitated or exacerbated by the bereavement. Pharmacological interventions should be accompanied by psychotherapy.

Most individuals seem to ameliorate grief in that, over time, they can remember the loss without the intense reactions experienced earlier. Nevertheless, anywhere from 20 to 33 percent seem to experience more complicated grief reactions (Rando).

Complicated Grief

While models of complicated grief vary (Rando; Worden), complicated grief reactions generally involve intensifications and exaggerations of the earlier described responses to grief that effectively impair the individual's ability to function. Complicated grief can also be evident in masked reactions—that is, the grief is masked by another problem such as substance abuse.

One factor that can complicate grief is disenfranchisement. The term *disenfranchised grief* refers to a grief that results when a loss is not socially sanctioned, publicly acknowledged, or openly mourned. Grief may be disenfranchised because a loss is not recognized (e.g., the loss of an animal companion), a relationship is not recognized (e.g., a friend or therapist), the griever is not acknowledged (e.g., a very young child or a person with developmental disabilities), the death evokes shame or censure (e.g., an execution), or the way the person expresses grief is considered inappropriate or unacceptable. In such cases, the person has experienced a loss, but has "no right to grieve," no expectation of public acknowledgement or support (Doka, 1989, 2002).

Ethical Issues in Grief

Ethical issues in grief may emerge from three sources. First are general issues for counselors. Grieving persons can be highly vulnerable. Counselors have to have personal integrity and follow the ethical standards of their profession, including maintaining confidentiality, preventing harm to the client or others, assuring competence, and upholding standards of professional behavior. Counselors should familiarize themselves with their respective codes of ethics. They may wish to review as well the Code of Ethics of the Association for Death Education and Counseling.

In addition to the normal standards of professional conduct, counselors should be aware of two other ethic-related issues that might arise in grief counseling. Ethical issues within the course of the medical treatment of the deceased person may affect responses to grief. For example, a person who decided to terminate treatment may struggle with that issue within the grief process. In similar ways, ethical decisions made after the death—such as the disposition of the remains or inheritance—may also be reviewed in the grieving process. For example, the deceased may make requests regarding the disposition of remains or property that families may be reluctant to follow. Such situations can exacerbate grief—intensifying guilt or anger and causing conflicts that lessen mutual support and add concurrent stresses.

KENNETH J. DOKA

SEE ALSO: *Care; Death; Dementia; Healing; Health and Disease; Medicine, Anthropology of; Mental Health, Meaning of Mental Health; Mental Health Therapies; Pain and Suffering; Palliative Care and Hospice*

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HARM

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Harm is a central concept both in the practice of medicine and in ethics. Hence, it is no surprise that in bioethics harm plays a prominent role. The proper goal of medicine is to prevent, alleviate, or eliminate harm to patients that result from disease or injury. Moreover, some medical interventions themselves have a serious potential to cause additional (iatrogenic) harm—for instance, pharmacological side effects or even death from surgery.

General prohibitions against inflicting harm on others supposedly belong to the principles of any moral code, and an attitude of non-malevolence (taking care that others do not suffer harm) is widely regarded as a core virtue and as a decisive source of moral motivation. Beyond this, bioethics is concerned with harm-related judgments, obligations, prohibitions, and problems. The harm at stake is most often harm to patients. Such debates as those about professional duties toward patients, about matters of resource allocation, or about the limits of patient self-determination all deal in part with actual or potential suffering, dysfunction, pain, or death of patients. Some problems, however, relate to potential harm to third parties. For example, HIV-positive patients risk infecting uninformed sexual partners and pregnant women who consume drugs risk harm to their unborn children. Other ethical questions deal with harm to health professionals themselves—when, for instance, a physician faces treating a contagious patient under substantial personal risk. And finally, various arguments in bioethics address the possibility of long-term social harm resulting from certain permissive practices (the so-called slippery slope argument). For example, critics of prenatal selection against severe genetic diseases predict shrinking social solidarity with the handicapped and with their justified claims to social support.

While its central role in bioethics thus cannot be disputed, *harm* remains a vague and contested concept that in and of itself does not provide much moral guidance. What counts as harm varies greatly, as do the scope and relative importance of the prescriptions not to inflict, to prevent, or to remove harm.

Conceptual Questions

An instance of harm may be assessed with reference to kind, degree, and duration. Risk assessment, not considered here, also includes the probability of harm's occurrence. According to the *Oxford English Dictionary,* harm is "evil (physical or otherwise) as done to or suffered by some person or thing; hurt, injury, damage, mischief." As far as harm is relevant to moral deliberation, however, this broad concept must be restricted.

First, harm should be understood as person- (or animal-) regarding, that is, as consisting of events or states of affairs that are negative for someone—as expressed in Joel Feinberg's definition of harms as "setbacks to interest" (p. 31). As long as the sticky question of what counts as interests remains open, this concept of harm is still neutral to various ethical positions. Problems start with determining who counts as a bearer of interests; for instance, do embryos (as potential persons), the deceased or permanently unconscious (as former persons), or animals bear interests? These issues, although obviously important for evaluating abortion, transplantation, decisions to end treatment, or animal protection, will not be pursued here.

Secondly, ethics in general ethics and bioethics in particular have to restrict their focus on those instances of harm that are in some way or other linked to human action. It would not make sense to morally deliberate about ineluctable evils, deplorable though they may be. Rather, harm is ethically relevant only if it occurs or persists in consequence to human agency, be it by action or omission, from intention or negligence, but not from unavoidable ignorance. Thus, what counts as harm with relevance to bioethics is context-relative: harm is contingent upon professional knowledge and medico-technical progress.

Thirdly, bioethics, reflecting both ordinary moral and non-moral language usage, commonly differentiates between harm on the one hand and mere loss or lack of benefit on the other. Harm is not simply conceptually complementary to benefit (interest satisfaction), but it also represents a significant disservice to its *victim.* Along the scale of interest satisfaction, there are numerous positions of submaximal satisfaction (disbenefits) that it seems inappropriate to call *harms.* There is thus an asymmetry between harm and benefit in the sense that harm pertains exclusively to the basics of well-being. It may be wrong to prevent someone from obtaining a luxury good, but nevertheless, its consequence does not qualify as harm. Another argument elucidating this asymmetry emphasizes that harm has or leads to distinct phenomenal qualities of bodily or psychological painfulness and suffering, which is by no means true for all instances of lacking benefit (e.g., Noddings). Moreover, pity for someone's experience of harm is a motivation distinct from other forms of benevolence (e.g., Sidgwick).

Not to inflict, to prevent, or to remove harm usually takes moral precedence over providing those benefits the lack of which does not count as harm. Such asymmetry between harm and benefit has been traditionally acknowledged (e.g., by John Stuart Mill), but a more systematic focus on harm is a rather recent development of applied ethics, with its eye to more concrete moral rules (a notable exception being Jeremy Bentham's 1789 taxonomy of "pains" by sources, kinds, and circumstances). The improvement of people's well-being being a more or less central goal of any moral code, concrete efforts must first focus on the most important obstacles to well-being, that is, on existing or potential harm.

Understanding harm as a significant setback to someone's interests already implies that usually it ought to be avoided. In this sense harm is a weak normative concept, carrying a presumption of evaluative negativity. However, not every infliction or non-prevention of harm to another person is, all things considered, necessarily wrong, and in just this sense harm is not a strong normative concept. For instance, not to treat a particular patient in a tragic triage situation may be a deplorable but ethically-justified decision. Likewise, foregoing life-saving surgery on a competent patient because he autonomously decided against it, by no means "wrongs" him, in the sense of violating legitimate moral claims (Feinberg). Where harming thus does not necessarily mean wronging, the same is, of course, also true the other way round. One ought not conflate people's legitimate claims to justice or self-determination with those of not being harmed. Less clear cut is the distinction between harms and *offenses,* where the latter cause unpleasant, though not harmful, mental states. In the context of medicine, patients might be frustrated, shocked or irritated by inefficient hospital structures or by physicians who behave rudely. Whether such states of offendedness turn into proper harm seems to be but a matter of degree and duration.

Harm and Harm-Referring Duties in Bioethics

Assessing harm and distinguishing it from offenses, minor hurts, or non-harmful instances of lacking benefit requires an analysis of harm's nature and of how to determine its significance. Particularly in the context of healthcare, many instances of harm and potential harm to patients are widely uncontested, namely: severe lack of functioning resulting from bodily or mental disease, enduring pain, substantial suffering, gross disfigurement, or premature death. Another, easily neglected category of possible harm in the context of medical practice is of a psychosocial nature: for example, patients may experience absorbing anxiety, mistrust, alienation, helplessness, loss of self-control, loneliness, or annoyance due to structural and human deficits. In particular, the work of feminist ethicists (e.g., Noddings; Warren) and physician-ethicists (e.g., Cassell; Pellegrino and Thomasma) has created a new awareness of widely neglected kinds of harm to patients that occur in daily medical practice and that can largely be reduced or avoided when caregivers are humane and sympathetic. Even beyond the individual patient-caregiver relationship, general loss of trust in contemporary biomedical institutions and practices, in researchers and clinicians seems to be a prevalent and deeply troubling problem (O'Neill).

Finally, harm may occur as a setback to patients' higher-level "critical interests" in living a life they consider good (Dworkin). Notably, decisions about one's time and manner of dying are likely to relate to such highly personal, critical interests. Focusing on these issues would involve yet another conceptual enlargement of (modern) medical harm.

All of these states or events are setbacks to individuals' interests in basic well-being, and thus univocally considered harmful. In principle, they can be relevant to bioethics whenever they potentially occur or persist as a consequence of intentional behavior, where behavior must be understood in a broad sense. Hence, ethically-relevant harm can result from both omission and commission, from individual or collective acts, from a patient's own decision or from someone else's.

Harm can be intended, merely foreseen, or accepted as a lesser evil when compared to the consequences of all available alternatives, and it can be intended with regard to an identified or to a statistical addressee. Take a patient's premature death, to illustrate the broad variance of agents and victims and of causal and intentional modes under which ethically relevant-harm can occur in medicine. This premature death could, for instance, be the consequence of: a physician's decision to stop life-saving treatment, a negligently wrong treatment, an unfortunate research intervention, the patient's own decision against further treatment, a rationing policy, or a negligent infection from undisclosed sexually transmittable disease.

To emphasize it once more: it seems hard to find even one bioethical problem that does not somehow involve aspects of harm to patients or, less frequently, to health professionals or third parties. In all these matters, however, dissent arises when it comes to the comparative evaluation of a particular harm's negativity; in setting standards for professional, social, or personal responsibilities for people's health, and corresponding duties; and in the assessment of distinguishing harm from mere lack of benefit in healthcare.

With regard to duties, some scholars in ethics formulate a distinct duty of nonmaleficence, expressing a prohibition on actions with foreseeable harmful effects. Others, however, include this prohibition as part of a duty of beneficence. This, and whether such obligation is construed as a prohibition on causing net harm to someone (such that, say, shooting a murderer to save the lives of his three victims would not count as maleficent), or on harming itself (the shooting would be maleficent, though perhaps justified), is a question of terminological and classificatory preference. The duty of nonmaleficence is still indeterminate under any of these descriptions, not only because they reintroduce the problems of harm assessment but also because they are silent about permissible limits and trade-offs.

Recognizing a distinct principle of nonmaleficence is fairly common in medical (in contrast to general) ethics. It is meant to guide actions by caregivers in those situations that are most likely to produce harm. However, depending on both formal tailoring of concepts and on normative perspectives, there exist formal and substantial differences among bioethical perspectives in what is understood as nonmaleficence. Tom Beauchamp and James Childress, for instance, turn to the four duties of beneficence originally distinguished by William Frankena in 1973. Frankena's classification of duties is based on a distinction between harm and benefit and on the action's causal mode:

1. not to inflict harm;
2. to prevent harm;
3. to remove harm; and
4. to promote good.

Beauchamp and Childress modify Frankena by subsuming the first duty under nonmaleficence and leaving the last three duties under beneficence. Their distinction between the two duties of nonmaleficence and beneficence thus corresponds to the difference between negative and positive duties (i.e., duties of omission versus duties of commission), again depending on aspects of causality. Beauchamp and Childress do not, however, take this classification as such to be normatively decisive; rather, they intend to capture ordinary language usage, mirroring the empirical fact that noninfliction of harm often is achievable at lower cost to the agent than is obeying positive duties. It is in this generalized sense that the obligation of nonmaleficence frequently has priority over beneficence.

Along these lines, Allen Buchanan and Dan Brock have suggested that appeals to nonmaleficence in medicine be understood as specific reminders: in Hippocratic times, not to forget that some treatments were only burdensome and not beneficial; in contemporary times, to correct "for professional biases toward over-treatment of non-communicating patients in conditions of great risk or profound uncertainty" (Buchanan and Brock, p. 256). These reminders pay attention to medicine's increasing potential not only to benefit patients but also to inflict iatrogenic harm upon them (Sharpe and Faden).

The duty of nonmaleficence may conflict with the autonomy of patients who request treatment that physicians consider harmful (e.g., unjustified surgery, futile chemotherapy, or drugs). With an eye to precisely this conflict, H. Tristram Engelhardt, Jr., understands the duty of nonmaleficence as a justification to limit patients' self-determination.

Problems with Harm in Medicine

As to the more precise nature of harm and to the scope of harm-related duties, bioethics inherits some of the controversies of general ethical theory. A crucial question is to what extent there are objective criteria for identifying and evaluating harm. If such criteria could be found, this might, for example, justify a physician's overriding a patient's own "harmful" preferences. Or, such criteria could be adduced in surrogate decision making for noncommunicating patients, as well as in matters of allocative justice (where it becomes crucial to evaluate medical interventions in terms of their comparative tendencies to avoid or alleviate net harm).

The issue of determining criteria is linked to the objectivity/subjectivity debate concerning people's well-being and ability to live a good life (see Griffin), and the setbacks to these. With most experts agreeing that there is an irreducible plurality of harms, the subjectivist view takes harm to be a significant setback only to actual wants or desires, possibly after procedural safeguards have been met. Here, for instance, a patient's death due to intentional non-resuscitation would be harmful only if the patient, when informed and asked, would opt for treatment. In the objectivist view, harm is a significant setback also to interests that are want-independent, but related to ideals of a good life. Here, death due to non-resuscitation could be harmful to a patient, regardless of whether he or she wants it.

The fundamental distinction between "want regard" and "ideal regard" (as a difference between subjective versus objective concepts of interest) was introduced by Brian Barry in political philosophy. In that area, lack of autonomy in forming one's wants is less obviously a danger than it is in medicine, where patients can so easily be ill informed, manipulated, or otherwise incompetent when forming their preferences. Therefore, at least certain procedural safeguards—such as standards of informed consent—are not inconsistent with "want regard" in medicine. Other safeguards, like elevating standards for patient competence to a level commensurate with the expected harm that would result from acting in accordance with patient choice (e.g., Buchanan and Brock), arguably cross over into "ideal regard." In any case, there is room for hybrid positions between the extremes of pure want regard and ideal regard. Consider forcing a Jehovah's Witness to be transfused with blood. Justifying this by reference to the patient's presumed objective interest in the preservation of his life falls under ideal regard. Arguing that the patient would want the transfusion if she were not bound to her irrational belief system puts harm assessment by want regard under some ideal-regarding constraint.

A common argument in favor of taking harm as an objective concept stresses the broad consensus in what "rational persons desire to avoid for themselves" (Culver and Gert, p. 70). Reference to the obvious consensus about the desirability of avoiding disease, disability, pain, premature death, and suffering, presupposed in daily medical work, is familiar from the debate over concepts of disease (Culver and Gert). To concur on this point does not imply acknowledging universal standards for all sorts of harm. Rather, pain, disability, and premature death are seen as universal harms simply in being setbacks to very basic interests, the satisfaction of which is instrumental to practically all conceptions of a good life. It would, of course, not come as a surprise to find this true for many kinds of harm, in contrast to mere lack of benefits.

Even more serious problems with defining medical harm hinge on the need to compare two instances of harm, such as those from alternative treatment courses or from alternative resource distributions. Such ranking judgments are needed on kinds of harm (for example, pain versus addiction; premature death versus disfigurement; disease versus a restricted lifestyle) and on how much, when, and for how long harm is to be accepted, and for what purpose. At least implicit comparative evaluations of risks of harm and benefit are involved in virtually any treatment decision or medical indication (Veatch). Here, more fundamental disagreement starts: Some authors emphasize the great variability in comparative harm assessment, pointing to its relatedness to the context of each patient's irreducibly personal or parochial conception of a good life (e.g., Engelhardt; Veatch). This position has nurtured so-called autonomy-centered bioethics, which considers the assessment of harms and benefits to be the patients' business only. In contrast to this position, other scholars want to keep at least some objective ground for evaluations: medical interventions should, according to them, be determined futile not by patients, but by professional standards whenever they appear to be disproportionately harmful and thus "not reasonable" (Brody); or these scholars see interpersonal variability in ranking harm—though it exists—as not predominant and therefore not ruling out a beneficence-centered bioethics.

Other fundamental problems relate to the legitimate scope and relative importance of the obligations to prevent or to remove harm. First, some such actions, although morally laudable, are not required of the agent because they pose undue burdens or risks for him. For example, a therapist need not risk his own death in treating a violent patient. But how far do these agent prerogatives go? And how are they determined and justified? Secondly, harm preventing or removing actions sometimes ought to give way to other overriding duties (e.g., the duty to remove still greater harm from another or to respect patient self-determination). However, there are many different views as to what counts as overriding duty. Between the two extremes—understanding nonmaleficence as the trivially indeterminate principle "avoid harm (whatever that is) unless it is outweighed" or having as many specified duties as there are different normative theories—attempts have been made to give a more specific meaning to nonmaleficence without leaving the middle ground of broader consensus.

How to Handle Pluralist Harm Assessment

Undeniably, different people have very different notions of what *medical harm* would be for themselves or for others. Autonomy-centered bioethics has seen its task as spelling out procedures to foster a "morality of mutual respect" (Engelhardt) and patients' self-determination. This approach leads to particular concern for informed consent, policies for advance directives, substituted judgment, and so on. A contrasting approach urges that instead of inviting radical individualism in assessing medical harm, we redetermine medicine's substantive goals. Daniel Callahan, for example, argues that such individualism results in net harm to all by consuming too many resources for marginal benefits and setting wrong priorities in our lives. Stressing the importance of expectations and cultural presumptions in determining what individuals view as harm, Callahan hopes to find arguments acceptable to the whole of society—in favor, for instance, of decreasing individual expectations for life-prolonging treatment in old age.

Other authors concur that individualistic harm assessment is the wrong paradigm for medicine: "Moral atomism" is viewed as impoverishing medical practice socially and morally, that is, as giving up grounds on which a sense of community and good decision making should develop (Pellegrino and Thomasma). Others see "moral atomism" as leading to a waste of physicians' power to assist patients in pursuing their goals (Brody, p. 50), or as leading to paralysis in crucial policy questions, such as how to determine the best treatment interests of incompetent patients (Emanuel). Ezekiel Emanuel opts for communitarian healthcare settings, where groups of patients and physicians shape medicine according to their shared assessment of harms and benefits; others are confident that the consensus on harm in the context of medicine is substantial (Pellegrino and Thomasma; Cassell; Brody). They see the main problem in "the view that the physician respects autonomy by taking a negative, hands-off stance" (Brody, p. 50), which they argue ought to be given up in favor of assisting patients, in a critical and trustworthy manner, to assess harms and benefits.

Prominent Controversies on Medical Harm

A prohibition on killing is often taken to be the most important negative duty of nonmaleficence, death being a major harm for most people. Generally, the same is true for the medical context, with the contested exception of assistance in dying. Proponents of active voluntary euthanasia for terminally-ill patients are not only prepared to give priority to patient self-determination in these situations, but would not even consider the resulting death a harm and its intentional provision maleficent—rather to the contrary. Controversies over these issues across many cultures result from different views on the allegedly harmful or benefiting nature of a patient's death from assistance—be it by active killing, by withholding or withdrawing life support, assisted suicide, or indirect euthanasia. Those who insist on normative differences between these various forms of assistance often give normative weight to the involved causal or intentional differences. A prominent instance of such an argumentation is the controversial Roman Catholic doctrine of double effect, according to which, for example, indirect euthanasia can be justified in spite of the death that may result, since the latter is not intended but merely foreseen as a by-product of beneficent painkilling. Other opponents of aid in dying argue with the social harm than could be expected from one or several of these practices once, established as legitimate option for the terminally ill (the slippery slope argument).

Yet another debate centering on the concept of harm-concerns cases of sexually-active patients who carry a sexually-transmittable virus (e.g., HIV) and refuse to inform their partners. Legal prescriptions aside, bioethicists are divided as to whether the treating physician, who cannot convince his patient to the contrary, has a duty to inform those at risk. Obviously the obligation to prevent harm to others conflicts with the professional obligation to confidentiality; violating confidentiality might also lessen the general trust in physicians' patient advocacy.

The heated controversies on prenatal diagnosis, gene therapy, and wrongful birth and wrongful life issues focus on possible harm to future children or their parents, but also on those who are living with genetic handicaps. Once again, bioethicists dissent on what to identify as harm, how to evaluate its negativity, and how to balance related duties against other ethical obligations.

In summary, there is a remarkable tension between harm's undisputed importance in bioethics and the numerous different ways in which it comes to be conceptualized and evaluated, thus mirroring the plurality of existing ethical approaches.

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SEE ALSO: *Animal Welfare; Bioterrorism; Buddhism, Bioethics in; Circumcision; Competence; Death; Death, Definition and Determination of; Double Effect, Principle or Doctrine of; Environmental Ethics; Ethics; Harmful Substances, Legal*

Control of; Holocaust; Homicide; Human Rights; Infanticide; Injury and Injury Control; International Health; Law and Morality; Malpractice; Mistakes, Medical; Moral Status; Pain and Suffering; Paternalism; Psychiatry, Abuses of; Research, Unethical; Smoking; Utilitarianism and Bioethics; Warfare

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HARMFUL SUBSTANCES, LEGAL CONTROL OF

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At the beginning of the twenty-first century, opium, its constituent morphine, and the derivative heroin were viewed with fear and suspicion. As both popular and professional attitudes in the United States turned against drug use in the United States around 1980, physicians began to fear prescribing potentially addictive analgesics, and likewise, patients began to fear taking them. This attitude contrasts sharply with that of one of the leading American physicians in the mid-nineteenth century, George Wood, of the University of Pennsylvania, who wrote in 1868 that opium produces "an exaltation of our better mental qualities, a warmer glow of benevolence, a disposition to do great things, but nobly and beneficently, a higher devotional spirit, and withal a stronger self-reliance, and consciousness of power" (Vol. 1, p. 712).

Clearly, the ethical position a person takes regarding the availability of a drug is affected profoundly by whether that person believes that the drug is risky in any amount or that reasonable doses of the drug are a boon to humankind. These two positions have alternately influenced experts and the public since at least the eighteenth century in English-speaking countries. In times when one of these attitudes has held sway, the opposite ethical position has been dismissed as wrongheaded and refuted both morally and scientifically.

Attitudes toward Alcohol

Alcohol, a drug with a long history of easy availability and widespread consumption in the West, provides instructive examples of these dramatic shifts of opinion and their impact on ethical positions. The history of fermented beverages such as beer and wine goes back millennia, and distilled spirits began to be produced by about 1300 in Europe. For centuries afterward, nearly pure alcohol was produced in small amounts, and extraordinary characteristics were attributed to it. *Aqua vitae,* as certain distilled alcohol products were termed, was said to prolong life. In its qualities it approached the quintessence, or fifth element (along with earth, air, fire, and water). The "spirit" derived from distillation, according to John French, a seventeenth-century English physician, had wonderful "vertues … for there is no disease, whether inward or outward, that can withstand it" (p. 132).

In England, new scientific data challenged the old beliefs during the "gin epidemic" of the eighteenth century. For the first half of the century a battle raged between the populace—especially in London, where gin was cheaper than an equal volume of beer —and some religious and secular leaders who were appalled by the spiraling number of public drunks, "weak, feeble, and distempered children" (Plant, p. 9), and deaths attributed to the massive and cheap consumption of distilled spirits. Hogarth's print *Gin Lane* of 1751 captures the social destruction resulting from a substance that once had been thought of as an unadulterated good.

The new view of distilled spirits was incorporated into voluntaristic plans for self-improvement, most notably the religious movement led by John Wesley. In his attempt to revitalize the Church of England and establish a strict morality of behavior, Wesley argued for a distinction between fermented spirits and distilled spirits. He described distilled spirits as "a certain, tho' a slow poison," although he conceded that they might have medicinal uses (Wesley, p. xix). Eventually Wesley's Methodism moved, especially in the United States under the guidance of Wesley's chosen missionary, Francis Asbury, to a rejection of alcohol in any form.

In addition to moral objections, in the United States criticism of alcohol was based upon social and medical observations. Benjamin Rush, perhaps the most distinguished American physician of his time, launched an attack on alcohol that was based on his experiences as a physician in the War of Independence. Rush countered the popular notion that distilled spirits were a healthy means of invigorating soldiers and field workers, and a stimulant to intellectual activity. However, like Wesley, he focused on spirits, not on all forms of alcohol. His pamphlet *An Inquiry into the Effects of Ardent Spirits upon the Human Body and Mind,* written in the 1780s (reprinted in Musto, 2002a, p. 27), was distributed by the thousands throughout the nation and was still being reprinted and distributed four decades later.

TEMPERANCE MOVEMENTS. Later reformers, most notably Lyman Beecher in his monumental *Six Sermons on Intemperance* (reprinted in Musto, 2002a, p. 44), which first appeared in 1826 (reprinted 1828), adopted a more extreme attitude, condemning not only distilled spirits but all alcoholic beverages. Moderation was no longer recommended as an ideal; instead, it was presented as a dangerous delusion that would draw many people into alcohol abuse. Alcohol itself, Beecher argued, not the amount or type consumed, was an evil.

Thus, the United States experienced a positive attitude toward alcohol consumption in the eighteenth century, followed by a reversal dominated by the image of alcohol as a fundamentally evil substance that led to widespread prohibition in the 1850s. That first peak of prohibition faded under the resentment of the public, the difficulty of enforcement, and the monumental distraction of the Civil War. Later in the nineteenth century, opposition to alcohol revived, centering on the burgeoning urban saloon, a center of political and moral corruption, and a symbol of the rising fear of recent immigrants crowding into the cities. This anti-alcohol campaign was even more successful than the previous crusade, achieving by 1920 a total legal prohibition of alcohol except for sacramental, industrial, and medicinal uses.

AFTER PROHIBITION. After 1933, the year of the repeal of the Eighteenth Amendment, the backlash against Prohibition made advocacy of alcohol control an object of ridicule until about 1980; then another change in attitude toward alcohol—perhaps the beginning of a third temperance movement— once again put the issue of the damaging social consequences of alcohol in the forefront of public concern. In 1984 the federal government established a national drinking age of twenty-one, and since 1989, all containers for beverage alcohol manufactured for sale in the United States have been required by federal law to bear a government label warning against the dangers of alcohol. Since the 1980s state drunk-driving laws have been made much more punitive. Per capita consumption of alcohol, which hit a third historical peak in 1980, has been in a gradual decline since that time.

Attitudes toward Other Drugs

The image of alcohol did not wax and wane in isolation from the public's perception of drugs such as morphine, heroin, and cocaine, although the peaks of their favorable and unfavorable public images did not coincide precisely with those of alcohol. The use of cocaine rose rapidly after its introduction into the United States in the mid-1880s. Not until the Harrison Act of 1914 did the federal government prohibit the sale of cocaine without a prescription. A similar restriction on alcohol, National Prohibition, was enacted five years later, and by the mid-1920s the federal government had moved to eliminate heroin completely as a legally obtainable substance (Musto, 2002b).

When one reviews the history of drugs and alcohol in the United States, it is apparent that the ethical debate and extent of control have been related to the healthy or poisonous image of those powerful substances. Interestingly, neither extreme was buried by the victory of the contrary position. The ascendancy of one point of view seems to have created the conditions for the gradual emergence of the opposite attitude. A further point worth noting is that in the campaign against drugs and alcohol, the American practice has been to condemn them as being without any but the most limited value as medicine, and to hedge any exemption with tight restrictions. The periods of favorable and unfavorable attitudes are rather lengthy compared with the human life span, and so each tends to be seen as the settled opinion of science and society, and the presence or absence of controls seems to be based on what appear to be established premises.

The Control of Drugs and Alcohol

The control of drugs and alcohol involves both practical and philosophical considerations. Practically, a nation or locality has a limited array of controls, and those controls usually depend on the compliance of the public.

EFFECT OF LICENSING AND TAXATION. During the English gin epidemic, Parliament was limited to using a variety of license fees and taxes, which were not always easily enforced, to curb the production of gin. Success in the campaign did not begin to be acknowledged by observers until after 1750, by which time, presumably, the baleful effects of gin and the prolonged campaign against it by reformers had changed public attitudes toward that form of alcohol.

Control of opiates and cocaine initially took a different turn because, by the late nineteenth century, the licensing of physicians and pharmacists had become widespread in the United States. As a result, the first form of control over those drugs, after a period of free access, consisted of making them available by prescription only, although commonly a small amount would be permitted in an over-the-counter remedy. To alert the public, the Pure Food and Drug Act of 1906 required that the amount of drugs in a remedy be included on the label.

During the Progressive Era (approximately 1890–1920), reformers worked to give the central government more power, so that the benefit of uniform national laws could be applied to problems such as tainted meat, adulterated medicines, the destruction of forests, and drug abuse. With regard to drug abuse, the knotty constitutional problem was addressed by basing the Harrison Act of 1914, which was meant to regulate the distribution of opiates and cocaine, on the federal power to tax. Each transaction, from importation to retail purchase, had to be recorded, and a small tax had to be paid. Evasion of that law would be punished as a violation of the tax statutes. The restriction on maintenance doses of opiates for addicts was effected through Treasury Department regulations that were promulgated to carry out the Harrison Act. That part of the regulation was overturned by the U.S. Supreme Court in 1916 as a violation of states' rights, but it was effectively reinstated on another basis by the Court in 1919 during a peak of concern over drug addiction and in the face of the impending prohibition of alcohol.

The impact of alcohol prohibition on the severity of other drug laws illustrates a common factor in the control of drugs that might be called the *hydraulic model,* which implies that repression of one drug shifts use to another substance. This analysis encourages a blanket control of drugs and is especially popular at times when it is believed that abuse of a particular drug is a sign of an "addictive personality" (as in the late twentieth century) or the affliction of "inebriety" (late nineteenth century). These diagnoses suggest that the afflicted individual is pressured to use alcohol and drugs, and that if one substance is not available, he or she will switch to another.

EFFECTIVENESS OF DRUG CONTROL MEASURES. The question of "availability" raises the controversial issue of the effectiveness of control measures. Do laws against drugs accomplish much more than raising the price of drugs? Can prescription controls or international interdiction reduce the supply of drugs? Can prohibition reduce the supply of alcohol? The answers to these questions are elusive, but one can say that in general the reduction in drug and alcohol use that accompanied the restrictions in the United States beginning with World War I (and ending with the start of a second drug epidemic in the 1960s) occurred during a period of extraordinary antagonism toward drugs. Drugs came under progressively more severe laws, with the exception of alcohol, whose prohibition was repealed in 1933.

Confidence in legal control was reinforced by the obvious decline in drug use, and alcohol consumption fell from 1.7 U.S. gallons per capita in 1910, to about 0.6 gallons between 1920 and 1930, and did not return to the 1910 level until the mid-1960s (Rorabaugh, p. 232). Anti-drug legislation became increasingly severe, even after Prohibition was repealed in 1933, including mandatory minimum sentences and, in 1956, federal enactment of the death penalty as an option in some cases of drug trafficking.

To understand the doubts concerning legal sanctions in the late-twentieth-century drug "epidemic," it is necessary to compare the two drug epidemics. During the first wave of drug use, laws did not exist until the public's fear demanded them. The more recent wave of drug use found the most severe drug laws in effect at a time when a favorable attitude toward drug use was spreading across many sectors of American life. The apparent weakness in the enforcement of these laws, their clash with a new attitude among experts and the public, and the failure to recall the earlier experience with drugs led to ridicule and comfortable evasion of the law. A renewed harmony between anti-drug attitudes and anti-drug laws followed in the 1980s and later.

In the 1930s, at the end of the epidemic that peaked at about the time of World War I, the United States, after requiring general anti-drug and anti-alcohol education through state laws, adopted a policy of silence regarding drugs. When silence was not possible, exaggeration was instituted to complement the increasing severity of the drug laws. That policy may account for the loss of public memory of that early "epidemic"; the style of calling any drug use fraught with extreme danger (for the purpose of discouraging experimentation) contributed to the lack of balanced knowledge about drugs that characterized both adults and youth in the 1960s. The ultimate effect of the policy was to undercut the credibility of official statements on drug use.

In addition to the issue of changes in attitudes toward drugs and the practical problem of what control mechanisms exist, there is the broader question of control philosophy. Should drugs be controlled at all? Should the state try to protect citizens from their own desire to use drugs? Is drug control a law-enforcement problem, a public-health task, or a moral or religious issue? For Beecher (1828), alcohol had to be controlled because, whereas drunkenness ruined health and family life, it also impaired the individual's ability to hear and respond to God's message of salvation. Alcohol produced temporal death and eternal damnation.

Beecher's British contemporary John Stuart Mill rejected American prohibition laws and similar restrictions on the buyers of alcohol as an unjustified interference with liberty. Mill was particularly harsh on actions designed to protect individuals from themselves. To questions of policy he applied this prime principal: "Over himself, over his own body and mind, the individual is sovereign" (p. 11).

The debate between law-enforcement and public-health approaches to drug and alcohol abuse is particularly sensitive to public attitudes toward the nature of the drugs themselves. In an era of drug toleration, public-health methods and medical treatment in general are advocated and practiced. The concern is not so much with a drug itself as with the bad effects that it may have on an unwise or excessive user. As the attitude turns against the use of drugs in any amount, frustration and anger support police action, arrests, and punishments for violations of a strict rejection of drug use that leaves no room for *recreational* drug use.

The War against Drugs

The nature of the American drug experience changed quickly in the mid-1960s. The use of illegal drugs, which had existed at the fringes of society for more than three decades, moved to the center of youth culture. The drugs of choice were cannabis and other psychedelics, such as LSD. Advocates claimed that using those substances gave a person an experience of ultimate reality, a kind of insight that saints had achieved only after lengthy meditation and asceticism. Aldous Huxley gave an early cachet to psychedelic use with two accounts, *The Doors of Perception* (1954) and *Heaven and Hell* (1956), based on his use of mescaline. Huxley believed, however, that such experiences were best confined to an intellectual elite. In the 1960s Timothy Leary expanded that concept in the 1960s to include everyone. "Turn on, tune in, and drop out" was his advice to America. A striking example of faith in the drug revolution was Charles Reich's *The Greening of America* (1970), which saw marijuana as the "truth serum" that would create a new consciousness and a new society.

Passage of the Drug Control Amendments of 1965—an early response to the use of psychedelics, stimulants such as amphetamine, and sleeping medications such as barbiturates—was intended to restrict licit pharmaceutical production. Legal production of amphetamines was reduced from 100,000 pounds annually to less than 1,000 pounds by 1990. By 2002 the amount had risen to 20,000 pounds, largely as a result of the use of amphetamines in treating hyperactive children. The basis of anti-drug laws beginning in 1965 was shifted from the taxing power of the federal government to the Interstate Commerce Clause, a precedent that would be followed in the future.

Another significant element in the 1965 law was the creation, within the U.S. Food and Drug Administration, of the Bureau of Drug Abuse Control (BDAC), which would have as its targets all dangerous drugs except the opiates, cocaine, and marijuana; those traditional substances continued to be the province of the U.S. Treasury's Bureau of Narcotics. Then, because separating out the turfs of the two control agencies proved difficult, they were merged in 1968 as the Bureau of Narcotics and Dangerous Drugs (BNDD) and moved from the U.S. Treasury Department and the U.S. Department of Health, Education, and Welfare Department to the U.S. Department of Justice.

The Nixon administration (1969–1974) confronted growing public alarm over rising drug use among youth and, in response, created the basic element of the war on drugs that continues to the present (Musto and Korsmeyer). One of the Nixon administration's major goals was to reduce crime. Persuaded by the successful record of methadone treatment in the District of Columbia that indicated adopting such treatment could lower crime rates, Nixon gradually came to favor the use of methadone as a substitute for the illegal opiates used by addicts. The fact that Nixon, who was known to have a visceral antagonism to drug use, would initiate a national policy of substituting a legal addiction for an illegal one surprised many people.

Out of the Nixon era came the first "drug czar"; the first federal strategy (1972) that attempted to coordinate all federal anti-drug efforts; the creation of the Drug Enforcement Administration (DEA), the successor to the BNDD and the Office of Drug Abuse Law Enforcement (a temporary effort by the federal government to affect local drug dealers); and the National Institute on Drug Abuse (NIDA).

Under Nixon the budget to fight drugs rose to heights never before attained in the federal government; thousands of additional BNDD and DEA agents were trained and were placed internationally as well as nationally. Nevertheless, throughout the Nixon era the American people grew more tolerant of the use of drugs, particularly cannabis. Public opinion did not turn against drugs until about 1980, at the end of Jimmy Carter's presidency. The 1970 Drug Abuse Prevention and Control Act reflected a liberalization of the drug laws through the elimination of mandatory minimum sentences and a provision for clearing the record of an individual convicted of personal possession of cannabis. Although Nixon would seek a resumption of mandatory minimum sentences in 1974, as his administration was collapsing, that punishment was not resurrected until the Anti- Drug Abuse Acts of 1986 and 1988.

Perhaps the most alarming change in drug use habits in the 1970s and 1980s was the use of "crack" cocaine, a method that allows the user to inhale cocaine fumes and results in an intense brain response. The deaths of prominent sports figures from cocaine use crystallized public opinion against drugs and led Congress and a series of presidents to wage a war on drugs that was unprecedented in American history. Drug law convictions crowded prisons and caused a backlash to the anti-drug campaign.

Decriminalization

In the era of increased drug use that started about 1965, an attack on prohibitory laws began with criticism of the extraordinarily long sentences meted out to persons who possessed small amounts of marijuana. By 1970 the federal law had been softened and advocates of legalizing marijuana were organized. With the rise in cocaine and heroin use, many people called for legalizing or "decriminalizing" those drugs on the grounds that their dangers had been exaggerated. In 1972 the term *decriminalization* was proposed in the first report of the U.S. Commission on Marihuana and Drug Abuse as a compromise between arresting persons with small amounts of marijuana for personal use, and allowing a free market in marijuana. Decriminalization would allow use while still permitting a national policy warning against the drug and maintaining legal sanctions against those who produced and distributed large amounts of the plant.

Libertarians, such as the economist Milton Friedman, added a philosophy of freedom from state interference in private acts, such as drug use, to the debate over controls. Although the public has been increasingly opposed to drug use (reflected also in reduced consumption of tobacco and alcohol) and in favor of strict anti-drug laws since about 1980, analyses questioning the campaign against drugs have continued (Friedman).

Opposition to the "war against drugs" has centered on two themes: interdiction of drugs from foreign nations and domestic enforcement of stricter anti-drug laws. Critics have argued that interdiction has not affected the availability of drugs, especially cocaine, the chief target of the U.S. Coast Guard and the other "uniformed" services as well as the U.S. Drug Enforcement Administration. With regard to domestic policy, application of harsh criminal penalties to drug offenders is condemned as a source of prison crowding that does little or nothing to reduce crime or hard-core drug use.

A recent suggestion offered by those opposed to overreliance on the criminal justice approach is "harm reduction," a phrase that attempts to describe Dutch drug policy. The Netherlands is noted for allowing personal use of drugs, providing sterile needles to drug injectors, and generally tolerating drug availability. The expectation is that in the long run this policy will allow more users to survive and experience a life less dominated by, or free from, drug use.

Criticism of any policy that would appear to encourage or facilitate drug use has been severe. Arguments against legalization include the observation that laws pressure users into treatment, the symbolic importance of an anti-drug policy, and the fear that drug use would increase if drugs were easily available and inexpensive.

Conclusion

The history of drug and alcohol control illustrates the slowly shifting assumptions societies make regarding those powerful substances. At the extreme of each attitude the good or evil nature of drugs seems so obvious that contrary notions are rejected with dispatch. Consequently, the ethical debate is deeply influenced by these alterations in attitude. These contrary positions also make an indefinitely sustainable drug policy difficult to frame.

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SEE ALSO: *Addiction and Dependence; Alcohol and Other Drugs in a Public Health Context; Alcoholism; Bioterrorism; Environmental Ethics; Hazardous Wastes and Toxic Substances; Smoking*

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HAZARDOUS WASTES AND TOXIC SUBSTANCES

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Developed nations such as the United States annually use more than 60,000 hazardous chemicals in their agricultural and manufacturing processes. Because at least 10,000 are introduced each year, often we know very little about their effects. When we began massive use of such chemicals, we did not know that by the 1970s human breast milk would become more contaminated with toxins than any allowable manufactured foods. We did not realize that measurable amounts of DDT would appear in the polar ice caps. We did not suspect that by 2000 Silicon Valley would have more Superfund sites, twenty-nine, than any other single U.S. location—all because of toxic wastes from manufacturing high-tech products such as disk drives and semiconductors. We did not realize that, because of their long lifetimes, many hazardous chemicals would be able to migrate from their present waste sites and would threaten persons living thousands of years in the future. On the whole, we have assumed that dangerous chemicals are *innocent until proved guilty.* Because we do very little sophisticated epidemiological testing and rarely take account of food-chain and synergistic effects, thousands of chemicals have become both important to our agricultural and manufacturing processes and ubiquitous in our environment. Hence, it is often difficult to prove that any one chemical is responsible for specific harms, even when we know that it is theoretically able to cause many *statistical casualties.*

Hazardous wastes, byproducts of manufacturing, scientific, medical, and agricultural processes, have at least one of four characteristics: ignitability, corrosivity, reactivity, or toxicity (Wagner). Hazardous substances become wastes only when they have outlived their economic life. They include solvents, electroplating substances, pesticides such as dioxin, and radioactive wastes. Toxic substances, a subset of hazardous substances, have the characteristic of toxicity: the ability to cause serious injury, illness, or death.

Many persons became aware of the threat of hazardous wastes and toxic substances when American scientist Rachel Carson (1907–1964) wrote *Silent Spring* (1962), one of the earliest warnings of the dangers of pesticides, or when Michael Brown wrote his spellbinding account of hundreds of cancers, genetic damage, and birth defects near Love Canal, New York, and other waste sites in 1980. Indeed, hazardous-waste management has become one of the most serious environmental problems facing the world. In the United States alone, more than 5 billion pounds of toxic chemicals are released each year into air, water, and land. Approximately 80 percent of hazardous waste has been dumped into thousands of landfills, ponds, and pits throughout the world, from Love Canal in New York, to Mellery in Belgium, to North-Rhine in Germany. It has polluted air, wells, surface water, and groundwater. It has destroyed species, habitats, and ecosystems. It also has caused fires, explosions, direct-contact poisoning, and numerous cases of cancer, genetic harms, neurological disorders, and birth defects.

Surprisingly, one-quarter of the mercury and nearly one-half of all dioxin released into the American environment is from the healthcare industry. The mercury comes from blood temperature gauges and batteries, for example, while the dioxin comes from burning chlorinated plastics, like the PVC tubing used in kidney dialysis. Both mercury and dioxin are emitted by hospital incineration, and each patient-day is responsible for 9 kilograms of solid waste. Much of the dioxin emitted is from biochemical waste, 60 percent of which is not handled adequately.

In part to protect workers and the public from the dangers associated with hazardous substances, the U.S. Congress passed laws such as the 1954 Atomic Energy Act; the 1975 Hazardous Materials Transportation Act; the 1976 Resource Conservation and Recovery Act (RCRA); the 1976 Toxic Substances Control Act (TSCA); the 1977 Clean Water Act; the 1977 Clean Air Act; and the 1980 Comprehensive Environmental Response, Compensation, and Liability Act known as CERCLA or Superfund (Dominguez and Bartlett). These laws include provisions that require monitoring pollutants, reporting spills, preparing manifests describing particular wastes, and special packaging for transporting specific types of hazardous materials. The Clean Air Act regulates smelter emissions, for instance, and the Clean Water Act regulates mining-caused water pollution (Young). RCRA was passed to fill a statutory void left by the Clean Air Act and the Clean Water Act, which require removal of hazardous materials from air and water but leave the question of the ultimate deposition of hazardous waste unanswered. Although RCRA addresses the handling of such waste at current and future facilities, it does not deal with closed or abandoned sites. CERCLA focuses on hazardous-waste contamination when sites or spills have been abandoned; through penalties and taxes on hazardous substances, CERCLA provides for cleaning up abandoned sites.

Despite laws that govern dangerous substances, and despite the fact that 50,000 environmental assessments are prepared annually in the U.S., many to evaluate waste sites under the 1969 National Environmental Policy Act, hazardous wastes remain a major problem. One reason is that well-financed industrial waste polluters can dominate under-funded government regulators. Another reason is that the North American Free Trade Agreement (NAFTA) has allowed more U.S. waste to go to countries such as Mexico. The U.S.-to-Mexico waste flow doubled, for example, from 1994 to 1999, and yet Mexico has only one licensed hazardous waste facility. A third factor is that the use of toxic substances and the management of hazardous wastes raise ethical issues that have not been adequately addressed by existing regulations. These issues include siting, rights of future generations, workers's rights, free and informed consent, compensation, due process, appropriate ethical behavior under conditions of uncertainty, where to place the burden of proof regarding alleged waste harms, and workers's and the public's right to know.

Equity Issues

Those who can afford to avoid hazardous wastes and toxic substances typically do so. Those who cannot are usually poor or otherwise disadvantaged. For this reason, public and workplace exposure to such hazards raises questions of intergenerational, geographical, and occupational equity. Intergenerational-equity problems deal with imposing risks and costs of hazardous wastes and toxic substances on future persons. Geographical-equity issues have to do with where and how to site waste dumps or facilities using toxic substances. Occupational-equity problems focus on whether to maximize the safety of the public or of the people who work with hazardous materials because we often cannot protect both groups at once. For example, effective decontamination and safety assurance at waste sites typically require more worker exposure to toxins but reduce public risk. Using mechanical or nonhuman decontamination and safety procedures, however, is safer for workers but usually increases public risk because such procedures are less effective than those controlled closely by people (see Kasperson).

Intergenerational equity requires us to ask whether we ought to mortgage the future by imposing our debts of buried (or stored) hazardous wastes on subsequent generations. Current plans for future U.S. government storage of high-level radioactive waste, for example, require the steel canisters to resist corrosion for as little as 300 years. Nevertheless, the U.S. Department of Energy admits that the waste will remain dangerous for longer than 10,000 years. Government experts agree that, at best, they can merely limit the radioactivity that reaches the environment, and that there is no doubt that the repository will leak over the course of the next 10,000 years (Shrader-Frechette, 1993). To saddle our descendants with the medical and financial debts of such waste, much of which is extremely long-lived, is questionable at best: We have received most of the benefits from the use of industrial and agricultural processes that create hazardous wastes, whereas future persons will bear most of the risks and costs. This risk/cost-benefit asymmetry suggests that, without good reasons or compensating benefits, future generations ought not be saddled with debts of their ancestors. Moreover, any alleged economies associated with storage of hazardous waste are, in large part, questionable because of the practice of discounting future costs (such as deaths) at some rate of x percent per year. For example, at a discount rate of 10 percent, effects on people's welfare twenty years from now count only for one-tenth of what effects on people's welfare count for now. Or, more graphically, with a discount rate of 5 percent, 1 billion deaths in 400 years count the same as one death next year. A number of moral philosophers, such as Derek Parfit, have argued that use of a discount rate is unethical, because the moral importance of future events, like the death of a person, does not decline at some x percent per year.

Another issue related to intergenerational equity is what sort of criteria might justify irreversible damage to the environment, such as that caused by deep-well storage of high-level nuclear waste. On the one hand, irreversible management schemes for nuclear waste, because they are premised on the nonretrievability of the waste, theoretically impose fewer management burdens on later generations, but they also preempt future choices about how to deal with the hazards. On the other hand, schemes that are reversible allow for wider choices for future generations, but they also impose greater management burdens. If we cannot do both, is it ethically desirable to maximize future freedom or to minimize future burdens? The technical problems associated with storing long-lived hazardous waste for centuries are forcing us to take a great gamble that our descendants will not breach the waste repositories through war, terrorism, or drilling for minerals; that groundwater will not leach out and transport toxins; and that subsequent ice sheets, faulting, seismic activity, and geological folding will not uncover the wastes.

Using and storing toxins also raises questions of environmental justice, that is, spatial or geographical equity in the risk distributiuon (Shrader-Frechette, 2002). One such issue is whether it is fair to impose a higher risk (of being harmed by seepage from a hazardous-waste dump, for example) on persons just because they live in a certain spot. Or, is it ethical for people in one area to receive the benefits of products created by using toxic substances, while people in another area bear the health risks associated a hazardous-waste dump? How does one site hazardous facilities equitably, and how does one transport toxic substances safely (see English)?

Questions about the equity of risk distribution are central to the issue of managing toxic substances because thousands of persons—such as the 1984 victims of the Union Carbide toxic leak in Bhopal, India—have already died as a consequence of exposure to hazardous substances.

Current trade agreements also allow much hazardous waste of developed nations to be shipped to developing ones. Economic comparisons of alternative chemical technologies and different waste sites typically ignore the externalities (or social costs) such as the inequitable distribution of health hazards benefits associated with them. Geographical and intergenerational inequities are typically *external* to the benefit-cost schemes used as the basis for public policy. Consequently, decision makers almost always ignore them (Shrader-Frechette, 2002).

The most serious problems of geographical equity in the distribution of risks associated with dangerous substances arise because developed nations often ship their toxic chemicals and hazardous wastes to developing countries. One-third of U.S. pesticide exports, for example, are products that are banned for use in the United States. These exports are annually responsible for 40,000 pesticide-related deaths, mainly in developing nations (Shrader-Frechette, 1991). Likewise, the United Nations estimates that as much as 20 percent of the hazardous waste produced in developed nations is sent to other countries where health and safety standards are virtually nonexistent. The Organization of African Unity has pleaded with member states to stop such traffic, but corruption and crime have kept the waste transport going (Moyers). Indeed, exporting toxic substances and hazardous wastes may be the current version of the infant-formula problem. During the last three decades of the twentieth century, U.S. and multinational corporations have profited by exporting infant formula to developing nations and by encouraging young mothers not to nurse their children. They have been able to do so only by extremely coercive sales tactics and by misleading persons in developing countries about the relative merits and dangers of the exports.

Some of the greatest risks associated with toxic substances and hazardous wastes, whether in developed or developing nations, are borne by workers. One of the main questions of occupational equity is whether it is just to impose higher health burdens on workers in exchange for wages. Is it fair to allow persons to trade their health and safety for money? This question is particularly troublesome in the United States, because many other countries—such as the Scandinavian nations, Germany, and the former Soviet Union—have standards for occupational exposure to risks from toxins that are just as stringent as standards for public exposure. The United States, however, follows the alleged *compensating wage differential* (CWD) of Scot economist Adam Smith (1723–1790), presupposing that wages compensate workers for increased occupational exposures to toxic substances. As a consequence, U.S. regulators argue that, in exchange for facing higher risks than the public faces from toxic substances, workers receive higher wages that compensate them for their burden. Other countries do not accept the economic theory underlying the CWD and argue for equal health standards, for making public and worker exposure norms the same (Shrader-Frechette, 1991).

Consent and Right to Know

One reason critics question the theory underlying the CWD is its presupposition that, by virtue of accepting certain jobs, workers exposed to serious hazards give free, informed consent to the risks. Yet, from an ethical point of view, those most able to give free, informed consent—those who are well educated and who have many job opportunities—are usually unwilling to do so. Those least able to give genuine consent to a risky workplace or neighborhood—because of their lack of education or information and their financial constraints—are often willing to give allegedly informed consent.

The 1986 U.S. Right-to-Know Act requires owners or operators of sites using hazardous materials to notify the Emergency Response Commission in their state that toxins are present at a facility. However, at least three factors suggest that this law may fail to ensure full conditions for the free, informed consent of persons likely to be harmed by some hazardous substance. First, owners or operators (rather than a neutral third party) provide the information about the hazard. Often those responsible for toxic substances and hazardous wastes do not inform workers and the public of the risks they face, even after company physicians have documented serious health problems. Employers in the chemical industry, for example, frequently spend money on genetic screening to exclude susceptible persons from the workplace rather than to monitor their health on the job (Draper). Second, the existence, location, and operational procedures of dangerous facilities are likely things to which citizens and workers have not given free, informed consent in the first place. Third, mining is not included among the industries required to report their toxic emissions to state and federal regulators. For example, Utah's Bingham Canyon Copper Mine, owned by Kennecott Copper, ranks fourth in the nation in total toxic releases, yet it and other mining companies do not report their releases (Young).

Sociological data reveal that, as education and income rise, people are less willing to accept either work in hazardous facilities or risky jobs; those who do so tend to be poorly educated or financially strapped. The data also show that the alleged CWD does not operate for poor, unskilled, minority, or nonunionized workers. Yet these are precisely the people most likely to have risky jobs, such as handling nuclear wastes. In other words, the very persons *least* able to give free, informed consent to occupational risks are precisely those who *most* often work in risky jobs (Shrader-Frechette, 1993).

At the international level, a similar situation occurs. The persons and nations least able to give free informed consent to the location of facilities for using or storing toxic substances are typically those who most often bear such risks. Hazardous wastes shipped abroad, for example, are usually sent to countries that will take them at the cheapest rate, and these tend to be developing nations that are often ill informed about the risks involved. In 1989, the United Nations passed a resolution requiring any country receiving hazardous waste to give consent before it is sent. Because socioeconomic conditions and corruption often militate against the exercise of free informed consent, however, it is questionable whether the U.N. resolution will have much effect (Shrader-Frechette, 1991).

Industrial offers of financial benefits—for storing hazardous waste in a developing nation or in an economically depressed community—create a coercive context in which requirements for free informed consent are unlikely to be met. Likewise, high wages for desperate workers who agree to take risky jobs may jeopardize their legitimate consent. In such contexts, we must admit either that our classical ethical theory of free informed consent is wrong or that our laws and regulations fail to provide an ethical framework in which those most affected by hazardous substances can give free informed consent to the risk.

Given the many consent-related problems relevant to risk from hazardous substances, a crucial issue is: Who should give consent? Liberty and grass-roots self-determination require local control of whether a hazardous facility is sited in a particular area. Yet, equality of consideration for people in all regions and minimizing overall risk often require federal control. Should a particular community be able to veto the location of a hazardous facility, even though that site may be the best in the country and may provide the most equal protection of all people? Or should the national government have the right to impose such risks on a local community, even against the wishes of that group?

On the one hand, federal jurisdiction is more likely to protect the environment, to avoid the tragedy of the commons, to gain national economies of scale, and to avoid regional favoritism. Federal jurisdiction is also more likely to provide compensation for victims of spillovers from another locale and to facilitate the politics of sacrifice by imposing equal burdens on all. On the other hand, local jurisdiction is more likely to promote diversity, to offer a more flexible vehicle for experimenting with waste regulations, and to enhance citizen autonomy and liberty. Local jurisdiction also is likely to encourage cooperation through participation in decision making, to discourage some kinds of inequitable federal policies, and to help avoid many violations of rights.

Compensation

Current U.S. laws do not typically provide for full exercise of due-process rights by those who may have been harmed by toxins or hazardous wastes. Many of the companies that handle dangerous substances do not have either full insurance for their pollution risk or adequate funds to cover their liability themselves. RCRA and CERCLA, however, require such companies both to show that they are capable of paying at least some of the damages resulting from their activities and to clean up their sites. Because enforcement of liability and coverage provisions of these laws is difficult, many hazardous-waste industries often operate outside the law. Furthermore, most insurers have withdrawn from the pollution market, claiming that providing such coverage carries the risk of payments for claims that would bankrupt them.

Just as insurers fear potentially large liability claims in cases involving hazardous-waste substances, so do members of the public. For example, in 1987 when the U.S. Congress chose Yucca Mountain, Nevada, as the likely site for the world's first permanent facility for high-level nuclear waste, local residents and the state asked for unlimited, strict-liability coverage for any nuclear-waste accident or incident. The U.S. Department of Energy's response to the citizens, based on the 1957 Price-Anderson Act, was that the government would allow the waste facility to bear only limited liability. Consequently, the U.S. nuclear program, including radioactive-waste management, has operated under a government-imposed limit for liability coverage. This limit, designed to protect the nuclear-waste industry from bankruptcy caused by accidents, is less than 3 percent of the government-calculated costs of the April 1986 Chernobyl nuclear catastrophe, and Chernobyl was not a worst-case accident (see Shrader-Frechette, 1993).

Limits on government or industry liability for hazardous-waste and toxic-substance incidents are problematic for several reasons. First, liability is a well-known incentive for appropriate, safe behavior. Second, refusal to accept full and strict liability suggests that hazardous- and radioactive-waste sites are not as safe as the government maintains they are. Third, if government officials may legally limit due-process right then, in the case of an accident at a hazardous-waste facility, the main financial burdens will be borne inequitably by accident victims rather than by the perpetrators of the hazard. Fourth, because much less is known about the dangers from hazardous wastes and toxic substances than about more ordinary risks, full liability seems a reasonable requirement. And finally, the safety record of hazardous facilities, in the past, has not been good. Every state and every nation in the world have extensive, long-term pollution from toxins. Even in the United States, the government has been one of the worst offenders. A congressional report has argued that cleaning up the hazardous and radioactive wastes at government weapons facilities would cost more than $300 billion (U.S. Congress; Shrader-Frechette, 1993). Such problems argue for citizens's rights to full liability.

Uncertainty, Human Error, and the Burden of Proof

Inadequate compensation for victims of toxins, inequitable distribution of the risks associated with hazardous wastes, and the uncertainties and potential harm associated with such substances provide powerful arguments for reducing or eliminating exposure to them. To decrease exposures and to move *beyond dumping,* however, we must have market incentives for reducing the volume of toxic substances and hazardous wastes (Piasecki; Higgins). To reduce the volume of these threats, we must know exactly what effects they cause, and we must make risk imposers accountable for their behavior. Ensuring accountability is not easy. Adequate tests for medical responses to low-level chemical exposures require samples of thousands of persons, because so many toxic substances produce health effects synergistically, because there are many uncertainties about actual exposure to hazardous substances, because the effects of such exposure often are unknown (Ashford and Miller), and because phenotypical characteristics among individuals often vary by a factor of 200. All four variables cause extreme differences in humans's responses to toxins.

Uncertainties about exposure and about the consequences of exposure to hazardous substances are compounded by the fact that the industries that produce toxic substances and hazardous wastes—and that profit from them—usually perform the required tests to determine toxicity and health effects. Pesticide-registration decisions (about allowing use of the chemicals) in the West, for example, are tied to a risk-benefit standard that combines scientific and economic evidence. Because industry does most or all of the testing, and because environmental and health groups are forced to show that the dangers outweigh the economic benefits of a particular pesticide, there is much uncertainty about the real hazards actually faced by workers and consumers. As a consequence, virtually no groups want toxic substances or hazardous wastes used or stored near them. Hence the protest: *Not in my backyard*—NIMBY.

NIMBY responses also arise as a consequence of public mistrust of human institutions for controlling hazardous wastes and toxic chemicals. All dangerous technologies are unavoidably dependent upon fragile, sometimes short-lived, human institutions and human capabilities. Faulty technology, after all, did not cause the injuries and deaths at Three Mile Island, Bhopal, Love Canal, or Chernobyl. Human error did. Human error and misconduct also may be the insoluble problem with using toxic substances and managing hazardous wastes. According to risk assessors, 60 percent to 80 percent of industrial accidents are due to human mismanagement or corruption (Shrader-Frechette, 1993). For example, at the nation's largest incinerator for hazardous wastes, run by Chemical Waste Management, Inc., in Chicago, a 1992 grand jury found evidence of criminal conduct, including deliberate mislabeling of many barrels of hazardous waste. They also discovered deliberate disconnection of pollution-monitoring devices. More generally, corruption in the waste-disposal industry has been rampant in the United States ever since the 1940s, when the Mafia won control of the carting business through Local 813 of the International Brotherhood of Teamsters. In the mid-1990s, three Mafia families still dominated hazardous-waste disposal and illegal dumping: the Gambino, Lucchese, and Genovese/Tiere crime groups (see Szasz). Given the potential for human error and corruption, citizens are frequently skeptical regarding whether hazardous and toxic substances will be handled safely, with little threat to workers or to the public.

Because of scientific unknowns and uncertainties about human behavior and corruption, several moral philosophers have argued that potentially catastrophic situations—involving hazardous wastes and toxic substances—require ethically conservative behavior (Cranor; Shrader-Frechette, 1991; Ashford and Miller). Such situations often require one to choose a *maximin* decision rule to avoid situations with the greatest potential for harm, as John Rawls (1971) has argued. Ethical conservatism, in a situation of uncertainty, also may require society to place the burden of proof—regarding risk or harm—on the manufacturers, users, and disposers of hazardous substances, rather than on their potential victims. This, in turn, may mean that we will need to reform our laws governing so-called *toxic torts* (Cranor).

Given the longevity and the catastrophic potential of many toxic substances and hazardous wastes, we may need to reevaluate the human and environmental price we have paid for our economic progress. Although our society may not be able to avoid use of certain toxic substances and disposal of some hazardous waste, it is clear that we need to maximize the equity with which we distribute the risks associated with such threats. We also need to guarantee, so far as possible, that potential victims of toxins are informed about the risks they face and that they freely consent to avoidable risk impositions. Finally, we ought to ensure that those put at risk from toxic substances and hazardous wastes are compensated, so far as possible, for harm done to them. Because of numerous uncertainties about their effects, and because of the catastrophic potential and the longevity of many hazardous materials, our behavior regarding them ought to be ethically conservative.

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SEE ALSO: *Environmental Ethics; Environmental Health; Environmental Policy and Law; Future Generations, Reproductive Technologies and Obligations to; Technology*

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HEALING

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Health and Wholeness

Healing is an action whose goal is the restoration of health. The English word *health* literally means *wholeness* and *to heal* means *to make whole.* Ancient Greek had two words generally translated as "health": *hygieia,* meaning "a well way of living," and *euexia,* meaning "good habit of body." Leon Kass (1985) notes that the English and both Greek words for health are totally unrelated to all the words for disease, illness, and sickness. This is also true for German, Latin, and Hebrew. In addition, the Greek terms for health, unlike the English, are unrelated to all the verbs for healing. Health for the ancient Greeks was a state or condition unrelated to, and prior to, both illness and healers. The English emphasis on wholeness, Kass also notes, is comparatively static and structural, implying a whole distinct from all else and complete in itself and connoting self-sufficiency and independence. The Greek terms, in contrast, stress the functioning of the whole, and not only its working but its working well. Kass sums up this Greek understanding of health by defining it as a natural as opposed to a moral norm that reveals itself in activity as a standard of bodily excellence or fitness. It is the well-working of the organism as a whole, an activity of the living body in accordance with its specific excellences.

The work of healing in Western culture is the proper activity of the profession of medicine. Howard Brody (1987) calls medicine a craft in which scientific knowledge is applied to particular patients for the purpose of "a right and good healing action," employing the now-classic phrase of Edmund Pellegrino (1982). Unlike the Greek, the English language sets up a relationship between medicine, whose business is healing, and health that is problematic. Kass states the problem this way: Health and only health is the doctor's proper business; but health, understood as well-working wholeness, is not the business only of doctors.

HEALTH AS EQUILIBRIUM. A less formal starting point than Kass's from which to examine the relationship between health and medicine is Pellegrino's definition of health as a state of accommodation, defined in different terms by each person. We feel healthy, he says, when we have found an equilibrium between our already-experienced shortcomings and our aspirations and have adjusted our goals to the gap between them. This means that health cannot be understood apart from a person's life history, or to use José Ortega y Gasset's phrase, one's "personal project" (p. 45). Healing, according to this definition of health, occurs when a new equilibrium is found between one's hopes and one's failures that can be incorporated into one's personal project. As such, healing must be based on an authentic perception of the experience of illness in the particular person.

THE CONTEXT OF HEALING. It follows that for an action of someone who professes to heal to be a right and good healing action, it must be situated in the context of a personal history so as to restore the direction of a personal project. This requires that a dialogue be established between healer and patient whose goal is the creation of a common ground of meaning shared by the healer and the patient. How extensive that common ground must be to constitute a right and good healing action is open to question. In taking a medical history, physicians have traditionally tended to restrict the province of illness to the *facts of diseases,* leaving unexplored the *fact of illness*—that is, the physical, psychological, and moral vulnerability the patient suffers in the attack on his or her very being that Pellegrino calls "the ontological assault of illness" (1982). However, this concentration on facts and diseases does not result from simple, unreflective traditionalism. Rather, it has enabled the profession of medicine to set very definite limits to the boundaries of healing and thereby to maintain control over the responsibilities that physicians take upon themselves as healers.

THE BOUNDARIES OF HEALING. The attempt by physicians such as Pellegrino to enlarge the boundaries of what counts as healing has often produced frustration and anger. For example, Franz J. Ingelfinger, in a classic editorial in the *New England Journal of Medicine,* rebukes those who would expand medical treatment to include families, not just individuals: "The curious idea is abroad that the doctor should be a factotum of health. By some singularity of reasoning, his role as healer is disparaged, and the words 'care, not cure' are becoming as tiresome as 'death with dignity'" (p. 565). He continues by lamenting that if the doctor is insensitive to the "multiple environmental conditions that threaten our mental and physical selves, he is regarded as failing the holistic image that many—both lay and medical—wish to impose on the physician" (p. 565). Ingelfinger concludes by asserting that the physician's primary concern, in spite of utopian claims to the contrary, should be sickness, not overall health; medicine should concentrate on "scientifically accurate diagnosis and treatment."

THE NATURE OF HEALING. The resistance of physicians such as Ingelfinger to what they regard as an unwarranted expansion of their role in society signals a fundamental disagreement within Western society about the nature of healing. Holistic approaches to medicine challenge traditional assumptions about who can be called a healer, what the goal of healing should be, and, most important, who can say what constitutes a right and good healing action: the healer or the one to be healed. Those who take positions like Ingelfinger's insist that only those who engage in "scientifically accurate diagnosis and treatment" deserve to be called healers, that healing aims at the cure of disease, and that the healer's profession alone can determine what constitutes a right and good healing action.

Those who disagree with these assumptions often attack their opponents as simply *uncaring*. Victor Kestenbaum, however, argues that the point of departure and method, not the lack of feeling, is the real issue. By distinguishing between caring and curing and limiting medicine to the latter, Ingelfinger and his colleagues take as normative the physician's perception of illness, shaped by the method of science, and then seek to derive global professional obligations from it. Thus they cut the phenomenon of illness to fit a prior conception of role and discourse. Pellegrino, Kestenbaum notes by way of contrast, starts with illness as experienced by the patient and derives professional obligations from the distinctly human dimensions of being ill and in distress. The responsibilities of the healer follow from the complexity and scope of the phenomenon of illness, not from the self-declared duties of the profession.

The Healing Profession

In the 1950s Pedro Laín Entralgo observed that "the curative activity of the physician is always determined by the reality of the human being towards which it is directed, that is, by the 'personal' conditions of the disease and of the patient" (p. xv). Pellegrino believes that this accommodation to the reality of the patient follows from the promise that the medical profession, in the person of the physician, makes to the patient: "The promise of help that shapes the nature of every healing act and defines the requirements for successful healing—even when cure is not possible" (p. 160). But, Pellegrino notes, considerable confusion exists between doctor and patient about what healing means. Physicians, he says, often fail to comprehend what the patient understands by the promise of healing; patients often fail to understand what the physician thinks he or she is promising. Physicians, in response, are moving toward a restricted sense of promise, emphasizing technical competence, whereas patients expect not only competence but compassionate help as well. The wider the gap between professional promises and lay expectations, the more difficult becomes the collaboration between physician and patient to discover the equilibrium that constitutes genuine healing. As the gap increases, Pellegrino also notes, patients will be more tempted to seek alternatives to the "medical model" and lose the benefits of scientific competence.

COMPETENCE AND COMPASSION. Healing requires, Pellegrino insists, both competence (in scientifically accurate diagnosis and treatment) and compassion (the capacity to enter into the experience of illness with the patient). Competence is a necessary but not sufficient condition of healing. Healing "must be shaped at every step by the purposes of the healing acts—by the good of the person who is ill—his bodily good, of course, but also his concept of health, his value system, and his sense of the kind and quality of life he thinks is worthwhile" (p. 161). Pellegrino sums this up by declaring that the physician therefore has the obligation to protect the moral agency of the patient, to enhance it even in the face of the special vulnerabilities of being ill.

This protection of the moral agency of the patient lies at the heart of compassion; it is essential to the performance of a right and good healing action. Healing thus requires that the conversation between physician and patient encompass more than what can be accommodated by scientifically accurate medical language. As Jay Katz has observed, despite the quantity of words overflowing patients' medical charts, the world shared by doctor and patient is often one of profound silence, offering not the humaneness of shared understanding but the humaneness of services silently rendered (Katz).

The Silent World of Medicine

Yet modern scientific medicine owes its success to silence of a sort, a disbelief in words that Laín Entralgo traces to two tenets of the Hippocratic school of medicine. First, the latter rejected the use of words as a therapeutic tool; medicinal remedies were preferred to exorcism, which relied on the curative power of "fine words used in the manner of charms" (Laín Entralgo, p. 47). In addition, Hippocratic physicians trusted the patient's symptoms to reveal the causes of disease and dismissed the patient's own words about the source of his or her condition as unreliable opinion.

THE CLINICAL GAZE. Michel Foucault (1973), in his discussion of the antecedents of modern medicine, discovers a similar kind of silence in the "clinical gaze," a reorganization of medical perception that took place in the eighteenth century. Disease ceased to be perceived as an alien force inserted into the body and subject to the words of exorcism; instead, disease was the body itself, become diseased. Healing became the task of deciphering corporal space, a work of seeing instead of speaking. The model physician is Hippocrates, who applied himself only to observation, despising all preconceived systems that might bias the observer. This clinical gaze flourishes only in the relative silence of theories, imaginings, and whatever serves as an obstacle to the sensible immediate. In addition, when physicians question the patient, they question only what they can see—the body become diseased—and only in the language proposed by the body. All other languages, including that spoken by the patient, must fall silent before the absolute silence of observation. Within this double silence, Foucault says, things seen can be heard at last, and heard solely by the virtue of the fact that they are seen. It is in this sense that "the clinical gaze has the paradoxical ability to hear a language as soon as it perceives a spectacle" (p. 108).

The conversation that emerges from this double silence is an interior dialogue that the observer has with him- or herself, not a dialogue with the object of gaze. In the context of the physician-patient encounter, the language describing what the physician has seen gives structure to the encounter, not any language the patient might speak. The profundity of this silence derives from its absoluteness: Not only must the patient keep quiet about theories and imaginings that might relate to his or her illness, absolutely nothing the patient says can have any significance for the physician because no language can exist that has priority over the language of observation. This muting of the patient's own voice gives rise to what Foucault calls "the great myth of a pure Gaze that would be pure Language: a speaking eye" (p. 114). What it sees, it gathers and organizes; and as it sees, and sees more clearly, it speaks and teaches. The speaking eye becomes "the servant of things and the master of truth" (p. 115).

THE LANGUAGE OF CURING. Secretiveness, or what Foucault terms "esotericism," arises from this model for the physician-patient relationship because, as Foucault observes, one sees the visible (the true) only because one knows the language. Unlike Molière's physicians, who spoke Latin merely in order not to be understood, Foucault's clinicians speak openly about that which anyone can see but only they can understand, because through the language of clinical description they have the means to see and hear at the same time, having access to a language that masters the visible. At this point, the earlier epistemological silence (Foucault's "double silence") that results from a constriction of perception changes into the silence of which Jay Katz speaks, a silence made even more baffling and profound by having as its vehicle a multitude of words that make every pretense of being understandable.

In effect, this model of medical perception insists that healing cannot be spoken or even thought of apart from the language of curing, that is, scientifically accurate diagnosis and treatment. This clinical perception and its promise of truth tend to overshadow all other claims to truth, reducing the promise to help those who suffer illness to the promise to be scientifically competent. Attempting to expand that visual horizon—particularly in the direction of the perspective of the patient—risks introducing an unacceptable noise into the silence of the medical clinic, an unwelcome and meaningless distraction from the work of curing.

Healing and Cultural Reality

Healing, of course, is a much broader cultural phenomenon than that encompassed by Western scientific medicine. Admittedly, the success of Western medicine at curing has helped justify its claim to be the model for healing in the world today. Yet, as Eric Cassell notes, "the success of medicine has created a strain: the doctor sees his role as the curer of disease and 'forgets' his role as healer of the sick, and patients wander disabled but without a culturally acceptable mantle of disease with which to clothe the nakedness of their pain" (Cassell, 1976, p. 51). This strain also appears in the way patients perceive their physicians. Western culture has conferred upon doctors the role of the care of the sick; but although doctors' role as the curers of disease is clear, their role as healers remains obscure. The latter role, Cassell adds, depends less on their ability to provide a scientifically accurate explanation of their patient's illness than to provide an explanation consistent with the culture of the patient. The reality that counts is cultural reality, and the system used by the healer or doctor need be accurate only in terms of the culture in which it is being used, for it serves to explain illness. The importance of the healer's explanation, Cassell insists, cannot be overemphasized.

THE HEALING RELATIONSHIP. As Cassell sees it, the healer's knowledge, imparted to the patient, helps move the world of illness from the unknown to the rational world. This knowledge allows the patient to "work on" the illness and to make an essential link between conscious process and body process that, Cassell says, marks the "educated" patient. Such healing is not cognitive alone. In addition to educating the patient, healers also play an active physical part in providing a link between symbolic reason and the body: They use their hands. Cassell calls this the "tenderness phenomenon," as important as education in the process of healing. He associates this phenomenon with parenting, and, in this sense, healers serve as parents. In addition to other aspects of the parental role, we transfer to them the right to lay hands on us, to be tender to us, and to pass through our territorial defenses.

The connectedness that underlies the tenderness phenomenon works in both directions. Healer and sufferer become exquisitely sensitive to one another; each can sense the feelings of the other. If healers can accept that the feelings they have can come from the patient, they can use their own feelings in the presence of the patient to provide a vital link with the patient's interior emotional state that is otherwise closed to the clinical observer. Cassell emphasizes that the ability of healers to establish this connectedness with the patient is not an exception to the role of healer but is rather an integral part of the healing function. It shatters the silence of which Katz writes, and substitutes for clinical detachment the "constant will of one trying to recognize" (Brody, 1992, p. 263).

Establishing this connectedness does not make of the healer a great person but does place both healer and patient in the presence of a deep human mystery that is greater than both of them. It is to be present at a creation that Elaine Scarry likens to the rediscovery of language: "Physical pain is not only itself resistant to language but also actively destroys language, deconstructing it into the pre-language of cries and groans. To hear those cries is to witness the shattering of language. Conversely, to be present when the person in pain rediscovers speech and so regains his powers of self-objectification is almost to be present at the birth, or rebirth, of language" (p. 172).

Explanation, education, and connectedness form the core of Cassell's understanding of the healing relationship. The problem with the scientific explanation of illness is not that it is incorrect, since, as Cassell notes, "we know that it need not be correct, since for most of the history of medicine it has not been correct" (1976, p. 128). Put differently, the virtue of scientifically accurate diagnosis and treatment does not lie in its correctness. The fact that it seems correct does not entitle it to stand as the only and sufficient explanation of illness. Although science has been empowered by Western culture to dictate diagnosis and disease categories, Cassell notes that it has little or nothing to say about sick persons, their behavior, patient-healer communication, and so on. "If the whole point of the clinical encounter is to decide what is the right and the good thing to do for a specific patient, then traditional medical theory is sorely lacking" (1991, p. 6).

The Power of the Healer

Although he recognizes the limitations of traditional medical theory, Cassell does not intend to belittle or dismiss the role that the scientific explanation of disease has in Western culture or the promise it holds for the world. He wishes, in fact, to acknowledge its power: "The therapeutic power of the doctor-patient relationship grows in importance as the technology of cure becomes more powerful" (1991, p. 69). Yet, unfortunately, even as the importance of the relationship between doctor and patient grows under the stimulus of technology, so does the isolation of the patient, who becomes lost in a maze of tests, procedures, and treatment teams. To disregard this relationship only adds insult to the injury inflicted by isolation. "It has been one of the most basic errors of the modern era in medicine to believe that patients cured of their diseases—cancer removed, coronary arteries opened, infection resolved, walking again, talking again, or back home again—are also healed; are whole again" (1991, p. 69). What has been forgotten, he says, is that technology itself has no power—humans acquire power by employing the technology.

The importance of power in the therapeutic relationship has been explored at length by Howard Brody (1992). He analyzes the healer's power in three components: Aesculapian, charismatic, and social. The healer acquires Aesculapian power by virtue of training in the craft of healing. The power is impersonal, transferable to any other healer of comparable skill and experience. Charismatic power is founded on the healer's personal qualities and character and cannot be readily transferred. It is independent of the disciplinary knowledge and skill belonging to Aesculapian power. Social power arises from the social status of the healer within a particular society. It derives its authority in part from the implied contract between the healing profession and society that empowers the profession to determine truth in regard to illness.

The power to heal involves a complex interplay among all three kinds of power; it is a mistake, Brody notes, to limit the power of healing to Aesculapian power alone. Any discussion of what constitutes a right and good healing action must entail an exploration of the proper use of the other forms of power that the healer possesses. These forms of power risk what Brody calls "the dark side of the force."

This is “a lust, half childish, half sadistic, to use whatever power we might have to victimize others less powerful, and to enjoy it—to glory in the fact that they and not we are the victims, and to escape for a moment into the fantasy that since we can avoid their victimhood through our power, we are invulnerable and need never again feel fear” (Brody, 1992, p. 21).

THE VIRTUE OF COMPASSION. Healers can find the antidote to the dark side of the force by acknowledging the feelings of vulnerability and weakness that arise in them as they face the patient. They can do this only if they are open to the experience of being ill and in distress. To do this effectively, Brody says, healers need more than to be told they have an obligation to be open; they need to develop the virtue of compassion, an internalized habit of character that becomes an instinctive attitude of openness and vulnerability.

A major irony in the healer-patient relationship emerges here. To be compassionate in response to the suffering of the patient is itself a powerful act of healing. In showing compassion, the healer empowers the patient in a way that merely curing disease cannot. Curing disease eliminates a threat to bodily function and integrity; alleviating suffering, without which healing is a mere charade, restores the sufferer’s connections with humanity and the ability to make sense of his or her own life. Yet, Brody says, this act of empowerment is possible only to the extent that the healer is willing to adopt a position of relative powerlessness, to acknowledge that the patient’s suffering has incredible power over her or him and that it is impossible to remain unchanged in the face of it.

SHARED POWER. Western medical training urges compassion as a duty of the profession but at the same time warns, “Don’t get too involved.” Brody interprets this warning as a form of false reassurance that the power to heal does not entail the felt powerlessness of compassion. This denial of the power that the patient’s suffering has over the physician is a rejection of the concept of shared power, which Brody states is the essential element in the ethical use of power. This denial also betrays a fundamental misperception of power as a zero sum game, that is, the belief that anything that increases the power of the patient within the healing relationship must necessarily decrease the healing power of the physician.

This *competitive* notion of power conforms to the type of moral reasoning that Carol Gilligan discovered among non-minority males in North American culture. The dominant male culture emphasizes the importance of finding the rules that govern a relationship and then selecting courses of action in keeping with the rules, even if such devotion to rules means sacrificing someone’s interests to the considerations of abstract justice (Gilligan). She counters with a type of moral reasoning common to the women she studied: They tend to focus on the nuances of personal relationships and seek solutions that protect the interests of all affected parties and that avoid bringing harm to anyone.

RESTRUCTURING THE POWER OF HEALING. Following the lead of Gilligan, other voices have appealed to an understanding of moral relationships from the perspective of women, such as Nel Noddings (1984), whose work on caring has influenced nursing ethics (Bishop and Scudder); and Virginia Warren (1989), who applies a feminist point of view to the conduct of medical ethics itself. Although these critics represent a wide range of opinion on the means to be used and even on the foundational reasons for doing so, most of them would agree with Susan Sherwin that there is a need to develop conceptual models for restructuring the power associated with healing and to clarify how “excessive dependence can be reduced, how caring can be offered without paternalism, and how health services can be obtained within a context worthy of trust” (p. 93). Sherwin notes with approval that, for many mainstream medical ethicists, compassion is frequently claimed to be more compelling than justice, a tendency she finds especially common in the contribution of physicians to medical ethics.

If this need for compassion is admitted, the significant question then becomes, What can allow a physician to experience the powerful suffering of a patient in a way that encourages the physician to share power and therefore to become not only a curer but also a healer? What is needed is a way for healers, and physicians in particular, to experience the felt reality of shared power without seeing it as a betrayal of their Aesculapian power, no matter how evident in this process its limitations may appear to become.

THE LIMITS OF AESCULAPIAN POWER. The strategy employed by many patient advocacy groups of leaving physicians’ Aesculapian power undisturbed while severely restricting their social and charismatic power avoids the issue by ceding to physicians their chosen territory. Such an approach abandons the project of power sharing and attempts to render the healer-patient relationship “doctor-proof” by segregating Aesculapian power from the other forms of power. This strategy errs because it assumes that “we can wring morally acceptable actions out of any physician no matter how good or bad his motives if only we have the right rules for him to follow” (Brody, 1992, p. 55). As feminist critics have noted, this strategy endorses the *masculine* assumption that solving moral problems means discovering the right rules while leaving intact the existing power relationships. It cannot succeed because, as Brody points out, it mistakenly presumes that the healer's power comes in two neatly differentiated categories: power that helps fight illness, and power that can be used to violate patient's rights. But no such easy distinction is possible because the same powers can be easily redirected for good or ill.

The realization of shared power can take place only if those who profess to heal acknowledge responsibility for all the forms of power they possess. They must be reassured that owning up to their charismatic and social power does not imply that their Aesculapian power is fraudulent, although it may require them to admit that something like the placebo effect is present in almost every healing encounter (1992). For physicians to profess to heal requires the realization that their Aesculapian power, despite the warrant of its scientific accomplishments, is limited in both its scope and effectiveness. Curing does not ensure healing, and healing is possible even if there cannot be cure; nor is every human ill subject to cure. Such an admission, however, does not exempt those who profess to heal from attending to the needs of the poor, the oppressed, or those victimized by war, prejudice, and despotism. It only reminds them that their social and charismatic powers alone have authority in these difficult areas.

AESTHETIC DISTANCE. Compassion, lest it degenerate into codependency, does need to maintain a certain strength and thus a certain distance from the plight of the sufferer. Brody characterizes this distance as aesthetic rather than emotional; it resembles the reader's approach to a work of fiction (1992). To regard the suffering patient as a text, attended to at an aesthetic distance, still permits and even encourages intense emotional involvement. In reading the text presented by the sufferer, the healer must maintain in his or her imagination that separate vantage point from which the experience of the sufferer can be reinterpreted and reconnected to the broader context of culture and society.

Healing and Community

Healing reconnects the sufferer both to the self and to the world. The final and perhaps least appreciated aspect of healing is the need for this reconnection to take place in the context of a community, a need as real for the healer as it is for the sufferer. Healing requires from the healer a commitment over time to become a person capable of compassion and therefore of healing, who has the deep knowledge of how to fuse power and powerlessness, strength and vulnerability. This openness to vulnerability required of healers is more than a simple disposition to the notion of vulnerability. As Brody notes, there is a difference between being "disposed" to something and striving over time to become something. It is the latter that is the mark of virtue.

In cultivating compassion as a professional virtue, healers must be willing to be formed by a compassionate community, "confident that they will receive empathic compassion and support from each other as they attend to the sufferings of their patients" (Brody, 1992, p. 267). In this arena, Brody ruefully notes, implicit issues of power have most stood in the way of the profession's reform. The self-imposed image of the physician as a powerful, scientific, objective individual, he says, works against the development of any effective peer support system. But it also cripples the physician's ability to be present to those in pain, which, as Stanley Hauerwas notes (1985), should be the goal of medical training.

For Hauerwas, "the physician's basic pledge is not to cure, but to share through being present to the one in pain" (p. 220). This pledge is difficult to carry out on a day-to-day basis. No individual has the resources to see so much pain without that pain hardening him or her. Pain, as Scarry notes, is destructive of human community; hence the prime directive of the healer to be present to those in pain carries with it an embodied threat to the ability to continue to be a healer. She or he must not only be formed as a healer by a compassionate community, but must also be continually sustained and nurtured by such a community—the kind of community, Hauerwas notes, that the Christian church claims to be.

There is a rich and varied tradition of healing not only within the Christian church but also in virtually every religious tradition. In fact, the role of healer in early societies encompassed not only the people's health but their entire welfare, including their spiritual welfare. The specialization that has accompanied modern civilization, however, makes discussion of the relationship between healing and religious belief problematic in that it is no longer clear who is priest, who is healer, and whose authority should predominate. The relation of medicine to particular religious traditions (Numbers and Amundsen) and the relevance of theological ideas, particularly that of covenant, to medical ethics (May) have opened up areas of fruitful exploration for both medicine and religion. But it may be well to concentrate, as Hauerwas does, not on these theoretical relationships but on the practical relation between communities, between those who practice religion and those who practice healing.

It is in this sense, Hauerwas says, that those who profess to heal need religion—not to provide miracles when there is a failure to cure, not even to supply a foundation for their moral commitments, but rather as a source of the habits and practices necessary to sustain them over the long haul as they care for those in pain. There needs to be a body of people who have learned the skills of presence to keep the world of the ill from becoming a separate world, both for the sake of the ill and for those who care for them. “Only a community that is pledged not to fear the stranger (and illness always makes us a stranger to ourselves and others) can welcome the continued presence of the ill in our midst” (Hauerwas, p. 223).

In the final analysis, healing is a communal action whose goal is the restoration not only of physical and mental wholeness to those who suffer illness but also of their integrity as persons, that is, as beings-in-relation to themselves and to other persons. It is a communal action in two senses: It reaches out to those isolated by illness to reconnect them to the human family; and it is sustainable only within a community that practices compassion as a virtue. The future of the healing professions everywhere depends as much on this nurture as on technical competence and the wise use of material resources. Those who profess to heal must know that no one is fully healed until all are healed.

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RICHARD VANCE (1995)
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SEE ALSO: *African Religions; Alternative Therapies; Body: Cultural and Religious Perspectives; Care; Christianity, Bioethics in; Compassionate Love; Daoism, Bioethics in; Disability; Grief and Bereavement; Health and Disease; Hinduism, Bioethics in; Human Dignity; Life, Quality of; Medicine, Art of; Narrative; Native American Religions, Bioethics in; Professional-Patient Relationship; Teams, Healthcare; Trust; Virtue and Character*

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HEALTH AND DISEASE

• • •

I. History of the Concepts
II. Sociological Perspectives
III. Anthropological Perspectives
IV. Philosophical Perspectives
V. The Experience of Health and Illness

I. HISTORY OF THE CONCEPTS

Health and disease are among the fundamental experiences of human life. The concepts that people in various cultures have used in an attempt to understand and respond to those experiences have to do with the way humans relate to nature and culture. The concepts of health and disease have far-reaching consequences for diagnosis and therapy, the attitude and behavior of physicians, how patients deal with disease, social attitudes and structures, the shape of moral choices, and the cultural significance of sickness and wellness behaviors.

Health and disease are not merely medical terms; they are also vital themes in art, philosophy, theology, sociology, and psychology. In fact, these very disciplines remind medicine again and again of its distinctly *anthropological* character, in the sense that medicine deals with the nature and destiny of humans. Neither medicine nor the concepts of health and disease with which it deals can be properly understood by using the starkly contrasting categories of natural sciences and human sciences as a framework. Just as medicine cannot be reduced to either of the two, so it is also necessary to connect nature and culture in order to understand health and disease.

A universally valid definition of health has been as hard to formulate as a universally valid definition of disease. Health and disease are physical, social, psychological, and spiritual phenomena that can be represented in concepts that are both descriptive and normative (the latter meaning based on norms), although these two sorts of concepts have not always been clearly distinguished in the historical development of these ideas. Humans not only determine what will be regarded as health and disease; at the same time they also interpret these experiences and decide how to respond to them.

Concepts of disease and health are especially important because they influence the manner and goal of medical treatment. Thus a mechanical or technologically structured understanding of disease (which views the human as a defective machine) requires a mechanical or technologically structured therapy (regarded as repair) and therapeutic relationship (a relationship of technician to defective machine). More personal or holistic concepts urge corresponding types of therapy and healer–patient relationships.

Contemporary medicine increasingly faces the task not only of overcoming sickness but also of preserving health. Prevention and rehabilitation play increasingly important roles alongside curative therapies. Treatment is understood to include attentive caring and support. Chronic suffering and death place different demands on the doctor–patient relationship than do acute illnesses. In light of such developments, concepts of health and disease require new definitions. A historical retrospective may assist in arriving at those definitions.

This entry does not attempt to offer a thorough cross-cultural analysis of concepts of health and disease; rather, it presents essential dimensions and changes in these concepts in the general course of history, their relationships with sociocultural backgrounds, and their practical and ethical consequences (Diepgen, Gruber, and Schadewaldt; Riese; Rothschuh; Schipperges, Seidler, and Unschuld; Temkin). A consideration of these historical developments can stimulate new reflections and initiatives, but history differs from any theoretical system. History has its own rules and logic. A progressionist explanation of the gradual development of notions of health and disease is inadequate. There are continuities and discontinuities, progress and regress, even within a single event or movement. This complex nature of history in general characterizes the history of medicine and specifically the history of the concepts of health and disease.

Health and disease suggest a variety of meanings from psychological, social, and spiritual perspectives. The word *illness* in the English language refers to the subjective or personal side of disease, whereas *disease* refers to the medical conception of pathological abnormality. It is possible for a person to feel ill without having a disease, and conversely, to have a disease without feeling ill. The term *sickness* transcends both of these concepts by focusing on social consequences. The concept of the *sick role* corresponds to the social nature of disease. The way in which societies vary in their interpretations of physical and mental disorders and in their treatment of and symbolic reactions to them reflects the cultural dimension of disease.

Nonetheless, some basic categories will be useful in the following discussion. One category is the explanation of disease, illness, and sickness. From a physical perspective, the different approaches of the past attribute disease to either liquid or solid components of the body or to the relationship between the body and the soul. Other distinctions refer to whether diseases should be regarded as existing entities (the ontological notion of disease) or as phenomena affecting individual persons in a variety of ways (the symptomatic notion of disease); and whether and to what extent the constitution and disposition of the individual (endogenous factors) and/or external (exogenous) factors play a significant role in determining health and disease.

A second category concerns response to disease, illness, and sickness. These responses have frequently been shaped by the explanation of disease, illness, and sickness. These two categories evolved into the science and clinical practice of medicine.

Primitive Peoples

There is no life without disease and pain; their ubiquitous nature is demonstrated by history. The skeletons of the first humans (500,000 B.C.E.) display bone disturbances and fractures. It is difficult to offer accurate descriptions of the health and disease of historically primitive peoples, because claims must depend on limited and problematic archaeological, paleopathological, and written sources (Clements).

At the dawn of human history, medicine had a magicomystical, demonic-religious character. Exogenous factors such as spirits, spells, and gods were considered responsible for disease. Personified living entities, spirits, took over a healthy body and made off with the soul of the person or allowed foreign elements to invade the body. Spirits, dead or living, could exercise fateful effects, acting out of revenge for breaches of taboos. Disease, directly related to sin and wrongdoing, represented not only an individual but also a social destiny. What befell one person befell the whole family, group, or tribe.

The diagnostic and healing powers of the healer or priest-doctor were supernatural. The healer had to be able to recognize which forces were at work in any given case. He did this by reading the stars or by drawing meaning from minerals, plants, and animals. Amulets and magic spells, oracles, atonement and confession, exorcism, bloodletting, and ceremonies of purification functioned as both preventive measures and cures. The whole community took part in the healing process; even pets were brought into it. Primitive peoples exhibited great cleanliness for the sake of prevention and strictly observed their cultural taboos.

There are remnants of these primitive notions of disease in today's lay language. For example, in English slang menstruation is sometimes called "the curse"; the German word for lumbago, *Hexenschuss,* means witch's wound. To what extent one can observe these assumptions about sickness and health, and the social structures that correspond to them, among the primitive peoples of today is hard to say. Modern civilization and medicine have left their impact in every part of the world. Primitive peoples, too, change over time.

Ancient Cultures

Precursors to medical systems and theories of disease were found in the ancient cultures of Mesopotamia and Egypt between the fourth millennium B.C.E. and the first, which established connections between concepts of nature and religion, on the one hand, and views of sickness and health on the other. Parallels between Chinese, Tibetan, Indian, and Greek perceptions of sickness and health indicate that these cultures may have derived these ideas from the same sources. Ancient American cultures also shared similar perceptions.

For these cultures health and disease were physical as well as religious phenomena. Sickness was still associated with sin, even as empirical interpretation of health and disease began to spread. Egyptian papyri (2000–1500 B.C.E.), for example, describe the courses of various diseases and categorize them according to regions of the body. The papyri list causes, symptoms, and prognoses, as well as empirical interventions. Putrefaction within the body in the form of spoiled material (*materia peccans*) caused sickness; these substances had to be removed if the patient were to be cured. The Greek historian Herodotus (fifth century B.C.E.) describes monthly purifications in Egypt.

Dietetic, medicinal, and surgical interventions were used, and much attention was given to public health. The medicine of ancient cultures combined religious ritual with empirical treatment. The Babylonian code of Hammurabi (d. 1750 B.C.E.) contained the first list of surgical fees and penalties in the case of failure; each varied according to the social status of the patient.

The explanatory dimensions of medicine, such as symptomology, nosology (the classification of diseases), diagnosis, and etiology (the study of the causes of diseases), as well as clinical dimensions such as prognosis, therapy, and prevention, began to establish themselves in these centuries. The traditional healer became the professional doctor; specialization developed. In this era, empirical observation, causal explanation, magic, and faith coexisted in medical theory and practice.

Greece and Rome

More extensive and reliable historical sources exist for ancient Greece and Rome. The ancient Greeks (500 B.C.E.) explained health and disease cosmologically and anthropologically, that is, in close relation to nature in general and to human nature in particular. Medicine sought not only to cure disease but also to maintain health. The pre-Socratic philosophers, who were the physicians of this time, developed a universal model of health, whose outlines can be found in the medical texts of Hippocrates (c. 460–c. 377 B.C.E.) and other physicians of the Corpus Hippocraticum (400 B.C.E.–200 C.E.). These pre-Socratic physicians must be distinguished from magicoreligious healers, who still existed at that time (Kudlien).

The great physician Galen (129–c. 199 C.E.) elaborated a model of health and disease as a structure of elements, qualities, humors, organs, temperaments, times of day, and times of year (Schöner). Health was understood in this perspective to be a condition of harmony or balance (*isonomia*) among these basic components that make up both nature in general and the individual body. Disease, on the other hand, was regarded as discordance, or the inappropriate dominance (*monarchia*) of one of the basic components. Disease in the perspective of humoral (pathology determined by bodily fluids) was interpreted as the disproportion (*dyscrasia*) of bodily fluids or humors: phlegm, blood, and yellow and black bile. Solidistic pathology traced disease to disturbances among the solid components of the body (shape, consistency, distance, etc.). The pneumapathological (spirit) approach attributed disease to a failed relationship between body and soul. Health (*eucrasia*) was characterized by equilibrium in the body.

Dietetics was considered of primary importance to the therapeutic process, followed by medication and lastly by surgery, a hierarchy exactly opposite to the prevailing Western approach of today. In the ancient perspective, dietetics involved much more than a health-conscious regulation of food and drink. Rather, it entailed a broad concept of how one should live a healthy life. Dietetics was concerned with six aspects of life that, although natural, did not regulate themselves, as did such physiological functions as respiration and digestion. Because they required human manipulation, these six aspects of life were called “non-natural” (*sex res non naturales*). These areas included how humans deal with:

1. air and light;
2. food and drink;
3. sleep;
4. motion and rest;
5. secretions; and
6. passions of the mind (Rather).

According to Galen, and in contrast to contemporary views, health and sickness were not the only states of existence. Rather, there was a third condition, an intermediate state of *neutrality* that existed between health and sickness: Medicine was therefore conceived as the science of health, sickness, and neutrality. In this notion of medicine, the overcoming of sickness was secondary to the preservation of good health or to aiding patients in living with impediments and handicaps. Galen said that because health precedes illness both in time and in esteem, one should try first to preserve health and only second to cure the illness as far as possible.

Philosophy and medicine mutually influenced one another in antiquity, although Hippocrates is said to have separated medicine from philosophy. Health and disease are not only empirical descriptions. They always have philosophical implications and practical effects. The Greek philosopher Plato (c. 428–c. 348 B.C.E.) defined medicine as the theory of health, and in the perspective of his ethical concept of health, he legitimized the active euthanasia of the physically handicapped and the mentally ill. Plato and his student Aristotle (384–322 B.C.E.) developed a typology of three physicians with corresponding types of relationships with the patient. The *slave doctor* commands, and the patient has to obey. The *doctor for freemen* explains the treatment to the patient and the patient’s family. Doctors understood to be *medically educated laymen* signified individuals who take responsibility for their own health, sickness, and death.

While abortion and active euthanasia were forbidden as therapeutic acts for the Hippocratic physician, the Stoics justified these practices in situations in which the patient had lost or was in danger of losing moral autonomy and rational awareness. Harmony of the mind was placed above health and disease, above wealth and poverty. For the Stoic philosopher Seneca (c. 4 B.C.E.–65 C.E.), disease meant physical pain (*dolor corporis*), the suspension of joy (*intermissio voluptatum*), and the fear of death (*metus mortis*)—implying that disease combines physical, psychological, social, and mental dimensions. While being persecuted by the Roman emperor Nero, Seneca ended his own life through active euthanasia with the help of his friend and doctor Statius Annaeus.

The Middle Ages

The Christian Middle Ages (500–1300) interpreted health and sickness in a theological perspective. Cosmological (or natural) and anthropological (or human) approaches were subordinated to, without being supplanted by, the supernatural notion of transcendence. Christian beliefs and natural causes for health and disease were not mutually exclusive. Sicknesses could be described simultaneously as physical entities and as acts of God's intervention. The Christian, Arabic, and Jewish traditions all viewed health or *quality of life* as the outcome of a good relationship with God.

Medicine consisted of theory and practice, each of which was further divided. Medical practice consisted of dietetics, medicaments (therapeutic substances), and surgery. Galen's humoral pathology prevailed throughout the Middle Ages, and dietetics in antiquity's broad sense of the term continued to function as the most important form of treatment. The emphasis on spirituality did not run counter to medical aid and health education. As the vessel of the soul, the body warranted careful attention.

During the Middle Ages, a variety of specific health rules (*Regimina sanitatis*) were developed for people of various ages, occupations, and classes, as well as for both sexes. One famous example, the *Regimen Sanitatis Salernitanum* from the thirteenth century, has survived in various medical customs and was published in all major European languages.

According to the medieval Christian viewpoint, the figure of Christ as healer (*Christus medicus*) stood behind every doctor, and behind every patient was the figure of the suffering Christ. Health, disease, and healing gained their meaning from this perspective. These concepts were related intimately to the idea of salvation history (eschatology), seen as a progression of the world starting with its establishment in paradise (*constitutio*), through its earthly existence (*destitutio*), and finally to resurrection (*restitutio*).

These concepts also had their practical consequences, manifested in biographies and other documents of arts and literature. Each transition from health to sickness and from sickness to health represented this eschatological process on an individual level. Even though sickness, suffering, and death had salvific significance or were essential traits of human life, they were fought with dietetics and medical therapy. But they were also to be accepted, because earthly life is different from paradise. In this regard, Saint Augustine (354–430) remarked that people have to say "yes" to some forms of pain but are not forced to love them.

The Greco-Roman link between health, beauty, and morality was abandoned during the Middle Ages. Every sick, suffering, or handicapped individual had the right to receive medical treatment. Hospitals, first founded during the Middle Ages, were open to all suffering and helpless people, based on Jesus' words: "I was sick, and you cared for me" (Matthew 25: 26). At the same time, however, the Bible was used to justify excluding lepers from society.

The classical and Christian concept of the seven cardinal virtues (prudence, temperance, fortitude, justice, faith, hope, and love) applied to healthy people as well as to the sick, doctors, and the community. Suicide and euthanasia were regarded as sins because they were deliberate attempts to shorten life. Therefore the ancient Hippocratic oath was continuously accepted in this epoch. The art of dying (*ars moriendi*) was considered a central part of the art of living (*ars vivendi*). Sickness could be traced to inherited sin, personal guilt, demonic possession, or a test from God. Job of the Old Testament represented a classic example of the latter.

In contrast to present-day attitudes, health was also viewed as negative in the moral and religious sense ("corrupting health": *sanitas perniciosa*) and sickness as positive ("a healing sickness": *infirmitas salubris*). Coping with illness was believed to manifest a person's fortitude; furthermore, a life without physical or psychical damage or pain was thought to produce a false image of earthly life and the human condition. A contemporary biographer, writing about the constant illness of the saintly German abbess Hildegard of Bingen (1098–1179), who was also a prominent naturalist and physician, said that her whole life could be compared to a "precious dying."

The Modern Era

With the coming of the modern era at the time of the Renaissance, which began in the fourteenth century, an emphasis on this world, nature, and the individual replaced the medieval focus on the hereafter. The secularization of paradise—or the hope of realizing beauty, youth, and health in an earthly life—has influenced human thought and action and the course of medicine up to the present. Empirical observation, causal explanation, and rational therapy became the ideals of education, research, and practice in medicine. Nevertheless, magic, astrology, and alchemy continued to play a role in medicine for quite some time.

At the transition from the Middle Ages to the modern era, the German physician and philosopher Paracelsus

(1493–1541) designed an all-encompassing system of medicine. Along with philosophy, astronomy, and alchemy, ethics acquired a fundamental role. Paracelsus replaced the ancient humoral pathology with three rudiments from alchemy: salt, mercury, and sulfur. Dominance of one of these biochemical components over the others led to different types of diseases. Disturbances in the spiritual principle also led to disease. According to Paracelsus, the general factors that contributed to disease belonged to nature as well as culture: (1) cosmic influences (*ens astorum*); (2) material influences (*ens veneni*); and (3) individual constitution (*ens naturale*), spirit (*ens spirituale*), and God (*ens Dei*). Paracelsus's concept of disease is ontological or essentialistic: Disease is a "thing," which he compared with a parasite, a separate organism. This notion contrasts with the Hippocratic concept, which explained sickness as an individual, symptomatic phenomenon.

The utopian writings of the English statesman Thomas More (1478–1535), the English philosopher Francis Bacon (1561–1626), and the Italian philosopher Tommaso Campanella (1568–1639) include basic categories for determining health and disease as well as guiding principles for eugenic public health policies. Their concepts justified suicide and euthanasia—but only under the condition that it be done freely (at the decision of the individual). During the Renaissance the different types of euthanasia, still relevant in the discussions of the subject today, were already established. Not everyone supported active euthanasia as a social reaction to sickness. The German theologian Johann Valentin Andreae (1586–1654), unlike More and Bacon, expressly rejected euthanasia in his 1619 work *Christianopolis.* He stated that "reason commands that human society should be more gently disposed toward those who have been less kindly treated by nature" (p. 274).

The philosophy of the French mathematician René Descartes (1596–1650), with its mechanical model of health and disease, became highly important for the concepts of disease and therapy. According to Descartes, the body is a perfect clockwork mechanism set in motion by God to function mechanically. The soul, also divinely created, acts independently from the body. This dualistic system of body (*res extensa*) and soul (*res cogitans*) was widely accepted in medicine and produced a mechanistic view of physiology, still accepted in the present, that also existed in lay interpretations of health and disease. Scientific explanation concerned the discovery of the fixed rules of mechanistic structures and their processes. Clinical medicine concerned the detection of damaged structure, malfunction, and departure from these rules, and the restoration of proper anatomic structures and physiology.

During the Enlightenment (eighteenth century), the real beginnings of a public health movement began to take shape. The German philosopher Gottfried Wilhelm Leibniz (1646–1716) made numerous recommendations for public health. The American statesman and philosopher Benjamin Franklin (1706–1790) formulated a characteristic phrase of the time: "Health is wealth." The German physician Johann Peter Frank (1745–1821) and the French philosopher Jean-Jacques Rousseau (1712–1778) represented the opposition between state policies and individual agendas. According to Rousseau, civilization and the state had ruined human health in its natural state. Frank, in contrast, believed that social reforms lead to progress. Several books were published primarily on prevention and rehabilitation. The German physician Christoph Wilhelm Hufeland (1762–1836), author of the widely distributed *Makrobiotik* (1797), manifested again the relationship between concepts of health, disease and therapy —especially as normative categories—with the social attitudes and reactions. He believed that physicians should not be allowed to engage in active euthanasia, pointing out that physicians who start to decide which sick persons are worthy of living become "the most dangerous people in the state."

The concepts of health and disease vacillate between anatomy and physiology. The definitions of disease and health of the Scottish physician John Brown (1735–1788) received great recognition in the medicine, philosophy, and literature of his time. His 1780 work *Elementa Medicinae* defined health and disease in terms of the relationship of opposing forces within a person: of organic excitability and external and internal stimuli, resulting in an excited or irritated condition of the organism. According to Brown, disease is the result of overstimulation (*sthenie*) or insufficient stimulation (*asthenie*). Health, on the other hand, is characterized by equilibrium between the capacity to be stimulated and internal and external stimuli. Treatment, therefore, functioned either to strengthen or subdue stimuli. Bloodletting and diet calmed a condition of overstimulation, whereas ether, camphor, and opium had the opposite effect. Equally important for the further progress of medicine was the anatomical foundation of pathology by the Italian physician Giovanni Battista Morgagni (1682–1771) with his fundamental work *De sedibus et causis morborum* (On the seats and causes of disease), published in 1761.

Romanticism and idealism, around 1800, introduced interpretations of health, disease, and death that are of general importance and transcend substantially the limits of medicine (Leibbrand). These three states were regarded as dialectically connected with one another and interpreted as the main stages of the genesis of Spirit out of nature, a

Hegelian theme (von Engelhardt). According to the German poet Friedrich von Hardenberg (1772–1801), who wrote under the pseudonym Novalis, there is always disease in health and health in disease; illness or sickness is given a central value: “Medicine should be an elementary science of every cultivated person” (Novalis, p. 474). Illness can be an experience or medium of personal growth. The personhood of the patient becomes a central claim: “Human being = person; that is the point of unity,” (Heinroth, p. 158) categorically announced the german physician Johann Heinroth (1773–1843). The German philosopher Joseph Schelling (1775–1854) held that health is the harmonious relationship of the basic organic functions of sensibility, irritability, and reproduction. The German philosopher Georg Hegel (1770–1831) argued that life would be impossible without disease, that each organism contains the “germ of death” from birth, and that all therapy presupposes that disease is not a total loss of health but rather a conflict within physical or psychical forces. Only through disease and death of the individual does the universal and eternal world of the spirit come into being. “Above this death of Nature, from this dead husk, proceeds a more beautiful Nature, proceeds Spirit” (Hegel, p. 443).

MEDICINE AND THE NATURAL SCIENCES. Medicine in the remainder of the nineteenth century followed the model of the natural sciences and not that of natural philosophy and philosophical anthropology of the romantic-idealistic era. This increasingly self-conscious scientific medicine concentrated on curing disease and neglected the maintenance of good health. It also neglected the contributions of the arts, literature, and theology. The patient became more and more an object. The patient’s subjectivity or personality was disregarded, and the history of the patient was reduced to the history of the disease. Anatomy and physiology were connected; the cell replaced tissue as the center of attention. Experimentation, statistics, and causal thinking became the basis for medical research. A Cartesian concern for mechanistic structure and function according to discernible rules became paramount.

The German pathologist Rudolf Virchow’s (1821–1902) definition of disease was widely accepted: “Disease begins at that moment when the regulatory system of the body is not sufficient to overcome a disturbance. It is not life under abnormal circumstances, nor the disturbance as such which produces a disease, rather the disease begins with the insufficiency of regulatory mechanism” (p. 193). According to Virchow, the body’s regulatory ability varied from person to person. The healthy body is capable of bringing an abnormal situation back into equilibrium. Disease was an observable phenomenon in the living body, caused by internal and external factors. The cell became the basis of disease, and—using a political metaphor—it deserves recognition, along with blood and nerves, as the “third estate.” The infection of cells, and thus the body, by external infectious agents became the dominant explanation of disease. The clinical response was to eradicate the infection.

In the nineteenth century, dietetics lost its broader or anthropological meaning and came to refer simply to the intake of food and drink. Thus a 2,000-year-old tradition, already limited in the eighteenth century, reached its end. Nevertheless, the tradition of dietetics survived longer in the area of hygiene than in pathology. Scientific medicine in its modern form considered heredity, psychical, and social factors relatively unimportant to the etiology of disease. Infection was the decisive explanatory factor; therapeutic results from the period substantiated this theory. Thus, the development of concepts of health and disease and of clinical responses to them was synergistic, a historical process that continues into the present.

At the beginning of the twentieth century, constitutional pathology and anthropological medicine began to counteract the one-sided approach of infectious disease modules of medicine. Medicine recovered the importance of the individual and social circumstances in health and disease—constitutional pathology on the physical level, anthropological medicine on the psychical or mental level. Human beings were conceived as participating in nature as well as in culture. The German physician Viktor von Weizsäcker (1886–1957) reintroduced in his anthropological medicine “the person as subject,” in regard to the patient, the doctor, and science.

In medicine as well as in biology, the concept of finality (*causa finalis*) regained attention; diseases not only have a physical cause (*causa efficiens*) but also manifest a sense of meaning. The controversy between monocausal thinking (*causalism*) and multifactorial thinking (*conditionalism*) influenced medicine during those decades around 1900 and is still lively: Can disease be deduced from one cause, or is it necessary to take different causes of different areas of reality into consideration? The concept of cause not only has consequences for the theory of disease origin and disease process but also affects medical therapy, prevention, and rehabilitation, all of which in turn shape the individual and social situation of the sick person.

Philosophers and theologians, as well as writers and artists, hoping to give people assistance that the natural sciences and medicine were unable to provide, continued to produce valuable interpretations of health and disease that took the spiritual or cultural nature of human experience into account, calling into question the established normative equation of health as positive and disease as negative. The French writer Marcel Proust (1871–1922) stated that humankind owes its major cultural accomplishments to sick and suffering people: “They alone founded religions and created masterpieces” (p. 405). Increasingly, arts and literature have been acknowledged as being helpful in coping with disease, pain, and death.

The German philosopher Martin Heidegger (1889–1976) claimed that he wrote his analysis of death in *Being and Time* (1927) especially for doctors; in this work, Heidegger emphasized that only the human beings have the consciousness of death and of their own death. The German physician and philosopher Karl Jaspers (1883–1969) defined disease and health in the perspective of his philosophical position. Neurosis being “a failure in the marginal situations (*Grenzsituationen*) of life,” he visualized the goal of its therapy “as a self-realisation or as a self-transformation of the individual through the marginal situation, in which he is revealed to himself and affirms himself in the world as it is” (p. 275). Jaspers contended that psychiatry shared two major methodologies: that of “explanation,” which characterizes the natural sciences (disease), and that of “understanding,” which is typical of the human sciences (illness). The ethical and practical consequence of his concept of disease in the objective, subjective, and cultural sense is outlined in his concept of the existential communication between the physician and the patient. Existential communication combines the subjective and cultural dimensions in an ethical perspective.

In the twentieth century, psychology and sociology expanded the scientific understanding of health and disease, emphasizing the difference between *disease* as objective and physical, and *illness* and *sickness* as subjective and social. According to this general perspective, contemporary people associate disease with the following interpretations: challenge, enemy, punishment, weakness, relief, strategy, loss or damage, and value (Lipowski). Medicine concentrates on weakness, loss, and damage, that is, the physical components of this model.

In the sociological perspective the role of the sick person is characterized by:

1. freedom from daily duties,
2. freedom from the responsibility for the sick condition,
3. the obligation to want to become well again, and
4. the obligation to seek medical help (Parsons; Schaefer).

Descriptive and normative aspects permeate this sociological definition of the role of the sick person. Disease is not only described in its social causes and consequences; demands and expectations are formulated. Subsequent studies have revealed further processes of different levels (age, sex, socioeconomic state, type of disease, etc.) of defining a person as sick. Also important are the differentiation between “bad” and “ill,” or criminal behavior and sickness, and the negative or stigmatizing consequences of diagnostic acts.

The 1947 World Health Organization (WHO) definition of health—“a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity”—has to be interpreted in its social and political context and purposes. These included attempts to justify international involvement in the internal affairs of countries. It is another matter whether medicine can offer explanations and therapies to achieve *complete,* multifunctional wellbeing, the definition of which includes social and spiritual as well as medical aspects. The WHO definition was used as the starting point for intense bioethical debates on the moral and political responsibilities of the international community in regard to healthcare—especially for corresponding projects in developing countries. But this definition, taken generally, is limited in its sharp contrast between health and disease and its exaggerated estimation of health. With good reason, health can also be regarded as the ability to bear injury, handicaps, and the anticipation of death, and to successfully integrate these abilities into one’s life. Integration is the capacity to cope with death; death is a part of life and not only its contrary or end.

Conclusion

The history of concepts of health and disease is the history of concepts that explain and direct response to disease, illness, sickness, and health. These concepts are deeply rooted in physical and psychical experiences and have medical and social consequences. The importance of scientific explanations, with their roots in Cartesian medicine and developments in the nineteenth century, is obvious. Of equal importance, perhaps, are attempts to counterbalance an excessive emphasis on scientific medicine with anthropologic, social, ethical, and political dimensions of the concepts of health and disease. After all, for much of its history medicine has not been confined solely to disease but also took responsibility for health. Therapy in the past meant more than just curing; it also meant prevention or preservation of health and assistance in chronic disease and in dying. Disease was interpreted as a disturbance of the organism, the sick person, and his or her social situation. Furthermore, medicine did not have sole domain over health and disease; a multitude of important interpretations originated from the arts, theology, and philosophy. In this holistic perspective, people of the present also expect medical and social aid.

Sickness and health, in their natural and cultural breadth, remind medicine of its fundamentally scientific and humanistic nature. Health and disease are concerned with life and death and are closely connected to the physical, social, psychic, and spiritual nature of humans.

Today, disease and health are conceived as more closely connected (Canguilhem; Engel). The transitions and parallels are seen more strongly, and the interplay of the body, soul, spirit, and environment is more carefully observed. Attention is shifting from infectious diseases to chronic illness and death, though the experience of acquired immunodeficiency syndrome (AIDS) and other diseases prove the continuity of those events. The emergence of molecular medicine, with its reliance on genetic concepts of health and disease, may lead to a reintegration of the scientific and humanistic dimensions of the concepts of health and disease. The global scientific and economic limitations of medicine have made the concepts of health and disease a central topic in theory as well as in practice, for science as well as for everyday life.

Developing countries have special problems to overcome that stem from their own cultural changes and from their reception of Western medicine. The Western world must be critical of its own normative position in regard to these developing countries as in regard to its own concept of life. Disease should not be understood merely as a limitation or a loss, but also as a challenge. Coping with illness can manifest courage and compassion; meeting this challenge strengthens self-confidence, causes social reform, and enriches the world of culture.

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REVISED BY AUTHOR

SEE ALSO: *Addiction and Dependence; Aging and the Aged: Anti-Aging Interventions, Ethical and Social Issues; Alcoholism; Anthropology and Bioethics; Biology, Philosophy of; Consensus, Role and Authority of; Dementia; Emotions; Feminism; Genetics and Human Self-Understanding; Homosexuality; Insanity and Insanity Defense; Mental Illness; Metaphor and Analogy; Transhumanism and Posthumanism;* and other *Health and Disease* subentries

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II. SOCIOLOGICAL PERSPECTIVES

The sociology of health and disease has two distinct traditions, each with somewhat different implications for the field of bioethics. The first tradition is socioepidemiologic in nature, which is to say it focuses on understanding how the distribution of death and illness is influenced by such factors as age, gender, race, and social class. The second tradition is oriented to the doctor-patient relationship and is concerned with the meanings of illness for patients and practitioners, and with how these meanings reflect the nature of power and authority in society.

The Social Epidemiology of Illness

ORIGINS. Sociological perspectives on health and disease can be traced to the French sociologist Emile Durkheim's classic treatise, *Suicide* (1951). In this work, Durkheim examined the impact on the suicide rate of such variables as residence (urban or rural), marital status, and religious affiliation. Durkheim's basic assumption was that if suicide were purely an individual phenomenon, these variables would have no impact on group rates. Using public health statistics, Durkheim determined that the suicide rate was higher among urban dwellers than among those who lived in rural areas, that the rate of the unmarried exceeded that of the married, and that of Protestants exceeded that of Catholics. He theorized that social ties linking individuals to society inhibit suicidal impulses, while the absence of such ties does not. Much subsequent socioepidemiology of illness echoes Durkheim's findings that those with a greater stake in society fare better than those with a lesser stake.

Since Durkheim published this work, sociologists have dedicated themselves to showing that who becomes ill is not just a matter of individual constitutions, but is heavily influenced by the standard variables of sociological explanation; namely gender, race, and class. While the proposition that one's social position predicts one's health status is generally accepted, attention is also now being paid to the pathways that explain this phenomenon. Bruce Link and Jo Phelan, for example, argue that individually based risk factors need to be contextualized in order to consider what puts people at risk, and that social factors, such as socioeconomic status, are fundamental causes of disease because their association with disease remains constant even when intervening factors change.

GENDER. Despite their greater life expectancies, women report more morbidity and utilize health services more frequently than do men (Verbrugge). Explanations advanced for the higher rates of illness among women include less satisfying social and economic roles; greater stress; more cultural permission for reporting discomfort; and biological differences.

CLASS. The relationship between class and mortality and morbidity is well documented. At all age levels in the United States, there is an inverse relationship between morbidity and social class (Syme and Berkman). This means that as class standing increases, the prevalence of illness decreases, and vice versa. Similar relationships have been demonstrated for other countries in the industrialized West. There is also evidence that the association between socioeconomic status (SES) and health exists at all levels of the SES hierarchy (Adler, et al.). It has been argued that socioeconomic status is a key factor in the creation of disparities in health, and that the reduction of health disparities will rely on addressing the components of SES, particularly income, education, and occupation (Adler and Newman).

Although the link between social class and the prevalence of illness is not disputed, the reasons for it are. A number of explanations have been advanced to account for this relationship, including lack of access to healthcare resources; lifestyle (there is an inverse relationship between obesity, as well as tobacco and alcohol consumption, and social class); and increased exposure to economic and social stress. Work has been indicted as a causal factor in the relationship between social class and heart disease (Siegrist, et al.; Marmot and Theorell). Lower-class jobs provide less autonomy, more constraint, and less opportunity for expression than middle-class occupations. In addition, the causal direction of the link between class and illness has been questioned, with some analysts suggesting that since the less well are unable to compete in the economic system, they have their class standing lowered as a result. This is known as the *downward drift hypothesis.* There is some evidence to suggest that inequality itself, independent of income, is detrimental to health, and not only to those who have fewer resources but also to those with higher SES (Kawachi and Kennedy).

RACE. Race is another variable that affects mortality and morbidity. Vincente Navarro argues that once class is taken into account, differentials between whites and blacks disappear. This may be so, but at a pragmatic level there is a very real association of health status with urban poverty and race. This association accounts for morbidity and mortality associated with violence, infant mortality, and HIV infection associated with intravenous drug use and prostitution. The problems of the urban poor in gaining access to healthcare services have also been well documented. Compliance with treatment regimens is also an issue for inner-city populations, with the most common explanation being the cultural distance between providers and patients.

STRESS AND DISADVANTAGE. Stress has been used as a variable to explain relationships among gender, social class, race, and illness. While the "fundamental cause" concept (Link and Phelan) attempts to expand the causal pathways studied between SES and health, the "stress theory" specifies one particular aspect of the relationship between social position and health. Persons of lower SES experience more stressful environments, such as economic strain and insecure employment (Brunner), and these stressors influence susceptibility to disease by impacting (among other things) the nervous and immune systems. Stress seems to better account for variations in rates of mental, rather than physical, illness (Lin and Ensel). Despite the widespread agreement on how to measure it, there is confusion about what *stress* is. There is also widespread agreement that social supports and networks buffer stress, but there is some confusion about how (Kessler, et al.). Moreover, stress does not have an equal impact on men and women. Marriage, for example, buffers stress better for men than for women.

ELIMINATING HEALTH DISPARITIES. Having demonstrated that health disparities often follow the contours of social disadvantage, a great deal of work has been focused on how to specify the causal pathways of this disadvantage, with the goal of eliminating disparities in health. This has led to disagreement about what the causal pathways to health differentials are, and about the ways in which efforts to reduce disparities can reach the intended beneficiaries without widening the very gap they are intended to close. Medical innovations and public-policy interventions to reduce disparities are often introduced and carried out in a context of inequality (Mechanic), and it has been argued that targeting facets of socioeconomic status, such as a living wage, may go furthest in reducing health disparities (Link and Phelan; Adler and Newman).

Social Epidemiology and Bioethics

The social epidemiology of illness demonstrates that sickness does not fall equally upon rich and poor, men and women, or upon black and white. Distributional inequities are more than simple political and economic problems—they have an ethical dimension as well.

Bioethicists need to pay greater attention to issues of justice and equity at a political level; that is, to the ethical dimensions of political decisions. As the allocation of scarce resources becomes a public issue of greater salience, the underserved will need advocates. The championing of individual patient rights that marked bedside bioethics in its formative years needs to be extended to the class of uninsured and underinsured patients as healthcare grows in importance on the national political agenda.

As its scope of inquiry expands, bioethics may have the opportunity to play a greater role in policy making. However, there is a danger here as well. So long as bioethics is focused on the bedside, both the subject matter and the texts appropriate to it are limited. Once the links between class, race, gender, and illness are illuminated, the boundaries of bioethics become murky. The doctor-patient relationship may be fraught with moral complexity, but it is a rather neatly defined, bounded whole. This is not so for the entire distributive system of society.

The Social Construction of Illness

The second tradition in the sociology of illness is less concerned with the distribution of illness by race, class, and gender, and more concerned with the social meanings attached to illness. It is more concerned with the roles of provider and patient, and with what these roles say about the distribution of power and authority in society. The social epidemiological tradition is involved in the analysis of large data sets (such as national samples) to determine statistical correlations between health status and social traits such as gender, class, and race. The social-constructionist approach is more likely to involve firsthand observation of behavior in a limited number of settings. These observations of behavior provide a basis for drawing conclusions about the nature of healthcare more generally. Favored themes in the social-constructionist approach include the management of uncertainty, the difficulties of lay-professional communication, and the use and misuse of professional authority.

THE SICK ROLE. Sociological speculation about the nature of the doctor-patient relationship begins with Talcott Parsons's discussion of the "sick role" (1951). Although Parsons's unique insight is so commonplace today that we do not appreciate its originality, he was among the first to focus on the doctor-patient dyad as a role relationship with a set of reciprocal rights, duties, and obligations.

Parsons begins with a discussion of the basic social situation in which patients and physicians find themselves. Patients are: (1) not to blame for their condition, (2) powerless, and (3) technically incompetent. Physicians' existential position is one beset with uncertainty about what ails the patient and how best to treat it. In addition, they are unable to cure many of the ills of patients, and there are difficulties with access to both patients' bodies and the intimate details of their lives.

Each role consists of four interlocking imperatives that grow out of the social assumptions made about each actor. The sick patient is granted a temporary exemption from normal social responsibilities. In exchange for this exemption, the patient must seek technically competent help, must be motivated to get well, and must comply with treatment regimens. The passivity of the patient stems from what has been called the "power asymmetry," which Parsons says characterizes the relation of doctor and patient. The only positive action Parsons ascribes to the patient is to seek help. By making this a role obligation, Parsons ignores the complexities of help-seeking behaviors. Such complexities include the recognition of a condition as *illness,* of the cultural and economic barriers to access, and of the nature of lay networks. In addition, with his stricture on technically competent help, Parsons invalidates any and all alternatives to allopathic medicine.

Physicians, according to Parsons, occupy roles whose demands are dictated by their existential situation. First, physicians achieve their roles by mastering basic areas of knowledge. Some physicians are smarter than others, and some know more, but all have completed the same core medical curriculum. Parsons calls this "universal achievement." Second, physicians limit their ministrations to areas of competence. They are expert in areas of health and illness, and their advice is limited to these areas. Parsons identifies this as "functional specificity." The limits of functional specificity have widened as the links between lifestyle, stress, and illness have been documented. Nonetheless, there are limits. Physicians maintain an attitude of affective neutrality. Renee Fox and Harold Lief identify this as "detached concern." Physicians are involved with the problems of their patients, but not so involved as to interfere with rational decision-making. Finally, physicians act from a stance that Parsons identifies as "collective neutrality." The physician is not guided by self-interest or the profit motive. Rather, physicians' actions are guided by altruism, by what will restore health, whatever the sacrifice or cost to the physician, patient, or collectivity.

Parsons's analysis describes normative patterns rather than empirical occurrences. His physicians live in a world in which they share values with patients and always act in the best interests of the patient. They also act as agents of social control. The physician provides legitimate excuses from work, directs treatment, and controls access to healing resources. Tension may arise because the interests of the social system and of the patient may not coincide.

THE SOCIAL CONSTRUCTION OF ILLNESS. Parsons's "sick role" is the first sociological theory to recognize that the experience of illness is determined by social factors. Many sociologists accept Parsons's basic insights but differ with him on how the experience of illness is shaped by values and beliefs that are implicit, tacit, unexamined, and variable across cultural groupings. Conflict theorists, for example, emphasize that society is made up of competing groups with different values, rather than, as Parsons argued, cooperating groups with shared values (Freidson). For these sociologists, the physician's role as a fiduciary whose actions express the interests of patients is disputed; the physician is seen instead as a *moral entrepreneur* who cloaks self-interest or the interests of his or her social class in a neutral scientific language.

Conflict, or *labeling,* theorists share with Parsons the understanding that physicians act as agents of social control but they differ about who benefits from these gatekeeping activities and what the consequences of these activities are. For Parsons, the physician's actions certifying illness serve the entire society by promoting an environment in which the individual designated as *sick* can later return to productive social and economic roles. There are no long-term consequences to the labeling of individuals.

Labeling theorists contend that labeling is used by the dominant classes to protect their interests, suppress the less fortunate, and reinforce established hierarchies (Becker; Freidson). Casting an individual in the sick role stigmatizes him or her and spoils life chances (Goffman; Scheff). Susan Sontag has argued that the vocabulary of illness leads those who are sick to blame themselves. Those who are vulnerable to labeling engage in a variety of social strategies to avoid it. Peter Conrad and Joseph Schneider have described how those with epilepsy, for example, attempt to stay "in the closet" with their condition rather than suffer the discrimination that attends candor.

Much of the work of labeling theorists depends on the contention that the locus of social control in the modern state has shifted. Conrad and Schneider observe that explanations of deviance now rely on "madness" instead of "badness." The dominant agents of social control are no longer clergy, but physicians. Social problems become medicalized, and the targets of therapeutic activity are more likely than not to be the socially disadvantaged. Jane Mercer, for example, found that the label *mentally retarded* was significantly more likely to be applied to members of minority populations.

In labeling theory a key variable of interest is social power. Labels are used to depress the social chances of the disadvantaged are also manipulated to aid the powerful. New categories of pathology emerge that create opportunities for healthcare professionals who use newly discovered syndromes to expand their power, while the social and structural conditions that generate problems remain, or become, invisible. For example, Stephen Pfohl views the discovery of the "battered-child syndrome" as a boon to pediatric radiologists and other pediatric professionals. The beating of children is not new, however, but its treatment as a medical problem is novel. Entire diagnostic classification systems may be viewed this way. Joel Kovel has criticized the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III; now replaced by the DSM-IV), the official diagnostic system of mental health professionals, for hiding social and political meanings in apparently neutral language. The purpose of the DSM, in this view, is to enable the psychiatric profession to control the institutions of mental health.

Individuals may actively seek some labels and avoid others. Tsunetsugu Munkata points out that in Japan the label *neurasthenia* is widely adopted to avoid the stigmatizing term *schizophrenia,* while Peter Conrad has shown how both parents and school professionals embrace the label of *hyperkinesis* to describe unruly children. Parents accepted the label because it absolved them of blame for their children's conditions; school officials accepted the term because it offered an individual-level explanation for restive behavior, allowing them to overlook deficiencies in school organization. Many illness designations signify entities whose precise, objective markers of disease are unclear. Sufferers, however, seek the legitimation of the disease label. Suffering is a powerful determinant of self-labeling, as the proper label serves to excuse and explain behavior that would otherwise be unacceptable. The early labeling theorists concentrated on labeling as a top-down phenomenon, stressing the repressive features of labels while ignoring the benefits some labels conferred.

The fact that the powerful resist—as well as discover, create, or construct—disease classification should also not be overlooked. Phil Brown and Edward Mikkelsen describe how the inherently conservative bias of epidemiological methods that depend on population-based measures retarded the identification of an environmentally generated cancer cluster in Woburn, Massachusetts. In another case, scientific medicine and organized mining interests retarded the recognition of "black lung" as an occupational disease (Smith). Both cases illustrate how the alliance of organized science with corporate interests can burden and delay successful efforts to discover or construct disease or the cause of disease.

Social Construction and Bioethics

Two key points of contention distinguish Parsons's theory of the sick role from labeling theory. The first is whether physicians have patients' interests reliably at heart. Parsons, in claiming that physicians have a "collectivity orientation," signals his confidence that they do. For labeling theorists, however, claims of altruism are utilized to cloak self-interest. This difference in attitude is very apparent in the writing from each orientation on the role uncertainty plays in medicine. From a Parsonsian orientation, uncertainty is a problem to be overcome and a psychological burden to physicians (Fox, 1959). From a labeling orientation, uncertainty is a ploy that physicians magnify in order to control patients (Davis).

The second key difference between Parsons and the labeling theorists concerns patient autonomy. For Parsons, the only autonomous decision made by the patient is the one to seek care. After that, patients simply, and appropriately, follow the doctor's orders. Since the physician has the patient's best interest in mind, there is no reason for the patient to balk or to question. For labeling theorists, there is no reason for the patient to follow medical regimes without question, since there is no guarantee that the physician has the patient's best interest in mind.

Informed consent is based on the principles of autonomy and self-determination. Sociological description of the doctor-patient relationship, whether from Parsons or from the labeling theorists, illuminates the absence of autonomy and self-determination. Sociologists differ on the necessity and value of such principles.

The earliest sociological studies of death and dying (those of Barney Glaser and Anselm Strauss, published in 1965) described the extent to which autonomy and self-determination were missing in the doctor-patient relationship. Physicians operated in what Glaser and Strauss called a "closed awareness context." Physicians knew of fatal conditions but routinely did not pass this information on to patients, and they often colluded with family members to keep this information from patients. These practices were rationalized as kinder than being candid.

Because of informed consent, a veritable revolution occurred in the doctor-patient relationship. Candor replaced evasion. With informed consent, patients are more than ever the masters of their own treatment. The paternalism that marked Parsons's description of the doctor-patient relationship has given way to a more egalitarian, more formally contractual, relationship. While there is much to celebrate in these changes, something may have been lost. There are costs involved with a fuller patient autonomy. Under the banner of autonomy, physicians may hide behind their role as technical experts and leave weighty matters to patients. There are also new possibilities for the psychological abandonment of patients.

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SEE ALSO: *Alternative Therapies; Anthropology and Bioethics; Bioethics, African-American Perspectives; Body; Eugenics: Historical Aspects; Feminism; Insanity and the Insanity Defense; Lifestyles and Public Health; Medicine, Sociology of; Mental Illness; Race and Racism; Sexual Identity; Women, Historical and Cross-Cultural Perspectives;* and other *Health and Disease* subentries

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III. ANTHROPOLOGICAL PERSPECTIVES

Medical anthropologists focus on people's life worlds (the subjective experience or phenomenology of sickness and healing), their cultural systems of meaning (e.g., ideas about what causes disease and how it is diagnosed), and the material conditions in which experiences and beliefs are situated (e.g., local disease ecology). Medical anthropologists attempt to understand and describe the medical beliefs and practices of people whose cultures and life worlds are often very different from their own. They routinely are confronted with the problem of translating unfamiliar meanings and experiences into familiar (Western) terms and concepts without taking them out of context or subordinating them to Western assumptions about sickness, health, efficacy, autonomy, and the like (Lock and Gordon; Kleinman, 1988; Gaines).

The anthropological perspective makes it possible to examine and clarify bioethical issues from multiple cultural points of view. The current debate over the bioethics of organ harvesting—the surgical removal of transplantable body parts such as the heart, liver, and kidneys—illustrates why it is important to have a clear understanding of cultural points of view. For transplantation to succeed, organs must be removed either (1) from a living donor in cases in which the organ is not vital to the donor's survival (e.g., a single kidney) or (2) immediately after a donor's death, before the organs have begun to decompose.

In most Western societies the line between life and death in the context of organ harvesting is identified with brain death, the irreversible loss of higher brain functions. The decision to identify death with brain death is consistent with Western cultural notions: Selfhood is identified with the mind, and the mind is by convention situated in the brain. This arrangement has the practical advantage of leaving a working heart in a harvestable body, facilitating the collection of transplantable organs. Japanese culture, in contrast, recognizes a different relationship between selfhood and the body: The self is not identified with a single body region. From this perspective a brain-dead body with a functioning heart has not crossed the line from life to death and is not yet a harvestable resource (Lock, 2002). Clearly, cultural definitions of selfhood and personhood have a profound impact on people's responses to bioethical issues.

Orientations to the Body

The history of medical anthropology is to a large extent a history of scrutinizing and challenging Western assumptions about sickness, beginning with the distinction between biomedicine and traditional medicine. (Most medical anthropologists prefer the term *biomedicine* to the alternative terminology: *scientific, modern,* and *Western* medicine. For an explanation see Leslie.) At first glance the distinction appears to be a commonsense way to classify different kinds of medical systems; in practice it rests on a set of problematic assumptions.

First, it implies that *traditional* medical systems have something fundamental in common, whereas in reality so-called traditional systems are highly diverse in both their medical theories and their practices and share little as a category other than being different from biomedicine (Leslie and Young). Second, juxtaposing traditional medical systems with biomedicine implies that biomedicine is a monolithic system, beyond the reach of culture. However, social scientists have demonstrated significant variation in biomedical notions, technologies, and clinical practices both within communities and across cultures (Brodwin, 2000; Hahn and Gaines; Lindenbaum and Lock; Lock, 1993; Lock, Young, and Cambrosio). Third, comparing biomedicine to other medical systems also sets biomedicine as the standard of medical care because it is based on scientific principles; this conveys the idea that other medical systems are not as *real* or therapeutically effective.

A more useful way to compare medical systems across cultures is to start with the question, How do the beliefs and practices of a medical system orient healers and patients to their bodies? An answer from the Western perspective might be that because the body is the site of the pain and suffering associated with sickness, the body must be the focus of attention for patients and healers everywhere. In reality, medical systems are not equally interested in the body. Rather, those systems and their perspectives are distributed along a continuum that includes the biomedical perspective among many others.

At one end of the continuum are systems whose orientation to the body can be called externalizing in that their diagnostic and therapeutic ideas and techniques direct people's attention away from the sufferer's body. In those systems the medical gaze looks outward, scanning networks of people and beings (e.g., ancestral spirits, possession spirits, demons) for morally significant encounters and events involving the sick person or that person's close relatives. The diagnostic goal is to construct a useful etiology, that is, a string of circumstances and events that lead to the onset of suffering and distress and identify the ultimate source of the sickness. The therapist's goal in those systems is to insert himself or herself into the patient's sickness narrative and, once there, persuade or coerce the pathogenic agents to stop afflicting the patient. The classic account of diagnosis and treatment in an externalizing system is E. E. Evans-Pritchard's *Witchcraft, Oracles, and Magic among the Azande* (1937).

A sick person's body is a site of discomfort and distress, and in this sense sickness is the same all along the continuum. At the externalizing end, however, the patient's bodily experiences and transformations are mute. Typically, the body is a black box in that although people may have names for certain body parts and organs, they can posit no functions or systemic connections for them. Pain, suffering, and the visible transformations that accompany sickness and disease signify only themselves; they reveal nothing about processes and events that biomedicine recognizes are taking place inside. Although practitioners may give patients medicaments to take, those medicines are characteristically anodynes or substances that are intended to make the patient more comfortable while the actual cure is being pursued elsewhere. In short, in externalizing systems medical meanings and experiences are created and connected by discrete socio-logics rather than by a universal bio-logic (Lock and Gordon).

Anthropologists describe three broad types of therapeutic strategies that operate in externalizing medical belief systems: agonistic strategies, in which the goal is to eliminate or neutralize pathogenic agents; initiatory strategies, in which the goal is to bring the patient and the pathogenic agent into a permanent and manageable relationship (Boddy); and strategies of persuasion, in which the goal is to persuade the pathogenic agent through offerings or appeals to cease afflicting the patient (Lewis). Beyond these generalizations, externalizing systems are highly heterogeneous.

Biomedicine is at the opposite end of the continuum, among the internalizing systems, in which diagnosis and therapy orient patients and healers toward the body. Here sickness coincides with the limits of the body, and the goal of diagnosis and therapy is to get inside the body, to take control of its internal parts and processes. Circumstances and events outside the body are interesting only to the degree to which they lead to inferences about pathological processes taking place inside. It is in these systems that one finds theories of pathophysiology, the grammars that enable people to read bodily changes symptomatically.

Medical Efficacy

Common sense inclines people to suppose that because internalizing systems are able to read embodied symptoms, they are more empirical and realistic than externalizing systems are. Ethnographic research, however, indicates that all medical systems, externalizing as well as internalizing, are generally empirical and realistic. That is, they are capable of routinely producing self-vindicating outcomes, evidence that demonstrates their efficacy.

Medical efficacy can be demonstrated by two different kinds of results. First, efficacy is sometimes a capacity for producing hoped-for results, such as the amelioration of pain or the remission of symptoms. In practice it is not difficult for externalizing and internalizing systems to produce hoped-for results in light of the fact that the majority of medical problems consist of either (1) transient or recurrent symptoms that are perceived as being discrete disorders or (2) self-limiting diseases, episodes that end in either spontaneous remissions or death. In these circumstances medical practices acquire a reputation for hoped-for efficacy when three conditions are met: An intervention routine occurs between onset and outcome, remissions predominate over deaths and other unwanted outcomes, and superior alternative interventions are absent or inaccessible.

Second, efficacy can take the form of producing expected results. This occurs when practices and procedures are able to produce evidence that affirms the line of reasoning and the underlying assumptions that persuade patients and practitioners to select particular interventions. Expected results can be produced without also producing hoped-for results. Thus there is the grim joke that the operation succeeded but the patient died: The patient's body, once opened up, reveals a pathology that affirms the correctness of the assumptions and choices that have led from diagnosis to surgery, but the intervention is unsuccessful because of circumstances beyond the clinician's control. All medical systems, whether internalizing or externalizing, appear capable of distinguishing between hoped-for results and expected results.

In addition, serious sickness is a source of distressing feelings that are only incidentally connected to the pain and suffering of a sick person. Medical practices may have the effect of reducing such distress by connecting sickness events to local systems of moral and cosmological meaning. This power to give meaning to and impose moral order on chaotic and threatening events may be sufficient to perpetuate certain medical practices even when those practices have no great reputation for producing cures. Those practices sometimes are called healing rituals by anthropologists.

The Mind-Body Problem

One of the current debates in biomedicine surrounds the mind-body problem, which has arisen from the observation that sickness is simultaneously an objective phenomenon and a subjective phenomenon. In the language of the social sciences the objective (or bodily) component is called *disease,* and refers to abnormalities and dysfunctions in organs and organ systems. The subjective component is called *illness,* and refers to the patient's unique and holistic experience of either disease-related distress or certain other socially disvalued states, such as psychogenic mental disorders, that conventionally are bracketed together with diseases. Disease can occur in the absence of illness, as in the case of undiagnosed and asymptomatic hypertension, and illness can occur without disease, as in adjustment disorder and somatization disorder.

Anthropologists have critiqued the mind-body distinction in two ways. The first critique calls for a reconceptualization of the relationship between mind and body. The argument is that people need to free themselves from the objective-subjective comparison and take account of the continuous interaction between mind and body: the capacity of the mind to affect bodily states positively and negatively, the mind's predilection for using bodily states as idioms of distress, and so on (see Csordas).

The second and more radical critique refers back to anthropology's task of translating unfamiliar meanings and experiences into intelligible concepts without subordinating them to Western assumptions about sickness, healing, and agency. Both Western culture and biomedicine assume the existence of a mind situated in the brain. In practice, the mind is one of the Western ways of talking about the self: the body's seat of consciousness, the subject of its experiences, the initiator of the body's purposeful actions, the repository of its memories, and the locus of moral agency. To anthropologists the Western mind/self is a cultural artifact; it exists because people have practices that make it exist in the same way that possession spirits exist in the Sudanese *zar* cult. Indeed, there are many cultures and systems of medicine that are *mindless* in the sense that they have no corresponding network of mental and moral meanings, and they constitute people and experiences in fundamentally different ways. Thus, the mind-body distinction has been criticized not because there is a need for more effective concepts for connecting psyche (mind) to soma (body) but because the notion of mind itself and the practices through which that notion emerges subordinate non-Western cultures and realities to a distinctively Western ontology (Good and Kleinman; Kleinman, 1988).

Patterns of Resort

The idea that in any community an individual's medical behavior is congruent with a unitary set of meanings concerning sickness and its causes, diagnosis, and treatment is an obstacle to translating medical realities between cultures. Anthropologists make a series of distinctions between medical traditions, sectors, and systems so that they compare cultural norms of medical behavior:

1. A medical tradition is a set of practices and technologies organized around historically situated ideas about etiology, symptomatology, and treatment. Biomedicine, Ayurvedic medicine, and the zar cult are examples of medical traditions. Traditions are simultaneously vocabularies for interpreting the world and plans of action and technologies for producing facts that confirm their interpretations of the world.
2. The actual forms a tradition takes in a specific community make up its medical sector. A particular medical tradition can be put into action in various ways. It can be used to justify a range of practices,

technologies, and routines, and it can be adapted to a variety of institutional settings. For example, in many less developed countries the biomedical tradition is practiced in four sectors: licensed professionals (physicians, nurses, etc.), fee-for-service injectionists (who inject clients with substances from the biomedical pharmacopeia), pharmacists (who can diagnose symptoms as well as prescribe treatments), and domestic settings (where the biomedical tradition is employed mainly to diagnose problems). Although the four sectors share a single tradition, they include different sets of options. In the first sector clinicians monopolize diagnosis and treatment choices and decide which etiologies will be tested and confirmed and which sets of cultural meanings and socioeconomic implications will be realized through these practices. Injectionists and pharmacists represent patron-dominated sectors of biomedicine in the sense that patients or members of their families make their diagnoses before consulting the practitioner. Practitioners may be asked for alternative diagnoses, but the ultimate decision is the patient's.

3. A medical system is equivalent to the collection of traditions and sectors that are available to the people in a particular community. Medical beliefs and practices are useful to patients and their families because those people know how to incorporate them into patterns of resort. These are the paths that people create in the course of actual sickness episodes as they navigate their way from one medical sector to another, picking and choosing from among their options.

The ethnographic literature suggests two main patterns of resort. In the first the patient or a surrogate simultaneously consults alternative traditions. People have various motives for following this strategy. In some cases patients believe that the effects of multiple interventions are cumulative; in other cases they are unsure which, if any, of the available traditions will provide an effective cure. In some communities, notably in southern Asia, the simultaneous pattern of resort reflects a therapeutic division of labor. Biomedicine is prized for its quick effects against causal agents such as microbes and its ability to treat symptoms such as high fevers. The Ayurvedic tradition is valued for its ability to counter the perceived side effects of biomedicines, especially antibiotics, and its ability to restore an equilibrium among the body's organs and humors, that is, the state synonymous with health. The alternative strategy consists of a sequential pattern of resort in which the individual exhausts the resources of a tradition or sector before moving on to an alternative tradition in the medical system (Young, 1983).

The paths that individuals follow through their medical systems are determined by a variety of factors. For example, patients who want to avoid stigmatizing etiologies (ones that would contaminate or spoil an individual's social identity) or diagnoses with a poor prognosis are likely to compare the range of diagnoses and etiologies that belong to the various traditions in their medical system and then start off with the tradition that offers the most favorable outcomes. The choice may be influenced by cost-benefit calculations. That is, a practitioner's or sector's economic and geographic accessibility are weighed against the perceived seriousness of the patient's sickness and the value of the patient to his or her family (Nichter).

Implications for Bioethics

Why is it important for bioethics to understand that health, illness, and disease are socially shaped, culturally constructed, and historically situated? Basically, those ethnomedical beliefs and values inform people's health-related behavior. More specifically, culture shapes the ways in which people make decisions in the context of morally charged healthcare situations. Culture also shapes the kinds of ethical situations that can arise in a particular healthcare or healing setting and the frameworks for understanding and models for responding to those ethical dilemmas. Anthropology's cross-cultural or comparative perspective, combined with ethnographic methodological approaches, helps people (1) recognize that moral norms vary cross-culturally and (2) challenge tacitly held cultural assumptions in biomedicine and bioethics about what counts as human, self and other, normal and abnormal, life and death, right and wrong, and other key moral concepts (Marshall and Koenig, 1996, 2001; Haimes).

Anthropological investigation into contemporary debates about bioethics raises new questions, provides insights into the ways in which people experience ethical issues, and broadens the scope of inquiry. Anthropological research on genetics, for example, shows that women's decisions to undergo prenatal genetic testing are informed by cultural definitions of risk, perceived acceptable forms of disability, and social dynamics between women and genetics counselors (Browner et al.; Rapp). These factors may come as a surprise to bioethicists, who may expect attitudes toward abortion to take a primary role in women's prenatal decisions. With regard to examining the genetic basis of medical conditions such as Alzheimer's disease and sickle-cell anemia among African Americans, anthropologists have been at the forefront in pointing out the problems with using the term *race*. For instance, using that term risks perpetuating essentialism about clinical phenomena. They also have identified how notions of heredity hinge on cultural ideas of kinship and the implications of genetics research for defining claims to group identity (Koenig and Silverberg; Brodwin, 2002; Gordon; Wailoo, 1997).

The ability to explicitly recognize the cultural basis of bioethical constructs, such as the concept of autonomy, can help bioethics scholars rethink the premises of moral arguments. Furthermore, by recognizing that medical systems maintain their own logic, bioethicists and biomedical practitioners are more likely to attempt to understand patients rather than label them as irrational or incompetent. Patients' perceived levels of competency—from both legal and ethical perspectives—can affect their involvement in medical decision making.

As an example one might consider the case in which a Mien mother from Laos brings her daughter to a pediatrician for her four-month immunizations (Crigger). The pediatrician observes a number of burns on the child's stomach and considers whether to call the Department of Child and Family Services, thinking that the mother has abused her child. The burns actually were the result of a healing ritual designed to ameliorate the child's symptoms that were identified as meaningful to Mien culture. Understanding that the burns are a result of a therapeutic regimen can help the pediatrician realize that the mother was not abusive or neglectful; instead, she was attentive to improving the health of her child (Brown and Jameton). In contrast, one might consider the physician's attempt to pierce skin with a needle as unnecessarily harmful even though it is intended to improve health. Different cultures have different conceptions of what therapeutic interventions constitute acceptable harms or risks and benefits. This case illuminates how culturally shaped ethical notions of risk and benefit are. With a cultural perspective in mind bioethicists can reconstruct arguments regarding risk-benefit ratios. Biomedical healthcare practitioners who recognize these cultural dynamics can better provide not just culturally competent care but also high-quality care.

Conclusion

A community's medical beliefs do not correspond to a homogeneous set of meanings. Both in complex societies and in *traditional* and *tribal* societies individuals are drawn by sickness into multiple and often contradictory systems of meanings and action. The appearance of unity and homogeneity within a specificcommunity is not accidental, however. Usually it is an expression of power, of the capacity of one segment of the community—its medical experts, political leaders, moral authorities, and others—to define and control which of the alternative sets of medical meanings will be carried over into public discourse. In this sense power is the ability to convince people that the socially dominant meanings of sickness are also the authentic meanings (Young, 1982).

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SEE ALSO: *Anthropology and Bioethics; Bioethics, African-American Perspectives; Body; Eugenics: Historical Aspects; Feminism; Insanity and the Insanity Defense; Lifestyles and Public Health; Medicine, Anthropology of; Medicine, Philosophy of; Medicine, Sociology of; Mental Illness; Race and Racism; Sexual Identity; Women, Historical and Cross-Cultural Perspectives;* and other *Health and Disease* subentries

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IV. PHILOSOPHICAL PERSPECTIVES

Concepts of health and disease—as well as of sickness, wellness, deformity, disability, dysfunction, and disfigurement—direct social energies. They inform medicine and healthcare policy regarding what is wholesome, what is to be avoided, and what is to be treated—all else being equal. Concepts of health and disease either directly or indirectly describe, evaluate, and explain reality and help to assign social roles. Decisions about the meaning and scope of concepts of health and disease profoundly influence the character of healthcare. For example, if alcoholism, homosexuality, menopause, or aging are considered diseases, then medical treatment, resources, and research will be focused on treating them. These concepts therefore become the focus of public-policy debates, and they may conceal value judgments that should be treated more explicitly as bioethical issues.

Diseases and sicknesses are usually distinguished from sins, crimes, and social problems in that they are not directly under the control of the will and are explainable, predictable, and (usually) treatable by an appeal to somatic or psychological laws, generalizations, and associations. Pains that are directly under one's own control or that of others (e.g., the pain from standing on one's own foot), difficulties of a moral sort (e.g., being blameworthy), problems of a spiritual sort (e.g., refusing to repent for one's transgressions), or legal disabilities (e.g., being a convicted felon) are thus contrasted with states of disease or illness. This contrast discloses a boundary between disparate human practices (e.g., blaming the immoral, convicting felons, exorcising demons, treating diseases), and the criteria used to distinguish between any of these practices will vary from culture to culture and shift within the history of a particular culture. In addition, the line between medical and other problems is, in part, a function of the competencies of those making the judgment. Diseases and illnesses are what medicine treats.

Illnesses and diseases are generally identified because they involve a failure of function, a pain that is considered abnormal (compare the pain of teething with that of migraine [King]), a deformity, or the threat of premature death. Insofar as judgments regarding proper function, normal pain, correct human form, and normal span of life can be made without reference to culture-dependent values, concepts of disease will not depend on social norms of proper human function. The same can be said with regard to concepts of health. Though much is said regarding healthcare, health, and wellness, one may question whether such notions can be understood only in positive terms. The positive concepts of health must be understood in relation to the absence of particular dysfunctions, pains, or deformities, and there may be numerous concepts of human well-being and exemplary function (Boorse,1975). It is also difficult to provide a positive account of health and well-being that will not include concepts of economic, political, and social health. For example, the World Health Organization's 1958 definition of health as a "state of complete physical, mental, and social well-being" (WHO, p. 459) has been criticized for being too broad and ill defined to guide the formation of health policy (Callahan). The philosophical literature, aside from addressing these difficulties with concepts of health, has focused mainly on concepts of disease and illness.

Philosophical concerns regarding concepts of health and disease can be organized under six questions:

1. Are disease entities to be discovered or are they and their classifications instrumental constructs that are created to achieve certain ends?
2. How do explanatory models shape the boundaries between health and disease and determine the meaning of disease?
3. What values shape concepts of health and disease, and to what extent are these culturally determined?
4. Is the definition of mental disease and health different from that of somatic (or physical) disease and health?
5. Do concepts of animal disease function in the same way as concepts of human disease?
6. How can concepts of health and disease be used for overt political and social ends?

The *ens morbi*

The history of medicine is replete with talk of clinical findings constituting an *ens morbi* (disease entity). Disease entities have been conceived of as metaphysical entities, clinical entities, pathological entities, etiological entities, and genetic entities. These ways of considering diseases generated a significant dispute in the nineteenth century between those who held that disease entities (and the classifications within which they are understood) identify realities in the world and those who held that disease classifications are at best distinctions imposed on reality to achieve certain goals (e.g., of diagnosis, therapy, and prognosis). The first were termed *ontologists,* while those who took a more conventionalist, instrumentalist, or nominalist position were termed *physiologists.* This distinction appears to have been articulated in 1828 by Françlois-Joseph-Victor Broussais (1772–1838), who denounced ontological accounts of disease (1821). Carl Wunderlich (1815–1877), Ernst von Romberg (1865–1933), Alasdair MacIntyre, Samuel Gorovitz, and others have, in various ways, taken positions in sympathy with Broussais.

Ontological theories have held that disease terms or classifications name things in the world. Though Broussais had directed his criticisms against clinical classifications, disease ontologists can be taken to include any who perceived diseases as entities, including metaphysical views advanced by individuals such as Paracelsus (1493–1541), who held that diseases are specific entities that arise outside the body.

Disease entities have also been understood as clinical realities, or as recurring constellations of findings. Thomas Sydenham (1624–1689), in classifying disease entities, construed them as enduring types and patterns of symptoms: "Nature in the production of disease is uniform and consistent; so much so, that for the same disease in different persons the symptoms are for the most part the same; and the selfsame phenomena that you would observe in the sickness of a Socrates you would observe in the sickness of a simpleton" (p. 15). It is within such a view of disease that one can speak of a person having a typical case of typhoid. Such language expresses the view that there is a central identity for a disease that is its essence, or *type.* One can therefore classify diseases by type, as well as speak of instances of a disease as approximating a *typical* case. Within this understanding, one can also talk of typical cases as rare: "One rarely sees a typical case of secondary syphilis." Patients embody clinical realities where *typical* means the full and complete expression of a disease, or an ideal type, but not necessarily its usual expression. It was against this genre of account that Broussais spoke.

Etiological accounts, like metaphysical views, focused on the cause of the disease as the disease entity, but regarded disease entities as empirical, and usually infectious, agents. Rudolf Virchow (1821–1902) characterized this view as "ontological in an outspoken manner" (p. 192). Virchow considered this understanding of disease entities to rest on a confusion between a disease and its cause. "The parasite," he wrote, "was therefore not the disease itself but only its cause" (p. 192). The confusion of the disease with its cause led to a "hopeless, never-ending confusion, in which the ideas of being (*ens morbi*) and causation (*causa morbi*) have been arbitrarily thrown together, [and] began when microorganisms were finally discovered" (p. 192). The mature Virchow embraced a view of disease entities grounded in pathological findings, and he held that a disease entity is "an altered body-part, or, expressed in first principles, an altered cell or aggregate of cells, whether tissue or organ" (p. 192). Further, "this conception is expressly ontological. That is its merit, not its deficiency. There is in actuality an *ens morbi,* just as there is an *ens vitae* (life force); in both instances a cell or cell-complex has the claim to be thus designated" (p. 207).

Genetic accounts can also interpret the disease entity as an empirical reality, to be found in genetic abnormalities (Anderson; Fowler, et al). The promise of somatic-cell gene therapy raises the question of a disease entity once again. That is, does the disease exist in the genetic structure, or is the structure the cause of the disease?

Current uses of the term *disease* in standard nomenclatures and nosologies (classifications) have a predominantly nonontological character. A conventionalist view allows one to choose, for example, whether one wishes to treat tuberculosis as an infectious, genetic, or environmental disease (recognizing that all three sorts of factors contribute to the development of tuberculosis), based on which variables are most easily manipulated. One may decide that it would be best to treat tuberculosis as an infectious disease because little is known about the inheritance of resistance against tuberculosis, or because any eugenic programs to eliminate tuberculosis would be very slow in taking effect. It may also be seen as an environmental disease that is brought about by socioeconomic conditions such as housing, food, and other such factors. It is meaningless to ask whether such a definition of disease is true or false, only whether it is useful (Wulff).

Diseases as Clinical Findings and Explanatory Accounts

Many people take the term *illness* to identify a subjective experience of failed function, pain, distress, or unwellness. *Disease,* in contrast, is then an explanatory concept, or part of an explanatory account (Boorse, 1975). Or one might identify illnesses as constellations of signs and symptoms and diseases as illnesses joined to disease models or explanations, where the content of the illness is augmented by the phenomena found on the basis of a disease model. But to recognize a state of unwellness as a state of disease is already to have begun to explain it and to recast the meaning of the findings within an interpretive context. A constellation of phenomena is held to be recurrent, and if such a constellation of phenomena is encountered again in the future, it can be identified. A specific set of symptoms, for example, can be identified as a case of chronic fatigue. Diagnoses of syndromes, of recurrent patterns of signs and symptoms, allow predictions to be made (prognoses) as well as the management of outcomes (therapy). Such predictions and attempts at therapy can succeed even in the absence of causal explanations.

During much of its history, medicine has been concerned with classifying patterns of signs and symptoms so that they can be recognized in the future with greater ease. Thomas Sydenham's classic *Observationes medicae* (1676) suggested classifying diseases in definite species, following the methods of botanists in classifying plants. His work was followed by Carolus Linnaeus's Genera morborum in auditorum usum (1759), François Boissier de Sauvages de la Croix's Nosologia methodica sistens morborum classes juxta Sydenhami mentem et botanicorum ordinem (1763), and William Cullen's Synopsis nosologiae methodicae (1769). These classifications functioned without causal explanations, though these were also given. Such medical descriptions and explanations at a clinical, phenomenological level are still employed whenever a new illness is identified for which a causal explanation is not yet forthcoming. For example, acquired immunodeficiency syndrome (AIDS) was first identified as a clinical, phenomenological entity.

Medicine also explains health and disease by relating what is observed via general laws of physiology, anatomy, psychology, genetics, and so forth to other phenomena. The result is a two-tier account of diseases. The first tier is that of the observed constellations of phenomena, such as a clinical description of yellow fever. The second tier is that of a model advanced within the laboratory medical sciences to explain the observed clinical phenomena, such as an explanation of the clinical findings in yellow fever in terms of the effects of a group B arbovirus (a group of viruses transmitted by mosquitoes and ticks) that causes the death of essential cells in the liver.

The laws of pathophysiology (the physiology of disordered function) and pathopsychology (the psychology of mental disease) relate new phenomena to the original clinical constellations of signs and symptoms. Some of these phenomena are then recognized as the causes of the illness. The concept of disease thus comes to identify disease models that support the search for unnoticed causal factors and expressions of disease. For example, Giovanni Battista Morgagni (1682–1771) in his *De Sedibus et causis morborum per anatomen indagatis* (1761) correlated clinical observations with postmortem findings, and Philippe Pinel (1745–1826) incorporated anatomical considerations into his *Nosographie philosophique* (1798), producing nosologies that embraced not only clinical observations, but anatomical considerations as well. This change in focus was strengthened when Marie-François-Xavier Bichat (1771–1802) argued that constellations of symptoms and signs could be explained in terms of underlying pathological processes. According to Bichat, medical advances are best achieved through autopsies (Foucault). This shift to the study of pathological findings as a way to explain clinical observations was then supplemented by accounts drawn from microbiology, endocrinology, biochemistry, genetics, and other fields, producing contemporary explanations of illnesses.

In the process of moving from accounts of illness that were predominantly clinical observations to accounts based on observable illnesses of the anatomy, the meanings of diseases were altered. Individuals who once were thought to die of acute indigestion were now understood to die of a myocardial infarction. The meanings of the phenomena observed (e.g., clinical signs and symptoms) were reinterpreted in terms of disease models. As a result of this recasting, medical complaints often came to be considered legitimate only to the extent that they had a demonstrable, underlying pathophysiological or pathoanatomical lesion.

Health and Diseases: Discoveries or Cultural Inventions?

If certain physiological and psychological functions can be identified as natural or essential to humans, then their absence can be used to define disease states. Leon Kass and Christopher Boorse have argued that one can specify those functions that are integral to being human, and thus secure accounts of disease that are not relative to a particular culture or set of values. Such understandings of health and disease could then be used to sort out essential from nonessential (if not proper from improper) applications of medicine. However, such naturalistic views may depend on particular understandings of what is *natural.* Others appeal to an evolutionary account of what should count as species-typical levels of species-typical functions appropriate for age and gender (Boorse 1976).

In contrast, Joseph Margolis, H. Tristram Engelhardt, and others have argued that definitions of disease and health depend on sociological, culturally determined value judgments, and that these definitions can be understood only in terms of particular cultures and their ideologies (Margolis). A value-free account of disease cannot be given, some have argued, because diseases are defined not by their causes, but by their effects (Resnek)—and their effects gain significance within a cultural context. K.W.M. Fulford has also indicated deeply hidden but still crucial evaluative elements in medicine. He has done this through a linguistic-analytic examination of how disease language appears to be value-free, while still entailing values, with the result that controversies in medical health are engendered where relevant values are sufficiently diverse. Fulford also argues that part-function analysis, which focuses on the proper function of each part of the body, fails with psychotic mental disorders where the rationality of the person as a whole is disturbed. Others have explored the nature of disease through the use of action theory and by placing concerns about disease and illness within the larger holistic context of health (Nordenfeldt, 1995, 2001). Still others ground disease language in a notion of malady dependent on the universal features of human rationality, thus eliminating culture as a factor (Clouser).

The view that the concepts of health and disease are culturally determined has been supported by feminist writings on healthcare. Many authors have pointed out that the practice of medicine has had an androcentric (masculine) focus, that women's issues have largely been ignored, and that experiences reported by women that could not be documented have been treated as invalid (Rosser; Oakley).

Partisans of the view that social and cultural ideas influence concepts of health and disease stress that a definition of disease tied to evolution makes disease concepts dependent on particular past environments and past adaptations. Successful adaptation must always be specified in terms of a particular environment, including a particular cultural context. A culture-dependent account of concepts of health and disease need not deny that there will be great similarities as to what will count as diseases across cultures, for certain symptoms and conditions will probably be understood as diseases in most cultures. Supporters of a value-infected, culture-dependent account of disease have argued that those who would attempt a purely evolutionary account of disease have not reconstructed the practice of medicine, but rather some practice of characterizing individuals as members of particular biological species (Engelhardt, 1975). The practice of medicine, in this view, depends on culturally constructed understandings of health and disease.

How one understands health and disease will in turn influence how one conceptualizes medical practice. Henrik Wulff has argued that an exclusively biological or empirical model of illness contributes to paternalistic medical practice, for if concepts of health and disease can be fully understood in biological terms, then there may be no need to assign the patient an active role in the decision-making process. If, however, determinations of health and disease are not just empirical concepts, but are also related to cultures and values, the patient will have a more active role in determining the burden of the disease and the extent of treatment.

The conceptualization of medicine will certainly be influenced by developments in genetic research, which hold the promise not only to correct diseases in patients, but to prevent them in future generations of patients (Anderson; Zimmerman). Thus, as the capacities of genetic medicine increase, preventive medicine will expand. Somatic and germ-line therapies will also be affected as choices are made about which genetic variances should be treated as disease abnormalities (e.g., homosexuality, alcoholism, shortness of stature).

Physical, Mental, and Social Diseases

It has been argued that only somatic diseases are legitimately diseases, while *mental diseases* are problems with living (Szasz). Following similar lines of argument, individuals have contended that enterprises such as psychotherapy are tantamount to applied ethics (Breggin), or that the cure of somatic disease constitutes the prime goal of medicine (Kass).

In response, some argue that such stark dichotomies or dualisms fail to offer satisfactory accounts of reality. If mental life is dependent on brain function, then all mental diseases can, in some sense, be tied to physical pathology or abnormal anatomy. For example, depression can be presumed to be dependent on a neurophysiological substrate, and thus, in principle, is open to pharmacological treatment. If one views diseases as explanatory models for the organization of signs and symptoms, then it does not matter whether the signs and symptoms identify physiological states (“I have a rash”) or psychological states (“I feel depressed”). Nor does it matter whether models employed to correlate these phenomena are pathophysiological or psychological. Most accounts of disease will, in fact, mingle physical and psychological symptoms. As a consequence, one may come to view distinctions among somatic, psychological, and social models of disease in terms of pragmatic needs—of accenting the usefulness of particular modes of therapeutic intervention. One may even advance sociological models of disease, construing diseases primarily in terms of social variables and giving secondary place to the pathophysiological.

Distinctions between medical and nonmedical models of therapy, unlike somatic, psychological, and sociological accounts of disease, are often meant to contrast the autonomy of clients in nonmedical therapeutic models with the dependence of patients on healthcare practitioners in medical models. Talcott Parsons characterized the “sick role” as: (1) excusing ill individuals from some or all of their usual responsibilities; (2) holding them not responsible for being ill (though they may be responsible for becoming sick); (3) holding that they should attempt to become well (a therapeutic imperative) and seek out experts to treat their illness. Medical models tend to support paternalistic interventions by healthcare practitioners and to relieve patients of responsibility for directing their own care. Nonmedical models, in contrast, tend to accent the patient’s responsibility.

Somatic models of disease may be employed within both medical and nonmedical models of therapy. For example, hypertension may be treated with antihypertensive agents or by enjoining the afflicted individuals to find ways to change their lifestyles with regard to stress, eating patterns, and so on. The same is true of psychological models of disease. Depression can be treated chemotherapeutically or by enjoining individuals to make changes in their ways of living.

As predisposing factors toward particular diseases become better known and easier to control or avoid, individuals are held increasingly responsible for becoming ill, even though they will remain nonresponsible for being ill. A person is not held to be responsible for having bronchogenic carcinoma in the same way that one is responsible for being a willful malingerer. In other words, one cannot be told to stop having cancer, but one can be held responsible for having developed cancer through one’s smoking habits. As the impact of lifestyle on the development of diseases becomes clearer, the responsibility of individuals for their health may increase the possible scope of nonmedical models of therapy.

Animals and Disease

If concepts of human illness, disease, and health are, in part, social constrictions, there will be differences between the ways in which diseases are identified for humans and the ways they are identified for other animals. Illnesses and diseases in animals will be judged through the social or cultural criteria of human beings. Pets or domestic animals may be regarded as having disease or being healthy depending on how they are viewed through human purposes and constructs. The diseases or illnesses of those animals that are not pets, however, along with those of plants, may be understood less in terms of human social or cultural criteria and more in terms of generalized knowledge about the species. In the case of animals in the wild, there may not be concern for individual suffering, disability, or deformity, but rather with the general health of the species. Identifying the role human values play in the concepts of animal disease and illness expands the discussion of the ethical treatment of nonhuman animals in bioethics.

The Social Force of Diagnosis

Concepts of disease have been used to impose political judgments. For example, in the United States prior to the

Civil War it was proposed that the flight of a slave to the North and the absence of a wholesome inclination to do effective plantation work were diseases for which explanatory accounts and treatments could be provided (Cartwright). Masturbation was once viewed as a serious disease for which castration, excision of the clitoris, and other invasive therapies were employed. Individuals were even determined to have died of masturbation, and postmortem findings "substantiated" this cause (Engelhardt, 1974). In the case of the diseases of slaves, the motivation may have been to protect slaves from punishment. In the case of masturbation, the influence of cultural values on the psychology of discovery was not appreciated.

Historical perspective can increase our awareness that medical practitioners and researchers have tended to "discover" what already was assumed. More recent political uses of disease concepts (e.g., in psychiatry) have been closely connected with repressive goals and political agendas of certain governments. Social employment of disease definitions is often meant to be benevolent, however, such as advocating a view of alcoholism and drug addiction as diseases so as to recruit the forces of medicine to aid in their control. Moreover, such conditions may be termed diseases in order to relieve alcoholics and drug addicts of the social opprobria that attend what is often viewed as immoral behavior.

Summary

Concepts of health and disease shape descriptions of medical reality, convey explanations, advance value judgments, and structure social reality. They influence not only the scope of medicine, but healthcare policy as well. Because they may involve not only moral values but values associated with physical and mental excellence, they raise questions pertinent to both bioethics and the philosophy of medicine. These special concerns regarding medical explanation may sufficiently define a distinctive problem area so as to establish the philosophy of medicine as a field in its own right, despite arguments to the contrary. In any event, the concepts of health and disease, as well as their application, will continue to be the subject of debate in societies that are morally and culturally pluralistic.

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SEE ALSO: *Anthropology and Bioethics; Bioethics, African-American Perspectives; Eugenics: Historical Aspects; Feminism; Lifestyles and Public Health; Medicine, Anthropology of; Medicine, Philosophy of; Medicine, Sociology of; Mental Illness; Women, Historical and Cross-Cultural Perspectives;* and other *Health and Disease* subentries

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V. THE EXPERIENCE OF HEALTH AND ILLNESS

Some would argue that given the wide range of historical, cultural, and individual differences concerning health and illness, little could be said on the topic that would have universal validity. Others would point toward certain invariant features of the human body, psyche, or society that could ground cross-cultural commonalities. Presented here is a description of health and illness as experienced within a contemporary Western context. While this description may not be universally applicable, it nonetheless provides a starting point for elucidating similarities and differences among cultures and individuals.

The Experience of Health

In setting out to portray the experience of health, one is struck by how little people are used to focusing on it. This tendency to overlook health—to take it for granted—is also reflected in the paucity of descriptive literature on the subject. In many ways this is precisely the point. To be healthy is to be freed from some of the limitations and problems that promote self-reflection. A healthy person need not pause before scheduling a dinner for later in the week or grabbing a shovel to clear the driveway of snow. The state of health that allows for such engagements remains the tacit background of what Maurice Merleau-Ponty, drawing on the work of Edmund Husserl, calls the bodily “I can”: I can get out of bed, move across the room, brush my teeth, and so forth, without a need to explicitly define or acknowledge these abilities—or the wellness that make them possible.

Sometimes people are provoked to reflect on their good health: they revel in their renewed strength after a bout of flu, for example. Health is thus illuminated by contrasting experiences. Certain practices, such as yoga, tai chi, and exercise programs, can systematically teach one to cultivate and appreciate the healthy state, heightening self-awareness.

However, Western culture has tended to neglect or demean bodily experience in favor of a detached rationality or cultivation of the soul (Leder, 1990). People learn to overlook or overcome the body until it seizes their attention, as it does at times of pain and illness. Even preventative *health education* tends to focus on external guidelines concerning exercise, diet, and the like, but do little to cultivate an inner awareness of the body’s own voice. Perhaps many illness states could be avoided if people were better listeners to the subtler messages of the body that signal a departure from good health. Yet to be healthy is ever a temptation to overlook, or look beyond, the body. The word *health* comes from the same root as the word *whole.* The healthy body operates as a harmonious whole, allowing one to feel at home in the world (Svenaeus) without the need for undue self-reflection.

Disease and Illness

Illness makes one aware of the precariousness of the world. To capture the profound dislocations caused by illness, it is useful first to distinguish between *illness* and *disease* (Cassell, 1985; Engelhardt, 1982). Modern medicine has been largely concerned with understanding and treating specific diseases. Yet to diagnose an individual as having a disease means looking beyond that particular individual: one notes a cluster of signs and symptoms that have repeatedly presented in a range of cases. The disease label also frequently (and ideally) invokes an explanatory etiology, a prognostic picture, and a set of treatment options, all drawing upon the theories and knowledge base of medical science. Since the eighteenth century, disease classifications have progressively moved from a basis in the patient's reported symptoms to one grounded on the pathological lesions and processes exposed after death or, by medical technologies, in the living (Engelhardt, 1986; Foucault). Hence, *dyspepsia* has become *peptic ulcer disease.* This shift has greatly advanced the explanatory and therapeutic powers of modern medicine, but it has also diminished the attention paid to the patient's experience.

In contrast to the medical characterization of disease, the term *illness* refers to the *experience* of sickness. To fall ill is to undergo a series of transformations that distinguish this state from health. In a sense, any illness is inescapably individual. Even if one shares the same disease with another, the challenges, limitations, and suffering involved can vary considerably from person to person. Yet just as the physician-researcher can uncover the repeated patterns typical of a disease, one can describe certain features that commonly accompany the illness experience (Toombs, 2001).

ILLNESS AND THE EXPERIENCE OF THE BODY. If health is a kind of wholeness—an integration along a number of dimensions—illness involves a set of experienced *dis-integrations.* This is first seen in relation to the body. Ordinarily, the body operates as a seamless whole (Merleau-Ponty, 1962): in response to one's perceptions one moves through and acts upon the surrounding world, with the internal organs supplying the needed life energy. In illness, however, the body can split into problematic parts and functions. An aching stomach or a pulled muscle suddenly stands out from the rest of the body, demanding attention. As one's organic harmony is disrupted, so too is one's integration with the world. The ill body is no longer at home in its world, but is awkward and limited, and even simple physical acts become difficult.

This dis-integration of the body within itself and from its world also brings about a felt split between the body and the self. Ordinarily, the body is an inseparable part of one's identity, grounding one's interactions with the environment. When one falls ill, however, this body becomes something alien (Leder, 1990; Zaner, 1981), causing pain, limiting movement, or humiliating the ill person with an unpleasant look or odor. One's own flesh seems capable of thwarting and opposing one in a way health had not fully revealed.

This experience presents a severe challenge to one's usual sense of selfhood and autonomy. The ill person may neither understand nor control what is happening within the body, though one's life may depend upon the outcome. One's knowledge of the body becomes mediated through others: the physician who diagnostically probes it, or the surgeon who opens it up, scrutinizing organs the patient has never seen.

ILLNESS AND THE EXPERIENCE OF SPACE AND TIME. These modes of embodied dis-integration typical of illness also suffuse experiences of space and time. When a person is healthy, space unfolds as a field of possible movement, of activity, of desires to be fulfilled (Straus, 1963), whether it be a flight of steps one knows one can climb or an open street one can cross. With many forms of illness this spatial field is disrupted. One may remain confined in a bed or unable to climb a flight of stairs due to arthritis or a neuromuscular disease.

As space is thus altered by illness, so too is time. Ordinarily, human beings dwell largely in the future (Heidegger), with present activities geared toward the future accomplishment of desired goals—on the way to the paint store, one is envisioning the fully painted room. But when one is sick the way toward the future is blocked, and a claustrophobic world of concern closes in on the sufferer. Even a world traveler or delightful raconteur can transform into an intolerable bore who obsesses about illness minutiae.

There are avenues of escape for the ill person. One can "lose oneself" in a good book or television. One can dwell in nostalgia for a pain-free past or dream of a future restored to health. But these wanderings never fully lose their character as modes of escape from the confinements of illness.

ILLNESS AND THE EXPERIENCE OF OTHERS. This dis-integration of our spatiotemporal world is often matched by a felt disunity with others. When healthy, one is a part of the mainstream, involved with work, family, and socializing. Yet as simple a sensation as pain can suddenly open a profound distance (Scarry). Though just inches away and sympathetic, another person cannot experience one's pain. It may not even be possible to communicate one's pain, for this most private of experiences is notoriously resistant to expression.

Illness can cut one off from others not only through pain, but through disabling effects. One lingers in bed while everyone else heads off to the duties of a busy life. The energy to work and socialize may be lost. "I don't want you to see me like this" is a frequent refrain of the person reduced by illness to sallow skin or loose bowels, and the healthy may often wish to avoid the world of the sick, which only serves as a reminder of one's own vulnerability.

Loneliness can thus contribute greatly to the suffering of the ill. There is a sense of exile—from one's body, from one's activities and goals, and from one's fellows. In the face of this exile, social connection often takes on heightened importance for the sick person. The compassion (etymologically, "to suffer with") that grounds another's willingness to listen to, touch, and care for the sick person can do much to alleviate suffering (Kane).

ILLNESS AND THE EXPERIENCE OF THE COSMOS. The term *cosmos* refers to the world discerned as an ordered and harmonious whole. This is precisely what illness can bring into question. Imagine discovering in the midst of an ordinary day a growth that is subsequently diagnosed as malignant. Questions scream forth: "Why has this happened?" "Why now?" "Why to me?" The possibility arises that these questions have no good answers. Ordinary structures of meaning are shattered.

This felt meaninglessness can prove all but intolerable. Any meaning may be preferable, even a negative one such as: "I have been bad and this illness is my punishment" (Kopelman). The ill often search for their offending infractions, be it smoking, eating fatty foods, having a "cancer-prone personality," or transgressions against God. This association of sickness and sin preserves the coherence of a just universe, as well as the sense of one's own power within it. However, this reading of illness brings its own sense of painful exile. Sickness remains a scarlet letter, branding the ill person's moral failings. The healthy, eager to strengthen their own illusions of security and superiority, may be willing to collude with this judgment.

Illness, then, is not simply a biological event; it is also an existential transformation. One may be stripped of one's trust in the body, reliance on the future, taken-for-granted abilities, professional and social roles, and even one's place in the cosmos.

Of course, this need not always be the case. The experience of illness varies widely, and much depends on the nature of the attacking disease, the vagaries of individual psychology, and the social milieu. Some of this diversity is captured in the growing literature on medical phenomenology and so-called pathographies—accounts of illness written by or about the sufferers (Brody; Hawkins). One can ultimately imagine textbooks of illness, as there are now for diseases, that would describe experiences typically or possibly associated with severe psoriasis, heart attacks, neurological diseases (Sacks), and other conditions.

ACUTE ILLNESSES AND INFLICTED TRAUMAS. With acute but transitory illnesses, such as the flu, discomfort and disability can shrink one's world and distance it from that shared by others, but the horizon of health remains visible. One is buoyed by the assurance that this illness is temporary, that after this brief visit to a foreign land one will surely return home. The sense of suffering and cosmic dislocation are thus held in check.

Then there are illnesses and traumas of acute onset but more catastrophic consequences. One may have a car accident, for example, or suffer a serious heart attack that threatens one's life even after recovery. The sudden anomalous nature of such events leaves its own psychic scars. The world and one's body seem less safe, more a house of horrors in which dangers can leap forth from anywhere. This sense may be especially acute when trauma is inflicted by another, as through a gunshot wound or sexual assault (Brison). The embodied self is revealed as profoundly vulnerable to disruption, penetration, or violation by others.

In the face of acute catastrophe, William F. May suggests that a person may experience something of an existential obliteration. He describes a patient suffering from severe burns covering two-thirds of his body, who calls out: "Don't you see, I am a dead man" (May, p. 16). However, this "death" can be followed by rebirth. This is not simply a reclamation of one's previous self, but the forging of a new self, with its own strengths and virtues (Brison).

This can be especially difficult, however for those victimized by others, as in cases of child molestation or spousal battering. Here, the confinements imposed by illness take on new dimensions. The victim is entrapped not only within physical suffering but by a double imprisonment, both external and internal. There are external barriers to breaking free of the violence—in the case of molestation, the power adults exert over children; in the case of a battered wife contemplating escape, the difficulty in attaining employment, financial independence, shelter, and child care. There are internal barriers as well. The victim often feels guilty, tainted, or shamed by his or her participation, and may thus become secretive and complicitous. Feelings of powerlessness and low self-esteem set in: "This will never change. There's nothing I can do. I'm not worth it anyway." Finally, as awful as this abusive world is, it is familiar, and one may cling to it for security amid the fear. Many break free, but social and psychological forces can also pull victims back, making escape an arduous struggle.

CHRONIC ILLNESS AND DISBILITY. Many illnesses are neither transitory nor based on acute events: Instead, they are chronic, lifelong, and involve relatively stable or progressive patterns of disability (Toombs et al., 1995). Forms of arthritis, bronchitis-emphysema, kidney disease, diabetes, Alzheimer's disease, colitis, and autoimmune diseases, for example, fall into this category. While onset may come early in life, the elderly often suffer from such degenerative conditions. Due to the aging of the overall population, along with advances in the prevention and cure of acute disease, chronic illness is increasingly the staple of medical practices and hospital care.

Chronic illness can bring with it all of the dis-integrations described above. Unlike acute and treatable illness, there may be no horizon of health that allows one to look beyond present suffering. The day-in, day-out persistence of pain and disability, without hope of relief, can bring about a kind of existential fatigue that leads to despair. With severe arthritis, for example, even tying one's shoe can become difficult. But the chronic nature of such conditions can also give one time to work through its meanings, and to build strategies for physical and psychological coping. One needs to realistically accept limitations, while also claiming the possibilities that remain for fulfillment.

The burgeoning field of *disability studies* has supported sustained reflection on the phenomenology of specific conditions, such as paralysis (Robillard) or blindness (Hull), and the way these are socially constructed (Michalko). There is a danger to assimilating such conditions, sometimes present from birth, to an illness model that emphasizes suffering and limitation. The disabled individual has often developed alternative abilities that are powerfully life enhancing. It is therefore important to develop attitudes and social policies that respect the diversity of human embodiment.

Disability resulting from chronic progressive illnesses can pose a particular challenge to the individual. S. Kay Toombs, in her book *The Body in Multiple Sclerosis* (1992), discusses her condition in this light. The disease is typified by sudden exacerbations and remissions (e.g., of visual disturbance or bowel and bladder incontinence), but with a gradual buildup of neurological deficits over time. There is thus a continual need to redefine the self in the face of new incapacities. Adjusting to muscle weakness, one becomes accustomed to using a walker until, as the disease advances, one becomes wheelchair-bound. The dignity associated with the upright posture is thus lost, together with passage to regions formerly accessible. The ill person faces the Sisyphean task of repeated readjustment without promise of rest. Yet even under such trying conditions, individuals find modes of strength, support, courage, and consolation to meet the existential challenge.

Medical Treatment and Healing

Taken seriously, the experience of illness leads to the question of what impact the medical profession has upon the sufferer (Toombs, 1992b). When illness results from an easily curable disease, medical treatment surely plays a powerful role in restoring the individual to wholeness. Such a remedy is not always possible or immediate, however, nor are the experiential impacts of healthcare always benign.

While the concept of *iatrogenic disease* (disease caused by medical intervention) is well known, there is also the possibility of *iatrogenic illness.* Many of the experiential dis-integrations associated with illness can also be brought about or exacerbated by the process of medical treatment. When illness fragments the body into problematic parts and functions, and renders it alien to the self, the process is often intensified in the doctor's office. The physician has the patient disrobe, probes and palpates different organs, investigating the body as if it were a malfunctioning machine, and the patient learns to internalize an objectifying gaze on the body.

Similarly, treatment can exacerbate the disruption of space, time, and social relations. Hospitalization provides a vivid example. One's clothes, a mark of personal identity, are replaced by a hospital gown embarrassingly open at the back. One is dislocated from the routines of everyday life, leaving friends, family, home, and community for a world of strange rules and protocols, frightening technologies, and authorities who loom and disappear. Just when one's world most needs shoring up, it is further fragmented.

Medical language also effects subtle but pervasive displacements. Struggling to make existential sense of what is happening and why, the patient may find little help in diagnostic labels. In Tolstoy's story "The Death of Ivan Ilych," Ivan grapples with the profound issue of his life and death, but for the doctor, "the real question was to decide between a floating kidney, chronic catarrh, or appendicitis" (Tolstoy, p. 121). This exclusive focus on disease leaves the illness unaddressed. Loneliness is intensified when one most needs communion; the search for meaning is truncated by a heap of scientific words.

Some of these deficiencies so characteristic of contemporary medicine emerge from its basis in a mechanistic worldview. The seventeenth-century philosopher René Descartes, who helped lay the groundwork of modern science and medicine, took a dualist position. The human being, he argued, is a conjunction of two very different parts—the mind, imbued with rationality and free will, and the body, a mechanism governed by the same physical laws as the rest of nature. In this view, bodily disease can be understood according to the model of machine breakdown. Doctors become scientists or technicians who fix or replace broken parts. This Cartesian paradigm has generated the search for precision drugs and surgical procedures, the emphasis on scientific (rather than humanistic) training for the physician, and the hospital conceived as a temple to technology. Much of the efficacy of modern medicine rests on its dualist and mechanist foundations. But this focus on the body-as-machine has also led to a neglect of the ill person struggling with profound existential dislocations (Leder, 1992).

Nonetheless, many sensitive clinicians do seek to be healers of illness. To "heal" is to begin reweaving into wholeness the tapestry of life shredded by illness. Even when disease is not curable, the practitioner can try to relieve pain and preserve physical function, explain what is happening within the patient's body, and encourage the patient to be an active participant in treatment. Thus, the ill person regains a measure of knowledge and control.

Cut off from others by the privacy of pain and the loss of function, the sick person may reach out to the provider with the longing of a shipwrecked castaway who spies a sail on the horizon. When the patient is permitted to tell his or her story—to voice fears, ask questions, and hear genuine responses—a social reconnection is forged. The practitioner furthers this process by informing and mobilizing the patient's support system. The participation of family and friends is welcomed, and isolating modes of treatment such as hospitalization can, when possible, be avoided.

Just as the body seeks to heal itself, so individuals seek an interpretive healing by trying to make sense of what has occurred (Kleinman) and telling stories about it (Frank, 1995). Anne Hawkins has studied written accounts of illness and charted out the mythic motifs the sick often use. People suffering from disease may see themselves in an heroic struggle against a dangerous foe, or as journeying to the underworld to retrieve a great prize. These myths can sometimes turn disabling, however. For example, the battle metaphor provides little guidance or solace when the disease finally emerges as the victor. Susan Sontag, in *Illness as Metaphor* (1990) focuses on such dangers of understanding disease metaphorically, suggesting that the practitioner may need to challenge a patient's unhelpful fantasy. But these mythic interpretations can also play a healing role, helping the ill person to render events coherent, to rise to the occasion, and to work creatively with the challenges faced (Hawkins). The practitioner who resists the temptation to rely on reductionist "medicalese" or on metaphors foreign to the needs of the patient can support the patient's own healing narrative.

Ultimately, healing is not just a reconstruction of a prior life, but the building of something new. Through illness people often develop a deeper compassion for others, a greater intimacy with loved ones, an attentiveness to the joys of ordinary living, or a reordering of lifestyle and priorities. It is not unusual to hear a patient say "This cancer [or heart attack, etc.] is the best thing that could have happened to me." For such people, illness is not the diametrical opposite of health. Rather, it is the first stage on a healing journey, summoning the person to needed changes, whether physical, emotional, social, or spiritual.

The suggestion that illness can be a grace is not a license to grow callous to the suffering involved, however. Few seriously ill people wish to be told, "Cheer up, this disease is great for you." But the patient and practitioner alike can remain open to the healing gifts that illness may bring, albeit wrapped in a dark package.

Bioethical Implications

The illness experience has implications not only for clinical practice but for the field of bioethics. Bioethical reflections need not be *top-down* starting from overarching theories and principles that then are applied to cases. They can be *bottom-up* commencing with the concrete situation of the ill and drawing out the needs and moral claims that follow. Indeed, some suggest that bioethics is undergoing a paradigm shift, with a new openness toward methodologies that pay close attention to the experiences of illness and caregiving (DuBose et al.; Welie). Several consequences might ensue for the field.

First, taking lived experience more seriously may shed new light on the traditional issues of bioethics. For example, *truth-telling* and *informed consent* are often supported by reference to a Kantian framework of "respect for persons." Within this framework, emphasis is placed on preserving the individual's autonomy. However, when moving from this abstraction to the concrete situation of the ill, new features come into view. It is not simply the *autonomous individual* of ethical theory who arrives at the doctor's office in pain. By this time the person's sense of lived autonomy may already be compromised by uncertainty and confusion, emotional turmoil, a threatened future, and a body run amok. In this light, informed consent becomes not simply a way to preserve autonomy prior to treatment; it also becomes a part of the treatment itself, restoring autonomy through enhancing the patient's knowledge, control, and trust in others.

Of course, much depends on how the *truth* is conveyed. Medical jargon that sets forth *the facts of the case* can actually disempower the ill person. As with Ivan Ilych's doctor, the physician's terms may obliterate the patient's narrative. Moreover, the theater in which this conversation is enacted is the physician's domain. He or she is in a position of power, with privileged knowledge, authority, and professional status (Zaner, 1988). To really understand informed consent these inequalities of power that define the doctor-patient encounter must be understood. In such ways, paying close attention to the experience of health and illness could reshape the current approach to traditional issues of bioethics—including those of organ transplantation, abortion, the termination of life-support, and many others (Toombs, 2001).

At the same time, an experience-based bioethics might call attention to other issues that have hitherto been neglected. Bioethical discourse has typically focused on particular quandaries brought about by new technologies and conflicting moral intuitions. When should one "pull the plug"? Who has the right to refuse treatment? When can confidentiality be breached? While such issues are real, they often leave unquestioned the general context of medical practice, as if only special dilemmas call for bioethical thought. But the experience of illness and treatment is intrinsically a moral theater. The ill person is confronted with the dis-integration of his or her world and must grapple to restore "the good" or forge a new vision of it. The individuals and institutions involved in healthcare participate in this drama in myriad ways—the language used, the texture of personal relations, the fees exacted, and the structuring of space and time all have ethical significance.

One promising topic for an experience-based bioethics is thus the *moral ecology* of healthcare institutions. One example is George Agich's 1993 study of long-term care, which details how the lived experience of autonomy is enhanced or diminished by environmental patterns. Are schedules set for the convenience of a nursing home bureaucracy, or are the client's needs kept in mind? Are there spatial cues to orient the elderly resident, or does the layout of the home contribute to confusion, powerlessness, and isolation? Is infantilizing baby talk the everyday language, or is there an atmosphere that enhances dignity? Such issues are not as dramatic as those that make bioethics headlines, but they are at least as significant to the lives of many. One can imagine the day when institutional ethics committees attend to such issues of moral ecology, not simply the exceptional-quandary cases.

An experience-based bioethics would also look at the burden placed upon the individual practitioner by the special situation of the ill. This is not just a matter of "What action do I take?" (the focus of deontological and utilitarian ethics), but of "What kind of person should I, the caregiver, be?" (the focus of virtue ethics). The isolation and incapacity of the ill underscore the importance of needed virtues in the practitioner, such as compassion and trustworthiness (Pellegrino and Thomasma).

An experience-based bioethics also demonstrates that it is not simply the practitioner who is a moral actor, but also the ill person (Zaner, 1993). Though defined as *patient,* he or she is also an agent wrestling with a profound existential challenge (May) as described in illness narratives (Broyard; Price). In the face of the dis-integrations described above, the sick person cannot evade responsibility, literally the ability to respond to circumstances. Depending upon the qualities of this response, the individual can either forge a good life even in the face of suffering or yield in to bitterness and despair. Special virtues are called for in meeting the challenge of illness, including courage, patience, hope, humility, and proper assertiveness. Sickness is an arena that calls people to test and reforge who they really are and who they wish to be. For too long the ill person as agent has been absent from bioethical reflection, and from much of clinical practice. Close attention to the illness experience can help remedy this situation.

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SEE ALSO: *African Religions; AIDS; Alcoholism; Anthropology and Bioethics; Bioethics, African-American Perspectives; Care; Compassionate Love; Epidemics; Family and Family Medicine; Genetics and Racial Minorities; Grief and Bereavement; Healthcare Systems; Human Dignity; Informed Consent; Life, Quality of; Mental Illness; Narrative; Patients' Responsibilities;* and other *Health and Disease* subentries

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HEALTHCARE INSTITUTIONS

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Healthcare institutions are often overlooked in discussions of healthcare policy, biomedical ethics, and the allocation of resources. Institutions, however, are major players within the ethical and policy arena of healthcare and should be considered when one examines the forces at work in any specific issue in healthcare.

A healthcare institution usually has been thought of as a hospital, a nursing home, a rehabilitation facility, or another such single-site entity. Such an institution consists of the human beings who work in many different capacities within it, the leaders who direct and manage it, and its governing body—usually a board of directors or board of trustees that is responsible for hiring (and firing) the chief executive officer (CEO) or president of the institution and for setting policy and direction in partnership with the employed leaders. Many institutions now, however, are much larger than a single facility. For example, there are integrated hospital healthcare networks that include everything from physician group practices to long-term-care facilities. There are also networks that provide a single level of care, such as nursing home chains and hospital chains. As the competitive environment of healthcare continues to drive efforts to reduce costs and capture market share, institutions made up of multiple components will become increasingly more common. Nonetheless, whether institutions are single units or made up of multiple units, they have important characteristics in common that must be considered.

Institutional Missions

One of the most important functions of leadership and governance in an institution is to establish and articulate that institution's mission. This is usually written in a mission statement. An academic health center may have a mission that includes research, education, and patient care as equally strong components. A community hospital may point to excellent patient care and improvement of community health as its mission. A for-profit hospital or hospital chain may articulate excellent patient care and optimal return to shareholders as its mission. As one can imagine, this latter bipartite mission can lead to troubling conflicts of interest, which have been examined by ethicists in some detail (Gray).

The mission of an institution may also be articulated in the framework of its membership in a larger institution such as a church or religious network. Thus, some Catholic hospitals provide care to a large number of American patients (who are not necessarily Catholic), and their mission specifically derives from values espoused by the Catholic Church. Similarly, many other hospitals have emerged from religious systems because of the latter's commitment to helping the vulnerable and caring for the sick and suffering. Institutional missions may sometimes conflict with bedside ethical decisions, such as the decision to forgo life-sustaining therapy or to have an elective abortion. In these settings it is important for patients and providers alike to be clear about the underlying moral environment of the institution and the degree to which it may or may not be flexible on certain issues. Patients who feel strongly that they do not want care with those articulated standards should then have access to other institutions. Besides the question of abortion, the issue of forgoing life-sustaining treatment has been one of the most prominent in this kind of conflict. For example, the member of the patient's family who makes a decision about discontinuing nutrition and hydration in a comatose or unresponsive patient with far advanced dementing illness may find that the institution housing that patient does not allow nutrition and hydration to be withdrawn. If the underlying reason is fear of malpractice or liability concerns, it is sometimes possible for the institution to figure out a way to work together with and respect the wishes of the patient and family. If, however, the underlying reason is a moral or religious belief consistent with the underlying values of the governance of this institution, then it is less likely that a compromise can occur (Miles, Sinder, and Siegler).

Value Systems

To generalize about these many and varied institutions—both secular and religious, for-profit and not-for-profit—is not a simple matter, but it is useful to explore certain issues relating to the value systems that undergird their several missions and roles in society. Many of the older institutions were launched on the bedrock principle of simply caring for the sick and suffering, and many in the public still, quite unrealistically, think of all healthcare institutions in this way. Because the United States as a nation has not yet realized the right of equal access to healthcare for all its citizens and embraced the concept of healthcare as a social good, there is no consistent underlying covenant between the society and these institutions. A social covenant would lead to some kind of centralized planning for healthcare needs, and institutional missions would flow from this. Instead, the United States relies on marketplace values combined with a variable and often unreliable "safety net" of public institutions. It has proven to be very difficult for any of these institutions to live up to their traditional charitable-based institutional values and at the same time survive the economic and social realities of U.S. culture. The one shared ethical principle that all would espouse is the commitment to competence and excellence, values that have permeated Western medicine through its physicians since the time of the Greek physician Hippocrates (c. 460–c. 377 B.C.E.). This principle is not purely altruistic, however, because a minimum of quality is required for accreditation, and because evidence of excellent quality gives some institutions a market edge in attracting paying patients.

The public institutions created by a county, city, or state for the purpose of delivering health services to a specific population have an unambiguous mission and foundational institutional ethic: to carry out the function for which they were created and for which they continue to receive operating funds from the public sector. The objective of these institutions is to provide care in an appropriate and highly competent fashion to the specified population, usually those who are poor and without access to other sources of care. Whereas, on paper, the goals and objectives of these institutions never change, the public's commitment wavers from year to year, with the obvious result that there is considerable variation in the level of financial support the public is willing to provide; serious underfunding for many public hospitals thus significantly compromises the quality of care in many places. So there remains the paradox, despite an unambiguously consistent mission statement: Compromised public commitment to provide services for the poor has translated to a serious loss of quality in some of these institutions. The profit motive seldom creates an untoward tension among workers at these institutions; the limits imposed by funding sources may, however, lead to the curtailing or closing of certain expensive services, perhaps to the detriment of the patients.

The private, not-for-profit institutions that were established for the purpose of serving the community may share a public-service vision with the public hospitals. Private, not-for-profit hospitals also, however, experience extreme pressures that run counter to their community-service mission. In the United States, since the early 1980s, these institutions have often thrived financially by maximizing income from insurance and philanthropy, both of which have supported the enormous growth of specialty medicine and heroic high-technology care. Governed by boards of directors made up of citizens of the community, these institutions can be expected to have an awareness of community needs. On the other hand, the charity care these hospitals may provide generally must be paid for in one of two ways: (1) by using available reserve funds, or (2) by shifting costs, overcharging those who can pay more, in order to make up for the losses in primary care, chronic care, and general care for the poor or uninsured.

The CEOs of the larger of these hospitals, especially those at the more prominent academic and tertiary-care institutions, are treated and paid as though they were corporate executives. This trend toward providing top-level management for these institutions came from the growing awareness beginning in the early 1970s that these institutions were administratively out of control or at the very least generally ill-prepared to fulfill their potential in a volatile marketplace. Few would argue that the majority of these institutions have become heavily bottom-line oriented. Balancing cross-subsidization among the various payers with issues of access for the poor is a fine art. Many of these hospitals, though losing money on every Medicaid and uninsured patient, manage to produce an overall surplus. They do this by increasing the volume of high-paying expensive procedures on insured patients. This goes far afield from a care mission of investing in prevention to foster healthier populations. Positive bottom lines are often then used to implement programs aimed at increasing "market share" for the hospital, rather than increasing services for the most needy.

Some not-for-profit institutions have extraordinarily idealistic community-service orientations, expressed through their written missions and goals. These orientations have sometimes become so consumed by the direction provided by bottom-line oriented, high-priced management teams that a variety of less-desirable and short-sighted practices have been implemented to produce a positive bottom line. These include the following:

(1) salary incentives to unit managers based primarily upon the financial performance of their cost centers;
(2) high-tech and manpower investment strategies determined primarily by their potential for high earnings;
(3) transfer policies that favor keeping patients whose care will add to the bottom line ("cream-skimming");
(4) policies to reduce existing teaching programs because of uncompensated expenses and negative impacts upon marketing strategies designed to reach more desirable clienteles; and
(5) different patterns of care based on whether or not patients possess ample insurance coverage or other financial resources.

Whether or not one finds these practices appropriate or inappropriate, whether they are more or less typical of not-for-profit as compared with for-profit institutions, the main lesson from these examples is that the pressures and forces inherent in the competitive market-oriented environment that has become dominant since the early 1980s have served to overtake the charitable values and philosophies that were central to the creation of many of these institutions. There is a tendency for healthcare institutions to believe that they are involved in a competitive fight for survival, and they all, in various ways, try to combine that pressure as best they can with the imperative to serve the sick.

Even institutions sponsored by religious organizations charge paying patients more than cost in order to cover the costs of nonpaying patients. Financial stability is the key to survival and thus to carrying out an altruistic mission. It is therefore more realistic to stop envisioning Saint Francis of Assisi when thinking about not-for-profit hospitals and begin thinking instead of "Saint Robin of Hood," robbing the rich to care for the poor.

Most observers see this behavior less as human frailty than as a system failure, the result of an environment that is filled with perverse incentives. In their detailed analysis of the ethics of for-profit as compared to not-for-profit healthcare institutions published in 1986, Dan W. Brock and Allen Buchanan concluded that there are no rationally compelling grounds upon which to find ethical fault with the profit motive in healthcare under the ground rules by which U.S. society now operates. Improvements can come only when the ground rules and societal expectations are altered; it is not enough simply to hope that institutions will take the lead in changing their behavior, in the face of existing incentives to the contrary.

Governance

The role of governance is very important in the character of institutions. In many healthcare institutions, including those in the not-for-profit sector, the board of trustees may be made up largely of prominent businesspeople with a great deal of experience in running large and successful businesses, as well as otherwise wealthy and influential members of the local social circle who may themselves be important philanthropic supporters of the hospital and able to draw others into making major donations. Thus, it is often a minority of individuals on the board who have direct experience with healthcare, such as physicians or nurses, or whose major concerns are with education or research. Therefore it is not surprising that as healthcare has become a trillion-dollar business in the United States, even not-for-profit hospitals and health systems have looked at the bottom line as a marker of how well they are doing. Even though there are no shareholders to pay, an excess of revenue over expenses allows a nonprofit institution to initiate new programs and, in many cases, to salt away substantial reserves that both provide interest income and allow for a cushion in case of adversity.

Because so much money is involved and because of the business orientation of much of hospital governance, it is not surprising that the investments in new programs or the capital investments that are made when excess funds are available are not always, or even primarily, directed toward care of the poor and underserved but are often directed toward ensuring a continuing stream of revenue for the hospital. This usually means investing in additional high-technology medical care that will be marketed to insured patients. For this reason it is not hard to see why the Internal Revenue Service in recent years has begun to ask whether the not-for-profit hospital sector really ought to remain tax exempt. In order to maintain their tax exemption, these institutions must demonstrate that they are community-service organizations and that the educational research missions remain important to them, if not central.

Pressures for Change

In their comprehensive 1986 treatise, Brock and Buchanan made an important distinction between for-profit chains, generally owned by investors and listed on a stock exchange, and individual for-profit institutions, usually owned by an individual or small group of individuals (frequently physicians from the community). These organizational differences create different incentives and different institutional behavioral responses. In this entry it is the latter subset of for-profit institutions that are of interest, but this in no way ameliorates the validity of these conclusions. The thrust toward identifying healthcare as a commodity distributed according to business rules has, since the early 1980s, been the overwhelming ethical reality for private and not-for-profit private institutions. All of these factors have fueled the debate about the appropriateness of maintaining the tax-free status of not-for-profit hospitals (Gray). If the societal pendulum swings back toward the treatment of healthcare as a right, alterations in institutional behavior may occur that, nevertheless, need not drive the individual for-profit institution out of business.

It is probable that the implementation of national and regional policy decisions about healthcare (such as the trend toward capitation, community rating of insurance, universal access to care, and regional databases capable of rendering comparative institutional quality-of-care estimates) will have more to do with affecting the behavior of these independent institutions than anything else. The most far-reaching impact may result from the pressure on these institutions to join effective consortia or networks of healthcare providers; they may well need to become part of an organized delivery system in order to survive. Thus, by around the year 2005, the number of independent institutions may be severely reduced. Certainly, one already sees a trend in the direction of independents moving into organized systems, not only in the hospital industry but also in the traditionally “Mom and Pop” nursing home arena.

A wide variety of individually governed institutions play a wide variety of roles in the inchoate patchwork quilt of healthcare delivery in the United States. As the forces for systemic reform build, it seems clear that they will have a predominant influence on alterations in the behavior of these various entities. Until such changes occur, one can conclude that this independent sector will in general deliver the best healthcare it can under the vagaries of access, quality, and cost that are in general dictated by the perverse organizational and fiscal incentives created by U.S. society. As a result of a wise reform movement, one can hope for an improved, more equitable, and more uniform performance from this sector of the healthcare distribution system.

Future Trends

In an article in the December 5, 2001, *New York Times,* Milton Freudenheim reported that most of America’s largest insurers of healthcare are moving toward insurance design that increases segmentation of the private insurance market, with the sickest having to bear more of the costs while the well will be able to get coverage more inexpensively. This gives further impetus to the movement of employers to defined contribution for health insurance and the growth of high-deductible plans, leaving workers to decide for themselves how much to add from their own sources to acquire coverage. While framed as "choice," this leads to higher costs for patients, especially for the chronically ill or genetically at risk.

All this leads Victor Fuchs (2002) to join others in predicting that there will be a reemergence of interest in social insurance and a national insurance program, essentially because of the inequity and unfairness of what the employment-based system will have become.

At this point, it is safe to assume that healthcare institutions in the United States are caught in a continuing confluence of marketplace forces churning against strong ethical and social currents. Until this ambiguous situation is resolved, it is hard to predict the future for these institutions, but it is clearly more and more difficult for institutions such as hospitals and healthcare systems to be moral leaders.

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SEE ALSO: *Healthcare Resources, Allocation Of; Healthcare Systems; Hospital, Modern History of the; Long-Term Care; Mergers and Acquisitions; Privacy in Healthcare*

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HEALTHCARE PROFESSIONALS, LEGAL REGULATION OF

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Licensure is "the process by which an agency of government grants permission to persons meeting predetermined qualifications to engage in a given occupation"; certification is "the process by which a nongovernmental agency or association grants recognition to an individual who has met certain predetermined qualifications specified by that agency or institution" (Welch, p. 179). The purpose of licensure, regulation, and discipline is to protect the public at large; the assumption that grounds these practices is that governmental and nongovernmental institutions are competent to judge how such protection should be accomplished.

Background

Public efforts to regulate the health professions, especially by imposing restrictions on those who shall be allowed to practice them, go back to the Babylonian emperor Hammurabi (d. 1750 B.C.E.). Rules for medical practice existed in ancient Greece and tenth-century Baghdad. By the Middle Ages in Europe, it was customary for civil powers to demand a university education, examination, and experience as conditions for permission to practice medicine. In this period the first professional societies were founded, modeled on the merchant guilds (Gross). University and guild combined to link education to licensing—government permission to practice.

The first licensing statutes were passed in the American colonies in the seventeenth century, although not until the eighteenth century did the statutes seek to restrict practice. According to Eliot Freidson (1970), medicine did not emerge as a consulting, as opposed to a teaching, practice until the late nineteenth and early twentieth centuries. Throughout the two millennia since the time of the Greek physician Hippocrates (c. 460–c. 377 B.C.E.), the medical elite created by education and licensed by the state was supplemented by a vast number of unlicensed healers, mostly women (generally barred from medicine), who treated the common folk.

The trend to state regulation, endorsement, and protection of the health professions suffered a brief hiatus in the nineteenth century in the United States, when there arose a deliberate experiment in egalitarian deregulation following from a democratic belief that the common folk were as good as the educated elite in most matters. The experiment was abandoned later in the century, as Texas passed a medical practice act in 1873 and California followed suit two years later; by 1905, thirty-nine states licensed physicians (CSG). Nurses formed a national professional association in 1896; by 1926 forty states required licenses of nurses.

The trend is not, however, universal. Professional recruitment, standard setting, and discipline can be carried out by professional groups and associations without the protection of the state. Typically, groups of serious practitioners band together, agree to set standards, and develop informal review procedures for adherence to standards—for members only. Professional ethics and oaths, including professional standards of education and compensation, can be enforced by the professional association alone, and in some cases (various psychological and holistic health professions, for example) the process goes no further. In several healing professions, there is no regulation beyond that of the voluntary association; the only penalty for professional wrongdoing, if it is discovered, is loss of membership in that association.

Regulation tends to be reserved for those health professions that are widely perceived to have powers the abuse of which can lead to public injury. At one time, only the profession of medicine was included in that category; now it has extended through dentistry, nursing, pharmacy, and others (close to fifty, on one count; CSG/CLEAR), on a state-by-state basis (naturopathy, for instance, is regulated in some states but not in others). Licensure varies in kind as well as in range: As of 1973, nine states still had *permissive* licensing for nurses—an unlicensed nurse could practice without hindrance as long as she did not claim to be licensed. *Scope-of-practice statutes* ordinarily accompany licensure, defining the procedures for which the practitioner is licensed.

The Limited Competence of the State

Well established as the custom is, there is a certain awkwardness of fit between professional standards and state enforcement. The request by the health professions for state protection of their monopoly is certainly plausible. While the state can play little part in instructing or defining the work of the professions, it certainly has always had as part of its police power the protection of the public from outright dangers to health, including health frauds—quacks, charlatans, and sincere professionals whose education was simply inadequate to their tasks (*Dent v. State of West Virginia,* 1889). But a profession is defined in large part by its esoteric knowledge: Only professionals can set professional standards, determine when they have been violated, and, by extension, determine the sanction that would be appropriate as a punishment.

The result is that the public ends up enforcing rules that only a private association can set, presumably for its own benefit as much as for the public good. Nor is it clear that licensing in general, especially in the context of rigid scope-of-practice statutes, is in the public interest. The costs of licensing will normally be passed along to the consumer in the form of higher costs, and the license requirement restricts entry into the profession to those who can afford the initial outlay. The scope-of-practice acts make sure that auxiliary professions, with less expensive preparation and lower fees, cannot perform certain procedures that they may in fact be perfectly competent to perform (CSG/CLEAR). Built into the arrangement, if it is to be tolerable, is a strong presumption of altruism on the part of the professional and trust on the part of the public. Let either fail, and the system is in danger.

Professional Exclusion: The Flexner Report

In 1906 Abraham Flexner, an educator, obtained a grant from the Carnegie Foundation for the Advancement of Teaching to review the quality of medical schools. When his report was published in 1910, it revealed wide discrepancies among the 155 schools studied and produced a strong impetus to regulate medical education at the state and federal levels. Having no independent standards of their own, nor any idea of how to develop them, the states appealed to the American Medical Association's (AMA) Council on Medical Education, which set new standards for accreditation of the medical schools. Physicians also staffed the state licensing boards. The consequence of this major public intervention in the healthcare professions was that by the mid-1920s the AMA had a virtual monopoly, guarding the gate to the medical profession at several levels: admission to medical school, choice of specialty, and obtaining a license to practice.

Such a state-sponsored monopoly is clearly subject to abuse, but it was widely imitated as succeeding levels of health professions sought and obtained state endorsement and protection. By tradition, the major regulatory role in the United States is played by the states, and the licensing laws are typically administered by state agencies and boards dominated by professionals.

Disciplinary Procedures

Disciplinary procedures responding to charges of fraud, incompetence, or malpractice occur at several levels. A certain amount of discipline is carried out by the professional association and is entirely a private matter among the professionals. At the state level, the procedure for disciplining delinquent practitioners varies, but generally it requires that some aggrieved party—a dissatisfied patient, a cost-conscious insurance company, or the plaintiff's lawyer in a malpractice case—register a complaint with the disciplinary board of the state. The agency in charge of these matters will investigate the case, assemble evidence, schedule a hearing, make a finding, and recommend appropriate action. Possible actions include dismissing the complaint, requiring some hours of community service, and removing a license. Increasingly, part of the decision is a refresher course in medical ethics.

The state medical boards are empowered to revoke a physician's license. Short of actual revocation of license, all actions taken against a professional are recorded and circulated through the National Practitioner Data Bank, where misconduct and malpractice findings are logged. The data bank is available to regulators in all fifty states. There are exceptions, but most health professions and practitioners are in the data bank.

Consumers' Protest

The federal government was active in the regulation of health matters for most of the twentieth century. The Pure Food and Drug Act, under which all drugs are approved for sale in the United States, was passed in 1906; since then the federal government has taken an active role in protecting occupational health and public accountability. Early in the 1970s, corresponding to the general wave of public skepticism regarding professional and corporate claims of authority and trustworthiness, a citizen/consumer rebellion turned on the health professions. Seminal works by Eliot Freidson and others spearheaded a literature of public protest against professional privilege and urged vigorous and vigilant oversight of the health professions, medicine in particular.

The protest tended to portray state legislatures as weak, ignorant, or pawns of the powerful professions and urged a drastic widening of the federal oversight function. Such expansion was made possible by the passage of Medicare legislation (1965), followed by Medicaid and other programs that cast the federal government in the role of major funder of healthcare. In a 1976 report titled *A Proposal for Credentialing Health Manpower,* the U.S. Public Health Service recommended that a national certification commission be established "to develop, evaluate and oversee national standards" for agencies that certify healthcare personnel. The National Commission for Health Certifying Agencies was formed on that recommendation, charged with developing universal standards for credentialing healthcare personnel. This effort was supported through the 1980s by the U.S. Department of Health and Human Services, through the Health Resources and Services Administration (CSG/CLEAR).

The origins of consumerism are generally attributed to Ralph Nader, whose investigations of the safety of the American automobile alerted a generation to the possibility that the goods and services available from the trusted providers of the American marketplace might not be as good as advertised. A Nader offshoot, Public Citizen's Health Research Group, maintains that the disciplinary and regulatory powers and laws currently available to the American public are completely inadequate to the task. These groups have changed the broad direction of legislative action. In the era of consumerism, the people's authority exercised at the state or federal level now protects the consuming public from the professional provider instead of aligning itself with the professional against fraudulent competition.

In a return to the democratic assumptions of the nineteenth century, the mantle of legal and moral credibility as protector of the public has passed from the profession to the elected legislature: In the areas of technical expertise and professional wisdom, as well as in the areas of economic self-interest, the American voters are now assumed to be the best guardians of their own interests. Patients' autonomy vis-à-vis their physicians has been generalized to public autonomy vis-à-vis the profession as a whole.

Typical of consumerist initiatives in healthcare is congressional action requiring nationwide licensing of nurses' aides. The bill was demanded by, among others, AARP, an interest group of older Americans with a strong stake in the conduct of nursing homes and chronic-care facilities. The passage of the legislation at the federal level (incorporated into the Omnibus Budget Reconciliation Act [OBRA] of 1987) made the law immune to the objections of state organizations of such facilities. Now the states must implement this law.

Also typical are the regulations proceeding from the work of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, established by Congress in the 1970s in response to claims that patients were being abused by their physicians in pursuit of scientific research (and that aborted fetuses were being used for research). The commission's work resulted in an immense number of federal regulations to protect the rights of human subjects of clinical research, including the formation of institutional review boards in any institution where such research is carried on, charged with reviewing all research that receives any federal money (in effect, all research in the institution).

A third example of such initiatives is the Patient Self-Determination Act, passed as part of the Omnibus Budget Reconciliation Act of 1990, which requires that healthcare providers inform adult inpatients of their rights to refuse treatment; to submit to the provider a document, generally known as a *living will,* specifying their desires regarding treatment or nontreatment should they become terminally ill and unable to give consent to treatment on their own; and to appoint any adult to speak for them to ensure that the living will's instructions are carried out, should they become unable to speak for themselves.

The contrast between profession-oriented and consumer-oriented approaches can be seen in the norms governing confidentiality of investigations of professionals charged with incompetence or negligence. If government is to protect the profession, then the identity of credentialed professionals who are under investigation for wrongdoing must be kept secret until it is determined that they are unsalvageable in the profession, so as to maintain their good name and practice. Consumer advocate groups, on the contrary, demand that the names of accused professionals be made public as soon as the investigation begins, so that the public can take steps to protect themselves.

Rejoinders to consumerism in healthcare have come from diverse sources. One very influential reply, from the perspective of the medical profession, is Charles L. Bosk's 1979 account of a surgical training program, *Forgive and Remember.* In the training of surgical residents, as chronicled by Bosk, supervision was strict, the patients' interests were paramount, and discipline was swift, although generally informal, and highly effective. Bosk found in place an unwritten but well-understood set of rules, rapidly internalized by all surgical residents as a condition of success as surgeons and regularly enforced at all levels. The suggestion that emerged, although not explicitly, was that bureaucratic regulations could not possibly be as effective as this method of professional socialization in producing successful surgeons—at least at the level of the elite practitioners. On the other side, libertarian theorists have attacked regulation of all kinds, formal or informal, arguing that any regulation puts an artificial and uneconomic barrier in the free market. The libertarians achieved major gains in the last decade of the twentieth century.

Alternatives to licensing can easily be imagined. In 1984 Stanley J. Gross outlined a system of state registration of unlicensed practitioners whose competence is determined by the consuming public on the basis of full disclosure of background and skills. Given full disclosure and the absence of coercion, on the principle of freedom of contract, any two persons of mature years should be free to make between themselves any contract for goods and services. The point is primarily theoretical but of very wide application: If accepted, this doctrine would abolish a few dozen federal agencies and all state licensing and disciplinary functions. Concretely, this doctrine has been invoked as primary in cases in which patients request drugs not approved for distribution or sale, such as laetrile and other unproven cancer remedies or experimental AIDS drugs, or marijuana for medicinal purposes.

The Unwanted Participant: Business and the Professions

In the last decade of the twentieth century and the first few years of the twenty-first, the whole philosophy of licensing and regulation of the healthcare professions has undergone a sea change. By 1990, there was a strongly felt undercurrent that healthcare was taking up too much of the national budget (13 percent, higher than any other developed nation) and that it was badly distributed. Often the poor in this rich country had only minimal access to healthcare: They could not afford private fees, they received no health benefits through their employment, and they fell somehow through the cracks of the government-sponsored programs, Medicare (federally funded, for the elderly and disabled) and Medicaid (state funded, for the poor.) In 1992 Bill Clinton was elected U.S. president, and aided by his wife, Hillary

Rodham Clinton, he set out to create a single-payer system, a national health insurance plan, to provide universal access to decent healthcare. Overwhelmed by special interests (especially the private insurance companies, who wanted to run the system themselves), the Clinton plan failed in 1994.

In the aftermath of this failure, major insurance companies took over payment arrangements for the practice of healthcare, under a confusingly diverse pattern of plans. Some insurance company plans simply employ physicians, or contract with physicians' group practices, to provide services for all their subscribers. In such plans, a patient has to consult either physicians employed by the company or those in the groups under contract to the insurance company whose policy the patient purchased (or more likely, whose policy the patient's employer purchased). Other plans offer a choice from a select list of physicians and specialties. Most require preapproval for at least some medications and treatments, and some require preapproval for visits to the emergency room. No two plans cover quite the same list of consultations, treatments, medications and devices, under quite the same terms. The insurance companies arrange the terms, as they have had every right and duty to do, to serve the financial interests of their shareholders. Such arrangements include deliberate policies of delaying reimbursement payments to physicians and medical groups, because all funds retained can be invested for interest; refusal of authorization for payment for medical procedures or hospital days for those cases in which it seems that the patient would have no choice but to avail himself or herself of the service and pay anyway, out of pocket; and *selective deselection* of physicians who cost the plan more than the average over the course of the year because of referrals to specialists or the ordering of tests.

Deselection means that the plan subscribers can no longer receive reimbursement for consulting that physician. In effect, a deselected physician can no longer have those subscribers as patients. If the physician's income heavily depends on that group of patients, she may effectively find herself unemployed; if she belongs to a medical group that depends on a contract with that company, she may find herself rapidly separated from that group in order to preserve the contract. In both cases, because most practices depend heavily on insurance contracts and no group can afford an "outlier" who will attract negative attention to the group, the physician may be separated from all chance of making a living in the practice of medicine. Under the circumstances, it is not surprising that physicians feel that they have little choice but to stay well within the unspoken insurance guidelines, even if that means effectively turning away or deceiving certain patients.

The insurance contracts place healthcare professionals in a clear conflict of interest, a conflict that can affect the lives and health of their patients. (A conflict of interest, for a professional, involves any arrangement in which the personal interest of the professional [physician] is adverse to the interest of the client [patient].) Because all parties to the contract are competent adults, there is nothing the law can do to prevent such contracts from being signed. (Incidentally, according to the code that governs the ethical practice of law, which has legal force, any lawyer who put himself in such a position vis-à-vis a client could be disbarred.) The accrediting body for most U.S. hospitals, the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO), has a special section on "Organizational Ethics" in the 2001 edition of its *Comprehensive Accreditation Manual for Hospitals.* The requirement of the main standard (RI.4) is simply the following: "The hospital operates according to a code of ethical behavior." Of particular interest in the context of bioethics is Standard RI.4.4: "The hospital's code of ethical business and professional behavior protects the integrity of clinical decision making, regardless of how the hospital compensates or shares financial risk with its leaders, managers, clinical staff, and licensed independent practitioners." Translated, this means that whatever impossible conflicts of interest physicians may have signed themselves into, it is the hospital's job to make sure that patient care is not affected. It is not clear how this standard might be met.

Bringing Miscreants to Justice

Notorious problems attend the disciplining of professionals for negligent, fraudulent, or otherwise unacceptable conduct. It is not the wealth or social status of the offenders that obstructs justice; there is no difficulty with trying these people for common crimes. But conflicting expectations arise around professional discipline—that the profession will discipline itself; that the hospitals will take responsibility for the competence of the professionals on their staffs; that state agencies will police the health marketplace and arrest wrongdoers; that the federal and state governments will use their power to withhold Medicare and Medicaid reimbursement to drive crooks and incompetents from the profession; that somehow insurance companies will act for and not against the interests of the patient; and that because the contract between professional and patient is a private one, private litigation is the best protector of rights.

The end product of these conflicting expectations is a nightmare of overlapping jurisdictions. There are, for example, clear cases of the *impaired physician,* usually a physician involved in substance abuse, where there is a clear trail of substance consumption (e.g., bills from the liquor store, prescriptions not justified by patient need) and substandard practice. These are handled at the state level, with reasonable penalties and conditions of rehabilitation. For the remainder of allegations of inadequate care, no one is clearly in a position to initiate action. But once a health professional has been accused of misconduct, every agency—federal, state, or professional—involved at all with the profession typically attempts to get into the case. Routine involvement in all cases is the only way the agencies can ensure public perception of their importance and continued public support. Private lawyers preparing malpractice or negligence suits often alert public agencies to the possibility of professional (usually medical) incompetence because public citation will strengthen their case. When all the agencies take off after a physician at once—threatening loss of hospital privileges and/or the right to prescribe drugs, fines for incorrect billing of Medicare or Medicaid and insurance companies, and devastating publicity for the whole affair—the result can be personally and professionally catastrophic, and quite unjust. On the other hand, complaints continue that physicians work essentially without supervision, that it is very difficult for patients to criticize or check their work, and that bad physicians are practicing, able to evade all scrutiny.

Not all problems are technical or supervision problems. There are conflicting principles at the root of some problems. One of the most common is the conflict between patient autonomy and the protection of patient welfare. If adults regularly choose treatments or interventions that serve very little medical purpose (e.g., liposuction, cosmetic surgery or implants, experimental drugs), who shall be held responsible for the undesirable outcomes? To what extent shall the medical profession be forbidden, by law, to provide such services?

Another typical conflict is that between the salvaging of a professional career and patient protection. A health professional's training is long, difficult, and expensive, and society cannot afford to lose the investment that it represents. There is good reason, then, to try to rehabilitate health professionals who have mismanaged their practices. The problem lies in deciding which lapses are remediable and which are not. There is always a danger that the professional who has offended once will do so again, no matter how tight the supervision. The problem is compounded by the need, given the nature of the professional–client relationship in healthcare, to keep the professional's problems absolutely confidential. Typically, if the physician or other practitioner is *impaired*—psychologically incapacitated, found not guilty of a crime by reason of insanity, alcoholic, drug abusing, or otherwise unable to practice until a course of therapy has been completed—the records will be kept confidential while the person undergoes therapy. Should the physician leave therapy or breach other agreements (by testing positive for controlled substances, for instance), the matter becomes one of *misconduct* rather than *impairment* and is no longer confidential.

Another typical case of conflict, becoming more common, is between the patient and the insurance company, with the health professional caught in the middle. If the physician says that a treatment, test, or referral is needed, and the insurance company disagrees, whose side is the physician on? Since Hippocrates, the physician has been expected to advocate for the patient; under the new market dispensation, such advocacy may threaten a professional career.

The Future

In the future, licensing, regulation, and disciplinary action will no doubt respond to greater consumer insistence on quality and cost control, thus limiting professional autonomy still further. Meanwhile, new communication modalities will make possible much greater communication with all healthcare professionals as well as with the public. Three major trends can be discerned.

First, higher and more public standards for certification can be expected. Nonprofessional members have already been added to licensing boards in most states (CSG/CLEAR). It is likely that legal statutes will be enacted requiring that health professionals be recertified at some point or at regular intervals in their careers. The public is acutely aware that the scientific foundations of healthcare are rapidly changing, and that professional education has a half-life of less than ten years—five, in the case of certain medical specialties. Mandatory continuing-education requirements are already part of the licensing laws for medicine and nursing; it is not a large step from there to provisions for occasional retesting. Some observers foresee that "good moral character" requirements—already part of the licensing statutes in most states but undefined—will be made more precise and will be more vigorously enforced (CSG/CLEAR).

Second, the effort to control costs will be continued, whatever the fate of current insurance arrangements. There is still a widely held perception that health costs are too high and out of control. Major initiatives to limit them have been less than fully effective and have roused ire among health professionals and the general public alike. Yet to this moment there are no laws specifically excluding commercial arrangements from the healthcare marketplace, even those that entail the exclusion of sick people from private health insurance. The Health Insurance Portability and Accountability Act of 1996 (HIPPAA) at least ensures that a person who becomes ill when insured, and then must change insurance plans, can enroll in the new one. In the past, the illness would constitute a *pre-existing condition,* a sufficient disqualification for enrollment in a new plan. But we have still no way to care for those suffering from serious chronic conditions prior to any insurance coverage.

Third, the entire process of licensing, regulating, and disciplining health professionals will become much more transparent. Both professionals and consumers have demanded this. As an encouraging start, many states have created web sites containing information on how to apply for licensure, listing job openings, and publishing all state laws regarding licensure.

The United States entered the twentieth century with the assumption that only one consent was needed for medical treatment: that of the physician or other health professional. In the last decades of that century it became clear that three consents are needed: the professional's, the patient's, and the payer's—the government agency or the private insurance company. That third consent may become much more problematic. Patients are also taxpayers and ratepayers. There is an increasing mandate to limit the amount of the national wealth that goes into healthcare, and there is no telling how far this new stringency will go in reshaping the health professions.

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REVISED BY AUTHOR

SEE ALSO: *Impaired Professionals; Just Wages and Salaries; Labor Unions in Healthcare; Malpractice, Medical; Mistakes, Medical; Nursing, Profession of; Research, Unethical; Nursing as a Profession; Nursing Ethics*

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HEALTHCARE RESOURCES, ALLOCATION OF

• • •

I. Macroallocation
II. Microallocation

I. MACROALLOCATION

The allocation of healthcare resources involves distributing health-related materials and services among various uses and people. The concept of allocation can imply that a designated individual or group is responsible for each level of decision making within a system that is designed to distribute fixed amounts of resources. Nevertheless, the degree to which such a system exists and such explicit allocation decisions occur varies widely. In the United States, for example, allocation of resources to and within healthcare has long been more the product of millions of individual clinical decisions and various market forces than the result of an overall social policy. Even in the United States, however, arenas exist where more explicit allocation occurs, such as the U.S. Veterans Health Administration with its Veterans Equitable Resource Allocation System (U.S. Veterans).

Healthcare allocations are commonly classified in terms of two levels of decision making: microallocation and macroallocation. Microallocation focuses on decisions regarding particular persons. It often involves "patient selection": determining which patients among those who need a particular scarce resource, such as a heart transplant, should receive treatment. Sometimes, however, microallocation entails deciding for an individual patient which of several potentially beneficial treatments to provide, particularly when only a limited time is available for treatment.

Macroallocation, on the other hand, entails decisions that determine the amount of resources available for particular kinds of healthcare services. Macroallocation decisions include how particular health-related institutions such as hospitals or government agencies such as the U.S. National Institutes of Health budget their spending (sometimes referred to as mesoallocation). Macroallocation also encompasses the decisions a nation makes concerning what resources to devote to particular institutions or, more broadly, to high-technology curative medicine as opposed to, for example, research or primary and preventive care. The extent to which health is fostered through medical care as opposed to nonmedical interventions such as environmental regulation is also a matter of macroallocation, as is the amount of money, time, and energy a society allocates to the pursuit of health rather than to education, defense, and other activities.

The term *rationing* is a much less clearly defined term that appears in discussions of macroallocation and microallocation alike. Because the debate over rationing raises issues at the foundation of healthcare allocation, it is the focus of the opening section below. The remainder of this entry discusses substantive standards for judging macroallocation, under three headings: the individual's right to healthcare, the community's responsibility for healthcare, and the importance of efficiency in healthcare.

Rationing

Rationing involves leaving some people, at least temporarily and against their wishes, without particular forms of healthcare that might benefit them. Some use the label "rationing" only if a person is barred from treatment by an explicit policy or decision. Those operating from this definition often oppose rationing because they believe there are sufficient resources, if managed and distributed correctly, to address at least the most important health needs of all. Others view the unavailability of care as rationing, whether or not explicit policies or decisions are involved. While part of this group also holds that there are sufficient resources to avoid rationing for the most part, the majority see implicit or explicit rationing as unavoidable and tend to favor developing explicit, ethical criteria (Ubel; Blank; Wikler).

A fundamental ambiguity, then, attends the word rationing. Moreover, the word's association with a short-term policy for handling a temporary crisis, such as a shortage of goods in wartime, makes it a misleading word to designate society's long-term task of healthcare provision. So the less ambiguous terminology of macroallocation and microallocation is probably more helpful in most discussions. Nevertheless, the debate over the term rationing has identified two important issues that should be examined before embarking on a more detailed consideration of macroallocation: (1) Does implicit allocation of desired and potentially beneficial healthcare actually occur? (2) Will some form of allocation be necessary in the future?

There is little dispute that implicit allocation of beneficial care does take place. For example, waiting lists for certain types of healthcare have been commonplace in Canada and Europe. There the structure of the system (referral and reimbursement policies, acquisition and location of technologies), rather than the explicit exclusion of people or services from coverage, has limited overall national spending on healthcare (Grogan). In less developed countries, some resources are typically located only in major urban centers and have been unavailable to most of the population (Attfield).

Even in the United States, where per capita spending on healthcare exceeds that of any other country, many have not been able to obtain certain forms of beneficial healthcare. In recent decades, tens of millions annually have gone without any health insurance, and at least as many more have been underinsured—predicaments that have resulted in reduced access to healthcare and in poorer health (U.S. Congress). Employer decisions to limit employee health-benefits packages, as well as governmental decisions to omit services from the Medicaid and Medicare programs, have excluded certain people from potentially beneficial healthcare. So have decisions by health facilities not to operate in the most accessible locations or at the most convenient times, and insurance company decisions to exclude from coverage people with preexisting conditions or other high-risk factors.

Greater controversy surrounds the second question, whether healthcare resources can be allocated so that no one has to go without potentially beneficial healthcare (Kilner, 1990). The possibility of avoiding rationing in this sense of the term hinges on achieving sufficient cost containment. Proposed strategies include reducing expenditures on items less vital to society (e.g., potato chips and advertising); eliminating medical procedures with little health benefit; placing greater emphasis on preventive care that preempts the need for more expensive acute care; reforming tort law to reduce the need to practice defensive medicine; simplifying administration; imposing global budgets on the entire healthcare system; and limiting the large gap between the incomes of physicians and other full-time workers. Various forms of “managed care” arrangements pursue several of these strategies simultaneously by restricting patients to approved providers (e.g., in preferred provider organizations or health maintenance organizations) who agree to limit their charges or forgo fee-for-service entirely in exchange for a salary or per-enrollee payment.

Some commentators contend that significant cost savings could be obtained through each of these strategies. Others disagree, arguing that the scope and cost of potential healthcare benefits are so vast that any savings will prove insufficient to fund needed benefits for everyone. Time will tell how effective various cost containment strategies can be in reducing the need for limiting the access to healthcare. After initial cost savings, however, managed care in the United States apparently has been unable to check the growth of healthcare costs (Ginzberg). Meanwhile, ethical questions have arisen concerning the extent to which physicians can truly pursue patient well-being if they must also serve as “gatekeepers” to conserve society’s resources (Willems; S. Daniels). At the same time, the experience of other countries such as the Netherlands, with healthcare systems more nationally coordinated than that of the United States, suggests the pragmatic limits of cost containment (The Netherlands, Government Committee on Choices). Such challenges underscore the importance of making allocation decisions explicit if allocation is not to be shaped by unknown factors and unethical considerations.

Major Macroallocation Standards

Numerous people have proposed ways to prioritize the potential uses of limited resources. These proposals tend to be rooted in one or more of three major ethical concerns: the individual’s claim to healthcare, the community’s responsibility for healthcare, and the importance of efficiency in healthcare. Within these three concerns, different understandings of justice are at work, and different weights are attached to competing ethical considerations such as liberty, care, and utility.

THE INDIVIDUAL’S CLAIM TO HEALTHCARE. Those who are primarily concerned about the healthcare that is due to each individual often invoke the notion of a right to healthcare. When the World Health Organization in its 1946 constitution affirmed the “enjoyment of the highest attainable standard of health” to be one of the fundamental rights of every human being, the statement both reflected and fostered a growing debate over health-related human rights.

The concept of a human right promotes the idea that each person is entitled to have something or to be free from something. It commonly reflects the basic conviction that each human being has special and great significance. While this conviction is not necessarily religious in nature, it receives special emphasis in theological traditions such as Christianity, Judaism, and Islam (Kilner, 1992; Zoloth; Rahman).

Negative and positive rights are frequently distinguished, as are moral and legal rights. Negative (or liberty) rights guarantee freedom from certain types of interference with the pursuit of one’s interests. Positive (or material) rights guarantee access to important services and goods. Accordingly, a right to protection from anything that is seriously harmful to one’s health is a negative right; a right to receive certain forms of healthcare is a positive right. Whereas moral rights involve claims about what one ought to have on ethical grounds, legal rights involve claims about what one is actually entitled to by law. Whether everyone has an ethically justifiable right to healthcare is debated in the United States, yet Medicare legislation confers a legal right to healthcare on the country's elderly people.

Differing views. In light of such distinctions and the conflicting conceptions of justice and freedom that underlie them, it is not surprising that people have fundamentally different views about the meaning and legitimacy of a "right to healthcare." Some hold that there is a right to health. The point of the right is to make sure that people actually have health itself, not just access to resources. Others insist on a right to healthcare. Because of the fundamental importance of health, people should have guaranteed access to resources that foster it. Still others reject both positions. While all of these claims represent worthwhile aspirations, they argue, such claims are not rights because no one has the obligation to satisfy them. Probing this last argument first provides useful entry into the debate.

The most prominent basis for rejecting a right to healthcare is a libertarian view of justice that emphasizes negative rights over positive rights (Engelhardt). According to this view, people ought to be free to pursue their own life plans, including their economic livelihood. Government should prevent others from interfering with that pursuit. A right to healthcare that forces healthcare professionals to provide care—or that forces certain people to give up part of what they have earned to pay for other people's care—directly contradicts what justice requires. That some people lack healthcare (or the ability to pay for it) is simply unfortunate rather than unfair. No rights are violated in a market-based system where people are free to buy and sell as their resources permit.

Critics of this position argue that it is self-defeating and mistaken. It is self-defeating because in its zeal to protect people's freedom to use their resources for healthcare and other desired goods, it effectively ensures that those with insufficient resources will not have the freedom to obtain healthcare (Brennan). It is mistaken in three assumptions. First, some note the implausibility of assuming that the present distribution of general resources is fair. In their view, the vastly unequal distribution of the means by which people pay for healthcare is attributable to forces that have affected the fairness of the market over time.

Others doubt a second assumption, namely, that a free-market approach is appropriate for healthcare. Consumers in this case are frequently sick patients with limited knowledge about healthcare. For a free market to function well, consumers would have to be able to understand the costs and benefits of all the available medical options and be willing and able to trade health or even life for money. A free-market approach, then, unfairly discriminates against those who are uneducated as well as those who are poor because of social circumstances or genetic endowments beyond their control.

A third debatable assumption, most frequently questioned by those who operate from a theological perspective, is the understanding of liberty as autonomy. The term *autonomy,* derived from the Greek words *auto* (self) and *nomos* (law), tends to emphasize people's separateness from others. According to a more relational understanding, freedom entails "freedom *for*"—the ability (and obligation) to help others—as much as it involves "freedom *from*" the interference of others.

Some of those who reject a libertarian approach instead affirm the right to health. They insist that health, like life itself, is something so fundamental to human existence that it must be fostered as much as possible. Precisely what the right to health entails, though, is not always clear. It may involve only the negative right that would protect one's freedom from actions that undermine health. This formulation of the right is compatible with the libertarian outlook already discussed. Alternatively, the right to health may entail that people have an entitlement to be healthy and that others have failed in their moral obligations toward individuals who are not healthy.

Those who find this outlook objectionable worry about the prospect of making one person's health another person's responsibility. Such a view tends to undermine people's responsibility for their own health. Opponents also note that it is not possible to maintain someone else's health indefinitely—given that everyone dies eventually—so it seems mistaken to suggest that anyone has an obligation to do so.

A right to healthcare. To avoid these problems some people advocate the right to healthcare. The right to healthcare is a positive right that holds that all people are entitled to receive some measure of healthcare. Whereas some others argue that people are entitled only to an amount of monetary resources that they can spend on whatever they deem important (Brody), supporters of the right to healthcare insist that people must be assured healthcare in particular. Rights, they maintain, do not involve the sort of discretionary items on which people place differing priorities. Rather, they concern goods that all people require in order to pursue their various life courses.

Sometimes the right to healthcare is formulated in comparative terms. According to this view, everyone should have access to whatever healthcare is necessary to provide for a level of access—or even of health itself—equal to that of others (Veatch). Many have resisted this egalitarian outlook because it tends to focus more on the value of equality than on the healthcare people receive. People with chronic illnesses or congenital disabilities may never achieve a level of health equal to that of others and so could claim an infinite amount of healthcare resources by invoking an egalitarian right to healthcare. Alternatively, this right could justify leaving all at a relatively low level of access or health, as long as everyone was treated alike. If, on the other hand, this egalitarian approach requires that everyone be able to receive every treatment that may provide any benefit, then it seems hopelessly unsuited to a world of limited resources.

To correct these deficiencies, various people have proposed identifying the right to healthcare with some sort of achievable standard of healthcare that could be guaranteed to all. They often suggest that because healthcare is provided in response to need, some standard of need should determine the level of healthcare to which all people have a right.

Others would similarly root the individual's claim to healthcare in a person's need for that care, but would appeal to various understandings of justice rather than to the notion of rights. For example, a contractarian approach, which appeals to what all people would agree to in hypothetically fair positions, usually advocates people's access to basic goods that anyone must have in order to carry out a personal life plan. Healthcare is one such good, and whatever amount is essential to enable people to function at a normal level is mandated by justice (N. Daniels; compare Toenjes, who sees the contract as one between physicians and society). Religious traditions that posit a divinely created world also tend to espouse a needs-based understanding of justice. They may, however, view *normal* more in terms of how people were created to be than how they typically are (Mackler).

A utilitarian conception of justice might also undergird a right to healthcare, but the support is tenuous. Because classical (or act) utilitarianism advocates acts that will produce the greatest good for the greatest number of people, it is often criticized for lacking any concept of justice to protect individuals from oppressive majorities. On the other hand, rule utilitarianism, which supports standards that produce the greatest good for the greatest number if followed consistently, might well support a standard of justice.

Standard of need. In light of the important place a standard of need commonly has in formulations of the right to healthcare and in conceptions of justice, it is essential to consider what this standard entails. Defining the standard and delineating its implications are not easy, because even marginal benefits can be considered *needs* (President's Commission). One definitional approach is to think of meeting needs in terms of restoring normal functioning. Another ties the meeting of needs to providing *significant* health benefit. Establishing significance might involve a careful assessment of the quality and length of life that various forms of healthcare would likely provide in various situations, together with some individual or societal evaluation of those benefits.

A broad range of considerations is relevant to the delineation of healthcare needs. In particular, needs less dramatic than the need for acute medical care must receive sufficient attention. Some non-healthcare goods can make an important claim on whatever portion of its resources a society devotes to the pursuit of health. Food, education, and shelter, for example, all contribute directly to health (Tuckson). So do programs that encourage healthy lifestyles. Habits of eating, drinking, sleeping, and drug use can all have a dramatic impact on health, although positive habits resulting in greater longevity may not reduce total healthcare expenditures over the course of an individual's lifetime (L. Russell).

Preventive medicine, supportive care, and medical research must similarly receive sufficient attention along with curative medicine. While preventive medicine is not necessarily less expensive or more effective than curative medicine, it can be both (Hope). Prenatal care for a mother as opposed to neonatal intensive care for her low-birthweight infant is a case in point. Analyses of need must give due attention to the importance of supportive care such as long-term care for elderly persons or effective pain relief for dying patients. Finally, fascination with current curative capabilities can all too easily siphon resources away from medical research. Without sufficient attention to research, there will be fewer new medical resources in the future, to the long-term detriment of society's health.

In the face of such a broad array of healthcare needs, many people believe that not everything that is needed can be provided for all. Accordingly, they conclude that justice or the right to healthcare must mandate only that each individual receive some reasonable level of healthcare—so-called essential care or a *decent minimum* (Eddy). Determining this exact level presents the same challenges as determining need, with the added task of tailoring the determination to the level of overall resources available at the time.

Moreover, people in different locations differ dramatically in their perceptions of need and essential care. Those in European countries, for example, avoid the notion of a decent minimum altogether. Nevertheless, each country's effort to provide comprehensive care is unique in terms of the particular forms of care that receive emphasis (Grogan).

Canada has typically acknowledged differences by allowing each of its provinces to determine which health-related services will be included in the package of guaranteed benefits.

The United States, lacking the nationally coordinated financing system of Canada, has traditionally left its states to develop their own priorities and healthcare systems (Moon and Holahan). For instance, Oregon has explicitly ranked all health-related services in terms of their funding priority. Hawaii has required all employers to provide health insurance to all employees working over twenty hours per week (Hawaii acted in 1974 before federal legislation barred this approach). Minnesota has linked improving healthcare access with an array of measures to control costs.

The differences among these and other state initiatives underscore what an international comparison also illustrates: that varying perceptions of need call forth different healthcare priorities and systems. Cross-cultural sensitivity will be essential if efforts to meet health-related needs are to cross national and international boundaries successfully (Attfield).

Employing need as a basis for allocation, then, presents various challenges. Challenges can be reasons for rejecting an idea. But challenges may be no more than obstacles to overcome so that a good idea may be implemented effectively.

THE COMMUNITY'S RESPONSIBILITY FOR HEALTHCARE. The substantial disagreement over the idea of the individual's claim to healthcare has made many people doubt its usefulness as a basis for allocating healthcare resources. Some have rejected the idea on more principled grounds as well. One prominent concern has been the impact that a preoccupation with the rights of the individual can have on the well-being of the community as a whole (Churchill). A case in point is the United States, a highly individualistic culture in which the use of the language of rights has been particularly prominent. The demand of U.S. taxpayers, patients, health professionals, and healthcare financers for the rights to pursue and satisfy their own various interests may have inhibited the development of an integrated, comprehensive healthcare system.

Those who would not jettison completely the notion of rights may argue—on theological or other grounds—that while people have rights, they have no "right to rights" (Kilner, 1992). According to this view, rights themselves (in the sense of freedoms and goods all people ought to have) are not the problem. The problem is people's preoccupation with their own (right to) rights—a preoccupation that undermines the commitment to pursuing the rights of all. In this sense, group rights are as problematic as individual rights, because attention to the claims of one's own group tends to encourage the same kind of self-focus and neglect of others as the pursuit of individual rights.

Therefore, some favor deemphasizing the notion of the individual's claim to healthcare—as well as rights language in general—or even replacing the notion with a more explicit conception of the community's responsibility for healthcare. Sensitivity to the needs of individuals and particular groups is not absent in this approach, but the driving concern is the community's obligation to ensure the well-being of the whole community.

In European societies such as Germany and the Netherlands, for example, discussions of healthcare have often invoked social solidarity as a fundamental goal to be pursued through resource allocation (Netherlands, Government Committee on Choices). In the United States, an increasing emphasis on community responsibility has been reflected in the ethics literature (Dyck; Tauber) and in the appearance of such interdisciplinary journals as *The Responsive Community.* Appeals to the common good have also become more frequent, especially in religious circles (Catholic Health Association). Increasingly, people are concluding that ethical macroallocation of healthcare resources in the United States will probably require a different way of thinking about the relationship between the individual and society.

Accordingly, the U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, in its 1983 report titled *Securing Access to Health Care,* explicitly rejected the rights-oriented language in the 1952 report of the U.S. President's Commission on the Health Needs of the Nation, titled *Building America's Health.* Instead the 1980s commission affirmed the community's ethical obligation to provide all with equitable access to an "adequate level" of healthcare. In *Securing Access,* the commission argued that a community must ensure that all of its members can obtain such care because healthcare is so important in relieving suffering, preventing premature death, restoring functioning, increasing opportunity, providing information, and strengthening relationships of caring. This approach affirms that ungenerous or uncaring healthcare allocations are clearly as wrong as those that are unjust.

Caring in this context entails looking beyond what theoretical formulations of justice require. It means giving special consideration to those who have been marginalized in the allocation of healthcare resources. Identified in certain religious and liberationist contexts as "the preferential option for the poor," this sensitivity toward disadvantaged persons is characteristic of much feminist analysis as well (Caes; Holmes and Purdy). It embraces the notion of the "common good," but not in the utilitarian or majority-rule sense of the term. It insists that there is no true common good if all do not have the good in common.

Emotional as well as rational, engaged as well as theoretical, a caring commitment to those who are least well-off may or may not justify a different healthcare allocation than that which a rights- or justice-based approach to healthcare allocation would advocate. Its proponents, however, maintain that such a commitment almost certainly will make a difference in the ways in which allocation is implemented. For example, it may be widely acknowledged that justice requires directing more healthcare resources toward African Americans and other disadvantaged groups in the United States (LaVeist). Reallocation, however, is not likely to take place as long as people do not see others' health as their responsibility in any way.

Basing allocation on the community's responsibility for healthcare, then, differs from basing it on the individual's claim to healthcare. But attributing responsibility to the community does not absolve the individual from responsibility. Because individuals are part of the community and share in its well-being, they must share the burden of paying for the cost of the community's healthcare in an equitable manner. Moreover, they have some responsibility for their own health. The implications of this responsibility are controversial. In particular, does an apparently irresponsible person forfeit the community's care?

Both justice and respect for people's liberty may entail that those who voluntarily cause their own health problems should take responsibility for them, particularly when there are insufficient resources to meet the healthcare needs of all. Holding people responsible in this way might have the added benefit of reducing illness and injury resulting from risky behaviors, thereby lowering related healthcare costs as well.

It is extremely difficult in most cases to prove, however, that people caused their illnesses and did so voluntarily. Often there are many causes of an illness, few of which are within a person's control. Even if a person's behavior, such as smoking or overeating, does cause an illness, the voluntary nature of the behavior is difficult to demonstrate conclusively. The person may have engaged in the behavior without understanding that it could cause the resulting illness. Regardless of foreknowledge, other factors—advertising, peer pressure, cultural values, dietary deficiencies, psychological instabilities, or genetic predispositions—may have significantly impaired the ill person's ability to act freely.

Even if a society becomes sufficiently adept at identifying those who have voluntarily caused their own health problems, three further ethical considerations are relevant. First, fairness may require that an allocation policy based on personal responsibility not apply only to those engaging in the least socially desirable behaviors. In other words, the policy should apply not only to smokers and intravenous-drug abusers but also to those who overwork or overeat, if responsibility can be established in all four types of cases.

Second, the idea that a society would have a responsibility to truly care for its members may call for the provision of more healthcare than strict justice alone requires, even for those who voluntarily engage in risky behavior. The healthcare professions have a long-standing tradition of offering care without making such offers contingent on the extent to which ill people caused their own need. Finally, if caring with fairness requires some form of accountability for risky behaviors, requiring payment of a tax to engage in those behaviors, say on cigarettes and alcohol, would be more humane than denying needed healthcare.

THE IMPORTANCE OF EFFICIENCY IN HEALTHCARE. Efficiency is also a central and disputed issue in ethical resource allocation. How best to eliminate health-related expenditures that are not truly beneficial in order to maximize funding for beneficial healthcare is only part of the efficiency problem. Even greater controversy surrounds proposed mechanisms for determining which forms of beneficial care are most worth their cost.

Two mechanisms for comparing costs and benefits have received particular attention as promising ways to pursue efficiency in healthcare: cost–benefit analysis and cost-effectiveness analysis. While both mechanisms typically involve assessing the costs of various forms of healthcare in monetary units, cost–benefit analysis also uses monetary units exclusively to assess the benefits of care, whereas cost-effectiveness analysis does not.

Cost-benefit analysis. Cost-benefit analysis is well-suited in principle to a broad range of resource allocation decisions both within and outside of healthcare. It employs identical units, such as dollars, to measure all costs and benefits. Accordingly, it can subtract total costs from total benefits to determine if an expenditure is wasteful (i.e., its costs outweigh its benefits). When applied to different health-related and other uses for the same funds, cost-benefit analysis can also determine which use will provide the greatest net benefit. This approach has proven particularly attractive to economists and policy analysts who must prioritize diverse uses of limited funds (Emery and Schneiderman; Oliver, Healey, and Donaldson).

Because cost-benefit analysis is the more familiar efficiency mechanism of the two, and because it alone has the potential to compare all possible uses of available funds, it appears at first glance to be the superior mechanism for allocating healthcare resources. But cost-benefit analysis has a number of pragmatic and substantive weaknesses in its most common forms (B. Russell). Some of these difficulties are inherent in the overall way the mechanism operates. Identifying the numerous ways that people are affected by particular allocation decisions is difficult enough, but reducing the entire range of healthcare outcomes (including continued life itself) to monetary value is virtually impossible. More substantively, while cost-benefit analysis helps to identify the allocation of resources that yields the greatest balance of benefit over cost for a society as a whole, it may fail to consider how fairly the benefits and burdens of that allocation are distributed throughout society. Programs targeting affluent suburbs, for example, can tend to have better cost-benefit ratios than programs in poor inner-city areas because of the bad health fostered by poor social and economic conditions. Ethics, though, must attend to more than economics.

Other difficulties concern the methods cost-benefit analysis uses to convert lives saved and other benefits of healthcare into monetary units. One approach is the *past decisions* approach, which compares how much money a society spent on selected programs to save lives in the past with how many lives were saved as a result of those programs. The unique funding and implementation context of each such program, however, renders generalizations risky.

Two more popular conversion methods involve future earnings (human capital) and willingness to pay. The future-earnings approach determines the monetary value of a health benefit by calculating how much more money patients will earn in the future if they receive treatment than if they do not. Fairness again is a major problem, for this approach implies that the life of a person making twice the income of another person is twice as valuable (i.e., important to save) as that of the other person. Because women and minorities tend to receive less pay than white males for comparable work, this approach devalues the lives of women and minorities. In fact, whatever employment-related discrimination already exists in a society becomes compounded when healthcare allocation reflects salary level.

A willingness-to-pay approach, on the other hand, calculates the value of a health benefit on the basis of the amount of money people would pay to receive a specified increase in the likelihood of receiving that benefit over a particular length of time. This approach, like the previous one, tends to compound certain forms of discrimination. Because wealthy people are generally able to pay more for a program to reduce the risk of illness and death than are poor people, a willingness-to-pay approach systematically reproduces existing injustices in the distribution of wealth.

All forms of cost-benefit analysis, then, are vulnerable to the charges that they are inadequate measures of the value of lives and that they neglect some important ethical considerations in resource allocation. Accordingly, a better mechanism for maximizing the benefit of limited healthcare resources has been sought.

Cost-effectiveness analysis. Cost-effectiveness analysis has generally been the favored alternative because it avoids a major difficulty that troubles cost-benefit analysis: the need to convert health outcomes, including continued life itself, to a monetary equivalent. Cost-effectiveness analysis typically calculates the cost of alternative health initiatives in monetary terms. But it can adopt a nonmonetary unit for comparing the health benefits of these initiatives, such as degree of mobility restored or years of life saved. If, for example, two treatments for hip problems claim to improve mobility, cost-effectiveness analysis can determine which one restores more mobility for the same cost or identical mobility for less cost. It can also determine which use of earmarked funds will produce the greatest health benefits. While this approach cannot determine if costs outweigh benefits or compare all benefits inside and outside of the healthcare field, it can identify the cost per standardized unit of benefit for alternative health-related interventions.

Broad societal healthcare allocations, however, necessitate a more generic measure of health benefit than mobility. Because increased quality and length of life are the two primary goals of healthcare, the standard of *quality-adjusted life years* (QALYs) seems to many to provide a suitable measure (McCulloch; Nord). To determine the number of QALYs that a health-related intervention will produce, the number of years people will likely live after the intervention is multiplied by a percentage reflecting the quality of life to be experienced during those years—0 percent (0.00) signifying death, and 100 percent (1.00) signifying perfect health with no disability.

While QALY-based cost-effectiveness analysis represents an improvement over cost-benefit analysis for the purpose of comparing health-related allocations, it, too, has proven controversial (Harris; Menzel; Stolk, Brouwer, and Busschbach). For example, certain analysts, while affirming the approach in principle, note that studies to date have not yet gathered all of the necessary data on healthcare outcomes, costs, and quality-of-life preferences. More data is needed before cost-effectiveness can be consistently employed as a basis for making comprehensive healthcare allocations.

The state of Oregon, for instance, originally intended to use a form of cost-effectiveness analysis during the early 1990s when it redesigned its approach to allocating public healthcare funds. Through a telephone survey, the state asked people to rank various functional limitations and other symptoms on a quality-of-life scale. The goal was to ascertain a quality-of-life score and cost figure for every health-related intervention so that these interventions could be prioritized for budgetary purposes. Reliable cost data proved so difficult to acquire, though, that the quality-of-life information was employed essentially only to identify which interventions produced the most benefit, irrespective of costs (Garland). Moreover, some rankings had to be altered in the end. The state discovered that interventions producing relatively little health benefit—if inexpensive enough—could rank higher than much more beneficial (even lifesaving) interventions.

Another methodological debate over cost-effectiveness analysis concerns who should assess quality of life (Fleck). The QALY approach determines the quality-of-life percentages for particular outcomes by interviewing large numbers of healthy people concerning the value they place on various qualities of life. Some insist that healthy people are the right ones to make these judgments because resource allocation is like purchasing health insurance. People will appropriately weigh alternative benefit packages before they contract a particular disease, but after contracting it they place disproportionate weight on covering that disease. Others cite studies documenting that healthy people frequently underestimate the quality of life of people who are ill or disabled. One inference drawn is that only those who have experienced such conditions can adequately assess the degree to which they render living more difficult (Lawton, Moss, and Glicksman; Kaplan).

The most heated disputes over the QALY approach, however, involve problems of fairness similar to those attributed to cost-benefit analysis. Although QALY-based cost-effectiveness analysis does not intentionally discriminate against certain groups, it tends to disadvantage patients who are older or disabled—in fact, anyone whose future length or quality of life is comparatively limited. Because QALY calculations are based on precisely these two variables, the treatments most beneficial to such persons tend to receive lower QALY scores and so receive low funding priority. For many who believe in the sanctity of human life, this discrimination is typical of the devaluing of certain types of people that generally results when anticipated quality of life is employed as a basis for ranking patients rather than as a desirable outcome to be sought for each individual patient.

As it turned out, the U.S. government refused the state of Oregon's initial application, which sought legal permission to allocate the state's limited Medicaid funds by ranking health-related interventions based on public quality-of-life judgments. The government's controversial rationale was that the approach discriminated against persons with disabilities. Oregon successfully revised its proposal by eliminating reliance on quality-of-life data. While cost-effectiveness analysis, then, attends well to efficiency, like other efficiency mechanisms it can easily be insensitive to other ethical concerns such as degree of need and fairness (Menzel et al.; Rosenthal and Newhouse).

Conclusion

The individual's claims, the community's responsibilities, and efficiency's importance all represent widely held ethical sensitivities to which resource allocation must attend. The ongoing challenge is to determine how to affirm the best elements of each, where they are not mutually contradictory, in a way that also minimizes their ethically objectionable features.

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SEE ALSO: *Aging and the Aged; Autonomy; Beneficence; Contractarianism and Bioethics; Economic Concepts in Healthcare; Ethics; Human Rights; Justice; Long-Term Care; Managed Care; Medicaid; Medicare; Natural Law; Profession and Professional Ethics; Utilitarianism and Bioethics;* and other *Healthcare Resources, Allocation of* subentries

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II. MICROALLOCATION

When the need or demand for healthcare resources exceeds the available supply, resources must be distributed on some basis. The more explicit the criteria, the more likely it will be that the term *rationing* will be applied, although the meaning of the term varies considerably in the bioethical, healthcare, economic, and public-policy literature. Rationing often refers to general limitations placed on the availability of certain types of healthcare, but it may also encompass specific treatment decisions for particular patients. Distribution of healthcare at a broad institutional or societal level is referred to as *macroallocation.* Macroallocation includes the way a hospital budgets its spending, as well as the amount of resources a nation devotes to primary and preventive care compared with high-technology curative medicine and nonmedical activities such as education and defense.

Microallocation, on the other hand, focuses on treatment decisions regarding particular persons. It may entail deciding which of several potentially beneficial treatments to provide an individual patient, particularly when only a limited time is available for treatment. Caregivers most commonly employ various medical criteria in order to make such decisions. These decisions, however, take place in institutional and societal contexts of limited resources. Accordingly, the relative merits of devoting particular resources to one patient rather than to others may exert at least an unconscious influence on treatment decisions, and nonmedical considerations may become involved. Patients’ values and beliefs often play a role here as well.

Other microallocation decisions, sometimes referred to as *patient selection decisions,* more explicitly involve choices among patients. In the less developed countries of the world, large numbers of people continue to die for lack of vaccines to prevent disease, antibiotics to cure infections, oral rehydration therapy to replenish fluids lost through severe diarrhea, and healthcare personnel to administer such interventions (UNICEF, 1993, 2003). Microallocation decisions constantly determine who will receive the limited care that is available. Some countries not only continue to wrestle with these low-technology scarcities but also face the high-technology microallocation dilemmas commonly encountered in the more developed countries, where expensive medical technologies have proliferated.

Organ transplantation and hospital intensive care are two primary examples of such technologies. The expense of heart, liver, and other types of organ transplantation keep some patients from even considering such operations. Of those seeking transplantation, more than 6,000 patients in the United States alone die each year while waiting for a suitable organ to be donated (Organ Procurement and Transplant Network [OPTN]). Microallocation of hospital intensive care, meanwhile, must occur whenever more patients could benefit medically from access to it than the available space can accommodate—a persistent occurrence even in the more developed countries (Truog; Lantos, Mokalla, and Meadow).

Scarcities of vital healthcare resources are not likely to disappear in the future. The degree of scarcity in the less developed countries will likely decrease through worldwide cooperative efforts. Nevertheless, social, political, and economic constraints will continue to hamper such efforts. Even in the more developed countries, the need for microallocation will persist (and probably grow) for at least three reasons. First, many emerging technologies such as artificial organs and imaging techniques are so expensive that the cost of making them available to all who could benefit from them is prohibitive. Second, the scarcity of some treatments (e.g., organ transplantation) is not simply a matter of funding but reflects the limited supply of the critical resource itself (e.g., the donated organ). Third, technological development will continue to yield new resources that only a limited number of patients can obtain until the capacity to produce those resources expands sufficiently. The history of healthcare is filled with examples of such scarcity, including the early years of the polio vaccine, the antibiotic streptomycin, the hormone insulin to treat diabetes, the iron lung to enable patients with polio to breathe, and the dialysis machine to filter people’s blood when their kidneys fail (Mehlman).

Those responsible for microallocation decisions have adopted a wide range of criteria for determining which patients receive available resources. Sometimes a *triage* model has been used, drawing on the experience of prioritizing the treatment of casualties on the battlefield or patients in the emergency room (Rhodes, Miller, and Schwartz; Bell). At other times these criteria have only been implicit, as was common during the early years of kidney dialysis in the

United States, prior to universal funding by the federal government in 1972. Many dialysis centers employed an ad hoc approach, in which particular patients were selected from eligible pools without any set of guidelines developed in advance. The resulting decisions were widely criticized as arbitrary. Of greater concern is the tendency of ad hoc decision making to reflect the biases and preferences of the decision makers (Fox and Swazey).

Ad hoc decision making continues to take place when individual caregivers, ethics committees, or healthcare institutions make microallocation decisions without first developing an explicit set of allocation criteria to guide them. Nevertheless, significant attention in practice and theory has been devoted to formulating a more ethically acceptable decision-making approach. Overall approaches are discussed in the closing section of this entry.

Allocation Criteria

Before examining such approaches, this entry addresses the justifications and weaknesses of the major allocation criteria from which implemented or proposed approaches have been constructed. As one nationwide questionnaire study of microallocation criteria favored by selected medical directors has documented (Kilner, 1990—hereafter, "U.S. Study"), these criteria can be clustered into four major types: social, sociomedical, medical, and personal criteria.

SOCIAL CRITERIA. The characteristic feature of social criteria is that they seek to promote some particular or general social good as a result of the allocation decisions made. There are five such criteria: social value, progress of science, favored group, resources required, and vital responsibilities.

Social value. Of the social criteria, the most basic is a social value criterion. Given some place in microallocation decisions by 56 percent of the U.S. Study participants, this criterion gives preference to patients judged to be of greatest value to society, according to whatever standards of value the decision makers decide to employ. While the criterion may be explicitly invoked, it can also operate covertly to influence treatment decisions. One result in the United States has been that socially privileged groups such as whites and males have received scarce treatments disproportionately often (AMA, 1990, 1991; Institute of Medicine).

The primary attraction of employing a social value criterion is that it helps to maximize the amount of benefit derived from healthcare resources. Because society has invested its resources in a patient's treatment—or at least in developing the possibility of that treatment—it is understandably interested in a good return on its investment. Absent this criterion, there might well be an undesirable loss of some of society's most gifted people. A social value criterion usually employs a utilitarian calculus, according to which the patients judged most likely to be most valuable to society in the future are favored. Past contributions to society may also enter the calculus on the basis of just reward or gratitude for a patient's past.

In any form, this criterion is highly controversial. Conscientiously ranking people according to social value is a virtually impossible task. Agreeing on a ranking of all possible social contributions—based on an accurate understanding of future as well as present needs—is extremely problematic even in a setting much more homogeneous than the United States. Assessing how particular individuals rank on this scale requires a virtually unobtainable level of knowledge about people's lives. The omniscience and wisdom required has led critics to label the use of this criterion "playing God." The criterion is also criticized for unfairly discriminating against individuals or groups who cannot contribute as much to society as others. Their relative inability may be due to unchangeable genetic factors or uncontrollable social circumstances (e.g., past discrimination that has undermined either their ability or society's appreciation of their contributions). Moreover, the toll on the caregiver–patient relationship can be severe. Patients can no longer be sure that confidential information about embarrassing symptoms or lifestyle habits, which caregivers often must know in order to treat patients effectively, will not be used to deny them treatment in deference to another more socially promising patient.

Progress of science. Closely related to a social value criterion is a progress of science criterion, which received roughly the same support in the U.S. Study (58% of the participants). It gives priority to patients whose treatment will yield the most scientifically useful information. For example, during the years when kidney dialysis was still scarce in the United States, a hypothesis surfaced that dialysis might alleviate the mental disorder schizophrenia as well as replace kidney function. Under such circumstances, a progress of science criterion favors treating patients who have both medical needs. Because the same number of people will be treated with or without the criterion, it is arguably best to learn as much as possible, through careful patient selection, about the full beneficial potential of a scarce resource.

On the other hand, many of the shortcomings of a social value criterion also apply to a progress of science criterion. For example, the pragmatic difficulties of identifying precisely which patients or groups of patients, if treated, will yield the most important scientific information loom large. So does the coercion inherent in the experimentation (with possible added tests or procedures) the criterion entails. Those eligible for priority treatment must either consent or risk a lower priority of being treated—which could mean substantial suffering or even death. Ultimately the criterion may not really be necessary, because patients with scientifically interesting conditions are usually selected through the application of other criteria. Such patients can volunteer for any special tests or procedures, and data on those patients can be pooled in a central location.

Favored group. According to a favored-group criterion, people of a certain type (e.g., children or military veterans) or who live within certain geographic boundaries receive priority. Much of healthcare operates on this basis, both for the sake of convenience and in order to enhance the quality of care for particular groups. Such justifications become problematic, however, when resources are limited and people who are denied care at a particular facility on the basis of this criterion cannot always obtain it in a different location. Accordingly, only 27 percent of the participants in the U.S. Study supported it.

On the other hand, some rationales for this criterion are more strictly medical and may apply to any patient. For example, when either patients receiving treatment and follow-up care or perishable resources such as transplantable organs must travel long distances, medical outcomes may suffer considerably. If medical considerations are central, though, then at issue is really some form of medical criterion, not one's group identity per se. Moreover, it is arguably better to try to remedy barriers to treatment—for example, by relocating people nearer to a treatment facility—than to employ barriers as grounds for denying treatment.

In certain cases, a very different favored-group justification is at work. A group, even an entire state or country, should arguably have the freedom to produce special resources available only to its own members, as long as the resources available to others are not thereby limited. In practice, though, such is rarely the case. Consider organ transplantation. Because the supply of organs itself is limited, giving some people special access means less access for others. Moreover, neither a particular U.S. state nor the country as a whole can claim all the credit for developing every aspect of the technology required. Accordingly, some have proposed eliminating geographic boundaries or at least implementing regional or national quota systems that would establish priorities without completely excluding any group (Task Force).

Resources required. A resources-required criterion received somewhat more support (66% of the participants in the U.S. Study) than the preceding social criteria. It prioritizes treating those who need less of a given resource before patients who need more of it, though it is usually restricted to situations in which its application will likely increase the number of lives saved. Saving lives is a central task of healthcare and a praiseworthy goal from most philosophical and religious perspectives. The requirement of a greater lifesaving potential most clearly distinguishes the criterion from a more general social value criterion. Usually only patients requiring substantially fewer resources than other patients are favored by the criterion. For instance, patients needing temporary rather than long-term use of a scarce drug receive priority, as do patients needing a single-organ rather than multiple-organ transplant. The criterion is not designed to bias patient selection automatically against patients who have previously been treated for the same problem, such as those whose failing organ transplants must be replaced.

A resources-required criterion can be criticized as too attentive, or not attentive enough, to maximizing good results from treatment. It is too attentive if the life-threatening needs of each patient requiring a particular treatment should receive equal weight regardless of the overall number of lives saved. It is not attentive enough if many characteristics of people should be considered other than whether or not they will survive. From this latter perspective, saving the life of one outstanding person could be preferable to saving two who are not.

Vital responsibilities. According to 69 percent of the participants in the U.S. Study, a vital responsibilities criterion has a legitimate role in microallocation decisions. Intended for exceptional situations only, this criterion accords special priority to patients on whom others depend. The broadest form of the criterion favors any patient who has *family dependents.* Generally, though, there must be some sort of unusual social need that requires special treatment for particular people. In a disaster situation, for example, treating those with medical expertise first may make it possible for them in turn to save additional lives. As in the case of a resources-required criterion, the strictest form of the vital responsibilities criterion requires more than producing general social value: Additional lives must be saved every time the criterion is applied.

Without this lifesaving requirement, the criterion is merely a specific type of social value criterion and therefore open to all of the critiques to which that criterion is vulnerable. Invoking the criterion to favor patients with family dependents is particularly problematic because not everyone has equal access to having children. In some cultures, moreover, sustaining the life of one who has not yet maintained the family name by having children is more important than treating one who already has children. On the other hand, if the pursuit of general social value in microallocation decisions is ethically legitimate, then allowing a vital responsibilities criterion to apply only when additional lives are saved by it is unduly restrictive.

SOCIOMEDICAL CRITERIA. Three other microallocation criteria—age, psychological ability, and supportive environment—are similar to the social criteria, in that they generally seek to promote some social good. They are distinctive, however, in that their stated justifications are often medical in nature, and they are therefore known as sociomedical criteria.

Age. Old age has long been employed as a reason for limiting medical treatment on the basis that elderly people do not sufficiently benefit from it because of their weakened physical condition. At issue may be the likelihood of benefit, the length of benefit, or the quality of benefit. So it is not surprising that 88 percent of the participants in the U.S. Study supported an age criterion to some degree.

In response to book-length justifications of an age criterion that addresses far more than aspects of medical benefit (e.g., Callahan; Daniels), a wide body of literature has emerged (e.g., Homer and Holstein; Walters; Thomasma; Hansen and Callahan). Some supporters of the criterion favor younger candidates for treatment over older candidates in order to give all an equal opportunity to live. A healthcare system, first of all, should keep people from dying "early." Others argue that whereas all people may have an equal claim upon available healthcare resources, that claim diminishes once people have achieved their so-called natural lifespan (perhaps seventy-five or eighty years). Furthermore, were people themselves given the choice, they might prefer to concentrate life-sustaining resources in their earlier years if that would make possible better long-term and supportive care in their elderly years.

Those who reject an age criterion find all such justifications unconvincing. Medical justifications arguably support medical criteria rather than a criterion based on age per se. Equal regard for persons appropriately focuses on persons as a whole—persons who should receive needed healthcare whenever that need occurs—rather than on persons as accumulations of life years, the number of which is to be maximized in the name of equal opportunity. Limiting equal access to people who have not yet lived their natural lifespan, meanwhile, relies on the debatable notion that there is a fixed natural lifespan. Moreover, it imposes on older people the judgment that, relatively speaking, their lives are not worth living, even if they disagree. (At least such is the case if age per se, rather than quality or length of life, is at issue.) Finally, if given a choice, people might well prefer criteria other than age for allocating limited resources. They would likely recognize that in people's actual experience, they would not be denying certain forms of healthcare to their own older selves, but rather the rest of the community would be denying needed life-sustaining care to a certain group of its members. This denial is more discriminatory than it may at first appear, because the group denied is not only old but also largely female (Jecker).

In the end, all rationales for limiting healthcare for elderly persons are often suspected of being fueled, at least unconsciously, by a utilitarian preference for the achievement and economic productivity more characteristic of younger persons. Not only is the unbounded pursuit of social value itself controversial, but the economic productivity orientation of that pursuit also reflects the questionable bias of Western culture toward productivity even at the expense of personal relationships (Kilner, 1992).

Psychological ability. In the U.S. Study, 97 percent of the participants acknowledged that psychological ability plays at least some legitimate role in allocation decisions. The ability of patients to cope emotionally and intellectually with treatment is commonly assumed to be essential to effective healthcare. Without this ability, patients are unable to follow medical instructions and may even reject treatment or life itself after considerable resources have been expended. Such patients are the most difficult to treat and tend to be the least valuable to society.

These justifications also constitute arguments against the criterion. Rationales that are medical in nature actually support medical criteria rather than a psychological ability criterion per se. When psychological ability per se is invoked, the convenience of the staff or the presumed social value of the patient is problematically allowed to override the patient's claim to equal access. Moreover, caregivers' judgments about the coping abilities and cooperativeness of patients are much more subjective than the physical assessments they conduct and are therefore vulnerable to personal bias. Like everyone else, caregivers find that they can work best with those most like themselves, and many observers question the appropriateness of ranking human lives based on how well-matched patients are to caregivers.

Supportive environment. A supportive environment criterion is one that favors those patients who will have the most supportive living environment during and following treatment. Considered potentially valid by 61 percent of the participants in the U.S. Study, this criterion favors patients with the best access to personal and professional caregivers as well as facilities and other material resources relevant to effective treatment. Without sufficient postoperative care, for example, not only may scarce resources be wasted, but a treatment such as a heart transplant may result in a worse death than if the patient had received no treatment at all. Alternatively, the absence of a supportive environment may indicate that the patient warrants low priority on social value grounds.

A supportive environment criterion per se, however, is unnecessary if the concerns it addresses are already accounted for by medical benefit or social value criteria. Even as a form of another criterion, supportive environment is a problematic consideration, because the connection between people's environment and their medical outcomes or social value is far from precise. Helpful supports are not always necessary for a satisfactory medical outcome, and personal bias easily intrudes when assessing lifestyles or home situations quite different from one's own. In fact, this criterion by its very nature can be unjust when it denies treatment to patients (e.g., children with an inadequate home environment) on the basis of the irresponsibility of others (e.g., parents) or society at large. Arguably, the special needs of such situations call for extra care, not less.

MEDICAL CRITERIA. The third cluster of criteria are explicitly medical in nature, having to do with health-related outcomes of treatment. There are five of these criteria: medical benefit, imminent death, likelihood of benefit, length of benefit, and quality of benefit.

Medical benefit. The most basic of the medical criteria is a medical benefit criterion, acknowledged as a legitimate allocation criterion by 95 percent of the participants in the U.S. Study. Unlike many other medical criteria that compare and rank candidates for treatment, this criterion includes for further consideration everyone with a reasonable likelihood of receiving from treatment significant medical benefit in terms of length and quality. This criterion casts a wide net: any degree of likelihood, length, and quality that can reasonably be considered minimally significant is sufficient. Treatments not offering such benefit are commonly excluded as futile, though futility itself is a concept that requires careful definition (Jecker and Schneiderman).

The requirement that patients benefit medically from scarce medical resources is rooted in ethical standards of efficiency and justice. Without this requirement, precious resources would be wasted on patients who would receive no benefit from them. Moreover, according to many theological and philosophical traditions, need constitutes the major exception to the egalitarian presumption generally built into concepts of justice. The notion of need includes the ideas that some disease or injury condition is present (or will be, where the need for preventive care is in view), and that a person's life is thereby undesirably altered. A need for a lifesaving resource, for example, implies that a person's life is in jeopardy without it; no preferable alternatives remain.

The major difficulty with this criterion is the way in which standards of need can be manipulated. A classic illustration is the provision of kidney dialysis in Great Britain (Aaron and Schwartz). Resources allocated for dialysis by the government-run healthcare system have been insufficient to treat all who could benefit medically from dialysis, according to normal standards of need. Yet many have claimed that all who need treatment receive it. Matching of available resources and need has been achieved by tightening standards of need in sections of the country where resources are particularly scarce. Also, general practitioners do not even refer certain patients to kidney specialists for dialysis when practitioners know that sufficient resources are not available.

Imminent death. The second medical criterion, imminent death, takes the standard of need a step further. Sometimes called an *urgency* criterion, it accords special priority to patients who will die soon without treatment (support for it was not measured by the U.S. study). While the term *imminent* is not precise—generally ranging from a few days to a few weeks—it has been found workable by many in clinical and legal contexts alike (Kilner, 1990).

Not only does this criterion recognize situations of special need, it also results in more lives saved. (A necessary stipulation, though, is that it be applied together with the medical benefit criterion, so that priority will not be accorded to patients for whom treatment is futile.) Because patients whose death is not imminent can survive for a period of time while imminently dying patients receive priority care, a new treatment may become available in the interim, enabling patients in both categories to live. Alternatively (and more likely), additional resources may be made available at any point as the life-threatening situation becomes better known. In fact, the scarcity itself may be only intermittent, as is often the case with intensive care space.

An imminent death criterion, though, is more problematic in practice than it may appear to be in theory. In many situations it is impossible to determine with precision whether or not a patient's death is imminent. In others, caregivers can overstate the urgency of their patients' conditions in order to give them priority access to lifesaving resources. While doing so may be unfair, it may represent an understandable attempt to avoid another problem with the criterion. By making patients wait until they have deteriorated almost to the point of death before they receive priority access to treatment, the criterion ensures that resources will be devoted to the sickest patients. Worse medical outcomes for those treated and greater suffering for those who might wait are bound to result. Moreover, additional resources may never become available for those not prioritized by the criterion.

Likelihood of benefit. Each of the three remaining medical criteria addresses a particular aspect of medical effectiveness. The first of these, likelihood of benefit, was affirmed by 96 percent of the participants in the U.S. Study. This criterion assumes that more than a minimal likelihood of medical benefit is a necessary prerequisite for receiving scarce medical resources. Those with the greatest likelihood should be favored to ensure the most productive use of available resources. While this justification resembles the rationale underlying a social value criterion, the benefits in view here are limited to medical benefits experienced by the persons receiving the scarce resources. Moreover, more lives may ultimately be saved if this criterion is applied, although such will not be the case in every situation in which the criterion is applied.

Several obstacles attend this criterion. Precisely quantifying the probabilities of every patient's benefiting from a particular treatment so that all can be comparatively ranked is quite difficult. Furthermore, while a productive use of resources may be applauded, the cost of achieving it is arguably too great. Many patients have significant (albeit lesser) likelihoods of benefiting from treatment; yet the criterion leaves them with no realistic prospect of receiving lifesaving care if enough patients with better prospects are waiting for the same treatment. Patients can no longer trust caregivers with essential information that suggests their cases may be complicated, because caregivers must steer resources to the patient with the best prospects rather than simply attending to the needs of each patient. Ultimately, this criterion tends to discriminate against whichever groups in society have the poorest health in general and thus the lowest likelihood of having optimal outcomes from any treatment. Poor persons, disabled persons, and members of racial minorities are particularly vulnerable on this score.

Length of benefit. With a length of benefit criterion, all patients are ranked according to the length of time, rather than the likelihood, that they will benefit medically from treatment. As in the case of other comparative medical criteria, the underlying concern is to achieve as much medical benefit as possible from the available limited resources. Specifically in this case, the criterion helps to maximize the success of treatment by maximizing the length of time patients live following treatment. Of the participants in the U.S. Study, 96 percent indicated that a length of benefit criterion should have some place in microallocation decisions.

Several of the difficulties with this criterion parallel those of a likelihood of benefit criterion. Accurately predicting the length of time patients will survive following treatment is extremely hard. The criterion also tends to discriminate against the same groups of people disadvantaged by a likelihood of benefit criterion, because these typically less-healthy groups on average do not live as long as others following various types of treatments. This discriminatory effect extends to elderly patients as well, because they tend to have fewer years of life remaining regardless of the treatment in view. The significance of this concern, however, is as debatable as the age criterion itself. The most fundamental problem with a length of benefit criterion may be its presumption that length of life rather than persons per se is the appropriate focus of allocation decisions. Each person's life is uniquely important to that person. Those who argue that all people have a right to life (including life-sustaining resources) add that rights do not diminish the sicker one gets.

Quality of benefit. The final medical criterion, quality of benefit, shares the wide support expressed for other medical criteria, including acknowledgment by 97 percent of the U.S. Study participants. Like the two previous criteria, it ranks patients on a scale, in this case a scale of quality of life following treatment. This criterion rejects the common preoccupation with merely keeping patients alive and insists that healthcare is also responsible for producing lives with as high a quality as possible. Good quality of life is important to patients because it contributes substantially to their happiness as well as to their autonomy (their ability to make uncoerced decisions concerning their own lives). From a social standpoint, higher quality lives have a tendency to be more socially productive lives.

Quantifying all qualitative considerations in order to compare patients on the same scale, however, may be impossible. Even if it were possible, predicting the quality of life that will follow treatment sufficiently precisely to distinguish most patients remains problematic. So does achieving agreement as to what factors characterize a good quality of life and how these factors should be ranked. While such measures as QALYs (quality-adjusted life years) have been developed to assist macroallocation decision making, they have not proven as helpful in distinguishing individual patients at the microallocation level. Another difficulty arises when some people (usually caregivers) must assess the quality of others' lives. People judge others' quality of life on the basis of objective, observable quality of life indicators. Unfortunately, evidence has long suggested that such objective indicators do not correlate well with patients' subjective experience of their own lives (U.S. Congress). In fact, what is unacceptable to the well may be quite acceptable to the sick.

When some people impose their standards of quality on others, moreover, biases against such groups as disabled, poor, and elderly persons can easily intrude.

PERSONAL CRITERIA. The final four criteria may be designated as *personal* because their justifications are rooted in personal values such as liberty and the worth of the individual. These four are: willingness, responsibility, ability to pay, and impartial selection.

Willingness. Supported to some degree by 89 percent of the participants in the U.S. Study, a willingness criterion ensures that only patients who genuinely want treatment receive it. This criterion respects patients' rights to bodily integrity, as well as their autonomy, or freedom, to make vital decisions that primarily concern their own lives. People have unique life plans and values, and only they can accurately assess the balance between the benefits and burdens of their own treatment. For many, a right to the free exercise of religion is at stake. When resources are allocated to willing recipients, the recipients themselves are happier and the resources are less likely to be ineffective or rejected midcourse. Even if people choose to forgo treatment because other qualified patients need the same treatment, the choice can be applauded as an act of giving rather than simply branded as a typical suicide.

Nevertheless, a willingness criterion can also be problematic. For it to be employed ethically, patients must have complete information concerning the healthcare treatment in question, including the costs and benefits of receiving it; they must understand this information; they must be free from the (sometimes subtle) coercion of family, professional, or other caregivers who might want them to accept or reject treatment; and they must have the mental capacity, despite their current health predicament, to make and communicate decisions that reflect their values. A willingness criterion can also easily become a cover for patients' selfish behavior—for example, suicidal rejection of life-sustaining treatment with no regard for others who in some way depend on them.

Responsibility. Responsibility is actually a willingness criterion of a different sort. It steers resources away from people who willingly engage in unhealthy lifestyles or risky activities that result in the need for treatments (support for it was not measured by the U.S. study). Most commonly invoked as a macroallocation criterion, this criterion has provoked significant debate. Proving responsibility in specific cases is particularly controversial (Wikler).

Ability to pay. As a criterion for microallocation of healthcare resources, ability to pay received support from 43 percent of the participants in the U.S. Study. People with insufficient funds or other necessary resources are explicitly excluded by this criterion from access to certain forms of healthcare. The criterion functions in many indirect ways as well. The uninsured, in fact, use health services only about half as much as the insured and are more likely to die from treatable conditions as a result (Evans; Institute of Medicine). The inability of some patients to pay for the support services that necessarily accompany certain treatments—such as travel expenses and postoperative care—has also in effect excluded some patients from treatment. When transplantable organs have been the scarce resource, those with the ability to mobilize the media or key politicians have occasionally gained special access to the necessary organs. The ethical considerations here are essentially those attending a market approach to macroallocation.

Impartial selection. When all other ethically justifiable criteria have been applied, and there remain more eligible candidates for resources than there are resources to provide, caregivers sometimes invoke an impartial selection criterion. Affirmed by 31 percent of the participants in the U.S. Study, this criterion mandates a random selection from among eligible candidates. Its rationale is that each person who has an equal moral claim on a scarce resource should have an equal opportunity to receive it. The apparent arbitrariness of the selection helps to keep the tragedy of the situation clearly in view. It focuses more attention on the need for additional resources to be made available at the macroallocation level, if possible. There is no comforting illusion that the "best" candidates are being treated.

Some forms of impartial selection, though, may be better than others. One option is a first-come, first-served approach. Because the time that each person is stricken with a medical condition and seeks treatment is more or less random, this approach functions as a sort of natural lottery. Its appeal stems from the familiarity of waiting lines inside and outside the realms of healthcare and from the way that this approach does not seem as starkly random as an explicit lottery. True randomness, however, is the whole point of an impartial selection criterion. First-come, first-served is inferior to a genuine lottery on this score. Patients with the greater power, mobility, information, and confidence associated with the relatively wealthy have better access to healthcare generally and to referral networks in particular. Accordingly, they tend to get on the waiting lists for scarce resources sooner than those who are less wealthy and empowered.

Some weaknesses of an impartial selection criterion, though, are not unique to a particular form of the criterion but are inherent in the criterion itself. For instance, many of the social benefits that other criteria generate are lost when an impartial selection criterion is applied. Socially destructive persons such as dangerous criminals are sometimes selected instead of people who have made great positive contributions to society. Rather than respecting human dignity, impartial selection may demean it by not considering the unique features of each person. Admittedly, people cannot make infallible decisions. In the eyes of some, however, human judgments are arguably better than blind chance.

Allocation Approaches

Allocation criteria, the building blocks of microallocation, must be prioritized and arranged into some sort of basic approach if microallocation decisions are to be ethically consistent. This approach can then serve as a framework for designing specific allocation procedures tailored to particular resources and settings. Approaches tend to be justified ethically by appeals to norms such as productivity, equality, and freedom, but relatively little grounding is typically provided for these norms in the context of allocation discussions. Such norms have long had broad intuitive appeal in Western culture. Nevertheless, increasing ethical pluralism together with the tensions among the norms themselves underscore the need for a larger frame of reference (religious, rationalistic, or otherwise) within which such norms can be justified (Palazzani).

The many approaches to microallocation that have been advocated sort ethically into two groups. One group of approaches is oriented primarily toward making the most productive use of resources; the other, toward ensuring that suitable candidates have equal access to treatment through some form of impartial, or random, selection. Impartial selection may play a minor role in productivity-oriented approaches, but usually only to break ties. Furthermore, all approaches generally affirm or assume some sort of willingness criterion because of the importance of respecting people's freedom.

PRODUCTIVITY. Three forms of productivity-oriented approach can be distinguished. One form focuses exclusively on medical considerations (e.g., Leenen). Employing only medical criteria, along with sociomedical criteria whenever they are essential to good medical outcomes, this approach seeks to allocate resources to those most likely to benefit medically. Medical criteria, particularly when rooted in the notion of meeting needs, can be defended on the basis of ethical concerns other than productivity: for example, a principle of justice. But when all (or virtually all) decision making depends on comparative medical judgments among patients, a more utilitarian concern to maximize productivity is typically at work. The strengths and weaknesses of such approaches will vary depending on which of the three comparative medical criteria (likelihood, length, and quality of benefit) are employed.

A second, related form of productivity-oriented approach attempts to enhance the productivity of an exclusively medical orientation by allowing special exceptions on the basis of value to society. The concern may be to ensure treatment for particularly valuable individuals (e.g., Langford) or to exclude particularly unworthy candidates (e.g., Bayles). In the former case, the relevant rationales are those supporting social value and/or vital responsibilities criteria; in the latter, rationales undergirding a responsibility criterion also apply.

The third form of productivity-oriented approach takes this concern about social value one step further. It makes social considerations primary, combining whatever criteria are necessary to yield the most productive use of scarce resources. The ethical justifications and weaknesses of this form of approach are fundamentally those of the social value criterion itself—most obviously when such approaches affirm social value per se as the overarching consideration (e.g., Basson). When social criteria such as social value and progress of science are combined with comparative medical criteria and/or sociomedical criteria (e.g., Rescher), the additional justifications and weaknesses of those criteria come into play secondarily.

IMPARTIALITY. The major alternative to productivity-oriented approaches seeks to give suitable candidates equal access to treatment through some form of impartial selection. The pool of suitable candidates typically includes all who meet the medical benefit criterion. Priority groups within this pool are identified on the basis of nonutilitarian criteria: vital responsibilities alone (e.g., Childress), vital responsibilities plus resources required (e.g., Winslow), or both of these criteria plus imminent death (e.g., Kilner, 1990). (A priority may also be given to any group of people whose likelihood of benefit is substantially higher than that of all others, though the productivity-oriented nature of this priority creates ethical tension within an impartiality-oriented approach.) Finally, candidates are ordered within each priority group through impartial (usually random) selection.

In contrast to the explicit or implicit utilitarian bent of productivity-oriented approaches, in which benefit to society is the primary goal, the justification of this last type of approach is more egalitarian in nature. Within certain limitations designed to save as many lives as possible, all potential recipients of scarce resources are ensured an equal opportunity to receive them. This commitment to life and equality may simply be intuitive or reflect popular sentiment. Alternatively, respect for life and equality may be grounded in a philosophical or religious understanding of ethics. One philosophical example would be social contract theory, in which such respect may be seen as something to which all people would agree, if they had to decide upon ethical standards to govern society under certain ideal conditions (Winslow; Rawls). A religious example would be the biblical accounts of God's exemplary commitment to even the poorest, which is foundational to Christianity and Judaism (Mitchell; Ramsey; Zoloth; Mackler).

PARTICULAR SETTINGS. Implementing any approach requires tailoring it to particular settings. For instance, medical assessments are handled differently when allocating intensive care (Zoloth-Dorfman and Carney; Lantos, Mokalla, and Meadow) as opposed to transplantable organs (Caplan; Schmidt) or kidney dialysis (Cummings; Rutecki and Kilner). In the intensive care setting, a tool often used has been the APACHE (Acute Physiology and Chronic Health Evaluation) System. Through laboratory tests and bodily measurements, the APACHE System is able to predict patient death rates and length of intensive care stay when patients are first admitted to intensive care (Knaus et al. 1993; "Medical Algorithms Project"). A different quantitative system has been developed for assessing both medical and nonmedical considerations in organ transplantation. The United Network for Organ Sharing (UNOS) has developed a national point system to prioritize patients needing transplants. In the case of kidney transplants, for instance, candidates whose blood type is compatible with that of the donated organ are ranked according to point totals. These totals represent the sum of points given for medical considerations such as antigen matching and for nonmedical considerations such as time on the waiting list (OPTN). Methods of quantifying social value rankings in particular geographic settings have also been developed (Charny, Lewis, and Farrow).

Numerical systems are helpful in facilitating consistent comparisons among potential recipients of healthcare. Nevertheless, the need for judgment in microallocation is unavoidable (AMA, 1993). Caregivers must help identify medically appropriate courses of action, assess the likely outcomes of those courses, and assist potential recipients in their decision making. Potential recipients must evaluate the benefits and burdens of all available courses of action in light of their own sets of values and beliefs. Interdisciplinary committees and healthcare teams in public-policy and institutional settings must not only craft ethically sound allocation criteria into workable allocation approaches; they must also determine what shape such approaches take in specific settings and discern how they apply to particular people. Microallocation, like healthcare itself, remains an art as well as a science.

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SEE ALSO: *Dialysis, Kidney; Long-Term Care; Managed Care; Medicaid; Medicare; Organ Transplants;* and other *Healthcare Resources, Allocation of* subentries

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HEALTHCARE SYSTEMS

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A healthcare system can be defined as the method by which healthcare is financed, organized, and delivered to a population. It includes issues of access (for whom and to which services), expenditures, and resources (healthcare workers and facilities). The goal of a healthcare system is to enhance the health of the population in the most effective manner possible in light of a society's available resources and competing needs. By the beginning of the twenty-first century access to healthcare had come to be regarded by most countries and the United Nations as a special good that is necessary either as a matter of or pursuant to basic human rights. An examination of healthcare systems therefore includes consideration of the ways in which a particular system addresses commonly held values.

The extent and form of a specific system are influenced by a variety of factors, including the unique culture and history of a population or country. What is considered healthcare can vary markedly in accordance with a country's level of development, culture, and social values. Some populations put emphasis on the prevention of disease, whereas others emphasize only the care for or cure of particular illnesses. Definitions of health and disease and of *appropriate* healthcare providers also are subject to cultural variability.

A second major influence derives from the priorities given to various ethical values: "There is no way to adjudicate disputes among the Holy Trinity of cost, quality and access unless a court of values is available to dispense its wisdom" (Reinhard, pg. 1). Those values include respect for the autonomy of both patients and providers, the maximization of benefit, and the promotion of justice or fairness, understood as equality or liberty.

Balancing those values has posed a dilemma in the United States. Public opinion polls have revealed that most Americans see access to healthcare as a fundamental right. However, Americans' equally strong belief in individual autonomy and responsibility, the use of the market as a means for distributing goods and services, and fears about government interference create conflict and have led to a fragmented healthcare system.

A third influence on the structure of a healthcare system is the level of economic resources available. There is a strong positive correlation between economic resources as measured by the per capita gross domestic product (GDP) and both healthcare expenditures and the proportion of a nation's GDP that is spent on healthcare (Gerdtham and Jonsson). This indicates that although healthcare generally is valued, countries and individuals may consider food, shelter, and in some instances spending for the military more important. However, although the economic resources available to a country have a great effect on that country's overall expenditures on healthcare, there is nearly as much variation in the forms of the healthcare systems in countries that are economically poor as there is in wealthy countries.

Public versus Private Control

All governments have some degree of involvement in healthcare because essentially all countries have a centrally funded agency that is concerned with public health issues. The proportion of healthcare expenditures spent on public health tends to be higher in low-income countries, although the level of effort varies greatly from country to country. Government involvement usually includes surveillance of communicable diseases and interventions to prevent or curtail epidemics. Some countries have more extensive government involvement through direct delivery of services (e.g., immunizations, well-child care, screening for developmental disabilities, and treatment of communicable diseases) and programs of health promotion. Public health efforts in the United States are fragmented but have begun to receive more attention as the costs of personal, disease-oriented healthcare and concerns about bioterrorism have increased.

Beyond public health measures, healthcare systems vary dramatically with regard to the degree of public versus private control (Anderson et al.). In fact, the extent of government control is probably the most distinguishing characteristic among systems. In most member countries of the Organization for Economic Cooperation and Development (OECD) the healthcare system is dominated by the public sector. The OECD countries with a high percentage of revenues from the public sector in 2000 included Luxembourg (93%), the Czech Republic (91%), and the Slovak Republic (90%) (OECD). In a few countries the majority of revenues come from the private sector. In the United States the private sector accounts for about 56 percent of healthcare expenditures. The only other OECD countries that receive a majority of funds (more than 50%) from the private sector are South Korea (56%) and Mexico (54%).

The public side of healthcare systems in industrialized countries can be placed into two categories: countries with comprehensive programs and strong government control of virtually all aspects (financing, delivery, quality monitoring) of the system, such as Great Britain, the Scandinavian countries, and the countries of the former Soviet Union, and countries in which the government's role is limited to financing or guaranteeing enrollment for all citizens in a health insurance plan, such as Germany, Belgium, France, and Canada. Both types of systems are characterized by public financing or mandates that guarantee universal coverage, payment that is negotiated between the public sector and providers, and policies regarding facilities and healthcare workers that are modulated predominantly by the public sector.

In countries in which the private sector is the dominant payer for healthcare universal coverage is less common, payment varies from provider to provider and insurance company to insurance company, and policies regarding healthcare workers are negotiated in the marketplace. In the United States, for example, patient and professional autonomy are dominant (Reinhard). Most individuals or employers are free to choose from among multiple insurers and providers, and most provider groups have the freedom to choose whom to serve, how much to charge, and what credentials are required to join the group.

Especially notable has been the strong distrust of government interventions except when they are deemed necessary to guarantee access to a group that is seen as *entitled* because of a special service it has rendered (retirees, veterans) or special need (disability, poverty). However, even in the United States there have been a number of occasions (as in 1910, 1935, 1948, 1965, 1972, and 1994) when a reasonably strong attempt was made to provide a substantial increase in government involvement in the healthcare system. Except in 1965 those attempts failed because of a combination of factors, including provider opposition, lack of public consensus, fears of increased government involvement, and relatively comprehensive healthcare benefits that most working Americans receive from employment-based private insurance.

Financing

The means of financing healthcare, perhaps more than any other aspect of a healthcare system, mirror the values and priorities of a society. As was noted above, unlike the case in the majority of the OECD countries, healthcare financing in the United States is mostly private. There is also little public financing of healthcare in most low-income countries. Because of the high cost of many interventions and the unequal distribution of healthcare costs among individuals, lack of a broad-based system of public financing creates a system in which healthcare is rationed on the basis of the ability to pay.

Beginning with Germany in 1883, most industrialized nations have implemented a government-coordinated or government-controlled system of financing for personal healthcare services. This varies from the systems in countries such as Great Britain and the former Soviet Union, in which virtually all healthcare is financed through general tax revenues collected by the national government, to systems, such as Canada's, that are financed from both state and national revenues, to those of Germany, France, Belgium, and the Netherlands, in which financing is mandated by the national government through required participation in a community- or employment-based insurance funds.

In the third type of system most funds are obtained through required contributions based on wages. All countries with strong central control have at least a small market of privately financed healthcare that is used predominantly by the rich and the politically connected. For example, in Germany and the Netherlands the most affluent people are not required to purchase health insurance, and most choose to purchase private health insurance, which gives them better access to medical services. Some countries with mixed systems (e.g., Japan and Australia) have a small market for private health insurance that complements the public-sector benefits.

The proportion of public financing of healthcare in the United States has been increasing steadily, rising from about 23.3 percent in 1960 to nearly 44.3 percent in 2000 (OECD). In spite of these increases, there is no universal government-guaranteed or compulsory health insurance. Employer-based or individually purchased private insurance is the most common way people obtain health insurance coverage. A variety of publicly financed programs (e.g., Medicare and Medicaid) provide insurance to persons over age sixty-five and some poor people. They are financed by a spectrum of public financing mechanisms, including federal and local government revenues, the use of income and employment-based taxes, and in some states the revenues from a lottery.

Financing for active-duty military personnel, veterans, and Native Americans mirrors the centrally controlled healthcare systems of Great Britain and the former Soviet Union. Revenues come from the federal income tax, and services are provided by public-sector employees. The Medicare program is financed primarily from a wage tax, whereas Medicaid (for certain categories of disabled and low-income persons) is financed from a combination of state and federal general tax revenues. Financing for some care for the poor who are not eligible for Medicaid comes from general tax revenues at the state or local level that are paid to city and county public hospitals and state mental hospitals.

The dominance of a private system of financing in the United States is a reflection of not only that nation's values but also of a number of historical events. The Blue Cross program began in Texas when Baylor Hospital enrolled schoolteachers in an insurance system during the Great Depression as a method to guarantee that hospitalized patients could pay their health bills. Private health insurance grew slowly during the 1930s.

The real spread of private health insurance occurred during World War II, when wages but not fringe benefits were frozen as a wartime price-control measure. As more firms began to offer health insurance as a benefit, private insurance companies saw the potential for expanding their markets and encouraging those enrolled in health-insurance plans to buy their other insurance products. Another impetus to the market was the decision by the federal government to exempt healthcare benefits from federal income tax. The large number of insurance plans in the United States, each with its own marketing, benefit packages, premiums, deductibles or copayments, billing, and payment requirements, together with the thousands of private physicians, clinics, and hospitals, has created an immense administrative bureaucracy with aggregate administrative spending of $89.7 billion in 2001 (Center for Medicare and Medicaid Services; Levit et al.).

Access and Delivery

A second major characteristic of a healthcare system is access, which has multiple definitions, including the following:

1. The ability to obtain needed care
2. The potential and actual entry of a given population into the health system
3. The timely use of personal health services to achieve the best possible outcome
4. The timely use of needed, affordable, convenient, acceptable, and effective personal health services

Different countries approach the issue of access in various ways and define the term differently. Health systems with strong central control, such as those in Great Britain, the Scandinavian countries, and the countries of the former Soviet Union, emphasize equal access to care for all their citizens. Those countries have a single-payment system, with most healthcare providers working as salaried government employees and a single government-defined set of benefits. There tends to be strong emphasis on primary care by general practitioners and relatively tight control of the number and distribution of providers and facilities that provide highly technical services. In some countries this degree of government control results in substantial waiting times for some services and limited access to advanced technologies. Thus, whereas this approach produces an apparently high level of equal opportunity to obtain needed health services, it may deny some individuals access to lifesaving technologies and restrict both provider and patient choices. This depends on the level of spending a country is willing to commit to healthcare.

Countries with less centralized systems vary more in regard to the level of access. In some countries access to healthcare for the poor is restricted by the ability to pay. Moreover, providers' freedom to choose their patients can restrict access to medical services among insured low-income individuals. For example, many providers in the United States refuse to serve Medicaid recipients because of the low payment rates. In countries with less centralized health systems working individuals employed in low-paying jobs often face financial barriers (high out-of-pocket expenses for copayments, deductibles, or premiums) to receive needed care (Lee and Tollen). Similarly, the limited control of healthcare workers and facility location tends to result in geographic maldistribution of providers and healthcare facilities.

The degree of access varies widely in the United States. Financial barriers to access are substantial for more than 41 million Americans without health insurance coverage and about the fifth of insured individuals who have inadequate insurance (Mills; Hadley and Holahan; Kaiser Commission on Medicaid and the Uninsured). Studies have shown that those who are poor and have no health insurance have a markedly lower use of almost all forms of healthcare despite their tendency to have a lower baseline health status. This lack is especially great in terms of primary care and preventive services (Bayer and Fiscella). Although the uninsured have some access to high-technology care, especially in urban areas, through use of the emergency rooms and outpatient clinics of public hospitals, research has shown that they have poorer outcomes of hospitalization (controlling for severity) and a markedly lower use of high technology compared with those who have insurance. There is also growing evidence that limited access to primary care results in not only poorer health outcomes but also higher overall costs through delayed treatment, reduced patient adherence to therapeutic regimens, and increased emergency room and hospital admissions.

Payment

The level and means by which providers of healthcare are paid has a substantial effect on access, costs, and the quality of care. In countries that rely on a private healthcare delivery system (the United States, Canada, France, and Belgium) the predominant mode of payment for physicians who provide ambulatory care is fee-for-service. In most instances physicians bargain with insurers or the government over a fee schedule. In some countries there is a provision that physicians can charge patients more than the allowed fees in certain circumstances. There is concern that the financial incentives inherent in a fee-for-service system result in over utilization of services, especially those reimbursed at higher levels relative to other services. However, the autonomy of providers is preserved, and there is an incentive for increased productivity. Additionally, there is no conflict between the financial interests of providers and their duty to provide all services that are of benefit to patients. Cost- or charge-based reimbursement for institutions (hospitals, nursing homes, etc.) has similar risks and benefits.

Some insurers in the United States and the Netherlands use capitation (a set payment per person per year) or a set payment per case to pay providers. Capitation payments provide an incentive for healthcare workers and facilities to limit the volume of provided services and allow providers to determine precisely which services to provide. At the same time, case-based payment and capitation create a conflict between the financial incentive of the provider and the interest of the individual patient in receiving all services that are of possible benefit. This can be a problem for people with multiple chronic conditions, who are often the most expensive to treat.

In many countries, hospitals are paid on prospectively negotiated global budgets and hospital-based providers, including physicians, are paid on a salaried basis. These methods of payment have little apparent effect on the provision of services to individuals. However, the level of payment may have a profound effect on which technology is acquired and on whether providers expend the time and effort required to provide a given service in general.

Expenditures and Cost Controls

Since 1960 in virtually every country expenditures for personal healthcare services have been rising in absolute terms and in relation to GDP (Anderson et al.). Health expenditures have been increasing at a rate nearly double that of other major sectors of some national economies. In some countries concerns are being raised that spending on medical care is occurring at the expense of other socially desirable goods and services. This is especially true in the United States, where despite the highest per capita and GDP-adjusted healthcare spending in the world, healthcare is still not accessible to all, and there is growing concern about other social problems such as deteriorating schools, homelessness, poverty, and crime.

One reason for controlling health spending is that there is strong evidence that more healthcare spending does not necessarily buy better health (Newhouse). Even more compelling is the growing evidence that a substantial number of medical-care services may provide only small marginal benefits. Although small benefits and high cost are the norm in industrialized countries, many developing and economically disadvantaged countries cannot provide their populations with even basic public health measures such as immunization and sanitation.

In many industrialized countries cost controls have created the potentially unpopular phenomenon of waiting lists. Some countries, notably the United Kingdom and the Scandinavian countries, have implemented a policy of increasing health spending to eliminate waiting lists.

The response of different healthcare systems to the growing problem of cost has in general reflected the basic organization and values of each country. In countries with strong central control there has been increasing pressure to create fixed budgets and establish tight control over the acquisition of advanced technologies (supply-side control). Access to basic health services for everyone has been maintained at the expense of not providing expensive services that are potentially lifesaving for a few individuals.

By contrast, in the United States there are relatively fewer advocates for global budgeting. Efforts to reduce costs have focused primarily on enhanced competition (demand-side control). These cost-control mechanisms appear to have produced some one-time reductions in healthcare spending but have had a very modest effect on the rate of growth of expenditures.

Because of the seemingly inexorable rise in costs in the United States, employers have been shifting more of the cost of healthcare to employees by increasing employee-paid premiums, eliminating coverage for dependents, increasing copayments and deductibles, or eliminating coverage altogether. The response of private insurance companies to growing cost concerns has been to refuse to insure high-risk employees (medical underwriting) or to tie premiums directly to the previous year's expenditures by a particular group (experience rating). Employers became more aggressive in eliminating benefits such as health insurance for retirees when the labor market became looser and profits decreased. All these factors, along with a rise in the number of part-time workers and employment in small, nonunion service industries that lack medical benefits, have been primary determinants in the increase in the number of working-age individuals in the United States who are without health insurance.

Resources

The most visible aspects of any healthcare system are the facilities and personnel involved in the delivery of healthcare. Centralized systems have attempted to provide greater equality in the distribution of facilities and healthcare workers by focusing on the needs of a community rather than on the autonomy of providers and patients. In some centralized systems the national government may determine how many and which types of physicians, nurses, and other healthcare workers are produced; the location of hospitals and the technology they may purchase; and the location of hospital-based and outpatient-care providers. Care is strongly regionalized, with easily accessible primary care for most common healthcare problems, some specialty care available in regional hospitals, and subspecialty and tertiary care confined to a few large teaching centers.

In contrast to most other countries, the healthcare system in the United States provides little central control. There has been almost complete autonomy for providers, starting with a system of health-professional education with a substantial number of private schools and little or no restriction on specialty choice, practice, or hospital location or on the availability of technology. Because of the prestige and generous payments for new technology nearly all hospitals provide a full array of high-technology services. This complements a strong trend toward subspecialization among health professionals. In the case of physicians the percentage of generalists versus specialists declined from nearly 50 percent in 1961 to the current 28 percent; if OB/GYN and emergency medicine physicians are included in the generalist category, the figures are 32 percent primary care physicians and 68 percent specialists (Bureau of Health Professionals; Council on Graduate Medical Education). The abundance of specialists, especially those who are trained to perform high-technology procedures, is thought to exacerbate the over utilization of some healthcare services. Conversely, the decline in the number of generalists is believed to be a contributing factor in the poor access to healthcare experienced by persons in rural areas and those with low incomes in urban areas.

Choices for the Future

All countries are continuing to search for better cost-containment and cost-effectiveness mechanisms, including the difficult task of placing limits on the healthcare technologies that provide small marginal benefits to a few individuals at a great cost to the community.

Tension will grow between the values of individual autonomy (reflected in the assumption by patients that the *right* to healthcare includes all interventions that are of possible benefit and the assumption by providers that they have the *right* to set prices and choose where and whom to serve) and concern for the good of the community and other societal needs. Attempts to achieve equality in the systems of financing, payment, cost control, and delivery will have to take into account increasing competition for limited resources and the perceived infringement on personal freedom. Balancing these competing claims will be especially difficult in the United States with its multiple systems and distrust of government involvement in human services.

A renewal of a sense of community and a careful balancing of values will be necessary in achieving a reasonable solution. Although the future is unclear, the United States probably will reconsider policies for rational allocation between healthcare and other sectors of the economy, government regulation to require universal and equitable access to defined *basic* insurance policies, mandated employer-based insurance with a publicly financed safety net, payment based on capitation with some adjustment for the severity of illness in a specific group of patients, and incentives (including scholarships and loan forgiveness) for providers who choose to provide primary care in shortage areas.

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SEE ALSO: *Advertising; Health Insurance; Health Policy in International Perspective; Health Policy in the United States; Healthcare Institutions; Healthcare Resources, Allocation of; Hospital, Contemporary Ethical Problems of*

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HEALTH INSURANCE

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The social and economic vulnerability of wage laborers gave rise to nineteenth-century reforms that are the forerunners of modern health insurance. When the flow of resources to a household depends on wage labor, sickness for any prolonged period threatens the family's ability to secure food and shelter. The practice of organizing workers to contribute a portion of their wages to health (or sickness) insurance funds was a response to this vulnerability, and set a social pattern in industrialized nations that has continued for more than a century. The two principal ethical concepts associated with health insurance are social solidarity and social justice.

Health Insurance and Social Solidarity

As was evident in the European sickness funds, the insurance compact expresses an underlying solidarity among insurance pool subscribers. Persons facing a common vulnerability organize into a group whose shared resources, built up from relatively small individual contributions, will assist members who suffer financial loss as a result of illness or injury. Since the anticipated harm is a matter of probability, the group that pools its resources must be large enough and composed of persons with sufficiently variable risk levels so that, in a given period of time covered by the contributions (or premiums), only a minority of those at risk will actually experience illness or injury. The majority will contribute without needing to draw on the pooled resources. Those who do not encounter harm stand in a relationship of fiscal solidarity with those who do. The smaller the group, the more vulnerable it is to being overwhelmed by a small number of very large claims. If the group includes a large number of persons with high probability of need (the elderly, for example), a high level of member contributions will be required to guarantee adequate resources to cover every claim.

In addition to the purely fiscal relationship among contributors, reigning social and political ideas affect the conscious feelings of solidarity they experience as members of an insured group. Compulsory sickness insurance for workers, providing for both lost wages and the cost of medical care, was first organized at a national level in 1883 in Germany by the conservative chancellor Otto von Bismarck as a defensive maneuver against the rising influence of the German Social Democratic Party. As Paul Starr noted in his 1982 work, Bismarck believed workers were less likely to demand more radical reforms if certain harsh realities of the industrial revolution could be tempered with benevolence flowing from the monarchy.

In the closing decades of the nineteenth century, several other European nations took similar actions to protect workers' vulnerability, but the United States showed little interest in the idea until the Progressive reformers began to press the issue in the early years of the twentieth century (Hirshfield). They promoted compulsory health insurance as a form of enlightened self-interest on the part of the middle class: The survival of individual freedoms essential to capitalism required taming the tendency of free enterprise to pursue profit without concern for the precarious circumstance of wage laborers. Robert N. Bellah, et al. (1985) noted that the vocabulary of individualism typical of the culture of private consumption has shaped public discourse about health insurance in the United States, and the concept of social solidarity is only faintly evident in the debate that has evolved since the early twentieth century (Churchill).

In some societies, social consciousness about health insurance sees it as a component of the nation's system of social insurance—that is, a public guarantee that certain basic human needs will be met at some minimum level for all members of the community. This has typically been the meaning of health insurance in Western Europe. Conversely, health insurance may be seen as a marketable service properly residing in the private sector, which has been the dominant, though not unanimous, social understanding in the United States (Greenlick, 1988).

The Progressives' compulsory insurance campaign had failed prior to 1920, and by the late 1930s, the idea of voluntary health insurance for workers as a fringe benefit of employment had taken over as the prevailing rationale for social change. The appeal of voluntary insurance, supported by tax subsidies for employers and workers, was fully compatible with the Progressives' individual freedoms argument. Indeed, the voluntary approach seemed capable of solving the solidarity problem, as the percentage of the whole population with voluntary hospital insurance shot up from less than 10 percent in 1940 to 57 percent in 1950 and to nearly 90 percent by the early 1970s (Anderson). With health insurance spreading widely through the working community, yet systematically leaving those not in the workforce outside the fold, the idea of national health insurance based on explicit appeals to solidarity and social justice emerged periodically but each time failed to pass into law (Hirshfield; Starr).

Health Insurance, Social Justice, and Rights

The concept of justice is the second major ethical theme associated with health insurance. Concerns about justice and health insurance derive from the question whether it is fair for some, but not all, citizens to have insured access to healthcare. Originally, health insurance was viewed as required by social justice not for everyone, but only for those made vulnerable by the conditions of wage labor. Compulsory insurance schemes were designed to help capitalism by making the working class more secure. The U.S. middle class broadly committed itself to the voluntary purchase of health insurance when, as a means of winning better fringe benefits through collective bargaining (intensified under wage and price controls during World War II), getting health insurance as a benefit became a normative expectation of workers.

Once the idea of health insurance takes hold in a society and is widely believed to give access to a fundamental benefit of social existence, it comes to be seen as the way members of the society purchase their healthcare, not merely the way they protect themselves from potential financial loss. Having insurance and getting needed healthcare become closely linked in the logic of justice. (For an account of how social expectations give rise to the perception of entitlement and societal obligation, see the work of Michael Walzer.)

The idea of a right to healthcare as a requirement of social justice is intimately connected to the practice of collectively financed healthcare. The notion that healthcare might count among positive human rights derives from the widespread belief that healthcare successfully meets fundamental human needs, such as security, relief from suffering, prevention of premature death, and maintenance of functional capacity. (For a philosophical argument about the grounds and limits of universal entitlement, see Norman Daniels's work and Charles J. Dougherty's publication.) Creating legal protections for that right becomes a problem of political will.

The injection of rights language into political arguments about health insurance is itself evidence of the evolution of the concept and expansion of its original limited goal of protecting wage laborers from the effects of major illness. In the absence of a constitutional or statutory declaration of a right to healthcare, opinion leaders use human rights language to motivate members of society and to provoke legislative action aimed at helping persons whose needs are being ignored. While specific contractual rights to healthcare exist between insured persons and their insurance carriers, that is not what advocates of a right to healthcare have in mind. When reformers argue for a right to healthcare, they mean that basic relationships of solidarity and interdependence among all members of society create a societal obligation to ensure access to healthcare for all. (For a discussion of issues raised by rights discourse in relation to health insurance and access to healthcare, see the U.S. President's Commission Report, and the 1994 work edited by Audrey Chapman.)

During the second half of the twentieth century, aggregate expenditures for healthcare rose at such a dramatic rate that by the 1980s, cost control in healthcare became a central issue for reformers. However, the question of setting limits makes debate about a right to healthcare politically difficult. Unlike rights to liberty or the pursuit of happiness, which entail noninterference by others, a right to healthcare entails paying someone to provide costly services. By 1990, the need to speak of a limited right was clear to many leaders, although negative reaction to the idea of rationing healthcare led many to deny its necessity, and how to define limits was hotly debated (Strosberg). In 1989, the state of Oregon intensified the debate when it organized a unique social experiment to guarantee coverage to uninsured persons while setting limits on what would be covered based on a prioritized list of healthcare services (Garland, 1992, 1994, 2001).

Organization and Financing of Health Insurance

The fundamental concept of any form of insurance is risk sharing: A large number of people who face a common threat of harm (auto accident, fire damage, costs of treatment for illness or injury) share their risks by paying premiums to an insurer who promises to finance payments to those who in the future actually suffer misfortune. All members of the risk-sharing group get a sense of security in return for their contributions even if they do not receive specific insurance payments (as a result of being personally harmed).

Ethical issues in risk sharing through health insurance are shaped by the insurer's decisions about how to organize and finance the common fund that members of a group rely on for protection against potential financial loss. For example, insurers may organize risk-sharing pools among individual subscribers, various age groups, business firms, or labor organizations. Financing might be done through a single, community-wide premium or through variable premiums tied to past utilization, health-risk or ethnic group or age or gender. The European approach was to develop social insurance mechanisms, or sick funds, initiated by the public sector. In the United States, the free market casualty insurance model was adapted in a unique form to fulfill the social insurance function. The resulting hybrid fails to satisfy either free market norms or social insurance ideals.

The major development in U.S. health insurance in the 1930s and 1940s was led not by government or business but by nonprofit corporations such as Blue Cross (hospital insurance service corporations), Blue Shield (physician insurance service corporations), and a variety of consumer and producer cooperatives that provided coverage for hospital and medical services. The corporate missions and characteristics of these organizations gave U.S. health insurance a strong social insurance tendency without fully incorporating the European approach.

Because they believed that the nonprofit organizations' approach to health insurance violated the basic tenets of casualty insurance, commercial insurers initially showed no interest in this market (Iglehart). Casualty insurance assumes that a hazard insured against is measurable and not something the insured person wants (such as checkups or preventive services), or can control (such as pregnancy).

From the beginning in the United States strict casualty insurance principles were ignored. While health insurance protects subscribers from the financial impact of relatively rare high-cost medical services, plans commonly also cover many low-cost services used every year by most members of the insured group. The typical health insurance plan provided to employees of large corporations includes coverage for some ambulatory care costs (office visits, X-rays, and laboratory services) and the major portion of emergency room and hospital charges. About 80 percent of the population will use some ambulatory care services, while only 10 percent of the population will need hospital care in any given year.

By the time the commercial insurers overcame their suspicion of the field, the nonprofit insurers had already brought much social insurance philosophy into the market. Consequently, while the health insurance language includes many standard insurance terms ("adverse selection," "moral hazard," "product lines," "lives covered by plans"), leading the casual observer to conclude that the field is a traditional casualty insurance market, it is, in reality, a form of social insurance peculiar to the United States. However, the competitive practices of commercial insurers have led to widespread use of experience rating, which undermines the social insurance spirit by making health insurance more expensive for those in greatest need. Health insurance plans use three basic methods to protect subscribers: indemnity benefits, service benefits, or direct provision of service. Indemnity insurance, typical of commercial insurers, reimburses a patient for a portion of incurred medical expenditures. Service benefits, typical of nonprofit insurers, pay physicians and hospitals directly on behalf of subscribers. Health maintenance organizations, by contrast, actually organize and deliver services directly to their members at clinics and hospitals that the plans usually own and operate, paying for professional services by salary or contract, not on a fee-for-service basis.

In a widespread effort to control medical care costs in the 1990s, managed care systems, especially those who were not associated with organized delivery systems, used various discounting and risk-sharing reimbursement mechanisms to pay medical service providers. By 2000, providers and patients had grown increasingly unhappy with the restrictions imposed by managed care strategies and the organizations could claim little success in controlling medical costs (Levit, Smith, and Cowen). New strategies relied on shifting costs to patients and members of insurance plans (Draper, Hurley, and Lesser; Christianson, Parente, and Taylor; Trude, Christianson, and Lesser). Six major tendencies characterize the way U.S. health insurance adapted casualty insurance concepts to serve a social insurance function: leadership by nonprofit corporations; a gradual shift from financing based on equal shares (community-rated premiums) to financing based on unequal shares (experience-rated premiums); consumer preference for comprehensive benefits; use of service and indemnity methods of benefit definition; carriers' preference for group rather than individual marketing of plans; and persistent ambivalence in the general public about the role of government in health insurance.

NONPROFIT STATUS OF HEALTH INSURANCE PIONEERS. Because the pioneers in U.S. health insurance were nonprofit, charitable organizations, they were developed to provide a social function beyond creating a profit for shareholders or syndicate owners. However, the social objective was not always to benefit consumers. Blue Cross was first organized to provide for the financial survival of the American voluntary, nonprofit hospital system during the period of the Great Depression. Although organized medicine initially opposed the new insurance schemes as unwanted intrusions into the privacy of the patient-physician relationship, Blue Shield was eventually formed as a preventive measure to keep mechanisms for paying physicians under the direct control of organized medicine. Provider cooperative prepaid group practices, such as Kaiser Permanente, were formed because some reform-minded physicians believed that prepaid group practice was a more satisfying and socially responsible way to practice medicine.

These nonprofit institutions were chartered in the public domain and were guided by boards of directors who were reminded that they represented society at large, rather than a group of stockholders. The corporate cultures that emerged under this influence generally produced organizational behavior different from that found in commercial insurance companies (Greenlick, 1988). The nonprofit corporations possessed a sense of mission to the community, a sense nurtured by their close ties to community hospitals and physicians' organizations. In the 1970s, pressured by their large corporate customers to contain costs, the nonprofit insurers began to behave like their competitors, the commercial insurance companies, and moved from community rating of premiums to experience-rating practices. Consequently, premiums increased for high-risk groups, making it difficult for the most needy to maintain health insurance coverage.

COMMUNITY-RATED VERSUS EXPERIENCE-RATED PREMIUMS. In an institutionalization of the concept of solidarity, the pioneer U.S. health insurance organizations originally used community-rating principles to fund their programs. In pure community rating, the premium is set by estimating the required budget for the covered population for the next year and dividing the total budget by the number of people expected to be covered. The result is the premium charged to each member of the population for the coming year. Thus, all employers in an insurer's service area would be charged the same per capita premium for their employees.

By contrast, in an experience-rated system, the approach favored by commercial carriers, the most recent available claims experience is analyzed to define a risk profile for specific groups. These risk profiles are applied to the next year's expected total budget to calculate group-specific premiums. Experience rating increases the premiums for groups that include high-use subscribers and reduces premiums for groups that include infrequent users. Consequently, people with serious and chronic health problems, who most need the risk-sharing of health insurance, are forced to pay higher and higher premiums, until they can no longer afford the cost of coverage (Greenlick, 1989).

As experience rating became more common, people with preexisting health conditions were frequently excluded from insurance coverage. This led many states during the 1980s to create special high-risk pools for "uninsurables." The practice also made health insurance too expensive for thousands of firms with small numbers of workers, especially those where even one worker had recently experienced a high-cost illness episode. The shift toward experience rating by nonprofit insurers has led to a disturbing incongruity between a social policy that favors free market practices in U.S. health insurance and a prevailing public expectation that private health insurance should fulfill a social insurance function.

COMPREHENSIVE BENEFIT PACKAGES. Because pioneer health insurance organizations had among their objectives supporting the providers of care, they designed insurance plans based on comprehensive benefits that would cover not only infrequently needed high-cost services but also many low-cost services that might be used regularly by most subscribers. The idea of comprehensive benefits was very popular with the employees whose employers were paying most, or all, of the premiums for health insurance. This popularity was supported by the post-World War II belief that economic growth could permanently keep pace with new demands. During the 1960s and 1970s, most Blue Cross Blue Shield and prepaid group practice plans covered, with little deductible or coinsurance cost to the insured, most of the costs of physician, laboratory, X-ray, emergency room, and hospital medical and surgical services. During the 1970s, insurers increasingly added coverage for prescription drugs. To keep pace, commercial insurance companies increased the breadth and depth of their coverage, particularly for low-risk groups.

The preference for comprehensive benefits contributed to the explosive rate of growth in the health services industry during the postwar era. In 1940 healthcare accounted for 4.1 percent of the gross national product (GNP). It had expanded to 7.2 percent by 1970, reaching 10.7 percent in 1985 (Eastaugh). By the late 1970s, a chronic sense of crisis afflicted business and government administrators of health insurance budgets. Cost-containment strategies that used deductibles and coinsurance to reduce the use of health services by insured persons achieved only modest success. However, these typical casualty insurance mechanisms conflicted with the social insurance function of health insurance and were hotly debated among health insurance reformers in the early 1990s.

SERVICE BENEFITS VERSUS INDEMNITY BENEFITS. A distinguishing characteristic of the Blue Cross/Blue Shield programs and the prepaid group practices is that they sell their customers a promise to provide medical care services (service benefits) rather than a promise to reimburse incurred expenses (indemnity benefits). Service benefit organizations concern themselves with issues of delivery of care more than indemnity insurers, who cover only a specified portion of medical care expenses.

Preferred provider organizations (PPOs) and multiple forms of health maintenance organizations (HMOs) emerged from the cost-controlling strategies of the 1970s and 1980s. These service-delivery reforms sought cost savings through peer group review of practice patterns, favoring those that produced effective care while reducing frequency and length of hospitalizations, using fewer repeat visits, and increasing the use of outpatient care in place of costly hospital services. U.S. insurers took a hand in designing and administering these delivery system reforms, giving them a significant role in healthcare that went far beyond merely paying the bills.

GROUP ENROLLMENT VERSUS INDIVIDUAL MARKETING. Like the European social insurance movement, the development of health insurance in the United States was based on enrollment through employment groups. As more Americans left rural occupations and moved to the cities during and after the Great Depression of the 1930s, they found work in large industrial companies that increasingly offered comprehensive health insurance coverage as a fringe benefit of employment. The health insurance industry focused on enrolling members through work groups. As long as employment in these industries grew, so did the proportion of U.S. citizens covered by health insurance. Labor market forces seemed to be producing social insurance goals without the need of centralized decisions.

Employment-based group enrollment ultimately comes up short from the social insurance perspective, however, since many persons with significant healthcare needs are not in the work force and will not have access to health insurance. This way of distributing health insurance leaves workers doubly vulnerable to fluctuations in the labor market: Low-wage jobs frequently do not include health insurance benefits, and business cycles or industry competition may cause work force reductions leading to loss of health insurance for employees and their dependents (homemakers and children).

Inequities in the labor market carry over to health insurance when employment is the basis for its distribution (Jecker). Women's groups argue that healthcare services important to women, such as mammography, have tended not to be covered. Women who work are less likely than men who work to have employer or union contributions to their insurance. Women are also more likely to work part-time and receive no fringe benefits. Women are less likely to belong to a labor union and they change jobs more frequently than men, making them more vulnerable to preexisting condition exclusions from insurance. Women predominate in low-paying jobs where insurance is usually not offered as a benefit. Many of these distribution inequities also affect minorities, leading some reformers to argue for uncoupling health insurance from employment.

After vigorous growth between 1940 and 1960, the employment-based system had generated health insurance coverage for nearly 70 percent of the population under sixty-five, while only slightly more than 40 percent of the elderly were covered, leading to the establishment of Medicare and Medicaid in 1965 (Anderson). These two programs brought health insurance protection to virtually all of the elderly, and to a significant proportion of those living in poverty, as well. They did not, however, provide coverage for everyone, so that the United States entered the 1990s with more than thirty million citizens having no health insurance. This fueled a vigorous revival of interest in a national health insurance program capable of guaranteeing coverage for every citizen.

During the 1980s, self-insurance emerged as a cost-control strategy among large corporations. These firms stopped buying health insurance for their workers and set themselves up as the at-risk entity for healthcare costs incurred by their employees. The practice put these corporations beyond the reach of state insurance regulations because of a 1974 federal law, the Employee Retirement Income Security Act (ERISA). The intent of ERISA was to protect pension trust funds in companies with employees in several states from inconsistent and burdensome state regulations. The effect on health insurance, while not a primary goal of ERISA, so complicated health-insurance reform that, by the late 1980s, it became a critical element in all proposals that relied on employee benefits as the primary vehicle for distributing health insurance to citizens.

At the beginning of the twenty-first century, the concept of *defined contribution* to employee benefit packages (rather than defined benefits) became popular among free market reformers (Christianson et al.). This concept responded to employers' desire to be less involved in insurance purchasing and shift decision making to their employees. The strategy combined a set amount of employer contribution with a responsibility on employees to purchase their own health insurance. Employees could use a portion of the defined contribution for direct purchase of services. In the final analysis, employees in such a plan would be individually responsible to cover the costs of their care with a combination of out-of-pocket spending, insurance protection, and limited access to the defined contribution pool created by the employer. This approach can be understood as an effort to deemphasize the social insurance model by insisting on increased consumer responsibility for non-catastrophic healthcare needs.

The Government Role in U.S. Health Insurance

The U.S. government has had a role in health insurance since the eighteenth century, when it accepted the responsibility to provide medical care for the U.S. Merchant Marine. During the growth period of private health insurance in the United States prior to Medicare and Medicaid (1940–1965), the federal government let the private market work, limiting itself to indirect involvement through tax incentives for employers and employees who favored the purchase of health insurance as a fringe benefit. State and local governments were expected to provide care to the indigent and to the mentally ill. As a large employer, the federal government became a major purchaser of health insurance for its employees.

Finally, the federal government is a major supplier of social insurance for medical care for Native Americans, active-duty military personnel and their dependents, and veterans. The total public expenditure for medical care services in 2000 was $590 billion, 45 percent of the $1.3 trillion total national expenditure for health services and supplies during the year.

Government involvement in U.S. health insurance differs distinctly from paths followed by most other industrial nations. In Europe, several nations have made the direct delivery of healthcare a national government responsibility (e.g., the United Kingdom and the Scandinavian countries); others have taken up the role of coordination in mixed public-private systems (e.g., Germany, the Netherlands, Switzerland); others have assumed the role of providing health insurance to the citizenry, allowing hospitals and physicians to operate in a fee-for-service environment (France).

In the late 1960s, Canada adopted an approach similar to France's: Each province has a monopoly on health insurance for basic services, while the federal government plays a coordinating role. Canadian Medicare rests on five essential principles: universal entitlement, accessibility of services, comprehensive benefits, portability of benefits across provincial boundaries, and public administration of the system within each province.

Questions about the proper role of government in health insurance continue to be central issues in debates among U.S. health insurance reformers. Proposals put forward in the first decade of the twenty-first century will succeed or fail on the basis of their ability to make the case that they have found an acceptable balance point on the public-private continuum where private markets (insurance carriers, providers, suppliers) come together under public policy constraints to produce an acknowledged common good.

Conclusion

As the twenty-first century dawned, the evolution of health insurance in the United States and elsewhere had reached a point where significant new public policy decisions were increasingly demanded by the consumer groups, business, politicians, and health professionals (see Rashi Fein's work).

In all industrial nations, the rates of growth in total expenditures for healthcare were creating economic strains and social concern (see the report of the Government Committee on Choices in Healthcare). Particularly in the United States—with the highest percentage of its GNP devoted to healthcare—business, government, and consumer groups insisted on effective control of total healthcare expenditures. Some argued that the solution had to come from submitting healthcare to a competitive market. Others preferred government regulation through global budgets, delivery system reforms, and limitations on services that qualify for collective financing. Most reformers insisted that health insurance had to stop fueling uncontrolled growth in healthcare spending.

Expenditure control has major consequences for the social insurance aspect of health insurance schemes. Many European nations and Canada have sought to control total expenditures without sacrificing the healthcare component of their social insurance commitments. In the United States, many providers, social reformers, and the general public have demanded explicit commitment to the social insurance dimension of health insurance: a universal system that would guarantee a decent minimum of healthcare to every citizen. Reformers were particularly concerned to have the nation address the equity issue. During a thirty-two-month period in 1990–1992, one-fourth of the entire population outside of institutions were without health insurance for at least one month; more than one-third of the African-American population and nearly one-half of the Hispanic population found themselves excluded from coverage (Pear).

Growing public awareness of the size of the uninsured population and the vulnerability of the middle class to loss of job-related health insurance have led to growing dissatisfaction with the system and sparked a renewed interest in health insurance reform. Dozens of proposals emerged in the late 1980s and 1990s driven by several key questions. Should America continue its multiple payer, public-private system, or embark on a new path with a streamlined single-payer system? Should the single payer be the federal government or each state? If there were to be multiple payers, who would conduct the negotiations needed to coordinate their practices so that universal coverage would be achieved and maintained?

The multiple-payer approach continues the path of adapting casualty insurance and free-market forces to serve the social insurance function. In the mid-1990s, President Bill Clinton proposed a market-structuring, multiple-payer solution (White House Domestic Policy Council; Zelman), and was immediately criticized by sponsors of competing market proposals for interfering too much with market forces and not trusting them to achieve efficient allocations (Enthoven and Singer). Single-payer advocates, arguing that Clinton was fundamentally mistaken and that the private health insurance market was simply the wrong vehicle for achieving universal coverage and cost control, invoked the social insurance model, abandoning market pluralism in favor of uncomplicated universality and administrative efficiency achievable through centralized financing.

Finally, the Clinton proposal failed politically. Backing away from universal coverage, the Clinton Administration launched a special program to increase children's access to coverage in 1997 (Title XXI of the Social Security Act, the State Children's Health Insurance Program). By 1999, all fifty states had approved programs that either created a special program for children, an expansion of Medicaid, or some combination of the two. Despite success in reaching children, the percentage of Americans without health insurance has grown, costs have not come under control, and the critics of the status quo remain unable to attract sufficient political consensus to bring about universal coverage.

Health insurance in the United States continues to evolve. The tension between the casualty insurance practices and social insurance ideals frustrate reformers in both camps. The enduring challenge is to formulate policies that can control total expenditures while allocating resources fairly and promoting the common good.

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SEE ALSO: *Conflict of Interest; Corporate Compliance; Economic Concepts in Healthcare; Genetic Discrimination; Healthcare Institutions; Managed Care; Medicaid; Pharmaceutical Industry; Profit and Commercialism; Race and Racism; Sexism*

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HEALTH POLICY IN INTERNATIONAL PERSPECTIVE

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Health polices of international agencies and individual countries reflect choices involving diverse ethical issues, including rights and responsibilities of individuals versus society, choices over who benefits and who pays for healthcare services, trade-offs between saving identifiable lives and statistical lives, and choices involving interpersonal and intergenerational equity. This entry begins by examining the role of international agencies in providing public health services, ethical issues raised by testing and use of new drugs, and government involvement in purchasing and providing healthcare. It then outlines four generic models for healthcare financing and delivery that many countries have adapted to their unique circumstances. These four healthcare financing and delivery models reflect different choices about an individual's right to basic healthcare services, and views about whether an individual's ability to pay should influence access to certain services.

Public Health and Preventive Services

International agencies play a critical role in health policy, first by setting public health and health-status goals, and then by monitoring an individual country's progress toward these goals. For example, over the past twenty years the World Health Organization (WHO) has established goals and specific targets for the *Health-for-All* initiative. Two fundamental objectives of this initiative are: (1) making health central to human development and (2) building sustainable health systems (Antezana, et al.). In order to monitor these objectives, Health-for-All in the 21st Century has identified global health targets that each country should meet, such as eliminating certain infectious diseases through childhood immunization and improving access to water, sanitation, food and shelter (Visschedijk and Simeant). In 2000 the WHO began ranking and assessing health systems's performance in 191 countries based on five composite indicators. The WHO hopes to make this assessment a regular activity, which will help policy-makers to monitor their performance in comparison to other countries (WHO, 2000a).

In most countries, public health agencies have the primary responsibility for creating programs that will achieve specific health objectives. International agencies like the World Bank and the United Nations and some affluent countries have programs to assist developing countries. The U.S. Agency for International Development (USAID), for example, operates programs that help developing countries to establish and operate a variety of public health activities.

While there is generally a consensus that government agencies should finance and provide public health and disease-prevention services, policy differences and financial commitments affect the success of specific programs. For example, the childhood immunization rates for six major infectious diseases (diphtheria, pertussis, tetanus, measles, poliomyelitis, and tuberculosis) vary greatly from country to country. In 2000 the immunization rates for diphtheria, pertussis, measles, and poliomyelitis ranged from 55 percent of infants in Africa to over 90 percent of infants in Europe (WHO, 2001). In most countries the WHO's target rate of 90 percent coverage for the year 2000 was not achieved (WHO, 2001).

Another public health activity, the testing and approval of drugs, highlights conflicting ethical values. Beneficence, in terms of concern for public welfare, is reflected when nations employ comprehensive but time-consuming approval processes in order to ensure a safe and efficacious drug supply. The U.S. Food and Drug Administration, for example, has adopted strict regulatory standards that prevent the domestic adoption of new drugs and devices until their safety and efficacy are established beyond reasonable doubt (Sheinin and Williams). In contrast, a respect for autonomy, in terms of individual access to healthcare, is obstructed when the length of the drug approval process delays access to potentially lifesaving treatments—particularly for patients who have exhausted current treatment options and are willing to take experimental drugs.

Since the early 1990s, people with acquired immunodeficiency syndrome (AIDS) have been the most vocal proponents of allowing individuals unrestricted access to unproven medical treatments. Advocates of placing greater weight on beneficence, on the other hand, point to the approval of thalidomide by the United Kingdom in the 1960s, while it was still in testing stages in other countries. The drug was never approved in other countries and was pulled from the British market after it became apparent that severe congenital deformations resulted from maternal use of the drug (Burger).

The principle of justice can be jeopardized when drug trials are carried out in developing countries by investigators and sponsored by agencies from developed countries (Beyrer and Kass; Council for International Organization of Medical Sciences [CIOMS]). Some developing nations have used drugs not approved in industrialized countries. Lower costs of unapproved drugs make them a relatively affordable medical treatment option for poorer nations. In some cases, individuals in low-income nations benefit from access to various drugs, while in other cases individuals are harmed by access to unsafe or inefficacious therapies. For example, HIV/AIDS accounts for about 20 percent of all deaths in Africa, which creates urgent need for new drugs and effective vaccines for HIV infection (Creese, et al.). This urgency is being used to lower the ethical standards of international research and result in ethically controversial actions (e.g., not providing drugs after the conclusion of the clinical trial or make the drugs available at unaffordable prices) (Greco, Stolberg, Okie). In order to assist the efficient purchase of safe and efficacious drugs by developing nations, the WHO and other international agencies have established *essential drug lists* that identify drugs satisfying the healthcare needs of the majority of the population, and are revised every two years (WHO, 2000b).

Medical Services

Particular attention should be paid to ethical choices in the financing and delivery of medical services, since these services account for a large portion of most countries's total healthcare spending (Organization for the Economic Cooperation and Development [OECD]). The provision of medical-care services requires policymakers to debate myriad ethical values and conflicts, and each country's medical-care system reflects its choices about underlying ethical matters.

Unlike public health activities, which are considered to benefit all members of society, medical-care services are generally considered as private goods, since it is the individual who benefits directly from them. Some countries consider access to medical care a merit good—a good that, although private, benefits society as well. Health insurance is a major determinant of access to care. In most industrialized countries health insurance coverage is universal. In the United States, however, 14 percent of Americans did not have health insurance in 2000 (Mills).

Similar value choices are exemplified by the benefits package that countries's health systems offer. Some countries's health systems cover only hospital and physician care, while others include such items as long-term care, drugs, dental care, home health services, and eyeglasses (Healy). In addition, many European countries incorporate housekeeping, spa vacations and social services into their provision of healthcare services. Cultural norms also affect countries's health systems. Japan, for example, did not establish a formal system of long-term care until recently, in part because of the tradition that the eldest son and his wife have had responsibility for the son's parents (Campbell and Ikegami).

Countries's decisions about government involvement in provider issues can highlight conflicts between the individual liberty of providers and patients's access to care. Some countries, such as Israel, have adopted policies that restrict providers's ability to practice in areas that exceed a certain physician-population ratio and have developed policies that encourage them to operate in underserved locations (Anderson and Antebi). Other policies may limit the total income that can be generated by health professionals, either through restrictions on the salaries that physicians can earn or by limiting the volume of services the physicians may provide (White). In addition, some countries, such as the United Kingdom, permit providers to operate publicly (through a national health service) and have a private practice (Healy). Other countries, like most of the provinces in Canada, require a provider to work completely in the publicly financed plan or completely in the privately financed sector (Flood and Archibald).

Countries use three basic mechanisms, in addition to out-of-pocket payments, to finance medical-care services. One option is to use general tax revenues. With this method, citizens pay for medical services based on the structure of the overall tax system. This option is considered by economists to be the most progressive. For economists, progressive means that the income tax rate increases as the taxpayer's income rises. A second basic method to generate funds for medical-care services is through a payroll tax earmarked for the health system. This is referred to as a proportional or flat tax since the tax rate does not vary with income. The third basic method to finance medical-care services is through health-insurance premiums. This method is considered to be regressive by economists because the rate falls as income rises.

A related financing and access issue is that of the cost sharing by individuals. Cost sharing, such as coinsurance, copayments, and deductibles, is introduced when health insurance systems want to give patients a financial incentive not to use certain health services—especially services they believe to be only marginally beneficial. However, the patients' ability to make appropriate choices is debatable especially when they are poor (Fuchs). Poor patients's demand for care depends more on whether they have money at the time than on their own judgment of the seriousness of the condition (White). Some countries, such as the United Kingdom, Canada, and Germany, operate with no or nominal deductibles and coinsurance (Glaser, U.S. General Accounting Office 1991a, 1991b). Other countries have substantial cost-sharing requirements. For example, 10 to 20 percent coinsurance requirements are typical in the United States and France, and 20 to 30 percent coinsurance requirements are typical in Japan and Korea (U.S. General Accounting Office 1991b, Anderson).

Four Healthcare Financing and Delivery Models

As individual countries design their own healthcare financing and delivery systems, they make a number of policy decisions that are based upon ethical considerations. These decisions involve choices regarding who is covered, the method of financing the medical-care delivery system, and whether the delivery system is public or private. These healthcare financing and delivery systems are categorized below into four models and specific countries are identified that exemplify each type of model. It is important to recognize, however, that no country fits any model precisely, and that healthcare systems are dynamic. The four generic models are national health service, national health insurance, social insurance, and private voluntary health insurance.

NATIONAL HEALTH SERVICE. National health service systems usually collect revenues from general taxation, mandate the use of public facilities, and have limited cost sharing. As a result, countries with national health service generally offer the greatest equality in access to care and employ the most progressive financing methods. However, some critics have expressed concern that national health services may be relatively inefficient and unresponsive to individuals's healthcare service preferences (Enthoven).

The United Kingdom's National Health Service (NHS) is the archetypal example of this model. Since its creation in 1948, the guiding principal of the NHS has been equity—equal access to healthcare services for all inhabitants. The NHS offers a comprehensive array of government-provided services, a national benefits package, and is financed by general tax revenues. During the early 1990's, the concerns about inefficiencies and customer service led to introducing some market incentives and development of a system of competition within the NHS (Enthoven). However, subsequent reforms initiated by the Labor government largely abolished the quasi-market and emphasized the idea of collaboration with a return to strong elements of command and control (Le Grand).

NATIONAL HEALTH-INSURANCE PROGRAM. National health-insurance systems usually generate revenues from general taxation, have private providers and facilities, allow the government to set payment rates for healthcare providers, and may have limited cost sharing. The major difference between national health insurance and national health service is the ownership of the facilities.

The Canadian health system is an example of a national health-insurance system. Revenues are generated from general taxation, the government sets payment rates for the providers who participate in the system, and there is no cost sharing. Healthcare professionals must choose between participating in the national health-insurance system and opting out of the system entirely to work in the privately financed sector (Flood and Archibald).

SOCIAL INSURANCE. In social insurance systems, revenues are generated from payroll taxes, the private sector provides health insurance, private facilities are common, and the government sometimes sets payment rates for providers. Although insurance is compulsory, and thus accessible to all, the scope of healthcare benefits may vary by plan.

Social insurance, the first type of health insurance to be developed, was introduced in Germany by Otto van Bismarck [1815–1898] in 1883. Germany has continued to use the social insurance system, and several European nations and other countries like Japan and Korea have modified the basic social insurance model to meet their own needs (Glaser, Powell and Anesaki, Anderson).

PRIVATE VOLUNTARY HEALTH INSURANCE. In the private voluntary health insurance system revenues are generated by a variety of sources including premiums, payroll taxes, and general taxation, private facilities are the norm, the government may or may not set provider payment rates, and coinsurance is common (Maxwell, Storeygard and Moon). This system is likely to have the greatest disparity in access to healthcare services, since access is based upon ability to pay. In addition, it is common for a proportion of the population to be uninsured. In theory, this system should be more efficient than government-run health systems, because free-market competition should result in greater efficiency (Enthoven and Kronick). However, it is believed by many that free-market principles, such as a free flow of product information and price sensitivity among consumers, do not fully apply to the healthcare sector, and consequently competition and greater efficiency do not always occur (Rice et al.). The United States and many low and middle-income countries use a system of voluntary private health insurance.

Summary

Health financing and delivery systems are influenced by divergent views on a number of ethical issues. Countries must resolve ethical dilemmas such as (1) whether access to basic healthcare services is one of the fundamental rights of every human being, and (2) how scarce resources should be allocated between the old and the young, between medical and preventive care, and between healthcare and other social needs, as they develop their healthcare systems.

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SEE ALSO: *Access to Healthcare; Aging and the Aged: Healthcare and Research Issues; AIDS; Beneficence; Children; Economic Concepts in Healthcare; Freedom and Coercion; Future Generations, Reproductive Technologies and Obligations to; Healthcare Resources, Allocation of; Human Rights; International Health; Justice; Labor Unions in Healthcare; Managed Care; Medicaid; Medicare; Patients' Rights; Pharmaceutical Industry; Public Health; Research Policy*

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HEALTH POLICY IN THE UNITED STATES

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Issues of health and healthcare are rather similar across countries, and there are many commonalities in the ways that governments deal with them through health policies. All industrialized nations, for instance, have public health programs and license and regulate healthcare providers to some extent. But there are many differences among their health policies as well—policies that both address and raise issues of justice. Much of the variation in approaches can be traced to the histories, ideologies, and institutions of respective political systems. The relatively unique character of the American political tradition is an essential context for understanding the distinctive aspects of health policies in the United States and their bioethical implications.

Impact of Liberal Ideology

Compared with other industrialized nations, the political ethos of the United States emphasizes the importance of the individual rather than the collectivity (see Gøsta Esping-Andersen). U.S. political ideas, institutions, and behavior uniquely reflect a virtually unanimous acceptance of the tenets of seventeenth-century English political philosopher John Locke, whose liberal philosophy was in harmony with the laissez-faire economics subsequently propounded by Adam Smith in *The Wealth of Nations* (2000 [1776]). As Locke propounded in *Of Civil Government, Two Treatises* (1924 [1690]), the individual should be much more important than the collective, and one of the few important functions of a limited state is to ensure that the wealth that individuals accumulate through the free market is protected. The framers of the U.S. constitution, strongly influenced by the atomistic individualism of Locke's philosophy and his views on the sanctity of private property, took pains to limit the power of government. The constitutional rights they established for American citizens are largely protections for the individual and his property from governmental actions.

This ongoing ideological tradition helps to explain an important distinctive feature of the American political system's approach to health policy. Although U.S. governments intervene a great deal in the health arena, on some matters they are more inclined to rely on the individual and the free market than most other industrialized nations.

Unequal distribution of access to healthcare is a prime example of the effects of this approach. Most industrialized nations, for instance, use the power of government to assure health insurance coverage for virtually 100 percent of their citizens. The rate of government-assured health insurance in the United States, however, is only 33 percent, by far the lowest among industrialized nations (Anderson and Poullier), because the expectation is that most financing of personal healthcare is the responsibility of individuals and their employers (some exceptions are discussed below). Consequently, in 2000, 14 percent of Americans, nearly forty million persons, had no health insurance (U.S. Census Bureau). Lack of insurance, of course, limits access to care, and has been documented by researchers such as David W. Baker, Joseph J. Sudano, Jeffrey M. Albert, et al., (2001) as increasing the risk of poor health.

Impact of Power Fragmentation

Even as the framers of the Constitution were enamored of Locke's political philosophy, they and many other early Americans were heavily influenced by French philosopher Baron de Montesquieu's *The Spirit of the Laws* (1949 [1748]), in which he urged that the powers of governments should be separated in order to thwart the development of tyrannical states. Accordingly, the framers divided the very limited powers of the national government they established into executive, legislative, and judicial branches—each with the power to check the actions of the others. This structure, of course, made it difficult for government to act and thereby interfere with individuals and their property.

The separation of powers exacerbated what was already a characteristic of the American political system, the endemic fragmentation of power in a federal form of government. Not only did the state governments retain most of their power in the federal system but, reflecting the influence of Montesquieu, the powers in each of them were also separated. The fragmentation of governmental power in the United States is astounding: Altogether, there are some 80,000 governments—including counties, municipalities, special district governments, and independent school districts, as well as the state and national governments—and the powers of each of these are usually separated, and even further fragmented. Therefore, generally speaking, government intervention of a sweeping nature is difficult in the American political system. Health policies and other policies tend to be incremental rather than systemic or comprehensive.

One consequence in the health arena, for example, is that various American presidents since the 1920s have failed in their efforts to secure national health insurance, including President Bill Clinton who declared it the prime legislative goal of his first term (1992–1996). One of them may well have succeeded if he had been the head of a disciplined ruling party in a parliamentary system of government, with no separation of powers. Another consequence is that many important health policies are carried out in disparate and uneven fashions throughout the nation because they are primarily the responsibility of state and local governments. These responsibilities include: public health; regulation of hospitals, nursing homes, home health agencies, hospices, and other healthcare provider organizations; licensing of healthcare professionals; and regulation of private health insurance plans. Still another and related consequence is that it is difficult to establish national standards for healthcare.

Government Health Insurance and Direct Care

Despite a political culture that emphasizes individualism and the free market, about three-fifths of all U.S. spending on personal healthcare is financed, directly or indirectly, by governments (Woolhandler and Himmelstein). About 25 percent of this amount is used to support the employer-sponsored system of private health insurance through tax subsidies and public employee benefits. About 20 percent of it is spent on direct government provision of healthcare to veterans and members of the armed forces (and their dependents), and to Native Americans (under treaty obligations). Almost all of the remaining 55 percent is spent on Medicare and Medicaid, two government health insurance programs for selected groups of Americans that have been politically legitimized as especially deserving of collective help. A central rationale for the establishment of these two programs has been "market failure"—the fact that employer-sponsored private insurance does not tend to reach these particular groups.

Medicare, enacted by Congress in 1965, provides national health insurance for about forty million persons. One group covered by the program is all persons aged sixty-five and older who are eligible for Social Security benefits (or Railroad Retirement Benefits)—over 99 percent of Americans in this age range—about thirty-five million people at the turn of the twenty-first century. The political threshold for legitimating older people as a special deserving group worthy of collective assistance had already been crossed during the Great Depression when the Social Security Act of 1935 created government-funded old-age retirement benefits at the age of sixty-five. The rationale for establishing Medicare was that older persons, retired from employment, had no way to obtain group health insurance. Comparatively few had employer-sponsored retiree health insurance. Moreover, most older people could not afford the comparatively steep premiums charged for individual insurance policies, and many could not obtain them because of pre-existing medical conditions.

Medicare coverage was extended in 1973 to another select group, younger individuals who become eligible after they have received Disability Insurance (DI) benefits from the federal government for at least two years; about five million such persons were covered at the turn of the century. These are persons who, due to a medically certified physical or mental impairment (but not other circumstances), are unable to engage in any kind of *substantial employment* (earning $500 monthly or more) for at least a year. They have been politically legitimized as deserving of Medicare coverage because without employment they cannot obtain group health insurance or afford it on their own. Until the year 2000, DI recipients who were able to return to substantial employment lost their Medicare coverage after two years. However, in recognition of the fact that many employers of former DI recipients do not provide health insurance, this disincentive to work was attenuated by the Ticket to Work and Work Incentives Improvement Act of 1999. It enables DI recipients who become substantially employed to participate in the Medicare Program for an additional four and one-half years.

The Medicaid program, established by the federal government along with Medicare in 1965, is a jointly-funded cooperative venture between the national and state governments that provides healthcare insurance coverage for some poor Americans. But Medicaid policy does not fully equate poverty with *deservingness.* Federal law only requires states to provide coverage for specific categories of deserving groups among the poor that, in their nature, are unlikely to be able to obtain employer-sponsored insurance through the market. Although the list of these requirement categories is long and detailed, the principal eligible groups are children, adults with dependent children, disabled persons (who are not eligible for federal DI benefits), blind persons, and older people (to cover their long-term care costs and certain other expenses not covered by Medicare). Persons within these categories are eligible for Medicaid if their income and financial assets fall below thresholds determined by each state (within minimum federal guidelines). Poor working age men generally do not qualify for Medicaid; the vast majority of those who are eligible in the "adults with dependent children" category are single women. Altogether, the program covers over forty million persons.

Because state governments have considerable latitude in setting income and asset thresholds for Medicaid eligibility, there are substantial interstate inequalities in program participation by persons within the categorical groups designated in federal legislation. An example is the range of low-income thresholds used by states to determine whether infants are eligible for Medicaid. At the most generous end of the range of low-income thresholds used by states in 1999 was Tennessee's 400 percent of the federally-established poverty line; at the other extreme were eight other states with a threshold of 133 percent (Ku, Ullman, and Almeida).

Federal Regulation

The federal government's Food and Drug Administration has long played a role in protecting consumers through regulation. The agency is responsible for ensuring that medicines, medical devices, blood supplies, and certain experimental medical treatments (e.g., gene therapy) are safe and effective, and that foods and cosmetics are truthfully labeled and not harmful. It is only since the late 1980s, however, that the federal government has entered the broader arena of regulating healthcare providers and health insurers, traditionally the bailiwick of state and local governments. It has done so principally to address bioethical issues.

Some policies have been enacted to compensate for perceived inadequacies in state regulation, such as measures in the Omnibus Budget Reconciliation Act of 1987 established to reform the quality of nursing home care. Others have responded to new developments in thinking about ethical patient care. For instance, in the context of growing concerns about protecting patient autonomy, the federal Patient Self-Determination Act was enacted in 1990. It requires healthcare organizations to immediately inform new patients of their rights to refuse medical and surgical treatment and to execute written legal documents, called *advance directives,* regarding their preferences in this regard.

In 1996 alone, the federal government enacted three regulatory laws intended to protect consumers by addressing ethical issues. The Mental Health Parity Act of 1996 responded to inequities in coverage for mental healthcare by requiring that if a group insurance plan covers mental health, the annual and lifetime benefits available must be equivalent to those available for medical and surgical services. The Newborns' and Mothers' Health Protection Act of 1996 addressed perceived issues in quality of care by mandating minimum inpatient stays for mothers and their newborns following deliveries and caesarean sections. And the Health Insurance Portability and Accountability Act of 1996 made obtaining group health insurance easier for individuals with pre-existing health problems and disabilities or previous illnesses, and for those who lost their coverage because of changing jobs or job termination.

The role of the federal government in addressing ethical issues through regulatory policy is likely to expand continually. Technological and biomedical discoveries and innovations inevitably generate questions of fairness and equity that lend themselves to the possibility of government intervention, such as whether genetic tests should be used as screens to exclude applicants for private insurance, whether or in what circumstances stem cell research should be allowed, or how scarce societal resources (e.g., organs for transplantation) should be distributed.

Major Ongoing Issues

The agenda for government policy action grows larger and larger because new issues do not obliterate ongoing concerns. Perhaps the two broadest and most important ongoing issues from a bioethical perspective are: (1) how government will deal with issues of increased longevity; and (2) whether government will remedy the unequal distribution of access to care by securing insurance for the uninsured.

INCREASED LONGEVITY. One set of issues involving increased longevity is generated by the aging of the baby boom, a cohort of 76 million Americans born between 1946 and 1964. During the early decades of the twenty-first century the ranks of older Americans will swell enormously. By 2030, the population of Americans aged sixty-five and older will double, from about 35 million in 2002 to 70 million, and make up 20 percent of the population. Because of this population aging, and ongoing developments in medical technology, the nation will need to greatly increase its financial commitment to the Medicare program if it is to be sustained.

Various commentators are alarmed by this prospect. Bioethicist Daniel Callahan, for example, has described future healthcare costs of older persons as "one of the great fiscal black holes" (p. 216) and argues that these costs will pose an enormous and unsustainable economic burden for the nation and drain resources that could be used for other worthy social causes—an issue of so-called intergenerational equity. Thus, he and others maintain that rationing healthcare on the basis of old age is essential from an economic point of view. Moreover, from a philosophical perspective, Callahan regards it as inappropriate for older people to live beyond what he terms a "natural life span." Accordingly, for both economic and philosophical reasons he has urged that the Medicare program should not pay for life-saving care for anyone aged about 80 or older, and he hopes that this practice will extend to the private sector. Others (e.g., Binstock and Post) have sharply critiqued the arguments of Callahan and other proponents of old-age-based rationing on both economic and ethical grounds. It is not clear that such rationing at the age range suggested would save a great deal of money. And among the ethical arguments against it is the specter raised by the notion that a demographically-defined group might be singled out as unworthy of life-saving care, and be the first of many groups to which such a designation might be applied.

Another dimension of longevity that raises important bioethical policy questions is the quest to slow, arrest, or reverse processes of aging. The U.S. National Institutes of Health (NIH) not only support research to understand the basic biological processes of aging, but promote efforts to substantially increase average life expectancy or the human life span. In 1999, for example, two NIH institutes convened a clinical advisory group of more than fifty scientists to set a research agenda for slowing the fundamental processes of aging and extending maximum life span (Masoro). The desirability of such a policy has been questioned from a number of quarters.

Among bioethicists, Leon Kass, appointed in 2001 as chairman of the U.S. President's Council on Bioethics, opposes such efforts. He believes that even if the human life span were increased by only 20 years, we would lose the benefits that finitude confers:

1. interest and engagement in life;
2. seriousness and aspiration;
3. beauty and love; and
4. virtue and moral excellence (Kass).

Even one of the premier biological researchers in the field of aging, Leonard Hayflick (1994), rejects the goals of substantially extending life expectancy and life span because of distributional justice issues that would arise regarding access to longevity technologies and because of various other social and economic consequences. Other biologists, however, particularly those who are engaged in efforts to slow or reverse the processes of aging, acknowledge such concerns but do not feel that they warrant a halt to their quest to achieve increased longevity (e.g., de Grey, Ames, and Anderson; Miller). And bioethicist John Harris argues that it is doubtful that coherent ethical objections can be generated against the achievement of immortality and urges that we "start thinking now about how we can live decently and creatively with the prospect" (p. 59).

INSURING THE UNINSURED. Finally, as noted above, about forty million Americans have no health insurance in the early years of the twenty-first century. Trends in the labor market suggest that the outlook for expansion of health insurance coverage through the private sector is dim for the foreseeable future. Although the percentage of employed Americans grew to its highest level in many decades during the economic expansion that took place in the 1990s, employer-sponsored healthcare benefits did not grow apace. When the economy began to flag in the early years of this century, the ranks of the uninsured grew. In the absence of a new government health insurance initiative that reaches beyond the present selected, politically legitimated groups, it is unlikely that many of the uninsured will be covered; indeed, their number could grow.

Since 1994, when Congress rejected President Clinton's initiative for national health insurance, no such policy has been on the political agenda. When and how might such an effort be renewed, and how might it have a chance of success?

The proportion of voters who are poor and members of racial and ethnic minority groups will grow sharply over the next several decades, and these groups are disproportionately represented among the uninsured. Perhaps they will be mobilized effectively in a demand for access to the healthcare that their fellow citizens are receiving.

Another possible scenario is that the swiftly changing dynamics of American healthcare will threaten profits in the healthcare industry. Government insurance for an additional forty million persons (and perhaps a larger number in the future) would be a bountiful source of revenue. Unlike the American Medical Association, which vigorously opposed initiatives to secure universal insurance during the twentieth century, the contemporary healthcare industry might appreciate what government can do for it. As Bruce Vladeck observed in 1999, Medicare financing has largely built and sustained the modern medical industrial complex. The political power of the healthcare industry, although fragmented into various interests, is substantial; it might very well carry the day for universal coverage if united by a vision of what further governmental largesse could do for it. If so, despite a political tradition that has been dominated by emphasis on individualism and the free market, the United States will be able to eliminate major inequalities in access to healthcare.

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SEE ALSO: *Access to Healthcare; Health Insurance; Health Policy in International Perspective; Managed Care; Medicaid; Medicare*

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HEALTH SERVICES MANAGEMENT ETHICS

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Health services management ethics encompass the myriad ethical issues, virtually all of which directly or indirectly affect clinical services, faced by the managers of organizations that deliver health services and the moral context in which these decisions are made. Health services managers plan, organize, control, direct, and staff health services organizations (HSOs) and lead, coordinate, and integrate their activities so that clinical care can be provided. In essence, by managing the HSO, managers provide the workshop and wherewithal that enable clients and patients to receive health services. These preventive, acute, restorative, and supportive services may be provided in and through a variety of organizational settings that include inpatient services, outpatient (clinic) care, and home health services. The most intensive or acute services are provided to hospitalized inpatients; the least acute are provided in the home and in hospice, where the emphasis is comfort care and pain control. The types of health services management ethical issues that arise in the various settings are similar and run a gamut that includes macro-level resource allocation, conflicts of interest, staffing levels, and providing the structure and support for patients and families as they decide whether to withhold or withdraw life-saving treatment.

Health services managers are commonly educated in professional masters degree programs where there is emphasis on the skills of business and the ethics of medicine. In other words, these programs socialize health service managers to understand that they are entering a field in which they manage a social enterprise with business dimensions, rather than a business enterprise with social dimensions. This fact in itself makes the HSO and those working in it unique and unlike any other type of service organization. The persons served by the HSO have a unique relationship with it. This relationship is expressed through a level of trust in the organization and implicitly in its management that is rarely found in the service industry.

Health Services Management as a Profession

Health services management was recognized as a distinct academic discipline in the early 1930s. This makes it a relative late-comer to a field including the long-established professions of medicine and nursing. In seeking professional status, health services managers have established and joined professional associations that, in turn, have developed and adopted codes of ethics. These vary in their level of proscription and prescription and the methods of enforcement, but all have the common thread of doing what is in the patient's best interest—usually as defined by the patient. The codes tend to emphasize beneficence, nonmaleficence, respect for persons (autonomy, truth-telling, fidelity, and confidentiality), and justice. Applying the ethical principles often used in clinical ethical decision making is sometimes strained, nevertheless they provide a useful starting point that is supplemented as needed by other principles.

A few states flirted with licensure of hospital administrators, but this appears to be a dead issue. In response to federal regulation that was stimulated by scandals in nursing homes, however, nursing home administrators are licensed in all states. Future scandals and abuses in the health services field likely will stimulate new government regulatory forays. As with state licensing of health professions such as medicine and nursing, regulation of HSO managers probably will include codification of ethical expectations.

It is noteworthy that managers in the health services field are often held to a higher standard than managers in business and other sectors of the economy. This may result in part from their association with the healing professions of medicine and nursing. It may also be a function of the not-for-profit tradition that is so dominant in the health services field. The higher standard also may arise from the expectation that none of those served by such an organization should have their trust breached—the trust inherent in the intimate, emotional, and vital relationship established in the process of delivering health services.

Personal Ethic

In addition to the guidance provided by the codes of ethics of professional associations, health services managers should develop a personal code of professional moral conduct—a personal ethic. Formal academic instruction in ethics is an expected part of graduate-level health services management education. Students enter health services management education with a moral framework developed from life experience, family environment, religious values, introspection, and self-study. The academic preparation in their professional education sensitizes them to the managerial and clinical ethical issues that they are likely to encounter and provides a framework for analysis and problem-solving ethical issues. Because of the pragmatic and applied nature of their work, health services management ethics tend to be normative and ask the question "What ought I (we) to do in this situation?"

Even with additional academic preparation, however, health services managers are likely to understate the importance of having a prospectively-developed, coherent, comprehensive, and consistent personal ethic. Their academic preparation is likely to give them a mind set that they can reason through and solve almost any problem that arises. While partially true, such an approach will not aid managers in anticipating ethical issues and prospectively working to prevent them or minimizing their effect when they arise. Lack of a personal ethic is likely to result in a relativistic approach to ethical problem solving, which is generally undesirable and certainly inconsistent with the value frameworks so ubiquitous in HSOs. It is difficult to overstate the importance of a well-developed personal value system.

Organizational Culture and Values

HSOs have mission and vision statements framed within the context of stated organizational values. The values identified reflect the culture of the organization; this implies that the organization's culture has been *discovered.* All organizations have a culture—the shared values that make each HSO unique. Rather than having *discovered* the culture and organized these discoveries into a mission statement, however, it is more typical that senior management developed a statement of values that they hold themselves or that they think should be the HSO's. The resulting organizational values statement may or may not reflect the culture of the HSO. Culture (and values) can be affected over time, but it is a slow, almost glacial process. Managers must beware of the trap of failing to model the organization's stated (desired) values, but asking of staff that which they are unwilling to do themselves. This will do naught but lead to cynical, noninvolved staff. Leading by example is essential.

The organization's values should be key to and provide the context for all HSO activities. These values must be the context in which staff are recruited, screened, and hired. Failure to measure candidates against the framework in which they will work invariably lead to mismatches of context and staff. The result will be higher costs and unnecessary and counterproductive levels of dissatisfaction, or worse. In terms of the HSO's services and how they are provided, its values should be inviolate. This is to say that, despite the demands of users, the organization can maintain its integrity only if it refuses to act in ways inconsistent with its values. It must be true to itself.

Questions arise as to the need for congruence between the organization's values and the personal ethic of staff, especially staff in management positions. Sectarian HSOs are likely to demand that senior leadership be adherents to their faith, a decision within the prerogatives of private organizations. It is more important, however, and often forgotten, that the values (personal ethic) of staff at all levels be congruent with the HSO's. Only by achieving a high level of congruence is the HSO able to live its values by developing a strong, pervasive culture. Managers may assume staff members have a *tabula rasa* or a generally compatible value system, and then must teach the HSO's culture tothem; the HSO's values must be reinforced by the actions of all, especially those in leadership positions. A strong culture, with clearly defined and shared values, will drive from it those whose interests and actions are contrary and this in itself is a worthy goal. High levels of cultural conformity do tend to stifle innovation, but this risk can be overcome in other ways, such as including innovation as an identified, important value in the culture.

Addressing Ethical Issues in the HSO

Health services managers have a multi-faceted role in preventing, identifying, and solving ethical problems. The importance of a personal ethic has been discussed. As a resource allocator, the health services manager is obligated to provide the support needed by the organization and its staff so that they are educated about ethics issues, have learned a methodology for addressing the ethical dimensions of management problems, and have the systems and procedures to support these efforts. Education about the HSO's values is an essential first step toward these goals; celebrating heroes of the culture and providing case examples are very useful. In addition, the manager is the driving force in ascertaining that the policies and procedures of the HSO address all of the areas where it is likely ethical problems will arise. For example, a comprehensive policy about accepting gratuities that is communicated to staff will go far to prevent conflicts of interest.

Ethics committees are required by institutional and programmatic accreditors and, thus, are ubiquitous in HSOs. Most commonly these committees are involved in clinical ethical issues and in this regard are charged with clinical case consultation, developing and reviewing clinical policies, and educating staff. Clinical staff tend to predominate on ethics committees, although social workers, clerics, and managers usually participate. Ethics committees are less likely to be involved in management ethics problems. Managers seem reluctant to allow ethics committee involvement in reviewing ethical implications of macro-resource allocation, for example. Support for ethics committees by management should include a modest budget, some staff assistance, and the prestige of recognizing their importance to the organization. Ethics committees commonly use ethicists as consultants.

Key Issues in Managerial Ethics

CONFLICTS OF INTEREST. Conflicts of interest arise when someone has two sets of duties or obligations and meeting one set makes it impossible to meet the other. They embody the biblical admonition against serving two masters. Whether a conflict of interest is present is fact-dependent, and accurate determination requires careful scrutiny. The potential for a conflict of interest does not necessarily mean that there is a conflict of interest. It is useful to distinguish differing interests that might lead to conflicts of interest from actual conflicts of interest. Even when differing interests are present it is possible to avoid actual conflicts of interest, but the slope is slippery.

Differing interests are present, for example, when an HSO manager has an ownership interest in a supplier that could service the HSO. If the manager approves purchases from that supplier at higher-than-market prices, a conflict of interest has occurred. However, if the price is lower than available elsewhere the differing interests continue, but no conflict of interest has occurred. In fact, the better pricing is an advantage to the HSO. However, if the manager uses the position of authority to cover up inadequacies in the supplies being provided, the differing interest has produced a conflict of interest.

All HSOs should have a policy defining conflicts of interest. Conflicts of interest can be avoided by disclosing the conflicting interest and recusing oneself from the decision. Using competitive bids also reduces the probability of conflicts of interest. Managers must avoid even the appearance of a conflict of interest. Few revelations are as devastating to one's moral leadership as the suggestion of improper gain from a position of authority. Health services managers, generally, are held to a higher standard than managers in the business sector, and the mere appearance of impropriety is considered more stringently than would be the same activity if performed in another enterprise.

CONSENT. Although it is commonly considered a purely clinical ethics issue, consent is an issue that should concern the HSO manager. If it is to operationalize the patient's autonomy, the HSO must assure itself that the patient has been adequately informed as to the services that are to be rendered under its auspices. The legal requirement is that the physician obtain the patient's consent after explaining benefits, risks, and alternatives to the services that are to be rendered. However, the HSO should have policies and procedures that involve nursing or other appropriate clinical staff in ascertaining that the patient adequately understands what is happening. The manager is obliged to recognize that assuring the adequacy of consent is important; establishing the means by which it can be done and providing the staffing will make it a reality.

RESOURCE ALLOCATION. Resource allocation in HSOs occurs at the macro and micro level. The macro level includes new plant, capital equipment, and services. These decisions have major resource implications for the HSO. In turn, macroallocation decisions have major implications on the microallocation decisions made by clinicians. For example, a decision not to expand the intensive care unit (ICU) (macroallocation) means that decisions about individual patients (microallocation) will be constrained by the number of ICU beds. This, in turn, may mean that patients who might benefit from ICU services may be unable to readily receive them. Macroallocation decisions invariably have clinical implications, whether direct or indirect, and successful managers involve physicians in making these decisions. Nevertheless, resource constraints mean that not all that is clinically desirable is available.

RESOURCE CONSTRAINTS. Concomitant with ethical issues of macroallocation is the problem of resource constraints. Reimbursement from all funding sources is increasingly sparse. Most HSOs are barely achieving a modest surplus; many are running deficits. This change has occurred because of the dramatic funding reductions that began in the 1980s, after the halcyon days of the 1960s and 1970s. It is likely that the problem of inadequate reimbursement will continue unabated as patients demand more from HSOs and third-party payers are increasingly unwilling to pay at adequate levels and in a timely manner.

STAFFING. Severe shortages of several health professions plague HSOs. Registered nurses have received the most attention, although other health professions such as pharmacists and imaging technologists have also attracted too few. In addition, it has been projected that the emphasis on primary care in the 1980s and 1990s will result in too few physicians in some procedure-based specialties in the twenty-first century. HSOs have responded to nursing shortages by reducing the ratio of registered nurses to other types of staff who provide direct care to patients and instituting tuition benefits programs to encourage staff to enter nursing. Although health services managers and HSO trade associations assert that these shortages have not led to a diminution in quality of care, it stands to reason that doing more with less will eventually affect quality negatively, thus raising questions of beneficence and nonmaleficence.

COSTS. As the costs of providing health services continue to climb at double the rate of inflation in the general economy, and as the rate of reimbursement declines, the health services manager is caught in a double squeeze. Higher costs mean that more resources must go into providing basic services, and there is less capital for new equipment, programs, services, and innovation. This further exacerbates the resource allocation issue discussed above.

QUALITY OF CARE. It is estimated by researchers and quality improvement experts that 30 percent of the costs of providing a good or service occurs because of waste, delay, and rework. Such costs in the HSO setting are even more significant because to them must be added the discomfort, pain, morbidity, and mortality that can occur. The HSO manager has an ethical obligation to undertake quality improvement throughout the organization in all of the many clinical and administrative processes.

CLINICAL ETHICS ISSUES. Managers must assure that clinical staff have the support needed to prevent, minimize, and solve clinical ethical issues that arise. In addition, managers must be aware of clinical ethics issues that arise and make changes and improvement in the support available. Managers are expected to participate in ethics committees and institute and participate in ethics grand rounds in the HSO. Only by such hands-on involvement can the manager be aware of failings and issues that arise in the HSO.

The Future

The future promises to be even more challenging to health services managers than the past has been. The types of problems noted above are likely to continue, both in their present forms and in new permutations. New or exacerbated problem areas include terminal illness and futility care, advance directives, serving the underserved, marginal practitioners, multiculturalism (especially the differing meanings of life, death, disease, and treatment held by American subcultures), corporate compliance, employment practices, and whistleblowing. Three of these areas are noteworthy.

FUTILITY CARE. Futility care has been discussed since the early 1990s, but remains inadequately addressed. Acute care hospitals face families (and, less often, patients) who demand that care offering no hope of benefit be continued.

Fear of legal action and bad publicity have prevented hospitals from acting to withhold or withdraw services in such situations.

MULTICULTURALISM. Effectiveness in a multicultural society requires that the HSO's values are clearly communicated to patients, lest the HSO be pulled in many directions with inconsistent demands. Patient interests must be accommodated when possible, but not in contravention of the organization's values.

CORPORATE COMPLIANCE. Corporate compliance is the hot button issue of the new millennium. An organization whose culture and values include honesty, respect, and fair dealing will require little attention to corporate compliance, even though compliance officers are mandated by law. Its values already encourage staff to act honestly. Managers must assure that the organization's culture has no incentives for staff to do otherwise.

Conculsion

Health services managers face a future paradoxically marked by a bleak economic outlook and a challenging, hopeful outlook for providing services. Even as they endeavor to bring high quality health services to all who need them, health services managers will have to do so with fewer resources and under heavier constraints then ever in the profession's history.

KURT DARR

SEE ALSO: *Corporate Compliance; Hospital, Contemporary Ethical Problems of; Medicaid; Medicare; Mental Health Services; Mergers and Acquisitions; Organizational Ethics in Healthcare; Pharmaceutical Industry; Profit and Commercialism*

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HINDUISM, BIOETHICS IN

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The following is a revision and update of the first-edition entry "Hinduism" by A. L. Basham. Portions of the first-edition entry appear in the revised version.

Hinduism is a religious system that has grown and developed from the Vedic religion identified with Aryans who invaded the Indian subcontinent over a period of centuries in the second millennium B.C.E. It is rooted in an oral tradition that gave rise to four groups of sacred texts during a period that is difficult to pinpoint more precisely than 1500 to 900 B.C.E. Based on this informal collection of traditions, beliefs, and practices and the corpus of formal written treatises, which together provided a context for development of the medical system known as *Ayurveda,* Hinduism encompasses a range of values and codes of conduct highly relevant to a study of Indian bioethics.

Hinduism as we might recognize it today took shape in the Gupta Period (c. 300–500 C.E.), often regarded as the classical age of Hindu India. This entry will identify and briefly discuss basic concepts, which clarify the setting for analysis of bioethics in Hindu India, before focusing on medical ethics in *Ayurveda.* Just as they do now, social and cultural values defined standards of medical education and practice, ideas about ethical behavior as a determinant of health and disease, the balance of commercial and altruistic motives of clinicians, access to care and humane treatment, and the rights and responsibilities of patients and physicians.

Hindu Worldview

The doctrine of transmigration is a definitive concept for Hinduism. It postulates the existence of an innermost self (*ātman*) for all beings, ranging from the highest god to the meanest insect, that is essentially immutable. By becoming incarnate, this self becomes further involved with matter, which some philosophical systems hold to be fundamentally illusory and others regard as the primordial source of intellect, ego, elements, and the material world. According to the conduct of the embodied being, the soul or self is carried at death to another body, in which it flourishes or suffers according to previous behavior (the law of *karma*). This process is called *samsāra.* From an outsider's perspective, the force of *karma* operates as a tangible manifestation of an ethical system associated with principles of righteous conduct and moral values inherent in the concept of *dharma,* a difficult-to-translate term that embodies cosmic order, sacred law, and religious duty. Within the system, however, the effects of *karma* are typically conceived more as the operation of natural law governing the effects of behavior than a statement of moral and ethical values.

Transmigration links all living beings in a single system. Unlike the Judaeo-Christian and Islamic religious systems, Hinduism makes no sharp distinction between human and animal. *Dharma* as a guide to proper behavior is relative, not the same for different people or different beings. The ideas of *karma* and *saṃsāra* motivate values of nonviolence (*ahimsā*) and vegetarianism. Nonviolence, which was never so prominent a value in Hinduism as it was in Jainism and Buddhism, has less stringent implications for laypersons than for ascetics, and it does not interfere with righteous warfare, punishment of criminals, or self-defense.

The process of transmigration is considered painful, and the main quest of classical Hinduism has been to find "release" (*mokṣa*) from the cycle of birth and death and thereby enter a state of timeless bliss. For the orthodox schools of Hindu philosophy and systems of Buddhism and Jainism that sprang from them, knowledge provides a means of escaping this repetitive cycle of birth, death, and rebirth. Each of these schools has a somewhat different interpretation of the problem and the solution. Both the *Sāṃkhya* school, identified with yoga practice and once very influential, and the heterodox sect of Jainism, define release as the complete separation of the individual soul from matter. The *Advaita* Vedanta system, which exerts the greatest influence on intellectual Hinduism, interprets it as a full realization of the illusory character of the material world, the speciousness of individual personality, and the recognition of the soul's identity with an underlying impersonal world spirit, often called *Brahman.* Theistic Hinduism of the *ViśIṣṭādvaita* school, which has had the greatest influence on popular ideas, interprets release as union with the personal God not through knowledge but through devotion to *Viṣṇu,* who is identified with *Brahman,* the ultimate reality of the universe and out of whom the world repeatedly emerges in the course of cosmic cycles.

Ideally, release is the aim of all striving, but Hinduism recognizes the validity of other aims, which for laypersons are fully legitimate. The ascetic (*sannyāsi*), on the other hand, "who has given up the world," should pursue only release. Ordinary people approach this goal through gradual stages over many lives. For them there are three legitimate aims: *dharma,* adherence to religious and ethical norms in order to ensure a happier rebirth; *artha,* amassing wealth for the benefit of oneself and one's family; and *kāma,* seeking pleasure and the satisfaction of personal desires. These three aims are valued in descending hierarchical order, but each is fully acceptable for different persons at a particular stage of life and for caste-based communities, which may emphasize one of them.

The Hindu pantheon begins with one primeval being, or God, and innumerable supernatural beings, all of whom are endowed with individual volition. Some of these beings adhere to the will of the higher gods, but others oppose the work of creation. Battles between gods and demons, light and darkness, and good and evil were important features of the earliest Hindu literature, and these themes are widely represented in popular beliefs and practices. Complementing more intellectual naturalistic explanations that are also a prominent feature of Hinduism, some look upon the world as a place full of demons, which are normally at war with gods, and which can be potent factors in causing misfortune and disease.

Hindu cosmology refers to four ages (*yuga*) over the period of a great cycle (4,320,000 years). The current cycle, the *Kali yuga,* is the worst, but fortunately the shortest, lasting 432,000 years, about 5,100 of which have elapsed. Looking backward to better times provides a guide in this troubled age. Neither the doctrine of *karma* nor that of cosmic decline, however, implies fatalism. Human effort may influence the process, and it holds potential for gaining release from the personal cycles of birth and rebirth. Hindu texts emphasize the virtue of human effort (*puruṣakāra*), rather than passive acceptance of adversity that may follow from destiny or chance.

Social Norms

The four great classes (*varṇa*), constituting an eternal hierarchical social order, were believed to have emerged at the beginning of time from the body of the Creator as the fundamental basis of society. The *Brahman* (priest), the *Kṣatriya* (warrior and ruler), the *Vaiśya* (merchant), and the *Sūdra* (worker) formed these four classes, each with different roles, responsibility, and status. Maintaining differences that distinguish each of them was a prerequisite of the social order, and any effort to violate the boundaries of social organization and behavior was an affront to nature and the gods, degrading for those at the top and punishable for those at the bottom. Below the four great classes were the untouchables, theoretically outside, but operating at the bottom of the social order. They performed important social functions that others considered polluting, such as removing garbage, cremating corpses, working in leather, and so forth. Contact between them and the other classes was strictly limited.

Although aspects of this class structure persist in Hindu society today, social conditions rarely operated according to textbook norms. More important and more complex in everyday life was the caste (*jāti*), a group of families generally following the same profession and theoretically contained within one of the four classes, though not always recognizably so in practice, especially in South India. Castes were also hierarchically graded and normally endogamous. Local councils of elders exerted great power over their members.

Family

Social research in recent years has emphasized the primacy of the family over the individual in Hindu and other societies outside North America and western Europe. Hindu individuals were more likely to define themselves with reference to the extended family (*kula*) as a corporate unit. Social responsibilities, which constitute underpinnings for the concept of *dharma,* rather than individual rights, were clearly the priority among ethical concerns. Except in some parts of South India, primarily Kerala, the family was patrilinear, patriarchal, and patrilocal, though the authority of the patriarch was limited by traditional law. He did not have the right to dispose of family property arbitrarily, nor did he have complete control over the lives of family members.

The ritual of *śrāddha,* whereby dead ancestors retained a presence, sustained by the living, was a powerful force in shaping the character of Hindu family life. A male descendant to perform the *śrāddha,* a ritual offering of rice balls (*piṇḍa*), was needed not only to sustain the ancestral lineage but also to avoid one's own suffering in the afterlife. In view of heavy child mortality, it was incumbent upon families to produce as many children as possible, in the hope that at least one surviving son would maintain the lineage, attend to the spiritual needs of the ancestors, and contribute to the economic well-being of the family.

A Hindu wife was integrated into her husband's family, and theoretically (though not always in practice) completely subordinate to him. In many communities it was considered indecent to leave a girl unmarried after her first menstruation, and marriage normally required the payment of a heavy dowry. Thus, the birth of a daughter was often looked on as a misfortune. Although female infanticide has been practiced and persists in some parts of India, the practice is completely without foundation in the Hindu scriptures, which look upon abortion and infanticide as grave forms of murder.

Prospective parents employed various techniques to increase their chances of bearing a male, rather than female, child. Diet and activities of a pregnant woman were believed to influence the sex, physical features, and character of the offspring. Treatises of *Ayurveda* advise that intercourse on even days after the onset of menstruation produces sons, and on odd days it produces daughters (Caraka, iv. 8. 5). *Pumsavana* rites to alter the sex of a recently conceived embryo and ensure the birth of a male child are discussed in the texts of *Ayurveda.* They are also discussed in religious treatises of the Veda and other texts that detail proper Hindu codes of conduct (*dharmaśāstra*) (Kane).

In recent years profitable ultrasound clinics have proliferated in India, in some states illegally, to make use of modern technology to identify and abort female fetuses. Responding to a culturally based gender bias and a persisting dowry system that taints perceptions of female children as economic liabilities, this ultrasound technology challenges the viability of *pumsavana* clinics previously established in some *Ayurvedic* hospitals and employing traditional Hindu medical methods for assuring the birth of male children.

Individual Conduct

Within the framework of the three aims of life (*purusārtha*) acceptable for the high-caste individual were a series of ritual observances and taboos throughout life. Sacraments beginning before birth and continuing after death marked the progress of life. The Brahman was expected to devote a considerable amount of time each day to prayer and ritual, and members of other castes were encouraged to imitate him.

The aim of many of these sacraments and taboos was to maintain ritual purity. Although conceived with reference to another conceptual framework, many practices also maintained a hygienic standard contributing to health in a tropical climate. Notable examples include insistence on a daily bath, the custom of eating with the right hand and washing the anus and sexual organs with the left, the ban on eating cooked food left overnight, and a strict taboo against contact with human corpses and animal carcasses. The bodily fluids of others, such as saliva and mucus, are considered polluting, and contact with anything contaminated by them, such as used dishes or drinking glasses, was to be avoided.

Social values and a conflicting emphasis in various texts of classical Hinduism portray an ambivalent attitude that both exalts and denies sexuality. *Vedic* texts regard sexuality as a metaphor for a ritual sacrifice. The *Bṛhadāraṇyika Upaniṣad* (vi. 2. 13), among the best known of this speculative genre of Hindu scriptures (*Upaniṣad*), identified woman as a sacrificial fire fueled both by her own and her male partner's genital organs in the act of sexual intercourse.

Semen is an offering to this fire, which may generate a person.

In later texts, however, sex is affirmed as a valid source of gratification, a legitimate pursuit among the three aims of life: righteousness, wealth, and pleasure. Erotic temple art and texts devoted to the details of enhancing sexual gratification, such as the *Kāma Sutra,* document a cultural sanction of pleasure seeking for men. These texts acknowledge female sexuality but consider it primarily from a male perspective—how to attract and please a man. Hindu texts concerned with moral codes of conduct (*Dharmaśástra*) emphasize chastity and procreation more from the classical period onward than previously (Bhattacharyya).

Even for men, classical Hinduism confines sexual activity to one stage of a man's life. An initiation ceremony (upanayana) that preceded a long period of celibate studentship was a milestone for upper-caste boys. Afterwards, a young man was married, normally to a bride chosen by his parents, and raised a family. According to the ideal, he was expected to give up family cares in late middle age to devote the rest of his life to religion and to strive for liberation. Ascetic values discouraged sexual activity, which not only distracts the individual from a quest for release from the cycle of rebirth but also results in the loss of physical and spiritual power.

In addition to the emphasis on a moral code of religious practices, Hinduism also emphasizes ethical principles of social relations. The principle of nonviolence has often been interpreted in a positive sense, as actively benefiting others. Though subject to the constraints of conflicting values in a comprehensive social order, Hindu texts and practices encourage virtues of honesty, hospitality, and generosity. Explicit codes detailing how guests are to be received, fed, and looked after emphasize hospitality as a social value (see chap. 21 on receiving guests in Kane). The *Taittirīya Upanisad* (i. 11. 2) admonishes students to treat parents, teachers, and guests as gods.

Hindu Medicine

A complex medical system, known as *Ayurveda,* "the science of (living to a ripe old) age," developed in India over the first millennium B.C.E. The theory of health and disease according to *Ayurveda* refers to a humoral physiology based on the balance of three substances (*dosas*): wind (*vāta*), bile (*pitta*), and phlegm (*kapha*). They are recognizable indirectly by their impact on health and illness. The excess of one or another and their locus in the body or among bodily elements (*dhātu*) determines the nature of specific physical and mental diseases, their manifestations, and subtypes. Although *karma,* demons, and deities may also play a role in producing ill health, it is a relatively minor role in the medical texts and more of a concern in other settings. The role of a physician practicing *Ayurveda* is to restore the harmony of humoral balance with medicines, purification, massage, diet, and directives for appropriate lifestyle. Experience with an exceptionally wide pharmacopoeia and careful observations of the symptomatology, clinical course, and treatment response of various diseases—especially chronic conditions for which Western medicine does not provide a clearly superior alternative—have enabled practitioners of the system to maintain the respect of a large number of South Asians who continue to use it.

Health, Disease, and Morality

Ayurveda, despite its emphasis on the humoral basis of health and disease, also recognized external (*āgantu*) causes that provided a better account than endogenous (*nija*) causes—that is, humoral imbalance—to explain some medical conditions. *Karma* referred to the impact of misdeeds in a previous life. Irreverent, unethical behavior and other violations of codes of conduct (*prajñā-aparadha*) in one's current life were not limited to effects on that individual; they could also affect offspring (Caraka, iv. 8. 21, 30). Serious transgressions of the king might also produce epidemic disease and disasters (*janapadoddvamsana*) in his kingdom (Caraka, iii. 3). Moral conduct, affecting individuals, distinct from epidemics affecting populations, operated through the all-embracing doctrine of karma; in some instances, *karma* explained health or disease if the humoral theory or demonic possession could not, and in other instances, it provided a complementary explanation.

Illnesses might be caused by the sins or shortcomings of a previous existence; longevity was also explained by this idea of *karma.* The doctrine encouraged inner acceptance of disease and gave a ready-made explanation of its cause, but nowhere is a person advised to submit to illness without attempting its cure. *Karma* could explain otherwise mysterious congenital defects. Someone born with a deformed hand, for example, could be said to have incurred this misfortune as a result of an evil deed (for instance, striking a *Brahman*) committed by the same hand in a previous life. This did not necessarily discourage efforts to improve the condition by surgery, since the duration of the punishment through *karma* was not known, and the trouble might be only temporary. Since the evil brought about by *karma* cannot be estimated with certainty, and the bad effects of sins can be offset by the merit gained by good deeds, there was every reason why a sick person should seek all available medical help to achieve health.

Other factors besides *karma* were believed to promote health or disease. Devotion (*bhakti*) to God, who might set aside the law of *karma* for the faithful, promoted longevity and health. Neglect of religious duties and lack of faith, on the other hand, might lead to the withdrawal of divine protection, increasing the risk that demons might exert their influence, leading to disease or madness.

More closely linked with ethics was the general view in the medical treatises that equanimity and kindness are therapeutic in their effects. Excess in every respect is looked on with disfavor by the medical texts. An impressive emphasis on the values of moderation, altruism, and love to promote health and longevity is found in the seventh-century text of the Buddhist physician Vāgbhata, the *Aṣṭāṅgahṛdayasaṃhitā* (1965, i. 2). This work, along with the *Caraka Samhitā* and the *Suśruta Samhitā*, is among the so-called great-three (*brhattrayī*) texts of classical *Ayurveda.* After reviewing the benefits of exercise and symptoms resulting from overexercise, it enjoins the physician to support those who are sick, poor, or needy and to treat them with respect.

Mental and spiritual training in concentration and meditation, commonly known as yoga, was also believed to promote health and longevity. Yoga is still widely practiced both as treatment for clinical problems in yoga clinics of some Indian hospitals and more generally to promote health and well-being. Different forms of yoga practice involve physical postures and exercises (*hatha-yoga*), meditation (*rāja-yoga*), or both. These produce not merely health and longevity; they also provide a way for the most advanced adepts to attain liberation from the cycle of rebirth, and hence immortality.

Ethics of Medical Practice

The activities of the physician (*vaidya*) were closely linked with the doctrine of the three aims of Hindu life (Caraka, i. 30. 29; Vāgbhaṭa, i. 2. 29). Viewed as complementary, rather than contradictory, they guide appropriate behavior. By relieving suffering and adding to the sum of human happiness, a physician (assumed in the texts to be a man) fulfills the first aim, carrying out his religious duty; from the generous fees of his wealthy patients he achieves the second aim, riches; while the third aim, pleasure, is achieved by the satisfaction he obtains, first, from a high reputation as a healer and, second, from the knowledge that he has cured many people whom he loves and respects.

The last two aims were not to be disparaged. The few famous physicians described in story and tradition were not selfless servants of humanity but very wealthy men—in that regard resembling successful practitioners of modern times. There appears to have been no ban to keep a physician from advertising his skill. As the example of Vāgbhata indicates, Hindu and Buddhist medical traditions were closely linked. A Buddhist text, the *Mahāvagga,* provides more biographical detail than the Hindu sources about medical practice in the same society. It refers to the material interests of a renowned doctor in his youth, *Jīvaka,* recently qualified and in search of patients. As he entered an ancient Indian city, to earn money for his onward journey, he walked through the streets inquiring, “Who is ill here? Who wants to be cured?” (Mahāvagga, viii. i. 8–13).

Although Jīvaka’s concern for his fees was matched by qualifications and skill, it appears that quackery was also rampant in ancient India; charlatans would come canvassing as soon as they heard that a well-to-do person was sick (Caraka, i. 29. 8–12). Recognizing such problems, Suśruta (i. 10. 3) referred to a system of licensing qualified medical practitioners. Texts on politics and statecraft suggested punishments for doctors whose ineffective treatment resulted in injury or death (*Kauṭilya,* iv. 1; Kane). Caraka also advocated a high moral standard for a proper physician, based on religious duty (*dharma*). At the outset, a physician’s training began with a solemn initiation, at which his teacher (*guru*) instructed him that he was to live a frugal and ascetic life, celibate and vegetarian, while undergoing training. He must obey his teacher implicitly “unless instructed to commit a mortal sin.” The prescribed instruction continues:

> When you have finished your studies, if you want to have a successful, wealthy, and famous practice, and to go to heaven when you die, you must pray every day, when you get up and go to sleep, for the welfare of all beings, especially cattle and brahmans, and you must strive with all your power to heal the sick. You must not betray your patients, even at the risk of your own life.… You must always be pleasant of speech … and always strive to improve your knowledge.… Having entered a patient’s home, a physician’s speech, mind, intellect, and senses should be devoted to nothing other than caring for the patient. Any peculiarities of the household you may learn about should not be disclosed outside. (Caraka, iii. 8. 13. 4–5, 7)

This well-known passage has been compared with the Hippocratic oath. The text also addressed other persisting dilemmas of medical practice. If it becomes clear that a patient in treatment has a fatal condition, the matter of whether or not a doctor should disclose this information was left largely to the doctor’s discretion. Caraka advised that if a physician concludes that the condition of the patient is hopeless and if he believes that it might shock the patient or others, he should keep this knowledge to himself.

The same chapter of the Caraka Saṃhitā also contains advice about when a physician should refuse to provide treatment. He should not treat the king's enemies, women unattended by a husband or guardian, or patients for whom a request for treatment comes as they are about to die (Caraka, iii. 8. 13.6). Accepting a terminal case might damage his reputation.

The Hindu medical tradition is based on a relatively stable theory of health and illness, but it advocates a policy of openness to new ideas about treatments. Although the theoretical basis rooted in the doctrine of the three humors has always guided *Ayurveda* and undergone little modification over the course of time, the *vaidya* was advised to be constantly on the lookout for new drugs and treatment methods. Compared chronologically, the texts show a steady increase in the number of items in the pharmacopoeia. Even after his long apprenticeship was over, the physician was counseled to continue to improve his knowledge by studying his patients and inquiring about unusual but potentially useful remedies from hermits, cowherds, and hillmen (Suśruta, i. 36. 10).

Professional gatherings of physicians were regarded as valuable opportunities for the exchange of knowledge that could enhance a clinician's skills. The descriptions of these colloquiums distinguish friendly discussions from hostile debates, and the exchange of information was not necessarily free and open. Many physicians guarded proprietary knowledge not recorded in professional textbooks, knowledge they might reveal to prove a point in the heat of impassioned debate. Entering into professional discussions, the clinician is advised not to boast, embarrass others, or fear discomfort. In the company of knowledgeable colleagues, he is advised to listen attentively and speak freely. The text also advises how to handle hostile discussions with superiors, inferiors, and equals. "The wise never applaud a person engaging in hostile discussion with a superior … but the following methods help in quickly overpowering an inferior disputant.…" (Caraka, iii. 8. 15–21; see also the remainder of chap. iii. 8).

The texts encouraged the physician, though he might be wealthy and unfettered by any rules of an ascetic character, to consider himself a sort of secular priest with a special, almost supernatural charisma bestowed on him by the initiation ceremony at the beginning of his studies. The high-caste man who had undergone the normal Hindu initiation (*upanayana*) was "twice-born" (*dvija*), and thus superior to the Śudra or woman, who had only one birth. The *vaidya* was even a step beyond, "thrice-born" (*trija*). As the prescribed words of his teacher show, this exalted status required a high standard of fortitude and conduct. The student was taught that as a physician he should always be "of calm mind, pleasant speech, … the friend of all beings" (Suśruta, i. 10. 3). To some extent professional identity relieved him of the burden of caste taboos. He could enter the homes of people of a lower caste than his, handle their bodies, and even taste their urine when making a diagnosis.

Notwithstanding vegetarian cultural values, treatment employed animal products to compound drugs, and they appear to have been prescribed freely. The taboo that proscribed handling a corpse, however, may have applied to most physicians. Most medical texts do not advocate the actual dissection of a cadaver; *Suśruta Saṃhitā* (iii. 5), however, is an exception. It advises that for a surgeon to study the position of internal organs, a carefully selected dead body should be placed in a cage after removing excrement from the entrails, positioned in a stream with a swift current, and examined after seven days as it begins to decompose. In that way the body might be studied in each anatomical layer, beginning with the skin.

Although concerns about ritual pollution and principles of nonviolence inhibited anatomical study and surgery in *Ayurveda,* in recent years they appear to have had surprisingly little influence on modern medicine in India, known as allopathy, with respect to the burgeoning surgical practice of organ transplantation. Concern about the adverse impact on the transmigration of souls has had a negligible effect on the transmigration of vital organs from one person to another. Bombay has acquired a dubious distinction as a world center for transplants from unrelated live donors, spawned by a profitable private-practice medical industry, an impoverished subpopulation willing to donate organs for a fee, and enterprising brokers whose activities reflect little concern for the ethics of these practices.

Access to Healthcare

The provision of free medical care to the poor was looked on as part of a king's duty to protect his subjects, which was generally interpreted in a positive sense (Caraka, i. 30.29; see also the background essay in vol. 1, pp. 254–264 of P. M. Mehta's translation). From the days of the benevolent Buddhist emperor Aśoka in the third century B.C.E., the better rulers of India responded in some measure to this responsibility. Medical clinics of one kind or another, where professional doctors provided free services to the poor, existed in many cities. These were sometimes supported by the states, but others were often financed by private charity. In South India especially, hospitals and dispensaries were often attached to the great temples. Medical services might have been subsidized by doctors themselves, for they were encouraged to treat the poor, learned Brahmans, and ascetics without charge (Suśruta, i. 2. 8; vi. 11. 12–13). Free medical services in South and Southeast Asia, however, were more extensive in Buddhist Sri Lanka and Cambodia.

Reasoned Suicide and Mental Health

The aim of the idealized ascetic to attain release and end the cycle of rebirth provided an acceptable rationale for suicide in highly selected circumstances. *Sallekhanā* is a Jain practice sanctioned for elderly mendicants involving ritual fasting that ends in death; its aim is for the individual to meet the final moment with utmost tranquillity (Settar). The *Dharmaśāstra* literature, which outlines Hindu codes of conduct, also refers to another form of religious suicide, the "great journey," justified by incurable disease or great misfortune (Kane). Those who undertake this ultimate renunciation in the final stage of life proceed in a northeasterly direction, "subsisting on water and air, until his body sinks to rest" (*The Laws of Manu,* 6. 31). Other means of accomplishing religiously motivated suicides include jumping from a height (*bhrgupāta*), often associated with pilgrimage sites where these suicides were most frequent, such as Śravana Belgola, west of Bangalore in South India, and Prayaga (modern Allahabad) in the North.

Questions about these carefully reasoned suicides, usually sanctioned only for the elderly, were framed in religious rather than medical contexts, unlike current debates about euthanasia and assisted suicide in the West. Nevertheless, issues identified as appropriate justification by those who advocate these practices in both settings are comparable, especially the role of terminal illness and functional disability. Whether one regards these socially sanctioned self-willed deaths as suicide or something else is a debatable matter. Some scholars avoid the stigmatized English term (Settar), although more commonly suicide is used descriptively, regardless of whether it is proscribed.

Although Hindu texts were very much concerned about ethical questions that ultimately lead to sanctioning or condemning suicides, based on their circumstances, the context of the discourse was strikingly different from that of present-day debates about physician-assisted suicides. Suicide in the West typically raises questions about deviance and mental disorder. Concerns for victims are framed in clinical terms with a focus on prevention and cure of psychopathology associated with suicidal impulses. Hindu traditions that consider suicide are concerned with a different set of questions, which focus not on deviance but on cultural values. Religious suicides of ascetics and pilgrims and the self-immolation of a widow on the funeral pyre of her husband (*anumarana*)—an act that has come to be known as *sati,* after the Sanskrit term for the "righteous woman" who undertakes it—were not discussed in medical contexts. Modern criticism of *sati* proceeds from social, economic, and feminist perspectives; it focuses on questions about the deviance and disorder not of the victims but of societies that disvalue women, especially widows.

Suicide was regarded neither as a defining feature nor an important symptom of mental disorder. Mental disorders (*unmāda*), however, were recognized and classified according to threatening, disorganized, and disordered behaviors, and by disturbing emotional states. The classification of some of these mental disorders fit the characteristic humoral framework, but others did not. Like some childhood diseases discussed in the texts (but few other health problems), they were explained by the influence of demons and deities. The texts prescribe a mix of gentle, humane treatment, as well as not-so-gentle efforts to restrain and shock patients into normalcy with threats of harm and false reports of the death of loved ones. Offerings to demons and deities (*bali*) and medicines to correct a humoral imbalance of excessive wind, bile, or phlegm were also prescribed for mental illnesses attributed to these respective causes.

Conclusion

Many issues that remain concerns in modern medical practice were recognized and addressed by Hindu religious texts, codes of conduct, and Sanskrit treatises of *Ayurveda.* The medical texts discussed responsibilities of the physician to society, patients, and colleagues in terms that recognized the professional nature of these interactions, distinctive social values, and political forces. Medical theory, which was primarily humoral, incorporated a moral basis for explaining health and illness of individuals. Some questions that have become major concerns for medical ethics in the West, such as the status of rational suicide, were considered in the context of Hindu traditions other than medicine.

Recent developments in biotechnology have placed controversial questions about bioethics and cultural values near the top of an agenda for equitable social policy in South Asia. The ongoing debate that follows from the impact of new technologies should be informed by an appreciation of the cultural and historical contexts in which these questions emerge.

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SEE ALSO: *Buddhism, Bioethics in; Confucianism, Bioethics in; Daoism, Bioethics in; Death, Eastern Thought; Ethics, Religion and Morality; Eugenics and Religious Law: Hinduism and Buddhism; Healing; Health and Disease; Jainism, Bioethics in; Sikhism, Bioethics in*

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HOLOCAUST

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Bioethics is a type of *discourse,* defined as "any collective activity that orders its concerns through language" (Zito). As members of a discourse community, bioethicists use rhetorical strategies to make arguments, define terms, and influence the direction of the discourse as a whole. One of those strategies is to invoke the Holocaust as a way to warn, cajole, criticize, or silence those who have opposing or divergent views. The use of the Holocaust as a rhetorical instrument raises important ethical and strategic questions for bioethics.

The Holocaust

The Holocaust lies like a specter behind modern bioethics. Contemporary bioethical discourse derives much of its moral legitimacy from the legacy of the Holocaust. The unfathomable cruelty of the Holocaust is paradigmatic of the degree to which the unfettered power of the majority over despised minorities can distort human relationships. The eugenic philosophy that undergirded social engineering and extermination campaigns informs all current debate about genetic engineering and population genetics. The genocidal strategy of the Nazis, coupled with the complicity of large segments of the German public, including medical professionals, showed the depths to which human beings could go in the pursuit of misguided philosophies of science and in-group politics. The atrocities committed in the name of medical research revealed individual subject vulnerability in the hands of investigators so starkly that virtually all modern standards for protecting human research subjects originated in the aftermath of the Holocaust.

The events that occurred in Germany under National Socialism have come to represent evil in pure form, without caveat or ambiguity. The Holocaust thus has come to signify the ultimately evil act; the Nazi enterprise, the ultimately evil political and social movement; and Hitler, the ultimately evil leader. By extension, those who were inactive in the face of evil are invoked as the paradigm of complicity and those who did not speak out are emblems of culpable silence. It thus is not surprising that evoking the Holocaust as a rhetorical strategy has enormous symbolic power.

However, such power cannot be wielded without risk. Drawing on symbols of ultimate evil to buttress arguments about the undesirability of lesser evils may be emotionally satisfying, but it is rarely a persuasive rhetorical strategy. If the analogy is seen as inapt, it tends to weaken rather than strengthen the case being made. Still, the temptation to employ the Holocaust is strong, and it has become a central metaphor for a variety of social movements (Stein), special interests (Novick), and political actors (Lin and Gur-Ze'ev) as well as in popular culture (Hungerford, Mintz, Zelizer).

The use of the Holocaust in bioethics has taken on a particular character. Bioethics is a normative discourse, and the Holocaust is a signifier with great normative power. The Holocaust frequently is invoked in bioethical discourse to draw analogies, suggest threats to vulnerable groups, or warn against perceived slippery slopes. After a brief historical summary, some of those strategies will be examined in this entry to explore their impact on bioethical discourse.

Rhetoric and the Holocaust

The term *holocaust* is derived from the Greek *holokauston,* meaning "burnt whole," which was a derivation of the Greek translation of the Hebrew *olah,* a biblical term for a burnt sacrifice. Historically, the term was used to denote great destruction of human life, especially through conflagration. For that reason it was employed often by journalists in World War II to refer not only to the destruction perpetrated by the Nazis on Jews and others but also to Allied acts such as the bombing firestorms that destroyed much of Hamburg and Dresden. It is ironic that the German press used the term first to refer to the bombing of German cities.

The use of *holocaust* in reference to the destruction of the European Jewish community at the hands of the Nazis gained currency by being the preferred English translation of the Hebrew word *shoah.* The 1948 Israeli Declaration of Independence, for example, makes reference to the *shoah,* which is rendered as "the Nazi holocaust" in official English translations (Novick). However, in the decades after World War II the destruction of European Jewry was rarely part of American public discourse. It was only during the 1960s, particularly with the advent of the trial of the Nazi official Adolf Eichmann, that the term *holocaust* began to be used in common discourse to refer to World War II. At first the term often was used to refer to the death of all the millions of people who were killed by the Nazis. By the late 1960s, however, *the Holocaust* (capitalized and usually preceded with the word *the*) was defined in dictionaries as the genocidal killing of millions of Jews by the Nazis during World War II.

The lowercased term *holocaust,* however, still is used commonly to describe great loss of human life at the hands of others, as occurred in Biafra in the 1960s, Cambodia in the late 1970s, Afghanistan in the 1980s, and Rwanda and Serbia/Bosnia in the 1990s. Over 2,000 books in print include the word *holocaust* in their titles, many of which do not refer to World War II: *The Real Holocaust* depicts the African slave trade, *The Silent Holocaust* describes victims of famine, and two books titled *The Forgotten Holocaust* discuss South American Indians and the rape of Nanking; *Holocaust Island* is a book of poetry about Australia by an aboriginal poet.

Despite the widespread and diverse use of the term, controversy over its proper usage outside the Nazi context remains. The *American Heritage Book of English Usage* reports that 99 percent of its Usage Panel, composed of over 180 experts who determine the correct employment of terms, accept the term *nuclear holocaust.* However, only 60 percent accept its use for the 1 million to 2 million victims of the Khmer Rouge, only 31 percent for the millions of victims of drought in Africa, and a mere 11 percent in reference to the AIDS epidemic.

The use of the term *holocaust* in other contexts is confounded by the fact that the rhetorical power of the word largely has been taken over by its single exemplar; every use of the term, even in lowercase or in other contexts, inevitably becomes a referent. Another complication is that the penetration of the term into the American consciousness has been astonishing. Ninety-seven percent of the public in one poll knew what the Holocaust was, a higher percentage than could identify Pearl Harbor or knew that the United States had dropped an atomic bomb on Japan. The majority in a second poll said that the Holocaust "was the worst tragedy in history" (Novick, p. 232). The casual use of the term outside the Nazi experience can provoke the sensitivities and strong voice of the Jewish community, which was affected singularly by the Nazi campaign of eugenic eradication and for which the Holocaust remains a powerful and personalized event. Such factors complicate the term's use in contexts other than the Nazis' actions in World War II.

The Uniqueness of the Holocaust

The controversy surrounding the use of the Holocaust as a metaphor revolves in part on claims of the Holocaust's *uniqueness.* The targeting of one ethnic group said to be singularly evil; the use of medical and public health justification for the destruction of that group; the relentless and single-minded searching out and destruction of all men, women, and children in that group as an end in itself; the widespread collaboration of the public in each new country conquered; the dedication of enormous economic, military, and social resources to that end; and the systematic technological extermination of the group are said to set the Holocaust apart from all other cases of genocide in human history.

Lucy Dawidowicz (*Hastings Center Report*) has argued that the Nazi experience cannot be used to gain insight or help resolve the conflicts of other eras. If the Holocaust is *unique* and thus is a singular, exceptional, disjunctive moment in the course of human history, it lies outside the flow of normal events and cannot serve as a historical lesson. It therefore cannot be used to understand *normal* evil or even the periodic emergence of extraordinary evil. Conversely, if the Holocaust is just one, however singularly tragic, example of many historical examples of genocide or hatred, what is to keep its particularities intact when it is used constantly as the referent for the killing of the Armenians, African slaves, or embryos? The Nobel Prize winner Elie Wiesel, who is known for his advocacy of the uniqueness of the Holocaust, has tried to resolve the dilemma by arguing that the Holocaust was "a unique Jewish tragedy with universal implications" (quoted in Novick, p. 239). However, it is difficult to maintain that an event is both absolutely unique and universally applicable.

Arguments against the use of the Holocaust as an analogy to other cases of suffering take two major forms. One suggests that the Holocaust had a uniquely Jewish context and that to use the term as a referent cheapens and discounts the Jewish experience of suffering and loss. Edward Alexander in an article titled "Stealing the Holocaust" indicts those who use the Holocaust to call attention to other instances of injustice, arguing that they *use up* something accumulated by Jews through their suffering. A second argument suggests that use of the referent blunts the true horror and extremism of the event. Discussing the related use of the label *Nazi* in a Hastings Center Report Conference on bioethics and the Holocaust, Milton Himmelfarb lamented the "overly hasty invocation of 'Nazism' and the rather free and easy use of Nazism to brand practices with which we disagree.… By universalizing Nazism, one makes it shallow, and one removes the actual reality of Nazism. If everything is Nazi, then nothing is Nazi, and even Nazism wasn't Nazi" (*Hastings Center Report,* p. 7).

Insisting that the Holocaust lies outside history and has no role in creating an understanding of other cases of mass killing is also problematic. The argument for the incomparability of the Holocaust trivializes other crimes and can lead to discussions such as the reported argument about whether the Bosnian slaughter was "truly holocaustal or merely genocidal" (Novick, p. 14). Some analogies are clearly apt. The discussion of the *Rwandan holocaust* in a medical journal, indicating with the lowercase *h* that the term is used as a noun and not explicitly as a reference to the Jewish Holocaust, seems a proper usage (Decosas). The tragic events in Rwanda are well described as a holocaust.

The Holocaust in Bioethical Discourse

In bioethical contexts the Holocaust often is invoked as a form of moral approbation. The development of the Nuremberg Code in the wake of the Holocaust was the clear precursor to the emergence of modern protection measures for human subjects and therefore often is referenced legitimately (Caplan). However, the Holocaust-Nazi analogy also is invoked regularly to condemn a wide range of practices (e.g., abortion, physician-assisted suicide), healthcare strategies (e.g., managed care, age rationing), and even people (e.g., by opponents of the work of philosopher Peter Singer). Sometimes the analogies are so overblown as to be easily dismissed, for example, when the breast implant controversy was referred to at an Institute of Medicine meeting as the "silicone holocaust" (Ault). However, it is instructive to look at a number of cases in which the use of Holocaust metaphor or imagery is employed to make a bioethical argument in a professional or public forum.

ANIMAL RIGHTS. Animal rights activists have called fur farms *Buchenwalds for animals* and have likened animal experimentation to the human medical experiments of the

Nazi doctor Josef Mengele. A best-selling book in the animal rights movement called *Eternal Treblinka* (Patterson) argues that there are many parallels between animal exploitation and the Nazi exploitation of people and points out that the slaughterhouse was the model for the death camps. In 2003 People for the Ethical Treatment of Animals (PETA) mounted a graphic campaign and exhibit called *Holocaust on Your Plate,* which placed 60-square-foot panels displaying gruesome scenes from Nazi death camps side by side with disturbing photographs from factory farms and slaughterhouses. One exhibit shows a starving man in a concentration camp next to a starving cow. The campaign, which highlighted medical research using animals along with other forms of animal exploitation, used the slogan "To animals, all people are Nazis" (Specter). Jewish leaders, as well as many others, objected strongly to the exhibition.

AIDS. AIDS activists often use the slogan "silence equals death" to liken the purported indifference among bystanders in the face of the epidemic to the inaction of those who let the Holocaust occur. It also has become common for activists to refer to AIDS as the "Gay Holocaust" (Bamforth). At the 2000 AIDS summit in South Africa delegates accused drug companies of a "holocaust against the poor" for refusing to provide Africans with inexpensive AIDS drugs (Smith). Used in tandem with the slogan about silence, that phrase is an implicit rebuke of the claimed unwillingness of the drug companies and others to dedicate the resources and attention to its eradication that the activists believe AIDS deserves.

ABORTION AND EMBRYONIC STEM CELLS. In the abortion debate and more recently in the human embryonic stem cell (hES) debate both sides have made use of Holocaust metaphors to defend their positions. The pro-life and anti-hES movements commonly refer to the destruction of embryos as "the American Holocaust" and use symbols and images from the Holocaust as a primary metaphor in their literature (Neustadter). When he was surgeon general of the United States C. Everett Koop warned of a progression "from liberalized abortion … to active euthanasia … to the very beginnings of the political climate that led to Auschwitz, Dachau, and Belsen" (quoted in Novick, p. 241). At a Senate Labor and Health and Human Services Appropriations Subcommittee meeting in April 2003 Senator Sam Brownback of Kansas likened embryo research to Nazi research on Holocaust victims.

Conversely, the pro-choice side often argues that state control of women's bodies is the first step toward state ownership of people and ultimately toward genocide. The Holocaust thus is also used to argue against state involvement in reproductive freedom. Pro-choice advocates point out that abortion was illegal in Nazi Germany and that the state prominently expressed an interest in controlling women's reproduction through antimiscegenation and compulsory sterilization laws.

END-OF-LIFE ISSUES. Public discussions about end-of-life options, from disconnecting life supports to physician-assisted suicide, inevitably raise comparisons to the *euthanasia* campaign in World War II, especially in Germany (Kottow, Spannaus et al.). In a *Hastings Center Report* commentary, the *Village Voice* columnist Nat Hentoff compared Dan Callahan's argument in *Setting Limits* (in which Callahan argued that some categories of people, notably the elderly, should not be entitled to the same access to healthcare as others) to the Nazi policy of *lebensunwertes leben,* "life unworthy of life." Hentoff also stated that the Hastings Center's 1987 Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying would have been welcomed by defense attorneys for Nazi doctors. Although the respondents, including Callahan, addressed some of Hentoff's arguments against Callahan's points, the responses focused predominantly on the appropriateness of the Nazi analogy. Ironically, the epithet also was hurled from the other side of the issue as Jack Kevorkian assailed doctors who were not willing to help patients die as Nazis (*New York Times*).

THE HOLOCAUST AS AN IMPEDIMENT TO PROGRESS. Some people argue that the focus on the Holocaust has become an impediment to medical progress. In a keynote speech to molecular biologists in Berlin in 2002 the Nobel laureate James D. Watson, the codiscoverer of the structure of DNA and the first director of the Human Genome Project, told his German audience that the time had come to "put Hitler behind us" and embrace the good that genetic science can do (Koenig).

Rhetorical Strategies

The uses of the Holocaust in bioethical argumentation tend to follow a number of rhetorical strategies. The Holocaust may be used comparatively to suggest that a targeted act or position is morally equivalent: "What is happening here is no different from (or no better than) what was done during the Holocaust." Others use the Holocaust as a referent for a slippery slope argument: "Actions like these, if they continue, will lead to a Holocaust." Some use the term to chastise their colleagues or adversaries: "Your actions are no different from those of the Nazis or those who stood silent in the face of the Nazis." Conversely, the Holocaust can be used to justify an action by arguing that a criticism is misplaced: "After all, this is not like the Holocaust."

Conclusion

The cautions enumerated above are not meant to suggest that there are not appropriate and thoughtful attempts to use the Holocaust in bioethical argumentation. The Holocaust stands as a signal moment in the human encounter with euthanasia, unconscionable medical experimentation, victimization of the marginalized and powerless, relentless bureaucracy, eugenic extremism, and other acts and philosophies that bioethics forgets at its peril. Clearly, the considered use of the Holocaust can illuminate and strengthen a moral position. For example, many antiabortion and anti–embryo research scholars have tried to use the Holocaust as a thoughtful and nonsensational analogy to explore issues of vulnerability and medical justification (Neuhaus).

Bioethics is most effective when it pursues reasoned moral discourse, and the use of hyperbole and rhetorical strategies that depend on shock and insult cheapens the enterprise as a whole. In such cases the Holocaust does not inform bioethical debate but instead erodes it. The lessons of the Holocaust have profound meaning for modern bioethics, and the atrocities committed must stand as a bellwether against moral recidivism. Invoking the Holocaust to score rhetorical points, however, fails as a rhetorical strategy and degrades the genuine lessons that the Holocaust offers to bioethical discourse.

PAUL ROOT WOLPE

SEE ALSO: *Bioterrorism; Eugenics: Historical Aspects; Genetic Discrimination; Harm; Homicide; Life Sustaining Treatment and Euthanasia: Historical Aspects of; Medical Codes and Oaths; Metaphor and Analogy; Minorities as Research Subjects; Moral Status; Race and Racism; Research, Unethical; Warfare: Medicine and War*

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HOMICIDE

• • •

Homicide has been defined as "the killing of one human being by the act, procurement, or omission of another"

(Black, p. 867). However, federal homicide statistics reflect the police classification of homicide deaths as either murder or nonnegligent manslaughter, with deaths caused by negligence, suicide, or accident excluded. Some deaths that are not included in these federal statistics may ultimately be ruled homicides by a coroner or a court. Reported statistical data derive from various sources, including the FBI's Uniform Crime Reporting (UCR) Program and the FBI's Supplementary Homicide Report (SHR). Homicide figures reported from these databases are estimates, rather than exact numbers, because: (1) the classification is based on police investigation rather than coroner findings or judicial determinations; (2) many homicides are unsolved, resulting in the omission of data related to offender, and sometimes victim, characteristics; and (3) state agencies may fail to report details relating to homicides. These omissions in the available data may result in biased conclusions. For instance, the SHR does not include details related to approximately 8 percent of the homicides reported in the UCR, so conclusions from the SHR may be biased.

Despite these limitations, it is believed that homicide is the least underreported of any serious crime in the United States. Available data underscore the increasing frequency with which homicide occurs in U.S. society. As an example, the nation's murder rate in 1997 was 6.8 per 100,000 persons, compared to a rate of 4.6 per 100,000 in 1950.

Once considered to be an issue for law enforcement only, homicide is now recognized as a major public health problem (Novello, Shosky, and Froehlke). Because of disparities in the risk of homicide across subgroups, homicide must be considered as an issue of ethical, as well as public health, concern.

Epidemiology

Homicide data for the years 1976 to 1999 indicate that, compared to whites, blacks are six times more likely to be homicide victims and eight times more likely to commit homicide. Males represent nearly 75 percent of all homicide victims and almost 90 percent of all offenders. Compared to females, males are three times more likely to be killed and eight times more likely to commit homicide. Younger individuals are also at greater risk; almost one-third of victims and nearly one-half of offenders are under the age of twenty-five (Fox and Zawitz).

Homicide among intimate partners and family members remains a major concern, despite decreases in the rates of such events. In comparison with males, females are more likely to be killed by their intimate partners (defined as current or former spouses and current or former boyfriends and girlfriends, including those of the same sex). Women in the United States are at higher risk of homicide victimization than women in any other high-income society (Hemenway, Shinoda-Tagawa, and Miller). In 1998 the deaths of almost three-quarters of all women murdered were attributable to their intimate partners (Rennison and Welchans). For the period from 1993 through 1999, intimate partners killed 32 percent of all female murder victims ages twenty to twenty-four (Rennison, 2001). Analysis of homicide data for the years 1981 through 1998 indicate that the highest rates of intimate partner homicide during these years were among black and white females in the southern and western states (Paulozzi, Saltzman, Thompson, et al.), and most female victims were killed by an unarmed partner. Additionally, homicide is a major contributor to deaths occurring during pregnancy (Dannenberg, Carter, Lawson, et al.).

Women who kill their intimate partners often do so in response to repeated batterings. These beatings may result in the development of trauma symptoms, such as anxiety and psychic numbing, as well as lowered self-esteem and the development of self-destructive coping responses to the violence. The victimization may also lead to a total loss of the woman's social self. In general, a battered woman does not attack her abuser when harm is imminent but, instead, during a hiatus in the assaults. The incidence of female-perpetrated partner homicide appears to be lower in states that have strong domestic-violence legislation and greater access to supportive services such as shelters, crisis lines, and support groups (Dutton).

Disparities also exist in the disposition of cases involving intimate partner homicide. Of the 156 wives and 256 husbands convicted in 1988 in the United States for murdering their partners, wives received prison sentences that, on average, were twenty years shorter than those received by convicted husbands, even when comparing only those husbands and wives who were not provoked prior to the homicide (Langan and Dawson).

The United States has the highest rate of childhood homicide of any industrialized nation in the world (CDC). In fact, homicide represents the leading cause of infant deaths due to injury in the United States (Overpeck, Brenner, Trumble, et al.). An estimated 37,000 children were killed in the United States between 1976 and 1994, and one-fifth of these murders were committed by a family member (Greenfield). Of all children under the age of five who were murdered from 1976 to 1999, 61 percent were killed by parents or stepparents, and an additional 29 percent were killed by other relatives or by a male acquaintance. Most of the children killed were male and most of the offenders were male (Fox and Zawitz). Children under the age of eighteen accounted for nearly 11 percent of all murder victims in the United States in 1994, and nearly half of these children were between the ages of fifteen and seventeen. Among those killed in this age group, nearly 70 percent were killed with a handgun, while almost 20 percent were killed by another child. In addition, infants born to very young mothers have an increased risk of homicide (Overpeck, Brenner, Trumble, et al.).

The number of homicides involving adult or juvenile gang violence has increased fourfold since 1976 (Fox and Zawitz), and an increasing proportion of these homicides are now associated with firearm use. In Los Angeles County, for example, firearms were used in 94.5 percent of homicides in 1994, compared to 71.4 percent in 1979. Homicides committed with semiautomatic weapons also increased substantially during this period (Hutson, Anglin, and Kyriacou).

As of 2000, firearm use accounted for approximately 70 percent of all murders in the United States (Rennison, 2001). From 1973 to 1999, more than 80 percent of all workplace homicides were committed with a firearm (Duhart). The rate of homicides involving firearms has historically been higher in the southern states than in other regions (USDOJ, Homicide Trends). This regional variation has been attributed to both sociocultural factors and to the ease of access to firearms in the South.

Despite the increase in gun-related homicides, numerous state legislatures eased restrictions on the availability and use of firearms during the closing decades of the twentieth century, allowing citizens to carry concealed weapons even into churches and some government buildings. Public surveys indicate, however, that such increased gun-carrying actually reduces, rather than increases, public perceptions of safety (Hemenway, Azrael, and Miller).

The risk of homicide is also associated with the use of alcohol or illicit substances by the perpetrator and/or the victim immediately prior to the killing (Pernanen). Chronic alcohol use has been found to increase by up to tenfold an individual's risk of being a homicide victim (Rivara, Mueller, Somes, et al.). It is believed that the use of alcohol and illicit substances may adversely affect an individual's ability to process and interpret information correctly, thereby increasing the likelihood of miscommunication, which may lead to violence. Additionally, because alcohol use may impair an individual's judgment, intoxicated persons may be more likely to place themselves in situations that entail a high risk of violence. Chronic alcohol use may also indicate that an individual has an antisocial personality disorder, which is associated with increased rates of violence and victimization (Rivara, Mueller, Somes, et al.).

Prevention

Prevention efforts may focus on one or more of three levels. Primary prevention efforts attempt to prevent the onset of a condition—such as preventing violent behavior. These efforts often utilize a broad-based approach aimed at the general public, including messages urging the use of nonviolent means to resolve disputes and problems. Secondary prevention efforts target populations considered to be at high risk, such as individuals who have already committed some act of violence. Tertiary prevention is analogous to damage control after an event has already occurred, and most frequently consists of arrest and incarceration following the commission of a homicide.

Various primary prevention strategies have been utilized in an attempt to reduce the relatively high rates of homicide in the United States. Numerous jurisdictions have adopted *child access prevention laws,* which hold adults criminally liable for the unsafe storage of firearms in environments where children live or are present (Webster and Starnes). Such laws remain controversial, however, due to the ease with which children can obtain firearms outside of the household (Hardy). Pediatric-based counseling of parents to increase their safety-related behavior has also been recommended, but the effectiveness of this approach is questionable due to physicians' lack of time, their inability to accurately assess actual gun ownership among parents, and their perceived lack of credibility as a source of information (Hardy).

Homicide prevention efforts must also address the use of alcohol and other substances. Primary prevention efforts have included the imposition of increased excise taxes on alcohol, the use of anti-alcohol advertising and promotion, and the development of responsibility training programs for servers of alcohol (Rivara, Muller, Somes, et al.).

Secondary prevention efforts have included the counseling of individuals through court-ordered programs in an effort to intervene before violence becomes a pattern and before the violence escalates to the level of homicide. Healthcare providers are now more likely to ask female patients about domestic violence—in large part due to focused training of providers and recent accreditation requirements and legal mandates imposed on healthcare institutions. It is believed that the early identification of violence in the home, coupled with modifications in legal policy—such as the increased enforcement of laws prohibiting and punishing violence—will decrease the rate of intimate partner homicide. However, efforts also require that healthcare providers assess individuals' risk for becoming violent offenders before violence has begun, and to then refer those at high risk for appropriate intervention. Patient counseling by primary care providers to reduce excessive alcohol use and binge drinking may also help to reduce the rate of homicide by reducing the use of alcohol (Rivara, Muller, Somes, et al.).

Secondary prevention strategies also include the issuance of civil protection orders by courts. These orders prohibit individuals who have committed an act of intimate partner violence from further abusing their victims. In general, victims are more likely to seek such orders if they are financially independent from the perpetrator, if they are no longer living with him or her, and if they have seen family members or friends threatened or abused by the perpetrator (Wolf, Holt, Kernic, et al.).

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SEE ALSO: *Abortion; Abuse, Interpersonal; Bioterrorism; Death; Death Penalty; Embryo and Fetus; Harm; Infanticide; Insanity and Insanity Defense; Medicine, Profession of; Mistakes, Medical; Pain and Suffering; Race and Racism; Right to Die: Policy and Law; Sexism; Smoking; Warfare*

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HOMOSEXUALITY

• • •

I. Clinical and Behavioral Aspects
II. Ethical Issues
III. Religious Perspectives

I. CLINICAL AND BEHAVIORAL ASPECTS

It is believed that 2 to 10 percent of the U.S. population is gay or lesbisan (Gadpaille). However, there is no consensus among clinicians and behavioral scientists about the definition of homosexuality (Mondimore) and there are multiple definitions of the terms *bisexual, gay,* and *lesbian* (Francoeur, Perper, and Scherzer). Researchers, for instance, often fail to distinguish between sexuality (I am gay/lesbian), sexual behavior (I have sex with men/women), and community participation (I am a member of a gay/lesbian community) (Rothblum). These three dimensions, although somewhat overlapping, are not synonymous. Additionally, individuals' self-identity may change over time and in different contexts (Rothblum), as may the meanings ascribed to these terms by society.

Historically, homosexuality has been defined by reference to a person's physical behavior. An individual's orientation was determined by his or her biological sex and by the sex of his or her sexual partners. This view focuses on behavior as determinate and assumes that (1) only two sexual orientations—homosexuality and heterosexuality—exist and (2) an individual acquires his or her sexual orientation when he or she has sex for the first time.

Additional perspectives, however, may be critical to an understanding of sexual orientation. The self-identification view posits that sexual orientation may be discordant with behavior. Accordingly, the fact that an individual self-identifies as a homosexual does not preclude the possibility of that person having sexual relations with an individual of the opposite sex. Similarly, self-identity as a heterosexual allows for the possibility of sexual intimacy with a person of the same sex. The dispositional view of sexual orientation also considers an individual's sexual desires and fantasies and the sexual behaviors in which he or she is disposed to engage in ideal circumstances.

Dimensionality of Sexual Orientation

In the past sexual orientation was understood somewhat simplistically. Sexual orientation was treated as a binary construct: An individual was either heterosexual or homosexual. However, that understanding failed to explain bisexuality. The bipolar view of sexual orientation utilized by Alfred Kinsey conceived of sexual orientation along a continuous scale, with exclusive homosexuality at one end and exclusive heterosexuality at the other. According to this view, bisexuals are individuals who (1) are strongly attracted to people of the same sex and to those of the opposite sex, (2) are moderately attracted to those of the same sex and to those of the opposite sex, or (3) are weakly attracted to those of the same sex and to those of the opposite sex. The bipolar conceptualization of sexual orientation has been criticized for being one-dimensional and characterized as being similar to seeing masculinity and femininity as the opposite ends of a scale.

Most recently clinicians and researchers have employed either a two-dimensional or a four-dimensional scale to determine sexual orientation. The two-dimensional view posits that one dimension represents the degree of an individual's attraction to individuals of the same sex whereas the second dimension represents the degree of that person's attraction to those of the opposite sex. The four-dimensional view, which considers the varying levels of complexity inherent in defining sexual orientation, focuses also on an individual's choice of a sexual object, that is, the sex and sexual orientation of the individual and of those to whom that individual is sexually attracted, such as gay men, gay women, and straight men.

Theories on the Cause of Homosexuality

Same-sex eroticism and sexual behavior often have been viewed as abnormal or maladaptive. For instance, Richard von Krafft-Ebing, a late nineteenth-century neurologist, concluded that homosexuality represents an aberration in sexual behavior that results from the effect of worldly stress on a neuropathic disposition; thus, it constitutes a pathological condition rather than an immoral, criminal act (Mondimore). Havelock Ellis, a late nineteenth-century physician with a strong interest in anthropology, viewed homosexuality, or *sexual inversion,* as an inborn trait that reflects a permanent deviation in sexual development.

In contrast to those views, Kinsey concluded from his research that homosexuality is the product of cultural and socialization processes and therefore should not be considered criminal or the basis for the social ostracism of individuals (cited in Pomeroy). John Money, a sexologist, ultimately determined that homosexuality is a normal variation of sexual expression that results from prenatal influences interacting with environmental influences at critical unspecified periods.

A number of biological models have been developed in an attempt to explain sexual orientation and, specifically, homosexuality. The permissive model asserts that biological factors shape the brain structure on which experiences inscribe sexual orientations, whereas genetic factors constrain the period during which that experience can affect an individual's sexual orientation. The direct model attributes the responsibility for sexual orientation directly to genes, hormones, and other biological factors and their direct influence on the brain structures that underlie sexual orientation. The indirect model posits that biological factors shape an individual's temperament and/or personality, which in turn shapes the development of sexual orientation; genes may predispose a person to homosexuality in certain environments.

Proponents of biological theories of homosexuality have claimed support for their view from various findings. First, precursors of the reproductive organ systems of both sexes are present in the both male and female embryos. Second, various conditions related to sexual differentiation are thought to support the role of biology in determining sexual orientation. For instance, androgen insensitivity syndrome results from an inherited defect in the receptor molecule for testosterone; in persons with this syndrome testosterone has no effect on any of the target tissues. Individuals with this condition appear to be women and most often are attracted to men. Individuals with congenital adrenal hyperplasia experience abnormally high levels of circulating testosterone during embryonic development. As a result, genetic females develop masculinized genitalia. The condition 5-alpha-reductase deficiency results in the absence in genetic males of the enzyme required to develop external genitalia. At puberty females with this condition may experience an enlargement of apparently female organs into a penis-size organ, the secretion of testosterone, and a deepening of the voice.

Experiential theories of homosexuality encompass four major perspectives. One view focuses on the nature of an individual's early sexual experience and posits that through the process of operant conditioning an early pleasurable experience with an individual of the same sex will result in same-sex attraction. This theory has provided the basis for the seduction and first-encounter theories of homosexuality, which assert that individuals are *recruited* into a *homosexual lifestyle.* Other experientialists focus on the importance of family dynamics, theorizing that male homosexuality results from the influences of a strong mother and a distant father. This theory has served as the basis for many of society's stereotypes about the development of homosexuality and the characteristics of homosexuals and their families. Childhood gender roles are also a focus: It is believed that gender-atypical children such as girls who are "tomboys" and boys who are "sissy boys" develop into homosexuals.

Unlike these first three perspectives, experience-based developmental theory recognizes the potential role of biology and posits that biological factors code for childhood personality types and temperaments, which then are molded into gender roles. Once children develop gender roles, those who are different are seen as exotic and other. Lesbians develop from girls who fit masculine gender roles, and heterosexual women develop from girls who fit feminine gender roles. This theory is similar in many respects to the indirect biological model of homosexuality.

These biological models have proved to be controversial for a number of reasons. First, replication studies are lacking. Second, the results have significant implications for society's response to individuals who self-identify or are labeled as homosexuals. Some individuals argue that if homosexuality results from biology and does not signify a *lifestyle choice,* homosexuals cannot be considered morally depraved or criminal and consequently should receive the same legal rights and social recognition as any other identified group. Others fear that the identification of a biological basis for homosexuality ultimately will lead to attempts to correct what is perceived of as a biological *mistake.*

Only relatively recently has psychiatry declassified homosexuality per se as a mental illness by eliminating it as a category of illness in the *Diagnostic and Statistical Manual,* which guides clinicians in the diagnosis of mental disorders. However, the concept of illness has been retained through the incorporation into that text of a category for "sexual disorder not otherwise specified," which applies to individuals who experience "persistent and marked distress about sexual orientation" (American Psychiatric Association, p.

582). This definition does not recognize that the distress may result not from a person's sexual orientation but from the societal response to that orientation. Despite these changes some professionals and laypersons continue to view homosexuality as the result of an abnormal process of development and as reflective of an underlying pathology (Socarides).

The Formation of Gay Identity

Research suggests that individuals develop their sexual identity in stages. However, the specific process by which people develop sexual identity is not well understood and is subject to great variation across individuals.

Troiden (1989), who has written extensively about the process of identity formation among homosexuals, has posited that identity formation proceeds through four phases: sensitization, identity confusion, identity assumption, and commitment. Troiden observed that children may first feel a sense of "differentness." For example, boys may feel less interested in sports than do their male peers. Often this sense of differentness is experienced at an early age. Troiden has labeled these years of sensitization to one's differentness as the "sensitization stage," which generally spans the ages of six through twelve. During these years, children do not think of themselves as sexually different and the term *homosexual* has little, if any, meaning for most of them. In addition to feelings of differentness, children may become sensitized to a set of labels and attitudes inflicted on them by their peers; those labels may include terms such as *faggot, dyke,* and *queer*. An antihomosexual bias may be absorbed by children from their parents and peers, resulting in an internalized homophobia that causes extreme psychic damage during adolescence and adulthood.

It is during adolescence, generally before the age of fifteen, that children may recognize an incongruity between their sexual feelings and those reported by their peers. This stage in the process of identity formation has been labeled *identity confusion* (Cass; Troiden, 1988). The confusion often results from the conflict between an awareness of their sexual feelings toward members of their own sex and the others' assumption that they are like everyone else. A child's confusion may exacerbated by fears that he or she is not *normal* but instead is *abnormal, perverted,* or *sinful.*

As a result the child may experience cognitive dissonance, a psychological state that results when one is confronted by contradictory facts that both appear to be true. This disorienting state often is accompanied by intense fear and anxiety. The conflict may be resolved through an acceptance of one's homosexuality or a complete refusal to acknowledge one's feelings, that is, denial. Adolescents who are in denial may isolate themselves from individuals of the opposite sex or, conversely, engage in a frenzy of heterosexual dating. Denial may be accompanied by alcohol and drug use in an attempt to create distractions from these uncomfortable feelings. Some individuals may experience *identity foreclosure,* in which they use their energy to deny, avoid, or redefine homosexual thoughts and feelings in an attempt to prevent their incorporation into their identity (Cass). It is believed that most homosexuals go through a period of cognitive dissonance.

Once individuals have self-labeled as homosexuals, that is, have reached the stage of *identity assumption or acceptance* (Troiden, 1989), they must decide how to incorporate that information into other aspects of their lives. This decision may be extremely difficult because of the potential for stigmatization and rejection by their families and friends and in the workplace. Individuals may become increasingly aware of the discrepancy between their positive attitudes toward homosexuality and society's disparaging views and discriminatory treatment. In an effort to cope with this stigmatization some individuals may seek to separate themselves completely from the heterosexual world, viewing everything that is gay as "good" and everything that is not gay as "bad." This approach constitutes one variation of identity foreclosure (Cass). Others may proceed to the *commitment* phase, in which they disclose their sexual orientation to others, experience same-sex intimacy, and become involved with the homosexual community (Troiden, 1988).

A number of factors have been found to be helpful to individuals as they struggle with their identity. They include the presence of a gay or lesbian family member who has disclosed his or her own sexual orientation, the presence of a gay or lesbian role model, the support and acknowledgment of heterosexual friends, the presence of gay-positive media messages, the increasing visibility of gay issues, and open discussions in the course of receiving confidential healthcare services (Perrin).

Medical and Social Attitudes toward Homosexuals

Medical professionals have participated in widespread discrimination against individuals who self-identify as gay or lesbian. A study of 278 nursing students found that 38 percent believed that lesbians try to seduce heterosexual women and provide a negative role model for children (11%) (Eliason, Donelan, and Randall). A survey of 100 nursing educators found that 24 percent believed that lesbian behavior is wrong, 23 percent believed that lesbianism is immoral, and 15 percent felt that lesbians are perverted (Randall). Heterosexist and homophobic attitudes also have been noted among social workers (Berkman and Zinberg) and physicians (Douglas, Kalman, and Kalman; Matthews et al.; Oriel et al.; Pauly and Goldstein). These attitudes have been found to affect the quality of the care provided (Schatz and O'Hanlan; Wise and Bowman) and may interfere with the ability of gay and lesbian parents to obtain pediatric care for their children (Perrin and Kulkin).

A number of professional organizations have attempted to dispel prejudice among their members. The American Academy of Pediatrics, for example, stated:

> Teenagers, their parents, and community organizations with which they interact may look to the pediatrician for clarification of the medical and social issues involved when the question or fact of adolescent homosexual practices arises.… The American Academy of Pediatrics recognizes the physician's responsibility to provide healthcare for homosexual adolescents and for those young people struggling with the problems of sexual expression. (pp. 249–250)

Various other changes reflect an increasing acceptance of homosexuals, including the adoption of antidiscrimination provisions by many state and local governments, the availability of healthcare and other benefits to partners of gay and lesbian employees, and the ability of gay and lesbian couples to adopt children (Cain). However, there also has been an escalation in the number of hate crimes reported. National attention most recently was focused on antigay sentiment as a result of the 1998 murder of Matthew Shepard in Wyoming (Loffreda).

Ethical Issues in Psychiatric and Psychological Care

Ethical issues arising in the context of psychiatric and psychological care provided to homosexual patients are similar, for the most part, to issues that arise in the context of providing care to individuals who are heterosexual. Ethical issues related to the "conversion" of homosexuals to heterosexuality arise only for those who continue to believe that homosexuality is abnormal or an illness. There is no evidence that therapy will result in long-term change in the sexual orientation of adults (Coleman). Although parents may place their children in therapy to ensure that they are or will become heterosexual, evidence indicates that such experiences may be psychologically injurious (Isay).

Nevertheless, some psychoanalysts believe that attempts to change an individual's sexual orientation are ethical as long as the individual wants that change (Nicolosi; Socarides). Significantly, Gerald C. Davidson (pp. 97–98), one of the original pioneers of conversion therapy, ultimately concluded:

> Change of orientation therapy programs should be eliminated. Their availability only confirms professional and societal biases against homosexuality, despite seemingly progressive rhetoric about its normalcy. Forsaking the reorientation option will encourage therapists to examine the life problems of some homosexuals, rather than focusing on the so-called problem of homosexuality.
>
> It is critical that health professionals create an atmosphere in which their patient can openly discuss issues related to sexuality and sexual behavior. As with heterosexual patients, the focus should be on the patient's sexual behavior, not his or her sexual orientation. (quoted in Perrin)

Additional research is needed to address many unresolved issues. Physicians and therapists may be called on to offer their professional opinions in cases involving adoption by gay or lesbian parents. There is no evidence of mental health problems among children raised by lesbian mothers in the absence of a biological father. However, a related but relatively unexplored issue is the extent to which children may be especially vulnerable to societal stressors as a result of the societal bias against homosexuality.

Further research is needed to examine whether the sexual orientation of a clinician should be a factor in the selection of a healthcare provider, whether a provider should disclose his or her sexual orientation during the therapeutic process, and what effect the disclosure of the sexual orientation of a provider may have on the therapeutic process and its outcome.

ELI COLEMAN (1995)
REVISED BY SANA LOUE

SEE ALSO: *Lifestyles and Public Health; Mental Health, Meaning of Mental Health; Mental Illness: Conceptions of Mental Illness; Psychiatry, Abuses of; Sexual Behavior, Control of; Sexual Ethics; Sexual Identity; Sexuality, Legal Approaches to;* and other *Homosexuality* subentries

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II. ETHICAL ISSUES

The practice of medicine involves a body of knowledge, a body of practitioners, and the people who seek healthcare services. Homosexuality is of moral interest to medicine in all these areas. The term *homosexuality* was coined in 1869 by Karoly Maria Benkert to refer to same-sex eroticism, and it has prevailed over other proposed names, such as sodomy, contrary sexual feeling, inversion, and Uranism (Kennedy). To be sure, same-sex eroticism predates contemporary terminology and has a long—if contested—cultural history. The relationship between medicine and homosexuality has reflected both cultural prejudices as well as scientific advances.

History and Prevalence

In ancient Greek and Roman cultures, same-sex interactions were part of the cultural background, notwithstanding critics in those very societies. Educational relations among the Greek aristocracy took the form of mentoring relationships between older men and adolescent males, and schools for women sometimes followed this model (Marrou). It is not surprising that intimate mentoring relationships would sometimes become sexual. Roman civilization also had its share of same-sex eroticism, with some notorious emperors having harems of male lovers at their disposal (Gibbon). The

Emperor Hadrian was so distraught after the death of a beloved youth, Antinous, that he deified him, erected statues of him through the empire, and founded a city in his name (Birley).

In later times, the social and religious circumstances of medieval Europe worked to limit the visibility of homosexuality, but subcultures and literary and artistic expressions of same-sex love were far from unknown even in ecclesiastical communities (Boswell). Homosexuality has expressed itself elsewhere around the globe, as well, including Africa, China, and among Native American cultures.

In ways without precedent in human history, a same-sex culture has emerged in the large contemporary cities of the developed world and, it is a social force in communication, entertainment, business and commerce, and politics. Men and women who acknowledge their homosexuality hold prominent and influential social positions, as do men and women who choose not to disclose their homosexuality. The social visibility of homosexuality has not dispelled all moral and religious condemnation. In less developed parts of the world, homosexuality is sometimes far less visible but not altogether absent.

The extent of homosexuality in a given human society is difficult to estimate, for a number of reasons. Studies of sexual behavior face certain methodological problems, including adequate study samples and reluctance to discuss sex freely. Several ambitious studies have nevertheless tried to estimate the extent of homosexuality among men and women in the United States. In the mid–twentieth century, one Kinsey study of approximately 6,000 men showed that about 4 percent of them behaved exclusively as homosexuals after adolescence, and that 37 percent of men overall had some sexual experience with another man to the point of orgasm at some point during their lives (Kinsey). Another study showed that 1.32 to 2 percent of approximately 6,000 women behaved exclusively as homosexuals after adolescence, and that 13 percent of the women overall had had sexual experience with another woman to the point of orgasm at some point during their lives (Kinsey). At the end of the century, Laumann and colleagues also found that many people engage in homosexuality at some point. They found that 2.8 percent of their 1,749 male subjects and 1.4 percent of their females subjects claimed a homosexual identity (Laumann et al.).

Taken together, these studies show that many adolescents, and adult men and women, have same-sex fantasies and desires and engage in same-sex behavior. That said, there is often a fluidity to human sexuality that does not allow any easy division of humanity into homosexuals and heterosexuals, even if most people come to have entrenched sexual interests in males or females alone. This fluidity sometimes stands in the way of precise definitions of homosexuality, and of scientific accounts of why people behave a certain way.

Scientific Study

For most of human history, the origins of homosexuality did not elicit scientific interest. Neither was homosexuality treated as a pathological state. Instead, homosexuality was evaluated in moral and religious terms, and it was often condemned. In nineteenth-century Europe, however, many researchers and physicians began to study homosexuality in a systematic way and treat it as pathological. Describing homosexuality as a disease or disorder laid the foundations for discovering its causes and for developing treatments. For a variety of reasons, these researchers were often more interested in the origins and treatment of male homosexuality than female homosexuality. This emphasis may have resulted from greater social visibility of male homosexuality and a bias toward the selection of male subjects in medicine.

Many studies worked to show that homosexuality represented a kind of degenerate or defective human biology (Kraft-Ebing). Locating the origins of homosexuality in biology did not, however, always impose a pathological interpretation. For example, the German sex researcher Karl Heinrich Ulrichs (1825–1895) argued that homosexual men and women represented a *third sex,* and he offered an elaborate account of how the biological natures of men and women were blended in this sexual variation (Ulrichs). This view led Ulrichs to argue that homosexual men and women should not be punished by the law or mistreated by medicine for acting according to their biological natures (Hirschfeld).

Biology was only one field of study, of course, and not all theorists held that biology dictated the nature of one's sexual interests. Many psychologists looked to experiences in development for the factors that determined the nature and scope of homosexuality in men and women (Ellis). By contrast, the father of psychoanalysis, Sigmund Freud (1856–1939), drew no sharp distinctions between biology and psychology. He looked rather to an interplay of psychology and biology, believing that some people developed homosexually for psychological reasons, while biology played a more decisive role in the sexual development of others (Freud, 1953). In any case, Freud did not think that homosexuality was inherently pathological, though he did not think it represented full sexual maturity.

In the United States, organized psychiatry in the twentieth century first affirmed, and later repudiated, the view that homosexuality was pathological (Bayer). In 1952 the

American Psychiatric Association (APA) described its categories of disease for the first time, and it labeled homosexuality as a "sociopathic personality disorder" (APA, 1952). A 1968 revision of this classification described homosexuality as a "personality disorder," and in 1973 the APA formally abandoned the view that homosexuality was pathological. Yet another revision, in 1980, led the APA to identify homosexuality as an "ego-dystonic disorder," meaning that it could be treated as a disorder if an individual suffered from it. There is no specific mention of homosexuality in the most recent versions of the APA diagnostic nomenclature, but the APA does recognize "sexual orientation distress," which involves persistent and marked distress about sexual orientation (APA, 1994). However, sexual orientation distress would apply to all unwanted and distressing orientations, not just homosexuality. In 1981 the World Health Organization removed homosexuality from its list of diseases. Despite this sea change in the views of the medical profession generally, some physicians and psychologists still maintain that homosexuality is a serious disorder.

Even after the APA depathologized homosexuality, debates about the relationship of homosexuality to health, disease, and illness continued. Some commentators in bioethics tried to describe health and disease in *naturalist,* or objective, terms that transcended cultural and social variation. These commentators described disease in terms of impediments to the central species functions of survival and reproduction. Heart dysfunction, for example, poses a threat to individual survival no matter the culture in which it occurs. Other commentators were not persuaded that categories of disease and health could be identified apart from moral evaluations about the worth and merit of particular states. For these *normativist* commentators, human moral evaluations always played a role in determining how a given society defined its states of disease and health (Engelhardt). From either the naturalist or normativist perspectives, it is hard to make the case that homosexuality is necessarily pathological.

Arguing from a naturalist perspective, the philosopher Christopher Boorse has maintained that homosexuality can be treated as a disease because of its interference with reproduction—whatever else it is, homosexuality is sterile (Boorse). In fact, however, homosexuality does not rule out having children, and some cultures manage to accommodate the marriage and parenting of people whose sexuality is primarily homosexual.

It is also doubtful that homosexuality is always a threat to species survival. Sociobiologists have hypothesized that homosexuality might even confer survival advantages to groups, since homosexual men and women may play roles in a society that offset any reduced number of children they might have (Ruse). As to their own survival, homosexual men and women may face individual health risks that others do not, but these risks may be tied to social circumstance rather than to homosexuality itself. For example, even if homosexual men face increased risks of disease and death, those risks are contingent, in the sense that successful treatments and vaccines could significantly dispel the danger.

As for normativist evaluations, it is clear that many men and women embrace their homosexuality without complication, and many cultures have also accommodated those people in one way or another. It is therefore hard to argue that—all other things being equal—homosexuality must lead to disorder and suffering. This is not to deny that some people and some cultures may disapprove of homosexuality, but the variance of response seems to show that it is not homosexuality per se, but how it is valued and treated that sometimes provokes its designation as disease.

For most of human history, medicine did not think of homosexuality in terms of disease. As both naturalist and normativist approaches show, what counts as disease—and what therefore deserves biomedical study and treatment—very much depends on one's theoretical starting points.

More recent commentary has challenged not the roles of health and disease in the study of homosexuality, but the very idea that homosexuality has root causes that science can discover. Indeed, the very fluidity of sexuality—both in individuals and in the sexual roles of various cultures—leads some commentators to maintain that sexual orientations are socially constructed. In this view, there are no homosexuals or heterosexuals in the sense that these are distinct kinds of people (Halperin). It would therefore be a mistake to look for genetic or hormonal causes of sexual orientation, just as it would be a mistake to study the biology of human beings in order to learn why some people are baseball fans and some people are not. Circumstance and society shape baseball fans, not human nature, and some commentators, known as *social constructionists,* hold the same view of sexual orientation.

In contrast, *essentialists* argue that human beings have sexual orientations by reason of their given nature, and that sexual orientation is likely rooted in biology. In other words, people are of *natural kinds* in regard to their sexual nature, and there are homosexuals and heterosexuals in the same way that there are elm trees and maple trees or people with blue eyes and people with brown eyes. From this perspective, sexual orientation amounts to an essential trait, and people express sexuality according to their natural kind (Stein). To essentialists, it is not a mistake to search out the root causes that distinguish people by sexual orientation.

The scientific study of fantasies, desires, and behaviors does not commit social-science researchers to either social constructionism or essentialism. It is possible to study many aspects of sexual psychology and behavior whether sexual orientation is rooted in nature or is simply a reflection of habits and patterns that people acquire in the course of their social development. However, the debate between constructionism and essentialism does have important implications for the causal study of sexual interests. It would be a mistake to look for the root biological causes of sexual interest where they do not exist.There is no well-validated account of how human beings come to have the entrenched sexual interests they have, though it is clear that genetics, anatomy, hormones, and psychological history all play a role. So it is not unscientific to ask why homosexuality comes to the fore in some people, why heterosexuality comes to the fore in others, and why others blend their sexual interests. There may well be genes or neurological features that dispose some people to the sexual interests they have. To be sure, there may be dubious motives behind some researchers' quest to understand the pathways of sexual development, but it is not unscientific to investigate the origins and determinants of sexual orientation.

The origins of sexuality—and homosexuality in particular—have attracted a good deal of scientific interest. Researchers across the life sciences have looked to see whether homosexual men and women have traits in body or mind that others do not have, and to learn whether those traits are causally connected to their sexual interests. Researchers have looked at body shape, the nervous system, hormones, genetics, and so on to discern the influences behind sexual orientation. They have also looked at psychological and behavioral differences, including the ability to whistle, the preference for certain colors, and relationships with family members (LeVay, 1996). There has been no shortage of studies along these lines, and contemporary researchers have continued to add to this domain of research.

In 1991 the neuroanatomist Simon LeVay published a report showing that some brain structures in homosexual men are statistically smaller than the same structures in heterosexual men. But because the size of these structures does not correspond exactly with sexual orientation, this study could not establish any definitive link between neuroanatomy and sexual interests. In 1993 the geneticist Dean Hamer and colleagues published a study showing that homosexual men are more likely than others to have male homosexual relatives, and the pattern of distribution of these male homosexual relatives suggests a genetic inheritance passed through mothers. The study also showed that male homosexual brothers are more likely to share a genetic region in common than nonhomosexual brothers, which also suggests there is a genetic contribution to sexual orientation. Again, however, because this shared genetic region does not correspond exactly with sexual orientation, these patterns do not prove that there is a "gay gene."

Both the LeVay and Hamer studies are preliminary and suggestive, but they are not definitive. Some commentators have nevertheless interpreted these studies as showing that homosexuality is *natural,* in the sense that there is a describable biology behind it (LeVay, 1993). These commentators think scientific study will protect homosexuality from social condemnation by confirming it as part of human biological nature. Others fear that these studies will revive theories that homosexuality is pathological (Bersani).

Where there is scientific uncertainty, there will be speculation and disagreement. For this reason, many analysts turn to ethics rather than science as a guide to the meaning and significance of homosexuality. Ethical analysis of homosexuality has a far longer history than its scientific study, and it will continue to have a role as the findings of science unfold.

Ethical and Legal Evaluation

Ethical theories try to describe an overarching view of what is good for human beings and to describe ways of distinguishing among states, choices, and behaviors that contribute to—or at least do not detract from—that overarching good. Ethical theories vary in their interpretations of homosexuality.

PREMODERN ETHICAL THEORIES. In ancient Greece, there were disagreements among intellectuals about erotic interactions between males. According to his chroniclers, Socrates (470–399 B.C.E.) experienced attraction toward other males, but he saw it as a means to achieve spiritual wisdom rather than physical gratification. Plato's (427–347 B.C.E.) views modulated over his long lifetime—from prudential accommodation of the spiritual aspects of homosexuality to more or less outright condemnation of this sexuality as being contrary to nature (Dover). His sympathetic references to erotic attraction between adult and adolescent males do not undercut his more fully considered view. Aristotle (384–322 B.C.E.) had less to say about homosexuality, though he also disapproved, describing homosexuality, in his *Nicomachean Ethics,* as a pleasure of those with bad natures.

In Medieval Europe, it was Thomas Aquinas (1225–1274) who—from a Catholic background—offered the next major treatment of homosexuality, calling it the most sinful species of lust. He did so in the context of *natural law*—a law defined in terms of the goals said to be inherent in human life. In his *Summa Theologiae,* he describes homosexuality as a violation of animal nature and of the order of sexual acts generally. The historian John Boswell has criticized this view by arguing that bodies and body parts have multiple purposes, and that the use of human genitals is meaningful only in sexual acts capable of begetting children. It is also the case that that there are analogues to homosexuality in other animals (Bagemihl), though even if there were not, it is unclear why animal behavior should be taken as a guide for human beings capable of reasoned evaluations of their choices.

MODERN ETHICAL THEORIES. The German philosopher Immanuel Kant (1724–1804) had a number of things to say about homosexuality, though he found doing so distasteful. Kant defended the categorical imperative as the central guide to human action. There are various formulations of the categorical imperative. What they share in common is the counsel to abide by rules that one would wish to see function as universal law. To use a negative example of how this would apply, one should not like because one would not wish to live in a world where lying was the universal norm. To use a positive example, one should be charitable because one could possibly want charity from others in the future. Kant argued that homosexuality was wrong because it could not function as a universally accepted practice. Applied to everyone, the sterility of homosexuality would put an end to the birth of children. Kant also found same-sex erotic behavior especially degrading to the parties involved.

By way of response to the Kantian view, it should be noted that it is sometimes difficult to see how precisely, or how broadly or narrowly, a moral maxim should be drawn. For example, it might be possible to frame a maxim of behavior this way: if—and only if—people find themselves sexually attracted to their own sex, then they should act accordingly, but not otherwise. In this way, the future of the human race would be secure and people would not have to act contrary to their actual sexual interests. And, of course, some heterosexual acts are just as disrespectful of sexual partners as homosexual acts—selfish sexual gratification is not the province of one sexual orientation alone.

In striking contrast to Kant, the British utilitarian philosopher Jeremy Bentham (1748–1832) came to almost the opposite conclusion about the morality of homosexuality. In works that were not published in his lifetime, he defended homosexuality for those inclined to it, saying it gives them pleasure and leads to happiness. In keeping with his utilitarian view that actions should be judged in terms of their capacity to contribute to human happiness through pleasure, Bentham thought it undeniable that homosexuality was one way to human pleasure. For some people, therefore, the pursuit of same-sex relations would be a positive good. Bentham was not especially worried that social accommodation of homosexuality might lead to more homosexuality, for if there is nothing wrong with homosexuality (for those interested in it), then increasing the amount of homosexuality in a society is not wrong either. He was convinced, too, that the forces of heterosexual lust were stronger than any threat to the birth rate that homosexuality might pose. In a strict sense, from this point of view, homosexual orientation and behavior are not of inherent moral interest.

Another utilitarian philosopher, John Stuart Mill (1806–1873), also believed that actions were moral to the extent that they promoted happiness. Given that adults are ordinarily the best judges of what makes them happy, Mill wanted to limit social interference with individual pursuits. He articulated his "liberty principle" in order to define a sphere of behavior that did not warrant social action. To Mill, social interference with the actions of others is justified only to prevent harm to others. Harm to one's own self is not a sufficient reason for interfering with an adult's beliefs and choices. With this conceptual background, it is possible to articulate a formidable boundary against social interference with homosexuality. Unless their behavior harms others—as in rape, for example—men and women should be able to pursue same-sex partners without social interference.

Alan H. Goldman, a commentator on sexual ethics, has argued that there are no moral rules specific to sexuality alone. He argues that the moral rules or precepts that apply across the range of human relations are the rules that should apply to sexuality as well. This means that the same rules that apply in heterosexual relationships should apply in others as well: if sexual fidelity is promised, it should be honored; there should be no deception or mistreatment; and so on. In one sense it is this very attempt to make social relations consistent across sexual orientations that has led to ambitious attempts to reform laws that criminalize homosexuality.

DEVELOPMENTS IN THE LAW. The ethical standards reflected in laws around the world are widely variable. In some nations, sex between males or between females is strictly forbidden and severely punished. In others, homosexuality is illegal as a matter of formal statutes but is not punished in practice. In other countries, homosexuality is not an object of legal interest in itself, only insofar as sexual relations may be involuntary or public. In 1957, in England, the Committee on Homosexual Offenses and Prostitution issued a report, commonly known as the *Wolfenden Report,* that recommended that the United Kingdom decriminalize consensual "sodomy" among adults. In coming to this conclusion, it drew heavily on notions of privacy and protection from social intrusion. In this regard, the report shared parallels with the Napoleonic Code, put in place in 1804. In that code there was no explicit mention of homosexuality, only of criminalization of involuntary and public sexual crimes, regardless of the sex of the parties involved. Lord Patrick Devlin argued against the conclusions of the *Wolfenden Report* by saying that society's moral revulsion toward homosexuality should count as a valid reason for legal restrictions. Devlin argued that a society requires shared moral values and political beliefs and that even acts that occur in private threaten the existence of society, and are not beyond the reach of social suppression. Nevertheless, Britain did decriminalize homosexuality among adults.

In 1986 the U.S. Supreme Court, in *Bowers v. Hardwick,* affirmed the right of states to enact laws prohibiting homosexuality among adults. In the case of *Romer v. Evans* (1996), however, the Court maintained that states could not deprive homosexual men and women of particular rights. As of this writing, the Court has heard a sodomy case which may undercut the conclusions of *Bowers v. Hardwick.*

In general, there is a trend in the United States to decriminalize homosexuality. In many other jurisdictions around the world, the legal battles have shifted away from the simple question of whether sexual relations between men and between women should be criminal or not. Newer legal battles have engaged such topics as protection from discrimination in employment, housing, and public accommodations, and many jurisdictions are debating broader civic rights for same-sex couples. For example, the Netherlands and Belgium have recognized same-sex marriage. In the United States, the state of Vermont recognizes a *civil union* that parallels marriage. Other issues advancing on the legal frontier for homosexual men and women are the right to custody of children and the right to serve openly in the military.

The Uses of Sexual-Orientation Science

Despite social and legal acceptance in many quarters, the place of homosexual men, women, and adolescents is not secure in all societies. Many societies, for example, lack basic protections for homosexual men and women. For this reason, some observers are wary of going forward with sexual-orientation research. Some observers believe that sexual-orientation science is not valuable (Suppe), while others believe it will be harmful to homosexual men and women (Bersani). Such research might be used to "treat" homosexuality in adults, or even to control the sexual orientation of children, sometimes through prenatal interventions. Each of these uses raises moral concerns.

SEXUAL-ORIENTATION THERAPY. As a matter of ethics, sexual-reorientation therapies should be guided by the standards of informed consent that guide clinical treatmentin other areas. At the very least, patients should understand and freely consent to treatment, appreciate the risks and benefits of treatment, and be advised about alternatives to treatment. These conditions have not always been met in sexual orientation therapy, especially involuntary treatment imposed by family and the state. As a matter of science, a broad array of techniques has been used with men and women to redirect sexual orientation from homosexuality to heterosexuality. Techniques used toward this end have generally reflected prevailing treatment methods of the time. Drug and hormone treatment, behavioral therapy, surgery, and psychotherapies have all been deployed at one time or another (Murphy, 1992). While some of this therapy has gone forward with professional integrity, there has also been involuntary treatment, gruesome castrations in the Nazi camps, and chemical and electrical aversive therapies that can only be called abusive.

While there are some reports in the scientific literature that describe successful re-orientations (Spitzer), it is unclear that sexual orientation therapies consistently deliver what they promise, especially when applied to randomly selected groups of people. Reports of success in reorientation come most typically from psychoanalysts, behavior therapists, and religious programs. These reports have been criticized for problems related to method, sample size, the lack of long-term assessment, a focus on behavior change (instead of psychic change), and the lack of control groups.

For therapists and their patients who still maintain that homosexuality is pathological, research that led to truly effective therapy would be all to the good. Other therapists do not maintain that homosexuality is pathological, but still believe that some treatments are justified in the name of respecting wishes about unwanted traits (Schwartz and Masters). For these therapists, research into treatments is also highly desirable, but it would remain a matter of debate whether the extinguishing of unwanted traits is a legitimate objective for medicine. Some commentators have argued that sexual-orientation therapy is immoral because it contributes to social prejudice against gay men and lesbians. For these commentators, further investigation into causes and therapies for sexual orientation is objectionable. The psychologist Gerald C. Davison has held that the mere availability of such therapy encourages its use, thereby perpetuating oppressive views about homosexuality. In contrast, the philosopher Frederick Suppe has pointed out that such an argument is persuasive only if the therapy: (1) presupposes that homosexuality is inherently inferior to heterosexuality, and (2) is socially influential in perpetuating injustice. It is not always clear that therapy programs meet these two conditions. It can be said, however, that pursuit of sexual orientation therapy may be an artifact of social injustice rather than an injustice in itself. In other words, people might look to therapy as a remedy for mistreatment in society at large.

THERAPY WITH ADOLESCENTS. Sexual orientation therapy is not confined to adults. In the past, parents have turned to punishment, moral exhortation, religious counsel, reform school, and even electroshock therapy in order to bring their children to heterosexuality. Both ethics and the law converge in the view that the people with the strongest immediate interest in protecting children are their parents. For this reason, parents are ordinarily entrusted to make even profoundly life-affecting decisions about their children. However, if parents' choices interfere with their children's well-being, then those children are entitled to protection. For example, the state can intervene when parents endanger children, deprive them of essential food and medical treatment, interfere with their education, and so on. Should ethics and the law recognize the right of parents to choose the sexual orientation of their children? The answer is "it depends."

To the extent that children do not have an interest in one sexual orientation over another, it would seem that parents should be able to plot the course of their children's lives, provided their actions are not harmful. For example, if parents wanted to ensure that they have only heterosexual boys, they might encourage their young boys to act in ways that they think (rightly or wrongly) will ensure that sexual orientation. They could therefore encourage boys to play vigorous contact sports and socialize with other boys. Unless it is hectoring and abusive, this encouragement does not by itself interfere with the child's well-being.

However, as they mature, children develop some degree of moral right to protection from parents' choices, even if those choices are well-meaning. Both ethics and the law recognize, for example, the rights of maturing adolescents to enroll in clinical trials and to refuse life-sustaining treatment when they are profoundly ill. That is, maturing adolescents are entitled to act in ways that protect their interests, even if their parents profoundly disagree with the choices made. This model can be extended to sexual orientation therapy as well: if maturing adolescents are profoundly unhappy about their emerging sexual interests, they might well accede to their parents' wishes and seek therapy. If, however, adolescents are not unhappy about their emerging sexual identity, it is unclear, as a matter of morality, why their parents' choice ought to prevail, especially if therapies or treatments carry risks that outweigh the possible gains of success.

PRENATAL INTERVENTIONS. Some commentators worry that research programs aimed at identifying the origins of homosexuality may lead to the elimination of homosexual progeny through prenatal interventions. They worry that markers for sexual orientation might be discovered that could predict a child's eventual sexual orientation. If this were possible, some parents might want to use various interventions to control the sexual interests of their children. This might be done—hypothetically speaking—through gamete selection, embryo biopsy, genetic manipulations, fetal treatments, or even abortion. This discussion is speculative, but it does illuminate key moral issues in parents' choices about their children.

In the United States, women are entitled, as a matter of ethics and law, to the prenatal information that bears on their choice whether to have children or not, as well as information related to fetal well being. They are also entitled to make abortion decisions for reasons of their own. The question under debate is whether this general approach is appropriate for choices about the sexual orientation of children. On one level, it would be idiosyncratic to forbid the use of prenatal diagnostics or even abortion when there are no legal barriers to doing so in regard to other traits of children (LeVay, 1996; Murphy, 1999). Some commentators worry, however, that the use of prenatal interventions could jeopardize the status and well-being of homosexual men and women in general (Stein). If used widely, these interventions could reduce the total number of homosexual men and women in the world, making group self-protection more difficult. By the same token, legal interference with parents' choices about the use of prenatal diagnostics could lead to circumstances in which homosexual children are born into families that do not want them. Parents could also use these techniques as a way of having homosexual children, and some parents no doubt would choose this option.

These considerations weigh against a moral conclusion that society should forbid prenatal interventions in the name of protecting homosexual men and women in general. In order to reach that conclusion it would have to be shown that sexual minorities could only be protected by such intrusive measures, and that these measures are ultimately more important than allowing parents to have children according to their own best judgments. It is to be remembered that this discussion is hypothetical, and there are no known means for ensuring the sexual orientation of a child.

Beyond Diagnosis and Treatment

Since the 1800s, the debate about the pathology of homosexuality has occupied center stage in the relationship between homosexuality and medicine. That focus notwithstanding, the vast majority of homosexual men and women never wanted, sought, or received therapy for their sexual orientation. Each one of these men and women has, however, other healthcare needs. At the very least, males who have sex with males and females who have sex with females have specific risks to their health, and this is especially true for homosexual youth who seem to be at increased risk of suicide (Gibson). Against this background, it is important to ask whether health professionals have the knowledge and communication skills necessary to meet the health needs of this group. Certainly some health professionals and academic commentators have paid attention to the healthcare needs of homosexual people (Solarz). However, medicine's own history in regard to homosexuality can stand in the way of appropriate degrees of study and effective healthcare.

No matter what their sexual interests, patients already face a problematic relationship with healthcare: medicine is distant from them by reason of its complex and intricate knowledge, cultural expectations about the role of the physician, and professional commitments within medicine (Engelhardt, p. 291). People with same-sex interests are perhaps at a further disadvantage because they cannot uniformly expect to encounter healthcare practitioners who are conversant with the specific health risks of homosexual men and women and who are comfortable with the nature of their sexual lives.

Indeed, some practitioners may believe that health risks associated with homosexuality are *deserved* and therefore require less social attention than other problems. In the 1980s, for example, some commentators argued that the AIDS epidemic was a divine punishment for immoral homosexuality. This view is hard to credit for a variety of reasons. In the first place, the view is suspect because the "punishment" is applied inconsistently. Some men who have sex with other men have developed AIDS, but most others—across history and even in the present—have not. Further, why should homosexuality receive this sort of punishment while other moral transgressions go unpunished? How is the punishment proportionate in its effect, and why should consensual behavior be punished so severely?

Rather than tie AIDS to divine punishment, some commentators pointed to social injustice as a root cause of the epidemic. These commentators argue that the sexual behavior of many homosexual men is affected by social prejudice. In other words, some men take sexual risks as *adverse preferences,* something they would not do if they had the same array of options in relationships and social status as others. Because they do not, they make poorer choices. According to these commentators, society has an obligation to make amends to those whose disease can be traced back to social inequality (Mohr).

Are there social factors that stand in the way of the health of homosexual men, women, and adolescents? One factor might be obstacles to the formation of long-term relationships and families that are especially important when it comes to healthcare and caregiving. Some homosexual people have no access to health insurance through their partner's employment, as married partners have, and others have no presumptive right of inheritance or decision making at the bedside of a partner who cannot direct his or her medical choices. The law does allow homosexual men and women to make health decisions for their partners who lose the ability to do so, but this recognition ordinarily requires advance directives such as a power-of-attorney for healthcare. When such arrangements are not put in place, some partners are excluded from decision making. Some healthcare services are not available to homosexual people. Some commentators think infertility clinics should not offer services to people in same-sex relationships, and some clinics do exactly that (Ford). For reasons like these, it is certainly worth asking whether deficits in the health and well-being of homosexual men and women are rooted in social injustice, with injustice minimally defined as the social failure to treat like cases alike.

Patients are not the only people in healthcare relationships, of course, and it is important to note that many gay and lesbian health professionals—physicians, nurses, and others—believe that certain social attitudes work against their full acceptance in the medical community. For example, some residency directors do not wish to have homosexuals in their graduate training programs. These hurdles may not have the same force everywhere and for everyone, but they nevertheless work against the equal standing of gay, lesbian, and bisexual healthcare practitioners (Potter).

The debate about the ethics of homosexuality has extended into discussions about cloned human beings. Some commentators have argued broadly that no one—single people, coupled partners, or married people—ought to use cloning to have children (President's Council on Bioethics). Others open the door to the use of cloning by some infertile couples and would allow same-sex female couples to use cloning technologies if they become safe and effective, since these couples have fewer options available to them. Still other commentators have argued that if cloning technology is safe and effective, there is no obvious reason why all same-sex couples should not have access to it. In cloning, as in other aspects of social and moral life, unwritten ethical rules and social opinion often guide the application of biomedical technologies and the distribution of healthcare benefits. When it comes to homosexuality and healthcare, it is often these unwritten rules of social opinion that are decisive and most in need of analysis.

TIMOTHY F. MURPHY

SEE ALSO: *AIDS; Autonomy; Behavior Modification Therapies; Epidemics; Freedom and Coercion; Human Nature; Natural Law; Human Rights; Law and Morality; Lifestyles and Public Health; Narrative; Public Health; Sexual Ethics;* and other *Homosexuality* subentries

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III. RELIGIOUS PERSPECTIVES

Homosexuality is one of the most contentious issues of contemporary times, though important scholarship has indicated that it was not always so. This article will trace Western religious perspectives on homosexuality in Judaism, Roman Catholicism, and Protestantism from Greco-Roman times to the twenty-first century, as well as summarize homosexuality's position in Islam.

Pre-Christian Greece and Rome

In the Greco-Roman ancient world, same-sex relationships were parts of the warp and woof of civilization, though there is no evidence that the word *homosexuality* existed in either Greek or Latin. However, same-sex unions paralleling heterosexual marriage appear to have existed from ancient times through the Middle Ages (Boswell, 1994). Both Jonathan Ned Katz and John Boswell argue that *homosexuality* is a nineteenth-century invention. Anne Zachary reports that "the term, 'homosexuality,' was first coined as recently as 1869 by Benkert."

Scholars have long known that in ancient Greece, adult male citizens engaged in pederasty (sex between men and boys), a practice that was a thoroughly acceptable part of Greek social and cultural anthropology. It was common for adult male citizens (not slaves) to initiate young boys into the rituals of manhood, which included sexual partnering. This same practice was not followed in ancient Rome, though same-sex relationships did exist there.

In the Mediterranean world, social stratification was commonplace and included rigid demarcations between free men and slaves, as well as between adult males and adult free women. Bernadette Brooten has argued that attitudes toward same-sex relationships between women in the ancient world ought to be viewed within the context of attitudes towards women in general (1996). Since gender stratification undergirded the Mediterranean worldview, the ancients commonly regarded women as inferior to males, and they held derivative positions by virtue of their relationships to their husbands and fathers. Such a realization is important in understanding the place of same-sex relations within the Greco-Roman context.

In Greek and Roman anthropology, human nature was bifurcated—either active or passive. Under this view, males were thought to possess an active nature and women a passive nature. In terms of sexuality, the ancients recognized a fluidity that extended to any sexual expression of the male nature. Sexual expression would have taken place between "one active and one passive partner, regardless of gender.…" (Brooten, 1996, p. 2). Some scholars point to social condemnation of the penetrated male because he was thought to violate the male *nature* by assuming a role fitted for women. The male penetrator did not appear to be similarly reviled, since he was acting in accord with man's *active nature.*

Within the context of this worldview, sex between two women simply had no place in the social and gender hierarchy of the ancient world. However, the ancients may have been less condemnatory of the partner who was penetrated as she was at least behaving according to nature (*kata physin,* in Greek). Both Roman and Greek sources indicate a knowledge of female homoeroticism: *frictrix/fricatrix* and *tribas/tribades* in Latin, for women who "rubbed" other women, as well as the Greek words, *tribas* and *Lesbia.* Although ancient authors were certainly aware of female homoerotic relationships, it remains unclear whether this was regarded as a matter of particular concern since it was out of the bounds of gender hierarchy on which the ancient world was based.

Was there an anti-homosexual attitude in ancient Greece and Rome? The question is itself reflective of a twenty-first-century bias. It has been established that the term was unknown to the ancients, and scholars such as Brooten (1996) argue that what the ancients condemned was the transgression of rigid gender hierarchies (the active/passive distinction), rather than *homosexuality.* Boswell (1994) argues that same-sex relationships were not condemned, though he did not apply a gender analysis to his research. R. T. France, an Evangelical scholar, holds that "Homosexual partnerships, whether pederastic or between adults, are accepted without comment, and described with appreciation, across a wide range of Greek literature" (France, p. 248).

Some scholars argue that a bias against same-sex relations did exist, though most write chiefly of male-male relations. Ward, for example, argues that such a bias can be found in Plato (*The Timaeus,* and *Laws*), as well as in Philo, a first-century C.E. Hellenistic Jewish philosopher, and in the *Sentences of Pseudo-Phocylides,* contemporary with Philo (Ward). The bias articulated in these sources, according to Roy Bowen Ward, is one of anti-hedonism and pro-procreationism. In this view, homoeroticism in the Greco-Roman world was seen to be *para physin* (against nature) because it is hedonistic behavior that cannot lead to procreation.

Biblical Issues

By far the most contentious terrain in the battle over homosexuality and religion is that of the Bible; this is particularly so for Christians. Genesis 19: 1–11 and Judges 19: 22–30 each contain a reference to a similar story in which God punishes ancient Israel for its behavior. Exactly what *kind* of behavior is the hermeneutical issue for biblical scholars. Theological conservatives tend to interpret Genesis 19 and Judges 19 as stories of God's condemnation for attempted homosexual rape, while more liberal exegetes have taken the position that the violations condemned are violations against the ancient code of hospitality so central in the Biblical world. Feminist biblical scholars have pointed to the misogyny of Judges 19 as an interpretive key.

There are only two places in the Hebrew Scriptures (Old Testament) that contain explicit prohibitions against what is referred to as homosexuality, though the word itself is never mentioned in the Bible. Both are contained in the book of Leviticus, mentioned in the context of the codes of ritual purity by which Israel is to set itself apart from other people. The New Revised Standard Version (NRSV) of the Bible translates as follows: Leviticus 18:22, "You shall not lie with a male as with a woman; it is an abomination"; Leviticus 20: 13, "If a man lies with a male as with a woman, both of them have committed an abomination; they shall be put to death; their blood is upon them."

Scholars debate both the meaning of word choices (what does it mean to "lie with a male as with a woman"? what does *abomination* mean?), and of historical/cultural context. Not surprisingly, Evangelical and conservative Christian exegetes tend to interpret the passages to mean that God condemns acts of same-sex eroticism between men; a few Biblical literalists use Leviticus 20:13 to argue for the death penalty for homosexuals today (see <www.godhatesfags.com>). If the writer of Leviticus does intend to signal God's condemnation of homosexual sex between men, what is the basis for the condemnation? Conservative exegetes argue that the *abomination* (*toevah* in Hebrew) in question is quite simply *sodomy,* or anal intercourse between two men; hence the meaning of to "lie with a male as with a woman." Lynne C. Broughton claims that *toevah* signifies something inherently wrong and contradictory to nature.

More liberal Christian exegetes make two kinds of hermeneutical claims. The first view is that the ritual codes of ancient Israel were written for a particular context and that few of these commands are observed today (Borg). Indeed, few Christians observe other prohibitions found in Leviticus, such as having sex with a menstruating woman (18:19), eating certain foods (19:26), cutting beards (19:27), wearing clothes made from two kinds of fabrics (19:19), or tattooing (19:28). Marcus J. Borg maintains that Christians who set aside these laws must assume the burden of proof for following any one of them, including the proscription on *homosexuality.* Others who view the New Testament as superceding the Old Testament might claim that the New Testament already invalidates much of the Levitical ritual concerns, rendering them less authoritative for Christians.

A second view, characteristic of William L. Countryman and Brooten, holds that the concerns of Leviticus 18–20 are not those of ritual and morality, but rather, as Brooten puts it, "holiness, impurity, defilement, shame and abomination" (1996, p. 288). On this view, the Levitical codes exist to secure the holiness of the people of Israel, a people bound to God. It is important to recognize the centrality of group welfare in ancient Israel—the writer's concern is not for securing individual purity, but the purity and survival of the whole people. This runs counter to the modern sense of individual liberties and rights. When seen from the perspective of group purity, many of the pieces of the Levitical codes that contemporary readers find objectionable (execution for adulterers, execution for perpetrators and victims of pederasty, and so on) can be understood as relevant to group survival and holiness: the offending violation and the violators must be cleansed from the midst of the community.

Similarly, Daniel Helminiak holds that the Levitical proscriptions are not against male homogenital relations (women are never mentioned), but must be seen within the context of ritual purity; the taboo (a translation of *toevah*) that concerns Leviticus is one of uncleanliness or defilement in a religious sense, but not in an ethical or moral sense. The chief concern of the writer is the purity of the people of Israel over and against the Gentiles; all of the purity violations in the holiness codes are cited as *abominations* or *taboo.*

Scholars generally agree that Paul relies on Leviticus in his proscriptions against same-sex expression, particularly in Romans 1:26–27, though also in I Corinthians 6:9 and again in I Timothy 1:10. The latter texts concern lists of behaviors to be avoided by Christians (lying, adultery, idolatry, and so on), and included among the lists we find the Greek word, *arsenokoitai,* which is generally translated as "men lying with men." While this word has been translated "homosexual," it has been variously translated "sodomites" or "male prostitutes," "homosexual perversion," and even as "abusers of themselves with mankind" (Borg, p. 4; Helminiak). Boswell (1980) argues that *arsenokoitai* refers to male prostitution and not homosexuality generally. *Arsenokoitai* also appears in the Septuagint Greek translation of Leviticus 18:22, 20:13. Some scholars hold that it refers to the specific practice of pederasty in ancient Greece and that it is this practice, along with male prostitution, that is condemned by Paul, and not homosexuality per se (Scroggs; Borg, 1994; Ackerman). Others disagree with this interpretation (e.g., Furnish; Wright).

First Corinthians 6:9 also contains the word *malakoi,* which refers to soft or weak persons, though Brooten translates this term as "men who assume a passive sexual role with other men" (1996, p. 260). This translation undergirds her argument that what was reviled by the ancients, including Paul, was the violation of the active/passive distinction on which society was based. Countryman and Boswell (1980) argue that *malakoi* does not refer to homosexuality at all.

Romans 1:26–27 is cited by most Protestant religious denominations, as well as the Roman Catholic Church, as the cornerstone of a variety of positions opposed to homosexual sexual expression. It merits citing here: "For this reason God gave them up to degrading passions. Their women exchanged natural intercourse for unnatural, and in the same way also the men, giving up natural intercourse with women, were consumed with passion for one another. Men committed shameless acts with men and received in their own persons the due penalty for their error" (NSRV). Scholarly debate generally turns on the context of the passage: what is it that Paul is concerned to communicate to his audience? and what is meant by the terms *natural* (*kata physin*) and *unnatural* (*para physin*)?

Does *para physin* mean contrary to nature in keeping with the Stoic insight on the right and natural order of things (Hays, contra Boswell), or does it mean, as Boswell suggests, beyond nature, meaning extraordinary or peculiar, but not unnatural (1980)? Boswell's claim is that the term was in some sense morally neutral for Paul, since he used it with respect to salvation of the Gentiles as well as to sex between men. Picking up from Boswell, Helminiak suggests that Paul meant *surprising* behavior, which is to say, "When people acted as was expected … they were acting 'naturally.' When people did something … out of character, they were acting 'unnaturally'" (Helminiak, p. 64). Thus "exchanging natural intercourse for unnatural" would have indicated sex that was surprising and out-of-the-ordinary, but not inherently wrong or disordered in the Stoic sense of "the laws of nature."

Stoic philosophy did make use of the term *para physin* and the Stoic philosophy of the *natural law* was pervasive in the Roman Empire. Robin Scroggs, however, maintains that *para physin* was "a commonplace Greco-Roman attack on pederasty" (p. 115), while Ward sees in it echoes of the emphasis on the importance of procreation typical of the Hellenistic Jewish community (and Stoic thought) of which Paul was a part. In terms of the procreation concern, Helminiak believes it would have been inconsistent for Paul to have made a priority out of this issue since, as we know, the early Christian community expected the imminent return of Jesus; thus marriage and procreation were not their chief concerns.

Among the more persuasive arguments is Brooten's (1996), that *para physin* did mean *contrary to nature,* but that what is referred to as *kata physin* (according to nature) is the non-biological active/passive distinction: any sex act had to have an active and a passive partner. Accordingly, sex between two women would certainly be thought of as shameful, unnatural and impure because *natural* sex meant penetration, characterizing the active dimension of the male. "Impurity applied to gender thus means that people are not maintaining clear gender polarity and complementarity" (Brooten, 1996, p. 235).

Similarly, for a man to have intercourse with a man, instead of a woman, would be a violation of the social order in which the *male nature* was believed to be active and penetrating. Boswell, on the other hand, argues that to exchange natural for unnatural intercourse refers to heterosexuals engaging in homosexual sex, since Paul presumes that such persons are capable of *natural intercourse.* He further maintains that Paul is making a distinction between homosexual persons and homosexual acts, and is really concerned only with the latter (Boswell, 1980). Richard B.

Hays disputes Boswell on this point, arguing that for Paul homoerotic expression does constitute a willful upending of the sexual differences that God intended for creation. Brooten adds that neither scholar takes a gendered analysis of Paul's position and his cultural assumptions into account, and that "Gender ambiguity is also the best framework within which to view Paul's understanding of unnatural relations in Romans I" (Brooten, 1996, p. 252).

Homosexuality and Judaism

Rabbinic Judaism, emphasizing the *halakhic* or legal side of the Talmud, has been largely opposed to same-sex sexual expression between males. Such expression between women is not addressed in the Torah, although it was later condemned by the rabbis (e.g., *Sifra* 98 and *Mishneh Torah Issurei Biah* 21:8). Perhaps silence on same-sex eroticism between women in the biblical period of ancient Judaism reflects the patriarchal nature of culture; one cannot really be certain. However, it is clear that male homoeroticism was condemned as an "abomination" (*toevah*) in Leviticus 18:22 and punishable by death in Leviticus 20:13. The reasons for the condemnation have been debated both in the Talmud and by scholars up to the present.

In contemporary Judaism, Saul Olyan, for example, argues that what the Torah actually prohibits in Leviticus is male anal intercourse and not other instances of male-male coupling (see also Boyarin). For contemporary explanations on the differing treatment of male and female homoeroticism in Jewish law, see the work of Rebecca Alpert and Rachel Biale. One of the debates in contemporary Judaism has been whether or not *halakhah* is open to change on homosexuality in light of new realities, or whether its character is fixed. In one sense, within *halakhic* Judaism it is apparent that homoerotic acts (though not necessarily inclinations) between men are to be regarded as an abomination, and as an aberration from the commonly held norm of heterosexual acts that ensure procreation and the promotion of family life, primary values in Judaism. David M. Feldman, for instance, does not agree that the proscription in Leviticus has anything to do with procreation. He summarizes three possible reasons for the prohibition according to his reading of rabbinic sources: that male homosexuality cannot result in procreation; that such sexual activity will result in men leaving their wives and families; that it constitutes "going astray" (*toeh attah bah,* play on *toevah*) from the Creator's design for creation (Feldman, p. 428).

Following the rabbis, Feldman regards homosexual acts as sinful, but makes the distinction that "If the aberration is the result of 'sickness,' no guilt can attach to it; if it is advocated as an 'alternative lifestyle,' this then is consciously immoral and soberly sinful"; thus volition plays a key part in the condemnation (Feldman, p. 426). Under this view, *halakhah* and homosexuality are regarded as incompatible, and it is interesting to note that the rabbis apparently regarded male homosexuality and Judaism as an unlikely combination—that Jews could not really *be homosexual.* There is much discussion, from Talmud to Maimonides, on *yihud,* "being alone together." Generally, proscriptions against *yihud* reflect concerns with heterosexual adultery so that the Talmud actually allows two men to be alone together and even to sleep under the same blanket. This might reflect the relative lack of attention paid to homosexuality as a reality in ancient Judaism, in contrast to the gentile communities in Greece and Rome.

Robert Kirschner, opposing Feldman and David J. Bleich, argues that *halakhah* is capable of change on this matter, as it has been on many others (e.g., the debate over *heresh* deaf mute), since the power of interpretation is a cornerstone of rabbinic tradition. Kirschner makes a case for Judaism taking into consideration scientific evidence about sexuality, including theories on the etiology of homosexuality. Contemporary science confirms, for example, what the rabbis did not think to be the case—that sexuality and its expression is variable, fluid and not dichotomous; therefore, homosexuality can be seen "not as a perversion but, rather, in its multiple manifestations, a state of sexual being" (Kirschner, p. 457).

Currently, the four branches of Judaism in the United States (Orthodox, Conservative, Reform, and Reconstructionist) take a variety of positions on homosexuality. Orthodox Judaism is largely settled on these questions and it accepts the Levitical condemnation on male same-sex acts as an abomination. Some more liberal Orthodox Jews maintain a distinction between the act and the person (the sin and the sinner), regarding the homosexual Jew as sinning, but a Jew nonetheless. In recent years, support networks of Orthodox homosexual Jews have emerged, despite the fact that Orthodoxy does not recognize homosexuality as an orientation or state of being. Examples of these networks include: Gay and Lesbian Yeshiva Day School Alumni Association (GLYDSA), Orthogays, and Orthodykes, all of which have a presence on the Internet. In 1999, Rabbi Steven Greenberg became the first Orthodox rabbi to *come out* as a homosexual Jew, a subject of great controversy in Orthodox Judaism (see Grossman). In 2000, the Rabbinical Council of America condemned the position taken by the Reform rabbis to affirm same-sex relationships in Jewish ritual. In 1999, the Council publicly opposed the state of Vermont's ruling legalizing same-sex civil unions, on the grounds that marriage is only between heterosexuals.

In 1991, the Conservative Movement in Judaism (both the Rabbinical Assembly and the United Synagogue of Conservative Judaism) passed a resolution affirming its *halakhic* commitment to heterosexual relationships, while simultaneously opposing civil restrictions on and expressions of hatred against gays and lesbians. The movement officially welcomes gay and lesbian persons at synagogue and encourages education among Jews about homosexuality. Since 1992, the official policy of the Conservative movement's Committee on Jewish Law and Standards has been to prohibit the ordination of gay and lesbian rabbis, as well as to prohibit same-sex marriages or commitment ceremonies. That policy was under discussion at the beginning of the twenty-first century, and is opposed by some rabbis within the movement. Conservative rabbis are permitted to serve gay and lesbian congregations, but they are *halakhicly* prohibited from officiating at commitment ceremonies. For a helpful and balanced overview on homosexuality in Judaism, see *Matters of Life and Death,* by Conservative rabbi Elliot Dorff (1998). The Rabbinical Assembly of Conservative Judaism published an official rabbinical letter on human intimacy in which it stated, with reference to the Levitical codes, that some acts of sexual expression are abominations (cultic, oppressive, or promiscuous sex, whether by homosexuals or heterosexuals), but that monogamous, loving sex is sacred and should be sanctified, whether heterosexual or homosexual (see Dorff, 1996).

For the Reform Movement and for Reconstructionist Judaism, homosexuality is almost a non-issue, in that the Union of American Hebrew Congregations (UAHC) voted in 1973 to accept full membership of a synagogue that had a specific outreach to homosexual Jews. In the 1980s the official seminary of Reform Judaism, Hebrew Union College, voted to accept gay or lesbian rabbinical students; the Reconstructionist Rabbinical College preceded Hebrew Union in doing so. In 1993, UAHC adopted a resolution calling for full legal equality for gay and lesbian monogamous partnerships. In 1997, the UAHC reaffirmed its commitment to welcoming gays and lesbians into full participation in all aspects of Jewish life, and officially resolved (1) to support efforts towards civil gay and lesbian marriages; (2) to urge Reform congregations to honor monogamous gay and lesbian partnerships; (3) to support the Central Conference of American Rabbis (CCAR) in its study of the possibility of religious commitment ceremonies for gay and lesbian unions between Jews. In March 2000, the CCAR became the first major congregation of American clergy to give its clergy permission to perform gay and lesbian commitment ceremonies. Although the UAHC and the CCAR have been very supportive of gay rights issues, there is no official position on the adoption of children by homosexuals.

Homosexuality and Roman Catholicism

Since Roman Catholicism and Christianity were synonymous until the Reformation, Christian attitudes towards homosexuality were, *de facto,* Roman Catholic attitudes, although popular attitudes were not necessarily synonymous with official Catholic teaching, as is true today. Boswell (1994) contends that evidence from liturgical texts and cultural history indicates that Christians once accepted same-sex relationships. Moreover, he argues that a distinctive contribution of early Christianity was an emphasis on the celibate life as spiritually superior to the heterosexual married state; eroticism thus became suspect and marriage was seen as a distraction from the important preparation of the Second Coming, and at best a compromise with the material world. These attitudes held sway in the church for the first thousand years of its existence (Boswell, 1994). Mary Rose d'Angelo shows how pairs of women missionaries in the New Testament can be seen as evidence of commitment both to the mission and to each other. Boswell, too, discusses the influence of "paired saints," such as Perpetua and Felicity, Serge and Bacchus, and even Jesus and John, on ordinary Christians.

Christian thinkers from late antiquity to the high Middle Ages have had an influence on official Catholic teaching on homosexuality. Among these are Augustine of Hippo, John Chrysostom, Clement of Alexandria and Thomas Aquinas. St. Augustine (354–430) contributed heavily to the Catholic view that marriage was for procreation, monogamy, and fidelity, or as Augustine put it, *fides, proles, sacramentum* (Boswell, 1994; Augustine, 2000). So influential was this view that traces of it are found in papal documents up through the twentieth century. Augustine was influenced by his membership in the Manichean movement that viewed the natural world as an inherent evil. Hence one finds in Augustine an insistence on sex within marriage exclusively for the purpose of procreation—husbands were encouraged to make use of prostitutes if they had a need for non-procreative sex (Augustine, 2000). Boswell (1980) maintains that Augustine's view of *nature* is to be understood in the sense of *out of the ordinary,* not the *normal* use of something. Thus Augustine condemned same-sex eroticism since it was certainly not the *normal* use of sex with which he was familiar. *Contra naturum* meant that which did not conform to *ordo,* or order of the world, the divine plan (see Augustine's "De ordine.") In this view, conformity was the issue for Augustine, not *nature* itself. Part of the order of things, as Brooten tells us, is the maintenance of gender boundaries. Augustine was one of the Christian thinkers who, perhaps reflecting the culture around him, insisted on the male nature as superior to the female.

Clement of Alexandria (150–c. 215) argues against homosexuality in the *Paedagogus,* an instruction manual for Christian parents. Clement did espouse the procreation argument for moral intercourse, but his rationale against same-sex eroticism was grounded primarily in the Epistle of Barnabas's view that such acts were *animalistic.* (The comparison to animals figured prominently in theological treatises up through Thomas Aquinas.) This popular first century Epistle (now part of the Catholic Apocrypha) equated the eating of certain animals in Leviticus (notably the hare, the hyena, and the weasel) with sexual sins. Though regarded as erroneous, the Epistle's influence is evident in Clement's writing, which itself was influential in the early church. Clement is one of the few sources who explicitly opposed *woman-woman marriage,* believing it to be unnatural in that it flaunts God's plan for woman as the receptacle of male seed. Drawing on both Plato and St. Paul, Clement held that same-sex relations were *para physin.*

John Chrysostom or John of Antioch (347–407) was another of the early Christian thinkers who was influenced by the Manichees, as well as by the Stoics, a combination of belief systems that "led him into the paradoxical position of condemning sexual pleasure … while at the same time denouncing homosexual acts for not providing pleasure: 'Sins against nature … are more difficult and less rewarding, so much so that they cannot even claim to provide pleasure, since real pleasure is only in accordance with nature.'" (Boswell, 1980, p. 156). Chrysostom, also a product of Mediterranean misogynistic culture, was repulsed by the idea of a male taking on the role of a woman and this transgression was part of his opposition to same-sex eroticism. Both Boswell and Brooten agree on this. Brooten notes that Chrysostom began to use the language of disease with respect to same-sex eroticism, adding this to the language of sin in early Christianity and ancient Judaism (1996).

Thomas Aquinas (c. 1225–1274), the influential Dominican scholar, argued that same-sex acts were to be regarded as sinful because they thwarted the *natural law,* as ordained by God. The thirteenth century is the period in which civil laws against homosexuals arose; anti-homosexual rhetoric became vitriolic and remained so through the twentieth century. In this light, Boswell (1980) regarded Aquinas as reflecting the popular attitudes of his time rather than responding to the substance of church tradition on this issue. It is important to recall that Aristotle, the Stoics, and *natural law* discussions of the first centuries of Christian history heavily influenced Aquinas. His articulation of what constitutes *nature* and *natural law,* particularly in his *Summa theologiae,* has been given decisive weight in Roman Catholic moral theology up through the present day. Aquinas devotes much of the *Summa* to considerations of *natural law*; one succinct definition is as follows: "It is clear that natural law is nothing other than the participation of rational creatures in eternal law" (Aquinas, 1952, Ia.2ae.91.2). Aquinas held that reason is that which distinguishes what is natural to humans from what is natural to animals. Therefore, one might expect Aquinas to argue that homosexual acts are contrary to reason, and in this sense unnatural. But this was not the rationale that he employed.

In the *Summa* there are three places of commentary on same-sex eroticism (Ia.2ae.31.7; Ia.2ae.94.3 ad 2; 2a.2ae.154.11–12), though "only the last has received scholarly attention in the context of Scholastic attitudes towards homosexuality" (Boswell, 1980, p. 323). In 2a.2ae.154.11–12, Aquinas discusses "vices against nature," which for him included heterosexual intercourse without intent to procreate, intercourse with animals, homosexual intercourse, and masturbation. These constitute the most sinful forms of lust, though Aquinas does not here discuss what order of nature is violated by these sins; he does hold that all sins are unnatural because they are "against the order of reason, which must order all things according to their ends" (Aquinas, 1952, 2a.2ae.153.2 Resp.). Why then is homoeroticism particularly unnatural? One might expect Aquinas to ground his opposition in the "spilling of seed" argument that had been popular (nature intended semen to find its end in procreation of children), and indeed he did consider this rationale (Aquinas, 1923). But he disposed of the argument after considering that nature fitted other body parts for uses to which they were not always put and therefore, misusing a part of the body could not be the sin; the sin was rather to impede the propagation of the species, which itself is a good. If homosexual sex precludes procreation, he the might have applied the same argument to celibacy and to virginity, but he did not.

However, Aquinas considered that there were some things that might seem against human nature generally, though peculiar to certain individuals and, therefore, *natural* to those individuals as everything in nature was believed to be ordered by God to some good end. One might have a *defect* of nature, but that defect of nature could be quite *natural;* indeed this was the way in which Aquinas regarded females (as "defective" males) (see Aquinas, 1952, Ia.92.I). As he writes, "In fact, because of the diverse conditions of humans, it happens that some acts are virtuous to some people, as appropriate and suitable to them, while the same acts are immoral for others, as appropriate to them" (Aquinas, 1952, Ia.2ae.94 ad 3). And in a footnote to history, Boswell writes, "It would seem that Saint Thomas would have been constrained to admit that homosexual acts were 'appropriate' to those whom he considered 'naturally' homosexual"

(1980, p. 327). Perhaps reflecting the attitudes of his day, Aquinas did not do so, as he also did not show why homosexual acts were immoral theologically, apart from being unnatural—neither is this point considered in official Catholic teaching on homosexuality.

The Roman Catholic Church has issued five key statements that are meant to instruct the faithful as to its official teaching on homosexuality:

1. in December 1975, homosexuality is considered within the document, "Declaration on Certain Problems of Sexual Ethics" ;
2. in October 1986, the Vatican issued "The Pastoral Care of Homosexual Persons";
3. in July 1992, "Responding to Legislative Proposals on Discrimination Against Homosexuals" was issued;
4. in 1995 the Catechism of the Catholic Church was revised, containing three sections on homosexuality (paragraphs 2357, 2358, 2359);
5. in 1997, the United States Catholic Bishops issued a pastoral letter on homosexuality, "Always Our Children."

With remarkable consistency, the church has always held that homosexual acts are *disordered* and against nature. Thus the church has never sanctioned such acts, though its documents on the matter do indicate a shift from a complete condemnation in the documents from 1975 and 1986 (Congregation for the Doctrine of the Faith, 1982; Congregation for the Doctrine of the Faith, 1986) to a more recent distinction between the act and the actor, or the sin and the sinner in the documents from 1995 and 1997. For an alternative claim by a contemporary Catholic moral theologian, see Margaret Farley, "An Ethic for Same-Sex Relationships."

If the church is now making a distinction between homosexual acts, which it condemns as against the natural law, and homosexual persons, who deserve compassion, it does so because it believes that homosexuality is not chosen (Roman Catholic Church). Earlier, the church had distinguished between curable and incurable homosexuals, yet it counseled the faithful to instill hope "in them of one day overcoming their difficulties and their alienation from society" (Congregation for the Doctrine of the Faith, 1982, para. 8). It would seem that Pope John Paul II is aware of the scientific data about the origins of homosexuality and that his position in the Catechism accounts for some openness to science and social science. In rather non-judgmental language, the *Catechism* observes: "Homosexuality refers to relations between men or between women who experience an exclusive or predominant sexual attraction toward persons of the same sex. It has taken a great variety of forms throughout the centuries and in different cultures. Its psychological genesis remains largely unexplained" (Roman Catholic Church, p. 2357).

All of this notwithstanding, the Roman Catholic Church does not condone homosexuality and recommends celibacy as the only acceptable form of sexual expression for homosexuals. Accordingly, it does not approve of civil unions, such as the state of Vermont's; nor does it condone homosexual marriages or unions in its churches, nor adoption of children by gay and lesbian persons. It should be noted, however, that there is a substantive gay-affirming movement within the Roman Catholic tradition known as Dignity. During the 1970s, 1980s and into the mid-1990s, a Catholic priest, Robert Nugent, and a Catholic nun, Jeanine Gramick, ran New Ways Ministry, a ministry to gay and lesbian Catholics. In 2000, they were ordered by the Vatican to cease teaching publicly or face expulsion from their respective orders.

Homosexuality and Protestantism

Most of the major Protestant denominations in the United States have positions on homosexuality. Since Martin Luther's movement back to the authority of the Bible defined Protestantism, interpretations of scripture tend to play the major role in shaping Protestant denominations. Protestantism in the United States exists on a kind of continuum with conservative Protestant denominations on one end (Southern Baptist Convention, Assemblies of God, independent Evangelical churches), liberal Protestant churches on the other end (Episcopal Church, American Baptist Church, United Church of Christ), and moderate Protestant churches in the middle (Presbyterian Church U. S. A., United Methodist Church, the Evangelical Lutheran Church in America).

In general terms, conservative Protestants tend to regard homosexuality as a perversion of God's intent for creation (heterosexual marriage and children). They regard the institution of the heterosexual family as the bedrock of God's plan and are opposed to anything that thwarts this plan. Homosexuality is a grave sin and homosexuals are regarded as sinners; some conservative Protestants believe that there is an inherent contradiction between being Christian and being homosexual. Such Protestants hold that the Bible condemns homosexuality unequivocally and Christians are called to do likewise and to help homosexuals repent of their sin (see, for example, <www.sbc.net>). *Conversion ministries,* in which ex-homosexuals help homosexual persons convert to heterosexuality through Jesus Christ, are a suggested means of dealing with this aberrant lifestyle (see Exodus International, for example). Conservative Protestants view homosexual *inclinations* as either a depravity of nature or a willful choice to violate God's intent, and thus these denominations retain an ambivalent attitude with regard to developments in science and genetics (Green and Numrich).

Liberal Protestant denominations, on the other hand, tend to regard homosexuality as an alternative expression of the variety and goodness of sexuality given by God. While affirming the inherent dignity of homosexual persons, such churches have taken advocacy positions for full civil rights for gay, lesbian, and transgendered persons, usually including recognizing legal status of domestic partners, and adoption of children. Some of these churches perform holy unions or commitment ceremonies for same-sex members of their churches, and some also ordain "out" homosexual clergy. Liberal Protestants tend to embrace developments in science; in fact many are sanguine about the benefits of science for humankind, particularly genetic science. One finds openness to the possible genetic etiology of homosexuality among liberal Protestants. The United Church of Christ has taken several public stands affirming gay and lesbian persons and "it was also one of the first American churches to affirm and ordain gays and lesbians in ministry" (Green and Numrich, p. 23). The Episcopal Church has called for full participation in the life of the church for gay and lesbian persons, including church leadership, and is studying the possibility of holy unions. Still, many of these churches struggle over the issue of how to regard homosexuality within the confines of their respective traditions.

Moderate Protestant denominations are a hotbed of struggle over homosexuality. The question of whether homosexuality is compatible with Christian teaching (especially the Bible) is intensely debated, and some have speculated that it could produce a schism in the church. Moderate Protestants are clear, however, that homosexuals are children of God and deserve a place in their congregations. Commitment ceremonies for same-sex unions have been intensely debated in recent years in these denominations, as has the ordination of *practicing* homosexual clergy. The Presbyterian Church (U.S.A.) agreed to lift its ban on ordination of gay and lesbian clergy in, though the issue appears far from settled. The Methodist Church has been in conflict over the disciplining of clergy who perform same-sex union ceremonies in its churches, as well as over the sanctioning of clergy who have "come out" as homosexual. The Evangelical Lutheran Church will spend until 2005 studying issues of ordination of homosexual clergy, same-sex blessing ceremonies, and so on.

Currently, "out" homosexual clergy in most denominations are expected to be celibate. Moderate Protestants are not settled on these questions, or on the issue of whether homosexuals may adopt children. However, rooted in an affirmation of Biblical justice, all moderate Protestant denominations reject efforts to curb the civil rights of homosexuals, and advocate non-discrimination of gay and lesbian persons.

There are also movements within a variety of Protestant denominations to affirm the rights and dignity of homosexuals. For example, in the Presbyterian Church there are "More Light churches"; the United Church of Christ has the "Open and Affirming Movement"; the Episcopal Church has a national gay and lesbian affirmation movement called "Integrity."

Homosexuality and Islam

The Western concept of *homosexuality,* as sexual orientation and lifestyle, is unknown in the Islamic world. As Amreen Jamal notes, "the term 'homosexuality' is erroneous when it is used in Islam, unless it is used by Muslims who identify also with the Western description of the queer lifestyle which includes both behavior and orientation" (Jamal, p. 69). It must be stated that just as there are many versions of Christianity and Judaism, so Islam is not monolithic in its expression. For the purposes of this discussion, however, it may be assumed that Islam is in wide agreement in its outlook and teachings on same-sex activity.

The authoritative text for Muslims, *Al-Qur'an* (believed to be the divine revelation from God to the Prophet Muhammad as told to him by Gabriel) is generally thought to be explicit in its condemnation of same-gender sexual activity. Al-Qur'an (Koran) references the same story that some Jewish and Christian scholars reference in the Hebrew Bible, the story of Lot and the destruction of Sodom (Genesis 19), as evidence of God's condemnation of same-gender sex. "In Islamic terminology," Khalid Duran notes, "homosexuals are called *qaum Lut,* Lot's people, or, briefly, *Luti*" (Duran, p. 181). Traditional Islamic scholars tend to interpret this story as evidence of God's disproval of the actions of Lot's people, anal penetration.

Beyond the Lot narrative (mentioned five times in Al-Qur'an), the Qur'an permits sex for pleasure, but indicates that the express purpose of sex is procreation. Marriage and procreation are central values of Islam, and the Prophet Muhammad is reported to have said, "Marriage is half the religion." In light of this, the *shari'a* (traditional Islamic law) finds same-sex activity, particularly between men, to be a punishable offense, though the offense must offend publicly and solid evidence of the offense must be established. In other words, the *shari'a* has little concern for what occurs in private, but what is publicly offensive is punishable. While there is a range of opinion among scholars, traditionalists interpret homosexuality as a crime and not just a sin; since the penalty is not specified in the Qur'an, it is a matter for contemporary authorities to debate, and death has been interpreted as one of punishments. In summary, Islam generally teaches that such sexual acts are against the natural order God intended for humans and are therefore sinful violations, and a deviation of the proper intent for human sexuality, marriage and procreation.

At least one scholar notes that there may be some openness to reform of the Muslim position within the context of its mystical branch, Sufism, and the freedom and justice teachings of Ustadh Mahmud Muhammad Taha (d. 1985) of Sudan. Ustadh Mahmud's teachings involved the development of a new or revised *shari'a* that was not dependent on the social constructs of seventh-century Islam (Duran). For an interesting contemporary study of the possibility of reform interpretations of homosexuality in Islam, see Amreen Jamal, 2001.

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SEE ALSO: *African Religions; Authority in Religious Traditions; Christianity, Bioethics in; Judaism, Bioethics in;* and other *Homosexuality* subentries

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HOSPICE

SEE *Palliative Care and Hospice*

HOSPITAL, CONTEMPORARY ETHICAL PROBLEMS OF THE

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Hospitals are complicated institutions that bring together technological innovations and social services, salaried and unsalaried personnel, private and public funding, a charitable mission and a business orientation. Hospitals are accountable to patients, physicians, board members, employees, the local community, third-party payers, business partners, and other providers. It is no wonder that hospitals encounter ethical issues and problems.

Ethical concerns confronting hospitals in the United States are discussed in the following categories: identity and mission; special sponsorship; clinical issues; and relationships with healthcare professionals.

Identity and Mission

Perhaps the most fundamental ethical issue has to do with identity and mission. Is a hospital a business like any other, subject to the pressures of the marketplace, and primarily motivated by commercial interests and incentives? Or is it a social institution, primarily responsible for serving the health needs of the community and sometimes suffering financial loss in the process? These questions fall within the purview of the relatively recently established field of organizational ethics in healthcare. Two edited volumes (by Boyle, DuBose, Ellingson, et al.; and Spencer, Mills, Rorty, et al.) elaborate on these questions and show how hospitals experience tensions between their role as community servants and their role as entrepreneurs. These roles can coexist, as for-profit hospitals have tried to show. However, the public has come to expect more from the nonprofits—for example, that they provide care that is not reimbursed, support unprofitable services, and be alert to community healthcare needs.

Hospitals in the United States face more difficult questions of identity and mission than do hospitals in countries where healthcare is typically regarded as an essential service, not subject to the usual marketplace forces. A confluence of factors—including the growth of scientific medicine, the alliance of physicians and hospitals, the phenomenon of specialization, enormous capital investments, commercial ventures, and the payment system—has caused U.S. hospitals to behave much like businesses. Public policy has encouraged this by endorsing antitrust laws that discourage hospitals' collaboration with one another; by inadequate government-reimbursement programs; and by the failure to ensure universal entitlement to healthcare. These factors create financial incentives for hospitals that conflict with their stated mission, namely, to serve all people and to meet the needs of their communities.

Most hospitals remain not-for-profit and therefore tax-exempt. Voluntary hospitals, whose boards of trustees receive no pay because they are understood to serve the community, believe that this community orientation is the most effective way to deliver care. In their rhetoric, they cultivate an image of benevolence and moral worth that obscures their business orientation, seeking government subsidies but eschewing government control. Some business practices adopted by both for-profit and not-for-profit hospitals have tarnished this image of benevolence. These practices include aggressive marketing, advertising, and competition for paying patients; the creation of for-profit ventures, often with physicians, thus creating the potential for conflict of interest; resistance or refusal to care for the indigent; and expensive duplication of services to compete with other hospitals.

Until the latter part of the twentieth century, hospitals could count on the public's trust and support. The special nature of healthcare and the religious affiliation of many hospitals fostered this trust. Contemporary hospitals, however, face increasing skepticism and criticism from patients and the public at large. This dissatisfaction with hospitals' behavior arises from an expectation that hospitals will behave differently from ordinary businesses, that they have a "higher purpose." Distrust also stems from the Institute of Medicine's 2000 report, *To Err is Human,* which documents high rates of medical errors or unanticipated outcomes occurring in hospitals. It is imperative for hospitals to establish policies toward disclosure of such outcomes, since disclosure facilitates patient trust and reduces legal liability. Yet some hospitals are regaining public trust by various innovations that aim to empower patients to participate in their care (Nolon, Dickinson, and Bolton). Thus, one of the most pressing ethical issues facing hospitals is whether to rededicate themselves to a mission based on altruism and community service. The decision may be compounded by new hospital networks, mergers, and acquisitions. Hospitals still have fundamental ethical choices about whom they serve, how they allocate their resources, and what sort of leadership and vision they bring to providing quality healthcare.

Special Sponsorship

Hospitals under religious sponsorship—Catholic, Jewish, Episcopal, Lutheran, Adventist, Presbyterian, Methodist—have special concerns. They were founded by traditions having particular beliefs and aspirations, yet they provide care in a pluralistic society. They neither employ nor provide care solely for persons of the faith of their founders. Like other hospitals, they are heavily dependent on state and federal payment for services rendered. In some cases, a hospital under religious sponsorship may be the only hospital serving a particular community. Ethical conflicts may arise between hospitals' allegiance to their religious sponsors and their obligation to provide needed services to the community.

This is especially the case in rural settings where, with government funding cuts, hospital closures or consolidations are increasingly common and Catholic health systems acquire nondenominational hospitals in the process. When Catholic hospitals become the primary source of healthcare in a region, rural residents, especially lower-income women, may find it difficult to obtain reproductive health services (Bennett; Bellandi).

Identity and mission are of particular concern here. In the United States, the majority of hospitals are *private,* that is, they are free to follow their own moral mission in religious matters. A hospital may therefore choose, on religious grounds, to offer different services from others in the community; for example, to follow certain dietary practices, or not to perform blood transfusions, abortions, or sterilizations. Hospitals are also heavily affected by the liability insurance crisis which has lead to the elimination of medical services, such as trauma, and to considerations of tort reform (Haugh; Taylor).

Thus far, the policies of hospitals with religious affiliations have not been proscribed by law, and arguably should not be proscribed ethically, unless they create undue hardship for patients. This would occur if patients could not gain reasonable access to needed services in any other way. The definition of what is reasonable will be interpreted variously, of course, depending on whether the perspective adopted is that of the sponsor and its adherents or of those who desire the service. Sponsored hospitals occasionally find themselves with conflicting loyalties, as they strive to be faithful to both their religious tradition and their constituents.

The growth of managed care and alliances among hospitals of different sponsorships creates another set of ethical conflicts for religious hospitals. If they are part of the new system of healthcare delivery, they will be closely associated with those who practice differently from them. This will result in their cooperating with and financially profiting from the very practices they prohibit in their own hospitals. How hospitals work this out requires careful consideration of their various ethical commitments.

Clinical Issues

With advances in medical technology, hospitals have encountered a number of new and perplexing ethical questions, some of the most contentious arising in relation to the use of life-sustaining treatment. When is it appropriate to withhold or withdraw medical treatment from a critically ill patient? Who should make the decision if the patient cannot? What are the rights and obligations of nurses, physicians, family members? What role should the hospital play in disputes among these groups? What policies should the hospital have in place to deal with these questions?

In 1991, the Joint Commission on Accreditation of Healthcare Organizations (findings published 1992) mandated that hospitals have a process for addressing ethical issues in patient care to protect patients' rights. To satisfy this policy, most hospitals created interdisciplinary ethics committees and used ethics consultants to aid physicians, hospital staff, and patients and their families in mediating individual cases as well as to recommend new policies on forgoing treatment that recognized the preeminence of patient choices. Resuscitation, ventilation, tube and intravenous feeding, renal dialysis, and antibiotic therapy continue to be some of the treatments discussed. Regardless of treatment, patients became entitled to full disclosure about the risks, benefits, and alternatives of treatment; and they, or surrogates, now have the ethical and legal right to accept or refuse any treatment. Many, but not all, physicians and hospitals changed their policies and developed new practices to reflect this situation.

The principle of patient autonomy caused additional ethical dilemmas for hospitals. In the early 1990s, some well-publicized cases arose in which patients' surrogates wanted life-sustaining interventions, but physicians and hospitals did not want to provide them. A claim of medical futility was the usual reason for this reluctance, although disputes about whether research had shown the desired treatment, such as cardiopulmonary resuscitation (CPR), to be reasonably effective also arose. Patients and surrogates invoked the principle of autonomy to justify their demands for treatment. These demands were particularly strong if the patient, or the patient's insurer, was willing to pay for the treatment.

Physicians and hospitals thus faced new issues: What are the limits of patients' or surrogates' rights to medical treatment? Are there situations in which physicians are justified in refusing to provide it? Is it ethical for physicians to have in mind scarce hospital resources when treating individual patients? What is the meaning, and what are the ethical implications, of medical futility? What are the economic and/or ethical conflicts of interest for hospitals in these cases?

These questions are inextricably related to the nature of insurance coverage. If insurance companies pay on a per diem or fee-for-service basis, it is to the hospital's advantage that patients have extensive treatment and long hospital stays, particularly if the insurance pays close to the actual cost of caring for the patient. In the late 1980s, many insurers changed the method of payment to capitation. Under this method, hospitals are *at risk* and receive a predetermined reimbursement for each patient, regardless of the actual costs of caring for the patient. Capitation creates very different economic incentives for physicians and hospitals than they have under a fee-for-service system. Thus, money becomes a factor in responding to the ethical question of *who* should decide when treatment should be provided. If the public thinks it is not receiving the medical care it needs because hospitals and/or physicians fear losing money, trust between healthcare providers and those they serve will be further eroded. Hospitals must therefore demonstrate their commitment to community service and educate the public about the importance of cost control. In order for trust to be renewed, the public must understand the connection between limiting expensive treatments for some patients and providing more basic care for others. They will need to agree that such changes are not primarily for the economic benefit of healthcare providers but are for the benefit of society as a whole.

Public trust in hospitals and clinical care is also waning due to greater awareness or experiences of sociodemographic disparities in healthcare (Smedley, Stith, and Nelson). The U.S. Department of Health and Human Services has established as a top priority the elimination of health disparities across racial/ethnic groups, sex, age, and geographic location. Hospitals have the capacity to contribute substantially toward this aim by ensuring the availability of qualified interpreters, employing healthcare professionals of diverse ethnic backgrounds, and providing culturally competent care. When justice can be secured through the provision of healthcare to individuals regardless of their cultural or religious backgrounds, the quality of healthcare will improve (Smedley, et al.; Committee on Quality of Health Care in America).

Relationships with Healthcare Professionals

Hospitals and physicians have always had an uneasy alliance: They need each other but often do not trust each other. For the first half of the twentieth century, hospitals were referred to as the "physicians' workshop." Hospitals provided the beds, equipment, nurses, and other personnel, and physicians provided the patients. Except in teaching institutions, hospitals and physicians had few common goals and mutual responsibilities beyond providing a place to care for patients. Physicians directed all aspects of patient care, and expected hospitals and their personnel to provide whatever the physicians deemed necessary. Until the middle of the twentieth century, hospitals themselves were not legally responsible for the care provided by physicians. At that time, courts began finding hospitals and their employees liable for not intervening to protect the patient when physicians provided inferior care. Since that time, hospitals have instituted mechanisms to monitor and intervene when necessary in physicians' care of patients.

This change was good for patients, but strained the relationship between hospitals and physicians. It created ethical conflicts for hospitals when, for example, physicians who admitted large numbers of patients were questioned or disciplined regarding quality of care. Some of these physicians left the hospitals, taking a large source of revenue with them. Accountability to patients required that hospitals and their organized medical staffs be vigilant about monitoring and intervening in the quality of care practiced by physicians. Economic self-interest, however, tempted hospitals to be more lenient with physicians.

Toward the end of the twentieth century, relationships between hospitals and physicians began to change again. Integrated delivery systems, through which healthcare providers and payers (such as insurance companies) collaborate to deliver care to patients in a particular geographic region, align the economic incentives affecting both physicians and hospitals. Capitation, a fixed fee paid to a group of providers to provide care for a fixed number of patients, resolves some of the ethical problems of the past related to hospital reimbursement. But capitation creates new ethical issues due to economic incentives to provide the least expensive care to patients. This change is good for some patients, but may not be good for others. Hospitals will continue to face ethical dilemmas of conflicting loyalties to patients and physicians.

The introduction of integrated delivery systems changes the relationships between hospitals and physicians in other ways. Some managed care plans require that primary-care physicians be the "gatekeepers," seeing patients first and referring them to specialists only if absolutely necessary. This, combined with capitation systems, creates incentives for hospitals and primary-care physicians to offer their services as one unit. However, the retreat of managed care has signaled increased access to healthcare providers while increasing healthcare costs (Robinson, 2001). Many hospitals that purchase physicians' medical practices manage the business side of the practices. This is extremely difficult to accomplish with ethical integrity on both sides, because physicians and hospitals have historically operated independently of one another—both psychologically and practically—even though they are in the same building.

A related problem is that, after having courted specialists for years, hospitals now rely on primary-care physicians to direct patients to specialists. Nevertheless, ethical issues of loyalty and integrity are raised, as physicians in specialty practices find themselves in professional and economic jeopardy when their interests no longer match those of their hospital.

In response to the restrictions healthcare organizations impose upon physicians to control costs and medical decision-making, the American Medical Association established a union, Physicians for Responsible Negotiations, in 1999. Subsequently, medical residents separately unionized in 1999, limiting the number of work hours required per week. These unionizations can have a profound impact on hospitals (Yacht; Cohen). Some hospitals and physicians are concerned that unionization will lead to strikes, interfere with education and patient care, and add to hospital finances, as well as undermine the meaning of medical professionalism. Accounts of unionization at some hospitals, however, reveal that such fears do not materialize, given that these labor organizations have banned strikes to prioritize patient care (Yacht).

Hospitals face other problems with the delivery of medical care in relation to physicians and managed care. Managed care plans are increasingly utilizing evidence-based medicine guidelines to enhance efficiency in medical care by eliminating overtreatment and undertreatment (Sackett, Straus, Richardson, et al.). Many physicians fear that such guidelines interfere with personalized patient care, which deters their willingness to implement them. Consequently, hospitals may not be able to reach levels of clinical practice to which they aspire.

Much attention has also turned to the relationship between hospitals and nurses, given the critical shortage of nurses. This shortage results from efforts to contain hospital costs, and it contributes to medical errors and poor patient care. Although technicians and nursing aids have been hired to perform some nursing duties, it remains to be determined how hospitals will recruit a sufficient number to provide appropriate nursing care.

Conclusion

Contemporary hospitals encounter many ethical concerns and problems. All constituents—patients, physicians, employees, board members, volunteers, the community at large, payers, business partners—have a stake in the way these ethical issues are considered and resolved.

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SEE ALSO: *Advance Directives and Advance Care Planning; Artificial Nutrition and Hydration; Cancer, Ethical Issues Related to Diagnosis and Treatment; Compassionate Love; Conscience, Rights of; Healthcare Resources, Allocation of; Informed Consent; Malpractice, Medical; Managed Care; Mistakes, Medical; Nursing Ethics; Organ Transplants; Patients' Responsibilities; Patients' Rights; Pharmaceutics, Issues in Prescribing; Professional-Patient Relationship; Research Policy; Right to Die: Policy and Law; Teams, Healthcare; Women as Health Professionals, Contemporary Issues of*

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HOSPITAL, MEDIEVAL AND RENAISSANCE HISTORY OF THE

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Hospitals have become the primary theaters of modern medical practice. The early history of these institutions dates from about 400 to 1600, and includes these developments: (1) the origins of hospitals; (2) their development in the Byzantine and Islamic worlds; (3) their history in medieval western Europe; and (4) their flowering in Renaissance Italy. For purposes of this discussion, the term *hospital* refers to an institution that focused on caring for patients and, if possible, curing them. *Hospice* describes an institution that offered food and shelter to the poor, travelers, and the homeless sick but did not maintain specific services, such as the attentions of physicians, to treat those who were ill.

Hospital Origins

Several early cultures developed institutions to care for the sick. Ancient Indian sources describe centers that dispensed medicines and engaged specially trained personnel to care for the ill. Classical Greek society produced the *asklepieia*, the temples of the god of medicine, where the sick sought divine and natural cures. The Roman Empire supported *valetudinaria* (infirmaries) providing medical care to legionaries stationed on the barbarous northern frontier. None of these institutions, however, was strong enough to survive the upheavals that destroyed much of ancient civilization in Eurasia between 200 and 600. Modern hospitals trace their origins, and even their name, not to Indian treatment centers, Greek *asklepieia*, or Roman *valetudinaria* but to the hospices and hospitals established by the Christian church during the late Roman Empire.

From its earliest days, Christianity demanded that its adherents aid sick and needy people. Christians believed that on the Last Day, God would judge according to the love one had shown those in need. Had one fed the hungry, sheltered the homeless, visited the sick (Matt. 25:31–46)? By the early second century, bishops such as Polykarp of Smyrna expected Christian clergy to take care of the sick, orphans, and widows.

Local Christian clergy assisted the unfortunate without any formal charitable institutions until the fourth century. Thereafter, in the eastern Greek-speaking provinces of the Roman Empire, the demand for charity became so great, especially in the larger cities, that specialized institutions called *xenodocheia* (hospices) appeared. By the 320s the church in Antioch operated a hospice to feed and shelter the poor of Syria. By the mid-fourth century, the pagan emperor Julian referred to hospices as common Christian institutions.

Before 360, Christian hospices did not focus attention on the sick; but during the 370s Basil, bishop of Caesarea in Asia Minor, opened an institution where physicians and nurses treated patients. Two decades later, Bishop John Chrysostom supervised hospitals in Constantinople where doctors tended the sick. By about 410, the monk Neilos of Ankyra considered the hospital physician a common figure in the Greek Christian world. These early hospitals thus evolved from simpler hospices by expanding their services to include free medical care for needy guests.

Christian bishops built hospices during the fourth century and subsequently created more specialized hospitals for the sick, not only because they wished to follow Christ's command to practice charity but also because they sought support for the new religion among the urban lower classes. During the fourth century the cities of the Eastern provinces experienced an influx of rural poor who migrated to towns in search of food and employment. Classical civic institutions could not feed, house, and care for these new residents. The local bishops used the expanding resources of the Christian church to build hospices and hospitals for these migrants, and thereby won support both from the many poor and from the urban aristocrats. When Emperor Julian (361–363) tried to halt the spread of Christianity, he emphasized that the "Galilaeans" had succeeded in part because of their charitable institutions.

Early hospitals met their expenses from the revenue of lands that local bishops had donated. Subsequently, wealthy aristocrats and the emperors augmented these resources. As Christianity expanded it destroyed some aspects of classical civilization, but others it simply reoriented. For example, Christianity wholeheartedly accepted the classical obligation of aristocrats to benefit local cities, but the Christian church encouraged donors to endow institutions such as hospitals rather than traditional theaters, baths, and ornamental colonnades. By supporting hospitals a Christian aristocrat not only acted charitably but also fulfilled the classical duty toward the city. Moreover, such benefactions cemented local political support. This same combination of Christian morality, classical traditionalism, and political realism motivated emperors in their benefactions (Miller, 1985).

Hospitals of the Byzantine and Muslim Worlds

Hospitals developed most rapidly where they had first appeared, in the eastern half of the Roman Empire. The large cities of the eastern Mediterranean and the stable political conditions of the eastern Roman, or Byzantine, Empire fostered their hospitals' further evolution. By the late sixth century, Christian hospitals such as the Sampson Xenon (hospital) of Constantinople maintained specialized wards for surgery patients and those with eye diseases. Moreover, the premier physicians (*archiatroi*) of the Byzantine capital were assigned monthly shifts to treat patients in the Sampson and in other hospitals of the city. By the twelfth century the hospitals of Constantinople had evolved into relatively sophisticated medical centers. The Pantokrator Xenon maintained five specialized wards, seventeen physicians, thirty-four nurses, eleven servants, and a store of medicines supervised by six pharmacists. The Pantokrator treated outpatients as well as those who were hospitalized. Emperor John II (1118–1143), the founder of the Pantokrator, reminded the hospital's staff that the sick were God's special friends and that caring for patients was more important than maintaining buildings (Volk).

From their beginnings, the Christian hospitals of Byzantine cities were designed for the poor, but as these institutions became increasingly sophisticated medical centers served by the best physicians, some middle-class and a few wealthy patients began to use them. In this regard Byzantine practice differed markedly from the medieval West, where the bourgeoisie and nobility shunned hospitals as institutions solely for the destitute.

Medieval Islamic society maintained hospitals (in Persian, *bimaristani*) that equaled those of Byzantium. The first Islamic hospitals were founded in Baghdad during the reign of the caliph Harun al-Rashid (786–809). According to a governor of the caliph, Islamic hospitals had become common by the 820s; subsequently Muslims considered support of hospitals a mark of true piety.

Like Byzantine hospitals, *bimaristani* had evolved from earlier Christian philanthropic institutions in large cities of the Byzantine Empire. When Emperor Zeno expelled Nestorian Christians from Syria in 489, many sought refuge in Persia, where they established institutions, including hospitals, modeled on those in Byzantine cities such as Antioch. After the Muslims conquered Sassanid Persia in the seventh century, they came in contact with Nestorians. Impressed by Nestorian medical skills, they adopted many Syrian medical traditions—teaching methods, scientific texts, and hospitals—as models for shaping Islamic institutions.

Although Islamic hospitals evolved from Christian institutions, they experienced a unique development. They differed strikingly from their Byzantine counterparts by including separate sections for mental patients. Gradually these psychiatric wards became the most prominent features of *bimaristani.* Neither Byzantine nor medieval Western hospitals had wards for mental patients (Dols).

Medieval Western Europe

Hospitals developed more slowly in the western Roman Empire. Saint Jerome (ca. 331–420) mentioned two small hospitals near Rome about 400. During the early Middle Ages, however, social conditions retarded hospital development in western Europe. Barbarian invasions from the north and Muslim advances in Africa inhibited political, economic, and social life. Few towns of the size and complexity that could support medical centers such as the Byzantine and Muslim hospitals survived. In the domains of Charlemagne (768–814), hospitals did not evolve beyond simple hospices. As late as the thirteenth century, hospitals were rare in Europe. None of the 112 houses for the sick in medieval England provided physicians for their patients, nor did they stock any medicines (Carlin).

In the twelfth century, a new religious order, the Knights of the Hospital of Saint John of Jerusalem (known today as the Knights of Malta) reintroduced into Europe specialized medical care for the sick when they organized their renowned hospital in Jerusalem. Under Byzantine influence, the Knights' rule for this hospital mandated a permanent medical staff of four physicians and four surgeons to treat patients. Moreover, the Knights developed a unique philanthropic ethic by adapting feudal notions to the traditional Christian command to aid those in need. The Knights were to treat the sick in the Jerusalem hospital as vassals served their overlords. As the Knights expanded, they built many smaller hospitals in the towns of Europe where they introduced practices they had established in Jerusalem (Sire).

The Knights' hospital in Jerusalem inspired many similar institutions throughout western Europe. Using its rule as a model, Pope Innocent III established in 1200 the famous Hospital of the Holy Spirit in Rome. In 1217 the church in Paris reorganized its ancient hospice, the Hôtel-Dieu, by drafting a new constitution based on the regulations of the Jerusalem hospital (Miller, 1978).

The Knights of Saint John had such a wide-ranging effect not only because their rule inspired western Europeans to help the needy, especially the sick, but also because Latin Christendom was entering a new phase of urban growth. As country dwellers migrated to the towns in growing numbers, these newcomers were exposed to a wider range of diseases. Hospitals became necessary to treat the rapidly growing number of sick among the urban poor. In fact, the economic and social conditions in the expanding towns of thirteenth-century Europe were remarkably similar to those in the fourth-century Byzantine cities where hospitals had first appeared.

An examination of the rule for the Roman Hospital of the Holy Spirit, however, indicates one important difference between the new institutions of the West and the Jerusalem hospital. The Roman rule mandated many of the Knights' practices, but it omitted any reference to physicians or surgeons. The same is true of the rule for the Hôtel-Dieu of Paris. Only gradually did physicians come to serve in these hospitals. The records of the Hôtel-Dieu do not mention a permanent staff physician until 1328. As late as the eighteenth century a physician visited Saint Bartholomew's Hospital in London only once a week. That trained doctors did not assume a major role in caring for patients in Western medieval hospitals distinguishes them from Byzantine *xenones* and Moslem *bimaristani*, where doctors not only treated the sick but supervised hospital administration.

It is also clear that some of the Western medieval hospitals did not provide care on the same level as did the Eastern medical facilities. The twelfth-century hospital at Saint-Pol in northern France maintained only six nurses (or nursing sisters) for sixty patients. Iconographic evidence indicates that at the Hôtel-Dieu in Paris patients sometimes shared beds. The wards of many medieval hospitals were also poorly heated. Conditions such as these no doubt made it difficult for hospitals to heal the sick and provided some support for the charges of later Enlightenment reformers that all medieval hospitals had in fact been death traps (Miller, 1985).

Renaissance Italy

Inspired by the Jerusalem hospital, the communes of Tuscany began building hospitals during the thirteenth century. Before 1300, for example, the town of Siena built an institution that differed from the Hôtel-Dieu of Paris in that it maintained on its staff a physician, a surgeon, and a pharmacist. In 1288 Folco Portinari, the father of Dante's Beatrice, founded the Hospital of Santa Maria Nuova in Florence; by the fifteenth century, this institution had developed into an elaborate center for medical treatment. A document dated 1500, but reflecting earlier arrangements, reveals that Santa Maria paid six of the best physicians of Florence to visit patients each morning. In addition, three young interns lived permanently at the hospital. In return for room and board and a valuable opportunity to gain experience in medical practice, they served the hospital's 300 patients by monitoring their conditions and making daily reports to the senior physicians.

Santa Maria Nuova was not a death trap, as were some less well-organized hospitals, nor was it a hospice where poor sick people were simply nourished. It provided its patients access to society's best physicians and boasted an excellent rate of cure. Hospital records reveal that about 85 percent of the patients recovered from their ailments (Park; Henderson).

At Santa Maria Nuova, the interns were willing to serve patients for free not only because such service was virtuous but also because it offered them an unparalleled opportunity to observe the course of many diseases. During the sixteenth century, the medical professors of Padua (in Venetian territory) established formal clinical instruction at the Hospital of San Francesco. Many students from northern Europe came to study at Padua because of its excellent empirical training (Bylebyl).

Conclusion

Modern scholars have not been inclined to examine medieval hospitals because of the prevailing view that these were poorly equipped asylums that offered the sick only minimal medical care. Such institutions supposedly had nothing in common with today's hospitals. This view has its origins in Enlightenment skepticism concerning religious institutions. Eighteenth-century intellectuals contrasted the efficacy of science in curing human ills, including disease, with the helplessness of Christian charity, which at best provided only comfort, not true remedies.

However, hospitals in Renaissance Italy, as well as those in medieval Constantinople and Baghdad, demonstrate that philanthropic institutions were not necessarily isolated from scientific medicine. In fact, hospital service in Italy came to form a vital part of medical training, first in Florence and then at the University of Padua. In hospitals such as Santa Maria Nuova, the Christian command to aid the needy interacted with a sense of civic pride and with a concept of professional ethics on the part of physicians to create institutions that were both truly philanthropic and efficient in curing the sick.

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SEE ALSO: *Care; Christianity, Bioethics in; Islam, Bioethics in; Medical Ethics, History of: Europe; Professional-Patient Relationship: Historical Perspectives; Public Health: History*

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HOSPITAL, MODERN HISTORY OF THE

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Although a few Renaissance institutions supplemented charitable assistance with professional medical care, the hospital's gradual *medicalization* occurred from the seventeenth century onward, within changing social and scientific frameworks. Three distinct periods can be identified within this development: (1) the early shift of the hospital from welfare to medical establishment, 1650–1870; (2) the evolution of a successfully medicalized institution for all social classes, 1870–1945; and (3) the creation of a specialized showcase of scientific medicine, 1945 to the present.

From Welfare to Medicine: 1650–1870

During the early modern period, hospitals in Europe's urban centers were charitable shelters for the poor and working classes, functioning primarily as instruments of religious charity and social control with minimal involvement of the medical profession. Whether the patients were Catholic or Protestant, hospitalization continued to be an opportunity for physical comfort as well as moral rehabilitation. However, in time of epidemics such as plague and syphilis, specialized hospitals were created to ensure the isolation of the sick and thus avoid the spread of contagion. Given the expanding institutionalization of charity, the decline of religious institutions, and new roles in the preservation of public health, hospitals increasingly came under lay control, including municipal governments, fraternal organizations, and private patrons.

After 1650, new geopolitical agendas designed to increase the power and prosperity of the emerging national states pressed hospitals into new roles. Human life was given greater financial value as population policies were aimed at increasing the number of inhabitants as a base for state power, economic development, and military strength. Proponents of emerging European mercantilism viewed labor as the key source of wealth and urged that the nation's workforce be mobilized and kept at an optimum state of productivity. Within such a framework, the desire to promote the health of citizens inspired new programs of public health, hygiene, and medical care.

At the same time, more optimistic visions of health preservation and rehabilitation elaborated by Enlightenment thinkers suggested that sickness, instead of an inevitable, sinful, and often long-term human burden, could be controlled and eliminated. In addition to their traditional moral and physical aims, hospitals were now envisioned as institutions for physical rehabilitation and cure, places of early rather than last resort, especially for military personnel and the labor force. This agenda implied a greater involvement of the healthcare professions with large sectors of the population hitherto without such contacts.

To implement their new health policies, national governments, local authorities, and corporate professional bodies organized efforts to reform the existing medical and surgical professions. Physicians and surgeons were granted new forms of access to hospitals and given new rules to guide their institutional activities. Early models for the medicalization process came from military and naval establishments that provided for the sick and wounded members of Europe's expanding military forces. Later, medical professionals working in civil hospitals also began to argue successfully that their management of patients provided a valuable addition to the rest and food traditionally furnished to inmates in religious shelters. During the late eighteenth and early nineteenth centuries, medical objectives dramatically reshaped hospital routines from admission to the discharge or death of the patient. Acute rather than chronic illnesses were preferred; young rather than old patients were accepted. Rehabilitation and cure were the new goals.

HOSPITALS AS TRAINING INSTITUTIONS. At the same time, surgeons—and later physicians—recognized the great opportunities hospitals offered to improve their clinical skills and thus increase their power and status. By the eighteenth century, shifts in scientific ideology emphasized the importance of empirical studies and the construction of knowledge based on observed facts. Surgeons in France and Great Britain were especially keen to acquire practical knowledge of anatomy, pathology, and clinical management. After the French Revolution, physicians in that country initiated a new strategy of professional and social advancement under the banner of what was generically called the *medicine of observation.* With significant numbers of sick people assembled in hospital wards, doctors could observe at the bedside the evolution of individual diseases and their diagnoses on a much larger scale than they could in private practice. Postmortem dissections performed on former hospital inmates provided further information on the pathology responsible for the symptoms. Moreover, patient management offered unequaled opportunities to check the usefulness of the traditional medical regimens, especially the effects of older remedies. Efforts to upgrade the preparation and uses of drugs involved clinical trials and statistical analysis. Hospitals became the focal points of comprehensive bedside research programs.

Finally, the expanding medical and surgical presence in European hospitals made such institutions increasingly attractive as places for education and training of rank-and-file practitioners. Hospitals were seen as "great nurseries" that could "breed some of the best physicians and chirurgeons because they may see as much there in one year as in seven any where else" (Bellers, 1714). In certain establishments, the authorities created special teaching wards where professors and attendants, followed by their students, made regular rounds of the patients. Instruction varied greatly, from passive observation to supervised and even independent, hands-on examination and management of the patients by students and apprentices.

REORGANIZATION OF THE HOSPITAL STRUCTURE. How did the hospital as an institution adapt to these new agendas? France possessed several types of organizations, including massive *hôpitaux générales,* or hospices, for the elderly poor, beggars, vagrants, incurables, and prostitutes. There were also small welfare establishments at the parish level for similar cases. In larger urban areas, the traditional *Hôtels-Dieux* now limited admissions to the sick but excluded incurables, the insane, and venereal cases. All original ward layouts were based on medieval principles, providing in a shelter as many beds as possible and still crowding three to four individuals into each bed. Hospital size was fiercely debated, with advocates of medicalization arguing for smaller institutions to prevent cross-infections.

In Great Britain and the young American republic, major population centers possessed a number of *voluntary infirmaries,* or private hospitals, founded and operated by local philanthropists and often financed by a system of yearly subscriptions solicited from local merchants and professionals. Except for accident cases, these establishments admitted only a very restricted number of the sick poor. These persons, recommended for admission by the subscribers, were judged by the community to be willing to work and thus *deserving* of hospital care and rehabilitation. In addition, there were a number of private special hospitals, especially in London after 1800, supported by contributions and patient fees and operating under the direction of medical professionals. By contrast, English "poor law" infirmaries were supported financially by parish taxes and linked to local workhouses, which provided free care to the sick poor deemed able bodied, or vagrant, and thus *undeserving* of other charitable assistance. Later, in the nineteenth century, many of these workhouse infirmaries evolved into municipal hospitals and were placed under the direction of salaried medical superintendents. At the same time, and with financial support from leading local citizens, Great Britain also created a string of small cottage hospitals, providing paid medical care to those who could afford it.

To support expanding medical services and teaching activities, nineteenth-century hospitals required more money and changes in their physical plants and administrative organizations. By the 1870s, hygienic principles had come to dominate the construction and functioning of new establishments, now equipped with single beds for the sick and providing ample ventilation in their pavilion-type wards. Isolation chambers, surgical amphitheaters, emergency rooms, morgues, libraries, and outpatient facilities became indispensable adjuncts. Medical control also shifted power from patients and caregivers to attending physicians, thereby creating conflicts between traditional charitable practices and scientific goals of disease identification and management. Medicalization implied a shift from the primary focus on shelter and food for the needy to the diagnosis and treatment of diseases exhibited by sick patients.

A Hospital for All Social Classes: 1870–1945

Thanks in part to advances in medical knowledge and technology, the medicalization process of Western society was significantly advanced before the end of World War II. By 1900, upper- and middle-class patients in Europe and the United States were seeking and paying for medical care in hospitals. Staffed by competent medical and nursing professionals, and equipped with clinical laboratories and other diagnostic tools, hospitals became the preferred destination of those who were acutely sick and in need of surgical and medical care. The newly created demand for hospital care, spurred by urbanization and industrialization, expanded further to include the needs of birthing and child care.

In the United States, such requirements were eagerly met by the establishment of a vast, decentralized system of voluntary hospitals fiercely competing for community resources, physicians, and their patients. Local private citizens provided the necessary funds and volunteer service required to create general community hospitals. Alongside schools, police stations, and firehouses, U.S. general hospitals became emblems of community life, the pride of Main Street. In Europe, many hospitals became governmental facilities managed by paid professionals.

The new hospital mission was a result of converging ideologies, policies, and needs, some traditional, others new. Religious values and charitable donations still played an important role in the early 1900s, while developing economic tenets based on capitalism suggested that the health of workers in the industrial world was of great importance both to the state and to the private sector. In the United States, new social conditions favored the creation and utilization of more hospitals. Urbanization was accelerating at a rapid pace, bringing an ever-increasing number of adults into crowded city quarters. Among them were waves of new immigrants with multiple healthcare needs and few resources. Industrialization, in turn, created a new panorama of occupational diseases and accidents. Without the means or family networks to get the necessary help, many sick or injured individuals were thus forced to seek medical care in hospitals.

Under the new banner of scientific medicine, hospitals became the institutions of first rather than last resort. Thanks to the increasingly sophisticated diagnostic and therapeutic procedures offered in hospitals after 1900, optimistic Enlightenment notions of physical rehabilitation and cure were becoming a reality. Radiology, electrocardiography, and the clinical laboratory greatly improved the ability of hospital personnel to refine diagnoses. In addition to providing rest and a healthier diet, hospitals focused increasingly on managing acute diseases, especially life-threatening conditions that required intensive and highly technical care. A new generation of chemotherapeutic agents and vaccines improved the odds of success in the battle against certain diseases. Following the adoption of anesthesia and antisepsis, hospitals became the primary centers for surgical operations. Surgeons recognized the advantage of centralizing their new and expensive equipment within the *surgical suites* of a hospital.

THE CHANGING STATUS OF NURSES, PHYSICIANS. For patient care, hospitals relied increasingly on a new generation of nurses, drawn from the middle class and trained in professional education programs based on the model established by Florence Nightingale (1820–1910). Shedding their previous low-status role of cleaning women and servants, these new hospital nurses gradually displaced the dwindling number of religious staff members who had traditionally performed patient services. In time, the Nightingale nurses became valuable assistants to the medical profession in patient management.

By the 1910s, more physicians joined hospital staffs, staking their professional reputations on the achievements of scientific medicine such institutions seemed to make possible. In U.S. voluntary hospitals, medical staff organizations remained flexible, bestowing admission privileges on both local general practitioners and specialists who could deliver paying patients. In Great Britain, however, traditional social and professional barriers between general practitioners, on the one hand, and hospital-appointed physicians and surgeons, on the other, created insurmountable barriers in voluntary establishments. Although referring their patients to hospitals, the former were not allowed to practice within them. As so-called consultants, the latter operated small units and exclusively took care of a specific number of patients.

Since the hospital was rapidly becoming the physician's primary workshop in the 1920s, medical goals, including specialization, education, and research, needed to become top institutional priorities. Twentieth-century hospitals witnessed a dramatic growth of specialized care through the creation of clinical departments, an increase in student doctors, called *house staff,* and the performance of clinical research. Such activities became central to educational and licensing requirements, and conferred prestige and higher professional status on those allowed to work in the most preeminent institutions.

THE CHANGING FOCUS OF HOSPITALS. Once again the hospital as an institution adapted to these new agendas. Some new hospitals were associated or affiliated with medical and nursing schools. Others, especially in the United States, sprouted between 1890 and 1920 in ethnic urban neighborhoods, or strategic suburban locations, their creation influenced by state and local governments, population, philanthropy, or industry. Sectarian Jewish, Catholic, and Protestant institutions, German- and French-speaking clinics, municipal and state hospitals, private establishments sponsored by railroads and universities—all formed a constellation of autonomous units across the U.S. landscape.

In Europe, governments became increasingly involved in sponsoring and managing hospitals. In Great Britain, the Public Health Act of 1875 encouraged municipalities to establish isolation hospitals for persons suffering from infectious diseases. The poor law infirmaries were gradually taken over by local health departments and converted to general hospitals. The National Health Insurance Act of 1911 eliminated the charitable character of the voluntary hospitals and brought their services under the umbrella of regional healthcare schemes.

In the United States, hospital organizations in the 1920s changed to serve the new medical objectives and compete for paying patients, an ever-greater source of needed revenue. The rapid growth of medical technology generated further budgetary pressures, forcing voluntary hospitals to redouble their fundraising efforts and use endowment income for capital expenditures. As they became individual corporations in a competitive healthcare market, demands for greater efficiency prompted hospitals to bolster their administrations and institute stringent financial measures. Institutional care became a commodity, a product to be furnished mostly to those willing to pay for it directly or through health-insurance policies.

By the 1930s, economic conditions stemming from the Depression forced the creation of new funding systems, such as the Blue Cross health-insurance companies, organized by physicians. As competition for philanthropic support and patient revenue accelerated, accountability and public relations dominated the hospitals' administrative agendas. Since each U.S. institution was the proud product of individual community efforts, cooperation among hospital administrations was resisted.

As the hospital became the preferred locus for the application of scientific principles to medicine, new ethical problems appeared. The medicalization of life processes expanded the range of life experiences now addressed as medical problems by health professionals in hospital settings: Birth and death, formerly events that occurred in the home, now took place in the hospital. Since the early nineteenth century, a depersonalized, disease- and organ-centered approach had already replaced earlier holistic notions of sickness. As hospital routines became increasingly technical and standardized, patients came to be seen as merely embodiments of diseases that were the primary objects of inquiry and treatment. This approach affected the nature of the physician-patient relationship, as professionals focused primarily on successful problem solving in diagnosing and arresting human pathology. The physician's moral authority, hitherto based on personal qualities, now became grounded in scientific competence. Clinical experimentation became rampant, sometimes abusive, with few safeguards provided for the patients.

The Hospital as Biomedical Showcase: 1945 to the Present

Following World War II, the hospital rapidly consolidated its position as the embodiment of scientific and technologically sophisticated medicine. An explosion in medical knowledge led to the expansion of diagnostic and therapeutic services at hospitals. This development had far-reaching implications for institutional access, cost, and quality of care as delivered to a broad spectrum of the public under various private and state-sponsored health plans. The hospital's mission continued to reflect converging agendas, including the religious, political, economic, and scientific goals set in preceding decades.

In the United States, the federal government's involvement in sponsoring hospital care gradually expanded as the demand for institutional beds and services multiplied. Beginning with the Hill Burton Act in 1946, the federal authorities supported the existing system of decentralized, private hospitals—first, through the provision of construction subsidies, and later, through reimbursement schemes for services, such as the Medicare and Medicaid programs in 1966. This supportive rather than regulatory role preserved a network of independent and competing municipal, sectarian, and academic hospitals in each community. In marked contrast with events in Europe, the 1950s through the 1970s witnessed an impressive growth in U.S. hospital facilities, including neonatology and intensive-care units, imaging facilities, and transplantation services. Individual hospitals continue to operate as independent business organizations within a burgeoning healthcare *industry.* Periodic institutional accreditation by a joint commission of the American Medical Association and the American Hospital Association ensures compliance with a number of performance standards.

To work in hospitals of their choice, all practicing physicians in the United States must secure admission *privileges* in such institutions. Most hospital care is indeed rendered by private practitioners who briefly visit the hospital to check on the status of their patients. This system allows the establishment of larger and more mobile medical staffs whose authority remains diffuse. To exert some measure of control, medical staffs usually create a number of committees to deal with the issues of credentials, admissions, education, and quality control. (Hospital ethics committees grapple with a host of issues, from informed consent and patient autonomy to advance directives and the definition of death.) The resulting administrative complexity and instability require a great deal of consensus building, achieved through frequent meetings and written communications. This record keeping effort is especially important among the attending physicians and more permanent hospital personnel to achieve a necessary degree of internal standardization of medical and administrative procedures.

Hospitals in Europe, even those owned by municipalities or private bodies, continue to be closely supervised by central governments. All hospital planning, construction, management, and recruitment of medical personnel remains subject to state control. In Great Britain, the government has assumed responsibilities for ensuring free access to hospital care as a social right. The implementation of the National Health Service Act of 1946 brought about the outright nationalization of all hospitals and placed them under the authority of regional boards appointed by the government and responsible to the Ministry of Health. In many European communities, the larger municipal and voluntary hospitals erected more than a century earlier remain in full operation. Greater administrative uniformity has allowed for smaller staff requirements. Given these hospitals' outdated physical plants, limited technology, and often a lingering stigma from their charitable past, well-to-do patients still prefer smaller, privately owned hospitals or clinics, many of which are still owned or managed by religious orders.

European hospitals operate with closed, full-time medical staffs hierarchically organized within smaller, autonomous divisions, each of which operates its own clinical, diagnostic, and rehabilitative services. While such internal arrangements reduce administrative overhead and foster more stable relationships among patients, physicians, and nurses, the schism between hospital and private practice remains. In Great Britain, this decentralized staffing framework follows the traditional, voluntary models of allocating a specific block of beds to each hospital physician or consultant, who is assisted by a stratified junior medical staff in training for specialist status.

Financial Difficulties of Hospitals

Although outpatient facilities are quickly becoming an integral component of professional education, hospital-based training continues to be the backbone of all medical education programs. Given the range of diagnostic and therapeutic options available, hospital practice remains at the center of biomedicine, providing the specialized clinical experience and technical proficiency required for today's professional status. With medical specialization and subspecialization on the rise, U.S. hospitals have expanded dramatically and have extended their residency training programs. As a result, physicians in training exercise greater management responsibility and are better remunerated than ever before.

Due to restrictive reimbursement schemes instituted by government and the private insurance industry, and the escalating costs of technologically assisted medical care, together with a gradual fragmentation of the medical marketplace, many U.S. hospitals find themselves increasingly under siege, victims, in part, of their previous success. Excessively bureaucratized and inefficient, their physical facilities overexpanded, hospitals are struggling to maintain their patient volumes as costs continue to increase. Unable to survive in a highly competitive environment, some institutions have already merged while others are closing wards or their doors altogether, thus forcing a major restructuring of the entire medical-care delivery system. Many hospitals are being reorganized into for-profit corporations, extending their services into networks of clinics and practitioners, and offering health insurance and service plans.

Conclusion

Ultimately, the evolution of the hospital in recent centuries poses the central question of whether care is still the primary function of this institution. While subjected to competing agendas—including religious beliefs, social control, secular philanthropy, scientific curiosity, communal pride, and economic autonomy—the hospital's original purpose was to shelter and comfort all sufferers in need. To a great extent, hospitals now restrict admission to seriously ill patients who require the most sophisticated diagnostic and therapeutic measures. The tilt toward acute episodes of physical illness, complex technological interventions, and the increasing costs of confinement have made hospital stays episodic and brief. Bureaucratization, financial constraints, and the pervasive presence of instrumentation only accentuate the essential impersonality of institutional care. The trade-offs are clear. Three centuries of medicalization transformed the hospital from a caring shelter for the poor into a disease-oriented machine for the sick who can afford to be cured.

GÜNTER B. RISSE (1995)
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SEE ALSO: *Aging and the Aged, Societal Aging; Care; DNR; Ethics: Institutional Ethics Committees; Informed Consent; Long-Term Care; Medicaid; Medical Education; Medicare; Mergers and Acquisitions; Patients' Rights; Research Ethics Committees*

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HUMAN DIGNITY

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Few terms or ideas are more central to bioethics or less clearly defined than human dignity. Although the core idea of human dignity has to do with the worth of human beings, the precise meaning of the term is controversial. Respect for human dignity is an ethical mandate to which both sides of many bioethical debates appeal. For example, the state of Oregon legalized physician-assisted suicide by passing the Death with Dignity Act, but opponents claimed that legalizing that practice would undermine the dignity of elderly, disabled, and dying patients. Similarly, in response to claims that respect for the dignity of those patients demands the pursuit of cures through the production of embryos by means of cloning for embryonic stem cell research, others claim that producing human beings in embryonic form and destroying them for the benefit of others is an affront to human dignity.

Views of Dignity

This term also is surfacing more frequently in important bioethical and other public documents. It has played a role in the constitutions of a politically diverse array of countries, including Afghanistan, Brazil, Canada, Costa Rica, the former Federal Republic of Germany, Greece, Guatemala, Ireland, Italy, Nicaragua, Peru, Portugal, South Korea, Spain, Sweden, and Turkey. In some of those countries, such as Germany, the role of human dignity is substantial. Affirming that “the dignity of the human being is inviolable,” the German constitution recognizes various human rights that the law must respect. Even in countries where the term has not been influential in constitutional language, it has come to play an important role. For example, the U.S. Supreme Court has employed the term in its deliberations over the meaning of the First, Fourth, Fifth, Sixth, Eighth, and Fourteenth Amendments to the Constitution.

International documents that are relevant to issues in bioethics also have affirmed the critical importance of human dignity. The United Nations, whose charter celebrates the “inherent dignity” of “all members of the human family,” issued a Universal Declaration of Human Rights in 1948 whose preamble contains the same language. Article 1 specifically affirms that “all human beings” are born “equal in dignity.” Two other documents—the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights—were joined to that document in 1966 to constitute the so-called International Bill of Rights. All three documents ground the various rights of all human beings in their human dignity. In line with this outlook, the Council of Europe’s 1996 Convention on Human Rights and Biomedicine was designed explicitly to “protect the dignity” of “all human beings.”

These documents reflect the primary sense in which human dignity is invoked today: as an attribute of all human beings that establishes their great significance or worth. The word *dignity* comes from the Latin words *dignitas* (“worth”) and *dignus* (“worthy”), suggesting that dignity points to a standard by which people should be viewed and treated. Although the standard usually has an egalitarian bent today, in ancient Greece and Rome the standard more commonly was attached to inegalitarian traits such as physical prowess and intellectual wisdom, as exemplified in figures such as Hercules and Socrates. People differed in dignity according to the degree to which they manifested the relevant traits, and the honor due them varied accordingly. This sense of dignity persists today when one speaks of dignitaries who warrant special honor or behavior that is dignified or undignified. Dignity in this sense can increase or decrease, can be gained or lost (Spiegelberg).

Dignity can refer to something that is variable in other ways as well. There is a difference between having dignity, on the one hand, and having an awareness of dignity or being treated with dignity, on the other hand. Someone may not be aware of having dignity though possessing it nevertheless; someone may not treat people in a particular group as having dignity though they may possess it. Such variability, however, should not be confused with the contemporary concept of dignity that is beyond the perceptions or actions of particular individuals and is rooted in what all human beings have in common. This is the concept that typically is operative when human dignity is invoked as the basis for the ways in which human beings should be viewed or treated.

Respect for human dignity is connected to a virtue as well as an ethical standard. A virtue-oriented approach to human dignity may take different forms. For example, exhibiting human dignity (usually referred to simply as dignity) can be a virtue in a way that is reminiscent of the notion of dignified behavior discussed above. To say that certain people exhibit dignity or are dignified can be a way of commending their courageous attitudes or actions in the face of adversity. However, the virtue of human dignity may refer to a person's capacity to recognize and live in accordance with a particular standard of human dignity. This form of the virtue serves as a reminder of how important it is that respect for human dignity be lived out in practice rather than existing only as an abstract concept. Exercising such a virtue still requires specifying what human dignity is.

People most commonly view human dignity in one of two basic ways. Some see it as grounded in particular characteristics of human beings; others view it as attached to being human per se. Both understandings are examined below, and then this entry surveys some of the bioethical implications of those views. First, it is necessary to clarify the significance and meaning of the concept by noting arenas in which it has been denied.

Challenges to Human Dignity

In the twentieth century perhaps the most widely decried denial of human dignity took place under the fascist regime in Germany; this accounts for the emphasis on dignity in the German constitution and the international and European documents discussed above. Millions of people were forced to be subjects of experimentation against their will or were tortured or killed for other reasons. As a result, the importance of human freedom and bodily integrity became much clearer and the danger of compromising them in the interests of the larger society became widely evident.

A tension necessarily exists between the idea of human dignity and ethical outlooks, such as utilitarianism, that, at least in their more popular and influential forms, affirm human dignity only to the degree that doing so is recognized to be sufficiently beneficial. Although the good of society is important, it potentially can justify doing anything to certain individuals, no matter how destructive, unless some standard of human dignity prevents that from happening. From a utilitarian perspective, what ultimately matters is the benefit itself (e.g., pleasure or preference satisfaction), not the individuals who benefit.

Others who are not well disposed to the notion of human dignity reject its high regard for freedom of choice or bodily integrity. Those who are most skeptical about freedom of choice include some in the social and biological sciences. Psychiatrists and psychologists who follow Sigmund Freud, for example, argue that freedom of choice is an illusion: Choices are driven largely by unconscious and irrational forces. Behaviorists who follow B. F. Skinner see such freedom as illusory because in their view behavior is driven more by environmental stimuli than by freely willed choices. Some biologists are skeptical about attributing any special dignity to humans because they are less impressed by any apparent differences between the abilities of people and animals to make free choices than they are by biological similarities between humans and animals. Those similarities go beyond the ability to experience pleasure and pain to encompass certain genetic, physiological, and other mental similarities.

Those who are skeptical about the high regard for bodily integrity in the notion of human dignity include so-called postmodernists and posthumanists. Postmodernists reject the "modernist" notion of a universally binding objective truth that has a wide range of implications for the ways in which people should be treated. Many postmodernists would characterize as oppressive the idea that certain applications of technology to the human body are inherently unethical (i.e., violations of human dignity). Posthumanists, in contrast, doubt the value of the human body. Bodily form is seen as an accident of history that eventually will be replaced through developments in cybernetics and artificial intelligence. According to this view, because human beings have no lasting significance, human dignity is an illusion.

Characteristics That Give Humans Dignity

In the face of such challenges there has persisted a widely shared commitment to human dignity: the conviction that human beings have a special worth that warrants respect and protection. The big question is: For what reason? Many people have addressed this question, and their responses are basically of two types. The first type of response maintains that human beings have dignity because of one or more characteristics that are typically human. This view can be traced back at least to Marcus Aurelius and earlier Stoic philosophers who held that human beings have a basic equality that is rooted in their common ability to reason. It can be spotted occasionally in later periods—for example in Renaissance thinkers such as Pico della Mirandola and Enlightenment philosophers such as John Locke.

A full-blown account of human dignity rooted in reason took on its most complete form in the work of Immanuel Kant, especially in his *Groundwork of the Metaphysics of Morals,* where he argues that "morality, and humanity so far as it is capable of morality, is the only thing which has dignity" (p. 102). In other words, human beings do not have dignity simply because they are human but because and to the extent to which they are capable of morality. Because for Kant "morality lies in the relation of actions to the autonomy of the will" (p. 107), he concludes that "autonomy is therefore the ground of the dignity of human nature" (p. 103). Simply put, human beings have dignity because autonomous reason rather than impulses or the pursuit of personal or social benefit governs their actions.

According to Kant's principle of autonomy, a human being "is subject only to laws which are made by himself and yet are universal" (p. 100). Both parts of this principle are essential. Moral decisions must be self-made rather than imposed by others, even by God, but they also must be decisions that could be made consistently and acted on by everyone rather than products of an individual's personal view of reality, as in postmodern autonomy. In Kant's words, "all merely relative" ends are excluded: "The principle of autonomy is 'Never to choose except in such a way that in the same volition the maxims of your choice are also present as universal law'" (p. 108). Because they have autonomy, human beings have dignity, as opposed to price: "Everything has either a price or a dignity. If it has a price, something else can be put in its place as an equivalent; if it is exalted above all price and so admits of no equivalent, then it has a dignity" (p. 102). Accordingly, human dignity requires that a human being be treated "never merely as a means" but "always also as an end" (p. 105).

Deryck Beyleveld and Roger Brownsword, among others, have tried to go beyond Kant and develop a reason-based approach to human dignity together with its implications for bioethics. They affirm Kant's attempt to root human dignity in people's reason and capacity to be moral agents, but they prefer to follow Alan Gewirth in adopting an understanding of agency that is focused more on choice. For Beyleveld and Brownsword "the essence of the dignity of agents resides in their capacity to choose, to set their own ends" (p. 5). Consequently, they prefer to see human dignity more as empowerment than as constraint. Whereas Kant's emphasis on people as "ends in themselves" fosters significant attention to limits on the ways in which people may be treated, even by themselves, these authors see the protection of each individual's right to choose as the primary mandate flowing from the rooting of human dignity in reason.

Despite the preoccupation with individual rights in many discussions of human dignity, especially in the West, the focus on the individual as opposed to the community is not inherent in the concept. A communitarian approach can champion human dignity in various ways. For example, it can establish respect for autonomy and choice as the hallmark of what should characterize a society. However, it also can promote a vision of how people should and should not be treated that limits individual choices.

Regardless of its individualistic or communitarian bent, any attempt to root human dignity in human characteristics such as reason and autonomy faces at least two important hurdles. First, it is possible for a living human being to lack such characteristics yet still be recognized as a human being. Are there human beings who lack human dignity? If having human dignity requires possessing the ability currently to exercise moral capacity or autonomy, for example, those who have mental disabilities, are comatose, are children, or are still in the womb do not have human dignity even if they are recognized as human beings (Gaylin). Often these are the individuals who are most in need of the protection that a concept of human dignity is designed to give.

Proponents of autonomy-based approaches have tried to give at least partial status and protection to those human beings in various ways. For example, Gewirth ties the level of a being's moral status to the degree to which that being has the necessary characteristic or characteristics. However, if human dignity is something one either has or does not have, as is affirmed typically, and if autonomy is the characteristic on which human dignity is based, then anyone without true autonomy does not have human dignity. Beyleveld and Brownsword agree but think it possible to grant those persons moral status on the basis and to the degree to which they may be moral agents who have autonomy. However, in cases in which there is a significant possibility that beings with autonomy are present, many people would consider it better to recognize and respect their human dignity rather than giving partial respect even to the simplest life forms under the assumption that they may be autonomous beings.

The second hurdle for this approach to human dignity is the plausibility of holding that what matters about human beings can be reduced to specific characteristics. Kant, for example, has been criticized for reducing what ultimately matters about human beings to the mind—to the rational—for that demeans bodily existence, which is essential in matters of bioethics (Kass). In fact, the focus on characteristics is vulnerable to the very criticism that it uses against its alternatives: It reduces human beings to what people in general or a particular community values about them and so in principle invalidates ascribing human dignity to them. The view that a particular characteristic such as moral capacity or autonomy is a sufficient basis for granting human beings an exalted status called human dignity may seem intuitively plausible to many, but it does not seem so to others. Accordingly, this approach is "based upon an anthropological 'creed'—not necessarily a religious creed" (Hailer and Ritschl, p. 99).

Dignity Rooted in Being Human

Because basing human dignity on particular human characteristics has difficulties, it may be preferable to root that dignity in being human per se. One way to do that is to focus on a basis from which all characteristics may be said to flow, such as the human genetic code. The 1997 Universal Declaration on the Human Genome and Human Rights of the United Nations Educational, Scientific, and Cultural Organization, for example, affirms that all human beings are equal in dignity because of the underlying unity provided by the human genome. Although this commonality may suggest a basic equality in all human beings, it does not address the significance of all human beings.

If their significance cannot be rooted in who people are, that is, in the specific characteristics discussed above, perhaps it can be found in something or someone beyond themselves. One candidate would be the sort of universal force acknowledged in Buddhism (Inoue). Because that force is in all living things, though, whatever dignity it imparts is not particularly human. However, if there is a God who establishes a special relationship with human beings that confers special worth on them, all people may be said to have a dignity that is distinctively human.

No such account of human dignity has had greater influence than the one portrayed in the authoritative writings of several major religious traditions, in which human beings are described as the "image of God." In addition to its role within religious traditions such as Judaism (Cohn), Christianity (Moltmann), and Islam (Bielefeldt et al.), this account has had a substantial impact on public formulations of the concept of human dignity (Bayertz). For illustrative purposes, this entry will consider this notion as it appears in the Christian Bible, since much of the Bible's relevant content is shared by other religious traditions.

The Bible uses two basic terms for *image*: the Hebrew *tselem*/Greek *eikon* (generally translated as *image*) and the Hebrew *demut*/Greek *homoiosis* (generally translated as *likeness*). Although there have been attempts to distinguish the two terms, it generally is recognized that they are used almost synonymously throughout the Bible. Usually one or the other appears, but occasionally, as in the account of the original creation of humanity in Genesis, both are employed. The sense conveyed is that of an image that is truly representative of God (Bray). In this view human dignity is not tied to a claim that human beings are divine or inherently worthy apart from God, and it is not because of human autonomy independent of God that people assume the authority to declare their own worth. Instead, human dignity is grounded in humanity's unique connection with God, by God's own initiative. This connection has three aspects: creation, alienation, and renewal. The first two have special significance for human dignity as an ethical standard, and the third for human dignity as a virtue.

In terms of creation, Genesis 1 (with a reaffirmation in Genesis 9) indicates that the image of God attaches to that which is human as opposed to that which is animal or plant. As a human child was considered the *tselem* of a parent (Genesis 5) and a *tselem* in the ancient Near East could refer to a statue reminding people of a king's presence (Westermann), human beings were created to have a special, personal relationship with God that includes their being God's representative in the world. Accordingly, the Bible speaks of human beings not only as being created in the image of God but also as being the image of God. This is striking because images of God are strictly forbidden in the Bible (e.g., Deuteronomy 4). However, the consistent message is that people are not to fashion images to make God the way they want God to be any more than they are to be God themselves. They are to manifest God to the world in accordance with the way God has made them and continues to direct them to be.

There have been attempts to attach more specific content to being the image of God. Some have seen its essence as involving humanity's (like God's) ability to reason, relate to others, or rule the world. However, others have maintained that those interpretations are read into the biblical text rather than read from it. For instance, Genesis does identify creation in God's image as unique to human beings, as opposed to other living things, and does instruct people about their responsibility to exercise stewardship over the rest of creation. However, the second instruction, some note, is not part of the description of what creation in God's image is; it is a separate matter that exemplifies what can be expected of one who is created in God's image. Similarly, they add, it is not surprising to find rational and relational abilities in those created in God's image, but they are never identified as what constitute that image (Cheshire). Angels, for instance, appear to have similar abilities but never are identified as being created in God's image. The picture presented in the biblical writings is that human beings themselves, not particular attributes or functions, are through God's creation the image of God.

The Bible goes on to record, however, that human beings were not and never have been content simply to be who God made them to be. In deciding to do things their own way, to give in to the temptation to "be like God" on their terms rather than God's (Genesis 3), they have experienced alienation not only from God but also from their own best selves, other people, and the rest of creation. Their capacities to reason, relate, and rule well have been damaged severely (Psalm 14, expanded in Romans 1, 8), and people now seek to create images to worship (including themselves) because they have lost sight of the fact that they are images of

God created to reflect and direct worship toward God rather than to be worshiped themselves.

Even in this alienation human beings remain the images of God, for God will not allow all connection with their Creator to be broken. The ethical standard of respect for human dignity gains its force precisely from this ongoing connection, for those who are dealing with human beings are dealing in a significant sense with God. Killing an innocent human being is equivalent to destroying an image of God without warrant from God and for that reason is unacceptable (Genesis 9), as is the attempt to tear down a human image of God verbally through cursing (James 3). Human dignity as constraint thus joins human dignity as empowerment once alienation has occurred and protection of human beings has become necessary.

The ethical standard of respect for human dignity rooted in the biblical accounts of creation and alienation, as was noted above, is affirmed in various religious traditions, as is the virtue of recognizing the dignity of human beings in words and actions, along with the difficulty of doing that once one is alienated from God. What the remainder of the biblical story adds is a particularly Christian account of how that marred image of God can be renewed, and with it the ability to live out the virtue of human dignity. For alienation to be replaced by reconciliation—for renewal to occur—according to this account, people literally must undergo a new creation (2 Corinthians 5). They must recognize the hopelessness of their alienation, give up all attempts to improve their situation through their own (futile) efforts, and invite God to re-create them in the image of God revealed in Jesus Christ. Although the creation is new, the image on which it is based is not, for Christ is identified not only as the image of God but also as God who created humanity in God's image in the first place (Colossians 1).

The new creation is portrayed as both ontological and logical. It is ontological in that it is an event in time that involves a change in being; it is logical in that it involves a process that flows logically from that event. People become in practice who they already are in being. This is said to be God's doing—people "are transformed" into the image/likeness of Christ (2 Corinthians 3)—but it also requires them to "be who they are" and "put on the new self, created to be like God" (Ephesians 4).

When people are renewed "in the image of their Creator," the result is described in terms of not only renewed individuals but also a renewed community: "Here there is no Greek or Jew, circumcised or uncircumcised, barbarian, Scythian, slave or free" (Colossians 3). Differences no longer divide; they disappear or in some cases can even enhance community, in which the human dignity of all is recognized. Those who are renewed images of God warrant no better treatment than does any other human being in this view because all human beings have human dignity by virtue of their original creation in God's image. However, those who are renewed images are characterized as increasingly more capable of exercising the virtue of human dignity than they would be otherwise.

God makes covenants with human beings, became a human being in Jesus Christ, retains that humanity eternally, died in humanity's place to pay the penalty for human rebellion against God, and will appear personally to bring humanity into an unending celebration of life with God, at which point people finally will understand all that being in the likeness of God entails (1 John 3). All these historical developments fill out the biblical account of human dignity but also rest on the basis that human beings are images of God, which some identify as the *essence* of what it means to be human (Berkouwer).

Rooting human dignity in being human, like basing it on specific human characteristics, faces at least two important hurdles. First, although it avoids the problematic idea that there could be human beings without human dignity, it begs the question of who is a human being. Does anyone with a human genome qualify, and if so, how much of the human genetic code must be missing or nonfunctional before status as a human being is lost? Are certain capacities instead or in addition what constitute a human being, and if so, must the exercise of those capacities be actual or may it be potential?

The second hurdle for this approach also has to do with its plausibility. Those who reject the existence of God or the notion of the image of God necessarily reject this approach. Some go further and find the idea of according a special dignity to the human race per se to be a form of "speciesism" that is ethically akin to racism or sexism (Singer). Just as that critique is not necessarily a religious one, attempted refutations do not necessarily depend on religious argument (Chappell). In any case, as was noted above, every approach to human dignity rests on some form of an *anthropological creed* whose plausibility must be assessed.

Specific Implications for Bioethics

As has been suggested here, people most commonly invoke human dignity in situations in which the worth of human beings is brought into question when they are used, forced, or injured. Human beings should not be used because their dignity requires that they be treated as having intrinsic, not merely instrumental, worth. They should not usually be forced because their dignity mandates that their wishes be respected. They should not normally be injured because their dignity entails that their well-being be preserved.

In some bioethical issues these dignity-related concerns argue persuasively against other considerations and typically claim to trump them. For example, in evaluating a form of human experimentation people commonly insist on obtaining the informed consent of participants lest the participants' dignity be violated when something is done to them against their wishes. No amount of benefit to society warrants such a violation. In matters of resource allocation some people invoke human dignity to argue that the allocation producing the greatest overall social benefit is not the right one if the burden that certain individuals must bear to bring it about is too heavy. Not only may some people be injured, the very process by which anything can be done to them if it results in greater benefit to society is demeaning. Human dignity also is invoked to protest the injury involved in human cloning for reproductive purposes as long as animal studies show that attempts to clone humans almost certainly would result in the birth of children who eventually would develop serious deformities.

In other bioethical debates human dignity is not so unambiguously on one side of the issue. The reason for this is that more than one anthropological creed is influential, leading to competing conceptions of human dignity. Sometimes the clash involves a conflict between those concerned about injuring people and those concerned about forcing people. In the debate over abortion, for instance, people who consider the freedom to choose as central to human dignity often see no conflict. In regard to the mother and the fetus there is only one human being with the ability to choose, and so her decision prevails. Opponents of abortion with a different view of anthropology may hold that two human beings are present. Accordingly, they see the situation as a conflict between two affronts to dignity in which a greater violation would be done by fatally injuring the unborn child than would be done by forcing the mother to carry the child to term. The debate over embryonic stem cell research can be construed similarly, with supporters championing the dignity (choice) of researchers and the potential beneficiaries of the research and opponents decrying the greater violation that would occur if embryonic human beings were destroyed.

Other bioethical debates are even more complicated in that two elements of human dignity—preventing people from being injured and preventing people from being used—are in conflict with a third element: preventing people from being forced. For this reason the groups of people on each side of these debates are not the same groups as those in the debates mentioned above. For example, in the debate over germline intervention to enhance future generations of human beings those who see the only threat to human dignity as the limitation of people's choices tend to favor giving parents and society freedom to pursue such avenues. Others, more concerned to protect people against injury even if their choices are limited in the process, identify a threat to human dignity in subjecting young human beings to such procedures when the potential negative effects of genetic alterations for enhancement purposes are not well understood. That opposition is strengthened for many by seeing not just the potential injury involved but also the fact that the people doing the enhancement unacceptably use other human beings by altering them to exhibit traits that parents or society may like but that the ones who are altered may not. Similar issues arise in the debate over the genetic determination of human beings through cloning; the indignity involved is made worse for some if the cloning is done with the intentional injury, that is, death, of the cloned embryo in view.

In end-of-life debates a similar complex of considerations involving human dignity commonly arises. On one side are those who insist that human dignity requires that people have all choices open to them at the end of their lives, including physician-assisted suicide. On the other side are those concerned that the dignity of patients will be demeaned by overt or subtle pressures to give up their lives or by the necessity for them to justify their continued existence in the face of familial and societal burdens. As some see it, patients who are mentally disabled may even be injured directly by inadequate treatment or acts of euthanasia.

Conclusion

Human dignity plays a significant role in many bioethical debates. Because human dignity can be invoked on both sides of various issues, there is a pressing need for those who use that term to clarify what they mean by it. At some point they also need to defend the plausibility of the *anthropological creed* that underlies their view.

JOHN F. KILNER

SEE ALSO: *Aging and the Aged; Autonomy; Care; Compassionate Love; Competence; Confidentiality; Dementia; Death: Cultural Perspectives; Disability; Emotions; Environmental Ethics; Life, Quality of; Life Sustaining Treatment and Euthanasia; Moral Status; Palliative Care and Hospice;*

Reproductive Technologies; Research Policy; Transhumanism and Posthumanism

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HUMAN EVOLUTION AND ETHICS

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The idea of evolution—that all organisms living and dead come by a naturalistic process of development from one or just a few forms—dates to the eighteenth century, but it was not until 1859 that Charles Darwin (in his *Origin of Species*) proposed the causal mechanism that today is generally thought the main force behind evolutionary change. Noting the potential population explosion existing among animals and plants, Darwin argued that there will be an inevitable struggle for existence and that this in turn leads to a natural selection of the ones with certain advantageous features. *Adaptations* like the eye and the hand are, therefore, the key mark of living beings.

The earliest of evolutionists all saw humans as being part of the process—usually the end point of a progressivist march upwards, from the primitive to the complex. Darwin initially said little about *Homo sapiens,* not because he did not want to include them in the evolutionary picture, but because he wanted first to establish the main outlines of the general case. In 1871 he did turn explicitly to humankind, and in the *Descent of Man* he argued that humans are completely and utterly part of the natural, living world. Drawing on a secondary mechanism, sexual selection, Darwin argued that the differences between men and women and between races are adaptive, although generally less for the immediate needs of survival and reproduction and more for the competition for mates between humans themselves.

Hominid History

It was around the time of the publication of the *Origin of the Species* that the first evidence of fossil humans were uncovered, remains of so-called Neanderthal Man, although it was not until the end of the nineteenth century that bones of the first unambiguous link between humans and their ancestors were discovered (Java Man, by the Dutch doctor Eugene Dubois). Since then a great deal of evidence has been unearthed about humans and their ancestors—the *hominids.* Most famously there is Lucy, *Australopithecus afarensis,* a being that lived in Africa about 4 million years ago, that walked upright and yet had an ape-size brain.

Modern thinking—based both on fossils and on molecular evidence—is that humans and the great apes (especially gorillas and chimpanzees) broke apart about 6 million years ago (Lewin). Most likely humans are more closely related to chimps than they are to gorillas. There was an upward growth of brain to the present size (about 1200 cubic centimeters), although there was a fair amount of diversification rather than one single line leading just to humans. Apparently all modern humans came from Africa about 150,000 years ago and are probably not related directly to the Neanderthals (who, incidentally, had slightly larger brains than present day humans). Sophisticated powers of speech are probably fairly recent (some argue that that was the key advantage of *Homo sapiens* over the Neanderthals), and full-blown culture and agriculture is very recent—only 10,000 years or more old.

Social Adaptations

As Darwin noted in the *Descent of Man,* apart from speech, one of the most distinctive aspects of humankind is that they are ethical beings. Humankind has a sense of right and wrong, and thus is led to act morally or ethically. Humans do things for others because they think them right rather than simply because they appeal to the self-interest of the doer. In fact sometimes people do things that are very much not in their own self-interest, like attempting to save a drowning child from a rapid river. If one takes a hard-line Darwinian position, arguing that adaptations are produced by selection to aid their possessors—I have eyes and hands because they help me—then the existence of the ethical sense is somewhat of a puzzle (Wright). Why do something for others when it puts the doer at risk? In the family situation, where the mother for instance aids her child, this is readily understandable. If the child does not survive then the mother does not reproduce. But what about the cases in which there is no relationship? One does not jump into the river only to save one's own children.

It has been stressed by students of animal behavior, especially by students of the behavior of higher organisms like the great apes, that there is no necessity to the appearance of an ethical sense and consequent behavior (Goodall, 1986). Ethical sense will not come into existence as a matter of course, even if the brain grows in size and power. There has to be a reason, and this reason most obviously is that this is an adaptation for social beings. There are great advantages to being social. Two or three can often do that which is impossible for one animal on its own—especially when the animals are foraging or hunting, practices that provide the high-protein supplies needed by organisms with high-maintenance adaptations like brains. At the same time, there are costs to being social, like the potential for spread of disease. Hence social animals tend to have (and need) special adaptations to exploit their sociality and to prevent the costs. Often, for instance, social animals have much better degrees of immunity against disease than do solitary animals.

Social animals—and humans are beyond all others, social animals—need abilities to help each other and at the same time to reduce intragroup strife. (It is for this reason that researchers often find that a better model for humans than close relatives like the orangutans—who are asocial—are less close relatives like the wolves—who are very social.) On the negative side, as one might say, humans are notable for not having very good physical methods of attack—their teeth, for instance, are puny besides those of chimpanzees. If one turns on a fellow human, the attacker is not very likely to rip the victim apart physically. Another important negative aspect of humans is the way in which the females do not come into heat or advertise their ovulation. There has been much discussion about the reason for this—sociobiologist Sarah Hrdy argues that a major reason for this behavior is that it keeps males guessing and hence in doubt about paternity, if they do not stay around and help with the family. Another reason obviously is that it keeps the group quieter and more stable—imagine trying to run complex social lives if women were often in heat.

On the positive side, a sense of morality is surely (in the opinion of Darwinian biologists) an adaptation for sociality. Organisms that take seriously their obligations to others are more stable and work together better than those that do not. Expectedly one finds what might at least be called proto-morality—with senior group members enforcing behavior—in other social animals, especially (as emphasized by ethologist Frans de Waal) the chimpanzees.

What sort of morality might one expect an evolutionary process to produce? Will it decide, for instance, between utilitarians and Kantians? Probably not, for it will be too coarse grained for that—giving just basic directions that will then be fleshed out by culture. Significant is that both utilitarians (like Peter Singer) and Kantians (like John Rawls) have welcomed an evolutionary approach. Rawls particularly points out that it solves the big lacuna in any social contract approach to morality, namely how did the contract get put in place in the first place. It was not a group of old men around a fire but the genes. “The theory of evolution would suggest it is the outcome of natural selection; the capacity for a sense of justice and the moral feelings is an adaptation of mankind to its place in nature. As ethologists maintain, the behavior patterns of a species, and the psychological mechanisms of their acquisition, are just as much its characteristics as are the distinctive features of its bodily strictures; and these patterns of behavior have an evolution exactly as organs and bones do. It seems clear that for members of a species which lives in stable social groups, the ability to comply with fair cooperative arrangements and to develop the sentiments necessary to support them is highly advantageous, especially when individuals have a long life and are dependent on one another. These conditions guarantee innumerable occasions when mutual justice consistently adhered to is beneficial to all parties.” (Rawls, p. 502–503).

Altruism

The technical biological term for organisms giving to others, at cost to themselves, is *altruism* (Wilson, 1975). It is important to note that this is a metaphor—it does not necessarily mean the altruism to which one refers when speaking of a good person, as in: Mother Teresa showed great altruism towards the poor of India. Ants helping others in the nest would be called altruistic, even though (as against the literal sense) there is clearly no implication that the ants consciously set out to do the right thing. Human altruism, or goodness as one might say, is therefore a sub-class of the general biological notion of altruism.

But why have humans developed so elaborate a method of interacting as a moral sense? Why, unlike the ants, are humans simply not hard-wired? There is a simple reason. Being hard-wired has virtues—there is no need for learning. The cost however is high. One cannot regroup and do something else if the situation changes. An ant will behave instinctively even though (because of changed circumstances) it may be doing itself or its nest a harm. Generally this does not matter, because ants are produced cheaply—a queen can afford the loss of a few thousand. Humans on the other hand are beings that require a great deal of care and only a few can be produced. (Technically humans are K-selected as opposed to ants that are r-selected.)

Humans need the ability to respond to change, especially to change brought on by fellow species members. A moral sense allows humans to do this. They can assess different or changing situations and act in the best interests of themselves and their brood. As philosopher Daniel Dennett has pointed out, this fact diffuses the oft-brought charge that any evolutionary approach to ethics must fail because it presupposed that humans have no real choices, they are *genetically determined.* It is true that humans are part of the causal chain, but they have a dimension of freedom not possessed by the ants. (In a sense humans are like the rockets that can adjust to moving targets, whereas ants are like cheap rockets that cannot change direction once fired.)

Selfish Genes

How does selection bring on altruism (using this now in the biological sense)? There is much debate. After Darwin most biologists assumed that selection could work for the group and that morality would emerge automatically—a species member that helped another was thereby helping the species. Famous was the notion of *mutual aid,* promoted by the Russian-born anarchist, Prince Petr Kropotkin. In the 1960s there was a sea change in opinion (going back in fact to the insights of Darwin himself). It was pointed out that group selection (selection for the benefit of the group over the individual) was too open to cheating. A selfish individual could take advantage of others (Williams). Hence came what Richard Dawkins has labeled the *selfish gene* view of the evolutionary process—in some sense, all adaptations (including social and behavioral adaptations) must be related back to self-interest. If they do not help the individual first and foremost, they will be wiped out.

The selfish-gene way of thinking was applied very fruitfully to the problem of altruism. William Hamilton (1964a, 1964b) introduced the idea of *kin selection,* arguing that altruistic behavior could be a very good strategy if one is helping others who share the same copies of genes as oneself—one is thereby reproducing by proxy as it were. Most dramatically Hamilton solved the question of why sterile workers (always female) in the hymenoptera (ants, bees, and wasps) devote their lives to their nest mates. In the hymenoptera only females have two parents, hence females are more closely related to sisters than to offspring and so it pays to raise fertile sisters rather than fertile daughters. More generally Hamilton showed that in any animal, if the conditions are right, then altruism will come into being.

Robert Trivers introduced a more general mechanism, that can function between non related organisms (even organisms of different species). *Reciprocal altruism,* so-called, suggests that if one gets a benefit by helping others, especially if others will thereby be more likely to help in response, then altruistic adaptations should come into play. Essentially, as Darwin himself realized, this is a case of: “If you scratch my back, then I will scratch your back.” In complex, thinking animals like humans, one could expect this to be a powerful mechanism. There will be times—when one is young, old, or sick—when even the most powerful will appreciate aid. In conjunction with this will be memory, so that humans are able to enforce reciprocation, and learn quickly to exclude those who do not play the game. Those who receive and do not give will soon be excluded.

More generally the ideas and techniques of game theory have been applied profitably to questions of sociability generally and morality particularly (Maynard Smith 1982). Sophisticated models can now be built showing how and when particularly moral traits might be expected to emerge (Skyrms). At the same time, experimentation can show whether or not specific hypotheses are well-taken. There have, for instance, been serious studies on questions about when commitments are kept and when broken. Also on how people respond to fairness or the lack thereof.

Group Selection

Criticisms of this whole selfish-gene approach tend to be of two kinds. On the one hand, there are more philosophical objections. Mary Midgely objects that the whole point about morality is that it is not selfish, nor is it simply enlightened self-interest. Morality means giving without hope or expectation of reward. But this objection is to misunderstand both the theory and the metaphor. Selfish genes do not necessarily cash out as selfish people. In fact humans might operate more efficiently (in their biological interests) if what they do is done precisely because they do not think it self-centered. One must make a distinction between what Dawkins (1982) labels the *replicators* (the genes) and the *vehicles* (the whole organism). To speak of selfish genes is to say that selection makes characteristics that rebound ultimately on the actor. Genes themselves are neither selfish nor unselfish. They just are. Individuals (vehicles) might be selfish at times and (genuinely) altruistic at times. It just depends on the situation.

On the other hand, there are objections of a more biological nature. Every biologist recognizes that sometimes a group selective force might overcome the individual selective force. For instance in a constantly fragmenting and reuniting population (that is with many sub-populations forming and disappearing) and with strong pressure towards altruistic behavior, group attributes might emerge before they can be eliminated by individual forces—these attributes might persist by being merged into the whole group. It has been suggested that the maintenance of sexuality might result from such a group force (Maynard Smith, 1978). (Others however, including Hamilton, think that sexuality can be explained at the individual level [Hamilton et al.].)

In particular, with the human case, some think that a group selective force might be the key factor in altruism (human, literal altruism, that is). Biologist David Sloan Wilson and philosopher Elliott Sober argue this way. Illustrating their position with a short story by Stephen Crane, in which a group are caught in a life boat and can survive if and only if they all work together, Wilson and Sober conclude that only a group analysis will explain the successful outcome. Because of our ability to think and plan, humans can and do overcome the forces of individual selection and are shaped by group forces. "Behaving as part of a coordinated group is sometimes a life-or-death matter in which the slightest error—or the slightest reluctance to participate—can result in disaster for all. Situations of this sort—in which the members of a group are bound together by the prospect of a common fate—have been encountered throughout human evolution, with the important fitness consequences, so it is reasonable to expect that we are psychologically adapted to cope with them" (Sober and Wilson, p. 335–336). In 2002 Wilson extended his analysis to look at issues to do with the evolution of religion and its moral codes. He argues that something like the Calvinism of sixteenth century Geneva can be explained in terms of a kind of group selection, where adaptations appear for the benefit of the whole against the individual.

This is still very contentious. English sociobiologist John Maynard Smith argues that nothing here makes even probable the group selection hypothesis. He argues that even humans are unable to overcome the strong tug of the selfish gene. In the lifeboat case, there is no need to suppose other than that each individual saw that it was in his own interests to cooperate. As Ben Franklin said on signing the Declaration of Independence: "Gentlemen, we must all hang together or assuredly we shall all hang separately."

Conclusion

In conclusion therefore the best assessment is that evolutionary biology has brought many new insights to our thinking about human nature, including human moral nature. It would nevertheless be overly optimistic to think that we are even close to ending all debate or offering all the materials needed to solve all outstanding problems.

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HUMAN GENE TRANSFER RESEARCH

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Human gene transfer research (HGTR) involves the deliberate transfer of genetic material (naturally-occurring, genetically-modified, or synthetic DNA or RNA) into human subjects. Clinical success has come more slowly than was first predicted, but HGTR remains a fundamentally novel approach to medical practice. It may one day enable clinicians to cure genetic disorders at their source, as well as provide oncologists with tools designed to disable or cure specific cancers. Nonetheless, HGTR differs from other clinical modalities in a number of ways. It involves creating genetically novel organisms that are potentially both transmissible and pathogenic, and there is a risk that this could modify the human genome. Human gene transfer techniques may also be extended beyond therapy into other, more controversial, areas (Verma). Consequently, while HGTR continues to capture the public's imagination, it has received an unparalleled level of public oversight. However, only when HGTR finally achieves success will ethical concerns become real issues.

Basic Terminology and Methods

Two distinctions shape the analysis and practice of human gene transfer: between therapy and enhancement, and between somatic and germline cells. The first refers to the transfer's intended outcome. Researchers may seek to prevent or cure disease (therapy), or they may want to alter an individual's characteristics or capabilities (enhancement). The second refers to whether researchers, in order to achieve these ends, seek to alter nonreproductive (somatic) cells or reproductive (germline) cells. Somatic alteration would affect only the individual subject, while germline alteration would change genes passed on to an individual's offspring. As of 2003, federal regulatory bodies will only entertain somatic-cell gene transfer protocols conducted for preventing diseases or developing treatments (U.S. NIH).

Genetic material can be transferred to human subjects in different ways, but most methods share certain similarities. Many protocols can be classified as either *ex vivo* or *in vivo. Ex vivo* protocols obtain tissue cells from the subject, genetically modify them in the lab, and return them to the subject's body. *In vivo* protocols employ different techniques to introduce genetic material into a subject's body, hoping that it will reach the appropriate tissues. Most protocols to date have used disabled viruses as the *vector* for transferring genetic material, though other vectors are also under development. Information on how frequently different methods are used can be obtained from the "Human Gene Transfer Protocol List" compiled by the National Institutes of Health (NIH) Office of Biotechnology Activities (OBA).

Clinical Successes and Setbacks

Certain milestones and setbacks mark the progress of HGTR from 1989 through 2003. Within this period, over 545 human gene transfer protocols, involving over 4,000 patients, were registered with the OBA. The field was launched on May 22, 1989, when Steven A. Rosenberg, Michael Blaese, and W. French Anderson injected genetically modified white blood cells into a male subject with advanced skin cancer. This protocol was not designed to intervene in his disease, but rather to track where the "marked" cells went in his body. The first protocol that sought a therapeutic outcome began on September 14, 1990, when W. French Anderson and colleagues transferred genetically modified white blood cells to Ashanti DeSilva, a four-year-old girl with severe combined immune deficiency (SCID). Ashanti's immune system was strengthened, but her underlying condition was not cured. Throughout the 1990s no other protocol was able to report clinical efficacy.

The first unambiguous clinical successes were reported in the spring of 2000. In April 2000 the French researchers Marina Cavazzano-Calvo and Alain Fischer reported that two baby boys (a number later raised to nine) with a version of SCID had normal immune systems ten months after receiving cells that were genetically modified to replace a missing gene. In March 2000 Katherine A. High and Mark A. Kay reported that subjects with hemophilia B experienced an increase in factor IX protein activity for at least six months after the gene transfer.

Yet this long awaited clinical progress has been tempered by setbacks. In December 2002 a subject in the hemophilia-B study developed signs of liver injury, halting the trial. The same trial was briefly halted in December 2001 when the gene-carrying virus was found in subjects' semen, raising the specter of inadvertent germline gene transfer.

And in January 2003 the second of the nine boys treated in France developed a leukemia-like illness.

More troubling for the field was the death of Jesse Gelsinger. On September 17, 1999, Gelsinger, an 18-year-old subject, died from a gene transfer experiment being conducted at the University of Pennsylvania's Institute for Human Gene Therapy. Gelsinger was affected by ornithine transcarbamylase (OTC) deficiency. Patients with OTC deficiency lack an enzyme needed for processing nitrogen with the result that toxic levels of ammonia accumulate in their bloodstreams, leading to severe mental impairment and even death. But Gelsinger's symptoms were manageable so that, unlike subjects in other gene transfer trials, he approximated a healthy volunteer. The viral vector used in this protocol was an adenovirus—a virus that usually causes the common cold. Although used in many protocols prior to Gelsinger's death, in his case the vector triggered a deadly immune response. An inquiry into his death resulted in severe sanctions against the University of Pennsylvania and the researchers involved, and it revealed major problems with HGTR oversight and conduct nationwide.

Public Oversight of Human Gene Transfer Research

HGTR is overseen in the United States by two agencies within the Department of Health and Human Services: the NIH and the Food and Drug Administration (FDA). While FDA review is "public" insofar as it involves federal oversight, NIH review through the Recombinant DNA Advisory Committee (RAC) is truly a forum open to the public. This aspect is unique to HGTR and reflects its historical development.

EARLY CONCERNS ABOUT "GENETIC ENGINEERING." Serious debate about human gene transfer began in the 1960s, when scientists, theologians, and philosophers raised many concerns about *genetic engineering,* or *genetic manipulation.* Theoretical concerns evolved into real possibilities in 1972 when scientists discovered how to combine genetic material from different organisms. Recognizing that biologically novel organisms created through these techniques could, if inadvertently released, imperil the environment, individuals, or society, the scientific community called for a voluntary moratorium on this research—referred to as *recombinant DNA research* or *rDNA*—until safety issues could be assessed (Berg et al., 1974). The 1974 moratorium was lifted after leading scientists met in Asilomar, California, and issued strict guidelines for the safe conduct of rDNA in 1975 (Berg et al., 1975).

The self-imposed scientific moratorium on rDNA research unnerved the public, who were already disenchanted by a decade of research scandals. In response to these scientific and public concerns, the NIH established the RAC, on October 7, 1974. The RAC embodied a novel approach to federal oversight of a novel biotechnology. Because concerns about rDNA were societal as well as scientific, the RAC was staffed by both scientists and nonscientists, and its meetings were open to the public. In 1976 the RAC issued its first set of guidelines. These guidelines focused on laboratory safety and containment, required federally funded institutions conducting rDNA research to establish an Institutional Biosafety Committee (IBC), and required all rDNA research to be reviewed first by the local IBC and then by the RAC.

HGTR OVERSIGHT. The RAC's early work focused on laboratory research that created recombinant organisms, and on work with animals and plants. As safety concerns raised by specific novel techniques were allayed, the RAC regularly shifted oversight responsibility to the IBCs.

By 1983 the RAC's attention had turned to HGTR. This shift was catalyzed by a number of events that captured public attention, including two unauthorized and scientifically ill-founded human gene transfer experiments (the 1970 case of Dr. Stanfield Rogers and the 1980 case of Dr. Martin Cline) as well as the controversial decision in *Diamond v. Chakrabarty,* allowing the patenting of genetically engineered organisms (for further information on these cases, see Walters and Palmer). One of the most important outcomes of these events was the 1982 publication of *Splicing Life,* a report on human gene transfer issued by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The commission argued that only transfer into somatic tissues to prevent or treat disease could be justified.

The President's Commission also recommended that the RAC broaden its responsibilities to include HGTR—and to attend to ethical and social implications as well as safety concerns. In 1983 the RAC created the Working Group on Human Gene Therapy (later renamed the Human Gene Therapy Subcommittee) to develop guidelines for human rDNA research and to review protocols (Walters, 1991). By 1985, this working group had produced "Points to Consider," the first version of the guidelines that would eventually govern HGTR.

CLINICAL TRIALS AND CHALLENGES TO PUBLIC OVERSIGHT. In April 1988 the RAC received its first actual human gene transfer protocol, and federal oversight of HGTR began. The field grew cautiously at first, and then exponentially, moving quickly from work with single-gene disorders to cancer research (Ross et al.).

By 1995 the NIH was spending $200 million per year (2% of its budget) on HGTR. Harold Varmus, the director of NIH, commissioned two reports on the state of the field. The first, coauthored by Stuart H. Orkin and Arno G. Motulsky, criticized researchers for exaggerating prospects for therapeutic success. They argued that more basic research was needed before moving to and investing in clinical trials. The second assessed the work of the RAC and concluded that the committee continued to serve important functions (Verma).

From the outset, RAC oversight of HGTR was contested. As early as 1990, RAC review was assailed for delaying vital medical research (U.S. NIH-RAC; Culliton). Biotech companies objected to the public nature of RAC review, while researchers felt that RAC review unnecessarily duplicated FDA review, which holds statutory authority for such approval. Human gene transfer protocols, unlike other areas of research, must be reviewed both by the RAC and by the FDA, either simultaneously or sequentially. At the FDA, responsibility for human gene transfer lies with the Center for Biologics Evaluation and Research (CBER), and review focuses on the safety and efficacy of rDNA products, the safety of the manufacturing process, and the control of the final product (Coutts). To protect proprietary interests, CBER review is closed, and it cannot, by charter, address the ethical or social implications of research. The FDA has developed its own "Points to Consider" document to advise investigators (U.S. FDA, 1998).

In 1996, with the urging of biotech lobbyists, researchers, and politically powerful patient activists, Varmus proposed to abolish the RAC, and only overwhelming public support for the RAC averted its demise. Although not abolished, the RAC was downsized and could no longer recommend approval or disapproval of specific protocols. From 1996 through 2000, the RAC reviewed approximately 10 percent of the HGTR proposals submitted to the NIH (those proposing novel methodologies) and convened occasional Gene Therapy Policy Conferences.

THE AFTERMATH OF THE GELSINGER CASE. The Gelsinger case revealed major problems with the oversight of HGTR. A primary finding concerned the reporting of adverse events (bad reactions or deaths during a human gene transfer experiment). According to the NIH Guidelines, all adverse events must be reported in a timely fashion to the RAC, but Gelsinger's investigators failed to report three adverse events to the FDA in a timely manner. Moreover, only 37 of 970 adverse events that occurred between 1993 and 1999 in trials using the adenovirus vector (approximately 25% of the HGT protocols underway at that time) were properly reported to the NIH (Walters, 2000)—these adverse events were reported to the FDA, but not relayed to the RAC.

The inquiry also uncovered problems in the informed-consent process. The informed-consent document given to subjects in Gelsinger's protocol differed from the one approved by the RAC and FDA, and it did not mention adverse events in animal studies. Public reporting about HGTR had led the Gelsingers to believe that patients had been cured by "gene therapy," and they reported that the investigators had led them to believe subjects in their particular protocol had experienced clinical benefit. Finally, adverse events experienced by other subjects in the protocol were not communicated to the Gelsingers, as required by federal guidelines (Stolberg). Ironically, the RAC's attention to informed consent was one reason given by Varmus for abolishing it (Marshall).

The Gelsinger case led to Congressional inquiries, multiple hearings, and soul-searching at the NIH and FDA. The RAC provided a unique and crucial forum for gathering, analyzing, and publicizing information relevant to this crisis. This resulted in two notable outcomes: (1) the FDA formally agreed to inform the NIH of all adverse events reports it received, and (2) the Advisory Committee to the Director of the NIH recommended that the RAC receive novel protocols at an earlier stage in their development—namely, prior to submission to the IRB and FDA.

Ethical Issues in Human Gene Transfer Research

Early ethical and social concerns surrounding HGTR were outlined in 1985 in the NIH's "Points to Consider." Since then, broader public and commercial contexts of HGTR have raised additional concerns, especially involving subject recruitment and economic conflicts of interest. These issues become increasingly important as HGTR moves toward new applications and methods.

THE ETHICAL COMMITMENTS OF THE "POINTS TO CONSIDER." The "Points to Consider in the Design and Submission of Protocols for the Transfer of Recombinant DNA Molecules into One or More Human Subjects" consists of over 100 specific questions that HGTR investigators must address for RAC approval (U.S. NIH, Appendix M). The RAC Working Group on Human Gene Therapy tested the document and developed its process of protocol review by working through a prototype HGTR protocol submitted in April 1987 by a team led by W. French Anderson (Walters and Palmer).

The ethical commitments of the "Points to Consider" reflect its historical context. The document reflects both the RAC's involvement with debates surrounding rDNA and a decade of national deliberations on the use of human subjects in biomedical research (Juengst). Its ethical framework hinges on six moral concerns. The first three derive from specific concerns about rDNA technology:

1. the need for special biosafety precautions;
2. the need for public participation in genetic research policy; and
3. potential broad and long-range research consequences (Juengst).

The final three concerns reflect the *Belmont Report*'s three central principles (beneficence, respect for the person, and justice) and the federal guidelines for the protection of human subjects issued in 1981:

4. clinical benefit to subjects;
5. free and informed consent by subjects; and
6. fair subject selection (Walters and Palmer; Juengst).

The RAC deliberations based on the "Points to Consider" tended to focus primarily on issues of safety and informed consent. Biosafety concerns focused on whether genetically modified viral vectors might be *shed,* or infect others who come into contact with research subjects. There was concern that viral vectors might revert to *wild-type* strains and become *replication competent*—that is, capable of replicating and infecting subjects or others in unanticipated ways. Further, might transferred genetic material integrate into the wrong place in the subject's genome, thus causing cancer (a hypothesized cause for the illnesses seen in the French SCID boys)? Might it inadvertently integrate into the subjects' germline tissues and be transmitted to their descendants? Scientific and clinical questions further attended to the risks particular protocols might present to subjects themselves. Nonscientific members (patient advocates, ethicists, attorneys) consistently raised concerns about informed consent and subject recruitment.

THE CHALLENGE OF RECRUITMENT. There are also important concerns about subject recruitment. HGTR initially targeted only life-threatening, incurable conditions for which no other effective therapy existed. Theoretical benefits to these subjects were believed to outweigh any possible risks. Initially, disease candidates included only single-gene disorders. By 2002, however, the pool of disease candidates had expanded to include cancers (64% of all protocols), HIV, peripheral artery disease, rheumatoid arthritis, and erectile dysfunction (U.S. NIH-OBA).

Subjects with life-threatening, incurable conditions are often in desperate straits, and it is not clear that consent can be truly voluntary in such situations? Too often, subjects misunderstand experimental protocols as their last or only *hope,* or as *therapy,* when in fact most human gene transfer trials are designed only to test safety, not efficacy. Subjects are aided in this misunderstanding by informed-consent documents that describe experimental interventions as *treatment,* or that mention a possible *benefit.* This, coupled with the misleading label of *gene therapy,* has led the field to be redescribed more accurately as "human gene transfer *research*" (Churchill et al.)

Misunderstanding gene transfer as therapy has led to questions about fair access to protocols. Before the first protocol was launched, concerns were raised about how to decide which members of even a limited subject pool would have access to the *potential benefits* of the research. Such thinking climaxed in 1993 when, in response to political pressure, Bernadine Healy, then the director of the NIH, allowed researchers to enroll a subject in an unapproved human gene transfer protocol as a last-chance therapy on the basis of "compassionate use." This would not be the last time the RAC faced political pressure to alter protocol approval (Lysaught).

COMMERCIAL INTERESTS AND "ORPHAN DISEASES." Another important issue is that of rare diseases and commercial interests. Early advocates of HGTR emphasized that this novel methodology promised, at long last, to provide cures for some 4,000 single-gene disorders. Ashanti DeSilva was afflicted with just such a disorder. But investigators quickly began applying human gene transfer techniques to clearly non-Mendelian disorders (e.g., cancer). As of 2002 only 10 percent of human gene transfer protocols approved by the RAC involved monogenic disorders. Most monogenic disorders are quite rare, with a small market for eventual therapies, and those involved in HGTR have been accused of abandoning persons with genetic disorders in order to cash in on big market payoffs (Meyers; Anderson).

The Orkin-Motulsky panel raised concerns about economic incentives surrounding human gene transfer in 1995. Due to these incentives, they noted, virtually every NIH institute had created a gene transfer program, whether equipped to do so or not, and they cautioned that the rush to find the gold in HGTR might lead investigators to ignore the pursuit of other, easier-to-achieve, conventional treatments.

Commercial interests, and the potential for conflicts of interest, also emerged in the Gelsinger case and led to a renewed examination of the relationship between academic research and industry. In Gelsinger's case, the University of

Pennsylvania's Institute for Human Gene Therapy received one-fifth of its $25 million annual budget from a company founded by the Institute's director, James M. Wilson. In return, the company had exclusive commercial rights to Wilson's discoveries. None of the subjects in the study had been informed of this relationship or this arrangement. In 2000 the American Society of Gene Therapy established a policy that its researchers should be free of significant financial involvement with companies that sponsor their studies.

FRONTIER ISSUES. Although HGTR has yet to achieve unambiguous clinical success, "frontier issues" such as prenatal gene transfer, nonrecombinant methods of DNA transfer, and the likelihood of enhancement merit mention.

Prenatal gene transfer might offer certain advantages, as early intervention might prevent the devastating effects of some conditions. The prenatal environment may provide better conditions for gene transfer and facilitate sustained gene expression. It could also offer parents at risk for conceiving a child with a genetic disorder an actual therapeutic alternative to selective abortion or preimplantation genetic diagnosis. However, *in utero* research entails unknown risks to the fetus and mother and raises the real possibility of germline modification (Fletcher and Richter). In January 1999 the RAC concluded (based on a Gene Therapy Policy Conference) that allowing prenatal gene transfer research would be premature. However, the RAC indicated its willingness to entertain *in utero* gene transfer protocols if current scientific questions were to be addressed (U.S. NIH-RAC).

Jesse Gelsinger's death and setbacks in the French SCID and hemophilia trials raised anew concerns about the risks of viral vectors. Researchers are therefore pursuing alternative methods of DNA transfer, including approaches that do not involve DNA recombination. Microinjection, where DNA or RNA is directly injected into a cell's nucleus using a glass pipette, is currently used for germline modification in animal research. A similar approach involves the injection of *naked DNA* (DNA not contained within a vector) directly into tissues. Another protocol uses high pressure to push short DNA sequences into graft tissue. Others suggest attaching DNA to other macromolecules, such as liposomes. These complexes can navigate cell membranes without the risks posed by viral vectors. And yet others are developing methods of inserting not just genes but entire *artificial chromosomes.* While these approaches may reduce certain safety concerns, they may also introduce others. For example, transmission of artificial chromosomes to offspring via germline integration raises questions about the creation of individuals with more than the standard complement of forty-six chromosomes. How does this challenge our understanding of what it means to be human? Moreover, given our limited knowledge of chromosomal interaction and gene mutation, the long-term consequences of such modifications cannot be known.

Finally, researchers clearly have an interest in pursuing gene transfer for enhancement purposes. The same techniques used for legitimate medical therapies could be used for decidedly non-therapeutic purposes by athletes for example, looking for a competitive advantage. Somatic-cell interventions might be able to strengthen muscles and bones or boost oxygen efficiency, while germline enhancements could provide a way for parents to engineer children with superior athletic skill. Researchers further anticipate developing techniques that will enable inserted genes to be "turned off" by an additional intervention if necessary. While such developments might prove therapeutically useful, they could also allow a mechanism for avoiding detection of genetic modifications. What responsibilities do researchers and physicians have with regard to such practices? Although clearly decades away at best, the World Anti-Doping Agency is taking this possibility quite seriously. With the advent of stem cell and cloning techniques, the prospect of gene transfer being used for enhancement purposes becomes increasingly probable. Certainly such applications of gene transfer technology raise serious questions about the just allocation of resources in a world where over 2 million people each year die from a lack of adequate sanitation and clean water and 44 million people in the U.S. remain without adequate health insurance.

Conclusion

The possibilities of prenatal or germline gene transfer and genetic enhancement suggest that the need for public oversight of HGTR is far from over. Initial safety and societal concerns surrounding rDNA research and HGTR have not materialized, in part because the research has received careful scrutiny and oversight in a public forum that has earned respect through hard work and responsiveness to changes in its social and scientific contexts. Unlike other biotech developments, HGTR is not perceived as being driven solely by the momentum of the market, with technology racing ahead of society's moral compass. Nor has it become intractably polarized. Public oversight has provided both a forum for discussing ethically controversial applications of human gene transfer and a mechanism for exercising prudence and caution.

Public oversight of HGTR also provides a unique venue for addressing concerns that are not unique to HGTR, but are applicable to the practice of scientific research in general. These include concerns about the commercial influence on scientific research, the practice of informed consent, and about vulnerable patients. But because it proceeds in public view, HGTR may serendipitously lead to significant improvements in the conduct of human-subjects research in the United States and throughout the world.

M. THERESE LYSAUGHT

SEE ALSO: *Genetic Engineering, Human; Genetics and Human Self-Understanding; Public Policy and Bioethics*

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HUMAN NATURE

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Theories of human nature offer systematic and comprehensive accounts of human beings' most significant distinguishing characteristics. Such accounts are central in people's perennial attempts to organize their understandings of the cosmos; to figure out their relation to God, to nature, and to each other; and to uncover the possibilities, meanings, and purposes of human life.

Western Understanding of Human Nature

Modern Western theories of human nature, which will be the focus of this essay, typically differ from their classical and medieval predecessors in appealing to the findings of a variety of life and social sciences, including anthropology, medicine, physiology, psychology, economics, sociology, and even ethology. Nevertheless, although these sciences undeniably help us to understand specific aspects of human life, even contemporary theories of human nature are never simply summaries of the results of empirical research—despite their frequent claims to scientific authority.

One reason that theories of human nature are not simply generalizations from the conclusions of scientific study is that they enter into empirical investigations not only as conclusions but also as presuppositions, structuring the conceptual frameworks within which research programs are conducted. Contemporary psychological investigation, for instance, proceeds with a variety of models of the human mind, including the Freudian, the behaviorist, the existentialist or humanist, and the computer models. Empirical research cannot fully evaluate the adequacy of its own framework relative to others; determining the adequacy of an entire framework requires reference to considerations beyond empirical data, including how the framework coheres with other respected theories and even its moral and political implications.

A related reason that theories of human nature go beyond ordinary scientific claims is that typically they aspire to provide a comprehensive conceptual framework that will render coherent the contributions of all those disciplines and discourses that investigate various aspects of human life. These often represent human beings in ways that, at least on the surface, appear quite incompatible with each other; for instance, lawyers assume that people ordinarily are responsible for their actions, while psychologists may suggest that people's behavior is determined ultimately by factors outside their control. Theories of human nature endeavor to resolve these incompatibilities in a variety of ways, ranging from reinterpreting the meaning of a discourse, such as the religious, to setting limits on the domain within which its claims are accepted; occasionally, a theory of human nature may even proclaim the invalidity of a whole realm of discourse, such as the parapsychological. Rather than simply summarizing the conclusions of the various life and social sciences, therefore, theories of human nature typically perform a regulatory function, authorizing some methodological approaches while delegitimating others.

Yet another respect in which theories of human nature differ from scientific theories, at least as science is ordinarily understood, is in the prominence of their normative or evaluative component. Even if one contends that all knowledge is to some degree value-laden, the evaluative element is far more evident in theories of human nature than it is, for instance, in modern theories of the physical universe. All theories of human nature provide a general account of human capacities and human needs, human potentialities and human well-being, and thus contain at least an implicit, and often an explicit, diagnosis of human malaise and a prescription for human flourishing.

Like all theoretical constructions, theories of human nature are developed in specific historical circumstances and are designed to address specific conceptual puzzles or practical concerns; consequently, they shift their emphasis according to the scientific, moral, and political preoccupations of the time. Despite variations in focus and emphasis, however, the Western project of understanding human nature historically has centered on two questions. The first of these addresses the human aspect of *human nature*: How can human be distinguished from nonhuman nature? The second addresses the natural aspect: How can what is natural for humans be distinguished from what is unnatural, abnormal, or artificial? The concerns inherent in these two questions constitute continuing themes that link the variety of Western inquiries into the nature of human beings.

Reflection on these themes reveals that the Western project of providing a systematic theory of human nature has been predicated historically on certain assumptions. They include the following: (1) that it is possible to discover specific qualities or features that characterize human beings universally and transhistorically; (2) that these characteristics decisively distinguish humans from all other beings, notably nonhuman animals; and (3) that, from the discovery of these characteristics, it is possible to derive specific prescriptions about the proper conduct of human life. In other words, the Western project of understanding human nature generally has been motivated by a desire to derive from it universal and unchanging values.

These assumptions went unquestioned and often unarticulated throughout most of Western history. Once they are made explicit, however, it is easy to see that they are all contestable; and we shall see how, in the nineteenth and twentieth centuries, each of them was contested. For instance, Karl Marx (1818–1883) and John Dewey (1859–1952) challenged the first assumption; Charles Darwin (1809–1882) and the twentieth-century sociobiologists challenged the second; and the theorists of positivism and neopositivism challenged the third.

Since the 1970s not only these assumptions but the whole project of developing a comprehensive theory of human nature has been subjected to more fundamental critiques, launched by poststructuralist or postmodern French writers such as Michel Foucault (1926–1984), Jacques Derrida (1930–), and Jean-François Lyotard (1924–). While these authors differ on many points, they are united in rejecting the possibility of any overarching philosophical framework capable of unifying and legitimating the specific disciplines. Such totalizing frameworks or discourses, they claim, reflect unrealizable aspirations to discover universal and absolute truths in morals, politics, or science. These authors deny that any genuinely universal truths can be found, and assert that claims to them typically are propounded by groups who wish to use them for promoting their own political agendas. Truth, they argue, is relative to specific discursive practices that are historically contingent and self-justifying. Consequently, there is no need for, as well as no possibility of, a *master* discourse designed to be the ground or foundation of these more specific discourses.

As described so far, the dominant tendency in Western thought has been to conceptualize human nature as both *universal* and *transhistorical.* Its conceptualizations typically take the form "All human beings throughout history have characteristics x, y, z," implying that x, y, and z are necessary, as well as universal, characteristics of human nature. However, the Western tradition also includes conceptions of human nature that are not universalistic although they are transhistorical. These *relational* theories take the form "Group x is inferior to group y with respect to characteristics x, y, z"; typically, relational theories are used to justify the dominance of one group over another. Finally, some Western conceptions of human nature are *historical* rather than transhistorical, used within theories that claim that as human cultures change, so do certain important human characteristics. Some theories contain elements both universal and relational—for example, the theories of Aristotle and the sociobiologists—or both transhistorical and historical—for example, the theories of Karl Marx and John Dewey.

Three Classic Western Approaches

ARISTOTLE. The origins of Western philosophy, in the sense of systematic and rational inquiries into the nature of reality, knowledge, and value, are often traced to the reflections of ancient Greek thinkers in the fifth and fourth centuries B.C.E. Plato (ca. 428–347) and Aristotle (384–322), two of the three philosophical giants of this period (the third being Socrates, ca. 470–399), developed systematic theories of human nature. Aristotle's view has been particularly influential on the Western tradition because it was incorporated into the Scholastic philosophy that dominated Europe in the Middle Ages and early Renaissance, and continues to shape the thinking of the Roman Catholic Church.

Aristotle conceptualized human beings as complexes of soul and body. The soul was the distinctively human element—the essence or form or intelligible principle of the body—but it existed only in conjunction with a living human body. Aristotle's conceptualization of the soul as inseparable from its body contrasted with Plato's view that human beings were souls united only temporarily with bodies, but Aristotle also acknowledged the possibility of the actively knowing and thinking part of the soul, the mind or intellect, being "set free from its present conditions … immortal and eternal." When this happened, however, Aristotle asserted that the mind remembered nothing of its former embodied activity and, because all connection with a specific human body was thus lost, he did not regard the human soul as personally or individually immortal.

Aristotle's view of human nature, like Plato's, was *teleological,* which is to say that he regarded human beings, like other things in the world, as having a "function" or activity peculiar to them. He further assumed, again like Plato, that the good life, or *eudaimonia,* consisted in the successful or efficient performance of that function. For Aristotle, the distinctive function of human beings was reasoning, or "an active life of that which possesses reason," and so he inferred that the good life was one in which the rational part of the soul governed the appetitive or desiring part, thus avoiding excess and living in accordance with virtue.

For Aristotle, human beings were, by nature, political animals who needed to live in a community: "He who is unable to live in society, or who has no need of it because he is sufficient to himself, must be either a beast or a god." Within human communities, however, not everyone was capable of citizenship: The nature of some was to rule and of others to be ruled. Among those whose nature was to be ruled were children, barbarians, and Greek women; thus, while Aristotle posited a universal standard for human nature, he simultaneously asserted that some groups of humans were less than fully human. The theme of dominance and subordination runs not only through Aristotle's account of the relations between human beings but even through his account of the nature of individual humans. He compared the controlling relation between form and matter with the relation between male and female, and he asserted that the proper relation between mind and body was like that of master to slave.

AQUINAS. The dominant philosophical figure of the Middle Ages was Thomas Aquinas (1226–1274), later Saint Thomas, who synthesized Greek thought and church doctrine into a Christian philosophy. He conceptualized human nature in terms that were basically Aristotelian, with some (often Platonic) modifications made in order to adapt Aristotelian views to church doctrine.

Aquinas believed, like Aristotle, that there was a distinctive and essential human nature that could be understood teleologically; he also shared the Aristotelian belief that the good life or *eudaimonia* was action in accordance with this function. A proper understanding of the ends or purposes of human life was therefore essential to morality and should be achieved by discovering the precepts of *natural law.* Natural law, as Aquinas conceptualized it, was universal and unchanging. It described supposedly universal human tendencies, such as preserving life, but presented them not simply as empirical facts about human nature but also as manifestations of God's design for humanity. For Aquinas, therefore, natural law simultaneously described how things were and prescribed how they should be. It was discoverable by reason, which, because it gave insight into God's purposes, provided guidance on how humans should live.

Like Aristotle, Aquinas saw humans as combinations of soul and body, with the soul as the form of the body. To allow for the possibility of personal or individual immortality, however, Aquinas diverged from Aristotle, declaring that the soul was a "substantial" form, capable of existing separately from matter. Not only was personal immortality conceptually possible, according to Aquinas; it was humans' destiny. God would not have implanted the universal—and therefore natural—human desire to live forever unless this desire had an object.

While Aquinas shared the Aristotelian view that human nature had an end or purpose, he believed, in accordance with church doctrine, that this end was supernatural rather than natural: It was to spend eternity united with God in heaven, where alone perfect happiness might be enjoyed. Human life as we know it was no more than a preparation for life after death, and this world was simply a testing ground for the next. So long as humans inhabited this world, however, they should strive to live in accordance with natural law, which provided a test for the moral validity of the laws of the state.

DESCARTES. The thought of René Descartes (1596– 1650) is generally considered to mark the beginning of modern philosophy. Refusing to accept the authority of tradition, Descartes developed "rules for the direction of the understanding" and a "method for rightly conducting reason" designed to enable each individual to establish certain truth in science and philosophy. He wrote in the vernacular (French) as well as in Latin, in order to reach lay as well as clerical readers.

Descartes's conception of human nature was even more *dualistic* than that of Aristotle and Aquinas. Living human beings, for Descartes, were composed of two entirely different kinds of entities: souls, which were active, intellectual substances, immaterial and immortal; and bodies, which were unthinking, passive mechanisms, spatially extended and temporally finite. Individual humans were to be identified not with their bodies but with their souls, which were able to survive the death of the body. While Descartes's model allowed for the soul's separation from the body after death, it rendered problematic the relation of the soul to the body during life, since it was unclear how material and immaterial substances could have a causal influence on each other. Descartes never succeeded in providing a satisfactory explanation of mind-body interaction.

As a scientist, Descartes wanted his theory of human nature to be compatible with both the new developments in physical science and the doctrines of the Roman Catholic Church. He attempted to reconcile these two worldviews by postulating two spheres of reality, each governed by entirely different laws or principles. The laws of God governed spiritual or mental reality; the laws of science governed physical reality, understood by Descartes in mechanical terms. Although Descartes never developed a systematic moral philosophy, his assertion that all "men" were potentially equal in their capacity to reason laid the foundation for later egalitarian moves in ethics and politics. Simultaneously, his conceptualization of animals as mere stimulus-response mechanisms, lacking consciousness because they lacked souls, justified the exclusion of animals from moral consideration. Cartesian biologists, in defense of vivisection, have compared the howls of cut-up dogs to the squeaks of unlubricated machines.

SHARED FEATURES OF DOMINANT PRE-DARWINIAN CONCEPTIONS OF HUMAN NATURE. There are at least six common features of pre-Darwinian conceptions of human nature:

1. Human nature is the same transhistorically.
2. It is distinguished primarily by possession of a soul.
3. Human souls are characterized by their capacity to reason. This capacity exists, perhaps in varying degrees, as a potential innate in all humans, sharply distinguishing them from all other beings, including animals.
4. Humans' possession of a rational soul gives them special moral worth.
5. Lacking such a soul, animals lack comparable moral worth or value. Those biological features that are similar in humans and animals comprise humans'

"lower" nature, which humans should strive to rise above.

6. Developing our potential to reason is a key to the good life for humans. Reasoning not only tells us how to live well but actualizes our distinctively human potential. Thus, the concept of human nature is clearly normative: Our task is to realize our humanness by fulfilling our potential for rationality; those who are incapable of fulfilling this potential are less than human.

The Materialist Tradition and the Darwinian Pivot

The features listed above as characterizing pre-Darwinian conceptions of human nature represent the dominant Western tradition prior to the nineteenth century. Running counter to this *rationalist* and dualist tradition, however, Western thought also includes a less prominent *materialist* or naturalist tradition.

Anaximander (ca. 500 B.C.E.), an early pre-Socratic philosopher, developed a speculative theory of evolution in which human beings were descended from lower forms of animal life. Democritus (460–370 B.C.E.), a contemporary of Socrates, developed a speculative atomic theory in which even the human soul was composed of atoms. The English philosopher Thomas Hobbes (1588–1679) assimilated individual behavior and politics to the laws of mechanics, regarding desire as motion toward an object, and human beings as motivated entirely by self-interest. The French philosopher Julien de La Mettrie (1709–1751) accepted Descartes's assertion that animals were like machines but insisted that so, too, were human beings. The German philosopher Baron Paul Henri d'Holbach (1723–1789) argued that thinking could be reduced to the functioning of the brain and explicitly denied the existence of a soul. Another of the French philosophes, Claude-Adrien Helvétius (1715–1771), argued that all mental faculties were ultimately reducible to physical sensation and that all humans were motivated by the desire to achieve physical pleasure and reduce pain. This latter idea was developed into an elaborate ethical calculus by the nineteenth-century British utilitarians, Jeremy Bentham (1748–1832), James Mill (1773–1836), and the latter's more famous son, John Stuart Mill (1806–1873). Collectively, these philosophers suggested an alternative understanding of human nature—one that focused more on the body than on the soul, on the emotions and desires more than on reason, and on the similarities rather than the differences between humans and animals. It remained for Charles Darwin to give this materialist tradition a scientific basis by providing a naturalistic analysis of the relations between humans and animals.

In his landmark work, *On the Origin of Species* (1859), Darwin argued that the distinctive features of human nature were not divinely created in an instant but had evolved over many millennia through a process he called "natural selection". Although the word *selection* suggested conscious purpose, Darwin's use of it was metaphorical, since nature *selects* only in the sense that certain new traits or mutations that appear accidentally are sufficiently adaptive to the environmental conditions within which the organism lives for the new organism to survive. The view that human beings had evolved through accidental mutations implied that there was no preordained nature, no ultimate meaning or cosmic purpose for human life to fulfill. In an attempt to escape this conclusion and reconcile science with Christianity, some later theorists postulated a direction and a goal in evolution, characterizing more recently evolved species as *higher* or otherwise superior; but such teleological and evaluative interpretations were ultimately alien to the basically antiteleological spirit of the concept of natural selection.

When Darwin first proposed his theory of evolution, the wife of the canon of Worcester Cathedral was said to have remarked, "Descended from the apes! My dear, we will hope it is not true. But if it is, let us pray that it may not become generally known." Indeed, the church denounced Darwin, recognizing that his theories challenged not only the beliefs in divine creation and a radical discontinuity between humans and animals but also the idea of an immortal soul with special moral worth. Darwin argued that morality had developed from the social instincts of animals; and he construed the uniquely human capacity for rationality, which Aristotle had seen as the telos of human existence, as the outcome of natural selection operating on accidental mutations.

Biological Determinism: A Critique

Once Darwin had demonstrated an evolutionary continuity between humans and other animals, questions arose about the causal role of human biology in relation to other aspects of human life. For many scientists, the project became the *reductionist* one of showing how the various psychological and social characteristics of human beings were causally determined by human biology.

Many *biological determinist* theories have negative social implications because they present human characteristics like aggression and dominance as biologically determined and therefore inescapable. For instance, Sigmund Freud (1856–1939), the founder of psychoanalysis, insisted that all human motivation could be reduced to two basic drives—the sexual drive, or libido; and the aggressive drive, an ineradicable instinct to hurt, torture, or kill other human beings (Freud). The German ethologist Konrad Lorenz (1903–1989) also posited an aggressive instinct in humans similar to that he found in his study of various animal species in their natural habitats. In each species, the instinct had evolved to serve one or more life-preserving functions, such as territorial dispersion, selection of the strongest for reproduction, defense of the young, and the establishment of a hierarchy that could provide the group with social cohesion. In species armed with sharp teeth, claws, or beaks, the aggressive instinct was generally coupled with an inhibitory mechanism preventing fighting animals from killing each other; Lorenz argued that there had been no need for such an inhibitory mechanism to evolve in humans because they were not naturally armed. With the development of weaponry, however, the absence of such a mechanism was often lethal, and the advent of nuclear weapons made it a threat to the survival of the species (Lorenz).

More recent studies of animal behavior have generated a new form of biological determinism called *sociobiology.* Two precursors of sociobiology, anthropologists Lionel Tiger (1937–) and Robin Fox (1913–1971), proposed the concept of a "biogram," a code or program genetically "wired" into the brain that produced certain forms of social behavior, including patterns of dominance and submission—hierarchy among males and dominance of males over females. Both of these were assumed to be the evolutionary heritage of the hunting life of early hominids (Tiger and Fox). The same general line of thinking was employed by entomologist Edward O. Wilson (1929–), who first coined the term *sociobiology.* Wilson insisted that "genes hold culture on a leash" and play a significant role in determining such human social behavior as altruism toward kin, communal aggression, nationalism, racism, homosexuality, and the dominance of males over females. Wilson has conceded that these biologically based tendencies might be counteracted through extreme social measures, but he argues that humans would pay a high price for doing so (1977).

While Wilson's assertion of a universal genetic tendency toward ethnocentric and racist attitudes was not an attempt to justify racism, there is a long Western tradition of using evolutionary theory to denigrate certain racial or ethnic groups. In the nineteenth century, some scientists in this tradition asserted that Caucasians and Orientals had crossed the *Homo sapiens* threshold before "Negroes," or that *Homo sapiens* had begun in Asia and migrated to Africa, where the original stock had degenerated. Others sought to prove racial, ethnic, and class inequalities in intelligence through the use of IQ (intelligence quotient) theory. Frances Galton (1822–1911), a cousin of Darwin who coined the term *eugenics,* attempted to show that the upper classes had superior intellectual capacities and that blacks were "two grades" below whites. Many of the early IQ theorists in the United States made similar claims about various immigrant groups.

After World War II, when the Nazis had shown the possible social consequences of eugenic ideas, such theories fell into disrepute. They were revived in 1969 when educational psychologist Arthur Jensen (1923–) published an article in the *Harvard Educational Review* arguing as follows: Intelligence testing has demonstrated that whites score on average about fifteen IQ points above blacks; IQ is 80 percent *heritable*; therefore, the mean difference between the scores proves a hereditary difference in innate intelligence between the two groups (Jensen). Shortly after Jensen's article appeared, Harvard psychologist Richard Herrnstein (1930–) made a similar argument concerning the difference in IQ scores between *upper-class* and *lower-class* people. He concluded that humans should give up any aspirations to democratic equality and accept the idea of a natural meritocracy (Herrnstein).

Biological determinist theories were highly controversial in the late 1960s and 1970s, but in the 1980s and 1990s they became increasingly fashionable—claiming, for instance, genetic factors in alcoholism; locating homosexuality in the structure of the brain; and asserting that men with XYY chromosomes have a tendency toward criminal violence. However, biological determinist theories of human nature are problematic in a number of respects.

Empirically, the evidence for such theories is at best inconclusive. Even within the psychoanalytic tradition, some theorists have argued against Freud that aggressive desires may be explained as derivative manifestations rather than primary instincts, resulting from situations that frustrate other, nonaggressive desires. Ethologists and sociobiologists typically move incautiously from observations of certain animal species or conjectures about early hominids to claims about modern human beings. Sometimes, like Lorenz, they focus on the behavior of fish, birds, and other animals considerably removed from humans—while they ignore studies indicating that many higher mammals, especially primates, display almost no hierarchical organization or intraspecies aggression, being instead peaceful and cooperative. Finally, regardless of how nonhuman species behave, similarities in behavior between humans and nonhuman animals do not establish that the human behavior in question is biologically determined; it may still be a learned response.

Claims for the universality of human aggression, hierarchy, and male dominance also are not confirmed by anthropological evidence. Many hunter-gatherer societies are reported to be remarkably lacking in aggressive behavior, and some enjoy an exceptionally high degree of social equality. Assertions of women's *natural* dependence on men are undermined by evidence that gathering, a task often performed predominantly by women, is a more reliable food source than hunting in many hunter-gatherer societies. The sexual division of labor varies widely cross-culturally, and even where certain constants are observed, such as a tendency for women rather than men to care for young children, this may be a social adaptation to prevailing conditions rather than a biological predetermination.

Claims about the genetic basis of racial and ethnic differences in IQ are equally suspect. The idea of different evolutionary paths for different races is contradicted by the paleontological evidence; indeed, the concept of race itself is now widely discredited, with anthropologists preferring instead to talk about the statistical frequency of certain characteristics within a geographical population. Further, the idea that IQ tests measure innate intelligence is undermined by the recognition that all tests are culturally biased, since they all require prior learning, and that learning experience can significantly raise IQ. Finally, the very concept of *heritability* is a technical one, designating a ratio of the contribution of heredity to environment within a given population; it cannot be used, therefore, to compare one population against another.

Biological determinist theories of human nature are not just empirically unconfirmed; they also fail to acknowledge what is most distinctive of our species. The human genetic constitution determines highly developed learning and cognitive capacities that allow humans to respond flexibly rather than instinctively to environmental problems, as well as to develop a range of distinctively human cultural characteristics. The implications of this were noted by one of the world's foremost geneticists, Theodosius Dobzhansky (1900–1975), who wrote, "In a sense, human genes have surrendered their primacy in human evolution to an entirely new, nonbiological or superorganic agent, culture. However, it should not be forgotten that human culture is not possible without human genes" (p. 113). In short, what has developed in the human evolutionary process is a primate with a genetic structure capable of a new kind of evolution, cultural evolution.

Biological determinist theories of human nature contrast sharply in content with their pre-Darwinian counterparts, but they are often inspired by the same motivation of discovering universal and unchanging social values. Typically, they describe as *natural* aspects of behavior thought to be biologically determined; though few would assert that natural behavior is always to be encouraged or even permitted, characterizing some behavioral tendencies as natural provides a certain legitimation for them. Because they are understood as resulting from natural selection, such tendencies are regarded as having been necessary at least at some time for human survival; in consequence, they cannot be entirely deplored, and they may even be romanticized as clues to a more *natural* way of life. Thus, biological determinist approaches to understanding and evaluating human nature may be seen as secular analogues of Aquinas's theory of natural law.

It may be the social function of biological determinist theories of human nature, rather than their scientific credentials, that accounts for their continuing popularity. Put simply, these theories tend to rationalize existing manifestations of aggression and inequality: Biological determinist analyses of violence, war, and crime tend to deflect attention from the social and economic causes of these phenomena, just as theories about the biological determinants of male and female behavior distract us from the ways in which men and women are socialized for their respective roles. The implication often drawn from biological determinist theories is that significant social movement in the direction of peaceful cooperation and equality is impossible because it is alleged to go against *human nature.* Clearly, those in power benefit from such an assumption and are likely to encourage the development of such theories.

Behaviorism: Another Form of Post-Darwinian Reductionism

The Western materialist or naturalist tradition has not always moved in a biological determinist direction. It also includes thinkers who claim that environmental or cultural factors are the primary determinants of the human mind or behavior. The philosopher John Locke (1632–1704) saw the human mind as a kind of blank tablet to be written upon by sensory impressions, while Enlightenment figures like Helvétius assumed that education could shape human beings into almost any form.

In the first part of the twentieth century, environmentalist ideas became popular in the United States through a psychological movement known as behaviorism. John B. Watson (1878–1958), who first systematically developed the theory, insisted that in order for psychology to become a rigorous experimental science, it must give up its introspective orientation. It should no longer take its task to be analyzing private mental states, such as feelings, desires, and thoughts, but instead should study the relation between publicly observable behavior and the environment. For Watson, the two basic forms of this relation were the *unconditioned* and the *conditioned reflex.* The former was the basic human physiological endowment, consisting of automatic responses to environmental stimuli, such as salivating in the presence of food and contracting pupils in the presence of light. Watson based his analysis of the conditioned reflex on the work of the Russian experimental psychologist Ivan Petrovich Pavlov (1849–1936), who had demonstrated that a hungry dog, repeatedly presented with both food and the ringing of a bell, would eventually salivate at only the bell-ringing. The sound of the bell had become a *substitute stimulus,* and the salivation was now a *conditioned response.* For Watson, all human behavior could be reduced to these two kinds of reflexes.

Watson's version of behaviorism was superseded by that of B. F. Skinner (1904–1990), who argued that reflex action could account for only a small part of human behavior. For Skinner, human behavior was primarily shaped by what he called *operant conditioning,* which *reinforced* certain spontaneous movements of the organism. For example, when a pigeon raised its head above a certain height and food was released into its cage, the result was a higher frequency of that behavior. Unlike the stimulus in Watson's model, the "reinforcer" (the food) was introduced *after* the "response" (the raising of the head to the desired height) occurred. For Skinner, most human behavior other than automatic reflex action, even human language, could be explained as the result of *positive* or *negative reinforcement,* which, by adding something to the situation (food, sex, money, praise, etc.)—or by removing something from it—increased the frequency of some behavior. While not denying that feelings and thoughts existed, Skinner refused to characterize them as residing in a special mental domain, consciousness, and claimed that they had no causal effect on human behavior (Skinner, 1953).

Both Watson and Skinner believed that human beings could be conditioned to develop almost any pattern of behavioral responses. Watson boldly declared that he could take almost any infant "at random and train him to become … doctor, lawyer, artist, merchant-chief, and, yes, even a beggar man and thief." Skinner insisted that operant conditioning "shapes behavior as a sculptor shapes a lump of clay." One evident consequence of the behaviorist program was that human freedom was an illusion. For Skinner, in particular, such concepts as freedom, moral responsibility, and human dignity were the conceits of a prescientific age (Skinner, 1973).

Behaviorism, just as much as biological determinism, is heir to the evolutionary paradigm because human behavior is still explained in terms of genetic dispositions regarded as having survival value. For behaviorism, however, these predispositions are not instincts or drives. Instead, specific unconditioned reflexes have evolved in the human species because they have survival value, while the human organism's susceptibility to conditioning helps it survive by allowing it to adapt to environmental changes more rapidly than its genetic structure could.

There are a number of difficulties with the behaviorist conception of human nature. First are the primary data of consciousness, such as desires, feelings, reflection, and decision making; it is hard to believe that these do not have at least some causal influence on human activity. Second, the fact that pigeons, rats, and human beings can sometimes be controlled by operant conditioning does not mean that all human behavior can be understood in this way. Linguist Noam Chomsky (1928–), for example, has argued against Skinner that linguistic competence requires creativity that goes beyond responses to prior conditioning because we are constantly constructing sentences that we have never before encountered. Finally, there is no room in the behaviorist model for human agency: The environment acts, human beings merely react. In this, behaviorism may be seen as ideologically reflecting a world in which people are continually managed and manipulated by technocratic and bureaucratic elites.

Social and Historical Conceptions of Human Nature

Social and historical conceptions of human nature offer an alternative to seeing human beings either as primarily determined by their biological drives or as passive clay to be molded by their physical and social environment. These approaches, while not ignoring human biology or the role of social conditioning, emphasize the importance of human social activity within specific historical contexts. The work of the revolutionary social theorist Karl Marx, together with his collaborator Friedrich Engels (1820–1895), and of the U.S. pragmatist philosopher John Dewey, provides two examples of this approach.

Marx and Engels's view of human nature (Schmitt) was embedded in their more general theory of human history, *historical materialism.* Human history, they contended, began with humans' attempt to satisfy their basic biological needs through producing their means of subsistence, so that human beings were, first and foremost, producers. Human production differed from that of nonhuman animals in that it was deliberate rather than instinctive, involving imagination, planning, and tool use. It was also inherently social, not only in requiring the coordination of human effort but also in utilizing skills and knowledge transmitted from one individual, group, or generation to another. In societies producing a surplus beyond that needed for immediate survival, human production typically involved a division of labor going beyond a division into separate tasks, to a division between intellectual and physical work and between work considered appropriate for men and for women. Most important for Marx and Engels was the class division of labor between those groups who owned the means of production and those who had to work for them, a division generating the class struggles regarded by Marx and Engels as the motor force in history.

Different economic systems, or what Marx and Engels called modes of production, established forms of social life through which human beings individuated and understood themselves. Peasants and artisans, ladies and gentlemen, merchants and professionals, corporate capitalists and industrial workers would tend to think and act differently from each other. Changes in the mode of production would generate new forms of social life, new ways of understanding the world, and new ways of thinking and acting—in effect, new kinds of *individuals.* Thus, human nature itself would change. Since human beings were active in the class struggle that caused these social and economic changes, however, it could also be said that human beings actively changed their own natures over the course of history.

For John Dewey, as for Marx and Engels, human beings were neither governed by instincts nor passive recipients of environmental forces; rather, they were social agents who changed their own natures in the process of changing their societal conditions. However, in contrast to Marx and Engels, Dewey regarded the motor force of social change not as class struggle but as the product of reflective intelligence.

Dewey acknowledged that human beings had instincts—or impulses, as he preferred to call them in order to discourage associations of inflexibility. Impulses, in his view, were extremely flexible in that they could take on a variety of meanings, depending on the social context. Thus, the impulse of fear might become cowardice, caution, reverence, or respect; while the impulse of anger might become rage, sullenness, annoyance, or indignation. Impulses took on these meanings as habits, predispositions to certain kinds of thinking and acting, ultimately embodied in social customs and institutions. The content of these habits constituted our historical nature. However, when the habits proved inadequate to new social problems, humans could employ their reflective intelligence to redirect their impulses into new habits. For example, as war became increasingly problematic or as certain economic institutions become increasingly outmoded, human impulses could be rechanneled, creating new institutions embodying new habits.

To make sense of the claim that human nature changes, we need to remember the distinction between transhistorical and historical conceptions of human nature. For both Dewey and Marx, it is precisely because a certain transhistorical human nature exists—socially productive and reflectively intelligent—that the content of human nature can be changed historically. To put this point in a more contemporary idiom: Our distinctively human capacity to transform social institutions transforms social roles and, in so doing, transforms historically specific character structures.

Giving more weight to the social and historical aspects of human nature offers a new model of the relation between genetic determination and social conditioning, on the one hand, and social behavior, on the other. What is determined by our genes is our capacity to learn, reflect, and work for change. Humans can, thus, be agents of their own history. Biology determines certain potentialities, but it is only through concrete historical activities that humans develop certain specific cultural and psychological characteristics. Genes dictate the ability to develop general modes of response, such as learning languages, engaging in productive labor, and developing forms of social relatedness; but they do not dictate that humans learn English, produce nuclear weapons, or become selfish and competitive as opposed to altruistic and cooperative. Thus, historical and social conceptions of human nature do not deny biology but refuse to privilege it as the primary cause of human action. Similarly, they do not deny conditioning but equally refuse to privilege it in explaining human action. Certain social conditions undoubtedly encourage the development of certain habits, but these are not merely behavioral responses; instead, they are social patterns of meaning that connect thought to action. Furthermore, human beings do not merely react to social conditions but individuate themselves within them and can reflect intelligently on them. Thus, both individually and collectively humans can decide to change their habits and work to transform the social conditions from which they arose.

A Social and Historical Conception of the Human Body

Although many theorists are willing to acknowledge that people's character or personality or behavior is socially shaped, at least to some degree, the biological constitution, the body, is often viewed as a presocial given, the universal and unchanging foundation on which elaborate cultural edifices are erected. According to this way of thinking, the body constitutes the most natural aspect of human nature. Itself a product of natural selection, the body sets the *natural,* that is, biologically determined, limits of social variability.

While it may be true that there is less systematic cross-cultural and transhistorical variation in people's bodies than there is in their personalities and social institutions, it is too simple to regard the human body as a presocial given. Although the human body may sometimes be experienced as a given, in fact, like the mind or the personality, bodies are socially and historically shaped on several levels.

It is not difficult to recognize some of the ways in which human bodies are influenced by their social context. Different kinds of work and living conditions develop or distort the body in various ways. For instance, scarcity of food results in stunted growth, so that body size and development vary systematically not only between cultures but often also between social classes. While many of these bodily marks are unintended side effects of social practices, others are deliberately induced. Social norms are consciously inscribed on the body in a variety of ways, ranging from foot-binding and circumcision to diet clinics and cosmetic surgery. The varying social meanings assigned to bodily characteristics and functions influence a person's experience of his or her body, which, depending on the social context, may become a source of pride, joy, pain, or embarrassment.

Social influences on the human body operate not only on the level of observable physical structure, the phenotype; in the past, they have also influenced the genotype, our genetic inheritance, and they continue to do so. While human prehistory is highly speculative, it seems likely that some genetically heritable characteristics have been selected not only *naturally,* as adaptive to such nonsocial circumstances as climate and food availability; but also socially, as adaptive to certain forms of social organization or perhaps even as the results of conscious social preferences. For instance, the average size difference between human males and females may have been a consequence as much as a cause of male dominance: If the dominant males fed first and most, only smaller-framed women could survive on the leftover food. Even today, the human gene pool continues to be influenced by social factors. For instance, exposure to environmental pollutants sometimes leads to genetic mutations, and modern medicine now makes it possible for people to survive and reproduce with genetic conditions that otherwise would have led to their early deaths. Finally, genetic engineering is rapidly becoming a real possibility.

The recognition that even the genetic constitution is influenced by social factors has far-reaching consequences for understanding human nature. The point is not simply that most versions of biological determinism are false because they fail to give sufficient weight to the social determinants of human characteristics. It is, rather, that the usefulness of the whole nature-culture distinction as an analytical framework for understanding human beings comes into question. Just as we cannot identify any cultural or social phenomena uninfluenced in some way by human biology, neither can we identify any human biological or *natural* features that are independent of social influence. The biological and the social are so intertwined in the human past and present that it becomes impossible in principle to distinguish the natural from the social or cultural components in the constitution of human beings. As far as human beings are concerned, the relation between nature and culture is mutually constitutive: To oppose one to the other is incomprehensible. Everything that we are and do is revealed as simultaneously cultural and natural.

Ethical Implications for the Life Sciences: A Cautionary Tale

What are the bioethical implications of these various conceptions of human nature? First, a cautionary note. Practical ethics reflects on a host of considerations in practical contexts and cannot simply deduce specific moral conclusions from general ethical principles, let alone from some general conception of human nature. Thus, the relation between the various conceptions of human nature and any specific bioethical position is unlikely to be one of logical entailment. This does not mean, however, that concepts of human nature have no relevance to bioethical issues. They may serve as starting points for bioethical analysis, raise suspicions about certain bioethical claims, or even rule out certain bioethical positions. In general, certain conceptions of human nature may be said to cohere, or provide a better *fit,* with certain bioethical stances than with others.

The dominant pre-Darwinian conceptions of human nature view physical nature, including the human body, as the realm of the material, the immanent, and the profane, and identify God with the spiritual, the transcendent, and the sacred. It is only because human beings are endowed with a soul that they are regarded as capable of partaking in the sacred, and their mission is to transcend their bodies and realize their spiritual nature. Insofar as they are part of God's creation, nonhuman animals are sometimes assigned a degree of moral worth, but the view that they lack souls typically rationalizes the claim that nonhuman animals are merely resources to serve human purposes. Saint Francis of Assisi notwithstanding, the dominant view of the Judeo-Christian tradition is that God created nonhuman animals and, indeed, all of nonhuman nature, primarily for the use of human beings. This sharp bifurcation between human and nonhuman nature not only permits but even legitimates the human subjugation and exploitation of all nonhuman nature, and may therefore contribute to the contemporary ecological crisis.

Within this ontology, the human body occupies a unique and somewhat ambiguous moral status. Although material, and therefore a source of temptation, the body is nevertheless sacrosanct because it is indispensable to human life. God is thought to have a divine plan for humanity, and any attempt to subvert this plan by tinkering with the human body is regarded as at least prima facie wrong. When applied to humans as opposed to nonhuman animals, therefore, reproductive technology, genetic engineering, and euthanasia are viewed with suspicion, if not censure; and *brain death* may not be considered sufficient reason to switch off a life-support system, depending on when the soul is believed to leave the body. If, for example, the soul is thought to remain in the body until the last breath of life, then euthanasia can never be justified: Even the suffering and dying body must be revered as the house of the soul. Finally, because humans are morally distinguished by the possession of a soul, abortion is condemned at whatever point the fetus is believed to acquire a soul. It is interesting to note that the Catholic Church has not always held that fetal ensoulment occurs at the moment of conception: Saint Thomas Aquinas, for instance, argued as an Aristotelian that the fetus did not have a soul until it assumed human form, which he thought occurred after three months' gestation for the male fetus and six months' for the female.

In contrast with the pre-Darwinian dichotomies between human and nature, spiritual and material, sacred and profane, post-Darwinian conceptions of human nature posit an evolutionary continuity between human and nonhuman animals. This continuity is sometimes used as a basis for moral challenges to the human exploitation and domination of animals, especially animals that are close to human beings in evolutionary terms. It is precisely those nonhuman animals most like humans, however, that are most useful for many purposes, such as medical experiments and organ transplants; in consequence, some philosophers have sought to undercut moral challenges to the human exploitation of nonhuman animals by arguing that beings *lower* on the evolutionary scale may be sacrificed for the good of *higher* species. Opposing this position is a growing minority in the bioethics community that argues that such a position is an example of unwarranted human chauvinism or *speciesism,* a term invoked to suggest parallels with racism and sexism.

Although post-Darwinian assumptions of an evolutionary continuity between humans and nonanimals may be used to challenge the view that animals are simply a resource for human use, they have also been used to justify radical interventions in human life processes. If it is legitimate to experiment on nonhuman animals, for instance, it may be equally legitimate to experiment on human beings. If *Homo sapiens* is the accidental outcome of natural selection, if there is no inherent purpose for which we are created, then there is no a priori reason to assume that further modifications in human biological processes should not be made via reproductive technologies or even genetic engineering. Since the human nervous system is a defining component of human life, the fetus at an early stage of brain development is likely to have a different moral status than it does once the brain has developed. Certainly, the post-Darwinian conception of human nature would generally assume that *brain dead* means dead.

These conclusions reflect the absence of the concept of a soul in post-Darwinian views of human nature, since it was the soul that, in earlier conceptions, provided the philosophical grounding for human dignity. Unless an adequate substitute for the concept of the soul can be found, post-Darwinian conceptions of human nature may permit the drastic manipulation of human beings. Behavior regarded as undesirable may be treated either as a biological abnormality or as a failure of social conditioning. Biological determinists may regard alcoholism, addictive gambling, violent criminal behavior, schizophrenia, depression, and even homosexuality as candidates for treatment with a variety of biological techniques: psychosurgery, shock therapy, hormonal therapy, psychopharmacological interventions, and perhaps, in the future, even genetic manipulation. Behaviorists, of course, emphasize the use of various conditioning techniques to modify human behavior, raising the prospect of a *Clockwork Orange* world. Skinner, in fact, wrote a utopian novel, *Walden Two* (1948), in which behavioral managers conditioned people from birth to make choices in accord with the goals and institutions of that society. Both biological and behavioral interventions often work toward the same goal—direct control of human behavior.

But who will control the controllers, and how far will such control be allowed to extend? There are already biological determinists who advocate the use of genetic manipulation to raise IQ or to alter certain *undesirable* tendencies in the human species, perhaps to create a Superman. Others would clone the embryo and store it for future use, perhaps in case of some failure of the original stock. Brave New World may be just around the corner unless we can reclaim the concept of human dignity. Social and historical conceptions of human nature offer a secular basis for doing so.

Although people who accept a social and historical conception of human nature may still utilize some concept of naturalness in describing various human activities, such as conceiving or giving birth, they recognize that what is taken to be natural or unnatural changes historically and culturally, so that ethical decisions cannot be grounded in some unchangeable concept of human nature. However, this does not prevent us from ethically evaluating various attempts to manipulate and control human nature. Indeed, those who accept social and historical conceptions of human nature are likely to urge caution in the use of biological interventions and conditioning techniques for the purposes of altering human behavior. They will be suspicious of all treatment and research modalities that fail to respect human agency, reflective intelligence, and decision-making capabilities, since it is precisely these transhistorical capacities that make possible the continuous transformation of our historical natures. In short, social and historical conceptions of human nature will tend to reaffirm the concept of human dignity. In the sphere of medicine, for instance, they are likely to insist on the dignity of medical subjects and emphasize informed consent and coparticipation in physician-patient relationships.

The recognition that human beings individuate themselves within and through social processes may also have implications for the abortion controversy; at the very least, it suggests that women and fetuses cannot have the same moral status. Moreover, social and historical conceptions of human nature emphasize that consideration of bioethical problems must be sensitive to concrete social and political contexts; in a society with an expressed commitment to human equality, for example, questions like procreative technology or contract parenting must be evaluated with special reference to their implications for people of different classes, genders, abilities, races, and ethnicities. Finally, social and historical conceptions regard human beings as transhistorically creative, productive, social, and capable of reforming their habits through reflective intelligence; and people who accept these conceptions are likely to valorize those capacities and seek to develop social institutions—including healthcare, psychiatric, and research institutions—through which they would be enhanced.

The open-ended nature of these last implications serves as a reminder that ethical conclusions are not strictly entailed by any general conception of human nature, especially by social and historical conceptions. In addressing particular bioethical problems, therefore, the values implicit in these conceptions must be supplemented by explicitly ethical criteria, such as historically specific understandings of justice, freedom, and human well-being.

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SEE ALSO: *Behaviorism; Enhancement Uses of Medical Technology; Eugenics; Freedom and Free Will; Genetics and Human Behavior; Genetics and Human Self-Understanding; Human Dignity; Natural Law; Nanotechnology; Transhumanism and Posthumanism*

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HUMAN RIGHTS

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Human rights constitute a set of norms governing the treatment of individuals and groups by states and nonstate actors on the basis of ethical principles incorporated into national and international legal systems. Because the subject matter of the norms in question relate to the treatment of human beings, human rights overlap to a considerable degree with ethics, but they nevertheless should not be confused with ethics. Similarly, because human rights include the right to health and refer to essential social determinants of health and well-being of people, they overlap with many principles and norms of bioethics. Human rights and bioethics differ, however, in scope, sources, legal nature, and the mechanisms of monitoring and applying the norms.

The *scope* of bioethics is the ethical issues arising from healthcare and biomedical sciences, whereas that of human rights embraces the claims individuals and groups can legitimately make against states and nonstate actors to respect their dignity, integrity, autonomy, and freedom of action as defined in an officially endorsed set of standards or norms. Bioethics regulates clinical encounters with patients on the basis of principles; human rights, by contrast, are the special rules agreed upon in a given society to achieve justice and well-being.

The *source* of human rights is the norm-creating process of national and international legal systems, whereas that of bioethics is the deliberations and published opinions of leading thinkers, constituted review boards, and professional associations on the health-related ethical issues they address. Bioethics and human rights share an ethical concern for just behavior, built on empathy or altruism. The proximate formal source of human rights is typically an international human rights treaty or declaration while that of bioethics is a professional code or review board guidelines. The proximate source occasionally is identical, as when an instrument of international law directly addresses an issue of bioethics and human rights, for example, in the United Nations Educational, Scientific and Cultural Organization’s (UNESCO) Universal Declaration on the Human Genome and Human Rights or the Council of Europe’s Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine, both of which were adopted in 1997.

The *legal nature* of human rights norms ranges from merely aspirational claims to justiciable and enforceable legally binding obligations. An important distinction is made between *rights* and *human rights.* In ethics a right refers to any entitlement, the moral validity or legitimacy of which depends on the mode of moral reasoning the ethicist is using. In law, a right is any legally protected interest. In human rights discourse, a human right is a higher-order right authoritatively defined using the expression *human rights* with the expectation that such a right carries a peremptory character and thus prevails over other (ordinary) rights. Another distinction is between the natural law and positive law foundations of human rights. The former refers to rights deriving from the natural order or divine origin, which are inalienable, immutable, and absolute, whereas in positive law rights are recognized through a political and legal process that results in a declaration, law, treaty, or other normative instrument. These may vary over time and be subject to derogations or limitations designed to optimize respect for human rights rather than impose an absolute standard. Human rights emerge from claims of people suffering injustice and thus are based on moral sentiment, culturally determined by contextualized moral and religious belief systems. They become part of the social order when an authoritative body proclaims them, and they attain a higher degree of universality based on the participation of virtually every nation in the norm-creating process, a process that is law-based but that reflects compromise and historical shifts. The International Bill of Human Rights (consisting of the Universal Declaration of Human Rights [UDHR] of 1948 and the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, both of 1966), along with the other human rights treaties of the United Nations (UN) and of regional organizations, constitute the primary sources and reference points for what properly belongs in the category of human rights.

The *methods of monitoring compliance* with human rights include moral judgments made with reference to recognized human rights, quasi-judicial procedures of investigation and fact-finding leading to official pronouncements of political bodies, and enforceable judicial decisions. The parallel methods of bioethics focus more on codes of bioethics and official pronouncements of professional bodies that may result in altering research design or the behavior or liability of health professionals in their relations with patients or in policies affecting the health of populations.

The overlap of human rights and bioethical discourse and the differences between the two become clearer as one clarifies the following: the emergence of human rights in political and legal discourse, the content of the right to health as defined in human rights instruments, the other human rights as they relate to health and well-being, and the role and means of promotion and protection of human rights.

Emergence of Human Rights

The early formulation of the norms that are characterized today as human rights is inseparable from historical and philosophical manifestations of human striving for justice. Ultimately, human rights certainly derive from basic human instincts of survival of the species and behavior of empathy and altruism that evolutionary biology is only beginning to understand. Since human evolution is driven by reproductive selfishness, one could wonder why the human species would develop any ethical system, like that of human rights, according to which individuals manifest feeling for the suffering of others (empathy) and—even more surprising—act in self-sacrificing ways for the benefit of others without achieving any noticeable reproductive advantage. And yet, as Paul Ehrlich notes in *Human Natures*, “empathy and altruism often exist where the chances for any return for the altruist are nil” (p. 312). Natural selection does not provide the answer to moral behavior as “there aren’t enough genes to code the various required behaviors” but rather “cultural evolution is the source of ethics” (p. 317) and therefore of human rights.

Religion and law have an ambiguous role in this historical process. The history of religions is replete with advances in the moral principles of behavior—many of which directly influenced the drafting of human rights texts—but also in crimes committed in the name of a Supreme Being. Similarly, the emergence of the rule of law has been critical both to advancing justice and human rights against the arbitrary usurpation of power in most societies and to preserving the impunity of oppressors.

Scholars trace the current configuration of international human rights norms and procedures to the revolutions of freedom and equality that transformed governments across Europe and North America in the eighteenth century and that liberated subjugated people from slavery and colonial domination in the nineteenth and twentieth centuries. Enlightenment philosophers derived the centrality of the individual from their theories of the state of nature. Social contractarians, especially the eighteenth-century French philosopher Jean-Jacques Rousseau, predicated the authority of the state on its capacity to achieve the optimum enjoyment of natural rights, that is, of rights inherent in each individual irrespective of birth or status. Rousseau wrote in *A Discourse on the Origin of Inequality* (1755) that “it is plainly contrary to the law of nature … that the privileged few should gorge themselves with superfluities, while the starving multitude are in want of the bare necessities of life” (p. 117). Equally important was the concept of the universalized individual (“the rights of Man”), reflected in the political thinking of Immanuel Kant, John Locke, Thomas Paine, and the authors of the French and American declarations. Much of this natural law tradition is secularized in contemporary human rights.

World War II was the defining event for the internationalization of human rights, with the latter anticipated by Roosevelt’s “Four Freedoms” speech (1941), confirmed by the inclusion of human rights in the UN Charter (1945), and applied at the trial of Nazi doctors, leading to the

Nuremberg Code (1946). In the war's immediate aftermath, bedrock human rights texts were adopted: the Genocide Convention and the UDHR in 1948 and the Geneva Conventions in 1949, followed in 1966 by the two international covenants. Nongovernmental organizations (NGOs) played a role in all these developments and in subsequent drafting of treaties, as well as in the creation of investigative and accountability procedures at the intergovernmental level and at the national level. These processes were instrumental in bringing down South African apartheid, transforming East-Central Europe, and restoring democracy in Latin America. Human rights NGOs are now active on all continents.

The Normative Content of Human Rights: The Right to Health

The current catalogue of human rights consists of some fifty normative propositions. They are enumerated in the international bill of human rights, extended by a score of specialized UN treaties, a half-dozen regional human rights treaties, and hundreds of international normative instruments in the fields of labor, refugees, armed conflict, and criminal law.

The meaning, scope, and practical significance of the right to health are particularly relevant for bioethics. The right to health as understood in international human rights law is defined in article 25 of the 1948 Universal Declaration of Human Rights ("Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services.") and in article 12 of the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR) ("the right of everyone to the enjoyment of the highest attainable standard of physical and mental health"). Variations on these definitions are found in most of the core UN and regional human rights treaties. In 2000 the Committee on Economic, Social and Cultural Rights (CESCR), which was created to monitor the ICESCR, analyzed the normative content of the right to health in terms of availability, accessibility, appropriateness, and quality of care and specified the duties of the state to respect, protect, and provide this right. The committee also listed fourteen human rights as "integral components of the right to health." These related rights define to a large extent the determinants of health.

The right to health does not mean the right to be healthy, because being healthy is determined only in part by healthcare; it is also determined by genetic predisposition and social factors. The field of social epidemiology has excelled at establishing correlations between discrimination based on race, class, or gender, denial of education and of decent working conditions, as well as other factors that contribute directly to increased rates of mortality and morbidity. These social determinants may also be defined in human rights terms as deprivation of these health-related rights, which are among the most salient social factors that contribute to healthy lives. The summary below seeks to underscore the function of human rights as determinants of health by highlighting their normative content and their relation to health.

Health-Related Human Rights

Health is profoundly related to human rights both because human right violations have health impacts—such as those on torture survivors—and because human rights concern the dignity, integrity, autonomy of action, and conditions of social functioning of people. Some examples will be provided in each of these areas.

Foremost among the human rights relating to physical and mental integrity is the right not to be arbitrarily deprived of life, which does not rule out death resulting from lawful acts of warfare or capital punishment, although international humanitarian law limits the former, and newer protocols and regional conventions, supported by UN resolutions and social movements, define the latter as a violation of human rights. Special treaties and procedures exist for prevention and repression of torture, disappearance, summary and extrajudicial execution, crimes against humanity, genocide, slavery, racial discrimination, and various forms of terrorism. Most of these are also dealt with in international humanitarian law, which was established to protect victims of armed conflict (injured and shipwrecked combatants, prisoners of war, and civilian populations notably under occupation) and codified in the four Geneva Conventions of 1949 and the Additional Protocols of 1977.

The right to "a standard of living adequate for the health and well-being" of oneself and one's family was defined in the UDHR as including "food, clothing, housing and medical care and necessary social services" as well as "the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond [one's] control." Subsequently, the rights to health, work, safe and healthy working conditions (occupational health), adequate food and protection from malnutrition and famine, adequate housing, and social security (that is, a regime covering long-term disability, old age, unemployment, and other conditions) have been further elaborated by the International Labour Organisation, the UN Commission on Human Rights, and the work of special rapporteurs and treaty bodies.

Dignity tends to be mentioned as both the basis for all human rights and a right per se. The great civil liberties—freedom of oral and written expression, freedom of conscience, opinion, religion, or belief—as well as freedom from arbitrary detention or arrest, rights to a fair hearing and an effective remedy for violations of human rights, and protection of privacy in domicile and correspondence, all support the autonomy of individuals to act without interference from the state or others. A separate but related human right is that of informed consent to medical experimentation, which was included in post-1945 enumerations of rights because of the extensive abuse of that right during World War II.

Equality and nondiscrimination are human rights that are at the same time principles for the application of all other human rights, because they require that all persons be treated equally in the enjoyment of their human rights and that measures be taken to remove discriminatory practices on prohibited grounds. Freedom of movement means the right to reside where one pleases and to leave any country, including one's own, and to return to one's country. The right to seek and enjoy asylum from persecution is also a human right, which has been developed and expanded by international refugee law, the practice of the UN High Commissioner for Refugees, and recent codes relating to internally displaced persons. This right, like many others, is not absolute; limitations may be imposed, for example, in time of epidemic, as long as certain safeguards, defined in human rights law, are observed.

Social well-being depends in large measure on group identity, education, family, culture, political and cultural participation, gender and reproductive rights, scientific activity, the environment, and development, all of which are the subject of specific human rights. The basic human rights texts affirm a limited number of group rights, notably the rights of *peoples* to self-determination, that is in the terms of the ICCPR and the ICESCR, to "determine their political status and freely pursue their economic, social and cultural development" and to permanent sovereignty over natural resources. They also enumerate the rights of persons belonging to minorities to practice their religion, enjoy their culture, and use their language. Indigenous peoples have defined rights that take into account their culture and special relation to the land.

The right to education is defined in the ICESCR and by the CESCR, as well as specialized instruments of UNESCO. Other rights of the child have been codified in the 1989 Convention on the Rights of the Child. Political rights include the right to run for office and to vote in genuine and periodic elections. Cultural rights refer primarily to the right to participate in the cultural life of the community; the protection of writers, artists, and performers; and the preservation of cultural heritage.

Health issues loom large in human rights standard-setting and policy determination regarding gender and sexual and reproductive rights. The basic human rights texts have been supplemented by a specialized Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) of 1979. Considerable advances in mainstreaming women's rights as human rights were made at international conferences, a 1993 Declaration on Violence against Women, the work of a special rapporteur on this problem, and statements and programs on traditional practices harmful to health, such as female genital mutilation. Reproductive rights include the right of "men and women … to decide freely and responsibly on the number and spacing of their children" (CEDAW, article 16) and "to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice" (ICPD 1994). Various internationally approved programs and plans of action have set out in considerable detail the specific ways in which this right can be realized.

Bioethical concerns overlap with human rights with respect to the right to enjoy the benefits of scientific progress and rights in scientific research. The former refers to the positive and equitable use of scientific advances, while the latter protect freedom to conduct research and disseminate results and the requirement of informed consent of human subjects.

Occasionally, scholars refer to solidarity or third-generation rights to certain global values such as peace, a healthy environment, development, communication, and humanitarian intervention or assistance. Two rights in this category have become more systematically developed and enshrined in authoritative texts: the rights to a healthy environment and to development. The former has been recognized in many national constitutions and in the regional human rights texts. The latter has been recognized in numerous UN resolutions and specifically in a 1986 declaration, as well as in the African Charter on Human and Peoples' Rights. The 1986 Declaration on the Right to Development defines the right to development as "an inalienable human right by virtue of which every human person and all peoples are entitled to participate in, contribute to, and enjoy economic, social, cultural and political development, in which all human rights and fundamental freedoms can be fully realized."

Finally, article 28 of the UDHR proclaims the right of everyone to "a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized." This right is perhaps the broadest but also the most significant in making human rights the ordering criterion for national societies and international relations. The required social order suggests a democratic constitutional regime in which human rights of all categories are recognized in law and effectively observed in practice. It also suggests that international relations provide support for global efforts to further human rights and to establish means of accountability for persons and groups to obtain redress from countries that fail to fulfill their human rights obligations.

The Enforcement and Implementation of Human Rights

The term *enforcement* refers to coerced compliance, whereas *implementation* refers to supervision, monitoring, and the general effort to hold duty-holders accountable. Implementation is further subdivided into promotion—preventive measures to ensure respect for human rights in the future—and protection—responses to violations that have occurred in the past. The means and methods of implementation may be summarized in three forms of promotion and five forms of protection.

Promotion of human rights is achieved through developing awareness, standard-setting and interpretation, and creating national institutions. Awareness of human rights is a precondition to acting on them and is advanced though dissemination of knowledge and human rights education at all levels, for which the UN proclaimed a decade of action for the period from 1995 to 2004. Standard-setting means the drafting of human rights texts, for which the UN Commission on Human Rights, established in 1946, plays a central role, along with other UN and regional organizations. These norms are interpreted by various international courts and treaty-monitoring bodies. The third preventive or promotional means of implementation is national institution-building, which includes improvements in the judiciary and law enforcement institutions and the creation of specialized bodies such as national commissions for human rights and offices of an ombudsman.

The *protection* of human rights involves a complex web of national and international mechanisms to monitor, judge, denounce, and coerce states, as well as to provide relief to victims. Monitoring compliance with international standards is carried out through the reporting and complaints procedures of the UN treaty bodies and regional human rights commissions and courts. Special procedures of working groups and special rapporteurs study countries or issues, taking on cases of alleged violations, reporting back on their findings, and requesting redress from governments. Among the *thematic* rapporteurs, one is specifically mandated to study the right to health, and others deal with a variety of health-related issues. The second means of protection is adjudication of cases by fully empowered human rights courts, the main ones being the European Court of Human Rights of the Council of Europe, the American Court of Human Rights of the Organization of American States (OAS), and the African Union's African Court of Human and Peoples' Rights, which was not yet functioning in mid-2003.

Political supervision refers to resolutions judging the policies and practices of states adopted by the Commission on Human Rights, the UN General Assembly, the Committee of Ministers of the Council of Europe, the Assembly of OAS, and other political bodies that denounce governments for violations of human rights and demand that they redress the situation or provide compensation to the victims.

The use of coercion is available only to the UN Security Council, which can use its powers under Chapter VII of the UN Charter to impose sanctions, cut off communications, create ad hoc criminal tribunals, and authorize the use of force by member states or the deployment of UN troops to put an end to a threat to international peace and security, which it has on occasion interpreted to include human rights violations (e.g., Haiti, Somalia, Bosnia, Iraq). This forceful means of protecting human rights is complex and dangerous and can have harmful health consequences, as has been the case with sanctions imposed on Haiti and Iraq. If used properly it can be a modern and legitimate form of the nineteenth-century doctrine of humanitarian intervention, according to which states use armed force to halt atrocities committed in another state while respecting the principles of necessity, proportionality, disinterestedness, and collegiality. The North Atlantic Treaty Organization (NATO) sought to employ such a doctrine in Kosovo in 1999 but without the necessary authorization from the Security Council engaged in what most scholars consider a legitimate but illegal use of force. Each case of action (e.g., no-fly zones over Iraq imposed in 1991) or inaction (e.g., Rwanda in 1994) regarding the use of armed force for human rights purposes has complex ethical and legal difficulties.

The final means of responding to human rights violations is through humanitarian relief or assistance. Provision of food, blankets, tents, medical and sanitary assistance, and other forms of aid saves lives and improves the health of persons forcibly displaced often as a result of large-scale human rights violations. Refugees and internally displaced persons come under the protection of the UN High Commissioner for Refugees (UNHCR), which deploys massive amounts of aid, along with the International Committee of the Red Cross, UNICEF, World Food Program (WFP), United Nations Development Programme (UNDP), the

UN Office for the Coordination of Humanitarian Affairs, and other agencies, as well as major NGOs such as Oxfam International, CARE, and the International Rescue Committee.

Conclusion

Every country in the world has accepted that human rights are universal, but all are challenged, in one way or another, to achieve progress with respect to those rights they neglect, however proud they may be of achievements with respect to other rights. Thus Cuba may be rightfully proud of its record on rights to health and education but is challenged to do more for political and civil rights; the United States may pride itself on the degree to which freedom of expression or civil rights are guaranteed but is challenged to take seriously economic, social, and cultural rights, including universal access to healthcare. The normative content of the corpus of human rights standards is probably the most complete catalogue of the determinants of physical, mental, and social well-being. The methods of implementation or intervention to ensure compliance are not directly linked to medical and health practice or to health policy, as is the case with bioethics. They nevertheless constitute a potentially rich framework for the improvement of health policy and practice, which is the objective of the emerging subfield of health and human rights.

STEPHEN P. MARKS

SEE ALSO: *Death Penalty; Ethics: Normative Ethical Theories; Genetic Discrimination; Harm; Human Nature; Justice; Law and Bioethics; Law and Morality; Natural Law; Pain and Suffering; Reproductive Technologies; Warfare; Women, Historical and Cultural Perspectives*

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Stephen G. Post
Editor in Chief

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I

IMMIGRATION, ETHICAL AND HEALTH ISSUES OF

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As of March 2000 it was estimated that approximately 10.4 percent of the United States population, or 28.4 million individuals, were immigrants. Prior to 1965 the majority of immigrants came from European countries, such as the United Kingdom, Greece, Poland, Portugal, Germany, and Ireland. Since then, however, an increasing number of immigrants has come from Latin American, Asian, and Caribbean countries, including El Salvador, Colombia, Vietnam, China, Haiti, and the Dominican Republic.

Individuals may seek to enter the United States for any number of reasons, including a desire to reunite with family members, the acceptance of a new employment opportunity, or a need to leave one's country of origin due to persecution. The majority of individuals entering the United States from other countries do so legally, through established immigration procedures. Others enter illegally, oftentimes in search of a safe haven from persecutors.

Findings relating to the health of immigrants have been inconsistent, in part due to reliance on different definitions of *immigrant.* For instance, some studies consider the health or illness of all foreign-born individuals, regardless of the legality or duration of their residence in the United States, while others may examine either the health of those who are here legally or of those who are here illegally (Loue and Bunce). Some studies have utilized the term *newcomers* to encompass those who are here permanently and temporarily, as well as those who are here legally and illegally (Smith). Refugees who are seeking safety from persecution within their own countries may be considered separately, or they may be included in broader discussions relating to immigrants.

Morbidity and Mortality

The risk of morbidity and mortality varies by immigrant group and by disease. In general, the health problems of immigrant populations mirror those that are prominent in the countries from which they have come. For instance, between 14 percent and 20 percent of Indo-Chinese refugees carry hepatitis B, and up to 15 percent of Southeast Asian refugees may be chronic carriers of the infection. This is not surprising in view of the fact that hepatitis B virus is endemic in many Asian countries (Tong and Hwang). During the period from 1986 through 1994, the rate of mycobacterium tuberculosis was four times higher among foreign-born individuals than among those born in the United States. Because more than half of the cases among the foreign-born were diagnosed less than five years after their arrival in the United States, it appears that imported tuberculosis is responsible for the majority of tuberculosis cases among immigrants in the United States (Zuber, McKenna, Binkin, et al.).

However, a number of studies have found that immigrants to the United States may experience lower rates of mortality than persons who remain in the sending countries. In addition, immigrants' risks of smoking, substance use, obesity, hypertension, and some forms of cancer are lower than the risks experienced by United States-born individuals of equivalent demographic and socioeconomic backgrounds. It has been hypothesized that this health advantage may result from a self-selection for immigration by healthier individuals (Swallen). However, for a number of immigrant groups, the risk of these illnesses appears to increase with increasing length of residence in the United States (Frisbie, Cho, and Hummer).

Immigrants may be at particularly high risk for a variety of occupationally related illnesses. Many may be able to find employment only in sweatshop-like conditions or in agricultural work where they may face continuous exposure to pesticides and herbicides, generally without adequate protection (Stephenson).

Women who immigrate to the United States may experience a number of gender-related health problems. Women may suffer significant trauma during their transit to the United States, including sexual assaults and forced labor (sometimes in the form of sexual slavery). Once they arrive in the United States, they may confront additional gender-related problems. For instance, many immigrant women are more willing than their male partners to accept low-paying jobs in order to support themselves and their families. Once they become wage earners, they may be introduced to North American conceptualizations of gender roles. Their male partners may, as a result of their own unemployment, feel threatened by what appears to be a shift in the power structure within the family due to their inability to earn a living and their partners' newfound independence. For some women, these changes in family structure have been associated with an increase in domestic violence. Still other immigrant women may become subject to abuse by spouses or boyfriends who are United States citizens or legal permanent residents. These men may have promised to file immigration papers on the women's behalf, but failed to do so. The women may be afraid to leave their abusive partners or to report their abusers to law enforcement authorities because of their own illegal status and the consequent fear of deportation. Often, the women may be financially, as well as legally, dependent on their abusers, so that it becomes difficult for them to leave these situations. Specific provisions in U.S. immigration law now permit abused immigrant women in such situations to file petitions on their own behalf so that they will not have to remain captives in abusive relationships.

Barriers to Care

Immigrants may be reluctant to rely on Western-style medicine due to differing traditions of symptom identification, diagnosis, and healing. Additional barriers are presented by language differences and the relative unavailability of competent interpreters, by transportation difficulties, and by providers' lack of familiarity with the healing beliefs and practices of their immigrant patients. For example, a study of the utilization of mental health services by a sample of Mexican Americans in Fresno County, California, found that those who were born outside of the United States had a utilization rate that was only two-fifths that of the Mexican Americans born in the United States (Vega, Kolody, Aguilar-Gaxiola et al.). This differential utilization rate may have been attributable to the nonexistence of Spanish-speaking mental health professionals, a lack of insurance, the lack of a regular doctor or course of care, or to physical isolation in rural areas.

Southeast Asian immigrants have been found to have the lowest levels of Pap testing of any racial or ethnic group in the United States. A recent study of Cambodian immigrants found that barriers to the use of the Pap test included a traditional orientation to the prevention, causation, and treatment of disease; a lack of familiarity with Western concepts of early disease detection; low levels of knowledge about cervical cancer; concerns about the Pap test procedure; and difficulties with transportation and language interpretation (Jackson, Taylor, Chitnarong et al.).

Immigrants, both those who are in the United States legally and those who are not, must often confront a patchwork of federal programs that, despite their number and complexity, often do not assure access to necessary care. The Centers for Disease Control and Prevention (CDC) oversee specific programs for infectious diseases. The CDC is also responsible for the review of applications for waivers from those immigrants seeking legal entry who may be excludable from the United States pursuant to legal provisions prohibiting the entry of those with specified diseases, such as active tuberculosis, various sexually transmitted diseases, and various forms of mental illness. The Office of Refugee Resettlement of the U.S. Department of Health and Human Services provides funds to the CDC to oversee the infectious disease programs. The Migrant Health Program also provides some funding for preventive services and immunizations.

Numerous federal and state laws place restrictions on immigrants' ability to access care that is publicly funded. In 1994, for instance, California's Proposition 187 severely curtailed the ability of individuals who were in the United States illegally to obtain publicly funded care and required that specified agencies and healthcare professionals report these individuals' presence to the Immigration and Naturalization Service. Although numerous portions of the law were ultimately found by the courts to be unconstitutional, researchers noted a 5 percent decrease in the number of clients appearing at clinics for the diagnosis and treatment of sexually transmitted disease immediately following the law's passage (the law was not implemented because it was immediately enjoined by the court). Approximately 25 percent of these individuals indicated that they were in the country illegally (Hu, Donovan, Ford, et al.). A similar decrease was noted in the number of individuals presenting for other medical services (Marx, Thach, Grayson, et al.). The possibility that physicians and other healthcare professionals would report their patients' illegal presence to government authorities raised significant ethical concerns about the imposition of conflicting loyalties, the breach of physician–patient confidentiality that would attend such reporting, and the potential threat to public health as a result of delays in seeking care due to fear of disclosure (Ziv and Lo).

Despite several amendments since their original passage, the provisions of the 1996 Personal Responsibility and Work Opportunity Reconciliation Act (commonly known as the Welfare Reform Act) and the Illegal Immigration Reform and Immigrant Responsibility Act (IIRAIRA) continue to severely restrict the ability of even legal immigrants to rely on publicly funded medical services, apart from emergency medical needs and the diagnosis and treatment of specified infectious diseases. The legislation has engendered significant controversy because many of the immigrants who are denied publicly funded care, such as Medicaid, actually pay into the system through their taxes. In addition, many states have not adopted state legislation that would permit immigrants to rely on publicly funded care when they do not have privately funded health insurance. This is particularly problematic for women of childbearing age, who may not have the funds or the private insurance to cover the costs of prenatal care, labor and delivery services, or care for their newborns.

Within those states that have implemented legislation permitting immigrants to receive publicly funded care, many may still be denied access to recommended treatments. In New York, which has been one of the most forward-thinking states in the provision of publicly funded health services to immigrants, a panel consisting of physicians, medical ethicists, and AIDS advocates charged that physicians are withholding certain HIV-related treatment regimens from immigrant patients in the belief that they will not adhere to the recommended regimen (Newsline People AIDS Coalition New York).

Both the Welfare Reform Act and IIRAIRA limit the ability of immigrants, whether legal or not, to utilize other types of publicly funded services, such as food stamps. The impact of welfare reform has thus disproportionately affected immigrant groups. For instance, although noncitizens represented only 9 percent of the households receiving welfare, they accounted for 23 percent of the total decline in welfare caseloads following the enactment of these laws (Fix and Passel).

Healthcare providers also face difficulties due to the limitations imposed on access to public funds by federal laws. Hospitals are required by the federal Emergency Medical Treatment and Active Labor Act (1986) to provide emergency medical care to those presenting for such care, regardless of their legal status in the United States (Galloro). There may be an ethical, as well as a legal, responsibility to care for those presenting at emergency departments with life-threatening situations. The hospitals are not reimbursed by the federal government for the full cost of these services, although the federal government is responsible for the enforcement of the immigration laws, and many of the injuries that are treated result directly from dangerous attempts to cross the border. As a result, many hospitals in border areas are experiencing critical losses in revenue due to uncompensated care (Galloro). Of the five states that are most impacted by illegal immigration (California, New York, Texas, Florida, and Illinois), two have unsuccessfully sued the federal government in an effort to obtain reimbursement for the costs incurred in providing uncompensated care to illegal entrants.

Negotiating the Provider-Patient Relationship

Numerous issues may arise in the context of the provider–patient relationship due to differing beliefs regarding, and experiences with, such relationships, concepts of autonomy, and understandings about disease and illness. Some patients may have come from countries in which medical practitioners functioned as agents of the government, reporting to law enforcement officers the names of patients whose illnesses may have been related to illegal activities (e.g. sexually transmitted diseases that may have resulted from extramarital sexual relations or commercial sex activities, or pelvic infections resulting from illegal abortions). Others may have experienced torture at the hands of government-employed medical professionals. Not surprisingly, such experiences may hinder the patient's willingness and ability to divulge sensitive information to a healthcare provider. A lack of provider sensitivity to this possibility may inadvertently exacerbate the difficulty of communication. Even patients who have not experienced such trauma may feel reticent to discuss deeply sensitive issues due to perceived disparities in power between the healthcare provider and the patient.

Western medicine emphasizes the importance of self-determination and autonomous decision making in the context of medical care. However, some immigrant patients, and particularly those from non-Western cultures, may conceive of the individual not as an autonomous and disconnected entity, but rather as a function of the roles that one maintains in relation to those around one, such as extended family members and community members. In such instances, the patient may want the healthcare provider to discuss the details of his or her situation in as much, or even more, detail with the family or community members as with the patient. For instance, the patient may believe that the entire family should be involved in a decision to undergo chemotherapeutic treatment for cancer. Other patients may not want to know their own diagnosis, but may want family members to be fully informed.

The use of interpreters may also present challenges. At the most basic level, English phrases or terms may not be easily translatable into the language used by the patient. Other aspects of the interpreting function, however, may be more subtle and, consequently, more difficult to remedy. Differences in social status between the interpreter and the patient may influence the quality of the communication in ways that are not obvious to the healthcare provider. Interpreters may also incorporate their own beliefs and agendas into the communication. For instance, family members who serve as interpreters may inadvertently or intentionally minimize or exaggerate aspects of the information to be communicated.

Providers cannot realistically be expected to understand and be familiar with every possible culture and language. Providers may find it helpful, however, to consult with professionals in community-based organizations and agencies who have experience working with particular cultures. Family members of patients may be willing and able to provide additional background, particularly when it is clear that the provider is making a sincere effort to understand his or her patient.

Issues in Health Research

Immigrants may also face significant difficulties in the context of health research. For instance, many clinical trials do not provide care to trial participants. In such cases, examinations are provided only for the purpose of the trial and individuals are advised that they must consult with their own physicians for any necessary medical attention. In some cases, individuals are excluded if they do not have health insurance of some sort or if they do not have a regular provider of care. As a result, many immigrants may be ineligible for participation in a research study because they do not have employment-based health coverage, because they do not earn a salary that is sufficient to cover the costs of health insurance, or because they do not have a regular provider of care. In addition, many studies may limit participation to speakers of English, and those immigrants who have not yet mastered the language may be excluded from participation. Individuals may also be excluded due to the instability of their legal status and residence, in part because of the possibility that follow-up with them during the course of the study will be difficult and costly.

As in the clinical context, the development of a satisfactory informed-consent process for use with immigrant participants may require significant attention to ensure that the information provided to participants is understandable, both in terms of the language used and the sophistication of that language. An appropriate process may require, depending upon the culture of the participants, that the participant's family members or community members be engaged at some level. For example, information may be provided to the male head of the household, in addition to the prospective participant, so that the prospective participant can discuss the study with him. This does not, however, obviate the need for the individual consent of the participant.

As noted above, many immigrants may face extraordinary obstacles in attempting to obtain medical care. As a result, the offer of financial compensation or medical care in conjunction with participation in research may inadvertently place undue pressure on immigrants to agree to participate.

In the United States, immigrants have not traditionally been conceived of as constituting an especially vulnerable class of persons in need of special protections in the context of research. However, many of the characteristics of at least some members of this population may render them especially vulnerable. Poverty, lack of access to care, illiteracy, traumatic experiences, language, and illegal status can all have an effect in this regard. It is significant that Uganda has taken official note of these circumstances and has designated refugees as a class as being especially vulnerable and in need of special protections in the context of research. To address this situation, Ugandan institutional review committees reviewing proposed research that will involve refugees must include in its membership at least one individual from an agency whose primary responsibility is attention to refugee concerns, as well as a representative from a human rights organization.

SANA LOUE

SEE ALSO: *Human Rights; Justice; Medicaid; Organ and Tissue Procurement; Population Ethics: History of Theories; Public Health Law; Race and Racism; Warfare*

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IMPAIRED PROFESSIONALS

• • •

Impairment is a widespread problem of professional life. An impaired member of any profession creates legal and ethical difficulties for himself or herself, and can cause harm to others as well. For these reasons, the impaired professional merits serious attention (Boisaubin and Levine; Allan).

Defining the Problem

In common usage, the word *impair* connotes worsening or deterioration. An impairment diminishes the value or excellence of an individual or item. An impaired person has deteriorated significantly enough to endanger his or her capacity to function adequately.

When impairment refers to a professional, its meaning becomes more technical and restrictive. Because professions are self-regulating and resist external oversight, professionals largely determine for themselves what impairment means. Things that might impair an individual in the eyes of the lay community might not be defined as impairments within the professional community.

Typically, the impaired professional is one whose ability to function in his or her professional capacity has deteriorated because of a physical or mental difficulty. Impairing conditions traditionally have included drug dependency, alcohol dependency, illness, and disability (physical as well as mental). The American Medical Association (AMA), for example, defines the impaired physician as one “unable to practice medicine with reasonable skill and safety to patients because of physical or mental illness, including deteriorations through the aging process or loss of motor skill, or excessive use or abuse of drugs including alcohol” (La Puma and Schiedermayer, p. 91). A professional also may be regarded as impaired if abilities are significantly compromised as the result of stress or other factors (Nelson and Jennings).

While impairment raises concerns about an individual’s professional competence, being impaired is not necessarily the same as being incompetent. An incompetent professional lacks the minimally acceptable levels of knowledge and skill needed to practice within a field. Such a person once may have been competent, then fails to maintain adequate knowledge and skill. One can be incompetent without being impaired.

Impairment's Social and Professional Implications

The impaired professional poses a serious problem to self and others. An impairment may adversely affect the professional's relationships with colleagues, patients and families, and the professional's institution or workplace. It can affect a professional's relationship with friends and family. An impaired professional may engage in self-destructive behavior.

Impairment is a grave problem to those who put trust in professionals and expect them to be competent and to protect the public against impaired practitioners. Members of the public seldom possess the expertise needed to evaluate the quality of services being provided to them. Their potential vulnerability becomes even more significant when other factors (e.g., being sick or injured, being in an unfamiliar setting, or being a member of a different socioeconomic class) make it difficult for a layperson to question a professional's assistance. People have a right to expect competent help from an unimpaired professional.

If severe, unrecognized and unaddressed professional impairment can spell disaster. The impaired professional can cause severe harm, even death, to others. This can give rise to legal liability for the professional, colleagues, coworkers, and the institution in which the impaired professional works.

The Persistence of Impairment

For many reasons, impairment is an enduring, ubiquitous phenomenon of professional life. First, instead of responsibly discharging the responsibility of self-regulation, professionals sometimes abuse their power or office. Second, professionals may protect inept colleagues. Third, professional impairment does not receive much attention in the education and training of those who are entering a profession. While medical students may be quick to identify and chastise a patient who has a serious emotional or drinking problem, they are less likely to learn how to recognize or respond constructively to self-impairment or impairment in a colleague. Fourth, some professions foster impairment. The idealized image of the competitive, self-reliant practitioner drives professionals to succeed and to work in isolation, patterns of behavior that are conducive to impairment.

Even a medical professional who knows about professional impairment may not recognize it (Boisaubin and Levine). Medical professionals still are relatively autonomous practitioners, which means that they tend to be self-supervising. When contact is occasional, they may neither have the opportunity to discern that a colleague is impaired nor feel responsible for doing something if they suspect it. When contact is frequent, they may cover for an impaired colleague. To the extent that medical professionals practice as independent contractors without supervision or sustained periods of collaboration and regular contact, the ability to recognize that a professional is impaired is impeded. To the extent that medical professionals work together, collegiality may supplant professional concern.

Initial signs of impairment are frequently subtle, not obvious. Moreover, just as few individuals are looking for impairment, few wish to discover that someone is impaired. The ability to recognize impairment is affected by the willingness to see it. Missed appointments, tardiness, or sloppiness in one's work might be attributed to a passing stress and not taken as signs of something seriously wrong. A friendly inquiry met with a plausible response may be enough to assuage concern about a colleague.

Professionals may sympathize or identify with a troubled colleague. Given how much time, money, and effort professionals invest to establish their careers, the potential consequences of finding impairment can be enough to cause a professional to accommodate rather than report a colleague who is in trouble. The tendency of professionals to protect an inept colleague limits society's ability to respond to the impaired professional.

Fear of possible recrimination from the individual and one's peers also affects the professional's response to the suspicion or recognition that a colleague is impaired. The professional may worry that reporting or taking action on another's impairment may cause exposure to civil liability. Even if reporting a colleague poses no genuine threat of legal action, peers may de facto punish an individual for initiating the process of exposing a colleague to shame and institutional or legal action. These and other anxieties may make even conscientious professionals reluctant to report an apparently impaired colleague.

The professional and institutional response to professional impairment may be significant. A reported impaired professional is likely to encounter problems at the place of employment and difficulties regarding licensure (see below) and obtaining liability insurance. Depending on the nature and severity of the impairment, rehabilitation and recovery may not resolve these difficulties.

Confronting or reporting an impaired professional may be more difficult when that person is unable or unwilling to recognize the impairment. Admitting an impairment may damage one's image and reputation in the community and be fatal to a career.

The risk an impaired professional poses does not disappear or diminish if the impairment is ignored or unaddressed. On the contrary, it is likely to worsen. To ignore or dismiss the signs of impairment creates and sustains a potentially tragic situation. When the professional's impairment manifests itself, it is likely to be severe. At that point, those around the impaired professional are likely to be asked why no one intervened sooner, when the harm done could have been avoided or minimized.

Legal Implications

In every state, professional practice Acts specify as a grounds for professional discipline (including suspension or revocation of the license to practice) the inability to practice one's profession according to acceptable and prevailing standards of care by reason of mental or physical illness or habitual or excessive use or abuse of drugs, alcohol, or other substances that impair the ability to practice (Sanbar). In many states, professional boards operate treatment programs for impaired professionals (Ameringer; Talbott). Generally, successful participation in an approved treatment program is a prerequisite to licensure reinstatement for a rehabilitated, previously impaired professional (Spoon).

In many states, professionals are required by law to report impaired colleagues to relevant state professional boards and pertinent healthcare facility/agency administrators. Professionals are granted immunity from liability when they make such reports. When the reporting of impairment is mandatory under state law, failure to report is grounds for disciplinary action, although the actual enforcement of such statutes remains lax. Because the purpose of the law is prophylactic and arises out of the state's interest in protecting the public against harm, actual harm to a patient need not occur in order for a physician to be considered impaired. Because professional regulation is a matter of state law and is in constant flux, specific requirements, immunities, and programs vary considerably over place and time (Walzer).

Legal and ethical issues regarding informed consent arise in the case of impaired professionals who care for patients or clients. It has been suggested, for example, that the professional has an affirmative obligation to notify a patient/client about any impairment of that professional that might influence the decision to receive care from that professional, and that failure to share such information is a violation of the professional's fiduciary obligations (Furrow). Other commentators argue that information about specific professionals' impairments should be listed on publicly available data bases, raising a tension between the public's right to know and the professional's personal interest in privacy (Pape).

The Americans with Disabilities Act, 42 U.S.C. §§ 12101–12213, and §504 of the Rehabilitation Act, 29 U.S.C. § 794, prohibit discrimination against persons with physical and mental disabilities in such areas as employment and public accommodations These statutes affect, among other things, the licensing, discipline, institutional privileges, and insurability of impaired professionals (Rothstein, Piltch et al.).

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SEE ALSO: *Alcohol and Other Drugs in a Public Health Context; Alcoholism; Competence; Conflict of Interest; Conscience, Rights of; Disability; Emotions; Harm; Healing; Medicine, Profession of; Mistakes, Medical; Nursing, Profession of; Race and Racism; Responsibility; Sexism; Trust; Virtue and Character*

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INFANTICIDE

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Infanticide is the practice of intentionally killing human newborns. Because the term *infant* descends from a Latin word that means *not speaking,* infanticide should be distinguished from feticide, or abortion, intentionally killing fetuses, on the one hand, and felicide, intentionally killing children who are mature enough to speak, particularly one's own, on the other.

Infanticide has been practiced all over the world throughout the whole of human history. Newborns who have not yet learned to talk have been intentionally killed because they were thought to be:

1. terminally ill;
2. experiencing unbearable pain or suffering;
3. born with unacceptable anomalies;
4. of the wrong gender, race, class, maternity, or paternity;
5. political threats;
6. economic threats;
7. fitting sacrifices in religious rituals; and
8. embarrassing, frustrating, or inconvenient.

The single most common reason for the practice of infanticide in the past and present has been the desire to be rid of female newborns. The histories of infanticide and gender bias are interwoven. Not to study them together is to overlook their interdependence.

Human newborns, particularly females, have been intentionally killed in many ways. They have been incinerated, decapitated, and suffocated. They have also been sundered, stabbed, stoned, shot, hung, drowned, struck, shaken, stomped, crushed, raped, poisoned, buried, starved, fed to animals, and exposed to the elements. They have been denied air, food, water, warmth, and protection from diseases. Their blood vessels have been injected with toxic substances and bubbles of air. It is impossible to understand the history of infanticide without taking into account its diverse and often cruel methods.

In many societies infanticide was not only tolerated but also sometimes promoted as a solution to the problem of unwanted infants, whether deformed or healthy. This entry provides a historical account of infanticide in Western societies, beginning with its practice in Graeco-Roman antiquity and concluding with modern evidence.

Infanticide in Antiquity

In Greek society, an infant's worth was measured by its potential to fulfill a useful function in society. Thus Plato, in his *Republic,* maintained that society was better served if deformed newborns were "hidden away, in some appropriate manner that must be kept secret," a practice that likely included infanticide (460). Similarly Aristotle wrote in *Politics*: "As to the exposure and rearing of children, let there be a law that no deformed child shall live." Aristotle also condoned abandonment as a method of population control, although he recommended early abortion in regions where the "regular customs hinder any of those born being exposed" (1335b). In Sparta, where military strength was highly valued, infanticide may have reached its zenith. In *Life of Lycurgus,* Plutarch gives an account of the Spartan custom: "But if it was ill born and deformed they sent it to … a chasm-like place at the foot of Mount Taygetus, in the conviction that the life of that which nature had not well-equipped at the very beginning for health and strength, was of no advantage, either to itself or to the state" (16).

It is difficult to distinguish between infanticide, with the intent to kill the infant, and abandonment, which may or may not have involved this intention. Failure to distinguish between the two has made accurate assessment of each difficult (Boswell). Historians have generally interpreted the Greek word for abandonment, translated as "exposure, putting out, or hiding away," as equivalent to infanticide. However, the Greek terms for abandonment do not convey the sense of injury or harm associated with infanticide. Historical evidence is not clear as to whether abandoned infants usually died or if those who abandoned them intended their death. Often abandonment was viewed as an alternative to infanticide. Nevertheless it is reasonable to infer that some deformed and healthy infants, particularly females, were exposed with the intent that they would not survive. Further it is likely that direct infanticide was practiced for both eugenic purposes and population control. Laws neither prohibited the killing of defective infants nor protected healthy infants from death by exposure.

Evidence from classical sources suggests that infanticide was practiced widely and with impunity in Roman society. While Romans continued the practice of disposing of defective infants for eugenic and economic reasons, an additional motivation stemmed from the Roman belief in the phenomenon of unnatural events, or *prodigia* (Amundsen). The Greeks saw deformities in newborns as natural occurrences. In contrast the Romans viewed *portentosi,* meaning *unnatural* or *monstrous* births, as ominous or numinous signs that needed to be destroyed in order to rid the community of guilt and fear. The historian Livy of the first century B.C.E. wrote, in *Histories,* about the birth of an infant who was both unusually large and of indeterminate gender:

> [M]en were troubled again by the report that at Frusino there had been born a child as large as a four year old, and not so much a wonder for size as because … it was uncertain whether male or female. In fact the soothsayers summoned from Etruria said it was a terrible and loathsome portent; it must be removed from Roman territory, far away from contact with earth, and drowned in the sea. They put it alive into a chest, carried it out to sea and threw it overboard. (37.27)

Roman literature is rife with testimony to such killings. According to the Laws of the Twelve Tables (fifth century B.C.E., considered to be the basis of Roman law), deformed children, *puer ad deformitatem,* were to be killed quickly. Historians disagree whether the law required that these infants be killed or whether it merely allowed infanticide. In any case Roman society appears to have accepted infanticide as a reasonable solution to the problem of deformed infants both for eugenic and superstitious motives. In a gynecological treatise entitled "How to Recognize a Newborn Worth Rearing," the Graeco-Roman physician Soranus (first–second century C.E.) specifies that such an infant "immediately cries with proper vigor, is perfect in all its parts, members and senses [and] has been born at the due time, best at the end of nine months. And by conditions contrary to those mentioned, the infant not worth rearing is recognized" (*Gynecology,* p. 79–80).

In his *Moral Essays,* Seneca argued that the practice of infanticide is rationally motivated: "Mad dogs we knock on the head; the fierce and savage ox we slay; sickly sheep we put to the knife to keep them from infecting the flock; unnatural progeny we destroy; we drown even children who at birth are weakly and abnormal. Yet it is not anger, but reason that separates the harmful from the sound" (1.15). Even if it were not legally mandated, it is unlikely infanticide was penalized in Roman society given the tradition of *patria potestas,* which granted fathers absolute authority over other members of the family. Roman fathers had power of life and death over their children and were allowed to execute even a grown son (Boswell). The most likely victims, however, were infants, especially deformed ones *and* female children who—even when healthy—were considered of little social value.

Some Roman philosophers objected to abandonment and infanticide. Musonius Rufus, writing in the first century C.E., opposed infanticide because it reduced the population. Epictetus, a Stoic philosopher and a contemporary of Musonius, condemned abandonment as a violation of the natural affection that parents should have for their offspring. Such apparent concern for the infant was not based on a belief in the child's intrinsic right to life, but was motivated by the desires to follow natural law and to increase the population. Thus, although evidence for the practice of infanticide under the Roman empire is somewhat inconclusive, Roman law and custom apparently did not prohibit parents from killing their children.

Early Jewish and Christian Traditions

The people of ancient Israel were acquainted with infanticide, particularly as it was practiced in the religious rituals of their neighbors. As evidenced by the frequency and vigor with which infanticide was denounced by their leaders, it appears that some Israelites were attracted to it. The ancient story of Abraham's apparent willingness to sacrifice his son Isaac, who was not an infant but a young man, only to be instructed by a heavenly messenger to kill a ram instead, was told and retold over the centuries (Genesis 22). Among other things, the recitation of this story reiterated a preference for animal sacrifices in Israel's religious rituals, at least until the some of Israel's prophets condemned that practice too.

Jewish scholars were thus among the first to clearly condemn the killing of infants. Jews believed that humans were created in the image of their creator, Yahweh. Hence all human life was sacred from the moment of birth. The Torah speaks of defective individuals as Yahweh's creations and it mandates protection to the blind, the deaf, the weak, and others who are needy (Leviticus 19:14). Human life had intrinsic value by virtue of divine endowment, not merely instrumental value by virtue of social utility, as in classical Greek and Roman society.

The first-century Jewish philosopher Philo denounced infanticide and emphasized adults's duties toward children. His account equated abandonment with infanticide:

> Some [parents] do the deed with their own hands; with monstrous cruelty and barbarity they stifle and throttle the first breath which the infants draw or throw them into a river or into the depths of the sea, after attaching some heavy substance to make them sink more quickly under its weight. Others take them to be exposed in some desert place, hoping, they themselves say, that they may be

> saved, but leaving them in actual truth to suffer the most distressing fate. For all the beasts that feed in human flesh visit the spot and feast unhindered on the infants, a fine banquet provided by their sole guardians, those who above all others should keep them safe, their fathers and mothers.

Philo further condemned the practice, in *Works,* by claiming, "Infanticide undoubtedly is murder, since the displeasure of the law is not concerned with ages but with a breach to the human race" (Vol. 7).

However, it was the advent of Christianity, rooted in Judaism, that significantly altered public attitudes toward the practice of infanticide. Christians inherited the Jewish doctrine that humans were divinely created, including the emphasis on the sanctity of all human life. They also recalled with horror the New Testament report that King Herod had slaughtered many infants in his attempts to exterminate the infant Jesus (Matthew 2). Believers were urged to emulate Christ's self-sacrificing love through benevolence and charity, providing a new rationale for philanthropy (Ferngren, 1987a). The consequences of this philanthropy were seen in Christian charities and endeavors for the poor, the sick, and the needy. Rescue and care of exposed infants was viewed as a special Christian duty. During the medieval period through the nineteenth century, Christians established foundling hospitals, and institutions for abandoned and unwanted children.

Two other Christian concepts important for their effect on the practice of infanticide were original sin and its correlative ritual of infant baptism, thought to have become common during the third century. Christians believed that infants who died without baptism were condemned to eternal hell. Because baptisms were performed only on holy days, not necessarily soon after birth, many parents already were committed to raising the child by the time of the ritual. Thus baptism served as an important deterrent to both abandonment and infanticide.

Although Jews and Christians vigorously opposed infanticide, their opposition had little impact until Christianity became widespread and officially recognized in the fourth century. A church council in Spain issued the first canon against infanticide in 305 C.E., and soon after, both local and ecumenical councils throughout Europe took similar actions. The penalty prescribed by the church for infanticide was either penance or excommunication.

The first secular law concerning the killing of children was issued in 318 C.E. by Constantine, the first Christian emperor. However, the law mentions children killing parents as well as parents killing children and thus was not directed specifically against infanticide. In 374 C.E. Valentinian enacted legislation declaring infanticide to be murder and punishable by law. Soon after a statute was issued that appears to have prohibited exposure of infants. Although Christian emperors promulgated many laws reflecting Christian morality, fear of losing salvation made the penitential system of the churches far more effective in influencing moral behavior than did state legislation. Church leaders continued to put pressure on the state, bringing about a series of legal codes aimed at protecting newborn children.

Although the laws did not distinguish between healthy and defective infants, one may assume that Christian condemnation of infanticide extended to all infants. Early Christian apologists reflect this position. In *City of God,* Saint Augustine (354–430) argued that differences between healthy and deformed people should be seen in the same light as racial and ethnic diversity:

> If whole peoples have been monsters, we must explain the phenomenon as we explain the individual monsters who are born among us. God is the Creator of all; He knows best where and when and what is, or was, best for Him to create, since He deliberately fashioned the beauty of the whole out of both the similarity and dis-similarity of its parts.… It would be impossible to list all the human offspring who have been very different from the parents from whom they were certainly born. Still all these monsters undeniably owe their origin to Adam. (16.8)

Augustine's writings show a concern for children unusual in his time, placing the infant and the child under the protection of the Lord.

Despite decisive changes in attitudes and laws, infanticide persisted even after the official triumph of Christianity as the imperial religion. While the practice may have diminished, episodic killing of infants continued throughout Western history. What changed in subsequent periods were the motivations, methods, and penalties associated with infanticide as well as the options available to parents of unwanted children.

Medieval Period

Christianity's beliefs mixed with pagan myth, superstition, and folklore during Europe's medieval period. This commingling had significant implications for deformed infants and the practice of infanticide. Some thought, for example, that parental sexual behavior or *ill-timed passions* generated abnormal births or that sexual relations during menstruation, pregnancy, or lactation resulted in dire consequences for the unborn. In addition the birth of an anomalous infant was sometimes attributed to demonic intervention: Such births were seen as the product of either a sexual liaison between the mother/witch and the devil or a changeling left by the devil as punishment for parental sins. Parents, particularly mothers, were held morally responsible for their infants's abnormalities.

The changeling myth, derived from pagan sources, maintained that fairies, motivated by jealousy, substituted an elf child for the real child (Haffter). This version did not impute guilt to the parents; instead, blame was placed on demon fairies of the underworld and their envy of humans. Once the myth was Christianized, however, it became the devil who stole the real child and left a demon-child in its place. Thus God allowed parents to be punished for impiety or for bearing children outside matrimony. This change transformed the rationalization for the birth of defective infants from external forces to parental responsibility. Brutal and frequently lethal methods were employed either to exorcise the devil from the child or to compel the devil to return the normal child. Few infants survived the ordeal. However violent infanticide of this sort was probably the exception rather than the rule, even during the Middle Ages.

There was some secular legislation against infanticide, particularly in the later medieval period, and the crime was usually considered to be homicide. But overlaying (suffocation in the parental bed), the most frequent cause of infanticide, was easy to conceal and intent was nearly impossible to establish, thus making prosecution extremely difficult. When cases of infanticide did reach secular courts, the accused were readily acquitted on pleas of insanity or poverty. Secular authorities displayed remarkable ambivalence toward the killing of infants. By law it was considered a serious crime, yet in practice it was generally excused (Damme).

Throughout most of the medieval period, infanticide was regulated largely by church courts rather than civil courts. Ecclesiastical penalties for married women convicted of infanticide were also remarkably light, considering the Church's position. Punishment involved penance and was comparable to that imposed for sexual offenses such as adultery and fornication. Once the penance had been performed, the guilty person was not prosecuted in civil courts. The relatively light penance and the failure of secular authorities to prosecute cases of infanticide suggests that the crime was considered something less than homicide (Helmholz). Cases involving unwed mothers, however, were treated differently. Unmarried mothers who killed their infants were often accused of being witches. In fact, infanticide was the most common charge brought against *witches* during the Middle Ages. Unlike their married counterparts, alleged witches were punished severely, usually by drowning, burial alive, or impalement.

The only reference to the status of infants under medieval secular laws was a civil law definition of a freeman (in the law "Of Different Kinds of Children"), which appears to have excluded both illegitimate and seriously deformed infants from what little protection the law offered: "Among freemen there may not be reckoned those who are born of unlawful intercourse … nor those who are created pervertedly, against the way of human kind, as for example, if a woman bring forth a monster or a prodigy" (Fleta 1.5). As legal historian Catherine Damme comments, "Clearly, these pitiful non-persons were vulnerable to the murderous attacks of their progenitors" (p. 7).

Although direct infanticide was practiced to some extent, the more common and insidious cause of infant death during the Middle Ages was abandonment. The distinction between infanticide and abandonment became increasingly important because abandonment was generally regarded as a venial offense, punishable only if the child died. In the early-Middle Ages, abandonment was widespread, motivated primarily by poverty and illegitimacy. Although a few churchmen believed it was equivalent to infanticide, two forms of abandonment were virtually institutionalized: oblation (or donating infants to the Church) and leaving infants at foundling hospitals. From a Christian point of view, both were improvements over the morally objectionable practices of exposure and infanticide. A canonical decree of the tenth century urged women to leave their illegitimate infants at the church rather than kill them (Boswell). Although oblates were tied irrevocably to the Church for life, the Church provided food, clothing, and a secure monastic life.

Foundling homes were established to diminish the practice of exposure and to provide a humane solution to infanticide. In reality, however, the foundling home often was equivalent to consigning the child to death through neglect, disease, and sometimes more direct action. Once infants arrived at a foundling home, they frequently were sent to the country with a wet nurse who was likely to be negligent and more interested in a steady flow of babies than in nurturing. Death rates were high, especially for female infants (Trexler). Markedly high demographic ratios of males to females throughout Europe during this period suggest that selective female infanticide may have been widely practiced. The disparity between male and female deaths was probably due to greater social value for males and a greater likelihood that, when put into foundling homes, they would be reclaimed by their parents. Thus such institutions did little to secure the lives of unwanted infants. They were successful only in transferring the problem of unwanted infants from a public arena to an institutional one, shielding society from the realities of abandoned children and possibly encouraging the very practice they were intended to alleviate.

Renaissance and Reformation

During the sixteenth and seventeenth centuries there was a concerted effort to stem the practice of infanticide throughout Europe. Despite a dramatic surge in reported cases, it is not clear whether or not the increase meant more frequent practice; urbanization undoubtedly made it more difficult to destroy infants secretly. Authorities were more successful at promulgating harsh legislation aimed at ending the practice and were also increasingly vigilant in prosecuting murdering mothers. An intense focus on the problems of poverty and sexual promiscuity and their purported ties to infanticide led to laws that were strongly moral in tone and selective against unmarried mothers.

The first attempt to strengthen and unify infanticide laws under the Holy Roman Empire was a statute known as the Carolina, issued in 1532 by Emperor Charles V. The law decreed that those found guilty were to be buried alive, or impaled, or drowned. The law also made concealment of pregnancy a crime, as it was presumed that such secrecy indicated infanticidal intentions. Many judges, under the pretext of the Carolina, "engaged in a policy of terror," the most notorious being the Saxon jurist Benedict Carpozof, who claimed that he assisted in the executions of 20,000 women (Piers, p. 69). The Carolina was only the first in a series of laws over the next few centuries that dealt severely with alleged infanticidal mothers.

In England Henry VIII's split from the Roman Catholic church resulted in increased secular control. Growing concern about sexual immorality and criminality among the swelling numbers of urban poor led to the enactment of several social control laws. The Poor Law of 1576 (18 Eliz. I, c.3) made bearing bastard children a crime. The fact that punishment was severe and involved substantial social disgrace for the mother increased the incentive for these women to commit infanticide. It is not surprising, therefore, that English criminal court records show that the number of indictments and guilty verdicts for infanticide rose dramatically after 1576. Most cases involved bastard children, and concealment of pregnancy was mentioned frequently (Hoffer and Hull).

The reasons for the increased zeal in punishing illegitimacy are somewhat obscure, but Puritan interests seem to have played a role. The 1623 Jacobean infanticide statute (21 Jac. I, c.27), influenced by the Puritan element in parliament, allowed courts to convict on the basis of circumstantial evidence of concealment and prior sexual misconduct. The law presumed that the child was born alive and then killed unless the mother could prove otherwise. Prosecutions of infanticide showed a fourfold increase immediately following its enactment (Hoffer and Hull).

Ideas about the role of witches in the death of infants, even the deaths of children in foundling hospitals, persisted. Infanticide and witchcraft were so strongly interrelated during this period that their rates of indictments rose and fell in parallel. Witchcraft continued to play a major part in the drama of infanticide until the early 1800s.

Foundling hospitals continued to remove unwanted and abandoned children from public view throughout the sixteenth and seventeenth centuries. As in earlier centuries, the fate of these children was precarious. Overcrowded conditions, disease, lack of enough wet nurses, and general neglect continued to claim the lives of many of the institutions's charges.

The overwhelming majority of the victims of infanticide during this period were children born out of wedlock. Demographic information does not show the strong gender bias seen in the medieval years, nor is there evidence that defective newborns were consistently selected out. Apparently the shame associated with immoral sexual behavior was the primary selective force associated with the killing of infants.

Eighteenth and Nineteenth Centuries

In the eighteenth century, a steep decline occurred in indictments for infanticide; the courts showed greater leniency toward those accused of killing their children. In addition illegitimacy was more common; as a result the stigma associated with it lessened and its strong correlation to infanticide began to diminish. Attitudes toward parenting changed as well, with a new emphasis on the emotional nurturing of children. Wet-nursing lost popularity, and it became more common for children to spend their early months with their mothers. The greater value placed on children resulted in increased beneficence in child rearing, and so parents were probably less likely to kill their offspring. In any case juries were less willing to convict parents of infanticide solely on the basis of concealment.

New defenses for the suspected infanticidal mother were developed and more readily accepted by juries. One of the first of these defenses, known as *benefit of linen,* was based on evidence that the mother had made linen for the baby before its birth and therefore had no intention to kill it. This line of argument became very popular after 1700 and virtually guaranteed acquittal. Another major defense commonly used was the *want of help* plea. Various accidents and calamities, such as failure to tie the umbilical cord, falls of either the mother or baby, illness of the mother, and unheeded cries for help, all effectively helped to sway jurors.

Efforts to reform the English infanticide statute of 1624 began in 1773 but were not successful until 1803. In the ambivalence of eighteenth-century English society, infanticide was considered homicide yet somehow not quite the equivalent of killing an adult. Despite the failure of reform resolutions until the nineteenth century, juries tended to ignore the severe infanticide law aimed selectively at unwed mothers.

A similar trend occurred in Prussia during the reign of Frederick the Great. In his *Dissertation sur les raisons d'établir ou d'abroger les lois* (1756), Frederick argued that the prevalence of infanticide was due to the harsh penalties for illegitimacy. He therefore abolished laws penalizing pregnancies out of wedlock and eventually provided legal protection for unwed mothers. Scholars throughout Europe, including Cesare Beccaria, Voltaire, Johann Heinrich Pestalozzi, and Johann Wolfgang von Goethe, also called for legal reform and urged authorities to prevent the circumstances leading to infanticide.

Despite moderately successful reform efforts, however, infanticide did not disappear. During the nineteenth century high rates of illegitimate births continued; so, consequently, did infant killing. Corpses of infants found in privies, parks, rivers, and other public places fueled the perception that infanticide was reaching intolerable proportions. This perception may or may not have represented an actual increase in the incidence of the crime, but it did serve to stimulate an unprecedented public outcry. By the mid-nineteenth century, the concern over the *slaughter of innocents* appeared in the press (Behlmer). The British newspaper *Morning Star* (June 23, 1863) declared, "This crime is positively becoming a national institution"; and the *Pall Mall Gazette* (April 30, 1866) protested, "It is exceedingly unpleasant to find ourselves stigmatized in foreign newspapers … as a nation of infanticides.… 13,000 children are yearly murdered by their mothers in heretical England." *The Saturday Review* (1865, p. 161–162) asserted that infanticide "is the characteristic at once of the rudest barbarism and of that more terrible epoch of national life when the wheel has gone its full circle, and society falls to pieces by the vices of civilization."

Physicians were among those who led reform efforts. In his essay on infanticide in 1862, William Burke Ryan wrote passionately against the horrors of infant murder; he and several colleagues formed the Infant Life Protection Society. By 1870 the group had achieved many of its goals, including mandatory registration of all births. In 1872 Parliament passed the first Infant Life Protection Act requiring registration of all *baby farms,* houses with more than one child under the age of one.

Legal prosecution of infanticide also underwent significant changes. Ellenborough's Act of 1803, which replaced the Infanticide Act of 1623, reinstated the common-law presumption of stillbirth, shifting the burden of proof from the defendant (mother) back to the prosecutor. In 1828 the law was expanded to include legitimate as well as illegitimate births, removing the obvious selection against unwed mothers. The fact that courts consistently acquitted the accused or mitigated penalties on the basis of insanity is testimony to the court's continued hesitancy to consider infanticide the moral equivalent of murder. There was a "visceral feeling that such a crime simply could not be a rational act.… [t]he minds of the jury and jurist could not accept that such a heinous act could be committed by a rational person—the accused's mind had to be deranged, if only temporarily" (Damme, p. 14).

Twentieth Century

The most notorious instances of infanticide in the twentieth century were committed secretly in Nazi Germany, under the auspices of the Committee for the Scientific Treatment of Severe, Genetically Determined Illness. Doctors, nurses, and teachers were required to register all children with congenital abnormalities or mental retardation. Failure to comply meant civil penalties or imprisonment. Defective children were removed from their homes and routinely euthanized at hospitals by morphine injection, gas, lethal poisons, or sometimes starvation. To ensure secrecy, the bodies were cremated immediately. Parents who protected their children were sent to labor camps and their children were taken from them. Documents reveal substantial public support for the euthanasia of defective children, even from parents with abnormal children (Proctor).

Calls for legalized euthanasia also arose from the United States, where it was justified primarily as a way of limiting the social costs associated with defective infants. W. A. Gould, writing in the *Journal of the American Institute of Homeopathy,* cited the "elimination of the unfit" in ancient Sparta as a defense of the economic arguments for euthanasia in the twentieth century (Gould). In 1938 W. G. Lennox advocated the "privilege of death for the congenitally mindless and for the incurable sick who wish to die" because saving these lives "adds a load to the back of society" (Lennox, p. 454). But as the realities of the Nazi extermination programs began to surface in the United States in the 1940s, promotion of euthanasia in general began to decline.

Yet in 1942, Foster Kennedy, professor of neurology at Cornell Medical College, wrote an article entitled "The Problem of Social Control of the Congenital Defective" advocating "euthanasia for those hopeless ones who should never have been born—Nature's mistakes." Kennedy believed "we have too many feebleminded people among us," and it was most humane to relieve defective individuals of their tortured and useless existence (Foster). Furthermore, he maintained that in diagnosis and prognosis there could be no mistakes in this *category* of children. A Gallup poll conducted twelve years earlier indicated that Kennedy's position probably was not without support within the American community. According to the poll, 45 percent of Americans in 1930 favored euthanasia of anomalous infants (Proctor, p. 180).

Toward the end of the twentieth century, the possibility of killing newborns with anencephaly in the course of acquiring transplantable organs from them was debated in professional circles. Babies with this condition are born without cerebral hemispheres, with an open skull that is empty except for the top of the spinal cord. They are wholly and permanently unconscious. Some viewed the possibility of acquiring rare transplantable organs from such infants as a way to squeeze something of value out of a tragic set of circumstances. This option was restricted by the convergence of two widely accepted norms, however. The first was that vital organs must be acquired only from dead donors. The second was that death must mean either the irreversible loss of spontaneous circulation and respiration or the irreversible loss of the functioning of the whole brain, including the brain stem. Several attempts at Loma Linda University in Southern California to acquire transplantable organs from babies born with anencephaly within the constraints of these two norms established that either the dead donor rule or the usual definition of death must first be changed. Several years later, The Council on Judicial and Ethical Opinions of the American Medical Association (AMA) proposed that in cases of anencephaly the requirement that donors of vital organs must be dead be relaxed. Shortly thereafter it withdrew this proposal in deference to intensely negative reactions. Some believed that the Council had put the wrong foot forward while attempting to move in a helpful direction. They thought that when babies are born with anencephaly it would have been less controversial to allow parents to opt for a *higher brain* rather than a *whole-brain* definition of death. If this change had been made, babies born with accurately confirmed cases of the anomaly would have been declared legally dead before transplantable organs were acquired from them. Some held that this would have honored the important ethical conviction that no one of any age or condition should be killed merely to provide transplantable organs for someone else.

The practice of infanticide was debated in the popular culture of the United States and elsewhere when Peter Singer of Australia joined the faculty of Princeton University one year before the end of the twentieth century. An accomplished utilitarian moral philosopher who was well known beyond academic circles for his advocacy of animal liberation, Singer troubled many. He contended that in general it is ethically permissible to treat human newborns in ways that parallel the ways we are morally permitted to treat other animals with approximately the same traits and abilities. He held that it is ethically acceptable to kill infants born with some serious anomalies. He also suggested that there is a sense in which parents are free to kill a handicapped infant and rear a healthier one instead. His point was that in infancy the value or interests of one newborn can often be interchanged with those of another with little or no overall loss of value, and sometimes with a gain.

These issues proved difficult to resolve in academic and popular settings in the last part of the twentieth century. This was partly because, even in many of the most widely used English dictionaries, the ability to distinguish between the basic meanings of *possible* and *potential* had all but vanished. The claim that a human infant is a potential embodiment of value, interests, or rights weighty enough to protect him or her from death at the sheer discretion of others was typically understood to mean that for a newborn this eventual state is merely possible. Common although it was, this understanding of potential failed to capture and convey the senses of inner *power, capacity,* and *endowment* in its root meaning, as was still sensed in related terms like *potent, potentiate,* and *potentate.* Wider recognition of the differences in basic meaning between potential and possible would not have settled the debates about infanticide in the last part of the twentieth century; however, it would have enabled these exchanges to proceed with greater precision and plausibility.

Conclusion

Authors who have explored the ethical dimensions of infanticide have frequently prefaced their discussions with surveys of its practice throughout history. The ostensible purpose of these discussions generally has been to provide a broader, less culturally bound perspective. However, Stephen Post argues that many writers selectively present "a one-sided and reductionist view of the history of infanticide to support their position … that active killing of neonates is morally acceptable" (Post, p. 14). He contends that the extent of infanticide has been misrepresented and overstated. The argument is that commentators on the history of infanticide have drawn, at least to some extent, from historical surveys plagued by interpretations that tend to view history in a positivist or linear fashion. The French historian Phillipe Ariès maintains that the idea of a separate childhood was unknown until the later Middle Ages (Ariès). Similarly Lloyd DeMause contends: "The further back in history one goes, the lower the level of child care, and the more likely children are to be killed, abandoned, beaten, terrorized, and sexually abused" (DeMause, p. 1).

Revisionist historians, focusing on social, economic, and cultural forces, offer a significantly altered perspective on infanticide. While infanticide has been practiced continuously throughout Western history, it is not obvious that filicidal tendencies are widespread among parents. On the contrary, parents have usually resorted to infanticide only in exceptional circumstances. Although accurate estimates of the frequency of infanticide are almost nonexistent (largely due to inadequate and inconsistent record keeping), the prevalence of infanticide throughout Western history seems to have been episodic. Rates of infant killing have shown a tendency to rise and fall depending on prevailing economic and social forces. There have been striking discrepancies between the official position of the law, the frequency of the crime, the rate of prosecutions, the severity of punishment, and public sentiment concerning infanticide. Although the law has been relatively consistent in prohibiting its practice, the law has not always been an accurate gauge of societal values. Finally the availability of alternatives to infanticide—including abandonment, foundling hospitals, oblation, contraception, and abortion—appears to have had more impact on its practice than have official prohibitions.

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SEE ALSO: *Abortion: Contemporary Ethical and Legal Aspects; Abuse, Interpersonal: Child Abuse; Children; Family and Family Medicine; Harm; Holocaust; Homicide; Human Rights; Infants; Insanity and the Insanity Defense; Maternal-Fetal Relationship; Mentally Disabled and Mentally Ill Persons; Moral Status; Natural Law; Sexism*

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INFANTS, ETHICAL ISSUES WITH

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The birth of a baby can be one of the most satisfying, fulfilling experiences of a parent's life or a couple's marriage. After months of *infanticipating,* the experiences connected with the first few hours and days of the baby's life can be intensely rewarding for the parents, providing them with joy, gratitude, and perhaps humility as they contemplate the new life that is now entrusted to them for care and support. If they are religious believers, they may be inclined to think of the baby's life as a divine gift and to regard their parental role as involving responsible stewardship over that gift. At the very least, they will probably be thankful that the baby has a normal brain, the correct number of fingers and toes, and the rest of a physical endowment that would suggest normal human development.

Unfortunately, in a small minority of cases the months of parental dreams and plans for a normal baby turn out to be false hope. In some instances, even when prenatal diagnosis has already indicated that the baby will not be normal, there may still be parental surprise and disappointment at the range of medical problems and the degree of neurologic impairment the child has. In other instances, when prenatal diagnosis was not done and the potential parents had no opportunity for anticipatory grief over the loss of a normal baby, the birth of a premature and/or congenitally disabled infant can have an enormous emotional impact on the parents that severely tests their most deeply held beliefs, values, and hopes for the future.

The birth of such a baby can also reflect the diversity of ethical perspectives that exist among parents, physicians, and other persons regarding the value of infants with life–threatening medical conditions, especially when the projected future lives of these children are filled with a mixture of neurologic impairments, mental and physical disabilities, and, sometimes, considerable medical uncertainty regarding the degree of those disabilities. For many persons, such cases raise important substantive questions: What is the moral status of infants with mental and physical disabilities? Should all of these infants receive life-sustaining medical interventions regardless of the severity of their medical conditions? What should be the ethical standard according to which a few infants would not receive life-sustaining efforts? Is there any moral difference between withholding and withdrawing life-sustaining treatments? Are there important moral differences between decisions about life-sustaining treatment in cases of severely disabled infants compared with cases of adults who have never been autonomous because of severe mental retardation? Would it be justifiable, in rare cases, intentionally to kill any of these infants?

Cases of premature and disabled infants also raise important procedural questions: Who should have the authority to make these life-and-death decisions? Should physicians, and in particular neonatologists, make these decisions because of their greater technical knowledge and experience with similar cases? Should the infant's parents decide because of their roles in conceiving and caring for the child, and because of their greater emotional and financial stake in the child's death or disabled life? Should a collective body (e.g., a pediatric ethics committee) make the borderline decisions?

In addition, important questions are sometimes raised about contextual and methodological matters related to decisions about the care of infants: What lessons can we learn about caring and nurturing from parents who have learned to cope with and transcend one of life's personal tragedies? Is a philosophical approach that focuses on principles, rights, interests, and obligations the correct model for ethical analysis? Do theological claims about the sanctity of life, the meaning of suffering, and the importance of stewardship over life have a significant place in decisions about the appropriate level of care for infants, whether normal or abnormal in some way? To what extent should the realities of medical economics influence the decision about whether a premature and severely disabled infant lives or dies? How much should decision makers in individual cases consider the implications of their decisions in terms of public policy?

This article has five parts: (1) a brief historical overview; (2) international perspectives among pediatricians; (3) alternative perspectives on the moral status of infants; (4) perspectives on abating life-sustaining treatment; and (5) the emerging mainstream ethical perspective. Additional information on some of these points is found in the other articles in this entry.

Historical Overview

Throughout history, as at the present time, the birth of a baby has often been the occasion for joy, celebration, and thanksgiving. In earlier centuries, the birth of a healthy, normal baby was frequently the occasion for celebration because the baby, especially if the infant was male, offered future promise for the family: another hunter for food supplies, another worker for the field or factory, another opportunity for continuing the family lineage. The birth of a baby was often an occasion for celebration for another reason: the mother had survived the dangers inherent in pregnancy and childbirth, dangers that posed a significant risk to maternal health and life in every pregnancy before the advent of modern medicine.

However, not all births were celebratory occasions. In many societies and in virtually all historical periods, very young infants, female infants, bastards, and infants and older children believed to be *defective* in some way were frequently killed. The intentional destruction of infants and children through starvation, drowning, strangulation, burning, smothering, poisoning, exposure, and a variety of lethal weapons was a tragically common practice. Such practices were widely accepted ways of dealing with unwanted children, with the responses of governments varying from required infanticidal practices (e.g., in Sparta), to acceptance of or at least indifference to the killing of female infants (e.g., in China and India), to considerable uncertainty as to how to punish parents who may have committed an illegal act by killing one of their children under questionable circumstances.

Mothers and fathers have historically had several possible reasons for killing one or more of their children. Some of them have killed for economic reasons: A dead child would mean one less mouth to feed. Others have killed their infants because of social customs and pressures: An illegitimate child, an *extra* child beyond a certain number, or another female child was especially vulnerable. Still other parents have killed their children because the infants were physically or mentally abnormal, with their congenital abnormalities being interpreted as works of the devil, signs of fate, punishment for the sins of the parents, or tricks played by witches (Weir).

Some of these older explanations of congenital disabilities seem strange now, but two features of traditional infanticidal practices remain a part of the modern world. First, infants are still sometimes killed by their parents or, perhaps more commonly, abandoned without food, shelter, or parental protection. No society is exempt from such events, with media reports of dead or abandoned babies coming from China, India, Brazil, the United States, Romania, and other countries. Second, even for parents who cannot imagine killing their own children, the birth of an extremely premature and/or severely disabled infant is a mixed blessing. For that reason, parental decisions about medical efforts to prolong a child's life frequently involve concerns about the future of the family as well as considerations about the welfare of the child.

In many parts of the world, such decisions, whether made by a child's parents or physicians, are strikingly similar to decisions made about sick and disabled children in earlier historical periods because many countries still lack the medicines, the medical and nursing personnel, and the medical technology that are common to the rest of the world. In technologically developed countries, by contrast, the development of neonatal intensive-care units (NICUs), neonatologists and other pediatric subspecialists, sophisticated medical technology, new medicines, and new surgical techniques has brought unprecedented opportunities and challenges to physicians, parents, nurses, and all other persons interested in prolonging the lives and improving the health of critically ill children. Likewise, changes in neonatal medicine since the 1970s have meant that physicians, parents, or some combination of health-care professionals in a hospital can sometimes decide that the appropriate course of moral action in a case is not to initiate or continue life-sustaining treatments, given the child's severe neurologic impairments and likelihood of continued suffering.

Such decisions—not to use medical technology to sustain an extremely premature or severely disabled infant's life—are usually difficult and sometimes controversial. In the United States, public and professional responses to publicized pediatric cases in the 1980s generated two efforts at regulating selective nontreatment decisions. The two attempts at regulation, while not always in conflict, reflected two quite different ethical perspectives regarding how and by whom selective nontreatment decisions should be made.

One effort at regulation took the form of two sets of published federal regulations during the administration of President Ronald Reagan. The *Baby Doe* regulations, first proposed in 1983, and the subsequent childabuse regulations, established in 1985, differed in legal philosophy, implementation, and influence. Yet both agreed on the ethical perspective that should govern life-and-death decisions made in NICUs and pediatric intensive-care units (PICUs): Every infant, unless permanently unconscious, irretrievably dying, or salvageable only with treatment that would be "virtually futile and inhumane," should be given life-sustaining treatment, no matter how small, young, or disabled the infant might be.

The other effort at regulation was made by the U.S. President's Commission for the Study of Ethical Problems in Medicine (1983), the American Academy of Pediatrics, and numerous writers on ethics in pediatric medicine. Given the complexity of some pediatric cases and the life-and-death nature of selective nontreatment decisions, the common recommendation was to have an ethics committee consult on the cases and give advice to the physicians in the cases. The ethical perspective at the heart of this recommendation was straightforward: In truly difficult cases, the most prudent procedure for decision making is the achievement of consensus by a multidisciplinary committee that is knowledgeable, impartial, emotionally stable, and consistent from case to case.

Similar efforts at regulating selective nontreatment decisions in NICUs and PICUs have not occurred in other countries having technological medicine. In Britain and Australia, for example, governments interested in regulating assisted reproduction technologies to protect pre-embryos have not had a similar interest in regulating selective nontreatment decisions to protect young infants, either from premature deaths or from profoundly impaired lives. Likewise, neither the governments nor the medical societies in these countries have chosen to establish pediatric ethics committees, preferring instead to leave decisions to abate life-sustaining treatment for young infants to the discretion of the physicians and parents of the children.

Nevertheless, some themes and problems are common as decision makers in technologically advanced countries confront the difficult choices presented by premature and disabled infants. First, the ongoing technological development of pediatrics (e.g., the use of exogenous surfactants and high-frequency oscillatory ventilation for treating pulmonary problems) has resulted in improved mortality and morbidity rates for numerous infants and young children. Second, unprecedented surgical techniques (e.g., surgery for short-bowel syndrome and for hypoplastic left ventricle) have resulted in the prolongation of life for many infants who would have died without surgery only a few years ago. Third, these technological and surgical achievements have created a trend in some pediatric subspecialties toward overtreatment of premature and disabled infants, a trend that seems to be contrary to the best interests of some of these children (Caplan et al.). Fourth, even with the technological progress in pediatrics, neonatologists and the parents with whom they work in individual cases are still frequently confronted with an inescapable problem: medical uncertainty regarding the degree and range of disability a neurologically impaired child will have, if the child survives with medical treatment (Hastings Center).

Compared with earlier historical periods, the period of technological medicine has produced unprecedented changes and challenges for parents, physicians, and other persons concerned about the care of infants. The rapidity and extent of the change is noticeable in the types of cases that now present the greatest ethical challenges for parents and physicians in NICUs. In the 1970s and 1980s, considerable debate centered on whether infants with Down's syndrome plus complications and infants with myelomeningocele should receive surgical correction of their physical abnormalities. In the 1990s these types of cases have largely been replaced as ethical challenges by other kinds: (1) cases of extremely premature neonates with birth weights below 600 grams, gestational ages of approximately twenty-four weeks, and severe cardiac, pulmonary, and neurologic impairments; (2) cases of very small and disabled neonates whose low birth weights and disabilities are the result of factors during pregnancy, such as maternal malnutrition, infection (e.g., HIV and AIDS), smoking, consumption of alcohol, or use of cocaine and other drugs; and (3) cases of neonates with anencephaly whose organs could be transplanted into other infants, if the parents of the anencephalic infants were to consent and the law were to permit the transplantation (Walters).

International Perspectives among Pediatricians

The roles of physicians, parents, and nurses in the care of premature and disabled infants vary significantly from country to country. In general, pediatricians in countries that in recent decades have been characterized by authoritarian or totalitarian political regimes tend to take a similar approach to decisions made in NICUs: The decisions to treat or not to treat are made by physicians with only minimal participation by parents, nurses, or other health professionals. By contrast, pediatricians in democratic societies tend to have a more democratic attitude toward decisions made in NICUs: With some variation from physician to physician, the decisions to treat or not to treat are often made in consultation with the parents of the imperiled infants, with some physicians also finding merit in having pediatric ethics committees consult on some of the truly difficult decisions.

For example, one study indicated significant differences between pediatricians in Poland and pediatricians in Australia. The majority of both groups of physicians indicated that they had been confronted with the necessity of making decisions regarding the withholding or withdrawing of life-sustaining treatment from severely disabled infants. However, their views regarding the substantive and procedural features of such decisions were quite different. Whereas virtually all the pediatricians surveyed in Australia (98.2 %) indicated that they did not believe that "every possible effort" should be made to sustain life in every case, half of the pediatricians surveyed in Poland (50 %) stated that they thought that all possible efforts at sustaining life should be made in every case. Regarding specific diagnostic cases, significant numbers of Australian pediatricians thought that life-sustaining treatment could be withheld or withdrawn in cases of anencephaly and microcephaly (29.7 % of the responding physicians), spina bifida and myelomeningocele (25.2 %), extreme prematurity (9.0 %), Down's syndrome with complications (16.2 %), and brain damage with projected mental retardation (26.1 %). By contrast, the pediatricians in Poland, while agreeing with the Australian physicians regarding cases of extreme prematurity and brain damage, were much more reluctant to abate life-sustaining treatment for infants having microcephaly, spina bifida, or Down's syndrome (Szawarski and Tulczynski).

The differences between the Australian and Polish pediatricians were even more significant when they were asked about the procedural aspects of decisions that would probably result in an infant's death. The majority of responding Australian pediatricians indicated that they discussed such decisions with other physicians (90.9 %), the parents of the infant (90.1 %), and nurses (84.7 %). The Polish pediatricians, by contrast, almost always consulted with other physicians (99.0 %) but rarely discussed the decisions with the parents (8.1 %) or nurses (4.3 %).

Another study suggested that there are differences among pediatricians in the United States, Sweden, Britain, and Australia on both substantive and procedural aspects of selective nontreatment decisions. According to this interpretive study, the dominant practice among American pediatricians, especially neonatologists, is to initiate aggressive life-sustaining treatments early, continue those medical interventions while diagnostic tests are being done and various pediatric specialists are consulted, and talk with parents about the alternative of abating treatment only when the parents bring up the subject or when a grim prognosis becomes increasingly clear. This perspective is described as a "wait until certainty" approach, an approach involving a clear ethical choice: Saving an infant who will have severe-to-profound disabilities is preferable to permitting the death of an infant who could have lived a tolerable life. This strategy ensures that all errors are in one direction: the promotion of the infant's life, even a severely disabled life. Treatment that sustains the infant's life can therefore be terminated only when death or profoundly impaired life is inevitable (Rhoden).

This study suggests that pediatricians in Sweden have a different perspective, one that is described as a "statistical prognostic" strategy. This approach seeks to minimize the number of infants whose deaths would come slowly as well as those whose lives would be characterized by profound disabilities. At the risk of sacrificing some potentially normal infants to avoid prolonging the lives of severely impaired infants, this approach uses statistical data, like birth weight, gestational age, and early diagnostic tests, to make selective nontreatment decisions. This strategy also ensures that all errors are in one direction: the promotion of healthy life, even at the cost of allowing some infants to die who could have lived with disabling conditions.

Pediatricians in Britain and Australia are described in the study as having medical and ethical perspectives that frequently differ from those of their American and Swedish counterparts. In contrast to many pediatricians in the United States, pediatricians in Britain and Australia are willing to withhold or withdraw treatment with much less prognostic certainty. Yet in contrast to many pediatricians in Sweden, British and Australian pediatricians are willing to engage in time-limited trials to give various treatments a chance to work, even when the child being treated is likely to have ongoing disabilities. Called an "individualized prognostic" strategy, this approach reflects an ethical perspective that realizes the inherent uncertainty in medicine, permits some role for parental discretion, and affirms the appropriateness of selective nontreatment decisions once a child's prognosis appears poor (Rhoden).

In much of the world, the ethical perspectives among physicians are quite different from the approaches described above because the provision of care to infants takes place outside the confines of technological medicine. In the People's Republic of China, India, the countries of the former Soviet Union, and many of the other countries in the world, the differences in medical management that have just been described have no significance. The shortages of medicine, the obsolescence of medical equipment, the inadequacies of prenatal care, the limited number of pediatricians, and the ongoing problems of malnutrition and infectious disease contribute to a social context in which the lives of infants are frequently short and often characterized by disease and disability.

Alternative Perspectives on the Moral Status of Infants

Ethical perspectives on the care of infants are significantly influenced by views that are held regarding the ontological status and moral standing of infants, whether premature, disabled, or normal. What kind of entity is it whose life, health status, or death is at stake in the decisions made by physicians and/or parents? Is a neonate, in terms of ontological status, the same as an older child and an adult? Does an infant count as a person, in the same way that you and I count as persons? Or are questions about personhood irrelevant in terms of the moral standing that adults choose to grant infants? In terms of moral standing, what kinds of moral rights do infants possess? Do human infants possess full moral standing, making them morally equal to adult persons? Is the moral standing of neonates to be understood as somehow less than that of human adults but more than of human fetuses, or are fetuses, neonates, and adults to be understood as morally the same?

For many philosophers in recent years, questions related to the moral standing of infants have been addressed in the broader context of a discussion about ontological status and, more specifically, the meaning of personhood. One approach is to define *person* as meaning *a living being with full moral standing.* According to this definition, all persons have such standing, leaving open the question of just which characteristics give that standing.

Given this general philosophical perspective on personhood, at least three positions can be identified that link the ontological status of neonates with the moral standard granted to infants. The first position holds that all neonates, whether normal or neurologically impaired, count as actual persons in the same way that you and I count as persons. According to this view, the personhood of neonates is merely an extension of the personhood possessed earlier by fetuses. With this ontological status, neonates, like all other actual persons, have the moral right not to be killed or prematurely allowed to die, since the possession of personhood entails full moral standing, regardless of the age of the person. Personhood, according to this view, is based on genetic code or some other characteristic possessed at conception, not on possession of consciousness, self-awareness, rationality, or any other neurological characteristic.

The second position holds that in order to count as persons, infants (and other beings, whether human or nonhuman) must possess the intrinsic qualities or traits often defined by philosophers as being the threefold combination of consciousness, self-awareness, and at least minimum rationality (Feinberg). If infants lack these core properties, they have an ontological status that is more similar to the status of human fetuses than to the status of older children or adults. Holders of this view claim that all neonates, including normal babies, fail to pass the neurologic tests for personhood and are thus to be classified as nonpersons. In this view, all neonates lack the cognitive qualities that make a human into a person. In addition, the notion of potential personhood is discarded as flawed, largely because the advocates of this second position argue that personhood cannot be possessed in varying degrees. Holders of this second view also claim that only those who have the neurological characteristics of persons possess the rights of persons, including the right not to be killed or prematurely allowed to die. The result, in terms of the moral standing of neonates, is straightforward: Neonates do not possess the moral rights of persons, leaving them at risk of being killed or prematurely allowed to die unless their parents and physicians are motivated by psychological or legal considerations to sustain their lives (Tooley).

The third position stands between the other positions. It identifies the same neurological characteristics of personhood, but according to this view, most neonates (those lacking severe neurologic impairment) are to be regarded as potential persons, not yet possessing the ontological status of actual persons but on the way to the possession of the core properties of personhood through the normal course of human development. Agreeing with advocates of the first two positions on the linkage between ontological status and moral standing, philosophers holding the third position maintain that when infants develop and subsequently become persons, they will acquire full moral standing. Until that time, including during the neonatal period, they are regarded as having a prima facie claim not to be killed, prematurely allowed to die, or significantly harmed in some other way, precisely because they will subsequently and naturally become actual persons.

The differences in these philosophical views have practical consequences in terms of the ways that adults value the lives of infants, including infants who may be extremely premature or severely disabled. Advocates of the first position tend to call for life-sustaining treatment to be administered to all infants in NICUs regardless of birth weight, gestational age, or neurological status, because all infants are actual persons in possession of the full panoply of moral rights common to persons. By contrast, any parents or physicians in NICUs who regard neonates as nonpersons (and who believe that only persons bear the rights borne by persons) are likely to be ready to withhold or withdraw treatment much more quickly, if the law permits them to do so, because the infant lives that are lost do not yet count for much morally. For advocates of the third position, the concept of potential personhood provides an intellectual framework in which difficult prognostic judgments make some sense. In this view, at least part of the difficulty in making decisions to provide life-sustaining treatment or to abate treatment, especially in cases of severe neurologic impairment, has to do with judgments about whether a particular baby has the potential even to become a person in the normal course of his or her development.

Other perspectives on the moral status of infants, some of which are grounded in theological ethics, suggest that the philosophical debate about the personhood of infants is intellectually restrictive and of little practical significance. For example, one fairly common view is that the moral standing of infants cannot depend on whether they meet a philosophically strict definition of personhood, because all infants fail to meet that standard. Rather, what is important is a social understanding of *person* according to which infants are regarded by their parents, physicians, and others *as if* they were persons. This social sense of personhood involves the imputing of personlike rights to infants because of their special roles in families and in society. The practical consequence of this view is that infants, who are given the imputed status of *person* in a social sense, have the same kind of moral standing as older human beings who are persons in a more formal sense (Engelhardt).

Another widely held view is that the personhood question simply does not apply to infants, either in a strict sense or in a social sense. Rather, what is important is that infants are understood to have moral standing as *fellow human beings.* Advocates of this view may regard fetuses and infants as having equal moral standing as human beings, or they may have a developmental view in which viable fetuses and infants, but not nonviable fetuses, have equal moral standing as human beings. Either way, infants are regarded as having the same kinds of moral rights that older human beings have, including the right not to be killed or allowed to die prematurely unless, in unusual cases, the burdens of continued life are regarded as outweighing the benefits of that life to the child (Fletcher). Holders of this view give the same moral standing to infants and fetuses as do holders of the first position above, but deny that these beings have to be called persons.

The personhood approach to the moral status of infants, according to another theological view, is unrelated to the possession of the neurological characteristics identified with personhood discussed above for another reason. The limiting of an infant's value to the question of whether that infant possesses the intrinsic properties of personhood entirely omits another approach to the understanding of the value that infants have: namely, a relational view of value that results from interpersonal bonding, affection, and care by parents and other adults. Even when an infant has a future that will, because of neurologic impairments, be characterized by developmental delay and mental retardation, the parents of the child still usually go through a process of bonding with the child. That process of bonding, which involves the replacement of a hoped-for child with a healthy attachment to the child one has been given, results in a valuing of the child by parents that is surely equal to the valuing of normal children by their parents (May).

A related view is that philosophical arguments about the moral status of infants need to be supplemented, if not replaced, by an experiential ethic of care. This view emphasizes the importance of the various perspectives that parents, physicians, nurses, and other persons bring to pediatric cases. Rather than focusing on the ontological and moral status of infants, most commonly with questions related to the possession of personhood and moral rights, this approach concentrates on the various values and virtues present, or possible, in the context of decision making about an infant's impending death or projected life with disabilities. The practical result is that questions in difficult cases are raised not only about what should be done for the patient but also about what kinds of moral agents the parents, physicians, and nurses should be as they provide care for an imperiled infant (Reich).

Ethical Perspectives on Abating Life-Sustaining Treatment

The ethical perspective that became enacted into the *Baby Doe* regulations and child abuse regulations was only one of the ethical perspectives on the medical care of infants that received considerable attention in the United States in the 1970s–1990s. Other ethical perspectives have also been widely held, both before and after the federal regulations became policy.

For example, for some persons the important ethical question is not whether a given infant can be salvaged through medical treatment. Rather, the important question is what quality of life the child will probably have later, especially if the child's future is predicted to be dominated by severe-to-profound neurologic impairments, multiple surgeries, and numerous other medical problems. The question is sometimes posed in terms of the future relational potential possessed by a child with severe neurologic impairments, with the moral judgment being that an infant who lacks relational capacity will never have the quality of life that would justify the continuation of the child's life (McCormick).

A closely related ethical perspective focuses on a child's best interests. For persons holding this position, the important question is whether the life-sustaining treatment that could be given to imperiled newborns will, on balance, provide the infants with more benefits than burdens. Since quality-of-life projections can sometimes extend to include persons other than the patient, this position's strength is in framing the ethical debate primarily in terms of the patient's best interests, not the interests of the family or society (U.S. President's Commission).

Another ethical perspective emphasizes procedural issues. According to this view, the most important aspect of decisions not to sustain some infants' lives is the question of who should make these difficult decisions. Advocates of this position maintain that in most cases, the parents of a premature or disabled infant are the appropriate decision makers.

A very different ethical perspective on selective treatment decisions also has some advocates. As described in the previous section, some philosophers hold that life-sustaining treatment can morally be withheld or withdrawn from any infant, regardless of birth weight or disability, because the only deaths that matter are the deaths of persons, and no infants meet the requirements of personhood.

Three of these ethical perspectives continue to play major roles in selective nontreatment decisions, with the dominant perspective in individual cases varying from hospital to hospital, physician to physician, parent to parent, case to case. The perspective that calls for life-sustaining treatment to be administered to all infants who are conscious, not dying, and for whom treatment is not "virtually futile and inhumane" remains influential, even if the federal regulations that reflect this perspective have been largely unenforced throughout the country. The reasons for its continuing influence are twofold. First, this perspective is consistent with the reasons that motivate neonatologists to do the work they do: to prolong and enhance the lives of the youngest, smallest, most disabled, and most vulnerable human beings among us. Second, this perspective offers the simplest way of dealing with the multiple problems that constitute the *ethics lab* known as the NICU: It minimizes the factor of medical and moral uncertainty in cases, the role of parents as decision makers, and any considerations of the harm that may be done through prolonged, aggressive efforts to salvage imperiled young lives.

The second perspective that remains influential is the position that emphasizes the role of parents as decision makers. Advocates of this view rarely suggest that parents alone should make the selective nontreatment decisions that could result in the deaths of their children, or that parents should be given unlimited discretion in making such decisions. Rather, the claim that is often made is that parents should, in response to appropriate medical information and advice, have reasonable discretion in making a life-and-death decision regarding their child in the NICU, subject to certain ethical and legal constraints. They are the ones, after all, who may be saddled with the enormous financial costs of neonatal intensive care. They are the ones, in addition to the child, who will have to deal with the child's ongoing medical problems, repeated hospitalizations and surgeries, neurologic abnormalities, and developmental delays. They are the ones who will have to struggle to sustain their marriage, their family life, their careers, and their own physical and mental health.

The third perspective that remains influential is the patient's-best-interests position. Advocates of this position acknowledge the medical and moral uncertainty inherent in many cases, affirm an important role for parents as decision makers, and recognize that the same medical and surgical interventions that produce great benefit for some patients can produce undue harm for others. In contrast to the parental perspective, proponents of this view emphasize that the focal point of decision making in neonatal and pediatric cases should be the best interests of the patient, even when the patient's interests conflict with the interests of the parents. In this manner, the patient's-best-interests position emphasizes the linkage between life-sustaining medical treatment and patient-centered considerations regarding the quality of life—without broadening quality-of-life judgments to include the family, the society, or arbitrary standards for normalcy and acceptability, as quality-of-life projections sometimes do.

The Emerging Mainstream Perspective

If any of these positions can be correctly designated as the mainstream ethical position, at least in the United States, it is the patient's-best-interests position. Advocates of this position are concerned about the treatment-related harms that sometimes occur when neonatologists and other pediatric subspecialists persist, perhaps under the influence of the federal regulations, in overtreating infants who have extremely low birth weights and severe disabling conditions but who are neither unconscious nor dying. At the same time, proponents of the best-interests view are reluctant to grant the parents of premature and disabled infants as much discretion in deciding to abate life-sustaining treatment as some parents would like to have.

In clinical cases, the best-interests position relies on eight variables that help to determine whether to initiate, continue, or abate life-sustaining treatment: (1) the severity of the patient's medical condition, as determined by diagnostic evaluation and comparison with (a) all infants and (b) infants having the same medical condition; (2) the achievability of curative or corrective treatment, in an effort to determine what is meant by *beneficial* treatment in a given case; (3) the important medical goals in the case, such as the prolongation of life, the effective relief of pain and other suffering, and the amelioration of disabling conditions; (4) the presence of serious neurologic impairments, such as permanent unconsciousness or severe mental retardation; (5) the extent of the infant's suffering, as determined by the signs of suffering that infants send by means of elevated blood pressure, elevated heart rate, degree of agitation, and crying; (6) the multiplicity of other serious medical problems, with the most serious cases usually involving a combination of neurologic, cardiac, pulmonary, renal, and other medical complications; (7) the life expectancy of the infant, because some of the severe congenital anomalies involve a life expectancy of only a few weeks or months; and (8) the proportionality of treatment-related benefits and burdens to the infant, a medical and ethical "bottom line" for determining whether life-sustaining treatment or the abatement of such treatment is in a particular infant's best interests (Weir and Bale).

Even with these variables, the ethical analysis of cases involving neonates or other young pediatric patients is anything but easy. Although there are numerous cases about which almost everyone agrees, there continue to be many cases that combine unprecedented medical and moral territory, advances in medical management and technology, medical uncertainty, and ethical conflicts between physicians and parents in such a way as to present serious ethical challenges to all the parties involved in the cases. In such instances, the discernment of the infant's best interests can be a challenging and humbling experience.

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SEE ALSO: *Abuse, Interpersonal: Child Abuse; Care: Contemporary Ethics of ; Children; Clinical Ethics; Compassionate Love; Embryo and Fetus; Family and Family Medicine; Feminism; Genetic Testing and Screening; Life, Quality of: Quality of Life in Clinical Decisions; Maternal-Fetal Relationship; Medicaid; Moral Status; Pediatrics; Research Policy, Risk and Vulnerable Groups; Sexism*

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INFANTS, MEDICAL ASPECTS AND ISSUES IN THE CARE OF

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Overall, there are three relatively distinct groups of babies who are admitted to neonatal intensive care units (NICUs). These groups are different in ways that are ethically relevant. The first group consists of full-term or near-term babies with acute illnesses such as pneumonia or sepsis, as well as babies with surgically correctable anatomic abnormalities. The second group comprises babies with congenital anomalies, including chromosomal anomalies, which are not correctable at the present time. Many of these babies have problems that can be ameliorated but not corrected with surgical or medical treatment. The final group of babies includes those born prematurely who are otherwise physically normal—that is, they have no acute illness or congenital anomaly except their prematurity. The first two groups raise problems that are essentially similar to those that arise in other patient groups. They are different from other patients only in that they are babies. The third group is entirely unique. There are no other clinical populations in which the primary clinical problem arises from an arrested developmental process, and in which the clinical problem will correct itself if development is allowed to continue. This entry describes, in separate sections, the three groups and the different ethical issues associated with them.

Acute Illnesses

Acute illnesses in full-term babies are usually the least morally controversial of the clinical problems that arise in neonatology. Most acute illnesses can be treated if they are accurately diagnosed. The problems that arise in babies are similar to the problems in other high-risk populations. Diagnosis must be made quickly and treatment initiated expeditiously. The babies generally either get better quickly or they die quickly.

Rarely, treatment is only partially successful, and the babies survive but with severe long-term complications of their acute illness. For example, term babies might develop meningitis. The disease can be diagnosed and treated, but some babies are left with severe neurological impairment. In situations where treatment is only partially successful, the babies become similar to babies with uncorrectable congenital anomalies. The only difference is that, in these cases, the anomaly was acquired after birth rather than before. The process of decision-making, however, will be similar to that outlined below.

In general, the issues that arise in this group of NICU patients are not unique to NICU patients. The primary concerns are accurate diagnosis and appropriate treatment. If there is a treatment that works, it should be provided. There is rarely disagreement between doctors and parents in these cases. The ethical issues are driven almost entirely by the medical indications for treatment. Ethics simply dictates that doctors should be competent and should communicate well with parents.

Congenital Anomalies

Congenital anomalies were the primary focus of legal and moral controversy in the 1970s regarding treatment decisions for newborns (Lantos). The key cases focused on syndromes such as trisomy 21 (Down syndrome), spina bifida, and cases of multiple congenital malformations. Generally, the issue that arose was whether or not to attempt surgical treatment to correct some but not all of the congenital anomalies. Thus, for babies with Down syndrome, the issue was whether to correct an associated intestinal or cardiac malformation. In babies with spina bifida, the issue was whether to treat the hydrocephalus by placing a shunt in the brain, or whether to close an open lesion of the spinal canal.

It is understood that, in these situations, the underlying syndromes themselves cannot be treated. Babies with Down syndrome will still have Down syndrome, even if their intestinal or cardiac anomalies are repaired. Babies with spina bifida will still have the long-term neurological problems associated with the spinal cord injury, even if their hydrocephalus is treated. Thus, the issues that drive these decisions are fundamentally different from those in cases of acute illness. The primary focus in these cases is on long-term quality of life for survivors.

Congenital anomalies focus discussion on anticipated quality of life as opposed to prognosis for survival. The discussions often involve the ethical implications of active intervention as opposed to "letting nature take its course." In many of the discussions, there is a sense of fatalism in the face of what are seen as mistakes of nature. Perhaps, the thought goes, these babies were somehow meant to die, and interventions are both unnatural and inhumane.

Many congenital malformations that were once thought to be incompatible with life can now be treated. Given the capabilities of modern intensive care, there are very few congenital anomalies that are truly incompatible with life. Babies with severe congenital heart disease can have open-heart surgery, babies with no intestines can be given total parenteral nutrition, and babies with minimal brain function can be kept alive on ventilators. Unlike cases of acute illness, decisions in these cases are not driven primarily by the medical indications for treatment. Those are usually straightforward. Instead, the decisions are driven by judgments about whether the results of successful treatment will be acceptable. In other words, will the consequential quality of life be sufficient to make the life worth living? In analyzing such decisions, it is necessary to have a nuanced understanding of the different components of "quality of life."

QUALITY OF LIFE COMPONENTS. Quality of life can be broken down into a number of ethically relevant components, each of which must be considered in these cases. These components include the anticipated cognitive or neurological function, the anticipated physical disabilities, the pain and suffering that is associated with the disease itself, and the burdens of the treatments that will be necessary in the future.

Most people today hold that a certain minimal level of cognitive or neurological function is essential for a life to be considered worth living. This was one of the rare areas of consensus in the 1980s controversy about federal regulation of nontreatment decisions for newborns. The agreement, in principle, that cognitive function is an important consideration begs the question of appropriate thresholds. Babies with no cortical function at all, such as babies with anencephaly or babies with prolonged cortical unresponsiveness as a result of anoxic (oxygen-deficiency) injuries, define one extreme. Babies with syndromes such as Down syndrome that lead to mild mental retardation are at the other end of the spectrum. In between are babies with other chromosomal or genetic anomalies, babies with intraventricular hemorrhages, or babies with neurological damage as an aftereffect of treatment for an acute illness.

The process for decision making in such cases requires recognition of a real but constantly shifting boundary or threshold that has clearly defined extremes and a well-recognized “gray zone” in the middle. Today, as a matter of societal consensus, the quality of life in Down syndrome is considered to be above the threshold, so these babies, and babies like them, must be treated. The quality of life in anencephaly is considered to fall below the threshold, so babies with this syndrome generally ought not be treated. There are, occasionally, exceptional cases of anencephaly in which treatment is provided at the parents’ insistence, but they are noteworthy because they are exceedingly rare. Exceptions to the rule do not undermine the validity of the rule, they simply highlight the difficulty of imposing universal compliance with the rule. Cases in between these extremes are still difficult and controversial.

The physical disabilities associated with a condition must be addressed separately from the cognitive or neurological disabilities. Often, babies have an intact brain but have other physical disabilities. In severe spina bifida, for example, the spinal cord damage may make it impossible for a person to move about independently. Generally, physical disabilities, by themselves, cannot justify a decision to withhold life-sustaining treatment. It is clear from studies of adults with spinal cord injuries that it is possible for a person with severe physical disabilities to lead a rich and satisfying life. Thus, in such cases, the focus of discussion is usually on developing an adequate support system and insuring access to rehabilitation services so that function can be maximized.

A third part of any assessment of quality of life has to do with the pain and suffering associated with the disease. Some diseases lead to unrelenting pain and suffering. For example, severe epidermolysis bullosa is a disease that causes blistering of the skin over the entire body, including the oral cavity and intestinal tract. Swallowing is impossible. Scarring of the skin leads to contractures (permanent shortenings) of all the joints. Even comfort care is difficult because merely handling babies with this syndrome causes pain and exacerbates the condition. In such a case, an attempt to prolong life inevitably prolongs the suffering. It is appropriate in such cases, or in cases like them (though there are not many other syndromes that are relevantly similar to epidermolysis bullosa), to withhold life-sustaining treatment based solely on the pain and suffering associated with the disease.

Another component of quality of life has to do not with the pain and suffering of the underlying condition but with the pain and other burdens associated with the necessary treatments. Babies with short gut syndrome, for example, can survive, but only with indwelling venous catheters placed into large veins in the chest or neck. These central lines often become infected and must be replaced. When they become infected, patients must be admitted to the hospital for intravenous antibiotics. Parenteral nutrition often causes secondary problems such as liver failure. In extreme cases, patients are frequently hospitalized to deal with the complications of the treatment, and further treatment predictably exacerbates these complications in ways that cannot be prevented. Another example of excessively burdensome treatment is the provision of mechanical ventilation for babies with progressive and degenerative motor neuron disease. Some such babies are unable to eat, breathe, or talk, but their cerebral cortex is intact, so that they can think. Prolonged mechanical ventilation can prolong life for such babies, but the burdens of the treatment are thought to be high enough that a decision not to initiate mechanical ventilation, or to discontinue it once started, is usually considered acceptable. In such cases, the burdens of treatment drive the decision.

Any adequate discussion of quality of life must separate the components. Nevertheless, in most cases, a combination of these components exists. Generally, the task of moral reasoning about any unique individual case requires doctors and parents to analogize the case with better known paradigm cases. For doctors and parents, the question may be whether a particular case is more like Down syndrome than it is like anencephaly, or whether a burdensome treatment is more like lifetime mechanical ventilation than it is like lifetime dependence on insulin.

Extreme Prematurity

Babies with extreme prematurity comprise the third group of babies admitted to the NICU. The moral considerations involved with these babies include not only all of the considerations in the other two groups but also an important new one—long-term prognostic uncertainty.

Prematurity is both an acute crisis and a chronic condition. The acute crisis requires an emergency response driven by medical indications, just as in the cases of full-term babies with acute medical problems. At the time treatment is initiated, however, the baby’s prognosis is usually uncertain in a different way than in the other two situations. With acute pneumonia, treatment usually either succeeds, in which case the problem is completed resolved, or it fails, in which case the baby dies. There is almost no middle ground. With congenital anomalies and syndromes, treatment cannot cure the underlying disease. So a baby with Down syndrome will still have Down syndrome, even if the congenital heart disease is repaired. The long-term prognosis for survivors is clearly predictable. Again, there is almost no middle ground of uncertainty. With extremely premature babies, by contrast, the prognosis is radically uncertain. It ranges from early death through later death to survival with severe disabilities, moderate disabilities, or no disabilities.

The disabilities can be cognitive, pulmonary, or involve virtually any other organ system. When treatment must be initiated, nearly all babies are in a prognostic gray zone. The outcome for any particular baby simply cannot be known, and it can range across the entire spectrum of possibilities from the very best to the very worst. This raises a whole different set of ethical considerations.

PROGNOSIS FOR SURVIVAL AND THE BIRTHWEIGHT FACTOR. At the time of birth, it is difficult to say whether a particular baby will live or die. It is difficult to predict how long life can be prolonged in cases where death will ultimately ensue. And it is difficult to predict whether survivors will have mild, moderate, or severe chronic problems or no problems. Obviously, an accurate prognosis for a particular baby would be essential to making the best ethical decision for that baby. If survival is impossible, then treatment should not be provided. If intact survival is likely, then treatment is morally obligatory. To a certain extent, clinical research in neonatal intensive care since the early 1980s has helped bring about a greater understanding of these issues and helped to refine, though not perfect, doctors' prognostic abilities.

The goal of this research has been to develop a method to precisely predict the anticipated outcome for each premature baby. The most powerful prognostic measure has always been birthweight. Overall, bigger babies do much better than smaller babies. Almost no babies who weigh less than 500 grams at birth survive, whereas nearly all babies who weigh more than 875 grams at birth survive. The zone of controversy is in between these two birthweights. The weights correspond, roughly, to the time between about twenty-three weeks of gestation and twenty-six weeks of gestation, or between the fifth and sixth months of pregnancy.

One plausible response to these data would be to suggest that only babies over 850 grams should be treated. If this course were taken, however, there would be many babies in the 500- to 850-gram birthweight range who might have survived but who would be allowed to die. Another response might be to treat all babies over 500 grams. With this option, however, treatment is provided to many babies whose death is likely. One way to refine the prognostic estimates is to look a little more closely at the clinical course of these babies.

It turns out that most premature babies who are going to die do so in the first few days of life. The sickest babies are very sick. Because the sickest babies die quickly, the babies who survive for even three days are, by definition, much more likely to survive than other babies of the same birthweight. In fact, by seventy-two hours of age, birthweight virtually disappears as a relevant predictor of survival. The 600-gram babies who survive do just as well as the 1,000-gram babies who survive (Meadow, Reimshisel, and Lantos).

These clinical epidemiological facts have shaped the moral responses of NICU professionals. Prior to the 1980s, discussions about the appropriateness of decisions involving whether or not to treat premature babies presumed that the decision should be made at birth and in the delivery room. It was seen as a one-time, either/or decision. The newly understood clinical realities show why that did not make sense. Among all babies born at less than 750 grams today, half can be saved and half cannot. At the time of birth, however, it is almost impossible to tell which baby will be in which group. The only way to separate the two groups is to initiate treatment on all of them. The sickest babies then *declare themselves* by getting sicker in spite of medical treatment, and the healthier babies *declare themselves* by improving.

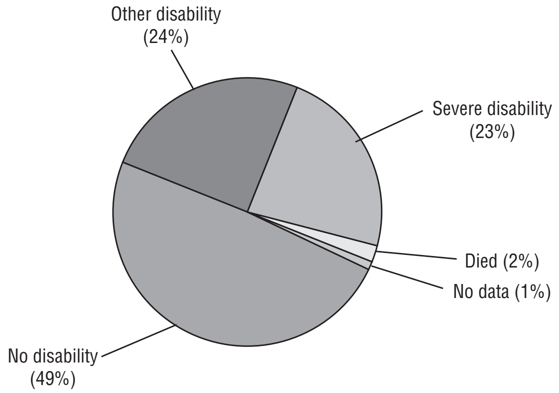
NEUROLOGICAL OUTCOMES. Determining the prognosis for neurological outcome is even more difficult than determining the prognosis for survival. Clearly, premature babies have worse neurological outcomes than full-term babies. Numerous studies have shown a higher incidence of cerebral palsy, seizures, chronic lung disease, and educational problems among premature babies than among their full-term peers. Nicholas S. Wood and colleagues summarized outcomes for tiny babies in a 2000 issue of the *New England Journal of Medicine* (see Figure 1).

These statistics, however, are like the statistics showing poor survival for tiny babies. The relevant question for clinicians and parents is not whether, overall, a group of babies has a worse prognosis but whether for any particular baby the likely outcome can be predicted. There are predictors of bad outcomes, but they are imperfect.

As they reported in 2002, Carl T. D'Angio and colleagues studied long-term neurologic, cognitive, and educational outcomes for babies born at less then twenty-nine weeks of gestation. They showed that the only predictors of bad neurologic outcomes were neonatal intraventricular hemorrhage, severe lung disease, and low socioeconomic status. Betty R. Vohr and colleagues found similar results in a 2000 study. Interestingly, the first two factors are physiological while the third is social, but each is independently associated with bad outcomes. At the very least, this suggests a complex interplay between physiological and sociological factors. Importantly, neither birthweight nor gestational age is, by itself, associated with poor neurological outcomes for these babies. This again suggests that, in the clinical setting, a simple criterion for treatment or nontreatment based on birthweight alone is likely to be relatively inaccurate in tailoring treatment decisions in an ethically appropriate way.

FIGURE 1

Summary of Outcome with Respect to Overall Disability at 30 Months for 314 Children Born at 22 through 25 Weeks of Gestation.



SOURCE: Wood et al., 2000.

Implications of Clinical Knowledge for Ethical Decision Making

These epidemiological facts help define the zone of parental discretion. In order for a decision to withhold life-sustaining treatment to even be considered, doctors must first determine that a baby has an appropriately severe condition. Thus, doctors initiate most discussions of treatment withdrawal. Sometimes, parents will initiate the discussions but when they do, the doctor's task is the same—deciding whether or not the baby fits into one of the categories in which treatment withdrawal is permissible. If not, the doctor must rebuff the parents' request. If so, the doctor should facilitate the process in a way similar to the way she would if she had initiated it herself.

Over the years, different schools of thought have evolved about the proper tone and structure for such discussions. These might be characterized as the *objective information* approach and the *broad shoulders* approach.

In the objective approach, doctors see it as their responsibility to give parents information in the most nondirective way. They simply provide the facts and try to empower parents to understand those facts and to come to a decision that reflects the parents' personal moral or spiritual values. In this approach, the doctor does not make a recommendation about the appropriate course of treatment. If they are asked what they would do, they refuse to answer. The moral psychology of this approach is based upon a fear of being coercive. It views doctors as inappropriately empowered and parents as problematically vulnerable to being overpowered. Given that sociological background, doctors have a moral obligation to restrain their own implicit dominating impulses. Sociologists, who examine the power structures of human communities, often see this sort of pattern of interaction. Some philosophers, especially those for whom individual autonomy is a paramount moral principle, are the most articulate defenders of this approach.

The broad shoulders approach takes a different tack. By this view, parents' particular vulnerabilities require doctors to take some of the burden of decision making upon themselves. Instead of simply giving parents the facts, doctors are obligated to make a recommendation. Advocates of this approach point out that the circumstances of serious illness are circumstances of personal moral and psychological crisis in which ordinary moral principles may not be applicable. Individuals may not be capable of the same sort of autonomy in such situations as they are in other situations. They may need subtle and often implicit assistance to understand their own wants, needs, and values, and they may have trouble owning the decision that flows from these values.

In spite of these radical differences in understandings of the moral underpinnings of the conversations that lead to decisions, in practice, the structure of conversations between doctors and parents look similar in both. The first discussion is one of facts and possibilities. The clinical facts are explained. The possibilities for treatment or nontreatment or presented. Questions are answered. Usually, this first discussion is then adjourned, and parents are allowed time to think. In most cases, they seek outside support—from extended family, from clergy, or from mental health professionals.

A second discussion, during which a decision is reached, usually follows within a few days. Three sorts of conclusions can be reached. In the first, parents decide that they do not want to stop treatment and do not want to reconsider their decision in the future. They want *everything done* to keep their baby alive. Generally, this leads to a discussion of the ambiguity of the term *everything done* in today's medical environment. The second sort of conclusion that can be reached is for a *time-limited trial* of continued treatment. By this approach, doctors agree to continue treatment for a defined period and to set certain parameters or endpoints that they might then look for to see if the treatment is leading to anticipated goals. For example, doctors might offer to continue mechanical ventilation for another week and if, at that point, the ventilator can be safely discontinued, then it will be. If not, however, it will be discontinued anyway in a manner that will likely lead to the death of the baby. The final sort of conclusion that can be reached is a decision to withdraw life-sustaining treatment immediately.

In these situations, a standard set of rituals, familiar to the staff in most NICUs, ensue. The baby is moved to a separate room, the parents are called in, the ventilator or the intravenous fluid pumps are removed, and the parents are allowed time alone to hold their dying baby.

These approaches reflect the inherent uncertainty of the process. When death is inevitable, there is no moral decision to be made. In those circumstances, heroic efforts are often made to prolong life and those efforts fail. A moral statement has been made, a moral commitment fulfilled. Moral decisions arise only when there is ambiguity or uncertainty about the prognosis and about the efficacy of treatment. As has been shown above, however, there is almost always uncertainty. Uncertainty creates the necessity for moral, as opposed to simply clinical, decision making.

Conclusion

The current state of ethical decision making for infants in neonatal intensive care units involves several tasks. The first task is to correctly categorize the clinical indication for intensive care treatment. The second is to determine, as accurately as possible, the baby's prognosis for survival. Finally, doctors must estimate the prognosis for long-term outcome among survivors in terms of neurologic disability and quality of life. These facts ground discussions of the proper ethical course of action. In most cases, they lead quickly to a consensus about the proper course of action.

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SEE ALSO: *Abuse, Interpersonal: Child Abuse; AIDS; Care: Contemporary Ethics of; Children; Clinical Ethics; Compassionate Love; Embryo and Fetus; Family and Family Medicine; Feminism; Genetic Testing and Screening; Infants, Ethical Issues with; Life, Quality of: Quality of Life in Clinical Decisions; Maternal-Fetal Relationship; Medicaid; Moral Status; Pediatrics; Research Policy: Risk and Vulnerable Groups; Sexism; Trust*

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INFANTS, PUBLIC POLICY AND LEGAL ISSUES

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Medical decisions regarding infants vary in the seriousness of their consequences for infants, families, health providers, and society. They range from decisions about home birth and male circumcision—debatable but generally agreed to be matters of private choice—to vaccination, genetic screening, female genital mutilation, and high technology interventions for critically ill newborns. In the United States, parents' legal right to select even the most invasive treatment—or to refuse lifesaving measures—was nearly unquestioned until late in the twentieth century. From the early 1980s into the early twenty-first century, this right became a focal point of litigation, extensive scholarly comment, and public concern. Because much of the legal and public policy debate has focused on infants who require life support, decision making will be discussed here in that context.

The Infant's Interests

The increasing complexity of decisions about the treatment and nontreatment of infants has exacerbated the struggle over who may make these decisions. Advances in medical technology, surgical procedures, and pharmaceuticals allow severely compromised infants to survive. These new technologies frequently entail painful procedures for the infant and the possibility of adverse effects that further attenuate the infant's already fragile hold on life. For example, resuscitation techniques allow many more premature infants to survive; but these infants frequently need prolonged ventilatory assistance and invasive diagnostic and treatment procedures. They are also at increased risk both for cerebral hemorrhages, which create severe neurological deficits, and for significant treatment-related adverse effects, such as blindness and deafness.

Decisions on treatment have traditionally rested with parents, healthcare providers, or some combination of the two. Since the 1980s, the decision-making powers of these parties have been challenged. In the United States, the older body of law has been partially eroded by legislative enactments and court decisions that highlight the rights of the infant (Cooper). Indeed, recognition of the infant's individual rights arising from the celebrated 1982 Baby Doe case became the basis for substantial federal intervention in medical practice and family life.

Baby Doe was afflicted with Down syndrome, a chromosomal abnormality resulting in mental retardation and a propensity for cardiac and other congenital malformations. The infant had such a congenital defect, a tracheoesophageal fistula (an abnormal passage connecting the trachea and esophagus), which if not surgically corrected results in death. The parents, after consultation with and with the concurrence of their attending physician, refused to consent to the surgery, primarily on the grounds that a child with Down syndrome could not attain a "minimally acceptable quality of life." That conclusion was, and continues to be, strongly disputed. A trial court, however, ruled that the parents had the right to refuse surgery for their child (*In re Infant Doe,* 1982).

Immediately after the infant's death, President Ronald Reagan directed the U.S. Department of Health and Human Services (DHHS) to issue regulations protecting infants with disabilities from treatment discrimination by parents, healthcare providers, or both. Through the regulations, issued in March 1983, DHHS claimed authority under the Rehabilitation Act of 1973 to order healthcare facilities receiving federal assistance to provide sustenance and aggressive medical treatment to infants with disabilities. The regulations required posting signs announcing the new federal protection in treatment areas of hospitals; established "Baby Doe Squads" to investigate alleged instances of treatment discrimination; and provided for a toll-free hot line to facilitate the reporting of discrimination (Lawton, Carder, and Weisman). Most healthcare providers, as well as many members of the public and of Congress, reacted negatively. A prestigious national group studying healthcare decisions—the U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereafter, U.S. President's Commission)—and the American Academy of Pediatrics (AAP) both vehemently criticized the regulations. The U.S. President's Commission argued for a standard that would focus on the "best interests" of the infant. The AAP, along with several other parties, sought help from the federal courts, which invalidated the regulations only a few weeks after they became final (*American Academy of Pediatrics v. Heckler,* 1983).

DHHS next produced the "Baby Doe II" regulations, modifying the requirements for signs and providing for an infant-care review committee in each hospital rather than an outside investigative team. These regulations too were rejected—ultimately by the U.S. Supreme Court—on the grounds that the Rehabilitation Act did not give DHHS any authority to regulate parental decisions about infant treatment (*Bowen v. American Hospital Association,* 1986).

In a final effort to influence the care of newborns, Congress enacted the Child Abuse Amendments of 1984, which directed DHHS to develop regulations governing infant care and guidelines for hospital infant-care review committees. As of 1985, federal funding for state child-abuse prevention and treatment efforts was conditioned on compliance; only a few states chose to decline the funding. Under the amendments, the child protective service agency of a state is the only party that may initiate an action of neglect. Nevertheless, the act broadened the definition of child abuse to include "withholding of medically indicated treatment," thereby affecting physician practice standards. The amendments require that an infant with a disability receive appropriate nutrition, hydration, medication, and the "most effective" treatment according to the reasonable judgment of the treating physician. In only three situations may treatment be withheld: (1) when the child is chronically and irreversibly comatose; (2) when treatment could not save the child's life for any substantial length of time; or (3) when the treatment would be inhumane and "virtually futile" with respect to survival. The distinction between inability to save the life (situation 2) and "virtually futile" (situation 3) lies in the "degree of probability or uncertainty in determining the futility of treatment" (Boyd and Thompson). This distinction has become increasingly difficult to draw, in the context of both withdrawal and continuation of treatment.

In the wake of the Child Abuse Amendments, the U.S. President's Commission continued to advocate that the standard for infant treatment or nontreatment be based on the "best interests" of the infant. This standard draws on the standard of "substituted judgment" that is often applied to incapacitated, but once competent, patients. In such cases, a proxy attempts to make treatment decisions, as she or he believes the patient would, if able. For newborns, the commission recommended that decision makers attempt to assess the best interests of the infant "by reference to more objective, societally shared criteria." In sum, the commission recommended that decision makers "choose a course that will promote the patient's well-being as it would be conceived by a reasonable person in the patient's circumstances" (U.S. President's Commission, pp. 135–136). Numerous courts have since adopted the "best interests" standard in making infant treatment decisions, and it has become the prevalent standard.

Ascertaining the infant's best interests generally falls to the primary caregivers—in most cases, the parents, who, although assisted by numerous directors, nurses, and social workers, must make and bear the brunt of these difficult decisions. Unfortunately, the guidelines available to decision makers from the U.S. President's Commission and subsequent case law are far from concrete. In describing the "best interests" standard, the commission stressed that normal adults must not impose their values or external concerns upon the beleaguered infant. In its guidelines, the commission stated that futile treatment for severely compromised infants with a lifespan of hours or days need not be provided; at the other end of the spectrum, the commission condemned the withholding of treatment for a correctable problem when the infant was afflicted with an unrelated, non-life-threatening disorder, such as Down syndrome (U.S. President's Commission, 1983). For the vast territory in between, however, there is little guidance.

Determining the best interests of a compromised infant using the commission's guidelines presents considerable problems of interpretation (Rhoden, 1985). Some believe that the best interests of the infant require providing maximum treatment in virtually all cases (Smith; Wells; Wells, Alldridge, and Morgan). Under this construction, infants express their interest in surviving by responding positively to treatment (Cooper). Others believe that nontreatment may be justified when the infant's life can be viewed as an injury rather than as a gift to the infant; an *injury* is inferred when there is no prospect of meaningful life, which might occur because: life expectancy is very short, there are severe mental deficits, or no curative or corrective treatments are available (Weir).

Some argue that the rational interests of the infant in treatment or nontreatment should not be limited to avoiding suffering (including the pain of treatment) and to minimizing physical and mental deficits, but should also include factors such as the burden on the family and society (Wells, Alldridge, and Morgan; Smith). Such a view holds that when an infant's condition lacks any "truly human qualities" or "relational potential," the best decision is not to treat (Smith, p. 56). One can presume that an infant has an interest in his or her "standing and memory within the family" (Mitchell, p. 341). If so, the infant's best interests cannot be determined in isolation from the feelings and concerns of others. Although such "quality of life" considerations are given short shrift under the current federal law and under the U.S. President's Commission's best-interests standard, they are an inevitable subtext to the debate (Rhoden).

Parents' Interests

U.S. jurisprudence still strongly favors parents as decision makers for children's medical care, although it does not accord constitutional status to this preference (*Cruzan v. Director, Missouri Department of Health,* 1990). Though some dispute the basis for a parental preference—asking whether it is for the parents' sake, the children's, or society's (Schneider)—the law is willing to assume that parents, with physicians' help, generally can best judge the child's interest and will best protect it. Moreover, it seems fair to defer to those who will live intimately with the results of the decisions.

Nevertheless, the wisdom of this presumption is challenged on many fronts, both from within and outside the legal establishment. Parental authority is not absolute, but rather conditional. It is settled law that the state may intervene if necessary, superseding parents' authority by proving them unable or unwilling to safeguard the child's welfare. In the late 1990s and early 2000s, there was increasing willingness to resort to child-endangerment provisions to subvert parental decision making with respect to critically ill infants (*Tabatha R. v. Ronda R.,* 1997; *In re K.I.,* 1999; *In the Matter of D.R.,* 2001). Some scholars have posited that paradoxically greater deference is given to parental authority when an adolescent is involved as compared to when an infant is involved, with parents of compromised infants frequently being referred to child protection authorities for questioning or opposing the recommendations of physicians (Rosato). In extreme cases, parents may be criminally prosecuted for failing to fulfill their responsibility to provide ordinary care (*Lundman v. McKown,* 1995).

Many scholars and practitioners question how well parents are able to judge the needs of a critically ill infant. The task is daunting, because the medical specialists on whom parents depend often cannot predict a child's chances of survival or normality with any certainty at the point when decisions must be made, nor adequately warn of the suffering that treatment may eventually entail (Bouregy). In addition, parents come to the task exhausted by childbirth and the child's medical crisis, grief-stricken, and in near shock (Jellinek et al.). Physicians do not always share essential information with parents, and parents often absorb poorly the limited information they receive (Perlman et al.). Even observers who find parents the best possible decision makers speak of their vulnerability during the crisis, especially to manipulation by physicians and others (Rushton and Glover).

On the other hand, parents may wholly reject medical guidance. Parents have sought to prevent necessary medical treatment of their infants despite entreaties of medical professionals (*In the Matter of D.R.,* 2001; *HCA, Inc. v. Miller,* 2000). Conversely, parents have fought to continue extraordinary medical intervention for infants and children, despite physicians considering such treatment virtually futile in terms of ultimate survival (*In the Matter of Baby "K",* 1994; *Rideout v. Hershey Medical Center,* 1995; *In re K.I.,* 1999). Several have protested the removal of a *legally* dead infant from life support, insisting on continued treatment (*In the Matter of Long Island Jewish Medical Center,* 1996). In other cases, parents have commandeered treatment; in one notorious incident, a father, Rudy Linares, disconnected his infant son's respirator and held off nurses at gunpoint until the boy died (Gostin).

A second criticism of giving parents authority is that they may deliberately elect not to satisfy an infant's dire needs. In this view, it is naive to posit an identity of interest between infant and parent. Parents guard their own interests, those of the family as a unit, and those of current and future siblings—all of which may be gravely threatened by the sick newborn. Some observers of such behavior describe it neutrally. To a sociobiologist, "individual infants may attempt to extract greater investment from their parents than the parents have been selected to give," causing parents to reduce their investment in the child (Hrdy, p. 410). A philosopher writing on the subject actively encouraged parents to weigh the child's interests, including life itself, against others' needs: "The neonate is not born into the family circle so much as outside it, awaiting inclusion or exclusion. The moral problem the parents must confront is whether the child should become a part of the family unit" (Blustein, p. 166). But other commentators condemn any deviation on the part of parents from pursuit of the child's interest. Among these were the proponents of the Baby Doe regulations and, later, a majority of the U.S. Supreme Court, which noted that family members "may have a strong feeling—a feeling not at all ignoble or unworthy, but not entirely disinterested either—that they do not wish to witness the continuation of the life of a loved one which they regard as hopeless, meaningless, and even degrading" (*Cruzan v. Director, Missouri Department of Health,* p. 286). Echoing this view, in a case from 2000 (*HCA, Inc. v. Miller*), a couple sued their healthcare providers for having resuscitated their prematurely born infant, against the parents express wishes, when all agreed that the infant would be severely impaired if she survived.

Practitioners—doctors, lawyers, and social workers—observe parents acting from mixed motives in accepting or rejecting medical care. By forgoing treatment, they may hope to spare the infant suffering and lessen their own, avoid financial and other burdens on the family, and/or prevent the child's eventual institutionalization (Newman). They may instinctively fear the damage to parent-child relations created by medicine's lifesaving technology (Boyce; Kratochvil, Robertson, and Kyle).

Not infrequently, the parents' religious beliefs discourage medical intervention. When the infant is in peril and medical attention will ameliorate or cure the illness or disability, there is an increasing tendency to seek a court order to terminate parental rights to further the best interests of the child. In a case from 2001 (*In the Matter of D.R.*), the parents were followers of the Church of Truth, which rejects medical treatment of all illnesses in favor of spiritual healing. Their infant was beset with developmental delays and numerous disabilities, including a severe seizure disorder. Unmedicated, the seizure disorder was likely to cause additional neurological injury to the infant, worsening her already poor prognosis. At the insistence of the paternal grandparents, the child came to the attention of physicians and child protection authorities. The parents steadfastly refused to comply with the infant's medication regimen, and ultimately the court deemed the child deprived and neglected, awarding custody to the paternal grandparents. The court professed respect for the parents' religious preferences and their right to raise their child in concert with those preferences but was bound to take action to preserve the child's health and welfare. The court noted that the statutory requirements for deeming the infant *deprived* had little to do with the parents' religious beliefs, but rather turned on the child's need of special medical care and the parents' willful failure to provide such care.

This increasingly protective posture toward the infant is evident even before birth. In the case of a pregnant Jehovah's Witness with a dangerously low blood count, a court asserted custody over the thirty-four-week-old fetus and mandated blood transfusion against the mother's will to safeguard the fetus. An appeals court subsequently held that the unconsented-to blood transfusion was an invasive medical procedure and a violation of the mother's rights to bodily integrity (*In re Fetus Brown,* 1997). This case demonstrates the willingness of the courts to favor the alleged best interests of the child, or even fetus, over the well-enunciated religious beliefs of the parent.

Parents also may insist on extraordinary measures in an attempt to be faithful to their understanding of their religion's tenets, as well as to assuage perceived guilt; or to please the other parent, friends, and family; or from selfless devotion to the child that the parent cannot reconcile with consenting to death (Nelson and Nelson). In such cases, ultimately, the best interests of the child are likely to be valued above the parents' beliefs and needs. Before a decision is made to cease extraordinary life-support measures in opposition to the parents' wishes, however, the parents must be afforded appropriate due process to argue for continuation of therapy (*Rideout v. Hershey Medical Center,* 1995). Although parental rights are not absolute, they are a formidable factor in medical decision making for infants and children and remain so even if the parents are not *model parents* (*Tabatha R. v. Ronda R.,* 1997).

The law is relatively clear in its expectation of parents, though the mandate may be excruciatingly difficult to follow. Federal and state constitutions, as well as statutory and decisional law, accord equal status to all living human beings. Parents must act in their child's interest, weighing the immediate physical and long-term emotional suffering for the infant to be expected from aggressive treatment against the consequences of no or lesser treatment. Thus, while some object to consideration of the infant's quality of life in these decisions, such factoring is central to the parents' legal duty.

Healthcare Providers' Interests

Historically, treatment decisions rested with the midwife or physician caring for the newborn and its mother. Although parents ostensibly *owned* their children, they routinely ceded control to the healthcare provider. During the twentieth century, the decision-making model shifted to one in which the parent and the provider jointly decided on medical intervention for the infant. In recent decades, the parents' role has markedly increased as a result of a greater number of treatment options, increased parental knowledge and awareness, and greater respect for patient autonomy (Cooper).

Organized medicine has not opposed this development. A 1975 AAP survey indicated broad support among pediatricians for the proposition that infant treatment decisions should be made jointly by the parents and physician, with the parents taking the pivotal role. In a 1990 report, the Society of Critical Care Medicine's Task Force on Ethics recommended that parents set priorities for the treatment of critically ill pediatric patients. The American Medical Association also defers to parents but emphasizes use of the best-interests standard proposed by the U.S. President's Commission.

Physicians readily acknowledge the frequent conflicts between their dual commitment to save lives and to alleviate suffering. In reality, these factors are rarely the only ones that affect the physician treating a critically ill infant. Healthcare providers may have varying philosophies with respect to treatment of infants afflicted with certain disabilities; they may also be influenced by their research agendas, possess insufficient knowledge to assess accurately the infant's disability and prognosis, or be influenced by real or perceived risk of legal liability (Rushton and Glover; Rosato). In addition, physicians focus on the diagnosis rather than on the prognosis and long-term care of their infant patients (Perlman et al.). As a result of all these factors, physicians may not be optimally effective partners for the parents in the decision-making process. For example, an obstetrician may act in a paternalistic fashion toward a patient, a mother, seeking to protect her from the tragedy of dealing with the fate of an impaired infant. Alternatively, a neonatologist may be overly optimistic in judging and discussing with the parents the infant's potential for meaningful life (Cooper).

Frequently, nurses serve as the primary information conduit between doctors and parents, and naturally there are biases inherent in their perspective, too. Because they are the healthcare providers who care for patients most intimately, they may personalize severely disabled infants beyond reality in order to deal with the burden of nursing them on a day-to-day basis. As a result, nurses may be incapable of advocating against treatment when it is futile and thus be unable to serve as effective advocates for either the infant or the family. In addition, they are limited by the practical realities of their role in the employment hierarchy of the hospital (Mitchell).

In some cases, healthcare facilities and providers may overtreat a severely compromised infant to avoid legal liability. The Linares case, while an extreme example, arose from tensions that are often present. The healthcare providers in that case, despite their acknowledged sympathy and agreement with the father's desire for his son's death, insisted for many months on treating the infant. They did so, they said later, because they believed that state law required continued life support. Critics alleged that individual healthcare providers and the facility (through its lawyer) had abandoned the best interests of both the child and the family to protect themselves. Indeed, some see an "overwhelming fear of possible, indeed theoretical, adverse legal repercussions" among healthcare providers (Nelson and Cranford, p. 3210). This fear is not unfounded; as mentioned earlier, in the 2000 *HCA, Inc. v. Miller* case, healthcare providers were sued, albeit unsuccessfully, for wrongful resuscitation of a severely premature infant. On the other side of the treatment coin, the 1994 Baby "K" case, in which healthcare providers were forbidden to refuse to provide treatment they considered futile, also speaks to the risk of legal reprisal. There is no safe harbor that ensures freedom from liability for healthcare providers in these difficult, emotionally charged situations.

Society's Interests

A society such as that of the United States has numerous, sometimes contradictory, interests in the healthcare of infants. These include preservation of the life and health of the next generation; the guarantee of the rights of individuals; the support of families; the conservation and wise expenditure of economic resources; the maintenance of a just and predictable legal system; and the compromise between—or at least the orderly expression of—clashing values of groups within society. Two of these issues, cost and the social effect of litigating treatment decisions, are discussed below.

Concern for the cost of neonatal intensive care—the most expensive element in the care of infants—preceded the currently intense focus on health costs in general. This treatment is the exception to the rule that the United States directs resources disproportionately to adults, especially the elderly. Technological advances in the treatment of newborns halved the neonatal death rate between 1970 and 1980 (U.S. President's Commission, 1983). Since then, the extraordinary cost of the technology has helped to focus attention on how many and which infants should be treated.

Many families cannot cover the cost, and there is debate over whether the resources available for a particular infant should be taken into account by decision makers. Most commentators share the view expressed in a seminal article from 1975 on the subject: "Just as a parent is not obligated to attempt to save a drowning child if the parent cannot swim, neither is he obligated to incur enormous expense in providing treatment with a slight chance of success" (Robertson, p. 236; see also Newman). No judicial decision, however, accepts the proposition that personal resources should dictate life or death. Usually, the issue is avoided in litigation. When it is specifically cited, a typical court reply is that the "cost of care in human or financial terms is irrelevant" (*In re Care and Protection of Beth,* p. 1383).

Whether or not cost should affect decisions on treatment, there is evidence that it does. Although providers may not abandon a patient without incurring liability, a study comparing medical need to the services sick newborns receive indicates that healthcare providers do not allocate services solely according to need, but are instead influenced by the newborn's insurance coverage—private, governmental, or none (Braveman et al.). Governmental insurance is less attractive to providers than private insurance because government does not reimburse the full cost of care. Thus, at times it appears that while society insists on extending the life of premature and seriously ill infants, it simultaneously refuses to absorb the cost of their immediate and long-term care—a result described as "political hypocrisy in its cruelest form" (Holder, p. 113).

A second salient issue for society is whether it has erred by assigning this category of treatment decisions increasingly to the courts. Criticism of the failure to treat Baby Doe was widespread and severe, but the legal processes that ensued were also criticized. Numerous objections are raised to the removal of medical decisions from the private sphere. The judicial system may be too cumbersome and costly and may further traumatize family members and invade their privacy. The publicity surrounding infant-care cases may prevent other parents from exercising their right to forgo treatment. In addition, the practice of medicine is negatively affected. Explicit direction from some courts to extend life whenever possible and the implicit threat of litigation reinforce U.S. medicine's alleged tendency to overtreat (Newman). For example, one in three neonatologists state that the Baby Doe regulations require treatment *not* in an infant's best interest (Fost). Finally, in investigating and deciding these cases, judges and other officials must choose among competing moral and religious philosophies, a problematic choice in a society that values diversity (Newman).

Obviously, the law is disadvantaged in attempting to supervise medical care for particular infants. In most jurisdictions, understanding of the legal requirements for forgoing treatment is imperfect, even among lawyers (Gostin). The scarcity of prosecutions and precedents suggests a high degree of social ambivalence on this subject—leading, according to Carl Schneider, to "a troubling disjunction between the law on the books, which seems to make neonatal euthanasia criminal, and the law in action, which does not punish it" (p. 152). Schneider further contends that there is no social consensus on the central questions: What is human life? When is death preferable to life? What do parents owe their children? What does society owe the suffering? As a result, he and others see a tendency to abandon the search for substantive principles in the law and instead adopt procedures for reviewing individual cases (Schneider).

One such procedure is the assignment of a role in decision making to institutional ethics committees. Virtually unknown before 1983 (fewer than 1 percent of U.S. hospitals had such committees at that time), they came to prominence through two avenues. First, the influential U.S. President's Commission report in 1983 recommended their use; second, the establishment of committees became a major point of compromise in negotiations between the government and healthcare providers over the Baby Doe regulations (Lawton, Carder, and Weisman). By 1986 the AAP, which had strongly endorsed the committees, found them in 60 percent of hospitals.

In some instances, the committees have functioned as it was hoped they would. For example, in the case of Baby "L," a physician applied to the hospital's ethics committee for permission to cease extraordinary treatment of an infant who was capable only of pain perception and to transfer the infant to another facility and provider. The parent opposed this action and sought an opinion from the courts. The court upheld the decision of the hospital and the physician and allowed the transfer of the child to a facility willing to continue treatment (Paris, Crone, and Reardon). In other cases, however, a hospital's ethics committee failed to persuade either the parent or the trial court that treatment was futile (*In the Matter of Baby "K",* 1994; *Rideout v. Hershey Medical Center,* 1995). Although concerns are expressed about the committees' role, makeup, criteria for decision making, influence, results, and effectiveness, ethics committees appear entrenched as a visible, albeit not dispositive, representative of society in controversies over care for infants.

Long-standing respect for the discretion of parents and healthcare providers in making infant treatment decisions appears to be gradually giving way to greater emphasis on the rights of the infant. Debate is ongoing as to whether this emphasis has been overaccentuated, to the detriment of parents and critically ill infants alike. Parents and healthcare providers continue to look to the courts and society at large for guidance, finding precious little consensus.

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SEE ALSO: *Abuse, Interpersonal: Child Abuse; AIDS; Children; Clinical Ethics; Family and Family Medicine; Healthcare Resources, Allocation of; Infants, Ethical Issues with; Infants, Medical Aspects and Issues in the Care of; Life, Quality of: Quality of Life in Clinical Decisions; Maternal-Fetal Relationship; Medicaid; Pediatrics; Research Policy: Risk and Vulnerable Groups*

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INFORMATION DISCLOSURE, ETHICAL ISSUES OF

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Since 1970, ethically recommended healthcare practice in the United States has increasingly supported a high level of information disclosure to patients. This article reviews the change, notes some reasons for it, and explores several concerns about disclosure and its implications for particular information types.

Philosophical Background of Current Opinion

Generally, philosophical discussion has supported veracity as a moral principle, obligation, or virtue. Veracity draws its strength from the complex support it provides to diverse values—respecting others, avoiding coercion and manipulation, supporting community, maintaining reciprocity in relationships, supporting the value of communication generally, eliminating the costs and complexities of deception, refraining from unduly assuming responsibility, and maintaining trust.

Philosophers have generally treated veracity as an obligation flowing from more fundamental theoretical principles, such as utility, religious duty, respect for persons, or some combination of beneficence, fidelity, and autonomy. John Stuart Mill, for instance, regarded truth-telling as justified by utilitarian considerations, and W. D. Ross included honesty among the duties of fidelity. A few have given it more basic status. Some theologians, such as Dietrich Bonhoeffer, have set truth telling in the context of greater religious truths and treated false doctrines as forms of deception. Aristotle described falsehood as "in itself mean and culpable" (Bok, p. 24); G. J. Warnock listed veracity as a major virtue with the same status as beneficence and justice. Immanuel Kant and Augustine are notable for having defended truth-telling most strongly. In a brief article, Kant argued that it would be wrong to lie even to a murderer seeking the hiding place of an intended victim.

However, not all theorists have defended veracity; Henry Sidgwick denied that it could stand as a "definite moral axiom" because of its variable applications and numerous exceptions (Bok, p. 293). David Nyberg argued that trusting relationships among people normally require "the adroit management of deception" (Nyberg, p. 24). Moreover, most philosophers have defended deception in at least some cases. Plato defended lying to the public for the sake of society as a whole, and many philosophers have warranted deception when truthfulness might result in serious harm (Bok).

Application to Healthcare

Until the late twentieth century, philosophers often regarded a physician's withholding a fatal diagnosis from a patient as a stock exception to general precepts of veracity. Philosophers and physicians regarded the distress expected from such news as sufficiently harmful to outweigh the presumption favoring disclosure. Withholding a fatal diagnosis functioned as a paradigm for sharing other medical information with patients. The ethical tradition concerning the doctor-patient relationship thus tended, with some notable exceptions such as Worthington Hooker and Richard Cabot, to emphasize the obligations of confidentiality and to ignore and even deprecate disclosure (Radovsky). Oaths and codes omitted truth telling, and precepts and discussions of talking with patients tended to recommend caution in revealing information. Ethicists perceived the doctor-patient relationship as oriented to therapy, reassurance, and avoiding harm; physicians were to provide lies and truth instrumentally only insofar as they aided therapy.

Since the 1960s, opinion on the role of disclosure in healthcare has changed rapidly in the United States. The patients' rights movement and the rise of bioethics have created a climate of opinion supporting honest disclosure of medical information. The affirmation in 1972 of "A Patient's Bill of Rights" by the Board of Trustees of the American Hospital Association notably marked this shift in opinion. The bill stated, "The patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand" (Lee and Jacobs, p. 41).

These changes in opinion developed in concert with the spread of informed consent as standard practice in research and therapy. Informed consent derived from a view of respect for persons that emphasized an individual's power to make decisions adequately. This view required honest disclosure. Thus, most ethicists in the 1970s and 1980s supported fuller disclosure as a means of respecting patient autonomy (Katz).

The patients' rights movement favored empowering patients and increasing their control over medical care. As Howard Waitzkin argued in his observations of physicians' communications with patients, the traditional pattern of withholding information reflected a habit of dominating patients and keeping the course of therapy firmly under professional control (Waitzkin). Reformers saw a wider patient understanding of care as supporting a less paternalistic and more contractual relationship, as well as empowering particular classes of patients, such as women and people of color. Susan Sherwin, for example, identified one of the main tasks of feminist healthcare ethics as being to increase equity "by distributing the specialized knowledge on health matters in ways that allow persons maximum control over their own health" (Sherwin, p. 93).

The codes of ethics of the health professions began to reflect this important shift in opinion. The American Nurses' Association's Code for Nurses linked disclosure with truth-telling and self-determination: "Clients have the moral right … to be given accurate information, and all the information necessary for making informed judgments." The code counseled nurses to avoid "claims that are false, fraudulent, misleading, deceptive, or unfair" in their relations with the public (American Nurses' Association, p. 2). The 1980 revision of the American Medical Association's "Principles of Medical Ethics" included the principle, "A physician shall deal honestly with patients and colleagues, and strive to expose those physicians deficient in character or competence, or who engage in fraud or deception" (Council on Ethical and Judicial Affairs, p. ix). The American College of Physicians' (ACP) Ethics Manual recommended that patients be "well informed to make health care decisions and work intelligently in partnership with the physician." The manual advised that communication can "dispel uncertainty and fear and enhance healing and patient satisfaction." In general, the ACP held, "disclosure to patients is a fundamental ethical requirement" (p. 950). Subspecialty ethics codes—such as those of the American Academy of Orthopaedic Surgeons, the World Psychiatric Association, and the American College of Obstetricians and Gynecologists—also began to include recommendations supporting veracity.

Changing Contexts for Veracity in Healthcare

While a high level of disclosure became the recommended practice, cross-currents of thought emerged regarding the motivations for informing patients. First, observers discussed the psychological benefits and risks of giving patients bad news. Second, the increasingly institutional setting of healthcare practice influenced patterns of disclosure. Third, discussion distinguished the obligation to disclose information from the obligation to refrain from lying. Fourth, the uncertainty of medicine modulated the obligation to disclose. Finally, an increasing philosophical emphasis on relational aspects of practitioner-patient ethics broadened the foundations for veracity beyond the single element of respect for autonomy.

HEALTHY DISCLOSURE. Medical works prior to the 1970s tended to assume that revealing a fatal diagnosis would cause patients to experience painful emotions, commit suicide, refuse needed care, or give up hope and die more swiftly. In her important work *Lying: Moral Choice in Public and Private Life,* Sissela Bok argued that traditionalists exaggerated such problems. Patients generally want to be informed, and the benefits to a well-informed and cooperating patient outweigh the risks of disclosure (Bok). Others supplied case histories illustrating the emotional perils of withholding a terminal diagnosis from vulnerable and trusting patients (Dunbar; Sherwin).

Elisabeth Kübler-Ross provided crucial support for the psychological benefits of disclosure by her research on the emotional processes of coming to terms with expected death. In extensive interviews with dying cancer patients, she observed that patients' initial negativity was normally followed by a staged sequence of feelings resolving in acceptance with hope. She regarded disclosure as part of the healthy process of maintaining ongoing communication with dying patients, and her stage theory permitted clinicians to engage in a therapeutic process around disclosure of a fatal diagnosis. The hospice movement accepted this perspective as key to humane care of the dying. Kübler-Ross nevertheless strongly opposed disclosing detailed predictions of life expectancy.

Patients' powerful emotional reactions and personal transformations during grave illnesses involve caregivers in intimate, significant connections with patients. The belief that knowledge of death is healthy has changed the image of the clinician from that of maintaining a cool distance to one of performing emotional work with patients (Hochschild). Ethicists often suggested that health professionals who withheld information from patients reflected several concerns: denial of their own and the patient's fear of dying, unconscious wishes to foster dependency in their clients, concern that discussing death constituted admitting failure, and manipulation of hope to encourage more extensive treatment choices.

Some commentators have challenged the positive emotional benefits of discussing death. Ernest Becker argued that the fear of death is too powerfully terrifying to permit most people to accept it (Becker). Some studies have found at least a few patients showing regret over being informed (Temmerman). Others have criticized the cold delivery of information, the image of the physician "bearing down" on the patient with bad news (Byrne). But in most of the literature, the question has become not whether to tell but how to tell; sharing bad news involves timing and a commitment to continuing empathy, compassion, reassurance, and conversation (Buckman and Kason; Kessel; Kübler-Ross; Radovsky).

THE INSTITUTIONAL CONTEXT. Expanding healthcare delivery organizations and complex technologies have multiplied the number of personnel providing patient care. These changes have magnified the obstacles to easily orchestrated and effective deception; a physician must not only deceive the patient and family but also involve dozens of other staff in the process. Institutional growth has also increased the need for accurate recordkeeping to cope with the expanding quantity of information.

Although information flow to patients has traditionally been the responsibility of physicians, other healthcare team members spend more time with patients, have the knowledge and opportunity to disclose information to patients and their families, and belong to professions assuming responsibility for educating patients. Coordinating communication has become an organizational challenge as hospital staffing has become more efficient, patient acuity greater, and lengths of stay shorter (Zussman). Who should talk with the patient when the physician is absent poses ethical questions for staff members, who may feel reluctant to provide information without explicit delegation even though disclosure may be timely for the patient. Nurses experience ethical conflicts when physicians order them to withhold information to which patients are entitled (Chadwick and

Tadd). Staff members may make promises to patients and their families about disclosure, promises that other staff members cannot keep.

Legally, the information in the hospital record belongs to the patient (Annas), but patients are not employees, and so patients' rights are hard to define procedurally. Patients' responsibility to provide honest disclosure to healthcare staff similarly lacks explicit definition. Thus, although large healthcare institutions have fostered a need for improved communication with patients and made systematic deception difficult, smoothing the flow of appropriate information to patients presents a daunting institutional task.

DISCLOSURE AND DECEPTION. The principle of veracity suffers ambiguity; it may simply prohibit lying and deception, or it may express a broader obligation to disclose information. Ethicists have tended to deploy arguments against lying and deception to support a high level of disclosure in healthcare, because lying and deception have often accompanied withholding information in maintaining illusory hopes. But, one can avoid lies and deception and yet disclose scant information. Since the obligation of full disclosure is role-dependent, supporting it involves considerations beyond criticizing deception. Arguments for full disclosure require normative arguments concerning appropriate relationships of healthcare professionals and institutions to patients in their service.

In healthcare, the principle of full disclosure stands in a reciprocal relationship to the obligation to keep confidentiality. Clinicians often have an obligation to disclose information to the patient, and at the same time, keep the same information from others. Moral judgment requires appreciating the range of application of both principles, that is, knowing which information should be disclosed or withheld in what circumstances (Jonsen and Toulmin). The more formal arguments justifying disclosure parallel the arguments for informed consent by appealing to autonomy, but broader notions of serving patient psychological good and building relationships provide less clear guidance as to the full extent of disclosure. Although favoring disclosure of a fatal diagnosis, as the worst possible news, has tended to encourage wide disclosure of less frightening information, it is still unclear what patients should or should not be told about hospital procedures, student participation in procedures, financial information, names of manufacturers, opinions on the skills of clinicians, personal information about practitioners, mistakes, and so on.

DOUBTS AND UNCERTAINTIES. The phrase "information disclosure" connotes a level of certainty absent from many diagnoses, prognoses, and therapeutic options. Do guesses and projections *belong* to the patient as much as the contents of the case record? Kathryn Taylor observed that physicians diagnosing cancer often exaggerate their uncertainty in order to soften the blow of a diagnosis or suppress it in order to hide feelings of doubt (Taylor). Physicians diagnosing symptoms often consider unlikely possibilities, which would frighten patients if shared unnecessarily with them. Nurses may discover or obtain information about which they are uncertain or lack authority to know and wonder whether or not to share it with patients.

Prevailing uncertainty has motivated some physicians to argue that the truth is so uncertain and variable that veracity is irrelevant to patient care. They argue that prospects and options can be framed in so many ways that clinicians inevitably control patient decisions. Even in the relatively well-studied area of informed consent, what to tell about unlikely dangers remains a contested area. Although some physicians have chosen to limit disclosure on the grounds of uncertainty, David Hilfiker characterized giving false reassurances and concealing uncertainty as forms of dishonest misrepresentation.

BUILDING RELATIONSHIPS. Although bioethics in the 1970s and 1980s rooted disclosure in autonomous decision making, the practice of disclosure has become so widespread in the United States that it has received support on broader grounds. Feminist ethics began to shift the basis of philosophical discussion from the language of autonomy to the language of caring and community. This trend, by diminishing the use of rights language, might have relaxed the new emphasis on disclosure; however, the trend expanded grounds for it, and a conception of the practitioner-patient relationship developed that sees disclosure as a key element in a good professional-patient relationship, apart from its role in decision making.

Lorraine Code, for instance, noted that there is "no stark dichotomy between interdependence and autonomy" (p. 74). Howard Brody recommended that as part of the ongoing "conversation" between physicians and patients, physicians should "think out loud" (Brody, p. 116) in order to share medical reasoning more fully with patients. Charles Lidz and his colleagues found that patients generally wanted procedures explained to them, not to participate in decision making, but as a sign of respect and to assist in therapy. Annette Baier advocated the necessity of going beyond the contract model and of appreciating disclosure in a context in which power relationships are unequal. Baier emphasized trust in relationships as a priority over decision making. Trust thrives most readily in relationships free of deception and where good mutual communication maintains connections between people.

Specific Concerns in Disclosure

Although terminal diagnoses have served as the paradigm for exploring disclosure, they cover only a portion of the possible concerns involving communication with patients. This section briefly describes a few of the other concerns. Many can arise, such as using placebos; therapeutic privilege; giving patients information about the costs of care; disclosing brain death to the family; lying to an insurance company to obtain coverage for a treatment or diagnostic test; falsifying records to help patients escape war service or school busing; reporting an accidentally discovered serious condition to the patient when the doctor-patient relationship is undefined; offering information to patients concerning futile therapeutic options; deceptively introducing medical students to patients as *doctor*; concealing the histocompatibility (mutual tolerance of tissues or organs to be grafted) of an unwilling potential organ donor; revealing to patients that a caregiver has tested positive for the human immunodeficiency virus (HIV); revealing HIV diagnoses to patients; encouraging patients to disclose HIV diagnoses to sexual partners; communicating psychiatric interpretations to patients; expecting disclosure by patients to health professionals; and disclosing genetic information to patients.

DISEASES LACKING EFFECTIVE TREATMENT. When a diagnostic test can predict a dread and incurable disease—such as Huntington or Alzheimer's disease—some physicians consider the possibility of withholding the diagnosis. An instrumental view of communication tends to support the view that the burden to the patient of knowing outweighs the value of disclosure. This concern arose with regard to Huntington disease when a levodopa test became available in the early 1970s; the concern was renewed when genetic marker tests became available in 1983. Although some critics continued to express reservations, genetic counselors tended to find that disclosure helped both patient and family to make long-range plans. Gwen Terrenoire emphasized that a consensus favoring testing and disclosure resulted from counselors working with organized patient groups involved with Huntington disease (Terrenoire). In 1989, the Huntington Disease Society of America published guidelines for testing for the condition. They recommended counseling patients prior to the screening decision and before disclosing results. They also recommended against screening patients who have conditions that diminish judgment, while thoroughly evaluating them for suicide risk (DeGrazia).

DISCLOSING DIAGNOSTIC TESTS. Hospitals and clinics often screen patients upon admission for a wide range of conditions without informing them of the reasons for testing. Services may standardly screen for HIV, sexually transmitted diseases, or pregnancy without informing the patient. They may also wish to make surreptitious tests when they believe a patient is claiming false symptoms. One case study described a patient as suffering from mysterious bruising, which could most probably be explained by drug abuse; she denied taking drugs and refused to permit a blood test. Physicians considered whether to administer the diagnostic test without informing her of its purpose. The discussants of the case argued that a contractual model of the doctor-patient relationship is inadequate because patients frequently lie to physicians and are poor historians. They suggested also that such tests need not be disclosed since they yield such diverse results; they are often based on guesses; and their interpretation depends on patient histories (Vanderpool and Weiss).

REVEALING MISTAKES TO PATIENTS. Surely, practitioners should tell patients of mistakes pertinent to their welfare or requiring changes in treatment plans. However, the possibility of lawsuits, the fear of losing patient confidence, painful feelings of incompetence, and solidarity between healthcare team members often outweigh patient benefits in frankness regarding errors. Charles Bosk observed that discussion of medical errors tends to be highly ritualized, confined to well-defined hospital subgroups, and used to reaffirm a strong collective sense of competence. Hilfiker, however, in a remarkably frank discussion of his own errors, recommended that patients can be accepting of physician limitations, that maintenance of illusions about competence tends ultimately to undermine trust in physicians, and that hiding mistakes tends to alienate caregivers from the healing process of confessing and handling mistakes. The ACP Ethics Manual also recommends disclosing significant "procedural or judgment errors" (American College of Physicians, p. 950).

PATIENT REFUSAL OF INFORMATION. The bioethics literature has debated the proper handling of patient refusals of information (Ost; Strasser). On the one hand, the literature usually has regarded refusing information as an autonomous choice and therefore has supported it: A caregiver may ethically choose to respect a patient's wish to rely more heavily on the caregiver. Raanan Gillon argued that "forcing" information on a patient is both harmful and disrespectful of autonomy. The issue can also be regarded as a feature of relational style; Edmund Pellegrino noted that "some patients need a more authoritative approach than others" (p. 1735).

On the other hand, autonomy is not the only basis for disclosure; caregivers have some role-dependent duties to disclose information to the reluctant; and patients have responsibilities as well as rights to use information on their own behalf. Some information may be so surprising and crucial for patients or so necessary for a working partnership that caregivers have an obligation to disclose despite patient protests. Caregivers may feel that a patient's denial is slowing recovery, or that patients may have a duty to act on information, such as that they are HIV-positive, in order to protect others. It is thus doubtful that the question of refusals can be answered generally.

DISCLOSURE TO FAMILY MEMBERS. Kübler-Ross suggested entrusting some information to family members rather than the patient; this has also been the pattern reported in several countries, such as Hungary, Italy, Japan, and China. This approach may result from seeing the patient as "an extension of the family" (Christakis and Fox, p. 1101), respecting the family as a strongly interdependent unit, or wishing others to carry the burden of knowledge. Yoshitomo Takahashi reported that some Japanese practitioners consider talking about death as threatening family relationships and separating the patient from others (Takahashi), and Eric Feldman noted that many Japanese practitioners perceive disclosing terminal diagnoses as "a callous practice" (p. 21). However, supporters of patient autonomy have expressed concern that leaving the patient uninformed is more likely to isolate the patient psychologically (Quill and Townsend). From both perspectives, the main concern appears to be to include the dying patient in the community, but it is difficult to make reliable cross-cultural generalizations because recommended practices, actual practices, and patient attitudes often vary widely within each culture.

Difficult questions balancing disclosure and confidentiality arise in keeping family members appropriately informed along with the patient. The family may be the recipient of disclosure when an unconscious patient is admitted to the hospital; when the patient recovers competency, the pattern of leaving the family in charge may continue or the family may become excluded from communication. Or family members may give clinicians important information about the patient and ask that the patient not be told; however, the ACP Ethics Manual holds that practitioners are "not obliged" to keep such secrets and should "use sensitivity and judgment" in disclosing such information (American College of Physicians, p. 949).

DISCLOSURE IN THE SOCIAL ARENA. Although bioethical discussion has focused primarily on disclosure and honesty at the bedside, similar issues arise in the larger healthcare arena. For instance, a study of advertising in medical journals showed that a high proportion of pharmaceutical advertisements failed to meet U.S. Food and Drug Administration standards for honesty (Wilkes et al.). Many physicians rely on advertisements and pharmaceutical representatives for their information. Consequently, deceiving physicians leads to misinformed patients.

Occupational and public-health physicians face conflicts affecting disclosure. For instance, some clinicians and medical researchers cooperated for many years in industry suppression of information on the carcinogenicity of asbestos (Lilienfeld); other health professionals have been active in political struggles over posting health warnings on cigarette and alcohol labels. In recent years, the U.S. Occupational Safety and Health Administration has expanded workers' rights to know about their exposure to toxic materials in the workplace, although the complexity of state and federal regulations makes application difficult. Pressures arising from fear of litigation, protection of trade secrets, and concern for individual confidentiality create tensions in pursuing public-health goals of improving public health by keeping workers and the public better informed of their exposure (Ashford and Caldart).

Conclusion

Beneath this sketch of disclosure lie a number of ethical concerns of great subtlety and depth. Brief reflection on honesty links veracity primarily to telling others what one believes. But the complex interactions between clinicians and patients require clinicians to consider carefully how patients interpret their words; skill in listening to patients has often been identified as the key element in effective patient teaching. Moreover, health professionals bear serious duties to service and science that require them to examine honestly the limits of their knowledge, the help they can promise, and their insights into the meanings of illness and death. Thus, accepting honest disclosure calls upon professionals to reflect deeply on the relationship of medical science to health, the consequences of individual service to public health, and the impact of healthcare institutions and practices on the public's understanding of health, illness, and death.

ANDREW JAMETON (1995)
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SEE ALSO: *Advance Directives and Advance Care Planning; Autonomy; Coercion; Competence; Freedom and Free Will; Genetic Testing and Screening; Human Dignity; Human Rights; Informed Consent: Meaning and Elements; Pastoral Care and Healthcare Chaplaincy; Patients' Rights; Professional-Patient Relationship*

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INFORMED CONSENT

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I. History of Informed Consent
II. Meaning and Elements
III. Consent Issues in Human Research
IV. Clinical Aspects of Consent in Healthcare
V. Legal and Ethical Issues of Consent in Healthcare
VI. Issues of Consent in Mental Healthcare

I. HISTORY OF INFORMED CONSENT

Informed consent is not an ancient concept with a rich medical tradition. The term *informed consent* first appeared in 1957, and serious discussion of the concept began only around 1972. As the idea of informed consent evolved, discussion of appropriate guidelines moved increasingly from a narrow focus on the physician’s or researcher’s obligation to disclose information to the quality of a patient’s or subject’s understanding of information and right to authorize or refuse a biomedical intervention.

Early History of Associated Ideas

Prior to the late 1950s, there was no firm ground in which a commitment to informed consent could take root. This is not to say, however, that there is no relevant history of the physician’s or researcher’s management of information in the encounter with patients and subjects. The major writings of prominent figures in ancient, medieval, and modern medicine contain a storehouse of information about commitments to disclosure and discussion in medical practice. But it is a disappointing history from the perspective of informed consent. Beginning with the classic text of ancient medicine, the Hippocratic Corpus, the primary focus of medical ethics became the obligation of physicians to provide medical benefits to patients and to protect them from harm. The purpose of medicine as expressed in the Hippocratic oath was to benefit the sick and keep them from harm and injustice. Managing information in interactions with patients was portrayed as a matter of prudence and discretion. The Hippocratic writings did not hint even at obligations of veracity.

Throughout the ancient, medieval, and early modern periods, medical ethics developed predominantly within the profession of medicine. With few exceptions, no serious consideration was given to issues of either consent or self-determination by patients and research subjects. The proper principles, practices, and virtues of truthfulness in disclosure were occasionally discussed, but the perspective was largely one of maximizing medical benefits through the careful management of medical information. The central concern was how to make disclosures without harming patients by revealing their condition too abruptly and starkly. Withholding information and even outright deception were regularly justified as morally appropriate means of avoiding such harm. The emphasis on the principle “First, do no harm” even promoted the idea that a healthcare professional is obligated not to make disclosures because to do so would be to risk a harmful outcome.

Eighteenth and Nineteenth Centuries

Benjamin Rush and John Gregory are sometimes cited for their enlightened views about disclosure and public education in the eighteenth century. However, neither was advocating informed consent; they wanted patients to be sufficiently educated so that they could understand physicians’ recommendations and therefore be motivated to comply. They were not even optimistic that patients would form their own opinions and make appropriate medical choices. For example, Rush advised physicians to “yield to [patients] in matters of little consequence, but maintain an inflexible authority over them in matters that are essential to life" (p. 323). Gregory (1772) was quick to underscore that the physician must be keenly aware of the harm that untimely revelations might cause. There is no assertion of the importance of respecting rights of self-determination for patients or of obtaining consent for any purpose other than a medically good outcome. Gregory and Rush appreciated the value of information and dialogue from the patient's point of view, but the idea of informed consent was not foreshadowed in their writings.

Thomas Percival's historic *Medical Ethics* (1803) continues in this same tradition. It makes no more mention of consent solicitation and respect for decision making by patients than had previous codes and treatises. Percival did, however, struggle with the issue of truth-telling. He held that the patient's right to the truth must yield to the obligation to benefit the patient in cases of conflict, thereby recommending benevolent deception. Percival maintained that

> [T]o a patient … who makes inquiries which, if faithfully answered, might prove fatal to him, it would be a gross and unfeeling wrong to reveal the truth. His right to it is suspended, and even annihilated; because its beneficial nature being reversed, it would be deeply injurious to himself, to his family, and to the public. And he has the strongest claim, from the trust reposed in his physician, as well as from the common principles of humanity, to be guarded against whatever would be detrimental to him …. The only point at issue is, whether the practitioner shall sacrifice that delicate sense of veracity, which is so ornamental to, and indeed forms a characteristic excellence of the virtuous man, to this claim of professional justice and social duty. (pp. 165–166)

Percival was struggling against the arguments of his friend, the Rev. Thomas Gisborne, who opposed practices of giving false assertions intended to raise patients' hopes and lying for the patient's benefit: "The physician … is invariably bound never to represent the uncertainty or danger as less than he actually believes it to be" (Gisborne, p. 401). From Percival's perspective, the physician does not lie or act improperly in beneficent acts of deception and falsehood, as long as the objective is to give hope to the dejected or sick patient.

The American Medical Association (American Medical Association) accepted virtually without modification the Percival paradigm in its 1847 "Code of Medical Ethics." Many of the above passages appear almost verbatim in this code as the AMA position on the obligations of physicians in regard to truth-telling (American Medical Association, 1847). This code and most codes of medical ethics before and since do not include rules of veracity although many codes today do contain rules for obtaining an informed consent. For more than a century thereafter, American and British medical ethics developed under Percival's vision.

There was, however, a notable nineteenth-century exception to the consensus that surrounded Percival's recommendations. Connecticut physician Worthington Hooker was the first champion of the rights of patients to information, in opposition to the model of benevolent deception that had reigned from Hippocrates to the AMA (Hooker). He and Harvard professor of medicine Richard Clarke Cabot were the best known among physicians who championed this model prior to the second half of the twentieth century. Moreover, there may never have been a figure who, in regard to truth-telling, swam so much against the stream of indigenous medical tradition as Hooker.

Hooker's arguments are novel and ingenious but do not amount to a recommendation of informed consent. Hooker was concerned with "the general effect of deception" on society and on medical institutions. He thought the effect disastrous. But in Hooker no more than in the AMA Code is there a recommendation to obtain the permission of patients or to respect autonomy for the sake of autonomy. Hooker's concerns were with expediency in disclosure and truth-telling rather than with the promotion of autonomous decision making or informed consent. The idea that patients should be enabled to understand their situation so that they are able to participate with physicians in decisions about medical treatment was an idea whose time was yet to come.

Although the nineteenth century saw no hint of a rule or practice of informed consent in clinical medicine, consent practices were not entirely absent. Evidence exists in surgery records of consent-seeking practices and rudimentary rules for obtaining consent since at least the middle of the nineteenth century (Pernick). However, the consents thus obtained do not appear to have been meaningful informed consents, because they had little to do with the patient's right to decide after being appropriately informed. Practices of obtaining consent in surgery prior to the 1950s were pragmatic responses to a combination of concerns about medical reputation, malpractice suits, and practicality in medical institutions. It is at best physically difficult and interpersonally awkward to perform surgery on a patient without obtaining the patient's permission. Such practices of obtaining permission, however, do not constitute practices of obtaining informed consent, although they did provide a modest nineteenth-century grounding for this twentieth-century concept.

The situation is similar in research involving human subjects. Little evidence exists that, until recently, requirements of informed consent had a significant hold on the practice of investigators. In the nineteenth century, for example, it was common for research to be conducted on slaves and servants without acquiescence or consent on the part of the subject. By contrast, at the turn of the century, American army surgeon Walter Reed's yellow-fever experiments involved formal procedures for obtaining the consent of potential subjects. Although deficient by contemporary standards of disclosure and consent, these procedures recognized the right of the individual to refuse or authorize participation in the research. The extent to which this principle became ingrained in the ethics of research by the mid-twentieth century is a matter of historical controversy. Although it has often been reported that the obtaining of informed and voluntary consent was essential to the ethics of research and was commonplace in biomedical investigation, it is unclear that consent seeking on the part of investigators was standard practice. Anecdotal evidence suggests that biomedical research often proceeded without adequate consent at least into the 1960s.

Early Twentieth-Century Legal History

The legal history of disclosure obligations and rights of self-determination for patients evolved gradually. It is the nature of legal precedent that each decision, relying on earlier court opinions, joins a chain of authority that incorporates the relevant language and reasoning from the cited cases. In this way, a few early consent cases built on each other to eventuate in a legal doctrine. The best known and ultimately the most influential of these early cases is *Schloendorff* v. *New York Hospital* (1914). *Schloendorff* used rights of *self-determination* to justify imposing an obligation to obtain a patient's consent. Subsequent cases that followed and relied upon *Schloendorff* implicitly adopted its justificatory rationale. In this way, self-determination came to be the primary rationale or justification for legal requirements that consent be obtained from patients.

In the early twentieth century, the behavior of physicians was often egregious, and courts did not shrink from using ringing language and sweeping principles to denounce it. The same language was then applied as precedent in later cases in which physicians' behavior was less outrageous. As the informed-consent doctrine developed and problems grew more subtle, the law could have turned away from the language of self-determination but instead increasingly relied on this rationale as its fundamental premise. The language in the early cases suggests that rights of freedom from bodily invasion contain rights of medical decision making by patients.

The 1950s and 1960s: Law and Medicine

The emerging legal doctrine of informed consent first brought the concept of informed consent to the attention of the medical community. "The doctrine of informed consent" is a legal doctrine; and informed consent has often been treated as synonymous with this legal doctrine. A remarkable series of cases in the second half of the twentieth century brought informed consent to the attention of lawyers and physicians alike.

During the 1950s and 1960s, the traditional duty to obtain consent evolved into a new, explicit duty to disclose certain types of information and then to obtain consent. This development needed a new term; and so *informed* was added onto *consent,* creating the expression *informed consent,* in the landmark decision in *Salgo* v. *Leland Stanford, Jr. University Board of Trustees* (1957). The *Salgo* court suggested, without accompanying analysis, that the duty to disclose the risks and alternatives of treatment was not a new duty but a logical extension of the already established duty to disclose the treatment's nature and consequences. Nonetheless, *Salgo* clearly introduced new elements into the law. The *Salgo* court was not interested merely in whether a recognizable consent had been given to the proposed procedures. Instead, *Salgo* focused strongly on the problem of whether the consent had been adequately informed. The court thus created not only the language but the substance of informed consent by invoking the same right of self-determination that had heretofore applied only to a less robust consent requirement.

Shortly thereafter, two opinions by the Kansas Supreme Court in the case of *Natanson* v. *Kline* (1960) pioneered the use of the legal charge of negligence in informed-consent cases, rather than that of battery. The court established the duty of disclosure as the obligation "to disclose and explain to the patient in language as simple as necessary the nature of the ailment, the nature of the proposed treatment, the probability of success or of alternatives, and perhaps the risks of unfortunate results and unforeseen conditions within the body" (*Natanson* v. *Kline,* 1960). Thus, the *Natanson* court required essentially the same extensive disclosure—of the nature, consequences, risks, and alternatives of a proposed procedure—as had *Salgo.* After *Natanson,* battery and negligence appeared virtually identical in their disclosure requirements for informed consent.

Not surprisingly, the number of articles in the medical literature on issues of consent increased substantially following these and other legal cases. Typically written by lawyers, these reports functioned to alert physicians both to informed consent as a new legal development and to potential malpractice risk. How physicians reacted to these legal developments in the 1950s and 1960s is not well documented, but a handful of empirical studies of informed consent in clinical medicine provides some insights. A study done in the early to mid-1960s indicates that a preoperative consent form was not yet a ubiquitous feature of the practice of surgery. Surgeons at several hospitals refused to participate in this study precisely because they were not using a consent form for surgery.

This indifference to consent procedures seems to have changed by the late 1960s, when most physicians appear to have come to recognize both a moral and a legal duty to obtain consent for certain procedures and to provide some kind of disclosure. There is also evidence, however, that physicians' views about proper consent practices even in the late 1960s differed markedly from the consensus of opinion and convention today. For example, in one study, half of the physicians surveyed thought it medically proper, and 30 percent ethically proper, for a physician to perform a mastectomy with no authorization from the patient other than her signature on the blanket consent form required for hospital admission; more than half the physicians thought that it was ethically appropriate for a physician not to tell a cancer patient that she had been enrolled in a double-blind clinical trial of an experimental anti-cancer drug.

On the basis of the volume of commentary in the medical literature, many physicians before the 1970s were at least dimly aware of informed consent. Empirical studies conducted at the time suggest that there was at least enough documentable consent seeking in such areas as surgery, organ donation, and angiography to warrant empirical investigation. Also during this period, the procedure-specific consent form was gaining acceptance, although it was not yet universally in use. Whether in the 1960s physicians generally regarded informed consent as a legal nuisance or as an important moral problem is unclear, but an explosion of commentary on informed consent emerged in the medical literature in the early 1970s. Much of this commentary was negative: Physicians saw the demands of informed consent as impossible to fulfill and—at least in some cases—inconsistent with good patient care. In tone the articles ranged from serious critique to caustic parody. Predictions were voiced that fearful patients would refuse needed surgery after disclosure. In much of this literature, only the legal, not the moral dimensions of informed-consent requirements were recognized. This began to change in the 1970s, with the ascendancy of an interdisciplinary approach to medical ethics. Gradually, informed consent became a moral as well as a legal issue.

The 1950s and 1960s: Biomedical Research

The histories of informed consent in research and in clinical medicine have developed largely as separate pieces in a larger mosaic of biomedical ethics, and these pieces have never been well integrated even when they developed side by side. Research ethics prior to World War II was no more influential on research practices than the parallel history of clinical-medicine ethics was on clinical practices. But one event that unquestionably influenced thought about informed consent was the Nuremberg trials. The Nuremberg military tribunals unambiguously condemned the sinister political motivation of Nazi experiments in their review of "crimes against humanity." A list of ten principles constituted the Nuremberg Code. Principle One of the code states, without qualification, that the primary consideration in research is the subject's voluntary consent, which is "absolutely essential" (Germany [Territory Under Allied Occupation], 1947).

The Nuremberg Code served as a model for many professional and governmental codes formulated in the 1950s and 1960s, but several other incidents involving consent violations subsequently moved the discussion of post-Nuremberg problems into the public arena. Thus began a rich and complex interplay of influences on research ethics: scholarly publications, journalism, public outrage, legislation, and case law. In the United States, one of the first incidents to achieve notoriety in research ethics involved a study conducted at the Jewish Chronic Disease Hospital (JCDH) in Brooklyn, New York. In July 1963, Dr. Chester Southam of the Sloan-Kettering Institute for Cancer Research persuaded the hospital's medical director, Emmanuel E. Mandel, to permit research involving injection of a suspension of foreign, live cancer cells into twenty-two patients at the JCDH. The objective was to discover whether a decline in the body's capacity to reject cancer transplants was caused by the cancer or by debilitation. Patients without cancer were needed to supply the answer. Southam had convinced Mandel that although the research was nontherapeutic, such research was routinely done without consent. Some patients were informed orally that they were involved in an experiment, but it was not disclosed that they were being given injections of cancer cells. No written consent was attempted, and some subjects were incompetent to give informed consent. The Board of Regents of the State University of New York later censured Southam and Mandel for their role in the research. They were found guilty of fraud, deceit, and unprofessional conduct (*Hyman v. Jewish Chronic Disease Hospital,* 1964).

Another major controversy about the ethics of research in the United States developed at Willowbrook State School, an institution for "mentally defective" children in Staten Island, New York. Beginning in 1956, Saul Krugman and his associates began a series of experiments to develop an effective prophylactic agent for infectious hepatitis. They deliberately infected newly admitted patients with isolated strains of the virus based on parental consents obtained under controversial circumstances that may have been manipulative. The issues in the Willowbrook case are more complex than those in the Jewish Chronic Disease Hospital case, and today there are those who still defend, at least in part, the ethics of these experiments. Krugman's research unit was eventually closed, but closure on the debate about the ethics of the studies conducted in the unit was never achieved (New York University).

The most notorious case of prolonged and knowing violation of subjects' rights in the United States was a Public Health Service (PHS) study initiated in the early 1930s. Originally designed as one of the first syphilis-control demonstrations in the United States, the stated purpose of the Tuskegee syphilis study, as it is now called, was to compare the health and longevity of an untreated syphilitic population with a nonsyphilitic but otherwise similar population. These subjects, all African-American males, knew neither the name nor the nature of their disease. That they were participants in a nontherapeutic experiment also went undisclosed. They were informed only that they were receiving free treatment for "bad blood," a term local African-Americans associated with a host of unrelated ailments, but which the white physicians allegedly assumed was a local euphemism for syphilis (Jones).

Perhaps the most remarkable thing about Tuskegee was that, although the study was reviewed several times between 1932 and 1970 by PHS officials and medical societies as well as reported in thirteen articles in prestigious medical and public-health journals, it continued uninterrupted and without serious challenge. It was not until 1972 that the U.S. Department of Health, Education and Welfare (DHEW) appointed an ad hoc advisory panel to review the study and the department's policies and procedures for the protection of human subjects. The panel found that neither DHEW nor any other government agency had a uniform or adequate policy for reviewing experimental procedures or securing subjects' consents.

The 1970s and 1980s

Although the Jewish Chronic Disease Hospital case, the Willowbrook study, and the Tuskegee study had a profound effect on public consciousness with respect to the ethics of research and medicine, these events are insufficient to explain why informed consent became the focus of so much attention in both case law and biomedical ethics between the late 1960s and the late 1980s. Many hypotheses can be invoked to explain this phenomenon. Perhaps the most accurate explanation is that law and ethics, as well as medicine itself, were all affected by issues and concerns in the wider society about individual liberties and social equality, made dramatic by an increasingly technological, powerful, and impersonal medical-care system. It seems likely that increased legal interest in the right of self-determination and increased philosophical interest in the principle of respect for autonomy and individualism were instances of the new rights orientation that various social movements had introduced. The issues raised by civil rights, women's rights, the consumer movement, and the rights of prisoners and the mentally ill often included healthcare components and helped reinforce public acceptance of rights applied to healthcare. Informed consent was swept along with this body of social concerns, which propelled the new bioethics throughout the 1970s.

Three 1972 court decisions are widely recognized as informed consent landmarks: *Canterbury* v. *Spence, Cobbs* v. *Grant,* and *Wilkinson* v. *Vesey. Canterbury* had a massive influence. In its most significant and dramatic finding, the *Canterbury* court moved in the direction of a more patient-oriented standard of disclosure:

> The patient's right of self-decision can be effectively exercised only if the patient possesses enough information to enable an intelligent choice. The patient should make his own determination on treatment. Informed consent is a basic social policy for which exceptions are permitted (1) where the patient is unconscious or otherwise incapable of consenting, and harm from failure to treat is imminent; or (2) when risk-disclosure poses such a serious psychological threat of detriment to the patient as to be medically contraindicated. Social policy does not accept the paternalistic view that the physician may remain silent because divulgence might prompt the patient to forego needed therapy. Rational, informed patients should not be expected to act uniformly, even under similar circumstances, in agreeing to or refusing treatment. (*Canterbury* v. *Spence,* 1972)

As the impact of *Canterbury* filtered down to medical practice, the U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research began in 1974 what would be a four-year struggle with a variety of concerns about informed consent in research involving human subjects. The commission developed an abstract schema of basic ethical principles for research ethics that gave informed consent a major role (U.S. National Commission, 1978):

Principle of	*applies to*	*Guidelines for*
Respect for Persons		Informed Consent
Beneficence		Risk/Benefit Assessment
Justice		Selection of Subjects

Under this schema, the purpose of consent provisions is not protection from risk, as some earlier federal policies had implied, but rather the protection of autonomy and personal dignity, including the personal dignity of incompetent persons incapable of acting autonomously (for whose involvement a third party must consent). This conclusion develops an explicit philosophical position on informed consent for the first time in a government-sponsored document.

Among the most important publications in the medical literature to appear during this period was a statement by the Judicial Council of the American Medical Association in 1981. For the first time, the AMA recognized informed consent as "a basic social policy" necessary to enable patients to make their own choices even if the physician disagrees. The AMA's statement is a testament to the impact of the law of informed consent on medical ethics: The AMA's position closely followed the language of *Canterbury* v. *Spence* (Judicial Council, 1981).

The U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research provides further evidence regarding the status informed consent had achieved by the 1980s. The commission was first convened in January 1980, with informed consent as a main item on its agenda. In 1982 it produced a three-volume report that dealt directly with informed consent: *Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship.* The commission argued that although informed consent has emerged primarily from a history in law, its requirements are essentially moral and policy-oriented. It held that informed consent is ultimately based on the principle that competent persons are entitled to make their own decisions from their own values and goals, but that the context of informed consent and any claim of "valid consent" must derive from active, shared decision making. The principle of self-determination was described as the "bedrock" of the commission's viewpoint.

In addition to the efforts of the U.S. President's Commission and the statement of the AMA, the 1980s saw the publication of several books devoted to the subject of informed consent, as well as hundreds of journal articles, and the passage of procedure-specific informed-consent laws and regulations. These events provide powerful testimony of the importance of informed consent in moral and legal thinking about medicine in the United States. By themselves, however, they tell us little about physicians' or researchers' actual consent practices or opinions or about how informed consent was viewed or experienced by patients and subjects.

As might be expected, the empirical evidence on this subject is mixed, although it is clear that procedures of informed consent have taken a firm hold in some parts of medical practice. For example, routine practice encourages the obtaining of signatures on consent forms and the disclosing of information about alternative treatments, risks, and benefits. The best data on this subject are the findings of a national survey conducted for the U.S. President's Commission by Louis Harris and Associates in 1982. Almost all of the physicians surveyed indicated that they obtained written consent from their patients before in-patient surgery or the administration of general anesthesia. At least 85 percent said they usually obtained some kind of consent—written or oral—for minor office surgery, setting of fractures, local anesthesia, invasive diagnostic procedures, and radiation therapy. Only blood tests and prescriptions appear to have proceeded frequently without patient consent, although about half of the physicians reported obtaining oral consent (1982).

The overall impression conveyed by this survey is that the explosion of interest in informed consent in the 1970s had a powerful impact on medical practice. However, evidence from the Harris survey and other sources questions the meaningfulness of the increase in consent-related activity. The overwhelming impression from the empirical literature and from reported clinical experience is that the actual process of soliciting informed consent often falls short of a serious show of respect for the decisional authority of patients. As the authors of one empirical study of physician-patient interactions put it, "despite the doctrine of informed consent, it is the physician, and not the patient, who, in effect, makes the treatment decision" (Siminoff and Fetting, p. 817).

The history of informed consent, then, indicates that medicine has undergone widespread changes under the influence of legal and moral requirements of informed consent, but it also remind us that informed consent is an evolving process, not a set of events whose history has passed.

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SEE ALSO: *Autonomy; Competence; Information Disclosure, Ethical Issues of; Professional-Patient Relationship;* and other *Informed Consent* subentries

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II. MEANING AND ELEMENTS

Appropriate criteria must be identified to define and classify an act of informed consent properly. If overdemanding criteria such as “full disclosure and complete understanding” are adopted, an informed consent becomes impossible to obtain. Conversely, if underdemanding criteria such as “the patient signed the form” are used, an informed consent becomes too easy to obtain and the term loses all moral significance. Many interactions between a physician and a patient or an investigator and a subject that have been called informed consents have been so labeled only because they rest on underdemanding criteria; they are inappropriately referred to as informed consents. For example, a physician’s truthful disclosure to a patient has often been declared the essence of informed consent, as if a patient’s silence following disclosure could constitute an informed consent. The existence of such inadequate understandings of informed consent can be explained in part by empirical information about physicians’ beliefs about informed consent.

Contemporary Assumptions in Medicine

Data about the relevant beliefs of physicians in the United States were gathered in a 1982 survey of physicians conducted by Louis Harris and Associates. One question of this survey asked physicians, “What does the term informed consent mean to you?” In their answers, only 26 percent of physicians indicated that informed consent has something to do with a patient’s giving permission, consenting, or agreeing to treatment. In a related question, only 9 percent indicated that it involves the patient's making a choice or stating a preference about his or her treatment (Harris and Associates; U.S. President's Commission, 1982). Similar results were found in a survey of Japanese physicians (Hattori et al.).

The majority of these physicians appear to regard disclosure as the primary (and perhaps sole) element of informed consent. That is, they conceive of informed consent as explaining to patients the nature of their medical conditions together with a recommended treatment plan. But if physicians regard informed consent as nothing more than an event of conveying information to patients, rather than a process of discussion with and obtaining permission from the patient, then claims that they regularly "obtain consents" from their patients before initiating medical procedures are both vague and unreliable.

Other polls conducted in the United States indicate that the majority of physicians understand an informed consent to be either a signed consent form or a disclosure. Some also conclude that no evidence exists that informed-consent practices are widespread in clinical medicine and that many agreements by patients that are called informed consents in some clinical settings fall far short of being meaningful informed consents (Lidz and Meisel).

The Elements of Informed Consent

Literature of bioethics often analyzes informed consent in terms of the following elements: (1) disclosure; (2) comprehension; (3) voluntariness; (4) competence; and (5) consent (see U.S. National Commission, 1978, U.S. President's Commission, 1982; Meisel and Roth, 1981). This analysis is sometimes joined with a corresponding thesis that these elements collectively define informed consent. The postulate is that a person gives an informed consent to an intervention if and only if the person receives a thorough disclosure about the procedure, comprehends the disclosed information, acts voluntarily, is competent to act, and consents.

This definition is attractive because of its consistency with standard usage of informed consent in medicine and law. However, medical convention and malpractice law have special orientations that tend to distort the meaning of informed consent in ways that need correction. Analyses that use the five elements listed above, as well as conventional usage in law and medicine, are best suited for cataloguing the analytical parts of informed consent and for delineating moral and legal requirements of informed consent, not for conceptually analyzing the meaning of informed consent. Neither requirements nor parts amounts to a definition.

The U.S. Supreme Court addressed the definition of informed consent in *Planned Parenthood of Central Missouri* v. *Danforth* as follows: "One might well wonder … what 'informed consent' of a patient is.… We are content to accept, as the meaning, the giving of information to the patient as to just what would be done and as to its consequences …" (*Planned Parenthood of Central Missouri* v. *Danforth,* 1976, p. 67). The essential element or part of informed consent, as described here, is disclosure, an analysis that recalls the assumptions made by physicians in the Harris poll (Harris and Associates). However, as we will see, nothing about an informed consent requires disclosure as part of its meaning, and this element does not amount to a definition. Moreover, to make disclosure the sole or even the major condition of informed consent incorporates questionable assumptions about medical authority, physician responsibility, and legal liability. These norms delineate an obligation to make disclosures so that a consent can be informed, rather than a meaning of informed consent. Even all five of the above elements merged as a set do not satisfactorily capture the meaning of informed consent.

Both the elements and the meaning of informed consent, then, need a more comprehensive treatment. The following seven categories express the analytical components of informed consent more adequately than the above five categories—although this sevenfold list does not adequately express the meaning of informed consent either (Beauchamp and Childress):

I. Threshold elements (preconditions)
    1. Competence (to understand and decide)
    2. Voluntariness (in deciding)
II. Information elements
    3. Disclosure (of material information)
    4. Recommendation (of a plan)
    5. Understanding (of terms 3 and 4)
III. Consent elements
    6. Decision (in favor of a plan)
    7. Authorization (of the chosen plan)

The language of material information in (3) is pivotal for an adequate analysis of the elements of disclosure (3) and understanding (5). Critics of legal requirements of informed consent have often held that procedures sometimes have so many risks and benefits that they cannot be disclosed and explained in a reasonable period of time or in an understandable framework. The demands in this misreading of the nature and requirements of informed consent must be pruned, as many courts have pointed out. Material risks are the risks a reasonable patient needs to understand in order to decide among the alternatives; only these risks and benefits need to be disclosed and understood.

Corresponding to each of the above elements, one could construct informed-consent requirements. That is, there could be disclosure requirements, comprehension requirements, noninfluence requirements, competence requirements, authorization requirements, and so forth. These requirements would specify the conditions that must be satisfied for a consent to be valid.

Two Meanings of Informed Consent

Translating the above seven elements directly into a definition or meaning of informed consent invites confusion, because the term *informed consent* has subtleties not captured by these elements. A subtlety that has generated considerable misunderstanding is that two very different meanings of informed consent operate in current literature and social practices.

In the first meaning, an informed consent is an autonomous authorization of a medical intervention or of involvement in research by individual patients or subjects. An autonomous authorization requires more than merely acquiescing in, yielding to, or complying with an arrangement or a proposal made by a physician or investigator. A person gives an informed consent in this first sense if and only if the person, with substantial understanding and in substantial absence of control by others, intentionally authorizes a health professional to do something. A person who intentionally refuses to authorize an intervention but otherwise satisfies these conditions gives an informed refusal. This first sense derives from the philosophical premises that informed consent is fundamentally a matter of protecting and enabling autonomous or self-determining choice by patients and subjects and that final authority for making decisions about medical treatment or research participation properly rests with patients and subjects, not physicians or research scientists.

In the second meaning, informed consent is analyzed in terms of institutional and policy rules of consent. This sense expresses the mainstream conception in the regulatory rules of federal agencies and in healthcare institutions. Here *informed consent* refers only to a legally or institutionally effective approval by a patient or subject. An approval is therefore effective or valid if it conforms to the rules that govern specific institutions, whatever the operative rules may be. In this sense, unlike the first, conditions and requirements of informed consent are relative to a social and institutional context and need not be autonomous authorizations. This meaning is driven by demands in the legal and healthcare systems for a generally applicable and efficient consent mechanism by which responsibilities and violations can be readily and fairly assessed (Faden et al.).

Under these two contrasting understandings of informed consent, a patient or subject can give an informed consent in the first sense, but not in the second sense, and vice versa. For example, if the person consenting is a minor and therefore not of legal age, he or she cannot give an effective or valid consent under the prevailing institutional rules; a consent is invalid even if the minor gives the consent autonomously and responsibly. ("Mature minor" laws do sometimes make an exception and give minors the right to authorize medical treatments in a limited range of circumstances.)

The Relationship between the Two Meanings

Rules governing effective authorization have often not been premised on a carefully delineated conception of autonomous decision making, but current literature in bioethics suggests that any justifiable analysis of informed consent must be rooted in autonomous choice by patients and subjects. An act is increasingly recognized in this literature as an informed consent only if (1) a patient or subject agrees to an intervention based on an understanding of material information; (2) the agreement is not controlled by influences that engineer the outcome; and (3) an authorization for an intervention is given by the patient or subject with the understanding that it is an authorization.

In principle, although less clearly in practice, these conditions of informed consent (in the sense of an individual's autonomous authorization) can function as model standards for fashioning the institutional and policy requirements for effective consent. The model of autonomous choice would then serve as the benchmark against which the moral adequacy of prevailing rules and practices should be evaluated. The postulate that policies governing informed consent in the second sense should be formulated to conform to the standards of informed consent in the first sense is grounded in the premise that the primary goal of informed consent in medical care and in research is to enable potential subjects and patients to make autonomous decisions about whether to grant or refuse authorization for medical and research interventions (Katz).

It does not follow that institutional policies regarding informed consent are justifiable only if they rank the protection of decision making above all other values. Consent requirements imposed by institutions should be formulated and evaluated against a range of social and institutional considerations. The preservation of autonomous choice is the first but not the only consideration. For example, a patient's need for education and counseling in order to achieve a substantial understanding of a medical situation must be balanced against the interests of other patients and of society in maintaining a productive and efficient healthcare system. Accordingly, institutional policies must consider what is fair and reasonable to require of healthcare professionals and researchers and what the effect would be of alternative consent requirements on efficiency and effectiveness in the delivery of healthcare and the advancement of science.

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III. CONSENT ISSUES IN HUMAN RESEARCH

"The voluntary consent of the human subject is absolutely essential." This, the first sentence of the Nuremberg Code, signals the centrality of the consent requirement in research involving human subjects (Germany [Territory under Allied Occupation], p. 181). Before the Nuremberg Code was written in 1947 as a response to the atrocities committed in the name of science by Nazi physician-researchers, statements of medical and other professional organizations apparently made no mention of the necessity of consent. Ironically, the only nations known to have promulgated regulations that established a requirement for consent to research were Prussia and Germany (Perley et al.). Subsequently, the tendency to focus on informed consent has been reinforced by public outcry over the inadequacy of consent in certain landmark cases in the United States, such as the Willowbrook Studies (1963–1966), Jewish Chronic Disease Hospital Study (1963), Tea Room Trade Study (1970), and Tuskegee Syphilis Study (1932–1972) (Katz, Capron, and Swift; Levine). Indeed, the issue of informed consent has so dominated recent discussion of the ethics of research that one might be led to think erroneously that other ethical issues (e.g., research design, selection of subjects) are either less important or more satisfactorily resolved.

This entry is concerned with the conceptual aspects of informed consent. For an extensive review of empirical studies of informed consent, see the 1999 article written by Jeremy Sugarman and Douglas C. McCrory.

Grounding of Informed Consent

The requirement for informed consent has philosophical, religious, and legal foundations.

PHILOSOPHICAL BASIS. The philosophical foundations of the requirement for informed consent may be found in several lines of reasoning (Veatch 1981; Faden, Beauchamp, and King; Brock 1987). Based on the Hippocratic admonition "to help, or at least, to do no harm," one can justify seeking consent for the benefit of the patient; to do so provides a mechanism for ascertaining what the patient would consider a benefit. Allowing individuals to decide what they consider beneficial is consistent with the perspective affirmed in U.S. public policy that competent persons are generally the best protectors of their own well-being (Brock 1987). A focus solely on patient benefit, however, would allow physicians and scientists not to seek consent when they judge that doing so might harm patients or subjects. Thus this justification alone does not suffice to establish a requirement to seek consent.

The requirement can also be justified on grounds of social benefit: The practice of seeking consent may contribute to producing the "greatest good for the greatest number" by forestalling suspicion about research, thus ensuring a subject population and increasing the efficiency of the research enterprise. Again, however, the justification fails to stand alone, because it can also be used to justify not seeking consent; the social good might be better served by avoiding the inefficient and frequently time-consuming consent process. Some commentators express concern that, carried to its extreme, the social-benefit argument might support the use of unwilling subjects, as in Nazi Germany; such a position would necessarily rest on a very limited vision of the relevant social consequences.

The firmest grounding for the requirement to seek consent is the ethical principle *respect for persons,* which according to the U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (hereafter, U.S. National Commission) "incorporates at least two basic ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy and thus in need of protection are entitled to such protection" (U.S. National Commission, p. 4). Although this term suggests a Kantian or deontological (a foundational ethical principle holding that the moral rightness of an action resides in the action itself without regard to its consequences) grounding of the principle, this was not the intent of the commission; a substantially similar principle, self-determination, may be grounded in rule utilitarianism deontological (a foundational ethical principle holding that the moral rightness of an action must be evaluated in terms of its consequences) (Brock, 1987). In a legal context, American jurist Benjamin Cardozo stated in 1914 that "every human being of adult years and sound mind has a right to determine what shall be done with his own body" (Katz, p. 51). To return to the Kantian approach that will be used often in this entry, this principle of respect for persons, autonomy or self-determination ensures that the research subject will be treated as an end and not merely as a means to another's end (Beauchamp and Childress). Thus the purpose of the consent requirement is not only to minimize risk but also to give persons the right to choose.

RELIGIOUS BASIS. Several fundamental tenets of the Judeo-Christian and other traditions also provide grounding for the requirement to seek consent. This tradition affirms that each human life is a gift from God and is of infinite and immeasurable worth (the "sanctity of life"). The infinite worth of the individual requires that persons treat each other with respect and not interfere in each other's lives without consent. The consent requirement can also be grounded explicitly in the notion of covenant. Seeking consent is an affirmation of the basic faithfulness or care required by the fundamental covenantal nature of human existence (Ramsey, 1970).

LEGAL BASIS. The legal grounding for the requirement for consent to research (Annas, Glantz, and Katz) is based on the outcome of litigation of disputes arising almost exclusively in the context of medical practice. There is virtually no case law on which to define the basis of the legal standards for consent to research, as distinguished from consent to practice (there is one Canadian case, *Halushka v. University of Saskatchewan* [1965]). The law defines, in general, the circumstances under which a patient, or by extension, a subject, may recover damages for having been wronged or harmed as a consequence of failure to negotiate adequate consent.

The legal bases for the consent requirement—which also shed light on the ethical dimensions of consent—are twofold (Annas, Glantz, and Katz). First, failure to obtain proper consent was traditionally treated as a battery action. Closely related to the principles of respect for persons and self-determination, the law of battery makes it wrong to touch, treat, or do research upon a person without the person's consent. Whether or not harm befalls the patient/subject is irrelevant: It is the unconsented-to touching that is wrong.

The modern trend in malpractice litigation is to treat cases based on failure to obtain proper consent as negligence rather than battery actions. The negligence doctrine combines elements of patient benefit and self-determination. To bring a negligence action, a patient/subject must prove that the physician had a duty toward the patient, that the duty was breached, that damage occurred to the patient, and that the damage was caused by the breach. In contrast to battery actions, negligence actions remove as a basis for the requirement for consent the simple notion that unconsented-to touching is a wrong. Rather, such touching is wrong (actionable) only if it is negligent and results in harm; otherwise, the patient/subject cannot recover damages. Under both battery and negligence doctrines, consent is invalid if any information is withheld from the patient/subject that might be considered material to the decision to give consent.

Functions of Informed Consent

In their 1975 book, *Catastrophic Diseases: Who Decides What?* Jay Katz and Alexander Morgan Capron identified the following functions of informed consent: promoting individual autonomy, encouraging rational decision making, avoiding fraud and duress, involving the public, encouraging self-scrutiny by the physician-investigator, and reducing the civil and/or criminal liability of the investigator and her institution.

In general, the negotiations for informed consent are designed to safeguard the rights and welfare of the subject, while documentation that the negotiations have been conducted properly safeguards the investigator and institution (Levine). The net effect of the documentation may, in fact, be harmful to the interests of the subject. Retaining a signed consent form tends to give the advantage to the investigator in any adversarial proceeding. Moreover, the availability of such documents in institutional records may lead to violations of privacy and confidentiality. Consequently, federal regulations permit waivers of the requirement for consent forms when the principal threat to the subject would be a breach of confidentiality and "the only record linking the subject and the research would be the consent document" ("Documentation of Informed Consent," pt. 46.117c).

Those who are interested in making operational the requirement for consent have a tendency to focus nearly all of their attention on the consent form. Federal regulations prescribe what information must be included in and excluded from these forms. Members of institutional review boards and researchers collaborate in a struggle to create reproachless forms. This seems to reflect an assumption that the consent form is an appropriate instrumentality through which researchers might fulfill their obligation not to treat persons merely as means. Most commentators on informed consent disagree, however, seeing consent as a continuing process rather than an event symbolized by the signing of a form; for example, Robert J. Levine (1986) characterized informed consent as a discussion or negotiation, while Katz (1984) envisioned consent as a searching conversation.

Whether or not negotiations for informed consent to research should be conducted according to different standards than consent to practice is controversial. In a 1974 article, Alvan R. Feinstein observed that it is the custom to adhere to a double standard: "An act that receives no special concern when performed as part of clinical practice may become a major ethical or legal issue if done as part of a formally designed investigation" (p. 331). In his view there is less need for formality in the negotiations for informed consent in a relationship in which the interests of research and practice are conjoined—for example, as in research conducted by a physician-investigator who has the aim of demonstrating the safety and/or efficacy of a nonvalidated therapeutic maneuver—than when the only purpose of the investigator–subject relationship is to perform research. Capron, on the other hand, asserted in a 1972 publication: "Higher requirements for informed consent should be imposed in therapy than in investigation, particularly when an element of honest experimentation is joined with therapy" (p. 574). Levine (1986) concluded that patients are entitled to the same degree of thoroughness of negotiations for informed consent as are subjects of research. Patients, however, may be offered the opportunity to delegate some (but not all) decision-making authority to a physician, whereas subjects should rarely be offered this option. The most important distinction is that the prospective subject should be informed that in research, in contrast with practice, the subject will be at least in part a means and perhaps primarily a means to an end identified by someone else.

Two Interpretations of the Consent Requirement

Interpretations of the meaning and application of informed consent reflect a tension between respecting the autonomy of persons and protecting them from harm. Hans Jonas (1970) and Paul Ramsey (1970) have developed a covenantal model in which subjects are respected and protected by ensuring that they give truly informed consent. Benjamin Freedman (1975) stressed the legally competent individual's freedom of choice, whether or not the choice is informed.

For Jonas and Ramsey, the consent requirement is derived from the duty to treat persons as ends, not merely as means. In research, subjects are *used* as means to the end of acquiring knowledge. (In Jonas's terms, they are "sacrificed" for the collective good.) Such *use* of persons is justified only if the subjects so identify with the purposes of the research that they will those purposes as their own ends. Only then are they not being *used,* but instead they have become, in Ramsey's term, "co-adventurers." The consent requirement thus affirms a basic covenantal bond between the researcher and the subject and ensures respect for the subject as an end, not merely a means.

To establish a true covenant, the subject's consent must be informed. Only subjects who genuinely know the purposes and appreciate the risks of research can assume those risks and adopt those purposes as their own ends. Ideal subjects, therefore, would be researchers themselves (Jonas). The less one understands the risks and identifies with the purposes of research, the less valid is one's consent. Jonas therefore established a "descending order of permissibility" for the recruitment ("conscription") of volunteers. Both Ramsey and Jonas restrict the use of subjects unable to consent or to understand what is involved, permitting the use of such subjects only in research directly related to their own condition (Jonas) or their own survival and well-being (Ramsey).

This interpretation reflects certain assumptions that can be challenged. First, while neither Jonas nor Ramsey focused exclusively on patients as subjects, their approach appears to be influenced largely by the medical practice model. That approach may not be adequate to deal with research not based on the medical practice model—for example, social-science research.

Second, while Ramsey argued that it is wrong to use a person in research without consent irrespective of risk (because one can be *wronged* without being *harmed*), he nonetheless appears to share with Jonas the assumption that most research is risky and involves *sacrifice* on the part of the subject. In fact, most research does not present risk of physical or psychological harm; rather, it presents inconvenience (e.g., of urine collection) and discomforts (e.g., of needle sticks) (Levine). Even Phase I drug testing, which involves the first administration of new drugs to humans and is usually assumed to be highly risky, has been estimated to present subjects with *risks* slightly greater than those involved in secretarial work and substantially less than those assumed by window washers and miners (Levine).

But the most important challenge is Freedman's (1975) alternative interpretation and use of the basic principles. Like Jonas and Ramsey, Freedman derived the consent requirement from the duty to have respect for persons. Unlike Jonas and Ramsey, however, he interpreted the requirement of respect for competent persons to allow the possibility of a "valid but ignorant" consent.

Freedman proposed that striving for *fully informed consent* is generally undesirable and that what is required is *valid consent,* not necessarily *informed consent.* To be valid, consent must be responsible and voluntary. Thus valid consent "entails only the imparting of that information which the patient/subject requires in order to make a responsible decision" (Freedman, p. 34). A choice based on less or other information than another responsible person might consider essential is not necessarily a sign of irresponsibility. Overprotection is a form of dehumanization and lack of respect; for example, to classify persons as incompetent to protect them from their own judgment is the worst form of abuse.

This approach also has several weaknesses. Much hinges on what is taken to be a responsible choice. Freedman suggested that responsibility is a dispositional characteristic and is to be judged in terms of the person, not in terms of a particular choice. There can be still, however, an element of paternalism introduced in judging another to be an irresponsible person. Moreover, this approach may not provide sufficient protection for those subjects who tend too readily to abdicate responsibility for choice, or who lack sufficient capacity or information to choose prudently.

It is clear that debates over the interpretation of informed consent depend on interpretations of the basic ethical principle of respect for persons and the extent to which that principle requires protection from harm or respect for autonomy.

Informed Consent: Conditions and Exceptions

According to the Nuremberg Code, to consent to participate in research one must:

1. be "so situated as to be able to exercise free power of choice";
2. have the "legal capacity" to give consent;
3. have "sufficient … comprehension" to make an "enlightened" decision; and
4. have "sufficient knowledge" on which to decide (Germany [Territory under Allied Occupation], p. 181).

More recent discussion emphasizes the knowledge or information component of consent—hence the term "*informed consent*" (Katz). The Nuremberg Code's focus on freedom of choice rather than on the quantity or quality of information transmitted is represented by its use of the term *voluntary consent,* instead of *informed consent.* It is worth recalling that a demand for informed consent at the expense of other styles of self-determination such as Freedman's responsible choice is not necessarily respectful of persons. Most commentators agree that compromise on any one of the four conditions specified by the Nuremberg Code jeopardizes the ethical acceptability of the consent.

"FREE POWER OF CHOICE." The Nuremberg Code proscribes "any element of force, fraud, deceit, duress, overreaching, or other ulterior forms of constraint or coercion" (Germany [Territory under Allied Occupation], p. 181) in obtaining consent. Any flagrant coercion—for instance, when competent, comprehending persons are forced to submit to research against their expressed will—clearly renders consent invalid. There may be more subtle or indirect "constraints" or "coercions" when prospective subjects are highly dependent, impoverished, ignorant, or "junior or subordinate members of a hierarchical group" (CIOMS, p. 65). Some argue that consent obtained from such persons violates the intent of the Nuremberg Code. This argument has been posed most sharply with respect to prisoners and other institutionalized populations, because institutionalization often involves both dependency and impoverishment. (Biomedical research involving prisoners as subjects has become quite rare since 1976 when the U.S. National Commission recommended very stringent standards for its justification [Dubler and Sidel 1989].) Some argue that consent to participate in research is not valid when it is given (1) to procure financial reward in situations offering few alternatives for remuneration; (2) to seek release from an institution either by evidencing "good behavior" or by ameliorating the condition for which one was confined; or (3) to please physicians or authorities on whom one's continued welfare depends (Branson).

But in his contribution to a 1976 U.S. National Commission report, Cornel R. West argued that such indirect forms of constraint do not constitute coercion in a strict sense and thus do not render consent involuntary. "Coercion," says West, consists in a threat to render one's circumstances worse if one does not do something. Hence, a threat to withdraw basic necessities of existence, or in some other way to render a prison inmate's situation worse if he declines to participate in research, would constitute coercion and render consent invalid. Similarly, to condition release from prison upon participation would constitute coercion, because it would make the inmate's situation worse by removing normal alternatives for seeking release. But the provision of better living conditions in exchange for participation in research does not constitute a threat to make conditions worse; rather, it is an enticement to make conditions better. While enticement and bribery can invalidate consent by undermining the rational grounds for choice, they do not undermine the voluntariness of the choice (Cohen). Similarly, a desire to *get well* or to favorably influence institutional authorities is not an *ulterior* constraint in the strict sense of the Nuremberg Code, though it may be a very real psychological constraint.

Other commentators, however, are less concerned with a sharp distinction between coercion and other forms of constraint or undue influence (Levine; CIOMS). Even outside such total institutions as prisons there are many situations in which junior or subordinate members of hierarchical groups may be exploited or manipulated. Such persons may assume that their willingness to consent to research may be rewarded by preferential treatment or that their refusals could provoke retaliation by those in positions of authority in the system. Whether or not such assumptions are justified, it is the assumptions themselves that make such persons susceptible to manipulation. Examples of such persons are medical or nursing students, subordinate hospital and laboratory personnel, employees of pharmaceutical firms, and members of the military services. Other persons whose dependency status can be exploited include residents of nursing homes, people receiving welfare benefits, patients in emergency rooms, and those with incurable diseases.

Apart from those populations identified by regulations and ethical codes as requiring *special protection*—fetuses, children, prisoners, and those who are incompetent by reason of mental incapacity—there is no clear consensus about how to respond to the problems presented by those whose capacity to consent may be limited by virtue of their dependency status. For example, whereas some medical schools have policies that forbid the involvement of medical students as research subjects, others have required investigators to invite them to participate in certain complex projects, reasoning that their highly sophisticated understanding of the risks, benefits, and purposes of such projects ensures a high quality of consent (Levine). Involvement of medical students, it is further argued, is consistent with Jonas's "descending order of permissibility" and contributes to their socialization into the medical profession.

While most regulations and ethical codes proscribe undue material inducements, there is no consensus on what this means. Some commentators argue that in most cases in which competent adults are recruited to serve as subjects in research that presents only slight increases above minimal risk, the role of the research subject is similar to that of an employee (Levine). Consequently, the amounts of cash payments or other material inducements can be determined by ordinary market factors. Others protest that because participation in research entails *selling one's body* as opposed to *selling one's labor* the role of the research subject might be considered more akin to commercial sex work than to any other type of employment (Wartofsky). According to this view, research subjects should not be paid at all; rather, they should be motivated by altruism.

Attempts to regulate the amounts of permissible material inducements are inevitably problematic (Levine). Setting the rates at a low level results in inequitable distribution of the burdens of participation among those who have no opportunities to earn more money for each unit of their time. Higher rates may overwhelm the capacity of the impoverished to decline participation.

In multinational research it is essential to evaluate the ethical acceptability of material inducements in the light of the gift-exchange traditions of the culture or community in which the research is to be carried out (CIOMS).

COMPETENCE AND COMPREHENSION. The Nuremberg Code requires both "legal capacity" to consent (often called *competence*) and "sufficient understanding" to reach an "enlightened" decision. Definitions of competence often include elements of comprehension, for example, to evaluate relevant information, to understand the consequences of action, and to reach a decision for rational reasons (Stanley and Stanley).

ASSESSMENTS OF INCOMPETENCE. The various standards employed for assessing competence are variations of four basic themes (Appelbaum, Lidz, Meisel):

1. *Reasonable outcome of choice.* This is a highly paternalistic standard in that the individual's right to self-determination is respected only if she makes the "right" choice—that is, one that accords with what the competency reviewer either considers reasonable or presumes a reasonable person might make.
2. *Factual comprehension.* The individual is required to understand, or at least be able to understand, the information divulged during the consent negotiation.
3. *Choice based on rational reasons.* Individuals must demonstrate a capacity for rational manipulation of information. They may, for example, be required to show that they not only understand the risks and benefits but also have weighed them in relation to their personal situations.
4. *Appreciation of the nature of the situation.* Individuals must demonstrate not only comprehension of the consent information but also the ability to use the information in a rational manner. Furthermore, they must appreciate that they are being invited to become research subjects and what that implies.

While there is disagreement as to the grounds for assessing incompetence, most commentators agree that such assessments are limited in several ways (Faden, Beauchamp, and King). First, a judgment of incompetence may apply to only certain areas of decision making, for example, to one's legal but not to one's personal affairs. Second, confinement to a mental institution is not in itself equivalent to a determination of incompetence. Third, some people are legally competent but functionally incompetent, whereas others are legally incompetent but functionally competent.

The Nuremberg Code does not permit the use of subjects lacking legal capacity or comprehension. Most subsequent codes and discussions allow their use with certain restrictions: for example, that mentally competent adults are not suitable subjects, that the veto of a legally incompetent but minimally comprehending subject is binding, and that consent or permission of the legal guardian must be obtained (Levine).

In its 1982 report, *Making Health Care Decisions,* the U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereafter, U.S. President's Commission) wrote that "decisionmaking capacity requires, to a greater or lesser degree: (1) possession of a set of values and goals; (2) the ability to communicate and understand information; and (3) the ability to reason and deliberate about one's choices" (p. 57). Moreover, individuals may have sufficient capacity to make some decisions but not others (Brock; Kopelman). In the words of the U.S. President's Commission:

> Since the assessment [of capacity] must balance possibly competing considerations of well-being

> and self-determination, [one should] take into account the potential consequences of the patient's decision. When the consequences for well-being are substantial, there is a greater need to be certain that the patient possesses the necessary level of capacity.… Thus a particular patient may be capable of deciding about a relatively inconsequential medication, but not about the amputation of a gangrenous limb. (U.S. President's Commission, p. 60)

PROXY CONSENT. The debate between Paul Ramsey and Richard A. McCormick over the legitimacy of proxy consent to authorize the participation of an incompetent person in research is one of the classics in the brief history of bioethics. Adopting the battery argument, Ramsey claimed that the use of a nonconsenting subject is wrong whether or not there is risk, simply because it involves an unconsented touching. Unconsented touching is not wrongful, however, when the guardian judges it is for the good of the incompetent individual. Hence, proxy consent may be given for the use of nonconsenting subjects in research only when it includes therapeutic interventions related to the subject's own recovery (Ramsey, 1970).

Ramsey acknowledged, however, that benefit does not always justify unconsented touching; such touching of a competent adult is wrong even if it benefits that person. Why, then, can benefit be presumed to justify such touching for a child (or other subject unable to give consent)? McCormick proposed that the validity of such interventions rests on the presumption that the child, if capable, would consent to therapy. This presumption in turn derives from a child's obligation to seek therapy, an obligation that the child possesses simply as a human being (McCormick, 1974). Because children have an obligation to seek their own well-being, it is presumed that they would consent if they could, and thus presumed also that proxy consent on their behalf would not violate respect for them as persons.

By analogy, McCormick suggested that, as members of a moral community, children have other obligations to which one would presume their consent and give proxy consent on their behalf. One such obligation is to contribute to the general welfare when such contribution requires little or no sacrifice. Hence, nonconsenting subjects may be used in research not directly related to their own benefit so long as the research fulfills an important social need and involves no discernible risk. Ramsey countered this argument with respect to children, claiming that McCormick's position fails to recognize that children are not adults with a full range of duties and obligations. Instead, they have rights that must be protected by adults (Ramsey, 1976).

Adopting this premise about the nature of the child as a moral being, Freedman drew different conclusions. Because a child is not a moral being in the same sense as an adult, he argued, the concept of wrongful touching does not apply. The child has no right to be left alone but only a right to be protected. Hence, Freedman concluded that the only relevant moral issue is the risk involved in the research, and, like McCormick, that children could be used in research unrelated to their therapy, provided it presents them no discernible risk. Thus, the debate centers on the status of the child (a paradigmatic incompetent) as a moral being and on interpretations of the requirements of respect for persons.

Although disagreements persist over both standards of competence and the use of incompetent subjects, one issue seems to have been settled by the U.S. National Commission in several of its reports (Levine). Parents, guardians, and, in some cases, other *responsible relatives* may give *permission* (a term that often replaces "proxy consent") to involve an incompetent in research if there is no more than minimal risk, if incompetents who are capable of giving their *assents* (knowledgeable agreements that do not meet the legal standards for informed consent) do so, and if certain other criteria are satisfied. If there is more than minimal risk, the standards for ethical justification of the involvement of incompetents are more stringent.

DISCLOSURE OF INFORMATION. The Nuremberg Code requires that the subject be told "the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come (Germany, [Territory under Allied Occupation], p. 182)." These requirements have been modified by subsequent codes and regulations. U.S. federal regulations require:

1. a statement of the purpose of the research and a description of its procedures;
2. a description of foreseeable risks and discomforts;
3. a description of benefits;
4. disclosure of appropriate alternatives, if any;
5. a statement of the extent of confidentiality;
6. an explanation of the availability of medical treatment for injury and compensation for disability;
7. an explanation of whom to contact for answers to questions; and
8. a statement that participation is voluntary and that neither refusal to participate nor withdrawal at any time will result in a loss of benefits to which the subject is otherwise entitled ("General Requirements" 1993).

The regulations further specify six additional elements of information to be provided when appropriate:

1. additional risks to the subject or to the fetus if the subject becomes pregnant;
2. circumstances in which a subject's participation may be terminated without his consent;
3. additional costs to the subject that may result from participation;
4. the consequences of a subject's decision to withdraw and procedures for orderly termination of participation;
5. a commitment to divulge significant new findings developed during the research that may relate to the subject's continued willingness to participate; and
6. the approximate number of subjects in the study.

Finally, the regulations forbid use of any exculpatory language through which the subject or her representative is made to waive any of their legal rights or that releases of the investigator, sponsor, or institution from liability for negligence.

While these requirements have the force of law, they are by no means exhaustive of possible standards for disclosure. To them one might add the following: a clear invitation to participate in research, distinguishing maneuvers required for research purposes from those necessary for therapy; an explanation of why the particular person is invited (selected); a suggestion that the prospective subject might wish to discuss the research with another person; and an identification of the source of funding for the research. Robert M. Veatch (1978) would add the names of members of any review boards that had approved the research and an explanation of the right, if any, to continue receiving treatments found useful. In short, there is no universal agreement on standards for disclosure of information or on what it takes for a person to have *sufficient knowledge* to give *informed* consent.

Those who agree on the need for disclosure of information in a particular category—the risks, for example—often disagree on the nature of the information that must be made known. The Nuremberg Code requires explication of hazards "reasonably" to be expected. Does this include a very slight chance of a substantial harm, or a substantial chance of a very slight harm? Neither the quality nor the probability of the risks to be divulged has been clearly determined legally.

Disagreements over particulars arise in part from disagreements about underlying standards: Is disclosure to be determined by (1) general medical practice or opinion, (2) the requirements of a *reasonable person,* or (3) the idiosyncratic judgment of the individual? While the legal trend may be shifting from the first to the second, it may be argued that only the third, the *subjective standard,* is truly compatible with the requirement of respect for the autonomy of the individual person (Faden, Beauchamp, and King; Veatch, 1978).

Yet even those who adopt the subjective standard disagree as to its implications. As noted earlier, Freedman (1975) held that the idiosyncratic judgment of the individual is overriding, to the point that the prospective subject can choose to have less information than a "reasonable" person might require. Veatch (1978), however, argued that anyone refusing to accept as much information as would be expected of a "reasonable person" should not be accepted as a subject.

In the context of medical practice, two exceptions to the requirement for informed consent are recognized—*emergency exception* and *therapeutic privilege.* The former, which permits the doctor to proceed without delay to administer urgently required therapy in emergencies, is reflected in a limited form in two provisions of the regulations of the U.S. Food and Drug Administration: (1) In some "life-threatening" emergencies in which informed consent is "infeasible," physician-investigators are authorized to employ investigational drugs and devices for therapeutic purposes (Levine). (2) In carefully defined circumstances, research designed to evaluate the safety and efficacy of investigational drugs or devices in emergency conditions may be carried out without the consent of the patient-subjects or the permission of their representatives. In such protocols either consent or permission must be obtained within a reasonable period of time after the initiation of the research; this entails authorization of the research participation already completed as well as the continuing participation of the subject in the research (Biros et al.).

The therapeutic-privilege exception to the informed-consent rule permits the doctor to withhold information when, in her judgment, disclosure would be detrimental to the patient's interests or well-being (Levine). Most commentators agree that invoking the doctrine of therapeutic privilege to assure a subject's cooperation in a research project is almost never appropriate; it gives the investigator entirely too much license to serve vested interests by withholding information that might be material to a prospective subject's decision. U.S. federal regulations do not explicitly endorse the use of the therapeutic-privilege exception in research, although some authors have suggested that they could be interpreted as an implicit endorsement (Levine).

The success of some research activities is contingent upon withholding from the subjects information about the purposes or procedures of the activities or, in some cases, upon deliberate deception (providing false information).

U.S. federal regulations permit *waivers and alterations* of consent requirements if there is no more than minimal risk; if the waiver or alteration will not adversely affect subjects' rights or welfare; if without the waiver or alteration the research "could not practicably be carried out"; and if the subjects will be debriefed (given a full and accurate explanation afterward) when appropriate ("General Requirements," pt. 46.116d).

There are some categories of research which, until recently, have been customarily carried out without individual informed consent; waiver of the requirement for informed consent in these categories was generally considered justified according to the *waivers and alterations* provisions of the regulations. Such activities included most research involving medical records and "leftover" specimens of tissues and body fluids obtained for either clinical or research purposes. Institutional patient information brochures generally contained notices of such routine research activities (Levine). Such routine uses of medical records without consent have had to be reconsidered in the light of the requirements of the Health Insurance Portability and Accountability Act of 1996 (DHHS). Similarly, routine use by researchers of specimens of tissue, without informed consent, have had to be reevaluated in the light of rapidly evolving standards (Clayton et al.); there is general agreement that such research is permissible without informed consent if the specimens are anonymous.

In a 1979 article, Diana Baumrind expressed her opposition to deceptive practices, arguing not only that they violate the principle of respect for persons but also that in the long run they will invalidate research on scientific grounds. Various proposals have been made to minimize the need for and harmful effects of deceptive practices: Subjects might be invited to consent to incomplete disclosure with a promise of full disclosure at the termination of the research; subjects might be told as much as possible and asked to consent for specified limits of time and risk; or approval of the plans to withhold information from or to deceive subjects might be sought from *surrogate* populations that resemble the actual intended subject populations in relevant respects (Levine).

"Secondary" Research Subjects

U.S. federal regulations define a human subject as "a living individual about whom an investigator … conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information." (45 CFR 46.102f). Until 1999 it was generally assumed that this definition applied only to those individuals who were the targets of the researcher's interest and that part (2) of the definition was intended to cover the use of records and specimens of tissue and body fluids. In 2000, however, the federal Office for Protection from Research Risks (now the Office for Human Research Protections, part of the Department of Health and Human Services) issued a novel interpretation: Questions asked of research subjects calling upon them to report on private information of their relatives, friends, or associates had the effect of turning these friends, relatives, and associates into *secondary* research subjects. If the private information solicited could be considered *sensitive,* then it would be required that the informed consent of the *secondary* subjects be obtained. This is a highly controversial matter, a full discussion of which is beyond the scope of this entry (Botkin).

Conclusions

The use of a person as a research subject can be justified only if that person, or one authorized to speak on the person's behalf, consents to such use. The legal and ethical requirement for consent is grounded in fundamental tenets of the Judeo-Christian religious tradition as well as in basic ethical principles that create the universal obligation to treat persons as ends and not merely as means to another's end. The consent requirement also reflects the perspective that competent persons are generally the best protectors of their own well-being. Most major disagreements over the form and substance of the consent requirement derive from conflicting interpretations of one or more of the basic principles.

A widespread tendency among researchers to focus on consent forms seems to reflect an assumption that the consent form is an appropriate instrumentality through which they might fulfill their obligation not to treat persons merely as means. Most commentators on informed consent disagree, however, seeing consent as a continuing process rather than a single event consummated by the signing of a form. Moreover, whereas the primary purposes of informed consent are to foster self-determination and to empower prospective subjects to protect their own well-being and other interests, the primary purpose of its written documentation is to protect the investigator, the institution, and the research sponsor from legal liability.

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SEE ALSO: *Children: Healthcare and Research Issues; Competence; Coercion; Holocaust; Human Rights; Information Disclosure, Ethical Issues of; Minorities as Research Subjects; Placebo; Race and Racism; Research Policy: Risk and Vulnerable Groups; Students and Research Subjects;* and other *Informed Consent* subentries

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IV. CLINICAL ASPECTS OF CONSENT IN HEALTHCARE

Decision making is an everyday event in healthcare, not only for doctors and patients, but also for nurses, psychologists, social workers, emergency medical technicians, dentists, and other health professionals. Since the 1960s, however, the cultural ideal of how these decisions should be made has changed considerably. The concept that medical decision making should rely exclusively on the physician's expertise has been replaced by a model in which healthcare professionals share information and discuss alternatives with patients who then make the ultimate decisions about treatment.

The concept of informed consent gained its initial support as part of the general societal trend toward broadening access to decision making during the 1960s. Thus, the initial support for informed consent came from legal and philosophic circles rather than healthcare professionals. In the legal arena, informed consent has been used to develop minimal standards for doctor–patient interactions and clinical decision making (Berg et al.). Although there are some differences by jurisdiction, widely accepted legal standards require that healthcare professionals inform patients of the risks, benefits, and alternatives of all proposed treatments, and then allow the patient to choose among acceptable therapeutic alternatives.

In academia, informed consent has served as a cornerstone for the development of the discipline of bioethics. Based on the importance of autonomy in moral discourse, philosophers have argued that healthcare professionals are obligated to engage patients in discussions regarding the goals of therapy and the alternatives for reaching those goals, and that patients are the final decision makers regarding all therapeutic decisions.

While many physicians would express some support to the concept of shared decision making, this support is largely theoretical and does not seem to have made its way into routine medical practice. Physicians typically think of informed consent as a legal requirement for a signed piece of paper that is at best a waste of time, and at worst a bureaucratic, legalistic interference with their care for patients. Rather than seeing informed consent as a process that promotes good communication and patient autonomy, many healthcare professionals view it as a complex, legally prescribed recitation of risks and benefits that only frightens or confuses patients.

Objections to Informed Consent

There are various objections to informed consent that clinicians often make, and it will be useful to review those objections here.

CONSENT CANNOT BE TRULY "INFORMED." Many practicing clinicians report that their patients are unable to understand the complex medical information necessary for a fully rational weighing of alternative treatments. There is considerable research support for this view. A variety of studies document that patients recall only a small percentage of the information that professionals present to them (Meisel and Roth); that they are not as good decision makers when they are sick as at other times (Sherlock; Cassell, 2001); and that they often make decisions based on medically trivial factors. Informed consent thus appears either to promote uninformed—and thus suboptimal—decisions, or to encourage patients to blindly accept healthcare professionals' recommendations. In either case informed consent appears to be a charade, and a dangerous one at that.

However, the fact that patients often do have difficulty understanding important aspects of medical decisions does not mean that healthcare professionals are the best decision makers about the patient's treatment. Knowledge about medical facts is not enough. Wise house buyers will have a structural engineer check over an old house, but few would be willing to allow the engineer to choose their house for them. Just as structural engineers cannot decide which house a family should buy—because they lack knowledge about the family's pattern of living, personal tastes, and potential family growth—healthcare professionals cannot scientifically deduce the best treatment for a specific patient simply from the medical facts. What matters to individuals about their health depends on their lifestyles, past experiences, and values, so choosing the *optimal therapy* is not a purely objective matter (U.S. President's Commission). Thus, patients and healthcare professionals both contribute essential knowledge to the decision-making process: patients bring their knowledge of their personal situation, goals, and values; and healthcare professionals bring their expertise on the nature of the problem and the technology that may be used to meet the patient's goals (see Brock).

Informed-consent disclosures, even if they are well done, may not lead to what clinicians might consider optimal decisions. Most people make major life decisions, such as whom to marry and which occupation to take up, based on faulty or incomplete information. Patients' lack of understanding of medical information in choosing treatment is probably no worse than their lack of information in choosing a spouse, nor are medical decisions more important than spousal choice. Respecting patient autonomy means allowing individuals to make their own decisions, even if the healthcare professional disagrees with them. The informed-consent process can improve patient decisions, but it cannot be expected to lead to perfect decisions.

Moreover, although sick persons have defects in their rational abilities, so do healthcare professionals. In fact, some of the most famous research on the difficulties individuals have with the rational use of probabilistic data involves physicians (Dawson and Ackes). Health professionals must be careful not to be too pessimistic about patients' ability to become informed decision makers. Patients may not be able to become as technically well-informed as professionals, but they clearly can understand and make decisions based on relevant information. One study, for example, showed that patients' decisions regarding life-sustaining treatment changed when they were given accurate information about the therapy's chance of success and that patients, when given increased information about screening tests for prostate cancer, were less likely to have the test change their decision on having the test (Murphy et al.). Moreover, what seems to be an irrational decision may turn out to be, from the patient's point of view, rational. Thus, a patient may turn down a recommended treatment because of personal experience with surgery or because the long-term benefit is not seen as being worth the short-term risk.

Most important, the difficulty of educating sick persons does not justify unilateral decision making. Rather, it places a special obligation on healthcare professionals to communicate clearly with patients. Using technical jargon, trying to give all of the available information in one visit, and not asking what the patient wants to know is a recipe for confusing even the most intelligent patient. A growing literature deals with informational aides—ranging from question prompt-sheets to giving patients audiotapes of the interaction and formal decision aides—that can be used to promote patient understanding and shared decision-making. New technologies like interactive DVD offer patients the opportunity to participate more fully in shared decision making at their own rate. A limitation of many of these aides is that they are limited helping with specific decisions and need to be updated frequently (Barry). Healthcare professionals also need to become more familiar with different cultural patterns of communication in order to talk with patients from different cultural backgrounds. For example, although a simple, factual discussion of depression and its treatment may be acceptable to most middle-class Americans, it would be seen as inappropriate by a first-generation Vietnamese male, whose culture discourages viewing depression as a disease (Hahn). There is no reason, in principle, why a person who makes decisions at home and work cannot, with help, understand the medical data sufficiently to become involved in medical decisions. Healthcare professionals must learn how best to present that help and involve patients in the decision-making process.

PATIENTS DO NOT WISH TO BE INVOLVED IN DECISION MAKING. Many healthcare professionals believe that it is unfair to force patients to make decisions regarding their medical care. After all, they argue, patients pay their healthcare professionals to make medical decisions. The empirical literature partially supports the view that patients want professionals to make treatment decisions for them (Steel et al.). For example, in a study of male patients' preferences about medical decision making regarding hypertension, only 53 percent wanted to participate at all in the decision-making process (Strull et al.). More recent data suggest that sicker patients are less interested in information about their disease and more willing to have doctors make decisions (Butow 1997; 2002).

There is no reason to force patients to be involved in decisions if they do not want to be. However, unless the health professional asks, he or she cannot know how involved a patient wants to be. Studies suggest that doctors' ability to predict their patients' interest in information, or their desire to be involved in decision making, is no better than flipping a coin (Butow 1997, 2002). In addition, roughly two-thirds of patients want to be involved in decision making, either by being the primary decision maker (the minority) or in shared decision making with the physician.

Patients may not always want to be involved in decision making, since many have been socialized into believing that "the doctor knows best." This is particularly true for poorer patients. Studies have shown that physicians wrongly assume that because patients with fewer socioeconomic resources ask fewer questions, they do not want as much information. These patients may in fact want just as much information, but they have been socialized into a different way of interacting with healthcare professionals (Waitzkin, 1984).

Patients may choose to allow someone else to make the decision for them. However, when a patient asks, "What would you do if you were me?" the underlying question may be, "As an expert in biomedicine, what alternative do you think will best maximize my values or interest?" If this is the case, the healthcare professional should respond by making a recommendation and justifying it in terms of the patient's values or interests. More frequently, the patient is asking, "If you had this disease, what therapy would you choose?" This question presumes that the professional and patient have the same values, needs, and problems, which is often not the case. Healthcare professionals should respond by pointing this out and emphasizing the importance of the patients' values in the decision-making process.

Although many patients do not want to be actively involved in decision making, they almost always want more information concerning their illness than the healthcare professional gives them. Healthcare professionals should not assume that just because patients do not wish to choose their therapy, they do not want information. Patients may desire information so as to increase compliance or make modifications in other areas of their lives, as well as to make medical decisions.

THERE ARE HARMFUL EFFECTS OF INFORMING PATIENTS. Healthcare professionals often justify withholding information from patients because of their belief that informing patients would be psychologically damaging and therefore contrary to the principle of nonmaleficence. Many healthcare professionals, however, overestimate potential psychological harm and neglect the positive effects of full disclosure (Faden et al.). Some discussions that physicians assume are stressful, such as advance care-planning, have been shown to decrease patient anxiety and increase the patient's sense of control. Moreover, bad news can often be communicated in a way that ameliorates the psychological effects of the disclosure (Quill and Townsend). Truth-telling must be distinguished from "truth dumping." Explanation of the care that can be provided, and empathic attention to the patient's fears and uncertainties can often prevent or mitigate otherwise more painful news. Finally, sometimes the harm associated with bad news is unavoidable. It is normal to be sad after finding out that one has an incurable cancer, for example. That does not mean that one should not convey the information, only that it should be done in as sensitively and supportively as possible.

INFORMED CONSENT TAKES TOO MUCH TIME. Respecting autonomy and promoting patient well-being—the values served through informed consent—are fundamental to good medicine. However, adhering to the ideals of medical practice takes time—time to help patients understand their illness and work through their emotional reactions to stressful information, to discuss each party's preconceptions and to clarify the therapeutic goals, to decide on a treatment plan, and to elicit questions about diagnosis and treatment.

In U.S. healthcare, time is money. As many commentators have noted, physicians are less well reimbursed for talking to patients than for performing invasive tests. This may discourage doctors from spending enough time discussing treatment options with patients. This, along with the pressures of managed care has decreased the average outpatient encounter, allowing even less time for doctor–patient communication. The ultimate justification for spending time to facilitate patient decisions is the same as that for spending any time in medical care: that patients will be better cared for. Moreover, some of the new decision aides, such as question prompts, may in fact decrease the time spent in the patient visit, while simultaneously increasing patient understanding.

Clinical Approaches to Informed Consent

Many of the problems in implementing informed consent result, at least in part, from the way informed consent has been implemented in clinical practice. Informed consent has become synonymous with the *consent form,* a legal invention with a legitimate role in documenting that informed consent has taken place, but hardly a substitute for the discussion process leading to informed consent (Andrews).

A PRO FORMA APPROACH: AN EVENT MODEL OF INFORMED CONSENT. In many clinical settings, consent begins when *it is time to get consent,* typically just prior to the administration of treatment. The process of getting the patients' consent consists of the recitation by a physician or nurse of the list of material risks and benefits and a request that the patient sign for the proposed treatment. This "conversation" is a very limited one that emphasizes the transfer of information from the physician or nurse to the patient. While it does meet the minimal legal requirements for informed consent efficiently, it does not meet the higher ethical goal of informed consent, which is to empower patients by educating and involving them in their treatment plans. Instead, it imposes an almost empty ritual on an unchanged relationship between provider and patient (Katz).

The procedure just described assumes that care involves a series of discrete, circumscribed decisions. In fact, much of clinical medicine consists of a series of frequent, interwoven decisions that must be repeatedly reconsidered as more information becomes available. When "it is time to get consent," there may be nothing left to decide. Consider the operative consent form obtained the evening prior to an operation. After patients have discussed with their families whether to be admitted to the hospital, rearranged their work and child-care schedules, and undergone a long and painful diagnostic workup, the decision to have surgery seems preordained. The evening before the operation, patients do not seriously evaluate the operation's risks and benefits, so consent is pro forma. No wonder some healthcare professionals feel that *consent* is a waste of time and energy.

The event model for gathering informed consent falls far short of meeting the ethical goal of ensuring patient participation in the decision-making process. Rather than engaging the patient as an active participant in the decision-making process, the patient's role is to agree to or veto the healthcare professionals' recommendations. Little attempt is made to elicit patient preferences and consider how treatment might address them.

A DIALOGICAL APPROACH: THE PROCESS MODEL OF INFORMED CONSENT. Fortunately, it is possible to fulfill legal requirements for informed consent while maximizing active patient participation in the clinical setting. An alternative to the event model described above, which sees informed consent as an aberration from clinical practice, the process model attempts to integrate informed consent into all aspects of clinical care (Berg et al). The process model of informed consent assumes that each party has something to contribute to the decision-making process. The physician brings technical knowledge and experience in treating patients with similar problems, while patients bring knowledge about their life circumstances and the ability to assess the effect that treatment may have on them. Open discussion makes it possible for the patient and the physician to examine critically their views and to determine what might be optimal treatment.

The process model also recognizes that medical care rarely involves only one decision made at a single point in time. Decisions about care frequently begin with the suspicion that something is wrong and that treatment may be necessary, and they end only when the patient leaves follow-up care. Decisions involve diagnostic as well as therapeutic interventions. Some decisions are made in one visit, while others occur over a prolonged period of time. Although some interactions between provider and patient involve explicit decisions, decisions are made at each interaction, even if the decision is only to continue treatment. The process model also recognizes that various healthcare professionals may play a role in making sure that the patients' consent is informed. For example, a woman deciding on various breast cancer treatments may talk with an oncologist and a surgeon about the risks of various treatments, with a nurse about the side effects of medication, with a social worker about financial issues in treatment, and with a patient-support group about her husband's reaction to a possible mastectomy.

Ideally, then, informed consent involves shared decision making over a period of time; it a dialogue throughout the course of the patient's relationship with various healthcare professionals. Such a dialogue aims to facilitate patient participation and to strengthen the therapeutic alliance.

Tasks Involved in Informed Consent

Consent is a series of interrelated tasks. First, the patient and professional must agree on the problem that will be the focus of their work together (Eisenthal and Lazare). Most nonemergency consultations involve complex negotiations between healthcare professional and patient regarding the definition of the patient's problem. The patient may see the problem as a routine physical examination for a work release, the need for advice, or the investigation of a physical symptom. If professionals are to respond effectively to the patients' goals, they must find out the reason for the visit. Whereas physicians typically focus on biomedical information and its implications, patients typically view the problem in the context of their social situation (Fisher and Todd). The differences between the patient's perceptions of the problem and the professional's perceptions must be explicitly worked through, since agreement regarding the focus of the interactions will lead to increased patient satisfaction and compliance with further treatment plans (Meichenbaum and Turk).

Even when the professional and patient have agreed on what the problem is, substantial misunderstandings may arise regarding the treatment goals. Patients may expect the medically impossible, or they may expect outcomes based on knowledge of life circumstances about which the physician is unaware. Since assessing the risks and benefits of any treatment option depends on therapeutic goals, the professional and patient must agree on the goals the therapy aims to accomplish.

Finding out what the patient wants is more complicated than merely inquiring, "What do you want?" A patient typically does not come to the professional with well-developed preferences regarding medical therapy except "to get better," with little understanding of what this may involve (Cassell, 1985). As a patient's knowledge and perspective change over the course of an illness, so too may the patient's views regarding the therapeutic goals.

Because clinicians provide much of the medical information needed to ensure that the patient's preferences are grounded in medical possibility, healthcare professionals play a significant role in how a patient's preferences evolve. It is important that they understand that patients may reasonably hold different goals from those their practitioners hold. This is particularly true when they come from different economic strata. For example, a physician's emphasis on the most medically sophisticated care may pale in the light of the patient's financial problems. Therapeutic goals, like the definition of the problem, require ongoing clarification and negotiation.

After agreeing upon the problem and the therapeutic goals, the healthcare professional and the patient must choose the best way to achieve them. If patients have been involved in the prior two steps, the decision about a treatment plan will more likely reflect their values than if they are merely asked to assent to the clinician's strategy.

Healthcare professionals often ask how much information they must supply to ensure that the patient is an informed participant in the decision-making process (Mazur). There is, however, a more important question: Has the information been provided in a manner that the patient can understand? While the law only requires that healthcare professionals inform patients, morally valid consent requires that patients understand the information conveyed. Ensuring patient understanding requires attention to the quality as well as the quantity of information presented (Faden).

A great deal of empirical data has been collected concerning problems with consent forms. These forms have been criticized, for example, as being unintelligible because of their length and use of technical language (Berg et al.) Healthcare professionals thus need to be aware of, and facile in using, a variety of methods to increase patients' comprehension of information, including verbal techniques, written information, and interactive videodiscs (Stanley et al.).

Still, the question of how much information to present remains. The legal standards regarding information disclosure—what a reasonable patient would find essential to making a decision or what a reasonably prudent physician would disclose—are not particularly helpful. Howard Brody has suggested two important features: (1) the physician must disclose the basis on which the proposed treatment or the alternative possible treatments have been chosen; and (2) the patient must be encouraged to ask questions suggested by the the physician's reasoning—and the questions need to be answered to the patient's satisfaction (Brody). Healthcare professionals must also inform patients when controversy exists about the various therapeutic options. Similarly, patients should also be told the degree to which the recommendation is based on established scientific evidence rather than personal experience or educated guesses.

Two other factors will influence the amount of information that should be given: the importance of the decision (given the patient's situation and goals) and the amount of consensus within the healthcare professions regarding the agreed-upon therapy. For example, a low-risk intervention, such as giving influenza vaccines to elderly patients, offers a clear-cut benefit with minimal risk. In this case, the professional should describe the intervention and recommend it because of its benefits. A detailed description of the infrequent risks is not needed unless the patient asks or is known to be skeptical of medical interventions. Interventions that present greater risks or a less clear-cut risk-benefit ratio require a longer description—for example, the decision to administer AZT to an HIV (human immunodeficiency virus)-positive, asymptomatic woman with a CD4 cell count of 350. In this situation, the data regarding starting medications are unclear and a patient's preference is critical. In this situation, one would need to talk about the major side effects of the medicines, the burden of taking medicines daily, the immunological benefit of anti-virals, etc. In neither case is a discussion of pathophysiology or biochemistry necessary. It must be emphasized that there is no formula for deciding how much a patient needs to be told or the length of time this will take. The amount of information necessary will depend on the patient's individual situation, values, and goals.

Finally, an adequate decision-making process requires continual updating of information, monitoring of expectations, and evaluation of the patient's progress in reaching the chosen or revised goals. Thus, the final step in informed consent is follow-up. This step is particularly important for patients with chronic diseases for which modifications of the treatment plan are often necessary.

The process model of informed consent has many advantages. Because it assumes many short conversations over time rather than one long interaction, it can be more easily integrated into the professional's ambulatory practice than the event model. It also allows patients to be much more involved in decision making and ensures that treatment is more consistent with their values. Furthermore, the continual monitoring of patients' understanding of their disease, the treatment, and its progress is likely to reduce misunderstandings and increase their investment in, and adherence to, the treatment plan. Thus, the process model of informed consent is likely to promote both patient autonomy and well-being.

Unfortunately, there are situations in which this approach is not very helpful. Some healthcare professionals, anesthesiologists, or emergency medical technicians, for example, are not likely to have ongoing relationships with patients. In emergencies, there is not time for a decision to develop through a series of short conversations. In these cases, informed consent may more closely approximate the event model. However, since most medical care is delivered by primary-care practitioners in an ambulatory setting, the process model of informed consent is more helpful.

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SEE ALSO: *Autonomy; Clinical Ethics: Elements and Methodologies; Competency; Information Disclosure, Ethical Issues of; Hospital, Contemporary Ethical Problems; Law and Bioethics; Life, Quality of: Quality of Life in Clinical Decisions; Paternalism; Patients' Rights: Origin and Nature of Patients' Rights;* and other *Informed Consent* subentries

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V. LEGAL AND ETHICAL ISSUES OF CONSENT IN HEALTHCARE

This article, by Jay Katz, is reprinted from the first edition, where it carried the title "Informed Consent in the Therapeutic Relationship: II. Legal and Ethical Aspects." It is followed immediately by a "Postscript," prepared by Angela R. Holder for purposes of updating the original article.

The doctrine of informed consent, introduced into U.S. case law in 1957, represents judges' groping efforts to delineate physicians' duties to inform patients of the benefits and risks of diagnostic and treatment alternatives, including the consequences of no treatment, as well as to obtain patients' consent (*Salgo v. Stanford University,* 1957). The doctrine's avowed purpose was to protect patients' right to "thoroughgoing self-determination" (*Natanson v. Kline,* 1960). The legal implications of informed consent, however, remain unclear. The doctrine is in fact more of a slogan, which judges have been too timid or too wise to translate into law, at least as yet. It has been employed with little care but great passion to voice a dream of personal freedom and individual dignity. Though its legal impact in protecting patients' right to self-decision making has been scant, the threat of informed consent has opened profound issues for the traditional practice of medicine.

The Medical Framework

It has been insufficiently recognized, particularly by judges, that disclosure and consent, except in the most rudimentary fashion, are obligations alien to medical practice. Hippocrates' admonitions to physicians are still followed today: "Perform [these duties] calmly and adroitly, concealing most things from the patient while you are attending to him. Give necessary orders with cheerfulness and serenity, turning his attention away from what is being done to him; sometimes reprove sharply and emphatically, and sometimes comfort with solicitude and attention, revealing nothing of the patient's future or present condition." Thus it is not surprising that the Hippocratic oath is silent on the duty of physicians to inform, or even converse with, patients. Similarly Dr. Thomas Percival, whose 1803 book *Medical Ethics* influenced profoundly the subsequent codifications of medical ethics in England and the United States, commented only once on the discourse between physicians and patients, restricting his remarks to "gloomy prognostications." Even in that context he advised that "friends of the patient" be primarily informed, though he added that the patient may be told "if absolutely necessary" (Percival, p. 91). The Code of Ethics of the American Medical Association, adopted in 1847, and the Principles of Medical Ethics of the American Medical Association, adopted in 1903 and 1912, repeat, in almost the same words, Percival's statement. The AMA Principles of Medical Ethics, endorsed in 1957, delete Percival's wording entirely and substitute the vague admonition that "physicians … should make available to their patients … the benefits of their professional attainments." The pertinent sections of the *Opinions of the Judicial Council* of the AMA, interpreting the principles, note only the surgeon's obligation to disclose "all facts relevant to the need and performance of the operation" and the experimenter's obligation, when using new drugs and procedures, to obtain "the voluntary consent of the person" (American Medical Association Judicial Council). Nine years later, the AMA House of Delegates in endorsing, with modifications, the Declaration of Helsinki, asked that investigators, when engaged "in clinical [research] primarily for treatment," make relevant disclosures to and obtain the voluntary consent of patients or their legally authorized representative.

Thus in the context of therapy no authoritative statement encouraging disclosure and consent has ever been promulgated by the medical profession. The AMA's tersely worded surgical exception was compelled by the law of malpractice. Its experimental exception represented primarily an acquiescence to the U.S. Public Health Service and the U.S. Department of Health, Education, and Welfare requirements, which in turn were formulated in response to congressional concerns about research practices. When disclosure and consent prior to the conduct of therapeutic research were endorsed by the AMA, it did not extend those requirements to all patient care but limited the exception to "clinical [research] primarily for treatment."

Two significant conclusions can be drawn: (1) *Informed consent* is a creature of law and not a medical prescription. A duty to inform patients has never been promulgated by the medical profession, though individual physicians have made interesting, but as a rule unsystematic, comments on this topic. Judges have been insufficiently aware of the deeply ingrained Hippocratic tradition against disclosure and, instead, seem to have assumed that individual physicians lack of disclosure was aberrant with respect to standard medical practice, and hence *negligent,* in the sense of *forgetful* or *inadvertent,* conduct. (2) When judges were confronted with claims of lack of informed consent, no medical precedent, no medical position papers, and no analytic medical thinking existed on this subject. Thus physicians were ill prepared to shape judges' notions on informed consent with thoughtful and systematic positions of their own.

The Legal Framework

With the historical movement from feudalism to individualism, consent, respect for the dignity of human beings, and the right of individuals to shape their own lives became important principles of English common law and, in turn, of American common law. Yet, as these principles gained greater acceptance, questions arose in many areas of law about the capacity of human beings to make their own decisions and about the need to protect them from their own "folly." The tug of war between advocates of thoroughgoing self-determination and those of paternalism has continued unabated. The informed-consent doctrine manifests this struggle. While in physician-patient interactions the legal trend during the past two decades has been to increase somewhat the right of patients to greater freedom of choice, the informed-consent doctrine has not had as far-reaching an impact on patients' self-determination as many commentators have assumed. This fact has been insufficiently appreciated and has led to confusion, further compounded by the courts' rhetoric that seemed to promise more than it delivered.

Consent to medical and surgical interventions is an ancient legal requirement. Historically an intentional touching without consent was adjudicated in battery. The law has not changed at all in this regard, and a surgeon who operates on a patient without permission is legally liable, even if the operation is successful. In such instances any inquiry into medical need or negligent conduct becomes irrelevant, for what is at issue is the disregard of the person's right to exercise control over his body. The jurisprudential basis of these claims is personal freedom:

> … under a free government at least, the free citizen's first and greatest right, which underlies all others—the right to himself—is the subject of universal acquiescence, and this right necessarily forbids a physician or surgeon, however skillful or eminent … to violate without permission the bodily integrity of his patient by … operating on him without his consent.… (*Pratt v. Davis,* 1906)

But what does consent mean? In battery cases it means only that the physician must inform the patient what he proposes to do and that the patient must agree. Medical emergencies and patients' incompetence are the only exceptions to this requirement.

In mid-twentieth century, judges gradually confronted the question whether patients are entitled not only to know what a doctor proposes to do but also to decide whether the intervention is advisable in the light of its risks and benefits and the available alternatives, including no treatment. Such awareness of patients' informational needs is a modern phenomenon, influenced by the simultaneous growth of product liability and consumer law.

The law of fraud and deceit has always protected patients from doctors' flagrant misrepresentations, and in theory patients have always been entitled to ask whatever questions they pleased. What the doctrine of informed consent sought to add is the proposition that physicians are now under an affirmative duty to offer to acquaint patients with the important risks and plausible alternatives to the proposed procedure. The underlying rationale for that duty was stated in *Natanson v. Kline*:

> Anglo-American law starts with the premise of thorough-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery, or other medical treatment. A doctor might well believe that an operation or form of treatment is desirable or necessary but the law does not permit him to substitute his own judgment for that of the patient by any form of artifice or deception. (*Natanson v. Kline*)

The language employed by the *Natanson* court in support of an affirmative duty to disclose derives from the language of the law of battery, which clearly makes the patient the ultimate decision maker with respect to his body. Thus the courts reasoned, with battery principles very much in mind, that significant protection of patients' right to decide their medical fate required not merely perfunctory assent but a truly *informed consent,* based on an adequate understanding of the medical and surgical options available to them.

Yet in the same breath judges also attempted to intrude as little as possible on traditional medical practices. In doing so their impulse to protect the right of individual self-determination collided with their equally strong desire to maintain the authority and practices of the professions. Law has always respected the arcane expertise of physicians and has never held them liable if they practiced "good medicine." The law of consent in battery represented no aberration from this principle since most physicians agree that patients at least deserve to know the nature of the proposed procedure. However, the new duty of disclosure that the law, in the name of self-determination, threatened to impose upon physicians was something quite different. For the vast majority of physicians significant disclosure is not at all part of standard medical practice. Most doctors believe that patients are neither emotionally nor intellectually equipped to be medical decision makers, that they must be guided past childish fears into *rational* therapy, and that disclosures of uncertainty, gloomy prognosis and dire risks often seriously undermine cure. Physicians began to wonder whether law was now asking them to practice "bad" medicine.

In the early informed-consent cases, judges simply did not resolve the conflict between self-determination and professional practices and authority. The result was distressing confusion. In obeisance to the venerable ideal of self-determination, courts purported to establish, as a matter of law, the physician's

> … obligation … to disclose and explain to the patient in language as simple as necessary the nature of the ailment, the nature of the proposed treatment, the probability of success or of alternatives, and perhaps the risks of unfortunate results and unforeseen conditions within the body. (*Natanson v. Kline*)

The threat of such an obligation greatly disturbed the medical profession. It recognized that serious implementation of such a standard would significantly alter medical practice. Physicians argued that in order fully to serve patients' best interests, they must have the authority to exercise medical judgment in managing patients. Courts likewise bowed to this judgment. In the very sentence that introduced the ambiguous but exuberant new phrase "informed consent," the court showed its deference to medical judgment and its hesitancy to disturb traditional practice:

> … in discussing the element of risk a certain amount of discretion must be employed consistent with the full disclosure of facts necessary to an informed consent. (*Salgo v. Stanford University*)

Thus the extent to which evolving case law, under the banner of individualism, was challenging traditional medical practice—which for millennia has treated patients paternally as children—remained confusing. In those earlier cases (*Salgo v. Stanford University, Natanson v. Kline*) judges were profoundly allegiant to both points of view, but the balance was soon tipped decisively in favor of protecting medical practices.

BATTERY OR NEGLIGENCE. The striking ambivalence of judges toward the doctrine of informed consent manifested itself in the competition between battery and negligence doctrines as a means of analyzing and deciding the claims of lack of informed consent. Battery offered a more rigorous protection of patients' right to self-determination. The inquiry into disclosure and consent would not be governed by professional practices but instead would rest on the question: Has the physician met his expanded informational responsibility so that the patient is able to exercise a choice among treatment options? A negative answer to this question would show that the physician's actions constitute trespass, rendering him liable for an unauthorized and *offensive* contact (*Dow v. Kaiser Foundation*).

However, in virtually every jurisdiction judges resolved the competition in favor of negligence law. In doing so, judges were able to defer to medical judgment by evaluating the adequacy of disclosure against the medical professional standard of care, asserting that this standard will govern those duties as it does other medical obligations. As a consequence, physicians remain free to exercise the wisdom of their profession and are liable only for failure to disclose what a reasonable doctor would have revealed. Furthermore, negligence theory does not redress mere dignitary injuries, irrespective of physical injuries, and requires proof that the patient, fully informed, would have refused the proposed treatment. Interferences with self-determination, standing alone, are not compensated.

In rejecting battery, judges made much of the fact that such an action required *intent,* while negligence involved *inadvertence*; it was the latter, they believed, that accounted for the lack of disclosure. They overlooked that the withholding of information on the part of physicians is generally quite intentional, dictated by the very exercise of medical judgment that the law of negligence seeks to respect. In stating that the nondisclosures were *collateral* to the central information about the nature of the proposed procedure and hence not required for a valid consent, judges discarded the very idea of informed consent—namely, that absence of expanded disclosure vitiates consent. They refused to extend the inquiry to the total informational needs of patients, without which patients' capacity for self-decision making remains incomplete. At bottom, the rejection of an expanded battery theory and of its proposed requirement of informed consent followed from the threat they posed to the authority of doctors and traditional medical practice.

Thus informed consent, based on patients thoroughgoing self-determination, was a misnomer from the time the phrase was born. To be sure, a new cause of action has emerged for failure to inform of the risks of, and in most jurisdictions alternatives to, treatment. Some duty to disclose risks and alternatives, the courts were willing to say, exists; the extent of that duty is defined by the disclosure practice of a reasonable physician in the circumstances of the case. The new claim is firmly rooted in the law of negligent malpractice, in that plaintiffs are still required to prove the professional standard of care by means of medical expert witnesses. In these, the majority of jurisdictions, traditional medical practice—which generally opposes disclosure—has scarcely been threatened at all in legal reality. The legal life of informed consent, except for dicta about self determination and the hybrid negligence law promulgated in a handful of jurisdictions, was almost over as soon as it began. Judges had briefly toyed with the idea of patients' self-determination and then largely cast it aside. Good medicine, as defined by doctors, remains good law almost everywhere.

MODIFICATIONS IN PROFESSIONAL STANDARD OF CARE. In a few jurisdictions, beginning in 1972 in the District of Columbia with the decision in *Canterbury v. Spence,* the new cause of action for failure to inform combined elements of battery with negligence, creating a legal hybrid. The court purported to abandon the professional standard of care with respect to disclosure, asserting that

> … respect for the patient's right of self-determination on particular therapy demands a standard set by law for physicians rather than one which physicians may or may not impose upon themselves. (*Canterbury v. Spence*)

Thus the court laid down a judge-made rule of disclosure of risks and alternatives, which for all practical purposes resembled an expanded battery standard of disclosure.

The preoccupation with risk disclosure, however, continued unabated. From the very beginning, despite all the talk about *informed consent,* judges did not lay down any rules for a careful inquiry into the nature and quality of consent, which on its face any meaningful implementation of the doctrine required. Instead major emphasis was placed on risk disclosures. Since in the cases before courts plaintiff-patients only complained of the injurious results of treatment, this emphasis is understandable. Yet to focus solely on risks is to bypass the principal issue of self-determination—namely, whether the physician kept the patient from arriving at his own decision. The *Canterbury* court, too, restricted its concerns largely to risk disclosures and added the requirement that

> an unrevealed risk that should have been made known must materialize for otherwise the omission, however, unpardonable, is legally without consequence. (*Canterbury v. Spence*)

Thus the court foreclosed legal redress for the patient who, fully informed of the potential effects of, for example, a maiming operation, would have chosen an alternative medical course, even though some of the risks did not materialize.

But to the extent these jurisdictions have abandoned the professional standard of disclosure, traditional medical practice has been challenged; "good medicine," in the eyes of the profession, may no longer be a sufficient defense. Seemingly, in these jurisdictions self-determination has begun to encroach upon the province of medical paternalism. That encroachment, however, may be substantially an illusion, for the touted abandonment of the professional standard of disclosure in *Canterbury* was far from complete. Medical judgment to truncate full disclosure must be "given its due," the court said, when "it enters the picture." The court left ambiguous when the plaintiff must establish the appropriate standard of disclosure by an expert witness, or when he must produce such a witness in order to rebut a defendant-physician's claim that good medical judgment was exercised.

What is clear is that the physician has a *therapeutic privilege* not to disclose information where such disclosure would pose a threat to the *well-being* of the patient. But the ambit of this privilege as well as the relationship of its invocation to a directed verdict is not clear, and this for "good" reasons: Even in these most liberal jurisdictions with respect to patients' rights, courts still cannot face squarely the question of how much they are willing to challenge the traditional medical wisdom of nondisclosure. The law remains ambiguous with respect to this, the core issue of informed consent.

TENSIONS BETWEEN SELF-DETERMINATION AND PATERNALISM. Beyond its allegiance to medical paternalism, noted above, the *Canterbury* court showed its preference for paternalism in another way. Under negligence law, the courts have stated that lack of disclosure cannot be said to have caused the patient's injury unless the patient, if adequately informed, would have declined the procedure; this is the crucial problem of causation in informed-consent cases. Such an approach to causation is quite appropriate where law seeks not to compensate interference with self-determination, but only physical injuries resulting from inadequate disclosure. Yet the *Canterbury* court, and every court that has considered the matter subsequently, held that the decision whether or not to undertake therapy must be examined not from the point of view of the patient-plaintiff but from that of a "prudent person in the patient's position," limiting the inquiry to whether a "reasonable patient" would have agreed to the procedure. This substitution of a community standard of a "reasonable" person cuts the heart out of the courts purported respect for individual self-determination. Questions of the influence of hindsight and bitterness are familiar to juries, as is the problem of self-serving testimony generally. While those are delicate problems, they do not justify abrogating the very right at issue in cases of informed consent: the right of individual choice, which may be precisely the right to be an "unreasonable" person.

EPILOGUE ON LAW. Thus law has proceeded feebly toward the objective of patients' self-determination. While a new cause of action, occasionally hybridized with battery, has emerged for the negligent failure to disclose risks and alternative treatments, it remains a far cry from the avowed purpose of the informed-consent doctrine, namely, to secure patients' autonomy and right to self-determination. In not tampering significantly with the medical wisdom of nondisclosure, yet creating a new cause of action based on traditional disclosure requirements, courts may have accomplished a different result, very much in line with other purposes of tort law—namely, to provide physically injured patients with greater opportunities for seeking compensation whenever it can be argued that disclosure might have avoided such injuries. In doing so judges may have hoped, through the anticipatory tremors of dicta, to urge doctors to consider modifying their traditional disclosure practices. But judges have been unwilling, at least as yet, to implement earnestly patients' right to self-determination.

Whither Informed Consent?

The disquiet that the doctrine of informed consent has created among physicians cannot be fully explained by the small incremental step courts have taken to assure greater patient participation in medical decision making. More likely it was aroused by the uncertainty over the scope of the doctrine and by an appreciation that medical practice, indeed all professional practice, would be radically changed if fidelity to thoroughgoing self determination were to prevail. In what follows, some of the issues raised by the idea of an informed-consent doctrine, based on a premise of self-determination, will be discussed.

PATIENTS. Traditionally patients have been viewed as ignorant about medical matters, fearful about being sick, childlike by virtual of their illness, ill-equipped to sort out what is in their best medical interest, and prone to make decisions detrimental to their welfare (Parsons). Thus physicians have asserted that it makes little sense to consult patients on treatment options: far better to interact with them as beloved children and decide for them. In the light of such deeply held convictions, many physicians are genuinely puzzled by any informed-consent requirement. Moreover, its possible detrimental impact on compassion, reassurance, and hope—ancient prescriptions for patient care—has raised grave ethical questions for the medical profession.

Those concerns should not be dismissed lightly. What may be at issue, however, is not an intrinsic incapacity of patients to participate in medical decision making. For not all patients, and probably not even most, are too uneducated, too frightened, or too regressed to understand the benefits and risks of treatment options available to them. Moreover, their capacities for decision making are affected to varying degrees, for example, by the nature of the disease process, its prognosis, acuteness, painfulness, etc., as well as by the personality of patients. The medical literature is largely silent on the question of who—under what circumstances and with what conditions—should or should not be allowed to participate fully in medical decision making.

But why has not the sorting-out process, distinguishing between those patients who do and those who do not have the capacity for decision making, been undertaken long ago? One answer suggests itself: Once those patients have been identified who, in principle, can make decisions on their own behalf, physicians would be compelled to confront the questions of whether to interact with them on a level of greater equality; whether to share with them the uncertainties and unknowns of medical diagnosis, treatment, and prognosis; and whether to communicate to them their professional limitations as well as the lack of expert consensus about treatment alternatives. Such an open dialogue would expose the uncertainties inherent in most medical interventions; and to the extent medicine's helpful and curative power depends on the faith and confidence which the physician projects, patients may be harmed by disclosure and consent.

Physicians' objections to informed consent, therefore, may have less to do with the incompetence of patients as such than with un unrecognized concern of the doctrine's impact on the dynamics of cure. Put another way, the all too sweeping traditional view of patients has misled doctors into believing that medicine's opposition to informed consent is largely based on patients' incompetence, rather than on an apprehension, however dimly perceived, that disclosure would bring into view much about the practice of medicine that physicians seek to hide from themselves and their patients; for example, the uncertainties and disagreements about the treatments employed; the curative impact of physicians' and patients' beliefs in the unquestioned effectiveness of their prescriptions rather than the prescriptions themselves; the difficulty in sorting out the contributions that *vis medicatrix naturae* ("the healing power of nature") makes to the healing process; the impact of patients' suggestibility to cure, etc. Thus the question: When does informed consent interfere with physicians' effectiveness and with the dynamics of cure?

Little attention has been paid to the fact that the practice of Hippocratic medicine makes patients more incompetent than they need be. Indeed patients' incompetence can become a self-fulfilling prophecy as a consequence of medical practices. That the stress of illness leads to psychological regression, to chronologically earlier modes of functioning, has been recognized for a long time. Precious little, however, is known about the contributions that physicians' attitudes toward and interactions with their patients make to the regressive pull. Also, little is known about the extent to which regression can be avoided by not keeping patients in the dark, by inviting them to participate in decision making, and by addressing and nurturing the intact, mature parts of their functioning. This uncharted territory requires exploration in order to determine what strains will be imposed on physicians and patients alike, if Anna Freud's admonition to students of the Western Reserve Medical School is heeded:

> … you must not be tempted to treat [the patient] as a child. You must be tolerant toward him as you would be toward a child and as respectful as you would be towards a fellow adult because he has only gone back to childhood as far as he's ill. He also has another part of his personality which has remained intact and that part of him will resent it deeply, if you make too much use of your authority. (quoted in Katz, p. 637)

PHYSICIANS. Traditionally physicians have asserted that their integrity, training, professional dedication to patients' best medical interests, and commitment to "doing no harm" are sufficient safeguards for patients. The complexities inherent in medical decision making, physicians maintain, require that trust be patients' guiding principle. The idea of informed consent does not question the integrity, training, or dedication of doctors. Without them, informed consent would be of little value. What the idea of informed consent does question is the necessity and appropriateness of physicians' making all decisions for their patients; it calls for a careful scrutiny of which decisions belong to the doctor and which to the patient.

Physicians have preferences about treatment options that may not necessarily be shared by patients. For example, no professional consensus exists about the treatment of breast cancer. The advantages and disadvantages of lumpectomy, simple mastectomy, radical mastectomy, radiation therapy, chemotherapy, and various combinations among these are subject to much controversy. Dr. Bernard Fisher, chairman of the National Surgical Adjuvant Breast Cancer Project, has said that we simply do not know which method is best (Fisher). Thus the question must be answered: How extensive an opportunity must patients be given to select which alternative? Informed consent challenges the stereotypical notion that physicians should assume the entire burden of deciding what treatment *all* patients, *whatever* their condition, should undergo. Indeed, can the assumption of this burden be defined purely on medical grounds in the first place? Is not the decision in favor of one treatment for breast cancer over another, like many other treatment decisions, a combination of medical, emotional, aesthetic, religious, philosophical, social, interpersonal, and personal judgments? Which of these component judgments belong to the physician and which to the patient?

Much needs to be investigated in order to learn the practical human limits of any new obligations to disclose and to obtain consent:

1. Informing patients for purposes of decision making requires learning new ways of interacting and communicating with patients. Such questions as the following will have to be answered: What background information must patients receive in order to help them formulate their questions? How should physicians respond to *precipitous* consents or refusals? How deeply should doctors probe for understanding? What constitutes irrelevant information that only tends to confuse? What words and explanations facilitate comprehension? Physicians have not been in the habit of posing such questions.
2. Underlying informed consent is the assumption that physicians have considerable knowledge about their

particular specialties, keep abreast of new developments, and are aware of what is happening in other fields of medicine that impinge on their area of professional interest. This is not so; indeed, it may be asking too much. Moreover, since physicians have their preferences for particular modes of treatment, can they be expected to present an unbiased picture of alternative treatments?

3. Physicians have consistently asserted that informed consent interferes with compassion (Silk). Doctors believe that, in order to maintain hope or to avoid the imposition of unnecessary suffering, patients in the throes of a terminal illness, and other patients as well, should not be dealt with honestly. But the evidence for such allegations is lacking. When physicians are asked to support them with clinical data, they are largely unable to do so (Oken). Indeed, the few studies that have been conducted suggest that most patients do not seem to yearn for hope based on deception, but for hope based on a reassurance that they will not be abandoned, that everything possible will be done for them, and that physicians will deal truthfully with them. Moreover, evidence is accumulating that informed patients become more cooperative, more capable of dealing with discomfort and pain, and more responsible. Whether the often alleged conflict between *compassionate* silence and *cruel* disclosure is myth or reality remains to be seen. Disclosure may turn out to be a greater burden to those who have to interact with patients than to the patients themselves.
4. Informed consent confronts the role of faith in the cure of disease and the complex problems created by the uncertainties inherent in medical practice. To some extent the two issues are intertwined. The effectiveness of a therapeutic program, it has often been said, depends on three variables: the "feeling of trust or faith the patient has in his doctor and therefore in his therapy … the faith or confidence the physician has in himself and in the line of therapy he proposes to use … and the therapy [itself]" (Hoffer, p. 124). Informed consent could interfere with the first two variables and thus undermine the effectiveness of treatment. Precisely because of the uncertainties in medical decision making, the physician, to begin with, defends himself against those uncertainties by being more certain about what he is doing than he realistically can be. There is perhaps some unconscious wisdom in what he has been doing since Hippocrates' days, for the unquestioned faith the doctor has in his own therapy is also therapeutic in its own right. Thus, to be a more effective healer, a physician may need to defend himself against his uncertainties by believing himself to be more powerful than he is. That defense will be threatened by informed consent, for it would now require him to be more aware of what he does not know, and therapeutic effectiveness in turn might suffer. Finally, patients' response to treatment also depends on faith in the physician and his medicines. Knowing of the *ifs* and *buts* may shake patients' faith and undermine the therapeutic impact of suggestibility, which contributes so much to recovery from illness.

Physicians' traditional counterphobic reaction to uncertainty, adopting a sense of conviction that what seems right to them is the only correct thing to do, has other consequences as well. Defensive reactions against uncertainty have led to overenthusiasm for particular treatments that have been applied much more widely than an unbiased evaluation would dictate. The ubiquitous tonsillectomies performed to the psychological detriment of untold children is a classical example. Moreover, by not acknowledging uncertainty to themselves, doctors cannot acknowledge it to their patients. Thus consciously and unconsciously physicians avoid the terrifying confrontation of uncertainty, particularly when associated with poor prognosis. As a result, communications with patients take the form of an evasive monologue. The dialogue that might reveal these uncertainties is discouraged (Davis).

While disclosure of information would reduce patients' ignorance, it would also diminish doctors' power within the physician-patient relationship. As Waitzkin and Stoeckle have observed, the "physician enhances his power to the extent that he can maintain the patient's uncertainty about the course of illness, efficacy of therapy, or specific future actions of the physician himself" (p. 187). Thus new questions arise: What consequences would a diminution of authority have on physicians effectiveness as healers? How would patients react to less powerful doctors? Would they accept them or turn to new faith healers?

LIMITS OF SELF-DETERMINATION. Patients' capacity for self-determination has been challenged on the grounds that neither total understanding nor total freedom of choice is possible (Ingelfinger). This of course is true. Any informed-consent doctrine, to be realistic, must take into account the biological, psychological, intellectual, and social constraints imposed upon thought and action. But those inherent constraints, which affect all human beings, do not necessarily justify treating patients as incompetents. Competence does not imply total understanding or total freedom of choice.

What needs to be explored is the extent to which medicine, like law, should presume competence rather than incompetence, in interactions with patients. Neither presumption comports fully with the psychobiology of human beings; both of them express value judgments on how best to interact with human beings. Once the value judgment is made, one can decide on the additional safeguards needed to avoid the harm that any fiction about human behavior introduces.

The idea of informed consent asks for a presumption in favor of competence. If that is accepted, it may also follow that human beings should be allowed to strike their own bargains, however improvident. The then Circuit Judge Warren E. Burger, in commenting on a judicial decision to order a blood transfusion for a Jehovah's Witness, had this to say: "Nothing in [Justice Brandeis's `right to be let alone' philosophy, suggests that he] thought an individual possessed these rights only as to sensible beliefs, *valid* thought, *reasonable* emotions or *well-founded* sensations. I suggest he intended to include a great many foolish, unreasonable and even absurd ideas which do not conform such as refusing medical treatment even at great risk" (*Application of President of Georgetown College*). A physician may wish, and even should try, to persuade his patients to agree to what he believes would serve their medical interests best; but ultimately he may have to bow to his patients' decision, however "senseless" or "unreasonable," or withdraw from further participation. The alternatives, deception or coercion, may be worse, for either would victimize not only patients but physicians as well.

Conclusion

The narrow scope that courts have given to the informed-consent doctrine may reflect a deeply held belief that the exercise of self-determination by patients is often against the best interests of otherwise responsible adults and that those interests deserve greater protection than personal freedom. It may also reflect a judicial recognition of law's limited capacity to regulate effectively the physician-patient relationship. Therefore, once having suggested that patients deserve at least a little openness in communication, courts may have concluded that they had gone as far as they could. Judges, at least for the time being, have largely left it up to the medical profession to confront the question of patients' greater participation in medical decision making.

Despite their snail's pace, the courts' approach may have merit. Implementing a right of self-determination has tremendous consequences for medical practice. Many difficult problems, each with vast ethical implications, need to be considered by the medical profession. Thus introspection and education, responsive to the legal and professional problems that new patterns of physician-patient interaction will create, may ultimately provide firmer foundations for new patterns of physician-patient interactions than forced change through outside regulation. The latter, however, may increase if the profession does not rise to the challenge of addressing these long-neglected problems.

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POSTSCRIPT

Courts have broadened the doctrine of informed consent well beyond its initial construct. For example, informed consent was, in a few states, applicable only to physical touching, as courts held that a failure to obtain informed consent was a claim for battery, not for negligence (e.g., *Morgan v. MacPhail,* 1997; *Gray v. Grunnagle,* 1966). This meant, for example, that a physician who failed to warn a patient about the risks of a prescribed medication before the patient had life–threatening consequences would not have violated the patient’s right to informed consent. The clear trend by the beginning of the twenty–first century, however, was to treat any claim for informed consent as one in negligence, so no *touching* is required (*Matthies v. Mastromonaco,* 1999; Hanson). Of course, if a procedure is performed without any consent (i.e., a surgeon performs a different or additional procedure from the one to which the patient had consented while the patient is under anesthesia) an action for battery is still appropriate (*Montgomery v. Bazaz–Sehgal,* 2002).

Several court cases broadened the doctrine of informed consent, establishing that in order to give informed consent, the patient must understand the risks of refusing the proposed therapy (*Truman v. Thomas,* 1980; *Battenfield v. Gregory,* 1991; *Arato v. Avedon,* 1993).

Informed consent jurisprudence at the turn of this century also explored whether the patient is entitled to some information about the physician’s abilities as well as about the contemplated procedure. Does the patient have a right to know that the surgeon has never performed the procedure on anyone else? Does the patient have the right to know that the Health Maintenance Organization to which she belongs will reward her physician economically at the end of the year if he does not refer patients to specialists, even if her disease should be treated by specialists? Most cases in which disclosure of fiscal issues have arisen have imposed liability, if at all, on the HMO and not on the physician (Kurfirst; Potter; Simmons).

In one case from Illinois, the intermediate appellate court held that the physician had breached his fiduciary duty when he did not disclose to the patient that he made more money if the patient was not referred to a specialist. The Illinois Supreme Court held that since the failure to refer the patient to a cardiologist constituted malpractice, the reason the physician did not do so was irrelevant (*Neade v. Portes,* 2000). If a physician knows or should have known that he should refer a patient to a specialist or other more qualified physician and does not do so, if the patient’s condition becomes worse, the failure constitutes malpractice even if the patient never raises the issue of informed consent (*Johnson v. Kokemoor,* 1996). The earliest case to this effect was decided in 1898, decades before there was any concept of *informed consent* (*Logan v. Field,* 1898).

Other informed consent cases involved a physician’s failure to disclose inexperience with performing the procedure. Most courts take the position that the doctrine of informed consent applies only to the risks of the procedure or treatment itself, and not to information about the physician (*Ditto v. McCurdy,* 1997; *Duttry v. Patterson,* 2001). This was even true in one case where the surgeon failed to inform a child–patient’s parents that he was an alcoholic and unlicensed (*Kaskie v. Wright,* 1991). A 2002 decision by the New Jersey Supreme Court, however, held that outright misrepresentation of experience or credentials (as opposed to failure to disclose) does constitute failure to obtain informed consent (*Howard v. University of Medicine and Dentistry,* 2002).

Special Situations

Some situations involving particular groups of patients create unusually complex problems in providing information or obtaining consent.

PREGNANT PATIENTS. During the 1980s there was a series of cases in which pregnant women were subjected to blood transfusions to which they had religious and other objections and, in some cases, court–ordered cesarean sections when they had refused the procedure. In the infamous case of A.C. (*In re A.C.,* 1990), the woman and her premature infant both died following her court–ordered cesarean, and professional organizations began to issue statements urging that such refusals be respected (George Washington University, 1991). Since that ruling, although there has been one reported case of a court–ordered cesarean (*Pemberton v. Tallahassee Memorial Regional Medical Center,* 1999), there have been many more cases in which the courts rejected such requests by hospitals (*In re Baby Boy Doe,* 1994; Levine, 1994; Oberman, 2000). Several states have also held that a pregnant woman may not be transfused against her will, even to save her fetus (*The Stamford Hospital v. Vega,* 1996; *Harrell v. St. Mary's Hospital,* 1996).

During the 1990s, several states attempted to decrease drug abuse among pregnant women by criminalizing it as *child abuse.* While these statutes are still being enforced in a few states, the Supreme Court has ruled that testing women for drugs without their knowledge or consent when they come to a clinic for prenatal care is a violation of their constitutional rights against search and seizure and, of course, in violation of any concept of informed consent (Barton; *Ferguson v. City of Charleston,* 2001). Moreover, many medical groups issued statements that they feared that the threat of prosecution would drive away from medical care the women who needed it most (see, for example, the 1990 statement of the American Medical Association's Board of Trustees; Annas).

Women have been increasingly successful in informed consent suits alleging that they were not told during prenatal care about diagnostic tests that would have revealed serious handicaps in time to abort their fetuses (*Quinn v. Blau,* 1997; *Kassama v. Magat,* 2001). Since many states refuse to permit *wrongful birth* cases, an action for failure to obtain informed consent may be the patient's only recourse (Gantz). In other cases, women have successfully sued when physicians refused to respect their wishes on such matters as Cesarean sections and the newborns had handicaps as the result. All of these cases allege obstetrical malpractice as well as an absence of informed consent (*Schreiber v. Physicians Insurance Co.,* 1998).

MINORS. Minors over age fourteen are increasingly able to make medical decisions for themselves, although many states in which a minor by herself could make decisions about major surgery or other serious interventions have abortion statutes that restrict the same young woman from deciding to have a first–trimester abortion. The standards of informed consent—the patient's capacity to understand the nature of the procedure and the risks (including foregoing treatment) and benefits—is the same for adolescent as it is for an adult (English).

Parents occasionally ask a physician not to tell their adolescent child his or her diagnosis. Although it may be negotiable in some illnesses, if an adolescent is HIV positive or has another serious communicable condition, the physician must tell him or her and make sure the patient understands safe sex and other means to keep others from contracting the infection. The physician can be found liable if the uninformed adolescent patient infects a third party (*Reisner v. Regents of the University of California,* 1995; Committee on Pediatric AIDS, American Academy of Pediatrics).

While minors may refuse treatment in many situations, courts rarely allow them to refuse life–saving therapies. In a few cases (*In re E.G.,* 1989, rehearing denied,1990 *Belcher v. Charleston Area Medical Center,* 1992), judges have allowed minors to refuse life–saving therapy, but most courts have ruled that minors do not have "the right to die." (*In re Application of Long Island Jewish Medical Center,* 1990; *Novak v. Cobb County–Kennestone Hospital Authority,* 1996). In no state is a minor permitted to create a valid Living Will or Durable Power of Attorney (Hawkins; McCabe). When the minor is dying, however, the fact that she or he cannot make a legally binding decision does not mean that the physician should not be the patient's advocate in arguing for that perspective if the parents wish to "try one more thing" (Leiken, 1993; Evans, 1995).

If the diagnosis and treatment of a minor is undertaken without the involvement or knowledge of the parent, the young patient is entitled to the same degree of confidentiality accorded an adult patient (Council for Scientific Affairs, American Medical Association; Sigman, Silber, English, et al.; American College of Obstetrics and Gynecology).

PSYCHIATRIC PATIENTS. Admission to a psychiatric hospital, even if a patient has been involuntarily committed, does not preclude a person's ability and right to consent to many aspects of his or her care, including agreeing to or refusing medication (Berg, Appelbaum, and Grisso; Wirshing, Wirshing, and Marder). In order to medicate a patient over his or her objections, the patient must be found incompetent to make that decision by a court (*In re Qawi,* 2001; *Hamilton County v. Steele,* 1999). Moreover, a psychiatric patient may consent to participate in research to the same extent that she or he may consent to treatment (Carpenter; Dunn and Jeste; Roberts; Capron, 1999).

Limits on Self-Determination

A patient is not always entitled to whatever care he or she wishes. A physician who does not think a therapy would be beneficial does not have to offer it to a patient, although if it is a treatment which a minority of physicians find acceptable, the physician may have the duty to refer the patient to such a practitioner. Therapies which have no adherents in mainstream medicine—for example, laetrile to treat cancer—do not impose a requirement of referral.

The physician does not have the right to discontinue a therapy he or she believes is *futile* over a family's objection as long as a patient is not brain dead (Jecker and Schneiderman; Blake, Maldondo, and Reinhardt; Capron, 1991; Cantor; Council on Judicial and Ethical Affairs, American Medical Association). Conversely, if an adult patient has made clear to his or her physician that he or she wishes to forego further treatment, the physician has the obligation to support the patient's decision, even if the family objects.

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VI. ISSUES OF CONSENT IN MENTAL HEALTHCARE

Since the 1970s informed consent has been at the center of an evolving doctor-patient relationship whose characterization has shifted from strict paternalism to information exchange, shared decision making, and patient-centered care. In research, informed consent operates in concert with research regulations to protect human subjects while enabling research participation that is regarded, alternatively, as a burden or potential benefit to subjects. Concerns about informed consent in mental health treatment and research touch upon all of these issues.

Informed Consent in Mental Healthcare

The dual ethical goals of informed consent are the protection of the welfare and promotion of the autonomy of patients. As a legal doctrine, informed consent guarantees certain rights of patients in determining their treatment. Informed consent's legal history can be traced to the Supreme Court case of *Schloendorff v. Society of New York Hospitals* (1914), in which Justice Benjamin Cardozo declared that "every human being of adult years and sound mind has a right to determine what shall be done with his body" (*Schloendorff,* p. 126). The questions of what constitutes a sound mind and the rights of those with *unsound* minds remain central to discussion of informed consent in the context of mental healthcare.

At the beginning of the twentieth century, in the earliest stage of what would become the informed consent doctrine, battery provided the legal theory for a cause of action; physicians were required to obtain consent to invasive treatment (Katz). Informed consent's second stage was marked by increasing judicial pressure for consent to be not only free, but also informed; physicians were to disclose treatment alternatives and the risks of the proposed treatment, and then to obtain consent. Still, the California court in *Salgo v. Leland Stanford Junior University Board of Trustees* (1957), which ushered in this second stage, failed to articulate precisely the type of information that was required by this duty to disclose. The decision in *Canterbury v. Spence* (1972) initiated the third stage of informed consent doctrine by articulating a patient-oriented standard of disclosure that required physicians to disclose to patients what a reasonable person would find material to making treatment decisions. Since 1972, the literature on informed consent has burgeoned (e.g., Appelbaum, Lidz, and Meisel; Berg, Appelbaum, and Lidz; Faden and Beauchamp; Meisel, Roth, and Lidz).

Informed consent serves to protect individual autonomy, respect the patient's status as a human being, avoid fraud or duress, encourage doctors to carefully consider their treatment decisions, foster rational decision making by the patient, and involve the public in medicine (Capron). The law of informed consent is based on guaranteeing patients the right to receive sufficient information to make informed choices about treatment, and the right to accept or decline the physician's recommendations. As a process, informed consent involves active exchange of information between patient and physician. Elements fundamental to this process are *disclosure* of the risks and potential benefit of treatment options (or of participation in a research protocol), *comprehension* by the patient (or subject) of such information, *competence* of the decision maker, *voluntariness* of the decision, and the consent (or refusal) itself (Beauchamp and Childress). Competence and voluntariness have special import in the mental health context.

COMPETENCE. Determination of competence functions as a gatekeeping mechanism for informed consent in any healthcare context, because a decision maker's competence is a prerequisite for being able to give informed consent and thus have his/her treatment preferences or decisions respected. In bioethical analyses, competence pertains to a specific task (e.g., making a particular decision); it is not a general quality of persons (Buchanan and Brock). Conceived as decision-relative, competence is a variable or sliding-scale standard; in other words, the greater the degree of risk to patient welfare associated with a particular decision (e.g., to refuse likely life-saving treatment), the higher the standard of competence required of the patient choosing that option (Buchanan and Brock). Nevertheless, determination of competence is based on evaluation of the patient's process of decision making, not the acceptability or reasonability of its outcome. The capacities requisite for competent decision making are the ability to understand and appreciate the risks and benefits of treatment options, the ability to reason and deliberate about those options, and the ability to weigh options against a relatively stable set of values (Buchanan and Brock).

The difference between *competence* and *capacity* can be confusing, and the terms are often used interchangeably (Wolpe, Moreno, and Caplan). Medical or mental health professionals determine patient capacity, whereas incompetence is a legal construct, a legal determination that a patient is incapable of making decisions. The standards for determining incompetence are vague given the lack of judicial consensus. Although courts are available to make the determination, it is typically made by the attending physician. Whether the final determination of incompetence must be made by a court or in the clinical setting with judicial consideration remains unsettled (Berg, et al.; Berg and Appelbaum). Despite attempts to establish standardized means for assessing decisional capacity and competence, in clinical practice such judgments are still highly dependent on individual psychiatric evaluations (and attending physicians' judgments). Competence assessment remains difficult, especially when a patient's decision seems contrary to his/her ostensible best interests.

In mental health contexts, competence determinations may be especially complicated. Although an ethical, legal, and medical consensus now exists that a competent adult's voluntary informed choices must be respected in the course of treatment and research, it is not entirely clear how to proceed when a person's decision-making capacity may be compromised by mental illness. Historically there has been an erroneous presumption that mental illness obviates the patient's ability to make competent decisions and that either professional paternalism or surrogate decision making is therefore warranted. While some mental disorders may impair the cognitive faculties upon which the capacities for competent decision making rest, a blanket generalization regarding such an adverse effect of mental illness on decision-making capacity is unwarranted. A person with Alzheimer's disease or late life dementia, for example, may be incapable of making some decisions at some times, but at other times may ably comprehend information and weigh options; a patient with bipolar disorder may be quite capable of decision making while medication controls his/her illness, but be incapable if such medication becomes inadequately adjusted to control symptoms of depression or mania. In reality, many people with mental illness may be competent to make medical decisions at least much of the time (Buchanan and Brock; NBAC).

Responses to patient incompetence—specifically, decision making by a surrogate (or proxy) or by a court—serve as an exception to the usual process of informed consent. Nevertheless, surrogate decision making pursues the dual ethical goals of informed consent: the promotion of patient autonomy and protection of patient welfare. Customarily, the surrogate decision-making process involves obtaining informed consent for treatment (or its refusal) from a surrogate named by the patient in an advance directive, or in the absence of such a directive, by the patients' family members. In the absence of such family members, or in the case of irresoluble conflict among them, courts may appoint a guardian to make healthcare decisions on behalf of an incompetent patient. Advance directives for psychiatric treatment allow for a currently competent person to make plans for a future period during which he/she may lose decision-making capacity due to mental illness. These advance directives may include choices about treatment (including electroconvulsive therapy and emergency interventions), medications, hospitalization, research participation (discussed below), and, through the vehicle of a durable power of attorney, the appointment of a surrogate decision maker. Persons who have reason to think they may lose decisional capacity or be subject to involuntary psychiatric commitment may complete such advance directives to guide their psychiatric care and even to help arrange such necessities as temporary custody for their children.

VOLUNTARINESS. In order to constitute an informed consent (or refusal), a competent patient's decision must be both informed and voluntary. Legal discussions of conditions that would impugn the voluntariness, and thus validity, of informed consent focus on undue pressures, threats, and coercion imposed by external factors. However, the medical setting is replete with pressures stemming from the experience of illness (e.g., pain, discomfort, and fear), as well as physicians' recommendations and family dynamics. These situational factors may be especially intense in mental health settings, especially inpatient psychiatric settings, and their effect on the voluntariness of patient decision making must be examined. Philosophical accounts of voluntariness differ, but for the purposes of the informed consent process, a decision is considered voluntary if it is made in the absence of substantially controlling influences (Faden and Beauchamp).

The practice of involuntary psychiatric commitment presents a unique challenge to the doctrine of informed consent, as it entails involuntary hospital admission, while consent to admission is usually sought in other (at least, nonemergency) contexts. The ethical and legal justification of the practice of involuntary commitment resides in balancing the patient's right of self-determination, the patient's well-being, and the protection of third parties from harm. Although statutes may differ, most states permit at least temporary involuntary commitment when there is reason to believe that a patient poses a danger to him/herself or to others, or is unable to take care of him/herself as a result of profound mental illness.

Historically, the involuntary commitment and treatment of mentally ill patients was an exception to the theory of informed consent (Appelbaum). Prior to the 1960s, involuntary commitment to psychiatric facilities on the basis of a mental disorder was considered *ipso facto* a determination of mental incompetence. As the grounds for psychiatric commitment evolved in the 1960 and 1970s from criteria based on the perceived need for treatment to criteria based on perceived dangerousness to self or others, the grounds for commitment came to be distinguished from the justification for treatment. Judicial scrutiny of involuntary hospitalization has led to the widespread opinion that institutionalization is not always in the service of treatment, that it is certainly not equivalent to a determination of incompetence, and that therefore at least some involuntarily committed patients have the right to refuse treatment (Berg, et al.). In short, some individuals who meet criteria for involuntary commitment—to prevent harm to themselves or others—may nevertheless be competent to refuse (or consent to) treatment for their symptoms and/or underlying condition. Even if competent to refuse treatment, however, involuntarily committed patients may feel substantial pressure to agree to the recommendations of healthcare providers. The context of their treatment may unduly pressure them to consent in the (sometimes accurate) belief that only by agreeing to and undergoing treatment will they be permitted to leave and remain outside the institution. Further complicating this issue is the fact that some courts recognize a state interest in reducing the danger a patient poses to others and in restoring a patient sufficiently to warrant his/her discharge from the hospital. In some jurisdictions, then, treatment may be imposed without the patient's consent, although some jurisdictions at least require legal review of the medical appropriateness of the proposed intervention or the patient's competence, or both (Berg, et al.).

Informed Consent for Research in the Mental Health Context

Reflecting the Belmont Report's 1979 articulation of the ethical principles underlying research ethics and human subjects' protections, as well as provisions of the Nuremberg Code (1947) and the Declaration of Helsinki (1964, subsequently revised), federal regulations governing federally-funded research with human subjects consistently give priority to research subjects' rights and welfare over the pursuit of scientific and social interests (Title 45, Code of Federal Regulations). Informed consent's goal of welfare protection assumes prominence in research, because the right to refuse participation functions as an ultimate line of (self-) protection, in concert with other human subjects protections, or in the event that other protections prove inadequate. "Legally effective informed consent" is required of all research subjects (or their legally authorized representatives [LAR]).

Eight informational elements must be disclosed: a statement that the study involves research, as well as a description of the research and its purposes; a description of reasonably foreseeable risks; a description of reasonably expected benefits; disclosure of appropriate alternatives; a statement about maintenance of confidentiality; for research involving more than minimal risks, an explanation about possible compensation if injury occurs; information about how the subject can have pertinent questions answered; and a statement that participation is voluntary (i.e., the refusal to participate involves no penalties or loss of benefits). Subjects should also be given information regarding: unforeseeable risks; circumstances under which the subject's participation will be terminated; additional costs that the subject may incur; the consequences of a subject's decision to withdraw; the dissemination of findings developed during the study that relate to a subject's willingness to continue; and the approximate number of total subjects (Berg, at al.; Title 45, Code of Federal Regulations). Because the consent must be in writing, there has been a tendency to equate giving informed consent with signing a consent form; in reality, informed consent is a legally-mandated process that is merely documented by signing the consent form. During the informed consent process, care must be taken to prevent the therapeutic misconception (Appelbaum, Roth, and Lidz) or institutional and psychosocial factors from undermining subjects' understanding and voluntariness.

One of Belmont Report's principles is that individuals should be respected as autonomous agents and that those with diminished autonomy should be afforded additional protection in research. Mental health research is conducted on a diverse range of mental health conditions, and only some of these conditions diminish autonomy by impairing the decision-making capacity requisite for the informed consent process.

Guidelines that have been developed to protect *mentally or cognitively impaired* research participants—whether in mental health research projects or not—are relevant for understanding aspects of informed consent in mental health research. Simultaneously, the conflation of mental illness or impairment with incapacity or incompetence must be avoided, not only for conceptual clarity and ethical appropriateness, but also to avoid further stigmatizing those with mental illness. Indeed the 1998 report of the National Bioethics Advisory Commission (NBAC), "Research Involving Subjects with Mental Disorders That May Affect Decision-Making Capacity" has been criticized for perhaps perpetuating discriminatory attitudes by focusing on persons with mental disorders rather than selecting all incapacitated persons as the focus of concern (Oldham, Haimowitz, and Delano, 1999a).

Perhaps recognizing that special protections may themselves be stigmatizing, the Federal Code or "Common Rule" does not identify the mentally ill as a vulnerable group in need of such protections. Special guidelines do address research with children (considered a vulnerable group) and on substance abuse (Office for Protection From Research Risks). As part of the informed consent process, researchers must be prepared to address, perhaps with federal certificates of confidentiality (Title 42, Code of Federal Regulations), and at least in disclosure of the psychosocial and economic risks of participation (McEnvoy and Keefe), the stigma that attaches to mental illness and to substance abuse (Gorelick, Rickens, and Bonkovsky). Because substance abuse and mental illness may impugn both decisional capacity and behavior control (and thus voluntariness), researchers may need to turn to surrogate decision makers in the consent process. Further, researchers must be cognizant that parents of children with mental disorders are also frequently stigmatized (Jensen, Fisher, and Hoagwood).

Thus, informed consent for mental health research is complicated, first, by the need to determine when mental illness or impairment renders patients incapable of giving informed consent (or refusal) and when it does not; second, by the institutional contexts of much psychiatric research and the myriad pressures that may impugn the voluntariness of such decisions; third, by the need for research to develop effective treatment for mental illness to alleviate the suffering it causes; and finally, by the difficulty that surrogates might have in appreciating the situation of those with mental illness so that they may decide as prospective subjects would if they were competent to do so.

Recognizing that some research potentially benefiting the *mentally infirm* cannot be conducted with any other group, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, created in 1974, sought ethical means to include in research subjects incapable of giving consent. In two reports (1977 and 1978), the Commission recommended that research involving children and the institutionalized mentally infirm be placed in three categories according to level of risk presented: minimal risk, minor increase over minimal risk, and more than a minor increase. Contrary to provisions in both the Nuremberg Code and the Declaration of Helsinki, the Commission concluded that subjects incapable of giving informed consent could be enrolled in both studies that offered the potential of direct benefit and studies that did not offer such a prospect, so long as the burdens and risks of participation did not exceed a certain level. Also proposed were provisions for incapable participants to assent or object to study participation (i.e., to say "yes" or "no" when asked about willingness to participate); such a recommendation is in keeping with the current Council for International Organizations of Medical Sciences (CIOMS) comment that incapable subjects' objections to participation must be respected except in the rarest instance involving direct therapeutic benefit to the subject and the absence of alternative therapy. The Commission also recommended that institutional review boards (IRBs) appoint an auditor to assure the adequacy of the consent process for research involving more than minimal risk, and that informed consent be obtained from the incompetent patient's legal guardian, which parallels provisions of the current version of the Declaration of Helsinki. While a substantial number of the Commission's recommendations regarding research with children were adopted as part of the Common Rule, due to a lack of consensus and concerns about auditing the informed consent process, its recommendations regarding the *mentally infirm* were not adopted.

Concerns about review and audit of research also plagued reception of the 1998 NBAC report, including its recommendations that a qualified expert "independent of the research team" assess subjects' decision-making capacity and that an "independent consent auditor" observe and approve the informed consent process with decisionally-impaired subjects. Most contentious, however, was the NBAC's proposed categorization of research based on risk levels, coupled with its recommendation that a Special Standing Panel (SSP) be created at the Department of Health and Human Services to which IRBs could submit some protocols for prospective review and authorization.

NBAC proposed adhering to a two-tier categorization of risks for research involving decisionally-incapacitated subjects: (1) minimal risk and (2) greater than minimal risk. NBAC recommended that IRBs approve protocols involving minimal risk, or greater than minimal risk that is potentially beneficial to the subject, only if the subject gives informed consent, or has given prospective authorization and his/her LAR also gives permission, or if the subject's LAR gives permission, and if there is no dissent by the subject. (IRBs may also waive the consent requirement for some minimal risk protocols.) LARs are to make decisions about participation based on "a best estimation of what the subject would have chosen if capable of making a decision," and must monitor the subject's participation to make decisions about continuing or withdrawing from participation. Patients with mental illness or with other conditions that may at some time(s) impair their decision-making capacities may execute research advance directives giving *prospective authorization* to research participation and naming a LAR (Sunderland and Dukoff). Prospective authorization cannot be a *blanket* authorization and must be limited to specific classes of research about which the (then capable) subject understood the relevant risks, potential benefits, and other conditions (NBAC). The degree of specificity of the prior prospective authorization must increase as the risk presented by a particular protocol increases. For research presenting greater than minimal risk and not holding out the prospect of direct medical benefit, NBAC recommended that IRBs approve such protocols under the same conditions, or if the protocol is approved by the SSP or falls within its guidelines and the potential subject's LAR gives permission for participation. This final provision drew criticism from two sides.

Recognizing that research involving greater than minimal risk and not presenting the prospect of direct benefit to subjects may nevertheless promise "significant increases in understanding their conditions," and thus warrant further review, the NBAC envisioned that IRBs could refer such protocols to a SSP for case-by-case review through an *open consensus process* with the prospect that, over time, guidelines for conducting such research would emerge. NBAC viewed its recommendations as consistent with the two-tier risk-level scheme found in the majority of the Common Rule (and the National Institutes of Health Clinical Center Policy on the Consent Process in Research Involving Impaired Human Subjects), and stated that the SSP could evaluate research protocols that could not be approved otherwise under provisions of its 1998 report while providing patients, their families, and advocates with confidence that such protocols were receiving independent review (NBAC).

Some critics, however, argue that the NBAC's approach would greatly hamper valuable moderate-risk research that would otherwise be categorized as minor increase over minimal risk research (Miller and Fins; Oldham, et al., 1999a, 1999b). They argue that if federal regulations result from the NBAC recommendations, relatively low-risk research, including routine medical procedures such as positron emission tomographic scans and magnetic resonance imaging with sedation, would be subject to the same restrictions as research that is categorized at the highest level of risk (such as internal organ biopsies). In a statement appended to the NBAC report, similar concerns are voiced by two NBAC commissioners (Lo and Flynn). Some of these critics advocate a tri-level risk classification including an intermediary category of research presenting "a minor increase over minimal risk" derived from the National Commission's 1978 report and the Common Rule's regulations governing research involving children (Miller and Fins). Responding to these concerns, NBAC commissioners suggest that a SSP would only review those protocols involving persons incapable of giving informed consent and who have not provided advanced authorization (Childress and Shapiro). Yet, argue John M. Oldham and his coauthors, the number of protocols involving low-risk procedures that would require SSP review would be large, given the infrequency of advance directives for research and the inclusion of so many different protocols based upon the two-tier categorization of risk (1999b).

Although the majority of concerns expressed about the NBAC's recommendations take issue with allegedly unnecessary and cumbersome layers of oversight for research involving subjects with impaired capacity, a second line of criticism urges the opposite. Beverly Woodward argues that human research subjects are now threatened by increased research-related risks as a result of pressures to reduce restrictions on research involving subjects with impaired decision-making capacity. She charges that by downplaying the conflict between the progress of science and the protection of human subjects, and in departing from protections afforded by the Nuremberg Code and the Declaration of Helsinki to those who cannot give informed consent, the NBAC has endorsed the primacy of scientific interests over human subject welfare. Woodward finds particularly troubling NBAC's recommendation that would "permit a waiver of the consent requirement for research involving greater than minimal risk" that is without the prospect of direct benefit, so long as the subject's surrogate consents and the SSP also "grants permission based on a finding that the research 'offers the possibility of substantial benefit to the population under study'" and that the risks presented to subjects are commensurate with this possible benefit (p. 1948). Woodward believes that in some of the NBAC's recommendations, the "rapid march of science" is being advanced over the interests of individual research subjects, which, if true, would constitute a serious departure from the consensus that has grounded research ethics and the requirements for informed consent in research since the Nuremburg Code. Much remains to be examined—both at the level of drafting regulations and at the point of their implementation—to determine whether any such shift is indeed occurring.

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SEE ALSO: *Autonomy; Competence; Institutionalization and Deinstitutionalization; Mental Health Services; Mental Health Therapies; Mentally Disabled and Mentally Ill Persons; Patients' Rights: Mental Patients' Rights;* and other *Informed Consent* subentries

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INJURY AND INJURY CONTROL

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The factual assertions used to demonstrate the importance of injuries as a public-health problem are well known: Injuries are the leading cause of death for the majority of the human life span; injuries deprive people of more potential years of life than any single disease; and the cost of injuries, whether measured in dollars or in human suffering, is staggering (Rice et al.). Injuries are generally defined by those working in the field of injury prevention as human damage due to the acute transfer of energy or the lack of essentials such as oxygen (as in asphyxiation) or heat (as in hypothermic injuries) (National Committee for Injury Prevention and Control).

Actions taken to control injury provide prototypical clashes between the personal liberty of the individual and the goals of public health. These conflicts—referred to in ethical terminology as conflicts between paternalistic beneficence and individual autonomy—are experienced in such public interventions as those that mandate helmet use by motorcyclists or that require the wearing of seat belts by drivers and passengers in automobiles. However, injury control also illuminates how public health makes progress by redefining the nature of the problem—in this case, by shifting from the term *accident* (which points to the individual who is injured or an "act of God" as the responsible agent) to *injury* (which suggests that equipment, environment, and those responsible for equipment and environment share responsibility).

Historical Development

Although injuries have plagued the human race since its earliest times, it is only in the twentieth century that science has been applied to this public-health problem. For most of history, and to some extent up to the present, injuries have been misperceived as the equivalent of accidents; that is, chance occurrences that are basically unpredictable, and therefore unpreventable. The notions that some people are accident-prone, and therefore we should expect them to be injured, and that people are injured as punishment for a prior moral offense, have substantially retarded the ability to approach injuries and injury prevention scientifically.

A turning point in the historical development of injury control occurred in the early 1960s, when scientists first recognized that injuries, like diseases, had agents that interacted with hosts in specific environments to produce human damage (Gibson; Haddon). By modifying the agent (which was recognized as transferred energy), the human host, or the environment, one could substantially reduce the likelihood and/or the severity of an injury. William Haddon is generally recognized as the individual who most clearly "moved injury prevention into the mainstream of public health research and policy" (Baker). He developed the conceptual tools for the analyses of injury etiology and prevention that form the foundation of modern injury control.

In the decades that followed, scientists applied epidemiologic methods to the investigation of injuries and developed a new body of knowledge on how, when, where, and to whom injuries occur. Data are now available to dispel definitively the notion that injuries occur at random. The clear patterns of injury, which include identified high-risk groups (e.g., elderly persons at risk for hip fractures), geographic patterns (e.g., the distribution of firearm fatalities in the United States), and temporal trends (e.g., the increasing rate of adolescent suicide), make injuries both predictable and, more important, preventable (Baker et al.). Interventions can be focused on high-risk persons and sites, and the effects of the interventions can be scientifically evaluated by comparisons of injury rates.

Shifting Conceptions: Environmental and Product Modification

Notwithstanding these significant advances in the science of injury control, the field remains troubled by popular misconceptions that impede effective prevention programs. The reduction of injuries is still considered a matter of common sense by many. Unlike disease prevention, which is generally recognized to depend upon expert knowledge, injury prevention is commonly misperceived as a matter of an individual's responsibility rather than of public policy, and the importance of expert advice in preventing injuries is often not acknowledged. Thus the false orientation that the only way to prevent injuries is to teach people to be careful remains a popular bias, even among key decision makers who are in a position to protect millions from injury. The exclusive focus on the behavior of individuals for the prevention of injuries characterizes what was once known as accident prevention. Accidents were understood as the result of imprudent behavior; the remedy was to teach people to be constantly careful and vigilant. An example of this is the early approach to reducing highway fatalities. The method relied upon was improvement of drivers' skills through education and frequent reminders to be careful delivered in public service announcements. By the mid-1960s, however, there was a growing awareness that lives could be saved by shifting the focus of attention from the driver to the highway and the automobile. Crashes were recognized as foreseeable events. By altering the construction of vehicles and highways, the human cargo of the vehicles would not have to suffer serious injuries if and when a crash occurred.

The U.S. Congress took notice of the increasing number of highway fatalities and the opportunity to reduce this toll by mandating "crashworthy" vehicles. In 1966, Congress passed the National Traffic and Motor Vehicle Safety Act, which provided for the creation of motor vehicle safety standards. These standards, which anticipated driver error and provided a more forgiving environment within the vehicle, have saved tens of thousands of lives (Robertson).

The idea of paying attention to products as well as behaviors has not been restricted to highway safety. Efforts to prevent childhood scald injuries from hot tap water provide an example of this trend toward product alteration. Hot water coming out of faucets in homes is often at a temperature that can cause a severe burn injury to a child's skin in a matter of a few seconds. Rather than relying on parents to keep young children away from faucets, efforts have been made to direct the parents to turn down the setting on their water heaters so that water will not be discharged at temperatures greater than 125°F (Katcher et al.). This prevention strategy, however, still relies upon motivating parents to reset the water heater. An even more effective strategy has been to influence appliance manufacturers to set the heaters at the proper level before they leave the factory, thus eliminating the need to modify parental behavior.

A general principle of injury control, illustrated by the prevention of scald injuries, is to shift the focus of prevention from the individual to the community (Beauchamp; Barry). Legislation and regulation that require safer products and environments are more effective in preventing injuries than are efforts to have individuals control their own behaviors. When safety legislation or regulation has been difficult to accomplish because of strongly resistant political influences, litigation has been used. An example of this is product liability litigation, which transfers the cost of injuries from a dangerous product back to the manufacturer, thus giving the manufacturer a strong incentive to improve the safety aspects of its product (Teret).

Altering Behaviors: Paternalism and Prevention

Sometimes product modification is not available to achieve a desired prevention strategy, and reliance upon altering behaviors is necessary. Such is the case with motorcycle helmet use. The effectiveness of helmet use in preventing or reducing the severity of head injuries is well established, but helmet use is not universally accepted by motorcyclists. Legislation requiring helmet use is effective both in increasing the use rates and in decreasing motorcyclist death rates. These laws, however, have been bitterly fought by some motorcyclists, and most states have passed and then repealed mandatory helmet use laws.

The debate over motorcycle helmet laws has raised many issues that apply to other areas of mandating safe behaviors. The propriety of governmental paternalism, the relevance of who pays the costs of injuries, and the constitutionality of laws that interfere with personal decisions are all included in the helmet issue. Assuming a definition of paternalism as institutional interference with individual action for the sake of some greater good, motorcyclists question whether their enforced safety is a good substantial enough to deny them their freedom of choice to ride without a helmet.

Opponents of helmet laws categorize such laws as *hard* legal paternalism, in that the laws regulate voluntary behavior that can harm only the motorcyclist (see Feinberg, p. 12, for distinction between *hard* and *soft* legal paternalism). Proponents of the laws point out that the increased harm inflicted on a helmetless motorcyclist eventually affects the public as a whole. The public pays about 85 percent of the costs of motorcyclists' injuries; helmet laws would reduce the human capital costs by about $400 million per year in the United States (Rice et al.). Arguments have been raised that the solution to the cost-of-injury problem is to require adequate medical insurance of those who choose to assume risks, but the flaws of this argument are apparent. Some motorcyclists will not purchase insurance, through lack of money or indifference; and it would be unacceptable to have the injuries of these motorcyclists go without medical attention (Dworkin).

The motorcycle helmet issue illustrates a problem that permeates the field of injury prevention. As a society, Americans will still permit the manufacture and marketing of some inherently dangerous products, and then rely upon limited efforts to control the behavior of the individuals to whom these products are distributed. Guns provide a striking example. There are about 38,000 firearm fatalities each year in the United States, and most of the policy to reduce this toll focuses on modifying the behavior of the individual who possesses a gun. There are few effective regulations governing the number and types of guns that can be manufactured in the United States (Webster et al.).

The future success of injury prevention appears to be highly dependent upon the willingness of government to regulate business. The products people use and the built environments in which they place themselves are highly determinative of the risk of injury. Since people do not always act in a prudent fashion, and since government is unwilling and unable to mandate such behavior, the greatest opportunity to reduce the incidence and severity of injury rests in the regulation of products and environments.

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SEE ALSO: *Autonomy; Paternalism; Public Health: History; Public Health Law*

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INSANITY AND THE INSANITY DEFENSE

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A defendant’s legal responsibility for his or her criminal conduct is a controversial issue that continually draws public attention, particularly after highly publicized crimes. The insanity defense relates to the defendant’s mental condition at the time of the crime rather than at the time of the trial. The latter issue, which is discussed as the defendant’s competency to stand trial, is not the subject of this entry. The insanity defense deals with the criminal competency of an individual at a time in the past rather than at the time of the trial and sentencing.

Legal insanity is by definition a legal issue and should be distinguished from *clinical insanity,* which is not a term that is recognized by mental health professionals. The term *temporary insanity* sometimes is used by the general public to refer to a brief episode of mental illness and abnormal behavior that was present only at the time of the offense rather than before or after it. Legal insanity, however, is always temporary in the sense that it refers only to the defendant’s behavior at the precise time of the alleged offense.

The insanity defense represents a special defense to a criminal offense. Although the prosecution generally has the responsibility of proving the defendant guilty beyond a reasonable doubt, a defendant is legally entitled to raise defenses to the charge, whether self-defense, alibi, misidentification, insanity, or another defense.

The insanity defense is one of many issues subsumed under the rubric of criminal responsibility. Although this entry reviews several of the important issues related to the special defense of insanity, it excludes several related issues, such as diminished mental capacity, diminished responsibility, guilty but mentally ill, and the sentencing of a mentally ill defendant after conviction.

There are public misperceptions about the insanity defense. That defense is used infrequently in criminal trials in the United States and is rarely successful. Empirical research has revealed that it is introduced in less than 1 percent of felony trials and is successful in fewer than one-quarter of those trials. Many insanity acquittals occur through a stipulation between the prosecution and the defense rather than as a result of a contested trial. There is substantial variation among the states in the use and success of the insanity defense, with some states having more than seventy-five acquittals each year and many others having fewer than five. After acquittal insanity acquittees can remain hospitalized longer than they would have been imprisoned if they had been convicted of the same criminal offense and incarcerated. Generally, the public is not sympathetic to defendants who use the insanity defense for serious violent crimes except in cases of infanticide by severely depressed or mentally ill women.

Purpose of the Insanity Defense

The contemporary insanity defense had its origins more than 2,500 years ago, when it was recognized that certain categories of individuals, such as children, the mentally ill, and the developmentally disabled, could not be considered to be at fault for their offenses. A twentieth-century judge in the United States, David Bazelon, noted in the 1954 court decision *Durham v. United States,* "Our collective conscience does not allow punishment where it cannot impose blame." Generally, however, the criminal law posits that individuals act with *free will* should be held responsible for their behavior. Mentally ill individuals can be excused from moral, and sometimes legal, blameworthiness when they act in ignorance, under compulsion, or irrationally.

Many people in the lay community mistakenly believe that a crime is defined by the perpetrator's behavior so that a homicide is a homicide. In contrast, most criminal offenses require the presence of a physical element and a mental element. The physical element, the *actus rea,* refers to the actual behavior of the perpetrator, such as aiming and firing a weapon at the victim. The mental element, the *mens rea,* or guilty mind, addresses the state of mind of the perpetrator at the time of the offense. There are, for instance, several types and degrees of criminal homicide, and they usually are distinguished by the intent of the perpetrator, such as the presence of malice, criminal intent, or advance deliberation. In many states murder is charged in several degrees. Criminal homicides may be charged as involuntary manslaughter, voluntary manslaughter, third-degree murder, second-degree murder, or first-degree murder. The most serious homicide charge requires the presence of premeditation and deliberation by the defendant at the time of the crime. Each homicide crime has different mental elements, although all involve the killing of a victim by a defendant, and the punishments vary considerably among them.

The special defense of insanity builds on this inclusion of a mental element in the offense but advances it further to inquire about the defendant's state of mind beyond criminal intent. A defendant who makes detailed advanced preparations and then kills a person upon hearing voices from God commanding that act has criminal intent but may lack criminal responsibility for that offense, depending on the legal definition of insanity in the jurisdiction.

A handful of state jurisdictions in the United States have eliminated the legal defense of insanity. In those jurisdictions evidence regarding the defendant's mental illness at the time of the offense sometimes still can be introduced at trial to attempt to prove that the defendant did not have the requisite mental element or intent to commit the offense. Thus, if the defendant was so mentally ill that he or she could not have intended to commit the offense, then evidence of that illness and mental state is admissible at trial.

Legal Standards of Criminal Responsibility

Elements of the insanity defense are defined in different ways. The definition of the underlying mental disorder and the specific components of the defense are defined by state and federal statute but sometimes are defined by case (judge-made) law. The states vary widely in the definition, implementation, and outcome of the insanity defense.

Statutes and case law also describe the applicable procedural issues related to evaluations of criminal responsibility, such as the right of the defense and the prosecution to request an examination, the court appointment and payment of forensic experts to conduct the examination, and the extent of the waiver, if any, of the attorney client-privilege in conjunction with the examination.

For centuries courts, legislators, and policy makers have struggled to articulate an appropriate threshold and definition of legal insanity to exculpate a criminal defendant. The concept of a "wild beast" test was introduced centuries ago, excusing only individuals who did not know what they were doing because they resembled infants or wild beasts in their intellectual function. A New Hampshire court decision in 1868 (*State v. Pike,* 49 N.H. 399) offered the "product test" of insanity, stating, "No man shall be held accountable, criminally, for an act which was the offspring and product of mental disease." The product test subsequently was adopted in 1954 for the federal courts in the Washington, D.C., Federal Circuit. The product test was abandoned because of its breadth and concerns about abuse in light of the fact that symptoms of many mental disorders not deemed exculpatory can be expressed as criminal acts.

The contemporary legal standards for the insanity defense are composed of two principal factors: cognitive standards and volitional standards. Cognitive standards relate to the defendant's cognitive ability or actual knowledge of the criminality, illegality, or wrongfulness of his or her conduct at the time of the crime. Cognitive abilities include the ability to perceive reality accurately and make rational decisions that are based on that reality. Originating in the United Kingdom in 1843, the M'Naghten standard, for example, asks whether the defendant was suffering from a "defect of reason, from disease of the mind, as not to know the nature and quality of the act he was doing; or if he did know it, that he did not know he was doing what was wrong." *Wrong* is defined variously as legally wrong (the defendant knew his or her action to be illegal) or morally wrong (the defendant knew his or her action to be morally wrong in his or her own eyes or in those of the public). As a symptom of severe mental illness, a command hallucination from God instructing a defendant to kill someone could be accompanied by an impairment in the defendant's cognitive ability or knowledge regarding wrongfulness. Cognitive tests of legal insanity are the most common test in the United States and characterize the legal insanity test used by the federal courts since 1984.

The alternative insanity defense standard is concerned with the defendant's ability to control his or her behavior at the time of the offense as a result of a mental disease or disorder. This volitional test asks whether the defendant lacked partial or total capacity to control the behavior that led to the offense independent of cognitive knowledge or appreciation of the offense and its wrongfulness. This standard originally was described as an "irresistible impulse test" in which the individual's desires were so strong that he or she could not help acting on them. The individual was in effect compelled to perform the criminal acts. Mental disorders such as bipolar disorder, with a euphoric mood, elevated energy, insomnia, impulsive behavior, and racing thoughts, can reduce an individual's ability to control his or her behavior.

There are several specific variations of the cognitive and volitional tests of insanity. A cognitive test that employs the language of the defendant's ability to appreciate the wrongfulness of his or her conduct is significantly different from one that relates to the defendant's ability to know its wrongfulness. Appreciation is a broader mental ability than simple knowledge and encompasses emotional as well as cognitive or intellectual abilities. Similarly, the test that asks whether a defendant lacks substantial capacity to conform her or his conduct to the requirements of the law is a looser or broader test than one that asks whether the defendant was unable to control herself or himself because of the mental illness.

The federal test of criminal responsibility, which was enacted by Congress in 1984 after the acquittal of John Hinckley, Jr., by reason of insanity for the attempted assassination of President Ronald Reagan, applies to federal crimes. It states: "It is an affirmative defense to a prosecution under any federal statute that, at the time of the commission of the acts constituting the offense, the defendant, as a result of severe mental disease or defect, was unable to appreciate the nature and quality or wrongfulness of his acts" (18 u.s.c. section 17a).

Some states use both a cognitive prong and a volitional prong. The American Law Institute (ALI) proposed a model test in 1962 through the Model Penal Code. The ALI test states: "A person is not responsible for criminal conduct if at the time of such conduct as a result of mental disease or defect he lacks substantial capacity either to appreciate the criminality of his conduct or to conform his conduct to the requirements of law." This test had been adopted by approximately half the states before the Hinckley trial and the subsequent reforms.

Post-Hinckley Reforms of the Insanity Defense

After John Hinckley, Jr.'s, acquittal by reason of insanity in federal court many states as well as the federal government enacted changes to the insanity defense. Those changes included altering the test by making it stricter and changing certain procedures for its use. Some states and the federal courts eliminated the volitional test. Some states and the federal courts shifted the burden of proof at trial from the prosecution having the burden of proving that the defendant was not legally insane (beyond a reasonable doubt) to the defense, which must prove that the defendant was legally insane (by clear and convincing evidence). Other states added a guilty but mentally ill verdict to their criminal laws, offering a jury an alternative verdict to the insanity acquittal for mentally ill defendants who failed to satisfy the insanity defense requirements at trial.

Other statutory changes implemented stricter controls and supervision over individuals acquitted by reason of insanity, such as initial automatic hospitalization at least for psychiatric evaluation, with tighter procedures to prevent the premature release of dangerous individuals. Connecticut and Oregon have established special security review boards that intensively monitor insanity acquittees even on an outpatient basis, similar to criminal probation. Acquittees can be rehospitalized involuntarily if they are deemed to be too mentally ill or dangerous to remain in the community.

Clinical Evaluation

Statutes and case law variously use and define the terms *mental disease, mental disorder, mental illness,* and *mental defect* as the condition underlying a defendant's loss of cognitive or volitional function. The evaluator must be familiar with the legal definition of the term *mental disease* and the precise language of the criminal responsibility test in the defendant's jurisdiction. Statutes may or may not clearly define a mental disease or defect and usually do not employ accepted psychiatric nomenclature. Severe mental disorders such as schizophrenia, schizoaffective disorder, bipolar disorder, and other mood disorders with psychotic features generally qualify as mental diseases or defects for purposes of the insanity defense. Impulse control disorders such as kleptomania, pyromania, paraphilia, and pathological gambling may or may not be grounds for an insanity defense under the law. Other conditions not formally recognized as mental disorders by the mental health community, such as *battered woman syndrome,* may not constitute a mental disease or defect for purposes of the insanity defense.

The criminal responsibility evaluation is a retrospective evaluation of a defendant's criminal competency and is readily distinguished from an evaluation for treatment purposes. Therefore, forensic evaluators must have adequate training, experience, and forensic knowledge to conduct such evaluations properly. Evaluators typically attempt to interview the defendant about his or her thinking, behavior, and emotional controls at the time of the offense. However, evaluators cannot rely exclusively on the defendant's account of the crime because of the possibility of feigned mental illness and also must review crime scene data such as police reports, autopsies, witness accounts, and other information that can lead more objectively to an understanding of the events. Psychiatric treatment records of the defendant also are made available to the evaluator. Collateral interviews with family members or friends of the defendant, current treatment personnel, coworkers, and victims and witnesses also can be conducted. Psychological or neurological testing can be helpful in establishing a psychiatric diagnosis but cannot provide direct evidence that the defendant satisfies the insanity test standard. Evaluators may not be able to interview a defendant until months or years after the crime. Thus, reconstructing the defendant's mental state at that earlier time is a challenging task.

Clinical Issues

After the forensic mental health evaluator has obtained the necessary data regarding the defendant's mental health history and the defendant's state of mind at the time of the offense, the evaluator must provide to the retaining attorney or court an opinion about the defendant's psychiatric diagnosis and address the insanity defense standard. There are no biological tests that can prove directly whether a defendant had a mental disorder at the time of the crime or met the insanity defense standard, and the evaluator uses clinical judgment to reach conclusions in this regard. A defendant's assertion of a severe mental disorder at the time of the crime is more credible when there is a previous history of that disorder and documented treatment for it.

The evaluator must attempt to exclude mental conditions that are not deemed to be exculpatory by the applicable law. Personality disorders and intoxication by alcohol and drugs at the time of an offense are typically not exculpatory, and so the effects of those disorders on a defendant must be considered but separated from those of disorders that are potentially exculpatory. In other words, the evaluator must establish the relationship between the mental disorder present at the time of the offense and the criminal behavior.

There are many challenges in determining whether a defendant meets the legal insanity standard. The evaluator focuses on the defendant's thoughts, feelings, and behavior at the time of the crime but also inquires about those issues before and after the crime. If the defendant is charged with multiple crimes, the evaluator performs the analysis for each of those crimes. The evaluator must analyze the defendant's thoughts, feelings, and behavior carefully to determine whether the specific cognitive or volitional criteria for the applicable insanity defense are satisfied. It is likely that a defendant will satisfy the criteria for one insanity defense test but not for another.

If a jurisdiction uses a volitional insanity defense test, the evaluator must determine whether the defendant lacked the ability to control his or her behavior as a result of a severe mental disorder or simply failed to control his or her behavior because of anger, revenge, greed, envy, sexual arousal, or another condition unrelated to a severe mental disorder. The fact that a defendant acted on an impulse or desire does not mean that that impulse was irresistible; most, if not all, impulses can be resisted in certain circumstances. Volitional assessments involve a determination of whether the defendant attempted to delay or resist the impulse, pursued alternatives to gratifying the impulse, and planned or prepared for the crime while avoiding apprehension.

The insanity defense has been a complex yet compelling subject for centuries, attracting extraordinary public attention, especially after well-publicized crimes. The defense has survived many attempts to abolish it, with only a few states having done that. Although there are moral and legal bases for excusing an individual's criminal activity, most societies have struggled to adopt exculpatory rules that are politically acceptable and fair to mentally disordered individuals. Increasing attention has been paid in the United States to adopting postacquittal treatment and monitoring procedures to maximize the treatment of insanity acquittees while providing for the public safety.

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SEE ALSO: *Autonomy; Behaviorism; Competence; Conscience; Freedom and Free Will; Mental Illness; Mentally Disabled and Mentally Ill Persons; Responsibility*

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INSTITUTIONALIZATION AND DEINSTITUTIONALIZATION

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Deinstitutionalization, the mass exodus of mentally ill persons from state hospitals into the community, was accomplished in the United States during the seventh and eighth decades of the twentieth century. The process has taken away from persons with long-term, severe mental illness the almost total asylum from the pressures of the world and the care, however imperfect, that they received in these institutions. The central ethical question is: Does society not have an obligation to provide the care and treatment that they need in the community? The fact that a significant proportion of the severely and persistently mentally ill population is now living in the streets, in jails, and in other squalid conditions is evidence that adequate community care has not been provided. Moreover, it may be that some mentally ill persons who cannot be effectively treated in the community have been deinstitutionalized. Does society not have an obligation to correct this situation as well?

Before the current era of deinstitutionalization, persons with long-term, severe mental illness were usually institutionalized for life in large state mental hospitals. This institutionalization often began after a first acute mental breakdown in adolescence or early adulthood. Sometimes these patients went into remission in the hospital and were discharged, but at the point of their next psychotic episode were rehospitalized, often never to return to the community.

In the 1960s, British social psychiatrist John Wing and others observed that persons who spent long periods in mental hospitals developed what has come to be known as *institutionalism,* a syndrome characterized by lack of initiative, apathy, withdrawal, submissiveness to authority, and excessive dependence on the institution (Wing and Brown). Sociologist Erving Goffman argued that in what he called *total institutions,* such as state mental hospitals, impersonal treatment can strip away a patient's dignity and individuality and foster regression. The deviant person is locked into a degraded, stigmatized, deviant role. Goffman and others believed that the social environment in institutions could strongly influence the emergence of psychotic symptoms and behavior.

Other investigators, however, observed that institutionalism may not be entirely the outcome of living in dehumanizing institutions; at least in part, it may be characteristic of the schizophrenic process itself. With deinstitutionalization, these researchers observed that many persons with long-term, severe mental illness who were liable to institutionalism seemed to develop dependence on any other way of life that provided minimal social stimulation and allowed them to be socially inactive. They gravitated toward a lifestyle that allowed them to remain free from symptoms and painful and depressive feelings.

Is this dependent, inactive lifestyle bad? For many deinstitutionalized persons, it may lead to unnecessary regression and impede their social and vocational functioning; thus, for these patients it should be discouraged. However, this restricted lifestyle may meet the needs of many deinstitutionalized individuals and help them stay in the community. Mental-health professionals and society at large need to recognize the crippling limitations of mental illness that do not yield to current treatment methods. They also need to be clear about the importance of providing adequate care for this vulnerable group of severely mentally ill persons so that the end result is not like the fate of the mentally ill in the back wards of state hospitals—neglect, abysmal conditions, extreme regression, and marked deterioration of their mental states. For those persons who can be restored to social and vocational functioning only to a degree, many mental-health professionals advocate lowered expectations and the provision of reasonable comfort and a dignified, undemanding life.

The Origins of Deinstitutionalization

In 1955, the number of persons in state hospitals in the United States reached its highest point: 559,000 persons were institutionalized in state mental hospitals out of a total national population of 165 million. In 1998, there were approximately 57,000 institutionalized persons out of a population of 275 million. In 43 years, the United States reduced its number of occupied state hospital beds from 339 per 100,000 population to 21 per 100,000. Some individual states have gone even further: in California in 2000, for example, there were 9 state hospital beds per 100,000 population, including forensic patients (committed through the legal system); nonforensic beds numbered only 3 per 100,000.

Until the deinstitutionalization movement, state mental hospitals had fulfilled the function for society of keeping the mentally ill out of sight and thus out of mind. At the same time, before the advent of modern psychoactive medications, the controls and structure provided by the state hospitals—as well as the granting of asylum—may have been necessary for many of the long-term mentally ill. Unfortunately, the ways in which structure and asylum were achieved, and the everyday abuses of state hospital life such as neglect, abysmal living conditions, and deterioration of the patients' mental states, left scars on the mental-health professions and on the reputation of state hospitals, as well as on the patients. Periodic public outcries about these deplorable conditions, documented by journalists such as Albert Deutsch in his influential book *The Shame of the States* (1948), set the stage for deinstitutionalization. These concerns, shared by mental-health professionals, led to the formation by Congress of the Joint Commission on Mental Illness and Health (1961), which issued recommendations for community alternatives to state hospitals. When psychoactive medications appeared in the 1950s, along with a new philosophy of social treatment, the majority of the long-term psychotic population seemed to have been left in an institutional environment that was no longer necessary or even appropriate.

Other factors also came into play. First, the conviction that mental patients receive better and more humanitarian treatment in the community than in state hospitals far away from home was a philosophical keystone of the community mental-health movement. Another motivating force was concern that the system of indefinite commitment and institutionalization of psychiatric patients deprived them of their civil rights. Finally, many financially strapped state governments wished to shift some of the fiscal burden for these patients to federal and local governments, that is, to federal Supplemental Security Income (SSI) and Medicaid, and to local law-enforcement and emergency-health and mental-health services.

Two developments at the federal level accelerated the process of deinstitutionalization in 1963. Under the provisions of categorical Aid to the Disabled (ATD), the Secretary of Health, Education, and Welfare issued an administrative order making the mentally ill eligible for federal financial support in the community. Moreover, Congress passed legislation to facilitate the establishment of community mental-health centers. With ATD, psychiatric patients and mental-health professionals acting on their behalf now had access to federal grants-in-aid, in many places supplemented by funding from the state. This enabled patients to support themselves or be supported either at home or in such facilities as board-and-care homes (boarding homes) or old hotels, at little cost to the state. ATD is now the Supplemental Security Income referred to above, and is administered by the Social Security Administration. Instead of maintaining patients in a state hospital, the states, even those that provided generous ATD supplements, found the cost of maintaining these patients in the community to be far less than the cost of maintaining them in state hospitals. Although the amount of money available to patients under ATD was not a princely sum, it was sufficient to pay for a board-and-care home or to maintain a low standard of living elsewhere in the community.

Many individuals in the community discovered that they could earn substantial additional income by taking former mental patients into their homes, even at the rates allowed by the ATD grants. Some entrepreneurs set up board-and-care homes holding as many as one hundred persons or more in large, old houses and converted apartment buildings and rooming houses. Although these board-and-care-home operators were not skilled in the management of psychiatric patients, they were able to accommodate tens of thousands of persons who had formerly been in state hospitals and who did not now have major behavior problems (primarily because they were being treated with the antipsychotic drugs).

In 1963, too, Congress passed the Mental Retardation Facilities and Community Mental Health Centers Construction Act, amended in 1965 to provide grants for the initial costs of staffing newly constructed centers. This legislation was a strong incentive to the development of community programs with the potential to treat people whose main recourse previously had been the state hospital. However, although rehabilitative services and pre-care and aftercare services were among the ten services eligible for funding, an agency did not have to offer them in order to qualify for funding as a comprehensive community mental-health center. Many community mental-health centers chose to focus on persons with neuroses and problems of living—the healthy but unhappy. Persons with long-term, severe mental illness were often just as neglected in the community as they had been in the hospitals.

Sweeping changes in the commitment laws of the various states also contributed to deinstitutionalization. In California, for instance, the Lanterman-Petris-Short Act of 1968 provided further impetus for the movement of patients out of hospitals. Underlying this legislation was a concern for the civil rights of the psychiatric patient. (Much of this concern came from civil rights groups and individuals outside the mental-health professions.) The act made the involuntary commitment of psychiatric patients a much more complex process, and holding psychiatric patients indefinitely against their will in mental hospitals became much more difficult. Thus, the initial stage of what had formerly been the career of the long-term hospitalized patient—namely, an involuntary, indefinite commitment—became a thing of the past.

Deinstitutionalization in Practice

One of the most important lessons to be drawn from the experience with deinstitutionalization was almost totally unforeseen by its advocates. The most difficult problem is not the fate of those patients discharged into the community after many years of hospitalization. Rather, the problem that has proved most vexing and that has presented the most difficult ethical dilemmas has been the treatment of the generation that has grown up since deinstitutionalization. It is largely from this generation that the homeless mentally ill are drawn. The large homeless population with major mental illness—that is, schizophrenia, schizoaffective disorder, bipolar illness, and major depression with psychotic features—tends to be young.

Why is this so? In the older generation of long-stay, hospitalized patients, chances were that most of those who were least appropriate for discharge—because of their propensity to physical violence, very poor coping skills, or marked degree of manifest pathology—were not discharged, or if they were discharged and failed in the community, were be sent into the community again.

Those who have been hospitalized for long periods have been institutionalized to passivity. For the most part, they have come to do what they are told. This is not presented as a beneficial effect of long-term hospitalization, but simply as a clinical observation. When those for whom discharge from the hospital is feasible and appropriate are placed in a community living situation with sufficient support and structure, most (though by no means all) tend to stay where they are placed and to accept treatment.

Long-term, severely mentally ill persons of the new generation, however, have not been institutionalized to passivity. Not only have they not spent long years in hospitals, they have probably had difficulty just getting admitted to an acute hospital, whether or not they wanted to be admitted, and even greater difficulty staying there for more than a short period on any one admission. Acute psychiatric inpatient care is extremely expensive, and there is a great reluctance to use scarce mental-health funds to provide it.

Existential Problems in the Community

A young person just beginning to deal with life's demands struggles to achieve some measure of independence, to choose and succeed at a vocation, to establish satisfying interpersonal relationships and attain some degree of intimacy, and to acquire some sense of identity. Lacking the abilities to withstand stress and to form meaningful interpersonal relationships, the mentally ill person's efforts often lead only to failure. The result may be a still more determined, often frantic effort with a greatly increased level of anxiety and desperation. Ultimately, this may lead to another failure accompanied by feelings of despair. For a person predisposed to retreat into acute mental breakdowns, the result is predictably stormy, with acute psychotic breaks, and repeated—and usually brief—hospitalizations often related to these desperate attempts to achieve. The situation becomes even worse when such persons are in an environment where unrealistic expectations emanate not just from within themselves, but also from families and mental-health professionals.

Before deinstitutionalization, these *new long-term patients* would have been institutionalized, often from the time of their first mental breakdown in adolescence or early adulthood. After their initial failures in trying to cope with the vicissitudes of life and of living in the community, such patients would have been exposed no longer to these stresses, but given a permanent place of asylum from the demands of the world.

Such an approach now tends to be the exception, not the rule; since large-scale deinstitutionalization began, hospital stays tend to be brief. In this sense, the majority of *new* long-term patients are the products of deinstitutionalization. To observe this is not to imply that society should turn the clock back and return to a system of total institutionalization for all persons with long-term, severe mental illness. In the community, most of these patients can have something very precious—their liberty, to the extent they can handle it. Furthermore, if the resources are provided, they can realize their potential to pass some of life's milestones successfully. Nevertheless, it is this new generation of long-term, severely mentally ill persons that poses the greatest ethical challenge to deinstitutionalization and the most difficult clinical problems in community treatment, and that has swelled the ranks of the homeless and the incarcerated mentally ill.

Problems in Treatment

As recently as 1950, there were no psychoactive drugs to bring long-term, severely mentally ill persons out of their world of autistic fantasy and help them return to the community. Even today, many patients fail to take psychoactive medications because of disturbing side effects, denial of illness, or, in some cases, the desire to avoid the depression and anxiety that result when they see their reality too clearly; grandiosity and a blurring of reality may make their lives more bearable than a drug-induced relative normality.

A large proportion of the new long-term patients tends to deny the need for mental-health treatment and to eschew the identity of the long-term mental patient. Admitting mental illness seems to many of these persons to be admitting failure. Becoming part of the mental-health system seems to them like joining an army of misfits. Many of these persons also have substance-abuse disorders and/or medicate themselves with street drugs. Another contributing factor is the natural rebelliousness of youth.

The problem becomes worse for those whose illnesses are more severe. These persons' problems are again illustrated by the problems of the homeless mentally ill. Evidence is beginning to emerge that the homeless mentally ill are more severely ill than the general mentally ill population. At Bellevue Hospital in New York City, for example, approximately 50 percent of inpatients who were homeless on admission are transferred to state hospitals for long-term care as a result of the severity of their illnesses, as opposed to 8 percent of other Bellevue psychiatric inpatients.

Functions of the State Hospital

Valid concerns about the shortcomings and antitherapeutic aspects of state hospitals in the United States often overshadowed the fact that the state hospitals fulfilled some crucial functions for persons with long-term, severe mental illness. The term *asylum* was in many ways appropriate: these imperfect institutions did provide asylum and sanctuary from the pressures of the world with which, in varying degrees, most of these persons were unable to cope. They also provided medical care, patient monitoring, respite for the patient's family, and a social network for the patient, as well as food, shelter, and needed support and structure.

Furthermore, in the state hospitals, the treatment and services that did exist were in one place and under one administration. In the community the situation is very different. Services and treatment are under various administrative jurisdictions and in various locations. Even the mentally healthy have difficulty dealing with a number of bureaucracies, both governmental and private, and having their needs met. Patients can easily get lost in the community. In a hospital, they may have been neglected, but at least their whereabouts were known.

These problems have led to the recognition of the importance of case management. Many of America's homeless mentally ill would not be on the streets if they were on the caseload of a professional or paraprofessional trained to deal with the problems of persons with long-term, severe mental illness, monitor these persons (with considerable persistence when necessary), and facilitate their receiving services.

The fact that persons with long-term, severe mental illness have been deinstitutionalized does not mean they no longer need social support, protection, and relief, either periodic or continuous, from external stimuli and the pressures of life. In short, they need asylum and sanctuary in the community. Unfortunately, because the old state hospitals were called asylums, the word *asylum* took on an almost sinister connotation. Only in recent years has the word again become respectable, signifying the function of providing asylum, rather than asylum as a place.

The concept of asylum and sanctuary in the community becomes important in post-discharge planning because, while some long-term, severely mentally ill persons eventually attain high levels of social and vocational functioning, others have difficulty meeting simple demands of living on their own, even with long-term rehabilitative help. Whatever degree of rehabilitation is possible for each patient cannot take place unless support and protection in the community—from family, treatment program, therapist, family-care home, or board-and-care home—are provided at the same time. Moreover, if the need for asylum and sanctuary within the community is not taken into account, many persons with long-term, severe mental illness may find it impossible to live in the community.

Ingredients of a System of Community Care

Has community care in the United States been better than institutionalized care for persons with long-term, severe mental illness? The answer appears to be both yes and no. With deinstitutionalization, for instance, some long-term dysfunctional and mentally disordered individuals gradually, over a period of years, succeed in their strivings for independence, a vocation, intimacy, and a sense of identity. For them, deinstitutionalization has indeed been a success. The deinstitutionalization movement has also taught administrators much about what good community care should be: a comprehensive and integrated system of care, with designated responsibility, accountability, and adequate fiscal resources.

More specifically, such care requires an adequate number and ample range of graded, stepwise, supervised community-housing settings; adequate, comprehensive, and accessible psychiatric and rehabilitative services provided assertively and through outreach services when necessary; and available and accessible crisis services. A system of responsibility for persons with long-term, severe mental illness living in the community should ensure that each patient has one case manager, a mental-health professional or paraprofessional who is responsible for seeing that the appropriate psychiatric and medical assessments are carried out. This case manager should formulate, in collaboration with the patient, an individualized treatment and rehabilitation plan, including the proper pharmacotherapy; monitor the patient; and assist him or her in receiving services. Respite care, a period when families can be relieved of the responsibilities of caring for their mentally ill relatives, is needed for the more than 50 percent of the long-term, severely mentally ill population in the United States who live with their families, so that the family is better able to provide a support system. The entire burden of deinstitutionalization should not be allowed to fall on families, as it sometimes has.

Setting up such a comprehensive and integrated system of care for persons with long-term, severe mental illness in the United States has proven far more difficult to accomplish than was envisioned. A large proportion of the many hundreds of thousands of persons with long-term, severe mental illness has not been well served in the community. In addition, some patients who cannot be effectively treated in the community have been deinstitutionalized. Probably only a relatively small minority of long-term mentally ill persons requires a highly structured, locked, twenty-four-hour setting for adequate intermediate or long-term management. But for members of this small minority, such institutional management may be critical—for their sake and for the sake of the community. Attempts to treat persons characterized by such problems as assaultive behavior; severe, overt major psychopathology; grossly inappropriate social behavior; reluctance to take psychoactive medications; inability to adjust to open settings; problems with drugs and alcohol; and self-destructive behavior in the community have required an inordinate amount of time and effort from mental-health professionals, various social agencies, and the criminal-justice system. Many patients have been lost to the mental-health system because their treatment needs have not been met, and these people, for the most part, are on the streets or in jail.

The result has often been seen as a series of failures on the part of both mentally ill persons and mental-health professionals. As a consequence, a number of long-term mentally ill persons have become alienated from the system that has not met their needs, and some mental-health professionals have become disenchanted with the treatment of these persons. The heat of the debate in the United States over the issue of whether or not to provide intermediate and long-term hospitalization has tended to obscure the benefits of community treatment for the great majority of the long-term mentally ill, who do not require such highly structured, twenty-four-hour care.

Where to treat—hospital versus community—should not be an ideological issue; it is a decision best based on the clinical needs of each person. Unfortunately, efforts to deinstitutionalize have, in practice, too often confused locus of care with quality of care. Where mentally ill persons are treated has been seen as more important than how they are treated. Care in the community has often been assumed by definition to be better than hospital care. In actuality, poor care can be found in both hospital and community settings.

Independence

For many long-term mentally ill persons, nothing is more difficult to attain and sustain than independence. The issue of supervised versus unsupervised housing provides an example. Professionals would like to see their patients living in their own apartments and managing on their own, perhaps with some outpatient support. But, as described in the 1992 American Psychiatric Association Task Force's report on the homeless mentally ill, the experience of deinstitutionalization has shown that most long-term, severely mentally ill persons living in unsupervised mainstream housing in the community find the ordinary stresses of managing on their own more than they can handle. After a while they tend to not take their medications and to neglect their nutrition. Their lives unravel; eventually they find their way back to the hospital or to the streets.

Mentally ill persons value independence highly, but they often underestimate their dependency needs and their needs for structure—for instance to have a living situation where their medication is dispensed to them and their meals are provided. Professionals need to be realistic about their patients' potential for independence, even if the patients are not.

Freedom

What about the issue of freedom? Persons with long-term, severe mental illness enjoy much more liberty than when they were institutionalized; in most cases, as was discussed earlier, this is appropriate. But that freedom may well be damaging to some patients if they are given more than they can handle. Many of those on the streets and in the jails suffer from the lack of structure and organization in their lives; they need, because of their illnesses, to have these elements imposed upon them.

However, involuntary treatment presents an extremely difficult ethical dilemma. Beliefs about civil liberties come into conflict with concerns for the welfare of persons with long-term, severe mental illness. A basis for facing this dilemma is provided by the belief that the mentally ill have a fundamental right to treatment, even if at times the treatment must be involuntary when, because of severe mental illness, they present a serious threat to their own welfare or that of others and are not able to make a rational decision about accepting treatment. Reaching out to patients and working with them to accept help on a voluntary basis is certainly a mandatory first step. But if this fails and the patient is at serious risk, professionals with direct responsibility for patients usually see that ethically they cannot simply stop there.

In such cases, humane commitment laws facilitate a prompt return to acute inpatient treatment when such treatment is needed. Ongoing measures, such as conservatorship or guardianship, court-mandated outpatient treatment, and appointing a payee for the person's disability check are components of a treatment philosophy and practice that recognizes that external controls such as these are a positive therapeutic approach for mentally ill persons who lack the internal controls to deal with their impulses and to cope with life's demands. Such external controls may help interrupt a self-destructive, chaotic life on the streets and in and out of jails and hospitals.

Conclusion

Further deinstitutionalization must be preceded by careful planning and the establishment of community services. In fact, community services set up in the United States have in most cases been swamped by the number of patients coming out of the hospitals or who are already in the community and in need of care. Clearly, deinstitutionalization should be implemented only to the extent that each long-term, severely mentally ill person in the community can be properly and adequately housed and treated. This should also be done for those mentally ill persons already in the community. Those who implement a policy of deinstitutionalization must take into account not only those still in hospitals but those mentally ill persons who are reaching an age where their mental illness is becoming manifest and who will never be long-term hospitalized mental patients.

For this latter group, it is essential that there be a system of case management with staff who understand their problems and their needs, as well as a range of supervised housing in the community that is sufficiently structured to accommodate those who require it. Although adequate case management, appropriate housing, and treatment should greatly decrease the need for involuntary treatment, there should still be a willingness to use it when it becomes necessary. It also needs to be recognized that there is a significant subpopulation of persons with long-term, severe mental illness who should not be deinstitutionalized.

Having dismantled such a large proportion of the institutions for the mentally ill, society surprisingly continues to face the grave ethical and clinical question of whether there is still an obligation to provide care and treatment in the community for the mentally ill persons who used to inhabit these institutions. It is a matter of priorities among the various social needs of our society. Mental-health professionals, at least those in public service, are coming around to giving this population the highest priority. With regard to legislators and the general public, there is much more ambivalence, and persons with long-term, severe mental illness often fare poorly in the struggle over setting priorities and allocating funds.

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REVISED BY AUTHOR

SEE ALSO: *Autonomy; Beneficence; Coercion; Mental Health Services; Mental Health Therapies; Mentally Disabled and Mentally Ill Persons: Healthcare Issues; Paternalism; Patients' Rights: Mental Patients' Rights; Psychiatry, Abuses of*

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INSTITUTIONAL REVIEW BOARDS (IRBs)

SEE *Research Ethics Committees*

INTERNATIONAL HEALTH

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The term *international health* has a variety of meanings that depend on the context in which it is used. In a geopolitical sense the term is used in regard to the numerous governmental and nongovernmental organizations (NGOs) throughout the world that are concerned with human health and disease. Those organizations broadly deal with health issues that involve both economically advanced and less developed nations, although the focus is frequently on impoverished populations in both settings. Examples include the World Health Organization (WHO); the United Nations (UN) and its various agencies, such as UNDP (United Nations

Development Programme), UNICEF (United Nations International Children's Emergency Fund), and UNHCR (United Nations High Commission on Refugees); the World Bank; and NGOs supported by philanthropy, such as the Wellcome Trust, the Rockefeller Foundation, and Médicin Sans Frontières. Those organizations work with national and regional health authorities to address operational and research issues. The creation and maintenance of those groups have resulted from moral, social, and financial obligations and altruism (Basch; Merson et al.).

International health also relates to biomedical research and health policy issues that cross national boundaries and increasingly involve the participation of people who live in developing countries. Bioethical issues arising from the conduct of research on people in economically depressed regions have received much attention over the last several years. This entry deals with ethical issues that have been sources of controversy and debate in the context of international health.

History of Bioethical Principles and International Health

Bioethical guidelines for the conduct of research involving humans originally were put forth formally in the Nuremberg Code, a document that was generated after World War II, when atrocities conducted by physicians under the Nazi government became widely known. In 1964 the World Medical Association Declaration of Helsinki elaborated on those principles. The Declaration of Helsinki was concerned primarily with medical experimentation involving persons in economically advanced developed countries and made a distinction between *therapeutic* and *nontherapeutic* research. Bioethical issues concerned specifically with research that involved vulnerable populations and people in developing countries were addressed by the Council for the International Organization of Medical Sciences (CIOMS), which was last revised in 1993. Controversies about the interpretation of those documents have been commented on by several authorities in the field of bioethics (Levine; Singer and Benatar; Zion et al.).

When it became public knowledge that treatment for neurosyphilis was withheld deliberately from African-American men in Tuskegee, Alabama, to examine the natural course of the disease, a commission was organized to outline the principles of conducting research involving human subjects. This resulted in the publication of the Belmont Report, which built on the Declaration of Helsinki. The Belmont Report emphasized the notion that individual autonomy, beneficence, and justice were central to the ethical conduct of research involving humans (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research). Committees in the United States (National Bioethics Advisory Commission) and the United Kingdom (Nuffield Council for Bioethics) later addressed bioethical aspects of research in the international setting. Those principles are being refined by organizations and people from developing countries where the research is being conducted (Bhotta).

Major Issues in Biomedical Research Ethics in Developing Countries

Research involving human subjects implies a wide range of responsibilities on the part of the participants and their communities, the investigator, and funding agencies. In the context of international health those issues generally have been viewed from the perspective of the cultural and legal norms of developed countries, which historically have been interpreted by institutional review boards (IRBs) (Shuklenk and Ashcroft).

Issues issues of recent debate and controversy in international health are illustrated by a clinical trial that tested the efficacy of the antiretroviral drug zidovudine in limiting maternal-infant transmission of human immunodeficiency virus (HIV). A study conducted in East Africa in the mid-1990s involved randomization of HIV-infected pregnant women to either short-duration therapy with zidovudine or inert placebo. The lack of any treatment with an antiretroviral drug was the normal standard of care in Africa at that time. When it became widely known that earlier research conducted in developed countries (AIDS clinical trial group protocol 076) showed that a longer course of zidovudine therapy reduced the risk of transmission of HIV from mothers to their offspring from approximately 25 percent to 8 percent (Connor et al.), several highly cited publications in the lay and professional press suggested that the African study was unethical because it denied therapy of known efficacy to participants who were randomized to the placebo group (Lurie and Wolf, 1997, 1998; Angell et al).

Moreover, on the basis of the concept that the *best available therapy* should be made available to HIV-infected women, it was suggested that the duration of a course of zidovudine in developing countries be as long as the course given in developed countries (Angell et al.). The cost of the longer course of the antiretroviral drug at that time was $800, an amount that far exceeded the annual per capita financial allocation for healthcare in African countries where the HIV pandemic was present.

This controversy highlights several bioethical concepts that are germane to research in international health, including (1) local standards of care and achievement of equipoise,

(2) informed consent, (3) incentives and benefits of biomedical research and clinical trials to the individual and the community, and (4) disparities in global health between developed and developing countries.

LOCAL STANDARDS OF CARE AND EQUIPOISE. It is a central tenet of clinical research trials involving humans that hypotheses generated to evaluate new therapies be compared with the established standard; that is, the design of a trial must achieve equipoise. The controversy cited above is paradigmatic of the differing perceptions of this issue as it applies to a disease that affects resident populations of both the developed world and the developing world. The standard of care for HIV-infected pregnant women in Uganda at the time the study was conducted—no treatment with an antiretroviral drug—was strikingly different from that for residents of the United States, who had reasonable access to long-duration zidovudine despite its cost.

Acknowledgment of differences based on economic and cultural differences is important in the design and implementation of international research studies so that real or perceived issues that imply ethical imperialism can be avoided (Mbidde). This constitutes a broad rather than a narrow interpretation of the concept that the best therapy be made available to participants in research studies and their local community. A stricter interpretation inadvertently may led to a situation that, ironically, some may consider unethical because clinical research not performed in developing countries cannot possibly benefit the local population; that is, the efficacy of short-term zidovudine would not be known unless the African study were performed. Tensions arising from the fact that financial support for research studies conducted in developing countries comes mainly from governmental organizations and NGOs based in developing countries undoubtedly will continue to raise these issues. It is thus a positive development that training in the bioethical aspects of international research is receiving greater emphasis in both developed and developing countries, for example, through programs supported by the Fogarty International Center of the National Institutes of Health in the United States.

Bioethical aspects of international health research have been focused on disease and health issues that affect the inhabitants of both developed and developing countries, such as HIV infection. With increasing attention to research on health issues that primarily or exclusively affect residents of developing countries, such as the global health initiatives of the Gates Foundation, it is important that investigators and IRBs with different backgrounds come together to develop study designs that are acceptable in a broad cultural context.

It is critical that a study have potential benefit to the local population and not entail exclusively the care or prevention of a disease in persons in developed countries. For example, the development of a vaccine against blood-stage infection with the parasite *Plasmodium falciparum* has advanced to clinical trials in Africa and other areas in the tropics. The need for such a vaccine is great because falciparum malaria is estimated to kill approximately one million African infants per year. Residents of developed countries, where funding for the development and testing of vaccines comes from, are at minimal risk of malaria unless they visit endemic areas and do not take appropriate chemoprophylaxis. At the extreme, some diseases, such as lymphatic filariasis, do not exist in economically advanced countries, yet global initiatives for research and treatment of those health problems will benefit impoverished residents of developing countries exclusively.

On the one hand, investigators engaged in these research activities are largely from developed countries and stand to benefit from the conduct of clinical trials through increased scientific stature and competitiveness for additional funding and fame. On the other hand, agreement to participate in clinical trials by local populations may be motivated by the perceived short-term health benefit for oneself and one's family, community, or nation. It is therefore important that the topic of the research study and the details of its design address the health needs that are important in the local context. Moreover, participants in such studies need to understand how and in what time frame the research ultimately will benefit them and their community (Participants in the 2001 Conference on Ethical Aspects of Research in Developing Countries).

INFORMED CONSENT. European and North American concepts of informed consent generally are aimed at preserving the integrity and autonomy of the individuals who are recruited to participate in a research study. Excessive financial or other types of incentives are considered coercive. In the case of the United States the litigious nature of the interaction between the research subject and the investigator is also a significant factor in the process of obtaining and documenting informed consent.

Informed consent in many developing countries is an equally complex process with important variables that distinguish it from the process in developed countries. Community participation and educational sessions that include an ongoing dialogue with the researchers before, during, and after the completion of clinical research studies are prominent features, especially when the disease or health issue being studied has great significance for public health. Because many studies in international health involve investigators who are not residents of the area where the participants live, it is prudent and appropriate that scientists, public health officials, and community leaders be involved in developing methods of obtaining informed consent that are culturally appropriate. For example, although documentation of consent by signing a piece of paper that describes the risks and benefits of participation generally is done in developed countries, the residents of many rural areas of sub-Saharan Africa and developing countries in Asia and Latin America may not have achieved a literate status that enables them to be competent to appraise such a document critically. An extreme example would be to ask an illiterate individual to mark a piece of paper that contains information that that person cannot read. In this scenario oral informed consent obtained from local persons trained for this purpose is appropriate. Attention to this process is especially important for vulnerable populations in developing countries who may feel pressured to cooperate because of gender or economic biases that are prevalent in developed as well as developing countries (London 2001, 2002).

INCENTIVES AND HEALTH BENEFITS. Financial incentives to participate in clinical trials have been the subject of debate. Some have argued that financial incentives are coercive, especially in populations that are considered vulnerable because of extreme poverty. Reasonable financial inducements that account for time spent away from normal daily activities, for example, farming in populations in which subsistence agriculture is common, may be appropriate. In the international health setting, in which village and neighborhood life is common, inducements in the form of community improvements may be considered not coercive at the individual level and as representing reasonable "payment" for participation by community members. For example, financial support for a local health center may benefit populations that participate in malaria vaccine trials. Thus, although the benefit of a malaria vaccine may not materialize until years after the completion of a specific clinical trial, education of mothers in recognizing the symptoms of malaria in infants and improved access to antimalarial drugs will improve the local standard of care.

EQUITY AND GLOBAL DISPARITIES IN INTERNATIONAL HEALTH. Consideration of bioethical principles in international health must be seen in the context of the moral dilemma that more than 87 percent of the annual global health budget is devoted to 16 percent of the world's population in the most affluent developed countries (Iglehart). As the amount of money and scientific talent committed to the examination of health issues associated with the changing demography of developed countries, such as Alzheimer's disease and other dementias associated with old age, is increasing, infectious diseases that are rampant in developing countries continue to perpetuate the cycle of poverty and high childhood mortality and morbidity. This inequity may increase as the servicing of debt limits the economic advancement of developing countries and the internationalization of industrial and agriculture markets influences research priorities (Benatar). In the long term political advocacy on the part of those who conduct international biomedical research is needed to change this power disparity and increase research capacity training in developing countries (Nchinda).

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SEE ALSO: *AIDS; Bioterrorism; Environmental Ethics; Epidemics; Health and Disease: History of the Concepts; Human Dignity; Human Rights; Minorities as Research Subjects; Pharmaceutical Industry; Population Ethics; Population Policies; Public Health; Race and Racism; Research, Multinational; Responsibility*

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ISLAM, BIOETHICS IN

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Islam, the last of the Abrahamic religions (literally meaning “submission [to God’s will]”), was proclaimed by Muhammad (born ca. 570 C.E.), the prophet of Islam and the founder of Islamic public order in the seventh century C.E. in Arabia. This article will focus on the historical development of Islam, its fundamental teachings, Islamic legal thought, the Islamic theological and ethical tradition, Islamic mysticism, and Islam and modernity. Throughout the article an attempt will be made to relate religious-moral belief to practice, thereby indicating implications of the tradition in molding attitudes toward maintenance and preservation of life, including ways of dealing with suffering, pain, illness, death, and connected issues.

Historical Development

Seventh-century Arabia was socially and politically ripe for the emergence of new leadership. When Muhammad was growing up in Mecca, a city that had become an important center of a flourishing trade between Byzantium and nations on the Indian Ocean, he was aware of the social inequities and injustices that existed in the tribal society dominated by a political oligarchy made up of a few powerful chiefs. Monotheistic traditions like Judaism and Christianity were known to the Arabs; but they had persisted in worshiping their pagan deities, who dwelt in sanctuaries in and around Mecca. The most important shrine in Mecca was the Kaaba, a rectangular building, to which tribes made annual pilgrimage, using the occasion to trade with people who came from all over Arabia.

Religious practices and attitudes before Islam, then, were determined by the tribal aristocracy who also upheld tribal values: “bravery in battle, patience in misfortune, persistence in revenge, protection of the weak, defiance of the strong,” generosity, and hospitality as part of their moral code (Watt, p. 20). The growth of Mecca as a commercial center where individuals acted more freely in their own private interest than in the interest of the tribe, had weakened this tribal ethic to the extent that weaker members of a tribe and those who had been marginalized were left without security. Islam emerged in the midst of a serious socioeconomic imbalance between the rich and the poor, between extreme forms of individualism and tribal solidarity.

Muhammad was born into the Hashimite clan of the powerful Quraysh tribe in Mecca. His father died before he was born, and his mother died when he was six years old. In accordance with Arab tribal norms, he was brought up first by his grandfather, then, following the grandfather’s death, by his uncle, with whom he traveled on trade missions to Syria. As a young man he was employed by a wealthy Meccan woman, Khadija, as her trade agent. He was twenty-five when he accepted a marriage offer from Khadija, who was fifteen years his senior. When Muhammad received his prophetic call at the age of forty, Khadija was the first person to become *muslim* (“believer in Islam”).

This was the beginning of Islam as a struggle to establish a monotheistic faith and create an ethical public order embodying divine justice and mercy. Meccan leadership resisted Muhammad and persecuted him and his followers, who were drawn mainly from among the poor and disenfranchised. Under unbearable conditions, Muhammad decided to emigrate to Medina, an oasis town in the north, where two warring Arab tribes had invited him to arbitrate their affairs. This emigration in 622 C.E. marks the beginning of the Muslim calendar and the genesis of the first Islamic polity: Muhammad as a statesman instituted a series of reforms to create his community, umma, on the basis of religious affiliation. It also established a distinctive feature of Islamic faith, which does not admit the separation between the religious and temporal spheres of human activity, and has insisted on the ideal unity of civil and moral authority under the divinely ordained legal system, the *shariʿa.*

Muhammad died in 632 C.E., having brought the whole of Arabia under the Medina government. However, he had left no explicit instructions regarding succession to his religious-political authority. The early Muslim leaders who succeeded him as caliphs exercised Muhammad's political authority, making political and military decisions that led to the expansion of Muslim domains beyond Arabia. The community leaders were convinced that the Islamic domain, and not necessarily Islamic faith, was to prevail over all other nations. This conviction, in addition to the political need to consolidate the Muslim polity threatened by internal tribal strife, became the driving force behind the early territorial expansion. Within a century Muslim armies had conquered the region from the Nile in North Africa to the Oxus in Central Asia and as far as India. This vast empire required an Islamic legal system for the administration of the highly developed political systems of the conquered Persian and Byzantine regions. Muslim jurists formulated a comprehensive legal code, using the ethical and legal principles set forth in the Qur'an, the collected revelations of Muhammad, and the precedents set by the Prophet and the early community, in addition to the customary law in the conquered regions.

Differences of opinion on certain critical issues emerged as soon as Muhammad died. The question of succession to Muhammad was one of the major issues that divided the community into the Sunni and the Shia. Those supporting the candidacy of Abu Bakr (d. 634), an elderly associate of the Prophet, as caliph (political successor) formed the majority of the community, who gradually came to be known as the Sunnis; those who acclaimed ʿAli (d. ca. 660), Muhammad's cousin and son-in-law, as the imam (religious and political leader) designated by the Prophet, formed the minority group, known as the Shia ("partisans").

The dispute had profound implications beyond the political. The ideal nature of prophetic prestige in the community, established both in the Qur'an through persistent admonition to obey the prophet and through the prophet's personal exercise of discretionary power in shaping the public order, meant acknowledgment of an authority whose decisions in all spheres affecting Muslim life would be binding on posterity.

The early years of military victories over the Persians and the Byzantines were followed by the civil wars that broke out in 656 C.E. under Muhammad's third successor, ʿUthman. The tension occasioned by the existence of political and social injustices in the Muslim polity gave rise to two distinct, and in some ways contradictory, attitudes among Muslims: quietist and activist. The supporters of a quietist posture supported authoritarian politics, which feigned unquestioning and immediate obedience to almost any *de facto* Muslim authority who publicly promised to uphold Islamic norms. The exponents of an activist posture supported radical politics and taught that under certain circumstances, it was imperative to remove an unjust authority from power. Gradually the quietist and authoritarian stance became associated with the majority of the Sunnite Muslims. The activist and radical stance came to be associated with Shiite Islam.

By the end of the third Islamic century (ninth–tenth C.E.), these two distinct responses to the question of political-religious authority were expounded by the Sunni and Shia schools of thought. Despite the disintegration of the caliphal authority in the thirteenth century C.E., the Muslim community has continued to live in the shadow of the idealized history of early Islam, when the religious and secular authority was united under the divinely guided caliph.

Fundamental Teachings

The two authoritative sources of Islamic teachings are the Qur'an, regarded by Muslims as the book of God, and the *sunna,* the exemplary conduct of the Prophet. The Qur'an consists of the revelations Muhammad received intermittently from the time of his call as prophet in 610 C.E. until his death in 632. Muslims believe that the Qur'an was directly communicated to the Prophet by God through the archangel Gabriel; accordingly, it is regarded as inerrant and immutably preserved. It has served as the source for ethical and theological doctrines and principles for the public organization. The *sunna* (meaning "trodden path") has functioned as the elaboration of the Qur'anic revelation, providing details about each and every precept and deed purportedly traced back to the Prophet's own precedent. The narratives that carried such information were designated as *hadith.* In the ninth century, Muslim scholars developed an elaborate system for the theological and legal classification of these *hadith* to deduce certain beliefs and practices.

The *hadith* literature describes the Muslim creed and practice as "the Five Pillars of Islam." The First Pillar is the *shahada,* the profession of faith: "There is no deity but God, and Muhammad is the messenger of God." Belief in God constitutes the integrity of human existence, individually and as a member of society. The Qur'an speaks about God as the being whose presence is felt in everything that exists; everything that happens is an indicator of the divine. God is the "knower of the Unseen and the Visible; … the All-Merciful, the All-compassionate, … the Sovereign Lord, the All-holy, the Giver of peace, the Keeper of faith, the All-preserver, the All-mighty, the All-powerful, the Most High" (Qur'an, 59:23). Faith in God results in being safe, well integrated, sound, and at peace.

Life is the gift of God, and the body is the divine trust given to humankind to enable it to serve God as completely and fully as the wonderful creation of God has made that serving possible. The humble origin of humans is established by the Qur'anic reference to their creation from "dry clay of black mud formed into shape" (15:26). Through the well-proportioned creation of the human body and the perpetual guidance provided to perfect it both spiritually and morally, human beings have been given the trusteeship of their body. On the Day of Resurrection, all parts of the human body will have to account for the actions of the person whose bodily organs they formed. God has set limits on what human beings may do with their own bodies. Suicide, homicide, and torturing one's body in any form are regarded as transgressions.

The Qur'anic affirmation of bodily resurrection has determined many religious-moral decisions regarding cadavers. Dead bodies should be buried reverently, as soon as possible. Islamic law prohibits mutilation of the cadaver and, thus, cremation. Under certain circumstances, in order to determine the cause of death, autopsy is permitted. Postmortem dissection is permitted, for instance, to retrieve a valuable object belonging to another person that might have been swallowed by a deceased person. There was doubt about the use of human cadavers for medical research until fairly recently.

The rulings are now well established in regard to the cadavers of non-Muslims, which do not require any monetary compensation for their mutilation (as required by the *shari*ʿ*a* for the cadaver of a Muslim). However, if the research for a cure of a disease is dependent on the dissection of a Muslim cadaver, then most Sunni and Shi`ite jurists rule it permissible and, as a precautionary measure, require the payment of compensation to the family of the deceased (*Fiqh al-tabib* [Islamic Laws for Physicians], pp. 159–180). Some recent rulings from Shi`ite jurists make no distinction between a Muslim and a non-Muslim cadaver, thereby permitting research and use of organs for transplantation (*Fiqh al-tabib* [Islamic Laws for Physicians]).

The Qur'an affirms reverence for human life in reference to a similar commandment given to other monotheists: "We decreed for the Children of Israel that whosoever killeth a human being for other than manslaughter or corruption in the earth, it shall be as if he had killed all humankind, and whoso saveth the life of one, it shall be as if he saved the life of all humankind" (5:32). This passage has provided modern Muslim jurists with religious documentation to legitimize medical advances in saving human lives. It has also served as an incentive to protect humanity against peril by choosing to save oneself and others from perdition and to serve humanity as service to God.

The corollary of the belief in God's guidance is human accountability to further divine purposes on earth. The purpose of creation is to allow human beings, created with cognition and volition, freely to accept the responsibility of perfecting their existence by working with the laws of nature grasped by the divinely endowed innate disposition (*fitra*) and by understanding principles of causality that regulate their well-being. The Qur'an emphasizes God's benevolence, all-forgivingness, and mercy. But it also accentuates God's justice, and stresses that humanity should develop moral and spiritual awareness (*taqwa*) in fulfilling everyday requirements of life.

Human existence is not free of tension and inner stresses caused by rejection of truth (*kufr*) and impairment of moral consciousness. To help humanity, God sends prophets "to remind" humanity of its covenant with God (Qur'an, 7:172). There have been 124,000 prophets from the beginning of history, of whom five (Noah, Abraham, Moses, Jesus, and Muhammad) are regarded as *messengers* sent to organize their people on the basis of the guidance revealed by God.

The Second Pillar is daily worship (*salat*), required five times a day: at dawn, midday, afternoon, evening, and night. These very short prayers entail bowing and prostrations. A Muslim may worship anywhere, preferably in a congregation, facing Mecca. Muslims are required to worship as a community on Fridays at midday and on two major religious holidays, celebrating the end of Ramadan and the completion of the pilgrimage in Mecca. The congregational prayer gives expression to the believer's religious commitment within the community. Women are exempt from the obligation of congregational participation, and the tradition recommends that they worship in the privacy of their homes. However, they have always worshiped at designated areas in the mosque, apart from men. The Qur'an prescribes physical purity for the worshiper through the performance of ablutions, and a full washing after sexual intercourse or a long illness, prior to undertaking worship. Women are required to perform a full washing after the menstrual cycle and childbirth, because blood is regarded as ritually unclean. Islamic law prescribes regular cleansing and physical hygiene as expressions of one's faith.

Prayer in Islam is regarded as therapeutic. Besides seeking medical treatment, Muslims are encouraged to seek healing, especially of psychological illnesses, by praying to God. Many illnesses, according to the teachings of the Prophet, are caused by psychological conditions like anxiety, sorrow, fear, loneliness, and so on. Hence, prayer restores the serenity and tranquillity of the soul.

The Third Pillar is the mandatory "alms levy" (*zakat*). The obligation to share what one possesses with those less fortunate is stressed throughout the Qur'an. The Muslim definition of the virtuous life includes charitable support of widows, wayfarers, orphans, and the needy. Islamic law includes technical regulations about how much *zakat* is due and upon what property it is to be levied. These legal rulings, which originated before the disintegration of the Islamic public order, do not necessarily prevail in contemporary Muslim nations. Although *zakat* has for the most part been left to the conscience of Muslims, the obligation to be charitable and contribute to the general welfare of the community continues to be emphasized. In a number of poor Muslim countries this benevolence, provided by wealthy individuals, has underwritten badly needed healthcare for those who cannot afford the rising cost of medical treatment. It has also led to the creation of private charitable foundations that compete with the cumbersome and poorly administered government welfare institutions.

The Fourth Pillar is the fast during the month of Ramadan. Since the Muslim calendar, which has been in use since the seventh century, is lunar, the month of fasting moves throughout the year over a period of time, because the lunar year is shorter than the solar. Ramadan is regarded as the holy month during which the Qur'an was revealed to Muhammad. During the fast, which lasts from dawn to dusk, Muslims are required to refrain not only from eating, smoking, and drinking but also from sexual intercourse and acts leading to sensual behavior. The fasting is meant to alter the pattern of life for a month, and Muslims are required to make necessary adjustments in their normal schedules of work and study. The end of the month is marked by a festival, `Id al-fitr, after which life returns to normal.

Instituted to cultivate individual spiritual and moral self-control, Ramadan also provides a community experience in which families and friends share both fasting and evening meals in the spirit of thanksgiving. Like prayer, fasting possesses therapeutic value. Prophetic medical tradition prescribes fasting for various kinds of ailments, including psychological problems caused by fear and anxiety. It was regarded as a remedy for excessive sexual drive.

The Fifth Pillar is the pilgrimage, the *hajj,* which all Muslims are required to undertake once in their lives, provided they have the financial means. The rituals of the pilgrimage at Mecca are a collective commemoration of the sacrifice story of Abraham and of lessons to be derived from it. Its spiritual objective is to inculcate a form of asceticism accompanied by renunciation of worldly desires (sexual intercourse, use of perfumes, and so on) and concern with the hereafter. The experience brings together Muslims of diverse cultures and nationalities to achieve a purity of existence and a communion with God that will exalt the pilgrim for the rest of his or her life.

Islamic Legal Thought

Islamic jurisprudence (*fiqh*) was developed to determine normative Islamic conduct as detailed in the *shariʿa,* the sacred law. The *shariʿa,* the divinely ordained blueprint for human conduct, is inherently and essentially religious. The juridical inquiry that led to the *shariʿa* code was comprehensive because it necessarily dealt with every case of conscience covering God-human relations, as well as the ethical content of interpersonal relations in every possible sphere of human activity. Most of the legal activity, however, went into settling more formal interpersonal activities that affected the morals of the community. These activities dealt with the obligation of doing good to Muslims and guarding the interests of the community.

Islamic legal theory recognized four sources for judicial decisions: the Qur'an, the *sunna,* consensus (*ijmaʿ*) of the early community of the Muslims, and analogy (*qiyas*), a method of reasoning from data furnished by the Qur'an and the *sunna* in an attempt to estimate the unknown from the known ruling. Al-Shafi`i (d. 820), a rigorous legal thinker, systematically and comprehensively linked the four sources in order to derive the *shariʿa* to cover all possible contingencies. The legal precedents and principles provided by the Qur'an and *sunna* were used to develop an elaborate system of rules of jurisprudence. Human conduct was to be determined in terms of how much legal weight was borne by a particular rule that rendered a given practice obligatory or merely recommended.

For instance, if it is deemed that by risking one's life, one may be able to save another person from impending death, then the law permits not only donation but also sale of a needed body part or an organ after a careful risk-benefit analysis. Vital organs like eyes are excepted in this ruling. Likewise, it had to be decided whether an obligatory act, because of its social relevance and the degree of applicability of a given rule or precedent, was to be enforced by penalties in the courts or left to God's judgment in the hereafter.

In family law, the rights of women, children, and other dependents were protected against the male head of the family, who, on the average, was stronger than a woman and more independent, being free of pregnancy and having to care for children. Islamic marital rules encouraged individual responsibility by strengthening the nuclear family. *Shari^{c}a* protected the prerogative of the male because he was required to support the household; the woman was protected primarily by her family. Muslim jurists gave the husband one-sided divorce privileges because for a woman to divorce a man would mean to unsettle her husband's economic investment. Under these rules a husband could divorce a wife almost at will; a wife who wished to leave her husband had to show good reason.

The main legal check upon the man in divorce was essentially financial and a matter of contract between equal parties that included a provision about the bridal gift. Part of the gift, which might be substantial, was paid at the time of marriage; if a husband divorced his wife without special reason, he had to pay her the rest. The equality of women in the *shari^{c}a* carried with it an important financial independence. The Muslim woman could own property that could not be touched by any male relative, including her husband, who was required to support her from his own funds. Moreover, she had a personal status that might allow her to go into business on her own. However, this potential female independence was curbed primarily by cultural means, keeping marriages within the extended family, so that property would not leave the family through women marrying out.

Muslim jurists, although tending to give the male an extensive prerogative, presupposed a considerable social role for women. The Qur'anic injunction to propriety was stretched by means of the *sunna* to impose seclusion. The veil was presented simply in terms of personal modesty; the female apartments, in terms of family privacy. It was not intended to become a form of social distinction, as it did with upper-class women living in rigorous segregation. Among the latter it became a mark of a woman of a quality that she was secluded from all men but those in her own family.

Segregation of the sexes as required by the *shari^{c}a* has led to untold problems in the teaching and practice of medicine today. The problems cover such areas as closely examining and touching the reproductive organs (male-female, female-male, male-male, and female-female); looking at photographs of naked persons for studying physiology and anatomy; taking the pulse and other vital signs of patients of opposite sex. While the classical decisions were prohibitive in all these cases, the majority of the modern Muslim jurists have casuistically accommodated the need to carry out necessary medical training, research, and treatment.

In the patriarchal family structure, and not necessarily in the *shari^{c}a,* women were assigned a subordinate role in the household and community. Through certain cultural practices women's reproductive capacity was controlled. In some parts of the Muslim world women are subjected to traditional practices that are often harmful to their well-being and that of their children. One of the controversial and persistent practices is female circumcision (*khafd* or *khifad*), without which it is believed that girls cannot attain the status of womanhood. Islamic views on female circumcision are ambiguous. While Islam does not condone the practice, neither does it forbid it. The operation was performed long before the rise of Islam. It is not a practice in many Muslim countries, including Saudi Arabia, Tunisia, Iran, and Turkey. There is nothing in the Qur'an that justifies female circumcision, especially its most severe form, infibulation. The Prophet opposed the custom as found among pre-Islamic Arabs, since he considered it harmful to women's sexual well-being. Yet the official juridical position among the majority of Sunni jurists is that female circumcision is sanctioned by the *sunna.* However, the *shari^{c}a* does not regard it as obligatory. It is merely a recommended act.

As Islamic jurisprudence became highly technical, disputes about method and judicial opinions crystallized into legal schools designated by the names of prominent jurists. The legal school that followed the Iraqi tradition was called Hanafi, after Abu Hanifa (d. 767), the great imam (teacher) in Iraq. Those who adhered to the rulings of Malik ibn Anas (d. 795), in Arabia and elsewhere, were known as Malikis. Al-Shafi`i founded a legal school in Egypt whose influence spread widely to other regions of the Muslim world. Another school was associated with Ahmad ibn Hanbal (d. 855), who compiled a work on *hadith* reports that became the source for juridical decisions of those who followed him. Shiites developed their own legal school, whose leading authority was the imam Ja`far al-Sadiq (d. 765).

Normally, Muslims accepted one of the legal schools prevalent in their region. Most Sunnites follow Hanafi or Shafi`i; the Shiites follow the Ja`fari school. In the absence of an organized *church* and ordained *clergy* in Islam, determination of valid religious praxis was left to the qualified scholar of religious law. Hence, there emerged a living tradition, with different interpretations of the Qur'anic laws and prophetic traditions, giving rise to different schools of the *shari^{c}a.*

The scope of *shari^{c}a,* understood as the norm of the Muslim community as a community, was defined by two essential areas of human life: acts of worship, both public and private, connected with the pillars of faith; and acts of public order that ensure individual justice. The *shari^{c}a* reflected Muslim endeavors to ensure that Islam pervaded the whole of life. However, many areas of human existence, including the ethical problems connected with the medical treatment of ailments, received little systematic attention in the classical formulations of the legal thought.

Islamic Theological and Ethical Tradition

In the first half of the eighth century, the debates about qualified leadership, the existence of injustices in the community, and the appropriate response to redress the situation, formed the rudiments of the earliest systematic theology of the group called Muʿtazilites. Before them, some Muslim thinkers had developed theological arguments, including a doctrine of God and human responsibility, in defense of the Islamic revelation and the prophethood of Muhammad when these were challenged by other monotheists. The Muʿtazilites undertook to show that there was nothing repugnant to reason in the Islamic revelation. Their theological system was worked out under five headings: (1) belief in God's unity, which rejected anything that smacked of anthropomorphism; (2) the justice of God, which denied any ascriptions of injustice to God's judgment of human beings, with the consequence that humans alone were responsible for all their acts, and thus punishable for their evil ones; (3) the impending judgment, which underscored the importance of daily righteousness and rejected laxity in matters of faith; (4) the middle position of the Muslim sinner, who, because of disobeying God's commandments was neither condemned to Hell nor rewarded with Paradise but was regarded as reformable; and (5) the duty to command the good and forbid the evil in order to ensure an ethical social order.

In defining God's creation and governance of the world, these early Muslim theologians sought to demonstrate the primacy of revelation. At the same time, their theology reflected Hellenic influences. From the ninth century on, translations of the full Greek philosophic and scientific heritage became available in Arabic. The result was the development of a technical vocabulary and a pattern of syntax that enriched theological terminology.

The Ashʿarites, reacting to Muʿtazilite rationalism, limited speculative theology to a defense of the doctrines given in the *hadith* reports, which were regarded as more reliable than abstract reason in deducing individual doctrines. The Ashʿarites emphasized the absolute will and power of God, and denied nature and humankind any decisive role. What humans perceive as causation, they believed, is actually God's habitual behavior. In their response to the Muʿtazilite view on the objective nature of good and evil, and in their effort to maintain the effectiveness of a God, at once omnipotent and omnibenevolent, who could and did intervene in human affairs, they maintained that good and evil are what God decrees them to be. Accordingly, they cannot be known from nature but must be discovered in the sources of revelation, like the Qur'an and the Prophet's example. There are no inherently unchanging essences and natural laws that self-subsistent reason can discern. God transcends the order of nature. Hence, the notion of free will is incompatible with the divine transcendence, which determines all actions directly.

Ashʿarite theological views remained dominant well into modern times, and had a profound effect upon scientific (and particularly medical) theory and practice among the Sunnites. The attitude of resignation, a by-product of belief in predestination, is summed up in the Sunni creedal confession: "What reaches you could not possibly have missed you; and what misses you could not possibly have reached you" (*Fiqh akbar,* art. 3, in Wensinck, p. 103). This belief in overpowering destiny was bound to have negative implications for some Sunni Muslims encountering adversities caused by illness and other forms of suffering. The Shiite theological and ethical doctrines were based on the Mu`tazilite thesis about the justice of God and the objective nature of moral values.

Positive sciences, especially medicine and astronomy, emerged from the rationalism of Muslim theologians influenced by translations of the works on these subjects from Greek into Arabic. Nature studies in Islamic civilization were pursued by intellectuals who contributed to the Muʿtazilite and Shiite rational theology. Human nature was studied in order to deduce rational principles that could help direct human life to create an ideal society. Ethics and politics were regarded as rational knowledge necessary to harmonize human existence in the universe.

At the practical level, medicine involved the training necessary to apply techniques that demonstrated tact and insight in the treatment of patients. Medical practice was based on a tradition of clinical observation, which became the source for encyclopedic works like the *Canon* (*al-Qanun*) of Avicenna (d. 1037). Since dissection of human cadavers was impossible because of the prohibition in Islamic law against mutilation of the dead and the requirement of immediate burial, physicians treated their patients partly on the basis of their knowledge of anatomy and partly by relying on their understanding of the rationality and harmony of the cosmos. Diagnosis and prognosis were also based on their insights about psychological and environmental factors. Despite the disapproval of some orthodox Muslims, who rejected Greek medicine as not provided for in the Prophetic medical tradition, many of these Greek-influenced philosopher-physicians came to be known as the *hakim* (wise). Prophetic medicine (*al-tibb al-nabawi*) was believed to have arisen to counter the authority of Greek-based medical tradition by positing the notion that certainty in knowledge, including medicine, depended upon revealed sources. However, although seemingly based on the Qur'an and statements attributed to the Prophet, Prophetic medicine actually was the remnant of the medicine customarily practiced among the Arabs in the pre-Islamic age.

Islamic Mysticism

In the early days of the Islamic empire under the Umayyads (eighth century), the mysticism that began as an ascetic reaction to growing worldliness in the Muslim community became institutionalized. Sufism, as Islamic mysticism came to be known, aimed to interiorize the formally undertaken ritual acts, and emphasized rigorous self-assessment and self-discipline for the achievement of spiritual and moral perfection. In its early form Sufism was mainly a form of ascetic piety that involved ridding oneself of any dependence on satisfying one's desires, in order to devote oneself entirely to God. Mystical practices developed by the Sufi masters comprised a moral process to gain the relative personal clarity that comes at moments of retreat and reflection. A further dimension of this reflection was to cultivate an ability to face reality about oneself and to love any being capable of needing love. The mystic experienced more intense levels of awareness, which could take ecstatic forms, including ecstatic love of God.

This aspect of Sufism brought the mystics into direct conflict with orthodox Muslims. Sufi teaching that a symbolic and spiritual fulfillment of religious duties was as good as the actual rites was seen by orthodox Muslims as a kind of antinomian behavior within the community that considered literal adherence to the requirements of law as the valid form of religiosity. In general, Sufis increasingly tended to minimize religious differences among various faiths and cultivated humanism based on universalistic spiritual and moral qualities.

By the eleventh century the Sufi masters had developed a new form of religious orientation that brought about the acceptance of Sufism in many parts of the Islamic world. Near the end of the twelfth century, several formal Sufi brotherhoods or orders (*tariqa*), in which women also participated, were organized. Each order taught a pattern of invocation and meditation that used devotional practices to organize a group of novices under a master. Special controls of breath and bodily posture accompanied invocative words or syllables to make possible more intense concentration. The orthodox, who had been suspicious of early elitist Sufism, were now persuaded to accept the Sufism of the masses and to try to discipline it. The ultimate approval of Sufism as a genuine form of Islamic piety was facilitated by Abu Hamid al-Ghazali (d. 1111), who taught Islamic law and theology in Baghdad. His writings in connection with his personal spiritual crisis at the height of his professional success demonstrated that Sufism could be a powerful discipline for curing doubt and experiencing truth.

A number of Sufi masters served as analysts for younger Sufis, helping them to understand their psychic states and making sense of their place in the universe. In the premodern Islamic world, where medical treatment was not generally available to an average person, some prominent Sufis practiced traditional medicine based on the theory of the four humors that kept the body functioning. Herb remedies were used to treat ailments caused by imbalance in the four qualities of the body (hot and cold, moist and dry), which led to an imbalance of the humors. Other Sufis treated physical and psychic disorders through the writing of talismans and amulets. Talismans, some using sections of the Qur'an, and exorcism are used in treating mental disorders even today in rural areas of the Islamic world.

Islam and Modernity

The modern age brought Islam and Muslims face to face with intellectual as well as political challenges both from within and from without. From within, Muslims faced the deterioration of Islamic religious life caused by centuries of stagnation and petrification of doctrines and beliefs. From without, the hegemony of the West since the mid-nineteenth century resulted in alien domination of Muslim societies. Since that time, Muslims have endeavored to strike a balance between the divine promise of earthly success to Muslims and their tenuous contemporary situation by introducing internal reforms to prevent further degeneration of Islamic life, and by resisting any form of domination of Muslim societies by the Western powers.

Islamic fundamentalism in modern times stems from the acute awareness among Muslims of a conflict between the religion that promises worldly as well as eternal prosperity to its followers, on the one hand, and the historical development of the Muslim world, which points to the breach of a divine promise, on the other. Muslim leaders call for a return to the original teachings of Islam in the Qur'an and the Prophet's exemplary life. To regain the power and prestige of early Islam, they propose fashioning the modern nation-state on ideals derived from the practices of the original Muslim community. Muslim brotherhoods throughout the Islamic world have joined forces to implement strictly religious reform in a modern society, requiring adherence to the restrictive traditional social-cultural norms.

Resistance to modern secular ideologies and their implications has posed a greater challenge to the Muslim leadership. It has meant providing an Islamic alternative to intentionally imported or externally imposed sociopolitical systems. Such an alternative entails creative interpretation of religious ideas and symbols. Thus far, the traditional Muslim leadership has not succeeded in providing such an alternative as the only viable solution to the multifarious problems faced by the Muslim societies.

A case in point is provided by enormous problems that have arisen with the technological advancement in medicine. Muslim jurists are faced with a crisis because, by its own standards, Islamic jurisprudence has ceased to progress toward some further stage of development. The methods of inquiry and the forms of argument have disclosed inadequacies to furnish solutions to concrete problems faced by the community. Hence, important questions connected with the role of female physicians and patients in a male-dominated profession; conflict between rigorous religious observance and medical education; state policy toward family planning; and social and cultural factors that affect women's health adversely are among numerous pressing issues that remain to be authoritatively resolved.

The judicial decisions issued so far in various Muslim countries, where conferences on bioethics have been held in the last three decades, are mostly in the form of supposition or opinion, and lack the intellectual rigor to become part of state-sponsored health policy.

The greatest challenge to Muslim leadership, both religious and political, remains that of correcting the social and political injustices endured by the common people, who encounter a modern, materialist world over which they have minimal control.

Muslims living as a minority outside the geographical sphere of Islam face the challenge of integration and assimilation in the non-Muslim social universe. Muslim communities belonging to various ethnocultural groups in the West, including North America, are engaged in working out socially interactive strategies that will enable them to establish their identity as Western Muslims. African-American Muslims in North America have reminded the immigrant Muslims of the difficult process of integrating ethnic-cultural and religious identities in modern secular society. African-American Muslims, having been part of American society for a long time, have emerged with a rare ability to combine the most relevant and applicable facets of the modern American social universe and their adopted religion, Islam.

ABDULAZIZ SACHEDINA (1995)

SEE ALSO: *Abortion, Religious Traditions: Islamic Perspectives; African Religions; Authority in Religious Traditions; Christianity, Bioethics in; Eugenics and Religious Law; Hinduism, Bioethics in; Judaism, Bioethics in; Medical Ethics, History of: Near and Middle East; Population Ethics, Religious Traditions: Islamic Perspectives; Sikhism, Bioethics in; Women, Historical and Cross-Cultural Perspectives*

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JAINISM, BIOETHICS IN

The Jaina religious tradition originated in India. Its adherents currently number approximately seven million, most of them living in India. According to tradition, the founders of the faith were not emissaries or embodiments of a supreme being, but were human beings who through their own efforts reached an elevated spiritual state called Kevala, characterized as blissful, omniscient solitude free from all karmic suffering and hence liberated from rebirth. According to Jaina lore, twenty-four persons known as Tīrthaṇkaras crossed over the river of rebirth and conquered the influences of negative karma. They then established and promulgated the Jaina religion. Their stories extend back into the prehistory of India. Historical records exist for the two most recent Tīrthaṇkaras: Parśvanatha, who lived around 850 B.C.E., and Vardhamāna Mahāvīra, the Jina or Conqueror, whose approximate dates are 599–527 B.C.E. The term *Jaina* means "follower or disciple of the Jina."

The belief structure and lifestyle of the Jainas are closely linked. In Jainism, there is no creator God. Rather, the Jaina religion is rooted in a unique respect for all life forms that serves as the basis for a sophisticated system of ethics based on the observance of nonviolence (*ahiṃsā*).

According to the Jainas, there are two categories of reality: one possesses life (*jīva*); the other is lifeless (*ajīva*). However, unlike Western definitions of life, which require "metabolism, growth, response to stimulation, and reproduction," the Jainas regard even seemingly inanimate objects as possessing life. The universe is said to be suffused with countless life forces grouped in five categories: earth, water, fire, and air bodies; microorganisms (*nigoda*); plants; animals; and humans. These *jīva* take the shape of their particular life form, whether it be large as a whale or small as a pebble. Each of these life forces is involved in a process of transmigration, moving after death into a new form.

According to Jaina tradition, sticky particles of nonliving matter called karmas adhere to *jīvas* when acts of desire, passion, or violence are committed. Though not visible to the naked eye, six subtle color distinguish this karma. Black, blue, and gray are associated with sinful or brutish karma, and yellow with less serious offenses. Pink and white indicate that one's karmic burden is being lessened. Through unethical passionate or violent behavior, one increases the inhibiting influence of darker, heavier karma. Through adherence to the Jaina code of ethics, one can expel the negative karma and cultivate the purer forms. Eventually, the goal of Jainism entails breaking free from all karmic influence. In this state, referred to as Kevala, one gains omniscience and freedom from rebirth, dwelling eternally in energy, consciousness, and bliss.

Jaina ethics consists of taking vows (*vrata*) designed to eliminate karma. Both lay Jainas and members of monastic orders are expected to observe these vows, though the rules for nuns and monks are much more stringent. Earliest Jaina tradition lists four vows: nonviolence (*ahiṃsā*), truthfulness (*satya*), not stealing (*asteya*), and nonpossession (*aparigraha*). Vardhamāna Mahavīra is credited with adding a fifth vow, chastity (*brahmacarya*). Scriptures such as the *Acārāṇga Sūtra* serve as authoritative sources for religious life.

From ancient times to the present, Jaina monks and nuns have served as preceptors and living symbols of this tradition. Though there are many "lineages" within the Jaina tradition, all modern Jainas can be classified as belonging to either the Śvetāmbara (White Clad) or the Digambara (Sky Clad) group. In the former group, all monks and nuns wear white robes. In the latter group, the highest order of monks renounces all possessions, including clothing. Both sects allow women to take advanced religious vows, though only the Śvetāmbara allow women to take final vows.

Jaina monks and nuns wander throughout India, teaching the lay community about the lives of earlier saints, advocating the practice of nonviolence, and discussing such topics as the all-pervasiveness of life forms and the karmic effects of behavior. Depending upon the rules of their particular subsect, they may cover their mouths with cloth to avoid injuring insects and microorganisms, or gently sweep the path in front of them to remove insects. In 1949, Acārya Tulsi, head of the Terāpanthi Śvetāmbara monastic order, began teaching a twelvefold system of vows, including modern adaptations such as "not to resort to unethical practices in elections" and "to avoid contributing to pollution."

Although these vows are most intently observed by members of monastic communities, the Jaina lay community has developed a culture anchored in the practice of nonviolence. Lay Jainas generally enter professions in which they can avoid violent action that would increase the depth and darkness of one's karma. Many Jainas engage in trade and commerce, provided that animal products and weaponry are not involved. All Jainas, both laypersons and members of religious orders, are lacto vegetarians.

Although the Jaina system was originally conceived as outlining a path of personal liberation and spiritual enlightenment, many of the practices inspired by a desire to avoid the accumulation of karma have found new relevance in the modern ethical context, especially vegetarianism, animal protection, attitudes toward death, and the Jaina ideal of tolerance.

Jainas regard vegetarianism as a way to ensure that one does not accumulate the negative karmas associated with animal slaughter. In modern medical terms, it also purifies one's body, minimizing the violence done to the body that is often associated with the consumption of meat. Jaina eating habits, rooted in the ancient doctrine of nonviolence, are compatible with modern, scientific concerns about enhancing personal health through a low-fat, low-cholesterol diet.

Respect for animals has long been a mainstay of Jaina tradition. Throughout Indian history Jainas have lobbied for animal protection, building shelters and providing food for lost or wounded animals, and successfully campaigning to ban animal sacrifice in most parts of India. The Mogul emperor Akbar (1556–1605), influenced by Jaina monks, proclaimed days of restraint from hunting and renounced the consumption of several types of meat. Jaina laypersons periodically visit slaughterhouses and purchase animals for release and protection. In India, pharmaceutical companies owned by Jainas, though required to test medicines on animals, rehabilitate their test animals and then release them.

Jaina tradition regards the death of an older person to be both natural and an opportunity for spiritual advancement. For many centuries, Jainas of advanced age or infirmity have engaged in a practice known as *sallekhanā,* referred to by modern Therāpanthi Śvetāmbara Jainas as *santhārā.* Rather than prolonging death when the process of decline becomes irreversible, some Jainas obtain permission from their religious preceptor to engage in a fast unto death. This final ritual is deemed in Samantabhadra's *Ratnakarandaśrāvakācāra,* a Jaina text of the second century, as acceptable only in "calamity, severe famine, old age, or illness from which there is no escape." One first renounces food, then milk, then water, and is encouraged to "depart from the body repeating the *nammokkāra mantra* [prayer] until the last." The Jainas assert that such a fast is neither suicide, which is done out of despair or hopelessness, nor euthanasia, which requires the assistance of a second party and a violent act. This practice, associated with a quest for spiritual freedom, embodies the Jaina ideal of encountering and embracing death without fear.

In a more philosophical vein, the Jainas have developed an ethic of debate, according to which each position or opinion is given provisional status. Any statement or perspective is said to be perhaps true or partially true, including the religious views held by non-Jainas. This ethic both reflects and fosters an attitude of tolerance for which the Jainas have become well known. Mahatma Gandhi, Albert Schweitzer, and Leo Tolstoy were all influenced by Jaina principles.

Technology and modernity present new challenges to the Jaina tradition in that they have spawned new forms of violence not discussed in the original Jaina texts. At Jaina Viśva Bhārati, a university dedicated to the teaching of Jainism located in western India, a curriculum has been developed to help apply Jaina principles to contemporary life, to minimize conflict among groups of people, and to encourage sensitivity to ecological issues.

The Jaina worldview sees the world as a biocosmology, a reality suffused with life. From the perspective of bioethics, this religion is unique in its advocacy of vegetarianism, animal protection, tolerance of multiple perspectives, and philosophical approach to the inevitability of death.

CHRISTOPHER KEY CHAPPLE (1995)

SEE ALSO: *Animal Welfare and Rights: Ethical Perspectives on the Treatment and Status of Animals; Animal Welfare and Rights: Vegetarianism; Death: Eastern Thought; Harm; Hinduism, Bioethics in; Medical Ethics, History of: South and East Asia: India*

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JEHOVAH'S WITNESS REFUSAL OF BLOOD PRODUCTS

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Jehovah's Witnesses are members of a biblically based, semi-Christian religious denomination that forbids its adherents from accepting transfusions of blood and blood products. This religious tenet is based on a literal interpretation of specific passages in the Bible. As a result of this doctrine, most baptized Jehovah's Witness *believers* refuse blood transfusions in their pursuit of medical treatment and healthcare. Some nonblood, transfusion-like replacement techniques and agents derived from minor blood fractions are left to individual believers to accept or reject. Jehovah's Witnesses do not subscribe to "faith healing," and thus seek the assistance of modern medicine as needed, excluding blood transfusions. This belief creates ethical questions and dilemmas related to patient autonomy, informed consent, advance directives, decisional capacity, surrogate decision making, professional integrity and promotion of patients' best interests, medical treatment for children, maternal–fetal conflicts, and the use of healthcare resources.

Historical Development and Organizational Structure

Jehovah's Witnesses trace their historical roots to Charles Taze Russell (1852–1916) and the nineteenth-century North American Adventist movement (a group of Christians who predicted an imminent "second coming" of Jesus Christ). In 1881, as a result of his teaching and writings, Russell founded the Zion's Watch Tower Tract Society. Russell had calculated and predicted that Jesus Christ would return in 1914, when God's direct rule would be established on earth and humanity would be restored to perfection. At the time of Russell's death, he had not appointed a successor.

Russell's religious movement floundered and fractionated until 1931, when Joseph Franklin Rutherford (1869–1942), a lawyer from Missouri, took over leadership. At a meeting of the renamed Watchtower Bible and Tract Society in Columbus, Ohio, in 1931, the name *Jehovah's Witnesses* was adopted and Rutherford became the group's president. Rutherford believed that because the Hebrew name for God was Jehovah, God's people should be known by the same name. In addition to authoring twenty books and numerous pamphlets that greatly influence the denomination's evolving belief system, Russell focused the lives of Jehovah's Witnesses on local congregations and places of assembly known as *Kingdom Halls,* which were established throughout the United States. A principle tenet of Jehovah's Witnesses is to inform the world about Jehovah's reign and kingdom via missionary activity, including door-to-door evangelization.

Nathan H. Knorr (1905–1977) succeeded Rutherford as the society's president in 1942. During Norr's term, the belief about the divine mandate to refuse blood transfusions was first introduced and promulgated in one of the Society's official publications, *The Watchtower* (July 1, 1945). By 2002, there were 6 million Jehovah's Witnesses participating in over 90,000 congregations in 230 countries.

Similar to other religious groups, Jehovah's Witnesses have developed a theologically justified organizational structure with accompanying degrees of hierarchical authority. God's will and direction are revealed primarily through the Bible, and secondarily through the leadership at the international headquarters of the Watchtower Bible and Tract Society, based in Brooklyn, New York. The teaching and organizational authority of the Society is composed of a president and a governing body of seventeen members who head up various committees.

Educational and instructional resources, including printed materials such as official publications (e.g., *The Watchtower,* and *Awake!*) are primarily written, produced, and published at the Brooklyn headquarters. Distribution of materials takes place through branch offices, districts, and circuits, the last consisting of approximately twenty congregations. Districts and circuits have overseers appointed by the society's governing body. Local Kingdom Halls, where individual congregations are centered, are presided over by elders responsible for worship, training, and evangelization.

Biblical Beliefs about Blood

As noted above, the Jehovah's Witness belief system is biblically based. The exegetical method used to interpret biblical texts is a literal, or fundamentalist, method (what the words literally state or do not state), rather than a historical-critical method (taking into consideration the human author's intention and the cultural and historical milieux of the text). Jehovah's Witnesses view the sixty-six books of the Bible as inspired by God and historically accurate. As a result of this literal exegesis of the scriptures, Jehovah's Witnesses find biblical support for pacifism; the practice of adult baptism by immersion; the practices of not saluting national flags and not celebrating birthdays or Christmas (because such celebrations are not mentioned or mandated in the Bible); a belief that the reign of God will be established on the earth, where people will live forever; and the belief that the number of the "spiritual sons of God" who will rule with Jesus Christ in heaven is limited to 144,000. The literal interpretation of the "Christian Greek Scriptures" (their official name for the New Testament) has led Jehovah's Witnesses to conclude that Jesus Christ is God's son, but is inferior to God and was the first of God's creations. This last set of beliefs about Jesus Christ technically places Jehovah's Witnesses outside of mainstream Christian denominations, which profess God as a trinity of "equal persons," including Jesus Christ as God incarnate.

A literal interpretation of the Bible helps to explain why, in 1945, the governing body of the Watchtower Bible and Tract Society determined that accepting blood or blood products for medical purposes violated the biblical word of God. Pertaining to blood, there are at least three scriptural passages that have great significance for Jehovah's Witness belief and practice. These passages are:

> Every moving animal that is alive may serve as food for you. As in the case of green vegetation, I do give it all to you. Only flesh with its soul—its blood—you must not eat (Gen. 9:3–4).
>
> As for any man of the house of Israel or some alien resident who is residing as an alien in their midst who eats any sort of blood, I shall certainly set my face against the soul that is eating the blood, and I shall indeed cut him off from among his people (Lev. 17:10).
>
> The holy spirit and we ourselves have favored adding no further burden to you, except these necessary things, to keep abstaining from things sacrificed to idols and from blood and from things strangled and from fornication (Acts 15:28).

Viewed as inspired by God and to be interpreted literally, these three scriptural texts forbid the eating or ingestion of blood. An important step in the reasoning and interpretive process for Jehovah's Witnesses is that the relatively recent medical practice of intravenous blood transfusion is seen as a way of nourishing or feeding the human body. With this understanding and perception of blood transfusions, a literal interpretation and application of the cited biblical texts becomes clear: Through God's inspired and literal word contained in the Bible, he has expressly forbidden the eating of blood, and, when applied to modern medical practice, this means that God has forbidden the nourishing of the human body with blood transfusions. This divine prohibition applies in all circumstances, including emergency and life-threatening situations. Jehovah's Witnesses who knowingly and willfully accept transfusions of blood or blood products violate God's commandment and disassociate themselves from the congregation of believers.

What Is Forbidden and Permitted

Because of medicine's increasing abilities and techniques to collect, store, dissect, develop, infuse, and salvage blood and blood-based products, numerous and specific questions about what is forbidden and permitted have arisen among Jehovah's Witnesses, as well as among healthcare professionals who treat them. For example, can a Jehovah's Witness accept the use of an intraoperative cell-saver technique or the administration of albumin, erythropoietin, bone marrow, stem cells, or clotting factors for hemophilia?

Jehovah's Witnesses are officially and specifically prohibited from receiving whole blood, packed red blood cells, white blood cells, plasma, and platelets. This explicit prohibition remains the same regardless of the source of the blood, that is, whether the donation is autologous (derived from the same individual) or donated by someone else. Once blood has left the body and the body's circulatory system, it cannot be transfused into a Jehovah's Witness patient. Some techniques and blood-based agents, however, are left to the discretion and conscience of the individual believer. One example is an intraoperative cell-saver procedure that involves salvaging blood from a surgical field (e.g., a body cavity), cleansing the blood, and then returning the blood to the patient. If during this process a continuous, closed circulation of the blood is maintained as it moves from the body of the patient through the tubing of the salvaging machine and then back into the body, this external circulatory process can be viewed as an extension of the body's own circulation system, consequently the procedure can be acceptable. Also left to the individual believer's conscience and decision are the use of agents derived from minor fractions of blood components, such as immune globulins, albumin, clotting factors for hemophilia, as well as bone marrow and stem cells.

Medical Management of Jehovah's Witnesses

With the exception of transfusions of blood and blood products, Jehovah's Witnesses do not have religious objections to any other medical treatment or procedure that promotes the patient's health. In fact, seeking medical treatment for disease and the promotion of health are seen as concrete ways for believers to respond appropriately to God's gift of life. Thus, as long as blood transfusions are not involved, and when medical necessity arises, Jehovah's Witnesses will seek solid organ transplantation, surgery (including coronary artery bypass grafting, dialysis, and various life-sustaining measures such as intubation and ventilatory support), and medically supplied nutrition and hydration.

When blood loss is a likely risk with an accompanying decrease of hematocrit, hemoglobin, and blood pressure (such as during many surgeries), Jehovah's Witnesses hope for and encourage the medical team to engage in a variety alternative medical and surgical methods that obviate the need for blood transfusions. These methods include limiting phlebotomies or using pediatric needles for blood draws; inducing hormonal suppression of menstruation; stimulating red-blood-cell production through administration of recombinant (synthetic) erythropoietin; utilizing proven and published techniques to reduce surgical blood loss (e.g., cooling a patient to lessen oxygen needs; electrocautery; using laparoscopic and minimally invasive instruments; administration of desmopressin, aprotinin, antifibrinolytics); or preventing shock (from inadequate blood flow to the body's peripheral tissues) by use of nonblood volume expanders such as saline solution, lactated Ringer's solution, and dextran.

To promote respect for their beliefs and help educate healthcare professionals, many Jehovah's Witness congregations and circuits have formed Hospital Liaison Committees to educate healthcare professionals and hospital administrators about the nuances of what is forbidden and permitted, according to Jehovah's Witness beliefs. Committee members have available current literature and bibliographies, usually from prestigious peer-reviewed clinical journals, that reference bloodless management and blood-substitute treatment techniques that have had successful outcomes.

Most of this medical reference material is also available from the Brooklyn headquarters. Hospital Liaison Committees also strives to identify physicians, especially surgeons and anesthesiologists, who are willing to treat Jehovah's Witness patients while respecting their beliefs about blood. Of special significance for Jehovah's Witnesses are hospitals and surgery centers that are willing to develop and advertise bloodless surgery programs (deCastro). Hospital Liaison Committees promote a five-step protocol addressed to healthcare professionals treating Jehovah's Witnesses:

1. Review nonblood medical alternatives and treat the patient without using homologous blood.
2. Consult with other doctors experienced in nonblood alternative management at the same facility.
3. Contact the local Hospital Liaison Committee for locating experienced and cooperative doctors at other facilities to consult on alternative care.
4. Transfer the patient, if necessary, to a cooperative doctor or facility before the patient's condition deteriorates.
5. In a rare situation, if the above steps have been exhausted and governmental or court intervention is deemed necessary, the patient, the parents, or the guardian should be notified as soon as possible of such intended action.

Ethical Evaluation and Analysis

In general, informed adult patients with decisional capacity have an ethically supported right to refuse medically recommended treatment, including treatment that is life-sustaining and death-preventing. This is true regardless of the patient's motive or rationale and whether the refusal is religiously based or not. The American Hospital Association's "Patient's Bill of Rights" echoes this ethical and legal consensus when it states: "The patient has a right to make decisions about the plan of care prior to and during the course of treatment and to refuse a recommended treatment or plan of care to the extent permitted by law and hospital policy" (Right # 3). Some ethical and legal limitations on this right have been argued when the adult refusing treatment has dependent minor children; that is, when there are *innocent third parties* who will be affected by the adult's refusal.

Thus, adult Jehovah's Witnesses with decisional capacity have the right to refuse blood transfusions, even in life-threatening situations. Although the recommended treatment of a blood transfusion can be presumed in most situations to be in the patient's best interests, a patient's right to self-determination (i.e., autonomy) and the corresponding norm of informed consent, ethically and legally "trump" a physician's or medical team's recommendations and perception of the patient's best interests.

This right to refuse can be extended to include patients who once had, but no longer have, decisional capacity, if such patients have indicated their wishes through an advance directive. In anticipation of such situations, many Jehovah's Witnesses sign and carry a specially prepared, wallet-size *medical directive/release* card indicating their wishes not to receive blood transfusions "even though physicians deem such vital to my health or life." In general, such an advance directive should be honored unless there is clear evidence that the patient revoked the advance directive or completed it when coerced or inadequately informed.

An adequate informed-consent process has great ethical significance for Jehovah's Witnesses' refusals of blood products. In the usual fashion for informed consent, the nature, purpose, risks, benefits, and alternatives associated with consenting to or refusing blood products should be explained to Jehovah's Witnesses. This proactive process is even more important prior to medical and surgical interventions that risk significant blood loss. Many hospitals and surgery centers have informed-consent forms that specifically address the use of blood transfusions. However, a form signed by a patient is less important than the conversation and education between physician and patient, which can be triggered by the presentation of a form to be signed.

Unless there has been an acute event or an emergency situation, there is usually time for physicians to present sensitively and clearly the likely outcomes should blood be needed and not provided, and for patients to be queried about their willingness, for each projected outcome, to consent to blood, blood products, agents partially derived from blood, and nonblood alternatives. Also, during such discussions, physicians should communicate their willingness (or unwillingness) to honor Jehovah's Witnesses' refusals of blood transfusions. Because physicians' professional integrity should be protected and respected as much as possible, the transfer of a Jehovah's Witness patient to another qualified physician, who is willing to limit treatment according to the patient's religious beliefs, might become necessary and is ethically supportable as long as continuity of the patient's care is preserved.

When Jehovah's Witness patients have lost decisional capacity and healthcare decisions must be made, the healthcare team may need to involve surrogate decision makers (often family members or someone specifically designated by the patient through a medical-power-of-attorney document). The surrogate should provide a substituted judgement on behalf of the patient; that is, consent to or refuse a specific treatment in accord with the patient's wishes, values, and beliefs. Providing a substituted judgement may be especially difficult for a surrogate who does not share the patient's beliefs and if the outcome could be death or serious debilitation (e.g., a stroke) if blood is not transfused.

When the interests of *innocent third parties* will be affected by a refusal of treatment, additional cautions and considerations are in order. Such situations occur when a pregnant woman refuses life-sustaining treatment, or when a parent's refusal of treatment will likely result in death or serious and permanent disability and any dependent children will subsequently be abandoned or lose parental support and nurturing. An analysis of the latter situation should include whether support is available from other family members or the community. In such instances, some courts have intervened in the decision process in favor of preserving life (*Raleigh-Fitkin Hospital v. Anderson; Werth v. Taylor*), while other courts have supported the patient's refusal (*Fosmire v. Nicoleau; Norwood Hospital v. Munoz; Stamford Hospital v. Vega*). Because neither a consistent ethical nor legal consensus exists for such *third party* circumstances, in actual cases of this kind professionals should seek the guidance and support of institutional ethics committees, hospital legal counsel, or the courts.

When the Patient Is a Child

Jehovah's Witnesses who are parents generally refuse to give permission for blood transfusions for their children when transfusions are needed. Members of healthcare teams usually experience such refusals as much more troublesome and problematic than when adult patients refuse recommended treatments for themselves. With treatment decisions involving children, it is usually not a situation of patient autonomy clashing with medical perception of best interests, but rather parental perception of best interests (based on parental religious beliefs) clashing with medical perception of best interests.

At least for younger children who have not achieved a level of cognitive and emotional development to make their own decisions, most ethicists and legal commentators echo the sentiments of the 1944 U. S. Supreme Court conclusion that, "Parents may be free to make martyrs of themselves.

But it does not follow [that] they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves" (*Prince v. Massachusetts*). Especially in life-threatening situations, there is ethical support (based primarily on a best interest standard) for providing needed blood transfusions for patients who have never had decisional capacity.

The American Academy of Pediatrics (AAP) supports such a stance: "The AAP … advocates that children, regardless of parental religious beliefs, deserve effective medical treatment when such treatment is likely to prevent substantial harm or suffering or death" (AAP, 1997). This position can be extended to include patients with severe mental retardation, regardless of chronological age. However, outside of life-threatening situations, and when nonblood alternatives have a reasonable likelihood of being effective, physicians should give serious consideration to honoring the parent's religious tenets that the child not be given transfusions. If a decision is made to seek a court order to permit blood transfusions, the parents should be informed about this decision before it is carried out.

More ethically complex are cases of adolescent Jehovah's Witness patients who have not reached the legal age of majority or adulthood (usually age 18), or who have not been declared emancipated minors by a court, and who refuse blood transfusions. Some of these adolescents may have the requisite cognitive skills to give an informed consent or refusal (Leikin; Weir; Weithorn). From an ethical perspective, healthcare professionals should use the same criteria for assessing decisional capacity (Grisso) and the same process of informed consent and information disclosure as is used for legal adults. Some courts in North America have affirmed this judgement, specifically if adolescent patients can demonstrate sufficient cognitive skills to consent to or refuse medical treatment (Robb).

Use of Resources

From one perspective, Jehovah's Witnesses could be accused of increasing medical expenses and the use of scarce medical resources because of their idiosyncratic beliefs. Although there have not been comprehensive studies comparing and calculating costs for medically managing Jehovah's Witness patients versus non–Jehovah's Witness patients with similar diseases, many physicians and hospitals caring for Jehovah's Witness patients could likely provide individual case reports demonstrating a greater use of resources for some specific patients. A few published reports have claimed an increase in expenses because the usual *standard of care* could not be followed due to patient wishes (Busuttil). As healthcare teams work for good medical outcomes while honoring patients' refusals of blood transfusions in some individual cases, there can be increases in hospital lengths-of-stay, occupancies of intensive-care beds, time in operating rooms, and costs for medications.

But from another perspective, Jehovah's Witnesses could argue that respect for their religious beliefs has occasioned discoveries and developments that conserve a scarce resource—blood products—while benefiting all patients. Jehovah's Witnesses can make the claim that their refusals of blood have accelerated research and the adoption of innovative practices that reduce, eliminate or substitute for the use of blood transfusions. Further, because transfusions of blood and blood products always involve some risk to recipients, any reduction of transfusion therapy by using safe and effective nonblood alternatives and techniques decreases potential medical risks for all patients.

Treating some Jehovah's Witnesses within the context of their beliefs about blood may indeed increase costs and the use of resources in comparison to the general population. But without sufficient comparative studies, such claims remain hypothetical. Even if it can be shown that Jehovah's Witness beliefs increase healthcare costs, would that be sufficient justification for either not honoring refusals of blood therapy or expecting Jehovah's Witnesses to contribute more financially for their healthcare (e.g., in the form of higher insurance premiums)? Such a conclusion seems to fail, based on fairness, until such time as all or most individual behaviors and decisions that increase demands on healthcare resources (e.g., smoking, routinely eating foods high in fat, not wearing seat belts) result in those individuals being either denied treatment or paying more for their healthcare as well.

Conclusion

In general, there is strong ethical and legal support for honoring Jehovah's Witnesses' informed refusals of blood transfusions. Some exceptions to this general principle do exist, however. Because persons can have varying degrees of commitment to religious beliefs, and because the Jehovah's Witness leadership leaves some issues for individual judgement and decision, physicians and healthcare professionals should explore the limits and desires for specific treatments with each Jehovah's Witness. For this patient population, as much as possible, safe and effective nonblood alternatives should be used to promote restoration of health and preserve life. Healthcare professionals and others do not need to agree with Jehovah's Witnesses' beliefs and biblical exegesis in order to show them respect, honor their religiously based refusals of transfusion therapy, and provide them with high-quality care.

MARTIN L. SMITH

SEE ALSO: *Authority in Religious Traditions; Autonomy; Children: Rights of Children; Competence; Coercion; Conscience; Conscience, Rights of; Infants*

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JUDAISM, BIOETHICS IN

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As a specific discipline, bioethics is as new to Judaism as it is to human culture in general. To be sure, every cultural tradition throughout history has developed various ethical norms or rules to govern the different areas of human action. But it is only with the great innovations in biomedical science and technology during the second half of the twentieth century that there has been a need for a distinct schematization of traditional rules, and even the formulation of new ones, for this increasingly complex area of human action.

Judaism is no exception to this general cultural phenomenon. Indeed, Jewish ethicists have been particularly eager to make a Jewish contribution to bioethics, not least of all because of the great interest Jews have always taken in medical practice throughout history, and because many Jewish scholars maintain that there is no area of human action, however unprecedented, to which the rules formulated in the Jewish tradition do not somehow apply. Furthermore, the increasingly cross-cultural context of bioethics gives Jewish ethicists a much larger audience of interested parties than they have had heretofore.

Origins and Development of Jewish Bioethics

Historically, Judaism has seen the normative authority of Jewish life, both communal and individual, as stemming from a twofold teaching (Torah): Scripture and Tradition, or the Written Torah and the Oral Torah. The Written Torah consists of the divinely mandated precepts of the first five books of the Hebrew Bible. The Oral Torah consists largely of the legislation of the rabbis of the Talmudic period (first century B.C.E. to the sixth century C.E.) along with a few ancient traditions (*halakhot*) accepted as having been revealed to Moses at Mount Sinai. Regarding many ethical (as opposed to ritual) norms, moreover, especially those dealing with basic human questions of life and death, Judaism has seen the Torah's commandments as binding on all humankind, at least in theory. This area of the law has been designated as *Noahide Law,* the descendants of Noah being the name for humankind. Since it has long been accepted that there cannot be a double standard differentiating between Jews and non-Jews in questions of life and death (*Sanhedrin* 59a; *Tosafot* s. v. "leika"), and since virtually all medical treatment and so much contemporary Jewish discussion of bioethical issues is conducted in the context of a pluralistic society, this universal aspect of Jewish law has become the most prevalent standard for the formulation of most Jewish views on the subject.

Scriptural law is subject to human interpretation, but it cannot be amended or repealed (Num. 15:23; Deut. 4:2; *Kiddushin* 29a; cf. *Sotah* 9.9) because it is taken to be the direct word of God. Because rabbinic law is considered human-made law only, although legislated by authority sanctioned by Scripture (*Shabbat* 23a), it has been much easier to change and adapt than scriptural law. Rabbinic legislation, at least in theory, admits of amendment and repeal (*Eduyot* 1.5), but since the demise of the *Sanhedrin* as the central Jewish legislative authority, reinterpretation of already existing norms has been the method of changing rabbinic law. Since the actual practical rules of any area of Jewish law—certainly those pertaining to bioethics—are much more rabbinic than scriptural, the authorized range for the exercise of human reason is the widest.

Within the immediate confines of the traditional Jewish community, the method of judgment employed in Jewish bioethics is not different from the method employed in any other area of Jewish law. The basic scriptural norm is located, its rabbinic elaborations are traced through the Talmud and related literature, its authoritative structure is determined, relevant precedents (if there are any) are culled from the vast literature of legal responsa by individual rabbinical authorities, and finally the person accepted by a community of Jews as their legal authority frequently seeks the counsel of learned colleagues. This process involves the ordering and application of rules to apply adequately to a case at hand, and occasionally the recognition of more basic principles behind the rules as well as procedures that direct their application. More and more frequently, in the cases posed by the new medical technology we see a greater role for principles. It is often much more difficult to find appropriate rules for the novel situations at hand, and principles must more directly guide the formulation of rather tenuous analogies from existing rules. Also, in the context of cross-cultural discussion of bioethical issues, the general guidance suggested by principles is sought much more than the governance of the rules of a singular tradition.

Theological and Moral Principles in Jewish Bioethics

A number of theological-moral principles operate in Jewish discussions of bioethics. The most prominent of these principles are God as creator, God as covenanter, the sanctity of human life, human benevolence, the authority of medical expertise, and the personal prerogatives of the patient.

GOD AS CREATOR. All the great Jewish theologians throughout history have emphasized that the first principle of Judaism is that God is the creator and Lord of the entire universe, who maintains its perpetual order (*ma*ʿ*aseh beresheet*), its "nature." Accordingly, God is considered to be the only possessor of absolute property rights. All creatures are the subjects of varying privileges granted by their divine creator. In accordance with its exalted status as the image of God, the human creature is given duties (*mitsvot;* Gen. 2:16) as well as the highest privileges (Gen. 1:26). However, whatever powers humans have are legitimate only when they are seen as from God for the sake of God, and not as the possessions of the individual or the community in any way. "Indeed, all lives are Mine" (Ezek. 18:4).

This principle is at the very heart of the differences between Jewish law and the secular norms based on the primacy of human autonomy or utility. This is especially apparent in the current intense debates concerning the beginning of human life in relation to abortion, and concerning the end of human life in relation to euthanasia. Arguments insisting upon a *right* to abortion or a *right* to euthanasia, be that *right* the individual's or the community's, essentially deny divine creatorship and lordship as the fundamental norm, which is contrary to what Judaism teaches. Therefore, one can see that the most intense debates in bioethics are quite often more about theological principles than ethical precepts as such.

GOD AS COVENANTER. God is not only the creator of the universe and its perpetual Lord but is also in intimate historical relationship with the people of Israel. This relationship is called the "covenant" (*berit*). According to Moses Maimonides (1135–1204) and other Jewish theologians, Christians and Muslims, who also see themselves as related to this covenantal God, share in some of this covenantal intimacy (*Mishneh Torah: Melakhim,* chap. 11, uncensored ed.). This theological principle impinges upon the main issues of bioethics because it largely determines the status of human personhood as the "image of God" (*tselem Elohim*), a term that seems to designate the essential human capacity for a direct personal relationship with God. Accordingly, human persons are not seen as being primarily defined by innate capacities such as intelligence or freedom of choice, because these qualities vary too much from person to person and are not possessed by everyone born into the human race. Thus, according to the first-century sage Ben Azzai, the most all-encompassing principle of the entire Torah is expressed in the verse "This is the book of the human generations" (Gen. 5:1; quoted in *Palestinian Talmud: Nedarim* 9.3/41c). This means that full personhood is gained solely by one's birth to human parents, and not by less comprehensive criteria based on such capacities as rationality or freedom of choice.

The principle of God as covenanter is also at the heart of the issue of care for the sick. If the sick have the privilege of making special claims upon those able to care for them, claims that translate into the duties of caretakers, then these privileges and duties are rooted in God's care for his creation, care that is epitomized by God's covenantal involvement with Israel. This is clearly seen in the role of prayer in the treatment of illness, both the special privilege of the prayers of the sick themselves (*Shabbat* 12b) and the duty of those who care for them to pray for them as well (*Nedarim* 40a). In fact, the Talmud interprets the scriptural command that the sufferer from the disease tsaraʿat (mistranslated as *leprosy*—but actually a skin disease with symptoms close to those of eczema or psoriasis) publicly declare himself "unclean! unclean!" (Lev. 13:45)—to be a cry to those hearing these words of anguish to pray for the sufferer (*Moʿed Qatan* 5a). In another Talmudic text this requirement is extended to include prayer for the plight of anyone suffering from any other illness of calamity (*Sotah* 32b). Those with whom God has covenanted must show genuine sympathy to one another. The extension of this sympathy is, finally, seen as reaching even to nonmembers of the covenant in the interest of peace and general goodwill (*Gittin* 61a).

THE SANCTITY OF HUMAN LIFE. The term *sanctity of human life* does not appear in the classical Jewish sources but is an accurate expression of the principle that "one human life is not pushed aside for another" (*Ohalot* 7.6; see also *Tosefta: Terumot* 7.20), that is, that one human life has no more inherent value than another, that the blood of one person "is not redder than someone else's" (*Pesahim* 25b; cf. *Sefer Hasidim,* ed. Parma, no. 252; Luria, *Yam shel Shlomoh: Baba Kama,* 8.59). The underlying assumption of the basic sanctity of each individual human life is expressed by the Mishnah: "Whoever saves even one human life, it is as if he saved an entire world" (*Sanhedrin* 4.5; *Palestinian Talmud: Sanhedrin* 4.5/22a).

However, this does not mean that the value of any human life is infinite. In certain cases Judaism demands martyrdom, especially when continued life requires that the God of Israel be denied (*Sanhedrin* 74a). Moreover, at times, priorities are assigned when only one life in a particular situation can be saved as opposed to all lives in that same situation being lost (*Horayot* 3.7–8; *Tosefta: Terumot* 7.20; *Baba Metsia* 62a; *Sanhedrin* 72b). It is in the realm of ritual practice that the sanctity of human life and the duty to rescue are paramount (*Yoma* 85b). Any doubt is to be resolved in favor of human life; thus the practice of any ritual act that endangers human life is proscribed (*Shabbat* 129a). The classic example of this is the rule that rescue efforts are to be conducted on the Sabbath or on the Day of Atonement, irrespective of whatever labors are involved, as long as there is any chance that human life might be saved (*Yoma* 85a). But once the death of the person endangered is ascertained, all ritual restraints are in effect once more (*Tosefta Shabbat* 17.19; *Shabbat* 30b, 151b).

The principle of the sanctity of human life can be seen most clearly operating in cases of nonviability, that is, when there is no reasonable expectation of survival. Thus a child born so defective as to be considered nonviable is still to be nursed by its mother (*Yevamot* 80b, *Rashi* and *Bach* thereto; also, *Tosefta*: *Ketubot* 5.5; *Tosefta*: *Niddah* 2.5), that is, not abandoned to die, as was the case in many ancient cultures. And a human life in the very last stages of its existence, in its death throes, is not to be extinguished on the assumption that death is inevitable (*Shabbat* 151b).

There is debate among later authorities as to what measures may or may not be taken to extend the death throes called goses (Isserles's note on *Shulhan Arukh: Yoreh Deʿah* 339.1; cf. *Bach* on Tur: *Yoreh Deʿah* 339). This debate anticipates current ones as to whether one can distinguish between active and passive euthanasia. Those authorities who argued that not extending the death agony automatically shortens the life of the patient would seem to support the view that no cogent distinction can be made in euthanasia: either one must permit it per se (as Judaism clearly does not) or one must prohibit it per se (as Judaism seemingly does). This is based on a rejection in the Talmud of any *double effect* rationale (*Shabbat* 75a).

However, the treatment of pain is something that may be done as an end in itself as long as it is not simultaneous with the actual death of the patient (*Avodah Zarah* 18a). Moreover, one is allowed to pray for the death of the patient in cases where agony is extreme and there is no real hope for recovery (*Ran* on *Nedarim* 40a re *Ketubot* 104a). Yet this is always an appeal for divine action and not an endorsement of humans acting in place of God. Even in cases of extreme suffering, the taking of human life is never to be the purpose of any intervention (*Avodah Zarah* 18a). Whereas a cure cannot always be effected, care is always mandated until the very end of human life. That is why, for example, a dying person is not to be left alone even when there is very little time left (*Shulhan Arukh: Yoreh De*ʿ*ah* 339.4).

HUMAN BENEVOLENCE. The duty to care for the sick, and to heal them whenever possible (*biqur holim,* literally, "visitation of the sick"), is derived from two different sets of biblical and rabbinic sources. The difference in the selection of the sources indicates two distinct approaches to the issue of medical treatment in general.

Maimonides, who was the prototypical rabbi-physician for later generations, categorized the specific duty to care for the sick as a rabbinically mandated act stemming from the general duty of benevolence commanded in Scripture: "You shall love your neighbor as yourself" (Lev. 19:18), which, undoubtedly basing himself on earlier rabbinic sources (*Shabbat* 31a; *Targum Jonathan* on Lev. 19:18), he paraphrased as "Everything you want others to do for you, you do" (Mishneh Torah: Evel 14.1). As for the duty actually to save a human life, Maimonides based this directly on the scripturally mandated act: "Do not stand idly by your neighbor's blood" (Lev. 19:16), that is, whoever can save a life and does not do so has violated a negative commandment (*Mishneh Torah: Rotseah* 1.13).

Finally, he located the specific duty to heal the sick by those competent to do so in the scriptural command concerning the duty to return lost property to its owner (Deut. 22:2). He reasoned, as the Talmud had earlier (*Sanhedrin* 73a), that if one is to return someone else's lost property, then certainly one is to return someone else's *lost body* to him or her—namely, the bodily function lost through illness or injury (*Mishnah Commentary: Nedarim* 4.4). All of this is quite consistent with Maimonides's high regard for the regularity of the natural order and the role of medicine as part of the general human attitude of respect for that order and cooperation with its inherent teleology (*Guide of the Perplexed,* 2.40). Any special role for medicine, by separating it from the commandment of general benevolence, might very well lead to its being considered a magical function. This would contradict the essentially scientific role of medicine insisted on by Maimonides (*Mishnah Commentary: Pesahim* 4.10).

Many commentators wondered why Maimonides never quoted the most direct Talmudic source for the duty to heal the sick: "It was taught in the School of Rabbi Ishmael that from the words of Scripture 'he shall surely provide for his healing' (Exod. 21:19) we derive permission for a physician to heal" (*Baba Kama* 85a). Perhaps he did not think that the verse itself supported this inference, since the text refers directly to the duty of an assailant to pay the medical bills of his or her victim, not the duty of the physician to heal. Also, the use of the word "permission" (*reshut*) might have seemed to him too weak to ground a duty, since it seems only to allow an option.

Nevertheless, Moses Nahmanides (1194–1270) does use this Talmudic text, reflecting his entirely different approach to the practice of medicine. He sees this use of the word "permission" as being an answer to those who might say that medicine is an unwarranted interference with divine healing. Just as a judge is not interfering with God's dispensing justice, he argued, so is a physician not interfering with God's dispensing healing. Both judge and physician have the exalted role of participating directly in acts that are seen as essentially divine (*Torat Ha'Adam,* ed. Chavel, 41–43). Both roles are forms of *imitatio dei*. This follows from Nahmanides's emphasis that medicine is needed by those in less than a full state of grace, who are within the confines of nature alone, and that the truly righteous will not need any such human intervention, being assured of direct divine attention (*Torah Commentary:* Lev. 26:11).

Nahmanides's connection of medical treatment with what the rabbis called "following after God's attributes" (*middotav*) has a precedent in the rabbinic location of the duty to attend to the sick in God's visitation of Abraham immediately after his circumcision (*Sotah* 14a re Gen. 18:1; also *Baba Metsia* 30b re Exod. 18:20; 86b). Indeed, attending to the needs of the sick has been seen in Jewish tradition as being more than general benevolence; it is an act having even mystical connotations. This appears in the many biblical texts that see illness and healing as specifically supernatural interventions (e.g., Gen. 18:14, 25:21–22; Exod. 15:26; Lev. 26:16; Num. 5:21; Deut. 28:20–22, 32:39; 2 Kings 5:7–8, 20:1–5; Jer. 17:14; Ps. 103:1–3; 2 Chron. 16:12). The rabbis, too, saw any affliction as being God's special visitation that calls for a special human response (*Berakhot* 5a re Isa. 53:10; cf. *Shabbat* 55a–b).

PROTECTION OF THE HUMAN CONDITION. The human condition is always to be the subject of care, and its infirmities are to be cured if possible. The question of the relation between care and cure is especially acute today, when the new means to extend life provided by advances in medical technology are seen by many as simultaneously compromising care by extending the agony of the terminally ill. Contemporary Jewish bioethicists certainly struggle with this problem as much as any other group. One can find no sufficient body of rules on this subject in the tradition, because the death agony in the past was seen as being quite brief (*Mordecai: Mo*ᶜ*ed Qatan* no. 864). There do not seem to be any rules at hand for dealing with persons in irreversible comas lasting weeks, months, or even years.

Some precedent for this dilemma, however, can be found in an eighteenth-century responsum by Rabbi Jacob Reischer. He asked whether one may risk one's life by undergoing surgery that has a chance to prolong it, but also a chance to terminate it sooner than would be the case if nothing were done and nature were left to run its course. Reischer permitted such surgery if there was reasonable consensus of medical opinion that there was a good chance for success (*Shevut Ya*ᶜ*agov: Yoreh De*ᶜ*ah* no. 75). But without this consensus, it seems that the patient might have the right to refuse what is in effect an unwarranted invasion of his or her body.

The most immediate phenomenon that medicine treats is pain. Whereas the patient knows he or she is alive by inference from consciousness, one is immediately conscious of the presence of pain. Pain is a primary datum for all sentient beings (Maimonides, *Guide of the Perplexed,* 3.48). Jewish tradition mandates the treatment of unbearable pain in much the same way it mandates the treatment of mortal danger to human life. This can be seen by looking at the laws pertaining to the Sabbath, which is the most important religious observance in Judaism (*Palestinian Talmud: Nedarim* 3.9/38b). Just as the Sabbath is to be violated in case of a threat to human life (*sakkanat nefesh*), so may medical procedures normally prohibited on the Sabbath be performed when they can alleviate bodily pain. Such procedures as lancing a painful boil (*Shabbat* 107a; *Tosafot* s.v. "u-memai") and a woman removing by hand milk from her engorged breasts (*Shabbat* 135a; *Tosafot* s.v. "mipnei") are mentioned in the Talmud.

The great public-health problem of AIDS entails another challenge to Jewish tradition and its ability to rule in the interest of protecting the human condition of all sufferers from any disease whatsoever. That challenge arises when it must be determined what is to be done with those who have contracted AIDS through acts that the normative tradition regards as sinful. Most AIDS sufferers have contracted the disease through male homosexual acts and intravenous drug use. These acts are proscribed by Scripture and Jewish tradition (Lev. 18:22; Maimonides, *Mishneh Torah: Ishut,* 1.4; *De*ᶜ*ot* 4.1). Furthermore, one Talmudic text minimally prescribes neglect for those who are seen to be "habitual sinners" (*Avodah Zarah* 26b). Nevertheless, the important twentieth-century authority Rabbi Abraham Isaiah Karelitz contended that this harsh law no longer applies because its intention is to dissuade sinners, and in this day and age such harshness would be counterproductive (*Hazon Ish: Yoreh De*ᶜ*ah* sec. 2). His opinion has rarely been contested, for it is not unprecedented (*Teshuvot Ha-Rosh* 17.1). This legal opinion is important because it removes the one main impediment in the tradition for treating AIDS patients with the same concern as those suffering from any illness not contracted through acts the tradition considers illicit.

MEDICAL EXPERTISE. Jewish tradition has long recognized that a trained medical profession is a requirement of a humanly sufficient society. This can be seen in the Talmud's ruling (*Sanhedrin* 17b; cf. *Baba Batra* 21a; *Bach* on *Tur: Hoshen Mishpat* 156) that no educated Jew should live in a locality where there is no physician (*rofe*). Because of this, members of the medical profession have special duties and special privileges connected with these duties.

The first duty of medical professionals is to attend to whoever requires their attention. The centrality of this duty is seen in the interpretation by *Rashi*, the great eleventh-century commentator on the Bible and the Talmud, of the rather bizarre statement in the *Mishnah* that "the best of the physicians are destined for hell" (*Kiddushin* 4.14). Rashi takes this to be an indictment of persons who are physicians rather than of the institution of medicine as such (Nahmanides, *Torat Ha'Adam,* ed. Chavel, 43). He emphasizes the frequent carelessness and arrogance of physicians, and that they often refuse to treat the poor. This final indictment presupposes that lack of funds should not be an impediment to a person's right to medical treatment (*Tur: Yoreh De*ᶜ*ah* 336; see also *Ketubot* 67b re Deut. 15:8).

Medical practitioners are considered to be "experts" (*beqi'im*), and thus have a professional status (*Yoma* 8.5). Hence they are to be publicly licensed (*Avodah Zarah* 26b–27a). Publicly licensed medical professionals are exempt from paying damages to their patients unless it can be proven that they were grossly negligent or actually malicious in performing their medical duties (*Tosefta*: *Baba Kama* 9.11, 6.17; *Gittin* 3.8). Based on the analogy between physicians and judges, Nahmanides (*Torat Ha'Adam,* ed. Chavel, 41) sees the basis of this unusual dispensation from civil and even criminal liability in the Talmud's acceptance of the inherent subjectivity of judgment in even the most precise human activities: "The judge only has what his eyes see" (*Sanhedrin* 6b). However, this dispensation applies only to licensed personnel and does not extend to unlicensed personnel, even if they are otherwise "expert" (*Sanhedrin* 44).

Because medical professionals are engaged in an activity commanded by the Torah (*mitsvah*), they are not to be paid directly for their services because no one is to receive direct monetary benefit for the performance of a commandment (*Sanhedrin* 44 re *Bekhorot* 29a; see also *Rosh Hashanah* 28a). In this respect they are like Torah scholars, who are to study and teach the Torah for its own sake and not for the sake of any monetary benefit (*Avot* 4.5; *Nedarim* 37a). Nevertheless, based on this analogy, one cannot be expected regularly to deplete his or her own income when benefiting someone else. If this were the case, only those of independent wealth could possibly function either as scholars or as physicians, or in any other necessary communal function. For this reason, then, both scholars and medical personnel, being deemed necessary for a well-functioning Jewish community, are to be paid, not for what they actually do but for what they do not do—in other words, what they would be paid if they were making a living doing something else. This legal fiction is called "payment for idleness" (*sekhar betalah*).

Medical personnel are exposed to the danger of contagion in treating persons suffering from diseases. The question arises of how much danger they are required to expose themselves to in the course of their work, and how much danger is considered to be above and beyond the call of duty. This question has become especially acute today with the proliferation of a number of highly contagious diseases, such as hepatitis B.

In cases of clear and direct danger to one's own life, Jewish tradition mandates the priority of one's own life (*Baba Metsia* 62a re Lev. 25:36) irrespective of whether one is a layperson or a professional. Acts above and beyond the call of duty are considered forms of supererogatory piety. Such acts cannot be seen as being derived from a universal rule applicable to everyone and anyone, however meritorious they might be to the person performing them (*Palestinian Talmud: Terumot* 8.4/46b). However, the real moral problem arises in cases where there is possible danger (*safeq sakkanah*) to those involved in treating the sick. There is a passage in the Talmud that states, "When there is a plague in the city, gather up your legs" (*Baba Kama* 60b re Isa. 26:20; Deut. 32:25), which implies that one should save oneself in the face of possible danger.

Nevertheless, the sixteenth-century commentator Rabbi Solomon Luria argued that in the absence of clear and direct danger to oneself, one ought to remain in the city if one is able to save other lives there. He also indicates that those who had already suffered from "the plague" (he probably meant smallpox) were in no danger of further recurrence and so should remain in the city to help others in distress (*Yam shel Shlomoh: Baba Kama* 6.26). Earlier, Rabbi Joseph Karo (1488–1575) had ruled that one was to expose oneself to possible danger if this enabled one to save other human lives (*Kesef Mishneh* on Maimonides, *Mishneh Torah: Rotseah* 1.14; *Bet Yosef* on *Tur: Hoshen Mishpat* 426; cf. Rabbi David ibn Zimra, *Teshuvot Ha-Radbaz* 3, no. 627). Of course, the difference between certain possible danger can be decided only on an ad hoc basis. Nevertheless, the distinction must always be kept in mind, that is, one can rule neither that healthcare personnel must treat every patient nor that they may absolve themselves from treating any patient whom they consider at all dangerous to their well-being.

Medical professionals are to keep abreast of scientific developments that affect their ability to treat patients. Along these lines, the tenth-century authority Sherira Gaon argued that the medical opinions of the rabbis of the Talmud, unlike their legal opinions, had no inherent value and should be accepted or rejected solely on the basis of whether they are actually effective (Jakobovits). Maimonides made the same point two centuries later (*Mishnah Commentary: Yoma* 8.4). In cases where human viability is to be determined, Maimonides ruled that current medical opinion is the criterion to rely on (*Mishneh Torah: Rotseah* 2.8; cf. *Shehitah* 10.13). As in all scientific questions, it is irrelevant whether those offering the accepted opinion are Jews (*Pesahim* 94b; Maimonides, *Shemonah Peraqim,* intro.).

However, other authorities were more conservative in their treatment of the medical counsels of the rabbis of the Talmud. Some of them held that the cures prescribed by the Talmud are ineffective in later times because human nature has changed significantly (*Moʿed Qatan* 11a; *Tosafot* s.v. "kavra"; Isserles's note on *Shulhan Arukh: Even HaʿEzer* 156.4). This view denies that earlier sages were deficient in any knowledge whatsoever, a point in keeping with the general rabbinic tendency to consider past sages always to have been wiser than present sages (*Shabbat* 112b). Thus, present sages are taken to be incapable of making some of the fine scientific distinctions that were made by past sages in medical issues pertaining to the law (Isserles's note on *Shulhan Arukh: Orah Hayyim* 330.5).

Nevertheless, whether one accepts changed medical practice on the more radical grounds suggested by Sherira Gaon and Maimonides, or on the more conservative grounds suggested by the tosafists (medieval Franco-German glossators on the Talmud) the Isserles, the fact is that no Jewish authority sees the medical remedies from the Talmud or any other classical source as being valid in the present. This has enabled the most religiously traditional Jewish medical professionals to take advantage of all the current and future advances in medical technology.

PERSONAL PREROGATIVES OF THE PATIENT. Current bioethics has stressed the personal prerogatives of those who are ill so that they can take a more active and responsible role in their own treatment and not simply be the passive *patients* of medical professionals. Most advocates of patient activism in medical treatment have looked to the modern principle of autonomy for grounding—namely, that human individuals are essentially their own masters. Clearly, the theocentric Jewish tradition does not underwrite autonomy in this strong sense of the term. However, it does supply the basis for allowing patients to take an active role for other reasons.

Pain, for example, is to be treated immediately, and the patient is considered the final authority in determining just how much pain he or she can stand, even if that personal determination contradicts expert opinion. It is assumed that the person is the best judge of his or her own condition at this most elementary level of experience (*Yoma* 83a re Prov. 14:10; see also *Baba Kama* 8.1). This judgment by the suffering person can exempt that person from the same ritual obligations (such as fasting) as an expert's judgment concerning a life-threatening condition can. Unbearable pain is considered worse than death, and to escape it, anything short of direct killing is exonerated (*Ketubot* 33a; *Shir Ha-Shirim Rabbah* 2.18; Rabbi Tsvi Hirsch Chajes, *Tiferet Yisrael,* beg.).

A second personal prerogative of the patient is the right to be told the exact nature of his or her illness and the opinion of the experts about whether death is imminent. Thus the Talmud rules that when it is determined that one's death is imminent, one is to be told so that there may still be time for the patient to offer the deathbed confession known as *vidui* (*Shabbat* 32a). This is considered extremely important because whether one dies in a state of repentance could very well affect whether one merits the life of the world to come (*Sanhedrin* 6.2). If the life in this world is considered a preparation for the unending life of the world to come (*Avot* 4.16), and if no one but the person himself or herself can make the proper preparation, then it follows that one may not be kept in ignorance about the gravity of one's condition. Only persons considered too emotionally unstable to be able to make proper use of this information are to be spared (Nahmanides, *Torat Ha'Adam,* ed. Chavel, 46).

The Stages of Human Life

Judaism is concerned with the human condition from conception to death. Especially at the edges of life, where there is much public dispute, Jewish teachings have been very much in the forefront of current debate.

ABORTION. The abortion debate has usually centered on the question of when human personhood begins. Those on the *pro-life* side of the issue argue that human personhood begins at conception, and abortion is therefore murder. Those on the *pro-choice* side of the issue argue that human personhood begins at birth, and abortion is therefore not murder and ought to be the option of the individual pregnant woman.

In Jewish tradition there seem to be two differing views as to when human personhood begins. One view (*Sanhedrin* 57b re Gen. 9:6; see also *Sanhedrin* 91b re Job 10:12) is that it begins at conception; another view (*Ohalot* 7.6; *Sanhedrin* 72b; *Rashi* s.v. "yatsa rosho") is that it begins at birth. Nevertheless, these views are more statements of principle than actual rules. Rules are not directly derived from principles in Jewish law (*Baba Batra* 130b). Instead, principles are formulated to explain rules, coordinate them with other rules, and guide their application. Therefore, one should not automatically deduce from principles defining human personhood just what the rule concerning abortion is to be.

The rule proscribes abortion unless there is a threat to the life or health of the mother. Those who hold that personhood begins at conception thus see abortion as being akin to murder (although, on technical legal grounds, not literally murder that is liable for capital punishment; see *Niddah* 5.3; *Niddah* 44b re Lev. 24:17). They would tend to be more conservative in judging what constitutes a threat to the life or health of the mother. Yet even they would judge some abortions (however few) to be mandated. Those who hold that personhood begins at birth, and who are thus likely to be more liberal in judging just what constitutes a threat to the mother's life or health, still hold that abortion is usually proscribed because even fetal life has enough rights of its own (*Yoma* 82a; *Rashi* s.v. "ubar"). It may not be destroyed unless it is a threat (*rodef*) to the mother's life or health. Even assuming that the fetus is still considered part of the mother's body in utero (*Sanhedrin* 80b) does not lead to permission for elective abortion because self-mutilation is proscribed (*Baba Kama* 91b).

Hence traditionalist authorities, however they might view the actual beginnings of human personhood in principle, all regard abortion as generally proscribed, and permitted only under specific conditions. Their practical debates all center on the interpretation of the exceptions to the general proscription of abortion. In that sense, the more conservative authorities are no more absolutely *pro-life* than the more liberal authorities are absolutely *pro-choice.* In fact, abortion is not an option at all. Either it is proscribed in most cases, or it is prescribed in some exceptional cases. Nonetheless, less traditionalist Jewish feminists have argued that the whole issue of abortion must be reconsidered inasmuch as it most directly affects women, and women's voices have been absent from the legal debates about it in the Jewish community heretofore (see Davis).

DEFINITION OF DEATH. The question of precisely when human life ends is an issue of much current debate among contemporary Jewish bioethicists. Some of the more conservatively inclined have insisted that the traditional criteria for determining death be literally interpreted: the cessation of spontaneous reflexes, heartbeat, and breath (*Yoma* 85a; Teshuvot Hatam Sofer: *Yoreh De*ʿ*ah* no. 338). Yet other Jewish bioethicists, more liberally inclined, or more influenced by current scientific trends, have argued that *brain death* can constitute a ground for taking a patient off a respirator, inasmuch as breathing in this case is not being done by the patient, but by a machine (Task Force on Death and Dying). In fact, not doing this might constitute a violation of Jewish law, the prohibition against leaving the dead unburied (*Sanhedrin* 46b re Deut. 21:23). However, the motive behind this innovation, whether stated or not, is that the interpreters of Jewish law must accept growing medical consensus on any major issue if their rulings are to be taken seriously in the general society, where even the most pious Jews receive their medical treatment.

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SEE ALSO: *Abortion, Religious Traditions: Jewish Perspectives; Authority in Religious Traditions; Christianity, Bioethics in; Death, Definition and Determination of: Philosophical and Theological Perspectives; Death: Western Religious Thought; Eugenics: History of; Eugenics and Religious Law: Judaism; Genetics and Racial Minorities; Holocaust; Islam, Bioethics in; Medical Ethics, History of, Near and Middle East: Israel; Population Ethics, Religious Traditions: Jewish Perspectives; Research, Unethical; Women, Historical and Cross-Cultural Perspectives*

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JUSTICE

• • •

At some time or another, virtually all of us become involved in disputes about justice. Sometimes our involvement in such disputes is rooted in the fact that we believe ourselves to be victims of some form of injustice; sometimes our involvement is rooted in the fact that others believe us to be the perpetrators or at least the beneficiaries of some form of injustice affecting them. Sometimes the injustice at issue seems to require for its elimination a drastic reform, or even a revolutionary change in the political system. Sometimes it seems to require only some electoral pressure or administrative decision, as may be required in ending a war. Whatever the origin and whatever the practical effect, such disputes about justice are difficult to avoid, especially when one is dealing with issues, like the distribution of income or healthcare resources, that have widespread social effects.

Reasonable resolutions of such disputes require a critical evaluation of the alternative conceptions of justice available to us. In philosophical debate at the end of the twentieth century, five major conceptions of justice are defended:

(1) a libertarian conception, which takes liberty to be the ultimate political ideal;
(2) a socialist conception, which takes equality to be the ultimate political ideal;
(3) a welfare liberal conception, which takes contractual fairness or maximal utility to be the ultimate political ideal;
(4) a communitarian conception, which takes the common good to be the ultimate political ideal; and
(5) a feminist conception, which takes a gender-free society to be the ultimate political ideal.

All these conceptions of justice have certain features in common. Each regards its requirements as belonging to the domain of obligation rather than to the domain of charity; they simply disagree about where to draw the line between these two domains. Each is also concerned with giving people what they deserve or should rightfully possess; they simply disagree about what it is that people deserve or rightfully possess. These common features constitute a generally accepted core definition of justice. What we need to do, however, is examine the aspects of each of these conceptions of justice over which there is serious disagreement in order to determine which conception, if any, is most defensible.

Libertarian Justice

Libertarians frequently cite the work of Friedrich A. Hayek, particularly *The Constitution of Liberty* (1960), as an intellectual source of their view. Hayek argues that the libertarian ideal of liberty requires “equality before the law” and “reward according to market value,” but not “substantial equality” or “reward according to merit.” Hayek further argues that the inequalities due to upbringing, inheritance, and education that are permitted by an ideal of liberty actually tend to benefit society as a whole.

In basic accord with Hayek, contemporary libertarians define “liberty” as “the state of being unconstrained by other persons from doing what one wants.” Libertarians go on to characterize their moral and political ideal as requiring that each person have the greatest amount of liberty commensurate with the same liberty for all. From this ideal, libertarians claim that a number of more specific requirements—in particular a right to life; a right to freedom of speech, press, and assembly; and a right to property—can be derived.

The libertarians’ right to life is not a right to receive from others the goods and resources necessary for preserving one’s life; it is simply a right not to be killed. So understood, the right to life is not a right to receive welfare. In fact, there are no welfare rights in the libertarian view. Accordingly, the libertarian’s understanding of the right to property is not a right to receive from others the goods and resources necessary for one’s welfare but, rather, a right to acquire goods and resources either by initial acquisition or by voluntary agreement.

By defending rights such as these, libertarians can support only a limited role for government. That role is simply to prevent and punish initial acts of coercion—the only wrongful acts for libertarians.

Libertarians do not deny that it is a good thing for people to have sufficient goods and resources to meet their basic nutritional needs and basic healthcare needs, but they do deny that government has a duty to provide for such needs. Some good things, such as the provision of welfare and healthcare to the needy, are requirements of charity rather than justice, libertarians claim. Accordingly, failure to make such provisions is neither blameworthy nor punishable.

A basic difficulty with the libertarian's conception of justice is the claim that rights to life and property, as the libertarian understands these rights, derive from an ideal of liberty. Why should we think that an ideal of liberty requires a right to life and a right to property that excludes a right to welfare? Surely it would seem that a right to property, as the libertarian understands it, might well justify a rich person's depriving a poor person of the liberty to acquire the goods and resources necessary for meeting basic nutritional needs. How, then, could we appeal to an ideal of liberty to justify such a deprivation of liberty? Surely we could not claim that such a deprivation is justified for the sake of preserving a rich person's freedom to use the goods and resources he or she possesses to meet luxury needs. By any neutral assessment, it would seem that the liberty of the deserving poor not to be interfered with when taking from the surplus possessions of the rich what they require to meet their basic needs would have priority over the liberty of the rich not to be interfered with when using their surplus possessions to meet their luxury needs. But if this is the case, a right to welfare—and possibly a right to equal opportunity as well—would be grounded in the libertarian's own ideal of liberty.

Socialist Justice

In contrast with libertarians, socialists take equality to be the ultimate political ideal. In the *Communist Manifesto* (1848), Karl Marx and Friedrich Engels maintained that the abolition of bourgeois property and bourgeois family structure is a necessary first requirement for building a society that accords with the political ideal of equality. In the *Critique of the Gotha Programme* (1891), Marx provided a much more positive account of what is required to build a society based on the political ideal of equality. In such a society, Marx claimed, the distribution of social goods must conform, at least initially, to the principle "from each according to his ability to each according to his contribution." But when the highest stage of communist society has been reached, Marx added, distribution will conform to the principle "from each according to his ability to each according to his need."

At first hearing, this conception might sound ridiculous to someone brought up in a capitalist society. The obvious objection is, how can you get people to contribute according to their ability if income is distributed on the basis of their needs and not on the basis of their contributions?

The answer, according to a socialist conception of justice, is to make the work that must be done in a society as enjoyable, in itself, as possible. As a result, people will want to do the work they are capable of doing because they find it intrinsically rewarding. For a start, socialists might try to get people to accept currently existing intrinsically rewarding jobs at lower salaries—top executives, for example, to work for $300,000 rather than $900,000 a year. Yet ultimately, socialists hope to make all jobs as rewarding as possible, so that after people are no longer working primarily for external rewards while making their best contributions to society, distribution can proceed on the basis of need.

Socialists propose to implement their ideal of equality by giving workers democratic control over the workplace. They believe that if workers have more to say about how they do their work, they will find their work intrinsically more rewarding. As a consequence, they will be more motivated to work, because their work itself will be meeting their needs. Socialists believe that extending democracy to the workplace will necessarily lead to socialization of the means of production and the end of private property. Socialists, of course, do not deny that civil disobedience or even revolutionary action may be needed to overcome opposition to extending democracy to the workplace.

However, even with democratic control of the workplace, some jobs, such as collecting garbage or changing bedpans, probably cannot be made intrinsically rewarding. Socialists propose to divide such jobs up in some equitable manner. Some people might, for example, collect garbage one day per week and then work at a more rewarding job for the rest of the week. Others would change bedpans or do some other menial work for one day per week and then work at a more rewarding job the other days of the week. Socialists believe that by making jobs intrinsically as rewarding as possible, in part through democratic control of the workplace and an equitable assignment of unrewarding tasks, people will contribute according to their ability even when distribution proceeds according to need.

Another difficulty raised concerning the socialist conception of justice is in the proclaimed necessity of abolishing private property and socializing the means of production. It seems perfectly possible to give workers more control over their workplace while the means of production remain privately owned. Of course, private ownership would have a somewhat different character in a society with democratic control of the workplace, but it need not cease to be private ownership. After all, private ownership would also have a somewhat different character in a society where private holdings, and hence bargaining power, were distributed more equally than they are in most capitalist societies, yet it would not cease to be private ownership. Accordingly, we could imagine a society where the means of production are privately owned but where—because ownership is so widely dispersed throughout the society and because of the degree of democratic control of the workplace—many of the criticisms socialists make of existing capitalist societies would no longer apply.

Welfare Liberal Justice: The Contractarian Perspective

Finding merit in both the libertarian's ideal of liberty and the socialist's ideal of equality, welfare liberals attempt to combine both liberty and equality into one political ideal that can be characterized as contractual fairness or maximal utility.

A classic example of the contractual approach to welfare liberal justice is found in the political works of Immanuel Kant, who claimed that a civil state ought to be founded on an original contract satisfying the requirements of freedom (the freedom to seek happiness in whatever way one sees fit as long as one does not infringe upon the freedom of others to pursue a similar end), equality (the equal right of each person to restrict others from using his or her freedom in ways that deny equal freedom to all), and independence (which is necessarily presupposed for each person by the free agreement of the original contract).

According to Kant, the original contract, which ought to be the foundation of every civil state, does not have to "actually exist as a fact." It suffices that the laws of a civil state are such that people would agree to them under conditions in which the requirements of freedom, equality, and independence obtain. Laws that accord with this original contract would then, Kant claimed, give all members of society the right to reach any degree of rank that they could earn through their labor, industry, and good fortune. Thus, the equality demanded by the original contract would not, in Kant's view, exclude a considerable amount of economic liberty.

The Kantian ideal of a hypothetical contract as the moral foundation for a welfare liberal conception of justice has been further developed by John Rawls in *A Theory of Justice* (1971). Rawls, like Kant, argues that principles of justice are those that free and rational persons who are concerned to advance their own interests would accept in an initial position of equality. Yet Rawls goes beyond Kant by interpreting the conditions of his "original position" to explicitly require a "veil of ignorance." This veil of ignorance, Rawls claims, has the effect of depriving persons in the original position of the knowledge they would need to advance their own interests in ways that are morally arbitrary.

According to Rawls, the principles of justice that would be derived in the original position are the following: (1) Special conception of justice, involving (a) A principle of equal political liberty; (b) A principle of equal opportunity; and (c) A principle requiring that the distribution of economic goods work to the greatest advantage of the least advantaged. (2) General conception of justice: a principle requiring that the distribution of all social goods work to the greatest advantage of the least advantaged.

The general conception of justice differs from the special conception of justice by allowing trade-offs between political liberty and other social goods. According to Rawls, persons in the original position would want the special conception of justice to be applied in place of the general conception of justice whenever social conditions allow all representative persons to benefit from the exercise of their political liberties.

Rawls holds that these principles of justice would be chosen in the original position because persons so situated would find it reasonable to follow the conservative dictates of the "maximin strategy" and maximize the minimum, thereby securing for themselves the highest minimum payoff.

Rawls's defense of a welfare liberal conception of justice has been challenged in a variety of ways. Some critics have endorsed Rawls's contractual approach while disagreeing with him over what principles of justice would be derived from it. These critics usually attempt to undermine the use of a maximum strategy in the original position. Other critics, however, have found fault with the contractual approach itself. Libertarians, for example, have challenged the moral adequacy of the very ideal of contractual fairness because they claim that it conflicts with their ideal of liberty.

This second challenge to the ideal of contractual fairness is potentially the more damaging because, if valid, it would force its supporters to embrace some other political ideal. This challenge, however, would fail if it were shown that the libertarian's own ideal of liberty, when correctly interpreted, leads to much the same practical requirements as are usually associated with the welfare liberal ideal of contractual fairness.

Welfare Liberal Justice: The Utilitarian Perspective

One way to avoid the challenges that have been directed at a contractarian defense of welfare liberal justice is to find some alternative way of defending it. Historically, utilitarianism has been thought to provide such an alternative defense. It has been claimed that the requirements of a welfare liberal conception of justice can be derived from considerations of utility in such a way that following these requirements will result in the maximization of total happiness or satisfaction in society. The best-known classical defense of this utilitarian approach is certainly that presented by John Stuart Mill in *Utilitarianism* (1861).

In Chapter 5 of this work, Mill surveyed various types of actions and situations that are ordinarily described as just or unjust and concluded that justice simply denotes a certain class of fundamental rules, the adherence to which is essential for maximizing social utility. Thus Mill rejected the idea that justice and social utility are ultimately distinct ideals, maintaining instead that justice is in fact derivable from the ideal of social utility.

Nevertheless, a serious problem remains for the utilitarian defense of welfare liberal justice. There would appear to be ways of maximizing overall social utility that do injustice to particular individuals. Think of the Roman practice of throwing Christians to the lions for the enjoyment of all those in the Colosseum. Did this unjust practice not maximize overall social utility?

John Rawls (1971) makes the same point somewhat differently. He criticizes utilitarianism for regarding society as a whole as if it were just one person, and thereby treating the desires and satisfactions of separate persons as if they were the desires and satisfactions of just one person. In this way, Rawls claims, utilitarianism fails to preserve the distinction between persons. But is Rawls right? It may well be that a proper assessment of the relative merits of the contractual and utilitarian approaches to welfare liberal justice will turn on this very issue.

Communitarian Justice

Another prominent political ideal defended by contemporary philosophers is the communitarian ideal of the common good. Many contemporary defenders of a communitarian conception of justice regard their conception as rooted in Aristotelian moral theory. In the *Nicomachean Ethics* (332 B.C.E.), Aristotle distinguished between different varieties of justice. He first distinguished between justice as the whole of virtue and justice as a particular part of virtue. In the former sense, justice is understood as what is lawful, and the just person is equivalent to the moral person. In the latter sense, justice is understood as what is fair or equal, and the just person is the one who takes only a proper share. Aristotle focused his discussion on justice in the latter sense, which further divides into distributive justice, corrective justice, and justice in exchange. Each of these varieties of justice can be understood to be concerned with achieving equality. For distributive justice, it is equality between equals; for corrective justice, it is equality between punishment and the crime; and for justice in exchange, it is equality between whatever goods are exchanged. Aristotle also claimed that justice has both its natural and conventional aspects: this twofold character of justice seems to be behind his discussion of equity, in which equity, a natural standard, is described as a corrective to legal justice, a conventional standard.

Few of the distinctions Aristotle made seem tied to the acceptance of any particular conception of justice. One could, for example, accept the view that justice requires formal equality, but then specify the equality that is required in different ways. Even the ideal of justice as giving people what they deserve, which has its roots in Aristotle's account of distributive justice, is also subject to various interpretations. An analysis of the concept of desert would show that there is no conceptual difficulty with claiming, for example, that everyone deserves to have his or her needs satisfied or that everyone deserves an equal share of the goods distributed by society. Consequently, Aristotle's account is helpful primarily for clarifying the distinctions belonging to the concept of justice that can be made without committing oneself to any particular conception of justice.

Yet rather than draw out the particular requirements of their own conception of justice, contemporary communitarians have frequently chosen to defend their conception by attacking other conceptions of justice; by and large, they have focused their attacks on the welfare liberal conception of justice. Alasdair MacIntyre, for example, argues in "The Privatization of the Good" (1990a) that virtually all forms of liberalism attempt to separate rules defining right action from conceptions of the human good. MacIntyre contends that these forms of liberalism not only fail but must fail because the rules defining right action cannot be adequately grounded apart from a conception of the good. For this reason, MacIntyre claims, only a version of a communitarian theory of justice that grounds rules supporting right action in a complete conception of the good can ever hope to be adequate.

But why cannot we view most forms of liberalism as attempting to ground moral rules on part of a conception of the good—specifically, that part of a conception of the good that is more easily recognized, and needs to be publicly recognized, as good? For Rawls, this partial conception of the good is a conception of contractual fairness, according to which no one deserves his or her native abilities or initial starting place in society. If this way of interpreting liberalism is correct, in order to evaluate welfare liberal and communitarian conceptions of justice properly, we would need to do a comparative analysis of their conceptions of the good and their practical requirements. Moreover, there is reason to think that once the practical requirements of both liberal and communitarian conceptions of justice are compared, they will be found to be quite similar.

Feminist Justice

Defenders of a feminist conception of justice present a distinctive challenging critique to defenders of other conceptions of justice. In *The Subjection of Women* (1869), John Stuart Mill, one of the earliest male defenders of women's liberation, argued that the subjection of women was never justified but was imposed on women because they were physically weaker than men; later this subjection was confirmed by law. Mill argued that society must remove the legal restrictions that deny women the same opportunities enjoyed by men. However, Mill did not consider whether, because of past discrimination against women, it may be necessary to do more than simply removing legal restrictions: he did not consider whether positive assistance may also be required.

Usually it is not enough simply to remove unequal restrictions to make a competition fair among those who have been participating. Positive assistance to those who have been disadvantaged in the past may also be required, as would be the case in a race where some were unfairly impeded by having to carry ten-pound weights for part of the race. To render the outcome of such a race fair, we might want to transfer the ten-pound weights to the other runners in the race for an equal period of time. Similarly, positive assistance, such as affirmative-action programs, may be necessary if women who have been disadvantaged in the past are going to be able to compete fairly with men.

In *Justice, Gender and the Family* (1989), Susan Okin argues for the feminist ideal of a gender-free society, that is, one in which basic rights and duties are not assigned on the basis of a person's sex. Being male or female is not the grounds for determining what basic rights and duties a person has in a gender-free society. Since a conception of justice is usually thought to provide the ultimate grounds for the assignment of rights and duties, we can refer to this ideal of a gender-free society as *feminist justice.*

Okin goes on to consider whether Rawls's welfare liberal conception of justice can support the ideal of a gender-free society. Noting Rawls's failure to apply his original position-type thinking to family structures, Okin is skeptical about the possibility of using a welfare liberal ideal to support feminist justice. She contends that in a gender-structured society like that of the United States, male philosophers cannot achieve the sympathetic imagination required to see things from the standpoint of women. In a gender-structured society, Okin claims, male philosophers cannot do the original position-type thinking required by the welfare liberal ideal because they lack the ability to put themselves in the position of women. According to Okin, original position-type thinking can really be achieved only in a gender-free society.

Yet, at the same time that Okin despairs of doing original position-type thinking in a gender-structured society, she purportedly does a considerable amount of just that type of thinking. For example, she claims that Rawls's principles of justice "would seem to require a radical rethinking not only of the division of labor within families but also of all the nonfamily institutions that assume it" (Okin, p. 104). She also claims that "the abolition of gender seems essential for the fulfillment of Rawls's criterion of political justice" (Okin, p. 104). So Okin's own work would seem to indicate that we can do such thinking, and that her reasons for thinking we cannot are not persuasive. To do original position-type thinking, it is not necessary that everyone be able to put themselves imaginatively in the position of everyone else. All that is necessary is that some people be able to do so. Some people may not be able to do original position-type thinking because they have been deprived of a proper moral education. Others may be able to do original position-type thinking only after they have been forced to mend their ways and live morally for a time.

Of course, even among men and women in a gender-structured society who are in a broad sense capable of a sense of justice, some may not be able to do such original position-type thinking with respect to the proper relationships between men and women; these men and women may be able to do so only after the laws and social practices in our society have significantly shifted toward a more gender-free society. But this inability of some to do original position-type thinking does not render it impossible for others, who have effectively used the opportunities for moral development available to them, to achieve the sympathetic imagination necessary for original position-type thinking with respect to the proper relationships between men and women.

Drawing Conclusions

What conclusion should we draw from this discussion of libertarian, socialist, welfare liberal, communitarian, and feminist conceptions of justice? Should we draw the conclusion defended by Alasdair MacIntyre in *After Virtue* (1981) that such conceptions of justice are incommensurable and, hence, there is no rational way of deciding between them? Many philosophers have challenged this view, and even

MacIntyre, in *Three Rival Versions of Moral Enquiry* (1990b), has significantly qualified it, now claiming that it is possible to argue across conceptions of justice.

Another conclusion that we might draw from this discussion of conceptions of justice is that if the ideal of liberty of libertarian justice can be shown to require the same rights to welfare and equal opportunity that are required by the welfare liberal conception of justice, and if the communication critique of welfare liberalism can be rebutted, it may be possible to reconcile, at a practical level, the differences between welfare liberal justice, socialist justice, and feminist justice. If this can be done, all that would be necessary to reasonably resolve disputes about justice would be to clarify what the shared practical requirements of these conceptions of justice are and simply to act on them.

The Provision of Just Healthcare

Assuming that it is possible to show that libertarian, welfare liberal, socialist, communitarian, and feminist conceptions of justice have the same practical requirements as a right to welfare and a right to equal opportunity, then in order to determine the morally appropriate level of healthcare, it would be necessary to determine what provision of healthcare would be required by these rights. Since a right to welfare and a right to equal opportunity are usually associated with a welfare liberal conception of justice, it would seem reasonable to use Rawls's original position decision procedure—a procedure favored by welfare liberals—to determine what level of healthcare would be required by a right to welfare and a right to equal opportunity.

In *Just Health Care* (1985) and *Am I My Parents' Keeper?* (1988), Norman Daniels develops just such an account of healthcare. Daniels imagines people behind a veil of ignorance trying to determine how they should allocate healthcare services over their lifetimes. Behind this veil of ignorance, people are to imagine themselves ignorant of their actual age so that they could be young or old. Daniels claims that people using this Rawlsian decision procedure would reserve certain life-extending technologies for their younger years and thus maximize their chances of living a normal life span, even if that meant reducing the medical resources that would be available in their old age.

The consequences of using a Rawlsian decision procedure to determine the morally appropriate level of healthcare required by a right to welfare and a right to equal opportunity are (1) a focus on death-preventing level of healthcare for the young, (2) a focus on a life-enhancing healthcare for both young and old, and (3) a willingness to cut back on death-preventing healthcare for the old to some extent when it conflicts with (1) and possibly when it conflicts with (2) as well.

Yet these consequences remain indeterminate until we can specify the amount of resources that are to be devoted to healthcare rather than to meeting the various other needs and wants that people have. It will not do simply to have each person choose the level of healthcare that he or she prefers, because we cannot assume that everyone will have sufficient income to purchase whatever level of healthcare he or she wants or needs. Rather, there seem to be two options.

One option is to specify an optimal and affordable level of healthcare and then guarantee this level of healthcare to all legitimate claimants. The other option is to specify a decent minimal level of healthcare and guarantee that level of healthcare to all legitimate claimants, but then allow higher levels of healthcare to be purchased by whoever has the income and desire to do so. Of course, both these options will leave some people dissatisfied. The equal-healthcare option will leave dissatisfied people who would have preferred and could have afforded a higher level of healthcare that would have been available under the multi-tiered healthcare option. The multi-tiered healthcare option will leave dissatisfied people who would receive only the decent minimum level of healthcare under that option but who want or need more healthcare than they will be receiving. Is there any just resolution of this conflict?

Assuming again that we are trying to determine the morally appropriate level of healthcare required by a right to welfare and a right to equal opportunity, it is surely the case that nothing less than a guaranteed decent minimum level of healthcare to all legitimate claimants would be morally acceptable. But is a multi-tiered option for healthcare morally permissible, or is the option of an equal level of healthcare morally required?

To answer this question, we must take into account all the morally legitimate claimants to our available resources. They include not only the members of the particular society to which we happen to belong but also distant peoples and future generations as well. Once we recognize how numerous are the morally legitimate claimants on the available resources, it becomes clear that all that we can hope to do is provide a decent minimal level of healthcare to all claimants. Given the morally legitimate claims that distant peoples and future generations make on our available resources, it is unlikely that we will have sufficient resources to allow people to purchase higher levels of healthcare (the multi-tiered option). Morally, we would seem to have no other choice than to favor the same level of healthcare for everybody (the equal-healthcare option).

In preferring the equal-healthcare option, we appealed not to the ideal of equality itself but, rather, to the goal of providing all legitimate claimants with a decent minimum level of healthcare. Given that available resources are limited, to meet the goal of providing a decent minimum of healthcare to all legitimate claimants, equality of healthcare for all legitimate claimants is required. In this context, no one can have more than equality if everyone is to have enough. This choice would clearly be favored by people behind a Rawlsian veil of ignorance, assuming that the hypothetical choosers are understood to represent all morally legitimate claimants.

Nor could one reasonably object to the ideal of including distant peoples and future generations within the class of morally legitimate claimants, because each of the five conceptions assumes that each human being has the same basic rights. So if these basic rights that each human being has include a right to welfare and a right to equal opportunity, the requirements to provide each human being with a decent minimum of healthcare would clearly follow.

Nevertheless, there remains the question of how to specify this minimum level of healthcare that all legitimate claimants are to receive. The problem here is how to specify how much of the available resources should go to providing everyone with a decent minimum of healthcare rather than providing for the satisfaction of people's other needs and wants. Yet here, too, the question seems resolvable with the aid of a Rawlsian hypothetical choice procedure. We simply need to introduce behind the veil of ignorance the knowledge of the relevant technology for meeting people's basic needs and the knowledge of available resources to decide how much of the resources should be devoted to providing a decent minimum level of healthcare and how much should be devoted to meeting the other needs and wants that people have.

In this way, we should be able to determine what specific requirements of just healthcare are grounded in a right to welfare and a right to equal opportunity. Moreover, these specific requirements of just healthcare would be further supported if it can be shown that the rights from which these healthcare requirements are derived are themselves the shared practical requirements of libertarian, welfare liberal, socialist, communitarian, and feminist conceptions of justice.

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SEE ALSO: *Aging and the Aged: Societal Aging; Children: Rights of Children; Communitarianism and Bioethics; Economic Concepts in Healthcare; Ethics: Social and Political Theories; Future Generations, Reproductive Technologies and Obligations to; Healthcare Resources, Allocation of; Human Rights; Health Insurance; Health Policy in International Perspectives; Health Policy in the United States; Just Wages and Salaries; Managed Care; Medicaid; Medicare; Utilitarianism and Bioethics; Warfare: Introduction*

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JUST WAGES AND SALARIES

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The ethics of just compensation are informed by the continual effort to balance three powerful principles; several other considerations contest and limit the reach of these ethical principles.

Overview of Ethical Dimension of Just Compensation

The first ethical principle is that every working person possesses an inherent dignity and deserves respect. All workers, no matter how high or low their skills or compensation, are important and valued members of the institution. In fact, ethically, each person, no matter what job they perform, is entitled to the same amount of respect as any other worker.

The second ethical principle is that each working person has the right to be able to support themselves and their families by the fruits of their work. Few argue with the proposal that people who work full-time should earn enough to support themselves and their families. That means people who work full-time should earn at least a living wage. How much constitutes a living wage is open to discussion, but most people of goodwill agree that part of being a good employer involves paying workers a living wage. While an employer has many obligations and paying fair wages is not their only duty, it is certainly one of the most important.

The third ethical principle is that economic considerations and the health of the employer are also important. Without an economically healthy employer, opportunities for jobs paying living wages are limited. Wages are an important part of the overall budget of all healthcare providers and must be set with the economic health of the institution in mind. If an employer is in a precarious financial situation, then the obligation to pay a living wage must be adjusted accordingly. Ethically, however, the employer is obligated to pay living wages to workers before spending money on other, less important matters. For example, corporations have a duty to produce returns for shareholders. But the corporate duty of employers to shareholders is not as compelling ethically as the duty to pay living wages to employees. Healthcare institutions often present themselves as, and are expected by the public to be, community resources. As community resources, healthcare employers are viewed differently than, for example, the local food and beverage industry or other retail businesses. This creates different and legitimately higher justice expectations for the healthcare employer. Unlike other corporations, healthcare institutions are expected to operate with a commitment to the common good and not just for private gain.

Several countervailing arguments are used to attempt to limit these ethical considerations in determining just compensation. The first and most pervasive argument is that economic market forces alone set ranges of compensation. To many, these market forces are apart from and unaffected by ethical principles. From this perspective, the ethical duty of employers to pay each and every worker at least a living wage is a discussion that philosophers may engage in, but is not realistic enough to engage business decision-makers.

A second argument, which arises out of the first, is that the labor of some people is inherently worth more than the labor of others. In this perspective, considerations of productivity, educational achievement, difficulty of replacement, and competition from other institutions are the real standards for determining compensation. Considerations of human dignity and the right to a living wage are at best peripheral. The determination of what is just compensation is analyzed, evaluated, and decided in the continual contest between these considerations.

Just Compensation

Justice demands that all compensation decisions start with the recognition that each worker has a fundamental human dignity and worth that is equal to every other worker. People work to support themselves and their family members. Thus, at a minimum, each worker must earn enough to support themselves and their family as a result of their labor. Justice does not demand, however, that all persons earn the same amount.

Compensation decisions involving individuals engaged in the same type of occupation are often based on considerations of ability to perform the task assigned, demonstrated and consistent effort, overall quality of work performed, and special skills, ability, or training that allow the person to perform tasks that coworkers do not or cannot. Compensation decisions involving allocation of funds between different categories of workers are often based on principles of productivity, scarcity, comparative effort, and market forces.

Justice demands that the basic needs of all workers be respected as a first principle, and that the decisions about how to apportion the surplus be made in a manner which is fair in both process and result. Fair process for determining compensation in a healthcare institution means that the needs of all workers, the needs of the recipients of healthcare, and the economic needs of the institution are given fair opportunity to be heard and balanced in decision making. To be fair, the process of determining just compensation must be transparent, inclusive, responsible, and participatory. The ability of workers to bargain collectively if they choose to do so must be protected and respected. Fair results in determining compensation are difficult to define, because there are so many competing needs. At a minimum, fair results require decisions that are rational, explainable, and non-discriminatory. Even when fair results are achieved, rapidly changing circumstances can undermine the appropriateness of prior decisions.

Lowest-Paid Workers

A critically important part of the ethical evaluation of any institution is how it compensates its lowest-paid workers. This is the point where the contest between living wages and market forces is played out.

Living wages are the ethical goal of all responsible employers, but as noted above, there are considerations opposed to living wages for the lowest-paid worker. The need to keep overall lower-skilled labor costs down is a constant concern of management. Part of the determination of what is fair compensation is the answer to the question of "what is everyone else, at least those in the surrounding community, paying for similar work?" Employers who pay less than prevailing wages will find it hard to attract and retain a full complement of good workers. Employers who pay a living wage when others pay less will be faced with internal and institutional criticism that there is an overpayment of wages that may harm the financial health of the institution. And, in some lower-wage communities, healthcare institutions need not pay a living wage to attract and retain entry level or lower-skilled employees.

What is a living wage? While there are many definitions of what constitutes a living wage, all involve the worker earning enough to be able to be self-sufficient and to have enough income to support their family. While the precise amount needed to be self-supporting varies by locale, it is always significantly higher than the federal minimum wage. Some living wage laws have calculated the amount of living wages as the amount necessary for a full-time worker to lift a family of four over the federal poverty guidelines, roughly twice the federal minimum wage. The living wage is sometimes even called the family wage.

Highest-Paid Workers

While ethics indicates that all persons are entitled to be treated with human dignity and respect, there is also general agreement that just compensation does not mean that all people must earn the same amount. Once the basic needs of all workers have been met, justice recognizes that more educated and skilled workers have first claim to higher compensation out of the surplus that remains. This recognizes that higher pay is a partial motivation for people to continue education and to defer other work opportunities while learning higher skills.

Higher compensation is particularly called for in healthcare, where many of the higher-skilled workers have developed their expertise by accumulating substantial educational debt and where the risks associated with their practice require significantly higher insurance costs. People who invest more in their education, who continually improve their skills, who sacrifice more, who are more difficult to attract to provide needed work, and who risk more to provide needed services to others, are ethically deserving of extra compensation.

Compensation for higher-skilled workers should be calculated after consideration of many factors: the overall economic health of the institution, the provision of quality care to those who seek healthcare, and the needs of the lower-paid workers to receive living wages.

There is an ethical caution in the actual calculation of compensation for higher-paid workers: the duty to provide fair and adequate compensation for low-wage workers is ethically more important than the goal of providing competitive compensation for the highest-paid workers. Where there is a conflict within an institution between providing more attractive compensation for higher-wage workers versus paying a living wage to lower-wage workers, the needs of the lower-wage workers ethically trumps the wants of the higher-salaried workers.

Pay Equity Considerations

Equity issues in determining just compensation are aimed at eliminating the effects of gender-, race-, age-, and disability-based wage discrimination. While these types of wage discrimination are now illegal, the effects of discrimination remain. For example, a quick look at most institutions will show that occupations dominated by women and people of color usually pay less than others within the same institution. Gains have been made toward removing the barriers of intentional discrimination. Most people of goodwill agree that intentional acts of discrimination are wrong and should be immediately corrected. But discrimination is not confined to overt acts of prejudice on the part of individuals. Discrimination continues in many institutions as the structural effects of past practices continue to have a negative impact. Differences in education, experience, and time in the workforce form a part of the legitimate criteria for determining compensation. However, concerns for pay equity require the institution to continually question and readjust the institutional respect for the value of work performed by lower-paid workers. Action should be taken to upgrade lower-paying jobs and to correct unjust wage discrimination based on gender, race, age, and disability.

Another equity issue is the large income gap between the highest-paid workers and the lowest-paid workers found in many institutions. Economic inequality within an institution often reflects an uneven participation in the decision-making process within the institution. Further, income disparity within institutions usually becomes a heightened source of concern in times of economic trouble and transition. While some accept this disparity as inevitable, it is not. Like all economic decisions, wage and salary scales are set by people in an ethical, legal, economic, and community context.

Role of Government

The government has an obligation to provide the legal and economic framework necessary for employers and workers to engage in fair and just compensation relationships. Government has a duty to help citizens secure basic justice and to protect the civil and human rights of those without the power to secure those rights for themselves.

The government exists to protect the common good. Just compensation of all members of the community is certainly in the common good. Government must protect the rights of the employer and all workers to fair and just determinations of compensation. Where there are unequal power relationships between workers and employers, the government should participate in leveling the playing field. Government has a role in securing fair labor practices that lead to just compensation.

If the government assists the common good, it acts justly; when individuals or institutions prompt the government to assist the common good, they act justly. When the actions of government are contrary to the common good, they are unethical and unjust; when private individuals or institutions attempt to prevent government from regulating for the common good, their actions are unjust. The government has an important role to promote fairness and equity in the continual process of securing just compensation, particularly for lower-paid workers and those who have been the victims of pay inequity.

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SEE ALSO: *Healthcare Management Ethics; Justice; Labor Unions in Healthcare; Organizational Ethics in Healthcare*

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LABOR UNIONS IN HEALTHCARE

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The relationship between unions, employers, and employees in healthcare raises a wide range of ethical issues at the levels of policy, strategy, and practice. From initial attempts at employee organization, through union elections, contractual negotiations, and interactions over the life of the contract, to strikes, lockouts and union decertification activities, all have an ethical dimension. But the ethical stance taken at the level of policy, strategy and practice depends upon the way three fundamental questions are answered: Do employees have a right to *self-organization;* and, if so, what does that right mean? Do healthcare employees have a right to strike? Do healthcare employees through their self-organization have broader social responsibilities?

The term *self-organization* refers to the shared means employees establish to have a voice in the terms and conditions of their employment. It includes joining a union, forming a union, and developing other types of concerted effort.

In addressing the ethical dimensions of self-organization in healthcare, two points need to be made. First, self-organization in healthcare and other human service organizations is different from self-organization in other forms of employment not because it is completely distinct but because it adds the further component of responsibility to the public served. Second, in considering employee self-organization as a right from an ethical perspective, it is important also to look at that right from a legal perspective. Within the United States, labor law is based on a specific ethical understanding of that right; and often little distinction is made between ethics and law, with the legal being accepted as the ethical.

Self-Organization as a Right

HISTORICAL BACKGROUND. At the beginning of the twenty-first century, the right of employees to organize is widely accepted. Even libertarians acknowledge the right of individuals to choose what groups they wish to join. But getting that right accepted was difficult and costly in human suffering. The experience in the United States is instructive. While the U.S. Constitution guarantees "the right of the people peaceably to assemble," the courts found early attempts by employees to establish permanent organizations to achieve improvements in wages and working conditions through concerted action to be criminal conspiracies in constraint of trade. Later judges granted injunctions against strikes and picketing. Following World War I, unions were branded as *un-American* and *Bolshevic.* Employers used intimidation and violence to break up unionizing efforts and strikes.

In 1935 President Roosevelt signed the National Labor Relations Act (Wagner Act) which recognized employees's right to organize. According to Section 7 of the Act, "Employees shall have the right to self-organization, to form, join or assist labor organizations, to bargain collectively through representatives of their own choosing, and to engage in concerted activities for the purpose of collective bargaining or other mutual aid or protection." Two years later, in *National Labor Relations Board v. Jones & Laughlin Steel Corp.,* the U.S. Supreme Court termed this right a *fundamental right,* stating that labor unions grew "out of the necessities of the situation; that a single employee was helpless in dealing with an employer; … that union was essential to give laborers opportunity to deal on an equality with their employer" (p. 33).

In 1947 in the face of problems in labor-management relations following World War II, Congress passed the Taft-Hartley Act which restricted union powers, adding to the employee rights set out in the Wagner Act the right to *refrain from* self-organization and concerted activities. While the Taft-Hartley Act exempted not-for-profit hospitals, denying those employees the right to organize, this exemption was lifted in 1974. Employees of public hospitals cannot organize under the National Labor Relations Act. In 1987 the National Labor Relations Board (NLRB) established the number of separate bargaining units within a healthcare institution as eight (Lichtenstein).

CIVIL RIGHT. Terming self-organization a right within the United States generally means interpreting it in light of the rights set out in the U.S. Bill of Rights. Those rights, known as civil rights, which include freedom of speech and freedom of assembly, focus on the individual and emphasize freedom. They allow the individual freely to pursue self-interest, protecting the individual against external coercions. While legally the rights contained in the Bill of Rights pertain only to the relation of the individual to the government, an ethic embodying this perspective views the protections of individual freedom broadly.

From the perspective of self-organization as a civil right, the right of the individual to choose freely is a primary focus. This focus has played an important role in addressing the racism and sexism which have marked the history of unions in the United States, upholding the right of each and all to join unions regardless of gender or race. But emphasizing individual choice also has implications for the effectiveness and even the future of unions. The right to choose includes the right to forego. As a result, interpreting the right to self-organization from a civil rights perspective often leads to the conclusion that individuals not only should have a say on whether a unit within a healthcare facility is unionized but also should have a right to refuse to join a union. This has led to so-called *right to work* legislation which supports such a refusal. But, bargaining collectively and engaging in concerted action require a cohesiveness that can be undercut by individual free choice. Allowing an individual to exercise a right of refusal with regard to union membership also opens the possibility that the individual will enjoy the benefits from union activity while bearing none of the costs.

Equally important from a civil rights perspective is the right of freedom of speech. As this right relates to and impacts employees's right to self-organization, there are ethical concerns about what limits, if any, should be placed on the right to free speech of the various parties with an interest in the self-organization process. In the years immediately following the Wagner Act, the NLRB took the position that employers should remain neutral while employees were determining their form of self-organization. By 1941, however, employers's free-speech right to voice their opinion and take sides on employees's self-organization was recognized. In exercising that right, employers, according to the National Labor Relations Act, were not allowed to "interfere with, restrain, or coerce employees in the exercise of their right" to self-organization. That raises questions about what counts as interference, restraint, and coercion. The greater the emphasis on freedom of speech, the greater the latitude employers have to express through word and deed their negative reaction to unionization. Allowing employers to voice their opinion about unionization recognizes their right to free speech; but it can also have the effect of shifting the focus of the exercise of the right to self-organization from the efforts of employees to the interaction between union and employer. The self-organization process can move from one of deliberation among employees to one of antagonism between employer and union.

As the right to free speech of employees, employers and unions comes more to the fore, the danger is that the differentials of power existing between employers and individual employees will be lost to sight, and employers and employees will be treated simply as individuals with different and competing interests, each struggling to achieve their own ends. The right to self-organization then becomes primarily a matter of self-determination. Employees can choose to exercise or not exercise this right; and, even after exercising it, they can retreat from their decision through decertification of the union.

Employees's ability to deal with an employer from a position of equality is especially important in healthcare. In addition to their proper concern about wages and working conditions, healthcare employees have a responsibility as advocates for their patients. Without the power from collective bargaining and concerted action made possible by self-organization, healthcare employees's ability to carry out that responsibility can be severely restricted (White).

SOCIAL RIGHT. Employee self-organization, however, can also be viewed as a social right. Unlike civil rights, which protect the individual against external intrusions and coercions, particularly by the government, social rights set out the basic elements each individual requires to participate within society. Participation here means more than just not being hindered from voting, assembling or speaking one's mind. Its focus are the basic resources needed to take one's place within society and interact substantively with one's fellow citizens to achieve personal and communal good. Social rights include the right to food, housing, education, and healthcare.

Self-organization can be understood as a social right. Then, the right to self-organization, just like the right to food, education, housing, and healthcare, is not treated as a right in conflict with civil rights. It is a basic need that must be met to achieve and ensure social participation for individuals, to establish the foundation needed for exercising civil rights. For example, from this perspective, to say that a person who is homeless or without an education has the right of freedom of expression is formalistic and empty.

Understood as a social right, employees's right to self-organization is not in competition with an employer's right to self-expression. Employees need to exercise their right to self-organization in order to make use of their right of freedom of expression with regard to their working conditions and, in the case of healthcare, with regard to their responsibility for patient care. Thus, in 1999, the American Medical Association (AMA) announced its intention to develop an affiliated national labor organization to represent employed physicians to help them advocate more effectively on behalf of their patients.

Clearly employers have an interest in the results of employees's self-organization; but employees also have an interest in their employer's self-organization. Employees of course are free to make comments about an employer's self-organization. But, because of the power differentials between employers and employees, those comments have neither the power nor the possibility of interference and hindrance that an employer's words have during employees's self-organization.

Viewing employees's right of self-organization from the perspective of social rather than civil rights also has implications for employees's exercise of individual freedom. An approach emphasizing civil rights focuses on the individual as the fundamental element within society and the exercise of freedom as a primary defining factor for the individual. An approach emphasizing social rights looks to the community as the basic building block of society and emphasizes participation as a primary defining activity of the individual. From the latter perspective, freedom is mainly concerned with the way an individual participates, not whether one participates. Applying that to employees's right to self-organization understood as a social right, employees's exercise of freedom goes toward determining the form of their self-organization, not whether there will be some form of self-organization. Loss of a union election does not remove the discussion of employee self-organization from the table; it simply moves the discussion to other possible forms that self-organization might take. Underlying this is an understanding that, given the differentials of power between employees and employer and given the right and responsibility of healthcare employees to advocate for their patients, healthcare employees can exercise freedom only through self-organization (Hirschl).

Ultimately, these two categories, the right to employee self-organization as a civil right and as a social right, are points on either end of a continuum. Where one comes down on the continuum affects the policies, strategies and actions of the parties involved. For example, as already noted, the stronger the emphasis on self-organization as a civil right, the greater the stress on employer freedom of self-expression and on employee individualism; the stronger the emphasis on self-organization as a social right, the greater the stress on seeing employees's self-organization activity as fundamental for, and thus a prelude to, their exercise of freedom of speech. Regardless of where one is on the continuum, it is important not to lose sight of the fact that the employees are the center focus. When union organizing efforts are underway, events can easily escalate to what can best be described as a war where the focus shifts from the employees's attempts at self-organization to antagonism between the employer and the union. It is also important not to forget the differentials of power that exist between employees and employer.

Right to Strike

A second issue, closely related to the right to self-organization, is whether healthcare employees can strike. Those replying in the negative often base their response on the adverse effect such an action would have on the community at large, taking away a basic resource, and/or on the patients at the healthcare facility, depriving them of needed immediate care. Those replying in the positive often add a qualifier, indicating that in any strike action healthcare employees have a responsibility to ensure that immediate, emergent care is available.

Differences between human service organizations such as healthcare facilities and other organizations involving employees, while they exist, should not be exaggerated, because doing so often leads to the conclusion that healthcare employees should be denied the right to strike. In healthcare, as in other organizations, employee interests differ from, and at times clash with, employer interests in all areas, including patient or resident care. In healthcare, as in other organizations, a power differential exists between employees and employer that always has the potential of hindering employees from pressing their case for proper benefits and working conditions and (in healthcare) proper patient care. The power to strike is essential in light of that power differential.

While a strike can have a negative effect on patient care and the availability of medical care to the community, this result can be the consequence of employer as well as employee action. If, for example, the managers of a healthcare facility have developed policies that result in less than proper benefits, working conditions, or patient care and refuse to bargain fairly with employees, their responsibility for a strike cannot be overlooked. Actions must be evaluated in light of the totality of the circumstances. In addition, during a strike, managers share with employees responsibility for ensuring that basic healthcare resources continue to be available.

Employees's right to strike should not be undercut by the hiring of permanent replacement workers. Such action takes away from managers any incentive to address the concerns employees have about benefits, working conditions and patient care (Gibson; Lauer; Muyskens, 1982a, 1982b; Priest; Weber).

Social Responsibility of Unions

Third, the right to self-organization carries with it social responsibilities. This is especially true when the right to self-organization is seen as a social right. But even civil rights, which, although not created by society, require social promotion and protection, must be exercised in a socially responsible manner and at times give way to the good of the whole. The social responsibilities attendant to healthcare employees's exercise of their right of self-organization require that they take into account the effects their actions (seeking greater benefits, demanding better working conditions, striking) have on the care of patients and the ability of the community to access healthcare. At the same time, employee action in this regard should not be termed *self-interest* and placed in opposition to the common good of the community. Adequate salary and benefits, proper working conditions, and a voice in one's work are all as much social rights as is access to healthcare. At issue is appropriately allotting the resources of society so that each and all can meet their needs and participate in society. Moreover, the responsibility for working to provide access to healthcare to the community rests with management as well as employees.

Finally, healthcare employees have a duty to use the power they achieve through self-organization to actively advocate for better and broader access to healthcare. The dedication of healthcare employees to care for the injured and diseased should not stop with their ministrations to those seeking help at their facility. Through the power self-organization gives healthcare employees, they should be a voice for those lacking adequate healthcare and work to address the stark inequities in the United States where the only access to healthcare for too many is through emergency departments or through healthcare providers willing to offer *charity care* as well as to address the stark inequities worldwide with so many people lacking access (Muyskens, 1986).

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SEE ALSO: *Healthcare Management Ethics; Just Wages and Salaries; Organizational Ethics in Healthcare; Profession and Professional Ethics; Responsibility*

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LAW AND BIOETHICS

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Bioethics began as, and remains, an interdisciplinary field. If developments in biology and medicine have fueled the bioethics train and philosophy has laid down the tracks on which it has run, then law has been the engineer at the controls of the locomotive and statutes and court decisions have thrown the switches that guided the train through the rail yards. Law's influence on bioethics has been so pronounced as to be unmistakable, yet so pervasive as sometimes to be unnoticed.

It might be argued that law's role was pronounced for purely historical reasons: Bioethics began as an American phenomenon and hence was shaped by certain aspects of American culture. Lacking an established church or a single heritage of values, though committed to the rule of law and to the equality of all persons, Americans have a habit of turning to courts to resolve moral conflicts. Moreover, other features of the terrain also indicated a major role for the law. Bioethics frequently presents central civic issues, among them these: When does a human entity first become (or cease being) a legal person? What conduct of healthcare professionals treating incurably ill patients would constitute murder? May parents be paid for transferring to other persons the rights of custody and control over their children? Does the prospect of gaining knowledge of potential benefit to the community ever justify using people without their consent or even their knowledge?

Dependence on the legal system to settle many ethical and social issues generated by medicine and the life sciences does more than merely provide a means for resolving disputes. Reliance on the legal system denotes that an issue should be understood as having two opposing sides that will do battle for their respective rights to act in a particular fashion or to restrain the other side from acting in a contrary fashion. Moreover, as a means of discovering and articulating principles, the law favors certain implicit and explicit values.

The relationship of law and bioethics has not, however, been unidirectional: Bioethics has also affected the law. While much of law is concerned with commerce and institutions, both public and private, bioethics is essentially about people and about the fundamental choices that determine and even define their lives. If the law has brought to bioethical cases an attention to rights and procedure, bioethics has enriched legal analysis with life-and-death dramas. It would strain the point to say that medicine saved the law, as Stephen Toulmin observed medicine did for philosophy. But the ethical dilemmas arising from medicine and its associated scientific disciplines have helped to humanize the law, providing a setting in which the central struggles of our times—of individual rights and the collective good, of liberty as against equity and equality, of justice and fairness, of personal wishes versus expert judgment or the will of the majority—are played out with unparalleled urgency and vitality. When the question is whether a life is worth living, for example, the answer is consequential. And when legal institutions falter in answering such questions, then lawyers and others are reminded that perfect legal solutions may not exist for all bioethical dilemmas. Bioethics raises fundamental challenges for theorists as well as practitioners of the law about the harm that society may impose upon a minority in order to uphold values believed to be of fundamental importance to the majority, or the limits of the law as a guide to human conduct. Yet the focus of this essay is not the theoretical connection between morality and law, but rather the law as a practical force in shaping and defining bioethics.

What Is the Law?

SOURCES OF LAW. The term *law* carries a number of meanings. In ordinary speech, it usually refers to specific criminal or regulatory provisions ("It's against the law to …"). This usage also reflects the common equation of law with statutes, denoting not just criminal statutes but also those governing civil or procedural matters, such as the ownership of property or how one is called for jury duty. A fuller understanding of the law would emphasize other important sources. Of particular prominence today are the detailed and voluminous regulations issued by governmental departments and administrative agencies to implement the powers and carry out the duties conferred on them by statutes. Although statutes are sometimes quite detailed, many areas of human activity (especially of an industrial or commercial nature) are so complex that the legislature must almost of necessity confine itself to framing the basic legal structure, while delegating the task of supplying all the details to those with greater time and expertise at the administrative level, subject to various degrees of public, executive, legislative, and judicial oversight.

Especially in countries, including the United States, whose legal systems are derived from the English model, judicial decisions are a source of law at least as important as statutes. In some decisions, judges interpret statutes and hence give meaning and shape to them; while in others, judges decide issues not directly addressed by statutes and effectively make new law. At one time, when statutory rules covered only a small portion of human affairs, most of English law consisted of judicial resolution of individual disputes, collectively known as "the common law." To this day, many areas of law have a strong common-law flavor, which is constantly reinforced and renewed by judges' decisions about novel issues. Even in countries with civil-law systems based on Roman law or the Napoleonic Code, judges participate in the crafting of the law by their interpretation of code provisions.

Finally, in legal systems that follow the model of the United States, in which all activities of the government—including making and interpreting the law—are subject to limits specified in a constitution, no statement of the law would be complete without reference to the text of that supreme law, as well as the authoritative interpretations of its provisions by the courts.

Even these sources—statutes, regulations, judicial decisions, and the constitutions—do not exhaust the meaning of *the law,* which also connotes the legal system, the institutions, and the processes through which the law is applied. In this sense, the law encompasses the processes and rules of courts and administrative bodies (for example, on admission of evidence), as well as the more informal standards or practices that are reflected in the action of those law-applying people and institutions (such as public prosecutors or bureaucrats) who have wide discretion in administering statutes and regulations. Within their sphere of authority, the law is what they say it is. Indeed, to the extent they are not expressly forbidden, the customs and practices of people in any field may properly be described as part of the law, though those customs and practices may formally be denominated *law* only when explicitly incorporated into a judicial opinion, statute, or regulation.

Seen in this way, the law is a basic framework for society; it is a system not only for promulgating official policies and procedures and for administrating prosecutorial, judicial, and regulatory affairs but also for providing explicit or implicit sanction for the private arrangements through which activities and relationships are ordered. Of course, many people would not identify the law as the source for the way they conduct their affairs. Instead, they would point to the influence of family and community customs or values, as well as to explicit moral or religious teachings. But as members of society, they must still operate within the law; this means that if their private arrangements run afoul of the expectations of society as embodied in the law, these arrangements may be limited or nullified. For example, in a number of U.S. jurisdictions, legislatures or judges have declared contracts for women to bear children for couples (so-called surrogate motherhood) to be null and void, as against public policy, even though a purported contract is freely and knowingly agreed to by all parties.

The existence of such private ordering as an important but often overlooked source of lawmaking also serves as a reminder that even in a society, such as the United States, with a high proportion of lawyers, lawmaking is not restricted to lawyers. From the local to the national level, many members of the legislative and executive branches of government are not lawyers; indeed, the federal constitution does not even require that judges be legally trained. Law is one of the three traditional learned professions (along with medicine and the clergy). Its members are licensed by the state and admitted "as officers of the court" to practice "at the bar of justice." Accordingly, like physicians, they are governed by ethical standards articulated by their profession through its associations as well as through the decisions of judges passing on cases of alleged transgression of professional obligations.

Around the world, most legal education occurs in schools affiliated with universities. Characterizing legal education in the early twentieth century as akin to a trade school, Thorstein Veblen opined that "the law school belongs in the modern university no more than a school of fencing or dancing" (p. 211); but this complaint is no longer justified, if indeed it ever was. Today, schools provide much more than mere vocational training, and scholarship is not limited to exegesis of doctrine; it encompasses empirical, normative, and theoretical work. Nonetheless, the law is a practical field, not simply one of the liberal arts and sciences.

DIVISIONS OF THE LAW. Traditionally, for purposes of basic study and classification, law has been divided along such doctrinal lines as tort law, criminal law, contract law, constitutional law, equitable remedies, property law, wills and trusts, and civil and criminal procedure. Each of these areas is characterized by prototypical relationships among parties and a set of analytic and practical devices for structuring those relationships and determining the outcomes of disputes. In recent years, legal scholarship has taken on several additional layers.

One is an enrichment of the tools brought to the law's tasks by combining with another discipline: legal anthropology, law and economics, legal history, law and literature, law and philosophy, law and psychology or psychoanalysis, sociology of law, and law and religion, to mention prominent examples. Each of these combined subdisciplines has not only a methodology but also its own theories and assumptions. Furthermore, additional schools of thought have arisen—such as legal realism, critical legal studies, feminism, and critical race studies—that provide perspectives on the law by combining the tools of several disciplines and a set of attitudes toward legal, social, economic, and personal relationships. Plainly, a person working in an interdisciplinary field may bring one of the analytic perspectives to bear—for instance, a feminist approach to legal history or a legal-realist perspective on law and economics.

A third way of dividing the domain of law is by focusing on its application to specialized types of personal, commercial, institutional, and sociopolitical activities. (The range of specialized areas of the law seems virtually limitless; attorneys now practice antitrust law, art law, bankruptcy law, civil-rights law, commercial law, education law, employment and labor law, entertainment law, family law, insurance law, intellectual-property law, juvenile and dependency law, media and broadcast law, mental-health law, probate law, public and private international law, regulated industries law, sports law, securities law, and even space law, to name a few.) Whether from an academic or a practice vantage point, specialized fields of law usually link traditional doctrinal categories with information and methods derived from the disciplinary and analytic approaches just described. For example, people working in family law will draw not only on legal doctrines from remedies, from property law, from wills and trusts, and from criminal and civil law and procedure, but also on psychological, sociological, or feminist analyses and perspectives; while those pursuing antitrust law will draw not only on various aspects of business law and criminal and civil law but also on law and economics studies and perhaps historical and sociological analysis as well.

HEALTH LAW. Traditionally, medicine and law intersected in civil or criminal cases in which proof of medical facts was at issue. From the medical side, those involved were usually pathologists, who became specialists in "forensic medicine," as the field was known to prosecutors and criminal-defense attorneys; on the legal side, torts specialists who handled a large proportion of malpractice cases (and some of whom held degrees in both law and medicine) described their expertise as encompassing "medical law." With the tremendous growth in healthcare and research beginning in the mid-1960s, healthcare law—or more simply health law—emerged as a new field that includes these areas and more. It is one of the fastest-growing, most diverse, and most exciting legal specialties.

Health law draws on practically the entire corpus of traditional doctrinal fields—civil, criminal, constitutional, property, and procedural—as well as many other specialized areas, such as labor, insurance, antitrust, and government regulation. Practitioners represent hospitals and other healthcare providers; academic research centers; physicians, nurses, and other healthcare professionals and nonprofessional employees; insurance carriers and employers that provide health insurance as an employee benefit; manufacturers and distributors of drugs and medical devices; patients and their families; and governmental departments and agencies that finance and regulate the individuals and institutions providing healthcare. Although cases involving ethical dilemmas are the ones that draw public attention, they are the exception for most health lawyers, who are more likely to spend their time drafting contracts for the purchase of goods and services; bargaining about insurance reimbursement; preparing staff bylaws, checking professional peer activities, or handling other issues that arise in accreditation, credentialing, or certification of practitioners or institutions; negotiating with government agents about licensing, taxation, and environmental controls; or litigating a case of professional malpractice (Macdonald et al.).

The Impact of Law on Bioethics

The relationship of law and bioethics is complex and multifaceted. One need not share the view of a leading legal commentator—"American law, not philosophy or medicine, is primarily responsible for the agenda, development, and current state of American bioethics" (Annas, 1993, p. 3)—to conclude that the law has strongly influenced the methodology of bioethics, the central focus of bioethics, and the values of bioethics. "And—to the considerable extent that bioethics is an American invention and export—the influence of American law has been felt even in societies in which legal institutions play a less pronounced role than they do in the United States" (Capron, p. 43). Law's role in shaping bioethics has at least five facets.

FAMOUS LEGAL CASES. Notable cases have played a major role not merely in the development of bioethics but also in making it, by the 1990s, a prominent part of private reflection and public discourse. Difficult ethical issues are nothing new to the health professions. Yet until recently, issues were examined largely behind closed doors by physicians and nurses and an occasional theologian. In democratic societies, legal proceedings are usually open (though sometimes parties are permitted to use fictitious names, to help preserve their privacy). Consequently, the media are able not merely to report about a difficult decision that must be taken but also to put a human face on it by recounting the drama as it unfolds in the hearing room.

And bioethics cases are often very dramatic. A familiar example: As Karen Quinlan's parents argued during

1975–1976 in the New Jersey courts for authority to order her ventilator turned off, her photograph appeared so often in the media that it was probably more familiar to most Americans than the faces of their local members of Congress. Likewise, bioethical breaches—particularly scandalous ones, such as the Nazi physicians' experiments on concentration camp prisoners and the Tuskeegee syphilis study—not only generate landmark judicial rulings but also provoke adoption of new statutory or administrative law.

METHODOLOGY. Related to the addressing of bioethical cases through the law is a second facet, the law's largely inductive methodology. This method is especially associated with the common law, the process through which judges render decisions specific to the facts of the individual cases before them that are grounded in, or justified by, the decisions in prior cases whose facts are sufficiently analogous. Not only do judges often apply the same methodology when interpreting statutes, but legislatures, in drafting statutes, usually operate concretely and incrementally, building on court decisions and existing legislation (or borrowing from other jurisdictions) rather than attempting to operationalize grand principles. The law's fact-based, inductive method provides a counterpoint to the "principlism" that characterizes much philosophically oriented analysis in bioethics. Of course, this approach is not unique to the law, but it reinforces other case-based traditions in ethics, such as casuistry and Jewish ethics.

PROCEDURAL EMPHASIS. Third, recognizing that midlevel ethical principles such as autonomy, beneficence, justice, and nonmaleficence cannot solve most bioethical dilemmas (which arise precisely when conflict occurs among these unranked principles), and that pluralistic societies do not necessarily hold enough moral views in common to agree upon the correct resolution of most controversies, many bioethicists have welcomed "a procedural ethic, based on respect of the freedom of the moral agents involved, even without establishing the correctness of any particular moral sense" (Engelhardt, p. 45). This emphasis on procedure is familiar to lawyers, though the suggestion that bioethics should concentrate on acceptable decision-making processes rather than substantive rules draws objections from some legal scholars who see in proceduralism the risk of a slide into "the arbitrary exercise of power" (Annas, 1988, p. xiii).

Even when they have mandated that procedures be followed, the courts have not insisted that bioethical disagreements outside court employ all the procedural niceties that attach to judicial proceedings. Indeed, judges, legislators, and administrators alike have not always been very clear about the mandate and membership, much less the process, of institutional committees to make judgments about medical treatment and research. For example, in its landmark *Quinlan* decision, the New Jersey Supreme Court held that the guardians of unconscious patients could order life-sustaining treatment forgone with the agreement of the treating physician, provided a multiprofessional committee at the hospital concurred; yet it said nothing about how that committee should gather, hear, or evaluate evidence or otherwise reach conclusions (*In re Quinlan,* 1976).

RIGHTS ORIENTATION. The issues in bioethics are some of the most sensitive and most divisive confronted by our society, not least because of the rapid development of the life sciences. In both the laboratory and the clinic, novel problems are constantly generated by new capabilities for organ transplantation and mechanical replacement, for genetic diagnosis and therapy, for assisting reproduction, for sustaining life, for modifying human behavior, and for myriad other means of altering nature; such problems also arise out of major changes in the way health services are organized and financed. These developments and changes challenge existing social and professional norms; where those challenges are substantial and intractable, the people involved not infrequently turn to courts, legislatures, or executive agencies to protect their rights. "The concept of rights … has its most natural use when a political society is divided, and appeals to cooperation or a common goal are pointless" (Dworkin, 1977, p. 184).

Concern over abuses of patients and research subjects has been a major theme in bioethics, reinforced repeatedly by instances in which healthcare professionals and institutions have acted—sometimes from good motives and occasionally not—to the detriment of people in their care. The law has offered bioethics not just a procedural response but also a long tradition of protecting people from harm by assertion of their rights; indeed, a rights orientation seems inherent in the law's perspective on the relationship of the healthcare system to patients and research subjects.

Certain risks to patients arise from the imbalance inherent in this relationship—the vulnerability and dependence that illness creates, physicians' superior knowledge and technical mastery, and the way the organization of healthcare enhances professionals' power and prestige. From ancient times, medical ethics proclaimed the duties of beneficence and fidelity to patients' interests in order to guard against harm to patients. Yet, as bioethicists have pointed out from the first, this traditional view of medical ethics is problematic because physicians not only promised to serve their patients' interests but often took it upon themselves to define those interests. Lawyers aided this assault on medical paternalism with concepts borrowed from civil-rights law, such as political liberty and equality of treatment. From the 1960s onward, bioethicists adopting this stance "had much in common with the new roster of rights agitators" for consumers, racial and sexual minorities, and women (Rothman, p. 245).

The increase in the rights orientation coincided with the increasing effectiveness of medical interventions. Armed with wonder drugs, high-tech surgery, and new methods of resuscitation and intensive care, physicians saw their power to influence their patients' futures increase dramatically from the middle of the twentieth century; and that power became the subject of disputes concerning how it was to be distributed in the physician–patient relationship. Legal commentators suggested—and most bioethicists embraced—a reformulation of that relationship in terms of patients' rights (Annas and Healy). The dominance of the rights orientation dismays many healthcare professionals, who lament the adversarial tone they feel law has introduced into the practice of medicine. There may be a legitimate complaint here, but physicians have historically denied that they are making anything but medical decisions for patients. It has taken bioethicists to point out that once alternatives become available, the choice between them is usually based on value judgments, not medical judgments, and doctors have no special expertise that justifies their values taking precedence over patients' values. Rights are crucial to dealing with power inequality, even where one might prefer to conceive of relationships in terms of caring and connection. This tension remains a recurring theme in law and bioethics.

Although the incorporation of such central legal doctrines as informed consent into the core of bioethics can hardly be doubted, the transformative effects of law on medical practice are less clear. Commentators such as George Annas, who take a patients' rights approach, find many instances where those rights are still abused (1988); whereas scholars such as Jay Katz, who look at physicians' behavior, emphasize that powerful factors in physicians' training and psychology have prevented them from adopting a stance of open discussion and shared decision making. At the same time, other critics argue that the authority the law took from physicians is often transferred to lawyers and judges, not to patients; and that moreover, by replacing professional discretion with legal rules, the law has given physicians the unintended message that they need not exercise ethical judgment (Hyman). Even if physicians do not react in this fashion, the law's inclination to view relationships in terms of rights changes the way bioethical issues are analyzed and potentially displaces other forms of moral discourse traditionally associated with medicine. For example, by emphasizing what one has the right to do without helping to define what is the right thing to do, the law may have undermined the specifically moral aspects of bioethics (Schneider, 1994). "[N]othing but confusion of thought can result," as Justice Oliver Wendell Holmes observed, "from assuming that the rights of man in a moral sense are equally rights in the sense of the Constitution and the law" (p. 172).

SPECIFIC VALUES. Besides leading toward a rights orientation, the reliance upon the legal system imports specific values. These values are not unique to the legal system, though they tend to be associated with it, nor are they controversial, though they are not without consequence. That is, when one of these values is given preference in the resolution of a problem, other values, such as those that may be favored by medicine or by other philosophical systems, are likely to be overridden. The values usually associated with the law include justice, as opposed to progress or efficiency; equality, as opposed to inherent differences or measures of quality; due process, as opposed to scientific proof; and individual self-determination over one's life and body, as opposed to beneficence, psychological interdependence, or communal welfare. The law's values are generally those of liberal society: personal autonomy within a setting of ordered liberty in which individuals have wide but not unlimited freedom. Especially in pluralistic democracies, the law sets boundaries on the enforcement of majoritarian morality, thereby protecting many individual choices from interference.

Not all liberal societies treat the values involved in the same way. For example, although revolutions in France and the United States in the late eighteenth century drew on the same sources in articulating basic rights, the Declaration of the Rights of Man and the Citizen in France in 1789—unlike the Declaration of Independence in the United States in 1776—emphasized that individuals have duties as well as rights (Glendon). This difference between the American and European views of rights, which persists to this day, has important implications as bioethicists attempt to address such issues as self-risking behavior and limits on the allocation of scarce community resources to healthcare.

Law and Bioethics as a Field

As a field of study, law and bioethics can be viewed from several perspectives. First, from the vantage point of a nonlawyer doing bioethics—whether at a policy level or in individual clinical situations—one needs at least some understanding of the law and legal institutions. Moreover, institutional ethics committees usually include at least one lawyer, who can provide analytic abilities as well as expertise on statutory, regulatory, and case law.

Second, "law and bioethics" is a subject of increasing interest to students, scholars, and practitioners of law. In one view, law and bioethics can be seen as a subset of health law that deals with medical decision making, genetic and reproductive technology, human subjects research, and the like. In fact, health-law casebooks today typically include chapters or sections on bioethics. But this view does not fully capture the way in which bioethics is generally conceived. By the early 1960s, long before health law emerged as a separate field, courses dealing with bioethics were being taught at American law schools, although the first casebook with the title *Cases, Materials, and Problems in Bioethics and Law* was not published until 1981 (Shapiro and Spece). That volume, like other legal books dealing with bioethical issues, not only describes "the new biology" and recounts the dilemmas engendered by modern medicine and bioetechnology; it also discusses ethical theories and concepts, such as proportionality and personhood, that have crept from ethics into legal opinions. Nonetheless, law and bioethics is not just a subset of law and philosophy (or law and religion), since attention is usually focused on philosophical concepts not for their own sake but as they relate to understanding society's appropriate responses to technical developments that deeply affect people's lives and relationships. Most of the text of such books is drawn from reports of medical and scientific developments and from the rich array of relevant cases, statutes, and regulations, as well as commentaries about them (Capron and Michel).

In addition to academic attention, law and bioethics has been examined through commissions established by national and state governments through statutes and executive orders. These bodies have advanced bioethical analysis and promulgated legislative and administrative proposals (U.S. Congress).

Although people looking at the topic "law and bioethics" from the perspective of the latter field are likely to view it as a legitimate area of scholarship and practice, it is largely unrecognized among lawyers at large, who treat it neither as one of the distinctive "law and …" interdisciplinary fields nor as a distinct special application of law ("bioethics law") akin to employment law, sports law, and the like. The Association of American Law Schools does not categorize courses or teachers under such a heading, nor does the *Index to Legal Periodicals,* despite the existence in law journals of bioethics symposia as far back as the late 1960s (Capron and Michel). The literature of law and bioethics is not found only in law reviews or, for that matter, in scholarly journals of other disciplines such as philosophy. It also appears in medical and health-policy journals and in bioethics publications, such as the *Hastings Center Report,* the *Kennedy Institute of Ethics Journal,* and the *Journal of Law, Medicine, and Ethics.*

One important aspect of legal scholarship that can legitimately be said to be part of the "law and bioethics" literature is abortion. Recent treatments of this subject have been enriched by feminist legal analysis, which itself is greatly influenced by theorists such as Carol Gilligan and Nel Noddings, whose work concerns moral development and the different ways in which women and men may resolve moral dilemmas. This influence is perceptible not only in subjects dealing directly with women, such as abortion, maternal-fetal issues, and reproductive technology, but also in less obvious places such as analyses of ethics committees. Since feminist analysis emphasizes relationships and nurturance, it is not surprising to see that as the literature of law and bioethics moves beyond the rights orientation, feminist insights become important in developing a better legal understanding of the relationship between patients and health caregivers (Capron and Michel).

Conclusion

Scholars differ on the precise influence the law has had in shaping the content, methods, and focus of the interdisciplinary field of bioethics, but all would agree that the influence has been significant. Both those who applaud and those who bemoan the law's influence seem to agree that the law has done more than merely allow the enforcement of, or provide redress for breach of, existing moral rights possessed by participants in the healthcare system. Rather, the law has—through its orientation toward rights and through the values implicit in the processes it has fostered—established new rights and preferred certain values over others. On the positive side, this has helped promote the autonomy of patients and subjects, the openness of the processes by which decisions are reached, and equality of respect and concern for all participants. On the negative side, it has diminished the sense of community and of duties that attach to rights, while increasing many providers' sense of adversariness in their relationship to patients.

In a society in which ethical standards were sufficiently complete to address even novel technical problems, widely enough shared to be accepted without question by all or nearly all persons, and consistent and coherent enough never to lead to uncertain or contradictory results, bioethics might operate with little reference to the law. As Grant Gilmore observed, "A reasonably just society will reflect its values in a reasonably just law. The better the society, the less law there will be. In Heaven there will be no law and the lion will lie down with the lamb" (p. 1044). Until that time, the law will continue to play a large role in bioethics—not only providing a relatively neutral means through which troubling issues can be addressed and contended points resolved in a manner that is socially sanctioned, but also shaping bioethics through its concerns for justice and fair procedures, equality, and personal self-determination.

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SEE ALSO: *Animal Research: Law and Policy; Death, Definition and Determination of: Legal Issues in Pronouncing Death; Disability: Legal Issues; Environmental Policy and Law; Human Rights; Informed Consent: Legal and Ethical Issues of Consent to Healthcare; Insanity and the Insanity Defense; Maternal-Fetal Relationship: Legal and Regulatory Issues; Medical Futility; Organ Tissue and Procurement: Ethical and Legal Issues Regarding Living Donors; Public Health Law; Right to Die: Policy and Law*

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LAW AND MORALITY

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Bioethical problems are often discussed in legal as well as in moral contexts. Lawyers as well as ethicists are involved with such questions as abortion, euthanasia, and experimentation upon human beings. This is not surprising; the law is seriously concerned with protecting such basic rights as life, bodily integrity, and privacy—the rights involved in these ethical questions.

The overlap between law and morality has been a source of the substantial debate about the relation between law and morality, a debate not confined to the bioethical context. It is best divided into two main issues, although the discussion of these issues often overlaps: (1) What, if any, bearing does the moral status of a rule have on its status as a law? (2) To what extent, if any, should the legal system be used to enforce moral perspectives?

Moral Status and Legal Status

Western legal thought has been dominated by a natural-law tradition. There are many variants of this tradition, and the differences among them will be discussed below; what they have in common is a belief in a body of laws governing all people at all times, and in a source for those laws other than the customs and institutions of a given society. Such beliefs are frequently accompanied by the additional beliefs that no society is authorized to create laws that conflict directly with natural laws, and that any such conflicting laws may therefore be invalid. In short, the natural-law tradition asserts the existence of a set of laws whose status as laws is based upon their moral status.

The beginning of this tradition lies in the ancient world. Aristotle (384–322 B.C.E.) drew a distinction between the part of justice that is natural and should have the same force everywhere, and the part that is legal and has its force only in those places where it has been adopted by the people who live there. That distinction was developed extensively by the Stoics, who emphasized two further points about natural justice: that it is based upon right reason and that it is in agreement with nature. Cicero (106–43 B.C.E.), whose legal writings are based upon the Stoic tradition, emphasized the claim that no legislation can alter the validity of natural laws, which remain binding on all people. Some of these ideas were incorporated into Roman law, and the later Roman lawyers probably identified *jus naturale* (the philosophical notion of natural law) with *jus gentium* (a system of laws that had developed in the Roman world and governed the relations among free men independently of their nationality). This identification strengthened the idea of natural law as universal law.

These classical ideas gave rise to a number of different natural-law traditions, the two most important of which are the religious tradition culminating in the writings of Saint Thomas Aquinas (1224–1274) and the secular tradition, exemplified by Hugo Grotius (1583–1645) and John Locke (1632–1704).

Saint Thomas Aquinas defined a law as an ordinance of reason for the common good, promulgated by the individual who has the care of the community. He then distinguished four types of laws: eternal laws, natural laws, human laws, and divine laws. The eternal laws are laws promulgated by God on the basis of divine reason. The natural laws are the eternal laws implanted by God in human beings, in that human beings are naturally inclined toward their proper acts and ends. In short, Saint Thomas postulated an eternal, unchanging set of laws implanted by God in human beings and knowable by reason. Human laws are valid only insofar as they do not conflict with divinely promulgated, unchanging laws. Valid human laws either are conclusions drawn from the basic natural laws or are determinations of details left undetermined by the natural laws.

The natural-law theories of Grotius and Locke also contain theological references, and Saint Thomas does emphasize the rational basis of natural law. Nevertheless, Grotius and Locke represent a different tradition of natural law, one that puts more emphasis on natural law as rationally derivable than on natural law as divinely ordained. In addition, their tradition, especially in the writings of Locke, puts great emphasis on the natural law's protection of natural rights, rights that all human beings have independently of the state and its laws. Locke explicitly drew the conclusion that a state loses its legitimacy insofar as its laws are in violation of natural rights, such as the right to life or liberty.

These natural-law traditions continue to influence discussions about the relation between the law and bioethics. Writers influenced by the theological version of the natural-law tradition continue to argue that any valid law must be in conformity with the divinely ordained natural law. Thus, many Roman Catholic writers (e.g., Grisez and Boyle) argue that there must be civil laws prohibiting abortion and euthanasia because those procedures are in conflict with the natural law. To those who would object that this is an illegitimate use of the law to enforce morality, these writers reply that it is the very nature of legitimate law to prohibit such activities. The most important recent reiteration of this view is found in the 1987 statement from the Congregation for the Doctrine of the Faith titled *Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation.* Having argued that abortion from the moment of conception and various forms of assisted reproduction are immoral, the Congregation goes on to claim that there must be laws prohibiting both because "The task of the civil law is to ensure the common good of people through the recognition of and the defence of fundamental rights and through the promotion of peace and of public morality" (p. 35).

Writers influenced by the ideas of natural-rights thinkers like Locke continue to argue that no purported law is legitimate if it allows the violation of the basic rights of human beings. This type of argumentation is particularly prevalent in countries such as the United States, where the courts possess the ability to declare laws unconstitutional when they infringe upon basic human rights. U.S. Supreme Court decisions from *Griswold v. Connecticut* (1965), in which the Supreme Court ruled that a Connecticut law prohibiting the use of contraceptives is unconstitutional, to *Roe v. Wade* (1973), in which the Supreme Court ruled that women have a constitutional right to abortions at least in the first two trimesters, have indicated that jurists are prepared to extend those rights to include ones not explicitly mentioned in the Constitution, suggesting to many—but by no means all—commentators that they are implicitly invoking some natural-law theory of rights.

The natural-law tradition has not been universally accepted. There has also been a long tradition of thinkers, dating back to antiquity, who have insisted that the only laws that exist are those adopted by a given society, and that there is no necessary connection between the legal status of a law and its moral status. Defenders of this position, the position of legal positivism, are not opposed to the moral criticism of individual laws and of whole legal institutions; positivists often advocate changes in the law on the basis of moral considerations. But the positivists insist that an immoral law, however much it should be changed, remains valid as a law until it is repealed by the society's appropriate social mechanisms.

Jeremy Bentham (1748–1832) and John Austin (1790–1859) were the two most influential proponents of this view, although earlier figures like Jean Bodin (1530–1596) and Thomas Hobbes (1588–1679) should also be mentioned. The basic thesis of positivism has often been conflated with another of Austin's theories, the imperative theory of law, which held that law is the command of the sovereign. Since this latter theory has not survived critical examination, it is crucial to distinguish it from the basic theme of positivism: that what the law is, is a separate question from what the law ought to be. H. L. A. Hart, the most influential contemporary positivist, placed particular emphasis on drawing this distinction.

Some legal positivists have taken their view to mean that laws must be obeyed no matter how immoral they are. But the most important positivists, Bentham and Austin, clearly argued that there are circumstances in which an immoral law should be violated despite its status as a law; this of course weakens the force of the claim that a law retains its status as a law despite its immorality.

In any case, legal positivists insist that questions about the relation between law and morality must be settled independently of questions about what the law is. The legal status of a rule is independent of its moral status. This leads us, therefore, to the second of our questions: When ought the law to be used to enforce certain moral positions?

Use of the Legal System to Enforce Morality

The law is clearly used on some occasions to enforce moral viewpoints. We believe that murder is wrong and that the coercive mechanism of the law should be used to prevent murders. However, even if we believe that euthanasia is wrong or that one should come to the aid of others in distress, should the law be used to enforce these beliefs?

John Stuart Mill (1806–1873), in his classic *On Liberty* (1859), advocated the liberal answer to that question—that society should use the coercive mechanisms of the law only to prevent actions that harm someone other than the performer or another who has consented to the performance of the action. In other words, Mill argued that the social enforcement of morality was inappropriate when only the agent or others who had consented would be harmed. In his elaboration of this position in *The Moral Limits of the Criminal Law* (1984–1988), the most important elaboration of the liberal position in the twentieth century, Joel Feinberg has argued that actions might be criminalized if they were profoundly offensive, even if not harmful, to others. Mill's followers have therefore opposed the existence of laws creating "victimless crimes," among which they have included laws against suicide and voluntary euthanasia, unless such laws are required to protect against mistake and abuse. They have also approved of court decisions that allow rational adults to refuse medical treatment on religious or on other grounds, even though the refusal would result in their dying.

A number of points must be kept in mind about the liberal position. First, it does not require legislation prohibiting all actions that harm others. Whether there should be legislation will depend upon such factors as the existence of harmful consequences and the possibility of enforcement. All that the liberal position entails is that such actions, because they harm others, are candidates for appropriate legal prohibition.

Second, actions that harm others may be prohibited legally, even when others consent, if their consent is not valid. This point is extremely important in connection with legislation governing medical experimentation. Consider, for example, the problem of experiments on children, where the experiments are not primarily intended to aid in their therapy and where there are potential hazards. Given that the consent of the children may not count if they are young enough, and given that the relevance of parental consent is unclear, Mill's principles could allow for enforcing some socially determined moral standards in this area. In fact, the 1993 U.S. regulations on research involving children enforce a very strict moral standard; the risks must represent only a minor increase over minimal risk, and the information must be of vital importance.

Third, this liberal position is not identical either with the English common-law tradition or with American constitutional law. Both have allowed for legal prohibitions that are unacceptable in the liberal framework. For example, the consent of the person killed in an act of voluntary euthanasia has been, at least until the early 1990s, no defense against a charge of murder in either legal system. Some of the language in the U.S. Supreme Court case *Cruzan v. Missouri Department of Health* (1990) suggests that many judges are now prepared to say that the right of a competent adult to refuse life-preserving therapy is a protected constitutional right, a result that liberals would applaud. Nothing in the text of this decision, however, suggests the extension of that view to assisted suicide or voluntary active euthanasia.

Adherents of the liberal approach have in recent years expanded upon it and modified it in a number of ways. One question that has received considerable attention is determining whose consent is valid. The current understanding of mental illness makes it very difficult to accept a sharp dichotomy between those competent to consent and those incompetent, since there are many degrees of mental disturbance. Some (including Buchanan and Brock) have responded that the standard for competency must be more demanding when the decision is more momentous. Others (including Brody) insist that we must recognize that competent decisions may be overridden when the costs to the individual are great and the person's decision making is impaired, even if he or she is somewhat competent.

Another question that has received considerable attention is the extent to which society can legitimately use the law temporarily to prevent an individual from carrying out certain decisions, to see whether the individual will change his or her mind or whether the choice is truly voluntary. Within the liberal framework, could we legally require, for example, a period between a request for voluntary euthanasia and the implementation of that request? Following Joel Feinberg, many liberal authors have allowed for this form of weak or soft paternalism.

A third question that has received considerable attention is the legitimacy of legally imposing certain positive moral duties. Mill was primarily concerned with challenging the legitimacy of laws prohibiting immoral actions; it is unclear how he would have dealt with Good Samaritan laws—laws that would, for example, require trained medical personnel to come to the aid of accident victims. Would such laws that require positive actions, and not mere forbearances, be a legitimate legal enforcement of morality? A final question that has received considerable attention is whether society can pass laws designed to prevent harm to animals. If it could, this would markedly change the liberal attitude toward laws governing experimentation on animals. Peter Singer and Tom Regan are two liberal authors who have advocated the extension of the liberal tradition in this way.

From its very beginning, the liberal tradition has had its critics. Writers in the natural-law tradition objected, of course, to the liberal presupposition that the moral and legal status of rules could be separated. But even some of those who agreed with positivism have argued that there is a wider scope for legislating morality than the scope allowed by Mill.

James Fitzjames Stephen (1829–1894), in his influential *Liberty, Equality, Fraternity,* argued that one of the purposes of both the criminal and the civil law is to promote and encourage virtue while discouraging vice. Stephen conceded that certain areas of morality could not be dealt with by the law because the relevant laws could not be enforced without destroying privacy and individual rights; he claimed, however, that there are many areas of morality that should be treated by the law despite Mill's strictures. This point of view has been extended by Patrick Devlin, a distinguished English jurist. Devlin contends that the continued existence and strength of a society require a common moral code. There is, therefore, a social interest in the preservation of such a code, and it is at least sometimes appropriate to enforce part of the code through the use of the law. Devlin limits his conclusions to cases where this enforcement of morality will not violate human rights. He applied this approach to English abortion legislation in the 1960s. He argued that the severe punishment of the illegal abortionist cannot be justified on the grounds that such a person poses a threat to the health of the mother, since that threat exists primarily because the abortionist's activities are illegal. Instead, such laws can be explained and justified only as an attempt by society to protect its fundamental views on sexuality and on human life.

A number of recent authors (Bellah et al.; MacIntyre; Sandel) have emphasized, in different ways, the importance of communities and a sense of community values, and they have seen this as standing in opposition to the liberal account. This new communitarianism no doubt has significant implications for the legislation of morality in areas related to bioethics, but those implications have not yet been studied systematically. There are, then, a number of differing systematic approaches to the question of which aspects of morality should be enforced legally. In addition to those systematic approaches, various authors and courts have suggested additional considerations that must be weighed in deciding whether legally to enforce moral standards. Among the most prominent of the considerations are the following.

1. Respect for differing views in a pluralistic society. In the 1973 discussion of abortion statutes in *Roe v. Wade,* the U.S. Supreme Court suggested that legislation enforcing a moral viewpoint is inappropriate when those who are experts in the relevant area disagree as to the legitimacy of that viewpoint. This principle is in keeping with a wider movement against legislating disputed moral positions. A number of important considerations support this mode of thought. To begin with, people seem to have a right to follow their own conscience rather than to be compelled to follow the conscience of the rest of society. Moreover, there are tremendous detrimental consequences for a society when many of its citizens feel that the law is being used to coerce them into following the moral views of others. Such considerations are even more important in societies where there are substantial moral disagreements among the citizens. One author who has particularly stressed the importance of respecting differing views in a pluralistic society is H. Tristram Engelhardt, Jr.

2. Respect for privacy. There are laws that cannot be enforced without infringing the privacy of the citizens involved. Following a long tradition that appealed to this point, the U.S. Supreme Court suggested (in *Griswold v. Connecticut,* 1965), that such laws are illegitimate because of the inability to enforce them in an acceptable fashion. For that reason, the Court declared unconstitutional a Connecticut law prohibiting the use (and not merely the production) of contraceptive devices. It has also been argued that laws regulating the patient–doctor relation are inappropriate because they can be enforced only by the state's entering into and examining a relation that must be private. Many authors have criticized the U.S. "Baby-Doe" law (P.L. 98–457, 1984), which limits on moral grounds the decision-making authority of parents and physicians with regard to severely disabled newborns, because it involves state intrusion into a private relation.

3. The consequences of passing such a law. It is sometimes argued that certain moral positions ought not to be enforced legally because the laws that codify them will be violated anyway, and their surreptitious violation will lead to many tragic results. Thus, it has been argued that laws prohibiting abortion only result in women seeking unsafe, illegal, and very dangerous abortions. Again, it has been argued that laws prohibiting voluntary euthanasia or allowing to die only result in surreptitious acts of voluntary euthanasia and in informal decisions to "let the patient die," acts and decisions that can be abused. Many studies of such abuses (by, e.g., Bedell and Delbanco; Evans and Brody) led in the 1980s to more formal policies governing such decisions.

Considerations 1–3 are reasons why certain actions should not be illegal, whether or not they are immoral. Most authors would agree that these legitimate considerations must be balanced against others that argue for the criminalization of the acts in question. These include the extent of the harmful consequences of the actions in question and the extent to which they involve infringements of the rights of others. There are, in addition, considerations for making actions illegal even if they are not immoral. Two deserve special notice:

4. The difficulty of distinguishing between fraudulent and legitimate cases. Suppose that there are no moral objections to voluntary euthanasia. Some have argued that it would be wise legally to prohibit such killings because it is difficult to distinguish cases of honest requests from cases of consent obtained by subtle fraud or duress. Again, some have argued that despite the moral permissibility of experimenting upon consenting adults, there should be laws prohibiting experiments conducted upon prison inmates, because one cannot tell when the consent of such inmates is truly voluntary.

5. Slippery-slope arguments. It is often argued that legalizing certain morally acceptable actions would later lead to irresistible pressures for legalizing immoral actions, and that the only way to avoid sliding down this slippery slope is to prohibit even the acceptable actions. Thus, it has been argued that voluntary euthanasia should be illegal, even if morally acceptable, as a way of ensuring against the later legalization of involuntary euthanasia. Naturally, both of these factors must be weighed against the possible desirable results of legalizing the morally acceptable actions.

Conclusion

It is clear, then, that there are no easy answers to questions about the relation between law and morality. There are strong considerations favoring legal positivism, but there are other considerations favoring a natural-law doctrine. And even if one is a legal positivist, there are conflicting considerations that one has to weigh in deciding on the appropriate relation between one's moral code and society's legal code.

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SEE ALSO: *Conscience; Conscience, Rights of; Consensus, Role and Authority of; Contractarianism and Bioethics; Ethics; Human Dignity; Human Rights; Justice; Law and Bioethics; Moral Status; Natural Law; Paternalism*

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LIFE

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Like many of the concepts foundational to the field of bioethics, life is a subject about which there is both longstanding conviction and increasing uncertainty. The beginnings and endings of life, as well as its creation, have become subject to greater technological modification, particularly through the rise of the modern biological sciences and new reproductive and genetic technologies. In the late twentieth century, increasing technological control over the management, regulation, and production of life and lifelike systems, as well as the accelerating commodification of life forms, raise questions about the limits of what can or should be done to life itself. Hence, seemingly timeless and universal human attitudes toward life, such as mourning in the wake of its loss and joy in its creation, are today accompanied by profound ambiguities concerning the meaning, value, and definition of life.

Some commentators have claimed that even a few decades ago life was more often understood as an absolute value—for example, among medical professionals, for whom the protection of life was an unquestioned moral duty (Parsons et al.). Related arguments hold that the technologization of life has produced a shift away from an understanding of life as an absolute value, and toward more relative assessments of the quality of life (Parsons et al., pp. 405–410). The appearance of an entry entitled “Life” in an encyclopedia of bioethics would support the position that life itself has become the object of increased management in the form of decision making.

In contrast to the urgent call for guidelines concerning the subject of life is the difficulty of defining this term. Neither philosophers, theologians, nor scientists can offer a clear understanding of life. This is in part due to the wide-ranging uses of the term. Not only does life have many meanings as a noun, it is a key term within a wide range of systems of thought from religion to science. In all of the many senses in which the word is used, definitions of it have varied historically in relation to changing social forces and cultural values. Contemporary moral, legal, theological, and scientific uncertainty attends the origins of life, the relative importance of human versus other forms of life, the beginnings and endings of life, the creation and destruction of life, and the nature of life. These and other concerns follow from the definitional issues, raised by the concept of life itself, that remain subject to dispute and ongoing transformation.

Historical and Cultural Variations

To be animate or vital is a condition for which cross-culturally and transhistorically there exists a range of modes of recognition. Broadly speaking, notions of life, or of a vital force, are often connected to beliefs about the supernatural, divinity, and sacredness. It is also generally the case that understandings of life are often made most explicit in relation to death (Bloch and Parry; Huntington and Metcalf). These features characterize both Judeo-Christian and classical understandings of life, the two predominant sources of its definition in the Euro-American tradition prior to the rise of modern science.

According to the Judeo-Christian tradition, life is interpreted and valued as a gift from God. The Old Testament relates that God created man (Adam) in his own likeness, with dominion over all living things. In the Garden of Eden, life was everlasting; and Adam and Eve’s expulsion, through which they became mortal, was both a sign of divine displeasure and a partial rescinding of the gift of life. According to the New Testament, the gift of everlasting life was restored through the sacrifice of God’s only begotten son, Jesus, and his resurrection to the kingdom of Heaven. Consequently, only those who believe in the resurrection of Christ have “life” in the Christian sense. When Jesus states “I am life” (or “I am the way, the truth, and the life”), it is the resurrection promised to believers in the life, death, and salvation of Christ that is invoked. The historian Barbara Duden notes:

> In most of the New Testament and in two thousand years of ecclesiastical usage, to “have life” means to participate as a believing Christian in the life of Christ.… Even the dead live in Christ, and only those who live in Christ can have life in this world. Of those who exist outside this relationship, the Church has consistently spoken of those who “live” under conditions of death. (p. 102)

Blood is a key symbol of life in the Christian tradition as well as in much secular culture, most notably medicine. To give the “gift of life” is more literally possible today than ever before in the context of organ donation, whereby a body part of a deceased person may “live on” in the body of another person, or a living donor may sacrifice a body part (such as a kidney) on behalf of a relative. The capacity to donate not only blood and vital organs but also egg and sperm cells, and the increasing availability of bodily tissues through a service sector and a marketplace, complicate the understanding of life as a "gift" (Parsons et al.; Titmuss). The sacrificial importance of the body and the blood of Christ makes the exchange of body tissue a potent symbolic practice, as does the definition of kin ties in terms of "blood relations."

The association between the flow of blood and the flow of life anticipates the notion of germ plasm (the hereditary material of the germ cells) as the basis for heredity; this in turn gives rise to the modern scientific concept of the gene, which is today described as the essence of life. While the gene in some senses represents the triumph of mechanistic explanations of life itself, the most reductionist accounts of genes as "selfishly" reproducing entities defined by the attainment of their own inbuilt "ends" may seem not dissimilar from that of the most influential proponent of vitalism, Aristotle. Aristotelian definitions of life were predominant for nearly two millennia, in part because Aristotle was among the few philosophers of antiquity to pay significant attention to the problem of defining life. According to Aristotle, life is defined by the possession of a soul, or vital force, through which an entity is rendered animate and given shape. The attainment of a predetermined end point is seen as the purpose of life in Aristotelian terms, a purpose that is contained in itself, independent of any external causal agent. This view is known as *entelechy*—a *telos,* an ultimate end that is self-defined as the achievement of a final form.

Although the Aristotelian view was based on close observations of the natural world and eschewed any notion of divine creation, it is strongly criticized by modern scientists for its *teleologism* (conflation of an endpoint with a cause) and *essentialism* (predeterminism), which are dismissed as metaphysical and therefore insufficiently empirical. Cartesian accounts of animation, which defined life in terms of the organization instead of the essence of matter, succeeded Aristotelian vitalism in the seventeenth century. From the perspective of mechanism, which explained motion or aliveness purely in terms of the articulation among parts of a whole (as in the ticking of a watch), Aristotelian vitalism came to be seen as mystical, nonobservable, and therefore unscientific.

The history of the concept of life in Western science, from which many of the most authoritative contemporary definitions of it are derived, underscores the importance of change and variation in the meanings of this term (Canguilhem; Schrödinger). Eighteenth-century natural historians employed a horizontal ordering strategy to classify diverse life forms into taxonomies of kind or type. A vertical ranking of the value of these life forms (known as the great chain of being, descending from God to humanity and thence to other living entities) was based on their proximity to the divine. According to this conceptual framework, *life* comprised a diverse array of animate entities classified epistemologically and ranked theologically in terms of proximity to God. The sacred act of divine creation that brought life into being was, in this schema, paralleled by the secular production by natural philosophers, such as Carolus Linnaeus (1707–1778), of a classification system through which life forms were named, defined, and ordered according to their perceived nature, which was seen to be immutable.

The stability of these vertical ranking and horizontal classifying axes was irrevocably shaken by the gradual acceptance of the evolutionary model of life, in particular the work of Charles Darwin, which, over the latter half of the nineteenth century, gained acceptance in Europe and America. With the rise of Darwinian theories of evolution came a radical new understanding of life: as an underlying connectedness of all living things. It was the evolutionary view of life as a distinct object of study in its own right that gave rise to the modern notion of *life itself*; not until this time could such a thing have been conceived. Many of the current dilemmas in bioethics demanding our attention came to be understood as a direct result of the emergence of this particular conceptualization of life.

As the historian Michel Foucault points out, life itself did not exist before the end of the nineteenth century; it is a concept indebted to the rise of the modern biological sciences.

> Historians want to write histories of biology in the nineteenth century; but they do not realise that biology did not exist then, and that the pattern of knowledge that has been familiar to us for a hundred and fifty years is not valid for a previous period. And that if biology was unknown, there was a very simple reason for it: *that life itself did not exist.* All that existed was living beings, which were viewed through a grid of knowledge constituted by natural history. (p. 128; emphasis added)

Life, in the sense of life itself, is thus a concept linked closely to the rise of the modern life sciences, founded on notions of evolutionary change, the underlying connectedness of all living things, and a biogenetic mechanism of heredity through which life reproduces itself. As the foundational object of the modern life sciences, the concept of life itself does not exist as a thing, as something visible or tangible. Only its traces are accessible, through the forms in which life manifests itself. Like Newtonian gravity, Darwinian life is a principle or force subject to an orderliness decipherable by science, such as the process of natural selection by which evolution is understood to proceed.

Life as Defined by Modern Science

From the vantage point of the modern life sciences, life itself has come to be associated with certain qualities, including movement, the ability to reproduce and to evolve, and the capacity for growth and development. Other criteria for defining life as opposed to nonlife include the capacity to metabolize, in particular through the possession of cells. These characteristics of aliveness in turn comprise key areas in the study of life forms, and in the forms of connectedness and interrelatedness among them. Whereas the comparative anatomy or morphology of animals and plants was the definitive technique for the classification of life forms during the classical period of natural history, it is molecular biology that today provides the primary analytic perspective on the essence of life, which is seen to be DNA, or the genetic code. It is DNA, composed of nucleotide chains that guide the manufacture of essential proteins, that all living beings are said to have in common. Thus DNA is the substance and mechanism of heredity intrinsic to the neo-Darwinian notion of life itself. (For a historical account of Darwinian notions of life itself, see Jacob. For a contemporary view, see Pollack.)

The most definitive accounts of life itself today rely on evolutionary and genetic models. “The possession of a genetic program provides for an absolute difference between organisms and inorganic matter,” claims the biologist Ernst Mayr, one of the great twentieth-century exponents of evolution as a unifying theme in modern biological thought (p. 55). “Life should be defined by the possession of those properties which are needed to ensure evolution by natural selection,” states John Maynard Smith, one of the leading evolutionary biologists in Britain (p. 7).

In addition to offering the most definitive accounts of life, the modern life sciences provide the most detailed and substantive information on the subject. In the article “Life” written for the *Encyclopaedia Britannica,* Carl Sagan notes: “A great deal is known about life.… Anatomists and taxonomists have studied the forms and relations of more than a million separate species of plants and animals.” A range of biological specialties have together compiled “an enormous fund of information” on the origin, diversity, interaction, and complexity of living organisms and the principles that order their existence (p. 985).

Yet even such definitive accounts of life from established scientific figures are often admittedly provisional. Both within and outside the scientific community there is considerable uncertainty about what is being studied when the subject is life itself. As Sagan notes perfunctorily, “There is no generally accepted definition of life” (p. 985).

Problems in Defining Life

The definition of life is not only contested from within the scientific community; it is also troubled by the proximity of lifelike systems, especially those that are computer-generated, to the requisite features of animate existence. There may well be, as Stephen Levy notes in his account of artificial life, a “particular reluctance to grant anything synthetic or man-made the exalted status of a life-form” (p. 6). Yet insofar as the biogenetic definition of life itself relies on an informational model, of DNA as a message or a code, the distinction between life and nonlife is readily challenged by complex informational systems that are to a degree self-regulating and that have the capacity both to replicate themselves and to evolve. If, as some have claimed (Oyama), information is the modern equivalent of form, then life is transformed from an absolute property into a receding horizon merging with artificial, synthetic, or virtual *life.* (see also Langton, and Levy).

Today, both the border between human and nonhuman life and the distinction between life and death are increasingly blurred. Genetic science offers the possibility of transspecies recombinations effecting a merging of human and animal body parts. Artificial-life scientists using information technology distinguish computer-generated organisms, which live, evolve, reproduce, and die, from the “wet” life forms they imitate (Levy). Health professionals distinguish degrees of death: dead (in the sense of brain-dead); double dead (respiratory failure); and triple dead (no body parts suitable for donation). Such distinctions indicate the increasing difficulties of establishing the parameters of life and death.

In sum, life itself may be charted along the course of its four-billion-year history to its estimated point of origin, and along this path may be classified and analyzed scientifically according to established principles, such as the operation of natural selection, and specific qualities, such as the possession of DNA. It is from the perspective of the modern life sciences that the most elaborate and definitive accounts of life are constructed, and from these in turn that the concept of life itself emerges. Yet the instability of these definitional parameters, like those of previous eras that they replaced, ensures their continued transformation.

Life as a Moral Issue

Despite the ubiquity and authority of biological definitions of life, they are also reductionist and materialist, relying upon mechanistic and objective terms that are ultimately most meaningful to professional specialists. Most people, when asked “What is life?” do not appeal to Darwinian principles.

Many of the more everyday definitions of life can be classed as processual or phenomenological, referring to the course of events comprising the life of an individual or other entity (including inanimate objects, as in the expression "shelf life"). Expressions such as *c'est la vie* ("that's life") invoke the fortuitous and inexplicable dimensions of life, very much in contrast to scientific accounts, which emphasize order and predictability even while admitting great uncertainty. Such expressions convey a sense of limits to the capacity for rational understanding, and especially prediction or control, in relation to the vicissitudes of life and living.

The lengthy debate in early modern science concerning *mechanism* (the presumption that animate and inanimate entities alike are composed of matter, which can be explained through inherent principles of structure and function) versus *vitalism* (the presumption of an inherently inexplicable vital force differentiating the quick from the dead) opposes the ancient association of lifelike properties with mystery and the sacred to their accessibility through instrumental reason (see Merchant). In relation to the moral questions concerning life—whether as a process, a possession, or a right—the vitalistic notion of life as something inexplicable and deserving of reverence and protection is far more prevalent than the more mechanistic and instrumental account dominant within science. In both secular and religiously derived accounts, life does not need to be fully explicated or rational to be seen as uniquely deserving of protection, especially human life.

The Protection of Life

In his discussion of abortion and euthanasia, two of the most controversial areas of debate concerning human life, philosopher Ronald Dworkin emphasizes the importance of recognizing that life is not exclusively or even primarily understood by many people in terms of scientific explanations, but rather in terms of a value more akin to sacredness. In relation to moral dilemmas, he claims, life does not present itself as a question of objective fact, but rather as a truth, or a "quasi-religious" principle held to be self-evident through "primitive conviction."

Dworkin's approach thus differs from the more utilitarian arguments about the beginnings and endings of life propounded by philosophers and other commentators who use rights or interest-based approaches to questions of the meaning and value of life. In demarcating the value of life as a "quasi-religious" one, something essentially felt rather than reasoned, Dworkin returns the question of the value of life to an older, more traditional paradigm linked to notions of divinity or a vital force.

Social scientists have shown the value of life to be a key symbolic resource in struggles of many kinds, including both ways of life (as in the preservation of ethnic traditions or indigenous cultures) and life forms (such as endangered species). Anthropologist Faye Ginsburg's study of the abortion debate in a midwestern American community, for example, demonstrates the symbolic dimensions of life as a subject of dispute extending to notions of citizenship, nationalism, and the sexual division of labor. Precisely because the preservation of human life may be seen as an absolute moral value, it proves readily amenable to the social function of grounding other beliefs and practices.

Abortion is one of the best-known arenas of controversy in which both definitions of life and the value of human life are paramount and explicitly formulated. Opponents of abortion argue that life begins at conception and therefore that the deliberate termination of a pregnancy is the taking of a human life, which is seen to be immoral or even comparable to murder. Proponents of a woman's right to control her own fertility, including the choice to terminate an unwanted pregnancy, often argue on the basis of consequentialism, that is, that the moral value of an act should be measured in reference to its outcome. Rights-based claims are used by both sides, antiabortionists stressing the right to life of the fetus, which they argue to be paramount, and pro-choice advocates stressing a woman's right to control her own reproduction, on which they, in turn, place primary importance.

Current legislation on abortion in many industrialized countries, including the United States, invokes a combination of rights-based arguments and biologically based distinctions. Hence, for example, the 1973 U.S. Supreme Court decision in *Roe v. Wade,* which currently determines abortion law in the United States, combines protection of the individual right to privacy with a biologically based definition of fetal viability as the determinant of the upper time limit for abortion. The same standard holds in Great Britain.

Both the notion of biological viability and the definition of the person to whom rights are ascribed invoke a particular construction of life. Viability, for example, is strictly biologically determined: It is measured by the ability of a fetus to survive biologically. The question of the social viability of a child's life, such as its likelihood of receiving adequate nurture, shelter, protection from disease, or sustenance is not considered part of the criteria valid in determining the morality of a decision to terminate a pregnancy. Feminists have been prominent in the challenge to the notion of the *person* often used by antiabortionists on similar grounds. It is undeniably the case that an embryo is human, that it is a being, and that it is a form of life. That it is a living human being is therefore undeniable. Yet it is no more or less a living human being in this sense than an egg or sperm cell, or for that matter a blood cell, none of which is considered a person or seen as entitled to civil rights. Increasingly, antiabortionists have used biologically based arguments to support their position, even when it is derived from religious principles. Hence, it is the potential for an embryo—unlike an egg, a sperm, or a blood cell—to develop into a human being that is often stressed. This argument is based on an embryo's possession of a unique genetic blueprint, which some established theologians claim is evidence of ensoulment (see Ford).

Hence, arguments against abortion based on fetal viability, or those that stress the genetic potential of the fetus to develop into a person, are based on a particular model of life, according to which its sanctity may be represented in biogenetic terms. Historian Barbara Duden has called this historically recent turn toward biology as an arbiter of moral decision making the "sacralisation of life itself." Life, in this sense, is not a biological fact but a cultural value, an essentialist belief, or even a fetish.

The Geneticization of Life Itself

Similar claims have been made regarding the biogenetic definition of life as possession of a genetic blueprint. Critical biologists have argued against the genetic reductionism or genetic essentialism such definitions risk (see Hubbard). Social scientists also have warned of the dangers of eugenicism implicit in such a view (Nelkin and Lindee); other scholars have minimized such risks (Kevles).

Advocates of a "strong" genetic essentialism argue not only that genes are the essence of life but that life itself is consequently based on the selfish desire to reproduce itself. From this vantage point, humans are mere epiphenomena of a primordial genetic drive to self-replicate, and human moral or ethical systems are a complex admixture of altruism motivated by strategic sacrifice, which benefits one genetic trajectory or another (Dawkins).

The belief that life processes will one day be subject to much greater control through instrumentalized understandings of their genetic code is the basis for a major expansion in the biotechnology industry, and corresponding scientific research, since the early 1980s. International scientific projects, such as the attempt to map the human genome by sequencing all of the DNA in the twenty-three pairs of human chromosomes, reflect the increasing importance of genes and genetic processes to the understanding of life itself (for a description of the Human Genome Project, see British Medical Association, and Cook-Deegan; for an account of the ethical dimension, see Kevles and Hood; for a critical account, see Hubbard and Wald). In turn, increasing information about the role of genes in heredity will pose new choices and decisions, as well as dilemmas, for many. On the one hand, new diagnostic procedures utilizing genetic screening to detect severe, chronic, degenerative, and often terminal disorders caused by a single gene are claimed to offer greater reproductive choice and control, and the potential to alleviate human suffering and disease. On the other hand, the identification of gene "defects" poses worrisome questions, especially when linked to notions of individual predisposition, genetic selection, and the elimination of "undesirable" traits. Controversies such as that attending the putative discovery of a "gay gene" underscore the dangers of social prejudice wedded to genetic determinism in the name of greater reproductive choice and control.

Altering the genetic code of an individual entity, be it human, plant, or animal, is most controversial when the alteration has the potential to be replicated in subsequent generations, therefore resulting in irreversible and cumulative hereditary effects. Although a distinction is currently maintained between somatic cell gene therapy (genetic alteration of nonreproductive bodily tissue) and germ-line gene therapy (genetic modification of the egg or sperm cells, or the early embryo), this boundary is known to be unstable. Considerable ethical concern therefore surrounds the advent of human gene therapy, now practiced in both Great Britain and the United States (for further discussion, see British Medical Association). The release of genetically engineered organisms into the environment, largely in the form of plants and microorganisms, has also attracted controversy, in particular concerning the labeling of foodstuffs and the limits of acceptable risk.

It is the biogenetic definition of life, then, that informs many of the moral debates about the protection of life, whether human, animal, or environmental—the latter category denoting the ecosystem as a complex "living whole" (for a discussion of protecting life as "biodiversity," see Wilson; also Kellert and Wilson). Confusions about when life begins, for example, as in debates about fetal rights, derive from a biogenetic definition of life, which is continuous: each life form has its origin in the lives of those preceding it, and their connectedness underscores the interrelation of life itself. Given such a definition of life, clear demarcations concerning the beginnings and endings of life, of a life, or of life itself are understandably subject to dispute.

Artificial Life

New techniques for technologically assisting the creation of life (e.g., assisted conception) and for prolonging life or redesigning life (genetic engineering) add to the difficulties of establishing a clear basis for decision making by health professionals, relatives, policymakers, or legislators. Technology now enables the production, extension, and even redesign of life forms, including humans, animals, plants, and microorganisms. Increasingly sophisticated medical technology has affected both the beginning and the ending of human life. Life-support technologies can artificially sustain human life in the context of severely restricted life functions both at the beginning of life (perinatal support) and toward the end of life, in cases where the individual becomes fully dependent on technology for respiration. Cases of prolonged "vegetative" human existence raise difficult questions as a result of the availability of technologically maintained biological viability. Insofar as a person is more than a biological life, difficult decisions concerning continued treatment for a person who is only minimally alive are the inevitable result of modern technology's capacity to sustain baseline survival functions indefinitely.

Technology also affects the creation of life itself. As medical scientists acquire ever greater command of genetic structure, the question of the ethical acceptability of the creation of life forms such as the Harvard "oncomouse," genetically engineered to develop cancer so it can be used in the design of new drugs for the treatment of human disease, must be addressed. The subject of a major patent dispute in the European Parliament, and removed from the market in 1993 by its manufacturer, DuPont, the oncomouse was among the first higher life forms to be defined as a technology, comparable to other forms of laboratory apparatus. As both a mammal and a scientific instrument, the oncomouse inhabits a domain subject to increasing ethical, commercial, and political controversy (Haraway).

Most significant, the oncomouse raises the question of ownership of life, which is established as an inviolable right for humans within the liberal democratic tradition and was described by humanist philosopher John Locke as "ownership of one's person." This principle, used in arguments favoring the emancipation of women and the abolition of slavery (both women and slaves being considered chattels), is more recently evident in disputes concerning body parts. In the landmark case of *John Moore v. California Regents,* conflict over the use of Moore's body tissue in the design of a drug, through production of an immortal cell line derived from his spleen cells, culminated in a U.S. Supreme Court decision prohibiting the individual ownership of bodily tissue. Ownership of human life in this case was declared not subject to extracorporeal extension.

The question is again different in the case of the "right to life" of the oncomouse, or the "geep," the transspecies hybrid of a goat and a sheep produced through genetic manipulation. Here, the question concerns the deliberate production of a life that brings great suffering to the resultant organism. Only the greater good to humans of such developments can justify their deliberate creation by scientists. But the basis for ethical decision making in such an instance remains indeterminate.

Conclusion

Many of the ethical questions addressed to life itself concern the degree of protection it requires. These questions in turn depend on how life is defined. Whether they concern the beginnings or endings of life, its creation, redesign, or sustenance under technological conditions, the underlying definition of life itself is a fundamental force shaping ethical decision making. Scientifically, life is defined according to the modern life sciences in a biogenetic idiom, which constructs it as a continuous and connected force unto itself, manifested by the self-replicating properties of DNA. In the liberal humanist tradition, human life is also seen as a possession, and the persistent association of life with sacredness is well established. The rights to life, the protection of life, and the quality of life are extended to some degree to other life forms, on the principle of avoiding cruelty and suffering. In none of these areas are definitive boundaries or limits available upon which to base ethical practice. Instead, as definitions of both life and death are subject to ongoing transformation, so are the ethical frameworks brought to bear on the creation, management, and protection of all life forms.

SARAH FRANKLIN (1995)
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SEE ALSO: *Abortion; Animal Welfare and Rights: Ethical Perspectives on the Treatment and Status of Animals; Cloning; Embryo and Fetus; Environmental Ethics; Human Nature; Life Sustaining Treatment and Euthanasia; Life, Quality of; Moral Status; Palliative Care and Hospice; Value and Valuation*

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LIFE, QUALITY OF

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I. Quality of Life in Clinical Decisions
II. Quality of Life in Healthcare Allocation
III. Quality of Life in Legal Perspective

I. QUALITY OF LIFE IN CLINICAL DECISIONS

Quality of life is one of the most important but controversial issues in clinical ethics. The contemporary development of the concept and its use as a normative criterion in clinical decision making date from the period after World War II, when advances in medical technology increased tremendously. Along with other ethical criteria—for example, a medical indications policy (Meilaender; Ramsey; U.S. Department of Health and Human Services); the ordinary-extraordinary means criterion (Connery; Johnstone; Reich, 1978a); or the reasonable person standard (Veatch)—quality of life is used in conflict situations to help make clinical decisions about whether or not to forgo or to withdraw medical treatment from patients.

Modern medicine has the capacity through the application of technology to save lives that until relatively recently would have been lost to acute disease or accident. As a consequence, some of these lives either are shaped by severe disabilities or chronic illness or continue to exist only at the biological level (for example, infants born with multiple congenital abnormalities; elderly patients who suffer chronic illnesses after recovery from an acute illness; and patients in a persistent vegetative state (PVS). Quality of life is frequently proposed as a criterion in making treatment decisions about these patients, whose lives might be saved only to be lived out in severely impaired conditions.

Quality-of-life considerations arise in several key areas of clinical ethics: termination or shortening of human life, including issues of abortion and euthanasia; limiting human reproduction, such as through contraception, sterilization, or abortion; interventions that alter the genetic and biological nature of humans, such as embryo cloning or eugenic engineering; and public policy areas, including economics, ecology, and cultural development (Reich, 1978a). This article will focus principally on the first issue.

Quality-of-life considerations raise a number of important questions that bear specifically on clinical ethics: (1) Given the tremendous advances in medical technology and the implicit imperative to use it, what are the goals and limits of medicine? (2) What is normatively human, and thus, what is it that we value about life? (3) Are quality-of-life judgments purely subjective, or are there objective criteria that guide them? (4) Can there be a life that is so burdened by pain or disability that it can be judged not worth living? (5) Who should decide to terminate treatment? (6) Is it morally legitimate to include considerations of the patient's prior medical condition in a decision about forgoing future medical interventions? and (7) Is it morally legitimate to include in treatment decisions the potential burdens on affected others who will have to care for a severely handicapped patient?

The following sections will provide some preliminary clarifications and conceptual frameworks for understanding quality of life; define quality of life and identify the spectrum of positions that come under the general heading of this normative criterion; articulate the evaluative status of life that is adopted in the various quality-of-life positions and compare the so-called quality-of-life ethic with the sanctity-of-life ethic; and analyze both the normative dimensions of quality-of-life judgments and the normative theories that justify these judgments.

Preliminary Clarifications

Statements or claims about a "quality" or "qualities" of life can be either evaluative or morally normative (Reich, 1978a; Walter). Evaluative claims or statements indicate that some value or worth is attached either to a characteristic of the person (for example, capacity to choose) or to a type of life that is lived (for example, free of pain and handicap). Thus, evaluative statements assess that the quality, and by implication the life that possesses the quality, is desired, appreciated, or even considered sacred. These statements, however, do not establish whether an action to support or to terminate life is morally right or wrong, nor do they specify which action would be morally obligatory. On the other hand, morally normative or prescriptive claims about a quality of life always involve a moral judgment on the valued quality and, by implication, a judgment on the life that possesses the quality. These latter statements, then, not only presume that a quality—for example, cognitive ability—is valued, but they also entail judgments about whether, and under which conditions, one must or ought to protect and preserve a life that possesses the valued quality or qualities. Thus, one could formulate a prescriptive claim that "any life that has cognitive abilities always ought to be given all medical treatment." Evaluative statements about quality of life do bear on clinical decisions, but the more important and controversial issues are concerned with the validity and use of the normative claims about quality of life, especially with regard to patients who lack any ability to participate in the clinical decision.

Many different perspectives could be used in establishing, defending, and assessing evaluative and normative claims in the area of quality of life. A feminist perspective could be used to analyze and critique an evaluative claim that proposes the discursive quality of rationality to be superior to a rationality based on the qualities of affectivity and caring (e.g., Gilligan; Sichel). A perspective from the elderly (Kilner) or the disabled community could be used to assess the normative claim that the qualities of youth, physical beauty, independence, and athletic ability—qualities that are extolled and prized in modern Western culture—are necessary for one to live well. Sociological perspectives could be used to study the cultural patterns of commitment to quality of life (e.g., Gerson), or legal perspectives to study the jurisprudential implications of these claims on the disabled (e.g., Destro). Each of these perspectives, and more, would be important to consult in adequately assessing both evaluative and normative claims about quality of life. However, the remainder of this article will use only the philosophical and theological perspectives that have been developed in the literature on quality of life vis-à-vis treatment decisions.

Definitions of Quality of Life

There is much ambiguity about what *quality of life* means, and consequently there is little agreement about the definition of this criterion. First, there is the word *life.* It can refer to two different realities in this context: (1) vital or metabolic processes that could be called *human biological life*; or (2) *human personal life* that includes biological life but goes beyond it to include other distinctively human capacities, for example, the capacity to choose or to think. Anencephalic infants and PVS patients have biological life, but they do not possess human personal life.

Similarly, *quality* can refer to several different realities. Sometimes the word refers to the idea of excellence. So defined, its meaning is bounded only by the horizons of our imaginations and desires. It is difficult to discover any objective criteria to assess quality-of-life judgments under this definition. Consequently, one may fear that patients whose lives cannot achieve the expected level of imagined or desired excellence, such as the handicapped or the dying, will either not be offered any life-sustaining treatment or will be actively killed.

Another possible definition is to understand *quality* as an attribute or property of either biological or personal life. Most proponents of quality of life subscribe to this general definition. Some authors identify quality of life with a single valued property of life, while others identify it with a cluster of valued properties. Thus, this definition represents a spectrum of positions. At one end of the spectrum is the original position of Richard McCormick, who isolated only one quality or attribute to be considered as the minimum for personal life: the potential for human relationships (1974). For McCormick, a Down syndrome baby would possess the potential for human relationships, but an anencephalic infant would not. At the other end of the spectrum, Joseph Fletcher originally defined the indicators of “humanhood” by reference to fifteen positive qualities, among them self-awareness, concern for others, curiosity, and balance of rationality and feeling, and five negative properties, among them, that humans are not essentially parental (1972). He believed that many, if not all, severely handicapped children would not possess the attributes necessary to live a life of quality. Between these two ends a number of “median” positions exist that identify quality of life with valued properties of life. For example, Earl Shelp has proposed minimal independence as the central property in his quality-of-life position. He includes in this basic property the abilities to relate to others, to communicate, to ambulate, and to perform the basic tasks of hygiene, feeding, and dressing. From this perspective, many, but not all, Down syndrome children would possess the necessary attributes to live a life of quality.

James Walter has suggested that the word *quality* should not primarily refer to a property or attribute of either physical or personal life. Rather, the quality that is at issue is the quality of the relationship that exists between the medical condition of the patient, on the one hand, and the patient’s ability to pursue human purposes, on the other. These purposes are understood as the material, social, moral, and spiritual values that transcend physical, biological life. The quality referred to is the quality of a relation and not a property or attribute of life. Thus, for patients to judge that they possess a quality of life means that the patients themselves would evaluate that, based on their medical condition, they are able to pursue values important to them at some qualitative or acceptable level.

Evaluative Status of Life

When quality of life is defined by reference to a property or attribute of physical life, then some basic questions are raised about the value of physical life itself. What is it that we value about our physical lives? Do we value biological existence in and for its own sake, or because of the presence of some property or attribute in that life, for example, cognitive ability? What theological or philosophical justifications can be offered for one's evaluations of life?

Many who define quality of life basically by reference to a property do not attribute intrinsic value to physical life. For example, in some of his writings McCormick has suggested that physical life does not possess inherent value but is a good to be preserved precisely as the condition of other values (1981, 1984). Based on his theological convictions that physical life is a created, limited good and that the ability to relate to others is the mediation of one's love of the divine, McCormick resists attributing to physical life itself the status of an absolute value. Kevin O'Rourke and Dennis Brodeur have stated that physiological existence as such is not a value if that life lacks any potential for a mental-creative function. Other quality-of-life proponents such as David Thomasma and his colleagues have described physical life as only a conditional value. According to these positions, what is valuable or worthwhile about physical life is either the properties that inhere in life or the values that transcend biological existence but whose pursuit is conditioned on the presence of physical life.

When quality of life is not defined as a property or attribute but rather as a qualitative relation between the patient's medical condition and his or her ability to pursue human values, then a different evaluative status is accorded to physical life. Walter has argued that physical life, as a created reality, is an ontic value, that is, a true and real value that does not depend on some property to give it value. He has tried to acknowledge that physical life is objectively a value in itself, though it may not always be experienced as such by some patients. Thus, physical life is not simply a useful or negotiable good; on the other hand, neither is it an absolute value that must be preserved in every instance.

Some commentators have attempted to address questions about the evaluative status of life by contrasting the quality-of-life ethic with the sanctity-of-life ethic (e.g., Johnstone; Reich, 1978b; Weber). Most proponents of a sanctity-of-life ethic (e.g., Connery; Johnstone; Meilaender; Reich, 1978a) do not argue that physical life itself is an absolute value. In this regard, at least, they agree with all proponents of the quality-of-life ethic. However, these authors frequently claim that when quality of life is understood as a property of life, either no value or only varying degrees of value is accorded to physical life. Possessing no intrinsic worth, physical life must receive its value based on whether it possesses one or more of the valued qualities, for example, neo-cortical function.

The sanctity-of-life position argues that this view is intolerable on several counts. First, quality of life does not acknowledge the equality of physical lives and the equality of persons because it assigns only relative or unequal value to physical lives and persons when certain valued qualities are only partially present or totally absent. Second, quality of life denies that all lives are inherently valuable, and so it leaves open the possibility that some lives can be deemed "not worth living." Finally, it is charged that the quality-of-life position adopts a two-level anthropology committed to protecting physical life only as an instrumental value (Reich, 1978b). Consequently, it is argued that the sanctity-of-life position is far superior because it affirms the equality of life on the basis that physical life is truly a value or good in itself. Life is not merely a useful or negotiable value, dependent on some other intrinsically valuable property.

In conclusion, it is not always clear how useful it may be to contrast sanctity of life with quality of life, as if each position could be represented by an individual and distinct "ethic." Because there are many positions that fit under each one of these "ethics," the terms and results of the comparison really depend on which two positions are selected.

Normative Considerations of Quality of Life

The most important issues related to quality of life in clinical decisions are those concerned with the normative dimensions of the criterion. This level involves several considerations: (1) assessments about what is considered normatively human, or what reasons can be adduced to consider a certain trait or property of life decisive in making a clinical decision to treat or not to treat; (2) the normative moral theory that grounds and justifies moral obligations; and (3) the limits or exceptions to moral obligations to preserve life and the moral justifications for these limits or exceptions. The first issue is definitional in nature, although it also entails some normative features. The second issue relates to the debate over deontology, which determines the rightness of actions by reference to moral rules or the doing of one's duty, and teleology, which determines moral rightness by reference to the ends or consequences of actions. The third issue involves a discussion of the nature and degree of obligation in moral duties to preserve life.

Before turning to actual positions and their normative implications, it is important to distinguish cases where quality-of-life judgments are made by patients who possess decision-making capacity, and those cases where patients—for example, PVS patients, neonates, or severely mentally handicapped adults from birth—lack the capacity to decide. Many issues need to be faced once patients with decision-making capacity are permitted to make treatment choices based on their own assessments of quality of life. However, these problems may pale in comparison to the application of the quality-of-life criterion to situations where a proxy or surrogate must make a decision to terminate treatment.

Some authors (e.g., Ramsey) argue that quality-of-life judgments should never be permitted in treatment decisions for patients who lack decision-making capacity. Only competent patients can make these judgments for themselves; no one may morally substitute his or her quality-of-life judgments for those of someone else. Thus, the moral criterion that applies in treatment decisions for patients who lack decision-making capacity is whatever is medically indicated. However, quality-of-life proponents argue that the medical indications policy could be devastating for these patients. If surrogates do not apply some measure of the quality-of-life criterion, these patients may be condemned to lives of pain, suffering, or burden that no person with decision-making capacity would reasonably choose (Hastings Center). Most of the following considerations will be concerned with the use of quality-of-life judgments in cases involving patients who lack decision-making capacity.

When some proponents of this criterion define quality of life as a property or attribute that gives value to physical life, they are either implicitly or explicitly defining what is normatively human, that is, how personhood ought to be defined. For example, when Fletcher originally defined the fifteen positive and five negative indicators of humanhood, he was defining the nature of personhood, and therefore, who is morally entitled to medical care. If a handicapped neonate or adult lacked a number of the indicators of humanhood but needed medical treatment to survive, in Fletcher's view (1972), the patient should not be treated.

The moral obligation to treat or not to treat patients is derived from the objective presence or absence of a valued property that gives worth and moral standing to the patient's life. When the properties that define humanhood are absent, the patient is not considered a moral subject who possesses any rights to healthcare. The moral theory that Fletcher adopts in his quality-of-life position is a form of teleology called consequentialism. In this theory, any moral claim about the value of a patient's life or any moral duty to provide medical treatment is almost entirely based on predictable qualitative consequences for the patient or for others whose interests are involved in the situation.

In a similar position on quality of life, Earl Shelp has sought to articulate the quality or property that defines the normatively human for handicapped neonates and the extent to which parents and the medical community have moral obligations to these never-competent patients. He adopts a quality-of-life position that corresponds to the main features of a property-based theory of personhood. A property-based theory, as opposed to a genetic-based theory, seeks to designate a desired quality or property that must be present before one can consider a particular human life to be an unqualified member in the moral community.

Shelp has argued that any neonate must possess the possibility of attaining a "minimal independence" before the child can be considered a person in a full sense. If the newborn will never have the capacity of minimal independence, even with the help of modern medicine, then the parents can decide on the basis of quality-of-life considerations that their child, who is in need of medical treatment, should not be treated.

The normative position that underlies Shelp's quality-of-life criterion is a type of a socially weighted calculus. Because he believes that no newborn, whether normal or impaired, is a full member of the moral community (person), he maintains that there is no compelling reason why a severely defective newborn's interests should take priority over those of the parents or siblings who are already persons in a moral sense. In fact, the interests of the ill newborn can be weighed against the independent interests of those whom the child will affect. Thus, if the burden imposed on others is unreasonable or disproportionate, then a decision to forgo or terminate all treatment for the imperiled child is morally legitimate.

What may be problematic in both Fletcher's and Shelp's versions of quality of life, and certainly what worries all opponents of quality-of-life positions, is that their views appear to define and prescribe the "good life" in terms of the quality or qualities necessary to live a minimal moral existence. Their positions then become entrapped within what William Aiken has called the "exclusionary" use of quality of life. The lack of certain valued qualities in a patient's life is a way of positively excluding potential patients from the normal standards of medical and moral treatment.

Other versions on the spectrum of quality-of-life positions do not limit the meaning of quality of life merely to a property of life and then establish moral obligations on the basis of the presence or absence of the property. In addition, these positions do not define the normatively human by reference to a valued attribute and then identify it with quality of life. For them, quality of life functions as a way to include in the clinical decision what they believe are morally relevant factors that are often excluded by other criteria. In other words, some proponents of this normative position hold that quality of life is a patient-centered way of discovering the best interests of a patient.

These authors (e.g., Sparks) argue that in the clinical situation for noncompetent patients, we should be trying to discover what is in their best interests. They recognize that other criteria, such as the ordinary-extraordinary means criterion, have also been used to determine the patient's best interests, and that these criteria have been used to ground moral duties to patients in treatment decisions. However, they argue that these criteria often exclude some morally relevant factors needed to make an adequate and informed moral judgment, for example, the experienced burdens of the patient's prior medical condition in cases of spina bifida.

A comparison of the quality-of-life criterion with the ordinary-extraordinary means criterion might be helpful in illustrating the point that these authors are making. Those who subscribe to the ordinary-extraordinary means criterion argue that all ordinary means of preserving life are morally obligatory, but extraordinary means are morally optional. They do permit surrogates to use what could be called a limited version of the quality-of-life criterion. Surrogates can legitimately include quality-of-life considerations in their treatment decisions, but these considerations are only valid where the treatment itself would cause either excessive harm or leave the patient in a debilitated state (Connery; Reich, 1978b). For example, a surrogate could morally refuse quadruple amputation because the surgery itself would leave the patient with such an extremely low quality of life that the patient would have no duty to undergo the surgery.

All too often, however, the use of this criterion excludes all quality-of-life considerations that cannot be directly connected to the treatment itself or to its application. For example, the fact that a child who is born with Lesch-Nyhan syndrome will have a very poor quality of life is not considered relevant in the clinical decision to treat the child for a life-threatening condition. Lesch-Nyhan is an incurable genetic disease that causes its victims to suffer uncontrollable spasms and mental retardation. Once the young patients of this disease develop teeth, they gnaw their hands and shoulders, and they often bite off a finger or mutilate other parts of their bodies.

Some proponents of the quality-of-life criterion (e.g., McCormick, 1986; Sparks) identify this criterion with the category of "patient's best interests." They adopt what they believe is a patient-centered, teleological assessment of the best interests of the patient. If a patient in a life-threatening condition does possess at least a minimal ability to relate to others, then it can be presumed that the patient would want treatment; thus, treatment should be provided. This form of the quality-of-life criterion maintains that physical life itself is the ground of a prima facie duty to preserve it.

However, other factors—for example, the patient's prior medical condition, which might include permanent loss of all sentient and cognitive abilities, or the financial cost to the family and society of caring for these patients—also come to bear in determining the actual moral duty these patients have to preserve their own lives. Proponents of this version of the criterion argue that medical interventions to continue the lives of accurately diagnosed PVS patients and neonates born with anencephaly or hydranencephaly are unwarranted. These patients have reached the limits of their moral obligations to preserve their own lives, based on an assessment of their best interests. Any medical intervention to save their lives would only perpetuate a condition that most people who possess decision-making capacity would judge burdensome and intolerable. These authors do not judge that some patients' lives are not worth living; however, they do argue that the experienced burdens on patients' lives prior to treatment must be considered in determining the patient's best interests, and thus whether the patient himself or herself has a moral obligation to preserve life.

One of the more difficult questions involved in the debate over the use of quality-of-life judgments is whether one can include in the assessment of best interests of the patient any of the burdens that accrue to affected others. For example, when a family must face the tragic situation of financially and psychologically caring for a severely handicapped child, many would find such a lifelong commitment quite burdensome. Must one discount in treatment decisions the burdens experienced by the family and society in caring for these children, and focus only on the burdens imposed on the child either by the disease or by the treatments themselves? Or is it morally legitimate to include at least some of the burdens imposed on the family and society in assessing the patient's best interests? In other words, how broadly should one interpret the category of "best interests of the patient"? And finally, should the interests of others be considered in their own right? These are some of the questions that the proponents of quality of life regularly ask in clinical situations.

Richard Sparks (1988) is critical of any position that tries to understand the proportionality of benefits and burdens in a way that weighs a severely handicapped child's claims against the interests, claims, and rights of others who are affected, whether within the family or in society. He is also critical of quality-of-life proponents like McCormick, whom he sees as too narrowly defining the range of burdens in these cases. Sparks suggests the phrase "total best interests" as a way not only of including the burden experienced by the patient but also of including the broader social factors, for example, the financial cost, psychic strain, and inconvenience borne by others. He reasons that the patient's social nature must be taken into account, not only in calculating benefits (for example, the benefit to the patient derived from his or her ability to relate to others), but also in calculating burdens (for example, psychic strain to the family or financial cost to society).

Sparks's version of the quality-of-life criterion rejects a socially weighted calculus similar to the one Shelp adopts in determining the best interests of the patient. He judges that such a calculus denies the inherent worth of each individual patient, and that it weighs the benefits and burdens experienced by the patient against those of affected others. Although he argues that the burden to others should be included in assessing the total best interests of the patient, this burden is only one factor among many that must be considered. What is essential is that one not construe the burden to the patient and the burden to affected others as being in competition with one another when making decisions to terminate medical treatment.

By trying to construe the social burdens from the patient's perspective, Sparks believes one can avoid the competitive atmosphere that is part of the socially weighted position. His version of quality of life seems to imply that the child would not, and perhaps should not, want to be treated if it were an excessive social burden because the child's best interests would not be served if these burdens were placed on those who must care for him or her.

The spectrum of definitions and positions representing quality of life makes it difficult to identify any one quality-of-life ethic for analysis or critique. Though there are some shared features among the various positions, in the end it is necessary to assess the validity or invalidity of each position on its own merits.

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SEE ALSO: *Abortion; Aging and the Aged; Death; Ethics: Normative Ethical Theories; Family and Family Medicine; Genetic Testing and Screening; Life Sustaining Treatment and Euthanasia; Long-Term Care; Mentally Disabled and Mentally Ill Persons; Narrative; Pain and Suffering; Palliative Care and Hospice; Rehabilitation Medicine; Virtue and Character;* and other *Life, Quality of* subentries

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II. QUALITY OF LIFE IN HEALTHCARE ALLOCATION

Issues concerning quality of life in healthcare allocation arise from three factors. First, there is an important project that a society wants to undertake: in this case, to provide access to healthcare for more of its citizens. Second, unlike the ordinary marketplace, in which individuals purchase what they want for their own reasons, with no need to seek anyone else’s agreement about what to purchase, a society that collectively funds a community project such as healthcare must agree on what outcomes will count as fulfilling that goal. Third, resources are limited partly because taxpayers cannot be expected to forfeit an unlimited amount of their income, and partly because there are other important projects that command taxpayers’ funds. Together, these three factors mean that a society needs reasonable assurance that expenditures will actually enhance health without wasting resources.

Prioritizing expenditures becomes urgent because healthcare is extraordinarily expensive, commonly consuming around 15 percent of the gross domestic product of the United States. The need is further dramatized by various cases in which families of patients with anencephaly or persistent vegetative state have insisted on unlimited medical support, regardless of the cost, on the grounds that all life is infinitely precious (*Matter of Baby K,* Miles). Many who have commented on such cases deem it wasteful to prolong the life of someone who will never be conscious while so many other social needs, from healthcare to education, are underfunded. More controversial examples point out the trade-offs between costly new technologies that benefit a few identified patients versus more routine kinds of care that benefit many more people whose identities may never be known (Eddy, 1992a, 1992b). Cases such as these raise the question of whether it is permissible, and if so in what way, to consider quality of life in healthcare resource allocation.

There are two ways to do so. Negatively, one might rule out certain kinds of expenditure on the grounds that they produce little or no benefit for the patient. This might be based on evidence that the treatment has not been shown to be effective, as when a treatment is highly experimental or when a patient is so close to death that no medical interventions can help. Positively, one might invoke quality-of-life judgments to give funding priority to health interventions that will produce the greatest overall benefit for the money spent. Since healthcare is intended to improve as well as prolong life, quality-of-life judgments could shape this quest for the greatest benefit.

It is important to identify some basic distinctions. To speak of the quality of life is not equivalent to making judgments about the value of that life. Persons suffering from a painful terminal illness might have a poor quality of life even though their value and dignity as human beings are every bit as precious as those of healthier persons. Similarly, the quality that someone’s life has for himself or herself is not equivalent to the impact that the person has on another person’s quality of life. A patient suffering from advanced Alzheimer’s disease or other dementia, for instance, might be content and free of suffering, while posing serious burdens and sorrow for family members. Finally, judgments about the quality of an individual’s life might come from the individual himself or herself, or from others. Several of the most commonly used instruments for measuring quality of life rely on views elicited from the public at large as they contemplate the life quality caused by certain illnesses or disabilities. However, these opinions may not match the views of people who actually experience these conditions.

Formulas for Measuring Health Benefits

A variety of instruments have been developed to measure the benefits of healthcare interventions. The *human capital* approach, for instance, measures the value of saving or prolonging a life by projecting that person’s future earnings. This method is not widely accepted, mainly because it looks only at market valuation of economic contributions, and not at broader features of the person’s experiences, relationships, and noneconomic contributions.

A more sophisticated instrument, the *willingness-to-pay* approach, hypothetically lets individuals determine what value they place on a prolongation or improvement of their lives by indicating how much they would actually be willing to pay in order to avoid a certain risk of mortality or morbidity, or to gain a chance at improving their lot. Though this approach permits individuals to make their own quality-of-life judgments, its main disadvantage is that it could represent wealth status rather than personal preferences, which may in turn reflect factors such as social injustices (Brock).

A still more sophisticated approach does not try to translate morbidity and mortality directly into cash equivalents, nor to count lives saved or the number of years saved by a particular healthcare intervention. Rather, it attempts to determine the effect that an intervention has on the quality as well as duration of life by computing Quality-Adjusted Life-Years (QALYs). Extending an extra year for a patient in a vegetative state, for instance, is presumably not as worthwhile as adding a year of vigorous, healthy function. This approach estimates the quality of life that may accompany a particular set of circumstances before and after a proposed intervention, such as a medical treatment or a course of physical therapy, and calculates how long the change is expected to last. The net value of that intervention can then be compared with the value of other healthcare interventions to determine which ones produce the greatest value.

Quality of Life Measurements: Application and Controversy

Various instruments have been used to measure quality of life. The Quality of Well-Being (QWB) Index defines twenty-four health or functional states from perfect health to death. Through questionnaires and community surveys, each QWB state is given a weight, from zero for death to one for perfect health (Kaplan, 1992, 1985; Kaplan et al.). Other scales, such as the Quality of Life Index or the Sickness Impact Profile, evaluate quality of life according to factors such as ability to perform daily activities, feelings of satisfaction with one's health status, and the like (Brock; Zeckhauser; Zeckhauser and Shepard; Wenger et al.).

The state of Oregon used the QALY approach in an effort to ensure, on the negative side, that it does not waste limited state dollars, and on the positive side, to maximize the good achieved by its Medicaid program by avoiding marginally valuable expenditures while expanding coverage to encompass numerous uninsured people. Initially, a series of town meetings and phone surveys elicited community opinions about the value of a variety of conditions, such as perfect health, feeling depressed and upset, being burned over large areas of one's body, and so on. The value system thus generated was then combined with physicians' estimates of the magnitude and duration of effects produced by various medical interventions for those assorted conditions. After combining the QALY units derived for these treatment/condition pairs with their respective costs, a priority list was developed. Taking the prevalence and cost of treatment for each condition on that list, accountants were able to tell the legislature how much money would be required to fund the program as the next lower priority item was added. The legislature then set its Medicaid budget and identified a cutoff point: Eligible recipients would receive all services prioritized above that line, but not below it (Garland; Eddy, 1991; Hadorn; Kaplan, 1992). This first attempt yielded enough unexpected and unsatisfactory results that the priority list was significantly changed before the program was finally approved (Eddy, 1991).

The problems the Oregon process encountered illustrate the ethical challenges in using quality-of-life considerations in healthcare allocation. They begin with methodological problems. Oregon's plan, and QALY approaches generally, are criticized for ignoring the wide variations of severity that can characterize any medical condition, from broken bones to lupus, and the equally varying results that any given treatment can have for a particular condition. Further, it is not clear whose values should be attached to these factual descriptions. Opinions solicited from the public at large may be based on a poor understanding of the medical condition at stake. A one-sentence summary on a questionnaire, for instance, is hardly sufficient for understanding what it is like to live as a paraplegic. The Oregon plan, in particular, was criticized for eliciting values mainly from articulate, middle-class persons rather than from the poor and disabled, who would be most affected by the resulting distribution of healthcare resources. On the other hand, it is not always possible to discover patients' views on their own quality of life. Advanced dementia, infancy, stroke, retardation, and a host of conditions can prevent the individual from expressing his or her views or even, in some cases, from conceptualizing his or her quality of life. These and other methodological criticisms (Morreim, 1986, 1992) are important, because even if one can on principle justify allocating healthcare resources according to treatments' impact on life quality, it is morally more difficult to justify using measures that may not capture what they should.

Moral issues also concern the very idea of using quality of life as a basis on which to allocate care. Vitalists who believe that all life is infinitely valuable, regardless of its quality, simply reject the idea that interventions should be graded according to how well they enhance quality of life.

Others, however, insist that it is wasteful, if not unconscionable, to spend limited resources sustaining the lives of permanently unconscious or imminently dying patients.

A corollary objection insists that the cost of treatment is no reason for restricting it. Individuals should not suffer needlessly just because their care is costly. Rather, costs should be contained in other ways, such as by eliminating wasteful expenditures. In reply, it is argued that needs are always greater than resources, rendering rationing inevitable, and that overt public decisions are preferable to covert priorities.

A further critique holds that maximizing QALYs, somehow reified as a good in themselves, ignores the justice of the distribution. In one of the classic challenges to utilitarianism, critics point out that a pure cost–benefit approach can ignore terrible suffering, simply because some other intervention may be cheaper and help larger numbers of people. The first listing of Oregon's priorities, for instance, ranked dental caps for pulp exposure higher than surgery for ectopic pregnancy, and splints for temporomandibular joints higher than appendectomies for appendicitis. Although some people might reply that only the methodology needs to be adjusted (Eddy, 1991), others would argue that this approach is inherently incapable of honoring the preciousness that attaches to the lives and well-being of individual people (Hadorn). Severely disabled persons may not be capable of enjoying as great a benefit as healthy persons snatched from the jaws of death, but their comfort and personhood are not necessarily less important.

Another controversy concerns whose values should shape estimates of life quality. If the purpose of medical interventions is to help individuals, perhaps patients should be permitted to define for themselves what constitutes a benefit. Studies indicate that persons afflicted with a particular malady often rate their quality of life higher than observers do (Evans et al.). On the other hand, a broader kind of fairness might require recognizing that sometimes individual preferences are costly and idiosyncratic, and acknowledging that the community paying for care should be permitted to use its own community values to determine monetary allocation (Morreim, 1986, 1992).

A related concern points out that the QALY approach inherently discriminates against the elderly and the disabled, whose prognoses and initial quality of life are typically lower than average. In reply, it is argued that the elderly at least have had the opportunity to complete their life's biography (Callahan), and that while methods to value the comfort and improved function of the disabled can be developed, aggressive medical interventions may not serve the most severely compromised patients well.

Conclusion

The issues cannot be resolved here, but a few comments seem pertinent. First, society is not required to fund every expenditure that each citizen might find worthwhile. Vitalists should arguably be permitted to seek life support for permanently unconscious loved ones, but this does not entail that a society that does not share this belief must pay for their quest (Morreim, 1992). Second, the moral character of a society is at least partly reflected by the ways it treats its weakest members. The fact that someone is not useful to others does not entail that his or her sensibilities are insignificant or undeserving of help. Third, those obligations are not unlimited. There is a virtually endless variety of ways in which society can arrange its resource priorities, and none of them is the single morally correct approach. What is probably most important is to implement procedures that are fair and open to wide participation, are sensitive to varying viewpoints, and embrace a respect for citizens as persons (Brock, Engelhardt).

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SEE ALSO: *Chronic Illness and Chronic Care; Communitarianism and Bioethics; Consensus, Role and Authority of; Economic Concepts in Healthcare;* and other *Life, Quality of* subentries

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III. QUALITY OF LIFE IN LEGAL PERSPECTIVE

Law has addressed quality-of-life issues primarily in the context of the withholding or withdrawal of life-sustaining medical intervention. The legal dilemma arose when medical technology became capable of keeping alive persons with gravely debilitating and potentially fatal afflictions long beyond the point that most people would wish to live. The questions became: Under what circumstances is the removal of life support lawful? Can decisions to remove life support be grounded on quality-of-life factors?

Many sources contend that deteriorated quality of life—in the sense of a patient's mental and physical debilitation—is a natural and inevitable element in shaping the bounds of medical intervention in the dying process. Most people, faced with a prolonged and debilitated dying process for themselves or a loved one, prefer that life support be withdrawn at some stage of deterioration. Decisions about life support for formerly vital people are therefore often grounded on factors such as extreme mental dysfunction, immobility, and helplessness.

The opponents of using quality-of-life factors in ending people's lives cite numerous concerns. The most common is that judicial or legislative sanctioning of quality-of-life considerations will undermine the traditional focus of both criminal and tort law on preserving and protecting all human life, regardless of quality. One asserted hazard is that quality of life will be measured in terms of utilitarian elements such as cost of care, social productiveness of the patient, and burdens imposed upon the people caring for the patient. Such a utilitarian calculus would place the lives of the weak and vulnerable—the very young, the developmentally disabled, and the elderly—at particular risk (Destro).

Even if quality-of-life considerations are confined to factors that, from the patient's own perspective, make existence intolerable, some observers find moral hazards. If dismal quality of life focuses on physical and mental dysfunction, a concern is that the lives of disabled persons generally might be devalued and their morale eroded. Surrogate decision makers for incompetent patients might also be insensitive to the true quality of life as a disabled person, so that vulnerable populations would be endangered by arbitrary determinations. Some sanctity-of-life proponents prefer to protect and support all human existence even in the face of fatal afflictions and severe degeneration.

This tension between sanctity of life and quality of life has surfaced in a number of legal settings. Each of the following sections discusses the resolution of that tension in a particular legal context.

Patients Competent to Make Their Own Decisions

Current law, rooted in concepts of self-determination and bodily integrity, establishes that competent patients are entitled to reject life-sustaining medical intervention. The relevant cases recognize that patients can and often do base their rejection of life-sustaining treatment on quality-of-life factors. That fact emerges most clearly in cases involving severely disabled persons who reject treatment capable of preserving their existences for many years.

The typical situation involves a quadriplegic person dependent on mechanical life support who finds the debilitated existence so painful or demeaning that he or she orders the cessation of life-sustaining measures (*McKay v. Bergstedt,* 1990; *State v. McAfee,* 1989; *Bouvia v. Superior Court,* 1986). Courts uniformly uphold the patient's decision. These courts recognize that patient self-determination encompasses personal values and preferences about whether a prospective medical state is intolerably painful or degrading—that is, constitutes an unacceptable quality of life. A California court explained:

> Since death is the natural conclusion of all life, the precise moment may be less critical than the quality of time preceding it. Especially when the prognosis for full recovery from serious illness or incapacity is dim, the relative balance of benefit and burden must lie within the patient's exclusive estimation: "That personal weighing of values is the essence of self-determination." (*Thor v. Superior Court,* 1993, p. 384)

These same courts reject any notion that judicial acceptance of debilitated patients' fatal decisions weakens respect for life generally or devalues the lives of the disabled. The judges view their decisions as upholding individual autonomy and thereby promoting a critical element of human dignity, rather than as denigrating the sanctity of life.

Incompetent Patients

Many medical patients lack the capacity to make their own decisions about life-sustaining treatment. A surrogate must then act on the patient's behalf. Some commentators oppose the use of quality of life—determining whether a patient's life is "worth" preserving—in decision making for incompetent patients (see Wicclair, pp. 56–60). Again, the concerns include use of utilitarian factors such as economic costs and social unproductivity of the patient. Beyond that, sanctity-of-life proponents fear arbitrary decisions by surrogates who are insensitive to the value of disabled persons' lives or motivated by self-interest.

In some instances, the now-incompetent patient has exercised personal autonomy by previously, when competent, issuing written or oral instructions about terminal medical care. Both courts and legislatures accept in principle this prospective autonomy (though some state legislatures have confined their endorsement of advance medical directives to situations in which the patient is in a "terminal" state). Through advance instructions, people can seek to discontinue medical intervention at a point when their existence becomes intolerable according to their own previously expressed definitions of quality of life.

The situation is more complicated when a now-incompetent patient facing a potentially fatal affliction has never clearly articulated personal values and preferences about life-sustaining medical intervention (Cantor, 2001). Courts in a few states disallow any terminal decision on behalf of an incompetent patient who has never issued advance instructions that clearly and convincingly express the patient's desire to forgo life support in the medical circumstances at hand (*In re Westchester County Medical Center,* 1988; *Cruzan v. Harmon,* 1990; *Mack v. Mack,* 1993; *DeGrella v. Elston,* 1993). A few state courts insist on clear and convincing evidence of the now-incompetent patient's prior wishes only when the patient is still conscious (*Spahn v. Eisenberg,* 1997; *In re Martin,* 1995; *Matter of Wendland,* 2001). These courts all express grave apprehension about allowing surrogates to determine that another person's life is not worth preserving. To foreclose end-of-life decisions grounded on the surrogate's values rather than the patient's, they insist either upon the patient's personal prior assessment of an intolerable quality of life or upon legislative guidance concerning what kinds of deteriorated existence are so undignified as not to be worth preserving.

Insistence upon clear-cut prior instructions as a prerequisite for withdrawal of life support from an incompetent patient disregards certain interests of people who have simply neglected to address the issue of terminal care (as well as those of people who have never been competent). The hazard is that such persons, once afflicted with debilitating medical conditions, will be indefinitely maintained in a status that the patients themselves would deem intolerably painful or demeaning, were they able to express their wishes. In the words of one judge, invariable preservation of life without regard to the incompetent patient's prospective deteriorated status "transforms human beings into unwilling prisoners of medical technology" (*In re Guardianship of L.W.,* 1992, p. 74). To avoid this unfortunate consequence, most courts that have spoken to the issue allow some surrogate decisions to reject life support even in the absence of prior instructions.

Courts subscribing to this position usually articulate a best-interests-of-the-patient standard to guide the surrogate decision maker (*In re Conroy,* 1985; *In re Grant,* 1987). This normally means that in order to justify removal of life support, the "burdens" to the patient must clearly outweigh the "benefits," with irremediable suffering being the primary burden and pleasure being the primary benefit. The relevant cases carefully exclude "social utility" or "personal worth" as factors in the best interests calculus (*Conroy,* pp. 1232–1233). However, the role of quality of life (in the sense of a severely deteriorated and undignified patient status) is uncertain. Quality of life or dignity of the patient is often mentioned as an element within the best-interests formula (*Rasmussen v. Fleming,* 1987; *Grant,* 1987). Indeed, in 1983 the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research listed "quality as well as the extent of life sustained" as a major component within the best-interests standard. But in application in the reported cases, quality of life has been a determinative factor primarily in the context of permanently unconscious patients.

A few commentators have suggested that the concept of "medically inappropriate" or "futile" treatment ought to fix the bounds of life support for gravely debilitated patients (e.g., Jecker). Futile treatment, in the sense of medical intervention that cannot achieve a particular physiological goal, may be a meaningful and useful concept. But when medical intervention can extend life, albeit debilitated life, the futility concept is much less helpful. A determination that life-sustaining medical intervention is futile really represents a judgment that the quality of life is so dismal that life support ought to be withdrawn as inconsistent with the best interests of the incompetent patient or as contrary to the patient's likely preferences. That determination may be appropriate for surrogate decision makers (in conjunction with medical staff), but it cannot be the province of medical personnel alone (Cranford and Gostin; Veatch and Spicer, 1992).

Patients in a Permanent Vegetative State

A permanently unconscious patient cannot experience suffering or sense the bodily invasions that normally constitute "burdens" to be assessed under a best-interests-of-the-patient standard. At the same time, permanent unconsciousness represents a dehumanizing condition, with the patient indefinitely devoid of sensation, emotion, or human interaction. The vast majority of people contemplating such a status deem it so degrading that they would not want to be medically sustained in that insensate condition. (Some commentators even argue that the legal definition of death should be changed to include permanently vegetative beings, a suggestion that has not yet been adopted [Schrode].)

The clear majority of state court decisions regarding permanently unconscious patients have permitted surrogate decision makers to end life support. Still undecided is the precise legal rationale for this result and whether this line of cases represents use of quality of life as a determinative factor in surrogate decision making.

In some instances, the courts upholding removal of life support rely on prior expressions (whether written or oral) by the now unconscious patient. Those courts simply respect the patient's self-determination and accept the patient's own declaration of permanent unconsciousness as an unacceptable quality of life. These cases sometimes disclaim any surrogate's prerogative to define another person's quality of life as unacceptable (e.g., *DeGrella,* 1993).

A number of cases, however, uphold removal of life support from a permanently unconscious patient even in the absence of prior expressions. Some of these cases include never-competent patients, such as infants. None of the cases relies on the burdens placed upon society or surrounding family by having to care for the insensate patient. Rather, the judges articulate diverse rationales. Some courts use the substituted judgment rationale and accept that the patient, if competent, would have wanted removal of life support (*In re Fiori,* 1995; *Matter of Tavel,* 1995; *In re Guardianship of Jane Doe,* 1992). Other courts purport to apply a best-interests standard but rely on the patient's dismal existence without cognitive function as warranting removal of life support (*In re Guardianship of Crum,* 1992).

Most courts confronting the fate of permanently unconscious patients recognize, either explicitly or implicitly, that the patient's status is so dehumanizing that it represents what most people would regard as an unacceptable quality of life. These courts sometimes demand that the surrogate decision maker not rely on his or her personal views about the value of an unconscious person's life (*Guardianship of L.W.,* 1992). But they do allow for surrogates' reliance on the common judgment that most people wish to avoid a permanently unconscious state (because it lacks dignity and is devoid of value from the perspective of the unconscious patient), as long as the patient's ostensible preferences did not deviate from that norm (*Guardianship of Jane Doe,* 1992).

By contrast, courts in a few jurisdictions have refused to endorse removal of life support from a permanently unconscious patient in the absence of clear-cut prior expressions from that patient (*Cruzan,* 1990; *Mack,* 1993; *DeGrella,* 1993). These courts see the removal decision as a quality-of-life determination that should be made, if at all, pursuant to legislative directions. Some judges also fear that permission to remove life-sustaining medical intervention from the permanently unconscious would ultimately endanger vulnerable populations, such as the severely retarded (*Mack,* 1993; *Guardianship of Jane Doe,* 1992, dissent).

Infants and Young Children

Some congenital anomalies entail a foreshortened lifespan, as well as neurological impairment, physical incapacity, repeated bodily invasion, and suffering so severe that the affected infant is arguably better off dead than alive. As patient autonomy cannot function in this setting, the question becomes whether parents, in conjunction with medical sources, can withhold life support on the basis that the child's life would be so burdened or devoid of personal value that death is preferable. Some commentators oppose this surrogate option, fearing that decisions would be based on prejudice or ignorance about life as a disabled person or concern for parental burdens, rather than burdens upon the child (Field).

Only a small number of cases have been litigated, and the legal picture concerning removal of infants' life support is murky. A few cases use a best-interests standard and rely on likely physical suffering to uphold parental decisions involving withholding of life-sustaining intervention (*In re C.A.,* 1993; *Newmark v. Williams,* 1991). A few cases purport to apply a substituted judgment rationale (reasoning that the child, if competent, would choose death) in order to uphold removal of life support from a permanently vegetative child (*In re L.H.R.,* 1984; *In re Guardianship of Barry,* 1984). In a 2001 case, a court declared that Texas law prohibits any parental effort to remove life support from a newborn (*Miller v. Hospital Corporation of America*).

The best-interests approach seems most plausible, allowing consideration of irremediable suffering and continuous bodily intrusions (Weir). An unresolved issue is the extent to which a dismal quality of life—in the sense of total helplessness and minimal potential for human relationships—can be used legitimately in this best-interests calculus. As a practical matter, it is hard for decision makers to exclude extreme debilitation in applying a best-interests standard. Extreme disability is commonly associated with hardship for the affected child. This element apparently emerges in decision making not only in the United States but also in Australia, Canada, and Great Britain (Charlesworth).

At the same time, stereotypes about disabled persons might prompt inappropriate terminal decisions. This happened in one case involving an infant afflicted with Down syndrome (*Baby Doe v. Hancock County Board of Health,* 1982). One possible limitation appears in U.S. federal statutes and regulations prohibiting hospital discrimination against the disabled and requiring states to protect the interests of disabled infants (see *In re Baby K,* 1993; *Johnson v. Thompson,* 1993). (Note that quality of life issues arose under the Americans with Disabilities Act in the context of state funding priorities under Medicaid.) The effect of these antidiscrimination measures is still unclear. U.S. federal regulations purport to bar quality-of-life considerations in decisions about infants' medical treatment (Clark). Those regulations are applicable to states participating in certain child abuse prevention programs and do not directly apply to individual hospitals. Moreover, decisions about medical treatment ineluctably involve consideration of the hardship and debilitation to be encountered by the patient after treatment. Where a patient's disability is intertwined with the contemplated medical service (as in spina bifida), a nontreatment decision cannot be deemed unlawful discrimination if the decision is grounded on a reasonable assessment of the suffering and hardship to be encountered by the affected individual. The disabled infant's fate is being determined by the same criteria—overall best interests—applicable to any child under treatment.

Conclusion

Diminished quality of life, in the sense of grievous bodily deterioration, is a frequent consideration in shaping the bounds of medical intervention in the dying process. The current challenge for law and medicine is to fix quality-of-life criteria for surrogate decision makers that avoid arbitrariness and abuse toward vulnerable, incapacitated patients. The key, for previously competent patients without advance instructions, should be assessment of which levels of deterioration the great majority of competent persons would consider (for their own dying processes) to be so undignified that they would prefer that life support be withdrawn (Cantor, 1996).

By using this shared vision of dignity as a guideline, decision makers will better replicate the likely wishes of now-incompetent patients, thus ultimately attaining results as consistent as possible with personal preferences. Empirical data for measuring common notions of dignity can be gleaned from public surveys as well as from scrutiny of patterns in advance medical directives. Anyone whose preferences diverge from common notions of dignity can provide individualized instructions reflecting those preferences.

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SEE ALSO: *Death, Definition and Determination of: Legal Issues in Pronouncing Death; Disability: Legal Issues; Environmental Policy and Law; Human Rights; Informed Consent: Legal and Ethical Issues of Consent to Healthcare; Medical Futility; Organ Tissue and Procurement: Ethical and Legal Issues Regarding Living Donors; Public Health Law; Right to Die: Policy and Law*

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LIFE, SANCTITY OF

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The sanctity of life is the theological or philosophical understanding that all human life has an inherent dignity, worth and sacredness that sets it apart from all other beings within the world. This perspective does not assert that human life is sacred in the sense of being divine, but that its very essence is distinct within the biological world and of incalculable worth, thus warranting protection throughout the course of its entire existence. The sanctity of life as a doctrine has both religious and philosophical roots and is applied to a wide range of bioethical issues such as abortion, euthanasia, genetic engineering, and cadaver organ transplants. Advocates often consider this understanding of human life to be the foundation of moral civilization, and have applied it to issues outside of bioethics such as human rights, suicide, and care for the poor and weak in society.

Religious Foundations

Various religious traditions have articulated and defended a concept of human sanctity in reference to their overarching worldview conceptions. In the Hebrew tradition the doctrine is rooted in human creation in the image of God: "Then God said, 'Let us make humankind in our image, according to our likeness; and let them have dominion over the fish of the sea, and over the birds of the air, and over the cattle, and over all the wild animals of the earth, and over every creeping thing that creeps upon the earth.' So God created humankind in his image, in the image of God he created them; male and female he created them" (Genesis 1:26–27, NRSV). The creation in God's image became then for the Hebraic tradition the foundation for protecting human life and for justice when it was de-sacralized (Genesis 9:6). The duty to protect human life extended to the necessities for life, such as food and clothing (Deuteronomy 24:6,12–13), and especially to justice for the poor and disenfranchised (Leviticus 19:15, 33–34).

Within the Jewish tradition the taking or defacing of human life is morally wrong because it violates a sacredness that "inheres in life itself, and that life, by its very being calls forth an appropriate human response, whether of veneration or restraint" (Kass, p. 235). The tradition does not teach that humans are God, but rather, "To be an image is also to be different from that of which one is an image. Man is, at most a mere likeness of God" (Kass, p. 242).

Jakobovits notes that in Jewish law and moral teaching, "The value of human life is infinite and beyond measure, so that any part of life—even if only an hour or a second—is of precisely the same worth as seventy years of it" (Jakobovits, p. 380). In contrast to Roman Catholic thinking and some Protestants, this intrinsic value does not extend to the life in the womb. "An unborn fetus in Jewish law is not considered a person … until it has been born" (Rosner, p. 136). For most Jewish scholars this does not give automatic sanction to abortion, for as Rosner points out, "The destruction of the unborn fetus, although legally not considered murder, can be considered to constitute 'moral murder'. The unborn baby has a heartbeat, a brain, arms, legs, and nearly everything with which a healthy newborn baby is endowed" (Rosner, p. 146). Within the various branches of Judaism there is wide variation on the issue of abortion, though fairly uniform agreement that a person is not present until birth. At the other end of life, Jewish moral teaching repudiates active euthanasia or assisted suicide on the grounds that it cheapens life and constitutes murder.

The Christian tradition, incorporating and building from the Hebrew Scriptures, similarly articulates the sanctity of human life on the basis of creation in God's image. This has not only been a warrant for rejecting the willful taking of human life, but also for treating every human life with respect and dignity. Thus, the epistle of James calls for restraint of the human tongue on the basis of this foundation: "No one can tame the tongue—a restless evil, full of deadly poison. With it we bless the lord and Father, and with it we curse those who are made in the likeness of God" (James 3:8–9). The application of human dignity rooted in the *imago dei* is often extended more broadly to social realities, in that it forms the foundation and the ideal of inalienable rights and intrinsic human values that have long been articulated in Western cultures.

The Christian church has also grounded the sanctity of human life in the doctrine of the incarnation, God taking on human flesh in the person of Jesus Christ. As theologian Karl Barth put it, "The respect of life which becomes a command in the recognition of the union of God with humanity in Jesus Christ has an incomparable power and width" (Barth, p. 339). Barth and other theologians argue that the very fact that God became human in Jesus of Nazareth and then died for human beings is an affirmation that human life has great worth and value.

The sanctity of life tradition stemming from Judeo-Christian sources has historically argued that the value of human life is not dependent upon its being valued by others or by the presence of certain functional capabilities such as rationality or relationality. Rather, sanctity and dignity inhere within the human person. Thus, with regard to bioethical issues of life and death the late Protestant ethicist Paul Ramsey argued against a benign neglect of infants with severe physiological handicaps on the grounds that their value is not dependent on extrinsic characteristics. He noted, for example, that a Tay-Sachs baby is born destined to die, but their dying is no different from our own dying. "For about the first six months it is like any other baby; living and growing and presumably enjoying human existence as any other infant would. In religious perspective there is no reason for saying those six months are a life span of lesser worth to God than living seventy years before the onset of irreversible degeneration" (Ramsey, p. 191).

The Roman Catholic Church has been without doubt the most consistent voice in defense of the sanctity of life. In the words of the Church's catechism, "Human life is sacred because from its beginning it involves the creative action of God and it remains forever in a special relationship with the Creator.… No one can under any circumstance claim for himself the right directly to destroy an innocent human being" (*Catechism,* p. 544). As Pellegrino and Thomasma put it, "The person is to be affirmed as a person, possessing dignity simply because he or she is a person. Man is a personal being, created and loved by a personal God and destined to be united face-to-face with the Creator" (Pellegrino and Thomasma, p. 143).

The Roman Catholic application of this doctrine extends not only to abortion and euthanasia, but also to matters such as research on human subjects. "Research or experimentation on the human being cannot legitimate acts that are in themselves contrary to the dignity of persons and to the moral law. The subjects' potential consent does not justify such acts" (*Catechism,* p. 553).

The sanctity of human life is by no means only found in the Jewish/Christian traditions, though these traditions have given the most explicit renditions of the doctrine due to their common theology of creation. Traditional and contemporary Islamic teaching does not generally use the language "sanctity of human life," but there is a conception of the sacredness of human life: "And do not kill anyone whom Allah has made sacred, except for a just cause" (Qur'an 17:33). In the contemporary setting the Islamic Code of Medical Ethics states that "Human life is sacred…and should not be willfully taken except upon the indications specified in Islamic jurisprudence, all of which are outside the domain of the medical profession" (van Bommel, p. 211). A sense of sanctity seems to be implied in the teaching that humankind is granted a vice-regency (*khalifa*) by Allah, but that role must be carried out consistent with the commandments of Islamic moral law. In the Islamic tradition ensoulment or becoming a person takes place at 120 days in the gestation period. Thus, "It can be said that although abortion in the first 120 days of gestation is morally wrong in Islamic law, it is not considered to be murder or even killing. Rather, abortion in this early period would fall into the categories of bodily injury or breaking of an oath, both of which require some type of penance" (Rogers, p. 129).

Philosophical Foundations

The sanctity of life doctrine is not limited to religious foundations. Various philosophers have attempted to articulate the unique, intrinsic value of human beings on the basis of experience and/or reason. Immanuel Kant, for example, argued that a person should be treated as an end, not as means to an end. The foundation for this assertion is that humans are rational and autonomous beings who thus possess a freedom which must be protected. Human freedom for Kant is not a license to do with life as we please, but rather a warrant for maintaining and protecting human dignity as an absolute inner worth. The problem in Kant's account, for those who today affirm the sanctity of life, is his insistence on rationality as its foundation; for if rationality is no longer present it would seem that human sanctity or personhood is no longer present, if indeed rationality is its foundation and primary indicator.

In the contemporary scene Arthur Dyck has argued for the sanctity of life on the grounds that it is a necessary prerequisite for communal life in society. As Dyck sees it, "Our lives did not and could not originate and persist because we valued it but because someone else valued it, parents to begin with, but also a whole network of individuals and groups. Our lives depended upon and continue to depend on the persistence of the moral behavior that makes life, and the communal protection of it, possible at all" (p. 52). Killing, including oneself, is thus morally wrong because it undermines mutual moral responsibilities which are necessary for human life to exist.

Humans throughout history, says Dyck, have had a natural love of life that has been enshrined even in law as a protection of the sanctity of human life. He notes, for example, that the U.S. Supreme Court in 1997 rejected the individual's right to exercise control over one's life to the point of seeking assistance in suicide. In rejecting the right to assisted suicide the Court appealed to the American Bar Association's Model Penal Code: "The interests in the sanctity of life are represented in the criminal homicide laws" (p. 59). Dyck, therefore, concludes that there is a moral structure for life's worth and protection, which is based legally, not on religious doctrines, but on the necessary requirements for communal life in society. "If laws were permitted to embody the idea that in some circumstances life loses its worth, or that some people lack sufficient worth to have their lives protected, individuals would no longer enjoy equal protection of the law so far as their lives are concerned" (p. 60).

Challenges to the Sanctity of Life

There have been various challenges to the sanctity of life doctrine from both religious and philosophical frameworks. These challenges have invariably led to different conclusions on a host of bioethical issues.

One set of challenges has been metaphysical, arguing that the human person is not inherently different in nature from the rest of biological life. Thus, there is no warrant for a notion of exclusive human sanctity. Peter Singer, for example, argues against speciesism, the view that *Homo sapiens* life is to be valued above all others. "The wrongness of inflicting pain on a being cannot depend on the being's species, nor can the wrongness of killing it. The biological facts upon which the boundary of our species is drawn do not have moral significance" (p. 128). Thus, he contends that the sanctity of life doctrine is false, for there is no special value to a being by virtue of its species identity.

In contrast to the sanctity of life doctrine, Singer argues that the primary moral criterion for determining the protection of life is its ability to experience pain and pleasure. There are many beings that are capable of experiencing pain and pleasure who do not fit the ordinary conception of personhood (i.e., animals), and there are beings who are often considered persons that are not capable of experiencing pain and pleasure (i.e., some newborn infants and severely mentally disabled adults). Thus, says Singer, "If we value our own pleasures … then the universal aspect of ethical judgments requires us to extend our positive evaluation of our own experience of these pleasures to the similar experiences of all who can experience them" (p. 139). This leads Singer to a strong affirmation of animal rights on the one hand, and to a belief that in some cases deformed children may be euthanized.

Peter Singer utilizes a utilitarian framework for his ethical judgments, but his ethics, including his rejection of the sanctity of life doctrine, ultimately rests on metaphysical commitments about the nature of life. Sanctity of life adherents note that the root difference between Singer and themselves is distinct foundational world views.

A second challenge to the sanctity of human life commitment is theological in nature. Some have argued that the conception overstates the nature of human essence and is idolatrous in its insistence that human life is sacred, an attribute reserved only for God. Margaret Mohrmann believes that the notion of sanctity of life is intrinsically idolatrous. "Theologically speaking there can be no argument based on a purported 'sanctity of life', both because there is no 'life' as such and because we are on very shaky ground when we speak of anything or anyone but God as unqualifiedly sacred" (Mohrmann, p. 22). She notes that "Christians do not believe that God is somehow generically present in something called 'life'. We believe that God is present in individual human persons" (p. 30). And God alone is sacred.

Adherents of the sanctity of life perspective generally counter that such conceptions are caricatures of their understanding. They believe that sanctity of life in no way implies that human life is sacred in the sense of being divine, but rather is set apart by God and hence distinct within the created order.

A third challenge to sanctity of life thinking is the charge of medical vitalism, the notion that all means must be utilized to keep a human being alive in the face of death. Vitalism is the view that because human life has incalculable worth, there must be a commitment to keeping patients alive at all costs. Many critics of the sanctity of life perspective have assumed that vitalism is an inherent part of the tradition.

But advocates of human dignity and worth respond that vitalism is not implied in the commitment to human sacredness, for there is natural cycle to human life, even under divine providence, that must be accepted. Gilbert Meilaender, a strong advocate of the sanctity of human life, notes that "we indefinitely transcend our historical location. But it is as embodied creatures that we do so, and our person cannot be divorced from the body and its natural trajectory. This is not vitalism; it is the wisdom of the body" (Meilaender, p. 22).

A fourth challenge to sanctity of life formulations is the emphasis on quality of life as an ethical criterion. In contrast to the assumption that all human life has an inherent value and dignity, a number of bioethicists have suggested that quality of life measures ought to be determinative in ethical dilemmas throughout the course of life. Joseph Fletcher a number of years ago argued that for one to be considered a person, four functional traits must be present: neocortical function, self-awareness, relational ability, and happiness (1974, pp. 4–7). There is a clear rational bias in this formulation of personhood, as he questions whether one with an IQ below 40 is a person and concludes that those below 20 are clearly not persons. As Fletcher sees it, "Mere biological life, before minimal intelligence is achieved or after it is lost irretrievably, is without personal status" (1972, p. 1).

Other bioethicists and philosophers have argued similarly for quality of life indices over against sanctity of life. Mary Anne Warren, for example, believes that we can never get away from some notion of speciesism (contra Singer), but she does believe that we must make distinctions within humans on the basis of their capacities. Warren sees two ways in which we speak of humans: humans in the genetic sense, and humans in the moral sense. Being a member of the human species does not ensure that one is human in the moral sense. Warren believes that inclusion in the moral community of humanity entails qualities such as consciousness, reason, self-motivated activity, self-awareness, and the ability to communicate (pp. 457–458).

Sanctity of life advocates counter that while quality of life may be a medical category used to determine when treatment is futile, it is not an ethical category to determine human dignity or personhood.

Applications of Sanctity of Life

The sanctity of human life is not the only ethical norm utilized by its advocates. Nonetheless, they claim, it is a foundational assumption for bioethical issues surrounding life, death, and human treatment.

One of the applications of the doctrine is in the ethics of abortion. Sanctity of human life does not automatically imply that a human or person is present from the moment of conception, but its advocates tend in that direction because human value and dignity is not dependent on functionality. Continuity in human life is usually emphasized, and thus the protection of a fetus or human embryo is just as important as protecting a healthy, mature adult. As a result, most advocates of the sanctity of human life reject abortion on demand and the use of embryonic stem cells in research and therapy.

Sanctity of life is also applied to death and dying issues. Advocates, as noted above, do not generally espouse vitalism and the necessity of futile treatment, but they do raise strong ethical objections to euthanasia or assisted suicide, contending that allowing to die and causing to die are not identical. Sanctity of human life proponents emphasize the role of palliative medicine and compassionate presence as is provided by hospice care in the face of pain and impending death.

Other applications of the sanctity of human life include organ transplants and genetic engineering. In transplantation one of the crucial issues is triage, the allocation of scare resources. Advocates of human sanctity argue that justice in this realm should not depend on merit or the way one is valued in society, but rather must entail a blind-folded egalitarian justice which gives equal opportunity to all potential candidates. With regard to genetic engineering, human sanctity usually means not transgressing one's essential humanness and not utilizing experimental measures for the sake of knowledge, at the expense of human dignity.

In summary, the doctrine of the sanctity of human life teaches that "all human beings possess equal dignity and worth regardless of the level of maturity they have achieved.… Thus, all humans—not just those who are rational or self-conscious—retain the right to life" (Hui, p. 148).

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LIFESTYLES AND PUBLIC HEALTH

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The people of every nation would be healthier if they adopted healthier lifestyles. Ninety percent of those who die of lung cancer would not have contracted the disease if they had not smoked. Exercise, sensible diet, and compliance with treatment for high blood pressure can, and do, prevent countless episodes of cardiovascular disease. Practicing safe sex reduces the risk of contracting AIDS. Use of seat belts and motorcycle helmets lowers the chance of injury from accidents on the road.

The prospect of improving health and reducing illness through changes in living habits rather than through curative healthcare is attractive on a number of grounds. Since it is preventive, it avoids the distress of disease; side effects and iatrogenic consequences may be fewer; cost may be lower; and the healthier ways of living may be rewarding in their own right. For these reasons, any government that failed to promote healthy lifestyles could be faulted on ethical grounds.

Nevertheless, the encouragement of healthier lifestyles has drawn moral criticism in the literatures of bioethics and health policy. The chief concern is that governmental (and even private) attempts to bring about changes in living habits will encroach on personal liberty or privacy. A second complaint is that lifestyle-change programs may have the wrong motives, and may have undesirable social and psychological effects.

Health versus Liberty

INTERVENTION: WHAT JUSTIFICATION? Nearly everything we do affects health in some way, if only because the time spent could be devoted to exercise or other health-enhancing behavior. The notion of unhealthy lifestyles, however, is typically associated with a small number of habits. Smoking, the leading killer in the United States, always takes first place, closely followed by alcohol and other drug abuse, lack of exercise, and being overweight. Other risk factors affected by individual choice veer toward the medical, including behavioral change intended to control serum cholesterol and hypertension, perhaps including compliance with doctors’ orders. Construed still more broadly, a “healthy lifestyle” would include living in a region not plagued by pollution or recurring natural disasters; avoidance of unsafe jobs; and purchasing the safest cars and appliances.

Attempts to change unhealthy behavior through education and exhortation are relatively unproblematic from the moral point of view. But these measures are less likely to be effective than programs that seek to influence behavior more directly through penalties, taxes, restrictions, or prohibitions. These, however, involve or border on coercion, and in some cases, as with sexual behavior, they necessarily intrude into a person’s most private domains.

The fact that good health may be valued by every person does not by itself justify these interventions, since for some people the health risks seem to be less important than the benefits derived from the risk-taking behavior. Few would seriously assert that eating rich ice cream or smoking falls within the category of fundamental human rights, but each encroachment on individual autonomy is commonly regarded as standing in need of justification, especially in the United States, which has a cultural history marked by an ideology of individualism. Three kinds of justification have been offered for programs aiming to change lifestyles: (1) paternalist concern for the person's good; (2) protection of others from burdens involuntarily imposed by the risk-taking behavior; and (3) the public's stake in the nation's health.

PATERNALIST JUSTIFICATIONS. In the United States, paternalist justifications are rarely provided as such. Though exceptions and counterexamples abound, lip service is still paid to the tradition of John Stuart Mill's *On Liberty.* It is easier to argue for motorcycle helmet laws as a means of reducing the costs of medical care than as a means of protecting human life, despite the greater importance of the latter. When paternalism is explicitly defended, however, it is usually on the grounds that the choices the paternalistic policy prohibits are not fully voluntary ones: Bad habits, such as smoking and overeating, may be sustained by addiction or genetic predisposition. This "soft" paternalism avoids the need to argue for the "hard" paternalist view that even fully voluntary choices may be overruled if the state concludes that the individual might benefit.

For many unhealthy habits, the argument that the behavior is not fully voluntary is easy to make. The individual choice may be determined by chemical, psychological, or social causes. Once a person is addicted to nicotine, it is extremely difficult to stop smoking, as millions of unhappy smokers know; the same holds true for alcoholics and those addicted to legal or illegal drugs. The original decision to try cigarettes, alcohol, or drugs is often made during adolescence, when the individual's ability to resist peer pressure is typically weak.

Nevertheless, the soft paternalist argument faces a number of objections. Not all unhealthy choices are obviously involuntary. The decision to engage in unprotected sex, for example, may be the result of partner coercion, or inner compulsion or denial, but it may also stem from the individual's dislike of condoms or not having a condom. Moreover, even the person whose behavior is shaped by an addiction may be capable of deciding to seek professional help in breaking the addiction. The decision to forgo seeking help, a "second-order" choice about choice, is not necessarily rendered involuntary by the "first-order" addiction. In these instances, paternalistic intervention will be of the hard variety, which involves the authorities acting on the principle that their goals for the individual should be imposed on the individual's own goals.

Intervention aimed at altering lifestyle choices on paternalist grounds may overemphasize the goal of health at the expense of other goals. If the paternalist justification is strongest when the unhealthy choices are least voluntary, these may also be the occasions when the choices are most difficult to influence, and the degree of coercion required may be objectionable in itself. Smokers subjected to very high excise taxes, for example, may suffer from the taxes without giving up cigarettes. Finally, the behavior in question may be difficult to change without considerable meddling in the individual's culture and milieu, whether these champion "wine, women, and song," or risk taking and violence, or quiet (and unathletic) contemplation. The life of the fitness-loving moderate is not for everyone, even if it is most conducive to long life and good health.

FAIR DISTRIBUTION OF BURDENS. Mill's principle of liberty sought to limit intervention to the protection of others from the effects of one's own actions; "self-regarding" behavior is thus the domain of the individual, while others have a say in the regulation of "other-regarding" behavior. Critics have long noted that the boundary is indistinct; nearly everything we do has effects on others. Sexual behavior, the most private of acts, is not at all self-regarding in the era of the AIDS epidemic. And since few people pay all their healthcare bills out of pocket, any behavior that necessitates care will impose a financial burden on other parties.

If these behavioral choices are to be protected, they will have to find some shelter other than Mill's principle. In the case of AIDS, an argument might be made that intrusive regulation would violate a right of privacy, where "private" does not mean "self-regarding" (AIDS transmission is anything but that) but "intimate" or "personal." This right might not be defensible in light of the seriousness of the AIDS epidemic, however; and in any case, other unhealthy habits and choices—for example, smoking, which incurs risks to others through passive smoke inhalation—fall outside of this personal zone. Since there is no general right of liberty when our choices affect the lives of others, the individual's prerogative to maintain unhealthy practices must be decided on other grounds.

Paternalist arguments aim at justifying interventions that seek to curb unhealthy behavior. Arguments that point to the burden of unhealthy behavior for other people, however, may or may not share this aim. They may indeed seek to justify curbs on the behavior in order to forestall the imposition of burdens. But this can also be accomplished by requiring the individual to pay his or her own way, perhaps through excise taxes, without any diminution of the unhealthy behavior. Finally, the individual whose choices result in illness may be made to pay for his or her own healthcare, or to forfeit any claim on the resources of others, or, at the least, to be placed at the end of the line when resources are scarce.

These steps represent a particular understanding of distributive justice. They seek to impose the true costs of choices on the one who chooses, so that these costs will be taken into account at the moment of choice. Those who believe that the welfare state should assist its citizens in meeting their basic needs, in this view, should not regard all needs as equal. Unhealthy lifestyles create avoidable needs, and individuals should be held responsible for these choices. Those who refuse to take care of themselves, in this view, forfeit at least some of the liberties (to individual choice) and the entitlements (to help, on an equal footing, in time of need) that others deserve.

As with the paternalist justification for intervention in lifestyle choices, this argument concerning the fair sharing of burdens faces a number of objections. One might argue that distinguishing between patients with similar healthcare needs on the basis of personal responsibility for illness introduces a concept of fault more at home in the legal world than in the system of healthcare. Treating all patients according to need, without regard to such factors as status, ability to pay, or fault, is a powerful way of affirming the importance of those aspects of people in virtue of which they are equal, relative to those that divide, distinguish, and rank us. This equality is important both to us as patients and to doctors and other healthcare providers, whose first instinct should be compassionate response to human suffering.

On more technical grounds, the burden-sharing argument rests the case for intervention into unhealthy lifestyles on the outcome of an economic calculation: that the habit in question incurs a net cost. The problem is that those who die prematurely because of unhealthy habits avoid burdening others with the cost of maintaining them in their old age. Economists have long debated whether smokers burden others or relieve others of a financial burden of care; the answer may vary by country, depending on such variables as the cost of healthcare and the cost of living. If there are places in which smokers actually save society money, the burden-sharing argument would entail penalties for those who do not smoke.

Care must be taken, moreover, in stating the burden-sharing argument. Insurance, including health insurance, protects against risk, but it also can make risk taking less unwise. Those Americans who play football, for example, can regard America's healthcare system as a partial safety net; the sport would be too dangerous for many without it. In this light, the burden-sharing argument might succeed in justifying special and higher insurance premiums for risk takers, but unless the risk takers refused to pay these fees, it would not justify curbs on the actual risk taking. Even the special fees would be unjustified if there were rough equivalence in the degree of risk taken by a large number of coinsureds, one person's motorcycle riding offsetting another's sedentary library dwelling.

PUBLIC HEALTH. The third justification for intervention on behalf of healthier lifestyles points to the collective health of the public as a common good. In material terms, a healthy population enhances economic productivity and the nation's capacity to defend itself. General health also provides some degree of protection from the spread of infectious disease. Theorists of public health have contended, moreover, that the *public health,* meaning the sum of each person's health, constitutes a further goal of public policy that can be distinguished from both the paternalist and the burden-sharing arguments.

Another feature of the public-health perspective is the "prevention paradox," the observation that many critical prevention policies affecting lifestyles produce large aggregate savings in lives but little demonstrable benefit to each individual. For example, seat-belt policies may save thousands of lives nationally but only marginally reduce the risk for each individual who drives. Similarly, changes in fat intake will strongly reduce the number who die prematurely from heart disease but affect the chances of each individual only slightly.

The prevention paradox thus arises from the fact that even small changes in the behaviors of tens of millions of individuals involved in low to moderate lifestyle risks avert thousands of deaths. The prevention paradox further underscores the emphasis in public health on rates of disease and deaths averted, and the difficulty of producing mass changes in behaviors through voluntary measures alone.

Far more important than the government's stake in a healthy work force is the centuries-old tradition of governmental responsibility to protect the health and safety of the public, construed as a public or common good. The public-health perspective is rooted in the democratic and constitutional tradition of assigning to elected officials and members of executive agencies responsibilities for protecting the common good, where this has been interpreted by courts as involving the protection of health and safety (and morals as well, which accounts for the long entanglement of public health and moralism). The public-health or regulatory power of government has long been justified on the grounds that reasonable restrictions on liberty and property, as weighed by the legislature, to promote the common good are the very essence of the regulatory power. This tradition is rooted in theories of government and the duties of citizens that antedate the rise of concerns with paternalism and Mill's famous essay.

Motives and Effects of Intervention Programs

The preceding discussion of arguments for intervention in unhealthy lifestyles has taken the arguments at face value. Critics, however, have suggested that the real motivations for these policies are usually unannounced. The actual motivation, in this view, is moral—or, to be more precise, moralistic, proceeding from a rarely examined and rarely defended set of moral premises. Once these are made explicit, according to the critics, both the motive and the policies are rendered less attractive.

One sign that lifestyle intervention has a moralistic motive, according to critics, is the selectivity of targets. Many kinds of behavior have negative health effects that are not equally addressed. Promiscuity, lack of exercise, and being overweight are merely the medieval vices of lust, sloth, and gluttony. These habits have negative effects on health, to be sure; but so do other kinds of behavior not viewed as vices. Childbirth, for example, presents a certain level of risk to every woman and a decided risk for some; but because it is socially approved, there is no thought of penalizing, taxing, or discouraging the behavior. The burden-sharing argument presents itself as a neutral act of accounting; but, in the critics' view, it is actually concerned with the costs of behavior deemed undesirable on moral grounds while it tolerates behavior of which it approves, no matter how costly.

The moral perspective from which lifestyle intervention is urged, moreover, has been criticized as *healthism,* a parochial view that elevates health from a self-interested goal to a virtue. In this light, "personal responsibility for health" stems not from the need to avoid burdening others with the costs of one's care but from the conviction that healthy people (at least, those who choose health) are better people, morally speaking. This perspective is also said to be linked to an ideology that emphasizes the degree to which one's state of health is a function of choices one makes, rather than the whims of nature or the safety of one's environment and workplace.

One of the most frequent complaints about the lifestyle debate is that it is used to "blame the victim" and undercut the justification for collective action. Thus, those who wish to restrict in various ways the availability of alcohol or tobacco, to limit overall use of these risky products, meet counterclaims that these are not problems of regulation but of individual responsibility and education. The advocates for regulation, in effect challenging the motivation of this view, argue that their opponents do not really want to see a well-financed campaign against smoking and drinking but want no official action at all. Instead, they want wider acceptance of the view that these are problems that will be resolved only when people take more responsibility for their own health and safety.

Conclusion

Though this entry has dwelt on the difficulties in making a convincing case for intervening in unhealthy lifestyles, the collective weight of such lifestyles should not be exaggerated. Much of the bioethical literature on lifestyles indicates that the choices posing the greatest problem for public-health authorities are those which involve personal or intimate behavior, are entirely self-regarding, and represent fully voluntary behavior. Little in our behavioral repertoire falls in this narrowly defined category, however, and those who wish to pursue this promising avenue to health can enter the argument on an even footing.

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SEE ALSO: *AIDS; Autonomy; Coercion; Economic Concepts in Healthcare; Freedom and Free Will; Healthcare Resources, Allocation of; Justice; Paternalism; Public Health Law; Responsibility*

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LIFE-SUSTAINING TREATMENT AND EUTHANASIA

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I. Ethical Aspects
II. Historical Aspects

I. ETHICAL ASPECTS

Ethical and legal norms exist in virtually all societies to help protect human life and regulate when taking or not prolonging life is ethically permissible. In most Western societies, the Judeo-Christian religious tradition has given great importance to the sanctity of life. Modern medicine has also gained extraordinary new powers to prolong life. Within the last few decades, medical treatments such as kidney dialysis, cardiopulmonary resuscitation, organ transplantation, respirator support, and provision of food and water by artificial means have become common in hospitals.

While these new treatments often benefit patients, restoring them to well-functioning lives, they also can be employed in circumstances where they may be neither a benefit to nor wanted by patients. Where once pneumonia was the "old man's friend," the way in which "nature" ended a life that had become seriously debilitated, now the time and manner of death has been brought increasingly under human control. In coming to grips with sustaining, taking, or not prolonging life, medicine has drawn on both its own ethical traditions and society's broader ethical and religious traditions.

This entry will first develop an ethical framework for life-sustaining-treatment decisions around which a considerable, though hardly universal, consensus has developed, and contrast it with the distinction between ordinary and extraordinary care. It will then consider broad alternative positions on the morality of taking life and some of their implications for care of the dying. Focusing on more specific controversies, it will then address the intentional taking of life versus pain relief that hastens death, killing and allowing to die, not starting versus stopping treatment, and four prominent examples of end-of-life treatment—resuscitation, artificially administered food and water, terminal sedation and futile treatment. Finally the entry will conclude with discussions of life-sustaining treatment and suicide and of physician-assisted suicide and voluntary euthanasia.

An Ethical Framework for Life-Sustaining-Treatment Decisions

An ethical framework for life-sustaining-treatment decisions should be sufficiently general to apply to all forms of such decisions and to both competent and incompetent patients.

COMPETENT PATIENTS. In the United States in the twentieth century, healthcare-treatment decision making came increasingly under the dominion of the ethical and legal doctrine of informed consent. This doctrine requires that treatment not be administered without the informed and voluntary consent of a competent patient. From a paternalistic and authoritarian tradition, in which the physician made almost all treatment decisions and the patient's role was to follow the doctor's orders, a new ideal emerged that involves shared treatment decision making between physicians and patients. Physicians use their knowledge, experience, and training to determine the patient's diagnosis and prognosis with different possible alternative treatments, including the alternative of no treatment, and the risks and benefits of each. Patients, on the other hand, use their own aims and values to discern and decide which option is best for them. Shared decision making is based on the recognition that sound, individualized-treatment decision making requires both contributions.

The principal ethical values that underlie shared decision making involve promoting the well-being of patients while respecting their self-determination or autonomy. The term *well-being* is meant to signal that what is best for a particular patient depends not only on the "medical facts" but also on the patient's own aims and values. It is also meant to signal the extremely important point that preserving or sustaining life is not always a benefit to patients; whether it is depends on the nature of the life sustained and whether the patient values that life. Self-determination is the interest ordinary persons have in making important decisions about their lives for themselves and according to their own values or conception of a good life. The capacity for self-determination allows people to take control over and responsibility for their lives and the kind of persons they become. The fundamental importance of self-determination has consistently been the central appeal in the United States both in the long line of informed-consent legal cases going back at least as far as the 1914 case *Schloendorf v. Society of New York Hospital,* and in the more recent life-sustaining-treatment cases.

On the basis of these two values, as well as the ideal of shared decision making and the requirement of informed consent they support, competent patients have the right to weigh the benefits and burdens of alternative treatments, including the option of no treatment, and to make their own selection. While this ethical framework applies to any treatment, it provides especially strong support for patients deciding about life-sustaining treatment. When forgoing life-sustaining treatment is seriously in question, the patient is often critically or terminally ill and near death and also often in a seriously debilitated state. Whether a particular patient will want to fight to stay alive as long as possible, or will instead at some point find continued life no longer a benefit but now a burden, is highly variable and unpredictable. Self-determination on so important a decision as when and in what ways one's life comes to an end or is sustained by medical treatment is of particular importance.

INCOMPETENT PATIENTS. When forgoing life-sustaining treatment is seriously in question, patients are often—probably usually—incompetent to make the decision for themselves, and so another person must decide for them. Bioethics and the law have given much attention to who should decide about life support for incompetent patients and what standards should be used. A number of ethical grounds support the common practice, employed by physicians and sanctioned by the courts, of turning to a close family member of the patient, when one is available. Most patients would want such a person to make these decisions for them when they are unable to do so; in most cases, then, turning to a close family member respects the patient's self-determination. Moreover, a close family member will usually know the patient best and will therefore be in the best position to determine what the patient would have wanted. This person is also likely to care most about doing what is best for the patient. Turning to a close family member thus promotes both the patient's self-determination and the patient's well-being. Finally, in most societies the family is the social unit in which important social bonds and responsibilities to care for dependent members are developed; one exercise of this responsibility is to serve as surrogate for an incompetent family member. These ethical grounds usually, but do not always, apply and so can be thought of as establishing an ethical presumption that a close family member is the appropriate surrogate to make life-sustaining-treatment decisions for an incompetent patient. When these reasons do not apply—for example, when there is evidence that the patient would have wanted someone else to serve as surrogate or there is a serious conflict of interest between the family member and surrogate—then the presumption in favor of the family member as surrogate can be rebutted and another should be selected to serve instead.

How should a surrogate make life-sustaining-treatment decisions for an incompetent patient? A significant consensus has developed, both in ethics and in law, that there are three standards for a surrogate's decisions. First, if the patient has made an advance directive (e.g., a “living will” or a “durable power of attorney for healthcare”) that includes instructions about the individual’s wishes as to the decision in question, then the patient’s choice expressed in the advance directive should be followed, with only limited qualifications. Second, when most patients do not have an advance directive or their advance directive is too general to determine the actual treatment decision, the “substituted judgment” standard should be used. This directs a surrogate to attempt to make the decision that the patient would have made, in the circumstances that then obtain, if the patient were competent. More informally, the surrogate should use his or her knowledge of the patient and the patient’s values and wishes to attempt to decide what the patient would have wanted. Third, when there is no knowledge available of the patient and the patient’s values that bear on the decision at hand, the “best-interest” standard should be used. Here, the surrogate should determine what is in the patient’s overall best interests by a more objective and communal conception of best interest. This often amounts to asking what most reasonable persons would want; in the absence of available evidence about how, in relevant respects, the patient is different from most people, this is justified. These three standards constitute a way to promote patient well-being and self-determination to the extent possible when the patient lacks capacity to make decisions.

These standards have not gone unchallenged (Meisel; Veatch; Dresser and Whitehead). For example, parents are given significant discretion, especially in the case of young children, in deciding what would be best for their child and are permitted to give some weight to the effects of different options on important interests of other family members. The authority of both advance directives and substituted judgment have also been challenged when following them would conflict with important interests of the now-incompetent patient or when the patient has undergone such profound mental changes that he or she appears to be a “new person” with new interests. Despite the substantial consensus on the ethical framework sketched above, it is not uncontroversial.

This ethical framework for life-sustaining-treatment decisions by competent and incompetent patients does give weight to a narrowly focused quality-of-life judgment: Is the best life possible for the patient with treatment sufficiently poor, according to the patient’s evaluation of that quality, that it is worse than no further life at all? No weight is given, on the other hand, to the fact that the patient’s quality of life may have diminished from what it once was or from most people’s lives, or to any evaluation of the social worth or social value of the patient. The fundamental feature of this ethical framework is that it entitles the patient or surrogate to weigh the benefits and burdens of possible treatments, including the option of no treatment, according to the patient’s aims and values, and to select from among available treatments or to refuse any treatment. This decision-making framework has now largely supplanted the distinction between ordinary and extraordinary treatment.

Ordinary versus Extraordinary Care

The distinction between ordinary and extraordinary care has its origins in Roman Catholic moral theology, where it is employed to distinguish between obligatory care—ordinary—and care that may be permissibly forgone—extraordinary. The two central issues about this distinction are: (1) What is the difference between ordinary and extraordinary care? and (2) Why should that difference determine whether care is morally obligatory or optional?

The distinction itself has been criticized as being unclear and resulting in confusion and controversy about how it should be applied (U.S. President’s Commission). For example, it has been used to mark the difference between statistically usual and statistically unusual care (perhaps the most commonly held understanding of the terms), between noninvasive and highly invasive treatments, and between treatments that employ low- and high-technology interventions. Because the distinction has many different, natural understandings, confusion often arises about what it means. None of the possible meanings of the distinction explains why the difference itself should determine whether the treatment is morally obligatory or optional. For example, treatment that is statistically common or involves the use of low technology might be beneficial to a particular patient in particular circumstances, but not beneficial or, perhaps, even burdensome to another patient in different circumstances.

The correct understanding of the traditional distinction is the difference between treatment that is beneficial and treatment that is unduly burdensome (or without benefit) to a patient. Of course, treatment is unduly burdensome only when the benefits it provides are insufficient to warrant its burdens. Unlike the other interpretations noted above, this interpretation of the ordinary–extraordinary distinction does mark a morally significant difference. Understood in this way, however, no general list of kinds of treatments that would be consistently ordinary or consistently extraordinary is possible; any treatment may be beneficial in some circumstances but not in others. More important, when the distinction is understood in this way it ceases to be an alternative to the benefit–burden framework. The judgment that a treatment is “extraordinary” places a label on treatment already and independently determined to be without benefit or unduly burdensome to the patient. The benefit–burden assessment does the substantive work in assessing treatments. For this reason, most commentators have given up the ordinary–extraordinary analysis in favor of the clearer and more direct appeal to the assessment of the benefits and burdens of treatment to a particular patient.

Of course, no ethical framework of the sort sketched here can be applied mechanically to make decisions to forgo life-sustaining treatment easy and unambiguous; even with the best efforts and the clearest reasoning, many decisions will remain ethically problematic and emotionally wrenching. While this is also true of many decisions about treatment that is not life sustaining, decisions concerning whether to sustain or shorten life raise several special ethical issues. In the 1960s and 1970s, it was common to distinguish between "active" and "passive" euthanasia. Passive euthanasia was understood to include forgoing life-sustaining treatment, either by stopping it or by not starting it. Active euthanasia was understood to be a deliberate intervention to end a patient's life, for example, by administering a lethal injection. Because euthanasia is often understood to be only active euthanasia, it has become common to avoid the term passive euthanasia in favor of referring to forgoing life-sustaining treatment. Most of these additional ethical issues raised about life-sustaining treatment represent special constraints or limits to be considered regarding the ethical framework just discussed for decisions where life itself is at stake.

The Morality of Taking Life

Any view about the morality of forgoing life-sustaining treatment or of euthanasia will depend in large measure on the basic moral principle presupposed concerning the taking of human life. This principle will differ depending on the general moral theory or conception of which it is a part or from which it is derived. Moral conceptions regarding taking life and killing may be divided into those that are goal-based, duty-based, and rights-based. A goal-based position, of which utilitarianism is the best-known variant, prohibits taking life when doing so fails to maximize the goals or consequences the position holds to be valuable, for example, human happiness or the satisfaction of people's desires. In this view it is a factual matter whether any particular killing produces better consequences than any other available alternative. Because this position not only permits but requires taking an innocent person's life when doing so will produce the greatest balance of benefits over harms, it is in sharp conflict with the patient-centered, ethical framework, which does not permit sacrifice of the patient for the benefit of others.

In a duty-based view, taking life is wrong because it violates a fundamental moral duty not to take innocent human life intentionally. This view looks not to the consequences produced by a particular killing but to the action itself, which is prohibited by the duty not to kill. It is often found within religions that view life as a gift from God, and therefore subject only to God's decision about when to take it. Perhaps the most serious difficulty for this view is its failure to give moral weight to the consent of the person whose life may or may not be taken. In this view, a competent patient's free request that another take her life need not morally justify doing so; instead, it is a request or temptation to do evil and should be resisted by a moral person.

In a rights-based view, taking human life is morally wrong because it violates a basic moral right not to be killed. In this view, killing harms its victims because it denies them their future, together with all that they wanted to pursue or achieve in that future. It wrongs its victims by taking from them without their consent what is rightfully theirs—their lives. In contrast with the duty-based view, however, when a competent individual freely requests that another person take his or her life because that life has become a burden and no longer a good for the individual, that request would be understood to be a waiving of the individual's right not to be killed, and acceding to it would be morally permissible.

The most important, substantive moral difference between duty-based and rights-based views is whether an individual's free and informed consent can make taking the person's life permissible. The distinction between duty-based and rights-based views is a natural way in which this moral difference is often expressed. Nevertheless, the duty not to kill could be understood to apply only to individuals who wish to live, and the right not to be killed could be understood to be unwaivable, as many in the right-to-life movement understand it. The distinction between rights-based and duty-based accounts of the morality of killing is used in this entry only to distinguish whether an individual's consent to be killed does or does not make killing that individual morally permissible.

Which of these alternative positions is correct is controversial and raises general questions of moral theory that cannot be addressed here. An ethical position that gives fundamental ethical importance to individual self-determination—as the ethical framework for life-sustaining-treatment decisions sketched above does—is most naturally formulated as a rights-based position. Whichever basic view is adopted, however, there are two important questions: (1) What actions are included under the moral prohibition of taking life, broadly construed? and (2) Is this prohibition absolute or does it have exceptions? The duty-based view is sometimes understood to make absolute the prohibition on intentionally taking human life; but it also typically distinguishes acts that intentionally take life from acts in which death is a foreseen but unintended consequence. Both duty-based and rights-based views about the morality of taking life tend to share the position that allowing to die is a less serious wrong than taking a life by killing.

Intended versus Foreseen but Unintended Taking of Life

When caring for dying patients, health professionals sometimes take actions that may shorten the patient's life. They may, for example, provide larger and larger doses of morphine when necessary to relieve a patient's pain, and in doing so, risk bringing on respiratory depression and earlier death. When this is done with the patient's or surrogate's knowledge of the risk and consent, it is morally justified. For the rights-based moral view about taking life, consent to the risk is crucial. In many duty-based positions, however, the consent of the victim does not justify taking human life, and a distinction is drawn instead between whether the resulting death was intended and whether it was only foreseen but unintended.

This intended/foreseen distinction has a long history. Invoked in the thirteenth century by the Italian theologian and philosopher Thomas Aquinas to justify killing in self-defense, the distinction is central to the Roman Catholic doctrine of double effect. (Double effect here refers to actions that may have two effects, one that is directly intended and the other one only indirectly intended or foreseen.) In some form, it is also common in much secular thinking about the morality of taking life.

Two central questions must be answered in order to evaluate whether this distinction really can or should be used to distinguish some morally permissible from impermissible taking of life. First, what precisely is the nature of the difference between "intended" and "foreseen"? Second, why is this difference morally important? In treating a dying cancer patient's pain, it may seem clear that the physician's primary or direct intention is to treat the pain; the earlier death from respiratory depression caused by the morphine the physician prescribes to treat the pain is, at most, a secondary or indirect intention, or more accurately, a foreseen but unintended consequence. (It is also clinically rare, especially for patients who have been receiving morphine for a considerable period of time.) Many physicians would not give this same patient a lethal injection if all other means of pain relief had failed, because then the death would be intended. Yet the physician's primary intention in the case of killing by lethal injection might also be to relieve the patient's pain, though then the means of doing so is to kill the patient. This distinction between what is intended as a means and what is a foreseen but unintended consequence, however, is not always clear. Killings that seem plainly wrong because they are an impermissible means to a good end can be redescribed as only a foreseen but unintended consequence of achieving the good end, and as, therefore, morally permissible. An extreme example will illustrate the point. Suppose a renowned transplant surgeon removes the heart and liver from a healthy person without the person's consent in order to transplant them in two patients who otherwise will die from heart and liver failure. Such killing is wrong even though it is a means of saving a greater number of persons. But suppose the surgeon denies that the killing is the means of saving other patients: The means of saving the other patients, he claims, was by removing the healthy person's organs and transplanting them, whereas the death of the healthy person was merely foreseen but not intended. Proponents of this distinction have not clarified it in a way that prevents such unwelcome misuse of it.

In many cases, such as giving morphine as opposed to a lethal injection, there is agreement about how to apply the intended-versus-foreseen-but-unintended distinction. The question then arises, what is its moral significance? Critics of the distinction note that in each case the physician's end is to relieve suffering, and that to gain such relief, both physician and patient are prepared to accept the risk of the patient's earlier death. Whether by morphine or a lethal injection, relieving the patient's suffering will bring about an earlier death. These similarities cast doubt on the moral importance of this difference. In the case of morphine, there may be only a risk of death, whereas in the case of a lethal injection the death is certain. But sometimes the amount of morphine necessary makes the likelihood of earlier death extremely high, and then this small difference in probabilities is too slim a foundation for the very great moral difference between permissible and impermissible killings. In any event, this is a difference in the certainty or risk of the outcome of death, not in whether it is intended or unintended.

Critics of the distinction between intended and foreseen deaths argue that physicians are morally responsible for all foreseen or reasonably foreseeable consequences of their actions, whether intended or foreseen but unintended, because foreseeability brings these consequences under the control of physicians and so makes physicians responsible for them. This disagreement in medical contexts about the moral importance of whether death is intended is often a particular instance of a broader disagreement between goal-based or utilitarian theorists who are concerned only with good results and duty- or rights-based theorists who place moral restrictions on how good results may be brought about.

Killing and Allowing to Die

Many moral theorists distinguish between duties not to kill, called negative duties, and duties to save or not to allow to die, called positive duties (Steinbock and Norcross). They argue that, unless this distinction is used to set reasonable moral limits, moral responsibilities will extend far beyond what they are usually thought to be and will deeply limit people's pursuit of their various life plans. Persons can usually satisfy the duty not to kill simply by pursuing their particular aims and purposes, although these goals may have to be altered if necessary to avoid killing. But if there is an equally stringent duty not to allow to die, it might seem that people must likewise set aside nearly all their usual aims and activities and devote their lives to saving those whose lives are in peril, such as victims of famines or extreme poverty. The implications of whether killing is morally worse than allowing to die are far-reaching both within and outside of medicine.

There are again two distinct issues. First, what makes one particular "doing," understood to include both acts and omissions, a "killing," and another, an "allowing to die"? Once the difference is clear, the second issue is whether and why this difference between killing and allowing to die is morally important. Killing is usually distinguished from allowing to die by establishing whether something was done, or not done, that resulted in death. A person who kills performs an action that causes a person to die in a way and at a time that the person would not otherwise have died. For example, two people are in a boat; Person 1 cannot swim. Knowing this, Person 2 pushes Person 1 out of the boat; Person 1 drowns.

A person who allows another to die knows that there is an action she could perform that would prevent another's death, but she does not take this action, and the person dies. For example, Person 1 accidentally falls out of the boat. Person 2 does not throw out an available life preserver, and Person 1 drowns. Some philosophers have argued that if the difference between killing and allowing to die is predicated on acting or not acting, killing is not morally worse than allowing to die.

The meaning of this claim has often been misunderstood. The claim is that the mere fact that one doing is a killing, while the other is an allowing to die, does not make one morally better or worse than the other, or make one morally justified or permissible when the other is not. This is compatible with saying that a particular killing, all things considered, is morally worse than, or not as bad as, a particular allowing to die because of other differences between the two, such as the motives of the agents or the presence or absence of the consent of the victim. This is also compatible with holding that most killing, all things considered, is morally worse than most allowing to die, but once again, that must be because of other morally important differences between them.

The usual argument for the position that killing is not in itself morally worse than allowing to die has consisted of comparing two cases that differ in no other morally relevant respect except that one is a killing, the other an allowing to die. Such a comparison helps focus on whether this difference by itself is morally important. James Rachels provided the following well-known example:

> In the first [instance], Smith stands to gain a large inheritance if anything should happen to his six-year-old cousin. One evening, while the child is taking his bath, Smith sneaks into the bathroom and drowns the child, and then arranges things so that it will look like an accident.
>
> In the second, Jones also stands to gain if anything should happen to his six-year-old cousin. Like Smith, Jones sneaks in planning to drown the child in his bath. However, just as he enters the bathroom Jones sees the child slip and hit his head, and fall face down in the water, Jones is delighted; he stands by, ready to push the child's head back under if it is necessary, but it is not necessary. With only a little thrashing about, the child drowns all by himself, "accidentally," as Jones watches and does nothing. (1975, p. 79)

Whereas Smith killed, Jones allowed to die. Rachels argued that there seems to be no basis for saying that what Smith did was any worse than what Jones did; there must be other factors in real cases that account for any moral differences. The conclusion that killing is not, in itself, morally worse than allowing to die remains controversial. Those who hold that there is a significant moral difference between the two argue that it is important to establish which of the two types of forgoing of life support, if either, comes under the stronger moral prohibition against killing. Because forgoing life support includes both not starting treatment and stopping treatment, the issue of whether either is equivalent to killing can be pursued by asking whether or not starting life support and stopping life support are morally different.

Not Starting Treatment and Stopping Treatment

When a decision is made not to initiate some form of life-sustaining treatment, such as kidney dialysis or respirator support, and the patient dies as a result, this is commonly understood to be an omission and so an allowing to die. Even if active killing is wrong, its prohibition does not apply to not initiating life support. But what of stopping life support—for example, stopping respirator support at the persistent, voluntary request of a clearly competent and respirator-dependent patient who is terminally ill and undergoing suffering that cannot be adequately relieved? If such action is taken by the physician with the intent of respecting the patient's right to decide about his or her treatment, most people would consider it a morally justified instance of allowing the patient to die. If only killing, but not allowing to die, is prohibited, then stopping life support and not starting it are both allowing to die and morally permitted.

But some philosophers have argued that stopping this patient's respirator is killing, not allowing to die (Brock). Suppose, for example, the patient has a greedy son who mistakenly believes that his mother will never decide to stop treatment and that even if she did, her physicians would not comply with her wishes. Afraid that his inheritance will be exhausted by a long hospitalization, he enters his mother's room while she is deeply sedated and removes her from the respirator, and she dies. If upon being found out, the son protested, "I didn't kill her; I merely allowed her to die; it was her disease that caused her death," this claim would be rejected. The son went into his mother's room and deliberately killed her.

Does the physician who did the same thing, performed the same physical action, kill the patient as well? Even if the physician in such a case does kill, other moral differences make the physician's killing morally justified, whereas the son's is morally wrong. The physician acts with a good motive, to respect the patient's wishes, with the patient's consent, and in a professional role in which the physician is socially and legally authorized to so act; the son acts with a bad motive, without consent, and with no social or legal authorization to do so. But these do not appear to be differences in whether either kills or allows to die: One can kill or allow to die with a good or bad motive, with or without consent, and in or not in a role that authorizes the action.

Those who reject this analysis and hold that stopping and not starting life support are both allowing to die usually have a different account of the kill/allow-to-die difference than the act/omission account offered in the last section. They hold that when a patient has a lethal illness such as lung disease, whose usual fatal outcome is being held off by a life-sustaining treatment such as a respirator, removing this artificial intervention amounts to allowing the patient to die by letting the disease process proceed unimpeded to death. But this account is problematic, not least because it requires one to accept that the greedy son also allows to die, but does not kill.

Whether stopping life support is killing or allowing to die, some physicians and others have contended that it is an ethically graver matter to stop a life-sustaining treatment than not to start it, or that it is permissible not to start it in circumstances in which it would not be justified to stop it. But consideration of cases such as the following has led most persons to reject the argument that stopping life support is different from or more serious morally from not starting it:

> A gravely ill patient, Mr. S, arrives at the hospital in respiratory distress and is sent to the intensive care unit (ICU) to be intubated and placed on a respirator. Before he is intubated, his family and physician arrive at the ICU and inform the staff that while clearly competent Mr. S, after extensive consideration and because of his debilitated and terminal condition, had firmly rejected being put on a respirator under any circumstances. The ICU staff respect his wishes, keep him comfortable, and he dies of respiratory failure. Now suppose instead that heavy traffic had delayed the family and the physician and they arrive at the ICU just after Mr. S is put on the respirator. His treatment now must be stopped instead of not started as before. (Brock, p. 209)

It is hard to see why the same factors that morally justified not starting his treatment do not, equally, morally justify stopping it.

Those who hold that stopping life support is not different ethically from not starting it usually stress two bad effects of a greater reluctance to stop life support. First, it will result in continuing treatment beyond the point at which it is a benefit to or still wanted by the patient. Second, and less obvious but at least as important, the belief that it will be harder to stop life support once it is begun can make physicians, patients, and family members all reluctant to try treatment when the benefits are uncertain or unlikely, for fear that if the treatment proves not to be beneficial they will not be able to stop it and the patient will end up "stuck on machines." The result is to deny patients possibly beneficial life-sustaining treatment.

In fact, there is often better reason to stop a life-sustaining treatment than not to start it. Often, before a life-sustaining treatment is started, it is uncertain whether it will bring the hoped-for benefits to the patient. Once it has been tried, and it is clear that it does not produce the benefits sought, a reason exists for stopping it that did not exist for not starting it. This supports the use of time-limited trials of life-sustaining treatment, with the understanding that if the treatment does not prove to be beneficial it will be stopped.

Four Kinds of End-of-Life Treatment

Four forms of treatment of patients near death that have received special attention are resuscitation, artificial nutrition and hydration, terminal sedation, and so-called futile treatment.

RESUSCITATION. Life-sustaining-treatment debates in the United States during the 1970s and 1980s often focused on the use of cardiopulmonary resuscitation (CPR) for persons who suffer cardiac or pulmonary arrest. Because CPR, to be effective, must be administered immediately after a patient suffers an arrest, hospitals have developed policies generally requiring that CPR be administered to any such patient, unless there is a “do not resuscitate” (DNR) order already in effect for the patient. The presumption of these policies—that anyone in medical need of resuscitation should receive CPR unless there was a prior order not to use it—made CPR different from many other life-sustaining treatments, which required a physician’s explicit order to start them.

CPR is the most prominent example of a class of emergency procedures for which consent is presumed unless the patient or the patient’s surrogate has explicitly refused it beforehand. Because CPR in the hospital is usually not successful, is associated with significant morbidity for the patient even when it is successful, and often would, at best, extend the lives of dying patients only briefly, there is widespread consensus that forgoing it is often ethically justified so long as patients or their surrogates agree and explicitly withdraw the presumption of consent for it. As a result, resuscitation, or “code status,” is probably the most frequently raised life-sustaining-treatment decision.

ARTIFICIAL NUTRITION AND HYDRATION. Those who seek to limit the life-sustaining treatments which it is ethically permissible for patients or their surrogates to decide to forgo have usually focused on the provision of nutrition and hydration by artificial means, such as intravenous, nasogastric, and other forms of tube feeding. Some people have argued that food and water are not medical treatment but are instead the most basic form of caring for dependent persons; all people, not just medical patients, need food and water. Others argue that when the patient’s medical condition necessitates the artificial provision of food and water, and when this is done by medical personnel using medical means, there is not much difference between this situation and the provision of oxygen by respirators to patients with lung disease.

Other opponents of forgoing food and water focus not on the issue of whether it is medical treatment, but on the strong symbolic meaning and importance of feeding those in need. The usual symbolism of food and water, however, may be misleading in the circumstances in which the question arises in medicine. There the cultural and social symbolism and meaning associated with eating and feeding are largely absent, as is the suffering typically associated with starvation. Applying the benefits-and-burdens analysis, food and water should be forgone only if doing so would not cause significant suffering to the patient. The benefits-and-burdens analysis will support forgoing nutrition and hydration either when continued life itself is burdensome or not a benefit to the patient, or when providing nutrition and hydration increases, rather than decreases, the patient’s suffering. For example, many patients in a persistent vegetative state—that is, those who have permanently and completely lost the capacity for any conscious experience—would not want nor consider it a benefit to have their lives continued. Consequently, treatment that sustains life is not beneficial, and its withdrawal cannot impose any burden on such a patient. In other cases, providing normal levels of nutrition and hydration may increase the awareness and suffering of some dying patients; for these patients, feelings of thirst can be assuaged, for example, with ice chips, without providing a level of hydration that would make their dying less peaceful and comfortable (Lynn). In still other cases, the benefits of continued life for seriously demented patients must be weighed against the burdens of physical restraints necessary to keep them from removing feeding tubes.

A different form of forgoing food and water can occur when a competent patient refuses them because the patient wishes to die. Some have argued that because competent patents always have not only the right to refuse artificially provided nutrition and hydration but also the right to refuse to eat or drink by ordinary means, physician-assisted suicide is an unnecessary option. Refusing to eat or drink will always result in the patient’s death, and so a competent patient who wishes to die but who does not have any life-sustaining treatment to be forgone does not need access to physician-assisted suicide to do so. Stopping eating and drinking, however, can take considerable resolve on the patient’s part and may not meet many patients’ views of a humane and dignified death. Proponents argue that it still may be a better policy option than physician-assisted suicide if the latter has substantial risks that stopping eating and drinking does not have.

TERMINAL SEDATION. Related to stopping nutrition and hydration as an alternative to physician-assisted suicide is the use of terminal sedation (Quill, Lo, and Brock). This typically involves sedating a patient with otherwise intractable pain to the point of unconsciousness and then withdrawing nutrition and hydration, with the inevitable result of the patient's death. Terminal sedation is used by some hospices and is defended as an acceptable practice because treating patients' pain is an uncontroversial responsibility of physicians and withdrawing nutrition and hydration is within patients' general right to refuse any treatment. The practice remains controversial, however, both because it raises the previously discussed problems with the distinction between intended and foreseen but unintended consequences, and because it is subject to abuse, especially if employed with incompetent patients. Others argue that because it may take up to a week or more for the patient to die, physician-assisted suicide would usually provide the patient with a preferable death.

FUTILE TREATMENT. A final recent controversy concerns futile care. As physicians have come to accept patients' rights to refuse treatment, they have increasingly encountered patients, or more commonly the families of incompetent patients, demanding treatment that the physicians judge to be futile. The debate began with CPR but has expanded to other forms of life-sustaining care. When physicians are asked to actively provide a treatment, it has seemed to many that the treatment should be acceptable both to the patient and to the physician; typically, in any joint enterprise, such as that between patient and treating physician, what is done must be acceptable to both participants. This may help account for the asymmetry many support between patients' right to refuse any treatment but to choose only from among medically acceptable alternative treatments.

A central issue in the futility debate has been how to define futility. Some have tried to narrowly restrict it to only those treatments known with certainty not to achieve their goal. The attempt is to eliminate value judgments from futility determinations and to make them only an empirical matter about which the physician should be expert. But others have pointed out that it is not possible to eliminate all value judgments. How certain is certain enough, and what are the legitimate goals of the treatment? Others have more broadly characterized futility to include cases in which the probability of benefit is considered too low, or the size of benefit too small, to warrant the burdens of the treatment. Here, the value judgment in determining futility is whether the treatment's benefits are likely enough, or large enough, to warrant its burdens. This value judgment seems in most cases appropriately left to the patient or surrogate, not the physician. The courts that have addressed futility cases have largely sided with patients or surrogates seeking treatment rather than with physicians who wish not to provide it.

Life-Sustaining Treatment and Suicide

Suicide is difficult to define precisely but is usually understood as the intentional taking of one's own life. In some religious traditions, suicide has long been and continues to be prohibited and considered a sin, and some important moral philosophers such as Immanuel Kant (1724–1804) have held that suicide is morally wrong (Battin). Historically, the law often reflected these views, although in the United States no states now criminalize suicide or attempted suicide, but a majority prohibit assisting in suicide.

The different, basic moral positions discussed earlier on the morality of taking human life have different implications for the morality of suicide. Despite these differences, most people agree that a public policy of seeking to prevent most suicide attempts is morally justified. Even strong defenders of individual self-determination generally agree that most suicide attempts are dramatic pleas for help and occur when a person's decision-making capacity is seriously disordered by such conditions as depression. These features justify intervention to prevent the suicide, so as to determine if the patient is competent and not subject to impaired decision making, in which case, some believe, others should cease coercive interference.

Because a patient's decision to forgo treatment correctly believed to be life-sustaining will result in the patient's death, the question arises whether this is suicide. In some cases, the patient may not intend her own death, or seek death, but only be unwilling to undergo the burdens of a particular life-sustaining treatment. In other cases, however, the patient's decision may also be made in the interest of seeking an end to an excessively burdensome existence; in such cases, therefore, there is an intent to cause one's own death, making it hard to differentiate the decision from suicide. Many legal decisions about life-sustaining treatment, and most Western religious traditions, have sought to distinguish forgoing life support from suicide, often by characterizing the former as an exercise of self-determination about one's medical treatment, not intentional self-destruction. (The courts may have sought to distinguish forgoing life support from suicide to protect participating physicians and others from potential prosecution under legal statutes prohibiting assisting in suicide.) Yet the normative judgment a competent person makes justifying each act is often essentially the same: The best future life possible for me (with life-sustaining treatment, in the case of a decision to forgo treatment) is so bad that it is worse than no further life at all. The principal difference between some cases of forgoing life-sustaining treatment and suicide appears to be only a difference in the means a person uses to bring about her death. Nevertheless, even if some or all forgoing of life support is essentially suicide, it need not, for that reason, be morally wrong, but might instead be considered a justified exercise of self-determination.

Physician-Assisted Suicide

In nearly all countries, neither professional practice nor the law permits physicians to grant patients' requests for physician-assisted suicide or voluntary euthanasia. An example of physician-assisted suicide is when a patient ingests a lethal substance provided by a physician for that purpose; voluntary euthanasia, by contrast, involves the physician administering the lethal substance. In both cases, the choice rests fully with the patient, and the patient can change his mind up until the moment the lethal process becomes irreversible. The only difference need be who performs the last physical action of administering the lethal dose, for example, placing potassium chloride in the patient's intravenous line. This small difference in the part played by the physician in the causal process leading to death does not seem to support a substantial moral difference between physician-assisted suicide and voluntary euthanasia.

Those who nevertheless believe that it is morally worse for physicians to perform voluntary euthanasia than physician-assisted suicide can argue that in the former, the physician kills the patient, whereas in the latter, the patient kills herself. But it may be more accurate to say that in physician-assisted suicide, the physician and the patient together kill the patient—a case of joint action for which both together bear responsibility. This suggests that physician-assisted suicide and voluntary euthanasia may not be substantially different morally.

Voluntary, Active Euthanasia

Considerable public and professional attention, spurred by publicity about the practice in the Netherlands (Van Der Maas, Van Delden, and Pijnenborg) and several notorious cases in the United States, such as those of Dr. Jack Kevorkian, has focused on voluntary, active euthanasia. In significant part, the public interest in euthanasia reflects fear of loss of control and dignity while dying. It also reflects recognition that the same values of patient self-determination and well-being that have been accepted as guiding treatment decision making in general, and decisions about life-sustaining treatment in particular, can in some cases support voluntary, active euthanasia as well. If this positive support for voluntary euthanasia is granted, opponents have in general offered two kinds of arguments against it.

The first argument is that any individual instance of euthanasia is morally wrong because it violates the duty not to kill innocent human beings. As noted earlier, in some duty-based accounts of the wrongness of killing, the consent of the one killed does not make the killing permissible. Nevertheless, given the centrality of the patient's consent in ethical accounts of the permissibility of forgoing life-sustaining treatment, some special argument is needed for why consent has no relevance for euthanasia. Moreover, if the argument in the earlier section on killing and allowing to die is correct—that some stopping of life support is justified killing—then euthanasia cannot be morally condemned simply because it is killing. Many duty-based moral accounts of the wrongness of killing either implicitly or explicitly depend on theological premises that give God sole dominion over life and death. However, in pluralistic societies that respect religious freedom, public policy should not be based on religious beliefs that many members of that society do not share. The rights-based account of the wrongness of killing, however, gives decisive weight to the consent and self-determination of the patient who seeks it.

The other general kind of argument against euthanasia is that although it may be morally permissible in some individual cases, it would nonetheless be bad public policy to permit voluntary, active euthanasia. This argument depends on an assessment of the likely good and bad consequences of permitting euthanasia, only a few of which can be noted here. Among the potential good consequences that proponents cite are: respecting the self-determination of those who request euthanasia but have not been able to get it; assuring the much larger number of people who believe it should be permitted so that should they request it, it would be available; ending the pain and suffering of dying patients that cannot be relieved by any other means; and providing for some patients a more humane and peaceful death than they would otherwise have.

Among the potential bad consequences opponents cite are: its apparent incompatibility with the aim of medicine of protecting life in all its frailty; the erosion of the trust of patients in their physicians as caregivers; the erosion of the social commitment to provide appropriate care to the dying if euthanasia, in an era of cost containment, is seen as an acceptable and cheaper alternative; and fear that permitting voluntary euthanasia would, over time, lead to involuntary euthanasia, or at least to nonvoluntary euthanasia of incompetent patients. Evaluating the likelihood and relative seriousness of these and other possible good and bad consequences of permitting either physician-assisted suicide or voluntary euthanasia is difficult and controversial. In 2003 in the United States, physician-assisted suicide is legal in the state of Oregon, and that state's accumulating experience with the practice is the basis for considerable debate (Sullivan, Hedberg, and Hopkins; Nuland). Whether either practice should be permitted remains one of the most deeply controversial issues in medical ethics.

Conclusion

Since the 1960s, the capacity of medicine to prolong patients' lives has steadily increased, making the time and circumstances of a person's death increasingly a matter of human choice and control. The debates considered and the ethical framework for life-sustaining-treatment decisions sketched in this entry have been responses to this new control over how and when humans die. Perhaps the central feature and accomplishment of the great public and professional attention to death and dying in recent decades has been securing the rights of patients or their surrogates to decide about care near the end of life together with focusing the medical profession's attention on improving care at the end of life. However, the deeply personal, emotionally complex, and ethically controversial nature of decisions about care at the end of life ensures that they will continue to be a prominent part of bioethics.

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SEE ALSO: *Advance Directives and Advance Care Planning; Anthropology and Bioethics; Autonomy; Clinical Ethics; Competence; Death; Death, Definition and Determination of; Dementia; Healthcare Resources, Allocation of; Holocaust; Informed Consent; Long-Term Care; Medical Codes and Oaths; Metaphor and Analogy; Palliative Care and Hospice; Right to Die: Policy and Law; Surrogate Decision-Making;* and other *Life Sustaining Treatment and Euthanasia* subentries

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II. HISTORICAL ASPECTS

The history sustaining and ending of human life in the West has three facets: a chronology of the meanings of euthanasia, the major cultural heritages that have influenced the beliefs and actions of physicians, and changing modes of medical practice. This entry explores this multifaceted history from its ancient Hebrew origins to the rise of the "right to die" and "death and dying" movements after the1960s.

The Meanings of Euthanasia

All the meanings of the term *euthanasia* can be related to the etymology of the Greek term *euthanatos*: *eu* meaning "good" and *thanatos* meaning "death." At the present time the word is used to denote a doctor's painlessly terminating the life of a suffering, terminally ill patient who wishes to die: physician produced or physician induced death (*Oxford English Dictionary*). Advocates for euthanasia often call it mercy killing.

The current meaning is actually the *second* way the term was used in Western history. The term's *first* and most longstanding use denoted a gentle and natural or noninduced death. The Roman historian Suetonius (c. 69–135 C.E.) described how Augustus Caesar was "blessed with an easy death" when he expired peacefully at age seventy-five: "For almost always on hearing that anyone had died swiftly and painlessly, [Augustus] prayed that he and his might have a like 'euthanasia'" [here *euthanatos* is inserted in the Latin text] (Suetonius, p. 281).

Francis Bacon (1561–1626) appears to have been the first scholar to maintain that the practice of medicine should include knowledge and skill that enable doctors to help patients to die easily and naturally. Bacon entitled this dimension of medicine *euthanasia exteriori* ("outward euthanasia") to distinguish it from "that euthanasia, or sweet calm dying, procured by a due preparation of the soul" in religious literature on consoling the dying (Bacon, pp. 124–125; Beaty). By saying that doctors should help patients "make a fair and easy passage out of life" Bacon meant that they should enable patients to die as Augustus Caesar had or like the aged Antoninus Pius, who died calmly "as though he were falling asleep" (Bacon; Bryant). This analysis of what Bacon proposed corrects the claim that he advocated doctor-induced death (Fletcher; Wilson; Emanuel).

For the next two centuries the term denoted physician-aided natural dying. The replacement of this meaning by the current understanding of euthanasia occurred between 1870 and the 1920s. A defense of doctor-induced peaceful death was made by Samuel D. Williams in 1870, after which heated debate ensued in Great Britain and the United States (Williams, 1872; Vanderpool, 1997). The fact that the debate has continued accounts for the current use of the term.

The meaning of euthanasia in its original sense continued into the 1920s, but its equation with mercy killing was so common by the turn of the century that some suggested that the original term should be replaced with the term *euphoria* ("Euphoria vs. Euthanasia"; Rosenberg and Aronstam). Later proponents of the duty of doctors to help patients die peacefully and naturally dropped such terminology in favor of phrases such as *caring for the dying* (Worcester; Alvarez).

Third, during the first four decades of the twentieth century the practice of extinguishing the lives of unwanted persons also was called euthanasia. Newspapers, films, books, physicians, professors such as Harvard's Charles Eliot Norton, clergy, scientists such as the Nobel laureate Alexis Carrel, and other eugenicists in the West called for euthanasia, that is, a painless extermination of various groups: "lunatics," "degenerates," "cripples," and others ("Dr. Norton on Euthanasia"; "The Right to Kill"; Pernick). That eugenics euthanasia movement played a complex role in Nazi ideology and the legitimization of Nazi genocide (Pernick).

Fourth, at times euthanasia was identified with the use of sedatives to "secure easy deaths" to the point of shortening life (South Carolina Medical Association, p. xvii). *Fifth,* the term occasionally was associated with what is now called assisted or physician-assisted suicide (Sperry, 1948), in part because some of the legislative bills sponsored by the Euthanasia Society of America were essentially assisted-suicide bills (Sperry, 1950).

Sixth, euthanasia became attached to the practice of withdrawing terminally ill persons from life-prolonging medical measures. After 1970 that practice commonly was termed *passive* or *indirect* euthanasia to distinguish it from *active* or *voluntary* euthanasia: doctor-produced death (Vanderpool, 1997). Although some authors disassociated the right to refuse life-sustaining measures from the term *euthanasia* (Pope Pius XII; Rynearson), the distinction between active and passive euthanasia made as early as 1884 ("Editorial: Permissive Euthanasia") had significant staying power.

An understanding of the major cultural heritages that informed and still inform the beliefs and actions of physicians sets the stage for the history of euthanasia and the sustaining of life in medical practice.

Hebraic and Jewish Perspectives

The Hebrew Scriptures proclaim an understanding of human life that has been immensely influential in Western history. Humans are created by God (Genesis 2:2–27), life and consciousness are gifts of God, and as Lord of life, God alone should determine when and how humans die (Job 1:21). As God's property, no individual has the right to destroy his or her life as if it were self-owned. It also is not lawful wantonly to take the life of another person (Exodus 20:13, Genesis 9:5–6).

On the basis of this legacy, Jewish tradition requires that when life is threatened by illness or injury, it must be sustained if possible. Because Jews were and are obligated to prolong their lives, they must not settle in communities where no physician is available. Obligations to save and extend life are drawn from Scripture: "You shall not stand idly by the blood of your neighbor" (Leviticus 19:16). Advanced medical interventions are urged for critically ill persons as long as it seems probable that those treatments will save or prolong life (Bleich). Rabbinic debate continues over situations in which life can be prolonged for a while, but at the expense of great pain and no hope for a real cure. Past and present, Jewish authorities have held that active pain relief can be undertaken at the risk of a patient's dying sooner (Jakobovits; Brody).

Doctors who induce death to spare patients from pain are considered murderers (Exodus 20:13, Carmi). Destroying those who are socially unwanted is absolutely prohibited. This includes neglecting or killing severely deformed newborns (Bleich).

Although it forbids mercy killing, Judaism defends the morality of letting fatally ill persons die naturally. The meaning of *honorable death* (*Mita Yafa*) in the Talmud centers on merciful dying, not mercy killing (Carmi). Each dying person should be comforted by relatives, friends, and physicians. Prayers for life to end are permissible. Once a patient is near death, treatments that interrupt dying should be discontinued (Bleich).

Greco-Roman Antiquity

By the fifth century B.C.E. Greek physicians and elite citizens were praising health as one of the greatest human goods. The goals of the physician's art were "to bring health in all cases of sickness [and] preservation of health to those who are well" (Hippocratic Corpus, "Regimen in Acute Diseases," p. 71). Greek physicians recognized the limitations of their art. Modestly conceived, their goals were "to do away with the sufferings of the sick, to lessen the violence of their diseases, and to refuse to treat those who are overmastered by their diseases" (Hippocratic Corpus, "The Art," p. 193). Physicians would abuse their art and ruin their reputations if they attempted to prolong the lives of the severely sick and injured. A terminally-ill patient's death would be blamed on the physician's lack of skill, so it behooved the physician to refuse even to try to treat at all. Galen (131–201 C.E.) and other Roman physicians adapted those values and goals to Roman life and its institutions.

Although the Greek heritage is unambiguous about the limits of life prolongation, it includes two traditions related to physician-aided death. Vastly influential in Western medicine, the Hippocratic Oath has physicians swear that they will not "give a deadly drug to anybody if asked for it" or even "make a suggestion" to that effect (Edelstein, p. 6). Debate continues over whether that oath reflects a Pythagorean origin or some other origin (Edelstein, Carrick, Anagnastopoulos). Insofar as it reflects opinions of the Pythagorean sect, it would oppose physician-assisted euthanasia in an almost Hebraic sense. With the gods as keepers and humans as their possessions, people sin against the gods if they seek to escape from their posts in life. Insofar as it is non-Pythagorean, the oath could reflect the philosophical logic of Plato (c. 427–348 B.C.E.) and Aristotle (384–322 B.C.E.): Because health is one of the greatest human goods and restoration of heath is the ultimate end of medicine, the termination of life is contrary to medical practice (Anagnastopoulos).

In contrast to the prohibition of physician-assisted death in the oath, Plato, Aristotle, and Stoic philosophers from Zeno (c. 336–264 B.C.E., Greece) to Seneca (4 B.C.E.–65 C.E., Rome) argued that incurably sick adults who consume vital resources of the city—the polis—should die from neglect or be put to death involuntarily (Carrick; Anagnastopoulos). Similarly, deformed and sickly infants should be exposed or drowned for the good of the community, the highest and greatest human end according to Plato and Aristotle. Exposure included taking newborns to rock caverns or casting them into the sea. By law in Sparta and Rome newborns were examined by nonparents for anatomic flawlessness and vigor to determine which ones should be exposed (Amundsen, 1987).

Seneca praised the ability of humans to choose when to end their lives. People should quit life nobly rather than await the cruel endings "either of disease or of man" (Seneca, quoted in Carrick, p. 145). Certain elite citizens, virgins, married women, slaves, common persons, and soldiers ended their lives when they were faced with humiliation, a fearful future, illness, or old age (Van Hooff).

Opposed to suicide in those instances, Aristotle held that death is "the most terrible of all things" (quoted in

Carrick, p. 51). Suicide also conflicted with Aristotle's theory of human virtue: the nobility of facing death bravely versus the cowardly quitting of life when one is faced with misfortune.

Christianity

Christianity emerged from Judaism and flourished in the Roman world. The early churches regarded Hebrew Scripture as the authoritative word of God even as they reinterpreted it as forecasting the life, death, and resurrection of Jesus. Christians thus inherited Hebraic and Jewish teachings about life and death.

EARLY CHRISTIANITY. Christians regarded God as the creator and sustainer of human life and opposed suicide in response to suffering or despair. Contrary to the myth that Christians were inclined to commit suicide to escape from life and be with God, Christ, and their departed loved ones, early Christians ardently opposed self-induced death (Amundsen, 1998).

With Jesus as their model, Christians added new themes to Jewish opposition to suicide and mercy killing. They accented the redemptive dimensions of suffering (2 Corinthians 12:7–10, Hebrews 12:5–11). Faced with pain and death, they too should exclaim, "Not my will, but thine be done" (Luke 22:42). Beginning with the early church (James. 5:10), Christians praised Job, who endured grave suffering steadfastly. Patience and steadfastness were valued all the more because of frequent persecutions (1 Peter 4:12–5:1).

Based on Jesus's teaching that all humans are the children of a loving Father (Luke 15), Christians also displayed mercy and offered care for sick, infirm, and dying persons (Luke 4:16–21, 6:36, 8:26–56, 10:29–37). Believing that no human group should be despised or considered unworthy of life, they condemned cruel executions, abortion, infanticide, and suicide by the second century (Amundsen, 1987).

AUGUSTINE. Augustine (354–430 C.E.) developed systematic criticisms of suicide. Like Aristotle, he argued that self-inflicted death was cowardly. He also viewed it as contrary to the Sixth Commandment, "Thou shall not kill." He regarded suicide as a mortal sin because it excluded the possibility of repentance (Amundsen, 1989). With the establishment of Christianity as the official religion of the Roman Empire after 325, self-killing was equated with homicide. In central and northern Europe the properties of suicides were confiscated, their corpses were desecrated, and they were excluded from Christian burial grounds.

THOMAS AQUINAS AND MODERN ROMAN CATHOLICISM. Thomas Aquinas (1225–1274) expanded on Augustine's arguments against suicide in ways that have shaped Catholic perspectives to the present time. Suicide and by extension induced euthanasia for sufferers were and are viewed as contrary to Christian tradition, natural law, the well-being of society, Christian compassion, and, most important, the dominion of God over human life (O'Malley; Sacred Congregation for the Doctrine of the Faith).

Through the centuries Catholics condemned physician-induced euthanasia as well as ending the lives of mentally or physically handicapped persons. At the same time, decades before the right to die movement began, Catholic authorities distinguished between "ordinary" and "extraordinary" medical treatments and argued that incurably ill persons in most circumstances had the right to refuse advanced medical interventions (Kelley; Pope Pius XII).

PROTESTANTISM. On issues involving life and death the Protestant reformers of the sixteenth century differed little from their early Christian and Roman Catholic predecessors. By the seventeenth century, however, certain Lutheran and Calvinist theologians were arguing that some self-inflicted deaths stemmed from mental imbalance. Holding that traditional arguments that cosigned the souls of suicides to eternal damnation were subject to human hubris, they also argued that the soul's eternal destiny was for God alone to decide (Ferngren). Directly countering the inclusive condemnation of Catholic heritage, the English poet and Anglican prelate John Donne (1572–1631) reasoned that some suicides did not violate natural law, human reason, Scripture, or the dominion of God over human life.

The lack of unanimity within seventeenth-century Protestantism increased in the ensuing centuries (Numbers and Amundsen 1998 [1986]). In the 1930s and afterward Anglican, Episcopalian, and Unitarian clergy played active roles in euthanasia societies in Great Britain and the United States. Beginning in the 1950s, a Protestant Episcopalian priest, Joseph Fletcher, became the most influential advocate of mercy killing in the United States (Fletcher;Vanderpool, 1997). Fletcher opposed the declaration against legalized mercy killing by his own denomination in 1952, by the Presbyterian General Assembly in 1951, and by the assertion of Willard L. Sperry, dean of the Harvard Divinity School, that legalized euthanasia cuts "against the whole basis and practice of medicine" (Sperry, 1948, p. 988).

Nevertheless, Jews, Catholics, and Protestants remained united about the virtue of helping persons die peacefully and naturally not by inducing death but by alleviating suffering and isolation through attentive care. The literature on consoling the dying that first flourished in Catholicism in the fifteenth century was adopted readily by Calvinists (Reformed Protestants) and Anglicans and transformed by Methodists and those in other denominations (Beaty; Vanderpool, 1998 [1986]). Francis Bacon rightly forecast how this literature harmonized with medical euthanasia in its original sense: special care of the dying.

The Law

Continental and Anglo-American law during the centuries following the advent of Christianity included a mixture of Roman law, the customs of various ethnic groups and communities, and canon laws developed and systematized by Roman Catholic jurists. Having inherited the Hebraic-Jewish conviction that God is the ultimate law-giver and judge and holding to the view that universal truths can be rationally discerned from the laws of nature, Catholic canonists sought systematically to adapt Roman law to Christian teaching (Plucknett). The cohesiveness, power, and geographical expansion of the Church enabled canon law to exert a profound influence on national laws, including the tradition of common law in England and its colonies.

Canon law was first adopted in England at the Council of Hereford in 673 C.E. Rooted in centuries of custom, canon law influenced the development of the common law from the time of the reforms of William the Conqueror (1027–1087 C.E.), to the vastly influential interpretations of the common law by Sir Edward Coke (1552–1654), to the present time (Plucknett; Williams, 1957). The canon laws adopted at the Council of Hereford included prohibition of suicide (*Washington et al. v. Glucksberg et al.*).

Savage penalties for suicide—bodily desecration, property forfeiture, and exclusion from Christian burial grounds—were set forth in common law by the thirteenth century and were rigorously enforced between 1500 and 1700. Coke wrote in 1644 that suicide is a category of murder and the property of suicides should be forfeited. In the middle of the sixteenth century, the Court at Common Bench—one of the pivotal councils of English sovereigns that developed and defined the common law—observed, as if it were taking a page from Thomas Aquinas, that suicide "is an Offence against Nature, against God, and against the King … To destroy one's self is contrary to Nature, and a Thing most horrible" (quoted in *Washington et al. v. Glucksberg et al.*)

Penalties against suicide were removed in England in 1823, followed by abolishment of suicide as a crime in 1961 (Markson). Beginning with Pennsylvania in 1701, the harsh common law penalties enacted in several American colonies were also abolished (*Washington et al. v. Glucksberg et al.*).

Nevertheless, laws in England, the majority of American states, and most western democracies associated assisted suicide with homicide and with suicide as a grievous wrong (MacDonald; Markson; *Washington et al v. Glucksberg et al.*). Considered a criminal offense ranging from second degree murder to manslaughter, laws against assisted suicide never contained exceptions for those who helped to end the lives of persons who were terminally ill, fatally wounded, or condemned to death (*Washington et al v. Glucksberg et al.*). American statutes that explicitly outlawed assisted suicide were first enacted in New York in 1828, then most other American jurisdictions. The Model Penal Code of the twentieth century, including its official 1980 draft, opposes anyone's "willingness to participate in taking the life of another, even though the act may be accomplished with the consent, or at the request, of the suicide victim" (quoted from *Washington et al v. Glucksberg et al.*).

Criminalization of assisted suicide was and is based on States' interests to protect and preserve human life, prevent suicides by persons who are young, elderly, or suffering from mental disorders, and protect the ethical integrity and healing roles of the medical profession (*Washington et al v. Glucksberg et al.*; Kamisar). The relatively high incidences of acquittals, suspended sentences, and reprieves of citizen- and doctor-induced euthanasia proves that, "The Law in Action is as malleable as the Law On the Books is [in almost every State] uncompromising" (Kamisar, p. 408).

Secular Legacies

As minority opinions in the dominant Christian culture, various humanists from the sixteenth through the eighteenth centuries spoke of the permissibility of suicide for seriously sick and injured persons. Enamored with Greco-Roman culture, Michel de Montaigne (1533–1592) voiced the unorthodox views that the "most voluntary death is the finest" and that "God gives us permission" to take our lives "when he reduces us to such a condition that living is worse than dying" (Montaigne, 1946 [1580], p. 338).

Skepticism, secular interests, and an emphasis on personal pleasure became more pervasive during the seventeenth and eighteenth centuries. English playwrights such as John Dryden (1631–1700) and Deists such as Charles Blount (1654–1693) defended certain suicides motivated by honor, suffering, lost love, or self-willed destiny (Ferngren). These themes informed the thought of one of the Enlightenment's most influential representatives, David Hume (1711–1776).

HUME. Hume began his essay "On Suicide" (1963 [1783]) with an attack on "superstition and false religion," which compel a person to prolong "a miserable existence … lest he offend his Maker" (pp. 252–253). He held that overwhelming suffering and wishes to die should be regarded as calling persons from life "in the clearest and most express terms" (p. 259). Like Socrates and Plato, Hume argued that persons plagued with suffering that negates social usefulness are not obligated to prolong their lives. He also held that each person's "native liberty" consists of carrying out an autonomous course of action in keeping with one's "chance for happiness" (p. 261).

Hume's critics included Immanuel Kant (1724–1824), who censured self-killing because it cannot be willed as a universal action without undermining the possibility of morality, that is, the existence of rational beings. Kant also viewed suicide as a violation of one's duty to God, the sovereign of all life. Unlike Kant, nineteenth-century thinkers such as Friedrich Nietzsche (1844–1900) adopted Hume's view that autonomous persons have the right to end their lives when disease extinguishes pleasure and social usefulness.

DARWINISM. Charles Darwin's (1809–1892) theory of evolution played a pivotal role in reshaping Western religion, science, literature, and political philosophy and policy (Vanderpool, 1973). The secular understanding of the world advanced by Darwin and Darwinians directly affected views of euthanasia. The Darwinian theme that human progress depends on the survival of the fittest through natural selection engendered a Westernwide eugenics movement that promoted active interventions to rid the world of the "unfit" (Vanderpool, 1973; Pernick). Other Darwinians argued that euthanasia in the form of doctor-induced painless death was permissible because "nature certainly knows nothing" of the sacredness of life ("Euthanasia," p. 91) and "the doctrine of evolution" justifies shortening the lives of sufferers in the face of outmoded religious opposition (South Carolina Medical Association, p. xv).

EXPERIMENTAL MEDICAL SCIENCE. Well before the Darwinian revolution physician scientists performed extensive laboratory experiments on the physiology of death and resuscitation from which they developed a mechanistic understanding of life and death. After describing his experiments on "the laws of the vital functions," the British doctor A. P. W. Philip concluded that human life is not "a subject of peculiar mystery" (p. 211).

That mechanistic understanding led to the dominant twentieth-century view that the human body is a physical-chemical and mechanical entity that can and should be salvaged with sufficient repair. Ivan Pavlov's (1849–1936) vivisection experiments with dogs proved how severe and sequential injuries could be repaired one after the other to the point where a dog's death could be seen to represent a failure in technical mastery. This was the backdrop to ever greater attempts to sustain human life and to the neglect of care for dying patients after 1945.

Modes of Medical Practice to 1870

In keeping with the cultural heritages of Judaism, Christianity, and experimental medical science, physicians from the seventeenth century to 1870 focused on mitigating the effects of disease and the ultimate goals of saving and sustaining human life. In the eighteenth century the goal of saving life engendered a Western-wide movement to establish humane societies to rescue persons who appeared to be dead from drowning and other causes. Imbued with a sense of progress, physicians, human society members, and others discovered many means by which life could be restored and extended: manual breathing methods, ammonia, strychnine, bloodletting, tongue stretching, and electric shocks (Liss).

Nevertheless, in keeping with the admonition of Francis Bacon in the seventeenth century, a number of notable physicians lectured and wrote about the duty "to soothe the last moments of existence" (Ferriar, p. 392). Addressing his German faculty of medicine colleagues, Carl F. H. Marx termed the physician's "skilful alleviation of suffering" as "that science, called euthanasia, which checks oppressing features of illness, relieves pain, and renders the … inescapable hour a most peaceful one" (p. 405). Marx and others stressed shared themes: the painlessness of dying versus myths about "death agonies," the necessity of not disturbing dying patients, the comforting presence of physicians, expertise in symptom relief, the skilled use of opiates, the immorality of purposefully shortening life, and steadfast opposition to "dangerous and dubious treatment measures" to prolong life (p. 407).

These advocates of euthanasia in its original sense of helping patients to die naturally and peacefully appealed to moral, philosophical, and spiritual values: how close attention to the process of dying causes "the physical process of death [to lose] much of its horror" for patients and physicians alike (Ferriar, p. 392), the virtue of alleviating "the supreme anguish of the patient's mind" (Marx, p. 411), the humanity of caring for "a powerless and suffering creature" when "the scene of life is closing" (Dendy, p. 121), and the assurance that humane and steadfast care "will ever prove consolation to the hearts of attached friends" (Dendy, p. 124). Predicated on these values, end-of-life care was deemed "not unworthy of the attention of the most scientific physician" (Dendy, p. 124).

All these physicians strongly opposed futile life-prolonging measures utilized by inexperienced and uninformed practitioners. Physicians ought to be able to know "when any hope [of cure] has departed" (Marx, p. 405) and they should honor the moral principle of refraining from harm. John Ferriar criticized "ignorant practitioners" who "torment" dying patients with "liquors of different kinds" (pp. 393, 397). W. C. Dendy spoke of the cruelty of using stimulants such as brandy or ammonia "when hope is gone" (p. 122). Marx decried the use of caustics, "external irritants," "and other tortures" (p. 409).

In the first half of the nineteenth century when educated physicians were closing ranks against poorly trained and unorthodox practitioners, this tradition of terminal care was set forth as a profession. Thomas Percival's (1740–1804) widely published code of medical ethics shaped the codes of several U.S. medical societies and became the primary moral foundation for membership in the new American Medical Association (AMA). The AMA's Code of Ethics was unanimously adopted in 1847, and its sections on the care for dying patients were lifted verbatim from Percival's Medical Ethics. When doctors find that they cannot "revive expiring life," they should "soothe the bed of death" and not "abandon a patient because the case is deemed incurable, for [their] attendance may continue to be highly useful … by alleviating pain … and by soothing mental anguish" (Code of Medical Ethics of the American Medical Association p. 221).

Medical Practice and Turmoil: 1870–1945

SUSTAINING LIFE AND CARING FOR THE DYING. The ability to cure diseases and repair injuries increased exponentially between 1870 and 1945. The sophisticated advances in surgery and curative medicine during this time were symbiotic with the creation and explosive growth of modern hospitals. Increasing from 200 in 1873 to 4,438 in 1928, these hospitals were monuments to scientific medicine. They became and remain the central places in which an ever increasing number of medical specialists treate countless patients from all walks of life. Within these hospitals, new techniques for resuscitation and life prolongation were readily developed and adopted: "the struggle to reactivate the whole organism" with blistering benzine compresses (Jellinek, p. 216), injections of epinephrine via long hypodermic needles directly into the failing heart in the 1900s, open-chest message during cardiac surgery in the 1930s, and positive- and negative-pressure ventilation apparatuses and masks in the 1930s (Liss; Hermreck).

The resulting institutionalization of curative medicine and life-sustaining techniques detracted from care for dying patients. The increasing lack of concern is mirrored in revisions of the AMA Code of Ethics. The two paragraphs on care for the dying in the 1847 code were reduced to four lines in 1903, then to this part of a sentence in 1912: "a physician should not abandon or neglect the patient because the disease is deemed incurable" (Vanderpool, 1997, p. 40).

Only a few increasingly isolated physicians continued to explore and write about "the medical art" of "euthanasia" as "aid of an easy, gentle, and placid death" (Munk, pp. 4–5). By the late 1920s doctors were beginning to leave dying patients in care of nurses, clergy and sorrowing relatives. Alfred Worcester considered "this shifting of responsibility" to be "unpardonable" (p. 33). Worcester also lamented the lack of teaching about terminal care in medical schools and decried the increasing use of "modern methods of resuscitation" such as cardiac stimulation for dying patients. Worcester exclaimed that his peers "ought to know better" (p. 47). Beyond his criticisms, Worcester published a lengthy book chapter that outlined what medical students should be taught about care of the dying. Years later Walter C. Alvarez praised Worcester's "excellent little book" as one "every physician in the land should read and re-read" (Alvarez, p. 87).

DOCTOR-INDUCED DEATH FOR THE DESPERATELY ILL. Many factors contributed to the post-1870 turmoil over the morality of doctors' inducing the deaths of suffering and incurable patients. Several of these preceded the development of modern hospitals by a few decades, but included factors—such as the discovery of anesthesia—that made modern surgery in these hospitals possible. The factors underlying the debate included the resurgence of secular challenges to traditional Jewish and Christian understandings of human life and death in the second half of the nineteenth century, the discovery and refinements of anesthesia after 1846, the development the hypodermic syringe (introduced in the United States in 1856) by which morphine could be injected by physicians with quick and powerful results, paternalistic physician supervision of patients with dread disease in modern hospitals, and the public's increasing reliance on physicians to relieve their aches and pains (Vanderpool, 1997, p. 37).

Turmoil over the painlessly putting to death of incurable sufferers began after the speech by Samuel D. Williams before the Birmingham Speculative Club in 1870 was turned into a pamphlet and seized upon as newsworthy. Williams defended the proposition that in "all cases of hopeless and painful illness it should be the recognized duty of the medical attendant, whenever desired by the patient to administer chloroform … or … other anesthetic … so as to destroy consciousness at once, and put the sufferer at once to a quick and painless death" ("Euthanasia," p. 90).

Williams's speech became newsworthy for several reasons. It directly challenged doctors who regularly used chloroform and hypodermic morphine and were responsible for dealing with catastrophic illness and determining when patients' conditions were incurable. It challenged lawyers because Williams's proposition was illegal. It alarmed the clergy because of the clergy's historical opposition to induced death. It engaged the American public because opiates were unregulated before 1920 and because dying persons often were cared for at home.

Through the years journals and newspapers perpetuated the debate and reported about euthanasia societies, attempts to legalize euthanasia, and individuals who admitted to ending the lives of desperately sick persons or were brought to trial for doing so ("Euthanasia"; Rosenberg and Aronstam; "Shakers Justify Killing Sister"; "Physician Admits to 'Mercy' Killings"). The arguments set forth in the early years of the debate became fixtures in the years to come (Vanderpool, 1997).

Proponents argued that euthanasia is merciful and that refusal to perform it is cruel. Doctors have the duty to alleviate pain as well as prolong life. Life racked with pain is hardly sacred, and evolution undermines the value of individual life ("Euthanasia"). The fact that some physicians were already practicing it surreptitiously attests to its moral acceptability. People deserve "at least as much kindness and sympathy" as animals that readily are put out of their misery (Wolbarst, p. 354).

Medical societies and most physicians found "insuperable objections" to the practice (Victor Robinson, 1913, p. 145). Intentionally ending the lives of suffering patients repeatedly was declared to be antithetical to the traditions of medicine. That "ghastly" practice would undermine the physician's premier goal of saving life and turn doctors into executioners ("The Moral Side of Euthanasia"). Euthanasia was a crime, and legalized euthanasia would be abused by devious physicians and nonphysicians. It would display cruelty to dying patients who would question their worth and fear for their lives rather than receive the care they deserved. It would devalue suffering, cheapen life, and undermine the dominion of God. Between 1906 and 1969 opponents of physician-caused death in Great Britain and the United States united to defeat the many attempts to legalize euthanasia.

KILLING UNWANTED HUMAN BEINGS. Advocacy to end the lives of unwanted human beings—euthanasia in the *third* sense—emerged in Europe and the United States toward the end of the nineteenth century. Those who promoted euthanasia for "defectives" often claimed that civilized sentimentality "nullified nature's methods of eliminating the unfit" ("Foreign Letters," p. 1617). Others spoke of the "benevolent extermination of degenerates," (Smith, p. 50) the "inhumanity" of not relieving a "gibbering driveling idiot" from his or her misery (William Robinson, p. 88), and the need to "liberate" retarded and insane persons from "tortured mentalities" (Wolbarst, 1935, p. 332). Those despised groups were thought to be interfering with the progressive evolution of the human race (Smith).

Devotees of eugenic euthanasia differed over which groups should be eliminated and how their lives should be ended: denying treatment to newborn "monstrosities" and/or actively ending the lives of insane persons and/or others. After Dr. J. J. Haiselden created a storm of controversy between 1915 and 1919 over his refusal to save the lives of several severely defective newborns and young children, eugenic euthanasia rhetoric continued, but its practice remained hidden and rare in the United States (Pernick).

In Germany proposals for exterminating unwanted persons became political policy. In 1868 Ernst Haeckel (1834–1919), a disciple of Darwin, argued that Germany's physical and mental incurables should be put to death painlessly. Haeckel praised the Spartans for killing their deformed and weak children, in contrast to the "antiselection" of Christian compassion for the infirm and sickly (Lifton).

Germany was considered the new polis. Each doctor should become a "physician to the Volk" for the "perfection of the health" of the people (Lifton, p. 30). The "biological body of the German people" should be invigorated through programs of physical fitness and the science of "race hygiene" (Ernst, p. 574). Preceded by the recommendation of a child-welfare pioneer Sigmund Engle that "cripples, high-grade cretins, idiots, and children with gross deformities" should be destroyed painlessly (quoted in Pernick, p. 23), a jurist Karl Binding and academic psychiatrist Alfred Hoche called for the elimination of mentally ill and retarded persons in their influencial book titled *Release and Destruction of Lives Not Worth Living,* 1920.

Eugenic beliefs infused the thinking of mainstream physicians, academicians, and scientists in Germany well before their adoption by Adolf Hitler (1889–1945) as National Socialist (Nazi) policy (Shevell). Physicians played a critical role in creating the concept of racial hygiene, supporting the Nazi rise to power, and administering sterilization and extermination programs (Ernst; White).

Shortly before Germany's invasion of Poland in September 1939 Hitler directed that children with severe mongolism, hydrocephaly, paralysis, and deformities be registered. In thirty pediatric departments across Germany doctors supervised the registering, sorting out, and killing of 5,000 children (Lauter and Meyer). Within months Hitler issued a decree that mentally incurable adolescents and adults should "be granted a mercy death." That decree created an agency that orchestrated physician-directed killing of over 70,000 persons in gas chambers disguised as showers (Shevell).

When they were stereotyped as destructive to the health of the body politic, Jews, Gypsies, and others were consigned to a massive, bureaucratic doctor-run extermination program that was modeled on its medical predecessors. Those programs lasted only six years, but their horror is unforgettable. After World War II the World Medical Association (WMA) and several national medical associations condemned the Nazi extermination programs.

Medical Practice and Debate: 1945–1960s

MERCY KILLING. The revulsion against Nazi practices did not curtail campaigns to legalize mercy killing (Vanderpool, 1997). At the end of the war a new campaign to legalize euthanasia backed by 1,776 physicians and 54 eminent clergypersons began in New York, and from 1945 through 1969 petitions were signed and legislative attempts were made in the United States and Great Britain (Wilson). In spite of those efforts and the passionate defense of euthanasia by Joseph Fletcher, bills to legalize mercy killing were not introduced for a vote or were voted down. At its meeting in 1950 the World Medical Association resolved that national medical associations should "condemn the practice of euthanasia in any circumstances" ("Official Notes").

THE PREEMINENCE OF PROLONGATION. Effective and sophisticated ways to save life were developed during and after World War II, including penicillin and other antibiotics and methods to overcome cardiac arrests through the use of open-chest heart massage in the 1950s and closed chest defibrillators in the 1960s. The reversal of cardiac arrest was called "the restoration of life after death" in the media (Bains, p. 1346). The use of nasogastric feeding tubes and blood transfusions became widespread, and mechanical ventilators as a "complete substitution of the spontaneous ventilation of the patient" were refined (Petty, p. 2).

Along with these technological advancements, the physician's duty to sustain life achieved a preeminent status in hospitals from the 1940s through the 1960s. Lest they betray their training, many doctors felt that they should do everything possible to sustain life rather than "just let the patient die" (Glaser and Strauss, p. 196). Even in the face of dire prognoses heroic treatments often were continued until a patient's organ systems deteriorated, extensive pain was experienced, the patient's family reached "an advanced stage of grieving," or a doctor's colleagues intervened (Glaser and Strauss, p. 199).

Graphic accounts of attempts to prolong life became news in the 1950s. No story was more influential than that of a widow's anguish over her husband's treatment in a metropolitan hospital in 1957. "If you are very ill," the widow said, "modern medicine can save you. If you are going to die it can prevent you from so doing for a very long time." She lamented the use of "all the latest wonder drugs, the tricks and artificial wizardry" that "deprived death of its dignity." Upon begging a doctor to "cease this torture," she was told that "they had to maintain life" ("A Way of Dying," pp. 53–54). The reasons for the priority of prolongation included the equation of medical practice with mastery of the new technologies, death as the ultimate evil, the equation of death with defeat and medical failure, and lost concern with care for the dying. "Who causes these extraordinary measures to be continued indefinitely?" one doctor asked. "In most cases, it is the physician himself" (Rynearson, p. 86).

CARE FOR THE DYING. The few physicians who perpetuated the tradition of natural dying displayed despair. Describing how he was "bringing comfort to the slowly dying" in their homes, Walter C. Alvarez wrote that dying persons "should never be cast off and neglected simply because they cannot be 'cured'" (pp. 89–90). Alvarez observed that "rarely does anyone ever discuss the subject in medical schools, at medical meetings, or in the journals." Like his predecessors, he decried the abuses of prolongation:

> When I myself lie dying, I hope that I will have by me some wise and kindly physician who will keep interns from … puncturing my veins, or putting a tube down my nose, or giving me enemas and drastic medicines (p. 91).

Depicting his medical training between 1957 and 1960, Roger Bulger described how students were taught "the intricacies of every method or technique that might possibly bring someone back from *extremis* but no one has ever suggested that we ought to attempt to care" for the person beneath "the multiplicity of tubes that are entering him from every direction" (Bulger, pp. 23–24). In hospitals doctors probe and test, nurses are indifferent, and the dying "'crock' is a second class citizen" (Kohn, p. 1180).

SHORTENING LIFE AND ASSISTING IN SUICIDE. In the context of the preeminence of prolongation, instances of euthanasia in the *fourth* sense—painless death to the point of shortening life—were designated "invisible acts" by hospital personnel in the late 1950s (Glaser and Strauss, p. 198). At times, however, a patient's right to receive pain relief at the cost of abbreviating life was advocated openly (Fletcher; Ayd).

Euthanasia in the *fifth* sense—assisting patients to end their lives—was practiced even more surreptitiously. Suffering patients who begged to die at times were relegated to a "dying room" where overdoses of pills were left at the bedside and patients were unwatched for long periods so that they could "manage" their own deaths (Glaser and Strauss). Stories of doctors giving overdoses of opiates for patients to take at home were told to clergypersons and known by physicians (Sperry, 1948). The extent of the practice of shortening life and assisting suicide in medical practice remains unknown.

TWO IMPENDING REFORMS. Descriptions of dreadful and often futile attempts to prolong life increased in medical and popular journals in the 1950s and 1960s. Those descriptions identified two problems: how to curtail life-prolonging attempts so that patients could die naturally (passive euthanasia) and how to care for sick persons and aged individuals at the end of life.

Father Gerald Kelly wrote a sophisticated analysis of the first problem in 1950, and a way to resolve it was announced by Pope Pius XII seven years later: "The doctor … has no separate or independent right where the patient is concerned … he can take action only if the patient … gives him permission" (p. 285). Despite opposition, several physicians, including non-Catholics, citing the widow's story and the pronouncement of the Pope, agreed that "the decision concerning further treatment should be in terms of the patient's own interests" (Rynearson, p. 86). In their articles those doctors occasionally outlined "components of the care of the dying patient": death with "dignity, respect and humanity," minimal pain, and familiar surroundings that promote sharing with family and friends (Rynearson, p. 87).

In 1966 Charles Hofling observed that the problem of determining when to terminate life by withholding various medical interventions had "thus far received little thoughtful, and very little authoritative, attention" from his fellow practitioners. In fact, "the typical approach has been to arrive at a course of action with a minimum of discussion." Convinced that this approach "will force the whole matter on the public's attention," he called for "multidisciplinary consultations" on the part of physicians, lawyers, clergy, sociologists, and "quite possibly" philosophers (pp. 43–46).

Those authors were the prophets of two impending reforms: the "right to die" movement and the "death and dying" movement.

Conclusions

An untutored glance at the title of this entry could give the impression that it would be far more conceptually balanced—though less provocative—if it were entitled "Ending and Sustaining Life, Historical Aspects." In fact, due to the multiple meanings of euthanasia in medical history, this entry does balance the many ways doctors have dealt with ending human life on the one hand and sustaining and extending life on the other.

This history is filled with an intriguing combination of continuities and tensions. The continuities surface in the first cultural legacy explored in this entry—Hebraic and Jewish perspectives. Its major motifs forecast enduring themes for the ensuing three thousand years: a commitment to saving and extending life whenever possible, a mandate to display concern and care for dying persons, and, based on the sacredness and ultimate value of human life, an opposition to mercy killing of incurably sick persons, disabled children and others.

Christianity inherited these motifs from Judaism and embedded them within Western culture to the extent that they became moral givens. The cultural transformation that occurred over the centuries included the way canon law infused common law and the way those motifs shaped codes of conduct, common commitments, and the increasing power of the medical profession.

Historical tensions were both exterior to and inherent within these continuities. Exterior to them, Nazi programs of extinguishing unwanted and despised persons appealed to Greco-Roman precedent, but due to the depth of Western cultural transformation that had occurred, became equated with unspeakable moral deviance. The Nazi programs secured the loyalty of a number of German physicians enamored by Aryan supremacy and eugenic-based notions of evolutionary progress. These programs were condemned as betrayals of professional ethics that continued to uphold the moral mandates transmitted to Western culture through Judaism and Christianity. Euthanasia in its current meaning—a doctor's terminating the life of a terminally ill patient—began and remained contentious because it drew upon factors that were both inherent within and external to the reigning motifs of Western medicine. Advocates of mercy killing appealed to the themes of mercy for sufferers of fatal illnesses and the cruelty of not relieving persons from pain. At the same time, against the strictures of common law and in the name of naturalistic evolution and/or secular notions of self-ownership and autonomy, these advocates countenanced circumscribed forms of homicide and assisted suicide.

Within the historic continuities, tensions developed between the primacy of prolonging human life and humanitarian care for the bodily, emotional, and spiritual needs of persons who could not be cured. By the eighteenth century physicians devoted to this humanitarian ideal began opposing the sustaining of life by every available means for persons at the end of life. The last decades of history covered by this essay end when experimental science provided means by which to extend life in hitherto fore unimagined ways. Devoted to the prolongation of life, scientific medicine became entrenched in modern hospitals and the preoccupation of medical training.

The agonizing stories of patients, the troubled concerns voiced by a handful of physicians, and the voices of historical continuity from the Pope and physicians with similar concerns declared that modern medicine was losing its moral moorings. The seeds for the impending reforms regarding the rights to refuse advanced life-prolonging treatment and to receive attentive humane end-of-life care were sown in the late 1950s and 1960s. Their germinating power lay in the fact that they were gleaned from dominant cultural motifs that had shaped the practice of medicine through centuries of Western history.

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REVISED BY AUTHOR

SEE ALSO: *Advance Directives and Advance Care Planning; Clinical Ethics; Death; Death, Definition and Determination of; Holocaust; Informed Consent; Medical Codes and Oaths; Palliative Care and Hospice; Right to Die: Policy and Law; Surrogate Decision-Making;* and other *Life Sustaining Treatment and Euthanasia* subentries

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LITERATURE AND HEALTHCARE

• • •

If dialogue—sophisticated, passionate, often angry dialogue—is the mark of a lively field of inquiry, then the study of creative literature is thriving. Central to the dialogue has been the question of the relation, if any, of literature to the world outside itself—that is, to the so-called real world of culture, politics, and ethics. Some of the most influential philosophers of literature (e.g., Derrida; see also Belsey) have been warning readers that they can no longer go to the classics of literature to mine gold nuggets of knowledge about life. Ironically, all this has been happening at the same time that certain prominent ethicists have been rediscovering the moral value of literature while speaking of “virtue” (MacIntyre) and—most prominently—“narrative ethics” (Hauerwas and Burrell; Nelson, 1997; Chambers; Charon and Montello). Have literature and ethics passed each other in the night? This much is clear: Before anyone can speak responsibly of the relationship of bioethics to literature, it is necessary to understand the general terms of the literary professionals’ fight about meaning.

Theoretical Contexts

Of course, the agitation is far more complicated than it will appear here in a nontechnical summary. But the commentators can fairly be divided into two loose groups called values-oriented and language-oriented theorists. This distinction is related to the ethics/aesthetics, art for life’s sake/art for art’s sake, and content/form divisions of the past in that the first term of each pair (values, ethics, life, content) encourages the use of literature as a tool for living a good life, and the second term (language, aesthetics, art, form) points to a view of literature as an important end in itself. But today’s values/language debate, particularly the language side, is by no means strictly congruent with past positions. Values-oriented people can be taken to include those who believe that the relationship between literature and ethics can be richly productive of change in individuals and society; the language-oriented group includes those who believe that, given contemporary understandings of language, such a relationship is an illusion. Thus far, the language theorists have prevailed—if not in the classroom, then certainly in the scholarly conferences and journals as well as in the commercial reviews.

VALUES-ORIENTED THEORIES. The values side has nevertheless been accorded intelligent attention, too, and their side is showing strong signs of renewal (Booth, 2001). Using various technical terms for values in literature (e.g., *classic realism, hermeneutics, ethical criticism,* and *moral imagination*), literary commentators have: (1) suggested that, in the words of Mark Twain, the reports of their death have been greatly exaggerated and would, in any case, be disastrous for both literature and society (Graff); and (2) proclaimed that moralists may very well have died but should be resurrected and readmitted, within certain limits, to the practice of criticism (Booth, 1988). Influential endorsement for the values-oriented position has also come from outside literature. Most notably, the philosopher Martha C. Nussbaum has insisted in a string of influential books that literary narratives of ideas and emotions constitute an essentially—and, for her, sometimes the solely—adequate depiction of ethical dilemmas. Another philosopher, Geoffrey Galt Harpham, agrees. And psychiatrist Robert Coles has championed the traditional view of literature as balm for the human spirit.

The complete history of values-oriented critics must make space for the two towering figures who, in the first half of the twentieth century, took up the mantle of the English poet and critic Matthew Arnold (1822–1888) to proclaim that a commitment to individual and social morality was the mark of supreme writers. In 1967 F. R. Leavis wrote in *The Great Tradition* that the finest novelists "are all distinguished by a vital capacity for experience, a kind of reverent openness before life, and a marked moral intensity" (p. 9). And Lionel Trilling, whose influence in the United States was once as widespread as Leavis's in England, said in *The Liberal Imagination:* "For our time the most effective agent of the moral imagination has been the novel of the last two hundred years" (p. 209).

Today, the two men are ignored or reviled by many of the most famous critics of literature. To some of them, Leavis's and Trilling's classics-minded disciples share part of the blame for enthroning the traditional academic canon—largely produced, in the now infamous phrase, by "dead, white, male writers"—as opposed to a more flexible list that is open to writers of both sexes and those of multicultural origins. The followers of Leavis and Trilling are among those who have been tagged as "liberals" and "humanists" by self-proclaimed "radicals" of the Marxist, African-American, and feminist schools of literary criticism. But, if examined closely from the perspective of this entry, these arguments are all in the family—the family of literary critics whose guidelines promote discussions of values. So are the arguments of the so-called reader-response critics, such as Wolfgang Iser, who locate the meaning of literature in the interaction between the text and the reader, and, probably, even the "formalists" of various stripes (e.g., Mikhail Bakhtin), who emphasize form over—and occasionally at the expense of—content.

LANGUAGE-ORIENTED THEORIES. The true opposition to the values-oriented approach comes from the theorists who, under several different banners (most often "semiotics," "deconstruction," and, according to some definitions, "postmodernism"), deny that literary texts have an objective relationship to the world outside themselves. The founding father of these language-oriented thinkers is often said to be Ferdinand de Saussure, whose revolutionary book, *Course in General Linguistics,* was published in 1916 and is still being analyzed for its contributions to literary studies. Paul de Man, Roland Barthes, and Jacques Derrida are other influential writers whose theories undermine literature's direct contribution to ethics.

The basis of their position, which is introduced by Catherine Belsey, is roughly this: Contrary to the empiricist-idealistic tradition that language, and therefore literature, is a reflection of the real world of facts, objects, and transcendent states of being, language is arbitrary and constructed solely by cultural convention. Language does not name things that are already in existence, but is, instead, responsible for a person's recognition of distinctions in what would otherwise be a blurred continuum. If, for instance, our language recognizes a difference between the color blue and the color green, we will see a line on the horizon over land. If there is no such distinction, the sky will melt into the earth. In other words, the language-oriented literary critics say, we cannot experience the world except through language; there is no reality except for language. In effect, we are prisoners of the languages we understand, for language structures our world.

None of these ideas is remotely startling anymore. But trouble arises when they are logically extended, because, with these ideas in place, it is foolish to speak of a literary text as possessing any "truth" about ethical matters or about an empirical world in which ethical matters must be considered. Language is not related directly to the world, but only to other language, texts only to other texts. Does this post-Saussurean conclusion leave any room for ethicists seeking help from literature? For the most extreme of the language theorists, the answer is "very little." They would grant that literature might portray people making moral decisions or, at most, shame readers into feeling "a little ethical flutter, a little frisson" (Bly, p. xix). But they would add that because language by itself has no agency—that is, no power to bring anything about in the real world—then neither has literature.

For bioethicists, what is finally important about the maelstrom of contemporary literary/linguistic theory is that, first, whether they acknowledge it or not, people who think about bioethics and literature (e.g., Brody, 1987, 1992; Jones; Brock and Ratzan; Clouser and Hawkins) generally derive their theoretical justification from the values-oriented thinkers, and, second, these ethicists are thereby ignoring the dominant literary epistemology of recent decades.

The Ethics of Literary Form

To be sure, there have always been routes through literature to ethics that circumvent the entire values/language debate. A number of these routes are a matter of form as opposed to content.

THE STUDY OF NARRATIVE FORM. Chief among these routes is the form called "narrative" or "story." Narrative is not exclusively literary: Writers from nearly every academic discipline have asserted that human beings tend to perceive life not as isolated ideas, facts, or problems, but as stories—series of plotted events involving characters and told from certain perspectives. In literature, the study of narrative form has become highly sophisticated (Martin; Newton), and literature-and-medicine scholars have participated in its development (Hunter, 1991). Narrative ethicists use the narrative paradigm to counter, or at least to supplement, an ethics based solely on abstract principles (Reich; Clouser and Hawkins; Nelson, 1997; Charon and Montello). In other words, narrative ethics is an attempt to return ethical dilemmas to the messy, complicated lives from which they arose and to plumb those narrated dilemmas with other stories that are coherent and meaningful.

Narrative ethics usually stops there, and it should not. No one looking to literature for moral anecdotes should think that the task is complete when they are found, for the narrative form itself may present—or, more commonly, mask—ethical problems. Most ethical problems derive from questions about the adequacy and authority of what is called the "narrative point of view." Whether a story is oral or written, whether it is from life or art, the audience needs to know the narrator's angle of perspective. That is, who is telling a particular story, and what constitutes his or her authority for doing so? Did the narrator witness the events related or is the report secondhand? Is the narrator deeply involved with the events, distant from them, or perhaps not able to understand them? T. Hugh Crawford points out that one needs to determine the narrator's social privilege, which, in the case of physicians, may be so great that the truth of their stories will go unchallenged. An ethicist should also realize that the narrator always functions as an editor and therefore inevitably omits some elements of the imaginary "complete story" that may have a substantial moral impact. A second set of questions should concern the audience to whom the narrator directs the story, for the tale will be adjusted accordingly.

The questions become more complicated when a story is written, more complicated still when it is part of literary art. For instance, the narrator must not be unthinkingly identified with the real man or woman who composed the story, especially when the story is written in the first person, or even when authors use their own names for the narrators. The doctor who narrates the William Carlos Williams stories about patients in Rutherford, New Jersey, where the author practiced medicine, is not the same person as the Dr. Williams who made house calls or the Bill Williams who was Floss's husband; for the simple truth is that the author is never precisely the same as the narrator. Medical ethicists, writing about paternalism in Williams's famous short story "The Use of Force" (1933), do not always make this distinction, and their conclusions are thereby less precise.

Nevertheless, most literary narratives are written in the third person (e.g., "Sid was thinking that the surgeon seemed unresponsive"). It is an ethical, as well as an aesthetic, question to ask whether the narrator is positioned inside Sid's head, as it were, and therefore knows authoritatively only what Sidney knows, or whether the narrator also knows that "the surgeon was thinking about Sid's gall bladder," that outside "the wind was pushing the fall leaves around the parking lot," and that in the world at large "it was the worst of times." The first kind of narrator is technically a "concealed narrator" or "center of consciousness," the second an "omniscient narrator." Fashion in the twentieth and early twenty-first centuries has favored the first kind for its epistemological and ethical qualities because the omniscient narrator's sweeping knowledge is suspect. In the United States, especially, people tend to balk at according anyone—a president, a spouse, a doctor, a narrator—that kind of power.

These sticky questions about narrators lie in wait for medical ethicists when they are using their favorite narrative form, the case history. When "participant–observer" David Barnard published an extended case history, his intentions were to broaden the social and temporal bases from which ethical decisions are made and to show that a given illness affects the caregivers as well as the patient. He achieved these goals, but literary critic Eric Rabkin challenged the form of the case, asserting that Barnard-as-narrator and the physician, Valerie Walsh, had unconsciously produced "a story in which each could be the hero" (Banks, et al., p. 52). The resultant furor, summarized by Barnard (1992), who later (2000) accepted the criticism as valid, has helped to clarify the ethics of narrative form, but some aspects are still underexplored.

THE IMPORTANCE OF GENRE. The study of narrative is only one of the important ways to understand how literary form affects ethics. In fact, an awareness of what genre a given work falls into—is it a story or a play, a comedy or a tragedy?—is almost always important for the ethicist. Because drama, for instance, is distinguished from other literary forms by virtue of its dialogue and conflict, perhaps ethical conflicts should be presented in dramatic form rather than in narrative case histories. Not only would the various positions on a problem be fully embodied in the individual language of each "character," the format would also encourage the greater objectivity for which drama has a reputation. An argument can also be made that great plays and their first cousins, films, ought to be studied by ethicists to sharpen their awareness of not only dialogue and conflict but also such matters as role, costume, setting, set speeches, and audience reaction, because all of these factors change the moral climate of any scene from life. It would not matter whether the play chosen was specifically about bioethics or not. Any good play would serve the ethical goals (Banks, 1990).

Genre also affects more pervasively and subtly, because genres are, finally, forms that cultures select to convey their deepest values. Granted, for language-oriented theorists, the traditional distinctions among the genres have blurred—even disintegrated. Texts are texts, no matter what the form. They refer solely to other linguistic productions in an endless line of what literary critics call "intertextuality" and "subjectivities." These are important concepts. Nevertheless, traditional genres yield valuable information for ethicists. For example, the form of Greek tragedy inevitably introduced certain ethical values. One of the most troublesome for modern individualists is the widespread attitude toward fate (often personified as the vengeful Erinyes, or, in Rome, the Furies), whereby the Greeks believed that once a sequence of events had been set into motion, human beings had no ability to prevent its outcome. Once Oedipus had unknowingly killed his father, he was destined to marry his mother. Furthermore, he had to be punished for these acts even though he had no evil intention. That is, in order for the good to triumph in the ultimate balance of the universe, all those who had done wrong, whether consciously or not, had to pay. Like all great artists, Sophocles (c. 496–406 B.C.E.) lived in creative tension with what conventional form forced upon him: His Oedipus sees himself as free enough to be blamed and to inflict his own punishment by blinding himself. Nevertheless, a belief in what might be called the "Greek tragic plot" not only affected ethical decisions—in a sense, it precluded them. Though less confining, certain ethical perspectives are already inherent in modern authors' affinity for mixing the traditional genres, as in "tragicomedy" and "docudrama." We may be too sophisticated to separate the serious from the funny, the real from the make-believe; or—and here is the ethical issue—we may be too confused to understand the difference.

AN EXAMPLE FROM SHAW. If literary form may thus limit ethics, form may also free it. The British playwright George Bernard Shaw's *The Doctor's Dilemma* can serve as an efficient illustration of both capabilities. Next to Williams's "The Use of Force," Shaw's play is probably the most oft-cited example of medical ethics in literature (see, e.g., Brody, 1991, on teaching Shaw in an ethics class). Shaw, of course, was a first-rate comic writer: The pompous, ignorant, and fee-grabbing physicians in this play are squarely in the tradition of the hilariously unethical doctors created by the seventeenth-century French playwright Molireè. But Shaw was also a playwright of great moral passion, an unabashed didact who mounted theatrical soapboxes to preach his ideas about social reform. The play form simply did not give this second Shaw enough room. Therefore, to most plays he published, he attached an essay of polemical prose that allowed him to go over much of the same material in a different literary form. In the case of *The Doctor's Dilemma,* this material was medical ethics.

The two forms, preface and play, dictate two startlingly different takes on the same ideas. Whereas the preface requires precision, the play requires ambiguity, or, more accurately, encourages it. In the play, Sir Colenso Ridgeon, who has recently discovered a successful treatment for tuberculosis, is forced by limited resources into deciding whom to treat and whom to allow to die. Specifically, he must choose between a poor, worthy—and dull—doctor, and a poor, reprehensible—and uniquely brilliant—artist. The situation is complicated by Sir Colenso's amorous feelings for the artist's wife, whom he imagines as an available widow. That is the dilemma of the title. Sir Colenso resolves it by treating the doctor. His justification for this action is that because the artist has no moral integrity, he, Sir Colenso, is saving the wife from discovering her husband's deceit and killing herself, as she has threatened. When he reveals his reasoning to the wife, now the widow, she accuses him of murder. In reply, he justifies his actions by citing Arthur Hugh Clough's satiric poem, *The Latest Decalogue:* "Thou shalt not kill, but needst not strive / Officiously to keep alive."

Shaw's play raises more questions than it answers. When he writes polemical prose, Shaw argues easily, logically, and from an unshakable moral perspective. But when he takes ethics into the personal realm of drama, he cannot manage equally clear conclusions. So the play, as distinct from the preface, reverberates with moral ambiguity. Sir Colenso and an older, sensible physician soundly debate the central dilemma—but no conclusion is drawn by Shaw. Similarly, Sir Colenso's decision is padded with ethical red herrings. When, with no apology, he recommends as a physician for the artist a man of eminent reputation but shameful ignorance, Sir Colenso is behaving in a superficially licit manner that serves to distract him from the ethical problem. What the playwright does face directly is that ethical decisions in medicine are difficult to sort out logically; that no physician alone, or even in consultation with other professionals, can make them on objective grounds; that the results, when allocating limited medical resources, will be a type of murder; and that these burdens are too much for one person to bear.

For Shaw the playwright, then, the dilemma of who shall live and who shall die cannot be answered without dishonor and tragedy. (He calls this play, and this play only, a tragedy.) For Shaw the political philosopher, the same question is answered in terms that, by contrast to the subtleties of the play, are chillingly clear. He asserts in the preface that "invalids, meaning persons who cannot, beyond reason, expect to be kept alive by the activity of others," must be allowed for social reasons to die. "The theory," Shaw concludes firmly, "that every individual alive is of infinite value is legislatively impracticable … the man who costs more than he is worth is doomed by sound hygiene as inexorably as by sound economics" (pp. 86–87). And that's that.

Abortion and AIDS, among Others

Shaw, Williams, Molireè: These names are the beginning of a long, long list of first-rate creative writers who have narrated, dramatized, and, in general, illuminated specific topics of bioethics. Hundreds of other names and their works could be added. A partial roll call of the most useful would include Tobias Smollett's *The Adventures of Roderick Random* (1748), Herman Melville's *White-Jacket* (1850), Anthony Trollope's *Doctor Thorne* (1858), George Eliot's *Middlemarch* (1871–1872), Georg Büchner's *Woyzeck* (1836), Henrik Ibsen's *An Enemy of the People* (1882), Sinclair Lewis's *Arrowsmith* (1925), Albert Camus's *The Plague* (1948), Peter Nichols's *A Day in the Death of Joe Egg* (1967), Joyce Carol Oates's *Wonderland* (1971), and Peter Shaffer's *Equus* (1973).

In the first bibliography of literature and medicine (Trautmann and Pollard), which annotated about 1,400 literary works from classical to contemporary times under thirty-nine categories, ethicists can check for information not only under "medical ethics" but also under "abortion," "euthanasia," and "evil doctors." The years since the bibliography's publication have, of course, added more authors, and many more works, to the inventory of resources. It is intriguing that the years have also changed the categories. Among the bibliography's topics, "age," "handicaps," "mental retardation," "plague," "suicide," "venereal disease," and "women as patients" have taken on extensive political, and therefore ethical, implications. New categories have emerged too. "Cross-cultural," for instance, must be clearly distinguished from the old "poverty and health"; "AIDS" deserves its own category, having grown beyond "plague" and "venereal disease" (which itself has developed into "sexually transmitted diseases").

Bibliographic assembly for literature and healthcare has, since 1993, been under the direction of Felice Aull at the New York University (NYU) School of Medicine. Aull and a large board of editors and annotators have brought their subjective, interactive, and regularly revised bibliographic work where it needs to be—to the Internet. The NYU group has tripled the number of Trautmann and Pollard's subjects and mirrored the movement in literary criticism toward cultural studies, thereby broadening the definitions of text and literature to include, for example, film and the visual arts. Following the trend in ethics, medicine has also been broadened to include not only nursing but also all the newer healthcare professions.

Along with the expansion of creative work about bioethics, the field of literature and healthcare has seen an enormous growth of books *about* these works. The studies are generally about topics and people at some distance from U.S. culture's centers of power: the feminist body (Grosz); disabilities (Thomson); aging (Wyatt-Brown and Rossen); pain (Scarry; Morris); and caregivers (Poirier and Ayres).

To demonstrate precisely how literature illuminates bioethics, it might be helpful to analyze, first, a traditional work on an established ethics topic—in this case, abortion—and, second, a group of fiery works about a newer topic, AIDS.

ABORTION AND *THE CIDER HOUSE RULES*. One of the most important novels on U.S. medical ethics is John Irving's *The Cider House Rules*, which was made into an influential film that was released in 1999. Morality—the metaphorical "rules" of the title—is its central concern, specifically the morality of abortion before *Roe v. Wade,* the 1973 U.S. Supreme Court case that established abortion's constitutionality. One of the book's two main characters is

Dr. Wilbur Larch, who performs illegal abortions at the orphanage he has established in a remote area of Maine. He offers women a choice—an orphan or an abortion. The other character is Homer Wells, one of those orphans, who, as a young man, is an ardent antiabortionist, able to articulate arguments in opposition to Larch. But, in the end, breaking his own and society's rules, Homer assumes a medical identity that allows him to take over Dr. Larch's practice.

As is so often the case in life, Homer's position begins with an image rather than an idea. At the age of thirteen, Homer sees a dead, nearly nine-month-old entity, whom Dr. Larch wants to call a "fetus," but Homer feels compelled to call a "child." After that, Homer immediately links any argument from Larch about "the products of conception" before the quickening to the image of the dead baby. Now the pictures of even the eight-week-old fetuses in Gray's *Anatomy* strike Homer as having an "expression," or, the narrator tells us, what other people call a "soul."

Nor is Dr. Larch initially won over to abortion by arguments. As a medical student, Larch sees for himself the damage inflicted on women by the alleyway butchers and poisonous aborticides. He stares into the dead face of a woman to whom he had refused an abortion. He witnesses the deprivations of orphans. Later, Dr. Larch adds reason to his emotions. He has a large array of arguments at his command, including, for instance, his disgust at someone "who cares more for the misgivings suffered in his own frail soul than for the actual suffering of countless unwanted and mistreated children" (Irving, p. 260). He presents another argument that finally convinces Homer. Written in a letter, it reads: "If abortions were legal, you could refuse—in fact, given your beliefs, you *should* refuse. But … how can you feel free to choose not to help people who are not free to get other help?" (p. 488).

These characters, these events, and these ethical concepts are all embedded in a form that must be described and its intimate connection to the ethical content made plain. Basically, the form is adapted from the nineteenth-century, realistic, English novel because it suits Irving's traditionalism—his sense that fiction has as its chief mission the examination of values. In that regard, his model is surely Charles Dickens. *The Cider House Rules* has Dickensian size. Like a Dickens novel, it is openly concerned with individual and social ethics. Every night, Homer reads Dickens's *David Copperfield* or *Great Expectations* to the boy orphans, who unquestioningly accept the novels as portals to morality.

To the girls, by the way, Homer reads Charlotte Brontë's *Jane Eyre,* whose orphan heroine is blatantly offered as a role model—and is sometimes blatantly rejected. Jane's sweet optimism is too much for one angry, world-weary orphan. In a vividly comic instance of what scholars such as Wayne C. Booth and Nussbaum would be forced to call "ethical criticism," the hulking, teenaged orphan demonstrates the power of literature:

> "Even for me [chirped little Jane Eyre], life had its gleam of sunshine."
>
> "'Gleams of sunshine'!" Melony shouted in violent disbelief. "Let her come here! Let her show me the gleams of sunshine!" (Irving, p. 84).

From the nineteenth century, too, comes the novel's narrative voice. It is omniscience, moving freely in and out of any character's mind and making such general observations as: "Society is so complex that even [the little town of] Heart's Haven had a wrong part to it" (Irving, p. 125). The narrator knows everything in this created world. If he (let us say) can build an aesthetically convincing world, readers may believe he knows a great deal about the real world, too. Irving has tried to buttress the authority of his novel's narrator by appending the scholarly apparatus of endnotes. Tied to certain pages and narrative "facts," these notes assert that Irving has researched his material. He has read medical texts, both old and modern. He has consulted with physicians, including one of the canonical authors in literature and medicine, Richard Selzer. All the evidence points to this author being very serious about the real world, a values-oriented thinker as described earlier, rather than one for whom language is a closed system.

Irving writes tragicomedy. One distinguishing mark of an Irving novel (the most successful was *The World According to Garp* [1978]) is that, after much humor, someone innocent dies. This is Dickensian too: Think of Little Nell in *The Old Curiosity Shop.* As noted earlier, the mixed genre of tragicomedy is a favorite twentieth-century form, and cultural critics are still sorting out its implications. More and more, tragicomedy seems appropriate to the creative literature of medical ethics because the genre deals simultaneously with patients' tragic losses and caregivers' need to continue in spite of them. Tragedy ends something, but comedy always implies continuation, and the two are interdependent. Here is a literary lesson that bioethicists, whose "quandary ethics" proceeds from an exclusively tragic premise, have yet to learn. As that wily moralist, Shaw, has Dr. Ridgeon say in *The Doctor's Dilemma,* "Life does not cease to be funny when people die any more than it ceases to be serious when people laugh" (p. 185).

SEVERAL WORKS ABOUT AIDS. Literary writers have responded to AIDS faster and more often than to abortion. They have also tended to leap more aggressively from art to ethics. Taken as a group, the narratives, plays, poems, films, and critical essays about AIDS (see Nelson, 1992, for a bibliography) are fervently contesting the ethical boundaries of language itself. For a start, some of the creative writers and critics who write about AIDS are activists. Larry Kramer, author of *The Normal Heart,* was an early and loud voice. These activists insist that the first goal of AIDS literature must be to change the critical circumstances of the disease and its sufferers. They call for "stridently interventionist cultural practice" (Nelson, 1992, p. 8, citing Douglas Crimp). They say that to write about AIDS at all is automatically to be a moralist, for, in this battle, no sidelines exist. Demurrers about art for art's sake are irrelevant and themselves immoral. So one question about activist AIDS literature is: Does such work fit into the artistic genre called "social realism" or is it not art at all, but, instead, blatant propaganda whose first and last goal is social change? To the first category, literary historians have assigned, for instance, Ibsen's *An Enemy of the People,* which is an ardent piece about an idealistic doctor's crusade to warn tourists about his town's polluted public baths in the face of community pressure, as represented by his brother the mayor, to keep his mouth shut. The play is comparable to Kramer's *The Normal Heart,* in which another doctor battles to get money for AIDS research in a New York whose mayor seeks to prevent would-be tourists from knowing about the epidemic. But where do we draw the line between taking a stand and propaganda, wherein the end shapes, even justifies, the means?

What might any writer, activist or not, be excused for saying in order to bring about a desired end? What language—which images, which metaphors—may validly be used to inflame audiences with a just passion? One of the most common metaphors for the AIDS epidemic in the homosexual community is the Holocaust (e.g., Nelson, 1992), which was said in the early days of activism to be recurring through the establishment's lack of a plan to prevent the genocide of gay men. Is this horrifying image apt? Is it logical? Alternatively, are these questions themselves out of place in view of the absolute primacy, for some people, of subjective data about illness?—that is, "I have AIDS, and it feels as though I am living through another Holocaust. What do you know about it?"

The morality of metaphor is the territory famously covered by Susan Sontag in *Illness as Metaphor* (1978). There she argues that to substitute metaphors, especially negative metaphors, for the reality of bodily suffering is to impose a spurious meaning on illness and a sense of guilt on the patient. If cancer, in the common military metaphor, is a battleground, then the patient can be blamed for not winning. Sontag comes back to her point in *AIDS and Its Metaphors* (1989), where she contends that "plague," the most common metaphor for AIDS, implies judgment on a corrupt society. In her own story about AIDS, "The Way We Live Now" (1987), there are no metaphors for the illness. Moreover, in what would seem to be a further attempt to free AIDS from contaminating linguistic associations, she does not even name it.

Sontag's reasoned approach to this crisis is similar to the theories of the German playwright Bertolt Brecht (1898–1956). Unlike the AIDS plays, most of which are designed to be deeply cathartic, Brecht's plays aimed for the "alienation effect" in order to limit his audience's emotional involvement in the work. He used various devices to remind audiences that they were watching illusion, not reality—a play, not life. This distancing, he hoped, would free their minds to reason clearly that humanitarian action was needed in the world outside the theater. A former medical student, Brecht wanted to achieve the theatrical equivalent of clinical objectivity. His goal, like that of AIDS activists, was to change society, but, unlike some of them, he thought it unethical to reach minds by manipulating emotions.

In arguing against metaphor, Sontag seeks to chip away at the use of language as a shield to protect people from difficult experience. Given the symbol-making nature of the human mind, she has chosen a position that finally may be impossible to defend. She seems to know that, and yet she thinks it eminently worthwhile to fight for the "thereness" of the human body, for the indisputable fact of its physical presence. So does literary and film critic James Morrison, who is worried that postmodernism (read: "language-oriented thinking") has infected criticism about AIDS literature. Defining allegory as "a series of metaphors arranged in sequence" (Nelson, 1992, p. 169), Morrison complains that the postmodern attraction to allegory—that is, to expressing experience as an abstract text that refers only to other language and not to the real world—has moved readers further away from the actual experience of AIDS. In his eyes, allegories dictate that both AIDS and the person with AIDS be classified as "other"—something, at any rate, that cannot be approached without the intervention of elaborate figures of speech. The allegory to which he objects most vehemently is the series of metaphors that describe the body as text. When logically extended, he says, such an allegory would allow someone to "read," as it were, "the lesions of Kaposi's sarcoma as indexical signs" of the body-book (Nelson, 1992, p. 171). This he thinks a ludicrously unsympathetic way to approach the body in pain.

Morrison may not realize it, but his challenge implicitly goes out to the scholars in the interdisciplinary field of literature and medicine for whom the patient-as-text is both metaphor and method. He might just as well challenge every one of us, because the process of abstracting that he condemns in the case of literary criticism and AIDS seems to be a universal human phenomenon. The combined evidence of the writers examined here suggests that all of us are trapped between our suffering bodies and our symbolizing minds—that is, between a world whose existence we can prove simply by stubbing a toe and the engrossing stories that we are constantly creating about that world. It would appear to be nearly useless to ask which level of experience, the physical or the imaginative, is more real; or to look to one, at the exclusion of the other, for ethical insight.

In a sense, this brings us back to the values/language split with which this entry began. In calling for a clear-sighted view of every specific person with AIDS, Morrison aligns himself with the values-oriented camp. He wants not only creative writers but also commentators on literature to write justly. So does Sontag. But, as she demonstrates in her own fictional works, language is a powerful and playful human trait that tends to seek its own ends, regardless of its possible relationship to the real world of ethical problems. Language, in fact, creates new worlds all the time. Consider only Tony Kushner's *Angels in America,* so magnificent an achievement that it transcends the category of AIDS play. In short, the values/language dichotomy is more properly seen not as a true division but as a perpetual ethical tension.

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SEE ALSO: *Bioethics; Ethics; Narrative*

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LIVING WILL

SEE *Advance Directives and Advance Care Planning*

LONG-TERM CARE

• • •

I. Concept and Policies
II. Nursing Homes
III. Home Care

I. CONCEPT AND POLICIES

Long-term care (LTC) is an individualized mix of personal care, healthcare, and social services for persons whose functional impairments dictate that they need help with tasks of everyday living (Kane and Kane). Consumers of LTC may live in congregate residential settings such as nursing homes, assisted living settings, adult foster homes, or board-and-care homes, but most live in their own homes and are candidates for community-based LTC programs including home care, adult day care, home-delivered meals, emergency assistance, and home renovation. LTC may be provided by paid workers, but most often it is provided voluntarily by family and friends. The need for LTC is assessed by evaluating the person's ability to perform activities of daily living (ADL), such as bathing, dressing, using the toilet, getting in and out of bed, eating, and performing household and other practical tasks including cleaning, cooking, shopping, managing money, and transporting oneself. LTC services correspond directly to measured impairments in ADL performance and to other functional impairments. People may choose to purchase similar services for convenience alone, but a service is defined as LTC only if a measurable disability prevents the RAK (people receiving care) person from performing the given task.

Most LTC consumers are elderly and, indeed, well over age seventy-five. But many younger people also need and receive LTC. These include physically disabled adults with conditions such as multiple sclerosis, spinal-cord injuries, head injuries, and late-stage cancer; persons with late-stage acquired immunodeficiency syndrome (AIDS); technology-dependent, severely disabled children; and persons of all ages with developmental disabilities such as cerebral palsy. Anyone who needs and receives help with everyday functioning because of a disability may be considered to be receiving LTC. They may, of course, also receive preventive and curative acute medical care from time to time. Some disability activists prefer to replace the term LTC with a substitute such as "long-term services," both because LTC is often equated with nursing homes in the popular mind and because they prefer to distinguish the emotional and nurturing aspects of "care" from the concept of services.

The goals of LTC may be multiple and often are ambiguous. Sometimes the goal appropriately includes rehabilitation or improvement of the consumer's functional abilities, but frequently the most reasonable goal is to enable consumers to live as meaningfully as possible given their impairments, abilities, interests, and life-cycle stage and roles. Sometimes LTC providers treat the LTC services (e.g., bathing assistance and cooking, or any particular mix of services in the plan) as the actual goal of LTC. Other LTC programs promulgate ambitious goals, for example, that LTC consumers should be well satisfied with life and score well on absolute indicators of well-being or social adjustment. In either case, practitioners and policymakers struggle to attend to rehabilitation possibilities while avoiding grandiose or intrusive goals. For service providers to assume responsibility for global outcomes of someone's life along with their provision of routine services requires some hubris, and LTC professionals are perplexed about how comprehensively to cast their goals.

A number of other factors make LTC unique. LTC is an enterprise in which the services are diverse though often ordinary, the providers are diverse (including professionals, paraprofessionals, and family members), the clientele is diverse, and the goals are often unclear. Furthermore, much LTC, and most publicly subsidized LTC, takes place in nursing homes, where the functionally impaired consumer may have been involuntarily relocated, and the high cost of LTC in residential settings and in the community is of concern to private and public payers. Finally, LTC is a women's issue because the consumers, the family caregivers who are pressed into service, and the paid caregivers are predominantly female. Of course, husbands give care to their wives as needed, but the typical LTC consumer is a widow, and the typical family caregiver is a wife, a daughter, or a daughter-in-law.

Trends in the 1990s and Early 2000s

Several trends in the United States during and following the 1990s have also helped shape the key ethical issues involving LTC. In the United States, publicly funded LTC is usually offered on a means-tested basis and is a matter of state rather than federal policy (although the Medicaid program matches state funds and sets some broad program parameters). State governments expend most of their funds on care in nursing homes, although consumers prefer to live anywhere else. The magnitude of this disproportionate spending has receded somewhat since 1990, and a concomitant growth has occurred in what is called the home- and community-based services (HCBS) sector. Three elements are highlighted: the growth of assisted living, the promotion of consumer-centered approaches to care, and the pursuit of LTC as a civil right for persons with disabilities.

Assisted living is an umbrella term for a variety of residential settings that provide or arrange care and are not licensed as nursing homes. They have proliferated, partly because of consumer interest in alternatives to nursing homes. At their best, assisted living settings combine a high level of privacy and autonomy-enhancing architectural features with a capacity to provide substantial care to residents in their own assisted living apartments. At their worse, they fail to offer high privacy or high service or both, they are costly, and they evict residents when they have real care needs. The presence of almost a million assisted living units by 2002, and the coverage of the services provided or arranged by assisted living programs in most states (Mollica), has given rise to concerns about quality, punctuated by highly publicized scandals in the print media and a 1999 U.S. General Accounting Office study showing that consumers had poor and incomplete information prior to purchase. The extent to which the federal government should regulate assisted living programs and how they should be regulated is now a matter of spirited debate.

Consumer-directed care and consumer-centered care are slogans that reflect a growing sentiment that the users of services should as much as possible direct the nature of those services and that their views should be solicited for quality reviews and program development. At the extreme end of this view, advocates suggest that funds for services be provided directly to consumers or their agents, who would then hire, train, supervise, and dismiss care workers. Advocates of this view prefer the use of personal attendants or personal assistants to home care from agencies. In some European countries, notably Germany, cash is offered in lieu of services in LTC insurance programs, and the United States launched in the late 1990s a randomized trial of the effectiveness of cash with the cash amount established as somewhat less than the average cost of service plans versus services for HCBS under Medicaid. Care patterns that emphasize the authority of the consumer, however, raise problems about the rights of paid care workers, who themselves have been making strides toward collective bargaining.

Finally, the Americans with Disabilities Act (ADA) of 1990 provided leverage for social action related to LTC in a different vein than advocacy for better health and human service programs. In the closely watched *Olmstead v. L.C.* case, the U.S. Supreme Court in 1999 enunciated a right to care in the most integrated setting based on the ADA (although the right was circumscribed by vaguely stated requirements for "appropriateness"). This brought the Office of Civil Rights into the business of enforcing decisions related to quality of care (Rosenbaum; Rosenbaum, Teitelbaum, and Stewart). Younger persons with disabilities, even people with developmental disabilities and mental retardation, have made greater progress toward care outside of institutions than have older people. Comparisons between HCBS received by seniors and younger people with disabilities reveal sharp discrepancies; for example, the former often must be homebound to get publicly funded help at home, whereas the latter can use publicly funded personal attendants to help them leave their homes. Some argue that older people prefer the more secure; institutionally based services, but others suggest ageism is at work in the discrepancies. Also, older LTC consumers tend not to perceive themselves as being disabled and having rights under the ADA. Possibly the options and services would be better for seniors if pursued as a rights issue rather than as a healthcare quality issue.

Ethical Themes in LTC

Nine interrelated themes can be identified that give rise to ethical dilemmas for those who provide, administer, plan, or finance LTC.

INTIMACY OF LTC. Whether it is provided in consumers' own homes or in group residential settings, LTC is inextricably tied to daily routines. The way it is provided literally affects how LTC consumers live, where they live, whom they see, and how they spend their time. Ethical issues arise concerning the extent to which personal preferences and wishes should be honored, especially when they conflict with operating procedures of a caregiving organization or when they entail public costs. For example, should a person receiving home care be permitted to establish the timing for getting up and going to bed, even if this requires an attendant to visit late in the evening? Because LTC plans can be so comprehensive and intrusive, many believe that the consumer should be given as much choice and control as possible. Further, George J. Agich suggested in his 1993 book, *Autonomy and Long Term Care,* that a legalistic ethic based narrowly on the right to noninterference ignores the existential reality of LTC. He argued that respect for autonomy must include provision of meaningful choices and maintenance of personal identity. Writing largely about nursing homes, Bart Collopy, Philip Boyle, and Bruce Jennings also argued for a view of autonomy that takes into account "the moral ecology" of LTC settings. A large ethnographic and anthropological literature offers insights into the complexity of this moral ecology, that is, the settings and arrangements of care (Henderson and Vesperi).

With its focus on intimate, repetitive tasks and assistance with bodily functions that adults usually handle independently and privately, LTC can profoundly affect the dignity of the consumers and alter their sense of personal identity and worth. Cognitively intact LTC consumers may retain a keen sense of privacy concerning their bodies, their possessions, and even information about themselves. Assembly-line approaches to dressing, toileting, and bathing may be perceived as demeaning. Questions arise about how much energy LTC providers should be obliged to expend protecting the dignity of consumers and helping them preserve their sense of identity. Even if consumers are cognitively incapacitated and completely helpless physically, many believe it is wrong to subject them to procedures that are inherently undignified.

DEPENDENCY OF LTC CONSUMERS. Functionally impaired people are, by definition, dependent to some degree. Some people receiving care, though they may have the ability to conceive, plan, and choose actions, are virtually helpless to initiate or carry out actions. This creates a paradox: The more physically dependent the LTC consumers, the more they must depend on the help of others to exercise autonomy. Although providers taking a rehabilitation stance may strive to have consumers do things for themselves, respect for the consumer's autonomy dictate that great care be taken in fulfilling requests. Striking the right balance between encouraging independence and providing help is an ethical issue for LTC providers.

GROUP-LIVING SETTINGS. When LTC is provided in a collective, residential setting, the needs and interests of residents can collide. Residents in group settings are always expected to modify their individual wishes and behaviors to adjust to collective situations, and such expectations are usually well understood by all who enter such a setting. But it is unclear what rules of conduct and mutual expectations should govern a nursing home, an entity that is neither a hospital nor a housing unit. To some degree, the facility's search for efficient routines defines permissible behavior and opportunities for nursing-home residents.

Typically, nursing homes accommodate, in multiple-occupancy rooms and close quarters, residents who are markedly varied in physical ability, cognitive ability, prognosis, age, social class, interests, and personal taste. Some now question, however, whether continuing to house residents in shared quarters is ethically justifiable. One reason why assisted living is attractive in the private market is the greater availability of singly-occupied quarters; as states begin covering assisted living services under Medicaid, they face a decision about whether to fund privacy as a minimum expectation or to encourage a two-class system of assisted living with publicly subsidized clientele living in boarding home situations. The advent of assisted living also challenges the very nature of congregate LTC and obfuscates the boundaries between home care and institutional care. If assisted living consumers are viewed as tenants of their own apartments, where they receive services as well, then laws pertaining to fair housing may prevent providers from moving them to a reputedly higher care setting such as a nursing home.

Nursing homes themselves are in considerable ferment about how to adapt to the current LTC world. A social movement, originally called the Nursing Home Pioneers, gained momentum in the 1990s. Dedicated to culture change in nursing homes, those identified with the Pioneers recommend a variety of remedies, including empowering the line staff, flattening nursing-home hierarchical structures, and refashioning the physical settings into smaller neighborhoods and households (Lustbader). Within this group are proponents of specific changes such as the Eden Alternative (Thomas), an approach to combat boredom, loneliness, and lack of meaning in nursing homes; and the Wellspring model, a version of continuous quality improvement directed at empowering nurse's aides (Stone et al.). Many of these developments are antithetical to more traditional approaches to nursing-home reform proposals such as establishing higher nursing-staff–to–resident ratios and vigorously enforcing quality of care standards.

FAMILY ROLES. LTC is inevitably a family affair. Family members provide most of the care given to people at home. Indeed, much paid home care is organized explicitly to give relief, assistance, or training to family members, who in turn are expected to do most of the work. Questions arise about what is right to expect of various family members, and even whether older persons should be forced to accept, against their will, help from a family member. One also wonders whether family anxiety for a relative's safety should lead to the placement of that relative in a nursing home. On the personal level, LTC evokes questions about the duties and rights of spouses, parents, adult children, and other relatives.

In practice, LTC providers, and especially case managers who coordinate and allocate care, sometimes view the whole family constellation as the client, especially if all the family members are elderly or if they live in the same household as the person getting care. But family members' interests are not always identical to those of the consumers, nor are their intentions always benign. For example, nursing-home staff often find that family members disagree with each other about the resident's care. They also sometimes note that the decisions of family members are motivated by an interest in minimizing the costs of care. Nursing-home personnel, who may themselves have a conflict of interest involving payment and money management, for example, when their recommendations entail more payment to the nursing home, often turn to the state's nursing-home ombudsperson to resolve such disputes. Home-care providers and state-designated case managers who purchase publicly subsidized home care also often disagree with family members about the type and amount of care needed and about whether a nursing-home admission is in the LTC consumer's best interest.

END-OF-LIFE ISSUES. Death typically occurs during a period of LTC, either at the end of decades of care or after a relatively short episode. For this reason, many of the issues about death that confront acute-care providers also arise in long-term contexts, including the use of cardiopulmonary resuscitation, starting or stopping a respirator, or starting or stopping tube placement for nutrition and fluid intake. Issues of active or passive euthanasia also arise, which in turn evoke basic questions about the extent of the obligation of the healthcare professional to preserve life on the one hand and to avert suffering on the other. It is a challenge to give proper, systematic attention to end-of-life issues in LTC, while also giving weight to the everyday ethical matters that shape the quality of LTC consumers' lives (Kane and Caplan, 1990).

RISKS, RISK AVERSION, AND LIABILITY. Functionally disabled people are frequently unable to protect themselves against outside dangers such as fending off an intruder or escaping from a fire. Increased risks are associated with the simplest activities—walking to the bathroom, getting out of bed, or boiling a pot of water. People with precarious physical health may be at increased risk of a fall or of a sudden health incident, such as a stroke or heart attack, that needs immediate attention. If the LTC consumer suffers memory loss, the risks to safety because of forgetfulness or bad judgment increase. At the same time, supervision and surveillance exact a high price in both dollars and personal freedom.

In every type of LTC, questions arise about when it is right to leave a vulnerable person unprotected and subject to risk. The corollary question, asked less often, is when is it right to force a functionally impaired person to accept protection and eliminate risks, even risks the person prefers to take. The extreme example of restricting people for their own protection is the use of physical restraints, which were formerly ubiquitous in nursing homes but have been curbed by regulatory changes following a highly publicized Institute of Medicine study, published in 1986, on the quality of LTC settings. Sedatives and psychoactive medications also have been used as a form of restraint and behavior control, presumably for safety reasons. On a less dramatic level, numerous organizational routines and professional practices and decisions designed to keep a consumer safe also restrict personal freedom and may conflict with consumer preferences. Although attorneys point out that LTC providers have rarely been sued successfully for injuries sustained by a consumer while the consumer was pursuing an expressed preference or choice, the fear of liability is pervasive in LTC industries (Kapp).

A concept variously called negotiated risk agreement, negotiated risk contracting, or managed risk agreement has gained prominence since the early 1990s as a mechanism for LTC consumers or their agents to take conscious risks and behave in a way that professionals fear endangers their health. Based on contractual principles, the notion is that the consumer who had been informed of risks related to certain behavior should be able to take those risks unless the well-being of others is clearly threatened. This is an emerging area of practice that has advocates and many detractors; it raises the potential for adjusting the power balance somewhat in favor of the consumer, but raises the specter of provider negligence masquerading as respect for autonomy. The effort to put negotiated risk agreements into place sharply reveals the flimsy information base for many of the risks that are guarded against in LTC (Kane and Levin; Kapp and Wilson).

PROFESSIONAL STANDARDS AND PARAPROFESSIONAL ROLES. It is a truism that ethical care must be competent care. The codes of ethics that govern health professionals generally require that health professionals act within the framework of correct and up-to-date scientific knowledge and that they comply with the standards of adequate professional practice. Such judgments are easier to make about specific medical and nursing procedures than about the more amorphous and less specialized services of LTC, even when professionals are delivering the services. Without clear criteria for an adequate assessment of LTC needs or a competent care plan for a person with particular characteristics, it is difficult to promulgate standards or hold any one individual accountable.

One might argue that standards for care be set high and held to rigidly, to ensure safety. The more particular educational and other standards (e.g., caseload size) are mandated, however, the higher the cost of services. Professionals may unwittingly deny services to some older persons by advocating standards that inflate prices. Because professional self-interest usually accompanies concern for consumers in advocacy for professional standards, this subject has ethical import. Also, the more rigid the standards, the less flexibility there is for consumers to work out plans that suit their individual preferences.

The mainstays of LTC are the nursing assistants, home-health aides, homemakers, chore workers, and personal-care attendants who do the bulk of the difficult, labor-intensive, sometimes unpleasant work. Little consensus has been reached about either the responsibilities of the paraprofessional LTC worker or the extent to which the worker should be expected to do independent problem solving. Historically, little attention has been paid to the rights of the paraprofessional worker, who is typically paid a poor wage and sometimes faces substandard working conditions in people's homes. The worker may also suffer verbal or physical abuse from consumers or their family members. The care providers are often members of ethnic or racial minority groups serving a largely white, middle-class clientele. With the movement toward consumer-directed care that began in the early 1990s, however, the rights and needs of workers have been raised as a major obstacle to such consumer control.

RESOURCE LIMITATION. Decisions about what ought to be done must take costs into account, particularly when governments pay or subsidize payment of the bills. For each element of LTC services and programs, one can ask whether it is worth the money, compared to other good uses for the resources. Limited resources result in fewer caregiving staff in residential facilities, poorly paid home-care attendants or limited hours of home care for each person, less space, less privacy, and less personal attention overall.

A scarce resource might be a single room in a nursing home or an extra half hour of attention at home. Without explicitly translating cost-consciousness into human terms—such as the numbers of baths or assisted trips to the toilet an LTC consumer is entitled to or the number of minutes an LTC consumer should have to wait after pushing a call button—authorities tacitly accept that the resources available are limited and that resource constraints will compromise the best care for functionally impaired persons.

INTERGENERATIONAL ISSUES. Finally, LTC forces consideration of what an ethical society should offer to older people. Older people—people over seventy-five—are by far the most numerous group needing LTC, but the lifetime costs of LTC may be greater for a younger person. Some LTC planners ask whether the claims on society for care of a younger person with a disability and an older one are different in kind, degree, or justification.

Although justifications are often made for caring for older people based on reciprocity across the generations, the elderly are given resources and encouraged to manage their own care less often than are younger persons with disabilities. Indeed, political action among younger persons with disabilities has led to changes for older people receiving community LTC. In the 1980s and early 1990s, several states restructured their LTC programs under Medicaid and state financing to include adults of all ages with disabilities. As a result, these administrators now need to determine how to allocate resources fairly among consumers of widely different ages and circumstances. Advocacy groups representing younger persons with disabilities argue for a model of LTC that gives more power to the LTC consumer or his or her agent (Litvak, Zukas, and Heumann). Such groups prefer a social rather than a medical model of care that would, as much as possible, relegate to the consumer the prerogative of selecting, training, supervising, and firing those who provide personal care. A personal-care assistant who accompanies the consumer as needed is perceived as liberating, whereas home care was seen as restricting. Authorities disagree about whether the personal-assistant model is desirable or feasible for the much larger group of elderly LTC consumers.

Policy Issues

As with acute care, LTC poses interrelated problems in access, quality, and cost. Access to care is uneven because of geographic variation in supply and price. Care is most available in the least-preferred nursing-home form, because that is the form that is publicly subsidized. Quality concerns are present for both nursing-home care and home care. Public and private costs are high. Reimbursement methods and levels for LTC often create perverse incentives. Flat-rate systems discriminate against those who need the most care. At the same time, "case-mix-adjusted" systems, which increase payment for persons with greater disabilities, provide clear incentives against rehabilitation (Kane and Kane).

BENEFITS AND COVERAGE. The 1.9 million U.S. nursing-home residents represent about 5 percent of the country's elderly population. It is estimated, however, that an additional 10 percent of the elderly population have comparable functional impairments requiring LTC (Wiener, Illston, and Hanley). In contrast to many other industrialized countries, publicly funded LTC in the United States is available only to persons of low income, and, moreover, the vast bulk of public LTC expenditures are for nursing-home care. Despite expectations that LTC costs be met first by the consumers themselves, at least 50 percent of nursing-home costs in the United States are borne publicly (largely through Medicaid), because private resources are quickly exhausted. The public share of the costs also increases because some older people, to qualify for Medicaid, divest their resources in the years before they expect a nursing-home admission. The extent to which divestment increases public costs has been sharply debated. Publicly financed home-care benefits, though they became more widely available in the 1980s and 1990s, accounted for a relatively small outlay and were used by relatively few consumers. Further, almost all publicly funded home care has been capped at a rate less than the rate of public reimbursement for nursing-home care for the same consumer in the same state.

Nursing homes are perceived negatively. People do not want to live in them, send their family members to them, or expend their life savings and deplete their estates to pay for them. If the LTC-service setting were less aversive in terms of unappealing settings, rigid routines, and high costs, presumably some who now depend on volunteered family help would use paid LTC. This consideration dampens the enthusiasm of officials for expanding home-care benefits; they fear that home care, rather than substituting for nursing-home care, would be received by people formerly receiving uncompensated care from families.

Private LTC insurance is financially viable for only a fraction of the group at risk (Rivlin and Wiener). Both private insurers and public policymakers worry that if benefits were more desirable, they would be heavily used. After all, some LTC services (e.g., cooking, housekeeping, laundry) are intrinsically desirable even for people without LTC needs. Moreover, despite earlier beliefs, research has conclusively shown that at certain disability levels home care is more expensive than nursing-home care (Carcagno and Kemper). Economies of scale are achieved when brief, intermittent services and protective oversight are offered in centralized locations.

When community-based LTC is financed through Medicaid or state appropriations, case managers, usually social workers or nurses, typically perform initial assessments, authorize payments for home care, and monitor the quality of care and its continuing appropriateness. The case-management role promotes equity and efficiency in the use of benefits across a population but also creates a powerful agent, involved in the allocation of benefits, who may have no clear professional ethic, training, or authority. Home health agencies often complain that interposing a case manager between them and their clientele is wasteful and interferes with consumer choice; state officials argue that case managers who are separate from service delivery provide a disinterested advocate for the consumer. Juggling the roles of advocate and gatekeeper creates ethical tension for the case manager (Kane and Caplan, 1993). Case managers often have difficulty reconciling these roles but, at a minimum, should disclose to consumers the assumptions under which they work. In the early 1990s and before, informed-consent processes for case management were rudimentary.

Reimbursement issues are confounded by confusion about the extent to which LTC is a health program. In the United States, healthcare is considered a public responsibility (at least in part), whereas housing and social services are typically considered private responsibilities to be purchased with private income and with government subsidies for the poor. LTC includes social services and, when provided in nursing homes, housing. Policymakers have not determined whether they should extricate these components for financing purposes, or how to do so. Assisted living programs, such as those developed in Oregon in the early 1990s (Kane and Wilson), combine housing and board with service to functionally disabled, nursing-home-certifiable tenants in private apartments with kitchenettes, full baths, and doors that lock from the inside. Such programs may use outside home-care agencies to deliver the care, and in many states Medicaid reimburses the service component. This blurs the distinction between institutional care and home care. It also permits separating the financing of the room and lodging from that of the personal-care and nursing services, so the latter can be funded publicly and the former privately.

LTC costs and payment are also complicated by unclear boundaries between LTC and primary healthcare, acute hospital care, and post-acute care. Medicare, the universal health insurance program for persons over sixty-five, covers rehabilitation, skilled nursing-home care, and skilled home care in the immediate aftermath of an acute illness. These types of services, known as “post-acute” or “sub-acute” care, fall in an ill-defined area between acute care and LTC. Efforts to save money in acute care and post-acute care—for example, through earlier hospital discharge or denial of Medicare claims for post-acute care—can result in higher LTC costs. Demonstration projects have paid a per capita rate to care providers who are then responsible for both acute care and LTC costs; the projects are meant to determine whether better or more efficient use can be made of the total dollars when acute care and LTC are integrated into a single program. The social health maintenance organization is one such model, and another is the Program of All-Inclusive Care for the Elderly, which was modeled on an innovative program in San Francisco’s Chinatown that uses a day healthcare center as a key feature.

STANDARDS, REGULATION, AND QUALITY. The more professional standards are exacted for LTC services and the more providers are regulated, the more expensive LTC becomes. Because family members provide much LTC, some state policymakers suggest that professional-practice acts in most states are unduly restrictive in their requiring licensed nurses for many procedures routinely done by family caregivers. Others believe that vulnerable LTC consumers need protection by high standards for professional practice and managed professional supervision of nonprofessionals. This issue is salient because many LTC consumers would like to purchase cost-effective services. The break-even point, at which the price of community services exceeds that of home-based services, can be reached rather quickly and is influenced not only by the disability levels of the consumer but also by the price of the services. These, in turn, are influenced by regulations governing professional practices and agency licensure.

Regulation of care providers such as nursing homes and home-care agencies through state licensure, quality inspection, and federal certification programs also drives up costs, stifling innovation and consumer choice. Protection of vulnerable adults and avoidance of politically damaging incidents fuel these efforts. The supply of nursing homes is also regulated to stimulate community care and to save money (on the theory that a licensed bed will be used). This form of regulation has been criticized by those who believe that if market forces prevail, quality will improve.

Regulation of care settings, especially residential settings with great potential to affect quality of life, is hampered by disagreement about what should be included in the definition of quality and how various components of quality should be weighted. Although quality of life can be measured through direct interview with residents, including those with substantial cognitive disability (Kane et al.), the usual methods of accountability give greatest credence to low rates of negative health outcomes such as bedsores, infections, and weight loss. An Institute of Medicine committee charged to study the quality of LTC reported in 2001 that the field is characterized by profound disagreements about the very nature of quality; indeed, these very disagreements led to the inclusion of a minority report by committee members that placed higher emphasis on quality of life and consumer control as elements of quality (Wunderlich and Kohler).

FAMILY POLICY. Case managers make implicit and explicit decisions about the ability of family members to provide help before allocating publicly funded services to LTC consumers. LTC policymakers do not want to replace family care with public programs but want to protect families from undue burden. Respite programs have been developed specifically to provide episodic or emergency assistance to family caregivers. Various forms of compensation for family members have been suggested, ranging from tax credits to direct payment. In some states, LTC consumers have received cash payments, which they, in turn, can and often do use to pay relatives. Supporting these strategies, Nathan L. Linsk and his colleagues, in their 1992 book, *Wages for Caring,* noted the irony of paying strangers but not relatives. Direct payments to family caregivers are also seen as an income transfer to poor families. Opponents of family payment cite the cost implications. A midway position argues for family payments only when the caregiver has left the labor force to provide care—disqualifying most retirement-age spouses—and only for low-income families.

LTC LABOR FORCE. Paraprofessional workers in nursing homes and, more particularly, in home care, may receive minimum wages and no benefits. The cost implications of paying the workers an adequate wage are enormous. Although advocates of greater LTC benefits for senior citizens historically ignored the situation for workers, in the 1990s groups such as the Older Women's League formally recognized the condition of care workers as an issue. The very persons who perform the hands-on LTC tasks—typically, persons with low wages and nonexistent benefits—will become at risk for needing LTC themselves, without any personal financial reservoir from which to draw.

Conclusion

With the aging of the population and the chronicity of disease, long-term-care policies may be expected to continue to receive great attention. Many specific policies are in flux, and thematic and policy changes may be expected in response to current debates. The nagging questions about how a society can meet the ordinary needs of people with functional impairments competently, efficiently, and fairly—without compromising the autonomy and quality of life of the clientele—are likely to endure.

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SEE ALSO: *Abuse, Interpersonal: Elder Abuse; Aging and the Aged; Alternative Therapies; Autonomy; Care; Compassionate Love; Dementia; DNR; Grief and Bereavement; Healthcare Resources, Allocation of; Human Dignity; Informed Consent; Life, Quality of; Life Sustaining Treatment and Euthanasia; Medicaid; Medicare; Mentally Disabled and Mentally Ill Persons; Moral Status; Nursing, Profession of; Profit and Commercialism; Surrogate Decision-Making;* and other *Long-Term Care* subentries

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II. NURSING HOMES

The decision to enter a nursing home is the most wrenching outcome of long-term-care decision making. It changes almost every aspect of the life of an elder, who moves to new surroundings, may acquire a perfect stranger as a roommate, and must adhere to the nursing-home schedule. The either/or nature of the decision and the move to what has been described as a "total institution" (Lidz, Fischer, and Arnold) marks the decision about nursing-home admission as a "nodal" decision (Agich, 1993, 1995).

A nursing home is an institution in which persons, usually elderly (sixty-five years of age and older), live and receive nursing care and supervision. The provision of nursing care and supervision differentiates nursing homes from other senior residences; the lack of advanced medical and surgical services, and the fact that a nursing home is also a residence, differentiate it from a hospital. At any time, about 5 percent of those in the United States over sixty-five years of age are in nursing homes, many more than in acute-care hospitals. Over 40 percent of those over sixty-five will spend at least some time in a nursing home (Kemper and Murtaugh). Residents of nursing homes tend to be old, poor, and sick; younger patients, often with mental disorders, chronic conditions such as HIV-related disease, or post-traumatic conditions, account for a relatively small number. Nursing-home residents are disproportionately female and white.

Most nursing-home residents have trouble performing normal daily activities, such as bathing and dressing. They often have multiple long-term problems, such as confusion or walking difficulties; these changes frequently precipitate nursing home admission, when they overwhelm informal support systems. Nursing homes are increasingly used to provide further care after hospital discharge (Densen).

Ethical problems in nursing homes differ in several ways from those seen in other settings. Decision making often involves multiple related decisions made over time. There are multiple participants, and family members are often intimately involved. Many nursing-home residents are unable to make or communicate decisions, resulting in reliance on proxy decision makers. Institutional policies and practices act as powerful constraints on the autonomy of decision makers (Lidz et al.; Kane and Caplan, 1990).

Demographic changes in developed countries that have led to an increased need for nursing homes include an increase in the aging population in both absolute numbers and percentage of the population, nuclear rather than extended families, and more women in the work force. The emphasis on autonomy and the fear of lawsuits on the part of healthcare providers and institutions may be unique to the United States, but basic ethical conflicts between respecting personal autonomy and ensuring personal safety occur in nursing homes everywhere in the world.

Reimbursement

In the United States, nursing-home care is paid for almost entirely by Medicaid and "self-pay," with Medicare and long-term care insurance accounting for only a small percentage. Over two-thirds of those in nursing homes for more than six months are covered by Medicaid. Medicaid reimbursement is usually low, and nursing homes may react by raising the rates for other payers to subsidize the Medicaid population, maximizing the number of self-payers, or minimizing the amenities offered.

Asset management, in which assets are shielded or transferred while the elder becomes eligible for Medicaid, raises several questions. Is it ethically justified for relatively well-off elders to use programs meant for the poor? Alternatively, should those elders have to spend all their resources in the last few months or years of life? Several state programs have been developed in response to these questions, in which elders who purchase long-term care insurance are covered by Medicaid when their insurance runs out (Mahoney and Wetle).

Major questions regarding reimbursement remain. Who should bear the responsibility for the long-term care of elders? What are the ethically justified means of financing nursing-home care? What mix of long-term care settings should be offered as a matter of public policy? What incentives to improve care ought to be provided to those who care for nursing-home residents? In the United States, changes in healthcare policy in the future may affect reimbursement for long-term care, including nursing-home care.

The Admissions Process

A sustained effort by families to keep elders at home or in other community settings usually precedes nursing-home admission. Problems leading to admission may include increasing confusion, decreasing ability to care for oneself, and collapse of social supports.

Pertinent questions concerning nursing-home admission include "Who is making the decision?" and "Who ought to participate in making the decision?" The circumstances in which decisions are made exert powerful influence. Thus, a hospital may put pressure on the physician and family to have the patient discharged to a nursing home after acute problems are resolved. Involved parties may have conflicting interests and obligations. For example, family members may be involved as overburdened caregivers, concerned relatives, and proxy decision makers. These factors should be identified to prevent ethical conflict in the decision-making process.

Many conflicts arise between respecting the elder's autonomy and protecting his or her safety (Collopy). Participants may disagree about whether the elder's safety is actually threatened (elder: "I'm all right, I've just tripped once or twice"; versus family: "She falls all the time. I'm terrified she's going to break her hip"). This has been called the problem of "competing realities" in long-term care decision making (McCullough, et al.). Participants may also disagree about the relative safety of the nursing home. Healthcare professionals and family members may perceive the nursing home as a safer environment than it is. Confusion, falls, and increased dependency are common sequelae of nursing-home admissions. However, those admitted to nursing homes are often very frail, and it is usually not clear whether they would have fared better at home.

The nursing home itself challenges the elder's autonomy. Lack of privacy, regimented schedules, and uniform treatment of residents without regard for their wishes or interests are common. Autonomy is also constrained by other factors, including mental and physical disorders that limit the ability to make and carry out decisions, the elder's obligations to respect the legitimate interests of caregivers and family members, and the lack of a stable public policy establishing the obligations of society to elders and of elders and their families to society (Jecker, 1991, 1995). The ethical complexity of long-term-care decision making throws into question the relevance of the acute-care model of decision making, with its emphasis on patient autonomy (Agich, 1993, 1995; Hofland, 1990; McCullough et al.). A distinctive ethic may be required for long-term care, perhaps based on mediation and negotiation of opposing views (Collopy, Boyle, and Jennings; Moody).

Decision Making in Treatment

After admission to a nursing home, everyday issues such as phone access, roommate selection, and opportunity for spiritual growth must be addressed, requiring mediation among several concerns: respect for the elder's autonomy, the obligations of residents to each other, the institution's legitimate interests, and the family's role in decision making (Agich, 1993; Kane and Caplan, 1990, 1993). The task for nursing homes is to identify meaningful possibilities for the elder's exercise of everyday autonomy in the context of these legitimate constraints on autonomy.

Under the Patient Self-Determination Act (PSDA), implemented in 1991 in response to the case of Nancy Cruzan in Missouri, advance directives must be explained to the patient upon admission. The impact of the PSDA on the low rates of advance directives for nursing-home patients in the 1990s (Gamble, McDonald, and Lichstein) is not yet apparent. Issues requiring decision making that often arise in nursing homes include hospital transfers, artificial feeding, antibiotic use, amputation, and the use of restraints (Besdine; Volicer et al.).

Discussions of treatment choices should involve the resident, if he or she is able to participate, and family members or designated proxy decision makers, if the elder is unable to participate or desires their involvement. Although family members may not make the same choice the elder would make, many elders would still rather have family members make decisions for them (Menikoff, Sachs, and Siegler). Demented patients may be able to make some decisions about their healthcare. Decision-making capacity should be assessed by the physician relative to the particular decision that must be made. For example, a patient with moderate dementia might be able to decide not to have a leg amputated, and yet be unable to remember to take her medications without being reminded.

Competent patients or surrogate decision makers have the well-established right to refuse any treatment, though there is debate about whether they have the right to demand any treatment (Brett and McCullough). Trying a therapy for a time to evaluate its effectiveness may be a better choice than simply using or not using a treatment. However, institutions and caregivers, who have traditionally been reluctant to stop a treatment once begun, must be flexible if this approach is to succeed. Before such a trial of therapy, specific goals (such as expected improvements in status) should be agreed upon.

Conflict between family members and staff is often exacerbated by serious illness. For example, a family member who has not previously been involved in the patient's care may demand inappropriately aggressive care (Molloy et al.). When family members or staff members cannot reach a decision without significant disagreement, they may refer the matter to a nursing home ombudsman, an ethics committee or consultant, or, if there are issues of neglect or abuse, initiate a state inspection. Clerics may be helpful in addressing conflicts arising out of religious beliefs held by various participants. Legal proceedings are usually a last resort.

Many nursing-home residents with severe dementia who are not able to eat are kept alive with feeding tubes; many of these persons might not have wished to be kept alive under these circumstances. Legal decisions in U.S. courts in the 1980s and 1990s treated the provision of nutrition and hydration as medical decisions and recognized that artificial feeding is not always obligatory. However, withholding of nutrition poses special problems for some because of the special standing of "food and water" in human life. Many nursing-home policies require the use of artificial feeding if the resident's weight or oral intake falls below specified guidelines, even if this is against the patient's or family's wishes. This default position of artificial feeding is problematic in light of recent studies showing that feeding tube placement for administration of nutrition is associated with very low survival rates, and that it does not improve survival in patients with advanced dementia (Finucane, Christmas, and Travis; Mitchell and Tetroe; Rudberg et al.). Policies requiring artificial feeding may be questioned on both ethical and legal grounds. When nursing-home residents develop serious illness requiring treatment not available in the nursing home, transfer to the hospital becomes an issue. If a decision to limit medical intervention has been made, transfer may be unnecessary. Such decisions are best made well in advance of a crisis (Volicer et al.). When patients are transferred, advance directives written in the nursing home may not be sent to or considered valid by the hospital, and emergency services and other treatment unwanted by the elder or family may be given. Nursing-home administrators and physicians need to address this problem of the "portability" of advance directives.

Restraints

Restraints are commonly used in nursing homes to prevent falls and injuries to the patient and others, to prevent wandering, and for behavioral problems. Restraints can be physical (e.g., vests or wrist restraints) or chemical (e.g., drugs that alter behavior). Restraints may be used to protect the patient or for the convenience of the staff and can cause adverse physical and psychological outcomes, including death. Less use of restraints enhances the autonomy of nursing-home residents and several studies show either no change or a decrease in the risk of falls and injuries. However, restraint-free environments are often opposed due to inadequate staffing levels, fear of litigation, and the weight of traditional practice in the United States. The informed-consent process should address the benefits and risks of a restraint-free environment versus restraint use.

Research

Research in nursing homes (for example, into the treatment of urinary incontinence) may contribute to the quality of life of nursing-home residents. However, nursing-home research is complicated by problems of obtaining permission from nursing-home administrators to do such research, obtaining adequate informed consent or proxy consent in this vulnerable population, and ensuring privacy and confidentiality (High; Sachs and Cassel). Professionals should balance the protection of this vulnerable population with an accurate assessment of each elder's ability to give consent, and should allow those who are able to consent to participate. Proxy decision makers should consider what is known about an elder's preferences as well as the benefits, risks, and need for the research.

Staff Concerns

Nursing-home staff perform difficult, frustrating tasks, are usually poorly paid and poorly trained, and are often criticized by clients, family members, or better-paid staff members who do other jobs. Staff turnover is high in most nursing homes, affecting continuity of care and staff-elder relationships. Staff members are also often people of color, in contrast to nursing-home residents, which can lead to a mutual lack of understanding and, on occasion, to racist remarks and abuse from elderly residents or their families.

Staff members who provide regular personal care often develop strong emotional ties to residents; they are exposed daily to the outcomes of treatment choices and may disagree with patients, family members, or healthcare professionals about treatment choices. Information from staff members about the patient's wishes should be considered by those responsible for the patient's care.

Local, state, federal, and accrediting requirements and regulations pose ethical challenges to administrators in allocating the scarce resource of staff time. Complying with these regulations absorbs significant staff time and resources, diminishing the time and energy staff can devote to the care of residents. The worst institutions are unlikely to be caught, and the best are likely to spend substantial amounts of time on paperwork that does not clearly contribute to care. In addition, regulatory overemphasis on the safety of residents may restrict the autonomy of elders (Lidz et al.).

Death and Dying

A common cause of death in nursing homes is an infection or another acute illness superimposed on a chronic or progressive illness. Often, patients or family members, together with physicians and nursing home staff, have decided not to treat such illnesses aggressively. Many terminally ill patients in nursing homes are eligible for the Medicare hospice benefit. Hospice care may ensure that these patients receive improved treatment of pain and other symptoms; it may also make it easier for the family and staff to accept care focused on maintaining patient comfort rather than on treating disease. Hospice units have been developed in nursing homes; some have been designed specifically for the care of severely demented patients (Volicer et al.; Keay and Schonwetter).

Cardiopulmonary resuscitation (CPR) initiated in nursing homes or in seriously ill patients is rarely successful (Applebaum, King, and Finucane). Nursing homes may be justified in not offering CPR because of the very low probability of success. In any case, patients and family members should understand that CPR is only an attempt at resuscitation with little likelihood of success. "Do not resuscitate" (DNR) orders should not be equated with "do not treat" orders. Decisions about specific treatments should be discussed and well documented in advance.

When death is imminent, many nursing homes transfer the resident to a hospital or contact emergency medical services so that death can occur elsewhere. This may be contrary to the elder's and the family's wishes. Most emergency medical service protocols require cardiopulmonary resuscitation to be attempted, which may be traumatic to the staff and family.

Conclusion

The bioethics literature tends to typify ethical conflicts among people as involving a clash between beneficence and respect for an individual's autonomy. Nursing-home ethics is far more complex and subtle, both intellectually and practically; it includes the obligations of elders to family members, other residents, staff, and institutions; the management of scarce resources, especially in response to external constraints; the limits of caregiving obligations on the part of family members and nursing-home staff; and the anticipation and prevention of the ethical problems discussed in this article.

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SEE ALSO: *Abuse, Interpersonal: Elder Abuse; Aging and the Aged; Alternative Therapies; Autonomy; Care; Compassionate Love; Dementia; DNR; Grief and Bereavement; Healing; Healthcare Resources, Allocation of; Human Dignity; Human Rights; Informed Consent; Life, Quality of; Life Sustaining Treatment and Euthanasia; Medicaid; Medicare; Mentally Disabled and Mentally Ill Persons; Moral Status; Nursing, Profession of; Palliative Care and Hospice; Profit and Commercialism; Surrogate Decision-Making;* and other *Long-Term Care* subentries

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III. HOME CARE

Home care is an almost limitless array of preventive, therapeutic, restorative, and supportive services delivered to persons living in their own homes or the home of another in the community. In the long-term care context, home care comprises home-based services delivered to chronically ill or impaired persons. Although this care may, and increasingly does, involve high-technology medical services, the majority of care is directed at functional support (Koff). Home-care services can be divided into those services considered "skilled," such as skilled nursing, rehabilitation, speech therapy, occupational therapy, and physician home visits; and those considered "unskilled," such as personal assistance with activities of daily living (like bathing or dressing), household maintenance, monitoring, supervision, and instrumental assistance (for example, shopping or financial management).

Until the twentieth century, virtually all medical care was provided in the home. As modern medicine developed more effective and technically sophisticated interventions, medical care shifted to hospitals and physicians' offices. However, by World War I, the steadily growing numbers of persons with chronic illness reignited interest in formal home-care services. During the 1940s, limitations in the ability of hospitals to meet the increased demand for inpatient services contributed to the development of hospital-based home-care services. The 1965 amendments to the U.S. Social Security Act that created Medicaid and Medicare were intended, in part, to expand the supply of home care. Further amendments in 1967 made home care a mandatory benefit, and others in 1972 streamlined the terms of Medicare program participation for home-care agencies (Benjamin). By the mid-1980s, home care was described as the fastest-growing service under Medicare (Reilly et al.).

Growth in the home-care industry has been attributed to several factors, including the preference of patients for care at home rather than in institutions such as nursing homes, the availability of informal caregivers, the increased number of users, the intensity of utilization, and the increase in public reimbursement of services. As of 1987, home-care services were provided to about 7.7 million persons of all ages in the United States, but almost three-fourths of these persons were over the age of sixty-five (Wieland et al.). The elderly (over sixty-five) population in the United States is projected to increase by 40 percent by 2020, and the use of home care is expected to increase by 60 percent during that time (Rivlin and Wiener). Among the non-aged (under sixty-five) population, use of home-care services has been profoundly affected by the growth, in certain major cities, of the population of persons with acquired immunodeficiency syndrome (AIDS)—a 600 percent increase between 1984 and 1990 (Burbridge). The increasing use of formal home-care services—those paid for directly or by third-party reimbursement, such as Medicare, Medicaid, or private insurance—has triggered concerns regarding the cost, quality, and availability of home care. The home-care "industry" has experienced increased competition, oversight, and regulation as well as growth of the for-profit sector. There has also been a steady "medicalization" of home-care services, driven to a great degree by third-party reimbursement (Estes and Binney).

About 85 percent of home care is provided by informal caregivers, usually unpaid family members, friends, or acquaintances, and a majority of both formal and informal caregivers are women (Stone et al.). Care is provided in the most personal and intimate aspects of daily life to persons who may be vulnerable because of physical frailty and/or cognitive impairment. Several aspects of home care other than the location in which it is provided differentiate it from institutionally based long-term care. Because care is provided in the home of the client or of another individual, the client may have a stronger sense of autonomy and control, may be more comfortable, and may have the protection and security of others in the home. However, care at home raises concerns of quality assurance in unsupervised settings and the protection of the client from unscrupulous or abusive providers of formal and informal care.

Several concerns are shared in institutional and home-based long-term care. For example, problems arise in addressing autonomous decision making for persons with diminished cognitive function. There are also stresses involved in receiving intimate care from strangers. Many persons needing long-term care encounter serious limitations in the availability of services and in the funds to pay for them. Clear methods to ensure quality in both settings are lacking. And families experience stress whether care is provided at home or in institutions. There are, however, important differences. Autonomy is more strongly asserted by many home-care patients, but home-care patients may be more isolated and thus dependent on family caregivers

(Young et al.). The remainder of this article considers ethical issues that pertain to the individual receiving home care, to families, to paid workers, and to the system of care more generally.

The Home-Care Patient/Client

Chronically impaired patients, particularly elderly patients, may be at "ethical risk" of being excluded from decisions regarding their care, of having their preferences disregarded, and of having no voice in social policy decisions that affect them. This risk may result from several factors, including ageism, negative stereotypes regarding disability, misinformation, well-meaning but misguided paternalism, or reactions to spiraling healthcare costs driven in part by public spending for the old and disabled. The home setting itself may influence the nature and degree of ethical risk (Collopy et al.).

Home care may enhance the opportunity to make autonomous decisions, but it may also constrain and influence decision making. The traditional view of autonomy assumes that action is intentional, self-initiated, and not influenced by others; in reality, however, we live in a complex web of influences, including those of family members, loved ones, acquaintances, and professional caregivers. Nowhere is this web more evident than in care provided at home. Family, friends, and neighbors, as well as formal care providers, may all have an interest in the decision-making process regarding the nature and scheduling of care, the selection of workers to provide the services, and even whether or not the client can be maintained safely at home.

Safety and the assessment of risk are major considerations in the provision of home care and contribute to some of the most perplexing ethical dilemmas for providers of care. Most people of any age prefer living at home, no matter how humble or risky, to entering an institution. This preference, combined with an overestimation by some clients of their own abilities and an underestimation of the risk of living at home, frequently results in an insistence to be at home despite substantial safety concerns on the part of family and professionals.

Determination of risk is an inexact science, and it is not unusual for family and professionals to underestimate or disregard the comparable risks of institutional life. Caregivers feel strong obligation to act in the best interests of clients or loved ones by protecting them from harm, and these feelings are compounded by fear of liability should harm come to the client. While some commentators argue that fears of lawsuit have been exaggerated, they remain a powerful force in evaluating the safety of a home-based-care plan (Detzel and Kapp). An emerging model for addressing the question of risk involves "negotiating" what is an acceptable risk with the client and family by being clear about the nature of the risk and about their willingness to accept both the risk and the outcomes of negative events.

The level and nature of autonomy afforded the home-care client depends in part on the characteristics of the clients, such as their age or their cognitive or physical impairments. There are significant differences in the philosophy and organization of services for the elderly as compared to younger disabled persons (Simon-Rusinowitz and Hofland). Home healthcare for older persons tends to emphasize the avoidance of nursing home placement, to employ case management to coordinate services, and to use public regulation of providers to ensure quality of care (Eustis and Fisher). What is termed *personal assistance* in the support of the non-elderly disabled, however, evolved from the independent-living movement among working-age disabled persons who maintain that they are handicapped primarily by environmental barriers rather than by individual impairments or disabilities (DeJong et al.). Personal assistance encompasses a broader array of services than is usually found in medically oriented programs; it aims to maintain the client's well-being, personal appearance, comfort, safety, and interaction beyond the home. To the extent possible, these services to the disabled non-elderly are user-directed, with consumers supervising their personal care when possible. By comparison, for older clients, despite an emphasis on client autonomy, decisions such as scheduling services and selecting caregivers are made primarily by agency personnel without significant attention to consumer preferences (Hofland and David).

Clients may be motivated in several ways to control formal and informal caregivers. Clients are, after all, living in their own homes, and they are accustomed to having tasks accomplished in specific ways. They have habits and routines, and they may be supported by family members who share their preferences. Caregivers, for their part, are prompted to provide care and perform tasks not just by the wishes of the client but by their own values, preferences, work styles, and competing demands—and for formal caregivers, by the rules and regulations of their agencies and payors. Harry Moody argues that a model of decision making that focuses on accommodating and reciprocating autonomies is most appropriate in addressing these multiple interests. By this, he refers to a negotiation among competing needs and preferences. For example, a home-care client may not be able to refuse all formal care and remain at home and engage in behavior that is dangerous and disturbing to other persons in the building. He or she may, instead, negotiate staying at home with unwanted services.

Family Issues

Families are intimately involved in home care in several ways: They may be direct providers of informal services, may be involved in care decisions, or may live in the same home as the client and thus have their lives directly affected by formal care providers. While clients and their families might be expected to share values, preferences, and living styles, they often do not; sometimes, in fact, interests and values clash. For example, a family member may value safety and cleanliness more than the client does; the client may be more interested in preserving privacy and avoiding having a stranger "messing with my things." The relationship between formal and informal caregivers is poorly understood, raising concerns that the increased support of formal services may "erode" family caregiving (Hanley et al.). Ethical concerns arise when "needs assessment" for formal services includes consideration of the availability of family caregivers, as is required by law in some U.S. states. This raises the question of whether clients with family members who might provide services should be considered less eligible for home care than those with no such family members.

Conflicts may also arise about what can reasonably be expected from informal caregivers. Most families do not "dump" disabled family members into institutions but rather struggle to maintain elders at home for as long as possible. Surveys of family caregivers document a variety of stress-related illnesses, such as heart disease, stomach ulcers, and sleep disturbance, as well as alcohol or drug problems and marital difficulties (Brody). Because women are more likely to be caregivers, they carry a disproportionate share of the burden. Many women find themselves "sandwiched" between the care needs of an older parent or grandparent and the needs of a spouse, child, or grandchild. Because the extent of filial obligations is unclear, family caregivers may feel guilt and shame for not "doing enough," and persons needing care may feel either that they have been abandoned or that they are asking too much. Stephen Post argues that there are limits to familial obligations, and that social policy should do more to support the family in meeting its obligations.

Although we speak of the moral obligations of "the family," it is usually an individual family member, either explicitly or implicitly designated, who bears most of the burden of caregiving. These caregivers are usually women, most of whom have been providing care for more than five years; 35 percent of them are over the age of sixty-five, and 80 percent provide assistance every day of the week (Stone et al.). Women who provide home care to a parent, spouse, or other family member may do so at substantial personal cost, including personal health, lost professional and work opportunities, other personal interests, and other relationships. The interests of and burdens on caregivers should be considered when care plans are developed. If the care plan places heavy demands on an informal caregiver, it may justify constraints on client autonomy. Although "caregiver burden" is a well-recognized concept, Jaber Gubrium argues that we should hesitate to identify caregivers as "victims," noting that there are important factors that mitigate caregiver stress, including social supports, attitude toward caregiving prior to caregiving crises, personal well-being, a sense of mutuality between the caregiver and persons receiving care, and how prepared caregivers feel for the caregiving role (Archbold et al.; Zarit et al.).

Families differ in many ways that directly influence informal care and use of the formal system. While high levels of diversity exist within ethnic groups, differences among ethnic groups have been noted. Blacks and Native Americans have more widowed and divorced persons of both sexes than do whites, and they are somewhat more likely to live in extended family structures. There is also substantial home care provided by minority family members, attributable both to preference and to other factors, such as poverty, racial bias in the service system, and willingness to tend to young children in return for care (Brown; Cueller).

In healthcare, we tend to focus on the individual client; for most persons, however, there is a family context in which decisions are carried out. This context may constrain choices, but it also provides the individual with support and assistance that would otherwise be unavailable. Moreover, for clients whose capacity to make decisions is impaired, the family usually provides guidance in decision making (Nelson). This practice is supported in common law, and many states have enacted "family decision" laws that formalize this custom. The priority list is similar in most states: court-appointed guardians, spouse, adult children, parents, adult siblings, close friends, and extended family (Capron).

Although the family is usually viewed as a resource and source of support for the client, there are circumstances in which the family may perpetrate abuse and neglect. Protection of clients from abuse is difficult for several reasons. Abuse in the home may go undetected: The client may be unable or reluctant to report abuse due to extreme disability, fear of the caregiver, or shame. The client may be unwilling to act, preferring to stay in an abusive setting because alternatives are unknown, unavailable, or unattractive. Many states require that professional caregivers report suspected abuse of elderly persons via "elder abuse reporting laws," but responding to family failure in care is strategically difficult and ethically complex (Collopy et al.).

The Work Force

The paid work force for long-term home services consists of both skilled professionals and "unskilled" aides and personal assistants. Workers may enjoy the relationships that develop with patients and families, the opportunity to help others, and some flexibility in hours. However, workers may also face difficult working situations, travel to unsafe or dangerous neighborhoods, homes that are unclean and sometimes hazardous, and close contact with clients and/or family members who may be unpleasant, noncompliant, and even abusive. For unskilled workers such as aides and assistants, these difficulties are compounded by fluctuating schedules and hours, limited benefits, minimal training in necessary skills, and limited opportunities for promotion. The majority of home-care workers, both paid and informal, are women.

The quality of care and the reliability of workers are heavily influenced by the nature of the work, which may be monotonous and unpleasant, and by difficulties in attracting quality workers for minimum wage. In some cities, workers are drawn heavily from immigrant and/or minority populations, sometimes resulting in cultural conflicts and language difficulties between workers and clients. Clients may be uncomfortable having unfamiliar persons in their house, and workers may be treated with suspicion or hostility and confronted with racist comments. Work-force difficulties are increasingly exacerbated by the entry of women (who would otherwise provide informal care) into the paid labor force. Increased competition for workers from other service industries has reduced the availability of home-care workers in some areas. The affordability of some home-care services has been based, in part, on the low wages and benefits paid to unskilled workers, who are mostly women; this fact raises concerns regarding the exploitation of persons unable to find employment elsewhere.

The Healthcare System

Despite legislation intended to increase home-care services, restrictive eligibility requirements, perverse reimbursement incentives, and gaps in the continuum of care impede the home-care system. Not-for-profit agencies, such as the Visiting Nurse Association, face increasing competition for "attractive" clients, that is, those who are eligible for sufficient reimbursement. Hospitals, responding to reimbursement incentives, discharge patients who require heavier and more complex care. Third-party care "managers" regularly review clients' needs and have expanded paperwork and administrative reporting.

Case management, which has become an integral component of the home-care system, involves assessment of clients, determination of eligibility for public funding or insurance benefits, development of a care plan, and monitoring the quality of services (Quinn). While case management is viewed by many policymakers as fulfilling necessary gatekeeping and quality assurance functions, many home-care agencies view case management as yet another layer of bureaucracy and an additional expense in the system. Most case management agencies seek to empower clients by assisting them in implementing decisions. In their role as client advocates, case managers may find themselves in conflict with home-care agencies or family members who do not agree that the plan of care is safe, or who argue for more services than the agency can "afford" to provide under spending limits for individual clients or budget caps for groups of clients. The ethical conflicts case managers face as they balance the roles of gate keeping, quality assurance, and client advocacy are just beginning to be explored (Kane; Wetle).

Conclusion

Home care involves a complex and growing industry that is intricately intertwined with family caregiving. Most persons would prefer to remain at home, even when their need for assistance is substantial. Many persons would also prefer to give and receive care within a family context. However, the demand for home-care services can overwhelm the ability of family members to provide care in the face of other, competing family and work demands. Emerging changes in the healthcare system, including long-term-care insurance and public-healthcare reform, may encourage increased reliance on home care for persons with chronic conditions and illnesses. While additional resources for home care would be welcomed, we must be vigilant to the ethical concerns and values, not only of the home-care client but also of family caregivers and the paid work force, particularly women and disadvantaged persons. Efforts should also be made to develop formal services that are culturally appropriate and that meet the special needs of persons from diverse cultures and racial minorities.

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SEE ALSO: *Abuse, Interpersonal: Elder Abuse; Aging and the Aged; Alternative Therapies; Autonomy; Care; Chronic Illness and Chronic Care; Compassionate Love; Dementia;*

DNR; Family and Family Medicine; Grief and Bereavement; Healthcare Resources, Allocation of; Human Dignity; Informed Consent; Life, Quality of; Life Sustaining Treatment and Euthanasia; Medicaid; Medicare; Mentally Disabled and Mentally Ill Persons; Moral Status; Surrogate Decision-Making; and other *Long-Term Care* subentries

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MALPRACTICE, MEDICAL

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Medical malpractice is a legal system that permits victims of certain medical errors to sue for their injuries. It is a branch of tort law and, like tort law generally, is intended to achieve several policy objectives. (The discussion below focuses on medical errors committed by physicians, but the medical malpractice system may hold accountable other types of healthcare professionals as well as institutions such as hospitals and managed-care organizations.)

Objectives of the System

The first objective of the medical malpractice system is to compensate the victims (or in some cases their families) for the losses they sustained as a result of the malpractice. Although some of these losses, such as pain and suffering, are non-economic in nature, the malpractice system awards only money damages. The idea is to use money to restore the victim as much as possible to the condition the victim would have been in if the malpractice had not occurred. Along with pain and suffering, a successful plaintiff can recover the additional medical expenses necessitated by the malpractice episode, lost earnings (including both lost wages from having missed work and reduced earnings in the future as a result of diminished earnings capacity), and monetary compensation for other types of emotional deprivations, such as loss of enjoyment from being unable to engage in certain activities like sex or sports. It follows from these measures of damages that the same act of medical misfeasance—for example, the failure to correctly diagnose a treatable illness in a timely manner—can yield dramatically different damage awards for different victims. Someone who is old, for example, will have fewer years of work left than someone who is young, and therefore will receive less for diminished future earnings capacity.

A second objective of the malpractice system is to deter physicians from making medical errors that injure patients. The premise is that medical mistakes can be prevented by taking greater care, such as by spending more time with patients, employing more sophisticated diagnostic tools, and so forth. Taking greater care, however, consumes greater resources. The malpractice system gives physicians an incentive to invest these additional resources in order to avoid being liable for damages.

The third objective of the malpractice system is retributive justice—to punish wrongdoers and to enable victims to exact revenge. Along with sanctions imposed by criminal law, tort liability reduces the risk that victims will take the law, so to speak, into their own hands.

Functioning of the System

A plaintiff in a malpractice case must prove certain propositions in order to recover damages, including that the physician actually caused harm to the plaintiff and that the defendant was negligent, meaning that the defendant's behavior deviated from the applicable standard of care—that of a reasonable physician under the same circumstances. Typically, the plaintiff must prove through the testimony of expert physician witnesses how a reasonable physician would have behaved. At one time, before courts adopted more flexible approaches, only a physician from the same locality could testify about the standard of care, which made it difficult or impossible for plaintiffs in small towns to find suitable expert witnesses. The expert testimony, including testimony from opposing experts for the defendant, is supposed to describe how physicians *should* behave. In practice, however, experts may testify about how physicians *do* in fact behave, and judges and juries typically accept this evidence of professional custom as the standard of care. A notable exception is the case of *Helling v. Carey,* in which the Supreme Court of Washington State held that the entire profession of ophthalmology was failing to meet the standard of care by not routinely testing younger patients for glaucoma.

In theory, establishing whether or not someone is negligent involves a cost–benefit analysis; actors are negligent if the cost of preventing the injury is less than the risk of the injury, measured in terms of its probability and severity. In order to avoid being negligent, physicians therefore should expend enough resources to reduce patient risk to the point that any further expenditure on prevention would exceed the value of the risk being prevented, and therefore be inefficient. But because the value of a risk can be expected to vary from one patient to another, how is it to be calculated?

Here is where the doctrine of informed consent enters into malpractice law. In addition to promoting patient autonomy, informed consent assists patients and physicians in making accurate calculations about how much to spend to reduce the risk of error. By assigning a high cost to a particular injury, for example, risk-averse patients will demand greater risk-reduction expenditures. This raises a difficult question concerning how far the law will allow patient preferences to control the standard of care. Suppose a patient opts for a treatment approach that is contrary to mainstream medical practice. Does the patient's choice relieve the physician of malpractice liability? Traditionally, the law has recognized the need to permit physicians to deviate from customary practice in appropriate circumstances, such as when the mainstream approach has failed to provide a benefit to a specific patient; physicians who deviate from the mainstream approach are not negligent if, in addition to obtaining the patient's informed consent, they can prove through expert testimony that their approach would have been followed by a "respectable minority" of other physicians.

But why should a fully competent and informed patient not be permitted to agree to an alternative and complementary treatment that no other physician would employ? To what extent should malpractice law protect patients from their own folly? A related question is whether a patient ought to be permitted to waive the physician's malpractice accountability, in return, say, for a discount in the price of care. The law traditionally has frowned upon such releases from liability, fearing perhaps that patients who made such agreements must not be able to afford to pay for needed services, and therefore they should not be deemed to be acting voluntarily. But from the physicians' perspective, this traditional view may no longer be feasible in the era of managed care, where patients may be covered by low-cost plans that do not pay for some services that the medical profession considers to be customary.

Physicians are covered by malpractice insurance, which pays the damage award, up to the policy limits, if plaintiffs are successful, and also covers the costs of the physicians' defense attorneys, who typically are hired and controlled by the insurance companies. Insurance covers only a portion of the physician's malpractice costs, however; physicians also incur uninsurable costs in the form of time lost from practice while defending cases, emotional costs, and possible loss of membership on hospital medical staffs and in managed-care networks. Malpractice insurance premiums are based principally on the physician's geographic location and area of medical specialty, rather than on the physician's past malpractice history ("experience rating"). Increasing premiums for physicians who are repeatedly and successfully sued for malpractice would seem to be an obvious means of helping to deter future misfeasance, but insurers contend that they cannot experience-rate physicians because the number of claims is too small.

Evaluation of the System

How well does the malpractice system perform its intended functions? According to the Harvard Malpractice Study, which examined hospital records in New York State from 1984, only about one out of eight patients whose records revealed that they had suffered a malpractice injury filed a claim, and only about half of these claims resulted in compensation. Other empirical data, however, have shown that the more severe the injury, the more likely the victims are to be compensated, and the greater the amount of recovery. Critics of the current system assert that the awards recovered are excessive, but others disagree. The system is clearly time consuming; claims take an average of twenty-five to thirty months to be resolved after they are filed with the insurer, which can create severe economic problems for victims who lack healthcare or disability insurance. In the United States, plaintiffs' lawyers take cases on a contingent fee basis, receiving an average of approximately 33 percent of the plaintiff's recovery if the case is successful. If the case is not successful, the attorney not only recovers nothing, but typically must pay out-of-pocket for court costs and expert fees. Attorneys therefore can be expected to refrain from taking cases that are marginal on their merits or that do not involve a substantial amount of damages. Because, as noted earlier, the amount of damages is contingent on such factors as the victim's age, some victims accordingly have difficulty finding lawyers to represent them. On the other hand, there are anecdotal reports that some plaintiff's attorneys file frivolous lawsuits in the hopes that the defendants will settle in order to avoid litigation costs. Unlike in Great Britain, where a plaintiff who loses a malpractice suit must pay the defendant's attorneys' fees and court costs, defendants in the United States must bear those costs themselves, and defense attorneys, unlike attorneys for plaintiffs, get paid regardless of whether they win or lose.

There is little empirical information on why so few malpractice victims assert claims. Clearly one reason is that they do not realize that they have been the victims of malpractice. Studies also have shown that patients who have positive interactions with physicians are less likely to file claims despite becoming aware of malpractice, and that patients are less likely to sue after physicians have apologized for mistakes. The latter practice is discouraged, however, by the fact that, in all but a handful of states, the physician's apology is admissible in a lawsuit as an admission of liability.

There are no good data on how well the malpractice system performs its deterrence or retributive functions. Some critics point out that medical errors persist despite the malpractice system and that the number of claims is growing. Others argue in effect that the system is overdeterring physicians by causing them to practice defensive medicine.

Malpractice insurance premiums comprise a substantial portion of the overhead of the practice of medicine. Premiums have tended to increase over time, due at least in part to significant increases in the number of suits filed (known as *frequency*) and the size of damage awards (known as *severity*). Premiums also reflect the cost of defending suits, including the costs of attorneys and expert witnesses. It is estimated that for every dollar of malpractice insurance premium, only 30 cents actually goes to victims.

Malpractice premiums also have gone through periods of rapid increase, especially around 1975, 1985, and beginning again in 2001, leading these periods to be characterized as *malpractice crises.* In addition to large premium increases, these crises are marked by insurance companies exiting certain markets, and anecdotal evidence suggests that some physicians switch from higher to lower risk specialties, move to geographic locations with lower premiums, or retire from practice prematurely. The malpractice crisis of 1985, for example, has been blamed for physicians leaving rural practices and abandoning obstetrics. The semicyclical nature of these crises, and their proximity to economic downturns, suggest that at least a partial explanation for why they occur can be found in the behavior of the malpractice insurance industry itself, which creates what are termed *insurance cycles.* These begin when insurance companies reduce premiums to attract more business. As claims frequency and severity continue to increase, the amount of premium funds becomes too small to pay claims, and a weak economy decreases the return on the insurance companies' investment portfolios, which they had counted upon to make up the shortfall. This leads to sudden, rapid increases in premiums, insurer insolvencies, and withdrawal of companies from less profitable markets. Eventually the market stabilizes, and insurers once more decrease premiums, beginning another cycle.

These crises have led to two main types of legislative responses. In reaction to the malpractice crisis of the mid-1970s, state legislators took steps to help ensure that healthcare providers had access to medical malpractice insurance. They provided for the creation of physician-owned mutual insurance associations, joint underwriting associations and similar entities called reinsurance exchanges, and state-run reserve funds, intended to augment the coverage provided by the market. The second major legislative response was that a number of state legislatures changed the rules governing the malpractice system to make it more difficult and less remunerative for victims to sue. These so-called reforms include *caps,* or statutory limits on the amount of damages or the amount of non-economic damages that a successful plaintiff can collect; reductions in the maximum length of time (set by statutes of limitation) that victims have in which to file suits; prerequisites to filing suits (such as first having the claim reviewed by a panel of physicians); and repeal of the collateral source rule, which allows plaintiffs to recover medical and other expenses from defendants even though these had been paid by third parties, such as health insurers. (The collateral source rule typically does not result in a windfall for successful plaintiffs, because insurers usually are "subrogated" to the plaintiffs' claims, meaning that the plaintiffs have to reimburse the insurers from the proceeds of their recovery. The effect of repealing the collateral source rule is that healthcare costs that once were shifted from health insurers to malpractice insurers must now be borne by the health insurers.) One of the broadest sets of reforms was enacted in California by the Medical Injury Compensation Reform Act (MICRA), which limits damages for pain and suffering to $250,000, places restrictions on attorney contingent fees, repeals the collateral source rule, allows health plans to require enrollees to submit malpractice claims to binding arbitration, and requires large damage awards to be paid in installments rather than in a lump sum.

Of all of the changes in the traditional malpractice system, only caps on damages and repeal of the collateral source rule appear to have reduced malpractice cost indicators, such as premiums. Many of the caps have been overturned by state courts as unconstitutional violations of equal protection laws or deprivations of the constitutional right to a jury trial. Courts have questioned, for example, why it should be more difficult or less remunerative for victims of medical malpractice to receive compensation than for persons who have suffered other types of injuries covered by tort law.

Another malpractice crisis is taking place in the early 2000s. Renewed calls are being made for state legislative action. One recurrent proposal is some form of "no-fault" system, whereby the current tort approach would be replaced with an administrative scheme similar to workers' compensation. Victims no longer would have to prove that a physician was negligent in order to recover damages; instead, an administrative body would promulgate a list of compensable events and a schedule of associated compensation amounts. Proponents argue that more victims would receive compensation, and do so more quickly and with lower administrative costs, than under the current system. Opponents point out that, in order to be affordable, no-fault proposals would have to reduce the maximum amount of damages that victims could recover, with some proposals eliminating compensation for pain and suffering altogether. Critics question the fairness of depriving those who are most seriously injured of the large recoveries they are entitled to under the current system.

So far, the no-fault program has been adopted only in a limited fashion, in Florida and Virginia. In both states, one set of malpractice claims—those that stem from birth-related injuries—has been withdrawn from the traditional tort system, and victims are compensated under an administrative system similar to workers' compensation. Neither state program provides compensation for pain and suffering. Florida provides no award for lost future earnings. Nevertheless, some studies suggest that if attorneys' fees are subtracted and if the portion of the no-fault award that is placed in reserve for future expenses is included, the Florida program provides the same amount of compensation to victims as comparable cases do under the tort system. It remains to be seen, however, whether a no-fault program extending to a wider set of malpractice claims would be economically feasible without more significantly reducing the size of recoveries.

One legislative development that has affected the medical malpractice system is the National Practitioner Data Bank. Mandated by federal law, the data bank receives reports of all payments made by insurers in response to malpractice claims, including settlements, as well as adverse actions by state medical boards, hospitals, and managed-care plans. Hospitals are required to check the database in the course of making privileging and credentialing decisions, and state medical boards are permitted to access the data bank when considering applications for medical licenses. The purpose of the data bank is to prevent physicians (and other healthcare professionals) who have had their licenses or hospital medical staff privileges revoked, suspended, or limited, or who have been involved in a number of malpractice actions, from concealing these facts when they seek licensure, hospital privileges, or membership in a managed-care physician network. One result is that physicians may be reluctant to settle malpractice cases, preferring instead to go to trial and hope to be vindicated, in which case no report will be filed with the data bank. This in turn may place physicians in conflict with their malpractice insurers, who may prefer settlement as a means of keeping down their litigation costs.

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SEE ALSO: *Competence; Expert Testimony; Harm; Hospital, Contemporary Ethical Problems; Impaired Professionals; Law and Bioethics; Mistakes, Medical; Professional-Patient Relationship: Ethical Issues; Whistleblowing in Healthcare*

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MANAGED CARE

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With the growth of employer-based medical insurance following World War II, fee-for-service indemnity insurance became the prevailing mode of financing healthcare delivery. Even prior to the rise of indemnity insurance, care was provided—for those who could afford it—in exchange for a fee or as part of a barter arrangement. Thus, a physician’s order for care and the resultant delivery of care essentially commanded a payment from a payer source (for example, from a health insurance company, a self-insured employer, the government, or an individual patient) to a provider. For those who were insured and who could afford paying their co-pays and deductibles, there were few, if any, financial constraints on the delivery of healthcare in the fee-for-service era. Both healthcare costs and provider wealth soared under fee-for-service insurance; and there is compelling evidence of over-utilization of services, variable quality of services, and an increasing percentage of uninsured Americans in this period. If three cardinal measures of a well-functioning health system are quality, cost control, and access, fee-for-service financing was an across-the-board failure.

In this era, a mentality of entitlement arose among both physicians and insured patients. The insured patient was entitled to any care deemed beneficial by their physician; and the physician (by virtue of professional prestige and the resulting presumption that practice would be ethically balanced by the duties to both benefit and do no unnecessary harm to patients) was entitled to order any treatment he or she deemed to be consistent with that ethic. While physicians have, at the beginning of the twenty-first century, lost the political and economic power to practice in such an unfettered way, insured patients carry the mentality of entitlement forward, and Americans generally exhibit little understanding of the cost problems in healthcare. This is not to blame the general public as patients or consumers, but instead to assert the need for a more educated citizenry, as part of a next effort to seek a solution to the healthcare crisis of balancing quality, cost, and access.

The Rise of Managed Care

Between the end of World War II and the early 1980s, there were a few health maintenance organization (HMO)-precursor and healthcare cooperative arrangements in the United States in which individuals pooled their resources to assure themselves and their families access to medical care. In these arrangements, physicians usually settled for salaries for managing the care of their enrolled patients and population within a budget. The 1973 HMO Act created economic incentives for the creation of *federally qualified* HMOs. In essence, the act allowed for competition on cost and quality between HMO and fee-for-service arrangements. In the early 1980s, a major shift in the financing of healthcare began occurring in the United States. As a result, the financing and delivery of healthcare came to be integrated in a new way known as *managed care.* This shift also represented a significant change in the balance of power between the providers (physicians, hospitals, and delivery systems) and the financiers of healthcare private and public insurers.

In 1983, with the imposition of Medicare diagnosis-related groups (DRGs) the federal government took a major step to institute financial constraints on healthcare delivery. DRGs, which then applied only to hospitals, required hospitals to manage the care of a patient with a particular diagnosis for a set dollar or reimbursement amount. Hospitals, of course, began facing new economic threats under this arrangement. A critical unmanaged element in the healthcare delivery equation remained the physicians’ accustomed approaches to ordering patient care. A hospital’s failure to manage care within the Medicare reimbursement amount meant incurring a financial loss that needed to be recovered elsewhere. It also meant that surplus funds that used to be available through overpayments by Medicare could no longer be *cost-shifted* and used to support education, medical research, and charity care. Initially, this led to raising the costs for services to the privately insured, which translated into higher insurance premiums for employers and individuals. When employers or individuals could no longer afford premiums, the number of uninsured rose.

For physicians, as it had for hospitals, managed care arrangements represented a decisive change in the relationship between dollars and decisions to order healthcare services for patients. Physicians had historically been the directors of care, unconstrained by the payers in fee-for-service arrangements. Now the payers had achieved sufficient power to financially constrain physicians’ ways of practicing medicine. Cost ceilings were created for the provision of specific services; physician utilization patterns became targets of payer scrutiny and additional financial controls; physicians were required to enter into risk-sharing arrangements in exchange for access to patients in insured networks; financial incentives like bonuses and withholds were instituted to control physicians' utilization of services; and physicians were encouraged to follow practice guidelines developed from a population perspective and focused on cost-effectiveness to manage patient care. In many ways medical practice had been absorbed into the insurance side of healthcare. Thus arose managed care: a way of integrating the financing and delivery of healthcare so that the former drives, rather than is driven by, the latter. Managed care includes various organizational arrangements, approaches, tools, and strategies. It is not a single definable practice. Common threads are fiscal incentives concerning healthcare service delivery.

At the same time that the economic struggle was going in progress who would control the price tag and reap the profits of healthcare, important efforts were underway to raise the quality of healthcare by encouraging a transition to medicine as an evidence-based practice, not simply an individually-practiced art. One way to manage healthcare dollars is to restrict payment to what we know works, that is, to pay only for healthcare that has been proven to generate valued patient outcomes. Managed care reasonably declared itself to be focused on payment for medically necessary, cost-effective care.

The Managed Care Backlash

Managed care ran into significant public opposition in the imposition of policies such as twenty-four hour hospital stays for new mothers and the refusal to pay for unproven interventions for patients with life-limiting diagnoses. (Interestingly, though it is managed care organizations that have been assailed for excluding coverage for experimental treatments, this exclusion is a carry-over from fee-for-service days. Traditionally fee-for-service insurers also refused to cover unproven interventions.) What was rational to a managed care mind was fundamentally irrational or uncaring to the public's mind. Disconnected from the growing cost crisis in healthcare, the public was deeply at odds with the ethic inherent in the workings of managed care. This sentiment should have led the managed care industry to assess the ethical difference and adjust its coverage and pricing accordingly, or engage the American citizenry in a deeper discussion of these important issues in the interest of managing healthcare costs. A few managed care organizations chose to acknowledge the difference between their ethic as the manager of healthcare for a population within a defined budget and the ethic of their individual constituents and to work toward a resolution. Many if not most others ignored the fundamental tensions between individual and population good and the even larger tensions associated with for-profit healthcare payers displacing providers in the healthcare driver's seat. To date none of the significant health system stakeholders has prioritized an effective, rational public conversation around the polarizing goals of improving access, improving quality, controlling spiraling healthcare inflation, and enhancing patient and physician autonomy.

Managed care grew out of a serious need and effort to reduce healthcare spending. There were also serious concerns about quality in healthcare that were being pursued in tandem with and as part of the move toward managed care. If fee-for-service encouraged a culture of over-utilization, it also promoted harm through over-treatment; unbridled access to specialists undermined primary care and the coordination of care; and patients were subject to care recommendations that reflected the experience of the individual physician rather than systematic empirical information about patient outcomes. If the quality improvement movement rather than the struggle over wealth between providers and payers had led the managed care evolution, and communication with the public had been deliberate, things might have gone very differently.

And yet, who could take seriously discussions on such issues instigated by huge for-profit healthcare organizations that have come to dominate the healthcare marketplace? The public was never a real player in considering the big issues and has yet to be educated to understand the deeper questions that face the American healthcare system. The next evolution of our system will see a new group—or groups—in control. The options are: providers (who do not organize well); healthcare financing companies (the payers that have amassed incredible economic and political power along with potentially insurmountable public relations crises); medical manufacturing industries (the pharmaceutical and technology companies that are currently able to pass largely unregulated costs onto payers); group purchasers of insurance (employers, unions, and government that increasingly search for ways to cap their own financial risk and empower individual decision making and choice); individual purchasers of insurance (who have no market clout whatsoever and poor options for affordable insurance); patients (who are divided up into a myriad of insurance arrangements in ways that undermine their ability to organize and who feel entitled to all beneficial care); and the uninsured (40 million residents of the United States and growing).

The public backlash has been too significant to ignore: The public is now called upon to spend more for healthcare, while still facing threats to their felt entitlement to all beneficial care. Managed care organizations are assailed for failing to control costs, even as legislatures, courts and the court of public opinion prohibit them from implementing many of the tools that constrain costs. For-profit healthcare conglomerates now dominate the health system as a whole, and are among the only good bets on the stock market in 2003. Clearly, there is money there, but patients are not happy, providers are not happy, purchasers are not happy, and costs continue to rise exponentially.

In principle, managed care offers the major purchasers of healthcare (employers, unions, and government) competitively priced insurance, institutes quality-control measures to determine and encourage cost-effective care, and provides enrollees (the insured) fair access to quality healthcare from credentialed providers within a finite budget. If one assumes that effective cost control will promote a lower percentage of uninsured, managed care has the potential to serve the goals of quality, cost control, and access in a manner far superior to fee-for-service.

Yet between the principle of managed care and its implementation have fallen the shadows of public discontent and the ongoing struggle among stakeholders for economic ascendancy. The assumption has been that the market-guided evolution of managed care would issue in cost-contained, accessible, high quality healthcare for a larger share of Americans. That assumption has not been true at the beginning of the twenty-first century.

Many analysts believe that managed care is here to stay, although in forms rather markedly different from the classic HMO model of the 1980s. It is now best thought of as multiple arrangements that use selected elements of a managed care toolkit, the defining elements of which include definitions of medical necessity, practice guidelines, risk-sharing arrangements, financial incentives, and coverage policies.

Ethical Issues Raised by Managed Care Arrangements, Strategies, and Tools

From an ethical perspective, the most serious concern with managed care is that it threatens the fiduciary or trust relationship between physician and patient. Many have argued that the special *covenantal* relationship between the physician and patient necessitates a nearly absolute freedom from financial constraints on the part of the physician. While the physician–patient relationship has never been free from financial conflicts of interest, it has been argued that conflicts that induce under-treatment rather than overtreatment more seriously threaten the fiduciary quality of the relationship. In either case, however, the fiduciary character of the relationship appears sorely threatened. Despite this, the public seems to fear the withholding of necessary care more than overtreatment, and sees the physician's integrity to be more easily undermined by risk-sharing arrangements with insurers than by a more traditional for-profit practice arrangement. Ultimately, those who pursue the fiduciary profession of medicine are the last, best strongholds of the values we all hold concerning this vital human relationship. Both forms of financial conflict threaten the fiduciary role, and it falls to the moral character of the physician and other clinicians to hold the line against the compromising of that role.

Perhaps the truth is that it is easier to summon the moral courage and fortitude this requires under fee-for-service than under managed care. After all, if risk-sharing and financial incentives/disincentives and other threats are too onerous and direct, physicians will be hard-pressed to avoid the influence of the dollar on their decisions to order services. It seems clear that in the interest of maintaining the fiduciary quality of this professional role, some managed care *tools* for constraining physician utilization are themselves unethical and must be regulated.

It also seems clear that in addition to the responsibilities physicians have to their individual patients, physicians have obligations to the population of patients they serve—not only the patients in the same enrolled population, but all of the patients they might be called upon to serve (including patients requiring pro bono services due to being uninsured). The ethical tension in this role is unavoidable: Physicians must, at the same time that they seek to provide for their patients' needs, assume a resource management attitude. Physicians do not have the option of arguing that they should be able to practice without concern for cost. Somehow, in their everyday practice, they must manage this tension with an ethic of proportionality: The most serious of patient needs must be met with an appropriate outpouring of human and financial resources, while lesser needs are addressed proportionately.

This raises another issue as well: Some patients and groups of patients are much more expensive to treat than others. In short, there is a financial disincentive that automatically attaches to treating the neediest patients, unless risk-adjustment enters into the picture to protect providers. The very fact that an epidemic of service line closures is affecting the most vulnerable and costly patients (e.g., behavioral healthcare) suggests that very different solutions to the provision of certain healthcare services are needed where the market-based effort to control healthcare costs has collapsed.

The fact that resources are to be managed to deliver quality care to individuals based on their medical needs and to fairly distribute healthcare resources throughout a covered population represents a series of ethical quandaries. Managed care tools designed to manage the extreme ethical tension created by this dual goal include definitions of medical necessity, practice guidelines, and coverage policies. In managed care arrangements, evidence gathered about what works (i.e., improves the level of health from a population perspective) is captured in practice guidelines and coverage policies, that are then applied to coverage determinations for individuals.

One of the reasons medicine has always been considered an art is that it requires a depth of attention to the patient as a physical body and also as a person. While there may be algorithms to assist in determining care options when diagnoses are clear, when they are not clear, or the patient is outside clear diagnostic parameters, population-based formulas may well be off the mark. If medicine is both science and art, and contributes to healing and/or comforting through both intellectual and personal power, then clinical autonomy remains an essential feature of the practice of medicine that must somehow be blended with the power of population-based practice guidelines and coverage policies.

Further, one of the great fears must be for patients with conditions for which there are little or no practice guidelines and for which medical research has yet to find good options—and may even have few incentives to seek options. Vulnerable populations have been historically neglected in research. Mental and physical rehabilitation, crucial to quality of life, in some cases lack good evidentiary bases. Coverage for such interventions should not be denied when they may well represent a best chance for a functional life.

This leads to the issue of managed care's assumption that coverage be determined by a standard or set of criteria of medical necessity. What constitutes medically necessary care? Care that *may* restore function? That is *known* to restore function? Care that will *enhance* function beyond the normal range? Here again, the managed care disconnect from public sensibilities has been extreme. For the public, if something stands a chance of improving function or extending life, however small that chance, it is medically necessary care. For managed care organizations, there must be evidence that an intervention will improve function, as expressed in coverage policies and practice guidelines.

An Ethical Framework for Managed Care

The cornerstone of the traditional clinical ethics framework was, of course, patient autonomy or self-determination. The additional principles were beneficence, nonmaleficence, and justice. Can this framework be exported from clinical settings to organizational situations in which financing constrains patient care decisions and arrangements, or is a new ethical framework needed?

A novel framework seems to be required. One *could* say that the justice principle of the clinical ethics framework could be extended to guide the resource management responsibilities of managed care arrangements for their covered populations. But the principle of justice of the clinical ethics framework was always more individually than communally focused. It concerned the primacy of individual claims to benefits and individual rights not to be unfairly burdened for the sake of others, not communally beneficial distributions. Because managed care arrangements manage healthcare access and serve *both* populations and individuals, they have duties of *stewardship* and of protection of the fiduciary quality of clinical relationships. Because the personal good of healthcare is now available to individual patients through complex insurance businesses, *advocacy* supporting patient *autonomy* in clinical decisions and rights as an insured member of an enrolled population becomes an additional ethical imperative. Neither the patient-population tension nor the dependent relationship of care to coverage can be eliminated. The ethical tensions inherent in managed care must be named in a new healthcare organizational ethical framework, just as the tensions in clinical care were named in its ethical framework. If stewardship, autonomy, and advocacy should be included in the new framework, so must be principles of *truth telling* (both about clinical options and coverage), and *confidentiality.* Additional ethical principles, carryovers from the clinical ethics framework, are *beneficence* and *nonmaleficence.* Each of these principles must be interpreted for the financing and delivery arrangement that currently dominates the U.S. healthcare system: namely one in which financing constrains delivery.

Because managed care arrangements and tools provide the context for clinical relationships, a broader ethical framework for the analysis of ethically problematic situations is required. In addition, guidelines for the protection of essential features of clinical relationships are required. In the absence of these ethical principles and guidelines, there is no disciplined way to identify and remove unjustifiable threats to individual patients, or for that matter, to the population.

The ethical responsibilities of managed care organizations arguably extend to the broader community and society. They control distribution of healthcare resources, and as explained above, have compromised the capacity of provider organizations to cost-shift to support education, research, and charity care commitments. Society has yet to come to terms with the obligations of managed care organizations to support community needs such as these. This issue is even more problematic when one draws the distinction between nonprofit and for-profit health systems. Due to their tax-exempt status, the former are required to provide community benefit. Due to the fact that they pay taxes, the latter have no parallel requirement; they may operate like any business, supporting community interests as they deem conducive to their own interests, despite that they exert substantial control over the healthcare resources available to their community. It is essential to determine, from an ethical perspective, the stewardship responsibilities that exist for these organizations to support the health of the broader community.

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SEE ALSO: *Healthcare Resources, Allocation of; Health Insurance; Health Policy in the United States; Justice; Professional-Patient Relationship; Profit and Commercialism*

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MATERNAL-FETAL RELATIONSHIP

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I. Medical Aspects
II. Ethical Issues
III. Legal and Regulatory Issues

I. MEDICAL ASPECTS

During the last decades of the twentieth century, perinatal medicine made tremendous advances in scientific knowledge and in the successful application of this knowledge toward improving pregnancy outcomes. These advances have also brought a dramatic change in medicine's conceptualization of the fetus. No longer is the fetus defined predominantly as a part of the pregnant woman, but rather as a distinct entity that can be the independent focus of diagnostic tests and individual therapies: "A second patient with many rights and privileges comparable to those previously achieved only after birth." It is the widely shared view of obstetricians that the fetus is a patient to whom they owe ethical duties. The purpose of this entry is to delineate the medical advances that have brought about this change in fetal identity and to discuss the impact of these changes on pregnant women and the obstetrical decision-making process.

Pregnancy and Maternal Health

Maternal morality in pregnancy fell dramatically in the United States from more than one in 200 in 1935 to 7.7 per 100,000 in 1999. Most of this reduction was accomplished earlier in this century through improved surgical techniques and increased access to safe blood products, antibiotics, intravenous fluids, and improved prenatal care.

Despite these improvements, pregnancy still poses the risk of serious illness and, in rare cases, death. It has been calculated that the risk of mortality in pregnant women is 179 times that of the risk of death among women using the safest method of birth control. The major causes of maternal death are hypertensive disorders of pregnancy, pulmonary embolism, uterine hemorrhage, and sepsis. The risks of pregnancy are proportional to the age of the pregnant woman and to her underlying state of health. Women with medical illness may note worsening of their disease during pregnancy, sometimes with serious long-term consequences. But even women who begin a pregnancy in excellent health may find themselves suddenly confronting the morbidity and mortality risks associated with cesarean section (nearly 25% of all U.S. deliveries in 2000), postpartum hemorrhage (4–8% of all deliveries), or pre-eclampsia (a pregnancy-related condition that can lead to seizures, strokes or death in the pregnant woman) (5% of all pregnancies).

Pregnant women may experience preterm labor (U.S. incidence was 11.9% in 2001), the development of premature contractions that if not stopped can result in delivery of the fetus before adequate development has occurred. Preterm delivery poses significant risk of disability and death for the fetus. While preterm labor itself does not pose a health risk to the pregnant woman, many of the treatments recommended for its treatment have significant maternal side effects. The three drugs commonly used to treat (attempt to stop) preterm labor have serious side effects ranging from nausea, vomiting, dizziness, flushing, tremor, and jitteriness to life-threatening risks of pulmonary edema (fluid in the lungs), alterations in blood chemistries (hypokalemia, hyperglycemia), heart rate abnormalities (tachycardia, arrhythmias), hypotension, respiratory depression, and cardiac arrest.

For all women, pregnancy is a complex physiologic process; almost every organ system undergoes adaptation to support the maternal-fetal unit. It is important to appreciate the range of symptoms experienced by many pregnant women due to these physiologic changes. These include nausea, vomiting, fatigue, syncope (fainting), round ligament pelvic pain, backache, heartburn, hemorrhoids, constipation, urinary frequency, carpal tunnel syndrome (numbness and tingling of the hands), pedal edema, and sciatica (hip and leg nerve pain). Thus, while pregnancy is described as a normal physiologic process, it is not without common discomforts and the potential for serious illness. Most pregnant women willingly assume these sacrifices for their developing fetus.

Pregnancy and Fetal Therapies

Perinatal technologies have benefited the fetus by increasing the understanding of normal fetal development as well as improving prenatal diagnostic capabilities and therapeutic interventions. The fetus can be visualized with ultrasound, its well-being assessed with fetal heart-rate monitoring, and its diseases diagnosed with chorionic villus sampling, amniocentesis, and fetal blood sampling. Increases in diagnostic capabilities have been accompanied by the development of techniques to treat the fetus directly in utero. Our increasing ability to act on behalf of the fetus has made its claims to our care more compelling.

Prenatal technologies designed to benefit the fetus range from the simple to the complex, with differing risks and benefits for both the pregnant woman and her fetus. The most commonly used technology with the intention of improving fetal outcome is electronic fetal monitoring (EFM). EFM was introduced in the United States in the early 1970s with the promise that it would enable early detection of fetal hypoxia in labor and alert the physician to perform an immediate delivery, preventing the serious consequences of oxygen deprivation, including brain damage and stillbirth. Its use rapidly expanded from high-risk pregnancies to all pregnancies; in 1996, it was estimated that three-fourths of all U.S. pregnancies were monitored. Unfortunately, the wide acceptance of this technology occurred before adequate studies had been done to assess its efficacy and safety. There have been numerous randomized and controlled trials of EFM that have been unable to demonstrate a decrease in intrapartum fetal death or better newborn health in low-risk pregnancies. However, the use of EFM was shown to double the C-section (cesarean section) rate for the indication of fetal distress, thus exposing more women to the increased morbidity and mortality risks of C-section without the promised fetal benefit.

Other technologies include internal monitoring, used almost exclusively in high-risk situations, and telemetry monitoring, which uses radio waves and is non-invasive. Internal monitoring can cause fetal injury and infection to both the mother and baby.

A C-section entails a greater risk of maternal morbidity and mortality than does a vaginal delivery. The mortality rate associated with C-section is between two and four times that associated with a vaginal delivery. Maternal morbidity is also more frequent and usually more severe with a C-section. The common causes of morbidity associated with C-sections are infection, injury to the urinary tract, risk of placenta accreta (where the placenta attaches to the incision in a subsequent pregnancy) and hemorrhage with the possible risk of transfusion. Even an uncomplicated C-section requires a much longer recovery period for the mother at a time when she is experiencing increased physical and emotional demands.

The simplest fetal therapies are medications given to a pregnant woman for the benefit of her fetus. A well-accepted treatment of a woman who develops mild diabetes during pregnancy is to give her insulin until delivery. This practice benefits the fetus by preventing its excessive growth and associated birth trauma and by avoiding the potential neonatal difficulties of an infant of a diabetic mother. While insulin is not essential for the pregnant woman's health, it may be beneficial by reducing her risk of C-section delivery and the potential harms of a mildly elevated glucose to her own organ systems. Digoxin is a medication administered to pregnant women for the benefit of a fetus with cardiac arrhythmia. Unlike insulin, digoxin offers no benefit to the health of the pregnant woman. The risks to the pregnant woman of ingesting insulin or digoxin are minimal if administered appropriately. In summary, these pharmacologic fetal therapies confer benefit upon the fetus and are minimally invasive; one offers some benefit for the pregnant woman; the other solely benefits the fetus.

An accepted but more invasive therapy of sole benefit to the fetus is a fetal blood transfusion for isoimmunization from Rh disease (a condition in which the immune system of the pregnant woman destroys the blood cells of the fetus resulting in fetal death if severe and untreated). The most common technique is cordocentesis, in which a needle is placed through the maternal abdominal and uterine wall into the umbilical blood vessel for the purpose of transfusing blood into the fetus. This technique is not without its risks for both the fetus and the pregnant woman. This procedure poses a 2 percent chance of fetal death. It also increases the risk of fetal bradycardia (a dangerous lowering of the heart rate), a condition that mandates an emergency C-section for the safety of the fetus. All the maternal risks of C-section delineated above are increased in an emergency C-section, with the addition of the increased risk of death from general anesthesia. Cordocentesis is an example of an accepted fetal therapy that is potentially beneficial for the fetus and invasive for the pregnant woman, with significant risks to her in complicated cases.

The most invasive fetal therapy is in utero fetal surgery. While these procedures are still uncommon, some successes have occurred. One example is the surgical removal of a lung mass in the fetus. The rationale for the surgery is that without prenatal removal, the fetal lungs will be unable to grow sufficiently to support survival after birth. Intrautrine shunt therapy for hydrocephalus (abnormal amounts of brain fluid causing brain damage and enlargement of the head) is an experimental surgical procedure. Another, more controversial surgery involves fetal surgery to fuse the spinal hole caused by myelomeningocele (spina bifida). Because spina bifida is not a life-threatening disease, some ethicists and physicians have called the procedure into question. In 2003 the National Institute of Child Health and Human Development began a study of prenatal and postnamtal closure of myelomeningocele to determine the long-term benefits.

In all maternal-fetal surgeries, the pregnant woman must undergo a major abdominal operation and take medications to prevent the preterm labor that might be caused by the surgery. The surgery entails the usual risks associated with a C-section but at a higher rate because of the type of uterine incision, the thickness of the uterine wall, and the need for general anesthesia. Because of the type of uterine incision necessary for this fetal surgery, the woman must have a C-section in this pregnancy, even if her fetus is stillborn, as well as in all future pregnancies.

Neonatal Advances and Obstetrical Decision Making

Simultaneous advances in neonatology have had a significant impact on obstetrical knowledge and care. The gestational age at which survival is possible in the modern intensive care nursery has been pushed back continuously over the past few decades to the age of twenty-four to twenty-five weeks (fifteen to sixteen weeks premature). Many fetuses/babies who in the past would have been considered nonviable now survive and develop normally. However, the cost of this success is measured in hundreds of thousands of dollars per premature infant and in the potential for severe lifelong impairments.

This improved neonatal survival has had two significant influences on the perspective of obstetrical providers. Most have seen or participated in the care of very premature babies; thus fetuses in utero from twenty-four weeks on possess a very concrete human image for those who care for them. In addition, the possibility of survival beginning at twenty-four gestational weeks creates an argument for aggressive obstetrical management at earlier and earlier stages of pregnancy. The lower the gestational age at birth and the lower the birth weight, the lower the chance of survival and the higher the risk of severe physical and mental impairment. Between twenty-four to twenty-eight weeks the likelihood of survival increases from 20 percent to 90 percent, with a 20 percent incidence of severe neonatal impairment in the survivors. Complicating this situation is the inaccuracy of techniques to estimate gestational age and fetal weight. The inability to predict with certainty before birth either the survival or the likelihood of impairment creates legitimate divergent perspectives on what to do in individual pregnancies and ensures difficult decision making for obstetricians and pregnant women.

Formerly, a woman who developed preterm labor at twenty-five weeks would have been allowed to deliver vaginally and comforted regarding the certain death of her baby. Today, that pregnant woman will be faced with the option and probable recommendation that the fetus be monitored in labor and delivered by C-section if needed for fetal benefit. A C-section at this gestational age is riskier for her than one at term and because the type of uterine incision required commits her to C-section delivery of future pregnancies. The chance of the infant's survival is between 30 and 50 percent depending on its weight (which is difficult to predict prior to delivery). If the infant does survive, there will be a significant chance of neurologic or physical impairment. Some women will choose to take any risk for a slim possibility of fetal benefit, and accept aggressive obstetrical management. Other women decide that the risk of C-section in this and future pregnancies combined with the potential suffering for their premature infant is not worth the slight chance of being able to take home a normal or mildly impaired child. They choose to let "nature take its course," and hope that their next pregnancy will be free of complications. For the obstetrician faced with this clinical dilemma, the uncertainty of prognosis (this fetus might do well), the availability of technologic intervention (C-section), the desire to do something, and the legal fear of doing nothing may prompt him or her to advocate intervention as the baby's only hope. This is a persuasive argument for most pregnant women, especially if alternatives are not presented as legitimate.

The beneficial effects of fetal therapies and neonatal advances are impressive when successful: Babies previously at high risk of stillbirth, birth trauma, hypoxia, and neonatal death now have a greater chance of being born safely and having a near normal development. However, some babies who would have died now survive but with significant handicaps and at a significant cost to the physical, emotional, and financial well-being of the mother, her child, and her family. Some therapies are recommended with hope of fetal benefit but without good scientific evidence and with known maternal risks of death and morbidity. Pregnant women must be able to choose the best medical option based upon accurate scientific knowledge and an honest appraisal of the uncertainties involved in medical science.

Pregnancy and Fetal Development

Increased understanding of fetal development has allowed identification of environmental factors that can promote or impair the development of a healthy fetus. The placenta was once felt to operate as a barrier allowing only those substances beneficial to the fetus to pass. Now it is known that the placenta is an efficient transporter of many substances to the fetus, regardless of their toxicity, including both therapeutic and recreational drugs. Media coverage has focused on the rising incidence of crack cocaine use by pregnant women. It has been estimated that 11 percent of pregnant women use an illegal drug during their pregnancies and that 75 percent of these women use cocaine. While there are methodologic shortcomings in the studies of cocaine's effect on pregnancy, many serious sequelae of using this drug have been suggested, including an increased spontaneous abortion rate; suspected cardiac, genitourinary, facial, and limb abnormalities (though these may be alcohol-related); growth retardation; and in utero strokes. Obstetrical complications include preterm delivery, abruption (placental separation), and fetal distress. Newborns who have been exposed to cocaine in utero experience withdrawal symptoms, making them more irritable and less able to bond with caregivers. Many believe that cocaine-exposed babies will be more likely to experience learning disabilities, though some research has shown that there is no difference in learning scores between cocaine-exposed children and other children at age 4.

Alcohol is a well-known danger to the developing fetus. Fetal alcohol syndrome has been identified in the offspring of women who consumed excessive alcohol during their pregnancy; it is defined by a triad of symptoms: gross physical retardation; central nervous system dysfunction, including mental retardation; and characteristic facial abnormalities. Fetal alcohol effects are more common; they include cardiac, genitourinary, skeletal, and muscular anomalies; hypoxia; irritability; and hyperactivity. While excessive alcohol use during pregnancy has clearly been documented to cause significant fetal harm, no minimum safe level of consumption has been established. Many experts have recommended total abstinence from alcohol during pregnancy as the only way to avoid all possible harm.

Smoking has significant effects on pregnancy outcome. Approximately 30 percent of U.S. women of childbearing age smoke. Cigarette smoking results in reductions in birthweight, length, and head circumference. It has been estimated that between 20 and 40 percent of all low birthweight births in the United States can be attributed directly to smoking. Smoking has also been associated with higher rates of spontaneous abortion, preterm birth, perinatal mortality, and deficits in later physical, intellectual, and emotional development. A comparison of the known perinatal dangers of alcohol, smoking, and cocaine consumption illustrates that the legal substances a pregnant women may ingest are no less medically harmful than the illegal ones.

Public policy aimed at improving perinatal outcomes by reducing the use of fetotoxic substances by pregnant women must be grounded in medical knowledge. Recreational drug use by most pregnant women is an addiction; they do not consume the drug to harm the fetus but to satisfy an acute physical or psychological need. To address the problem of addiction, comprehensive and supportive programs designed to enlist the individual in her own recovery are necessary. There have been documented successes in programs that emphasize early identification of women at risk for substance abuse and that utilize comprehensive education, prenatal care, psychological intervention, and social services. However, there are very few substance abuse programs available to pregnant women. In one notable case of criminal prosecution of a woman for drug use during her pregnancy, the accused woman had sought drug treatment during her pregnancy without success.

Punitive approaches to addictive disease are generally ineffective. They have the potential to drive the addicted individual away from the very care that could be beneficial. Because the developing fetus is so vulnerable to uterine exposure to toxins, it is critical that pregnant women not be deterred from care. Prenatal care alone, in the presence of continuing drug use, can improve perinatal outcome for the drug-exposed fetus.

Obstetrical Decision Making

While a pregnant woman and her fetus may be conceptualized as two independent patients, they are in fact intimately interdependent, and actions taken to benefit one may pose a risk to the other. A pregnant woman may suffer from a serious illness that requires a treatment that will itself pose risk to her fetus; premature delivery to improve maternal health and chemotherapy for maternal cancer are two examples. Alternatively, treatment for the benefit of the fetus (C-section delivery, treatment of preterm labor, fetal surgery) may pose a risk to the pregnant woman. In addition, a medical treatment for presumed fetal benefit may interfere with the nonmedical needs of the pregnant woman.

These situations have been described by many as maternal-fetal conflict when they more accurately might be described as maternal-physician conflict. When an obstetrician agrees with the pregnant woman's choice and underlying values, no conflict ensues, even in the presence of potential fetal risk. The disagreement that does occur often is based on differing views of what is beneficial for the pregnant woman and her fetus and what are acceptable maternal risks to achieve obstetrical goals.

Obstetricians have a predominant focus on the current pregnancy. Appropriately, they emphasize the medical health of their patient and the fetus, give expert advice to improve pregnancy outcome, and urge women to follow this advice as a priority in their lives. However, medical recommendations are at times influenced by the fear of malpractice, research interests, a reluctance to give up, and a provider's own personal values.

A pregnant woman's values may differ from those of her providers and she may place a different value on the physician's medically based goals. Like other adults, a pregnant woman must and does make decisions about her prenatal activity within the broader context of her life. Her obligation to her fetus is sometimes weighed against her obligations to her other children, her parents, her partner, or others with whom she has a special relationship. Her decision may be influenced by religious or other strongly held personal beliefs.

Some have argued that pregnant women should be forced to undergo certain treatments if the benefit to the fetus would be substantial and the risk to the woman would be minimal or low. Medical uncertainty and medical practice make this a difficult policy to administer rationally or fairly. As delineated above, perinatal medicine is limited by diagnostic and prognostic uncertainty. This is best illustrated by a legal case in which a judge ordered a woman to undergo a forced C-section. In seeking the court order, the obstetrician testified that without delivery by C-section, the fetus had a 99 percent chance of dying and the pregnant woman had a 50 percent chance of mortality. However, the pregnant woman fled the court's jurisdiction and had an uneventful vaginal delivery. The ability to predict fetal distress in labor is frequently inaccurate. Because of this uncertainty, a policy of enforcing obstetrical recommendations would allow obstetricians to make the wrong decisions sometimes but would never allow a pregnant woman to be wrong or right about decisions that profoundly affect her life.

The problem of precisely defining fetal risk is matched by the complex task of delineating what constitutes an acceptable risk of harm for the mother. Risks, no matter how small in the medical context, may take on a different meaning within the context of an individual's life. The small risk of maternal death from a C-section may be very significant to a single woman who is the sole supporter of her children. Bed rest for the prevention of preterm labor may mean the loss of work and health insurance for her whole family. A Jehovah's Witness who is forced to receive blood may believe she is condemned to eternal damnation and may undergo significant stress or rejection within her religious community.

If obstetricians are given the authority to force pregnant women to follow their recommendations, this force may be used in a very arbitrary way. Not only is there variation in obstetrical diagnostic and prognostic accuracy, there are obstetrical debates about the appropriate management of various conditions. The medical justifications in the reported cases of requests for court-ordered C-sections have included breech presentation, prior C-section, and rupture of membranes for twenty-four hours without signs of febrile morbidity. Many obstetricians would disagree with each of these indications for C-section. Furthermore, the women who have been subjected to court orders have been shown to be more likely subjects of other forms of discrimination. In one study of forced C-sections, 81 percent of the women belonged to a minority group and 24 percent did not use English as their first language, and all requests for the court orders involved women who received care at a teaching hospital or who were receiving public assistance.

If the use of force by doctors against pregnant women were to be legitimized, it would have negative implications for their therapeutic relationship. The relationship would become less cooperative and supportive and more adversarial; compromise in situations of disagreement would become less and less possible. Under these circumstances of care, some women might lie about their behaviors or symptoms, fearing that their obstetrician would use this information to force upon them unacceptable treatment. Others might avoid prenatal care completely. The adversarial climate created by the use of force would decrease the effectiveness of obstetricians in improving maternal and fetal health.

Conclusion

Perinatal advances have dramatically improved the perinatal survival and well-being of fetuses/babies, fulfilling the obstetrical goals of prenatal providers and the personal goals of pregnant women. Increased understanding of the developing fetus and improved technologies have given the fetus an enhanced human identity and status as a direct patient of the obstetrician. The new therapeutic options with their maternal risks have created difficult ethical decisions for the pregnant woman and her obstetrician. A discussion regarding the legitimate use of force against pregnant women for fetal benefit has begun. The resolution of this debate must take into account the implications of the uncertainty inherent in medicine, the maternal risks associated with fetal therapies, the inevitable influence of an obstetrician's personal values upon his or her medical recommendations, the harmful influence of force in any therapeutic relationship, and the ethical and constitutional rights of all parties, including pregnant women.

NANCY MILLIKEN (1995)
REVISED

SEE ALSO: *Abortion; Alcohol and Other Drugs in a Public Health Context; Alcoholism; Care; Compassionate Love; Embryo and Fetus; Feminism; Fetal Research; Genetic Screening and Testing: Public Health Context; Infants; Mental Health, Meaning of Mental Health; Mental Illness; Professional-Patient Relationship; Women, Historical and Cross-Cultural Perspectives;* and other *Maternal-Fetal Relationship* subentries

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II. ETHICAL ISSUES

Only since the 1960s has it been recognized that the fetus in utero can be harmed by a range of maternal behaviors. Now that it is known that drinking, smoking, and using drugs during pregnancy can harm the unborn child, the question of what moral obligations a pregnant woman has to the fetus she carries has become a significant issue in biomedical ethics. When conflicts arise between what a pregnant woman wants to do or believes is right to do, on the one hand, and what may be best for the fetus, on the other, how and on what basis should those conflicts be resolved? And who should be involved in resolving them?

This article attempts to provide a conceptual framework for thinking about maternal–fetal conflicts. Whether one believes that women have moral obligations to their fetuses in utero depends largely on one's view of the moral status of the fetus—possibly the central issue in the abortion debate. The debate over whether (and at what developmental stage) fetuses can be harmed is a heated one. Pro-lifers think that fetuses can be harmed, and base their opposition to abortion on the ground that being killed is the ultimate harm. They also oppose behavior on the part of pregnant women that is likely to have less severe effects on the fetus. By contrast, many pro-choicers deny that fetuses (or at least early gestation fetuses) can be harmed. However, even if the pro-choice view of the fetus is the correct one, it does not follow that pregnant women are free to drink, smoke, or use drugs during pregnancy, if they are planning to have the baby. For if the pregnant woman does not abort but goes to term, her behavior during pregnancy can have lasting, destructive effects on the born child. Concern for the born child is a common ground that unites all people, regardless of their stance on abortion. This distinction between the fetus per se and the fetus-who-will-be-born differentiates maternal–fetal conflicts from the issue of abortion. Yet these conflicts are not entirely unrelated to the problem of abortion, because both issues concern justifications for restricting or controlling women's behavior during pregnancy.

The Moral Status of the Unborn

One of the thorniest issues in bioethics is the moral status of the fetus. (Here, the term *fetus* is used to refer to the unborn during all stages of pregnancy.) One view is that fetuses are merely potential children who do not have full-fledged moral rights, or perhaps any rights at all. According to this view, attempts to limit reproductive choices or coerce behavior during pregnancy violate very basic moral rights to bodily self-determination.

A different view is that fetuses are *pre-born children,* with all the rights of born children. Someone who regards the fetus in this way will think that a pregnant woman has the same moral obligations to protect her fetus from harm as she has to protect her born children. In keeping with this view of the fetus, some states have adopted *fetal rights* legislation, for example, making behavior during pregnancy that puts the fetus at risk of damage or death a form of child abuse.

Those who differentiate morally between fetuses and children tend vigorously to oppose fetal rights legislation, often seeing it as part of a larger political agenda to make abortion illegal. Even apart from the abortion question, many people are concerned that any attempts to control women's behavior during pregnancy violate their rights to privacy and self-determination. At the extreme, the position taken by some feminists and civil libertarians is that whatever a woman does during her pregnancy is her own business. They have opposed even noncoercive measures, such as a bill requiring the posting of signs warning pregnant women of the dangers of alcohol consumption (Sack).

However, if a woman decides not to abort, but to carry to term, then her behavior during pregnancy may have an adverse effect not only on the fetus but also on the child who is born. Whatever one's position on the moral standing of fetuses, born children clearly have moral status and rights.

The right not to be injured is one of the most basic moral and legal rights. To extend this right to prenatal injury requires only the recognition that a person can be injured by events that occurred before his or her birth—indeed, even before conception. Here is an example of preconception injury: In the 1940s, diethylstilbestrol (DES) was sometimes prescribed to prevent miscarriage. Not only was the drug ineffective, it sometimes resulted in damaged reproductive systems in the female children of women who used it. When these girls grew up, their reproductive abnormalities sometimes led to miscarriages and premature births. Prematurity can cause cerebral palsy. Thus, a child might be born with cerebral palsy due to a premature birth ultimately caused by her grandmother's ingestion of DES years before her own conception (*Enright by Enright v. Eli Lilly & Co.*, 568 N.Y.S.2d [Ct.App. 1991]). The legal right to recover for injuries negligently inflicted during pregnancy has been widely recognized in the United States since the landmark case of *Bonbrest v. Kotz* (65 F. Supp. 138 [D.D.C. 1946]). Courts have been much more reluctant to accept a right to recover for preconception injuries, primarily out of a concern to confine liability within manageable limits. The important point for bioethics is that recognition of a moral right to be free from injuries inflicted before birth is not based on recognition of the fetus as having the moral status of a person. The concern is not primarily for the fetus but for the surviving child. At the same time, attempts to protect children from prenatal injury can be accomplished only through the body of the pregnant woman. As a result, some women have been subjected to forced cesareans (Annas, 1982; Rhoden, 1986, 1987; Nelson and Milliken). With the development of new fetal therapies and surgery, women could be asked, or even required, to undergo possibly painful and risky procedures for the sake of the not-yet-born child (Robertson). Thus, if the focus is exclusively on the prevention of harm to the future child, there is a risk of forgetting that the pregnant woman is a person in her own right, not merely a “fetal container” (Annas, 1986). The moral question, then, is how to balance the interests and rights of the pregnant woman against those of her not-yet-born child.

Most women who are expecting a child voluntarily adapt at least some of their behavior to protect their babies. But what if the woman is an alcoholic or a crack addict? What if, for religious or other reasons, she refuses a cesarean section her doctor thinks is necessary to prevent serious damage to her nearly born baby? Such cases “pit a woman’s right to privacy and bodily integrity … against the possibility of a lifetime of devastating disability to a being who is within days or even hours of independent existence” (Rhoden, 1987, p. 118). How should such conflicts be resolved? What moral obligations do women have to prevent harm to the children they intend to bear?

Conceptualizing Maternal-Fetal Conflict

People have moral obligations to other people, both those existing today and those who will exist in the future. The mere fact that people do not now exist is no reason to discount the interests they will have when they come into existence. If people today do nothing about the national debt, if they allow the ozone layer to be depleted, if they pollute the air and water, then actual (as opposed to possible or potential) individuals, living in the future, will be harmed by what is done, or is not done, today. There is a responsibility to these actual, though future, people not to destroy the world they will live in. That they do not now exist does not obviate present obligations to them. Similarly, women have moral obligations to their future children, that is, the ones they will bring into the world.

In the United States, as in most societies, the primary responsibility for protecting the interests of children belongs to their parents. Although parents have a great deal of discretion in deciding how to care for and raise their children, they do not have absolute freedom. In industrialized nations, at least, it is widely accepted that parents are not only morally but also legally obligated not to inflict injury on their children, to feed and clothe them, to provide them with necessary medical care. It would seem, then, that pregnant women who intend to complete their pregnancies have comparable moral obligations to avoid harming their not-yet-born children. However, preventing prenatal harm is not the only morally relevant consideration. The woman’s own interests count, too. How are conflicts between the interests of the future child and the interests of the pregnant woman to be resolved?

Some object to the very notion of *maternal–fetal conflict*. They regard this as being misleadingly adversarial, pitting pregnant women against the children they will bear, when in most cases their interests are inseparably intertwined. A less adversarial framework stresses that what is good for pregnant women, such as better prenatal care, is also good for fetuses. While this is undeniable, some women want to do things, such as smoking or using drugs or alcohol, that risk harming their unborn children. Admittedly, behavior that endangers the fetus often endangers the health of the pregnant woman, but this does not necessarily make their interests identical. What if the woman is willing to risk her own health for the enjoyment the tobacco or alcohol or cocaine brings? She may decide—perhaps irrationally, perhaps not—that use of the substance is in her own interest, all things considered. That does not mean it is in the interest of her as-yet-unborn baby. It is wishful thinking to pretend that the possible harmful effect on the pregnant woman prevents the possibility of conflict.

Others object to characterizing the conflict as one between mother and fetus. In the so-called obstetrical cases (e.g., forced cesareans), the conflict may not be between mother and fetus. Rather, it is between mother and doctor, who disagree about what is best for both mother and child. In one case, doctors sought a court order because the fetus’s umbilical cord was wrapped around its neck, a clear indication for an emergency cesarean. The woman, who had nine children, refused surgery out of concern for her own health, a belief in “natural childbirth,” and an intuition that the delivery would turn out fine, despite the doctors’ dire predictions. She delivered vaginally, and the child was fine (Rhoden, 1986).

Attempts to prevent prenatal harm often impose risks or burdens on pregnant women, particularly when an intervention, such as a cesarean section or blood transfusion, is deemed necessary to protect the unborn child. The moral question then becomes how much risk, burden, or sacrifice a woman must undergo for the sake of her future child.

Moral Obligations to the Not-Yet-Born

It is important to distinguish the question of moral obligation and responsibility from legal obligation. Only the most extreme legal moralist would advocate compelling people to do whatever they morally ought to do. Claims that women have moral obligations to their future children should not be construed as advocating legal coercion. Thinking about moral obligations to future children in the context of general parental obligations to children prevents sentimentalizing pregnancy and the imposing of especially stringent obligations on pregnant women, or thinking that pregnant women are morally required to subordinate all their interests to their fetuses. After all, parents are not morally required to avoid any and all risks to their children's health. The obligation is, rather, to avoid unreasonable risks of substantial harm.

With a few notable exceptions (King; Robertson; Shaw), most commentators have argued that a pregnant woman should not be forced to undergo medical treatment even when this is judged necessary to preserve the life or health or her fetus (Annas, 1982; Gallagher; Johnsen; Nelson and Milliken; Rhoden, 1986, 1987). Cesarean sections are major surgery and, while generally very safe, are associated with higher rates of maternal mortality, morbidity, and increased pain than occur with vaginal delivery. Requiring a woman to undergo a cesarean requires her to risk her own life and health for the sake of her not-yet-born child. This is contrary to our legal tradition, which forbids the forced use of the body of one person to save another. In one widely cited case, *Shimp v. McFall* (10 Pa. D. & C.3d 90 [1978]), a court refused to order David Shimp to donate bone marrow to his cousin, Robert McFall, who was dying of aplastic anemia. The court emphasized that there is no legal duty to rescue others. It would seem to follow that compelling a pregnant woman to undergo medical treatment for the sake of the fetus, when this is not required of other potential rescuers, violates equal protection.

There are compelling arguments against the government's using coercive and punitive measures to regulate women's actions in order to promote healthy births. Most people do not want to live in a society in which they can be compelled to undergo surgery or to sacrifice body parts, even if it would be morally incumbent on them to do so. Placing limits on what can be demanded of citizens, especially where bodily integrity is involved, is essential to a free society. This helps to justify the conviction that people are not legally obligated to donate parts of their bodies, even if others need them for life itself.

The situation is different when we consider people's moral obligations. While an absolute ban on forced donation seems the correct legal response, a balancing approach seems more appropriate from a moral perspective. Whether one has a moral obligation to donate a body part, or undergo invasive surgery, depends on the degree of risk and sacrifice incurred, balanced against the need of the endangered individual. Perhaps people are morally required to donate replenishable body parts, such as blood, to others who need it. Blood donation takes only an hour, has no lasting effects, and causes only slight discomfort to most donors. Where a special relationship exists between the potential donor and the needy person, there may be a moral obligation to incur greater risks and sacrifices. Parents may be thought to have a moral obligation to donate blood and bone marrow, and perhaps even nonreplenishable body parts, such as kidneys, to their children, because of their duty to protect and care for their children, and because parents are supposed to love their children. Certainly a parent who refused to give a kidney to a dying child, saying, "It's my body, and I do not feel like donating," would be rightly regarded as morally deficient.

What are the implications for women whose doctors advise a cesarean section for fetal indications? Most women, faced with the possibility of a stillbirth or having a baby born with cerebral palsy, readily consent to the treatment their doctors recommend. Occasionally, however, a woman rejects a physician's recommendation. The moral justifiability of her refusal depends largely on her reasons for refusing. Typically, women who refuse cesareans do so out of religious objections, concern for their own health, or belief that a vaginal birth is best for the baby, and they disagree with the doctors' assessment of the risk. These are not selfish or unimportant reasons. Refusing a cesarean for such reasons is not obviously immoral. By contrast, it would be immoral for a woman to refuse a cesarean, and risk having her nearly born child die or suffer permanent disability, for a trivial reason, such as wanting to avoid a scar in order to be able to wear a bikini. One can morally condemn such a refusal, even if one thinks that she should not be compelled to submit to a cesarean.

"Lifestyle cases," where the risk to the child comes from nonessential behavior, such as drinking alcohol, smoking tobacco, or using drugs, present a different situation. In lifestyle cases, the welfare of the future child appears paramount. If the woman forgoes these substances, the only harm done to her is loss of pleasure and choice—in fact, abstention is likely to benefit her physically—while the potential harm to the child is serious. On the other hand, when the risk to the fetus is slight, the obligation of the pregnant woman is less clear.

Consider, for example, drinking during pregnancy. Heavy drinking during pregnancy can cause fetal alcohol syndrome (FAS), which is typically marked by severe facial deformities and mental retardation. One study showed that even moderate drinking—defined as one to three drinks daily—during early pregnancy can result in a lowering of IQ by as much as five points (Streissguth et al.). Perhaps most important, there is no established "safe" level of alcohol consumption. While there is no evidence that a rare single drink during pregnancy does damage, there is no guarantee that it does not. The safest course is therefore total abstention. But is the safest course the morally obligatory one? We do not require this standard of parents regarding their already born children. Having a single drink occasionally in pregnancy is arguably morally permissible, primarily because the risk of causing harm is very low (perhaps nonexistent), but also because the nature of the harm (loss of a few IQ points) is not so serious as to justify moral condemnation.

For a child of normal intelligence, the loss of five IQ points is not devastating. (At the same time, five IQ points can mean the difference between a mildly and a severely retarded child.)

If the occasional drink should be considered a matter of individual discretion, binge drinking, which has a 35 percent chance of subjecting a baby to full-blown FAS, clearly qualifies as an unreasonable risk to the health of a baby. So does smoking crack cocaine. Whether women have a moral obligation not to drink heavily or smoke crack during pregnancy is profoundly complicated by the fact that these behaviors are often the product of addictions. They are less than fully voluntary—some would say they are not voluntary at all. If a woman cannot modify her behavior, then she cannot have a moral obligation to do so.

But is it true that someone who is addicted cannot modify his or her behavior? The distinction should be drawn between being able to stop doing something at will, and not being able to stop at all. Although it is difficult to get over addictions, many smokers, alcoholics, and drug users do manage to change their behaviors. We can recognize that it may be very difficult for some women to fulfill their moral obligations to the babies they intend to bear, and acknowledge that they will need help to do so, without denying that they have such obligations.

Should drug or alcohol treatment be imposed on addicted pregnant women? Perhaps—if it could be shown that coerced treatment works, and therefore protects babies from prenatal harm. However, discussion of the justifiability of coerced treatment seems premature when there are not enough treatment programs for pregnant addicts who want to get over their addictions. Many in-patient alcohol rehabilitation programs exclude pregnant women, largely due to a fear of liability. The situation is even worse for pregnant drug addicts (Chavkin); sudden withdrawal of drugs can be as damaging to the fetus as continued exposure. As a result, a few treatment programs are able or willing to treat pregnant addicts. Even in areas where there are such treatment programs, there are not nearly enough spaces for all who want help. The absence of treatment programs makes it virtually impossible for substance abusers to fulfill their moral obligations to the children they intend to bear, even with the best will in the world.

To summarize, all women who intend to bear children have moral obligations to protect those children from the serious risk of substantial harm. Heavy smoking, binge drinking, and use of drugs such as crack cocaine and heroin constitute such risks. However, the moral wrongness of engaging in such behaviors during pregnancy is affected by the woman's ability to stop. A woman who is not addicted to cocaine, but who goes on using it during her pregnancy (perhaps on the weekends, because she enjoys it), fully aware of the risks she imposes on her future child, acts very wrongly indeed, and is properly blamed. It would be inappropriate similarly to condemn the pregnant woman who wants what's best for her baby and tries to get help with her addiction, only to be turned away because of the dearth of drug programs. Such a woman is trying to do the right thing; blame properly belongs with society for failing to help her. Nevertheless, if her baby is born damaged due to her drug use, she will—and should—feel moral regret at the harm caused by her drug habit, even if she should not be blamed.

The Intention to Bear a Child

Some people object to making the future child, rather than the fetus, the locus of moral obligation, on the grounds that the existence of the future child depends entirely on the pregnant woman's decision. These critics find it unacceptable that a woman can avoid her obligations to her not-yet-born child by ensuring that it not be born (that is, by aborting it). Moreover, a woman may decide to abort, but later change her mind and continue the pregnancy. During the period when she thought she would have an abortion, she may have continued to smoke and drink. As long as she did not intend to bring a child into the world, there was no one for whose sake she should abstain; continuing to smoke or drink seems morally acceptable in this light. Yet if she changes her mind and continues the pregnancy, she may have harmed the child she bears. Is she now morally blameworthy for the harm she causes?

Two responses can be made. The first is to recognize that moral responsibility for outcomes can extend beyond harms knowingly risked, to harms unintentionally caused. The fact that a woman did not intend to continue a pregnancy at the time she engaged in heavy drinking or used drugs does not entirely absolve her from blame. Even though she does not intend to have a baby at the time of the risky behavior, the failure to consider the possibility that she might change her mind may be negligent, and thus blameworthy. The second response concerns the futility of crying over spilt milk. It says that there is nothing a woman can do about her past behavior, and that if she changes her mind and decides to carry the pregnancy to term, she should focus on what she can do to ensure her baby's health. For example, giving up smoking in the second or third trimester gives the not-yet-born child a better chance than continuing to smoke throughout the pregnancy. If, despite her efforts, the baby is born damaged (a fairly unlikely result), the woman does not completely escape responsibility, but her blameworthiness is mitigated by the fact that she acted rightly once she decided to continue the pregnancy.

Another objection to making “the child she intends to bear” rather than the fetus the object of the pregnant woman’s moral obligation is that often women do not “intend” to bear children. Drug addicts, in particular, may regard pregnancy as something that “happens” to them, often as a result of bartering their bodies for drugs, rather than something they intend. Nor do they necessarily choose to give birth: They may not be able to afford an abortion, or it may not be available in a particular geographical area. For some women, abortion is not a morally or culturally acceptable option. Do restrictions on the choice of whether to bear a child affect the woman’s moral obligations to the child she bears? It can be argued that these restrictions do not affect how the woman ought to act, but they may affect how much she is to be blamed if she acts wrongly.

Consider a woman who deliberately gets pregnant, intending to have a baby. If she goes on drinking and smoking and using recreational drugs, knowing of the possible effects on her baby’s health and making no effort to stop, she acts very wrongly indeed. By contrast, consider a woman who has no responsibility for becoming pregnant (she was raped), in a jurisdiction that prohibits abortion. She is the victim of two grave injustices, first in being raped and second in being denied an abortion. Still, that would not justify behavior likely to inflict severe damage on the child she will perforce bear. Ideally, she should behave as if the pregnancy were chosen, since she is prevented from terminating the pregnancy. That is, she should stop smoking, drink moderately or not at all, and so on. However, her failure to do so is certainly less blameworthy than the failure of a woman who has chosen to conceive and bear a child. Most cases will fall somewhere in between the extremes of deliberate conception and forced childbirth. In general, the fewer options a woman has regarding pregnancy and childbirth, the less she deserves blame for failing to fulfill her obligations to her future child. However, women are not relieved of moral responsibility simply because they do not see pregnancy as a choice.

Conclusion

Deciding to have a baby carries with it certain moral responsibilities. Children have a moral right to be protected from harm, whether inflicted post- or prenatally. This right to be free from harm imposes obligations on those in a position to protect children, including their mothers during pregnancy. Yet a single-minded focus on the risk of harm to the future child ignores the impact on the pregnant woman. She is not a “fetal container” but an individual in her own right, one whose interests must be considered in determining morally permissible options.

Another factor in determining the moral obligations of pregnant women to their future children is the degree of risk and the nature of the harm. Just as parents are not morally required to avoid any and all risks to their born children, neither are pregnant women morally obligated to curtail their own interests to avoid even the slightest risk of harm.

Distinct from the question of the obligations women have to their future children is the issue of their blameworthiness for failing to fulfill those obligations. In general, blameworthiness is mitigated by the inability to have done otherwise. Such factors as addiction and the degree of control over reproductive ability must be considered in assessing morally the conduct of pregnant women.

BONNIE STEINBOCK (1995)
BIBLIOGRAPHY REVISED

SEE ALSO: *Abortion; AIDS; Alcohol and Other Drugs in a Public Health Context; Autonomy; Beneficence; Care; Coercion; Embryo and Fetus; Feminism; Genetic Screening and Testing: Public Health Context; Life; Professional-Patient Relationship; Women, Historical and Cross-Cultural Perspectives;* and other *Maternal-Fetal* subentries

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III. LEGAL AND REGULATORY ISSUES

The intimate relationship between a woman and a fetus developing within her body has long given rise to vital questions of morality, religion, science, medicine, law, and public policy. The abortion controversy in the United States is perhaps the most easily recognized context for this debate over the extent of a pregnant woman's right to autonomy. But over the course of recent decades, this issue has extended far beyond the abortion debate to encompass numerous legal and public policy issues concerning the maternal–fetal relationship when women continue pregnancy and give birth. Courts, legislatures, state prosecutors and doctors have sought to compel women to behave in ways deemed likely to promote the birth of healthy babies. Women have faced pregnancy-related restrictions and penalties, including civil suit, criminal prosecution, and court-ordered surgery, aimed at a wide range of conduct: driving an automobile, failing to follow a doctor's advice, drinking alcohol, taking prescription and illegal drugs, among others. This entry describes the status of such efforts and explores the implications for children's well-being and women's liberty.

Biological Aspects of the Maternal–Fetal Relationship

Beliefs about the independent moral and religious status of the fetus vary widely among Americans. The physical status of a fetus, however, is clear: A fetus cannot exist apart from a particular woman prior to *viability,* which occurs at approximately twenty-four to twenty-eight weeks's gestational age. That a fetus does not and cannot exist wholly apart from the pregnant woman makes the maternal–fetal relationship unique.

A fetus makes unparalleled physical and psychological demands on a woman, subjecting her body to tremendous physical adjustments and creating significant risks for even the healthiest woman. Concomitantly, with the fetus completely dependent upon and entirely within a particular woman's body, her actions, experiences, and physical health during and even prior to pregnancy substantially affect fetal development and the health of her child at birth. Throughout their reproductive lives, women inevitably confront innumerable decisions, large and small, that create varying probabilities of harm or benefit to fetal development.

The biological realities of the maternal–fetal relationship may not dictate any particular social response, but they highlight the need to scrutinize the impact on women of any law or policy aimed at fetuses. If not formulated with care, governmental policies adopted to promote healthy births can substantially and unnecessarily intrude upon women's fundamental liberties, limiting their ability to decide how to live their lives, and creating tension between women and their healthcare providers.

Law Versus Morality

In general, women have a strong interest in giving birth to healthy children and go to great lengths to increase the likelihood that they will do so. Widespread consensus exists that a woman who chooses to bear a child has a moral obligation to consider the effects her actions will have on her future child. Current public policy recognizes a role for the government in supporting women's ability to have the healthy pregnancies they desire. Existing programs seek to help women overcome obstacles such as poverty and dangerous addictions by providing prenatal care, food, housing, and drug and alcohol treatment, though the adequacy and appropriate scope of such programs is hotly debated.

Far more controversial are the rare instances when governmental action coerces rather than supports, and seeks to compel women to change their behavior. Should the government use punitive measures to regulate women's actions in an effort to promote healthy births? Should the government thereby transform women's moral obligations into legally required standards of conduct?

In spite of the moral complexity of these issues, U.S. law is quite consistent in granting pregnant women the right to make virtually all decisions affecting their bodily integrity and the well-being of their fetuses during pregnancy. For the most part, U.S. law does not recognize, let alone privilege competing fetal rights. Women retain the freedom to make their own judgments and to balance their obligations to their future children against other responsibilities, such as to family, religion and work. This approach is consistent with women's constitutional rights to liberty, privacy, and equal protection, guaranteed by the U.S. Constitution as well as by state constitutions.

Over the course of the past several decades, this legal consensus has been tested in a variety of contexts. These *tests* arise out of conflicts between pregnant women and their doctors—conflicts that look to the law for resolution. (Oberman, 2000). Often termed *maternal–fetal* conflicts, these issues have generated a veritable cottage industry for scholars in legal, medical, ethical, religious and philosophical circles (Kolder et al.; Markens; Nelson; Reid; Roberts, 1997; Steinbock). Legal and academic debates over the clashing rights of mothers and fetuses have emerged in various contexts, including substance abuse by pregnant women, home births, mandatory HIV screening in prenatal care, and a pregnant woman's rights to utilize a living will (Balisy; Dyke; Hafner-Eaton et al.; Oberman, 1996). As before, the center of the maternal–fetal conflict debate is the question of when and whether it is appropriate for the law to dictate a pregnant woman's behavior in an effort to benefit her unborn fetus. The medical, ethical and legal literature on maternal–fetal conflict is rich in analysis of the competing rights of mother and fetus. Yet, for all their depth and diversity, the overwhelming majority of articles reach an identical conclusion: In all but the most extreme circumstances, it is impermissible to infringe upon the pregnant woman's autonomy rights (But see Finer; Parness; Robertson).

The remainder of this entry examines some forms of pregnancy-related restrictions aimed at women, including exclusionary employment policies, civil suits for prenatal injuries, criminal prosecution, loss of child custody, court-ordered surgery and HIV screening.

Civil Suits for Prenatal Injuries

Some commentators have suggested that women should be subjected to civil liability for breaching *prenatal duties* (Shaw), such as the "duty to bring the child into the world as healthy as is reasonably possible" (Robertson, p. 438). The only appellate court to adopt such a standard, which was in Michigan, ruled in *Grodin v. Grodin* (1980) that a child could sue his mother for prenatal injuries if she failed to comply with the standard of a *reasonable* pregnant woman.

More recently, courts have refused to impose such duties, claiming that they are inherently subjective and that they would carry with them a host of unacceptable policy ramifications. The only state supreme court to consider the issue, the Supreme Court of Illinois, ruled in 1988 that a child could not sue her mother for prenatal injuries allegedly caused when the woman was in an automobile accident while she was pregnant. In rejecting the girl's request to recognize a legal right to begin life with a sound mind and body, the Illinois court noted the serious ramifications that would result for women: "[M]other and child would be legal adversaries from the moment of conception until birth" (*Stallman v. Youngquist*, p. 359).

A 2002 decision of the Superior Court of Massachusetts cited *Stallman* and similar decisions when ruling in favor of a mother's motion for summary judgment in an action brought on her child's behalf (*Remy v. MacDonald*). The child, through her father and appointed guardian, alleged that her mother's negligence in operating a vehicle resulted in numerous medical complications. The Court ruled that holding a pregnant woman legally accountable to her unborn child, "would present a court with problematic and impossible tasks of determining when the duty arises and how the nature of the duty is to be defined." (*Remy*, p. 7–8). Moreover, the court stated that civil liability, "rather than discouraging conduct so difficult to define in terms of duty, may unwittingly have the opposite negative effect of women fearing civil liability so that they may not reveal critical facts about their condition to their physicians resulting in less than adequate prenatal care." (*Remy*, p. 9).

Criminal Prosecutions for Actions During Pregnancy

The most common form of adversarial governmental action against women for engaging in behavior viewed as harmful to fetal development has been criminal prosecution. State prosecutors have relied on laws that clearly were not intended to create special restrictions on women's actions during pregnancy, including laws prohibiting child abuse, distributing drugs to a minor, and murder.

Several prosecutions have been based on women's otherwise lawful actions. One of the first occurred in 1986, when a California woman was prosecuted for allegedly causing her infant son to be born severely brain damaged, and ultimately to die, as a result of her own excessive loss of blood during delivery (*People v. Stewart*). The prosecution claimed that, by waiting a number of hours before obtaining medical care when she went into labor and began bleeding vaginally, the woman had violated a statute that required parents to provide their children with clothing, food, shelter, and medical care.

Other prosecutions have involved alcohol use during pregnancy. A Massachusetts woman who suffered serious injuries in a car accident, including a miscarriage, was prosecuted for involuntary manslaughter of the fetus because she allegedly caused the accident by driving while intoxicated (Loth). In another reported case, a pregnant woman in Wyoming who notified the police that her husband had physically assaulted her was arrested for child abuse when they detected she had been drinking. The charges ultimately were dismissed in all three of these cases.

By far the most common reason for prosecuting pregnant women involves the use of illicit drugs during pregnancy. Of course, a woman's pregnancy does not immunize her from prosecution under generally applicable laws prohibiting the use or possession of drugs. In many cases, however, women have been subjected to special prosecutions and more severe penalties for the express reason that they were pregnant at the time they used drugs.

Although some women charged in these cases have pled guilty in return for reduced sentences, those who have gone to trial have prevailed in the overwhelming majority of cases. This is largely due to the fact that courts find the statutes under which the women are charged were not intended to apply to prenatal behavior (Brody and McMillin). The first three high state courts that reviewed the legality of prosecution for prenatal drug use all found that the statutes had been misapplied. In 1992, the Supreme Court of Ohio dismissed an indictment for child endangerment against a woman who allegedly used cocaine while pregnant (*Ohio v. Gray*). Also in 1992, the Supreme Court of Florida reversed a woman's conviction under a statute prohibiting the distribution of a controlled substance to a minor and imposing a penalty of up to thirty years imprisonment. In holding that the statute was not intended to apply to prenatal behavior, the court rejected the "State's invitation to walk down a path that the law, public policy, reason and common sense forbid it to tread." (*Johnson v. State,* p. 1297). In 1997, the Supreme Court of Wisconsin held that the state could not initiate proceedings to remove a child from his or her mother's custody, due to the mother's use of illegal drugs, because the term *child* in the statute does not include a viable fetus (*Wisconsin v. Kruzicki*). The court reasoned that the statute would be rendered absurd if the word child included a viable fetus, because a fetus cannot be, as worded in the statute, "removed from his or her present custody" (*Wisconsin v. Kruzicki,* p. 736).

However, in another 1997 decision, the Supreme Court of South Carolina upheld the trial court's conviction of a mother for child abuse following the mother's use of crack cocaine during her pregnancy (*Whitner v. South Carolina*). The court concluded that the word child in the state's child abuse and endangerment statute includes viable fetuses. In reaching its conclusion, the court reviewed earlier South Carolina decisions recognizing a fetus's legal rights and decisions, and distinguished other states's decisions holding that maternal conduct before the birth of a child does not give rise to criminal prosecution. It concluded that those other states's decisions were distinguishable because those states had "entirely different bodies of case law from South Carolina." (*Whitner,* p. 782).

The *Whitner* court also concluded that a woman's constitutional right to privacy is not violated when she is prosecuted for using illegal drugs during a pregnancy. It stated that the state's interest in protecting the life and health of viable fetuses is compelling, and that no fundamental rights are implicated in such prosecutions. The court reasoned that the use of crack cocaine is illegal by anyone, not just by pregnant women, and the additional penalty on pregnant women "simply recognized that a third party (the viable fetus or newborn child) is harmed by the behavior" (*Whitner,* p. 786).

The issue of prosecuting pregnant women for drug use reached the U.S. Supreme Court, albeit indirectly, in the case of *Ferguson v. City of Charleston* (2001). The case involved a hospital that routinely tested pregnant women for drugs, without obtaining informed consent. The hospital then used the results of these drug screens in order to facilitate criminal prosecutions. The Court held that, as a state-operated facility, hospital staff members were actors subject to the Fourth Amendment's strictures. As such, the drug testing of pregnant women without their informed consent amounted to *searches,* and violated the women's constitutional rights.

Loss of Child Custody for Actions During Pregnancy

States have attempted to deprive women of custody of their children based solely on women's actions during pregnancy, rather than on the customary determination of the current ability of the woman and other family members to care for the child. While most cases involved a woman's use of illegal drugs during pregnancy, several courts have based custody decisions on activity that was lawful but seen as detrimental to fetal development. For example, in 1987 a Michigan woman temporarily lost custody of her infant and was charged with child abuse because while pregnant she had taken Valium without a prescription to relieve pain from injuries she suffered in a car accident (*In re J. Jeffrey*).

The first high state court to consider this issue, the Supreme Court of Connecticut, ruled in 1992 that state law did not allow the termination of parental rights based on a woman's use of cocaine during pregnancy. The court cited the legislature's determination that the threat of losing custody of their children would cause women to avoid prenatal care and substance abuse treatment, and "would lead to more, rather than fewer, babies being born either without adequate prenatal care or damaged by prenatal drug abuse.…" (*In re Valerie D.,* p. 764). However, the Supreme Court of Ohio, in *In re Baby Boy Blackshear* (2000), affirmed a Court of Appeals decision, holding that it is appropriate to remove a child from his or her mother's custody when drug testing proves, after the child's birth, that the child has cocaine in his or her system due to the mother's consumption of such drug. The court reasoned that, for purposes of the state's child abuse statute, R.C. 2151.031, a child born with cocaine in his or her system is an *abused child.*

Although the use of illegal drugs during pregnancy may at first glance seem to be the strongest justification for punitive governmental action such as the imposition of enhanced criminal penalties or deprivation of child custody, these approaches have been widely repudiated. The government clearly has a strong interest in preventing pregnant women from using dangerous drugs. With remarkable consistency, experts agree that this interest is best pursued through programs that help women overcome drug and alcohol dependencies and obtain prenatal care. Entities such as the U.S. General Accounting Office (GAO) and the American Medical Association (AMA) have argued that fear of prosecution and loss of custody of their children will discourage women from seeking care and increase the number of unhealthy births. As the Florida Supreme Court noted, "Rather than face the possibility of prosecution, pregnant women who are substance abusers may simply avoid prenatal care or medical care for fear of being detected. Yet the newborns of these women are, as a group, the most fragile and sick, and most in need of hospital neonatal care" (*Johnson v. State,* p. 1295–1296).

Court-Ordered Cesarean Sections

Courts in at least eleven states have ordered women, against their wishes, to give birth by cesarean section rather than vaginal delivery (Kolder et al.). The severe bodily intrusion of this court-ordered surgery contrasts sharply with our legal system's general refusal to order invasive medical procedures or to force one person to assume any personal risk to save the life of another. Although judicial opinions are rare in these time-pressured cases, three published appellate court decisions illustrate both the motivations behind and the harm caused by such court orders.

In the first published appellate court decision, the Supreme Court of Georgia in 1981 declined to lift a court order authorizing the performance of a cesarean section against a woman's religious objections where the examining physician found a "ninety-nine percent certainty" that the child would not survive a vaginal delivery and a 50 percent chance the woman would die (*Jefferson v. Griffin Spalding County Hospital Authority,* p. 459). With no analysis of the constitutional and policy implications, the court granted *temporary custody* of the fetus to the state and gave it full authority to make all surgical decisions concerning the birth. In the end, a court-ordered cesarean section was not performed; despite the physician's predictions, the woman gave birth by vaginal delivery to a healthy baby without adverse effects.

More recent appellate court decisions have ruled that compelling a pregnant woman to undergo a cesarean section against her will violates the woman's fundamental constitutional rights. (*In re A.C.*; *Baby Boy Doe v. Mother Doe*). In the most widely cited case, in re A.C., a three-judge panel of the District of Columbia Court of Appeals ordered a woman who was twenty-six weeks pregnant and terminally ill with cancer to undergo the surgery. The woman did not consent to the cesarean and her husband, parents, and attending physicians all opposed it on the ground that the woman's health and comfort should be the first priority. The cesarean section was performed nonetheless. The fetus was not viable and did not survive. The woman died two days after the cesarean section.

Following her death, the full Court of Appeals reversed the panel's decision, ruling that "in virtually all cases the question of what is to be done is to be decided by the patient—the pregnant woman—on behalf of herself and the fetus" (*In re A.C.,* p. 1237). The court found that a court order compelling a woman to have a cesarean section violates her rights to bodily integrity and to refuse medical treatment, which are protected under both common law and the U.S. Constitution. The court graphically described the violent bodily intrusion that would be required to enforce an order against a woman who resisted: "[She] would have to be fastened with restraints to the operating table, or perhaps involuntarily rendered unconscious by forcibly injecting her with an anesthetic, and then subjected to unwanted major surgery. Such actions would surely give one pause in a civilized society…" (*In re A.C.,* p. 1244, n. 8). Indeed, in another case a court-ordered cesarean section was performed by tying the woman to the operating table and forcibly removing her husband from the room (Kolder et al.).

An Illinois appellate court similarly ruled in 1994 that ordering a woman to give birth by cesarean section would violate her constitutional rights. Citing *In re A.C.,* the court held that "a woman's competent choice in refusing medical treatment as invasive as a cesarean section during her pregnancy must be honored, even in circumstances where the choice may be harmful to her fetus" (*Baby Boy Doe v. Mother Doe,* p. 330).

At least one federal court has disagreed with the state decisions holding that court-ordered cesarean sections violate women's constitutional rights. In *Pemberton v. Tallahassee Memorial Regional Medical Center, Inc.* (1999), a federal district court held that a court-ordered cesarean section did not violate the mother's substantive constitutional rights. Pemberton was advised by a number of doctors that a vaginal delivery would likely harm the newborn. However, Pemberton opposed having a cesarean section. She returned to the hospital following a full day of labor and requested an IV because she had become dehydrated. Pemberton was denied an IV, and then returned home against the wishes of doctors at the hospital. Following a hearing conducted at the hospital, Pemberton was returned to the hospital, against her will, where her child was delivered via cesarean section.

Pemberton sued, claiming that numerous substantive constitutional rights were violated by the court-order. However, the court stated, "Whatever the scope of Ms. Pemberton's personal constitutional rights in this situation, they clearly did not outweigh the interests of the State of Florida in preserving the life of the unborn child" (*Pemberton v. Tallahassee Memorial Regional Medical Center, Inc.,* p. 1251).

A number of medical and public-health organizations have opposed court orders overriding a pregnant woman's decision concerning medical treatment. The AMA is among the organizations that has endorsed respect for women's constitutional right to bodily integrity: "[D]ecisions that would result in health risks are properly made only by the individual who must bear the risk. Considerable uncertainty can surround medical evaluations of the risks and benefits of obstetrical interventions. Through a court-ordered intervention, a physician deprives a pregnant woman of her right to reject personal risk and replaces it with the physician's evaluation of the amount of risk that is properly acceptable" (AMA, p. 2665). The practice of seeking court orders not only violates women's right to evaluate the risks and uncertainties involved in their medical care, it is counterproductive to the goal of promoting healthy pregnancies and births because it causes women to distrust physicians. Citing a case in which a woman left the hospital to avoid a court-ordered cesarean section, the AMA expressed concern that "women may withhold information from the physician.… Or they may reject medical or prenatal care altogether…" (AMA, p. 2665–2666). Furthermore, AMA Policy H-420.969 states as follows, "Judicial intervention is inappropriate when a woman has made an informed refusal of a medical treatment designed to benefit her fetus." Paragraphs 2 and 3 of H-420.969 further provide, "The physician's duty is to provide appropriate information, such that the pregnant woman may make an informed and thoughtful decision, not to dictate the woman's decision. A physician should not be liable for honoring a pregnant woman's informed refusal of medical treatment designed to benefit the fetus."

Exclusionary Employment Policies

In an effort to reduce perceived liability risks, some employers have sought to restrict the access of pregnant, or even fertile, women to jobs that might expose them, and consequently, their fetuses, to potentially hazardous conditions. In a unanimous decision, the U.S. Supreme Court ruled that such policies violate federal anti-discrimination law. The policy at issue in the case prohibited fertile women from working with lead in the production of batteries. The Supreme Court acknowledged that holding such jobs "late in pregnancy often imposes risks on the unborn child," but found that "Congress made clear that the decision to become pregnant or to work while being either pregnant or capable of becoming pregnant was reserved for each individual woman to make for herself." (*International Union, United Auto Workers v. Johnson Controls, Inc.*, p. 205–206).

Mandatory HIV-Testing and Treatment of Pregnant Women

Approximately 4 million women give birth each year in the United States. Of these, approximately 7,600 women are HIV-infected, and run the risk of passing on the fatal virus to their fetuses. (Eden, p. 661).

In 1994, a study known as Protocol 076, administered by the Pediatric AIDS Clinical Trials Group (PACTG), demonstrated a two-thirds reduction in perinatal transmission of HIV by administering Zidovudine (AZT) to pregnant women and newborns, reducing rates from approximately 25 percent to 8.3 percent. (Connor). Later studies demonstrated that the perinatal transmission rate may be as low as 3 percent when mothers are treated with AZT. (Eden, p. 661).

Most states reacted to this news by enacting statutes delineating procedures for doctors to counsel and test pregnant mothers for HIV. Some called for the mandatory HIV testing of all pregnant women, but a broad coalition of physicians, policy-makers, lawyers and public health specialists warned that such a move would discourage *at-risk* women from seeking prenatal care. As a result, no state mandates HIV testing for pregnant women.

Interestingly, at least two states mandate HIV testing of all newborns. (See N.Y. Public Health Law § 2500-f, for New York; and C.G.S.A. § 19a-55, for Connecticut). Because a newborn will not test positive for HIV unless his or her mother is infected with the virus, the HIV testing of newborns is effectively a test of the mother, as well. The ostensible purpose of such laws would be to notify the new mother of her HIV status, so that she might avoid transmitting the virus to her newborn via breast-feeding, and so that the infant might begin antiviral medications.

As implemented, there are several problems with these laws, stemming largely from the lack of appropriate training and funding for those who implement them. First, many women who have been indirectly *tested* for HIV via the testing of their newborns never receive appropriate counseling. Years of work with HIV patients demonstrates that pre- and post-test counseling is vitally important in assuring that infected individuals will obtain the information and treatment necessary to protect themselves and others (McGovern). Second, no mechanisms exist for monitoring the medical privacy of mothers of newborns who test positive for HIV. In virtually all other contexts, the law recognizes this loss of privacy as a grave risk, and vigorously protects the confidentiality of an individual's HIV status (McGovern). Finally, as late as 2003, the efficacy of these laws has been hampered by slow response times, such that mothers do not learn of the HIV status for several weeks after giving birth (McGovern).

Mandatory testing policies, whether directed toward pregnant women or newborns, are predicated upon the belief that the benefits of testing and treating the children outweigh the risks to their mothers. This reasoning rests on somewhat shaky scientific knowledge, as the long-term side effects of AZT on both the mother and child are not clear. In

2003, however, it seems that AZT does not inhibit cognitive function, growth, cause cancer, or impair immune function (Culnane et al., p. 152). Nonetheless, this risk-benefit calculus treats pregnant women (or new mothers) differently from the rest of the population, according them fewer rights, simply by virtue of the fact that they have given birth. As in other contexts, this treatment suggests that pregnant women are uniquely incapable of making morally trustworthy healthcare decisions, and that the state is therefore entitled to intervene. If the knowledge of one's HIV status were indeed so vitally important, one would expect to see widespread calls for mandatory testing of the entire population. Well into the third decade of HIV-related policy making (in even the first years of the twenty-first century), there has been no real effort in that direction.

Racial Disparities

In addition to the concerns about gender discrimination raised by pregnancy-related restrictions and penalties, virtually all of these pregnancy-related legal interventions have a disproportionately negative impact upon women of color. A 1987 survey of court-ordered cesarean sections published in the *New England Journal of Medicine* found that 80 percent of the women against whom orders were sought were African American or Asian (Kolder et al.). A 1990 study, also published in the New England Journal of Medicine, found that African-American women were ten times more likely than white women to be reported to health authorities when they tested positive for illegal drug use during pregnancy (Chasnoff et al.). Another 1990 survey of forty-seven women prosecuted for behavior during pregnancy found that 80 percent of the prosecutions were against women of color (Paltrow). As Dorothy Roberts effectively demonstrates in her book, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty,* these policies not only are problematic in terms of law, ethics and policy, but also they reflect a sentiment that the women of color are somehow *public property.* In a sense, these fetal-protection policies may be viewed as the contemporary legacy of slavery.

Conclusion

Attempts to impose special pregnancy-related restrictions or penalties on women have been relatively rare and typically have been invalidated by courts and opposed by interested organizations and most commentators. The threat of criminal prosecution, loss of custody of children, and court-ordered medical interventions risk deterring those women who are most at risk of poor birth outcomes from seeking prenatal care and drug and alcohol treatment.

The government can, however, do a great deal to improve the health of children by helping women to have healthy pregnancies. For example, experts agree that the high rate of infant mortality in the United States can be drastically cut by providing prenatal care to the approximately one-third of American women who receive inadequate or no prenatal care. Drug treatment programs routinely turn away pregnant women, and the few that will treat women during pregnancy have long waiting lists. Government studies have shown that expending the funds necessary to provide these services would actually save taxpayers three to four times as much in reduced infant healthcare costs.

While creating legal conflicts between a woman and the fetus within her is ineffective and even counterproductive, laws and policies that respect women's rights can effectively promote the healthy pregnancies and births that are in the interests of all.

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SEE ALSO: *Beneficence; Coercion; Communitarianism and Bioethics; Conflict of Interest; Conscience, Rights of; Fetal Research; Genetic Testing and Screening: Reproductive Genetic Screening; Infanticide; Infants; Insanity and the Insanity Defense;* and other *Maternal-Fetal Relationship* subentries

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MEDICAID

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Medicare and Medicaid were created in 1965, and together they revolutionized public health insurance in the United States. Before Medicaid, healthcare insurance for the poor was not perceived as a societal or governmental responsibility.

Initial Goals and Early Challenges

Medicare and Medicaid could not be more different in their underlying philosophies and structures. Medicare was designed to be a universal entitlement program like Social Security. It was established to provide basic hospital and physician-care insurance for all elderly Americans and is financed through a special trust fund. Its benefits are controlled by the federal government and do not vary by state.

In contrast, Medicaid was designed to be a means-tested program funded by general revenue from the federal government and the states. Within federal guidelines and options states determine who will be covered, what services will be paid for, how much providers will be paid, and how the program will be administered. It was not designed to provide social insurance to the full poverty population but to cover particular recipients of public aid, mainly those receiving Aid to Families with Dependent Children (AFDC) and Supplemental Security Income (SSI). Soon after its inception Medicare was thought to be a model for the next step toward universal health insurance, whereas Medicaid was seen as a stigmatized program for the poor.

The history of the two programs, however, has shown that Medicaid has been the more important and effective vehicle for increasing access to healthcare services. Medicare has remained largely constant and rigid in its covered population and its structure. By contrast, the Medicaid program has been the structure to which policymakers have turned to repeatedly over the years to make incremental additions to the population covered by health insurance.

Growth in the Medicaid Safety Net

Medicaid began small. In 1966, there were four million enrollees and the annual cost was $400 million. Those numbers increased as persons in need of long-term care were added to the program after 1972. Although the number of recipients grew slowly between 1975 and 1990 (22 million to 26 million), total government costs for Medicaid increased dramatically, rising from $12 billion to $72 billion. By 2002 the number of enrollees had reached 47 million, making Medicaid slightly larger than Medicare, and total costs had reached $257 billion. However, not everyone who is eligible for Medicaid enrolls. Seventy-two percent of eligible children and 51 percent of eligible nonelderly adults are estimated to be enrolled. In 1999 Medicaid covered 5 percent of nonelderly adults and 15 percent of those with incomes below 200 percent of the poverty level.

The Medicaid program has grown in several important ways. Although originally it was limited to those who received cash benefits under AFDC (poor women and children) and SSI (the permanently disabled), more than half the persons Medicaid covered in the early years of the twenty-first century did not receive cash benefits from other programs. Indeed, Medicaid at that time was the principal source of funding for a vast infrastructure that served the poor and disabled, including safety-net hospitals, community and migrant health centers, mental health clinics, and school-based health programs.

Long-term care was added to the mandated benefits in 1972. Without private insurance, middle-class Americans may become impoverished because of out-of-pocket nursing home costs and “spenddown” to qualify for Medicaid. Institutional coverage also is provided for inpatient mental health services and intermediate-care facilities for the mentally retarded. Medicaid is also the largest payer for medical services for persons with AIDS.

The largest and most important expansions of the scope of Medicaid have been in the areas of prenatal care for poor women and healthcare for children. In 1989 poor women began to receive coverage for prenatal care. In 1997 the State Children’s Health Insurance Program (SCHIP) was enacted to cover low-income children who did not qualify for Medicaid under the previous criteria. Together Medicaid and SCHIP account for 16 percent of the nation’s healthcare spending, nearly as much as Medicare’s share (18%).

Impact on the Nation’s Health

Medicaid has achieved significant advances in the healthcare of the poor and previously middle-class persons who require mental health services or long-term care. With Medicaid, poor persons use health services at the same rate as nonpoor persons with a similar health status. Medicaid also provides access to a broader service package that supplements physician care, such as dental care and prescription coverage.

Medicaid has proved to be a better vehicle for incremental reform than Medicare because it is more flexible and does not have the high level of national political visibility and volatility that Medicare has. Additions to the Medicaid program typically have had three effects; they have (1) increased access to care, (2) shifted at least part of the cost to the federal government, and (3) increased the uncompensated care burden on healthcare providers. Overall, the health of the poor has improved significantly in the post-Medicaid era, with substantial declines in infant mortality, maternal mortality, and death rates for major diseases for which medical intervention is effective.

Major Criticisms of the Program

Medicaid is not a "user-friendly" program. Many persons who are eligible for the program are not enrolled. Once a person is enrolled, eligibility status is evaluated periodically, as frequently as every month in some programs. When income eligibility standards are no longer met, Medicaid coverage is suspended. This results in poor continuity of care and personal hardship.

The state-based nature of the program has resulted in variations in coverage and benefits across the states. Federal requirements ensure relatively uniform coverage for children, pregnant women, the elderly, and the disabled across the states. Childless adults are not covered by Medicaid regardless of their income level. Adults who are parents are the group for whom Medicaid eligibility varies the most widely from state to state. Half the states set eligibility below 40 percent of the federal poverty line; those whose incomes put them at the poverty level ($15,020 for a family of three in 2002) make too much to qualify for Medicaid in all but eighteen states.

Throughout its history there have been repeated cycles of cutbacks and expansions in response to fiscal pressure in the states. From the 1970s until the mid-1980s cutbacks eroded Medicaid coverage of the poor and began to reverse the progress that had been made in closing gaps in access to care across income groups. Since the mid-1980s, however, the trend has been to expand Medicaid eligibility and services. This has not been due to the increased political leverage of the poor but has occurred because from both the federal and the state point of view the cost-sharing arrangement makes it attractive to add to the program. Only in the early 2000s did the nation begin to reenter a period of fiscal crisis at the state level. As a result of a general economic downturn, state revenues declined while Medicaid costs expanded to account for a very significant portion of state governmental budgets.

The prospects for the future of Medicaid are unclear. Some states want the authority to cap enrollment levels and create waiting lists so that even those who qualify with incomes at 40 percent of less of poverty may not be enrolled. About half the Medicaid enrollees in the country are in managed-care plans, but that has not stemmed the tide of rising costs.

Issues for the Future of Medicaid

Medicaid reform is charged with moral issues that frame the fundamental policy decisions. Can public health insurance be equitable when it is targeted only to the poor, or is the inevitable outcome a lesser program? Can an equitable package of minimum benefits be determined? Will the trend toward using Medicaid to expand access to health insurance incrementally be reversed by a weakening of federal requirements and the fiscal crisis of state governments that began at the turn of the twenty-first century? How should society share the costs that a decent healthcare safety net will incur?

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SEE ALSO: *Access to Healthcare; Healthcare Resources, Allocation of; Health Insurance; Health Policy in the United States; Medicare*

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MEDICAL CODES AND OATHS

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I. History
II. Ethical Analysis

I. HISTORY

The following is a revision and update of the first-edition article “Codes of Medical Ethics: History” by Donald Konold. Portions of the first-edition article appear in the revised version.

In the ethics of healthcare, explicit statements of ethical standards have been formulated for physicians and members of the other health professions, for persons conducting medical experiments involving human subjects, for administrators, and for patients and other laypeople who make healthcare decisions. These have often been written by members of the relevant practitioner group, but they may also be written by members of religious, cultural, national, or international bodies. While codes of ethics have long been regarded as the classic expression of these directives, various principles and rules have also been stated in the form of prayers, oaths, creeds, institutional directives, and statements. Prayers state a very personal commitment of duty; oaths publicly pledge the oath taker to uphold specified responsibilities; and codes provide more comprehensive standards to guide the practicing health practitioner, patient, or other decision maker. Each form of ethical statement implies a moral imperative, either to be accepted by the individual personally or to be enforced by a practitioner organization, religious community, or governmental body.

While practitioner bodies have often assumed responsibility for writing their own codes of ethics for their members, governmental, religious, and cultural bodies have also claimed authority to articulate the moral norms of conduct in healthcare. Disputes over who has the authority to articulate codifications of ethical duties in the medical sphere reveal important controversies over who can legitimately claim moral authority in determining what these duties are. This article first examines prayers, oaths, and codes written by health providers or practitioner groups, and then examines those written outside the profession.

Documents Created by Practitioners

MEDICAL PRAYERS. Healthcare providers in all ages have composed prayers expressing gratitude for divine blessings and asking for divine inspiration in their practitioner conduct. Such prayers signify that the writer stands within a religious tradition and grounds medical duties in that religion’s moral framework.

An ancient Greek poem that has the quality of a prayer or a hymn was found inscribed on a monument in a sanctuary of Asclepias, originally on the south slope of the Acropolis. According to the poem, the physician should be “like God: savior equally of slaves, of paupers, of rich men, of princes, and to all a brother, such help he would give” (Etziony, p. 21).

Likewise, ancient Jewish sources include texts extolling the physician’s healing. An early Jewish prayer was written by the early-twelfth-century Spanish poet, philosopher, and physician Yehuda Halevi (Etziony). The most widely acclaimed Jewish example is the Daily Prayer of a Physician, once ascribed to the Jewish physician and philosopher Moses Maimonides (1135–1204) but now believed to be the work of the eighteenth-century German Jewish physician

Marcus Herz (Rosner). In the manner of most medical prayers, the Daily Prayer asks for courage, determination, and inspiration to enable the physician to develop skills, meet responsibilities, and heal patients. It commits the physician to place duty to patients above the physician's own concerns and places the physician's healing in clear subordination to divine authority.

Many examples of Christian prayers of physicians exist from ancient and medieval times. More modern prayers sometimes reflect more eclectic, nondenominational perspectives. The theology expressed in the prayers of these physicians, who, theologically, are laypeople, is sometimes not an authoritative reflection of the tradition in which they stand.

OATHS FOR PHYSICIANS. In the ancient world physicians often expressed their ethical commitments in the form of oaths, which were an integral part of the initiation ceremony for medical apprentices. Like many medical prayers, ancient oaths reflect the physician's belief that success in the healing profession required an alliance with the deity in the treatment of disease. The ancient oaths often beseech the deity to inspire physicians to fulfill their moral obligations, reward those who honor their sacred trust, and punish those who violate it.

One of the oldest of these oaths, a medical student's oath taken from the *Charaka Samhita* manuscript of ancient India, contains concepts that had pervaded Indian ethical thought for many centuries before their inclusion in the oath at about the beginning of the common era (Menon and Haberman). Pledging the medical student to live the life of an ascetic and a virtual slave of his preceptor in accordance with Indian custom for apprenticeships, the path requires personal sacrifice and commitment to duty from the student comparable to the physician's responsibilities to patients. By the terms of the oath, the student physician is to place the patient's needs above personal considerations, serving day and night with heart and soul; abstaining from drunkenness, crime, and adultery; and scrupulously observing practitioner secrecy.

In sharp contrast to the medical ethics of the Western world, the Indian oath obliges the physician to deny services to enemies of his ruler, evildoers, unattended women, and those on the point of death. Ancient Indian thought condemned aid to anyone who was immoral or was involved in any circumstance that might suggest illicit sexual contact; it also condemned interference with the process of dying. Despite these differences, the oath of the Indian student reveals significant parallels between the medical ethics of India and those of the Western world, which may suggest a diffusion of ideas, probably from India to the West.

The most enduring medical oath of Western civilization is the Oath of Hippocrates. Despite its renown, its origin is obscure. It is a part of the Hippocratic Collection, which was catalogued and edited by a group of Alexandrian librarians sometime after the fourth century C.E. Copies of these writings available to modern scholars, however, date from the tenth to the fifteenth centuries C.E. and do not preserve the original text with verbal accuracy. None of the manuscripts in this collection can be positively verified as genuine works of the great Greek physician, and clearly the documents are the products of many contributors, with the earliest predating the latest by at least a century.

Twentieth-century scholars, especially Ludwig Edelstein (1943), have suggested that the oath conforms closely to the teachings of Pythagoras (fourth century B.C.E.). He noted the similarities with the principal ethical beliefs of the Pythagoreans, which included reincarnation, avoidance of shedding of blood, prohibition on taking of life, and commitment to sexual purity and secrecy. Edelstein held that the oath was composed by a group of Pythagoreans who practiced the healing arts. More recent historians of medical ethics have argued over whether the dependency is as close as Edelstein maintained, suggesting that the influence of other philosophical/ethical traditions may also be present (Carrick). Nevertheless, some degree of affinity of Hippocratic with Pythagorean thought is generally conceded. The oath, in accord with Pythagorean ethics, proclaims a more strict morality for physicians than was established by Greek law, Platonic or Aristotelian ethics, or common Greek medical practice.

The Oath of Hippocrates consists of two parts, the first serving as a contractual agreement between pupil and teacher and the second constituting an ethical code. The opening sentences pledge the novice physician (invariably a male) to become an adopted member of his teacher's family, to help support his teacher and his teacher's children in case of need, and to instruct his teacher's children free of charge. The oath forbids sharing the precepts and medical knowledge with anyone who has not taken the oath. Since familial bonds between teacher and pupil implied careful selection of those admitted to the family group, the covenant enabled physicians to prevent unworthy persons from entering the profession and to keep tight control on knowledge transmission.

The ethical code contained in the Oath of Hippocrates places restrictions on the medical techniques of the physician and defines relations with the patient's family. One who takes the oath pledges, "I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice" (Edelstein, 1943, p. 3). He also agrees to refuse to dispense poisons or abortive remedies, and to leave surgery (including lithotomy or removal of a stone from the urinary bladder) to those trained in that art. He makes the commitment that "whatever houses I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice" (Edelstein, 1943, p. 3). The taker of the oath swears to abstain from sexual relations with all those in the houses the physician enters. Regarding confidentiality, in an ambiguously qualified way, the physician promises not to disclose that "which on no account one must spread abroad." The oath ends with a plea for reward that is unusually self-serving for a code of ethics: that if the physician keeps the oath he be "honored with fame among all men for all time to come." If he transgresses it, "may the opposite of all this be my lot" (Edelstein, 1943, p. 3).

The oath's provisions contrast sharply with what is otherwise known about ancient Greek medical practice, which permitted physicians to abet suicide and infanticide and to perform surgery. They introduced an element of respect for slave as well as freeman and, even though the secrecy requirement is qualified, it is extended outside the practitioner relationship. These precepts, though they represent the thought of only a small group of medical practitioners, extended their influence beyond the importance of the Hippocratic school of medicine in the ancient world.

For centuries following the appearance of the Hippocratic oath, the practitioners of the medical art showed no inclination to accept it. Hellenistic physicians ignored its injunctions without compunction. It is sometimes held that the rise of Christianity, which had certain ethical positions similar to Hippocratic ethics, is responsible for the ascendancy of the Hippocratic oath (Edelstein, 1943; Carrick). There is, however, very little evidence of early Christian interest in the Hippocratic oath; increasingly there is emphasis on important ethical differences between the Hippocratic and Christian traditions (Veatch and Mason). Medical historian Owsei Temkin has identified considerable tension between Hippocratic and Christian medicine and their ethical commitments. One exception to this generalization is the fourth-century Christian figure Jerome, who explicitly mentions the Hippocratic oath, but in doing so he points out that the Christian physician's obligation is even more stringent.

Precisely what happened to bring the oath into prominence during the Middle Ages is uncertain. Perhaps the early post-Constantinian Christian culture found similarities between Christian and Hippocratic views, as has been suggested. A strong case can be made, however, that although there were significant differences between Greco-Roman and Christian medical ethics, lay physicians were simply not sufficiently schooled in Christian theology to perceive them. One way or another, increased attention to the oath led to renewed interest in it. Modifications were introduced in order to bring it somewhat more into harmony with Christian ideological concepts and practices. This could be taken either as evidence to support the convergence hypothesis or to support the contrary claim that the oath had to be corrected significantly to bring it into harmony with Christian thought.

The earliest of these extant revisions, titled "From the Oath According to Hippocrates Insofar as a Christian May Swear It" (dating from the tenth or eleventh century), substitutes a statement of Christian adoration of God for the references to the Greek deities in the original oath and replaces its covenant with a statement of teaching responsibilities based on Christian brotherhood, pledging the physician to teach the medical art to whomever wants to learn it (Jones; Leake). The injunction against surgery does not appear in this version of the oath. No reason is known for its omission, but later Christian versions do contain it. The appeal for reward and honor for the physician should he follow the oath is abandoned, probably because it is inconsistent with Christian views of grace.

The Oath of Asaf, from the seventh-century *Sefer Asaf* manuscripts of the oldest Hebrew medical work, reveals Hippocratic influences in its injunctions against administering poisons or abortifacient drugs, performing surgery, committing adultery, and betraying practitioner confidences (Rosner and Muntner). Like the medieval Christian oaths, it is consistent with Talmudic ethics and instructs physicians to give special consideration to the poor and needy, a concern absent from the Hippocratic oath. A revision of the Oath of Hippocrates also appeared in medieval Muslim literature, where the only significant changes replaced references to Greek gods with statements in harmony with Islamic theology. The oath in its original form was also known to Christian and Muslim scholars; however, among the Christian church fathers, only rare mention is made of it. The texts that do refer to the oath reveal a perception of a difference between Hippocratic and Christian medicine.

Following the transition from medieval to modern Western civilization, the Oath of Hippocrates apparently continued to be a model for ethical pledges by physicians. Its legacy is ambiguous. On the one hand, it repudiates exploitation of the sick, often the most vulnerable. On the other hand, it locates all authority about what constitutes a benefit in the physician's "ability and judgment." In this way, the oath has sanctioned a medical paternalism throughout the ages that is in conflict with the modern assertion of the right of patients to determine for themselves the benefits they seek from medical care.

Western medical schools in the eighteenth and nineteenth centuries, seeking to impart high ethical ideals to their students, administered oaths to their graduates. It is unclear whether or how often the Hippocratic oath itself was used, but certainly the typical oaths, such as that of the great medical school of Montpellier, incorporated Hippocratic ideas (Etziony).

Our knowledge of professional medical ethics in the early modern period is very limited. Historians have not done enough specific research in European and American medical schools and professional societies to know what local religious, philosophical, and political influences helped shape medical education. Additional research is underway. The received tradition holds that Western medical schools, seeking to commit their students to the pursuit of high ethical ideas, continued a tradition begun in the Middle Ages of incorporating Hippocratic concepts in oaths for their graduates, especially the covenant's requirement for the physician to instruct his teacher's children and the ethical injunctions for secrecy and against administering harmful drugs. During the nineteenth century, some medical schools in the United States required their graduates to take the Hippocratic oath in its original form, and that continued to be a common practice in the twentieth century, even though many of the oath's provisions were archaic or offensive to some of the students. A study published in 1991 found that 60 of 141 U.S. medical schools administered the Hippocratic oath (Dickstein et al.).

A document patterned after the Oath of Hippocrates appeared in 1948, when the newly organized World Medical Association (WMA) adopted the Declaration of Geneva. In 1991 forty-seven U.S. medical schools used it (Dickstein et al.). (Of the remainder, fourteen schools used the Prayer of Maimonides or more recently written oaths.) The declaration attempts to make the original oath applicable to modern conditions of medical practice and diverse cultural, religious, and ethnic groups in the world community. In doing so, it raises serious questions of how any one single ethical text could be made appropriate for a wide range of religious and cultural groups that clearly have fundamental differences, not only about significant medical ethical controversies, but also about the very foundations and meanings of ethical propositions. The Declaration of Geneva is a secular oath that contains no reference to religious tenets or loyalties, thus appealing to secular physicians while perhaps offending those who continue to ground their ethics in some particular religious framework.

Although the claim is made that the Declaration of Geneva simply updates the Hippocratic oath, the reformulation clearly involves significant differences. The declaration commits the physician to make the patient's health his or her first consideration, a provision reminiscent of the Hippocratic oath's pledge to use dietetic measures for the benefit of the sick. But in addition to the secularization of the declaration by the removal of the religious references, the 1948 text deletes the pledge to refuse to reveal information to those who have not taken the oath. The loose Hippocratic pledge of confidentiality is replaced with an exceptionless pledge, one that conflicts with the increasingly recognized necessity of disclosing in order to protect third parties from serious threats of harm, as well as with the more paternalistic exceptions seen in many modern interpretations of the oath. The oath's surgical restriction is also omitted from the declaration, as is the injunction against sexual contact with those in the patient's household.

The physician of the declaration vows not to let considerations of religion, nationality, race, party politics, or social standing interfere with his duty to his patient. Obviously, those who conceived and adopted the declaration found united support for clearer condemnation of these prejudices than the original oath provided. In sharp contrast, however, the declaration's statement of the physician's responsibility regarding suicide, mercy killing, and abortion is obscured in generalities that conceal modern controversy on these matters among physicians and laypeople alike. The physician of the declaration pledges only to maintain respect for human life from the time of conception and not to use medical knowledge in ways that are contrary to the laws of humanity. While the Declaration of Geneva has found some acceptance among medical professional groups, it has not been endorsed by significant national professional associations, and it certainly conflicts with the ethical precepts of many secular and religious groups in both East and West.

PRACTITIONER CODES. Physicians of the modern world have not been content with the spiritual inspiration of prayers and the moral commitments of medical oaths. The large medical institutions of urban society have required complex relationships among medical personnel who demand detailed procedures to prevent embarrassing ethical controversy and disruption of services. Lengthy treatises on medical subjects, which had enlightened physicians on ethical matters since the earliest times, were not easy to cite by paragraph and line and frequently concealed ethical instruction in needless verbiage. Reducing these essays to lists of rules, proponents of practitioner control produced elaborate ethical codes.

A code is an ordered collection of injunctions and prohibitions, usually created by an authoritative body and adopted as a statement of ideals and rules for a group or organization. The modern idea of codes derives ultimately from the Renaissance ideal of rationalizing Roman law, putting the diverse parts into some order and stating briefly and clearly the essence of the rule. Sometimes individually authored documents, such as the work of Sun Szu-miao and Thomas Percival discussed below, have taken on the status of systematic codifications.

One of the earliest codes of medical ethics appeared in China, where the Oath of Hippocrates never made a significant impression. From the seventh century, an indigenous Chinese tradition in medical ethics developed in works by Sun Szu-miao. Generally regarded as Taoist, his writing stresses the importance of preserving life and the subordination of self-interest to compassion for the patient. It reflects the differentiation of an elite group of physicians referred to as "great physicians" and marks the emergence of a group claiming special medical authority. A Confucian response authored by Lu Chih (754–805) attacks this elitist trend, indicating medicine should be the responsibility of all persons. This tradition received clear expression in the Five Admonitions and Ten Maxims listed by Ch'en Shih-kung in a seventeenth-century treatise on surgery (Unschuld). Along with much guidance for social intercourse, Ch'en's precepts instruct physicians to give equal treatment to patients of all ranks, to keep expenses modest, and to treat the poor without charge, providing the same services regardless of the amount of payment. Above all, the physician is to know the principles of Confucianism. The key Confucian virtues are compassion and "applied humaneness," terms that do not enter Western medical ethics until the twentieth century.

These instructions continue to characterize Chinese medical ethics in modern times, but they have had little influence elsewhere. Although they bear some resemblance to ethical concepts in Western medicine, there are significant differences and little evidence of crossfertilization.

In the West, the Royal College of Physicians provides an interesting example of a professional code. In the first Statutes of the College in 1555, and in the revision of 1647, there is a section entitled, *De statutis moralibus seu penalibus.* This contains precepts requiring good behavior in the meetings of the college, regular attendance and, in addition, proper etiquette between several physicians called into consultation. They admonish physicians not to disparage or accuse one another in public, but only before the college. They also prohibit physicians from telling their patients and the public the names and composition of medicines, "lest the people be harmed by abuse of them" (Clark, p. 384).

A treatise published in 1803 by Thomas Percival, an eminent physician of Manchester, England, strongly influenced the development of codes of medical ethics (Leake; Baker et al., 1993; Baker, 1993). Originally prepared in 1794 to mediate a dispute among surgeons, physicians, and apothecaries in Manchester, and expanded in 1803 to include physicians in general practice, *Medical Ethics; or, A Code of Institutes and Precepts Adapted to the Professional Conduct of Physicians and Surgeons* expresses standards of morality and etiquette that were in sharp contrast to the quarrelsome conduct of British practitioners of that era. Percival's treatise places emphasis on the professional relationships of physicians to one another; to hospital personnel, apothecaries, and others engaged in the care of the sick; and to the law.

In its advice to physicians to treat patients with the eighteenth-century virtues of "tenderness, steadiness, condescension, and authority," it conveys the attitudes of the English gentleman philanthropically bestowing benefits on patients who are expected to show proper gratitude. Percival's *Medical Ethics* stands in the Hippocratic tradition, but begins to acknowledge obligations of physicians to the society as well as to patients. Unlike the Hippocratic oath, Percival holds both surgery and medicine as acceptable practices.

As befits a volume having its origins in a local dispute among professions, a principal concern of Percival's *Medical Ethics* is with the etiquette of professional conduct. It offers elaborate procedures for consultation among physicians in difficult cases and for preservation of distinction of rank in relationships between junior and senior physicians on hospital faculties and in consultations. It cautions physicians to display respect for one another, to avoid criticizing the practice of their colleagues, to conceal professional differences from the public, and not to steal patients from one another. In justifying these procedures, Percival reasoned that criticism of the profession was usually unfounded and always degrading both to the doctors criticized and to the profession. In most of its provisions, Percival's *Medical Ethics* suggests a modified utilitarian philosophy, calling for individual physicians to conduct themselves in a manner that would enhance public respect for the entire medical profession.

Among the earliest American writings in physician-authored ethics were those by Columbia University physician Samuel Bard and revolutionary patriot Benjamin Rush; early codes were also prepared by the medical associations of the cities of Boston and Baltimore and the state of New York. When the American Medical Association (AMA) was organized in 1847, it adopted a code of ethics drawn from Percival's *Medical Ethics* as well as these other sources. The code of ethics made no mention of etiquette for hospital staff and barely referred to the relations of physicians with pharmacists and courts of law, but it expanded and elaborated the principles for physicians in private practice, even presuming to include a statement of obligations of patients and the public to physicians.

The medical profession in the United States faced a crisis in public confidence in 1847. Medical licensure laws in most states had been repealed with the result that uneducated practitioners and charlatans had begun to compete for patients with educated physicians. In addition, a vigorous debate raged between various schools of medical science over which was the correct or orthodox system. Proponents of the code of ethics hoped that the public would cooperate with allopathic physicians in establishing standards for medical practice that would reinstate public respect for the medical profession.

The code of ethics contained a variety of restrictions on open competition among physicians. It branded as quacks all medical practitioners who lacked orthodox training, claimed special ability, patented instruments or medicine, used secret remedies, or criticized other practitioners. In doing so, it also became a weapon in the internal dispute among physicians of different schools, particularly challenging the homeopaths. The requirement of orthodox training made outcasts of physicians who belonged to medical sects such as the homeopaths, the eclectics, the Thomsonians, and later the osteopaths and chiropractors. Since each sect claimed superior results from its form of treatment, practitioners with sectarian designations were guilty of claiming superior ability as well as handicapped by their incomplete education.

Charging that these offenses resulted from selfishness and efforts to discredit rivals, the code of ethics also demanded that reputable physicians avoid any appearance of soliciting the patient of another doctor. Although these provisions united the profession against heterodoxy and quackery, the prohibition on claims of special ability produced conflict between general practitioners and aspiring specialists. This ethical rule ceased to cause dissension only after the establishment of specialist organizations to certify the credentials of their members and after specialization won sufficient acceptance to permit physicians to restrict practice to their specialties.

The code of ethics provided orthodox physicians with one means of exposing those undeserving of confidence. It stated that physicians should not consult professionally with anyone who lacked a license to practice or was not in good professional standing. Since professional standing was determined by the local medical societies, this provision had the effect of substituting a collective professional judgment for that of individual physicians and patients, thus superseding the Hippocratic oath's focus on the individual physician's judgment. In those cases where the patient insisted on inviting a consultant who was not approved by the local medical organization, the attending physician would have to retire from the case in order to retain professional standing. While physicians argued that they could not fulfill their obligation to patients if they admitted a right for fraudulent practitioners to advise in any capacity, their ethics required that they withdraw, thus giving full charge of the case to the allegedly unqualified practitioner. Moreover, the majority of physicians found the consultation restriction a useful means for excluding many qualified physicians from association with the dominant organization. Thus the codes served a monopolistic function as instruments for restraint of trade. Before 1870, regular medical societies excluded from membership and forbade consultations with female physicians and Negro physicians and, throughout the latter half of the century, with physicians who adopted a sectarian designation, even if they were certified by licensing boards. Because of mounting criticism, the consultation restriction was eliminated from the code of ethics in 1903, but its spirit was revived by a 1924 resolution of the American Medical Association forbidding voluntary association of its members with cultists. In effect, the AMA code, so vociferously debated in the nineteenth century was double edged: It did state, in Percivalian terms, certain ideals of good practice, but at the same time, it was an instrument to create a monopoly.

Establishment of the World Medical Association in 1948 encouraged physicians to develop international standards of medical ethics. The new organization adopted an International Code of Medical Ethics (International Code) in 1949, which attempted to summarize the most important principles of medical ethics. Since 1900, certification laws had reduced the prevalence of unqualified medical practitioners, and scientific advances had increased the effectiveness of trained physicians. By mid-century, physicians were directing their attention more to the actual treatment of patients and less to the formality of relations between one doctor and another, or between doctor and patient. The International Code reflects these new concerns in a shift away from the detailed regulations of the preceding 150 years. In place of elaborate etiquette for consultations and other medical confrontations, it recommends only that physicians behave toward colleagues as they would have colleagues behave toward them, that they call specialists in difficult cases, and that they not entice each other's patients. It warns against the profit motive and prohibits unauthorized advertising, medical care plans that deprive the physician of professional independence, fee splitting or rebates with or without the patient's knowledge, and refusal to treat emergency cases. It also commits physicians to honor professional secrecy in an unqualified way, an obligation that continues after the death of the patient, according to an amendment to the code adopted in 1968.

The International Code only hints at the ethical problems of abortion and euthanasia by asserting the physician's responsibility to preserve life. It does, however, warn specifically against any action that would weaken the patient's resistance without therapeutic justification. Applicable to the dying patient and experimental subject alike, this standard requires the physician to consider the patient's well-being above all else. The International Code also recognizes the need for adequate testing of innovations by urging great caution in publishing discoveries and therapeutic methods not recognized by the profession.

Using the International Code of Ethics as an example, the American Medical Association reduced its elaborate code to ten one-sentence Principles of Medical Ethics in 1957 (Ten Principles). This was intended as an epitome rather than a reduction. ("Every basic principle has been preserved," according to the Council that submitted the draft.) It retained the essentially Hippocratic focus on benefit of the patient, but added that the responsibilities of the physician extend also to the society.

Most of these principles had been anticipated in the International Code, but there are a few noteworthy exceptions. Reflecting a continuing distrust of sectarian practitioners by regular physicians in the United States, the 1957 principles warn against professional association with unscientific practitioners. They also oblige physicians who are AMA members to expose the legal and ethical violations of other doctors. Instead of warning against premature publication of discoveries, the 1957 principles urge physicians to make their attainments available to patients and colleagues. Finally, while reaffirming the principle of confidentiality, the 1957 principles authorize physicians to violate this principle when required by law or to advance the welfare of the individual or the community. This provision suggests more discretionary authority for the physician than do the codes of most nations and the World Medical Association, which emphasize the inviolability of professional secrecy.

By the late 1970s, there was again dissatisfaction with the principles. A special committee was appointed to prepare a new draft that would clarify and update the language, eliminate reference to gender, and seek a "proper and reasonable balance between professional standards and contemporary legal standards in our changing society" (American Medical Association, 1989, p. viii). The report submitting the new version acknowledged the increasing recognition of laypeople's role in defining the moral terms of the patient–physician relation. Nevertheless, the new code was prepared and adopted by a group made up entirely of members of the association. The new principles affirm the virtues of compassion and respect for human dignity. It, for the first time, shifts to the use of the language of "rights," saying that "a physician shall respect the rights of patients, of colleagues, and of other health professionals" (p. ix). It generally removes the traditional Hippocratic paternalistic authorization for physicians to act for the benefit of the patient according to the physician's judgment. For example, it permits breaking confidentiality only "within the constraints of the law" (p. ix).

Scientific advances and changing social standards in recent decades have raised ethical questions in a number of areas that are not adequately covered by existing general codes. The Council on Ethical and Judicial Affairs of the American Medical Association regularly issues opinions that elaborate (and occasionally contradict) the principles adopted by the AMA's legislative body, the House of Delegates. In recent years, other medical organizations, such as the American College of Physicians, have prepared and issued codes of ethics for their members.

Codes from Outside the Profession

GOVERNMENTAL CODES. In the twentieth century, a number of national governments have incorporated ethical codes into legal statutes governing the medical profession, to be enforced by an official, publicly appointed medical board. The precepts in these codes sometimes accord with the broader principles of the Percival tradition, but many provisions deal with problems of recent origin and reflect a modern concern for both public and individual welfare.

Some of these codes deal with single subjects. For example, the Nuremberg Code, which is the product of international law, deals with medical research on human subjects. In the United States, the federal government's regulations on the same subject function as a code of conduct as does the Belmont Report, a set of ethical principles on research developed by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1978).

Underlying the development of these codes is a fundamental issue of ethics: Is the professional group or the general public responsible for deciding what the ethical norms of the lay–professional relation should be? Even if the profession is deemed the proper authority for determining what constitutes ethical conduct, it is not clear exactly who should have the authority to speak for the profession and what the content of the codes should be. Some functions of the codes are clearly more for public relations and control of competition rather than for articulation of ethical norms. Many provisions that clearly are normative in content are still controversial. It is increasingly doubtful that the organized professional associations should have the authority to speak even for the profession as a whole (including the large numbers of physicians who are not members of the organizations) and that these groups should have any authority to speak on ethical matters that affect laypeople.

While modern medical ethics has often presumed that the profession should define its own code of conduct, this has not always been the case. Religious as well as governmental groups have sometimes claimed this prerogative. Increasingly, professional groups as well as laypeople are insisting that judgments about ethics are not the exclusive province of the professions and that the norms of lay–professional relations should be grounded in cultural, philosophical, or religious commitments.

A government-sponsored medical oath was adopted in the former Soviet Union, where its Presidium approved the Oath of Soviet Physicians in 1971. Modeled after an oath that had been used at the University of Moscow since 1961, the Soviet oath pledged the physician to conduct himself in accordance with communist principles and to order his responsibility to the Soviet government. This commitment to political creed and government was unique among medical oaths. The Soviet oath did not neglect other moral obligations, however; it instructed the physician to honor professional secrets, constantly improve knowledge and skill, always be available to calls for medical care or advice, and dedicate all knowledge and strength to professional activities. Like other recent oaths, the Soviet oath voiced virtually the same ideal of humanitarian duty to individual patients that appears in the earliest medical creeds, but it also pledged the physician to serve the interests of society.

Postcommunist Russia is undergoing a major reassessment of its healthcare policies, including its medical ethics (Tichtchenko and Yudin). In November of 1991, the Russian Supreme Soviet adopted the Declaration of Rights and Liberties of Citizens, which includes the principle of voluntary consent for participation in medical experiments and declares a right of every citizen to qualified medical care in the state healthcare system.

The Russian Medical Academy has developed a "Solemn Oath" (1993) to replace the Oath of the Soviet Physician. The new oath is a modernized revision of the Hippocratic oath. Approved by the Minister of Health in 1992, it is an official government document, not merely the product of a professional medical association.

NONGOVERNMENTAL GROUPS. Throughout history, codes, prayers, and oaths dealing with medical ethics have also been sponsored by private groups, religious bodies, and consumer groups that do not represent the medical profession.

For centuries, the Catholic church has articulated moral views about medical matters including abortion, euthanasia, and fertility control. These have appeared, at least since the medieval era, in systematic theological treatises, cases of conscience (collections analyzing morally perplexing cases), and in the theology manuals of the early modern era (Kelly; Griese). Formal codes of medical ethics, such as the Ethical and Religious Directives for Catholic Health Facilities prepared by the United States Catholic Conference (1975; Griese), are not only considered binding on Catholics but also affect non-Catholics who are associated with Catholic health facilities and others who find their reasoning persuasive.

The statements of the directives on secrecy, consent, organ transplantation, and terminal care closely resemble those of other codes. It prohibits abortion, except when justified by the principle of double effect, that is, when it is an unintended result of a procedure employed to protect the mother. It prohibits both male and female sterilization except in the treatment of a serious pathological condition, and it prohibits artificial insemination. Thus, the directives articulate the Vatican's "Instruction on Respect for Human Life" (Sacred Congregation for the Doctrine of the Faith).

The modern consumer movement has also influenced the ethics of medical practice. As hospitalization became a major consumer service, consumers increasingly demanded the right of patients to minimum standards of care and respect. In 1972, the American Hospital Association responded to consumer pressure and adopted "A Patient's Bill of Rights," which pertains primarily to hospitals but involves physicians with several responsibilities to patients ("Statement," 1973). A physician who subscribes to the bill of rights is obligated, with limited exceptions, to keep the hospitalized patient informed of diagnosis, treatment, and prognosis, to instruct the patient fully regarding possible consequences and alternatives before obtaining consent for medical procedures, to honor a patient's refusal to consent to treatment to the extent permitted by law, to protect the patient's right to confidentiality and privacy from physicians and staff not involved in his or her case, and to instruct the patient of his or her care requirements after discharge. These standards represent a significant departure from the traditional paternalism prevailing in the patient–physician relationship.

Still, the Patient's Bill of Rights was generated by a professionally dominated group. On some issues, such as informed consent, it actually incorporates traditional paternalistic exception clauses that might be rejected by those emphasizing the rights of patients. Other bills of rights have been developed such as those for nursing home patients, the mentally retarded, children, and other vulnerable groups. It is not clear how the statements of these documents are to be sanctioned, since no mechanisms of enforcement are specified.

Conclusion

The difficulties that confront professional leaders, patients, surrogates, and public policymakers who undertake the establishment of ethical standards on new issues reflect the conflicts in fundamental values inherent in diverse views of medical ethics. The traditional professional ethics of physicians places great emphasis on the virtue of benevolence and the physician's responsibilities to serve the patient. This tradition honors the individuality of the patient–physician relationship, professional secrecy, and the physician's duty to promote the patient's welfare. In these and other matters, ethical formulations by physicians have been paternalistic, making the physician the dominant party in determining which action will best further both the physician's and the patient's interests. Codes prepared by interests outside the medical profession (including those written by religious and governmental bodies) have advanced other philosophical tenets as foundations for medical ethics. Some of these codes have focused on justice or equity in allocating resources. This has resulted in mounting ethical confusion as physicians become subject to competing ethical authorities with conflicting standards.

Responsibility for the development of ethical guidelines relative to the physician–patient relationship may be shifting from the physician to the society as a whole. In those contingencies not anticipated by accepted guidelines, the responsibility for ethical criteria rests partly with the individual physician, partly with patients, and partly with society's general ethical standards. Future success in the use of codes to control medical practice may well depend on an accommodation of the ethical norms of physicians with those of the larger society.

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SEE ALSO: *Abortion; Advertising; Confidentiality; Death, Definition and Determination Of; Double Effect; Informed Consent; Judaism, Bioethics in; Life; Life Sustaining Treatments and Euthanasia; Medical Ethics, History of; Patients' Rights; Professional-Patient Relationship; Profession and Professional Ethics; Race and Racism; Research, Human: Historical Aspects;* and other *Medical Codes and Oaths* subentries

BIBLIOGRAPHY

[*The bibliography for this article and its companion article can be found following the companion article.*]

II. ETHICAL ANALYSIS

The following is a revision and update of the first-edition article "Codes of Medical Ethics: Ethical Analysis" by the same author.

Codes, oaths, and prayers of medical ethics have emerged over the centuries from disparate sources, representing disparate societies, time periods, organizations, and perspectives. It is not surprising that they differ significantly in style and content. This article will examine systemically the ethical content of this divergent collection of documents from the earliest to contemporary times. In the Appendix, the reader will find the texts of codes and additional bibliography of codes and commentaries on codes for ethics of the medical and other health professions.

Ethical analysis of the codes of medical ethics creates problems. Such codes are not fully developed, systemic theories of medical ethics. On the other hand, the codes, at least the modern ones, are normally the product of much discussion, debate, and review. These codes, along with the historical documents that have had lasting significance, can reasonably be expected to reflect the basic ethical views of the organizations that have endorsed them.

When one turns to the substance of the codes, especially the codes written by physicians, one can identify what might be called a central ethical obligation, a basic principle that provides the physician with a core moral stance for resolving ethical dilemmas. Striking features are the presence of contradictions among the codes and the controversial nature of these central ethics.

Hippocratic Oath

Modern Western medical ethics has reiterated the central ethic of the Hippocratic oath into the twentieth century. The core ethic of the Hippocratic oath is the physician's pledge to do what he or she thinks will benefit the patient. This is repeated twice in the oath, once as applied to matters of diet, and once when referring to visits to the homes of patients.

The principle that the physician's first obligation is to do what the individual physician thinks will benefit the sick person is picked up in the Declaration of Geneva, where the physician swears, "The health of my patient will be my first consideration," and in the International Code of Medical

Ethics of the World Medical Association (WMA), which proclaims, "A physician shall owe his patients complete loyalty and all the resources of his science." Likewise, the postcommunist Russian oath has the physician pledge, in Hippocratic fashion, to work always for the patient's good (Solemn Oath of a Physician of Russia).

THE HIPPOCRATIC OATH'S INDIVIDUALISM. The first characteristic of the Hippocratic ethic is that it is individualistic; it concentrates only on the benefit to the individual patient. In contrast, classical utilitarian ethics of the tradition of Jeremy Bentham (1748–1832), John Stuart Mill (1806–1873), and G. E. Moore (1873–1958) would consider such a narrow focus on consequences for the patient to be ethically unjustified, unless it would serve the greater good of the greater number in the long run. They would consider benefits to all persons and to society as a whole. There is no evidence that the Hippocratic authors or their twentieth-century counterparts had such an indirect utilitarianism in mind. Rather, they seem to hold that the physician has a special ethical obligation to benefit his or her patient, independent of the net consequences for others who are not patients. The real test comes in cases in which the physician believes that one course will produce the most good in total, but another course will most benefit the patient. A physician who feels required to choose the course most beneficial to the patient is faithfully following the oath and rejecting the utilitarian alternative.

The American Medical Association (AMA), in its 1957 Principles of Medical Ethics, did not accept the Hippocratic individualism. It instructs the AMA physician that "the principle objective of the medical profession is to render service to humanity." The tenth principle made this interpretation unambiguous:

> The honored ideals of the medical profession imply that the responsibilities of the physician extend not only to the individual, but also to society where these responsibilities deserve his interest and participation in activities which have the purpose of improving both the health and the well-being of the individual and the community.

This focus on the community continued in the major revision of 1980. The last principle of that version is, "A physician shall recognize a responsibility to participate in activities contributing to an improved community" (American Medical Association, 1989, p. ix).

Here the AMA is closer to the now-abandoned Soviet physicians' oath of 1971 than to the Oath of Hippocrates. The Soviet physician more boldly swore "to work conscientiously wherever the interests of society will require it" and "to conduct all my actions according to the principles of the Communistic morale, to always keep in mind the high calling of the Soviet physician, and the high responsibility I have to my people and to the Soviet government." By contrast, the postcommunist Russian oath reverts to the pure Hippocratic focus on the good of the individual patient, abandoning any reference to the interests of the community or state (Solemn Oath of a Physician of Russia). The Criteria for Medical Ethics of the Ministry of Health of the People's Republic of China (1989) are actually closer to the postcommunist Russian oath and its Hippocratic ancestors by focusing on the interests of the patient. It lacks any appeal to the duty of the physician to the community that is seen in the AMA and the Soviet oaths.

THE HIPPOCRATIC OATH'S PATERNALISM. The central ethic of the Hippocratic tradition is also paternalistic. The physician is to benefit his or her patient "according to my ability and judgement" (Edelstein, 1943, p. 3).

Addressing the meaning of the injunction to protect the patient from mischief and injustice, Edelstein concludes that the oath means that "the physician must protect his patient from the mischief and injustice which he may inflict upon himself if his diet is not properly chosen" (Edelstein, 1943, p. 24).

This paternalism is also seen in the provision of the Hippocratic oath that medical knowledge is to be kept secret and not disclosed to people outside the Hippocratic group. A similar provision is seen in a sixteenth-century Japanese medical code called the Seventeen Rules of Enjuin, which actually required that, if a successor trained in the School of Enjuin could not be found upon retirement or death, the medical books of the school had to be returned to the school.

Physicians, according to Percival (1740–1804) (who also shared in this Hippocratic paternalism), should study not only tenderness and steadiness but also "condescension and authority, as to inspire the minds of their patients with gratitude, respect, and confidence" (Leake, p. 71). The AMA principles of 1957 and the 1959 British Medical Association (BMA) codes held that medical confidences could be broken if, in the judgment of the physician, it was in the patient's interest for them to be broken.

THE HIPPOCRATIC OATH'S FOCUS ON CONSEQUENCES. Finally, one sees the controversy of the Hippocratic patient-benefiting ethic when it is contrasted with other theories that can be called nonconsequentialist, that is, ethical theories in which certain principles are taken to be simply inherently right-making or where certain claims are taken to be "inalienable rights." Holders of views in which there are certain characteristics of actions that make them inherently tend toward being right (other things being equal) or holders of the view that certain things, such as life, liberty, and the pursuit of happiness, are "inalienable rights" would have to reject the ethic of doing what one thinks will benefit the patient. At least they would reject patient benefit in cases where benefiting the patient will be at the expense of fulfilling prima facie duties or respecting basic rights of the patient.

There may be a paradox in the Hippocratic oath. The physician is to do what he or she thinks will benefit the patient but is not to give an abortive remedy or a deadly drug and is not to "use the knife, not even on sufferers from stone." What is the physician to do who believes that giving a deadly drug or an abortifacient remedy, or using the knife, will benefit the patient? Perhaps this apparent contradiction is resolved by the belief of the Pythagorean physician that such actions can never be beneficial to the patient. In that case, the oath simply spells out some rules that guide the physician in deciding what will be beneficial. More likely, however, these actions are seen as inherently wrong even if they might be of benefit. If so, then the Hippocratic ethic abandons its consequentialism, at least for these cases.

Codes Written by Groups Outside the Medical Profession

Many of the more recent codes written by governmental and religious groups have not shown these characteristics of individualism, paternalism, and consequentialism. The Nuremberg Code (1947), one of the first codes relevant to medical ethics emerging in international law, could have addressed the problem of abuse of human subjects in medical research by retreating to Hippocratic individualism, thus making all use of subjects for purposes of gaining knowledge immoral (because, by definition, doing something for the pursuit of general knowledge is not acting for the purpose of benefiting the patient). It did not. Instead it acknowledged the legitimacy of physician participation in efforts to benefit society by doing research on human subjects. It introduced protections for those subjects by abandoning the exclusive focus on consequences—on producing benefits and avoiding harms—and replacing it with an ethic that speaks in terms of duties and responsibilities, including the duty to ensure that the subjects give their informed consent.

Other codes coming from governmental and religious sources adopted the language of rights as a way of signaling their break with the professional medical ethical traditions that focus exclusively on consequences. This focus on rights is influenced heavily by the tradition of the liberal political philosophy of John Locke, Thomas Hobbes, Jean Jacques Rousseau, and the authors of the Bill of Rights of the United States Constitution. It is a moral tradition significantly different from that of the traditional, professionally written medical codes.

The focus on rights and duties includes an emphasis on the right to give informed and voluntary consent not only for research but for all clinical, medical treatments. Consent, grounded in the moral principle of autonomy and the legal notion of self-determination, is totally absent from the classical codes written by medical professional groups. The introduction of the perspective of rights and duties, and the underlying moral notion of respect for persons (including the principle of autonomy), signals a rejection of both traditional Hippocratic paternalism and consequentialism. It also provides a way of moving away from pure individualism, incorporating a more social ethic without lapsing into a social utilitarianism that would completely subordinate the individual to the aggregate social good.

The first healthcare association that used the language of rights was the International Council of Nurses' Code for Nurses (1973, reaffirmed 1989). Still using gender-specific language, it nevertheless signaled a revolution in the philosophical orientation of professional codes when it said, "Inherent in nursing is respect for life, dignity and rights of man." This use of "rights" language also appeared in the American Nurses' Association (ANA) code revision in 1976, when it proclaimed (with more gender-neutral language), "Each client has the moral right to determine what will be done with his/her person." By making self-determination of clients its first principle, the ANA announced it was the first organization of healthcare professionals to abandon Hippocratic paternalism and exclusive focus on consequences. However, ambivalence persists; after announcing that self-determination is its first principle, it says that "the nurse's primary commitment is to the health, welfare, and safety of the client" (American Nurses' Association, 1985, p. 6). At this juncture, the nursing profession seemed unable to decide whether to abandon Hippocratic paternalism in favor of respect for rights of self-determination or remain Hippocratic.

The AMA followed this pattern in its 1980 revision. It begins to use rights language saying, "A physician shall respect the rights of patients, of colleagues, and of other health professionals" (American Medical Association, 1989, p. ix). It commits the physician for the first time to deal honestly with patients, reversing the long-standing, more paternalistic approach in which physicians were expected to withhold information when they believed it might harm the patient. Yet, it still proclaims the Hippocratic notion that the AMA's ethical statements are developed "primarily for the benefit of the patient," and not, apparently, to protect the patient's rights.

Specific Ethical Injunctions

The strictures against abortion, euthanasia, and surgery in the Hippocratic oath are examples of specific injunctions that occur from time to time in the codes and oaths of medical and physician ethics. Code-by-code comparison of these injunctions reveals interesting differences. The conflict among the codes on the question of confidentiality is perhaps the most dramatic.

CONFIDENTIALITY. The Hippocratic injunction on breaking confidentiality is sometimes taken to forbid breaking medical confidences. The text is really much more ambiguous. It says, "Whatever I may see or hear in the course of treatment in regard to the life of men, which on no account one must speak abroad, I will keep to myself holding such things shameful to be spoken about." The individual physician, however, is left with the question of just which things he or she hears "on no account must be spoken abroad." Possibly physicians are to use the "patient-benefiting" criterion for deciding when breaking the confidence is appropriate. That was the explicit principle in the 1959 version of the BMA code, which said:

> The complications of modern life sometimes create difficulties for the doctor in the application of this principle of confidentiality, and on certain occasions it may be necessary to acquiesce in some modification. Always, however, the overriding consideration must be the adoption of a line of conduct that will benefit the patient, or protect his interests.

The World Medical Association's International Code of Medical Ethics (1949, amended 1968 and 1983) and the Declaration of Geneva (1948, amended 1968 and 1983) both close any such patient-benefiting loophole in the confidentiality principle. They simply require "absolute secrecy," much as did the ancient Jewish Oath of Asaph. No exception is considered even in a case where the physician has learned that the patient is about to commit mass murder. The Ethical and Religious Directives for Catholic Health Facilities (1975) is almost as blunt. It requires that

> professional secrecy must be carefully fulfilled not only as regards the information on the patient's charts and records but also as regards confidential matters learned in the exercise of professional duties.

In keeping with their more social commitment to the welfare of others as well as the patient, the now outdated 1957 American Medical Association Principles (1957, revised 1971), and the American Psychiatric Association's (1973), which were based on them, were quite explicit in providing three exceptions to the general principle of confidentiality:

> A physician may not reveal the confidences entrusted to him in the course of medical attendance, or the deficiencies he may observe in the character of his patients, unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the society.

Confidences could be broken not only when the physician thought it would benefit the patient but also when he or she thought it would benefit society or when it was required by law, for example, informing the police of a bullet wound incurred in a crime. The ethical problem of such broad exceptions, of course, is not only the paternalism of the patient-benefiting exclusion but also the potential subordination of the patient's interests and rights to the interests of the society.

The BMA was confronted by a particularly difficult case in which the physician disclosed to the parents of a sixteen-year-old that she was taking birth-control pills. He defended the breaking of the confidence on the grounds that he thought it was for her benefit. Since this was explicitly permitted by the BMA code at the time, the General Medical Council acquitted him of the charge of unprofessional conduct. After that case, the BMA in 1971 amended its confidentiality principle and became the first to recognize the patient's right to confidence in cases where the patient and the physician disagreed. The new position stated that "if, in the opinion of the doctor, disclosure of confidential information to a third party seems to be in the best medical interest of the patient, it is the doctor's duty to make every effort to allow the information to be given to the third party, but where the patient refuses, that refusal must be respected."

However, in the years that followed, the BMA's position seems to have reverted to a modified version of the old policy permitting disclosures "if it is in the patient's own interest that information should be disclosed but it is either impossible, or medically undesirable in the patient's own interest, to seek his consent" (British Medical Association, 1988, p. 21). The BMA also has added a provision permitting disclosure for social purposes when it is necessary to safeguard the national interest or when the doctor has an "overriding duty to society."

ABORTION. On the controversial subject of abortion, groups authoring codes have followed the ethical stances of their subcultures. The Hippocratic oath follows the Pythagorean prohibition on abortion, even though abortion was not considered unethical in the broader Greek culture (Edelstein, 1943). In the Oath of Asaph, the early medieval Jewish medical initiate is instructed, “Do not prepare any potion that may cause a woman who has conceived in adultery to miscarry.” The 1975 Ethical and Religious Directives for (U.S.) Catholic Health Facilities follow, consciously and precisely, a traditional, theological explanation of official church teaching, devoting seven of forty-three principles to the subject. Directly intended termination of pregnancy before viability is never permitted nor is the directly intended destruction of a viable fetus. Treatments not intended to terminate a pregnancy but which nonetheless have that effect are permitted, provided there is a proportionately serious pathological condition of the mother and the treatments cannot be safely postponed until after the fetus is viable.

When the cultural base of the group writing the code is very broad, the code is predictably less specific about the ethics of abortion. The Declaration of Geneva said, “I will maintain the utmost respect for human life from the time of conception,” without directly prohibiting abortion. Its 1983 revision softened the position even further, changing “from the time of conception” to “from its beginning” (Declaration of Geneva, 1948, amended 1968 and 1983). The WMA’s International Code in its draft, but not in its finally adopted form, stated, “Therapeutic abortion may only be performed if the conscience of the doctors and the national laws permit.” The American Nurses’ Association (ANA), which also represents individuals with a wide variety of viewpoints, similarly avoids direct comments. In its code, revised in 1968 and in effect prior to the 1976 revision, the ANA says that “the nurse’s respect for the worth and dignity of the individual human being extends throughout the entire life cycle, from *birth* to death” (italics added). The implication may be that fetal life is not included. A 1966 statement approved by the ANA Board of Directors recognizes “the right of individuals and families to select and use such methods for family planning as are consistent with their own creeds and mores,” again appealing to individual conscience. Is the combined implication a toleration of the nurse’s participation in abortion?

EUTHANASIA. An explicit obligation to preserve life is strikingly absent from the codes of ethics, both professional and public. In light of a widely held view that the duty, or one of the duties, of the physician is to preserve life, one would expect to find this duty emphasized. The only explicit, well-known reference is the weak formulation in the International Code (1949, amended 1968 and 1983), which says that “a physician shall always bear in mind the obligation of preserving human life.” This obligation to “bear in mind” rather than explicitly attempt to preserve life is a very soft injunction, especially when combined with the patient-benefiting principle the code emphasizes.

Proscribing active killing is much more common in the codes, as might be expected from the general ethical prohibition on active killing, even for mercy, in many cultures and subcultures. The Hippocratic oath’s formula is, “I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect.” Interpretation of this prohibition is controversial. Some take it to forbid any criminal, malevolent homicide. What seems more likely, however, is a prohibition against merciful killing or assisting in suicide. While suicide, especially in the face of medical suffering, was not uncommon in ancient society, it was forbidden by the Pythagorean cult. This fact is cited by Edelstein in his defense of the hypothesis that the Hippocratic oath is a Pythagorean document (1943). According to the *Caraka Samhita,* acts “causing another’s death” were one of the few things the Indian medical student should not do at his teacher’s behest. The oath of Asaph instructs the Jewish medical student to “take heed that you not kill any man with a root decoction.”

In the professionally written codes or those of the Catholic church, however, the prohibition against assisting in an act of killing has never been extended to apply to cooperating in withdrawal from treatment. The distinction between active killing and withdrawal of certain treatments is clear in the Ethical and Religious Directives for Catholic Health Facilities, according to which “the directly intended termination of any patient’s life, even at his own request, is always morally wrong,” and “euthanasia (‘mercy killing’) in all its forms is forbidden.” The directives go on, however, to say that while “failure to supply the ordinary means of preserving life is equivalent to euthanasia … neither the physician nor the patient is obliged to use extraordinary means.” Nor is it considered euthanasia “to give a dying person sedatives or analgesics for the alleviation of pain, when such a measure is judged necessary, even though they may deprive the patient of the use of reason, or shorten his life.”

The AMA states in its Judicial Council Opinions that “the physician should not intentionally cause death” (American Medical Association, 1989, p. 13). At the same time, it acknowledges the legitimacy of forgoing life-sustaining treatment in accord with the preferences of the patient or surrogate. The postcommunist Russian oath, following the original Hippocratic language, commits the Russian physician never to give a deadly drug.

The distinction between active killing and forgoing treatment is made clearer when rights language is used, as in A Patient's Bill of Rights (1973), written under the auspices of the American Hospital Association. That document proclaims that "the patient has the right to refuse treatment to the extent permitted by law," presumably even if the result will be the death of the patient. However, there is clearly no corresponding right to drugs that will actively hasten death.

TRUTH-TELLING. One conspicuous conflict between the patient-benefiting principle and the more deontological ethical theories is over the question of what one ought to tell a dying patient. Historically, many of the professional codes are simply silent, presumably expecting the patient-benefiting principle to apply. The Indian oath of the *Caraka Samhita* is explicit: "Even knowing that the patient's span of life has come to its close, it shall not be mentioned by thee there, where if so done, it would cause shock to the patient or to others." The 1847 version of the AMA code instructs: "A physician should not be forward to make gloomy prognostications … but he should not fail, on proper occasions, to give to the friends of the patient timely notice of danger, when it really occurs; and even to the patient himself, if absolutely necessary." The violation of confidentiality in communicating to family or friends before informing patients either is not noticed or is justified on patient-benefiting grounds. Using the patient-benefiting principle as a basis for withholding the truth is traditional in professional physician ethics. The 1847 code makes the grounding explicit: "It is, therefore, a sacred duty … to avoid all things [that] have a tendency to discourage the patient and to depress his spirits."

The latent paternalism that justifies withholding information from patients for their own good is retained even in the period after 1980 when the AMA principles themselves pledge unqualified honesty. In the AMA Council on Ethical and Judicial Affairs' interpretation, an exception can be made to the requirement of informed consent "when risk-disclosure poses such a serious psychological threat of detriment to the patient as to be medically contraindicated" (American Medical Association, 1989, p. 32).

Even the authors of "A Patient's Bill of Rights" seem to yield to the paternalistic patient-benefiting principle when it conflicts with the patient's right to know. The bill first states that "the patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand." But it then qualifies this by stating, "When it is not medically advisable to give such information to the patient, the information should be made available to the appropriate person in his behalf." The potential conflicts of such an exception with the right to privacy or the right to receive information necessary for informed consent are not discussed. By contrast, U.S. courts and many codes generated outside the Hippocratic tradition insist that information be adequate for the patient to make a self-determining choice, even if that information is potentially upsetting.

JUSTICE IN DELIVERING HEALTHCARE. Many of the codes of physician and other medical ethics have some reference to the duty to deliver healthcare justly or equitably. The Hippocratic oath uses a term, *adiki'e,* often translated into English as "justice," but it really means "wrongdoing" more generally; it does not refer to equality of treatment or equitable distribution of benefits. The statement in the Hippocratic oath that physicians must abstain from sexual relations with males and females, free and slave, during a medical visit is as close as the text comes to a pledge of equal treatment.

The ancient Chinese medical ethical codes are much more far-reaching in emphasizing equal treatment of rich and poor. The commandments written by Chen Shi-Kung, a seventeenth-century physician, include the explicit commitment that "physicians should be ever ready to respond to any calls of patients, high or low, rich or poor."

Equality of access seems generally recognized as an ideal in many modern codes even if it is absent in the Hippocratic original. The twentieth-century Declaration of Geneva holds forth this ideal: "I will not permit considerations of religion, nationality, race, party politics, or social standing to intervene between my duty and my patient." The American Nurses' Association code declares, "The nurse provides services with respect for the dignity of man, unrestricted by considerations of nationality, race, creed, color, or status." The AMA recognizes that society must make decisions regarding the allocation of limited healthcare resources and urges that they be allocated on the basis of "fair, socially acceptable, and humane criteria." At the same time, it emphasizes that the physician's duty is "to do all that he can for the benefit of his individual patient" (American Medical Association, 1989, p. 3). The postcommunist Russian oath, by contrast, pledges never to deny medical assistance to anybody and to provide care with equal diligence to patients regardless of means or national or religious affiliation.

The Ethics of Professional Relations

In contrast with the lay or public codes or bills of rights, virtually all professional codes devote significant attention to relationships among professionals. The Hippocratic oath begins with a covenant by which the new physician pledges "to hold him who has taught me this art as equal to my parents and to live my life in partnership with him, and if he is in need of money to give him a share of mine, and to regard his offspring as equal to my brothers in male lineage and to take them this art—if they desire to learn it—without fee and covenant." It includes a pledge to keep secrets, much as any initiation ritual into a cult might.

The longest of the three sections of the AMA code of 1847 is devoted to "the duties of physicians to each other and to the profession at large." Since many of the codes emerged at a point historically when the profession was separating itself from others claiming to offer treatments and cures, there is often, even to modern times, strong language forbidding association with those not properly members of the group. The American Osteopathic Association, for instance, requires that a physician "shall practice in accordance with the body of systemized knowledge related to the healing arts and shall avoid professional association with individuals or organizations which do not practice or conduct organization affairs in accordance with such knowledge."

In terms of the sociology of the professions, it has been suggested that restraints on advertising, rules structuring referral of patients, instruction on the ways of handling an incompetent member of the profession, or exclusion of those not properly initiated into the profession have important functions in maintaining the professional monopoly. Apart from their role in protecting professional interests, however, it is also pertinent to analyze them as sets of ethical obligations.

Three different kinds of ethical arguments may underlie the detailed formulations of professional obligations to other professionals. First, such duties to one's colleagues may be defended on what could be called "universal" grounds. That would be the case if the ethical principles claimed as the foundation of such intraprofessional obligations are principles generally recognized by all persons. For instance, the AMA code of 1847 states detailed rules regarding professional consultation prohibiting "exclusion from fellowship" of duly licensed practitioners and requiring punctuality in visits of physicians when they hold consultations as well as secrecy and confidentiality so that the patient will not be aware of consultants' disagreements. These standards for consultation are defended on the grounds that "the good of the patient is the sole object in view." Although it is not generally argued, there is a presumption that rational patients should accept this principle. We have seen, however, that the principle of patient benefit is quite controversial when put up against competing ethical principles.

A second foundation for intraprofessional duties might be a special ethic for a special group, which nonmembers would not be expected to share or even understand. This would be the case, for example, if the profession is viewed as a kind of club or fraternity that invents its own norms and applies them only to its own members. The ethic of a profession is in part the ethic of fraternal loyalty, of special obligation to one's adopted brothers. The professional obligation may be seen deriving from the professional nexus rather than from some more universal source. It is a special ethic of a special cult.

The ethic of the AMA's 1847 code, like the ethic of the code written by Percival, is an ethic of dignity and honor among gentlemen: "There is no profession, from the members of which greater purity of character and a higher standard of moral excellence are required, than the medical." The discussion of duties of physicians to each other begins with the admonition that "every individual, entering the profession, as he becomes thereby entitled to all its privileges and immunities, incurs an obligation to exert his best abilities to maintain its dignity and honor, to exalt its standing, and to extend the bound of its usefulness." The text goes on to entreat the physician to avoid "all contumelious and sarcastic remarks relative to the faculty, as a body; and while by unwearied diligence, he resorts to every honorable means of enriching the science, he should entertain a due respect for his seniors, who have, by their labors, brought it to the elevated condition in which he finds it."

This gentlemanly ethic of honor and purity (the Hippocratic phrase is "purity and holiness") gives rise to special ethical burdens for the medical profession that the layperson cannot be expected to grasp. Professional "courtesy" (gratuitous services for practitioners, their wives, and their children) should probably be understood in these terms. "Courtesy" is an ethical expectation for members of the brotherhood.

A third possible foundation confounds the two. It could be that professional duties are defended as being in the public interest (or in some other manner consistent with a more universal ethic), but that only members of the profession can be expected to understand this to be so. Advertising, for instance, could be attacked, as it is in the AMA's 1847 code, as "derogatory to the dignity of the profession," but it is defended as necessary to separate the profession from "the ordinary practices of empirics." The authors might well hold that it is really in the public interest that the separation be made, but also concede that only members of the profession could see the necessity of that separation.

If there are special ethical obligations for members of the profession that in principle cannot be recognized from outside the professional group, it follows that there are likely to be conflicts between the profession's formulation of its ethical obligation and the broader public's formulation. The issue is not the existence of different ethical responsibilities attaching to different roles, but rather a disagreement between the profession and the broader public over what constitutes the proper behavior of the professional in his or her specific professional role. Even if a profession agrees that it has a special duty to preserve life or limit advertising, it is still an open question whether the public wants physicians always to act on that norm. If the professional group holds that there is a special professional source of norms, then conflict is predictable.

A specific example of such conflict involves the ethics of advertising. Many professional codes, in the manner of the 1847 AMA code, prohibit or restrict advertising by members of the profession. The 1957 Principles of Medical Ethics of the AMA claim that "this principle protects the public from the advertiser and salesman of medical care by establishing an easily discernible and generally recognized distinction between him and the ethical physician." While such prohibitions on advertising might be seen as the behavior of a cartel restraining price competition, it is also possible that physicians really believe that they are engaged in a service that must not be peddled as a commodity. Whether the medical profession sees such advertising as unethical or not, the public may see restraint on advertising as unethical. At stake are not only two different perceptions of ways to maximize benefits to potential patients, but also two sources of ethical norms—one from within the professional nexus and the other from the broader society. In this regard, an important transition occurred when the committee responsible for the 1980 revision of the AMA principles acknowledged that increasingly the public will be determining the norms for moral conduct in the lay–professional relationship.

Conclusion

The codes, oaths, prayers, and bills of rights derive from disparate contexts, representing differing professional groups, public agencies, and private, lay organizations such as churches and patients' groups. It is not surprising that radically different ethical conclusions are reached and that they are based on radically different fundamental ethical theories and methods of ethical reasoning.

One critical problem faced by health professionals as well as laypeople is what ethical directives should be decisive when an individual professes identification with more than one group. A health professional may also be a member of a religious or cultural group that has an ethical framework relevant to the moral problems faced by the individual. For example, if the ANA position can be interpreted as endorsing the nurse's tolerance of a woman's right to choose abortion, what is the Catholic nurse to do, or what is a nurse who works in a Catholic health facility to do if he or she believes in the right of the individual to select methods for family planning? These conflicts for individuals who are simultaneously members of more than one group, each of which has authored a code, arise for many ethical issues in healthcare. Moreover, individuals may reach conclusions of conscience that fail to conform to any codes of ethics whether written by healthcare professions or by religious, cultural, or governmental groups. An active understanding of the ethical differences among these codes is needed to begin developing a response.

ROBERT M. VEATCH (1995)

SEE ALSO: *Abortion; Autonomy; Beneficence; Confidentiality; Competence; Human Dignity; Medical Ethics, History of; Principalism; Profession and Professional Ethics; Virtue and Character;* and other *Medical Codes and Oaths* subentries

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MEDICAL EDUCATION

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When this subject was addressed in the first edition of this encyclopedia, the paucity of systematic analyses of the ethical issues peculiar to medical education was underscored (Pellegrino, 1978). In recent years, this deficiency has gradually been redressed, so that today, a considerable body of literature is available. This entry is therefore a substantial revision of the first. The emphasis has shifted from underlying values to more specific, normative issues, particularly in clinical education.

Ethical issues arise in medical education because of the special societal role of medical schools, the necessary intermingling of patient care with education, and the conflicts that may arise because of the obligations among students, patients, faculty members, and society. Similar ethical issues are present in the education of nurses, dentists, and the allied health professions.

The Social Mandate of Medical Schools

Medical schools occupy a unique moral position in society. They are mandated to meet society's need for a continuous supply of competent practitioners who can care for the sick and promote the public's health. For this reason, medical schools are supported as loci for the advancement and transmission of medical knowledge and are granted authority to select who shall study medicine, what shall be studied, and what standards of performance shall be established.

To achieve these goals, medical schools require certain special privileges, for example, to dissect human bodies, to provide "hands on" practical experience for students in the care of sick people, and to conduct human experimentation. These practices would be criminal were they not socially mandated for a good purpose. When medical schools, students, and faculty avail themselves of these privileges, they enter an implicit covenant with society to use them for the purposes for which they are granted.

To fulfill this social covenant, medical schools and their faculties must perform a tripartite function with respect to medical knowledge: 1) they must preserve, validate, and expand it by research; 2) transmit it to the next generation by teaching; and 3) apply it by practice in the care of the sick. However, these three functions have different aims. The aim of research is truth that requires dedication to objectivity, freedom of inquiry, rigorous design, as well as peer review and publication. The aim of teaching is learning that requires dedication to student welfare, competent pedagogy, and opportunities for students to practice their skills. The aim of practice is the welfare of the patient that requires dedication to compassion, competence, and ethical concern for the vulnerability, dignity, and autonomy of the sick person.

In the past, these three functions were less often in conflict with each other than they are today. This conflict is the result of several factors in the evolution of medical education since the late nineteenth century. The first factor is the realization of the power of the physical and biological sciences to advance medical knowledge and their integration into medical education. Second is the incorporation of teaching hospitals into medical schools for the clinical education of medical students (Flexner). Third is the increasing reliance on practice income to support salaries of medical teachers. Previously, teachers had been self-supporting practitioners from the community, while only a few were university-funded full-time teachers. Today's "tenure track" clinical faculty member is expected to excel in research, to support himself or herself financially through practice and overhead cost recovery from grants, and to teach at the bedside. Each function has its own legitimacy, but taken together, these functions conflict with each other.

Ethical Obligations of Medical Schools

The ethical obligations of medical schools as societal entities are defined in terms of the constituencies they serve: society, faculty, student body, and patients (Pellegrino, 1976).

Medical schools have been granted a virtual monopoly over the number of students they admit and the number of training places in the various specialties in teaching hospitals. Medical schools are the sole portal into the practice of the profession and, as a result, medical schools incur a responsibility to match the kind and number of physicians they produce with the needs of society. This requires a socially responsive appraisal by medical schools of the way resources are used and curricula are designed, as well as how faculty rewards are distributed. Societal aims sometimes can, and do, conflict with a medical school's pursuit of esteem among its peers, which usually comes not through renown in teaching or the quality of practitioners it produces, but excellence in producing research and academic leaders.

Another important obligation of medical schools is to ensure that graduates are competent to enter postgraduate training and are free of obvious traits of character that would make them dangerous practitioners. Today, most of those admitted to medical school graduate and obtain licenses. Few fail, particularly in the clinical years. This places an obligation on medical schools to evaluate not only a student's knowledge and skill, but some facets of his or her character as well. Close supervision by clinical teachers is mandatory if dubious character traits are to be detected. Educators must balance fairness in their evaluations of students against their obligations to protect future patients from unsafe or dishonest practitioners.

Another societal responsibility of medical schools is to ensure equal opportunity for admission to all qualified students. Despite early progress, there is recent evidence of retrenchment in the support, financial and otherwise, available for minority student recruitment in the United States and in Great Britain (Hanft and White; Esmail and Everington). Subtle forms of discrimination probably still exist in the interview process where it is difficult to detect and prove (Connolly). Gender discrimination and sexism are no longer legally tolerable, but remain a persistent social problem (Hostler and Gressard). Academic administrators and faculty members are morally obliged to ensure equitable treatment of all applicants and must assume collective responsibility for inequities and injustice. In doing so, medical schools must thread their way carefully through an ethical maze of competing claims for preferential treatment and reverse discrimination.

Ethical obligations exist in the relationship between medical schools and faculty members. Faculties are owed freedom of inquiry in research and teaching, justice in hiring, tenure, promotion, compensation, and redress for injury or grievances. Faculty members in turn are morally responsible for the quality of their instruction, for fairness in the evaluation of students, and for properly apportioning their time and effort between teaching and personally remunerative activities such as clinical practice and consultation. Imbalance among these activities compromises the societal responsibilities of a medical faculty.

Faculty and administration are therefore obligated to detect inadequate teachers and to rehabilitate and reassign them or terminate their appointments when necessary. Tenure is among the most privileged benefits of academic life. The obligation to use it responsibly rests squarely on faculty members and administrators.

Incidents of scientific fraud, abuse of consulting and travel privileges, and conflicts of interest are cause for legitimate public concern. While the number is small, such abuses by faculty members invite external limitations and regulation of privileges that can interfere with the educational mission. The ethics of medical academia cannot be a private matter since the moral behavior of academics affects students, patients, the use of public funds, and the quality of fulfillment of the medical school's covenant with society.

Some Ethical Issues Peculiar to Clinical Education

The ethical issues outlined thus far are particular only in part to medical education. What is unique is the medical school's engagement in clinical education, i.e., in providing "hands on" experience for students in the actual care of patients. It is here that serious conflict may arise between patient care and student learning.

Physicians since Hippocrates have taught their students from actual cases. Usually, this was accomplished by preceptorship with a practicing physician or by case demonstrations to entire classes of students. In the mid-nineteenth century, it was a rare school that incorporated more intimate involvement in the care of patients in its teaching (Ludmerer). Toward the end of the same century, William Osler involved students more directly as clinical clerks at the Johns Hopkins Hospital, where they " … lived and worked … as part of its machinery, as an essential part of the work of the wards" (Osler, p. 389). This practice lagged in other schools until the reform of education in 1910 (Ludmerer). Since then, however, it has become standard pedagogic practice.

Today, clinical education centers on practical experience under supervision at every level, from medical school through postgraduate specialty training to lifelong continuing education. Until recently, the merits of this training have been so much taken for granted that the ethical conflicts inherent in the process have been neglected (Fry; Pilowski).

Clinical education by its nature unavoidably puts the aims of caring for patients into potential conflict with the aims of teaching and learning. The involvement of medical students, interns, and residents in patient care slows the process of care, increases its discomforts and fragmentation, and, at times, poses significant danger to the patient. With close supervision by experienced clinical teachers, these potential conflicts are tolerable. The clinical teacher therefore carries a double responsibility for balancing the quality of his or her pedagogy with the quality of patient care.

The moral status of medical students is ambiguous. They are physicians in utero, that is, in a developmental state of competence to provide care. When they enter medical school they are laypersons. When they graduate they are physicians, still in need of further training before they can become safe and competent practitioners. During this process, they take on progressive degrees of responsibility associated with the privilege of caring for patients, although their capacity to fulfill that responsibility is limited.

Patients come to university hospitals primarily to receive optimal treatment, not to be subjects of teaching. They may understand in a general way what being in a teaching hospital means. This in no way suggests, as some assume, that patients give implicit consent to become "teaching material." Patients in teaching hospitals preserve their moral right to know the relative degrees of competence of those caring for them. They have a right to give informed consent to any procedures and to know whether an untrained or partially trained person will perform that procedure. When unskilled students participate in procedures, patients are owed appropriate supervision by someone of significantly greater competence who can protect their safety.

Medical students, therefore, should disclose the fact that they are students to avoid the attributions of knowledge and trust patients still associate with anyone bearing the title "doctor" (Greer; Ganos; Brody; Liepman). They should be introduced as students by their supervisors before procedures like spinal taps and chest taps are performed. For their part, students as well as their supervisors must thoroughly acquaint themselves with the procedures in question and must observe a sufficient number performed by experienced clinicians. Students are under an obligation to refrain from conducting a procedure until these requirements are met and to resist the "see one, do one" philosophy of some clinical teachers. They must also receive instruction on how to obtain a morally and legally valid consent (Johnson et al.).

Students must also be sensitive enough to discontinue even the simplest procedures, such as a venipuncture, if their efforts cause discomfort (Williams and Fost). These injunctions are particularly important in highly personal and sensitive situations such as learning to do vaginal or rectal examinations (Bewley et al.; and Lawton et al.).

Medical students also face problems of personal ethical integrity with respect to abortion, treating patients with acquired immunodeficiency syndrome (AIDS), and attitudes toward the poor (Christakis and Feudtner; Dans; Crandall et al.; Currey et al.; Holleman). They may observe unethical or unacceptable behavior of teachers or colleagues (Morris). The extent of their responsibility and the real possibility of punitive treatment if students "blow the whistle" is a difficult, unresolved, but genuine ethical issue. Students may cheat on exams or see others do so (Rozance; Stimmel). By virtue of their presence at the bedside as members of the "team," they may be drawn prematurely into advising about the ethics of other colleagues. Helping students to deal with these moral dilemmas poses a new challenge to students and to their clinical teachers. This is a crucial part of the ethical maturation of the student (Drew; Andre; Wiesemann).

Two final examples of recently debated ethical dilemmas center on the moral status of dead human bodies and of animals of other species similar to humans. To what extent may recently dead human bodies be used to teach intubation, resuscitation, and tracheostomy? Who can, or should, give permission? May it be presumed? Is it necessary at all (Benfield et al.; Iserson)? Are the moral rights of other animal species to be considered so that they never or rarely should be used in teaching or research? Do computer models or tissue and cell preparations adequately replace animal experimentation?

Conclusion

Despite the sanction society gives to clinical education, there are important ethical obligations that limit this privilege. In no sense can learning by practice be a "right" of medical students or medical schools no matter how high the tuition or the degree of social utility. The privileges of clinical education cannot be bought at any price by the student, or granted even for good purpose by the medical school. Only a social mandate can legitimize the invasions of privacy a medical education entails.

The ethical issues of clinical education have just begun to receive the ethical scrutiny they deserve. Fundamental conceptual issues like the moral status of medical students, dead bodies, and animals are coupled with very practical issues regarding student–faculty and student–patient relationships. Clearer guidelines are needed to deal with the ethical issues characteristic of clinical education. We can expect the literature on this topic to expand in size, sophistication, and importance in the immediate future.

EDMUND D. PELLEGRINO (1995)

SEE ALSO: *Clinical Ethics; Competence; Conflict of Interest; Dentistry; Ethics; Family and Family Medicine; Informed Consent; Nursing Ethics; Profession and Professional Ethics; Race and Racism; Sexism; Virtue and Character; Whistleblowing*

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MEDICAL ETHICS, HISTORY OF AFRICA

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I. Sub-Saharan Countries
II. South Africa

I. SUB-SAHARAN COUNTRIES

The geographic region of sub-Saharan Africa includes all the African countries immediately below the Sahara Desert, together with all the associated island states but excluding the Republic of South Africa. Although the latter is within the region, it is excluded from this text in view of the heavy influence that apartheid exerted on indigenous African cultures. All the countries considered are bound by the Tropic of Cancer on the north and the Tropic of Capricorn on the south. In addition to a multitude of indigenous languages, the majority of the countries are either Anglophone or Francophone; five are Lusophone (Portuguese-speaking).

Medical ethics in sub-Saharan Africa is extremely complicated and cannot be considered homogeneous in any sense. This is because the vast geographic area (almost 23 million square kilometers, or about nine million square miles) contains forty-three independent countries with innumerable sociocultural groupings. Many of the countries are nation-states only superficially, since their borders enclose ethnic groups that have little in common with their fellow citizens, being more closely affiliated with groups in other countries. Quite apart from the matter of indigenous cultures, these countries were under the domination of European colonial powers that sought to impose their cultures upon local cultures. Some countries gained political independence only in the 1980s, and in some supposedly independent countries (Angola, Mozambique, Sudan) civil strife based on ethnic differences has raged throughout most of their independent period. The interaction between an externally introduced culture and a local one is more complicated in the field of medicine than in any other. The differences in urban-center development in East Africa and West Africa demonstrate the role that colonial power had in influencing cultural and ethical values (Larson).

Traditional and Scientific Methods

Some of the countries have had contact with scientifically based European medicine for less than 50 years, and others for little more than 100 years. The development of medical ethics in all the African countries has therefore tended to follow the existing European ethical values, principally those of France and Great Britain, the two dominant colonial powers. European medical professionals, faced with traditional African medical practice, took the position that all such medical practices and values, as well as their practitioners, were bad. Traditional African healers were considered no more than quacks and deceivers and therefore were either ignored or actively persecuted. Even the traditional midwives or “birth attendants,” as they are now known, who from time immemorial have provided help to women at a most difficult time, were looked upon with disfavor. To a certain extent such attitudes were underwritten by the beliefs and practices of the colonizers’ religion, Christianity. Since much of traditional healing relied on the intervention of gods and spirits, which Christians found abhorrent, the practice of traditional healing was strongly discouraged. Furthermore, European medical ethics required that European doctors not associate with practitioners whose training and beliefs differed from their own.

With the rise of black consciousness and the acceptance of the notion that blackness is not a sign of inferiority, African peoples have begun to reappropriate the medical knowledge gained over centuries by traditional medicine and medical practice. In some countries laws have been passed recognizing traditional medical practice as legal and effective. This process has been very slow. Many African medical schools still do not offer any instruction in traditional medicine, and where interest exists, it is only at a research level. Financial grants have been made for research into the methods and preparations of traditional medicine. In a few instances medical scientists are actively involved with traditional practitioners.

This new collaboration between traditional and imported medical practice is likely to be furthered by the indigenization of African churches and the improvement of the quality of their leadership. Previously, priests and ministers in the majority of churches had been inadequately trained, and they tended to assume a patronizing approach to their congregants. Now, a growing number can be considered well educated; some can even be viewed as theologians who are able to help formulate the churches' views on subjects of such crucial importance as the conflict between traditional and modern medical practice. Medical professionals in the majority of countries now feel relatively free to develop new ways of practice and to work with traditional birth attendants, herbalists, and other healers without fear of losing either the respect or the comradeship of colleagues in Europe.

Traditional and Western practices are seeing crossover training in the areas of psychiatry, childbirth, and grassroots education. Much of traditional medicine touches on the realm of psychiatry. Involvement of traditional practitioners in psychiatric treatment makes for a more humane treatment and much better integration of patients into society (Lambo). Among other efforts that may be cited is the involvement of the University of Ghana Medical School in training programs for traditional birth attendants. In many countries the medical schools (Makerere University in Uganda, University of Nairobi in Kenya, and University of Yaounde in Cameroon, for example) are striving to identify relevant practices within their own societies, such as use of peer groups to educate members of their societies on health-related issues. These medical schools are, therefore, embarking on programs that identify and preserve traditional practices considered valuable (Jelliffe and Bennett). In these programs, traditional practices considered harmless or beneficial are to be permitted, and those practices considered truly harmful are to be eliminated.

Standards for Medical Practice

Most English-speaking countries have general medical councils or boards responsible for registration, accreditation, and supervision of medical practice. In most of these countries the boards of control are generally quite distinct from the ministries of health (Kenya Government). Many of these medical councils or boards, however, have fashioned policies more responsive to western European norms and needs than to African ones. These boards have had little time to devote to the development of ethical guidelines relevant to social and cultural conditions peculiar to life within African countries. Some principles remain fundamental, however: Privacy of the patient is respected, and so is confidentiality, although here and there disclosure is required by the government for various reasons, including payment for medical service, granting of sick leave by employers, and mandatory registration of births and deaths.

Healthcare Service

There are very few scientifically trained medical personnel in Africa. The ratio of scientifically trained doctors to population ranges from 1:3,000 in such better-off cities as Dakar (Senegal), Accra (Ghana), and Nairobi (Kenya) to 1:200,000 in some poorer rural areas, such as most of the Northern Region of Nigeria and all of the immediate sub-Saharan countries including Mauritania, Mali, Burkina Faso, Niger, and Chad, which are sometimes referred to as the Sahel. There are countries within which there may not be a single specialist in any recognized field of medicine. This immediately raises the issue of what kind of medicine is most suitable in such conditions.

European medicine has developed and gained the reputation of being "one-on-one" medicine, and it also has concentrated more on curative than on preventive medicine. In Africa, on the other hand, the practice of one-on-one medicine, if it is accepted as the ideal, means excluding 80 to 90 percent or more of the population, who have no access to Western-oriented medical facilities. Such medical practice also places an inhuman load on the few medical practitioners and quickly reduces them to no more than purveyors of drugs and injections. Fendall sees this as the "quantity versus quality" dilemma, although not all agree with his view.

Doctors in Africa are now being asked to view their role in light of certain priorities—the first being promotive and preventive health services and the second being curative—in terms of individual patient treatment in offices or hospitals. In attempting to respond to the first priority, many have pointed out that not much can be done until medical practice is so arranged that the community is both the consumer and the provider of its own healthcare. This can be done only if delegation of healthcare to nonphysician personnel, such as traditional birth attendants and community leaders, is done on a basis of genuine need. The debate will continue, but almost all the new medical schools have agreed that doctors' training should be responsive to the needs of the community and to the organization and priorities set by ministries of health.

Many African countries depend on the use of paramedical personnel in the running of health services at the level of primary healthcare. Paramedics are often the only healthcare personnel available at this level. They include clinical officers, laboratory technologists, public-health technicians, environmental health officers, and various kinds of nurses. They are usually trained at medical training colleges, which are non-university, diploma-awarding institutions established in countries including Zambia, Kenya, and Tanzania. Apart from the nurses, who take an oath at graduation, paramedical personnel are not subject to any ethically binding oath. This cadre of personnel has on occasion been the source of breaches of confidentiality.

Pharmacies and pharmacists, too, have presented new dilemmas to medical practice in Africa. The regulation of the drug supply has been the prerogative of the ministries of health and their relevant licensing bodies. In keeping with the increased number of university-trained pharmacists, there is increased licensing of private pharmacies, especially in Zaire, Kenya, Cameroon, and Nigeria. Pharmacists regard themselves as trained "doctors" and dispense drugs without prescription, including drugs that have previously required doctors' prescriptions. Pharmacies also may dispense inactive drugs or drugs that have no relevance to the patient's illness (World Health Organization, 1992).

The Ethics of Educating and Remunerating Doctors

Medical education has had to contend with the issue of "excellence versus quantity" in the training of doctors. Most African medical schools have felt it necessary to enroll students of the highest possible scientific caliber and to train them to internationally accepted standards. (These students are chosen based on their national high school final examination results.) The result has been that very few doctors can be graduated in any given year; but much more important, in many countries the best and sometimes the only available scientific skills are channeled into medicine, depriving other socially important areas of potential contributors. This is an ethical issue of considerable importance. In the end, many of the doctors produced choose to become specialists who can practice medicine only where they find quite sophisticated support facilities and services. Frequently they serve existing hospital needs rather than those of preventive medicine. The frustration and wastefulness of this situation underscore one of the major ethical issues on the African medical scene.

Doctors' fees have been the subject of debate in many African countries. Poverty is a major socioeconomic problem in all the countries of sub-Saharan Africa. Civil wars, political instability, ethnic violence, drought, and famine have transformed millions of already poor individuals into refugees who have fled across borders. In the midst of extensive poverty, charging fees for care raises serious ethical questions. In most of these countries, physicians are employed by the government and are not supposed to charge fees for their services. However, government pay schedules have not kept up with the cost of living, and many government doctors engage in private practice to supplement their salaries. In the late 1980s, the Kenya Medical Association considered fee schedules that would charge standard amounts for various services, without waivers or reductions for the poor. Objections were raised, and the schedule was not adopted. In Ghana, attempts have been made to adjust doctors' salaries to costs of living. In general, the costs of physicians' services, drugs, and hospitalization amid such serious deprivation deserve serious ethical scrutiny.

Population, Family Planning, and Abortion

Population control as advocated in the Western world unfortunately has blurred the issues of family planning and led to a debate that should have been completely unnecessary. There are two basic concepts in family planning. The first is to regulate total family size to a level that can be comfortably maintained using the available resources. The second is to space the intervals between pregnancies in order to promote the health of both mothers and children (King). Many African countries rightly consider themselves underpopulated. Some, such as Gabon, Cameroon, and the Central African Republic, want much larger populations. All feel that they need development for the benefit of their people; but with very few exceptions, they refuse to admit that curbing population growth is relevant to the need for increased development.

Unfortunately, some doctors have failed to recognize the doctor's role in articulating relevant issues in family planning. Many doctors seem not to understand the medical importance of postponing pregnancies until a woman is biologically most prepared and of helping to stop reproduction when biological factors are no longer in a woman's favor. They also fail to recognize that spacing of births—which used to be practiced in Africa based either on sexual abstinence or on a geographic separation of husband and wife—is necessary to ensure the health of both mother and child. The excessive mortality in childbirth for women fourteen to forty-five years of age has not been fully appreciated by most of the medical profession in Africa (World Health Organization, 1975). Even where this situation is recognized, continued adherence to inappropriate laws and practices imposed from Europe often means that family-planning services are withheld from the majority of the population in need. The Catholic church, through its influence in the French-speaking countries, did much to prevent medical leadership in family planning. French laws passed in 1920 prohibiting contraception are still on the statute books of many French-speaking African countries, despite their repeal by France and Mali in 1972 (Wolf).

In the field of contraception, the major ethical question the doctor faces is, therefore, whether he or she should encourage free provision of contraceptives by nonmedical personnel, knowing that Europe and the United States, which are the sources of these supplies, require that they be dispensed almost exclusively by doctors. The doctor must weigh the possibility of breaking outdated laws against the results of withholding such supplies from populations that have no other source.

Other serious ethical questions are raised in providing contraception to women who are not married, according to the traditional norms prevailing in their locality, or who want to practice contraception without the knowledge of their regular partner. Yet so tenuous are some of the marital relationships, so difficult is it to get some husbands into a hospital or family-planning clinic, that insistence on consent by both parties might, in the end, do an injustice to the woman. Physicians must resolve this ethical dilemma within their own national frontiers.

African societies generally do not accept abortion because they value highly the continuity of lineage; the unborn child, for example, may be a reincarnation of an ancestor. However, it would be untrue to say that abortions were not known in Africa before the arrival of white colonizers. In many African cultures, pregnancies resulting from taboo relationships or from adultery are terminated generally by women and the men are kept in the dark.

The question of abortion is now debated seriously. Many of the abortion laws in Africa are based on those of England and France, which repealed them in 1967 and 1974, respectively. However, in the majority of former British and French possessions the old laws are still on the statute books. The increasing number of illegal abortions, with their consequent mortality, morbidity, and sterility, have still not prompted the collective conscience of medical practitioners to have the laws reviewed. Zambia did review its laws and amend them in 1973, but stipulations within the new law, particularly one that the approval of two medical practitioners is required, make it unlikely to serve the majority of those in need. The Africa Regional Conference on Abortion held in Accra, Ghana, in 1973 agreed to call for a review of the laws, but little has been done.

The doctors' dilemma regarding abortion is twofold. Despite the law, increasing numbers of women risk their lives by recourse to back-street abortionists. At the same time there are so few doctors to respond to such a wide range of needs that to make abortion laws more liberal may mean increasing the load on doctors still further. Given these problems, it is difficult to understand the view of some doctors in African countries that education, information, and services for fertility regulation should be limited.

Healthcare and Research in the Era of AIDS

The acquired immunodeficiency syndrome (AIDS), first recognized in 1981, has had the most profound impact on healthcare in Africa. Major concerns in healthcare provision are related to confidentiality, informed consent, counseling, research, drug therapy, serotesting, and care of the sick.

When AIDS was first identified as a major public-health problem and a rapidly spreading epidemic in Africa, many African governments reacted with violent denials. This behavior, which was attributed in part to the claim that AIDS originated in Africa, received support from some physicians and ministries of health. The early rapid spread of AIDS in Africa was partly a result of the fact that it was not acknowledged as a major public-health problem and thus received only slow governmental response (Ndinya-Achola).

Confidentiality and counseling are two components in AIDS-control programs that have received, at best, lip service in Africa. Counseling is an extension of preventive educational campaigns. At population levels these campaigns use information, education, and communication as their basic tools, and public-health officials as their main promoters. Counseling deals directly with the individual. The personal interaction between counselor and patient enables individuals to better understand their personal risks, to make informed decisions, and to take appropriate action.

Under ideal conditions, counseling is provided on a one-to-one basis and each case is dealt with on its own merit. Counseling also involves providing facilities that respond to the physical and emotional needs of the affected individuals and their loved ones. In Africa, AIDS counselors began to be trained in 1988; the needs of the society far exceed the number of counselors available. Much of the counseling that is provided is done by individuals who have no training. In many instances it amounts to informing an individual that he or she is infected with the AIDS virus; the healthcare provider is faced with the ethical question of whether to withhold information about the illness because there are no facilities to cater to individual needs.

Even where conditions are adequate and counseling facilities are available, confidentiality is a major issue because some of the trained counselors are not ethically bound to keep confidentiality. In particular, confidentiality is lacking in Africa for individuals diagnosed with AIDS. Counselors, however, are not the only healthcare providers ignoring confidentiality. Information regarding AIDS diagnosis often is leaked by hospital laboratory and other care staff.

Biomedical Research

Care for those with AIDS and drug therapy are two additional areas of major ethical concern. In many African settings the diagnosis of AIDS results in patient neglect because of the stigma attached to the disease. AIDS is a stigmatized disease in Africa mainly because the earliest information linked it to homosexuality, which is regarded as antisocial behavior in many parts of Africa. After it was ascertained that AIDS was being transmitted primarily by heterosexual contact, the homosexual stigma of AIDS lessened; but then AIDS became further stigmatized because of the rapid spread among heterosexuals by means of multiple sex partners and increased promiscuity. AIDS educational programs also had the inappropriate but true message that death is the final outcome. For these reasons, AIDS has had a negative impact on social interactions. Many people fear to be associated with a person with AIDS. This fear is evident even among professionals. Nurses have been a little more ethical in their approach to care of AIDS patients than physicians, perhaps because the nurses' increased contact with the patients makes them more sympathetic to the patients' plight.

During the early years of the AIDS epidemic, researchers from all over the world quickly identified populations in Africa for epidemiological studies (Van de Perre et al.; Kreiss et al.; Piot et al.). Clinical studies on drugs and vaccines are also being done. This research brings to the fore ethical questions about biomedical research in African countries that predated the AIDS epidemic: Should Western scientists do studies on populations that may never benefit from the results? Can appropriate informed consent be obtained in cultures that have different values? These questions are much debated within Africa and abroad (IJsselmuiden and Faden). Standards of research have been improved: Some medical journals, such as *East African Medical Journal,* insist that proof of informed consent be provided before articles are accepted; granting agencies in Europe and the United States require local ethical review before funding is provided; and local review boards are becoming quite strict.

One of the important contributions of biomedical research in AIDS is the development of antiretroviral drugs for treating infection caused by human immunodeficiency virus (HIV), the causative agent of AIDS. Although the available drugs do not currently offer a cure, some of them have been shown to prolong life significantly. These drugs are far too expensive for African populations. The same research groups that solicited funds for epidemiologic studies should be persuaded to do the same in order to make anti-AIDS drugs affordable for African populations. The first ten years of the AIDS epidemic has had profound social, cultural, economic, and health impacts in sub-Saharan Africa. These effects, which include loss of social structure, orphaned children, reduced productivity, and severe depletion of healthcare budgets, no doubt will significantly increase over the next decade. Even if medical care or a vaccine were made available immediately, the already large number of infected individuals will continue to burden the society. Healthcare standards will be influenced by the AIDS epidemic for a long time. The decade of the 1990s is the right time for African healthcare services to review their programs and put in place relevant practices and resources without compromising their ethics in caring for people with AIDS. It would be heartening to see African countries taking a lead in the care of people with AIDS.

Conclusion

Significant improvements are continually being made in medical training and standards of healthcare throughout sub-Saharan Africa. These improvements, however, are still not matched by proportionate improvement in medical ethics. Many African medical schools' curricula do not include ethics. Where it is included, the subject is still accorded very little time (usually a one-hour lecture). In order to sensitize doctors and other healthcare personnel on issues related to medical ethics, African medical schools and medical training colleges should be encouraged to develop curricula on ethics. It may also be necessary to sensitize populations on the subject along the same lines that disease prevention has been brought to the community level through health education.

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II. SOUTH AFRICA

The histories of medicine and of medical ethics in South Africa are intimately linked to political, social, and economic aspects of that country’s development, dominant components of which include racial discrimination and social segregation. A brief review of some key political events will provide an illuminating backdrop to a description of the evolution of medical services and the ethics of medical practice in this controversial country, which typifies in microcosm many of the world’s diverse human problems and arguably poses the most challenging contemporary opportunity to demonstrate human ability to resolve conflict peacefully.

Political Background

During the period of the Dutch settlers (1652–1820) the indigenous Khoi-Khoi (pastoral people) and the San (hunter-gatherers) were treated with the arrogance and paternalism that for subsequent centuries epitomized European domination over blacks and exploitation through enslavement and colonial/cultural imperialism. These attitudes, together with warfare and the introduction of new diseases (e.g., smallpox in 1713), led to the decimation and destruction of the organized cultures of these indigenous peoples (Burrows; Laidler and Gelfand).

British annexation of the Cape (1795) and the arrival of British immigrants in Algoa Bay were followed by ninety years of conflict that included devastating wars between rival black tribes, the freeing of slaves (1833), the “importation” of Indians to work in the cane fields of Natal (1860), the first Anglo-Boer War (1880), several wars against the Zulus, and the bitter second Anglo-Boer War (1899–1902), during which twenty-six thousand Afrikaner women and children died in British concentration camps.

The British Parliamentary Act of Union (1910), which gave whites the right to self-determination, and the subsequent failure of the British to exercise their veto powers to restrain the Union Parliament from enacting oppressive racial laws (Native Land Act of 1913, depriving blacks of their land, and the Native Administration Act of 1927, depriving them of their right to self-determination), set the scene for the growth of Afrikaner political and economic dominance. The rise to power of the Nationalist Party in 1948 was followed by proliferation of apartheid policies, relentlessly entrenched through legislation that oppressed and dehumanized the black people of South Africa.

Black opposition evolved from powerless peaceful protest into a politically powerful process of potentially peaceful progress. It was hampered, however, by a growing culture of individual and group violence, fueled by brutal elements within the state security forces and by internal sources of conflict that horrified the world (Schlemmer). Intensification of black resistance, more clearly articulated demands for human rights globally, and changing foreign policy agendas progressively isolated South Africa from its previous friends and from international markets. By the 1980s economic decline, rapid population growth, urbanization, destabilization in the neighboring states, and collapse of communism in eastern Europe and the Soviet retreat from regional conflicts constituted the matrix from which arose the Nationalist Party's acceptance of the need to seek, with the black opposition parties, a negotiated settlement as a step toward developing a democratic South Africa (Benatar, 1992).

Legislative changes since the "unbanning" of the black opposition movements in February 1990 have included repeal of the 1913 Native Land Act, the 1927 Native Administration Act, the 1950 Population Registration Act, and the 1950 Group Areas Act, which together formed a powerful core of statutory discriminatory policies. While the transition period abounds with ironies and ambiguities, optimism that peaceful and constructive pathways to progress could and would be found followed the December 1991 Convention for a Democratic South Africa (CODESA) Conference and the March 1992 referendum. It is against this background that the history of medicine and medical ethics in South Africa can now be briefly reviewed.

History of Medicine

The first manifestation of any formalized medical service was the erection of hospital tents following a smallpox epidemic introduced by a visiting fleet in 1713. Further episodes of smallpox (1751 and 1755) led to the construction of two rudimentary hospitals, one for poor Europeans and the other for slaves, the well-to-do being treated at home.

Medical practice developed in two directions: a private commercial venture predominantly for those who could afford to pay, and a public service for the poor, to which the mission medical service (introduced by the Missionary Society of London) made a major contribution in rural areas for well over a century. Concern for public health, stimulated by the 1918 influenza epidemic, generated decades of successful research on infections in close collaboration with the World Health Organization (WHO). Public health services of a high standard were developed through the creation of medical schools with public teaching hospitals open to all—on a segregated basis; ostensibly separate but equal.

The developing systems of medical practice and of medical education mirrored the diverse characteristics of South African society. Undisputedly high standards of medical education in the Western tradition, dedication of generations of practitioners to high standards of medical practice and patient care, considerable goodwill between doctors and patients of all races, extensive public-health facilities—including teaching centers of excellence and well-funded private medicine—reflect the successes. Privileged access to medical education; fragmentation and duplication of health services; lack of planning; wide disparities in health and in access to healthcare (predominantly on a racially discriminatory and unequal basis); focus on curative hospital-based medicine; paucity of preventive, promotive, and rehabilitative services; paternalistic attitudes to patients; and dismissive attitudes to African traditional medicine reflect the racist and oppressive aspects of a system doomed to failure through its institutionalized neglect of civil and social justice (Van Rensburg and Benatar).

Deficiencies in the healthcare system were clearly articulated in the 1940s, and the case for reform toward a unitary health service has been the subject of intense debate since the 1980s (Benatar, 1986, 1990b, 1991). Traditional African medicine continues to be practiced, particularly in rural areas. While black Africans have increasingly accepted Western medicine, they eclectically choose varying combinations of modern and traditional medical advice (Edwards).

Medical Ethics

The South African Medical and Dental Council (SAMDC), a statutory body, was established in 1929 with the primary purpose of protecting the public through maintenance of high professional (including ethical) standards of practice and with a view to serving the interests of the medical and dental professions—insofar as these interests are compatible with high standards. The wide range of powers vested in SAMDC included the power to institute inquiries into any complaint, charge, or allegation of improper or disgraceful conduct of its members and to exercise disciplinary power over them.

As in most other Western countries in the first sixty years of the twentieth century, discussions on medical ethics in South Africa largely took place within the framework of the authoritarian, paternalistic behavior expected of professionals supposedly adhering to the Hippocratic Oath and similar codes. The first South African text on medical ethics (Elliott) was limited to discussion of ethical codes, professional secrecy, advertising, the conduct of consultations, fees and financial matters, and upholding the "traditions" of medicine, with only brief reference to abortion and sterilization, and to the ethics of investigative medicine. This text, based on Guy Elliott's experience of deliberations on ethical matters by the Medical Association of South Africa (MASA) and the SAMDC, provides a succinct outline of accepted medical ethics in South Africa (and in many Western countries) in the first half of the twentieth century.

Issues of bioethics have usually been stimulated by the widespread application of technological advances in everyday medical practice, the social changes that challenge many traditional professional values, cost considerations, uncertainty regarding the effectiveness of innovative treatments, and increasing concern for individual autonomy and shared decision making in the United States and Europe.

The pace of social change, and of change in medicine and bioethics in South Africa (a middle-income country—per capita gross national product (GNP) less than one-tenth that in the United States and falling), has been much slower. Expenditure on health has increased only marginally and, despite their high profile, modern lifesaving medical treatments are available only on a limited scale. Public and even professional debates on ethical issues in medicine have been very limited in a repressive, authoritarian society lacking a patients' rights movement and unaccustomed to public discourse on civil and political liberties (Benatar, 1988).

As in the United States, theologians have played a pioneering role in reawakening interest in bioethics; several conferences were held in South Africa (in the 1960s and 1970s) under church or theological auspices. The first, stimulated by the historic heart transplant in Cape Town (December 1967), was on the ethics of tissue transplantation (Oosthuizen). Others followed on abortion (Oosthuizen et al., 1974), euthanasia (Oosthuizen et al., 1978), professional secrecy (Oosthuizen et al., 1983), and clinical experimentation (Oosthuizen et al., 1985). These provoked little ongoing public or professional debate. In the 1980s some medical schools began developing modern bioethics education programs, but progress has been slow and the programs remain (1) in a fledgling state, (2) dependent on enthusiastic physicians who have heavy professional responsibilities and minimal formal training in philosophical ethics, and (3) without the financial and institutional support to develop formal programs with committed support from other disciplines (e.g., philosophy, law). One medical faculty has published the proceedings of four symposia on bioethics (Benatar, 1985, 1986, 1988, 1992). These have encompassed theological, philosophical, and sociological debates on death and dying; resource allocation; the doctor–patient relationship; abortion and in vitro fertilization; research on humans; principles of biomedical ethics; moral reasoning; withholding and withdrawing treatment; healthcare of detainees; hospital ethics; the right to healthcare and the structure of health services; ethical considerations in relation to acquired immunodeficiency syndrome (AIDS); and teaching medical ethics. These proceedings reflect progressive movement toward the views being popularized in bioethics debates in the United Kingdom and the United States. By retaining a degree of "cultural sensitivity" they endeavor to avoid the pitfalls both of "ethical imperialism" and of "ethical double standards."

A milestone event in the history of medical ethics in South Africa was the inadequate SAMDC and MASA responses to the unethical manner in which state-employed medical practitioners provided professional attention to prominent black activist Steve Biko prior to his death during detention without trial in 1977. Failure of SAMDC to exercise its duty to protect the public by acknowledging the unethical behavior of Biko's doctors and taking appropriate disciplinary action against them, and MASA's response to SAMDC's deficient protection of the public met with resounding criticism nationally and internationally (Nightingale et al.). The sequence of events through which the efforts of a small group of rank-and-file members of the profession led to a Supreme Court injunction against SAMDC, which resulted in a reversal of its previous decisions and the imposition of disciplinary action, is well documented. The National Medical and Dental Association (NAMDA), formed in 1982 as a result of discontent with MASA's actions following the death of Steve Biko, has received international acclaim for its outspoken advocacy against discriminatory practices. MASA, which came under considerable criticism for its inadequate reactions to the Biko affair, has, to its credit, taken some sincere steps in an attempt to rectify its previous shortcomings. Its statements are now clearly on public record, and the challenge ahead is to ensure their further implementation in practice. Greater attention to ethical responsibilities toward prisoners, detainees, and hunger strikers has been a gratifying response to the Biko case (Benatar, 1990a; Kalk and Veriava). The public confession of guilt by the district surgeon who bore major responsibility for Biko's medical care, emphasizes the need to maintain professional independence in the face of state security and other coercive pressures.

Professional institutional responses intended to stimulate higher standards of ethical practice include the MASA and the Medical Research Council (MRC) guidelines on professional ethics and the ethics of medical research, respectively (both currently under further revision), and the publication by the College of Medicine of South Africa of its Credo. The long-standing requirement by some universities that all proposals for human and animal experimentation need approval by institutional ethics committees is spreading to other universities, and such prior approval has now become a requirement for all funding applications to the South African Medical Research Council.

Conclusion

In a period characterized by national economic attrition, real per capita expenditure on health of less than one-twentieth of what is spent in the United States, burgeoning population growth, rapid erosion of financial support for academic medicine, and political liberation with rapidly escalating human expectations, development of the discipline of bioethics in South Africa has been initiated and sustained more as a hobby by a few enthusiasts than as an integral component of medical education and practice. The need to include formal teaching of bioethics and clinical ethics in professional schools, which has gained widespread acceptance in the developed world, remains to be achieved in South Africa, as in other developing countries. Who should teach, what should be taught, how teaching of this discipline can be made most effective, and the ways in which such teaching can enrich medical and social education and practice are, as in any new discipline, matters of ongoing debate. If South Africa can learn from the developments in other countries and, with international support, use these lessons to build a national bioethics program and a better healthcare system in South Africa, this could contribute toward restructuring a new South Africa that could play a vital role in helping to rehabilitate southern Africa.

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MEDICAL ETHICS, HISTORY OF THE AMERICAS

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I. Colonial North America and Nineteenth-Century United States
II. The United States in the Twenty-First Century
III. Canada
IV. Latin America

I. COLONIAL NORTH AMERICA AND NINETEENTH-CENTURY UNITED STATES

North American physicians fashioned their ethics as professionals from the dominant cultural ideals of their era, from norms hallowed through centuries of professional tradition, from rules and regulations of newly established medical institutions, and from laws and legal institutions operative in the communities in which they practiced.

Christian Practitioners

The soil of religious values grounded the quest for professional ethics. For the majority of British and French physicians who settled North America in the seventeenth and eighteenth centuries, Jesus was as real and significant as Asclepius, Hygeia, and Panaceia had been to the author of the Hippocratic Oath. An intimate causal connection existed between character and professional righteousness. The beliefs and rituals of Christian institutions formed character. The ethically acceptable physician displayed the characteristics of a Christian.

Cotton Mather, a Puritan cleric who wielded considerable power throughout New England during the early eighteenth century, was a major figure in the evolution of North American medical ethics. He believed that Christian physicians who abided by the secrecy clause of the Hippocratic Oath became special confessors who had extraordinary opportunities for offering "admonitions of piety" to their trusting and needful patients (Mather, 1966). Because sin was the ultimate cause of all diseases—spiritual, mental, and physical—Mather expected physicians to prescribe Christian beliefs as well as drugs (Mather, 1972). Though he acknowledged confusion about the variety of remedies proposed as cures for any single disease, he would not dishonor "skillful and faithful" physicians (Beall and Shryock).

Though many Bostonians objected, Mather advocated inoculation during smallpox epidemics. He believed that the ultimate success of smallpox inoculation depended on God's mercy, but the validity of inoculation required trial-and-error testing and statistical comparisons between those naturally infected and those artificially inoculated. If deaths were prevented or suffering mitigated, as had occurred in Africa and Turkey, then inoculation was a good practice for doctors in North America. Its goodness as praxis was determined by the scientific demonstrations of practical trials involving mathematical standards and utilitarian outcomes that would be the basis for the reform of medical therapeutics during the nineteenth and twentieth centuries.

Gentlemen Practitioners

North American physicians repeatedly urged students and colleagues to be both Christians and gentlemen in their interactions with each other and with patients. The principal characteristics of a gentleman included proper birth, sufficient wealth, unblemished character, adequate learning, and civic service. While the importance of birth and wealth faded in the more egalitarian atmosphere of the New World, that of character, learning, and civic virtue grew stronger. Was a physician good because he cured many sick patients, or because he was a Christian and a gentleman? Doctors who prepared the earliest biographical dictionaries of deceased physicians in the United States and Canada judged their worth by Christian and gentleman standards, not by curative or preventive statistics (Thacher). Hallmarks of professional goodness depended on allegiance to the dominant cultural ideals.

Educated Doctors

Those who promoted higher standards for judging physicians frequently decried the immoralities of uneducated practitioners. In 1765, two years after the British assumed rule of New France (Canada) and ten years before the battles of Lexington and Concord, John Morgan proclaimed that most North American practitioners were ignorant, unsteady, irresolute, idle, negligent, and merciless. After six years as an apprentice to John Redman in Philadelphia, four years as a military surgeon, three years of medical studies in London and Edinburgh, and the luster of a European "grand tour," it was easy for Morgan to feel superior.

Wanting to improve this deplorable situation, Morgan and others established the first colonial medical school at the College of Philadelphia (1765). Samuel Bard, another Edinburgh graduate, delivered the first commencement address at King's College Medical School in New York City in 1769. Bard's judgment, no less harsh than Morgan's, was a fusion of Christian ethics, gentlemanly values, and academic ideals: "As those who have neither emulation nor honesty, who neither have abilities, or will give themselves the trouble of acquiring them, I would recommend it to such, seriously to consider the sixth commandment, 'Thou Shalt Do No Murder'" (Bard, p. 6). Morgan, Bard, and others fervently advocated formal education to produce morally acceptable doctors.

Because of the influx of practitioners from the United States and Great Britain, and because of British restrictions on degree-granting institutions in the colonies, enduring medical schools were not established in Canada until the third decade of the nineteenth century. In 1830, when the medical school at McGill University was one year old, twenty regular medical schools functioned in the United States. Graduates of these schools usually championed academic norms as measures of professional goodness: collegiate studies before medical ones, a systematic formal education in a medical school, improving medical science by careful clinical observations, development of effective teacher-pupil relationships, and continuing studies after formal education. Physicians were professionally good if they were Christians, gentlemen, and scholars.

Legal Proprieties

North American physicians were not considered wholly ethical unless they were law-abiding citizens. Throughout Canada's early history, its doctors associated professional propriety with approval by licensing authorities, established as early as 1788 when the British Parliament passed a licensure act governing the Canadian settlements (Heagerty). Two Canadian groups assumed licensing responsibilities: the College of Physicians and Surgeons of Lower Canada in 1847 and the College of Physicians and Surgeons of Ontario in 1869. The voluntary medical societies organized in Canada before 1850 were not concerned with licensing.

The situation was quite different in the United States. Legislators granted exclusive licensing rights to medical societies in some states and to separate boards of physicians in other states. Such licensing bodies had been established in most states by 1832. During the subsequent forty years, however, existing states repealed or ignored their medical licensing laws, and new states adopted none. Since possession of a medical degree was sufficient for licensing in many states, there seemed to be little need for sustaining separate powers for societies or boards. No group enforced these laws uniformly or effectively. Nor had the laws prevented the growth and development of medical quackery and sectarianism.

Legislators believed that free Americans could be trusted to discover the good physician and to sue the bad one. Even if a physician in the United States could be judged a good professional without being licensed, as was the situation between 1835 and 1875, he did not want to be accused of malpractice, much less convicted in court.

During the first half of the nineteenth century, the American culture, unlike the Canadian, experienced an outburst of religious pluralism, the populist effects of expansion to the West, an economic atmosphere of laissez-faire, and widespread opposition to centralized regulation by governmental authorities. These conditions fostered the lack of interest in licensure laws and the willingness of legislators to charter schools for homeopaths, hydropaths, and other sectarian practitioners.

These social and cultural conditions caused many practitioners to believe that standards of professional propriety were disappearing in a sea of populist relativism. If models of personal morality, such as Christian or gentleman, were so varied and even conflicting (Could Jewish doctors be good?), and if standards of knowing were so pluralistic that legislators relinquished efforts to distinguish among them, what could be done by practitioners who still believed in the integrity and dignity of a medical profession?

Codes of Ethics

To cope with the pluralism and relativism of the modern era, physicians created codes of professional ethics. During the last decade of the eighteenth century, Thomas Percival, a general practitioner in Manchester, England, had developed a systematic view of medical ethics based on the premise that it was possible to comprehend a moral order suitable for all medical practitioners. Universal truths about good professional behavior could be learned and applied by all conscientious and respectable doctors. Percival delineated these truths within a fourfold categorization of physicians as persons, caregivers, livelihood competitors, and civil servants.

The following admonitions exemplify Percival's approach. Physicians should be Christian gentlemen: considerate, reasonable, self-critical, temperate, educated. Doctors ought to interrogate patients privately and have special regard for their feelings and prejudices. Practitioners should consult openly and respectfully with each other, searching for proper remedies and sharing responsibilities in the care of the sick. Doctors ought to honor the trust of their communities by providing medical services free to public institutions and by providing medical knowledge needed by courts and governing officials. Percival included these and numerous other exhortations in a book on medical ethics published in 1803.

This book, together with John Gregory's lectures on medical education and medical ethics published in 1772, became a handy guide for North American practitioners who wanted practical criteria for judging propriety but had little interest in theoretical formulations of moral philosophy that might bring them too close to the Catholic traditions of the medieval universities. Most of these doctors were Protestants, and many were stalwart Puritans who, like Cotton Mather, deliberately rejected the "new moral philosophy" of the seventeenth and eighteenth centuries. In their view, these modern philosophies contained too much ancient paganism and too little Christianity, and placed more reliance on observation and reason than on faith and ritual.

Despite such theoretical objections, American physicians became exemplars of the "new moral philosophy" as they created codes of professional ethics during the first half of the nineteenth century. In 1808 an association of Boston physicians adopted a code of medical ethics composed of nine sections that addressed consultations between physicians, interfering with another doctor's practice, arbitration of differences between doctors, discouraging the use of quack medicines, promoting professional respectability, fees and exemptions from fees, practicing for a sick or absent doctor, and seniority among practitioners. All of these precepts could be found in the second chapter of Percival's *Medical Ethics.* Titled "Boston Medical Police," this code became the model for codes adopted by at least thirteen medical societies in eleven states during the ensuing thirty-four years.

In 1823 the New York State Medical Society adopted a code that resurrected the broader scope of Percival's original view. The New York doctors presented ethical claims about the personal character of physicians, quackery, consultations, patient care, and public obligations. In 1832 an original code was adopted by the Medico-Chirurgical Society of Baltimore. Norms were offered about the obligations of physicians to each other, quackery, consultations, and fees. This code also included a separate section about duties of patients toward physicians, an approach that had been taken by Benjamin Rush in a lecture to students. Rush thought that citizens should employ only serious-minded, educated doctors. Patients should not burden doctors with too many details of their illnesses, and they should strictly follow their doctors' orders and pay their fees promptly.

These examples of distinctive codes from Boston, New York City, Baltimore, and Philadelphia demonstrate the extraordinary interest in codifying professional ethics among American doctors, an interest that culminated in the adoption of a national code in 1847 by the newly established American Medical Association (AMA).

The AMA doctors accepted Percival's fourfold pattern of categorizing professional ethics and many of the specific claims cherished by the British practitioner. They advocated excellence of moral character, though Christian norms were no longer identified as the exclusive grounds for this character, probably because Isaac Hays, a prominent Jewish physician in Philadelphia, was a member of the committee that drafted the code. Though the AMA doctors valued proper education, they insisted that loyalty to professional colleagues was more important than scientific attainments. Article IV explicitly forbade association or consultation with irregular practitioners, that is, physicians whose "practice is based on an exclusive dogma, to the rejection of the accumulated experience of the profession," an injunction directed primarily against homeopaths. Standards of patient care included careful attention to professional secrecy, a proper number of visits to the sick, absence of gloomy prognoses, and refusal to abandon patients who have incurable diseases.

Physicians also had excellent opportunities for influencing the personal character of patients. Section 7 of Article I of Chapter 1 of the code is quite specific: “The opportunity which a physician not unfrequently enjoys of promoting and strengthening the good resolutions of his patients, suffering under the consequences of vicious conduct, ought never to be neglected.” Sustaining Cotton Mather’s view of the sickroom as a stage for confession and redemption, the AMA doctors accepted professional roles as moral therapists. Since “moral” then included what would be called psychotherapy today, the AMA code also sanctioned the devotion of those physicians who had chosen careers as superintendents of institutions caring for the mentally ill.

The AMA doctors emphasized the ideal of shared obligations between physicians and patients, between the profession and the public. Copying Rush, the AMA committee codified the rights of American physicians in a long list of obligations of patients toward their physicians. In the last chapter of the code these duties of patients were expressed more generally as the obligations of the public to the profession, for example, in supporting medical schools and allowing them to acquire cadavers for anatomical dissection. In return, the profession acknowledged a relatively new dimension of professional ethics by its willingness to provide medical knowledge to the governing groups of their communities. This knowledge was needed, for example, in adjudicating civil and criminal proceedings as well as in deliberations about the proper kinds of laws and institutions needed for sanitation, quarantine, and other public health measures.

Worthington Hooker, a general practitioner who later became a professor at Yale, focused on the ideal of reciprocal obligations in *Physician and Patient* (1849), the only comprehensive view of professional ethics published in book form by a North American practitioner before 1900. Hooker’s religious beliefs were almost as conservative as those of Cotton Mather, but Hooker believed that moral philosophizing was acceptable for a Christian apologist. He became a moral philosopher of medicine. Like other conscientious midcentury doctors, he knew that religious, educational, and legal institutions had failed to provide a fully acceptable set of moral standards for judging physicians. Hooker believed that doctors were obliged to discover acceptable standards of professional behavior, to publicly proclaim these standards in a format that would be comprehensible to both professionals and the public, and to determine whether such standards had been honored by individual doctors. A code of medical ethics adopted and enforced by a national organization could become the cultural and social instrument for shaping a uniform and universal moral order for American doctors. Hooker viewed his book as an extensive commentary on the AMA code.

Thus, Hooker and many others touted the advantages of the AMA code. Professional righteousness in the United States could be measured by the extent of adherence to this code. Professionally virtuous doctors maintained professional secrecy, made the proper number of visits to the sick, did not offer gloomy prognoses, cared for the incurably sick, requested consultations as needed, and abided by the numerous other precepts in this code that was adopted voluntarily by many societies. In 1855 the AMA decided that all state and local societies wishing to send delegates to its meetings had to adopt its code of ethics.

Not a few chided the AMA’s officers about the absence of enforcement procedures. Some state and local societies reprimanded members for consulting with irregular practitioners and occasionally expelled members for criminal offenses, gross immorality, or the sale of secret medicines. The AMA established a judicial council in 1873, but there is no evidence that the council enforced the code regularly or extensively. Similar difficulties affected Canadian practitioners.

One year after its establishment in 1867, the Canadian Medical Association adopted a code of ethics that was almost identical with the AMA code. Minor changes had been made in wording. One clause in the article about obligations of the public to physicians had been omitted, and a new paragraph in Section 3 of Article I permitted beginning practitioners to announce the existence of their offices in the public press. Although some doctors lauded its rules and enforcement was attempted, this code was hardly the final word in matters of medical ethics for most Canadian practitioners.

The attitudes of Canadians contrasted sharply with the sentiments of many practitioners in the United States who believed that the AMA code was as important as the Bible and the Constitution. If the American government could create a bill of rights suitable for all citizens, then the American medical profession could prepare a bill of rights suitable for all reputable medical practitioners. The AMA code of 1847 was that document. In filling a moral vacuum caused by religious pluralism, unacceptable educational standards, loss of confidence in traditional remedies, and ineffective licensure laws, the AMA code became the set of sacred values voluntarily created and professed by respectable and honorable doctors. Sick patients could place their trust in practitioners who gave their allegiance to this code.

In 1880, when one editor doubted that the majority of Canadian medical practitioners had ever read the code adopted by the Canadian Medical Association (“Code of Medical Ethics,” 1880a), journal editors in the United States were about to receive an onslaught of articles for and against the AMA code. The problem involved the prohibition against consultation with any practitioners other than those exhibiting allegiance to the code. In 1882 the New York State Medical Society revised its code of ethics so that its members could consult with legally qualified practitioners regardless of their scientific or sectarian status. Seventeen state societies condemned this action, and the AMA refused to admit the New York delegates to its annual meeting. In the following year, the AMA expected all delegates to sign a pledge to obey its original code of ethics. Articles for and against the code and supporting or opposing the renegade New York physicians appeared in nearly all state medical journals. The code-loving conservatives withdrew from the New York State Medical Society and started a new organization that became larger than the original society. Conservatism was the order of the day; the code of 1847 withstood revision until 1903.

Exemplifying a practical application of the moral philosophy taught as a senior year course in most American colleges of the nineteenth century, the AMA code and its predecessors had nurtured professional unity and social respectability during the heyday of Jacksonian egalitarianism in the United States. These codified norms sustained important traditions in Western medicine, reminded all practitioners of essential duties to their patients and colleagues, and encouraged doctors to participate in those public institutions designed for the health and welfare of all.

Science Versus Codes

Those members of the New York State Medical Society who revised their code of ethics in 1882 exemplified a new breed of medical practitioner emerging in North America during the last three decades of the nineteenth century. These individuals could not accept the AMA code's claim that intraprofessional loyalty was more important than scientific truth. When Francis Delafield announced in 1886 that he and his colleagues wanted an association in which there would be no medical politics and no medical ethics, he heralded a fundamental change in the approach of North American practitioners to the perennial challenge of fashioning an acceptable set of professional ethics. Delafield and his colleagues wanted to associate with those practitioners who were able "to contribute something real to the common stock of knowledge" in medical practice (Konold, p. 39). They could no longer tolerate those practitioners who rested secure with a fundamentalist allegiance to the code of one organization whose precepts were rooted in eighteenth-century British experiences. The iconoclastic doctors of the late nineteenth and early twentieth centuries advocated a professional morality that would judge physicians in terms of their skillful application of specialized scientific knowledge in caring for the sick and the healthy. This new moral philosophy of medicine gradually became institutionalized in some medical schools and societies between 1870 and 1900.

The more progressive schools established teaching and research laboratories, and hundreds of North American practitioners journeyed to the laboratories and clinics of Europe for instruction in the basic sciences, especially microbiology and pathology, and in the clinical specialties, especially the surgical ones. Between 1864 and 1894, American physicians organized more than a dozen national societies for medical specialists (e.g., pediatrics, obstetrics, urology).

These groups did not adopt written codes of ethics. Instead they proclaimed—by word and deed—the values of a liberal premedical education and a thorough education in the medical sciences, allegiance to the experimental method as the proper approach to truths about health and disease, and a strong belief in research and continuing education.

These doctors espoused the rightness of their values as dogmatically as those who believed in the AMA code. Physicians and patients knew of numerous practitioners who did not accept the code but were reputable as persons and successful as healers. The same could not be said for doctors who ignored the bacteriological discoveries, the vaccines, the antiseptic principles, the improvements in diagnostic technology, the pharmacological therapeutics—all based on the methods of experimental science and clinical trials. Good doctors were those who competently and humanely applied this medical science.

These values led to numerous reforms in North American medical education, facilitated and sanctioned by the reestablishment of licensure policies in all of the United States by 1898. In 1902 the Medical Council of Canada became the central licensing agency for the provinces. These new licensure approaches not only sanctioned the reform measures adopted by the progressive American and Canadian medical schools but also upheld obedience to law as an important measure of professional virtuosity.

The physicians who supported these laws and schools recognized that the AMA code said nothing about the more technically proficient environments of the modern hospitals emerging after 1870. To provide competent surgical care, doctors needed instruments and assistants. By the late 1890s, scientific practitioners needed X-ray equipment and laboratory machines that could not be carried in black bags. Technically imprecise care was immoral to these doctors.

Technically adequate care, especially surgical care, required the services of trained nurses. As hospitals became cathedrals of applied science, doctors supported the training schools for nurses initiated by London's Florence Nightingale in 1860. At least fifteen of these schools existed in North America by 1880 (Rosenberg, p. 219). The ethical values espoused by these professional nurses encompassed certain cultural ideals about women, as well as specific norms about knowledge and obedience. Women were believed to be the moral standard-bearers of Victorian society. Those who chose to become nurses were special women who sacrificed much for the glory of God and the needs of the sick. Soldiers in the fight against disease, these nurses organized militaristic training schools that prepared women, attired in starched and pressed white uniforms, to assist physicians obediently in applying scientifically derived medical knowledge.

The AMA code had said nothing about nurses or women or blacks. Physicians and patients welcomed trained nurses who were social products of a new moral philosophy of medicine that assigned special values to some women. Overcoming objections by most males, other women became doctors. Nearly 400 women physicians practiced in 21 states by 1881 (Burns, 1988). Excluded from the AMA, black physicians adapted to the segregationist culture of their era by organizing the National Medical Association in 1895. The AMA codifiers made no revisions to accommodate these scientific, professional, and social changes.

The most significant change involved the transformation of the hospital into a powerful institution that incorporated the moral values of religious charity, scientific excellence, specialized patient care, and social justice. The number of hospitals in North America grew from about 300 in the 1870s to more than 4,000 by 1910. These hospitals became arenas for moral confrontations between medical practitioners and nonprofessional administrators and other laypersons. They fostered the emergence of new healthcare workers and professionals, including laboratory technicians, nurses, occupational and physical therapists, social workers, and hospital chaplains. Each group forged its particular ethical agenda. Hospitals also supported the rapidly expanding urge for specialty differentiation among physicians. At the turn of the twentieth century, hospitals became the interpersonal crucibles that sustained and transformed the legacies of North American medical ethics.

Conclusion

Before 1900, North American physicians were morally acceptable if they cherished dominant religious ideals, behaved as gentlepersons, learned the fundamentals of medical science, revered a code of professional ethics, and abided by the laws of their communities. Professional virtuousness was measured by the extent of allegiance to the cultural and professional traditions of the West, as those traditions had been adapted to North American conditions. During the last quarter of the nineteenth century, a small group of doctors began to challenge some of the value claims for professional orthodoxy. They believed that favorable results in curing and preventing specific diseases in particular humans made possible by the technically proficient behaviors of skilled professionals applying scientifically derived knowledge were more important than the status-seeking rituals of AMA codifiers or the religious beliefs of the professionals. Yet, the conservative tendencies were so tenacious that the majority of practitioners, at the opening of the twentieth century, still believed in codification as the primary method for establishing professional ethics and still displayed loyalty to the values of one association's code even though major changes in the cultural, scientific, technological, and institutional legacies had changed the nature of the quest for professional ethics.

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II. THE UNITED STATES IN THE TWENTY-FIRST CENTURY

The field now called bioethics originated in the 1960s in the United States. It has its roots in the traditional medical ethics of Anglo-American medicine, in the cultural setting of American healthcare, and in certain social, religious, and moral perceptions that had emerged in the American ethos. This entry will first delineate the background for the development of bioethics and then relate the events, issues, and concepts that stimulated its growth during the latter half of the twentieth century (Jonsen, 1998).

The Culture of U.S. Healthcare

Bioethics, in the broad sense of the study of ethical problems encountered as humans interact with the biological within themselves and in their environment, comprehends much more than medicine and medical science. Nevertheless, the development of bioethics can best be understood against the background of the development of medicine in the United States from 1900. The twentieth century saw enormous growth in American medicine—in the amount of money devoted to medical care, the number of persons with access to care, the number of personnel and specialties, the complexity of institutional systems, and the extent of scientific technology. Three principal lines of development that contribute to the interest in ethical questions are the changing role of the hospital, the predominance of science and technology, and the development of specialization (Jonsen, 1998).

Beginning in the late nineteenth century, hospitals were founded at an increasing rate and eventually became the principal sources of medical care in the United States. As medical diagnosis and treatment increasingly involved elaborate techniques and devices, it was seen as more efficient and economical to centralize care in hospitals. Physicians could allocate their time more conveniently; nurses, technicians, and medical specialists could coordinate their work more effectively. Communities desired hospitals as a matter of pride; cities needed hospitals for indigent patients. The passage in 1946 of the Hill-Burton Act, which provided federal support for local hospital construction, and the tendency of the newly popular health insurance to reimburse hospital care rather than office or home care accelerated the evolution of the hospital in the United States (Rosenberg; Stevens, 1989).

With seminal discoveries in bacteriology, pathology, and physiology during the nineteenth century, scientific medicine came into its own. But it became an integral part of medical practice in the United States only after the extensive reorganization of medical schools in the decades around 1900—a period marked by the vigorous efforts of the American Medical Association to reform medical education and to improve the standards of medical practice. Medical school reform was greatly stimulated by the Flexner Report, *Medical Education in the United States and Canada,* sponsored by the Carnegie Foundation for the Advancement of Teaching. Scientific investigation, increasingly supported by the federal government, especially during and after World War II, brought research physicians into medical education and patient care. Experimentation involving human subjects, both patients and health volunteers, became more widespread as the National Institutes of Health opened and sponsored clinical research centers in the 1950s. The twentieth century brought a "new" medicine, one profoundly shaped by the biological sciences. Diagnosis and treatment took on forms dictated by the scientific knowledge generated in the laboratory, tested in clinics, and assessed by statistical methods.

The fascination of scientific knowledge and techniques drew many physicians into narrower fields of concentration. The vastly increased body of knowledge became too much for individual physicians to master. Moreover, it became possible for physicians to build careers by performing procedures focused on limited aspects of patient care. Thus, scientific medicine fostered the growth of specialties. Specialty boards, organized to test and certify competence in the particular fields of medicine, were established in a variety of specialties and subspecialties, beginning in the United States with the Board of Ophthalmology in 1917 (Stevens, 1971). The social and economic status of physicians improved significantly during the first half of the twentieth century and American physicians gradually moved from middle- to upper-class status, which distinguished them in attitudes, lifestyle, and place of residence from many of their patients (Starr).

In general, the three developments described above set the scene for the ethical concerns that began to surface in the United States in the 1960s. The concentration of specialized medical care in hospitals encouraged an impersonal, organizational approach to medical care. While social, behavioral, environmental, and personal aspects of illness were not totally neglected, scientific medicine focused on the biological and physical aspects; complaints that physicians had lost the ability to care for "the whole patient" were increasingly heard. As scientific knowledge increased, teaching in the sciences tended to crowd other concerns from the basic medical curriculum. Specialization narrowed attention to particular organ systems and diseases, and patients were shuttled between a variety of specialists rather than cared for by the family doctor. Leading medical educators felt obliged to continually stress the more comprehensive view of medicine, but educational, economic, and professional pressures constantly obscured these calls. By the 1960s, physicians, formerly close and familiar to their patients, had become "strangers at the bedside." This alienation was an important impetus for the emergence of bioethics (Rothman, 1991).

Social and Cultural Trends

In addition to these directions within medicine, cultural and social movements involved the public in the ethics of medical care to an unprecedented extent. The mass media stimulated public interest in medicine. By emphasizing new discoveries, dramatic incidents, and "human interest" stories, the media underlined growing tensions between complex medical technology and its humane use. Growing urbanization and the consequent uneven distribution of population heightened existing obstacles to healthcare. A higher standard of living and increased educational achievement for many increased the sophistication of patients. Growing support of biomedical research by the federal government during the 1950s and 1960s thrust research into the realm of public policy. The ability of persons to purchase healthcare, dramatically improved by the introduction of employment-based insurance in the 1930s and augmented for the poor and the elderly by the passage of Medicare and Medicaid in 1965, gradually began to erode. Healthcare in the United States, while technically superb, became extremely costly and, because of its cost and organization, excluded large numbers of Americans from adequate care. This situation had evolved into a social and political crisis by the late 1980s. No resolution had been found as the twenty-first century opened.

The slow but incessant influence of consumerism, from the concern about adulteration of food in the early decades of the twentieth century to the militant demands for consumers' rights in the 1970s, began to influence the healthcare system. The patients'-rights movement in the 1970s was a segment of a larger movement for civil rights. The women's movement brought attention to the care of women patients and the distribution of women professionals in healthcare. These movements heightened sensitivity to the unmet healthcare needs of women and people of color. The issues of birth control and abortion divided the public on the role of health professionals in family and population policies. Medicine began to draw practitioners from a culturally broader population, and many new allied health professions and technical specialties were added to the healthcare team, enriching and intensifying debates over values among healthcare providers. The peace movements of the 1960s and 1970s and growing ecological movements drew attention to burgeoning international health problems arising from war, environmental hazards, and pollution (McCally and Cassel; Leaf). These concerns challenged the role of medicine in maintaining the overall health and well-being of

Earth's population. Physicians for Social Responsibility was founded in 1971, on the premise that the health risks of nuclear armaments fell within the social responsibilities of physicians. Although threats to the global biological environment emerged as major research and political concerns in the 1970s, the study of ethical issues in these areas remained rather separate from the study of ethical issues in medicine and health sciences (Geiger; Jonsen and Jameton; Cassel and Jameton).

These social and cultural trends, together with the direction of the biological and medical sciences, were the background for the bioethics movement that began in the 1960s. Bioethics as it is known today had its roots in general public concerns over issues of individual rights, social justice, and environmental quality that marked American culture in that era. Before examining the bioethics movement itself, it is advisable to examine the ideas, activities, and interests that were its precursors.

Traditional Medical Ethics

The effort to establish a unified medical profession during the nineteenth century and the accompanying internecine strife among physicians of various doctrinal allegiances profoundly influenced the nature and content of medical ethics at the opening of the twentieth century. Although strains of the Hippocratic, medieval, and Enlightenment tradition were invoked, the dominant themes stressed the respectability and collegiality of the profession and detailed the etiquette of professional relationships that promoted those themes. At the beginning of the twentieth century, this goal of a unified profession was within reach. The American Medical Association (AMA), through the strenuous efforts of its chief spokesman, Joseph McCormack, represented the profession as dedicated to orthodox scientific medicine, the advancement of medical education, the elimination of quackery, and the promotion of public health, particularly through support of pure food and drug legislation (Burrow, 1977; Jonsen, 2000; Baker et al.).

One crucial mandate of professional ethics—that ethical physicians did not consult with or refer patients to unorthodox practitioners—was firmly in place in the early twentieth century. Decades before the turn of the century and for several decades afterward, many ill-trained or untrained persons practiced "medicine." A vast number of substances and devices were promoted as cures for various or all disorders. A strong public voice favored freedom of choice of practitioner, claiming that the "scientific" practitioners and drugs offered nothing better than their untutored and untested competitors. Others, particularly the more educated practitioners, set out to discredit quacks, nostrums, and patent medicines.

This concern stimulated the debate among physicians over cooperation between physicians and "irregular" practitioners. Many regular physicians refused to treat patients who had received prior treatment from irregulars; medical society codes of ethics barred irregular practitioners from society membership, hospital admitting privileges, and joint practice with regular practitioners (Gewitz). During the years before World War I, the AMA led a fight that finally persuaded state legislatures and Congress to pass legislation controlling the practice of medicine and the sale of drugs. Midwives were among the targets of the campaign against quackery, and despite better health outcomes by many midwives at the turn of the century, the campaign for "scientific" practice won public support and midwives have been largely displaced by obstetricians (Leavitt). During the era before World War I, medical ethics appeared to some as exclusively concerned with the criteria that restricted practice to "orthodox" physicians. While self-interested motives can be imputed to organized medicine, many repudiated the "freedom of choice" argument out of the sincere concern that medicine "at least do no harm" (Burrow, 1977). Still, as many commentators have noted, medical ethics, in this matter, served the ends of medical monopoly (Berlant).

A second important question about consultation and referral was vigorously debated: whether referring physicians were entitled to a fee or "kickback" for having sent a patient to a specialist or consultant. This practice was particularly common in surgery. Some surgeons solicited patients through general practitioners who, in turn, found it lucrative to refer patients who sometimes did not require surgery. The abuses of fee splitting scandalized the public and many professionals. The American College of Surgeons, founded in 1915, required its fellows to take an oath that explicitly repudiated fee splitting. Although branded by all professional organizations as unethical, this practice continued in a covert way for many years (Davis).

Perhaps the most agitated debate in traditional medical ethics during the first half of the twentieth century was over the integrity of the patient–physician relationship. Fee-for-service practice by solo practitioners who sought to develop their own followings of patients was the predominant model. However, some "contract practice," in which a physician undertook to provide unlimited service to a designated population for an agreed amount, had long existed. Plantations in the American South had used this method for the medical care of slaves. Fraternal organizations formed by immigrant populations had insured their members in this way, and in the West, the railroad and lumber industries contracted with physicians to care for their workers. Many in the organized profession, however, objected to contract practice, condemning it as "cut-rate medicine," as inferior to private practice in the quality of care and personal relationship, and as allowing a "third party" to dictate conditions of care, to the possible detriment of the patient. The same objections met the forms of group practice that evolved from contract practice in the first half of the twentieth century. Bitter battles raged over these issues; many medical societies excluded physicians who were involved in these "schemes." A series of antitrust decisions by the U.S. Supreme Court, beginning in the 1940s and continuing into the 1970s, gradually cleared the way for the development of a variety of corporate practice forms, such as health maintenance organizations, that a few decades before would have been considered unethical forms of medical practice.

Another ethical issue was closely related: the debate over payment for medical care. The traditional ethics had required physicians to charge their patients fairly and to provide free or discounted services to those who could not pay. The emergence of free public clinics and hospitals in the late nineteenth century threatened that ethic. Many physicians claimed that even patients who could pay sought free care, draining the physicians' practices and making it impossible for them to provide charitable services, because they needed a steady income from paying patients to be able to afford to provide such services. Thus, at the turn of the century, extensive public use of free clinics was debated as an ethical question. Some argued that it was conducive to continued pauperization; others claimed that forcing poor people to pay for needed medical care was immoral. Some practitioners opposed free clinics because they viewed them as unfair competition by medical schools, which they saw as using free clinics to obtain patients for medical education. At the same time, the organized profession realized that the costs of care were beyond many persons and that physicians' incomes were low. Initial support was given to proposals emanating from organized labor for government-supported compulsory health insurance. By 1916, a broad coalition of organized medicine, labor, and social reformers had almost achieved the passage of national health insurance. World War I intervened, and the coalition was weakened: National health insurance seemed a "Germanic" proposal to many (Germany had long had such a program) and "socialistic" to others. Organized medicine, from then on, firmly opposed almost all forms of government health insurance. Again, it was proclaimed that because this would interpose government between doctor and patient, such programs would be unethical. This opposition persisted down to the passage of Medicaid and Medicare in 1965 (Marmor; Fein).

The AMA revised its 1847 Code of Ethics in 1903, 1912, 1947, 1957, and 1980. The revisions, successively more succinct, reflected an increased sense of professionalism and ideals about the scientific excellence of the practitioner. At the same time, the professional ethics expressed in official codes and in the positions taken by organized medicine on social questions reflected an interest in maintaining the status quo of the profession and the practice of medicine as it had been evolving in the late nineteenth and early twentieth centuries. With few exceptions, such as increased tolerance for group practice, the 1957 revision of the AMA Code, which consists of a condensation into ten "principles of medical ethics," bears little evidence of the major social changes that had begun to affect medical care in the United States. In 1985 the AMA Judicial Council changed its name to the Council on Ethical and Judicial Affairs; it now issues regular statements on issues of current ethical import, such as euthanasia, the obligation to care for patients with AIDS, and financial conflict of interest. Many major medical organizations, such as the American College of Physicians and the American Academy of Pediatrics, have formed ethics committees with a similar purpose. Although commentaries and informal codes on the conduct of nurses can be found as far back as the inception of the profession by Florence Nightingale (1820–1910), the American Nurses' Association did not adopt an official code of ethics for nurses until 1950.

Thus, during the first half of the twentieth century, medical ethics consisted of professionally devised propositions to enhance the unity and monopoly of the profession. Professional self-interest sometimes hid behind ethical claims that were often to the detriment of the public. At the same time, the profession, in encouraging improved medical education and advocating public health and safety measures, lived up to its more noble traditions (Jonsen, 1990).

The Influence of Theological and Philosophical Ethics

The medical profession in the United States imbibed an ethic from the Judeo-Christian culture of the nation. The ethical physician was expected to be respectful of religion and to be a "good Christian gentleman" (Burns, 1977). The dominant Protestant culture offered some admonitions about health and medicine. For example, in the nineteenth century physicians of strong Protestant faith urged the enactment of strict laws against abortion (Mohr). Nevertheless, theological ethics was relatively silent on particular issues concerning medicine and health.

Roman Catholic moral theology, however, had a long tradition of concern with moral questions in medicine. Since the seventeenth century, principles of Scholastic philosophy and theology had been applied to such issues as abortion, sterilization, and the duties of physician and patient. Acute analyses had been made of the duty to sustain life and the circumstances under which the death of a patient could be permitted. This tradition was conveyed to students in the Catholic medical schools that were founded in the nineteenth century. Father Charles Coppens, S. J., lectured in the Medical Department of Creighton University at the turn of the century. His 1905 book, *Moral Principles and Medical Practice: The Basis of Medical Jurisprudence,* treated abortion, sexual behavior, and the duties of physicians in light of philosophical and theological principles. His work represented "the emergence of medical ethics as a medical school subject, especially at religiously affiliated schools" (Burns, 1980, p. 282). During the 1940s and 1950s, this tradition was carried on in the extensive writings of theologians Edwin Healy, Gerald Kelly, Charles McFadden, Francis Connell, and Patrick Finney. In 1949 the Catholic Hospital Association issued *Ethical and Religious Directives for Catholic Health Facilities* (revised in 1954 and 1971), which obliged all physicians and health professionals working in Catholic institutions to follow Catholic moral tenets with regard to a number of specific medical procedures (U.S. Catholic Conference).

Catholic reflection on medical moral issues continues in the *Linacre Quarterly,* published by the National Federation of Catholic Physicians' Guilds since 1932. Theologians Charles Curran, Richard McCormick, Kevin O'Rourke, Margaret Farley, and Lisa Sowle Cahill are now the principal voices of this tradition. The Catholic tradition, in its doctrine of natural law, has affirmed that moral questions can be analyzed from a philosophical viewpoint, without explicit reference to revealed theological truths. Thus, common ground can be found with those who do not share the Catholic faith. This somewhat nonsectarian approach has allowed Catholic analysis of problems to have a significant influence on the intellectual development of secular bioethics.

The Protestant denominations, while not producing a detailed analysis of medical-moral problems, had taken positions on such questions as suicide, euthanasia, abortion, and contraception. In 1950 Willard Sperry, dean of Harvard Divinity School, published lectures given at Massachusetts General Hospital and the University of Michigan Medical School under the title, *The Ethical Basis of Medical Practice.* He offered reflective, humane, literary, but unsystematic commentary on such problems as truth telling, prolongation of life, and euthanasia as the era of medical technology was opening. Four years later, Episcopal theologian Joseph Fletcher published the groundbreaking and prescient study *Morals and Medicine.* Fletcher's work was the first to emphasize the patient's rights as the center of an ethics of medicine and to argue "the ethical case for our human rights … to use contraceptives, to seek insemination anonymously from a donor, to be sterilized and to receive a merciful death from a medically competent euthanasist" (p. 25). He strongly asserted the patient's right to be told the truth about his or her diagnosis and prognosis. Fletcher's book is the pioneering work of the new medical ethics.

Sixteen years later, Methodist theologian Paul Ramsey produced the foundational work of bioethics, *Patient as Person.* Ramsey, professor of religion at Princeton University, took the unusual step of spending a year in intense dialogue with physicians, scientists, and students at Georgetown University and immersing himself in the clinical activities of the Georgetown University Hospital. *Patient as Person,* first delivered as the Beecher Lectures at Yale University in 1969, examined questions, such as organ transplantation, experimentation with human subjects, and the use of life-supporting technologies, that had not been on the agenda of previous commentators on the moral aspects of medicine. Although he spoke from a very different theological ground than did Fletcher, Ramsey also placed the freedom and rights of the patient at the center of his ethic but subsumed patients and physicians within the scope of a theologically defined covenant. Despite the theological tone and language of Ramsey's work, its cogent analyses of issues such as consent were widely influential (Ramsey, 1970b). At about the same time, James Gustafson of Yale Divinity School produced thoughtful essays on the implications of medical and scientific advances. Many Protestant theologians followed the paths laid down by these pioneers, among them Kenneth Vaux, William May, Harmon Smith, James Childress, and Stanley Hauerwas. In 1987 the Park Ridge Center for the Study of Health, Faith, and Ethics was founded under the auspices of the Lutheran Hospital Association to foster religious reflection on the issues of bioethics. The center has published a fine series of volumes describing the teachings about medicine and morality of major Christian denominations and other world religions (Marty; Vaux). The distinctive features of modern bioethics begin to appear in Fletcher and Ramsey: attention to the effects of new technologies, affirmation of the centrality of the patient as free and responsible agent, and the invocation of the concepts and method of moral analysis from the classical disciplines of theology and philosophy.

The Jewish faith has an ancient tradition of reflection upon questions of life, death, health, and medical care. Issues in medical ethics, such as allocation of scarce resources, risk–benefit evaluation, quality of life, abortion, contraception, and indications of death, are discussed in great detail in Talmudic literature. The doctoral thesis of Immanuel Jakobovits, published in 1959 as *Jewish Medical Ethics,* drew these teachings together and brought them into contact with modern scientific advances. In so doing, Jakobovits gave a distinct identity to a field of study that had not been previously singled out in Jewish scholarship. Talmudic scholars such as Moses Tendler, David Bleich, David Feldman, Elliot Dorf, Laurie Zoloth, and the physician Fred Rosner have continued this effort. The first course in Jewish medical ethics was taught by Rabbi Tendler at Yeshiva University in 1956, and the Institute for Jewish Medical Ethics was established in San Francisco in the early 1980s.

The influence of moral philosophy came rather late to the analysis of medical-moral questions. Although the first AMA Code of Ethics was strongly influenced by the English physician Thomas Percival (1740–1804), who was affected to some extent by the philosophers of the Scottish Enlightenment, American philosophers paid scant attention to these questions. In 1927 Chauncey D. Leake noted in his edition of *Percival's Medical Ethics* that all of the classic codes represented "medical etiquette" or the tenets of professional courtesy rather than medical ethics. "It is interesting," he wrote, "that writers on medical ethics have seldom availed themselves of the philosophical analyses of the principles of ethical theory made by recognized ethical scholars" (Percival, p. 3). In words that predict the bioethics movement of the 1960s, Leake called for a medical ethics that would bring the systems of moral philosophy to bear on the problems of medical practice. He undertook to do this in a dialogue with philosopher Patrick Romanell (Leake and Romanell). Three decades later, moral philosophers were important figures in the elaboration of ethics of healthcare.

Secular academic philosophy did not find it easy to approach the practical problems posed by evolving science and medicine. In the 1950s philosophical ethics was struggling with the diverse theoretical challenges of naturalism, relativism, utilitarianism, Marxism, linguistic analysis, and positivism; hardly any attention was paid to the analysis of actual moral problems. This began to change in the 1960s as students vociferously raised questions about the moral legitimacy of the war in Southeast Asian and racial discrimination with their professors of moral philosophy. Interest in practical philosophy slowly appeared within academic philosophy. The questions of life and death raised by new technologies began to intrigue some philosophers. In 1969 Nicholas Rescher wrote an early article on the allocation of "exotic medical lifesaving therapy," such as dialysis and transplantation. Medical ethics began to be taught as an undergraduate philosophy course for which textbooks were produced (Gorovitz et al., 1973; Gorovitz et al., 1976). Daniel Callahan, trained in the analytic philosophy tradition at Harvard University, realized the ethical dimensions of the new medicine and in 1979 founded, with psychiatrist Willard Gaylin, the Institute of Society, Ethics, and the Life Sciences, later renamed the Hastings Center. Although slower to enter the field of practical ethics than the theologians, philosophers such as Baruch Brody, K. Danner Clauser, Tom Beauchamp, and Stephen Toulmin made significant contributions to the methods and substantive analysis of biomedical problems. Indeed, as Toulmin has claimed, "Medical ethics saved the life of philosophy," imparting an intellectual vitality and moral urgency to a field that had turned from the moral concerns of personal and social life to arid speculation.

Legal scholars were also prominent in the early years of bioethics. William Curran and Paul Freund of Harvard University and Jay Katz of Yale University contributed to the important symposium on experimentation with human subjects sponsored by the American Academy of Arts and Sciences in 1966; Katz subsequently published major work in this area (Freund; Katz, Capron, and Glass). John Noonan wrote perceptively on abortion and contraception. As the issues surrounding death and dying became prominent, particularly with the Karen Ann Quinlan case in 1975, lawyers became deeply involved, because law has always taken a serious interest in the determination of the causes of human death. Similarly, the evolution of the doctrine of informed consent has been strongly influenced by jurisprudence and judicial opinion. It is difficult to distinguish between the lawyer and the bioethicist in such figures as George Annas, John Robertson, Alexander Capron, and William Winslade. Indeed, one of these scholars, in a 1993 book, asserted, "American law, not philosophy or medicine, is primarily responsible for the agenda, development and current state of American bioethics" (Annas, p. 2).

Many physicians and scientists have become interested and adept in bioethics. As the field developed, however, the majority of its practitioners came from theology and philosophy; relatively few physicians have devoted themselves to scholarly productivity. Notable exceptions are Edmund Pellegrino, Mark Siegler, Howard Brody, Eric Cassell, and Christine Cassel. They bring to their contributions the sense and sensitivity of the practicing physician.

Although ethics was once taught in American colleges as the summit of the curriculum (often by the president of the college), as the twentieth century opened, ethics had retreated from that academic prominence to a refined and remote subspecialty of philosophy. Many believed that ethics was "caught" rather than taught. Medical ethics, it was said, was best conveyed to medical students by the example of prominent physicians, such as William Osler, as well as by the role models of the leading teachers in individual medical schools. Their lives and writings were common touchstones of discussion. Moreover, resolution of ethical issues tended to emphasize the need for the excellent overall character and reputation of the physician, that is, an ethics of virtue. This emphasis on the good intentions of the physician was congruent with the model of practice then supported by the AMA—the independent practitioner in contract with the individual patient.

Medical jurisprudence, the study of the relationship between medical practice and the law, had been taught in American medical schools with some regularity during the nineteenth century. No course on medical ethics as such is known to have been offered until the late 1920s, except in the Catholic medical schools. The curriculum of the first known course in a secular medical school, offered by Park White at Washington University School of Medicine, St. Louis, in 1924, included discussion of group practice, consultations, relations with other practitioners, quackery, eugenics, euthanasia, and birth control (Burns, 1980). In 1926 the AMA recommended that medical ethics be made part of the medical curriculum. By 1931 it was reported that 43 percent of the sixty-seven American medical schools offered a course in medical ethics, most of these courses in the required curriculum. Approximately the same level was maintained through the 1950s, although course time was stretched to cover other subjects, such as medical sociology and economics, and it is unclear what topics were covered as medical ethics. During this era, Richard Cabot, who was both professor of medicine and professor of social ethics at Harvard University, was a dominant figure. He stressed the importance of personal integrity and honesty in the physician, as had the earlier professional ethics, but he placed this within the evolving framework of scientific medicine: Integrity must be manifested in clinical competence, the primary ethical obligation of the practitioner (Burns, 1977).

As the century progressed and the social and psychological sciences spread in collegiate education, discussion of the art of character development became increasingly overlaid with psychological and psychiatric analysis of the physician's character. Indeed, in the 1940s and 1950s, the Freudian model of psychological dynamics and of the doctor–patient relationship became prominent in the analyses of the virtues of physicians (Binger). Meanwhile, the increasing midcentury confidence in the social sciences tended to displace ethics terminology with concepts of "professional development," "human engineering," and so forth, sometimes even denigrating the admonitions of traditional morality as no more than "taboos." Ethics was often seen as so colored by religion that its teaching was bound to be covert indoctrination. In the secular climate of that time, any formal acknowledgment of ethics was suspect: Even the National Endowment for the Humanities, which eventually became a strong supporter of bioethics, originally excluded ethics from the list of the humanities whose study it would fund. Thus, ethics was rarely taught in higher education and even more rarely in medical education. This hiatus in the teaching of medical ethics during the 1950s may be seen as a prelude to the bioethics movement, in which neglected ethical questions forced their way back into the consciousness of the profession and the public alike.

The first national conference on the teaching of medical ethics was held in 1972 under the sponsorship of the Institute of Society, Ethics, and the Life Sciences and the Columbia University College of Physicians and Surgeons. By this time, out of 114 medical schools, only three required an ethics course and only thirty-three offered ethics as an elective (Veatch, Gaylin, and Morgan). The Society for Health and Human Values, formed in 1969, and its attendant Institute on Human Values in Medicine, encouraged medical ethics teaching. In the decade that followed, the number of schools providing organized teaching of ethics increased, and faculty members, often philosophers and theologians, were appointed. The content of the course shifted from the traditional topics, such as truth telling, confidentiality, care of the poor, care of the dying, and relations among practitioners, to the newer problems raised by technology and the social setting of modern medical care. In 1987 ninety-five American medical schools reported that they required a course in medical ethics, and the Association of American Medical Colleges strongly urged the inclusion of ethics in the curriculum (Bickel).

Nursing Ethics

Although medical students received little formal instruction in ethics, nursing schools developed a strong tradition of ethics teaching. Several major works on ethics were published by nurses at the turn of the century, notably *Nursing Ethics* by Isabel Hampton Robb (1901). Although her text is marked by a stern and self-sacrificing message to nurses, it includes sensitive discussion of many aspects of nurse–patient and nurse–physician relations. Textbooks on nursing ethics published in the first two decades of the century went through many editions before fading from popularity in the 1940s and 1950s. Notable among the authors were Charlotte Aikens and Thomas Verner Moore, whose books made extensive use of case studies. In 1931 religious educator Paul Limbert published a defense of nursing ethics courses: They were needed, he argued, to make ethical concerns explicit and to assist student nurses in interpreting their clinical experiences in such a way as to foster good professional character. As in the medical ethics of that era, the emphasis was on the character development of the nurse rather than on principle-centered or patient-centered ethics.

An important theme for nursing ethics has always been the impact of the feelings and character—the "humanness"—of the practitioner on the care and cure of the patient. As new technologies developed with increasing efficacy, practitioners felt the need to redefine the role of their personality in relationship to those technologies.

At the beginning of the twentieth century, nursing was predominantly a home-based practice; by the end of the century, it had become predominantly institution based. This redefinition of the nursing role provided a stimulus for some of the recurring issues in the nursing literature of the early part of the century. For instance, whether a nurse should do housework, such as washing diapers or tending the fire in the grate, was a significant issue until the 1950s. How the nurse should react to the errors of quacks and regular physicians continued to be a prominent issue. In all such cases, texts resolved the questions in terms of dedication to the welfare of patients. Indeed, nursing ethics took an early stand against permitting patients to be injured by other practitioners, including physicians, and nurses have taken an increasing role in institutional quality control.

Like physicians, nurses struggled with the problem of "irregular" practitioners. In the earliest part of the century, the "untrained nurse" was represented in the nursing ethics literature as ethically, as well as technically, incompetent. The emergence of the licensed practical nurse in the 1930s and the increasing number of nursing aides during the century challenged professional nursing, and the ethics of relationships with these occupations has been delicate. In the 1970s the American Nurses' Association took a stand that a bachelor's-level education was necessary for professional nursing, calling into question the standing of nurses trained in hospitals and community colleges. In the 1980s nursing was again challenged by a recommendation from the AMA, calling for the creation of a "registered care technician" to perform some of the technical functions of nurses. The ethics of the relationship of nurse to physician is still being debated in the nursing ethics literature. It is commonly asserted that power and gender relationships are central to the ethics of nursing. Original presentations of the ethics of nursing have appeared: The works of Mila Aroskar, Martin Benjamin, Joy Curtis, Anne Davis, Marsha Fowler, Sara T. Fry, Sally Gadow, Amy Haddad, Andrew Jameton, Christine Mitchell, James Myskens, and Michael Yeo are notable. Their work carries the themes of nursing ethics into the broader stream of bioethics. The bioethics movement has also touched the many other professions involved in the care of patients: dentists, occupational therapists, pharmacists, physical therapists, physician assistants, medical technicians, and social workers.

Ethical Issues in the Emerging Biomedical Technologies

In the years after World War II, the rapid advances of biomedical science were translated into clinical interventions that could save and sustain life in ways never before possible. These technological advances brought not only the benefits of improved health and prolonged life but also a range of puzzling moral questions (Jonsen, 1998). One of the first of these technologies to raise explicit ethical concerns was the 1961 invention by Belding Scribner at the University of Washington of a technique for chronic hemodialysis of persons with end-stage renal disease. Because the first artificial kidney center in Seattle, Washington had limited machines and trained personnel, it could serve only a tiny portion of the 15,000 or so persons in need of such lifesaving care. A committee consisting of seven lay members and two physician-advisers was chosen to select patients who would be admitted. Those who were not admitted would die. The committee employed social criteria, such as productive livelihood and respectable citizenship, for selecting candidates from among the many medically eligible patients. There was a strong public reaction and much severe criticism of using social values in life-and-death decisions (Fox and Swazey, 1974).

Philosophers and theologians noticed the issue and engaged in debate over it (Rescher; Childress; Ramsey, 1970b). The issue of rationing the scarce resource of dialysis was resolved in 1972 by an amendment to the Social Security Act providing payment for about 90 percent of the high cost of dialysis. This led to further discussion comparing the plight of other persons in high-cost disease categories, such as hemophilia, with that of kidney patients. In justice, the argument ran, various other groups ought to receive similar public aid. This early example of the ethical dilemmas posed by the new technology exemplified some of the themes that would become central to bioethics: the acceptance of lay opinion into decisions formerly reserved to physicians, the appearance of philosophical and theological analyses of the issue, the recognition of questions of fairness in application of medical resources, and the profound implications of life-and-death decisions. Indeed, the questions "Who should live? Who should die? Who should decide?" became the theme of bioethics.

The first heart transplantations were done in South Africa in 1968; similar operations were attempted shortly thereafter in the United States. Optimistic claims by medical innovators fostered public enthusiasm, which turned to disillusionment when, after three years, the very poor survival rate resulted in a virtual moratorium on heart transplants (Fox and Swazey, 1974). As heart and kidney transplantation became more effective, ethical issues surrounding organ donorship arose. To encourage cadaver donorship, the Uniform Anatomical Gift Act was proposed by the U.S. National Conference of Commissioners on Uniform Laws in 1968 and subsequently adopted by all states (Katz, Capron, and Glass). Because of high costs and the scarcity of organs, transplantation forcefully raised questions of whether the gains of new technology could justify the costs. At the same time, the determination of death, traditionally done by noting the cessation of cardiorespiratory functions, began to be questioned: These criteria seemed obsolete under conditions of artificial respiratory support and did not allow for removal of organs for transplantation. A vigorous debate ensued about the ethical and legal implications of shifting to clinical criteria that would focus on cessation of brain activity. In 1968 a committee at Harvard Medical School formulated a statement defining *brain death* as a criterion for declaring death (Harvard Medical School). Brain death criteria were accepted and legalized slowly, beginning in Kansas in 1970. Still, considerable confusion required further refinement of the concept, leading eventually to the recommendation of a Uniform Statute for the Determination of Death, which has now been adopted in most jurisdictions (U.S. President's Commission for the Study of Ethical Problems in Medicine, 1981).

During this same period, artificial implants to assist or replace the heart were being developed. Denton Cooley in Houston, Texas, unsuccessfully attempted to implant an artificial heart in 1969. In anticipation of the time when such a device might be ready for use in humans, the National Heart and Lung Institute in 1971 established a panel to study the possible ethical, social, economic, legal, medical, and psychiatric consequences of its development. This was the first effort by the federal government to explore the ethical implications of new medical technologies (National Heart and Lung Institute; Jonsen, 1973). The first actual implantation of an artificial heart—in Barney Clark, at Salt Lake City in 1982—aroused considerable debate about the appropriateness of this device (Shaw).

By the mid-1960s, issues of research ethics had begun to ferment among scientists (Ladimer and Newman). The Nuremberg trials in 1947 revealed the horrors of the Nazi concentration camps, where cruel and lethal medical experiments had been performed on prisoners. Several articles on the ethics of human experimentation had appeared in the American medical literature, but the ethical issues of biomedical experimentation with human beings were not widely discussed, perhaps because many believed that nothing so horrible could happen in the United States (Alexander; Annas and Grodin). During World War II, however, the intense efforts to improve the capabilities of military medicine occasionally spurred researchers to design experiments in which persons were treated dangerously and without their consent. In the years after the war, biomedical research was fueled by large infusions of funds from the newly expanded National Institutes of Health, and research projects were sponsored in hospitals throughout the country. As the volume and intensity of research increased, questionable practices appeared and were tolerated as the price to be paid in the war against disease. Informed consent of research subjects was rarely obtained, and oversight by anyone other than the researcher was unusual. In 1962 a number of children were born with serious congenital defects due to their mothers' ingestion of thalidomide, an unapproved drug. This tragedy stimulated congressional hearings at which the ethics of human experimentation, then largely uncontrolled, was aired. Subsequently, amendments to the federal Food, Drug, and Cosmetic Act in 1964 required full and free consent of all subjects of drug trials.

In 1966 Henry Beecher, professor of anesthesia at Harvard University, brought problems in the ethics of experimentation to the attention of the medical community. He detailed twenty-two medical experiments carried on by respected investigators that he branded as unethical because of lack of consent or inappropriate assessment of risks in relation to benefits (Beecher; Rothman, 1991). In 1966 (with revisions in 1968) the U.S. Public Health Service formulated guidelines for protection of the rights and welfare of human subjects in all federally supported research. In 1971 these guidelines became regulations of the Department of Health, Education, and Welfare, requiring research institutions to set up medical and lay panels to review all federally funded experimentation to ensure that subjects are informed and freely consent to the research procedure, and to determine that the scientific benefits justify the risks of the research (Levine).

A number of scandals in research ethics brought public attention to the need for regulation. At Willowbrook State Hospital in New York, a series of studies on hepatitis were conducted from 1965 to 1971 that involved infecting mentally retarded children with hepatitis virus. At the Jewish Chronic Disease Hospital in Brooklyn in 1963, live cancer cells were injected into senile patients without their knowledge or consent. In 1971 a study begun in the 1930s at Tuskegee, Alabama, came to public attention: A number of rural black men suffering from syphilis had been left untreated in order to ascertain the "natural history" of the untreated disease (Jones). In response to these and several other scandals, the U.S. Congress established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1974–1977) to make recommendations for federal policy on the broad problems of human subjects in research as well as the special problems posed by research with fetuses, children, prisoners, and other dependent or vulnerable persons. These recommendations were codified in federal regulations and are now widely enforced in research institutions. The field of bioethics was significantly advanced by the work of this commission. Several scholars in ethics sat on the commission, and many philosophers, theologians, lawyers, and sociologists were asked to contribute to its deliberations, thereby stimulating thought about the issues and making public careful analyses of the problems and principles. The commission's *Belmont Report* (1978), stating the principles of research with human subjects, first enunciated the triad of bioethical principles: autonomy, beneficence, and justice. Federal regulations codified the commission's recommendations, and for the next several decades clinical research, scrutinized for ethical probity by institutional review boards, proceeded without incident. In the late 1990s, however, several deaths and widespread evidence of inadequate review of research led to a revival of concern. The ethics of research returned to the agenda of bioethics.

It became increasingly common during the twentieth century for people to die in a hospital, often under conditions of dehumanizing technology. This reawakened age-old discussions of death, dying, and euthanasia, now in light of the new technical potential of modern medicine. Although there had been several unsuccessful attempts to make euthanasia legal in the early years of the century, death and dying had become a taboo subject in medicine. Elisabeth Kübler-Ross's sensitive interviews with dying patients, captured in her 1969 book, *On Death and Dying,* did much to awaken interest in the psychology of dying.

In 1976 the state of California passed novel legislation about termination of life support. The Natural Death Act authorized patients to sign a legal document directing physicians to remove or to withhold life-support devices under carefully defined circumstances. Many states have followed California by enacting legal forms of "advance directives" to guide physicians in following the wishes of their dying, incompetent patients. In 1976 a New Jersey Supreme Court decision allowed the parents of Karen Ann Quinlan—a young woman not quite dead by the Harvard brain death criteria, but who could be maintained indefinitely on a respirator with no hope of recovery—to have their daughter removed from the respirator (*In the Matter of Karen Ann Quinlan,* 1976). Subsequent judicial decisions in many states and one U.S. Supreme Court decision—*Cruzan v. Director, Missouri Department of Health* (1990)—have elucidated the conditions under which life support might be forgone. Many of these decisions have been influenced by the bioethical debates over active and passive euthanasia. In the 1990s, the debate over legalization of active euthanasia was renewed, spurred by the public perpetration of euthanasia by the physician Jack Kervorkian and by the advocacy of the Hemlock Society, which promoted legislation that would authorize physicians to provide "aid in dying" at the request of terminal patients. In the 1990s several states held initiatives to legalize this practice but only in the state of Oregon did the voters approve. Since 1994 citizens of that state have been permitted to seek, under stringent conditions, the aid of a physician to end their life. This and other efforts to make euthanasia legal have prompted important judicial decisions, even in the U.S. Supreme Court (*Vacco v. Quill,* 1997; *Washington v. Glucksberg,* 1997; Hillyard and Dombrink). These questions about the nature of appropriate care for the terminally ill, as well as many other ethical questions, are made more urgent by the increase in the numbers of elderly people in the United States: Since the beginning of the twentieth century, the number of Americans over the age of sixty-five has tripled in proportion to the general population (Jecker).

In 1978 the U.S. Congress reestablished the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research as the U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Among the new commission's mandates were studies of brain death, genetic screening, access to healthcare, and the use of life-sustaining technologies (U.S. President's Commission, 1981, 1983a, 1983b, 1983c). Like its predecessor, it called on scholars from many disciplines to contribute to its deliberations. Its reports make up a veritable canon of bioethics. Its recommendations on the definition of death have been enacted into law in all states as the Uniform Definition of Death Act.

The ascendancy of technological medicine inspired critical study of the nature of the healthcare professions and institutions. Popular and academic works investigated the conceptions of health employed in medicine and the efficacy of medical services offered (Illich). They explored the nature and authority of the health professions and raised questions about ethical responsibilities of health professionals whose attitudes are shaped by economic and social forces (Freidson). The proper role of health professionals has been questioned in many contexts, including the right of health professionals to strike and the extent to which they bear responsibility for patients' lives, for behavioral factors affecting health, and for social and political factors causing disease. The helplessness of individuals in the face of a massive medical establishment led to a patients' rights movement. As evidence of this concern, the American Hospital Association published *A Patient's Bill of Rights* in 1973, with the suggestion that it be adopted by all hospitals. Attempts to pass federal legislation in support of a Patient's Bill of Rights have been unsuccessful.

Reproduction and reproductive technology also fostered debate. During the first part of the century, birth control was an important issue in the feminist movement. Not until the late 1960s were restrictions on the use and teaching of birth control removed in most states. The feminist movement, especially through Margaret Sanger (1879–1966), also sponsored and encouraged research on new birth-control methods (Gordon). In the 1960s abortion became a center of debate. The discussion began with the American Law Institute's model statute permitting abortion for medical and psychological conditions as well as after rape and for fetal defect. The "responsibility for pregnancy" issue for the most part dropped from the debate as it became an issue of women's right to control their bodies, on one side, and the claim of the fetus's right to life, on the other, a claim largely, although not exclusively, urged by Catholics. The U.S. Supreme Court in *Roe v. Wade* (1973) chose a position protecting the mother's decision in the first trimester of the pregnancy, with increasing possibility for legal restrictions during the second and third trimesters. Abortion, because of its intriguing questions about personhood, stimulated considerable professional, philosophical, and theological reflection (Callahan, 1970; Grisez). That reflection has, in the 1990s and early 2000s, ceded to vigorous, even violent political activism. Whether the reflection or the activism will prevail in policy remains to be seen.

In the 1960s advances in genetics and reproductive technology caused much speculation about social consequences of such possible innovations as cloning, in vitro fertilization, and extrauterine gestation. The concern over cloning human beings, vigorously debated in the 1960s, when the question was still speculative, resumed in 1996, after the successful cloning of the sheep Dolly by two Scottish researchers (Ramsey, 1970a; MacKinnon). Interest in the potential and the dangers of genetic manipulation was heightened by the development of recombinant DNA technology in the mid-1970s. Amniocentesis (a test to diagnose certain fetal disorders during early pregnancy) and improvements in genetic history-taking made possible the development of genetic counseling as a profession in the late 1960s, with attendant ethical questions (Hilton et al.). Many questions considered speculative in the 1980s came close to realization by the early twenty-first century. The federally sponsored project to map the entire human genome has become a focus for the study of the ethical questions involved in genetic diagnosis, treatment, and social policy. Its Ethics, Legal, and Social Implications Project has sponsored a wide variety of scholarly and institutional activities in the ethics of genetics (Juengst and Watson; Cooke-Deegan).

Questions about the biological basis of personality, achievement, and social behavior continued to arise. In the early part of the twentieth century the eugenics movement fostered many state laws requiring or allowing sterilization of persons with mental retardation or illness. Debate over sterilization arose again around 1970, when protection of women and minority groups against pressure for sterilization became an issue. The role of genetics in behavior continued to be debated with the development of sociobiology and studies on IQ and heredity. There was disagreement over the goals of genetic counseling, as well as over whether genetic factors in behavior could or should be identified. Screening of populations for genetically determined conditions was much debated (U.S. President's Commission, 1983c; Holtzman).

Biology and behavior was also an issue in the treatment of mental disorders by surgical methods. Prefrontal lobotomy was widely used but much debated after its introduction in 1935. With improvements in surgical techniques in the 1960s, new types of brain surgery were attempted for treatment of violence and other indications. The use of psychosurgery on prisoners became a public issue (Valenstein). The National Commission for the Protection of Human Subjects issued a report on this practice that recommended only its strictly controlled experimental application. A related but quite different form of brain surgery involves the implantation of tissue from aborted fetuses into those suffering from certain neurological and endocrine disorders. This practice, initiated in the late 1980s, aroused great debate. Several advisory committees convened by the National Institutes of Health approved this form of research as acceptable public policy, yet the federal government refused for almost six years to fund studies (Vawter et al.). Although this precise form of therapy has yet to be proven efficacious, scientific interest in the therapeutic value of embryonic stem cells stirred up an ethical storm. On August 9, 2001, President George W. Bush told the nation that "Embryonic stem cell research is at the leading edge of a series of moral hazards." He announced that he would appoint a council to monitor stem cell research and investigate other bioethical questions. The President's Council on Bioethics was established on January 16, 2002, headed by a distinguished bioethicist, Dr. Leon Kass (U.S. President's Council, 2002; Green).

Although psychosurgery is the most physically invasive mode of treatment for behavioral problems, all levels of psychiatric treatment were subject to ethical inquiry. The warrant and nature of involuntary commitment to mental hospitals had been a source of contention for many years (Rothman, 1980). Commitment laws in many U.S. states were modified in the 1960s to increase protection of individuals from arbitrary commitment, although at the same time, the policy of deinstitutionalization thrust many mental patients into a world for which they were unprepared. The right of hospitalized mental patients to receive treatment was established in the United States initially by the Supreme Court decision in *Wyatt v. Stickney* (1972). The use of drugs in treating psychiatric disorders became an issue after chlorpromazine and related major tranquilizers became widely available in the 1950s, reducing the need for hospitalization. The conventional medical view of behavioral problems as disease came under attack from radical psychiatrists such as Thomas Szasz (1961). Goals and values in psychotherapy came to the fore in discussions about treating patients who manifested "antisocial" behavior. The growth of behaviorism and behavior modification seemed also to challenge traditional libertarian values. Rapid evolution of the neurosciences has resuscitated ancient ethical questions about free will and responsibility and raised new ones about the limits of enhancement of cognitive and affective life. Scholars in bioethics are only beginning to study these questions.

In 1981 a previously unknown disorder of the immune system appeared, at first in men known to engage in homosexual activities. This disorder, named acquired immunodeficiency syndrome (AIDS), was quickly traced to a blood-borne retroviral infection. The resulting disease was relatively slow to appear but was, given the therapeutic possibilities available, inevitably fatal. It spread in epidemic fashion among gay men and among those who shared needles while taking drugs intravenously. Fear of the disease and widespread homophobia led to discriminatory actions against those infected. Old ethical questions about restricting freedom of persons suspected of having a communicable disease were revived. Public health needs appeared to conflict with personal rights. The duty of healthcare professionals to treat infected persons was vigorously debated, as was the right of infected care providers to practice. Bioethics, by now adept at the discussion of practical ethics, made a major contribution to these debates (Bayer).

The problem of just allocation of healthcare had been noticed in the earliest days of bioethics. At that time, however, it was largely defined in terms of selection of patients for rare and expensive technologies, such as dialysis. In the early 1980s, it was recognized that some 35 million Americans were not covered by any healthcare insurance (U.S. President's Commission, 1983b; Dougherty; Churchill). Ethical questions about the justice of such a system were raised as health-policy experts began to note the rapid inflation in healthcare costs. Lack of access to care competed with cost containment in public debate and political maneuvering. These problems became central to the concerns of many bioethicists, who began to produce acute analyses of the issues of justice in the healthcare system and its financial base. These ethicists raised and examined the politically unpalatable issue of rationing of healthcare resources (Daniels; Callahan, 1988; Menzel; Morreim).

Academic Bioethics

As the 1970s opened, a number of scholars were beginning to attempt to analyze the issues discussed above within the perspectives and methodologies of the two disciplines traditionally concerned with ethics, philosophy and theology. As these scholars began to publish and communicate, a distinct field of study called bioethics came into being. The word *bioethics* was first applied to the ethics of population and environment (Potter), and soon became the rubric for a diverse collection of considerations about the ethical issues inherent in healthcare and the biological sciences (Callahan, 1973). The term, although considered unsatisfactory even by some of those who employed it, was canonized by the inauguration of the *Encyclopedia of Bioethics* project in 1972 and by the publication of the first edition, edited by Warren T. Reich, in 1978. The scholars in this new field now come from many disciplines, such as theology, philosophy, social sciences, and law. Bioethics concentrates on a specific set of issues, such as those mentioned above, and employs a range of analytic methodologies, explained in texts such as *Principles of Biomedical Ethics* (Beauchamp and Childress) for the more theoretical questions and in *Clinical Ethics* (Jonsen, Siegler, and Winslade) for the more practical questions. It has professors, students, texts, journals, learned societies, and research centers. At the beginning of the twenty-first century, more than a dozen graduate programs offer higher degrees to students trained in the topics and methods of the field.

Bioethicists show considerable interest in the theoretical definition of the field and its methodologies. Albert Jonsen and André Hellegers published an essay in the early days of the field's existence in which they saw it as a mélange of traditional professional ethics, philosophical ethics, and theological ethics (Jonsen and Hellegers). Robert Veatch, however, was the first to attempt a full exposition of the theoretical underpinnings of bioethics. His 1981 book, *A Theory of Medical Ethics,* set the field firmly on the ethical considerations relative to autonomy of the patient. H. Tristram Engelhardt Jr. followed in 1986 with *The Foundations of Bioethics,* an even more strongly stated thesis about autonomy as the basis of the discipline. Nevertheless, some have asserted that bioethics, while it had its origins in the strong affirmation of autonomy for patients, may have moved too far in this direction and thereby neglected other aspects of healthcare, such as benevolence, community, and social justice (Pellegrino; Daniels).

The study of bioethics, together with other fields in applied ethics, has inspired much debate about the methods appropriate to studying practical ethics in general. Many of these nascent methods have lent a richer, more detailed texture to ethical discussion than is permitted by principle- and theory-based ethics. The long-abandoned casuistry that employs rhetorical and analogical reasoning to examine cases is now being viewed with renewed and critical interest (Jonsen and Toulmin; Arras; Sugarman and Sulmasy). Mathematical decision analysis has been used to study values through systematically related cases (Smith and Wigton). Stories, real and fictional, are used as texts open to moral interpretation according to the methods of hermeneutics (Brody; Hunter), and phenomenology seeks to capture the ethical subtleties of clinical encounters (Zaner; Carson). Echoing the language of ethics from the nineteenth century, but with much greater attention to depth and detail, interest in virtue- and character-based ethics is vigorous (Drane; Shelp).

Although the early development of bioethics was dominated by male scholars, women such as Elizabeth Fee, Renée Fox, Loretta Kopelman, Karen Lebacqz, Ruth Macklin, Ruth Purtilo, and Judith Swazey have made significant contributions to theoretical and practical bioethics, and feminist ethics has begun to attract much attention. Feminist bioethics offers social criticism of the treatment of women as patients and physicians, discusses the interrelationship between gender and power, provides fresh analyses of issues of traditional concern to women (such as pregnancy, birth, and reproductive choices), and emphasizes important theoretical concepts—such as caring, community, and responsibility—neglected by male scholars (Holmes and Purdy; Sherwin).

Other authors note the ethnocentricity of U.S. bioethics; it has been charged with a failure to reflect the concerns of people of color, and new work is beginning to appear that increasingly reflects diverse viewpoints. Collections of narratives of the African-American experience with disease and healthcare have begun to appear (Secundy and Nixon; White). A Center for Bioethics was inaugurated at Tuskegee University at the time of President Bill Clinton's formal apology to African Americans for the Tuskegee syphilis experiments; this center will concentrate on ethnic issues in bioethics. Some authors have discussed the tensions between expressed philosophical ideals and systematic patterns of discrimination, such as abuses of birth control, sterilization, and selection of subjects for research (Dula; Flack and Pellegrino). U.S. bioethics is becoming more international and less ethnocentric in its concerns: American bioethicists visit many nations, and bioethicists from around the world spend time in American programs, stimulating cross-cultural comparisons and analyses (Fox and Swazey, 1984; Harding; Sagoff). American scholars are active in the International Association for Bioethics.

The tendency of ethics researchers to study clinical questions cooperatively with clinicians has inspired empirical study of ethics in healthcare. This in turn has fostered cooperation between the social sciences and normative philosophical ethics. Termed the *contextual approach* by some authors, it has begun to call attention to significant social and cultural features of life that affect ethical expression and debate (Weisz; Thomasma). Some researchers have used in-depth ethnographic techniques, such as participant observation and interviews, to study the microcontext of clinical settings; others are employing epidemiological methods to ascertain frequency of behaviors, such as resuscitation. The empirical social sciences and philosophy are beginning to converse with each other on the common ground of bioethics (Guellemin and Holmstrom; Bosk).

In the 1970s, as faculty members were appointed to teach ethics in medical schools, it became common for the ethicist to accompany physicians on teaching rounds. This led to the participation of ethicists in consultations about cases that presented particularly difficult ethical decisions. This practice came to be called clinical ethics. In 1977 ethicist John Fletcher was appointed assistant for bioethics to the director, Clinical Center, National Institutes of Heath, with responsibility for ethics consultation. Because philosophy itself provides little guidance about how to assist in actual decision making, various methods were devised to apply principles to practice. Clinical ethics spread from university hospitals to community hospitals; many individuals, physicians and philosophers alike, now act as clinical ethics consultants. The *Journal of Clinical Ethics* was initiated in 1991. As might be expected, some dispute surrounds the idea and practice of ethics consultation, because it seems to imply that some persons are "ethical experts," a notion rather foreign to a morally pluralistic culture (Fletcher, Quist, and Jonsen). The American Society for Bioethics and the Humanities published criteria for clinical-ethics consultation.

As the field of bioethics was beginning to form and as yet lacked institutional support for regular teaching and discussion, conferences and symposia were an important source for developing literature, teaching, and publicity. Some of the more important early conferences were the Joseph P. Kennedy, Jr., Foundation's International Conference on Abortion, held in 1967 in Washington, D.C.; a New York Academy of Sciences' conference, New Dimensions in Legal and Ethical Concepts for Human Research (Ladimer and Newman); a U.S. National Academy of Sciences Institute of Medicine's conference, Health Care and Changing Values, held in 1973; a series of transdisciplinary symposia on philosophy and medicine, the first of which was held in Galveston, Texas, in 1974 (Engelhardt and Spicker); and the 1975 conference Experiments and Research with Humans: Values in Conflict, sponsored by the National Academy of Sciences. In the 1990s such conferences, on a wide variety of topics, were announced at a dizzying pace.

Several privately funded institutes are devoted primarily to the study of bioethics. The Institute of Religion, established in 1954 at the Texas Medical Center, Houston, began to devote attention to bioethical issues in the late 1960s. The Society for Health and Human Values evolved in 1969 from a smaller interdisciplinary group that had formed the Committee on Health and Human Values in 1963 with support from the ecumenical United Ministries in Higher Education. In 1998 the Society for Health and Human Values, the Society for Bioethics Consultation, and the American Association for Bioethics united to form the American Society for Bioethics and the Humanities, which by 2002 had enrolled 1,500 members, drawn from bioethics, medicine, nursing law, religion, and the social sciences. The Hastings Center, originally called the Institute of Society, Ethics, and the Life Sciences and founded in 1969 by Daniel Callahan and Willard Gaylin, investigates social, legal, and ethical aspects of the health sciences. It conducts a program for visiting fellows and associates; publishes the most widely read of the ethics journals, *Hastings Center Report* and *IRB: A Review of Human Subjects Research;* organizes study groups on special topics; and conducts courses for health professionals and others. In 2002 the Hastings Center had 109 fellows and almost 12,000 members.

For several years in the 1970s, the Joseph P. Kennedy, Jr., Foundation funded the Interfaculty Program in Medical Ethics, which joined Harvard University's Medical School, School of Public Health, and Divinity School to train scholars in this new field. In 1971 André Hellegers founded the Joseph and Rose Kennedy Institute for the Study of Human Reproduction and Bioethics, now known as the Kennedy Institute of Ethics, at Georgetown University. This program, initially financed by the Kennedy Foundation, has supported research by permanent and visiting scholars, courses and workshops in bioethics, and cooperative and consulting programs with private and governmental institutions. The Kennedy Institute has specialized in the creation of fundamental research tools in the field of bioethics. Starting in 1972, the institute sponsored Warren Reich's project for the preparation of the *Encyclopedia of Bioethics,* a landmark in U.S. bioethical studies. Its National Resource Center prepares the computer-based bibliography of bioethical literature called Bioethicsline, a part of the National Library of Medicine's Medlars network; Bioethicsline is also published in book form as *Bibliography of Bioethics* (Walters). The Kennedy Institute originated the important *Journal of Philosophy and Medicine,* which is now published independently, and currently produces the *Kennedy Institute of Ethics Journal.* In 1993 the American Association of Bioethics came into existence to promote the exchange of ideas among bioethics scholars, encourage the development of new scholars, and maintain contact with international societies in bioethics.

As bioethics flowered, many ethical issues were being debated as matters of public policy. Some bioethicists found themselves working as public employees to aid in policy formation, and others served as members of and consultants to advisory bodies such as the National Commission for the Protection of Human Subjects, the U.S. President's Commission for the Study of Ethical Problems in Medicine, the now defunct Ethics Advisory Board of the Department of Health and Human Services, and state bodies such as New York's Task Force on Life and the Law and New Jersey's Bioethics Commission. Ten of the eighty-two "special government employees" working with the 1993 Task Force on Reform of Health Care were persons identifiable as bioethicists. The National Bioethics Advisory Commission was established by an executive order of President Clinton in 1995, and during the next six years this commission produced a series of excellent reports on such issues as cloning of human beings, stem cell research, and research involving persons who have mental disabilities. Beyond these official bodies, several thousand physicians, nurses, clergy, and laypersons sit, often with bioethicists, on the hospital ethics committees that have, since the 1980s, become part of most medical centers in the United States. Grassroots bioethics activities, such as the Oregon Health Decisions Project, strive to involve laypersons in making decisions about the ethics of healthcare allocation policy. Bioethics has become, to some extent, a philosophy for the people.

The bioethics movement has demonstrated extraordinary vitality in the United States since the 1970s. Its work effected significant changes in the practices of healthcare. Its first historian, David Rothman, wrote, "The record since 1966, I believe, makes a convincing case for a fundamental transformation in the substance as well as the style of medical decision making" (Rothman, 1991, p. 251). That transformation consists largely in the flow of lay opinion and judgment into the formerly closed world of medical decision and policy, in both clinical and research settings.

By the 1990s, bioethics was firmly established as a field of study within academic settings. This gives it a prestige and institutional base that it had previously lacked, but that may also imperil its vitality and independence. Although initially seen by some as a fad, bioethics is linked with social and personal issues deeply rooted in the culture of the United States during the twentieth century. The impact of technology on human life, the distribution of increasingly scarce health resources in an otherwise affluent society, the role of government in the pursuit of health by individuals and populations, and the voice of the consumer-patient in decisions about medical care—all these issues are central to the concerns of bioethics. Inevitably, ethical issues in the life sciences also embrace the larger social problems of environment and population. It is likely that the diffuse field of bioethics will take shape as it increasingly finds its place in the education of future health professionals, as it becomes part of the attempt by schools and consumer organizations to increase personal responsibility for health and environment, and as it attends to the formulation of public policy about social life in the biosphere.

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III. CANADA

Two aspects of Canadian society are particularly determinative of the Canadian approach to bioethics: (1) the country's universally accessible, publicly funded healthcare system, and (2) the role of law. While a multitude of bioethical issues have occupied Canadians since the 1960s, there have been three major areas of bioethical activity: clinical ethics, research ethics, and ethics in public policy. The history of bioethics in Canada can be divided into two time periods: from 1800 to the 1960s, and from the 1960s to the present. During the first period, medical ethics predominated, although theological ethics and the ethics of nursing were also important. Since 1960, the field of medical ethics has been incorporated into the broader field of bioethics.

Medical Ethics: 1800–1960

In 1867, the year of Canada's formation as a nation, the Canadian Medical Association (CMA), came into being. At its first annual meeting in 1868, the CMA adopted the Code of Ethics of the Canadian Medical Association, which was closely modeled on the American Medical Association's code of ethics. Since then there have been a number of revisions to the CMA Code of Ethics, most recently in 1996. This code outlines general responsibilities, responsibilities to the patient, responsibilities to society, responsibilities to the profession, and responsibilities to oneself.

The Canadian Nurses Association (CNA) was established in 1908. However, the association did not have a code of ethics until 1954, when it adopted the one that had been prepared the previous year by the International Council of Nurses. In 1980 the CNA moved to establish its own code, which was published as *CNA Code of Ethics: An Ethical Basis for Nursing in Canada.* This code has since been revised on a regular basis (1985, 1991, 1997, and 2002) and is now entitled *Code of Ethics for Registered Nurses.* The content is structured around three themes: (1) the nature of ethics in nursing, (2) nursing values defined, and (3)nursing values and responsibility statements.

The Roman Catholic Church has played an important role in healthcare in Canada since colonial times. The Catholic Hospital Association of the United States and Canada (CHAUSC), founded in 1915, adopted a code of ethics in 1921 that dealt primarily with surgical issues in obstetrics and gynecology. This document was updated in 1935, and in 1949 it was revised and published as *Ethical and Religious Directives for Catholic Hospitals.* In 1954 the Catholic Hospital Council of Canada (established in 1942) declared its independence from CHAUSC and renamed itself the Catholic Hospital Association of Canada. It adopted its own moral code in 1955. Now known as the Catholic Health Association of Canada, this organization updated and renamed its moral code, the *Health Ethics Guide,* in 1971, 1991, and again in 2000. This document addresses issues related to social services and organizational ethics. The core focus areas for the Catholic Health Association of Canada are ethics, spirituality, values development, and social justice.

Canadian contributions to the medical ethics literature were few and far between until the 1940s. The most renowned Canadian physician of this period, Sir William Osler (1849–1919), made few references to medical ethics in his many publications. He did, however, have a great deal to say about the practice of medicine and about physician behavior. The chief virtues of the individual physician are variously referred to in his writings as equanimity (*aequanimitas*), imperturbability, and detachment. His stated ideal for the medical profession was that of "noblesse oblige" (Osler).

Not until the 1940s did a significant number of Canadian publications in medical ethics begin to appear, most of them written by Catholic theologians (e.g., LaRochelle and Fink). Some Catholic schools of medicine (e.g., the University of Ottawa) and nursing (e.g., the University of Montreal) made faculty appointments in medical ethics; and the professors who took these posts contributed to the growing body of Catholic literature in this field (e.g., Paquin,). However, comparable work by philosophers and health professionals was noticeable by its absence.

Bioethics: 1960s–2000s

Beginning in the mid-1960s, the field of medical ethics underwent a radical transformation, and by the end of the 1970s it displayed all the features of what has become known as bioethics. In Canada the major actors in the development of bioethics have been professional associations, public commissions, and academic institutions.

The major professional health associations expanded their ethics activities during this period. In the early 1980s the CMA remandated its Committee on Ethics to deal with the whole range of bioethical issues, rather than those affecting only physicians. In 1989 the CMA established a Department of Ethics and Legal Affairs. The Royal College of Physicians and Surgeons of Canada created a Biomedical Ethics Committee in 1977, and the College of Family Physicians of Canada followed suit in 1991. The Canadian Nurses Association established an ad hoc ethics committee that met regularly from 1985 to 1997 to revise its code of ethics. In the Spring of 1997 this committee was given permanent standing.

A favored way of dealing with contentious social issues in Canada is through public commissions, such as federal and provincial law reform commissions. The federal Law Reform Commission was established in 1971 to review the federal laws of Canada on a continuing basis, and to make recommendations for their improvement, modernization, and reform. Bioethical issues were dealt with in the Protection of Life Project, one of four commission projects. Between 1979 and 1992, a dozen or so study papers, working papers, and reports to Parliament were published on topics such as euthanasia and assisted suicide, experimentation on human subjects, and medically assisted procreation. In 1992 the commission was terminated by the government for budgetary reasons. Five years later, in 1997, the federal government created the Law Commission of Canada. This commission has not undertaken specific projects concerning bioethics, but it has supported work on the governance of research involving humans.

Academic institutions have experienced tremendous growth in the area of bioethics since the 1960s. Courses in this field have proliferated in philosophy and religious-studies departments, where they are often the most heavily subscribed offerings. Bioethics instruction is now offered in every Canadian medical school at the basic degree level and is rapidly expanding into residency training programs. Nursing, health administration, and dentistry programs have also formalized ethics teaching, and in many universities instruction in the ethical aspects of animal experimentation is required for biology, zoology and psychology students.

Research in bioethics has been fostered by the creation of centers, institutes, and professional associations for practitioners in this field. The Center for Bioethics of the Clinical Research Institute of Montreal, established in 1976, was the first such organization in Canada. It was followed three years later by the Westminster Institute for Ethics and Human Values, based in London, Ontario (now defunct). By 2002 there were at least nineteen research centers and groups in Canada, most of them university based. A national association, the Canadian Bioethics Society, was formed in 1988 through a fusion of two previously established associations.

The Institutional Matrix of Bioethics

The Canadian healthcare system and Canadian law have been two of the most important forces shaping the context within which bioethics has developed in Canada. The healthcare system has also been the source of some of the most difficult bioethical issues Canadians have faced since 1971, when the country's national health insurance program was fully set in place (Taylor). Although Canadian legislation and jurisprudence have largely guided and supported work in bioethics, there have also been points on which they have clashed.

THE CANADIAN HEALTHCARE SYSTEM. The Canadian healthcare system is in reality not a single system, but rather a network of ten provincial and three territorial healthcare systems. The coherence of this network derives from the Canada Health Act (1984) and a series of accords between the federal, provincial, and territorial governments. The federal government provides funds to the provinces and territories for healthcare; the latter governments, in return, agree to incorporate the essential features of the national health insurance program into their healthcare systems. This sharing of responsibility is currently being challenged, however.

The Canadian national health insurance system, as defined in the Hospital Insurance Act (1957) and reaffirmed in the Canada Health Act (1984), is founded on a values system to which the Canadian people fiercely adhere. The principal features of this program (comprehensiveness; universality; accessibility; portability; and public administration) derive from Canadians' commitment to the principle of equality. Equality before the healthcare system, as Robert Evans has phrased it, is as strong a principle in Canada as equality before the law (Evans). The basis of this principle is that all Canadians should have access to a similar level of care, regardless of their ability to pay for it.

There have been challenges, however, to the Canadian healthcare system's principle of universal access to hospital and medical services. The practice of user fees and extra billing by doctors, which is prohibited by the Canada Health Act, represented one such challenge. Extra billing would allow doctors to bill patients for charges exceeding what the national health insurance plan paid doctors for a medical service. For a short time in the mid- to late 1980s extra billing occurred in seven provinces. In response to this violation of the Canada Health Act, the federal government stopped transfer payments to these provinces, thereby providing the provincial governments with the necessary incentive to enforce the principles of the Canada Health Act. Extra billing has not occurred since.

The way a country organizes its healthcare system as a whole is not just an issue of economics and administration. It is also an issue of public ethics and is deeply rooted in the conflict between powerful interest groups and the requirements of justice (as interpreted by a society's governing ethos. The Canadian ethos of universal access with equal terms and conditions for all is being challenged by new questions of fairness. For example, the current Canadian Medicare program pays for physician and hospital services, but not drugs (unless these are administered in a hospital). For many patients, good health depends upon access to expensive medications, and since these are not covered by the national health insurance system they are at risk of incurring significant debt or, worse, doing without their medications.

Another issue concerns waiting lists. Some individuals who do not want to wait to access needed health services and who have the resources to pay for these services argue that they should not be prohibited from purchasing what they are able to pay for. Some of these concerns are examined in the final report of the National Forum on Health, which focused on values, striking a balance, the determinants of health, and evidence-based decision making The forum paid particular attention to the need to balance resources within the health sector, and between the health sector and other sectors of the economy (National Forum on Health). The emphasis in these reports was on the core Canadian value of equal access to care irrespective of ability to pay. The National Forum on Health called on the federal government to expand public health insurance to home care and drugs.

In 2002 there was renewed debate about the future of the Canadian healthcare system with particular focus on two issues: (1) public administration (whether there should be a single- or multi-payer system), and (2) delivery of goods and services (whether this should be public, private not-for-profit, or private for-profit). Two reports looked at the sustainability of the universally accessible, publicly funded healthcare system with particular attention to the question of whether Canada should move to a two-tier system by allowing the use of private hospitals and private insurance. The first of these reports was issued by the Senate Standing Committee on Social Affairs, Science and Technology, which undertook a study on the state of the healthcare system in Canada. The report is widely known as the Kirby Report—in reference to Senator Michael Kirby, who chaired the Committee. It endorses an increased role for private healthcare corporations.

The second report, Building On Values: The Future of Health Care in Canada, is by the Commission on the Future of Health Care in Canada (widely known as the Romanow Report, after the commission chair, Roy Romanow). The report examines four strategies for continuing to ensure access to high quality of care regardless of ability to pay: (1) more public investment (paid for by raising taxes or diverting resources from other programs), (2) more user pay (through charging fees as an incentive to deter abuse), (3) an increase in private choice (either for-profit or non-profit), or (4) a complete reorganization of the healthcare delivery system. A commitment to health care as a social good and service, not an economic commodity only available to those who can pay, informs the analysis.

BIOETHICS AND LAW IN CANADA. In Canada, the Constitution Act (1867) was amended in 1982 through the introduction of the Canadian Charter of Rights and Freedoms. This charter obliges government actors not to violate rights considered fundamental. Such rights include life, liberty, and security of the person; freedom of conscience, thought, belief, and expression; and freedom from discrimination. Democratic support for legislation that violates the charter does not compel the courts to uphold the legislation, since the charter protects fundamental freedoms and legal rights against even democratically composed majorities. This is illustrated in the 1988 Morgentaler decision of the Supreme Court of Canada, in which a law passed by a democratically elected government was struck down by the Supreme Court of Canada because it violated the charter.

Another significant case is the 1991 Ontario Court of Appeal decision in *Malette v. Shulman.* A Jehovah's Witness woman was taken to the hospital unconscious and bleeding after a car accident. The physician attending her was informed that she was carrying a signed but undated card refusing blood products, but he nonetheless gave her a transfusion in order to prevent her death from heavy loss of blood. The patient, Georgette Malette, sued him for the civil wrong of battery (unauthorized touching) and was awarded a favorable judgment, which the Ontario Court of Appeal upheld. The trial judge observed that, while the transfusion may have saved her life, the principle of respect for autonomous persons prevailed over principles of beneficence and nonmaleficence. In other words, society may not share her priority of interests, but it must respect her autonomy.

From the mid-1970s through the mid-1980s, numerous symposia, workshops, and position papers reflecting the thinking of a cross-section of Canadians supported the conclusion that contraceptive sterilization, in some circumstances, would be truly beneficial for some mentally disabled persons, as it would allow them to enjoy sexual fulfillment without the risk of bearing and rearing children. There was controversy only regarding the process that would be used to select individuals eligible for sterilization. It was not clear what conditions had to be fulfilled to protect mentally disabled persons from being sterilized for someone else's benefit. However, a 1986 decision of the Supreme Court of Canada (*Eve v. Mrs. E.*) clarified the law and dramatically affected practice. The Court declared categorically that sterilization should never be authorized for nontherapeutic purposes. In the absence of the affected person's consent, the Court believed that it can never be safely determined that such sterilization is for the benefit of that person. This decision has proved to be difficult for clinicians, parents, those with institutional responsibility for the care of mentally disabled persons, and, perhaps, for the latter themselves, for their social lives and privacy in relations with members of the opposite sex may be restricted for fear of pregnancy. This decision also serves as a focus for continuing discussions about what should be done when what is judged by some to be ethically justifiable has been declared to be illegal or unconstitutional.

Key Issues

Although Canadians have been preoccupied with many bioethics issues, the following discussion is limited to those issues that have most intensively mobilized the thought and action of Canadians in the fields of clinical ethics, research ethics, and ethics in public policy.

CLINICAL ETHICS. Several court cases in Canada illustrate the interplay between clinical ethics and jurisprudence when decisions have to be made regarding cessation of medical treatment. An ethical and legal consensus has grown in Canada since the late 1980s in support of the view that physicians are justified in withholding or discontinuing treatments that do little more than prolong a patient's dying and suffering. However, there continues to be debate about physician-assisted suicide and euthanasia, as illustrated in the legal cases summarized below.

In 1992 the Superior Court of Quebec affirmed that the request of a competent patient to discontinue life-supporting treatment should be honored (*Nancy B. v. Hôtel-Dieu de Québec*). Nancy B., a twenty-five-year-old woman, was permanently dependent on a respirator due to Guillain-Barré syndrome. After two years, while lucid and without clinical depression, she asked that the respirator be stopped, knowing that this would lead to her death. The court held that discontinuing treatment would not constitute criminal negligence or homicide. In so ruling, it cited the Canadian Law Reform Commission's recommendation that ambiguous sections of the Criminal Code of Canada should be changed so that the criminal law of Canada could not be interpreted as obliging physicians either to treat patients against their informed and free refusal or to initiate or continue treatments that are therapeutically useless and not in patients' best interests (Law Reform Commission).

A year later, in 1993, Sue Rodriguez—a competent woman suffering from amyotrophic lateral sclerosis who wanted to commit assisted suicide—brought a challenge to the prohibition against assisted suicide found in the Criminal Code. The Supreme Court of Canada upheld the prohibition by a five-to-four margin based on their application of the Charter of Rights and Freedoms to the facts of the case. Despite this decision, Sue Rodriguez ultimately died as a result of physician-assisted suicide, and no one was prosecuted in connection with her death.

Also in 1993, Robert Latimer was charged with first-degree murder in the death of his twelve-year-old daughter, Tracy Latimer. Mr. Latimer had placed his severely handicapped daughter (a quadriplegic child with the intellectual capacity of a three-month-old) in the cab of his truck and, with the intent of alleviating her suffering, asphyxiated her with carbon monoxide. In 1994 Mr. Latimer was convicted of second-degree murder and given the mandatory sentence of life imprisonment without eligibility for parole for ten years. He successfully appealed his conviction to the Supreme Court of Canada, and a new trial was ordered. In 1997 Mr. Latimer was tried again on a charge of second-degree murder, was again convicted, but was now sentenced to two years less a day (instead of the mandatory sentence of at least ten years in prison). Mr. Latimer again appealed his conviction and the Crown appealed the sentence. The Court of Appeal dismissed Latimer's appeal, allowed the Crown's appeal, and imposed the mandatory minimum sentence. Mr. Latimer then appealed to the Supreme Court, and in 2001 the Court upheld the conviction and the life sentence with no parole for ten years.

These cases show that the courts in Canada will respect the wishes of competent patients to refuse life-sustaining treatment, reject the wishes of competent patients to actively bring about their own death through physician assisted suicide, and not tolerate deliberate actions to bring about the death of another person even when the motive is to alleviate suffering.

RESEARCH ETHICS. Canadians have been intensively occupied with elaborating the conditions for ethically acceptable research involving humans. In August 1961, Walter Halushka volunteered to be a research subject in a project to test a new anesthetic drug. Halushka suffered a cardiac arrest during the experiment, and though successfully resuscitated, he was left with some brain damage and could no longer continue his university studies. The Court of Appeal found that the physician-researchers had failed to inform Halushka that the test was of a new drug, that they had little previous knowledge about this drug, that the drug was an anesthetic, and that there was risk involved in its use. The investigators also failed to tell the subject that the test would involve putting a catheter up a vein in his arm into his heart. The Court of Appeal clarified the requirements for consent in the research setting:

> There can be no exceptions to the ordinary requirements of disclosure in the case of research as there may well be in ordinary medical practice.… The subject of medical experimentation is entitled to a full and frank disclosure of all the facts, probabilities and opinions which a reasonable man might be expected to consider before giving his consent. (*Halushka v. the University of Sasktchewan et al.*)

Though patients are rarely harmed seriously in clinical research, serious harm, and even death, can and does occur. It is particularly tragic when a research-related death occurs that might have been avoided if consent negotiations had been adequate. On October 13, 1981, Julius Weiss, a sixty-two-year-old man, died in a Montreal hospital while participating in a research project being conducted to test the efficacy of a drug (indomethacin, administered by eyedrops) designed to reduce swelling in the eye after cataract surgery. This project also required that Weiss undergo a series of radiological examinations called fluorescein angiograms to gauge the effects of the indomethacin eyedrops. Weiss had a history of heart problems and went into convulsions following a drop in blood pressure after the first injection of fluorescein dye. His heart stopped, resuscitation attempts failed, and he died. Weiss's widow and children sued the two physicians involved in the clinical study and the hospital where the study was conducted. In his judgment on this case, rendered on February 23, 1989, Judge Louis De Blois of Quebec Superior Court found that the patient would not have agreed to be in this project had he known it carried even a small risk of cardiac arrest and death (see *Weiss v. Solomon*).

In Canada, unlike other countries, health research involving humans is governed primarily by guidelines, not legislation. The first such guidelines were promulgated by the Medical Research Council of Canada in 1978 and later revised in 1987. Some years later, in the wake of a number of research-related controversies, a Tri-Council Working Group involving all three federal research funding agencies—the Medical Research Council of Canada (MRC), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC)—was convened to develop a common set of ethics guidelines that would govern virtually all publicly funded research involving humans in Canada (an international first). In 1998 the Tri-Council Policy Statement on Research Involving Humans was adopted. These guidelines outline the expectations regarding ethics review and set out the rules for researchers and institutions that receive public funds for research.

ETHICS IN PUBLIC POLICY. Between the 1960s and the 1990s, the issue of abortion dominated the public-policy debate in bioethics. The debate was ignited in the late 1960s, when the federal government proposed changes to the Criminal Code that would relax restrictions on divorce, homosexual acts between consenting adults, the distribution of contraceptives, and abortion. The last issue was the most contentious and engendered widespread public discussion and lobbying of members of Parliament. The law in effect at the time prohibited termination of pregnancy under any circumstances, and criminal sanctions could be brought against the pregnant woman and anyone who would perform the abortion. In 1969 a new abortion law (section 251 of the Criminal Code) was adopted that retained the criminal sanctions against both the woman seeking an abortion and anyone who would perform the act, but legalized termination of pregnancy if the following conditions were met: (1) the abortion had to be performed by a qualified medical practitioner in an accredited or approved hospital; (2) it had to be approved by a therapeutic abortion committee of the hospital; and (3) the continuation of the pregnancy would, or would be likely to, endanger the life or health of the woman seeking the abortion.

Following this liberalization of the abortion law, there were many complaints of unequal access to abortion services, as well as accusations from antiabortion groups that the law was being applied too loosely. Since the federal government refused to revise the law, both proponents and opponents of abortion decided to challenge the law in the courts.

In 1970 Dr. Henry Morgentaler established an abortion clinic in Montreal, in clear opposition to the law. After his third jury acquittal, in 1976, on charges of performing an illegal abortion, the Quebec government allowed his clinic to operate, despite vigorous protests from antiabortion forces.

In 1983 Dr. Morgentaler set up an abortion clinic in Toronto and was promptly arrested and charged, along with two colleagues. A jury once again acquitted him. This decision was appealed, and in 1985 the Ontario Court of Appeal overturned the decision of the jury and ordered a new trial. Dr. Morgentaler appealed this ruling to the Supreme Court of Canada. On January 28, 1988, the Supreme Court, in a 5-to-2 decision, overturned the Court of Appeal decision and restored the original jury acquittal. The Court also declared the 1969 abortion law unconstitutional because it violated the Canadian charter of rights and freedoms.

The Supreme Court heard another abortion-related case in 1988, this one initiated by an opponent of abortion. In 1981, Joe Borowski, a former Manitoba politician and antiabortion activist, challenged the 1969 abortion law on behalf of the fetus. A Saskatchewan court heard the case in 1983, and in its judgment rejected Mr. Borowski's claim that the fetus is a person with legal rights. Mr. Borowski appealed this decision. In 1989 the Supreme Court declined to decide the case because the appeal was moot, due to the abortion law having been struck down.

Between 1988 and 1991, the federal government made several attempts to pass a new abortion law, but none were successful. A bill introduced in 1989 would have recriminalized abortion except when performed by a doctor "of the opinion that, if the abortion were not induced, the health or life of the female person would be likely to be threatened." (Bill C-43 An Act respecting abortion, 2nd Sess., 34th Parl., 1989; defeated in the Senate January 31, 1991). Health was defined as including physical, mental, and psychological well-being. The bill was approved by the House of Commons in May 1990 by a narrow margin (140–131), and it was then sent to the Senate, where it received detailed examination. In January 1991, a vote was taken, but the Senate was deadlocked. Under Canada's Senate rules, a tie is considered a defeat. As a result, Canada is in the unusual circumstance of having no criminal restrictions on abortion.

New reproductive technologies have also generated considerable public-policy activity in Canada and have been the subject of several public inquiries, including a federal Royal Commission, which received and commissioned many submissions focusing on the ethical aspects of reproductive technology. Feminist concerns (e.g., regarding commercialization in paid contractual pregnancies) have figured prominently in the Canadian discussion of these issues (Overall; Sherwin). In 1996, Bill C-47, the Human Reproductive and Genetic Technologies Act, was introduced in the House of Commons. This bill died on the Order Paper, however, when an election was called before the legislative process was complete. (Bills under consideration that have not received royal assent are on the Order Paper. When an election is called, all such bills are considered dead.) Years later, in May 2002, Bill C-56, the Assisted Human Reproduction Act, was introduced. Ironically, it too died on the Order Paper in September of the same year when Parliament was prorogued (to terminate or suspend a legislative session). Bill C-56 did not share the same fate as the earlier bill, however, in that it was reinstated as Bill C-13, which at the time of writing was continuing through the legislative process. Interestingly, much of the public debate around this bill has not been about assisted reproduction, but about whether the embryos that remain after infertility treatment can be used for human embryonic stem cell research.

The Future

Canada is a multicultural nation. For the most part, however, bioethics has been (and continues to be) monocultural, reflecting the values of the white, largely Anglo-Saxon, professional class that has dominated Canadian society, including its science and medicine. If bioethics is to be relevant to Canadian society in the future, it must develop a multicultural sensitivity and expand the range of issues it considers, the perspectives from which the issues are viewed, and even the backgrounds of individuals working in the field.

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IV. LATIN AMERICA

This entry presents a historical panorama of biomedical ethics in Latin America, the name given to a linguistic and cultural community encompassing South America, Central America, Mexico, and part of the Caribbean. From political, economic, and social points of view, the Latin American nations are quite different, although at present they have underdevelopment in common.

Since bioethics as a discipline flourished first in the United States, it is useful to compare medical ethics in North America, with its predominantly Anglo and northern European culture, and in Latin America, pointing out the differences between the two traditions within the Western culture.

First, the Latin American tradition of medical ethics is described; next, the incipient bioethics movement in Latin America is considered; then the major bioethical problems of the region are noted; and finally, the challenge to Latin American bioethics is discussed.

The Latin American Tradition of Medical Ethics

When Spain and Portugal established colonies in the Americas, they brought with them the profound influence of the Roman Catholic Church, heir to that Western culture whose roots are Greek philosophy, Judaism, and Roman law. The Catholic tradition has in fact defined Latin American ethics and the Latin American ethos. First, Catholic moral theology built a system of medical ethics based on (1) natural-law theory as the basis of morality; (2) the principle of the sanctity of human life as a moral criterion; and (3) the commandment of love, or the virtue of charity, as the golden rule. Second, through their pastoral role and religious authority, priests reinforced the paternalistic medical ethos of the Hippocratic tradition. The paternalistic model of medical responsibility centered on the principle of beneficence (that benefit must be produced and harm avoided); the principle of autonomy is not taken into account. Beneficent paternalism has dominated the relationships between doctor and patient, and between medicine and society, in Latin America up to the present day.

As the cultures of northern and southern Europe evolved in the Americas, the differences between the two were accentuated. Modernity did not have the same secular, liberal, and pluralistic cast in Latin America as it did in North America. In Latin America, morality was not detached from metaphysics and religion; it did not establish a new basis in scientific and political rationalism, nor did it set itself up as critical and autonomous over against the natural and supernatural order of the medieval epoch.

Beginning in the eighteenth century, it is possible to contrast two ethics: the classical tradition of virtue, represented by the Mediterranean peoples (particularly the Italians and Spaniards), and the tradition in which principles are central, dominant in the English- and German-speaking countries (Mclntyre). In Latin America, the political paternalism of the *ancien régime* and the medical paternalism of the Hippocratic tradition go together; the result is a paternalistic model on both the individual-clinical and the social policy levels.

The ethics and ethos of Latin American medicine are expressed in professional codes of ethics and in health policy and legislation. The forebear of all these normative institutions was the *protomédicato.* Originating in the Roman Empire, the *protomédicato* was a tribunal of royal physicians (*protomédicos*) that granted professional licenses and acted as a judicial and legislative body in health matters. In the thirteenth century, Castile was one of the first kingdoms to establish legal regulations for medical practice and public health; examples of this were found in the School of Salerno, and the laws of Frederick II in Sicily (Mainetti, 1989). The *protomédicato* was transplanted from Spain to the Americas, where it endured until the period of independence (early nineteenth century), at which point medical instruction, practice, and policy began to be modernized.

In the twentieth century, professional associations and medical colleges in various countries began to formulate their own codes of ethics, in accordance with the deontological tradition that regulates the relationships of doctors among themselves, with the public, and with the state. One of the first such codes was drawn up in 1918 by Luis Razetti, a leading Venezuelan physician who specialized in medical deontology, under the influence of the French—an influence that was at that time very perceptible in Latin American society in general and in the medical culture in particular. This same code was later adopted in Colombia (1919) and in Peru (1920); it provided a basic model for other Latin American codes, which are essentially traditional guides for professional courtesy or etiquette, the relationships of physicians among themselves, with the patient, and with the state (León).

The medical codes promulgated in many Latin American countries are influenced by a variety of factors, among them biomedical progress, malpractice legislation, and the political changes throughout the region after decades of military rule. Brazil's Federal Code of Medical Ethics (1988), for example, incorporates concern about new problems like AIDS, and reformulates the rule of medical confidentiality. The Medical College of Chile has been very active since 1984, demonstrating its sensitivity to—among other issues—the participation of Chilean physicians in torture during the years of authoritarian rule that ended in 1984 (Mainetti, 1990).

The state's responsibility for healthcare has constitutional status in Latin American countries (Pan American Health Organization, 1989). The right to healthcare is included among social and economic rights. The first nation to incorporate the right to healthcare in its constitution was Chile, in 1925, followed by Bolivia, Cuba, Guatemala, Guyana, Haiti, Honduras, Mexico, Nicaragua, Paraguay, Peru, Uruguay, and Venezuela. The responsibility of the state for health planning is legislated by many Latin American countries, which provide for universal access to essential medical services and a national healthcare system that is either free or based on co-payments, but with limited coverage. In Latin American government, health policy generally demonstrates a significant gap between principle and practice: between justice, which theoretically endorses the equal right to health care, and actual practice in societies that, owing to their social and economic development, are not able to guarantee that this and other rights will be respected.

Codes of ethics and health legislation are based on a moral view that is both dogmatic (codified and legalistic, in contrast with philosophic, analytic, and critical) and authoritarian (based on professional authority, which is partly religious and partly governmental, rather than civic or democratic). The Latin American tradition of medical ethics can be defined as naturalistic, paternalistic, dogmatic, and authoritarian. The new Latin American medical ethics, represented by bioethics, has developed in contrast with this older tradition.

The Bioethics Movement in Latin America

The bioethics revolution that has occurred in the industrialized nations has arisen both from the scientific and technological progress of biomedicine and from the liberal and pluralistic character of those nations. By contrast, in the developing Latin American countries bioethical interests correspond more to those of a low-technology society and a tradition of confessional morality (Mainetti, 1988). Bioethics, based on the principles of beneficence, autonomy, and justice, may be seen as civic morality to which the parties to an increasingly conflictual relationship—physician, patient, and society—appeal. Or bioethics may be seen as medical culture, expressed in the "introduction of the moral subject into medicine," the promotion of the rational, free agent in the therapeutic relationship. It is fair to say, however, that bioethics has barely arrived in Latin America in either guise.

Latin American bioethics evolved over a period of thirty years, in three decade-long stages, commencing in the 1970s: reception, assimilation, and re-creation. Public and academic interest in bioethical topics appeared in the 1980s with the proliferation of new medical technologies, such as those used in intensive care units, transplants, and assisted reproduction, and with the appearance of democratic governments in the region. On the one hand, legal intervention in medical cases increased, due perhaps to the distances created between the professional and the patient by specialization. Malpractice and a patient's rights movement in Latin America imitated the early history of U.S. bioethics. On the other hand, there was an academic rehabilitation of practical, moral, and political philosophy as they could be applied to medicine. This development was in keeping with the kind of ideological pluralism and consensus formation that has characterized bioethics as a discipline in the United States.

The academic and professional development of bioethics in Latin America has been a process of incorporating the U.S. model in stages. As the twentieth century neared its end, the institutionalization of the discipline as expressed in the creation of research centers, professorships at universities, ethics committees at hospitals, and national commissions on bioethics could not be said to be significant. Nor had the three main functions of bioethical studies been carried out. These are the educational function (deontology and legal medicine still stand for ethics at medical schools); the consultative function (clinical and healthcare ethics are not practiced in hospitals and other healthcare facilities); and the political function (groups of experts have not formed to advise public institutions on biomedical norms). Bioethics is also just beginning to capture the attention of the public and the media.

Among the groups active on the Latin American bioethics scene, several deserve mention: the Instituto de Humanidades Médicas y Centro de Bioética of the Fundación Mainetti (Institute for the Medical Humanities and Center for Bioethics of the Mainetti Foundation) in La Plata, Argentina, and the Instituto Colombiano de Estudios Bioéticos (Colombian Institute for Bioethical Studies) in Bogotá, Colombia. The former, established in 1972, combines the European and Anglo-American traditions of medical humanism, serving as a model and resource center for other countries in the region, particularly through its Escuela Latinoamericana de Bioética (Latin American School of Bioethics, ELABE), directed by Juan Carlos Tealdi. The latter, founded in 1985 by Fernando Sánchez Torres, former dean of the National University of Colombia, together with the ASCOFAME (Colombian Association of Medical Faculties) with its Center for Medical Ethics, directed by Alfonso Llano Escobar, S.J., and the Colombian School of Medicine and its Health Care Ethics Committee, also lead in the process of renovating medical ethics in the region.

Other academic and professional associations have emerged in Latin American countries in recent years for the purpose of developing programs of bioethical studies: the Department of Bioethics of the Catholic University of Uruguay; the Sindicato Médico of Uruguay, a very important professional organization that appointed a bioethics commission; the Department of Bioethics of the Chilean Catholic University; and the Chilean Medical College, mentioned above. These associations work actively on deontological questions, and the Brazilian Association of Medical Ethics Teachers emphasizes bioethical issues.

The bioethics enterprise also can be evaluated by the number of people interested in the discipline; by courses, conferences, and other scientific activities; and by the publication of books and articles. The classic 1973 Latin American text on medical ethics, by Augusto León, was followed by several bioethics texts (Mainetti, 1988; Varga; Vélez Correa). According to a 1990 report issued by the Pan American Health Organization, conditions in Latin America were expected to encourage the development of programs to integrate medical ethics into the health system. This integration could occur along a broad spectrum ranging from legislation and public policies to academic curricula, and should include the revision of the ethics codes of established medical associations. To this end, the Latin American School of Bioethics has been coordinating a regional program of hospital ethics committees since 1989 (Tealdi and Mainetti). The growth of interest in bioethics justified a Latin American bioethics association to unite isolated efforts, and thus to offer a concerted response to the needs of the region. Meeting in La Plata, Argentina, in December 1991, representatives from several Latin American nations founded the Federaciòn Latinoamericana de Instituciones Bioéticas (Latin American Federatíon of Bioethics Institutions, FELAIBE).

In 1990 the Pan American Health Organization (PAHO) commissioned James Drane of the United States to produce a decisive report that reviewed the development of bioethics in Latin America and proposed several steps for the further regional development of the discipline (Drane and Fuenzalida). That same year, PAHO published a special issue on bioethics, edited by Susan Scholle Connor and Hernàn Fuenzalida-Puelma, formally introducing bioethics in Latin America. This was the first collection in which early authors in the field addressed diverse topics and set out different perspectives on the discipline. Finally, PAHO, a pioneer among international health organizations, created the Regional Program on Bioethics (1994) with headquarters in Santiago de Chile, but whose activities are decentralized in order to serve all the member countries of PAHO. This program—a comprehensive policy in bioethics and its associate disciplines—entered a new stage under the outstanding scholar Fernando Lolas Stepke's leadership (Programa Regional de Bioética, 2000).

Bioethics has become a field of new challenges in Latin America. A seeming uniformity hides a rich, heterogeneous set of activities. Not only European and Christian influences but also indigenous intellectual traditions are very important in the development of Latin American bioethics. It does not have its own philosophy, as Anglo-American bioethics is perceived to have, but it does have its own literature or narrative. The particular historical setting, cultural ethos, and social reality of Latin America could infuse new life into the global bioethics community. In this sense, a symptom of the new times is the fact that the Second Congress of the International Association of Bioethics took place in Buenos Aires, Argentina, in 1994, and the Sixth Congress was held in Brasilia, Brazil, in 2002. A “new Brazilian bioethics” or “hard bioethics,” inspired by Brazil’s contradictory social reality, began to flourish at the turn of the twentieth century, and explores alternative perspectives to traditional bioethical currents (Garrafa).

Bioethics first arrived in Latin America as a foreigner, and later underwent a transcultural shaping. Transplanted to a new habitat, bioethics took on its own distinctive character and voices and has become a strong intellectual and political enterprise (Lolas Stepke, 1994; 1998).

In comparison to the North American style of bioethics, Latin American bioethics takes a more theoretical and philosophical approach. As a search for a *critical, radical* and *global* bioethics, Latin American bioethics represents a global, “post-bioethical” age (Drane, 1998; Spinsanti). Although Latin American bioethics is far from being a unified theoretical system or a single coherent perspective, it represents the *ethica spes* of the new millennium.

Major Topics in Latin American Bioethics

Latin American countries share a concern about a number of problems with implications for both law and policy. A common sociocultural and public-health situation defines the Latin American biomedical ethos. Ethnomedical ethics ought to be an essential topic, because the health and disease conceptions, practices, and values, as well as the needs, of the native (precolonial) Latin American peoples are not properly understood by academic medicine and the health policy of the dominant culture. These peoples still await the fulfillment of the World Health Organization’s proclamation calling for the integration of their healing arts into modern medicine. Among the most pressing bioethical issues facing Latin America are the following.

REPRODUCTIVE ETHICS. Both the prevention of human reproduction (contraception, sterilization, and abortion) and assisted human reproduction (reproductive technologies) are central issues for Latin American population policy. This policy is clearly linked to health and to religious, secular, and geopolitical factors. Underdevelopment and overpopulation form a vicious circle that distances societies more and more from the goal of sustainable development. The Catholic Church does not tolerate what it calls “artificial” control of fertility and condemns abortion, which is legally prohibited in most Latin American countries. To date neither public debate nor legislative reform has occurred, although the widespread and frequent practice of clandestine abortion effectively expresses Latin American governments’ laissez-faire policies. The ethical complexity of assisted reproduction provokes polemics about the status of the embryo without leading to a declared war between “Catholics” and “secularists, ” but this area requires legal regulation.

THE ETHICS OF DEATH AND DYING. In Latin America, death is not as medicalized nor is the medical profession as tormented about it as is the case in the First World. The technological assault on dying, the new *danse macabre* in the intensive care unit, does not offer the same sort of spectacle in Latin America as it does in the United States. Nevertheless, the contemporary “art of dying” is a challenge in Latin America, too, even if living wills, do-not-resuscitate orders (DNRs), the ethical principles of critical care medicine, and the pro-euthanasia movement have yet to become major issues. Palliative medicine, the hospice movement, and campaigns for death with dignity are the modern Latin American versions of *ars moriendi.* At the beginning of life, pediatrics ethics committees are improving regulations regarding the treatment of premature and disabled newborns. At the end of life, legislation authorizing removal and transplantation of organs has advanced markedly in many Latin American countries (Fuenzalida-Puelma).

RESEARCH ETHICS. Biomedical research in Latin America lacks both a legislative framework and an effective set of controls. Much research also lacks scientific validity and, motivated more by monetary interest than by interest in knowledge, overlooks patient’s rights such as consent and confidentiality. Developing countries must create the scientific and financial conditions for research itself; they must also attract projects that involve international cooperation while avoiding the risks such cooperation often brings with it, including economic and human exploitation. Oversight committees are needed so that international standards, with criteria appropriate to the cultural modalities of each community, may be applied. U.S. standards of consent, for instance, cannot be implemented easily in the social conditions of developing countries (Levine). Questions that must be considered in the future include research priorities, allocation of resources for research, and access to new, experimental drugs. This last issue, which has an especially high profile because of the global AIDS crisis, now involves not only the right of patients to protection from possible ill effects but also their right to have access to such drugs, which may prolong or save their lives.

HEALTHCARE ETHICS. Health status in Latin America must be seen within a larger picture of underdevelopment, poverty, hunger, and economic crisis aggravated by the foreign debt of the region. Two global short-term goals set by the World Health Organization have not yet been reached in Latin America: Infant mortality has not been brought below 5 percent, and life expectancy has not risen beyond sixty-five years. Healthcare expenditures in Latin America did not exceed 5 percent of the gross national product in the 1970s and 1980s, compared with 10 percent for the so-called developed countries.

Although there is a plethora of medical students and an oversupply of physicians, approximately 75 percent of the population of Latin America does not receive medical attention. This dramatizes the gap between the proclaimed right to healthcare and the conditions necessary to exercise it. Primary care—including family planning, maternal and child care, immunization, health counseling and education, campaigns against tuberculosis, and treatment of infectious diseases—should be the goal of health policy in all developing nations. Healthcare policy must be focused on health as an indicator of development, oriented to the basic needs of the majority of the population, and designed to promote medical care based on criteria of equity, integration, participation, and efficiency (Pan American Health Organization, 1989).

Between 80 and 90 percent of the resources allocated to healthcare in Latin America is spent on secondary and tertiary care. "Bioethics in the time of cholera," to paraphrase the novelist Gabriel García Márquez—medical ethics faced with plagues like cholera and AIDS—sums up the challenge to healthcare ethics in Latin America.

ENVIRONMENTAL ETHICS. The environmental problems of Latin America are in part peculiar to the region and in part similar to those in western Europe and the United States. Overpopulated cities like Mexico City, Caracas, and São Paulo are more polluted than their European counterparts, and the Latin American urban crisis ranges from street cleaning to disposing of radioactive wastes from nuclear power plants.

In agricultural areas, the indiscriminate use of biocides contaminates crops and reduces the fertility of the soil. The extinction of animal and plant species produces imbalances in the ecosystem. Of worldwide importance is the devastation of the Amazon rainforest, the largest jungle in the world. An ecological reserve with an influence on world climate, the area has been deforested by 10 percent. It faces the prospect of destruction within half a century, for reasons not unrelated to the sizable foreign debt owed by Brazil.

Governments and publics in Latin America are just beginning to become conscious of the importance of the environment to human and animal health; to national, regional, and world economies; to the preservation of nature and of life itself. Some countries have environmental protection legislation, projects to protect or preserve natural resources, and active ecology movements. Bioethics, however, has yet to raise its voice in civic and public arenas with regard to environmental ethics (that is, ecological rights), a new type of third-generation human rights, and policies of sustainable development (Pan American Health Organization, 1987).

The Challenge of Bioethics for Latin America

Because of its humanistic medical tradition and the social conditions of developing countries, Latin America can offer a distinctive bioethics perspective. There are two dimensions to this perspective. First, a discipline established along European lines of the general philosophy or theory of medicine, with three main branches (medical anthropology, epistemology, and axiology), may be better equipped to transform academic, scientific medicine into a new humanistic biomedical paradigm (Mainetti, 1988). Such an approach would guard against the accusations often lodged against bioethics in the United States and Europe: that the discourse of bioethics only appears to humanize medicine while obscuring the real dehumanization of the system. For example, the bioethical discourse on autonomy may hide the depersonalization of medical care and its risks of iatrogenesis, exploitation of the body, and alienation of health. In response to the development of biomedicine in a technological era, bioethics may be able to play a more critical role, one that is less complacent or optimistic about progress.

Second, the Latin American reality of "bioethics in the time of cholera" requires an orientation toward social ethics, with an accent on the common welfare, the good society, and justice rather than on individual rights and personal virtues (the modern and classical traditions of morality, respectively). A macroethics of health or public health may be proposed as an alternative to the Anglo-American tradition of micro or clinical ethics. Greater emphasis can be placed on the social importance of medicine; as far as medical ethics is concerned, the great need in the developing countries is fairness in the allocation of resources and the distribution of health services. Latin America has not lost hope that it might be the continent of justice.

Several decades after its birth, bioethics in the United States is moving toward new intellectual models. This movement shows up in the revisionist-foundationalist debate within the discipline; the application of ethics to other discourses, including the political arena; the rediscovery of ethics of virtue; the return to what is experiential; and the cross-cultural and international dialogue. The bioethics revolution in North America and Europe—summarized in a high-technology *bios* and individualized ethos—must be complemented in Latin America by a humanistic *bios* and a communitarian ethos.

A promising outlook is emerging as the bioethics traditions and problematics of the two Americas move closer to one another. Perhaps in the context of the new world order and the beginning of the twenty-first century, bioethics—the bridge toward the future of humanity—will also be a bridge of inter-American cooperation and integration.

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TRANSLATED BY MARY M. SOLBERG

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MEDICAL ETHICS, HISTORY OF AUSTRALIA AND NEW ZEALAND

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Medical ethics in Australia and New Zealand (Australasia) evolved slowly until the early 1980s, when major advances in reproductive technologies prompted widespread public discussion of bioethical issues surrounding human conception.

Early History

In the early decades of the twentieth century, ethical debates centered on issues of professionalism in the delivery of medical services, such as the permissibility of advertising by individual practitioners and the setting of standard fees to avoid “undercutting” by competitors. The branches of the British Medical Association (BMA) that had been set up in the colonial Australian states were federated in 1912, when a unified code of professional ethics, dealing mainly with the regulation of advertising and etiquette toward patients, was introduced (Egan). After World War I, medical schools in Australasian universities began to include brief didactic instruction in the ethical obligations of physicians. There was also some public discussion of abortion, methods of birth control, and confidentiality in relation to patients with venereal disease.

A Labour government with a strong social welfare platform was elected in Australia in 1941. In the late 1940s this government attempted to introduce a national health service, which would have provided universal access to healthcare for the first time in Australia. However, a bitter debate developed with the BMA, the majority of whose members saw the government’s plans as a threat to the autonomy of medical practitioners and as the first step toward the nationalization of medicine. After legal challenges, the plans for a national health program were defeated in 1949 (Gillespie). Under the free-market policies of subsequent Liberal governments, access to publicly funded healthcare was available only to recipients of old-age and invalid pensions. This situation persisted until 1975, when the Labour government introduced Medibank, Australia’s first national healthcare program, which provided access to government-subsidized healthcare for all. While the incoming Liberal/National coalition government gradually dismantled this program during the late 1970s, it was reinstated as Medicare in 1983 by the newly elected Labour government, and has continued to operate into the twenty-first century.

Ethical issues in reproduction became a major concern in Australasia in the early 1980s, following pioneering research on *in vitro* fertilization (IVF) carried out by a joint research team led by Carl Wood and Ian Johnston at the Monash University Queen Victoria Medical Centre and the Royal Women’s Hospital in Melbourne during the 1970s. In 1983 this research led to the world’s first live IVF births from frozen embryos and donated eggs, and the embryo research carried out by Monash University scientists in order to improve IVF and other assisted reproduction techniques sparked worldwide interest. These developments in reproductive technology stimulated much public discussion in Australia, particularly among Roman Catholics, who constitute over a quarter of the population.

Euthanasia

Care for the terminally ill became another widely debated issue in Australia in the 1980s. Influenced by the growing public support for voluntary euthanasia, the state governments of South Australia and Victoria passed legislation (in 1983 and 1988, respectively) permitting patients to refuse medical treatment in certain circumstances, even where such treatment might prolong their lives. In 1995 the Northern Territory’s single-chamber parliament passed the Rights of the Terminally Ill Act, making it the first jurisdiction in the world to legalize active voluntary euthanasia. This legislation permitted doctors to carry out voluntary euthanasia, under certain specified conditions, for terminally ill patients with unbearable suffering. The lives of several patients were lawfully ended under this act before it was overruled by the Euthanasia Laws Act, passed by the Australian federal parliament in 1997.

Ethics Centers

Australasia’s first research center in bioethics, the Monash University Centre for Human Bioethics, was established by the philosophy professor Peter Singer, together with colleagues in medicine, science, and the law, in 1980. A number of smaller research centers for bioethics were set up in Australasia during the next two decades, including Melbourne’s St. Vincent’s Bioethics Centre, Adelaide’s Southern Cross Bioethics Institute (both of which have a Christian perspective on bioethics), Sydney’s John Plunkett Centre for Ethics in Health Care, the Ethics Unit at Melbourne’s Murdoch Childrens Research Institute, and the University of Otago Bioethics Research Centre in Dunedin, New Zealand. Bioethics research is also pursued by several of the large groups of philosophers appointed to the Centre for Applied Philosophy and Public Ethics, which was established by Charles Sturt University in both Canberra and Melbourne in 2000. The interdisciplinary Australasian Bioethics Association was formed in 1990, and its inaugural conference was held in Melbourne in 1991.

With Helga Kuhse and others from the Monash Centre, Peter Singer has written extensively on ethical issues arising from the new reproductive technologies and on questions surrounding the care of terminally ill adults and infants. Other noteworthy Australasian writers in bioethics include the philosophers Max Charlesworth, Julian Savulescu, and Robert Young; the feminist academics Renate Klein and Robyn Rowland; the lawyers Michael Kirby and Loane Skene; and the theologian Norman Ford. In 1989 the Monash Centre introduced Australasia's first master's program in bioethics, and this institution also publishes Australia's only peer-reviewed bioethics journal, the *Monash Bioethics Review.*

Reproductive Technologies

In 1982 advances in infertility research in Victoria led the government of that state to appoint Louis Waller, a professor of law at Monash University and an Australian law reform commissioner, to chair a committee whose mandate was to consider the social, ethical, and legal issues arising from IVF. The three reports produced by this committee supported the use of IVF under certain regulations, prompting the Victoria Parliament, in 1984, to enact the Infertility (Medical Procedures) Act, the world's first legislation to deal specifically with these new reproductive technologies (see Charlesworth 1989). Among other provisions, this legislation allowed IVF to be carried out at approved hospitals, for married couples who have already sought infertility treatment for at least twelve months prior to attempting IVF.

At the federal level, the National Bioethics Consultative Committee (NBCC) was established in 1988 as an advisory committee on issues such as access to information about their origins for children conceived through IVF; artificial insemination by donor; surrogate motherhood; and embryo experimentation. In 1990 this committee issued a report that supported surrogacy arrangements and proposed draft legislation to regulate such arrangements. In light of the heated public controversy that ensued, however, the Australian government decided against implementing its recommendations nationally. Nevertheless, most Australian states have not outlawed IVF-assisted surrogacy in cases where the surrogate mother receives no fee, and in 1994 the Australian Capital Territory enacted legislation to regulate such surrogacy arrangements. In 1991 the NBCC was subsumed under the existing National Health and Medical Research Council (NH&MRC), which merged the functions of the NBCC and the Medical Research Ethics Committee to form the Australian Health Ethics Committee.

The groundbreaking work of Australian researchers with human embryonic stem cells and biotechnology became the focus of much public discussion at the beginning of the present century. The cloning of human beings was outlawed in 2002, following the recommendations of a federal parliamentary standing committee, but research will be permitted on stem cells that had been extracted from human embryos prior to early 2001.

Human Experimentation

Australasia's first recorded institutional ethics committee to review human experimentation was set up at the Royal Victorian Eye and Ear Hospital in Melbourne in 1957 (McNeill), and at the instigation of the NH&MRC (which allocates government funding for medical research), Australian universities began, in the 1980s, to form ethics committees to oversee medical and other research carried out at those institutions. Following wide community consultation and a 1996 federal government review of the relatively brief NH&MRC guidelines on human experimentation, the detailed and remarkably broad-ranging *National Statement on Ethical Conduct in Research Involving Humans* was issued by the NH&MRC in 1999 as a guide for all human research ethics committees in Australia. The basic principles in the *National Statement* are integrity, respect for persons, beneficence, and justice, which are developed in more detail through their application to a variety of different types of research.

In New Zealand, the Medical Research Council (set up in 1937 by the government to supervise medical research) decided in 1968 that all research must adhere to the World Medical Association's Declaration of Helsinki, which stressed nonmaleficence and the need for informed consent on the part of the experimental subjects. In 1987 unprecedented public outrage followed revelations of an experiment involving clandestine selective nontreatment of women with cervical cancer, which was carried out at the National Women's Hospital in Auckland from 1966 to 1981. The New Zealand government immediately set up an inquiry into the experiment, which resulted in an amendment to the Human Rights Commission Act of 1977, that added a statement of patients' rights to proper standards of care and adequate disclosures to enable genuinely informed consent. This amendment also provided for the appointment of a national health commissioner to encourage awareness of these rights by members of the medical profession (Campbell).

Patient's Rights

During the 1990s there was considerable discussion in Australia about patients' legal rights to treatment information, prompted by the Australian High Court decision in *Rogers v. Whitaker* (1992), which gave legal recognition to a patient-centered standard of disclosure of medical information. Following this decision, the NH&MRC issued a booklet containing guidelines on providing information to patients.

Influenced by the increasing recognition of patient's rights, Australasian medical schools have gradually woven the teaching of ethics into their curricula. For example, the University of New South Wales in Sydney and the University of Newcastle began teaching substantive courses in ethics to medical undergraduates in the 1970s, and the University of Adelaide's medical school introduced ethics into the undergraduate syllabus in the early 1980s. Following the recommendations of the National Inquiry into Medical Education—a committee of academics and health professionals set up by the federal minister for health, which heard submissions during 1987 and 1988—many other Australian medical schools have included clinical ethics as part of their undergraduate programs. These developments in bioethics education should help promote lively and informed discussions of medical ethics issues in Australasia as they arise in the future.

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MEDICAL ETHICS, HISTORY OF EUROPE

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I. Ancient and Medieval. A. Greece and Rome
I. Ancient and Medieval. B. Early Christianity
I. Ancient and Medieval. C. Medieval Christian Europe
II. Renaissance and Enlightenment
III. Nineteenth Century. A. Europe
III. Nineteenth Century. B. Great Britain

I. ANCIENT AND MEDIEVAL. A. GREECE AND ROME

Ancient Greece and Rome are often treated together by scholars who seek to describe in a limited space any aspect of those two civilizations. Greek history is typically divided into the Mycenaean period (2000–1200 B.C.E.), the "dark age" (1200–750 B.C.E.), the archaic period (750–500 B.C.E.), the classical age (500–323 B.C.E.), and the Hellenistic period (323–30 B.C.E.); and Roman history into three phases: monarchy (753–509 B.C.E.), Republic (509–31 B.C.E.), and

Empire (31 B.C.E.–476 C.E.). During the archaic period the Greeks engaged in considerable colonization in the Near East and throughout the Mediterranean basin, including southern Italy. The Hellenistic period, which was immediately preceded by Alexander the Great's conquest of much of the Near East, was marked by a fusion of Greek and various Near Eastern civilizations. Roman culture was influenced by the Greeks of southern Italy and, to a much greater degree, by the various Hellenized peoples whom the Romans conquered during the last two centuries of the Republic. The culture of the first three centuries of the Empire is appropriately labeled Greco-Roman. During the last two centuries of the Empire, a gradual division between the Latin West and the Greek East culminated in the emergence of the European Middle Ages in the former and the Byzantine era in the latter.

The Ancient Medical Profession

Although some herbal medicine and primitive surgery were employed by Greeks as early as the time represented in the Homeric epics (before 750 B.C.E.), the understanding and treatment of disease were predominantly magico-religious. It was not until the late sixth or early fifth century B.C.E. that Greek philosophy provided a rational/speculative theoretical framework for understanding health and disease, and hence for the emergence of what may be called a medical profession. The development of such a framework for the practice of medicine marks the origin of the expectation that physicians are above all products of a scientific training and orientation; that is, that they deal with disease and other physical ailments both empirically and rationally, not magically, mystically, or superstitiously (Amundsen and Ferngren, 1983). Desacralized medicine was an important aspect of Greek culture that spread throughout the Mediterranean world during the Hellenistic period and was adopted and adapted by the Romans during the late Republic.

There were no institutions that granted medical degrees or certification, nor was there a licensure requirement at any time or place. All who wished could call themselves physicians and practice medicine. Nevertheless, from the fifth century B.C.E. until the end of the period under consideration, the prevailing picture is of a population that typically distinguished between physicians (*iatroi* in Greek, *medici* in Latin) and those who practiced a magico-religious healing.

THE HIPPOCRATIC OATH. Professional standards enforceable by sanctions against physicians did not exist. Those who chose to call themselves physicians and undertake the practice of medicine were not required to swear any oath or to accept and abide by any formal or informal code of ethics. Several medical oaths, however, are known from classical antiquity. The most famous is the Hippocratic Oath, though no scholar today believes it was written by the historically elusive "father of medicine." Even the date of the oath's composition is unknown; some scholars place it as early as the sixth century B.C.E. and others as late as the first century C.E. Apparently it did not evoke much attention before the Christian era; the first known reference to it was made by the physician Scribonius Largus in the first century C.E.

Some of the stipulations in the oath are not consonant either with ethical precepts prevalent elsewhere in the Hippocratic Corpus and other classical literature or with medical practice as revealed in the sources. Attempts have been made either to explain away these inconsistencies or to attribute the oath to an author or school whose views were, in other respects as well, discordant with those characteristic of classical society. Most influential has been Ludwig Edelstein's theory (1967) that the oath was a product of the Pythagorean school, whose tenets included belief in reincarnation, the practice of vegetarianism and sexual purity, and a condemnation of abortion, suicide, and the shedding of blood. Although his thesis has appealed to many scholars, few now accept it (Deichgräber; Kudlien, 1970; Lichtenthaeler; Nutton, 1993). Parallels for even the most esoteric injunctions in the oath can be found outside Pythagoreanism. Furthermore, the Greek text offers many variant readings, some of which can be translated in significantly different ways.

THE IDEAL PHYSICIAN. One constant emerges from the variegated history of ancient medical ethics. When a Greek spoke of *iatroi* or a Roman of *medici,* each was using a word charged with meaning. Unless modified by a pejorative adjective, both meant compassionate, objective, unselfish persons, dedicated to their responsibilities. By the fifth century B.C.E. *iatros* was thus employed in a simile and metaphor; the good ruler, legislator, or statesman was frequently referred to as the physician of the state, and philosophers often described themselves as physicians of the soul. Such usage was carried over to the Latin *medicus.* The popular ideal of the physician was a dedicated, unselfish, and compassionate preserver or restorer of health—and, sometimes, inflicter of health-giving pain—always committed to the good of the patient, regardless of how far short of this ideal many physicians undoubtedly fell.

Beginning in the fifth century B.C.E., a body of medical literature developed that describes the ethics of Greek physicians. These books dealt with eminently practical concerns suggested by medical practitioners for their own benefit, such as issues of the physician–patient relationship, and obligations to the arts, to humanity, and to life itself.

General Etiquette and Deportment

Greek physicians' formulation of a standard of general etiquette and deportment provided the basis for a social expectation that has remained since that time: physicians are guided by certain basic standards of deportment or professional etiquette in dealing with patients (Amundsen and Ferngren, 1983). The physician should look healthy and be of suitable weight, "for the common crowd considers those who are not of excellent bodily condition to be unable to take care of others" (*The Physician* 1; in the Hippocratic Corpus). This is of particular significance, especially for classical Greek culture, in which health was considered by many both a virtue and an indicator of virtue. Health, the highest good, was set above beauty, wealth, and inner nobility. Health was a goal in itself, for without health, nothing else had value.

Especially in dealings with their patients, physicians should be cheerful and serene, but neither harsh nor silly. They should be reserved, speak decisively and briefly, exercise self-control, and not be excitable. Ostentation was regarded with particular distaste. Further, "It is disgraceful in any art and especially in medicine, to make a parade of much trouble, display, and talk, and then to do no good" (*On Joints* 44; in the Hippocratic Corpus). Physicians were urged to refrain from holding lectures for the purpose of drawing a crowd. Conducting one's practice with much fuss, although it might appeal to the vulgar crowd, smacked of charlatanism. Charlatans avoided consultations; good physicians, recognizing their own limitations and respecting their colleagues' knowledge, turned to other competent physicians for advice. Since consultations could lead to disputes, "Physicians who meet in consultation must never quarrel or jeer at one another" (*Precepts* 8; in the Hippocratic Corpus).

The Physician-Patient Relationship

Physicians' relationships with their patients usually commenced with an examination followed by a prognosis. Then the physician was faced with two or three ethical decisions: (1) whether to take the case if it appeared to be dangerous or hopeless; (2) what to tell the patient; and (3) what treatment to pursue.

INFORMING THE PATIENT. When determining what to tell their patients, two considerations impinged upon physicians: (1) the effect of their statement on the patient, and (2) the effect of these cases on their own reputation. There was considerable reluctance to take hopeless or doubtful cases. Some physicians, if they considered their cases hopeless, merely informed the patients that they were going to die, and left them. A treatise in the Hippocratic Corpus, probably written in the second century B.C.E., advises physicians to "conceal most things from the patient while you are attending to him … revealing nothing of the patient's future or present condition. For many patients through this cause have taken a turn for the worse" (*Decorum* 16). If the case was dangerous and the outcome uncertain but not hopeless, it was sometimes suggested that the patient's relatives or some other third party be informed, or that the patient should be told and advised to make a will. Sextus Empiricus, a physician and philosopher of the second century C.E., argued that "The physician who says something false regarding the cure of his patient, and promises to give him something but does not give it, is not lying though he says something false," since in saying it he has regard to the cure of the person he is treating (*Against the Logicians* 1, 43). The great diversity of advice and examples in both medical and other literature shows that opinions on this delicate question varied considerably then, just as they do now.

CHOICE OF TREATMENT. The question of what treatment to pursue posed an ethical problem for some ancient physicians. Therapeutics were placed in three categories: the mildest, dietetics; next, drug therapy; and the most drastic, cutting or cauterizing. Those who abided by the Hippocratic Oath swore not to "cut for stone," which some scholars interpret as a rejection of all operative surgery. Especially in the last century B.C.E. and the first century C.E., different medical sects vigorously debated whether drug therapy was unethical and whether milder therapeutics were preferable. But some, like Scribonius Largus, argued that it was even more unethical to refuse to employ drugs responsibly when their benefit to patients was so obvious (Hamilton).

THE PATIENT'S COOPERATION. The cooperation of patients was, of course, recognized as important (*Aphorisms;* in the Hippocratic Corpus), for if they did not obey their physicians' instructions, their condition might worsen or they might die, in which case their physicians would be blamed (*The Art; Decorum;* both in the Hippocratic Corpus). A brilliant prognosis, including a description of what course their illnesses had already taken, might so impress the patients that they would be inclined to obey their physicians (*Prognostics;* in the Hippocratic Corpus). Persuasion might be used; a passage in the *Laws* of Plato advances the idea that good physicians will reason with their patients and persuade them to follow the treatments prescribed (cf. *The Statesman*). Galen remarks on the importance of convincing patients that remarkable benefit will ensue if their physicians' orders are obeyed. But it is the patients' respect and admiration for their physicians that are most desirable. Since faith in one's physician could render treatment more efficacious, Galen, for example, maintained that patients should admire their physician like a god.

CONFIDENTIALITY. Should physicians treat as confidential any information they acquired in their contact with patients? In the Hippocratic Oath, the following injunction appears: "What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about." Edelstein sees in this stipulation a clear indication of Pythagorean purity, an insistence on secrecy "not as a precaution but as a duty" (p. 37). Those things that one ought not spread abroad, whether encountered within or outside of practice, are categorized as "shameful to be spoken about," or in another translation, "holy secrets." Elsewhere in the Hippocratic Corpus the physician is advised to "say only what is necessary. For … gossip may cause criticism of his treatment" (*Decorum* 7). In another treatise in the Hippocratic Corpus, the physician is urged "not only to be silent but also of a great regularity of life, since thereby his reputation will be greatly enhanced" (*The Physician* 1). While the stipulation to refrain from speaking too much may be motivated by a sense of duty to keep inviolable especially those private things physicians encounter in practice, the other two quotations belong in the context of a self-interested regard for reputation rather than a concern for the supposed "rights" of patients.

SEXUAL PROPRIETY. A very practical stipulation in the Hippocratic Oath reads, "Whatever house I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief, and in particular of sexual relations with both female and male persons, be they free or slaves." Edelstein stresses again the Pythagorean tone of this injunction, especially the emphasis on justice, and sees in the prohibition of sexual relations with members of the patient's household evidence of Pythagorean severity in sexual morality. Whether this advice was motivated by ideals of purity or by merely pragmatic concerns, physicians who used their close contact with patients or their households to satisfy their sexual passions would earn not only disrespect and contempt but also distrust. Having a reputation as a seducer of patients and their family members simply did nothing to enhance one's medical career (see also *The Physician*).

Duty to the Art, Society, and Life

LOVE OF HUMANITY. Sometimes ancient medical literature addresses very fundamental questions of motivations for practicing medicine, physicians' role in society, and the obligations incumbent upon them in that role. One statement in the Hippocratic Corpus—"Where there is love of humanity [*philanthropia*] there is also love of the art [*philotechnia*]" (*Precepts* 6)—has often been taken to demonstrate that for Greek physicians, love of humanity and love of the art were the foundational motivations for their practicing medicine. Sir William Osler saw in it the Greek physician's "love of humanity associated with the love of his craft—*philanthropia* and *philotechnia*—the joy of working joined in each one to a true love of his brother" (Edelstein, pp. 319f.). The precept in question, however, may not be so lofty. Vivian Nutton, for example, sees it as simply a pragmatic assertion that physicians' showing love for humanity will foster in their patients a love for the medical art (1993). In any event, it is evident that for many physicians, love of one's honor, glory, and reputation provided a greater motivation than *philanthropia* (Amundsen and Ferngren, 1982).

The statement quoted from the *Precepts* in the preceding paragraph occurs in the context of a discussion about fees that is introduced by the admonition "I urge you not to be too unkind." The noun *apanthropia,* the antonym of *philanthropia*, is here translated by the adjective "unkind." In the Hippocratic Corpus *philanthropia* generally is little more than kindness and compassion. Owsei Temkin, however, emphasizes that one must take care not to trivialize their philanthropy (1991), which one may easily do by contrasting it with the nearly religious flavor that philanthropy took on during subsequent eras. A profound change occurred in late Hellenistic and Roman thought, which, affected by the influence of humanitarian and cosmopolitan ideas on both philosophical and popular ethics, began to see *philanthropia* (Latin, *humanitas*) as humane and civilized feeling toward humanity in general; that is, the principle of the common humanity of all people as expressed by the Stoic philosopher Sarapion around 100 C.E. in a poem titled "On the Ethical Duties of the Physician": "Like a savior god, let [the physician] make himself the equal of slaves and of paupers, of the rich and of rulers of men, and to all let him minister like a brother; for we are all children of the same blood" (Oliver, p. 246).

This sentiment is strongly present in Galen (second century C.E.), for whom the best physician was also a philosopher, motivated by *philanthropia* (Brain). Galen, however, conceded that many physicians were motivated not by *philanthropia* but by the pursuit of money or love of glory (Temkin, 1973). Although a few sources, such as Scribonius Largus, held that to be truly a physician, one must be motivated by *philanthropia* (Hamilton), a majority of our sources concur with Plato that the motivation to practice any art, including medicine, has little or nothing to do with the integrity of the art itself: the practitioner must only be competent (*Republic*). Nevertheless, while few physicians or laymen may have regarded *philanthropia* as essential for the physician, most people probably regarded lack of kindness and compassion as distinctly undesirable for a physician. Ample evidence suggests that the "presence of compassion among doctors was taken for granted by authors of the first century" and that, even much earlier, physicians "could think of compassion as rooted in medical ethics" (Temkin, 1991, pp. 33, 34).

FEES. Ancient medical writers expressed much concern about fees. Physicians were acutely aware that the appearance of greed could have a detrimental effect on their reputations. Hence, in the Hippocratic Corpus physicians are urged to be more concerned with their reputation than with financial reward, sometimes to give their "services for nothing, calling to mind a previous kindness or [their] present reputation," and to avoid beginning a case by discussing fees, since it could adversely affect patients, particularly those whose condition was acute (*Precepts* 6). Physicians were admonished to consider their patients' economic situation in setting fees and to provide less expensive remedies for the poor than for the rich (*On Diet*). In spite of such sentiments, physicians do not appear to have engaged in much charitable activity from a sense of duty to humanity, to the community, or to the poor (Hands). Furthermore, the subject of medical fees in antiquity is complicated because some physicians objected to being considered "hirelings" and, especially during the Empire, some insisted that medicine was a liberal art, which entangled their remuneration with the complexities of Roman laws governing honoraria (Kudlien, 1976; Temkin, 1979).

EXPERIMENTATION. Ancient physicians strove to improve their proficiency and the efficacy of their art. The most extreme example of medical experimentation was vivisection of human subjects, a very controversial subject (Ferngren, 1982). Celsus states that Herophilus and Erasistratus in Ptolemaic Alexandria performed vivisections on condemned criminals supplied by the crown. Whether or not Celsus's statement is accurate is debated (Von Staden, 1989; Scarborough), but he presents the arguments for and against the value of vivisection, concluding that "to lay open the bodies of men while still alive is as cruel as it is superfluous … [since] actual practice will demonstrate [what can only be learned from the living] in the course of treating the wounded in a somewhat slower yet much gentler way" (pr. 74f.). There is ample evidence for the vivisection of animals either to gain new knowledge or to test new theories (Galen, *On Anatomical Procedures*).

Some physicians recognized that without attempting new procedures and remedies, medical knowledge and techniques would not advance (Michler). The author of *On Joints* in the Hippocratic Corpus, after describing the failure of a novel attempt at reducing a dislocation, writes, "I relate this for a purpose: Those things which after a trial show themselves to have failed and which show why they failed, also provide good instruction" (*On Joints* 47). The author of the same treatise urges physicians to study incurable cases. Commenting on the Hippocratic maxim "Experiment is perilous" (which can also be translated "Experience is unreliable"), Galen cautions that "In the human body, to try out what has not been tested is not without peril in case a bad experiment leads to the destruction of the whole organism" (Temkin, 1991, p. 60). Further, he asserts that in several instances he had refrained from testing some remedies when he had others whose effects he knew better, and he points out that rash experimentation presents a danger to the life of the patient (Ferngren, 1985).

Some physicians may have been deterred from experimenting on patients by a fear of being brought to court. Complaints can be found in classical sources that only the physician can commit homicide with complete impunity, but there were some very limited means for seeking redress against the negligent or incompetent physician, at least in Athenian and Roman law (Amundsen, 1973; 1977). But most physicians were probably deterred from any compelling desire to experiment primarily by concern for their reputations rather than by fear of litigation. Classical literature provides numerous examples of the worry expressed by laymen that physicians experiment at their patients' risk (Ferngren, 1982; 1985).

SHARING NEW TECHNIQUES. When new knowledge and techniques were discovered or developed, physicians were faced with the question of whether they should share this information with their colleagues—their competitors—and with the public at large. The Hippocratic Oath appears to have been composed for an exclusive sect. In it physicians swear not to impart their knowledge to those outside their sect. Similar sentiments are expressed elsewhere in the Hippocratic Corpus: "Things … that are holy are revealed only to men who are holy. The profane may not learn them until they have been initiated into the mysteries of the science" (*The Law* 5).

Apart from a few such statements, a desire to share new techniques or knowledge with other physicians pervades the medical literature. Those who published their medical knowledge and experience obviously did not desire to keep them secret. Galen was motivated in part by the wish to help physicians after him. But many physicians undoubtedly guarded their special techniques with jealousy. Galen shows no surprise at a surgeon's intentionally concealing his operative procedures from view, but expresses disappointment that even some of his own pupils would not share their anatomical knowledge with others (*On Anatomical Procedures*). His "philanthropy is not only that of the physician, but more comprehensively that of a philosopher who subjectively delights in study and objectively labors for the good of mankind. He thinks of his work as belonging to posterity …" (Temkin, 1973, p. 50). Some physicians wrote to instruct other physicians and also to edify laymen. In their desire to share medical knowledge with contemporaries and with posterity, at least a few Greek and Roman physicians achieved the most enduring manifestation of their *philanthropia* and *philotechnia* (Temkin, 1949).

Respect for Life

How did physicians view their responsibility to nature and, more specifically, to life? Or, to put it differently, how might they have interpreted and applied the maxim frequently quoted in the Hippocratic Corpus, "to help or at least to do no harm" (*Epidemics* 1.11)? Did the Greek or Roman physician feel bound by any sense of "respect for life"?

ABORTION. The Hippocratic Oath enjoins that the physician "will not give a pessary to a woman to cause abortion" (Jones's translation [1924]; Edelstein's [1967] "I will not give to a woman an abortive remedy" appears broader in scope than the Greek). Here again we encounter a situation in the oath that runs counter to the realities of ancient medical practice. Many physicians did perform abortions, and various techniques are described in the medical literature (Carrick). Both Plato (*Republic*) and Aristotle (*Politics*) encouraged abortion as a means of population control and for eugenics. Objections to abortion were relatively rare before the beginning of the Christian era; in both Greek and Roman law, abortion was a criminal offense only if performed without the consent of the woman's husband (or father, if she was not married). By the first century C.E., some pagan physicians such as Scribonius Largus (Hamilton), influenced as much by an increasing humanitarianism as by the Hippocratic Oath per se, refused to perform abortions under any circumstances. The physician Soranus of Ephesus (late first/early second century C.E.) gives three reasons for which a woman seeks an abortion: to rid herself of the consequence of adultery, to maintain her beauty, and to preserve her health. Only for the last would he perform an abortion (*Gynaecia*). Soranus was highly critical of physicians who so strictly adhered to the injunction in the oath that they refused to perform an abortion even to save the life of the mother. It appears, then, that some physicians would perform abortions on request, some refused to do so for any reason, and others assumed a position on therapeutic abortion consonant with that of Soranus. The decision to perform or not to perform an abortion ultimately rested on the convictions of the individual physician. The opposition to abortion of the author of the Hippocratic Oath and such physicians as Scribonius Largus and Soranus was based less upon an idea of the inherent value or sanctity of life than on an abhorrence of physicians' using their art in actively terminating even fetal life.

DEFECTIVE NEWBORNS. While some voices were raised against exposure of healthy newborns, the morality of killing weak, sickly, or deformed newborns appears not to have been questioned by either nonmedical or medical authors (Amundsen, 1987). Soranus, who condemned any but therapeutic abortion, not only raised no objection to rejecting a defective newborn; he also provided criteria to be used by midwives in determining which newborns were worth rearing (*Gynaecia*).

PROLONGING LIFE AND PASSIVE EUTHANASIA. *The Art,* a treatise in the Hippocratic Corpus, defines medicine as having three roles: doing away with the sufferings of the sick, lessening the violence of their diseases, and refusing to treat those overwhelmed by their diseases, realizing that in such cases medicine was powerless. The decision whether to take on a possibly incurable case was entirely the individual physician's. Some cases in the therapeutic treatises in the Hippocratic Corpus are introduced with the advice that certain procedures should be followed if the physician chooses to attempt treatment (Amundsen, 1978). Ancient medical literature is divided on the question of whether physicians should withdraw from cases once it becomes clear that they will not be able to help. Some urged that physicians ought not to withdraw, even if by so doing they might avoid blame. Others felt that they should withdraw if they had a respectable excuse, particularly if continuing treatment might hasten the patient's death. Physicians did, however, sometimes attend cases considered incurable. In the Hippocratic Corpus many diseases that then generally ended in death are described with no mention of prognosis and with no recommendation to the physician that such cases be undertaken or rejected. For most of them, medications to be employed are named. It was recognized that it was necessary to deal with incurable conditions in order to learn how to prevent curable states from advancing to incurability, particularly in the case of wounds (Michler). Opinions varied on the physician's responsibility to undertake treatment of hopeless or dangerous cases. In recent times it has become almost dogma to assert that the Hippocratic physician would not take on hopeless cases, but this is demonstrably false (Von Staden, 1990). Nevertheless, some laymen in antiquity held that, as Cicero wrote to his friend Atticus, "Hippocrates too forbids employing medicine in hopeless [cases]" (Temkin, 1991, p. 139).

Celsus, a medical compiler of the first century C.E., appears to represent the mainstream of medical thought: "For it is the part of a prudent man first not to touch a case he cannot save, and not to risk the appearance of having killed one whose lot is but to die; next when there is grave fear without, however, absolute despair, to point out to the patient's relatives that hope is surrounded by difficulty, for then if the art is overcome by the malady, he may not seem to have been ignorant or mistaken" (*De Medicina* 5.26.1.c). Available evidence suggests that physicians who prolonged or attempted to prolong the life of patients who could not ultimately recover their health were generally viewed as acting unethically (Amundsen, 1978).

ASSISTED SUICIDE OR ACTIVE EUTHANASIA. Would the ancient physician have thought it helping or harming to agree to assist those who for any reason wished to end their lives? To this question a majority of ancient physicians would probably have replied, "Helping, or at least not harming." The right of a free person to control his or her life as each saw fit—if not always in its living, at least in its termination—was a generally accepted view (Cooper). Suicide was, under most circumstances, outside the moral interest of the law; the exception was whether the suicide of one accused of a crime should be construed as an admission of guilt (Hooff). If a person who wished to commit suicide enlisted the aid of a second party, the latter was not legally culpable for rendering such assistance. Extralegal sources contain few objections to suicide in general, fewer still to the suicide of the hopelessly ill (Gourevitch; Hooff). Assisting in suicide was a relatively common practice for Greek and Roman physicians, and condemnations of the practice were infrequent.

One such condemnation appears in the Hippocratic Oath: "I will neither give a deadly drug to anybody, not even if asked for it, nor will I make a suggestion to this effect" (following Kudlien's translation, 1970, p. 118, n.47). This statement immediately precedes the prohibition of abortion. Both prohibitions have at least this much in common: They are inconsistent with the values expressed by the majority of sources and atypical of the realities of ancient medical practice as revealed in most medical and lay literature. Some physicians, however, may have preferred not to assist a suicide, for it could prove to be a messy business, at least from a legal point of view. Under Greek and Roman law, physicians could be charged with poisoning their patients. Indeed, physicians were sometimes charged with, or at least frequently suspected of, doing so (Kudlien, 1970; Nutton, 1985). Some physicians refused to aid anyone in committing suicide; perhaps they condemned assisting suicide under all circumstances for philosophical or religious reasons, or on the grounds that such action was inconsistent with the role of medicine (e.g., the first-century physicians Scribonius Largus [Hamilton, 1986] and Aretaeus [Amundsen, 1978]).

AT THE MOST, A LIMITED "RESPECT FOR LIFE." In light of the Hippocratic Oath and several later sources that also condemn abortion and active euthanasia, Temkin asserts that "Sufficient material has now been gathered to prove the existence of a tradition which, in its uncompromising form, did not sanction any limit to the respect for life, not even therapeutic abortion …" (1976, p. 5). This tradition appears to have been entirely negative in its emphasis: The physician would not actively terminate life by abortion or euthanasia. But it laid no stress on the positive correlate that would require the physician actively to attempt to prolong life. This negative tradition did, indeed, become stronger with the rise of Christianity and its introduction of the principle of sanctity of life: Abortion, infanticide, suicide, and euthanasia became sins. In addition, philanthropy became a virtue—the highest virtue, in fact—and the love of humanity and Christian compassion became central to the Western ideal of medical practice.

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I. ANCIENT AND MEDIEVAL. B. EARLY CHRISTIANITY

Christianity arose in Palestine during the first half of the first century C.E. among the followers of Jesus of Nazareth, called the Christ, who believed him to be the Messiah and the Son of God. Although the first followers were almost exclusively Jews, this new faith spread quickly through the Mediterranean basin and soon attracted many non-Jewish converts. For its first three centuries it remained a religion of a small but steadily growing minority. Officially declared a forbidden religion by the Roman imperial government, its adherents endured spasmodic persecutions that culminated in the Great Persecution (303–311). Emperor Constantine, a convert to Christianity, pronounced it a legal religion in 313; Emperor Theodosius I (379–395) declared it the official religion of the state and abolished the public practice of pagan religious rites.

This article covers the Christian religion from its origins to the fifth century. The sources for early Christianity are primarily literary: the New Testament, composed by followers of Jesus during the first century; and the patristic literature (the writings of early church leaders and theologians until the end of the fifth century). During this era, the beliefs and practices of the new faith were articulated and refined amid many controversies, particularly about the divinity of Christ and the nature of redemption. Gradually, a core of beliefs and a canon of literature predominated as orthodox and a church organization emerged that promoted these beliefs. By the late fifth century, orthodoxy had achieved its enduring form in doctrine and hierarchy, both of which differed in some respects between western Europe and the Byzantine culture of the East. At the same time, certain heterodox or heretical Christian groups existed peripherally. One of these, Arianism, became a powerful political and religious force.

Medical theories and practice in the varied milieu of Greek and Roman paganism were so religiously neutral that a discussion of classical medical ethics need pay relatively little attention to the subject of religion. Christianity, however, is fundamentally different in its most basic tenets and principles from the salient features of the religious pluralism in which it took root. Issues of health, sickness, healing, life, and death are so integral to Christian theology that two questions need to be addressed before anything meaningful can be said about early Christian medical ethics: (1) What was Christianity's theological understanding of illness? (2) Were the use and practice of medicine regarded as appropriate for Christians?

What was the theological understanding of illness? Patristic theology viewed physical health as a good but not an absolute good, and much less the supreme good. Physical health could even be an obstacle to the supreme good, which was spiritual health. The church fathers emphasized that the soul is infinitely more valuable than the body, and that care for the latter is not to conflict with care for the former. Yet the majority of the sources maintained that the body is to be reasonably cared for, since God has provided the means for its care. The church fathers saw health as a blessing from God, but since it was only a relative good, it could be an evil if given a higher priority than it deserved. Conversely, sickness could be a good thing. A survey of the writings of the church fathers reveals the firm conviction that Christians should rejoice in sickness as well as in health. Sickness can correct or restrain one from sin, refine, admonish, increase patience, reduce pride, cause one to be less self-reliant and more dependent upon God, and make one more mindful of eternity and one's own mortality, thus helping to wean one from the material to the spiritual, from the temporal to the eternal (Amundsen, 1982).

Sin lurked in the background of all conditions of suffering. Without sin there would be no suffering, because the fall of the first humans created by God, Adam and Eve, was the ultimate explanation for the miseries of the present. Sin, in this sense, was generic in the human race. When the church fathers identified personal sin as the cause of sickness, it was usually in the context of pastoral exhortations intended to comfort and correct rather than to foster guilt.

In the literature of the first several centuries of Christianity, three sources of disease or illness were identified: God, demons, and nature. They were not mutually exclusive. While there appears to have been a hesitancy to attribute disease directly to God, the more his sovereignty was stressed, the more he was viewed as either sending or permitting illness through demonic or natural instrumentality. The subject of disease causality in the early Christian literature is rife with confusion and interpretive problems, especially considering the perceived role of demons.

What was thought to cause disease in any given case greatly affected the choice of means of healing: spiritual/miraculous (e.g., prayer, the sacraments, exorcism, and, beginning in late antiquity, the cult of saints and relics); medical (drugs, dietetics, and surgery—typically administered by a physician); or magical (demonic or occult practices). The first two of these approaches were often combined, and sometimes magic was employed, although its use was consistently condemned in Christian literature. A Christian was to depend upon God. Sometimes the line of dependence was direct; at other times it included one or several intermediaries. The church itself (i.e., its clergy and sacraments) and the saints became variable parts of a chain of dependence to which a spiritual/miraculous healing model was essentially integral. A magical model offered an inherently incompatible, conflicting, and competing structure of dependence. A medical model was not necessarily either harmonious and compatible with the church's structure of dependence, or incompatible, conflicting, and competing with it.

Did the potential for tension between Christianity and medicine ever lead to a rejection of medicine? Some scholars have maintained that several church fathers were diametrically opposed to medicine in any form for Christians (e.g., Harnack; Frings; Schadewaldt). Most sources that have been thus interpreted have lately been shown not to be hostile to medicine per se (Amundsen, 1982; Temkin). Although more scholarly work remains to be done, it is unlikely that any patristic source will ultimately prove to have made a blanket condemnation of medicine. Nevertheless, some church fathers maintained that only those who lacked spirituality sufficient for them to be able to rely exclusively on divine healing should use medicine (e.g., Origen [ca. 184–ca. 253], *Contra Celsum*). Others practiced an asceticism that so glorified suffering and disease that they would not avail themselves of help from any source, although they did not deny the propriety of medicine for other Christians (Harvey; Amundsen, 1982).

Even if no patristic sources totally condemned medicine, the existence of those passages that have been thus interpreted, together with numerous cautionary statements about medicine made by other church fathers, demonstrates an uneasiness and a real potential for tension. Scholars like Adolf Harnack, Hermann-Josef Frings, Hans Schadewaldt, and Vivian Nutton, have advanced two possibly complementary theories to account for the supposedly unequivocal condemnation of medicine by some church fathers and the general uneasiness about Christians' using medicine expressed by others: (1) An early, conservative hostility against medicine was gradually ameliorated by a Hellenistic, liberalizing influence; (2) Christianity's supposed emphasis on, and ostensible promise of, miraculous physical healing was a constant, major obstacle to compatibility. Both views betray a misunderstanding of the nature of the inherent, and hence enduring, tensions and compatibilities between Christianity and medicine (Amundsen, 1982), and the second compounds the error by exaggerating the importance of miraculous healing in the propagation of the Gospel and in the Christian community, especially during the second and third centuries (Ferngren, 1992). Generally the patristic sources see medicine and physicians as God's gifts. Christianity inherited from Hellenistic Judaism an appreciation of Greek medicine that defined disease naturalistically while denying neither God's sovereignty nor his prerogative to intervene in mundane affairs. Nevertheless, the church fathers regarded as both sinful and foolish the use of physicians and medicine apart from faith in God and the failure to recognize that all healing, other than magical (demonic or occult), comes from God (Amundsen, 1982; Temkin).

The Ideal Physician of Early Christianity

The tension between Christianity and medicine was overshadowed by their compatibility in one important sense: Jesus Christ was described as the great physician, the true physician, both the physician and the medication (Pease; Arbesmann; Schipperges, 1965; Temkin). Early Christian authors thus adopted and adapted a long-established tradition in classical literature that employed, in simile or metaphor, the idea of physicians as dedicated, unselfish, and compassionate preservers or restorers of health and, sometimes, inflicters of health-giving pain, always committed to the good of their patients. It was not uncommon for the term *Hippocratic art* to be used metonymously for the medical art, and Christian authors occasionally mention Hippocrates as an ethical ideal for the medical practitioner. Indeed, Christ was himself spoken of as being, "as it were, a spiritual Hippocrates" (Pease, p. 75), and it is to Hippocrates as the type of physician that Jerome (ca. 345–ca. 419), compares the Christian healer (*In Ioanem Commentarii*; cf. *Epistle* 125).

Early Christians found the "Hippocratic ideal" of decorum very appealing. Jerome wrote to a priest that it

> is part of your duty to visit the sick, to be acquainted with people's households, with matrons, and with their children, and to be entrusted with the secrets of the great. Let it therefore be your duty to keep your tongue chaste as well as your eyes. Never discuss a woman's looks, nor let one house know what is going on in another. Hippocrates, before he will instruct his pupils, makes them take an oath and compels them to swear obedience to him. That oath exacts from them silence, and prescribes for them their language, gait, dress, and manners. How much greater an obligation is laid on us who have been entrusted with the healing of souls! (*Epistle* 52.15; see Temkin, p. 182)

In a collection of letters incorrectly attributed to Clement of Alexandria (ca. 150–ca. 220), there is a passage that reads, "We are to visit the sick … without guile or covetousness or noise or talkativeness or pride or any behavior alien to piety.… [I]nstead of using elegant phrases, neatly arranged and ordered … act frankly like men who have received the gift of healing from God, to God's glory" (*De virginitate* 1, 112). This advice, which sounds as if it had been written for physicians, was intended for exorcists dealing with the demon-possessed. Every detail enunciated here, save for reference to piety and to God, is mentioned in the classical literature on medical etiquette, but one need not assume that the anonymous author of this letter was intentionally adopting principles of medical etiquette. Rather, the guidelines for conduct in both instances seem to be little more than practical etiquette for clergy as well as for physicians.

Compassion or philanthropy was the one feature of the "Hippocratic ideal" that the church fathers regarded as especially Christian. Origen writes that he followed "the method of a philanthropic physician who seeks the sick so that he may bring relief to them and strengthen them"

(*Contra Celsum* 3.74). In demonstrating the superiority of Christianity to pagan philosophy, he says that "Plato and the other wise men of Greece, with their fine sayings, are like the physicians who confine their attention to the better classes and despise the common man while the disciples of Jesus carefully study to make provision for the great mass of men" (ibid., 7.60). It was in caring for common people, especially for the destitute and the poor, that physicians evinced a Christlike compassion. Augustine (354–430) regarded his friend, the physician Gennadius, as "a man of devout mind, kind and generous heart, and untiring compassion, as shown by his care of the poor" (*Epistle* 159). He frequently mentions physicians who, motivated by charity, asked no remuneration for their services but undertook the most desperate cases among the poor with no thought of receiving any recompense (e.g., *Sermon* 175).

Eusebius of Caesarea (ca. 265–ca. 339) writes that Christ, "like some excellent physician, in order to cure the [spiritually] sick, examines what is repulsive, handles sores, and reaps pain himself for the sufferings of others" (*Ecclesiastical History* 10.4.11). And Origen paraphrases a well-known Hippocratic aphorism that a physician "who sees terrible things and touches unpleasant wounds in order to heal the sick … does not wholly avoid the possibility that he may fall into the same plight" (*Contra Celsum* 4.15; see Temkin, pp. 141ff.). Physicians, according to Augustine, should always have their patients' cure at heart (*Sermon* 9), for the practice of medicine would be cruelty if physicians were only concerned about engaging in their art (*In Psalmos*). Gregory of Nyssa (ca. 335–394) began a letter to the physician Eustathius with the statement that, "Philanthropy is the way of life [*epitedeuma,* "one's business"] for all of you who practice the medical art" (although almost certainly written by Gregory of Nyssa, it is usually printed as *Epistle* 189 of his elder brother, Basil). While philanthropy was a highly desirable attribute for many pagan physicians, it is no exaggeration to say that Christianity made it an ethical obligation for Christian physicians (Temkin). Indeed, for some it became the chief motivating factor for the practice of medicine.

Hence it is not surprising that Christians adopted and adapted the so-called Hippocratic Oath at some time before the end of the period under consideration. Several manuscripts of an "Oath of Hippocrates insofar as a Christian may swear it" are extant (Jones, pp. 54f.). The Christian Oath omits the enigmatic prohibition of cutting for stone and makes more specific and definite the antiabortion statement. Where the pagan oath reads "Into whatsoever houses I enter, I shall do so to help the sick, keeping myself free from all intentional wrongdoing and harm," The Christian Oath has "Into whatsoever houses I enter, I will do so to help the sick, keeping myself free from all wrongdoing, both intentional and unintentional, tending to death or to injury." While one should not make too much of the addition of the promise to keep oneself free from even unintentional harm, it is reasonable to suggest that this concern, although not inconsistent with pagan medical ethics, is even more consonant with an early Christian ethics of respect for life that manifested itself not only in a condemnation of such practices as infanticide and suicide (including active euthanasia) but also in a philanthropy that was regarded as owed to the destitute and the ill.

Philanthropy

There is an enormous gap between pagan and Christian concepts of philanthropy. Christian philanthropy was an outgrowth of the Jewish insistence that love, mercy, and justice were attributes of God and were essential for true worship of God (e.g., Mic. 6: 6–8). Christian philanthropy was the expression of agape, an unlimited, freely given, sacrificial love that was not dependent on the worthiness of its object, since it was the manifestation of the very nature of God, who himself is agape (1 John 4:8). It was incumbent upon all Christians to extend care to the needy, especially to the sick. By late antiquity the care of the sick had become a highly organized activity under the supervision of the local bishop (Ferngren, 1988). Institutions that with some qualification may be called hospitals, were established and maintained beginning in the fourth century. The most famous of these was the *nosokomeia* or *ptocheion* of Basil, who was the bishop of Caesarea from 370 to 379 (Miller; Temkin). These institutions, as well as orphanages and homes for the care of the elderly and destitute, first arose after the legalization of Christianity, were distinctly Christian, and were a direct outgrowth of Christian philanthropy.

During various outbreaks of plague, Christians responded with spectacular daring in their attempts to succor the ill, both Christian and pagan. One particular group, on whom we have only scant information, were known as the *parabalani* ("reckless ones") because of the risks they faced by caring for plague victims (Philipsborn). Their zeal in the face of imminent danger was motivated in part by the belief that death thus incurred ranked with martyrdom (Eusebius, *Ecclesiastical History*). Christians were so well known for their care of the destitute that Julian the Apostate (r. 361–363), the only pagan emperor after the legalization of Christianity, complained that the "impious Galileans support not only their own poor but ours as well" (*Epistle 22*). Henry Sigerist did not overstate the case when he said that Christianity introduced "the most revolutionary and decisive change in the attitude of society toward the sick.… It became the duty of the Christian to attend to the sick and the poor of the community.… The social position of the sick man thus became fundamentally different from what it had been before. He assumed a preferential position which has been his ever since" (p. 69f.).

The Sanctity of Human Life

The Christian imperative to a practical philanthropy that extended to the poor and the sick was not solely a manifestation of Christian love but was ultimately articulated as a theology of respect for life, a principle of the sanctity of human life predicated on the concept of the *imago Dei,* the belief that every human being was formed in the image of God (Ferngren, 1987). By virtue of sharing the *imago Dei,* all human life was of value, and therefore was owed compassion and care. Specific condemnations of contraception, abortion, and infanticide, however, are not found in the New Testament. And when they first appear in Christian literature during the second century, they seem not to be predicated upon a developed concept of the *imago Dei* as the basis of human value. Rather, such condemnations appear in the context of broad and fervent denunciations of the most offensive sins to which Christians felt pagans were especially prone, such as gladiatorial shows and other exhibitions of extreme cruelty, and sexual immorality of an extravagantly imaginative variety.

The history of the treatment of contraception and abortion in the early church is rife with difficulties. First, the distinction between contraception and abortion, at least in the early stages of pregnancy, was blurred in both medical and popular perceptions (Noonan, 1966). The question of when human life begins was, and still is, hotly debated. Ancient embryology, although scientifically inaccurate, was more helpful than modern science in answering this question. Aristotle's theory of fetal succession of souls—nutritive, sensitive, rational—had a profound impact on patristic discussions of abortion. A fetus that is "fully formed" (a very imprecise concept) is "ensouled," that is, possesses a sensitive soul and is "animate" (an equally imprecise concept). One that is not "fully formed" is not "animate," in that it is not yet "ensouled" with a sensitive rather than a nutritive soul. The transition from a nutritive to a sensitive soul—that is, animation—is marked by "quickening," the first movement of the fetus, which ostensibly happens about the fortieth day with males and the ninetieth day with females.

Furthermore, Christian condemnations of contraception and abortion were based on two quite different principles. One is that contraception and abortion before "ensoulment" are essentially sexual sins but not the destruction of human life. The other is that contraception and abortion at any stage are indeed the destruction of human life. Both, of course, regarded abortion after "ensoulment" as homicide (Noonan, 1970; Connery; Gorman; Dombrowski). Some recent revisionist historians advance the argument that the early Christian community did not condemn abortion at any stage of fetal development until two factors conduced to condemning it: the desire to rely not only on evangelism to increase the Christian community but also on internal growth, and the developing contempt for women within the church that relegated them to the role of childbearers (e.g., Hoffmann). Such special pleading has little to commend it.

The Christian condemnation of infanticide, including exposure, however, was unequivocal and inclusive, counting the active or passive killing of any newborn, whether healthy, sickly, defective, or even grossly deformed, as the murder of one made in the image of God (Amundsen, 1987). Active euthanasia, except as it was condemned in the "Hippocratic oath insofar as a Christian may swear it," is not discussed in the sources, but must have been regarded as murder, especially given the early Christian community's attitude toward suicide. Although suicide was not included in the broad spectrum of sins of pagans that aroused the moral indignation of early Christians, it was condemned by numerous church fathers, beginning with Justin Martyr, who in the second century replied to the hypothetical question why Christians do not just kill themselves and save pagans the trouble, "If we do so, we shall be opposing the will of God" (2 *Apology* 4). At about the same time the anonymous *Epistle to Diognetus* states that Christians do not kill themselves because God has assigned them for an important purpose to a post that they must not abandon. Clement of Alexandria flatly states that suicide is not permitted for Christians (*Stromateis*). The anonymous *Clementine Homilies,* which reached their present form in the mid-fourth century, but were based on an original composed in the late second or early third century, assign to suicides a severe future punishment (*Homily* 12). Lactantius (ca. 240–320) condemns suicides as worse than homicides, since they not only commit violence against nature but are impious as well. Nothing, in his opinion, can be more wicked than suicide (*Divine Institutes*; *Epitome* 39). John Chrysostom (ca. 349–407) writes that all Christians justly regard suicide with horror, "for if it is base to destroy others, much more is it to destroy one's self" (*Commentary on Galatians* 1:4). His contemporaries Ambrose and Jerome also categorically condemn suicide, the former flatly stating that "Scripture forbids a Christian to lay hands on himself" (*Concerning Virgins* 3.7.32), and the latter that Christ will not receive the soul of a suicide (*Letter* 39). Both Ambrose and Jerome make one exception to their condemnation of suicide: when it is committed to preserve one's chastity.

Augustine's rejection of this one exception led him to engage in a thorough analysis of suicide in books I and XIX of his *City of God*. His argument against the permissibility of suicide is fivefold. First, Scripture neither commands it nor expressly permits it, either as a means of attaining immortality or as a way to avoid or escape any evil. Second, the Sixth Commandment of the Mosaic law, "Thou shalt not kill," must be understood to forbid it. Third, since individuals have no right on their own authority to kill even a person who justly deserves to die, those who kill themselves are homicides. Fourth, the act of suicide allows no opportunity for repentance. And fifth, suicide violates the foundational Christian principle of patient endurance of all that the sovereign Creator permits to befall humanity (Amundsen, 1989).

While the church fathers firmly held that death was not to be sought, they proclaimed that Christians should not fear physical death, since it would furnish them entry into the ineffable delights of heaven. Hence numerous patristic sources marveled at Christians who were afraid of dying, and especially at those who desperately clung to any hope of sustaining their lives when afflicted with seemingly hopeless illness. They viewed such conduct as tantamount to blasphemy, or at least as a sad contradiction of Christian values (Amundsen, 1989).

It was bad enough to stake one's futile hope of a temporary reprieve on physicians; but to resort to magic was even more reprehensible (Amundsen and Ferngren). For example, in the late fourth or early fifth century, John Chrysostom praised a mother who chose to allow her sick child to die rather than use amulets, although her ostensibly Christian friends had urged her to do so and she herself was confident that it could save her daughter's life (*Homily 8 on Colossians*). About 150 years later, the physician Alexander of Tralles employed quite different reasoning when he argued that it was sinful not to apply any remedy that might possibly save a patient's life, even amulets and incantations (Temkin). Alexander's attitude is interesting for three reasons. First, it demonstrates that magical remedies had already obtruded themselves into medicine. Second, it graphically illustrates a conflict of priorities between the physician and the theologian. And third, it is a very early, perhaps the earliest, hint of a physician's expressing a moral, indeed a religious, obligation to prolong life, in this case based on the reasoning that the supposedly greater sin of not doing all in one's power to save a patient was justifiably avoided by the lesser sin of using magical remedies.

Christianity developed a theological basis for the sanctity of human life, condemning contraception, abortion, infanticide (even of the sickly and deformed), suicide, and (by implication) active euthanasia. Although it did not embrace any sense of obligation to attempt to prolong life (nor did it until several centuries more had elapsed), its theology of sanctity of life did conduce to the reasoning of Alexander of Tralles that is described above, an attitude that grew even stronger during the Middle Ages.

Conclusion

In early Christian literature a reasonably clear, if not exhaustive, picture emerges of ideal physicians who were "Hippocratic" in their decorum and motivated by Christian philanthropy, and who so cherished the sanctity of human life that they would neither perform abortions nor assist in suicide, yet regarded desperate attempts to forestall death as inconsistent with ultimate Christian values. Nevertheless, such a description tells us nothing directly about the ethics of early Christian physicians except insofar as individual physicians may have agreed with and attempted to conform to such an ideal.

The ideal physician had been posited in classical antiquity, and that ideal included compassion as a desirable characteristic. However, agape—Christian love, which was the basis of philanthropy—was so central a tenet of Christian theology that it was applied to the physician as not merely a desirable but as an essential characteristic. The philanthropic basis of medical practice and the principle of the sanctity of human life became the hallmarks of Western medical ethics until modern times.

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I. ANCIENT AND MEDIEVAL.
C. MEDIEVAL CHRISTIAN EUROPE

The Middle Ages are typically divided into early (500–1050) and high and late (1050–1545). This survey of the history of medical ethics in medieval Europe will first examine the sparse evidence from the early Middle Ages, and then deal thematically with significant developments during the high and late Middle Ages. The Middle Ages was a period of monumental changes. There was, however, one constant—the nearly complete identification of society with the Catholic church, which became the most thoroughly integrated involuntary religious system in human history. The Catholic church, of course, evolved throughout the Middle Ages. Nevertheless, the indirect influence of the church on most—perhaps all—aspects of life, as well as the effects of its efforts to define, direct, and regulate the details of secular and religious life, provide a backdrop for much of the discussion that follows.

The Early Middle Ages

We know of the existence of a variety of medical practitioners from the early Middle Ages. Here and there in the sources are physicians who had been trained in Alexandria or in Constantinople, Jewish or Islamic physicians, and public or civic physicians in some of the surviving Roman cities of Italy and southern France. But primarily there are those who seem to have been little more than craftsmen who had learned their techniques as apprentices. The sources, nevertheless, call all these varied types *medici,* and often contrast them with *incantatores* (enchanters, magicians, witch doctors). *Medici,* although sometimes depicted negatively in the predominantly religious literature of the early Middle Ages, are presented favorably as practitioners of an art not inherently inconsistent with the teachings of the church. The *incantatores,* however, are invariably condemned in the literature, including secular and canon law, as diabolical practitioners of illicit arts inherently opposed to the church (Flint, 1989, 1991). In this sense the physicians of the early Middle Ages—indeed, throughout the Middle Ages—were regarded by those who spoke for the church as providing a theologically neutral alternative to the spiritually pernicious ministrations of the nearly ubiquitous practitioners of those healing arts that the church condemned (Amundsen, 1986).

Not only are these physicians, of whose ethics we have little or no direct evidence, contrasted with the *incantatores*; they also are distinguished from monks or other clergy who practiced medicine as part of their religious calling. Surveys of medical history typically describe the early Middle Ages as a time when medicine was practiced predominantly by monks who treated the ills not only of their fellow monks but also of the laity of the surrounding community, as an act of Christian charity. The rule of Saint Benedict, founder of the Benedictine order (early sixth century), is often cited in this regard. Chapter 36 of the rule is addressed to those who tend ill monks. Since, however, this chapter says nothing about medical care of the laity, scholars have emphasized that the rule may not be used as evidence for a policy of monastic medical care of the ill by the Benedictines (e.g., Park). But the steward, who, according to chapter 36, is largely responsible for the logistics of the care of sick monks, is admonished elsewhere in the rule to "take the greatest care of the sick, of children, of guests, and of the poor, knowing without doubt that he will have to render an account for all these on the Day of Judgment" (chap. 31). The "children, guests, and poor" in this context certainly would not be monks, nor should the "sick" here be limited to them. Still, this is far from a concise articulation of a monastic obligation to succor the ill of the lay community at large.

In the mid-sixth century, Cassiodorus wrote a rule for the members of a monastery he had founded. The section governing monk-physicians begins with praise for their performing "the functions of blessed piety for those who flee to the shrines of holy men" (*Institutiones* 1.31), which suggests his expectation that the ill would come to the monastery for medical care. The availability and quality of medical care at monasteries varied enormously during those early centuries. Only from the ninth century on can we speak with any certainty about monasteries' playing a key role in providing medical care for the sick poor (Park). Various church councils during the early Middle Ages enjoined bishops to provide accommodations for the destitute. These, originally called *xenodochia,* but soon more commonly known as *hospitia* or *hospitalia,* were attached to cathedrals or other churches (Ullmann). These *hospitalia* were not hospitals in the modern sense of that term (Miller). Often they provided only food, shelter, and some amenities; only occasionally were they staffed with medical attendants, who would then not have been monks but other clergy who devoted part of their energies to practicing medicine.

Cassiodorus wrote two documents that describe the duties of physicians. One, already cited as evidence for monastic medical care of the laity, gives inspirational guidance to those of his monks who were also physicians (*Institutiones*). The other, which he wrote as an official in the service of King Theodoric, regulated the activities of the civic physicians of Ostrogothic Rome and of the royal household (*Variae*). While in both documents Cassiodorus lauds the medical art, there is little other similarity between them. He urges the secular physicians to place their confidence in their art, while the monk-physicians are to place their hope in the Lord and not in the medical art itself. Although Cassiodorus stresses that the secular physicians are to be dedicated to their learned art and mindful of the oath by which they were consecrated, swearing "to hate iniquity and to love purity," his major concern is nevertheless with correcting negative aspects of medical practice: professional jealousies, envy, an unwillingness to share techniques with colleagues, and bedside bickering. While this secular document places a minor emphasis on the calling, motivation, or qualities of the secular physicians, the monk-physicians are to be deeply compassionate, distressed with personal sorrow at the misfortunes of others, and grieved by their suffering and peril. Motivated by compassion, they will "perform the functions of blessed piety," and their reward will be received from the Lord. Similarly, Cassiodorus' contemporary, Benedict, had charged his monk-physicians, "Before all things and above all things care must be taken of the sick, so that they may be served in very deed as Christ himself" (*Rule*, chap. 36). Their reward would come from the Lord.

While Cassiodorus' guidance to the secular physicians has no distinctly Christian flavor, the peculiar qualities of the monk-physicians are those of the ideal physicians of earlier Christian thought and of a variety of clergy who were to devote their lives to the charitable care of the sick, especially the poor, during the high and late Middle Ages. The best-known example is the Knights Hospitallers of Saint John of Jerusalem (late eleventh to the mid-sixteenth century), an order founded to provide shelter and care for pilgrims. These Hospitallers vowed to "serve our lords, the sick" (Hume). This phrase not only is an inversion of the lord–vassal relationship but also conveys the same ideal as the injunction in the Rule of Saint Benedict that the monk-physicians should serve the sick as if the latter were "Christ himself." These highly spiritual ideals of monastic medicine merged with the secular tradition of medical ethics and etiquette in the medico-ethical literature of the seventh through the tenth century.

Numerous medical manuscripts survive from the early Middle Ages, including several that deal with medical ethics and etiquette (MacKinney). Unfortunately the authorship, intended audience, and purpose of these medico-ethical treatises remain uncertain. They may have been composed by monks or other clergy as purely literary efforts. They may have been used as part of clerical education in the liberal arts, of which medicine was typically a subdivision (Amundsen, 1979). It is most unlikely that they were intended for, or used in, the training of physicians. These treatises present a fusion of the classical tradition of medical etiquette with Christian principles of compassion and charity. The bulk of each treatise was apparently drawn from, and sometimes directly attributed to, Hippocratic writings on etiquette: The physician's aptitude and ideal character, conscientiousness and diligence in practice, bedside manner, confidentiality, sexual propriety, proper relations with colleagues, and the preservation of one's reputation, that is, decorum in the broadest sense of the word. There is nothing distinctly Christian about any of this. But intermingled with such commonsensical precepts are distinctly Christian emphases: The physician should serve the rich and the poor alike, looking for eternal rather than material rewards, making "the cases of others his own sorrow." MacKinney correctly observes that "the monastic spirit dominated … medical handbooks of the period." They were "classical as well as pious, and secular as well as ascetic" (p. 5).

We know little about the ethics of early medieval physicians except for some monks and other clergy who practiced medicine as an act of Christian charity, without thought of remuneration. We do not even know by whom, for whom, and for what purposes treatises devoted to medical ethics and etiquette were composed. Anyone could claim to be a physician and practice medicine. There were no licensure requirements and no professional organizations. Only rarely do we encounter evidence of legal efforts to regulate physicians' activities, for example, by the Visigoths (Amundsen, 1971). Nor did the church make any concerted effort, during these early centuries, to define the responsibilities and regulate the conduct of secular or monastic/clerical physicians, other than to wage vigorous warfare against the use of illicit means of healing that typically were employed not by *medici* but by *incantatores.* Much of the time, the lines blur between secular physicians and those practitioners of medicine who were monks or clergy but practiced medicine for financial gain; many physicians who appear to have been secular were in fact clergy. Nor do we have any evidence about the behavior of physicians during epidemics that affected the villages and countryside during the early Middle Ages. But all these matters were to change during the high and late Middle Ages.

The High and Late Middle Ages

MEDICAL AND SURGICAL PRACTICE BY THE CLERGY. At the beginning of the high Middle Ages most monasteries could provide medical care for their members without resorting to the services of secular physicians. Nunneries typically engaged secular physicians for serious illnesses, although nuns attended to the minor health needs of members of their communities. There were some nuns, however, who were as medically sophisticated as any monastic/clerical or secular physician. The outstanding example is Hildegard of Bingen (1098–1179). Well known to her contemporaries as a visionary and mystic, she was also famous for her scientific and medical writings. While the propriety of monks treating monks and nuns treating nuns appears not to have been questioned, the role of the clergy generally as physicians and surgeons was beginning to be subjected to close scrutiny.

In the early twelfth century, the Cistercian abbot Bernard of Clairvaux received a demand from another abbot to send back to his former monastery a monk who had fled to Clairvaux. This monk had left because his abbot "used him not as a monk but as a doctor," and compelled him "to serve not God but the world; that in order to curry favour with the princes of this world he was made to attend tyrants, robbers, and excommunicated persons" (Amundsen, 1986, p. 84), which had brought considerable financial reward to his monastery. The monk was troubled about the spiritual propriety of this. Bernard permitted him to remain. The Cistercians shortly thereafter forbade their monk-physicians to practice outside their monasteries or to treat the laity (Miller).

A general church council, Lateran II, in 1139 promulgated a regulation having the rubric "Monks and canons regular are not to study jurisprudence and medicine for the sake of temporal gain," which condemned the avarice that motivated some clergy to pursue such studies: "[T]he care of souls being neglected … they promise health in return for detestable money and thus make themselves physicians of human bodies" (Schroeder, pp. 201–202). This law also expresses concern that clergy who practiced medicine would see "inappropriate things." But the major focus was that if financial gain were the motive for the study and practice of medicine and secular law, such pursuits were not appropriate for those who had dedicated themselves to a religious life. We should note, first, that this stipulation did not apply to most clergy but only to monks and canons regular ("regular" means living under a "rule," which did not include most clergy) and, second—and worth noting—that it was never incorporated into canon law. A regional council at Tours in 1163 enacted a law much narrower than the one of Lateran II. It simply prohibited monks and other regular clergy from leaving their religious institutions to study medicine or secular law (Amundsen, 1978). This regulation, which did not forbid the practice of medicine by clergy, became part of canon law.

In 1219 Pope Honorius III issued a rescript, also included in canon law, that extended the prohibition of the study of medicine and secular law to virtually all clergy whose major responsibility was the performance of spiritual duties. Many clergy, however, were not affected by this stipulation, whose prohibitions were significantly lessened by subsequent enactments (Amundsen, 1978). By the end of the Middle Ages, canon law still had not prohibited the clergy from practicing medicine. Surgery, however, was a somewhat different matter, since it involved much greater risk to the patient and increased the danger that a clerical practitioner might be held responsible for a patient's death and hence excluded from exercising his clerical office. In 1215, Lateran IV forbade clergy in major (holy) orders (subdeacons, deacons, and priests) to practice the part of surgery that involved cautery and cutting, in which clergy in minor orders (porters, acolytes, exorcists, and lectors) could still engage (Amundsen, 1978).

Although the practice of medicine by the clergy was permitted, the church was obviously uneasy about their motivation and the possible effects that it might have on their spiritual obligations. Many of the clergy who continued to practice medicine and surgery, at least with the tacit blessing of the church, did so predominantly for charity. For example, some clergy composed medical treatises so that their fellow clerics could treat the poor gratis. Many clergy also wrote medical handbooks to help the poor help themselves. The outstanding example is Petrus Hispanus, "who publicly taught, wrote on, and practised medicine during the early stages of a highly successful ecclesiastical career that culminated with his election as Pope John XXI in 1276" (Siraisi, p. 25). He is the probable author of the *Treasury for the Poor,* which describes herbs the poor could gather to treat themselves.

During the high Middle Ages rapid urbanization brought about widespread suffering and disease in the growing towns and cities. In the late eleventh century, Augustinian canons (who were regular clergy like monks, but unlike them in that they did not live apart from society) and various lay brotherhoods established charitable institutions that included facilities for the destitute ill (Miller). A variety of such institutions were founded by bishops, kings, feudal lords, wealthy merchants, guilds, and municipalities as endowed charitable institutions. Members of various orders, like the Knights Hospitallers of St. John of Jerusalem, sometimes staffed these hospitals. Nursing orders also arose, committed to caring for the destitute ill in such institutions. The Knights Hospitallers' phrase "to serve our lords, the sick," perfectly captures both the idealism and spiritual motivation of these orders and the very essence of their ethics. But such practitioners constituted only a small proportion of physicians and surgeons of the high and late Middle Ages. By the mid-fourteenth century, most monasteries were paying secular physicians to treat their ill monks (Park). The church's desire to decrease clerical involvement in medical practice, especially for financial gain, combined with rapidly changing social conditions that, beginning around 1050, significantly altered the practice of medicine and the nature of medical ethics.

LICENSURE, GUILDS, UNIVERSITIES, AND A RECIPROCITY OF OBLIGATIONS. Stimulated by a dynamic revival of a commercial economy, dormant since the collapse of Roman civilization, a gradual transformation of European society began around 1050, an urban revolution that created a starkly altered context for nearly all aspects of life. One of its most salient features was the corporate nature of late medieval urban society, as manifested in increasing institutional sophistication and formalized specialization of labor, regulated either internally by guilds or corporations or externally by secular or ecclesiastical authority. Both regulatory features changed the basis for the practice of most trades and professions, including medicine and surgery. No longer would the practice of medicine be a right that anyone could claim, a free enterprise constrained only by individual conscience and criminal law. The practice of medicine would now be a privilege granted, enforced, and protected by the state or the church, at the state's or church's initiative or at the request of guilds or corporations of physicians or surgeons.

The earliest datable law instituting medical licensure is from the Kingdom of Sicily. In 1140, Roger II issued a statute specifying that those who wished to practice medicine were to appear before his officers and judges and be examined by their court. Those who practiced in defiance of this statute were to be imprisoned and their property confiscated. "… this has been arranged so that subjects in our kingdom may not be experimented on by inexperienced physicians" (Powell, p. 130; Hartung). A considerable advance over this legislation was made by Roger's grandson, Emperor Frederick II, who in his capacity as king of Sicily, in 1231 promulgated the *Liber Augustalis.* Thereafter the examination for licensure was to be conducted by the masters of the medical school at Salerno, and the license to practice would be issued by the emperor or his representative. Before the examination, the aspirant was to study logic for three years and medicine (to include surgery) for five years, and to practice for one year under the direction of an experienced physician. These revisions are introduced by the following justification: "We see a special usefulness when we provide for the common safety of our [faithful subjects]. Therefore, since we are aware of the serious expense and irrecoverable loss that can occur because of the inexperience of physicians …" (Powell, p. 131). Physicians must visit their patients twice a day and, at the request of the patient, once during the night. Fees were to be determined in part by the distance involved. The physician was required to swear to abide by the regulations fixed by the government, treat the poor gratuitously, and inform the authorities of any apothecary who prepared drugs at less than the required strength. Physicians were forbidden to make any contracts with apothecaries or to own apothecary shops (Powell; Hartung).

On the Iberian Peninsula, the first medical licensure regulation, in 1289, imposed no requirement for a course of study in a medical school; forty years later a new law established a university medical degree as a prerequisite for practice (García-Ballester et al.). The law of 1329 and subsequent legislation provided very specific regulations governing physicians' conduct and responsibilities. These regulations, which benefited both the general public and the qualified and responsible physician, evince a reciprocity of obligations between the profession and the state. Elsewhere in Europe, by contrast, artisans, merchants, surgeons, physicians, and professors were organizing into guilds, gaining charters from municipal, royal, or ecclesiastical authorities, and guaranteeing standards of quality of goods or services in exchange for the privilege of holding a monopoly in their service or commodity.

One of the most striking features of late medieval urban life was its corporative aspect, particularly its guild organization. Perhaps originally formed simply as social organizations under the auspices of a patron saint, guilds had three major interests: (1) social, manifested in both internal and external charitable efforts, and social life within the guild (banquets, etc.); (2) political, especially guilds involved in the production of economically vital commodities; and (3) commercial, involving the protection of financial and vocational interests. In respect to the last, the guilds, by obtaining charters, secured the right to exercise a monopoly on their product or service in a particular geographical area. Such a monopoly entailed the right to make and enforce standards of quality in their products or services, to control hours and working conditions, to limit competition among members, to limit entry into the craft or profession, and to ensure the proper treatment of customers. Part of the monopoly was the right to train and license new members, thus eliminating competition from outside the guild. Although one of the major aims of such measures was economic, the guilds frequently claimed that such restrictions were necessary to maintain a high level of competence and ethics in the trade or profession. Distinct from the merchant and craft guilds, the medieval universities were essentially educational guilds. Beginning in the late twelfth century, some universities gained charters and thus became corporate bodies designed to further educational interests and to protect their members. The *collegium* of teachers who examined the candidates for a degree was, at some universities, vested with the authority to grant a license or, at others, to recommend to secular or ecclesiastical authorities that a license be awarded.

Conditions were so diverse that generalities are often misleading. But usually surgeons were organized in craft guilds; physicians, at least in cities having a university, were not members of a craft guild but were part of, affiliated with, or under the supervision of the medical faculty of the university. In university cities, medical licensure requirements were generally instituted earlier than in those without a university but, from the early fourteenth century on, many cities and towns required those who wished to practice medicine within their jurisdiction to have a degree and license from an acceptable university. Physicians practicing in such places often organized themselves into *collegia* or guilds, and in some instances obtained the authority to examine and license physicians who wanted to practice within the community, regardless of the degrees held by the applicants (Siraisi).

Practitioners brought to trial for practicing without a license often accused medical and surgical guilds and faculties of self-interest (Kibre; Cosman). However, restrictions on medical and surgical practice, whether imposed by authorities or requested by medical faculties or medical or surgical guilds, were justified in terms of the common good, especially the grave dangers to the people if charlatans and quacks were permitted to undertake medical or surgical care. For example, the medical faculty of the University of Paris initiated medical licensure provisions and, in seeking ecclesiastical and royal support to enforce these regulations, continually appealed to the "public interest." The same appeal was made in the medical faculty's attempts to establish a right to oversee the activities of surgeons, apothecaries, barbers, and herbalists, and to prosecute unlicensed practitioners in ecclesiastical or secular courts. The unlicensed practitioners often were women who were frequently "caught in the crossfire" (to use Green's phrase, 1989, p. 447) of the legal battles between licensed groups like physicians and surgeons (see also Park, for analysis; Kibre, for narrative examples). As in the early Middle Ages, there was also a concerted effort to exclude the illicit supernatural from healing procedures. Often suspected of being "witches and exorcisoresses of the devil," unlicensed women practitioners were in double jeopardy (Amundsen, 1986, pp. 93–94).

Although guilds were organized to serve their members' self-interest, guild ethics generally were beneficial to the public. In 1423, the physicians and surgeons of London petitioned the mayor and aldermen to authorize the creation of a joint *collegium* of the two crafts. George Unwin, a historian of English guilds, remarks that their petition illustrates "the best spirit of professionalism at this period of London history." He summarizes its contents as follows:

> Their rules were meant to ensure that all practitioners in both branches should be duly qualified, if possible, by a university training, and they sought to provide a hall where reading and disputation in philosophy and medicine could be regularly carried on. No physician was to receive upon himself any cure [i.e., case], "desperate or deadly," without showing it within two or three days to the Rector or one of the Surveyors in order that a professional consultation might be held, and no surgeon was to make any cutting or cauterization which might result in death or maiming without similar notice. Any sick man in need of professional help but too poor to pay for it, might have it by applying to the Rector. In other cases the physician was not to charge excessive fees, but to fix them in accordance with the power of the sick man, and "measurably after the deserving of his labour." A body composed of two physicians, two surgeons, and two apothecaries, was to search all shops for "false or sophisticated medicines," and to pour all quack remedies into the gutter. (p. 173)

The foundational principles of medieval medico-surgical guild ethics were that each guild member must: (1) be ready to help the other; (2) protect the well-being and honor of the guild; and (3) help the sick. The order of these principles is very important. The guilds were functional, inherently selfish organizations designed to promote and protect members' special interests. They were brotherhoods, companies of people united more often than not by a common economic activity. The well-being and honor of the craft depended upon the mutual cooperation of its members. If these conditions were met, then the third—the service rendered or the commodity produced—could be effectively delivered. All these, in late medieval urban life, hinged upon the freedom of the artisans, merchants, professors, physicians, or surgeons to perform their functions unmolested by those who would illicitly meddle in their affairs. Hence they sought an exclusive right to fill a particular role; in exchange, a guild would guarantee a level of expertise in the production of its commodity or in the rendering of its service, and would assume the responsibility to police and to supervise its own members, both in respect to their qualifications, that is, training (leading to licensure), and to their performance. Regulations governing the minutiae of conduct, both within the guild and in relationships with customers or the community, varied considerably from guild to guild and from city to city. But the obligation to ensure competence and quality seems to have been a constant feature.

The highest guarantee of competence to practice medicine, recognized throughout Europe in the late Middle Ages, was a degree granted by a university medical faculty. A university curriculum in medicine, a set body of literature, and the presence of instructors qualified to teach and to test demonstrate that a standard of competence existed. The reality of such a standard has important ethical implications. Luis García-Ballester goes so far as to assert that "Everything connected with the conduct of the physician—from strictly technical matters … to the question of fees or the problems of etiquette …—was derived from this strictly technical organizational scheme … what later became known as medical ethics had this technical, intellectual origin. The specific morality of the practitioner derived, therefore, from his being a healer technically trained, and was essential for his status as an expert in medicine" (pp. 44–45).

An underlying and sometimes articulated principle of medical and surgical guilds was that the guild would ensure that the ill of the community, including the poor and the hopelessly ill, would not be abandoned at the whim of individual physicians or surgeons. This was based at least in part on the conviction, which was very strong in the late Middle Ages, that one had an *officium,* that is, an office or calling, that carried with it certain duties and obligations. In a work devoted to the responsibilities attached to kingship, Thomas Aquinas wrote, "Nor has [the king] the right to question whether or not he will so promote the peace of the community, any more than a physician has the right to question whether he will cure the sick committed to him. For no one ought to deliberate about the ends for which he must act, but only about the means to those ends" (*De regimine principum* 2). In late medieval urban (i.e., corporate) life, physicians and surgeons, by virtue of their privilege of engaging in a legitimate *officium* within the corporate structure of society, had responsibilities both to their *officium* itself, as represented by the guild, company, craft, or *collegium,* and to the community that granted them their privileges.

THE CHURCH'S EFFORTS TO DEFINE THE RESPONSIBILITIES OF PHYSICIANS. In 1215, a general church council, Lateran IV, promulgated a decree that required annual confession by all Catholics, on pain of excommunication. This decree was widely publicized and strictly enforced. In response, lengthy treatises on moral theology and numerous manuals to aid priests in interrogating penitents during confession were written by moral theologians in an effort to subject the broadest spectrum of human activities to Christian moral principles, including a wide variety of occupations. The discussion that follows is a very condensed summary of the sections of ten primary sources from the early fourteenth through the early sixteenth century that provided priests with a range of questions and moral guidance to be addressed to physicians and surgeons during their mandatory annual confession (Amundsen, 1981). Where the word *physician* appears, it should be understood to include "surgeon."

Competence and diligence. Physicians who are not competent according to accepted standards within the profession sin by practicing medicine. Simply possessing a degree in medicine does not in itself guarantee competence. Competent physicians sin if they do not conscientiously exercise diligence. Rashness, which may result from incompetence or negligence, is a sin in medical practice, especially if patients are harmed. Hence physicians should be cautious and not administer medicines about whose effects they are in doubt; patients should be left in God's hands rather than be exposed to additional danger. Generally, physicians sin if they engage in any experimentation at the patient's risk, especially if they experiment on the poor whom they treat without charge. Physicians also sin if they are so cautious that they fail to give the appropriate medicines, and especially if they do so in order to prolong the illness and thereby increase their fees.

Fees and charity. Beginning with the assumption that it is licit to receive remuneration for what one is not bound to do gratuitously, but bypassing consideration of how the scholastic principle of "just price" for services could be applied to medical practice, the moral theologians discuss a wide variety of moral aspects of medical fees. The most basic principle is that physicians should ensure that they accept only a "reasonable" fee, as determined by the quality of care; the physician's labor, diligence, and conscientiousness; the custom of the place; and the patient's means. A patient who is rich must not be exploited by exorbitant rates. More problematic is the sick pauper. Is the physician obligated to give free medical care to the poor? This, as we shall see when discussing the medico-ethical literature of the high and late Middle Ages, was a source of great frustration for physicians. Thomas Aquinas, beginning with the premise that "no man is sufficient to bestow a work of mercy on all those who need it," suggests that kindness ought first to be shown to those with whom one is united in any way. As for others, if one "stands in such a need that it is not easy to see how he can be succored otherwise, then one is bound to bestow the work of mercy on him." Hence a lawyer is not always obligated to defend the destitute, "or else he would have to put aside all other business and occupy himself entirely in defending the poor. The same holds with physicians in respect to attending the sick" (*Summa theologiae* 2–2, 71, 1). The authors of the confessional literature generally follow Aquinas and specify that physicians must treat the poor gratuitously if the patient would die without treatment.

An obligation to care (especially for hopeless cases). With the advent of medical licensure requirements and medico-surgical guild monopolies, the physicians' option of refusing to treat or of deserting hopelessly ill patients became more circumscribed. Social and religious pressures also changed. Typically the moral theologians maintain that "Desperate cases that, according to the judgments of men, are held to be fatal, sometimes the diligent physician is able to cure, but rarely … therefore, clear to the end the physician ought to do what he can to cure the patient" and should not entirely withdraw from the patient "as long as nature does not succumb." If a rich miser is unwilling to employ the services of a physician, the physician is obligated to treat him or her gratis, even to provide medicines without charge; otherwise the physician is killing such a person indirectly. If the rich miser recovers, the physician may sue for fees and expenses; if the miser dies, the heirs are obligated to pay (Amundsen, 1981).

Spiritual obligations of physicians to patients. While the theologians were quite concerned to protect the patient from physical harm and financial exploitation, they were even more determined to guard the well-being of the patient's soul. At Lateran IV in 1215, the following decree was enacted:

> Since bodily infirmity is sometimes caused by sin, the Lord saying to the sick man whom he had healed: “Go and sin no more, lest some worse thing happen to thee” [John 5: 14], we declare in the present decree and strictly command that when physicians of the body are called to the bedside of the sick, before all else they admonish them to call for the physician of souls, so that after spiritual health has been restored to them, the application of bodily medicine may be of greater benefit, for the cause being removed the effect will pass away. We publish this decree for the reason that some, when they are sick and are advised by the physician in the course of the sickness to attend to the salvation of their soul, give up all hope and yield more easily to the danger of death. If any physician shall transgress this decree after it has been published by the bishops, let him be cut off from the church till he has made suitable satisfaction for his transgression. And since the soul is far more precious than the body, we forbid under penalty of anathema that a physician advise a patient to have recourse to sinful means for the recovery of bodily health. (Schroeder, p. 236)

The stipulation that physicians must advise and persuade patients, before all else, to call a priest concerns the curative effect of confession rather than the opportunity to confess before dying. The moral theologians’ discussions of this stipulation vary enormously in length, detail, and sensitivity to the problems that it posed. Several maintain that this requirement applied only to cases of extremely dangerous or mortal illnesses. Some go so far as to provide lists of applicable diseases, symptoms, or injuries, especially those demanding immediate attention. This interpretation of the decree is surprising, since it flies in the face of the specific intent that patients be made aware that the requirement to call a confessor is not to be taken as an indication that their condition is hopeless. And some of the authors of the confessional literature interpret it strictly along such lines, making no exceptions. They wrestle with the question of whether a physician is obliged to withdraw from a case if the patient refuses to call a confessor, and reach a variety of answers ranging from a strict “yes” to an unequivocal “no,” some of the latter maintaining that if the physician were required to abandon the stubborn patient, “the precept of the church [would] seem against the precept of God.” At the end of the Middle Ages, there was no uniformity either of practice or of interpretation of this piece of canonical legislation.

In the context of discussions of the requirement that physicians have their patients summon a confessor, some moral theologians raise the question of whether physicians are obliged to inform terminally ill patients of their condition. There is some disagreement among the moral theologians who address this issue, particularly since physicians (and here Galen is cited) typically tell patients that they will recover, even if there is little hope, since predicting a fatal outcome will likely remove all hope of recovery and hasten death. Generally the authors of the confessional literature insist, however, that unless physicians are certain that their terminally ill patients have set both their spiritual and their temporal affairs in order, they must inform them of their imminent demise, since otherwise harm may ensue to patients’ souls and estates.

The second requirement of the legislation in question is for physicians to refrain from advising sinful means for the recovery of health. Several of the moral theologians simply quote that stipulation without elaboration. Others condemn specific matters, such as advising fornication, masturbation, incantations, consumption of intoxicating beverages, breaking the church’s fasts, and eating meat on forbidden days.

Abortion and euthanasia. The authors of the confessional literature almost entirely ignore the subject of abortion when discussing the responsibilities and sins of physicians. While all include thorough discussions of abortion under the rubric “homicide” or “abortion” or both, only two include it in their extensive considerations of medical ethics. Apparently the rest did not think that physicians or surgeons were confronted with requests for abortions. Women who sought abortions would probably not have turned to physicians or surgeons, the overwhelming majority of whom were men during the high and late Middle Ages, but to another woman, such as a midwife or an unlicensed female practitioner.

Abortion, regarded both as a sexual sin and, under some circumstances, as homicide, was an issue fraught with interpretive problems during the Middle Ages (Noonan; Connery). The opinion of Jerome and Augustine (fourth century) that abortion is not homicide unless the fetus is “formed,” that is, vivified or ensouled, was incorporated into medieval canon law, which also included a conflicting decree that applied the penalty for homicide to the induced abortion of a fetus at any stage of development. Theologians, canon lawyers, and the authors of the confessional literature were split between these two positions. The stricter interpretation generally forbade abortion at all times and under all circumstances. The more liberal interpretation, which was influenced by Aristotelian embryology, did not classify induced abortion as a mortal sin within the first forty days of pregnancy in the case of a male fetus, and eighty (or, according to some, ninety) days in the case of a female, and permitted abortion during these periods under a variety of extenuating circumstances. The conflict between the interpretations of these two camps was not resolved until long after the Middle Ages. Both, however, clearly condemned abortion as reprehensible if performed simply to destroy the unwanted consequence of sexual intercourse.

What we call active euthanasia is a subject that the moral theologians thus far surveyed never raised when discussing the sins of physicians; it was probably regarded throughout the Middle Ages simply as homicide on the physician's part and suicide on the patient's, assuming willing involvement by the latter. Martin Azpilcueta, better known as Navarrus, a leading canon lawyer and moral theologian of the sixteenth century, wrote in 1568 that the physician sins who gives any medicine that he knows is harmful, "even if he administers it out of pity or in order to please the patient." Navarrus's statement seems clear and unambiguous: active euthanasia, whether motivated by pity or by the wish of the patient, is sinful. This must be one of the earliest articulations regarding active euthanasia in such precise terms. Navarrus gives as his authority the canon lawyer Panormitanus (early fifteenth century), who had simply given the opinion that those having custody or serving a sick person sin greatly if, motivated by "a sort of pity," they obey or indulge the "corrupted desire" of the ill. Before active euthanasia was seen as a separate moral category, the closest the authors of the confessional literature could have come to including relevant comments in their sections on physicians' sins would have been to have stated that it was a sin for physicians to kill or poison their patients intentionally.

The effects of the moral theologians' efforts. Medieval European society was, with the exception of a small number of Jews and heretics (e.g., Albigensians and Waldensians), exclusively Catholic. Guaranteed the allegiance of virtually the entire population of western Europe and the prestige of ecclesiastical institutions, the church could exercise jurisdiction over areas of life that now would be the concern of either secular authority or the individual conscience. The church promulgated laws and expected obedience. Ecclesiastical courts imposed penalties ranging from penance to imprisonment to excommunication. The extent to which the confessional influenced ethics and conduct cannot be gauged with certainty. The authors of the confessional literature strove both to educate the laity so that they might be able to identify previously unknown sins, both of commission and of omission, and to correct sinful practices. The best confession was one that led to a changed life, and a changed life should be one in as close conformity to the expectations and standards of the church as possible. The priest's authority "to loose and to bind," although ultimately of eternal consequence, applied also to this life in that it included the authority—indeed, the responsibility—to grant forgiveness and restoration only to those who satisfied the requirements of the confessional, and to impose sanctions upon those who refused. The ultimate sanction, excommunication, when imposed upon those who exercised their vocation by license, would deprive them of their livelihood. Whether such steps were ever taken against physicians during the high and late Middle Ages remains unclear. Nevertheless, the morally educating (or possibly alienating) effects of this annual interrogation, which employed the detailed scrutiny available to every priest in his confessional manual, must have been profound.

PHYSICIANS' AND SURGEONS' ADVICE ON ETHICS AND ETIQUETTE. In the extensive medical and surgical literature that has survived from the high and late Middle Ages, one occasionally encounters comments made directly on matters of medical ethics or etiquette. Surgical manuals, for example, often begin with a discussion of the moral and educational qualifications of a practitioner, bedside manner, fees, and a variety of related matters. Medical and surgical literature also contains comments that indirectly reveal aspects of the ethical standards of the author, especially in the tractates written by physicians who attempted to understand and deal with the outbreaks of plague that struck Europe during the late Middle Ages.

Loren MacKinney perceived that, by the twelfth century, a change in spirit had occurred in medical literature from monastic to secular, a "shift of emphasis from ideals to practical considerations," a "despiritualization of the medical physician," particularly in the introduction of various "tricks of the trade" and a predominant concern with fees (pp. 23ff.). He credits this change to such factors as rapid urbanization, and he is probably right to a degree. But it is important to note the different walks of life from which the authors of the sources came. While the literature from the early Middle Ages was likely composed by monks, that of the high and late Middle Ages was written mainly by secular physicians. So it is not surprising that its tone is less otherworldly than that of the earlier treatises. The later literature was written with the clear intention of providing practitioners with two types of information: (1) the ideal physician's character, preparation, and practice; and (2) very practical and sometimes questionable advice on how best to survive in the profession. Both were at least moderately informed by the teachings of the medieval Catholic church.

The first category consists of the same range of commonsensical advice as appears in Hippocratic treatises and in the medico-ethical literature of the early Middle Ages. The second appeared especially in discussions of fees. As early as the tenth century, the physician is advised: "At the outset, accept at least half of the remuneration without hesitation, for he who wishes to buy [your services] is disposed to pay and to beg [for treatment]. Get it while he is suffering, for when the pain ceases, your services also cease" MacKinney, p. 24). Somewhat more enlightened is the suggestion by William of Saliceto (thirteenth century) that "a high salary, if demanded, imparts to the physician an air of authority, which strengthens the confidence of the patient in him … so that the sick man imagines from this that he is more skillful than others and ought therefore to be successful in curing him" (Mirfeld, p. 132).

Some of the advice that follows, written by physicians or surgeons, may appear particularly crass. It is, however, important to realize that the medical literature of the time stressed, in Luis García-Ballester's words,

> the mutual confidence that should exist between doctor and patient. Without such confidence the efficacy of the curative action would be greatly undermined …. the physician's or surgeon's confidence in his patient was demonstrated by two conditions of equal significance: the first was that the patient should carry out what had been prescribed by the healer; the second that the patient should pay the remuneration agreed upon. The fee would be for the doctor the objective and tangible expression of his relationship with the patient and that of the patient with the doctor, while, at the same time, it would be a guarantee of continuity in treatment. (p. 51)

Henry de Mondeville (fourteenth century) laments that "The chief object of the patient, and the one idea which dominates all his actions, is to get cured, and when once he is cured, he forgets his own obligations and omits to pay; the object of the surgeon, on the other hand, is to obtain his money, and he should never be satisfied with a promise or a pledge, but he should either have the money in advance or take a bond for it" (Hammond, p. 159; Welborn, p. 356). Mondeville's attitude was probably the fruit of bitter experience. Official documents from the late Middle Ages record many cases of physicians suing patients in order to collect their fees. In most cases in which the treatment had been unsuccessful, the suit went in favor of the patient. Quite unreasonable demands by patients for extensive credit, the necessity that physicians sometimes demand securities before undertaking treatment, and lucrative contractual arrangements all contribute to the complex and ethically ambiguous way in which late medieval medical and surgical practitioners made a living (Rawcliffe, for late medieval England).

One area in which physicians seemed to act against their more mercenary interests was in providing advice that would keep potential patients from needing their services. Mondeville wrestled with the problem presented by surgeons' advising their patients how to stay healthy, "because the treatment which stops the onset of a new disease is more useful to a patient than all other treatments. But this is, as one can see, useless and harmful to the surgeon because he thus stops the appearance of a disease whose treatment would be advantageous to himself" (Hammond, p. 155; Welborn, p. 355).

Neither Mondeville nor his contemporary, John Arderne, seem to have felt any embarrassment over pressing for as high a fee as possible. The former recommends that "The surgeon should pretend that he has no living nor capital except his profession, and that everything is as dear as possible, especially drugs and ointments; that the fee is nothing as compared with his services; and the wages of all other artisans, masons, for example, have doubled of late" (Hammond, p. 156). He considered it essential that the fee not be reduced too much. It would be better, then, to charge nothing.

In determining how much to charge, Mondeville recommends that the surgeon consider three things: "First, his own standing in the profession, then the [financial] condition of the patient, and, third, the seriousness of the illness" (Hammond, p. 156; Welborn, p. 356). It was the second of these that was probably the most trying. Mondeville advises the doctor not "to have too much faith in appearances. Rich people have a bad habit of appearing before him in old clothes, or if they do happen to be well dressed, they make up all sorts of excuses for demanding lower fees" (Welborn, p. 356). So strong, though, is the sense of obligation to succor the poor gratis, or at least to give the appearance of doing so, that physicians and surgeons probably were quite frequently faced with very difficult judgments.

The motivation of physicians and surgeons to extend charity to the poor was more than the advantages that might accrue to their reputation and to the honor of the profession; it was a product of enlightened self-interest, with eternal consequences, fully compatible with the theology of the time, as is succinctly expressed by Mondeville: "You, then, surgeons, if you operate conscientiously upon the rich for a sufficient fee and upon the poor for charity, you ought not to fear the ravages of fire, nor of rain nor of wind; you need not take holy orders or make pilgrimages nor undertake any work of that kind, because by your science you can save your souls alive, live without poverty, and die in your house" (Hammond, p. 156).

While some effect of the church's teaching is manifest in even Mondeville's fee policies, in other areas spiritual concerns are more evident. An anonymous twelfth-century Salernitan treatise advises: "When you reach [a patient's] house and before you see him, ask if he has seen his confessor. If he has not done so, have him either do it or promise to do it. For if he hears mention of this after you have examined him and have considered the signs of the disease, he will begin to despair of recovery, because he will think that you despair of it too" (De Renzi, vol. 2, p. 74). This work was composed some time before Lateran IV of 1215, and thus before physicians were required "before all else to advise and persuade" their patients to call a confessor. The anonymous author of this treatise does not appear unusually devout. Indeed, were one to attach an adjective to the work, "eminently practical" would describe it better than any other. The author, of course, was a member of a society in which the belief in the necessity of confession before death was deeply ingrained. While he may not have considered it especially his own spiritual duty to look after his patients' spiritual as well as physical health, he must have considered the alternative of advising patients to confess only when in dire straits to be potentially dangerous to them.

The advice on confession, as it appears in a treatise attributed to Arnald of Villanova (late thirteenth century), is significantly different in emphasis from that in the anonymous Salernitan piece: "[W]hen you come to a house, inquire before you go to the sick whether he has confessed, and if he has not, he should immediately or promise you that he will confess immediately, and this must not be neglected because many illnesses originate on account of sin and are cured by the Supreme Physician after having been purified from squalor by the tears of contrition, according to what is said in the Gospel: 'Go, and sin no more, lest something worse happens to you'" (Sigerist, p. 141). This version, written after Lateran IV, quoting the same Scripture as the canon law, demonstrates the direct influence of a constitution of canon law on a strictly secular piece of medical literature, as does even more strongly the following passage in an anonymous plague tractate composed in 1411: "If it is certain from the symptoms that it is actually pestilence that has afflicted the patient, the physician first must advise the patient to set himself right with God by making a will and by making a confession of his sins, as is set forth according to the Decretals; since a corporal illness comes not only from a fault of the body but also from a spiritual failing as the Lord declares in the gospel and the priests also tell us" (Amundsen, 1977, p. 416). About a century earlier, similar advice had been given by Mondeville: "Do not let the patient be concerned about any business except spiritual matters only, such as confession and his will and arranging similar affairs in accordance with the rules of the Catholic faith" (Amundsen, 1986, p. 90). Whether these writings composed after Lateran IV are simply examples of lip service to ecclesiastical authority or reflect genuine approval of the underlying principle upon which the legislation was based must remain an open question.

An eleventh-century treatise advises that the physician should "never become involved knowingly with any who are about to die or who are incurable" (MacKinney, p. 23). Although from the earliest times such counsel was common, in the late Middle Ages it was becoming increasingly less so. The previously quoted anonymous Salernitan treatise from the twelfth century advises the physician, just before leaving, to "promise the patient that with the help of God you will cure him. As you go away, however, you should tell his servants that he is seriously ill, because if he recovers you will receive greater credit and praise, and if he dies, they will testify that even from the beginning you despaired of his health" (De Renzi, vol. 2, p. 75). Although this treatise may be described as eminently practical, it is not clear that this particular bit of advice is ethical.

A parallel passage in a treatise attributed to Arnald of Villanova (late thirteenth century) is nearly identical, with the significant difference that instead of promising the patient "that with the help of God you will cure him," which still leaves the matter in doubt and at least partially in God's hands, it advises more crassly that "you promise health to the patient who is hanging on your lips" (Sigerist, p. 142). This treatise appears to have been hastily thrown together from various sources, since elsewhere it flatly contradicts the advice that the physician should promise health to the patient. Later it suggests that the physician "must be … circumspect and cautious in answering questions, ambiguous in making a prognosis, just in making promises; and he should not promise health because in doing so he would assume a divine function and insult God. He should rather promise faithfulness and attentiveness …" (Sigerist, p. 141). For two such opposing pieces of advice to be found in the same treatise is unusual. Such conflicting opinions, however, are typical of medical ethics in the late Middle Ages. For example, Bernard de Gordon (thirteenth–fourteenth centuries) advised that if there was little likelihood of a patient's recovering, "One should try to escape from such cases, provided one can do so honorably" (Demaitre, p. 153). Nevertheless, he also expresses a concern to do everything possible to postpone the death of terminally ill patients.

William of Saliceto (thirteenth century) recommends that the physician should "comfort his patient, and on every occasion should promise him restoration to health, even if the physician himself shall regard the case as desperate." He justifies this on the grounds that this will greatly encourage the patient, increasing his chances of recovering. He further suggests that the physician "acquaint the friends of his patient with the truth, and discuss the case fully with them as he shall deem best, lest he incur scandal or loss of reputation from inability to offer a satisfactory statement of the case, and lest the friends of the patient regard him with distrust: nor will he then be held responsible for having caused the death of a patient who shall die; but he will be given credit for having cured the man who lives and is restored to health" (Mirfeld, p. 122). William's reason for giving a favorable prognosis to the critically ill patient is strictly for the latter's benefit. He recommends that the physician tell the patient's friends the truth for the physician's own protection, a far different piece of advice from that in the two treatises previously discussed, which recommend that the physician, regardless of the patient's actual condition, advise those close to him or her that the case is dangerous and that the patient is not faring well.

Mondeville wrote that the surgeon "ought to promise a cure to every sick person, but he should refuse as far as possible all dangerous cases, and he should never accept desperately sick ones" (Welborn, p. 350). Physicians and surgeons were sometimes charged with the deaths of patients in the late Middle Ages, and the fear of facing blame for a patient's death still motivated some to recommend, as Mondeville did, that dangerous cases not be taken on. Mondeville, incidentally, writes at some length about how to ensure that a patient's friends or relatives can be compelled to exonerate the surgeon if a case should end in the patient's death (Welborn). Nevertheless, advice not to take on dangerous cases occurs much less often in late medieval sources than in the medical literature of ancient Greece and Rome. Instead, physicians are advised to protect themselves either by telling the relatives or friends of the patient that the situation is critical, regardless of the patient's condition, or to tell the truth in cases that actually are critical.

PLAGUE AND MEDICAL ETHICS IN THE LATE MIDDLE AGES. The devastating plague epidemics that periodically swept through Europe, beginning in 1348 and continuing well beyond the Middle Ages, tried and tested the ethics of medieval physicians far beyond conditions encountered in ordinary practice. Contemporary sources almost uniformly express the conviction that plague was extremely contagious. Merely being in the vicinity of the sick, many supposed, doomed one to become infected and die. Numerous sources describe parents deserting their dying children, children their parents, wives fleeing from their sick husbands, and husbands from their wives. All who could, fled the cities and towns to take refuge in the countryside. Not only were the sick deserted by their families; physicians would not come near them, and even priests would not meet the final spiritual needs of the dying. Such accounts are plentiful. But they must be set against abundant accounts of responsible actions by family members, magistrates, physicians, and clergy.

Some physicians undoubtedly did flee. In 1382 Venice stipulated that physicians who fled during epidemics would lose their citizenship. Barcelona and Cologne took similar action during the sixteenth century. While it is impossible to determine the extent to which physicians actually did flee from plague-ridden communities, the percentage was probably relatively small. A study of nearly three hundred plague tractates written by physicians between 1348 and the early sixteenth century found not even one allusion to physicians who fled from areas afflicted with plague (Amundsen, 1977). Medieval physicians were not at all timid in castigating their colleagues in writing. Vitriolic criticism, particularly of fellow physicians' theories and medical techniques, is found throughout the medical literature. If the flight of physicians had been extensive, then one should encounter among the plague tractates such statements as "Although many other physicians fled, I remained."

Many physicians did advise people to flee from plague-infected areas as the best form of prevention. This advice, however, was typically followed by the concession that since flight "rarely is possible for most people, I advise that, while remaining, you. …" Prevention is the primary concern of most of the plague tractates. Even if they are unanimous in urging flight, it does not follow that the physicians who wrote them intended by doing so to justify flight for themselves and their colleagues. The authors of the tractates appear simply to have assumed that their readers would be able to avail themselves of the services of physicians during plague epidemics.

Did physicians who fled, or who refused to visit and diagnose those perhaps afflicted with pestilence, or who abandoned patients actually suffering from plague, violate their responsibilities as conceived at that time? Contemporary sources make it abundantly clear that both the public at large and physicians themselves viewed those physicians who fled from plague as having acted disgracefully. In the mid-fourteenth century, Guy de Chauliac, at one time personal physician to the pope, wrote concerning his own activities during the Black Death, the earliest and most devastating of a long series of plague epidemics: "It was so contagious … that even by looking at one another people caught it …. And I, to avoid infamy, dared not absent myself but with continual fear preserved myself as best I could" (Campbell, p. 3). Faced with both extreme peril to themselves and with the knowledge of the extremely high mortality rate of plague victims, physicians found themselves in an ethical quandary. Chauliac wrote, "It was useless and shameful for the doctors, the more so as they dared not visit the sick, for fear of being infected. And when they did visit them, they did hardly anything for them, and were paid nothing" (Campbell, p. 3).

One tractate maintains that physicians "must treat the ill," and another that "they must treat or visit the ill" (Amundsen, 1977, p. 414). The difference between these two is very important. While the first holds that physicians must treat plague victims, the second asserts that physicians must treat or visit the afflicted. Physicians who fled from a plague-infected area or hid in fear obviously failed even to attempt to diagnose the condition. But if the sick were indeed afflicted with the plague (since not all who became ill during a time of plague were necessarily afflicted with the plague), did physicians have an ethical obligation to attempt treatment?

A basic feature of medieval medical and surgical guild ethics was an obligation to be available to treat the ill or injured of the community and not to abandon hopeless cases. To the moral theologians who wrote the confessional literature, the duty to treat and to stay with the patient was unequivocal, although they were considering normal conditions rather than the exigencies of plague epidemics. Physicians were ambivalent about whether to take on hopeless cases; so were authors of the plague tractates. During outbreaks of plague, some physicians viewed the disease as treatable and others as at least potentially curable. Many physicians felt compelled to investigate the various strains of plague and to seek ways both to prevent and to treat them. Many of the plague tractates discuss treatment, distinguishing among different varieties of plague and stressing their faith in the efficacy of their curative methods. Some physicians, however, considered all forms of plague to be incurable. Of course physicians had to visit the ill to determine whether they were suffering from pestilence. If the condition was diagnosed as plague, some physicians then sought to determine whether the patient was possibly curable.

A plague tractate composed in 1411 advises: "If the patient is curable, the physician will undertake treatment in God's name. If he is incurable, the physician should leave him to die, in accord with the commentary on the second of the aphorisms [probably a medieval commentary on *Aphorisms* II in the Hippocratic Corpus]. Those who are going to die must be distinguished by prognostic signs and then you should flee from them. He labors in vain who attempts to treat such as these" (Amundsen, 1977, pp. 416–417). A plague tractate written in 1406 suggests that physicians not immediately inform patients if their condition is diagnosed as hopeless. Nevertheless, the physician "should refrain from administering anything to the patient that will cause him to die quickly, for then he would be a murderer" (Amundsen, 1977, p. 417, n. 64).

Various contemporary lay accounts from the time of the Black Death accuse some physicians of hiding in their houses and refusing to visit the sick for fear of infection. The authors of many plague tractates, while advising the general public to avoid contact with those afflicted with plague, do not direct such advice to their colleagues. They recommend varied and imaginative prophylactic techniques for use when visiting plague victims. The variety and abundance of such recommended precautions show the extent to which many physicians thought they were effective; moreover, there are numerous artistic representations of physicians who employed prophylactic measures while visiting plague victims. Many tractates deal exclusively with prophylaxis because their authors feel that treatment must be left to the discretion of the physician handling the case. Those that do include a discussion of treatment generally express great confidence in the curative methods prescribed. Many introduce new methods claimed effective by physicians who say they have employed them.

Some people did recover from the plague, from some strains of the disease more than from others; and although such cases of recovery were often in spite of the treatments to which the patients had been subjected, the attending physicians would have thought that their techniques had indeed been effective. The success rate in medieval medicine was, of course, much lower than in modern medicine; hence the expectations of both physicians and the public were not nearly as high as those of the present. The efforts of physicians to combat and cure various strains of plague, as well as their attempts to educate people in prevention and treatment by writing plague tractates, graphically demonstrate a high level of ethical and professional responsibility.

Summary and Conclusions

The medico-ethical treatises of the early Middle Ages blend Hippocratic etiquette with Christian morality, particularly emphasizing compassion and charity. The high and late medieval treatises, while loyal to the traditional concerns of the genre, suggest a new pragmatism born of the realities of medical practice by secular Catholic practitioners in a society starkly different from that of the monastic ethos of the early medieval medical literature. Although no mention of guilds or universities appears in this later literature, its tone and emphasis demonstrate that its authors regarded the practice of the art of medicine as a privilege that required training and skill, and carried consequent responsibilities. While there is no direct articulation of physicians' obligations to their immediate community in this literature, the obligation to the Christian community at large—an obligation to extend medical charity to the poor and destitute—is implicit and sometimes explicit.

Treating dangerous and even desperate cases is not discouraged in the later literature nearly as often as it had been before. Warnings against it are so infrequent, compared with advice on what to tell critically ill patients and their relatives or friends, that one may conclude there was a growing tendency to take on dangerous or even hopeless cases. But were physicians who in the late Middle Ages declined to treat patients for whom they foresaw little or no hope of recovery, still acting within the strictures of accepted ethics? This was a time during which popular attitudes toward physicians' responsibilities to the terminally ill were changing. Physicians who refused to treat patients were accused of deserting them because they thought they would not be paid for their services, while physicians who continued to treat such patients were suspected of greed for ministering to patients they know would not recover.

We see these two extremes illustrated by two sermons preached in fourteenth-century England. Lanfranc of Milan exclaimed, "O wretched physician, who for the money that you may not hope to get, desert the human body travailing in peril of death; and allow him, whom, according to the law of God, you should love and have most concern for, of all creatures under heaven, to be in jeopardy of life and limb, when you can and know how to apply a suitable remedy" (Owst, p. 351). John Bromyard, by contrast, asserted, "All craftsmen would at once refuse a job for which unsuitable materials were provided. If a carpenter were offered wages for the building of a house with planks that were too short or otherwise unsuitable, he would at once say: 'I will not take the wage or have anything to do with it, because the timber is of no use.' Similarly the physician who can see no hope of saving his patient" (Owst, p. 351).

Bromyard's sentiments were deeply rooted in tradition, but attitudes were changing. This change is very significant for the history of medical ethics. It seems to have been the product of two complementary and possibly related catalysts. The first is that the practice of medicine and surgery had been changed from a right to a privilege. A specific authority, whether royal, ecclesiastical, or municipal, granted to a select few the privilege of practicing in a specified, limited region. The authorities who granted what was essentially a monopoly also were ostensibly responsible for protecting that monopoly, and the privilege of holding a monopoly carried certain responsibilities, among them to service the sick of the community indiscriminately.

The second source of the growing tendency to take on dangerous or hopeless cases is the increasing theological insistence that physicians should do all they could to cure until the end, or nearly the end, and the church's support for their right to receive fees under such circumstances. One sees in the confessional literature the seeds of what was later to blossom into a medical duty to prolong life. The view is strongly articulated that physicians are religiously obligated to extend care to a rich miser even if he or she both resists treatment and refuses to pay. Some moral theologians also maintain that even if patients refuse to call a confessor, physicians must not desert them, since help must be given to those who are in danger, regardless of how stubborn they are. While this is still far from an imperative to prolong life, it is a significant change from earlier medical attitudes and practice.

This fundamental change in perceived responsibilities of physicians to their patients is illustrated by the acts of a late-twelfth-century and a mid-eighteenth-century pope, both of whom address the request of physicians to enter the priesthood. Clement III, in the late twelfth century, ruled that the physician in question should search his memory to ensure that he had never, even inadvertently, harmed a patient by any treatment that he had administered. In the mid-eighteenth century, Benedict XIV's ruling centered on the problem that physicians can never be entirely positive that they have consistently used every available means for patients who died under their care (Amundsen and Ferngren). The concern in the twelfth century was with harm perhaps inflicted actively on patients: "Did you ever harm patients by the treatment you gave them?" But by the eighteenth century, attention focused on harm that may have resulted from oversight: "Did you ever harm patients by failing to give them the treatment you should have given?" These two papal rulings highlight a fundamental change both in physicians' sense of responsibility to their patients and in social and religious expectations, a change that occurred primarily in the late Middle Ages.

We look nearly in vain in the medico-ethical literature of the late Middle Ages for statements on two topics of medical ethics: abortion and euthanasia. We cannot conclude from this that both theologians and physicians considered abortion and euthanasia ethical for physicians to perform. Indeed, the presumption is quite the opposite. Theologians and physicians alike took it for granted that both were sinful, so much so that their sinfulness need not be mentioned explicitly. Rather, it would seem that abortion was a procedure for which women would turn to someone other than a male physician or surgeon. Facilitating the death of a patient was undoubtedly so repugnant to medieval moral principles that to mention it as unethical for a physician to do would have been gratuitous, at least in a general treatise on medical ethics.

When the contents of the late medieval medico-ethical treatises are supplemented by guild ethics and the moral pronouncements of the theologians, as well as by the evidence of physicians' conscientious response to the outbreaks of plague, the picture that emerges is of relatively high ethical standards. Although "Hippocratic ideals" persisted throughout the Middle Ages and provided the basis for medical etiquette, the role and responsibilities of physicians and surgeons were variously affected by Christian morality. This is particularly evident in concern for the gratuitous treatment of the poor, both by individual physicians and by professional associations. The discipline of moral theology provided distinct criteria for medical ethics from a late-medieval Catholic perspective. Secular law and medico-surgical organizations, including university faculties, established regulations and standards of competence for medical licensure, and guilds and university faculties set precise codes of conduct. Essentially, the creation of medical licensure, medical faculties, and professional organizations helped to formulate medical professionalism and ethics in a sense that is still very much present today.

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II. RENAISSANCE AND ENLIGHTENMENT

Medicine in early modern Europe (from the later fifteenth century to the end of the eighteenth century) is best characterized by its diversity of practitioners, practices, and conceptual foundations. Even by the end of the eighteenth century, few places in Europe had effective regulations to restrict medical practice to people with certain kinds of certification, or to regulate their practices. University-educated practitioners differed sharply with one another about the true conceptual foundations of good and effective medical practice, while among the merely literate, or even the illiterate, practitioners, views about the constitution of good medicine varied even more.

Many medical changes occurred during the period: The number of university-educated physicians rose considerably, as did the number of other formally trained (usually apprenticed) practitioners. With the proliferation of schooling, the educational level of many ordinary practitioners rose. And while the beginning of the period was marked by the proliferation of various philosophical and medical systems, by the end of the eighteenth century most of those systems had been set aside by the educated elite in favor of varieties of a more unified “science.”

Throughout the period, no formal systems of medical ethics existed per se. Yet medical practitioners took varying degrees of interest in ethical issues, issues that commonly focused on the personal character of the practitioner. The discussion of the period that follows is therefore divided into two parts: a description of the general structures of the period and the organization of medical practice; and the debates among the literate, and especially among the learned, over the foundations of good medical practice and behavior.

Social Structures of Medical Practice

European society underwent a major transformation from the fifteenth to the eighteenth century. Throughout the period, Europe remained an overwhelmingly rural region, and at times the population grew rapidly. And, because of demographic, economic, political, and intellectual changes, city life came to typify refinement. As a result, most of the great changes in medical practices and mores took place in the cities, although most of the people needing care continued to live in the countryside.

The vast majority of the people in Europe—nine in ten, or more, depending on when and where—lived in a rural environment: in small towns or villages, in hamlets, or on rural manors; a few even resided in the forests and fields. In the fifteenth century, many rural laboring people lived relatively well, since after the fourteenth-century plague (the Black Death), there was land enough for most. But during the sixteenth century, the European population increased rapidly (perhaps about 1 percent per year); it generally leveled off during the seventeenth and early eighteenth centuries; and late in the eighteenth century again began to increase rapidly. While at first, people could generally grow enough food for themselves and their landlords and a little extra, with the increasing population of the sixteenth century, the number of rural itinerant laborers and destitute began to rise rapidly (Flinn).

Ordinarily, rural people bartered with neighbors and used money only occasionally, relying on mental accounts of who owed what to whom. At local markets, though, they might purchase a few goods manufactured locally or imported from afar, and sell their own goods or labor. When they needed medical care, most ill people and those caring for them relied on practices long used: self-help; recipes for home remedies (or “kitchen physic”) passed down through kin or neighbors; and other traditional practices that could be gathered from local people, which might include ritual and invocation (or what the educated sometimes called “superstitious” practices). Beyond the resources of neighbors and kin, the sick often had available to them the services of people with special knowledge or powers: clergymen, herb wives, sorcerers or witches, and people who healed by special powers of touch. In return for medical help, payment might be in coin, but probably more commonly added a debt to the mental balance of favors, or earned the practitioner goods or services such as chickens or eggs, pasturing an animal on the patient's land, or the patient's help in doing certain chores.

In a few regions, however—mainly from northern Italy along the Mediterranean coast to southern Spain, in the Low Countries and northern France, a thin strip along the south edge of the Baltic, and in southeastern England—urban life was more common. In the fifteenth and early sixteenth centuries, people in towns and cities raised animals for slaughter, and sometimes kept a plot of ground nearby on which they grew food. But by the later sixteenth century, many towns were becoming too large and too densely settled for such practices. Much of the increasing population was drawn from the countryside into the cities or, later, pushed to the overseas colonies. Many people spent a part of their lives in a city working as laborers or servants, returning to their towns or villages after accumulating enough money to establish a family. Others migrated to the towns and cities permanently, causing a huge expansion of wealthy, middling, and poor neighborhoods. The largest city in Europe, Naples, soon had rivals in Paris and London. Just how brutal were the conditions of urban life has been vigorously debated; what is clear is that urban mortality and morbidity rates in the age before plumbing and sewerage were very high indeed.

The cities wrought important economic changes, especially a greater use of money. The demand for food among the urban populations also transformed nearby regions into centers of market agriculture where individuals or landlords produced cash crops. In some areas, such as southeastern England and the Netherlands, this agricultural revolution brought into being a free yeomanry; in other regions, such as Prussia and Russia, it brought about a reenserfment of the peasantry by great landlords. Whatever the local consequences, throughout Europe people increasingly grew used to buying and selling labor and goods, and to handling money; even rural laborers often had a few copper pennies at their disposal.

With the increasing importance of money as a means of exchanging value, more and more people supplemented their incomes by engaging in medical practice for money, or relied upon it entirely for their living. Many, undoubtedly most, such people offered their services to ordinary people, doing so in their neighborhoods or traveling to offer their services among strangers. If itinerant, they found their customers wherever gatherings occurred: markets, crossroads, taverns, inns, alehouses, coffeehouses, and even street fights. They might also gather a crowd by saying something interesting from a platform or from horseback, or by presenting an entertainment from a table, wagon, or stage: These people soon acquired the name of *quacksalver* or *quack* (a term of obscure origin), or *mountebank* (probably from climbing on benches).

With the spread of the printing press and the growth of literacy in the later sixteenth century, medical advertising could be used to heighten the practitioner's reputation or to attract more people to the shows. Medical advertising could also publicize the practice of someone who did not travel but practiced out of a shop, inn, or house. By the later seventeenth century, as the postal systems of many regions of Europe developed, advertisements could be sent to agents for posting throughout a region, and medical customers could order remedies through the mail. The medical practitioners who relied on such methods for their incomes might offer special services (like cutting for cataracts or bladder stones, or setting bones), or sell special remedies (what became known by the eighteenth century as "patent remedies") (Cook; Porter, 1989; Porter and Porter).

In the cities and a few large towns, craft guilds of medical practitioners came into being or expanded from their late medieval roots. Guilds had municipal charters allowing their members the rights and privileges of citizenship, and the group the right to act as a corporation: to stand as one person before the local courts, to own property, to pass internal rules regulating their members and organizing them by rank, and often to restrict certain practices to their own members. Throughout early modern Europe, guilds of barber-surgeons and surgeons, or groups of barber-surgeons and surgeons in other guilds, could be found. In general, guilds of barber-surgeons and surgeons restricted the use of instruments on the body to their members.

The barber-surgeons undertook barbering and minor operations, such as opening a vein to let blood, and were ordinarily among the lower-ranking members of the guild (Pelling). The surgeons, far fewer in number and generally among the higher-ranking liverymen, undertook major operations, such as amputating limbs, setting bones, repairing hernias and fistulas, extracting teeth, and tending to wounds, sores, and ulcers. Among the armies and navies of Europe, surgeons performed most of the general medical tasks, and the kinds of operations that could be successfully performed gradually increased. Consequently, the status and income of surgeons grew during the period, and they began to be increasingly trusted by monarchs to develop certain kinds of medical policies for their kingdoms or principalities (Temkin; Gelfand).

Another kind of medical craftsmen were the apothecaries, or pharmacists. Originally wholesale importers of spices, by the early modern period many sold medicines from retail shops; some of the medicines they sold could be dangerous unless used under careful supervision. Many cities therefore had guilds of apothecaries, who were subject to rigorous municipal regulations. In the Scandinavian and Germanic lands, cities often restricted the selling of medicines to a very few official apothecaries, sometimes to just one. As their numbers increased, so did the tendency of apothecaries to give medical advice. It was from the surgeon-apothecaries that the general practitioners eventually arose (Loudon).

One other kind of medical corporation proliferated in the early modern period: that of the university-educated physicians, usually called a "college" (*collegium*) of physicians. Ordinarily, colleges of physicians had formal standing from a municipal or royal charter that gave members of the group sole right to practice "physic"—the giving of medical advice—in their city and the surrounding area. Regular members had to possess a university degree in medicine (by the sixteenth century, ordinarily Medicinae Doctor). The colleges of physicians ordinarily were not authorized to grant degrees (an important exception to this rule was the Faculty of Medicine in Paris, which had its roots in the medieval university; the professors of medicine of the university were elected from the Faculty). Independent colleges of medicine first came into being in several northern Italian cities, and by the early sixteenth century had spread to Spain, France, and England. By the seventeenth century, physicians in northern European cities like Amsterdam had established their own colleges. These colleges not only governed the physicians of a city but also, sometimes, took on other regulatory powers, such as inspecting the apothecaries' shops, examining apprentices in surgery and pharmacy, and even looking into the behavior of all local medical practitioners.

In the view of the learned physicians, a medical hierarchy should exist: the physicians at the top, governing the practices of the apothecaries and surgeons, and most other practitioners being outlawed. While this ideal could seldom be thoroughly enforced, physicians often worked to obtain its legal foundations from municipal or national governments. As an important part of their argument, they fostered the idea that physicians ought to be trusted more than other practitioners because of their learning, which not only gave them knowledge but also inculcated good character. Physicians spoke often of defending the "dignity" of their profession, and concerned themselves with cultivating the outward manners that would best exhibit their inward virtues.

A final medical institution must be mentioned, that of the city physician and, eventually, the physician or surgeon officer of state. In the later Middle Ages, on the Continent, some large cities began to revive the ancient tradition of employing a physician to see to the needs of the municipality. In return for an annual salary, the city physician treated poor citizens, advised on medical regulations (including plague orders), and often served in one or more of the municipal hospitals for the sick poor (if the city had any) (Russell). By the later sixteenth century, city physicians had become important officers of local government in many places. Moreover, as unified territorial states came into being in the seventeenth century, and sovereigns tried to impose more uniform codes of law and government, they, too, began to use medical advisers to help them govern. Given contemporary international competition, princes deeply felt the need to try to increase the general wealth and power of their countries. Part of their domestic policy therefore was concerned with bettering the health of the public and increasing the population. To do so, sovereign rulers frequently tried to co-opt existing medical corporations or to establish new ones.

In central Europe, by the later eighteenth century, medical advice had become important enough to government that the phrase "medical police" (meaning medical policy promoted and enforced through government agents) had become a common topic in discussions about the structure of state institutions (Rosen; Hannaway; Jordanova; Fischer-Homberger). But associating themselves with magistrates and government might give physicians and surgeons more authority among those who supported the government; it also might make them more subject to criticism during periods of public unease. The revolutionaries in France, for example, demolished most formal medical institutions during the mid-1790s.

With a rising population, increased urbanization, the spread of the market economy, greater literacy and formal education, and the development of nations, the significance of medical help outside networks of kin and neighbors increased. These changes had many implications for those who practiced medicine. With regard to the gender of the practitioner, for example, women seem to have dominated the practice of traditional medicine, while it was predominantly men who flourished in the commercial medical market (although not to the total exclusion of women). When it came to medical guilds, outside of Italy, memberships were generally limited to men or to the widows of members. Since virtually all European universities excluded women from receiving degrees, nearly all medical doctors were men. In the eyes of the governments, if not always in the eyes of the public, a group who recognized themselves as professional men sat at the top of the medical hierarchy: the physicians, and gradually the surgeons. They obtained many new mechanisms of medical regulation from the state (for example, the French crown established a new College of

Surgery in Paris in 1750, and a Royal Society of Medicine in 1776), and increasingly tried to regulate all other practitioners. They could not always succeed in imposing medical order on society, but their professional ideals were influential.

Debates about Medical Practice and Practitioners

Because the increasingly literate and monied public of the towns and cities had a host of medical practitioners from whom to choose, the medical professionals could not impose their ideals on others. While noble and wealthy patients often consulted physicians, they often also consulted surgeons, apothecaries, "quacks," and traditional healers. Without a single, inclusive medical profession and firm regulation to govern practitioners or establish uniform requirements for their training, patients could pick and choose the kind of medicine they preferred, as long as they could pay for it or obtain it through charity. Consequently, medical practitioners cajoled and persuaded their paying patients to do what they considered right (Jewson; Porter, 1985). (Those they helped through charity could take what was offered or go without.) As a result, the various medical groups, even the physicians, had few clear ethical codes on how to treat patients that were distinct from general sentiments. Notions of virtue and good behavior existed everywhere; concepts of "medical ethics" per se were few (Waddington).

The humanist movement of the Renaissance brought to light a plethora of ancient philosophies of nature, each with its own ethical foundations. Renewed Aristotelianism, Platonism, Stoicism, Epicureanism, Hermeticism, and Hippocratism: Among the learned, each had its medical adherents. When modern natural philosophers began to take precedence over the old, physicians of a Baconian, Cartesian, or Newtonian stripe often adopted moral notions consistent with their philosophical system. For instance, with a renewed interest in Hippocratism came a renewed interest in the Hippocratic Oath (Smith); with the spreading of Cartesianism came a hard-hearted attitude toward the use of living automata (animals) in bloody experiments (Guerrini). But none of these philosophical positions was solely medical, and so none of the ethical implications were strictly medical. The physician took no more and no less interest in the ethical implications of the natural philosophy he adopted than did any other learned person.

Moreover, it is possible to discern some of the general public's ideas of ethical medicine. One can see such general notions at work in the plague. During the first outbreaks (from the mid-fourteenth century), the best advice on avoiding the pestilence that a practitioner could give or take was to "flee fast and far." But as magistrates worked to prevent or ameliorate epidemics, in part by working with city physicians, a sense that the legally privileged physicians ought to help in times of crisis grew up alongside older notions of charity and self-sacrifice (Amundsen). By the seventeenth century, colleges of physicians suffered public embarrassment when many of their members (even those who held no public office) left town during an epidemic. In the London plague of 1665, for instance, many of the physicians' rivals, especially the chemical physicians, gained the respect of the public by staying and treating victims of the plague, showing by this disinterested public service that they ought to take precedence over the cowardly physicians. For whatever reason, the public was beginning to expect higher standards of behavior from medical practitioners than from all but a few others.

Another place where public notions of ethics in medicine can be found is in the general sense that physicians should not be overly commercial. Journals of literate sentiment, like *The Spectator* or *Gentleman's Magazine* (both of London), made fun of medical commercialism. For their part, physicians generally tried to avoid becoming personally involved in public medical disputes, frowned on advertising their practices or medicines as beneath the dignity of their calling, considered fee splitting and the taking of part of a fee in advance as "quackish," and even began to accept "honoraria" instead of fees. They also continued to treat without charge some of the poor who sought their help and, when they took up hospital posts (where they saw the sick poor inmates), received no fees for their once-a-week (or so) visits. Such general notions of good and charitable behavior, ordinarily shared between patient and practitioner, underlay the more detailed treatment of medical etiquette in the statutes of the various medical corporations.

The topics of more specific debate about moral medical behavior in the early modern period included what constituted the best medical learning; what kind of person made a good practitioner; what kinds of people ought to be prohibited from practice; and what medical practices should be encouraged and which discouraged. Debates about each of these topics could hardly be separated from the others, however, since they all surrounded what might be called the early modern equivalent of "virtue" ethics.

The two most numerous kinds of documents regarding early modern medical practice illustrate how interconnected were ideas about good practice and good character. One kind is the internal regulations of medical guilds and colleges of physicians. The statutes of the London College of Physicians, Society of Apothecaries, and Surgeons' Company, for instance, governed the behavior of the members closely but had almost nothing to say about medical practice per se. (One of the few explicit prohibitions in the College statutes is against making prognoses from the inspection of urine alone; the practices of "urine-casters" came in for much scathing comment from physicians in the early seventeenth century.) In drafting the statutes of the College of Physicians, the officers devoted much attention to whether and in what kinds of cases members might consult nonmembers, how members should behave during consultations, what the order of precedence would be during meetings and on ceremonial occasions, how they should write prescriptions, and so on, all trying to maintain the dignity, gravity, and exclusivity of the group. The same is true of the College of Physicians in Amsterdam, and colleges elsewhere in Europe; and it is equally true for guilds. One sees the same concern with character in the record of whom the London College of Physicians tried for medical misbehavior: They rarely distinguished between illicit practice and malpractice, insisting that in their examinations for membership, applicants had to show that they were the right sort of people in character as well as in knowledge, anyone else being de facto and de jure incapable of practice.

The second major class of historical documentation discussing the foundations of good or ill medical practice is the antiquackery tracts that proliferated during the early modern period. In them, physicians and others discussed practitioners' behavior far more than their medical practices. In England, perhaps the best-known early piece of antiquackery literature is by John Cotta, who passionately condemned the multitude of nonphysicians: empirics, women practitioners, fugitives, jugglers, quacksalvers, practicing surgeons and apothecaries, practicers of spells, witches, wizards, the servants of physicians, "the methodian learned deceiver or hereticke Physition," beneficed practitioners, astrologers, urine-casters, and itinerants (Cotta).

Cotta not only condemned the ignorance and bad practices of such people, he condemned above all their undisciplined characters. He explained how even good remedies cause harm when recommended by those who do not possess the learning, and hence the virtue, of physicians (Cotta, pp. 2–8). As one of his contemporaries noted, because learning and character were so closely associated, ignorance in medical practitioners could be recognized by bad behavior: "loquaciousness," "haste" in judging diseases and promising cures before the cause had been ascertained, "forwardness" in condemning and slandering proper physicians, and "boastfulness" about their own skills (Dunk, pp. 20–21). These behaviors exhibited by empirics were not tests of their knowledge but demonstrations of their indiscipline: outward signs of an inward character. Character had so foundational a role in medical practice because, as Cotta explained, "the dignitie and worth of Physicks skill consisteth *not (as is imagined commonly) in the excellence and preheminence of remedies, but in their wise and prudent use*" (1612, p. 7; emphasis added). Wisdom and prudence could be built only on the coupling of solid learning with good character. Similar works on how the good physician alone could exhibit proper medical behavior can be noted throughout early modern Europe: Gabriele de Zerbi's *De cautelis medicorum* (1495); Laurent Joubert's *Erreurs populaires* (1578); Govanni Condronchi's *De Christiana ac tuta medendi ratione* (A Christian and Careful Manner of Healing, 1591); Rodericus à Castro's *Medicus-politicus* (The Responsible Physician, 1614); Paolo Zacchia's *Questiones medicolegales* (1621); and Friedrich Hoffman's *Medicus politicus* (1738).

In countering the links made by physicians between learning and virtue, other practitioners discussed their own notions of the sources of good character, frequently arguing that it came not from academic discipline but from an inner light. Since all knowledge ultimately stemmed from God and God's creation, they argued, their direct apprehension of things through experience and a properly prepared intuition made them the possessors of a more immediate wisdom than that of the pagan- and Islamic-influenced university physicians (as they often put it). Such arguments had been put forward forcefully by the influential chemical physician Paracelsus in the early sixteenth century; by the seventeenth century, these views had spread widely among medical chemistry's advocates (Debus; Webster).

Not only chemists but also many nonphysicians took the same view about godly practice. For instance, the Swiss Protestant surgeon Gulielmus Hildanus Fabricius wrote:

> Though godlinesse be needfull for all sorts of men, yet it is most requisite in such as practise Physick, for God Almighty doth often abate the power of the Medicines, when he which administers them, is an ungodly and blasphemous man: and contrariwise, doth give wonderfull power to things despicable and vile, when they are administered by good and godly Physitians. (Fabricius, pp. 53–54)

Given the deep and bloody struggles over religion in the early modern period, comments about character and godliness divided people. Fabricius's ideas about the personal godliness of the practitioner affecting the efficacy of his medicines is quite different from the learned physician Cotta's view that even good medicines used by the unlearned could cause harm. Different kinds of medical practitioners had very different views about the inner qualities necessary for good practice, and how those qualities could be acquired. For a good Anglican like Cotta, or for his professional colleagues in all orthodox churches, sentiments about intuition and inner light such as Fabricius's smacked of dangerous religious "enthusiasm" (the sense of being inspired directly by God); for practitioners like Fabricius, linking virtue with higher education could only reinforce the position of the "dogmatists" (those who privileged reason over intuition and experience).

By the later seventeenth century, however, many physicians, too, had come to accept the importance of learning from experience, although they continued to believe that it had to be coupled with a disciplined and knowledgeable mind rather than based on intuitions. The scientific revolution had introduced notions that associated virtue with knowledge as much as (or even more than) dignity, and associated knowledge with experience (or, in English, "experiment") rather than learned debate (Shapin and Schaffer). The "virtuosi" of Europe launched detailed investigations into things, finding the best evidences of God not in human testimony and argument but in creation itself. Consequently, by the eighteenth century, many physicians, as well as surgeons, apothecaries, and empirics, placed great weight on furthering curative and preventive medicine through scientific trials.

The foundation for experiments such as James Lind's work on scurvy, or William Withering's on digitalis, or Lady Wortley Montague's on smallpox inoculation and Edward Jenner's on vaccination, or Antoine Mesmer's on "animal magnetism," had been "folk" custom. Ignoring what they considered the superstitious explanations of what happened, and concentrating instead on the material causes and consequences of various practices, such medical investigators throughout Europe explored new medicaments and treatments. In this enterprise, surgeons and apothecaries, and even unlicensed ordinary practitioners, could make contributions equal to those of physicians. Debates among medical practitioners still implied notions of who might be the best sort of person; but as the nineteenth century loomed, medical debates focused increasingly on what might be the best treatment rather than who might be the best treater.

Conclusion

Throughout Europe in the early modern period, one finds implicit and explicit notions about what constituted a good medical practitioner. Given prevailing public ideas about morality being linked first to character and only second to behavior, the question of *who* ought to practice *what* dominated medical debates. Oral codes and written rules governing medical etiquette proliferated, while people devoted relatively little attention to what we might consider medical ethics per se in the rules of good practice. Without a united and powerful profession, no group of medical practitioners could hope to universalize their own rules, although they often tried. Instead, they had to abide by the ordinary notions of virtue and morality held by their peers and the public. Notions of public and private virtue could be vigorously contested and undoubtedly affected the behavior of practitioners, but they were seldom strictly medical.

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III. NINETEENTH CENTURY. A. EUROPE

In the course of the nineteenth century, medical ethics was profoundly transformed in European countries. Social, political, economic, professional, and scientific developments influenced the relationship of physicians to their patients, to their colleagues, and to the state. Focusing on continental Europe, this article first briefly characterizes medical ethics in the eighteenth century and then discusses its transformation after 1800, in connection with the evolution of the medical profession, public health and social medicine, and medical science. Most examples are drawn from Germany and France, where debates on ethical issues in medicine became particularly intense. The codification of medical morality was based on different models in these two countries. While in the German states (and to some extent also in Spain) medical ethics was clearly influenced by the early Anglo-American professional codes, in France national traditions of codes of honor in nineteenth-century bourgeois society appear to have shaped doctors' rules of conduct.

The Gentleman Doctor

Medical ethics in the eighteenth century was determined by the personal integrity and gentlemanly manners of the physician. His moral decisions were generally based, not on written rules of conduct of a college of physicians, nor directly on the Hippocratic code, but mainly on his medical knowledge, reasoning, and an internal code of honor. Enlightenment natural law theory, as developed by Samuel Pufendorf and Christian Thomasius, may have contributed to this approach. It encouraged a morality based upon rational reflection and individual conscience, rather than upon religious and ecclesiastical precepts (Geyer-Kordesch, 1993b). Eighteenth-century doctors usually treated only a small number of wealthy patients, leaving the majority of the population to the care of barber-surgeons (trained by apprenticeship), midwives, and diverse lay healers. Physicians, like their patients, felt bound to the traditional Platonic and Christian virtues of wisdom, moderation, courage, justice, and faith, hope, charity, as well as to bourgeois Enlightenment virtues like order, cleanliness, and industry (von Engelhardt, 1985).

In the German-speaking world of the eighteenth century, particularly in Prussia, modern professional ethics began to take shape within the academic discipline of medical jurisprudence. Physicians who were called on to give expert testimony on legal cases (e.g., consummation of marriage, paternity, infanticide, murder, poisoning, assault) were exhorted to build their statements truthfully on empirical findings, to admit uncertainty in medical evidence, and to behave with dignity (Geyer-Kordesch, 1993a, 1993b). At some universities, such as Halle and Göttingen, graduating physicians had to take vows of faithfulness to and respect for the academic institutions, careful and rational treatment of poor as well as rich patients, and medical confidentiality (Helm). Ethical demands like these helped physicians distinguish their conduct from that of quacks.

Social and Professional Change

The industrial revolution, urbanization, and pauperization shaped new forms of medical care during the late eighteenth and the first half of the nineteenth century. The migration of working people to the industrial regions led to an expansion of hospital medicine. Towns created publicly funded posts for physicians to treat the registered poor (i.e., those who were officially entitled to financial support from the municipal poor-relief fund). Accordingly, doctors were now confronted with a much broader range of patients, especially from the lower classes. At the same time, medical education began to require the acquisition of practical skills in surgery and obstetrics. Surgery was integrated as an academic discipline, and eventually the occupation of barber-surgeons was abolished.

Doctors became involved in public health through campaigns of smallpox vaccination, which was made compulsory in several European states as early as the first third of the nineteenth century, for example, in Bavaria (1807), Sweden (1816), and Württemberg (1818). Other states (e.g., France and Prussia) tried to support their national vaccination programs with a combination of encouragement (bonus paid to parents per vaccinated child, cash prizes and medals for vaccinators), constraint (refusal of welfare benefits to parents of unvaccinated children), and education (La Berge).

In France a public-health movement coalesced in the 1820s, in which "hygienists" of various professional backgrounds (physicians, pharmacist-chemists, engineers, veterinarians, and administrators) made efforts to solve common health problems by undertaking scientific investigations into their causes. Pioneering studies in occupational and industrial hygiene were carried out by the leaders of this movement, the physicians Alexandre Parent-Duchâtelet and Louis-René Villermé. Differential mortality studies by Villermé and the statistician Louis-François Benoiston de Châtauneuf further demonstrated a strong correlation between standard of living, and health and longevity. Following the model of the Paris health council (founded in 1802), *conseils de salubrité* were soon formed in other French cities and departments to advise prefects and mayors in regulating public health. Some hygienists, especially Villermé, saw themselves as moral reformers who would enable workers through better material and environmental conditions to emulate the values of the middle class (La Berge).

As the connection between bad living conditions and disease became more and more obvious—particularly after the onset of cholera epidemics in Europe beginning in the 1830s, and through the experience of the typhus epidemic in parts of Silesia in 1848—liberal physicians such as Rudolf Virchow argued for the social character of medicine and recognition of the doctor as an "advocate for the poor" (Ackerknecht).

In this period of social and professional change, physicians' concern about medical competition and secure incomes deepened. The breakdown of the so-called patronage system, in which a doctor's services were remunerated by the patient with a voluntary lump sum at the end of the year, raised debates about new models of payment that could maintain the dignity and independence of the physician and defuse competition. The concept that all practitioners should become medical officials (employees of the state)—an idea originating from reform proposals of the French Revolution—was discussed in France and Germany, and was temporarily implemented in the German duchy of Nassau (Brand). An 1823 proposal to found societies of physicians that would collect and redistribute fees, suggested by the Bonn clinician Christian Friedrich Nasse in a monograph *Von der Stellung der Ärzte im Staate* (On the Position of Physicians in the State), was apparently not realized (Nasse). Instead, Russia, Prussia, Hanover, and Bavaria instituted a policy of limiting the number of licensed physicians during the first decades of the nineteenth century. Some medical ordinances, for instance, those of Baden (1807) and of the canton of Zurich (1821), made licensing as a physician contingent on a number of ethical obligations, such as helping patients at any time irrespective of their social status, being discreet, and continuing one's medical education (Anner; Brand).

Duties and Rights

Increasingly, doctors wrote about the duties entailed by their profession, often using the expression *deontology* (science of duty), a title that is still sometimes found in European literature about medical ethics. In 1831 the Spanish physician Félix Janer published a book *Elementos de moral médica,* which dealt with the "dignity and importance" of the medical profession and examined the doctor's relations to the patient, within the profession and to other healers, and to the state and law. Being strongly influenced by the *Lectures on the Duties and Qualifications of a Physician* (1772) of the Edinburgh professor of medicine John Gregory, Janer adopted the Scotsman's demand that medical men show temperance, sobriety, firmness of character, humanity, and candor. Interestingly, he also extended these moral requirements to surgeons. These developments in Spain occurred in the context of arising competition and disputes over competence between traditional university-trained physicians (*médicos puros*) and new *médicos colegiales,* who from 1827 on began to graduate from colleges for medicine and surgery. These institutions granted the title *médico-cirujano,* which gave access to hospital positions. Janer himself was involved in teaching these future "medico-surgeons," eventually becoming director of the Barcelona College. Not surprisingly therefore, he defended the unity of medicine and surgery and pleaded for harmonious relations between the two types of medical practitioners (Ortiz Gómez et al.).

Other important examples of literature on medical deontology from the first half of the nineteenth century are Christoph Wilhelm Hufeland's "*Die Verhältnisse des Arztes*" ("The Relationships of the Physician," the last chapter of his authoritative manual of medical practice, *Enchiridion medicum,* 1836; ten editions until 1857; English, 1842) and Maximilien Armand Simon's *Déontologie médicale* (1845; Spanish, 1852). Like Janer, both these authors dealt with the relationships and ethical duties of the doctor to colleagues, to patients, and to society. Simon added a part on the moral rights of physicians, including a right to political activity, especially in the reform of laws pertaining to public health. Here Simon differed from Hufeland, who wanted to keep physicians out of any involvement in politics, permitting them only to educate the public on rational behavior in matters of health and disease. Both Hufeland and Simon described altruism as the central moral principle of the medical profession. For Simon, Christian faith formed the undisputable basis of this altruism and of all specific duties of the physician.

Both physicians' renewed admonition to care equally for the rich and the poor reflects the larger social spectrum of patients, as compared to the eighteenth century. Simon welcomed the "now multiplied" number of hospitals and dispensaries for the sick poor, yet warned his colleagues, as did Hufeland, not to abuse this group of patients for harmful scientific experiments. On the question of euthanasia, both physicians stressed that the sufferings of the dying should be alleviated, if necessary by a liberal use of opium, but that any life-shortening measures were strictly forbidden, even if the patient demanded them. Hufeland feared dire consequences for society if the physician once transgressed the line by judging the necessity of a human being's existence; Simon advanced the religious argument that man is not the master of his life. These statements were in keeping with those of the Göttingen professor of medicine Carl Friedrich Heinrich Marx, who had discussed the topic in detail in his inaugural lecture *De euthanasia medica* (1826). They expressed a general point of view within the medical profession that remained undisputed until the end of the nineteenth century.

Contemporary problems involving competition among doctors are reflected in Hufeland's strong plea for cooperative conduct—"Disparaging a colleague means disparaging the art and oneself!" (p. 906)—and in his discussion of proper behavior during joint consultations, a topic treated in 1798 by the Hanoverian court physician Johann Stieglitz in a monograph *Über das Zusammenseyn der Ärzte am Krankenbett* (On the Meeting of Doctors at the Bedside). In cases of malpractice, however, Hufeland exhorted his profession to set greater store by the "saving" of the patient than by consideration for the colleague. Difficulties with the transition of medical practice from a gentlemanly calling to a modern, economically oriented profession are evident in Simon's energetic defense against the reproach that doctors were guided by commercial interests.

Codification and Control

For physicians in the states of the North German Confederation, and soon for those of the whole German Empire, the trade ordinance of 1869 became an important step in that transition. It defined medical practice as a trade that anyone could exercise (*Kurierfreiheit*), yet granted legal protection of the title *Arzt* (physician). It abolished the doctor's duty to help any patient in case of "urgent danger," which had been included in the Prussian penal code in 1851 and was regarded by many physicians as a coercion to provide treatment. The trade ordinance intensified the resolve of academic, state-certified physicians to distinguish themselves from lay healers by establishing professional societies.

In 1873, two years after the foundation of the German Empire, an association of German societies of physicians (*Deutscher Ärztevereinsbund*) was formed. Its main activities consisted of representing professional and economic interests. Many societies of physicians had codes of appropriate conduct, some of which were modeled directly on the code of ethics of the American Medical Association (AMA) of 1847, and thus basically on Thomas Percival's *Medical Ethics* of 1803. The disciplinary powers of those societies were limited to their own members, however.

In contrast to this, the so-called chambers of physicians (*Ärztekammern*), founded in German states beginning in the mid-1860s, formed state-controlled medical courts of honor, which were given authority to punish professional misconduct by all physicians in the respective district (except army doctors and medical officials, who were under the direct control of the state). Once created, the medical courts of honor seem to have been very active. It has been estimated that they engaged in more than 3,000 proceedings between 1904 and 1909 in Prussia, which at this time had about 15,000 physicians who were not employed by the state or the army. Most proceedings dealt with charges of misconduct in medical competition, such as unlawful advertising, underbidding other doctors, disparaging colleagues in the presence of laypeople, and unauthorized use of specialist titles (Huerkamp).

This German path toward well-organized intraprofessional self-control, authorized by the state, contrasted with developments in France. Here, the formation of medical professional organizations was hindered by postrevolutionary legislation that followed the principle of liberal individualism. The Le Chapelier law of 1791 prohibited members of the same occupation from forming organizations that would promote their common interests, and in 1810 associations of more than twenty people formed without approval of the government were forbidden. Physicians were subject to legal responsibility for malpractice: Harm to a patient was a tort, as defined by the civil code of 1803, and was also punishable as a criminal offense under some articles of the penal code of 1810 (Ramsey).

The "medical marketplace" of early-nineteenth-century France, however, led to proposals for additional disciplinary provisions. Legislation in 1803 had established the first uniform licensing system for medical practitioners in the whole of France, distinguishing "doctors of medicine" and "doctors of surgery," *officiers de santé* (health officers), and certified midwives. While the doctors were required to have studied at least four years at a medical school, health officers could qualify after three years' study but also by serving six years under a doctor or five years in a hospital. Unlike doctors, the *officiers*, destined to provide constant medical care for the rural population, were permitted to work only within the *département* that had given them license to practice. On the one hand, these legal requirements drew a sharp line between regular, licensed practitioners and irregular healers, such as itinerant quacks, sedentary empirics (vendors of special remedies), and folk healers, who could now be prosecuted for illegal medical practice. On the other hand, the institution of health officers, who represented a class of less-well-trained physicians, created fears of a lapse in standards and professional decline among doctors. Moreover, economic need caused many regular practitioners to collaborate with unqualified empirics, to promote their own proprietary medicines, or to offer special cures. In these circumstances, medical reform commissions from 1812 onward repeatedly suggested the establishment of "chambers of discipline" or "medical councils," whose jurisdiction would include both illegal practice and professional misconduct. None of these proposals was put into action, however, partly because they were linked to the controversial question of reforming the institution of health officers, and partly because many doctors did not wish any further intervention by the state. In 1892 legislation abolished the title of *officier de santé,* as well as that of "doctor of surgery" (Ramsey).

Beginning in the 1850s, the number of physicians relative to the population grew steadily in France, leading to still fiercer competition and precarious incomes. In addition, legislation between 1874 and 1905 imposed new duties on French doctors, such as treating poor patients in return for a moderate state remuneration, testifying as experts in courts, and surveying the standards of public health (e.g., quality of water supply, housing conditions). In the 1880s, in response to these developments, doctors began to form medical unions (*syndicats*) to promote their professional interests. Initially illegal but tolerated, the *syndicats* were legally recognized in 1892. The ultimate aim of their most radical members was to create an obligatory *Ordre des Médecins,* analogous to the *Ordre des Avocats* for lawyers (founded in 1810). Such an order did not emerge; Both the government and a majority within the medical profession opposed it. But in an attempt to set ethical standards for doctors, to regulate intraprofessional relationships, and to form a unified front toward the public, the medical syndicates adopted deontological statutes that were binding on their membership.

These syndical deontologies were modeled upon the male honor codes of bourgeois social and recreational societies (*cercles* or *sociétés à plaisance*), which flourished in mid-nineteenth-century France (Nye, 1993b). Like these societies, the syndicates regarded the personal honorability (*honnêteté*) of their members as essential and had a policy of solving internal conflicts *intra muros* (i.e., without recourse to the courts). Members were obliged to report cases of malpractice to the *syndicat,* which had the right to withdraw membership. In this context, the old idea of "chambers of discipline" was taken up again, for example, by the medical syndicate of the *arrondissement* of Avesnes, which prescribed the formation of such a "tribunal of honor" in its statutes of 1910 (Nye, 1993a). Generally, however, the disciplinary powers of French professional organizations remained relatively weak throughout the nineteenth century, compared to those of their counterparts in Germany, Britain, and the United States (Ramsey).

In 1900 the Paris medical syndicate organized an international congress on "professional medicine and medical deontology," at which key speakers proposed that the problems created by overcrowding and competition should be solved through "confraternity" and "the force of moral law." Many French treatises on medical deontology, published around the time of the congress, reflected the same demands. They furthermore insisted on medical confidentiality to protect not only the privacy of the patient but also the reputation of the profession. Accordingly, the medical syndicates in the 1890s resisted requirements of the public-health legislation to divulge the names of patients with contagious diseases, whereas doctors in the first half of the nineteenth century had done so freely during smallpox and cholera epidemics (Nye, 1993a).

Controversial Issues

In the second half of the nineteenth century, ethical issues arising from developments in preventive medicine, medical science, and hospital medicine became topics of intraprofessional as well as public debate in several European countries. Following the introduction of compulsory smallpox vaccination in the German Empire in 1874, the many newly established antivaccination societies agitated intensely until World War I. Refusal to have one's children vaccinated was based mainly on reasons of conscience resulting from individual weighing of benefits and risks. In part, the reasons also reflected a protest against the restriction of personal freedom in matters of health (Maehle, 1991). This aspect had surfaced as a problem already around 1800, when Johann Peter Frank, then director general of public health of Lombardy (Cisalpine Republic), proposed universal state-controlled health care in his *System einer vollständigen medicinischen Polizey* (Haun). Antivaccinationism was basically a medical lay movement. Societies against vaccination were guided by academics and few physicians, who were influenced by ideas of natural healing (through water cures, diet, exercise, sun, and fresh air) and social hygiene. The same was true for the organized antivivisection movement (Maehle, 1993), which emerged as a result of the increasing scientific use of animals associated with the rise of experimental physiology (Claude Bernard, Carl Ludwig), pathology (Virchow), and bacteriology (Louis Pasteur, Robert Koch). Antivivisectionist activities, imported from Britain in the 1860s, were particularly strong in Tuscany, Germany, Switzerland, and Sweden (Rupke). A general antiscientific and antimaterialistic attitude was often behind the overt argument that animal experiments were useless cruelties (Maehle, 1993).

The growing importance of hospital medicine, reflected in the large clinics of Vienna and Paris in the first half of the nineteenth century, combined with the progress in medical science, brought the ethical problems of human experimentation into the foreground. In 1880 the courts of Bergen, Norway, sentenced Gerhard Armauer Hansen, the discoverer of the leprosy bacillus, for inoculating a female hospital patient suffering from a particular type of leprosy with leprous material from another patient (with a different type of the disease) without prior information or consent (Vogelsang). Albert Neisser, professor of dermatology in Breslau, was fined in 1900; hoping to induce immunity against syphilis, he had injected syphilitic blood serum into eight uninformed female hospital patients (three children and five prostitutes) in 1892. These and other cases stimulated intensive public debate, which—like the vivisection controversy—often had antiscientific and anti-Semitic undercurrents. Prevented from careers in the German civil service, Jews were strongly represented in the so-called free professions, such as medicine or law. In medical university careers, doctors of Jewish origin tended to concentrate in the experimental disciplines (physiology, pharmacology, immunology) and the new specialty of dermatology and venereology, because they could hardly find entry to the prestigious "classic" professorships in internal medicine and surgery. Anti-Semites advanced propaganda arguments that animal and human experimentation was an expression of "Jewish materialism" (Elkeles).

A concrete consequence of the debate on human experiments was a decree by the Prussian Ministry of Education in 1900 that required informed consent of the research subjects and prohibited scientific experimentation on minors and other persons who were not fully competent (Grodin).

New ethical challenges also emerged with the passage in the German Empire of the Health (1883), Accident (1884), and Retirement and Disability (1889) Insurance Acts; the scheme was soon copied by Austria (1888), Hungary (1891), Luxembourg (1901), and Switzerland (1911). The task of certifying sickness and disability placed physicians between the often conflicting interests of patients and insurance companies. Medical insurance tended to strengthen the patient's position; doctors began to complain that patients behaved as if they were their employers (Brand). On the other hand, insurance companies owned by factories could serve as a means for the social control of working-class patients (Frevert). For physicians the insurance scheme created hopes of economic improvement. In the long run, however, it heightened medical competition by drawing an increasing number of individuals into the profession.

Teaching Medical Ethics

Against this background, the proposal to include medical ethics in the curriculum for medical students was debated in Germany during the 1890s. At an 1898 conference on internal medicine at Wiesbaden, those who argued that an ethical attitude must be inculcated by the family, not at the university, and that ethics could not be subdivided according to the different professions, won the day. Yet the debate generated a spate of books that advocated the teaching of medical ethics. The Berlin medical historian Julius Pagel published a *Medicinische Deontologie* for prospective medical practitioners in 1897 (Pagel), the Wiesbaden physician Oswald Ziemssen, cousin of the renowned clinician Hugo von Ziemssen, a monograph *Die Ethik des Arztes als medicinischer Lehrgegenstand* (The doctor's ethics as a medical teaching subject) in 1899. Pagel gave a great deal of space to cooperative behavior among medical colleagues, demanded solidarity in cases of professional error, and advised doctors to act with self-confidence when seeing patients. Furthermore, the doctor should take care not to speak familiarly with members of the lower classes. Ziemssen built his book on codes of German societies of physicians and above all on Jukes de Styrap's *A Code of Medical Ethics* of 1878 (de Styrap). To some extent, he also drew on German philosophical traditions, arguing that the ethics of the physician were based on a combination of Immanuel Kant's categorical imperative, Arthur Schopenhauer's voice of feeling, and Johann Friedrich Herbart's practical judgment.

Contemporary philosophers, such as Friedrich Paulsen and Max Dessoir, also acknowledged the importance of teaching medical ethics with books and lectures. Paulsen pointed to the growing importance of medicine for modern society (von Engelhardt, 1989). Dessoir wanted the profession to compensate for a loss of ethical values in depersonalized doctor–patient relationships that resulted from specialization and the influence of medical science. Accordingly, he suggested a teaching program that would cover not only the "profession and character of the physician" and his "relationship to colleague and to the public" but also "vivisection and human experimentation" and "ethical principles in general" (p. 382).

Dessoir also served as an adviser to the Berlin neurologist Albert Moll, who provided the most significant contribution of this period with his 650-page *Ärztliche Ethik*. Moll argued that concern for medical ethics had concentrated on the physician's duties to colleagues and the profession (i.e., on medical etiquette), rather than on duties to the patient. He therefore put particular emphasis on ethical problems of medical practice, such as the doctor's refusing and breaking off treatment, euthanasia, deceiving the patient, advising extramarital sexual intercourse (e.g., in neurasthenia due to sexual abstinence, or in impotence), cosmetic surgery, and abortion. Moll devoted much attention to the issue of human experimentation, quoting numerous examples from the scientific literature. He oriented medical ethics to the well-being of the individual patient, not to the general welfare. Explicitly renouncing any basis in theological or philosophical systems of morality, he defined the doctor–patient relationship in legal terms, as a contract. This implied the physician's duty to fulfill the contract and the patient's obligation to respond by paying the fee. With this positivist approach, Moll reflected a general intellectual tendency of his time. In its comprehensiveness, his book provides a good overview of ethical issues in late-nineteenth-century European medicine.

Summary

In the nineteenth century there was a significant shift from reliance on largely implicit and nonsystematic notions concerning the gentleman doctor to written codes of professional etiquette and to a growing body of literature and theoretical perspectives concerning specific issues in medical ethics. In this century many of the concerns and methods now employed in medical ethics were first articulated.

ANDREAS-HOLGER MAEHLE (1995)

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III. NINETEENTH CENTURY. B. GREAT BRITAIN

Questions of medical ethics acquired heightened significance in nineteenth-century Great Britain. The reform of the medical profession and the growing prominence of medicine within public policy brought ethical and medicolegal issues into sharper focus. For the first time, medical ethics assumed codified form.

The period from the early sixteenth century to the close of the eighteenth saw the founding of medical colleges and societies in Britain, among them the Royal College of Physicians. But such bodies played only a minor part in imposing ethical codes upon the profession as a whole—or even suggesting them. The Royal College of Physicians and the Royal College of Surgeons possessed jurisdiction over one city, London. There was no centralized medical regulation over most of the nation. With few exceptions, it was only in the nineteenth century that medical ethics were written down, the watershed being the publication in 1803 of Thomas Percival's *Medical Ethics; or, A Code of Institutes and Precepts Adapted to the Professional Conduct of Physicians and Surgeons.* Two circumstances provided impetus for codification, one intellectual, the other socioeconomic. Intellectually, the moral philosophy of the Scottish Enlightenment and the reawakening of religious conscience associated with Evangelicalism concentrated attention on man's (concern was almost wholly with males) duties to society. John Gregory, professor of medicine at Edinburgh, had published his *Observations on the Duties of a Physician* in 1770, and Rev. Thomas Gisborne, a friend of Percival, had included a section on obligations attending the calling of a physician in his *An Enquiry into the Duties of Men in the Higher and Middle Classes of Society in Great Britain, Resulting from their Respective Stations, Professions and Employments* (1794). Percival certainly drew on both in shaping his *Medical Ethics*, though it would be a mistake to assume that Percival was significantly concerned with academic philosophy. His handbook was first and foremost practical. It contained no discussion of any philosopher by name and did not refer to particular formal philosophical schools.

At the same time, the tremendous social transformations precipitated by the industrial revolution were posing exacting problems for medical practitioners. Newly emergent urban communities had severe medical needs but no deep-rooted traditions of professional service. In Britain's laissez-faire, free-market economy, doctors were tempted to adopt entrepreneurial attitudes, operating according to the law of "let the buyer beware." Moreover, new medical institutions were springing up, above all charity hospitals and dispensaries for the poor. Codes of practice governing the duties of doctors attached to these distinctive establishments needed to be formulated.

Thomas Percival (born in 1740) had studied medicine at Edinburgh. He became a senior and well-respected Manchester practitioner, and a leading light in the town's Literary and Philosophical Society. When a virulent intraprofessional feud flared up at the Manchester Infirmary in 1792—a sordid fracas concerning nepotistic appointments—he had been called in as a kind of peacemaker. His *Medical Ethics* arose from his musing on that unseemly rumpus. It was thus a work that spoke directly to the needs of its times. Percival set out some precepts, of a somewhat platitudinous nature, about the general duties and responsibilities of the physician to his patients, to society, and to his calling. Above all, he addressed himself in a direct manner to the tangible difficulties facing doctors in a commercial society.

High on Percival's list of priorities was the desire to secure harmony among practitioners and between the different grades of the profession. He addressed such questions as seniority and precedence, spelling out in detail the protocols of joint consultations. Though little interested in formal professional bodies, he was adamant that "medical men" should not compete against each other; instead they should cultivate, and be seen to cultivate, a comradely esprit de corps. Professional rivalries, naked jealousies, and controversies in public conducted through the medium of pamphlets would poison intraprofessional relations and ultimately work to the disadvantage of patients. Charging lower than normal fees, for instance, would deny a living to poorer brethren, and discourage the young from investing in a thorough medical education and training. A liberal profession could not be supported, Percival insisted, except as a "lucrative one."

Sentiments such as these give support to those, like Chauncey Leake and Ivan Waddington, who argue that Percival's *Medical Ethics* was misnamed, being in truth a work of "medical etiquette," primarily designed to bolster the collective status, dignity, and monopolistic power of the profession vis-à-vis the public. Percival certainly aimed to regulate "the official conduct and mutual intercourse of the faculty"; but it should not be forgotten that he added that this was to be accomplished "by precise and acknowledged principles of urbanity and rectitude"—that is, the unwritten but generally acknowledged code of gentlemanly behavior. In other words, he was concerned not with self-serving expediency but with humanitarianism, prudence, and honorable standards of virtuous conduct as understood by a gentleman.

Some American philosophers of medical ethics are inclined to see Percival as having written a work with strong foundations in academic ethical philosophies. It has, for example, been suggested that Percival and his successors may have drawn upon utilitarianism. There is little warrant for this reading in Percival himself. The great bulk of his text was concerned with resolving practical problems among medical men.

Percival upheld the ideal of the professional pyramid. Where wealth and density of population permitted a professional division of labor, the traditional hierarchical separation between physicians, surgeons, and apothecaries was to be maintained because it stimulated specialist skills. Yet physicians were not to lord it over the lesser "gentlemen of the faculty": in small communities, the humble apothecary was often the best expert on the circumstances of patients, and so his advice should be heeded.

Percival thus required courtesy among practitioners. A compassionate man, he insisted that the fears and feelings of the sick should be respected. Ever the realist, he acquiesced in the authority deriving from social status that the gentry were accustomed to wield. Wealthy patients would exercise the right to a second or third opinion: It was up to the doctors involved to manage such delicate circumstances with tact, preventing the dangers of "divide and rule." Likewise, though nostrums were an abomination, Percival judged that the astute physician would sometimes comply when a patient insisted on a worthless, but safe, favorite proprietary remedy.

With affluent patients, the one who paid the piper would evidently call the tune. But different rules must apply, Percival observed, when practitioners gave their services without charge. Charity patients in infirmaries could not expect to pick and choose among the physicians or to negotiate over treatments. Disobedient hospital patients must face dismissal. Likewise, it was permissible to experiment with new remedies or surgical procedures upon charity patients, so long as such innovations were attempted with due caution and humanity.

Prizing the close clinical relationship between practitioner and patient, Percival believed this depended primarily upon the character of the physician. The ideal practitioner was an academically educated, liberal gentleman who would combine "tenderness with steadiness," and "condescension with authority," displaying proper composure, dignity, tact, and courtesy. He must govern himself: be temperate, avoid intoxication, and take care to retire from practice before age eroded his powers and judgment. He must be civil to colleagues, benevolent toward patients. It was a paternalist ideal, entailing a gentlemanly noblesse oblige.

Percival's book became immensely influential in the United States, serving as the basis for the American Medical Association's (AMA) code of 1847. Though reprinted in 1849, it achieved less celebrity in Britain. This was not because it was superseded by any other more illustrious tome or rival ethical scheme. For subsequent works, like William Ogilvie Porter's *Medical Science and Ethicks: An Introductory Lecture* (1837) and Abraham Banks's *Medical Etiquette* (1839), largely echoed Percival's platitudes; and as late as 1878, Jukes de Styrap was still lifting phrases out of Percival in *A Code of Medical Ethics.* Rather, in contrast to that in the United States, the medical profession in nineteenth-century Britain seems to have felt little need for explicit ethical codifications.

The contrast is readily explained. In early-nineteenth-century America, no standard, universal, and accredited licensing procedures unambiguously demarcated orthodox practitioners from quacks and irregulars. Hence, when regulars banded together into state medical societies to enhance their prestige, the adoption of a code of ethics was of immense significance as a conspicuous shibboleth. In Britain, by contrast, licensing was already well entrenched; since 1815, the Apothecaries Act had stipulated nationwide minimum qualifications for practice as an apothecary or general practitioner. Thus, in Britain, regular doctors did not need written codes of ethics to prove their standing in relation to irregulars. In Britain regulars were already adequately defined in contrast with quacks.

Nor did regulars need codes of medical ethics to affirm their personal bona fides. British practitioners were confident that they were, first and foremost, *gentlemen*. Gentility came from birth and breeding, education, wealth, contacts, manners, mien, and so forth—or at least from the capacity to create a show of such attributes. (Needless to say, most medical practitioners were not, in the literal sense, the sons of gentlemen; rather, they aspired to genteel status.) Gentlemanly behavior depended heavily upon notions of personal honor rather than upon formal ethical or religious principles. A written ethical code might have seemed to impugn a gentleman's honor, rather as the British prided themselves politically upon not having a formal written constitution. It is thus no surprise that the British medical profession was indifferent to collections of medical ethics. Neither the Royal College of Physicians nor the Royal College of Surgeons drew up an ethical code for its members.

From professors of forensic medicine, students learned a little about the rules governing evidence to be given in court. The Manchester Medical Ethical Association was formed in 1847, aiming to bind its members to a slate of regulations outlawing the marketing of nostrums and the giving of testimonials for patent medicines. And the British Medical Association—the newly formed society of general practitioners and family doctors—set up its own medical ethics committee in 1853. Over the next fifteen years, however, it signally failed actually to draw up a corpus of medical ethics. Despite such token activities, no comprehensive manifesto of ethical principles was codified in Britain that was binding upon the profession as a whole.

Yet this is not to say that the profession was indifferent to ethics. As was vehemently argued in Thomas Beddoes's *A Letter to the Right Honourable Sir Joseph Banks … on the Causes and Removal of the Prevailing Discontents, Imperfections, and Abuses, in Medicine* (1808) and in countless subsequent works, it was at bottom ethical commitments that distinguished honorable practice from quackery (although, Beddoes implied, all too often eminent regulars disgraced their vocation by unprincipled practices). And, of course, ethical dilemmas often arose that urgently needed resolution. A formal mechanism for upholding ethical standards was constituted in 1858 as a consequence of the establishment of the Medical Register, a public roll of all duly licensed practitioners. The body appointed to act as guardian of the register was the General Council of Medical Education and Registration of the United Kingdom, commonly known as the General Medical Council (GMC). The GMC was to admit properly qualified practitioners to the register, and to delete those whose conduct was professionally inadmissible—for example, those who had been convicted of a crime or who had been judged guilty of infamous professional conduct (such as adultery with a patient or vilification of colleagues). Sitting in camera, the GMC thus served as a sort of moral inquisition for the profession.

But what constituted "unprofessional conduct"? For most of the Victorian age, practitioners were held to less taxing standards than have generally been enforced in twentieth-century Britain. Considerable leeway was still permitted to engage in commercial and entrepreneurial activities. It was not unknown for eminent Victorian physicians to puff proprietary preparations with impunity, or to lend their names to extravagant publicity for spas, clinics, and balneological establishments. Such respectable medical organs as the *British Medical Journal* and *Lancet* published advertisements every week for nostrums, health foods, and medical institutions of doubtful probity (for example, so-called nursing homes that probably served as abortion clinics).

Nevertheless, the profession grew increasingly mindful of the fact that, in an age priding itself upon public probity, respectability, and heightened moral sensibilities, doctors had to be seen as above scandal. Trying situations easily occurred. For example, from the 1840s, thanks in part to the development of anesthetics, the scope for surgical intervention rapidly grew. Enterprising gynecologists and surgeons newly claimed to be able to treat a wide range of women's ailments, physical and psychosexual, through hysterectomy, ovariotomy, and similar operations upon the reproductive system. In the first flush of enthusiasm, some practitioners leapt in before the ethical implications had been adequately debated and resolved: Was proper informed consent being obtained for such operations? In the case of the removal of a womb, was it desirable to obtain the consent of the husband as well as of the patient? In the absence of diseased organs, was it permissible to perform operations for purely preventive or psychological reasons? Anxiety that the good name of the profession was being jeopardized by overenthusiastic intervention led to the expulsion, in the 1860s, of Isaac Baker Brown, a prominent advocate of clitoridectomy and similar surgery, from the Obstetrical Society (though he was disciplined not for the operations he performed but for the self-seeking manner in which he publicized them). Greater caution was subsequently exercised.

Whenever possible, the medical profession aimed to police its operations discreetly, retaining in its own hands the right to set moral standards. Thus, in ethically sensitive areas such as abortion, it was contended that termination of pregnancy was essentially a matter of clinical judgment in the individual case; in the last resort, only the personal physician was in a position to decide. Likewise, when legislation was proposed to control the sale of dangerous drugs, the profession was successful in safeguarding the right to supply narcotics on prescription.

In other medical spheres, however, ethical controversies arose that could not be kept within the circuit of professional discretion. This was because the Victorian age witnessed an unprecedented expansion of doctors' involvement in implementing state policy. For example, by 1900 new lunacy laws resulted in the compulsory confinement of nearly 100,000 mental patients. All had to be certified by due medical authorization. This created ethical predicaments for doctors that could not be resolved within Percival's notion of a tacit contract between physician and patient. Certain doctors, like the distinguished early Victorian psychiatrist John Conolly, warned of what a later generation was to call "psychiatric abuse": Some patients, Conolly feared, were being stripped of their rights and liberty not because they were sick but because they were nuisances or were merely eccentric.

It was in public health that the greatest ethical dilemmas arose. Before 1800, Great Britain had lacked the apparatus of medical police controls already in place on the Continent. This changed. The success of Jenner's variolation techniques (giving a dose of cowpox to create immunity against smallpox) led Parliament to make smallpox vaccination compulsory in 1853. Poor Law doctors—doctors appointed under the New Poor Law (1834) to tend to the parish poor, particularly those confined to workhouses—were to act as state agents in enforcing the legislation. Resistance and protests grew common during the next half-century, condemning compulsory vaccination as an iniquitous annulment of natural liberties and condemning doctors for serving as the lackeys of a coercive state.

A similar crisis arose in 1864 with the Contagious Diseases Acts. These sanctioned, under certain circumstances, medical inspection for signs of venereal disease of women detained by the police under suspicion of prostitution. Once again, opponents accused medical men of prostituting their art in the service of a corrupt state, and feminists argued that the acts were designed to provide disease-free vice for men. Around the same time, antivivisection agitators began accusing medical experimenters and scientists of inflicting cruelty upon dumb and defenseless experimental animals. The widening circle of medicine began to raise medical-ethical issues never dreamed of in the innocent days of Percival's *Medical Ethics.* Just before World War I these dilemmas came to a head when convicted suffragettes (militant feminists) went on a hunger strike, and prison doctors were instructed to administer forced feeding. Did their duty lie to society or to the prisoner (hardly a patient in the normal sense of the term, one who voluntarily seeks medical aid)?

In a characteristically British manner, professional bodies judged that the decision must be left to the doctor's scruples. The ingrained habits of individuality, specific to English liberal politics, and the cult of the gentleman that formed the unspoken code of male elites in all contemporary European societies meant that in professional eyes and, to a large degree, equally in the public mind the ethical dilemmas raised by medicine were best handled not by the law courts, jurists, academic philosophers, or Parliament but by the integrity of private practitioners following clinical judgment and their own consciences. These precepts, for better or worse, left a potent legacy to twentieth-century Britain. They certainly offered great latitude to the medical profession while placing heavy burdens upon its shoulders. Radical critics of the professions and their ideologies have contended, surely correctly, that the formulation of medical ethics enhanced the status and exalted the independence of the nineteenth-century doctors. How far this process helped to protect the public is more difficult to judge.

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MEDICAL ETHICS, HISTORY OF EUROPE: CONTEMPORARY PERIOD

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I. INTRODUCTION

Bioethics was flourishing in most of the countries of late-twentieth-century Europe. However, as a field of ethical reflection and an instrument of public policy, bioethics is hardly uniform across the continent. The development of medical science and technology, as in many countries throughout the world, has stimulated an interest in the attendant ethical issues. Yet the ways various countries have experienced that development differ, as have their ethical responses. Although influenced by social and political events, and by philosophical, literary, religious, and cultural ideas common to the European milieu, various countries and cultures have contributed in unique ways to the formulation of bioethical ideas. There is now a European Association of Bioethics, and in its deliberations, the commonalities of European bioethics can be found, as well as the distinct accents of the various national participants. This introduction will state some of the common themes; the articles that follow will emphasize national and regional distinctions.

Role of Medical Science and Technology

An important prerequisite to twentieth-century discussions and positions was the establishment in the nineteenth century of a natural scientific basis of medicine. Impressive progress in diagnosis and treatment, coupled with this development, led to new ethical problems. Concurrent with this process was an anthropological reduction—a loss of humanistic dimensions in the natural sciences and medicine leading to various attempts at balance and correction in the early twentieth century.

Philosophical Influences

Anthropological medicine and philosophical or existential psychiatry are important twentieth-century reactions to the one-sided natural scientific orientation of medicine. Various philosophical directions, associated with the names of Edmund Husserl, Martin Heidegger, Karl Jaspers, Jean-Paul Sartre, Maurice Merleau-Ponty, Gabriel Marcel, and José Xavier Zubiri, have influenced medicine. Theology has also made important contributions. An independent, intramedical discussion of methods and theory, beginning in the late nineteenth century, and the integration of psychology and sociology into medicine in the last few decades, have also affected contemporary European bioethics.

The situation of medical history in the medical faculties of the universities of Europe presents a different picture. The grand tradition of the presentation of history and theory, including the study of medical ethics, as part of the formal education required of medical students during the preclinical and clinical years was abandoned in the empirical, scientific nineteenth century. Only in Germany was it possible to establish a chair for medical history in almost every medical faculty.

These impulses and initiatives sought to bridge the separation between the natural sciences and humanities. The history of the patient was considered to be as important as the history of the illness. The ethical dimension was recognized anew in the understanding of disease, the concept of treatment, and the physician–patient relationship.

After 1900, discussions of the concept of cause led to a new appreciation of the anthropological dimensions of medicine. The concept of monocausality has been countered by that of multiconditionalism: Disease cannot be explained by one cause but by several causes. Constitution and disposition (i.e., the physical conditions of the individual) supplement the principle of exogenous infection; cause (*causa efficiens*) and aim (*causa finalis*) should not mutually exclude one another. Physical as well as mental illness can fulfill a purpose or meaning, can represent freedom in unfreedom, in the type of coping with these damages.

Literary Influence

The arts—in particular literary texts—also proffer important influences and models. Medical ethics has profited and will continue to profit from a unification with medical humanities. Novels and stories describe the attitudes and behavior of the patient as well as the physician in detail, drawing the reader into the context of the hospital as well as the wider social environment. Such literary depictions and interpretations, in providing examples, can play an important role in medical training. The scientific pleas for euthanasia at the beginning of the twentieth century find their supplementation or preparation in the literature of the nineteenth century. The texts of Guy de Maupassant, Henrik Ibsen, Theodor Storm, Anton Chekhov, and Hjalmar Söderberg describe conflicts in which the killing of a suffering and dying person is suggested; at the same time, there are warnings against active euthanasia. Normative opinions that equate health with the positive and illness with the negative are relativized or even reversed in the works of Marcel Proust, Thomas Mann, Robert Musil, Virginia Woolf, and many other writers. Health should also be understood as the ability to live with illnesses and disabilities, which may harbor opportunity and challenge. The patient has rights and duties, as does the physician; both can exhibit virtues. Their relationship manifests both asymmetry and symmetry such as differences in medical knowledge and experiences of pain and disease.

Political Influences

Ethical discussions of medical issues took place in all European countries even before World War II. Numerous essays and monographs were published on the ethics of the physician, ethics in research, and the ethics of patients, as well as the ethics of the family and of society. In 1901, the first

Congrès International de Médecine Professionelle et de Dèontologie Médicale took place in Paris. Many conventions on the subject of forensic medicine had already taken place. Bioethics in Europe is not uniform; different accents can be found in theory and practice. The differences are based on each country's respective artistic traditions as well as on the respective political and economic situations and legal regulations.

Undoubtedly, World War II and, after its end, the Nuremberg Code were turning points in bioethics. On the one hand, an increased tendency toward international uniformity in bioethics was reflected in such international declarations as, for example, Helsinki (1964) and Tokyo (1975), and in the introduction of ethics committees. On the other hand, the multitude of differing orientations retains its validity, even gaining a new weight through the presence of foreign labor and long-term migration in the European countries. Radical political changes in Eastern Europe and Germany through the collapse of communism made manifest the continuity of ethical opinions and social conditions that had been thought to be relics of the past; these hold new meaning for bioethics in the future.

Problems in bioethics must be solved on many levels, particularly in the Eastern European countries. At the center stands the task of finding a convincing ethical or humanistic solution for the vacuum of ideals left by the collapse of communism and the pressure of technical-scientific progress. Here, as is generally the case in the realization of ethical principles, the applicable legal regulations are of decisive importance. When moral principles are weak, laws can offer protection.

Medical Ethics and Bioethics

Because of the plurality of traditions that make up contemporary European bioethics, it is not possible to isolate a single path of development. The word *bioethics* itself denotes many things. Bioethics has been used to propose norms in the practices of modern biomedicine, norms of a religious-ethical nature, and norms of legal or philosophical ethics. Sometimes, under the new label *bioethics,* the method and arguments of already consolidated disciplines (moral theology, law, ethical guidelines for health professionals, moral philosophy) are easily recognizable, enriched only by the content of new problems.

In the different European cultural contexts, bioethics has had to confront a strong tradition of medical ethics that was developed and defended by physicians as their exclusive property. The proprietary claims of health professionals on medical ethics have produced ambivalent results. The independence of medical ethics has sometimes been able to protect the profession from the pressures that totalitarian ideology exerts on physicians to conform their behavior to the values imposed by the regime. Under the fascist and Nazi regimes (Italy and Germany) and in countries ruled by communism, medical ethics was denied an independent status in order to subordinate it to particular ideological visions (including racism, eugenics, the class struggle, and the dictatorship of the proletariat). In such situations, medical ethics' independence from the values that regulate the society created space for an ethics tied to philanthropic and universalistic ideals.

Nevertheless, the medical ethics elaborated by professional physicians can also obstruct the rise of formulations better adapted to the changing cultural situation. This is evident in many European countries by the many physicians who turn to traditional medical ethics, inspired by the ideals of Hippocratic medicine and strongly anchored in a paternalistic attitude toward the sick person, in order to oppose the medical models that are centered on the value of individual autonomy and the practice of informed consent.

The thrust toward bioethics is characterized, if compared with the strong tradition of an ethics developed by the medical profession itself, by the need for a civil ethics or an ethic of ordinary life elaborated in many voices. Bioethics is differentiated from medical ethics in being a consensual reformulation of rights and obligations in the context of medical practice and healthcare. This includes the professional obligations of physicians, but does not derive only from these. A further characteristic trait of bioethics in regard to civil or general ethics is the minimal ethical consensus, which obliges all citizens, in contrast to the maximal ethical consensus, which focuses on individual preferences.

A second issue that bioethics in Europe must face is its relationship with religious ethics. The weight of religious ethics relative to the moral problems posed by the corporality of man (sexuality, procreation, disease, health, death) and healthcare varies according to cultural context and type of religious communities in the society. In societies in which a single religion dominates, especially of the Catholic tradition (Ireland, Poland, Italy, Spain), religious ethics tends to superimpose itself onto bioethics, shaping it to its own norms. In countries in which a tradition of pluralism prevails, the two normative contexts—religious ethical and bioethical—are more clearly distinct.

Where religious ethics is seen as antithetical to secular ethics, a clear polarization can appear in the society; possible examples are Ireland, Poland, or Portugal, with their Catholic tradition. Justification of ethical judgment then consists of making reference exclusively to one set of values instead of another. This happens, for example, when clinical decisions are evaluated exclusively in terms of values considered to be absolute: sacredness of life versus quality of life, benefit of the medical act versus self-determination of the patient, and so on.

A third issue in the contemporary development of bioethics in Europe relates to the challenge of universalism. Developments in the ethics of medicine and biological sciences reveal two opposing challenges for bioethics: the need to be rooted in the particular, with respect to the cultures, traditions, and local communities of belonging, and the need to refer itself to universal values. Universalism is an intrinsic dimension of ethical rationalism. At the same time, universalism is necessary to ensure normative rules and moral obligations. The directives, for example, of "Good Clinical Practice for Trials on Medical Products in European Community" (1991) have had the aim of producing one practice of experimentation in this field. In Europe, in fact, the crowded national frontiers would easily create "enclaves" where biomedical practices prohibited beyond these frontiers would be legitimate. An international consensus has to be created to prevent a "tourism" in medical research.

The various bioethics developing in Europe face the challenge of particularism as much as that of universalism. The best forms of European bioethics are clearly those that are trying to respond to both these challenges.

Recommendations of the Council of Europe

The most relevant innovation for the history of bioethics in Europe is the approval of a "Convention for the Protection of Human Rights and Dignity of Human Being with regard to the Application of Biology and Medicine" by the Council of Europe. After almost five years of work and lively discussions, the steering Committee on bioethics of the Council of Europe (CDBI) presented a text which was approved by the Council of ministers in Oviedo (Spain), on April 4, 1997. The Convention is therefore known as the Oviedo Convention or "Convention on human rights and bio-medicine." Its main purpose is to reinforce the idea that, since Europe is becoming more and more integrated from a cultural point of view as well as economically and politically, it is necessary to find a common orientation also on the subject of bioethics.

Eighteen out of the forty countries of the Council of Europe have signed the Convention. The parliaments of the signatory States are now called upon to ratify this Convention, thus agreeing to bring national legislation into line with the principles enunciated in the agreement. Indeed, unlike "Recommendations" of the Council of Europe and "Treaties," which are a mere expression of principles, the instrument of the Convention is particularly effective because it is binding on those states that ratify it, obliging them to apply its standards within their individual sets of laws. This means that the Convention is not an "exhortation," to the individual states, but has a normative value. As of September 2002, thirteen countries have also ratified the Convention they signed.

The choice made with the Convention was to focus on principles and rules that can help create a consistent set of laws, real European common rights in the bioethics area: the prevalence of human beings over science, respect for individual independence, protection of integrity and dignity, confidentiality of medical and genetic information, non-commercialization of the human body. In the Convention no position has been taken on widely debated topics, including medically assisted procreation, the cloning of embryos, or genetic engineering. The most controversial aspects of bioethics are expanded upon in additional protocols. Two of them have been drawn up so far: on the Prohibition of Cloning Human Beings (January 12, 1998) and on Transplantation of Organs and Tissues of Human Origin (January 24, 2002).

The essential elements of the Convention are: the primacy of the human being (article 2: "The interest and welfare of the human being shall prevail over the sole interest of society or science"); equitable access to healthcare (article 3: "Parties taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to healthcare of appropriate quality"); the central role of information and consent (article 5: "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks").

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II. SOUTHERN EUROPE

The term *southern European countries* includes all the occidental European countries in the Mediterranean area (Spain, France, Italy, Greece, Malta, and Cyprus), plus an Atlantic country closely related to them (Portugal). In addition to geographical and climatological affinities, these seven countries have for many centuries shared a common history centered on the Mediterranean Sea. Although they maintain local peculiarities and differences, the nations of southern Europe can be said to have a common identity.

This common identity is particularly evident in ethical issues (Gracia, 1993). Occidental ethics had its origin in the Mediterranean Greco-Latin culture, and since the days of the Greek philosophers, this ethics has centered on the concepts of virtue and vice. Only with the Enlightenment did a new ethical tradition, with right and duty as its main concepts, begin to take shape in central Europe. Since then the two approaches have widely been considered opposites, although they are in fact complementary. The ethics of virtue has persisted in those countries in which the Enlightenment had less influence, such as the Catholic or Orthodox southern European nations (Savignano), while the ethics of duty has prevailed in the Protestant central European and Anglo-Saxon countries (MacIntyre).

Today the occidental world harbors three palpably different ethical traditions, each with its own characteristics: the Anglo-Saxon, the central European, and the Mediterranean. Because modern bioethics is a product of the Anglo-American culture, Mediterranean countries have not attempted simply to import or “translate” bioethics but, rather, to re-create or remake the discipline according to their own cultural and ethical traditions (Gracia, 1990).

A “Latin Model” of Bioethics

If traditional Anglo-American philosophy is generally classified as empiricist, European philosophy has been more influenced by rationalism. Anglo-American ethics is generally more teleological and consequentialist, and European ethics more deontological. This explains why, for instance, the term *autonomy* has acquired a different meaning in the United States than in Europe. According to North American ethics, autonomy is the capacity to act intentionally, with understanding, and without controlling influences. On the other hand, European ethicists often interpret the principle of autonomy in a Kantian sense, as the capacity of human reason to impose absolute moral laws upon itself. The latter is a metaphysical assumption, while the former is only the lack of constraints. To European ethicists, acting autonomously means that the human reason is capable of freely establishing absolute and compulsory moral laws (freedom to). In the Anglo-American, on the contrary, freedom is understood only negatively, as the capacity to act without constraints (freedom from). The first is a maximal concept of autonomy, and the second a minimal one. These two meanings are so disparate that an autonomous person, according to the European point of view, may not act autonomously from the Anglo-American perspective because of constraints such as ignorance or coercion. Moreover, it is also possible to deny the capacity of reason to impose on itself absolute moral laws, and to accept the concept of autonomous choice as the absence of external constraints.

The rational foundation of ethics is closely linked to the discussion of whether the principle of autonomy is relative or absolute. In Europe, the Anglo-American propensity to base ethical analysis on several theories, such as utilitarianism and contractualism, and on a few principles, such as autonomy and beneficence, is usually considered insufficient or less adequate. Europeans generally search for more universal or transcendental ethical foundations. The meaning of the concept of *transcendental* differs in central and southern Europe. Central European ethics often attempts to reach the transcendental dimension through an intersubjective procedure, such as the universalization of personal interests. According to many Mediterranean ethicists, the transcendental universality of ethical norms is reached in a more objective way, based on metaphysical concepts like *reality, human nature,* or *personhood* (Russo). The latter is, of course, the most classical position in occidental philosophy. It is no coincidence that this classical concept of metaphysics was born on the Mediterranean coast.

Modern northern European ethics, based on the concepts of right and duty, has been the matrix of ethical minimalism (or the ethics of duty), while the traditional Mediterranean ethics, based on virtue, has tended more toward ethical maximalism (or the ethics of happiness). While minimalistic ethics looks for the basic rights and duties of every human being and society, maximalistic ethics is concerned with life projects and ideals of perfection and happiness (in Greek, *eudaimonia*). During the sixteenth century, Mediterranean countries adopted anti-Protestant, and therefore antimodern, attitudes; they considered certain aspects of modernity to be fundamentally hostile to their cultural traditions: their medieval political, ethical, and religious ideals. These attitudes may explain why many Mediterranean nations belatedly and with difficulty adopted the doctrines of human rights and parliamentary democracy, the greatest achievements of the Anglo-American world. This may also explain the relative weakness of democratic practices in these countries in comparison with other areas. This antimodern stance enables one to understand the history of southern Europe since the nineteenth century, particularly the potency of antidemocratic movements and authoritarianism during the first half of the twentieth century. And while western European countries definitively adopted democracy and liberal systems following World War II, some of the Mediterranean countries maintained a markedly different identity.

All these elements help clarify why southern European countries have tried to elaborate a "Latin" model of bioethics (Leone). While the Anglo-American model is structured around the four classical principles of autonomy, nonmaleficence, beneficence, and justice, Salvino Leone, following Elio Sgreccia, bases the so-called Latin model on the four principles of the fundamental value of life; liberty and responsibility; totality (or therapeutic wholeness); and social subsidiarity (the idea that smaller units are always preferred to larger ones when it comes to addressing social problems) (Sgreccia; Palazzani). This search for distinctiveness also led Mediterranean ethicists to seek to establish their own terminology. The French expression *éthique biomédicale,* "meaning the desire to promote a new style of questioning in the field of biomedical sciences, both theoretical and educational" (Moulin, p. 280), has been adopted as an alternative term to the Anglo-American bioethics not only in French but also in other Mediterranean languages, such as Italian (Spinsanti, 1987) and Spanish. The reason for this terminological change is that for many authors, the word *bioethics* seems overly biologistic and suggests that ethical behavior is biologically determined. The alternative expression *biomedical ethics* was coined to avoid this danger. It situates the term *ethics* as the noun, with *biology* and *medicine* in secondary adjectival position. Of course, the term *bioethics* is also frequently used in Mediterranean countries, just as North American literature occasionally uses the expression *biomedical ethics* (Beauchamp and Childress).

The Ethics of Virtue and the Doctor-Patient Relationship

Mediterranean countries have created a realistic and personalist model of biomedical ethics, based on the classical Aristotelian-Scholastic philosophy and complemented with more modern European philosophical traditions such as phenomenology, axiology, and hermeneutics (Viafora, 1990). In this model, the idea of virtue acquires much more significance than in any other occidental tradition, a fact that has important consequences in the medical field. For example, trustworthiness is considered more crucial than the right to information (Dalla-Vorgia et al., 1992). Patients in southern European nations are generally less concerned with receiving detailed information or having their autonomy respected than with finding a doctor in whom they can place their full confidence (Gordon; Spinsanti, 1992; Fletcher; Loewy).

One virtue is particularly important in establishing a satisfactory doctor–patient relationship: friendship. The Spanish physician and humanist Pedro Laín Entralgo has written extensively on this topic, especially in his book *The Doctor–Patient Relationship* (Laín Entralgo, 1983 [1969]). This relationship must be based on what Laín Entralgo calls "medical friendship," composed of benevolence, beneficence, and confidence. His studies have had a substantial but not exclusive impact in Mediterranean and Latin American medicine; as a result, the idea of friendship as the cornerstone of the relationship between doctor and patient has gradually acquired importance in bioethics. The influence of his studies is also visible in North American bioethical literature (Siegler, 1979, 1981; Pellegrino and Thomasma; U.S. President's Commission; Cassell; Drane).

Friendship includes trust and confidence, which is why we talk about intimate friends; friendship is the ambit of trust. The three theological virtues (faith, hope, and love) are common between friends. The core of this relation is hope, understood as trust: we trust friends, we have faith in them, and we trust them because we love them. Friendship is more than ethics; it is almost a religion. Charity, or agape, is considered the most important virtue in the Judeo-Christian tradition. But, according to Laín Entralgo, agape can be considered perfect only when benevolence and beneficence, its main components, join friendship's trust and confidence (Laín Entralgo, 1985 [1972]). The result is, as Edmund Pellegrino and Warren T. Reich, two U.S. authors influenced by Laín Entralgo, have written, "com-passion," the act of putting oneself in the place of another in order to understand his or her experiences (Pellegrino, 1986, 1988, 1989; Reich, 1989, 1991). Compassion is not pity but, rather, the human relationship based on devotion, constancy, personal respect, and responsibility. As Reich says, it is the relation with the other, based on love, benevolence, comprehension, and friendship. Mediterranean bioethics has emphasized the study of the friendship aspect of the physician–patient relation, and the Spanish contribution has been important (Gracia, 1989).

Ethics and Law

The relationship between ethics and law is peculiar in the Mediterranean. In its origins, Roman law was substantially influenced by Stoicism, a school of thought that assimilated law and morality. Stoics considered nature the source of both law and morality; natural law could be known rationally, and thus formulated deontologically and axiomatically into a legal code. Because law expresses what is morally correct, ethics and law converged. Ethical goodness, the intention with which an act is performed, only added to the legal rightness of the act and to the virtue of the person involved.

Christian thinkers adopted this relationship between ethics and law without substantial changes, and it has been a latent presence both in canon law and in the moral theology of the Roman Catholic church. Thus, in Catholic nations such as those of southern Europe, law and morality are difficult to distinguish conceptually.

One of the problematic outgrowths of this tradition is legalism, the tendency to believe that every human act can be legally prefigured, that laws precede facts, making it possible to regulate beforehand every real or possible situation. Thus, in these countries court rulings are considered nothing more than the concrete application of statutory law. This law is prior to individual rulings, quite the opposite of the Anglo-Saxon common-law system. The traditions also diverge in that the Roman model is largely centralized and state-oriented and places less importance on social dynamics. The prevalence of state over society explains why Mediterranean countries have fostered more authoritarian and less democratic political practices than Anglo-Saxon ones.

Health Systems

That the state must, in southern European countries, take responsibility for what in other countries is considered the realm of private enterprise, illuminates another distinctive characteristic of Mediterranean bioethics: its overwhelming concern with healthcare justice. In fact, the health systems of these countries are mainly state-run. Justice plays the decisive role in European biomedical ethics that autonomy plays in North American bioethics (Thomasma).

France, Italy, Greece, Portugal, and Spain have similar national health insurance systems. Their common origins date back to the German Krankenkassen (patients' fund) system, designed by Otto von Bismarck in the final decades of the nineteenth century as a means of assuring medical assistance for workers. In distinction to the socialist European countries, where all the population was covered by an insurance system financed by public funds, Mediterranean countries, following the German model, began insuring only workers, and financing the system with the economic support of both workers and employers. Coverage was later extended by public funding, and today nearly the entire population of each country is protected. This process of generalization of the health insurance system took place during the zenith years of the welfare state, between the end of World War II and the economic crisis of 1973. In the mid-1970s, health insurance as well as the entire social security system, and perhaps the welfare state itself, experienced a crisis, mainly because of the costs explosion that made it impossible to satisfy the population's health expectations. To find solutions for this complex problem, most countries set up reform commissions aimed at proposing measures to make health insurance viable in the future.

In Spain, compulsory health insurance for all workers was enacted in 1942 and implemented in 1943. Over the next three decades, coverage was gradually extended. In 1986 it became a national health system very similar to those in Britain and Italy, covering the healthcare of most of the country's population (Gracia, 1987). This satisfied one of the people's greatest wishes but at the same time gave birth to a new problem, which became more and more acute as time went by: the scarcity of economic resources and the subsequent need to limit free health services. In order to analyze and evaluate the needs of the national health system, in 1990 the Spanish parliament set up a commission, known as the Comisión Abril Martorell. The commission's main report, published in July 1991, asserted the importance of the national health system in maintaining the level of health and well-being in Spain, and proposed certain amendments to increase efficiency without altering the basic system. One such modification would require every user of healthcare services to pay a percentage of the total cost, in an attempt to make everyone shoulder the burden of the constant increases in health expenses.

Patients' Rights

The way patients' rights were established marks another differentiating factor of Mediterranean countries. In the United States these rights, particularly the right to informed consent, took shape in the field of common law, while in Mediterranean countries their entry was directly through statutory laws and codes (Council of Europe, 1976; Gracia, 1989). In these countries, protecting patients' rights is a duty of the state more than the duty of individuals. In Spain, patients' rights were first established legally in Article 10 of the Health Law of 1986, and then socially.

In all Mediterranean countries the respect for patients' autonomy and their right to make decisions about their own bodies has grown remarkably in the last decades (Cattorini and Reichlin). This has produced profound changes in the role of healthcare professionals, as well as more litigation against physicians and other healthcare workers. The old juridical terms *professional incompetence* and *negligence* that referred to faulty medical procedures have come to be overshadowed by new complaints about health workers' lack of skill or their negligence in giving information, or about battery, for handling the patient's body without consent.

The patients' rights movement of the 1970s provoked wide-ranging legislative changes (Council of Europe, 1976).

For example, the large antipsychiatry movement in 1978, led in the Mediterranean area by Italy, prompted some countries to modify laws on the compulsory restraint of the mentally ill by passing new legislation more respectful of these patients' human rights and providing greater protection against possible abuse by family members or health professionals. In 1997, the Council of Europe introduced the "Convention on Human Rights and Medicine"; the fifth article of this document states that "an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time" (Council of Europe, 1997) The convention has been signed by all the Mediterranean countries, and has influenced national legislation about the rights of patients and informed consent.

Additional consequences of this new respect for patients' rights are the strict regulation of biomedical experimentation and the creation of institutional review boards to monitor every clinical trial and research project protocol, analyzing not only technical and methodological but also ethical aspects. On November 24, 1986, the Council of the European Community approved a directive on the protection of the animals used in research and other scientific projects (European Union). Every country of the European Community adopted its own legislation in the following years, and by the end of the twentieth century, research with animals was strictly controlled (Illera).

In an attempt to promote organ transplants while avoiding any kind of commerce and abuse in the donation process, all Mediterranean countries have introduced legislative criteria for brain death and have elaborated laws regulating transplants. The legal regulation of medical care to the dying has encountered greater obstacles, and has provoked heated debates over euthanasia (Gracia, 1987, 1988; Lefevre; Dracopolou and Doxiadis; Bompiani).

Issues related to the origin of life, especially abortion and new techniques for human reproduction, have been the subject of the most intense debates. Mediterranean countries have adopted conservative positions in these debates. In these nations the U.S. Supreme Court decision *Roe v. Wade* (1973), based on the right to privacy and restricting the right of states to legislate on abortion in terms of viability and trimesters, is not easily understood. In Mediterranean countries, abortion is held to be a public rather than a private issue and therefore a matter of justice and not of autonomy, since the life of a human being is believed to be at stake. Hence, in these countries, laws governing the interruption of pregnancy are based on exceptional circumstances or indications rather than on periods of time or terms of pregnancy. These laws allow abortion in three exceptional indications: great danger to the mother's health or life; important defects of the fetus; and rape. Only a few countries, such as Italy and Cyprus, have included a fourth indication: socioeconomic incapacity, valid during the first trimester of gestation. The Veil Act (1975) in France established that any pregnant woman can undergo an abortion during the first ten weeks of pregnancy if gestation is a source of anguish (*détresse*) for her, an indication that, in practice, is analogous to a law of terms (a period of time in which abortion is permitted without any indication). Since 1986 Greece has had a law of terms: Abortion is permitted in the first twelve weeks of pregnancy. After this period, gestation can be interrupted only with an ethical (nineteen weeks), eugenic (twenty-four weeks), or therapeutic indication (Glendon).

The problems presented by new techniques of human reproduction are so various and complex that every southern European country has established a specific commission for their study. The Comisión Palacios of Spain and the Commissione Santosuosso of Italy are examples. Both bodies have elaborated reports for legislative enactment, which has been achieved in both countries (Gracia, 1988; Fagot-Largeault; Mori; Walters; Bompiani). More important, these commissions highlighted the need for national committees on bioethics, which were firmly established in the Mediterranean area by the end of the century. This same process has taken place in Europe as a whole, where the Council of Europe in 1983 established the Ad Hoc Committee on Ethical and Legal Problems Related to Genetic Engineering, which a few years later became the Ad Hoc Committee of Experts on Bioethics and was later called the Steering Committee of Bioethics.

National Committees of Bioethics

National committees of bioethics have been set up because of the increasing complexity of biomedical research and to avoid dangerous research like that which made possible the construction of nuclear weapons during the 1940s and 1950s and the experiments carried out in Nazi concentration camps. The main aim of these committees is to help those involved in biomedical research by offering prudent criteria for conduct. On February 23, 1983, French President François Mitterrand created the first national bioethics commission in a European country, the Comité Consultatif National d'Éthique pour les Sciences de la Vie et de la Santé (CCNE). Its purpose is mainly to elaborate recommendations on ethical problems stemming from scientific research in biology, medicine, and other health professions (Isambert, 1989). It deals not with healthcare problems but with ethical questions raised by biomedical research. The CCNE is composed of thirty-six members plus a chairman who is appointed by the president of the republic. The departments of Education, Research, Industry, Health, Justice, Family, and Communication appoint sixteen members with proven competence and interest in ethical issues. Fifteen posts are filled by researchers and representatives of universities and the National Institutes of Health and Research. Five members, named by the president of the republic, are drawn from the "spiritual and philosophical" fields. Committee members are divided into working teams to prepare reports and recommendations. The documents so far produced have dealt with the use of fetal and embryonic tissues for diagnostic, therapeutic, or research purposes; techniques of artificial procreation; prenatal and perinatal diagnosis; the use of the abortion-causing drug RU-486; and the noncommercialization of the human body, among other topics. Every year, the committee organizes meetings of study and debate called the Journées Annuelles d'Éthique, in order to release the year's work to the public.

The French commission's work has stimulated bioethics studies in the Mediterranean area, much as the National and President's Commissions have done in the United States. Of the two possible methodologies identified by the Belgian philosopher of medicine Jean-François Malherbe—that of the lowest common denominator (the search for a formula everybody agrees with, even if it is ambiguous and makes room for very different interpretations) and that of the highest common denominator (requiring much more work, reflection, and dialogue)—the Comité Consultatif National opted for the second. This decision had an evident impact on the text of a report the committee issued, "Biomedical Research and Respect for the Human Being" (CCNE). French bioethics is coming to be, as Malherbe noted, "an active center of public morality in the life of people" (Malherbe, p. 227). The French ethics of the highest common denominator is similar to some of the most creative ideas from Jürgen Habermas and Karl O. Apels's "ethics of communication," which is based on the idea that in the context of a pluralistic society, ethics will flourish only if it takes into account the interests of every person actually or virtually involved in the conflict. The French committee has integrated German dialogic ethics with French personalism, widespread among French philosophers of the last century, and firmly established in certain Catholic (Maurice Nédoncelle), Protestant (Paul Ricoeur), and Jewish (Emmanuel Lévinas) phenomenological thinkers. According to Lucien Séve, these ideas have proved fundamental for the elaboration of a working procedure based on rational consensus and not on a merely strategic consensus.

The French committee has had great success, and hence this model has spread throughout Europe, including the Mediterranean countries. Malta instituted its Health Ethics Consultative Committee in 1989 (Le Bris). In March 1990 the Italian government approved the creation of the Comitato Nazionale per la Bioetica, directly responsible to the prime minister. The body is composed of forty members and, like the French group, is aimed at controlling research involving human beings. It has published documents on gene therapy, definition of human death, ethics of the use of seminal fluid for diagnostic purposes, biotechnological security, bioethical learning in the clinical setting, healthcare and terminally ill patients, organ donation, and ethics committees.

Portugal, following the French pattern, established the National Ethical Council for Life Sciences in June 1990 (Martinho da Silva). The body started functioning January 1, 1991, and in its three first years published three reports: on organ donation and transplantation (1991), on the use of human corpses in research and teaching (1991), and on new reproductive technologies (1993).

In 1984 Spain created a special committee known as the Comité Palacios to study problems related to new techniques of assisted reproduction (artificial insemination, in vitro fertilization, and so forth). In July 1992 the Department of Health published a legal order creating a health advisory committee whose main goal was assessing and informing the secretary of the department on scientific, ethical, professional, and social questions. This committee deals not only with problems of biomedical research but also with those raised by healthcare. This innovative feature distinguishes it from others in the region.

In southern Europe, institutional ethics committees were rare until the 1990s, in part due to the prevalence of socialized medicine and in part because Mediterraneans are not completely conscious of patients' rights. In Spain, for instance, such committees only became standard in hospitals late in the 1990s, following the General Health Law of 1986 that specifically mandates the protection of patients' rights.

Goals and Challenges for the Future

In the last decade of the twentieth century, new problems emerged; two of the most important were population ethics and ecology. Ecology is of increasing importance in all Mediterranean countries, and is beginning to be not only an ethical and intellectual issue but also a political force (Gafo; Poli and Timmerman). Latin European countries are neighbors of the underdeveloped nations situated on the southern Mediterranean coast, and they therefore understand very well that only a sustainable development can correct the unsustainable development of the First World and the underdevelopment of the Third World. Ecology in these countries will be not only an ethical compromise but also a political project, prompted by the left-wing parties. With the death of the Marxist ideology, ecology assumes the place once held by economic theory.

Due to the increasing importance of bioethics in the life of these countries, research and teaching are growing quickly. The teaching of bioethics has been introduced not only in schools directly related to healthcare, such as medicine, pharmacy, and biology, but also in theology, philosophy, and humanities (Comitato Nazionale per la Bioetica; Gracia, 1992). Literature is being published, and universities are supporting new research centers (Viafora, 1993). All of the research centers have been integrated into the European Association of Centers of Medical Ethics. Since 1990 the Milazzo Group has published *International Journal of Bioethics.*

DIEGO GRACIA
TERESA GRACIA (1995)
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III. THE BENELUX COUNTRIES

The Benelux countries—Belgium (population 10 million), the Netherlands (population 15 million), and Luxembourg (population 400,000)—with three languages (Dutch, spoken by 20 million; French, by 5 million; and German, by 500,000), and two Christian religions (Roman Catholicism and Protestantism)—have been leaders in European bioethics. Institutes for bioethics were founded in these countries in the early 1980s, the region's universities developed a full curriculum for medical ethics, and European bioethics associations of both organizations and individuals were founded in the Benelux nations.

Of the three possible approaches to medical ethics—the deontological, the forensic, and the philosophical–theological approach—the third one, particularly since the 1960s in Belgium and in the Netherlands, has produced a considerable amount of literature in both religious and lay ethics.

During the 1960s, early warning signals were issued by physicians and philosophers. Prominent among them was Jan H. van den Berg (1961; 1969), who warned against inevitable medical failures once patients become objects of medical science instead of persons and subjects of care.

The real boom in bioethics, however, did not come until the mid-1970s and 1980s, when bioethics gained institutional status. From then on, not only doctors and a few ethicists but also ordinary people, among them patients and politicians, became interested in bioethical issues. In 1974 a famous case of active euthanasia in the Netherlands, in which a physician terminated the life of her terminally ill mother at the latter's request, marked the beginning of a debate that would last several decades.

The institutionalization of bioethics is apparent in the existence of three centers for bioethics in Belgium (two in Brussels, one in Leuven) and six centers in the Netherlands (Amsterdam, Ede, Groningen, Maastricht, Nijmegen, Utrecht), as well as in a number of interfaculty working groups. In Luxembourg a national consultative ethics commission for the life sciences and health has existed since 1988 by government decree.

Belgium

In 1993 Belgium underwent a major constitutional change. Belgium became a federal state made up of three communities (French, Flemish, and German-speaking) and of various regions. Bioethics has been impacted because issues are always compounded by the institutional complexities of multiple governments, parliamentary assemblies, and powers. The Belgian approach to AIDS provides an example: preventive measures are taken by the communities, healthcare is provided by the federal state, and the hospital infrastructure is established by the regions (Binamé). Religiously speaking, the country was almost entirely Roman Catholic, though in matters of medical ethics—for example, contraception—a group of postwar Catholic doctors and moral theologians of the personalist tradition had taken a rather liberal stance. The Roman Catholic Church still plays an influential, albeit no longer a decisive role in Belgian bioethics in the twenty-first century. Academically, its bioethical message is carried by the universities of Leuven-Louvain, Namur and Antwerp. However, during the last decades of the twentieth century strong lay trends entered bioethics. The universities of Brussels, Ghent, and Liège established centers or study groups for bioethics. In 1973 the Belgian Society for Ethics and Medical Ethics was founded. Since 1990, this association has had a Flemish-language section. Other important societies are: The Belgian Academy of Medicine and the National Foundation of Medical Research.

Medical ethics at universities was usually taught by faculty from either theology or philosophy departments. Rare exceptions where physicians taught medical ethics, such as Marcel Renaer at Leuven, proved the rule. In 1980 Leuven University created a chair of medical ethics that was held by Paul Schotsmans in 2002. The Leuven (Flemish-language) center and the Louvain (French-language) center, under the direction of Jean-François Malherbe and his successor Michel Dupuis, developed teaching programs for medical ethics at the graduate level and for members of ethics committees. The annual conventions on health law at Ghent University, started in the 1960s, bring together health lawyers and bioethicists from around the world.

LEGISLATION. The federal government took several initiatives in encouraging the development of bioethics. In 1987, the Ministry of Public Health organized a national convention in order to explore the key bioethical issues of the future. The congress was expected to generate significant policy recommendations. In fact, only a general proposal resulted: that vehicles for ongoing debate should be created and that medical practice ought to be protected against wild growth and carelessness in the new fields of biotechnology. In 1993 the National Consultative Bioethics Committee was created with thirty-five members. Its major task is twofold: to provide advice in the field of biomedical ethics, be it on request or on its own initiative; and to provide information to the public at large. Belgian legislation at the federal level covers the following bioethical areas: blood (1961, 1971) and issues of the contaminated blood (1994); organ transplants (1986); artificial insemination (1987); abortion (1990); human genetics (1992); euthanasia (2002); and patients' rights (2002). At the level of the French community, an agency for the prevention of AIDS was created in 1991.

ETHICS COMMITTEES. Strictly speaking, Belgium had no law on human experimentation as of 2002. In 1999 the Hospital Act (1964) was amended by an article that made the presence of an independent review board compulsory, thereby providing these boards with a legal basis. In fact, ever since the early 1980s, ethical guidance and control over biomedical experimentation emanated from the Order of

Physicians. Their National Council had already developed a set of ethical rules and guidelines in what was called a "code of deontology" by 1975, to be respected by all physicians. Then, in 1976, the National Foundation for Medical Research charged an ethics committee with as a prime task, the review of research at university centers. In the 1980s, several academic institutions insisted that medical research be done under proper ethical conditions. University hospitals and major centers quickly established institutional review boards (Delfosse). In 1984 the National Council ruled that research ethics committees had to give their approval before research could be initiated in any hospital. At the beginning of the new millennium, close to two hundred ethics committees were in place. Gradually many of these ethics committees have expanded their mandate: the original research ethics committees also became hospital ethics committees, thus covering clinical cases and healthcare policy. In principle these committees are advisory. It is fair to say that during the 1990s efforts were made to create greater consistency, if not uniformity, in the normative as well as the procedural working methods of ethics committees.

The Netherlands

Medical ethics in the Netherlands has, over the years, gained a solid basis and infrastructure. Most universities have medical faculties or working groups where medical ethics is taught. Research and training institutes provide medical ethics information for healthcare institutions and for policymakers, and, joined by professional organizations, they offer systematic ethical training for healthcare workers. In the world of healthcare, numerous ethics committees are in place, and at the public level, the media and politics play an important role. During the 1960s Christian traditions lost their grip on social life, leaving a gap that was gradually filled by, among other things, the new (medical) ethics. The debates in the Netherlands on contraception, on abortion, on euthanasia, as well as all other debates on bioethics, were characterized by lively public participation, including patients and their organizations, as well as the movements for autonomy and self-determination. Dutch society, known for its tradition of tolerance, has displayed an increasing moral permissiveness in problems of biomedical ethics (Moor). In the immediate post–World War II period, a number of theologians as well as physicians were active in the field. Many bioethicists, even into the twenty-first century, have a religious if not a theological background, although a profound change has occurred in their interaction with society. Having gone through secularization, many of them have acknowledged the *humanum* as a basic norm that carries common agreement in this pluralistic society.

INSTITUTIONALIZED BIOETHICS. Institutionalization of bioethics in the Netherlands is best illustrated in the area of ethics committees for both research and hospital ethics. The number of independent review boards (IRBs), which began to be established in the early 1970s, grew rapidly after 1984; hospital ethics committees (HECs) seem to have grown more slowly, mainly after the mid-1980s. IRBs needed several years of adjustment after the introduction of a European Directive for "Good Clinical Practice" (1993) (Berghmans et al., 1996). Finally, in 1999, the law on Medical Scientific Research was introduced. Since then, a tendency toward the legalization of ethical issues seems to have taken over (Dupuis).

A number of professional organizations (of physicians, nurses, and hospitals) have their own study services for ethics that help them to research and develop policies in healthcare. The six established centers for bioethics as well as medical schools run teaching programs, services to clinics and physicians, and research projects in bioethics.

Dutch society, particularly Dutch political society, has at its disposal five major advisory organs to assist in making healthcare decisions: the Health Council, the National Council for Public Health, the Sickness Fund Council, the Central Organism for Fees, and the College of Hospital Provisions. All these organizations may offer advice without being asked. The Netherlands Organization for Technology Assessment monitors the ethical aspects of applied medical technology.

Dutch universities played an important role in the development of medical ethics. In the 1970s the universities of Maastricht (Paul Sporken), Nijmegen (Theo Beemer, Maurice de Wachter), and Leiden (Heleen Dupuis) were leaders in curriculum development. During the 1980s several other teaching units were established throughout the country.

MAJOR TOPICS. During the 1960s discussion of bioethics in the Netherlands focused on contraception and abortion; since then, the new reproductive technologies have attracted increasing interest. Euthanasia has been a key issue since the 1970s, and scarce resources and distributive justice, since the 1980s. A few issues that otherwise might not have been considered of importance have become so due to their link with scarcity of resources; for example, reproductive technologies, organ transplantation, the issue of insurance in the context of clinical genetics, and access to healthcare, especially waiting lists. Pervading all of these major topics is the recognition that patients' autonomy is quasi-absolute. A patient's choice is often considered to constitute the value of medical service. This is particularly true for decisions at the beginning and the end of life.

DECISIONS CONCERNING THE END OF LIFE. Euthanasia remained, in principle and for many years, punishable under criminal law although it became legal under certain conditions, such as voluntary request, hopeless suffering, and a second opinion provided by a colleague physician. Furthermore, a lenient jurisprudence was favorable to the medical practice of euthanasia and assisted suicide during the decades after 1974. Despite the publication of well-documented national surveys (van der Maas et al.; van der Wal et al.), stating that only 2,300 cases of requested euthanasia and 400 cases of assisted suicide occurred, as well as 1,000 cases of active termination of the patient's life without request, some estimates still range between 2,000 and 20,000 cases of euthanasia per year. Another critical point of discussion was the low instance of notification by physicians to the forensic doctor about their practicing euthanasia. By 1995, 6 out of 10 cases of euthanasia still remained unreported. In 1998 five regional evaluation committees started evaluating all notified cases and would then report back to the Attorney General and Health Inspection. In January 2001 a law codified what already existed: carefully performed euthanasia and assisted suicide, followed by notification, would exclude physicians from being prosecuted. Dutch euthanasia practice and legislation is perceived as exemplary in several countries, including Belgium, although the legislation is strongly opposed by others (Keown). It is fair to describe the Dutch euthanasia development over the decades as a transition from a moral debate, carried out on a large public scale during the 1970s and early 1980s, to discussions during the 1990s about careful implementation of policies, procedures, and guidelines, bringing about a clearer perception of the real practice.

HEALTHCARE SYSTEM AND REALLOCATION ISSUES. The Dutch healthcare system is based on principles of egalitarianism and solidarity. The latter principle is characteristic of the financial organization of healthcare in the Netherlands. In the modern welfare state, the moral principle is not primarily to feel individually responsible for others in need but to be held communally responsible for helping those in need. In a sense society imposes the duty to contribute financially in order to succor the needy in society. Individuals agree with this principle out of well-understood self-interest (Government Committee). At the same time, in the actual system of healthcare distribution, regulatory and marketing strategies are not necessarily contradictory (Wachter). While the population does not like cuts in healthcare or increased premiums for healthcare insurance, there is general agreement that healthcare is for all, and that the cost of individual preferences of patients beyond the basic package should be paid by the individual. The list of items excluded from the basic package around the turn of the millennium included only dental care for adults. But critics also lobbied to privatize cosmetic surgery, nursing luxury, homeopathy, physiotherapy beyond nine sessions, and alternative medicine. The government has legislated on hospital provisions (1973), on fees (1980), and on budgeting in hospitals (1983), but some problems, for example the waiting lists, remain. During the 1990s, a reform system based on the following principles was introduced: (1) private initiative is possible, and government controls only quality of care, access, and cost; (2) hospitals may plan according to local needs; and (3) insurers are free to market care.

REPRODUCTIVE TECHNOLOGIES. During the 1980s the emphasis on reproductive technologies was prominent. In 1981 abortion was legalized, offering women in distress the possibility to be treated in officially licensed clinics. A conscience clause warrants the right of healthcare workers to refuse to participate. Meanwhile, artificial procreation had become the issue of the day. Commercial surrogacy remains prohibited; artificial insemination by donor is increasingly available in all kinds of relationships. Follow-up studies have shown that no serious problems have arisen in either the physical or the psychological development of children conceived through in vitro fertilization (IVF) (van Balen).

ORGAN TRANSPLANTATION. The Organ Donation Act (1998) was meant to increase donations, to provide for the just distribution of organs, and to fight commercialization. In fact, it appears that there are fewer donations every year. The main reason for this failure is the opting-in system, where only the individual can decide to donate. But then, only one-third of the adult population returned the request to the Central Organ Donor Registry.

CLINICAL GENETICS. Several commissions have studied issues of genetic counseling, registration, access, screening and testing, as well as therapy. During 1990 the government took a position on various issues. For instance, the government agreed with the intention of the private insurers to exempt applicants from the obligation to disclose data resulting from a previous genetic diagnosis. In the case of life insurance, for example, the exemption applies to a limit of 250,000 florins, meaning that for insurance below that amount the insurer will not ask for genetic information. The insurers have shown readiness to try this policy for five years, and have repeatedly renewed this agreement. They also will not ask for additional genetic investigation. Based on principles of privacy, confidentiality, and solidarity, this position finds broad support among ethicists. Also in the context of clinical genetics, the government asked in early 1993 that the research community end all embryo research of its own volition. Moreover, several governments intended to prohibit by law numerous types of embryo research, such as research on embryos older than fourteen days and the creation of embryos for the sole purpose of research. Although it had been suggested that the use of fertilized eggs as a source of stem cells in therapeutic research be accepted (Evers), the Embryos Act of 2002 prohibits, for a period of at the most five years, the creation of embryos—be it by IVF or by somatic cell nuclear transfer—for the sole purpose of research.

Luxembourg

The smallness of the territory of Luxembourg and the closeness of contacts intensify mutual knowledge and exchange of information. Within medical circles there is a remarkable amount of self-regulation under the guidance of the "collège médical," approved by the Minister of Health. In 1991 this body laid down an official compendium of laws, the "Mèmorial." Doctors and hospitals are still accepted as decision makers in healthcare. Public debate on issues such as euthanasia has rather been scant (Gillen). Having no medical school of its own, Luxembourg sends its medical students to neighboring countries, where they study in Belgian, French, or German universities.

In 1988 the government established the National Consultative Committee on Ethics in the life sciences and health care. As an advisory group it is supposed to study problems in a pluralistic perspective and to suggest solutions. The commission is also expected to develop programs of public information in bioethics. Reports thus far have covered patenting genetically modified organisms, reproductive technologies, youth protection, genetic research, and anonymity.

Ethics committees in hospitals and research centers are being developed in the early twenty-first century.

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IV. UNITED KINGDOM

This entry surveys the development of medical ethics in Britain in the twentieth and early twenty-first centuries and some substantive medical ethical issues arising in these periods. It describes the involvement of important organizations concerned with medical ethics, the development of academic courses in the subject, and the establishment of a largely charitably sponsored independent nongovernmental national bioethics committee and of national forums for teachers and students of bioethics. It suggests that a typically

British antitheoretical, commonsense, and situational approach to medical ethics is gradually modifying so as to include at least some theoretical issues in the teaching and study of medical ethics.

Medical Ethics at the Beginning of the Twentieth Century

Respect for the professions and for the churches—especially, in England, the established Anglican church—were well-entrenched characteristics of British society at the beginning of the twentieth century, and medical ethics conformed to these cultural realities. Thus the normative standards of medical ethics were left almost entirely to the profession itself to establish and maintain. It did so largely in conformity with Hippocratic medical tradition, the ethical norms of the British protestant churches (including prohibition of active euthanasia and of abortion except to save the life of the pregnant woman), and a reliance on selecting "gentlemen" of good and honorable character to join the profession. The Medical Act of 1858 had, at the instigation of the newly established British Medical Association, established the General Medical Council to protect the public by controlling admission to the medical register on the basis of explicit medical educational standards, including ethical standards, both to exclude "quacks" (unqualified practitioners claiming to be doctors) from practicing medicine and to ensure that only those orthodox practitioners who had attained the prescribed standards were admitted to the register of medical practitioners.

Moreover, qualified medical practitioners who fell below the prescribed standards were liable to disciplinary action, including removal from the register (and thus loss of their professional livelihood) if they were found guilty of "infamous conduct in a professional respect." Among the infamous activities that could result in removal were the carrying out of abortion or active euthanasia, and having a sexual relationship with a patient. Other matters of considerable ethical concern to the General Medical Council included abuse of alcohol and drugs, fee splitting, "covering" for medical practice carried out by unregistered persons, convictions in the courts that would bring dishonor on the medical profession, abuse of the financial opportunities afforded by medical practice, improper denigration of professional colleagues, advertising for the doctor's own financial advantage, and canvassing for patients. Thus, at the beginning of the twentieth century, British medical ethics was almost entirely the prerogative of the medical profession and was concerned with protection of patients and of the public health, and with maintenance of its own honor and dignity.

Social Justice and Healthcare: 1911, 1946, and Beyond

If concerns about more equitable distribution of healthcare were not part of the medical profession's medical ethics agenda at the beginning of the twentieth century, they undoubtedly were a concern for the reforming liberal government elected with a large parliamentary majority in 1906. By 1911 David Lloyd George, then chancellor of the exchequer and later prime minister, achieved passage of his National Insurance Act; this provided working people (not their families) with medical and unemployment insurance, which was funded by compulsory contributions from workers, employers, and government (Braithwaite; Fox). The medical profession, though not opposed to the principle of such general provision of healthcare, fought the government on grounds of inadequate fees and inadequate protection for patients' choice of doctor; more than 27,000 doctors threatened to withhold their services. By 1913, however, after compromising with the doctors, Lloyd George had won the day (Lloyd; Lawrence).

The extension of medical care to the general population remained a popular political objective in Britain, and a 1942 report by Sir William Beveridge led, via the 1946 National Health Service Act, to the Labour government's establishment of the National Health Service (NHS) in 1948. This offered preventive as well as curative medical care to every member of the British public; it was provided in response to need, free at the time of that need, and financed by taxes (Bruce; Klein; Webster). While the objectives and provisions of the NHS remain widely accepted, early expectations that widespread healthcare would produce a healthier nation with reduced requirements for healthcare have never been achieved. On the contrary, concerns about increasing, yet inadequate, health expenditure multiplied, especially from the 1970s (Maxwell); a government committee chaired by Sir Douglas Black produced a 1980 report showing vast inequalities of health status in the population correlating with economic and other social disadvantages. Conservative government policy in the 1980s was more concerned to reduce costs than to remedy such discrepancies, but the New Labour governments of the 1990s and early 2000s was explicitly committed to reducing health inequalities and committed considerable additional funding to the National Health Service for this purpose.

Voluntary Euthanasia: 1936 and Beyond

A quite different issue of healthcare ethics—voluntary euthanasia—has been of public concern in Britain for almost as long as the issue of justice in the provision of healthcare. Medical proposals for its legislation had appeared early in the twentieth century; and in 1936, following the creation of the Voluntary Euthanasia Society, the House of Lords debated and rejected a proposal to legalize voluntary euthanasia, which would have provided the legal right to request and be given medical assistance to die when suffering from incurable and fatal illness. Despite the admission by Lord Dawson, an eminent doctor, that euthanasia was carried out by many doctors (Dawson), he and another medical peer, Lord Horder, opposed the bill on the grounds that its proposals involved too many legal formalities and that, in any case, euthanasia was a matter best left to the discretion of doctors. (Many years later state archives were opened and revealed that Lord Dawson had deliberately accelerated the death of the dying King George VI, allegedly in order to enable the quality morning newspapers to report it first rather than risk the death being announced by a less-suitable evening newspaper.)

Euthanasia remains an intermittently burning public issue. Further proposals to legalize it were rejected by the British Parliament in 1969 and 1990; and in 1988 the British Medical Association (BMA) declared that, while allowing patients to die was properly a matter of medical discretion, active killing, even if requested by the patient in circumstances of severe and incurable suffering and disease, was always unacceptable and should remain illegal (BMA, 1988a). In 1992 a British doctor was convicted of attempted murder for administering undiluted potassium chloride to a long-standing patient of his who, in intractable pain, had repeatedly requested him to end her life (Brahams). His sentence of one year's imprisonment, however, was suspended, and the General Medical Council, while admonishing him, permitted him to continue practicing ("Decision on Dr. Cox," 1992). After the verdict a *British Medical Journal* editorial called for a royal commission to study active and passive euthanasia (the editorial's subtitle was "The Tide Seems to Be Running for Euthanasia" [Smith], and a *Lancet* editorial criticized the BMA's "unsympathetic public line" on euthanasia ["Final Autonomy," 1992]).

Nevertheless, the British debate about such cases and about the legalization of euthanasia in the Netherlands (e.g., Keown; Otlowski) did not result in any relaxation of British law. Two cases from 2002 clearly demonstrate the legal situation in the United Kingdom. On the one hand, refusal of life-prolonging treatment was undoubtedly a legal right: The High Court had admonished doctors for ignoring the instructions of a Ms. B. to cease treating her with artificial ventilation; after the doctors complied, she died. On the other hand, neither euthanasia nor assisting suicide was a legal right: On the same day that Ms. B. died, a Mrs. Pretty lost her case before the European Court of Human Rights to be helped to commit suicide (Boyd, 2002; JME, 2002). The distinction between killing and assisting suicide (legally forbidden) and withdrawing life-sustaining treatment at a patient's instruction (legally required) had once again been reaffirmed.

Experimentation on Human Subjects: 1947 and Beyond

Medical ethics in Britain—as in all parts of the civilized world—was given a shocking impetus after World War II by the revelations at the Nuremberg trials of Nazi medical war crimes, and the 1947 Nuremberg Code on Human Experimentation was as readily accepted within Britain as elsewhere (see Doyal and Tobias). In the early 1960s, however, Maurice H. Pappworth, an English physician, claimed that many orthodox medical research investigations were unethical, and in a book first published in 1967 he enraged the British medical establishment by likening examples of British medical research to the research of the notorious Nazi doctors. Whether cause and effect or coincidence, in the same year the Royal College of Physicians (RCP) published a recommendation that all clinical research proposals should be subject to ethical review; this advice was widely circulated by the British government's Department of Health and Social Security. Over the next few years "ethical committees," or research ethics committees (RECs), were established in the majority of hospitals and other institutions conducting medical research.

Nonetheless, development and practice of these committees was recognized to be variable, and in 1984 the RCP published guidelines for RECs, updated in 1990 (RCP, 1990a), as well as reports titled *Research Involving Patients* (1990b) and *Research on Healthy Volunteers* (1986). In 1991 the Department of Health published the first of its own guidelines for RECs. In both sets of guidelines the advice is detailed; it is designed, in the words of the RCP document, "to maintain ethical standards of practice in research, to protect subjects of research from possible harm, to preserve their rights, and to provide reassurance to the public that this is being done. In achieving these objectives ethics committees should remember that research benefits society and that they should take care not to hinder it without good cause. Ethics committees also protect research workers from unjustified criticism." (RCP, 1990a, p. 3). While the RCP guidelines were widely accepted in Britain as the national standard for ethics committees, and while research on human subjects must be submitted to RECs, there was and remains considerable doubt about what proportion of British ethics committees actually implement them (Nicholson; Gilbert, Fulford, and Parker; Neuberger).

In a 1997 government technology assessment review, Richard Ashcroft and colleagues expressed concern about the need to take careful account of the cultural and religious backgrounds of research participants. Revised guidelines on research were issued by the Department of Health in 2001, and new European legislation in the form of a "Clinical Trials Directive" was expected to take effect across the entire European Union in 2004. When this is incorporated into U.K. law, it is likely to include a statutory role for RECs for the first time; human research will thus catch up with animal research, which has been legally regulated in the United Kingdom since 1876.

Abortion: 1938 and Beyond

Another major medico-moral issue of British concern has been abortion. Under the Offences Against the Person Act of 1861, procuring an abortion was a felony punishable by life imprisonment. In 1938 an English obstetrician-gynecologist, Alec Bourne, challenged the law by reporting himself to the police after carrying out a therapeutic abortion on a girl who had been the victim of multiple rape. He was found not guilty on the grounds that the patient's life, in the sense of her mental well-being, was at risk if the pregnancy continued; just as "child destruction" (as the act calls it) to preserve the life of the mother was legally permissible under the Infant Life Preservation Act of 1929, so abortion for the mother's well-being might be lawful (see Mason, McCall Smith, and Laurie). In the 1967 abortion act the law was liberalized to permit abortion in cases in which two doctors certify that the continuation of the pregnancy would be a greater risk to the life or health of the pregnant woman, or her existing children, than a termination; or that termination would prevent grave permanent injury to the physical or mental health of the pregnant woman; or that there is a substantial risk that the child would suffer serious physical or mental disability.

In practice many British doctors, accepting that during the first three months of any pregnancy the risk of continuing to normal birth is greater than the risk of therapeutic abortion, agree to abortion for any woman who after deliberation continues to request it. The upper limit of gestation at which abortion is permitted was reduced by the Human Fertilisation and Embryology Act of 1990 from twenty-eight weeks to twenty-four weeks. No upper limit applies in cases in which the mother's life is seriously threatened and in cases in which the child, if born, would probably be seriously disabled. Significant, though minority, opposition to abortion persists both within the medical profession and among the public. In Northern Ireland, a part of the United Kingdom, opposition to abortion among the Protestant as well as the Roman Catholic population is sufficiently widespread for the Abortion Act not to apply there.

"Official" British medical ethics, as represented in this context by the General Medical Council, the British Medical Association, and the Royal College of Obstetricians and Gynaecologists, accepts abortion when carried out according to the law while recognizing any doctor's or nurse's right of conscientious objection. Such practitioners are expected to inform their patients of their moral objections to abortion, to advise them that they may seek assistance elsewhere, and to give information about sources of such assistance if requested (BMA, 1988b).

Reproductive Technology: 1978 and Beyond

In July 1978 the pioneering work of Patrick Steptoe and Robert Edwards led to the birth of the world's first "test-tube baby"—and to a paradigm shift in bioethical thinking about human reproduction and genetics. From 1982, when the British government appointed a Committee of Inquiry into Human Fertilisation and Embryology (Warnock), until the passing of the Human Fertilisation and Embryology Act in 1990, the British public and the British medical profession were gripped by a vigorous debate about the moral issues associated with in vitro fertilization (Snowden, Mitchell, and Snowden; Council for Science and Society; Bock and O'Connor; Bromham, Dalton, and Jackson). As with abortion, the central moral issue was seen by many to be the moral status of the embryo/fetus, though other issues included possible adverse physical and psychological effects on children conceived artificially and also on the women involved with such techniques, especially in the case of surrogacy. Feminist concerns included the continuing debate about access by single heterosexual women and lesbian women to reproductive technology (Hanscombe and Forster; Chadwick).

The issues were resolved in an extensive government bill that, unusually, offered alternative clauses on the most contentious issue of all: research on, followed by destruction of, the human embryo. Members of Parliament (MPs) were given a free vote (i.e., without any party pressure to vote in one way rather than another) and asked to choose between allowing such research for up to fourteen days of embryo development, as recommended by the Warnock Committee majority report, or forbidding all such research on human embryos except when done therapeutically—that is, to facilitate transfer of the embryo into the uterus of a woman. (The latter is the position of the Roman Catholic church, though it is worth noting that the eminent Jesuit theologian John Mahoney had argued in 1984 that the early embryo is "unlikely to be possessed of a soul and personhood in its existence at the simple cell-multiplication stage prior to diversification" [p. 85]). After cliff-hanging public, professional, and parliamentary debate, the MPs accepted research for up to fourteen days of embryonic development and established the national Human Fertilisation and Embryology Authority to monitor and control all such activities.

Informed Consent: 1985 and Beyond

Of the many other medico-moral issues that have exercised both healthcare professionals and the public in Britain, two legal cases are particularly notable: the Sidaway case on informed consent to treatment and the Gillick case on treatment of minors without parental consent. In the Sidaway case, finally determined by the House of Lords in 1985, the plaintiff complained that her surgeon had been negligent in not warning her of the small risk of spinal nerve root damage, which had occurred. Their lordships decided by a majority to uphold the existing English legal doctrine according to which a doctor is not negligent if acting in a way supported by a body of reasonable medical opinion (the "Bolam test"). Nevertheless, by indicating what reasonable doctors could be expected to do in certain circumstances (for example, answer their patients' questions and warn them of any substantial risks!), the judges brought English law "edging toward" the American "reasonable patient standard" whereby the requirements of a reasonable person in the patient's situation would determine what information was required (Kennedy and Grubb)—though not all legal commentators agreed that even this modest degree of change was achieved in the case (Brazier).

In the Gillick case a mother asked the court to rule that doctors should not be allowed to give medication (birth-control pills) to her children under the age of sixteen without obtaining parental consent. Once again the case went to the House of Lords, which in 1986 rejected Mrs. Gillick's claim; it ruled that a doctor ought to try to persuade the minor to involve the parents in the consultation, but if the patient refused—provided the doctor had good reason to assess the minor as having sufficient maturity and understanding—treatment could be prescribed without involving the parents (Kennedy and Grubb).

In the early 2000s increased emphasis on the need for doctors to obtain informed and explicit consent from patients in relation to use of and retention of tissues after surgery or postmortem became more stringent in response to two NHS scandals. Thus the reports of two inquiries, one into defects in pediatric cardiac surgery at a Bristol hospital (Bristol) and the other into storage of pediatric pathology specimens at a Liverpool hospital (*Royal Liverpool,* 2001), recommended (among a host of improvements) explicit informed-consent procedures for the retention of all tissues and organs (for research or teaching) removed for therapeutic or diagnostic purposes. These recommendation were put forth despite professional concerns that such explicit procedures would often cause unnecessary additional distress to recently bereaved families or to parents whose children were about to have surgery. The general trend in the early 2000s was to explicit and "fully informed" consent for all interventions (see, e.g., Doyal and Tobias), despite professional and philosophical concerns that such moves toward ever-greater "accountability" were excessively undermining trust in medical and other professionals, which though "old-fashioned" was nonetheless ultimately in the public interest (O'Neill 2002a, 2002b).

The Organization of Medical Ethics in Britain

At the beginning of the twentieth century, the final arbiter of medical ethics was the General Medical Council (GMC), a regulatory body largely composed of doctors. In the early twenty-first century, while the GMC's role remained pivotal, it was in the process of becoming a smaller organization with a larger representation of nondoctors and an organization far more open to influence from outside the ranks of the medical profession than ever before. In 2003 the GMC was reduced from 104 members to 35, of whom 19 were elected and 2 appointed by the medical profession, while 14 were nonmedical ("lay") (and thus comprising 40 % of the GMC in contrast to the previous 25 %). The lay members continue to be appointed by the Privy Council (a group of the United Kingdom's "great and good" appointed by the monarch and relatively independent of the government of the day, though many will have been appointed by virtue of their high office in current or previous governments). The GMC, as it notes itself on its web site, is "not here to protect the medical profession—their interests are protected by others. Our job is to protect patients."

The GMC licenses doctors to practice, and it can withdraw or put conditions on a doctor's license if a complaint is upheld. It is responsible for standards of medical education, including education in medical ethics, for quasi-judicial assessment of complaints against doctors, and for provision of advice on ethical standards and professional conduct. This advice used to come in a very slender volume, "the little blue book" (e.g., GMC, 1992), but more recently the GMC has provided a broader range of advisory booklets with more extensive "guidance on good practice," of which the core is covered in *Good Medical Practice* (GMC, 2001). This advice is sent to every registered medical practitioner and is also available to everyone on the GMC web site.

Although it has no official authority in matters of medical ethics, the British Medical Association, which is the doctors' professional association and trade union, provides considerable guidance on these issues to its members, to the government, and to the public. It has a multidisciplinary Medical Ethics Committee and an ever more impressive Medical Ethics Department of permanent staff. It provides individual advice and analysis to its members as requested, provides analysis and advice to government and official bodies, and publishes books relevant to medical ethics (e.g., BMA, 1993, 2001a, 2001b). (The BMA even experimented with what may have been one of the world's first computer programs offering doctors medico-moral advice [Sieghart and Dawson]).

Other professional influences on medical ethics are exerted during medical education by individual teachers, themselves influenced not only by the GMC and (often) the BMA but also by the Medical Research Council (a government run organization that funds and or carries out much of the UK's medical research program) and specialty organizations; the latter include the Royal Colleges of Physicians, Surgeons, Obstetricians and Gynaecologists, General Practitioners, Psychiatrists, and so on, all of which offer advice and guidance on medical ethics relevant to their specialties. So, too, do the medical malpractice organizations, such as the Medical Defence Union and the Medical Protection Society. In addition the employment contracts of most doctors in Britain exert some legally binding ethical pressure on their behavior. For example, general practitioners, though they are independent contractors, are required by their contracts with the NHS to provide emergency care in their vicinity whether or not those needing such care are registered with them; and they are also required by their contracts to accept "difficult to place patients" for a minimum of three months, when required by the NHS to do so. And surgeons in NHS hospitals, according to their contract of service, must, under normal circumstances, obtain written consent from their patients prior to operating. In addition there is a strong tradition in British medicine of consultation, especially with more experienced colleagues, about any difficult medical problem, including difficult medico-moral problems. A noteworthy if embryonic development at the end of the twentieth century was the creation of clinical ethics committees at some hospitals, set up to provide analysis and advice about particular ethical problems arising in clinical practice (not in research), to advise on ethical aspects of hospital policy matters, and to have at least some educational function (see, e.g., "Clinical Ethics Committees Supplement," 2001).

Nonmedical influences on British medical ethics include the range of forces typical of a modern Western democracy. The most important is undoubtedly the law, which, as noted above, has a major role in defining the arenas within which the medical profession may make its own choices about medico-moral issues. Nurses have undergone a metamorphosis from doctors' handmaidens to independent health professionals and have become increasingly influential in British healthcare ethics, especially through the activities and pronouncements of their disciplinary body, the (United Kingdom) Nursing and Midwifery Council or NMC (e.g., NMC), and of their professional association and trade union, the Royal College of Nursing or RCN (e.g., RCN 1991, 2001).

Many public pressure groups, patient groups, and special medical interest groups exist to try to influence the profession, the media, Parliament, and the public on such matters as healthcare ethics issues. Important examples include the Patients Association, the College of Health, the Consumers Association, MIND (which promotes the interests of the mentally ill), MENCAP (which promotes the interests of the mentally disabled or impaired), CERES (Consumers for Ethics in Research), GeneWatch (which is concerned with the ethics and risks of genetic engineering), and the local community-health councils and their successor organizations, the Patient Advocacy and Liaison Services (PALS), which protect patients' interests. Also important are several "right-to-life" activist groups such as the Pro-Life Alliance, LIFE, and The Society for the Protection of the Unborn Child, and "on the other side," the Voluntary Euthanasia Society and the Abortion Law Reform Association. And the media constantly, often daily, publish and broadcast on medical ethics issues.

From a plethora of possible examples, one media event is particularly worth noting: the prestigious BBC Radio Reith Lectures, given in 1980 by Ian Kennedy, then a lecturer in academic law (later to become a professor of medical law and ethics and a knight of the realm). Published in 1981 under the profession-provoking title *The Unmasking of Medicine,* the lectures brought into the arena of intelligent public discussion many of the standard themes of medical ethics, and argued forcefully that while doctors had special training and expertise in technical medical matters, they had no such training and expertise in moral matters. Even if they had had such training (which Kennedy advocated), they had no right to assume that moral decisions in medical practice were solely for doctors to make, in the way that technical decisions in medical practice might be. The resulting public and professional debate did much to achieve Kennedy's objective of bringing medical ethics "out of the hushed halls of Academe into the noisy market place of ideas" (Kennedy, 1981, p. xi).

The study and development of medical ethics in Britain has also been promoted by the Institute of Medical Ethics (IME). Originally named the Society for the Study of Medical Ethics, it was founded in the early 1960s by a Church of England priest, the Rev. (later Dean) Edward Shotter, who at the time had pastoral responsibility for medical students in London. Shotter soon recruited two other Protestant clerics, both from Scotland, who were to become influential in British medical ethics: Kenneth Boyd (Boyd, 1979, 1992; Boyd, Callaghan, and Shotter; Smith and Boyd; Gallagher and Boyd) and Alastair Campbell, founding editor of the IME's *Journal of Medical Ethics* from 1975 to 1980 and one of the earliest British contributors to the academic medical ethics literature (Campbell, 1972, 1978, 1984; Campbell and Higgs) and a Jesuit and psychologist Brendan Callaghan. Also recruited by Shotter was a secular Jewish doctor-philosopher, Raanan Gillon, who served as editor of the *Journal of Medical Ethics* from 1981 to 2001. Among the IME's activities have been the establishment of multidisciplinary ethics study groups within most of the British medical schools, various research projects, and the founding of two publications, the aforementioned *Journal of Medical Ethics* (1975) (by the end of the century the most highly cited journal in its field) and the *Bulletin of Medical Ethics* (1985; shortly afterward, the latter became independent of the IME, and it continues to be edited by its owner-editor, another Shotter medical recruit, Richard Nicholson).

Other organizations stimulating the early development of healthcare ethics in the United Kingdom were the medical ethics and or medical law centers at some of the universities. Pioneer centers in Britain included those at King's College, London; the University of Wales at Swansea; the University of Manchester; and the Universities of Birmingham, Hull, Oxford, St. Andrews, Leeds, and Warwick; the University of Wales at Cardiff; and the Universities of Glasgow and Bristol. Since the 1990s there has been considerable further expansion in the number of universities providing healthcare ethics, or law and ethics, teaching and research in the United Kingdom, and these have been joined by a few centers offering courses in medical humanities. In addition, the Society for Applied Philosophy is concerned with philosophical illumination of "areas of practical concern" that often include issues of healthcare ethics; it publishes the *Journal of Applied Philosophy.*

Of the various academic disciplines with an interest in medical ethics that has stimulated its development, and apart from law and theology as already mentioned, health economics has been particularly important in relation to resource allocation. Alan J. Williams (1985, 1996), Alan Maynard (1986; Maynard and Bloor), and Anthony J. Culyer (1992, 2001), from the Centre of Health Economics at York University, and Gavin Mooney and Alistair McGuire (1988) have been especially influential, particularly Williams, with his advocacy of the maximization of quality-adjusted life years (QALYS) as the centrally relevant criterion for health-service resource allocation.

Academic Courses, Degrees, and Chairs

The first British academic course in medical ethics seems to have been started by the ancient City of London guild, the Worshipful Society of Apothecaries (still a medical licensing body), when it instituted a diploma course in the philosophy of medicine in 1978, first taught by the Oxford philosopher Michael Lockwood. An annual one-week "intensive course in medical ethics for medical and nursing teachers" was started in 1983 at Imperial College, London, in cooperation with the IME, and in 1984 the Centre of Medical Law and Ethics at King's College, London, initiated a one-year postgraduate diploma in medical law and ethics, upgraded in 1987 to a master's degree. In 1985 the University of Wales introduced a highly popular part-time M.A. in healthcare ethics, and in 1987 the University of Manchester offered a multidisciplinary M.A. in healthcare ethics, administered by its Centre for Social Ethics and Policy. Since then various other British universities and colleges have developed a wide variety of courses in healthcare ethics.

British medical schools were slow to introduce the formal study of medical ethics; the Scots led the way at Edinburgh University and Glasgow University, with King's College Hospital in London being the vanguard in England under the leadership of the doctor-ethicist Roger Higgs. Full-time philosophers were appointed to teach the subject at medical schools at Liverpool and at the London Hospital; and St. Mary's Hospital Medical School London was the first to appoint a (part-time visiting) professor of medical ethics. Birmingham University Medical School appointed a veterinarian, David Morton, to the joint chair of biomedical science and ethics.

Although medical schools were stimulated into some activity by the report of an IME working group (Boyd, 1987) urging that they introduce the critical study of medical ethics, such teaching became widespread only after the GMC told medical schools that medical ethics and law should be part of the core medical curriculum and therefore compulsory for all medical students (GMC, 1993). In 1998 most of the teachers of medical ethics in U.K. medical schools, and others, published a consensus statement on the contents of a core curriculum in medical ethics and law in medical schools (Teachers of Medical Ethics).

By the early 2000s, however, although there were several professors of medical ethics holding personal chairs, and while many medical schools had at least one full-time teacher of medical ethics, the only established chair of medical ethics in a U.K. medical school had been established in 1996 at the University of Bristol Medical School, with Alastair Campbell holding the position until his retirement in 2003. While female let alone feminist influences cannot be said to characterise British medical schools, influential exceptions in the realm of medical ethics included Ruth Chadwick, Jenifer Jackson, Janet Radcliffe Richards, Donna Dickenson, Bobbie Farsides, Heather Draper, and Ann Sommerville, along with leading medical law and ethics specialists Margaret Brazier and Sheila Mclean.

Three National Groups Formed in the 1990s

At the beginning of the 1990s three national groups concerned with medical ethics were established. The first, the U.K. Forum for Health Care Ethics and Law, was designed to bring together the increasingly numerous and various academic and other organizations, teachers, and students in Britain concerned with healthcare ethics. The second was the Nuffield Council on Bioethics, a national independent and nongovernmental multidisciplinary committee established by the private philanthropic Nuffield Foundation, to review the ethical issues raised by medical research, starting with those involving genetic manipulation, The third was the Association for Healthcare and Medical Ethics Teachers, founded for medical ethics teachers in British medical and nursing schools.

The Nuffield Council on Bioethics has flourished, becoming as near to a national committee on bioethics as the United Kingdom seems likely to have. While it remains self-appointed and unofficial this enables it to be independent of government, and its funding seems secure now that the government's Medical Research Council and the Wellcome Trust have joined the Nuffield Foundation in supporting it. Helping to account for the high respect with which it is held are its independence and multidisciplinarity, as well as the high caliber of its reports and discussion documents, on subjects including ethical aspects of genetic screening, xenotransplantation, stem cell therapy, health research in developing countries, the patenting of DNA, genetics, and human behavior (all available through the organization's web site). Also likely to be relevant to the development of medical ethics in the UK is the creation in 2002 of the Association for Medical Humanities.

Continental Influences

Three continental European influences on the British approach to medical ethics are also important to note. The Council of Europe has an international bioethics committee and has produced a Convention on Human Rights and Biomedicine, which is legally binding on signatory states (Council of Europe) and is in effect an extension of its European Convention on Human Rights. A protocol to the convention banning human reproductive cloning is in effect, and protocols on organ transplantation, medical research, and the embryo and genetics are being developed. The United Kingdom has not signed on to the convention, in part because it forbids a form of scientific research that is accepted in the United Kingdom: the production of human embryos for the purpose of research.

The European Union also has an international bioethics committee, but more importantly for U.K. bioethics it has distributed significant funding for bioethics research projects if these involve cooperation between member nations. This has resulted in several U.K.–led projects involving such areas as education in bioethics, ethical aspects of HIV/AIDS, stem cell research, virtue ethics and chronic illness, and neonatal research. The United Nations Educational, Scientific and Cultural Organization (UNESCO) also has an international bioethics committee and has produced a (nonbinding) Universal Declaration on the Human Genome and Human Rights, which was adopted by the United Nations. Academic bioethics in the United Kingdom is also influenced from continental Europe through participation in the European Association of Centres of Medical Ethics and the European Society for Philosophy of Medicine and Health Care.

Religious Influences on Medical Ethics

Religious organizations are influential in medical ethics in Britain, both at a personal level, affecting the decisions of patients, healthcare workers, and others concerning medico-moral issues, and as a result of institutional activities. Relevant institutions include the Church of England Board for Social Responsibility (see, e.g., Dunstan, 1987; Dunstan and Seller); the (Roman) Catholic Bishops' Joint Committee on Bioethical Issues (see, e.g., Catholic Bishops' Joint Committee); the (Roman Catholic) Linacre Centre (see, e.g., Linacre Centre); the (evangelical Protestant) Christian Medical Fellowship (which holds regular meetings and publishes the *Journal of the Christian Medical Fellowship*); and the Jewish Chief Rabbinate (one of whose members, Lord Immanuel Jakobovits, obtained the first doctorate devoted to Jewish medical ethics; see Jakobovits).

The National "Flavor" of Medical Ethics in Britain

While it is always risky to generalize, a pragmatic, situationist, commonsense, antitheoretical, and antiregulatory approach tends to characterize the British approach to medical ethics (as to do many other aspects of British life—though resistance to regulation may be being increasingly overridden). Despite this national reluctance to theorize, however, it is gradually being acknowledged that some theoretical underpinning is needed even for commonsense ethical decisions. In the context of medical ethics, a distinction is increasingly recognized between two medical ethical concepts ("Two Concepts," 1985). The first is traditional medical ethics, in the sense of promulgating and enforcing within the medical profession certain medico-moral norms—what Gordon R. Dunstan called "the obligations of a moral nature which govern the practice of medicine" (1981, pp. xxviii–xxxi). This sort of medical ethics has characterized medical education and practice since Hippocratic times. The second, more recent sort—philosophical or critical medical ethics—sets out to examine rigorously, and in the light of argument, justification, and counterargument, the issues of medical ethics, including the claims of traditional medical ethics.

Prompted from without as well as from within, the British medical profession has, since the mid-1970s, increasingly accepted the latter medical ethical concept as a proper part of medical thinking and education. Evidence for this includes the General Medical Council's greatly increased interest in medical ethics since it held a conference on medical ethics teaching in 1984; publication by the *British Medical Journal* in 1985–1986 of a series of twenty-six articles under the title "Philosophical Medical Ethics" (Gillon, 1985–1986); publication of *The Pond Report* on medical ethics teaching (Boyd, 1987), recommending such teaching in medical schools; the GMC's requirement that medical ethics and law should be part of the core medical curriculum (GMC, 1993); publication of the consensus proposals for the core curriculum (Teachers of Medical Ethics); the increasing teaching of critical or philosophical medical ethics in medical schools; and the increased attention paid to critical medical ethics by the British Medical Association.

But virtually all involved in the British medical ethics scene agree on one issue: the central importance of real cases, manifesting real medico-moral problems, in their real human context, for any adequate critical study, teaching, or understanding of the "humanized version of ethics" called for by the moral philosopher Jonathan Glover (1999).

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V. REPUBLIC OF IRELAND

"Ireland" here refers to that part of the island of Ireland (twenty-six of the thirty-two counties) that achieved independence from British rule in 1921 and was declared a republic in 1949.

Ireland's moral traditions and its history in ethics are inextricably linked with centuries of religious history that are primarily rooted in the nineteenth-century Roman Catholic Church. After experiencing religious persecution under British rule, the government of the new Irish State reinforced the traditional religious ethos in its laws and institutions, particularly education and healthcare. The Irish Constitution of 1937 recognized the "special position" of the Holy Roman church as guardian of the faith of the great majority of Irish people. This constitutional recognition was deleted in 1972 when Ireland was preparing for membership in the European Economic Community; the deletion signaled recognition for a religiously pluralist state.

In what follows, bioethics in the Republic of Ireland is discussed in two time periods: 1922–1982 and 1983–forward. The period division marks a development of appeals to legal resolution to negotiate ethical diversity. Four areas of national development frame the discussion: reproductive ethics, research and ethics committees, obligations to prolong life, and establishment of the Irish Council for Bioethics.

Between 1922 and the early 1980s, a religious homogeneity of tradition and practice largely prevailed. While cultural changes are never abrupt, a change in Irish political and social conditions was initiated on January 1, 1973, when Ireland became a member of the European Economic Community (now known as the European Union). Ireland increasingly interacted with other countries whose philosophies of life were based on secular viewpoints. Moral questioning in the society, in politics, education, and healthcare practice became more sustained, open and tolerated.

Reproductive Ethics

In the early 1970s, women's groups actively protested a prevailing legal ban on contraceptives and the complete ban on elective abortion even in cases where women were victims of rape or incest. Women who could afford private healthcare could get contraceptives and abortion advice. Women who sought prenatal genetic testing generally could not be accommodated within the hospitals of the Republic of Ireland. The concern was that some test results might contribute to pro-abortion decisions. But private patients were often accommodated by referral outside the country. The justice of a two-tier health system came under moral and political scrutiny. A private citizen, Mrs. McGee, challenged the Irish government's long-standing prohibition of the sale and importation of contraceptives. Her efforts led to the Health (Family Planning) Act of 1979, in which the Irish state allowed restricted access to contraceptives. Outsiders may be incredulous at Ireland's preoccupation with reproductive ethics. However, this area of morality is central in Irish traditional religious teachings, which have consistently reaffirmed the primacy of women's procreative capacity and fetal life.

Until the 1980s, the topic of abortion was largely a closed moral and legal issue. Ireland had never rescinded the complete ban on abortion specified under the British Offences Against the Person Act of 1861. In practice, termination was permitted under the principle of double effect in exceptional cases, such as ectopic pregnancy. Yet Irish women did (and do) procure abortions. On average, six thousand Irish women a year go to England to have abortions under the provisions of the 1969 British abortion legislation. Irish women gradually became more politicized and organized public demonstrations, claiming their rights to control fertility. Serious polarization of views developed as other groups in society feared that elective abortion might be legalized in Ireland. A national campaign began to guarantee protection of embryonic life by means of constitutional amendment.

In 1983, the eighth amendment to the Irish Constitution gave "the unborn" the same rights to life as other citizens. Since then, this amendment has generated a complex series of political, legal, and moral challenges, leading to a Supreme Court judgment of 1992, *Attorney General v. X and Others,* which argues that abortions may lawfully be carried out in Ireland where continuance of the pregnancy constitutes a real and substantial risk to the life of the pregnant woman. A threat of suicide was specified as such a risk. Following the Supreme Court Judgment of 1992, it remains for the Irish government to provide legislation to specify the conditions under which it is lawful to have abortions in Ireland.

Moral concerns to protect fetal life also influenced the development of guidelines for in vitro fertilization (IVF) issued by the Institute of Obstetricians and Gynecologists. The guidelines specified that IVF should be offered to married couples who have been appropriately counseled and have given informed consent. Only sperm and ova from the consenting couple may be used, and all resulting fertilized ova should be placed in the potential mother's uterus. However, with the Government's establishment of a Commission on Assisted Human Reproduction in 2000, existing IVF guidelines and policies on all forms of assisted procreation began being researched and ethically assessed. Submissions from the public, service providers, and consumers were invited. The Commission consists of four working groups studying topics from the status of the embryo to gamete donation, anonymity or disclosure, access to assisted reproduction, and embryo research. The working groups draw on the expertise of fertility experts, lawyers, ethicists, geneticists, social theorists, and theologians. The debates on the Commission are evidence of the growing diversity of ethical and legal views on reproductive matters. The Commission's report is expected to form the basis for legal decisions on the status of the pre-implanted embryo, and implementation of policy recommendations or regulatory mechanisms for all forms of assisted reproduction and embryo research.

Research and Ethics Committees

For years, medical research and clinical trials in Ireland were assessed by Institutional Review Boards whose composition and procedures lacked any nationally agreed-upon guidelines. The ethical norms from the Declaration of Helsinki were applied. The death of a male participant in a nontherapeutic drug trial in Ireland resulted in the government's issuing of the Control of Clinical Trials and Drugs Act 1990. The principal features of this legislation are that, with certain exceptions, the minister for health must authorize all proposed clinical medical trials and members of the ethics committees examining protocols must be approved by the minister. Ethics committees have the responsibility for ensuring that participants in any trial give their informed consent personally or by proxy. The latter provisions allow for clinical trials with psychiatric patients who might not be considered competent to consent. To avoid a conflict of interest, investigators involved in any clinical trial are not allowed to give proxy consent.

Ethics committees in Irish public hospitals traditionally were given the job of adjudicating requests from doctors for female sterilizations. Women's groups and gynecologists are now rejecting this role for ethics committees, and criticize what is judged to be unwarranted religious influence on decisions of ethics committees in public hospitals. While doctors are increasingly trying to minimize intrusions into the privacy of the doctor–patient relationship, ethics committees are still established throughout the state for educational purposes and for consultation by patients, families, and healthcare practitioners.

Irish patients are now requiring more communication about diagnoses and prognoses, and also expect increased participation in medical decision making. The value of respect for patients and the importance of securing consent is a corollary of expectations for a role in decision making. In efforts to reinforce the values of respect for personal autonomy and informed consent, in 2001 the Irish government set up an inquiry into policies and practices surrounding post-mortems in the state since 1970, particularly with regard to the removal and retention of organs by hospitals. The stimulus for the inquiry came from parents of children who had died in hospital and whose organs had been removed and retained by hospitals for research without the consent of parents. The public, parents, hospital management, and scientific institutions recognize that the value of trust can be readily undermined if ethical guidelines are not in place to reassure relatives that consent will be sought for post-mortem tissue or organ procurement. While parents do not dispute the need for research, they argue that the issue is the informed consent of relatives and accountability of institutions in receipt of public money.

Since the 1980s, doctors in Ireland have experienced increasing lawsuits for alleged malpractice or negligence. Further analysis is required to determine the multiple causes for such an increase, but the Medical Defence Union, an indemnity insurer for doctors, continues to urge doctors to reflect on the quality of their relationships with patients and to work to improve levels of communication. The previously dominant model of strong paternalism characterizing the doctor–patient relationship and more general practices of healthcare institutions are under challenge due to changing educational experiences of doctors and nurses and a more questioning Irish population. Courses in ethics are taught in Irish medical schools, where almost 30 percent of students are now non-Irish. In their required university work, nurses are encouraged to reflect on reasons for their moral views and to consider the possible validity of diverse ethical positions. Religious orthodoxy is no longer taken for granted. Such courses are usually required of medical students and nurses, and vary in length from several weeks to a full year.

Obligations to Sustain Human Life

Public debate about moral obligations to prolong human life came to the fore in 1995. The family of a woman who was in a persistent vegetative state (PVS) for over twenty years appealed to the Irish courts to have a gastrostomy tube removed and to allow her to die naturally. The patient was made a ward of court because the healthcare institution responsible for her care had, many years earlier, differed ethically with the family concerning what life support measures were morally justified. In 1995, in *Re a Ward of Court,* the High Court and, on appeal, the Supreme Court judged that in the best interests of the woman, it would be legal to remove the feeding tube. Following the Supreme Court judgment, the Irish Medical Council and the Nursing Board issued statements for members, in effect disagreeing with the ethical basis of the Supreme Court decision and claiming that access to nutrition and hydration is one of the basic needs of human beings. The *Re a Ward of Court* case raised difficult questions about active and passive euthanasia, withholding and withdrawing life support systems. Who should be involved in life and death decisions is a concern with arguments to the effect that decisions about withholding life-support systems for the terminally ill are areas of medical decision making where patients and family members ought to have more voice. In trying to determine moral boundaries in the prolongation of life, the Roman Catholic tradition distinguishing obligatory and nonobligatory treatment (ordinary and extraordinary) may be justly recognized as a well-argued basis for granting patients considerable voice in their treatment decisions.

The Irish Council for Bioethics

In 2002, concerns about ethical questions in modern biotechnology and genetic engineering prompted the Irish government to establish the first Irish Council for Bioethics. Members are invited by virtue of their personal expertise and not as representatives of particular bodies or professions. The members range in specialty areas from genetics, molecular biology, nursing, fertility, theology, law, and ethics. The Council operates under the aegis of the Royal Irish Academy but is an independent body. The aims of the Council are to identify and interpret ethical questions raised by biological and medical research and to examine and report on a range of questions with a view to promoting public discussion and understanding. Where appropriate, the work will contribute to the formulation of new guidelines in areas such as genetically modified products, stem cell research, biological samples, Ethics Community and human genetic research.

As Ireland continues to be more actively integrated into the European Union, ethical pluralism is being acknowledged as a reality requiring open debate. The hope is that such efforts at public discussion will yield a stronger, because more consensual, public morality that will signal respect for the now undeniable differences of ethical viewpoints among Irish people. In the years ahead, the work currently under way should yield policy developments in assisted reproduction, research protocols, biotechnology, and debates about advance directives and obligations to prolong human life.

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VI. GERMAN-SPEAKING COUNTRIES AND SWITZERLAND

Interest in bioethics in the German-speaking countries (Germany, Austria, and Switzerland) originated, as it did elsewhere, with medical-ethics questions related to both modern biotechnological potential and a growing ethical pluralism. These factors not only induced physicians to debate these issues, they were part of the reason for a "rehabilitation of practical philosophy" among a number of German academic philosophers and theologians that included a renewed interest in moral, social, and political problems.

In several respects, bioethics in Germany, Switzerland, and Austria differs from that in the United States or other European countries. First, as a major, collective, and socially visible effort, it developed relatively late—in the 1980s. Some explanations for this are the lack of civil rights movements that would have endorsed issues of patients' rights; a widespread and deeply rooted medical paternalism; good, uniform access to medical care (and thus little need for allocation debates); a different philosophical tradition; and, in Germany, a severely disturbed moral self-assurance due to the relatively recent experiences of Nazi Germany's indescribable immoralities.

Second, there are many theological voices in German bioethics. In the German world, theology is given a legitimate academic presence within universities, where it enjoys the same juridical status as all other disciplines. It also possesses relative independence from religious institutions. Third, German law is solely statutory in nature and is not linked to case law, as it is in the American judicial system. Hence, going to court is a far less common way to trigger public discussion on difficult bioethics cases. In Switzerland, plebiscites (direct voting by the population on an issue) are an instrument of legislative decision making. In addition, legal authority resides partly with the Bund (federation) and partly with the 26 different cantons (states), which show remarkable legal differences in handling some bioethics problems.

Fourth, Germans place great importance on the study of the history of medicine and medical anthropology, the philosophical clarification of fundamental medical categories. Fifth, Germany labors under the historical weight of the Nazi regime's deadly medical experimentation, eugenics, and euthanasia—and of the concomitant moral degradation of many physicians. Thus, public mistrust of bioethics "experts" seems to be comparatively deep and widespread.

Not only does the Nazi specter affect the discussion of bioethics in Germany, but it is seen by many to have a direct connection to a number of issues discussed in contemporary bioethics. Concern is heightened by the fact that Nazi experimentation occurred despite the existence of guidelines for therapeutic and scientific research on human subjects that prohibited such treatment. These guidelines, thought to be the first of their kind, were originally published as a Circular of the Reich Minister of the Interior on February 28, 1931, and remained in force until 1945 (Sass, 1993). Several groups and movements have taken the position that preimplantation diagnosis, selective abortion, euthanasia, and gene therapy are not only immoral, but represent a continuation of Nazi ideology.

Philosophical Bioethics in Germany

The philosophical clarification of medicine's role, and of its fundamental categories (e.g., pathology, illness, healing) in Germany still has an influential intramedical tradition as medical anthropology (Weizsäcker). German medicine has long cultivated historical study, and the many institutes devoted to medical history increasingly view part of their work as preparatory to or incorporating moral reflection on medicine. Whereas medical ethics has traditionally focused primarily on aspects of the physician–patient relationship (e.g., truth-telling, confidentiality, humaneness), its spectrum has long since been broadened to cover all issues addressed by Anglo-American "bioethics." The latter, however, is opposed by many—be it merely as a label, as the writing of those who call themselves bioethicists, or as a discipline in general. Thus (in contrast to medical ethics), "bioethics" has frequently been understood as an ideological and uncritical defense of biotechnological progress or profit—or at least with a suspected (i.e., "analytical") style of philosophy.

German philosophers have thus been late to join the contemporary Anglo-American debate on any issue in applied ethics. Analytical philosophers had to leave the country under the Nazi regime—and continental philosophers of the period were rarely attracted by either utilitarianism or pragmatism, which are among the dominant theories in contemporary Anglo-Saxon ethics debates. Immanuel Kant (1724–1804), with his rejection of material ethical values and his predominant interest in a metaphysico-rational justification of ethics, has certainly been the major influence for those opposed to these theories.

At the beginning of the twenty-first century, this gap seems to have closed. Meanwhile, quite a number of philosophers consider bioethics a serious aspect of their own academic work. In 2003 the German book market still lacked a basic comprehensive textbook covering both in-depth theory and the whole spectrum of ethical problems in healthcare, which are covered by a number of influential Anglo-American examples. However, introductory anthologies (e.g., Wiesing; Düwell and Steigleder) and shorter monographs (e.g., Höffe; Schramme) have enriched the debate and provided educational material. Comparable to the Anglo-American context, bioethics has—not undisputedly—also become part of many public discussions and debates, with philosophers increasingly serving on ethics committees and presenting their views in newspapers and on talk shows. Simultaneously, this "expertise" (and its limits and dangers) has itself become subject of critical methodological reflection (Gesang; Ach and Runtenberg), again paralleling developments elswhere.

Institutions and Teaching

Paralleling the belated onset of bioethical debates in German-speaking countries, the development of institutions focused on the study of bioethics has also been comparatively slow. However, a number of chairs, institutes, and centers devoted to this field have been established, most of them university based. Many of them offer optional courses, but forthcoming revisons of federal regulations require medical ethics to be part of the medical curriculum. They are also involved, to various degrees, in consultation and research, with some publishing their own series on specific issues in bioethics and some drawing fellows and postgraduate students from different disciplines into collaboration and common discourse on ethical aspects of medicine, science, and the law. Since the 1980s, a pioneering role can be attributed to the *Institut für Geschichte der Medizin* (Institute for History of Medicine) at the University of Freiburg in Breisgau—now part of the *Zentrum für Ethik und Recht in der Medizin* (Center for Ethics and Law in Medicine); the *Zentrum für Ethik in den Wissenschaften* (Center for Ethics in the Sciences and Humanities) at the University of Tübingen; and the university-based *Zentrum für Medizinische Ethik Bochum* (Bochum Institute for Medical Ethics). Since the 1980s the *Forschungsinstitut für Philosophie* (Research Institute for Philosophy) in Hannover, founded with financing from—and under the auspices of—the Roman Catholic Church, has focused on issues at the intersection of religion and philosophy in the Catholic tradition of philosophical thought, offering a broad spectrum of activities in ethical research and education.

Among the more or less recently founded or reorganized bioethics institutions are the *Institut für Wissenschaft und Ethik* at the University of Bonn, the *Interdisziplinäres Zentrum für Ethik* at the University of Frankfurt/Oder; the *Ethikzentrum* at the University of Jena; the independent *Institut Mensch, Ethik und Wissenschaft* in Berlin (founded by various institutions that advocate for the rights of the disabled); and the *Institute für Ethik, Geschichte (und Theorie) der Medizin* at the Universities of Erlangen, Münster, and Göttingen. The institute in Göttingen is, moreover, linked to office of the interdisciplinary *Akademie für Ethik in der Medizin* (see below) as well as to the Information and Documentation Center for Medical Ethics (IDEM), which is part of Euroethics, a European database, and provides a database for German literature in the field. The institute in Bonn is in charge of the German Reference Center for Bioethics Literature (DRZE), which is a repository for both national and international literature.

In Switzerland, several institutes are active in the study and teaching of bioethics: most notably the *Institut für Sozialethik* and the *Arbeits- und Forschungsstelle für Ethik* (founded in 1989), both at the University of Zurich; the *Interdisziplinäres Institut für Ethik und Menschenrechte* at the University of Fribourg; the *Centre Lémanique d' Ethique* in Lausanne/GENF; as well as the *Institut für Angewandte*

Ethik und Medizinethik (IAEME; founded in 2000) and the unit of ethics in biosciences both at the University of Basel.

In Austria, the university-based centers in the field are the *Dokumentationsstelle für Ethik* in Vienna; the *Institut für Medizinische, Anthropologie, und Bioethik,* also in Vienna; and the *Koordinationsstelle für Grund- und Grenzfragen der Medizin* in Salzburg, In addition, the *Wissenschaftliche Landesakademie für Niederösterreich* (Scientific State's Academy for Lower Austria) has established an institute for the research, teaching, and study of bioethics. But, as in Germany and Switzerland, bioethics has become an expanding discipline, and is by no means restricted to established centers, but pursued by a growing number of academics in various disciplines and settings.

The first German-language journal for medical ethics, *Arzt und Christ* (*Physician and Christian*), was founded in Austria in 1955. Since 1993 the journal has been called *Zeitschrift für medizinische Ethik* (*Journal of Medical Ethics*) and is published in Bonn, Germany.

Professional and Government-Appointed Bodies

Common to all German-speaking countries is the existence of a governing body regulating the contact of healthcare professionals and possibly administering sanctions against those who disobey to their rules. Characteristically, these institutions focus on determining professional ethics and they have widely recognized authority in judging new medical practices.

In Switzerland, the *Schweizerische Akademie der medizinischen Wissenschaften* (Swiss Academy of Medical Sciences) is a foundation comprised of all Swiss medical schools and physicians' associations. Its Central Ethics Commission prepares guidelines on specific issues of medical or research practice that are considered ethically problematic, such as policies for new reproductive technologies for withdrawing life-supporting treatment. In addition, the fourteen-member commission serves as a permanent ethics counseling body for physicians and the public.

Similarly, in Germany, the Federal Chamber of Physicians (*Bundesärtzekammer,* membership in which is obligatory for German physicians) has established an Ethics Advisory Board to its Scientific Council to issue ethics guidelines for intraprofessional self-regulation and to serve as a counseling body. In areas of conduct that lack legal regulation, this type of binding professional self-legislation functions somewhat as a legal substitute for such regulations. Other important bodies are known as *Gesellschaften* or *Akademien* (societies of experts). They aim at promoting scientific debates and research among their members and the public. The body for medical ethics in Germany is the *Akademie für Ethik in der Medizin* (Academy for Medical Ethics). Founded in 1986, it has in 2003 an interdisciplinary membership of approximately 450 members, most of whom are German. The *Akademie* receives a mix of public and private funding and provides a forum for research (working groups on specific topics), for expert and public debate, and for teaching medical ethics. Since 1989 it has published the second German language journal on medical ethics, *Ethik in der Medizin,* and in 1993 it established the first German bioethics literature database, IDEM. Another professional body (of both law and medicine) worth mentioning is the *Deutsche Gesellschaft für Medizinrecht* (German Society for Medical Law), which formulated recommendations on the treatment of severely disabled newborns (the Einbecker Recommendations). In Switzerland, the most important professional body is the *Schweizerische Gesellschaft für biomedizinische Ethik* (Swiss Society for Biomedical Ethics).

Finally, governments or parliaments in these countries have increasingly appointed working groups or expert commissions to issue advisory reports on a variety of bioethical and legal issues. The first to be published in Germany (by the *Bundesminister für Forschung und Technologie*) was the 1985 report of the Benda Commission on assisted fertilization, genome analysis, and gene therapy. In Switzerland, the *Expertenkommission Humangenetik und Reproduktionsmedizin* issued the Amstad Report, dealing with the same subjects, in 1988. These initial efforts were followed by number of similar working groups and expert commissions dealing with a variety of topics. They contributed to the increasing gain in public attention to problems in bioethic, although the ethical analyses contained in their reports are certainly less in-depth, and also less balanced, than, for example, the reports of the various President's Commissions in the United States. Participants with a background in philosophy served on these bodies only in rare instances.

The three German-speaking countries created national ethics councils later then almost any other European country. In 2001 each of them established such a body: in Germany the *Nationale Ethikrat* was established (in fruitful competition with the nonpermanent Commission for Law and Ethics of modern medicine); in Switzerland, which already had a national ethics commission for questions of nonhuman genetic technology, the Bundesrat appointed a *Nationale Ethikkommission im Bereich der Humanmedizin* (Swiss National Advisory Commission on Bioethical Ethics); and in Austria, the 18-member *Bioethik-Kommission* was established at the Federal Chancellery. All three bodies exercise an independent advisory function and are supposed to stimulate public debates in matters of bioethics.

They have already come up with a couple of published recommendations.

Ethics Committees for Human Experimentation

Local *Ethikkommissionen* (ethics committees), functioning almost exclusively as review boards for medical experiments on human subjects, exist in Austria, Germany, and Switzerland. Only in very few hospitals, committees have also been established to consider different ethics questions such as treatment decisions for individual patients or the development of institutional ethics guidelines. As in other Western countries, the institutionalization of review boards for medical research on humans occurred in response to the Nuremberg Trials of Nazi physicians, in accord with the 1964 Declaration of Helsinki and its subsequent revisions.

In Switzerland, the pioneering 1970 guidelines on research involving human subjects (revised in 1989 and 1997) issued by the Swiss Academy of Medical Sciences (*Schweizerische Akademie der Wissenschaften,* or SAMW) required the establishment of ethics committees at hospitals and research institutes to make certain that proposed projects were important, well designed, and of acceptable risk—and that subjects were insured and had given informed consent. The participation of nurses on these committees was required, leaving other details to institutional discretion. Since 1993 experimentation on human subjects is covered by federal law. The Federal Act on drugs and medical products (in force since 2000) requires all research on human subjects—be it publicly or privately funded—to get prior (ethical) approval by a research committee. The about 25 existing such cantonal committees are to have members of both sexes, among them nurses, lay persons, and at least three nonmedical members with experience in social, ethical, or juridical matters.

In Germany (see Toellner; Wiesing, 2002), the introduction of ethics committees was not generally recommended until 1979, when it was endorsed by both the German Federal Chamber of Physicians (*Bundesarztekammer*) for the chambers on state and federal levels and by the Federal Association of Medical Schools for the medical schools. In 1983 the Working group of Medical Ethics Committees (*Arbeitskreis Medizinischer Ethik-Kommissionen*) was founded. It is comprised of all ethics committees at the state physicians' chambers and the medical faculties. The workgroup meets annually to share experiences, promote standardization, and revise its procedural principles.

In 1985 the *Bundesärztekammer* turned the requests for ethics-committee review into an obligatory standard of professional practice. And finally, the German Drug Law ACT (*Arzneimittelgesetz,*) of 1995—and under revision in 2003—is making it obligatory for any research on human subjects, their tissues or person-related data, to get approval from an ethics committee. For publicly funded research in 2003, there were 17 committees at the state chambers of physicians (*Landesärztekammern*), and 38 at the university-based departments of medicine. Most committees have between seven and nine members (plus substitutes) of a—legally required—interdisciplinary background. Local bodies possess some discretional freedom on how to interpret this requirement; only a minority of them include nurses or lay persons. Both public and professional trust and acceptance in those commissions' work seems to increase steadily, although a number of crucial issues are yet unsolved, for instance, regarding the missing evaluation and quality assessment procedures of the committees' work; or the lack of oversight, particularly of commercial or "free" (not institution-affiliated) committees. Other issues under debate are the coordination of different ethics committees in multicenter research, or possibilities to monitor ongoing research compliance to ethical standards.

In Austria, research ethics committees have been legally required since 1988 for the medical faculties and research hospitals. These prescriptions were revised in detail in 1993, and now require that the states issue legal regulations, according to which every ethics committee must include: (1) women; (2) at least one independent person and one physician with particular expertise in the research at stake; (3) at least one representative of the hospital's chaplain (or somebody else with ethical expertise related to patients, staff, and legal services; and (4) a pharmacist.

Specific Ethical Issues

EUTHANASIA. The *Guidelines on Assistance in Dying* of the Swiss Academy of Medical Sciences (issued in 1976, revised in 1981 and 1995) emphasize a patient's right to turn down any medical treatment. They further permit withholding treatment for irreversibly terminal patients, as well as for patients with a loss of consciousness considered irreversible. Dispensable "treatment" in such cases may explicitly include respiration and artificial nutrition. Decisions must include substituted judgments made with the help of the patient's next of kin, and they must consider the patient's best interests. As of 1995, living wills must be followed. Active voluntary euthanasia, however, is illegal under the Swiss Penal Code. Assistance in patient suicide, though not illegal, is not considered a proper activity for physicians. However, it is not explicitly and strictly said to be unacceptable under every circumstance. Assistance in suicide for competent terminally ill patients is provided by two Swiss societies, Exit and Dignitas, the latter being open also for non-Swiss patients. A highly controversial "suicide tourism" has thus developed, with 55 instances of assisted suicide by non-Swiss individuals in 2002.

The German Federal Chamber of Physicians modeled its 1979 guidelines on "assistance in dying" almost verbatim on the Swiss guidelines (Baumann). Remarkably, however, two points were left out: the explicit permission to withhold or withdraw respiration and artificial nutrition in the irreversibly dying patient, and the explicit permission to forgo treatment in patients with an irreversible loss of consciousness. Moreover, these early German guidelines consider living wills to be merely a nonbinding piece of evidence. In a 1993 update of these guidelines, this last point was explicitly reaffirmed. The 1999 revision of the guidelines, however, exhibit substantial changes. Advance directives (which have since become subject to separate guidelines) are granted a binding status, as long as they are precise and relevant. Furthermore, artificial nutrition, though part of the commonly indispensable basic support, can legitimately be withdrawn from an irreversibly terminal patient, as long as he or she is kept comfortable and neither hungry nor thirsty. Indispensibility of basic care and treatment, with the explicit inclusion of artificial nutrition, is, however, reconfirmed for patients with an irreversible loss of consciousness. Also reconfirmed is the impermissibility of active voluntary euthanasia.

The German Roman Catholic Conference of Bishops and the Protestant Church have repeatedly and strongly argued against active euthanasia, while emphasizing the need—and Christian obligation—to care in a humane and Christian way for the suffering and dying. A hospice movement that provides palliative care for the dying is seen by many as an appropriate way both to fulfill the obligation to care for the terminally ill and to eliminate the very reasons patients ask for voluntary euthanasia. In addition, any use of the term *euthanasia* in Germany conjures up vivid images of the use of the term by the Nazis as they carried out their goal of exterminating millions of fellow human beings who were deemed to be of "inferior" quality. The deeply emotional nature of this historical association explains current objections by many Germans to any discussion of euthanasia. The media and public culture are so aware of Nazi cruelties that lectures by Peter Singer and Helga Kuhse—Australian bioethicists who support both voluntary euthanasia and the permissibility of passive as well as active euthanasia (withholding treatment as well as directly killing) for severely disabled neonates on parental request—have been prohibited or protested in Germany and Austria (Schöne-Seifert). In the aftermath of this "Singer affair" (starting in 1989), organizations of disabled people and other political and interest groups have vehemently argued that those in favor of euthanasia for severely disabled newborns are making an indirect judgment about the worth of a life and are in danger of creating a climate in which elimination of the unfit or discrimination toward the sick, feeble, and disabled will again be accepted. These objections have also been raised in debates about selective abortion, creating a rather widespread antibioethics climate in both Germany and Austria.

In Switzerland, withdrawing treatment for most severely disabled newborns is considered morally permissible and is narrowly specified as such in the Swiss guidelines. The German Society for Medical Law had issued rather similar recommendations (the so-called *Einbecker Empfehlungen* [Recommendations of Einbeck]) in 1986. At the time, the Society considered it morally permissible to let newborns die when they either suffer from most severe mental disabilities or can only be kept alive by permanent intensive care. After the Singer affair, these recommendations were revised (in 1992), and forgoing treatment is now restricted to newborns with irreversible medical problems that will lead to death within a short period of time.

Legalized active euthanasia at the request of terminally ill patients has been advocated by some German voices. For example, the *Deutsche Gesellschaft für Humanes Sterben* (German Society for Humanely Dying, or DGHS), founded in 1980, advocates for respect for the dying patient's autonomy. This lay organization, which does not enjoy much support in the medical or legal communities, also provides its members with forms for living wills, and in the past it has provided assistance in suicide (because suicide is not a criminal offense, assisting it is not illegal either). Physicians, however, are seen by law to stand under specific professional obligations (*Garantenpflichten*), which some courts—in contrast to the view dominant in the legal literature—have interpreted to include suicide intervention. Hence, there is an unresolved legal tension that makes jurisdiction on physicians' assistance (and consequent nonintervention) in suicide unpredictable. The credibility of DGHS was severely shaken in early 1993 when its founder and president, H. H. Atrott, was arrested for selling cyanide capsules—moreover at inflated prices.

In 1986, the *Alternativentwurf eines Gesetzes über Sterbehilfe* (Alternative Draft of a Law for Assistance in Dying) was published by a number of reputable experts in medicine and law (Baumann). Among its suggestions was one to waive prosecution of euthanasia (though illegal) when it is persistently requested, and if the euthanized patient was competent and suffering from terminal illness. However, the draft never succeeded, due to lack of sympathy for it from the Federal Chamber of Physicians and the German Legal Association.

Advance directives (see Meran et al.), be they in the form of living wills or of durable powers of attorney, have slowly started to play a role in medical decision making in all three German-speaking countries. Although the 1992 Care ACT (*Betreuungsgesetz*) in Germany in principle provides for both instruments, and although various forms for living wills are publicly available, the legal status of advance directives is disputed and considered uncertain. This situation discourages both its acceptance by the medical profession and wider use by patients. In 2003 a critically debated Supreme Court decision upheld a ruling that decisions to stop life-saving treatment cannot be validly made by a patient's advocate without confirmation of the courts. Critics consider this position both nonrealizable and contrary to a patient's right to self-determination. In the same decision, however, advance directives, at least for the terminal phase of disease, were acknowledged as expressions of a patient's autonomy in former days and as legally binding.

In Austria, the overall situation is very similar to that in Switzerland and Germany: Active euthanasia is illegal under the national Penal Code; withdrawing treatment is not, by either law or policies, regulated in any detail; and advance directives seem to be slowly gaining in use and impact.

ABORTION. With the 1990 reunification of the German nation, most laws and regulations of the former Federal Republic of Germany (West Germany) were applied to the citizens of the former German Democratic Republic (East Germany). However, there were very different models of legal abortion in the penal codes of the two Germanys, which resulted in a heated debate. In the West, a 1974 law permitted pregnant women to choose abortion until the end of the first trimester. Based on a charge of nonprotection of the rights of the unborn, the constitutionality of this law was challenged in 1975. The resulting interpretation of the constitution (*Grundgesetz*) by the Federal Constitutional Court (*Bundesverfassungsgericht*) held that human dignity (*Menschenwürde*)—a conceptually loose term that is used by both sides of the abortion debate to support their position—is constitutionally protected from the moment of conception. It enforced an *indication model,* permitting legal abortion until the end of the first trimester only if a physician certified that certain social or medical indications were present. Under this model, the physician was the ultimate moral agent and an acknowledged right to life of the unborn was to be balanced against medical or social hardship. Generous interpretation of these criteria often led to a de facto policy of abortion on demand in the first trimester, but with different standards and variability in enforcement in the various states of the Federal Republic. In the German Democratic Republic, a *term model* for legal abortions operated since 1972, wherein abortion was allowed until the end of the first trimester and was cost-free.

In the new Germany, a heated public debate (though involving little philosophical analysis) took place on the underlying theological, moral, and political positions motivating the clashing views on abortion. In 1992 the federal parliament approved a compromise law under which abortion would be legal in the first trimester (and paid for by health insurance) as long as the woman had a consultation session prior to abortion. Mandatory counseling and education were intended as an additional step to strengthen fetal protection (a goal that was emphasized almost unanimously) and include informing a pregnant woman about existing supportive social, welfare, and employment programs, as well as kindergarten settings for the child, that might enable her to choose to continue her pregnancy.

However, conservative parliamentarians and the Roman Catholic Church petitioned the *Bundesverfassungsgericht* to declare the law unconstitutional. The German Supreme Court did just that in May 1993, stating that the counseling sessions did not go far enough in protecting fetal human life, as required by the (formerly West) German Constitution. The Court argued that the constitutional rights of a woman (to physical integrity, human dignity, right of personality) do not go so far as to allow her to claim a fundamentally protected legal right to kill an unborn child by means of abortion; that abortions at any point during a pregnancy are fundamentally wrong, and thus illegal; and that the state's duty to protect the unborn also includes maintaining and raising the public's consciousness of the unborn child's legal right of protection. However, the Court held that a future abortion law would be considered constitutional even if it abstained from prosecution of illegal first-trimester abortions that were performed at the pregnant woman's request, as long as she has undergone prior mandatory and explicit pro-life counseling. A new abortion law, which came into force in 1995, includes this requirement.

Both public and expert reactions to this legal reform are heavily split. Where some emphasize its being a socially integrative compromise, conservative critics deplore what they consider a violation of the embryo's human dignity, while others object to both the Supreme Court's and the legislation's blatant inconsistencies. For them, accrediting a full-blown right to life and dignity to the early embryo is incompatible with de facto permission of first trimester abortion on demand and the state's court-mandated provision of abortion facilities (Merkel). The required pro-life counseling is seen as a violation of women's right and competency to self-determination (Kuhlmann), and the preemption of prosecution for illegal abortions is considered to undermine the public's trust in the law.

In Switzerland (where women first began to acquire the political right to vote only in 1971), abortions had been permitted only for serious medical indications or in case of grave emergency (commonly interpreted to include rape and embryopathy). In the 1970s, opinion polls suggested that a majority of the Swiss people would opt for a liberalization of abortion law. However, a plebiscite in 1977 went narrowly against abortion on demand in the first trimester of pregnancy (with a majority of French-speaking and predominantly Protestant cantons [states] in favor of liberalization, and German-speaking and predominantly Catholic cantons against). A repetition of the plebiscite in June of 2002, however, saw 72 percent of the votes being in favor of first trimester abortions on demand, and they are now allowed, with only a prior comprehensive consultation with the physician who is going to perform the intervention.

In predominantly (85%) Roman Catholic Austria, first-trimester abortion on demand has nevertheless been legally permitted since 1975. Costs of medically indicated abortions are covered by insurance, while those resulting from abortions performed for nonmedical reasons must be paid for by the women themselves. A pro-life referendum initiated the year before the introduction of this law won only 18 percent of the vote, and none of the three major political parties supported the initiative.

NEW REPRODUCTIVE TECHNOLOGIES AND EMBRYO TESTING. A great deal of the public debate in German, Austrian, and Swiss bioethics continues to focus on reproductive issues. All three countries criminalize egg donation for reproductive purposes (and thus surrogate motherhood), the fertilization of more (3 eggs maximum) than are to be transferred (thereby theoretically preventing the existence of "spare" embryos), as well as any research on or manipulation of an embryo not in its own therapeutic intererest. Genetic manipulation on the germline cells (those from which gametes are derived) is prohibited.

In Germany, the Benda Report of 1985 recommended that a future reproduction law ban: (1) all forms of surrogate motherhood; (2) heterologous (with sperm other than a woman's spouse) in vitro fertilization (IVF) and assisted insemination by donor (AID), at least for single women; (3) research on embryos other than those that are purposefully left over from IVF; and (4) any genetic manipulation of germline cells. These measures were considered necessary to prevent violations of "human dignity." The first regulations, issued in 1985 by the Federal Chamber of Physicians, had the status of intraprofessional self-regulation. They were revised in 1988 and 1994, and now permit only homologous (using only the spouses' egg and sperm) IVF and GIFT (gamete-intra-fallopian-tube transfer), and only in married couples. Only somatic infertility is explicitly accepted as an indication for IVF, for example, and the restriction to homologity and marriage are justified by the well-being of the child-to-be. In accordance with the 1991 Embryo Protection Act, embryo donation and all forms of surrogate motherhood are prohibited (though, theoretically, unpaid-for donor sperm may be used in rare cases). However, no cases of AID have occurred since 1985, and issues of access to (heterologous) IVF—and its ramifications for family law—still await a long-planned reproductive medicine law.

In a second set of guidelines issued in 1985, the chamber prohibited the production of embryos for research and restricted embryo research to important questions of infertility treatment or embryo development—and to spare embryos less than 14 days old—after approval of the central commission. After heated public debates on the relevant meaning of human dignity and of reproductive autonomy, and on the permissibility of research even on spare embryos, the German Embryo Protection Act (*Embryonenschutzgesetz*) was introduced in 1991, setting unprecedented standards in terms of restrictivity. In summary, the law prohibits: (1) artificial insemination of an oocyte for any purpose other than a nonsurrogate pregnancy of the "possessing" woman, and (2) any kind of nontherapeutic manipulation or research on the embryo, even in case of spare embryos (whose occurrence is made unlikely by the first prohibition). In addition, (3) any single totipotent cell (an early embryonic cell from which a whole organism could still develop) is given the legal status of an embryo. Further restrictions rule out (4) reproductive egg donation and any form of surrogate motherhood, as well as (5) cloning or the creation of chimeras (organisms with a combination of human and animal genes). Violating these regulations can result in lengthy prison terms and monetary fines, but punishment applies only to third parties (i.e., physicians, researchers, and agencies), not to biological, gestational, or social mothers-to-be.

This law has been controversial, particularly in the light of the more recent options of "using" embryos for stem-cell research, which is clearly prohibited by this law. It has been praised by its proponents for its strict embryo protection, while critics claim it interferes with self-determination, responsible parenthood, and reproductive choice.

Preimplantation diagnosis (PID) is currently not practiced in Germany, but it is increasingly demanded by various people and groups. Initially, most legal experts considered PID implicitly prohibited by the Embryo Protection Act, though this view has been challenged by a growing number of experts. There is a broad consensus, however, that regulation of the issue is required before PID can be practiced. As can be witnessed in other countries, those strongly opposed to PID (and the involved selection of embryos) make several arguments. They consider the procedure to be: (1) a violation of the early embryo's dignity and right to life; (2) a form of, or at least an invitation to, unacceptable eugenics; and (3) discriminatory toward, or hurtful of, those disabled individuals who have been born with one of those diseases PID would select against. Those in favor of PID most commonly want it offered very restrictively to couples with a family history of severe hereditary disease. Not only do they question the plausibility of the above arguments, but they criticize what they consider an ethical double standard; that is, forbidding preimplantation diagnosis, while at the same time allowing elective abortion after prenatal diagnosis of the very same severe hereditary diseases (and even less severe ones) in significantly later stages of pregnancy.

Austria's Reproductive Medicine Act (*Fortpflanzungsmedizingesetz*) regulates both the use of new reproductive technologies and embryo protection. It was introduced in 1992 after long and heated debates, and it represents a political compromise between the Roman Catholic opposition to reproductive technologies on theological grounds and more liberal approaches that emphasize the benefits of new reproductive technologies to support individual reproductive freedom and choice. Both homologous and heterologous IVF or GIFT are permitted as infertility treatments for married couples or those in stable relationships, but embryo donation and all forms of surrogate motherhood are forbidden. Only freely donated sperm from living donors may be used, and, based on the concept of human dignity, a child conceived from donor sperm is permitted to know the identity of the biological father once he or she reaches maturity (records must be kept for thirty years). Issues of inheritance and other matters affecting IVF offspring are regulated elsewhere in the law. Preimplantation diagnostics, though not expressly mentioned, are considered forbidden and currently not practiced in Austria.

In Switzerland, the Swiss Academy for Medical Sciences (SAMW) issued guidelines on the use of new reproductive technologies in 1990. Homologous IVF in married or quasi-married couples, as well as IVF using anonymously donated sperm or eggs in married couples, are permitted as either infertility treatment or as a means to prevent transmission of a genetic disease. Embryo donation, all forms of surrogate motherhood, preimplantative sex selection, germline manipulation, and any research on embryos are all prohibited.

In 1992 the Swiss implemented Article 24, a constitutional amendment requiring federal regulation of embryo protection and of reproductive technologies according to the following restrictions: The manipulation of germline cells and embryos, the creation of chimeras, and the production of spare embryos are illegal; homologous and heterologous IVF are legal as an infertility treatment (allowing—like German and Austrian law, and in contrast to the SAMW guidelines—for later access to information about one's biological parent) or as a means to prevent transmission of a genetic disease; embryo donation and all forms of surrogate motherhood are illegal; but research on (the few available, see above) spare embryos is not explicitly ruled out. Since 2001 the federal Reproductive Medicine Act has been in force, prohibiting egg and embryo donation, the creation of surplus embryos, and the performance of PID. As in Austria and Germany, public opinion on these matters are heavily split.

EMBRYO RESEARCH AND CLONING. Since the late 1990s, embryo research is no longer an abstract ethical issue, but is being discussed with regard to stem-cell research with its promises of future therapeutic breakthroughs. In all three German-speaking countries, the creation of embryonic stem cells is prohibited by the above described laws. In 2001, both in Germany (by the *Deutsche Forschungsgemeinschaft*) and in Switzerland (by the Swiss National Fonds) the scientific communities questioned these prohibitions publicly and suggested that embryonic stem cells be imported from abroad, thus legally providing scientists with the tools to participate in the promising new research. Simultaneously, they and many others urged public debates and legal reforms that would allow Swiss and German scientists to use (deep-frozen) surplus embryos, the existence of which cannot completely be prevented even by the restrictive current laws.

In Switzerland, a research project on imported embryos began in 2001, while the issues were still subject to controversial public debates. In 2003 the country was awaiting a stem-cell research law, which will most probably permit the creation of stem cells from surplus embryos. The more general issues of embryo research will be handled in an additional future law regulating overall issues of research on human subjects.

In Germany, scientists have also started to work on imported stem-cell lines. Here, however, they waited for a clear legal basis, provided by a new stem-cell law implemented in the summer of 2002. While strictly prohibiting the destruction of early embryos, even for highly promising medical purposes, it nevertheless permits, under a number of restrictions, the importation of existing stem-cell lines. A majority of parliament members viewed this legislation as an acceptable compromise, whereas critics consider it to be another instance of ethical hypocrisy.

In Austria, no attempts have yet been made to legalize the importation of embryonic stem cells, and the whole matter of destructive embryo research is under debate.

Cloning, both for reproduction and for biomedical research, is one of the most recent bioethical issues dealt with in all three countries.Reproductive cloning by any method will certainly be ruled out by laws to come. Cloning for biomedical research purposes, on the other hand, has been rejected by a majority of experts and the public—though not unequivocally. Again, the moral status of (artificial) embryos, the moral claims of future patients, slippery-slope arguments, and the difficulties in handling the bioethical pluralism of modern societies will be prominent arguments in these discourses.

HUMAN GENETICS. The use of genetic testing techniques in Germany, Switzerland, and Austria is regulated quite strictly. Each of these countries has regulations regarding the use of genetic testing, the need for informed consent of the individuals involved, and the need to integrate genetic testing into a larger process of genetic counseling. The memory of eugenics experiments during the Third Reich inevitably generates negative emotions, especially in Germany, toward any medical intervention concerned with the prevention of hereditary disease. German reflection seems particularly concerned with the question of how far society and parents should go in accepting disabilities that can easily be discovered using prenatal diagnosis, while at the same time protecting the woman's right to decide whether or not to use prenatal diagnosis. Another major issue discussed in all three countries is the appropriate balance between people's autonomy (to know about a carrier status or genetic disease in themselves or their embryo, and to draw consequences they consider appropriate) and the protection of the same people from unwelcome or unbearable information, from unreasonable risk assessment, or from external sanctions upon their genetic status. There seems to be a strong public consensus for a ban on germline manipulation, whereas somatic gene therapy, although met with a much public suspicion, was applied for the first time in 1994 on somatic cells (cells other than those from eggs and sperm). The Federal Chamber of Physicians is currently at work on guidelines on somatic gene therapy.

The German Gene Technology Law of 1990 (revised in 1993) does not address questions of genetic testing or engineering in humans. Three commissions, one at the level of the federal parliament, and two composed of executives from state and federal governments have already issued recommendations for a law that would specifically regulate issues of genetic counseling and testing in embryos, neonates, carriers, high-risk persons, or at the workplace. For the time being, these issues are partly regulated intraprofessionally. Guidelines issued in 1991 by the German Federal Chamber of Physicians urge that genetic testing always be integrated with genetic counseling, that such counseling be provided by nonmedical personnel under medical supervision, and that consent be required for testing. The Commission of the German Society for Human Genetics also supports genetic testing only within nondirective genetic counseling. This commission also holds that screening for nonmedical information, such as the sex of the fetus, should be prohibited, and that information obtained by genetic testing is to be strictly confidential.

The Federation of Swiss Physicians asserted in 1991 that genetic analysis for occupational health or insurance issues must always be rejected, even if consent is given and the information is to be confidential. The Swiss Academy of Medical Sciences guidelines of 1993 assert that genetic testing must be part of a larger counseling relationship. The academy supports voluntary testing for (1) diagnosis of hereditary diseases, (2) carrier testing and genetic counseling for family or career planning, and (3) presymptomatic testing whenever medical intervention or changes in lifestyle may reduce or postpone disease. Counseling and education prior to testing are obligatory. Article 24 of the Swiss Constitution states that "the genetic endowment of a person cannot be analyzed, registered or revealed without that person's consent or a legal prescription." Probably still in 2003, a new federal act on human genetics will be enacted, regulating genetic testing in humans and providing safeguards against genetic discrimination.

In Austria a Gene Law was introduced in July 1994, regulating genetic counseling, diagnostics, and manipulation both inside and outside human beings. It prohibits any release of genetic information to third parties, notably insurance companies and employers.

ORGAN TRANSPLANTATION. Germany's long awaited Transplantation Act came into force in 1997. Basically, it confirms what had been the current policy regarding posthumous organ retrieval, namely the requirement of explicit prior consent by the donor, or substitute consent by his or her proxy. In addition, it restricts live donation, rules out any commercialization, and legally acknowledges the whole-brain definition of death (according to which a complete cessation of brain functioning indicates a person's death).

Various drafts for a transplantation law were debated over several years. The most likely legal regulation had once been a policy requiring that donation be requested of the deceased potential donor's proxy, consent of the patient being presumed if he or she had not objected to organ donation. Protests were raised against these suggestions, however, on the grounds that they disregard the right to self-determination and represent an uncritical protransplantation ideology. Among the protestors were a number of Protestant theologians, despite the fact that both the Protestant and the Catholic churches had officially praised organ donation.

The whole-brain definition of death was at the center of much debate and protest. German physicians officially adopted this definition in 1982, but this position has been a matter of intraprofessional policy, rather than legal statute. Rising concerns about the definition's underlying, allegedly reductionist concept of human life (spurred by recent cases involving attempted continuation of pregnancy in brain-dead women by maintaining them for weeks on life support, and by rumors that authorities of the former East Germany sold organs, sometimes prior to fulfillment of death criteria) had fueled public suspicion and professional objections, and had even raised the possibility of revision of the brain-death formula (Hoff and In der Schmitten).

In Austria, the 1982 *Krankenanstaltengesetz* presumes consent to organ procurement if the donor or his or her proxy do not oppose it—without, however, explicitly requiring that the proxy be informed about his or her right to oppose.

In Switzerland, the cantons (states) have different legal requirements for organ transplantation, with a majority having a presumed-consent policy. Efforts are being made to issue a federal transplantation law, which will likely be enacted in 2004.

Germany is a member of the Netherlands-based Eurotransplant Center, which computerizes the distribution of available organs, primarily according to tissue compatibility, among a network of European transplantation units. Organ information and distribution centers in Switzerland and Austria are more loosely affiliated with Eurotransplant.

RESOURCE ALLOCATION. Social-welfare systems in each of these countries provide almost universal coverage for health-related costs, as well as allowances for certain conditions (e.g., maternity, disability, old age, work-related injuries, dependent children). Overall health conditions, healthcare, and access to physicians are very good in each of these countries.

However, the steadily increasing costs of modern medical care have begun to endanger the unlimited approval of the underlying "solidarity principle" by which the rich and healthy pay for the care of the sick and needy. Moreover, various cost-containment policies that claim to increase cost-effectiveness without decreasing the quality of care have slowly increased public awareness of the underlying ethical questions of distributive justice and permissible rationing criteria. The debates on a decent maximum of generally accessible healthcare have only started. Again, public concern about a renaissance of Nazi spirit is raised by the prospect of rationing treatment, which might discriminate against the disabled and elderly.

ANIMAL EXPERIMENTATION. Strong concern exists throughout Europe for the ethical use and protection of animals in research. Swiss guidelines, inspired by animal-rights activists, have served as the basis for regulations in other countries. In the late 1970s, Switzerland became the first European country to include animal protection into its constitution, and in 1992 an amendment granted constitutional protection to the "dignity of creation." Germany's 1986 Animal Protection Act (*Tierschutzgesetz*) was revised in 1998 and contains detailed regulations concerning the type of experiments permissible, selection criteria for animals, supervision by qualified veterinarians, and standards for the treatment of animals in agriculture and as pets. Notice must be given to qualified animal-welfare commissioners. Animal-welfare committees exist in all states, with membership based on nomination by animal-welfare groups and academic training and professional experience. This legislation is supplemented by public education and information campaigns designed to bring about more humane treatment of animals in all spheres. The 1998 revision made it obligatory for any institution experimenting with vertebrates to appoint a qualified person to be officially responsible for animal protection. Experiments on dogs, cats, and apes require their being bred for research. Animal experiments for developing any kind of cosmetic product are prohibited.

In 2002 Germany finally—after more then ten years of debates, and through the addition of two words—incorporated animal welfare into its constitution. Article 20a of the German Constitution now reads "The state takes responsibility for protecting the natural foundations of life *and animals* in the interests of future generations." This amendment will not have any immediate effect, but it will influence the way in which future German legislation is drawn up and current laws are interpreted.

Austria passed its Animal Research Act (*Tierversuchsgesetz*) in 1989, which provides for criminal penalties if research is not reviewed or performed ethically or responsibly and according to current scientific standards. The law also calls for a reduction in the number of experiments performed and the number of animals affected. Attempts for a federal animal protection law unifying existing legislation in individual countries have so far been as unsuccessful as those for including animal welfare in the Austrian Constitution.

Conclusion

Despite a comparatively delayed academic and public interest in modern biothics in the three German-speaking countries, and despite some tendencies to avoid debates on certain issues regarding human life because of past atrocities, the field and its substantial and methodological problems have become widely acknowledged as important.

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VII. NORDIC COUNTRIES

This entry provides a brief overview of the modern development of medical ethics in the Nordic countries: Denmark, Finland, Iceland, Norway, and Sweden. The focus is primarily on the period after the beginning of the 1960s. The entry begins by giving an account of the establishment of ethics review committees and other medical ethics bodies and organizations. Then changes in the educational and research situation are described, along with the establishment of special institutions for medical ethics. Finally, attention is given to some essential features of the debate on a few principal issues.

Codes, Ethics Bodies, and Organizations

The attempt formally to regulate physicians' duties toward their patients and colleagues began early in the history of medicine. Ethics codes in the Nordic countries can be traced to the early practice of physicians taking an oath of office and allegiance. For example, in seventeenth-century Sweden, when physicians still received doctoral degrees abroad, usually in Holland, permission to practice medicine required the taking of an examination given by the Swedish association of physicians, the Collegium Medicorum, which was founded in 1663. When passing the examination the physician had to take a special oath. The taking of an oath was an obligatory part of the examination of physicians in Sweden until the late nineteenth century and still is required in Denmark, Finland, and Iceland.

It was only after World War II, however, that the making of ethics codes in the Nordic countries came to encompass areas outside clinical practice and to include professional categories other than physicians. The current ethical guidelines for physicians' clinical work were adopted in their original forms by the Danish Medical Association in 1976, by the Finnish in 1956, by the Icelandic in 1918, by the Norwegian in 1961, and by the Swedish in 1951. During the 1950s and 1960s other health professional groups, such as nurses and physical therapists, began to develop their current ethical codes. The 1964 adoption of the Helsinki Declaration by the World Medical Association extended the codification to the explicit inclusion of ethics in research. To facilitate its implementation the Nordic countries created a system of ethics review committees.

Those committees are organized somewhat differently in the different countries. Denmark and Norway have regional committees, whereas Finland and Iceland have local hospital committees and Sweden has both regional and local committees. The Danish system, which was established in 1978, consists of seven regional committees and a central scientific-ethical committee. The committees in Norway are organized in a similar way. In 1985 regional committees were set up in each of Norway's five national service regions. To establish a coordinating and advisory body for those regional committees, the Norwegian Medical Research Council's Committee for Medical Research Ethics, which was formed in 1978, became the National Committee for Medical Research Ethics in 1990. In Finland the first ethics committee was set up at Helsinki University in 1972; since 1977 all medical faculties have had ethics committees. In Iceland the two national university hospitals have had ethics committees since 1976. In Sweden an advisory council was formed at the Karolinska Hospital in Stockholm in 1965. That council was superseded the next year by the first medical-faculty ethics committee, which was established at the Karolinska Institute. By 1967 similar committees were in place at all medical faculties in that country.

Since those committees were established, the call for assessment of the ethical implications of new technologies and other advances in medicine has increased. To respond to growing pressures on political decision makers an additional type of national ethics body was created. Its principal task is twofold: to provide expert knowledge to the government, the parliament, and the health-service authorities and to contribute generally to a continuous exchange of information and opinions on medical ethics issues among researchers, politicians, and the public. To that end the Danish Council of Ethics was established by the parliament in 1987; the National Research Ethics Committee, by the Finnish Parliament in 1991; the National Biotechnology Advisory Board, by the Norwegian government in 1991; and the National Council of Medical Ethics, by the Swedish government in 1985. Iceland still lacks a national body of this kind. (For further information about the origin, composition, and activities of these national bodies and of the review committees see Council of Europe; Solbakk.) In 1988 the Nordic Committee for Ethics in Biotechnology was created by the Nordic Council of Ministers. Like some of the national bodies, this committee deals with bioethical issues in the broad sense of the term. Besides issues in medicine, the Nordic Committee addresses ethical questions in, for example, stockbreeding and agriculture.

Several other bodies and organizations play an important role in the analysis and debate of issues in medical ethics. For example, ethics committees were set up within the medical associations of Denmark (1969), Finland (1975), Norway (1962), and Sweden (1979), as well as within the National Finnish Board of Health (1988), the National Swedish Board of Health and Welfare (1984), and the Ministry of Health and Social Affairs in Norway (1988). In 1989 the Council of Ethics was established at the Office of the Director General of Health in Iceland. There are also a number of medical societies: the Delegation for Medical Ethics, established in 1969 within the Swedish Society of Medicine (earlier called the Swedish Society of Medical Sciences); the Society for Medical Law and Ethics, founded in Finland in 1980; the Danish Society for Medical Philosophy, Ethics, and Methodology, founded in 1988; and the Swedish Society for Medical Ethics, founded in 1989. In 1988 a section for medical ethics in the Nordic countries was established within the European Society for Philosophy of Medicine and Health Care.

Education and Research

Since the beginning of the 1970s medical ethics has been taught at medical faculties and nursing schools in all the Nordic countries. However, there are no uniform requirements regarding the scope and content of this teaching in any of the Nordic countries. At a meeting in Reykjavik, Iceland, in 1991, the medical associations of the Nordic countries agreed to work toward making medical ethics a compulsory subject at all medical faculties in those countries and creating teaching positions in the subject (Oldinger).

Textbooks have been written in most of the Nordic countries. For a long time *Medicinsk etik* (1971), a doctoral dissertation by Clarence Blomquist, a pioneer in Swedish medical ethics, was the only general introduction; it dealt with both metaethics and normative ethics and covered most of the principal issues in medical ethics at that time. Subsequently, a number of textbooks have appeared, including some broad general introductions (Fagerberg et al.; Andersen et al; Tranøy, 1991; Wretmark et al.), some more philosophically oriented works (Malmgren; Tännsjö, 1998), and some texts dealing not only with ethics but also with other philosophical issues in medicine (Bjarnason; Tranøy, 1978; Wulff et al).

The philosophical rather than the medical faculties have been responsible for most postgraduate education in medical ethics. Blomquist's *Medicinsk etik,* the first doctoral dissertation, was defended at the Department of Philosophy at Uppsala University in 1973. Since that time philosophy departments have produced dissertations on specific medical ethics issues such as suicide, paternalism, and abortion as well as on the nature and scope of philosophical medical ethics in general. Partly empirical doctoral dissertations that focus primarily on issues in medical ethics have been written within the fields of sociology, nursing research, and medicine.

The establishment of two special institutions for medical ethics, one in Norway and the other in Sweden, as well as the foundation of a unit for the philosophy of medicine in a broader sense in Denmark, has improved the opportunities at medical faculties for both graduate and postgraduate education in medical ethics. The Center for Medical Ethics at the University of Oslo was founded in 1989. A chair in medical ethics was created at the University of Oslo Medical Faculty in 1992. Lund University in Sweden established the Department of Medical Ethics in 1991. The department came into existence through the creation of a chair in medical ethics at the Swedish Medical Research Council in 1990. In 1988 the University of Copenhagen established the Unit of Medical Philosophy and Clinical Theory at the Panum Institute.

Those institutions have strengthened the position of medical ethics as an independent research field at medical faculties. Research in medical ethics otherwise is carried on normally only in the form of time-limited projects and mainly outside medical faculties in philosophy departments and departments of theology. Some institutions focus on medical ethics as a principal area of research. For example, the Department of Health and Society at Linköping University in Sweden has had a chair for the philosophy of medicine since 1987. Two institutes have been established: one in Iceland in 1989, the Ethics Institute at the University of Iceland, and the other in Sweden in 1988, the Ersta Institute for Health Care Ethics in Stockholm. In Finland the Center for Bioethics was founded in 1991 at the University of Turku.

Principal Issues

ARTIFICIAL INSEMINATION AND IN VITRO FERTILIZATION. Among the Nordic countries only Norway and Sweden have laws that specifically regulate the use of noncoital reproductive technologies to achieve pregnancy. The use of human sperm, ova, zygotes, and early embryonic forms (blastemas) for research purposes also is restricted in the Nordic countries.

The ethical and legal debate in the Nordic countries over the use of noncoital reproductive technologies has focused mainly on artificial insemination by donor semen (AID), in vitro fertilization (IVF), and ovum donation. The closely related issues of artificial insemination by the husband's semen (AIH) and gestational surrogacy (surrogate motherhood) have attracted less attention. Except among certain religious minorities the use of AIH has generally been accepted.

To a large extent the 1987 Norwegian legislation on artificial insemination and IVF corresponds to the 1985 Swedish legislation. One point on which the Norwegian and Swedish laws differ is of particular ethical interest: the issue of whether it should be possible for a child to obtain information about the identity of his or her natural father. Sweden legislated in favor of the child's right to this information, and Norway legislated against it.

According to the Swedish legislation, (1) only women married or cohabiting with a man in circumstances of marital character should be allowed to receive insemination treatment; (2) insemination requires written consent by the husband or cohabitant, who will by virtue of that act be regarded as the legal father of a child born as a result of the treatment; (3) AID should be undertaken only in general hospitals under the supervision of a physician who specializes in obstetrics and gynecology, and the sperm donor should be chosen by the physician; (4) information about the sperm donor should be kept in a special hospital record for at least seventy years; (5) when a child conceived by donor insemination is mature enough, he or she has a right to obtain information about the identity of the natural father; and (6) when requested, the public welfare committee is obligated to assist the child in retrieving that information. (For literature on the debate and official reports preceding this law see Lindahl, 1985, 1988; U.S. Congress.)

The most controversial issue has been the right to obtain information about a child's father. The main point of departure for the Swedish legislation was the needs and interests of the child. In this respect the legislators decided to follow the general direction of modern legislation toward a gradual strengthening of children's judicial standing and the movement in society toward greater openness in family relations rather than the traditional patient-oriented perspective of clinical medical ethics. These two contrasting perspectives have dominated much of the debate.

PRENATAL DIAGNOSTICS AND ABORTION. The laws on abortion vary among the Nordic countries. In Denmark women have a legal right to abortion regardless of the reason before the twelfth week (law of 1973, in force the same year); in Norway, until the end of the twelfth week (law of 1975, in force from 1979); and in Sweden, before the end of the twelfth week or, after special consultation with a social worker, up to the end of the eighteenth week (law of 1974, in force from 1975). In Finland (law of 1970, in force the same year) and Iceland (law of 1975, in force the same year) abortion is permissible before the twelfth week, but only on certain indications (see below).

The situation in Sweden illustrates the way in which the legal status of the fetus and the understanding of its relationship to the mother changed during the twentieth century. Until the abortion act of 1974 a fetus was viewed as a separate individual, even during the first three months, and thus was legally protected. According to the earliest legislation, in the eighteenth century, abortion carried a penalty of death because it was equated with infanticide. As late as the 1920s the penalty for abortion was one year's to six years' imprisonment at hard labor. However, exceptions were made if abortion was necessary to preserve the health or life of the woman. This practice was ratified by law in 1938. From 1939 abortion was permissible up to the end of the twentieth week on any of the following three indications: medical (i.e., when, because of disease, physical defect, or weakness, childbirth would cause serious danger to the life or health of the woman), humanitarian (e.g., pregnancy after rape or incest or in minors), and eugenic (when there was reason to believe that the expected child would inherit mental disease, mental deficiency, or serious physical disease). After the twentieth week abortion was permissible only on medical grounds. Two additional indications were introduced before the abortion act of 1974: in 1946, sociomedical (i.e., when, considering the living conditions and other circumstances, it might be assumed that childbirth or care of the child would reduce the woman's physical or emotional strength seriously) and in 1963 teratogenetic (i.e., when there was reason to believe that the expected child, as a result of injury during the fetal stage, would suffer from a serious disease or defect). All these indications, somewhat differently formulated, are still used in Finland and Iceland.

In the debate surrounding the 1974 law on abortion the fetus often was no longer viewed as a separate individual but as a part of the woman's body. Abortion therefore became, according to this view, not a matter of weighing the value of one individual's life against the value of another's but a question of a woman's right to make decisions about her own body. The only legal limit to that right is the point in time at which the fetus has become viable, that is, able to survive outside the uterus. In Sweden the operation still may be performed at that time, but only if the woman suffers from a disease or physical defect and continued pregnancy therefore constitutes a serious threat to her life or health. Unless the operation cannot be postponed without danger to the woman, permission from the National Board of Health and Welfare is always required after the eighteenth week of pregnancy.

That exception has been questioned in an official Swedish investigation of the abortion law (Justitiedepartementet, 1989). The investigation points out that because abortion, according to the common medical definition, amounts to the expulsion of a nonviable fetus, this exception must mean that the operation is performed in such a way that the fetus is dead at delivery. The investigation found that unacceptable and required that instead efforts be made to save the life of both the woman and the fetus at that stage of pregnancy.

The investigation calls attention to the reevaluation of the legal status of the fetus that was undertaken after the abortion law was instituted. During the 1980s recurrent demands were made that an unborn child be protected from the risk of injury resulting from the mother's abuse of alcohol or narcotics. That request led to the conclusion that the woman and the prospective child no longer can be viewed as a single individual.

EUTHANASIA AND THE CONCEPT OF DEATH. Until the 1990s the dominant view on euthanasia in the medical profession in the Nordic countries was virtually that expressed in the mid-1800s by the Finnish physician Immanuel Ilmoni in his book on medical ethics *Om läkarens yrke och pligter* (1847). Ilmoni called euthanasia one of the most important special disciplines of the art of medicine. At the same time he made it clear that a physician may not in any circumstances deliberately contribute to shortening the patient's life even in cases in which the patient is "incurably ill, tormented beyond description, [and] fervently desires and demands death" (pp. 45–46).

In the late 1960s and during the 1970s, when the debate on euthanasia was most intensive in the Nordic countries, it would have been hard to imagine the medical profession supporting legislation that allowed physicians to comply with a terminally ill patient's wish to die. Among the earliest and most thorough contributions to the debate was Clarence Blomquist's book on euthanasia, *Livet, döden och läkaren* (1964). In that book Blomquist discusses the five principal definitions of euthanasia that were used in the debate: (1) the original meaning: medical care in the terminal phase of life, for example, the mitigation or relief of pain and discomfort of the dying; (2) causing death as a predicted but not intended side effect of treatment; (3) the acceleration of death; (4) passive euthanasia: discontinuing treatment or refraining from initiating treatment; and (5) active euthanasia: intentional killing in accordance with the patient's explicit or implicit wish to die or irrespective of the patient's will. Obviously, these different forms of euthanasia may overlap.

A fundamental issue in the debate has been where to draw the line between life and death. Brain-related criteria of death were introduced by law in Finland in 1971, in Norway in 1977, in Sweden in 1988, in Denmark in 1990, and in Iceland in 1991. The introduction of those criteria eliminated a minor but important part of the problem.

Throughout the 1970s even euthanasia as part of medical care in the terminal phase of life was disputed. The administration of painkillers was restricted to prevent terminally ill patients from becoming addicted to those drugs. In Sweden, for example, that restriction was not lifted until 1979. There was also concern that a more liberal administration of painkillers and tranquilizers might shorten a patient's life. Blomquist was among those who found this unintentional form of euthanasia, as well as the passive form, morally justifiable but did not support active euthanasia. Others, such as the Swedish professor of practical philosophy Ingemar Hedenius, advocated active euthanasia.

In 1992 Denmark became the first Nordic country to break with the traditional legal view on medical care in the terminal phase of life, passing a law according to which, unless there is particularly good authority for acting differently, a physician may not initiate or continue life-sustaining treatment of a terminally ill patient against wishes expressed in the patient's "living will." The law further provides that in the absence of a living will the physician may discontinue or refrain from initiating treatment that may prolong the life of a terminally ill patient. The physician also may administer painkillers, tranquilizers, and similar substances necessary for easing a terminally ill patient's suffering even when that may shorten the patient's life.

Three organizations for terminal care have been formed: in Sweden in 1973, the national organization Right to Our Death; in Norway in 1977, the national association My Living Will—the Right to a Death in Dignity; and in Finland in 1993, EXITUS. In 1985 a special organization for active euthanasia, EXIT, was founded in Sweden.

Concluding Remarks

Among other areas that have attracted special attention in the Nordic countries are ethical problems in medical research, for example, questions of integrity and the difficulty of meeting the requirements of informed consent in epidemiological and healthcare research. The frequent use of personal numbers in computerized official registers provides unique potential opportunities for population studies. At the same time it creates special ethical problems (Hermerén). Another field of increasing importance is the ethical consequences of technological and scientific developments in human genetics (for an overview see Berg and Tranøy 1989; Bischofberger et al.; Therkelsen et al; Nordisk Ministerråd, 1992, 1994). Finally, the ethical questions of health economics and setting priorities in healthcare have been debated. In 1987 in Norway a government-appointed commission produced a report on guidelines for priorities in public healthcare (Sosialdepartementet).

From the early 1960s to the end of the 1990s medical ethics underwent a sweeping transformation in the Nordic countries. From being viewed primarily as a concern only between the patient and the physician and only between colleagues, medical ethics has evolved into a field of systematic studies and extensive interdisciplinary and public debate. The scope has broadened from discussions of normative ethical issues to include metaethical analyses of the norms, values, and basic concepts of medicine. General awareness of the conflicts of interest and the incompatibility of the goals inherent in medical decision making and research has increased considerably, a development that benefits both patients and medical professionals.

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VIII. CENTRAL AND EASTERN EUROPE

This entry covers Poland, the Baltic states, Hungary, Romania, the Czech and Slovak republics, the former Yugoslavia, Bulgaria, Albania, and Cyprus. In these nations to the east and southeast of the Elbe River, the doctor–patient relationship and biomedicine itself have been characterized by the paternalism and dominance of a powerful elite within the medical establishment. Furthermore, a number of factors have profoundly influenced the status of healthcare as well as bioethics in this region. Among the most important are: (1) a relatively small percentage (around 5 percent) of the gross national product spent on healthcare, biomedical research, and environmental protection; (2) Prussian-like feudalistic attitudes (e.g., a rigid hierarchical system with a small and arrogant elite at the top and a large number of disempowered people below) preserved within universities and medical colleges. For physicians the idea of being the "captain of the ship" is still self-evident, and many believe that the behavior of older doctors provides the right ethical model for future ones.

In Hungary, Poland, Romania, the former Yugoslavia and Czechoslovakia, the Baltic republics, Bulgaria, and Albania, another determining factor that shaped medicine, healthcare, and bioethics was the form of Marxism that became the official ideology after the end of World War II. The hard ideology of Stalinist Marxism prevailed in Albania much longer than anywhere else in eastern and central Europe. These ideologies instructed morals and morality, so that only behaviors that brought people closer to communism were considered morally correct. Only infallible and omniscient party leaders knew exactly what these behaviors were.

Before World War II

In central and eastern Europe a feudal-capitalistic system existed prior to World War II. Agriculture was so dominant that in most of these countries the peasantry, unskilled agricultural toilers employed by owners of huge tracts of land, made up more than half of the population. These peasant workers were not able to rise from serfdom to free citizenry. This situation existed in large part because there had never been any genuine democracy in this region. The high degree of illiteracy, and the struggle for survival within the context of wars and ethnic strife, had a great impact on the people's health as well as on medical ethics.

A significant majority of people (normally peasants and poor urban dwellers) had no health insurance, and thus no access to professional care. Infant mortality, tuberculosis, and high overall death rates due to lack of treatment were very common. It was quite natural, for example, to view patients, usually those who were unable to pay, as teaching objects in university clinics and teaching hospitals. Healthcare was basically private, a profit-oriented endeavor that brought high earnings and social prestige to physicians—who carefully controlled their own numbers, especially the number of specialists. There existed a unified medical profession and a system of professional and ethical control. Within the profession certain basic norms concerning referrals, regulation of payments (neither overcharging nor undercharging), and advertisements were generally honored, and violators were punished.

Some dedicated individuals in these countries, usually physicians, kept the Hippocratic ethics alive by writing books and articles that, for generations, exerted a strong influence over the practice of doctors: for example, in Hungary, Jozsef Imre's *Orvosi Ethika* (Physicians' ethics), 1925; in Poland, Wiadislav Bieganski's *Mysli i aforyzmy o etyce lekarskiej* (Thoughts and aphorisms on medical ethics), 1899. These authors concentrated almost as much on the duties of the patient as on those of the physician. In addition to the Hippocratic works as a source of ethical standards, Polish physicians relied heavily on Catholic moral theology in the development of bioethics, especially concerning such issues as abortion, birth control, genetics, and euthanasia.

After World War II

As a result of the Yalta agreement dividing Europe into spheres of interest, a large part of central and eastern Europe came under the dominance of the Soviet Union. The communist leaders launched a massive industrialization program in most countries of the region. This resulted in an unprecedented mobilization of people that contributed to significant changes in class structures (e.g., millions of peasants became industrial workers), disintegration of large family units, and increased migration to urban areas. All these changes occurred just after World War II.

These countries became monolithic states soon after the war. Moral pluralism existed only underground. Marxism shaped by Soviet communism or distorted forms of materialistic socialism provided the basis for the dominant philosophy and ethics. Moral rules were dictated by party leaders who claimed infallibility and ruled coercively, resulting in a monopolistic moral climate. Behind these rules there stood an irrefutable state power and an excessive bureaucratization of power, with extreme centralization of decision making.

Political theoreticians presented a future-oriented ethics in which every desirable human goal was placed in the future state of communism. At the same time they denied the right of existence to any autonomous professional ethics, believing that their form of Marxist ethics was adequate to answer all questions raised in any area of human endeavor. Ironically, the principal slogan in all these states was "The highest value in socialism is the human being."

However, as soon as a little freedom of speech was allowed beginning in the 1980s, it became obvious that the morals of socialism were in ruins, as was the socialist economy. Despite claims that the socialist healthcare system was of high quality, free, and accessible to everyone, it became evident that this was not so. Sociological surveys in these countries showed a very poor general state of health in the populations, high mortality rates, and severely reduced life expectancies. For example, in 1994 Hungary had one of the highest cardiovascular mortality rates in Europe for people below age sixty-five, and for all ages it placed fourth, after Romania, Bulgaria, and the former Soviet Union. This situation has not changed much into the twenty-first century. The percent of women in Hungary dying from cervical cancer is twice as high as the regional average; the suicide rate is the highest in Europe and about three times the regional average; the mortality rate from malignant neoplasm is also the highest in Europe, accounting for 21 percent of all deaths. Hungary and the former Czechoslovakia have the highest mortality rates for ischemic heart disease among countries in the region. There is a difference of almost five years in life expectancy between central/eastern and western Europe.

In addition, the crime, divorce, and suicide rates in the region rank among the highest in the world. Central and eastern European countries have placed a low priority on the prevention of accidents and illnesses and to occupational diseases. They have justified their notorious environmental pollution and destruction through the repeated use of slogans regarding the need to subdue nature for the sake of human progress.

The Soviet type of healthcare system was introduced in all these central and eastern European countries. Some of the features of the Soviet system, besides those already mentioned, included: little if any freedom for patients to choose their doctors; bribes and corruption, manifested mainly in the practice of patients' tipping physicians for services; injustices in distributing limited resources; prejudice against the elderly; mechanistic patient care; and a clash between heavy demand and very limited resources. There was also, incidentally, a predominance of women in the medical profession.

For decades the problems in Soviet-style healthcare could be hidden because fact-finding studies were regarded as "top secret" and revealing them was a serious political offense. Writers on the sociology or ethics of medicine were mostly either Communist party hacks or individuals afraid of writing the truth lest they lose their jobs. Consequently, it is little wonder that people in Western countries did not understand the decay and injustice that characterized the socialist healthcare systems of the region. Only after the political and economic collapse of these once-praised systems did they come under fierce criticism. The health laws of these countries seldom mentioned patient rights, and nothing at all was said about such principles as patient autonomy. In practice, physicians and healthcare institutions had no freedom in choosing patients, nor had patients any freedom in choosing doctors. Nevertheless, people could have access to healthcare that was theoretically free and officially had a high quality level. There is no doubt that many millions of people who, before World War II, might have died due to an inability to pay for medical care, could get essential treatments under the socialist system. This, in itself, was a great achievement.

Since state and party officials accepted no professional ethics beyond an exclusive Marxist version, teaching ethics meant teaching Marxist ethics. Its main features were the unrelenting struggle against the enemies of the working class and the constant urging of people to work and produce more. Ethics was taught in colleges and universities only by the departments (or institutes) of Marxism-Leninism. These institutes occasionally smuggled issues pertaining to medical ethics into medical universities, alongside the officially allowed themes of the Hippocratic Oath and the moral ills of private medical practice. Noticing the great interest of students in ethical issues in medicine, some teachers began to deal with euthanasia, transplantation, and confidentiality. But nowhere in these countries was the teaching of medical ethics/bioethics formally established or officially supported during the Marxist-Leninist era.

The pioneers who introduced a more contemporary medical ethics in health colleges and medical universities were quite often physicians. In Hungary, the first textbook on the subject was written by psychiatrist Janos Szilard in 1972; the second comprehensive textbook, written by Bela Blasszauer, a medical ethicist with a background in law and philosophy, appeared eighteen years later in 1990. In Poland, a popular collection of essays written by doctors was recommended for teaching medical ethics at medical universities (Kielanowski). These broadly based works on bioethics contained a number of previously undiscussed issues, including patient rights, informed consent, reproductive medicine, and refusal of treatment.

Since the end of the 1980s, and continuing into the twenty-first century, in Poland and Hungary more than six thousand hours are devoted to the six-year medical curriculum, and only thirty or less of these are assigned to the teaching of medical ethics. In certain medical schools there are no seminars, only lectures, depriving students of moral debates, discussions, and analysis of cases. In several countries seminar hours consist of surveying standard medical codes and existing health laws. Even in the early twenty-first century, a distinction was hardly ever made between laws and morals, laws and ethics. In Hungary, almost all the issues of bioethics were incorporated in the curriculum, especially such topics as informed consent, euthanasia, human experimentation, and patient rights.

Only a few countries at the turn of the twenty-first century, some years after the radical political changes throughout central and eastern Europe, encourage the teaching of bioethics, allowing bioethics to begin achieving a prominent place in the medical school curriculum. Whereas all Hungarian medical universities and health colleges teach thirty hours of bioethics, usually in the third year, in the Czech and Slovak republics bioethics is taught in ten medical schools; in Slovenia thirty hours of bioethics are given to medical students and fifteen hours to dental students. In Romania bioethics is on the medical school curriculum in Bucharest and Temesvar; in Estonia, one priority is to train bioethicists and to begin teaching in this area.

The war in the former Yugoslavia gave Croatia an impetus for developing medical ethics. Until the war, medical ethics was not taught as a separate subject in medical faculties but was a part of the history of medicine, social medicine, or forensic medicine. The same was true in Bulgaria and other Balkan countries. Since 1982, Croatia's capital Zagreb has been the seat of the Croatian Center for Medical Ethics and Quality of Life. In 1992, the medical faculty of Rijeka introduced medical ethics as an independent subject. It is the ambition of the Department of Social Studies at Rijeka to establish an international center of medical ethics for the neighboring countries.

Main Areas of Ethical Concern

Several issues are of universal and particular interest and are widely discussed in the media and are in the forefront of medical ethics education.

TIPPING. Sometimes referred to as *parasolventia,* gratuity, or even bribery, tipping was one of the most hotly debated medical ethics issues in many of these countries in the later years of the twentieth century (see, for example, Adam, 1986; Page; Szawarski, 1987; and Bologa). Outside of the healthcare system, tipping has long been a common practice in many of these societies. Where there is a real or artificially created scarcity, and a tradition of some occupations with obligatory tips (e.g., waiters, barbers, concierges), the spreading of the practice to medicine may not be so surprising. The practice of slipping envelopes containing money into physicians' pockets for the treatment that was provided was not only unlawful but a violation of the basic idea of free healthcare, an idea that was supposed to make socialism superior to capitalism. In Hungary from the 1950s until the 1980s, the Communist party and the government waged a campaign against tipping. It was doomed to failure at the very beginning. So far every such attempt to eliminate or at least curb tipping has been absolutely ineffective.

Still, in the few articles on medical ethics or medical deontology that did appear in these countries, only the most courageous or the most trusted authors dared to write about tipping. Generally, they would have been prosecuted for damaging the reputation of the socialist healthcare system. Moreover, though it was (and is) a well-known phenomenon, it is very difficult to prove who took such money, how much, when, and why. In Hungary, the irony is that tipping is illegal, but nevertheless it is taxed. In Poland, since tipping makes healthcare unregulated and uncontrolled, the Code of Medical Ethics forbids accepting tips (Extraordinary Congress of Physicians). The Hungarian Code of Medical Ethics, on the other hand, only forbids accepting tips if they are given before treatment or given by colleagues working in the healthcare system (MOK).

In undergraduate medical education, ethics classes were devoted to this phenomenon. Ethics teachers were expected to educate future doctors to uphold socialist morality, which condemns taking money or any other form of bribe or gift from patients. Tipping has penetrated the whole system of medical care and hinders radical reforms in the system. Whether the cause is low professional salary, lack of public resources, the patient's feeling of gratitude, or simply a general moral decay, widespread tipping has morally eroded the system of healthcare. Some experts believe that the system would collapse without this extra income, which in some cases is many times greater than the state-paid salary. Other experts claim that no reform can be successful as long as the practice of tipping exists.

To a much smaller degree, health professionals other than physicians supplement their wages with occasional tips. A common feature of central and eastern European state healthcare systems is the very low salaries of doctors and other health workers. Still, some of these professions remain attractive because financial rewards can be hoped for as long as the system of gratuities persists. One can expect that debates will continue to probe the causes of this practice that has been causing major problems in the physician–patient relationship and also greatly distorts the relationship between physicians and nurses, as well as nurses and patients.

EUTHANASIA OF ADULTS AND INFANTS. Although discussion of euthanasia was long considered taboo in central and eastern Europe, it surfaced from time to time and aroused tremendous public interest. While laws in these countries forbid both active and passive euthanasia regardless of the status and prognosis of the patient (thus making no distinction between the active and the passive forms)—the latter is widely accepted and practiced. In Poland, euthanasia debates have been rare because the Auschwitz, Birkenau, Stuthof, Gross-Rosen, Treblinka, and Majdanek concentration camps were the sites of Nazi doctors' criminal practices and experiments. The memories of crimes against humanity and the moral teachings of the Catholic Church have made the Polish people very hostile to any argument favoring either form of euthanasia (Szawarski, 1987, 1988). In Romania, even under the communist dictatorship of Nicolae Ceausescu, there were scholars who openly advocated passive euthanasia: Erno Kiraly and Karoly Daniel introduced and endorsed the use of the living will in that country in the 1980s. In Romania it was not even possible to talk about bioethics until 1989; now there are hospital ethics committees for special care issues. In Czechoslovakia, physician Pavel Lukl advanced the idea of passive euthanasia in 1970. In Slovenia the practice of passive euthanasia is openly accepted, while active euthanasia, as everywhere else, is rejected (Straziscar and Milcinskij).

The Hungarian euthanasia debate dates back to the early 1920s, when a crusade to legalize active euthanasia, led by Karl Binding and Alfred Hoche (a German lawyer and physician, respectively), was rejected. In the 1970s the debate was renewed, and several articles and a book appeared (Boldizsar; Blasszauer, 1984; Czeizel, 1982). Those sympathetic to euthanasia were accused of deviating from the socialist norms and advocating discrimination among people on the basis of social worth (Horvath; Monory). The former Hungarian Health Act of 1972 states, without mentioning the word "euthanasia," that the physician's duty is to do the utmost until the very end for all patients, even those who suffer from incurable conditions. There is no mention of consulting the patient about his or her wishes. Nor is there discussion of what is to be done when legally mandated heroic efforts require respirators, dialysis machines, or other lifesaving devices that are in short supply.

In the case of seriously ill newborns, those who argued for the need to select infants to receive life-sustaining treatment were harshly condemned and even accused of behaving like the notorious Nazi doctor of Auschwitz, Josef Mengele (Mestyan). Because of Hungary's low birthrate, obstetricians were rewarded with promotions or premiums for infants who survived at least to the age of one. Therefore, up to the age of one the statistics are closely monitored, while beyond that age there is no incentive to provide high-quality healthcare. The decision to extend treatment to seriously ill infants belongs exclusively to physicians; in most cases the parents are not consulted. At the turn of the twenty-first century, however, some universities and county hospitals established infant-care ethics committees.

Only after the radical political changes of the late 1980s and early 1990s could such topics be discussed openly without accusations and reprisal. In Hungary a survey asked physicians, "Do you believe, in all circumstances, every possible effort should be made to sustain life?" Seventy-nine percent of responding physicians who worked in neonatal intensive-care units answered no (Schultz).

INFORMED CONSENT AND TRUTH-TELLING. Until the end of the twentieth century, in harmony with the existing paternalism, patients in central and eastern Europe usually received little, if any, information about their conditions. Physicians' unwillingness to discuss diagnosis, prognosis, and intended therapy with the patient was due to their training, their limited knowledge of contemporary bioethics, and their characteristically negative judgment regarding their patients' medical knowledge and ability to make rational medical decisions. Since the physician is the "captain of the ship," it was taken for granted that the patient's duty is to follow his or her orders. Hungarian sociologist Agnes Losonczi described the situation well when she stated that a sick person does not have as many rights as someone who seeks to have a washing machine repaired.

Generally, relatives of the patient were given medical information and left to decide whether to reveal that knowledge to the patient. Disclosure is still not common in cases of incurable disease; silence is believed to be justified by fear of patient suicide. This claim is simplistic and unsupported by fact, but despite arguments against deceiving patients, the dominant principle was expressed by prominent internist Imre Magyar: "One must never tell a hopeless prognosis, instead one must always give hope" (1978, p. 2). As long as a high court judge writes that an incurably ill patient must not be informed that a planned surgical intervention will bring only temporary relief, there is little hope that lawyers will fight for patients' autonomy (Toro). Silence still remains a practice in many places, despite the fact that after the collapse of communism, new laws in most countries require health professionals to honor the principle of informed consent.

Considering the prevalence of this practice of silence in central and eastern Europe, little can be said about the principle of informed consent. Although the law requires it, in reality the principle is not always honored. The Hungarian Health Act of 1997, for example, explicitly states that informed consent must be obtained before any medical intervention. Patients have seen some progress in regard to the right to access to medical documents, and many healthcare institutions provide documents to patients on request, without court intervention. The failure to obtain the consent of the patient drives most contemporary malpractice suits.

HUMAN EXPERIMENTATION, REPRODUCTIVE MEDICINE, AND GENETIC SCREENING. Because high technology is still far from being widespread in central and eastern Europe, research is primarily related to pharmaceuticals. The Helsinki Declaration of 1975 is accepted everywhere as a guideline for ethical research using human subjects, and in some of these countries (e.g., Hungary and Romania) the guidelines have been incorporated into laws regulating biomedical research. Prisoners are excluded from any experimental or research protocol, and nontherapeutic research uses volunteers, usually students. The Polish Code of Medical Ethics (1991) makes no distinction between therapeutic and scientific research. In practice in central and eastern Europe, however, research ethical guidelines are often violated, and the region is infamous for its loose approach to honoring ethical principles.

In a few clinics and hospitals, artificial insemination, in vitro fertilization, and GIFT (gamate intra fallopian tube transfer) programs proceed under vague and inadequate legal and ethical norms.

Genetic screening is done in most central and eastern European countries, but in some of them (e.g., Hungary and Poland) it meets with opposition from the Catholic Church. In Cyprus, President Archbishop Makarios introduced compulsory screening for thalassemia, a hereditary blood disease. The screening has considerably decreased the occurrence of this disease.

CONFIDENTIALITY. Throughout this region confidentiality is highly valued. Cases of its violation, however, hardly ever come before the courts because the laws in these countries allow many exceptions (the interest of the state, divorce cases, etc.). In practice, the violation of medical confidence is very common and goes hand in hand with the frequent violation of privacy. In the Marxist-Leninist era, the state had exclusive access to all patient records—patients were not even allowed to see them. In certain countries, like Hungary, the laws overregulated confidentiality; thus everything was viewed as a secret, which led to nothing being honored as a secret.

ABORTION. In most of the former communist countries abortion was considered a hard-won right for women. Laws were lenient, allowing abortion for simple social reasons. In Hungary, for example, 4.5 million abortions were performed between 1956 and 1990. Some view this as a national tragedy, but the antiabortion movement has only been vocal since the Communist party's demise. Abortion was (and is) a major method of birth control: In the former Czechoslovakia there were ninety-four abortions for each 100 live births in 1988 (Albert).

In Romania, however, abortion was forbidden; as a result of illegal abortions, at least ten thousand women died from complications during the Ceausescu era. In Poland, a heated debate accompanies the attempt, strongly urged by the Catholic Church, to reverse liberal abortion laws. The 1991 Polish Code of Medical Ethics allows abortion under two special circumstances: if the mother's life and health are at risk, or if conception was the result of rape. In Lithuania, opposition to abortion is increasing, and the law that allows abortion on demand in the first trimester is considered by the antiabortion group in that country to be a crime against humanity. The debate is especially intense and interesting in the former East Germany, where abortion laws were far more liberal than in West Germany (Breese).

TRANSPLANTATION. The policy of presumed consent for the donation of organs, tissues, or other biological material is universal in central and eastern Europe and provides an almost unlimited possibility for procurement of such materials for research, transplantation, and drug production. Lawmakers influenced by prominent members of the medical establishment were instrumental in enacting presumed-consent legislation that made organ procurement quite easy and opened the way to organ transplantation.

In these countries, transplantation has so far been largely limited to kidneys. In spite of the policy of presumed consent for donation, organs are as scarce as everywhere else and demand is high. The problem of organ procurement cannot be blamed on individuals' lack of willingness to donate their organs, but on the indifference of many health professionals. Their lack of motivation leaves many available kidneys unreported: In the early 1990s it was estimated that only 10 percent of potential donors in Hungary are made available to transplant centers. Age is one of the main criteria for transplant recipients, and in the 1980s and 1990s no "new" kidney was available for persons over the age of fifty. Heart and liver transplants have also taken place (e.g., in Hungary) and have received tremendous media coverage.

Consequently, the problem of obtaining organs has drawn great public interest and has become an important ethical issue for discussion. In these countries, where the medical establishments are strong and have significant political influence, the consent by the spouse or relatives of the dead person to use organs in most places is not necessary and their refusal is seldom honored.

MALPRACTICE. Charges of malpractice are very rare in central and eastern Europe, and successful lawsuits are even rarer. The most likely reason is not the superior professional skills of physicians working in these countries but the lack of patient rights, and the very powerful medical establishment that displays a high level of solidarity at critical times. The laws are worded in such a way that carelessness, negligence, or incompetence is difficult to prove as causally connected with the patient's state of health. Despite the fervent opposition of the medical profession, however, with the process of democratization and the planned reform of healthcare, and especially with the introduction of market conditions, malpractice is finding its way slowly into the patient–physician encounter. Insurance against malpractice had appeared in several of these countries by the beginning of the twenty-first century.

Western Help: Promising Changes

In central and eastern Europe the transition from a one-party system to political pluralism has opened the way to democracy with free elections, public control, and constitutional guarantees. These countries have begun to reform healthcare, allowing free choice of doctors; encouraging health insurance; providing mechanisms to finance health provision; overseeing the constant separation and reunification of healthcare and social services; allowing the extension of private practice; and encouraging reimbursement in accordance with the type of disease and number of patients.

The changes have brought a divergence of opinions on bioethical issues to the surface. Such world organizations as the World Health Organization (WHO), United Nations Educational, Scientific, and Cultural Organization (UNESCO), and the Council of Europe promise to bring help to the region. These organizations hold meetings, work out guidelines, keep data banks on bioethical activities, and encourage such endeavors. The Hastings Center in the United States has played a key role in helping to bring together the central and eastern European bioethicists and their western counterparts. It has provided books, journals, forums, and scholarships to a number of bioethicists in this region. The Centre for Philosophy and Health Care of Swansea, Wales, joined the Hastings Center's Eastern European Program in the late 1980s. In the early 1990s it obtained support from the Nuffield Foundation, which has been quite generous in giving scholarships, libraries, and journals to many of these countries. The European Society for Philosophy of Medicine and Health Care, the European Association of Centers of Medical Ethics, the Jefferson Medical College of Philadelphia, the Inter-University Centre of Dubrovnik, the Center of Medical Ethics of Oslo, and the International Association of Bioethics have helped move bioethics out of the underground. Without such international help, bioethics in the region would be still back in Hippocratic times and would be poorer both intellectually and materially. In 1999 the Central and Eastern European Association of Bioethics was established with the participation of nineteen countries to promote dialogue among the former Soviet satellite countries and help each other to (re)humanize the healthcare systems.

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IX. RUSSIA

The history and state of medical ethics in Russia in the twentieth century has been defined by the influence of the communist regime. Communism, its evolution, and its deterioration, exercised and will exercise for a long time to come, a pervasive influence on the most diverse spheres of social life, including the area of medicine and health care.

Prerevolutionary Period

The ascendancy of the Bolsheviks in 1917 sharply interrupted the stormy development of Russian healthcare, whose beginnings coincided with the great reforms of 1861, which eliminated serfdom for a peasant population that comprised the overwhelming majority of the country. Prior to those reforms, peasants could turn only to the village folk doctor (practitioner of popular medicine) or, in certain cases, healers from among the Russian Orthodox monks. For the most part, the healthcare of serfs had been the responsibility of their owners.

One of the most important of the mid-nineteenth-century reforms was the creation of elected local self-governments: the *zemstvos,* which received some autonomy from the central authority. The organs of local self-government levied taxes that were used for general needs, including building and equipping hospitals, ambulances, homes for orphans and for the elderly, and other needs. *Zemstvos* also hired and paid doctors, doctors' assistants, nurses, and other medical personnel.

In 1864, 530 medical centers were opened in Russia. Each center served an average area of 4,860 square *versts* (one *versta* equals two-thirds of a mile) and a population of about 100,000 people. After fifty years, in 1914, there were 2,800 such centers, each of which served an area of 880 square *versts* and 27,000 people. Expenditures for *zemstvos* healthcare grew from 2.5 million rubles in 1870 to 57.7 million rubles in 1912. Before 1861, the country had 519 hospitals; by 1914, it had 1,715 (Solov'ev). The local doctor's ideals formed the ethos of Russian medicine. The ordinary *zemsky* (hired and paid by the *zemstvos*) physician had a modest social standing and a very modest income. He earned about as much as a factory worker. *Zemsky* physicians represented one of the largest groups within the Russian intelligentsia, along with *zemsky* teachers. Service to the people (i.e., the peasants) was a defining characteristic of the intelligentsia.

The ignorance and poverty of the peasants, whose work fed the whole country, evoked among the intelligentsia that considered itself dependent on the peasant class not only sympathy, but a guilt that moved them to active work on behalf of the peasants. Many of the intelligentsia, neglecting their own material well-being, saw as the highest meaning of their lives the unselfish service to the people. Thus was born the movement called the *narodniki,* that is, representatives of the intelligentsia who saw that their responsibility was to "go to the people," to work selflessly in the most far-away places in Russia. "Every comfort of life I have," wrote one of the most committed leaders of the *narodniki* movement, the philosopher and sociologist Petr Lavrov, "… is purchased with the blood, sufferings, and work of the millions.… I will discharge my responsibility for the cost in blood of my development, if I use my development to lessen evil now and in the future" (Solov'ev, p. 43).

Along with the more radically disposed social-democratic intelligentsia, the mass of *zemsky* physicians were very dissatisfied with the actual state of affairs, but they preferred the path of reform and the laborious work of education to the revolutionary path of violence. The first obstacles of the path of reform were the deep prejudices and lack of confidence of the peasants, their resistance to change from traditional lifestyles, including acceptance of medical aid or elementary hygienic recommendations.

The *zemstvos* system permitted physicians to achieve an unprecedented degree of professional autonomy; the government, however, constantly strove to curtail this autonomy. During these years, periodic meetings of local physicians were held to discuss current problems within the profession. In the *zemstvos*, physicians, together with representatives of the administration, participated in the formulation of local policies for healthcare. In 1883, the newly formed Society of Russian Doctors to the Memory of N. E. Pirogov assembled physicians of all specialties. The society, named in honor of the outstanding Russian surgeon Nikolai Pirogov (1810–1881), was the first independent organization of physicians. The Pirogov Society significantly influenced the formulation of ideas and policies about healthcare. It fought actively for improvements in the working conditions of peasants and factory workers, and mostly because of its efforts, in 1903 a law was adopted regarding the liability of owners for accidents in the workplace. The society strove to improve the health education of the people and battled for increases in budgets for medicine and healthcare. In 1910, the society blocked efforts of the authorities to unify the healthcare system and impose upon it strict government control. The society monitored physicians with regard to the norms of medical ethics, and fostered discussions about medical practice that touched on moral and ethical problems.

Medical ethics in Russia evolved, for the most part, in the light of European traditions, even though the specifics of Russian medicine left a noticeable mark. General practitioner and hygienist Matvei Mudrov (1776–1831), one of the first in Russia to concern himself with problems of medical ethics, believed that the Hippocratic Oath could be the foundation of a code of conduct for Russian physicians. Nikolai Pirogov, whose ideas attracted particular attention to the problem of medical mistakes, and Vjacheslav Manassein (1841–1901), general practitioner and organizer of state and local medicine as well as editor of the journal *Vrach* (Physician; 1880–1901), which devoted significant attention to discussions of medical ethics, developed their ideas along the same lines. Among the characteristics of Russian medical ethics of the prerevolutionary period, the marked paternalism connected with the long-standing tradition of subjugation of the personality to the state or to the peasant community stands out. Typical patients were illiterate and ignorant peasants who were considered unable to make reasonable decisions in their own best interests and, therefore, required direction from others.

The other significant characteristic was the peculiar understanding of social justice, which generated a feeling of eternal indebtedness to the most impoverished and unfortunate people in society. Not by accident, a physician of German origin, Fyodor Gaaz (1780–1853), who settled in Moscow and devoted himself to the medical care of prisoners in jails and their children, enjoyed great moral authority both during and after his life. Unselfish and self-sacrificing service was demanded of physicians who understood their duty, including the willingness to work at any time of the day or night, to venture into any weather at the first call to reach the bedside of a sick person as quickly as possible, and to spend as much time at his or her bedside as necessary. To appreciate this high idealism, one should bear in mind the vast expanses of Russia, which were (and are) far from being fully connected by roads.

These ideals were also reflected in the literary works of doctors who became famous writers: Anton Chekhov (1860–1904), Vikentii Veresa'ev (1867–1945), and Mikhail Bulgakov (1891–1940). Writers in Russia were traditionally leaders of public opinion and exerted great moral influence, so the works of Chekhov and Veresa'ev that were dedicated to *zemsky* physicians deeply influenced the education of the intelligentsia. In his *Physician's Notes* (first published in 1901), Veresa'ev sharply criticized violations of ethics in medical practice and research. For many years this book was at the center of significant discussions in Russian as well as western European literature. The ideal of the *zemsky* doctor was so deeply ingrained that it even survived the Bolshevik regime.

Communist Period

The communist regime came to power on the crest of a world war that was especially terrible and destructive for Russia. Immediately, the new government had to confront serious problems inherited from previous governments. Social collapse, hunger, and poor sanitary conditions caused huge epidemics of cholera, typhoid, and smallpox, so that the new government mounted a fierce fight against contagion (mass vaccinations, disinfections, isolation of infected, sanitary measures, and so on). Measures were taken to coordinate healthcare activities, resulting in extreme centralization. In July 1918, the Peoples' Commissariat for Health Care in the Russian Republic was founded.

This commissariat was the first national ministry for healthcare in the world, created a year before the British Ministry (Kazer). Under the leadership of the first Soviet People's Health Care Commissar, Nicholas Semashko (1874–1949), a doctor close to Lenin, all the departments of the government having anything to do with medical services were united under one ministry (Knaus). In subsequent years, however, organizations that were autonomous from this commissariat gradually appeared, though healthcare services for the railroads, the army, and other kinds of special services remained centralized. Healthcare services were supported financially by the state and were free to the people. These measures of the new authorities provoked severe criticism from members of the Pirogov Society who complained that the introduction by Soviet authorities of free healthcare would deprive physicians of their independence and initiative, both of which had been fought for during the earlier reforms. The regime, however, was not inclined to compromise with critics, especially with any type of organized opposition. The all-Russian Federation of Medical Workers (*Medsantrud*) was created in opposition to the Pirogov Society. The Pirogov Society was liquidated by 1922.

Medsantrud attempted to conserve the remains of democratic self-management of the ranks of medical workers, and this brought upon it the wrath of the authorities. For example, one of the principal organizers of Soviet healthcare, the People's Deputy Commissar for Health Care, Zinovii Solov'ev (1876–1928), wrote in 1923: "What is this 'public' and what in general can 'public' mean in the conditions of the Soviet government? Two different answers to these questions are not possible. Our public is to work on all aspects of Soviet life on the basis of the independent revolutionary class, the bearer of the proletarian dictatorship, the proletariat and its ally, the impoverished and the middle peasant class" (p. 54).

In this way the regime essentially redefined the social role of the physician. The physician was now considered a representative of the hostile bourgeois class, tolerated only as a specialist and permitted to work only under the strict control of the proletariat. In essence, however, that control was exercised by government and Party bureaucrats.

Meanwhile, the 1917 revolution and the ensuing civil war led to a serious decrease in the number of physicians in the country. In the first years after the revolution, about eight thousand physicians left Russia. Many doctors died from hunger and disease. Between November 1917 and August 1920, 46 percent of all physicians in Petrograd died (Knaus). In response, the authorities attempted the rapid training of new physicians. People were admitted into medical schools without even a secondary education and, at times, without even being able to read or write; final exams were eliminated. A system of "brigade education" was introduced whereby the knowledge of the group of students was evaluated on the basis of an oral exam of one of the students, on the grounds that the better prepared students would help the unprepared students in their training. There was, then, a rapid increase in the number of physicians, although, of course, at the cost of serious decline in professional standards.

Such reliance on collectivism was anything but accidental. Medicine, like everything else, was viewed from the class perspective. Individualistic bourgeois medicine was countered by collectivist proletarian medicine. The aim of the new medicine became the following: "The conservation of the life forces of the proletariat and the building of socialism in and of itself, of course, must be for us the main compass with respect to which a question regarding the tasks of our contemporary medical practice will be posed" (Solov'ev, p. 187). Consequently, the entire area of medical practice had to be reconsidered: "Characteristic of today's clinics is the fact that they were formed and exist today as the products of a discipline that is strictly individualistic. Contemporary capitalist society leaves its mark on medicine in the area of theory as well as particularly in the area of practice. The individualistic demand for care of a single person and not of a human collective creates corresponding methods of thought and practice" (p. 175). Key to the problem of shaping the approach and content of medical practice, according to Solov'ev, was the answer to the question of how "it is possible to strengthen the health of the human collective and restore [its] health once it has been destroyed" (p. 171).

These words affirmed the traditional approach of Russia regarding the importance of prevention in healthcare. This approach was implemented by making the work conditions and living conditions of people healthier, as well as by considering the social and ecological causes of many illnesses. At the same time, these comments by one of the leaders of Soviet medicine in its formative stages show clearly Bolshevism's negation of the self-worth of the individual, the reduction of human individuals to the role of cogs in a system of production, and the subjection of the individual to social expediency.

In the view of the Bolsheviks, considerations of class expediency defined the areas of morals and ethics. For example,

> The much celebrated theoretician of petty bourgeois morals, Immanuel Kant, advanced in his time a moral demand: "Never look on another person as a means to an end but always as an end in itself.…" Can you imagine how far the proletariat would have advanced in its revolution if it had allowed itself to be guided by such a demand and not by the completely contrary demand of class interests.… The highest wisdom of the proletarian struggle consists not in that everyone claims his own rights, but in that everyone must selflessly, almost spontaneously, without phrases of superfluous gestures, without demanding anything for himself, pour all of his energy and enthusiasm into the common stream, and work for the goal, with the entire class, perhaps be the first to fall on the road. (Preobrazhenskii, 1923, pp. 72–73)

A systematic elaboration of medical ethics that could have corresponded to the ideological purposes of the new regime and the new system of healthcare was, with rare exceptions, not attempted. To the extent that the physician was considered as only an auxiliary, rather than as an independent professional, the idea of posing questions of specific medical ethics was deemed superfluous. Even though some problems had a distinctly moral-ethical content and as such were quite controversial (for example, abortion, confidentiality, and medical mistakes), they were not viewed as problems specific to medical ethics. In general, medical ethics or, as it was usually referred to, "physicians' ethics" was understood as the affirmation of a corporate morality opposed to the class interest of the proletariat. The viewpoint was rather widespread that Soviet people, regardless of their sex and profession, should be guided solely by the norms of communist morality, and that any specific norms of professional morality would only limit the scope of and adherence to the general norms.

With respect to medical education, systematic courses in medical ethics did not exist in prerevolutionary Russia nor were they created by the new regime. After the revolution, in fact, the initiation of new physicians by means of a professional oath, a revision of the Hippocratic oath, was eliminated, even though that practice had been obligatory since the beginning of the twentieth century. The social humanitarian preparation of medical students was limited to a course in Marxism-Leninism.

Against this background of ethical relativism and nihilism characteristic of the Bolshevik scorn for traditional moral values and principles, the earlier traditions of medical ethics could still be found. Among those who received medical education, many were inspired by the ideals of disinterested and self-sacrificing service that had characterized the ethos of *zemstvos* healthcare. The medical profession attracted intellectuals drawn to that sphere because it was not under the sway of particularly severe ideological control. The norms and values of medical ethics were transmitted under these conditions by means of informal communication and daily contact between professors and students and between experienced physicians and new colleagues.

STABILIZATION OF THE REGIME. From the end of the 1920s to the beginning of the 1930s, the communist regime consolidated itself; its radical revolutionary policies were gradually transformed into pragmatism. This pragmatism, of course, was specifically Soviet, oriented to the resolution of problems of building a communist state. All aspects of civil life began to be affected by organs of administrative and bureaucratic planning and management. Healthcare also fell under the planning system: The number of physicians in various specialties and the number of hospital beds, hospitals, and polyclinics in cities and villages, the direction and topics of medical research, the development of facilities in sanitoriums and health resorts—all were centrally planned.

Planning presupposes qualitative evaluations and measurements, and from this perspective Soviet medicine obtained impressive results. The number of doctors had long since passed one million (about 1.2 million in 1983), and a single doctor had about half as many patients as his or her counterpart in the United States. Many infectious diseases were practically eliminated, the frequency of infant mortality was significantly lowered, and the average life expectancy was increased. By these and certain other indicators the country approached the level of more developed countries or became equal to them. The results of the Soviet organization of healthcare attracted much attention outside the Soviet Union, particularly among Third World countries.

Policy in the area of healthcare, however, was always viewed as subordinate to policy in the economic sphere. Thus, when the Communist Party began to emphasize the industrialization of the country in 1929, the central task of the healthcare system was designated as the improvement of medical services to workers in the industrial centers, especially in the mining and metallurgic centers.

The system of healthcare that developed and remained relatively stable for many years was quite original in several respects. The physician became a civil servant, a kind of clerk, whose activities, regulated by numerous bureaucratic rules, consisted largely of writing reports that reflected his or her implementation of these rules. Any appearance of personal initiative was dangerous, especially because the physician's mistake could easily be interpreted as intentional, the act of a class enemy.

In relations with patients, the physician was a representative of state authority rather than an autonomous actor. Lack of autonomy, in its turn, made less urgent the problems of personal choice and responsibility. Low salaries of ordinary physicians as well as their low social prestige were among the reasons for the large number of female physicians in the country (about 80 percent). It was thought that physician's work was not so difficult, did not demand essential physical force, and therefore was well suited for women.

The social interaction of the physician and the patient was paradoxically characterized by two mutually exclusive elements. On the one hand, the long-reigning paternalism became even more entrenched, to the point where the individual regarded his or her health as a kind of state property—and therefore no one's—which could be squandered. On the other hand, health was viewed as the highest and ideal value, so high in fact that it was simply indecent to measure it by any sort of material equivalent, such as money. So, it was presupposed that self-sacrifice and unselfishness on the part of a physician was a kind of moral norm. The combination of these alternative, conflicting attitudes permitted the rather modest financing of medicine and healthcare, at a level that would ensure only the replacement of the labor force. Another characteristic of Soviet medicine was that patients were not permitted to choose their physicians.

Medical Deontology

In 1939, the famous surgeon and oncologist Nikolai Petrov (1876–1964) published an article, "Questions of Surgical Deontology," in the *Bulletin of Surgery.* In 1945, he published a small book by the same title. These publications were the first steps in the rehabilitation of medical ethics. Petrov justified the use of the term "medical deontology" by arguing that the concept of "physicians' ethics" had a narrower meaning. The latter, Petrov maintained, referred only to a corporate morality, reflecting the scientific and professional career interests of doctors (Petrov). This may have been a subterfuge designed to circumvent the ideological taboo on the problems of medical ethics. It is noteworthy that such an attempt was made by a doctor who received his training and education before the 1917 revolution.

Wide discussion of the problems of deontology did not begin until the middle and at the end of the 1960s when writings on this topic by medical practitioners and philosophers began to appear. The 1969 First All-Union Conference on the Problems of Medical Deontology in Moscow played an important role in this development. In 1971, state authorities approved the text of a document called "The Oath of the Physician of the Soviet Union." The oath was required for all graduates of medical institutes who intended to enter into professional activities. The text of the oath demanded that physicians be governed by the norms of communist morals and spoke more of their responsibility to the people and to the Soviet government than to the patient.

At the same time, medical deontology was introduced into the curricula of the medical institutes. However, notwithstanding reports to the contrary in a number of Western sources, courses on deontology and medical ethics appeared only in the beginning of the 1990s. In most medical schools the subject of deontology appeared to be spread out in separate courses in medical specialties, and philosophers had not been drawn into its teaching.

After 1971, the stream of literature in the area of deontology increased sharply. The contents of these publications, however, were often one-dimensional, moralizing reflections: criticism of the anti-humanist Western medical system coupled with a confirmation of the indisputable moral superiority of Soviet free medicine and the disinterested Soviet doctor. Attention to concrete cases, mainly from the personal practices of the authors, was frequent. Authors, however, avoided discussion of truly difficult cases that presented moral or ethical conflicts. Apart from the fact that this literature signaled the presence of ethical problems in medicine, its real interest lay in its increasing references to the moral authority of prerevolutionary Russian medicine and its attempt to present Soviet medicine as a direct and uninterrupted continuation of the best traditions of the past.

Crisis and Breakdown of State Medicine

The government-supported awakening of interest in medical deontology coincided with the first signs of crisis in Soviet medicine. Starting in the 1970s, but primarily in the 1980s, the authorities and a small circle of specialists, and then finally the public at large, became aware of the high rates of infant mortality and the consequent reduction of life expectancy. The press began to write more often about failures in the medical field and about the callousness, greed, and low level of competence of physicians and other medical personnel. Notwithstanding the state's propaganda efforts, the people, who were losing confidence in physicians and in official medicine, turned more often to practitioners of alternative medicine.

These failures, as well as many others, revealed that the centrally planned and managed free medical system had used up all its own resources, among them the moral resource that had enabled the authorities to make do with "cheap" medicine for so long. It was clear that the communist modernization was accompanied by an erosion of traditional values, which was particularly noticeable as the medical profession became so large and more and more specialized. The turn to deontology was in some sense dictated by the efforts to mobilize the neglected moral factor in the face of growing medical crises. This attempt, to the extent that it appealed to values from the past, however glorious it might have been, could not succeed.

The attempt made during *perestroika* in 1987 to reform the system of healthcare without changing anything essential turned out to be unproductive. In 1991 the Russian parliament adopted a law providing for medical insurance for Russian citizens: This was an admission of the failure of state medicine. The stability during the last decades of the state system of healthcare was assured, even though the principles of free medicine and equal access to healthcare for all, in practice, deteriorated. The bribes that had to be given to physicians by patients and their families to some extent compensated for the pitiful financial circumstances surrounding healthcare. The availability of a special medical-care system for party members and other members of the *nomenklatura,* people given leading positions in various fields by the Communist party, made them less inclined to pursue radical reforms.

Previous stability itself made the process of thoroughgoing reform particularly painful for the people. The deeply rooted tradition of paternalism hindered the acceptance of personal responsibility for one's own health. In addition, social justice often was viewed as a pure leveling of differences. Finally, most people could not accept the idea that healthcare could be paid for, even though "free medicine" proved very inefficient.

Acute economic, ecological, sociopsychological problems during the period of reforms led to serious worsening of health of the population. For the first time since the beginning of the nineteenth century, mortality in Russia exceeded birth rate; morbidity, including infectious diseases, grew rapidly. These factors along with barely controlled commercialization of healthcare, limitation in access to medical services for most people, expense, and shortage of many crucial drugs generated on the part of many Russians a nostalgia about the free healthcare system of the past.

Specific Areas of Ethical Debate and Decisions

This section provides an overview of only those problems of medical ethics that have been treated in Russia in a rather original fashion.

ABORTION. Abortions in prerevolutionary Russia were considered criminal acts. In 1920, the Soviet government became the first in the world to legalize the artificial termination of a pregnancy at the request of the woman. Then, in 1936, in seeking means to improve the demographics, abortions were once again criminalized; in 1955, with some liberalization of the regime, they were again legalized to lessen the negative social consequences of widespread illegal abortions. The passage of legislation in 1993 permitted abortion at the request of the woman up to twelve weeks of pregnancy for any reason, and up to twenty-two weeks with consent of the woman for medical reasons. Abortion became a common means of birth control. The use of abortion for birth control may have resulted from a lack of contraceptive alternatives, as well as inadequate public knowledge and education about these matters.

Although abortions have been considered morally reprehensible, the attitude of people in concrete situations has been rather liberal. For many years the Russian Orthodox Church, the most influential confession in Russia, was prohibited from taking positions on any question of social significance. Even after the persecution of religion ceased, the church had not shown itself ready to express an opinion on most matters of biomedical ethics. One exception was the stance the church took on abortion. In 1990, the Patriarch of the Russian Orthodox Church confirmed the church's unequivocal censure of abortion; yet on a practical level priests tended to be more tolerant because of the hard economic situations of many women. In 1992, the Right to Life Society was formed to oppose abortions and was supported by the Russian Orthodox Church.

CONFIDENTIALITY. Controversial discussions occurred in the 1920s concerning the problem of physicians' secrets. The People's Commissar for Health Care, N. Semashko, announced "the abolition of physicians' secrets," which were understood as holdovers of bourgeois medicine. This position was based on the notion that an illness was not a disgrace but, rather, a misfortune. Full abolition of physicians' secrets would occur, it was thought, when that concept was accepted by the population. Until that time the necessity of maintaining physicians' secrets was linked to the fear that eliminating them would create an obstacle for people seeking doctors' advice and help.

Even though Semashko himself, no longer a people's commissar but a practitioner, spoke out in favor of physicians' secrets in 1945, his earlier viewpoint turned out to be more influential, for many healthcare workers did not understand the need for confidentiality. The requirement of confidentiality gained a legal basis only in 1970. Up to 1993, however, a patient who returned to work after illness was obliged to bring a sick-leave certificate from a physician. This certificate containing the patient's diagnosis was available to many people. New legislation changed this norm: A diagnosis would be filled in only with the consent of a patient; without consent only general reasons (disease, trauma, etc.) could be indicated.

DISCLOSURE TO PATIENTS. The subject of disclosure to patients has been marked by strong paternalistic tendencies. The overwhelming majority of those writing on the subject considered it unacceptable to inform a terminally ill patient of his or her diagnosis and prognosis. The practice of informing patients was not generally regulated, so concrete decisions were left to the discretion of the treating physician.

However, Russian laws on psychiatric treatment and on transplantation of human organs and tissues, which were adopted in 1992, contained norms of informed consent for patients and donors. Included in the legislation were norms governing the protection of the health of citizens, granting the patient the right to know his or her diagnosis and prognosis as well as the right to refuse this information.

The law also established specific rules regarding receipt and documentation of informed consent of patients undergoing biomedical experiments. The advent of *glasnost* (openness) in 1985 permitted public disclosure of the terrifying information about fatal biomedical experiments (such as testing of nuclear or chemical weapons, new drugs, etc.) carried out on soldiers of the Soviet Army and on prisoners under Joseph Stalin (1879–1953) and Lavrenti Pavlovich Beria (1899–1953) and even later. Some steps were undertaken for ethical control of biomedical experiments, but as of 1994 most researchers were not aware of internationally accepted norms of experimentation.

EUTHANASIA. As early as prerevolutionary times the well-known Russian jurist Anatoly Koni (1844–1927), opposing the dominant view, defended the admissibility of euthanasia under certain exceptional circumstances: (1) conscious and insistent requests of the patient; (2) the impossibility of lessening the suffering with known methods; (3) agreement by a commission of doctors on the impossibility of saving the life; and (4) preliminary notice of the decision to the prosecutors. A law permitting mercy killing of a patient was adopted in the criminal code of 1922, but in subsequent legislation it vanished. It was practically inoperative and little is known about its utilization.

Sociological studies conducted among physicians in Moscow indicated that about 40 percent of them viewed euthanasia as permissible if the patient wishes it or in exceptional cases. However, many respondents did not seem to know what the word *euthanasia* meant (Bykova et al.). The public's attitude toward euthanasia appeared more tolerant: According to the findings of one public opinion poll, 55 percent of the respondents approved and 19 percent opposed the mercy killing by a physician of a terminally ill patient who wishes to die.

The majority of specialists in medical ethics, including physicians, jurists, and philosophers, have with rare exceptions adopted a sharply negative opinion of active euthanasia. The prohibition of active euthanasia, understood as acceding to a patient's request to hasten his or her death by medical means, was included in a law for "the protection of the health of citizens of the Russian Federation." Nonetheless, such forms of passive euthanasia as the refusal by the patient of treatment or the withdrawal of life-sustaining treatment from a hopeless patient were considered acceptable. The public's attitude toward euthanasia remained rather tolerant.

EUGENICS AND MEDICAL GENETICS. In the first decades of the twentieth century, Russia was among the world's leaders in the development of genetics. This interest in genetics generated a rather strong eugenics movement, which flowered in the 1920s. To some extent this interest may be explained by the consonance of eugenics with the central communist ideology of the creation of a "new man" who would be free of the "birthmarks" of capitalism. One of the leaders of Russian genetics, Nikolai Kol'tsov (1892–1940), following Francis Galton, spoke of eugenics as the religion of the future that still awaited its prophets. It was the powerful ruler of nature and the creator of life that would permit the creation of a perfect type of human being (Adams). In the 1920s, when ideological control was not yet particularly strong, the possibilities for forming a new human being were suggested by psychoanalysts as well as by those in other areas of scientific research.

The paths of communist ideology and eugenics diverged rather quickly, however. The principal criticism of eugenics was that the new human being should be formed by social, and not by biological, methods. Eugenic projects in Russia, because of such criticism, were interrupted long before they had achieved any practical realization. Inasmuch as Russian eugenics at that time was a form of medical genetics, the blow to eugenics also impeded research in human genetics. This setback was only the first of many caused in the Soviet Union by the reigning ideology associated with Trofim Lysenko, who taught the thesis of inheritance of acquired characteristics, which lasted until Khrushchev fell from power in 1964. Even afterward the development of medical genetics ran up against ideological obstacles, since many associated it with the eugenics that served as a basis for the murderous racism of the German Nazis. Since the beginning of *glasnost* and the end of ideological censorship, some far-reaching proposals with possible eugenic interventions in the Russian population have been published, among them, killing newborns with serious defects and forced sterilization of alcoholics and drug abusers. Genetecists, however, have been rather passive in relation to public discussions of these topics. Despite the growing public concern about the genetic effects of radiation and environmental pollution and despite rather intensive research in the field of medical genetics, Russia now has only limited capacity for genetic screening and counseling except in a few large cities. In 1994, the Russian human genome project started to study possible ethical implications of recent developments in human genetics.

REPRESSIVE PSYCHIATRY. The practice of using psychiatry as a weapon in the struggle against political dissidents began under the regime of Nikita Khrushchev. The first victim was Zhores Medvedev, who was punished for wanting to publish a book on the crushing of genetics in 1948. Medvedev was diagnosed by state psychiatrists as mentally deranged and was committed for treatment. The widespread use of psychiatry in this manner did not occur until later, during the regime of Leonid Brezhnev. Hundreds of victims, without any judicial proceedings and often without even being physically present, were sentenced for indeterminate lengths of time to special psychiatric hospitals under the jurisdiction not of the Ministry of Health but of the Ministry of Internal Affairs. “Treatment” ranged from “wall therapy”—merely keeping patients inside four walls—to forcible psychotropic injections. The practice came to be used even against ordinary citizens who had conflicts with local authorities. The Soviet psychiatrist Andrei Snezhnevsky (1904–1987) worked out the basis for this method of repression, using the concept of “creeping schizophrenia” with symptoms such as the “spreading of slander,” “exaggerated religiosity,” and “excessive appreciation for the West.” The center for expert studies and diagnoses of such afflictions was the V. Serbsky Institute for Forensic Psychiatry in Moscow.

Many cases of psychiatric repression became well known in the West. This caused the breach in 1983 in relations between the World Psychiatric Association (WPA) and the Soviet All-Union Society of Psychiatrists and Narcologists. The membership of the society in the association was renewed only in 1989. That same year, the Independent Psychiatric Association, founded in the Soviet Union in 1988 and actively involved in exposing psychiatric abuses, gained unconditional membership in the WPA.

A 1989 fact-finding mission of U.S. psychiatrists to Soviet psychiatric hospitals discovered that the malice of psychiatrists or of repressive state bodies was not the only cause of the abuse of psychiatry. Other factors included the poor training of medical personnel, the absence of adequate judicial mechanisms for the protection of the rights of patients, and the low level of ethical standards for hospital personnel. The aim of a 1992 law was the improvement of psychiatric treatment. According to this law, involuntary hospitalization in a psychiatric hospital was permissible only on the basis of a court’s decision. The position of supervisor, to protect the rights of patients, was to be established in every psychiatric hospital. In 1993 the Russian Society of Psychiatrists—the most influential psychiatric association—adopted the Code of Professional Ethics of the Psychiatrist.

TRANSPLANTATION. The adoption in 1992 of a “law on the transplantation of human organs and tissues” provided an example of the direction of the reforms in Russian healthcare. Before adoption of this law, questions such as the determination of brain death, the rights of donors and recipients, and the permission for the removal of organs and tissues from cadavers were decided on by internal instructions of the Ministry of Health, instructions that were unknown to the population. On the one hand, this situation impeded the practice of organ and tissue transplants and, on the other hand, facilitated abuses, such as commercial use of human organs or the too-hasty declaration of brain death. The law on transplantation at last provided a legal basis for this area of medicine, and more important, became one of the first laws relating to healthcare using principles and practices accepted in the world community.

Perspectives for Russian Bioethics

Interest in the problems of bioethics grew as Russia emerged from isolation. Such interest evolved mainly through the efforts of a small group of enthusiasts. Neither the leadership of the healthcare system nor the government bureaucracy nor the public itself grasped the critical importance of problems in bioethics. Democratic reforms, to the extent that they will continue, will change this situation. As reforms develop, healthcare will become one of the most important priorities of social legislation and public interest. The reform of medicine and healthcare will make both physicians and patients much more independent and, consequently, responsible parties in social interactions.

Foundations of Legislation of Russian Federation on the Protection of the Health of Citizens, adopted in 1993, as well as other laws filled in many gaps in healthcare and legal regulations. The law opened the door for the creation of ethical committees (commissions) at federal (similar to France), regional, and local levels as well as in hospitals and biomedical research institutes to defend human rights in healthcare areas.

In 1992 the Russian National Committee on Bioethics (RNCB) was established under the aegis of the Russian Academy of Sciences. The main activities of the RNCB include the development of ethical guidelines for scientific research, proposal of legislation in healthcare and biomedicine, promotion of bioethical training and education, preparation of textbooks and methodical materials, stimulation of discussions on bioethical issues in the mass media, and encouragement of bioethics in Russian regions as well as in countries of the Commonwealth of Independent States. The RNCB prepared documents on such acute problems as mass vaccination and protection of human rights, ethical aspects of transplantation of organs, ethical regulation of new reproductive technologies, ethical control of biomedical experiments, and so forth.

“Free medicine” has not been a social priority, and whoever leads the government can find more critical need for expenditures than healthcare. But the failure of free medicine, however painful for the population, will provide the basis to hope for a better future. Already the harsh reality has caused people to realize that the government or the Ministry of Health is not alone responsible, nor will either pay for the people’s health; people themselves must do so. People are also beginning to realize that medicine and healthcare are areas in which the fundamental rights and vital interests of people are realized (or not realized) and, consequently, this area requires moral and ethical consideration as well as legal regulation.

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TRANSLATED BY RICHARD SCHNEIDER

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MEDICAL ETHICS, HISTORY OF THE NEAR AND MIDDLE EAST

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I. Ancient Near East
II. Iran
III. Turkey
IV. Contemporary Arab World
V. Israel

I. ANCIENT NEAR EAST

In its conventional sense the term *ancient Near East* includes a diverse range of cultures. This article limits its coverage to Mesopotamia from the Sumerian period (beginning ca. 3100 B.C.E.) through the Babylonian period (ending with the Persian conquest in 539 B.C.E.), Egypt from about 3100 B.C.E. to its conquest by Alexander the Great (332 B.C.E.), and Israel from the Exodus (variously dated from 1446 B.C.E. to 1280 B.C.E.) to the destruction of Jerusalem by the Romans in 70 C.E.

In both Mesopotamia and Egypt thriving medical professions existed throughout the period under consideration. In Israel a distinct medical profession appears to have developed very late (second century B.C.E.). If anything that could be called medical literature was produced in Israel, it was at the very end of our period. By contrast a large body of medical literature, some of which has survived, existed in both Mesopotamia and Egypt.

Conceptual Observations

No writer in the ancient Near East appears to have addressed what we call medical ethics as an area of specific discussion. No one seems to have written even on that weak precursor of medical ethics known as medical etiquette. Nevertheless, medical ethics existed as much in the ancient Near East as in any other culture. The medical ethics of any society is generally congruous with that society's moral perceptions. As a subset of its ethical values, medical ethics will be as simple or as complex as any culture is monolithic or pluralistic. An ethical framework exists for the practice of medicine wherever those who treat disease, even in a magico-religious form, administer healing. In seeking to reconstruct the medical ethics of any society, one must understand the broad cultural framework within which healers function in order to appreciate the ethical considerations that directly or indirectly govern the practice of their art. This picture may be supplemented by the incidental illumination of relevant aspects of medical practice gleaned from medical and other literature, as well as by evidence of legal constraints upon the activities of practitioners of the healing arts.

J. V. Kinnier Wilson remarks that "Medically, as in other respects, Egypt, Mesopotamia, and Palestine were three quite different worlds. Each developed along independent lines of thought and was of its own kind" (p. 337). While this statement is essentially correct, Mesopotamia and Egypt are sufficiently similar when contrasted with Israel that they may be considered together, while Israel, because of its unique religious and moral outlook, merits separate treatment.

Mesopotamia and Egypt

THE UNDERSTANDING OF DISEASE AND THE ROLE OF PHYSICIANS. In Egypt and Mesopotamia all aspects of life were molded by religions that were naturalistic and polytheistic, based on the worship of cosmic forces, and steeped in magic. Health and physical wholeness were perceived as being present so long as life remained in harmony with the forces of deified nature, while illness reflected a dissonance between the individual and his or her total environment. It was imperative to identify the cause of sickness in order that the appropriate treatment might be given for the restoration of health. Edwin Yamauchi isolates four main sources of illness, which were not mutually exclusive: (1) a divine source which sent illness as a punishment for sin; (2) a demonic source which indwelt or tormented the individual; (3) a magical source sent from a sorcerer or practitioner of black magic; and (4) a natural source as discerned by experience. The modes of treatment would include: (1) prayer, sacrifice and repentance; (2) the exorcism of demons; (3) counter-magic; and (4) empirical applications of medicine, drugs, or surgery. Quite frequently different kinds of treatment were combined. (p. 99)

In both Mesopotamia and Egypt the treatment of disease attributed to divine, demonic, or magical sources fell within the purview of a class of healers different from those who treated disease attributed to natural causes. In Mesopotamia the latter class (the *azu* or *asû*) appears to have emerged much earlier than the former (the *āšipu*). According to Kinnier Wilson, "In Sumerian times—as it would seem—the *azu* was the only doctor who was prominent in society. It is only at a later period, in Babylonia, that one meets the *āšipu,* a specialist in incantations and a kind of medical 'diviner,' capable of reading the 'signs' of suffering or of divine punishment" (p. 349). The two professions were functionally and ideologically distinct, and only the *āšipu* was a priest. Similarly, in Egypt, the *seynu* (or *swnw*), like the Mesopotamian *asû,* was concerned with the treatment of physical conditions, whether sicknesses or injuries, for which a proximate, natural causality was evident; the *heri-ha'ab,* the equivalent of the Mesopotamian *āšipu,* was essentially a magician or exorcist (Kinnier Wilson). In a third category was the *wabw,* the priest of Sekhmet, lion-headed goddess of war, who both caused and cured epidemics. The *wabw* often combined features of both the *seynu* and the *heri-ha'ab.* Although each constituted a distinct profession, any two or even all three might be combined in the same practitioner.

MEDICAL ETHICS. The ethics of healers reflected an environment in which the understanding and explanation of reality were thoroughly religious: All aspects of life, including sickness and healing, received their meaning from religion (see Amundsen and Ferngren). The therapeutics employed by the *asû* and the *seynu* in dealing with acute diseases and injuries seem rational when compared with the predominantly magico-religious techniques of the *āšipu* and the *heri-ha'ab.* But the words of Owsei Temkin are cogent here:

> To be historically comprehensive, medicine cannot be defined as a science or the application of any science or sciences. Medicine is healing (and prevention) based on such knowledge as is deemed requisite. Such knowledge may be theological, magic, empirical, rationally speculative, or scientific. The fact that medicine in our days is largely based on science does not make other forms less medical—though it may convince us that they are less effective. (1977, p. 16)

Those ancient Near Eastern practitioners who seem to have been more rational than their magico-religious colleagues were not more ethical. Theirs were complementary, not competitive, professions. We do not have here a case of medical rationalism vying with superstition. Within their cultures neither approach was more or less rational than the other. Both perceived the causality of disease within an epistemological context in which spiritual, magical, and natural categories were not clearly distinguished. Hence, in this environment, the ethical obligations of healers must be appreciated in terms of their role as interpreters of sickness and healing within the broader cosmological realities and social values of their community. Within this general framework we can glean from the primary sources some specific, although fragmentary, aspects of medical ethics of the ancient Near East.

TO TREAT OR NOT TO TREAT. The Egyptian physician, as revealed by the medical papyri, made a prognosis before undertaking treatment. If the prognosis was favorable, the physician's comment was "an ailment that I shall treat"; if it was uncertain, "an ailment that I shall combat"; and if the prognosis was unfavorable, "an ailment not to be treated." The Edwin Smith Papyrus (a sixteenth-century B.C.E. copy of an earlier text that was probably written between 3000 and 2500 B.C.E.) contains the record of fifty-eight examinations, each followed by either treatment or a decision not to treat (Breasted). The author recommends treatment in forty-two cases and leaves sixteen untreated. In three of the hopeless cases (6, 8a, and 20), some alleviating treatment is indicated. In the Papyrus Ebers (Ebbell), which dates from roughly the same period, a small number of cases are regarded as untreatable (e.g., cols. 108–110), and in one hopeless case there is an attempt to relieve the patient. That specific alleviatory instructions are given only in a minority of hopeless cases does not necessarily indicate a lack of compassion. Incidental remarks in these papyri suggest that physicians carefully and gently treated their patients and showed kindness to the ill, injured, and maimed.

In Mesopotamia *āšipus* were prognosticators whose medical repertoire consisted mostly of incantations and charms, occasionally supplemented by ointments and purgatives. They did not hesitate to withdraw from cases that they regarded as hopeless. Their colleagues, the *asûs,* who administered medicines, performed some surgery, and seldom used incantations, seem only rarely to have refrained from treating hopeless cases, but continued with treatment to the end. This difference may be due in part to the fact that the *āšipu* treated primarily chronic illnesses, while the *asû* usually dealt with acute diseases and injuries (Ritter).

EUTHANASIA AND ABORTION. There is no direct evidence pro or contra regarding the ethics of euthanasia. It appears that in both Mesopotamia and Egypt those who committed suicide were regarded as having cut themselves off from the gods. A touching dialogue between a man contemplating suicide and his *ba* (soul), survives from Egypt, dating from the end of the third millennium B.C.E. (Pritchard). Although the man is not considering suicide owing to illness, the psychological struggle portrayed reveals a culture in which suicide was not accepted simply as a personal option without moral and religious compunctions, although the text suggests that it was not uncommon. Whether physicians assisted in suicide or viewed active euthanasia as opprobrious is unknown.

Prescriptions for induced abortion are found in the Egyptian medical papyri, but its legality remains unclear. In Mesopotamia, Middle Assyrian laws (fifteenth century B.C.E.?; Pritchard, 1969) stipulate that if a woman has an abortion by her own act, whether or not she survives the ordeal, she is to be impaled on a stake and left unburied. The purpose here (as in much other ancient law prohibiting abortion) is not to protect the fetus but to protect the husband's right to have the child he fathered. There is no mention of the involvement of physicians in abortion.

REGULATION OF THE MEDICAL PROFESSIONS AND LEGAL PROTECTION OF PATIENTS. The first recorded attempt to protect the patient from the incompetent physician is from Babylonia, in the Code of Hammurabi (ca. 1750 B.C.E.; Pritchard). There it is specified that if a physician performs a major operation with a bronze lancet on a member of the nobility that results in the patient's death, or an operation with a bronze lancet on his or her eye that results in its loss, the physician's hand will be cut off. If an operation with a bronze lancet results in the death of a commoner's slave, or if the operation causes the loss of the slave's eye, the physician is to pay half the slave's value in silver. No punitive regulations are extant governing medical procedures other than surgery. This is understandable, particularly in a culture permeated by magical beliefs. The unsuccessful use of incantations or sympathetic magic (the administration of medicinal herbs may be included in this category), in which the healing role of the practitioner is nearly passive because of the supernatural agents at play, stands in marked contrast to the active immediacy of the physician in surgery. The Code of Hammurabi also establishes fees for surgery. The amount is determined by the social status of the patient, indicating the intention of the legislator to peg medical fees to the patient's economic means.

Little is known about the regulation of healers in Egypt. Although there appears to have been no system of medical licensure, medical procedure became rigidly prescribed over the centuries. A Greek historian, Diodorus Siculus (first century B.C.E.), whose material on Egypt was derived from the sixth-century-B.C.E. Greek geographer Hecataeus, writes that Egyptian physicians gave treatment in accordance with ancient written procedures. If their patients died, the physicians were absolved from any charge. If they deviated from traditional methods in any way, they were subject to the death penalty, on the assumption that few physicians could be wiser than the physicians of old. In the *Politics,* Aristotle describes a slightly more flexible situation in Egypt, in which physicians could alter their prescriptions after four days; if they altered them earlier, they did so at their own risk.

Little evidence exists from the ancient Near East regarding experimentation with novel procedures. In a letter to the Assyrian king (seventh century B.C.E.?), a physician suggests that a particular prescription be tested on members of the domestic staff before being administered to a member of the royal family. While cesarean section is known to have been performed in Mesopotamia in the second millennium B.C.E. as a last resort to save the infants of dying women, the evidence suggests that the procedure was used only on slaves. These examples suggest the fear of risk involved in novel procedures. But there were other hindrances to therapeutic experimentation: the tendency of empirical physicians to rely on traditional procedures; the existence of a written tradition of medical knowledge and procedures in both Mesopotamia and Egypt; and the fact that medicine was often allied ideologically with religion. These factors are likely to have inhibited innovation that deviated from accepted practice even in late Egyptian medicine. Although evidence is lacking for Mesopotamian attitudes to novel procedures, they are not likely to have been more positive.

Ancient Israel

The basic difference between the worldview of the Hebrews (ca. 1300 B.C.E.—70 C.E.) and that of their ancient Near Eastern neighbors was one of religious outlook. Israel's religion was monotheistic, while that of its neighbors was polytheistic, focused on the worship of natural forces, particularly those associated with fertility. In the Hebrew Scriptures, the cosmos is perceived as being under Yahweh's direction. Although there is a personal force of evil (Satan), he is subordinate to Yahweh and poses no significant challenge to his authority. While polytheism imposed no absolute moral standards, the ethical beliefs of Israel were grounded in the character of Yahweh, who was regarded as the transcendent creator and sustainer of the world. Religion and ethics were inseparable, since both were derived from Yahweh, who was holy and required holiness of his people. Yahweh's absolute character gave authority to his revelation to Israel, and his holiness provided the ethical basis of Israel's laws. The law of Israel, the Torah, grew out of Yahweh's covenant with the Hebrews, which made them his special people. As a requirement of maintaining the covenant, Israel was to reflect the moral character of Yahweh in its national life.

THE HEBREW UNDERSTANDING OF DISEASE AND HEALING. In the Hebrew scriptures illness is viewed in its moral and spiritual dimensions rather than as a merely physical phenomenon. A close relationship between sin and illness was believed to exist at two levels: (1) Physical evil, including illness, entered the world as a consequence of sin; and (2) illness was sometimes visited upon both individuals and nations because of their sin. Hence disease and injury were a consequence of sin, but they were also within the realm of God's control. Yahweh says, "I kill and I make alive; I wound and I heal" (Deut. 32: 39). Disease, as a manifestation of God's wrath against sin, could be seen on both an individual (e.g., Num. 12: 9–12; 2 Kings 5: 25–27; 2 Chron. 21: 11–18) and a national level (e.g., 1 Sam. 5: 6–12). Yahweh promises health and prosperity to his covenant people if they are faithful to him, and disease and other suffering if they spurn his love (e.g., Exod. 15: 26; Lev. 26: 14–16; Deut. 28: 21–22, 27–28, 59–61; Ezek. 14: 21; Hos. 6: 1).

Passages often considered messianic offer the hope of healing, physical as well as spiritual (e.g., Isa. 53: 4–5; Mal. 4: 2). When the Messiah comes, "No one in Jerusalem will say 'I am sick'; the people who dwell there will be forgiven their iniquity" (Isa. 33: 24). The mental and physical anguish that accompanies the guilt of a person smitten and disciplined by Yahweh for sin is spoken of repeatedly in the Psalms (e.g., Ps. 38: 3, 5, 8), while to acknowledge and repent of sin is said to bring healing (Ps. 32: 3–5). Forgiveness and consequent healing were not viewed as the result of appeasing a hostile deity through ritual and offerings (see, e.g., Ps. 51: 16–17). Suffering in general, and sickness in particular, represented Yahweh's chastisement of his people, which was corrective rather than retributive. This theodicy, however, did not make suffering easier to endure for those who searched their hearts but could find no specific sin to be confessed (e.g., Ps. 88; Job, passim). The righteous sufferer must acknowledge God's inscrutable ways and ultimate goodness (e.g., Ps. 94: 12; Prov. 3: 11–12).

PHYSICIANS AND MEDICINE. The judgment upon King Ahaziah for consulting the god of Ekron concerning his illness (2 Kings 1: 2–4) resulted from the same kind of sin for which Asa, king of Judah, was condemned. Asa was seriously ill, "yet even in his disease he did not seek the Lord, but sought help from physicians. And Asa slept with his fathers" (2 Chron. 16: 12–13). Asa is not condemned for resorting to secular medicine as such but, rather, for consulting physicians who were probably Mesopotamian or, less likely, Egyptian. The procedures practiced by these physicians, even if empirical, would have been magico-religious. There is no evidence that priests functioned as physicians or surgeons in Israel. Their only involvement in matters pertaining to health was in the enforcement of a highly developed code of personal and social hygiene (Lev. 12, 13, 15, 21). Were there healers in Judah whom Asa could have consulted, whose practices would not have violated Jewish religious scruples? This question cannot be answered with certainty since there is no evidence in the Hebrew scriptures of the existence of a distinct medical profession.

The Hebrew word for healer or physician is the participle of the verb *rapha,* the original meaning of which appears to be "one who sews together" or "one who repairs." Its first participial occurrence is found in Gen. 50: 2, where Egyptian physicians are said to have embalmed Jacob. The verb itself is often used literally in the sense of healing from disease or injury (e.g., Gen. 20: 17; Num. 12: 13; 2 Kings 20: 5–8). When Jeremiah (ca. 645–ca. 575 B.C.E.) writes, "Is there no balm in Gilead? Is there no physician there?" (Jer. 8: 22), although he is speaking metaphorically, he attests the existence of both balm, as a therapeutic substance, and some kind of healers. The Israelites, of course, had knowledge of the rudimentary treatment of wounds and of herbs that could be used to treat various ailments traceable to natural causes. The Torah stipulates that if a person injures another in a quarrel and the injured party survives, the assailant is to be held financially liable "for the loss of his time, and shall have him thoroughly healed" (Exod. 21: 18–19). This passage implies that the expense both for medicines and for healers to dispense or apply them was to be borne by the guilty party. Several incidental references suggest the existence of binders of wounds (Isa. 3: 7), knowledge of the setting of fractures (Ezek. 30: 21), and the use of various therapeutic substances (Isa. 1: 6; Jer. 51: 8).

Although the Hebrew scriptures represent Yahweh as the only healer (e.g., Exod. 15: 26) and command Israelites to refrain from resorting to magical or pagan healing practices (see, e.g., Ezek. 13: 17–23), the use of natural or medicinal means is not discouraged, but is resorted to even in ostensibly miraculous healings (e.g., 2 Kings 20: 7). Medical knowledge may have been limited to folk remedies, however, and there probably were no systematized therapeutics, much less medical practitioners who were distinctively Hebrew. Not until the second century B.C.E. is there evidence of a Jewish medical profession. Contact with Greek civilization in the Hellenistic age provided Jews with something that neither Mesopotamia nor Egypt could contribute: a religiously neutral theoretical framework for a rational understanding of disease and healing that allowed the coexistence of both divine explanations of ultimate causality and natural processes of proximate causality within Yahweh's created order.

The earliest mention of a Jewish medical profession is in the Wisdom of Jesus Ben Sira (also known as Ecclesiasticus), composed in Palestine early in the second century B.C.E. Ben Sira urges his readers to honor the physician as a servant of God, who gives him his skill. Dependence upon God is essential for the patient, because it is God who heals. The physician, too, must depend upon God, "for also he supplicates God that he may make his diagnosis successful and his treatment to save your life" (38: 1–15, Noorda's translation [1979]). In spite of an occasional critic like Philo Judaeus (an Alexandrian Jew of the early first century C.E.), who scathingly condemned fellow Jews who trusted in medicine without reference to God and turned to him only as a last resort (Temkin, 1991), Hellenistic Jews accepted rational medicine based on the Greek model as fully compatible with their faith. Apart from the available medical resources, which were limited, healing could come only from Yahweh by confession of sin, supplication, and prayer (e.g., Job 33: 19–30).

MEDICAL ETHICS. Central to understanding Hebrew and Jewish medical ethics is the concept of the image of God (*imago Dei*). In the Genesis account of creation, Yahweh is depicted as having created man and woman in his image (Gen. 1: 26–27). Endowed with rationality, self-consciousness, and volition, the human personality in Hebrew thought was represented as mirroring Yahweh's image. Persons are spiritual beings, created to have communion with God, and responsible for their own moral actions. The concept of the *imago Dei* had implications for the protection of human life, which was believed to possess intrinsic value, and hence to be sacred. Even human beings with physical defects are said to bear God's image. Yahweh asks Moses, "Who has made man's mouth? Who makes him dumb, or deaf, or seeing, or blind? Is it not I, the Lord?" (Exod. 4: 11).

As a result of the Hebrew view of humanity as possessing intrinsic worth, the Torah exhibits a greater humaneness than other codes of the ancient Near East (e.g., the Code of Hammurabi). There are, for example, provisions that protect the rights of the blind and the deaf (e.g., Lev. 19: 14). The fetus was regarded as having been created by Yahweh and designed for a specific purpose (Ps. 139: 13–16; Jer. 1: 5; Isa. 49: 1). Yet abortion was not explicitly forbidden by either the Torah or later rabbinic Judaism. In fact, in the Talmud it was permitted in some circumstances. Whether the practice was acceptable in the pre-Christian era is disputed. The accidental destruction of the fetus was not a capital offense, but required monetary compensation (Exod. 21: 22–25). The newborn child, however, was regarded as fully human and deserving of the same protection as an adult. Infanticide, a common practice in the surrounding Canaanite culture, was expressly prohibited (Lev. 18: 21, 20: 2), and the exposure of newborn children was also condemned (see Exod. 1: 17–21; Ezek. 16: 5). Castration, sometimes practiced by Canaanites for religious purposes, was also forbidden, and eunuchs were excluded from Hebrew religious life (Deut. 23: 1).

The Hebrew scriptures provide no information regarding the behavior expected of Jewish physicians. Mesopotamian and Egyptian physicians had an enormously varied repertoire of religious and magical techniques of propitiation and manipulation, as well as of natural therapeutics, from which to choose. They also had the freedom to be imaginative, active participants in processes in which the lines between what we call the natural and the supernatural were blurred. By contrast, Jewish physicians, working with and through natural means and processes, and eschewing any techniques involving magic or the demonic, were, along with their patients, to depend upon the Creator, from whom alone all true and licit healing came (Deut. 32: 39). Given the emphasis in the Hebrew scriptures on the compassionate nature of the God who heals, and the importance that Ben Sira assigns to the physician as an agent of God, it would be surprising if Jewish physicians were not encouraged to emulate the divine compassion in their treatment of the ill. This attitude would be especially compatible with the new emphasis on the meritorious nature of charity that is found in the Apocrypha (Jewish religious writings dating from third century B.C.E. to about 100 C.E. that were not included in the Hebrew scriptures). It is in the postexilic period (after 605–582 B.C.E.), too, that one begins to see a tradition of caring for the ill that makes the sick person no longer an object of stigmatization (e.g., Job 19, esp. 13–20; Ps. 42: 4–10), but a person deserving of special care, like widows and orphans (e.g., Sirach 7: 35; 2 Macc. 8: 28). This specific concern for the sick within the community of Israel is a theme that is extended and developed in the Talmud.

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II. IRAN

Iran, a vast country in Southwest Asia, was long called Persia by Europeans until, in 1935, its government requested that the common indigenous name, Iran, identifying the nation as the "land of the Aryan people," be used internationally. The extensive Iranian Plateau and surrounding lands have been the site of many powerful political regimes during its long history, beginning with the empire of Cyrus the Great, the first Achaemenid emperor, in 549 B.C.E.. Located along a highway for the movement of people and ideas from the prehistoric period on, its indigenous Aryan culture has been an important link between Hellenic, Indic, and Semitic intellectual and religious traditions. Within the limits of this article, the history of Persian medicine cannot be traced; only the ethics characteristic of that history will be treated.

Prehistoric Period

Little is known about the healing practices or beliefs of the earliest inhabitants of Iran. An epic poem, *Shāhnāmah* (Book of Kings), written in the tenth century C.E., relates ancient myths, legends, and stories that may reveal something of the ancient past. Surgery is mentioned in the tales of the superhuman exploits of the heros Rustam and Isfandyar. Rustam himself is said to have been delivered by an operation much like that now known as a cesarean section, while his mother was anesthetized with wine. Abortifacients were known. The Elamite civilization, centered around Susa in southern Iran from the third to the first millennium, had cultural contact (and often political enmity) with Babylon, and it is likely that the medicine of the Mesopotamian world was known by the Elamites (Sigerist). The Code of Hammurabi, ruler of Babylon (ca. 1750 B.C.E..), which contains strict injunctions and penalties regarding surgical practice and malpractice, is known primarily from a stela found at Susa in 1902.

The Aryan Period (Ninth-fourth Century B.C.E.)

The nomadic Aryan peoples migrated from Central Asia, north and east of the Caspian Sea, to the Iranian Plateau around the seventeenth century B.C.E. By the ninth century, they dominated the region, and in 549 B.C.E., Cyrus consolidated rule over its inhabitants and established the Achaemenid dynasty, the first Persian empire. He and his successors, Cambyses, Darius, and Xerxes, extended the boundaries of Persian rule from the Ionian Sea in the west to the Indus River in the south. During this period, Persian medicine was undoubtedly in contact with Greek medicine. A story related in ancient texts tells of an invitation from Persian King Artaxerxes to Hippocrates, on the advice of a Persian physician, to become physician to the Persian army during a plague; Hippocrates refused, saying, "I have no right to share the wealth of the Persians or to liberate from disease barbarians who are enemies of the Greeks" (Pseudepigrapha 3; see Temkin).

In the seventh century, the mysterious religious figure Zoroaster appeared in eastern Persia. Very little is known of his life, and the writings attributed to him are brief. However, by the first century B.C.E., a defined cosmogony and theology attributed to his influence had been collected in the vast literature called *Avesta,* of which his own *Gathas,* or hymns, are a small part. The doctrine is basically constructed around a cosmic duel between good and evil, of which light and darkness, life and death are the material symbols. The powerful spirit of good and light, Ahura Mazda, the wise and greatest god, battles Ahriman (or Angra Mainyu), spirit of evil and darkness, and the world is the battlefield. Humans participate in the battle through their free choices. As individuals, humans are to maintain purity of life through moral goodness, pursuit of truth and physical cleanliness, and avoidance of pollution by the dead and unclean substances. As members of society, humans are to assure justice between social classes.

The *Avesta* also contains the elements of a theory of health and disease. Diseases, created by Ahriman, come from dirt, stench, cold, heat, hunger, thirst, and anxiety, although magical causes are also recognized. Medicinal plants are the creation of Ahura Mazda. Rules of healthful living are prescribed; cupping and bleeding are recommended to reduce hot blood. The destruction of life is prohibited for theological reasons; it would contribute to the victory of Ahriman over Ahura Mazda. Thus, abortion is forbidden, and both men and women are punished as willful murderers. Special rules are laid down for the care of pregnant females (both human and animal). Surgery is recognized and strictly regulated; one ancient law requires that a surgeon have three successful cases before being licensed to practice.

Three kinds of healers are mentioned: healers with herbs, with knives, and with holy words (the latter, one text notes, being the most efficacious). There were also persons (*durustpat,* masters of health) trained to remove the causes of disease by purifying earth, air, water, and food. These physicians were often drawn from the noble and priestly classes. A modern Parsi (the contemporary Zoroastrians of India) scholar describes what he believes would have been the ideals of the Avestan physicians of ancient times:

> The first indispensable qualification of a physician was that he should have studied well the science of medicine. He should hear the case of his patient with calmness. He should be sweet-tongued, gentle, friendly, zealous of honour of his profession, averse to protracting illness out of greed and God fearing. An ideal healer heals for the sake of healing.… He should carefully watch the effect of medicine that he prescribes … visit the invalid daily at a fixed hour, labour zealously to cure him, and combat the disease of the patient, as it were his own enemy (Elgood, 1951, p. 13).

Hellenistic Period (330 B.C.E.–224 C.E.)

In 330 B.C.E. Alexander of Macedon brought down the Achaemenid empire. For the next five centuries, the Greek culture that had long flourished on the Ionian frontier of the Persian empire dominated Persian ideas and institutions. Although the historical record is meager, it may be assumed that Greek medicine and Hippocratic ethics were included in this general influx of Hellenic culture. The Zoroastrian faith languished during that era, but it would not be unlikely that Avestan ideals that had permeated the culture survived.

Sassanid Period (224–632)

The Sassanid dynasty, after victories over Roman and Parthian armies in the mid-third century, ruled Persia for four centuries, restoring the traditions, law, and culture of ancient Iran and, above all, reforming and fostering the Zoroastrian faith. In the earliest years of the Sassanid era, an event of great importance for the history of medicine occurred. In the mid-250s, King Shāpūr I, son of the founder of the dynasty, defeated the Roman emperor Valerian and sacked the city of Antioch. The king invited many of the Antiochean scholars, including physicians, to a new city, Gondishapur, that he established in 260. His son enlarged the city and founded a university that in time became the center of scholarly work in Persia.

To Gondishapur in the late fifth century came a group of Persian Christians of a denomination called Nestorian. These Christians had originally dwelt in and around the Persian city of Nisibis, then moved to the Byzantine city of Edessa, where in 363 they established a school of theology. After certain of their theological beliefs were repudiated and their leader, the patriarch Nestorius, excommunicated by the Catholic church at the Council of Ephesus (431), the Persian Christians accepted an offer of asylum at Gondishapur from the Persian king Qubād. They brought with them not only works of theology but also an extraordinary library including Syriac translations of the Hippocratic corpus and of Galen.

Another scholarly migration entered Gondishapur in 529 when the Sassanid king Anūshīrvān the Just welcomed the Neoplatonists exiled from Athens, at the urging of his chief minister Buzurgmehr, who according to legend was himself a physician and philosopher. He is quoted as having said, “I read in medical books that the best physician is one who gives himself over to his profession.… I exerted myself in the treatment of patients, those whom I could not cure I tried to make their suffering more bearable.… From no one whom I treated did I demand any sort of fee or reward” (Elgood, 1951, p. 52).

The king also sent missions to India to procure the arts and sciences of Hindu culture, including the works of Ayurvedic medicine. By his order, a massive work on poisons was compiled, and many Greek and Indian books were translated into Pahlavi (ancient Persian). He convened what may have been the first medical convention, summoning the physicians of Gondishapur to debate the major medical questions of the day. During his long reign, Gondishapur became a leading center of scholarship; within its walls Greek, Jewish, Nestorian, Persian, and Hindu ideas were exchanged and enriched, and Islamic, Christian, and Zoroastrian ethical ideas mingled. The art of translation of the classic texts from Greek, Latin, and Syriac into Pahlavi and Arabic was fostered. The school of medicine existed for five centuries, creating from many sources the medical science generally known as Arabic or Islamic, and its great hospital, Bimaristan (House of the Sick), was the model for the Muslim hospitals of Baghdad, Damascus, and Cairo and the Christian hospitals of Jerusalem and Acre (Whipple).

Islamic Period (636–)

The victory of Arabian Muslim armies at al-Qādisiyah in 636 inaugurated the era of Islamic rule and culture in Iran. The distinctive ethic of Islam entered and eventually predominated in the rich mix of Persian life. Gondishapur continued to flourish under Arab rule and became more influential as its scholars, teachings, and books spread through rapidly expanding Islam, carrying Greek and Arabic medicine across Africa and, through Sicily and Spain, into Western Europe. The new Muslim rulers summoned scholars from Gondishapur to their capital at Baghdad, where they established a new center of medical science. Studies in biology, human anatomy, and pathology were encouraged. The caliphs in Baghdad, Damascus, and Cairo organized public-health administrations, staffs of public-health doctors, public hospitals, and a public examiner of physicians, responsible for their skills and their ethical standards.

Some of the greatest names of medical history were Persian: Ṭabarī, Rhazes (known as the Galen of Islam), Haly Abbas, Avicenna (Ibn Sīnā), all of whom flourished in the tenth and eleventh centuries. Their scientific work was renowned. (Avicenna’s *Canon of Medicine* was used as a text in many European schools as late as the seventeenth century.) All of these distinguished physicians wrote treatises on the ethical qualities of physicians. The text of one of these, *Advice to a Physician,* by Haly Abbas, reflecting Hippocratic and Islamic sentiments, can be found in the Appendix of this encyclopedia. A book by the eleventh-century Iranian philosopher-physician Ibn-Hindū praises the nobility and criticizes physicians who use medicine only to win wealth and reputation, recalling the story that Hippocrates, when summoned by the Persian ruler, disdained to give his service only for gain (Mohaghegh). Another scholar of the next century, Niẓāmī ’Arūḍī, summarized the moral principles that should guide a physician:

> A physician should be of tender disposition and wise nature, excelling in acumen, this being a nimbleness of mind in forming correct views, that is, a rapid transition to the unknown from the known, and no physician can be of tender disposition if he fails to recognize the nobility of the human soul; nor of wise nature unless he is acquainted with logic, nor can he excel in acumen unless he be strengthened by God’s aid, and he who is not acute in conjecture will not arrive at a correct understanding of any ailment (Elgood, 1951, p. 234).

Modern Period

For many centuries medicine in Iran was more or less as has been described. The foundation of Dār-ul-Funūn (the Polytechnic School) in Tehran in 1852 changed the situation. At first it was a military academy, but it soon began to develop into a university. The foundation of the Faculty of Medicine was laid by a number of excellent European and Iranian teachers. The school curriculum at first was a combination of Iranian and Western medicine, and the ethical point of view was influenced by Iranian tradition.

Iranian students had been sent to Europe for medical studies for several decades before the founding of the medical school at Dār-ul-Funūn. With the return of these physicians and scientists and the establishment of a modern hospital in Tehran in 1868, the curriculum of Dār-ul-Funūn and the practice of medicine were gradually westernized. Also, during the nineteenth century, a number of Western physicians resided in Iran, the most famous being a Frenchman, Charles Fourier, physician to Shah Nāṣir al-Dīn.

Since the period of Reza Shah (1923–1941), the program of the medical school of the modern University of Tehran has been based completely on modern medicine; medical ethics and the history of the medical tradition are both taught. Graduates of the Tehran medical school are asked to take an oath, an excerpt from which follows:

> Now that I … have been found eligible to practice medicine, in the presence of you, the board of judgment of my thesis and others here present, I swear by God and the Holy Book of Koran and call to witness my conscience that in my profession I will always be abstemious, chaste, and honest and, as compared with the glory of the art of medicine, I will hold in contempt all else—silver, gold, status, and dignity. I promise to help the afflicted and needy patient and never divulge patients' secrets. I will never undertake dishonest work such as producing abortion and recommending a fatal drug. What I do, I will try always to be approved by God and be known for my uprightness.

In the Islamic Republic of Iran, founded in 1979, the interest in vivifying Islamic tradition and law touches medical ethics as well. Issues related to bioethics are sometimes treated in works dealing with Islamic religious law, the *shar'ia.* However, the premodern *shar'ia* contains little that can directly guide conscience and conduct in morally troublesome cases, such as the permissibility or prohibition of medical treatments. Muslim jurists have undertaken to provide new rulings, the most prominent of which states the rights of the patient in determining which modes of treatment are compatible with his or her religious and moral beliefs. These scholars are also grappling with the medical technology developed in the Western secular culture, technology that has altered conventional understandings of life and death and has posed perplexing questions for a new, religiously aware generation of Iranian physicians and their "believing" patients.

Some recent works in medical ethics, such as *Fiqh va ṭibb* (Islamic Jurisprudence and Medicine) and *Qānūn dar ṭibb* (Law in Medicine), reflect a change in the attitude of Muslim physicians, who have become increasingly aware of the role religion plays in the lives of Iranian men and women. Whereas in the early days of modernization and secularization, Iranian physicians, not unlike their counterparts in other Third World countries, "played God" in attempting to save and restore human health, the 1980s and 1990s are characterized by a growing concern about the religious and cultural values of the society. Thus, for instance, an important issue in Islamic law is the recommended segregation of females and males, which has implications for medical ethics. The ethical issue is whether it is permissible for a physician to treat a member of the opposite sex. While responses have varied among the Muslim jurists, there is a consensus that since a physician should never sexually abuse his or her patients, it is strongly recommended that a physician examine patients of the opposite sex only in the presence of a third person, as a safeguard. This applies to both male and female doctors. However, under special circumstances, when no doctor of the same sex as the patient is available and there is an urgency in treating the condition, the law permits male doctors to treat female patients and female doctors to treat male patients.

Advances in biomedical technology raise issues that challenge Islam to provide concrete and relevant solutions. A group of Muslim jurists and philosophers has begun to develop guidelines for dealing with ethical issues that confront the medical profession. Leaders in both secular and religious education have begun to prepare textbooks on medical ethics. Two of these works are especially significant: *Akhlāq-i pizishkī* (Medical Ethics), prepared and published under the supervision of the Ministry of Health in 1991, and a book with the same title, written by Manṣūr Ashrafī and published by the Medical Faculty of the Open University of Tabriz in 1988. The former includes chapters dealing with the juridical decisions by major Iranian religious leaders, including Ayatollah Khomeini, on issues related to what is known in the West as bioethics. The latter work is based more on the Western secular discussion of bioethical issues without any reference to Islamic or other religious views. Both are used as textbooks in the Iranian schools of medicine.

Major obstacles persist for those who work to solve the problems created when medical technology is brought into a culture steeped in religion. The most serious problem that confronts Muslims in general, and Iranians in particular, is denial of the ethical problems stemming from technicalization of the society and its adverse impact on interpersonal relationships. A striking example is acquired immunodeficiency syndrome (AIDS). To date, the Muslim ethical response to AIDS has characterized the disease as God's curse on those who engage in illicit sexual behavior. In this direct or indirect critique of the moral decadence of the West, important issues are overlooked, including the cause of the disease and its prevalence in the Muslim world, as well as guidelines for treatment of those affected.

Muslim jurists in Iran have not yet formulated relevant responses to some of the most complex ethical issues—those that arise because of human endeavors to improve health and extend life. The highly cherished religious value of compassion has been overshadowed by the language of condemnation for moral failure of humanity.

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III. TURKEY

The modern nation of Turkey is situated on the continents of Europe and Asia, with the majority of its landmass occupying the vast Anatolian peninsula of Asia Minor. Surrounded by three seas, the Mediterranean and the Aegean seas on the west and south, and the Black Sea on the north, its territory has been the home of many nations and civilizations. It was ruled by the Hittite and Phrygian kingdoms of the second and first millennia B.C.E., followed by the Persian, Hellenic, and Roman empires. In 330 C.E., the capital of the Roman Empire was moved to Byzantium, which was renamed Constantinople. In 1453, Mehmet II, the sultan of the Ottoman Turks, a people who during the previous century had invaded a great part of the deteriorating Byzantine Empire, captured Constantinople and established the

Ottoman Empire over Asia Minor (and, in the course of time, over much of the Islamic world, from the Crimea to Morocco and the Balkan peninsula). The Ottoman Empire lasted from 1299 to 1922, and in 1923 it became a republic under the leadership of Mustafa Kemal. Turkey's medicine and its ethics bear the marks of this long history.

The Turkic peoples, dwelling from time immemorial in Central Asia, migrated into China, India, the Caucasus, and Persia. The earliest Turkic religion was a shamanistic animism marked by totems and magic. Contact with the spirit world was mediated by male and female shamans, called *kam,* who healed the sick with magic and charms and music. Other healers, called *otaci,* are mentioned in various sources, and archeological findings related to *otaci* exist as early as the eighth century C.E. *Otaci* were described as wise people informed of the causes of illness, advising about healthy living and treating mainly with herbs, as well as by bonesetting, massage, acupuncture, moxa, branding, etc. *Otaci* joined in a guild of healers called *kutu.* They were, according to the sources, in frequent debate with exorcists, who taught that illness was caused by evil spirits and driven out by charms. This conflict was especially emphasized following the conversion of many of the Turkic peoples to Islam in the tenth century.

In Turkistan, where Turkic peoples were in contact with Chinese Buddhism, monks functioned as healers (*otaci bakshy* in Old Turkish). Although supernatural healing powers were often attributed to them, they practiced medicine without remuneration as a way of achieving Buddhahood. Monasteries were places of hospitality and healing. A medical literature in Uighur Turkish began to appear in the eighth century. During this period there was considerable mingling of Chinese, Indian, and Persian medical concepts. Although healers were no longer believed to have supernatural powers, the attitude of holding them in high esteem was part of the Islamic culture.

From the sixth to the thirteenth century, Turkish tribes formed kingdoms throughout Central Asia and the Near East. In the tenth century, many Turkic tribesmen who were employed in the armies of the Abbasid caliphs were converted to Islam (some tribes adopted Buddhism; others, Manichaeanism; and some followed Nestorian Christianity or Judaism). Following the rise and fall of several significant pre-Islamic and Islamic Turkic kingdoms, one tribe, the Seljuks, became the most powerful force in Anatolia. They extended their rule into Iraq, Iran, and Syria, and during the eleventh and twelfth centuries they created the first major Turkish state, which fostered a rich literary, artistic, and scientific civilization. In 1066, Nizamul Mulk, vizier of the Seljuk ruler Alp Arslan, founded the Nazamiye University in Baghdad. The first state university known in history, it included a hospital. The Nureddin Hospital, founded by the Seljuk Atabeg Nurredin Zenagi in Damascus in 1154, educated many famous physicians, such as Ibn Abi Usaibia, Ibn al-Nafis, and Ibn al Qutt, and was the center of medicine at that period. The curriculum of the medical schools in the Seljuk period was demanding; after training and the presentation of their theses, the graduates were examined in the course of medical practice by the *muhtasib,* a high-ranking public official, and then swore an oath to practice medicine with competence and virtue.

During the reign of the Anatolian Seljuks, the nobility founded charity hospitals: In Kayseri, the Gevher Nesibe Hospital was established by Princess Gevher Nesibe in 1206, and the Divriği Hospital in 1228 by Princess Turan Melik; both are still standing. The hospital and medical school founded at Sivas in 1217 also remains; and the original charter, still extant, shows that the staff consisted of physicians, surgeons, ophthalmologists, nurses, and pharmacists. All persons in need, Muslim and non-Muslim, were accepted for treatment in these institutions. Although a rich medical terminology had existed in the Turkish languages in the eleventh century, medical literature in Arabic and Persian flourished during the Seljuk era and hundreds of Arabic and Persian works were written by Turks. Turkish cities—Ferghana, Tashkent, Samargand, Bokhara, Khwarizm, Balkh, Maraghah, Kashgar, Farab, and others—were the birthplace of many famous Islamic scientists, including Ibn Sina, Ibn Turk, Biruni, Farabi, and Harezm, and were also the important centers of Islamic culture.

Medical literature in the Turkish language began to flourish again in the fourteenth century. After the conquest of Constantinople, the Ottoman Empire continued to promote care for the needy sick and to further medical science and education. It was common for the large complexes built around mosques throughout the land to have a hospital attached for the sick poor, whether Muslim or not. Sultan Mehmet II opened a hospital in his new capital in 1470. A great hospital and a medical school were established within the complex of the Süleymaniye Mosque (1536). According to the founding documents, the professor of medicine was expected to be a faithful Muslim, virtuous, charitable, self-confident, courageous, gifted with intuition and keen senses, and educated in the subtleties of logic and medicine. He was required to teach students both medicine and the virtues and duties of the physician. Those who sought admission to medical school were to have graduated from the *medresse,* or university. (The Ottoman *medresse* not only provided necessary services of religion, science, and instruction; it also trained administrative and judicial personnel to meet the needs of the bureaucracy.) Medical school applicants were required to be persons of high moral character, and to be faithful Muslims. All received scholarships from charitable endowments. The professor as well as the students were supervised by a dean.

A chief court physician was the minister of health; he was responsible for public health, for the proper training of physicians and the administration of examinations, as well as for the safety of drug preparations. Physicians employed in the palace and hospitals outside were paid by the state, and their income increased in relation to their skill and rank. Still, there were more physicians practicing medicine in their special offices than employed by the state. Pharmacists, trained in an apprentice system, worked in hospitals and palace pharmacies. A school for surgeons and ophthalmologists existed in the sultan's palace.

Women were admitted to the practice of medicine during the Ottoman period, particularly for the care of women. The Topkapi Palace in Istanbul had a well-appointed infirmary for women in the harem, as well as an infirmary for royal pages. Renowned female physicians were summoned to care for women of the harem when necessary. Nurses were employed in the palace infirmaries as well as in hospitals outside the palace and were expected to be gentle, dedicated, and devoted to their patients. Midwives were respected and given official recognition after an apprenticeship. Women prepared and sold herbal extracts, and women inoculated against smallpox. Women were also influential in the founding of hospitals and the support of charitable works.

The ethics of Turkish medicine were formed by Islamic morality, Turkish mores, and the Hippocratic ideas inherited from Greek medicine. Many medical manuscripts from the thirteenth to the nineteenth centuries state these values in chapters generally titled "Advice for the Physician." Chief among the qualifications required of the Ottoman physician was good character, which included mercy, generosity, honesty, modesty, and an even temper. Physicians were expected to be clean and properly attired, and never to exaggerate. Such virtues were said to have a positive effect upon the sick person. Advice was also given about preserving confidentiality, charging fair prices, and serving the poor without charge. Physicians were warned not to make definitive statements about prognosis, since the course of disease is not predictable with certainty. Medicine made from unknown herbs, folk remedies, and experimental treatments were not to be used. Administering poisons and abortion, except for a therapeutic purpose, were strictly forbidden. In general, as the eminent fifteenth-century Ottoman surgeon Sabuncuoğlu noted, the conscience of the physician should prevail over his desires and passions.

Physicians and surgeons were held responsible for injuries that resulted from their ignorance, incompetence, or use of unorthodox methods. Islamic law required that patients give personal permission, in the presence of a judge and witnesses, before undergoing surgery. Many records of the religious courts bear testimony to this practice. Edicts were often issued to bar quacks from practice, and, in order to ensure that only qualified practitioners served the sick, examinations for medical licensure were frequently repeated and only the licenses of the successful renewed.

Although Turkish medicine had been in contact with European medicine since the sixteenth century (inoculation against smallpox was originally introduced into Europe from Turkey at the beginning of the eighteenth century) (Ünver), European medicine became influential with the founding, by Sultan Mahmud II, of a school of medicine in 1827 and a school of surgery in 1832; these schools were combined in 1836 and moved, three years later, to Galatasari, then a suburb of Constantinople. Although it was primarily a military school, civil students were admitted, too; all students were given scholarships by the state. European physicians joined the Ottoman instructors on the faculty, and from 1839 to 1870 the language of instruction was French. A vigorous flow into Turkey of faculty members from the European medical centers and a flow of students and specialists from Turkey to Europe marked nineteenth-century medical education. An Ottoman professor, Nahabed Roussignan, lectured on ethics in 1876–1877 at the University of Constantinople School of Medicine. The course was continued for many years by Professor Hovsep Nouridjan, who published his lectures as *Précis de déontologie medicale,* one of the earliest books on this subject printed in Europe. In 1933, the first department of medical history and ethics was founded by Süheyl Ünver in Istanbul University. Doctorates in medical ethics are now awarded, and as of 1994, ten of the twenty-eight Turkish medical schools had departments of ethics and such courses were given in all schools of medicine.

After establishment of the Turkish Republic in 1923, new laws and regulations were passed regarding healthcare, public health, and the duties of physicians. A successful fight was waged against epidemic diseases, and many municipal and state hospitals were founded all over Turkey. The Turkish Medical Association was founded in 1929, and the current version of the medical ethics code appeared in 1960; it comprises rules dealing with patient–physician and physician-physician relationships, confidentiality, advertising, human research, termination of pregnancy, malpractice, truth-telling, consultation, fees, and organization of practice. This code has juridical standing. Provincial medical associations have disciplinary authority over physicians who violate the code. Dentists and pharmacists have formed associations in recent years and also have codes of ethics. A National Congress on Medical Ethics was organized by the Medical Faculty of the University of Istanbul in 1977. It opened discussion of many topics, such as organ transplantation, determination of death, reproductive technologies, and military medicine. A second such congress was held in 1994.

A law on organ transplantation was passed in 1979. It specifies procedures for consent, donation, and determination of death, and prohibits advertising and commercialization of organs. Regulations dealing with the education and duties of those who provide family-planning services, including abortion and sterilization, appeared in 1983. Abortion, available on demand for any reason if there is no medical contraindication for the mother, is permitted up to the tenth week of gestation, and therapeutic abortion after that time; married women must have permission of their husband, and minors, of their parents. Married persons seeking sterilization must have consent of their spouse. Centers providing assisted reproduction must be licensed by the Ministry of Health. Embryos are not to be used for purposes other than reproduction and cannot be sold. A professional committee has been established for the oversight of assisted reproduction.

The Turkish Medical Association endorses the Nuremburg and Helsinki declarations. In 1993, a state regulation governing research with human subjects required review committees in research hospitals, and a Central Ethics Committee was established in the Ministry of Health. Local review committees sometimes function as ethics committees as well. In 1992, the Turkish Human Rights Association, the Turkish Medical Association, and the Torture Victims International Rehabilitation Council sponsored the Fifth International Conference on Torture and the Medical Profession in Istanbul. This conference issued a declaration against torture and specifically against any physician's involvement.

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IV. CONTEMPORARY ARAB WORLD

The Arab world comprises the twenty-one Arabic-speaking countries extending from the south of Iran westward to the coast of the Atlantic. Not all the people in these nations are descendants of the Semitic Arabs of the Arabian Peninsula, but the spread of Islam outward from Arabia in the seventh century led to widespread adoption of Arabic, the language of the Qur'an, Islam's scripture. Islam is the religion of 95 percent of the inhabitants of the Arab world. Of the world's nearly one billion Muslims, some 20 percent are Arab. Classical Arabic has been preserved through the constant standard in the Qur'an (the Islamic scripture that Muslims believe is God's very words received verbatim by Muhammad); colloquial dialects are used regionally but are easily understood by all.

Despite religion and language, the Arab world is not politically, socially, or economically homogeneous. Some countries are ruled by hereditary monarchies; others, by revolutionary military or quasi-military governments. Democracy is, on the whole, lacking, although it is the aspiration of the masses. Some countries are affluent (usually due to oil wealth), while others are poor; some are overpopulated and others sparsely populated. Currently the Arab world is categorized as belonging to the Third World. The average birth rate is 38.3 per 1,000, and the average infant mortality rate (first year of life) is about 68.2 per 1,000 (United Nations).

A characteristic of the region is the religious orientation of its people and the influence of religion on their lives. Islam recognizes both Judaism and Christianity as religions that come from God; all three religions hold generally the same prevailing moral values and thus have a unified ethical base. Society (of all religious backgrounds) tends to be conservative, sanctifying family integrity and family ties, upholding moralities prescribed by religion(s), averse to unchecked liberalism, and falling back on religion to categorize social trends and new lifestyles as acceptable or unacceptable.

Islam has a comprehensive framework of a legal system based on the Qur'an and tradition, covering all aspects of life, that serves as the source of legislation and the derivation of ethical rulings. And yet the great majority of the Arab world is not ruled by Islamic law, most of the governments being practically secular. One area has uniquely remained under the jurisdiction of Islamic law: that of family law. It is in this area that the bulk of medical ethics resides. Although many non-Muslims are physicians and patients in Arab countries, there is little dispute about medical ethics among them, since many common positions are shared by Islam, Christianity, and Judaism.

The medical profession is highly esteemed in the Arab world, and the physician is still called "the wise man," a centuries-old nomenclature. The physician is very highly regarded, and the doctor–patient relationship, based on trust and confidence, tends to be paternalistic.

Seeking medical help when one is sick is a religious duty. Muhammad said, "Your body has a right over you," and "Seek treatment, for God has created a cure for every illness; some already known and others yet to be known." The establishment of the medical profession is a religious duty of the community, which should designate some of its members to study medicine and should provide for the needs and requirements of medical education. A doctor should be appropriately qualified, for Muhammad said, "Whoever practices medicine without the appropriate knowledge is liable to pay compensation [if harm comes to the patient]."

It is not uncommon for medical practitioners who enjoy the confidence of their community to be consulted on nonmedical problems faced by families or individuals. People tend to accept that therapeutic ability is not absolute, and as long as the doctor has done his (or her) best, there is a willingness to accept and even forgive undesired outcomes. Insurance against professional liability is nonexistent, and the judicial system heeds this fact; unless it is a clear case of neglect or inexcusable ignorance, the physician is rarely held responsible for damages.

Medical education has deep historical roots in the major capitals (Baghdad, Cairo, and Damascus) since the era of Islamic civilization (eighth to sixteenth centuries). Modern schools have emerged since the nineteenth century, and many are as recent as the oil boom late in the twentieth century. With one or two exceptions, all Arab countries have one or more medical schools, Egypt, as many as thirteen.

English is the common language of education, with French or Arabic used in exceptional cases. Conversion to Arabic is under debate. Medical education and practice are open to both sexes and all religions without discrimination. Coeducation is the rule except in a few schools. There is no ban on examining the opposite sex. Dissection of the human body and postmortem examination are permitted; some schools, however, have to import cadavers from abroad to satisfy the need for teaching anatomy.

Medical Ethics

The Arab world has known medical ethics since the writings of Imhotep of Egypt (3000 B.C.E.) and the Code of Hammurabi of Babylon (about the same time). The Oath of Hippocrates (ca. 460–355 B.C.E.) later took over, and since the ninth century various Islamic adaptions of it, as well as treatises and books on medical ethics, have been contributed by Al-Rahawi, Ibn Rabban, Avicenna (Ibn Sīnā), and many others.

In modern times, medical ethics has been taught as part of the curriculum of various disciplines, but since the 1940s it has become a separate course in the majority of medical schools, whether as a part of forensic medicine, community medicine, history of medicine, or on its own.

Although Islam is the principal source of medical ethics, the increasing complexity of biomedical discoveries and technological achievements during the latter half of the twentieth century have made it difficult for religious scholars to comprehend the issues and formulate rules on ethical acceptability from an Islamic point of view. There has been need for a forum in which religious scholars join with biomedical scientists and specialists in relevant disciplines such as law and sociology, policymakers, economists, and civic leaders of both sexes, to discuss specific issues in order to develop an Islamic consensus. To continue this collaboration, institutions have come into being since the early 1980s: the Islamic Organization of Medical Sciences (IOMS, Kuwait), the Islamic Research Congress (Egypt), and the Fiqh Congress of Makka (Saudi Arabia). The rulings of these government-approved agencies have a high moral weight and almost fill the legal gap that results because legislation usually lags behind new developments. These agencies have significantly contributed to Islamic medical ethics, addressing a number of issues that will be surveyed briefly.

An important milestone was the formulation of the Islamic Code of Medical Ethics (IOMS, 1981), ratified by the First International Conference on Islamic Medicine (held in Kuwait, January 1981) and endorsed by many Arab and Islamic countries. This code comprises eleven chapters: Definition of Medical Profession; Characteristics of the Medical Practitioner; Relations Between Doctor and Doctor; Relations Between Doctor and Patient; Professional Confidentiality; Doctor's Duty in Wartime; Responsibility and Liability; Sanctity of Human Life; Doctor and Society; Doctor and Biotechnological Advances; and Medical Education. All topics were authenticated by sources in the Qur'an and Islamic law. The code also includes the latest version of the Islamic Medical Oath, which reads (roughly translated):

> I swear by God: To regard God in practicing my profession; To respect human life in all stages,

> under all circumstances, and to do my best to rescue it from death, malady, pain and anxiety; To uphold people's dignity, cover their privacy, and keep their secrets; To be an instrument of God's mercy to near and far, virtuous and sinner, and friend and enemy; To pursue knowledge and to harness it for the benefit, not the harm, of humankind; to revere my teachers, teach my juniors, and cherish the fraternity with my colleagues; and to live my faith in private and in public … and God is my witness to this oath.

Derivation of Islamic Medical Ethics

The totality of Islamic law, called the Shari'a, is drawn from the Qur'an, the verbal teachings of Muhammad, followed by analogy and consensus. The Shari'a is expressed in a code of moral behavior that states what is sinful and what is not, as well as a body of laws that states what is legal and what is not. These two systems need not coincide. (An example is a person who commits adultery in the privacy of a closed room. Such a person has committed a sin but not a legal crime, since Islamic law requires four witnesses in order to establish the legal charge of adultery. The fate of such a sinner is left entirely to God, who will punish or forgive upon the perpetrator's repentance and appeal for mercy.) When ruling on the admissibility (or inadmissibility) of an issue, jurists take into consideration a number of rules such as "Necessities overrule prohibitions," "Choose the lesser of two evils if both cannot be avoided," "Public interest outweighs individual interest," and, especially in matters not specified in the primary sources of Shari'a, "Wherever welfare goes, there goes the statute of God." Examples of applying some of these will follow later.

Sanctity of Human Life

Human life should never be violated except in situations explicitly specified in the penal code and observing the rigorous criteria it establishes. Commenting on the killing of Abel by his brother Cain (the two sons of Adam), the Qur'an states: "On that account We ordained for the Children of Israel that if anyone killed a soul, unless it be for murder or mischief in the land, it would be as if he killed the whole people. And if anyone saved a life, it would be as if he saved the life of the whole people" (5:32). This principle has been invoked when ruling on abortion and euthanasia.

Abortion

In general terms abortion is legally prohibited and punishable. However, some physicians perform abortions illicitly, mainly in the private sector. In some countries, if abortion is done to avoid tarnishing the family name (pregnancy of the unmarried is a great shame in the Arab world), this circumstance is considered a mitigating factor if the case ever goes to court. Tunisia has gone a step further and legalized abortion after the third child, thus allowing it to be considered a form of family planning.

Among the religious community, various views on abortion have been held over the centuries. The writings of early scholars differed according to their perception of the beginning of life, and their views continued to be followed by generations of their adherents. On the belief that life started when the mother felt the movements of the fetus inside her (quickening, usually at the end of four months), some thought that abortion before then entailed no aggression on life. Others maintained that the fetus attained its human form at the end of the seventh week, and aborting it at or beyond this date would be unlawful. The majority, however, espoused the views of the great jurist Al-Ghazālī (eleventh century C.E.), who believed that life started with the fusion of the male and female seeds, and that it proceeded through an occult phase to the palpable phase felt by the mother. This view of the beginning of life therefore outlaws abortion and makes it reprehensible at any stage of pregnancy.

Modern juridical opinion has put an end to the historical diversity of opinion and settled for Al-Ghazālī's, following a number of conferences in the 1970s and 1980s (see, e.g., Gindi, 1989b) at which religious scholars met with medical scholars and a full account of the process of conception and early development was illustrated by ultrasound and cinematographic recordings of the fetus in utero. Five criteria were collectively acknowledged as signifying the beginning of life: (1) it is a fairly clearly defined event; (2) it exhibits the phenomenon of growth; (3) such growth, unless interrupted, leads to the known subsequent stages of life; (4) it contains the genetic package characteristic both of humanity and of a unique individual; and (5) it is not preceded by any stage combining the first four criteria (Gindi, 1989a).

Abortion is permitted if the continuation of pregnancy poses a serious threat to the life of a sick mother (the choice of the lesser of the two evils if both cannot be avoided). In Shari'a the mother is the root and the fetus the offshoot, and it is lawful to sacrifice the latter if it is the only way to save the former.

Selective abortion for the sake of sex selection is doubly unlawful, being an aggression on life as well as discrimination against the female (almost invariably the unwanted sex). The Qur'an severely rebuked pre-Islamic Arabs (up to seventh century C.E.) for practicing female infanticide (16:59). Sex selection by means not entailing embryocide, to suit the wishes of individual families, has been debated. There is consensus that its admissibility would eventually lead to an upset of the sex ratio in favor of male preponderance, which could lead to grave social consequences.

Euthanasia, Suffering, and Care of the Elderly

Euthanasia and suicide are completely unacceptable in Islam. There are no euthanasia proponents, and therefore there is no debate. Suicide and complicity thereto are legal crimes, but the problem is of minute dimensions. The Prophet Muhammad told about a man who took his own life due to an illness that taxed his endurance, upon which God said, “My subject has himself forestalled Me; I have forbidden him Paradise” (narrated by Al-Bukhari). Resort to medical or surgical means for alleviation of pain is lawful, but the taking of life is a matter of God’s sovereignty.

Patience in the face of unavoidable pain or adversity is an important value, and the Prophet teaches that through such patience a person’s sins are washed away by God, like a tree shedding its leaves. The right to die is therefore not recognized because humans do not own life; they are only entrusted with it. The same applies to the “duty to die,” recently proposed for human beings who, through age or infirmity, become consumers but not producers. Caring for a growing group of old and disabled can be very costly, as modern budget figures show, but under Islamic law society has to meet this need by rearranging expenditure priorities rather than allowing euthanasia. Care of the old is a principal value in Islam, especially with regard to one’s parents: “Your Lord has decreed that you worship none but Him and that you be kind to your parents.… Whether one or both of them attain old age in your life, say not to them a word of contempt nor repel them, and lower to them the wing of humility out of compassion, and say: ‘My Lord, bestow on them your mercy even as they cherished me in childhood’” (Qur’an 17:23, 24).

However, it is generally agreed that in his or her defense of life, the doctor is well advised to realize the limitation of medical efforts. It is the process of life that the doctor aims to maintain, not the process of dying. When treatment holds no promise, it ceases to be mandatory and withholding or discontinuing the artificial means is justified. No active intervention, however, shall be made to terminate life.

Death

Under ordinary circumstances the time-honored recognition of death based on cessation of heartbeat and respiration is workable, followed by a waiting period of two hours before the death certificate is issued. Nevertheless, advances in transplant surgery and the occasional need for a fresh heart for transplantation have called for a more sophisticated definition of death. Such a heart can usually be procured from a trauma victim whose brain—including brain stem—is dead and who therefore has been pronounced dead although artificial means are employed to maintain the functions of respiration and circulation.

The issue was discussed in a number of conferences bringing together high-ranking religious scholars and medical scientists (see, e.g., Gindi, 1989a). An old juridical rule, “The movement of the slain,” was reviewed. Centuries ago it was ruled that if an aggressor stabbed a victim in the abdomen and the bowel extruded, this was considered a fatal injury; although the victim could still move, his or her prospects for life were practically nil. “The movement of the slain” was the descriptive term given to the death throes. If a second aggressor finished the victim off, the first aggressor would still be charged with murder for having dealt the fatal injury; and the second aggressor would be punished, but not for murder. Realizing that abdominal trauma with extrusion of the bowel is no longer considered a fatal injury by contemporary surgical standards, the scholars removed it from the category of “the movement of the slain.” In its stead, the condition of brain death including the brain stem fulfills the description, since the victim has practically departed from life without the prospect of return and, in spite of the signs of life (circulation, respiration, etc.), is subject to the rulings governing the dead, including taking the heart for transplantation into a needy recipient, without the death of the patient being legally or morally attributed to the surgery. The disconnection of artificial life-support apparatus from such patients would be permissible.

Transplant Surgery

Transplant surgery is practiced in many Arab countries, and some have excellent units. The Qur’anic saying “And whoever saves a life, it is as though he has saved all the people” (5:32) is the basis of considering organ donation as an act of charity. It is a religious duty of the community to provide necessary donors, in analogy with the decree of Umar (the second caliph) that if a person dies due to lack of sustenance, the society should pay legal reparations as if they killed him. The human body is honored whether living or dead, but its surgical violation to procure a needed organ is ruled permissible by invoking the juridical rule of “choosing the lesser of the two evils,” for the alternative would be the death of the prospective recipient. Bodily organs should not be offered for sale, but if purchase is the only source, then buying is permissible under the rule “Necessities overrule prohibitions.”

In reality, however, apart from close relatives, most donors receive a price under the pressure of poverty. The need is felt for a governing authority to regulate the process, lest an exploitative market be created and patients with limited means be excluded. Donation should be purely and truly voluntary through consent of the living donor, bequeathed in a will or with the consent of the next of kin.

Transplantation of fetal suprarenal medulla to the brain to ameliorate certain diseases is lawful, although abortion performed specifically to obtain that tissue remains unlawful. The anencephalic fetus may be used as a donor, and its maintenance by artificial means for that purpose is acceptable, but removal of organs is permitted only after its natural death, without artificially terminating its life. Transplantation of sex glands to provide sex cells (ova or sperm) is unlawful because the prospective fetus would have been formed by elements not bound by a marriage contract. Sterile sex glands providing only hormones are devoid of that objection, but obviously their use is not medically feasible (Gindi, 1989c).

Hygiene and Preventive Healthcare

"Cleanliness is part of the faith," Muhammad said. Ritual ablutions are necessary before prayers several times daily, including a full bath (*tuhr*) after sexual intercourse, menstruation, and the puerperium. Muhammad forbade overindulgence in food and drink, and enjoined physical fitness. Circumcision of male children is required by Islam. Female circumcision, not an Islamic commandment, has been practiced in Sudan and Egypt since pre-Islamic times, and is now waning.

Preventive healthcare is well heeded. One of Muhammad's pertinent teachings is "If there is pestilence in a locality, do not enter it, and if you are already in it, do not go out." Alcohol is categorically forbidden by Islam (as are stupefying drugs, in order to protect mind and health). Nevertheless, the law in many Arab countries allows the sale and consumption of alcoholic beverages. Currently, there is widespread objection to the practice, and steps have even been taken to avoid alcohol in medicinal preparations. Extramarital sex is forbidden in Islam, although it certainly takes place in a clandestine manner. The virginity rate of girls at the time of marriage approaches 100 percent. The sexual revolution and its sequelae in the West since 1960 have not erupted in the Arab world, although the powerful influence of communications markets the Western model and at the same time evokes a strong reaction expressed in a revival of religious values.

Care of the environment is emphasized in Muhammad's teachings, but unfortunately poverty, overcrowding, and unbridled movement from rural to urban regions with limited and failing infrastructure have led to a gap between the real and the ideal in many Arab cities. Muhammad taught, "Faith has many branches, including the removal of dirt from the street," and "Beware of the triple curse of polluting water resources, shady spots, and trodden roads." On water conservation he instructed those expending much water while making the ritual ablution: "Economize, even if you are at a flowing river." Encouraging agriculture, he said, "Whoever farms land will be rewarded by God every time a person eats from its crop, even if a thief steals and eats from it." Another of his recommendations is "If the end of the world comes and you have a little shoot in your hand to plant, then plant it if you can."

Kindness to animals is a religious dictate. They should not be overburdened or worked to exhaustion or tortured, and they should not be killed except for food. Muhammad spoke of God's pleasure with a man who, encountering a thirsty dog unable to reach water in a well, filled his shoe with water and offered it to the dog, and—conversely—God's anger with a woman who imprisoned a cat. These concepts were borne in mind when discussing the ethics of animal experimentation. Although it is approved when necessary for medical research, due care and humaneness should be shown in keeping and handling the animals.

Contraception

Contraception is lawful provided both husband and wife agree. Contraceptive measures are easily available and in some countries are subsidized by the state to curb overpopulation. Family planning should not be directly or indirectly imposed; the method should not be harmful; it should not entail abortion. Governmental and voluntary agencies use propaganda and education to promote family limitation in overpopulated countries, whereas incentives for a larger family are given in the underpopulated, affluent countries. However, family limitation policies are often attacked by some religious elements for a variety of reasons (Hathout, 1989), including the accusation that they are "imperialistic" designs against poor countries (see Information Project for Africa). The use of the intrauterine contraceptive device has been controversial for fear that it acts by inducing abortion, but its use is widespread. The 1987 World Health Organization (WHO) announcement that its mechanism of action was contraceptive and not abortifacient was welcomed by religious authorities.

Breast-feeding is highly recommended in the Islamic tradition; the Qur'an says: "The mothers shall give suck to their offspring for two whole years, for those who desire to complete the term of lactation" (2:233). This would have been a potent measure for wider spacing of pregnancies at the level of the society at large, being associated with a high rate of ovulation suppression (of course it would not be a reliable prescription for contraception for the individual family). Unfortunately, the growing number of women joining the labor force does not work in its favor. Surgical sterilization (both male and female) is frowned upon except for pressing medical indications or at an advanced age (nearing menopause) for the highly parous woman.

Reproductive Interventions

The quest for fertility is legitimate, and treatment of infertility by medical or surgical means is lawful and available within the Shari'a. Artificial insemination is permitted only if the husband's semen is used; donor semen is forbidden (by religion and by law) because it is outside the marriage contract. Since legitimate marriage is the only approved venue for reproduction, in vitro fertilization technology is permitted only if it involves a married couple and is carried out during the span of their marriage. No alien "element" should be involved, be it donated sperm, donated ovum, donated embryo, or surrogate uterus. When the wife is widowed or divorced, she is no longer the wife of her husband, and she can no longer be impregnated by his semen that had been preserved in a semen bank, for the marriage contract has come to a conclusion. Surrogacy is outlawed, and contracts for surrogate pregnancy are null and void.

Alternative family structures, not based on legitimate marriage, have no place in Arab societies.

HASSAN HATHOUT (1995)

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V. ISRAEL

Medicine in Israel, like the country itself, is a blend of contrasts and contradictions, of compromises between tradition and modernity, between myth and reality. Israel, a tiny country made up of a dominant religion and culture (18 percent of the population are non-Jewish), is neither homogeneous nor monolithic. Over fifteen political parties are represented in the Knesset (parliament), and many Israelis are concerned about an ever-impending Kulturkampf between religious and secular factions.

Like all else in Israel, healthcare has been shaped by diverse inputs from a variety of lands of origin, and by the dialectic between the Mosaic and rabbinical tradition and modern Western secular humanism. Each of these major streams is itself heterogeneous. Lip service is paid to myths violated in practice, while traditions overtly denied and rebelled against often provide the spiritual sustenance in which rebels' values are rooted.

The ties that bind Jews to medicine are powerful and deeply rooted. Rabbinic leaders in the Middle Ages often practiced medicine for their livelihood, Maimonides being perhaps the best known in this tradition. In almost every society, Jews have been disproportionately represented in medicine. The most recent example is the 2.5 to 3 percent of Jewish immigrants to Israel from the former Soviet Union who are physicians, a ratio ten to fifteen times higher than that encountered in developed Western countries. The extraordinary value that Judaism places on human life explains in part the attraction of Jews to medicine. The Talmudic statement "He who saves a single life is regarded by the Scripture as if he saved an entire world" (Babylonian Talmud, Sanhedrin 37a) has led to the useful myth that life is of infinite value and to the "sanctity of life" concept that so permeates Jewish tradition.

The foundations of healthcare in modern Israel were laid by Zionist pioneers several decades before the creation of the State of Israel. These individuals were largely secularist, socialist ideologues with deep roots in the social justice ethos of Judaism and in the value placed on human life. Workers in 1912 created a "sick fund" for mutual assistance and healthcare insurance, similar in many ways to the *Krankenkasse* of Central Europe from which they had emigrated. But the principles underlying this Jewish institution were derived no less from the traditional principles of *gemilut hadisim* (loving charity or mutual aid) so clearly spelled out in the Torah, whose rituals the pioneers had often discarded or drastically modified. All were to be equal in the receipt of health care, and money was not to be collected from a person in time of need and distress. This nongovernmental Histadrut labor union sick fund continues to be the major healthcare provider in Israel today. It is both an insurer and a provider of healthcare, owning and operating hospitals and community clinics, and insuring about 80 percent of the population. Smaller sick funds, also funded by mandatory employee and employer contributions, cover the rest of the population.

During the last few years, as healthcare financing has become problematic worldwide—with citizens often placing a higher priority on such personal amenities as choice of physician and attractive waiting rooms than on the concept of equality—the egalitarian foundations of the healthcare system in Israel have been threatened. Gaps in the public sector are being met by a growing fee-for-service private sector. Nevertheless, Israel has managed to maintain both a respectably high level of healthcare and reasonably equal availability of this care, in spite of a relatively low national expenditure. Israel currently spends about 7.5 percent of its gross national product on health care, but since its GNP is considerably smaller than those of most Western European countries, the absolute per capita expenditure is modest.

Manifestations of the strong ethos for saving human life at all costs include the relatively high renal dialysis rates in Israel and the intense efforts made by the military medical corps to provide physician coverage virtually at the battle line, in order to enhance every possible chance to save soldiers' lives. Public appeals by private individuals regularly raise tens of thousands of dollars to send patients abroad for complex surgical procedures that are not performed in Israel.

Yet, simultaneously, there is much evidence that the myth of the infinite value of human life is often shattered in the face of economic realities. Open-heart surgery is rarely offered to those over eighty, and long waiting periods for critical surgical procedures are not uncommon because of limited resources. The distribution of physicians and facilities is not even, with development towns and Arab villages sometimes at a disadvantage compared with the major metropolitan areas. The continued public tolerance of preventable deaths due to smoking and traffic accidents also exposes the mythical nature of the commitment to human life "at all costs." Recently, however, there has been improvement in all these areas.

Consonant with the high priority given to life, the Jewish tradition, unlike Anglo-Saxon law, requires the physician to respond to a patient's call for help. This requirement to render assistance to someone in distress is not confined to the physician; it obligates any individual to come to the aid of a fellow human being. To refuse would fall under the prohibition "Neither shalt thou stand idly by the blood of thy fellow" (Lev. 19:16). A physician who does not respond to a sick patient's request is regarded as one who spills blood. This attitude is incorporated into Israeli secular law, under which a citizen's failure to render assistance at the scene of an accident is a criminal act. Just as the physician is obligated to render care, so is seeking of care by the patient mandatory. The reason for this obligation is that in Judaism, human beings do not possess full title to life or body. Humans are but the stewards of the divine possession they have been privileged to receive. The terms of that stewardship are not of human choice but are determined by the Almighty's commands. Jewish law forbids suicide and requires that all reasonable steps be taken to preserve life and health. When beneficence conflicts with autonomy, the former is given precedence by Jewish tradition, a view clearly in conflict with the modern Western consensus (Beauchamp and Childress).

While such a violation of autonomy for the patient's good is not enforceable in modern pluralistic societies, it is sanctioned in the Jewish tradition; and were Jewish courts fully empowered, they might force medical treatment on a patient if it were indisputably indicated. In modern Israel, in contrast with most Western countries, the courts have not always decided unequivocally for autonomy over beneficence. There has been at least one case where the Israeli Supreme Court permitted a surgical procedure against the expressed will of the subject in order to prevent danger to his life (*Kortam v. State of Israel* 40 [III] P.D. pp. 673–698).

Several medical ethical issues have attracted public attention in Israel over the years and provide interesting insights into the dynamics of Israeli society. For several decades, the issue of postmortem examinations and the laws regulating them were a major public and political issue (Glick). Judaism emphasizes respect for the human body in death as well as in life, and mandates early burial with integrity of the body preserved. Autopsies are permitted only if the information may contribute directly to the saving of a human life. With the creation of the first Israeli medical school, the rabbinate reached an agreement with the medical profession whereby autopsies would be permitted if three physicians attested that the cause of death was unknown. This exclusion of the deceased person's family from decision making and the subsequent frequent performance of postmortem examinations, even over strenuous family objections, turned the issue into a source of festering conflict. Subsequently, with a change in the political constellation that gave more power to religious parties, the law was changed radically as part of a backlash against the previous "liberalism." Not only is family consent now required, but other provisions, such as veto power for any member of the family, have led from one extreme to another. In all likelihood, the last word has not yet been said on the subject.

In spite of the religious limitations on postmortem examinations, the use of organs from the dead for life-saving transplants is religiously acceptable and even mandated. For many years, the hesitation of the rabbinate to accept brain death as the end of human life created difficulties for heart and liver transplants. After careful study, Israel's Chief Rabbinate in 1986 officially permitted heart transplants when donors' total brain death can be assured. This view has not been accepted by all rabbinical authorities, but religious objections now play a relatively minimal role in the limitations on organ transplantation.

Another area of conflict, as in most Western countries, has been abortion policy. Many factors lead to a restrictive policy in Israel. The Jewish tradition accords major rights to the fetus. The demographic and geopolitical situation of the Jewish people, particularly after the Holocaust, would seem to favor a strongly pronatal and antiabortion approach. Yet the Israeli public is quite permissive sexually, and its youth is very much a part of Western society.

The Israeli compromise, meant to satisfy all parties, includes a law forbidding abortions except for a "valid" medical or social reason, as determined by a hospital committee. These indications are liberally interpreted. Abortions performed outside this framework are illegal, thus satisfying religious sentiments. But no physician has ever been prosecuted for such illegal activities, thereby soothing the libertarians. This precarious balancing characterizes many of Israel's solutions to such conflicts.

Israel has a national committee appointed by the minister of health that advises the minister on many of the more complex and controversial areas in medical ethics, such as in vitro fertilization, genetic engineering, and the like. The committee, called the Supreme Helsinki Committee, is an outgrowth of a committee originally charged with the regulation of research in human subjects according to the Helsinki Declaration. It includes physicians, nonmedical scientists, jurists, philosophers, and clergy. It prefers to work by consensus rather than by vote, and makes every effort to weave its way through the maze of potential legal, religious, and sociopolitical conflicts. In the area of reproduction, the problems are great, since—unlike most areas of law that are adjudicated by the secular courts—marriage, divorce, and family law are largely in the hands of rabbinical courts (Shapira, pp. 12–14). Permissive decisions in the area of new reproductive technologies, unacceptable under religious law, might label the offspring of such practices as bastards, with serious consequences for them in their attempts to marry.

Israeli medical schools now have courses in medical ethics. Most provide the largely secular students with philosophical as well as religious approaches. The Israel Society for Medical Ethics serves as a forum for discussion, for the issuing of position papers, and for raising the consciousness of healthcare professionals regarding medical ethics.

Some militant secular Israelis, chafing under the restrictions of Jewish tradition, have taken a number of bioethical issues to the courts in attempts to force rulings in favor of their position. Cases pressing the right to die have been brought before the courts without clear-cut resolution. Similar suits have been brought with respect to the restrictions placed on surrogate motherhood. These and other court decisions may bring about changes that legislators have been reluctant to press because of their hesitance to upset the "status quo"—which, in this case, refers to a freezing of the situation regarding the influence of the Jewish religion within Israel's public life prior to statehood.

In summary, Israel is a relatively young country that sees itself as part of the modern Western world, yet is the heir to an ancient and wise cultural tradition dating back thousands of years. Jewish tradition is characterized by a strong duty ethic, with emphases on both physician and patient responsibility; a high value on human life; and a strong sense of justice. Time will tell how successful Israeli society will be in distilling and blending the best of both these worlds.

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MEDICAL ETHICS, HISTORY OF SOUTH AND EAST ASIA

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I. General Survey
II. India
III. China. A. Pre-Republican China
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I. GENERAL SURVEY

The entries that follow deal with the complex and varied traditions of medical ethics and practice in east, south, and southeast Asia. In many respects these three areas have always represented very different cultural and geographical entities. The Indian subcontinent derived its cultural and linguistic influences from central and western Asia, but produced in Hinduism and Jainism its own religious, cultural, and intellectual forms, shaping attitudes toward disease and the ethics of medical practice. Concepts of human life and disease evolved quite independently in east Asia, where an agrarian society grew up isolated from other Asian peoples both by steep mountains and by what were for the early Chinese equally impenetrable oceans. Chinese society developed its own characteristic political and social practices—particularly its religion focused on the present world, and orientation toward its ancestors. Early Japanese attitudes toward nature differed from the Chinese, as the conceptions of an island people dependent on the seas for a living differed from those of plains-dwelling farmers. Nonetheless, significant interaction between China and Japan from about the seventh century C.E. infused Confucian ideas into early Japanese foundations. Southeast Asia, today comprising Vietnam, Laos, Thailand, Malaysia, and Indonesia, and vividly characterized by Anthony Reid in *The Lands Beneath the Winds,* also evolved from independent social origins. As Reid writes: "Fundamental social and cultural traits distinguish Southeast Asia as a whole from either of its vast neighbors—China and India. Central among these are the concepts of spirit or 'soul-stuff' animating living things; the prominence of women in descent, ritual matters, marketing and agriculture; and the importance of debt as a determinant of social obligation" (Reid, 1988, p. 6).

Despite their very different cultural orientations, these societies are treated here as a group because they offered in traditional times a common contrast to Western medical practice and ethics, and have had throughout their histories a common influence from Buddhism. In more recent periods, the societies of east Asia have faced the common problem of reconciling the possibilities of Western medical technology with their own social goals. These common themes are explored here, by way of introduction to the more specialized articles that follow.

In traditional times, the societies of Asia never adopted the exclusively biological conception of disease that has become the norm in modern Western societies. In traditional Indian Ayurvedic medicine, as Desai Prakash argues, physicians classified the etiology of disease in three categories: external or invasive diseases caused by foreign bodies or possession states; internal diseases caused by disturbances of humors brought about by lapses in discretion; and a third category of disease brought about by the inexorable workings of karma. In ancient China, the metaphors were different but the origins of disease were understood to be equally complex, with health and illness deriving from the baneful or benevolent influence of departed ancestors, or the influence of demons. In Japan, the apprehension of human beings' relation to *kami,* (sacred world), and the southeast Asian conception of the relation of magic, religion, and health, allowed the possibility of social as well as strictly organic origins of disease.

These views of disease may reflect a general tendency in Asia to view the human order as more fully integrated with the natural and social orders than in the West. This contrasts with modern European conceptions of disease, which reflected a European, perhaps Promethean, notion that the human world could understand, analyze, and ultimately control the natural order. Asians' more complex vision of disease had important consequences for the relationship of the medical practitioner and his patient. Since disease could arise from a variety of sources, the Asian medical practitioner addressed a wider spectrum of issues in a patient's life than did his Western counterpart. Moreover, the Asian patient might be free to consult many more types of practitioners than the European counterpart. Hence varied traditions of medical practice existed side by side, with no single system of medicine having an exclusive legitimacy.

In part, this pluralism of Asian medical practice made it possible for Buddhist practitioners to spread throughout Asia, beginning in about the second century C.E. The notion of loving friendship, and its institutional expression in the establishment of charitable hospitals, dispensaries, and comfort stations on the way to famous shrines and temples, was one of the concepts Buddhist monks carried with them as they made their way across the trade routes of central Asia from India to China between the second and the seventh centuries C.E. Once in China, Buddhist monks found a social environment quite different from the one they had left, for although the Chinese intellectual world was open to Buddhist doctrines, Chinese society was not as open to monastic life with its implied rejection of family and ancestors. In China Mahayana or devotional Buddhism, which stressed the activities that the believer could perform while remaining within the realm of family and community, developed. Thus, in China, Buddhist healing practices not only were carried out within charitable institutions formally run by the Buddhist establishment but also came to merge with folk medicine and healing practices from other traditions.

By about the thirteenth century, the spread of Buddhism throughout Asia had provided a unity to traditional medical practice that had not existed previously. But this was at best a loose unity, in which Buddhist medical ideas came to coexist alongside traditional healing practices and institutions. When Western medicine came to Asia in more recent times, it experienced a similar fate. The importation of Western medicine to Asia was largely a product of colonial times; the earliest Western medical practitioners in Asia were often missionaries supported by European and American political or religious establishments. Twentieth-century Asian governments, consciously or unconsciously aware that Western medical technology could provide the same control over life and disease that Western military and social technology provided over political affairs, often vigorously pursued Western medical techniques. The Minister of Education of the government of Nationalist, or Guomindang, China declared in 1914 that he had "decided to abolish traditional Chinese medicine." Similarly, in 1874 the Meiji government in Japan decreed that all Japanese physicians had to have Western medical training.

Despite the vigorous efforts of Asian governments to promote Western medical education and practice, Western medicine has failed to supplant traditional medical practices in any of the countries under consideration, for several reasons. In part, the problem has been the absence of trained medical professionals: In China, for instance, despite the commitment of the government of the People's Republic to scientific medical practice, a realistic assessment of resources dictated that medical workers trained in traditional as well as modern Western techniques be employed. Possibly because of the paucity of trained personnel throughout Asia, Western medical practice has been and remains a largely urban and elite phenomenon. In part as well, traditional medical practices have proved their value as effective and inexpensive treatments for many of the maladies of modern life. As Pinit Ratanakul notes in the article on Southeast Asian countries, "This traditional method of healing may be especially suitable today for Southeast Asians, who, living in societies with increased urbanization and industrialization, need physical, psychological and spiritual care to enable them to cope with such change and the strains and stresses of modern life." Today, then, as in the past, different disciplines of medical treatment, each with its own ethical standards and requirements, exist side by side throughout much of Asia.

If modern Western medicine has not fully supplanted traditional medicine in Asia, the power and technology of modern medicine has in almost every country posed new ethical dilemmas. In some instances, as in the case of reproductive medicine, Western medicine has made accessible courses of action more radical than traditional medicine permitted. Abortion, though known and disapproved of in traditional Chinese and Indian medicine, has become much more common throughout Asia as population control has become an accepted political goal. Amniocentesis to determine the sex of a fetus has become a common practice in India, with female feticide often the consequence of the traditional religious imperative to produce a male heir. China's enthusiastic embrace of the Western market for blood products and the technology for obtaining them fostered the spread of AIDS in the 1990s in a population totally oblivious to the dangers of the technology and the disease.

In other areas of medicine, Western technology has fostered new and rather ominous practices in Asia. In China in the late 1980s, debate arose about the merits of sterilization of the mentally retarded and other types of genetic experimentation. Sadly, Asian practitioners of Western medicine have proved somewhat more willing to engage in experimentation on human subjects than have their Western counterparts, as well. Wartime experimentation during WW II by Japanese doctors in Manchuria has, of course, been condemned not only in the West but also in Japan. Unfortunately, such experimentation has also been carried out in contemporary Southeast Asia, though such action is increasingly condemned by Southeast Asian and Western governments. As a result of the new ethical dilemmas posed by Western medical technologies, medical ethics has become both a heated issue throughout contemporary Asia and the subject of frequent international conferences and journal articles.

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II. INDIA

In this article, India refers to the entire Asian subcontinent south of Afghanistan and the Himalayan range, including the modern nations of India, Pakistan, Bangladesh, and Nepal (often referred to as the "Indic" region) as well as the island nation Sri Lanka. In the third millennium B.C.E. there flourished a civilization in and around the Indus Valley known as the Harrapan city culture. Gradually, from the second millennium, the subcontinent was infiltrated by Indo-European tribes from Central Asia. These people formed the classical culture that survives to modern times with many transformations. In the eighth century, Muslim invasions began in the north, culminating in the powerful Mogul empire of the fourteenth and fifteenth centuries. Historic India is the home of two of the world's major religions, Hinduism and Buddhism, as well as of Jainism, and host to Islam, now the majority religion in Pakistan and Bangladesh, as well as to ancient Christian and Jewish communities in the south. From the interaction of Hinduism and Islam grew another religion in India, the Sikh faith. In the sixteenth century, India's cultural and religious influence extended into China and Tibet, as well as to the lands of Southeast Asia.

The origins of medicine in India stretch back to antiquity. The urban architecture of the earliest civilization, in the cities of the Indus Valley, demonstrates knowledge of sanitary techniques. One of the Vedas, the sacred lore of the early Indo-Europeans (ca. 1500–1000 B.C.E.), contains chants to ward off disease, and lists of herbal medicines. The ancient texts extolled by the *bhesaj,* persons skilled in the medicinal uses of herbs. Priest-physicians prescribed prayers and fasts, as well as herbal medicines. Out of this text, the *Atharvaveda,* and other systems of philosophical speculations developed a system of medicine based upon a theory of bodily humors and a therapeutic regimen of herbs and plants. The term "Ayurveda," meaning knowledge of vitality and long life, designated this classical Indian medicine that is widely practiced in India today. Ayurvedic medicine developed in the fifth century B.C.E.; its earliest classical treatise, *Carakasamhita,* can be dated to the first century C.E. The oldest known Sanskrit medical manuscripts, discovered in a Buddhist monastery in China and dating from about 450 C.E., reveal a developed medical system, mentioning elixirs for long life (including garlic), eye lotions, enemas, aphrodisiacs, and ways of caring for sick children. The text mentions Indian physicians of renown, including the most famous, Sushruta (second century C.E.). After the adoption of Buddhism by King Ashoka (273–232 B.C.E.), Buddhist monks, who were not bound by the rigorous Hindu laws of purity and pollution, were free to mingle with common people and to invite them into their monasteries, thus bringing their medical skills to the needy and hospitality to the sick. They also seem to have brought Ayurvedic medicine to Tibet and China. Monks of the Jain tradition, which arose about the same time as the Buddhist tradition, also contributed to the development of the medical system. Early medical speculations and observations about the body, mind, and illness were consistent with tenets of all three major religions.

There appears to have been a flowering of medicine during the first millennium C.E. (Jolly; Winternitz). In the course of time, six classic texts of Ayurveda were recognized. Two of these, *Sushrutasamhita* and *Carakasamhita,* are named after the most famous physicians of the tradition, Sushruta and Caraka (first century C.E.); it is suggested that the word "caraka," which also means "one who moves about," refers to the itinerant Buddhist monks; Sushruta was a physician to a Buddhist king. The other four—*Ashtangahridaya,* attributed to the physician *Vagbhatta; Madhavanidana; Sarangadharasamhita;* and *Bhavaprakasha*—date from the eighth, ninth, thirteenth, and sixteenth centuries, respectively. The latter two reveal the influence of Arabic medicine, and the last mentions *phirangi roga,* the disease of the Franks (the Portuguese who came to India in 1498), probably syphilis. The use of opium as a therapeutic agent is prescribed in these later texts.

Assumptions of Ayurveda

Ayurveda is deeply rooted in the great religious and philosophical traditions of India, whose visions of human nature and the universe informed medicine and, in turn, were enriched by the concepts formed in medical practice (Dasgupta). Ayurvedic constructs of the self and the body, concerns central to the medical enterprise, grew in tandem with the faith traditions. Ayurvedic physiology and pathophysiology rest on a doctrine of humors (*doshas*) and bodily substances (*dhatus*). The principal humors are wind (*vata*), bile (*pitta*), and phlegm (*kapha*), representing movement, heat, and moisture in the body, respectively. The primary body substance, *dhatu,* is "organic sap" (*rasa*) derived from food, transformed in various ways as it moves through the body, stored in various reservoirs, and excreted as waste. Sap is first transformed into blood, then into flesh, fat, bone, marrow, and semen, the last being the purest product of the transformation.

Health is a state of balance of bodily humors and substances (*dhatusamya*); illness is disequilibrium. The body is affected by external factors, such as food and climate, as well as internal influences, such as anger and jealousy; social experiences, such as praise or scorn, also affect bodily states. Each of these may cause disease or restore health. This interactive universe of substances blurs the boundaries between inside and outside, and makes for a constant flux. The body is in dynamic relationship with the cosmos, whose elements of wind, fire, and water are reflected in the body; similarly, the body is seen as a reflection of the mythic cosmogony, in which the primordial person arises from chaos and is differentiated into multiple forms. Breath (*prana*) is the supreme force that unites bodily parts and becomes the definition of life (*jiva*): "People say of a dead person, that his limbs have become unstrung," say the *Upanishads* (ancient religious discourses). Ayurvedic medicine visualizes the sick person as in a state of fragmentation; his or her bodily components must be taken apart, cleansed, and put together again (Desai, 1989). Breath also becomes equated with the narcissistic and metaphysical components: *ahamkara* and *atman. Ahamkara,* "I-ness," literally the saying of the word "I," is the perishable self; and *atman,* cognate with the Greek *atmos,* is visualized as a self beyond death, without properties, pure consciousness, and transcendental. Although Hindu, Buddhist, and Jain traditions have differing notions of the self, they share common beliefs about the transience of the perishable body, often a source of pain, and the consubstantiality of the body with the universe.

The theory of *gunas* (literally "strands" or "qualities") is an aspect of *samkhya* and an important foundation of Hindu ethics. Inherent and substantial, *sattva* (goodness), *rajas* (vitality), and *tamas* (inertia) are found in all material substances in various combinations and determine the overall constitutional disposition of persons, foods, activities, bodily substances, and so forth. Physically *sattva* is cool and light; *rajas,* hot and active; and *tamas,* heavy and dull. Psychologically they are calmness, passion, and lethargy or stupidity, respectively. In character they are purity or virtue, happiness or sorrow, and darkness or evil, respectively. Contemplation, meditation, silence, devotion, and fasting promote goodness; love, battle, attachment, pleasure seeking, and emotionality enhance vitality; sloth, sleep, and idleness increase inertia. In the hierarchy of values, the *sattva* categories tend to reign supreme and become less material and closer to the idea of *sat* (truth or essence); in Ayurvedic discourses they are understood to be the same as the mind or the self. The ethical aim, therefore, is to transform physical and mental dispositions from inertia to activity to goodness. Such transformations are promoted by ingestion of foods and performance of activities that are conducive to the higher strand. Therapeutic aims are also to transform the self and the body to higher levels of functions: from imbalance to equipoise, from idleness to activity, from agitation or pleasure seeking to calmness and contemplation.

The Physician

An Ayurvedic physician, called a *vaidya,* is one of the quartet (the physician, the drugs, the attendant, and the patient) responsible for amelioration of diseases. Although esteemed for their powers to bring about health and disease-free states ("the cause of virtue"), physicians were regarded with mixed feelings in ancient India; anxiety concerning disease and death was displaced onto them. Physicians contracted impurity from their handling of body products, lesions, and corpses, and through their "democratic practice of mingling with the common people" (Chattopadhyaya). Religious texts enjoined people not to receive food from physicians and to avoid them at religious ceremonies. Taboos concerning touching caused palpation to fall into disuse as a diagnostic tool.

The Ayurvedic texts demand that a physician excel in theoretical knowledge, have extensive practical experience, be dextrous, and observe the rules of cleanliness. A physician began his education as an apprentice, teacher and pupil choosing each other. A good teacher was free from conceit, greed, and envy; the student was calm, friendly, and without physical defects. The physician must be compassionate, virtuous, of high lineage, devoted to learning, rational, and always ready to act. The *Carakasamhita* regards the profession as suitable to the upper castes: Brahmins (for the welfare of all living beings), Kshatriyas (for their own protection), and Vaishyas (for livelihood). The *Sushrutasamhita* also permits the Shudras, the lowest caste, to be physicians. Later the vaidyas became a caste, an occupational division, and the profession passed from father to son. In modern India, physicians, Ayurvedic or otherwise, may be from any caste.

Carakasamhita contains an extensive ethical treatise in the form of an initiation oath to be sworn by one entering the practice of medicine. Among its injunctions are these:

> Day and night, however you may be engaged, you shall strive for the relief of the patient with all your heart and soul. You shall not desert or injure your patient even for the sake of your life or your living.
>
> You shall be modest in your dress and appearance and speak words that are gentle, pure, righteous, pleasing, worthy, true, wholesome, and moderate.
>
> When entering a patient's house, you shall be accompanied by a man who is known to the patient and who has his permission to enter. Having entered, your speech, mind, intellect, and senses shall be entirely devoted to no other thought than that of being helpful to the patient, and of things concerning him only. The peculiar customs of the patient's household shall not be made public.
>
> Though possessed of knowledge, you should not boast very much about it. Most people are offended by the boastfulness of even those who are otherwise good and knowledgeable.
>
> There is no limit at all to which knowledge of Ayurveda can be acquired, so you should apply yourself to it with all diligence. The entire world is the teacher of the intelligent and the foe of the unintelligent. Hence, knowing this well, you should listen and act according to the words of instruction of even an unfriendly person when they are worthy and such as to bring fame and long life to you, and are capable of giving you strength and prosperity. (Menon and Haberman, 1970, pp. 295–296)

Sushrutasamhita describes procedures that include an ingenious method of making a new nose when the original has been cut off (a form of humiliation that was a common punishment for criminals and unfaithful wives). The text also contains directions for dissection of the cadaver. However, dissection for purposes of teaching and study was not normally practiced. The objection to dissection was based on the deep-seated Indian taboo on contact with dead matter of any kind. The doctrine of *ahimsa* (nonviolence), which was taught by Buddhism and Jainism, did not prevent dissection of a dead body, provided the body was not deliberately killed for that purpose; but *ahimsa* did act as a check on vivisection of any creature.

Care of animals such as cows, horses, elephants, and even birds formed an integral part of the prevailing religious beliefs. Mention is made in the literature of hospitals for sick and wounded birds. Although ancient Indian physicians were taught the care and treatment of animals, there were also veterinarians who cared only for animals.

Quacks and charlatans were unequivocally condemned. They were known by their loose tongues, superficial knowledge, pretense, and arrogance. When the patient worsened, they abandoned him. The fate of their patients was worse than death; one can survive a thunderbolt, says *Carakasamhita,* but not the medicine prescribed by quacks. A physician, on the other hand, was to hold his tongue, not enter into needless debates, and apply himself continuously to new learning. He was to avoid women who belong to others, not to enter the house of a patient without the presence of a person known to the family, to maintain confidentiality, and never to mention a patient's approaching death.

Modern Indian physicians, especially those trained in Western medicine under the British, took the Hippocratic oath. The Indian Medical Council promulgated its code of ethics in 1970. The code directs physicians to serve humanity without regard to religion or race, social or political affiliation. A physician must provide pro bono services, maintain confidentiality, and hold teachers in esteem with a sense of gratitude. An adulterous relationship with a patient or with a patient's family member is considered a breach of ethical principles (Medical Council of India).

The Origin of Life

The origin of life is a major concern of the authors of traditional medical texts. An embryo is formed through the union of the woman and the man when both have appropriate humoral dispositions and appropriate nourishment. The life principle is thought either to enter at the moment of conception or to be a latent property of the seeds; the latter is comparable to fire in the rays of the sun becoming manifest on passing through a lens, or the combining of male and female germinal substances. At other times the moment of quickening or the descent of the fetus in the womb is seen as a moment of independent life or viability. Defective germinal substances, "unnatural" coitus, failure of nourishment or inappropriate nourishment, and weakness or disturbance in humors explain the unexpected, such as multiple pregnancies and infertility. Initially the fetus is visualized as genderless and becomes male or female in the third to fourth month of pregnancy. Among the rites of passage, *samskaras,* there is one that is performed at this stage of pregnancy to promote the development of a male child.

Having a male child is a Hindu religious obligation, for the performance of funerary rites by a son secures passage to the land of the forefathers. In this rite of passage, the son symbolically reconstitutes the body of the dead father and reunites him with his lineage. Therefore, a man must have a son; if necessary, he must take another wife to beget a son, invite his younger brother or a Brahmin of good conduct to impregnate his wife (a custom called *niyoga*), choose another willing woman, or otherwise adopt, procure, or purchase a son. The epic *Mahābhārata* provides examples of *niyoga*—the birth of the father of Pandavas, the protagonists, and of the Kauravas, the antagonists of the epic—and of in vitro fertilization—the development of embryos in pots, as in the case of the Kauravas. The birth of the last liberated sage of the Jain tradition, Mahavira, provides an example of embryo transfer from one womb to another, as does the birth of an older sibling of Lord Krishna (Desai, 1988). In light of these traditions, modern forms of surrogacy or new technologies present few problems.

Contraception and abortion also have precedents in Indian tradition. The medical texts dwell upon ways of enhancing the possibilities of conception through manipulation of a number of variables; the same variables can be manipulated to retard the chances of conception. In practice, sexual congress outside the Hindu religious Law was not prohibited for men, but women were scorned if found lacking in virtue—especially widows, who were forbidden to remarry—and means had to be sought to prevent unwanted pregnancies. *Bhavaprakasha,* a sixteenth-century medical text, provides a list of oral contraceptives. Modern methods of contraception have been introduced in India, and a massive family-planning campaign includes male and female sterilization. Research work on antipregnancy vaccine and depot preparations (large doses suspended in oil so that they are slowly released over a long period of time) of hormones is ongoing.

Medical texts, especially the *Sushrutasamhita,* describe various forms of arrested fetal development, fetal death, stillbirth, and obstructed deliveries, and the treatments for them that consist of induction of labor and/or destruction of the fetus. The text cautions against hasty action and requires royal permission to induce abortion and extraction of the fetus in case of danger to maternal life. Although early religious texts consider abortion to be a sin, equal to the killing of a Brahmin, by the seventeenth century Ayurvedic physicians were advising the use of an herb, administered vaginally, for the induction of labor, "a useful remedy for pregnant women in poor health, widows, and women of liberal morals" (as quoted from Vaidya Jeevanamin Chandrashekar, p. 45).

In colonial India abortions were governed by English law; in 1972 the government of India legalized abortion, mainly to prevent illegal abortions and to give further impetus to family planning. Abortions in the first trimester, and under special conditions in the second trimester, are available on demand. More recently, RU-486, "the morning after" pill, has been introduced in India on an experimental basis.

Amniocentesis has become extremely popular in India. Overwhelming preference for boys, permissive abortion laws, and the crushing burden of dowries have led parents to seek to ascertain the sex of the fetus, so that a female can be aborted. A vigorous debate, both for and against using the new technology for sex selection, has ensued, one camp arguing in effect that feticide is better than infanticide and the other decrying the culture's age-old cruelties against women (Desai, 1991).

Disease, Death, and the Laws of Karma

Karma is the operative principle of Hindu ethics and has come to mean that every action has a consequence: "As you sow, so shall you reap." Karma has explanatory power for questions like "Why me?" and encourages action for future rewards. The cycle of birth, death, and rebirth, as well as that of health and disease, is governed by the laws of karma. The laws of karma also have dominated Buddhist and Jain ethics.

The ancient physicians classified the etiology of diseases into three categories. External or invasive diseases were caused by foreign bodies, war injuries, possession, or infestation. Internal diseases were disturbances of humors brought about by lapses in discretion, which included faulty diets, overexertion, sloth, sexual indulgence, and mental disturbances. The third category was reserved for the workings of karma, fruits of action from past deeds or previous lives. Some disease states were also seen as the workings of time, as in aging. The unseen hand of karma was invoked in all diseases, a schema that brought ordinary actions like dietary habits and seasonal observances under the umbrella of ethics. Mental illnesses also arose from these etiologies: possession by spirits, disturbances in humors, and lapses in discretion. Like other conditions that defy easy explanations, epidemics and natural disasters were thought to be caused by the collective misdeeds of a population or of a ruler. Physicians of the era of Caraka and Sushruta paid homage to the principle of karma but argued that passivity on part of a physician who assumed predetermination of disease or death made the whole medical enterprise meaningless. Human effort was always a factor in the workings of karma, and the human body was the object of physicians, who held alleviation of diseases and restoration of health as their primary objectives.

On the other hand, there were incurable diseases. It was prudent of physicians to be wary of heroic efforts to prevent the inevitable, which not only brought loss of income but social censure and ignominy as well. If the physician knew that a case was hopeless, he was to do no more than sustain the nutrition of a dying patient. Thus, prolonging life with artificial means is not always acceptable. Those who have led a full life must, like ripened fruits, fall from the tree; untimely death of the young is another matter. Yet, death is not the opposite of life; it is simply the other end, the opposite of birth. Those who are born must die.

Debates in the West on the issues of aging, the care of the terminally ill, and euthanasia have prompted a reexamination of medical ethics in the East. Not surprisingly the Hindu, the Jain, and the Buddhist views converge and have a place for a "willed death" or, more correctly, "hastened death" (Young; Desai, 1991; Bilimoria, 1992; Fujii, 1991). Shrinivas Tilak (1989), after examining Hindu and Buddhist texts, concluded that aging represents points in a life cycle, indicating both growth and maturity as well as eventual decline and loss; at the end point it is an indicator of ultimate dissolution of life. Hindu texts bemoan the inevitability of death, and the Buddhist texts point to pain and unhappiness as inherent in life. In the face of approaching or inevitable death or debilitating and painfully long suffering, traditional ethics provides "permission to leave" voluntarily. Also, the anxiety occasioned by the uncertain timing of death is to be mastered by death that is willed; choosing the moment of death is permitted to ascetics or otherwise superior and elevated souls. Each of the three traditions provides for taking a vow to gradually refrain from taking food and water (and medications, when relevant); thus one ultimately starves to death. The early discourses do not regard this as suicide, which is a death brought upon oneself in a state of desperation and imbalance, and therefore belongs to a different category. The three traditions, which uphold *ahimsa* as central to the view of sanctity of all life, find little difficulty with death that is hastened by starvation. A telling episode in the life of Mahatma Gandhi illustrates this debate (Parekh). A calf that had no hope of surviving and was suffering was put to death with Gandhi's consent. Gandhi rejected the view that killing was never justified and always represented violence. He said that there is violence when the intention is to cause pain; otherwise it is simply an act of killing. When confronted by his critics, especially the Jain merchants of Gujarat, with the problem of euthanasia, Gandhi gave the following response:

1. The disease from which the patient is suffering should be incurable.
2. All concerned have despaired of the life of the patient.
3. The case should be beyond all help or service.
4. It should be impossible for the patient in question to express his or her wish.
5. So long as even one of these conditions remains unfulfilled, the taking of life from the point of view of ahimsa cannot be justified.

Although Gandhi believed that he had arrived at his position independently, he was building on the position advanced by ancient medical authorities.

Other Systems of Medicine

Yoga philosophy and the related tantra have enriched the Indian medical system on the periphery. In classical yoga thought, the *Yogasutra* of Pantanjali, the aim is to bring the mind to focus by inhibiting its waywardness, through successive disciplines of body and thought and by regulation of body functions. Thus body and mind are yoked and come into correct conjunction. Later elaborations have included arduous physical practices and other forms of meditation. Modern relaxation techniques and biofeedback, popular in the West, owe their origin to the discipline of yoga.

Yogic thought visualizes the body in concentric layers, proceeding from the less important outside to the vital inside, from gross to subtle, from hard to soft, and from more material to less material. The body is penetrable and its boundaries permeable; only the innermost self, which must be realized through yoga, is an adamantine core of permanent joy and bliss.

Other forms of yoga, especially the kundalini yoga, advance a concept in which the spine is a vertical axis along which are chakras (wheels or lotuses), centers of energy and impulses. The lower chakras represent vegetative functions (e.g., genitoexcretory, digestive, circulatory, and respiratory); the higher ones, centers of thought and emotion. In this dualism, kundalini, the spiritual aspect of a person, lies dormant in the lowest chakra at the base of the spine; it must be awakened through yogic exercises and made to travel up the spine, activating other chakras on the way and finally uniting with the highest chakra, where the principle of consciousness resides. The regulation of breath is critically important in these exercises, for the breath is the source of energy and must travel through the chakras into the various nerves or channels (*nadis*). The left-handed form, tantra, is a fringe discipline emphasizing esoteric sexual practices. The feminine powers are invoked and sought for the purpose of incorporating them in the self of the practitioner. The way to accomplish this is literally to reverse the flow of sexual fluids from men to women. Ultimately the enriched semen will be forced up the spinal axis to repose in the head as a collection of the most vital and purified energy.

Another Indian medical system is the siddha tradition, practiced mainly in southern India. Based on the Ayurvedic principles, it favors the Greek pharmacopoeia, especially the metallic oxides. The use of astrology in diagnosis and treatment, including the wearing of precious and semiprecious stones, is quite common in India. There is also a rich tradition of folk medicine, including exorcists, bonesetters, snakebite curers, and those who use mantras for cure.

The Yunani or Arabic system of medicine was brought to India by the Muslim invaders. Accepted by the rulers, it began to displace the older Ayurvedic practice to the periphery but also interacted with it. Its humoral thinking, based on Galenic principles, was congenial to Ayurveda. The examination of the radial pulse became a central feature of Ayurvedic diagnosis, and whereas the Ayurvedic pathophysiology had until then been exclusively humoral, the liver and blood were now implicated in folk pathophysiology. Muslim rulers patronized the system and founded publicly funded hospitals and dispensaries. Hakims, the practitioners of Arabic medicine, enriched the Ayurvedic herbal apothecary with their metallic oxides. They often specialized in the treatment of male sexual dysfunctions. This system is especially patronized by the Muslim population of the subcontinent.

"Allopathy" is the term by which modern Western medicine is known in India. European missionaries, especially from Portugal and France, brought it in the fifteenth century, and the British introduced the system in the delivery of care of their own personnel, later founding hospitals and medical schools in the major Indian cities. Allopathy pushed Ayurveda and Yunani to the periphery of medical practice. Today in India all systems are patronized, allopathy more in the cosmopolitan areas and the indigenous systems more in the rural. Patients often move from one to the other, depending on their own explanatory system or the success or failure of one or the other. The indigenous systems are more often chosen for the treatment of chronic conditions, which by definition have failed to be cured by modern methods. Although antibiotics have changed the epidemiology of acute conditions, they are seen as heavy and harmful with many side effects, in contrast to the gentler herbal preparations. Preparations for internal use have to meet the test of culturally constructed theory of inputs and fluxes. The most significant impact of modern antibiotics has been on maternal and infant morbidity and mortality.

In the 1990s most hospitals are staffed by practitioners of allopathic medicine. There are over 100 allopathic medical schools, over 500,000 hospital beds, and over 300,000 licensed medical practitioners. About 100 Ayurvedic colleges exist, and over 250,000 practitioners, but they have only 20,000 hospital beds. Research in Ayurvedic and Yunani medicine has been organized under central institutes.

Surgery, for which ancient India was famous, has passed into the domain of modern Western medicine. With anesthesia, asepsis, and blood transfusion, modern surgical practice has totally excluded the traditional forms. Organ transplants are becoming common, since traditional beliefs about construction of the body from discrete parts allows for removal and replacement. However, extreme poverty has created a widespread and unregulated market in which poor people offer corneas and kidneys for sale to the wealthy.

A fragmented, either commercialized or bureaucratic system of care that is neither easily accessible nor affordable is the major ethical problem of India. Emigration of physicians and nurses to the West has not helped. Multinational drug cartels and fly-by-night Indian drug firms with little regulation in manufacture or prescription form a lethal combination with diagnoses made by divination or without examination. The cultivation of public health and prevention points a way out of the current problems.

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III: CHINA. A. PRE-REPUBLICAN CHINA

The following article has been retained from the first edition, with minor revisions by the original author.

The cultural history of China, as reflected in its literature, shows that for at least two thousand years the Confucian worldview, an ideology concerned with the structure of social life, dominated Chinese society until the collapse of the empire early in the twentieth century. Although less obvious, the philosophy of Taoism exerted a strong influence on Chinese society in the same period. A third major influence in ancient China, that of Buddhism, was introduced from India about the first century C.E. Buddhism exerted its greatest impact on social life and scholarship in China from about the sixth to the early ninth century. Subsequently some of its metaphysical concepts were integrated into Confucianism, its worldly assets were secularized, and its teachings continued mostly on the level of a folk religion. Medical ethics in China, as a consequence of the parallel existence of these three major ways of life, reflects some of the values of all of them.

This article will focus on the history of explicit medical ethics in prerepublican China. By "explicit medical ethics" is meant those norms allegedly present in interactions between medical practitioners and their clientele. The historian has no way of investigating whether norms, as they were expounded by various groups providing health care in China, actually formed the basis of these groups' actions; it is a well-documented fact that explicit ethics are usually far more rigid than the norms actually followed. One can only infer, then, the ethical norms proposed as an appropriate basis of the actual relationship between individual practitioner and patient in prerepublican China. Evidence of appeals to a code of ethics is extant only with respect to a few individuals. One cannot infer from the explicit ethics of a few practitioners the ethics of the whole group. Professional organizations of medical practitioners that might have attempted to enforce a single code of ethics were unknown in prerepublican China.

Historical sources allow for an understanding of the values regarding life and death contained in various ideologies propagated in China. These values, of course, have their immediate bearing on norms regarding the provision of healthcare and medical services. The historical sources further make possible an understanding of the relationship among various practitioner groups and between these groups and the general public. In addition, the historical material forces one to distinguish between traditional explicit medical ethics and modern explicit medical ethics. The former was characteristic of a period in history during which no group of independent practitioners achieved a place in the top ranks of the respective culture's social hierarchy; values dominant in society concerning life and death seem to have been quite stable during this epoch. One purpose of traditional explicit medical ethics, then, may be understood as an attempt by the medical group expounding it to demonstrate its continuous adherence and conformity to fixed, well-defined values.

Modern explicit medical ethics, in contradistinction, results from technologically based advances in Western medicine during recent decades. It represents an attempt to transform values into norms for new situations. The age-old values regarding life and death cannot simply be extended to the consequences of recent developments in healthcare. In contrast to the past, medical scientists in all modern societies work at the forefront of medical progress, and new norms, often representing differing values, have had to be created to cope with situations that formerly were inconceivable, for example, organ transplantation, allocation of scarce primary medical resources, and the maintenance of physiological functions in the terminal patient.

Although statements about medical practice and practitioners are found early in various branches of Chinese literature, the first lengthy and explicit statement on medical ethics of physicians, that of Sun Ssu-miao, appeared in the seventh century. The probable causes for the emergence of such statements at that time demand closer investigation. Medical practice, in whatever form it is carried out, represents a basic necessity for survival not only of the individual but also of the society. Although communities are known that severely restrict, or even totally deny, medical practice, on grounds of the religious beliefs they follow, one otherwise finds an active acceptance in all cultures known so far.

The utilization and the improvement of available primary medical resources (i.e., medical knowledge and skills, drugs and medical technology, medical equipment and facilities) may be viewed as an integral part of most cultures. The problematic variable is which segment of society utilizes and controls these primary medical resources. At the beginning of the Confucian era in China, about two thousand years ago, several groups already participated in the utilization and control of the primary medical resources then available. These resources included preventive and curative therapeutic strategies that derived from separately conceptualized understandings of health and illness. These included a metaphysical perspective concerning the origin of health and illness, which identified the influence of ancestors and demons as responsible for illness, and a naturalistic concept that focused on the relationship between humankind and its physical environment.

The ancestral paradigm is the earliest known conceptual response in China to the experience of illness and early death. It is documented in inscriptions on oracle bones dating back to the Shang dynasty (approximately from the eleventh century B.C.E. on). Even though this perspective lost its dominant position as an explanation of illness and for the design of strategies to prevent or cure illness by the middle of the first millennium B.C.E., it has survived in China until the present. Ancestral healing places living humans in a community with their ancestors, who, although dead, continue to exist. The ancestors guarantee the health of the living as long as the latter adhere to certain norms, and they send individual illness or social catastrophe when they notice a departure from these norms by an individual or society. Prayers and sacrifices by the living may cause the ancestors to withdraw their wrath and restore health or social harmony.

The ancestral paradigm was superseded during the period of the Warring States, in the middle of the first millennium B.C.E., by a belief in the power of demons (i.e., metaphysical entities not directly related to a living human being) to cause illness. Demons, it was assumed, will cause harm to a person regardless of that person's lifestyle; protection is achieved not by adherence to specific moral tenets but by alliances with the forces of stronger metaphysical entities, especially those of sun, moon, the stars, or thunder. Spells and talismans served to demonstrate these alliances and scare away demons in the lesser ranks of the supernatural hierarchy.

When in the early 1970s, a tomb sealed in 167 B.C.E. was unearthed near Changsha in the Chinese province of Hunan, the artifacts found included numerous texts related to healthcare and therapy. These manuscripts offer the earliest available evidence of the development, in ancient China, of a broad gamut of empirical therapeutic strategies, ranging from minor surgery and massage, dietary concerns and recommendations concerning sexual intercourse, to cauterization and, most prominently, elaborate pharmacotherapy. The resort to herbal, animal, and mineral drugs, as well as man-made substances, to cure and prevent illness remained the most important strategy in Chinese medicine until the twentieth century. Most of traditional Chinese medical literature consists of a long series of ever more comprehensive and sophisticated herbals discussing all possible facets of drug lore, and an even greater number of prescription collections, ranging from specialized treatises focusing on one problem to encyclopedic works. Inherent in the use of drugs against illness is an ontological notion that derives from demonologic beliefs. If they did not serve to cure symptoms such as pain or diarrhea, fever, and cough, drugs could kill intruders causing trouble in the organism. At about the time China was united in the second century B.C.E., a further approach to understanding health and illness found its way into medical literature: the ideology of systematic correspondence. Based on a dualistic paradigm of yin-yang and on a scheme of five phases, the entirety of observed phenomena in the human organism and its environment was seen as a system of interrelated, and hence corresponding, items and processes. A person remained healthy as long as he or she was able to live in accordance with the underlying laws of this system; departure resulted in illness. Healthcare on the basis of these ideas was not so much focused on the treatment of manifest diseases as on prevention and on intervention at the earliest signs of change from a perceived status of normalcy. This system of healthcare did not rely on drugs but on an application of needles meant to exert stimuli that serve to regulate imbalances. Nevertheless, the medicine of systematic correspondence also included strong ontological notions. On a more abstract level, if compared with pharmaceutics, the medicine of systematic correspondence harbored as one of its central notions an idea of "evil" entering the organism from the outside or being generated inside. This "evil" could be transmitted inside the body through a complicated system of conduits and network vessels, and had to be located in order to be purged or eliminated.

The theoretical framework and the terminology of the medicine of systematic correspondence closely paralleled the basic tenets and the language of the social theory of Confucianism. Health of the individual body was achieved by the same means as harmony of the social organism, that is, by adherence to specific moral rules. Deviance resulted in illness or social disorder. Just as no enemy was believed to be able to disturb society from within or to enter from outside as long as these rules were upheld, no illness could emerge in the body or be stimulated by an intrusion from the outside as long as an individual followed a specific lifestyle.

For this reason one may call the medicine of systematic correspondence *Confucian medicine.* Confucian medicine, into which the utilization of drugs was integrated in the twelfth century C.E., was successfully challenged as the officially sanctioned healing system only with the downfall of the imperial society early in the twentieth century.

At the beginning of the Confucian era in the second century B.C.E., medical practice appears to have been in the hands of a variety of practitioners following the principles of the different known medical sciences. In addition there were practitioners, such as a mother treating her child or a neighbor, who possessed and utilized primary medical resources regarded as empirically effective. One has to keep in mind, then, that there was no group with any degree of professionalism practicing medicine in China at that time. In other words, no group of medical practitioners can be said to have been close to having control over all primary medical resources that were available in China almost two thousand years ago.

While it may readily be assumed that the motivation for some people to practice medicine was to help a family member or friend, there is no way to investigate the motives and the actual ethical bases of those persons who chose medicine over any other occupation to earn a living or to exert a social impact. Chinese texts concerned with medical ethics, however, clearly indicate that the desire for control over secondary medical resources (i.e., material and nonmaterial rewards that accrue from medical practice, such as financial wealth or social influence) was a major determinant of the way in which medicine was practiced. At the beginning of the Confucian era, medical practitioners had little control over secondary medical resources. The evaluation of their practice depended on public opinion, that is, on the satisfaction of the laity.

During the following twenty centuries, various groups attempted to reach higher levels of professionalization, that is, to increase the proportion of their control over available primary and secondary medical resources at the expense of the public. One of the important means employed to achieve this end was the appeal to medical ethics (Unschuld, 1979).

Prior to the seventh century C.E., outside of the imperial court in China, no systematic attempt to teach practitioners in medical schools or similar institutions is known. In the first half of the seventh century, the establishment of medical teaching institutions both in the capital of the empire and in the most important provincial cities was decreed. This may be interpreted as an attempt by Confucian decision makers to preserve control over medical resources for the ruling class, the gentry-bureaucracy. The founding of these medical institutions reflects a basic tenet of Confucian ethics, the prevention of the accumulation by any one group in society of control over primary and secondary resources of any kind, which might result in a shift of power and possibly a social crisis or even change.

The underlying principle of many political decisions made in Confucian China was the suppression of emerging groups that had been able to gain control over specific resources. Medical resources were obviously recognized by

Confucian decision makers as potential sources of power if accumulated and controlled by specific groups. Several political measures were undertaken to prevent the emergence of socially accepted, influential groups of practitioners. One was to emphasize the unethical character of practicing medicine for a livelihood by pointing out the evil practices employed by those doing so. It was urged that every educated man should possess sufficient medical knowledge to be able to care for his relatives. Another means was to place all extrafamilial care in the hands of civil servant physicians who were representatives of the Confucian class. Thus, it is not surprising that the education of medical officers in the seventh century was designed to supplement the common basic Confucian education. This tendency was further strengthened during later centuries.

The first noteworthy text of medical ethics appeared during the period when the first medical schools began to produce graduates. The author, a noted physician named Sun Ssu-miao (581–682?), was heavily influenced by both Buddhist and Taoist thought. Despite the fact that he was also well versed in Confucian scholarship, he refused on several occasions to accept calls to serve at the court. Sun Ssu-miao may well be called an outstanding representative of free-practicing physicians outside the Confucian group. By “free-practicing physicians” we mean those practitioners who traveled or stayed at home and treated all kinds of patients, in contradistinction to those physicians who had acquired their knowledge solely to assist family members or friends in need, or to serve as civil servants on medical assignments. The fact that Sun Ssu-miao’s explicit medical ethics appeared at the same time as the establishment of the medical schools might suggest that it was a well-timed presentation designed to expound to the public the medical ethics of the group he represented.

In his voluminous medical work Ch’ien-chin fang (The Thousand Golden Prescriptions), Sun Ssu-miao chose the heading “On the Absolute Sincerity of Great Physicians” for the chapter devoted to medical ethics. The selection of the term *ta-i* (great physician) implied on the one hand that Sun Ssu-miao did not intend to speak for all medical practitioners of his time, but only for those whom he regarded as “great.” It is a common characteristic of medical professionalization in East and West that at some time or other a few individuals form an elitist group that attempts to distinguish itself from the mass of its colleagues through the demonstration of its exclusive possession of superior primary medical resources. It should also be noted that Sun Ssu-miao’s choice of the term *ta-i* was meant to imply that his group had a status similar to that of the most highly regarded imperial court physicians, or *t’ai-i*. The Chinese characters for these two terms are closely related in structure and meaning. Considering the low-ranking social position officially accorded to free-practicing physicians in Confucian China, the use of this title represented a bold demand for the social elevation of their elitist group of practitioners.

Sun Ssu-miao’s treatise was meant to serve two purposes. First, by laying stress on the evaluation of treatment procedures rather than on the outcome of treatments, as was common at the time, he provided a measure of protection for the practitioner in instances where prognosis was unfavorable or outcome unsuccessful. The second purpose was to imply that his “great physicians” should be trusted more than was usually the case. As an introduction to his explicit medical ethics, Sun Ssu-miao provided his readers with a framework of the healing system he and other great physicians allegedly adhered to. It was based on the same theories and concepts that underlay the Confucian-supported medicine of systematic correspondence. Other writings of Sun Ssu-miao reveal, though, that he also favored demonic medicine, a healing system persistently repudiated by Confucians. In his explicit medical ethics, Sun Ssu-miao chose not to mention this aspect of his medical beliefs. He laid a great emphasis on thorough training for those who wish to practice medicine successfully and thus aspire to the title “great physician.” Such tactics were important at that time, because the medical practitioners approved for governmental service were being institutionally trained in official medicine and were thus calling into question the background of free-practicing physicians.

It is characteristic of explicit medical ethics, as propounded by individuals who strive for a higher level of professionalism for their group, to incorporate the basic social values of the dominant groups in society. Therefore, Sun Ssu-miao’s explicit ethics frequently stresses certain values central to Confucian and Buddhist thought, such as *jen* (humane benevolence) and *tz’u* (compassion). Furthermore, certain maxims are emphasized, for example, the obligation to maintain life and to treat human beings regardless of their status, origin, appearance, or the kind of disease they have.

Sun Ssu-miao seems to have grasped some important psychological aspects of the patient-physician relationship. He apparently realized that in order to gain the confidence of patients, and thus unlimited access to secondary medical resources, the physician must appear neutral and above normal human emotions, uncorrupted by even the most tempting worldly rewards.

One recognizes as well Sun Ssu-miao’s sense of belonging to the larger group of medical practitioners when he points out the inappropriateness of abusing physician-colleagues in public. The detrimental effects of such short-sighted behavior, directed toward individual gain, have been recognized by the best minds of the East and West as impeding group professionalization. Thus, from the very beginning of explicit ethics in medicine, elements were incorporated that seem to have little to do with the actual performance of medical treatment and may be regarded as beneficial solely to the medical practitioners.

Finally, Sun Ssu-miao touched on the problem of remuneration. Greed seems to have been one of the gravest complaints raised by the public against practicing physicians. Many statements, promulgated by Confucian interests, expressed this view. If the public were to be convinced that at least the "great physicians" did not intend to cheat their patients, then another system of equitable remuneration had to be elaborated. Sun Ssu-miao referred to a saying of Lao-tzu (604–? B.C.E.), the founder of Taoism, to the effect that good deeds would certainly be rewarded by fellow humans and that evil practices would induce retaliation from the spirits. Thus Sun Ssu-miao approached both the Confucian ideal of virtue as its own reward in the continuation of one's name or fame in posterity and the Buddhist idea of reward or retaliation through supernatural forces, in either this or a later life (if not in another world).

The history of explicit medical ethics in China in the centuries following Sun Ssu-miao very much resembles a debate among three main groups. These were the free-practicing physicians (including Buddhists, Taoists, and others) in whose interest Sun Ssu-miao had spoken, the orthodox Confucians, and a group within Confucianism consisting of ordinary scholars (and at least part-time medical officials) who practiced medicine as a paid profession.

About 150 years after Sun Ssu-miao had published his ethics, Lu Chih (754–805), a well-known scholar from the top ranks of the Confucian bureaucratic hierarchy, made some statements on medical ethics that might be regarded as a direct answer to Sun Ssu-miao. He elaborated on the idea that medical knowledge, and the ability to practice medicine, must be regarded as open to everyone. The implication is that practitioners who specialized in medicine would become superfluous. Lu Chih also chastised those who practiced medicine for living in a manner characterized by greed and evil, and noted that they did so without suffering any kind of retaliation. This observation put Sun Ssu-miao's system of retribution in question. However, Lu Chih also pointed out that those who had practiced medicine without undue concern for material gain but, rather, as an obvious consequence of their concern for humanity had been rewarded one or two generations later, through the happiness and prosperity enjoyed by their children and grandchildren. Lu Chih closed his remarks with an open critique of Taoist and magical practitioners, among whom Confucian historians counted Sun Ssu-miao. At the beginning of the thirteenth century a Confucian scholar-physician named Chang Kao published twelve short stories concerning medical ethics. While decrying the non-Confucian practitioners as "common physicians," Chang Kao recognized the need to allay the fears of orthodox Confucians, who were always suspicious of attempts to gain control over specialized resources.

In his stories, entitled "Retribution for Medical Services," Chang Kao conspicuously resorted to Buddhist concepts of reward and retaliation by forces of another world. These stories center on four major dimensions of medical ethics: greed vs. altruism; exploitation of sexual opportunities; conscientiousness in medical practice; and the problem of abortion.

The last is of special interest because other medical authors showed little concern over the practice of abortion. Relevant prescriptions are frequently provided in major collections. During the reign of the Mongol Yuan dynasty (1260–1367) an official decree prohibited unqualified women from performing abortions. Chang Kao's exceptional handling of this problem was certainly based on his adherence to Buddhist principles. The structure of his entire message seems highly psychological. In the first story, Chang Kao extolled the use of primary medical resources as an appropriate way to gain merit by giving assistance to others. In the second story, he recounted an example of very laudable behavior of a Confucian scholar-physician designed to reinforce confidence in that group. The third through the tenth stories portrayed the decay of morals and depicted examples of many "evil" practices (among them abortion) performed by physicians and others who openly practiced for money with the ulterior motive of cheating the patients. All of these characters received their proper punishment through the actions of gods, spirits, or demons. The last two stories again helped to create confidence in the group to which Chang Kao belonged.

About one century later Ko Ch'ien-sun (fl. 1348), a free-practicing physician, made an ethical statement that was somewhat different from others. In contrast to Confucian ethics, which stressed the study of literature, he emphasized the necessity of gathering clinical knowledge at the bedside as a prerequisite of the well-versed practitioner. Ko Ch'ien-sun departed even farther from official medicine in stating that the origin of his miraculously effective prescriptions rested with a supernatural being who had handed them to him and they were not, in fact, derived from concepts and theories of nature underlying Confucian medicine. Ko Ch'ien-sun is mentioned here as only one example of the vast heterogeneity often overlooked in Chinese traditional medicine.

Most interesting in Ko Ch'ien-sun's statements was the emphasis placed on the outcome of his own practice and the paucity of details concerning his treatment procedure. His reversion to outcome evaluation and other such evidence reminds one that ethical statements found in the literature cannot be taken as representative of the medical group as a whole. It must be assumed that they represent the views of a progressive minority, where "progressive" means an intention to increase professional control over the resources available in society.

In 1522, Yü Pien wrote an interesting modification of the orthodox Confucian claim that everyone ought to possess medical knowledge. Speaking for the group of practicing physicians, he stated that not everyone needed to have medical abilities but that those who called on "common physicians" for assistance could not be regarded as showing sufficient filial piety, and added that medical knowledge was imperative for those who wished to assist their relatives. This very cautious, almost paradoxical, statement may be interpreted as an attempt to legitimize free-practicing Confucian physicians and at the same time to discourage the public from resorting to practitioners outside the Confucian sphere of influence.

New dimensions were incorporated into medical ethics by Kung Hsin, who lived around 1580, and by his son Kung T'ing-hsien (fl. 1625), both of whom had been imperial court physicians. Kung Hsin explicitly rejected patient solicitation, a practice common in China in his time and later. Patient solicitation implies that a particular physician may be better than at least some of his peers. The awareness of differences in standards of performance necessarily leads to public distrust of the group as a whole and, therefore, constitutes an obstacle to further professionalism. Only where the notion predominates that all members of the practitioner group are alike in their standards of performance will there be confidence among potential clientele.

Kung T'ing-hsien, the son, wrote short treatises entitled "Ten Maxims for Physicians" and "Ten Maxims for Patients." In the first of these he underlined the mastery of Confucian knowledge as a prerequisite for medical practice, a point his father had not explicitly mentioned. In his ethical prescriptions for patients, Kung T'ing-hsien demanded that they resort only to "enlightened physicians," willingly take their medicines, start treatment early, avoid sexual intercourse, refrain from belief in heterodox medical resources (i.e., not Confucian-sanctioned), and not worry over medical expenditures. This last point was underscored with the familiar rhetorical question "I ask you what is more valuable to you: your life or your property?"

Ch'en Shih-kung (fl. 1605) also belonged to the free-practicing group of Confucian physicians. He was the first known Chinese physician to suggest that such persons as prostitutes could be treated without risking defamation. Ch'en Shih-kung also offered his colleagues what may be the first investment counsel for physicians when he advised them to invest excess capital in real estate and not to spend money in unethical places like wine houses. His profound sense of belonging to a larger group led Ch'en Shih-kung to urge his peers not only to avoid open criticism of each other but also actively to display benevolent loyalty among themselves despite differences in training and opinion. Finally, he elaborated upon the prohibition of patient solicitation. He counseled that it was inappropriate for physicians to give extravagant presents or costly dinner invitations to other people. His remarks represent a most pragmatic view of medical ethics (Lee). The progress in professionalization that becomes evident through the claims made in explicit medical ethics reached its peak at the end of the era of imperial China. Hsü Yen-tso (fl. 1895), the last author to be cited in this regard, followed the trend when he offered advice to both physicians and patients. He held that in order for a practitioner to maintain a proper level of morality, he was obliged to treat anyone who requested help, regardless of social or financial status; to provide conscientious treatments; to show extreme sincerity; and to respond to any call as soon as possible. In a statement regarding the patient-physician relationship he reminded his colleagues that patients await the arrival of the practitioner as if he were a supernatural being, like the Buddha himself. From this perspective it is not surprising that he asked patients to place themselves entirely in the hands of the practitioners. He demanded that patients have no secrets; that they bind themselves permanently to the physician, not only temporarily in case of an emergency; and that they be isolated from their normal social environment during treatment. The last stricture was possibly meant to prevent discussion of the case and the treatment provided, and had the effect of precluding criticism or interference from outsiders. Thus, at the end of the era of Confucianism, control by a specialized group over medical resources had progressed to a stage incompatible with the original Confucian maxims.

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III. CHINA. B. CONTEMPORARY CHINA

Republican Period (1912–1949)

In January 1912, after decades of social upheaval and a failed struggle to achieve a constitutional government, the Qing dynasty, which had ruled China since 1644, collapsed and the Republic of China was inaugurated, with Sun Yat-sen (1866–1925) as its first president. Although the Republic was enmeshed in constant political and social turmoil, a strong movement of visionary intellectuals pressed for the modernization of Chinese life in all its aspects. While many reformers called for the wholesale abolition of Chinese culture and customs, others sought to blend Western political forms and scientific technology with what they saw as “the essence of Chinese culture.” The Chinese attitude toward medicine during most of the twentieth century has been formed by these conflicts.

Western medicine had achieved recognition, principally among the elite but to some extent in the general population, during the latter decades of the nineteenth and first years of the twentieth centuries, largely due to the influence of Christian missionary physicians and nurses, and the hospitals they maintained. The effectiveness of the Northern Manchuria Plague Prevention Service, organized along Western lines to combat the 1910–1911 epidemic of pneumonic plague in Manchuria, heightened the prestige of Western medicine, particularly in its preventive and public-health aspects. (It was on the occasion of this epidemic that two practices abhorrent to Confucian morality, cremation and autopsy, were permitted by imperial edict.) This service was the first, and the prototype, public-health service in China (Wu). Peking Union Medical College, founded in 1915 with support from the Rockefeller Foundation, became the center of medical science and education in the Western mode. Although only a tiny segment of China’s doctors practiced Western medicine, they attained positions of influence in government, education, and circles of intellectual reform. In 1914, Minister of Education Wang Daxie told a delegation of traditional physicians, “I have decided to abolish Chinese medicine” (Croizier, p. 69). In the next few decades, eighty-nine Western-style medical schools were established, and thousands of Western-trained students graduated. Although this development was frequently interrupted by wars and civil unrest, the values of modern medicine gradually took root in the Chinese soil, where they grew in uneasy association with traditional values.

The abolition of traditional medicine, however, much desired by reformers and government, was not a simple matter. Three times the Republican central government attempted to abandon traditional medicine and prohibit its practice, but each time it met with strong resistance. In 1913, the central government promulgated regulations that excluded the teaching of traditional medicine from the curriculum. In reaction, some intellectuals insisted that traditional medicine could be made more scientific and even integrated with Western medicine. They also noted that traditional doctors were likely to be the only sources of care for most people for many years to come. In 1929 Yu Yan, a physician and an official of the Ministry of Health, outlined administrative measures to curb and eventually abolish the practice of traditional medicine: traditional doctors were to be reeducated and were not allowed to organize schools or to advertise. Traditional doctors responded by organizing the first national association, the Institute for National Medicine (1931), with the goal of protecting and promoting traditional medicine. Even this group, however, affirmed that traditional medicine must be made more scientific, advocating research on the pharmacological basis of the thousands of drugs used in Chinese medicine.

Nevertheless, during the 1930s almost all Western-trained physicians refused to compromise and adamantly rejected traditional medicine. Westernizing authors, physicians and nonphysicians alike, argued that traditional medicine was unscientific, as different from Western medicine as astrology from astronomy, geomancy from geometry, alchemy from chemistry. Efforts to make traditional medicine more scientific or to ally the philosophical views of traditional medicine to the scientific principles of modern medicine were repudiated as nothing more than another example of the reactionary conservativism that had harnessed Chinese life for centuries. Such proposals were called “ignorant, nonsensical, blind, babbling.” In the harsh words of one prominent physician, “Why should modern medicine accept this marriage proposal from such a lazy, stupid wife with bound feet wrapped in yards of smelly bandages?” (Croizier, p. 107). In 1933, the president of the Executive Department of the central government, Wang Jingwei, declared any discussion of yin yang or the five elements without anatomical dissection scientifically untenable, and the therapeutic efficacy of unanalyzed drugs doubtful. With his support, licensing authority over all physicians, Western or traditional, was located in the modernized Ministry of Health, thus holding traditional practitioners to standards they could hardly meet. Even so, attempts to abolish the practice of traditional medicine failed in the end. In 1949, 65 percent of all physicians practiced traditional medicine. The uneasy relationship between Western and traditional medicine would continue into the era of the People’s Republic.

MEDICAL ETHICS. *Ethics of Medical Practice* (1933), by the Western-trained physician Song Guo-Bin (1893–1956), might be called the first modern book on Chinese medical ethics. The author sought to integrate Western medical ethics with traditional ethics drawn from Confucianism. Ethics is the *tao*—path or way and, by extension, principle or reality—of practicing medicine, and is constituted by the Confucian concepts of humaneness and righteousness. Song defined humaneness as the Western concept of fraternity, and righteousness as what is appropriately done in compliance with humaneness. Physicians should have a spirit of love for people and a zeal to do good. The principle of humaneness requires physicians to treat poor patients at no charge when necessary; the principle of righteousness requires physicians to be competent, not to do harm, not to take advantage of the patient’s vulnerability for their own benefit, not to experiment uselessly, and not to practice favoritism. On the moral character of physicians, Song followed his predecessors, emphasizing the right ordering of one’s thoughts and feelings and the right ordering of one’s world: the physician who is not ordered in body and spirit can hardly order the body and spirit of his patient. The physician should have the virtues of diligence, devotion, warmheartedness, and dignity. The responsibility of the physician to the patient is to treat disease, promote health, and relieve suffering. Song was the first Chinese medical ethicist to argue systematically for the obligation of confidentiality, although he recognized that this obligation is not unconditional. The patient’s consent to disclosure, possible harm to others, or the legitimate needs of criminal justice release the physician from confidentiality. Among colleagues, physicians should respect self and others, and should maintain a friendly feeling and a modest attitude. The obligation of the physician to the state and society is prevention of disease and death, applying remedial measures, research on the cause of death, and the support of public charities. Song rejected contraception and abortion as immoral. Although Song’s volume was known principally within the academic world, it was acknowledged as the standard statement of ethics for modern Chinese medicine. In contrast to Song’s ethical idealism, the life of the woman physician Yang Chongrui (1891–1956) represents ethics in practice. After graduating from Peking Union Medical College in 1917, she went to the countryside as one of the first Chinese physicians to bring modern medicine to the peasants, in accord with her personal maxim, “Sacrifice in order to benefit the people.” She established the first school of midwifery in China and, at the end of her life, was chief of the Bureau of Maternal and Child Health. She is one of the heroines of Chinese medicine and is often cited as the ideal physician.

People’s Republic Period (1949–)

On October 1, 1949, the People’s Republic of China came into being, a “people’s democratic dictatorship” based on Marxist principles as interpreted for China by Mao Zedong. This event marked a radical break with Chinese tradition, which, based on Confucianism, had long been in decline and was considered by the new rulers to be incompatible with progress in a revolutionary society. Medicine and healthcare were to be thoroughly modernized, first on the Soviet model and later in harmony with indigenous practices. Medical ethics was to be reformulated to serve politico-ideological work performed by healthcare providers.

The availability of healthcare to the whole Chinese population was a major goal of the People's Republic, and remarkable successes were achieved, given the resources available. From the beginning, Chairman Mao took a personal interest in policies that would improve personal and public health. Statistics for life expectancy for the population as a whole and for newborns in particular were greatly improved over those of other Third World countries, and approached the statistics of developed countries. Many endemic infectious diseases, such as cholera, smallpox, and plague, as well as many nutritional diseases, were brought under control.

HEALTHCARE IN RURAL AREAS. The first national conference on healthcare was held in August 1950. Policies that would govern healthcare were announced: they were designed to respond to the needs of workers, peasants, and soldiers; to emphasize prevention; to effect cooperation between Western and traditional medicine. Soon thereafter, the policy of mass movements was added, that is, highly organized and rapid campaigns to eradicate filth and pests and to instill habits of good health and exercise. For the first time in Chinese history, affordable and competent healthcare became available to millions of laboring people and peasants.

In June 1964, Mao Zedong issued "Instruction on Putting Stress on the Rural Areas in Health Care," in which he criticized the existing healthcare system for its elitist and urban orientation. Urban practitioners, even scientific researchers, were sent to the countryside to practice and to train the public-health workers known popularly as "barefoot doctors." The implementation of this instruction did much to promote healthcare in the rural areas; nevertheless, at the end of the twentieth century, much remains to be done and, indeed, some deterioration has occurred. At the same time, these policies were detrimental to medical education and to scientific advances in medicine and healthcare.

TRADITIONAL AND MODERN MEDICINE. In the early years of the People's Republic, Marxist thought clearly favored modern scientific medicine and labeled traditional medicine as reactionary. Western medicine, however, was viewed as capitalist and imperialist. A realistic assessment of the need for healthcare made it clear that all available resources, including traditional medicine, had to be engaged in the vast work of bringing care to the masses. Mao Zedong issued "An Instruction on the Work of Traditional Chinese Medicine" (1954) ordering the integration of traditional and Western medicine into a unified new medicine. In research, education, and care, efforts were made to bring these two forms of medicine together. In *united clinics,* both sorts of practice were encouraged, Western-trained physicians were required to study traditional techniques, and many large hospitals had sections for Western and for traditional treatment. A document of 1958 stated, "The objective is … a new type of doctor, versed in both Chinese and Western medicines, and one who has acquired communist consciousness under the leadership of the Party committees" (Croizier, p. 185). The ancient practice of acupuncture, for example, was applied to surgical anaesthesia. Reports of this experiment stimulated great interest in acupuncture throughout the world (Risse).

Official policy now favors the coexistence and competition between traditional Chinese medicine and modern or Western medicine, and the integration of these two into a new medicine (Qiu, 1982). Now the debate focuses on whether traditional medicine should be taught in its pure form, which would make it difficult to attract young people, or whether it should be modernized, leaving an uncertainty about what it would then offer. By 1987, the number of traditional physicians had declined to 279,000, while the number of modern physicians had risen to 1,132,000, 80 percent of all physicians. A 1986 survey showed that only 7 percent of respondents depended exclusively on traditional physicians.

HUMAN EXPERIMENTATION. Traditional medicine had no place for human experimentation in the modern sense; research came to China with Western medicine. In the 1950s, the government revealed that during the 1930s and 1940s, some foreign and Chinese physicians at Peking Union Medical College had used poor patients as experimental subjects without their informed consent. One such experiment, done by the American physician Richard Lyman in 1936, involved filming drug-induced seizures of healthy rickshaw drivers, who had been paid the equivalent of two U.S. dollars. This film was shown publicly with sensational effect during the "Ideological Transformation" of 1951–1952 and again during the Cultural Revolution. Since that revelation, many health officials and members of the public have been hostile to human experimentation. As a result, some insufficiently developed or inefficacious therapies became widely available without adequate human testing. In the 1950s, for example, during the movement known as "Learning from the Soviet Union," Vladimir Filatov's tissue therapy, in which human or animal tissues were inserted under the skin as a "biogen" for the cure of a great variety of diseases, was widely used with some fatal results. At the same time, some medical researchers used themselves as subjects for herbal medicines or new drugs and died of poisoning. After 1980, the method of clinical pharmacological trials was introduced into China, together with the principle of informed consent. Institutional review boards to provide oversight began to be set up at the request of foreign groups sponsoring research in China, although as of 1993 there is no universal governmental regulation of research.

MEDICAL ETHICS. During the early years of the People's Republic, Mao Zedong's writings were required reading for every Chinese. In the field of healthcare all medical personnel were required to read his essays "In Memory of Dr. Norman Bethune" and "Serve the People," in which Chairman Mao urged the people to cultivate their moral character in terms of the values of life and death. When one died for the people, he argued, it was a worthy death, weightier than Tai Mountain; otherwise, it was lighter than a feather of the wild goose, as Chinese ancient historian Sima Qian put it. Mao held up as an exemplar for healthcare workers the Canadian physician Norman Bethune (1888–1939), who dedicated himself to the care of Chinese soldiers and civilians during Japan's war against China (1937–1945), praising him as a virtuous person, selflessly committed to those in need, conscientious in his work, warmhearted toward all people, and continually improving his skills. The essay on Bethune was viewed as an incomparable formulation of medical ethics during the Maoist era. Contemporary Chinese bioethics can be dated from 1979, when a conference on the philosophy of medicine, sponsored by the Chinese Society for Dialectics of Nature and the China Association of Science and Technology, was held in Guangzhou. Philosophers, physicians, and health administrators who attended this conference focused on two issues in medical ethics: the concept of death and the justifiability of euthanasia, and the delivery of healthcare without discrimination. The latter problem arose because the Cultural Revolution's emphasis on serving workers, peasants, and soldiers led to discrimination in healthcare services against persons labeled *capitalists* and *bourgeois reactionaries,* and to deaths of well-known persons as the result of negligence (Cai).

Until the 1980s, the discussion of medical ethics was confined to academic circles, specialized journals, and conferences on philosophy of medicine. Two journals, *Medicine and Philosophy* and *Chinese Journal of Medical Ethics,* appeared in the early years of the decade. In 1986 and 1987, however, two legal cases, one on active euthanasia and the other on artificial insemination by donor (AID), drew the attention of lawyers, journalists, policymakers, legislators, and the general public. The first two National Conferences on Philosophy of Medicine and Medical Ethics, devoted to social, ethical, and legal issues in euthanasia and in reproductive technology, were held in July and November 1988. The Chinese Society for Medical Ethics was established in 1988 and affiliated with the Chinese Medical Association. During the decade, most medical universities and colleges, as well as nursing schools, instituted required or elective courses on medical ethics. The curriculum includes study of the moral tradition, medicine in society, the patient-physician relationship, euthanasia, genetics, experimentation, reproduction, and health policy. Dozens of books on medical ethics were published, including Zhi-Zeng Du's *An Outline of Medical Ethics* (1985) and Ren-Zong Qiu's *Bioethics* (1987). Teachers of medical ethics, drawn from philosophy and medicine faculties, were trained in doctoral and master's programs and in special workshops.

DEATH AND EUTHANASIA. During the Cultural Revolution, the concept of brain death was criticized as "bourgeois, capitalist and reactionary," created by "Western doctors … to unscrupulously open up a source for organ transplantation" (Jiang et al., p. 225). In fact, the problem of brain death arose not so much because or organ transplantation, which is not widespread in China, but because respiratory support was increasingly being employed for terminally ill persons. This was considered both futile for the individual and wasteful of health resources. At the 1988 conference on euthanasia, all participants, including physicians, ethicists, and lawyers, endorsed the concept of brain death, following guidelines widely accepted in Western countries, such as the Harvard criteria (Qiu, 1982). As of 1993, however, no administrative or legislative rules legalize the definition of death by brain criteria. As modern techniques for life support, such as ventilation, dialysis, and artificial nutrition, have become more common, particularly in urban hospitals, the problem of their appropriate ethical use has been noted. Academic discussion of euthanasia has centered on how it might be identified as a special modality of death differentiated from natural death, accidental death, suicide, murder, and manslaughter. Ancient Chinese physicians were aware of the limits of medicine and asserted that when disease attacks the vital organs, it is beyond cure. Passive euthanasia for the terminally ill, long a part of traditional Chinese medicine, has been extended without qualm to the irreversibly comatose, seriously defective newborns, and very-low-birth-weight infants. At the 1988 conference, ethicists argued for the justifiability of euthanasia on the basis of the principles of beneficence, respect for autonomy, and justice. In the resolution passed at the conference, participants endorsed the right of terminally ill persons to choose the way of dying and encouraged the use of living wills. These principles and practices, while borrowed from U.S. bioethics, are compatible with the Confucian concept of *humaneness.* Other deeply embedded Chinese attitudes influence thought on this subject. For example, euthanasia for the defective newborn is rendered more acceptable in view of Buddhist beliefs that such an infant must have failed in virtue in a previous life, while Confucian filial piety often causes reluctance to allow one's parents and the elderly to die (Qiu, 1980).

Active euthanasia, however, remains a subject of debate. In 1986, in Hanzhong, Shaanxi Province, two children of a comatose woman suffering from liver cirrhosis asked physicians to end her life by an overdose of morphine, without informing their siblings. The legal case brought against them evoked widespread media discussion. After their conviction on murder charges, they appealed to the Supreme Court, which in 1991 ruled that the defendants were not guilty since the harm to the decedent was minor in view of her inevitable death. Several surveys in 1986 and 1988 showed that the majority of respondents accept passive euthanasia, and even active euthanasia in certain circumstances.

REPRODUCTIVE TECHNOLOGY. Under the influence of the Confucian view of the importance of having a male successor to carry on the ancestors' lineage, infertile couples experience heavy psychological and moral pressure. In a traditional family, the woman is often blamed for the infertility of the couple and stigmatized or abused. Eagerness for offspring is stimulating the development of reproductive technology that replaces the traditional customs of "wife borrowing" and, among the wealthy, concubinage. At the 1988 conference on social, ethical, and legal issues in reproductive technology, artificial insemination by husband (AIH) and by donor (AID) were asserted to be widely practiced among the population. Sperm banks existed in eleven provinces, most of them without procedures to address ethical and legal issues. Except for a few centers in large cities, AID is undertaken without policies relating to the selection of donors and recipients, and the legal status of the child remains unresolved. The clash of traditional values and modern society was manifested in the first legal case involving reproductive technology, in which a Shanghai family refused to accept a baby boy conceived by donor sperm. In some clinics, prenatal sex selection has been practiced. The participants in the 1988 conference argued against it on the grounds that it could worsen the sex imbalance and cause negative social consequences. In the following year, the Ministry of Health prohibited the practice. In vitro fertilization (IVF) is limited to a few centers.

FAMILY PLANNING. In the early years of the People's Republic, China's enormous population and its prospect for continuous growth were recognized as a serious threat to all the social and economic gains expected from the modernization. During the 1950s, limitations on childbirth were encouraged by mass propaganda and contraceptive education. In 1980 the government announced an official policy of "one couple, one child" (the census of 1982 showed China's population had surpassed 1 billion people). This policy has caused thorny ethical problems. Although there is widespread agreement that control of population growth and limitation of reproductive freedom are ethically justifiable in view of China's vast and growing population, argument continues over whether "one couple, one child" is the best policy and over the means employed to implement it. Not only does it conflict with the traditional value that associates more children with better fortune; it also imposes significant hardships on families in rural areas, where labor needs and the care of elderly parents require several children. A 1979 survey by the Chinese Society of Sociology found that a majority of peasants in the villages near cities want two or more children, whereas the majority of respondents in cities are satisfied with one child. The one-child policy is implemented by intensive contraceptive education, by economic incentives and penalties, by sterilization (sometimes compulsory), and by abortion (sometimes coerced). Although population-control programs are officially designed as programs of incentives, education, and persuasion, the line between persuasion and coercion is not always clear, and the efforts of zealous officials in some places have clearly crossed the line. Again, the policy is most burdensome on dwellers in rural areas, where contraceptive services are often inadequate and local officials, under pressure from above, may employ abusive means. In recent years, reports of compulsory sterilization and coerced abortion have convinced certain international agencies and foreign governments to withhold financial support for population-control efforts in China.

Traditionally abortion has not been seen as a serious ethical issue in China. Most Chinese would agree with the ancient sage, Xun Kuang (286–238 B.C.E.), who argued that human life begins at birth; abortion (and contraception) were rarely discussed in pretwentieth-century medical literature, even in treatises on gynecology. Today, however, repeated and late abortions do arouse concern among healthcare workers and ethicists. Unmarried women who become pregnant often seek a late abortion. Late abortion puts physicians in a dilemma, since it involves a conflict between obligation to the health of the patient, due to the dangers of late abortion, and obligation to the society to limit births. Finally, the socially imposed limits on reproduction and the desire for male offspring have encouraged some, especially in rural areas, to revive the ancient practice of female infanticide. This practice, long judged immoral by many commentators, such as the great philosopher Han Fei (third century B.C.E.), has always been abetted by the widespread and deep poverty of the peasants, for whom a girl child was a burden rather than a benefit. Condemned as criminal by the Law Protecting Women's Rights passed by the National People's Congress in 1992, this practice remains difficult to detect and to prosecute.

REFORM OF THE HEALTHCARE SYSTEM. Since the founding of the People's Republic in 1949, the healthcare system of China has consisted of four main components: workers' healthcare in state-owned factories or institutions; public medical service; free preventive immunization; and rural cooperative medical service. In all but the free preventive service, the costs of care are funded by the government, by employer/cooperative contributions, and by a small registration fee (typically less than the equivalent of ten cents per visit, although the fee can be graduated up to about one dollar if the patient wishes to see a professor in an academic hospital). The self- or privately employed must pay the full cost of their care. These programs have extended healthcare far more widely than ever before in China's history and have significantly improved the health of the population. Throughout most of China, patients have access to well-organized health services, provided by many levels of professionals at little cost.

Despite such progress, however, programs have faced major problems: the demand for treatment always exceeds the supply; ordinary people often receive less adequate care than officials; and almost all hospitals suffer large deficits, making renovation and replacement of equipment impossible. Since the implementation of a 1980 policy to dismantle the cooperative farms, the rural medical services have deteriorated and, in some poor rural areas, health care is not accessible to villagers. The government's most recent efforts to reform the healthcare system involve implementing the contract system that has proven successful in agriculture. In this way, hospitals can supplement their government budget by increasing fees for registration, tests, and drugs, after approval from the local Bureau for Prices. A portion of these increases will be paid by the patient and the remainder by the factories and institutions for which they work. Since 1988, economists, ethicists, health administrators, and officials of the Ministry of Health have argued over whether it is ethically justifiable to consider healthcare a market commodity.

PROFESSIONAL ETHICS CODE. In December 1988, the Ministry of Health promulgated an ethics code for medical personnel that consists of seven articles: (1) rescue the dying and heal the injured, carry out socialist humanitarianism, always keep the patient's interest in mind, treat disease and relieve suffering by every possible means; (2) respect the patient's person and rights, treat patients as equals without discrimination on the basis of nationality, sex, position, social status, and financial situation; (3) serve patients conscientiously and politely, deport oneself in a dignified manner, speak to patients in a refined manner, be amiable, care for patients with compassion, concern, and solicitude; (4) be honest in performing one's duties, conscientiously observe discipline and law, do not serve selfish interests with medicine; (5) maintain confidentiality for patients, saying nothing that would harm the patient or reveal the patient's secrets; (6) deal properly with the relationship between colleagues and coworkers, learning from each other and holding each other in respect; (7) be rigorous and dependable in work, vigorous in spirit and eager to make progress, endeavor to improve professional proficiency, continuously renew knowledge, and increase technical competence.

This is the first code of ethics promulgated in the People's Republic of China, although the Chinese Medical Association had published a very brief seven-article "Doctor's Creed" in 1937 (Wang). While the new code is quite similar to medical codes around the world, it should be noted that "respect for the patient's person and rights" does not directly translate into the Western concepts of autonomy and informed consent. While it is now much more common to inform patients fully and to allow them to choose the course of therapy, older paternalistic practices, such as refraining from telling patients their diagnosis and depending on families and even work units for decisions about a patient's care, still prevail. In China, "informed consent with the aid of family and community" might more accurately express the ethical standard.

COMPULSORY STERILIZATION OF THE MENTALLY RETARDED. A regulation for compulsory sterilization of the severely mentally retarded, promulgated in Gansu Province in 1988, specified that mentally retarded persons are to be sterilized when (1) retardation is caused by familial genetic factors, inbreeding, or other congenital factors; (2) the IQ is below 49; and (3) there is behavioral disability in language, memory, orientation, and thinking. Persons who meet these criteria are permitted to marry only after they have been sterilized. Women who meet the criteria and are pregnant must undergo abortion and be sterilized (Lei et al.). Other provinces, following Gansu's lead, drafted similar regulations on compulsory sterilization, while others were more cautious, incorporating sterilization into their comprehensive regulations on family planning. Proponents of such regulation argue that the proportion of mentally retarded persons in the population is too high, that the burden to support them is too heavy, and that the heavy burden has seriously impeded social development and will influence future generations.

At a 1992 national workshop on ethical and legal issues in limiting procreation, participants pointed out that genetic factors play only a minor role in the epidemiology of mental retardation and that data on the incidence, prevalence, and etiology of the mentally retarded population are of variable reliability and subject to widely differing interpretations. Conference participants argued that if the goal is to reduce the mentally retarded population, only those whose mental retardation is known to be caused by genetic factors should be selected for sterilization—a policy requiring an adequate number of medical geneticists to perform genetic tests and identify the causal factors of mental retardation. The effort to reduce the incidence of mental retardation should focus on improving perinatal care and maternal and child care, developing prenatal diagnosis and genetic counseling, preventing inbreeding, and implementing programs of community development. When sterilization is recommended, it should be in the best interest of the retarded person, as a contraceptive measure that reduces personal misfortune; proxy consent should be obtained. Also, it was argued that the relatively high proportion of mentally retarded persons is not a cause of economic underdevelopment, but an effect of it. From the legal perspective, compulsory sterilization infringes upon some civil rights laid down in the Constitution and other Chinese laws, such as the right to inviolability of the person and the right to guardianship for the incompetent. The considerations raised by the 1992 workshop were delivered to the government and apparently have impeded the expansion of compulsory laws. However, existing laws have not been repealed or revised, and there is no strong public protest against them.

CONTROLLING THE SPREAD OF SEXUALLY TRANSMITTED DISEASES. As a result of a major health campaign in the early years of the People's Republic, the incidence of sexually transmitted diseases in the Chinese population was drastically reduced through a combination of medical, educational, and social policies (sometimes quite harsh, particularly against prostitutes). After three decades of dormancy, sexually transmitted diseases (STD) began to rise in the 1980s: from 1980 to 1992, some 700,000 cases of STD were reported (the actual number is probably much higher), including about 1,000 persons who have tested positive for infection with human immunodeficiency virus (HIV). Countermeasures have been taken in recent years to check the epidemic of STD, and several laws, ranging from management and surveillance to prohibition of drug trafficking and prostitution, have been enacted. However, programs for controlling STD are inhibited by several factors. One is the revival of an ancient concept in which disease is seen as punishment for misbehavior instead of being caused by a particular microorganism. Sexually transmitted disease is sometimes called "Heaven's punishment for moral deterioration." The Chinese National Expert Committee on acquired immunodeficiency syndrome (AIDS) attempts to counter this view in "An Open Letter to Medical Care Workers," asserting, "The disease is not the punishment to an individual, but a common enemy to the whole of mankind.… Every medical-care worker ought to be full of love in the heart, and help our compatriots who are threatened by AIDS with our hands and knowledge" (National Expert Committee, p. 1). The second factor is discrimination against patients and infringement upon their individual rights. HIV-positive persons have been expelled from their jobs or schools; AIDS patients have been refused admission to hospitals. Many medical workers have expressed reluctance to care for AIDS patients. A Health Department requirement that doctors fill out an STD patient card and send it to the public health office drives patients away from care, sacrificing the opportunity for education and treatment. The third factor is the lack of legitimate and effective policy to change at-risk behavior such as drug use, prostitution, and unsafe sexual behavior. In 1992, some cities set up hot lines to provide counseling and to protect patients' rights to confidentiality and privacy.

Conclusion

Since the new policy of reform and openness initiated at the end of the 1970s, China has been undergoing yet another fundamental change. Marxism faces challenges from internal pressures and from Western ideas and economics. Confucianism is still deeply engraved in the Chinese mind, but Buddhism, Taoism, Islam, and Christianity are experiencing a revival. Tension and conflict are inevitable as diverse and often incompatible values come to the fore at this historical juncture. Many fields, including medicine, face new challenges, and in this environment the field of medical ethics is flourishing as never before in China. As in many other nations, scholars have delved into problems, published articles, initiated courses, and formed organizations devoted to bioethics.

The word *ethics* is now translated into Chinese as *lun li,* two characters signifying "hierarchical human relationships" and "principle" or "pattern." Combined, these two characters designate guidelines for interpersonal relationships. In

Chinese thought, ethics, or the guide for interpersonal relationships, blends with the laws that govern the universe. Thus, traditional Chinese philosophy, particularly Confucian, has a predilection for ethics, teaching how to be human within an orderly human community. In the last two centuries, Western influence in ideas and commodities has introduced an individualism not native to Chinese thought. Since the late nineteenth century, Chinese scholars have studied Western science and philosophy, with a particular interest in philosophical pragmatism. Marxist philosophy pays relatively little attention to ethics as such, since ethics is considered to be formulated by political ideology. Despite Western and Marxist influence, traditional Chinese ethics still weighs powerfully in the Chinese mind and in Chinese society.

The current interest in bioethics in China has been stimulated and influenced by American bioethics. Several leaders in Chinese bioethics are familiar with the American literature and participate in international bioethics activities. Also, since Western scientific medicine has long prevailed in China, Western ethical concerns are readily recognized, particularly as medical technologies are diffused. Thus, the principles of American bioethics—beneficence, nonmaleficence, autonomy, and justice—are frequently cited in Chinese discussions. However, these principles are not simply foreign imports: they correspond to significant Chinese values. Beneficence corresponds to the paramount Confucian virtue, *ren,* translated "benevolence" or "humaneness," which traditional Chinese medicine proposed as the primary virtue of the physician. It requires compassion and help for the sick, and the duty to avoid harm, as well as the obligation to care for the poor without charge (Qiu, 1988). Respect for autonomy, while not a traditional virtue in Chinese thought or medicine, which was strongly paternalistic, does correspond to the aspirations for personal freedom and social emancipation that marked the powerful current of modernization, sometimes known as the May 14th Movement, that began in the early twentieth century and continues to influence Chinese intellectuals (Spence, 1982). While not encouraged in the culture of the People's Republic, personal autonomy plays a real, if limited, part in modern thought about bioethical issues. Finally, justice in healthcare corresponds to the socialist ideal that a healthcare system accessible to all persons, regardless of social class or economic status, is best realized by a centrally controlled, nonentrepreneurial service system (Sidel and Sidel). This ideal prompted the vast extension of health services in the 1950s and inspires debates over contemporary plans to reorganize those services. Thus, while Chinese bioethics may occasionally speak in terms similar to Western bioethics, its spirit and ideas are properly Chinese: it is a blend of traditional, modern, and socialist Chinese thought, created in the unique conditions of an evolving great nation.

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IV. JAPAN. A. JAPAN THROUGH THE NINETEENTH CENTURY

The following is a revision of the first-edition articles on (1) the same subject by the same author, and (2) "Traditional Professional Ethics in Japanese Medicine" by Takemi Taro. Portions of the first-edition articles appear in the revised article.

The history of Japanese medical ethics must be seen in the context of the stratified development of Japanese culture. In each of the four layers discussed here, particular attention will be paid to medicine and ethics and the ways they were constituted with respect to changes in law, religion, custom, tradition, and social and political institutions.

Early Japan

The earliest layer of Japanese cultural stratification is the magico-religious universe of the ancient Japanese people, which persisted in subsequent periods (often submerged under later cultural layers and foreign traditions). From archaeological evidence, early mythic narratives, and poetry, we surmise that the ancient Japanese worldview was based on a mythic mode of apprehending the origin and nature of human beings, *kami* (usually translated as "deities"), the world, and the cosmos. This indigenous Japanese religion was later called Shintō or the "way of the *kami.*" Early Shintō understood life to be essentially good and beautiful; evil was simply that which was unclean, ill omened, or inferior. Even the term *tsumi* (often translated as "sin") meant defilement or lack of beauty—for example, sickness, disaster, and error, all due to the influence of evil spirits and removable by ablution and lustration. The early Japanese believed that there were numerous *kami* and *mono* ("spirits," especially those of the fox, snake, badger, and other animals), which could possess humans and cause sickness. As a result, people depended on diviners, shamans, healers, and magicians to deal with physical and mental problems, to prevent disasters or sicknesses, and to avoid pollution. For example, early writings refer to medicinal fruits and plants as well as to common practices to avoid pollution, such as avoiding contact with sick people, menstruating women, and death. The early Japanese resorted to herbal infusions, hot-spring baths, frequent bathing, or gargling for prevention and healing. These practices are mentioned in the eighth-century *Kojiki*, a compilation of Japanese mythology, and even in fourth-century Chinese chronicles that describe Japan.

Socially, early Japan was organized by *uji* (a lineage group often translated as "clan"); the Yamato kingdom, an old designation for Japan, which emerged around the third or fourth century, was in effect a confederation of semiautonomous *uji*-groups under the nominal political authority of the chieftain of the leading *uji,* later known as the imperial household.

The Ritsuryo System

In the wake of the political changes on the Asian continent in the sixth and seventh centuries, Japan acquired a second cultural layer, with the heavy influx of Chinese civilization through Sinified Korea, including Confucianism, Taoism, and the Yin-Yang school, as well as law, medicine, philosophy, ethics, and various sciences and technologies and Buddhism. Stimulated by the unification of China, Japanese leaders made a serious attempt to unify Japanese culture and society. The Ritsuryo system—an important and early synthesis of religious, cultural, social, and political ideas—is the concrete embodiment of this second layer of Japanese culture. Its basic principles, especially the doctrine of the mutual interdependence of Shintō-, Confucian-, and Taoist-inspired imperial ideology and Buddhism, survived until the sixteenth century. Thanks to the emerging synthetic cultural matrix, the Japanese learned that it was possible to apprehend a universal structure governing the world of nature and the human body. Especially noteworthy was the popularization of an East Asian tradition of medicine much later called *kampō-i,* or "Chinese-style medicine." As early as 602, a prominent Korean Buddhist monk, Kwalluk, brought to Japan a series of books on diverse subjects, including astronomy, medicine, and magic. From that time on, with active support from the Yamato court, Chinese medicine was spread rapidly throughout Japan by émigré Korean and Chinese physicians, pharmacologists, and Buddhist priests, who utilized their medical knowledge for healing as a part of their religious activities. Many Japanese physicians were especially attracted by the medical theories of the Chinese scholar Sun Ssu-mo (581–682?).

In the main, Chinese medicine combined an emphasis on the prevention and healing of disease with a concern for *ethical behavior,* in the belief that the body is not an individual's own possession but a gift from one's parents, and that one's health depends on the harmonious interaction of the negative (*yin*) and the positive (*yang*) principles. Thus it was one's filial duty to maintain one's health by maintaining harmony with the environment, inasmuch as sickness was believed to arise from imbalance at the physiological, psychological, or cosmological level. Chinese medicine also encouraged acupuncture (*hari*), massage (*amma*), moxa treatments (*akyu* or moxibustion, the application of plants as counterirritants, set on key acupuncture points and burned slowly), and herbal medicine. Chinese medicine did not stress anatomical studies and surgery, largely because of the Confucian emphasis on the sacredness of the human body.

Significantly, Buddhist leaders in Japan affirmed that what one learned from the Chinese medical-ethical tradition was in complete harmony with the fundamental Buddhist principle of compassion. In keeping with this principle, when Prince Regent Shōtoku (573–621) built a temple in what is today Osaka, he provided an asylum, a hospital, and a dispensary on the temple grounds. Following his example, pious monarchs and aristocrats sponsored medical and philanthropic works. Buddhism introduced to Japan not only the savior deity Amida (Amitâbha), and the bodhisattva of great compassion, Kannon (Avalokitesvara), but also the Buddha of Healing, Yakushi-nyorai (Bhaisajya-guru). The Chinese-inspired Taihō Code, promulgated in 702, stipulated the establishment of a Ministry of Health, to be staffed by ten physicians, who were massage specialists, herbalists, and magicians. Judging from the records of the imperial storehouse, the Shōsō-in, built in the mid-eighth century in the capital city of Nara, the Yamato court imported a variety of continental herbal medicines. Another subdivision of the government, the Onmyō-ryo ("*Yin-Yang* bureau") was staffed by specialists in divination, astrology, and calendar making; its main task was to combine magico-religious features (e.g., geomancy, divination techniques, fortune-telling, and exorcism) and the semiscientific art of observing planetary movements.

During the seventh and eighth centuries the imperial government supported the officially sanctioned Buddhist schools but also strictly controlled the activities of their clerics by enforcing the Sōni-ryo ("law governing monks and nuns"). The government also made a serious effort to (1) discourage the popularity of the unauthorized Buddhist clerics—the rustic shamans, magicians, and healers who came under the nominal influence of Buddhism and wandered from village to village, offering divination, magic and healing; and (2) confine legitimate monks and nuns to monastic quarters, keeping them from exercising black magic and practicing medicine. On both accounts, the government failed miserably. The unauthorized clerics, called *ubasoku,* continued their preaching, philanthropic, magical, and healing activities among the lower strata of society, which were all too often ignored by official Buddhist schools. On the other hand, some of the officially sanctioned Buddhist monks, notably Genbō (d. 746) and Dōkyō (d. 772), were reputed to have miraculous healing and incantational powers, and they wielded great influence in court circles.

During the Heian period (781–1191), two new Buddhist schools, Tendai and Shingon, were introduced from China, bringing with them new forms of magic, incantations, and cosmological speculation, all of which greatly facilitated the blending of indigenous Japanese (Shintō), Chinese, and Buddhist traditions. Similar eclectic tendencies appeared in medicine and ethics, as exemplified by the thirty-volume medical work *Ishimpo,* compiled in 984 by Tanba Yasuyori. This work integrated native Japanese insights into the T'ang Chinese medical framework and coupled this with ethical exhortations. From the Heian period on, the term *kampō-i* ("Chinese-style medicine") was used in Japan to refer to this hybrid system comprising Buddhist, Confucian, *Yin-Yang,* and Japanese beliefs and practices, and covering a wide range of subjects: acupuncture, herbalism, moxibustion, massage, cures for the diseases of various internal organs, nutrition, dermatology, hygiene, pediatrics, obstetrics, and so forth. It was also during the Heian period that the government actively promoted its health service and the training of physicians.

For the most part, however, medical services were monopolized by the upper strata of society. The masses had no recourse except to traditional, indigenous folk or popular practices, for example, moxibustion and massage coupled with talismans and incantations. Ironically, the Heian period also witnessed, among both the elites and the masses, the popularity of native as well as Chinese forms of omen lore, demon lore, directional taboos, and exorcism. In this situation, even though learned Buddhist leaders expounded the lofty themes of the compassionate Buddha Amida, their teaching was easily transformed into a "*nembutsu* [recitation of Amida's holy name] magic" by the peasantry.

During the Kamakura period (1192–1333), the Japanese polity was split between the courtier-based Kyoto court and the samurai-based feudal regime (*bafuku* or shogunate) in Kamakura, not far from present-day Tokyo. Understandably, the Ritsuryō ideology declined, as did the Heian government-inspired health service. In its place a new class of professional physicians emerged who charged fees for their services. The thirteenth century witnessed an unusual heightening of Buddhist spirituality, which added luster to outstanding medical and philanthropic activities by saintly Buddhist monks. One monk, named Ninshō, of the Ritsu school, is credited with having cared for 46,800 patients in his medical relief station in Kamakura, and with having established a leprosy sanatorium in Nara. Among the many dedicated priest-physicians of the Kamakura period, mention must be made of Kajiwara Shozen, the compiler of two important medical works—the *Tan-i-shō,* a fifty-volume work in Chinese, and the *Man-an-pō,* a sixty-volume Japanese work.

During the Muromachi period (1338–1578), a semblance of the feudal regime under the Ashikaga dynasty was maintained even as the social order steadily broke down. Toward the end of this period, three strongmen—Oda Nobunaga (d. 1582), Toyotomi Hideyoshi (d. 1598), and Tokugawa Ieyasu (d. 1616)—terminated the moribund Ritsuryō religious, cultural, social, and political synthesis. During the later Muromachi period, the various schools of Buddhism were unable to exert significant spiritual influence, the only exception being Zen, which inspired art, culture, and learning, and was instrumental in transmitting the syncretistic Neo-Confucianism of Sung Dynasty China (960–1279), as well as legal, philosophical, and medical classics of the Yüan (1276–1368) and Ming (1368–1644) dynasties. During the Muromachi period a number of Japanese physicians (both secular and clerical) studied in China, and able Chinese physicians migrated to Japan. Warfare among warrior families, especially the devastating Onin War of 1467–1477, promoted interest in surgery. Many prominent surgeons of this period were military men who combined medicine, Zen, and the martial arts.

The Muromachi period is also uniquely important in the history of Japanese medicine because of the coming of European medicine with the arrival of Portuguese traders and Roman Catholic missionaries. In the mid-sixteenth century, Jesuit missionaries established clinics, hospitals, dispensaries, and leprosy sanatoriums in Japan. One of the famous medical missionaries was Luis de Alameida, a successful surgeon-turned-Jesuit. For the most part, the European missionary-physicians admired the high quality of *kampō-ijutsu* (Chinese-style, mostly *internal* medicine) then available in Japan, and they contributed new knowledge and techniques in surgery, which were badly needed in the war-torn nation. After 1560, when the Society of Jesus terminated its medical activities, Japanese physicians who had been trained by European missionary-physicians carried on their work until the feudal regime decided to exterminate all traces of Catholic missionary influence from Japan in the mid-seventeenth century. Although the tradition of Namban (literally, "Southern Barbarian") medicine was short-lived, its scientific approach, coupled with an altruistic spirit and ethical imperative, left a significant imprint on the history of Japanese medicine and medical ethics.

The Tokugawa Era

In 1603, Tokugawa Ieyasu, one of the three strongmen mentioned above, inaugurated a shogunate that lasted until 1867, when the last Tokugawa shogun returned the prerogative of ruling the nation to the young Emperor Meiji. A different synthesis of religious, cultural, social, and political elements developed during the Tokugawa period. The Ritsuryō system discussed above tried to subsume two *universalistic* principles—*tao* ("the way"; *michi* in Japanese) of Confucianism and *dharma* ("the law"; *hō* in Japanese) of Buddhism—under the indigenous tradition represented by Shintō and the imperial system. The Tokugawa synthesis of religious, cultural, social, and political elements (the third layer of Japanese stratification) was based on universalistic Neo-Confucian principles of immutable natural laws and natural norms implicit in the human social and political order, grounded in the Will of Heaven (*t'ien*; *ten* in Japanese). Ironically, it was the Confucian thrust that stimulated the nativist *kokugaku* ("national learning") movement, which in turn fostered the resurgence of Shintō as the guiding principle for restoration of an imperial regime in 1868, inaugurating Japan's *modern period.*

From the perspective of medical history, the Tokugawa period was rich in variety, propelling the development of Chinese (classical Confucian and Neo-Confucian) and nativistic Japanese medicine, and the return of Western medical science. During the Tokugawa period, following the regime's policy in favor of Neo-Confucianism, Japanese medicine separated from its Buddhist underpinning and sought a new foundation in Neo-Confucian metaphysics, physics, psychology, and ethics. Under Neo-Confucian influence, *idō* (the "way or ethics of medicine") was summed up in the phrase *i wa jin nari* ("the practice of medicine is a benevolent art"). Significantly, the first systematic treatises on medical ethics written in Japan, the *Ibyo-ryogan* and the *Byoi-mando,* by Takenaka Tsuan, as well as the *Yojo-kun* ("Instruction on Hygiene"), by Kaibara Ekken (d. 1714), were published in the early Tokugawa period. About that time, among the physicians of *kampō-i* ("Chinese style medicine"), a group called *gosei-ha* ("school of later centuries") taught an intricate fusion of medicine and Neo-Confucian philosophy and became quite influential.

One of the most influential works on healthcare was the *Yojo-kun* ("how to live well"), by the samurai and physician Kaibara Ekken. A Neo-Confucianist scholar, Kaibara wrote widely on various subjects for the edification of people in all walks of life. His lifelong dedication to the cause of healthcare is summarized thus: "Medicine is the practice of humanitarianism. Its purpose should be to help others with benevolence and love. One must not think of one's own interests but should save and help the people who were created by Heaven and Earth." This represents the view that human beings are created by the union of Heaven and Earth, that is, the parents. Since medicine is an art that can make the difference between life and death, it is a profession of utmost importance. This means that physicians must be culturally and intellectually accomplished. Kaibara urged physicians to be conversant with the best medical books, to think logically and precisely, and to acquire important theories, practicing *lifelong education.* He proposed an ideal image of the physician, who excels in qualities of character and scholarship, in contrast to the *inferior physician,* who serves his own interests rather than saving others. At the end of his treatise Kaibara lists eight requirements for the physician: (1) to have a high goal in life; (2) to be cautious; (3) to acquire scholarship of broad knowledge; (4) to make the medical profession a full-time pursuit; (5) to be thirsty for new and ever greater knowledge; (6) to be humble; (7) to be clean at all times; and (8) to be magnanimous.

Meanwhile, in the latter part of the seventeenth century two interesting phenomena developed: (1) the emergence of "ancient studies" (*kogaku*) within the Japanese Confucian tradition, which encouraged *kampō-i* ("Chinese-style medicine") physicians to react against the Neo-Confucian orientation and to return to classical Chinese medicine; and (2) the emergence of the Japanese "national learning" school (*kokugaku*), inspired by Confucian *kogaku.*

Clearly, the *ancient studies* school was a reaction among Japanese Confucianists against the regime-sponsored Neo-Confucian orthodoxy that involved advocating a return to ancient Confucian sages. *Ancient studies* precipitated the rise of a school of medicine called *koihō-ha* ("school of ancient medicine") among Japanese *kampō-i* physicians, who advocated a return to ancient (i.e., Han dynasty, 206 B.C.E.—220 C.E.) Chinese medicine and, more specifically, tried to retrieve the medical work of a Han physician, Chan Ching-chung. For example, Chan's book on fevers and their remedies, the *Shokan-ron,* became widely read in Japan.

Paradoxically, the philological-philosophical approaches of *kogaku* inspired some nativists to apply its scholarly method to the study of ancient Japanese classics, thus developing the school of "national learning" (*kokugaku*), which soon grew into an influential movement and eventually joined with other nativists in the anti-Tokugawa and pro-royalist movement. One of the leading theoreticians of this school, Motoori Norinaga (1730–1801), was a physician. We are told that in his youth he studied both Neo-Confucianism and the Neo-Confucian-inspired *gosei-ha* tradition of medicine, but gradually discarded Neo-Confucianism in favor of national learning and repudiated the *gosei-ha* medical orientation, turning to the *koihō-ha* tradition. Other "national learning" scholars, such as Ueda Akinari (1734–1809) and Hirata Atsutane (1776–1843), were also physicians. Hirata attached great importance to mental therapy and excelled in taking his patients' psychosomatic conditions into account.

Western medicine, briefly introduced by the Jesuits, returned to Japan under Dutch influence. In order to exterminate Catholic influence, the Tokugawa feudal regime had proclaimed the policy of national seclusion in 1639, terminating all contacts with Western powers. It had allowed only non-Catholic Holland to maintain a small trading post in Nagasaki. Through this minimal contact, Dutch medical supplies and surgical methods continued to influence the Japanese medical profession. As early as the mid-seventeenth century a Dutch physician, Casper Schambergen, spent nearly a year at Nagasaki, teaching Dutch medicine. His influence greatly enhanced cosmopolitan (Westernized) medicine, especially surgery, then called the *aranda-ryu geka* ("Dutch surgical school"). This school became popular through a translation of the *Tavel Anatomia* (*Kaitai-shinsho*) by Mayeno Ryotaku, Sugita Gempaku, Nakagawa Jun'an, and Katsuragawa Hoshu in 1774. In 1823–1828, Philip Franz von Siebold, a German physician and scientist attached to the Dutch trading post in Nagasaki, was permitted to operate a clinic and an academy that attracted a number of able Japanese medical students. He revisited Japan in 1859–1862. Those Japanese students who studied Dutch learning had been well grounded in Confucian learning, which to them was essential for moral cultivation, whereas Dutch (and later, other Western learning in general) was considered practical learning. Hence the famous motto "Eastern ethics and Western science."

The Meiji Synthesis and Modern Japan

The once powerful Tokugawa feudal regime was exhausted politically when the last Tokugawa shogun surrendered feudal power in 1867. It was succeeded by the Meiji-era synthesis of religious, cultural, social, and political ideas that survived until the end of World War II in 1945. Unlike the Tokugawa regime, which authenticated its policy and culture in terms of *universalistic* Neo-Confucian principles, the Meiji regime reverted to *particularistic* Shintø and imperial traditions reminiscent of the Ritsuryō synthesis of the seventh century, notwithstanding the Meiji emperor's Charter Oath to the effect that "uncivilized customs of former times shall be abolished" and "knowledge shall be sought throughout the world." (Understandably, the basic contradictions of the Meiji synthesis have haunted modern Japan until our own time.)

In the modern period Japan welcomed Western knowledge and technology, which inspired, among other things, modern Westernized law, philosophy, ethics, and medicine. In medicine, the Japanese government officially adopted the German system of medical education in 1869. In 1873, there were slightly over five hundred Westernized physicians and twenty-three thousand traditional *kampō* doctors (or *kampō-i*). From 1876 on, the government required all physicians to study Westernized medicine, although *kampō* medicine, which never lost its official recognition, continued to flourish throughout the nineteenth century and into the twentieth. In retrospect it becomes evident that from early times to the modern period, through all the cultural layers, Japanese medicine and ethics—nurtured by Sino-Korean culture, Buddhism, and Western influences—never completely lost its ancient, indigenous orientations, including magico-religious beliefs and practices.

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IV. JAPAN. B. CONTEMPORARY JAPAN

Due to Japanese society and its distinctive historical understanding of medicine and the role and responsibilities of the physician, it was not until the 1960s that the bioethical and sociolegal concerns about the practice of medicine began to be deliberately reflected, and only during the 1980s that the notions of autonomy and rights in medicine, and of bioethics in general, became gradually influential (Kimura, 1979, 1987a, 1987b).

In the long tradition of Japanese medical practice, the Confucian notion of *jin* (benevolence) has been one of the most important ethical elements; medicine itself is known as *jinjyutsu* (the art of *jin*). Physicians, as conduits of *jin,* were required to act with benevolence toward their patients and were responsible for the welfare of patients in a fiduciary (trust) relationship (Kimura, 1991a). It was obligatory to use medicine, a gift of benevolence, for the good of others even without payment. Physicians fulfilled their responsibility toward their patients and the patients' family members by acting in a paternalistic and authoritative way; the Japanese, nurtured in the Confucian ethos to respect law, order, authority, and social status, acquiesced without murmur to the superior knowledge of the physician.

Traditionally, the socially reinforced mentality of thinking of oneself as a member of a group rather than as an individual could be seen as one key element to understanding the sense of "related-ness" in the Japanese society (Doi; Mitchell; Johnson). This unique character can be interpreted in the framework of "related-autonomy" or the making of autonomous decisions in relationship striving for harmony (*wa*) with other people in the Japanese cultural bioethics. The sense of relatedness and codependence extend to all living beings and to one's bond with the environment.

In keeping these twin notions of related-autonomy and harmony (*wa*) in mind, this entry will discuss the contemporary Japanese approach to various issues and problems of bioethics, in light of the social, cultural, and historical milieu in three stages of chronological development.

Confucian Virtues in a Paternalistic Medical Tradition (1868–1937)

In 1868, feudal samurai in particular *han* (local provinces), such as Satsuma, Choshu, Tosa, and Hizen, initiated the restoration of political power to Emperor Meiji after the Tokugawa shogunate's reign of 265 years (1603–1867). The Confucian ethical teaching, dominant among the samurai during the Tokugawa shogunate, was integrated into Kyoiku Chokugo (the Educational Edict of the Emperor, 1890) as the basis for moral teaching in the elementary school curriculum; the classes were compulsory. (This edict was not abolished until 1948.) Confucian ethics, as embodied in this edict, attributes great mercy and benevolence to the emperor and affirms the importance of virtues such as loyalty to the emperor as the head of the "state-family," and filial piety and respect for parents. It also emphasizes the importance of brotherhood and sisterhood, obedience to law and maintenance of order, the necessity of education, and devotion to the state (exemplified for men in military service). Grassroots movements for liberty and civil rights in the political process (*jiyuu-minkin undo*) were increasingly popular but were suppressed by the emperor's proclamation of the Meiji Constitution in 1889, which consolidated political power in the hands of the emperor and established the Diet (parliament) in his name. Modern Japanese medical ethics cannot be isolated from this social and political milieu. The strong paternalistic nature of Japanese medical practice is the natural outcome of Confucian teaching, which calls for respect of the master and for his authority as a source of unquestionable wisdom and truth.

As Japan became more open to the West, the Dutch ceased to be the sole source of Western culture, and other nationalities replaced them. The process of modernizing Japan began in the second half of the nineteenth century and continued into the twentieth century, aided by *oyatoi gaikokujin* (foreign advisers) from Western countries, hired by the Japanese government to provide development advice in industry, education, government, finance, science, technology, and medicine. Japan, seeking models for modernization, was drawn to the German approach because of the success and progress of German science and technology, and the similarity of the German authoritarian political system under the Prussian Kaiser to its own under the emperor. Official acceptance of Western, particularly German, medicine guided the development of Japanese policy on medical administration and education and set the course for the future (Oshima).

German physicians left a legacy of authoritarianism in medical education and practice that had far-reaching effects on the majority of the Japanese medical community. This approach, combined with the Confucian self-righteousness in rendering benevolence to the patient, undermined the development of any notion of patients' rights. Research became the supreme interest at many university hospitals, and patients who presented interesting cases were treated as research material. All of these influences can be seen in the Isei (seventy-six guidelines for medical administration) drafted by Sensai Nagayo in 1874. Traditional Japanese medicine (*waho*) and Chinese medicine (*kanpo*) have been out of the mainstream of medical science in Japan since the adoption of Isei, although acupuncture and moxibustion (quick, light heat from an ignited powder of medicinal leaves at key points of the body, called *tsubo*) have remained as folk medicine with popular support among the public (Otsuka).

As capitalism became established in Japan, serious social and economic inequities exacerbating the health problems (e.g., widespread tuberculosis, malnutrition) of factory workers, miners, farmers, and fishery workers became evident, particularly in the Taisho era (1912–1926). Even though the socially privileged physicians' group was not eager to address these health issues through social reform, some young physicians and medical students working for the settlement movement, introduced into Japan from England at the turn of the century, provided medical care in the slum areas of big cities such as Tokyo, Osaka, and Kobe in the 1920s. In 1919 the Medical Cooperative Movement (Iryo Seikyo Undo), which sought to establish community medical centers offering equal access, found great support among many Japanese (Seikyo).

During this period, Japanese medical ethics, guided by the two powerful influences of Confucian teaching and German authoritarianism, was generally understood simply to govern a physician's personal attitude in providing medical service to patients within the traditional model of a paternalistic trust relationship. It is important to note that during this time the eminent Japanese medical historian Yu Fujikawa asserted that physicians were bound by special obligations and responsibilities and must develop a special ethical consciousness in their daily practice. His advice was not accepted by Japanese medical experts, who were obedient to the military regime during the following war years.

Medical Loyalty to State and Authority (1938–1968)

Increasing concern about the health of the Japanese population led to the establishment of Koseisho, the Ministry of Health and Welfare, in 1938. The National Health Act and additional laws protecting factory workers were promulgated that same year. Many young radical physicians dealing with serious health problems among the population, such as tuberculosis, raised questions of justice and equitable distribution of resources, but concerns associated with the war with China (which began in 1937) now dominated. In reality, one of the government's main purposes in establishing the Koseisho was to strengthen the health of the nation to wage war. Similarly, the National Eugenic Law of 1940, promulgated ostensibly for the health of the people, reflected the government's desire for increased family size and the elimination of genetically transmitted diseases and defects. To achieve the latter goal, it authorized the use of a "eugenic operation"—voluntary or involuntary sterilization of individuals with mental illness or retardation and those thought to be at risk of transmitting genetic diseases or physical deformities to offspring. With the approach of war, the traditionally authoritarian, yet basically well intentioned, practice of medicine came under the control of a militaristic state regime; this had dreadful repercussions for medicine and medical ethics in modern Japan.

Several horrible and unethical human experiments performed during World War II were uncovered after the war. The similarity of response to state authority exhibited by Japanese physicians and by Nazi physicians has been viewed with dismay. German defendants accused of committing crimes against humanity were put on trial at Nuremberg, and the medical atrocities and experiments there recounted led to the development of the Nuremberg Code in hope of preventing such practices in the future. But Japanese medical experts serving in Unit 731, officially called the Water Supply and Epidemiological Disease Prevention Corps, who carried out and supervised experiments on Manchurian Chinese captives using bacteriological infections, frostbite, and mustard and poison gases, were not prosecuted by the international military court (Powell; Williams and Wallace).

Official documents exchanged between the United States and U.S. General Headquarters in Japan, now declassified and available at the U.S. National Archives, show that the U.S. military decided not to bring this case to trial. The interrogation task force of the occupation forces in Japan granted immunity to members of Unit 731, including the corps chief, on the condition that all related medical records and specimens be handed over to the United States (Kimura, 1997). The matter was regarded as highly important to national security because the United States wanted to prevent transfer of the medical knowledge gained through these experiments to the Communist governments in China and the Soviet Union (U.S. National Archives, 1949). The

Soviets held their own military trial at Khabarovsk for members of Unit 731 they had captured. Based on documentation and the testimony of witnesses, the accused were found guilty (Ivanov and Bogach).

The Kyushu University Medical School vivisection case also serves as an example of unethical experimentation. Eight American bomber pilots were captured in Japan after an air raid on Tokyo in 1945; some of them were sentenced to death by the local unit of the Japanese Imperial Army, but instead were used as objects of medical experimentation. To avoid prosecution by the Yokohama District Military Tribunal, one key person involved in this experimentation committed suicide; full details may never be known (U.S. National Archives 1949). The case served as the basis for a popular novel by Shusaku Endo, titled *Umi to dokuyaku* (1960), in which he dramatically depicts the quandary of a medical scientist tempted by unethical but very interesting experimentation. Endo's novel forced consideration of the meaning and place of ethics and medicine in Japanese society—which, he argued, lacked a standard of absolute value (Kimura, 1997).

Justified by state authority, professional experts in Japan sometimes lose critical consciousness and judgment. The Japanese national character nurtured during the Tokugawa era, and by an authoritarian government since the Meiji restoration, demands absolute obedience to the state and to authority. As Endo points out in his novel, such pressure often creates serious problems when individuals must make independent, and individual, ethical decisions. As a member of a group—such as a family, corporation, or community—and as a citizen, the individual Japanese tends to follow what other people do. Harmony (*wa*), or getting along with others, is an important element of the Japanese ethos for maintaining good relationships. To insist on individual opinions is regarded as egoistic and arrogant. Suppressing oneself in order to cope with other people is a daily practice in every aspect of life for the Japanese. This has serious ethical implications, especially in terms of weakening critical consciousness necessary in professional experts. The majority of Japanese medical experts and the lay public are not interested in drawing serious lessons from the horrible wartime human experiments because they reason that such actions are performed only in "abnormal war settings by abnormal people."

After the defeat of Japan, one of the first pieces of legislation implemented was the Eugenic Protection Law of 1948. Unlike the National Eugenic Law that it abolished and the Japanese Criminal Code, which since 1907 had held abortion illegal, the 1948 law permitted abortion for medical, and later for social and economic, reasons. Under the Japanese Criminal Code, abortion for other reasons remained a prosecutable offense. Nevertheless, because of vigorous opposition from advocates for the disabled, the new law did not provide legal justification for the abortion of a genetically defective fetus. The endorsement of this abortion law by the General Headquarters of General Douglas MacArthur aroused adverse reactions from religious bodies in Japan and the United States (Kimura, 1987a, 1987b). MacArthur defended the policy, saying that it had arisen from and was implemented by the Japanese Diet.

The way survivors of the atomic bombs dropped at Hiroshima and Nagasaki were treated by the Atomic Bomb Casualty Commission (composed of U.S. medical and genetic experts) is one of the historical sources of the development of Japanese bioethics because of its significance in discussions about the relationship between human beings and science, technology, and research. Individuals suffering from the effects of radiation came seeking treatment, but instead became material for research on radiation and collection of genetic data that were stored at the U.S. Atomic Energy Commission (AEC). This situation raised the serious issue of the researcher's responsibility to obtain fully informed consent for research. At that time, no government regulation or review boards existed to deal with the situation. The AEC is in fact the forerunner of the U.S. Energy Department, which initiated the Human Genome Project in the early 1980s on the basis of the voluminous data from the survivors of Hiroshima and Nagasaki (Cook-Deegan).

In 1951 the Japan Medical Association (JMA) issued a statement on physicians' ethics. This action clearly ushered in a new epoch in medical practice in Japan and signaled a return to the prewar state of medical ethics. Article I explicitly reaffirmed the fundamental and central place in medical practice of the ancient principle of *jin,* the benevolence of Confucian teaching, and asserted that physicians, as the elite of society, must embody the spirit of *jin,* always thinking about the welfare of the patient and the benefit of the treatment. Further, in cooperation with other professionals, physicians should take the initiative in social reform and, as ethically oriented people, should exercise great self-discipline (JMA, 1951).

In the 1960s Japanese society felt the effects of the worldwide trend of questioning established authority. Revolts occurred in many universities as dissatisfied medical students stood up against the traditionally paternalistic and authoritarian medical faculty they felt was exploiting them. Special legislation eased the unrest, but this first and radical challenge of the medical establishment, a very politically powerful group, had permanent ramifications for Japanese society and moved it into a new era.

Communal Involvement in Medical Decision Making (1969–2000s)

Toward the end of the 1960s, numerous social issues competed for attention in Japan. Health-related issues that drew increasing notice included air and water pollution, food additives, iatrogenic diseases (diseases caused by physicians), and the revival of *kanpo* (traditional Chinese medicine). There was also an increased emphasis on health. The growing number of older people focused attention on the need for healthcare for the elderly. Japan has been one of the most successful countries in decreasing the birthrate, and life expectancy in 2001 was the longest in the world, nearly eighty-five years for women and just over seventy-eight years for men (Minstry of Health, Labour, and Welfare). In 1997 the Long-term Health Care Insurance Law for the Elderly was enacted to create national mutual support systems for the elderly, who were traditionally cared for mainly by the family in the community. Advances in medical technology and healthcare have raised additional issues for the Japanese medical profession and society in general. The period from the late 1960s to the early 2000s has seen increased involvement in discussions about medical treatment and a strong desire to establish guidelines to protect the patient.

ORGAN TRANSPLANTATION. Progress in organ transplant technology created a demand to regulate and endorse cornea transplantation. A special law to this effect was enacted in 1958; it was combined with a law governing kidney transplantation in 1979.

The most vigorous public debate on bioethical issues was generated by the first heart transplant in Japan (1968), in which a heart was taken from a drowning victim and transplanted to a patient with heart failure. The patient died after eighty-three days. A surgeon at Sapporo Medical College, Juro Wada, was accused of mishandling the surgery on both the donor and the recipient, and questions arose about the justification for the transplant and about the criteria used to determine death; but Wada was never formally prosecuted. The aftermath of this case, however, gave rise to strong criticism of high-tech medical applications on ethical grounds. Concerns focused on the use of brain-based criteria of death, organ transplantation from brain-dead bodies, and the need to develop ethical guidelines to control the behavior of individual physicians who might seek fame through ill-prepared and drastic use of medical technology supposedly for the benefit of the patient.

This incident spawned the Patients' Rights Declaration in 1970 (Owatari et al.). This short, spontaneous expression of feelings, stating that the Wada case was a violation of the human rights of the patient and an example of the corruption of medicine and ethics, occurred in the public meeting at which Wada was accused of violating the donor's right to life.

In 1997 the Law on Transplantion went into effect. This law, reflecting the legal and ethical uniqueness of the Japanese situation, makes harvesting organs difficult because of two rigid consent provisions. The first provision is the requirement for advanced consent in accepting brain death. The "brain death criteria for death" box must be checked on the donor card, expressing the intention of the organ donor when alive. The second provision is the requirement for the consent of the family for harvesting organs from a brain-dead body. Article 6, Section 1, allows organ donation "in the event that a deceased person had during his lifetime expressed in writing his intent to donate organs to be used for organ transplants." Section 3 of the same article also states that "when the donor during his lifetime had expressed in writing his consent to the diagnosis—made based upon the provisions—and his family, informed of the removal, did not object to the diagnosis," organ transplants can be legally permitted (Kimura, 1998).

This law is supposed to promote—by endorsement—organ transplantation. From enactment through early 2003, however, Japan has had an only a small number (twenty-three) of organ transplants. Furthermore, these two elements of ethical and legal rigidness have made the enactment of more relaxed applications—such as allowing organ transplants involving infants—almost impossible to perform.

CRITERIA FOR DEATH. Leading objections to brain-death criteria are the fears that organs will be removed prematurely and that transplants will be performed in unacceptable circumstances (Kimura, 1991b). In Japan, transplantation of vital organs from dead bodies is rare because of a concern about causing the death of the donor. To a limited degree, anencephalic infants (those born without a brain or without a major part of the brain) have been used as sources for donor organs because they will die anyway, and because it is believed that they do not possess the fundamental consciousness necessary to be a human being. Declaration of death in the cases reported has ostensibly been based on the total cessation of heartbeat. Nevertheless, the use of organs from anencephalics has not been officially reported since 1981, because of clinical concerns about the condition of the organs from such donors and public concerns about the appropriateness of such practices (Kimura, 1989a).

Resistance to hastening death and harvesting organs also comes from the traditional Japanese image of human beings as completely integrated mind–body units, rather than as being composed of distinct and separate units of mind, body, and spirit. This mind–body unit, according to the Japanese, continues after death, so that removing an organ from a cadaver is seen as disturbing this spiritual and corporeal unity, not merely altering the physical body. It also explains why autopsies are abhorred in Japan (Fujita). According to the Buddhist and Shinto ways of thinking, this unity extends beyond the individual to all living things. To the Japanese, death disturbs the rhythm of all living things and therefore should not be hastened. Also, Confucian teaching places strong emphasis on family relationships and filial piety. There is a strong prohibition on harming one's body, because it is derived from one's parents (Kimura, 1991b).

In addition, in accepting the reality of human mortality, some Buddhists regard the extension of life by accepting organs from another individual's body as unnatural and unethical, because the procurement of those organs depends on the death of another person. Such an expectation of the death of someone else for the purpose of egoistic extension of life is not acceptable. Also, the totality of life should be supported by the notion of *arayashiki* (*alaya-vijnana*) (the fundamental consciousness within each individual being). This Buddhist notion holds that consciousness is not located solely in the brain; therefore the cessation of any one part or one organ (including the brain) of the individual does not extinguish consciousness and consequently cannot be regarded as the death of the individual person (Tamaki; Fujii). The basis for the uneasiness in accepting brain criteria for death and organ transplantation thus comes from both Confucian and Buddhist thought, which incorporate some ideas from Japanese traditional folk religions and Shintoism.

EUTHANASIA. Media coverage has made euthanasia one of the most debated topics in Japanese bioethics. The Japanese Euthanasia Society was established in 1976 (and was later renamed the Japan Society for Dying with Dignity [JSDD]), and the first international conference on euthanasia was held in Tokyo that same year. The Ninth International Conference of the World Federation of Right to Die Societies was organized by the JSDD and held in Kyoto in 1992. No legally established procedure for euthanasia exists in Japan, but as in many other countries, the use of elevated doses of narcotics to relieve suffering and pain is acceptable even at the risk of hastening death. According to Buddhist thought, the prolongation of life and suffering is not absolutely necessary, and ending the life of a dying, suffering patient might be regarded as a merciful act (Murakami).

A 1962 precedent-setting decision by the Nagoya High Court, which accepted the idea of euthanasia in principle, involved the case of a son who prepared poisoned milk as a result of his terminally ill father's repeated requests to die; the glass of milk was found by the man's wife, who, not knowing it was poisoned, gave it to her husband. Although the court found this case to involve unacceptable mercy killing, the court's ruling established six criteria for allowable mercy killing:

(1) the patient's condition must be terminal and incurable, with no hope of recovery, and death must be imminent (as determined by modern medical knowledge and technology);
(2) the patient's pain must be so severe that no one should be expected to endure it;
(3) the sole purpose of the act must be to relieve the patient's suffering;
(4) a sincere request and permission are required from competent patients;
(5) in general, the act should be performed only by physicians; and
(6) an ethically acceptable method must be used.

The Nagoya High Court ruled that, although the first four criteria had been met, the final two conditions had not. The son was sentenced to four years' imprisonment with three years' suspended sentence.

In the light of medical and technological advances, the conditions once considered fatal can now be treated effectively or even cured. Better methods of pain control have been developed, and new centers for palliative care have been developed.

The ruling of Yokohama District Court on March 28th, 1995 is significant for its clear statement of the principle of individual autonomy based on the patient's own intention to stop treatment. In this case, the physician prosecuted for murder claimed he had a clear request from the patient's son to alleviate his father's suffering. Later, the son denied, when questioned, any intention to end his father's life. The ruling does not endorse familial decision making based on the presumed wishes of the patient, however, if the patient has communicated openly enough with family members about his or her view of life, character, and values, the family will be able to make a conjectural decision to end his or her life in a natural way without aggressive over treatment (Kimura, 1998).

TREATMENT OF THE MENTALLY ILL. The Japanese Mental Health Act was passed in 1950 to prevent private home confinement of the mentally ill in violation of an identified right to be cared for in institutional situations. In the 1980s, however, disclosures of violations of rights of psychiatric patients led to serious questioning of the routine admittance and institutional treatment of the mentally ill. In 1987 an important amendment to this act passed after a nationwide campaign in its favor by the mass media and a strong recommendation for its passage by a special investigative mission of the International Commission of Jurists in Geneva, Switzerland. The amendment enacted more rigorous procedures for involuntary hospitalization of the mentally disabled and established rehabilitation and treatment centers to protect the rights of patients with mental disabilities. The commission's involvement underscores the importance and necessity of international cooperation on bioethical issues, especially those related to patients' rights.

EDUCATION OF THE PUBLIC IN BIOETHICS. Bioethical issues raised in the 1960s caught the attention of much of Japanese society, and in the 1970s concerned citizens formed bioethics study groups in Tokyo, Kyoto, and Nagoya. By the 1980s, members of these groups participated as bioethics volunteers in medical service organizations. The nationwide concern with health and medical services in Japan led to a new declaration of patients' rights, which was issued in 1984 by a group of patients, lawyers, physicians, and journalists. While this document carried no official authorization, it was more systematic than its 1970 precursor and showed the impact of discussions in other countries. The General Assembly of Japanese Medical Cooperatives, an official medical service organization of the Japanese Association of Life Cooperatives Union with 250 hospitals and clinics and a membership of 1.5 million individuals, endorsed its own version of a patients' bill of rights in May 1991—the first such action by a medical organization (Seikyo). The Patients' Rights Legislation Movement, largely initiated by medical malpractice lawyers and other members of the lay public, began in 1991 to urge passage of a statute on informed consent and respect for patient autonomy in medical decision making.

ETHICS COMMITTEES FOR ADVANCED MEDICAL RESEARCH. The first medical ethics committee in Japan was established at the Tokushima University School of Medicine in 1982 in order to review in vitro fertilization (IVF) technology and its application to infertile women. As of 2003, each of the eighty medical schools and major hospitals had its own medical ethics committee reviewing cases such as segmental liver transplantation, gene therapy, and embryonic stem cell research. Due to a lack of national legislation regarding these review committees for the advanced medical research, each has a different composition. With the exception of a few lawyers and ethicists, the majority of the committees are composed of the same medical faculty and are male.

In 1991 the Greater Tokyo Metropolitan Government established the first hospital ethics committee with membership of nonmedical practitioners, and the committee opened all its meetings to the public. This committee serves as a policymaking body for the fourteen hospitals operated by the Tokyo Metropolitan Government. One of the epochmaking outcomes of the committee was the adoption of the "Patients' Bill of Rights for the Hospitals of Tokyo Metropolitan Government" in 2001.

BIOETHICS ORGANIZATIONS. Since the mid-1980s, medical professionals and government organizations have been involved in the study of bioethical issues. In 1984, the Ministry of Health and Welfare set up the Special Advisory Board on Life and Ethics; it published an official report in 1985, after a series of research conferences, then ceased activity. The Japan Medical Association also set up the interdisciplinary Bioethics Council, consisting of medical experts and professionals from philosophy, anthropology, biochemistry, law, and industry. The council dealt with topics related to technological applications in clinical settings such as IVF (1986), sex selection of the fetus (1987), brain death and organ transplantation (1989), and explanation and informed consent (1990).

The Japanese Association for Bioethics, established in 1987, publishes a journal and a newsletter, and has more than 800 members who attend the annual national meeting and international meetings. The Japanese Association for Philosophical and Ethical Research in Medicine, the Japanese Society of Ethics, and the Japanese Society of Medical Law are also concerned with bioethical issues as they affect their respective disciplines.

In the early 2000s, the Bioethics Committee of the Science and Technology Council (part of the Ministry of Education, Culture, Sports, Science and Technology) has been active on bioethical issues relating to biomedical research, such as cloning. The Health and Welfare Council of the Ministry of Health, Labour and Welfare is also dealing with bioethical issues, mainly relating to clinical medicine. These two ministries worked with the Ministry of Economy, Trade and Industry to prepare a document titled "Ethics Guidelines for Human Genome/Gene Analysis Research," which was released in 2001. They jointly made an official announcement of the Guideline in 2001 for the first time as a result of cooperative work in bioethics public policy in Japan.

BIOETHICAL TRENDS IN COURT DECISIONS, CODE OF ETHICS, AND LEGISLATION. One of the most controversial legal issues relating to bioethics in the 1990s was the revelation that HIV-contaminated blood products were used for hemophiliac patients without heat processing, resulting in around 1,600 people being infected with HIV. After more than seven years of legal struggle, the Ministry of

Health and Welfare, pharmaceutical corporations, and the plaintiffs in the case agreed to a settlement involving a compensation fee of about 400,000 U.S. dollars per person.

In 1996 the Eugenic Protection Law was amended, and its name was changed to the Maternal Protection Law. In addition to deleting the word *eugenic* from the name, the new law eliminated all provisions related to eugenic operations, including the lists of genetic diseases that were the subject of eugenic operations, such as Hansen's disease (leprosy). The discriminatory Law for the Prevention of Leprosy, in effect since 1907, was abolished in 1996 following the initiation of legal action against the government of Japan. Later, in 2001, the Kumanoto District Court ruled against the Ministry for its responsibility and the government gave up the appeal. Diet members adapted an unanimous resolution on the issue of Hansen's disease expressing sincere remorse and apologized for committing human rights violations for over 90 years.

The bioethical principle of autonomy was strongly affirmed by a 1997 decision of the Tokyo High Court relating to a Jehovah's Witness who had been given a blood transfusion, a medical treatment forbidden by his religion. The decision was made in favor of the plaintiff, as he had not been told that he might be given a blood transfusion under certain circumstances. The notion of "informed consent" was thus taken seriously in legal terms in the context of religious beliefs and bioethical conflicts of decision making when life is at stake (Kimura, 2000).

In 2000, the Japan Medical Association adopted the "Code of Medical Ethics" in six provisions in simplified form. The emphasis on the public role of medical service and contribution to the society through medical works can be seen in provision five (JMA, 2000).

The social concerns facing the increasing number of elderly population and the need of mutual support systems by the local and state and government has led to the realization of "The Long Term Care Insurance Law " in 2000. This was the reflection of the shift in values from traditional ethos of family support to the mutual, societal support mainly to be managed by the community (Kimura, 2002; Ministry of Health, Labour and Welfare, 2003).

Toward Bioethics of Cultural Harmony: The Cloning Prohibition Law in Japan

The contemporary discussion of bioethics in Japan started as a movement among the lay public in the late 1970s. This fact remains symbolic and important in many respects, as evidenced by the increased degree of individual decision making about desired medical treatment, as well as in all areas of daily life.

Japan continues to struggle to recognize bioethics as integral to all spheres of life and to discuss public policy and the environment, as well as to deal with the tension between Western values and traditional Japanese cultural practices. Bioethics has been proposed and developed in Japan as a supra-interdisciplinary endeavor embracing all traditional academic disciplines in equal partnership, for the valuable exchange of ideas and criticism each field has to offer (Kimura, 1986)

There are specific cultural values and customs that are distinctive and non-Western in pattern, but there is heterogeneity, too, and in any case, ethical values change, particularly among the younger generations in Japan. It is true that different cultural and ethical values should be respected, such as key concepts of the dignity of each human person, the importance of the family unit, and community life. But justification of any act or behavior against human dignity and the rights of the person for the sake of cultural tradition is not acceptable.

The notion of harmony is reflected in Article 1 of the Law concerning the Regulation of Cloning Technologies and Other Similar Technologies Relating to Humans, which went into effect in June 2001. This article states that one purpose of the law is to "harmonize the society and peoples' lives with the development of science and technology."

In the international community of the twenty-first century, with the globalization of values focusing on a universally accepted notion of fundamental human rights, the reality of limited resources, and the increasing necessity of mutual cooperation, it is useful to emphasize the twin notion of "related-autonomy" and the Japanese principle of harmony (*wa*) in cultural bioethics.

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V. SOUTHEAST ASIAN COUNTRIES

Southeast Asia is part of the continent where the major faiths arose; it is still a melting pot of different religious traditions and cultural beliefs, including animism and magic. Despite the rapid social change Southeast Asia has been undergoing, these religious and cultural beliefs remain vital, conditioning people's perceptions, values, attitudes, and behaviors in health and all other areas. An understanding of these beliefs is imperative for the implementation of projects in medicine and public health, and for the maintenance and improvement of public welfare.

This article will first analyze the different types of traditional medicine in Southeast Asian countries, particularly Thailand, the Philippines, Malaysia, and Indonesia, their concepts of health and disease, methods of healing, their practitioners, and their ethics. Second, it will discuss some central biomedical issues in the practice of modern medicine, and the current efforts to teach the new medical ethics at medical schools in these countries. Finally, it will argue as a matter of great urgency the need to promote and strengthen bioethical education and research in Southeast Asia, in order to enable its medical community to cope with the new ethical and moral dilemmas, challenges to its traditional morality and religion.

Magic, Religion, and Naturalism

Medical systems in Southeast Asian countries may be classified into two types, traditional medicine and modern (scientific) medicine. Traditional medicine in turn can be very broadly grouped into three general types, depending on whether it is dominated by magic, religion, or naturalism. Beliefs concerning health, disease and its treatment, and preventive measures are in accord with the type of traditional medicine practiced. When magic is the focus, disease is believed to be caused by sorcery, and countersorcery and other spells are used as medical remedies. Similarly, when religion predominates, disease is attributed to supernatural forces, which must be appealed to or propitiated. When it is dominated by naturalism, disease is defined in terms of natural processes and the imbalance of elements or opposing forces in the body, and a judicious equilibrium is the basis of medical practice.

These traditional medical systems are often a blend of two or more types. Traditional Chinese medicine in Singapore, for example, is largely secular or naturalistic but includes magico-religious elements. Traditional Thai and Malay medicine is mainly magico-religious but is also permeated by elements of naturalistic medicine.

Healers, Shamans, and Mediums

Traditional medicine is integrated into a complex of beliefs and values comprising the worldview of Southeast Asian peoples. The magico-religious medicine of Southeast Asian countries is derived from magico-animistic beliefs that suffuse their cultures. In this cultural orientation, healers are shamans and mediums, and healing is effected through sorcery, exorcism, and spirit possession, assisted when necessary by herbal concoctions and massage.

Spirit possession is believed to be a channel by which deities or spirits of a high order (e.g., spirits of monks or saints) use their divine power to heal the sick. Healing includes a diagnosis of illness and the performance of corresponding magical rites. These magical activities are usually conducted within the religious framework of the healer. Thai Buddhist shamans, for example, do not practice on *wan phra,* a Buddhist Sabbath observed at the four phases of the moon, and they make use of recitations from the Pali Buddhist texts. The Malay Muslim shamans add verses from the Qur'an to their healing, while the Taoist shamans in Singapore recite Tao incantations in their practice.

Herbalists, Folk Medicine Doctors, and Monks

While the magico-religious medicine of Southeast Asia is tied to its culture, its naturalistic medicine is heir to the Indian ayurvedic medical system and traditional Chinese medicine. In these medical traditions disease is understood as a disturbance of inner equilibrium that can be corrected through the administration of herbal solutions. Thus this form of medicine is designated as naturalistic or herbal, and its practitioners are known as herbalists, ayurvedics, or folk medicine doctors. In Thailand many of these healers are Buddhist monks, who usually combine herbal treatment with religious rituals (e.g., the taking of religious vows and the sprinkling of lustral water) and meditation. Some of these monks have been credited with successful rehabilitation of drug addicts. The use of meditation differentiates traditional Thai medicine from the medicines of other Southeast Asian countries.

Medical Ethics in Traditional Medicine

The preoccupation of traditional medicine with magic, religion, and herbal concoctions is due to its holistic approach to health and healthcare. The practitioners work on their patients at both the physical level and the psychological/spiritual level. While herbal concoctions are mainly used to cure patients' physical illness, magico-religious rites have a therapeutic effect on their minds. The rites reassure patients of divine blessing and protection, and strengthen their self-confidence.

This traditional method of healing may be especially suitable today for Southeast Asians, who, living in societies with increased urbanization and industrialization, need physical, psychological, and spiritual care to enable them to cope with such change and the strains and stresses of modern life. Modern Western medicine with its advanced knowledge and technology has more effective means of healing, but it divides the patient into organ systems and treats only those parts of the person that are afflicted by a specific disease, rather than the whole person. Southeast Asians, who do not divide the person in such a way but need treatment with scientific medicine, will often seek traditional medicine as a supplement to scientific medicine. For example, a patient with a brain tumor might request magico-religious rites from a Buddhist shaman in order to ensure the success of an operation to be performed by a neurosurgeon. It was reported in the Thai press that the patient who uses this approach experiences such an operation with great calm and recovers more quickly.

Medical ethics in Southeast Asian traditional medicine is not codified but is inherent in the values and practices of its practitioners. Some of these healers are Buddhist monks whose ethic of conduct approximates the Buddhist ideal of showing compassion and loving kindness. For example, they do not charge fees and solicit no gifts for their healing. Other healers may demand fees for their service, but their code of ethics requires that they be under some self-imposed moral restraints, for example, that they not practice for monetary gain; that they serve their patients impartially, with only their benefit in mind; and that they not take cases that they cannot treat successfully. Having no common standard of practice to follow, the healers' success depends on their own virtues and healing powers. Their services are sought as long as they can instill belief and faith. They sink into anonymity when they are seen as charlatans or when doubt about their powers arises.

Modern Medicine and Healthcare Allocation

Modern medicine came to Southeast Asia during the colonial period, starting in the eighteenth century. Since then it has made tremendous progress. It has greatly benefited people in Southeast Asia, but beneath the surface of these benefits there is a multitude of attendant ethical problems.

The most important concerns the macroallocation of limited healthcare resources, specifically, grave inadequacies and inequalities in their distribution. Nearly 80 percent of the population of Southeast Asia lives in rural areas. Most of these people are poor and need more medical services than affluent people. Their health depends mostly on medical services provided by the government through hospitals and public health centers. Yet many of these services are inaccessible to them. In Thailand, for example, 62 percent of doctors and nurses are in Bangkok, where most of the country's hospitals are, while there are too few doctors and nurses in the provinces, where most of the people are. There are also too many hospitals in Bangkok and too few neighborhood clinics and public health centers in rural areas.

Southeast Asian countries, eager to bring the benefits of modern medicine to their people, have modeled patterns of healthcare and education of health personnel in their countries on those in more affluent and developed nations in the West, particularly Britain and the United States, without regard to social, economic, and cultural differences. As a result, limited healthcare resources are allocated to catastrophic or hospital-oriented medicine, despite the fact that most of the diseases afflicting the majority of people in these countries are preventable. Even though it has become increasingly clear that these patterns are irrelevant to the health needs of developing Southeast Asian countries, Western-trained health policymakers are very reluctant to deviate from these models, which are being questioned even in the developed nations where they originated.

Politically pressured to show more concern for the poor, governments in some Southeast Asian countries are now acting to correct some of the imbalance of resource allocation. The present Thai government, for example, though still following Western models, has increased funding for preventive health measures and public health services. More provincial hospitals and health clinics are being built, and paramedics and auxiliaries trained to staff them. Thai medical schools now require medical graduates to spend at least three years in the provinces and rural areas, and a plan is being devised to provide incentive subsidies to doctors and nurses working in poor rural areas. Many more corrective measures are needed to create a just and reasonable allocation of the country's overall healthcare resources such that the general standard of health and healthcare can be raised nationwide.

Shortages of health personnel in Southeast Asia have been aggravated by the fact that so many doctors and nurses are lured from their homelands, where they are in desperately short supply, to serve the less critical health needs of affluent nations. The Filipino Department of Health, for example, reported in 1990 that two hundred towns in the Philippines had no resident doctors and that seven out of ten persons died without even being seen by a physician. Only an estimated 32 percent of all qualified Filipino doctors and nurses practice their profession in their own country. This shortage of doctors and nurses, typical of developing Southeast Asian countries, makes it much more difficult for governments to provide adequate healthcare to many of their people.

Human Experimentation

Another important ethical issue in Southeast Asia concerns human experimentation. Since the adoption of modern medicine in the nineteenth century, medical schools in Southeast Asian countries have become more research oriented and are increasingly moving into the area of human experimentation. In violation of international agreements, Western researchers who have been restricted in the kind of human experiments they may do in their own countries are turning to Southeast Asia to conduct their research where there is less public awareness of the issue and less government regulation. These researchers are usually assisted by Southeast Asian colleagues, who engage in all kinds of human experimentation no longer permitted in the West, including forms of psychosurgery and genetic experiments. Drug testing and tests of new contraceptives have been carried out in Southeast Asian countries on a massive scale. Nearly all of these experiments use poor people as subjects, without their informed consent. Abuse of poor patients and the violation of their human rights in public hospitals often occur.

The governments and the medical communities in Thailand and the Philippines have taken some measures to prevent the exploitation of the poor by researchers. In 1985 the National Research Council of Thailand formulated guidelines for research involving human subjects; these guidelines were later revised and made more elaborate. In 1987 the Philippine Council for Health Research and Development published *National Guidelines for Biomedical Research Involving Human Subjects,* similar to those delineated by the World Medical Association at Helsinki in 1964 and revised at Tokyo in 1975. These guidelines on human experimentation laid special emphasis on voluntary informed consent of research subjects. Unfortunately, both in Thailand and in the Philippines there is as yet little compliance with these guidelines or accountability for their violation.

The creation of national ethics committees and institutional review committees in Thailand and the Philippines is another Southeast Asian response to the issue of human experimentation. These institutional committees are concerned primarily with the evaluation of the scientific value of research proposals; the national ethics committees are expected to deal with the ethical aspects of experiment proposals and their protocols. Both the proper role and the composition of national ethics committees are still being debated. At present such committees are far from being instruments for effective control of experimentation in Southeast Asian countries. The Thai committee, for example, does not scrupulously supervise procedures for gaining the needed informed consent. Nor does the committee intervene when it believes an experiment is being conducted without proper ethical consideration. A 1988 study in Thailand indicated that often the procedures followed in many hospitals made it unlikely that the patients were fully informed or gave genuinely voluntary consent. Though many questions are being raised about it, this national committee could become an effective means to prevent morally questionable experiments on human subjects from being performed.

Traditional Morality and New Ethical Issues

The traditional morality of Southeast Asia is permeated by the ethical traditions of Hinduism, Buddhism, Christianity, and Islam. The emergence of modern medicine has produced many new ethical issues that challenge traditional morality. For example, within this morality is the cardinal Buddhist principle of *adhimsa,* which directs that life not be taken and harm not be done. Modern medicine with its advanced technologies has produced ethical dilemmas concerning how to abide by these precepts. For example, does removal of a life-support system constitute violation of these precepts? Is allowing a seriously defective infant to die untreated a form of *harming* or *killing*? Is it morally acceptable for patients to take their own lives in cases of lingering terminal illness or chronic severe pain or disability? Is it morally acceptable that doctors or nurses act upon the expressed desire of patients and assist them in committing suicide when they are unable to act for themselves or to find the means to do so? Is removal of a kidney from a live donor a morally justified form of harming?

Traditional morality also dictates that we not deceive others. One of the five precepts of Buddhist morality prohibits falsehood. Does this include failing to tell a terminally ill patient the truth about his or her prognosis? Is administering placebos a morally justified exception to the moral rule against deception? Can the patient be deceived about a treatment if the doctor or nurse thinks it is in the patient's best interest? Must all the truth about a double-blind trial in human research be told in order to obtain the *informed consent* that the new medical ethics calls for? These are examples of new questions raised as a result of the encounter between modern medicine and traditional morality in Southeast Asia. Traditional morality is no more prepared to deal with these new moral issues than are the Southeast Asian scientists and physicians caught in the middle of them.

The development of modern medicine has raised questions about the adequacy of traditional morality. For example, the traditional Buddhist concept of death as the cessation of all vital functions cannot accommodate the recent development in modern medicine, in which some cells or organs may be sustained by artificial means after the cessation of all vital functions. Nor does it facilitate early retrieval of organs for transplantation. Southeast Asians must rethink and reinterpret the applications of their traditional morality to cope with the advanced knowledge and technologies of modern medicine. For example, as technologies for behavior control and modification are available through drugs, electrostimulation, electroshock treatments, psychological manipulation, psychosurgery, and genetic engineering, the traditional precept of "do no harm" to an existent being may be stretched to cover the question of whether we have the right to *create* a being of our own design.

Teaching and Other Bioethical Activities

Southeast Asian medical students usually learn about medical ethics in classes, and from time to time through lectures outside of regular classes. They are also encouraged to follow the example of morally respected elder doctors. In the past the teaching of medical ethics at medical schools in Southeast Asian countries was integrated into other courses and was primarily concerned with professional etiquette as developed in the West or culled from the teachings of Buddhism, Hinduism, or Islam.

The new medical ethics, or bioethics, was initiated in Southeast Asian countries as a response of scholars and medical professionals to the impact of modern medicine on the life and well-being of people in their countries. Through the combined efforts of Christian clergy and doctors, the Center for Biomedical Ethics Development was established in Indonesia in 1983, primarily to enhance the development of bioethics and Christian values in medicine. Its present activities include the formulation of hospital ethical codes for Indonesian doctors and nurses, and the promotion of bioethics education at hospitals and universities through lectures, seminars, and regular meetings.

Also in 1983, the Bioethics Study Group, consisting principally of Western-trained philosophers and doctors, was established at Mahidol University, a major education and research university in Thailand, to initiate the teaching of bioethics at the university and to bring the awareness of bioethical issues to the public and concerned authorities. By 1988 three full-credit, separate courses were being taught. Through these courses students are exposed to bioethical issues and the way these issues are being addressed and resolved in the United States and other Western countries. They are also encouraged to engage in ethical reflection on those issues as they arise in Thailand, and to find solutions that reflect Thai cultural values. The group has planned to initiate a graduate program in bioethics in 1993 and has created small teams at six other medical schools to stimulate and promote bioethical activities there.

The Southeast Asian Center of Bioethics was established in the Philippines in 1987 by a group of Catholic priests and doctors as a result of the visit of the International Federation of Catholic Universities in the same year. Since its inception the Center has focused its activities on the promotion of interest in and concern with bioethics through teaching, research, seminars, and monthly meetings to discuss bioethical issues confronted by the scientific and medical community in the Philippines. Thus the value of bioethics is appreciated in Thailand, Indonesia, and the Philippines, but it is less recognized in other countries.

All the work done in bioethics has been based on Western models of health and healthcare delivery systems, and on principles derived from the Western moral tradition and specific ethical issues that are relevant to the particularities of Western culture. It is urgent that Southeast Asian academics and medical professionals begin the task of defining and clarifying bioethical issues as they affect their own countries' health and healthcare systems, and that they find resolutions in keeping with the moral principles, values, priorities, and social needs of their countries.

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MEDICAL FUTILITY

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For the first three decades after the introduction of life-sustaining medical technology in the 1970s and 1980s, a central question was: When can patients or their families refuse life-sustaining interventions—including interventions wanted by physicians? More recently, an opposite question has been asked and heavily debated: When can physicians unilaterally refuse patient or family requests for life-sustaining interventions on the basis that such interventions would be futile? This debate has shed light on many issues, including the difference between positive and negative rights; the difference between futility and rationing as a basis for denying care; the nature of professional responsibility; and the optimum way to discuss end-of-life choices with patients and their families. In the end, however, futility has remained an elusive concept, and most commentators have rejected unilateral decisions by physicians in favor of good communication and institutional policies for negotiating disputes.

Positive versus Negative Rights

Arguably, the most prominent debate in bioethics from the early 1960s to the early twenty-first century has been the one surrounding the right to refuse treatment. From Karen Quinlan to Nancy Cruzan, the United States has seen a series of court decisions, professional guidelines, and laws that establish the rights of patients or their surrogates to make end-of-life decisions. These cases, however, all involved patients or families who sought to limit life-sustaining treatment in the face of physicians or institutions who wanted to continue treatment. It is simply mistaken to argue that because patients have a right to refuse treatment they also have a right to demand it.

The rights delineated in treatment refusal cases were negative rights, the right to be left alone and to not be touched without consent; such rights can be traced to the Constitutional rights of privacy, liberty, and religious choice, or to the common-law right against battery. In contrast, a positive right, the right that something be done, implies both the patient's right to choose a specific intervention and a coexisting obligation of the physician to provide it (Brett and McCullough). Claims to negative rights are generally considered to be more powerful than claims to positive rights.

It is obvious that patients do not have rights to treatment that falls well out of the standard of care—for example, hip replacement surgery when there is nothing wrong with the patient's hip. But do U.S. citizens have a right to beneficial care? The answer to that question is being hotly debated in the political arena and does not appear to be near resolution. Those in favor of limiting futile care argue that a patient cannot demand a treatment that is futile when a general right to medical care that is clearly beneficial has not yet been established.

Defining Futility

While the word *futility* has a categorical ring, it is actually quite difficult to define with precision. Futility must always be discussed with a specific intervention and result in mind. Intervention A is futile if it is not successful in achieving goal B. In contrast, intervention A might be successful in achieving goal C. Without specifying interventions and goals, discussions about futility can be misleading or confusing. For example, asking a patient if she would like to be put on a mechanical ventilator identifies a specific intervention, but no goal. One goal might be to stay alive as long as possible, even if this means spending the last weeks of life in an intensive care unit, attached to the machine. Another goal might be to recover, be removed from the ventilator, and return home. Without discussing specific goals, the patient's acceptance or refusal of mechanical ventilation leaves too much to the imagination.

In their 1990 article, "Medical Futility," Larry S. Schneiderman and his colleagues distinguished between the effects of a given medical intervention and its benefits. They argued that "the goal of medical treatment is not merely to cause an effect on some portion of the patient's anatomy, physiology, or chemistry, but to benefit the patient as a whole" (Schneiderman, Jecker, and Jonsen, p. 950). They also stated that futility should be defined within the context of evolving standards of care and that the goal of medicine is to achieve a benefit above a certain minimum qualitative or quantitative threshold.

Quantitative futility implies that the chance of achieving a specific goal, while statistically possible, is very improbable and cannot be systematically produced. Critics point out that physician experience is insufficient to form a consistent and reliable basis for quantitative judgments about futility. Moreover, physicians themselves do not agree about what the threshold should be for quantitative futility (McCrary et al.). Published series of cases are few in number and do not take adequate account of patient variables such as severity of illness or other, co-existing medical problems.

Qualitative futility, according to Schneiderman and colleagues, involves an intervention that may have a good chance of having a specific effect, but the effect provides no benefit to the patient. The problem here is that *benefit* is a value-laden notion, and patients may not have the same values as physicians (Youngner, 1988). Schneiderman and colleagues' two examples of qualitative futility illustrate this point. Their first example is the state of permanent unconsciousness. A patient in this condition, they argued, has no right to be sustained in a vegetative state. Critics, however, point out that a minority of persons (including a minority of physicians) does see such life as meaningful, and that in a pluralistic democracy it would be wrong for individual physicians to impose their *majority* values on others.

Schneiderman and colleagues cited patients who require constant monitoring, ventilatory support, and intensive care nursing as their second example of qualitative futility. While acknowledging that sometimes such patients might have worthwhile goals, for example, living long enough to say good-bye to a relative, Schneiderman and colleagues argued that judgment about the validity of the goal should be left to the *compassion* of the physician. Many would see this as an outmoded and unacceptable form of paternalism.

Thus, while the notion of futility captures an important concern about the harmful overtreatment of patients at the end of their lives, it remains difficult to define with precision. As we will see later, rather than serving as a trump card that physicians can play to unilaterally overrule the wishes of patients and family, discussions about futility may be most useful in stimulating a process of communication and negotiation about setting realistic patient-centered goals.

Futility and Rationing

The notion of futility is often confounded with that of rationing and justified by the need to limit the cost of healthcare. Despite important parallels between the concepts of rationing and futility (both have implications for resource consumption and the cost of care), they have distinct moral and conceptual meanings (Jecker and Schneiderman). Futility represents a clinical judgment that a specific intervention will not be successful in achieving a specific goal for a specific patient. Rationing means that interventions that do provide benefit will be denied to at least some persons who could benefit from them. While it is true that withholding futile care could save money, a treatment is futile whether resources are scarce or abundant. Futility is a judgment based on empirical evidence and clinical experience. Rationing is based on theories of social justice—that is, who is more deserving of limited medical resources. Rationing is a public issue and, in a democracy, should be resolved through the political process. Futility, at least according to its defenders, is an objective medical determination. As such, they argue, it can be defined by physicians. Certainly, in a rational scheme of cost management, futile treatments should be eliminated before beneficial ones are rationed.

Professional Responsibility

Much of the impetus for acting on futility judgments has come from physicians and nurses who think they are violating important professional values—to help and do no harm—when they cave in to demands for futile interventions, such as cardiopulmonary resuscitation (CPR). Physicians are more than body mechanics who follow the orders of patients no matter what the consequences to those patients. CPR, for example, is a very aggressive, but notoriously ineffective, intervention in severely debilitated and dying patients. It involves multiple invasive procedures that often cause tremendous suffering (e.g., broken ribs) and a loss of dignity.

Avoiding Futility Confrontations

Too often, confrontations about futility are the result of poor communication and the conditions under which care is delivered in acute care settings. For example, health professionals sometimes fail to identify and set treatment goals. In their discussions with patients and families, health professionals focus on specific treatment interventions rather than on the goals that such interventions may or may not achieve. Questions such as, “Do you want us to start your heart again if it stops?” or “Do you want to be placed on a mechanical ventilator if you stop breathing?” are confusing, and even misleading, until potential goals of those particular interventions have been discussed and agreed upon.

Medical interventions are not ends in themselves; they are means of achieving desired goals. The job of the physician is first to help identify patients’ goals and then to help them select among the treatments that can achieve those goals. For example, if a specific patient’s goal is to return home with an independent lifestyle, aggressive interventions such as CPR and mechanical ventilation might well fail to meet that goal. On the other hand, if the patient’s goal is extended life, even if its quality is significantly compromised, the aggressive intervention may not be futile at all. Sometimes the most difficult task of the physician is to help the patient and family come to terms with the reality that the goal they seek—for example, recovery and return home—cannot be achieved. Until goals have been understood and agreed upon, conversation about a particular treatment intervention is unlikely to be productive.

Sometimes, patients or families make unreasonable demands for care because they simply do not understand the clinical realities. It is not good practice to ask people if they want to be resuscitated when they do not know that the chances of resuscitation are small (near zero in patients with multiple failing organs) and the harms great (e.g., broken ribs, collapsed lungs). In a 1988 article, Donald J. Murphy reported that only 10 percent of multiply impaired elderly patients in a particular nursing home had “do not resuscitate” orders. A new medical director began informing patients and their families about the seriousness of their medical conditions, the burdens of aggressive intervention, and the small likelihood of success. As a result, twenty-three of twenty-four patients chose not to be resuscitated in the event of cardiac arrest.

Confusion is another reason patients and families demand treatment that physicians think is futile. There is no evidence that physicians agree on what counts as futility. Therefore, a patient or family may well become confused after talking with different physicians, each of whom has a different notion about whether the situation is futile. Moreover, confusion is aggravated by fragmentation and discontinuities in patient care. In large medical centers, patients are often seen by several specialist consultants. Each is responsible for one organ system and may communicate information that does not accurately reflect the overall prognosis of the patient. Communication may be further confused in academic teaching hospitals by the fragmentation of care caused by monthly rotations of medical trainees and supervising physicians, and shift changes for nurses and other healthcare professionals. If patients are lucky enough to have primary care physicians in the community, those physicians are too often not available to coordinate and manage the care of their patients who are in the hospital. The most important strategy for resolving conflicts about care at the end of life is to help everyone involved in a patient’s care operate with a common understanding of the realistic medical prognosis and to then focus on the goals of the patient and family that are achievable (Youngner, 1994).

Sometimes, demands for futile treatment grow out of mistrust. Although some people are suspicious by nature, people often have good reasons for mistrust. For example, patients and families may have heard previous predictions of doom that were not fulfilled. Others may have had dealings with physicians who were not straightforward. Socioeconomic and cultural factors may also influence perceptions and attitudes. African Americans, for example, have good historic reasons for mistrusting physicians and the institutions where they receive care. The legacy of the Tuskegee Syphilis Study, during the middle of the last century, remains a part of African-American consciousness. During this study, in which African-American men were enrolled, the researchers left the subjects untreated for syphilis so that the natural course of the disease could be studied. Even today, remnants of racial inequities remain in the U.S. healthcare system. For example, in many urban hospitals, few members of the medical staff and administration are minorities, whereas large numbers of the patients are. In addition, many people who are poor or members of minority groups have inadequate access to healthcare unless they are extremely ill. There is also evidence that minority and lower economic status are associated with preferences for more aggressive care (Garrett et al.). It is little wonder that some persons are suspicious when told by strange physicians in the middle of the night that further life-sustaining efforts would be futile.

Conclusions

There seems to be a growing consensus that futility has not been adequately defined or accepted by the medical community and the public. By and large, courts have rejected the notion that physicians should make unilateral judgments about what counts as a benefit to a patient or what chance is a chance worth taking. Paul R. Helft and his colleagues, in their 2000 article, “The Rise and Fall of the Futility Movement,” concluded that a consensus has not been reached regarding the arguments for the supremacy of the rights of physicians or patients/families in judging futility. Instead, many clinicians and institutions have shifted the focus to developing a framework for discussing and resolving futility disputes. For example, some authors have emphasized a preemptive approach in which primary care physicians take responsibility for setting goals and discussing futile treatments before a crisis develops. In both Denver and Houston, community-wide policies have been developed that neither define futility nor give physicians unilateral power to act on their futility judgments (Murphy and Barbour; Halevy and Brody). Instead, these policies outline formal steps for conflict resolution in healthcare institutions.

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SEE ALSO: *Beneficence; Competence; Health Policy in the United States; Medicine, Art of; Medicine, Profession of; Nursing Ethics; Pain and Suffering; Professional-Patient Relationship; Responsibility; Technology*

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MEDICAL GENETICS: PRACTICE OF MEDICAL GENETICS

SEE *Genetic Testing and Screening*

MEDICARE

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At its inception in 1966, the Medicare program was understood as a way to assure elderly persons a stable place in the mainstream of American medicine. Over the first quarter-century of its operation, however, Medicare increasingly came to be viewed as an instrument to influence the character and costs of doctors, hospitals, and health insurance. In 1986 Medicare marked its twentieth birthday with considerable fanfare. In 1991, along with American medicine, Medicare faced severe financial pressures, and its silver anniversary was not celebrated; nor was its thirty-fifth anniversary much celebrated on June 30, 2001.

The Origins of Medicare

When the Great Depression made economic insecurity a pressing national concern, the social insurance reformers thought health insurance should be part of a comprehensive American scheme of social protection. From 1936 through the late 1940s, there were recurrent calls to incorporate universal health insurance within America's nascent welfare state. But, despite the broad public support for national health insurance, a conservative coalition in Congress defeated such measures (Marmor, 1973).

By 1952 the original architects of Social Security, well aware of this frustrating opposition, had formulated a plan of incremental expansion of government health insurance. The proponents of what became known as Medicare restricted the category of beneficiaries to retired persons, while retaining the conceptual link to social insurance. Medicare would provide retirees with limited hospitalization insurance—a partial plan for that part of the population whose financial fears of illness were as real as their difficulty in purchasing health insurance at an affordable cost. So began the long battle to turn a national health insurance proposal acceptable to the public into one passable by the Congress.

These origins had much to do with the initial design of the Medicare program—and with the expectations of how it would develop over time. The incrementalist strategy assumed that hospitalization coverage was the appropriate first step in benefits and that wider benefits would be enacted later under a common pattern of Social Security financing. Likewise, the strategy's proponents assumed that eligibility would be expanded gradually to include most, if not all, of the population, extending first, perhaps, to children and pregnant women. Medicare enthusiasts took for granted that the rhetoric of enactment should emphasize the expansion of access to medical care, not its regulation and reform. The clear aim was to reduce the risks of financial disaster for older people and their families, and the clear understanding was that Congress would demand a largely hands-off posture toward the doctors and hospitals providing the care Medicare would finance. Some twenty-five years after the program's enactment, it is taken for granted that how—or how much—one pays for medical care affects the care given. In the buildup to the passage of the Medicare bill (in July 1965), however, no such presumption existed.

Once this incrementalist proposal was outlined, who and what shaped its fate? Medicare's principal antagonists, and their adversarial methods, illustrate a familiar American form of ideological politics. The most prominent opponents—national medical, business, and labor organizations—engaged in open, hostile communication and brought into their opposing camps many groups whose economic interests were not directly affected by the Medicare outcome. Both the contest and the contestants remained remarkably stable from 1952 to 1964—two well-defined camps with opposing views reigned, and few groups remained impartial or uncommitted.

The particular features of the political environment in 1965 help explain details of the original Medicare program that remain problematic decades later. The overwhelming Democratic victory of 1964 seemed to guarantee that hospitalization insurance for older Americans would pass in 1965. President Lyndon B. Johnson's commitment to Medicare was made plain in his presidential campaign, and the new Congress of 1965 acted to prevent further delays in the president's Great Society agenda. The result, however, was far more complex than expected. The certainty that a Medicare bill would be enacted transformed the struggle from a polemic over Medicare's wisdom to a complicated strategy game about exactly what the program would do. Out of that game came the benefits, financing, and administrative design of the operational Medicare program. Few participants had expected Medicare to pay physicians at all, let alone their "reasonable and customary" charges in a new "Part B" of the program. And, while reimbursing hospitals (under Part A) using the Blue Cross formula of reasonable costs was anticipated, the Department of Health, Education, and Welfare hardly imagined the inflationary impact this would have.

The Development of Medicare

Initially, Medicare's administrators accommodated the demands of medical providers for a largely hands-off stance by public regulators. Out of this period—described by Columbia University political scientist Lawrence Brown in 1985 as "consensual corporatism"—emerged rapid inflation in Medicare's expenditures and the fumbling efforts to find acceptable means to control its costs.

From 1972 to the beginning of the 1980s, Medicare's woes were masked by the national preoccupation with the mix of inflation and unemployment known as stagflation, with broader proposals to reform American medicine, and with the growing appeal of *pro-competitive* alternatives to public regulation of discrete programs like Medicare and Medicaid. This period was characterized by the growing dispersal of government regulation among federal and state agencies (what Brown called "inverted corporatism"). The frustrating experience with health planning, with experiments in hospital reimbursement, and with the rapid growth of costs prompted broader reform approaches. A striking illustration of both the problems and the frustration was the addition of a special disease program under Medicare: one for all Americans suffering from renal failure. Enacted with great fanfare in 1972, the End-Stage Renal Disease Program grew rapidly—in beneficiaries, in costs, and in complexity. And it soon became a symbol of disappointment with traditional ideas of government health insurance (Starr). Throughout the 1970s, health policy experts produced a bewildering array of reform proposals, but Medicare's reform remained a special world of policy specialists, congressional committees, and the responsible executive agency, Social Security's Bureau of Health Insurance, until the Health Care Finance Agency (HCFA; now called the Centers for Medicare and Medicaid Services, or CMS) took over in 1977.

A third period of Medicare's administrative history—which Brown labeled "technocratic corporatism"—flowered in the 1980s. With universal health insurance dislodged from the national agenda, the attention of policymakers and technical experts returned to Medicare itself. Medicare and Social Security had been protected under the mantle of social-insurance theories of entitlement, and by the elderly population's reputed political clout. That protected status was what the budget and tax politics of the 1980s were to challenge.

Three developments exemplify this period, which extended to the mid-1990s. First, there were continuing efforts to reduce the rate of expenditure growth in Medicare, efforts that initially shifted costs to the elderly population, and later burdened hospitals and physicians. Second, there was the surprisingly rapid enactment in 1983 of a new form of hospital reimbursement within Medicare: the widely noted diagnosis related group (DRG) method of prospective payment. Developed by technocrats in the academy and within HCFA, supported by policy experts within the Congress, and with some operational trials in New Jersey, DRGs dominated the hospital world of the 1980s and symbolized the faith in scientific, apolitical answers to Medicare's troubles. At this time, there was no specific provision for monitoring the quality of hospital care, though there was no question of the potential effects on patient care of changing hospital financial incentives so drastically (Smith).

The third development, a new federal institution named the Prospective Payment Commission, became the monitor of DRGs, and later in the decade it spawned a similar institution for Medicare's Part B medical insurance, the Physician Payment Review Commission. It was assumed that the associated peer review organizations would take care of balancing Medicare's cost and quality.

The irony of the Reagan era is that an administration committed ideologically to free markets produced the most obvious examples of administered prices—the payment of hospitals by the diagnosis related group method—in American medicine. At the same time, increases in the medical expenses paid directly by elderly persons prompted what came to be known as the *catastrophic debacle* of 1987–1989. The Reagan administration proposed, and the Congress more generously delivered, a complicated piece of legislation to cover the catastrophic expenses of the elderly. A firestorm of protest erupted over the financing of this benefit expansion (affecting largely the more affluent elderly), and in 1989, for the first time in Medicare's history, the Congress repealed a benefit that had been regarded as a gift to the program's beneficiaries.

Twenty-five years after enactment of the Medicare program, its budget woes were part of the national preoccupation with increasing public deficits. The catastrophic debacle had symbolized and worsened the charges of *generational inequity,* with *greedy geezers* caricatured as the enemies of America's children, future, and tradition of fairness. With deficits untamed, further cuts in Medicare's rate of expenditure growth remained on the policy agenda in 1992 and thereafter, even as the nation debated more comprehensive forms of medical-care reform.

Attempts at Reform

In fact, the period between 1992 and 2002 was full of surprises. Anyone who observed the fight over the Clinton health-reform proposal would hardly have expected Republican leaders in the Congress to later promote a system of vouchers for Medicare that resembled Clinton's model of universal vouchers. In debates over the Balanced Budget Amendments of 1997 and later, previous critics of managed competition for all Americans became advocates for using that model for Medicare. The puzzle is why this apparent reversal took place.

Understanding the reversal requires distinguishing Republican philosophical distaste for *big government* initiatives (like the Clinton proposal) from Republican pragmatism about how to control the budgets of existing federal programs (like Medicare). Vouchers for Medicare seemed, in the mid-1990s, an acceptable way to reduce federal expenditures and secure the balanced budget that fiscal policy conservatives had long sought (White). The presumption of the voucher advocates was that Medicare beneficiaries with a fixed sum (euphemistically described as *premium support*), would shop for the insurance plan they wanted, with competition among plans holding down inflation. Relying on that reasoning, advocates projected considerable savings from what Medicare had been predicted to spend in the decades ahead. And, with that, the game shifted to promoting expanded benefits, especially the coverage of prescription drugs that Medicare did not insure outside of the hospital environment. With cost control predicted, benefits expanded, competition at work, and choice to be enhanced, the conventional claim by the late l990s was that Medicare would finally be ready for the twenty-first century.

The suggestion that Medicare required fundamental alteration is precisely what a substantial proportion of the elite political community believed at this time. What is striking upon reflection is how unsubstantiated were the premises from which the reform proposals proceeded. Medicare was supposedly not sustainable in its traditional form. Sure to "run out of money" over time, Medicare was regularly labeled as archaic and out of touch with medical realities. This was what the Bipartisan Commission on the Future of Medicare sought to communicate in 1999, though their proposal fell short of enough votes in the commission.

In fact, Medicare was hardly unsustainable. In 1997–1998, Medicare's outlays increased by only l.5 per cent, and for most of its history its costs have increased no more than the private health insurance plans with which it has been compared. The claim that Medicare was archaic represented sheer perversity. The developments in American medical care during the 1990s had made managed care a source of jokes among ordinary Americans, not a model to be followed. The appeal to the supposed virtues of competition among managed-care plans was more interest-group rhetoric than a reflection of popular consultation or defensible policy analysis.

Just as with the birth of Medicare, the changing partisan composition of the Congress made a crucial difference in the nature of the claims about Medicare at the close of the century. The question for Medicare's future in the spring of 1999 was whether liberal Democrats could persuade President Clinton to reject the type of reform proposal his own rhetoric had helped to generate. And, by the fall, they succeeded.

Efforts to change Medicare reflect presumptions about the proper role of government in American life and the purposes of social insurance in paying for medical care. Medicare's fate will be linked to controversies about managed care and whether Medicare should embrace or reject its expansion. The agenda—and Medicare's place on it—is subject to transformation by both electoral and economic shifts, and no one can claim with certainty what the political and economic environment will be like a few years hence, let alone decades. What can be concluded, however, is that the politics of Medicare will continue to produce two types of policy disputes. First are the relatively narrow policy conflicts in which the ideological cleavages in the larger public are substantially irrelevant, and second are those relatively rare but important disputes where the deepest divides in the American political world are crucially relevant. This is what Medicare's origins and programmatic history reveal.

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SEE ALSO: *Access to Healthcare; Aging and the Aged; Health Insurance; Justice; Medicaid*

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MEDICINE, ANTHROPOLOGY OF

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Medical anthropology is the cross-cultural study of health, illness, and medical systems. Medical anthropologists describe how the collective meanings, social institutions, and dynamics of political power in a particular society construct local forms of medical knowledge and therapeutic action that are differentially distributed across gender, age, ethnic, and class lines. From hundreds of studies a deeper understanding has been gained of variation in illness beliefs and behavior and of pluralism in healing practices (see, e.g., Good, 1977; Janzen; Kleinman, 1980; Leslie; Lock; Nichter). Yet there are also universals in the mediation of suffering and in the therapeutic process about which the comparative method provides a special insight (see Kleinman, 1988a, 1988b).

Medical anthropologists or anthropologists of medicine (the terms are interchangeable) have brought different paradigms to bear on the study of health and disease. Ecological, political-economic, and applied public-health or clinical perspectives are all to be found in the literature. Yet since the 1970s the most original anthropological contribution is what has come to be called a meaning-centered or social constructionist paradigm.

In this perspective, the central concern is with the way that illness categories and experiences reflect culture, and in turn contribute to social change. Thus, Gilbert Lewis (1975), working with a small-scale preliterate society near the Sepik River of Papua New Guinea, shows how that society's master symbols are reflected in the illness behavior of withdrawal and isolation of seriously sick members and in the "days of shining red" animated by healing rituals. The smells, tastes, sights, sounds, and sensibility of everyday responses to shamans' songs among aboriginals in the Malaysian rain forest and Malays in rice-farming villages (Laderman, 1991; Roseman); of routine coping processes through which Haitian villagers make accusations about the sources of AIDS (Farmer); and of the social as well as personal experience of sadness among Yolmo Sherpas in Nepal (Desjarlais)—all are patterned by deep cultural codes and social structures. Much the same cultural dialectic between persons and collective institutions has been shown to pattern interactions in psychiatric emergency rooms in North America (Rhodes); in the training of medical students to see patients through the lens of biomedical reductionism at Harvard Medical School (Good, 1993); and in the practices of oncologists in Tokyo, Rome, Oaxaca, and Boston (Good et al.).

Global social change has proliferated, not limited, the numbers and types of traditional healers in both richer, industrialized societies and poorer, industrializing ones (McGuire). Industrialization on a worldscale has neither undermined traditional medical beliefs nor foreclosed on folk health practices; yet such global social change has made much less clear the division between *traditional* and *modern.* One finds in the so-called East Asian industrial dragons, for example, a greatly complex mesh of attitudes, values, and practices. There is no simple giving way of *tradition* to Western orientation; indeed, both tradition and Westernization are routinely reinvented. The Japanese may be moving to accept brain death as a marker of the end of human life, and thereby facilitate organ transplantation, which has been severely constrained by Buddhist ideas; but it is a movement strongly contested by large numbers of Japanese who maintain traditional values about death together with the most advanced technological orientation.

Patients and their families, when it comes to serious illness, are pragmatic; they cross back and forth between the professional and folk domains of healthcare. Scientific knowledge has not replaced cultural common sense but been integrated with it (Kleinman, 1980; Nichter). Biomedicine has been the leading edge of a worldwide culture of science, yet in Asian and African societies biomedical institutions and relationships have become indigenized in ways that reflect those societies' master values and particular forms of social life. As a result there are both certain similarities and even greater dissimilarities in the ways professional and lay members of those societies make therapeutic decisions, handle life and death events, respond to chronicity and disability, and negotiate the complexities of care (Laderman, 1983; Last and Chavunduka; Rhodes; Sargent; Young, 1977).

Because of their concern for value orientations and everyday decision making, anthropologists have written about the ethical sides of health and healthcare. For example, Peter Kunstadter (1980) and Morton Beiser (1977) wrote about the ethical quandaries that development projects, including medical ones, introduced into traditional communities, because the services they provide are temporary and therefore raise expectations that eventually will be frustrated. Mary Jo Good and colleagues (1993) and Margaret Lock and Christina Honda (1990) examined the moral exigencies of truth telling about cancer and determining death in biomedicine in Japan. Paul Unschuld (1979) analyzed the corpus of Confucian and traditional Chinese medical writings on ethical issues, and concluded that professional and cultural values of the literati class colluded to control the medical marketplace. Arthur Kleinman (1980) found that healers in Taiwan in the 1960s and 1970s—whether traditional Chinese medical practitioners, shamans, or physicians—were viewed ambiguously: as morally powerful to heal, yet potentially immoral sources of economic gain and even of evil power (sorcery). This finding is rather widespread cross-culturally.

Horacio Fabrega (1990), writing explicitly about an ethnomedical approach to medical ethics, saw biomedicine's ethical preoccupations growing from Greek medicine and the popular morality of ancient Greece. Following many anthropologists, he asserts that in small-scale, preliterate societies, healing and religion are inseparable; thus, for Fabrega medical mores are tied to ritual and theology in these societies. In larger-scale societies—both peasant and posttraditional—the specialized division of labor leads to practitioners who are popularly viewed both as healers and as financially benefiting from the healer's trade. Fabrega argues that all the great non-Western traditions of healers use ethical injunctions to control access to practice and to proscribe certain alternative healers as quacks. He asserts that *bioethics* is a unique version of medical ethics made possible by the development of biomedicine with its knowledge of biology and powerful biological applications.

Writing for a collection of social-science treatments of bioethics, Richard Lieban (1990), himself an anthropologist, focuses on anthropological interest in the ethical aspects of controversial folk practices—such as female circumcision, differential assistance to male children, and the lack of regulation of folk healers—as examples of what anthropologists can offer to bioethical issues in international health (see also Scheper-Hughes; Korbin; Gruenbaum; Kleinman, 1982). Allan Young (1990), in the same volume, demonstrates the value of ethnographic accounts of the hidden moral dimensions of psychiatric practice in a Veterans Administration unit for treating combat-related posttraumatic stress disorder among veterans who had served in the Vietnam War.

What characterizes anthropological approaches to ethical issues, in medicine as well as other fields, is an emphasis on questions that emerge out of the grounded experiences of sick persons, families, and healers in local contexts. Anthropologists have critiqued universal ethical propositions just as their professional perspective has led them to critique universalist models for economic development. In place of universalist propositions—philosophical or political-economic—anthropologists have focused upon the local interactions of everyday life and the moral issues in which they are clothed. In Isaiah Berlin's (1979) apt metaphor, they are more the fox than the hedgehog. The latter type of intellectual (e.g., the moral philosopher or the psychoanalyst) knows one big thing about the human experience, while the former (e.g., the historian or anthropologist) knows many small, particular things.

The remainder of this entry will adumbrate what anthropological studies tell us about health, illness, and care that is relevant to the practice of bioethics. Starting with a cross-cultural critique of leading bioethical orientations and commitments, the more powerful anthropological contributions will be reviewed, followed by a brief discussion of the possibilities and problems with a culturalist orientation. From the anthropological perspective, bioethics shares with biomedicine several determinative cultural orientations that constrain the standard approach to ethical issues in patient care. The anthropological approach, therefore, becomes particularly useful because of the comparative understanding it offers of often unexamined biases.

The *ethnocentrism, psychocentrism,* and *medicocentrism* central to biomedicine are prominent in the standard bioethical approach (see Lock and Gordon; Weisz). Most philosophically trained bioethicists draw on what Charles Taylor (1989) describes as the orthodox sources of the self in the Western philosophical tradition. The great works in that tradition, from those of the Greeks down to the present, assume an individuated self, set off from the collective—single, unchanging, and self-defining. Thereby, inter alia, the autonomy of the person is claimed to be a paramount value along with the ideas of justice and beneficence. From a cross-cultural perspective this intellectual commitment is problematic.

In the major non-Western societies—such as China, India, Japan, Indonesia, and most African societies—few people hold that the isolated individual is the locus of responsibility for therapeutic choice, or that therapy should work to maximize the individuation of the sick person. Rather, there is a paramount sociocentric consensus in which social obligation, family responsibility, and communal loyalty outweigh personal autonomy in the hierarchy of ethical principles. The self is viewed as sociocentrically enmeshed in inextricable social networks, ties that make interpersonal processes the source of vital decisions. More than 80 percent of the planet's population lives in cultures outside of North America and Western Europe or are members of minority ethnic groups outside of the Euro-American majority. That bioethics is able to avoid serious engagement with these alternative ethical traditions must represent one of the last tenacious holds of ethnocentric mentality. Indeed, there is evidence that bioethicists are commencing such decentering cultural engagements (Jennings; Loewy).

Similarly, from an ethnographic perspective, the use of abstract concepts of justice and beneficence as universal ethical principles in decision making is suspect because of the failure to take into account the local worlds in which patients and practitioners live—worlds that involve unjust distributions of power, entitlements, and resources. It is utopian, and therefore misleading, to apply the principles of justice and beneficence to practical clinical problems, unless we first take into account the brutal reality of the unjust worlds in which illness is systematically distributed along socioeconomic lines and in which access to and quality of care are cruelly constrained by the political economy. Beneficent social contracts may make good theory, but they deny empirical experience in local social worlds. Loewy's "beneficent community," which he claims is concerned with minimizing the suffering of its members, is a charming romance; no one lives in such a utopian state. Rather, real communities are sources of suffering at least as much as potential sources of assistance. They do not contain social contracts; but they are filled with different interests, status differences, class divisions, ethnic conflicts and factionalism. Little is gained by instantiating utopian virtues; indeed, much is lost, since illusion and exaggeration distort the practical realities of living.

The third "centrism"—medicocentrism—emerges from comparative studies as yet another bias of standard bioethical discourse. Like biomedicine, bioethics begins with professional definitions of pathology. The disease viewed as pathological physiology, and the professionally authorized array of treatment interventions, define the clinical situation (see Canguilhem). The experience of illness is made over, through the application of ethical abstractions such as those described above, into a contextless philosophical construct that is every bit as professionally centered and divorced from patients' suffering as is the biomedical construction of disease pathology.

The bioethicist, of course, is supposed to take into account the patient's perspective. But by and large the contextually rich illness narrative is reinterpreted (also thinned out) from the professional biomedical standpoint in order to focus exclusively on the value conflicts that it is held to instantiate. The folk categories of patients and indigenous healers are provided with only limited legitimacy. If they can be restated in the abstract terms of the standard bioethical orthodoxy, they are provided a place in the analysis. But if they cannot, then folk categories lose their authoritative imprint to define what is at stake for patients and families.

Take ideas, for example, of *suffering*—a powerful folk category worldwide. One is surprised to find so many professional ethical volumes in which this word does not appear as an entry in the index. Ethical systems that leave the problem of suffering (and related concepts of endurance and courage) to particular theological traditions cannot adequately engage the human core of illness and care. Here perhaps the standard version of bioethics shares yet another biomedical bias, the rejection of teleology. Biomedicine banishes the concepts of purpose and ultimate meaning to religion; yet most patients and practitioners struggle to make sense of illness with respect to great cultural codes that offer coherent interpretations of experience (cf. Frye).

Medicocentrism also leads bioethicists to construct cases that are centered in the professionally approved institutional structures of biomedicine—such as hospitals or nursing homes—despite the fact that most illness episodes, as social studies reveal, are experienced, interpreted, and responded to in the context of the family. The family—the mundane cultural setting of illness and care, where local social processes are so greatly influential—and the workplace frequently disappear in bioethical discourse, to be replaced by the biomedical staging of more extreme, even exotic value conflicts. Of course, the immense panoply of settings for healing is even less visible or audible in the bioethical construction of clinical reality.

This all too black-and-white portrait of bioethics is intended to draw out and highlight its deep difficulties and their cultural sources. In the practical flow of events, the working bioethicist struggles to overcome the constraints that limit his or her engagement with the obdurate particularity and inexpedient uncertainty of human subjects. And for that very reason he or she will find an ethnographic orientation to be liberating.

In contrast with the bioethicist, the ethnographer begins with the lived flow of interpersonal experience in a deeply particular local world. Not the Western tradition or North America, nor even New York State—which are too unspecified to provide a positioned *view from somewhere*—but, rather, the Puerto Rican community in the South Bronx, upper-middle-class Scarsdale, a working-class section of Queens, or a network of Russian immigrants in Brooklyn becomes the setting for grounding moral analysis in the concrete historicity, micropolitical economy, and ethnicity of a local world. Even within such a localized flow of experience, perspectives and preferences are further defined by gender, age, and other social categories of persons: for example, the cultural situation of poor women in rural Haiti who are responding to AIDS (Farmer and Kleinman). These indexes of social experience situate groups and their individual members along axes of power such that the forces of macrosocial pressures—economic depression, war, forced uprooting, ethnic conflict, state violence, the organizational control of substance abuse, the social structural sources of chronic illness and disability—are systematically attenuated for some, yet amplified for others. Some become successful or at least are protected; others are victims.

Each local world is characterized by what is at stake for its members. That structure of relevance—compared to a belief or a convention—gives to the meanings of illness and to treatment expectations the sense of something much closer to natural law. Families hold the world to be a certain way as an article of fundamental faith in local reality. In the infrapolitics of family, workplace, and community, which is empirically discoverable, the processes of strategic negotiation and interpersonal engagement over what is at stake can be properly regarded as processes through which a local moral order is constituted and expressed. Culture, then, is built up out of the everyday routines and rhythms of social life. It is the medium of experience, for example, in which one person's chronic pain affects an entire work unit, a family member's Alzheimer's disease is shared as an illness reality by the entire family, and cancer care is negotiated among parents, child, and professional care providers.

Hospitals, clinics, and disability programs also are grounded in the particularity of local worlds, as is the bioethicist. The ethnographic task for the practicing bioethicist, then, becomes the discovery of the meanings and relationships in distinctive local worlds, and their actual impact on particular patients, families, and practitioners. This is a kind of cultural analysis of moral conflicts and negotiations over plans and practices that make up the flow of everyday living. As part of this ethnographic work, the bioethicist needs to elicit the perspectives of the participants and place them in the contexts of family, workplace, and medical system. The bioethicist's involvement should be to facilitate communication and to help negotiate conflicting orientations. In this work, it is necessary to protect the participants from the dehumanizing imposition of hegemonic principles. This focus on the positioned, intersubjective perspectives of participants in a local context is a radically different vision of how to proceed with the ethical analysis of a case than that which originates in a philosophical quest for an illusory *transpositional objectivity*, a synthesis valid for an entire context, which in the anthropological vision is the problem, not the solution (Sen).

More specifically, anthropological analysis draws attention to the institutional context of ethical decision making (see Bosk; Fox; Mizrahi). Social institutions—a particular type of hospital, a clinic for alternative care, or a religious facility—refigure ethical issues in terms of efficiency and other technical criteria that make up everyday social routines. Hence, the special characteristics of a Veterans Administration hospital, a university-based teaching hospital, a military hospital, a member of a for-profit hospital chain, or a highly cost-conscious HMO constrain the day-to-day social processes that create the local moral order. What is at stake for a resident in training in a teaching hospital—generating new knowledge, securing a place in the academic hierarchy, and so on—is noticeably different from what is at stake for a senior physician at a small community hospital. The difference signals a distinctive institutional context for deciding what level of treatment is *routine,* which kinds of issues will be highlighted as *ethical* problems, when families will be involved, and so on. Quite obviously, such institutional contexts will also be distinctive cross-culturally.

In Japan, even in a university teaching hospital, the practice has been not to disclose to patients that they are suffering from cancer but to allow key family members to decide if and when the *truth* will be told. In China, family members will stay in the hospital with the patient to do the nursing, prepare meals, and make all the major decisions, even for the family head when he is seriously ill.

In Zaire and Senegal, members of the kinship-based therapy management group, including perhaps the doctor and the nurse, will decide if the patient is to be part of a research protocol (Beiser). In a Seventh-Day Adventist mission hospital run by American staff in Borneo, the structure for identifying and resolving a moral dilemma draws on a religious ideology that suffuses the institutional context in a manner that greatly differentiates this hospital from nearby hospitals run by transplanted Javanese Muslims or local animists. The responses of North American and Chinese psychiatrists to depressed patients in the United States and China have been compared with respect to their decidedly different institutional contexts for determining what kinds of therapeutic behaviors represent good care and what kinds of moral messages will be given and received in the patient-doctor interaction (Kleinman, 1988b). Renée Fox and Judith Swazey (1984) have shown how physicians in a Chinese hospital draw on both Confucian views and

Communist ideology to authorize local patterns of ethical decision making that challenge North American orientations. And cultural historians disclose how bioethics in North America has emerged out of the social problems and responses of a particular era (Rothman).

Besides cultural critique and comparison, what practical contributions can anthropology make to bioethics? The cultural formulation of diagnostic and therapeutic issues clearly should be as significant to the consulting bioethicist as it frequently can be made to be for the consulting physician, especially when the patient and family come from cultural and ethnic backgrounds that differ from those of their professional caregivers, or when the setting is outside North America (Kleinman, 1982). That formulation involves systematic steps in placing the illness and treatment experience in the culturally grounded context of family, work, and medicalsocial welfare systems, through the application of a mini-ethnography—a description and interpretation of how those settings affect, and are affected by, the illness. Cultural formulation identifies lay and professional explanatory models, compares them for evidence of cultural bias or conflict, and sets out a process of negotiation to assure cultural sensitivity (see Helman, 1984; Kleinman, 1988a; Rogler). These are technical procedures that should be part of the repertoire of the bioethicist. Ethnographic knowledge of the core ethical orientations and social patterns of different communities will be especially significant in planning and implementing medical research in ethnic minority and non-Western settings (Christakis).

What are the limits of cultural analysis, cross-cultural comparison, and the sensibility to variation and differences that come under the term *cultural relativism*? While epistemological and even ontological relativism—willingness to entertain the idea that there is no single form of knowledge or being in local worlds—will seem defensible to many, ethical relativism of the radical variety—the idea that there are no ethical standards cross-culturally—will not. Are such practices as infanticide of female children in South Asia, ritual murder of elderly women accused of being illness-causing witches in East Africa, and rationing of care based on color status under apartheid acceptable because the dominant group says they are? Clearly, this would be an unacceptable conclusion. Behind it lurks the terrible transmogrification of medicine under the Nazis, when biomedical ideology and technology, dominated by Nazi values, prepared the way for the death camps (Kleinman, 1988b; Proctor).

The anthropological argument advanced in these pages is for elicitation and engagement with alternative ethical formulations, a constrained relativism; it is for affirmation of differences, not automatic authorization of any standard or practice as ethically acceptable because it is held by some people, somewhere (Shweder; Wong). The limit to ethical relativism is that the bioethicist must compare alternative ethical formulations with those ethical standards he or she holds for the evaluation of a particular problem in a particular context. The outcome of such an evaluation could be acceptance or rejection of the alternatives or of the bioethicist's own standards, or some form of negotiation and compromise.

The idea of radical cultural relativism is unacceptable to all but a small group of diehards. It is, moreover, a serious misinterpretation of what ethnography, cultural analysis, and cross-cultural comparison have contributed: the idea that before we apply an ethical category we hold to be universal, we had better understand the context of practice and ideas that constitute a local moral world. The job should be to situate a bioethical problem in that local ethos in order to understand what is at stake for the participants, what is contested, and thereby to offer a cultural formulation of conflicting ethical priorities. That having been done, there are at least three further steps. First, we need to systematically compare local and professional bioethical standards for that particular problem; second, we need to negotiate that part of the difference on which both parties deem it ethical to compromise; and third, where a cross-cultural ethical conflict cannot be so resolved, both parties should specify the nature of the problem for further adjudication (Kleinman, 1982). This ethnographic strategy does not commit the deep error of assuming that "all goods, all virtues, all ideals are compatible, and that what is desirable can alternately be united into a harmonious whole without loss" (Williams, p. xvi). Compromise and negotiation may not resolve ethical conflicts; and even where they do, some losses must occur. The quest is not for integration and unification, but for multicultural pluralism.

Where possible, it is the obligation of the bioethicist not only to respect the specific views of others and to affirm the validity of the process of alternative moral formulations, but also to develop deep knowledge about those viewpoints and to test those alternative categories and practices for potential ways to resolve ethical conflict. This ethnographic approach emphasizes the process of engagement and negotiation with the lived moral orientations of others; it attempts to minimize the application of those bioethical standards that derive from the Western philosophical tradition, to settings for which they lack coherence and validity. In all other areas of cross-cultural research and practice this is the established procedure. This approach also protects the responsibility of the professional bioethical consultant not to accept value decisions that contravene human rights and other pan-national moral conventions. But it makes this universalist responsibility the final stage in a process of cultural translation that gives priority, initially at least, to alternative worlds of experience interpreted in their own terms. Perhaps the cardinal contribution of the medical anthropologist to bioethics is to deeply humanize the process of formulating an ethical problem by allowing variation and pluralism to emerge and receive their due, so that ethical standards are not imposed in an alien way; rather, these standards will then be realized as the outcome of reciprocal participatory engagement across different worlds of experience.

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SEE ALSO: *Alternative Therapies: Social History; Body: Cultural and Religious Perspectives; Death: Cultural Perspectives; Health and Disease: Anthropological Perspectives; Human Nature; Medical Ethics, History of; Medicine, Sociology of; Mental Illness: Cultural Perspectives; Women, Historical and Cross-Cultural Perspectives*

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MEDICINE, ART OF

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In the art of medicine physicians themselves become the diagnostic and therapeutic instruments that apply the knowledge and skills of medicine. The art of medicine includes not only what is required for a physical diagnosis and for healing, but also the ability to apply the generalized knowledge of medicine and medical science to individual patients. This latter aspect includes knowing the particularity of the patient, knowing how to shape the doctor’s knowledge of medicine to the particular patient, and developing the relationship between patient and doctor. Discrete skills serve these goals, among them understanding the behavior of patients and doctors, using the doctor-patient relationship for diagnostic and therapeutic ends, good judgment and decision making, and effective communication.

For bioethics, considering the art of medicine offers challenges because aspects of the art arise from the singular traits of sick persons and the special character of the doctor-patient relationship. These put in doubt the validity of some ideas about patients’ independent self-representation and self-determination that have been important in the recent development of bioethics.

In this context art does not refer to the general meaning of aesthetics or the fine arts. Instead, it is derived from the Greek word *techné,* meaning craft or skill. This distinction is important because it is commonly said, in error, that the art of medicine cannot be taught. Crafts and skills are said to be learned from others. The ancient Greeks classified medicine as one of the original arts, along with weaving, carpentry, and geometry. On the other hand, mere skill is not all there is to this art, which must be served by a deeper practical understanding of its complex subject, as in Aristotle’s *phronesis* (sound, considered judgment) or the Hippocratic phrase, “Life is short and the art is long.” It was only with the rise of science in the seventeenth century that the term began to have its current meaning of the personal skills of physicians. In the twentieth century, the “art of medicine” has been sharply distinguished from the “science of medicine” and has come to have a somewhat pejorative connotation.

The Effects of Science on the Art of Medicine

The identification of the art of medicine with subjectivity and particularity is what has led to its recent loss of stature. It has been an article of faith of medical science in the twentieth century that objective scientific evidence would eventually replace the subjectivity of the transaction between an individual patient and physician. A further canon of medical science is that the knowledge and the science make the diagnosis and effect the treatment. The individuality of the physician is irrelevant; doctors are interchangeable. However, as Samuel Gorovitz and Alasdair MacIntyre have pointed out, generalizations of scientific medicine from systems that may not involve humans and by abstraction from observations of particular patients must be reparticularized to this patient, at this time, in this context, by this physician (Gorovitz and MacIntyre). In the care of sick persons, there are no sharp distinctions between medical science and the art of medicine, since both kinds of knowledge reside in the individual physician. It is his or her individuality that allows the physician to practice the art of medicine. An impersonal agency like a computer can deploy the science of medicine, but a particular doctor must adapt this knowledge to an individual patient. To do this appropriately requires both tacit and manifest knowledge within the doctor.

Patterning knowledge to the patient is generally known as medical judgment—acquiring and integrating both subjective and objective knowledge to make decisions in the best interests of the patient. Recent advances in studies of the theory and practice of medical decision-making do not fully encompass clinical judgment, because they have focused more on solving problems that arise from the uncertainties of medical information than on the consequences that follow from the relevance or meaning medical information may have for the particular patient.

The tendency of physicians and medicine to conflate the patient with the disease obscures the importance of the art of medicine. It is impossible, however, for physicians to confront or treat diseases. Because they can only treat the patient who has the disease, the art of medicine will always be essential.

How the Individuality of the Patient Makes a Difference

THE DISTINCTION BETWEEN DISEASE AND ILLNESS. *Disease* is the pathoanatomical or pathophysiological entity that manifests itself in symptoms that the patient experiences and the doctor discovers (Cassells, 1985a). Diseases are abstractions that have no concrete existence except as instantiated in particular patients. *Illness* is the patient's experience of the effects of the disease process; it includes not only the symptoms—alien sensations or perceptions of distorted function—but the interpretations and meanings of the symptoms. The illness also embraces the impact of altered function on behavior and social existence. It is the illness that the patient presents to the physician as reported symptoms and dysfunctions. While the physician may be primarily interested in the disease, the ethicist should be concerned with the illness because of its effects on the patient, his or her relationships, and the community that put in doubt the moral agency of the sick person.

THE EFFECTS OF THE INDIVIDUALITY OF THE PATIENT. Onset, course, treatment, and outcome of identical diseases vary from patient to patient because of individual variation from the molecular level to the whole person to the community. The contribution of the individual to differences in his or her illness is sometimes difficult to appreciate if one thinks only about the acute infectious diseases or trauma. Chronic diseases, which produce the greatest burden of illness in the U.S. population, provide better examples. For example, diabetes in adults is genetically determined, but its severity and manifestations are influenced by variation in diet and exercise pattern from person to person. In addition, the availability, type, and utilization of medical care play parts in the effects of diabetes. Because disease is a process that occurs over time, the responses of the patient to the disease manifestations become part of the illness itself, as they alter the patient's behavior and change the illness. For example, whether patients report symptoms, visit physicians, take prescribed medications, alter their lifestyle, accept illness as inevitable, or fight its every intrusion—each of these factors has an influence on the illness and expresses the individuality of the sick person. Each modification requires a change in the approach of the physician dictated, for the most part, not by medical science but rather arising from the doctor's art. The physician can affect the patient only through the doctor-patient relationship, which is central to the practice of medicine and its art, but differences among individuals—for example, their degrees of trust versus suspicion, openness versus shyness, or friendliness versus hostility—influence the kind of relationship formed.

The Different Perspectives of Patients and Physicians

The patient's perspective on his or her affliction is different from the physician's. In such crucial dimensions as time, space, and the meaning of specific medical objects (such as bodily organs, technological devices, and medications), patients' experience of their world diverges from that of the physician, whose scientific perspective on their disease includes objective measures of time and space and precise definitions of objects (Toombs). In the case of hypertension, for example, patients may feel threatened with a stroke by this moment's elevated blood pressure, even though the dangers of hypertension lie in its effects on the heart, kidneys, and blood vessels over long periods. To patients, the felt immediacies of other disease threats also seem more a result of their seriousness than of their actual temporal proximity.

A patient's focus on a particular symptom depends more on the patient's interpretation of the symptom than it does on the actual experienced events. For example, a patient who interprets his or her chest pain as signaling heart disease may not be aware of, pay attention to, or report associated shoulder or neck pain that would tell the doctor that the chest pain is secondary to an entrapped cervical nerve and not heart disease. Further, patients rarely understand the probabilistic nature of medical information—that the facts of a case are most often not simply true or false, but only true with degrees of confidence—and even when they do, it is difficult for them to understand the meaning of these probabilities for them. Objectivity, always difficult, is virtually impossible for the sick person because of the nature of illness. Important alterations in thought processes, such as the inability to see things from the perspective of others and a concreteness of thought usually characteristic of children, accompany only serious illness, but this is where the reflections generated by bioethics are most important (Cassell, 1985b).

More than just medical science determines the physician's perspective of the patient's illness. Besides diagnostic and treatment goals that draw heavily on medical science, physicians have other aims. Some, such as the desire to save or prolong life, relieve pain, avoid doing harm, and provide information, are patient-centered. Others, such as being trustworthy and truthful, relate to their relationships with patients. As physicians among other physicians they also want to maintain their knowledge, to be considered good doctors by their peers, and to uphold the standards of their profession. Many of these ends are professional in nature, are part of the socialization of doctors, and reach back to antiquity. They, too, distinguish the doctor's point of view from that of even informed patients.

Although doctors and patients may appear to speak the same language about the same subjects, their differing viewpoints ensure that a physician may remain within the medical-scientific worldview and not attend to the patient's concerns. The care of the terminally ill often exemplifies such dissonance. Here, one of the ends of medical practice—staving off death as long as possible—may be at odds with the patient's desire not to be in pain or suffer. A necessary aspect of the physician's art is to understand the patient's goals and adjust professional aims and medicine's tools to these ends. This is the meaning of sayings throughout medical history exemplified by that of Bela Schick, "First the patient, second the patient, third the patient, fourth the patient, fifth the patient, and then maybe comes the science." That this principle is often violated or ignored does not obviate its centrality for the art of medicine.

The Doctor-Patient Relationship

The special nature of the relationship between doctor and patient has been appreciated since antiquity (Laín Entralgo). As much a part of sickness and medicine as the diseases that make people ill, this relationship makes a sick person a patient and a medical person a doctor and a clinician. It is the vehicle through which physicians exercise their authority (not to be confused with authoritarianism), without which the practice of the art is impossible (Needleman). An examination of the way the relationship is formed and its potential for effectiveness suggests that this special bond is a basic part of the human condition with cultural and social dimensions (Cassell, 1991).

In emergencies, when doctor and patient have never previously met, the power of the relationship can become effective immediately. Within moments a doctor who is a stranger can ease pain, make panic subside, and improve breathing. (Physicians can also worsen symptoms and exacerbate panic by wrong actions.) The bond between doctor and patient is effective across cultural boundaries, even in the presence of antagonisms, and despite sometimes formidable social and environmental impediments.

Physicianhood is a role—a set of performances, duties, obligations, entitlements, and limitations connected to a function or status. The socialization of medical students includes learning about the doctor's role so that they emerge both as physicians and in the role of physicians. Given its sociocultural nature, it has its counterpart in the patient, who provides for the doctor's words and action access to the patient and the patient's body not available to ordinary relationships. Because the connection between doctor and patient is bilateral, the power of sickness to make patients susceptible to change at all levels of the human condition is matched ideally by the power of this benevolent relationship to induce physicians to extend themselves at all levels.

Physicians, because of the relationship, are enabled to see the authentic person through the mess of sickness, read the history of self-determined purposes in the life before illness, and understand the aesthetic whole that is the patient's life prior to the unwelcome intrusion of disease. In a modern extension of the art, they therefore have the opportunity and obligation to help the patient maintain autonomy, which, for the sickest, would be almost impossible outside the relationship. Clinical ethicists share in this opportunity when and if the patient extends this special bond to them (Zaner).

These aspects of the doctor-patient relationship are frequently obscured from view or even contravened in the high technology atmosphere of modern medical centers. The patient's trust is necessary for the most successful diagnosis and treatment, and therapeutic intimacy arising out of the relationship creates confidence. As part of their art, skilled practitioners actively nurture the relationship, not only encouraging its growth and promoting trust by the patient, but negotiating between empathic intimacy and objectivity. One skill in the art of clinicians lies in coming as close as ethically possible to intimacy while maintaining independence of action. A strong bond is essential in negotiating the difficulties and uncertainties of serious illness. It is equally important in supporting and teaching patients through the long trajectory of chronic illness.

The Behavior of Sick Persons and Doctors

THE BEHAVIOR OF SICK PERSONS. Even mild sickness alters behavior; profound sickness alters behavior profoundly. This is culturally acknowledged by what has come to be known as the sick role, the exemption from everyday duties and obligations granted to sick persons. Changes in functioning are not merely those associated with the disordered part—for example, the inability to move around because of back pain. Sickness induces changes in cognitive function and in relationships with self, body, and others. Patients who are sufficiently ill—for example, in life-threatening infectious diseases, congestive heart failure, for a few days after bypass surgery, or in long-term hospitalizations—although they are cognitively normal by conventional measures, have patterns of reasoning that Jean Piaget showed in children under six. For example, the sick frequently fail a classic test of reasoning about the conservation of volume. Two containers identical in size, shape, and the volume of water they contain are shown to the patient with the statement, “These two glasses have the same amount of water.” The contents of one glass is then emptied into a tall thin cylinder and the patient is asked, “Which one of these has more water?” Sick persons will frequently indicate the tall thin cylinder. They may say, “I know that it shouldn’t have more water, but it does” (Cassell, 1985b).

Sick persons usually are also unable to alter their perspective sufficiently to understand the viewpoint of another. A child’s alphabet block shows this in its simplest form. Even if the block is rotated so that they have seen all of its sides, when looking at one face, they cannot report what is on the opposite face. One can routinely demonstrate many other similar changes in reasoning, of which the patient is almost always unaware. Because of the similarity of their reasoning (and other traits) to children, these characteristics have been considered regression. To avoid the error of treating the sick like children, it seems wiser to realize that this altered behavior is sickness expressing itself. Thus, in appropriate circumstances, patient self-determination will be enhanced by offering no more than two concretely worded alternatives at a time and avoiding choices couched in abstractions.

The sick are attached to their caregivers. How their attachment is expressed varies from love to anger or rebelliousness. The skillful physician is aware that these emotions are not directed at the doctor as a particular person (about whom the patient usually knows very little) but at the doctor in the role (Landis). As such, they are not to be taken personally but should be used in diagnosis or treatment. Changes in the patient’s relationship to the body are also a common characteristic of illness. The patient may become angry with the body because of what it has done to the patient, as though the disease was something the body “did” to the patient. Relationship to the body influences the patient’s other illness behavior and reactions to the events of the sickness and its treatment.

Illness brings about dependency on others and often induces feelings of loss of control, helplessness, inadequacy, and failure. As a result, it may awaken unconscious conflicts and cause the patient to act toward the physician as if he or she were the patient’s parent. The artful physician, aware of the problems that may follow reawakening of early childhood experiences or feelings and behavior brought on by illness, knows and acts in the knowledge that the sick person within the doctor-patient relationship may seem quite different in presentation and behavior from the same person when he or she is well.

THE BEHAVIOR OF DOCTORS. Physicians, too, may behave differently in the presence of the sick than they do outside the doctor-patient relationship. Physicians’ interactions with their patients may evoke feelings of anger, sexual attraction, sadness, grief, failure, rejection, and omnipotence, among others (Maoz et al.). Many years ago a psychiatrist, Michael Balint, recognizing that physicians are not trained to deal with the feelings clinical events evoke in them, organized physician discussion groups (Balint). Although sometimes replicated, these so-called Balint groups have not been widely employed. Awareness of whether and how doctors’ feelings and behavior interfere with their care of patients is important because physicians’ experience of their patient’s feelings is an essential source of information about the illness.

Physicians are powerful people who must employ their power judiciously if it is to do good and not harm (Brody). Yet, doctors are rarely trained in how to use their power or even to be aware that they have power, which may be abused perhaps more easily than it is used. An irreducible inequity of power between patient and doctor inheres in the clinical situation. Codes of medical ethics reaching back to antiquity and modern bioethics directly address this problem. It is widely recognized, however, that if physicians are not virtuous, all the precepts, principles, and regulations surrounding their conduct will be useless. Edmund Pellegrino and David Thomasma explain the virtues necessary to achieve the ends of the clinical encounter and the good of the patient, namely, to be made well again if possible, or to cope with sickness, pain, suffering, and impending death if necessary. These virtues include conscientious attention to technical knowledge and skill, compassion, beneficence, benevolence, honesty, fidelity to promises and to the patient’s good, prudence, and wisdom (Pellegrino and Thomasma). Walsh McDermott believes that thoroughgoingness and self-discipline are also central virtues of the good clinician (McDermott). It requires a good person to be a good doctor—now, as in times past. As Paracelsus said, “The art of medicine is rooted in the heart. If your heart is false, you will also be a false physician; if your heart is just, you will also be a true physician.”

It is difficult for a scientific (and cynical) era such as ours to accept the unavoidable necessity for virtue in doctors. As a consequence, the active training of doctors in the virtues of the good physician has largely been abandoned in the untested and probably wrong belief that medical virtue cannot be taught. During medical school and in postgraduate training, however, those who become doctors do learn, even if only through socialization, to restrain the employment of their skills in situations where more harm than good may follow, to be self-critical and admit error (at least to each other), to pursue the good of the patient, and to act benevolently (Bosk).

Medical Decision Making

Physicians are constantly making judgments, many of which are moral. The skill of exercising judgment, which has defied systematization, is the ability to apply the general to the particular; in medicine, this means to the particular patient, clinical situation, or context. To do this, physicians must obtain information of three distinct kinds—brute facts (also known in medicine as hard data); values; and aesthetics (patterns, relationships among the elements of a situation, and degrees of order or disorder). Often doctors are not aware of much of the information in the latter two categories that enters their judgments. Because of the necessity for such information, which is often neither obvious nor easily demonstrated, the art of medicine requires heightened skills of observation and synthesis. The art also requires that some systematic understanding be brought to judgment.

Alvan Feinstein was the first to closely examine the logic that underlies physicians' decisions; his work generated the field of clinical epidemiology (Feinstein, 1967, 1985). Feinstein's primary concern was the background evidence that the study of groups of people would provide for clinical decisions in patient care. Those who have followed him have elaborated his basic message and methods to assist physicians in judging the utility of a piece of evidence or information in the diagnosis or treatment of a particular patient (Wulff; Fletcher et al.; Sackett et al.). These writers have elaborated basic principles that determine the diagnostic meaning of a piece of clinical information, for example, a finding on physical examination, the result of a blood test, or a clinical measurement. The accuracy and validity of the test or measurement are important, as might be expected, but so is the likelihood that *any* similar patient would have the disease or state that is being tested for.

Put another way, to know how helpful a piece of information is diagnostically, one has to know the chance that any such patient truly has the disease. For example, even if a test for a rare disease is 99 percent accurate, when a large population of healthy people is tested and someone has a positive test, the chances are small that the person has the disease. The test will probably have been a false positive. Alternatively, in a population in a region where the disease is common, a positive test probably means the person has the disease. The test will have been a true positive. Because many conclusions of the clinical epidemiologists based on Bayesian mathematics are counterintuitive, their work has been extremely important in bringing objectivity and precision to decision making. (In the example given above, when the test is 99 percent accurate but the disease is rare, a patient who tests positive has only about a 10 percent chance of having the disease.) Terms such as specificity, sensitivity, and positive predictive value, which denote quantified measures of modern medical decision making, are now commonly heard in discussions about particular patients. Modern physicians must not only be conversant with these methods; they must also explain them to each patient so that the patient can participate effectively in the decision-making process.

Physicians rarely realize the degree to which each patient is different. Consequently, particularizing the generalizations of medical science to fit an individual patient requires great skill. The desires, needs, concerns, intentions, and purposes of patients are statements of values that must be elicited if they are to enter decision making. They are often faulted as hopelessly subjective and consequently not up to the standard of the hard data employed in the decision-making methods discussed above. A patient's desire for a certain outcome may be subjective, but the statement of that aspiration is objective and can be validated and given precision within degrees of confidence through discussion with the patient and attention to the pattern of the patient's previous actions and purposes. The artful physician is obligated to develop the mastery that gives these values decision-making weight—they are expressions of the patient's autonomy. Attempts to circumvent the need for such mastery by developing standardized methodologies, such as scales and questionnaires to assess individual values, have not proved clinically useful. It remains necessary, therefore, for the clinician to know the sick person to the greatest degree possible so that good clinical judgments can be made.

The clinical situation, like the disease and the illness, is always changing; therefore, decision making that integrates values and other clinical information constantly occurs in clinical medicine. Shifts occur not only because of the evolving process of the disease, but also because of the ongoing responses of both doctors and patients. In addition, the place care is given (home, doctor's office, hospital, etc.) and who else is involved (family, friends, medical students, etc.) influence the process of the illness. It is obvious why clinical judgments are not confined to the initial diagnosis or decisions about therapy.

The art of medicine requires that the physician be always mindful of changes in the circumstances, the illness, and the capacity of the patient. Although the formal principles of modern decision making may not always be applicable, newer ideas about the probabilistic nature of judgment and the need to integrate hard and soft data constantly inform the work of the artful physician.

Doctor-Patient Communication

The ability to employ the spoken language to obtain information from and about the sick person, gain the patient's cooperation, and provide information to the patient is a central element in the art of medicine. Doctor-patient communication is unlike many other verbal transactions, despite its use of ordinary language. The patient is in the conversation with the doctor for a specific purpose that is vital for the patient and diagnostically or therapeutically significant for the physician. The patient and the doctor have important joint purposes in the service of which the conversation is both necessary and crucial.

The patient wants the doctor to pay attention to his or her symptoms and concerns about the illness, and is worried lest these not be properly expressed or their importance not be appreciated. Doctors want to hear the clues to the diagnosis that only the patient's story can convey. Yet, some things that are important to the patient may not be of interest to the doctor and vice-versa. If the doctor attends solely to the evidence for disease, discarding everything else the patient says as irrelevant, then he or she may find the disease, but discard the sick person. A person's utterances convey not only the overt description of his or her actions and beliefs, but also the significance of the objects and events under discussion to the speaker. This other aspect of the speaker's message—the description of self of which the speaker is often unaware—lies in the specific choice of words, syntax, and paralanguage (Cassell, 1985c). The attentive, artful physician, listening to these specific aspects of the spoken language, has the opportunity to know more about the patient.

Conversation with the patient offers the doctor the opportunity to discover the patient's presuppositions and the beliefs according to which the patient assigns meanings. Similarly, doctors can inform their patients about the medical presuppositions and concepts that inform the doctors' actions. Such exchanges help avoid or correct the miscommunications that inevitably arise because of the differing perspectives of doctor and patient. Just as the patient's language informs the doctor about the patient, the doctor's utterances reveal himself or herself to the patient. The virtues of physicians are not abstractions, but are displayed in speech and actions. Trust is built by means of conversation as well as by action; compassion is communicated in words, in nonverbal communication, and in action. The constant flow of spoken (and unspoken) language provides a doctor the opportunity to build his or her knowledge of the patient and provides a patient evidence of the physician's skill and fidelity.

The doctor also has the specific responsibility of informing the patient about what is the matter, what it means, what actions might be taken, what options exist, and what choices the patient must make. The same is true, on occasion, of communication with the patient's family or significant others. Information, however, is also a therapeutic tool. Doctor-patient communication provides the physicians the opportunity to convey information that reduces the patients' uncertainties, enables the patient to act in his or her own best interests, and strengthens the relationship between the doctor and patient. On the other hand, poorly or inadequately communicated information can increase uncertainty, paralyze action, and destroy the relationship.

A specific aspect of doctor-patient communication is breaking bad news. When it is done poorly, it can destroy hope and leave a patient in shambles. As part of the art of medicine, doctors must learn to convey bad news so well that patients are enabled to make truly self-representative and self-determined choices (Buckman).

Patients, like everybody else, act and react because of what things mean to them. Meaning includes not merely denotative aspects of words, objects and events, but their connotative, or value-laden, content as well. With its cognitive and affective aspects, meaning has an impact on the physical and spiritual responses of the sick. By changing patients' meanings, physicians can alter, sometime profoundly, the patient's experience of illness (Cassell, 1985a). The effective use of spoken language, with its power of creating and altering the meaning of wellness and illness, is an important aspect of the art of medicine.

ERIC J. CASSELL (1995)

SEE ALSO: *Compassionate Love; Emotions; Healing; Health and Illness; Information Disclosure, Ethical Issues of; Medicine, Profession of; Narrative; Pain and Suffering; Professional-Patient Relationship; Social Medicine; Trust; Value and Valuation; Virtue and Character*

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MEDICINE, PHILOSOPHY OF

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Over the last two and a half millennia—since the beginnings of Greek philosophy and medicine—there have been rich conceptual reflections regarding medical findings, reasoning in medicine, the status of knowledge claims in medicine, and the special concepts that structure the science and art of medicine. The philosophy of medicine is a corpus of considerations and writings uniting these reflections by contributors as diverse as Plato, Aristotle, and Galen; René Descartes, Immanuel Kant, and Georg W. F. Hegel; and contemporary thinkers. Because these examinations of medicine are philosophical in different senses, the term *philosophy of medicine* is ambiguous, covering a heterogeneous field of intellectual concerns. For the purpose of this overview, they have been collected under four categories.

The first category, speculative philosophy of medicine, has existed from the beginning of medicine. Speculative medicine may be characterized as the attempt to discover the basic philosophical principles that lie behind the practice of medicine. Here philosophy attempts to discover theoretical frameworks or foundations that give shape or content to clinical data. In this sense, philosophy of medicine provides a priori points of departure for medical knowledge and practice. The second category, the logic of medicine, brings together attempts to clarify the character of scientific reasoning in medicine. It identifies the basic principles that make medicine a coherent science. This category of philosophy of medicine studies, for example, the way in which diagnoses are made and judged to be accurate in medical practice and research. A third area of the philosophy of medicine may be understood as a subspecialty of philosophy of science. This area is concerned with what is accepted as *knowledge* in medicine and the healthcare professions. Much of the recent exploration of the status of concepts of health and disease or the status of the unconscious and explanation in psychoanalysis falls into this third category. Finally, a fourth category describes the explorations of other philosophical issues that have special salience in healthcare, for example, the nature of persons and its implications for the morality of abortion. Philosophy of medicine in this fourth sense would include bioethics.

Just as there is ambiguity concerning the meaning of "philosophy" in "philosophy of medicine," so there is ambiguity about the compass of medicine. Medicine can be construed as a body of knowledge, skills, and social practices concerned with the health and pathology of humans. In its modern sense, medicine encompasses theory and practice, science and art. Traditionally medicine is the origin of all systematic concerns with healing, including nursing and the allied health sciences. The focus of the philosophy of medicine, as a consequence, can have a broad or narrow scope.

The Philosophy of Medicine as Speculative Medicine

The ancient Greek philosophers sought to understand the world on a rational rather than a supernatural basis. Early Greek medicine was influenced by philosophers who held that the primary goal of a scientist was to find one basic principle or set of principles that would explain the natural world known by the senses. These physicians developed theories as to how the body worked and how diseases might be understood and controlled. At first, there was little concern to justify these theories in experience or observation. One finds, then, a tension in early Greek medicine between those physicians who grounded medicine in rational speculation—the rationalists—and those who grounded medicine in experience—the empiricists.

This tension is evident in the Hippocratic corpus. In the corpus there is approval for theorizing that "lays its foundation in incident, and deduces its conclusions in accordance with phenomena" (Jones, p. 313). Nevertheless, the Hippocratic author rejects the systematic sweep of more speculative thought:

> Certain physicians and philosophers assert that nobody can know medicine who is ignorant what a man is; he who would treat patients properly must, they say, learn this. But the question they raise is one for philosophy; it is the province of those who, like Empedocles, have written on natural science, what man is from the beginning, how he came into being at the first, and from what elements he was originally constructed. (Jones, p. 53)

The author is rejecting what might be termed speculative or metaphysical medicine—namely, the attempt to construct a theory of medicine on the basis of self-evident, or basic, principles or concepts. The author also writes that medicine has no need of "an empty postulate," a concept that is not based in experience, because it has at hand the means for verifiable knowledge.

René Descartes (1596–1650) held that he could determine the fundamental laws of metaphysics, physics, and medicine (Descartes) by reason alone, without appeal to experience. On the basis of his work in speculative, metaphysical medicine, Descartes predicted that he would live an additional century or so, achieving a life span of one and a half centuries. He believed his own theories would issue in simple revisions of daily routine leading to such extensions of life expectancy (Descartes). Descartes's *Treatise of Man* (1662) attempts a mechanistic anatomy and physiology expressed in terms of matter and motion. Descartes explains how the human body works by comparing it to a machine. He found that this mechanistic approach could explain the physical functioning of the human body but not rational behavior. Still, Descartes's philosophical reflections concerning the body provided a framework for later explanations of human functioning that also relied on mechanical metaphors.

The success of Isaac Newton (1642–1727) in offering systematic explanations in physics inspired attempts to do this in medicine. The eighteenth-century Scottish physician John Brown (1735–1788), for example, suggested that the concept of excitability could serve medicine as the concept of gravity had served Newtonian physics: as the single concept upon which all explanations of health and disease could ultimately rest. Stimulation or excitation and response to it, he argued, resulted in an equilibrium or disequilibrium that defined *health* and *disease,* respectively. If an imbalance became too extreme, death would result. Brown's work attracted the attention of philosophers, including Hegel (1770–1831). This philosophy of medicine—as the gray area between scientific, empirical medicine and the philosophy of nature—led to the modern understanding of medicine that brings together empirical observation and theoretical construction (Tsouyopoulos).

Twentieth-century historians of medicine have appreciated this interplay between empirical and speculative medicine under the title "philosophy of medicine." William Szumowski in 1949 and Owsei Temkin in 1956 spoke of the importance of the philosophy of medicine. It is to Szumowski that much of the rebirth of the interest in this term, perhaps first coined by Elisha Bartlett in 1844, can be attributed.

Lester King (1978) has used the term to identify the theoretical reflections undertaken by both physicians and philosophers engaged in speculative as well as other conceptual explorations of medicine.

The Philosophy of Medicine as the Logic of Medicine

The relationship between medical reasoning and medical practice has been an area of perennial philosophical controversy and investigation. In ancient Greek and Roman medicine, the disputes between the rationalists and empiricists were, in part, disputes about how knowledge claims in medicine ought to be justified. By the Renaissance, medicine had failed to achieve the success in healing that is often attributed to it today. This failure to achieve therapeutic success led to attempts to make medicine more *scientific,* in the hope of duplicating the success of fields like astronomy and physics. Thomas Sydenham (1624–1689), whose *Observationes medicae* appeared in a third edition in 1676, proposed a disciplined methodology of observation and treatment. Sydenham brought to medicine the scientific method of Francis Bacon (1561–1626), which sought to ground reasoning in experience, observation, and data.

This method, however, raised questions about observer bias of which Syndenham was aware. The principal difficulty is that an investigator's findings may be influenced by his or her presuppositions. These concerns about observer bias were taken up in the eighteenth century by such theoreticians of medicine as Françlois Boissier de Sauvages de la Croix (1706–1767) in his *Nosologia methodica sistens morborum classes juxta sydenhami mentem et botanicorum ordinem* (1768). Influenced by the writings of Thomas Sydenham and Carolus Linnaeus, Sauvages organized diseases into a structure of class, order, genus, and species. In his *Nosologia* there is an appreciation of medical observation as well as a concern for a logical rigor that sought to coherently relate observations to predicted outcomes. Sauvages's principal undertaking included a classification of diseases primarily based on their signs and symptoms rather than on their causes. He also sought to tie observed signs of illness to relationships that had been noted between past, present, and predicted future states of patients. The logical rigor of disciplined observation and the collection of facts is also evident in the work of William Cullen (1710–1790) and Thomas Percival (1740–1804).

The major revolutions in medical understanding born of advances in anatomy and physiology in the late eighteenth and nineteenth centuries, along with the recognition that many established treatments did not work, required a fundamental reassessment of medicine. Philosophical reflections concerning medical reasoning gave way to major treatises concerning the character of reasoning in medicine. Works such as Sir Gilbert Blane's *Elements of Medical Logick* (1819), Elisha Bartlett's *Philosophy of Medical Science* (1844), and F. R. Oesterlen's *Medizinische Logik* (1852) range from listing the elementary principles of life to concern with material fallacies in medicine, including excessive deference to authority, fashion, or speculative reasoning without sufficient empirical observation. Oesterlen's work, which advanced criteria for inductive reasoning in medicine based on the work of John Stuart Mill, included an analysis of the methods and means of medical investigation, the character of the inductive method in medicine, and the status of experiments, hypotheses, analogies, terminologies, definitions, and classifications. He viewed medical logic as the application of general logical principles to the field of medicine for the purpose of securing a coherent inductive and empirical science that would be free from a priori speculation. His work was followed by other studies, including Władysław Bieganski's *Logika medycyny* (1894) and Richard Koch's *Die ärztliche Diagnose* (1920).

Growing philosophical sophistication characterizes twentieth-century assessments of medical knowledge and medical reasoning. Types of medical knowledge may correspond to the different functions of medicine. Medicine can be understood in a threefold manner: biological medicine, clinical research, and clinical practice. Biological medicine is concerned mainly with scientific research in biology, whereas clinical research is focused on the development of the knowledge and technology used in clinical medicine. Finally, the area of clinical practice involves the realities of patients and disease. A philosophical concern of those writing on the logic of medicine has been to clarify the nature of each type of medical knowledge and the relationship of these different areas of medical knowledge and reasoning to one another (Wulff et al., 1986).

Since the middle of the twentieth century, a renewed interest in the logic of medical reasoning and the character of medical decision making has been expressed in the computer reconstruction of differential diagnosis. This literature has examined the logic and principles of medical reasoning—for example, the applicability of Bayes's Theorem to medical decision making (Lusted; Wulff, 1976); the logic of the taxonomy of disease and classification, including the application of set theory to the analysis of clinical judgments (Feinstein); and the role played by morbidity, mortality, and other costs in determining when and how diagnoses are framed. For example, because of the human and financial costs, one will be much more concerned about false positive diagnoses of AIDS than of athlete's foot. Recent works have given special attention to the process of making diagnoses, including the principles of differential diagnosis (Caplan, 1986; Engelhardt et al.; Wulff, 1976), as well as the elaboration of nosologies as instruments for gathering clinical information. Many of these reflections have stressed the hidden role of values and conceptual assumptions in the process and logic of medical diagnosis (Schaffner; Peset and Gracia; King, 1982).

The Philosophy of Medicine as the Philosophy of the Science of Medicine

Philosophy of medicine may also be understood as a self-conscious reflection on the status of special concepts, such as health and disease, deployed in medicine. Rudolf Virchow (1821–1902), for example, argued that designating a state of affairs as an *illness* has a stipulative character; that is, such concepts are defined by agreement and there are no clear natural types or divisions of nature corresponding to nosological categories. This sense of the philosophy of medicine places the accent on issues in the theory of knowledge and the examination of what should count as a medical theory or explanation. In this, it is distinguished from speculative philosophy of medicine and from the more narrow concerns with the rules of evidence and inference proper to medicine that are the focus of medical logic and medical decision theory.

Since the 1950s a considerable literature has developed that is directed to the status of concepts such as health, disease, illness, disability, and disorder. Whether such concerns constitute a subspecialty of the philosophy of science is disputed (Caplan, 1992; Wulff, 1992). There has also been interest in the character of medical explanation (Canguilhem). This literature has also explored the application of such terms to nonhuman animals. In addition, there has been attention to the extent to which these concepts are normative and the extent to which nonnormative, value-free concepts can be elaborated. Those who have argued in favor of weak or strong normative understandings of concepts such as health, disease, and illness have also addressed the character and kind of values that structure such concepts. Investigations have included the extent to which concepts of disease are instrumental to medical practice, or instead identify natural divisions in reality. In addition, there have been attempts to place medicine within the general compass of philosophical explorations of scientific theory (Kliemt). Finally, the significant changes about the relationship of theories, facts, and values in the understanding of the history and philosophy of science that occurred in the 1960s and 1970s were anticipated in Ludwik Fleck's 1935 study of changes in the meaning of syphilis and venereal disease from the fifteenth to the early twentieth century (Fleck).

The Philosophy of Medicine as the Collection of Philosophical Interests in Medicine

Even if one were to hold that medicine offers no conceptual or philosophical problems not already present in the subject matter of the philosophy of science or the philosophy of biology (Caplan, 1992), there would still be merit in exploring the ways in which philosophical study and analysis can be directed to the understanding of medicine, as well as to the healthcare sciences and arts in general. In this sense, the philosophy of medicine encompasses the ways in which the philosophy of science, the philosophy of biology, the philosophy of mind, moral philosophy, and so on are engaged in order better to understand medicine. Perhaps one would wish to characterize such explorations as philosophy about medicine rather than of medicine, in the sense that the tools, analyses, and insights of philosophy in general are brought to the particular subject matter of medicine. Calling this endeavor the philosophy of medicine underscores the heuristic advantage of treating the domain as a whole, as a single focus of attention. There is also the advantage of recognizing that general issues of justice, fairness, rights, and duties confront the special challenge of taking account of the development of humans from conception to death.

In medicine, special questions of intergenerational justice become salient, distinctions between human biological and human personal life are raised, the irremediable character of loss must be confronted, and comparisons must be made between claims for the alleviation of suffering versus the postponement of death. Though the definitions of futility, of ordinary versus extraordinary treatment, and of the beginning of life and the beginning of death may arise outside the compass of medicine, such definitions take on a special philosophical cast and character in the context of medicine. The recognition that there is this special concatenation of conceptual issues is appreciated in employing the term *philosophy of medicine.* This use of the term approximates the one employed by the European Society for the Philosophy of Medicine and Health Care (founded 1987), which encompasses bioethics within a constellation of philosophical concerns and undertakings. The philosophy of medicine as speculative medicine, as the logic of medicine, and as the philosophy of the science of medicine all spring from the acknowledgment that medicine constitutes one of the cardinal areas of intellectual and moral attention, central to human life, and is worthy of sustained conceptual analysis and philosophical regard.

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SEE ALSO: *Medicine, Anthropology of; Medicine, Art of; Medicine, Profession of; Medicine, Sociology of; Professional-Patient Relationship: Historical Perspectives*

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MEDICINE, PROFESSION OF

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Professionalism is what distinguishes the professions. It gives each the character by which it is known. In our time many occupational groups have striven for professional status in a quest for authority, prestige, and income. “Professionalism, professionalization, and the professions are increasingly central to any grasp of modern societies,” Nathan Glazer claims, “yet persistently elude proper understanding” (p. 34). Many sociologists have written about the characteristics of professions, but most agree that all professions possess the five elements identified by Ernest Greenwood:

systematic body of theory;
authority to define problems and their treatment;
community sanctions to admit and train its members;
ethical codes that stress an ideal of service to others;
a culture that includes the institutions necessary to carry out all of its functions.

Jeffrey Berlant, following German sociologist and economist Max Weber’s (1881–1961) theory that professionalization is a form of monopolization, lists the steps in the process:

creation of a commodity—in the case of medicine and law, services for a fee;
separation of performance of the service from the satisfaction of the client, which means that a cure need not be guaranteed;
creation of scarcity by reducing supply and increasing demand;
monopolization of supply and control of privileges by legal means, such as licenses;
restriction of group membership, such as admission to study or to hospital staff;
elimination of internal competition;
development of group solidarity and cooperation.

The attributes used to describe professions include responsibilities and privileges, both derived by social contract. It is important to remember that the terms of the social contract change with changing social and economic conditions, and hence may vary from one region or historical period to another. Thus professionalism cannot provide a permanent set of values or standards. Instead it offers a series of guidelines designed to help specific people in specific places resolve important conflicts that arise from the nature of their duties. Each society has evolved some of its own standards, based on its own structure, values, and technological capabilities. Some standards of professional behavior originating in modern industrial societies may be meaningless in other cultural settings (Hughes).

In medicine, historical changes can be illustrated with the example of specialization. Today, specialization is cited as a hallmark of professions. In nineteenth-century U.S. medicine, however, the doctor who specialized was often looked upon as a quack (Rosen, Stevens). Today the physician who claims to have knowledge and expertise in all of medicine would be looked upon with suspicion.

To pose the question “When did medicine become professional?” is like asking “When did medicine become modern?” There are elements of professionalism and of modernity in ancient Greek medicine, as there are in the medicine of the Middle Ages, the Renaissance, and the eighteenth century. The definitions of a profession that appeared in the literature in the early part of the twentieth century, which stressed urbanization and industrialization as prerequisites for the existence of a medical profession, are no longer held. Although it has been true that an industrializing society is a professionalizing society, so far as medicine is concerned there was professionalization long before industrialization (Goode).

Professionalism in medicine developed in a continuous historical process, beginning in antiquity with institutions like state physicians and fraternities of physicians such as the Asclepiads, continuing with the medieval medical guilds, medical schools, and licensing requirements. The modern period, especially after about 1700, is characterized by the emergence of such institutions as medical societies, medical literature, licensing laws, and codes of ethics. In the twentieth century the professional is the recognized expert with special qualifications, and the professional ideal has become a hallmark of modern society (Bledstein, Perkin).

The medical profession of the mid-nineteenth century was very different from the profession of a century later. Yet in both periods many of the characteristics of professionalism were readily evident. The modern model of professionalism—university-based, peer-controlled, and based on merit rather than birth—is derived from the criteria we now use to study professions. Earlier forms of professionalism may have had quite a different set of characteristics; for this reason, the historical dimension of professions becomes increasingly central to an understanding of the development of medicine. The professional character of medicine has always been derived, in good part, from the institutional participation of the physician. These social and legal institutions provide credibility for medicine as a profession (Hall).

Despite the centrality of the professions in the United States, scholars have only recently begun to trace their history (Brown; Calhoun; Haber; Hatch; Kett; Kimball). With a few exceptions, such as Daniel H. Calhoun, historians have not deemed it necessary to engage in comparative histories of the professions, leaving this to sociologists (Abbott; Berlant; Freidson, 1970; Larson; Mechanic, 1968; Rothstein). Although Eliot Freidson has claimed that the status of scholarship in the professions is in a "state of intellectual shambles" (Freidson, 1984, p. 5), the historian Thomas Haskell has noted that "there is really no longer any excuse for scholars working on the professions to be divided into two shops, one made up of people who try to explain what professions are, without ever grasping how they came into being; the other composed of people who try to understand how they came into existence, without being quite sure what they are" (Haskell). For medical historians, generally, as John Burnham has pointed out, it was not until after World War II that the subject of the professions moved to the center stage of history.

Andrew Abbott's review of the sociological literature of the professions is a concise summary of how modern societies have institutionalized expertise as professionalism. He describes the professionalizing process in terms of a series of jurisdictional disputes. These disputes over the professional boundaries of medicine in the nineteenth and twentieth centuries do explain much of medicine's history (Abbott). Samuel Bloom's history of the field of medical sociology traces its institutional formation.

During the last few decades of the twentieth century, when social historians began to depict medicine as oppressive and more interested in social control than in social melioration, medicine began to be subjected to much closer analysis of its professional attitudes, values, and styles. Medicine as a twentieth-century profession could not always get what it wanted, but until the mid-1960s and the passage of Medicare and Medicaid legislation, it had great success in resisting what it did not want. As the twentieth century drew to a close, this negative power had begun to diminish with increasing speed.

Medicine as a Profession in Antiquity

Much of what we have come to believe about ancient medicine we have inherited from the views of nineteenth-century scholars, who tended to create a picture of ancient medicine that reflected their own contemporary institutions (Nutton).

In early Greek antiquity, Homer portrayed doctors among the fighting heroes: "A doctor," he wrote, "is worth many men put together …" (Nutton, p. 15). Plato, in his *Laws,* described doctors and doctors's assistants, who were also called doctors: "These, whether they be free-born or slaves, acquire their art under the direction of their masters, by observation and practice and not by the study of nature—which is the way in which the free-born doctors have learned the art themselves and in which they instruct their own disciples" (Plato, p. 307–309). The Hippocratic physician was a craftsman, and despite the high status of some of the crafts, there were in ancient Greece as yet none of the restrictive practices of the guilds of later centuries (Edelstein; Temkin, 1953). Only in one of the Hippocratic works, the *Oath,* was there a clear description of a closed, family-like guild that restricted entry to outsiders. But this does not represent Hippocratic medicine as a whole (Edelstein). Since ancient times it has been true that there have been several classes of doctors, and patients have always received care depending upon their own station in life and that of their doctor. Recent new scholarship about the Hippocratic Oath reaffirms its historical importance but also stresses its complexity. It should not simply be ascribed to the followers of Pythagoras, as Temkin, in 2002, and Dale C. Smith have noted.

The Alexandrian Library was one of the earliest institutional influences on medicine. It was here, according to the second-century physician/scholar Galen, that the writings of Hippocrates and the Coan school in which he taught were first assembled (Nutton). The ancient Greek physician did not receive a scholarly or systematic training; such was left to those who became philosophers and rhetoricians. Galen claimed that the best physician is also a philosopher. This implied that medicine could be understood only in terms of natural philosophy—biology, chemistry, and physics. Such a lofty sentiment implied that medicine was for the benefit of the whole community rather than for the private gain of the physician. This was the ideal toward which medicine should strive, according to Galen. It is a professional ideal we still recognize (Horstmanshoff).

The Medieval Medical Profession

In the later Middle Ages, with the development of cities, the rise of commerce, and the creation of universities, doctors found an expanding market for their services. These developments, in turn, led to the development of medical faculties in the universities, the passage of laws that defined the minimum education required for the physician, and a more rigorous definition of medical competence. Thus the trappings of professionalism and professional organizations became more evident after 1050. Debates began about what were the appropriate standards for a license to practice medicine, and who was to define the criteria and to enforce them. In the thirteenth century, the battle over training and licensing was between the new universities and their faculties of medicine, and the trade companies or guilds. University-educated physicians formed a professional elite. Guilds became the formal licensing bodies in some of the Italian cities, but generalization is difficult (Park, 1992).

In Florence, the medical profession can be traced to the medieval guilds, such as the Guild of Doctors, Apothecaries, and Grocers, established in 1293. It was a protective association and asserted monopoly privileges. Medicine was considered one of the prestigious occupations, along with law, banking, commerce, and notary practice. What really elevated some of the practitioners of medicine, and hence the whole profession, was that they taught and wrote. These activities, not just medical practice itself, elevated medicine from a mechanical to a liberal occupation and from an art to a science (Park, 1985). Medicine's place in the universities assured it an important and enduring role in the intellectual life of modern society.

Since the medieval period, universities have been the key to the professionalization of medicine, although in some countries, such as Great Britain and the United States, there were periods when medical schools were quite separate from the university. In antiquity the institutions that we associate with professionalization of medicine did not yet exist, though there were certainly groups of healers who were united by rudimentary professional bonds. In the Middle Ages, medicine became a more distinct, high-status, and terminal occupation (Bullough).

In the Middle Ages, then, medicine as a healing activity became distinguishable from medicine as a branch of higher learning. In the twelfth century, King Roger II of Sicily and his grandson, Frederick II, instituted licensing examinations by the masters of the School of Salerno. The objectives were to ensure competence and honesty to protect both society's and the profession's interests. There was as yet, however, neither uniform licensing nor a uniform medical profession in medieval and early Renaissance Europe (Siraisi).

Guild controls and restrictions were justified in the fifteenth century, as they would be in the twentieth, by members who claimed they needed to maintain high standards of competence and proper professional behavior. With an increasing service sector of the economy and an increase of prestige once it became a university faculty, medicine gained in stature (Cipolla).

The Medical Professions in Early Modern Europe

In late-fifteenth- and early-sixteenth-century England, there was little order in the practice or regulation of medicine. In 1511 Henry VIII introduced some governmental control. Although the parliamentary legislation he secured created no organized group of physicians, it brought a measure of state control over medical practice and made way for the conferral of substantial powers on medical groups. It stipulated that no one could practice physic or surgery in London or seven miles around without a license from the Bishop of London or the Dean of Saint Paul's Cathedral, and it required an examination of all candidates for licensure before a panel of experts selected by those officials.

The three main corporations or guilds of medical practitioners in early modern England were the Physicians, the Surgeons, and the Apothecaries. While they did represent a fairly distinct division of labor, their separation, particularly in the countryside, was not as rigid as often portrayed; in the early-sixteenth century there was as yet little order and no real regulation of practitioners. Margaret Pelling has argued cogently for the importance of the guild tradition in the history of medicine's professionalization in sixteenth- and seventeenth-century Great Britain. Earlier historiography of medicine often depicted professionalization as a continuous process, ultimately ending in the triumphal terms of the profession as we know it today. The strength of the social history of medicine, as that history is understood in the early-twenty-first century is to reveal the many complexities of and byways to what was earlier assumed to be a much straighter path to modernity (Pelling, 1987, 1998; Pelling and Webster).

In 1518, the humanist-physician Thomas Linacre (1460–1524) and five other physicians with university educations prevailed upon Henry VIII to grant them a charter for a Royal College of Physicians. Their resultant monopoly, however, extended only to London and its environs. The United Company of Barber Surgeons (made up of apprentice-trained barber-surgeons who carried out simple operations such as bleeding) received its charter in 1540, and the Guild of Apothecaries was granted a separation from the Company of Grocers (a rival guild) in 1617. Not until 1745 did George II grant the surgeons separate status from the barbers (Cook).

This tripartite division of British medicine is well known, but it should not be viewed as a simple or a unified system. In the rural areas, the surgeon-apothecary came to act as a general practitioner, and by 1809 was so acknowledged by name (Loudon). The physicians, who were at the top of the social scale of the medical practitioners, considered themselves gentlemen, had taken a classical university degree, received honoraria rather than fees, and made diagnoses, prescribed appropriate remedies, and made prognostic declarations for their patients. It was up to the apothecaries to give the remedies at the direction of the physicians. To the surgeons were left the tasks of bleeding, pulling teeth, setting fractures, and performing the few operations, such as amputations, that were carried out in this pre-anesthesia and pre-antiseptic age. For most of the population the medical tasks were often combined, as noted, or they were carried out by other healers such as midwives or a variety of traditional practitioners, some of whom were outright quacks (Christianson, Parry and Parry).

By the end of the seventeenth century, the apothecaries were intruding into the domain of the physicians so often that the College of Physicians brought suit against an apothecary by the name of James Rose, charging him with the practice of medicine for which he was not licensed. In 1703, hearing the case on appeal, the House of Lords ruled that the apothecaries could charge for medical advice as well as for the drugs supplied to the patient. This landmark case legalized the function of the apothecaries as ordinary practitioners of medicine in London. They were already enjoying these rights by custom in the countryside. Adam Smith, in his *The Wealth of Nations* (1776), recognized the apothecaries as the physicians of the poor (Hamilton; Holloway, 1966a, 1966b).

In France, a medical profession also existed prior to the period of industrialization. The profession that appeared abruptly at the time of the revolution in France at the end of the eighteenth century replaced one that had existed in somewhat different form (Gelfand, 1981, 1984; Ramsey). It was especially the professional character of the surgeons that changed abruptly in the 1790s. Earlier in the century, the surgeons already had a legal status, received their initial training as apprentices, and had a versatile medical practice including medicine and pharmacy as well as surgery, but still had a relatively equal social relationship with their patients. Thus the French surgeons—the ordinary practitioners, as Toby Gelfand described them—were more socially inclusive than would be the case in the twentieth century. With the breakdown of elitist distinctions, the post-revolutionary profession in which surgery and medicine were now united was generally even less elitist and exclusive than the earlier French physicians had been. However, in the course of the nineteenth century, elitism appeared in French medicine as it did in the professions in other countries. The new elitism was increasingly based on merit rather than on status, on accomplishment rather than on birth. Much of the history of medical professionalism is included in the history of medical education, but until recently we had had little comparative work. In 1995, Bonner filled this gap for Western Europe and North America for the two centuries after 1750.

The Medical Professions in Early U.S. History

American professionalism originated in the traditions and practices of seventeenth- and eighteenth-century England. Although any occupation might be termed *a profession,* the recognized learned or liberal professions continued to be law, medicine, and divinity. These required a collegiate education; exposure to the classics and the liberal arts curriculum provided the breadth of mind and personal character necessary for a gentleman. As a gentleman, the physician had a professional duty to play a role in all community affairs.

The North American colonies did not offer an attractive field for professional physicians until well into the eighteenth century. Unlike England, the North American colonies provided few examples of organizational development in medicine. The colonial environment required that practitioners assume all functions of the healing art and eliminated a form of rivalry that had brought about organization in England, where some medical groups had united to prevent the encroachments of others. Frontier conditions usually isolated physicians and discouraged organizational growth. The shortage of the ideal gentleman-physician in the colonies broke the traditional distinctions and divisions of medical labor. Thus, prior to the early 1700s, in the first century of colonial history, there were few doctors, no medical institutions, and little focus on medicine as a profession. Some healers were mainly working as midwives; others were ministers, whose professional identity was with religion, not medicine (Benes and Benes, Watson).

After 1700, as some historians have noted, there was a deterioration of the public's health as measured by a variety of vital statistics. This produced some increased demand for higher levels of medical skills. Besides the needs presented by the changing diseases and diminishing life expectancy, there were also great strains in the occupational structure. Fathers had typically passed to their sons their pulpits and their land. When population increased and there were neither enough pulpits nor sufficient land, the sons began to seek alternatives. Since many ministers also practiced medicine, it was natural that some of their sons turned to medicine as a career (Hall).

After 1750, some of the professional aspects of medicine became more visible, especially in the northern colonies. Young physicians with English and Scottish educations and degrees now began to want the institutional trappings for their profession. With the aid of Benjamin Franklin, the Pennsylvania Hospital was founded in Philadelphia in 1751. Modeled on the British voluntary hospitals, it was intended mainly to care for the sick poor and to provide medical teaching for young men who wished to become doctors. In the 1760s, the first medical schools appeared in Philadelphia and New York. The first colonial medical society was founded in New Jersey in 1766, and an early licensing law was passed in New York City in 1760. By the turn of the nineteenth century, a rudimentary medical profession existed, though it was responsive to local forces and conditions and had no national unity as yet. In many areas midwives continued to supply medical services to families and still routinely assisted at most births (Ulrich).

Although some medical leaders, such as John Morgan of Philadelphia, hoped to establish the British distinctions of physician, surgeon, and apothecary on the American side of the Atlantic, neither the social climate nor the political realities allowed it. As Richard H. Shryock has noted, it was not that the British distinctions were simply rejected in the more egalitarian ethos of the colonies. In fact, very few physicians had emigrated and there was no way to educate sufficient numbers in the colonies. The surgeon-apothecary or general physician simply assumed the title of doctor in the colonial setting. Like the merchants in North America, physicians, in the absence of a nobility, became part of the upper class (Shryock, 1960).

Licensing (and thus a rudimentary form of professional control) began to appear in the late eighteenth century, however these laws were not yet a means to restrict the practice of medicine as distinctly as they later would be. Licensing in the early nineteenth century merely gave those who were deemed legal physicians the right to sue for their fees. It did not as yet give the doctors any control over the medical marketplace. As a form of public recognition, licenses were uncontroversial; but as an attempt to be restrictive, they quickly became a source of sharply divided opinions. Some physicians, such as John Bard (1716–1799) and his son Samuel (1742–1821) in New York, favored restricting the practice of medicine. Others, such as Benjamin Rush (1745–1813) in Philadelphia, believed in "every man his own physician." Rush claimed medicine was sufficiently simple that anyone could learn to practice it.

Medical Practice in the Mid-Nineteenth-Century United States

During the mid-1800s in the United States, medicine was by no means a unitary profession. Its increasing professionalization was accomplished and stimulated by a similar process in science generally (Daniels). In both fields, compensation slowly increased. A wide variety of healers gave their allegiance to one or another medical philosophy, such as the Homeopaths and Eclectics, or followed the therapeutic doctrines of quite rigid systems, such as the Thomsonians or the water-cure doctors. Even among the so-called regular physicians, there was a wide diversity of education, medical belief, and medical practice (Kett, Rothstein).

In the three decades prior to the Civil War, the Jacksonian period, popular democracy had profound effects on the professions. Most states and localities repealed licensing laws for medicine, and what determination of professional competence there had been was transferred from the profession to the people. Contrary to the course of regulation in England, where the Apothecaries Act of 1815 and the Medical Registration Act of 1858 brought some order and governmental control to medicine, the North American states were abandoning regulatory efforts (Holloway, 1966a, 1966b; Shryock, 1967).

Between 1830 and 1850, the number of medical schools in the United States nearly doubled, from twenty-two to forty-two. The rising number of *regular* graduates produced by these largely profit-seeking, faculty-owned institutions competed with established practitioners, while the new schools lowered requirements to compete for students.

The physicians who established the American Medical Association (AMA) in 1847 had as their avowed goal the improvement of medical education (Davis). In drafting unrealistic requirements for admission to medical schools, however, they became vulnerable to charges that they sought merely to preserve the apprenticeship system and destroy most medical schools. By 1860, however, graduates of the many new medical schools founded in the nineteenth century outnumbered the so-called *irregular* doctors by a ratio of ten to one (Kett). Since the regular physicians as yet had no real claim to controlling medical activities, their professional strategy in these middle decades may be seen in the attempts to raise the standards of medical education by raising entrance and graduation requirements. Such strategy, while only partially successful before the ideology of science was added to the banner of reform at the end of the century, was aimed at reducing or at least controlling the number of doctors being produced.

The AMA, facing apathy among many regular physicians and hostility from sectarian groups, could do little to reduce physician supply or improve the quality of medical practice (Rothstein). Nor could the association move effectively to enforce its own version of professional ethics. It adopted substantially the principles of Thomas Percival's *Medical Ethics* (1803), which deals with topics such as the duties of physicians and surgeons and their "moral rules of conduct." Robert Baker and his colleagues have told the story of the origins, evolution, and fate of the 1847 AMA code, and have included the code itself and supporting documents in their useful book.

At the time of the Centennial celebrations in 1876, John Shaw Billings characterized three classes of physicians among the predominant or regular members of the medical profession. There were a few among them, he noted, who loved "science for its own sake, whose chief pleasure is in original investigations, and to whom the practice of their profession is mainly, or only, of interest as furnishing material for observation and comparisons. Such men are to be found for the most part only in large cities where libraries, hospitals, and laboratories are available for their needs.…" A much larger group of physicians, Billings claimed, was mainly interested in "money, or rather the social position, pleasures, and power, which money only can bestow." These doctors are well-educated because "it pays," according to Billings. But the great majority of physicians, Billings concluded, were not well-educated, having memorized only enough of the medical textbooks as was needed to gain a diploma (Billings, p. 479).

It was difficult enough for male physicians to achieve professional status in the United States during the nineteenth century, but for women it was even harder. Elizabeth Blackwell (1821–1910), the first woman to receive a medical degree from a regular American school, in 1849, thereafter wrote frequently on the important role women could play in bringing to medicine greater professional status (Blackwell). The admission of women to medical schools varied from region to region, but with only occasional exceptions it was less than 10 percent of the total. Not until the late-twentieth century did the proportion increase markedly, reaching 30 to 40 percent by 1990.

Like their male counterparts, women physicians also founded their own medical institutions, including hospitals, medical schools, and societies (Morantz-Sanchez). After 1876 there was token representation of women in the AMA; full membership was not granted until the early-twentieth century. The American Medical Women's Association was founded in 1915, but by then most of the women's medical colleges had closed or merged with predominantly male schools. In 1910, at the time of Abraham Flexner's report on U.S. and Canadian schools of medicine, only three of the seventeen women's medical schools still existed, and only half of all the 155 North American schools admitted women for the study of medicine. While virtually all accepted women by the middle of the twentieth century, as late as 1959, twenty-eight schools still explicitly said they preferred men (Walsh, 1992; Bonner, 1992; More).

Blacks who wished to study medicine had an even harder time. Todd Savitt has described ten black medical schools existing in 1900 (Savitt). A decade later only three survived. The AMA refused to accept black physicians for membership until the 1940s, so the National Medical Association, founded in 1895, served to promote the professional concerns of black physicians (Cobb, Morais).

Professionalization of Medicine in the Early Twentieth Century

Robert Wiebe and other historians have seen the increasing professionalization of medicine around the turn of the twentieth century as a key element in the emergence of a growing and more influential middle class in American society (Wiebe). The expanding middle class both increased the demand for professional services and also provided recruits for the professional ranks (Johnson). It also provided students for the growing universities and readily embraced science as the key to future progress of medicine. Science came to be the cornerstone of the reforms in medical education (Ludmerer, Rosenkrantz).

The reforms in medical education that occurred in the early years of the twentieth century were funded and spurred on by philanthropic foundations such as those established by industrialist and philanthropist Andrew Carnegie (1835–1919) and the Rockefeller family, but also came from within the profession itself. In 1900 only 8,000 of the country's 120,000 physicians belonged to the AMA. With reorganization based on a federation of the state and local medical societies, membership grew to over 70,000 by 1910, about 60 percent of all physicians.

The *new medicine* of the 1890s included a physiology heavily influenced by chemistry and physics. This new physiology in turn stimulated departures in experimental pharmacology as well as scientific hygiene. More medical schools, following the lead of a few such as Harvard and the University of Pennsylvania, became integral parts of universities—not merely in name, but in financing, administration, and educational philosophy as well. Schools of medicine began to assume what they called a university point of view, according to which research was an opportunity and a *natural* activity for all instructors (Weed).

In contrast to the medical professionalism of the early nineteenth century, which Thomas Bender has called a *civic* professionalism, the professionalism associated with the new medicine was based firmly on disciplinary loyalties. The values of late-nineteenth- and early-twentieth-century medicine were drawn increasingly from science and, by the middle of the twentieth century, from the medical specialties and their societies and journals rather than from localities or universities.

Science and research provided the main rationale for a firmer link between medicine and the university. For the would-be reformers of early-twentieth-century medical education, such as Henry Pritchett of the Carnegie Foundation, William H. Welch of Johns Hopkins, and Abraham Flexner, the future of medicine depended upon such a relationship. Flexner's 1910 survey, sponsored by the Carnegie Foundation and assisted by the AMA's Council on Medical Education, included visits to all 155 North American schools of medicine and osteopathy. The resulting report, a classic of the muckraking tradition of the Progressive period, is a landmark in the history of medical education. Now best viewed as a catalyst for continuing change rather than as a source for new or revolutionary ideas, the Flexner Report was a clear statement of the importance of science for medicine (Hudson). For Flexner, the data derived from the patient in the clinic or at the bedside was as scientific as that discovered in the laboratory.

The sciences basic to medicine—chemistry, physics, and biology—provided the foundation students needed to study and to understand the preclinical sciences such as anatomy, physiology, microbiology, pharmacology, and biochemistry. And from the advancing knowledge about health and disease derived from these preclinical sciences, the practice of medicine was to be placed on a firm scientific basis. Science—and therefore science-based medicine—was best taught and learned in the university setting.

In the decades after 1910, the Rockefeller philanthropies and other foundations provided millions of dollars to build up academic medicine in many universities. Teaching and research became full-time professional duties for an increasing number of faculty.

Flexner's report documented the inadequacies of many schools and accelerated the closing or merging of some of them. The number of schools fell from a high of 166 in 1904 to a low of 76 in 1929; it began only slowly to rise again in the following decades, reaching 127 in the early 1980s.

By the 1930s, with several newly discovered specific remedies available for diseases such as diabetes, pernicious anemia, and after 1937, for pneumonia, medicine was once again viewed by the public as a true profession, a special calling. But despite continuing discoveries of new therapies and spectacular new technologies for viewing the body and how it works, by the mid-1980s observers of the American medical scene were saying that "the profession is increasingly being seen as more nearly a commercial enterprise with vested economic interests than a calling of professionals whose foremost concern is the well-being of the patient" (Iglehart, p. 324). This profound shift in the public perception of medicine was accompanied by the increasing number of liability suits and the corporatization of medical care (Starr). The coming of the corporation doubtless has been both a positive as well as negative organizational force. A business view has become dominant in hospitals and medical schools, as well as in the private practice of medicine.

Medicine has never been a homogeneous profession. It is perhaps even more disparate at the beginning of the twenty-first century than it has ever been. Until the 1960s, most doctors in the United States ran their practices like independent small businesses. In the corporate world of the late-twentieth century, by contrast, bureaucracy came to define medical practice better than autonomy. Legal challenges to the status of the profession have also questioned whether medicine and the law have acted to restrain trade, as in the 1975 U.S. Supreme Court decision *Goldfarb v. Virginia State Bar* (Rodwin, Sheehan). In that case a young lawyer brought suit against his own profession because he found that no lawyer would perform a title search for a house he was negotiating to buy for anything less than one percent of the purchase price. This commonly fixed price, he argued, violated the Sherman Antitrust Act. The case became a landmark for application of the antitrust laws to all the professions.

Medical professionalism in the context of American culture has always been faced with two apparently conflicting ideals that have shaped its history. Professions, by their very nature exclusionary, have been forced to grow and to prosper in a society that has prized egalitarianism. Equal opportunity has been a basis for American society since colonial days, yet increasingly the medical profession has drawn its recruits from the more privileged strata of U.S. society.

Also, still characteristic of late-twentieth-century medical practice, the patient is often not in a position to judge the quality, the necessity, or the extent of the services provided by the physician. This has remained true despite much more consumer (patient) involvement in medical decision making since the 1960s. As is true for the notion of egalitarianism in society, this continuing separation of esoteric medical knowledge from that which is commonly held provides potential ethical dilemmas for doctors.

A continuing paradox has prevailed in medicine of the late-twentieth century. The more effective medical services have become, the greater has been the demand for them. At the same time they have become increasingly expensive and so more difficult to obtain by many, and nearly inaccessible to those with no insurance coverage. Thus two conflicting concepts of medical care that have always existed in American medicine continue: medicine as a public service and as a private enterprise (Brieger).

Organized medicine in current usage usually refers to the dominant professional societies that have worked in both the professional and the political realms to help doctors achieve or preserve desired ends such as social status, economic rewards, or professional authority. Since one of the hallmarks of a profession is its organizations, the term organized medicine is redundant, albeit commonly used. We have come to assume considerable political power on the part of organizations such as the AMA, the Association of American Medical Colleges, the American College of Physicians, and the American College of Surgeons. While their positive power may have waned somewhat in recent decades as consumer interests have become much stronger, medical organizations until the 1960s were very effective in preventing measures they did not believe were in their best interest from becoming public policy or law (Burrow, 1963, 1977).

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SEE ALSO: *Medical Codes and Oaths; Medicine, Anthropology of; Medicine, Philosophy of; Medicine, Sociology of; Nursing as a Profession; Professional-Patient Relationship*

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MEDICINE, SOCIOLOGY OF

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The sociology of medicine is characterized by a wide variety of concerns, approaches, and perspectives (Mechanic, 1978; Freeman and Levine; Fox; Waitzkin, 1991). The concerns of medical sociologists cover such diverse areas as the distribution and etiology of disease and impairments; disease concepts and their social construction; cultural and social responses to health and illness and the use of services; health and illness behavior and its determinants; sociocultural aspects of medical care and the social organization of helping services; the organization of the health occupations and the processes of providing care; social factors affecting trends in death and illness; the sociology of the health occupations; the social organization of the hospital; and comparative health organization. In collaboration with other disciplines, the field includes the study of social change and healthcare; changing technology and its role in care; medical education; public-health organization; stress, disease, and coping; social and community psychiatry; the social context of legal and ethical dilemmas; and medical politics.

Many medical sociologists attempt to illuminate how individuals define and respond to situations as they cope with the expectations and demands of their physical and social environment, how some types of response lead to stress and illness, and how services are used to reestablish social and personal equilibrium. Helping institutions can be examined similarly in terms of how the behavior of health personnel and organizations responds to problems of resources, time, and other situational constraints. All people, whether patients or health personnel, seek to establish mastery over their life and work environments, to reduce uncertainty, and to obtain gratification and esteem for their efforts.

One important aspect of medical sociology concerns how certain problems become manifest in a population, how they are defined, and how patients with these problems enter particular channels of care. The field also deals with the nature of therapeutic encounters between patients and practitioners, modes of communication and influence, types of discourse, and how all these are influenced by the cultural context, social characteristics of patient and therapist, changing knowledge and technology, organizational and payment arrangements, and resource constraints.

From a sociological perspective, medicine can be regarded as a sustaining or integrative institution in society (Parsons). Not only does it provide assistance to persons afflicted with disease and other life problems; it also serves as an important means for alleviating social distress and for excusing failures in social functioning or failures to meet social expectations (Mechanic, 1978; Kleinman, 1986). Medicine also has important social control functions that facilitate the removal of individuals from social settings to relieve tensions—whether in the family, in work settings, or in the community at large. It may also facilitate financial compensation or social benefits, for example, access to services or products, such as drugs, that are restricted to those who are not deemed ill.

The role of the physician, then, has not only technical dimensions but also social and moral ones. While the technical expertise of practitioners refers to a limited range of situations, their clientele and the scope of problems they deal with are very broad. Many of the judgments a physician makes are not medical judgments but decisions based on social considerations and values. Even those aspects of the medical role that appear to be purely technical, such as the labeling of disease, the specific management of the patient, and the choice of medications or other treatments, have profound consequences for performance of social roles and obligations as well as for future life opportunities. Patients' problems often result in part from conflicts with other persons and social groups, and the physician can sometimes help resolve difficulties by taking either the patient's or an adversary's perspective. Such conflicts are particularly evident in such areas as military, industrial, and prison medicine, where the physician is not the patient's personal agent, but they occur to some extent in many private patient-care contexts as well.

Patient flow from a community population to various helping agencies is usually thought to result almost exclusively from the occurrence of illness in that population, in contrast with other factors. Indeed, other factors distorting the selection process, such as differential propensities to seek care, are seen as *disturbances* that require correction through patient education or such economic disincentives as deductibles and coinsurance. Although illness is usually the major determinant of help-seeking, it fails to explain by itself much of the evident variation between those who seek and those who do not seek assistance (Mechanic, 1978).

It is common, for example, for medical scientists to assert that discovering a cure for an illness such as the common cold, one of the most frequent reasons for consulting a physician, would profoundly alleviate physical limitations, industrial absenteeism, and the loss of productive labor. But to the extent that the common cold is often an excuse rather than the reason for work absenteeism or seeking medical care, a *cure* might have much less social effect than commonly believed. If people who seek care for the common cold do so because they are unhappy or hate their employment, then the visit to the doctor may be little more than a justification for more complex motivations and behavior. There are various social and cultural inhibitions against persons openly acknowledging personal life problems, and often such problems are shielded by presentations of seemingly trivial illness. This process is now commonly referred to as somatization (Kleinman, 1986).

Medicine involves a distinctive set of meanings that limit the interpretations of patients' concerns (Waitzkin, 1991). Such meanings may obscure social problems and dilemmas and their causes, narrowing the range of possible remedies. This *medicalization* subsumes important social and ethical issues within clinical judgments that escape careful scrutiny. The differential diagnostic approach, which structures how doctors are educated and how they address problems, affects the ability of doctors and patients to explore comprehensively the sources of distress and disease as well as their implications for well-being (Waitzkin, 1983, 1991; Kleinman, 1986).

Social Distribution of Health, Illness, and Medical Care

Although the concept of health is difficult to define, numerous studies demonstrate that longevity, absence of impairment, and less illness and disability are associated with favorable socioeconomic conditions (Mechanic, 1989b). Many of the health problems of the poor stem from unfavorable environmental conditions, poor nutrition, and lifestyles harmful to health. Because persons of lower socioeconomic circumstances are less likely to receive high-quality services—whether because of limited income, less readiness to seek necessary care, or inaccessibility of facilities—they are more likely to suffer from disabilities, higher mortality, and secondary conditions (Bunker et al., 1989).

Secondary conditions, such as decubitus ulcers, cardiopulmonary problems, and psychological depression, are often causally related to an initial illness and occur because the primary condition is poorly managed (Institute of Medicine). Since 1965 social programs in the United States have given some attention to the equity in the provision of medical services, and the historic inverse relationship between socioeconomic status and use of physician services has been reversed. But socioeconomic differences continue to persist for many specialized services and for preventive care. Although mental disorders are very prevalent in the lowest socioeconomic groups (Robins and Regier), psychological and social services are particularly inadequate for the poor.

The poor suffer from other problems in the medical care sector. They are least likely to share assumptions and meanings with health practitioners, and thus most likely to suffer from misunderstandings and confusions resulting from such incompatibilities. They are likely to feel more embarrassed, anxious, and intimidated in dealing with medical personnel, and are less likely to receive care congruent with their values or life perspectives. They are frequently used as subjects for teaching and research, particularly in experiments that bring no particular benefits to the patient (Barber et al.); and they are more likely to have difficulty granting informed consent, particularly where explanations are quick and perfunctory (Gray). The poor not only have more illness and problems and less access to medical care relative to need but also are treated with less consideration and respect than affluent patients.

Above and beyond socioeconomic status differences, race and ethnic differences account for variations in health. Although much of the excess in mortality and morbidity among blacks and Hispanics is attributable to socioeconomic disadvantage, other factors associated with race and ethnicity are pertinent, including differences in culture and health-relevant behavior, discrimination, and biological differences.

Still other aspects of social stratification, including age and gender, are important determinants of health status. Age and gender affect exposure to risk and disease occurrence through both biological and social pathways linked to these characteristics. The prevalence of chronic disease and disability increases with age but is influenced as well by the individual's social participation and social networks, sense of personal efficacy, and subjective well-being, which vary over the life cycle.

Large differences in health indicators and health behavior are also found between men and women. The fact that women live longer than men is in part biological, but it is also substantially affected by different styles of behavior and response among men and women. Most of the higher mortality in men can be attributed to behaviors such as substance abuse, poor nutrition, risk-taking, and violence. Many other social factors, such as marital status and household structure, are associated with patterns of health and disease (Mechanic, 1978).

Organization of Medical Care

If medicine has social and ethical as well as technical dimensions, how do we develop organizational settings that can apply the necessary technical expertise in ways that respond to the patients and their unique individual and social needs? Even the very best hospitals and medical organizations often treat patients without empathy or respect, and show limited interest in managing their medical problems in light of their family, work, and community circumstances (Duff and Hollingshead; Kleinman, 1988). The personnel who carry out these institutions' medical functions behave as they do, not because they are inhumane, but because the pressures and constraints of work, the priorities they have been taught, and the reward structures of which they are a part direct their attention to other goals and needs. Successful modification of service institutions requires significant revisions in the organizational arrangements and incentives that affect the work of personnel and the tasks they perform. In a materialistic culture where persons may respond to money and prestige incentives more readily than to more lofty motivations, the design of economic and prestige incentives and an awareness of how they affect decisions become important elements in shaping behavior.

Some attention has been devoted to how the economic structure of medicine affects the work of physicians and other personnel. Fee-for-service incentives often result in high levels of professional commitment, a willingness to work hard, and responsiveness to those who pay the fees. They also often encourage excessive use of medical, surgical, and pharmaceutical modalities to earn more income. Data from a variety of nations suggest that when attempts are made to manipulate the system by increasing payments associated with certain procedures, these incentives shape what physicians do (Glaser). The difficulty with any such piecework system is that it tends to discourage procedures that are important but for which only modest or no remuneration is provided. Since payment systems typically reward technical procedures, the most neglected aspects are those concerned with social care, listening to the client, patient education, and grappling with ethical issues. Physicians are best rewarded financially when they provide the largest number of discrete technical services.

One antidote to the perversities of piecework medicine is to pay by salary or capitation (a uniform payment for each person the physician cares for), but these approaches also have disadvantages. Under such systems physicians are more likely to limit their work efforts, appear less committed to their work, and seem less flexible and responsive to the individual needs and circumstances of their patients (Mechanic, 1989a). Thus, the same incentive conditions that make it possible for physicians to allocate their time within their own concepts of the value of varying types of caring and curing—conditions that may dampen a tendency to overutilize expensive and perhaps dangerous therapies—may also encourage withholding necessary services or result in an unwillingness to respond to important concerns of patients.

Doctors paid by capitation seem to adjust their efforts in relation to the payments they receive, a form of perceived distributive justice. This concept is shaped by knowledge of the circumstances of other doctors with comparable training in different work settings. Many of the difficulties in capitation payment result because patient load is heavy and payment is small for each patient. The heavy patient load and the doctor's limited work hours encourage a pattern of care that many patients find unresponsive. But time and patient demand are not the only factors involved in the way physicians deal with social and ethical problems in their practice. Physicians may have more or less tolerance for a wide scope of work; may be more or less willing, and feel more or less competent, to deal with family problems, alcoholism, sexual adjustment, or child-care problems. To the extent that physicians are properly trained to deal with the broader problems of medical care, and thus feel more competent in their clinical management, they may be more willing to deal openly with social and ethical challenges. Many physicians probably avoid dealing with psychosocial issues because they feel an effective therapy is lacking; however, they often readily accept the responsibilities to treat physical illnesses for which they also lack effective treatment. It may be that a sense of confidence and clinical experience are more important than the objective efficacy of the care.

In the creation of new medical settings, the problem is how to maximize the advantages of both fee-for-service and capitation medicine while compensating for their more undesirable aspects. People are ingenious in undermining and thwarting incentive systems that are not sensitive to their work problems, that increase their uncertainties, or that appear inequitable. To design an organizational system adequately requires intimate appreciation of how individuals actually manage their work, rather than utopian but unrealistic conceptions of how people should function.

Sociology of the Health Occupations

The attention in this article to doctors, in contrast with nurses, technicians, pharmacists, or social workers, is no accident. Although physicians constitute less than one-tenth of personnel in the health sector, they define and dominate the nature of decision making and the division of labor in medicine (Freidson; Starr; Mechanic, 1991). Physician dominance is in part a process in which doctors gain political legitimacy that protects them against economic competition from other health workers and helps preserve their professional autonomy. Increasingly, the physicians' dominance is being challenged by a variety of forces in the society: by administrators wishing to achieve economies of production through shifting traditional medical tasks to less trained personnel; by government wishing to control the growing costs of medical care; and by such professional groups as nurses who wish to improve their own political power, income, and status. Thus, the health sector is characterized by increasing political acrimony and collective politics (Stevens).

Ethical Dilemmas and the Sociology of Healthcare

The advances of medical knowledge and technology confront modern society with awesome social and ethical dilemmas. Among these questions is whether an ever-increasing proportion of our gross national product ought to be spent on expensive modalities that provide marginal gains in health and longevity. Are such investments not better made in preventive approaches and environmental amelioration or in other social goals?

Bioethics has been more an activity with a normative focus than a field of inquiry that seeks to investigate the implications of varying courses of action (Wikler; Fox). During the two decades in which bioethics has grown as a discipline, relatively few bioethicists have utilized sociological materials and methods, and relatively few sociologists have studied bioethics (Weisz). Ethical reflection in healthcare could be very much enhanced by a sociological perspective that examines the empirical setting and implications of a given ethical choice. Whether to accept organs from live donors or allow subjects to participate in experiments posing possible danger to themselves must depend at least to some extent on the actual psychological and social consequences of such participation. The fact that such volunteers often experience great satisfaction from their participation is no small part of such policy considerations (Fellner and Schwartz; Gray). Similarly, the willingness to expend great resources in heroic efforts to extend life, irrespective of function, must be weighed against the consequences of extended lives for such patients and their loved ones. Sociological perspectives and methodology can contribute to the ultimate ethical decisions by clarifying some of the human factors relevant to resolving the conflicts between competing social and ethical values.

DAVID MECHANIC (1995)
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SEE ALSO: *Health and Disease: Sociological Perspectives; Organ Transplants, Sociocultural Aspects of; Professional-Patient Relationship; Race and Racism*

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MENTAL HEALTH, MEANING OF MENTAL HEALTH

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Notions of *health* and *mental health* neither arose nor developed in a cultural and conceptual vacuum; their ancestral and contemporary kindred and relationships are multiple and far-reaching. Traces of their past live on in present quandaries and controversies. The interpretation and analysis that follow are historical and sociocultural, as well as philosophical and clinical.

Historical and Philosophical Background

NEAR EASTERN AND CLASSICAL CONCEPTS. Our story begins with the high civilizations of the ancient Near East. Initially, disturbances in customary and acceptable human functioning were experienced and interpreted in magico-religious and moral modes. Ancient Near Eastern personhood blended into a cosmos permeated by the divine and comprising countless interactions among fluid and loosely bounded beings and forces. Demarcations such as those between religion and medicine, psychic and somatic, material and immaterial, or spiritistic, natural, and supernatural would have been incomprehensible to early Egyptians and Mesopotamians. Even surgical and pharmaceutical interventions were accompanied by prayer, rituals, and magical formulas and paraphernalia.

Much the same can be said for the people of Mycenaean and Homeric Greece, whose worldviews and concepts of human beings were inseparable and thoroughly magical, animistic, and religio-moral. Cognition, affect, and motivation were experienced as divinely or demonically implanted, or else literally *inspired* from the ambient air. The earliest Homeric internalizations of motivation were localized to a semiautonomous region of the midriff or diaphragm called *phthumos.* As in Near Eastern antiquity, all sickness or disease, including madness, was magical (caused by spells or curses), demonic, or religious and moral (caused by divine possession, or divine punishment for ritualistic infractions, taboo-breaking, and sins of all sorts).

Health or *wellness* referred equally to states of the cosmos, society, or person. For example, the Egyptian goddess Maat personified a diffuse constellation of truth, balance, and right ordering or right acting, understood as antithetical to the primal chaos of the universe. Likewise, preclassical Greek ideas of health or wholeness were religio-moral, the corrections of imbalances. These metaphors and concepts of equilibrium, refined and codified by the classical Greeks, have remained central to modern Western medical and psychiatric norms or ideals of healthy functioning.

Classical Greece is commonly deemed the birthplace of both the psychological individual and secular medicine. Actually, however, medicine's vocational identity, cosmology, and philosophical anthropology were still imbued with religious aspects. The Greeks invoked deities such as Asklepios/Apollo; and nature itself (Physis), and humanity as part of it, remained divinized. Maladies, healing, and health were at once medical and sacred. The more medical facet of Hippocratic doctors' *health* and *disease* concepts concerned the bodily humors and their ratios to one another (balance versus excess or deficiency). Madness was explicated humorally as well, in a sort of proto-"physiological psychology" and psychopathology (Jackson); and the brain was considered the organ of mental activity.

By contrast, Plato and his philosophical successors disseminated a psyche-body dualism that influenced Western medicine for centuries. Plato characterized as "divine" physicians who were also philosophers, who thus knew soul as well as body. Nevertheless, he apparently thought such practitioners so rare that he roundly criticized doctors' practices of "dietetics"—which included what we would call counseling, lifestyle management, and prevention. In line with his dualism, Plato argued that philosophers were the rightful "physicians of the soul," thereby inaugurating a lengthy tradition of philosophical therapy. Such philosophers progressively adopted medical models and metaphors for the psyche in states of wellness and disease (*pathé*). In the first and second centuries C.E., Epictetus termed the philosopher's lecture room a "hospital"; he likened the pain necessary in spiritual and moral healing to that in medical measures such as the lancing of an abscess (see Edelstein). Centuries later, Sigmund Freud characterized analysis with surgical metaphors, and Henri Ellenberger thought psychoanalysis itself a latter-day version of philosophical healing.

The Hellenistic and Roman Stoics and Epicureans were other famous proponents of psychotherapeutic philosophy. Like all philosophical physicians, they were infatuated with metaphors of balance. The soul's health was equated with states such as *ataraxia* or *apatheia* (equilibrium, tranquility, serenity). The Stoic idealization of reason, and concomitant depreciation of passion, probably influenced subsequent rationalistic criteria for mind in health and illness. In any event, Plato and company, with their dualism and healing ambitions, paved the way for current concepts of mental health and psychotherapy. Nonetheless, their images of such health were spiritual/ethical, and their healing was dialectical and pedagogical—and, hence, a far cry from our ostensibly metaphysically and morally neutral mental health and psychotherapy; though Freud himself emphasized the educational and ethical aspects of analysis far more than any presumable medical ones (Wallace, 1986).

Aristotle, Plato's greatest pupil, avoided a frankly dualistic mind-body position and touted the philosopher's role as ethical teacher. The doctrine of the *golden mean* and prudential and moral virtues, or *character ethics,* held the place in Aristotle's philosophy that had been occupied by psychical or spiritual health in Plato's. This "golden mean," yet another manifestation of balance, was the cardinal feature of the virtues—for example, courage as the midpoint between temerity and timidity. In light of the individualistic thrust of ancient philosophical therapies such as Stoicism and Epicureanism, and of many present-day psychotherapies and notions of mental health, it is noteworthy that Aristotle considered his Ethics and Politics integral to each other. Citizenship, reflecting the individual's self-acknowledged embeddedness in a community, was central to Aristotle's idea of proper human functioning. Whereas we might accuse Aristotle of collapsing mental health into social ethics, he might have charged us with the reverse.

MEDIEVAL AND RENAISSANCE CONCEPTS. In the Christian West, institutionalized medicine was in priestly hands. The closest thing to medical schools were monastic, and most medieval infirmaries were operated by the Church. Medical theory and therapy followed the Hellenistic Galen's final codification of humoralism and anatomy. Madness was explained and treated somatically, as well as with the prayers and healing rites offered for any severe medical condition.

Somatic perspectives on madness meshed nicely with the Church's Platonic dualism, since the immortal and immaterial soul, unlike the body and brain, was not corruptible by disease. Meanwhile, the Church continued to use medical metaphors for many spiritual and moral problems. It is hard to know whether some of these approximated our nonpsychotic and less severe categories of mental illness—such as *dysthymia* or the *personality disorders*; aspects of the latter clearly falling under the traditionally moral purview. Medieval clerics themselves meditated over gray zones, such as whether acedia, a common monk's affliction, was sin (slothfulness) or disease (a mild form of melancholia) (Jackson). There was nothing corresponding to contemporary concepts of mental health. Norms and ideals were spiritual and moral, biblically and theologically derived.

Thomas Aquinas added loss of free will to irrational thinking and behavior as another cardinal sign of madness. This has influenced juridical processes up to the present, posing problems to psychiatrists espousing determinism (i.e., that all human mentation and behavior are causally necessitated). It has also borne on contemporary conceptions of mental health, some presupposing a capacity for nonnecessitated choosing (e.g., humanistic and existentialist) and others (e.g., classical psychoanalytic and neuromolecular) usually not. The ramifications for morality and ethics are obvious (Wallace, 1986).

As the great universities arose between the twelfth and the fourteenth centuries, they incorporated monastic medicine. Nonpriestly physicians returned to the scene, but medical theory and the treatment of madness remained much the same. There was no real secularization in Europe until the Renaissance, with its novel and heightened forms of individualism among certain educationally and financially favored segments of Europe's populations and its protopsychological concept *imaginatio,* a catchall for feeling, imagination, and fantasy (the very items ignored by hitherto hyperrationalistic norms of personhood).

This same period, however, witnessed the Inquisition, and its mass persecution of heretics and alleged witches. Medical men such as Johannes Weyer, with special interests in madness, argued that accused and "confessed" witches were actually insane, one of the few conditions that legally exonerated them. Still, Weyer's diagnoses were not purely medical, for he thought the witches' delusions had been implanted by Satan. Many modern historians of psychiatry have lauded Weyer for his insight and courage (e.g., Zilboorg). Some psychiatrists and psychoanalysts, including Freud, followed Weyer's example and facilely diagnosed whole institutions and cultures as psychopathological. Several decades of careful scholarship suggest that most "witches" were not in fact psychotic (e.g., Spanos). Furthermore, concepts of normality and pathology are complex, and they vary greatly from one culture or historical period to another. Moreover, transferring concepts of mental health and illness from the individual domain to the arenas of groups, cultures, and even families is questionable at best (Ackerknecht, 1971; Wallace, 1983).

SEVENTEENTH- AND EIGHTEENTH-CENTURY CONCEPTS. The seventeenth century was characterized by the continuing expansion of individualism and by a rationalism that paid less attention to aspects of personality, such as *imaginatio,* explored by the Renaissance. Irrationality became the key criterion for madness, giving the social philosopher Michel Foucault (1965) the ostensible grounds for his thesis that seventeenth-century asylums were filled with persons who had violated their era's canons of reason and socially acceptable behavior. Foucault alerted us to possible linkages between sociocultural and political-economic special interests, and psychiatric institutions, concepts, and practices—including formulations of mental health and illness.

The epoch from 1600 to 1750, then, was a watershed in many ways. Its scientific paradigms, ultrarationalism, and sociocultural-economic developments paved the way for the West's ensuing secularism and capitalism. The coming age would require and give rise to different forms of humanity, with novel notions and modes of well-being, dysfunction, and distress. Not coincidentally, it would also spawn a new medical specialty: psychiatry.

Contemporary Concepts and Issues

The mid-eighteenth century constitutes the headwaters of the stream that culminates in the modern or postmodern mental-health complex. The rise of economic capitalism, with its emphasis on free-market competition and individual acquisitiveness, went hand in hand with the progressive breakdown of traditional social-political structures and cultural institutions, along with the Christian worldview that had hitherto sustained them. New modes of personhood appeared, modes that were exquisitely self-aware and self-oriented, shunning binding institutional and interpersonal commitments, and shrewdly combining hedonism with "social adjustment."

The Enlightenment witnessed novel varieties of what we would designate as *functional* (versus *organic*) psychiatric disorders: the *vapors, nerves,* and so forth, resembling *conversion, dissociative, anxiety, dysthymic, personality-disordered,* and *neurotic* categories (American Psychiatric Association, 1987). Initially comprehended and treated somatically with *magnetism,* or hypnosis, they were gradually conceptualized psychologically. Feminist historians (e.g., Decker) interpret these experiential and behavioral configurations as disguised forms of women's rebellion against male-dominated society.

Meanwhile, in early and mid-eighteenth-century Great Britain, a new breed of physicians began devoting their practices to madness. The most brilliant of these "mad-doctors," Alexander Crichton, influenced Philippe Pinel, generally called psychiatry's father. Previously an internist, Pinel flourished in post-Revolutionary and early nineteenth-century France. Until then, madness had not been institutionally medicalized. Asylums typically fell under lay management, with doctors no more than general medical consultants. Pinel's orientation was psychological as well as medical, and he came to favor abbreviated systems of diagnostic classification. However, his successors in the powerful French clinical school, presuming the inevitable degeneration of many conditions, became progressively and pessimistically *organic.* Notions approximating mental health were far from their minds.

Contemporary German psychiatry was pursuing a semimystical and Romantic psychological path (Ellenberger). Abstruse and difficult to summarize, it conceptualized nature and humankind as manifestations of a World Spirit or Soul. Although often obscure and moralistic, it contributed some genuine psychological insights, including many on unconscious mentation and motivation. In England and the United States, despite some admixture of somatic theory and practice, early nineteenth-century psychiatry—or *alienism,* as it was called (thus underscoring its subjects' social estrangement)—was predominantly psychologically and sociotherapeutically oriented. The Anglo-American *moral treatment* movement envisioned the then relatively small country asylum as a healing family, with the medical superintendent its *father.* For much of the nineteenth century, the word *moral* still denoted an amalgam of what was later divided into *mental* or *psychological,* and *moral* or *ethical.*

As the twentieth century approached, the number and size of asylums grew geometrically; treatment became custodial, and Anglo-American and European psychiatry grew increasingly neuropathologically inclined. Its interest in diagnostic classification and the results of autopsies contributed to what Foucault (1973) called the "objectification" of the patient. The rise of organic and custodial psychiatry reflected many social and demographic changes in the United States: rapidly increasing population; greater social and geographic mobility; replacement of small and culturally homogeneous communities by urban centers swelled by immigration; the continuing disempowerment of institutional religion; movement toward monopolistic capitalism, an orientation toward productivity and consumerism; individualism and waning local charity; and generally changing social mores. Together, such factors made moral therapy unworkable and led to further transformations in popular conceptions of personhood in wellness and illness. Communities and even families transferred responsibilities for their psychiatrically disturbed members to the large central facilities.

It is likely that such facilities came to house many who were merely elderly, socially deviant but not criminal, and economically unproductive. Certain contemporaneous *diagnoses*—such as *volitional old maid, vagabond,* and *eccentric character*—would be laughable if they had not also been socially coercive. State hospitals usually fell under the autonomy of those social agencies that dealt with the socially and economically marginal and dependent (see Grob, 1973, 1983). Drawing on such historical sources, as well as on present-day events, a school of social scientists and political philosophers underlines the status quo-supporting and professionally self-serving features of psychiatry and its related disciplines, including their diagnostic schemata and notions of health and illness (e.g., Foucault, 1965, 1973; Ingleby; Horwitz). These include gender, socioeconomic class, and ethnic biases (e.g., Chesler; Russell).

The organic orientation of the second half of the nineteenth century promoted a seemingly paradoxical soul-body or mind-body dualism among Anglo-American psychiatrists. In their view, psychiatric disturbance or disease was wholly a function of body and brain; the soul or mind, being immaterial and immortal, was not susceptible to disease. Such a schema, which obviously protected their theological tenets, virtually ruled out ideas of mental health and illness, and practices such as secular psychotherapy. Nevertheless, psychotherapeutic perspectives began forming in the late nineteenth century. They emerged among outpatient neurologists who were encountering increasing percentages of functionally disordered patients, and among psychologically minded psychiatrists, who were treating ambulatory patients with milder problems. The distress and dysfunction these professionals were treating became less commonly experienced and interpreted in religious and moral terms. Such problems were therefore less amenable to healing through confession, penance, and recommitment to the Catholic ideology, institutions, and community, or to their Protestant counterparts, often including more counseling ("the cure of souls").

Twentieth Century

To serve these new varieties of troubled persons, innovative therapies arose in the latter nineteenth century and the first decade of the twentieth. These *mind-cure* or *healthy-mindedness* approaches, as William James (1902) named them, comprised purely secular healings; heterodox religious approaches such as Seventh-Day Adventism and Christian Science; Americanized variations of Eastern religions and philosophies; and various integrations of religious, medical, and psychiatric proposals. In Europe, psychoanalysis emerged, the prototype of twentieth-century secular therapies and the ultimate progenitor of most current psychological theories and treatments. Psychoanalysis and its offshoot dynamic schools would contribute significantly to the clinical and popular dissemination of concepts of mental health and mental illness.

By 1910, events were gathering momentum. The important Mental Hygiene Movement, a joint lay-psychiatric venture, had been formed in Boston in 1909 (by former mental patient Clifford Beers and Harvard psychiatrist E. E. Southard). Though it had been started to improve the plight of the severely mentally ill (formerly the *mad*), its concerns shifted swiftly toward mild-to-moderate psychiatric problems and to community mental hygiene, which led eventually to the burgeoning community mental-health movement of the 1950s, 1960s, and 1970s. This movement, like the dynamic therapies, fueled public preoccupation with mental health (Grob, 1983).

During these same decades, psychiatrists in the United States had begun moving toward acute-treatment psychiatric facilities and wards in general hospitals, the *psychopathic* units that treated less chronically severe patients—those with acute crises, neurotic symptoms, and personality problems of all sorts. Outpatient work continued to grow as well. Clinical psychology and social work started evolving as professions. General medicine's public-health and preventive wings, joined by lay *wellness* proponents, enlarged their territory, too. These developments have led many critics, such as Ivan Illich (1976), to speak of medical and psychiatric *imperialism,* the *medicalization* of society, and so forth. Indeed, as early as 1856, physicians such as Oliver Wendell Holmes contended that doctors and deterministic medicine should replace priests and religion as society's moral arbiters. The eminent medical historian Owsei Temkin (1977) charges that health has become a "summum bonum," whose values encroach on morality and ethics (e.g., the virtual criminalization of smokers). Don Browning (1987) points out the various ethical, social-valuational, and cosmological dimensions of the major psychotherapeutic approaches.

Many have commented on the normative-prescriptive aspects of the mental-health and mental-illness concepts of the multifarious psychiatric and clinical psychological vantages.

Definitions of *health* as broad as the World Health Organization's (1991) "state of complete physical, mental, and social well-being," certain epidemiologic projects (Srole et al.), and categorizations of *mental disorder* as extensive as those of the American Psychiatric Association (1987, 1994), seem to ground the accusations of Illich and others. Aspects of hitherto *normal* aging are deemed *disease* and treated as such, and similar attitudes toward features of other developmental periods could be cited. Indeed, pathology has narrowed the domain of human physiology to the point that doctors and the public alike view death itself as all but a potentially preventable disease.

In any event, though most philosophers of general medicine (e.g., Pellegrino and Thomasma; Kass) declare promoting *health* to be the physician's primary objective, few medical authors conceptualize and elaborate it very explicitly. More often it is a negative notion—the *absence* of significant disease or illness. Although conceptions of mental health in psychiatric and related practitioners' textbooks and treatises are frequently negative as well, the writers of such books are more likely to attempt *positive* conceptions than are their general medical counterparts. Daniel Offer and Melvin Sabshin (1966, 1984, 1991) list dozens of notions or definitions of mental health by theorists and therapists of many persuasions. These range from simplistic extremes such as "social adjustment" or "self-actualization," to more complex and reflective notions. Some assess mental health, like mental illness, by dimensions and degrees; others proffer categorical constructs of both. There are naturalistic-universal, psychological, sociocultural-contextual, and biopsychosocial ones. In short, the ways of classifying conceptions and criteria of mental health are potentially exhausting. Through surveying an immense range of pertinent sources, Marie Jahoda (1959, 1977) identified the six indexes of mental health that appear most frequently: (1) the individual's attitudes toward himself or herself; (2) the person's "style and degree of growth, development, or self-actualization"; (3) a central synthesizing psychological function, or "integration"; (4) "autonomy," or "independence from social influences" (the single most cited index); (5) adequacy of reality perception; and (6) mastery of the environment.

However useful they may be, these criteria can hardly claim to be purely natural or scientifically derived; they are clearly a function of time- and place-bound cultural contexts, as well as of presupposition-laden psychological orientations. It is not so much a question of whether they imply values, for no theories and concepts escape their authors' values altogether. Rather, the questions concern the kinds of values, and their relationships to one another and to those in other endeavors and institutions.

Of Jahoda's indexes, most are self-oriented, depicting the natural and social environment as something virtually inimical to personal well-being. The "healthy" are independent of its influences, mastering it to their self-actualizing ends—which, ironically, may be quite serviceable to those of the prevailing political economy. Of course, there are also formulations of "mental health" at the opposite, or socially conformist, pole; their professional exponents probably have frequently fallen into the service of dominant socioeconomic agendas. In any case, Jahoda's analysis suggests that there are other sorts of dangers associated with ideas of mental health. Such common extremes in positive conceptions of mental health make one wonder whether they should be attempted at all. The American Psychiatric Association (1987) avoids defining mental health.

Many of the profoundest students of human experience and behavior, such as Freud, have not issued definitive pronouncements on mental health. Freud's theories and observations contain many items relevant to assessing dimensions and degrees of psychic well-being and its reverse (Wallace, 1986; Vergote; Wallwork). Nevertheless, apart from hearsay attributions to him of the spare desideratum *Lieben und Arbeiten* (loving and working), Freud bequeathed us no extensive positive constructions of mental health. In fact, he stressed the continuum from neurosis to "normality." Nor did he harbor utopian ambitions for psychoanalytic therapy, firmly denying that it promised happiness or contentment. It was quite enough if treatment alleviated the analysand's more troublesome, historically determined psychic and interpersonal conflicts, misapprehensions of self and others, and modes of gratifying and inhibiting hitherto repressed or symptomatically expressed desires and strivings. Such imperfect but significant transformations enhance the patient's grasp of his or her particular life's realistic problems and possibilities. Freud had no notions akin to Abraham Maslow's and Carl Rogers's of the easy and automatic harmonization between "self-actualization" and the requirements for a humane and civilized society. His concept of adaptation, hardly collapsible into Darwin's, implied neither mastery of nor submission to the sociocultural and political-economic surround, but rather a prudent and moral interweaving of "autoplastic" (self-transformative) and "alloplastic" (environmentally altering) activities (see Hartmann; Wallace, 1986; Vergote; Wallwork).

Although Freud was capable of psychoanalytically masked moral and metaphysical judgments, such as those about religion, he was usually quite sensitive to the interface between moral/ethical perspectives and theoretical/clinical ones. Psychoanalytic insights and findings might inform the ethical enterprise, but Freud did not think moral values themselves could be deduced from analytic premises. Regarding moral values in the psychoanalytic endeavor itself, he emphasized honest self-awareness and its potentially beneficent personal and interpersonal effects (Wallace, 1986; Rieff). Freud intended the clinician's analytic neutrality, with its customary suspension of explicit moral evaluation, purely as a means to enhance the patient's disclosure and self-discovery; it was confined to the consulting room and not suggested as a recipe for living.

Conclusion

Given the historical and cross-cultural variations in modes of conceptualizing personhood and ascribing abnormality, as well as the vicissitudes of sociocultural and natural environments, it makes little sense to seek timeless and placeless notions of health, illness, or even disease, psychiatric or otherwise. The extraordinarily complicated overlap and mutual determination among formulations and applications of mental health, and a host of external institutions, ensure that the former will reflect and affect myriad sociocultural dimensions and processes. Insofar as ethical and metaphysical purviews are separable from scientific and medical/psychiatric theories and findings, one cannot facilely deduce moral values and ethical systems from the latter.

A biopsychosocially oriented functionalism proffers the least metaphysical and reductionistic, and the most comprehensive and open, model of the human organism in its ongoing cultural and natural milieu. This conceives of self-conscious and symbolizing personhood as the complexly integrated function of a plethora of subsidiary structures and functions, interacting both among themselves and with aspects of the physical and sociocultural ambience. It avoids either a dualistic or a mechanistic stance on humankind; it affirms the necessity of psychosocial, as well as biomedical and neurobiological, approaches to persons in health and illness (Wallace, 1990). Moreover, it permits medicine, psychiatry, and the mental-health disciplines a public philosophy open to dialogue with vantages from ethics, theology, jurisprudence, politics, and elsewhere (Wallace, 1992). In other words, a *Homo sapiens* does not comprise separate ontological compartments of spirit, morals, mind, and body. Rather, he or she is appreciated as a self-consciously reflective whole, with a history in a community, whose various experiences and activities require separate, but overlapping and interrelating, spiritual, moral, medical/psychiatric, and social perspectives. However one understands mental health and mental illness, they point toward forms of distress, disability, and well-being that are real and pervasively human concerns.

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POSTSCRIPT

Western definitions and concepts of mental health have continued to multiply into the twenty-first century—usually permutations and combinations of desiderata already treated. However, there is a strengthening minority position taking sociocultural (including political-economic) and even spiritual parameters into account—both in definitions of mental health and in theories of causation of mental disorders (Kleinman and Good). This cadre is led by transcultural psychiatrists and psychological/psychiatric anthropologists (GAP). Western psychiatry is being cogently examined as one ethnopsychiatry among others (Kleinman). DSM-III and DSM-IV Axis I disorders such as Major Depression differ in core, and not merely peripheral, signs and symptoms—begging the question of whether psychiatry is dealing with different nosological entities (Kleinman and Good).

On the positive side, the psychiatrist and philosopher K. W. M. Fulford has proposed a notion of mental illness as "failure of action," rather than as the DSM-IV's "disturbed functioning." The latter implies component pathophysiological lesions about which the evidence is still very equivocal (Wallace, Radden, and Sadler; Ross and Pam; Bentall; Lewontin, Rose, and Kamin). "Failed action" refers to a variety of distressing or disabling experiences and behaviors that the person is unable to control (i.e., consciously will and enact otherwise). A definition of mental health is of course implied in this, and could be worked out conceptually. Fulford's notion does not rule out the potential explanatory and therapeutic applicability of both neurobiological/pharmacological and psychosocial/psychotherapeutic approaches.

A far more complex and controversial theorist of disease/illness and, by implication, of what he now prefers to call "normality" rather than "health" is Boorse (Boorse, 1977). Attacked by most bioethicists and medical philosophers (Humber and Almeder), Boorse has staunchly argued for human species-specific biostatistical, ostensibly objective and value-neutral, criteria for disease (Boorse, 1975). Initially limiting his argument to general medical *disease,* he later moved to biostatistically-based criteria for *illness* and for the mental disorders as well (Boorse, 1975, 1997). In a 1997 book chapter, he skillfully defended himself against a plethora of critics.

Since it is impossible to address his annexation of mental disorders (and, by implication, mental health) without appreciating Boorse's general medical concept of disease/illness, one must begin with the latter. His biostatistical criteria for disease/illness are extremely spare and Darwinian: the preservation of the individual (as opposed to the group or population) and his/her reproductive fitness. *Disease* is component pathophysiological dysfunction or subfunction *within* the organism. It is key to realize that Boorse is concerned with *medical scientific* (i.e., the pathologist's) or *theoretical* criteria for disease. He is not occupied with *practical* clinical diagnosis (which often deals with syndromes) or the *clinical* investigative and therapeutic manner of the physician. However, it is important to note that he appreciates the necessity for "disease-plus" concepts of humanitarian and ethical clinical behavior.

Moreover, in concerning himself with disease as *intra*-organismic component pathophysiological dysfunction or subfunction, he does not argue that the nexus of etiology is delimited to the subcomponent or even the organism itself. He includes physical environmental trauma and psychosocial causation (in the general medical, as well as psychiatric, realms). *Illness* is the systemic molar or total organismic (which may include the mind) subfunction or dysfunction accompanying the *disease.* Hence, *illness* represents the same sort of Darwinian impairment already addressed with reference to *disease.* By Boorse's criteria, it is possible to: (a) have a *disease* without an *illness* (e.g., molar dysfunction)—though eventually, of course, many or most diseases will also become illnesses; and (b) an illness (e.g., influenza) without a disease (e.g., delimited internal pathology).

One must also recognize that Boorse's biostatistical, Homo-sapiens-typical criteria are related to gender, age, and (to some extent) ethnic or racial reference-groups. This prevents a post-menopausal woman (who has lost reproductive fitness), a middle-aged man with some degree of "male pattern baldness," or a pygmy with group-wide growth-hormone subfunction from being deemed *diseased* or *ill.* Nevertheless, things become more complicated for Boorse with African or African-American individuals heterozygous for sickle-cell disease. On the one hand, this state is survival-promoting in malarial environments, but not at higher altitudes at which other "races" are not so vulnerable. Boorse attempts to sidestep this with his construct of "standard environment." This is problematic not only for general medical disease/illness, but especially for mental and behavioral functioning, since climatic, historical, and sociocultural relativity render the idea of a Homo-sapiens-specific standard physical and sociocultural environment suspect.

Finally, this author finds Boorse's insistence that component or circumscribed internal pathophysiology alone defines disease as bizarrely narrow; it excludes systemic dysfunction or subfunction, as well as the molecular level to which many pathological disease-formulations are now turning.

Turning especially to psychiatry, Boorse likewise stresses internal component pathology. To his credit, he considers psychological concepts a necessary subset of biological ones—to grasp human species-specific, symbolically-mediated mentation, communication, and behavior. This author has argued similarly in both monistic-dual-aspect and functionalist models of the mind-body relation (Wallace, 1988, 1990, 1997). In other words, Boorse contends that not only cerebral or extra-cerebral component pathophysiology (and here he chides biological psychiatry for its predominantly molecular approach) may be pathognomonic for mental disorders, but so might *component psychological functions* such as unconscious intrapsychic conflict among the psychoanalytically-conceived mental agencies and subsidiary functions. However, his delimitation of disease/illness criteria to individual self-preservation and reproductive fitness are problematic for notions of mental disorder and normality. For example, in non-Western cultures with intact, supportive kinship and community networks, psychiatrically-untreated schizophrenia does not pose the same personal survival or even reproductive fitness risks that occur in the urbanized West, with its relative dearth of community and kinship networks. And most DSM-IV Axis II sufferers (from perhaps Western culture-bound syndromes) often experience no increased physical survival or reproductive-fitness risks. In short, Boorse's two Darwinian criteria are insufficiently robust for a concept of mental disorder/illness, much less for *normality* or *mental health.*

Pending further research, some varieties of the major mental disorders may turn out to be diseases in the Boorsian circumscribed pathophysiological (or even molecular) sense. However, this author suspects that most (Axis II) mental disorders (which keep multiplying over time in new editions of the DSM) will remain best understood in the psychosocial categories of human biological discourse.

In conclusion, there is nothing in Boorse's argument as applied to psychiatry that would countenance psychiatry's recent (patently, if partly, economically-motivated) turn to a radical neurobiological/pharmacological reductionism. Such an approach entails the concomitant jettisoning of psychosocial/psychotherapeutic approaches that demand a more laborious intimacy with the patient-as-person-in-an-ambience rather than as simply the epiphenomenon of a twisted molecule or component brain limbic pathophysiology. Again, Boorse asserts that disease- and illness-plus concepts and approaches are necessary to anyone who would be an ethical and competent clinician.

Space does not permit treatment of the recent evolutionary psychiatry of Randolph Nesse and George Williams, and others. They are obsessively committed to imagining historically remote conditions in which disorders is incapacitating as schizophrenia were once adaptive (i.e., atavism).

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SEE ALSO: *Children: Mental Health Issues; Coercion; Confidentiality; Disability; Electroconvulsive Therapy; Informed Consent: Issues of Consent in Mental Healthcare; Institutionalization and Deinstitutionalization; Life, Quality of; Mental Health, Meaning of Mental Health; Mental Health Therapies; Mental Illness; Mentally Disabled and Mentally Ill Persons; Patients' Rights: Mental Patients' Rights; Psychiatry, Abuses of;* and other *Mental Health Services* subentries

MENTAL HEALTH SERVICES

• • •

I. Settings and Programs

II. Ethical Issues

I. SETTINGS AND PROGRAMS

Since the mid-1950s, fundamental transformations have taken place in the size, location, diversity, funding, and attitudes toward mental health services in the United States, changing the organized response to the identification and treatment of mental health problems. These changes have altered the central policy and ethical questions that arise in the mental health system as a whole. When involuntary commitments to custodial mental hospitals dominated the system, the central issues involved inappropriate social control. In the diversified system based upon community care and treatment that has evolved, the most pressing issues include how to fund and deliver services to the most seriously ill persons, allocate services to meet a potentially huge demand, and improve service delivery outside the traditional system of mental healthcare.

Evolution of Mental Health Services

Until the mid-1960s, two separate systems dominated mental health services: public mental institutions that treated a large population of inpatients and a smaller private sector that provided most outpatient psychotherapy. Large, impersonal, custodial facilities dominated the inpatient sector and housed poor, isolated, severely mentally ill persons (often elderly) for long periods of time (Grob, 1973). Most residents lacked family ties or were committed as a last resort by their families. The flaws of these institutions are well known: huge size, overcrowding, geographic isolation, involuntary confinement, depersonalization, coercion, and custodial emphasis (Goffman). Nevertheless, they provided the most seriously ill persons an integrated range of services—housing, food, symptom management, respite from stressful community conditions, medical treatment, and a locus for social interaction—in one centralized location. Alongside the core of state mental hospitals, a smaller outpatient sector dominated by private psychiatrists practicing analytic psychotherapy treated clients who could afford those services (Hale).

The mental health system at the beginning of the twenty-first century is much different. A revolution in mental health services began in 1955, when the average number of residents in state and county mental hospitals started to decline from a peak of 550,000, to 370,000 in 1969 and about 60,000 by 1998 (CMHS, 2001). Taking into account a growing general population, the number of residents in state and county mental hospitals fell from 339 per 100,000 persons in 1955 to 91.5 in 1975, and to only 21 in 1998 (CMHS, 2001). Typical patients in state hospitals have also changed: from the elderly to the young; from long-term to short-term patients; and from persons with deteriorating and untreatable diseases of the brain to ones suffering from concurrent substance abuse disorders.

As state mental hospitals became institutions of last resort for the most intractable patients, alternative forms of inpatient care grew substantially. Less than 10 percent of admissions to twenty-four-hour care facilities occurred in state and county mental hospitals in 2000, a four-fold decline since 1969 (CMHS, 2001). Most inpatient psychiatric services now take place in general hospitals, private psychiatric hospitals, specialized chemical dependency units, nursing homes, and residential treatment centers for children (Kiesler and Simpkins). These facilities generally do not treat the same types of persons who had been found in public mental institutions: Their residents are more likely to have affective and substance abuse disorders and less likely to have schizophrenia.

The overall growth in mental health service provision has also been dramatic. Between 1955 and 1997, the total number of patient episodes in mental health organizations rose more than 600 percent—from 1.7 million to 10.7 million (CMHS, 2001). By 1994, all expenditures for mental health and substance abuse services exceeded $68 billion (Mechanic). In constant dollars (with 1969 as baseline), spending by mental health organizations increased from $3.3 billion in 1969 to $5 billion in 1994.

Most of the growth in mental health services stemmed from the expansion of outpatient treatment. From only 23 percent of total mental health episodes in 1955, outpatient episodes grew to 76 percent of episodes in 1998. Nevertheless, inpatient episodes consume over 80 percent of expenditures for mental health (Kiesler and Simpkins). The number of mental health professionals also expanded commensurately during this period. For example, in 1975 about 20,000 licensed psychologists practiced in the United States; this figure grew to 46,000 in 1986 and to at least 73,000 by 1997 (CMHS, 1998). The growth of mental health professionals who are psychiatric social workers, school psychologists, marriage and family therapists, and counselors was even greater. For example, between 1972 and 1994 the number of full-time psychiatric social workers nearly quintupled and there were nearly twenty times the number of professionals in the category of *other mental health workers* (CMHS, 2001).

The analogue to the growing number of mental health professionals is the greater number of persons who seek help from them. By 1983, about 23 million people—15 percent of the adult population of the United States—sought some type of treatment for mental health or addiction problems over the course of a year (Regier, Narrow, Rae, et al.). Population surveys also indicate a growing readiness of the public to use mental health services. One large national survey showed that while less than 1 percent of respondents sought help from psychologists, counselors, and social workers for mental health problems in 1957, 18 percent of respondents reported seeking professional services in 1996 (Swindle, Heller, Pescosolido, et al.).

Another striking trend has been the expansion of psychotropic medications. In the decade between 1985 and 1994 alone, the proportion of psychiatric outpatient visits in which psychiatrists prescribed an antidepressant increased from 23 percent to 49 percent, and the number of prescriptions for psychotropic medications soared from about 33 million to about 46 million (Pincus, Tanielien, Marcus, et al.). Three of the seven most-prescribed drugs of any kind are now antidepressants (Horwitz). These drugs are not imposed on unwilling patients, but are highly sought-after and valued therapeutic aids promoted to the general public through ubiquitous advertising campaigns (Kramer).

Reasons for Changes in Mental Health Services in the United States

A number of technological, ideological, legal, and economic reasons led to the steep decline in the use of traditional mental institutions and the growth of mental health services. The introduction of psychotropic drugs in the mid-1950s provided an efficient and effective technology that could be used easily in community settings. The ideology of mental health professionals after World War II emphasized a broad concept of mental illness, noninstitutional care, and treatment for a wide array of emotional and social problems (Grob, 1991). Judicial and legislative mandates regarding mental health services also began to change in the late 1960s toward specific and restrictive standards for commitment and the expansion of civil rights during and after commitment proceedings (Appelbaum).

The locus of authority for mental health services also shifted after World War II. Until that time, states and localities were responsible for providing services. The creation of the National Institute for Mental Health in 1949 and the passage of the Community Mental Health Centers Act of 1963 created partnerships between the federal government and localities that bypassed hospital-dominated state mental health systems (Grob, 1991). The hundreds of community mental health centers that emerged in the 1960s and 1970s, however, did not serve the same population as the state hospitals, but instead provided psychotherapy to people suffering from emotional, behavioral, marital, and family problems. These centers made mental health services more accessible, brought more services to lower socioeconomic and minority populations, and enhanced the acceptability of mental health treatment. They did not, however, replace the services state hospitals once provided to chronically ill persons, and generally neglected the most seriously mentally ill (Rochefort).

Out of the array of technological, ideological, judicial, and political reasons for changes in mental health service provision, shifts in patterns of reimbursement were especially important. Although not developed to serve the mentally ill, Medicaid (a program jointly administered and funded by federal and state governments to bring medical services to the poor and disabled) and Medicare (a federal program funding medical care for the elderly and persons who have received disability payments for two or more years) grew into large sources of funding for mental health services. The eligibility of facilities to receive Medicaid and Medicare funds contributed to the changing patterns of inpatient services outlined above. Elderly persons with mental illnesses were transferred from state mental institutions ineligible for Medicare dollars to nursing homes that could receive these funds. Likewise, treatment episodes in general hospitals increased because federal programs reimburse inpatient psychiatric episodes in these settings but not in public mental institutions.

Changing patterns of private reimbursement have also altered the nature of mental health services. Private insurance coverage for both inpatient and outpatient services greatly expanded between the 1950s and 2000, although not at a level comparable to that for physical illnesses. Expanded eligibility of nonphysicians, including psychologists, nurses, and social workers, for third-party reimbursement has increased the pool of mental health professionals who provide outpatient treatment. A multitude of practitioners with different disciplinary allegiances, therapeutic ideologies, and treatment techniques have come to serve clients with acute disorders (Frank and Frank). Despite the great expansion of mental health services, however, no comprehensive system in communities has emerged to replace the services that persons with the most serious and long-term illnesses received in state hospitals.

Another recent change in service delivery is the rise of managed mental healthcare (Mechanic). Managed care refers to a variety of organizational forms that impose routinized strategies to monitor, regulate, and review the treatment that professionals provide patients in order to provide cost-effective care. Managed care is becoming the dominant form of treatment for mental health problems, and about three-quarters of persons with private health insurance now are in some kind of managed care plan (Kiesler). The principles of managed care dictate more rule-following, standardization, and regulated treatments that often conflict with individualized treatment plans (Luhrmann). Because persons with mental illness often require extensive and varied services, the requirements for their successful treatment often conflict with the restrictions and rigidities of managed care organizations.

International Mental Health Services

The major trends in the United States mirror changes in the provision of mental health services in most developed nations. Although the pace of deinstitutionalization differs across countries, the use of public inpatient facilities has sharply declined throughout most of the West (World Health Organization, 2001; Goldberg and Thornicroft). Persons who do enter inpatient facilities usually have short lengths of stay that typically average about one month or less. For example, the number of people occupying hospital beds in the United Kingdom fell even faster than in the United States, from a peak of 152,000 in 1954 to 39,500 in 1993. Italy has implemented the most ambitious plan of deinstitutionalization, which aims to completely eliminate all admissions to public mental hospitals (Donnelly).

The decline of public inpatient institutions has been accompanied by a decentralization of psychiatric services in most European and other developed societies (World Health Organization, 2001). Most of the smaller number of hospitalizations now occur in general hospitals and in facilities operated by non-profit or private agencies rather than by the national government. As in the United States, there has been a strong movement toward treatment in small facilities located in residential neighborhoods. Indeed, the ideology of community treatment—emphasizing keeping persons out of institutions, treating them in neighborhoods near their homes, and strengthening informal social support systems—is perhaps even stronger in Europe than in the United States. Client-centered movements of consumers of psychiatric services are also active in many countries. These movements have had a good deal of success in opposing mental hospitalization, coercive forms of psychiatric treatment, social stigma, and the power of psychiatric professionals, and in developing self-help groups of users.

There are exceptions to the general trend of declining use of inpatient hospitalization and increasing amounts of community treatment. For example, rates of occupied psychiatric beds in Japan increased between the 1960s and 1990s, and Japan has the highest number of inpatients of any country in the world (Shinfuku, Sugawara, Yanaka, et al.). Because public funds support inpatient treatment in private hospitals, these institutions have a financial incentive to admit many patients and keep them for long periods. In addition, most poor countries have rudimentary systems of outpatient treatment and the small amount of psychiatric care they provide typically occurs in large, antiquated inpatient facilities (World Health Organization, 1996).

Despite the success of most developed countries in reducing inpatient psychiatric populations, a number of common problems remain. Some of these problems are systemic. As in the United States, there is limited coordination between agencies that provide treatment, housing, social services, and social control. Insufficient amounts of adequate community housing also typify mental health systems. In addition, the most seriously disturbed and chronic patients continue to need inpatient care, severely straining the resources of most systems. Other problems stem from a poor fit between traditional modes of service delivery and particular types of clients (Goldberg and Thornicroft). The provision of mental health services to persons who are poor, homeless, immigrants, and substance abusers will be especially problematic in coming years. Most European nations have large immigrant populations who resist voluntary mental health treatment and are often subject to coercive forms of social control. Mental health systems rarely have enough personnel from minority backgrounds who could better relate to these patients. As in the United States, psychiatric patients who have co-morbid substance abuse problems are particularly difficult to treat within most mental health systems. As well, few mental health programs have established successful outreach programs to the homeless mentally ill. While the ideology of community treatment now dominates mental health service provision in nearly all developed countries, the implementation of this ideology lags behind.

Ethical Issues

The ethical issues that arose in a mental health system dominated by state hospitals were related to involuntary commitments, inappropriate hospitalizations, neglectful or abusive treatments and the validity of the label of *mental illness* itself (Szasz). In the huge but uncoordinated mental health system of the 2000s, the most pressing issue is to create coordinated service delivery systems for seriously disturbed persons. The dominance of medical models devised for specific acute conditions hampers efforts to create comprehensive services. Medicare and Medicaid, which were developed to finance treatment for acute physical conditions, usually do not cover long-term, comprehensive services that promote community living (although many states do use Medicaid options to finance a number of community-based services). Managed care organizations rarely have the expertise to provide appropriate treatment to persons with serious mental illnesses and lack the capacity to provide comprehensive mental health services (Mechanic). Drug therapies that form the core of medically-oriented treatment are effective in alleviating the symptoms of, although not curing, mental illness. These treatments are beneficial, but cannot address the needs for housing, monetary assistance, vocational training, and social interaction of seriously mentally ill persons who live in the community. The extent to which drug therapies cause harmful side effects is controversial (Healy; Valenstein). The dominant organizational forms and treatments in mental healthcare create great difficulties in developing comprehensive care programs for persons with serious mental illnesses.

COMMUNITY TREATMENT. A broad consensus has developed among consumers, families, and mental health professionals that community—rather than institutional—treatment is most consistent with the values of individual autonomy and choice that underlie contemporary policies toward disabled populations. In addition, evidence is accumulating that most persons with serious mental illnesses benefit more—and at no greater cost—from comprehensive community treatment programs than from hospital care (Mechanic and Rochefort). Although there is little evidence that comprehensive community treatment is cheaper than hospital care, such programs need not cost more than inpatient treatment (Weisbrod, Test, and Stein).

With the exception of a minority of violent, dangerous, and self-destructive persons, outpatient programs can allow seriously mentally ill persons to remain in the community with the help of an intensive range of mental health, psychosocial, and vocational services. One effective model uses assertive community treatment teams of mental health professionals who provide services in clients' natural living environments on a seven-day-a-week, twenty-four-hour-a-day basis (Stein and Test). The staffs of these programs do not wait for patients to seek help, but aggressively offer treatment when they think it is needed. The aggressive enforcement of medication compliance and occasional hospitalizations has created concern that these programs can be overly paternalistic and coercive (Diamond and Wikler). Such interventions, however, might be necessary to keep the most difficult, disruptive, and noncompliant persons in community settings over the long term. The Fountain House program, which emphasizes job rehabilitation and the creation of a family-like atmosphere, is another effective, but less intensive, model for community treatment (Beard).

Despite the advantages of community-based treatment for the most seriously ill, skewed funding and administrative structures have precluded its widespread establishment. States continue to fund state mental hospitals disproportionately: 60 percent of state funding goes to hospitals that serve only 7 percent of the seriously mentally ill (Sharfstein, Stoldine, and Goldman, 1993). Opposition from public employee unions and local communities that are economically dependent on state hospitals often prevents shifting funds from inpatient treatment to intensive community treatment programs. Likewise, federal and private reimbursement programs fund relatively expensive treatment in inpatient facilities outside of public mental institutions, but will not usually cover treatment in clients' homes or in noncoercive residential facilities in the community.

Fragmented administrative authority for mental health services also prevents the development of integrated service systems. Service delivery for the seriously mentally ill typically involves an unplanned and uncoordinated mix of visits to emergency rooms, short-term stays in inpatient units, inadequate outpatient treatment, and a variety of entitlement programs that may not meet the special needs of the mentally ill (Bloche and Cournos). Different agencies with different missions provide housing, financial assistance, vocational training, medical treatment, and mental healthcare to the mentally ill (Mechanic and Rochefort). Mechanisms such as comprehensive case management and mental health authorities that assume organizational, financial, and clinical responsibility over a range of residential and psychosocial services can help coordinate the various agencies that provide these services (Morrissey, Callaway, Bartko, et al.). Solutions for serious mental illness must go beyond the development of effective drug treatments or psychotherapies to encompass a variety of systemic and organizational factors.

The philosophy of community treatment has also led to new and complicated issues regarding family responsibility for caregiving. Many family caregivers—typically mothers—are aging, ill, and lacking in resources to provide adequate care (Lefley). Yet the scarcity of community treatment programs means that families often must provide housing, monetary and emotional support, symptom management, and personal care to seriously ill adult children. Although mental health professionals are now less likely than in the past to view families as pathogenic, they still too readily blame or neglect family members instead of appreciating the value of family resources. Likewise, confidentiality requirements that allow widespread information flow between mental health professionals but preclude the sharing of information with family caregivers need reconsideration (Petrila and Sadoff).

The manifest failures of deinstitutionalization—especially the highly visible problems of the homeless mentally ill—have given rise to public demand to reinstitute civil commitment for the most obtrusive among the seriously mentally ill. In fact, federal entitlement programs have allowed most formerly institutionalized patients to avoid homelessness (Goldman, Adams, and Taube). The more visible homeless mentally ill are likely to be young persons in urban areas with concurrent substance abuse disorders who have never experienced lengthy hospitalizations and who are resistant to traditional mental health service delivery (Lamb). While young, chronic, and sometimes homeless mentally ill persons present a particularly challenging task for mental health service delivery, flexible and nontraditional programs of service delivery that emphasize the provision of adequate housing can best meet the special needs of this population (Bachrach).

INAPPROPRIATE SERVICE PROVISION. While the most seriously ill persons are often unable to obtain needed services, the mental health system overemphasizes inpatient services for persons who could more efficiently and economically be treated in outpatient settings. Particularly troubling is the fact that reimbursement patterns and financial pressures to fill inpatient beds drive service delivery. Paradoxically, while many states have reduced hospital services for the most seriously mentally ill to save costs without providing needed treatment in the community, less seriously ill persons—especially those with affective and substance abuse disorders—are often unnecessarily treated through inpatient episodes in both general and private hospitals. Few data exist about the accessibility, quality, and effectiveness of mental health services in these settings, although good evidence from randomized studies shows that most patients who receive care in hospitals could receive more effective and less costly care as outpatients (Kiesler and Sibulkin). Youths under eighteen are particularly likely to be committed to residential facilities; contrary to trends in other age groups, inpatient treatment for youths rapidly increased from the 1980s to 2000 (CMHS, 2001). There is no evidence, however, that such treatment is necessary, effective, or appropriate, although it is very expensive (Kiesler and Simpkins).

A more effective and efficient mental health service system would place less emphasis on expensive inpatient interventions and more emphasis on comprehensive, long-term community services for the chronically ill. The disabilities associated with serious mental illnesses require long-term care that is responsive to the episodic and recurrent nature of these disorders. For the acutely disturbed, such a system would de-emphasize extended psychotherapy while supporting short-term, directed interventions of proven effectiveness (Kiesler).

Another obstacle to creating a more effective and efficient system lies in the largely hidden nature of much mental health service delivery. Despite the large and growing number of mental health professionals, general physicians are the leading providers of mental health services, accounting for about half of all mental health and addictive treatment services (Regier, et al.). Conversely, about 20 to 30 percent of medical visits are for mental, rather than physical, health problems. However, primary physicians often do not appropriately recognize and treat mental disabilities. Professional training of physicians should place more emphasis on the appropriate diagnosis and response to mental disorders in primary practice. Nonphysicians, such as nurse practitioners, could also play a greater role in the treatment of psychological problems in medical settings. Nursing homes—where growing numbers of the psychiatrically-disturbed elderly reside without receiving adequate mental healthcare—are another location where psychiatric need and mental health service provision are mismatched.

An additional problem of mental health services lies in the expansive definition of mental illness. Once equated with psychotic disorders, the definition of mental illness now includes a wide scope of emotional, behavioral, and psychophysiological disorders (American Psychiatric Association). These definitions encompass many ordinary problems of living as well as serious mental illnesses (Kirk and Kutchins; Horwitz). Those who hold an expansive view of mental health often call for mental health service provision to a wide spectrum of persons who suffer from mental disorders but who do not seek treatment. Advocates of this view cite statistics from community surveys showing that about 16 percent of the U.S. population has a current mental health or addictive disorder, about 30 percent have such disorders over a one year period, and up to 50 percent suffer a disorder over the course of their lifetimes (Regier, et al.,; Kessler, Beglund, Zhao, et al.). These surveys also indicate that only about 13 percent of disordered persons seek help from a mental health or addiction specialist, and only about 30 percent seek any help at all for their problem. In this view, there is a tremendous unmet need for mental health services in the community.

The emphasis on unmet need for mental health services has generated calls for parity in coverage of the treatment of mental and physical health problems. Most third party payers impose higher co-payments for mental health treatment, limit the number of mental health visits and total amount of payment for mental health treatments, and refuse to pay for the treatment of many mental health conditions. Advocates for parity argue that such restrictions unfairly discriminate against persons with mental health problems. Efforts to bring parity had some success when the U.S. Congress passed the Domenici-Wellstone Amendment in 1996. That legislation, with many restrictions and limitations, requires parity of limits on the treatment of mental health and other medical conditions (Mechanic). The Amendment, however, has not brought about major improvements in the funding of mental healthcare.

Advocates of parity between mental health and other conditions do not generally define the specific conditions to which parity should apply. A different view is that, instead of seeking parity in treatment for all mental health conditions, the highest priority for care should be the much smaller group of persons who have severe disorders that lead to serious functional impairments. Surveys that ask respondents if they or someone in their household has a serious mental illness that interferes with their daily life find prevalence rates of between 2 to 3 percent of the population (Kessler, et al.). Because these lower estimates still involve between four and six million people, and because services are finite, there is a clear need for some allocation criteria for mental health services (Boyle and Callahan). Targeting services toward individuals who neither perceive a need for mental healthcare nor suffer from serious functional limitations could be wasteful and ineffective and could direct attention away from the many unmet service needs of the people who are in the most desperate circumstances. Mental health reforms can reasonably include high co-payments for persons with less severe disabilities who desire psychotherapy, as well as higher standards of accountability for psychotherapeutic techniques eligible for reimbursement. These principles could help reorient service delivery toward community treatment of the most seriously ill without generating the huge costs of meeting the total demand for mental health services (Frank, Goldman, and McGuire).

SUCCESSES OF MENTAL HEALTH SERVICES. The many failures of the current U.S. mental health system should not detract from its successes. The expanded federal role in funding mental health services through Medicaid and Medicare has the potential to create a more adequate community-based system that is sensitive to the needs of the seriously mentally ill (Koyanagi and Goldman). States with the will to do so have the ability to devise more effective mental health systems, especially through the creative use of Medicaid waivers. The growth of public mental health treatment has led to declining social class differences in the receipt of services. Changing cultural definitions and understandings of mental disorders have lessened, although not eliminated, the stigma of mental illness and have increased public willingness to seek mental healthcare. Although flawed in many ways, there is more accessibility to mental health services than ever before.

Conclusion

U.S. mental health services at the beginning of the twenty-first century consist of unplanned and uncoordinated services driven by patterns of reimbursement originally developed to treat problems of physical health. Deinstitutionalization diminished the role of state hospitals without replacing the services once found in these settings. The most seriously ill obtain the least adequate treatment, while reimbursement patterns that emphasize acute care in hospital settings create inappropriate and unnecessary inpatient episodes for persons who could be treated equally well through less expensive outpatient therapy. As costs for all types of healthcare have escalated to reach 14 percent of the gross national product, and as managed care organizations have proliferated, some sort of controls over mental health service provision are inevitable. Reforms that would lead to a more equitable and effective system would place less reliance on expensive inpatient care and long-term psychotherapy and more on comprehensive and continuous community care for the most seriously ill, and short-term and directed care for the acutely ill. The knowledge exists about what changes are needed in mental health service provision, although fiscal inefficiencies, administrative fragmentation, and professional resistance might prevent reform. It will be difficult to create a mental health system that responds as adequately to the most seriously disordered as to the less seriously disturbed—but such a system will be more humane.

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SEE ALSO: *Children: Mental Health Issues; Coercion; Confidentiality; Disability; Electroconvulsive Therapy; Informed Consent: Issues of Consent in Mental Healthcare; Institutionalization and Deinstitutionalization; Life, Quality of; Mental Health, Meaning of Mental Health; Mental Health Therapies; Mental Illness; Mentally Disabled and Mentally Ill Persons; Patients' Rights: Mental Patients' Rights; Psychiatry, Abuses of;* and other *Mental Health Services* subentries

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II. ETHICAL ISSUES

At the beginning of the twenty-first century, American society is engaged in a continuing critical reexamination of fundamental issues in health matters. As healthcare reforms progress through the social and political process, the opportunity exists to remedy past failures in the management of health resources, to renew fundamental values and commitments to individual and public health, and to shape new priorities for a system of healthcare that is both fiscally sound and ethically justified. The most pressing challenge is to allocate health resources to those in need of them without unfairly compromising other cherished social goods such as education and defense, or other ideals such as economic prosperity and self-determination. This challenge is made even more complex by the relentless growth in technological and scientific achievements, and an ever-widening public concern about their responsible use and distribution in society.

Of increasing concern to many in American society is the system of goods and services to provide care to the mentally ill. The mental health system of the 2000s is a complex web of intersecting and often competing factors that reflect changing ideas regarding mental illness and the resources that are needed to deal with it. The mental health field is characterized by a stunning diversity of problems that reflect the complex shifts in society over the past several decades. Whether these problems are considered in terms of diagnosis, level of dysfunction or disorder, duration of symptoms or disease, or social attitudes regarding concepts of deviancy and dangerousness, mental illness is a problem of enormous complexity and heterogeneous characteristics. The ethical issues are no less complex, and raise some of the deepest philosophical questions regarding mind and body, the nature of suffering, the range of human potentialities, and the conflicts between individual and societal needs.

Although ethical considerations are implicit in nearly every aspect of mental healthcare, the emphasis in this article is on ethical aspects of the mental health service system. The most dominant issue is the problem of justice and the derivative question of how to strike a fair and equitable balance between the requirement that society protect its citizens from harm and its simultaneous duty to protect and promote the moral, legal, and civil rights of each individual. Answers to this particular question continue to be reflected in various mental health directives and policies that define the field of mental health services. In various ways, these directives and policies document the extent to which the problems of mental illness are valued or disvalued by society, the eligibility criteria of those persons who may receive society's goods and those who will not, and the perceived importance of mental health to the vitality and character of the nation.

This article addresses the issues of equity, parity, and fragmentation in relation to considerations of justice, and supports the argument that mental health concerns should be given higher priority in the healthcare system of the future.

The Mental Health Service System

Mental illness affects people throughout the entire life cycle, including all age groups and socioeconomic strata (Regier, Narrow, Rae, et al.; U.S. Surgeon General). According to one estimate, approximately one-third of Americans will experience some form of a mental disorder at some point in their lives; of the 28 to 30 percent of all adults who experience mental disorders in a year, 2.6 percent have chronic, severely disabling conditions such as schizophrenia (Kessler, Berglund, Zhao, et al.). Psychiatric patients are more likely than the general population to have substance abuse disorders as well. Furthermore, although 28.1 percent of the population received diagnosis of mental or addictive disorders in one year, only about 15 percent received any mental health services in that time frame (Regier, et al.; U.S. Surgeon General). In 1990, the annual direct cost of mental and substance-abuse services in the United States was estimated to be $99 billion. Indirect costs, such as lost days of work, has added another $79 billion (Rice and Miller; U.S. Surgeon General).

Many mental and substance abuse disorders are severe and chronic, and thus often produce emotional and financial burdens for patients and families that last a lifetime. Although 28 to 30 percent of all adults experience mental disorders in a year, only one third of this population receives mental healthcare (U.S. Surgeon General). Similarly, despite the fact that 7.5 million children in the United States under the age of eighteen suffer from an emotional problem severe enough to require treatment, as many as 70 to 80 percent do not receive the services they need (U.S. Office of Technology Assessment). Finally, Americans over sixty-five years of age are at high risk of developing mental disorders because of reputed stressors associated with aging, including concomitant physical illness, increasing isolation, and diminished social supports. Studies demonstrate, however, that just over half of older adults with mental disorders are provided services through the mental health sector (U.S. Surgeon General). The rest, often referred by physicians—whose poor abilities to recognize the psychological symptoms of older adult patients have been documented—obtain services from the general health sector. Consequently, many older adults with mental health problems may not receive the services they need from qualified mental health professionals (Gatz and Smyer).

The current system of mental healthcare in the United States is enormously complex and has the following characteristics that differentiate it from the more general system (Phelen, Link, Stueve, et al.; U.S. Surgeon General):

1. Mental health services are dependent upon public funding and are frequently subject to a high degree of government regulation.
2. Mental health services are provided by an increasingly diverse set of professionals, including psychiatrists, social workers, psychiatric nurses, and mental health counselors. Increasingly, these services are offered in a variety of settings, including state and mental hospitals; general, private, and government hospitals with psychiatric units; community mental health centers; nursing homes; and specialized alcohol, drug, and addiction disorder treatment units.
3. These diverse settings may alter the transaction between a patient and therapist, and create threats to the often private and intimate character of the therapeutic relationship.
4. The chronically mentally ill and other severely disordered persons constitute a highly dependent population that presents extraordinary challenges for administrators and providers attempting to maintain a responsive, accountable, and humane program.
5. Disputes regarding the diagnosis and etiology of mental health disorders and the efficacy of their treatments persist and make it difficult to evaluate the utility of treatment programs.
6. The boundaries of mental health services are difficult to define, and create diverse sets of expectations and conflicts regarding *medical* and *social* models of disease.
7. Mental health services are generally perceived as having a poor public image and as valuable for only a small group in society who have aberrant emotional or behavioral conditions.

These characteristics provide a clear portrait of the complex issues faced by mental health practitioners and policymakers. They may explain some of the reasons why mental healthcare has a low position on the American agenda.

Vulnerability

Illness of any kind, but especially mental illness, exacerbates the need to depend on others for help and to trust that this dependence will not be exploited or manipulated. Many severely mentally ill persons remain dependent on the healthcare and mental health services systems to provide necessities of life. The human tragedies generated by severe mental disorders are considerable; often not only the health and well-being of individuals but also that of their families and communities are destroyed. Persons with chronic mental illness such as schizophrenia, bipolar illness, and psychoses that impair or distort decision-making abilities may be particularly vulnerable to possibly unjustified paternalistic interventions in their lives. Although the stigma attached to the use of mental health services may be diminishing, it still endures in some forms, thus increasing the vulnerability of the mentally ill to negative social judgments. These vulnerabilities create moral obligations on the part of society and its institutions to provide the resources to meet basic human needs and promote policies that include strategies to avoid discrimination, stigmatization, and the exploitation of dependence. These obligations are grounded in moral beliefs regarding society's duty to help those who are weak or vulnerable, and on the moral principles of care and trust that form the basis of the therapeutic relationship between patient and provider (Carter).

Historical Features of Mental Health Services

Although mental healthcare represents a significant part of the overall healthcare system, it has been separated from the mainstream of healthcare by historical, institutional, and conceptual barriers. Historically, mental healthcare was linked to social welfare policies; mentally ill persons incapable of living in society were separated from it not so much because they were sick as because they were viewed as disruptive to society. They were cared for in local or state asylums. These institutions, and the cycles of reform they mirror, have been the subject of well-documented historical works (Deutsch; Foucault; Grob, 1991). Of relevance in this article are the underlying moral and social reasons that justified the various services provided within these institutions. For instance, in the early 1800s social reformers and physicians began to lobby against a shared responsibility by the state and local governments for providing services to the mentally ill. As a result, many mentally ill persons become wards of the state (Boyle and Callahan). In the institutions of the mid-nineteenth century, *treatment* consisted of providing a calm, humane, and disciplined environment. The ethical justification for these services was that the state could meet its responsibilities to the individual, family, and community by providing medical treatment for acute problems and humane, custodial care for those with chronic problems. Furthermore, the health of the general public could be served by protecting society from the threat of disease or dependency (Grob, 1992).

In the early twentieth century, the United States began to embrace the view that the individual is responsible for meeting the basic needs of life. Society, in the form of federal or state government institutions, would intervene only when an illness placed excessive burdens on the afflicted individual or family, when the disease posed a danger or threat to the community, or when the individual lacked the necessary resources to deal with it. Vulnerable people, such as those with tuberculosis, mental illness, or mental retardation, could obtain needed services such as those provided in the mental institutions of the day. There was no broad right of access to healthcare services; rather, the dominant social policy focused on the value of serving only those with special needs. Mental health policy in the 1940s was based on the assumption that society had an obligation to provide a severely and chronically ill person with both care and treatment in public mental hospitals. Gradually, in response to economic and cultural shifts, these mental hospitals became increasingly custodial and bureaucratic (Grob, 1992).

In the years following World War II, radical transformations shook American culture, and new ideas regarding individual and societal rights emerged. The social activism and political unrest of the 1960s provided the backdrop for a number of shifts in thinking about the nation as a whole. States began to reconsider their policies regarding the mentally ill, and people who had been cared for in mental hospitals were moved to newly created community alternatives. In the 1960s, the movement to deinstitutionalize the mentally ill was partly based on the idea that the chronically mentally ill could receive support in the community without infringement of their civil rights. The other assumption that fueled policies of deinstitutionalization was derived from intellectual and scientific disputes within the practice of psychiatry. Disagreements about the definition of mental illness, diverse explanations of its causes, and skepticism about treatment efficacy generated controversy and ambiguity. These disagreements in turn affected the nature of the services available to those with mental disorders.

Monumental revolutions in ideas regarding individual, civil, women's, and fetal rights provoked fundamental questions about the role of the state in a free democracy, and the power of technology to alter constructs such as life and death. As these social and intellectual events converged, new attitudes regarding the nature of medical care, research on human subjects, and the value components of therapeutic relationships began to be reflected in legal decisions, social policy, and ethical discourse. In the field of mental health, ethical concepts of autonomy, informed consent, and paternalism began to appear in the literature. Psychiatrists, social workers, psychologists, and other mental health providers began to critically examine their relationships with patients, colleagues, society, and the state. They were confronted with new puzzles, such as how to respect the recently enhanced rights to autonomy and individual freedoms, and yet protect society from the potentially harmful actions of a mentally ill person. Ethical values were often in conflict with other values, thereby dividing professional loyalties and obligations (Reiser, Bursztajn, Appelbaum, et al.).

In response to shifts in public values and attitudes, the federal government began to endorse social welfare programs aimed at prevention; new programs attempted to ameliorate the social problems that were said to foster mental illness. Mental health policy increasingly began to rely on federal government programs to administer, manage, fund, and reimburse for these services. The passage of the Omnibus Reconciliation Act of 1981 effectively eliminated previous policies that had emphasized community care outside the mental hospital (Kiesler). Federally-sponsored programs such as Medicare and Medicaid initiated cost-based reimbursement strategies that fueled the evolving rhetoric of the *right to healthcare,* and fed the expectation that such a right would be funded. Congressional passage of the Tax Equity and Fiscal Responsibility Act of 1982 and the Medicare Prospective Payment System (PPS) in 1982 altered this expectation by restricting future payments for inpatient hospital services.

These events, and many others detailed elsewhere, foreshadowed the current public debate regarding the existence and scope of this *right to healthcare* and its numerous philosophical, conceptual, economic, political, and social ramifications.

All of these transformations in ideology influenced policy directions and contributed to the evolution of a diffuse, heterogeneous system of services that provided a diverse set of services to assist the adjustment of the mentally ill to life outside the mental hospital. For instance, in the 1960s the view that mental illness did not require psychodynamic intervention, and that those experiencing *problems in living* could find the support they needed in the community, led to the policy of deinstitutionalization. This policy of transferring patients from public mental hospitals to community-based mental health centers, coupled with the emergence of psychotropic agents to control their symptoms, profoundly altered the mental health system.

Although many writers have analyzed the mixed impact on mental health services brought about by this policy (Mechanic and Rochefort), others underscore its abject failures in helping the seriously ill or reducing the number of inpatient services (Geller; Lamb and Bachrach). Other writers have argued that the community mental health policies not only overlooked the social and human needs of the severely ill, but also bifurcated therapeutic or treatment services from care and support services. The former were identified more with, and included in, the medical healthcare system, whereas the latter were affiliated with the welfare or social system. This bifurcation inadvertently distorted priorities, with more focus applied to providing therapeutic services in outpatient settings for a broadly defined population (Grob, 1992). Still others have argued that with the closure of state mental hospitals and related services, many chronically and severely ill individuals found themselves with nowhere to go for needed services and help (Lamb and Bachrach). Transformations in mental health laws to protect the mentally ill and promote their rights began to dominate intellectual discourse. New laws demonstrated the evolutions in understanding of the concepts of confinement, commitment, access to services, and the scope of individual autonomy in treatment decisions (La Fond). In the last decades of the twentieth century, mental health law became an able instrument of advocacy and protection of the civil, legal, and ethical rights of the mentally ill (Perlin; La Fond).

Access

Changes in the way mental health services are defined, distributed, delivered, and financed have produced a number of ethical concerns related to justice and other ethical principles. One of these is the problem of access to services. In the United States, healthcare is ordinarily covered by private or public insurance. Insurance reimbursement policies were originally constructed to shield both patient and provider against the worry about costs once an illness actually occurred. Reimbursements were quite generous and uncontested, with third parties acting as silent partners in the negotiation between physician and patient for needed services. The result of this is now obvious: a highly inflationary system with rapidly accelerating healthcare expenditures (Fuchs), which has in turn led to the growing managed care system.

Obviously, the 16 percent of the U.S. population currently estimated to be without public or private health insurance will also be without financial insurance against psychiatric or addictive disorders (Bureau of the Census). Yet even where insurance is provided, mental health insurance benefits are not on par with those in the general medical sector (U.S. Surgeon General). Moreover, Medicare and Medicaid place restrictions on the amount and setting of services for psychiatric and addictive disorders, thus further restricting the access and availability of needed resources for the mentally ill. While opportunities for mental health services increasingly exist under Medicare, only 5 percent of Medicare funding at present goes for mental health (U.S. Surgeon General). Finally, office-based care by psychiatrists, and often by other mental health providers, is generally covered by insurance firms but is rarely equivalent to other office-based physician care (Frank, Goldman, and McGuire, 1992).

Thus, although policies have been aimed at treating mental illness on an outpatient basis, all the incentives in insurance programs send the signal that inpatient treatment is what will be reimbursed. Of all mental health expenditures, an estimated 70 percent are designated for inpatient care. Many health insurance policies will reimburse fully for hospitalized care, but only partially cover outpatient care, and pay even less for prevention services. Nursing homes have not been integrated into any mental health system, although the Nursing Home Reform Act of 1987 mandates "active treatment." The predictable mental health needs of an aging population have not been factored into health policies, thus widening the gap between perceived need and access to service for a substantial segment of the population (Gatz and Smyer).

Moreover, simply being labeled as receiving treatment for a mental disorder can affect an individual's access to the general healthcare system. This occurs through the practice of medical underwriting, a process that denies individuals health insurance because of a *medical disorder* for which they received care in the past (Boyle and Callahan). These forms of discrimination not only impair the individual's access to services that are otherwise standard, but also further the antiquated idea of the dualism between mind and body.

These restrictions on the access and availability of services through insurance and financing mechanisms create inequities in many parts of the system. First, many Americans, especially the poor and underinsured, cannot afford the cost of needed mental healthcare. Second, many uninsured people at risk for major mental and/or addictive disorders will be denied appropriate prevention services and be inadequately protected against the possibility of catastrophic financial harm. Third, failure to provide meaningful access to services within the mental health system results in inappropriate and excessive use of the general resources of healthcare, creating further inequities for individual consumers and providers, and increasing the economic burden on the general medical economy as a whole. These inequalities of access to needed care are unacceptable to a decent and humane society (U.S. President's Commission; U.S. Surgeon General). Some of them may be explained by historical accounts of the various ideological, political, and societal events that helped produce them, but they are not justified from an ethical point of view. Any society concerned with the well-being of its citizens cannot promote the importance of healthcare in achieving well-being while allowing people to suffer because of arbitrary barriers to healthcare.

Parity

A related ethical issue has to do with whether funding of treatment for mental health conditions should be equal to that of the general health sector. Many commentators have noted a lack of parity both between the two healthcare systems and within the mental health system itself. The latter can be expressed as both the disparity of treatment between kinds of mental illness, and the disparity of treatment between different degrees of mental illness severity.

Despite several major legislative efforts in the 1990s and early 2000s, there is little evidence that any significant change in mental health parity has occurred. Aside from failing to be passed by Congress, these bills failed to greatly affect parity for many reasons, including: covering only a subset of the population; covering only selected illnesses, often based on an archaic and fictional division of the mental and the biological; only covering certain severities of illness, often based on diagnosis of a specific illness or by level of debilitation; exemptions for small businesses, or for large cost increases; unequal limits on annual costs, lifetime costs, outpatient visits, days of inpatient care, per visit co-payments, or annual deductibles; and a variety of nearly nonquantifiable disparities in the quality of care provided (Rochefort, 1996; National Advisory Mental Health Council, 1998,2000; Geller; U.S. Surgeon General's Report).

One such piece of federal legislation passed into law in 1996 was the Mental Health Parity Act (MHPA) (Domenici/Wellstone), which required all group health plans already covering mental healthcare to have equal cost restrictions on yearly and lifetime benefits as traditional medical and surgical services. The MHPA had little effect on parity due to provisions within the act that allowed for exemptions for small businesses and for businesses that experienced an increase in cost because of the act. Moreover, 87 percent of employers' plans that complied with the MHPA had one or more methods of restricting mental health benefits more than traditional medical or surgical services. Congress allowed the MHPA to expire in 2001 and failed to pass the proposed 2001 Mental Health Equitable Treatment Act (S. 543), which attempted to address most of the problems with the 1996 MHPA (Gitterman, et al.; Barry and Frank; Geller; General Accounting Office).

The greater focus on mental health parity by the federal government spread to the state legislatures with similarly ineffective results. As of 2001, thirty-one states had adopted mental health parity requirements for employee health insurance, with all but five doing so after the passage of the 1996 MHPA. However, the 1974 Employee Retirement Income Security Act prevents states from regulating self-insured plans, thus limiting the affected population to those in group health plans (Gitterman, et al.; General Accounting Office; National Advisory Mental Health Council, 1998, 2000).

Two possible successes for parity have occurred, though their future is unclear. First, President Clinton announced at the First White House Conference on Mental Health in 1999 that health plans for all federal employees must cover mental health at full parity (though the durability of this order was unclear with the change in administration in 2000). Second, the Americans with Disabilities Act (1990) provides some hope for protection for people with severe mental disabilities to receive basic mental health services and protection from discrimination, but the constitutionality, and thus the future, of the ADA is questioned by some (Geller).

In general, parity legislation has thus far had only a small effect on parity itself. Parity legislation appears to encourage the presence of managed care, which results in lower or stable costs for mental healthcare. In general, these lower costs seem to come from a combination of increased efficiency and lower quality and accessibility (National Advisory Mental Health Council, 1998, 2000; General Accounting Office; U.S. Surgeon General).

For decades, U.S. health policy has been centered on the short-term, acute-care general hospital, despite the fact that this does not match the population's health needs; this continued focus points to the problems of parity of mental health services between different groups within the population. Preventive services have until recently been largely neglected, as have the needs of chronically ill elderly, children, and youth. While healthcare in the acute-care hospital in the United States is arguably the best in the world, in mental health, care *outside* a hospital is demonstrated to be better and less expensive than care in the hospital (Kiesler). This raises the caveat that simply mimicking the flawed policies of the general health system may not necessarily prove to be the best strategy for mental health policymakers of the future, even though it may lead to greater parity between the two systems (Kiesler; U.S. Surgeon General). Arbitrary limits on outpatient services, inpatient hospitalizations, community-based health services, and higher co-payments for mental health services reflect the way mental health is disvalued in society, and its inferior status compared with physical health. Whenever a society establishes a priority system for the kinds of goods and services it makes available to its members, questions of fairness are evoked. If a society assigns insufficient or inadequate resources to a segment of the population at risk for or suffering from mental and addictive disorders without appropriate justifications, it violates ethical commitments to social beneficence, liberty, compassion, and justice.

Fragmentation

One of the most difficult ethical problems confronting the current mental health service system is the striking lack of coordination and collaboration among other human service agencies. The current mental health system is remarkable for a pronounced variation in the use of institutional and community-based services, admission rates, lengths of stay and services, and multiple funding sources and patterns.

Fragmentation in services is a consequence of developments in the larger healthcare system, as well as of the lack of integration in legal, social, economic, and scientific aspects of health policy. These problems stem from a cluster of ambiguities that prevail in the field of mental health: the diversity of beliefs regarding the concept of mental disease or disorder (Wakefield; U.S. Surgeon General); deeply-rooted cultural beliefs regarding behavior that seems inexplicable, bizarre, or threatening; and disagreement about which social policies to adopt in regard to persons whose autonomy is impaired by mental disorder, especially when this impairment may lead to the possibility of harm to self or others. Serious conceptual and normative questions regarding the definition of mental illness have led to practical disagreements about when and how to intervene. As of the mid-1990s, models of mental illness ranged from the purely medical model and its psychotherapeutic or psychoanalytical interventions, to a model that emphasizes the unity of biological, psychological, social, and personal factors in health and illness. Different mental health therapists subscribe to a variety of different theories on the nature of mental health. Specialists disagree, for example, about the boundary between mental illness and other forms of deviancy, and about the relative contributions of individual, family, environmental, and social variables in producing mental disorders (Rochefort, 1989). It has also been noted that a significant portion of the fragmentation and lack of coordination within the mental health system may be due to idiosyncratic factors related to politics, prejudice, and professional or civic self interest (Rochefort, 1989).

The lack of precise criteria to define and classify mental illness apparently has the following result: Both the person with catatonic schizophrenia, incapable of functioning in social life, and the person with an obsessive-compulsive neurosis, whose behavior is simply bothersome, are labeled as mentally ill. Both may be in need of some treatment to reduce distressing symptoms, but these services may be quite distinct from one another, and they raise significantly different concerns regarding what should count as a *mental health service* and what should not.

Thus, despite great expansion of mental health services, the system is remarkably fragmented. Without a centralized organization or locus of responsibility, quality of and accountability for services remain fragmented (U.S. Surgeon General). On the systemic level, the problem of fragmentation seems to have produced the following: under-treatment of the seriously and chronically ill; undervaluing of prevention services, rehabilitation, and long-term care; diminished access to available services for those with or at risk of mental and addictive disorders; restrictive barriers to insurance entitlement; and a generally lower position on the national healthcare agenda, despite data that demonstrate the efficacy of treatment for many forms of mental disorder.

These ambiguities exert a profound influence on normative and value questions, and can have a direct effect on the kind of mental health policy that is developed and the priorities it has in the overall healthcare agenda (Rochefort, 1989; Mowbray, Grazier, and Holter). Ultimately society's norms and values determine what kinds of services and resources will be made available, to whom they will be targeted, where they will be provided, and how they will be financed. Disparities of access and status provoke dilemmas of choice regarding principles of justice, on the one hand, and principles of cost-effectiveness on the other. They also expose the genuine difficulty of deciding which values should govern the policymaking process, when not all values can be equally promoted. For example, if society decides to purchase mental health services because of underlying commitments to humanitarian goals, then policy should probably be directed toward those individuals who have the most serious conditions and greatest needs. However, if society purchases mental health services because of commitments to principles of social or economic utility, then policy efforts would need to be driven by cost-benefit analyses and outcomes. In this instance, priority might be given to those individuals with depression, anxiety disorders, and alcohol addiction, because of the likelihood they would recover sufficiently to return to productive society (Klerman, Olfson, Leon, et al.). The principle of favoring the least well-off would have to be balanced against other considerations of justice that might be based on utilitarian assessments of what might provide the greatest benefits to the greatest number of people.

These priority decisions ultimately reflect political and social value judgments about how much society is willing to invest in caring for its mentally ill citizens. Although disagreements persist on a number of conceptual, scientific, and professional issues, there does seem to be consensus on one essential point: Mental health must have a higher status in the healthcare system. Furthermore, setting priorities regarding the relative value of mental health services will require a decision process based on principles of fairness, non-abandonment of those in need, public accountability, and objectivity (Boyle and Callahan; U.S. Surgeon General).

Ethical Values in Contemporary Mental Health Policy

Since the publication of the influential Flexner Report in 1910, the U.S. healthcare system has been based on a medical model firmly anchored to the concepts of scientific, physical medicine and notions of medical treatment and cure. Ideas of prevention, health, and public health were relegated to the "back porch" (Smith). American society has structured its health policies, programs, professions, and institutions on this model for many decades, as though there were little relationship between mental and physical health. However, there is a growing body of empirical knowledge that documents the role of mental state in the maintenance and deterioration of good physical health, and in the treatment and recovery from physical illness (Praeger and Scallet).

Contemporary mental health policy, whether developed in terms of prevention, accessibility to needed services, rehabilitation, or maintenance of persons most greatly in need, is in a process of change. These changes reflect shifting concepts of mental illness, new etiological formulations of mental disease, treatment interventions, epidemiological trends, past program successes and failures, and the broader social, political, and economic currents (Rochefort, 1989; Rochefort, 1996). Ultimately, policies represent society's effort to deal with one of the most difficult and persistent human problems: how to balance the classic conflict between the power of the state to act for the good of society, and the responsibility of society to ensure the full expression of individual rights and freedoms. Questions concerning who has the legitimate power to control the lives of the mentally ill continue to provoke philosophical debate. In contemplating the public and scholarly discourse in the mental health field over the past several decades, several difficult questions regarding past policies must be confronted before new ones are generated. For instance, what ethical values, if any, were promoted by policies of deinstitutionalization? Has the goal of returning the mentally ill and disabled to the community for care enhanced the rights of individuals, or has it produced in them, or their communities, some greater harm? How will mental health policy of the future balance the competing claims of liberty, equality, and social beneficence?

Such questions represent difficult value choices, made more complex by a climate of increasing public distrust (Jellinek) and scarcity of fiscal resources (Morreim). Past assumptions of political liberalism and economic expansion are no longer valid. Instead, policies of allocation are becoming more explicitly value-directed, not simply regarding cost-containment or efficiency but on principles of equity, justice, and compassion (Jennings). Allocation policies, insofar as they are regarded as socially legitimate and politically acceptable, may then be understood to be a mechanism by which society seeks to define and to express its sense of self, its values, and its integrity (Childress). In a time of great transition and transformation of the healthcare system at large, American society is at a crossroad in its attempt to understand the health of the human mind and of all the forces that seek to promote and sustain it (Praeger and Scallet). It is a time of constructive chaos, in which the very mission and telos of healthcare are being redefined. Along with this redefinition, the opportunity exists to raise the status of the mental health services field from the "poor stepchild of the health care delivery system" (Boyle and Callahan, p. 53) to a level that conjoins mental and physical well-being and integrates biomedical and behavioral knowledge regarding health parameters. To accomplish this, it will be necessary to pay close attention to issues of equity in the access, availability, and efficacy of all health-related services, and to avoid arbitrary demarcations between mental and physical well-being (U.S. Surgeon General; Mowbray, et al.).

At the beginning of the twenty-first century, there is clear and urgent need for serious ethical reflection on which values and priorities should govern the mental health policies of the future. What is needed is an integrated, comprehensive, and equitable strategy that builds on knowledge and research in mental and physical health, and links these to appropriate and beneficial services for those in need of them. Problems of individual and social justice penetrate all areas of society, but are especially powerful in relation to the needs of the mentally ill, and to the communities in which they live. Undoubtedly, care and treatment of the mentally ill pose a range of ethical concerns that will continue to challenge society well into this century.

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SEE ALSO: *Children: Mental Health Issues; Coercion; Confidentiality; Disability; Electroconvulsive Therapy; Informed Consent: Issues of Consent in Mental Healthcare; Institutionalization and Deinstitutionalization; Life, Quality of; Mental Health, Meaning of Mental Health; Mental Health Therapies; Mental Illness; Mental Institutions, Commitment to; Mentally Disabled and Mentally Ill Persons; Patients' Rights: Mental Patients' Rights; Psychiatry, Abuses of; Psychoanalysis and Dynamic Therapies; Psychopharmacology;* and other *Mental Health Services* subentries

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MENTAL HEALTH THERAPIES

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The endless variety of mental health therapies can be sorted out and compared only if it is recognized that they differ both in the ends for which they strive and in the means they employ to reach these ends. Some therapies are directed toward straightforward and concrete goals such as symptom relief. Relaxation training to address performance anxiety is one example. Other therapies are directed toward more complex and abstract goals, such as an increased capacity for intimacy. Psychoanalytic therapy to improve the quality of one’s romantic relationships is one example. Psychotherapeutic techniques can be compared and contrasted only if this difference in their goals is appreciated. The goals of therapy are at least partially implicit in the method of therapy employed by the therapist. Because no one therapist is skilled in all types of psychotherapy, choosing a therapist usually means choosing a therapy—a fact that patients choosing a therapist often do not understand.

The Goals of Therapy

This question of who should choose the goals of therapy is a form of the classic dilemma concerning paternalism in medicine, which involves balancing concern for patient welfare with respect for patient autonomy. Sidney Bloch (1982, 1989) has discussed this dilemma as it applies to psychotherapy. Beneficence dictates that therapists do whatever they think is best for their patients. Respect for autonomy means allowing patients the freedom to decide for themselves what is best. Because compromised mental health so often means compromised autonomy, balancing these values in psychotherapy can be particularly difficult. Therapists frequently believe that they should promote the capacity for autonomy in their patients even if the patients want only to feel better. In his 1989 article, Bloch described how he grappled with whether to address only his patient’s distressing writer’s block, as she preferred, or to explore the forces behind her general loss of autonomy. Her ability to choose rationally between short-term and long-term goals for therapy, such as relief from distress and greater capacity for choice, might itself have been compromised.

Clearly, psychotherapy must be conducted with some idea of mental health as a goal and a value. Thomas Szasz, a practicing psychiatrist who does not believe that mental disorders are diseases or that mental illness compromises personal autonomy, has long accused psychotherapists of inculcating social and ethical values under the guise of scientific medical treatment. If therapists are not restoring their patients’ lost capacity for choice, then they can only be brainwashing them to make choices as the therapists would. Because psychotherapy aims for the value-laden goal of mental health, it blurs the boundary between science and ethics more than other medical therapy. It has features that are associated with science, such as theories of causation, experiments, and experts. But psychotherapy also must always contain elements from ethics, because if it is not in part an "ideology of healthy conduct" (Karasu, p.91), it has no direction or goal. Doing psychotherapy is in part providing medical treatment and in part providing ethical education.

Because it is not possible to be perfectly value-neutral, vigilance and restraint concerning the imposition of values upon one's patient are among the foremost duties of the psychotherapist. Dynamically trained therapists are schooled concerning the dangers of *countertransference,* the distortion of the therapeutic process by the therapist's personal preferences and history. There are also dangers beyond the personal level. Each system of therapy operates with a value-laden notion of mental health, toward which it strives. Those therapies directed toward the relief of symptoms, such as depression and anxiety, strive toward distress-free function in a given environment. Normally this presents no particular ethical challenge. But in certain environments, relief of distress may be problematic. For example, Robert Jay Lifton, in his 1985 book, *Home from the War,* discussed the situation of American soldiers in Vietnam who were opposed to the war. The therapist treating patients in such situations faces the ethical question of whether the distress or the situation is pathological and needs changing.

Those therapies that operate with more elaborate models of mental health involving mature ego defenses, character development, or adaptive coping encounter different conflicts. Psychoanalytic thought long conceptualized homosexuality as a distorted or degenerate form of intimacy necessarily associated with character pathology. This evaluation of homosexuality has changed in recent years. But the challenge of distinguishing normal and pathological modes of human relationship will remain for psychodynamic psychotherapy because it defines mental health in terms of character. There are now those arguing that sadomasochistic or pedophilic relationships are not necessarily pathological.

In general, mental health treatment promotes adaptation to one's current social environment. It therefore tends to reinforce the prevailing norms of society. This is true both for *supportive* psychotherapy, which shores up a patient's usual ways of maintaining self-esteem, and for *uncovering* psychotherapy, which challenges these defenses in order to promote more mature modes of managing conflict and disappointment. The Austrian neurologist Sigmund Freud (1856–1939) proposed the capacity "to love and to work" as the mark of mental health. No better succinct summary of functions that indicate mental health has been made since. Nevertheless, the values of capitalist and bourgeois Victorian culture lie implicit in this prescription. Is adaptation to a repressive society indicative of mental health? Feminists have criticized models of love available to women. Marxists have criticized alienated labor as a legitimate lifetime pursuit.

Freud, and nearly all psychotherapists since, treated primarily upper- and middle-class Caucasians. The goals of therapy and the therapeutic means used have been derived within this class context. Public funding for psychotherapy has been and continues to be scant. Psychotherapy is considered by society to be less of a necessity than medical care. Community mental-health centers did do some psychotherapy in the 1960s and 1970s but are now directed toward medication and case management of the chronically mentally ill. It is virtually impossible in most states to obtain psychotherapy without insurance or discretionary income.

Whether psychotherapy can reach beyond its historical boundaries of class and race is not yet clear. It has traditionally addressed an educated, articulate, and motivated group of patients from the same social class and culture as the therapist. Because most psychotherapy is done with individual patients, it addresses individuals as the primary cause of their own problems. This is a valid approach to the denial practiced by middle-class patients concerning their life difficulties but may not be fair to lower-class patients facing poverty and prejudice. Proponents of *radical therapy* have tried to respond to this challenge by pathologizing the victimizing situation instead of the victimized individual. They thus construe the therapist as an agent for social as well as individual change. This approach avoids the problem of the therapist normalizing patients to the status quo. But it maximizes the problem of value imposition by the therapist, who now encourages the patient to reject society's view of the honorable life in favor of one advocated by the therapist. A middle ground has recently been explored through attempts to adapt psychotherapy to indigent patients through the addition of adjunctive social services (Wells et al.).

Mental health therapies not only respond to culture but also shape the culture within which they operate. As the values of mental health therapy have diffused into Western society, they have become a target for criticism. Since Philip Rieff spoke of "the triumph of the therapeutic" in 1966, numerous philosophers and sociologists have joined in criticizing "therapeutic values" that promote the welfare of the individual over that of the community. In 1978 Christopher Lasch accused the psychotherapies of promoting a form of narcissism in Western culture through the promotion of selfish motives and ignoring the broader social interest. In his 1971 book, *Against the Self-Images of the Age,* Alasdair MacIntyre specifically criticized the imposition upon society of such goals as personal satisfaction and interpersonal effectiveness. He contended that ethical evaluation of these goals had been bypassed in deference to the general idea of therapy. Whether the goal of self-gratification has gained preeminence as a result of therapy, or whether therapy has grown as part of a larger trend within society to look toward the individual as the vehicle for fulfillment, is beyond the scope of this entry.

Modes of Therapy

Though there are over 200 psychotherapies and supporting philosophies presently in use by mental health professionals, most of these have not been scientifically tested for effectiveness. Only a few of these therapies can be considered specifically in this entry. Emphasis will be given to recently developed and proven therapies. Although Hans J. Eysenck's claim, from his 1953 book, *Uses and Abuses of Psychology,* that psychotherapy in general offers no better chance for recovery from psychological distress than does spontaneous remission has been repeatedly disproved, it is not clear what aspects of psychotherapeutic technique account for its effectiveness. Responding to the question of whether one form of psychotherapy was better than another, Lester Luborsky and colleagues could only quote the nineteenth-century English writer Lewis Carroll and ask, "Is it true that 'everyone has won and all must have prizes'?" There has been much research since the late 1970s demonstrating therapeutic effects specific to the type of psychotherapy used, but the evidence favoring effects not specific to a particular psychotherapeutic method still predominates.

A number of reasons have been proposed to explain these findings (Beutler and Crago). First, there is strong evidence that a good therapist–patient match is a more powerful predictor of therapy outcome than is treatment method. Second, the measures used to assess efficacy for experimental treatment groups may be insensitive to important differences in outcome between individual patients. Furthermore, the goals sought by different therapies may be so different as to not be adequately captured by a common measure of outcome. Third, differences in the level of psychotherapist experience may have more impact than differences in psychotherapy approach. An attempt has been made to produce therapy manuals for clinical trials that minimize these factors. But these manuals have also come under criticism as retarding the therapist's ability to respond to the individual needs and style of the patient. In summary, it has been difficult to show the advantage of one psychotherapeutic method over another because personal elements of the patient–therapist interaction, not easily tested by current methods, appear to be critical to therapeutic success.

PSYCHODYNAMIC THERAPY. A number of therapies derive their understanding of the patient and the modes of therapeutic action from Freudian psychoanalysis. Almost from the moment that Freud formulated the foundations of psychoanalysis, they were subject to revision by his followers such as Carl Jung, Alfred Adler, and Karen Horney. Elaborations of psychoanalytic theory in the direction of ego psychology by Anna Freud and Erik Erikson, and in the direction of object-relations theory by Melanie Klein and Donald Winnicott, have been especially influential in contemporary psychodynamic psychotherapy. Nevertheless, there are important similarities among these different approaches. They all consider unconscious forces to be important in psychopathology and insight into these forces to be therapeutic. Contemporary psychodynamic therapies derived from these theories continue to use the therapeutic relationship to reveal unconscious determinants of behavior. However, various features of the treatment are modified, such as its frequency and duration (e.g., through brief dynamic therapy); its metapsychology (e.g., through self-psychology); or its understanding of basic conflicts (e.g., through existential psychotherapy).

In brief dynamic therapy, treatment is more focused, short-term, and directive than in classical psychoanalysis. Whereas the latter may involve four to five sessions per week over a period of years in psychoanalysis, brief dynamic therapy may be completed in as few as ten to twenty weekly sessions. The therapist tries to elucidate a *core-conflictual theme* that is then explored. Typical difficulties in one particular area of life, such as assertiveness on the job, are the focus of treatment. Like psychoanalysis, brief dynamic therapy considers the re-creation of important conflicted relationships in the relationship with the therapist—transference—to be an essential therapeutic tool. Lester Luborsky, David Malan, Habib Davanloo, Hans Strupp, Peter Sifneos, and John Mann have articulated different types of brief dynamic therapy. Its effectiveness has been demonstrated in the treatment of stress and bereavement, late-life depression, and adjustment, affective, and personality disorders (Goldfried, Greenberg, and Marmar).

Brief dynamic therapy is not simply a compressed form of psychoanalysis; it holds unique benefits and risks. Exploration of the patient's psyche is focused but intense. Patients must be well motivated, have a circumscribed problem, and be able to tolerate an unsettling and persistent confrontation of their customary psychological defenses. Therefore, appropriate selection of patients is crucial to the success of this mode of therapy.

Self-psychology, another descendant from psychoanalysis, was developed by Heinz Kohut (1913–1981) as an elaboration of the psychoanalytic concepts of narcissism and the self. Kohut conceived psychopathology in terms of deficits in the self rather than conflicts among unconscious drives. Kohut defined "self" as an independent center of initiative. Self-psychology sees the most fundamental psychological need to be the organization of the individual's psyche into a cohesive configuration, the self. The self must then establish sustaining relationships between itself and its surroundings.

The therapist, through empathic understanding, establishes herself as one of these sustaining relationships for the patient. Once the therapist has been established as a *self-object,* the stage is set for *transmuting internalization,* whereby the self of the patient is gradually able to perform those functions previously provided by the therapist. This occurs through gradual frustration of the patient's need for a perfectly empathic other. The result is the restoration of the self as a center of initiative, compatible with one's ideals and talents and capable of providing a sense of purpose to one's life.

Rather than presenting ethical challenges entirely different from other dynamic therapies, self-psychology highlights the power and peril present in all the transference-based therapies. In order to be effective, the therapist must become a *self-object* for the patient, that is, a source of self-esteem. Thus, the process of developing a cohesive and autonomous self in this therapy will involve periods of intense dependence and vulnerability for the patient.

Existential psychotherapy is heir to the humanist and client-centered approaches that flourished in the 1960s. Existential therapy is a psychodynamic therapy because it is primarily concerned with the interaction of psychological forces within the individual but, compared with psychoanalysis and its near cousins discussed above, "it is based on a radically different view of the specific forces, motives, and fears that interact in the individual" (Yalom, p. 8). Existential dynamics are not developmental in the way that Freudian psychodynamics are. Rather than focusing on how the past is recapitulated in the present, existential therapy focuses upon fundamental intentions or choices that are part of the "future-becoming-present." Irvin D. Yalom has detailed four "ultimate concerns" with which existential therapy deals: death, freedom, isolation, and meaninglessness.

Because existential psychotherapy rests its theory of psychopathology on universal human concerns, it sees a fundamental continuity between the normal and the pathological. Psychological symptoms are seen as a natural part of confronting the dilemmas and paradoxes of human life. This can mean that the patient seeking to *just feel better* or to pass from the pathological to the normal can be at odds with the existential therapist, who considers dread an inescapable part of life. For similar reasons, it has also been difficult to do good empirical research on existential psychotherapy. This form of therapy focuses upon the personal creation of meaning, thus presenting a view of the psyche not especially amenable to causal analysis. Existential and humanistic psychotherapies have generally had more theoretical than practical appeal. They offer a rich image of the psyche, devoid of reductionistic formulas, but have not found wide pragmatic application in reducing the distress of individual patients.

COGNITIVE-BEHAVIORAL THERAPY. Since the 1970s, a "cognitive revolution" has largely overtaken behaviorism in psychology. In psychotherapy, this revolution emerged in the form of cognitive–behavioral therapy. While behaviorism treated the mind as a black box upon which the powers of environmental reinforcement act, cognitivism holds that interpretations by the individual determine what constitutes positive or negative reinforcement in a given situation. Controlled clinical trials have demonstrated the efficacy of cognitive therapy for depression, chronic pain, anxiety, and a variety of other disorders. In cases of mild to moderate severity, its efficacy is similar to that of antidepressant medication, and it may provide a lower rate of relapse in such conditions as panic disorder (Beck, Emery, and Greenberg).

Cognitive–behavioral therapy essentially consists of training in problem solving. Cognitive therapy is based on the assumption that distress originates from ineffective responses to difficult life circumstances. Mediating between life events and emotions, and driving these responses, are spontaneous interpretations or *automatic thoughts* that are subject to a variety of common distortions. Therapy targets these cognitive distortions, such as overgeneralization and arbitrary inference, by helping the patient make a scientific "turn to the evidence" for these thoughts. Cognitive–behavioral therapy usually includes "homework" for the patient both of a cognitive (e.g., recording automatic thoughts) and a behavioral (e.g., completing small mastery-enhancing tasks) nature. The natural focus of cognitive therapy is upon the present situation and interpretations, though it is possible to plumb ever deeper into the personal assumptions and habits that lie behind current automatic thoughts. Because of this focus on the here and now, cognitive–behavioral therapy tends to be much more simple and straightforward than the psychodynamic therapies described above. Cognitive-behavioral therapy is focused on the amelioration of the current episode of depression or anxiety, whereas psychodynamic therapies also strive to address those factors that make a patient predisposed to episodes of depression and anxiety.

Cognitive therapy portrays mental health in terms of an absence of distorting cognitions. This lends a value-free, scientific air to this psychotherapy that may, however, not be entirely accurate. A body of research exists that suggests depressed persons' perceptions and judgments (especially of interpersonal situations) are quite accurate and realistic, whereas nondepressed persons show systematic optimistic biases and distortions (Taylor and Brown). If cognitive therapists are not bringing their patients back into the light of interpersonal truth, then the therapy can take on the flavor of "brainwashing for better social functioning." As discussed above, there is a tendency among all forms of psychotherapy to adapt patients to their current social milieu.

NONTRADITIONAL THERAPIES. A vast array of practices are marketed to improve well-being. Many are scientifically unproven, and some violate ethical precepts held dear by the more traditional psychotherapies. Massage therapy, Rolfing, bioenergetics, and a host of other techniques use physical methods, including the touching of the patient by the therapist, to relieve psychological as well as physical problems. These therapies function as psychotherapies insofar as they associate the release of muscle tension with the release of emotional tension. One of Freud's disciples, Wilhelm Reich (1897–1957), pioneered the idea of character armor as muscle tension and the incorporation of massage into psychotherapy.

Other therapies use techniques derived from Eastern religions to increase well-being. Meditation and guided imagery, for example, have become standard techniques at stress-management clinics. In the medical setting, they are stripped of their metaphysical elements and presented as secular relaxation training. This training varies in sophistication from deep-breathing exercises to Buddhist mindfulness meditation. The rationales offered for these therapies similarly vary from physiological calming to appreciation of the fundamental emptiness and interdependence of all events. There is mounting evidence of the effectiveness of this kind of treatment for stress-related physical disorders such as headaches or back pain. Certain sectors of society, however, remain suspicious of the religious roots of these treatments. These nontraditional therapies challenge people's sense of the proper boundary between psychotherapy and sexual gratification, on the one hand, and between psychotherapy and religious practices, on the other.

Ethical Issues in the Psychotherapies

Developing a method by which to choose the appropriate psychotherapy is a problem that has only recently received serious attention. Traditionally, the therapy received was determined by the therapist one selected. The appropriateness of the therapy was judged by the intuition of therapist and patient. The attempt to derive a *differential therapeutics* in psychotherapy, comparable with that found in other areas of medicine, is in its infancy. All patients with similar levels of depression do not need the same type or duration of therapy. In psychotherapy, unlike in physical medicine, diagnosis alone is inadequate to select appropriate psychotherapy. For example, more than a diagnosis of major depressive episode must be known about the patient, such as the person's individual history and personality. Researchers are working to specify the "intermediate-level psychological determinants of problems that mediate between diagnostic grouping and type of intervention" (Goldfried, Greenberg, and Marmar, p. 685).

The importance of factors other than technique to psychotherapy outcome has led some to stress the centrality of the therapeutic alliance in the treatment process. Section 1 of the psychiatric annotations to the first edition of the American Psychiatric Association's (APA) *Principles of Medical Ethics* (1973) states, "The doctor–patient relationship is such a vital factor in effective treatment of the patient that the preservation of optimal conditions for development of a sound working relationship should take precedence over all considerations" (p. 1060). Within this relationship, the greatest challenge for the therapist is the appropriate use of power. The *transference relationship* detailed above gives the therapist tremendous influence over the patient's life, which must be balanced by a viable *therapeutic partnership* (Karasu).

Informed consent for psychotherapy has been proposed as one way to address these concerns. In medical practice, informed consent usually means a discussion between patient and doctor about the risks and benefits of an invasive treatment prior to its initiation. The application of informed consent, even in this regard, has lagged in the area of psychotherapy. Informed consent is often thought unnecessary or implicit for something as low-tech as psychotherapy. But Peter S. Jensen and colleagues argued in 1989 that "informed consent is more than just an ethical or legal obligation: inherent in the process of informed consent is the potential for the enhancement of clinical work" (p. 379). That is, informed consent offers an opportunity to establish the treatment alliance on solid ground. Frank discussion of both the limitations and the benefits of therapy diminishes the illusion of therapist omniscience and patient helplessness so commonly present at the initiation of therapy.

Boundaries of Therapy

Psychotherapy has been criticized as *the purchase of friendship.* Because both friendships and therapeutic relationships are ideally honest, intimate, and supportive, the question of their difference is a natural one. The crucial difference is mutuality or reciprocity: friends serve each other's needs. A therapist is paid to serve the patient's needs. The therapist uses professional expertise to fashion a relationship with his patient that addresses and corrects the patient's psychopathology. The patient is not obligated to entertain, fascinate, or gratify the therapist; responsibilities are limited to regular attendance and payment for sessions. The theory is that a patient concerned with his therapist's well-being cannot give adequate priority to his own recovery.

In practice, this boundary between therapist and friend is more fuzzy. Therapists must find their patients worthy of interest and concern if therapy is to succeed. It is difficult for therapists to develop deep concern for their patients and yet to not need their approval or companionship. Most therapies proscribe social contact between therapist and patient in order to better define the therapist's role and task. Some therapies, such as those that offer *re-parenting,* specifically promote social therapist–patient contacts outside of sessions. Though some find this expansion of the power of the therapeutic relationship helpful, most would consider the lack of clear boundaries dangerous.

The most egregious violation of boundaries in psychotherapy is sexual contact between therapist and patient. Approximately 5 percent of psychiatrists and psychologists admit having sexual contact with their patients (Lakin). Given the intensely intimate atmosphere of therapy, such temptations are understandable. Nevertheless, sexual contact with a psychotherapy patient is considered the worst possible exploitation of the transference relationship. This is because therapists who become involved sexually with a patient are exploiting the trust established for therapeutic purposes for their own sexual gratification. The APA prohibits all sexual contact with current and former patients.

While there is general agreement that sexual gratification of the therapist is always a sign of exploitation and to be avoided, how this avoidance is accomplished is subject to considerable variation. Psychoanalysts allow free expression of all sexual fantasies concerning the therapist but prohibit all touching. Massage therapists and others who do body work rely upon the emotional release prompted by touch but avoid all sexual conversation.

Confidentiality has traditionally been one of the most important ways in which the boundaries of therapy are respected. Frank and open discussion of the patient's deepest hopes and fears is essential to psychodynamic therapy and would be inhibited by the possibility of public disclosure by the therapist. The stigma associated with psychotherapeutic treatment means that disclosure to employers, colleagues, or neighbors can produce actual damage to the patient's social well-being.

Since the 1976 *Tarasoff v. Regents of the University of California* case, which mandated that psychotherapists warn identifiable potential victims of violence, patients' rights to therapist confidentiality have been limited when "disclosure is necessary to avert danger to others." Justice Matthew A. Tobriner's comment in this case, "The protective privilege ends where public peril begins," means that therapists weighing disclosure must consider the public good as well as the good of their patients. Psychotherapy cannot exist in a legal and moral vacuum within society. The *Tarasoff* decision has at times, however, been used to expand the therapist's social responsibility for potentially dangerous patients. This responsibility can include not only warning potential victims of patient violence, on the basis of uncertain evidence, but also testifying against one's patients in court and providing preventive detention in psychiatric units for those considered potentially violent.

Mental Health in the Medical Model

Dynamic psychiatry, which emphasized the role of psychological processes and reactions, dominated mental healthcare for three-fourths of the twentieth century. This psychiatry had blurred the line between normal and pathological psychological processes, claiming that unconscious forces operated in both. Dynamic psychiatry focused on case formulation, a highly individualized, semibiographical account of the important events, relationships, and unconscious forces in a patient's life. Though these formulations could be formulaic or reductive (e.g., jokes about "head shrinking"), their intention was to bring out the unique situation of the individual.

In 1980 the 3rd edition of the APA's *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-III*) appeared, signaling the beginning of a new hegemony for diagnostic psychiatry. Diagnostic psychiatry, in contrast with dynamic psychiatry, sought to find the ways that patients were fundamentally similar to each other. It emulated the central role that diagnosis played in the rest of medicine. While the state of psychiatric science precluded a classification of diseases based on etiology (causes) and tissue pathology, psychiatric diagnosticians were able to provide categories of symptoms called mental disorders that were linked with prognosis, family history, and treatment implications. These categories allowed researchers to reliably document the prevalence of specific disorders, to determine the efficacy of treatments in groups of similar patients, and to explore patterns of inheritance for these disorders.

The overall effect of these changes was to bring psychiatry in much closer alignment with the prevailing medical model. Public mental health shifted away from community-focused efforts to improve overall mental health and toward preventing and treating specific disorders in individuals. Psychiatric research became tightly linked with specific disorders and much more concerned with the biological causes of these disorders. Aided by improvements in psychopharmacology, the emphasis in treatment also shifted from psychosocial to biological treatments. There are ethical implications of the focus on psychiatric diagnosis as well as ethical concerns about the use of psychopharmacology, and these issues are discussed next.

DSM-III, and its descendants, *DSM-III-R* (1987) and *DSM-IV* (1994), are designed to be symptom-based classifications that do not attempt to determine the causes of the disorders described. Some vestiges of causation remain (e.g., in the adjustment disorders, post-traumatic stress disorder, and the bereavement exclusion for major depression), but they are few. Clinicians used to distinguish between reactive (i.e., externally caused) and endogenous (i.e., internally caused) depressions, but this has fallen out of favor because of a lack of biological treatment implications. Psychiatric diagnosis simply looks at the symptoms displayed by the individual to determine if psychopathology is present. By suspending consideration of causation, psychiatric diagnosis removes the patient from her life. The diagnostic system has no way of encoding whether the symptoms constitute a *reasonable* or *unreasonable* response to the stresses of daily life (Horwitz). Clinicians must still make these determinations (e.g., is the top priority for treatment this woman's depression or her abusive husband?). But the diagnostic system offers little assistance in these essential and difficult determinations. Some have argued that deciding whether the person or the situation is *crazy* is the central ethical dilemma of psychiatric practice. It is claimed that this issue was behind the abuse of psychiatry for political purposes that occurred in the Soviet Union (Fulford, Smirnov, and Snow).

Diagnostic psychiatry has been widely criticized, generally by proponents of dynamic psychiatry, for minimizing the role of psychological processes in mental disorders. But a more serious flaw may be its omission of social factors in these disorders. A purely symptom-based diagnostic system necessarily omits consideration of the social context within which the symptoms arise. This decontextualization of mental disorders makes them appear to be problems of individuals rather than problems of society. Research and treatment becomes focused within individuals and their brains rather than where and how the individuals live. Psychiatric diagnosticians may counter that it is difficult to change the social context through clinical interventions. This is certainly true, but it is not an adequate excuse for a psychiatry that places all responsibility for misery that is manifested as mental disorders within the individual. Some psychiatrists have begun to argue against the claim that psychiatric diagnosis is neutral, objective, and disinterested. They have urged a move to a postmodern focus that emphasizes social and cultural contexts, recognizes the values implicit in definitions of mental health, and works to minimize medical control of coercive interventions (Bracken and Thomas).

Managed Mental Healthcare

Mental health services have never been distributed according to any systematic assessment of population need. Cultural and financial barriers have meant that upper-class patients have greater access to mental health services even though the distress of patients in lower classes may be more severe and disabling. Psychiatrists have historically gravitated toward patients interested in their services, so mental healthcare is among the most geographically and socioeconomically maldistributed of all medical specialties.

Some aspects of this mental health service maldistribution have been changing. Beginning in the 1970s, there was tremendous growth in the number of nonmedical psychotherapists and in clients seeking their services. Following the introduction of Prozac in 1987, there has been great expansion in the prescription of antidepressant medications, especially in primary-care medical settings (Olfson et al.). In the last years of the twentieth century, mental healthcare thus became generally more available to middle-class Americans. During this same period, overall medical costs for society were rising rapidly. In the 1990s, managed care arose as a method to contain these costs. Though mental healthcare comprised only a small percentage of these costs, insurers saw mental healthcare as discretionary and subject to no natural limits. Managed care therefore imposed strict limits on mental healthcare, especially on the number of psychotherapy visits and the number of inpatient psychiatric days. The overall result of these trends is that more people have access to more limited mental healthcare.

Managed care has reduced the average number of psychotherapy visits per patient and increased the proportion of patients who receive medication rather than psychotherapy. This has increased the number of patients who can receive mental health services, but it has left many practitioners feeling that they can no longer deliver adequate services to anyone whose care is covered by medical insurance. Rather than accept the limits imposed by managed care, many of the most skilled psychiatrists and psychologists have simply opted out of the medical insurance system. This is because therapists have traditionally understood that their duties involved providing good care to individual patients. Therapists are primarily concerned with the patient in their office, not with all the potential patients in the community. What responsibility society and individual therapists have for the mental health of the general community has been neither decided nor seriously debated.

Body, Mind, and Spirit in Psychiatry

Managed care has sharpened the tension between a dynamic psychiatry of the mind and a diagnostic psychiatry of the brain, but it did not create this tension. Its roots lie deep in the difference between the humanities and the natural sciences. Simply put, the former emphasizes a personal, first-person, and subjective perspective on the human situation. The latter emphasizes an impersonal, third-person, and objective perspective on the human situation. The battle for supremacy or synthesis of these perspectives is currently being waged within psychiatry. Anthropologist Tanya Luhrmann summarized this battle in her 2000 book, *Of Two Minds: The Growing Disorder in American Psychiatry,* which takes up a conflict over the nature of competent and compassionate practice in psychiatry. The battle achieved prominence in a lawsuit over the psychodynamic versus psychopharmacologic treatment of severe depression in a physician (Klerman; Stone). Many clinical issues are included in this battle. Perhaps the most central is the relative priority accorded to self-understanding versus symptom relief. Psychodynamic psychiatrists are trained that sometimes symptom relief must wait to allow self-understanding to occur. Psychopharmacologists believe that it is most important to provide relief to the suffering patient and that self-understanding can come later.

This is also a battle about the relation between disease and self in psychiatry, about the nature of empathy and compassion for those with psychiatric disorders, and even about the nature of humanity. Families of patients with serious mental illnesses, such as schizophrenia, are strong advocates of the disease model in psychiatry through organizations such as the National Alliance for the Mentally Ill. They have been successful at raising money for research and clinical care for mental illnesses seen as brain diseases. They see the disease model as the best way to fight the stigma of mental illness that has held back progress in clinical care. This model also takes the focus off the family environment as a cause for mental illness.

Some patients with mental illness, however, take strong exception to the disease model. As one patient with schizophrenia was quoted, “Can you imagine how insulting it would be if you turned to me and said, ‘I’m sorry you have a diseased brain.’? When it gets right down to it, the medical model is an insult to me. To say I have a diseased brain does not validate me. I have a complicated thought system, with different behaviors” (Luhrmann, p. 267). This patient does not accept the sharp distinction between his disease and himself. Schizophrenia is too much of who he is. If psychiatry cannot offer him a cure of his disease, why should he accept that he is damaged rather than just different?

Indeed, it has always been difficult to separate disease and self in psychiatry. So many psychiatric symptoms seem like willful misbehavior or self-inflicted suffering, that observers are inclined to make a moral judgment rather than a medical diagnosis. Severe mental illnesses distort a person’s intentions as well as the person’s behavior, so it is difficult to see the person as distinct from the disease. Diagnostic psychiatry minimizes the role of intentions in misbehavior, explaining that the disease rather than the person is speaking. Psychodynamic psychiatry leaves this misbehavior partially in the realm of intentions by attributing it to unconscious forces. Thus diagnostic psychiatry sees the pain of mental illness as arising outside the self, whereas psychodynamic psychiatry sees it as arising from within the self.

These differences are important because they shape people’s attitudes toward some of the most severe forms of human suffering. How people approach the pain of others strongly determines the nature of the human community. That is why mental health therapies have ethical implications beyond the medical setting.

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MENTAL ILLNESS

• • •

I. Definition, Use and Meaning
II. Cultural Perspectives
III. Issues in Diagnosis

I. DEFINITION, USE AND MEANING

The concept of mental illness, including its lay counterparts such as madness and insanity, has been subject to widely different interpretations since classical times and between different cultures (Robinson). Models of mental disorder, as they are now called, continue to be hotly contested between different stakeholder groups in mental health right up to the present day (Fulford et al., 2003). Running through these differences and disputes, as outlined later in this entry, is a tension between what may be called moral and scientific models. Mental illness, understood in terms of this tension, is poised between the everyday moral world of free agency, subjectivity and reasons, and a scientific world of determinism, objectivity and causal laws.

How the tension between moral and medical models of mental illness is resolved in a period of unprecedented advances in the neurosciences—in behavioral genetics, in functional brain imaging, and in psychopharmacology—is critical to a range of ethical issues in psychiatry: the insanity defense (Robinson), ethical aspects of diagnosis (Dickenson and Fulford, ch. 4), the nature of autonomy in psychiatry and psychotherapy (Hinshelwood, 1995, 1997), the boundary between medical psychiatric treatment and social control (Bloch and Reddaway; Fulford, Smirnoff and Snow), the growing role of users (or consumers) in the design and delivery of services (Department of Health), and not least, the fight against prejudice and discrimination, that brand of internal racism (Fulford and Radden) to which all those concerned with mental health, whether as users or as providers of services, remain subject.

This entry explores the meaning of the concept of mental illness, not directly, by way of a critique of the very large number of competing definitions available in the literature, but indirectly, by way of the use made of the concept in practice. This approach —examining the use of concepts as a guide to their meanings—is exemplified by the work of the English philosopher J. L. Austin (1911–1960) and others working mainly in Oxford in the middle years of the twentieth century (Warnock, 1923–1995). The approach, called linguistic analysis or ordinary language philosophy, although relatively neglected by subsequent generations of philosophers (Williams, 1929–2003), and certainly very far from being a philosophical panacea (Fann), provides a conduit or bridge between philosophical theory and medical practice (Fulford 1989, 1990, 2001). In psychiatry, linguistic analysis offers a number of helpful insights into: (1) the nature of the problem presented by the concept of mental illness; (2) the methods available for tackling the problem; and (3) the outcomes that can be expected in tackling problems of this kind.

The Problem: Many Definitions

Difficulties in the use of the concept of mental illness have traditionally been assumed to reflect difficulties of definition. This assumption, of a genetic link between difficulties of use and difficulties of definition, was not unreasonable given the successes of psychiatry in the second half of the twentieth century in improving the reliability of its diagnostic categories by clarifying the definitions of many of its key diagnostic terms: The US-UK Diagnostic Project (Cooper et al.), for example, and the International Pilot Study of Schizophrenia (World Health Organization, 1973), showed that difficulties in the use of the concept of schizophrenia were indeed due to difficulties of definition (discrepant rates of diagnosis turned out to reflect discrepant definitions). There are, furthermore, as this entry shall explore, many examples of continuing difficulties both in the use of the concept of mental illness and in its definition. These examples, however, understood linguistic analytically, point, not to the traditional assumption of a genetic link between use and definition, but rather to the need for a reformulation of the problem as one of difficulty in the use of the concept of mental illness *rather than* a difficulty of definition.

CASE EXAMPLE: SIMON. Simon, a forty-year-old African-American lawyer, was threatened with a malpractice action, which he believed to be racially motivated, by a group of colleagues. Although he had never been a particularly religious man, he responded to this situation by setting up a makeshift altar in his front room and praying all night. In the morning he found that wax had run down from a candle on to his bible, marking out certain words and phrases. This is how he described his experience: "I got up and I saw the seal (wax mark) that was in my father's bible and I called (my friend) and I said, you know, something remarkable is going on over here. I think the beauty of it was the specificity by which the sun burned through. It was … in my mind, a clever play on words." Simon continued to have similar experiences for eighteen months. His *seals* meant nothing to anyone else. But for Simon they were direct communications from God, showing that he was "…the living son of David…and captain of the guard of Israel."

TWO CLASSIFICATIONS, TWO DEFINITIONS, TWO DIAGNOSES. Simon's story, which is based on a real person's experiences, comes from a study of the differences between delusion and spiritual experience carried out by a British psychologist Mike Jackson, at the time working as a doctoral student with Gordon Claridge at Magdalen College, Oxford (Jackson, 1997; Jackson and Fulford). The study included blind ratings using one of the first carefully standardized instruments for assessing a person's mental state, the Present State Examination (PSE). Developed by John Wing, John Cooper and Norman Sartorius at the Institute of Psychiatry in London, the PSE includes a glossary of carefully crafted definitions that, together with a standardized interview schedule, allow the identification of over one hundred symptoms and signs of mental disorder with high degrees of reliability (Wing, Cooper, and Sartorius). PSE ratings of Simon's story identified his experience as a delusional perception, a form of primary delusion. The PSE defines this as a delusion which is "based upon sensory experiences (delusional perceptions) in which a patient suddenly becomes convinced that a particular set of events has a special meaning" (Wing, Cooper and Sartorius, p. 172–173).

What then does this delusional perception mean diagnostically? There are currently two major classifications of psychiatric disorders, chapter V of the tenth edition of the *International Classification of Diseases* (ICD-10), produced by the World Health Organization under the direction of Norman Sartorius (World Health Organization (WHO), 1992), and the fourth edition of the *Diagnostic and Statistical Manual* (DSM-IV),, produced by a taskforce of the American Psychiatric Association (APA) chaired by Allen Frances (APA, 1994).

The ICD-10 and the DSM-IV classifications are in many respects similar. In particular both are descriptive in orientation. That is to say, both seek to define mental disorders as far as possible descriptively, by reference to the presence of specific symptoms, like delusional perception, of known reliability. Yet ICD-10 and DSM-IV suggest radically different diagnoses in Simon's case. In ICD-10 delusional perception (as defined in the PSE) is one of a number of symptoms that, if present, are sufficient for a diagnosis of schizophrenia (or of some other psychotic illness—affective, organic, or other—depending on associated features). According to ICD-10, then, Simon had schizophrenia (or some related psychotic disorder). DSM-IV, by contrast, requires for a diagnosis of schizophrenia, not only one or more of the relevant symptoms (summed up in its Criterion A), but also deterioration in social and/or occupational functioning (Criterion B of "social/occupational dysfunction," p. 285). And inquiry about Simon's social and/or occupational functioning, reveals that, far from deteriorating, as required by Criterion B, it actually *improved!* He was empowered and guided by his experiences, idiosyncratic as they were; he won his court case; and his career consequently went from strength to strength. By the lights of ICD-10, then, Simon had a psychotic illness (albeit one with, in this instance, a benign course); but by the lights of DSM-IV, he had a positive (albeit idiosyncratic) spiritual experience.

MANY DEFINITIONS OF MENTAL ILLNESS. On first inspection, it is somewhat disconcerting, at least from psychiatry's point of view, to find that its two major classifications, although closely similar in their scientific orientations, should yield radically different ways of understanding Simon's story. This is the more surprising given that those responsible for the two classifications worked hard to make them compatible. Simon's case, furthermore, is not marginal in these classifications: Karl Jaspers, the founder of modern descriptive psychopathology, placed delusion among the central symptoms of mental disorder (Jaspers, 1913a); and the case for a medical model of mental disorder is regarded by many as being strongest for the psychoses. It was for this reason that Thomas Szasz, notorious for the slogan *mental illness is a myth* (Szasz, 1960), called schizophrenia, in the title of a later paper, the "sacred symbol of psychiatry" (Szasz, 1976).

Disconcerting, though, as this incompatibility between ICD and DSM may be, viewed in its historical context it is but a manifestation of the long-running tension between medical and moral understandings of madness. As noted at the start of this entry, this tension runs across many cultures and back at least as far as classical Greece (Robinson). In the early-twentieth century, the tension surfaced in Jaspers's insistence on the need for both causal (medical) and meaningful (moral) accounts of psychopathology (Jaspers, 1913b). Psychiatry, for much of the twentieth century, ran mainly with the causal side of Jaspers's psychopathology. But the tension continued to be evident in the conflicting scientific and hermeneutic interpretations of psychoanalysis (Ricoeur), in the rediscovery of meanings by psychology, and of causes by phenomenology, in the second half of the twentieth century (Fulford et al., 2003), and, perhaps most transparently of all, in the so-called debate about mental illness in the 1960s and 1970s (Siegler and Osmond; Caplan et al). In this debate the medical (causal-disease) model of mental disorder was directly opposed by a variety of non-medical models—for example, psychological (Eysenck), social role theory (Scheff), labeling theory (Rosenhan), political (Foucault), existential (Laing) and moral (Szasz 1960, 1987). Each of these alternatives to the medical model sought to shift our understanding of mental disorder away from the causal-disease framework of medicine towards frameworks in which, to varying degrees and in different ways, agency and subjectivity are retained. Szasz's model is among the most overtly moral in the sense that he takes mental disorders to be problems of living, defined by psychosocial, ethical, and legal norms, to which we should respond, not passively, by seeking treatment, but actively, by taking responsibility for them.

It has been rightly pointed out, in respect of this debate, that the term medical model in fact covers a number of rather different models (Macklin); and that psychiatry, in particular among medical disciplines, aspires to a balanced biopsychosocial approach in which different models represent no more than perspectives on (McHugh and Slaveney) or levels of (Tyrer and Steinberg) the subject. Modern psychiatric textbooks all emphasize the importance of considering social and psychological aspects of mental disorder alongside the biological. Anecdotal reports, nonetheless, from people who actually use services (Campbell), taken together with both surveys (Rogers, Pilgrim and Lacey), and empirical social science research (Colombo et al.), all suggest that, in practice, mental health professionals, whatever their theoretical commitment to a broad biopsychosocial model, tend in practice still to be guided by very different implicit models in their approach to their work.

MANY DEFINITIONS OF BODILY ILLNESS. The range and diversity of competing models of mental illness has been subject to different interpretations, none particularly flattering to psychiatry (Phillips). At best, psychiatry is taken to be scientifically primitive (Boorse, 1976), our use of models being assumed to be a temporary expedient reflecting the "limited information" about mental illness currently available (Tyrer and Steinberg, p. 2). Linguistic analysis, by contrast, offers a positive rather than negative interpretation, an interpretation in which the different models represent different aspects of the meaning of mental illness with complementary, rather than competing, roles in clinical work and research. This positive interpretation will be discussed further in the section on Outcomes. But a first linguistic analytic step towards it is to see that, so far as definition is concerned, one is *no more able to define bodily illness than mental illness.*

From the perspective of those wedded to a genetic link between transparency of definition and ease of use, this may seem to be a somewhat surprising claim. For the concept of bodily illness, after all, if not wholly unproblematic in use, is at least considerably less so than that of mental illness: In contrast with even the central cases of mental illness, such as schizophrenia, there is no dispute about whether heart attacks or appendicitis, for example, as central cases of bodily illness, are diseases.

That bodily illness, nonetheless, is no easier to define than mental illness, is shown by three considerations:

1. There is an on-going debate about the meaning of bodily illness, less high profile, certainly, than the debate about the meaning of mental illness, but, if anything, growing in volume and intensity rather than moving towards resolution. As recently as 2002, Richard Smith, the editor of a leading medical journal in the United Kingdom, the British Medical Journal, reignited the debate about the meaning of bodily illness by asking where we should draw the boundary of disease (Smith).
2. The derivations of some of the most contested positions on the meaning of mental illness stand in direct line of descent from equivalent positions on the meaning of bodily illness. Thus current attempts to define mental illness employing criteria derived from evolutionary biology (e.g., Neander, Wakefield) are derivative, through the work of the American philosopher Christopher Boorse (1975, 1976, 1997), on an earlier debate, which started in respiratory medicine, about the definition of bodily illness (e.g., Scadding).
3. Much of the debate about mental illness, although indeed ostensibly a debate about the meaning of mental illness, actually turns on differences of view about the meaning of *bodily* illness. The critical difference between Thomas Szasz (1960), for example, and his British opponent, the psychiatrist R. E. Kendell, the difference that led to their respective moral and medical interpretations of mental illness, was a difference in their understandings of the meaning not of mental illness but of bodily illness: Szasz took genuine illnesses as instantiated by a series of examples of bodily illness to be defined by anatomical and physical norms, which, being absent in putative mental illnesses, made mental illness a myth; Kendell took genuine illnesses as instantiated by (many of the same) examples of bodily illness to be defined by evolutionary norms of reduced life/reproductive expectations, which, being satisfied by (many) putative mental illnesses made mental illness no different in principle from bodily illness (see Fulford, 1989, ch. 1). Similar differences about the meaning of bodily disorder continue to drive current debates about the meaning of mental disorder (Fulford, 2000).

These three points about the concept of bodily illness have been spelled out at some length because they are the lynch pin of the linguistic analytic reformulation of the problem of mental illness. It is a matter of observation that the concept of mental illness is more problematic in *use* than that of bodily illness. But since bodily illness turns out to be no more transparent to *definition* than mental illness, the difficulties associated with the use of mental illness are unlikely to be derived (directly at least) from difficulties of definition. This is the sense in which, as indicated at the start of this section, the problem of mental illness is one of use *rather than* definition. The problem itself, indeed, reformulated linguistic analytically, turns out to be as much a problem of bodily illness as of mental illness. Before spelling out this reformulation of the problem more precisely, though, a brief look at two definitional blind alleys, the causal blind alley, and the dualism blind alley, is necessary.

THE CAUSAL BLIND ALLEY. One of the most widespread misperceptions in so-called biological psychiatry is that our current difficulties in defining mental illness will be resolved by future scientific advances. The origin of this misperception is the success of physical medicine in developing diagnostic tests to detect the *causes* of bodily illness, the employment of these tests diagnostically, and their incorporation into classifications of disease. A disease, so defined, is a change in the structure/function of the body that has a tendency to cause illness. But causation *as such* does not define pathology (health no less than illness is *caused*). The chain of causation does indeed, on this model, flow from disease (the change in bodily structure/function) to illness (the changes in the patient's experience and/or behavior). But the flow of *meaning* runs the other way, from illness to disease. It is the status of an experience and/or behavior *as* pathology which determines the status of the underlying bodily causes of that experience and/or behavior *as* pathology, not vice versa.

If, therefore, as in the case of many bodily illnesses, an experience and/or behavior is unequivocally pathological, the underlying causes of that experience and/or behavior will be unequivocally pathological as well. Conversely, though, if, as in the case of many mental illnesses, an experience and/or behavior is only *equivocally* pathological, then the underlying causes of that experience and/or behavior will be only *equivocally* pathological as well. Causation, then, or more precisely knowledge of causation, is, for the purposes of conceptual clarification, a blind alley. (See Fulford, 1989, chapter 4, for a more detailed treatment, including the place of "stipulative definition," in Urmson's sense of the term.).

THE DUALISM BLIND ALLEY. A second widespread misperception is that our difficulties with mental illness are derived in some (generally undefined) way from the (supposed) ills of Cartesian dualism, the separation of mind and brain as distinct substances. This misperception is evident in the positions of those both for and against the concept of mental illness (see, e.g., respectively, Roth and Kroll; Szasz, 1998). It can be taken as two rather different claims. As a claim that *solving* the mind body problem will solve the problem of mental illness, it substitutes for our local difficulties with mental illness, some of the deepest and most intransigent problems of general metaphysics—not much of a bargain, conceptually speaking! As a claim, alternatively, that there is no *real* difference between mind and body, and hence no real difference between mental illness and bodily illness, it simply begs the (operative) practical question, namely, just why mental illness (conventionally denotated) is so problematic in use compared with bodily illness. Either way, then, dualism, or more precisely the denial of dualism, is, like causation, a conceptual blind alley.

The distinction between bodily *illness* and mental illness it is worth adding, is, anyway, readily drawn at the relevant level, i.e. of experience and/or behavior (Fulford, 1989, chapters 5, 7 and 8). Thus, bodily illness is concerned (mainly) with movements (e.g. paralysis), perceptions (e.g. blindness) and bodily sensations (e.g. nausea, dizziness, and pain), while mental illness is concerned (mainly) with the higher mental functions, such as emotion, desire, volition, belief and motivation. The distinction between mental illness and bodily illness, drawn in this (ordinary language) way, is entirely neutral, equally to the provenance of different causal theories (biological, social, psychological, etc), and to the many different philosophical propositions on the mind-body problem. It is also, as will be shown below (section on Outcomes), the basis for a positive way of understanding the more problematic *use* of mental illness compared with bodily illness, derived from philosophical value theory.

A LINGUISTIC-ANALYTIC REFORMULATION OF THE PROBLEM OF MENTAL ILLNESS. The problem of mental illness, then, to return to the starting point of this section, really is a problem in use rather than a problem of definition. There *is* a problem of definition, certainly, but it is a problem of definition of the generic concept of *illness* (including related concepts of pathology, such as disease, dysfunction and disorder) whether bodily or mental.

This reformulation of the problem can be further clarified in terms of the linguistic-analytic distinction between lower-level and higher-level concepts. Thus the traditional assumption, that difficulties in the use of the concept of mental illness have their origin in difficulties of definition, was based, as noted above, on twentieth-century successes, as in the US-UK Diagnostic Project, in solving difficulties in the use of psychopathological concepts by clarifying their definitions. The psychopathological concepts in question, however, were all, linguistic-analytically speaking, lower-level concepts—the lower-level delusion of guilt, for example, proved easier to define than the higher-level concepts of delusion and psychosis. From the perspective of the traditional assumption, this was an (unexplained) failure of the definitional program. From the perspective of linguistic analysis, by contrast, it is a reflection of a property common to all concepts, namely, that higher-level concepts in general, although used with often effortless facility, are peculiarly difficult to define.

A standard non-medical example is the concept of time. Most of the time, the concept is used (as in this sentence) seamlessly. Yet, if pressed, one would not be able to define it. Saint Augustine (354–430), the early Christian philosopher and Archbishop of Hippo, in his *Confessions,* said, "So what is (a) time? If no one asks me, I know; if they ask and I try to explain, I do not know" (Bk. II, ch. 14, No. 17). We *can* define lower-level concepts, of course: a watch face is, simply, the display side of a watch; a watch is, almost equally simply, an instrument for measuring time; but time is … here, as with the concept of illness, we get stuck.

We can extend the parallel with the concept of time. For with time, as with the concept of illness, there are contexts in which the concept *does* run into difficulties in use. In the case of illness, difficulties in use arise in psychological medicine. In the case of time, difficulties in use arise in theoretical physics, for example. In theoretical physics, the difficulties in use arise because the concept of time has to be used in contexts and at scales very different from those in which it developed. Some might argue for a broadly parallel explanation in the case of illness: the French philosopher and historian, Michel Foucault (1926–1984), for example, argued that the concept of mental illness arose by extension from that of bodily illness as a response to the work ethic of the industrial revolution (Foucault); and, as will be discussed in the Conclusions, there is indeed a sense in which the concept of illness is increasingly under pressure through scientific advances in medicine, much as that of time has been in physics. But Foucault's explanation, and others like it, all fail to explain the long history of difficulties about the concept of mental illness, stretching back, as indicated at the start of this entry, at least 2,500 years.

The question, then, that should be asked regarding the concept of illness, is not why it is difficult to define: this is an interesting question, philosophically, that we can indeed ask of higher-level concepts in general. But the question that should be asked is just why the concept of illness is relatively difficult to use in psychological medicine compared with bodily medicine. Reformulated in this way, furthermore, in linguistic-analytic terms, the problem is no longer a problem merely of mental illness at all. The challenge, for analysis, is, indeed, to explain why mental illness is relatively *problematic* in use. But there is an equal and opposite challenge to explain why bodily illness, although no less easy to define, is relatively *un*-problematic in use. So how should we go about this?

The Method: Philosophical Field Work

The method of linguistic analysis, noted above, of focusing on the use of concepts as a guide to their meanings, directly exploits the fact that, with higher-level concepts, people are better at using than defining them. Austin, whose now classic paper, "A Plea for Excuses," illustrates the linguistic-analytic approach, called this philosophical "field work" (Austin, p. 25). As already noted, linguistic analysis is neither unproblematic nor a panacea. There is, furthermore, no *a priori* reason why someone may not still come up with a definition, a neat formula or code, which encapsulates the full meaning of illness, higher-level concept as it is, and explains, even-handedly, its relatively problematic use in psychiatry and its relatively unproblematic use in bodily medicine. There is no *a priori* reason, similarly, why someone may not come up with a simple formulaic definition of some other related higher-level concept, such as health (Nordenfelt) or disorder (Wakefield). Nonetheless, linguistic analysis, as a method, can be used to good effect both negatively, to critique proposed definitions of mental illness and related concepts, and positively, to raise awareness of aspects of the meanings of these concepts which would otherwise tend to remain hidden.

NEGATIVE USE OF LINGUISTIC ANALYSIS: AS A CRITIQUE OF DEFINITIONS. Linguistic analysis, then, involves attending to language use. Normally we attend to the message. Linguistic analysis involves taking a step back, as it were, and attending to the language—to the actual words and phrases—in which the message is delivered.

As applied to proposed definitions, this stepping back and attending to language use can be helpful in its own right. Jerome Wakefield, for example, has argued in a series of impressively detailed articles (e.g., Wakefield, 1999, 2000), that dysfunction, as a component of his proposed definition of disorder (the other component is harm), can be defined value-free by reference to evolutionary norms. In this Wakefield stands in direct line of descent not only from Boorse, Kendell, Scadding and others in the debate about disorder (noted above), but also from a long line of philosophers working on the concept of function in biology (e.g., Neander; Thornton). Wakefield's enthusiasm and his rhetorical style make him a particularly effective current advocate of this approach. If one steps back, though, from his message and considers the words in which his proposed definition of dysfunction is actually expressed, it is possible to see that many of these are, in part, ambiguous as to factual and evaluative meaning. The terms in which Wakefield's definition of dysfunction are expressed, that is to say, can be used (as is required to support his claim to a value-free definition) descriptively; but they can also be used evaluatively. His definition includes the word "failure," for example (Fulford, 1999, p. 412). From a linguistic analytic perspective, then, there has to be a suspicion that while the rhetorical effectiveness of Wakefield's claim to a value-free *definition* of dysfunction is carried by presenting us with the value-free side of the meanings of these terms, the actual *work* (the linguistic work) of the concept of dysfunction as it is actually used (even by Wakefield) nonetheless depends (in part but essentially) on the evaluative side of their meanings (Fulford, 2000).

Others have succeeded in producing unambiguously value-free definitions of relevant terms. Boorse, for example, whose work was also noted above, defined disease stipulatively as a "… deviation from the natural (= statistically typical) functional organization of the species … " (1975, p. 59), adding, to cover endemic diseases, that disease should be "… mainly due to environmental causes" (1975, p. 59). Boorse's definition of disease, then, unlike Wakefield's definition of dysfunction, is indeed unambiguously value-free. But its persuasiveness, even as a stipulative definition, is undermined by the fact that Boorse himself continues to *use* the term disease with clear evaluative connotations. Thus his value-free criterion of statistical deviation becomes, only four lines later, the value-laden "*deficiencies* in functional efficiency" (1975, p. 59 [emphasis added]) and the value-free "environmental causes" becomes, again only a few lines later, the value-laden "*hostile* environment" (1975, p. 59 [emphasis added]). Boorse has rightly pointed out that this is very far from being a knockdown argument against his definition of disease (Boorse, 1997). But from a linguistic-analytic perspective it is at least suggestive that the *meaning* of disease, and hence the *use* that people (including Boorse himself) make of the term, does include an essential element of evaluation.

The slips that Boorse, and others (Fulford, 2000), make from value-free definition to value-laden use, can be understood in terms of the idea that words are, as Austin put it, "our tools" (p. 24). Based on this then, we can say that Boorse defines say, a hammer, stipulatively in terms only of its handle (equivalent to the fact part of the meaning of disease/dysfunction). But as soon as he has to use a hammer for real, the head (equivalent to the value part) becomes essential. Without the handle, to extend the analogy, the hammer cannot do the job we require of it; but the use that we actually make of a hammer for *real,* shows that the head (the value part) is essential as well.

Further examples of use providing a critique of definition are to be found in psychopathology. As already noted, the reliability of psychiatric diagnosis has been much improved by careful definition at least of lower-level psychopathological terms. The *validity* of psychiatric diagnosis, on the other hand, far from being improved, has in some cases actually been prejudiced by attempts to extend the approach of simple formulaic definition from lower-level to higher-level concepts. Delusion, for example, a term, as noted above, of central importance in descriptive psychopathology, is regularly defined in textbooks by criteria that transparently fail to encompass the full uses of the term in practice (Fulford, 1989, ch. 10).

The concept of psychosis, a step higher up the hierarchy than delusion, provides an even more dramatic example. In ICD-9 (World Health Organization, 1978), mental disorders were divided up (consistently with traditional descriptive psychopathology) primarily into psychotic and non-psychotic varieties. In ICD-10 and DSM-III (American Psychiatric Association, 1980), this primary division was abandoned on the grounds essentially that the concept of psychosis is resistant to operational definition, both classifications adopting instead a larger number of primary divisions (10 for ICD-10; 15 plus Personality Disorders and V codes for DSM-III). Closer inspection, however, shows that these new primary divisions contain, implicitly or explicitly, the traditional subdivisions into psychotic and non-psychotic categories (Fulford, 2003a). In other words ICD-10 and DSM-III are, so far as the psychotic/non-psychotic division is concerned, just ICD-9 and traditional descriptive psychopathology, turned upside down! The implication, linguistic analytically, is that the psychotic/non-psychotic distinction, difficult as the concept of psychosis is to define, continues, like the head of the hammer in the example above, to be essential to the set of conceptual tools that we need in speaking of psychopathology.

POSITIVE USE OF LINGUISTIC ANALYSIS: TO RAISE AWARENESS. The above examples should all be understood, on the linguistic analytic model, as showing, not that this or that proposed definition is wrong, but that it is incomplete. The continued use of a concept with a meaning that is denied or excluded in a proposed definition, shows that the meaning in question is, again like the head of a hammer in our example above, essential to the work that that concept does for us, linguistically speaking. Linguistic analysis, then, as a former Professor of Psychiatry at the Institute of Psychiatry in London, Sir Denis Hill, put it, is in this respect like psychoanalysis, a consciousness-raising exercise (personal communication). Examining the actual use of concepts for real thus helps to raise awareness of aspects of their meanings which, otherwise, would be neglected or ignored.

It is important to be clear that very little is claimed for this positive use of linguistic analysis. In the first place, examining the use of concepts, is, as Austin put it, in the title to an informal talk on the subject, no more than "… one way of possibly doing one part of philosophy" (Warnock, p. 6): or, again, ordinary language, although always the first word, "… is *not* the last word" (Austin, p. 27). Then second, linguistic analysis is no Royal Road to a grand unified theory. Like empirical scientific work, linguistic analysis is piecemeal, tackling doable projects, and satisfied with small increments in understanding. As Austin, again, pointed out, this means that the work of linguistic analysis, like the work of a scientific research program, can be broken down across a team or community of researchers, in contrast to the lone scholar model traditional in philosophy (Warnock, ch. 1). And all this in turn means, finally, that linguistic analysis can be connected with other methods, philosophical and empirical, with, as will be explored in the next section, outcomes that are well-grounded and directly relevant to policy, practice, training, and research in mental health.

Outcomes: From Meaning to Usefulness

Recent linguistic-analytically oriented work on the concept of mental illness has been focused on raising awareness of the role particularly of evaluation (of judgments of good and bad) alongside description in our psychopathological concepts. The American psychiatrist, John Sadler, for example, has carried out a detailed study of the epistemic values shaping the construction of the diagnostic categories of personality disorder in DSM-IV (Sadler, 1996). Such epistemic values include coherence, comprehensiveness, simplicity, instrumental efficiency, and relevance. Sadler explored the roles of such values in shaping DSM-IV, however, not by general speculation, but by careful analysis of the language of a foundational paper on the classification of these disorders by the man who, as noted above, was later to become chair of the DSM-IV taskforce, Allen Frances published in 1982. Frances, like the DSM taskforce itself (APA, 1994, p. xv), was concerned (rightly) with the evidence base of the classification of personality disorders. Work in the philosophy of science, though, suggests that proposals for classifying these disorders would be likely to be driven, also, by epistemic and other kinds of evaluation (Luntley). Sadler's analysis showed that this was in fact so, and it defined precisely the kind and impact of some of the values actually involved.

THEORY: A MORE COMPLETE VIEW. The significance of Sadler's work, consistently with the consciousness-raising outcomes of linguistic analysis, is not to undermine the scientific basis of psychiatric classification. It is rather to show how the *science* of diagnostic classification (to the extent that this is confined to the evidence-base of our classifications) is combined with (generally unrecognized but nonetheless logically operative) *evaluations.* The importance of this more complete view of what another Oxford philosopher Gilbert Ryle (1900 – 1976) would have called the logical geography of our classifications, is evident in the case history of Simon at the start of this article. DSM, despite its claims to being a descriptively-based classification, is shot through with evaluations (Fulford, 1994). The DSM (like ICD) *is* descriptive, of course; but it is also evaluative. And Criterion B, the criterion of social/occupational dysfunction at the heart of the DSM classification, which, as discussed above, turned out to be crucial to the differential diagnosis in Simon's story, is a case in point. An exclusively factual account of dysfunction requires that Criterion B be understood, like the symptoms in Criterion A, as a matter exclusively of evidence. But when it comes to social and occupational functioning, it is hard to avoid the conclusion that what counts as good or bad functioning is, in part, a matter also of value judgments. In Simon's case, then, the operative diagnostic criterion, as to the differential diagnosis between delusion and spiritual experience, was not a descriptive but an *evaluative* criterion.

This of course raises the question of why evaluation is so much more prominent in psychiatric classification and diagnosis compared with their counterparts in bodily medicine. The answer one gives to this question depends on which model of disorder one accepts. Szasz, at one extreme, argued, as noted above, that psychiatry is value-laden in this way because mental disorders are really moral not medical problems. Kendell, Boorse (1976), and others have argued that psychiatry is value-laden because it is at a primitive stage of its development as a science. Linguistic analysis suggests a third kind of answer, namely that it is because psychiatry is concerned with areas of human experience and behavior, such as emotion, desire, volition, belief, and sexuality, in which human values *differ widely and legitimately.*

Thus, values, according to this linguistic-analytic answer, stand alongside facts in the definition of diagnostic concepts in *all* areas of medicine, bodily as well as mental. But the conditions with which bodily medicine is typically concerned, like heart attacks for example, tend to be painful and life threatening, and, hence, *bad* conditions by anyone's standards. There is no Criterion B for a heart attack, therefore, not because there is no evaluative element in the diagnostic concepts used in cardiology, but because what counts as bad functioning in hearts is widely agreed upon, hence is not problematic diagnostically, and hence can (generally) be safely ignored in practice. Where, however, cardiology, and disciplines like it, are, in this sense, evaluatively *simple,* psychiatry is evaluatively *complex.* Psychiatry *needs* a Criterion B in cases like Simon's, therefore, or some equivalent evaluative criterion, because what counts as bad functioning in areas such as emotion, desire, volition, belief, and sexuality, is *not* widely agreed upon, hence *is* problematic diagnostically, and hence *cannot* be safely ignored in practice.

This linguistic-analytic interpretation of the more value-laden nature of mental illness, which we owe to yet another Oxford philosopher, R. M. Hare, provides at least one reason why, in terms of the linguistic-analytical reformulation of the problem of mental illness developed in the first part of this article, the use of illness is relatively problematic in psychiatry while being relatively unproblematic in physical medicine. It is now clear that this is not because bodily illness is easier to define than mental illness, still less because psychiatry is less scientific than bodily medicine, but because psychiatric diagnostic concepts are evaluatively more complex than diagnostic concepts employed in (most) areas of bodily medicine.

PHILOSOPHY INTO PRACTICE. The recognition that the concept of mental illness is, in the sense just outlined, evaluatively complex, has been the basis for a number of recent developments taking philosophical theory into the heartland of mental health practice.

In the United Kingdom, for example, new training programs, aimed at giving mental health practitioners the skills for effective decision making where legitimately different values are in play (Fulford, Williamson, and Woodbridge), have been developed within the National Service Framework, a policy document defining the U.K. government's core strategies on mental health (Department of Health). These training initiatives draw in particular on the principles and skills-base of Values-Based Practice (Fulford, 2003b), and on research combining linguistic analysis with empirical social science methods to explore the different models of disorder implicit in multi-disciplinary teams (Colombo et al.). They are also closely linked with recovery-oriented and other innovative user-centered approaches to the development and delivery of services (Allott et al.). On a wider international canvas, these initiatives connect with practically-oriented research employing a growing number of other philosophical methods, including the German philosopher and mathematician Gottlob Frege's (1848–1925) logic of relations (Van Staden and Kruger), the use of discursive methods to reveal the meaning and intentionality implicit in the speech and behavior of Alzheimer's disease sufferers (Sabat), and a whole series of studies in phenomenological psychopathology (e.g., Musalek, Stanghellini).

Linguistic analysis, then, in itself and combined with other methods, empirical and philosophical, can help to clarify the place and roles of the evaluative elements of meaning in the concept of mental illness, adding fine-grained, and hence potentially practically useful, detail to our understanding of the concept.

There is of course a good deal more to the meaning of mental illness (and of our concepts of disorder generally) than just this element of evaluation. Many of the most difficult problems in the use of the concept turn, indeed, not on whether someone is in a *bad* condition (as in Simon's case), but on whether they are in a bad condition of a kind that is properly thought of as an *illness* (the problems associated with the insanity defense, noted at the start of the entry, for example). The DSM, in an important caveat, rightly emphasizes that psychopathology is not defined by negative value judgments alone (DSM-IV refers specifically to social value judgments, APA, p. xxi–xxii). Values, then, as the DSM's caveat makes clear, although indeed necessary (along with facts) to the definitions of psychopathological concepts, are very far from being sufficient.

This brings the argument back to the wider debate about models into which, as noted above, the long-running historical tension between scientific and moral understandings of mental illness has resolved in recent decades. Coming back to this debate, though, within the now more complete view of the conceptual structure of medicine revealed by linguistic analysis, opens up to psychiatry an extensive resource of powerful philosophical methods for exploring the full richness and subtlety of its diagnostic concepts: besides analytic philosophy (e.g., Bolton and Hill), such methods include discursive analyses of the inter-personal creation of meaning (Gillett; Harré), hermeneutics (e.g., Widdershoven and Widdershoven-Heerding), existentialism (e.g., Morris), the phenomenologies of both Martin Heidegger (1889–1976) (e.g., Bracken) and Maurice Merleau-Ponty (1907–1961) (e.g., Matthews), and classical philosophy (Megone). Contrary to the causal blind alley, furthermore, noted above, research in these new areas of philosophical psychopathology (Graham and Stephens), as those most directly concerned have been among the first to recognize (Andreasen), is set to become more, not less, important with future advances in the neurosciences.

The practical impact of such research, it is important to add, understood within a (linguistic-analytically) more complete view of the conceptual structure of medicine, will not be to secure the dominance of any one model, medical, moral or otherwise; still less will it be to create a super model, an unstable oil-and-water amalgam of incompatible elements of meaning. The impact of such research will be, rather, to clarify, piecemeal but progressively, the elements of the different models and thus to endorse their roles as complementary ways of understanding what is, after all, at the center of mental healthcare, the distinct perspectives of individual people with particular experiences of mental distress and disorder. If mental illness is a complex and multifaceted concept, this is because, encompassing as it does such areas of human experience and behavior as emotion, desire, volition, belief and sexuality, it reflects the complex and multifaceted aspects of human nature itself. Psychiatry, above all among medical disciplines, is concerned, not just with bodies or with parts of bodies, nor even just with minds or with parts of minds, but with what the Oxford philosopher Kathleen Wilkes, in the title of her seminal 1998 book on the relationship between philosophy and psychopathology, reminded us are *real people.*

Conclusions: Psychiatry First

This article has explored the problems raised by the concept of mental illness through the lens of linguistic analysis as exemplified particularly by mid-twentieth-century philosophers of the Oxford school, such as J. L. Austin. Although not currently fashionable in philosophy in general, in relation to the concept of mental illness this approach has a number of clear implications, summarized here under problem, method and outcomes.

As to the problem of the concept of mental illness, linguistic analysis shows that this should be reformulated in terms of use rather than definition. The challenge is not, directly, to *define* the concept of mental illness, since the (relatively) unproblematic concept of bodily illness turns out to be no less difficult to define. The challenge, rather, is to explain, even handedly, why mental illness should be relatively *problematic in use* while bodily illness is relatively *unproblematic in use,* despite both concepts being equally difficult to define. The method suggested by linguistic analysis, correspondingly, is to focus on use rather than definition, to step back from the message (proposed definitions) and become more attentive to the language (the actual words and phrases) in which the message is expressed. This approach delivers no simple formulaic definition. Combined with other methods, though, philosophical and empirical, it has a number of outcomes relevant to policy, practice, training, and research in mental health. These outcomes, as illustrated in this entry, amount to one answer to why mental illness is relatively problematic in use compared with bodily illness, namely, because mental illness, in contrast to bodily illness, is concerned, characteristically, with areas of human experience and behavior, such as emotion, desire, volition, belief, and sexuality, in which human values differ widely and legitimately.

K. W. M. FULFORD

SEE ALSO: *Medicine, Anthropology of; Mental Health, Meaning of Mental Health; Mental Health Services; Mental Institutions, Commitment to; Mentally Disabled and Mentally Ill Persons; Psychiatry, Abuses of; Psychopharmacology; Psychosurgery, Medical and Historical Aspects of;* and other *Mental Illness* subentries

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II. CULTURAL PERSPECTIVES

In the late 1970s and early 1980s anthropological researchers began to focus on the cross-cultural study of health and illness, both mental and physical, and systems of healthcare. In looking at Western views of mental illness, one finds the imprint of culture on the diseases distinguished and characterized, the symptoms associated with those diseases, and the etiological theories.

Anthropology and Medicine

The critical and reflexive view that leads to the the dissolution of traditional Western categories derives from anthropology's cross-cultural nature and tradition of long-term research on indigenous languages. That research demonstrates the created nature of those categories and highlights the culturally constructed nature of Western realities, whether popular, medical, or scientific (Carlson; Fausto-Sterling, 1992; Gaines, 1992a, 1992b; Geertz, 1973, 1983; Gould; Kleinman and Good).

Biological and social and cultural anthropologists study health, illness, and medical systems around the world. Biological anthropologists tend to use U.S. biomedical conceptualizations and research strategies in cross-cultural contexts. Although some medical anthropologists utilize biomedical definitions of illness in *ethnomedical* and *ethnopsychiatric* studies of specific cultural or ethnic forms of medicine and psychiatry, usually in non-Western cultures, many have abandoned that practice (Gaines, 1998c).

Those researchers have joined social scientists from all fields who utilize interpretive perspectives. In medical anthropology such scientists initially focused on folk medical traditions. However, since the late 1970s many have reflected on and analyzed the cultures of professional medical systems in the West and elsewhere (Kleinman, 1980; Leslie; Lock) and the sciences on which those systems draw (Gaines, 1979, Gaines, 1998c; Hahn and Gaines; Townsend; Young, 1995). Increasingly, anthropologically trained researchers come from the psychiatric profession (Kleinman, 1977, 1988; Littlewood and Lipsedge).

Interpretive social sciences have replaced Enlightenment science's ideas of cause and effect and use of universal laws to explain human behavior. Explanation has been supplanted by understanding and interpretation derived from idealist forms of social science theory and philosophy. Both popular and scientific realities now are seen as creations or constructions that are locally fabricated. In medical anthropology *cultural constructivism* is a major interpretive perspective that focuses on medical systems (Gaines, 1991, 1998c).

The interpretive constructivist perspectives allow one to see both professional and folk psychiatries equally as ethnopsychiatries, that is, cultural psychiatries. Constructivism suggests that psychiatry is a problematic but locally meaningful experience-near, ongoing historical construction that is constituted by various forms of embodied and disembodied discourse (Gaines, 1991, 1992a).

Constructivist perspectives have affinities to the history and philosophy of science (Foucault; Gilman, 1988; Gould; Hacking, 1983) and to gender studies (Fausto-Sterling, 1992, 2000; Gaines, 1992b). They have made it possible to penetrate the veneer of medical and other sciences to reveal their cultural assumptions and biases concerning madness, nature (human and otherwise), human development, human differences and biologies (gender, "race"), emotion, and identity (Duster; Fausto-Sterling, 1992, 2000; Gaines, 1987, 1992a, 1992b; Gaines and Farmer; Gilman; Kleinman and Good). Medical anthropology has added to these debates with ethnographic studies of healers, researchers, and patients in their cultural contexts (Gaines, 1979, 1992a; Hahn and Gaines; Kleinman, 1980, 1988; Lock; Marsella and White; Townsend; Young, 1995). Although each professional psychiatric tradition embodies culturally specific beliefs and values, they all represent their objects of concern (diseases) as real and universal. Depending on the culture or the cultural variations within a society, those realities are usually in the domain of nature but may have a more spiritual orientation (Gaines, 1998b).

Ethnopsychiatries represent distinct systems rather than versions of a unitary psychiatry. A review of mental illness in the cross-cultural record suggests that in other cultures illnesses often cannot be classified in accordance with Western nosologies such as the Diagnostic and Statistical Manuals (DSMs) of the American Psychiatric Association (APA). Novel disorders in traditional societies are not versions of homegrown disorders. Conversely, many disorders that are assumed to be natural entities in the West cannot be found in other cultures or lack key or even defining symptoms. This suggests that diagnostic criteria are altered to fit unruly entities into Western molds (Gaines, 1991; Gaines and Farmer; Kleinman, 1977, 1988; Kleinman and Good).

The Problem of Western Professional Psychiatry

A cultural focus on professional ethnopsychiatries, particularly that of the United States, shows that they differ in significant ways. This also shows a lack of a universally valid "gold standard" by which all forms of mental illness can be evaluated.

Although ethnopsychiatries can be expected to differ substantially, an advocate of biological causal realism would not expect that to be true of professional (ethno) psychiatries. The distinctiveness of ethnopsychiatries suggests their cultural construction; they are not the same psychiatry focused on *natural* illnesses as it is practiced in different countries.

Cross-Cultural Knowledge of Mental Illness

Research in ethnomedicine and ethnopsychiatry, in the philosophy of science and history, the history of medicine, and gender studies has converged to raise epistemological and ethical concerns for modern psychiatries in multicultural nation-states. Those concerns derive from the fact that popular and professional psychiatries have been revealed local cultural constructions. Hence, the key question of psychiatric systems—What is normal and what is abnormal?—may be posed in an ethical context: What are the ethical problems generated by one psychiatric theory or nosology applying its notions of normality and abnormality to members of distinct cultures in modern plural societies? A cultural assessment of U.S. professional ethnopsychiatry shows a diversity of opinions and the elusive nature of definitions and diagnoses of mental disorders, suggesting its inadequacy as a standard.

Are Mental Illnesses Natural and Universal? Deconstructing U.S. Ethnopsychiatry

The view that psychiatric illness is universal eschews culture as a formative influence and assumes that disorders have similar natures that are expressed everywhere. That is, each disorder is known by its symptoms, which by definition must be distinct, at least collectively, from those of other disorders. In this view, in studying mental illness cross-culturally, one studies the same things in different cultural settings.

To make that argument one must posit that psychiatric disorders are biologically based (biochemical or genetic) and thus are beyond culture. One also must assume that there is a single human psychology that can be manifested in aberrant forms. If this view is correct, the same disorders should be identified and treated in all professional and popular psychiatries. It is assumed that a professional psychiatry *discovers* those entities and then names and classifies them (e.g., American Psychiatric Association, 1987, 1994); it does not invent them.

Labeled phenomena exist apart from their labels, it is thought. However, psychiatry mistakes its labels for realities rather than models (Geertz, 1973) or representations of reality (Hacking, 1983) that are used for particular purposes. This view expresses an implicit empiricist theory of language, holding that disease labels correspond to independently existing entities in the natural world. However, the empiricist theory is a cultural theory about, not a factual description of, the relationship of language to the world (Hacking, 1983).

When differences in disease entities or in systems of classification (nosologies) across cultures are found, psychiatrists assume that those differences indicate that universal diseases are overlooked, mislabeled, or differently labeled by less sophisticated others. When professional psychiatries disagree, they assert that one is more *advanced* than the others (Kleinman, 1988; Kleinman and Good).

Both views are evolutionist in form and have little scientific merit. It now is known that cultures change historically, not through evolution, because of contact with and borrowing from other cultures as well as innovation. Cultures are distinct because of their unique histories, that are constituted as local culture and passed on through socialization. Cultures do not differ because they represent developmental stages of a single human *culture.*

It is inappropriate to assume that the understandings of U.S. professional ethnopsychiatry are more advanced than those of other countries. For one thing, U.S. psychiatry has borrowed many of its fundamental ideas from other cultures and used them for its own purposes. Also, U.S. psychiatry has changed its views of mental illness radically over time.

The changes have not been in a specific direction, building on past knowledge. Rather, they represent a shift in paradigms. U.S. psychiatry has had dominant etiological paradigms that have been social, hereditarianist biological, psychoanalytic, psychosocial (interpersonal), and biological. The sciences seen as key to psychiatric formulations also have changed over the years. They have included psychology, eugenics, biology, physiology, genetics, and neurology (Dowbiggin; Gaines, 1992b; Hacking, 1995; Kleinman, 1988; Littlewood and Lipsedge; Lurhmann; Young, 1995).

ANOREXIA NERVOSA, CHRONIC FATIGUE SYNDROME, AND MULTIPLE PERSONALITY DISORDER.

Anorexia nervosa. The potentially fatal disorder anorexia nervosa is found widely among middle- and upper-income Euro-American women. However, it is seen only rarely outside that narrow sociocultural context even in the United States.

In cross-cultural work key features of the disorder, such as fear of obesity and a distorted body image in the very thin, are not found (Mezzich et al.). Researchers have suggested dropping those symptoms, but in that case how could one find the same disorder with different symptoms when the disorder is defined by its symptoms?

Chronic fatigue syndrome. Chronic fatigue syndrome (CFS) is a disorder for which the search for a biological cause failed, yet it is referred to as if a somatic cause had been isolated as chronic Epstein-Barr virus infection or immune dysfunction syndrome. This disorder, which is fairly common in the United States but confined to specific ethnic and social class levels, is found in few other cultures. Currently, a century-old U.S. term, *neurasthenia,* is being resurrected and applied to CFS, moving it into the province of psychiatry from general medicine, although a somatic cause still is being sought (Kleinman, 1988).

Mutiple personality disorder. Multiple personality disorder is another condition that is found commonly in the

United States. It is invoked in criminal trials as a legal defense and in popular culture. However, it is absent from the classifications and practice of other professional psychiatries (See Hancking, 1995).

PERSONALITY DISORDERS. Several new disorders appeared in an appendix in DSM-III-R (American Psychiatric Association, 1987), including dependent personality disorder and sadistic personality disorder. Those terms appear to be gendered: The former is said to be found among women who "allow" physical abuse over time, and the latter among the men who abuse them. There was considerable political opposition to the tentative formulation of those disorders, which blame female victims of abuse while giving their abusers a legal defense. In English psychiatry the adoption of a premenstrual syndrome made it possible to explain women's injuries: they did it to themselves.

The gender component of those personality disorders recalls the history of U.S. psychiatry, in which traditional notions of women's nature were upheld by psychiatric findings, as were racist notions about minorities (Fausto-Sterling, 1992; Thomas and Sillen). A more explicitly racist psychiatry was that of South Africa, in which a lower psychological and psychiatric evolutionary status was attributed to *nonwhites* (Gaines, 1992a).

Depression and Schizophrenia

Two disorders are considered in biological psychiatry to be models of biogenetic mental diseases: depression and schizophrenia. However, the cross-cultural literature and the most advanced epidemiological studies have challenged that assertion (Gaines, 1992a; Kleinman and Good; Kleinman, 1988; World Health Organization). The formulations of those disorders in the West have been shown to conceal powerful cultural and moral assumptions about emotion, autonomy, sex, and gender as well as human difference (ethnic and so-called racial) (Gaines, 1992a, 1992b; Kleinman and Good).

To examine the epistomology of the formulations of depression and schizophrenia, one first must consider certain key underlying psychological dimensions. Those culturally defined dimensions are constructions of self, will, emotion, and cognition (Gaines, 1992b).

SELF. There are differences in cultural conceptions of self and person with respect to mental illness, its diagnosis, and its treatment. Conceptions of the self vary widely and may include spiritual elements. For example, it is common for people to have spirit siblings in Bali (Marsella and White), but this would be seen as pathological in the United States.

Formulations of the self in India, the Mediterranean countries, and Japan would be seen as incomplete, dependent, and/or unindividuated by U.S. psychiatric standards despite the fact that those familistic, interactionally altering *indexical* selves that maintain interactional harmony and family reputation exist in cultural environments that foster, support, and reward their *sociocentrism* (Marsella and White). Conversely, the *egocentric, referential* Northern European Protestant self (Gaines, 1992b; Marsella and White) with its asocial nature would be seen as antisocial, naïve, and alienated in other contexts. It is the locally conceived self in which psychological disorders occur. Logically, different selves must have different disorders and therefore require different healing strategies. To complicate matters further, many cultures do not exhibit a purely psychological self. Instead, they exhibit social selves (the self is a social psychological, not a psychological, phenomenon), and this is found even in Europe (Gaines, 1992b, 1998b; Marsella and White).

EMOTION AND COGNITION. The distinction between cognition and affect (thinking and feeling) in the West, which is central to the differentiation of psychiatric disease entities, does not exist universally in human nature or biology. The cross-cultural record indicates that these are cultural constructions (Kleinman and Good). Those findings challenge the validity of the construction of depression and schizophrenia as universal diseases grounded in biology, for the psychological domains in which disturbance is said to occur (cognition and affect) are not innate; they are Western cultural constructions.

DEPRESSION. Assessment methods for depression are often ethnocentric even when the approach is said to be entirely *descriptive,* as in DSM-III (1980), DSM-III-R (1987), and DSM-IV (1994). An example is dysphoric affect (an unpleasant, sad feeling), that is a central element of the Western depressive experience.

Dysphoric affect, although disvalued in some Western traditions, is highly valued in others, such as the Mediterranean world with its Latin Catholic, Orthodox, and Islamic traditions (Gaines, 1992a; Kleinman and Good), where suffering is seen as ennobling and indicative of divine interest in the sufferer (Gaines and Farmer). It serves as the basis for interaction in which the self is presented through the *rhetoric of complaint* as beset with problems and as a fellow sufferer (Gaines and Farmer).

In the Buddhist tradition recognition of the worthlessness of the world and the self and the futility of human activity is part of enlightened understanding (Kleinman and Good). Such thoughts therefore have positive personal value rather than being pathognomic: They are *eudysphoric* (Gaines, 1987).

The complexity of the dysphoric experience can be understood by reference to the interrelation of the cultural context and history, cultural psychology, symbols, and family, status, and gender roles and power relations that collectively contribute to its construction (Kleinman and Good; Gaines and Farmer). Only then is it possible to assess the need for assistance. The intricate patterning of social and cultural forces is complex and requires detailed contextual analysis (Good, 1994).

The patterning of symptoms can vary widely across cultures so that key features of Western-defined disorders such as depression are absent from the experience of members of other cultures even when they are diagnosed as depressed with U.S. psychiatric instruments. For example, there is no psychomotor retardation among *depressives* in France or Morocco, only short periods of dysphoric experience among the Hopi, and feelings of insight and satisfaction in Sri Lanka and India (Gaines and Farmer; Kleinman and Good).

No consistent definitive statement about the prevalence, the incidence, or even the forms of depressive manifestation across cultures can be made, although a variety of assessment techniques have been employed for that purpose (Kleinman and Good). One problem is that false positives appear in the West just as they do in epidemiological studies done in Mediterranean and other countries where there are social and personal values of suffering and social support for its expression.

In attempting to focus on a single disease entity known as depression one is confronted with a semantic problem. The term *depression* is used inconsistently in psychiatric literature. At various times and often in the same study it is used to refer to a mood, a disorder, and/or a symptom of a disorder. Some researchers stress a cognitive explanation of depression, and there are cognitive therapies that may equal or surpass biological/pharmacological interventions in speed and efficacy.

SCHIZOPHRENIA. Research on schizophrenia is hampered by a lack of consistent clarity of definition, particularly in regard to the boundaries of the disorder. Epidemiological, familial, twin, and adoption studies have been interpreted to suggest that a genetic factors is involved in schizophrenia. Although some work has shown a genetic or familial link in a few cases, no genetic link or common abnormality has been demonstrated or implicated in the vast majority of cases. Results involving genetic interpretations often are overstated, and important social/cultural information or explanations are ignored (Duster). Claims implicating various genes as causative of schizophrenia have been withdrawn.

Many findings of central nervous system (CNS) dysfunction appear in the literature, but none is specific or shared by all people who have the diagnosis of schizophrenia. Also, no symptom of schizophrenia is unique to that disorder; all the symptoms associated with or diagnostic of it appear in other disorders described by U.S. psychiatry

The World Health Organization's (WHO) study of schizophrenia (1979) found that schizophrenic patients with similar symptoms on initial evaluation whose disorders met strict diagnostic criteria showed marked variability in the two-year to five-year course and outcome within and across research centers. Patients in developing countries had a much more favorable course and outcome than did those in developed countries.

The disorder is chronic in the West, but this is not the case in the Third World, where the majority people with schizophrenia return to normal functioning (World Health Organization). It has been argued that schizophrenia is a culture-bound, Western *ethnic psychosis,* one specific to a single culture or ethnic group (Devereux). Cultural expectations may play a central role in chronicity; cultures that expect chronicity produce it, and those which expect recovery foster it. WHO data on the prevalence and incidence of schizophrenia in different cultures have been interpreted as establishing *broad* similarities across cultures (World Health Organization), suggesting similar processes, but similarities appear only when contextual evidence is excluded (Kleinman, 1988).

The assertion of the biological nature of psychiatric disorders in certain psychiatries appears to be a result of a patterned misinterpretation of cultural or social phenomena as biological. Those misinterpretations appear to be expressions of a professional *thought model,* a patterned way of thinking (Devereux). This model is a reflection of a folk form of biological essentialism borrowed from German psychiatry as well as a result of narrow biological training (Devereux; Kleinman, 1988).

Challenges to that theory include a resurgent psychoanalytic theory, feminist analytic theories, new psychologies, and cultural psychiatric studies. The biological model has dominated the field in the United States (Luhrman), but some movement away from it can be seen in the inclusion of a "Glossary of Culture-Bound Syndromes and Idioms of Distress" (Mezzich et al.) in DSM-IV (1994). However, cultural thinking has not been centrally present in the text of any edition of the DSM since 1980, when the classifications were intentionally fashioned to promote biological definitions of illness.

The Biological Perspective: Science or Folk Theory?

Researchers believe that the biological emphasis is a result of a long process of scientific advances. Studies of the development of psychiatries in anthropology, philosophy, and the history of medicine and psychiatry suggest otherwise. The biological view in psychiatry has its origins not in science but in the traditional folk culture of Germany and is at least a thousand years old (Gaines, 1992b). That view is an expression of a cultural theory that is a form of biological essentialism. That essentialism holds that the essence of self and other in terms of identity (ethnicity and kinship) and moral worth is determined by biology. *Blut* ("blood") is thought to be inherited and determines a person's identity, character, and moral worth.

The modern versions of this theory are the constructions of *genetic* and other somatic differences that are alleged to exist among people with specific disorders. In this view people who have mental illnesses are *different* kinds of people (Gaines, 1992a).

Some psychiatries, especially U.S., Scandinavian, and Russian, tended to follow in the footsteps of the nineteenth-century dean of German psychiatry, Wilhelm Griesinger, and his follower Emile Kraepelin, the founder of comparative psychiatry. Griesinger and Kraepelin after him in the early twentieth century asserted a biological basis for mental disorders. Kraepelin maintained Griesinger's dictum that "mental diseases are brain diseases," a notion borrowed from German (idealist) philosophy and French racial biology of the late 1700s (Gilman).

In first third of the twentieth century Carl Schneider, in the German materialist (and the Nazi racialist) tradition, advanced the notion of the "first rank symptoms" of schizophrenia. Those symptoms were pathognomic, or definitively diagnostic, of the disorder. Although many were influenced by that formulation in the United States and elsewhere, there was no analysis of the veracity of Schneider's theory until the 1980s when it was discerned that these symptoms were not unique to schizophrenia.

That biological model is dominant in contemporary U.S. psychiatry, although it competed with psychoanalytic and psychosocial perspectives before winning out in 1980 with the publication of DSM-III (Luhrman). Although the biological interpretation of mental illness is said to be based on empirical scientific evidence, its source in a foreign popular culture is apparent.

Social categories from the wider, lay culture—*races*—are construed in science as distinct biological groups, just as they were in German psychiatry and in South Africa. However, U.S. and German notions of race appear in different contexts and are applied to different experiences and thus are not the same folk biological theories. In the United States both the biological psychiatric perspective and the social categories are borrowed and reworked historical cultural constructions, rather than modern advances in psychiatric science.

CULTURE AND THE CLASSIFICATION OF MADNESS. Professional psychiatric classifications of diseases (nosologies), along with the diseases that are classified, change over time. Those changes are seen in psychiatric traditions as improvements and progress that may be viewed in evolutionary terms; that is, Western classifications are different from others because they are more *evolved.*

Changes in classification often represent shifts in assumptions about mental disorders that are products of ideological conflicts, competing explanations for which no data or ambiguous data exist. Rather than pointing in any direction, those changes simply show shifts in dominant theoretical models or political ideologies. They also may represent the imposition of foreign formulations and institutions (Gaines, 1992a).

Terms are deleted or reintroduced, but such actions do not indicate advances. Neurosis appeared in the disease classifications of U.S. psychiatry from 1952 to 1980 but was deleted from the 1980 and later classifications. These classifications are biological in orientation and thus exclude clearly psychogenic illness terms such as neurosis despite ample clinical evidence of their existence. French and other psychiatries continue to use the term and diagnose the illness. There are also "reconstructions" (old terms used for new disorders) in professional psychiatry, such as neurasthenia applied to chronic fatigue syndrome in the United States.

Interpretive analyses of U.S. psychiatric classifications reveal the underlying culture-, gender-, and age-specific viewpoint (Germanic Protestant, male, adult) from which U.S. nosologies are created. Behavioral or ideational differences perceived in others who vary in age, culture, or gender from the ideal are interpreted as a lack of (self-) control expressed as pathology such as depressive illness or psychotic conditions and personality disorders. That deficit is perceived as being caused by differences in group (age, "racial," gender) biology (Gaines, 1992b) i.e., local biology, culturally constituted biologies (Gaines, 1998c). This suggests that classifications are largely a cultural psychological discursive formations, not a classification of naturally appearing diseases (Gaines, 1992b).

Biological essentialism may be seen to act as a psychological defense because it allows one to claim that the afflicted are biogenetically different from *normals.* That is, members of the psychiatric profession, it is presumed, are normal and thus could not have the same biological defects as does a mental patient (Devereux).

PHARMACOLOGY AND "ETHNIC BIOLOGY." Biological essentialism can be seen in research in U.S. psychiatry that focuses on the study of ethnicity and psychopharmacology (called *ethnic psychobiology,* an oxymoron). Regarded as cutting-edge research, those studies recognize *ethnic differences* in biochemistry. Findings suggest that different doses of particular agents are appropriate for members of different ethnic groups with the same psychiatric disorder. This research takes as its units of research members of *ethnic or racial* groups. Biomedicine assumes that these terms are synonymous and refer to genetically distinct groups. The allegedly distinct biological ("racial") groups that appear commonly in such research are *Hispanics* (a language group), *Asians* (a geographical designation), *blacks* (a color), *Native Americans* (a geographical designation), and *whites* or *Caucasians* (a color or geographical designation, respectively). Those groups are in reality social categories that were created by a particular culture in the last two centuries and adopted by health research. The *racial* designations and the biological theory underlying them are neither universal nor biological.

Research that assumes that members in each category are biologically defined assumes that the members of each category are identical, or nearly so, in genetic composition; what is true of one person belonging to a *race* is generalizable to all members of the putative group. This perspective has several flaws.

The notion of race varies from culture to culture and is absent from most cultures in the present time; it was absent from all cultures in the past. Other modern sciences have different notions of the number and membership of human races. Japanese science considers the Japanese, Koreans, Chinese, and Indians to be members of different *races,* and the Germanic theory separates Germans from all other *white* groups on genetic bases. One may ask with reference to U.S. research, Why is one *racial* theory accepted whereas others are rejected?

This research ignores the substantial variations in doses seen and clinically "proved" to be effective within so-called races, including Europeans, in the practice of different national psychiatries. For example, much larger doses of antipsychotics are needed for *white* U.S. patients than for French, English, and German patients. If those patients all belonged to the same race, that variation would not occur in doses that are predicated on *racial* affiliation.

Biology is assumed to be the basis of physical and genetic distinctiveness and to be stable over time. However, physical anthropology and evolutionary biology have demonstrated that human biology has a common source (Africa) and is extremely plastic. That plasticity is responsible for the great morphological diversification of humankind that has occurred in the last 100,000 years (Gould).

These findings contradict the ideas of biological distinctiveness and constancy over time that the notion of race requires. In contrast, pharmacological work framed in racial/biological terms reflects the biological essentialism noted above. It serves to maintain the cultural construction of race and biological explanations of social and cultural differences. *Racial* biology is thus a form of what has been called local biology (Gaines, 1992a, 1998c).

Professional Ethnopsychiatry around the World

CHINESE PSYCHIATRY. Chinese psychiatry originally was borrowed from the West but also drew from classical Chinese medicine (Kleinman, 1988; Leslie). This suggests that psychiatry can be borrowed and adopted by a culture.

Because it represents China's understandings of Western notions of mental disorders, a number of Chinese disorders are unknown elsewhere. *Qi-gong* reaction is an acute episode that follows overly intense involvement in the *Qi-gong* exercises and breathing practices that are used to promote health and long life. Neither the condition nor the related health practice is known to U.S. psychiatry.

Shenjing shuairuo ("neurasthenia") is the most common psychiatric diagnosis in Chinese psychiatry (Kleinman, 1988; Mezzich et al.) and in areas within the sphere of Chinese influence. The label was borrowed from the United States, where the term was developed over a century ago but fell into disuse, as did the conception of disease it labeled (Kleinman, 1988).

Koro is an acute episodic event characterized by intense concern and anxiety about the withdrawal of the external genitalia into the body; it is related to the Chinese cultural belief that the genitals of the dead recede into the body. *Koro* is found in China and Southeast Asia, where there have been large epidemics. Western psychiatrists, ignorant about Chinese folk beliefs, might see *koro* as a psychosis or panic disorder.

In Chinese psychiatry psychological explanations are not regarded as sensible explanations of suffering (Kleinman, 1980, 1988; Kleinman and Good; Leslie). Patients present somatic (bodily) symptoms such as *koro* almost exclusively. Optimal intervention is somatic as well, often involving herbal medicines to enhance or unblock the passage of vital energies throughout the body. The physiological conception of mental phenomena is related to notions in India, where in the traditional Ayurvedic psychiatric theory mental phenomena are held to be expressions of bodily states, not psychological dynamics in the Western sense. Indian professional psychiatry is entirely somatopsychic (Leslie; Leslie and Young).

JAPANESE PSYCHIATRY. In Japanese psychiatry two important disorders are widely known in practice and in society: *shinkeishitsu* and *taijin kyofusho.* Both are considered social phobias in the West.

Taijin kyofusho presents as extreme concern over actions or personal hygiene that could be disturbing or disrespectful to others. *Shinkeishitu* is characterized by shyness, tension in social relations, feelings of inferiority, and fear of failure in maintaining appropriate interactions. It is treated successfully by Morita psychotherapy, a blend of Buddhism, German psychiatry, and understandings of Japanese life that is administered on an outpatient basis or in hospitals dedicated to the treatment of *shinkeishitu.* Inpatient treatments for this and most other disorders serious enough to warrant hospitalization are much longer than they are in the United States. This is expected by patients, who see the hospital as a second home and the psychiatrist as a teacher (Lock; Gaines, 1992a). There are a number of psychotherapies in Japan for which there are equivalents of neither the disorders nor the therapies in the West (Reynolds).

Several new disorders in Japanese psychiatry have been recognized by the medical anthropologist Margaret Lock (1980), including housewife syndrome and school refusal syndrome. Both relate to pressures for achievement and success and the relationship of the individual to the group in Japanese society and culture. In the Chinese and Japanese cases the importance of harmony, right role performance, and the social nature of the person is clear.

GERMAN PSYCHIATRY. In Germany research has demonstrated a striking parallel between lay beliefs about mental illness and those of mental health professionals (Townsend). In that country lay and professional segments believe that there are two basic types of mental illness: *Gemütskrankheit* (emotional sickness), which is transient and caused by outside events, and *Geisteskrankheit* (mental sickness), which is said to be inherited, chronic, and not amenable to treatment.

Since the twentieth century German psychiatry has attempted to formulate biological notions of serious mental illness and has influenced many other psychiatric systems, especially that of the United States. Psychiatry makes a sharp distinction between the ill and the well that strongly affects diagnosis and treatment. Mental patients are *different* kinds of people; they are biologically defective. Many family studies focusing on the inheritance of mental disorders have been done in Germany and Scandinavia (Duster; Townsend).

This biological notion was developed in the nineteenth century and was central to the mental hygiene movement of the Third Reich. Because those people were biologically defective, they could not be helped and were a burden to the *normal,* and their lives thus were *not worth living.* That ideology led to the killing of tens of thousands of mentally ill and retarded patients in a process that was the forerunner of the Holocaust.

That ideology also asserted that certain groups of people—so-called races (e.g., Jews, Slavs, Arabs, Gypsies, Celts, Latins, Africans, and people from the East)—although not insane, were nonetheless defective and represented a potential threat. In the German ideology defective and dangerous meant non-German.

SOVIET PSYCHIATRY. Before the dissolution of the Soviet Union Russian psychiatric practice was strongly influenced by German psychiatry and its biological approach. Also influenced by Pavlov, Soviet psychiatry banned psychological and psychoanalytic approaches. Marxist ideology attributed madness and other problems to the evils of nonsocialist economic systems. Because individuals manifested mental disturbances long after the revolution, the causes had to be personal and internal, not social or economic. Hence, dissent was seen as pathology.

Soviet psychiatry described a unique form of schizophrenia—creeping schizophrenia—whose symptoms were usually nonconformity and dislike of expected work duties. Diagnosis could lead to hospitalization and the administration of powerful drugs. The opening of the Soviet Union to the West included a new acceptance of psychoanalytic theory (Mitchell and Black).

FRENCH PSYCHIATRY. French psychiatry identifies and treats several disorders that are not known in the United States or elsewhere. The practice of psychiatry, like the society around it, is hierarchical and authoritarian (Gaines, 1992a). It developed a nonphysical notion of mental disorders in the late 1790s and therefore did not adopt German biological theorizing entirely despite the neurologist Jean-Martin Charcot's organic approach and the rise of hereditarianism. The latter helped the French psychiatric profession gain prominence and authority over the treatment of mental illness (Dowbiggin). French psychiatry historically has been much more intimately connected with the state than have other psychiatric establishments in the West (Dowbiggin; Foucault).

A number of conditions exist in France that have no equivalents in other countries, including *spasmophilie* (literally "prone to spasms" but referring to a variety of vague, nonspecific complaints that include tiredness, loss of appetite, and various somatic complaints) and *triste* (or *fatigué*) *tout le temps* (chronic sadness or tiredness as a result of a great loss or disappointment). In those formulations French ethnopsychiatry expresses its culture's notions of the burden and exquisite sadness of life (Gaines and Farmer; Marsella and White; Gaines, 1991). French psychotherapies aim not at change in but at recognition and acceptance of a historicized self.

French psychiatry has unique historical concerns, such as passion and obsession expressed as monomania (fixed ideas). It was in France that the notion of the toxic nature of the asylum developed.

Culture and Context: Beyond Biological Thinking

Sociologists have long considered social contexts in Western industrial societies as affecting people's psychological status. Classic studies suggested that there is a relationship between social class position, urban dwelling, and an increased incidence of certain forms of mental illness. Although the lower classes have a higher frequency of some illnesses, it was found that the upper classes have a higher frequency of others.

Researchers with anthropological expertise implicated high levels of social disorganization as contributing to increases in the incidence of mental illness. People subject to extreme pressures, such as discrimination and other forms of oppression, that limited their life chances would have less stable environments and therefore would be more vulnerable to psychological afflictions. It also is known that U.S. psychiatry commonly misdiagnoses members of minority groups, attributing serious mental illness to individuals largely on the basis of ethnic group and gender group membership rather than on the basis of symptoms. Thus, the same symptoms in members of different ethnic groups or genders produce different diagnoses and prognoses (Gaines, 1992a, 1992b; Kleinman, 1988; Littlewood and Lipsedge).

Related to social disorganization are the consequences of personal and group traumas such as accidents and criminal victimization (assault, rape, abuse) as well as war, state-sponsored violence and terror, racism, genocide and ethnocide, forced migration, epidemics, poverty, and starvation. Native Americans and African Americans have been the subjects of pogroms, genocide, and terrorism as well as abuse, discrimination, and neglect. It is difficult to deny that those experiences have had a considerable psychological impact.

Stress, a notion derived from World War II and modeled on combat experiences, is relevant in the United States for dispossessed ethnic groups and for veterans, as can be seen in the recent formulation of posttraumatic stress disorder (PTSD) (Young, 1995), which combines trauma and stress with ideas of the unconscious mind that are not found in most other cultures.

The notion of universal biological mental diseases limits the understanding of the known variety of detrimental as well as beneficial sociocultural conditions. It leads observers to see defective persons instead of social inequalities and to seek biological vulnerabilities instead of hopelessness born of despair or the horrors of war. It ignores conditions that are responses to noxious circumstances. As an example, there has been a move to redefine PTSD as a biological defect rather than a reaction to war in veterans and to persecution and torture among Latin American immigrants to the United States.

Biological reductionism cannot explain the appearance of mental disorders across cultures. Although all people are human, they do not have the same ways of living, feeling, thinking, and behaving. To argue that pathology is purely biological is to contradict the fact that normal behavior, although supported by biology, is not determined by it.

Standards of normality vary from culture to culture; what is sane in one culture is insane in another. There is no evidence of a biological basis for the heterogeneity of conceptions of normality and abnormality. The advances offered by biological psychiatry are considerably less than advertised: *Modern* views of the genetics and biology of madness recapitulate theories of eugenics and hereditarianism from the nineteenth century (Carlson; Dowbiggin; Foucault; Gaines, 1992b; Gould) and earlier.

Professional Psychiatries: Ethical Implications

Historical and cross-cultural studies of professional psychiatries suggest that each one is a cultural construction, not a system of dispassionate discernment of natural psychopathologies; there are psychiatries, not one psychiatry. The application of a single theory or practice in a culturally diverse world leads to an ethical question: Are there negative consequences of the application of one culture's psychological medicine as a standard of normality in the evaluation and treatment of cultural others, including immigrants (Gaines, 1998a)?

Bioethics in the United States has grown out of concerns involving personal autonomy (a cultural value), experimentation (including that in the Third Reich), technological change, and informed consent but also out of a cultural context that gives meaning to those concerns. Bioethicists sometimes excludes social, political, and cultural issues such as "race" and gender, asserting that those things lie outside its domain or that cultural others are "really" the same (Midgley). Such assertions ignore more than a century of cross-cultural research demonstrating the contrary. In much the same way biological psychiatry excludes cross-cultural and historical research that contradicts the current version of psychiatric reality. Thus, it is able to operate in a closed domain that ignores complex historical and cultural realities.

A universalistic bioethics that is beyond culture is illogical. What is ethical in one context is unethical in another. Telling a patient the diagnosis in Japan is unethical, not telling in the United States is (now) unethical; leaving a patient uninformed about a disorder or the rationale for treatment is normal and ethical in Japanese and Italian psychiatry but not in U.S. psychiatry.

Biological distinctions that are reified as *natural,* such as the concept of race in the United States, have negative consequences. Those distinctions produce unequal treatment, disproportionate institutionalization, and higher morbidity and mortality. Adherents of those social views do not address social justice.

Nearly a thousand years ago in Islamic medical ethics physicians were enjoined to be social activists and advocate better living conditions for their community members. That ideology potentially opens the door to change and adaptation as well as social justice. The need to integrate the importance of cultural and social differences into theory and practice while maintaining appropriate levels of care in the face of increasing cultural diversity is the moral dilemma of modern Western and Eastern professional psychiatries in a multicultural, postmodern world.

ATWOOD D. GAINES (1995)
REVISED BY AUTHOR

SEE ALSO: *Medicine, Anthropology of; Mental Institutions, Commitment to; Homosexuality; Mental Health, Meaning of Mental Health; Mental Health Services; Mentally Disabled and Mentally Ill Persons; Psychiatry, Abuses of; Psychopharmacology; Psychosurgery, Medical and Historical Aspects of; Race and Racism; Sexism; Women, Historical*

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III. ISSUES IN DIAGNOSIS

Diagnosis of mental or physical illness is the clinician's determination of a clinical state or disease. However, as used in ordinary discourse, *diagnosis* is both a noun, signifying or denoting a particular clinical state, as well as a verb, describing an activity or process of determining diseases and clinical states. Clinicians ask "What is the patient's diagnosis?" as well as "What is your approach to diagnosis?" Considerations of the denotative aspects of diagnosis implicate the general classification and nomenclature of disorders or diseases (nosology), while the notion of diagnosis as a clinical process implicates various normative considerations of diagnostic practice—that is, considerations of fair, valid, and elegant diagnostic procedure. Ethical issues concerning the diagnosis of mental illness concern all of these permutations.

Mental Illness and the Self-Illness Distinction

The ethical issues involved in the diagnosis of mental illness can be considered as closely related to, perhaps even derivatives of, the enigmatic character of mental illness itself. At the core of this enigmatic character is the relation between mental illness and the self. In Western societies, sufferers of *physical* illnesses, diseases, or injuries can almost always distinguish their sense of self (the sense of who they are, the ownership and experiential domain of their unique mental life) from their affliction. For instance, a patient may have cancer, heart disease, a brain tumor, a cold, or a broken leg, but these conditions are over and apart from who the patient is, her holistic identity as a person. Ordinary discourse about physical illnesses often betrays this ego-alien character, where common linguistic metaphors portray disease as a malign force from outside the self: "She was struck down by cancer." "He had a heart attack."

Through their character as afflictions of psychological experience, this phenomenal distinction between self and illness is blurred in the case of mental disorders. Consider a few examples. The experience of depression saturates a patient's perception of herself, where the depth of her sadness and self-doubt overwhelms her sense of competence and worth. A man's schizophrenia wildly transforms his views of and relations with others and the world. Even amidst recovery from a drug dependency, the addict longs for the pleasure and tranquillity of intoxication. As these examples of mental illness illustrate, the afflicted may be unable to distinguish features of the self from features of illness (e.g., "I am depressed," not "I have depression"). Further, the mentally ill person may even value, or seek to preserve, some features of the illness, as in the case of the addict noted above, or, as another example, the person with bipolar disorder (manic-depressive illness) seeking the euphoria, confidence, and vigor of mania.

This weakening or loss of the self/illness distinction sets the stage for other ambiguities, and with them, a host of actual and potential ethical problems concerning the diagnosis of mental disorders. The intermingling of the personal self and the manifestations of mental illness confound Western cultural assumptions about the sick role. Parsons's notion of the sick role involved a forgiving of the sick individual's usual responsibilities; in Western societies the physically-ill person is thought incapable of the full range of her usual responsibilities, so subsequently, such incapacities are excused. Because of the difficulties in distinguishing aspects of the self from the manifestations of mental illness, this forgiving attitude toward the sick is often absent in the case of mental illness. Moreover, the often incomprehensible, annoying, or bizarre behavior of the severely mentally ill may generate fear in observers. These and other factors conspire to generate the most prominent manifestation of the sick-role confound: stigma, the vilification of "the mad."

Social stigma adds the additional burden of shame, humiliation, and exclusion to the ordinary suffering of mental illness, a burden by and large not shared by individuals with physical illnesses. Stigma subsequently ups the ethical ante in diagnosis, as a mere diagnosis of mental illness often has stigma-driven adverse social consequences, consequences relatively independent of the features of the illness itself. For instance, stigma may manifest itself through insurance or employment discrimination, harsh attitudes toward the homeless mentally ill, unfounded generalizations about the mentally ill individual's capacities, or the avoidance of treatment for mental illness.

Stigmatization of what is today called *mental illness* has been present throughout the recorded history of madness (Porter). At the beginning of the twenty-first century, stigmatizing attitudes toward the mentally ill often are justified by the view that the manifestations of mental disorders are willful and responsible, and the mentally ill fully choose their misery, if indeed they are miserable at all. The most prolific spokesperson for this kind of view is Thomas Szasz, a psychiatrist who since the early 1960s has argued that mental illness is a metaphorical concept that functions to regulate deviant behavior outside the usual sociocultural channels, such as the law, education, and religion (Szasz). For Szasz and like-minded authors, because psychiatric authority regulates deviance outside these usual channels in free societies, psychiatric practice undermines civil liberties on the one hand, and the responsible conduct of citizens, on the other. Psychiatric diagnosis, then, is an instrument of this subverted political authority.

Because of the aforementioned ambiguities concerning responsibility and the self/illness distinction, it is easy to recognize the general moral implications of either accepting or rejecting the Szaszian critique. If one accepts the Szasz position uncritically, one risks building a callous, uncaring society toward what could be catastrophic, with miserable illnesses affecting large numbers of people. If one does not take Szasz seriously, one risks stripping the *mentally ill* of their morality and their autonomy, as well as their unique value as individuals through reducing them to mere expressions of psychopathology or disease states. On the face of it, both these extremes seem unacceptable, so more recent work on the ethics of psychiatric diagnosis has focused on rethinking this problem or seeking a middle ground between conceiving the mentally ill as fully autonomous, responsible actors versus conceiving them as helpless, dependent incompetents.

Scientific Classification and Prudent Practice

Perhaps most influential in the scientific classification of mental illness has been the efforts of the American Psychiatric Association's committees on diagnosis to qualify and stipulate their diagnostic categories in ways that, in the ideal, serve to both constrain mental disorder diagnosis and validate it. This was not always the case. In the early twentieth century, official diagnostic classifications of mental disorders were primarily aimed for hospital registries and the accounting of patient flow. Only with the publication of the first edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM) in 1952 was diagnostic classification intended as a tool of science and good clinical treatment. By the third edition (DSM-III) in 1980, and continuing to the present fourth edition (DSM-IV, 1994), the DSM's intentions have broadened even further (Wallace). Since DSM-III, the manuals have resolved to meet a number of objectives or goals:

1. To provide a useful aid to clinical diagnostic practice;
2. To provide a scientifically sound classification of psychopathology for mental health research;
3. To provide an enumerated coding system for record-keeping and billing purposes;

4. To provide a comprehensible nomenclature for education efforts; and, of particular interest for this discussion;
5. To provide an extensive introduction to the manual that specifies prudent diagnostic practice and use of the manual.

The capability of this or any other diagnostic manual to accomplish such an ambitious range of objectives has been a ongoing source of debate. Subsequently, ethics-oriented criticisms of the DSM editions often betray disagreement over the particular balance struck between the various objectives (Sadler). For instance, some critics have noted that enumerated, rigorously-defined and scientifically-tested diagnostic labels oversimplify the complex condition of mental illness and impede the ill from engaging in discussions about themselves and speaking on their own behalf (e.g., Kovel). On the other hand, other critics note that the DSMs are excessively tied to clinical diagnostic traditions and are not scientifically rigorous enough (summarized in Sadler, Hulgus, and Agich). The ethical implication here is that scientifically-compromised diagnostic categories undermine the moral justifications for interventions like involuntary hospitalization or involuntary treatment, or indeed, treatment at all. As a third example, commentators have noted tensions between the values of clinical utility and clinician acceptability in the DSMs versus the efforts to have DSM categories fully reflect rigorous scientific values like validity and reliability (Sadler, Hulgus, and Agich).

Diagnosis and Mental Health Pluralism

As might be expected under the conditions of the blurred self/illness distinction, mental illness has been subject to an extraordinary range of competing and contrasting formulations or understandings. Until the recent ascent of alternative medicine, physical medicine has enjoyed relatively little competition from rival clinical practices based upon nonbiomedical explanatory models. This, however, has not been the case for mental illness, as the woes of the psyche have a long history of ministrations from diverse healing and/or helping traditions. What psychiatrists call *mental illness* may be conceived by nonmedical practitioners as spiritual crises, or as secular problems in living, or the result of supernatural forces, or irregularities in various moral, dietary, lifestyle, or other habits. Analogously, ministration to such psychic woes is offered by not just physicians, but pastors or spiritual advisors, hundreds of varieties of lay and professional counselors and psychotherapists, folk healers, alternative clinicians, family, neighbors, and friends. Any effort, then, to provide a common nomenclature for mental distresses is bound to generate disagreement, and the existence of such diverse resources is bound to generate controversy over the relative value of each.

In this sense, then, any mental illness diagnosis (in the broadest sense) under any system of clinical thought, medical or otherwise, can be construed as having an ideological character. Hence, for instance, biomedical psychiatry's predilection for prescribing pharmaceuticals for DSM-diagnosed mental disorders is criticized as the capitalist commodification of everyday life, while interpersonal narrative-based psychotherapies may be praised as more communitarian in their political alliances. Diagnostic practices, if they lend themselves to one or the other ideology, then, are similarly implicated. The DSM approach to this problem has been to develop inclusive and diverse committees in the construction of the DSMs, and invite *outsider* input so that the DSM categories reflect some measure of such pluralistic practices, and hence are open to a range of therapeutic options (Frances, First, and Pincus). The World Health Association's *International Classification of Diseases—ICD-10 Classification of Mental and Behavioural Disorders* (ICD) has sought to provide a common language for mental health practices all over the world, and in developing its classification solicits input from all of its member countries (WHO). As such, its ambitions as a diagnostic manual are necessarily more modest, focusing on providing an enumerated coding for record-keeping and billing, preferring fewer numbers of categories, and adhering more closely to practice conventions than the more innovative, and American-regional, DSM manuals. Nonetheless, the DSM manuals and the ICD manuals have a close relationship, as the DSM is obligated by international treaty to provide compatible diagnostic categories for the ICD manual, and in recent decades the development of each manual has been closely coordinated with the other.

Even within the biomedical paradigm, however, mental health practice (psychiatry, clinical psychology, psychiatric social work, and related fields) has been characterized by a diversity of theoretical formulations, empirical-scientific approaches, and conventions of practice. The approach of the American Psychiatric Association's DSM effort, along with the ICD classification of mental disorders, has been to work toward a diagnostic classification which minimizes, even perhaps eliminates, theoretical assumptions about the causes of mental illness. Moreover, with the DSM-IV effort, the process has included assembling comprehensive scientific literature reviews, a *consensus scholar* approach in interpreting aggregated studies, and extensive and detailed documentation of the developmental procedures and findings used in constructing the manual. With the addition of extensive field trials (empirical studies) of proposed or revised diagnostic categories, the DSM process aims to continuously improve the scientific validity and reliability of its diagnostic classification. Nevertheless, many non-psychiatric mental health practitioners lament having their own practicable alternatives and may view the DSM/ICD efforts as a *de facto* hegemonic effort by psychiatrists to dominate the mental health field (Beutler and Malik).

Inspired by the problem of adequately circumscribing psychiatric diagnosis (e.g., assuring that people diagnosed are truly ill, and those not so diagnosed are truly well), significant efforts have been made since DSM-III to provide a rigorous definition of mental disorder. This effort is part of the aforementioned goal to recommend good diagnostic practices in the DSM introductory material. Such definitions of mental disorder, and the concepts underlying them, were developed in the introductions to DSM-III and later editions. Since then, such attempts at defining mental illness have been subject to heated debate, as discussed by K. W. M. Fulford in his article "Mental Illness: I. Conceptions of Mental Illness" in this volume.

Preserving the Dignity of the Self

While short of providing explicit moral and aesthetic rules for the proper conduct of psychiatric diagnosis, the introductions to the DSM manuals do prescribe, and proscribe, clinician conduct in significant ways, though these guidelines for use of the DSMs are thought by some to be inconsistently read and heeded. For instance, recent editions of the manuals have included explicit categories and codes indicating diagnostic uncertainty; have used a *multiaxial* diagnostic system that provides for diagnosis of not just mental illness, but other factors like complicating physical illnesses, environmental stressors, and the global adaptive function of the individual; and have provided a *cautionary statement* recommending against the use of DSM categories in forensic or other nonclinical settings. At question is the efficacy of these efforts to facilitate a thoughtful and responsible diagnostic practice; critics claim that despite these efforts, the DSM is still used in a "cookbook" fashion and the individual under diagnostic evaluation is still likely to be labeled narrowly and conceived simplistically (discussed by various contributors in Sadler).

Amidst these clinician-generated efforts to provide fair and scientifically valid diagnoses, the diagnosed and the families of the mentally ill have increasingly organized to protect themselves against what they view often as stigma-generating diagnostic pigeonholing and the diminution of their sense of self (Luhrmann). This movement is most concretely manifested in the terms the mentally ill increasingly use to refer to themselves: no longer *patients,* but now often *clients, consumers, users,* and even *psychiatric survivors* of mental health services. At present the mentally ill have little to no input into how their conditions are classified in systems like the DSM and ICD or how diagnostic criteria are phrased, nor do they have much of a forum for their views about prudent diagnostic practices (Sadler). How much influence this advocacy on behalf of the mentally ill will have on mainstream mental health diagnosis and practice remains to be seen.

The issue of the autonomy of the mentally ill and the ethics of diagnosis have collided in recent controversies over the handling of consent in clinical research settings. The issues were crystallized at the end of the 1990s by a debate in the United States over the National Bioethics Advisory Commission's (NBAC) report addressing the issue of protecting human subjects, as well as protecting research participation, with subjects with impaired decision-making capacity (Roberts and Roberts). Driven by concerns over the allegedly vulnerable but needy mental illness population, the NBAC recommended a series of protections that, from the research community's perspective, would make the clinical research enterprise a burden on researchers and subject-participants: these recommendations would make consent procedures and participation arduous, and create the risk of denying this population access to research participation, subsequently reducing the social benefits of the research. A significant component to this debate was the degree to which any diagnosis of mental disorder qualifies the potential subject as having an *impaired decision-making capacity.*

Cross-Cultural Validity

In the context of economic globalization and increasing cultural interchange, recent thought about the validity of mental disorder diagnosis has addressed the question of the validity of mental disorder diagnosis across cultures. Does the DSM-IV diagnosis of Schizophrenia apply equally to a white Anglo-Saxon Protestant from Normal, Illinois as to a Bantu African tribesman? What about Obsessive-Compulsive Personality Disorder or Anorexia Nervosa?

The issue of cross-cultural validity of mental disorder diagnosis has three general ethical ramifications. The first ramification concerns cultural assumptions of normality. The second concerns the practical matter of accurate detection of psychopathology in multicultural settings. The third ramification concerns which values should prevail in judgments concerning health or psychopathology.

As Dona Davis has noted, the sexual performance norms assumed by, for instance, DSM-IV sexual disorders do not apply to cultures where *sexual performance* as a cultural construct does not exist. For instance, how can someone have *anorgasmia* or *premature ejaculation* where there is no expectation of female orgasm? (Davis). The normative assumptions (taken-for granted beliefs about what is normal, adaptive, or acceptable) underlying diagnostic systems like the DSM or ICD classifications can pose dilemmas for clinicians working in diverse settings, where, for instance, couples of mixed ethnic origin may have clashes over acceptable and unacceptable behaviors. Normative assumptions underlying mental disorder diagnoses push the clinician into taking culturally-relative moral stands related to cultural assumptions, and more subtly, may mask the very cultural assumptions and beliefs that effective treatment must make explicit.

As a second example, mental disorders (like anorexia nervosa) that are closely conceived within cultural normative assumptions and expectations may not occur or may manifest themselves differently in other cultures. Diagnostic conceptions or criteria that are skewed toward the assumptions and values of Western industrialized cultures may have false-negative and false-positive diagnostic implications in practice. If Third World clinicians are not looking for anorexia nervosa, if indeed it occurs, they will likely miss an authentic disorder (false negative diagnosis). If Western clinicians are looking for anorexia nervosa in Third World populations where it is not endemic, they may nevertheless find cases who are not truly ill (false-positive diagnosis). Culturally invalid mental disorder diagnosis is then an ethical problem because of harms posed by the systematic potential for false-negative and false-positive diagnosis.

A third ethical ramification of cross-cultural validity concerns how mental phenomena are valued. Michael Jackson and K.W.M. Fulford present a case of a man who meets standard examination criteria for psychosis with the exception that his experiences are adaptive, and have enhanced his functioning and life satisfaction. M. Fakhr El-Islam notes that psychosis can be interpreted in fundamentalist Islamic cultures as a prophet's response to spiritual or religious stagnation, and the psychotic symptoms can confer positively valued mystical insights. How mental *symptoms* are valued have important implications on whether such phenomena are truly pathological.

Conclusion

Because of the ambiguity between mental illness and the self, mental illness poses a complex range of ethical challenges, whether one is a scientist engaged in the study of these conditions, a person afflicted with mental illness, or a clinician helping an ill individual. Ethical concerns arise from numerous directions, from the mere act of making a diagnosis, to considering the social impact of diagnosis, to the applicability of diagnosis across cultures.

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SEE ALSO: *Beneficence; Coercion; Homosexuality; Mental Health, Meaning of Mental Health; Mental Health Services; Psychiatry, Abuses of; Psychopharmacology; Psychosurgery, Medical and Historical Aspects of; Race and Racism; Sexism; Women, Historical and Cross-Cultural Perspectives;* and other *Mental Illness* subentries

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MENTAL INSTITUTIONS, COMMITMENT TO

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Throughout the world there are legal mechanisms by which mentally ill persons can be sent to psychiatric hospitals even when they do not wish to go (Appelbaum). In the United States this sometimes is done through the criminal justice system: A person may be judged incompetent to stand trial for a crime because of mental illness or may be tried for a crime and found not guilty by reason of insanity and then committed to an institution for mentally ill criminal offenders. The more common type of commitment is civil, and usually no criminal offense is involved: A person is judged to require hospitalization because of his or her mental condition but does not consent to it, but if certain legal criteria are fulfilled, that person may be hospitalized against his or her will. Commitment is a legal process and often is discussed mainly in terms of its case and statutory legal history (Wexler). This entry discusses important ethical issues that underlie the process of civil commitment.

Commitment raises serious ethical concerns. It involves depriving persons of their freedom for days, weeks, or longer, usually by incarcerating them in a locked psychiatric facility. Commitment is one of the ethically most serious actions in which psychiatrists engage. However, neither the process of commitment nor its ethical justification (or the related issue of forced treatment) is mentioned in the American Psychiatric Association's extensive handbook on psychiatric ethics (American Psychiatric Association, 2001b).

In most states this violation of a person's civil liberties can be carried out initially on an *emergency* basis on the strength of one physician's signature on the appropriate form. Most people agree that it is preferable that a psychiatrist be the initial committing physician, but there are too few psychiatrists in many rural areas for this usually to be mandated by law.

After the emergency commitment form is signed, the person who is to be committed is taken to the nearest locked psychiatric facility authorized to receive committed persons. Medical personnel there usually have the authority to question the appropriateness of the commitment and even to refuse to detain the person. In most states, under modern law, a probable-cause judicial hearing is held within two to three working days in an appropriate local court to determine the justifiability of continued detainment.

The vast majority of admissions to psychiatric hospitals, however, are voluntary and do not involve the commitment process. A small minority of voluntary admissions, however, result from persons being told that they will be committed if they do not enter the hospital "voluntarily." There seems to be nothing inherently unethical about giving a person who otherwise would be committed the opportunity to avoid the commitment process in that way, assuming that the planned commitment is ethically justified. It seems clear, however, that these persons have not entered the hospital entirely voluntarily. In addition, it would be prima facie unethical for a physician to use this process deceptively by manipulating a person into entering a hospital by threatening a commitment that in fact would not be carried out.

Legal Criteria for Commitment

Both within and outside psychiatry there is dispute about the commitment criteria that should be written into state statutes. Statutory language varies from state to state (Arthur et al.). All U.S. state statutes stipulate that to be committed a person must be mentally ill, although this concept is defined variously. The existing continuum of positions is based on the width or narrowness of the additional statutory commitment criteria. (For an excellent discussion of one state's commitment laws see Behnke, Winick, and Perez.)

The broadest additional criteria are advocated by those who think that physicians should be able to commit anyone whom they sincerely believe would profit from commitment. At one time many states had statutes with this breadth. Arizona law, for example, as recently as 1981 allowed persons to be detained if they were "mentally ill and in need of supervision, care or treatment" (Wexler, p. 74). Criteria with this breadth seem unsupportable to most commentators. For example, many persons with a moderate degree of depression are mentally ill in that they satisfy the criteria in the *Diagnostic and Statistical Manual, Fourth Edition* (DSM- IV) (American Psychiatric Association, 1994) for having a psychiatric disorder, and treatment almost certainly would make them feel better. No one, however, thinks that in most cases they should be forced into a psychiatric hospital if they do not wish to go. Thus, more than *mental illness* is necessary to justify commitment.

A narrower position is taken by many psychiatrists (see Chodoff for a classic description of this position and Buchanan and Brock for clear arguments supporting it). In addition to requiring that a person be mentally ill, supporters of this position advocate a criterion stipulating that that person be *gravely disabled* or manifest a *serious disruption of functioning* as a result of the mental illness. Being physically dangerous to oneself (suicidal) or to others (homicidal or physically threatening) represents one type of serious disruption of functioning but not the only one. The behavioral and social disorganization shown by many manic persons, for example, although often not immediately physically threatening to themselves or to others, may in the long run cause those persons serious social and financial harm. Under a *serious disruption* criterion many of those individuals could be committed.

A narrower position still is that advocated by many civil libertarians and some psychiatrists (American Bar Association). A diagnosis of mental illness is required, and there must be a high probability that because of the mental illness a person is a serious physical threat to himself or herself or to others. A minority in this group would restrict the criterion further and require that there be good evidence of recent behavior toward oneself or others that was in fact physically harmful, but most believe that evidence of strong threats of physical harm is sufficient. Most also believe that dangerousness toward oneself can be evidenced not only by threats of suicide but also by extreme self-neglect so that, for example, starvation or untreated serious disease can constitute an immediate threat. However, without the threat of imminent dangerousness of some kind, commitment would not be allowed.

The position at the far end of the continuum is taken by those who believe that psychiatric commitment is never ethically justified and thus that there should be no commitment criteria. Thomas Szasz, a psychiatrist, has been the foremost spokesperson for this position. Szasz believes that the concept of mental illness is mythical and argues that those who manifest what others regard as the symptoms of mental illness should be judged only by the standards of criminal law: If they have broken a law, they may be arrested or otherwise constrained; if they have not, their freedom should be preserved. Szasz believes that commitment is based on a false theory that "medicalizes" deviant behavior into illness and that psychiatrists who commit persons become unwitting arms of the criminal justice system.

For several reasons Szasz's position has not been persuasive to many people inside or outside psychiatry, including most civil libertarians. First, most scholars feel that some psychological conditions satisfy the criteria of a definition of *illness* (Gert, Culver, and Clouser, Margolis) and that Szasz's position has serious theoretical problems (Moore, Culver, and Gert) that he has not addressed. Second and more important, most believe that paternalistic interventions of the type that commitment usually represents are at least sometimes ethically justified.

The principal and enduring tension is between those who hold the two middle positions described above. Some states have commitment statutes closer to one, and some have statutes closer to the other. Those who advocate a broader criterion believe that dangerousness to oneself and others is only one of many manifestations of severe mental illness and that it is cruel and theoretically unjustifiable to ignore the needs of disordered or disabled persons, often homeless and wandering the streets, who clearly would benefit from treatment (Treffert, Peele, and Chodoff; American Psychiatric Association, 2001a). References are made to people "dying with their rights on" and to Janis Joplin's song line "Freedom's just another word for nothin' left to lose."

Those who advocate the narrower grounds fear that relaxing the criterion in the direction of *disruption of functioning* leaves the door open too wide to psychiatric paternalism and represents a threat to civil liberties. Images of forced psychiatric internment of political dissidents in the Soviet Union (Bloch and Reddaway) are invoked as a frightening example of giving psychiatrists the power to confine individuals who are not physically dangerous but only *disrupted* in their functioning. One of the necessary and willing prices of having a free society, they argue, is that people are free to make self-defeating choices and sometimes irrationally reject opportunities for help.

A cohort of persons are committable under a broader but not under a narrower set of criteria. An example is a person with a history of bipolar disorder who becomes increasingly hypomanic and is squandering his carefully accumulated savings in what are almost certainly hopeless financial schemes. He refuses all treatment. Everyone who knows him believes that his spending spree is due to his hypomania, that it would not be unethical to curtail his actions, and that if his behavior were curtailed, he almost certainly would be grateful later. However, although his current behavior is harmful to his long-term interests, he is not *dangerous to himself or others* as that criterion is explicated in many states.

Many persons, like this man, whose behavior meets broader but not narrower commitment criteria suffer from cyclical disorders: Their aberrant behavior occurs only episodically. Some authors have suggested that such persons might be offered during nonsymptomatic times the opportunity to create a contract stating that if their future behavior deviates from their usual behavior in certain specified ways, they will accept the use of appropriate interventions (confiscation of funds or forced hospitalization, *voluntary commitment*) that otherwise might not be legally permissible (Howell et al., Culver and Gert).

An important empirical issue discussed by Peele and Chodoff is the extent to which statutory criteria for commitment influence the behavior of psychiatrists. Are there patients who are not committed in states with narrow criteria who would be committed in states with broader criteria? Peele and Chodoff, after surveying the scanty evidence that exists on this point, conclude, “It appears that judges and juries base decisions about commitment on what they think is best for the person, regardless of formal criteria” (Peele and Chodoff, p. 436). This would be a useful issue to explore further.

Conceptual Issues Underlying Commitment

ETHICAL JUSTIFICATION. In discussing the ethical justification of commitment a distinction must be made between whether a commitment is intended primarily to help the person who is committed or to help others whom that person may be putting at risk (Gert, Culver, and Clouser; Buchanan and Brock). This distinction sometimes is not clear-cut because it is usually to the advantage of mentally ill persons to be prevented from harming others. The harm they might cause often would be serious and thus would constitute a crime. Committing the crime frequently would be a clear result of the mental illness—for example, obeying a voice commanding that someone be killed—and it is highly likely that the mentally ill offender would be apprehended, incarcerated, and then punished or at least hospitalized for a long time. Nonetheless, there is a distinction between paternalistic and nonpaternalistic commitments, and there is no doubt that the protection of others is the predominant reason for some commitments.

Paternalistic commitment. To the extent that commitment is intended to help the person who is committed, it essentially always qualifies as a paternalistic action. That is, the commitment is intended to benefit the committed person, it violates at least one moral rule (deprivation of freedom) and usually several, it is done without the consent of the person, and the person is at least minimally competent to give consent (Gert, Culver, and Clouser). Whether paternalistic commitment is ethically justified therefore depends on whether a particular commitment meets whatever theoretical criteria for justified paternalism are thought to be adequate.

Various sets of criteria, partly overlapping, have been proposed by Beauchamp and Childress, Buchanan and Brock, Childress, and Gert, Culver, and Clouser. Those criteria depend on theoretical concepts such as the degree of irrationality and voluntariness of the person’s behavior and the balancing of physician beneficence and patient autonomy. None of those authors seems to believe that as a species of paternalism, there is anything qualitatively unique about committing mentally ill individuals. Thus, particular acts of commitment are measured directly against the theoretical criteria of the particular justification procedure that is proposed.

However, in the judgment of many authors (Culver and Gert; Buchanan and Brock), the presence of mental illness does play an indirect role in the justification of paternalistic commitment by sometimes affecting concepts that those authors believe are centrally important in the justification process. Thus, some suicidal desires may be regarded as not truly expressing an individual’s autonomous wishes (Beauchamp and Childress), or some conditions of mental illness may be thought to affect a person’s competence to make decisions (Buchanan and Brock).

Nonpaternalistic commitment. When commitment is not paternalistic, it must be ethically justified on other grounds. To commit persons in an attempt to prevent them from harming others represents a kind of preventive detention that ordinarily is not legally permitted in the United States. In the presence of some kinds of mental illness, however, it is argued by some that nonpaternalistic commitment may be ethically justified.

For example, two men are brought separately to the emergency room by the police. In each instance the police have been called because the man has just threatened to kill his wife. Each man admits to the emergency room psychiatrist that this is true. The first man has a history of paranoid psychotic episodes and in recent days has heard voices instructing him to kill his wife. The second man has no symptoms or history of major mental illness, but he and his wife have a history of chronic marital discord. In both cases the psychiatrist feels that there is a reasonably high probability that the man will harm his wife if he returns home.

On the basis of the fact that in some kinds of mental illnesses persons are not held responsible for their actions, it may be argued that it is ethically justified to commit the first man but not the second. The second man, for example, presumably has the volitional ability to will or to refrain from willing to harm his wife, whereas the first may not have the volitional ability to will not to harm her (Culver and Gert). Dangerous mentally ill persons sometimes are not considered capable of guiding their behavior in accordance with promulgated social rules (Brock).

PREDICTING POSSIBLE FUTURE HARM. Civil commitment always involves a doctor's appraising a person's physical and mental status and deciding whether commitment is warranted. Sometimes individuals may be committed because they are in such a disabled condition that even more serious future harm seems all but inevitable. A woman may, for example, be hallucinating continuously, be unresponsive to the questions or actions of others, and be significantly malnourished because of a lack of interest in food. Much more often, however, serious future harm is only a possibility: For example, a person has threatened suicide or is hearing voices urging her to harm someone, and the physician must try to predict how likely it is that the harm actually will occur.

The process of predicting possible future harm in the commitment setting has the following components (Grisso): The criterion is what is being predicted (for example, the person's suicide), the cues are discrete pieces of available information about a particular case at a particular point in time (for example, the person's age, sex, state of intoxication, and history of impulsivity), and the judgment is the physician's conclusion after assessing the case (for example, to commit or not to commit). These are three separate elements. Empirical research has focused separately on the correlations among them. The judgment-criterion correlation shows how well physicians do in predicting that particular persons will kill themselves. The cues-criterion correlation shows the extent to which suicides can be predicted from whatever facts about cases can be isolated and measured independently of physicians' judgments. The cues-judgment correlation shows which data about cases lead physicians to make one judgment or another.

A critically important issue with respect to prediction is the extent to which commitment does prevent future serious harm. There are few data addressing this issue. If it were known, for example, that 90 percent of the persons committed would have harmed themselves or others seriously if they had not been committed, most people probably would feel that commitment was ethically justified. Committing one hundred persons would avoid ninety instances of serious harm, although at the *cost* of committing ten persons who would not have caused harm if they had not been committed. By contrast, if only one in a hundred persons would have harmed themselves or others, few would feel commitment was justified because ninety-nine persons would have suffered the evils of detainment to prevent one bad future outcome.

This kind of utilitarian calculus seems central to most writers who discuss the ethical justifiability of commitment. Commitment essentially always inflicts significant harm, but only sometimes does it prevent significant harm. Almost everyone acknowledges that even among those at relatively high risk of causing harm—for example, suicidal persons brought to an emergency room—only a minority would, if left alone, subsequently harm themselves. An emergency room physician thus faces a difficult task. To commit every person would be to commit too many, but which persons should be committed? Certain characteristics of persons (cues) are known to increase the likelihood of future harmful acts—for example, a history of impulsive or suicidal behavior, being inebriated, having access to lethal weapons, being male—but a physician must make a binary, yes-no decision about commitment, not a probability estimate.

Research (Monahan) suggests that physicians are poor predictors of whether harmful behavior will occur (judgment-criterion correlations). There is reason to believe that basing predictions on discrete, measurable pieces of information about a case (cues-criterion correlations) will yield greater accuracy (Monahan). There is, however, probably an upper limit to predictive accuracy; one reason for this is that whether a person commits a harmful act in the hours or days after a physician's assessment may depend at least as much on later fortuitous situational factors such as whether a friend returns a telephone call as on factors that can be measured during the assessment.

A very important statistical feature of prediction plays a key role in understanding the commitment process and making ethical judgements about it. In predicting relatively rare events such as the occurrence of a future suicide through the use of predictive signs of less than extremely high predictive accuracy (for example, a physician's judgment or whether a person has access to a lethal weapon), one inevitably will make a high proportion of false-positive predictions; that is, one frequently will predict future harm when in fact none will occur. This actuarial problem, which is an example of the application of Bayes' theorem, was described by Meehl and Rosen and later applied to the issue of commitment by Livermore, Malmquist, and Meehl.

Suppose that 10 percent of suicidal persons who are brought to an emergency room but are unwilling to be hospitalized would kill or harm themselves seriously if they were not committed. Suppose further that, using the available cues, physicians' predictions of who will and will not commit suicide have a sensitivity of 70 percent (*sensitivity* refers to the percentage of persons who will commit suicide whom physicians accurately predict will commit suicide) and a specificity of 70 percent (*specificity* refers to the percentage of patients who will not commit suicide whom physicians accurately predict will not commit suicide). It follows that physicians will commit and thus *save* seven of the ten persons destined for suicide but also will commit twenty-seven persons of every ninety persons (30% of ninety) who would not have killed themselves. These latter persons constitute false positives.

The ratio between the number of true positives (seven) and false positives (twenty-seven) shows that nearly four persons will be committed needlessly in order to save one. (These are hypothetical figures. Many would argue that subsequent suicide is rarer than 10 percent in the general psychiatric suicidal population and that 70 percent is too high an estimate of sensitivity (and of specificity); thus, the actual proportion of false positives would be much higher.) The physician would be correct a higher percentage of the time (90%) if he or she simply predicted that no one would commit suicide, but then none of the ten suicidal persons would be saved.

Is it ethically justified to commit four unwilling persons needlessly to save one life? Suppose empirical data existed (they do not) that enabled the construction of actuarial tables that would correlate the nature and number of signs and symptoms shown by mentally ill persons in emergency rooms with their subsequent likelihood of harming themselves or others if they were not committed (cue-criterion correlations). Each person thus could be assigned to a cohort: Some would have a one in five chance of harming themselves or others, some a one in ten chance, some one in twenty, some one in forty, and so forth.

Where should the line be drawn? What is the appropriate trade-off between saving one life and needlessly depriving many persons of their freedom? Reasonable people might disagree about where the line should be drawn, but this is a matter that could be opened to public debate. Psychiatrists probably have no special expertise in deciding where the threshold for commitment should be placed.

When confronted with the inevitable large numbers of false-positive commitments, some people recall the injunction often cited in connection with the U.S. criminal justice system—"Better that ten guilty persons go free than one innocent person suffer"—and conclude that civil commitment is ethically unjustified (Sartorius). Others, however, although concerned about the false-positive problem, believe that there are sufficient differences between the underlying conceptual justifications of the criminal justice system and the civil commitment system that some number of false positives can be tolerated in the civil system (Brock).

Conclusion

Although debates about involuntary hospitalization sometimes are framed in legal rather than ethical terms, it is important to be clear about the underlying ethical issues. Civil commitment involves incarcerating an unwilling person who has committed no crime for days, weeks, or longer. This type of prima facie unethical action requires clear justification in terms of a general moral theory. Current theoretical discussions of commitment emphasize concepts such as the degree of irrationality and the extent of voluntariness of a person's behavior. In applying theoretical concepts to the process of commitment it is critical to describe the components of the process clearly and take into account certain statistical features that are inherent in making predictions about a person's future behavior.

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REVISED BY AUTHOR

SEE ALSO: *Autonomy; Behavior Control; Coercion; Competence; Human Rights; Institutionalization and Deinstitutionalization; Mental Illness; Mentally Disabled and Mentally Ill Persons; Patients' Rights: Mental Patients' Rights*

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MENTALLY DISABLED AND MENTALLY ILL PERSONS

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I. Healthcare Issues
II. Research Issues

I. HEALTHCARE ISSUES

Primary healthcare providers for patients with mental illnesses bear the same ethical obligations as providers who serve patients with physical illnesses, yet they face special challenges in upholding those obligations. When mental illness causes a patient to be violent or suicidal, clinicians may confront situations in which their duties to the patient conflict with other ethical duties. At times, the decision about which duty to obey involves careful moral consideration. Additionally, because mentally ill persons are particularly vulnerable to abuse, the clinician has a special obligation to protect such patients against abuses.

For example, in the case of a patient who has attempted suicide, the duty to respect the patient's autonomy may conflict with the duty to protect the patient from harm. The patient may wish to go home, yet the clinician—who may be a physician in a hospital emergency room, a psychiatrist, or the patient's therapist—may decide to hospitalize the patient. At this point, the patient's fundamental right to refuse care has been denied. The moral justification may seem clear: The patient is not thinking rationally, so he or she should not be permitted to function autonomously. The patient deserves an explanation about why he or she is being hospitalized and has a right to information about the legal routes for challenging the decision.

It's true that in some cases, suicide may be a carefully reasoned choice. Far more often, though, planning or attempting to harm oneself results from a clinical depression or other psychiatric disorder. Discerning whether a patient's suicide reflects a rational decision is typically not possible in an emergency room setting. It would be ethical to hospitalize a patient to prevent suicide until a more thorough assessment could take place, including discussions with family members and or with healthcare providers who have known the patient over a long period of time.

Even when the clinician's overriding moral duties are clear, actual situations are complicated. There is often disagreement among patients, clinicians, families, and the courts about whether a patient's rights may be denied. This article explores common moral dilemmas in the medical and psychiatric care of individuals who are experiencing a major mental illness, such as schizophrenia or clinical depression, and those who suffer from the serious deficits in memory and intellectual functioning seen in dementia or mental retardation. Health professionals caring for such patients are likely to face one or more of the following questions and ethical concerns:

1. Does the person with mental illness have the capacity to decide about suggested treatments (informed consent for treatment)?
2. When is it ethical to hospitalize mentally ill persons against their will (commitment)?
3. Is it ethical to treat mentally ill persons against their will with psychiatric medications (coerced treatment)?
4. Is it ethical to use coercive methods to encourage a mentally ill person to comply with prescribed treatments (coerced compliance)?
5. When is it ethical to withhold information from a person because that person has a history of serious mental illness (truth-telling)?
6. When is it ethical to breach the confidentiality of a mentally ill patient (confidentiality)?
7. Under what circumstances is it ethical to withhold scarce health resources from a person because that person is seriously mentally ill (allocation of scarce resources)?

Informed Consent for Treatment

No patient should be treated by a doctor without first being informed about the nature of the treatment and then consenting to have the treatment. When a person with a history of serious mental illness is being treated for a medical condition, his or her doctors may consult a psychiatrist about the patient's capacity to make medical decisions.

Assessing the capacity to make medical decisions need not involve a comprehensive evaluation of intellectual functioning. A straightforward discussion regarding a patient's understanding of a specific medical decision is usually sufficient. The psychiatrist asks questions about the nature of the illness and possible treatments and determines from the responses if the patient understands the problem, the treatment choices, and the likely consequences of a given decision. A formal judgment of medical competence can only be made in court (Appelbaum and Grisso). However, the psychiatrist's informal evaluation can guide treatment in most clinical situations.

A person whose mental abilities are partly impaired may be competent to make certain decisions about medical care. This situation can arise with an elderly person who suffers from mild dementia or a younger person affected by mild mental retardation (Kaplan, Strang, and Ahmed). For this reason, decision-making capacity must be assessed on a case-by-case basis.

Also, a person who is incompetent at one time may be competent at another. Delirium and depression, conditions seen frequently among patients hospitalized for medical reasons, are examples of conditions that temporarily disrupt clear thinking. A person who is delirious or depressed may be found incompetent to refuse treatment, yet when the delirium clears or the depression lifts, that person is considered competent.

Consider the case of a thirty-five-year-old man with kidney failure (Shuchman and Wilkes). Doctors told him that he required dialysis to take over the function of his kidneys. The man refused dialysis, saying he would rather die. A psychiatrist determined that the man suffered from a severe depression that was interfering with his ability to think rationally, and the man was deemed lacking in the capacity to make medical decisions. Over time, and with treatment, including antidepressant medication, the depression resolved. Eventually, the man's doctors judged him capable of making treatment decisions. However, the man's uplifted spirits did not alter his desire to stop dialysis. The lifesaving technology was discontinued and he died within a few days. Though the outcome may be death, respect for patient autonomy requires that competent patients be allowed to refuse therapies (Angell; Hebert and Weingarten).

Commitment

Though involuntary confinement of mental patients decreased markedly over the last three decades of the twentieth century, it is still an essential tool used to protect patients who are potentially dangerous due to a mental illness. Since hospitalizing a patient against his or her will necessarily denies the patient's autonomy, it is essential that the act be morally justified. Yet, what qualifies as such justification is controversial.

During the 1960s, a person *in need of treatment due to mental disorder* met the criteria for involuntary admission to a psychiatric hospital in most states and provinces; in the 2000s, the criteria are significantly narrower. Individuals may be involuntarily hospitalized if they are deemed a danger to themselves (for example, if they are about to attempt suicide), a danger to others, or are unable to care for themselves due to mental illness. Typically, the assessment leading to involuntary hospitalization is done by a mental health professional, though such requirements vary in different states and provinces. Once confined, the person may be hospitalized for up to a few days. If commitment extends beyond a specified brief period, a court hearing generally must be held to determine whether further involuntary confinement is appropriate. The courts have also encouraged treatment of psychiatric patients in less restrictive settings than inpatient hospital wards when possible. Other treatment options include "day hospital" programs that allow patients to return home at night, and case management programs that ensure daily checks on outpatients.

In practical terms, the decision to hospitalize someone involuntarily is often a difficult one. Consider a woman who is depressed and has attempted suicide. She might be safest in a hospital, since there is a risk of her making a second suicide attempt while she remains depressed. But safety alone cannot be a reason for hospitalization, as very few of those who attempt suicide will go on to successfully complete suicides in the future. This woman might be safe outside a hospital if she is engaged in frequent outpatient counseling. Commonly, psychiatrists making a decision about committing a patient consider factors known to raise the risk that the person will be harmed or will harm themselves. For example, an individual who has made a serious suicide attempt in the past is at higher risk.

During the late 1980s, psychiatrists and patients' families began objecting to the narrowed commitment criteria, arguing that the rights of people with mental illness were being protected at the expense of their mental health (Appelbaum). These objections resulted in the grounds for commitment being broadened in some areas. The *outpatient commitment* system, in which outpatients are given court-ordered treatment or returned to the hospital in certain situations, is an example of the broadening of commitment laws to include individuals who are not clearly dangerous to themselves or others (Geller). This system, also referred to as *supervised discharge* or *community treatment orders* has been introduced in Australia, Canada, the United Kingdom, and Europe as well as the United States. Though not problem-free, it appears to be an effective means of offering mental patients increased care with greater freedom than inpatient commitment provides (Swanson, Swartz, and Borum, et al. and Swartz, Swanson, and Wagner et al.).

Coerced Treatment

Ethics demands that a competent mental patient's refusal of treatment must be respected. Even a patient confined to a mental institution cannot be treated against his or her will, unless the patient poses an imminent threat of harm to others. This concept received extensive legal backing from court rulings during the 1980s. Courts in Massachusetts, New York, and California ruled that unless a patient was found incapable of making treatment decisions, he or she could not be treated involuntarily with antipsychotic medications. The rulings were motivated by reports that psychiatric medications were overused at mental hospitals and staff were often indifferent to patients' risks of drug side effects.

In many states and provinces, psychiatric medications have since evolved into a special legal category of treatment. Forcibly giving a patient psychiatric medication is only permissible if the patient is behaving in a violent manner or is actively threatening to do so. As a result, clinicians treating mental patients typically cannot medicate a refusing patient without involving the courts. By contrast, physicians do not need to consult a judge in order to commit mental patients to involuntary hospitalization. The result is that mentally ill and psychotic patients may be hospitalized against their will but cannot be medicated against their will (Appelbaum). In these situations, psychiatrists often seek permission from the courts to medicate the patient, arguing that the patient has benefited from medication before or is judged highly likely to benefit from medication.

The courts often grant the permission and treatment proceeds in a practice sometimes known as *medication over objection.* Studies suggest that once a court ruling in favor of treatment is issued, patients often accept oral antipsychotic medications under duress, thereby avoiding forced injections of medication (Greenberg, Moore-Duncan and Herron).

The more stringent criteria for involuntary medication became a focus of controversy on similar grounds as the controversy over narrower commitment criteria. Psychiatrists described mental patients who refuse medication as 'rotting with their rights on,' conveying the image of a person who is not thinking rationally and whose condition is steadily worsening, yet who cannot be treated appropriately or faces delays in treatment because of judicial restraints (Appelbaum and Gutheil).

The mid- to late 1990s saw the start of a movement towards the use of psychiatric *advance directives.* These are treatment guides prepared by chronically mentally ill patients who are capable of making decisions about their psychiatric treatment when they are functioning well but experience repeated episodes of impaired decision-making during relapses. Most states accept advance psychiatric directives in some form but a survey suggests that psychiatric *advance directives* are easily ignored in crisis situations (Backlar, McFarland, Bentson, Swanson and Mahler).

Another area of care in which doctors may seek legal opinions regarding involuntary medication involves severely mentally ill female patients who decline birth-control treatments. Some authors suggest that there are situations in which it would be ethical to act to prevent pregnancy in patients who are incompetent to make medical decisions (McCullough, Coverdale, Bayer, et al.). The courts have held that when a mentally incompetent woman is pregnant, decisions about her obstetric care should involve a determination about what the woman would want if she were competent (Curran). In practice, when a severely mentally ill woman becomes a mother, child-welfare agencies are asked to evaluate the woman's ability to care for her child. In extreme cases, this evaluation may lead to court proceedings that can result in the woman's losing custody of her child.

Coerced Compliance

The idea that a patient's decisions must be voluntary is central to the concepts of patient autonomy and informed consent. Exceptions to the idea of voluntariness, such as commitment and involuntary medication, have been viewed as last resorts for patients considered incapable of making rational decisions. Occasionally, however, coercive methods are used to encourage mentally ill individuals to comply with treatments, even when these individuals' decision-making capacities are not in question. Substance-abusing pregnant women comprise one group that is increasingly coerced into treatment, either via incarceration or via compulsory addiction treatment programs (Abel and Kruger). This use of coerced compliance has been supported by state courts as a means of protecting the woman's future child. Yet the practice is controversial because the potential protection it affords the fetus requires overriding a competent adult's treatment decisions (Chavkin and Paltrow).

The coercive methods used with chronic mental patients are more subtle. An example is a man with a chronic mental illness who received disability payments from the government because of his mental condition. The man's government check was sent to the mental-health clinic where he was treated. To receive his check, the man was required to show up for his therapy session. The therapist believed this was a useful technique for encouraging adherence to treatment in a patient with disorganized thinking.

Mental-health practitioners justify such paternalistic strategies as a means of preventing deterioration in a patient's condition but such clinical justifications may not stand up to moral scrutiny. Yet these kinds of practices would be ethical if they were discussed openly with the patient and the patient consented.

Truth-Telling

A physician or therapist who shields a patient from the truth about his or her illness may unwittingly cause mistrust of care providers and of the medical system in a patient who needs to depend on that system (Sheldon). Yet clinicians caring for seriously mentally ill individuals sometimes do withhold information.

In one example, a physician withheld a diagnosis of cancer from a patient with a history of depression and suicide attempts (Lo). The physician feared that disclosing to the patient that she had a terminal illness could precipitate a suicide attempt. His intention was to protect the patient from harm, but the patient probably should have been informed about her diagnosis.

Though patients in general are likely to be told their diagnoses, studies of patients in psychiatric hospitals from the 1980s found that important information was frequently withheld from such patients. For example, psychiatric patients were prescribed medicines without being informed about potentially serious risks of the medicines (Lidz, Meisel, Zerubavel, et al.; Beck). More recent studies suggest that patients continue to be underinformed about their medications (Schachter and Kleinman). For informed decision making, a patient needs to understand the benefits and risks of prescribed medications and why the doctor believes that the benefits outweigh the risks.

Patients, even those with mental illnesses and disabilities, expect and deserve to be told the truth. This does not mean that the truth should be disclosed insensitively. Health professionals should consider how to convey difficult information in a manner most appropriate to a particular patient, but the information should be provided. Psychiatric patients, like all medical patients, need to feel they can trust their healthcare providers.

Confidentiality

All doctor-patient relationships demand confidentiality. In the special setting of psychotherapy the need to protect a patient's privacy can be paramount. The special importance of confidentiality in psychotherapy was underscored by a 1996 Supreme Court ruling that protects a patient's statements to a psychotherapist from compelled disclosure (*Jaffee v. Redmond*).

But a patient's need for privacy must be balanced against the rights and needs of others. Suppose a man in treatment for alcohol abuse reveals that he has been aggressive toward his child while intoxicated. State laws mandate the reporting of incidents of child abuse, yet a physician or counselor who reported this man would breach the patient's confidentiality. Here, the clinician must consider whether the man's actions towards his child constitute an offense that must be reported in order to protect this child or others in the future. The decision is made all the more difficult because the man's treatment could help to keep his child safe from harm yet the man may leave treatment if he feels the clinician has betrayed him to state authorities.

Situations other than child abuse pose similar dilemmas. Rules about a physician's duty to warn and protect a person who is threatened by a patient now apply in most states and provinces. Such rules do not dictate a therapist's decision, however. Since the majority of threats made by patients do not represent serious danger to others, clinical judgment is required to decide whether a threat, that a patient utters during the course of a psychotherapy session or merits a breach in confidentiality (Weinstock).

Allocation of Scarce Resources

It would be unjust to withhold healthcare resources from a mental patient strictly due to her mental illness. Yet an exception is sometimes made in the case of extremely scarce resources, such as organ transplants. A patient who is chronically mentally ill and also has severe liver or kidney disease might benefit from a transplant. But persons who receive transplants require drug-induced immunosuppression for the rest of their lives to prevent graft rejection, and it can be difficult for mental patients to comply with such extensive follow-up care (Bunzel and Laederach). Reasoning that transplanted organs should go to patients who will reap the most benefit from them, transplant programs may withhold organs from individuals who are seriously mentally ill (Wolcott). In a survey of heart-transplant programs, most programs considered certain psychiatric conditions to be an absolute contraindication to transplant: A person who has schizophrenia with active psychotic symptoms, or a person with a history of multiple suicide attempts will be automatically denied a transplant (Olbrisch and Levenson).

Such automatic denials are not clearly ethical. In the event that a transplant candidate has a serious mental illness, it is important that the potential for treating the mental illness be considered before the patient is refused a transplant (Council on Ethical and Judicial Affairs). The patient's desire to commit suicide, for example, may be caused by a treatable depression. For transplant programs, the question of how to respond to evidence of a patient's psychological instability is difficult. Case-by-case evaluations of individual patients may yield greater fairness in these sorts of situations than systematically applying formal guidelines. Some patients with mental illness may benefit from early intervention and psychosocial support, while other patients may be unable to adhere to post-transplantation treatment regimens even with help.

Conclusion

In a number of key areas, a mentally ill person may lose certain rights with regard to medical and psychiatric treatment due to the effects of mental illness. As a result, healthcare providers who care for such patients can face difficult ethical dilemmas. The decision to hospitalize a mentally ill person involuntarily is often easily justified on moral grounds. However, decisions to breach a patient's confidentiality, or to withhold scarce resources such as organ transplants, are generally not as clear. Finally, it is probably rare that a physician or therapist who withholds the truth from the patient, or coerces the patient into complying with a recommended treatment, will be acting in an ethical manner.

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SEE ALSO: *Autonomy; Coercion; Confidentiality; Electroconvusive Therapy; Freedom and Free Will; Healthcare Resources, Allocation of: Microallocation; Information Disclosure, Ethical Issues of; Informed Consent: Issues of Consent in Mental Healthcare; Medicaid; Medicare; Mental Health Therapies; Mental Institutions, Commitment to; Patients' Rights: Mental Patients' Rights; Psychopharmacology; Psychosurgery, Ethical Aspects of,* and other *Mentally Disabled and Mentally Ill Persons* subentries

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II. RESEARCH ISSUES

Protecting the interests of mentally ill and disabled people entails a delicate balance between two aims: a rigorous program of research into their medical problems and attention to the difficulties involved in using those people as subjects of research in ethically appropriate ways. Although the hope of understanding mental illnesses and disabilities depends on the results of medical research, persons who have those conditions are especially vulnerable to exploitation and abuse.

Research Guidelines

There are two major problems in conducting research on mentally ill and disabled persons. The first is competence, or decision-making capacity: Because of the nature of their problems some mentally ill and disabled subjects may not be able to make informed decisions about whether to participate in a research protocol. Issues surrounding informed consent are made even more problematic by the fact that mentally ill or disabled subjects may be living in institutions for patients with special mental disorders, and institutionalization can exert pressures that compromise a person's ability to make a free choice about participating in research. The second problem involves risk and the design of research studies. Under what circumstances, if any, can a mentally ill or disabled person be exposed to the risk of harm in a research study?

Some mentally ill or disabled persons may be incapable of giving valid informed consent to participate in a research study. However, prohibiting those potential subjects from participating would rule out much medical research that could benefit the subjects and others with similar disorders, in the long run harming the populations the studies are intended to protect. For that reason, since the last two decades of the twentieth century there has been a consensus that research on mentally ill and disabled persons can be justified in some cases, subject to certain conditions (National Bioethics Advisory Commission [NBAC]; Royal College of Psychiatrists [RCP]; Royal College of Physicians of London [RCPL], 1990; U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978, 1979; Wing; World Medical Association; National Institutes of Health; Medical Research Council of Canada [MRCC]).

Perhaps the most important of those conditions is the stipulation that research on incompetent mentally ill or disabled persons should be allowed only if that research cannot be done on competent persons (National Bioethics Advisory Commission; Wing; U.S. National Commission for the Protection of Human Subjects, 1979). The guidelines for biomedical research proposed by the World Health Organization (WHO) and the Council for International Organizations of Medical Sciences (CIOMS) make that requirement explicit, arguing that because of the risks and burdens involved, medical research should not be done on individuals who are unable to choose to participate if it can equally well be done on competent adult volunteers (World Health Organization).

A second condition concerns the amount of risk to research subjects that may be allowed. Many professional and regulatory bodies state that research on incompetent subjects such as children and the mentally ill or disabled ordinarily is approvable only when the research involves a minimal risk or a minor increment over minimal risk to the subject ("Federal Policy for the Protection of Human Subjects"; Royal College of Physicians of London, 1996). According to this reasoning, some research on mentally ill or disabled persons may be ethically justifiable, subject to specific additional conditions, even if it is nontherapeutic (Wing; National Institutes of Health).

Of course, there is considerable room for controversy in defining minimal risk. U.S. federal policy compares minimal risk to the risks of the everyday life of a potential subject or those of a routine physical or psychological examination ("Federal Policy for the Protection of Human Subjects"). The Royal College of Physicians of London (1996) defines minimal risk as covering two types of situations: those that might involve negligible psychological distress, including other trivial reactions such as a mild headache or a feeling of lethargy, and those that involve very remote risks of serious injury or death, comparable with the risk of flying in a scheduled passenger aircraft.

It is widely agreed that research proposals involving mentally ill or disabled persons should be approved by an ethics committee charged with reviewing research proposals, such as an institutional review board. Research should not proceed if a competent subject objects. When a subject is unable to give properly informed consent, consent should be sought from an appropriate surrogate decision maker, such as a relative (World Medical Association).

Competence and Informed Consent

A fundamental ethical requirement for most medical research is the informed consent of the subject. For consent to be valid the subject must be capable of understanding the relevant implications of his or her decision to participate: the purpose, nature, and duration of the research; its possible risks and benefits; and so on. Because of the nature of some mental disorders, it is often unclear whether a mentally ill or handicapped person is capable of giving proper informed consent. Although many mental illnesses and disabilities do not affect those capabilities, it is the duty of a medical researcher to ensure that a potential subject of research is capable of making an informed decision whether to participate.

The ability to make that decision often is termed competence or decision-making capacity. A competent person should be capable of making a decision for which he or she legitimately can be considered accountable (Elliott). Competence ordinarily is defined in relation to a particular activity; a person can be competent to make some types of decisions but not others. For that reason assessments of competence ordinarily should focus on the task at hand, in this case understanding the implications of participating in a particular research protocol.

Most proposed standards for assessing competence focus on the process of reasoning involved in making a decision rather than on the outcome of the decision (U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982; Buchanan and Brock; National Bioethics Advisory Commission). Because each person has different needs and values, often there is no single decision that can be judged correct for everyone. However, focusing primarily on a person's reasoning processes also can be problematic. A competent person sometimes may use faulty reasoning or make irrational decisions yet still be considered accountable for his or her choices (Elliott).

Probably the most influential tests of competence have dealt with consent to treatment rather than to research. A U.S. President's Commission report (1982) relates competence to three aspects of a person's mental abilities: (1) the possession of a set of values and goals, (2) the ability to communicate and understand information, and (3) the ability to reason and deliberate about one's choices.

However, competence criteria that focus primarily on rationality and reasonable deliberation may not be very helpful when the person making the choice has an affective disorder. For example, patients with depressive delusions may consent to hazardous research because they think they deserve to be punished (Elliott; Kopelman).

Furthermore, a mentally ill or disabled person may be able to satisfy a criterion partially but not fully or may be able to satisfy only some criteria. In cases like these it is a matter for debate how high the standards for competence should be set. For this reason some writers and professional bodies, including the U.S. President's Commission (1982), have endorsed a sliding-scale approach to assessing competence (National Bioethics Advisory Commission).

With this approach standards of competence are set higher for interventions with a risk-benefit ratio that is relatively worse and lower for interventions with a risk-benefit ratio that is relatively better. For example, to participate in a research protocol whose risks are great and whose benefits are small a subject might have to show not only that he or she understands the facts and issues but also that he or she *appreciates* the nature of the situation. This may be a very high standard of understanding: an affective as well as a cognitive recognition of the nature of the research, an awareness of how others view the decision, and an understanding that he or she has a mental disorder that is appropriate for study. In contrast, if the risk-benefit ratio is much better, the standard for competence might be set very low, for example, merely showing evidence of a choice to participate.

Even when a subject is clearly incompetent to give informed consent, many writers believe that research should not be done without the subject's assent; that is, researchers should ensure that the subject, to the degree that he or she is mentally capable, agrees to or expresses a positive interest in participating in the research. Research is much more difficult to justify when it is done in spite of a subject's verbal or behavioral objections (Wing). However, it is arguable that research without a patient's assent is justifiable if the patient is clearly incompetent and the research is therapeutic, involves minimal risk, has been consented to by an appropriate surrogate, and is clearly in the best interests of the patient.

Issues of competence and informed consent can be especially problematic in certain mentally ill patients whose competence may change over time. In the case of therapeutic research, for example, on antipsychotic medication, a research protocol may restore to competence a patient who previously was incompetent. In these situations the possible value of restoring the patient to competence should be part of the decision whether to enroll the patient in a research protocol. In cases in which a patient's competence fluctuates over time researchers should try to obtain consent at a time when the patient is best able to give it.

Further provisions may be needed to protect the interests of mentally ill and disabled patients who are incompetent or whose competence is questionable. The Belmont Report recommended that researchers seek the permission of third parties who are most likely to understand a subject's situation and act in that person's best interest (U.S. National Commission for the Protection of Human Subjects, 1979; National Bioethics Advisory Commission). Two standards have been employed widely in making decisions for incompetent patients: the best interests standard, in which third parties make decisions that are based on the interests of patients through the use of socially shared values, and in the case of previously competent patients the substituted judgment standard, by which third parties make decisions that are based on values and preferences the patient may have expressed in the past. The Belmont Report made the additional recommendation that those third parties be allowed to observe the research as it proceeds, with the option of withdrawing the subject from the research at any time (U.S. National Commission for the Protection of Human Subjects, 1979; National Bioethics Advisory Commission).

Institutionalized patients are often especially attractive as research subjects because their medication, diet, and compliance with a study can be monitored and controlled easily. Nevertheless, many writers have argued that institutionalized populations deserve special protection, pointing out the examples of the Willowbrook State School in New York, where mentally retarded children were injected with the hepatitis virus in 1956, and the Jewish Chronic Disease Hospital in Brooklyn, where nineteen chronically ill patients were injected with cancer cells in 1962 (U.S. National Commission for the Protection of Human Subjects, 1978; Kopelman). Some observers have argued that the fact of institutionalization invalidates informed consent and that research on mentally ill or handicapped persons in institutions should be ruled out entirely.

There are several grounds for the argument that institutionalization invalidates informed consent. One that has been rejected widely is that any person who has a mental illness or disability severe enough to warrant institutionalization is mentally incompetent to give informed consent. However, many people have illnesses or disabilities that impair them in ways that require institutional treatment but do not impair their ability to make competent judgments about participating in research. A second argument is that institutionalization itself deprives people of the ability to make their own decisions, for example, by placing them in a situation of constant subordination to authority (Annas et al.). A third argument is that institutions severely limit the choices available to their patients, thus placing constraints on their freedom of choice. Research on institutionalized patients also can be difficult for impartial external observers or regulatory bodies to monitor effectively. For these reasons many agencies and professional bodies require that researchers take special measures to guard against the manipulation of institutionalized subjects.

Risk and Study Design

At the turn of the twenty-first century a number of studies of mental illness attracted considerable criticism because their designs exposed subjects to an unacceptably high ratio of risk to benefit. The most controversial of those studies were placebo-controlled trials, symptom-provocation studies, and relapse studies.

PLACEBO-CONTROLLED TRIALS. The ethical controversy over certain placebo-controlled trials begins from the principle of clinical equipoise, according to which, before a randomized clinical trial can be started there must be genuine disagreement in the community of expert practitioners about which treatment is preferable (Freedman, 1987). If there is disagreement about whether a new psychiatric drug is superior to placebo, clinical equipoise would permit a trial to settle the question. However, would it be ethical to begin a trial comparing a new drug to placebo if there already was an effective standard treatment for the illness in question? According to the requirement for clinical equipoise, the answer is no.

Clinical equipoise is rooted in standards of sound clinical practice. The treatments offered to patients in a clinical trial must be in equipoise with the prevailing standard of care for the subject population in question so that the clinical care of those patients will not suffer as a result of enrollment in the trial. The Declaration of Helsinki states, “The benefits, risks, burdens and effectiveness of a new method should be tested against those of the best current prophylactic, diagnostic, and therapeutic methods” (World Medical Association).

In light of the proven efficacy of many psychiatric agents, it might be expected that placebo-controlled trials in psychiatry would be rare. However, new psychiatric agents are tested routinely against placebo even when failure to treat the illness in question adequately could cause serious harm to the subjects enrolled in the trial, such as patients with schizophrenia or major depression. Indeed, representatives of regulatory agencies such as the U.S. Food and Drug Administration and the Canadian Health Protection Branch have encouraged the use of placebo-controlled trials, especially in psychiatry, arguing that those trials are the only way to determine whether a new drug is effective (Addington). Defenders of placebo-controlled trials also argue that subjects are protected by the requirement for informed consent and that even if a subject’s mental illness worsens during a trial, the symptoms of such illnesses are temporary, reversible, and not sufficiently harmful to warrant a prohibition against placebos.

It is difficult to see how major depression and psychosis can be considered insufficiently harmful to subjects, especially when both conditions are associated with a higher risk of suicide. It is also doubtful that informed consent will protect research subjects from enrolling in potentially harmful studies. Many investigators do not conduct an adequate discussion with patients about the risks and disadvantages of taking part in a study, and even when investigators disclose those risks, many patients do not understand them fully (Appelbaum et al.).

The requirement for clinical equipoise does not mean that all or even most placebo controls are unethical. As Benjamin Freedman (1990) has noted, placebo controls are justified in testing treatments for conditions:

1. that have no standard therapy,
2. whose standard therapy has been shown to be no better than placebo,
3. whose standard therapy is placebo,
4. whose standard therapy has been called into question by new evidence warranting doubt about its net therapeutic advantage, and
5. whose validated optimal treatment is not made freely available to patients.

Charles Weijer points out two additional situations in which placebo controls are permissible. If a particular population has failed to respond to first-line treatments for a condition and no proven second-line treatment exists, that population may be enrolled in a placebo-controlled trial. Also, if a new treatment simply is added onto a standard treatment, that treatment may be tested against placebo as long as all the subjects in the trial get the standard treatment either with the add-on or with placebo.

SYMPTOM-PROVOCATION STUDIES. Another controversial psychiatric study is the symptom-provocation study or challenge study. The purpose of those studies is to learn more about the pathophysiology of mental illnesses by provoking their symptoms in mentally ill subjects. For example, in a number of different studies published in the 1990s researchers gave schizophrenic subjects a variety of psychoactive drugs to exacerbate the symptoms of psychosis. Symptom-provocation studies have generated far more outrage in the popular press and among patient advocacy groups than in the bioethics and medical literature, in which they have been defended for their scientific merit (Whitaker; Miller and Rosenstein). However, in those studies, unlike most clinical trials, mentally ill subjects often are exposed to risks without any expectation of therapeutic benefit. Also, unlike many Phase I clinical trials, symptom-provocation studies are performed not on healthy volunteers but on ill patients. Indeed, the very purpose of those studies is to induce harmful symptoms in patients who already have mental disorders.

RELAPSE STUDIES. A third source of controversy in psychiatry involves relapse studies or washout studies. In relapse studies mentally ill subjects are taken off their regular medications to determine whether they will relapse into their illnesses, how long it will take them to relapse, or whether their health can be maintained without medication. In a widely reported study at the University of California at Los Angeles that began in the 1980s, researchers required that subjects with schizophrenia who had recovered from their symptoms be taken off their medication. After the study was concluded, a subject committed suicide (Katz; National Bioethics Advisory Commission).

Defenders of relapse studies have argued that many mentally ill patients, particularly those with schizophrenia, are maintained on medications that can cause serious and irreversible side effects and that "drug holidays" are often an accepted part of standard therapy. Critics point out that it is in the interests of most patients to be maintained on the therapeutic regimen that has worked for them, that such patients are not informed of the risks of relapse studies, and that a relapse may increase the risk of future relapses (Katz; Shamoo and Keay).

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SEE ALSO: *Autonomy; Children: Healthcare and Research Issues; Confidentiality; Holocaust; Informed Consent: Consent Issues in Human Research; Mental Health Services: Settings and Programs; Mental Illness; Patients' Rights: Mental Patients' Rights; Psychiatry, Abuses of; Psychopharmacology; Research, Human: Historical Aspects; Research, Unethical; Research Ethics Committees; Research Policy;* and other *Mentally Disabled and Mentally Ill Persons* subentries

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MERGERS AND ACQUISITIONS

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Between 1980 and 2002 there were an unprecedented number of healthcare mergers and acquisitions in the United States, affecting hospitals and hospital systems, nursing facilities, clinics, physician group practices, pharmaceutical manufacturers, and managed-care and other health insurance providers. Predictably, this headlong rush toward consolidation and concentration has triggered increased scrutiny of such transactions by those state and federal agencies responsible for antitrust and tax regulation. It has also spurred increased reflection on the ethical issues at stake in these merger and acquisition decisions. Such issues include concerns about fidelity to organizational mission; effects of organizational restructuring upon community access to services and other benefits; impact upon the welfare, working environment, and overall culture of affected employees; and the prevention and resolution of conflicts of interest among involved parties.

The number and frequency of hospital mergers and acquisitions increased dramatically during the 1980s and early 1990s. The trend peaked in the period 1994–1997, according to data from Irving Levin Associates, with 163 deals completed in 1996 and a record 197 deals in 1997. During that period the number of hospitals belonging to health networks or systems also increased significantly, from 56.2 percent in 1994 to 70.9 percent in 1998. By the beginning of the new century, the frequency of deals had declined somewhat, to 86 in 2000 and 83 in 2001, yet these numbers remain much higher than pre-1990 levels. Among the factors apparently driving this high rate of merger and acquisition activity are reduced Medicare reimbursement rates, significantly increased managed-care pressures to provide more services at lower prices, and a declining market for inpatient hospital services.

Benefits and Burdens of Consolidation

Hospital mergers and acquisitions can provide substantial benefits for institutions, their employees, and the communities they serve. They can bring needed capital into a healthcare organization, providing economic vigor and repositioning in a difficult marketplace; offering opportunities for new or expanded service lines; and even ensuring survival and the capacity to provide services to those in need. They can strengthen an organization's bargaining power and provide economies of scale and increased efficiency, all of which could lead to decreased costs to consumers. And they can bring standardization to, and better assessment of, the quality of care delivered.

A 2002 study by Bazzoli and colleagues examined the self-reported reasons for merger cited by involved hospitals during the periods 1983–1988 and 1989–1996. For both groups, the top three reasons for merger were identical: to strengthen the institution's financial position, to achieve operating economies, and to consolidate services. Expansion of market share was another reason cited by a majority of respondents. Yet there were also certain changes in emphasis between the two study periods. Those citing expansion of visibility and service availability across the hospital's service area as a significant reason for merger increased from 33.3 percent in 1983–1988 to 53.2 percent in 1989–1996, while those citing expansion of provided service areas as a reason for merger decreased from 63.9 percent to 44.3 percent. In addition, respondents in the more recent period indicated an increasing emphasis upon nursing-staff downsizing as an intended cost-saving outcome of merger activity.

While the potential benefits of hospital consolidations via merger and acquisition can be manifold, these transactions can also create concerns about potential burdens for various stakeholders. One such concern has to do with the consequences of giving up local hospital control. When a community-based hospital merges with or is acquired by an organization or system headquartered elsewhere, especially out of state, what will the loss of local control mean in terms of the new organization's responses to the local community's specific needs? And what will be the postconsolidation status and level of service at the community-based hospital? Many consolidations, especially those involving a for-profit organization, include plans to increase profitability and market position by phasing out unprofitable service lines in favor of more profitable specializations. This can create hardships for communities—access to much-needed yet unprofitable services becomes more difficult, or the burden of providing these services is shifted to others. Another potential service limitation emerges when a merging or acquiring organization takes a strong religious or other principled position against providing certain services. Such consolidations raise understandable public concerns about whether reasonable access to those services will remain available within the community after consolidation.

Further, an increase in the price of services can be another potential community burden resulting from hospital merger or acquisition transactions. While consolidation-related efficiencies may allow for price reductions, or at least a hold on price increases, the newly consolidated and concentrated hospital organization will also have stronger market positioning and greater market power, and that power may be expressed through price increases. A 2000 study by Young and colleagues examined the relationship between market concentration and pricing patterns for three types of nonprofit hospitals: independent hospitals under local control, members of local hospital systems, and members of nonlocal hospital systems. The study showed that, in more concentrated markets, all three types of nonprofit hospitals exercised market power in the form of higher prices—and that hospitals that are a part of nonlocal systems were more aggressive in exercising this market power than either of the other hospital types.

Yet another community concern regarding hospital consolidations is their effect on the provision of charity care. According to American Hospital Association data, overall U.S. hospital expenses for uncompensated care (bad debt and charity care) were $18.5 billion in 1997, up from $6 billion in 1980 (Hall). Yet access to needed care remains difficult for many of the more than 42 million uninsured Americans who cannot afford that care. Thus, communities are often concerned about the effect of consolidation upon a local hospital's willingness to continue providing charity care, especially when a nonprofit community hospital is merging with or acquired by a for-profit hospital or system. There is evidence that for-profit hospitals are less likely to be accessible to the medically indigent and uninsured than nonprofit hospitals are, and that they tend to carry a smaller indigent-care load (Darr). One study of California nonprofit hospitals that were consolidated into for-profit organizations found that charity care declined in almost all cases analyzed. Moreover, in none of the deals did the sale proceeds, usually set aside in a foundation to provide charity care and other community benefits, sufficiently replace the community benefits provided by the former nonprofit hospitals (Mateo and Rossi).

One final area of community concern has to do with how consolidation might affect particular groups of internal stakeholders, namely hospital staff, trustees, and executives. Merger and acquisition activity can, and often does, involve downsizing and the loss of employment for some staff members. It can also lead to negatively perceived changes in working conditions, mission loyalty, and overall organizational culture. On the other hand, hospital executives and trustees, who are responsible for negotiating any possible consolidation, may be subject to various positive inducements, financial and otherwise, for their support of a transaction. Such a possibility appears all the more threatening to a community in which the actual details of a proposed consolidation have not been made public during the planning process.

Moral Obligations of Hospital Leaders

Community concerns have led to some significant changes in legal oversight of hospital consolidations at both state and federal levels, including transactions among nonprofit hospitals and between nonprofit and for-profit hospitals

(Peregrine). Yet it is clear that legal regulation cannot and will not ensure the fulfillment of healthcare leaders' moral obligations to the community as hospital consolidations are contemplated, planned, and executed. Nonprofit hospital trustees and executives, who are accountable for more than 80 percent of U.S. hospital beds, have particular fiduciary responsibilities to the communities served by their institutions, and there are specific moral obligations that should govern their participation in merger and acquisition activities.

MISSION PROTECTION. First, trustees and executives are responsible for upholding and protecting the mission and values of the institution they are already serving. According to the American Hospital Association Board of Trustees, a hospital's mission includes both caring for the sick and injured and improving community health, and any decisions regarding consolidation should thus emphasize the community's future health needs and the best overall organizational arrangements for meeting those needs. Trustees and executives, therefore, bear the moral obligation of participating in any proposed merger or acquisition as representatives of the community and its interests (Wilkins and Jacobson). They must ask how any proposed transaction would affect access to and delivery of health care in the community, seek independent assistance in assessing the impact of the transaction on the community, and work to avoid any unnecessary harmful effects upon quality of life in the community.

A critical aspect of a hospital's mission that should be protected, of course, is the provision of uncompensated care. Trustees and executives must consider the community's future health needs by ensuring that access to charity care will not be diminished or eroded by a merger or acquisition transaction, particularly when a nonprofit hospital is contemplating consolidation with a for-profit hospital or system. Further, as Leonard Weber points out, if a generally beneficial consolidation will also entail certain new community burdens, such as less-convenient location of services, then those segments of the community already experiencing greater social ills (such as poverty and environmental degradation) have a greater claim to be spared new social burdens than do better-off segments of the community.

In some instances a hospital's mission and values will involve specific principle-based exclusions from certain practices, as in the case of most Catholic hospitals' refusals to provide various reproductive services. When such an institution seeks a merger with or acquisition of another community hospital whose mission and values do not entail these service exclusions, then the obligation to consider the community's overall future health needs becomes somewhat more complex. Certainly the conscientious refusals of hospital leaders and sponsors to engage in certain practices should be respected. Yet the general obligation of hospitals to ensure adequate community access to those services normally and legally available in other communities places a potential limit upon the moral right of hospitals to restrict permissible practices (Weber). This becomes an especially strong concern where the postconsolidation institution would be the community's sole provider. In such circumstances, the costs of consolidation may simply be too high.

AVOIDING CONFLICT OF INTEREST. Second, trustees and executives have a moral obligation to disclose any potential conflict of interest and to avoid any private benefit in a proposed consolidation. They should not receive money during a consolidation process—nor should they accept any other incentive offered as a means of securing support for the transaction, such as promises of a job or board membership after consolidation. Any such offers should be disclosed to all involved parties, and negotiation practices should be utilized that will fully separate decisions about the transaction from decisions about positions in the post-transaction institution (Weber). Trustees and executives must be able to assure the community, which they serve as fiduciaries, that personal gain incentives have been removed from the negotiating table, and that the community's best interests are represented there.

PUBLIC DISCLOSURE AND HEARINGS. Third, hospital leadership should make the consolidation process fully public. Trustees should ensure that all objectives and processes of the transaction are made available to the general public and the state attorney general, and they should require public hearings and suitable waiting periods so as to hear and respond to community concerns about the transaction. Community-based consumer organizations should also be consulted in order to assess implications of the proposed consolidation that may not be immediately apparent to trustees and executives (Wilkins and Jacobson).

FAIR MARKET VALUE. Fourth, nonprofit trustees and executives are responsible for ensuring fair market value for their institution in the transaction, particularly when a nonprofit hospital is being acquired by a for-profit hospital or system. This requires, among other things, ensuring independent valuation by a third-party firm with experience in the healthcare field. In addition, the methodology used in determining fair market value should be made a part of public disclosure of the negotiations. A significant portion of a nonprofit hospital's value that must be included in any assessment of fair market value is the community benefit it provides: the hospital's value to community members (as owners of it), the value it provides in uncompensated care, and the value it holds from past publicly funded investment are all part of its value.

Trustees and executives, as fiduciaries of the community, must ensure that community-benefit value is not lost in consolidation transactions and that community benefit in the form of charity care and other community health initiatives is guaranteed into the future. In the sale of a nonprofit hospital to a for-profit, this usually involves using that portion of the sale price designated as the community-benefit value to establish a nonprofit charitable foundation or trust whose assets will be used to fund charity care and community health ventures. Nonprofit executives and trustees should require that the terms of the foundation—particularly regarding who will control its assets and the specific purposes for which they may be expended—be detailed and clear before consolidation can be completed, and that the foundation will provide regular public reports on its efforts to promote community health (Wilkins and Jacobson).

STAFF AND EMPLOYEE INTERESTS. Fifth, in addition to their community-oriented fiduciary responsibilities, hospital trustees and executives also have responsibilities to their institutional and medical staffs. When any consolidation is considered, staff and employees must be fully informed and educated about its perceived need and its intended goals and processes—and their responses and concerns must be heard. Just as a community assessment is necessary to determine the community interests that are at stake in any proposed transaction, an organizational assessment is necessary to recognize specific organizational cultures and how they may or may not fit with the cultures of other merging or acquiring facilities. The employees and staff in each facility should be oriented to the culture, history, and mission of the other facility or system.

Further, employees of institutions facing consolidation may have concerns not only about postconsolidation culture and working conditions, but also about the prospect of staff downsizing and loss of employment. Quite often these concerns are well founded. If the organization's ability to continue serving the needs of the community will necessarily require staff downsizing, then the trustees and executives have an obligation to ensure, among other things, that: (1) all employees to be laid off will be given advance notice that includes detailed explanation of the necessity of and criteria for their selection; (2) employees to be laid off will have opportunity to appeal their selection if they have reason to believe the criteria were inappropriately applied; and (3) laid-off employees will be provided with significant outplacement services and interim benefits (Weber).

Exit Provisions

Perhaps predictably, the large number of hospital mergers and acquisitions have produced not only many successes, but also quite a few organizational and financial failures. As Michael Peregrine has noted, this reality may suggest a final obligation of nonprofit hospital trustees negotiating a consolidation—namely to incorporate termination provisions (known as *exit* or *unwind* provisions) within the transaction terms. These terms might specify what particular events would indicate a failure of the consolidation's objectives and thus trigger an unwinding, any required mediation or arbitration related to the implementation of the unwinding, the time period during which the trigger would remain effective, and the actual mechanisms for implementing the unwinding if the consolidation fails to achieve its objectives.

Hospitals are, as Kurt Darr notes, "social organizations with an economic dimension, rather than economic organizations with a social dimension." The recent history of U.S. healthcare offers many examples of how the economic dimension of hospitals may be enhanced through mergers and acquisitions. Yet a recognition of the primary social dimension of hospitals illuminates a variety of community-oriented moral responsibilities and obligations that must not be ignored in such transactions, even for the sake of economic enhancement.

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SEE ALSO: *Access to Healthcare; Healthcare Systems; Profit and Commercialism*

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METAPHOR AND ANALOGY

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Many of our practices and much of our discourse in healthcare hinge on metaphor and analogy, whose significance is sometimes overlooked because they are considered merely decorative or escape notice altogether. Despite their relative neglect, they significantly shape our interpretations of what is happening as well as what should happen. This entry will examine metaphor before considering analogy, particularly analogical reasoning, noting their overlap where appropriate.

Metaphors in Bioethics

NATURE AND FUNCTION OF METAPHORS. Perhaps because medicine and healthcare involve fundamental matters of life and death for practically everyone, and in often mysterious ways, they are often described in metaphors. For instance, physicians may be viewed as playing God, or acting as parents, and nurses seen as advocates for patients, while medicine itself may be interpreted as warfare against disease. Metaphors involve imagining something as something else, for example, viewing human beings as wolves or life as a journey. “The essence of metaphor,” according to George Lakoff and Mark Johnson, “is understanding and experiencing one thing through another” (p. 5). More precisely, metaphors are figurative expressions that interpret one thing in terms of something else (Soskice).

In contemporary philosophical literature on metaphor, critics have challenged some traditional conceptions, contending that metaphors are more than merely ornamental or affective ways to state what could be stated in a more literal or comparative way, and that they can be and often are cognitively significant (see, e.g., Black, 1962, 1979; Ricoeur; Soskice). According to the traditional substitution view, a metaphorical expression is merely a substitute for some equivalent literal expression. For example, the metaphorical expression “John is a fox” substitutes for the literal expression “John is sly and cunning.” One common version of the substitution view, what philosopher Max Black (1962) calls a comparison view (elements of which can be found in Aristotle), construes metaphor as the presentation of an underlying analogy or similarity. Hence, metaphor is “a condensed or elliptical simile” (Black, 1962), or it is a “comparison statement with parts left out” (Miller). “John is a fox,” for example, indicates that “John is like a fox in that he is sly and cunning.” According to such views, metaphors are dispensable ways to express what could be expressed differently, but they often appeal to the emotions more effectively than their equivalent literal expressions or comparisons would do.

By contrast, many recent theories of metaphor stress its cognitive significance. In an early and very influential essay, Black (1962) defended an interaction view of metaphor, in which two juxtaposed thoughts interact to produce new meanings, through the metaphor’s “system of associated commonplaces” or “associated implications.” The metaphor—for instance, “wolf” in “man is a wolf”—serves as a “filter” for a set of associated implications that are transferred from the secondary subject (*wolf*) to the principal subject (*man*) in the sentence. In a full interaction or interanimation view of metaphor, the transfer of meaning occurs both ways, not merely from the secondary subject to the principal subject (Soskice).

Metaphors highlight and hide features of the principal subject, such as the physician who is viewed as a parent or as a friend, by their systematically related implications (Black, 1962; Lakoff and Johnson). When argument is conceived as warfare, for example, the metaphor highlights the conflict involved in argument, while it hides the cooperation and collaboration, involving shared rules, that are also indispensable to argument. Our metaphors thus shape how we think, what we experience, and what we do by what they highlight and obscure.

Metaphors are often associated with models. For instance, we have both metaphors and models of the doctor-patient relationship. The physician may be viewed through the metaphor of father and the patient through the metaphor of child, and their relationship may be interpreted through the model of paternalism. Models, for our purposes, state the network of associated commonplaces and implications in more systematic and comprehensive ways—according to Black, "every metaphor is the tip of a submerged model" (1979, p. 31).

Metaphors and models may be good or bad, living or dead. Both metaphors and models can be assessed by how well they illuminate what is going on and what should go on. We can distinguish descriptive and normative uses of metaphors and models, without admitting a sharp separation between fact and value. For instance, the metaphor of physician as father (or parent), and the model of paternalism (or parentalism), may accurately describe some relationships in medicine, or they may suggest ideal relationships in the light of some important principles and values.

MEDICINE AS WAR. The metaphor of warfare illuminates much of our conception of what is, and should be, done in healthcare. This metaphor emerges in the day-to-day language of medicine: The physician as the captain leads the battle against disease; orders a battery of tests; develops a plan of attack; calls on the armamentarium or arsenal of medicine; directs allied health personnel; treats aggressively; and expects compliance. Good patients are those who fight vigorously and refuse to give up. Victory is sought; defeat is feared. Sometimes there is even hope for a "magic bullet" or a "silver bullet." Only professionals who stand on the firing line or in the trenches can really appreciate the moral problems of medicine. And they frequently have "war stories" to relate. Medical organization, particularly in the hospital, resembles military hierarchy; and medical training, particularly with its long, sleepless shifts in residencies, approximates military training more than any other professional education in our society (Childress).

As medicine wages war against germs that invade the body and threaten its defenses, so the society itself may also declare war on cancer or on AIDS under the leadership of its chief medical officer, who in the United States is the surgeon general. Articles and books even herald the "Medical-Industrial Complex: Our National Defense." As Susan Sontag notes, "Where once it was the physician who waged bellum contra morbum, the war against disease, now it's the whole society" (p. 72).

The military metaphor first became prominent in the 1880s, when bacteria were identified as agents of disease that threaten the body and its defenses. The metaphor both illuminates and distorts healthcare. Its positive implications are widely recognized—for instance, in supporting a patient's courageous and hopeful struggle against illness and in galvanizing societal support to fight against disease. But the metaphor is also problematic. Sontag, who was diagnosed with cancer in the late 1970s, reports that her suffering was intensified by the dominance of the metaphor of warfare against cancer. Cancer cells do not just multiply; they are *invasive.* They *colonize.* The body's *defenses* are rarely strong enough. But since the body is under attack (*invasion*) by *alien* invaders, counterattack is justified. Treatments are also often described in military language:

> Radiotherapy uses the metaphors of aerial warfare; patients are "bombarded" with toxic rays. And chemotherapy is chemical warfare, using poisons. Treatment aims to "kill" cancer cells (without, it is hoped, killing the patient). Unpleasant side effects of treatment are advertised, indeed overadvertised. ("The agony of chemotherapy" is a standard phrase.) It is impossible to avoid damaging or destroying healthy cells (indeed, some methods used to treat cancer can cause cancer), but it is thought that nearly any damage to the body is justified if it saves the patient's life. Often, of course, it doesn't work. (As in: "We had to destroy Ben Suc in order to save it.") There is everything but the body count. (Sontag, p. 65)

Such "military metaphors," Sontag suggests, "contribute to the stigmatizing of certain illnesses and, by extension, of those who are ill" (p. 99). Other ill individuals have found the military metaphor unsatisfactory for other reasons. For instance, as a teenager, Lawrence Pray originally tried to conquer his diabetes, but his struggles and battles were futile and even counterproductive. Then over time he came to view his diabetes not as an *enemy* to be *conquered,* but as a *teacher.* Only then did he find a personally satisfactory way of living (Pray and Evans).

Still others with illness, by contrast, have found the military metaphor to be empowering and enabling. In her wide-ranging study of pathographies, that is, autobiographical descriptions of personal experiences of illness, treatment, and dying, Anne Hunsaker Hawkins identifies several "metaphorical paradigms" that offer themes of "an archetypal, mythic nature." In addition to illness as a battle, she notes illness as a game or sport (a subset of the military metaphor), illness as a journey into a distant country, illness as rebirth or regeneration— and, on a somewhat different level, healthy-mindedness as an alternative to contemporary medicine. While pathographies are individualized statements, they provide "an immensely rich reservoir of the metaphors and models that surround illness in contemporary culture" (p. 25). These various metaphorical paradigms structure individuals' interpretations of their experiences of illness. Patterns emerge in individuals' selection of metaphors. They vary in part according to the illness involved—for example, the military metaphor is more common in descriptions of experiences with cancer and AIDS, while the rebirth metaphor is more common in descriptions of a critical life-threatening event, such as a heart attack. Furthermore, the military metaphor is more prevalent than the journey metaphor because it better fits the experience of modern medicine—for instance, it is easier to construe the physician as a *general* in a war than as a *guide* on a journey. Nevertheless, these various metaphors are often mixed and complementary. They can be evaluated, Hawkins suggests, according to their capacity to enable and empower ill persons, for instance, by restoring a sense of personal dignity and worth. And, while expressing larger sociocultural patterns, the individual's choice of a particular metaphor is a creative act of assigning meaning to his or her illness.

The metaphor of warfare has been further challenged in modern medicine because of its apparent support for overtreatment, particularly of terminally ill patients, because death is the ultimate enemy, just as trauma, disease, or illness is the immediate enemy. Physicians and families under the spell of this metaphor frequently find it difficult to let patients die. *Heroic* actions, with the best available weapons, befit the military effort that must always be undertaken against the ultimate enemy. Death signals defeat and forgoing treatment signals surrender. Some clinicians even feel more comfortable withholding (i.e., not starting) a treatment for cancer, for instance, than they do withdrawing (i.e., stopping) the same treatment, in part because withdrawing treatment implies retreat.

According to its critics, the invocation of the military metaphor often fails to recognize moral constraints on waging war. "Modern medicine," William May writes, "has tended to interpret itself not only through the prism of war but through the medium of its modern practice, that is, unlimited, unconditional war," in contrast to the just-war tradition (1983, p. 66). In the spirit of modern total war, "hospitals and the physician-fighter wage unconditional battle against death" (1983, p. 66). One result is that many patients seek assisted suicide or active euthanasia in order to escape from this warfare's terrorist bombardment. Traditional moral limits in the conduct of war include the principle of discrimination, which authorizes direct attacks on combatants but not on noncombatants. In medical care, the opposing combatant is the disease or death, not the patient. However, the patient is regularly the battleground and sometimes even becomes the enemy. Furthermore, in accord with the just-war tradition's requirement of reasonable prospect of success and proportionality, the treatment should offer the patient a reasonable chance of success; his or her suffering must be balanced against the probable benefits of prolongation of life.

Other problematic or ambiguous implications of the war metaphor appear in the allocation of resources for and within healthcare. First, under the military metaphor, society's healthcare budget tends to be converted into a defense budget to prepare for and conduct war against disease, trauma, and death. As a consequence, the society may put more resources into healthcare in relation to other goods than it could justify, especially under a different metaphor, such as nursing or business (see below). Indeed, the society may overutilize healthcare, especially because technological care may contribute less to the national defense of health itself—through the reduction of morbidity and premature mortality—than other factors, such as the reduction of poverty.

Second, within the healthcare budget, the military metaphor tends to assign priority to critical care over preventive and chronic care. It tends to concentrate on critical interventions to cure disease, perhaps in part because it tends to view health as the absence of disease rather than a positive state. It tends to neglect care when cure is impossible. A third point is closely connected: In setting priorities for research and treatment, the military metaphor tends to assign priority to terminal diseases, such as cancer and AIDS, over chronic diseases. Fourth, medicine as war concentrates on technological interventions, such as intensive-care units, while downplaying less technological modes of care.

In short, the military metaphor has some negative or ambiguous implications for a moral approach to healthcare decisions: It tends to assign priority to healthcare (especially medical care) over other goods, and, within healthcare, to critical interventions over chronic care, killer diseases over disabling ones, technological interventions over care, and heroic treatment of dying patients rather than allowing them to die in peace.

Some of the negative or ambiguous implications of the war metaphor for healthcare can be avoided if, as noted earlier, the metaphor is interpreted in accord with the limits set by the just-war tradition. However, the war metaphor may require supplementation as well as limitation. It is not the only prominent metaphor for healthcare; since the early 1980s its dominance has been threatened by the language of economics and business, as reflected in the language of a healthcare industry. Providers deliver care to consumers, seek or are forced to seek productivity in light of cost-effectiveness or cost-benefit analyses, and may be concerned with "resource management, managed-care systems, and market strategies" (Stein, p. 172). This metaphor also highlights and hides various features of contemporary healthcare. Many critics of this metaphor worry that the language of efficiency will replace the language of care and compassion for the sick and equity in distribution of healthcare. Nevertheless, this metaphor has become more and more pervasive and persuasive as the structure of medicine and healthcare has changed, and as concerns about costs have become more central in societal discussions. Patients often fear undertreatment as hospitals and professionals seek to reduce costs, in contrast to their earlier fears of overtreatment under the war metaphor.

Both military and economics metaphors illuminate contemporary healthcare. But they may not be adequate, even together, to guide and direct healthcare. Whether any particular metaphor is adequate or not will depend in part on the principles and values it highlights and hides. Others have proposed nursing, a subset of healthcare, as a supplementary metaphor for the whole of healthcare, because of its attention to caring more than curing and to hands-on rather than technological care. Even though this metaphor of nursing is also inadequate by itself, it could direct the society to alternative priorities in the allocation of resources for and within healthcare, particularly for chronic care.

THE WAR AGAINST AIDS. Even as the military metaphor has been partially displaced by business and economics metaphors in the changing structure of healthcare, it has gained favor as a way to describe and direct society's response to the major epidemic of the acquired immunodeficiency syndrome (AIDS). Societies often resort to the metaphor of war when a serious threat to a large number of human lives requires the mobilization of vast societal resources, especially when that threat comes from biological organisms, such as viruses, that invade the human body. And AIDS activists have appealed to the military metaphor in an effort to galvanize society and to marshal its resources for an effective counterattack against the human immunodeficiency virus (HIV) that causes AIDS. However, critics charge that the war on AIDS has diverted important resources away from other important wars, such as the war against cancer.

Other controversies have emerged. From the beginning of the war against AIDS, identification of the enemy has been a major goal. Once the virus was identified as the primary enemy, it also became possible to identify human beings who carry or harbor the virus. This technology then led to efforts to identify HIV-infected individuals, even through mandatory screening and testing, as potential enemies of the society. In social discourse and practice, the carrier tends to become an enemy as much as the virus he or she carries, especially since society views many actions that expose individuals to the risk of HIV infection as blameworthy. Thus, the metaphor of war often coexists with metaphors of AIDS as punishment and as otherness (Ross, 1989a, 1989b; Sontag). In this specific case of war against AIDS, just as in the general war against disease, the military metaphor would be less dangerous if society adhered to the constraints of the just-war tradition, rather than being tempted by a crusade.

RELATIONSHIPS BETWEEN HEALTHCARE PROFESSIONALS AND RECIPIENTS OF CARE. Relationships between physicians and other healthcare professionals, on one hand, and patients, on the other, have been described and directed by a wide variety of metaphors and models (Childress and Siegler). For example, William May (1983) has identified images of the physician as fighter, technician, parent, covenanter, and teacher; Robert Veatch has identified several major competing models of physician-patient relationships: engineering, priestly (which includes the paternalistic model), collegial, and contractual models. Other metaphors such as friend and captain of the ship have also been used (King et al.).

Some critics contend that such models are *whimsical gestalts,* that many other arbitrary models could be invented—for example, bus driver or back-seat driver—and that moral points can and should be made more directly (Clouser). Such criticisms overlook how metaphors and models function in the interpretation and evaluation of interactions between physicians and patients. They miss the role of imagination, which can be defined as "reasoning in metaphors" (Eerdman). For example, opponents of paternalistic medical relationships usually do not eschew all use of metaphor; instead they offer alternative metaphors, such as partnership or contracts. And these various metaphors may be more or less adequate to describe what occurs and to direct what should occur in health care.

Metaphors and models highlight and hide features of the roles of physicians and other healthcare professionals by their various associated implications. For example, viewing the physician as a parent—or specifically as a father, based on the nineteenth-century model of the family—highlights some features of medical relationships, such as care and control, while hiding others, such as the payment of fees. In their use to describe, interpret, and explain relationships, such metaphors are subject to criticism if they distort more than they illuminate. And when they are offered to guide relationships and actions, they are subject to criticism if they highlight only one moral consideration, such as the physician's duty to benefit the patient or to respect patient autonomy, while hiding or obscuring other relevant moral considerations. It is also appropriate to consider the feasibility of various ideal relationships in light of significant personal, professional, and institutional constraints.

Several metaphors may be necessary to interpret healthcare as it is currently structured and to guide and direct actions, practices, and policies in healthcare. Some metaphors may fit some relationships better than others; for example, relations in clinical research, family practice, and surgery may be illuminated respectively by the metaphors of partner, teacher-student, and technician-consumer. Furthermore, not all of these metaphors conflict with each other; some may even be mutually supportive as well as compatible, for example, contractor and technician.

NURSING AS ADVOCACY. Major changes in the conception of nursing correlate with alterations in its primary metaphors. Whether situated within the military effort against disease or viewed as physicians' handmaidens and servants, nurses have traditionally been expected to cultivate passive virtues, such as loyalty and obedience. Their moral responsibility was primarily directed toward physicians and institutions, such as hospitals, and only secondarily toward patients. This interpretation of responsibility was shaped in part by nursing's military origins in the nineteenth century, as well as by societal conceptions of gender (Winslow; Bernal). Then in the 1970s, nursing was reconceived through the metaphor of advocacy. Nurses became advocates for *clients* and *consumers* (the term *patient* was often rejected as too passive). This legal metaphor, drawn from the advocate as one who pleads another's cause, especially before a tribunal of justice, highlights active virtues such as courage, persistence, and perseverance, and views the nurse as primarily responsible to the patient or client. This metaphor is explicit or implicit in formal nursing codes, and it is also featured in a large number of nurses' stories of advocacy and conflict in healthcare (Winslow; Bernal).

Critics note that the metaphor of advocacy reduces the range of services traditionally offered by nurses; it is thus insufficiently comprehensive (Bernal). In addition to distorting the human experience of illness, it distorts nursing by focusing almost exclusively on patients' or clients' rights, construed mainly in terms of autonomy, and it neglects positive social relationships in healthcare (Bernal). It highlights conflict among healthcare professionals because it implies that some of them do not adequately protect the rights of patients. Thus, the metaphor frequently supports a call for increased nursing autonomy as a way to protect patient autonomy. Because of its adversarial nature, many question whether the metaphor of advocacy can adequately guide relationships among healthcare professionals in the long run, even if it is useful in the short run. The metaphor may also assume that the nurse's responsibility to the patient/client is always clear-cut and overriding, even though nurses may face serious conflicts of responsibility involving patients, other individuals, associates, and institutions (Winslow). At the very least, sympathetic commentators call for further clarification of the metaphor of advocacy (Winslow); while critics seek alternative metaphors and models, such as covenant (Bernal), partnership, teamwork, or collegiality, that appear to offer more inclusive, cooperative ideals.

PLAYING GOD AND OTHER METAPHORS OF LIMITS. "Playing God" has been a common metaphor for both describing and directing the activities of scientists, physicians, and other healthcare professionals. They have been criticized for usurping God's power—for instance, the power over life and death—by letting patients die or by using new reproductive technologies.

There are theological warrants for playing God in the Jewish and Christian traditions, which affirm the creation of human beings in God's image and likeness. Thus, Paul Ramsey calls on those who allocate healthcare to play God in a fitting way: We should emulate God's indiscriminate care by distributing scarce lifesaving medical technologies randomly or by a lottery rather than on the basis of judgments of social worth.

Despite a few such positive uses of the metaphor of "playing God," the metaphor is generally used to identify two aspects of divine activity that should not be imitated by humans: God's unlimited power to decide and unlimited power to act. On one hand, users of this metaphor demand scientific and medical accountability over unilateral decision making. On the other hand, critics call for respect for substantive limits—for example, not creating new forms of life (U.S. President's Commission, 1982).

Edmund Erde contends that statements such as "doctors should not play god" are so unclear that they cannot function as commands and do not articulate a principle; thus, they cannot be followed because agents do not know how to conform their actions to them. Nor do they explain why certain actions should not be undertaken. Such phrases are, Erde argues, "metaphoric in that they tuck powerful feelings and images into descriptive language that cannot be understood literally" (p. 606). Any activity, such as mercy killing, that is "labeled `playing god' carries the implication that it is clearly wrong" (p. 607). These phrases are used for situations in which agents face choices, but one option is considered immoral and is rejected as arrogantly and presumptuously playing God. The background of intelligibility of this metaphor, according to Erde, is found in the Western idea of the great chain of being, which identifies appropriate responsibilities at each level and opposes the usurpation of power and the failure to respect limits.

Other important and widespread metaphors of limits include the "thin edge of the wedge" and the "slippery slope," both of which warn against undertaking certain actions because other unacceptable actions will inevitably follow. Examples regularly appear in debates about euthanasia. Even though such metaphors are often misused, they are appropriate in some contexts. In each use of these metaphors, important moral questions require attention—the evaluation of the first action and subsequent actions—and important conceptual and empirical questions must be addressed in order to determine whether the putatively bad consequences will inevitably follow what might be innocuous first steps. (Similar questions emerge for some analogies, such as the Nazi analogy, which is also widely invoked to oppose such practices as mercy killing.)

METAPHORS FOR BIOETHICS AND BIOETHICISTS. The role and function of the bioethicist have often been construed in metaphorical terms. The common language of *applied ethics* invokes the metaphor of engineering as an application of basic science that does not contribute to basic science. The expertise of applied ethicists resides in their ability to apply general theories and principles to specific arenas of human activity. The metaphor of application has been widely challenged on the grounds that it is too narrow and distorts much that is important in bioethics. The term *applied* suggests that ethicists are problem solvers rather than problem setters, that they solve puzzles rather than provide perspectives, that they answer rather than raise questions, and that they begin from theory rather than from lived experience. It implies a limited technical or mechanical model of ethics.

The term *applied* distorts the numerous theoretical controversies in bioethics, and neglects the way bioethics may help to resolve or recast some theoretical controversies. At the very least, the metaphor of application may need to be supplemented by various other metaphors for the task of practical ethics and the role of the practical ethicist: "Theoretician, diagnostician, educator, coach, conceptual policeman, and skeptic are also supplemental or alternative roles to that of the technician" (Caplan, p. 30).

Some other metaphors are drawn from ancient religious roles, such as prophet or scribe. Yet another metaphor is *conversation,* which is prominent in approaches to bioethics that emphasize interpretation, hermeneutics, and narrative. And the *stranger* has been proposed as the best metaphor for the ethicist in professional education because his or her outside perspective can challenge ordinary assumptions (Churchill).

Suggestions emerge at various times to retire all metaphors, not merely some metaphors in some realm of discourse—for instance, Sontag proposes retiring all metaphors for illness. However, it is not possible to strip our discourse in science, medicine, and healthcare, or in biomedical ethics, of all metaphors. Instead, we must use metaphors with care and must carefully assess their adequacy in descriptive and normative functions.

Analogies in Bioethics

ANALOGIES AND ANALOGICAL REASONING. Often metaphors and analogies are presented in ways that indicate their substantial overlap. Indeed, for the comparison view of metaphor, there is little difference between them, because metaphors are compressed analogies. Some recent theories of metaphor have stressed, by contrast, that metaphors create similarities rather than merely expressing previously established and recognized similarities or analogies. According to Black, comparison views of metaphor fail because they reduce the ground for shifts of meaning (from the secondary subject to the primary subject) to similarity or analogy (1962). Nevertheless, there is a strong consensus that metaphorical statements presuppose some resemblance, even when they also create resemblance (Ricoeur). Black later conceded that metaphors "mediate an analogy or structural correspondence." Metaphor is, roughly speaking, "an instrument for drawing implications grounded in perceived analogies of structure between two subjects belonging to different domains" (1979, p. 32). And yet metaphor does not merely compare two things that are similar, but rather enables us to see similarities in what would be regarded as dissimilar.

Metaphors and analogies are thus closely related, with metaphors both expressing and creating similarities. In general, good metaphors function cognitively to generate new meaning and insight, by providing new perspectives; while good analogies extend our knowledge by moving from the familiar to the unfamiliar, from the established to the novel. In stretching language and concepts for new situations, analogy does not involve the imaginative strain often evident in the use of metaphors (Soskice). Nevertheless, the differences in function between metaphors and analogies should not be exaggerated.

The term analogy derives from the Greek *analogia,* which referred to mathematical proportion. "An analogy in its original root meaning," Dorothy Emmet observes, "is a proportion, and primarily a mathematical ratio, e.g., 2: 4: : 4: X. In such a ratio, given knowledge of three terms, and the nature of the proportionate relation, the value of the fourth term can be determined. Thus analogy is the repetition of the same fundamental pattern in two different contexts" (p. 6).

Analogical reasoning proceeds inductively, moving from the known to the unknown. It appears prominently in problem solving and thus is featured in research in cognitive science and artificial intelligence (Helman; Keane). For instance, computer problem-solving programs must search for analogous problems that have been successfully solved to generate solutions to new problems whether in highly structured domains such as law or in less structured domains.

Analogical reasoning has an important place in moral discourse, not only because of its importance in problem solving, but also because of the widely recognized moral requirement to treat similar cases in a similar way. Often stated as a principle of universalizability or of formal justice or formal equality, dating back at least to Aristotle, the requirement to treat similar cases in a similar way also appears in the common law's doctrine of precedent. The basic idea is that one does not make an acceptable moral or a legal judgment—perhaps not even a moral or legal judgment at all—if one judges that X is wrong, but that a similar X is right, without adducing any relevant moral or legal difference between them. In general, analogical reasoning illuminates features of morally or legally problematic cases by appealing to relevantly similar cases that reflect a moral or legal consensus (precedent). Of course, much of the moral (or legal) debate hinges on determining which similarities and differences are both relevant and significant.

Since the early 1980s ethicists have directed new attention to the role of analogical reasoning in case-oriented or casuistical judgments in bioethics and elsewhere. In *The Abuse of Casuistry,* Albert Jonsen and Stephen Toulmin identify "the first feature of the casuistic method" in its classical formulations as "the ordering of cases under a principle by paradigm and analogy" (p. 252). For instance, the rule prohibiting killing is set out in *paradigm cases* that illustrate its most manifest breaches according to its most obvious meaning. Moving from simple and clear cases to complex and uncertain ones, casuists examine various alternative circumstances and motives to determine whether those other cases violate the rule against killing. They seek analogies that permit the comparison of "problematic new cases and circumstances with earlier exemplary ones," that is, the similar cases that constitute presumptions (Jonsen and Toulmin, p. 316).

Despite the claims of some modern casuists, it is not clear that analogical reasoning distinguishes casuistical from principlist approaches. For instance, in analyzing the novel microallocation problems of modern medicine, Paul Ramsey appealed to the analogous "lifeboat" cases—when some passengers have to be thrown overboard in order to prevent the lifeboat from sinking—as a way to interpret the requirements of the principle of equality of opportunity in distributing scarce lifesaving medical technologies such as kidney dialysis. Because principles and rules are indeterminate, and because they sometimes conflict, analogical reasoning can be expected in case judgments—mere application cannot be sufficient.

Analogies are often divided into two main types: analogies of attribution and analogies of proportion (Cahill). The analogy of attribution involves a comparison of two terms or analogates, both of which have a common property, the analogon, that appears primarily in one and secondarily in the other. As Thomas Aquinas noted, *healthy* is used primarily for a person in a state of health (a *healthy* person) and secondarily for those medicines and practices that help to maintain or restore health (e.g., a *healthy* diet) or specimens that provide evidence of the body's health (e.g., *healthy* blood). By contrast, in the analogy of proportion, the analogates lack a direct relationship, but each of them involves a relationship that can be compared to a relationship in the other (Cahill). This second type is most common in analogical reasoning in biomedical ethics, as is evident in debates about maternal-fetal relations and abortion, where analogies of attribution also appear, particularly with reference to the fetus.

Analogical reasoning in debates about maternal-fetal relations. Debates about maternal-fetal relations, including pregnant women's decisions to abort and to decline cesarean sections, illustrate the pervasiveness and importance of analogical reasoning. Traditionally, abortion has been construed as directly killing the fetus, an innocent human being, in violation of the duty of nonmaleficence. Hence, in traditional Roman Catholic moral theology, direct abortions are tantamount to homicide. Sometimes the analogy of the *unjust aggressor* appears in situations where the pregnancy threatens the pregnant woman's life or health; but it has not been accepted in official Catholic thought the way the similar analogy of the *pursuer* has been accepted in some Jewish thought to justify abortions when there is such a threat.

Some feminists and others have attempted to recast the debate about abortion to focus on the basis and extent of the pregnant woman's obligation to provide bodily life support to the fetus. Often accepting, at least for purposes of argument, the premise that the fetus is a human being from the moment of conception (or at some time during the pregnancy), they argue that this premise does not entail that the pregnant woman always has a duty to sustain the fetus's life regardless of the circumstances of pregnancy, the risks and inconveniences to the pregnant woman, and so forth. Their arguments often proceed through analogies to other hypothetical or real practices or cases, on the assumption that a judgment about those practices or cases will entail a similar judgment about abortion.

The fantastic abortion analogies introduced by Judith Jarvis Thomson (1971) have been particularly influential and controversial. In one of her artificial cases, an individual with a rare blood type is kidnapped by the Society of Music Lovers and attached to a famous violinist who needs to purify his system because of his renal failure. Part of the debate concerns whether relevant analogies can be found in such fantastic, artificial cases, in contrast to actual real-life cases. For example, against Thomson, John Noonan opposes abortion in part by appeal to a U.S. tort-law case, in which the court held liable the hosts who had invited a guest for dinner but then put him out of their house into the cold night even though he had become sick and fainted and requested permission to stay (Noonan).

Some feminists and others contend that other analogous real-life legal and moral cases support the pregnant woman's free decision to continue or to discontinue her pregnancy. For many the relevant analogous cases concern living organ and tissue donation. Such donations are conceived as voluntary, altruistic acts that should not be forced by others even to save the potential recipient's life. They are *gifts of life.* Requiring a pregnant woman to continue the pregnancy until birth imposes on her a heavier burden than others are expected to bear in analogous circumstances, such as a parent who could save a child's life by donating a kidney. Thus, the provision of bodily life support, whether through donating an organ or allowing the fetus to use the uterus, has been conceived as a gift of life that should not be legally enforced (Mattingly; Jung).

According to Lisa Sowle Cahill, much analogical reasoning about pregnancy overlooks what is unique about maternal-fetal relations and thus obscures the morally relevant features of pregnancy or makes some relevant features more significant than they are. Many analogies problematically narrow our moral perspective on abortion by portraying the inception of pregnancy as accidental and the fetus as strange, alien, and even hostile. Furthermore, they often rely on the connotative meanings of their terms, particularly as embedded in a story, such as Thomson's case of kidnapping the unwilling blood donor. Examples also appear in the rhetoric of abortion opponents who, for instance, speak of the fetus as a *child,* and thereby distort the unique dependence of the fetus on the pregnant woman (Cahill). Finally, Cahill contends, justifications of abortion based on analogy often rest on liberal convictions that special responsibilities derive only from free choice.

For all these reasons, Cahill holds that analogical reasoning needs supplementation through direct examination of the unique features of maternal-fetal relations, particularly total fetal dependence, and of the ways these unique features qualify maternal, professional, and societal obligations. She argues that, as a category or class of moral relations, pregnancy "is unique among human relations at least because in it one individual is totally and exclusively dependent on a particular other within a relation which represents in its physical and social aspects what is *prima facie* to be valued positively" (p. 283). Hence, she argues, most analogies hide what is distinctive and unique about pregnancy, even though they identify some morally relevant features of maternal-fetal relations.

With the emergence of other maternal-fetal conflicts, particularly regarding cesarean sections to benefit the fetus, similar debates have emerged about the appropriateness of the analogy with living organ and tissue donation. For instance, in the case of A.C. (1990), the majority of the court held that, just as courts do not compel people to *donate* organs or tissue to benefit others, so they should not compel cesarean sections against the will of pregnant women to benefit potentially viable fetuses. The dissenting opinion rejected the analogy with organ and tissue donation, insisting that the pregnant woman "has undertaken to bear another human being, and has carried an unborn child to viability," that the "unborn child's" dependence upon the mother is unique and singular, and that the “viable unborn child is literally captive within the mother’s body” (A.C., *In re,*).

Even though analogies with organ and tissue donation are now widely invoked to oppose state control of pregnant women’s decisions regarding both abortion and cesarean sections, there are important differences between these two contexts. In the abortion debate, pregnancy is viewed as the provision of bodily life support and is itself analogous to the donated organ. In the debate about cesarean sections, the surgical procedure is analogous to organ donation—the potentially viable fetus is removed for its own benefit rather than to benefit some other party as in organ or tissue donation. In the abortion debate, the pregnancy is viewed as invasive; in the debate about cesarean sections, the surgical procedure is invasive. The central issue is whether state coercion in these cases to benefit the fetus is morally and legally acceptable. The debate hinges in part on the appropriateness of the living organ and tissue donation as an analogy. Even the critics of the analogy engage in analogical reasoning, but they deny that the similarities are more morally or legally relevant and significant than the dissimilarities. Defenders of governmental coercion could also hold that the moral or legal precedent is mistaken and that organs and tissues should sometimes be conscripted or expropriated from living persons.

Similar disputes appear in other areas of contemporary bioethics—for instance, in debates about whether mandatory testing or screening for antibodies to the human immunodeficiency virus, which causes AIDS, can be justified by analogy to accepted practices of mandatory testing or screening; and in debates about whether transplantation experiments using human fetal tissue, following deliberate abortions, are analogous to the complicitous use of materials or data from the morally heinous Nazi experiments. In these cases, as in many others, the debates focus to a great extent on the relevance and significance of the proposed analogies.

Conclusions

Debates in biomedical ethics are often debates about which metaphors and analogies illuminate more than they distort. Far from being merely decorative or affective, metaphors and analogies are central to both discourse and practice. They must be evaluated specifically according to how well they function to describe and/or direct actions and relationships. Even though in recent bioethics metaphors and analogies have sometimes been offered as ways to circumvent or transcend principles and rules, particularly through attention to cases, narratives, and aesthetic dimensions of experience, they are not necessarily incompatible with principles and rules. Analogical reasoning is important within frameworks of principles and rules, as well as in casuistry, and metaphors and models often succeed or fail depending on how well they express the full range of relevant moral considerations.

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SEE ALSO: *Abortion; Cancer, Ethical Issues Related to Diagnosis and Treatment; Children: History of Childhood; Embryo and Fetus; Epidemics; Ethics; Holocaust; Literature and Medicine; Moral Status; Narrative; Responsibility; Value and Valuation; Women, Historical and Cross-Cultural Perspectives*

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MILITARY PERSONNEL AS RESEARCH SUBJECTS

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A key ethical issue in the use of military personnel as research subjects is whether individuals in the armed services are free to accept or decline participation in research. Voluntary participation has been recognized as an essential requirement for ethical human experimentation; it is the cornerstone of the Nuremberg Code, issued in 1947 as part of the prosecution of Nazi physicians. Some bioethicists have expressed concerns that military discipline, with its emphasis on following orders and the chain of command, may constrain an individual's ability to make uncoerced decisions about participation in research. It is not clear, for example, how participation in a research study differs significantly from other hazardous duties expected of military personnel.

Negotiating the balance between respect for individual autonomy and the needs of the military is more problematic when nations are at war. During World War II, the medical needs of the military were invoked to justify the experimental use of vaccines and drugs in military populations, as well as nontherapeutic research on conscientious objectors, orphans, prisoners, and the mentally ill. Nearly 60,000 American military personnel were recruited through "lies and half-truths" into secret tests of mustard agents (sulfur and nitrogen mustard) and Lewisite (an arsenic compound) (Pechura and Rall). In the Persian Gulf War of 1991, the military's decision to seek a waiver of its own regulations about informed consent for the administration of investigational drugs and vaccines to American servicemen and servicewomen prompted controversy between critics who condemned this deviation from the Nuremberg Code and supporters who argued that the principle of preventing unnecessary harm to military personnel made the decision necessary (Howe and Martin; Annas and Grodin). These issues, which have received little sustained analysis, require greater attention from bioethicists.

Historical Use of Military Subjects

Historically, the armed forces have provided both unique opportunities and special needs for the study of human health and disease. “He who would become a surgeon,” observed the Greek physician Hippocrates, “should join the army and follow it” (Hume, p. 78). Early efforts in disease prevention and treatment reflected the practical concerns of maintaining military personnel in good condition. One of the earliest clinical trials involving human subjects was conducted by the Scottish naval surgeon James Lind (1716–1794), who administered six different treatments to twelve sailors suffering from scurvy, and observed the beneficial effect of oranges and lemons in recovery from the disease (Carpenter).

Traumatic injuries from guns and other weapons have provided distinctive opportunities for military physicians to study human anatomy and physiology. In the 1820s, American army surgeon William Beaumont investigated the process of human digestion in a live subject after his repeated efforts failed to close the gunshot wound to French–Canadian trapper Alexis St. Martin’s stomach. Beaumont developed an employment contract with his research subject, who agreed to allow physiological experiments in exchange for room, board, and wages. Beaumont also persuaded the trapper to enlist in the U.S. Army, giving the physician more complete control of his subject and rendering St. Martin’s “faithless absconding” subject to military law (Numbers).

The rise of experimental science and the germ theory of disease in the late nineteenth century increased experimentation involving human beings. The Medical Department of the U.S. Army expanded its efforts to control infectious diseases, the major cause of mortality in the military before World War II. All U.S. Army commanders were directed to cooperate with the Medical Department to secure volunteers for experimental inoculations or other medical investigations approved by the War Department (Dow). Both the British and the American armed forces conducted experiments with newly developed vaccines for typhoid fever and other diseases (Tigertt). The introduction of aviation and its rapid development after World War I accelerated military research with human subjects (Pitts).

Introduction of Participant Consent

The shift from therapeutic experiments to nontherapeutic research in the early twentieth century fostered more formal arrangements with research subjects. In 1900 Major Walter Reed and members of the U.S. Army’s Yellow Fever Board adopted the first written agreements between research subjects and experimenters. The Spanish immigrants who participated signed contracts that described compensation for subjects (civilians received $100 in gold and an additional $100 if they contracted the disease) and identified some of the risks of participation (Lederer). American physicians working in the Philippines followed Reed’s example; prisoners in Manila’s Bilibid Prison signed agreements written in their own dialect for medical research studies (Chernin; Lederer). During World War I, some physicians continued the policy of having written agreements with American soldiers who participated in infectious disease research (Sellards).

The success of the yellow fever research gained public approval for human experimentation. Public reaction to the research-related deaths of Army nurse Clara Maas and two Cuban volunteers, however, led the surgeon general to suspend the Army’s work on a yellow fever vaccine in 1902. Most published reports of military medical research emphasized the voluntary nature of participation. References to cash payments and better duty assignments raised questions about the pressures to volunteer. In principle, American military personnel, although required to undergo standard medical procedures to enhance their military fitness, retained the right to refuse participation in medical experiments (Johnson).

The advent of World War II spurred massive changes in the organization and funding of medical research. The Committee on Medical Research, part of the Office of Scientific Research and Development, sponsored clinical research projects on an unprecedented scale. Pressures to find solutions for military medical problems encouraged investigators to conduct numerous trials with human subjects. As historian David J. Rothman has observed, the arguments that were used to justify sending men into combat were also invoked to sanction the use of conscientious objectors and civilians—prisoners, orphans, the retarded, and the mentally ill—in nontherapeutic research for military needs.

The wartime research ethos continued into the Cold War era. Both military and civilian researchers increasingly used human beings in experiments with little regard for the principles of consent and voluntary participation elaborated in the Nuremberg Code, or in the regulations governing research adopted by the secretary of defense in 1953 but classified as top secret until 1975 (Annas, Glantz, and Katz). During the Cold War, some 250,000 men and women were exposed to radiation as part of state-sponsored nuclear testing in Nevada and the South Pacific. In the early 1950s the American military conducted indoctrination and panic studies on troops at atom bomb tests (Moreno). Between 1955 and 1967, the U.S. Army and the Air Force supported more than eighteen research projects on the effects of hallucinogenic drugs on human performance in the United States and Canada (Annas and Grodin). Many of the nearly seven thousand servicemen who participated in drug tests at the Army Chemical Center at Edgewood Arsenal, Maryland, apparently received little information about the risks they incurred as a result of their participation in lysergic acid diethylamide (LSD) studies. Army investigators similarly failed to inform the more than one thousand participants about risks they incurred in tests of various nerve gases (Downey).

Amid the public condemnation of the LSD studies and the exposure of large numbers of servicemen to harmful radiation in the race to develop an atomic arsenal, the U.S. Army, Navy, and Air Force revised policies for research involving military personnel. In 1972 the American military banned all tests of nerve gases involving human subjects, and in 1974 issued new regulations for research on military personnel. In 1983, U.S. Department of Defense Directive 3216.2, "Protection of Human Subjects in DoD-Supported Research," established a uniform policy for research involving human subjects throughout the Department of Defense. In addition to adhering to the regulations for the protection of human subjects of the Department of Health and Human Services, the guidelines charged the military chain of command to ensure that the fundamental rights, welfare, and dignity of human subjects be protected to the maximum extent possible (Winter). Research involving American military personnel received greater scrutiny in the 1980s (Howe, Kark, and Wright; Maningas). Some military research subjects have received compensation for injuries they sustained in tests conducted without their knowledge.

New Complications in Military Research

Biological and chemical weapons pose some special problems for military personnel. Nations have approached the search for effective protections against these weapons in different ways. Whereas the American military discontinued the testing of toxic chemicals on human beings, the British Ministry of Defense continued to test antidotes for nerve gases on volunteer soldiers. Critics of the experimental exposure of soldier volunteers to nerve gases have cited safety concerns, as well as doubts that soldiers were "capable of giving full and informed consent to participate in complex toxicological experiments" (Mason, p. 30). Other North Atlantic Treaty Organization (NATO) countries have conducted similar testing of protective gear and drugs against nerve gas and a wide variety of other chemical weapons.

The threat of chemical and biological weapons in the Persian Gulf War in 1991 led the U.S. Food and Drug Administration (FDA) to grant the Department of Defense's request for a waiver of federal informed-consent regulations for administering investigational drugs and vaccines to troops stationed in Kuwait. Although the threat of chemical weapons did not materialize, the successful waiver of informed consent raised distinctive issues for military physicians. In the absence of informed consent, should a military physician follow orders and administer an investigational drug? Another related question for the military physician is whether his or her primary responsibility is the welfare of an individual patient or the success of a military mission (Howe; Annas).

Issues posed by research on military personnel are complex. As bioethicist George Annas has argued, these issues require critical attention in peacetime, since they are "not susceptible to rational analysis in wartime" (Annas, p. 773).

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SEE ALSO: *Research, Human: Historical Aspects; Research Policy: Vulnerable Groups; Research, Unethical; Warfare: Chemical and Biological Weapons; Whistleblowing in Healthcare*

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MINORITIES AS RESEARCH SUBJECTS

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In 1984 Margaret Heckler, secretary of the U.S. Department of Health and Human Services (HHS), established the Task Force on Black and Minority Health to investigate the health status and health needs of minority groups in the nation. A year later, that panel presented its report, noting the lack of data about many aspects of minority health and the need for greater inclusion of minorities (defined as blacks, Hispanics, Asian/Pacific Islanders, and Native Americans) in medical research projects (U.S. Department of Health and Human Services, 1985). In response, the National Institutes of Health (NIH), the largest financial supporter of medical research in the United States, began to urge that grant applicants include African-Americans and other minorities as research subjects in their projects. Applicants not incorporating minorities in proposed studies were expected to provide "a clear rationale for their exclusion" (U.S. Department of Health and Human Services, 1988, p. 3). The NIH Revitalization Act of 1993 turned those suggestions into requirements that minorities (categorized as American Indian or Alaskan Native, Asian or Pacific Islander, Black-Not of Hispanic Origin, and Hispanic) must be included in all NIH-supported biomedical and behavioral clinical research projects involving human subjects, except where clear and compelling rationale and justification existed for their exclusion from such studies (U.S. Department of Health and Human Services, 2000, 2002).

The HHS task force's rationale for promoting data-gathering and research studies on minorities was both practical and humanitarian: to "understand … the reasons underlying the longstanding disparity of health status in the United States" between minorities and the majority population, in order "to prevent or reduce much of the illness and death experienced by minorities in disproportion to their representation in the American population." Those reasons, according to the report, included "physiological, cultural and societal factors" (U.S. Department of Health and Human Services, 1985, vol. 1, p. 37). Therefore, Americans needed to conduct research and gather information about the health, health environment, and healthcare practices of all citizens in order to improve everyone's health.

The African-American Experience

Historically, U.S. medical researchers included—even preferred to use—minorities (for example, immigrants from Ireland, Germany, eastern Europe, and Africa) in their research studies; not until recently, however, did they select members of these groups for the humanitarian reasons delineated in the HHS task force report. In general, researchers used minorities as experimental subjects because they were easily exploited; they studied minority health when minority health threatened the majority population (for example, in times of epidemics). The African-American health experience provides a good historical example of these research practices. While examples of the use of other racial and ethnic minorities for human experimentation in the United States may be cited individually or during certain time periods, white employment of blacks for such purposes was a consistent practice that, sadly, encompasses the entire sweep of U.S. history.

Almost from the time of white settlement of the American continent, whites noted differences between themselves and blacks in health matters such as disease immunities and susceptibilities, and reactions to medications. Self-interest was an important factor in whites' use of blacks as objects of research and study in antebellum times. The following examples illustrate that self-interest. Blacks were unwilling immigrants to the New World—they were enslaved—and were, for their white owners, an economic investment. White physicians thus needed to know as much as possible about caring for their black patients when illness struck. Furthermore, blacks, especially house servants or laborers in small businesses or farms, often worked in close physical proximity to whites. It was important for whites to recognize and study the medical differences between themselves and blacks in order to understand the risk of contracting diseases brought into their homes or workplaces by ailing slaves (Savitt, 1978). Antebellum southern physicians like Josiah Clark Nott of Mobile and Samuel Cartwright of New Orleans spent parts of their careers noting and writing about black medical distinctiveness (Breeden). They and slaveholders did mostly observational and statistical studies, occasionally engaged in physical human experiments on African-Americans, and published their ideas in agricultural and medical journals (Savitt, 1982).

After Emancipation in 1865, concern about the spread of diseases prevalent among blacks to the entire population continued to motivate whites to study black illness. They noted a steep rise in such lethal diseases as tuberculosis among the newly freed population, and predicted the decline and disappearance of blacks from the United States by the turn of the twentieth century. Morbidity and mortality studies conducted by insurance companies confirmed these dire predictions and made it difficult for blacks to obtain life insurance (Haller, 1970b; Torchia, 1977). Further, African-Americans became the object of numerous medical studies and articles (Haller, 1970a; Torchia, 1977). Physicians in the late nineteenth century reported on the state of black health in their regions or in the South as a whole. Some prominent African-Americans, W. E. B. Du Bois in particular, engaged in research on the health status of blacks and published their findings to refute the misleading conclusions whites had drawn. In particular, Du Bois pointed out the inaccuracies and unscientific approach of those researchers who purportedly found blacks' brains smaller and less developed than whites' brains; reminded readers that whites also suffered greatly from consumption (tuberculosis), alcoholism, and syphilis; and pointed out that other factors besides race, especially living conditions and economic status, influenced people's health or susceptibility to disease.

Beginning in the 1890s, a significant population shift of African-Americans from the rural South to northern cities (termed the Great Migration) increased white awareness of black health problems and encouraged physicians all over the country to study diseases that affected both groups, such as tuberculosis and syphilis (Torchia, 1975, 1977; Jones). Diseases that primarily afflicted blacks, however, such as sickle-cell anemia, discovered in 1910, were not widely studied or publicized even in the black medical and lay communities. That disinterest in sickle-cell anemia did not change until the 1950s, when it was recognized as a molecular genetic disease, the first of its kind (Savitt, 1981; Scott; Wailoo). The civil rights movement of the 1950s and 1960s further raised the consciousness of white Americans about the exclusion of blacks from many aspects of American life, including healthcare and medicine. The HHS task force report of 1985 made explicit the need to include blacks in the mainstream of U.S. biomedical research.

Use of Other Minority Groups

African-Americans have a unique history as research subjects in the United States. They were not the only voiceless minority in American history, however, and not the only group used as research subjects. In the South most of the experimental subjects were black; in the North they were usually poor, recent ethnic immigrants, like the Irish, Germans, and eastern Europeans. Many of their graves were robbed by medical students or professional body snatchers known as *resurrectionists,* and their bodies were dissected. The segregated blacks and the poor white minorities who used the public hospitals and clinics run by U.S. medical schools became the objects of experiments and of surgical or medical demonstrations by teachers on behalf of their students (Bynum; Humphrey; Lederer; Bowman). As historian of medical research Stanley J. Reiser stated about the nineteenth and especially the early twentieth centuries: "[S]ome physicians viewed hospital patients as an experimental population from whom knowledge could be gained, and on whom students could also learn" (p. 11). This was the cost to the poor of obtaining free or low-cost medical care.

Investigators felt little need to ask these voiceless people for consent to perform experiments (Lederer). Until the 1947 Nuremberg Code—the result of blatant misuse of a minority population (Jews in Nazi Germany) for unregulated medical experimentation—there was no uniform requirement for gaining consent from research subjects in medical experiments. Even after 1947, minority groups were exploited in the United States. In one often-cited example, researchers in San Antonio, Texas, studied a group of Mexican-American women visiting a clinic to obtain birth-control assistance. Wishing to discover whether the reported side effects of birth-control pills were physiological or psychological, the researchers gave one group of women a placebo and instructed them to use a vaginal cream in addition. The patients in the study did not know they might receive a placebo or that using the vaginal cream alone put them at substantially greater risk for becoming pregnant. Seven women involved in the study became pregnant (Veatch).

The Tuskegee Syphilis Experiment

The most notorious example in American history of experimentation on members of a minority group without their consent was the Tuskegee Syphilis Experiment. Between 1932 and 1972 the U.S. Public Health Service (PHS) conducted an investigation into the natural history of untreated syphilis on four hundred unsuspecting black men from Macon County, Alabama. Building their research on an 1890s study of untreated syphilis among white males in Oslo, Norway, PHS officials wished to determine if racial differences existed in the natural course of the disease. The African-American men selected for the Tuskegee experiment thought that they were part of a select group receiving special medical care. In fact, they were receiving no care at all for their syphilis.

Physicians and officials from the Alabama State Board of Health, the Macon County Health Department, and the Tuskegee Institute, as well as local physicians, cooperated with the PHS in establishing the project, shunting the unwitting subjects to government physicians for their medical care, or providing the PHS with medical facilities for physical examinations and autopsies. The experiment continued even after the Nuremberg Code went into effect in 1947, after penicillin became available for the treatment of syphilis in the 1950s, and after the PHS had instituted strict guidelines on the use of human subjects in experiments funded by the NIH and other of its agencies in 1966 (Brandt; Jones; U.S. Department of Health, Education, and Welfare; Reverby). Those guidelines were reemphasized when the Tuskegee story became public in 1972, bringing home to the medical research community the importance of obtaining informed consent from research subjects, and of avoiding bias and using caution and sensitivity when considering the need for racial and ethnic medical studies.

Current Humanitarian Approach to Research Using Minority Participants

Since the 1985 HSS task force report, numerous articles have appeared discussing results of research that included minority population groups. The dilemma researchers face in reporting and interpreting their results has now become separating innate biological factors from cultural ones as determinants of the phenomena under study (e.g., disease incidence, drug efficacy, behavioral differences). There is general agreement among researchers that race is a social construct which becomes less and less meaningful in multicultural/multiethnic societies where interbreeding over decades or centuries has occurred. Definitions of white and black, for example, differ within and among countries and often are also tied to social and economic status. Diseases and behaviors express themselves for reasons that can relate to such non-biological factors as stress, diet, and living conditions. Minorities, having once served as the misused objects of research and human experimentation because it was convenient and in the self-interest of the majority population, have again been singled out to serve as research subjects for U.S. medicine—though for different and more humanitarian reasons. Interpreting and understanding the results of medical research that includes minority groups and sub-groups has now become the challenge (Benowitz; King; Osborne and Feit; Schwartz; Witzig; Wood).

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SEE ALSO: *Holocaust; Information Disclosure, Ethical Issues in; Race and Racism; Research, Human: Historical Aspects;*

Research Policy: Vulnerable Groups; Research, Unethical; Warfare: Chemical and Biological Weapons; Whistleblowing in Healthcare

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MISTAKES, MEDICAL

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With its report, *To Err is Human: Building a Safer Health System,* The Institute of Medicine (IOM) Committee on the Quality of Health Care in America performed a commendable public service. The report dramatized the extent of a hitherto under-appreciated public problem, harm to patients because of medical error. The report estimates that between 44,000 and 98,000 deaths occur each year due to adverse medical events, that one-half of these *adverse events* are preventable, that the total cost of these medical misadventures is between 17 and 29 billion dollars, and that the events rank eighth in causes of deaths in the United States.

The report does more than locate a problem largely unrecognized by the public. It points to faulty systems, rather than individual's performance flaws, as the source of the majority of adverse events. The report also sets forward policy recommendations to meliorate the problem. The IOM recommended a triad familiar to those who study safety and post-hoc accounts of accidents: 1) training to improve the performance of personnel, 2) developing new technologies to improve the performance of fallible human operators, and 3) implementing new procedures to improve the over-all functioning of the healthcare delivery system. These changes will bring to medicine the philosophies and work routines of *total quality improvement.*. The IOM report sets for itself the laudable operational goal of halving medical errors over five years. Success depends in large part on the providers of medical care accepting the IOM's diagnosis and implementing its treatment plan. There will be resistance on both fronts. No change will occur without a re-thinking of how healthcare providers define their obligation to provide quality care.

Error as a Systems Problem

The IOM report defines error in a way most involved in patient care would find unfamiliar: "the failure of a planned action to be completed as intended (i.e. error of execution) or the use of the wrong plan to achieve an aim (i e., error of planning)" (p. 28). This definition seems to ignore uncertainty inherent in medical practice. "An adverse event is an injury caused by the medical management rather than underlying condition of the patient. An adverse event attributable to error is a *preventable adverse event*" (IOM, p.28). The IOM's definitions presuppose that what should be done is clear, that outcomes are unproblematically attributable to treatment alone, and that what constitutes an *error* is not subject to debate. Notably, Troyen Brennan, one of the researchers involved in the Harvard Medical Practice Study (HMPS) questioned whether error or preventable adverse events are easily distinguishable from more innocent treatment failures (Brennan).

While the IOM report uncritically accepts the HMPS and subsequent replications and extensions of it and uses the HMPS to shape the basis of the IOM's recommendations, researchers have raised multiple questions about the HMPS findings and their interpretation. The HMPS bases its estimates of adverse events and preventable adverse events on retrospective chart reviews. Death was among the criteria used to select charts for reviews. This raises the strong suspicion that both *outcome* and *hindsight* bias influenced reviewers's judgments of the appropriateness of care. Researchers looked at physicians's responses to patient vignettes describing identical diagnoses and treatments but varying with respect to positive and negative outcomes. In these studies, doctors are more likely to find medical error in cases with negative outcomes. Even when raters are asked to pay no attention to outcomes, they still judge the treatment with poor outcomes more negatively than when identical treatment has a positive outcome. The HMPS does not establish a direct link between specific errors and outcomes nor does it address the possibility of attribution error or spurious causality. Finally, McDonald, Weiner, and Hui, have suggested that counting deaths attributable to error, as in the IOM report, is too gross a measure. Many of those who died from the identified errors had terminal diagnoses and complex multi-system problems. A more precise measure of the burden of error may be *days of life lost* (McDonald, Weiner, and Hui). None of these criticisms suggest that medical error does not constitute a serious problem or that there is not substantial room for improving medical care systems. However, reservations about the methods and assumptions of the HMPS and the IOM report suggest that reducing medical error is more complex and may leave more room for debate than the IOM report acknowledges.

One goal of the IOM report is to shift attention away from individual professionals's performance and to focus on system performance. The report embraces *normal accident theory,* a blend of organizational and management theory, cognitive psychology, and human factors engineering to understand and explain the occurrence of preventable adverse events (Perrow). The theory holds that modern technological systems are *error prone* (Paget) and that we should think of certain mishaps as *normal accidents.* Errors and mistakes, with all their baleful consequences seldom result solely from individual failings—what Charles Perrow a leading proponent of this approach, calls *ubiquitous operator error.* Rather, errors and mistakes are embedded in the organization of complex technological work like medicine. The two structural features most important to the production of normal accidents (in medicine, preventable adverse events) are interactive complexity and tight coupling. That is, each component of the system is intrinsically complicated and each component's performance affects the functioning of other system parts. Small deviations from expected performance ramify through the system in unpredictable ways through unanticipated feedback loops creating large consequences. For a complex technological undertaking such as medicine, this is an unpleasant fact.

The IOM report focuses on a rejoinder to normal accident theory, *highly reliable organizational theory,* to remedy the problem. This approach acknowledges that errors can never be eliminated and concentrates on what organizational features allow workers to operate risky and complex technological systems, such as nuclear-powered aircraft carriers, with a minimum of untoward incidents. The theory relies on work structures that have redundancy and overlap; teams that encourage constant communication among and between the ranks; constant surveillance and monitoring for even the smallest deviation from expectations; flexible authority systems that permit even low-ranking workers to question those with the highest authority; a rich oral culture that constantly uses stories to remind workers of behavior that can create trouble; a reporting system that takes note of *near-misses* and is constantly self-correcting and non-punitive when trouble arises; and technology designed to be user-friendly and cue workers to avoid the most common errors (Roberts; Rochlin, Laporte, and Roberts; Weick; Weick and Roberts).

Error in Professional Culture

Through its pleas to end inaction regarding adverse events and its call to break the pattern of *naming, blaming and shaming* engaged in by professionals, the IOM report acknowledges the need to change the shopfloor culture of medicine. Curiously, the IOM report neglects workplace studies of physician attitudes, beliefs, and behavior. As a result, the report ignores leverage points for and barriers to change in physician culture. Worksite studies of physicians concentrate on how doctors negotiate and understand the meaning of such terms as adverse event, preventable adverse event, and *negligent error.* Their meanings are not fixed but are fluid and flexible, highly dependent on context.

One of the earliest discussions of medical mistakes, by Everett C. Hughes, suggests a rough calculus for the frequency of mistakes, based on the skill and experience of the worker and the complexity of the task. Because academic hospitals involve front-line workers (students, residents, and fellows) who may have little experience and because many of the clinical problems encountered often deviate far from the routine, one might expect to find a fair number of mistakes and errors in such institutions. However, says Hughes, hospital work is organized to control and limit the occurrence of mistakes. The organization of physician work in teaching environments also reduces the recognition of error and makes responsibility and accountability difficult to pinpoint. Hughes describes a set of *risk-sharing* and *guilt-shifting* devices that obscure exactly where in a chain of events the error or mistake occurred. These work practices include supervision, cross-coverage, consultation, and case conferences. These practices make it harder to see and correct individual mistakes, or for that matter, system errors. Errors are a feature of the workplace, and an elaborate division of social and moral labor prevents mistakes and errors from coming plainly into view.

Eliot Freidson describes the social processes used in a group of physicians to bury mistakes and to sustain a *structured silence* about mistakes. Freidson's results are striking given that the group that he observed was designed self-consciously to maintain the highest imaginable professional standards. In a setting designed to maximize surveillance by colleagues of each other's behavior, Freidson found that peer monitoring and surveillance were unsystematic at best. Referral relations structured colleagues's knowledge of one another's performance. Knowledge gathered in this way was haphazard; the two main sources for information were patient gossip and colleague complaints. Regular procedures or mechanisms for evaluating colleague performance and sharing the results of such evaluations did not exist. Once an individual physician's knowledge and dissatisfaction with the poor performance with another group member had crossed some threshold for action, few options for action were open. Freidson labeled the most immediately available informal action employed by group members *the talking to.* Colleagues confront the offender, who either clears the air with a non-defensive response or increases distrust with defensive one. If the results of a talking to were unsatisfactory, a physician could engage in a private boycott by refusing to refer additional patients to the offending colleague. The possibility of formally making a complaint and having a physician removed from the group existed but was so administratively cumbersome as not to be a realistic option. In Freidson's work we see that that notions of error, mistake, and competence are conceived within the work group at the level of the individual and that there is a general reluctance to deal with these issues through formal organizational measures.

Charles L. Bosk's *Forgive and Remember: Managing Medical Failure* examines how surgical residents learn to separate blameless errors from blameworthy mistakes in the course of their training. Errors appear blameless, largely, if they are seen as part of the normal learning process. Attending faculty anticipate that inexperienced residents will make some technical or judgmental mistakes. These errors are considered a normal consequence of providing opportunities to the unpracticed. Errors are blameworthy when, in the eyes of senior surgeons, it is difficult to sustain a claim that a resident acted in good faith. Bosk identified two types of blameworthy errors: (1) normative errors, which breach universal rules concerning physician behavior and (2) quasi-normative errors, which mark a resident's failure to conform to an attending surgeon's cherished, but often idiosyncratic, way of doing things. A source of great confusion for residents is the fact that attending surgeons treat breaches of personal preferences as seriously as breaches of universal rules. Technical and judgmental errors, so long as they are not repeated, especially on a single rotation, are forgiven. Not so with normative and quasi-normative error; residents who commit these breaches are often dismissed from training programs. This public punishment, just as Émile Durkheim (1933) long ago suggested, works: (1) as a general deterrence for the not yet corrupted; (2) as reinforcement to the norms of the group; and (3) as a device to increase solidarity among those that share a commitment to the community.

Each of the studies reviewed above has a different focus and emphasis. However, when they, and other similar research that concentrates on the dynamics of the work group, are assessed together, a number of themes to which the recommendations of the IOM Report do not give sufficient weight emerge. These themes include the following:

1. The inherent uncertainty of medical action—diagnosis and treatment are assessed in prospect, probabilistically. After action is taken results are known and uncertainty evaporates. The relation between a treatment and outcome once so cloudy now appears over-determined.
2. The essentially contestable nature of error itself—everyone knows errors are untoward events whose occurrence needs to be minimized. What medical workers do not agree on is what happened and why. In each instance, we can agree that errors, in general, are to be avoided, while disagreeing, in each instance, that this action was an error.
3. The medical profession tolerates *normal error.* Workers in the same occupation share the same difficulties and have an artful appreciation of all the factors that can create negative outcomes in the face of what otherwise looks like flawless technical performance. What medical workers have in common is an understanding of the ever present possibility for the unexpected negative outcome and a set of beliefs about work that allow such outcomes to be neutralized.

These themes underscore how, on the one hand, the IOM Report is an attempt to encourage the medical profession to take more responsibility for its obligation to the larger society and, on the other, just how difficult that task is.

Perhaps these difficulties are seen most clearly in the recommendations to increase reporting of near misses. For such reporting to be effective, however, the participants in the current system have to possess the ability to recognize the events that they need to report. Workplace studies of error demonstrate, however, that workers's ability and/or willingness to do this should not be taken for granted. Inherent uncertainty, the essentially contested nature of error, and the normal tolerance for the risks of the workplace, when combined with the intense production pressure of hospital practice all create barriers to seeing near misses. What is not seen cannot be reported. What is not reported cannot be learned from. Successful implementation of the IOM recommendation requires that the context of the workplace be taken into account.

Ethics and Medical Error

Two issues dominate the ethical concerns associated with mistakes in medicine: disclosure and accountability. However, as the preceding discussion reveals, a third matter deserves moral scrutiny: definitions of terms. We need to know what counts as error before we can conclude who has a duty to reveal what information, who has the right to receive information, and how professional and legal systems should respond to misadventure.

Classic thinking about mistakes has focused on process and outcome. People may proceed erroneously (begin the wrong operation, administer the wrong medication, fail to do something prescribed or indicated) and, through care or good luck prevent or escape harm. On the other hand, things may expectedly work out poorly for the patient (e.g., they may die, as in the previous discussion) even though, upon close examination, no one omitted appropriate actions, committed inappropriate acts, or otherwise behaved *wrongly.* In many cases of adverse outcome, one simply finds a great deal of uncertainty about what happened and why. Medicine's lack of complete understanding of disease and physiology leaves a much unexplained or even inexplicable.

At the very least, despite human desire to eliminate doubt and fix blame, the world of human medicine leaves a great deal up in the air when one wishes to say a doctor, nurse, pharmacist, or other healthcare worker erred or that a system failed. Finding egregious behavior is easy; the problems arise when an observer does not like what has happened but cannot readily point a finger at the cause.

Starting in the last quarter of the twentieth century, attitudes and practices towards disclosure of clear-cut medical error changed from guild-like self-protectionism to more forthright, perhaps preemptive truth-telling. That is, both medical ethicists and risk managers now counsel practitioners to tell patients or their legally authorized representatives (parents, guardians, among others) when an obvious error occurs. Few now suggest hiding an overdose, administration of a mismatched blood product, or some clearly preventable difficulty in the operative field. Philosophers and lawyers take a pragmatic approach here. Not only do people want to know when something has gone wrong, not only do some argue wronged individuals have a right to know, the consequences of failed cover-ups include overwhelming anger and much larger jury awards. As Sissela Bok pointed out in *Lying: Moral Choice in Public and Private Life,* in a socially complex world, including that of modern medicine, lying just does not succeed.

Note, however, that the generally accepted admonition to tell the truth often fails to provide practical help. Did the surgical assistant pull *too hard* on the retractor, resulting in a lacerated artery and a much-prolonged operation for microvascular repair? Was this negligence or something about the patient's fragile tissues? If the patient's recovery is unimpeded, does it matter? Do patients and surrogates want to know every detail of what happened? Might *full disclosure* inappropriately undermine trust? While there might be objective agreement that the degree of disclosure should somehow follow the desires or psychological needs of patients, loved ones, and legal surrogates, it is not at all clear how one determines, in advance, how much an individual or family member wants to know in a given situation.

Regarding accountability, many problems remain. If the assistant in the hypothetical operation was a surgical intern scrubbing in on this kind of operation for the first time, how does that fact influence an assessment of whether she made a culpable mistake or made an excusable error? The legal system usually acknowledges that trainees do not bear the same level of responsibility as their supervisors—much of the time lawsuits drop involved students and residents from being named defendants in malpractice actions. However, there are no reliable systems for determining how professionals or society should factor (in)experience into judgments about moral responsibility for things going awry. Bosk, in his book on surgical training, *Forgive and Remember: Managing Medical Failure,* distinguishes between technical and normative error. This distinction assists in understanding that surgeons use social and behavioral standards to assess residents's ethics, but it is not clear how the law or patients can or ought to use such an approach.

How best to respond to ethically suspect or clearly wrong behavior must also be considered. Answers here might also take into account context as well as the specific acts or omissions. How might sleep deprivation play a role in evaluating someone's mistake? Would it or should it matter if the individual's lack of sleep were a result of staying on duty in the middle of a snow storm that precluded replacement staff from reaching the hospital? Should reactions to first offenses be limited, especially for those in training? Focused (re)education may suffice for the cognitive components of error. However, whether reviews of professional standards and obligations can effectively ethically rehabilitate those who seem morally indifferent or disinclined to take their duties as professionals seriously is not really known. Finally, relatively little attention has been paid to the affective consequences of mistakes on those who make them. As Joel Frader notes in "Mistakes in Medicine: Personal and Moral Responses," routine reactions to error should include counseling and support for those involved, especially regarding the guilt and fear common following errors that have produced or nearly resulted in serious harm.

The sometimes-conflicting contemporary Western tendencies to blame/find fault, to seek revenge or at least receive compensation for tragedy, and to excuse the young/naïve/inexperienced also clash with the move toward seeing medical error as a matter of system faults. If complicated processes inevitably include both faulty O-rings and distracted practitioners, those who feel wronged cannot easily point fingers and extract their pound of flesh. Moreover, systems-thinking may itself have negative unintended consequences. First, further diffusion of responsibility, beyond teams and identifiable persons, may decrease incentives to ferret out even recurring, systematic causes of error. If someone who must stop the buck cannot be identified, perhaps everyone will stop caring about reducing the incidence and seriousness of medical error. Second, turning away from notions of individual moral responsibility may allow (even more) moral bad actors to proceed through professional educational and monitoring systems and inflict their damage on patients, family members, colleagues, subordinates, and institutions.

Possible Solutions

The above considerations do not make for obvious or easy answers to the problems of medical mistakes. Regardless of the faults of the HMPS and the IOM report, it seems clear that much medical practice, at least that occurring in the modern hospital, does involve complex technological systems with multiple occasions and places for things to go wrong. Better attention to the components of *through-put* may indeed identify opportunities to implement technical fixes and safety checks. For example, computer order-entry of medications certainly can eliminate difficulties associated with illegible handwriting. Given the right software, such systems can markedly reduce errors associated with errors in dosing, misspelling of drug names, and so on. Barcodes on medication packets and patient identification bands may lower the incidence of administering drugs to the wrong patient. Routines of repeating oral orders back to the doctor—similar to what happens between pilot and co-pilots—may clarify confusion-prone exchanges and prevent some mishaps. Such interventions will likely bring on their own problems. Almost certainly, typing orders into a computer increases the amount of time physicians have to spend at that task. The additional time and potential for (inappropriate) inferences of lack of respect involved in oral repetition may create inefficiencies and raised tensions on the wards and in the operating room.

There is a clear need to continue and strengthen efforts to inculcate a sense of individual moral responsibility into healthcare professionals. Indeed, the idea that providers owe specific duties to patients (or clients) that transcend selfish goals constitutes the essence of what it means to become or remain a professional. While the U.S. healthcare education system has more or less, depending on local culture and resources, institutionalized ethics teaching at the student level, further medical training in residencies and fellowships often lack organized approaches and/or appropriately trained or experienced ethics educators, not to mention adequate role models. Of course, ethics education assumes trainees can and do learn ethical behavior at that relatively late stage of personal development. Perhaps healthcare education and training need better systems for identifying and screening-out individuals predictably inclined to behave in undesirable ways. (Such an effort would, in turn, assume valid and reliable methods to *weed out* disfavored characteristics.)

Current systems for professional *regulation* are notoriously ineffective in recognizing and intervening when doctors misbehave, even when they do so repeatedly. In hospitals organized medical staff systems for detecting and intervening in the face of misconduct and impairment face legal fear (of libel and restraint of trade lawsuits) and patterned social inhibition (*old boy* networks and other manifestations of group solidarity, as in *there but for the grace of God go I* concern). State regulatory bodies have unclear standards, inadequate resources, and some similar solidarity-based reluctance to act. Professional associations often lack mechanisms for investigating, judging, and acting on claims of misconduct or malfeasance. Without the devotion of considerable resources and a real dedication to making mechanisms for professional social controls actually work, healthcare providers should continue to expect malpractice lawyers to thrive.

Conclusions

At the end of the twentieth century, mistakes in medicine began to receive attention appropriate to their contribution to morbidity and mortality in the healthcare system. Public policy began to concentrate on recurring, systematic underlying causes of medical error and borrow concepts from cognitive science, social psychology, and organizational behavior to address the pervasive problem of medical mistakes. Whether this approach to improving patient safety will reduce the incidence or seriousness of medical error remains to be seen, especially as industrial thinking has not paid close attention to the actual and powerful culture of medicine. Also unclear is the effect that an impersonal line of attack on the problem will have on professional morality. Too great an emphasis on technical fixes may erode the sense of personal ethical obligation to patients that society wants its healthcare professionals to hold dear.

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SEE ALSO: *Competence; Harm; Malpractice, Medical; Medicine, Profession of; Responsibility*

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MORAL STATUS

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Moral status is a concept that deals with who or what is so valuable that it should be treated with special regard. Many cases are simple. A pebble on the beach is thrown into the water without a second thought. It is one of trillions of such rocks that for billions of years have rushed in and out with the tide. Beach pebbles possess no moral standing in themselves, although certain pebbles and sand may be treated with special regard for other reasons.

But the people bathing on that same beach are totally different. To wantonly toss one of them into that same water would constitute an immoral, reprehensible act. That is because normal adults possess interests and rights that morally obligate people to highly regard their well-being. But what about the toddler experiencing her first beach day, a dog joyfully retrieving a ball, the coral reef just offshore, the seaweed within sight? Does each entity have moral status? By what criteria does society decide? And once that is settled, is moral status absolute, or do circumstances and conflicting interests make a difference?

Moral status is not a new concept, but it does constitute a new entry in the third edition of this encyclopedia. Its inclusion likely relates to the fierce battle in Western, particularly American, society over the moral status of the human embryo. This issue is perhaps the most contentious bioethical debate in the early years of this new century. It follows and is related to the abortion debate, decades old but still controversial. The moral status of fetal and now embryonic human life commands attention because it juxtaposes questions of sex, identity, faith, humanity, and healing.

In this entry, theories dealing with single standards or issues—personhood, sentience, and environment—will be delineated and then compared with a multistandard approach for resolving questions of moral status. Then, leading moral theories are applied to the societal dilemma of care for patients with Alzheimer disease.

The Moral Status of a Human Embryo

President George W. Bush, believing that protectable human life begins at conception, asked Congress in his 2003 state of the union address to "pass a law against all human cloning." This president reflects the views of many Americans. The Roman Catholic Church and a host of conservative Protestants almost uniformly hold pre-embryonic human life as sacred—and hence of the highest moral status.

William E. May, a Jesuit moralist, acknowledges a significant difference between the capacities of a human embryo and a normal adult. Human individuals of intelligence and self-consciousness are "moral beings" because they have the capacity to comprehend, love, and choose. Although they are moral beings, because they are "minded" entities, their moral status is no greater than any other human being's, because all humans, including embryos, are "beings of moral worth." All share "something rooted in their being human beings," beginning at conception. This "something" is the soul, "the principle immanent in human beings, a constituent and defining element of their entitative makeup, that makes them to be what they and who they are: beings of moral worth capable of becoming minded entities or moral beings; it is a principle of immateriality or of transcendence from the limitations of materially individuated existence" (p. 425).

Protestant Scott Klusendorf, reflecting a similar view, contrasts a human "nature" or essence with the capacity for certain "functions" or abilities. A fetus may lack functional ability, but it "is nonetheless a person because he or she has a human nature from the moment of existence."

The origin of the idea that human nature is a manifestation of an eternal essence is ancient. Its roots go back at least to Plato, and extend up through the early church fathers to Aquinas and on to the philosophers Descartes and Kant.

Religious conservatives are not the only ones who are against a medical technology that violates the human embryo. For example, secular moralist Hans Jonas is particularly concerned about a genetics technology that could produce autonomous organisms. "If it is a categorical imperative for mankind to exist, then any suicidal gambling with that existence is categorically forbidden." Out of profound respect for the human product of a long trial of evolution, Jonas protests against humans playing as "creators at the roots of our being, at the primal seat of its mystery."

Despite the fervent pleas for recognition of the preembryo's full moral status, the majority of embryologists and bioethicists favor therapeutic use. The primary bioethical rationale is twofold: the supposed minimal moral status of preembryos, and possible use of them for treating up to an estimated 128 million Americans (American Association for the Advancement of Science) with a wide variety of ills.

Both opponents and advocates of therapeutic use agree that after conception nature doesn't delimit a threshold for moral status. Opponents argue for conception, but conception itself is more process than event. In the life sciences what earlier seemed an event is now known otherwise because of advanced instrumentation that can record microscopic change over milliseconds. In light of modern embryology, Ronald Green, in his *The Human Embryo Research Debate,* argues that bioethics should recognize that certain moral presuppositions underlie the choice of an ethically significant point on the "curve of biological change." In opposing transcendental and evolutionary determinists, he contends that the very idea that personal values lead one to choose morally particular points in an ongoing biological process, "converts us from passive identifiers of biologically fixed truths to active choosers of markers on life's spectrum" (p. 26).

Common belief holds that the zygote comes into existence when the sperm and ovum unite. But just when that union occurs is now unclear. The ovum chemically signals uterine sperm, not yet in the fallopian tubes. If that invitation doesn't initiate the union, there are other options: (1) when the successful sperm penetrates the ovum wall (zona pellucida) into the egg's cytoplasm, immediately emitting electrochemical charges that seal the zona; (2) when after the eight-cell stage the paternal chromosomes become active; or (3) when syngamy (literally, "spouses joining together") occurs, the pairing of twenty-three male and female chromosomes, eighteen to twenty-four hours after zona penetration. Thus, Green states, the "moment" of fertilization is a series of processes that take twenty-four to forty-eight hours. Moreover, for the next ten days the embryo may divide, resulting in twins, triplets, or larger multiple sets of offspring (pp. 27–29).

The moral status assigned to a preembryo depends on one's presuppositions. However, most conservatives and liberals alike tend to be asymmetrical in how they view a human's moral status at life's beginning and ending. That is because human life *attains* moral status due to its *nature,* but *loses* moral status due to *function* deficit.

On the one hand, at life's beginning, human genetic nature is prized, although function is minimal. For example, a universal ban exists on use of embryos for research after their fourteenth day, when the embryonic disk is pinhead size, and has only a fifty-fifty chance of live birth eight and one half months hence. No organs exist, and neurological cell differentiation is forty days off. Viability is five months ahead and dawning self-consciousness a year away.

Yet, on the other hand, at life's end, function—or its loss—is paramount, although human nature continues to be quite evident. When an adult is pronounced dead by neurological criteria, the heart hardly ceases to beat as it is transplanted from one body into another. Death has been pronounced, though millions of neurons may still be firing, just not coordinating any vital bodily functions. Spinal cord reflexes may be sufficiently coordinated to cause spontaneous limb movement, even as vital organs are procured for transplantation.

The above opposing, contemporary notions of the moral status of human tissue—be it pre-brain or post-brain—are a concrete illustration of how diverse ethical assumptions yield different moral conclusions. Society's assigning of moral status may be quizzical to some ideal observer, for it is a complicated process which not only involves logic, but also varying cultures, traditions, and religious beliefs—in a word, civilization, in all its variety.

Leading Single-Standard Moral Theories

Contemporary bioethicists divide into two camps on moral status: those who advocate a single standard and those who are eclectic. Three leading single-standard theories concern personhood, sentience, and environment.

PERSONHOOD. The personhood standard sounds simple, but it can have such diverse and conflicting meanings that some philosophers, particularly Ruth Macklin, question the value of its use. Nevertheless, moral agents are so conscious and appreciative of their own personhood that this criterion inevitably emerges as a primary consideration. Three primary views of personhood exist: genetic, mental, and developmental.

Genetic personhood, sometimes called minimalist or low personhood, includes all human beings, regardless of age or developmental stage. Although this position is more commonly called sanctity of life, it is included here because it has an important, biologically inclusive view of personhood. The Roman Catholic Church's statement on doctrine, "Respect for Human Life in Its Origins and on the Dignity of Procreation," (Vatican) speaks of the human embryo as "the unborn child" who "must be cared for, to the extent possible, in the same way as any other human being."

John T. Noonan argues that from conception until whole brain death, human beings possess necessary and sufficient qualities for full moral status. The criterion for personhood is simple and straightforward: If your parents are human, "you are human." Although the theory is clear, the implementation of its logical implications is limited. For example, if preembryos are of highest moral status, a national assault on the natural tragedy of early spontaneous embryonic abortions (over 60% of fertilized eggs) would be appropriate—or at least a vocal bemoaning of this wanton waste of human life.

Mental personhood is the category most commonly associated with personalist theory. Mental personalists hold that an autonomous individual's brain function warrants the highest moral status. The origin of this view was the Enlightenment philosopher Immanuel Kant (1724–1804). He believed that only a moral agent possesses the autonomy and freedom to attain full moral status, so he excluded women, children, and animals because they were considered to be deficient in mental capacity.

Several modern bioethicists have argued extensively for the significance of cerebral functioning. This capacity is variously perceived to include individuals who are: self-conscious and capable of self-direction (Engelhardt), able to enter meaningful relationships (McCormick), capable of minimal independent existence (Shelp), or in possession of a minimal IQ of 20 to 40 (Fletcher). Michael Tooley, author of *Abortion and Infanticide,* argues that his notion of personhood is common sense and that most people would agree

> that anything that has, and has exercised, all of the following capacities is a person, and that anything that has never had any of them is not a person: the capacity for self-consciousness; the capacity to think; the capacity for rational thought; the capacity to arrive at decisions by deliberation; the capacity to envisage a future for oneself; the capacity to remember a past involving oneself; the capacity for being a subject of nonmomentary interests; the capacity to use language. (1983, p. 349)

Tooley not only views prenatal human life as of limited moral status, he is a self-described "radical" in advocating limited infanticide. Peter Singer, in his 1979 book, *Practical Ethics,* basically agrees with Tooley.

H. Tristram Engelhardt Jr., author of the 1996 book, *The Foundation of Bioethics,* joins with other mentalists in viewing cerebral function as of highest importance morally. But he disagrees with Tooley and Singer on infanticide. According to Engelhardt, although newborns do not possess an intrinsic right to life, high moral status is "imputed" to them because of their vital social and cultural role. Critics, such as David H. Smith (2001), argue that this concession is inconsistent.

Singer's notion of significant moral status does not include human newborns, but it does include several mammals: chimps, monkeys, and probably cetaceans. A similar conclusion on mammals is held by Mary Anne Warren and Tom Regan, who each offer different rationales.

Developmental personhood, a variation of the mentalist type, contends that the closer an entity approaches undisputed personhood, such as a normal human adult possesses, the higher the moral status. This intuitive, commonsense approach is held by thinkers as diverse as biologist Clifford Grobstein, Catholic theologian Lisa Sowle Cahill, Protestant ethicist James W. Walters, (1997), and philosophers Warren and Judith Jarvis Thomson, the latter suggesting that a "newly fertilized ovum, a newly implanted clump of cells, is no more a person than an acorn is an oak tree" (p. 199).

In his 1997 book, *What Is a Person?,* Walters advocates the notion of "proximate personhood" as a developmental scheme positing three markers to aid in more concretely identifying the aspects of moral value that indicate escalating moral status. First, potentiality for undisputed personhood is important because the embryo is unlike any other tissue. After implantation in a young woman, if development is normal, an embryo will likely grow to adulthood. Given the advances in cloning technology, the notion of potentiality may not be as significant as it was, but because the gestating fetus, featured in large full-color coffee-table books, is such a powerful symbol of life, a developing fetus connotes more about life than it may intrinsically possess.

The second marker is development toward undisputed personhood. Strictly speaking, a nine-month fetus, or even a newborn, is no more a moral agent than is an early fetus or embryo. Most people, however, intuitively view the moral status of a preembryo as different from that of an advanced fetus. The more closely a fetus/newborn approximates a normal, mature individual, the greater its moral status. It is not that the newborn possesses great intrinsic moral status, but that its moral status is bestowed because of parents' and society's need to value something so personally symbolic.

A third marker is emotional bonding of the parents to the fetus or newborn. The greater the bond, the more moral worth is ascribed to the fetus/newborn. In his 1992 book, *Freedom and Fulfillment,* Joel Feinberg views infanticide as immoral for utilitarian reasons, arguing that the common good and social utility are the moral basis for the loving treatment of newborns. This third marker of proximate personhood, "bonding of," is a social criterion, whereas "potentiality for" is intellectual and "development toward" is physical.

The mental and developmental personhood views are powerful in underscoring the salience of the human brain, without which moral discussion would be impossible. Yet people intuitively sense that there is more to moral status than abstract mental capacity. For example, brilliant sociopaths ostensibly have the highest (personal) moral status, and are treated accordingly, whereas wolves are sometimes killed by hunters. Yet wolves, sentient and highly intelligent animals, mate for life, love their offspring and that of others, work cooperatively with other wolves, never kill for sport, and often share food. The eighteenth-century Scottish philosopher David Hume claims in his *Treatise of Human Nature* that he does not know of a convincing argument for the view that thinking is superior to nest building, because each is a "wonderful and unintelligible instinct in our souls" (p. 179). Thus, as important as development toward and achievement of personhood is, common sense suggests there is more to moral status.

SENTIENCE. Contrary to personhood's focus on the intellect, a number of thinkers contend that thinking is overrated. The English philosopher Jeremy Bentham (1748–1832), in his book titled *An Introduction to the Principles of Morals and Legislation,* claims that the pains and pleasures of animals matter: "The question is not, Can they reason; nor, Can they talk? but, Can they suffer?" (p. 283). Henry Sidgwick agrees, observing in *The Methods of Ethics* (1874) that given the utilitarian goal of maximizing pleasure, it would be "arbitrary and unreasonable" to exclude "any pleasure of any sentient being" (p. 414).

Moral consideration of nonhuman animals was revolutionary 200 years ago, and it still is. Concerned about challenges to human status, physician-ethicist Willard Gaylin asserts in his 1990 book *Adam and Eve and Pinocchio*:

> The order of change between the chimpanzee and the human being is of such a magnitude as to represent a break, a discontinuity. We are not the next step, or even a giant leap forward. We are a parallel and independent entity; a thing unto ourselves; in a class of our own; sui generis.… The distance between man and ape is greater than the distance between ape and ameba. (p. 12)

The moral status of animals has varied throughout human history. In the Ten Commandments, God commanded a Sabbath rest for people and cattle alike. Yet the father of modern Western philosophy, René Descartes (1596–1650), starkly contrasts immortally ensouled humans—even madmen—with even the brightest animals, which are merely divinely created "machines" driven by organ-derived passions. The anguished crying and screams of animals are but the grinding of a machine's gears and levers.

Nevertheless, if sentience, the capacity to sense pleasure and pain, is the sole criterion for judging moral status, where in the evolutionary scale is the line between sentience and nonsentience? Rats and mice are intelligent, sentient creatures, but humans hardly respect them. Yet the nineteenth-century English naturalist Charles Darwin, who studied earthworms, considered them sentient, even capable of some form of reason. Earthworms, after a drenching rain, slither onto hard surfaces, suggesting a basic sentience. Worms have identifiable sense organs and nervous systems, unlike unicellular animals such as amoebas. Nevertheless, there is dispute among knowledgeable microbiologists even about whether single-celled organisms can be sentient, with the American zoologist Herbert Spencer Jennings (1868–1947) claiming that if amoebas were large animals and a part of everyday human experience, their behavior would suggest feelings of pain and pleasure, hunger and desire.

If a moral line cannot be drawn between humans and all other animals, and if even amoebas may possibly be primitively sentient, are we to consider all 750,000 species of animal life sentient? In *Practical Ethics,* Singer draws a line between shrimp and oysters, the latter possessing a very simple nervous system. He further argues that different species have different interests. For example, only persons are sentient, self-aware beings who can conceptualize their own futures. The great apes, and possibly cetaceans, pigs, dogs, and cats, are persons; but mice, birds, and other small-brained animals are probably not. Thus for Singer, possession of sentience is necessary for full moral status, but it is not sufficient. Highest moral status is reserved for normal adult humans.

Following the lead of Bentham and Sidgwick, Singer advances a thoroughgoing utilitarian argument for determining moral status. Singer's utility is nuanced, however, taking into account a penetrating criticism of classical utilitarianism, namely that people value ends beyond enjoying pleasure and avoiding pain. Singer's preference utilitarianism holds that an individual's good is determined by that person's preferences or values. Further, in calculating the universal good, the preferred interests of all sentient beings are weighed equally: "The principle of equal consideration of interests acts like a pair of scales, weighing interests impartially. True scales favor the side where the interest is stronger or where several interests combine to outweigh a smaller number of similar interests; but they take no account of whose interests they are weighing" (1979, p. 19).

The idea of preferences or interests presupposes at least rudimentary mental life. And if organisms care if their interests are met, they may register this in behaviors suggesting pain or pleasure. Nonsentient organisms, by Singer's definition, cannot have interests and hence have no sense of pain or pleasure. Nevertheless, the boundary between sentience and nonsentience is indistinct, at best.

The notion of interests is controversial. In his 1980 book, *Interests and Rights,* Raymond Gillespie Frey argues that only humans can have interests, because interests presuppose beliefs, and beliefs require complex language use, a singularly human capacity. Steven Sapontzis decries such moral elevation of abstract rationality in his 1987 book, *Morals, Reason, and Animals.* He shows that most people are only sometimes rational, and they live by emotion, hope, rhetoric, eccentricity, and intuition as well. Reason has no unique moral quarter, because there is no generally recognized method of rationality that commands categorical obligation.

Sapontzis argues for animal-human equality, but he especially uses *reasons* to advance his claim that reason is overrated. Thus with Sapontzis, as with most other sentience-focused thinkers, humans, at least implicitly, receive preeminent moral status. It is no mere coincidence that human beings usually end up possessing the highest moral status via the rules of moral sentience they have devised.

ENVIRONMENT. "Environmental ethics stretches classical ethics to the breaking point," declares Holmes Rolston III, a leading environmental philosopher (p. 33). The radical significance of environmental ethics is that it alone raises the issue of whether there are nonsentient entities that can be objects of duty.

This issue was poignantly raised in 1973 by Richard Sylvan's thought experiment: Imagine you are the last human on Earth and you are about to die, and the idea occurs to you of gleefully destroying the last remaining redwood tree. The ethics of this "last person" dilemma raises important issues: for example, the nature and breadth of ethics and the moral status of organisms as individuals, as progeny of ecosystems, and even as possible moral equals.

Classical ethical theory, with its focus on the individual, is typified by Kant's autonomous person as the only morally considerable end in itself. But the post-Kantian John Rawls, author of *A Theory of Justice* (1971), desires to include children and other nonrational humans in his moral universe, so he defines persons as those who have the "capacity" for rationality, even if it is undeveloped.

Like sentience-focused ethicists, other thinkers are moving beyond what Robert Elliot calls "unjustifiable human chauvinism." Of course, humans are only a small part of nature, and now the moral status of other aspects of nature—trees, rivers, mountains, rare plant species—is on the ethics horizon. Environmental ethics challenges society to risk exploring uncharted terrain, to go beyond anthropocentric culture. Advocates contend that it is more serious than rights for rocks, citing how revolutionary the early steps leading to rights for women, children, and ethnic minorities were. With the increasing rate of environmental deterioration, these new thinkers suggest that environmental ethics is as important as medical or business ethics. Rolston contends that the planet's deterioration is as great a threat as nuclear war—and more probable.

Max Oelschlaeger, editor of *Postmodern Environmental Ethics* (1995), perceives a "linguistic turn" in contemporary ethical reflection. No longer is language seen as mirroring the real world; language is inseparable from humans' personal spaciotemporal culture. Language is not representative of an independent reality but rather plays an "ontogenetic" role in defining the human, "meaningful world." Humans are more "biologically underdetermined" and more culturally driven than previously thought. The ecocrisis originates in and is sustained by the older conception of language. Calling for a postmodern consciousness of language, Oelschlaeger suggests that "modern ethical theory is linguistically naïve" (pp. 2–9). He decries the separation of theory and practice, advocating a new cultural language of, above all else, environmental sustainability.

Individual organisms and complex ecosystems. On both deontological (duty-oriented) and utilitarian grounds, extending moral status to sentient beings makes sense. But on what basis is life itself the threshold of moral status? If speciesism (the moral elevation of a species simply because of its nature) exists, by a similar logic the charge of "sentientism" applies to animal rightists who would arbitrarily prohibit extension of moral consideration to all of life.

Animals can and should experience a good life, but biocentrists believe the standard for moral status is too high. They point to how interests can be served and harms avoided by letting all organisms fulfill their unique ends—loosely specifiable biological goals whose fulfillment results in a type of flourishing. Plants have no subjective life, only an objective one. "Nothing matters to a tree, but much is vital to it," says Rolston, who is an advocate for a "vital ethic" (p. 34). Deep, or thoroughgoing, ecologists explain that to act contrary to the purposes of a plant means that one impedes the plant's biologically given goals.

Whereas anthropomorphism holds that all moral status somehow relates to human well-being, biocentrism sees all life as possessing moral status. Paul Taylor and Gary E. Varner argue for biological individualism—that each organism of life possesses intrinsic value. That each organism possesses independent value follows from the premise that each organism's flourishing makes the world a better place.

Further, Taylor is a species egalitarian in that he sees all criteria that devalues any life-form as an equally arbitrary, immoral imposition. Varner agrees that all living things have intrinsic moral value, but contends that not all live entities are morally equal. He believes that it is softheaded to think that pulling a carrot is as wrong as killing a horse. A plant has only biological needs, whereas a horse also has sentient interests in life, and a human can possess complex interests that are not found in lower forms of life.

Unlike Taylor and Varner, most environmental philosophers tend to be holistic rather than individualistic. That is, they express more moral concern for ecosystems and species than for individual living things. Rolston rejects the confines of classical ethics, in part because of its fixation on individual entities: "In an evolutionary ecosystem, it is not mere individuality that counts; the species is also significant because it is a dynamic life-form maintained over time. The individual represents (re-presents) a species in each new generation. It is a token of a type, and the type is more important than the token" (p. 35).

Can moral status be assigned to ecosystems? If so, then logically the moral standing of a species would likely trump almost, if not all, claims of individual animals or plants when there is a serious conflict. Most environmentalists are primarily concerned with preserving evolutionary processes, and this involves predation that could sometimes be stopped by human intervention. Natural ecosystems appear to exist beyond the moral categories that have served anthropocentric interests in the past. Only environmental ethics challenges society to sort out maxims between conventional anthropomorphic morality and urgent planetary needs.

Multi-Standard Theory

In the postmodern era, confidence in single theories of right and wrong has diminished. Because academics keenly sense the historical conditionedness of every human construct, it is no happenstance that leading moral philosophers are eclectic in moral theory.

As indicated above, however, there are very thoughtful single-standard thinkers. In his 1989 book, *In Defense of the Land Ethic,* J. Baird Callicott, for instance, consciously rejects ethical eclecticism because in hard cases it inevitably leads to "moral incommensurability." This occurs because competing moral claims employ differing terms that thwart decisive comparison and resolution.

Nevertheless, a powerful case is made for a more modest, multi-standard theory. In Rawls's influential *A Theory of Justice,* the basis for choosing ethical theory is "reflective equilibrium." Rawls develops this concept in the context of arguing for an "original position" of personal anonymity hypothesized behind a "veil of ignorance," from which one chooses ideal norms of justice. The conditions of that initial situation are generally shared and "preferably weak." Those conditions are Socratically conceived, working "from both ends," going back and forth, altering conditions of the original position, making and withdrawing judgments.

One postulates reasonable conditions and assumes principles that finally match one's "considered judgments duly pruned and adjusted." This conceptual give and take is Rawls' reflective equilibrium: "It is an equilibrium because at last our principles and judgments coincide; and it is reflective since we know to what principles our judgments conform and the premises of their derivation." Rawls's notion of justice does not come from self-evident premises or principles; "instead, its justification is a matter of the mutual support of many considerations, of everything fitting together into one coherent view" (pp. 20–21).

Following Rawls' lead, Tom L. Beauchamp and James F. Childress, in *Principles of Biomedical Ethics* (2001), develop their own coherence theory. They too begin with "considered judgments," basic societal warrants, such as religious tolerance, that are accepted at first without "argumentative support." An ethical issue, considered in light of one's paradigmatic considered judgments, prompts a careful, nuanced assessment and then a more general account of the issue's moral warrants. All elements considered, one weighs and trims, cuts and adds, attempting maximal coherence. The resulting action guides are never absolute, however, and if their inadequacy is too great the process of finding appropriate norms begins anew. Regardless, ethical coherence is dynamic, as continually "we revise, generalize, specify, and balance moral beliefs" (pp. 397–400).

Warren, in her carefully reasoned 1997 book, *Moral Status: Obligations to Persons and Other Living Things,* advocates a "Multi-Criterial" theory, a commonsense, pragmatic approach to determining moral status, appealing to her readers' moral intuitions. It is such common/good sense intuitions, she notes, that give rise to ethical reflection and judgment in the first place. Warren argues that the burden of demonstrating the inadequacy of a society's given morality—its faulty reasoning or inadequate empirical data—rests on those who would challenge it.

Commonsense morality gains empirical support from the faltering of many single-standard advocates when confronting hard cases. Single-standard theorists are indispensable in focusing attention on society's specific moral inadequacies. These theorists often blink, however, when their theories are pushed to the limits; they often fail to take their rationales to their logical conclusions. For example, Roman Catholic thinkers do not call for a huge medical initiative against early naturally aborted human embryos. Engelhardt modifies his high-standard personhood by "imputing" moral status to human newborns. And Taylor argues for the equality of all life-forms, but if mosquitoes were spreading malaria, would he morally disallow eradication efforts?

The case that Warren makes for a "sliding scale" of moral status appeals to the basic moral intuitions of many people. The evolutionary scale extends from amoebas to normal human adults, with the more neurologically complex beings accorded greater moral status.

Despite its appeal, the multi-standard approach also has its downside. It can easily provide an ethical justification for the moral status quo. For example, despite Warren's argument for heightened sensitivity to the relative moral status of all organisms, she provides justification for several practices that many humane persons find morally objectionable: meat eating (and thus implicitly, factory farming), sport hunting, and sometimes caging animals. Acceptance of each of these practices is carefully nuanced, but their practice, according to Warren, can be a moral option.

Another related problem with a multi-standard, common morality is that by its very nature it fails to foster morally prophetic voices. Perhaps society's view of moral status is best served by a chorus of voices articulating various conceptions of moral status, thus stimulating careful thought about an array of viewpoints. In this way, democratic societies foster humane progress in ethical sensitivity. The relevance of competing bioethical theories is tested by many real-life dilemmas, not least of which is the modern scourge of Alzheimer disease.

Individuals with Alzheimer Disease

Concomitant with the advantages of longer lifespans is today's challenge of Alzheimer disease. Of course, the moral status of the newly diagnosed Alzheimer patient is very high, but what of the individual with severe Alzheimer disease? The case of Alzheimer disease is a fitting condition for comparison of the four leading theories' indications of moral status.

PERSONHOOD. The genetic variety of this theory would appear to be simple: As long as there is organic life, there is high moral status. However, the Vatican, holding the genetic view on perinatal life, favors a natural death in senescent cases. Mental (and developmental) personhood theory puts a premium on the moral standing of the fully competent person, suggesting that the registered wishes of an autonomous person for his or her care as an Alzheimer patient should morally hold.

An important unresolved issue, however, is whether the will of the fully competent person should trump the desires of the partially demented patient when a discrepancy exists regarding future care. In her response to Ronald Dworkin's autonomy argument for the fully competent person, Rebecca Dresser argues that the partially competent patient's current desires should be heeded, because the patient's present condition was not clearly foreseen, and, given that the patient will never return to full competence, these wishes should override earlier directives.

SENTIENCE. Sentience theory aims to maximize pleasure and minimize pain in all sentient creatures. As an Alzheimer patient's senses wane, moral status similarly decreases. To avoid speciesism, this view is egalitarian in that whatever treatment is good for nonhuman animals is appropriate for Alzheimer patients of similar sentience. Singer argues for equal consideration of interests, but not all interests are equal. Self-conscious beings receive "prior consideration," as they have a heightened capacity for suffering—or for happiness. In a different vein, Singer, who argues strongly for voluntary active euthanasia, says that it should be banned if the consequences of nonvoluntary euthanasia in demented patients would lead to "insecurity and fear" among possible future dementia patients (1979, p. 139). In practice, mainline personhood theory would assign a lower moral status to a moderately advanced Alzheimer patient than would sentience theory. This is because in Alzheimer disease, incompetence in reasoning precedes incapacity for sensual experience.

ENVIRONMENT. Given environmental theory's priority on the biosphere and ecosystems, the moral status of individual Alzheimer patients, it would seem, is hardly on the ecological radar screen. Nevertheless, environmental theory has considerable, albeit indirect, relevance: This iconoclastic theory dethrones the rational man (and it was *man* in the Enlightenment) as the exclusive measure of moral status.

Rawls continues the anthropomorphic scheme in *A Theory of Justice,* making an aside to demented individuals: "Those more or less permanently deprived of moral personality may present a difficulty. I cannot examine this problem here, but I assume that the account of equality would not be materially affected" (p. 510). Rawls's and previous philosophers' social contract models have fostered equality and other human goods, but this model's purview is narrow. According to Mary Midgley, in her 1995 article titled "Duties Concerning Islands," the social contract is a valid aspect of common morality, but it now dominates ethics, whereas ordinary people see moral claims more broadly. Midgley proclaims that humans have real moral duties to an array of entities beyond "sane, adult humans": for instance, the dead, the insane, embryos of all animals, artifacts, rivers, countries, landscapes, and the biosphere. By casting the moral net far beyond adult humans, Midgley shatters the wall dividing rational persons from the rest of life, thus supporting at least the relative moral status of all Alzheimer patients.

MULTI-STANDARD. Stephen Post exemplifies an ethical eclecticism in his extensive writing on Alzheimer disease. Like environmental ethical theorists, Post decisively rejects the identification of moral status with rationality. In his *The Moral Challenge of Alzheimer Disease,* he criticizes modern society's "hypercognitive" values of rationality and memory. Post appears to be against mainline personhood ethics, calling Alzheimer patients "persons" and citing them as Earth's neediest people who deserve "preferential moral significance." Post may be more personalist than he knows, however, because in the Dworkin–Dresser debate he sides with Dworkin's contention that the fully competent person's wishes trump the later, counterexpressions of a demented mind. And, further, Post equates being a valuable human being with one's capacity to "will, feel, and relate." Overall, however, Post is closest to the sentience camp because after the Alzheimer patient advances beyond a sentient state, he sees invasive, life-prolonging treatment as an "assault" on a patient oblivious to its purpose. As long as the Alzheimer patient can sense any pleasure in life, loved ones should embrace this live, sentient individual in light of what was once so much more. No vitalist, Post concludes the second edition of his book as follows: "Death is not the enemy; the only real enemy is the burden of technologically protracted morbidity under conditions of severe dysfunction" (p. 142).

Why a particular entity is treated with special regard, thus receiving a certain moral status, is dependent on what ethical standard one holds—personhood, sentience, environment, or ethical eclecticism. And why a person embraces one standard rather than another is finally a metaethical issue (literally, an issue beyond ethics; an issue involving one's religious or philosophical worldview). In liberal societies the existence of various foundational religious and philosophical positions ensures continued lively discussion of moral status, made possible by a consensus that other persons have significant moral status, thus allowing for such social debate.

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MORMONISM (CHURCH OF JESUS CHRIST OF LATTER-DAY SAINTS), BIOETHICS IN

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The religious movement that has become known worldwide as *Mormonism* began in an obscure region in New York State in the 1820s. The founder, Joseph Smith, Jr., declared to both followers and opponents that he had, beginning at age 14, received a series of visions and revelations from God, Jesus Christ, and angelic messengers. Smith maintained that through these divine ministrations, he had received authorization to "restore" the gospel of Jesus Christ in its purity and fullness to the world (*Pearl of Great Price* (PGP)). A principal form of tangible evidence for Smith's divine call was the production of a new scriptural record, called *The Book of Mormon,* which related an account of God's promises to the peoples of the western hemisphere. Smith, as well as close associates, stated that he had translated the text from inscribed golden plates through divine inspiration, and the Book of Mormon was published in 1830 (*Book of Mormon* (BM)). The terms Mormon and Mormonism derive from the title of this book, although the terms were most frequently invoked as epithets by opponents of the new religion.

Ecclesiastical Overview

In April 1830, Smith organized the *Church of Christ* in Fayette, New York. An aggressively evangelistic religion from the beginning, the new church gained adherents and inspired animosity as it gradually followed the westward migration of the American frontier, moving its central locus to Ohio, Missouri, and Illinois during the next fifteen years. Smith continued to receive revelations, which were first compiled in 1835 into another new record of scripture, entitled *The Doctrine and Covenants.* In 1837, Smith was instructed to call the organization "The Church of Jesus Christ of Latter-Day Saints" (LDS), the title by which the religion is formally known today. This title contains four defining themes:

(1) *Church*—The organization was deemed to be the repository of divine truth and ritual practices necessary for the salvation of human beings.

(2) *Jesus Christ*—The church was to understand itself as authorized and governed by the resurrected Jesus Christ, and not to take its identity from a book (the Mormon church) or a person. A theocratic hierarchy was established within which Joseph Smith (and his successors) were acknowledged as "prophets" or spokesmen through whom Christ would reveal his will for the church and for the world. Their ecclesiastical office and responsibility was portrayed as similar to that of Moses for the people of Israel (DC).

(3) *Latter-Day*—Church teachings were to emphasize a millenarian eschatology; the world was considered to be in its "final days" prior to the return or "second coming" of Jesus Christ.

(4) *Saints*—All members of the religion were to be known officially as "saints," as was deemed the practice of early Christianity.

The population concentration of communities of saints in what were at the time sparsely settled regions of the frontier often led to conflicts with previously-existing institutions, including churches, business, and political systems. Smith was frequently imprisoned, typically on charges of sedition or for posing threats to public morality. On one such occasion, in June 1844, Smith and his brother were murdered in a jail in Carthage, Illinois. After a period of controversy over Smith's successor, the senior member of the remaining ecclesiastical leadership, Brigham Young, assumed the role of presiding officer of the church and eventually was acknowledged as the "prophet" (Arrington and Bitton).

Beginning in 1846, Brigham Young led the LDS migration to a geographically isolated, and hence, religious oasis, founding Salt Lake City and other communities in the Great Basin and Rocky Mountains. Indeed, within the next three decades, fueled in large measure by emigrants from the British Isles, Young was responsible for organizing over 350 settlements in what are now seven states.

It also fell to Young to make a public announcement of the religious practice that would make the religion a pariah for the next seventy-five years, "plural marriage" or polygamy. Joseph Smith had initiated this practice among leading church elders in the 1840s. Smith prayed over the question of why the biblical patriarchs Abraham, Isaac, and Jacob, as well as the kings David and Solomon, had been allowed to have plural wives and concubines. The divine answer, he claimed, was a revelation regarding the "new and everlasting covenant of marriage," which included the eternal bond of the marital and family relationship, and permitted the "sealing" of faithful males to additional wives in special circumstances (DC). Plural marriage continued to receive formal endorsement by Smith's successors until 1890, when a *Manifesto* issued by prophet Wilford Woodruff officially renounced the practice (DC). In the intervening period, the U.S. government passed several laws that permitted the confiscation of ecclesiastical property and fines and imprisonment for practitioners. Despite well over a century of emphasis on monogamous marriage and the nuclear family, the polygamy legacy continues to be part of the public identity of the LDS religion. Indeed, splinter groups continue the theology and practice of polygamy in remote areas of southern Utah, and northern Arizona and northern Mexico.

In the post-polygamy era, ecclesiastical leaders made a concerted effort to move the church into the mainstream of American religious culture and social life (Bush, 1993). It sought to portray itself as exemplifying the work ethic of the larger culture, while ensuring a welfare program for those unable to work. Leaders advocated the family unit, structured around heterosexual marriage, as not only divinely required but a social necessity. The historical hostility to political and legislative paternalism was gradually transformed into a committed patriotism, with the U.S. Constitution portrayed as a divinely inspired document to be defended.

The acculturation of the LDS church to American civic mores was accompanied by the continuation of evangelism virtually worldwide. Since the middle of the twentieth century, church membership has grown eleven-fold to just over 11 million adherents, the majority of whom reside outside the United States. The twenty-first century internationalization of what was a very small and exclusive movement in the nineteenth century is the most significant ecclesiastical challenge at this time.

Scriptures, Authority, and Agency

As indicated previously, a distinctive feature of the LDS religious tradition from its inception is its explicit acceptance of continuing divine revelation, including an "open canon" of scripture. There are four recognized books of scripture, collectively known as *the standard works,* in that they provide "the standard" against which truth and error can be discerned. The source of Joseph Smith's original questioning about religious truth was the *Holy Bible;* in ecclesiastical practice and discourse, the King James Version is used as authoritative. The Bible does not have preeminence in the faith, however; that distinction is claimed by the *Book of Mormon,* which was described by Smith as "the keystone of [LDS] religion" (p. 194). An *article of faith* (comparable to a creedal statement) written by Smith in response to a query about the basic beliefs of the religion asserts: "We believe the Bible to be the word of God as far as it is translated correctly. We also believe the Book of Mormon to be the word of God" (PGP, p. 60).

The two books in principle are held to be theologically complementary, and both are considered authentic renditions of ancient history. *The Bible* is portrayed as the story of the word of God and the covenants of God's people in the Semitic, Hebraic, Jewish, and Hellenistic world. The *Book of Mormon* is considered to be the story of God's word and the covenants of his people among the original inhabitants of the continents of the Americas (c.a. 2000 B.C.E.–400 C.E.). At the core of both texts, the tradition believes, is a testament of Jesus Christ as Savior of the world. Indeed, responding to long-held perceptions that Mormons were not Christians, the *Book of Mormon* was given a subtitle in the 1980s, *Another Witness of Jesus Christ.*

A third authoritative text is *The Doctrine and Covenants,* which is comprised of some of the revelations and writings of Joseph Smith from 1823 to 1844, as well as some additional proclamations, declarations, and revelations promulgated by Smith's successors and accepted by the ecclesiastical body as canonical. The most recent addition to this book occurred in 1978. A fourth book, known as the *The Pearl of Great Price,* was not officially accepted as scriptural until 1880. It contains writings on the Genesis creation narrative attributed to the biblical figures Abraham and Moses, as well as a short history authored by Joseph Smith about his religious experiences.

These four texts constitute the ecclesiastical standards for assessing both sacred and secular knowledge. They are not, however, self-interpreting or always directly applicable to situations that individuals may confront in everyday experience. A second distinctive feature of the LDS religious tradition is that it relies on a lay clergy, which is hierarchically organized under the direction of two bodies of ecclesiastical leadership known as *The First Presidency* and *The Quorum of the Twelve Apostles.* These groups, typically comprised of fifteen males, were originated by Joseph Smith and are the principal resource not only of ecclesiastical governance, but also for scriptural interpretation (DC). In a tradition that does not have any formally trained priests or theologians, the scriptural interpretations rendered by the *general authorities* as these groups are called, are indispensable authoritative guides. Moreover, the LDS canon makes it clear that when general authorities speak as moved by divine influence, their words are the "ecclesiastical equivalent" of canonized scripture. The tradition is emphatic in claiming that God's words and works are "endless," and cannot be fully contained in one book, or even four books, but also include the words (and actions) of these ecclesiastical leaders (DC, PGP).

Divine influence is not confined to such leaders, however. Each baptized member receives a blessing that enables that person to receive the companionship of the divine spirit for his or her own personal, familial, religious, and even vocational, roles in life. Indeed, LDS scripture teaches that each person born into the world is given the capacity for "moral agency." Moral agency grants to capable persons the freedom of making decisions about moral right and wrong, virtue and vice, and good and evil. There are safeguards, however, that prevent a collapse of moral agency into subjectivism. First, while individuals are free to choose their actions, they cannot freely choose the consequences of their choice, and will be held accountable (by conscience, peers, God, etc.) for their actions. Second, the tradition teaches that human beings are more apt to choose the good and virtuous through relying on divine influence, whether that is manifested in the form of individual discernment or revelation, or from teachings of ecclesiastical leaders, or from the canonical scriptures. The concept of moral agency overlaps in important respects the bioethical principle of respect for autonomy; these similarities and differences will be highlighted in the section below on bioethical questions.

The Christian Status of Mormonism

Joseph Smith, Jr. insisted that he was an instrument in God's hands in restoring the good news or gospel that Jesus Christ had preached, as recorded in the *New Testament* and then practiced in the primitive Christian church. Smith's message of restoration was, however, often perceived by others as a demonic perversion of Christian faith. As Smith wrote of the response to his first vision, a minister "treated my communication … with great contempt, saying it was all of the devil, that there were no such things as visions or revelations in these days; that all such things had ceased with the apostles.…" (PGP, p. 50). The question of the Christian status of Mormonism has remained an enduring issue and source of controversy since the latter's inception.

Smith also maintained that the fundamental principle of the LDS religion concerned the redemption of humanity through the suffering, death, and resurrection of Jesus Christ, a theological claim that would seem to be in harmony with traditional Christian doctrine. However, Smith's call to restore and proclaim this gospel to the world in its last days presupposes that contemporaneous Christian religions had departed in some way from Jesus's invitation to salvation. As LDS theology developed, primarily in the formative years from 1830 to 1844, substantive differences with traditional Christian thought emerged over such matters as:

The nature of the Trinity;
The concept of the Fall and original sin;
The redemptive efficacy of Christ's sacrifice;
The necessity and timing of baptism;
The relationship of grace, faith, and works;
The presence of spiritual gifts (such as prophecy and healing);
The authority of extra-biblical sacred writing;
The source of ecclesiastical authority;
The meaning of divine revelation.

In the judgment of most Christian writers and denominations, LDS answers to these issues of orthodoxy, or right belief, have been cumulatively sufficient to place the tradition outside the boundaries of the Christian communion. This judgment has been reinforced by attitudes about particular LDS practices and rituals. Most prominently, these included the revulsion (informed by mores of the Victorian age) against polygamy, the LDS practice of which confirmed judgments of doctrinal deviation. Moreover, LDS evangelical zeal, with its presumption of privileged access to divine truth, seemed to run contrary to the emerging ethos of ecumenism and respect for religious pluralism. LDS evangelistic exclusivity has been reinforced by ritualistic exclusivity: The most sacred of LDS rituals, including the covenant of marriage, are performed in *temples,* special houses of worship that are not accessible to the public.

To be sure, in an age of increasing acceptance of religious pluralism, the Mormon version of the Christian message no longer seems to elicit a pariah designation among most mainstream Christian denominations in the United States. The Christian status question is currently most compelling among evangelical Protestant churches, particularly in areas of the world where there is evangelistic *competition* for converts.

Indeed, the evolving internationalization of the LDS Church has stimulated interest about commonalities and differences with the classical world religions, including Buddhism, Hinduism, Islam, and Judaism, as well as many indigenous faiths. Historically and conceptually, the LDS tradition situates itself within the Abrahamic family of religions including Islam and Judaism, as well as Christianity. However, LDS scripture indicates that God has provided religious truth to all peoples (BM); figures such as the Buddha, Confucius, Lao Tse, Mohammed, and Moses, as well as sacred writings such as the Qur'an or the Upanishads are considered prophetic figures and revelations of divine wisdom for their specific cultures and eras.

Worldview and Bioethics

LDS teachings on bioethics are embedded within a comprehensive worldview of divine design, human destiny, and ultimate meaning. Within LDS discourse, the worldview is most commonly referred to as "the plan of salvation." It includes the eternal nature of the self, the pre-mortal existence of persons, mortality as an educational and probationary realm, and genealogical research and liturgical rituals to offer salvation to individuals who have died.

PRE-MORTAL LIFE. A distinctive teaching of LDS theology is that all persons are spirit children of God, in whose presence they lived as individual selves in a life prior to mortality. During this pre-mortal existence, human spirits received instruction about their eternal nature and destiny, and the necessity of experiencing mortality. In this realm, all spirit selves subsequently born on earth made a defining use of their moral agency, choosing to accept God's plan for salvation articulated by and embodied in Jesus Christ.

This narrative of human origins informs certain LDS perspectives on bioethics questions at the beginning of life. The plan of salvation requires that all spirit children of God experience mortal life. This narrative is connected, in direct and indirect ways, to judgments on such issues as procreation and contraception, reproductive technology and abortion, and use of pre-conceptual and pre-natal genetic testing (Campbell, 1993).

MORTALITY. In the narrative of salvation, mortal life has very specific purposes. Mortality first of all provides each of God's spirit children with a physical body. In contrast to theological dualism or Cartesian mechanism, LDS scripture asserts that the human "soul" is constituted by spirit *and* body (DC).

Second, mortality is the proving ground for the responsible use of moral agency. Mortal life is unavoidably made of encounters that require persons to use their agency. These choices, to one degree or another, manifest the extent of their fidelity to their pre-mortal promise to follow the plan of God. The commandments articulated by God's Son and by God's prophets illuminate the ultimate purpose of these choices.

These mortal purposes and choices set out further LDS perspectives on bioethics issues. The theology of embodiment underlies positions on procreation, transplantation, and a health code known as *the Word of Wisdom* (DC). This teaching emphasizes a healthy diet through consumption of such things as herbs, fruits, and grains, as well as the discriminating use of meat, which is to be *used sparingly,* only in times of excess hunger and cold. The prohibitions of the Word of Wisdom are more culturally familiar, and more ecclesiastically enforced; they include specific prohibitions on the use of tobacco, consumption of wine or strong drink (alcohol), and *hot drinks* (which tradition has interpreted to refer to coffee and tea) (Bush, 1993).

Although there is, as described below, general ecclesiastical guidance on numerous bioethics issues, in almost all circumstances, this guidance directs adherents to rely ultimately on their personal moral agency. The two circumstances in which ecclesiastical teaching restricts or proscribes agency concern the intentional taking of life in abortion and euthanasia.

RESEARCH AND RITUALS FOR THE DEAD. The plan of salvation is universal in scope—God seeks to redeem all his spirit children—but is respectful of moral agency. All persons, regardless of their cultural or temporal epoch, must receive a fair opportunity to be educated about the plan, and the restoration to God's presence through the redemption offered by Jesus Christ. Persons cannot be held responsible for complying with theological commandments and moral standards about which they have no knowledge. With this knowledge, persons are positioned to enact their agency most fully. This understanding provides a theological warrant for a principle of informed consent.

LDS teaching acknowledges that its evangelical programs notwithstanding, in point of fact relatively few persons have received this opportunity during their mortal sojourn. What of those billions of persons who have lived and died without awareness of the gospel of Jesus Christ and its restoration? A defining mission of the LDS Church is to encourage its members to participate in genealogical research and trace ancestral lines. Such research intends, in part, to identify deceased persons who have not been informed of the story of salvation. This education, LDS scripture maintains, occurs through evangelization in the post-mortal world of disembodied spirits (DC). Meanwhile, living persons assume the role of proxies for the deceased and perform essential liturgical rituals of salvation, such as the covenants of baptism and marriage. Moral agency for the living is coupled with presumed consent for the dead to manifest the universal and eternal reach of the divine plan.

Specific Questions in Bioethics

Formal LDS engagement with contemporary medical ethics can be traced to a June 1974 ecclesiastical document entitled

Attitudes of The Church of Jesus Christ of Latter-Day Saints toward Certain Medical Problems. This statement was developed in the aftermath of the court decision in *Roe v. Wade* (abortion rights) and promulgated in 1977 in the wake of *In the Matter of Quinlan* (right to die). A good portion of the document was eventually incorporated into the general policy manual of the church, *The Church Handbook of Instructions* (CHI), and soon became an authoritative basis for local ecclesiastical leaders (Bush, 1979). These attitudes have undergone generally minor modifications in the intervening years in response to pastoral concerns and developments in biomedical technology and its professional regulation. What follows is a short overview of current guidelines on nine questions of bioethics shaped by issues at life's beginning and ending.

LIFE BEGINNINGS. ***Abortion.*** The LDS Church "opposes elective abortion for personal or social convenience" (CHI, 157). *Exceptions* to this prohibition may occur in circumstances where (1) medical prognosis confirms that continuation of the pregnancy places the life or good health of the mother in serious danger; or (2) the pregnancy is a result of rape or incest; or (3) a medical finding that "the fetus has severe defects that will not allow the baby to survive beyond birth" (CHI, p. 157).

Artificial Insemination, In Vitro Fertilization (IVF), and Surrogacy. The responsibility for resorting to artificial insemination by husband (AIH) or artificial insemination by donor (AID) should be determined by the married couple. The major ecclesiastical concern has to do with third-party gametes and about a supportive family structure for the child. Thus, both AID and IVF using donor gametes are "strongly discouraged," as such may complicate family harmony, but in both circumstances, ecclesiastical concerns acknowledge that the ultimate responsibility for such a decision is left to the married couple. Sperm donation and surrogacy are likewise strongly discouraged, but no decision-making latitude is explicitly recognized. The strongest ecclesiastical concern is directed to AID for single women, which "is not approved," and may incur ecclesiastical discipline (Hinckley).

Contraception. Of any LDS ecclesiastical teaching on medical ethics, the position and rationale regarding contraception has undergone the most extensive revision in the past quarter century. The moral agency of the couple is affirmed: "The decision as to how many children to have and when to have them is extremely intimate and private and should be left between the couple and the Lord" (CHI, p. 158).

Sterilization. Current ecclesiastical policy affirms: "The Church strongly discourages surgical sterilization as an elective form of birth control" (CHI, p. 160). Surgical sterilization is a consideration only in circumstances of (1) medical conditions that seriously jeopardize life or health, or for (2) persons who are mentally incompetent and not responsible for their actions owing to experiencing a birth defect or serious trauma.

LIFE ENDINGS. ***Cremation.*** Currently, cremation is "not encouraged" as a matter of ecclesiastical policy, but the final decision about disposition is entrusted to the agency of the family.

Dissection and autopsy. The contemporary ecclesiastical attitude is framed in terms of *permission*—autopsies may be performed—provided the following procedural guidelines are fulfilled: (1) compliance with applicable law, and (2) consent of the deceased's loved ones or family.

Euthanasia. Even as civil and professional society has become more tolerant of euthanasia and physician-assistance in suicide, the ecclesiastical attitude has become more rigid (Campbell, 1994). The 1970s term *mercy killing* has been discarded in current teaching and replaced by a definition of euthanasia: "Euthanasia is defined as deliberately putting to death a person who is suffering from an incurable condition or disease" (CHI, p. 156). This definition also encompasses "so-called assisted suicide." Resort to euthanasia is considered to "violate the commandments of God," although ecclesiastical instruction does not specify which commandments are contravened.

Transplantation. The donation of bodily organs for post-mortem transplant or research is a matter for individual conscience and agency.

Treatment termination. There is no obligation to "extend mortal life by means that are unreasonable" (CHI, p. 156). The determination of *unreasonable,* and implicitly, *reasonable* means is a matter for family determination, who may engage in prayer and fasting to receive divine guidance, as well as consult with professional caregivers, about end-of-life decisions. While there is no explicit ecclesiastical direction on the subject of advance directives, both the silence on the subject and the LDS cultural attitude that preparation alleviates fear suggest they may be appropriate mechanisms for members faced with end-of-life choices.

Ecclesiastical instructions on the above issues are very cryptic and do not provide explicit theological rationales for the conclusions addressed (e.g., the general prohibition of abortion makes no reference to the moral status of the fetus). However, as described above, these teachings are embedded within the broader LDS worldview of the plan of salvation, and this suggests some principles that the bioethics conclusions seem to presume, or without which the ecclesiastical teaching is incoherent. These principles include respect for moral agency, embodiment, family integrity, protection of the vulnerable, the sanctity of human life, and stewardship (Campbell, 1992, 1994). Some important issues in bioethics that are noteworthy for their omission in both ecclesiastical guidance and LDS writing in general include research on human subjects (as well as stem cell research), genetic screening and therapy, access to health care, and determination of death.

COURTNEY S. CAMPBELL

SEE ALSO: *Authority in Religious Traditions; Christianity, Bioethics in; Family and Family Medicine; Natural Law; Women, Historical and Cross-Cultural Perspectives*

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Encyclopedia of Bioethics, 3rd edition

Stephen G. Post
Editor in Chief

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NANOTECHNOLOGY

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Imagine a world in which manufacturing and medical treatments take place solely at a molecular level, a world in which human bodies are reengineered to include more durable tissues or to reverse past injuries. These are some of the dreams motivating scientists and engineers pursuing the field of nanotechnology. As the name implies, nanotechnology involves the engineering or manipulation of matter, and life, at nanometer scale, that is, one-billionth of a meter. (Ten hydrogen atoms side by side span 1 nanometer; the DNA molecule is 2.3 nanometers across). If feats such as those mentioned above were possible, then the structures of the human body and the current tools of humankind could be significantly altered. In recent years many governments around the world, including the United States with its National Nanotechnology Initiative, and scores of academic centers and corporations have committed increasing support for developing nanotechnology programs (Glapa).

The Birth of an Idea

The idea behind nanotechnology originated with Nobel laureate Richard Feynman in a speech he gave to the American Physical Society in 1959. He described the development of tools for molecular engineering, whereby things would be built molecule by molecule. He proposed, as a challenge to his colleagues, the writing of the entire *Encyclopedia Britannica* on the head of a pin. His startling claim was that this sort of task would not require a new understanding of physics and was completely compatible with what scientists already understood about the nature of force and matter. Little was done in response to the Feynman challenge until the publication of works by K. Eric Drexler in the 1980s and 1990s. Drexler demonstrated the feasibility of such manipulation from an engineering perspective and provided a vision for the possible benefits of such technologies.

What Could Nanotechnology Do?

The list of potential uses of nanotechnology continues to expand. The primary focus of research at this point concerns miniaturization of electronic components (Bachtold et al.; Hornbaker et al.), but nanoscale materials may dramatically improve the durability of materials used in machinery and could result in less polluting and more efficient production methods. The U.S. military has a significant interest in nanotechnology and has created the Institute for Soldier Nanotechnologies (ISN). Among the initial aims of the ISN is to create stealth garments (and coatings) that are difficult to see or detect, are highly durable, and provide increased protection from penetrating objects. The institute aims to develop devices to rapidly and accurately detect biological or chemical weapon attacks. The ISN is also interested in using nanotechnology to help seamlessly integrate electronic devices into the human nervous system—creating the cyborg soldier.

There are many possible medical uses of microscopic, subcellular machines. Medical applications of nanotechnology include rational drug design; devices specifically targeting and destroying tumor cells (McDevitt et al.) or infectious agents; in vivo devices for the manufacture and release of drugs and for tissue engineering or reengineering at the site of need; early detection or monitoring devices; in vitro diagnostic tools amounting to a laboratory on a chip (Park, Taton, and Mirkin); devices to clear atherosclerotic lesions in coronary or cerebral arteries; and biomimetic nanostructures to repair or replace DNA or other organelles. Nanotechnology might be used to provide artificial replacements for red blood cells and platelets (Freitas, 1996), to augment or repair interaction between neurons in the brain, to improve biocompatibility and the interface between brain tissue and cybernetic devices, and to develop more durable prosthetic devices or implants (Drexler, 1986; Drexler and Peterson; Freitas, 1999; Crandell; BECON). Such tools have also been envisioned to provide new means of cosmetic enhancement, such as controlling weight, changing hair or skin color, removing unwanted hair, or producing new hair simulations (Crawford). Also, some of the potential therapeutic uses previously listed would lead to more effective treatment of life's greatest killers, such as cancer, infectious disease, and vascular disease, leading in turn to greatly enhanced human lifespans.

One other possible project to arise from nanotechnology has become the focus of a rigorous debate among members of the nanocognoscenti. This controversial device is the self-replicating assembler, which was first envisioned by Drexler in 1986. The assembler is in essence a form of artificial life, for not only would it manipulate its environment on a molecular or atomic level, as other nanomachines would, but it would also be coded and designed to replicate itself, potentially making endless copies of itself. Alternatively, nanomachines could be designed to function more as viruses, using the mechanisms in other living cells to help duplicate constituent parts and assemble them into a new machine. While it is beyond the scope of this entry to detail the elements of the debate between those who contend such devices can and will be developed and those who adamantly claim that Drexlerian assemblers are a physical impossibility, the assembler is an excellent starting point for the discussion of the ethical aspects of nanotechnology.

Ethical Issues

The ethical issues of nanotechnology can be grouped into five categories:

1. the challenges of prospective technology assessment and regulation;
2. environmental impact of nanotechnologies;
3. issues of justice and access to the goods and services that might accrue from nanotechnology;
4. the ethical and social implications of increased longevity that might result from medical nanotechnology; and
5. the issues of augmentation or enhancement of human attributes and function.

Accidents, Abuses, and Regulation

The vision for medical uses of nanotechnology is exciting, and if only a portion of the proposed devices prove possible, nanotechnology may benefit many thousands of patients. Any device that can operate on the subcellular level, however, can just as easily be designed to destroy as to repair or heal. In fact, it will be far easier to develop devices that kill. One of the first applications of medical nanotechnology involves a device that can target and destroy cancer cells. Despite the arguments over the feasibility of creating assemblers, it is not a far stretch to envision nanoscale weapons that could be borne on the winds or delivered through the water or food supply. Even if not self-replicating, such devices, with appropriate targeting or with the ability to synthesize toxic substances once inside the host could prove to be quite lethal or disabling. If assemblers were ever created, with the ability to self-replicate like bacteria, then the level of personal or environmental harm could be substantial.

Concern over the potential military or terrorist use of such technology, which could ultimately be fairly cheap to produce, and thus impossible to sufficiently regulate once in existence, has led some (even within the technology community) to contend that the only safe way to proceed is to choose not to develop the tools and methods of nanotechnology at all (Joy). In this view, the only way to prevent the potential devastating harms of a technology, or the consequences of malicious use of knowledge and technology, is to not develop the technology, or acquire the knowledge, in the first place. Arguments of this type, however, assume the burden of proving:

1. that the projected abilities of the device in question are possible to achieve;
2. that the feared harms cannot be prevented, controlled, or mitigated to an acceptable degree;
3. that it is feasible to achieve universal consensus that the area of technology and/or knowledge in question should not be pursued; and
4. that such a prohibition can be sufficiently policed.

In the case of the first issue, it seems very likely that biological nanodevices will be developed, most likely using a so-called bottom-up approach. That is, existing biological molecules and organelles will be used as models for creating tools to achieve the desired function, or these "natural" materials will be used in new ways. An example of this is a project that involved the conversion of the ATPase molecule, ubiquitous in living cells, into a molecular motor (Soong et al.). Therefore, because the development of functioning biomechanical nanodevices is highly probable, it is morally imperative to prospectively evaluate the possible impact of these technologies as they are being developed, so that appropriate safeguards can be implemented to protect against accidents, unanticipated consequences, or inappropriate uses of the technology.

While many disagree with Joy's conclusions, his concerns for the potential harms that autonomous technology could produce are legitimate. It is his response to the second issue, the likely ability or inability to control or protect against foreseeable or unforeseeable harms, that has led to the most dissent. Concerns have been raised that autonomous, self-replicating assemblers could escape control, and/or mutate, in such a way as to destroy life and the environment on a massive, cataclysmic scale. This is Drexler's (1986) so-called "gray goo scenario." In a 2000 article, however, Robert A. Freitas Jr. calculated that this nightmarish scenario is unlikely because of the ability to detect the activity of such biovorous devices early on and to neutralize them. In the early days of recombinant DNA research, there were many concerns about releasing lethal plagues into the environment, quite similar to a number of the concerns being voiced about nanotechnology. Yet the scientific community responded strongly and wisely to the challenges of DNA research, establishing procedural safeguards that remain in use (Krimsky; Fredrickson) and that serve as a model for developing and containing potentially harmful technologies.

Pursuing a similar course of prospective risk assessment and guideline development, the Foresight Institute published the "Foresight Guidelines on Molecular Nanotechnology" in 2000. The guidelines remain voluntary recommendations, but they could be used as a framework for formal regulation and licensing of biologically active nanodevices. Some of the recommended design principles include: (1) dependence on a single fuel source or cofactor that does not exist in the natural environment; (2) requiring constant signaling from an external source for the device to continue functioning; and/or (3) programming termination times (similar to apoptosis in living cells). While it is hopeful that all responsible researchers and engineers would embrace suggestions such as these, there will need to be formal regulation with serious economic, licensure, and punitive penalties for failure to comply. Additionally, the granting of licenses to perform research in nonlaboratory settings or to market nanodevices, as well as the awarding of patents, should be contingent upon proof of the ability to detect and destroy the devices in both in vitro and in vivo settings.

The idea that humankind could reach universal agreement to limit or forbid certain areas of research is naive, and very unlikely to happen, particularly when the field of knowledge in question may lead to vast improvements in health, lifespan, productivity, and so on. Even if consensus could be achieved, policing such restrictions will be essentially impossible. The force of curiosity, as well as the stubborn human heart's universal propensity to rebel against restriction, will ensure that the research will indeed take place, just not as rapidly as it might have otherwise. Rather it is wiser to direct the development of the technology in such a way as to prepare defenses concurrently along with the devices themselves. It is only in this way that humankind and individual societies can be prepared to meet the threats of terrorism, accidents, and other calamities resulting from the creation and/or abuse of a particular technology.

The Nano-Improved Human

As mentioned above, medical nanotechnology may provide exciting tools for healing injured tissue, repairing DNA, and treating neoplastic and infectious diseases, as well as for cosmetic applications. It is conceivable that some nanodevices may also be used to strengthen normal tissue; to manipulate certain DNA strands to alter traits; or to augment mental function, either via enhanced electronic interfaces at the cellular level or by direct stimulation of certain neural pathways. These latter possibilities immediately bring up difficult questions.

Should such uses of bionanotechnology be permitted? If they should, should the medical profession be involved with nonhealing, elective augmentation, and if not, then who should? Should people be allowed to use health insurance to cover the cost of such interventions? How can just access be ensured otherwise? Such augmentations, if successful, would create significant differentials in performance in the workplace, physical abilities, and so on. Consequently, the wealthy would get stronger and wealthier, further increasing their advantage over those who might not be able to afford the technology in question.

In his 1999 book *Nanomedicine,* Freitas suggested that nanotechnology, and by implication other potentially augmenting technologies, requires a new concept of disease that transcends the classic model of disordered function. He calls this new model the volitional normative model of disease, and he described it as follows:

> Disease is characterized not just as the failure of "optimal" functioning, but rather as the failure of either (a) "optimal" functioning or (b) "desired" functioning. Thus disease may result from:
>
> 1. failure to correctly specify desired bodily function (specification error by the patient),

> 2. flawed biological program design that doesn't meet the specifications (programming design error),
> 3. flawed execution of the biological program (execution error),
> 4. external interference by disease agents with the design or execution of the biological program (exogenous error), or
> 5. traumatic injury or accident (structural failure). (Freitas, 1999, p. 20)

While encompassing traditional understandings of disease, this model additionally takes disease out of the context of an objective pathophysiological assessment and turns disease into whatever the patient defines it to be. Any limitation or undesired trait may now be declared disease. Though ostensibly continuing the contemporary trend of patient self-determination to a new level, this approach is fraught with both danger and injustice. To declare that a condition is disease imposes a moral claim that services ought to be rendered for its modification, elimination, or amelioration. The balance between beneficence (the obligation to do good) and nonmaleficence (the obligation to prevent harm) may be inappropriately tipped to what the patient desires, rather than needs. Physicians would be reduced to agents of wish fulfillment and to technicians, rather than remaining healers. These issues already exist to some degree in the area of cosmetic surgery but will expand to involve most other areas of medicine as well. Further, claims to "treatment" would unjustly deplete healthcare resources and funds, potentially depriving those in real need of legitimate healing.

Conclusion

Nanotechnology offers exciting new tools for materials processing, more powerful and integrated electronic devices, and new medical therapies. Nanodevices, however, may also become instruments of harm, and they require prospective regulation and engineering to prevent both foreseeable and unforeseeable negative consequences. Nanodevices join a number of other developing technologies that offer the potential to alter or augment the human body. A prospective, widespread discussion of the implications of these technologies for the human species, the profession of medicine, and the world's communities should occur as soon as possible.

C. CHRISTOPHER HOOK

SEE ALSO: *Biomedical Engineering; Cybernetics; Enhancement Uses of Medical Technology; Human Dignity; Transhumanism and Posthumanism*

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NARRATIVE

• • •

Human beings are a narrative species. We tell stories incessantly; we read and listen to them, watch them unfold on screen and stage. In making and absorbing narrative—news, gossip, fiction, drama, anecdotes, and history—we spin and untangle explanatory accounts of the way the world works and how we and our fellow human beings act in every conceivable circumstance. Memories of the past and ideas of the future are expressed in narrative accounts of how the world was and how it will, or should, become. Individual identities and self-conceptions are packaged in life stories, part (and heirs) of larger family, community, and national stories that shape the life events and choices to become the chapters that follow. There is even evidence that narrative, rather than simply a creative use human beings have found for language, is instead the motive for its acquisition: Young children learn to talk in order to give some account of occurrences in their daily lives (Bruner).

For the most part, the word *narrative* is used interchangeably with *story* to designate a more or less coherent written, spoken, or (by extension) enacted account of occurrences, either historical or fictional. *Story,* however, is used more often, especially informally, to denote spoken and fictional accounts, while *narrative* emphasizes the inclusion of nonfiction or indicates a contrast with visual or numerical data, as in historiography or book production or computer science. *Narrative* tends to be used generically in literary theory, perhaps following the Russian formalist and French structuralist distinction between *story* and *plot,* where *story* designates the events, and *plot,* the ordering of those events in the literary or historical account. Thus, the story of Oedipus begins with the prophecy his parents receive before his birth; the plot of Sophocles' play begins when, years later, he learns from the same oracle that the plague that afflicts his city is punishment for the unavenged death of the old king. Narrative refers to the whole and implies, for any particular telling, the inseparability of plot and story.

As it orders events, narrative asserts or connotes some causal relation among those events and imputes character and motives to the actors (Forster). Yet, despite this linearity, conclusions are never foregone. As narrative depicts events embedded in the lives and concerns of its protagonists, circumstances unfold through time in all their contingency and complexity (Ricoeur). Whether it is the life story essential to moral understanding (Burrell and Hauerwas; MacIntyre) or the political history of a nation (White), narrative explores the way cause and effect are entangled with the variables of human character and motivation, with luck and happenstance. When moral principles or political generalizations are abstracted from events without the use of narrative, those details are left behind as inessential, even though for those involved such particulars may represent what is most valued in a life or a history. Narrative remains mired in the particulars of human experience. From its designation of certain details as relevant "facts" and certain occurrences as "events" to the use of rhetorical strategies in the representation and description of those facts and events, narrative is concerned with the construction and interpretation of meaning.

Narrative and Medical Knowledge

Because narrative is the primary way of organizing and communicating the sense human beings make of the world, the interpretive process integral to shaping and understanding a story is at the heart of human knowing. Thus, the investigation of narrative forms and practices is a fruitful way of understanding how knowledge is acquired and transmitted. To understand medical knowledge—whether the patient's illness, the physician's practice, ideas of causality, issues of medical ethics, or activities of clinical research—it is helpful to look at the historical and explanatory narratives patients and practitioners tell themselves and each other (Charon, 1986, 1994; Hunter, 1991; Miles and Hunter).

Clinical medicine is a radically uncertain field of knowledge. Based on human biology, a science more complicated and multileveled than physics or chemistry, medicine has the task of applying scientific knowledge to the care of individual human beings. Not only does the living matter of biology change—the influenza virus mutates annually, tuberculosis and gonorrhea become drug-resistant, HIV gains purchase in the human community—but even more reliably, illness, that is, the manifestation of disease in human beings, varies unpredictably from person to person. Despite the triumph of the germ theory, "disease" remains a label given to a complicated interaction of physiological phenomena—none of which need be a necessary or sufficient cause—in circumstances identified and construed culturally, socially, and personally. Much about disease can be known scientifically, if not entirely predictably; but both the patient's illness and his or her response to treatment remain complex events with multiple causes occurring in circumstances that are impossible or immoral to replicate.

Given such uncertainty, narrative in its various guises is essential to the scientific practice of medicine. Patients relate the history of their illness when they present themselves for medical attention; disease plots make up the clinical taxonomy found in textbooks; their variant subplots are stored in physicians' memories; written accounts of medical care preserved in charts fill hospital basements; case reports contribute, one by one, to clinical research. In the physician's office where patients are well known and practice is solitary, narration may dwindle to a nearly invisible minimum. But in academic medical centers where medicine is taught and research carried out—just where one might expect to find narratives banished by the ever-present concern for scientific objectivity—narrative flourishes. The clinical case is not only the record of care but the mainstay of clinical education and academic discourse. Cases are presented at morning report, at teaching rounds, patient-care conferences, grand rounds, ethics conferences, informally in halls and locker rooms, and around lunch tables. The case record is compiled in the hospital chart by several hands. When anomalies occur, the case becomes the vehicle for communication and further investigation that may lead to sustained clinical or laboratory research. As the translation and interpretation of the patient's account of illness, augmented by further investigation, the medical narrative enables clinicians to apply scientific knowledge and therapeutic judgment to the understanding and relief of illness in particular human beings.

The case thus constitutes the scientific data in the investigation and treatment of a patient's malady. Confronted with the signs and symptoms, guided by the patient's story, the physician asks questions, sorts the information into a list of possible diagnostic plots, and then sets to work to eliminate from consideration the least probable and most life-threatening and to confirm the most likely. The goals of this medical retelling of the patient's story are representational: fidelity to the clinical observation of the patient and minimalization of the observer's (and the patient's) subjectivity. To this end the conventions of the medical case are strict and almost inviolable. The narrator is all but effaced, appearing only as a signature authorizing the passive voice, while the patient's experience is subordinated to the medical retelling of illness events and physical signs, a version that resolutely ignores the fear and bewilderment, the loss of control, and the suffering that may attend the experience of illness. This is not meant to be cruel; it is meant to provide the patient with an objective gaze that is capable of establishing with some certainty what the matter is so that treatment may begin and, with luck, health may be restored.

The physician's familiarity with other cases grounds the investigation and, indeed, the whole interpretive, diagnostic circle. Whether read and heard about or, better, observed and directly experienced, these cases make up an intellectual storehouse backed by the myriad of information accumulated in publications and through consultation. Well understood and ready to hand, this body of practical knowledge enables physicians to apply physiological principles, textbook summaries, and clinical wisdom to signs and symptoms presented by individual patients, testing each particular case against those established, more abstract patterns. There are no all-encompassing laws of disease, and physicians must learn not only operative rules and their variants, but also the habits of perception that narrative enforces, habits that will stand them in good stead for a lifetime of practice in a field where knowledge and practice constantly change—and new diseases appear. The case narrative is the means by which such a store of exemplars is assembled both in formal education and in practice (Dreyfus and Dreyfus), and is the medium for the consultation, further investigation, and publication that are the hallmarks of modern academic medicine.

Narrative and Bioethics

The centrality of narrative characteristic of clinical medicine is shared with other case-based disciplines of knowledge, such as law, moral theology, and criminal detection. In these domains, knowledge is not simply a "top-down," theory-driven activity. Research must be conducted retrospectively, and knowing is interpretive, accumulated from the experienced scrutiny of many individual instances in the light of general rules. The case—a term common to them all—functions as both exemplar and test of more general formulations: legislation, ethics, criminology, and biological science. In everyday practice, "in the trenches," these generalizations are extended or refined as they are applied, and practical expertise is developed in the continual search for more nearly adequate rules.

Narrative is also central to bioethics. Not only does it provide an opportunity for imaginative moral reflection for its audience, it is equally the proving ground of moral argument. Although the contemporary study of bioethics, especially medical ethics, until recently has focused almost exclusively on principles (Beauchamp and Childress; Pellegrino), the applicability of moral principles is inevitably gauged against the particular case, and cases regularly provoke the careful study and refinement of the rules. Indeed, the rehabilitation of casuistry—dealing with questions of right and wrong—has been the work of philosophers in bioethics (Toulmin; Jonsen and Toulmin; Jonsen).

The role of narrative in moral life is well established with regard to literature (Horace; Coles; Banks). Along with history, which is also strongly narrative, fictional narrative has long been regarded as a moral teacher—especially in that most narrative of eras, the nineteenth century. Both literary theory and historiography have struggled against this assumption of moral didacticism in the twentieth century. French historians of the *Annales* school and American cliometricians (mathematical and statistical analysts) have attempted to reduce the narrative element in history writing in favor of numerical data—the records of glacially slow and macroscopic social change for the former, and a microanalysis of economic statistics for the latter. In literature, from the "art-for-art's-sake" movement at the turn of the last century through Dadaist experimentation to the frequently reported "death" of the novel, twentieth-century writers defied critics to draw morals from their stories. For much of the century, literary critics, too, eschewed moralism in favor of the aesthetics of "the work itself," relegating morals to a matter of folk tales. Thus, it was oddly fitting that when structuralists reanimated a critical concern with narrative it was necessary to turn to Vladimir Propp's *The Morphology of the Folktale* (1968; Todorov; Brooks). More recently, literary theorist Wayne Booth and philosopher Martha Nussbaum have made strong cases for literature as the medium of moral knowledge.

Literature's usefulness for moral reasoning lies not only in its themes and characters—those elements the McGuffey Readers drew upon for the "morals" that concluded their tales—but also in the interpretive reasoning it requires. As in clinical reasoning, narrative negotiates the application of general truths about human experience to the individual case. Readers know that murder is evil, but they turn to *Macbeth, Crime and Punishment,* or *Native Son* to reflect on precisely why and how. At the same time, narrative also tests such moral truths. Its representation of the particular instance asks implicitly whether circumstances can ever be extenuating; it negotiates on behalf of ethical inquiry, as it does for medical diagnostics, the imprecise and uncertain fit between general rule and particular instance.

The narrative that constitutes the bioethics case likewise plays a role in moral reasoning. The purpose of constructing and presenting a case in bioethics should not be limited to the illustration of a rule or principle any more than in medicine (Arras; Donnelly). It is rather to set out accounts of events in order to explore imaginatively their meaning for the people they affect and to determine what action should be taken. Because narrative's representation of subjective experience gives its audience access to the perception and judgment of other human beings, good ethics cases offer a means of thinking about the meaning of illness in the life of the patient, and about the role of the physician and the meaning of a patient–doctor interaction in the life of the physician. These are traditional themes of literature, and beyond literature—the themes of the unwritten stories, the gossip, and the self-revelation—that convey and test social values and give texture both to individual lives and to culture. To read and listen to stories and to watch them enacted on screen and stage is to open the understanding to the experience of other people, and to the meaning that experience has for them. Physicians do the former all the time, asking their patients about pain or the history of an illness, talking about the effects of disability or the likelihood of death. But imagining the meaning of experience for other people is very difficult and rarely undertaken (Kleinman; Waitzkin); for physicians, traditional, professional reticence and self-protection are obstacles (Katz). The desire for just this sort of understanding from another person, especially one pledged to a certain disinterested concern, informs both nostalgia for the legendary general practitioner and Anatole Broyard's request that his physician "spend five minutes thinking about my case" (1992). A longing for an interpreter who will both hear our stories in all their physical starkness and nevertheless see in us human subjects, people who create meaning in the story of our lives, may underlie the burgeoning interest in medical ethics. The public discussion of troubling cases—in the mass media, in the courts, in drama and film and autobiography, and in ethics courses—reveals a narrative hunger for meaning in the face of death. Indeed, Walter Benjamin (1936) has located in death's certainty the closure that narrative meaning requires.

As in clinical medicine, the use of narrative in bioethics is necessitated by the limits of human knowledge, and an attention to narrative enforces an awareness of these limits for both narrator and audience. Not only does the audience understand that the narrator's knowledge is limited, but, in addition, both narrator and audience know—or soon learn—that the knowability of the narrated is limited (Hunter, 1993). What happens next? Then? And then? The unfolding of narrative through time captures the contingencies of causation, the radical uncertainty of the most ordinary life, the uncontrolled variables that resist attempts to regularize and codify social knowledge. More questions may yield more information, yet uncertainty is best met not by the pursuit of every elusive clue, but by a sense of the balance of knowledge and tolerable ignorance sufficient for action. Although always accountable to social and cultural norms—indeed, these norms are operating in the framing and interpretation of narratives—moral knowledge is inevitably subjective, always open to question, discussion, elaboration, retelling, and reinterpretation.

In bioethics as in clinical medicine, narrative knowledge is always situated knowledge. Just as every malady has its patient, every tale has a teller—either the voice of an omniscient author or a character who has been witness to the events—and every narrator has an audience, imagined or real, to whom the story is addressed. Narratives are enmeshed in the circumstances of their telling, even when, as with clinical cases, the form is specially designed to extricate itself from those circumstances. Cases do not drop pure and untouched from the sky, nor do they contain a truth or essence that could be revealed if only the circumstances of their telling were stripped away. Instead, they are narratives constructed and presented by human beings who are making an effort to be understood—or to deceive, to impress an audience, or to reinterpret an event. Even stories meant to be perfectly transparent—medical cases, news reports, ethics cases—are framed by their all-but-invisible tellers and interpreted by their audience. Though the narrator may be a disinterested and impartial observer, there is nevertheless a standpoint from which the story is told (Chambers). Some things will be emphasized or privileged, others will be out of the narrator's view. While norms exist and exert their force, they do so variously and unpredictably, and determining how they do so is one of the tasks that readers and listeners undertake. Narrators are revealed to their audience, in part, by the stands they take in relation to both the norms of society and the conventions of the narrative genre. This tension between tale and teller (or tale and the untold) is always a part of the narrative.

Where the sense of events offered by a narrative is contested or where its interpretation is in doubt, the narrative itself comes under scrutiny. The reader or listener begins to ask about the narrator and the narrative frame. Who is telling the story—the physician, the patient, a family member, an ethicist? Why is it told? In what circumstances? How does the teller frame the story to include or ignore culture, history, life stories, power relations, economic conditions, the history of the present question? Because an understanding of the problem turns upon the answers to these questions, this is where the study of ethical discourse must begin (Chambers, 1994). Cases may be narratively impoverished and morally inadequate even when bioethical principles are followed and apparently right conclusions are reached.

Through narrative, bioethics partakes of an ongoing dialogue among human beings perceiving and acting in the world. This is not a theoretical but a practical activity with strong resemblances to the clinical epistemology of which medical-case narrative is a part. As in medicine, the "facts" are sometimes of uncertain relevance and the circumstances may not be replicable, but the representation of experience through time acknowledges and puts to use the inevitable subjectivity of human understanding (Ricoeur). The subjectivity and apparent relativism unavoidable in narrative openly represents one of the conditions of moral discourse. There is no neutral position or Archimedean platform beyond nature from which a narrator, cleansed of bias, may see "truth" or "reality" in all its uncluttered purity. Indeed, narrative may be most valuable as a guarantee against this positivist assumption, for an awareness of narrative and its workings is a constant reminder that there is no absolute truth, no certainty. For the most part, stories are relatively straightforward about the conditions of their acquisition and telling. They make no pretense to objectivity—or when they do, the pretense is readily apparent as yet another storytelling genre. Narratives can be questioned: The potential prejudices of the narrator's situation beg to be understood. The interpretation of narrative may be one of the few ways human beings have of seeing our customary blind spots as both narrators and interpreters. As Ernst Hans Gombrich (1960) observed about the perception of art, there is no innocent, no "naked eye." And if there is no sight without a lens, it can become second nature to inquire into the character and quality of the lens in any particular instance—and to adjust it as needed.

Narrative exists in dialogue with other narratives, other interpretations—including the principles that, distilled from accounts of good and evil, have come to represent those accounts. Stories are not a substitute for norms and principles, just as clinical medicine does not replace medical research and case law does not render legislation irrelevant. Historians know well that every story implies an answering account, one that will surely—at last!—set the record straight. If the physician tells the patient's story, no one truly believes that it is the only story that matters; nor is the patient's story sufficient; otherwise the patient would not have sought medical help. The two are in dialogue. The goal is not a synthesis or a determination of a "truth" that will swallow up other accounts, but a sustainable representation of incommensurability, a consensus that may be acted upon. Ethics is practical knowledge, forged experientially and honed on circumstance. It is practiced in the negotiation of story and teller, story and listener, story and answering story. Because, in narrative, inquiry is inseparable from explanation, narrators and audiences must test the sources of our stories, compare versions, and sustain a healthy skepticism about answers. Thus, narrative represents the conditions of moral discourse, even as it is the principal medium of that discourse.

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SEE ALSO: *Ethics: Moral Epistemology; Health and Disease: The Experience of Health and Illness; Literature and Healthcare; Metaphor and Analogy; Value and Valuation*

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NATIVE AMERICAN RELIGIONS, BIOETHICS IN

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Using the phrase "Native American" signals a recognition that there are indigenous peoples on the North American continent who retain distinct ethical perspectives within the mainstream cultures of the United States and Canada. Terms such as "First Peoples," "American Indian," and "Amerindian" are also used to refer to the indigenous peoples of the Americas. Each term has a history of use and limitations in its reference. For example, there are no actual people who call themselves Native Americans in their traditional language; rather, there are distinct ethnic groups who were on the North American continent prior to the arrival of Europeans, Africans, and Asians. Prior to contact with European settlers in the fifteenth century, it is believed, there were over 2,000 different native communities on the continent. Over 700 of these ethnic groups have survived repeated invasions, epidemic diseases, cultural genocide, and ideological exploitation. Thus, when we use the term "Native American," it is at a general level of understanding and reference that is fictional and conceptual. A deeper understanding of Native Americans must move to another level of reference, beginning with the names by which indigenous peoples know themselves.

In this entry the following system will be used. The indigenous name will be followed by the popular name in Canada and the United States. The peoples who call themselves Anishinabe are also known as Chippewa/Ojibwe, Ottawa, and Pottawatomi. In some instances, there are historical and sociological reasons for differentiating specific tribal names among a larger nation such as the Anishinabe. So also, the term Haudenosaunee, or "Long-House People," is the name of the northeastern North American peoples whom the French called Iroquois. Either term is often used to indicate individual nations within the Haudenosaunee political confederation, or "long house": Seneca, Cayuga, Onondaga, Oneida, Tuscarora, and Mohawk. Other examples can be listed: Apsaalooke/Crow; Tsistsistas/Cheyenne; Muskogee and Miccosukkee/Creek; Dine/Navajo; Ashiwi/Zuni; Tohono O'odham/Papago; and Skittagetan/Haida. This usage recognizes the right of a people to be known by the name by which they describe themselves.

The term *religion* raises a similar ethical concern; it carries associated references that can mislead an inquiry into Native American ways. The term *religion* derives from the Latin *religio,* "to bind fast." Traditionally this has carried associations from its Mediterranean-Atlantic heritage, namely, to be reunited, after a pilgrimage through life, with the personal, monotheistic, creator God who transcends earthly existence. The connotations of monotheism, the one deity as personal and transcendent, and a pilgrimage orientation to life are embedded in the term *religion* for many Euro-American Christians.

In contrast, the term *lifeway* emphasizes the road of life as indigenous people see it. Such a perspective can be associated with the concept "worldview," a distinct way of thinking about the cosmos and of evaluating life's actions in terms of those views. The Dakota/Sioux lawyer and professor of history Vine Deloria, Jr., speaks thus of an Indian ethical view of the universe: "In the moral universe all activities, events, and entities are related, and consequently it does not matter what kind of existence an entity enjoys, for the responsibility is always there for it to participate in the continuing creation of reality" (Deloria, p. 63). This view understands all life forms as having purpose, as being related, and as being cocreators of the world they occupy. The religious structure that flows from these views gives rise to a moral imagination in which the sacred is immanent, within the earth, and revealed in one's contemplation of natural occurrences. All life in one's local bioregion is both interdependent and participating in the act of creation evident, for example, in the changing seasons. The term *bioregion,* is used here to suggest the Native American reverence and respect for all life forms in the local region. Indians have traditionally understood their local bioregion as filled with moral purpose, interrelated, and alive.

Cosmic Interdependence

Moral actions in Native American lifeways are acts in harmony with a sacred power that is believed to pervade the world and is experienced most immediately in the local bioregion. While moral actors are not limited to the human community, any particular human is seen as integrated into the larger harmony by means of his or her community. Someone who has committed a crime is not made into an outsider by virtue of an isolated act. Rather, the one who is out of balance must be brought back, if possible, into the community by ritual treatment with that power believed to pervade the cosmos.

Native peoples in North America have articulated terms such as Wakan Tanka (Lakota), Kitche Manitou (Anishinabe), or Akbatatdia (Apsaalooke), which convey an understanding of the mysterious presence and fullness of pervasive cosmic power. These terms have often been used by nonnative missionary traditions to communicate ideas regarding the sacred, especially belief in a personal God. While such usage may be sanctioned by Christian native peoples, some traditional practitioners object to this interpretation as misleading. Sacred power, and the native terms used to evoke that mystery, do not indicate a patriarchal deity but emphasize the web of cocreative relationships throughout the spiritual realms and the ecological terrain, or bioregion. This pervasive power is experienced in a plurality of manifestations, or spirits, that relate to the presence of transformative power in distinct spiritual realms of the cosmos but especially to the local bioregion. Thus, Native American lifeways may be described as manifesting an "ethical naturalism" in which moral choices flow from the desires of individuals and communities to flourish within the limits and opportunities of nature as understood by the people and as typically observed within the particular bioregional conditions of a people (Lovin and Reynolds).

Synthetic Ethics

Questions of the relation of ethics to ritual and myth are also analytical themes in the study of religion, but in Native American traditions these questions are inextricably linked. This article will attempt to communicate this ethical wholeness by describing practices related to both ritual and the daily life of native North American peoples. One term used throughout this entry, *synthetic ethics,* refers to the Native American effort to bring people into the most immediate and profound encounter with resources for thought and for food: the bioregion, the animals hunted, the human community, the seasons, and the spiritual realm.

Synthetic ethics signifies the seamless whole of the Native American world in which personal actions affirm mythic values and in which ritual actions reflect relationships established with the surrounding bioregion. Rather than abstract principles, these ethical relationships correspond to moral metaphors transmitted in the myth stories. Such generative metaphors as the living earth and purposeful animals cause a person to contemplate, as ethical experiences, the seasons, or the hunt, or the eating of local foods at their harvest time. American Indian moral imagination arises from formal structures that are believed to govern personal and community life as well as the bioregion and the larger cosmos. Such a worldview implies integration of a situational ethic, which guides one in daily life, and a cosmological ethic, which flows from the harmonious rhythms of nature. Thus, the terms *lifeway, synthetic ethics,* and *bioethics* are used in this entry to suggest the wholeness or totality of a good life that is lived in thoughtful relationship to the seasons and the living bioregion.

Each particular native people has its own terms for such concepts as synthetic ethics and lifeway. For example, Winona LaDuke writes:

> The ethical code of my own Anishinabeg community of the White Earth Reservation in northern Minnesota keeps communities and individuals in line with natural law. *"Minobimaatisiiwin"*—it means both the "good life" and "continuous rebirth"—is central to our value system. In *minobimaatisiiwin,* we honor women as the givers of lives, we honor our *Chi Anishinabeg,* our old people and ancestors who hold the knowledge. We honor our children as the continuity from generations, and we honor ourselves as a part of creation. Implicit in *minobimaatisiiwin* is a continuous habitation of place, an intimate understanding of the relationship between humans and the ecosystem and of the need to maintain this balance. (p. 70)

It is possible to find similar expressions by elders from indigenous communities in North America that articulate the relationship between social justice and ecojustice in their lifeway. The range of indigenous terms need not be discussed here but, where appropriate, such terms will be introduced.

Land and the Human Presence

Three features of Winona LaDuke's description of Anishinabe/Ojibwe ethical naturalism—enduring habitation (land), cosmological understanding (lifeway), and ecological balance (synthetic ethics)—can be used to frame the Native American appreciation of land and the human presence. The Winter Dance among the Okanagan/Salish/Colville peoples of Washington State provides a unique insight into the relationships of land, lifeway, and synthetic ethics. The Winter Dance introduces us to a developed native North American lifeway in which ritual participation is believed to transform individuals, communities, and bioregions. Moreover, the Salish understand the relationships established during the ritual as historical, that is, they deepen as an individual matures in the ethical path.

While this ritual, from the interior Salish-speaking peoples of the Columbia River plateau, has been selected for discussion here, it should be emphasized that the themes discussed have parallels in many distinct native North American rituals. The Green Corn, or Busk, ceremony of the Muskogee in the Southeast, the Shalako and Winter Solstice rituals of the Ashiwi in the Southwest, the Ashkisshe, or Sun Dance, of the Northern Plains Apsaaloke and many more rituals throughout Indian country continue to be performed in sacred settings by traditional practitioners.

OKANAGAN/SALISH/COLVILLE WINTER DANCE. Among many Salish people the Winter Dance begins the annual ritual calendar. Rituals performed during the calendar year include individual and communal activities, such as sweat-lodge ceremonies, vision questing, stick gambling, curing rituals, and first fruits and harvest festivals for deer, salmon, and root crops. However, the major ritual, which draws together all of the old subsistence and healing rituals, is the Winter Dance. This dance is a complex renewal ritual convened by individual sponsors from late December through February. An abbreviated form of the ceremony can be performed at any time for someone in need. Simply by ritually establishing the center pole, the most significant symbol of the bioregion, in the middle of the dance house the curative and transformative powers of the Winter Dance can be evoked.

The Winter Dance ritual complex is especially focused on the singing of guardian spirit songs over the successive days of the ceremonial (Grim, 1992). Singing begins in the evening of each day and continues until dawn. "Ceremonial" also refers to the accompanying ritual activity that occurs during the day, such as feasting, sweat-lodge rituals (healings, purifications, petitions), giveaways, stick-game gambling, and storytelling. At the ritual heart of the Winter Dance, however, is the individual-guardian spirit relationship. Most important, this spirit-human exchange generates and reenacts the time of the traditional mythic stories, or cosmogony, in which the universe was created. The Salish moral imagination is established in this cosmogonic symbolism that is believed to renew community life and to regenerate plants and animals. Thus, individual-guardian spirit relationships form the core of the Salish synthetic ethics in which stories, songs, and symbolic actions bind individual, community, and bioregion together to generate a sacred cohesiveness and a spiritual empathy. This Native American ritual, then, provides an excellent example of the close relationship between land, lifeway, and synthetic ethics.

Prior to contact with mainstream America and the establishment of the reservation system in the nineteenth century, the Winter Dance provided the major impetus for independent villages to undertake ritual diplomacy with other villages. The ritual was the locus of interaction that smoothed individual conflicts and encouraged group cohesion. Thus, the multifaceted Winter Dance diminished aggressive rivalry between villages and brought them together for the shared task of world renewal. Just as the Winter Dance was the locus for negotiation between fiercely independent and self-governed villages, so this ritual continues to be the central place for negotiation between the human and spirit realms.

As a world renewal ceremony the Winter Dance calls the spirit powers of the bioregion into reciprocal relationship with the human communities. This ceremonial makes explicit the interdependence of minerals, plants, animals, and humans through the songs that are sung by those who have had visionary experiences of these spirits in special places of the bioregion. There is no explicit recitation of a cosmogony during the Winter Dance; however, during the days between the evening and all-night ritual activity, individuals are encouraged to tell stories. Coyote stories are especially popular on these occasions. While there is no single cosmogony among the Salish people, the cycle of Coyote stories has cosmogonic features that describe the formative activities in the time of mythic beginnings (Mourning Dove, 1933). The often humorous Coyote stories are ensembles of generative moral metaphors in which the ambiguous and mistaken actions of Coyote are narrated as examples of inharmonious behavior. Thus, the formal activities of singing vision songs and the giving of gifts, as well as the informal storytelling, serve to activate a ritual logic that informs participants of both the sources of motivation for a moral life and the purposive world around them.

The most significant symbol of land and the human presence is the center pole, a lodgepole pine ninety or so inches high. The center pole, symbolic of the bioregion, is set up in the middle of the dance hall. It is the most significant place for contact with, and communication from, guardian spirits. Songs and giveaways are the mode of the moral imagination during this ritual, and the singers are said to experience a spirit sickness because of their proximity to the cosmogonic powers. The singers go to that center pole to sing, speak in moral exhortation to the assembled community, and give gifts just as the ancient mythic spirits gave to humans. While dancing around the pole to the songs of the visionaries, the participants are said to be like the animals who “are moving around” during the snows of the Winter Dance season. The very structure of the Winter Dance as animals moving about the land is presented as having moral force in Salish thought. More than simply isolated ritual acts or symbolic gestures, it is understood as bringing a person and a community into the moral order established during the time of the cosmogonic events when the mythic plants, minerals, and animals decided to give their bodies to humans for food.

In the traditional Winter Dance singers renewed themselves in the centering experience of the ceremony, and by doing so re-created their village communities. Much has been lost due to the intrusion of the dominant Euro-American worldview, which has devalued the sacredness of the community of all life forms and has often misunderstood the visionary experiences of guardian spirits. Still, the Salish Winter Dance retains striking continuity with a traditional ethics of giving, evident in the giveaway features of the ritual, and of empathy, apparent in the spirit sickness. This is because of the evocation in the Winter Dance ritual of the ancient cosmogonic knowledge transmitted in the sacred power (*sumix*) of the mineral, plant, and animal persons, in the spirit sickness of the singers, and in the cosmic symbolism of the centering tree. This relationship between ritual and ethics can be labeled “synthetic” to signal the holistic character of the traditional lifeway of these people.

Health, Sickness, and Healing

Knowledge of health, reproduction, and death among particular native North American peoples developed in relation to their investigative exchange with bioregions, and in historical contacts among indigenous peoples long before the arrival of Europeans. One ancient religious practice, that of the healer, or shaman, still embodies traditional knowledge of bioregions accumulated over centuries of historical change. Comparative studies in shamanism suggest that Native American peoples brought healing practices with them in their transcontinental passages from Siberia as long as 40,000 years ago. The shaman, as a specialist in psychological and spiritual healing, can be contrasted in some native North American traditions with herbalists, who also sought to cure ills. Among the Winnebago of the western Great Lakes region of Wisconsin the following advice was given to young men who were about to seek a vision experience:

> There are individuals who know [the virtues and powers]. It is sad enough that you could not obtain [blessings from the more powerful spirits] during fasting; but at least ask those who possess plants to take pity on you. If they take pity on you, they will give you one of the good plants that give life [to man] and thus you can use them to encourage you in life. However, one plant will not be enough for you to possess. All [the plants] that are to be found on grandmother's hair, all those that give life, you should try to find out about, until you have a medicine chest [full]. Then you will indeed have great reason for being encouraged. (Blowsnake, p. 75)

Such advice not only emphasizes the disciplined attention given to the plant world and to those who know the healing properties of plants but also suggests the broad connections between religion, ethics, and bioregion.

The last 500 years of historical contacts with Eurasia have brought "virgin soil epidemics," diseases against which native peoples had no natural defense (Crosby), resulting in demographic devastation among Native American populations (Dobyns). The initial challenge to and decline in the ritual authority of Native American shamans due to disease during the seventeenth, eighteenth, and nineteenth centuries did not lead to the disappearance of these ritual practitioners. Rather, as epidemics subsided, traditional practices were often given full credit for effecting cures (Trigger). Currently, traditional healers are often found working with scientific medical practitioners on many reserves and reservations.

Mainstream American popularizations of surviving Native American healing practices resulted, during the nineteenth century, in misunderstandings of herbal healers or medicine persons (Albanese). This has led to romantic fictional accounts of shamans as creative individualists. One characteristic that courses through all of this interest in Native American health systems is the close connection between medicine and religion. As we have emphasized in the use of the term *lifeway,* religion is a relational practice, and an indigenous shaman always stands in close connection with his or her bioregional community.

Ritual specialists capable of diagnosing disease, treating ailments, and guiding the dead are found in all traditional native North American settings (Hultkrantz). In many agricultural communities these specialists organized in priesthoods that transmitted traditional lore and ritual experiences that addressed specific sicknesses. Among the Ashiwi/Zuni in the Southwest, research on the human body was extensive and, during healing rituals, patterns symbolic of the somatic knowledge of Zuni healers were drawn on the patient (Hultkrantz). The physiology and anthropology informing this ritual, however, were not necessarily drawn from cadaver experiments or empirical observations of social structure. These healing societies typically abhorred cutting a dead body, for it still embodied ancestral animating principles in the process of release or dying. Often specialists in dreams, visions, and spiritual travel to other-than-human realms were believed to have acquired knowledge of the human body that could not have been obtained by observational means (Deloria).

The gathering-and-hunting societies of the period before the late nineteenth century, as well as many of these extant native communities, generally sanction individual shamans. Different from priests, who may be inducted into a healing cult through a personal healing or clan privilege to learn a traditional body of lore (Ortiz), shamans are usually called by vivid experiences of spirits that "adopt" them and enable them to respond to specific needs of their people (Grim, 1983). Myths among diverse native North American peoples, such as the Apsaalooke/Crow and the Dine/Navajo, often described a hero or heroine as someone who had been abandoned by the people and consequently, "adopted" by a spirit power (Eliade; Grim, 1983; Sandner; Sullivan).

Disease in a traditional Native American setting is usually attributed to transgression of a cosmological principle, performance of prohibited behavior, intrusion of an object "shot" into a diseased individual by witchcraft, or loss of a vital soul. Prohibitions in a native context often constitute a major ethical system involving hundreds of rules for the treatment of living organisms, handling the remains of organisms, and strategies for living with the spiritual powers in the bioregion. The Koyukon people of Alaska, for example, have an elaborate system of rules and regulations called *hutlanee* (Nelson). Disease and death can result from breaking these rules and disrupting the natural balance of *sinh taala,* "the power of the earth." Koyukon shamans, *diyinyoo,* know the spiritual powers that reside in the bioregion and use their power to diagnose disease, to treat illness, and to restore *sinh taala*, the foundation of their medicine. Shamans and elders teach the wisdom needed to restore the power of the earth and to meet death with knowledge of the paths to those places in the bioregion where the dead one will live. These teachings are found in the stories from the Distant Time, or *Kk'adonts'idnee,* in which the origin, design, and functioning of nature were established. Instituted in Distant Time, the *hutlanee,* moral codes for conserving game animals and the environment, are not simply superstitions but the Koyukon synthetic ethics that governs life.

Disease that results from “object intrusion,” or witchcraft, often implies a worldview in which balance or harmony between one’s body and the local bioregion has been purposely broken by a malicious individual. Among the Dine/Navajo, the health of an individual is not an isolated case but a matter of the whole community of life. The “beauty,” or *hozho,* inherent in the world can be put out of harmony by the malicious act of witchcraft. Cosmological ceremonies of great beauty, called chantways, are conducted by ritual specialists, or singers, to reestablish the diseased person’s bodily harmony by removing the intruded object or retrieving lost vitality. The key relationship in Dine/Navajo rituals is that between the Holy People, *Diyin Dine’e,* who are potentially malevolent as numinous forces in the landscape, and the Dine themselves, as earth-surface people. To reestablish health, the ritual evokes the Holy People, who are the inner forms of the elements of nature. Through the narrative power of language, especially in a form of the chantway called Enemyway, which exorcises evil, the chaos of witchcraft can be transformed into order and beauty (Witherspoon). The synthetic ethics of the Dine/Navajo people does not expel malicious people from the community, where there would be no opportunity to undo their evil. Rather the hope is that they also can be restored to “beauty” and cosmic harmony.

In the Dine/Navajo Emergence Myth, the basic narrative source for the chantway stories, the beauty of the earth is evoked in the following chant to restore health: “Then go on as one who has long life, Go on as one who is happy, Go with blessing before you, Go with blessing behind you, Go with blessing below you, Go with blessing above you, Go with blessing around you, Go with blessing in your speech, Go with happiness and long life, Go mysteriously” (Sandner, p. vii). Through this repetitive language, the chanters amplify sacred power and control the inner forms of themselves, of their patients, and of the spiritual powers in the landscape that have been evoked into the sandpainting ritual. The chanter restores the blessedness of the one sung over by bringing the patient into the healing environment.

Current Ethical Perspectives

Major ethical issues involving native North American peoples have coalesced around the following three areas: ancestral bones, religious freedom, and sovereignty. The passage of the Grave Protection and Repatriation Act of 1990 has helped to slow the pillage of ancestral Native American gravesites. So also the itemization of Native American holdings in major museums will enhance the possibility of the return of sensitive religious material to native peoples from whom it was often improperly obtained.

Serious questions of trust and sovereignty between the American government and Native American peoples have arisen in the late twentieth century in a series of court cases in which indigenous religious freedom has been curtailed. The history of mainstream American cultural and legislative antagonism toward Native American lifeways had been momentarily reversed in the passage in 1978 of the American Indian Religious Freedom Act. However, a sequence of Supreme Court cases (especially *Lying v. Northwest Indian Cemetery Protection Association* and *Employment Division v. Smith*) has challenged the sovereignty of Native American lifeways and demonstrated an unwillingness to recognize their sacred relationships to land.

The emergence at the end of the twentieth century of a global voice of indigenous people comes as a result of such negative factors as the environmental crisis and the proximity of indigenous peoples to undeveloped areas on the globe. In the United States and Canada, native North American peoples, having been pushed onto reservations and reserves away from the majority populations of mainstream culture, now manage resources and undeveloped land. Native American peoples have increased their close contact with other indigenous peoples around the globe in an effort to protect themselves from environmental racism, the imposition of projects such as hydroelectric dams and toxic dump sites that destroy the environments of minority peoples. Gatherings such as the United Nations Earth Summit in Rio de Janeiro in 1992 and the meetings titled “Changing Ecological Values in the 21st Century” in Kyoto, Japan, in 1993 have included native North American representatives. Meetings have also brought together representatives from the world’s religions to talk with elders from Native American lifeways about their traditional environmental ethics.

The remarkable resurgence of native North American peoples in the late twentieth century, after 500 years of suppression, derives from a complex process, but undoubtedly the knowledge transmitted in traditional ethics is a singular component of their endurance. Often dismissed as superstitious or derogatively labeled as primitive, the affective and holistic insights of native peoples are now recognized as ways of knowing grounded in close relationship with local bioregions. Those native teachers who still know this ethical system present their insights as a gift, a giveaway, to dominant America, which for so long juxtaposed the "nobility" of Enlightenment reason with the "contemptible character" of native thought. For traditional native North American peoples, the world is alive and, far from being a random collection of objects, is seen by some as our Mother and by many as a community of knowing subjects. Rather than a branch of knowledge, bioethics, in a native North American context, brings one to the heart of a way through life.

JOHN A. GRIM (1995)

SEE ALSO: *Abortion; Alternative Therapies; Animal Welfare and Rights; Body; Bioethics, African-American Perspectives; Conscience, Rights of; Environmental Ethics; Ethics: Religion And Morality*

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NATURAL LAW

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Natural law is perhaps the most ancient and historically persistent concept in Western ethics. Philosophers like Aristotle regarded nature as a ground of justice. Theologians like Thomas Aquinas distinguished between natural and supernatural sources of morality and law. By it Thomas Jefferson sanctioned a revolution. With it political reformers like Martin Luther King, Jr., justified civil disobedience. Upon it political philosophers like John Locke have built theories of the origin and limits of the civil state; and international lawyers, such as Hugo Grotius and Samuel Pufendorf, the order of justice between states. Despite disagreements about the theory of natural law, international bodies appeal to unwritten sources of rights to healthcare.

U.S. constitutional law has used natural law to clarify and sometimes amend the written law. Natural law undergirds the Thirteenth (1865) and Fourteenth Amendments (1868), which outlawed slavery and secured rights of U.S. citizens against state jurisdictions. Natural law also serves as a method of judicial interpretation, from which the judge looks beyond the written text of the Constitution in order to identify and vindicate rights of citizens. Today, constitutional debates have become the most public and controversial forum of natural-law discussion (Dworkin, 1985; Ely). Inasmuch as natural law is widely regarded as the moral basis for rights of privacy or personal autonomy, it is implicated in some of the most difficult biomedical issues, including abortion, reproductive technologies, and euthanasia.

The question of natural law emerges when we consider human laws and customs (Sokolowski). None is perfect, and some appear to be wicked. We then ask: What is the norm of reason in matters of morality and justice? Are moral norms merely the artifacts of human reason, devised to serve the circumstances of a particular culture? Or is there a ground that transcends cultures and histories? On what basis can laws be morally criticized and rectified?

Since these questions are fundamental to all ethical inquiry, what makes natural law different from other normative theories? There is no tidy answer. An array of moral theorists, using different theories, agree (1) that there are objective, though unwritten, moral grounds for right reason in the legislation and adjudication of human law; and (2) that moral reason must be guided by, and respect, certain values inherent in human nature (e.g., rationality and the capacity for free choice). If natural law means that moral and legal norms are grounded in reason, and that right exercise of human reason requires respect for goods inherent in human nature, then it would be exceedingly difficult not to hold a natural-law theory of one sort or another.

The healthcare professional exploring natural-law issues will face a debate often abstract and bewildering. First, what starts as a debate over particular issues in law, politics, or healthcare often becomes a debate over the concept of natural law itself. Second, what distinguishes one natural-law theory from another is not always clear; there seem to be as many different theories of natural law as there are theorists. In any case, one must remember that the rubric "natural law" often hides important disagreements among its proponents, as well as significant agreements among those who dispute its particular formulations and applications. Third, until recently natural-law thinking for the most part has not directly addressed biomedical issues. A well-developed body of natural-law literature, as found in legal, moral, and political theory, does not yet exist for biomedical issues. Thus, it will be helpful to summarize some of the main historical and philosophical themes of natural law.

Ancient Themes

Ancient Greek philosophers asked whether law and morality are due principally to nature or to convention. Aristotle, who is sometimes credited as the father of natural law, contended that "[w]hat is just in the political sense can be subdivided into what is just by nature and what is just by convention. What is by nature just has the same force everywhere and does not depend on what we regard or do not regard as just" (*Nicomachean Ethics,* 1134b18). While Aristotle certainly held that there are standards for judging whether a law is "in accord with nature" (*Rhetoric,* 1373b6), whether he had a doctrine of "natural law" is much debated (Miller). The proposition that moral judgment is rooted in the soil of nature, and not merely in human artifice, does not necessarily mean that nature is a "law."

The form of natural-law theory that came to influence Western culture arose from the confluence of Stoic, biblical, and Christian Scholastic ideas. Cicero, the ancient authority most often cited by Christians, wrote:

> True law is right reason in agreement with nature; it is of universal application, unchanging and everlasting; it summons to duty by its commands, and averts from wrongdoing by its prohibitions.… It is a sin to try to alter this law, nor is it allowable to attempt to repeal any part of it, and it is impossible to abolish it entirely.… [there is] one master and ruler, that is, God, over us all, for he is author of this law, its promulgator, and its enforcing judge. (*De Re Publica,* 3.22.33)

Similarly, Thomas Aquinas said that "the participation in the eternal law by rational creatures is called the law of nature" (*Summa theologica,* 1947, I-II, q. 91, a. 2). Nature *as law* requires the notion that natural standards are promulgated by God. The human intelligence finds itself not merely in a natural order but under a divine commonwealth, which is a rule of law in the exemplary sense.

Aquinas and Natural Law

Since the theory of natural law as developed by Thomas Aquinas is widely regarded as the epitome of the premodern position, let us summarize his view. In the *Summa theologica,* Aquinas maintains that for something to be called law, it must be: (1) reasonable, in the sense of directing action; (2) ordained to the common good; (3) legislated by the proper authority; and (4) duly promulgated (I-II, q. 90). The eternal law, whereby the world is ruled by divine providence, satisfies these criteria in an exemplary way (q. 91, a. 1). Natural law, however, is principally that part of divine reason accessible to the human intelligence. It is not to be confused with the order of the physical or biological world. Law is predicated only by a kind of similitude with the order found in nonrational entities (q. 91, a. 2 ad 3).

The first principle of the natural law is that "Good is to be done and pursued and evil avoided" (q. 94, a. 2). By nature, the human agent is inclined toward certain intelligible goods. Though Aquinas never claimed to provide an exhaustive list, these goods include life, procreation and care of offspring, entering into society, and knowing the truth about God. The first precepts of natural law take the form that something is to be done and pursued with respect to these goods, or resisted if contrary to them. Why call the precepts "natural"? Because the objectives of action are grounded in human nature antecedent to our deliberation and choice. In this sense, nature signifies the (human) essence directed to its specific operation. The term *natural* also indicates that the first precepts stand as the basic axioms of action, and are known naturally (*naturaliter*) rather than learned by study or by inference. Why call the objects of these inclinations "precepts" or "law"? Aquinas maintains that human agents are capable of seeing that certain goods are worthy of pursuit; they also grasp, in an elementary way, that in choices one is morally bound to act in accord with these goods.

The first precepts, however, are not a complete moral code. Aquinas holds that human reason must develop and apply them. First precepts are developed in terms of "secondary precepts," which spell out further implications for human action. For example, from the precept that one must act in accord with the good of life and resist what is contrary to it, we reason that murder is wrong. The first precepts also require "determinations," supplied by custom and positive laws. The "determinations" are ways that the natural law is made effective in the human community. Thus, while the care and education of offspring are enjoined upon humankind by a first precept of the natural law, how, where, and when the duty is discharged are determined by custom or positive law. Here, the virtue of prudence is paramount.

In the Thomistic scheme, the moral order in human law and politics is a kind of ecosystem, requiring for its proper function not only the universally binding precepts of natural law but also good customs, intelligently framed and emended positive laws, and acquired virtues, by which the laws are obeyed not just externally but also in the interior act of the will. It is therefore not advisable to isolate the doctrine of natural law in Aquinas from the rest of his account of moral agency. First, Aquinas flatly rejects the idea that human beings ever existed in a pure state of nature (I, q. 95, a. 1), unlike the ahistorical "state of nature" models of the modern era. Created in grace and wounded by sin, the concrete human condition, according to Aquinas, is in need of tutoring and, ultimately, of transformation by divine grace. Aquinas insists, for example, that the two great ends of the natural law—the love of God and of neighbor—obscured by sin and evil customs, require repromulgation by divine positive law (q. 100, aa. 5, 11). Second, the greater part of his *Treatise on Law* (I-II, qq. 90–108) puts the natural law in the double context of the divine positive law of the Old Testament (*lex vetus*) and the New Testament Law of Grace (*lex nova*). Biblical history shapes Aquinas's fully considered judgment and exposition of the natural law.

Aquinas can be absolved of the charge that he confuses moral and physical meanings of nature, as well as the charge that his account is ahistorical. Yet his theory of natural law does rely on a teleological conception of providence, and the historical cast of his thought is informed by the biblical narrative. These features are not accidental. To the extent that modern theorists reject the credibility of the teleological science of nature, and aim to provide an account of natural law that is neutral with respect to theological suppositions, the Thomist theory will be of more historical than systematic interest.

Modern Theories

In modern times, the concept of natural law has undergone considerable doctrinal and institutional development. Although the theological framework of natural law was maintained as part of public rhetoric well into the nineteenth century, it was no longer the main interest of natural lawyers. As Lloyd Weinreb notes: "The puzzles with which Aquinas and others grappled when they tried to understand the place of humankind in nature appear in [modern] guise as part of the effort to describe the relationship of the individual to the state" (p. 67). This shift of perspective and emphasis, from cosmological and theological themes to the more narrow political and legal issues of natural law, is complicated. Leo Strauss has argued that the ancient and modern theories are so radically different that they ought not to be confounded. Whether there is continuity or discontinuity between premodern and modern versions of natural law remains a disputed subject in the scholarly literature. While we cannot discuss this in detail, we can cite at least two problems that have shaped the modern approach.

NATURAL LAW AND MODERN SCIENCE. By the seventeenth century, the phrase "natural law" was expropriated by the modern sciences to denote purely descriptive or predictive aspects of natural bodies. In optics, astronomy, and physics, the relation between nature and law no longer expressed the *human* participation in divine providence but, rather, the intelligible, measurable, and predictable regularities in physical nature (Ruby). Teleological understanding was abandoned in favor of mechanistic explanations that relied exclusively upon material and efficient causes. The success and prestige of the physical sciences made it difficult thenceforth to interrelate the moral and physical meanings of natural law without falling into equivocation. How, for example, can law be predicated on nature without conflating physical and moral necessities? In the physical sciences, law denotes the measurable and predictable properties of things that have no freedom. But in the practical or moral sphere, law denotes principles that govern human freedom. These two meanings of natural law—nature as amenable to description and prediction, and nature as a prescriptive norm of freedom—present an ongoing theoretical difficulty in modern thought about the subject.

NATURAL LAW AND THE PUBLIC ORDER OF RIGHTS. The humane focus of natural law concerns legal and political problems of the relationship between the individual and the state. In the seventeenth and eighteenth centuries, human nature rather than authority allegedly vested in churches or kings came to represent the legitimate origin of the state and its rule of law. Philosophers and jurists wrested natural law from the controversial settings of religion and custom, and attempted to reduce it to self-evident laws of reason sufficient to ground a public order of law and rights. While the well-known dictum by Hugo Grotius that the natural law would have validity even if God did not exist captures something of the modern temper, even more pertinent is his assertion that "[j]ust as mathematicians treat their figures as abstracted from bodies, so in treating law I have withdrawn my mind from every particular fact" (Grotius, Prolegomena nos. 11, 58). Modern natural-law theorists emphasize apodictic, nongainsayable propositions, and filter out anything dependent upon the mediation of culture and religion. These theories are expected to cut through religious and political controversy in order to secure that minimum of rational consensus needed for public purposes (Gewirth). In contrast with the ancients and medievals, the minimalistic bent of modern theories is not designed to mesh with the virtue of prudence.

Natural Social Necessities

Given the new scientific meanings of nature and law, as well as the practical need to devise principles of justice sufficient to limit the modern state, two approaches to natural law dominate the modern period. One tradition keys natural law to what is needed for survival and societal peace. By nature, human beings are vulnerable, and need a certain minimal protection of their interests. Thomas Hobbes set the pattern of this tradition. Other examples of this approach are David Hume's "circumstances of justice," Oliver Wendell Holmes's "can't helps," and H. L. A. Hart's "minimum natural law." Natural law sets a background for customs and laws prohibiting violations of life, limb, and property. The advantages of this approach are at least threefold. First, the desire to protect one's life and property, insofar as it can be described and predicted, comports with the physicalist model of nature and law favored by the modern sciences. Second, it picks out elementary goods and bads that are apt to win consensus. These basic needs do not seem to depend upon the idiosyncrasies of particular individuals and their private life plans. Third, at least in the Anglo-American world, issues of life, limb, and property are easily recognized and adjudicated within a system of positive law.

However, natural necessities provide little or no reason to recognize absolute moral norms or rights that might resist the utilitarian calculations of a political majority acting for its alleged interests in peace and security. As Oliver Wendell Holmes said in his famous essay on natural law: "The most fundamental of the supposed preexisting rights—the right to life—is sacrificed without a scruple not only in war, but whenever the interest of society, that is, of the predominant power in the community, is thought to demand it" (p. 314). It is one thing to say that any system of positive law must work against the background of natural human necessities; it is quite another to hold that these pervasive natural facts about the human condition carry any prescriptive or moral force.

Natural Right of Autonomy

Another tradition, typified by Kant's dictum that one "[m]ust act as if the maxim of your action were to become through your will a universal law of nature" (Kant, no. 421, p. 30), emphasizes the autonomy of moral agents. This natural law can be expressed in the categorical imperative that humanity in one's person and in the person of others must be respected as an end in itself. As developed by many modern theorists, autonomy is a concept variously described as "moral independence" (Dworkin, 1985, p. 353), "the free choice of goals and relations as an essential ingredient of individual well-being" (Raz, p. 369), and "personal sovereignty" (Reiman, p. 43). Is autonomy a fact about human nature, or is it a moral ideal? There is disagreement about this (Schneewind). Reiman, for example, maintains that

"Personal sovereignty [indicates] a natural fact about human beings, consideration of which will lead us to the natural ground of equality between human beings" (p. 43). Put thus, autonomy embraces both a natural fact and a moral principle.

Some version of the autonomist theory is the preferred approach in much of contemporary natural-law theory, for the autonomist position emphasizes specifically moral principles of law rather than mere natural necessities. It seeks to tell us not what agents typically want or need, but how and why human beings must be respected. Moreover, it comports with the humanistic premise that human beings have a native dignity based upon a rational capacity to determine their conduct. It is the rational capacity that sets (at least some) human beings apart from other entities of nature, and constitutes the axioms of the moral world.

Despite its wide appeal, three problems routinely crop up in connection with the autonomist position. First, it is not always clear whether we are enjoined to respect the capacity for autonomy or the rightful exercise of that capacity. If we are enjoined to respect the capacity itself, are we thereby duty bound to respect the agent when he or she uses the capacity in a wicked way? In short, do agents have a moral right to do moral wrong? Second, the rights and obligations that flow from this "natural" fact of autonomy are difficult to formulate except in very general terms. What can a right to autonomy mean, except that persons ought not to be treated as mere objects; and what can this mean, except that a person ought to be treated according to sound moral considerations (Raz)? Hence, while autonomists emphasize a natural right to be treated equally, it is a humanist premise rather than the conclusion of moral reasoning (Raz). Third, we can ask whether the natural capacity for self-determination is adequate for moral reasoning about the status of other nonhuman species, prehuman entities (genetic material), incipient human life (embryos), and human beings whose autonomy is diminished.

Catholic Natural-Law Theory

The Roman Catholic Church is the only international institution to hold a natural-law doctrine in both the premodern and modern phases of the theory. Conciliar decrees, papal encyclicals, and canon law both reaffirm the natural law and have applied it across a range of moral issues (Fuchs; Finnis, 1980b). The encyclical *Veritatis splendor* (1993) gives considerable attention to natural law. Drawn chiefly from the work of Augustine and Aquinas, the papal formulation of natural law in *Veritatis* is traditional, emphasizing the status of natural law as real law, promulgated by God. Although there is only passing reference to biomedical issues, the encyclical represents perhaps the clearest exposition of the theoretical underpinnings of natural law by a modern pope. The concept of natural law has also recently been applied to natural rights. The new Code of Canon Law (1983) asserts the right of the church to address secular affairs insofar as such affairs pertain to "fundamental rights of the human person" (canon 747/2).

Over the past three decades natural-law debate has focused upon the encyclical *Humanae vitae* (1968), which condemned contraception as a violation of the natural law, not because it is artificial but because it is contrary to nature. The encyclical's premise is that marriage (apart from considerations of sacramental theology) naturally contains both a procreative and a unitive good. The moral question is whether these goods can be deliberately separated in the particular conjugal act. The natural-law reasoning of *Humanae vitae* has been interpreted in quite different, and sometimes contradictory, ways by moral theologians. A 1991 study finds that at least six natural-law positions have emerged in the debate (Smith). This is because the encyclical is terse, and does not spell out its argument in the fashion of an academic exercise. But it is also due to the fact that the encyclical outlines an argument at three levels, each of which is open to debate: (1) that the conjugal act must preserve the intrinsic order toward the procreative end; (2) that the unitive and procreative goods of marriage must not be separated; (3) that the integrity of marriage cannot be maintained in its totality unless it is maintained in each and every conjugal act. Hence, its analysis of nature concerns not only the natural order of the sexual function but also the natural goods of marriage as well as the nature of the human sexual act itself. Whatever might be said about the document, it does not present a simple natural-law argument.

Critics like Charles Curran have charged that *Humanae vitae* confuses the physical and moral structures of human acts. Curran also charges the encyclical with adopting a "classicist worldview and methodology" that comports with neither the methods of the sciences nor the relativizing of nature by the history of salvation. Bernard Häring raises objections similar to Curran's. Not only in matters of reproduction, but also more generally in biomedical issues, Häring notes that the physician no longer defines himself as a servant of "ordered potentialities and powers of nature." Rather, he "increasingly considers himself an architect and sculptor of the given stuff of nature" (Häring). So, too, the moral theologian, he argues, must emphasize the divine mandate to creatively mold and intervene in nature. As so often happens in debates about natural law, the practical issue at hand (in this case, contraception) quickly opens onto the more abstract philosophical and theological questions about the meaning of nature and how it relates to norms of conduct.

In 1987, Joseph Cardinal Ratzinger, prefect of the Congregation for the Doctrine of the Faith, issued *Instruction on Respect for Human Life (Donum vitae).* The *Instruction* addressed a number of biomedical issues, including experimentation upon human embryos; methods of prenatal diagnosis; and in vitro fertilization, both homologous (the meeting in vitro of the gametes of married spouses) and heterologous (the use of gametes coming from at least one donor other than the spouses). Whereas *Humanae vitae* contended that the procreative good cannot deliberately be suppressed in favor of the unitive good, Cardinal Ratzinger argued that the natural law also prohibits separating procreation from the unity and love of the spousal act. While the argument is similar to *Humanae vitae,* Cardinal Ratzinger makes it clearer that natural law is a moral law, not to be confused with a "set of norms on the biological level." By nature, the conjugal act is a "personal" act of love between spouses. This guarantees that the transmission of life is an act of procreativity rather than mere reproduction. The *Instruction,* therefore, maintains that in vitro fertilization, whether homologous or heterologous, is contrary to the personal and unitive meaning of the marital act.

With respect to human rights, Cardinal Ratzinger argues that in vitro fertilization violates not only the natural structure of the marital act but also the "inalienable rights" of the child. The child cannot be treated as an object serving the interests of the parents but, rather, must be treated as an end in itself. Parents have only the right to perform those acts that are per se ordered to procreation. Were parents to have a right to reproduce, by whatever means, then the child would be an object to which one has a right of ownership. At least on matters of bioethics, the *Instruction* represents an important development in the linkage between a traditional natural-law conception of the marital act with distinctively modern arguments concerning natural rights.

Natural-law theory is in a period of transition among Catholic scholars. Some scholars working in the Thomistic tradition now emphasize the role of the virtues rather than the juridical themes of natural law (Bourke; MacIntyre). Others, notably John Finnis (1980a) and Germain Grisez (1983), have developed a theory of the relationship between practical reason and "basic human goods" (e.g., life, knowledge, play, aesthetic experience, sociability, practical reasonableness, and religion). The aim of the theory is to identify moral norms governing how basic goods ought to be chosen. It was first undertaken by Germain Grisez (1964; 1983); John Finnis (1980a) has systematically applied Grisez's work to the whole field of jurisprudence. The natural-law component of the theory is much criticized. Some argue that it has no clear connection to the Thomistic doctrine of natural theology (Hittinger, 1987); others, particularly proportionalists, argue that absolute moral norms are not easily generated by such generalized forms of human well-being (McCormick). Although there is considerable agreement among Catholic philosophers and theologians that natural law is important, there is less agreement about how to deal systematically with the subject.

Natural Law in Law and Bioethics

Constitutional and legal issues have occupied recent secular debates over natural law. It is noteworthy that the philosophical ground of the debate between natural lawyers and legal positivists continues to be revisited (see essays in George, 1992). At a more concrete level, however, discussion has focused upon civil liberties, particularly the right of privacy. Since this area of the law is the bellwether for many important biomedical questions, we will briefly outline the state of this discussion.

In *Griswold v. Connecticut* (1965), the Supreme Court invalidated a Connecticut statute forbidding the sale to and use of contraceptives by married people. The Court held that a zone of privacy protects marriage from intrusive governmental actions. Since the Constitution and its amendments do not mention the right of privacy, the Court was widely regarded as using natural law in constitutional interpretation. Indeed, the use of natural law was more controversial than the result in this particular case. In *Eisenstadt v. Baird* (1972), which invalidated a Massachusetts statute prohibiting the sale of contraceptives to unmarried people, Justice William Brennan reasoned that the right of privacy generally covers the decision of individuals, married or single, to make decisions about whether to "bear or beget" children. In *Roe v. Wade* (1973), the right to privacy was extended to abortion. Since then, it has been cited by lower courts as precedent for paternal refusal to allow the implantation of embryos. Other biomedical issues have also surfaced in the courts in terms of natural rights: "There is a fundamental natural right expressed in our Constitution as the 'right to liberty,' which permits an individual to refuse or direct the withholding or withdrawal of artificial death-prolonging procedures …" (*Cruzan v. Harmon,* 760 S.W.2nd 408, 434 [Mo. banc 1988] [Higgins, J., dissenting]).

It is unfortunate that some of the thorniest biomedical questions have been formulated legally in terms of a right to privacy. The moral substance of the right is often moved to the periphery in favor of the controverted issue of natural law as a tool of constitutional interpretation. Setting aside the legal questions, we can ask what are the ground and scope of a right to privacy. It is widely held that the moral basis of the right rests upon the natural autonomy of individuals to make decisions about their bodies, with respect not only to sexual conduct but also to many life-and-death concerns. The notion of the body as property has a long philosophical pedigree in the Anglo-American world (e.g., John Locke); the notion that there exists a field of private or self-regarding actions is traceable to a number of different moral theorists (e.g., John Stuart Mill). Moral and legal theorists generally have attempted to unite these themes under a right of autonomy or moral independence (surveyed in Hittinger, 1990). In *Planned Parenthood v. Casey* (1992), the U.S. Supreme Court reaffirmed its holding in *Roe v. Wade.* It is significant, however, that the Court discussed the right in the language of autonomy, and brought this language under the legal rubric of "liberty" (in section one of the Fourteenth Amendment), rather than "privacy." Because privacy has such disputable grounds in the positive law, this move from privacy to liberty in *Casey* can be read as an effort to find more secure grounds in the positive law for the moral right to autonomy.

Two problems attend the formulation of a right to autonomy. First, it is not clear that a natural right to autonomy can be applied with analytic precision. Even if we narrow the scope of autonomous actions to those that relate to use of the body, it would seem that contraception, abortion, and euthanasia are very different kinds of acts—not only materially but also morally. Hence, it can be objected that although autonomy is a necessary element in our consideration of these issues, it is not a sufficient condition for how they ought to be settled. Second, in Western history, the great tradition of natural rights has concerned the limitation of the coercive power of the state. In legislation and in public policy, a natural rights argument can be expected to shed light upon the principles that ought to govern the ends and the means of public force. But the right of autonomy provides only the most inchoate ground for distinguishing between legitimate and wrongful actions on the part of the state. Why, for example, should the state be prevented from intruding upon decisions about reproduction but not those concerning suicide or euthanasia? All these acts concern the body, and are plausible instances of the individual's interest in his or her autonomy. If the difference consists in the moral specifications of the acts (if, for example, abortion is adjudged morally licit or at least indifferent, while suicide and assisted euthanasia are deemed morally wicked), then autonomy needs to be augmented with other principles in order to draw a line between what belongs to the individual and what belongs to the state. If, on the other hand, one has a natural moral right to act autonomously regardless of the moral specifications of the acts, then one would seem to have a natural right to do wrong. While a government might have other reasons to tolerate wicked acts, it is unclear how a government can be bound to respect a right to do a moral wrong.

Since bioethics encompasses matters of physiological well-being, moral choice, and justice, some version of natural law might seem indispensable to how we should frame and resolve the issues. Despite theoretical problems and disagreements, nature stubbornly remains a standard for health (Kass). Until nature is exorcised, it will continue to invite natural law reflection on norms of medical practice. Modern technology urgently bids us to investigate the moral relevance of the contrast between nature and art. Furthermore, it would be hard to imagine a future in which citizens stop making claims about rights in the area of healthcare and the allocation of its resources. Natural law has become part of our repertoire of moral discourse about rights. Yet, as one critic of natural law has stated the problem: "Either the allegedly universal ends [of natural law] are too few and abstract to give content to the idea of the good, or they are too numerous and concrete to be truly universal. One has to choose between triviality and implausibility" (Ely, p. 51). The same can be said of any of the standard normative theories of ethics, whether deontological or utilitarian. With respect to any abstract theory, especially one as prodigious as natural law, one must look carefully at its different versions, and also take the applications of the theories on a case-by-case basis.

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SEE ALSO: *Abortion, Religious Traditions: Roman Catholic Perspectives; Christianity, Bioethics in; Embryo and Fetus: Religious Perspectives; Enhancement Uses of Medical Technology; Ethics: Normative Ethical Theories; Ethics: Religion and Morality; Eugenics and Religious Law: Christianity; Fertility Control: Social and Ethical Issues; Law and Morality; Reproductive Technologies: Ethical Issues; Transhumanism and Posthumanism; Virtue and Character*

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NEUROETHICS

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Neuroethics involves the analysis of ethical challenges posed by chemical, organic, and electromechanical interventions in the brain. The term *neuroethics* is used by European neurologists to refer to ethical issues in brain disorders, such as strokes or epilepsy, and it has also been used at times for ethical concerns in psychiatry, child development, and brain injury rehabilitation. In 2001, however, the language expert William Safire reinvigorated the term, applying it to the ethical challenges of emerging neurotechnologies.

Neuroethics encompasses both research and clinical applications of neurotechnology, as well as social and policy issues attendant to their use. The literature predominantly focuses on psychopharmaceuticals and their proper clinical and social uses; brain scanning (especially its use for jurisprudence); regenerative neurology, such as fetal-cell transplants in the brain (e.g., for Parkinson's disease); implantable information-processing devices that interface with the brain (such as cochlear implants); and electrical stimulation of the brain, both externally (through transcranial magnetic stimulation) and internally (through deep brain stimulation).

Neuroethics is a content field, defined by the technologies it examines rather than any particular philosophical approach. The field's distinctiveness derives from novel questions posed by applying advanced technology to the brain, the seat of personal identity and executive function in the human organism. Advances in the understanding of brain function pose challenges to certain philosophical suppositions about human nature, exposing fallacies in people's self-conceptions, revealing disparities between social or biological groups in brain function, and tying together traits and states in novel ways. Intervention technologies raise questions about the proper limits of therapeutics, the desirability of human enhancement, and the right to access information directly from a person's brain that may even be hidden from his or her own conscious mind.

Neuroscientific Advances

Until the last few decades of the twentieth century, few ethical procedures were available that could directly reveal the details of brain functioning. Neurological and psychiatric interventions were crude. Scientists generally tried to understand the brain by correlating pathologies to loss of function, stimulating areas of the brain during surgery, or using electroencephalographs (EEGs) to glean how brain waves correspond to function. In contrast, technologies such as brain scans now provide less invasive access to brain activities. At the same time, new classes of psychopharmaceuticals and innovative neurotechnologies have increased medicine's ability to directly influence brain function.

Psychopharmaceuticals

Pharmaceutical advances are changing the way mental illness is conceptualized, defined, diagnosed, and treated. Medications that manipulate the major neurotransmitter systems (i.e., catecholamines, cholinergic and serotonergic systems), show great specificity and few side effects compared to older drugs. Psychopharmaceuticals pose two ethical challenges: (1) how to best utilize these tools in treating neurological and mental illnesses; and (2) how to assess the widespread use of these drugs outside medical settings.

MEDICAL USES. The proper role of drugs in treating mental illness has been a topic of ethical concern at least since the second half of the nineteenth century, and the issue periodically captures public attention. In the late 1980s, fluoxetine (Prozac), a drug classed as a *selective serotonin reuptake inhibitor* (SSRI), hit the market, and within three years it became the most highly prescribed antidepressant in the world. In his widely-read *Listening to Prozac* (1993), Peter Kramer described how patients on Prozac reported enhanced self-worth and confidence, less sensitivity to social rejection, and more risk-taking in their lives. However, as patients underwent these transformations, they began to wonder which was their "real self"—the pre-Prozac personality, or the personality improved by the drug?

What are the implications of a pill that seems to alter personality, not just cure illness? Will Prozac replace self-examination as the treatment of choice for life's challenges? Pharmaceutical research continues to produce drugs that can alter cognition (cogniceuticals) and mood, and the temptation will be to consider traits like shyness, irritability, or forgetfulness medically relevant simply because drugs that can alter these mental states are available. What are the social implications of drug choices—is it significant that when American society wanted women at home the drug of choice was Valium (a tranquilizer), and now that workplace assertiveness is valued it is Prozac?

Some have similarly criticized the widespread use of Ritalin to treat attention deficit disorders in children, suggesting that what is being treated is a normal variation in children's attentional capacities that would not be labeled pathological in other societies or other historical periods. The pressure for early diagnosis and treatment has resulted in calls for large-scale testing of children (Rowland et al., 2001; Shea et al., 1996) and claims of the overuse of psychiatric medication (Diller; Miller et al., 2001).

"LIFESTYLE" DRUGS. Inducing desired mental states through ingestion is at least as old as the discovery of fermentation. However, the growing power of modern psychopharmaceuticals to specifically alter mood or cognition, or to enhance traits such as memory or attentiveness is one of the most promising and challenging developments of the twenty-first century.

Pharmaceuticals developed for identified pathologies such as depression, erectile dysfunction, and narcolepsy also have the potential to improve or augment otherwise average or typical functioning. Drugs are often prescribed to help people moderate shyness, stage fright, occasional erectile difficulties, mild depression, or distractibility. Through such "cosmetic psychopharmacology" people will increasingly be able to chemically micromanage their mood states and cognitive skills. The demand for "lifestyle" drugs will alter the role of the clinician and strengthen the role of direct-to-consumer marketing of drugs. Drugs that can alter mood, attention, or cognitive functioning may also have social policy implications, such as their use to control prison populations or to enhance employee performance.

Brain Imaging

Brain imaging technologies generally look at blood flow to areas of the brain during mental activities. The technology began with the development in the 1970s of computerized axial tomography (CAT scans, which use X-rays), functional magnetic resonance imaging (fMRI, which uses magnets and radio waves), and positron emission tomography (PET scans, which use an injected radioactive isotope). By examining areas of metabolic activity in the brain during a specific cognitive or affective process, scientists can map that process to brain structure (morphometry), or identify irregularities. The use of imaging technology raises three general kinds of ethical issues: (1) our understanding of brain processes—and therefore of who we are; (2) proper medical uses of imaging; and (3) the desirable social uses of imaging.

UNDERSTANDING MENTAL PROCESSES. Neuroscientists suggest that, in principle, virtually all human states, from love to laziness to empathy to irritability, have brain correlates that may be detectable through brain mapping. J. F. Pujol and colleagues, for example, showed that the size of the cingulate gyrus (which coordinates sensory input with emotions) is significantly correlated with levels of emotions such as worry, fearfulness in the face of uncertainty, and shyness with strangers. If claims that imaging can identify emotional tendencies, musical talent, aggressiveness, or spatial acuity are true, this could alter ways of understanding people. Schools, employers, or the military could potentially use such technologies to categorize and track their students or workers.

Imaging research is exploring even complex activities such as moral judgments. For example, a 2001 study by Joshua Greene and colleagues used fMRI to study 100 subjects presented with a classic ethics vignette: given the choice, most people would redirect a train onto a track where one person would be killed rather than keep it on a track where five would be killed. However, they would not physically push a single person in front of the train to stop it from killing five others, even though both cases involve killing one to save five. The researchers found that emotional centers of the brain were much more active when considering physically pushing someone onto the track (a *moral-personal* scenario) than when simply pulling a switch (a *moral-impersonal* scenario). Such systematic differences in brain patterns may give us insight into hidden aspects of moral decision making.

MEDICAL USES OF IMAGING. Imaging studies have already challenged medical nosologies (classifications), discovering new pathological processes and revealing specific disease susceptibilities or risks. For example, the finding that psychiatric syndromes affect multiple brain structures has challenged the view that mental illness reflected particular abnormalities in discrete areas of the brain.

Familiar ethical concerns of medical procedures such as imaging include the risks of radiation and obtaining informed consent from the cognitively impaired. Imaging also raises novel concerns, however. A history of depression, drug abuse, or other brain pathologies, as well as certain behavioral traits, can leave lasting morphological traces that can be seen on certain types of scans. In 1977, Wayne Drevets and colleagues reported that people with a history of depression had 48 percent less gray matter in their left subgenual prefrontal cortex than those without such a history, while those with bipolar illness were 39 percent smaller. Scanning done for other purposes can be used to detect these morpholological signatures, raising significant privacy concerns.

SOCIAL USES OF IMAGING. Imaging technology will pose significant challenges to policymaking and jurisprudence. The ability to detect neurological signs of alcoholism, aggression, sexual inclinations, and other behaviors would be a tempting target for law enforcement personnel and other agents of social control. Scans can already detect identifiable responses in some people with phobias when they are presented with a feared stimulus (Birbaumer et al.), or former drug addicts when presented with drugs (Childress, et al.)—even if they try to suppress the response, and even if the stimulus is presented to them subliminally. In a controversial study, Phelps and colleagues showed white males pictures of unfamiliar black faces, and showed a correlation between their levels of racism and levels of activity in the amygdala (the seat of emotions such as fear). Other imaging studies have shown that some false memories can be distinguished from true memories (Schacter et al.), and that lies can be distinguished from truth-telling (Langleben et al.). The use to which such devices might be put raise significant privacy and justice concerns.

Brain-Computer Interfaces

Brain-computer interfaces (BCIs) are defined as systems in which commands from the brain to the external world are communicated technologically rather than passing through the brain's normal output pathways of peripheral nerves and muscles (Wolpaw et al.). BCIs include using EEGs to translate brain waves into actions and using neurologically implanted chips and electrodes that can communicate with external computers.

The most common BCI is the cochlear implant, used by over 30,000 people worldwide. The technology, which allows deaf people and those severely hard of hearing to perceive sound, is controversial, in part because it is imperfect and can thus trap users between hearing and deaf cultures. Much of the deaf community has also been opposed to the device, believing that deafness represents a culture rather than a disability, and that there is no need to try and "fix" it. In contrast, visual prostheses for persons with degenerative retinal disease have generated no such reaction from the blind.

Investigational BCIs include implanted extracellular electrode arrays that allow those with spinal chord injuries to control their environments by being able to manipulate mechanical devices with brain waves (Nicolelis). Integrating computer technology into human physiology is beginning to create cyborgs—organisms that are partly organic and partly machine. In the case of brain prostheses, which impact one's sense of identity and enhance basic human activity such as communication or cognition, questions of informed consent, privacy, and autonomy become important (Maguire and McGee).

Cell Transplants

Neural cells from fetuses have been transplanted (with mixed results) into patients with syndromes such as Parkinson's disease (Kordower et al.), raising ethical questions of informed consent, the appropriateness of implanting foreign tissue in the brain, and the potential destruction of a fetus or embryo for therapeutic purposes. In addition, integrating cells from one person into another's brain raises issues of identity and autonomy, which will become even more trenchant if proposals to attempt full or partial brain transplants are ever realized.

External and Internal Stimulation of the Brain

Transcranial magnetic stimulation (TMS) disrupts normal functioning of the brain using a pulse from a magnetic coil held over the skull. It "turns off" an area of the brain by creating a transient functional lesion, and certain kinds of TMS may even improve performance in memory and reasoning tasks. Researchers are also now using direct electrical stimulation of the brain to treat tremors associated with Parkinson's disease and severe chronic pain. The technology also seems to improve major depression, obsessive-compulsive disorder, and other psychiatric conditions. However, the long-term effects of these technologies are unknown, raising questions of safety and of obtaining informed consent when risks are difficult to define.

General Ethical and Social Concerns

Neurotechnologies have specific characteristics that raise unique concerns. However, the overall development of such powerful tools also has general implications for ethics and social policy.

SELFHOOD. The working assumption of most neuroscientists is that all human properties—personality, mind, and even soul—are emergent properties of the brain, and that no change in thought or sense of selfhood could occur without corresponding changes in neurophysiology. Neuroscience has already laid claim to the location of a sense of selfhood in the frontal lobes, for example. Frontotemporal dementia can result in significant changes in political social or religious values (Miller et al.), and frontal lobe trauma can cause personality change (Mataro et al.).

The attempts to trace human cognitive activity to brain structures raise important philosophical and religious questions. What would be the implications of discovering that traits like loving or moral reasoning have neurological (i.e., electrochemical) correlates? Does it reduce love to a biological artifact or epiphenomenon, or erode people's sense of free will? Further, if selfhood is embodied in specific areas of the brain, what are the implications of manipulating those areas pharmaceutically? Can neuroscience demonstrate that a beloved parent with Alzheimer's disease is no longer the person he or she was because the seat of selfhood in the brain has been damaged? And whether or not selfhood is actually an emergent property of the brain, what is the impact of neuroscientific materialism and determinism (the concepts that personhood is fundamentally rooted in brain substance and that it determines the shape and scope of our personhood) on the progress of neuroscience itself, or on the public's view of things like selfhood and the soul?

ENHANCEMENT. Human beings use many strategies and technologies to enhance their cognitive and affective functioning, from mnemonics (memory aids) to ingesting coffee or amphetamines. The enhancement debate centers primarily on the attempt to bypass mechanisms such as learning or behavioral reinforcement and directly moderate brain electrochemistry or structure (Wolpe). Drawing on the body's own resources, or manipulating the external environment to effect change, does not raise the same ethical challenges.

Enhancement, which refers to attempts to improve "normal" cognitive and affective functioning, poses two basic questions. The first, and more philosophical, question is about categorization: what do terms such as *average* or *normal* functioning, or even *disease* mean, when we can improve functioning across the entire range of human capability? If Prozac can lift everyone's mood, what then is "normal" affect? Will sadness or inner struggle be pathologized? If we can all be happy and well-adjusted through a drug such as Prozac, should insurance pay to reach that state of bliss? The second question addresses a broader social concern: should people be encouraged to, or discouraged from, ingesting pharmaceuticals to enhance behaviors, skills, and traits? What are the personal and social implications of using drugs or other neurotechnologies to micromanage mood, improve memory, maintain attentiveness, or improve sexuality?

Neurotechnologies ask one to explicitly consider the kind of "self" one wants to have or, perhaps, to be. For some, the astounding ability to manipulate human biology is an integral part of being human. For others, it is an affront to humanity. This is an argument for which there are no right or wrong answers, emerging as it does from two philosophically different visions of human life. Yet therein lies the tension of the enhancement debate, and there is little doubt that the debate will involve the ancient desire to control the workings of the mind.

Social Policy

PRIVACY AND CONFIDENTIALITY. Some brain-imaging technologies progressively image the skull as well as the brain, and computer programs can thus reconstruct the face of the person being scanned. Unlike other technologies, such as genetic analysis, imaging often cannot be done anonymously. Yet scientists have already founded brain-imaging data banks and made thousands of scans available to researchers (Van Horn et al.). Brain waves may also soon be as identifiable as fingerprints, and they may have social uses such as surveillance, raising serious questions about invasion of privacy.

JURISPRUDENCE. Imaging studies have often looked for structural differences in the brains of criminals and murderers, especially those diagnosed with antisocial personality. More recently, research has identified some functional signatures of lie detection, and now *brain fingerprinting,* a type of brain wave analysis, is being used to determine if people have ever seen particular faces, pictures, or crime scenes before (Farwell and Smith). Attorneys have tried to enter brain scans as evidence in criminal proceedings in a number of states, with mixed results. There is no doubt, however, that the use of brain scans in criminal justice venues will increase.

POLITICS AND POLICY. The quest to locate human traits in the brain also has political implications. Morphological attempts have been made to support or refute claims of racial intelligence hierarchies, and to attempt to demonstrate that sexual orientation has structural brain correlates. As the technology develops, society will have to answer questions such as: Should imaging be used in insurance profiling for life insurance or health insurance? Will it replace testimony or other clinical measures in determining competence or mental illness? Will employers be allowed to use imaging to screen employees or look for special aptitudes? Will pharmaceutical solutions to social problems become increasingly acceptable, as in the case of some uses of Ritalin in the classroom? The answers to these and other questions of neuroethics will have a powerful effect on the nature of American society in the coming decades.

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NURSING ETHICS

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The development of nursing ethics has paralleled the development of nursing as a profession. As nursing has evolved from the use of the rules of hygiene in caring for the sick (Nightingale) to a profession that defines its practice realm as the promotion of health, the prevention of illness, the restoration of health, and the alleviation of suffering (International Council of Nurses), so has nursing ethics evolved from following rules of conduct in attending the sick (Robb) to an identified field of inquiry within bioethics (Fry and Veatch).

Early Interpretations of Nursing Ethics

During the first half of the 20th century, interpretations of nursing ethics tended to view the nurse as a chaste, good woman in Christian service to others, and as an obedient, dutiful servant. To Florence Nightingale (1820–1910), who had responded to a religious calling to nursing, a good nurse was committed to the ideal of doing what was right. Being of the highest character, the good nurse was disciplined by moral training and could be relied upon to do her Christian duty in service to others.

This view of the good nurse as a good woman pervaded early textbooks on nursing ethics. Isabel Hampton Robb 1860–1910), the first president of the American Nurses Association (ANA), thought that the nurse must be a dignified, cultured, courteous, well-educated, and reserved woman of good breeding. Like Nightingale, she considered the nurse's work as ministry, as "a consecrated service, performed in the Spirit of Christ" (Robb, p. 38). Thus, moral virtue, moral duty, and service to others were established as important foundations upon which later interpretations of nursing ethics would be built.

At one time, nursing ethics was virtually indistinguishable from nursing etiquette and the performance of duty. Nursing etiquette included forms of polite behavior, such as neatness, punctuality, courtesy, and quiet attendance to the physician. The nurse demonstrated her acceptance of her moral duties by following rules of etiquette and being loyal and obedient to the physician (Robb). Early textbooks on the subject describe nursing ethics as the ideals, customs, and habits associated with the general characteristics of a nurse, and as doing one's duty with skill and moral perfection.

Some important distinctions were made between etiquette and ethics, however. Nurses learned proper ward etiquette in order to promote professional harmony in patient care, and this etiquette became the foundation for all other nursing behaviors. Ethics, however, was taught to promote moral excellence and technical competence on the part of the nurse. Ethics was viewed as a science, the knowledge of which would enable the nurse to carry out prescribed duties with moral skill and technical perfection.

Following World War II, the nurse's role in patient care slowly shifted from that of the physician's obedient helper to that of an independent practitioner who could be held accountable for what had been done or not done in providing patient care. A shift in the understanding of nursing ethics accompanied this shift in roles. The nurse's moral responsibilities were no longer couched solely in terms of obedience to authority and institutional loyalty. Instead, the nurse now claimed authority for independent clinical decisions in patient care, including ethical decisions.

In the second half of the twentieth century, contemporary nursing ethics began to develop in several directions. First, recently developed codes of nursing ethics were revised. Second, dramatic changes occurred in the teaching of nursing ethics. Third, nurses' attitudes and values, moral development, moral-reasoning abilities, and ethical practice or behavior were empirically studied. Fourth, the moral concepts of nursing practice were philosophically analyzed. Finally, consideration was given to the development of theories of nursing ethics.

The Development and Revision of Nursing Codes of Ethics

As professional nursing developed, nursing organizations began to discuss the need for a code of ethics for nursing practice. In the United States, the 1897 meeting of the newly constituted ANA was the first occasion for members of the profession to discuss such a code. The ANA House of Delegates, however, did not accept a code of ethics until 1950. Revised in 1960, 1968, 1976, 1985 and 2001, the ANA Code of Ethics for Nurses with Interpretive Statements "provides a framework for nurses to use in ethical analyses and decision-making" (p. 6). While the development of the ANA Code of Ethics for Nurses was in process, the International Council of Nurses (ICN), established in 1900, was developing an international code of nursing ethics. A draft of this code was presented and accepted at the 1953 ICN Congress held in Sao Paulo, Brazil. The ICN Code for Nurses was revised in 1965, 1973, and 2000 and has been translated into several languages. The ICN published guidelines on the use of the Code for Nurses in 1977, 1994, and 2002.

A significant number of national nurses' associations throughout the world have also developed codes of ethics. Among the areas of agreement are nursing responsibility for practice competence; the need for good relations with coworkers; respect for the life and dignity of the patient; protection of patient confidentiality; and the ethical responsibility not to discriminate against patients on the basis of race, religious beliefs, cultural practices, or economic status (Sawyer). Like other professional codes of ethics, nursing codes provide important ethical standards that nurses can refer to when faced with questions of ethics or unethical practices on the part of coworkers and institutions. They are also an important historical record of the ethical concepts and principles considered important to nursing practice over time. Their periodic revisions have thus helped to shape the development of modern nursing ethics.

Like all professional codes of ethics, nursing codes are hard to apply to patient care. Since such codes represent moral ideals rather than specific action guides, professional nursing organizations have developed lengthy interpretations of nursing codes of ethics, or produced guidebooks with case applications of a code (Fry and Johnstone). In the United Kingdom, the Nursing and Wifery Council has published advisory documents to supplement its Code of Professional Conduct.

Teaching Ethics in Nursing Education

During the 1970s, the models of nurses' ethical decision making used in nursing-education programs were critically examined. A study of ethics teaching in 209 accredited baccalaureate nursing programs in the United States revealed that general ethics content was integrated into the curricula of two-thirds of the programs surveyed (Aroskar). The majority of the programs also expressed a need for the teaching of more specific nursing ethics content. Several textbooks on nursing ethics have helped to define this content (e.g., Benjamin and Curtis; Bishop and Scudder; Fry and Veatch; Yeo and Morehouse). According to these textbooks, both the teaching of ethics in nursing curricula and the analysis of ethical conflicts as they occur in nursing practice can enhance nurses' ethical decision-making abilities. They also agree that the ethical problems nurses most often experience involve: (1) balancing harms and benefits in patient care; (2) protecting patients' autonomy; and (3) distributing nursing-care resources.

As various approaches to teaching ethics in nursing education developed, a consensus emerged that the overall goal of teaching ethics to nurses is to produce an ethically accountable practitioner who is skilled in ethical decision making. Intermediate goals of ethics teaching are to: (1) examine personal commitments and values in relation to the care of patients; (2) engage in ethical reflection; (3) develop skill in moral reasoning and moral judgment; and (4) develop the ability to use ethics for reflection on broader issues that have policy implications and for research on the moral foundations of practice. These goals focus on the fact that ethics is a form of inquiry used by every nurse in clinical practice. Broad general acceptance of these goals in nursing education prompted research into nurses' ethical decisions and the types of ethical issues nurses confront in patient care.

Nursing-Ethics Research

The earliest recorded nursing-ethics research project was Rose Helene Vaughan's 1935 study of the diaries of ninety-five student and graduate nurses who recorded the ethical problems they encountered in nursing practice over a three-month period. Vaughan's analysis identified 2,265 moral problems, 67 problems of etiquette, and 110 questions about ethical behavior. The ethical problem the nurses faced most often was the lack of cooperation between nurses and physicians, and among nurses in general. Other ethical problems noted were: duties to the nursing school, lying (including dishonest charting), duties to patients, lust, and problems of temperance. Vaughan concluded that the problem of lack of cooperation her subjects experienced signaled nurses' growing awareness of their responsibilities to society and the role they were playing in patient care. She recommended more emphasis on ethics education in nursing to ensure a high standard of individual morality, which she believed would "raise the nursing professional above and beyond the slightest suggestion of social disapproval" (p. 105).

Despite this early interest in nurses' ethical problems, nursing-ethics research did not begin in earnest until the 1980s. Research efforts initially focused on the ethical reasoning abilities and ethical behaviors and judgments among practicing nurses (Ketefian and Ormond). These studies focused on the ability of the nurse to make moral judgments, on the hypothetical ethical behavior of the nurse, and on nurses' perceptions of ethical problems. Methodologically, the studies were designed to document the cognitive abilities of nurses to make moral judgments.

A few studies in nursing ethics have measured nurses' ethical decision-making styles, factors influencing nurses' ethical decisions, and the consistency of the way nurses make ethical decisions (Ketefian and Ormond). Nursing-ethics research has also looked at the attitudes and values of nurses concerning ethical issues (Davis and Slater). Other topics studied include: how frequently nurses in different practice environments encounter specific ethical issues in their practices; how disturbed they are by ethical problems; and the influence of demographic and work-related variables on the frequency and the disturbance levels of ethical issues (Berger, Severson, and Chvatal; Fry and Damrosch; Fry and Duffy; Omery et al.; Scanlon).

The problems most frequently encountered by the nurse subjects in these studies are: (1) staffing patterns that limit patient access to nursing care, (2) pain relief and management, (3) inappropriate allocation of resources, (4) prolonging life with inappropriate measures, and (5) working with incompetent and irresponsible colleagues. However, it is still not known how nurses respond to particular issues when they experience them, or how nurses use resources in the workplace to handle specific issues. Furthermore, it is not clear which workplace factors influence the abilities of nurses to handle issues and which ethics resources in the workplace are most helpful to the ethical practice of nurses. Further research is clearly needed, particularly as changes occur in healthcare delivery and nurses are presented with new and more difficult etical issues that may affect patient outcomes.

The theoretical frameworks used to interpret study results in nursing-ethics research also need evaluation. Since nursing is largely practiced by women, theoretical structures should include the process of ethical decision making by women as well as men. Furthermore, researchers should use structures that can account for the nature and process of ethical decisions made by nurses—and how they contrast with those of other healthcare workers, such as physicians (Fry). This means that theoretical structures that are developed from the study of one gender alone, or that consider ethical decisions as decisions made by physicians, might not be appropriate for the study of nurses' ethical decisions. In considering appropriate theoretical frameworks, clarity about the moral concepts of nursing is very important.

Moral Concepts of Nursing Ethics

Advocacy, accountability, collaboration, and caring are foundational moral concepts for nurses' principled, ethical decision making (Fry and Johnstone). They are important because they enjoy a firm place in nursing standards and ethical statements throughout the history of the nursing profession and help define the ethical dimensions of the nurse–patient relationship.

ADVOCACY. Advocacy may be defined as the active support of an important cause (Fry and Johnstone). In nursing, it describes the nature of the nurse–patient relationship and has been interpreted as a legal metaphor for the nurse's role in relation to a patient's human and moral rights within the healthcare system (Winslow). Others have interpreted advocacy as the moral concept that defines how nurses view their responsibilities to the patient (Gaylord and Grace; Sellin; Snowball).

Advocacy has been associated with courage and heroism. It may also be understood as the means by which the nurse participates with the patient in determining the meaning that the experience of illness, suffering, or dying has for that individual (Gadow). Francesca Lumpp, a nurse educator, has even argued that two general ethical principles—respect for human dignity and fidelity—are rooted in the advocacy concept. Some nurse-ethicists have interpreted advocacy as the ethical principle that justifies what nurses do to protect the human dignity, privacy, choice (when applicable), and well-being of the patient (Fry and Johnstone). This last view of advocacy seems most consistent with the values expressed in nursing codes of ethics and the primary ethical responsibilities of the nurse.

ACCOUNTABILITY. The concept of accountability seems to have two major attributes: answerability and responsibility. Nurses are assumed to carry personal responsibility for nursing practice and are expected to justify, or "give an account" of, their nursing judgments and actions according to the profession's ethical standards or norms. Terms of legal accountability for nursing practice are contained in licensing procedures and state-regulated nursing practice acts, while terms of moral accountability appear as norms in codes of nursing ethics and other standards of nursing practice. By virtue of agreeing to perform nursing care, the nurse accepts accountability for performing such care according to these standards and norms.

While accountability is a basic moral value in nursing practice, mechanisms for evaluating the accountability levels of nurses need to be developed. A few codes of nursing ethics have focused on accountability as a central moral concept (ANA; Australian Nursing Council; United Kingdom Central Council, 2002), and at least one national nursing organization has provided documentation on the extent of nursing accountability in professional practice (United Kingdom Central Council, 1996).

COOPERATION. Cooperation is active participation with others to obtain quality care for patients, collaboration in designing nursing care, and reciprocity to those with whom nurses professionally identify, such as physicians and other healthcare workers. It implies consideration for the values and goals of those with whom one works. The concept of cooperation encourages nurses to work with others toward shared goals, to make mutual concerns a priority, and to sacrifice personal interests to maintain the professional relationship over time.

Cooperation has been included in several codes of nursing ethics as a moral concept of nursing practice (ANA; Australian Nursing Council, ICN; Irish Nursing Board). While early views on nursing ethics linked cooperation to a special loyalty shared by members of the professional group (Robb), later views linked cooperation to the need to compromise individual goals and interests in order to achieve a mutually determined and higher level of patient care (Benjamin and Curtis; Fry and Johnstone).

CARING. The moral concept of caring has long been valued in the nurse–patient relationship. Caring behavior is considered essential to the nursing role and is presumed to affect how humans experience health—as well as life itself. For nurses, caring is directed toward the protection of the health and welfare of patients, and it indicates a commitment to the protection of human dignity and the preservation of human health (Fry and Johnstone).

Recent feminist interpretations of human caring relate caring to the protection, welfare, or maintenance of another person (Noddings). Others have defined caring as a moral obligation or duty among health professionals (Pellegrino), or as a form of involvement with others that engenders concern for how they experience their world (Benner and Wrubel). These views indicate two attributes of the concept. First, caring is a natural human sentiment, the way all humans relate to their world and to each other (Noddings). It exists as a structural feature of human growth and development before caring behaviors actually commence. Second, caring is linked to moral or social ideals, such as the human need to be protected from the elements or the need for love. Caring, in this sense, might be interpreted as a commitment toward certain patient outcomes, especially the protection of human dignity and the preservation of human health (Shiber and Larson; Valentine).

It has been suggested that caring is really a therapeutic "presence" that includes both an attitude of personal concern and skill and knowledge about caring (Bishop and Scudder). Caring, in this view, is not emotion or sentimental, but is a way of being with others that assures them of personal concern for their well-being. Such a presence fosters the well-being of individuals by transforming how they experience their world, and it ultimately fosters the healing process. Patients know that they are not only being cared for, but that the one providing care really does care about them.

Theories of Nursing Ethics

Progress in the development of a theory of nursing ethics has been slow, partly because of disputes about the relationship of nursing ethics to medical ethics—and to the discipline of ethics itself. Some ethicists claim that there is little that is morally unique to nursing practice (Veatch). The same moral issues confront everyone in the healthcare setting, regardless of whether one is a physician, nurse, or patient. This means that *nursing ethics* is a legitimate term only insofar as it refers to a subcategory of medical ethics. Since medical ethics is the ethics of all judgments made within the biomedical sciences, nursing ethics is simply the ethical analysis of those judgments made by nurses, in much the same way that physician ethics is the ethical analysis of those judgments made by physicians. Any theory of nursing ethics will, therefore, be exactly like medical-ethics theory. According to this view, a theory of nursing ethics may not even be necessary.

Others argue that nursing ethics is not just another form of applied ethics or medical ethics (Gamete). If the moral concepts and obligations inherent in nursing practice are different from (yet compatible with) those of other health professions, then nursing ethics may have a distinct voice in healthcare. If so, nursing ethics will use traditional and contemporary forms of philosophical analysis to describe the moral phenomena of nursing practice, to critically assess the language and conceptual foundations of nursing practice, and to raise normative claims about the aims of nursing practice within the healthcare sphere. It will provide a perspective on what is good and bad, or right and wrong, in nursing practice, and will thus lead to ethical principles that can be used to guide nursing judgments and actions. It will be nursing-ethics theory and not medical-ethics theory.

Regardless of its form, any theory of nursing ethics will need to address the relevance of the moral concepts of nursing practice in the years ahead. As the twenty-first century reveals new moral challenges in healthcare, nursing ethics must respond with conviction about the integrity of its moral concepts and develop practice-based theories of nursing ethics. If it is to claim its promise as a form of philosophical inquiry for the field of bioethics, it must also continue to move ahead on the expansion of nursing-ethics research and identify what is known and not known about nurses' ethical practices in a changing healthcare environment.

SARA T. FRY (1995)
REVISED BY AUTHOR

SEE ALSO: *Autonomy; Beneficence; Care: Contemporary Ethics of; Compassionate Love; Feminism; Medical Codes and Oaths; Narrative; Nursing, Profession of; Nursing, Theories and Philosophy of; Palliative Care and Hospice; Professional-Patient Relationship: Ethical Issues; Profession and Professional Ethics; Teams, Healthcare; Trust; Women as Health Professionals*

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NURSING, PROFESSION OF

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Care for the ill or injured has existed since the beginning of recorded history, but modern nursing, as it is now known, had its beginnings in the nineteenth century with Florence Nightingale, who viewed nursing as a self-defining moral practice focused on caring. Nevertheless, for decades after Nightingale established the school of nursing at St. Thomas’s Hospital in London, nursing made accommodations to other established institutions, especially medicine and hospitals—accommodations that dimmed Nightingale's original vision. Only after the nursing profession accomplished the tedious but necessary task of developing its craft and the institutions that any new venture must have in order to establish itself within a society did it engage in a concerted effort to establish its identity. Beginning in the 1960s, nursing attempted to gain recognition as a profession by applying science to nursing. Then in the 1980s, it began to identify itself as a caring practice, using qualitative methods of the human sciences to articulate the meaning of nursing practice.

Nightingale's Vision

"A new art and a new science has been created since and within the last forty years. And with it a new profession—so they say; we say, *calling,*" wrote Florence Nightingale in 1893 to the meeting of the International Congress of Charities, Correction and Philanthropy in Chicago (Nightingale, 1949 [1893], p. 24). This congress initiated the organization of the nursing profession in the United States and Canada. Nightingale considered her "calling" a moral imperative from God (Woodham-Smith).

Nightingale preferred to designate nursing a "calling" rather than a "profession" to underscore its identity as a self-defining practice with a dominant moral sense. Nightingale regarded nursing as a way for women to make positive contributions to society. She recruited only women of the highest moral character, thus attempting to overcome the public impression that most nurses were alcoholics or prostitutes. In the male-dominated society of Nightingale's time, "refined" women did not work outside the home.

As medical science advanced, nurses increasingly came to be considered handmaidens of physicians, as Nightingale had feared. One reason she rejected the germ theory was that she feared it would lead to what eventually came to be called intervention medicine. She foresaw that intervention medicine would lessen the centrality of nursing care in healthcare (Rosenberg). Intervention medicine led to the belief that physicians cure by intervening in the development of disease, whereas nurses merely care for those being cured. Furthermore, science and applied science were regarded as masculine activities, whereas caring was believed to be a feminine activity.

The primary focus of caring was one's own family. Thus, in the early part of the twentieth century, much nursing care was given by young women who, for the most part, were waiting to fulfill what was seen as their primary calling: to care for family. While they were students, these young women were a cheap source of labor for hospitals. The few career nurses in hospitals directed these novice nurses, who gave most of the direct nursing care. Most nursing care in hospitals, then, was not given by nurses who could be called professionals in any sense of the word.

World War II (1939–1945) required that large numbers of women enter the industrial workforce for the first time, and nurses serving in the armed forces attracted greater attention to the importance of nursing. This apparent advance in women's professionalism, however, merely implied that it was permissible for women to work outside the home when unusual circumstances demanded it. During the 1950s, nursing seemed not to progress as a profession except that married women were accepted into schools of nursing and allowed to practice in hospitals; the traditional view of women's vocation continued to prevail. In her 1976 book, *Hospitals, Paternalism, and the Role of the Nurse,* Jo Ann Ashley argued that hospital paternalism and sexist attitudes of physicians contributed to the exploitation of nurses, who were kept subservient. Susan M. Reverby concluded in her 1987 book titled *Ordered to Care* that nurses were "so divided by class that their common oppression based on gender could not unite them" (p. 6), and that nurses saw caring for patients as a duty that "constrained nursing's effort to control its own practice and occupational future" (p. 199).

Throughout history, men, particularly in religious orders and in military service, provided nursing care for the ill and wounded. But since the development of modern nursing, few men have entered nursing as a vocation. Even with the encouragement of men to enter nursing in the last decades of the twentieth century, the percentage of male nurses in the United States remained fairly constant at approximately 3 to 5 percent (HRSA).

Nursing is mainly a woman's vocation throughout the world. According to Constance Holleran, writing in a 1992 issue of *Nursing Administration Quarterly,* one reason that few men enter nursing is that "the problems of nursing and nurses truly are universal: few well-prepared nurses, poor career structures, and lack of resources. It is only a question of degree" (p. 3). Holleran also observed that hospitals in many countries have no budget for nursing and that in some countries there are many nursing administrators but few nurses who give direct care.

Gaining Recognition as a Profession

The question of whether nursing is a profession has concerned nursing organizations and scholars since the 1960s. Early attempts to gain recognition as a profession were based primarily on criteria drawn from disciplines outside of nursing. Using sociological criteria, Amitai Etzioni contended in the 1969 book, *The Semi-professions and Their Organization,* that although nursing had some of the characteristics of a profession, it could not be classified as a profession. In a major study to assess how far nursing had advanced in its attempt to become a profession between 1970 and 1980, researchers used six sociological criteria to determine its progress: a long and disciplined educational process; discretionary authority and judgment; an active and cohesive professional organization; acknowledged social worth; significant commitment and contribution to human well-being; and a unique body of knowledge and skill (Lysaught). These sociological criteria are helpful in understanding the controversy surrounding nursing's claim to be a profession.

A LONG AND DISCIPLINED EDUCATIONAL PROCESS. The first criterion has been one of the most difficult for nursing to meet because of the tension between hospital and collegiate programs. In the United States, nurses are prepared to be registered nurses in multiple ways: by diploma programs in hospitals; by associate degree programs, usually in community colleges; and by baccalaureate degree and graduate degree programs in colleges and universities. Every major study of nursing in the twentieth century, however, recommended that nursing education should be placed in the mainstream of collegiate education (Committee for the Study of Nursing; National Commission for the Study of Nursing; National Commission on Nursing). As early as 1965, the American Nurses Association (ANA) recommended that all those licensed to practice nursing should be educated in institutions of higher education and that the baccalaureate degree in nursing should be the minimum preparation for beginning professional nursing practice. While many hospital diploma programs have closed because of falling enrollment and financial constraints on hospitals, associate degree programs have proliferated and now represent the largest proportion (57%) of basic nursing programs (HRSA). Baccalaureate programs have also steadily increased in number, as have accelerated programs for individuals who have undergraduate degrees in another field and wish to pursue a career in nursing.

As was true of the early history of nursing in the United States, other countries have traditionally prepared nurses for practice in hospital schools of nursing. In many countries there continues to be no university-level basic or graduate (postbasic) programs for nurses (Holleran), although the general trend is toward more formal, university education. Progress toward collegiate education as the basic entry level has, however, been varied. In Canada, for example, nursing education is well established in the university system, with more than eighty-five schools offering the bachelor of science degree. Prince Edward Island has had the baccalaureate degree as the required entry level for nurses since 1992 (Thomas and Arseneault). The baccalaureate degree is the basic preparation in Denmark, which has twenty-four schools of nursing and has offered graduate degrees since 1991. In Asia, many countries have nursing education models similar to the United States. Japan, for example, has baccalaureate degree programs in nursing as well as associate degree and diploma programs (Anders and Kanai-Pak). Korea has over 100 colleges offering a nursing degree, while China offers an associate degree in eighty-nine colleges and a baccalaureate degree in forty-nine universities, in addition to graduate programs.

Progress in nursing education in lesser-developed countries has been slow but encouraged by the support of the World Health Organization (WHO). Established in 1948 by the United Nations as its specialized agency for health, WHO supports advances in nursing education by designating "WHO Collaborating Centers" in universities in the United States and elsewhere. The WHO Centers then serve as resources for nursing schools and organizations in countries needing assistance, such as Uganda, Mexico, and some smaller European nations.

Graduate education in nursing in the United States began to develop in the 1960s. Master's degree programs were established primarily in the clinical specialties of nursing practice, such as adult health, maternal and child health, and psychiatric/mental health. Although doctoral programs in nursing in the United States originally developed slowly, they more than doubled, from twelve to twenty-seven, between 1974 and 1984 (Brodie), and by 1993 had doubled again. Other countries have followed a similar pattern, and doctorates in nursing can now be pursued in many countries.

DISCRETIONARY AUTHORITY AND JUDGMENT. In the United States, regulation of nursing practice and enforcement of standards for practice and education first occurred at the turn of the twentieth century through the establishment of state boards of nursing. These boards, composed of members of the nursing profession, set criteria for the practice of nursing and established evaluation procedures to ensure that nurses are capable of practicing safely and effectively. The state boards in the 1950s created standardized testing for licensure to practice at the basic level, and they also regulate advanced nursing practice (e.g., nurse practitioners, nurse midwives) in most states.

The National League for Nursing (NLN), an organization of nurses and citizens concerned with improving nursing, has significantly influenced the standards of nursing through the development of voluntary accreditation of educational programs. The NLN has established criteria to determine the quality of nursing education and formulated procedures for accreditation of all types of educational programs that meet their criteria.

State and national nursing associations have exercised their influence in the political arena since they first supported legislation to create state boards of nursing. In the 1980s and 1990s, they concentrated on developing a political agenda that sought a greater influence on state and national legislation affecting nursing practice, nursing education, and health issues. Prior to this time, nurses had little influence in developing healthcare policy. In 1992, however, two significant events demonstrated nursing's increased influence on healthcare policy. First, the Community Health Accreditation Program (CHAP) of the NLN won "deemed status" from the federal government; this means that community health agencies that have met the standards of accreditation by CHAP are considered to have met the federal government's conditions for participating in the Medicare program and can receive Medicare reimbursement. Second, the Joint Commission on Accreditation of Healthcare Organizations created an at-large nursing seat on its board of commissioners. This body is the official accrediting agency of hospitals and other healthcare organizations, and it consequently has a great influence on the standards of healthcare in hospitals.

As nursing education has advanced to the graduate level, specialized fields of practice have been established and formal organizations, such as the Oncology Nursing Society and the American Association of Critical Care Nurses, have been formed to establish standards of practice for these specialties. In order to ensure a high standard of practice, certification examinations for specialty practice are now available and are considered a necessary additional credential for professional advancement in some areas.

In 1965 a new level of nursing practice was created with the establishment of the first nurse practitioner program at the University of Colorado. Nurse practitioners are nurses who have completed an additional specialized educational program that extends practice into areas of responsibility traditionally thought to be part of medical practice, such as diagnosis and the prescribing of medications. Nurse practitioners focus primarily on the prevention of illness, maintenance of wellness, and management of chronic health problems. More recently, nurse practitioners have been employed by both hospitals and physician practice organizations to assist with the care of acutely ill, hospitalized patients. Other types of advanced practice nurses include clinical nurse specialists, nurse anesthetists, and nurse midwives.

Regulation and credentialing for the four types of advanced practice nurses are done through a variety of arrangements between boards of nursing and boards of medicine. Legislation has been passed in many states that authorizes nurse practitioners to write prescriptions. Many states permit nurses in advanced practice to receive direct payment for services from third-party payers such as Medicare, Medicaid, and private insurance. Because medical diagnoses are not always appropriate indexes for nursing practice, the North American Nursing Diagnosis Association was created in the 1980s to develop nursing diagnoses that would further standardize nursing practice and could serve as a basis for establishing a system of reimbursement for nurses.

In the 1980s and early 1990s, many nurses in the United States began to focus on providing primary healthcare. Nurse-managed centers for primary care were established across the country, often located in homeless shelters, housing projects, and other settings, expressly to meet the needs of the poor, who have limited access to healthcare.

ACTIVE AND COHESIVE PROFESSIONAL ORGANIZATION. The lack of a cohesive professional organization in 1981 was evident in the following statement made by Jerome P. Lysaught in a book published that year, titled *Action in Affirmation:* "What is needed for the professionalization of nursing is a new birth of leadership, individual and organizational, that can conceive of ways to unite the more than 20 associations that currently draw their membership from nurses" (p. 24). Activities in the international arena promoted by the International Council of Nurses (ICN) and the World Health Organization would eventually bring nursing in the United States to a more cohesive union.

The ICN, established in 1899 as an independent, nongovernmental federation of national nursing associations worldwide, is the only representative international body of the whole nursing profession. Nursing's involvement in the projects of WHO, an intergovernmental, interdisciplinary agency representing more than 160 countries, is administered by the chief nurse scientist, who maintains communications with the six regional offices of WHO and other international organizations related to nursing. There is a close working relationship between WHO and ICN, both of which are headquartered in Geneva, Switzerland.

In 1977 WHO set the year 2000 as the target date for the attainment of the highest possible level of health for all people and specified primary healthcare as the key to attaining optimal health. In keeping with WHO's goal, the ICN has encouraged its member associations around the world to prepare nurses to participate more fully in a primary healthcare system.

Nursing in the United States has been moving toward a greater role in primary care since the development of the nurse practitioner role. It has, however, needed political influence to achieve this and other reforms. Nurses gained greater political power in 1991 when the American Nurses Association, the National League for Nursing, and the American Association of Colleges of Nursing joined to form the Tri-Council for Nursing; the council was later joined by the American Organization of Nurse Executives. The increasing influence of nursing in the political arena is evident in a document titled "Nursing's Agenda for Health Care Reform" (ANA), developed by the Tri-Council and formally supported by sixty-four nursing organizations in early 1993 ("Additional Endorsements"). The Tri-Council has led the effort to gain acceptance by the U.S. Congress of measures that would increase primary healthcare in community-based settings; foster community responsibility for personal health, self-care, and informed decision making in selecting healthcare services; and facilitate the use of the most cost-effective providers in the most appropriate settings ("Fifty-eight Organizations").

ACKNOWLEDGED SOCIAL WORTH AND STRONG LEVEL OF COMMITMENT. The 1981 Lysaught study reported that the public had a high appreciation of nurses' social worth but that nurses ranked low in commitment because only 40 percent of licensed registered nurses were employed full-time. This was clearly an inappropriate use of quantitative criteria to measure commitment, which cannot be measured in this manner. Commitment in nursing refers to the nurse's determination to foster the well-being of patients/clients. Using qualitative methods, Patricia E. Benner found that commitment to the patient's well-being was present to a high degree in those who were considered excellent nurses. Anne H. Bishop and John R. Scudder Jr. (1990) also found such commitment evident in narratives in which nurses described their most fulfilling experiences as nurses.

The recognition of the "worth" of nursing as a profession has been greatly improved by research findings that have demonstrated the link between levels of nurse staffing in hospitals and adverse patient outcomes, including infections and increased mortality rates (Aiken, Smith, and Lake; Kovner and Gergen; Blegen, Goode, and Reed). This evidence, coupled with widespread shortages of nurses in almost every country, has brought enormous attention to the essential nature of nurses' contribution to healthcare. As has been true historically when shortages reached severe levels, these forces have also begun to prompt improved salary levels, better working conditions, and increased access to education through government subsidies (Buerhaus, Staiger, and Auerbach).

UNIQUE BODY OF KNOWLEDGE AND SKILL. The development of a unique body of knowledge and skill depends in significant measure on funding for research. During the 1970s, the federal Division of Nursing, which is within the U.S. Public Health Service, focused its priorities for research on clinical studies that would determine the health problems needing nursing intervention, the effectiveness of nursing practice, and the means of appropriating research findings into practice for the improvement of patient care. Funding for nursing research was enhanced with the establishment in 1986 of the National Center for Nursing Research within the National Institutes of Health (NIH). The later conversion of the center to an institute—the National Institute of Nursing Research—with the same status as other institutes within NIH, has further established the importance of continued development of nursing knowledge.

The majority of nursing research in the United States in the 1960s and 1970s tended to use scientific models and to approach nursing knowledge as an applied science. Often theories were imported into nursing from the natural and behavioral sciences in an effort to create a credible body of knowledge concerning nursing that would enhance nurses' status in the academic community. This applied approach was perhaps predictable, given that only one-third of nursing educators and scholars took their initial graduate degrees in nursing (Moses). Since the mid-1980s, however, a growing number of nursing scholars have used the qualitative methodology of the human sciences to conduct research in the practice of nursing. The significant increase in nursing scholars holding doctorates continues to broaden the approaches to research in nursing, and the different approaches can be seen in the increasing number of nursing journals, including many devoted specifically to nursing research.

Enhancing the Status of Nursing

A review of the nursing literature demonstrates that nursing continues to seek its identity in almost all parts of the world. Everywhere, nurses face difficulties in establishing the authority of their own practice because of the elevated status of men and the lowered status of women. In a 2001 report from WHO titled *Strengthening Nursing and Midwifery,* low salaries and poor working conditions, often stemming from the status of nursing as a women's profession, was identified as a major cause of persistent nursing shortages in many countries.

Nurses are increasingly attempting to enhance their legitimate authority to direct nursing care by establishing the worth of their own practice. For example, in her 1982 book, *On Nursing: Toward a New Endowment,* Margretta Styles contended that nursing would be "better served by a set of internal beliefs about nursing than a set of external criteria about professions." She proposed the "bare necessities" (p. 121) for professionhood: (1) nurses recognize the social significance of nursing by being certain about the nature and importance of their work; (2) nurses respond to the moral imperative of their work and perform to the utmost of their ability by being well prepared in knowledge, skill, and attitude; and (3) nurses realize that responsibility and authority are shared through collegiality and collectivity in order to preserve the wholeness of the profession.

Benner, author of the 1984 book, *From Novice to Expert: Excellence and Power in Clinical Nursing Practice,* attempted to learn about nursing by studying its actual practice rather than applying theories from outside of nursing. Working with a team of nursing scholars, she used the qualitative research methods of narrative and interpretative phenomenology to describe the experiences of nurses in practice. She identified seven domains of nursing: the helping role, teaching/coaching, patient diagnosing and monitoring, effectively managing rapidly changing situations, administering and monitoring therapeutic interventions and regimens, monitoring and ensuring the quality of healthcare practices, and organizational and work-role competencies. Furthermore, she identified the progression of nurses through five stages, from novice to expert, illustrating each stage with exemplars that reflect clinical knowledge. Benner's study is significant to the advancement of nursing knowledge because it illustrates, in part, that knowledge can be developed from nursing practice itself, as opposed to studies that attempt to reveal knowledge through the application of theories.

Like Benner, Bishop and Scudder Jr. (1990, 1991) showed that phenomenological interpretation of nursing practice is appropriate to the study of nursing. They concluded that nursing is a practice with an inherent moral sense and is appropriately studied as a practical human science. Benner, Bishop, and Scudder are part of a growing number of scholars who are attempting to define nursing by using the concept of caring. They employ qualitative research methodology to clarify the meaning of nursing and to improve nursing.

Conclusion

Those who are interpreting nursing from the inside of nursing approach the meaning of the term *profession* in a different way than those who follow the applied approach. The latter attempt to show that nursing is a profession by applying criteria for any profession to nursing. Using these criteria has helped to establish nursing as a profession; the criteria, however, often function as norms to be achieved, and thus actually form, rather than merely assess, nursing. Those who interpret nursing from the inside are not primarily interested in demonstrating that nursing is a profession, although they are confident that it is when its identity is disclosed. They are attempting to articulate the meaning of nursing as it is practiced and are focused on improving that practice. The nursing practice they describe has advanced in ways that Nightingale could not have foreseen. It is nevertheless the same self-defining moral practice focused on caring envisioned by her.

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SEE ALSO: *Autonomy; Beneficence; Care: Contemporary Ethics of; Compassionate Love; Feminism; Medical Codes and Oaths; Narrative; Nursing Ethics; Nursing, Theories and Philosophy of; Palliative Care and Hospice; Professional-Patient Relationship: Ethical Issues; Profession and Professional Ethics; Teams, Healthcare; Trust; Women as Health Professionals*

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NURSING, THEORIES AND PHILOSOPHY OF

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Any theory or philosophy of nursing involves a quest for nursing identity. The quest that began in the last quarter of the twentieth century has been fostered by several factors, including nursing education's move from the hospital to the academy, changes within nursing itself, and the feminist movement. Although there were nursing schools in a few universities before the 1950s, the movement to place nursing education and research in universities has accelerated since then. This move required nursing to establish its place in an academic setting. Usually nursing schools were placed in the natural or applied sciences, and consequently, nursing initially attempted to establish its identity as a science. The attempt to identify nursing with natural science led to scientific studies of nursing, but these studies, while important, did not show that nursing itself was a science. Recognition that nursing was a human practical activity led to the use of the behavioral sciences to give a scientific account of nursing. In both cases, nursing itself could, at best, be called an applied science. It was hoped that scientific studies of nursing would lead to a theory of nursing and that theory would prescribe nursing practice. But attempts to use theory to prescribe nursing practice were far removed from the way nursing was practiced.

Involvement in an academic setting eventually broadened the meaning of nursing beyond that of applied science. The applied approach had been fostered by nurses taking graduate degrees in other fields and applying their methods and concepts to nursing. The development of master's and doctoral degree programs in nursing fostered a movement away from this applied approach.

Graduate study in nursing developed as nursing became more complex and required nurses to make their own decisions concerning patient care. The development of intensive care units in hospitals initiated the expansion of specialization and technical knowledge into nursing care. As this trend grew, care for patients increasingly required nurses to make decisions without specific directives from physicians. As nurses became more responsible for patient care, they began to question the traditional control of nursing care by physicians and hospital administrators. Critical examination of their dependence on others encouraged nurses to seek an independent identity for nursing.

The feminist movement enhanced the desire of nurses to be independent from control of physicians and hospital administrators. Feminist theorists pointed out that society, including healthcare institutions, undervalued care and nurturing and overvalued command, technology, and hierarchical structure. Feminists enhanced the determination of nurses to become self-directing professionals rather than workers who followed the directions of physicians and administrators.

The Primacy of Caring

As nurses articulated their own practice, they became aware that nursing was focused on care rather than on science or applied science. Beginning in 1978, a series of annual conferences turned to the task of interpreting the meaning of caring as it related to nursing. The significance of this approach to nursing is evident in the following comment by a nurse who attended one such conference: "This is the first time I have ever heard nurses talk about caring or care as related to nursing care. I had nothing like these concepts in my nursing program, and yet they make sense and seem so logical and essential to nursing. In our classes, we were taught about curing medical diseases, understanding medical diagnostic techniques, and everything but caring" (National Caring Conference, p. vi). Published regularly, the proceedings of these conferences constitute a developing interpretation of caring as the source of identity for nursing. Philosophical interpretation of caring has been fostered by the International Association for Human Caring, initiated by Madeleine M. Leininger, and the Center for Human Caring at the University of Colorado, initiated by Jean Watson.

The Phenomenology of Nursing

In her phenomenological interpretation of nursing, Patricia E. Benner articulated the meaning of nursing by drawing exemplars of excellent nursing from concrete nursing practice. In sharp contrast to using theories to prescribe the meaning of nursing, Benner disclosed the meaning of nursing excellence through descriptions of care for patients/clients in specific situations. These exemplars of excellence were interpreted to clarify and enhance the meaning evident in nursing practice. From the study of these exemplars, she identified seven domains of nursing practice with thirty-one distinct nursing competencies. For example, one of the domains is the helping role, and two of the competencies of the helping role are: (1) providing comfort measures and preserving personhood in the face of pain and extreme breakdown; and (2) maximizing the patient's participation and control in his or her own recovery (Benner). Rather than following the tradition in nursing of using definitions of good nursing to prescribe practice, Benner conveyed the meaning of excellence through the work of excellent practitioners. Her study showed that knowledge of excellence gained from practice is essential to any adequate definition of nursing. Benner's work illustrated the use of hermeneutic phenomenological methodology in nursing in that she disclosed the meaning of nursing excellence through exemplars in actual practice and interpreted their significance for the identity of nursing.

Nursing is the practice of caring, according to Anne H. Bishop, a nurse, and John R. Scudder Jr., a philosopher. Like Benner, Bishop and Scudder employed hermeneutic phenomenology to articulate the meaning of nursing (Bishop and Scudder, 1990, 1991). Nursing is a practice in that it is a traditional way of caring for patients that fosters the patient's well-being. The moral sense of nursing inherent in the caring relationship between nurse and patient is disclosed by phenomenological interpretation.

Confused thought has been fostered in nursing by the tendency to use the term *nursing* to mean both care for patients and the study of that care. Bishop and Scudder called the study of nursing the "discipline" of nursing to distinguish it from the practice. They maintained that the discipline of nursing should be a human science because it studies how nurses care for patients. Furthermore, it is a practical human science because the discipline attempts to improve nursing practice as well as to study it. Practices, such as nursing, are expanded and enhanced by the realization of possibilities that are inherent in the practice.

Bishop and Scudder affirmed the tendency to find the identity of nursing in caring. Although they articulated the meaning of care primarily from nursing practice, they found the interpretations of care by feminists Carol Gilligan and Nel Noddings particularly helpful in their articulation. Gilligan's "web of connection" forms a context for an interpretation of nursing as the bringing together of patient, nurse, physician, hospital administration, and family into "wholistic care" (Bishop and Scudder, 2001). Noddings's interpretation of care as engrossment in the situation of the other and shift of concern to the well-being of the other enhances Bishop and Scudder's interpretation of nursing care as fulfillment of the moral sense of fostering the well-being of patients. Bishop and Scudder also argued that the integral relationship between the moral sense and nursing practice is clearly evident in Benner's description of nursing excellence (1984). Nursing practice, as they interpret it, consists of two fundamental stances: first, wholistic care that focuses on cooperative care, articulated by Bishop and Scudder; second, the stance of recognized nursing competence in which nurses are free to direct care, described by Benner. Nursing's purpose, however, is not to become autonomous, as is often stressed by nursing reformers, but instead to foster the patient's well-being. Because nursing has this fundamental moral sense, the primary purpose of ethical considerations of nursing should be to foster excellent care—a care that promotes wellness while respecting the dignity and rights of each person.

Unlike Benner and Bishop and Scudder, who seek the identity of nursing in nursing practice, Sally Gadow (1980) attempted to give nursing a new identity with her interpretation of nursing as "existential advocacy." She drew her conception of existential advocacy from the stress on authenticity that is central to existential phenomenology. "Being authentic," in existentialist phenomenology, entails choosing oneself. Because the primary meaning of being human, for the existentialist, is self-direction, it follows that nurses should become existential advocates who foster authentic human being for those facing illness, treatment, and possible death. The nurse becomes an existential advocate by "participating with the patient in determining the personal meaning which the experience of illness, suffering, or dying is to have for that individual" (Gadow, p. 97).

Nursing Ethics

Pursuit of nursing ethics began in earnest in 1979 when a series of meetings in New York and New England brought together philosophers and nurses to begin development of a specific nursing ethic. Since then, many books and articles on nursing ethics have applied philosophical understanding to the moral dilemmas faced by nurses. Most nursing ethicists have applied philosophical inquiry and/or systems to moral problems that nurses encounter, especially those originating in advances in medical science. A different approach to nursing ethics begins not with philosophical ethics but with the moral imperative inherent in nursing practice. When the moral sense of nursing is given its due, according to Benner (1984) and Bishop and Scudder (1990, 1991), the primary concern of nursing ethics becomes fulfillment of its moral sense. Hence, the primary thrust of nursing ethics becomes fulfilling the moral sense of nursing practice rather than resolving moral problems that, although arising out of practice, are treated as adjuncts to practice.

The philosophers who took part in the aforementioned conferences that brought nurses and philosophers together in search of a nursing ethic also asserted that "the long-standing concern of philosophy to assist in the process of emancipation" should be brought to bear on the "long subjugation of the nurse" by helping nursing move "away from its position of political and intellectual subordinance" (Spicker and Gadow, p. xiv). Nurses, who had long been impatient with being under the control of physicians and hospital administrators, were seeking greater individual and professional autonomy. The demand for greater autonomy was supported by feminist philosophy and by critical theory. Critical theory was used to disclose the hidden power structures in healthcare that denied nurses self-direction (Allen; Thompson).

Nurses also became interested in philosophy from their attempt to challenge the dominant scientific methodology and criteria for knowledge that prevailed when nursing first entered the academy. Recognition that nursing was primarily a human activity concerned with caring relationships between nurse and patient led nursing scholars to become involved in qualitative research and to use the methodology of the human sciences. A significant number of nurses became regular participants in the Society for Phenomenology and Human Sciences and the International Human Science Research Conference. Nursing scholars who found the stress on empirical rational science too restrictive welcomed Barbara Carper's expanded conception of knowledge. She contended that nursing knowledge should include not only scientific empirical knowledge but also three other ways of knowing in nursing—knowledge of how to make morally right choices, knowledge gained from personal experience, and knowledge of how to practice the art of nursing. Carper's patterns of knowing generated much interest among nurses who had long recognized that scientific knowledge alone was not adequate for nursing practice.

Attempts to Develop an Explicit Philosophy of Nursing

Initial interest in investigating nursing philosophically came from the quest for an independent identity for nursing and from encountering issues concerning ethics, knowledge, and justice within nursing itself. These first attempts could be called philosophical interpretations of nursing. An early attempt to foster the development of the philosophy of nursing was the establishment of the Institute for Philosophical Nursing Research at the University of Alberta, Canada. The institute invites nursing scholars with philosophical interests and talents to biannual conferences to discuss issues involved in developing a philosophy of nursing. The institute, through its conferences and publications, seeks to "establish common ground in nursing philosophy, accommodate diversity of thought in nursing philosophy, and articulate a sound philosophy of nursing" (Kikuchi and Simmons, p. 4).

Starting in the late 1990s and continuing into the early 2000s, the pace at which the philosophy of nursing was developing quickened. There is now a journal, *Nursing Philosophy,* that is broadening the philosophy of nursing beyond its former stress on hermeneutic and existential phenomenology to include the analytic, pragmatic, and postmodern traditions. The International Philosophy of Nursing Conference has met several times in Great Britain and Ireland, providing a forum for philosophical consideration. Discussion of the philosophy of nursing is being fostered on an Internet service called Nurse-Philosophy, which was initiated by Scottish scholars who also conduct a series of seminars on the same subject. An entire issue of *Scholarly Inquiry for Nursing Practice: An International Journal* has been devoted to the philosophy of nursing. Jan Reed and Ian Ground wrote an introduction to analytic philosophy, specifically for nurses, that uses nursing examples and considers nursing issues. New philosophies of nursing have expanded philosophical interpretations of nursing to include process and analytic philosophy. Janice M. Brencick and Glenn A. Webster, interpreting nursing from a process perspective, applied philosophical considerations of the universal and particular to nursing practice in their 2000 book, *Philosophy of Nursing.* Unfortunately, they disregarded previous studies of the philosophy of nursing with the exception of the work of Jean Watson. In contrast, Steven D. Edwards, in his 2001 book of the same name, developed an analytic philosophy of nursing in interaction with most of the extant works on the philosophy of nursing and developed a unified philosophy of nursing, thinking as an insider with degrees and standing in both nursing and philosophy.

Future Considerations

As the philosophy of nursing develops and matures, it may become a more integral part of the discipline of nursing. At present, however, many questions remain. Will the philosophy of nursing maintain its initial focus on the meaning of nursing, or will it refocus on philosophical issues and concerns? Will it bring nursing concerns into interaction with understandings, issues, and methods of philosophical traditions, or will it concentrate on philosophical issues and concerns that are to be applied to nursing? Furthermore, will philosophers of nursing become specialists who talk primarily to each other, or will the philosophy of nursing become an integral part of the development of a nursing discipline dedicated to the articulation and improvement of nursing practice?

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SEE ALSO: *Autonomy; Beneficence; Care, Contemporary Ethics of; Compassionate Love; Feminism; Medical Codes and Oaths; Narrative; Nursing Ethics; Nursing, Profession of; Palliative Care and Hospice; Professional-Patient Relationship: Ethical Issues; Profession and Professional Ethics; Teams, Healthcare; Trust; Women as Health Professionals*

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OBLIGATION AND SUPEREROGATION

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Much human behavior in the biomedical sphere is governed by moral principles. Due to their particular importance, medical relationships, in the wide sense of the term, have always been considered to be subject to evaluation in terms of justice, duty, obligation, and rights. Thus, the allocation of medical resources is weighed in terms of justice and fairness; the physician's professional role and powerful status define his or her professional duties; the contractual agreement and the special trust of patients places the doctor under a wide variety of obligations toward them; and the particularly urgent needs and interests of human beings (fetuses, handicapped persons, people in coma, and all sickly people included) grant them the right to be medically treated and respected. The regulation of medical practice under these terms of rights and duties has been acknowledged throughout history and formulated in a series of doctors' oaths. More recently there has been a growing trend to safeguard morally required behavior in medical practice under legal rules, on the one hand, and political (state) control, on the other. This institutionalization of medical relations has led to the effective enforcement of the moral rights and duties of patients and physicians, but also to the depersonalization, even dehumanization, of these relations.

Some forms of heroic sacrifice, volunteering, and beneficence have been traditionally treated as situated beyond the call of duty. This article seeks to establish the important (though limited) role of such behavior in the medical domain, especially against the background of the growing legislation, politicization, and commercialization of medical life. Eager to safeguard universal compliance, impartial distribution, and equal treatment, medical ethicists have tended to ignore the unique virtues of the morality of supererogation as a complement to the morality of duty.

The Theological Sources of Supererogation

The term *supererogation* derives from the Latin verb meaning "to pay out more than is required." The first source for its use as an ethical concept goes back to the Latin version of the New Testament. In the famous parable, the Good Samaritan offers money to an innkeeper to care for a wounded man found on the road, and promises to repay the innkeeper "over and above" for any extra expenses (Luke 10:35). Consequently, Good Samaritanism has been closely associated with supererogatory behavior.

Yet the parable of the Good Samaritan does not distinguish explicitly between the obligatory and the supererogatory, but rather between the merely legally binding (to which the priest and the Levite in the biblical story seem to be exclusively committed) and moral or truly virtuous behavior (manifest in the deeds of the Good Samaritan). The explicit distinction between two types of moral norms, the commanded and the recommended, is better formulated in the contrast between keeping one's lawful riches and leading a life of total poverty (Matthew 19:16–24), or between lawful marriage and self-imposed chastity (1 Corinthians 7:25–28), or between ordinary religious faith and total commitment to a religious way of life.

Perpetual poverty, perfect chastity, and perfect obedience thus became the paradigm cases of evangelical counsels (*consilia*), which, in contrast with the religious commandments (*praecepta*), were considered by the church fathers and medieval theologians (from Augustine to Thomas Aquinas) to be truly meritorious. Other acts, by which one could freely choose to go beyond the religious precepts, included penance, patience, fasting, and martyrdom, as well as mercy (as opposed to justice) and beneficence (as in the bestowal of gifts). Living by the commandments guaranteed salvation, but following the counsels exemplified perfection.

Both the ideal of monastic life and the institution of sainthood were based on the gradually evolving two-level morality of duty and supererogation. Accordingly, two separate systems of norms applied to two categories of believers, ordinary people and those who had a special vocation or a particular moral capacity. In a later stage in the development of the idea of supererogation, it was claimed that the superabundant merit of the acts of those who belonged to the second category of believers (Jesus and the saints) was bequeathed to the spiritual treasury of the church, and could be dispensed by the pope to help sinners achieve salvation. Thus, the two systems of religious morality were linked by a mystical principle of transference of merit, from those who have a surplus to those who are in debt. The system of indulgences was based on the idea that the supererogatory merit of saintly people could compensate for the sins of ordinary folk. But the papal distribution of indulgences, gradually commercialized in the late Middle Ages, became one of the central targets of the reformers' attacks on the Roman Catholic Church.

Martin Luther, John Calvin, and the Anglican Church questioned the theological foundations of the very idea of supererogation. If mortal human beings could not hope ever to carry out the religious precepts or commandments, how could they hope to do more than was required of them? The reformers' belief that salvation could be achieved only through God's grace, rather than through "good works," made the idea of supererogation absurd and blasphemous, a "superabomination." The denial of a two-tier religious morality directly challenged the ideas of sainthood, monasticism, and indulgences. The metaphysical rejection of freedom of the will undermined the Catholic idea of *licentia,* that playroom for the virtuous exercise of free choice to do more than is required, which served as the condition and moral justification of supererogation conduct. The theological debate over the concept of supererogation not only is the historical source for the parallel philosophical discussion in secular ethics, but also may serve as the model for this discussion. For despite the obvious differences between the two arenas (particularly on the objects of supererogatory acts, God and human beings, respectively), they share the basic features of the issue: the relation between goodness and duty, the limits of duty, the nature of free will, the place of virtue and perfection in a deontological theory, and the question of whether there are two categories of moral agents who are subject to moral requirements of different scope and stringency.

Supererogation in Ethical Theory

The subject of supererogation, rather surprisingly, did not receive much philosophical attention in ethical theory until the 1950s. In his pioneering article, James Urmson challenges the traditional tripartite classification of moral actions into the permissible (what one may do), the obligatory (what one ought to do), and the forbidden (what one ought not to do). Saintly and heroic acts are adduced as typical examples of actions that do not fall into any of these categories but still have a distinct moral value. However, breaking the neat framework of the threefold division of moral action turns out to be a controversial enterprise. For example, it has to overcome the resistance of logicians, who try to draw a systematic analogy between the permissible and the possible, the forbidden and the impossible, and the obligatory and the necessary, thus creating a unified system of logic. If an act is morally good, how can it not be obligatory? And if there are good reasons for leaving it *non*obligatory, cannot supererogation be analyzed in terms of the permissible? And finally, should supererogatory behavior not be considered forbidden, as a dangerous illusion of conceited and morally self-indulgent agents, who violate self-regarding duties and the principles of impartiality and fairness?

There are three kinds of answers to these questions regarding the seemingly paradoxical nature of supererogation: anti-supererogationism, qualified supererogationism, and unqualified supererogationism. Anti-supererogationism denies the existence of actions that go beyond the call of duty. Pure deontological theory, such as Kant's doctrine of the categorical imperative, is a typical example of this view. Obligatoriness (moral necessity) exhausts the moral sphere; duty is the only legitimate motive in morality; and universalizability is the ultimate test for the morality of actions. Hence there is no room for the nonobligatory, charity-based personal action that is typical of supererogation. Acts of beneficence or heroic self-sacrifice are either "imperfect duties" (which for Kant are no less binding than their "perfect" counterparts) or cases of moral fanaticism motivated by self-love.

Some forms of utilitarianism are no less anti-supererogationist. Thus, for the eighteenth-century utilitarian William Godwin, promoting the overall good (including the agent's) is the absolute and only moral duty. This view leaves no room for supererogatory action (e.g., doing a favor), since either its beneficiary has a "complete right" over it or it is wrong ("unjust") to do it because of other people's rights (including the agent's). The derivation of "ought" statements from statements about the good (utility, happiness) leads George Edward Moore, too, to a straightforward denial of supererogation.

Modern utilitarian theorists point to the logical difficulty in distinguishing between utility-promoting actions that are obligatory and utility-promoting actions that are not obligatory, since such a distinction requires an appeal to a nonutilitarian principle. The common ground on which deontological and consequentialist anti-supererogationists rest their case seems to be the purely impersonal conception of morality, a conception typically expressed by the universalization principle or the classical utility principle of an agent-independent promotion of overall goodness "in the world." Impersonalism of this kind leaves no room for altruism, personal sacrifice, or the expression of individual preference.

Qualified supererogationism tries to do more justice to our common belief in the value of supererogatory conduct. It concedes that in some abstract or ideal sense every good action is obligatory, but highlights the circumstances that make such a morality too demanding, even absurd. Some utilitarians, like John Stuart Mill, distinguish between the prevention of harm (which is obligatory) and the altruistic promotion of the good (which deserves gratitude, honor, and moral praise). Henry Sidgwick is willing to distinguish between what a person ought to do and what people are justified in blaming him or her for not doing. Thomas Aquinas states that while the commandments apply to everyone, the counsels are directed only to the few who are capable of following them or who have made the life of perfection their special vocation. Rule utilitarians, as well as contract theorists like David Richards, point to the possible decrease in overall happiness through the adoption of a general rule enforcing supererogatory action as a duty, and at the same time to the general social benefit derived from leaving it to individual discretion. Even Kant, in his later ethical writings, acknowledges the existence of "duties of virtue" that "others cannot compel us (by natural means) to fulfill," as they are concerned with the adoption of ends, are binding only in the "internal" sense, and create no corresponding rights in the recipient. Finally, John Rawls and Joseph Raz analyze supererogation in terms of exemption: the exemption that "natural duty" allows in cases of high risk or loss to the agent (Rawls), or that granted by the second-order "exclusionary permission" not to act on the best balance of first-order reasons (Raz).

Qualified supererogationism is reductive in nature: it insists on accommodating supererogatory acts within a deontic framework (i.e., the language of duties and obligations). Every moral action is in principle required, though considerations of exemption, risk, disutility of enforcement, personal (in)capacity, excuses, difficult psychological circumstances, and rights define a supererogatory subcategory. Unqualified supererogationism, on the other hand, insists on placing the supererogatory "beyond duty" in the absolute, nonreductive sense (Urmson; Feinberg; Heyd). Supererogatory behavior is fully optional, that is, it lies beyond any kind of duty, under any condition, and for any moral subject. No excuse is needed for not acting heroically.

Definition and Justification of Supererogation

Most definitions of supererogation display the same general form, pointing to the asymmetry of commission and omission of actions. Thus supererogatory acts are said to be those acts that are good to do but not bad not to do, or right (just, virtuous, praiseworthy) to do but not wrong (unjust, vicious, blameworthy) to refrain from doing. These definitions, however, fail to capture either the special merit of supererogatory acts or their particular optional character. More sophisticated attempts retain the asymmetry but mix the contrasted pairs (e.g., "non-obligatory well doings," according to Roderick Chisholm, or "meritorious non-duties," according to Joel Feinberg). Still, the definition of supererogation, at least of the unqualified version, must refer explicitly to the normative status of the acts in question, to their particular value, and to the person-relative features of these acts (the agent as well as the recipient).

A possible definition contains the following four conditions for an act to be supererogatory:

1. It is neither obligatory nor forbidden.
2. Its omission is not wrong and does not deserve sanction or criticism, either formal or informal.
3. It is morally good, both by virtue of its intended consequences and by virtue of its intrinsic value (being beyond duty).
4. It is done voluntarily for the sake of someone else's good, and is thus meritorious.

The first condition characterizes supererogatory acts in negative terms (being nonobligatory), but the second emphasizes their purely optional nature. This distinction between the permissible and the optional points to the specific double value of the latter as opposed to the moral neutrality of the former: it is not only the good effect of supererogatory action that makes it praiseworthy; it is its motive, which is completely "free," that is, not even an "ought." This combination of desirable consequences and virtuous motive is the source of the moral merit ascribed to the agent of supererogatory acts.

It should be noted that the goodness of supererogation lies in its leading to consequences that are of moral value, that is, of the same type or on the same scale as those of obligatory action. This is clearly manifest in supererogatory transcendence of duty, such as “going the second mile” or doing more than one’s job requires. In that respect, supererogation is continuous with the morality of duty. But the fact that the source of the value of a supererogatory act lies no less in the voluntariness of its motive points to its conceptual dependence on the idea of duty, that is, its being correlative to duty. It should be noted that there are ethical theories that are not based on the concept of duty at all (but rather on the idea of virtue, as in Aristotle). Such theories do not leave room for supererogation as it is defined here.

The general justification of supererogation is twofold: on the one (negative) hand, it has to do with the basic autonomy of individuals to lead their lives in ways not always subordinated to moral principles such as the overall good. On the other (positive) hand, it is associated with the supplementation of the impersonal and universal core of ethical theory with a personal dimension. This is expressed both by the agent’s discretion and by the choice of the particular recipient of the beneficent act. Supererogation in that respect is highly important for social cohesion, trust, and friendship in society—values that cannot be fully achieved even in an ideally just society in which every person performs his or her duties and obligations. This justification for unqualified supererogationism is reminiscent of the debate about the legal enforcement of morality: In the same way that there are moral reasons for leaving some moral duties beyond the reach of the law, so there are moral reasons for leaving some morally good acts out of the system of moral duties and obligations. The Good Samaritan first took care of the wounded man (which was not his legal duty but certainly his moral duty); then he offered to pay the innkeeper “over and above,” that is, for the expenses involved in housing and feeding the man (which was not even his moral duty).

Typical examples of supererogatory acts are saintly and heroic acts, which involve great sacrifice and risk for the agent and a great benefit to the recipient. However, more ordinary acts of charity, beneficence, and generosity are equally supererogatory. Small favors are a limiting case, because of their minor consequential value. Volunteering is an interesting case of supererogation, because it refers to the procedure by which the agent of an obligatory act is selected. That is to say, someone ought to do the act, but due to its particular difficulty or risk, it is hard to decide who. Finally, there are supererogatory forbearances, in which the agent refrains from taking a morally justified action that would have a negative impact on another. Forgiveness, pardon, and mercy are typical examples: we would have been justified in punishing a criminal, but we decided to exercise mercy or pardon.

Supererogation in Medical Ethics

The place of supererogation in medical ethics has been almost completely ignored, both in the theoretical discussions of supererogation and in the vast literature on medical ethics. This might be explained by the fact that both fields are relatively new, and by the tendency to bind the vital aspects of medical practice and relationship in a firm system of well-defined rights, duties, and obligations. The issues of confidentiality, informed consent, abortion, euthanasia, and allocation of scarce resources revolve around the debate on the rights of patients and the duties of doctors, the principles of justice, or the responsibilities of state and society to their members. However, there are some areas of medical practice in which supererogation has a central role to play, cases that could also help in understanding and justifying the theoretical distinction between obligation and supererogation: the collection and allocation of blood, organ donation, surrogate motherhood, and medical experimentation.

Anti-supererogationists would tend to deny that some medical matters lie beyond the sphere of moral duty and social justice. In their attempt to reduce allegedly supererogatory conduct to one of three categories—the obligatory, the permissible, and the forbidden—they may, for instance, claim that blood donation is a moral duty, that surrogacy arrangements should be completely forbidden, or that participation in medical experiments should be left to the morally neutral (permissible) regulation of the free market. Grounding vital medical relationships in supererogatory altruistic motives offends our moral sense of equality, both in the access to treatment and in the undertaking of risks. Legislation and the market are two powerful alternatives that safeguard impartiality and personal neutrality, which are principal values in the ethics of duty and justice.

Qualified supererogationists would admit that ideally all medical practice should be subjected to universal deontic principles, especially since it deals with matters of life and death in which we want people to have equal chances, rights, and duties. But they point to the limit of what can be expected of individuals by way of giving and taking risks, particularly when the sacrifices required are of the same kind as the health needs of others that create the call for sacrifice. Therefore, when the health of a sick person requires an organ donation that would expose the donor to serious health hazards, one must leave the decision to the personal discretion of the donor. Institutional control or regulation under impersonal rules (such as legislation) is immoral, either because most people cannot make the required sacrifice ("ought" implies "can"), or because it could be counterproductive in utilitarian terms (the sacrifice of the donor being greater than the potential benefit to the recipient). Furthermore, the market mechanism, which is so efficient in much of our economic life, may lead to the exploitation of the poor by the rich or to other morally repugnant consequences related to the commercialization of human life and health.

The unqualified supererogationist shares many of these apprehensions but adds a positive justification for a "moral free zone" in medical life. Beyond the realm of relations of duties and rights, there is in medical practice some room for a totally free exercise of giving. It is a reflection of personal autonomy; it is grounded in a personal interest in another individual, and it creates personal relations; it strengthens social ties and cohesion. Blood donation is a typical example. Collection of blood for medical use in modern society can be based on a free-market system in which blood is freely bought and sold, or on a legally enforced system of duties (e.g., of young people to donate blood once a year), or on a fully voluntary system, as in Great Britain, in which people volunteer to give blood and patients get it free. Economists like Kenneth Arrow favor "the economy of charity," and believe that the market can better handle the needed balance of supply and demand of blood. Furthermore, they claim that altruism is itself a scarce resource, and therefore should be used only when necessary. Richard Titmuss and Peter Singer, on the other hand, argue that the commercialization of blood donation is potentially destructive to society, especially because it concerns a "commodity" that has no price, that is, it is extremely valuable to the recipient and of almost no value to the donor. They add that altruism is not a scarce resource but, rather, a good that grows the more it is exercised. The supererogatory model is thus considered as superior both to the market mechanism and to the political (legal) arrangement of collection and allocation.

The donation of organs (like kidneys) is different in that it is much more costly to the donor than the donation of blood (particularly in the case of living donors). It is also more personal than the anonymous donation of a blood bank, as it usually involves someone personally close to the donor. Unlike blood donation (which may be considered morally obligatory though not legally enforceable), giving away a nonrenewable part of one's body is typically supererogatory, in the "saintly and heroic" sense. Ideals of personal responsibility, family ties, friendship, and particular emotional commitments make personal sacrifices like organ donation valuable beyond their sheer utility (which sometimes is tragically doubtful).

Surrogate motherhood can also be regulated by market mechanisms or left to voluntary, altruistic agreements. Beyond the controversial aspects of surrogacy (having to do with the interests of a third party, the child, and with the possibility of a change of mind by the surrogate mother), we may note that most legal systems prefer to leave it as a supererogatory matter. Thus, agreements on surrogacy are not considered criminal (forbidden) in many countries but are not enforced by the courts (in contrast with ordinary contracts). Commercialization is often treated as undesirable, even patently immoral and illegal.

Finally, medical experimentation on human subjects in most countries is now allowed only on the basis of volunteering. No person, sick or healthy, is required (legally or even morally) to take part in any experiment. On the other hand, participating in the enterprise of medical research and progress is definitely of great moral value. By altruistically giving our share to medical research, we express our gratitude to those in the past who made us beneficiaries of medical progress (Jonas). The supererogatory nature of participation in medical experimentation is typically connected to the case of volunteering, in which it is a moral "ought" that someone (in a group) do the job but no particular individual can be identified as having to do it. As opposed to any selection procedure based on substantive criteria (like merit), or formal criteria (like random devices, which are particularly attractive as a fair means of imposing burdens in risky situations), volunteering is completely supererogatory.

We may conclude, then, by pointing to the special status of supererogation in some aspects of medical ethics as combining the advantages of both morality and the market, as well as avoiding some of the dangers of both. A supererogatory system of blood collection is on the one hand of moral worth (no less, and even more, than its alternative regulation according to principles of duty fairness in a politically centralized system of collection and allocation), yet fully optional (as in the case of buying and selling in the market). On the other hand, it avoids the danger of exploitation, typical of the market mechanism, as well as the danger of compulsion, typical of often-abused political power or of social pressure. Supererogation can partly counter the undesirable trends of both commercialization and politicization of modern medical life by leaving an outlet for the autonomous and spontaneous exercise of supererogatory beneficence.

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SEE ALSO: *Beneficence; Care; Compassionate Love; Epidemics; Ethics: Normative Ethical Theories; Family and Family*

Medicine; Long-Term Care: Home Care; Maternal-Fetal Relationship; Medicine, Profession of; Nursing Ethics; Organ and Tissue Procurement; Professional-Patient Relationship

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OCCUPATIONAL SAFETY AND HEALTH

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I. Ethical Issues
II. Occupational Healthcare Providers

I. ETHICAL ISSUES

The workplace setting presents unique problems for public health because, on the one hand, virtually all its hazards are environmental and can be prevented or controlled, while, on the other hand, it is a setting for social conflict with large economic stakes. Occupational injury and disease are economic phenomena resulting from social decisions about technology and the use of labor in the production of goods and services. The rights of property owners, even in state socialist systems; the economic obligations of managers to owners of enterprises; and the imbalance of power between labor and management present particular problems for occupational health. The position of health and safety professionals in industry is frequently problematic because of tensions between their responsibilities to employers and the ethical codes of their professions. The imperatives of production and profit frequently override other responsibilities for the health and welfare of employees.

Industrial hygiene is the principal profession applying scientific and engineering methods to the protection of workers from toxic chemicals, dust, other air contaminants, and job hazards. The basic industrial-hygiene approach to the work environment places engineering controls at the top of a hierarchy of methods for workers' health protection. This approach is enshrined in the ethical codes of the profession. A typical listing of industrial-hygiene approaches places substitution, process change, and isolation or enclosure at the top of the list. Methods that rely on personal protective equipment are considered less effective and are to be resorted to only when engineering controls are not feasible. The professional emphasis is on management's responsibility to provide a safe work environment rather than on workers' self-protection or adaptation to hazardous conditions.

Equity, or fairness in the distribution of society's material benefits, is not a primary concern in the economic theory or operation of the modern market. Public policy is predicated on the assumption that market mechanisms promote and reward efficiency. Policymakers presume that tax and/or subsidy policy will be used to cushion the effects on individuals or groups damaged in socially unacceptable ways, such as utter impoverishment. The market model minimizes the costs of factors of production, including labor, through entrepreneurial pursuit of profit. The role of government is restricted severely. Since consumer choice rules in the model, firms are guided in the production of goods and services by the willingness of consumers to pay, and resources are directed to consumers' financially expressed desires. Selfish motives are presumed of everybody, yet the model claims efficient results.

Even the strongest advocate of the market economy understands the limits of market efficiency. In the market model, collective consumption of goods and services, such as national defense, malaria control, road building, and the like, may be handled legitimately by the government. Further, where there are monopolistic imperfections in markets, where information is restricted or the mobility of labor and capital is impaired, the government may intervene. In addition, where costs or benefits are not internalized by the firm, air, water, wild animals, and the like are "free goods"; they cannot be considered in entrepreneurial calculations and "inefficient" solutions may result. For instance, a firm may use a process hazardous to human health if it will not bear the cost of worker illness that occurs years later. The existence of externalities is an argument for government intervention to force private parties to internalize these costs.

On what grounds does the government intervene to protect workers' health? Some would argue that imperfect information, imbalances in bargaining power, and other deviations from the perfect market model require that the state intervene on behalf of workers' health and safety. Others would argue that even if markets were working perfectly, the society has an overriding interest in the health of its members, including workers, and that it has a longer time frame than any of the market participants is willing to consider. Thus, market failure to deliver socially desirable ends, because of either imperfections or externalities, justifies state intervention.

Historical Overview

Occupational health has rarely received much attention from the public. Historically, the commitment of the United States to economic advancement through technology has made its society myopic about its toll on workers' health. Through much of U.S. history, workers themselves have been too engaged in the pressing task of making a living for their families to pay much attention to widespread occupational safety and health problems. The labor movement has not been strong enough to force public attention to these issues on a continual basis.

In Europe, the tradition of occupational medicine is much greater. In the sixteenth century, the occupational health problems of miners and foundry and smelter workers were studied by Paracelsus. Bernardino Ramazzini (1633–1714) wrote a classic text on the occupational diseases of workers.

The industrial revolution brought a host of new health and safety problems to European workers. The social reform movements in England, for instance, sought protection for child labor and to restrict the working day to ten hours. Protective labor legislation was passed in 1833 (the Factory Act) and in 1842 (the Mines Act). Both occupational medicine and the trade union movement in Great Britain were launched in the nineteenth century as responses to awful conditions in many workplaces.

In the nineteenth century, the industrial revolution brought to the United States a host of safety problems and some public concern. Massachusetts created the first factory inspection department in 1867 and in subsequent years enacted the first job safety laws in the textile industry. The Knights of Labor, an early trade union, agitated for safety laws in the 1870s and 1880s, and by 1900 minimal legislation had been passed in the most heavily industrialized states.

After 1900, the rising tide of industrial accidents resulted in passage of workers' compensation laws; by 1920 virtually all states had adopted this no-fault insurance program. Previously, workers seeking financial compensation and medical care for industrial accidents had to sue their employers—and their employers had three extremely effective defenses. First, the courts accepted the notion that in a free market, workers assumed the responsibility for established occupational risks. Second, employers were absolved from responsibility for accidents to the extent that a worker's own actions contributed to the mishap. Third, in the eyes of the courts, employers were not financially responsible for injuries caused by fellow employees of the injured worker. In an economy of highly skilled artisans in which the labor process was controlled by the workers themselves, this defensive troika might have been reasonable; in an economy of mass production, high-speed assembly lines, and detailed division of labor, the illusion of worker autonomy fell of its own political weight. No-fault industrial accident insurance was the solution adopted by the states.

Throughout the 1920s, the rise of company paternalism was accompanied by the development of occupational medicine programs. Much attention was paid to preemployment physicals rather than industrial hygiene and accident prevention. Occasional scandals, like cancer in young painters of radium watch dials, reached the public attention, but until the resurgence of the labor movement in the 1930s, Congress did not pass important national legislation. The Walsh-Healey Public Contracts Act of 1936 required federal contractors to comply with health and safety standards, and the Social Security Act of 1935 provided funds for state industrial-hygiene programs. The Bureau of Mines was authorized to inspect mines.

After World War II, occupational health and safety again receded from public attention, as sympathy for the labor movement declined and the nation took a turn to the right. An exception to the general neglect of the field was passage of the Atomic Energy Act of 1954, which included provision for radiation safety standards. Not until the 1960s, when labor regained some political influence, did the issue reemerge. Injury rates rose 29 percent during the 1960s. A major mine disaster in 1968 at Farmington, West Virginia, in which seventy-eight miners were killed, captured public sympathy. In 1969, the Coal Mine Health and Safety Act was passed, and in 1970, the broader Occupational Safety and Health Act became law.

Regulatory Effects

A fundamental aspect of the new law was the unambiguous statement of employer responsibility for occupational health and safety. A new regulatory agency, the Occupational Safety and Health Administration (OSHA), was created in the U.S. Department of Labor. OSHA could require employers to provide safe and healthy workplaces and to promulgate and enforce safety standards. In addition, the OSHA Act established the National Institute for Occupational Safety and Health (NIOSH) as part of the U.S. Public Health Service, to do research and evaluate health hazards in the work environment.

Initially, OSHA adopted a host of so-called consensus standards. In addition to extending the Walsh-Healey regulations for government contractors to the rest of industry, the new agency adopted many of the voluntary guidelines developed by the American National Standards Institute and the American Conference of Government Industrial Hygienists. While this enabled OSHA to enter the field running, with standards to enforce, many of the guidelines were inappropriate as legal standards. Some were contradictory; others were overly detailed or anachronistic. For instance, OSHA adopted a requirement that toilet seats be split in the front, an idea that persisted from the day when people believed syphilis was caught from contaminated toilets. When Eula Bingham became head of OSHA in 1977, one of her earliest and most important tasks was standards simplification: throwing out inappropriate, ineffectual, or silly standards.

The process of developing new standards, however, was slow and cumbersome, involving substantial litigation before any new worker protection was extended. Perhaps the most tortuous path was that of the field sanitation standard for farm workers, which required that farmers provide clean water and toilet facilities for workers in the field. The standard took fourteen years to develop and ultimately was issued only because the courts required OSHA to do so. However, when OSHA, in a heroic effort to update its standards, adopted hundreds of new permissible exposure limits for air contaminants in the late 1980s, this wholesale revision was rejected by the federal courts as failing to meet the procedure required for standard development. In any case, since OSHA's inception, enforcement of standards has left much to be desired, largely because of understaffing.

While the OSHA Act covered most workers in the private sector, the Coal Mine Health and Safety Act established a special regulatory body to deal with the high-risk mining industry. Authority to regulate pesticide exposure of agricultural workers was assigned to the U.S. Environmental Protection Agency (EPA); OSHA bears responsibility for other aspects of farm employment, such as migrant-labor camp conditions and field sanitation.

The most important extensions of worker protection in recent years have been linked to growing public concern with general environmental issues. For instance, amendments to federal environmental laws in 1987 required both OSHA and the EPA to adopt safety and training requirements for a broad range of hazardous-waste workers and emergency personnel dealing with hazardous materials.

Federal government policy during the 1980s was characterized by a neoconservative, antiregulatory stance. Public-health advocates complained of the slow pace of OSHA standards promulgation, the federal ceding of enforcement authority to states, the failure to protect worker-complainants from employer discrimination, and the decimation of NIOSH's budget. The decline of the U.S. trade union movement has further weakened the political impetus for OSHA enforcement activity. In the early 1990s, efforts at legislative reform stressed streamlining OSHA procedures for developing standards and enhancing workers' right to act.

Perhaps the most pressing problems in occupational health arise from the increasing integration of the world economy. In North America, the development of a continental free-trade agreement may threaten the work environment standards of Canada and the United States while bringing a host of new hazards to Mexico. The export of hazardous technologies, products, and waste represents increasing challenges for public health worldwide. On the one hand, our understanding of the nature of health hazards to workers has been improving; on the other hand, the restructuring of the world economy may undercut the political will to control these hazards.

The Rights to Know, to Refuse, to Act

Until the 1980s, workers in the United States did not have a legal right to know the names of hazardous materials to which they were exposed. This seems odd, since even market economists argue that good information is necessary if markets are to reflect working conditions correctly. Nevertheless, it was not until 1980, in the final days of the Carter administration, that OSHA promulgated a “right to know” regulation. The Reagan administration withdrew the proposed rule in 1981, and a political fight for this right ensued on state and local levels. Time and again, coalitions of workers' organizations and community environmental groups won state and local laws mandating the right to know. Finally, OSHA came forth with the Hazard Communication Standard, which, although not as rigorous as some of the local ordinances, nevertheless extended a fundamental right to a wide range of workers across the country. This public-health regulation had to contend with competing property rights of corporations, such as the protection of trade secrets. Proposed legislation that would have required notification of workers discovered in NIOSH studies to be at high risk of occupational disease failed to pass Congress for such economic reasons. In addition, conservatives discovered that providing information involved economic costs to employers and sometimes to government. Companies argued that they should not be required to reveal essential substances or aspects of production processes because business competitors might obtain this information. OSHA was required to balance the protection of worker health with the protection of business's intellectual property rights.

Soon after the Hazard Communication Standard became law, labor advocates argued that the right to know was of little use as long as workers could not use such information to change hazardous working conditions. The OSHA Act made the violation of safety regulations an offense punishable by the government but gave workers only a very limited right to refuse hazardous work, and then only when there was objective evidence (not just fear) of imminent life-threatening danger. Moreover, the OSHA Act focused on the rights of individuals, not on collective worker action for health and safety. Health and safety advocates demanded an expanded right to refuse hazardous work, as well as the mandating of workplace health and safety committees with the right to act. Such committees, which already exist in countries other than the United States (Sweden, for instance), would mark a major departure in the regulatory approach in the United States. Worker empowerment is a substantially different approach from state regulation of the work environment.

Medical Monitoring, Reproductive Hazards, and Hazards to Minority Workers

Even though there is a long history of the use of preemployment examinations by occupational physicians in the United States, medical testing and monitoring remains a controversial area. Key ethical issues include confidentiality of medical records; inappropriate discrimination against minorities, women, and disabled or hypersusceptible employees; and “blaming the victim” vs. reducing exposures. Some OSHA standards require medical monitoring; perhaps one of the most distressing issues is the failure of OSHA and employers to analyze accumulated data systematically.

Because job segregation by gender continues to exist in the United States, women and men sometimes experience different health hazards. Perhaps the most controversial now concern reproduction. Some employers have sought to bar fertile women from jobs in which exposures to hazardous chemicals are within legal limits but may pose risks to a fetus. In some instances, where removal from such work involved serious income and/or opportunity loss, some women have agreed to sterilization in order to meet employer “fetal protection” requirements. Women's organizations and trade unions argue that such policies constitute unfair discrimination against women. The U.S. Supreme Court prohibited such policies in its decision in the case *Johnson Controls, Inc. v. UAW* in the spring of 1991 (110 S.Ct. 1522, 111 S.Ct. 1196).

Similarly, discrimination against and segregation of workers of color in the United States results in their having some of the most hazardous jobs. The situation of illegal immigrants exacerbates the problem, since they are fearful of turning to government for protection. Minority workers frequently have no union representation and are at the mercy of particularly exploitative employers. Migrant farm workers experience some of the most difficult conditions, in part because responsibility for their protection is split between the EPA, which regulates pesticides and related chemicals, and OSHA, which regulates labor camps. Domestic workers are another group largely composed of people of color who have little protection.

Workers' Compensation, Cost-Benefit Analysis, and the Value of Life

When workers are injured or killed on the job in the United States, workers' compensation programs at the state level are supposed to provide quick income support and medical care or a death benefit. These programs may provide a maximum of two-thirds of the average wage in the state, the rationale being that workers must have a financial incentive to return to work. No payment for pain or suffering is allowed. Workers are barred from suing their employers in this "no-fault" insurance scheme. There is no question that many workers suffer severe economic, as well as physical, hardship as a result of industrial injuries. Nevertheless, many employers complain about "cheaters" and fraud in the system, as well as about rising insurance premiums.

There is much debate about whether workers' compensation provides adequate compensation to workers who are injured on the job, and about the efficacy of the system for preventing injury; however, it seems evident that the system does not deal effectively with occupational diseases such as cancer and respiratory diseases. Workers have the burden of demonstrating that their illness is job-related. Diseases of long latency and that may have multiple causes are rarely diagnosed as occupational and workers suffering from them are rarely compensated. Because the workers' compensation system failed to deal with asbestos-related disease, workers' attorneys initiated third-party liability suits in the 1970s and thereafter against asbestos suppliers, who, although they were not direct employers of the sick workers, had failed to warn asbestos product users about the hazards of the material. In this way, the inadequacies of the workers' compensation system have driven the occupational disease problem into the civil courts. Essentially, both the workers' compensation system and the civil courts place dollar values on worker health or life by making employers or suppliers pay monetary compensation for occupational disease or injury. Massachusetts, for instance, publishes a chart indicating the amount of money a worker will receive, under its workers' compensation regulations, for loss of different parts of the body. This system is not a satisfactory way to provide equitable compensation to sick workers because of the lengthy proceedings, the legal expenses, and the high probability that suits will fail.

Workers' compensation programs are not the only situations in which dollar values are placed on workers' health or life. Under the Reagan administration, all regulatory agencies had to calculate the costs and benefits of proposed government regulations. Thus OSHA was forced not only to estimate the costs to industry of compliance with new standards but also was required to place a dollar value on the lives and/or health saved. Economists have devised a variety of ways to estimate the value of a life through surveys of "willingness to pay" to save a life, analyses of apparent risk premiums (higher wages for higher risk jobs) in labor markets, and other techniques for evaluating human capital. Estimates range from as little as $28,000 to several million dollars per life saved. Perhaps the most common approach is to imagine that a worker is a bond or security that will yield a return for some years in the future and that the stream of earnings a worker would receive is a reasonable measure of the worker's productivity. How much such a bond (or worker) would be worth now depends on the size of the earnings stream and on the interest rate that an investor could obtain on alternative bonds or securities. Thus, the present value of human capital can be calculated, and the value of lives saved or lost can be compared with the cost to industry of improvements in the work environment. It is important to note that economists always discount the future: Economists believe that the gain or loss of a dollar ten years from now counts less than a gain or loss of a dollar now. Another approach is to compare the wages of risky jobs with those that are less risky. Then the risk premium is considered to be the amount that workers themselves assign to their health. In a manner similar to the human capital approach, such calculations require us to assume that the markets work well and that wages are adequate measures of the value of labor and reflect the preferences of workers.

Some public-health advocates have argued that there is an inherent antiregulatory bias in such cost–benefit analysis because of the difficulties of placing dollar values on nonquantifiables such as pain, suffering, loss of loved ones, and the like. In addition, cost–benefit analysis attempts to equate economic losses of employers with health and life losses of workers, which critics argue is inappropriate. Another serious difficulty is the problem of discounting the future. What is the appropriate interest rate to use in calculating the present value of a stream of costs or benefits that extends into the distant future? Who should decide the worth of a health benefit twenty years from now? Proponents of such economic approaches claim that there is really little choice in the matter, that public policy requires such calculation. People balance costs and benefits in an ongoing, practical way, even if exact calculations are not made. Certainly, companies must do such balancing. Thus, cost–benefit analysis utilizes market-based evaluation in situations brought about by the failure of the market to treat worker well-being adequately.

Society, by enacting laws and regulations through the political process, has decided to try to override the market. In the United States, as in other nations, worker health and safety appear to be attended to inadequately by employers and managers in charge of production. Even when workers have this information about occupational hazards, they frequently seem to lack the economic power to act to protect themselves. When government intervenes to protect workers, business interests have reasserted their belief in the primacy of economic concerns. Worker health and safety is an important arena in which the values of the market and the values of health and society are in conflict.

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SEE ALSO: *Environmental Health; Hazardous Wastes and Toxic Substances; Harm; Public Health Law; Injury and Injury Control;* and other *Occupational Safety and Health* subentries

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II. OCCUPATIONAL HEALTHCARE PROVIDERS

Occupational-health services—the focus of professional personnel, their healthcare and equipment, the programs offered for the prevention of disease and promotion of wellness—have become an increasingly important field in preventive medicine and public health during the twentieth century. The goal of these services is to develop and implement interventions that improve the health and safety of the workplace. They have advanced not only as a result of general developments in preventive medicine and public health but also because of increasing emphasis on the rights of employees and their overall welfare.

The occupational-health profession faces challenges represented by global economic competition, changes in labor force demographics, expanding markets, and new and different occupational and nonoccupational hazards to which workers are exposed. Occupational epidemiology is flourishing, and detailed studies of groups at risk are demonstrating previously unrecognized associations between work exposure and certain adverse health effects. Striking advances in molecular biology are bringing new tools and new insights into cellular aberrations induced by occupational exposure to physical and chemical agents, potentially offering the possibility of very early detection of occupational disease or risk, including risks to the fetuses or offspring of workers. New rules and regulations are helping workers gain information on the toxicity of materials with which they are working and the precautions that must be taken to prevent excess exposure. Good translations of the technical literature into appropriate language ensure that previously guarded information becomes available to work groups. At the same time, the consumer movement has demanded and spread available data, and the Freedom of Information Act has brought disclosures of data not previously available. All these developments have significant ethical implications for the practice of occupational health, and therefore for those who engage in that practice: occupational-health professionals in occupational-health surveillance, specifically, screening programs. The ultimate goal of these services is to develop and implement interventions that improve some aspect or modify determinants of the health and well-being of people who work. Before embarking on an overview of these ethical issues, it is well to consider the relationships of occupational-health professionals to industrial management, relationships that may have ethical implications. Occupational health services may be provided through: (1) a complete in-plant health program with a full-time physician; (2) a partial in-plant health program with a physician in attendance for a portion of the day; (3) an out-of-plant medical program executed almost exclusively in the offices of private physicians; or (4) contract health programs.

In the complete in-plant health program, organizational placement of occupational-health professionals in the managerial structure may suggest to employees that the surveillance activities operate exclusively to protect the company. And although this situation has markedly improved, too often in the past many occupational-health professionals took the position that the company was always right. Such professionals ignored their responsibility to advise management on all matters pertaining to the health of employees, including deficiencies that required resolution or correction. The economic interest of the company may prompt management to pressure occupational-health professionals into a position of unilateral loyalty. This may lead to the expectation by managers that because the occupational-health physician is "one of them," some or all risk-assessment data, including information regarding chemical or other hazardous exposures for certain employees, will be shared irrespective of its confidential content. Unquestionably, the goal of a healthy company and the goal of healthy workers can collide, and when they do come into conflict, occupational-health personnel must be aware of their ethical responsibility to the health of the workers and to the principles of occupational medicine.

As industries seek to reduce the cost of health services, and as the social and scientific context of the workplace changes, less than full-time on-site occupational-health services may become more common. These arrangements can raise ethical issues of another kind, including questions about active advertising or direct solicitation of contracts for such services and about "self-referral"—the physician's referral of patients to an outside facility in which he or she has a financial interest. Growing evidence suggests that more and more physicians own healthcare facilities to which they refer patients for services but at which they do not practice. The danger in occupational medicine is that part-time physicians may be strongly tempted to see their work as a golden opportunity to generate patients for off-site, private treatment facilities in which they own an interest, including services covered by workmen's compensation (Swedlow et al.).

The principle that guides these relationships of service is that physicians and other occupational-health personnel cannot use their relationship with industry as a means to build their private practice. The American Medical Association's Council on Ethical and Judicial Affairs affirmed:

> However others may see the professional, the physicians are not simply business people with high standards. Physicians are engaged in the special calling of healing, and in that calling they are fiduciaries of their patients. They have different and higher duties than even the most ethical business purpose. There are some activities involving their patients that physicians should avoid whether or not there is evidence of abuse. (Council on Ethical and Judicial Affairs)

The Code of Ethical Conduct for Physicians Providing Occupational Medical Service emphasizes this principle in the following way: "Physicians should … avoid allowing their medical judgement to be influenced by any conflict of interest." Addressing the same issue, the *Guide to Developing Small Plan Occupational Health Programs* states:

> The plant physician should never use his industrial affiliation improperly as a means of gaining or enlarging his private practice. If he observes these ethical relationships, the plant physician should experience no difficulty in establishing cordial

> relationships with other physicians in the community and gaining mutual cooperation on the problem. (1983, p. 13)

Surveillance Screening

Issues of privacy, confidentiality, and informed consent pervade almost every program activity for the assessment, preservation, restoration, and improvement of the health of workers at the place of employment. In screening programs especially, these issues are brought into bold relief. They may relate to the screening program itself or to the use of the results, which are designed to determine if the worker's health remains compatible with the job assignment and to detect any evidence of impaired health that may be attributed to employment.

Many such programs are ill-conceived from both a scientific and an ethical point of view. Problems of test validity and predictive values may weaken any appeal of beneficence. For example, some employers may insist on genetic testing even though the science of identifying genetic factors that may contribute to the occurrence of job-related illness is still in its infancy. The correlation of a genetic risk presumed to pose dangers (i.e., chromosomal damage) for the later occurrence of disease may not mean that all or most with the risk factor will become ill. Also, other genetic factors or environmental factors (such as smoking) may be necessary for the development of the disease. Thus, the use of genetic screening to identify and protect workers who might be at increased risk of disease in a workplace cannot be justified by the ethical principle of beneficence where there are low correlations between risk factors like genetic markers and disease. Just as there is uncertainty about who, or how many, could be harmed, so there is uncertainty about how industry should respond. There would be some physical risks associated with medical testing procedures.

Second, there would be risks to the worker from use of the screening information. These include the loss of a job or reassignment to a lower-paying or less desirable job, loss of self-esteem, and, possibly, stigmatization as "genetically inferior." Such a label conceivably could result in the person's exclusion from certain jobs in an entire industry. Historically disadvantaged groups—women and/or ethnic or racial minority workers—would be further disadvantaged. The use of such tests, in short, may provide no real benefit to the company and may cause harm to the worker.

The rapid growth of new molecular and biochemical tools in occupational medicine has resulted in the development of biological indexes or markers for predicting occupational diseases. Scientists hope that these biological indexes or markers will stand as early warnings of the occurrence of occupational risk and disease. Occupational medicine may use biological markers to enhance early detection and treatment of disease; occupational epidemiology may use them as indicators of internal exposure at the workplace or of potential health risks and the need for workplace monitoring. The use of these tools in workplace screening touches on areas of basic concern to most people: opportunity for employment, job security, health, self-esteem, and privacy. In the case of a biological marker known to reflect susceptibility, for example, should a worker who tests positive or has a higher measurement be removed from the workplace? If so, should the occupational-health professional recommend that the worker be offered an equivalent job in the same industry? Or should the occupational-health professional recommend that management clean up the workplace to protect the most sensitive worker? To complicate matters, most biological markers of occupational disease are presumed to predict group risks (increased rates of disease among workers), and these levels of risk are still sufficiently low as to not be reliable guides to which individuals are threatened. Therefore, it is important that workers be informed in advance that the results are interpretable only on the group level. Test results given to workers should be presented and discussed on the basis and in the context of the information that is available on the variability within groups of workers and between individuals (National Research Council).

Of equal importance is the treatment of the data generated by biological-marker testing. One concern of employees who have been screened would be to prevent the spread of embarrassing, damaging, or false information about themselves, particularly to potential employers. The Code of Ethical Conduct for Physicians Providing Occupational Medical Service provides that employers are entitled to receive counsel about the medical fitness of an individual in relation to work but are not entitled to diagnoses or specific details. No one in healthcare challenges the fact that the medical record is a confidential document. But many managers believe they should have access to it when there is interest in an individual employee. However, diagnostic information is not needed for placement of an employee or for changes in his or her workstation because of change in health status. The occupational-health physician can state that an individual is physically or emotionally capable for all work or that an employee should not work in areas where there are high concentrations of certain organic vapors. This information meets the needs of management and does not change the privilege of the medical information under the control of the occupational-health physician. The Code of Ethical Conduct of the American Occupational Medicine Association is clear on this issue:

> Treat as confidential whatever is learned about individuals served, releasing information only when required by law or by overriding public health considerations or to other physicians at the request of the individual according to traditional medical ethical practice and recognize that employers are entitled to counsel about the medical fitness of an individual in relation to work but are not entitled to diagnoses or details of a specific nature.

Medical records usually need to be kept for a long time because of linkages between occupational exposure and disease or dysfunction with long latency periods. These are usually the kinds of disease (cancer, for example) that are most sensitive in terms of workers' feelings about privacy. Records become part of large data systems to which government regulatory agencies, courts, and law enforcement officials may have relatively easy access. Workers are concerned that leakage of sensitive information will affect their mobility and employability.

Confidentiality is seldom an absolute value. Information about patients may be revealed under certain circumstances, including those in which workers themselves give consent to provide it to insurance companies or other physicians. Because they are concerned about possible misuse of information from screening programs, or because they wish to know of risks to their health, employees may want access to their medical records. The ethical principle of autonomy implies a duty to provide employees with information about their health, even when it is not clear what the information means. The duty would be even stronger when the information is highly predictive of a risk of disease.

Autonomy would also appear to require that the workers be fully informed of the nature of any screening procedure to which they will be subjected. While the concept of informed consent would be most crucial in occupational-health research, it is also applicable to medical screening. In the latter case, even though the procedures are clearly beneficial, their application to work without informed consent is a paternalistic action.

Epidemiologic Investigations

The results of screening programs may suggest the need for epidemiologic studies to provide additional information on adverse health effects from occupational exposure. These studies may be conducted by occupational epidemiologists. Even prior to the U.S. Occupational Safety and Health Act of 1970, companies involved in formulating and synthesizing chemicals had hired epidemiologists to conduct in-house studies. Such research is an important aspect of an employer's obligation to employees, consumers, and the public in general.

In conducting epidemiologic studies, occupational-health professionals have obligations to workers who are the study subjects as well as to the company's management, who ordered the study and will pay for it. Sometimes these obligations conflict, and the occupational-health professional must sort out ethical as well as scientific priorities. Depending on where the request for the study originates, for example, there may be conflict even in the initial decision as to whether the study should be undertaken. The analysis and interpretation of the data the study generates may be affected by its expected implications. Economic implications may be intertwined with political ones. Epidemiologic studies of workers who are occupationally exposed to neurotoxins or reproductive toxins, for example, may lead to political conflict between labor and management, with government as a possible third party. The dispute is essentially about the occupational environment rather than economic issues with political factors as a secondary concern. Here the company's epidemiologist may be under pressure to respond more fully to his or her responsibilities to the employer than to any professional obligation to the workers (Gordis).

As the research project proceeds, the subjects should be kept informed of its progress, subjects' privacy should be respected, and confidentiality of data should be maintained. This is an important task because the concept of research can be disquieting to workers and to management as well. When, in the course of the study, management and other investigators who are not part of the study ask that investigators share data on an individual basis, investigators face conflict between professional obligations and legal ones. Under the provisions of the Toxic Substances Control Act, for example, epidemiologists are required to communicate substantial risk to the U.S. Environmental Protection Agency within fifteen days after learning of such risk. This information is then made available to the public. Here the professional obligation is to make the best interpretation of the facts, perhaps even to the extent of realizing that the best interpretation cannot be made without additional facts. When there is no time for the investigator to gather additional data, he or she has an obligation to make the best interpretation of the data that is available (Bond, 1991).

Ethical guides for communicating potential health risk have not been defined. In this context, occupational-health personnel are often called on to distinguish between the significant and the trivial. The problem does not lie where real risk can be identified and effective action by the company can result in real benefit to the worker. The technical and ethical conflicts arise when the occupational-health specialist must decide whether a given risk is acceptable, or whether it must be disclosed when not enough is known to be able to measure the presumed risk, and when there are acceptable alternatives. In such cases the occupational-health investigator must act judiciously, in the best interest of the health and well-being of the workers. Withholding pertinent information or providing unqualified, incomplete, or uncertain data may be detrimental to the worker and/or the company.

Conclusion

Economic performance is not the only responsibility of industry any more than educational performance is the only responsibility of a college or university. Unless economic performance is balanced with broader responsibilities for the health and safety of workers, industry will ultimately fail. The public's interest in health and safety, and its broader interest in the rights of workers, including the right to know of risks they face, seem a permanent feature of modern American capitalism. The demand for socially responsible industries and for workers' health and safety will not go away. These responsibilities involve concern about all factors that influence the health of employees, including assuring the availability of health services that are preventive and constructive. These services are not the work of any one group but depend on the cooperative activities of medicine, chemistry, toxicology, engineering, and many others. In this setting industry must recognize and respect the unique position of occupational-health-service providers and assist them in providing impartial, professional counsel to both management and employees. The occupational-health-service providers must be honest, consistent, courageous, and defenders of confidentiality.

Albert Jonsen states the case well:

> In a general way, the environment of modern industry comes about through investments from employer and employee alike, each making certain sorts of contributions. In our modern concept of relationship of those diverse contributions, we attribute right of ownership to employers and a variety of rights regarding wages and working conditions to employees. It is now common to consider that among these employees' rights is the right to know about hazards of the work environment.

They also have the right to know about interrelated elements of occupational safety and health. Ensuring those rights involves a great diversity and complexity of ethical responsibilities—interlocked with privacy, confidentiality, and professional and legal obligations—of the occupational-health-service provider.

Anticipating these complex ethical issues and developing sound approaches for resolving them are significant challenges to those healthcare professionals who have the responsibility to promote the health and well-being of people who work. Specifically, however, their responsibility is played out in the context of the workplace where many other healthcare professionals have the responsibility to promote workers' health.

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SEE ALSO: *Conflict of Interest; Corporate Compliance; Divided Loyalties in Mental Healthcare; Environmental Health; Hazardous Wastes and Toxic Substances; Harm; Public Health Law; Injury and Injury Control;* and other *Occupational Safety and Health* subentries

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ONCOLOGY

SEE *Cancer, Ethical Issues Related to Diagnosis and Treatment*

ORGAN AND TISSUE PROCUREMENT

• • •

I. Medical and Organizational Aspects
II. Ethical and Legal Issues Regarding Living Donors

I. MEDICAL AND ORGANIZATIONAL ASPECTS

Organ transplantation is high-technology medicine in one of its most extreme forms. It is very expensive, employs advanced biotechnologies, and requires large teams of highly trained specialists. It is used to intervene when the final stage of an illness is reached, and although it can save lives, it does not provide a "cure" or a return to a preexisting condition of health. Patients with transplants require constant, ongoing treatment with highly sophisticated and often quite dangerous medications.

But unlike most other advanced medical technologies, organ and tissue transplantation also depends on people. The only source of human organs and tissues is donations. In most instances these donations must be obtained from a young person who has died under sudden and tragic circumstances: by automobile accident, suicide, murder, and so forth. The organ procurement system's role is to provide a bridge between human tragedy and high technology.

The Supply of Organ Donors

During the first half of the 1980s the supply of cadaveric organ donors grew continually and rapidly. In 1982, there were 3,681 cadaveric kidney transplants. In 1986, there were 7,089, an increase of almost 100 percent (or almost 25% a year). Since 1986, the rate of increase has slowed. In 1992, 7,202 cadaveric kidney transplants were performed, representing donations from about 4,500 donors. In 2000, 8,089 cadaveric kidney transplants were done, representing 5,986 donors. According to the United Network for Organ Sharing (UNOS), the number of donors increased to 6,081 in 2001 and the number of transplants to 8,203. Although this was one of the largest number of organ donors in any year in U.S. history, the leveling out of the donor supply in the United States continues to cause disquiet and debate over the efficacy of the organ procurement system and the adequacy of the principles underlying it.

While organs have been transplanted in most nations of Western Europe, in Japan, and in some places in the Middle East, the infrastructure necessary to obtain organ donors routinely exists only in North America and Western Europe. (While Japan certainly has the necessary resources and expertise, cultural factors, including discomfort with brain death and a strong commitment to intact burial, have militated against the development of such a system there.) The Eurotransplant International Foundation, serving Germany, Austria, the Benelux nations, and Slovenia, is the second-largest organ procurement system in the world and the largest in Europe. In 2000, 3,099 cadaveric kidneys were transplanted in the Eurotransplant region, as well as more than 642 hearts and 1,285 livers. France and the United Kingdom have both operated national organ procurement systems since the 1980s, and 1,486 cadaveric kidneys were transplanted in the United Kingdom and Ireland in 2000 and 1,840 in France. Scandia Transplant (serving Scandinavia) is an organization of long standing; it provided kidneys for 630 transplants in 2000. Since the early 1990s, both Italy and Spain have developed transplantation and organ procurement systems. Spain's program now provides about 1,350 donors a year—the highest rate of donation in Europe. Over 1,900 cadaveric kidney transplants were done in Spain in 2000. Italy has been less successful, but 1,308 kidneys were transplanted there in 2000. About 19,000 kidney transplants were done in Western Europe in 2000, considerably more than in the United States. But the U.S. system remains the largest single system in the world, with almost 17,600 cadaveric kidney transplants completed in 2000 (UK Transplant; UNOS).

Of course kidneys are not the only organs being transplanted. In 1990 over 4,700 livers and over 4,100 hearts were transplanted worldwide, along with more than 1,000 pancreases and 250 lungs or heart–lung combinations. By 2000, 2,202 hearts and 4,664 livers were transplanted in the United States alone. In Europe an additional 1,991 hearts and 4,733 livers were transplanted. Since 1990 others organs have joined the list: intestines, lungs, and pancreases in particular. During the late 1980s, the total number of heart and liver transplants grew very rapidly, although the number of donors did not. This reflected an increase in multiple-organ donation. Donors who previously donated only kidneys were increasingly providing hearts, livers, and/or pancreases. In the United States, by 1992, 72 percent of all organ donors provided more than one organ (UNOS). In 2001 the percentage certainly exceeded 76 percent and was, perhaps, higher still. While trustworthy data are difficult to obtain, it is probable that in 1982 the percentage was less than 25 percent.

The number of actual donations must be understood in relation to the number of potential donors. A groundbreaking study headed by Kenneth J. Bart and conducted for the Centers for Disease Control estimated that in 1975 between 54.5 and 115.8 donors per million persons—about 25,000 to 26,000 potential donors—were available that year in the United States (Bart et al., 1981b). More recent work has applied more restrictive criteria to the examination of hospital death records, with one study finding an estimated national donor pool of between 10,000 and 12,500 (Nathan et al). Although divergent, these estimates both show that actual donation rates are not close to exhausting the potential supply of donors. They also indicate that the size of the donor pool is very sensitive to donor criteria, especially age. Medical criteria for acceptable donors are not fixed by immutable laws but change as transplant experience changes, and perhaps as the need for organs changes. The donor pool is itself a somewhat flexible and changing concept.

CRITERIA FOR DONATION. The one immutable medical criterion for organ donation has been brain death, or more exactly, the determination of death by brain-death criteria. Once the circulation of blood ceases, an organ very rapidly becomes useless for transplantation unless it is cooled. For this reason organ donors must be kept on machines that maintain respiration and heartbeat after death. Because the heart must be kept pumping, death must be declared on the basis of total and irreversible cessation of brain function—brain death. The causes of death that are consistent with organ donation are therefore sharply limited to those involving damage to the central nervous system. Trauma is the most common cause of such damage. Almost 43 percent of all donors in 2000 died of head trauma (about 25 percent died in auto accidents) and over 41 percent of kidney donors died of strokes (OPTN).

The need for organs is believed to be so severe that even the brain-death criterion is being questioned. Efforts are under way in a number of locations to test the feasibility of employing donors whose hearts are not beating for organ donation (i.e., donors who suffer cardiac arrest before organ retrieval). Professional support for this approach is reflected in the Institute of Medicine's 2000 report on non-heart-beating organ transplantation. This report cites studies estimating that up to a 20 percent increase in kidney donation could result from organ procurement organizations (OPOs) actively seeking non-heart-beating donors. Actual change, however, has been slow. As of 1998 only half of all OPOs had a protocol for obtaining donations from non-heart-beating donors. No more than a dozen OPOs are actively engaged in such efforts and less than 3 percent of all donors fall into that category.

Other medical criteria also limit the potential supply of organs. Cancer, systemic infections, HIV, hepatitis, and other diseases can exclude a donor because of the possible transmission of the disease to the organ recipient. High blood pressure, diabetes, and many other conditions can damage an organ and thereby render it unsuitable for transplantation.

The most general limiting factor is the age of the donor. There is little unanimity among transplant centers on acceptable donor age. In general the criteria for kidney donors is the least exclusive, and that for heart donors the most exclusive. Young donors are preferred; in the 1980s kidney donors over fifty-five were considered unsuitable, as were male heart donors older than forty. Over time, age criteria have loosened noticeably. From 1978 to 1987 the percentage of kidney donors over fifty went from 5 percent to 10 percent, and the percentage over thirty grew from about 30 percent to 40 percent (Takemoto and Terasaki). According to UNOS, in 2000 about 31 percent of cadaveric organ donors were fifty years old or older; almost 8 percent were over sixty-five. Eurotransplant protocols now consider kidney and liver donors up to age seventy-five as suitable—subject to individual evaluation. Increases in acceptable donor age can enlarge the donor pool substantially, especially when combined with an increasing percentage of donors dying from causes other than trauma.

The Procurement Systems

Organ donation requires an institutional structure to identify willing donors, obtain consent, procure the organ, and distribute it to the transplant team. These are the tasks of the organ procurement system.

LOCAL CONTEXT. The earliest organ procurement organizations in the United States were founded around 1970. They were purely local organizations that grew up around kidney transplantation teams and were meant to address those teams' needs for transplantable organs. By the mid-1980s, over ninety of these organizations had been formed; virtually no area of the nation was unserved.

While the organ procurement system has undergone many changes since the early 1980s, the local components of organ procurement success have not changed. The central factor in successful organ procurement is timely information about potentially suitable donors. Only a very small percentage of deaths can lead to an organ donation, and the window of time available for action is short. Cooperation from hospital personnel, specifically doctors and nurses in intensive care units (ICUs), is essential. A referral from these professionals (i.e., notification that a potential donor is under treatment) is required for the donation process to begin. OPO personnel typically spend more of their time encouraging doctors and nurses to make referrals than they do on organ procurement itself. This persuasion takes the form of in-service training sessions, one-on-one visits, and visits to the ICU itself. Success in obtaining referrals is the key determinant of successful organ procurement (Prottas, 1989).

A second factor of great importance is targeting appropriate hospitals. Not all hospitals are equally good sources of potential donors: Some see little trauma, and some lack the capacity to make brain-death determinations. OPOs that target their professional education efforts where the return can be the greatest are likely to be more successful than those that work with every hospital in their area.

The final step in the procurement process is obtaining permission from families. This is a very delicate matter. Families of potential donors have suffered a terrible loss. Some OPOs prefer to have their own, experienced staff approach the family. Others depend more heavily on hospital staff. All depend on the physicians involved to inform the family that their relative has died. U.S. law forbids paying families to permit donation. All organ donation decisions are therefore voluntary and altruistic.

THE DONATION DECISION. The American public, indeed the publics of all Western nations, appear to be very supportive of organ donation (Gallup Organization; Bergström and Gäbel; Moores et al.). Support levels for organ donation of 90 percent are routinely found in large-scale surveys. In the United States these rates vary by race/ethnicity, education, and income. White Americans, middle-class Americans, and well-educated Americans are more supportive of organ donation than are nonwhites and poorer and less-educated citizens. The differences, however, are all within the context of very high levels of support. African-American levels of support approach 80 percent (Prottas, 1994).

Actual willingness to donate is lower but still large. Survey data indicate that 75 to 80 percent of the population is willing to give permission for organ donation by a relative when they know that the person has been declared dead, even if they never discussed this issue with the deceased (Batten and Prottas). Here, too, there are significant differences across social classes and ethnicities. Actual permission rates obtained are another measure of public willingness to donate—although they are somewhat obscured by who is asked and the skills of those requesting permission. Permission rates vary among OPOs but generally lie between 45 and 50 percent (Siminoff et al., 2001).

There are two general categories of reasons that the public gives for being willing to donate the organs of a deceased relative. The more important is a desire to help another person. Families that have actually allowed a donation and the general public both report that they support donation so that someone's life can be saved. The families of donors also assert that they permitted donation in order that something positive could come out of the death of their relative—a factor that is only slightly less likely to be mentioned than the desire to save a life. The general public is less likely to give the solace of donation as a reason for its support of donation, but it still is the second most commonly given reason. Indeed, families and the general public agree that organ donation can help the families of the donor in the grieving process (Prottas and Batten; Batten and Prottas).

The reasons people give for their unwillingness to donate seem to reflect a mistrust of the medical establishment and the donation process. Among the most commonly given reasons is a fear that permission will compromise the care received or prolong the suffering of the relative. The second reason, closely aligned to the first, assumes that donation-related activities are occurring while the patient is still alive. From 45 to 65 percent of those unwilling to give permission for donation give answers of this sort as the explanation for their unwillingness. Of this group, 60 percent also say that they would not give permission because the donation process is too complicated. Finally, about a third attribute their unwillingness to expected resistance from other family members (Prottas and Batten).

Some of these reservations relate directly to the donation process itself and to communication between OPOs and the public. Others may reflect more basic mistrustful or alienated attitudes toward medical institutions. In this regard the greater unwillingness to donate found among ethnic minorities and among poorer citizens becomes more comprehensible.

The donation process itself seems to have important effects on willingness to donate. The core process of asking to donate is the same for all OPOs and hospitals, but differences in details can matter. Once the medical suitability of a patient has been determined, the family must be approached with the patient's terminal prognosis and—then or somewhat later—with a request for donation. A physician must present the fact of brain death, but the request for donation can be made by a doctor, a nurse, or a member of the local OPO. In different places the patterns vary. In some cases the organ procurement specialists carry the main burden of talking with the families because they are trained and experienced in this kind of encounter. In other locales, nurses will assume the responsibility because they often have the best rapport with the family, developed while the patient was being treated. A well-managed process, based on good communications and good relationships between families and the clinicians caring for the patients, can influence the permission rate (Siminoff et al., 2001).

The most common cause of death for an organ donor is accident trauma, and most donors are young; as a result, most family decision makers are parents. In recent years the age of donors has increased, and a larger percentage have died from cerebrovascular accidents. This has led to an increase in the percentage of decision makers who are spouses—most generally wives, because male donors outnumber female donors.

Donor families generally feel that the donation process was well handled, and almost 90 percent would make the same decision over again. The criticisms that do emerge usually regard the timing of the request and the clarity of the brain-death explanation (Batten and Prottas). Some of these criticism can be met by improved permission-seeking behavior (Siminoff et al., 2001), but others may reflect reactions to the loss of a loved one itself.

SYSTEM CONTEXT. Prior to 1986 the Southeastern Organ Procurement Foundation was the only regional OPO in the United States. It operated the United Network for Organ Sharing, a computer system listing most of the patients in the United States awaiting an organ. This computer list was simply a compilation of individual OPO lists, was readily accessible, and made inter-OPO organ sharing possible. However, the disposition of kidneys (few other organs were procured at that time) remained solely in the hands of the procuring agency.

Some OPOs were far more effective than others. Some procured forty kidneys per million population served; others, only eight. Cost per kidney also varied tremendously, from lows of $6,000 to $7,000 to highs of over $20,000. The percentage of organs not actually transplanted—in effect, wasted—was also very high and variable. In Europe 4 to 5 percent of the kidneys procured were discarded; the U.S. rate was almost 20 percent (a difference now virtually eliminated by improvements in the United States). Organ distribution criteria were different in different areas; often they were unwritten and inconsistently applied. Some transplant hospitals believed that when donor and recipient had similar immunological characteristics, the probability of successful transplantation was much higher. Others felt such matching was of little importance. Those who believed in matching offered to share organs more frequently than those who did not, and this tended to decrease access to transplants for their patients.

PUBLIC INVOLVEMENT. The dual issues of system efficacy in organ procurement and equity in organ allocation induced the U.S. Congress to become directly involved in organ procurement and transplantation matters. In 1972, Congress established the End Stage Renal Disease (ESRD) Program through an amendment to the Social Security Act. Under this program, people suffering from renal failure automatically became eligible for Medicare coverage. Although most of the budget of this several-billion-dollar program pays for renal dialysis, renal transplantation and organ procurement costs are also covered. Under the ESRD Program, the federal government began paying the expenses of the nation's ninety OPOs. This financial involvement of the government, coupled with public concerns about efficacy and equity, led to major changes in the organ procurement system in the late 1980s.

Starting in 1984 with the Organ Transplantation Act, Congress moved to restructure two key aspects of the organ procurement system by supporting the formation of a national organization to oversee the sharing of organs and by reforming the governance of OPOs themselves. By 1986 certain principles and structures were agreed upon that have come to define the U.S. organ procurement system. The most basic principle was that human organs are a public resource and that the organ procurement system was a steward of the public in its handling of organs. Each OPO and each transplant surgeon could be held accountable for organ allocation decisions. OPOs were now required to have public representatives on their boards.

A federally funded agency, the Organ Procurement and Transplantation Network (OPTN), was established to act as the public's agent in matters of organ allocation. This organization was given the authority to set rules controlling organ allocation at both the local and the interagency level and to enforce those rules on all OPOs. Only member agencies of OPTN could procure organs; only member hospitals could transplant organs, on pain of losing Medicare reimbursement. OPTN was also given the authority to set membership standards, including those regarding personnel training and transplant outcomes. These standards had to be met if an OPO or a hospital was to be involved in organ procurement or transplantation. While OPTN has been very conservative in the use of its powers, deferring to local practices and preferences whenever possible, the federal government now essentially has final say on how human organs are to be allocated to patients.

In the late 1980s, the Health Care Financing Administration (HCFA) exercised its right to set standards for the certification of OPOs, which included the definition of a service area for each OPO that was, to a large degree, the grant of a monopoly to procure organs in that area. Because HCFA rules precluded multiple OPOs in a single service area, there was a significant decrease in the number of OPOs in operation. As of 2000, the United States had some sixty-seven certified OPOs.

The next major increase in government involvement was the passage of "required request" laws at both the federal and the state level. The philosophical underpinning of these laws is the belief that organ donation is a right that families have and that medical institutions have an obligation to facilitate the exercise of that right. While there are differences among the various required request laws, they all share the same basic elements. Each requires that hospitals have a system in place to ensure that the family of every medically appropriate donor is asked if they wish to permit an organ or tissue donation. Reimbursement under Medicare can be denied to any hospital without such a system. These laws appear to have been reasonably successful in ensuring that families are given the option of donation (Siminoff et al., 1995). It is less clear that they have increased actual donation rates (Anderson and Fox; Viring).

In 1998 an additional step was taken when "routine referral" rules were promulgated. These rules require that hospitals inform OPOs of all imminent deaths. The goal of this regulation was to ensure that organ donation professionals are involved in the process from its earliest stages. It was predicated on a concern that not all suitable donors were being identified and that in-hospital personnel lacked the skills necessary to effectively request donation (OPTN). No systematic evaluation of the effect of this approach has been done but there is little indication of a system-wide increase in donation.

Finally, in the last years of the 1990s, the federal government became more actively involved in issues of organ allocation. There is a long-standing dispute over whether the queue for a transplant should reflect only patient characteristics or whether the OPO or the region procuring the donation ought to be given some form of preferred position. The dispute is complex and until recently the federal government took little active part. In the last half of the 1990s, however, the Department of Health and Human Services became actively involved in the debate and finally promulgated rules designed to minimize all allocation factors that did not pertain to the individual patient's characteristics. This appears to be the last in a decade-long series of changes that increased the influence of public bodies over professional ones in structuring the transplantation system.

DONATION RULES. Federal law defines the terms of exchange in organ donation. It is against federal law to buy or sell human organs and tissues. Organ and tissue donation requires explicit consent from the donor's family or a signed donor card. An alternative system exists called "presumed consent." This system reverses the burden of proof regarding family permission. Under it, if a family does not express an objection to organ donation, their permission is presumed. Austria, Belgium, Finland, France, Greece, Norway, Portugal, and Spain have presumed-consent laws (Eurotransplant), but it is unclear how often they are implemented. Certainly some nations do not actually procure organs under these laws but insist on obtaining explicit permission from families. Spain may be the only general exception, although even there detailed hospital-level data is hard to find.

In the United States, about half the states have some form of presumed-consent laws with regard to cornea donations. According to these laws, corneas can be removed from cadavers under the jurisdiction of the medical examiner, based on permission from the medical examiner's office. Some states require a minimal effort to contact families, but others do not.

ORGAN TRANSPLANTATION AND TISSUE PROCUREMENT SYSTEMS. The laws regarding organ procurement apply to tissue procurement in most ways. Tissue donation, too, must be voluntary and uncompensated, and families have the right to be given the option to donate when the medical circumstances are appropriate. However, the organizational structure of the tissue banking system is different from that of organ banking. Organ procurement is a closely regulated, federally financed system; tissue procurement is neither.

The system for procurement of musculoskeletal tissue (bone, tendons, fascia, ligaments) is virtually unregulated, except insofar as it falls under laws forbidding payments, certain Food and Drug Administration quality regulations, and required-request laws. Shared professional and technical concerns have begun to translate into discussion of procurement and distribution practices. Few rules have been agreed to, and there are no enforcement mechanisms. Government involvement in tissue banking is very recent and has occurred in response to public health concerns about the spread of AIDS and hepatitis via transplanted tissue.

The organ and tissue procurement systems, however, increasingly overlap at the operational level. Cooperation of hospitals and their medical staffs is central to the success of both, and there is overlap in terms of donor families as well. Because of this, OPOs and tissue banks have found themselves in conflict regarding access to hospital staff and to families. In response, most OPOs have expanded their activities to include tissue banking. Over 80 percent of OPOs report being involved in tissue procurement. Detailed data on the exact nature of those involvements is not available, but it appears that most OPOs now have some permanent organizational relationship within the tissue procurement field. This may take the form of having a tissue division or being within a larger organizational umbrella with a tissue procurement agency. In other cases, local agreements, especially with eye banks, have generated cooperation. The large size and unregulated nature of tissue banking, however, has left the relationships between the two systems diverse and complex.

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SEE ALSO: *Cybernetics; Death, Definition and Determination of; Dialysis, Kidney; Healthcare Resources, Allocation of; Medical Futility; Medicare; Mistakes, Medical; Organ and Tissue Procurement; Organ Transplants, Medical Overview of; Organ Transplants, Sociocultural Aspects of; Technology; Xenografts;* and other *Organ and Tissue Procurement* subentries

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II. ETHICAL AND LEGAL ISSUES REGARDING LIVING DONORS

History and Background

As the number of suitable cadaver organs available for transplantation has leveled off in the last decade, the use of living donors has become increasingly important. However, the history of living donors goes back to the earliest successes in transplantation. In 1954 Dr. Joseph E. Murray performed the first successful organ transplantation at Peter Bent Brigham Hospital in Boston by transplanting a healthy kidney from twenty-three year-old Ronald Herrick into his identical twin brother Richard—thus proving the viability of soild organ transplantation. While the histories of other types of transplantation primarily consist of cadaver donors, a shortage of organs as well as improved results have led to the use of living donors for kidney, lung, liver, pancreas, and small-bowel transplantations.

The first kidney transplantation surgeries were successful because there were no immunological barriers—the organs came from identical twins. Once transplantation was proven possible, research increasingly focused on overcoming immunological barriers that cause organ rejection. Success came in the early 1960s with the immunosuppressive agent azathioprine. "Its use in combination with chronic corticosteroid therapy provided the first effective means for preventing immune-mediated destruction of allografts in clinical transplantation" (Woodle, p. 902). Improved results throughout the 1970s led to an increasing shift to cadaver sources. Living donors were still used in this period, but until the early 1980s surgeons restricted living organ donations to kidneys and usually required the donor to be a parent, sibling, or child of the recipient (Fox and Swazey). Further success came in 1979 when results from trials at Peter Bent Brigham Hospital and the University of Colorado showed that cyclosporine combined with steroids controlled rejection better than any past drug therapy. By 1983 the FDA released cyclosporine for general use, increasing graft survival by 30 percent or more. Due to increasing public education throughout the 1980s, the number of cadaver organs available for transplantation continued to grow. This in conjunction with the increasing success of immunosuppressive agents led to an increased use of cadaveric kidneys; due to advances in immunosuppression there was no need for a genetic match. Outcome data were still better for living transplants than cadaver, but many speculated that the need for living organ donors would continue to diminish. In 1985 Thomas Starzl, a pioneering transplant surgeon, argued that advances in cadaver transplant would challenge the morality of living organ donations.

By the early 1990s the number of suitable cadaver donor organs leveled off and waiting lists grew, leading to a renewed interest in living organs. Other types of living organ transplantation became increasingly more successful. The first successful living related liver transplantation in the United States took place in 1989. At first the recipients were typically infants receiving a lobe from a parent. But transplantation between adults has been increasingly successful;

the first successful adult living liver transplantation was reported in Japan in 1994 and the first in the United States occurred in 1998. Adult to adult transplantation is technically more difficult than the pediatric procedure and the risk to the donor is far greater than a kidney donation. The death in January 2002 of Mike Hurewitz, who donated a portion of his liver to his brother at Mt. Sinai Hospital in New York, has increased safety concerns. The New York State Department of Health shut down the hospital's transplant program, one of the largest in the country, for six months. An investigation found no fault with the surgery, only with post-surgical care. Living donors for liver transplantation are almost always genetically or emotionally related to the recipient; so-called Good Samaritan or nondirected donations are very rare. UNOS reports that out of 5,327 liver transplants in 2002 only 359 were from living donors.

The first successful living lung transplantation took place at Stanford University in October 1990. In living lung donation a pair of adult donors each donate one lobe (left or right) to one recipient. The number of such transplantations is still quite low. In 2002 only 13 living donor lung transplants were reported in the United States (UNOS). Other living donor transplantations also include the pancreas and small-bowel. Because there is no shortage of cadaveric sources for either organ, living donor transplants are rare, but increasing due to better patient outcomes (Margrieter). Living donor pancreas transplantation is increasingly being supplanted by islet cell transplants.

Drug therapies continue to improve, and since the number of cadaveric organs remains fixed and there is a growing gap between the available supply and demand of organs and tissue, living donation increases. New technologies such as laparoscopic live-donor nephrectomy first performed in 1995 have made it less burdensome to be a living kidney donor. According to UNOS data, between 1999 and 2000 living donor kidney transplants increased 16.5 percent. In 2001, of the 24,076 organ transplantations performed in the United States, more than 6,507 were living donor transplantations. In 2000 UNOS began pilot testing "paired exchange" and "list-paired exchange" programs that provide further incentives for living donations. Transplant centers increasingly accept Good Samaritan or nondirected living kidney donors (Matas et al.).

Ethical, Legal and Policy Issues

ETHICAL ISSUES. While living organ donors were initially limited to blood relatives to reduce the risk of immune rejection, improved immunotherapy has expanded the pool of potential donors far outside of those related by blood, to those who are emotionally related to each other. This has resulted in expanding the notion of "relatedness" to include people related by marriage (spouses and in-laws) as well as those who are not traditionally considered relatives—friends, co-workers, members of the same church or other community group, and even those with very limited emotional ties, such as so-called Good Samaritans. With this extension of the concept of living donation, it became a logical and relatively short step from tangentially related directed living organ donors to organ donations from altruistic strangers.

How far should living donation be allowed to go? Is informed consent sufficient to justify any living donation to which a prospective donor would voluntarily consent? In other areas of medicine, and clinical research, there are limits to the risk to which healthy people—related or not—should be allowed to consent. For many, increasing risk to the donor tilts the balance away from being acceptable, meaning that at very high levels of risk, no living donor should be allowed to undertake organ donation.

One of the concerns in nondirected or Good Samaritan living donation is that strangers should not be allowed to accept the same level of risk as related donors. The argument is that relatedness matters, such that related donors have more to gain from the donation and so can be allowed to accept greater risk. The justification is that seeing a loved one's life saved or health improved is a greater benefit than the psychological benefit to a stranger of performing an altruistic act. But one can also argue that both types of donors stand to realize substantial benefits, albeit of different varieties, and that it should be up the individuals to determine whether the benefits are sufficient to justify taking the associated risks.

Some thinkers have argued that intimates may actually have an obligation to be a living organ donor (Ross), but this would seem to create a duty of heroism. There is a history of courts refusing to require beneficent acts on the part of individuals, even if they would be lifesaving (*McFall v. Shimp,* 1978). In moral philosophy, this is the distinction between actions that are obligatory and those that are supererogatory. We laud people to perform acts that are "above and beyond the call of duty," but do not require such acts of them—to do so would create a duty of heroism, demanding too much of individuals in the process and undermining the value of what it means to be truly heroic. That being said, we may think it is more understandable, and even expected, for relatives to donate an organ to someone within their family, which raises its own ethical concerns. The most important problem is pressure within the family to donate and the effect it can have on decision making—undermining effective informed consent, which must be a mainstay of any living organ donation (The Authors for the Live Organ Donor Consensus Group).

Many transplant centers go so far as to offer prospective donors false medical excuses so they do not need to tell their family member that they are unwilling to donate (ibid).

LAW AND POLICY. Specific laws covering living organ and tissue donors vary greatly between countries. In the United States the chief law addressing organ donation is the National Organ Transplant Act of 1984 (NOTA). NOTA established the Organ Procurement and Transplantation Network (OPTN), which is responsible for maintaining a national registry for organ matching, increasing the "effectiveness and efficiency of organ sharing and equity in the national system of organ allocation," and increasing the "supply of donated organs available for transplantation." The United Network for Organ Sharing (UNOS) administers the OPTN under government contract. The OPTN does not oversee living donor transplantation. However, UNOS collects data about living donor transplants in the United States and develops and recommends policies covering a range of issues including living donors. Living donation is handled by the center or hospital performing the transplantation and Medicare dictates the only organ transplantation regulations. A hospital or transplant center can opt to ignore these regulations, but will be ineligible for Medicare reimbursements.

A number of international organizations have adopted policies on human organ transplantation that include specific guidelines for living donors. For example, the World Health Organization's (WHO) "Guiding Principles on Human Organ Transplantation" states:

> Organs for transplantation should be removed preferably from the bodies of deceased persons. However, adult living persons may donate organs, but in general such donors should be genetically related to the recipients. Exceptions may be made in the case of transplantation of bone marrow and other acceptable regenerative tissues. An organ may be removed from the body of an adult living donor for the purpose of transplantation if the donor gives free consent. The donor should be free of any undue influence and pressure and sufficiently informed to be able to understand and weigh the risks, benefits and consequences of consent.

In addition, "The human body and its parts cannot be the subject of commercial transactions. Accordingly, giving or receiving payment (including any other compensation or reward) for organs should be prohibited" (WHO). The World Medical Association's "Statement on Human Organ and Tissue Donation and Transplantation" also states that "In the case of living donors, special efforts should be made to ensure that the choice about donation is free of coercion" and persons incapable of making informed decisions should be donors in only "very limited circumstances." The Live Organ Donor Consensus Group argues that a living donor should be competent, willing, and free of coercion as well as medically suitable and psycho socially suitable (The Authors for the Live Organ Donor Consensus Group). Living donor qualifications usually include good general health, physically fit, free from high blood pressure, diabetes, cancer, kidney, and heart disease.

Donation by Minors

The early case law in the United States focuses on minors or persons incapable of consenting to being living kidney donors. In 1957 the Massachusetts Supreme Court ruled in *Masden v. Harrison* that the 19-year-old twin brother Leonard Masden could be a living kidney donor to his brother Leon. Based on the testimony of a psychiatrist who had interviewed both brothers, the court recognized that although the operation had no therapeutic value to Leonard, it had a compelling psychological value. The death of his brother would have "grave emotional impact" on Leonard. While the NOTA does not specifically address the use of minors as donors, many countries have legislation specifically addressing this issue. For example, Spain, Greece, and the Russian Federation prohibit the removal of organs from minors, although many make exceptions for bone marrow donation to a family member. In France donation is restricted to first-degree relatives. The Live Organ Donor Consensus Group was generally opposed to the use of a minor, but recognized that there may be exceptional circumstances. When the donor is mentally retarded or ill, courts have often concluded that the donor would benefit emotionally or psychologically.

Financial Incentives

Title III of the NOTA prohibits the purchase of organs: "It shall be unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for *valuable consideration* for use in human transplantation if the transfer affects interstate commerce" (NOTA Sec. 301 [a]; emphasis added). Violators are subject to a fine up to $50,000 and/or up to five years in prison. According to the statute, "The term 'valuable consideration' does not include the reasonable payments associated with the removal, transportation, implantation, processing, preservation, quality control, and storage of a human organ or the expenses of travel, housing, and lost wages incurred by the donor of a human organ donor in connection with the donation of the organ" (NOTA Sec. 301 [a]). The Department of Justice is responsible for enforcing this prohibition, but there have been few public cases. There remains great confusion over how valuable consideration should be interpreted and understood. For example, a Pennsylvania plan to offer donor families $300 towards funeral expenses was replaced out of fear that it came to close to violating NOTA. Its replacement, the Expense Benefit Plan for Organ Donors and Their Families offers a $300 benefit per organ donor to pay for food and lodging costs.

There are reports of an increasing worldwide black market in human organs and there are few policy approaches to addressing it. For example, federal law does not prevent people from re-entering the United States after transplantation.

Health insurance coverage varies. If the recipient is covered by Medicare's end-stage renal disease program, Medicare covers the donor's expenses. The Organ Donor Leave Act of 1999 provides 30 days of paid leave for federal employees who are living donors for transplantations. A handful of states have passed similar laws. There have been some movements to provide donor insurance to cover the medical risk of donation.

Exchange Programs

The goal of exchange programs is to increase the supply of kidneys available for transplant to overcome problems of ABO and cross-match incompatibilities. In paired exchange, two living donors, who are mismatched donors for their intended recipient, effectively swap kidneys. In list-paired exchanges, a living donor donates a kidney to the general pool. In return, the intended (but mismatched) recipient advances on the waiting list for a cadaveric kidney. In 2001 Tufts-New England Medical Center launched the first exchange program, indicating it was approved by UNOS. But it is unclear what authority UNOS has over such programs. UNOS' general counsel argues that Section 301 does not apply to exchange programs, but others have expressed concerns over the meaning of "valuable consideration."

Distribution of Nondirected Donations

In recent years transplant centers have begun considering nondirected kidney donations by community members. A National Conference on the Nondirected Live Organ Donor advocates caution and suggest a framework for institutions that are considering accepting nondirected kidney donations. The conference document recommends ethical and practice guidelines. Some question how nondirected donations should be distributed. Should they remain at the transplant center first solicited, or should they enter the general pool? There is general agreement that donors cannot request that certain demographic groups do or do not receive their donation. There have been recent calls for a national system to be developed so that organs from nondirected donors can go to the first patient on a national list rather than to the first patient at the center where the organ is donated. Such an approach has been developed on a local basis by the consortium of transplant centers in the Washington, D.C. area, and may serve as a model for national expansion.

Conclusion

The growing gap between the available supply and the demand for solid organs means that the search will continue for new sources of organs. We can all agree that living donation is a growing source of solid organs, as evidenced by the fact that the number of transplanted kidneys from living donors has surpassed the number from cadaveric donors at some of the leading transplant centers in the United States. The question is not whether living organ donation will continue, but rather what conditions and policies ought to apply to make it ethically acceptable.

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SEE ALSO: *Beneficence; Bioethics, African-American Perspectives; Cybernetics; Death, Definition and Determination of; Dialysis, Kidney; Healthcare Resources, Allocation of; Informed Consent; Medical Futility; Medicare; Mistakes, Medical; Obligation and Supererogation; Organ Transplants, Medical Overview of; Organ Transplants, Sociocultural Aspects of; Technology; Xenografts;* and other *Organ and Tissue Procurement* subentries

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ORGANIZATIONAL ETHICS IN HEALTHCARE

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Organizational ethics in healthcare, which sometimes is referred to as institutional ethics, can be defined as the ethical analysis of decisions and actions taken by healthcare organizations, that is, institutional boards or committees and individuals acting as agents of those organizations. This entry begins with background observations about organizational ethics as a subfield and then addresses the history of concern about this topic, the major issues in the field, ethical perspectives and strategies for addressing those issues, the relationship of organizational ethics to clinical ethics committees, institutional review boards and compliance programs, the development of organizational ethics programs in healthcare institutions, and some of the current issues in the field.

Background

There has been much discussion of whether organizational ethics should be considered a subcategory of the clinical issues that normally are addressed by institutional ethics committees or is more closely related to business ethics. This issue is significant inasmuch as it affects the scope of the problems involved in the field, the perspective adopted to address those issues, and the question of who should have responsibility for dealing with these matters (for example, clinical medical ethics committees or administrative units). Organizational ethics clearly is related both to clinical medical ethics in that institutional policies and actions affect patient care and to business ethics in that many institutional issues are primarily business concerns involving financial matters, strategic planning, and compliance with legal regulations—issues that do not affect patient care directly. Healthcare organizations, of course, also have business relations with patients with respect to the payment of bills and insurance matters.

As in the field of business ethics generally, there has been some discussion in the published literature on healthcare organizational ethics of whether institutions and organizations can be considered moral agents in a meaningful sense in light of the fact that they are not individuals with moral sensitivities, motives, or consciences. Organizations do, however, set goals and take actions in pursuit of those goals, although their actions often result from collective rather than individual decisions. Also, organizations normally are evaluated and judged as to whether their goals and actions are morally acceptable, and they often are held accountable for harm done or are praised for morally worthy policies and actions. Although organizations may be thought to have a moral status slightly different from that of individuals, it cannot be doubted that they are responsible agents in an ethically meaningful sense.

History

In the United States ethical problems in relation to organizations have been recognized since bioethics as a field began to take shape. The issue of research involving human subjects was raised in the 1960s and came to public attention in the 1970s with the revelation of the disregard of informed consent and the misinformation given to African-American males in the Tuskegee Study. Although this was an issue with clear organizational implications, research ethics came to be treated as a special concern.

This led to the establishment of the institutional review board system rather than to consideration of other issues in organizational ethics. The distribution of scarce medical equipment for renal dialysis (as a matter of triage) was debated in the 1970s, raising procedural issues concerning who was to make such decisions on behalf of healthcare organizations and on what basis. The ethical propriety of for-profit healthcare institutions was the subject of conferences held by the National Institute of Medicine in the early 1980s and editorials in the *New England Journal of Medicine.*

It was not until the 1990s that healthcare organizational ethics began to be identified as a separate field. The American Hospital Association issued a management advisory in 1992 and later instituted its Organizational Ethics Initiative, an ethics education program for hospital administrators. The Woodstock Theological Center convened a seminar on organizational ethics in healthcare in 1994, although the framework that was adopted for consideration of the topics addressed was one of "professional" ethics. Almost simultaneously with the publication of the Woodstock report in 1995, the American College of Healthcare Executives issued a major revision of its 1970 Code of Ethics for healthcare management professionals, a document with lasting merit that spells out definite standards of conduct.

A major step in the development of the field came in 1995 when the Joint Commission for Accreditation of Healthcare Organizations unexpectedly added requirements for "Organization Ethics" to its accreditation standards for all healthcare organizations. Those standards required that hospitals have a code of ethical behavior addressing marketing, admissions, transfer, discharge and billing practices (issues related to patients), and "the relationship of the hospital and its staff members to other healthcare providers, educational institutions and payers." The required hospital code also must protect "the integrity of clinical decision making, regardless of how the hospital compensates or shares financial risk with its leaders, managers, clinical staff, and licensed independent practitioners" (Joint Commission on Accreditation of Healthcare Organizations). Although the full implications of these standards have not yet been determined, this action effectively established the field as an area of administrative responsibility and a discipline worthy of separate attention.

Organizational ethics in healthcare has been recognized as a concern in other countries, although these issues are more likely to be considered matters of health regulation and planning in public health systems. Numerous publications on the subject have appeared since the mid-1990s in Europe, and the Comisión Nacional de Bioética of Mexico held its first conference on organizational ethics in healthcare institutions in 2002.

Major Issues in Organizational Ethics

Concerns normally associated with organizational ethics in the United States include a wide variety of issues. Among the most common are the following.

Charity and uncompensated care pose financial problems for most institutions. From an ethical perspective, however, healthcare institutions must consider ways to provide a level of care consistent with their mission and the needs of the community. Not-for-profit institutions have an obligation to provide public benefits in return for their tax-exempt status; some states in the United States have begun to require community assessments to determine the nature and level of the services needed.

Ethical issues in managed care have been discussed widely under the heading of organizational ethics. These issues include conflict of interest problems, reasonable benefit and exclusion regulations, and the provision of fair hearings of appeals if treatment is denied.

After the promulgation of government regulations in 1999, confidentiality of patient information became more of an organizational issue than a matter of professional responsibility. This is appropriate in light of the multiplicity of providers involved in patient care and the maintenance and transfer of patient records electronically.

Consideration of employee wages and benefits involves judgments about a "living" or "just" wage at the lower end of the scale and merit at the higher end. The fairness of wages for employees relative to other employees, or the "comparable worth" of positions and responsibilities, is another factor. Hiring and promotion practices along with downsizing raise ethical issues for healthcare organizations, as do relations with labor unions.

Organizations that provide human services also face problems of discrimination either by employees or by clients on the basis of race, ethnicity, gender, disability, and religion. Diversity training that is based on a firm institutional commitment to equal and sensitive treatment often is considered necessary.

Advertising and marketing concerns require special attention to the needs of vulnerable populations as well as the common standards of fairness in advertising. Pharmaceutical companies, some of whose practices have been criticized for decades, should be considered healthcare providers. Professional associations and healthcare institutions can have a significant influence on the practices of pharmaceutical companies and other suppliers.

Environmental concerns of healthcare organizations constitute a serious issue. These concerns include not only proper disposal of medical and toxic waste but comprehensive plans for the reduction of waste and solid waste management.

Other ethical issues for healthcare organizations that have been discussed include governmental relations (including lobbying) and community relations, externally, and socially responsible investing and professional relations, internally.

Perspectives and Strategies

Traditional Western ethical perspectives have been applied to organizational ethics issues. Those perspectives include utilitarianism (which has a certain affinity with the stakeholder strategy noted below), rationalism (which has provided support for organizational policy development and codes of ethical behavior), virtues theory and idealism (which has been supportive of mission statement analysis), and various contextual theories, including feminist ethics (which have drawn attention to historical institutional responsibilities and relations). Leonard Weber has proposed a priority list of principles for decision making that takes into account patients' interests along with organizational interests and community benefit. In addition to the application of normative ethical perspectives to institutional ethics issues, the following organizational strategies have been proposed.

PROFESSIONAL APPROACHES. The American Medical Association has addressed organizational ethics issues from the perspective of the historical responsibilities and obligations of healthcare professionals. This approach has been expanded to include the obligations of professionals other than physicians: The Code of Ethics of the American College of Healthcare Executives (2000) established standards for healthcare administrators. The professional codes of lawyers, accountants, and engineers, along with those of clergypersons and social workers, also should be included in this approach inasmuch as professionals from those fields work in healthcare institutions.

Professional approaches to organizational ethics have been especially successful in addressing conflict of interest problems. Conflicts of interest occur whenever a decision maker has an interest in making a particular decision on the basis of factors other than the interest of the patient (if it is a professional decision) or the interest of the organization (if it is a decision made as an agent of an institution). The conflict can be a matter of personal gain from the decision in question or can be a conflict between responsibility to a patient and responsibility to an institution. Conflicts of interest also can occur when there is institutional pressure on an individual to depart from the spirit or letter of a professional code. Professional codes of accountants, social workers, clergypersons, lawyers, and administrators must be considered along with those of physicians and nurses.

THE STAKEHOLDER STRATEGY. This perspective, which has been borrowed from business ethics, focuses on the consequences of institutional decisions for the many stakeholders and stakeholder groups that are affected (Evans and Freeman). Stakeholders in healthcare organizations include professionals, employees, business partners, and the community, in addition to patients. Spencer et al. (2000) have proposed the adaptation of a stakeholder strategy that involves a specific priority list of stakeholder interests for healthcare institutions: patient populations, professional excellence, organizational viability, community access, and public health.

THE MISSION STATEMENT STRATEGY. This perspective derives a critical examination of organizational decisions and actions directly from the mission and goals adopted by an institution. Those goals can be subjected to ethical evaluation (Hall) and often have to be elaborated and applied through high-level institutional decision making.

CORPORATE CULTURE ANALYSIS. This approach represents an application of the organizational theory common in business ethics to the analysis of healthcare institutions (Boyle et al.). As collective entities, healthcare organizations generate patterns of behavior, both formal and informal, that can be analyzed with respect to their ethical dimensions and implications.

Although specific strategies may differ, there is general agreement among commentators that organizational ethics issues involve many dimensions besides ethical considerations and that a multidisciplinary approach is needed. The purpose of the organizational ethics perspectives and strategies described in this entry is to highlight the ethical dimension of institutional decision making at all levels.

Relationships with Clinical Ethics Committees, Institutional Review Boards, and Compliance Programs

Organizational ethics is closely related to clinical medical ethics in that many clinical ethical problems have organizational implications. Difficulties with nursing, pharmacy, and other professional services may result from staffing decisions. The availability, adequacy, and confidentiality of medical records are organizational matters. Institutional policies often govern clinical issues such as orders not to resuscitate and palliative care. The organization and availability of social services, including ethics consultation, also is an organizational responsibility. Healthcare organizations also have direct relations with patients with respect to admissions, discharge, and transfer as well as billing and other financial matters. Inasmuch as any of these issues involve organizational decisions and actions, they may move out of the jurisdiction of clinical ethics committees and into the wider realm of organizational ethics.

The relationship of organizational ethics to institutional review boards for the protection of human subjects in medical research involves less of an overlap of responsibilities. Healthcare organizations need to provide resources and staff for institutional review boards, but the activities of those boards is subject to specific federal guidelines. It is appropriate, however, for healthcare organizations to decide whether research projects are consistent with the mission of the institution and/or interfere with other staff responsibilities.

Organizational ethics also is closely related to compliance programs. Although organizational compliance programs have a responsibility for bringing institutional activities into conformity with federal and state regulations, such programs also may be considered to have responsibility for the conformity of activities to institutional mission statements or ethical goals. Although this responsibility is mentioned specifically in the Federal Sentencing Guidelines under which compliance programs are established, those programs have tended to focus on legal compliance and ignore ethical goals and objectives that go beyond the law.

Some authors have suggested that organizational ethics should be conceived of as a comprehensive perspective or program that would include clinical ethics, compliance, and institutional review board functions in a single organizational unit or division. These activities, however, are generally well-established institutional programs, and it may make little sense to attempt to include them organizationally under a new unit that has its own problems and issues to address.

Organizational Ethics Programs in Healthcare Institutions

Healthcare institutions have considered various methods for addressing organizational ethical issues and bringing ethical perspectives into organizational cultures. Because concern for these issues has been raised in discussions of clinical ethics, some commentators think that the mandate of clinical ethics committees could be expanded to include institutional issues. It generally is recognized, however, that organizational issues can be quite different from clinical matters and that clinical ethics committees normally do not include the administrators who have responsibility for these issues or individuals with relevant administrative competencies and experience. If organizational ethics concerns are to be addressed within the scope of a clinical ethics program, therefore, a separate track or process may be necessary.

A few healthcare organizations have formed separate organizational ethics committees, but considerable time probably will be needed for those new units to acquire the perspective, the sense of role, and the credibility within the organization necessary to be effective. Other suggestions for organizational ethics programs in healthcare institutions involve the use of consultants and governing board subcommittees and the assignment of the function to compliance programs. Although there has been general agreement that as a result of the nature of the issues involved, organizational ethics programs must involve top administrative and governing board representatives, the issue of the involvement of employees and professionals from all levels within the organization and outside community members is more problematic.

Current and Future Issues in Healthcare Organizational Ethics

Although the organizational ethics issues mentioned above are areas of organizational activity that will require attention well into the future, it is worth mentioning three issues that have not been addressed adequately to date.

First, providing access to basic healthcare for all people remains the foremost challenge for healthcare organizations. In countries with national health systems the challenge takes the form of finding adequate funding, educating skilled personnel and professionals, and eliminating bureaucratic problems. In countries with largely privatized healthcare systems, such as the United States, the problem entails providing care for those who, because they are unemployed, underemployed, or working poor, lack access to care for financial reasons. This may be considered a social or political issue with a scope wider than that of any individual healthcare organization, but in countries where healthcare is provided by nonprofit corporations it is an organizational problem as well.

Nonprofit organizations generally are thought to have a public obligation to provide healthcare to people who cannot afford to pay. Competitive pressures on organizations, however, in many cases have moved this mission off the corporate agenda. Many nonprofit healthcare organizations view charity care as a business loss rather than an essential organizational goal, and many investor-owned healthcare corporations refuse to accept the provision of charity care as either a mission goal or a public obligation. Serious attention to this problem would require community needs assessments and regular social audits of institutional performance.

Second, there is the question of how healthcare institutions can develop and promote ethical perspectives within the organization. Ethical concern for the issues mentioned above is still for the most part a matter of informal discussion among administrators, members of clinical ethics committees, and academic and social commentators. Including top administrators and governing board members in organizational processes for addressing ethical issues is essential but often difficult. Few organizations have formal mechanisms for an ethical consideration of organizational issues, and even fewer involve top administrators or governing board members in that process. Many administrators seem to believe that compliance programs can take care of ethical concerns adequately or that ethical concerns are a matter of community perspectives that should be left to the governing board.

Third, the excessively aggressive practices of pharmaceutical companies must be addressed. This issue has become more than just a matter of professional marketing practices. It is a social issue in that society is becoming increasingly dependent on prescription drugs. Healthcare organizations have a significant role to play in educating the public about the dangers of overmedication and in curbing the aggressive advertising practices of pharmaceutical companies.

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SEE ALSO: *Corporate Compliance; Healthcare Management Ethics; Just Wages and Salaries; Managed Care*

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ORGAN TRANSPLANTS, MEDICAL OVERVIEW OF

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The first successful kidney transplant, performed by Dr. Joseph Murray at Boston's Peter Bent Brigham Hospital, took place in 1954. Since then, remarkable advances have occurred in transplantation. Antirejection drugs have dramatically improved success rates, and the vast majority of recipients are restored to well-being and enjoy productive and active lives. Better preservation of organs allows longer storage times, so organs can be transported over greater distances. In addition to kidneys, numerous other organs, including livers, hearts, lungs, and pancreases, are commonly transplanted today. Certain areas remain problematic, however. The control of rejection of transplanted organs is not yet perfect, and post-transplant complications, such as infection and cancer, can still threaten the health of recipients. But the major obstacle remains the inadequate number of organs available to meet the need of potential recipients on the waiting list.

Development of Transplantation

Attempts to transplant a kidney from one person to another began in the 1930s. These attempts were based on laboratory experiments by Alexis Carrel, a researcher who had developed a technique for suturing blood vessels in 1902. These early transplants all failed because the recipient's immune system recognized that the transplanted organ (often called a *graft*) was a foreign substance. The immune system then attacked and destroyed the organ, a process known as *rejection*. Success was finally achieved in 1954 because the donor and recipient were identical twins. Identical twins have the same tissue type, so the recipient's immune system perceives the transplant organ as a part of its own body, and rejection does not occur. Because every healthy person has two kidneys, one kidney can be donated from a living person to another person.

An organ or tissue that is transplanted between genetically identical twins is called an *isograft. Allografts* are organs or tissues that are transplanted between genetically nonidentical people, which occurs when organs or tissues are donated from a deceased person (cadaver donor). An *autograft* is a tissue transplanted from one part of a person's body to another part, such as when a burn victim has healthy skin grafted from one area of the body to the burned area. A *xenograft* is an organ or tissue transplanted from a different species, for example, a pig liver transplanted into a human.

During the 1950s, antirejection drugs had not yet been developed, so transplants were limited to kidneys from identical-twin donors. In 1959, however, Murray and his colleagues at Brigham Hospital again achieved a historic feat. They transplanted a kidney from a nonidentical twin to his brother, who had undergone total body X-ray treatment (irradiation). This treatment suppressed the patient's immune response so that his body accepted the new organ, and he lived for twenty-six years after the transplant. Irradiation was also tried with kidney transplants from cadaver donors. For most patients, however, the outcome was fatal because the irradiation weakened their immune systems too much. Although they accepted the transplanted organ, patients died from infection because their natural defenses against bacteria and viruses were reduced. It seemed evident that irradiation for transplantation "was too dangerous to be practical" (Starzl).

During this time, chemical immunosuppression (drug therapy) was being studied. In 1960 the French surgeon René Küss achieved successful nonrelated kidney transplantation using a combination of total-body irradiation, steroids, and 6-mercaptopurine. Azathioprine (also called Imuran) was later derived from 6-mercaptopurine. The combination of azathioprine and prednisone (a type of steroid) to prevent organ rejection, suggested by Sir Roy Calne, was a clinical milestone in 1962, as kidney transplant results improved and fewer side effects occurred.

In 1967 a heart and a liver were each successfully transplanted—the heart by Dr. Christiaan Barnard in Capetown, South Africa, and the liver by Dr. Thomas Starzl in Denver, Colorado. These successful transplants were followed by a flurry of activity as hospitals worldwide rushed to perform transplant surgery. Lung, bowel, and pancreas transplants were all attempted during the 1960s. Most of these attempts failed, however, and many transplant programs were abruptly stopped. Methods of suppressing the immune system were too crude to achieve the fine balance needed to control rejection but avoid fatal infection. By 1975 there were only two liver transplant programs in the world. Starzl was continuing to transplant in Denver, Colorado, and Calne was leading a program in Cambridge, England.

The modern era of transplantation began in the late 1970s and the early 1980s, when drugs to prevent rejection were discovered that were vastly superior to existing ones. The first of these was cyclosporine, a drug that acted much more specifically on the patient's immune system. It primarily affected those cells that were responsible for initiating the rejection process. Other drugs followed, including FK506 and OKT3, which quickly found their place in patient management. The decade of the 1980s witnessed a proliferation of transplant centers worldwide.

Refinements in surgical techniques and better methods to preserve donor organs also contributed to improved patient outcome, and successful kidney, liver, and heart transplants became routine. Lung transplantation was developed at the Toronto General Hospital in Canada, where single-lung transplantation was established in 1983 and double-lung transplantation in 1986. By the year 2000 more than 600,000 organ transplants had been performed worldwide, and transplant centers with special interests accumulated huge experiences that benefited not only their own patients, but those in other centers as well. At the University of Minnesota alone, more than 1,000 pancreas transplants had been performed by 2000 (Sutherland et al.).

Success with bowel transplantation was more difficult to achieve compared to other organs. The intestine has a large number of cells called *lymphocytes,* which help trigger rejection and also react against the recipient (graft-versus-host disease). Bowel transplantation was not successfully performed until the late 1980s when a patient in Kiel, Germany, and another in Paris, France, had prolonged survival. The first successful combined small-bowel and liver transplant took place at University Hospital (London, Canada) in 1988. Experience from these centers and from Pittsburgh showed that bowel transplants could be worthwhile for selected patients who either had part of their bowel removed or had inadequate bowel function. The antirejection drug FK506 improved the success rate of bowel transplantation, and patients could resume eating a normal diet after their transplant without the need for special intravenous feeding solutions.

Transplantation of islet cells from the pancreas first occurred in the mid-1970s. Rather than transplanting the donor's whole pancreas, the insulin-producing islet cells were removed from the donor pancreas. The cells, injected into the portal vein of the recipient's liver, adhered to the liver. The cells then began producing insulin. For diabetic patients who had to take insulin to stabilize their blood-sugar levels, islet-cell transplantation eliminated or reduced the need for daily insulin injections. Although reports began to emerge of short-term and prolonged insulin independence in 1990 (Scharp et al.), it was not until ten years later that the most significant progress to date was made. The transplant team at the University of Alberta, in Edmonton, Canada, developed a specific protocol of antirejection drugs combined with the transplantation of fresh islets from more than one donor to supply a critical mass of insulin-producing cells (Shapiro et al.). That success has led the National Institutes of Health to sponsor an international trial of islet transplantation using the Edmonton protocol. Because of the inadequate number of cadaver donors, however, animal islet cells, probably from pigs, may be required in the future.

The Cadaver Organ Donor

Traditionally, death has been declared on the basis of cardiopulmonary criteria: The heart stops beating and the patient can no longer breathe. Once the heart stops, oxygen-rich blood is no longer pumped to the body's organs, and the organs' cell functions begin to deteriorate. During the 1960s, organs came either from living donors (for kidneys) or from cadaver donors who were declared dead by the traditional cardiopulmonary criteria (non-heart-beating donors). The first successful liver transplants in 1967 used organs from donors who were removed from ventilators (artificial breathing machines) and pronounced dead after the heart had stopped.

As medical technology progressed and it became possible to maintain bodies after death using mechanical support, doctors needed to determine when a patient could be declared dead. Accordingly, in 1968, an ad hoc committee comprising medical doctors, a lawyer, a philosopher, and a theologian convened at the Harvard Medical School to define acceptable criteria for brain death. They decided that death could be declared by neurologic criteria as well as traditional cardiac criteria. Brain-dead donors, with the assistance of a ventilator, have oxygen circulating in their blood, which maintains the usefulness of organs for transplant. Brain death is declared after a series of tests have been performed. The cause of death, such as trauma, intracerebral hemorrhage, hypoxia, or primary brain tumor, must be known. Patients with potentially reversible conditions, such as hypothermia or drug-induced coma, are not considered potential donors. To be declared brain dead, therefore, a patient must be in an irreversible coma and not respond to pain. There are no brain-stem reflexes, so the patient does not breathe, swallow, or blink. Apnea testing shows that the patient cannot breathe when taken off the ventilator. After death, tests ensure that the deceased patient is a suitable donor, without disease or infection that could possibly be transmitted to the transplant recipient. In 1971 Finland became the first nation to accept the legality of brain-death criteria. Most countries recognize the legal status of brain death and accept brain death as a medical basis to declare death.

Brain-dead donors are preferred for transplant, rather than non-heart-beating donors, because they almost invariably provide better quality organs. When non-heart-beating donors are used, transplants are usually limited to tissues and kidneys, and sometimes the liver. By the time the heart has stopped beating and death is declared through the absence of pulse and respiration, other organs, such as the heart and lungs, are too damaged for transplant. Because of the worldwide shortage of organ donors, however, many countries have explored the possibility of using non-heart-beating donors in addition to brain-dead donors.

Non-heart-beating donors fall into two categories: uncontrolled and controlled. Uncontrolled non-heart-beating donors are those in whom death is sudden and unexpected, without any preparatory time to plan for organ removal. Examples are victims of accidents or heart attacks who arrive in hospital emergency rooms *in extremis* (at the point of death), perhaps after the heart has already stopped beating. They do not respond to resuscitative measures, their lives cannot be saved despite all medical efforts, and they are pronounced dead. Consent for donation has to be obtained urgently, and organ removal is a hasty event, usually performed under far less than ideal circumstances. Still, the organs may have been deprived of blood flow and oxygen for so long that they are irreparably damaged and would not function if transplanted.

Controlled non-heart-beating donors are those in whom death is a planned event. The patient, with a hopeless prognosis, is going to have life support withdrawn because the patient and next of kin wish to forgo any measures or interventions that would prolong life. The patient has previously expressed the wish to donate after death, and consent for donation is obtained prior to death. Surgical removal of organs is timed to occur within minutes of cardiac arrest. In this situation, the organs are generally less damaged than they are with uncontrolled non-heart-beating donors.

Non-heart-beating donors have been used in Spain, the Netherlands, and the United States, although these countries have predominantly used brain-dead donors. Before 1988, when Sweden adopted its brain-death laws, transplant programs retrieved and transplanted livers from donors whose hearts had stopped beating. In 1995 an international workshop on non-heart-beating donors was held in Maastricht, Netherlands, and recommendations were put forward to guide transplant specialists on the use of nonheartbeating donors (Koostra).

The Living Organ Donor

Normal, healthy individuals can donate one of their kidneys or a part of another organ for transplantation. Because of the limited number of cadaver donors and the increasing population of patients developing kidney failure each year, greater use is being made of kidneys from living donors. The best long-term results of kidney transplantation are those achieved with living donors. In countries that typically use cadaver donors, the rate of living donors varies. In the United States, approximately 35 percent of all kidney transplants are from living donors; in Canada, 48 percent; and in the United Kingdom, only 6 percent. Japan has brain death-criteria, but acceptance of the concept for purposes of organ donation has been slow. Consequently, 78 percent of kidney transplants are from living donors.

Advances in minimally invasive surgery now allow kidneys to be removed from living donors through much smaller incisions, allowing for earlier discharge (as early as 48 hours), and shortening the overall recovery period for the donor. The procedure is referred to as *laparoscopic* kidney removal. Rather than making a long and painful incision over the flank with removal of a rib to retrieve the kidney, slender instruments the diameter of a pencil are inserted into the abdominal cavity through tiny incisions. Carbon dioxide is used to fill the abdominal cavity, which allows the organs to separate from one another. With the use of fiber optics, a camera sees the inside of the abdomen and projects the picture onto a screen for the surgeon. Then the kidney is dissected from its attachments and removed through an incision just large enough for the kidney to fit through the muscles and skin (2 to 3 inches). The donors experience much less pain after the surgery, they recover more quickly, and return to normal activity and employment sooner.

A portion of the liver, lung, pancreas, or bowel can be removed from a living adult and transplanted into a suitably sized recipient, either a child or an adult who is smaller than the donor. Blood-group matching and size matching of the donor and recipient are very important. In most instances, living donors are either genetically related to the recipients or "emotionally related," such as a spouse or close friend. Parent-to-child living-donor liver donation began in the early 1990s, and it has become common in major pediatric transplant centers. A small segment (one-quarter) of the liver is removed from the donor. The use of living liver donors has significantly reduced the number of children dying while on transplant waiting lists. Adult-to-child lung donation is also possible, by removing a lobe of a donor's lung and transplanting it into the chest cavity of a child whose diseased lung has been removed. Living liver donation can also be performed between two adults. Rather than using a small part of the donor liver, as in a parent-to-child transplant, the largest lobe of the liver, which makes up about two-thirds of the organ, is removed and transplanted into a size-matched adult recipient.

Given the severe shortage of donated cadaver organs, relatives, especially parents, may feel compelled to donate. The donor must understand the risks and benefits of donation. Although living donors place themselves at risk, they may experience a psychological benefit from saving, or attempting to save, their loved one's life. In addition, the recipient does not have to wait as long for the transplant and will likely be healthier. This factor, combined with a reduced ischemic time (the length of time the organ has no blood supply) may provide greater success than transplants from cadaver donors. Because the donor and recipient operations can take place simultaneously, the organ does not have to be stored and transported, and ischemia is reduced and organ function is not compromised.

The operative risk of a kidney donor dying is approximately 3 in 10,000 (Najarian et al.). There is general acceptance that the risk is considered low enough to justify the procedure. The risk for a person donating the major portion of the liver is estimated to be much higher, perhaps ten times as high. The exact percentage is not known because no national or international registry has accumulated all the donor data to document the risk. However, deaths have occurred, and some have been widely published in the press (Strong). Experience from individual centers indicates that the chance of a postoperative complication that may interfere with the recovery of the liver donor is as high as one in five patients. Some physicians and surgeons have questioned the justification for living donation that could potentially harm the donor. On the other hand, living donations are an important avenue to reduce the organ shortage. Without living donors, many patients would be denied transplantation.

Organ Retrieval and Preservation

After patients are declared dead and consent has been obtained, they are transferred to an operating room where organs and tissues are removed. Local surgeons may remove organs and send them to a transplant center, or often the transplant team travels to the donor hospital to remove and transport the organs. Surgical teams from different centers may be involved, and each team may remove a different organ before returning by air or ground travel (depending on the distance) to its own transplant center. Organ and tissue recovery is a delicate surgical procedure. Transplant staff are careful to prevent visible disfigurement so that usual funeral arrangements for the donor, including an open casket, are possible.

In the operating room, an incision is made on the donor that extends from the sternal notch (breastbone) to the pelvis. The rib cage and abdomen are retracted so the organs can be seen easily, and the organs are examined for damage or disease that may not have been detected by earlier tests. If the organ appears normal, the surgeon begins to carefully dissect, or cut away, the tissue surrounding the organ. The aorta (the blood vessel through which blood flows from the heart to the rest of the body) is then clamped, and a tube is inserted into it. Through that tube a specially prepared, cold solution (4°C) is infused to flush blood out of each organ and lower the organ's temperature. Cold acts as a metabolic brake, reducing the oxygen requirements of the organ to near zero, thereby helping to preserve the organ. If several organs are to be removed, the procedure takes approximately two to three hours. The heart or lungs are removed first, the liver and small bowel next, followed by the pancreas and kidneys. The kidneys are removed together and then separated—the kidneys are preserved and stored separately so that they can be transplanted into two patients.

Each organ is immersed in cold preservation solution and stored in a sterile container, which is surrounded by ice, and transported in an insulated cooler. Because storage times are limited, recipient surgery has to be timed in relation to the donor procedure. When the donor and recipient are at the same transplant center, the surgeries can be done simultaneously so that organs do not have to be cold-stored for long periods. When the ischemic time is shortened, initial organ function is better after transplant.

Various solutions have been developed to preserve organs, including Collins, Euro-Collins, HTK, and UW solutions. Different solutions can be used for different organs removed from the same donor. There are limits to the time that organs can be stored ("cold ischemic time") before permanent cell damage occurs and the organ cannot be used for transplant. Typically, kidneys are transplanted within 24 hours and livers are transplanted within 12 hours. Heart and lung preservation times remain limited to between 4 to 6 hours.

Whereas most organs are flushed and stored in a cold solution for transport, kidneys can be preserved by two methods: cold storage or machine perfusion. Most often, kidneys are immersed in a cold solution and stored in a sterile container (cold storage). With perfusion, the kidney is attached to a machine that periodically flushes a cold solution through the kidneys until they are transplanted. Long-term results show that kidney transplants are equally successful whether they are cold-stored or machine-perfused.

Organ Distribution

Potential recipients are assessed by transplant teams that evaluate each patient's disease to determine if a transplant is needed, and how quickly it is needed. General criteria are that the potential recipient has a disease for which transplantation is good treatment, and that there are no other health issues that would make a transplant too risky. Transplant centers define their own specific criteria for patient acceptance on waiting lists, such as age and rehabilitation potential. Once on the list, each patient should have an equitable chance of receiving an organ, because policy guidelines have been formulated to ensure appropriate and fair distribution of organs.

Several factors may be considered in selecting the recipient once an organ has been donated: blood group; tissue type (for kidneys); body size of donor and recipient; amount of time the patient has been waiting; proximity to the transplant center; and the patient's current health and "status rating." When their names are added to waiting lists, potential recipients are assigned a status code rating that describes their medical condition. For example, a rating of "1" is given to a patient whose health is stable and who is waiting at home. The highest number, "4," is given to a patient who is on life support in an intensive care unit and may die within days without a transplant. This number or rating changes as the patient's health changes so that the most urgent patients can receive transplants first.

When an organ becomes available, the most suitable recipient on the waiting list is identified through computer and telephone communication between transplant centers and organ procurement agencies. The role of the agencies is to facilitate the procurement of organs after a donor is identified, and assist in the distribution of organs to appropriate recipients according to allocation guidelines. In some countries, such as Canada and the United Kingdom, the agencies are run and funded by governments. In the United States, they are independent organizations that act as arms of the transplant centers. They cover specific geographic regions and charge the transplant centers for the costs they incur. The transplant centers pass on the costs to the recipients' medical insurance. Transplant centers maintain waiting lists of potential recipients for matching with donors in their own region. National waiting lists are also maintained for sharing donor organs between regions, depending on the priority of sick patients. In the United States, the United Network for Organ Sharing (UNOS) maintains a national, computerized list of potential recipients.

In Scandinavia (Norway, Sweden, Finland, and Denmark), Scandiatransplant organizes the exchange of transplant organs. Exchange rules have evolved over time, but transplant organs generally cross international boundaries easily. The UK Transplant Service serves all of Britain and is linked with other agencies in western Europe. In Europe, organ-matching agencies in Italy, France, Spain, and other countries arrange organ distribution according to agreed-upon rules. Eurotransplant, located in the Netherlands, registers potential recipients and distributes organs among the Netherlands, Belgium, Luxembourg, Germany, and Austria.

Rejection and Immunosuppression

After the transplant, the body's attempt to reject the organ is normal, since the function of the immune system is to recognize and attack foreign substances, including a transplanted organ. There are three types of organ rejection: hyperacute rejection; acute rejection; and chronic, long-term rejection. Hyperacute rejection occurs when the recipient's immune system, pre-sensitized by antibodies, immediately recognizes the transplant as foreign. The organ is rejected within minutes to hours. This type of rejection can be avoided if "crossmatch" tests using the donor's and the recipient's blood are performed before the transplant. Although hyperacute rejection can be avoided, acute or chronic rejection may still occur. Acute rejection is characterized by rapid onset, usually several days after the transplant. The closer the match between donor and recipient tissue, the less likely an acute rejection episode will occur. This is particularly important in kidney transplantation. Chronic rejection develops more slowly, occurring many months or years after transplantation, and it gradually compromises function of the graft.

Transplant patients take drugs to suppress the immune response and prevent rejection. Drug therapy (immunosuppression) is usually started during the transplant surgery, and continues after the transplant. Larger doses of drugs are given in the first few weeks after transplantation, when the risk of acute rejection is the greatest. The doses are tapered over time, and most patients need relatively small doses years after their transplant. If acute rejection occurs, the dosage of the patient's regular antirejection drugs may be increased temporarily. Alternatively, other immunosuppressants, such as OKT3, antilymphocyte globulin, or antithymocyte globulin, may be added temporarily to reverse rejection episodes. New immunosuppressants continue to be investigated in clinical trials and animal studies to assess their effectiveness and side effects.

The antirejection drug cyclosporine was first used in transplant patients in 1978. The first clinical studies showed improved patient and organ survival. Until the 1990s, cyclosporine was the mainstay of immunosuppression. Another drug, FK506 (tacrolimus) is a valuable alternative to cyclosporine. Although it is a completely different molecule from cyclosporine, it has a similar effect on the immune system. Either cyclosporine or FK506 is used as baseline immunosuppression in most organ recipients. Prednisone (a steroid) is commonly used as well, but much smaller doses are required because of the effectiveness of cyclosporine and FK506. There are other immunosuppressive drugs that may be added, depending upon specific patient characteristics, the organ transplanted, and the doses of the other drugs being given. Immunosuppression protocols vary among transplant centers, but, as a general principle, drug doses are reduced over time to low levels to minimize the risk of side effects.

Immunosuppression requires a careful balance so that organ rejection is prevented and side effects are minimized. All immunosuppressive drugs have some side effects. Because they affect the body's immune response, white blood cells may be less effective in fighting bacteria and infections. Infections may occur more frequently and be more difficult to treat. The more severe effects may include impaired kidney function, hypertension, or the development of cancer. In some patients, adverse side effects can be minimized or prevented when a combination of drugs is used and a large amount of a single drug is avoided. When large amounts of a

TABLE 1

Patient and Graft Survival Rates after Transplantation

Transplant	1 year patient	1 year graft	5 year patient	5 year graft
living kidney	98%	95%	91%	78%
cadaver kidney	95%	89%	82%	65%
liver	88%	81%	74%	66%
heart	86%	85%	70%	69%
lung	77%	76%	44%	42%
heart-lung	60%	58%	42%	41%
pancreas	93%	76%	84%	42%
bowel	79%	64%	50%	37%

SOURCE: UNOS Scientific Registry Data, 2001 OPTN & SRTR Annual Report.

drug are given, negative side effects, such as impaired kidney function from cyclosporine or weight gain and hypertension from prednisone, may be more likely to occur.

Success of Transplantation

Table 1 shows the survival rates after various organ transplants—success is highest with the kidney and lowest with the bowel. Usually, both patient and graft survival rates are measured. Patient survival rates may be higher because patients may survive even though the transplant fails. This is true especially for kidney recipients who can return to kidney dialysis machines if the graft fails, and pancreas or islet-cell transplant patients, who may resume insulin injections. For other organs, such as the liver, the patient can have a repeat transplant if the first graft fails, and thus patient survival is higher than graft survival. Success rates for a second or third transplant, if a patient is fortunate enough to receive one, are lower, however. When a patient has rejected a kidney transplant, it is often more difficult to find a "match" for a second kidney. The patient's immune system has memory cells and antibodies that persist and would aggressively attack a second transplant if it shared tissue proteins with the first graft.

While the most objective evidence of the success of transplantation is survival, more and more emphasis is appropriately being given to the patient's quality of life. With increasing numbers of recipients entering the second decade after their transplant, long-term goals should be aimed at restoring patients to their pre-illness level of health and social functioning. A major transplant study in the United States reported that 80 to 90 percent of kidney, heart, liver, and pancreas recipients are physically active (Evans). This study also asked transplant recipients to rate their quality of life—their "life satisfaction," "well-being," and "psychological affect." The average scores reported by kidney, heart, liver, and pancreas recipients are similar to scores reported by the general public, indicating a comparable quality of life (see Table 2). Many other studies have also shown that the majority of transplant recipients enjoy a good quality of life and complete rehabilitation (Pinson et al.; Bravata et al.; Ostrowski et al.). Transplantation produces improvement in their physical health, social functioning, and ability to perform daily activities. The sense of well-being and satisfaction with life of most recipients is similar to the general public—they are able to return to work, and they enjoy their families without any restriction on their physical activity. Before modern immunosuppression and all of the advances that have occurred in transplantation since the 1980s, recipients led precarious existences. Today, they are encouraged to live lives that are as close to normal as possible. Indeed, every second year the Transplant Olympic Games are held, and hundreds of organ recipients from around the globe compete at a high level.

Transplant recipients are expected to follow good health habits, including regular exercise and appropriate attention to diet and weight. Transplant patients take immunosuppressive drugs to prevent organ rejection for the rest of their lives, although there are occasional patients who have been able to be weaned completely from their immunosuppressive drugs. However, lack of compliance regarding medication is one of the causes for graft loss in the long term. Despite this need for continued medication, patients report remarkable life satisfaction and well-being.

Transplantation Costs and Reimbursement

Transplantation is expensive, as are many other medical therapies and surgical treatments. In view of limited healthcare resources, society must determine the extent of its willingness to fund transplantation. An important consideration, however, is the number of years and quality of life obtained from transplantation. Numerous studies have documented the cost savings of kidney transplantation when compared to its alternative, dialysis. It is widely recognized that transplantation is the most cost-effective treatment for end-stage kidney disease. Although transplantation initially costs more than dialysis, the costs are fully recouped within three years after surgery (Loubeau et al.). Other studies report that liver and heart transplantation are also cost effective. The cost effectiveness of lung transplantation is limited by its lower survival rates and high costs (Anyanwu et al.).

In the United States, funding through Medicare and Medicaid has provided coverage for many kinds of transplants at approved transplant centers. Approved centers must have performed at least a specified number of transplants with a certain level of success to receive these funds. Medicare has been the primary provider of kidney transplant coverage, although coverage has also been provided for certain patients requiring bone marrow, cornea, heart, or liver transplants. Medicaid coverage has varied from state to state, but usually bone marrow, cornea, kidney, and liver transplants have been covered. Heart transplants have been widely available, but coverage for heart-lung, lung, and pancreas transplants has been limited. Most states have covered the cost of organ retrieval, and every state has paid for antirejection drugs for the first year after the transplant. During the 1990s, drug coverage increased, and new transplant patients now have coverage for three years.

In the United States, private insurance and the patient's own financial resources are often necessary. Even when public and private insurance covers transplantation, patients may only be partially reimbursed. The total costs for organ retrieval, surgery, and follow-up healthcare may not be reimbursed, so the patient may have substantial medical bills to pay.

In Canada, provincial health programs cover the costs of organ retrieval, transplant surgery, and medical care. The major cost for recipients is transportation to the transplant center, which may be located in another province. The antirejection drug cyclosporine is paid for for all transplant recipients by a government-sponsored program. Costs are paid as long as patients take the drug, regardless of the socioeconomic status of patients. If patients take other immunosuppressive drugs, these costs may be completely or partially reimbursed by work benefits, private insurance, or special plans for patients with limited finances. Long-term follow-up care is covered by the patient's provincial healthcare plan.

TABLE 2

Quality of Life Assessment

Population	Life Satisfaction[1]	Well-Being[2]	Psychological Affect[3]
Kidney recipient	5.25	11.01	5.23
Heart recipient	5.11	11.11	5.49
Liver recipient	6.70	n/a	6.40
Pancreas recipient	5.40	11.03	5.35
General population	5.55	11.77	5.68

1. Range of values, 1.0 to 7.0, where 7.0 = positive satisfaction;
2. Range of values, 2.1 to 14.7, where high score = positive well-being;
3. Range of values, 1.0 to 7.0, where 7.0 = positive affect.

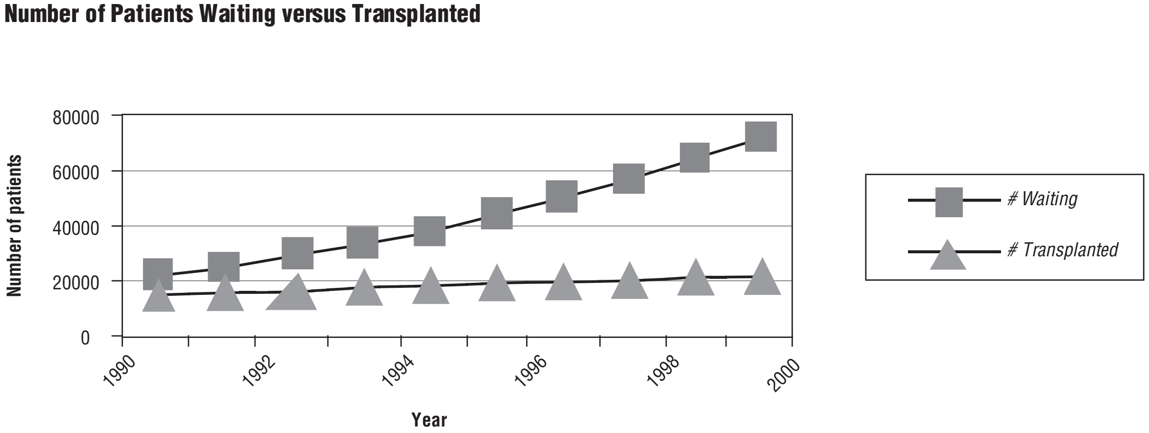
SOURCE: Evans, Roger W., 1991.

In Europe, according to European Economic Community (EEC) agreements, patients may be eligible for transplant in other countries, with their own governments paying the costs. Patients from countries outside the EEC may also receive transplants, but they have to pay the costs themselves. As more programs have developed, however, fewer patients need to travel to other countries for their transplants.

Expanding the Pool of Cadaveric Organs

Given the success of transplants, and the prevalence of diseases that result in organ failure, more patients are being referred for transplant surgery. The inadequate supply of organs, however, limits the number of transplants, so waiting lists continue to grow (see Figure 1). Transplant programs, therefore, continue to expand their criteria for acceptable organs and are trying innovative ways to procure more organs. One prime example is the use of organs from donors who are older than ideal. As a person ages, hardening of the arteries occurs to greater or lesser degrees in almost everyone, accompanied by deterioration in the function of various organs. Less-than-perfect donor organs have been used, and studies have shown that they can function adequately when certain criteria are met (Wall et al.; Loebe et al.). For example, both kidneys from an older cadaver donor can be transplanted into one patient, and this can provide the recipient with an adequate mass of functioning kidney tissue. The liver is affected by aging much less than other organs, and livers from donors in their seventies, and even eighties, can be successfully transplanted when other variables are satisfactory. For unknown reasons, the blood vessels that feed the liver are rarely affected by hardening of the arteries. Unsuitable hearts, which would not usually be used, have been transplanted as "biological bridges" in urgent situations until a suitable heart has been found.

FIGURE 1



SOURCE: UNOS Scientific Registry Data, 2001 OPTN & SRTR Annual Report.

The liver from a cadaver donor can be split in two for transplant into two suitably sized patients. The procedures are technically complex, however, and there is a greater risk of complications. The applicability of this procedure is also limited by the need for multiple surgical teams operating simultaneously. Additional constraints are those imposed by limited preservation times, especially if the intended recipients are located in different transplant centers. Nevertheless, good results are obtainable. The practice of *domino transplantation* allows a recipient's healthy organ to be removed and transplanted into another patient. For example, when a patient needs a double-lung transplant, he or she may receive a combined heart-lung transplant because it is easier technically to include the donor heart with the transplant as opposed to just the lungs. In this situation, the healthy heart of the recipient can be transplanted into another recipient rather than being discarded. So the recipient of the lungs is both a donor (heart) and a recipient (lungs and heart).

Transplant specialists face dilemmas when less-than-optimal donor organs are offered for transplantation. Obviously, they want the best outcome for their recipients, but the lack of donor organs may force them to make compromises. And while doctors must do what they can to make effective use of donated organs, society must also do its part to maximize organ donation rates. Even if organs were donated from every potential cadaveric donor, however, the supply would still not satisfy the need. Thus, other alternatives such as mechanical hearts and animals as sources for organs have to be explored.

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SEE ALSO: *Artificial Hearts and Cardiac Assist Devices; Body: Cultural and Religious Perspectives; Cybernetics; Death, Definition and Determination of; Dialysis, Kidney; Healthcare Resources, Allocation of; Informed Consent; Life, Quality of; Organ and Tissue Procurement; Organ Transplants, Sociocultural Aspects of; Technology*

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ORGAN TRANSPLANTS, SOCIOCULTURAL ASPECTS OF

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Transplantation has been defined by the American medical profession and by U.S. society at large as a "gift of life" since the first human organ grafts were performed in the mid-1950s. This conception has its roots in the Judeo-Christian tradition of American society, which defines the life of an individual as a gift that comes directly or indirectly from God and that creates an obligation to reciprocate (Parsons, Fox, and Lidz). The notion of organ transplantation as a gift is not institutionalized, or even invoked, in societies with other religious traditions (such as Japan with its Buddhist, Shinto, and Confucian background; or Pakistan, with its Islamic worldview). Initially in the United States, the idea of a gift was used metaphorically, with little awareness or analysis of its implications. Only gradually, through clinical experience and interpretive input from psychiatrists, social workers, and social scientists, did the psychological, social, and cultural meanings and repercussions of the gift-exchange aspects of transplantation become more apparent and better understood (Fox and Swazey, 1978).

Despite all the biomedical and social changes that have ensued within and around the field of organ replacement, the "gift of life" aspects of seeking, giving, and receiving a human organ have remained central to the dynamics and meaning of transplantation in U.S. society. The increased frequency of organ transplants, and their greater routinization in certain regards, have not eliminated the gift elements from these surgical and medical acts or reduced their effects on donors, recipients, and their families (Fox and Swazey, 1992).

Marcel Mauss's Gift-Exchange Paradigm

"The theme of the gift, of freedom and obligation in the gift, of generosity and self-interest in giving reappear in our society like the resurrection of a dominant motif long forgotten," wrote the renowned French sociologist Marcel Mauss in his classic 1925 essay *The Gift* (p. 66). To a remarkable degree, organ transplantation has been shaped by the triple set of "symmetrical and reciprocal" obligations that, according to Mauss, govern all gift exchange, no matter how spontaneous and expressive it may appear to be. These are the entwined obligations to offer and give, to receive and accept, and to seek and find an appropriate way to repay. Failure to live up to any of these obligations, Mauss pointed out, produces major social strains that affect the giver, the receiver, and those associated with them.

Mauss also emphasized that gifts have "emotional" and symbolic as well as "material" value and meaning. In this sense, he said, the gift and the obligations attached to it are "not inert." Rather, "the spirit of the thing given" and received is "alive and often personified." It "pertains to a person," and because it does, it creates a "sort of spiritual bond" between donor and recipient (pp. 10–11). Anthropomorphic and magical connotations of the gift have proved to be as characteristic of the modern medical, scientific, and technological milieus in which the giving and receiving of organs through transplantation take place, as of the settings in "primitive" and "archaic" societies that were the contexts of Mauss's study.

Obligations to Give Organs

The gift-exchange paradigm illuminates many of the distinctive psychological and social phenomena that donors, recipients, their families, and the transplant team encounter. To begin with, even though the U.S. organ donation system has been organized around the cardinal societal principles of voluntarism and freedom of choice, the situations in which transplants are performed subject prospective donors and their families to strong inner and outer pressures to make such a gift. This is most apparent in the case of live organ transplants, which usually involve the donation of a kidney to a parent, sibling, or child who is gravely ill with end-stage disease. Most transplant teams scrupulously try to avoid urging close biological kin to offer themselves as donors. Nevertheless, they do inform patients and their families that a live kidney transplant from a relative who is a "good tissue match" is likely to have a better prognosis than a cadaver transplant from a nonrelated donor. In addition to the biomedical reasons that favor a live kidney donation, its symbolic meaning virtually obliges every family member at least to consider making such a gift. The integrity, intimacy, and generosity of the family and each of its members are involved in their individual and collective willingness to give of themselves to a terminally ill relative in this supreme, life-sustaining way (Simmons, Klein, and Simmons).

It would be easy to assume that because cadaver organs come from persons who are unrelated and unknown to recipients, such donations are relatively free from inner and outer gift-giving pressures. Nevertheless, under the circumstances in which the option of donating cadaver organs arises, families may feel emotionally and spiritually constrained to make such a gift of life when this prospect is presented to them by an organ procurement team. Most cadaver organs are obtained from young, healthy persons who have been fatally injured in a vehicular accident or a homicide or who have taken their own lives. These sudden and unexpected deaths are especially tragic and fraught with problems of meaning. In the face of this sort of death, the grief-stricken family may be motivated to donate their young relative's organs by their intense need to make redeeming sense out of what they would otherwise experience as morally and existentially absurd.

Obligations to Receive Organs

The candidate-recipient who is offered a live or cadaver organ is subject to strong, complementary pressures to receive it. Whatever the potential recipient's reservations may be about a transplant, great reluctance or outright refusal to accept the lifesaving gift that is offered symbolically implies a rejection of the donor and of the donor's relationship to the recipient.

There are several recurrent sets of reasons why recipients may be reluctant to accept the kind of gift of life that a donated organ represents. First, the recipient may not want a living, related donor exposed to the degree of discomfort, danger, or sacrifice that a transplant entails. Second, the recipient may feel that receiving an organ from this individual would make the relationship between them too emotionally complicated and difficult. Third, whether the proffered organ comes from a live relative or a deceased stranger, the recipient may be heavily burdened by the realization that it is such an extraordinary gift that he or she will never be able to repay it. Fourth, the recipient may have great concern or apprehension about absorbing a donated part of another known or unknown individual into his or her body, person, and life.

Receiving a donor's organ summons up buried, often animistic feelings that people have about their vital organs and the integrity of their body, along with the sort of anthropomorphic reactions to such a gift that Mauss identified. Many recipients of cadaveric organ transplants grapple with the haunting sense that psychic and social as well as physical qualities of the unknown donor have been transferred into their body, personhood, and life. Writing about his experiences as a liver transplant recipient, Richard McCann vividly expressed such feelings—depicting the donor organ as a "bearer of its own cellular memories" and describing the long nights when he thought of the donor, always "with great tenderness," sometimes perceiving the donor as a male and sometimes as a female. The strong interest that many recipients of cadaver organs and their kin have in knowing what kind of person the donor was and what the donor's family is like is related to this phenomenon. So, too, is the eagerness of donor families to learn something about the persons to whom living parts of their deceased relatives have been given, and about their families.

In the early years of human organ transplants, during the 1950s to mid-1960s, medical teams were inclined to reveal the identities of the donors of cadaver organs, their recipients, and their families, and to provide details of their backgrounds and lives. Physicians believed that these intimate participants in the acts of transplantation giving and receiving were entitled to such knowledge. They also thought it would enhance the meaning of the transplant experience for the recipient and recipient's family and afford consolation and a sense of completeness to the donor's family.

With the passage of time and increased clinical experience, however, transplant teams became more wary about the information they conveyed. They were discomfited by the way in which recipients, their kin, and donor families personified cadaver organs, and by how many of them not only arranged to meet but also tried to become involved in each other's lives, as if they were indebted and related to one another. These interactions were major factors that led most transplant units to establish the normative practices of guarding the anonymity of cadaveric donors and of exercising great restraint in divulging any information about the donor to the recipient or about the recipient to the donor's family. Although transplanters developed this policy out of their desire to reduce some of the stress that the symbolically charged gift of an organ entails for all who are involved in it, they express some ambivalence about its merits and uncertainty about its consequences. The policy of anonymity has been challenged as paternalistic by donor families and recipients, in the "National Communication Guidelines" developed by the National Donor Family (NNF) council in collaboration with a number of transplant organizations including the United Network for Organ Sharing (UNOS) and the U.S. Department of Health and Human Service's Division of Organ Transplants (Corr et al., p. 625).

Obligations to Repay the "Gift of Life" and the "Tyranny of the Gift"

At the center of organ transplantation is a gift of surpassing significance—in the words of philosopher Hans Jonas, a "supererogatory gift … beyond duty and claim" (p. 16). Paradoxically, it is an offering that so perfectly epitomizes an ultimate Judeo-Christian value—the injunction to give of one's self to others in ways that include strangers as well as kin—that it transcends what is ordinarily asked or expected of people. The sublime meaning of what is exchanged, along with the literal and figurative sense in which a living part of the giver comes to reside and function inside the recipient, usually creates a very strong bond between the donor, the recipient, and their families. The sense of oneness and ennoblement that a donor or donor's family and a recipient often experience as a result of the life-giving and life-receiving acts in which they have participated can greatly enrich them, emotionally and spiritually.

But as Mauss could have foretold, what recipients believe they owe to donors, and the sense of obligation they feel about repaying "their" donor for what has been given, weigh heavily upon them. This psychological and moral burden is especially onerous because the gift the recipient has received from the donor is so extraordinary that it is inherently nonreciprocal. It has no physical or symbolic equivalent. As a consequence, the giver, the receiver, and their families may find themselves locked in a creditor–debtor vise. Because of their feelings of great indebtedness, recipients of live organs may have difficulty in maintaining psychic distance and independence from donors and in asserting their own separate identity and being. In some instances, their struggle to do so may cause a serious rupture in the relationship between recipient and donor. Renée C. Fox and Judith P. Swazey have called these aspects of the gift-exchange dimensions of transplantation "the tyranny of the gift" (1978, chap. 1).

Alterations in the Theme of the Gift: Efforts to Procure More Organs

The 1980s and 1990s brought a number of significant changes in the ways the U.S. medical community and public thought about the gift of a transplantable organ, and in how they acted in relation to their conception of it. The primary precipitants of these changes were the growing preoccupation with the shortage of organs and the increasing efforts that were made to augment the supply of both living and cadaver donors.

The 1980s were marked by a substantial expansion in the number and types of transplants and retransplants, in the number of hospitals doing these procedures, and in the number of patients on waiting lists. The discovery and pervasive use of cyclosporine, a more effective immunosuppressive drug for managing the rejection reaction triggered by transplanted organs, was a key biomedical factor that contributed to this transplant "boom." To the distress of organ procurement agencies and transplanters, these increases occurred in the face of a plateauing of cadaveric donors and a slight decline in living donors. The "alarming number of patients who die waiting" for a transplant (Peters, p. 1302) led members of the transplant community and their advocates to define the organ shortage as a "public health crisis" (Randall, p. 1223). In the context of various policy strategies that were deployed to combat this growing "crisis," the concept and theme of transplantation as a gift of life underwent a number of alterations.

GREATER USE OF LIVING DONORS. Efforts to enlarge the supply of organs included a greater interest in the use of living donors. This resulted in an expansion of the kinds of live-donor transplants that surgeons were willing to perform, and significant redefinitions by the transplant community of how, for purposes of giving and receiving an organ, donors and recipients can be nonbiologically "related" to each other. Increasingly active and large-scale campaigns to recruit future donors were also mounted, urging people to "make a miracle" by giving a gift of life through the provisions of the Uniform Anatomical Gift Act. (Promulgated in 1968 and adopted in some form by every state by 1973, the act enables individuals to legally signify their willingness to have their bodily parts used for transplantation after their death; if the deceased's wishes are unknown, the act grants the next of kin the right to make this decision.)

Beginning in the 1980s, the fact that the supply of cadaveric kidneys was not large enough to meet the growing demand for them, along with advances in immunosuppression, emboldened a number of medical centers to undertake kidney transplants from unrelated live donors. In effect, something akin to a collective taboo against performing this type of graft had previously existed among transplant physicians. A new term appeared in the medical literature: "emotionally related donors," meaning persons whose relationship to recipients, though not biological, was analogously close (including spouses, in-laws, adopted children, and kinlike friends). In 1985 the Council of the Transplantation Society (CTS) issued a set of "guidelines for the donation of kidneys by unrelated living donors" that legitimated their use in exceptional circumstances "when a satisfactory cadaver or living related donor cannot be found." These normative recommendations expressed continuing concern about the motives of such donors, about the recognition and protection to which they were entitled for such "a gift of extraordinary magnitude," and about the ever-present danger "in the current climate of commercialization" that, particularly in the case of "living stranger donors," the covert buying and selling of organs might be involved (CTS, p. 716). Because living donations have become a "burgeoning source of organs," some concern also has been expressed about the risk of "trading [the donor's] health or even life for that of [the recipient]" (Kahn, p. 4).

In the atmosphere produced by the acceleration in the number and range of transplants performed, the mounting sense of crisis over the organ shortage, and the increased support given to live-donor kidney transplants, liver and lung transplantation from living donors was tried for the first time in the United States. The initial liver recipients, in 1989, were two infants with biliary atresia, a congenital, usually fatal condition, each of whom received a liver lobe from a parent. In 1991 a nine-year-old girl received two successive live-donor lung-lobe transplants: first from her father and then, when this did not provide enough lung capacity, another transplant from her mother. During the second procedure, the child died of heart failure. Partly because the liver has the mysteriously unique ability to regenerate itself, live liver-lobe transplants have since included donations from friends and, in one instance, a "stranger"; but like lung-lobe transplants, they are still relatively uncommon and done only at a few highly sophisticated transplant centers.

Another form of live donation, employed since 1984, has generated even greater uncertainty and debate about "the permissible limits of one of our most powerful instincts, the one that leads us to fight for the life of our children" (Quindlen). These cases involve conceiving and giving birth to a baby in order to provide a bone marrow donor for one's dying child when no donor with a compatible tissue type can be located. In 1990 the case that received the most attention, because of the decision to go public, was that of the Ayala family, whose nineteen-year-old daughter, Anissa, was slowly dying of chronic myelogenous leukemia. Her parents announced that they had conceived a child on the one-in-four chance that the baby's tissue type would be compatible with Anissa's. There was a tissue match, and at age fourteen months the baby had her bone marrow withdrawn and infused into her sister. The Ayalas' story was viewed by many as an act of love as well as of science—all the more so because the parents made it clear that they never would have considered aborting the fetus if its tissue type did not match Anissa's. Pervading all the discussion surrounding this case, however, was disquietude about how morally acceptable it was to bring a baby into the world to provide life-sustaining treatment for another child; about the baby's inability to consent to this role; about the psychological impact that the condition of the donor child's birth could have on her sense of identity and of her reason for being; and about how blameworthy she might feel, or be made to feel, if in the end her transplanted tissue failed to help her sister (Kearney and Caplan).

By 2002 all these issues had been extended to an analogous situation, one in which hematopoietic stem cells from umbilical cord blood or bone marrow might cure or alleviate a disease affecting the blood or immune system of a child. Conceiving a baby to serve as a stem cell donor was a possibility for the parents of such a child, and using in vitro fertilization followed by selective abortion, or preimplantation genetic diagnosis and selective embryo transfer had become viable biomedical options (Robertson, Kahn, and Wagner).

NON-HEART-BEATING DONORS. Another effort to increase the supply of organs has been the use of what are termed planned or controlled *non-heart-beating donors,* an effort that was initiated by a 1991 protocol at the University of Pittsburgh. In such cases, a family agrees to have life-sustaining treatment withdrawn from a close relative who is terminally ill but not brain dead, so that the person's organs can be retrieved for transplants. In effect, this constitutes a return to the cardiopulmonary criteria that were used to pronounce donors of cadaver organs dead before the concept of brain death was adopted in the United States in the late 1960s and progressively took its place alongside the more traditional means for declaring a person dead on the basis of irreversible cessation of circulatory and respiratory functions. The use of non-heart-beating donors helped bring to the surface and intensify pervasive conceptual confusion and unease about the relationship between these dual means of determining and declaring death. It also raised troubling questions about the exact borderline between life and death; how long an interval should be observed after the complete cessation of cardiac and pulmonary function before death is pronounced; whether giving drugs to non-heart-beating donors to minimize the effects of warm ischemic time on the viability of their organs could hasten or cause their death; and the compatibility of procuring organs in this manner with the humane and respectful treatment of dying patients and their families (Fox; IOM, 1997; Arnold and Youngner; Youngner, Arnold, and DeVita).

BROADER STANDARDS FOR CADAVERIC ORGANS. Criteria for what are deemed to be acceptable cadaveric organs have also been "liberalized and expanded" in the drive to perform more transplants. These broadened, less stringent standards include using organs from donors of increasing age; from persons with medical conditions such as diabetes and hypertension and certain infections; and from persons with some hemodynamic instability or chemical imbalances, or whose organs have undergone increased preservation time (IOM, 1997). While transplant experts have hopefully predicted that using what are sometimes called such "marginal" organs could markedly increase the donor supply, they have acknowledged that the concomitant financial and human costs, and lower graft and recipient survival, should be seriously considered (IOM, 1997).

XENOTRANSPLANTATION. Along with the measures taken to increase the number of human donor organs, the 1990s brought a surge of renewed interest in xenotransplantation—grafting animal organs, tissues, and cells into human beings—accompanied by strong appeals to end the informal moratorium that had been called on interspecies organ transplants in the United States and numerous European countries because of the immediate postoperative deaths of all but one of the patients on whom the procedure had been previously tried. The reignited interest in xenotransplantation has been deliberated by bodies such as the U.S. Food and Drug Administration, the Centers for Disease Control and Prevention, the National Institutes of Health, and the National Academy of Sciences' Institute of Medicine. All these groups have focused special attention on the "greater than zero" risk that xenotransplants could trigger zoonosis, the transmission of known and unknown animal pathogens into the human population (IOM, 1996). In a historical era when the most daunting problems of world health emanate from the "emergence" and "reemergence" of infectious diseases in epidemic and pandemic proportions, this consideration has had a sobering and restraining effect on the intrepidness with which the prospect of providing animal organs for the long lines of people awaiting transplants has moved forward.

"REQUIRED REQUEST" AND "PRESUMED CONSENT." Seeking remedies for the shortfall of organs has also involved identifying and attempting to alter attitudes and role behavior of physicians and nurses. In this connection, in the mid-1980s bioethicist Arthur L. Caplan proposed the establishment of "required-request" procedures in hospitals to ensure that the next of kin or the legal guardian of every potential donor was notified of the transplantation option and was asked to make a donation of their relative's organs for this purpose (Caplan, 1984a, 1984b). Although required request had been drafted into state and federal legislation and incorporated into hospital accreditation standards by the end of the 1980s, studies suggest that its influence has been minor (Annas; Caplan, 1988).

In Western Europe, serious attention has been given to the use of "presumed consent" or "opting out" as a way to increase the number of cadaveric organs. This is a system that legally allows the use of a deceased patient's organs for transplantation, unless the patient had formally registered the desire not to be a donor. This system has resulted in notable increases in organ procurement rates in a number of European countries. There is evidence, however, that if the "opting out" system requires the next of kin to be informed about organ removal from their dead relative before it is done, physicians may be less inclined to initiate the procurement process and families more likely to object to the donation. Opinion polls have shown that there is a strongly held and wide-ranging resistance to its establishment as a basis for organ and tissue procurement in the United States, as well as in Great Britain and the Netherlands (Kokkedee). It has been suggested, but not systematically investigated, that "opting out"—rather than "opting in"—may run counter to the social expectations and cultural values of individuals, families, and health professionals in these societies.

From "Gifts of Life" to Market Commodities?

Throughout its history in the United States, human organ transplantation has been steadfastly defined and ardently promoted as a gift of life, and the National Organ Transplant Act of 1984 made it illegal for "any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation." Nonetheless, recurrent proposals have been made to provide some sort of financial recompense for this act of giving. These proposals have had a dual purpose: to recognize what donors and their families have contributed and to provide an additional incentive for organ donation. None of the proposals has involved the outright buying and selling of organs. Rather, they have entailed various forms of so-called regulated compensation, or what has euphemistically been termed "rewarded gifting," such as granting a paid medical leave to living donors (the Organ Donor Leave Act, enacted in 1999) or advocating the partial reimbursement of funeral expenses for cadaveric donors. Among the most pecuniary of these suggested measures has been a Congressional proposal to give tax credits or refunds for an organ donation (the Gift of Life Tax Credit Act of 2001). The most market-oriented notion, espoused by some jurists, economists, and health policy analysts and managers, is that of a "futures market" in cadaveric organs that would allow healthy persons to contract for the sale of their organs for transplantation, to be retrieved and used after their death (Cohen; Hansmann). Neither the tax credits nor the futures market plan has been implemented.

The search to devise monetarily expressed incentives and rewards for organ donation that will help alleviate the organ shortage, without violating the prohibition against buying or selling organs, has been occurring in the larger context of the existence of a global black market for organs from living donors (Scheper-Hughes). In the United States, the search has been characterized by a continuous veering toward financial incentives and a continuous veering away from them. This ambivalence is exemplified by the outcome of a bill, originally signed into law in Pennsylvania in 1994, that created an Organ Donation Awareness Trust Fund, part of which was intended to pay up to $3,000 to a cadaver donor's family to defray funeral expenses, and to study the impact of this arrangement. After nearly eight years of debate and delay, state health officials abandoned the program on the grounds that it came too close to offering cash for organs. Instead, in 2002 they created a program to offer a modest $300 benefit to pay directly for food and lodging costs incurred by a donor's family (Wiggins). Another proposal, which "released a torrent of protest" during a committee hearing, was introduced in June 2002 by the Council on Ethical and Judicial Affairs of the American Medical Association (AMA); it involved offering a $300 to $500 payment to families of cadaveric donors and was coupled with a study to determine the effects of such payments. If the AMA House of Delegates approved the council's recommendations, however, a pilot study would require changes in the federal law that prohibits such financial incentives (Peck). To date, at least in American society, every such attempt to institute compensatory measures for organ donation has elicited as much concern and opposition as support; and it has called forth strong affirmations about the "symbolic" association of organ transplantation with "altruism" and "social good" and the importance of not subverting its meaning by monetarizing the gift that it constitutes (Delmonico et al.).

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SEE ALSO: *Body: Cultural and Religious Perspectives; Cybernetics; Death, Definition and Determination of; Life, Quality of; Medicine, Anthropology of; Medicine, Sociology of; Organ and Tissue Procurement; Organ Transplants, Sociocultural Aspects of*

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PAIN AND SUFFERING

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Suffering demands explanation and relief. Some appear to suffer in excess of their actions, the innocent suffer as the evil do, and the best suffer with the worst. Theologies and theodicies attempt to cope with the paradox of a holy, omnipotent, omniscient, just god and the presence of suffering. Healers and systems of medicine arise in every culture in response to suffering. Yet what suffering is, where in the human condition it originates, and in what direction its solution is, remain poorly understood.

Pain is the most commonly considered source of suffering, so much so that the two terms are commonly linked—as in "pain and suffering." They are, however, distinctly different forms of distress. Understanding what pain is, and how it is related to but different from suffering, provides an introduction to the topic.

How the Nervous System is Involved in Pain: The Nociceptive Apparatus

The nervous system pathways—the nociceptive apparatus—involved in the transmission of noxious stimuli do not simply transfer information from an injured part to the central nervous system. They are part of a system in which the information can be either enhanced, diminished, or suppressed. The modulation of the noxious sensation occurs as part of the process of perception where meaning influences the original message.

Skin, muscles, and internal organs are supplied with nerve endings that come from several types of nerve fibers. Some are specifically responsive to mechanical, thermal, and chemical stimuli that give rise to the noxious physical sensation called nociception. These nociceptive nerve fibers enter the spinal cord and make complex connections with the spinal nerves that ascend to the thalamus and from there to areas of the cortex of the brain. Neural pathways from the higher centers, in what is called the endogenous pain control system, descend to make connections in the dorsal horn of the spinal cord in the area where the pain fibers make their initial central connections. These descending tracts are able to modulate the nociceptive signal by exerting an inhibitory effect specifically on pain-transmission neurons.

In addition to neural pathways, which do not merely transmit noxious sensations but change their character, chemical messengers and their receptors within the nervous system also have an influence on the message. Naturally occurring brain peptides such as enkephalin and beta-endorphin, collectively known as endorphins, exert analgesic effects in different areas of the nervous system by binding to specialized receptors. These same receptors also bind drugs such as morphine or meperidine, allowing them to provide pain relief. Other neurotransmitters, such as serotonin and dopamine, also have effects that temper the transmission of nociceptive messages.

Pain as Perception

Historically, knowledge about nociception as neural transmission of noxious stimuli predated knowledge about the modulation of the nociceptive process. This simplified view of nociception fits the mechanical understanding of the nervous system that has held until recent times. This view accounts for the fact that the noxious sensation that is nociception is so commonly confused with pain and that the two terms, although distinct, are often used interchangeably. Nociception provides the noxious sensation resulting from extremes of mechanical pressure or temperature that is interpreted by the organism as pain.

Because pain is a perception based on sensory information from the nociceptive apparatus—just as seeing something is a perception based on information from the visual apparatus—it involves a cognitive effort that requires judgment. The place of cognition in the process may be questioned in acute, severe, or momentary pain, but most pain is longer lasting and more ambiguous in source and meaning.

Nociception is usually followed by aversive action. The reflexive withdrawal of a burned hand, however, has little applicability to understanding human pain. The actions of humans in response to pain generally take into account the location, severity, cause, and anticipated course of the pain. Knowledge and judgment are required. Reactions to pain range from the momentary to well-laid future plans. While the former may depend on reflexes, the latter do not. *Pain is the entire process of sensing, interpreting, and modulating the nociceptive process, assigning cause, anticipating course, and determining response.* As a consequence, it is obvious why it is a source of confusion that human pain does not exist without sentience. Unconscious or comatose persons may demonstrate nociceptive reactions such as reflex withdrawal from noxious stimuli or elevations in pulse and blood pressure. Consciousness, however, is required for the full experience of pain. This is why a useful working definition of pain is experience reported in the statement "it hurts."

Attempts to refute the subjective nature of pain may take the form of statements that pain is usually accompanied by physiologic changes in, for example, pulse and blood pressure, but the body and its physiology are part of the person and nothing happens to one part that does not happen to all. Confusions such as this are residua of the mind–body dichotomy that has ruled medical science for centuries and still disorders understanding. The fact that pain cannot be measured has been a source of great frustration to investigators. Noxious stimuli and nociceptive responses can be quantified, but pain cannot. The difficulty of understanding pain is part of the age-old conundrum of how a physiological event becomes a feeling or a thought and how thoughts and feelings are translated into physiology.

Chronic Pain

Chronic pain—by definition, pain lasting more than six months—represents a greater challenge to understanding than acute pain. What is known about the nociceptive system does not explain the phenomenon of chronic pain. There is evidence that the reparative response that occurs after damage to peripheral nerves may alter their function in a manner that perpetuates or exaggerates their response to noxious stimuli. Similar modifications of the whole nociceptive apparatus, including the function of its neuroendocrine component (for example, endorphins), may provide some basis for pain that continues after the initial stage of tissue damage. Nonetheless, paucity of solid evidence to resolve the enigma of chronic pain has led to speculation and hypothesis based more on belief than on knowledge. For example, various schemata have been developed that explain chronic pain in many ways: as a result of continued tissue damage (e.g., rheumatoid arthritis); because of psychic perpetuation of organic pain (e.g., phantom limb pain); or from emotional factors believed to precipitate the organic (e.g., duodenal ulcer); as well as to hypothesized states of psychogenic pain arising from psychic conflicts experienced in a somatic manner (Whitehead and Kuhn).

The problem has also been framed as a conflict between peripheralists and centralists. The peripheralist believes that there must be continued nociceptive input and that treatment should be directed toward blocking the presumed nociceptive process with analgesics or nerve blocks and by other means. Centralists believe that although some peripheral pathology with nociceptive consequences initiated the pain, under some circumstances it can be continued "as a self-perpetuating physiological generator mechanism within the central nervous system" (Crue).

The Role of Meaning

Human pain, acute or chronic, involves the constant and interactive contribution of both psychic and physical determinants. The most important psychological component of pain is its meaning, that is, its significance and its importance. Significance denotes the event as a this or a that: "Chest pain (of this type) signifies a heart attack." Importance evaluates the event: "A heart attack will be the end of my active life." These two functions of meaning are always intertwined and arise from the concepts (e.g., heart attacks) to which they refer. The interpretation of a pain as arising from, for example, cancer, contains within it ideas of process: "Cancer comes from … and goes on to become …" as well as to ideas of the impact on the person: "Cancer pain is terrible and heralds death." Things have affective, physical, and spiritual as well as cognitive meanings. People act on their interpretation of the consequences of the distress, doing what is necessary on their part for it to improve. For example, a person who develops unexpected chest pain while walking may stop because it is impossible to continue. But the person may also walk more slowly in the future, deny the pain's significance, go to an emergency room, worry, panic, take nitroglycerin, or any of a variety of actions, in response to what the person believes the symptom means.

The Distinction between Pain and Suffering

Suffering is closely related to pain because pain is a common cause of suffering, but they are distinct forms of distress. People may report suffering when a pain, such as that caused by a dissecting aortic aneurysm, is overwhelming. Or they may tolerate even extremely severe pain if they know what it is, know that it can be relieved, or know that it will soon end. Less intense pain may be a source of suffering if the person does not know its source or believes that it has a dire cause (e.g., cancer), cannot be controlled, or will be "never-ending." Suffering can sometimes be controlled merely by changing the meaning of the pain. Clinicians working with terminally ill patients frequently see suffering patients grunting with pain who cannot be comforted. When their pain has been adequately relieved and it has been demonstrated that such relief will be forthcoming if the pain should return, they will frequently tolerate the same level of pain (by their report) without requesting medication. Once assured that relief is possible, suffering often subsides although the pain remains. It is difficult to relieve the suffering of patients who are frightened without also relieving their fear.

People may suffer from pain even when the pain is not present. Some who have had severe pain will suffer from the fear of the pain's return even when they are pain-free. People with severe and frequent migraine may suffer from their fear of a return of the headache. These headaches have repeatedly ruined what would otherwise have been pleasurable or important experiences: Family relationships, jobs, sports, and virtually everything that is dear to the person may have been negatively influenced by the headaches. Not surprisingly, such patients may be obsessed with their headaches and their attempts at relief virtually to the exclusion of other aspects of life. They suffer when they do have the actual pain and also when they do not.

The distinction between pain and suffering is clarified by the case of the pain of childbirth. Different kinds of pain relief, some more effective than others, are popular in different parts of the United States. The more important issue seems to be the degree to which the woman is in control of her own labor and delivery, rather than the absolute control of pain. Control of the process of childbirth does not relieve pain, but appears to prevent suffering. In other cases, symptoms such as dyspnea (labored respiration), choking, or even diarrhea may be sources not of pain but of suffering if they are sufficiently severe. In fact, suffering may be present in the absence of any symptoms. Parents, particularly if they are helpless in the situation, commonly suffer at the sight of their children in pain. Grinding poverty may be a source of suffering, as well as betrayal or the loss of one's life work.

The Role of the Future

The role of the future in these situations of suffering is crucial. In cases of overwhelming pain, in long-continued ("never-ending") pain accompanied by fear of the inability to continue to "take it," and in the situation where the pain is suspected of having terrible meaning, a sense of future is necessary in order to suffer. In each of these instances—when at the moment the pain is not overwhelming, the person is "taking it," and the fact of a dreadful disease does not yet exist—the body cannot worry; it knows no future. The body cannot supply information about the future because at any moment, for the body, the future does not yet exist. Only imagination, beliefs, memories, or ideas can supply the information necessary to provide a "future." In other words, in order to suffer, there must be a source of thoughts about possible futures.

To summarize thus far: Although suffering may attend pain, they are distinct. There may be pain without suffering. There may be suffering without pain. There seems to be no suffering without an idea of the future. Bodies do not have the beliefs, concepts, ideas, or fantasies necessary to create a future—only persons do. One can conclude that although bodies may experience nociception, bodies do not suffer. Only persons suffer.

Suffering Defined

Suffering is a specific state of severe distress induced by the loss of integrity, intactness, cohesiveness, or wholeness of the person, or by a threat that the person believes will result in the dissolution of his or her integrity. Suffering continues until integrity is restored or the threat is gone. The whole person does not mean solely the whole biological organism or the solid-bounded object, although it may be the object of the threat. Persons, while they may be identified with their bodies, cannot be whole in body alone. Nor should the threat to the whole person be understood as solely a quantitative matter (i.e., that persons subjected to more than X amount of pain or Y amount of tissue destruction suffer, even if this amount of pain or tissue destruction may virtually always cause suffering), since one individual may suffer from pain considered unimportant by another. Suffering may occur in relationship to any part of a person.

Wholeness, Self, and Person Defined

Suffering helps define the concept of person. Person is not mind, body, or self, although persons have all of these things. The word *self,* as employed here, denotes that aspect of the person that is an object of the consciousness of a person—the person's own consciousness or that of another. It has cohesive characteristics and it exists over time. Persons cannot be known in their entirety and they cannot be known by reducing them to their parts. As one does that, the person disappears. A topography, however, is possible. A person is the composite entity made up of its body, its selves, its history, its collected beliefs, its believed-in future, unconscious, incorporated society and culture, associations with others including the family, the family's history, its political dimension, secret life, and transcendent dimension.

Persons are also constructed by their ideas and beliefs, by the past, the present, and a sense of the future, as well as by a sense of some level of stability in the environment. Suffering may thus be initiated by profound changes in the person's physical, political, or social world. Clinical observation suggests that the suffering of some patients is initiated by their inability to explain what has happened to them. "What did I do that made this happen to me?" is not merely a question but a metaphysical statement about how the world works. If the person's beliefs and demand for explanations are too rigid and the person cannot accept fate or uncertainty, then the integrity of the person is violated by the unexplained injury.

If physicians focus on the sick person, as necessitated by suffering, they will require knowledge of persons in the way that they presently have knowledge of the body. Persons, however, are different from other objects of science and so they pose difficulties for twentieth-century understanding. Considering persons as ahistorical, atomistic individuals, in which the body is separate from the mind—largely the stance of the sciences, the law, and some schools of philosophy—is not supported by a knowledge of suffering. The sciences of humankind, including psychology and the social sciences, have followed the lead of the physical sciences in employing reductive methodologies, but these lead to a distorted understanding. Similarly, division of the sciences of humankind into the physical, psychological, and social leads away from an understanding of persons and therefore of suffering. Virtually everything that is social is also ultimately physical and psychological. A person is not an object with physical or temporal boundaries, but rather he or she is a process in a trajectory through time. The challenge to a scientific understanding of persons lies in accepting these characteristics.

Suffering is Unique and Individual

Suffering is always individual because it can arise in relation to any aspect of a person, and persons are necessarily unique and particular. If the suffering of two people is initiated by an identical physical insult (e.g., the same kind of severe burn or similar overwhelming pain), the suffering of each will be unique and particular because it becomes suffering by virtue of its effect on a particular dimension or characteristic of the suffering person. No one can know with certainty why another person suffers. One can know that someone is suffering, but not what it is about this specific person that leads to the suffering. Sufferers themselves may not know. What threatens the loss of wholeness of one person is not necessarily the same as that which jeopardizes another. In chronic illness this distinctiveness is more easily seen. Here, suffering can arise because the sick person may not be accepted by, feel at home in, or be able to meet the expectations of others. The way these feelings affect the person will be unique to that person. These difficulties may evoke loneliness, anger, or feelings of unfairness, abandonment, or hurt. The suffering person will be focused on the feeling and the external source that is seen as its cause, not on suffering per se. This is because the same feelings may cause suffering in one person but not in another, and the suffering itself is the result of the disruption of the person arising from the discomfort. Even when suffering is caused by physical pain, the person feels pain, not suffering.

Purpose

To be whole and able to suffer is to have aims or purposes. One of these purposes, central purpose, is the preservation and continued evolution of myself as I know myself. Purposes entail actions. When suffering exists, the identity that the sufferer fears will disintegrate is an identity expressed in purposeful action—legs walk, hands grasp, eyes see, minds have ideas. Purposes and their enabling actions may not require anything from consciousness, but they are nonetheless self-defining. Illness and other sources of suffering interfere with actions that may be conscious, below awareness, or habitual, and thus contribute to damaging the integrity of the person and lead to suffering.

The suffering of the chronically ill may start with the inability to accomplish their previously important purposes. It may actually begin when it finally dawns on the chronically ill person that the life of illness that has been held off for so long and with such effort and determination is now truly imminent. Again, notice that suffering begins not merely when persons cannot do something but when they become aware of what the future holds, even though at the time of recognition their function has not yet worsened. The task of the person, of identity, indeed of wholeness, is the centralization of purpose, while disease, pain, and suffering may contribute to the defeat of such purpose. Pain or other symptoms may focus the person's attention on the distressed body part so completely that central purpose is lost (Bakan). This is probably always true of suffering, which arises with the loss of the ability to pursue purpose and also defeats purpose. It is one of the wonders of humanity, on the other hand, to see how a central purpose, exemplified in the biblical story of Job, may overcome suffering as well as disease and pain.

Suffering Always Involves Self-conflict

The source of suffering is usually seen as outside the sufferer. What is usually identified as the origin of the suffering is the thing that causes the pain, or the pain itself, the life circumstances, or the stroke of fate. In fact, however, suffering always involves self-conflict. Thinking about acute pain, one wonders how this can be. The clue lies in the fact that meaning is essential to suffering. The threat to the person's intactness or integrity resides in the meaning of the pain or beliefs about its consequences. The book of Job provides an illustration of the place of self-conflict in suffering. That there is a God and that God is just are not merely facts for Job; they are part of his self-understanding. Job is a righteous man, but his friends taunt him: If Job is righteous as he says, God would not punish him. Job responds, "Yet does not God see my ways and count my every step?" (31: 4). On the other hand, he wants to defend himself before God: "I would plead the whole record of my life and present that in court as my defense" (31: 37). If God knows his every step and God is just, why would he have to defend himself? The suffering of Job, generally identified with the awful things that happen to him, has as its deeper source the conflict between that part of him that knows that God is aware of his every step and is a just God, and that part of him that believes (with his friends) that only the wicked are punished. Either he is wicked when he knows he is not, or God is not just.

The saints offer a contrary example. Reaching toward Christ by sharing the bodily suffering of others or through punishments imposed on the body are familiar aspects of early Christianity. Denial of bodily needs, tolerance of awful afflictions, and self-inflicted torture are commonplace in the histories of the saints. Adversities and pains are seen as allowing the holy person to identify with the suffering of Christ. Conflict with the body and the tolerance of the pain do not cause conflict within the person because they permit reaching a desired goal. If there were no Christ with whom to identify, then suffering would follow.

The sick, especially the chronically ill, are often unable to do what they need to do to ensure their self-esteem and their ability to be like others and be admired by others, to excel. But they do not stop wanting to meet these standards, which they usually picture as existing outside of themselves. The resulting internalized conflict of the sick person with the external world becomes self-conflict.

Confrontations between the person and his or her body, as well as dissension within the various aspects of the individual, can threaten to destroy the integrity of the person. This is most easily seen when the demands of the body conflict with the needs of the person. Pain or other symptoms, disabilities, medical care, or other needs may require attention to the body that deters the person from pursuits or purposes considered vital, or they may require attention to the body that the person finds extremely onerous. The body may become an untrustworthy "other" that fails the sick person when it is most needed. It may be a source of humiliation because of, for example, loss of bowel or bladder control. The body's needs, sexual or otherwise, may force the person to engage in behaviors that lead to social failures. Conflicts between the person and the body may cause suffering when no illness is present. The internal struggle that may occur in regard to sexual desire is notorious. Even in acute pain, self-conflict is present. If the person did not care about the pain or its consequences, did not resist its overwhelming force, and instead became completely passive or resigned to the injury, suffering would not occur. This represents extreme self-discipline. People want to live, to resist the pain, to fight back, and therein is the genesis of the suffering.

Suffering is a Lonely State

Because the individual is ultimately unknowable and suffering is unique and individual, involving a withdrawal of purpose from the social world and marked by self-conflict, suffering is inevitably a lonely condition. The inability to know with certainty why someone is suffering, and thus to identify truly with the sufferer, creates difficulties for its treatment. The treatment and relief of suffering, *even when pain cannot be relieved,* is often best accomplished by attempting to overcome its loneliness. This is illustrated in Tolstoy's superb story about sickness and suffering, *The Death of Ivan Ilych.* Virtually the only relief from his suffering that Ilych experiences late in his illness is the constancy and compassion of the servant, Gerasim, who stays with him when all others have effectively abandoned him (Reich).

Persons are communal in origin and by nature. They cannot be known or understood apart from their social being. As a consequence, the sufferer's inherent loneliness furthers the suffering. Because the sufferer's loss of connection with the group is one of the most important aspects of suffering both from the standpoint of its origins and its opportunities for relief, the loneliness of the sufferer is not only the feeling of being alone but an absence from the general "we-ness" of the world, from a shared participation in spirit. The idea of spirit reaches back into the history of both philosophy and religion. The word has many meanings in different traditions, but fundamentally, spirit has to do with the relationship of individuals to the group and to an overriding belief in the existence of God, Nature, or other transcendency. For the purposes of understanding suffering, spirit in a Hegelian sense is useful: some sort of general consciousness that unites all persons (Solomon).

Pain or Suffering in Special Groups

Until recently, minor surgical procedures were performed on newborns and very young infants without anesthesia in the belief that they did not feel pain. Whether their perception is of pain in the manner of fully functioning adults, where other psychological factors such as meaning play a part, is not as important as the understanding that newborns and very young infants (as known from neuroanatomic criteria, psychophysiologic measures, and their behaviors) experience nociception and resulting sensory pain and thus require anesthesia and analgesia. The situation is not as clear for fetuses, but they also exhibit aversive responses to nociceptive stimuli, suggesting the need for analgesia (Anand and Carr).

Depending on the depth of coma, patients in coma may or may not experience nociception as shown by whether they react to nociceptive stimuli. Reaction to painful stimuli is employed as a measure of the depth of coma and is often the first sign of recovery of central nervous system function. Nociception does not appear to be present in persons in a persistent vegetative state (Katayama et al.).

By definition, comatose patients and patients in a persistent vegetative state cannot suffer. Since suffering involves persons and their appreciation of their own intactness or threats to it, and requires a sense of identity, of the past, and of the future, these features must be present for suffering to occur. The applicability of these criteria to fetuses and neonates is unknown, but young children have the capacity to suffer.

Philosophical Issues

The history of medicine, like much of philosophy, has been marked by the dichotomy between empiricism and rationalism. In medicine, empiricism has also been identified with vitalism, the belief that there exist forces for health within the patient—the *physis* of the Hippocratics. For more than 150 years, medicine has been dominated by rationalist thought that has focused on disease as known by the objective criteria of pathoanatomic or pathophysiologic alterations. Diagnostic and therapeutic interventions and the actions of physicians have been based on the science of medicine and its conviction that all illness and pathophysiology would be explained by the laws of physics and chemistry. Symptoms and the reactions of sick persons to their diseases have been treated as epiphenomena, matters of less importance than science, and given over to the art of medicine, which was ranked lower than that of science.

In recent decades, however, the sick person has become more important. This is largely the result of vitalist-empiricist beliefs expressing themselves as a desire for a more "holistic" medicine, as well as changes in the social context of medicine since the 1960s. During the period of the civil-rights movement and the women's movement in the United States, patients (and more recently persons with disabilities) have achieved the social status of full personhood. The rise of bioethics in the United States during this period has played an important part in this social transformation. Recent interest in pain and suffering can be attributed both to the fact that they defy explanation on purely physicochemical grounds and to the increased attention being given to the experience of the sick person.

The concept of patient autonomy has been of central importance in bioethics, but suffering can put the sufferer's autonomy in question, creating ethical dilemmas. Autonomy implies a self-directed individual with consistent goals and intentions springing from a rational evaluation of situations and norms. Reasoning about choices is coupled here with coherence of purpose—central purpose. The ability to remain autonomous requires that things over which one has no control do not remove all of one's choices or the ability to choose. For the suffering person, autonomy is removed when purposes are directed by the immediate needs of the sick body or by the compulsion to address what is perceived to be the source of suffering. This creates difficulties for an ethics that relies heavily on the principle of autonomy. The exercise of authentic choice in this circumstance requires the help of others, individuals who can represent suffering persons to others and, perhaps, to themselves. The difficult task in these situations is to help the sufferer make choices and act as if suffering were absent. But suffering is marked by loneliness that can deny the help of others. The loss of autonomy following severe illness is usually obvious, while the fact that autonomy is no longer present because of suffering may not be apparent. Actions that are beneficent or even nonmaleficent in relation to the suffering person, in contrast to the ill person, may not be obvious. Thus, what is known about suffering casts doubt on the usefulness of an ethics of principle such as that advocated by Tom Beauchamp and James Childress. In contrast, the nature of suffering suggests the importance of a communitarian view of ethics where the relations of individuals to each other as members of a community guide notions of the right and the good. Stanley Hauerwas has raised questions about the obligations of physicians to relieve suffering—if, in fact, medicine could remove all suffering—in view of the importance often placed on the benefit of suffering. Rather, the duty to alleviate suffering highlights the physician's classical responsibility to have compassion for the suffering person, as in the story of the Good Samaritan, even in the absence of the ability to lift the burden of the sufferer (Hauerwas).

Theological Perspectives on Suffering

SUFFERING AS A RESULT OF HUMAN SIN. A commonly employed explanation of suffering is to see it as the fault of human beings, as punishment or retribution for individual or group actions or sins. The idea that God keeps tabs on individual actions and punishes sinners is widespread. This corresponds to the conviction of one of Job's friends: "As I have seen, those who plow iniquity and sow trouble reap the same" (Job 4: 8). Yet, it is obvious that the innocent as well as the evil are made to suffer. In the New Testament (Luke 13: 1 and John 9), Jesus indicates the mistake of interpreting each evidence of suffering as the consequence of someone's sins. A recent Apostolic Letter of Pope John Paul II (1984) on the Christian meaning of suffering acknowledges the Old Testament writings that show suffering as punishment inflicted by God for human sins, but goes on to disavow such a simple understanding.

SUFFERING AS EDUCATIONAL AND EVIDENTIARY. Where would we be without suffering to tell us what is important, make us better, to lead us back into the paths of righteousness? Suffering, in this view, offers the opportunity to learn humility.

> My son, do not spurn the Lord's correction
> or take offence at his reproof;
> For those whom he loves the Lord reproves,
> and he punishes a favorite son. (Proverbs 3: 11, 12)

But it could not provide such opportunities in the absence of a God of grace and love. The prophets provide many examples of this view of the importance of human suffering. But suffering also reveals to the sufferer a greater depth of human experience and meaning. After the experience of suffering, the person is led to a richer understanding of the meaning of being human, a greater concern for the suffering of others, and away from the superficialities that too often characterize daily existence.

SUFFERING AS SACRIFICIAL AND LEADING TO SOME GREATER GOOD. Both on a religious and a secular basis, it is not unusual for suffering persons to believe that their suffering is a form of selfless service to others. Through the acquisition of meaning in this fashion, the suffering is alleviated. It should be remembered that suffering occurs when the intactness or integrity of the person is threatened or disrupted, and it can be relieved when the person is reconstituted even if the agency of its occurrence continues. Giving meaning to the distress, which is what occurs in sacrificial suffering, is one way the person can be made whole again. The suffering of one may benefit many. The suffering of the prophets in the service of Israel is such an example. Another is the crucifixion of Jesus, an evil done by others, turned by God into Christianity's central saving act and a demonstration of the power of love over suffering.

SUFFERING RESULTING FROM THE FORCES OF EVIL OR CHAOS. This view suggests that God is not the only supernatural force and that there exist powers that are specifically evil. Satan is such an example, although he is specifically mentioned only three times in the Old Testament; the best known of these mentions appears in Job. In the New Testament, the Devil, Satan, demons, or evil spirits are frequently mentioned as sources of suffering. Modern peoples are frequently uncomfortable with such images, yet suffering on a huge scale has occurred so often in recent times that it seems necessary to draw on some other source of evil while keeping God a positive, loving, and just force. Another variant, nondemoniac, implies that there is a limit to the power of God and that he is just one force in the universe. God, in this view, should be called on for what he can do, but one should realize his limitations. A popular book employs this explanation for the problem raised in its title, *When Bad Things Happen to Good People* (Kushner). The mystical tradition of Judaism denies these limitations, insisting that to speak of God as one ("Hear, O Israel, the Lord is God, the Lord is One" [Deut. 6: 4]) is to speak of the unity of all. Everything is God, good and evil, joy and suffering. "And know today and bring it home to your heart that the Lord, He is God, in the heavens above and on the earth below—there is none other" (Deut. 4: 39) (Luzzatto).

SUFFERING AS MYSTERIOUS OR MEANINGLESS. For the classical Greeks, fate and the actions of the gods are indifferent to humankind's ideas of good or justice. Unconcerned fate has, however, a beginning, a middle, and an end and what starts must ultimately be realized. In the Greek tragedies, the terrible end is foretold in the beginning, the middle is the attempt of the hero to live the heroic existence, while in the end the suffering and tragedy that had been foretold must necessarily occur. Suffering and tragedy, then, have their origins in meaningless fate, but they follow from initial actions of humans. A somewhat similar conclusion is reached in the reincarnation religions such as Buddhism and Hinduism: Suffering in this life is inherent in existence, following, in part, from desire in a previous existence that determines the current behavior that leads to suffering. Since one cannot know what transpired in the previous animation, suffering in this life appears to be the result of capricious fate. Deliverance can only come by escape from individual personality, and ultimately, by giving up desire.

The Old Testament, particularly in Job and Ecclesiastes, explores the problem of suffering in depth, ultimately concluding that it is beyond the ability of ordinary mortals to explain. Explanation itself, and the reasoning on which it is based, may be the problem. In their early speeches, Job's counselors know that he must have transgressed, otherwise he would not be punished. Simple explanation—the connection of logically related, but largely unexamined, premises leading to a conclusion—particularly of the facile type presented by Job's counselors, prevents any deeper understanding. If, for example, Job's privations are not punishment directed at him, but occur as part of the natural order of God's universe, then the search for the explanation itself prevents an acceptance of the mystery. Yet the acceptance of mystery, of the fundamentally unsolvable, points the way to changes in fundamental presuppositions and to the relief of suffering. Religion for the Preacher of Ecclesiastes and for Job represents the general, not simple, truths, including the goodness of God, that have the capacity for transforming character and relieving suffering when they are sincerely held and vividly apprehended, even in the painful void of evidence for their truth. It belongs to the depth of religious spirit to have felt forsaken by God (Whitehead).

A consideration of the nature of suffering opens possibilities for reflection and study about the nature of persons, the relation of persons to their bodies, the goals of medicine, relationships between persons and within communities, and the place of spirit in the lives of individuals. It is little wonder that consideration of suffering and its place in the human condition and in the relationship of God to humankind has occupied human thought throughout the ages—and still the questions remain.

ERIC J. CASSELL (1995)

SEE ALSO: *Authority in Religious Traditions; Autonomy; Chronic Illness and Chronic Care; Care; Compassionate Love; Health and Disease: The Experience of Health and Illness; Life, Quality of; Life Sustaining Treatment and Euthanasia; Medicine, Anthropology of; Palliative Care and Hospice; Pastoral Care and Healthcare Chaplaincy; Rehabilitative Medicine; Suicide*

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PALLIATIVE CARE AND HOSPICE

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The terms *palliative care* and *hospice* are frequently used interchangeably to describe an approach to the care of individuals who are likely to die in the relatively near future from serious, incurable disease, for whom the principal focus of care is quality of life and support for the patient's family. The terms gained currency in the last third of the twentieth century as a result of significant changes in the leading causes of death in the developed countries of the industrialized world. In these countries prior to 1900, most people died relatively quickly, usually from acute, infectious diseases. They typically died at home, attended by family and friends. Because little in the way of medical technology was available to prevent or delay death, the costs of care were low, and the dying person and her caregivers could emphasize the interpersonal and spiritual aspects of dying.

By contrast, at the beginning of the twenty-first century most people in the developed world die from chronic, degenerative diseases such as cancer, cardiovascular disease, lung disease, and degenerative neurological disease. Death usually follows a prolonged period of progressive loss of function and numerous distressing symptoms, of which pain and shortness of breath are the most feared by patients, along with fear of the unknown. Because considerable medical technology now exists that can postpone death, costs are often high and most people die in hospitals or nursing homes, attended by strangers. For patients who die at home, the financial, physical, and emotional burdens of caregiving fall heavily on isolated nuclear families, and predominantly on women.

The Early Days of the Hospice Movement

The "hospice movement," as it is popularly known, is generally agreed to have started in 1967 with the opening of St. Christopher's Hospice in London under the charismatic leadership of Dr. Cicely Saunders. Hospices were a feature of the Middle Ages in Europe, usually run by religious orders, and offered safety, healing, and rest to weary and often wounded travelers. It was therefore an obvious name to give to institutions founded in France, Ireland, and England around the turn of the nineteenth century to care for the dying. What made St. Christopher's and those that followed different was Saunders's insistence on scientific rigor and professional education and training.

Few people were likely to return home from these pioneer hospices, but they would get skilled relief of their pain and suffering, whatever its nature or origin, in a sensitively nourished environment of love, safety, and peace for them and their relatives. That better care of the dying was needed was attested to by many comments of the dying themselves, grieving relatives who looked back in horror and sadness at what patients had had to suffer, and by an increasing number of papers published in reputable medical journals detailing this suffering. At what most must have felt the loneliest time of their life, the dying described themselves as having no attention paid to their suffering and getting no answers to their questions. They not only experienced a spectrum of physical suffering, but endured fear, depression, loneliness, and a sense of being undervalued by society. They often felt deserted by their doctors, whom they found difficult to trust when so rarely were they told the true nature of their mortal illness and what lay ahead. The dying either lived with relatives who, hoping to protect them, conspired with the doctors to keep them in ignorance, or in hospitals where the focus of attention was sophisticated investigations and aggressive treatments designed to cure.

Palliative Care

It was soon recognized that the word hospice, though widely understood and accepted by the English-speaking world, would never be universally acceptable because it had a different meaning in French and Spanish. Balfour Mount, who established a specialized unit at the Royal Victoria Hospital in Montreal in 1974 based on the principles he had learned at St. Christopher's, coined the term *palliative care* to circumvent the language problem. Because it was already in medical parlance, the healthcare professions accepted this term. Today physicians working in this field describe themselves as palliative medicine physicians and nurses as palliative care nurses, while the services where they work (the original hospices) are called specialist palliative care services.

The acceptance and adoption of palliative care by other healthcare professionals has not always been straightforward, however. Many claimed they were already providing it, in spite of the many reports of uncontrolled suffering. A few suspected it was euthanasia under another name. Some were convinced it was not based on well-proven therapeutic regimens but was simply complementary or alternative medicine applied to the dying. Others questioned why it seemed to focus on the care of people with malignant disease when patients suffering end-stage cardiac, neurological, and respiratory disease, or AIDS, had similar and often unmet needs (Addington-Hall).

Definition and Scope

It was easy to define hospice care when it focused on the final days of life. It soon became apparent, however, that better care was needed long before this terminal phase. Hospital-based teams were created to provide care for patients in the hospital units where they were still receiving treatments intended to cure or slow the progress of their underlying disease. Things could also be improved when people were being cared for at home, where most wanted to remain as long as possible, though, contrary to what has always been said, not necessarily to die there (Hinton; Ward). A range of services was developed to assist primary physicians caring for people at home, including home visits by nurses and other professionals and day-care units for patients who could be brought into a center for clinical assessment and creative occupational therapy.

Palliative care was no longer synonymous with "care of the dying." Yet, as the field has developed, it has struggled to define itself in a way that captures its broader scope—reflecting its appropriateness for patients earlier in their disease process, who are not imminently dying—without resorting to euphemisms chosen to disguise the fact that the care is for people who, sooner rather than later, will die of their illness. The most commonly used definition is that devised by the World Health Organization. It emphasizes that the principles of palliation—the relief of physical, psychosocial, and spiritual distress, and respect for the needs of relatives—are appropriate from the time of diagnosis. In an attempt to produce a more succinct definition, called for when palliative medicine was recognized as a medical specialty in the United Kingdom in 1987, palliative care was defined as the study and care of patients with active, progressive, far-advanced disease and a limited life expectancy, for whom the focus of care is the quality of life.

This definition does not limit palliative care to people with malignant disease, nor does it state a prognosis in terms of months or weeks. It is worded so as not to be confused with care of the elderly, care of the chronically ill, or care of the incurable (which would embrace many of the conditions seen daily by physicians). Unfortunately, it omits mention of relatives, or the fact that palliative care can be provided only by an interdisciplinary team. Its strength lies in its unequivocal focus on quality of life rather than on cure or prolongation of life, the declared objectives of much of modern medical care.

J. Andrew Billings, who in 1998 reviewed many of the competing definitions, concluded that the following definition achieves the best balance of completeness and concision:

> Palliative care is comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a terminal illness and for their families. Key elements for helping the patient and family live as well as possible in the face of life-threatening illness include assuring physical comfort, psychosocial and spiritual support, and provision of coordinated services across various sites of care. (p. 80)

Two further statements, endorsed by the government of the United Kingdom, have been found challenging and helpful:

> - It is the right of every person who needs it to receive high quality palliative care, irrespective of his or her diagnosis.
> - It is the responsibility of every clinician to provide high quality palliative care. (Doyle, p. 6)

In applying these principles in the complex, highly differentiated world of the health professions, it is helpful to note that palliative care can be provided at three levels: principles, techniques, and specialist care.

Palliative care principles are integral to all good clinical care, and they are applicable at every stage of a patient's care, whatever the nature of the illness. Every doctor and nurse should be applying these principles, even when they are still defining the nature and cause of an illness or its symptoms.

Palliative techniques are usually the responsibility of professionals such as surgeons and interventional radiologists, who, for example, create ostomies, insert stents, and provide palliative radiation. None of these procedures is intended to cure, but each can bring about relief in suffering.

Specialist palliative care is provided by those who have undergone specialist training as stipulated by their accrediting professional body. In such countries and regions as the United Kingdom, Australasia, and Hong Kong, specialist palliative care units are those where all senior doctors and nurses are accredited specialists and where members of professions allied to medicine (physiotherapists, occupational therapists, clinical pharmacists, clinical psychologists, and music, art, and stoma therapists) have all had additional training pertinent to palliative care. Such services are usually affiliated with local medical and nursing colleges.

Quality, Value, and Meaning of Life

As palliative care continues to develop, it is being recognized that with the drugs and techniques currently available, and the increasing skills to use them, it is relatively easy to achieve physical comfort, but that even when that has been achieved a person may still feel frightened, lonely, unwanted, or undervalued. Those working in the field now realize that, beyond the management of physical symptoms, palliative care is primarily concerned with three things.

First is quality of life. Many quality-of-life assessment tools specific to palliative care are now available to healthcare professionals (Clinch, Dudgeon, and Schipper; Higginson). Each attempts to measure quality as perceived by the patient or relative and not by the attending professionals. Robust research is now confirming what has long been suspected, that patients not given the information they seek experience more physical and psychosocial suffering and describe a lower quality of life than those kept informed according to their wishes. To many people's surprise, this has proven to be the case not only in the West but also in diverse cultures and among peoples of various faiths in the Middle and Far East.

The second concern is value of life. As people approach death they increasingly wonder whether their lives have been of any value to others and to the community, and whether they still have any value as persons when they are incapacitated by a fatal illness, dependent on others, and, as they are often reminded, expensive to care for. Surveys in the United States have shown that patients' loss of independence and fears of being a burden to others are more often the primary motivations in requesting assisted suicide or euthanasia than is physical pain (Emanuel et al.; Sullivan, Hedberg, and Fleming). Respecting the individual patient's assessment of the value of her life, while remaining vigilant for the effects of depression or social isolation, presents one of the most profound clinical and ethical challenges in palliative care. Yet, the skills for eliciting and responding to this form of suffering are seldom addressed in medical and nursing schools.

The third concern is meaning of life. When, and only when, their physical suffering has been relieved and their families cared for, do dying people begin to ask existential questions. Though a diminishing proportion of people in the West now claim to have a meaningful religious faith, more than 75 percent of dying people want to discuss the meaning of life, suffering, and death, and they may be disappointed if no one is interested in helping them. Once again, in the absence of some training in the humanities, doctors and nurses in the increasingly secularized Western society find themselves ill-equipped to help with this issue.

The Development of Palliative Care Worldwide

From the handful in operation in 1967, there are now more than 6,200 palliative care programs in over 100 countries. In its birthplace, the United Kingdom, palliative care services are readily and freely accessible to all. The National Health Service runs one-fifth of these services, and 25 percent of the operating costs of the others are met by government, the balance being met from voluntary funding of more than US$450 million annually. A typical palliative care in-patient unit in the United Kingdom, with 10 to 100 beds, admits annually twenty to twenty-five patients per bed, where each will stay for an average of eleven to fourteen days. The portion of patients able to return home varies between 40 and 60 percent, higher if there is an effective community palliative care service and a day unit. Seldom do more than 15 percent of patients who have conditions other than cancer receive palliative care in the United Kingdom, a considerably smaller percentage than in the United States.

Though palliative care services are being developed in many countries, most are modeled on those of the United Kingdom and the United States, rather than being designed to meet local needs and cultures. Palliative care is still not available to the 75 percent of the world's population, for whom curative treatment of life-threatening disease is either unavailable or inaccessible. There are still only a relative handful of medical schools worldwide that include palliative care in the curriculum, and fewer still where a specialist teaches it. Even when it is mentioned in undergraduate medical courses it is rarely included in the training of subspecialists who—in the West—provide the bulk of the care to critically ill patients. Only in those countries where there are doctors working full time in the field is palliative care rapidly gaining credibility and acceptance.

Palliative Care in the United States

The first hospice program in the United States opened in Connecticut in 1974. Most early programs relied heavily for financial support on private, local philanthropy and grants. Beginning in 1983, patients over the age of sixty-five could elect to receive a "hospice benefit" under the Medicare program. A patient certified by his physician as "terminally ill" (defined as having a life expectancy of six months or less) may waive access to Medicare coverage of curative treatments for the terminal illness, in return for a package of services aimed at symptom control and improved quality of life. These services would otherwise not be covered or would be provided in an uncoordinated manner. The Medicare hospice benefit (payable as a per diem reimbursement to Medicare-certified hospice providers) includes nursing care in the home (up to sixteen to twenty hours per week, with temporary twenty-four-hour care available under limited "crisis" circumstances); medical appliances and drugs; homemakers, home health aides, and volunteers for personal and respite care; physician services; short-term hospitalization; physical and occupational therapy; psychological and spiritual support; social services; and bereavement counseling (Center for Medicare Education).

Medicare requires hospices to conform to several procedural and staffing requirements in order to receive federal funds. Among the most significant requirements are that the hospice must have a core, interdisciplinary team made up of at least a physician, a registered nurse, a social worker, and a chaplain or other counselor; that patients must have an identified primary-care provider in the home (usually a family member or someone else who is available on a twenty-four-hour-per-day basis); and that no more than 20 percent of the total aggregate number of days of care provided by the hospice may be in inpatient settings.

Since Medicare funding became available, the number of hospice programs in the United States has increased dramatically. From 1982 to 2000, the estimated number of providers grew from 500 to 3,100. The number of patients served increased from approximately 1,000 to approximately 700,000 between 1975 and 2000. Cancer patients made up 57 percent of hospice admissions in the United States in 2000, followed by patients with heart disease (10%), dementia (6%), lung disease (6%), end-stage kidney disease (3%), and end-stage liver disease (2%) (NHPCO).

In contrast to community- and home-based hospice care, hospital-based palliative care programs are a much more recent development in the United States. As recently as 1998, only 15 percent of U.S. hospitals reported having any services devoted to end-of-life care (Pan et al.). In a survey of 5,810 member hospitals by the American Hospital Association in 2000, 13.8 percent of the 4,856 respondents reported having a palliative medicine service, while 22.7 percent reported a hospital-based hospice program, and 42 percent reported a pain management service.

Inpatient palliative care units on the British or Canadian model are still relatively rare in the United States. Hospital-based palliative care teams primarily provide consultation for symptom management, patient and family counseling, and conversations designed to determine appropriate goals of care (Pan et al.). Financial pressures on acute-care hospitals in the United States usually dictate the swift discharge (to home or nursing facility) of any patient for whom acute hospital interventions are no longer indicated. This restricts the ability of the hospital palliative care team to assist in the course of the patient's dying. The role of the team at that point is most often to assure as smooth a transfer as possible to another setting, which may or may not include ongoing palliative care by specialist professionals.

Unlike in Great Britain, where there are now more specialist palliative medicine physicians than oncologists, palliative medicine has not been recognized as a medical subspecialty in the United States. Beginning in 1996, however, the American Board of Hospice and Palliative Medicine began to administer a certifying examination for physicians who wished to be known for special competence in the field. A separate organization, the Hospice and Palliative Nurses Association, administers a certifying examination for nurses and began a certification program for palliative care nursing assistants in 2002.

Ethical and Policy Issues in Palliative Care and Hospice

Many of the ethical issues that arise in the care of the dying are similar to issues that arise in many other areas of healthcare, such as truthfulness and confidentiality, decision-making authority in the professional–patient relationship, the appropriate use and allocation of technology and other healthcare resources, the conduct of research, and the locus of ethical responsibility when care is provided by a team (Randall and Downie). Other issues are more commonly associated with the care of the terminally ill, though not absent from other arenas, such as decision making for patients who have lost the capacity to make or communicate their own decisions, withholding or withdrawing life-sustaining treatment, and hastening death by assisting in suicide or through active euthanasia.

The latter issue tends to receive the greatest attention from bioethics scholars and policymakers. Moral distinctions between various actions or choices that can hasten the time of death can be exquisitely fine (Quill, Lo, and Brock). Yet, for all the persistent and intense debate surrounding the issues of suicide and euthanasia (Battin, Rhodes, and Silvers), "terminal sedation" and the doctrine of double effect (Fohr), or the differences, if any, between "allowing to die" and "causing to die" (Brock; Clouser), another set of issues are no less vexing and affect far more people. These are the questions of access to and quality of palliative care services.

The dimensions of the problem of access to palliative care are suggested by the following data from the United States. According to the National Hospice and Palliative Care Organization (NHPCO), of the 2.4 million people who died in the United States in 2000, approximately one-fourth died while receiving hospice care. Approximately half died in hospitals, 25 percent died in a nursing facility, and another 25 percent died at home; the percentage of home deaths has remained relatively stable for several decades, despite Gallup polls that consistently indicate that over 85 percent of Americans would prefer to die at home.

It is true that dying at home is an imperfect marker for the adequacy of palliative care. In fact, in most developed countries, the better the palliative care provision in hospitals and the community, the fewer the number of people who die at home, with home deaths now approaching 20 percent in most European countries. A more telling statistic is that of patients who received hospice care in 2000, one-third died within seven days of admission, despite the six months of benefits allowed under the Medicare hospice program. The median length of stay for hospice patients in the United States has been dropping steadily for several years; the NHPCO reports that it was only twenty-five days in 2000. Although the reasons for these trends are still being investigated, the following are likely to be significant contributing factors: the difficulty of making precise estimates of life expectancy—as is required for Medicare hospice eligibility—especially for diseases other than cancer (Teno et al.); patients' reluctance to accept the label "terminally ill"; the requirement that patients forgo Medicare reimbursement for treatments with curative intent; and many physicians' identification of a hospice referral with "giving up."

In the United States, hospice and palliative care have not yet fully overcome the legacy of opposition to mainstream scientific medicine that characterized their beginnings in the 1970s. The growth of rigorous scientific research in palliative care, the publication of textbooks, and the growth of a cadre of palliative medicine specialists with a base in academic medical centers should ameliorate this problem in the years to come. For the present, however, hospice and palliative care remain near the margins of the American healthcare system. In the realm of education, a 1997 survey of fourth-year medical students and third-year medical residents found that both groups rated their preparation in end-of-life care worse than for many other common clinical tasks (Block and Sullivan), and analyses of leading medical textbooks reveal that, on average, end-of-life issues are addressed on only 1.6 percent of the pages (Block). In the realm of financing of services or research, the desire to forestall or prevent death overwhelms support for hospice and palliative care. Precise data are difficult to obtain, but one indicator of the relative lack of support for palliative as opposed to curative medicine is presented in a 1997 report from the Institute of Medicine of the National Academy of Sciences. The report cites a personal communication from an official from the National Institutes of Health (NIH), who estimated that in fiscal year 1996, NIH spent about $70 million on pain research out of an overall budget of $12 billion.

From the policy perspective, the greatest challenge facing palliative care in the United States at the beginning of the twenty-first century is to fashion a system of financing and delivery of care that is flexible enough to provide services as they are needed along the complete continuum from diagnosis of life-threatening illness through the (often unpredictable) period of disability and functional decline, into the last phases of active dying and family bereavement (Lynn). The system would, at a minimum, encourage the open acknowledgment by physicians and patients of the possibility of dying, advance planning to anticipate complications and likely needs for care, meticulous attention to physical symptoms and to psychological and spiritual suffering, support for the family, and the creation of settings for care that respect the personal and spiritual significance of death and loss.

Worldwide, the challenge of access to competent palliative care is no less daunting. Among the principal causes for alarm are the number of people living with HIV/AIDS—estimated by the United Nations at 40 million at the end of 2001—and the large projected increase in deaths from tobacco products, which the World Health Organization predicts could triple by 2020 from the 2000 level of 3.5 million (Brundtland). In both cases, almost all of the increase is expected to occur in the developing world. Global efforts to teach the principles of modern palliative care, and to incorporate them in healthcare systems, are lagging far behind the manifest need, despite curative technologies and medications remaining unavailable or unaffordable for most of the world's poor.

Where palliative care is available, there is the challenge of providing care in ways that respect different cultural and religious views. Most professionals who enter the field do so because they want to help people die well. But what does it mean to "die well"? What is a "good death"? There is no single, universal answer to either of these questions. That the modern hospice movement was first promulgated largely by Christians may have hindered its development among people of other faiths for whom the "hospice philosophy" may have been hard to separate from theological commitments that they did not share. Even with respect to elements of a "good death" on which most people could probably agree—freedom from pain, resolution of personal affairs, the supportive presence of loved ones—there is room for considerable personal variation. People differ in their willingness to face the reality of their imminent death; in their desire to talk about their feelings to friends, family, or caregivers; in how they balance pain relief against alertness; and in their willingness to tolerate increasing weakness, dependency, and uncertainty rather than trying to control the timing and manner of their death through an act of suicide or euthanasia. This variability requires health professionals to approach patients and families as individuals, in an effort to provide care that is consistent both with patient and family values and with their own conscience.

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SEE ALSO: *AIDS: Healthcare and Research Issues; Cancer, Ethical Issues Related to Diagnosis and Treatment; Care; Compassionate Love; Death; Dementia; Healthcare Resources, Allocation of; Informed Consent; Life, Quality of; Life Sustaining Treatment and Euthanasia; Long-Term Care; Nursing, Profession of; Pastoral Care and Healthcare Chaplaincy; Social Work in Healthcare; Teams, Healthcare*

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PASTORAL CARE AND HEALTHCARE CHAPLAINCY

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Pastoral care normally refers to the help given by ordained ministers, priests, and other persons with designated religious roles (such as deacons and members of Roman Catholic religious orders) to suffering, troubled, or perplexed persons. In the simplest and most profound sense, *pastoral care* has been defined from a Christian perspective as "the attempt to help others, through words, acts, and relationships, to experience as fully as possible the reality of God's presence and love in their lives" (Holst, p. 46). The term is primarily Christian but it is sometimes used analogously in other faith traditions (e.g., the rabbi's care in Judaism). Recently the term *spiritual care* has been introduced into secular healthcare settings as a less specifically Christian alternative term. In any case, when pastoral or spiritual care is provided in healthcare facilities by pastors or rabbis sponsored by the institution, it is known as *healthcare chaplaincy.* This article largely focuses on healthcare chaplaincy because it is the primary way in which contemporary pastoral care becomes involved with the issues of bioethics.

Historically, pastors have extended their care to a wide range of personal needs and concerns, from struggles of faith, doubt, moral failure, and problems of conscience to marriage and family conflict and the suffering involved in illness, tragedy, and death. In Christian care, the historic, ritualized "means of grace"—sacrament, scripture, prayer—continue to be important resources of pastoral care, especially in situations of crisis (e.g., dying). But in many situations conversational methods predominate. Pastoral conversation emphasizes the caregiver's psychological understanding and ability to foster a therapeutic or healing mode of relationship and style of conversation with the person receiving care. This includes empathic listening, the ability to form emotionally honest, trusting relationships, and the care receiver's active participation with the pastor in the search for healing and wholeness. At the root of their care, pastoral caregivers help persons find the kind of faith and value commitments that can sustain, enrich, and give redemptive meaning to their lives, and "to experience as fully as possible the reality of God's presence and love in their lives" (Holst, p. 46).

Pastoral care and healthcare chaplaincy are often distinguished from another ministerial specialization—pastoral counseling. When this distinction is made, pastoral counseling is commonly defined as a specialized form of ministry characterized by an intentional contract between the pastoral caregiver and the person or family seeking help, usually involving a series of prearranged counseling sessions. This structured form of care contrasts with the more casual and varied forms of caring relationships that parish pastors and healthcare chaplains typically form. Though many ministers, priests, rabbis, and healthcare chaplains provide short-term counseling of the more formal kind, pastoral counseling as a specialized ministry is devoted entirely to this work. To a large extent it is a form of psychotherapy or family therapy (and is often called "pastoral psychotherapy"), and usually involves a number of sessions and the payment of a fee. Pastoral counselors, like healthcare chaplains, have specialized training requirements, professional organizations (principally, the American Association of Pastoral Counselors), and standards of certification. They serve on the staffs of larger churches, in pastoral counseling centers, and in other professional settings, and are often licensed by state governments as pastoral (or other) counselors, psychologists, or marriage and family therapists.

Pastoral Care in Healthcare Settings: The Healthcare Chaplain

FUNCTIONS AND ROLE. Much of what healthcare chaplains do involves helping persons and families (of all faiths) with the emotional and spiritual dimensions of the healing process, offering support and therapeutic care in situations of crisis and grief, helping to resolve conflicts and communication difficulties, and consulting in situations of bioethical and other decision making. Most chaplains also develop an extensive ministry with nurses, physicians, aides, administrators, and others in medical settings who carry significant emotional burdens and moral concerns. Chaplains promote communication between patients, families, and staff concerning religious and cultural traditions that may bear upon medical decisions (e.g., concerning blood transfusion, abortion, and the use of life-support technologies). They often become involved in discussions with all parties involved in healthcare decisions. In addition, healthcare chaplains form educational relationships with local clergy and congregations, function as liaisons between the healthcare institution and the community, and serve on the boards of related community organizations. As more and more medical care is provided on an outpatient basis, and as more congregations develop healthcare emphases and programs, these aspects of their work are expected to increase.

Chaplains often play a significant role in hospital ethics committees; in many instances, they helped to organize these committees in the late 1970s and 1980s. The chaplains' role in ethics committees, as in their consulting with patients and families on bioethical decisions, consists largely in promoting good communication and mutual understanding, interpreting religious and cultural traditions, resolving conflicts, clarifying moral issues, and facilitating free and responsible moral decision-making. It is a basic principle of the Association of Professional Chaplains, the National Association of Catholic Chaplains, and similar national certifying organizations that healthcare chaplains respect the belief and value systems of others and refrain from proselytizing or trying to impose their own convictions on them.

Many healthcare institutions sponsor professional training programs in pastoral care called "clinical pastoral education" (C.P.E.). These programs train not only future chaplains in pastoral care, but also large numbers of theological students, pastors, and members of religious orders not seeking specialized ministry certification. C.P.E. students minister under the supervision of a highly trained and certified chaplain supervisor with whom they meet individually and as a group to analyze and reflect on their work. Such reflection involves intense examination of detailed case reports, personal reflection on the trainees' ways of caring for other persons, and consideration of the psychological, social, cultural, theological, and ethical questions involved in their experiences. Pastoral supervision evolved in the second half of the twentieth century into a distinct and important specialization within healthcare chaplaincy.

RELATION OF HEALTHCARE CHAPLAINCY TO OTHER HEALTHCARE PROFESSIONS. Most pastors who serve in healthcare settings hold a broad, liberal understanding of themselves and their ministries that enables them to cooperate easily with the medical profession and to work pastorally with a wide range of persons. They do not limit their ministries to persons with problems that are explicitly defined in religious or moral terms, but seek to become related to persons in supportive and therapeutic ways whatever the immediate, presenting needs or issues may be.

Thus their work often closely resembles, in certain respects, that of psychiatrists, psychologists, psychiatric nurses, social workers, and patient representatives. The chaplain functions as an integral member of the healthcare team. He or she is "cross trained" in a variety of institutionally valuable skills usefully integrated into a single profession: "psychosocial and spiritual counselor, clinical ethicist, patient representative and ombudsperson, cultural anthropologist and religious scholar, gatekeeper of community resources and public relations expert, and health promoter" (Burton, p. 2). But the chaplain's range of competencies also raises questions of vocational distinctiveness and identity for other professionals and sometimes for themselves. The situation is made more challenging by the fact that pastoral identity in healthcare facilities is usually not expressed solely or principally through the performance of religious rituals or conversation confined to overtly religious problems.

What then gives the chaplain's wide-ranging work comprehensive definition and focus? The answer to this question is much debated within the profession. In general, however, pastoral identity in healthcare settings has two intimately related poles of concern: healing and health, and religion (Burton). Chaplains are significantly identified with each. The distinctiveness of the profession lies in the way these two poles interrelate in an ambiguous but creative unity in the performance of the chaplain's professional function.

At one pole there is a concern for and participation in the processes of health and healing. While healthcare chaplains do not practice medicine or psychiatry, they believe that the meanings and values by which people live, and the quality of their personal relationships, play an important role in the organic processes of illness and health. They also believe that a comprehensive concern for human well-being, including health and healing, is integral to the faith traditions they represent. Thus chaplains believe that religion supports the fundamental aims of medicine and healthcare. And they see their ministries as essentially involved in the process of healing, which they understand in comprehensive terms as healing of the whole person—body, mind, and spirit. Consequently, they view themselves as significant members of the healthcare team, and increasingly they are being viewed in that way by the medical professions.

At the other pole, healthcare chaplains are committed to representing religious meanings and values that include but transcend the values of health and healing. They seek to enable people to find and experience, which ultimately can fulfill their lives and redeem them from the threats of meaningless shame, guilt, and death that pervade all of life, in illness as well as in health. And they set health and healing as values into an encompassing faith perspective that affirms the meaningfulness of life whether or not healing occurs. For the healthcare chaplain, this larger context is ultimately rooted in the reality and loving power of God, who makes health possible, but who also makes meaning, hope, and love possible in every circumstance of life, in illness and adversity as well as in health and wholeness.

Thus pastoral identity is bipolar, committed to both healing and religious faith and to their essential interrelationship. It is the ambiguous but disciplined interplay of these polar commitments that constitutes the distinctive orientation of healthcare chaplaincy.

EDUCATION, CERTIFICATION, AND LICENSURE. Nearly all specialized healthcare chaplains today hold college and seminary degrees or have other appropriate theological education, and have been ordained or otherwise endorsed by their religious denominations. Healthcare chaplains are not licensed by state governments, though some who also practice specialized pastoral counseling are licensed as pastoral counselors, psychologists, or marriage and family therapists.

Most full-time, professional healthcare chaplains have trained for their ministries through clinical pastoral education as described above. The C.P.E. certification is sponsored mainly by the Association for Clinical Pastoral Education, the National Association of Catholic Chaplains, the Canadian Association for Pastoral Education, and similar bodies in other countries. In 2002 the Association for Clinical Pastoral Education listed 350 accredited C.P.E. training centers and 600 certified C.P.E. supervisors. Similar organizations and C.P.E. programs exist in Canada and a number of other countries. An international organization closely related to the movement, the International Council for Pastoral Care and Counselling, meets quadrennially.

Various national professional associations also exist for specialized healthcare chaplains, principally the Association of Professional Chaplains, the National Association of Catholic Chaplains, and the National Association of Jewish Chaplains. These organizations set high standards for professional practice that are enforced through rigorous certification and review procedures. A consortium of these and related organizations publishes the *Journal of Pastoral Care.* There is also a large umbrella organization in the United States and Canada, the Congress on Ministry in Specialized Settings (COMISS), that sponsors joint meetings of pastoral-care organizations.

HISTORY OF HEALTHCARE CHAPLAINCY IN THE UNITED STATES. Hospital chaplaincy, like the hospital itself, had its origin in the ancient and medieval Christian church. The rise of the modern secular hospital in the late nineteenth century, however, was not immediately accompanied by the presence of chaplains as members of hospital staffs. Such pastoral ministry as occurred in secular hospitals was usually provided by retired clergy with no special training for the work beyond general parish experience, often on a voluntary and/or part-time basis. This pattern has continued in some smaller institutions, but today healthcare chaplaincy is fully established as a specialized ministerial profession, and chaplains are employed as regular staff members by most large healthcare institutions.

The turn toward specialized, highly trained, professional healthcare chaplaincy had its roots in the “religion and health” movement early in the twentieth century, in which a positive relation between religion and modern medicine was first seriously explored (Holifield). In the 1920s, this led to the first attempts to train theological students in clinical settings (Thornton). Notable was the groundbreaking work of a physician, William S. Keller, who placed theological students in a general hospital in Cincinnati in 1923, and Anton T. Boisen, a Congregational minister who began what became the “clinical pastoral training movement” with his pioneering program relating religion to mental disorders at Worcester State Hospital in Massachusetts in 1925. Boisen had the key support of two physicians, the distinguished Boston medical educator, Richard C. Cabot, and the progressive superintendent of Worcester State Hospital, William A. Bryan. Soon thereafter another physician, Flanders Dunbar, noted for her research in psychosomatic medicine, became a major leader of the movement. These and other early innovators were convinced that not books but intensive clinical experience—learning to interpret the experience of real human beings, to read the “living human documents” through clinical encounters—held the key to developing a realistic and profound theological understanding of human nature and the art of effective pastoral care (Boisen). The movement developed rapidly in the postwar period, when many training centers were organized, chaplain supervisors certified, and staff chaplaincy positions created in mental and general hospitals.

Clinical pastoral education was seldom undertaken in congregational settings, partly for pedagogical and practical reasons related to the abundance of pastoral opportunities in hospitals, and partly for financial reasons—hospitals were better able to pay for these programs than churches or seminaries. Most programs were sponsored by hospitals, and C.P.E. programs remained largely unrelated to the formal curricula of the theological seminaries until the late 1950s and 1960s. C.P.E. thus acquired a somewhat nonecclesiastical, "secular" style and appearance, and there has always been a concern that C.P.E. students would develop a confused professional identity as a result of C.P.E.'s close ties to the medical establishment.

Medical institutions still comprise the vast majority of C.P.E. training centers. Today, however, C.P.E. is widely embraced by the "mainline" Protestant and Catholic churches, and C.P.E. programs are a common, and often required, component of Protestant, Catholic, and some Jewish theological education. Healthcare chaplaincy itself is similarly established as a highly specialized, professionally trained and certified form of ministerial practice. Most hospital administrations require staff chaplains to have completed a year or more of C.P.E. or its equivalent. The Association of Professional Chaplains, the National Association of Catholic Chaplains, and similar organizations require C.P.E. in their certification standards.

Philosophical and Cultural Orientations

RELATION OF RELIGION AND HEALTH. The high degree of professional cooperation existing today between pastoral caregivers and medical professionals represents a remarkable and relatively recent development in both medicine and religion. In ancient and medieval times medicine and religion often enjoyed a close relationship; healing rites, exorcisms, pilgrimages, and health cults flourished. But with the Protestant Reformation and the later rise of modern science and scientific medicine, Christian ministry began a long retreat from its tradition of involvement in healing, and theology grew increasingly wary of making scientific, empirical claims about the natural world. An intellectual and professional schism between religion and medicine resulted. As medicine became scientific and ministry became confined to matters of God and the soul, corresponding spheres of professional influence were delineated: physicians cared (scientifically) for the body; clergy cared (spiritually) for the soul. Medical science assigned mental and emotional disorders, traditionally considered problems of the soul, to the body as organically caused, and regarded them as at least potentially treatable by physical (i.e., medical) means.

With the development of dynamic psychiatry and the religion and health movement in the early twentieth century, such distinctions began to blur. Psychoanalysis and related developments in psychiatry revealed psychogenic factors in many psychiatric disorders, while empirical studies in psychosomatic medicine demonstrated the profound effects of emotional and spiritual attitudes on physical health and healing. At the same time, theology began to recover biblical, holistic conceptions of human personhood, salvation, and the healing potential of religious ministry. In this theology the welfare of the whole person, physical, mental, and spiritual, was regarded as a profound unity. The result was a gradual closing of the theoretical gap between medicine and religion and the emergence of a more collaborative style of work between physicians and pastoral caregivers.

INFLUENCE OF THERAPEUTIC PSYCHOLOGY. Prior to the twentieth century, pastoral care was dominantly concerned with problems that could be clearly or outwardly identified as religious and moral in nature or as having religious significance, such as faith, doubt, sin, repentance, and the mysteries of suffering, illness, death, and dying. Contemporary pastoral care, however, at least as practiced in the larger Christian denominations (sectarian churches being the usual exception), holds to broader conceptions of Christian ministry, human welfare, and the meaning of salvation. In these traditions, physical welfare and emotional health play prominent parts in the overall meaning of salvation; ministry's sphere of concern includes the total health and welfare of persons and families in *this* world. Often this understanding gives prominence to psychology as an adjunctive discipline, and ministry acquires a distinctly psychotherapeutic style and orientation. This has been especially evident in the mainline Protestant denominations, but it is increasingly true of Roman Catholic and some conservative Protestant traditions. Judaism has historically emphasized the values of human health and welfare.

This therapeutic style of ministry has important ethical and professional consequences. Typically, it seeks to broaden moral discussion in healthcare settings from a focus on the content of moral decisions—what to do—to a focus on the process and quality of the decision making itself. Healthcare chaplains try to foster the psychological conditions that will facilitate free and responsible moral judgment and decision. These conditions include relationships of trust that permit open, honest communication among all parties concerning feelings as well as ideas and opinions. Though facilitating such conditions is not usually thought of as a form of moral guidance, it obviously has important moral value. Some pastoral authorities, however, while affirming this approach, have also urged pastoral caregivers to engage the substantive questions of ethics more directly in their caring ministries (Browning, 1976, 1983; Carnes).

AFFINITIES WITH SITUATION ETHICS AND CHARACTER ETHICS. Pastoral care, including healthcare chaplaincy, has not been highly articulate concerning the traditions of philosophical and theological ethics out of which it has operated (Carnes). Most pastoral theologians have concentrated instead on theological questions of human nature and the relation of religion to health (Browning, 1983; Holifield). However, much of the informal ethical reflection in the field has probably been influenced chiefly by some form of situation ethics. Situation ethics holds that fixed laws and rules are inadequate for moral decision making; decisions must be reached through a careful assessment of the particulars of each situation, guided by very general principles such as love, justice, and responsibility. Pastors with therapeutic training often exemplify this orientation since they tend to be concerned more about the specifics of situations than the application of abstract moral rules and principles (Poling, 1984b). Their typical ethical question is likely to be: "What is the appropriate, responsible, loving, or just thing to do in this situation, given its many complexities and dynamics?"

Pastoral care also has a close affinity with what is called the "ethics of character and virtue," though this connection is seldom recognized (Poling, 1984a). Conceptions of personality implicit in therapeutic psychology often function as secular character ideals within pastoral care. For example, healthcare chaplains commonly assume that psychological self-knowledge and the ability to experience oneself and others fully, without the distorting effects of emotional defensiveness, is desirable not only as an aspect of mental health but as a moral good—as a basis for free and responsible moral action. In many situations, as a matter of principle, healthcare chaplains are therefore likely to be as concerned about the emotional health and maturity of the persons exercising moral judgment as about the decisions they reach. This commitment to an ethic of character and virtue thus easily complements the field's general tendency to support situational or contextual forms of ethical reasoning.

RELATION OF THEORY AND PRACTICE. Many of the ways pastors have ministered to troubled and suffering persons over the centuries may be regarded as a practical implementation of the ethical principles of the pastors' religious communities and traditions. Practice has tended to follow theory, "applying" it.

But human needs and problems do not always fit neatly into prescribed categories and practices, and social and cultural forces change over time; contemporary problems of bioethics provide many cases in point. In such situations, pastoral care cannot operate as a straightforward application of established moral theories and principles. Conscientious improvising becomes necessary, especially in times of rapid social, cultural, and technological change.

Thus moral theory does not always easily or clearly guide practice; in fact, to some degree it reflects practice and is changed by practice. To this extent pastoral care, over time and in concert with other social and cultural factors, gradually helps moral theory to evolve. The Jewish *responsa* literature, representing the accumulated moral debates and evolving traditions of Judaism's encounter with novel problems over many centuries, provides massive evidence of this process in one tradition (Meier). A similar process, though often less explicit and legally constructed, has occurred in Christian pastoral care (Browning, 1976). This can be seen in changing contemporary pastoral attitudes in the mainstream Protestant churches on issues like divorce, remarriage, abortion, and artificial life support. Pastoral caregiving is thus culturally innovative as well as conservative, and represents (as Browning argues) a practical form of "moral inquiry."

Issues in Healthcare Chaplaincy

Like other health-oriented professions, healthcare chaplaincy faces a number of challenges as the technology and institutional forms of healthcare undergo rapid and extensive developments. Four major contemporary challenges may be noted:

1. Multiculturalism and minority concerns constitute an increasingly visible and important feature of the social landscape in which healthcare chaplaincy functions. This fact presents novel professional issues for healthcare chaplaincy. Today's hospital chaplains must understand a growing range of religious and ethnic cultures and find ways of relating their ministries with appropriateness and integrity to persons with religious faiths and social customs different from their own. They must also be able to help persons of non-Western cultural and religious traditions relate to the social values and practices of advanced Western healthcare facilities.
2. The overlap of professional roles in contemporary healthcare settings intensifies the problem of defining the healthcare chaplain's pastoral identity. This question is becoming urgent. As institutional budget pressures increase, many healthcare chaplains and pastoral departments have been forced to define their identities and defend the value of their ministries to healthcare administrators, often in quantifiable, cost-benefit terms alien to the traditional meanings and purposes of ministry.

3. How (in theory or practice) can chaplains maintain an institutionally appropriate neutrality yet remain significantly committed to their traditions of faith? Focusing on *process* rather than *content* in moral decision making, and maintaining an institutionally proper value-neutral stance on specific questions, are clearly helpful in this regard. But such public neutrality may beg important questions. Is there any way for ethical commitments and insights of particular religious traditions to contribute to contemporary moral reflection in institutional decision-making and policy formation? How can healthcare chaplains represent their traditions without imposing themselves inappropriately on others or abusing their institutional positions?
4. Healthcare chaplains are being drawn into *discussions* of healthcare policy in their institutions and in the larger society. This expanded arena offers new opportunities to witness to their moral and spiritual commitments, by questioning unjust policies and practices and advocating the rights of the poor, for example. But it also raises difficult questions. How far and in what way—if at all—should healthcare chaplains develop this expression of their ethical integrity in place of, or in addition to, their work of holistic healing, care and compassion?

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SEE ALSO: *Beneficence; Care; Compassionate Love; Death: Western Religious Thought; Grief and Bereavement; Mental Health: Meaning of Mental Health; Teams, Healthcare; Trust; Value and Valuation*

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PATENTING ORGANISMS AND BASIC RESEARCH

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Patents give inventors the right to prevent others from making, using, or selling their inventions for a limited time. The U.S. Constitution justifies the patent system as a way to promote technological progress (U.S. Constitution, Article I, Section 8, Clause 8). The U.S. patent system promotes technological progress through the financial incentives it creates for innovation and through its disclosure requirement. In exchange for exclusive rights patent applicants must disclose their inventions in terms that enable others who are skilled in the field to make and use them (U.S. Patent Act, Section 112). When a patent is issued, that broad disclosure becomes available to the public, and when the patent term expires, the public is free to make, use, and sell the patented invention.

Background and History

As commercial interest in biological products and processes has grown, inventors have turned to the patent laws, seeking rights to inventions that involve living materials. Under traditional patent doctrine, patents on living materials raise a number of concerns. For example, products and phenomena of nature are not patentable under U.S. law even when they are newly discovered (*Funk Brothers Seed Co. v. Kalo Inoculant Co.*).

Even before the explosion of modern commercial biotechnology, however, judicial decisions reduced the significance of that obstacle to patent protection by permitting patents on materials derived from natural sources through human intervention, such as purifications of naturally occurring products, as long as the patent claims did not cover the products in their natural state. Under that interpretation of the law, courts upheld the validity of patents on purified prostaglandins (*Bergstrom*), purified acetylsalicylic acid (*Kuehmsted v. Farbenfabriken*), and a purified adrenaline composition (*Parke-Davis & Co. v. H. K. Mulford & Co.*). Nonetheless, before 1980 it was not entirely clear that living materials were patentable. (*Funk Brothers Seed Co. v. Kalo Inoculant Co.*).

The 1980 decision of the U.S. Supreme Court in *Diamond v. Chakrabarty* stated unequivocally for the first time that living materials are patentable. In that case the Court held that a living single-celled bacterium that was transformed with DNA plasmids (small circles of bacterial DNA) through human intervention to give it the capacity to break down multiple components of crude oil could be patented as a "manufacture" or "composition of matter." In arriving at that decision the Court stated that the patent statute allows patents to be issued on "anything under the sun that is made by man" (*Diamond v. Chakrabarty,* p. 309).

With that broad directive from the Supreme Court the Patent and Trademark Office (PTO) quickly expanded the categories of living organisms it considered eligible for patent protection. In 1985 the PTO held that corn plants were eligible for standard utility patents, as opposed to the more limited plant variety protection (*Hibberd*), and two years later it held that polyploid oysters fell within the range of patentable subject matter (*Allen*). Shortly afterward the commissioner of patents issued a notice stating that the PTO "now considers nonnaturally occurring nonhuman multicellular living organisms, including animals, to be patentable subject matter" (U.S. Patent and Trademark Office 1077:24). Any claim covering a human being would not be considered patentable, however, because "the grant of a limited, but exclusive property right in a human being is prohibited by the Constitution."

The first patent on a genetically altered animal (U.S. Patent No. 4,736,866) was issued in April 1988 to Harvard University for the development of a mouse harboring a human oncogene that makes it susceptible to cancer (HARVARD/Onco-Mouse Application). The decision to extend patent protection to animals generated considerable public controversy and was the focus of numerous hearings in the U.S. Congress (Dresser).

In 1998 the PTO's policy of refusing to grant patents on human beings was tested by a patent application on "chimeric embryos" (embryos containing human and nonhuman cells) filed by Jeremy Rifkin. In rejecting the application the PTO argued that Congress did not intend product patents on human organisms to fall within the scope of patentable subject matter (Ho). The widespread adoption of cloning techniques has tested the PTO's policy once again. By 2001 the PTO had granted patents on cloning *processes* that produce mammalian embryos, both human and nonhuman (U.S. Patent Nos. 6,211,429 and 6,235,970).

Although national patent laws vary somewhat, as a general rule the range of biotechnology inventions that can be patented outside the United States is somewhat more restricted than it is under U.S. law. Two provisions of the European Patent Convention have presented obstacles to the issuance of standard utility patents covering plants and animals in Europe (Dickson). Article 53(b) of the European Patent Convention states that European patents will not be issued for plant or animal varieties and essentially biological processes for the production of plants or animals with the exception of microbiological processes and the products of those processes. Article 53(a) of the European Patent Convention bars the issuance of a patent on an invention if its publication or exploitation would be contrary to public order or morality. The European Patent Office (EPO) concluded, however, that neither of those provisions barred the issuance of a European patent to Harvard University for its transgenic mouse (HARVARD/Onco-Mouse Application).

The recently issued European Biotechnology Directive generally follows the European Patent Convention and the case law of the EPO but suggests that slight human interference is sufficient to make a process for the production of plants and animals patentable (European Community Directive 98/44, 1998). In addition, Article 6 of the directive specifically prohibits, among other things, patents on processes for cloning human beings and processes for modifying the germline identity of human beings.

Objections to Patenting Organisms

Some of the objections to patenting living organisms, including humans, that have emerged in the wake of these legal developments are better understood as objections to the underlying technology rather than to its protection under patent law (Dresser; Merges). Objections of this character include concerns about the hazards of genetic engineering to public health and to the environment and concerns that transgenic animal research involves cruelty to animals. With respect to humans many people believe that creating humans through cloning processes violates principles of freedom, equality, and human dignity (President's Council on Bioethics).

One might question whether these kinds of objections are the concern of the patent laws or whether they might be met better through other types of regulation or outright prohibition of the research. However, withholding commercial rewards may be an effective way to slow the pace of such research without prohibiting it altogether (Kass). Some have argued that the patenting of life forms promotes an unwholesome or irreverent materialistic conception of life (Hoffmaster). A strong version of this argument holds that characterizing a life form as a patentable manufacture or composition of matter reduces a patented organism to a material object (Kass). A more attenuated version of that argument would stress the potential for commercial interests to debase people's attitudes toward life when life forms are treated as commodities to be bought and sold in the market (Murray). However, because patents do not provide an affirmative right to use an invention (they provide only a right to bar others from using it), the extent to which patents contribute to commodification is not clear. Allowing the creation of particular life forms, as well as patents on those life forms, patents would be consistent, for example, with a regime in which sales of life forms were banned (Rai).

Ownership of Other Living Materials

Moral objections have been voiced to the ownership of living materials such as the human genome sequence and single-nucleotide polymorphisms (SNPs), which are single-base variations in the genetic code. In both of those cases, however, preemptive actions to put genetic information into the public domain largely have prevented such ownership. In the case of the human genome sequence the public Human Genome Project instituted a policy of putting large-scale genomic sequence information immediately into the public domain (National Human Genome Research Institute). As a consequence the private company Celera, which had undertaken its own sequencing project, could not patent raw genome data. Moreover, although Celera maintains its genome database as a trade secret, the value of that database is diminished by the fact that genome data are publicly available. In the case of SNP data a consortium of pharmaceutical companies that were worried about the effects of patents on those upstream research inputs came together to fund an effort to put SNPs into the public domain (SNP Consortium Website). The public domain also has been enhanced to some extent by the recent decision of the PTO to require that those who seek to patent DNA sequences show the functional significance of those sequences (Patent and Trademark Office).

A major arena in which the ownership of living materials continues to raise moral concerns pertains to the ownership of human genes. Companies that own those genes often require universities and other institutions that perform genetic tests to pay large licensing fees. In some cases the size of the fee has led institutions to stop performing such tests (Merz).

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SEE ALSO: *Agriculture and Biotechnology; Animal Research; Commercialism in Scientific Research; Environmental Ethics; Law and Bioethics; Pharmaceutical Industry; Private Ownership of Inventions; Technology*

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PATERNALISM

• • •

Paternalists maintain that restricting the autonomy of persons is justified if these persons would be likely to cause serious harm to themselves or fail to secure an important benefit for themselves. The main ethical issue is whether paternalistic interventions are morally justified, and if so, under what conditions. In bioethics, rightful authority in the patient–physician relationship and public-health interventions have been the focus of the discussion. For health policy, paternalism is central to questions concerning the government's role in promoting healthy lifestyles and preventing self-caused injury and illness.

Many actions, rules, and laws are commonly justified by appeal to some paternalistic principle. Examples include laws that protect drivers by requiring seat belts; restrictions on the availability of drugs; rules prohibiting a healthy subject of biomedical research from voluntarily undergoing a high-risk procedure; overriding adult refusals of treatment; disclosing confidential information about a patient to protect the patient's health; involuntary commitment to hospitals; interventions to prevent suicides; and denial of an innovative therapy to someone who wishes to receive it. Laws are the usual vehicle for translating paternalistic beliefs into public policy, but individual actions and institutional policies can also have paternalistic roots.

Early History in Ethical Theory

In an eighteenth-century discussion, the philosopher Immanuel Kant denounced paternalistic government ("imperium paternale") for its benevolent cancellations of the freedoms of its subjects (pp. 58–59). However, it was the nineteenth-century English philosopher John Stuart Mill who presented the first systematic attack on paternalism, a term he avoided, in his 1859 monograph *On Liberty*:

> The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier,

> because in the opinions of others, to do so would be wise, or even right. These are good reasons for remonstrating with him, or reasoning with him, or persuading him, or entreating him, but not for compelling him …. In the part which merely concerns himself his independence is, of right, absolute. (p. 223)

Mill thus articulated a principle that properly restricted social control over individual liberty, regardless of whether such control is political, religious, or of some other type. He defended his principle with the utilitarian argument that granting people liberty rather than subjecting them to paternalism produces the best possible conditions for social progress and for the development of individual character and talent. Independent of his commitment to utilitarianism, Mill's *On Liberty* has played a more important role in discussion of paternalism than any treatise in ethical theory.

Neither Mill nor Kant anticipated that a paternal model of justified intervention into the affairs of competent adults might be extended to interventions with adult persons who, like children, have only a restricted or compromised capacity to choose autonomously. Yet this latter and broader model has become the most widely defended account of paternalism.

Definitions of Paternalism

The word *paternalism* refers loosely to acts of treating adults as a benevolent father treats his children, but the term has been given both a narrow and a broad meaning in ethical theory. In the narrow sense, paternalism refers to acts or practices that restrict the autonomy or liberty of individuals without their explicit consent; justification for such actions is either the prevention of some harm they stand to do to themselves, or the production of some benefit for them that they would not otherwise secure. This conception of paternalism leads to the following definition: Paternalism is the intentional limitation of the autonomy of one person by another, where the person who limits autonomy justifies the action exclusively by the goal of helping the person whose autonomy is limited (Dworkin, 1992; Beauchamp and McCullough). Following this definition, an act of paternalism overrides the value of respect for autonomy on some grounds of beneficence. Paternalism seizes decision-making authority by preventing persons from making or implementing their own decisions.

Many writers object to this analysis of paternalism because it does not comprehend the meaning of the term as it has descended from common usage and venerable legal precedent, where the notion is linked to guardianship, surrogate decision making, and government intervention to protect the vulnerable. The root sense of paternalism in ordinary language ("government as by a benevolent father") is joined with the law's wide-ranging use of terms such as *parens patriae* to produce a broad meaning that includes interventions into both autonomous and nonautonomous actions. Those who follow this broad vision recommend the following definition: Paternalism is the intentional overriding of one person's known preferences by another person, where the person who overrides justifies the action by the goal of benefiting the person whose will is overridden. Under this second definition, if a person's stated preferences do not derive from a substantially autonomous choice, overriding his or her preferences can still be paternalistic. The only essential condition of paternalism is beneficent treatment that overrides a known preference; a condition of substantial autonomy is not essential (VanDeVeer; Kleinig).

Defenders of the first definition argue that there are compelling reasons for resisting this second definition. First, paternalism originates in ethical theory as an issue about the valid limitation of freedom and autonomy. To include cases involving persons who lack substantial autonomy, such as drug addicts or the mentally disabled, broadens the term in a way that obscures the central issue, which is how, whether, and when liberty or autonomy can be justifiably limited. Second, the legal concept of *parens patriae* powers has its own subtleties and complexities. Courts do not apply this notion across the same range of thought and conduct that paternalistic literature treats as problematic. To incorporate a marginal legal doctrine together with the vagueness of ordinary language might prove more confusing than instructive in the end.

These two definitions are currently contested in literature. However, defenders of these two definitions need not disagree on all controversies about the meaning of paternalism. For example, it has sometimes been said that the term *paternalism* is inherently pejorative because it implies that authorities may treat adults such as hospital patients as if they were children lacking considered preferences of their own; therefore, they reason, the term is tainted by illegitimate authoritarianism or repressive dominance (Feinberg, 1980, 1986; Sherwin). Proponents of the above two definitions are free either to accept or to resist this interpretation. For example, they can both resist this pejorative meaning by arguing that paternalism suggests nothing beyond an analogy to respectable parental benevolence, in which parents act in the best interests of their children for good reason.

Weak (Soft) Paternalism and Strong (Hard) Paternalism

Joel Feinberg's distinction between weak and strong paternalism has profoundly affected literature on the subject.

Although he switched to the language of "soft" and "hard" paternalism in his later work (1986), the terms "weak" and "strong" seem to have more deeply influenced the bioethics literature and will be used here.

In weak paternalism, one "has the right to prevent self-regarding harmful conduct only when it is substantially nonvoluntary or when temporary intervention is necessary to establish whether it is voluntary or not" (Feinberg, 1971, p. 113). This type of paternalism confines permissible limitations of autonomy to substantially nonautonomous (or nonvoluntary) behaviors. For example, it is permissible to pick up injured, partially incoherent victims of automobile accidents who refuse ambulance service and to admit against their will mentally ill persons who are dangerous to themselves. In strong paternalism, however, it is proper to protect or benefit a person by autonomy-limiting measures even if the person's contrary choices are autonomous. This paternalism supports interventions that protect competent adults against their will; that is, it controls or restricts substantially autonomous behaviors. For example, refusing to release a competent hospital patient who will die outside the hospital but requests the release knowing the consequences is an act of strong paternalism.

Weak paternalism is built on conditions of compromised ability or dysfunctional incompetence. When conduct that affects only the actor is restricted, some degree of autonomy may be present in the restricted actor, but the action must be substantially nonautonomous. Conditions that can significantly compromise the ability to act autonomously include the influence of psychotropic drugs, painful labor while delivering a child, and a blow to the head that affects memory and judgment. In medical situations, a patient's illness can be so devastating that it affects decision-making capacity. As the patient becomes weaker, less aware, or less alert, his or her dependence on the physician increases. A member of the medical profession who overturns the preferences of a substantially nonautonomous patient in the interests of the person's medical welfare acts paternalistically and justifiably by the standards of weak paternalism. For this reason, weak paternalism has been widely accepted in law, medicine, and moral philosophy as an appropriate basis for intervention.

Strong paternalism, by contrast, supports some interventions intended to benefit a person whose choices and actions are informed and autonomous. Strong paternalism usurps autonomy by either restricting the information available to a person or overriding the person's informed and voluntary choices. These choices may not be fully autonomous or voluntary, but in order to qualify as strong paternalism the choices of the beneficiary of paternalistic intervention must be substantially autonomous or voluntary. For example, a strong paternalist would prevent a patient capable of autonomous choice from receiving diagnostic information that might lead to suicide. Unlike weak paternalism, strong paternalism does not require any conditions of compromised ability, dysfunctional incompetence, or encumbrance as the basis of intervention (although strong paternalists of course accept the justifiability of weak paternalistic interventions as well).

Justification of Paternalism and Antipaternalism

Defenders of paternalism in ethical theory have paid more attention to the justifying grounds for paternalism than to the type of paternalism justified. Some justifications range widely and defend both strong and weak paternalism. Typically, however, a condition in the argument states or hints that only weak paternalism is justified, although strong paternalism is the most controversial and interesting type of paternalism and may be the only type worth the effort of justification.

JUSTIFIED PATERNALISM. Defenders of paternalism often appeal to either a principle of rational consent or a principle of welfare or beneficence in order to justify their position. In one prominent justification, Gerald Dworkin argues that paternalism should be regarded as a form of "social insurance policy" that fully rational persons would take out for their protection (1972, p. 65). That is, paternalism is justified under conditions to which an impartial rational agent would consent if he or she were to appreciate the possibility of being tempted at times to make decisions to commit acts that are potentially dangerous and irreversible. The agent might at other times be driven to do something that would be considered too risky if he or she could objectively assess the situation—for example, smoking or drinking so heavily that health and life are endangered. A paternalistic health policy would remove or severely restrict the availability of tobacco and alcohol. In other cases, persons might not sufficiently understand or appreciate the dangers of their conduct, or might distort information about their circumstances. Seat-belt laws and motorcycle-helmet laws have often been enacted on this paternalistic basis.

Dworkin argues that a paternalistic act that denies a person an immediate liberty may paradoxically protect deep autonomy (i.e., the person's deeper values and preferences about the principles and standards on which he or she ought to act). A physician might lie to a patient, for example, in order to prevent a suicide, if the physician knows that the patient really wants to live and will later calm down and not commit suicide, although the patient is presently in no position to appreciate this fact. Dworkin argues that rational consent (consent that would be given) is the only acceptable way to express the conditions of justified paternalism. Many philosophers subsequently agreed with this thesis and made some form of consent a necessary condition of justified paternalism. However, justifications on bases other than consent have also been attempted (Dworkin, 1972; see VanDeVeer; and Kleinig).

A justification based on consent may do more to obscure than to clarify the issues. If the paternalist's objective is to protect or improve the welfare of another, then intervention can be justified by harm-avoidance or benefit-production, as is the case in the justification of parental actions that override the wishes of their children. Children are treated paternalistically not because they will subsequently consent or would have consented were they rational, but because they will have better lives. This justification rests on providing for their welfare, not on respecting their autonomy.

THE JUSTIFICATION OF ANTIPATERNALISM. Some believe that paternalism is never justified. Mill supported this position, but with the important qualification that we are justified in restricting a person's liberty temporarily in order to ensure that the person is acting intentionally with adequate knowledge of the consequences of the action; once warned and informed, the person must be allowed to choose whatever course he or she desires. One need not be a follower of Mill's utilitarianism to defend this antipaternalism. For example, it can be defended by appeal to principles of respect for autonomy and privacy. Perhaps the most widely shared reason antipaternalists oppose (strong) paternalism is that it interferes with the authority of the individual, insults autonomous agents, and fails to treat them as moral equals (Childress).

The antipaternalist permits an initial, temporary infringement of liberty and privacy in the belief that persons who have a well-formed, autonomous resolution to do something harmful to themselves will have ample opportunity to perform the action after the temporary intervention has occurred. Intervention, in this limited respect, need not be a deep moral offense. Defenders of weak paternalism, however, view this qualified antipaternalism as insufficient because it disallows some highly desirable forms of intervention, such as long-term involuntary hospitalization for those in need of medical attention. Who, they reason, would not support altruistic beneficence directed at confused cardiac patients, ignorant consumers, frightened clients, and young persons who know little about the dangers of alcohol, smoking, drugs, and motorcycles? No caring and decent person would leave these individuals unprotected, and no reasonable philosopher would defend a normative thesis that permits such outcomes.

Weak paternalists thus project the appearance of steering a moderate and reasonable course between two radical and excessive extremes, strong paternalism and antipaternalism. The solution to the problem of paternalism, from their perspective, is to present the most defensible form of weak paternalism. But a severe stumbling block lies in the path of this tempting resolution of the issues: Weak paternalism has no clear substantive moral disagreement with antipaternalism, and therefore there is no reason to choose one over the other. Protection from harm caused to an individual by conditions beyond his or her knowledge and voluntary control—for example, by conditions beyond his or her self—is not an intervention that antipaternalists either criticize or disallow; they deny only the acceptability of intervention with substantially autonomous, self-caused harm. Weak paternalists too condemn such actions as an unjustifiable form of strong paternalism.

Weak paternalism, then, seems to be a defensible but noncontroversial position that virtually everyone accepts in some form. As Feinberg notes, it is "severely misleading to think of [weak paternalism] as any kind of paternalism," because weak paternalism is not "'paternalistic' at all, in any clear sense" (1986, pp. 12–14). Both weak paternalism and antipaternalism agree on the following critical claims:

(a) It is justifiable to interfere in order to protect persons against harm from their own substantially nonautonomous decisions; and
(b) it is unjustifiable to interfere in order to protect persons against harm from their own substantially autonomous decisions.

Weak paternalism is thus not a form of paternalism that can be distinguished in any morally important respect from antipaternalism. Weak paternalism does not seem to rest on a liberty- or autonomy-limiting principle independent of some moral principle of beneficence that supports prevention of harm to others (see Feinberg, 1971, pp. 107f., 124, and Feinberg, 1986, p. 13). Feinberg sarcastically suggests that the label "soft antipaternalism" seems to mean the same as "soft paternalism" (1986, p. 15).

The weak paternalist and the antipaternalist also join hands in opposition to the strong paternalist, who alone allows interventions that override and violate substantially autonomous actions.

THE JUSTIFICATION OF STRONG PATERNALISM. Although substantial autonomy is necessarily overridden in strong paternalism, conditions can be specified by a strong paternalist to restrict severely the range of justifiable interventions. For example, the strong paternalist might maintain that interventions are justified only if: no acceptable alternative to the paternalistic action exists; a person is at risk of serious harm; risks to the person that are introduced by the paternalistic action itself are not substantial; projected benefits to the person outweigh risks to the person; and any infringement of the principle of respect for autonomy is minimal.

Strong paternalism, so interpreted, will stand or fall on the strength of the argument that major welfare interests under some specifiable conditions legitimately override relatively minor autonomy interests. Many cases can be found that fit this model. For example, when healthy persons with no heart disease volunteered as subjects in a research study to have an artificial heart transplanted at the University of Utah, it was entirely reasonable that a review committee declared that the risk relative to benefit for a healthy subject is morally unacceptable and that they should not be allowed to undergo the procedure (Beauchamp and Childress).

Issues of Paternalism in Bioethics

Many examples of controversial paternalistic justifications are found in bioethics. Only a few general topics are treated here.

OVERRIDING REFUSALS OF TREATMENT. It is sometimes controversial whether procedures should be withheld or withdrawn even when the patient refuses the procedures. Justifications for overruling a patient's refusal of therapy need not be paternalistic, but they often are paternalistic because their objective is to prevent harm that would be caused by the patient's refusal. The issue is not whether a physician actually knows what is best for the patient, but whether the patient has a right to refuse treatment even if the refusal is harmful and the treatment beneficial.

Persons of questionable competence who refuse therapy present delicate moral problems and difficult conceptual issues about whether interventions are paternalistic. For example, do schizophrenic patients have a right to refuse a therapy for dehydration if a physician determines it to be safe and efficacious, and would an intervention after a refusal be paternalistic? Similarly, do children who understand what is being done to them have a right to refuse therapies when their parents and physicians judge these therapies to be essential, and are such interventions paternalistic?

OVERRIDING REQUESTS FOR TREATMENT. Patients or their legal representatives occasionally request medical procedures that physicians believe are harmful, ineffective, or futile. The physician may then refuse to act on these requests for paternalistic reasons. If the requests by patients are incompatible with accepted standards of care or conflict with the physician's conscientious beliefs about standards of care, a physician's refusal to comply may be justified for these apparently nonpaternalistic reasons of appropriate physician conduct. Nonetheless, the interventions are paternalistic whenever the primary ground of noncompliance with the request is that the treatment is not in the patient's best interests. Moreover, setting professional standards of practice is itself often a paternalistic attempt to protect patients' interests, and as such may be either justified or unjustified paternalism (Childress; Brett and McCullough). The same argument can be applied to drug policies of a government agency that refuses to accept requests for experimental therapies on grounds of risk to patients.

PARTIAL DISCLOSURES TO PREVENT HARM. Physicians and families often argue that a particularly devastating diagnosis or prognosis should not be disclosed to a patient. The concern is that bad news might adversely affect the patient's health or lead the patient to commit suicide. If the patient asks for the information or expects a truthful disclosure, it is paternalistic to withhold the truth. Physicians also occasionally make difficult medical decisions without consulting the parents of seriously ill newborns. These actions too are paternalistic if the objective is to prevent anguish to the parents. Other examples extend beyond serious patient illness. For example, genetic counselors sometimes use potential marital conflict for a patient as a reason not to disclose a condition such as nonpaternity, thereby depriving a patient of information generated in part by materials the patient provided.

In a much-quoted article on medical ethics, L. J. Henderson claimed that "the best physicians" use the following as their primary guide: "So far as possible, 'Do No Harm.' You can do harm by the process that is quaintly called telling the truth. You can do harm by lying.… But try to do as little harm as possible, not only in treatment with drugs, or with the knife, but also in treatment with words" (p. 823). The premise that some information may legitimately be withheld or disclosed only to the family for the patient's good is a clear instance of this rule and an equally clear case of paternalism. Why the family, rather than the competent patient, is given the information without the patient's prior permission is itself an important issue concerning paternalistic medical practices.

INVOKING THE THERAPEUTIC PRIVILEGE. Therapeutic privilege is a legally recognized privilege of the physician to withhold information from a patient if disclosure would cause serious deterioration in the physical, psychological, or emotional condition of the patient. This privilege has long been used in clinical settings to justify not obtaining consent and has elicited a particularly furious exchange over whether autonomy rights can be validly overridden for paternalistic reasons.

The courts have yet to develop a standard for appropriate use of the therapeutic privilege that renders it coherent with requirements of informed consent. If stated broadly, physicians can withhold information when disclosure would cause any countertherapeutic deterioration, however slight, in the physical, psychological, or emotional condition of the patient. If stated narrowly, physicians can withhold information if and only if the patient's knowledge of the information would have serious health-related consequences—for example, by jeopardizing the success of the treatment or harming the patient by critically impairing relevant decision-making processes. Confusion has also surrounded appropriate measures of rationality, psychological damage, and emotional stability under the standard of therapeutic privilege. Loose standards can permit physicians to climb to safety over a straw bridge of speculation about the psychological consequences of information, and this threat of abuse has made the therapeutic privilege highly controversial.

HEALTH POLICY FOR EXCESSIVE RISK. Antipaternalists argue that paternalistic standards for policy would authorize too much intervention. Paternalism could in principle prohibit smoking, drinking, and hazardous recreational activities such as hang gliding, mountain climbing, and white-water rafting, making such activities subject to criminal sanctions. Careful defenses of paternalism would disallow these extreme interventions, and at best antipaternalist arguments establish only a rebuttable presumption against paternalistic intervention. Nonetheless, antipaternalists are convinced that an unacceptable latitude of judgment would remain in contexts in which power is subject to abuse. Strong paternalism suggests that it would be permissible and perhaps obligatory to restrain and punish those who violate paternalistic rules. If so, antipaternalists argue, the state would be permitted to coerce morally heroic or valiant citizens if they act in a manner "harmful" to themselves. More generally, the state would be empowered to take away from persons the right to make decisions about their lives whenever officials view risks as excessive.

GOVERNMENT AGENCY RESTRICTIONS. Some government bureaus can be viewed, at least in part, as paternalistic guardians. For example, the Food and Drug Administration (FDA) in the United States is chartered to restrict persons from purchasing foods, drugs, and medical devices that are unsafe or inefficacious. A controversial decision by the FDA in 1992 to severely restrict the use of silicone-gel breast implants exemplifies paternalistic controversies that have beset the FDA. Women had elected implants for over thirty years, either to augment their breast size or to reconstruct their breasts following mastectomies. Over two million women in the United States had had these implants (three million worldwide) when, in April 1992, the FDA restricted the use of silicone-gel breast implants until additional studies could be conducted to establish their safety. Concerns centered on the implants' longevity, rate of rupture, and link with various diseases. Those who defended complete prohibition contended that no woman should be allowed to take a risk of unknown but potentially serious magnitude because her consent could not be informed. The FDA defended a restrictive policy, rather than prohibition, holding that patients with breast cancer and others have a legitimate need for breast reconstruction. The FDA distinguished sharply between reconstruction candidates and augmentation candidates, arguing that the favorable risk–benefit ratio is confined to reconstruction candidates (Kessler).

Critics of this decision charge that the government's decision is inappropriately paternalistic, especially in contrast to the more permissive public decisions reached in European countries. These critics argue that subjective benefits for many women outweigh the identified risks, and opinion surveys indicate that 90 percent of women receiving the implants are satisfied with the results (see Parker). Critics argue that the only defensible policy is to permit the continuing use of silicone-gel breast implants while requiring adequate disclosure of information about risks. Raising the level of disclosure standards is, from this perspective, more appropriate than raising the level of paternalistic restraints on choice.

THE MODEL OF PATERNAL AUTHORITY. The term *paternalism* has often been criticized as sexist and in need of correction to *parentalism.* However, some feminists in bioethics as well as some critics of paternalistic medical practices have argued that this usage is a rare case in which gendered language should be retained on grounds that an appropriate link is made between the privileges of a father in a patriarchical family and the privileges of physicians in an authoritarian medical system. The thesis is that just as hierarchical arrangements have long been the norm in the family, so paternalism has been the norm in medicine; to appreciate the need to revise authority structures in the family should similarly point to the need to revise the model of rightful authority in medicine (see Sherwin).

This criticism extends beyond analysis of the meaning of paternalism. It assumes the persistence among physicians, male and female, of the belief that a paternal model of authority is requisite in clinical practice because of compromised reasoning abilities in patients, the essential need for technical information in medical decision making, and the needs many patients have for an authority figure as healer. Susan Sherwin (1992) and other writers in bioethics have argued for replacing this traditional paternalistic model with a radically different model of the physician–patient relationship, such as a model based on friendship or on contract.

However, those who support justified paternalism in medicine believe that paternalism, properly understood, fits coherently with our normal expectations of altruistic beneficence and fiduciary responsibility in professional healthcare relationships. Their model is that of a dedicated professional who possesses superior knowledge, experience, and skills and who seeks to further a patient's best interest. Whether pieces of these two starkly different models can be joined consistently is a matter of widespread controversy in bioethics.

SUICIDE INTERVENTION. Many views about reporting, preventing, or intervening in suicide are paternalistic. Because of the extreme and irreversible effects of suicide, some defenders of intervention believe that a principle of respect for life creates an obligation to prevent suicide that overrides obligations based on the principle of respect for autonomy. A weaker account relies on Mill's strategy: Intervention is justified to establish autonomy in the person; but after it is determined that the person's decisions are substantially autonomous, further intervention would be unjustified. (Kleinig discusses several other paternalistic arguments for suicide intervention.)

Both this weaker account and stronger accounts have been defended on grounds that others do sometimes know our best interests with more insight and foresight than we do. It is often difficult to know how much ability persons have to act autonomously or how much insight they have into their "best interests." The stronger account is also defended on grounds that many suicidal persons are under intense strain or the influence of drugs or alcohol, clinically depressed, destabilized by a crisis, or simply wish to end their pain, and that these persons can be helped with their problems by health professionals. Another defense is that failure to intervene symbolically communicates to potential suicides an absence of communal concern and diminishes a feeling of communal responsibility. Finally, some argue that it is a justified form of paternalism for friends and healthcare professionals to infringe confidentiality by reporting suicide threats to those who may be in a position to help prevent the acts. Some even defend a paternalistic obligation to report suicide threats (Bloch).

INVOLUNTARY INSTITUTIONALIZATION. Finally, a vast literature surrounds the involuntary hospitalization of persons who have never harmed others or themselves but are thought to stand in danger of inflicting such harm or of being vulnerable to harm by others. A major part of the contemporary rationale for use of police powers for the emergency detention and civil commitment of those dangerous to themselves is a paternalism supported by the knowledge that treatment has often helped persons over a momentary crisis. These interventions can involve a double paternalism: a paternalistic justification for commitment and a paternalistic justification for forced therapy (e.g., psychotherapy) after commitment.

Conclusion

Bioethics in the 1970s and 1980s exhibited a strong tendency to reject paternalism as an unjustified tampering with autonomy. However, from the mid-1980s through the mid-1990s many voices began to be heard that were more sympathetic to various paternalistic appeals. Paternalism seems likely to continue to be a viewpoint that will gain or lose adherents as the issues and larger social context shift. We may never again see the concentrated flurry of scholarly interest in this subject that was exhibited from the mid-1970s to the mid-1980s, but paternalism is not likely to be an issue that will soon disappear.

TOM L. BEAUCHAMP (1995)

SEE ALSO: *Autonomy; Behavior Control; Beneficence; Coercion; Freedom and Free Will; Institutionalization and Deinstitutionalization; Professional-Patient Relationship; Public Health; Suicide*

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PATIENTS' RESPONSIBILITIES

• • •

I. Duties of Patients
II. Virtues of Patients

I. DUTIES OF PATIENTS

Today, popular culture in the United States seems to be stressing health promotion and disease prevention; it is easy to get the impression from many sources that if one does not exercise regularly, eat the proper foods, and avoid tobacco and other dangerous substances, one has failed in a fundamental duty. In medicine and nursing, a vast literature has accumulated on "patient compliance"; despite some reminders that patients ought to be viewed as autonomous agents—the wisdom of the term *compliance* has been called into question—much of this literature assumes that the patient has a duty to follow advice given by the health professional. By contrast, eighteenth- and nineteenth-century codes of medical ethics, which listed responsibilities that patients owed to their physicians in order to balance the responsibilities that physicians were said to owe to their patients, have been condemned by most modern authors as paternalistic and self-serving. Whether patients owe any duties to health professionals and to others, and the extent of those duties if they exist, remain problematic. The topic has been much less studied in bioethics than the duties owed by professionals to patients and to society.

Duties Owed to Health Professionals

Many helpful models of the professional–patient relationship are based on some variant of social contract or covenant; and those models would imply that patients owe at least some duties to the professionals. These models deny the assumption that underlies most eighteenth- and nineteenth-century codes of medical ethics, namely, that professional ethics is a matter to be decided solely by professionals themselves, with no necessary role for patients in determining the rights and responsibilities that constitute professional ethics. It is this exclusion of patients from defining professional ethics, and not the idea of patient responsibilities per se, that permits the criticism that the alleged responsibilities of patients are paternalistic.

Are there any duties patients themselves would agree they owe to health professionals? Duties that would reasonably fall under this heading are so closely linked to the adequate carrying out of the professional role that their violation would make it impossible for the professional to provide the patient with the care the patient expects and demands. Such duties, properly circumscribed, cannot pose a threat to any patients' rights, because all such rights exist within a relationship whose purpose is to provide the patient with healthcare from a professional. Indeed, Meyer argues that the very notions of patients' rights and autonomy presuppose such a relationship.

Martin Benjamin proposes two such patient responsibilities: (1) honoring commitments, including compliance with a treatment regimen one has consented to carry out; and (2) disclosing relevant information, especially data needed to reach an accurate diagnosis and management plan for the illness. He is careful to insist that no patient has a duty to adopt any treatment plan merely because a professional recommends it; otherwise, there would be no patient right to informed consent. However, once the patient has agreed to try a plan, the patient has an obligation either to continue with the treatment or to inform the professional in a timely manner if circumstances (such as medication side effects) have made it impossible to do so. In this way, we acknowledge both the patient's right to autonomous choice and the professional's need to rely on disclosure of information and honoring of commitments in carrying out the assigned role.

Duties Owed to Identified Others

In general, duties owed to identified others are justified by the nature of the relationship between the patient and that other party. For example, as an extension of the duty to protect the interests of and to avoid harm to members of one's family, patients could have a duty to disclose health information (such as information about communicable diseases and genetic conditions) that would otherwise be protected by the right of confidentiality.

Where it is difficult to specify the precise nature and scope of the relationship, there will be a corresponding disagreement about the duties one owes. For instance, there is controversy about the duties that a pregnant woman owes to the fetus or the unborn child, in avoiding behaviors that might pose a health risk to herself or to the fetus and, in some instances, in either seeking or failing to seek an abortion. Such controversy will be resolved at least in part by more satisfactory conceptions of the precise relationship between the pregnant woman and the fetus or child. For instance, viewing the mother and fetus as two strangers with a conflict of basic interests hardly seems to do justice to the actual nature of their bond.

Duties owed because of specific contractual relationships are much easier to understand and to justify. For example, if an insurance policy does not cover a particular laboratory test unless it is required to diagnose a specific condition, the patient has a duty not to ask the physician to falsify the claim form and say that he or she suspects the condition, when in fact the patient merely wants to know the laboratory value as a screening measure.

Duties Owed to Other Patients Generally

A patient in a modern technological society receives many benefits because of sacrifices made by patients in the past. I could not receive a medication for an infection unless that drug had been tested in research subjects. I could not receive care from a highly qualified physician or nurse unless that professional, as a student, had practiced on other patients, under supervision. It would seem at first glance that I would have a corresponding duty to serve as a research subject or as "teaching material" when I could do so with relatively little risk and inconvenience. But the healthcare system generally regards such participation as fully voluntary, not as arising out of any duty. The difference between these two views may be a result of differences in the level of moral analysis—one may acknowledge that one owes a moral duty as an individual, even if as a policy matter the institution is unwilling or unable to enforce any such duty. A full analysis of the duties, if any, that patients owe in such circumstances may nonetheless hinge upon the general theory of justice one adopts.

Duties Owed to Society

An important debate centers upon whether one's entitlement to healthcare services, or the portion of the cost of care that one bears, should hinge on the extent to which one has adhered to a healthy, low-risk lifestyle—an increasingly difficult task, as science regularly uncovers previously unappreciated health risks.

One proposal to fund expanded healthcare coverage and benefits in the United States, for instance, includes a substantial increase in the tax on cigarettes. This could be justified purely as a matter of public health, since empirical evidence suggests that a number of people will stop smoking as a result of the tax. In turn, the public-health agenda could be justified in part by referring to a patient's duty to himself or herself to avoid serious health risks (though some analytic philosophers would claim that a duty to oneself is incoherent, since if someone owes a duty to me, I can always voluntarily release him or her from that duty), or to the duty that an individual owes to close family members not to abandon them or decrease one's ability to support them by running unnecessary and substantial health risks. Alternatively, the tax could be justified as a matter of justice, with those who voluntarily adopt unhealthy behaviors having some responsibility to pay for a larger share of the overall health costs. According to this latter line of analysis, the tax is therefore justified even if it fails to persuade any current smokers to stop.

Some of the debate about a duty to avoid health risks centers upon the addictive nature of some undesirable behaviors. Addiction implies a loss of voluntary control, suggesting that any duty not to engage in that behavior is correspondingly weakened, assuming that I cannot have a duty to do what I cannot do. On the other hand, a careful analysis of most addictive behavior patterns reveals certain actions that do appear to be under voluntary control, even if other aspects of the pattern seem to be characterized by loss of control. For instance, smokers may elect not to sign up for smoking-cessation counseling, and may socialize in settings where they know the temptation to smoke will be high.

To some extent, linking entitlement to care with a duty to remain healthy depends on where one stands on a spectrum between individualistic and communitarian conceptions of healthcare justice. On a purely individualistic approach, I have no responsibility to help pay for the health needs of anyone else; on a communitarian interpretation, we all have a shared responsibility to provide decent care for all, and that sense of shared responsibility is undermined by efforts to assign differential duties to pay to different citizens on the basis of their personal behaviors. Also, a duty to avoid health risks seems more justifiable when it is applied even-handedly rather than being used to condemn those whose lifestyles differ from one's own. Finally, a policy based on a duty to avoid health risks seems justifiable in inverse proportion to its personal intrusiveness. Thus a tax on the sale of cigarettes appears more justifiable than refusing healthcare to those whose diseases are caused by smoking, or spying on citizens in their homes to be sure that they really have stopped smoking.

HOWARD BRODY (1995)
BIBLIOGRAPHY REVISED

SEE ALSO: *AIDS; Autonomy; Behavior Control; Confidentiality; Epidemics; Family and Family Medicine; Harm; Maternal-Fetal Relationship; Paternalism; Patients' Rights; Professional-Patient Relationship; Profession and Professional Ethics; Public Health; Substance Abuse*

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II. VIRTUES OF PATIENTS

Although considerable attention has been given to virtues in medicine (Drane; Pellegrino and Thomasma, 1993), most writings focus on the virtues of caregivers rather than on those of care receivers. Patients writing about their experiences of illness (Abram; Sacks; Scott-Maxwell) often struggle with questions of virtue and character, but they tend not to express those questions in systematic or theoretical form. Little has been written on patients' virtues per se.

Several commentators suggest that virtues of different people involved in medicine have to be correlated with the goals or purposes of the medical encounter (Drane; Pellegrino and Thomasma, 1993). For example, in *For the Patient's*

Good, Edmund Pellegrino and David Thomasma (1988) suggest that the virtues of a good patient include truthfulness, probity (or an effort to uphold one's end of the healing relationship), justice, tolerance, and trust (which includes some elements of gratitude and friendship). These virtues arise out of the model of obligations appropriate to the internal goods of the practice of medicine. In *The Virtues in Medical Practice,* Pellegrino and Thomasma add benevolence, humility, and courage. These virtues, which apply to practitioners as well as patients, "dispose both parties to act well in relation to the ends of medicine" (1993, p. 194).

However, Edmund Pincoffs argues that virtues cannot be reduced simply to qualities related to the internal goods of a practice. If virtues are correlative to role-specific duties, as Tom Beauchamp and James Childress suggest, then patients might be expected to exhibit the virtues correlative to their duties of truthfulness, compliance with treatment regimen, and respect. However, such a view would neglect important virtues, such as gratitude, that are not readily identified with action guides.

Both Karen Lebacqz and William F. May address the virtues of patients as qualities that emerge in response to the situation of illness or limitation, but not specifically as qualities having to do with the doctor–patient or caregiver–care receiver relationship and not specifically as correlated with duties. Drawing on both fictional (Solzhenitsyn) and real-life (Abram; Fox; Scott-Maxwell) stories of patients, Lebacqz addresses the virtues of patients generally. May treats the virtues of the elderly within the general context of their confrontation with limitation, adversity, and death.

In line with other commentators (Drane; Hauerwas; Pellegrino and Thomasma, 1988), Lebacqz argues that virtue, which can be defined as a unity of the self, is not the same as specific *virtues.* Virtues are qualities or traits of character judged to be excellent. They emerge as general stances toward the world or as responses to situations. The situation of patients is generally characterized by bodily change, threats to self-identity and understanding, and the assumption of a new social role—that of "patient," with all its indignities, loss of control, and powerlessness. The virtues of patients are "excellences" in response to these situational changes.

Using classical virtue theory (Pieper), Lebacqz proposes that two "cardinal" virtues and one "theological" virtue are particularly appropriate to the situation of patients. Fortitude, or courage in the face of fear, is the first virtue for patients, who often wonder whether they have the strength to do what is needed. Fortitude includes both endurance and attack: both accepting limits and railing against limitation.

Prudence, or acting in accord with the real, is crucial for patients, who must learn to deal with new realities in their lives. The first aspect of prudence is perception; the second aspect is the willingness to act on what is perceived. Perception includes both listening, or contemplation, and removing hardness from the heart in order to value the little things in life.

Finally, Lebacqz suggests that hope in the sense of trust in the attainment of ends is crucial for patients (cf. Hauerwas, who argues that hope forms every virtue). In the face of despair and even terror, hope keeps patients from falling into despair. Humor is a central component of such hope.

Lebacqz stresses that there is no single pattern of virtue for patients and no one way of expressing relevant virtues. While she follows the Aristotelian pattern of assuming virtue to be a mean between extremes, she notes that virtues are culturally conditioned and, hence, what is considered virtuous in one culture may not be in another. For example, patient waiting might be prized in some cultures while aggressive resistance would be in others. Whereas Pellegrino and Thomasma (1988) note that healthcare providers often consider the "good patient" to be the one who is willing to suffer, Lebacqz rejects long suffering as a central virtue for patients. Similarly, virtues might be assessed differently for men and women in different cultures.

May's treatment of virtues of the elderly stresses several of those noted by Lebacqz. May also puts courage at the head of the list, and includes in it both endurance and attack. He places the virtue of prudence into the broader category of wisdom, and uses traditional categories to propose that prudence includes *memoria,* or learning from the past; *docilitas,* or the capacity to be silent and thus to perceive; and *solertia,* a readiness for the unexpected and an openness to the future. He does not list hope per se, but does include humor or *hilaritas* ("celestial gaiety") as a virtue related to wisdom.

May also adds some virtues of the elderly in situations of illness. Since patients are "receivers," May argues that humility is a crucial virtue for them. It removes the sting from the humiliations that they must endure. While Lebacqz argues that patience is not always a virtue, May suggests that purposive waiting and taking control of one's own spirit under circumstances of adversity is a virtue. For the elderly, May adds the virtues of benignity, letting go of one's possessions in openhanded love, and simplicity, learning to travel unencumbered. Finally, he suggests that integrity is a virtue that expresses unity of character and implies both uprightness and wholeness. Although May does not list theological virtues per se, he does suggest that integrity points to the transcendent dimension.

These different treatments of patients' virtues suffice to indicate that there is no single list of virtues appropriate to patients and no agreed mechanism for deriving such a list. Nonetheless, using Pincoffs's sorting scheme, we might suggest that patients need both instrumental and noninstrumental virtues.

Instrumental virtues are geared toward the goal of restoring health. These fit best with the view that virtues are qualities intrinsic to the goods of an institution or practice such as medicine. In the case of patients, such instrumental virtues would include complying with appropriate treatment regimens (probity) and telling the truth about one's situation (honesty). These virtues support the goal of working toward the patient's health.

Patients also need noninstrumental virtues. In these, Pincoffs includes: (1) aesthetic qualities such as serenity, which comes close to May's virtue of simplicity; (2) meliorating qualities such as tolerance and tactfulness, which come close to notions of humor utilized by both Lebacqz and May; and (3) moral virtues such as fairness and honesty, akin to virtues urged by Pellegrino and Thomasma.

There is general agreement, then, that virtues are qualities of persons generally admired or praised in a culture, and that certain qualities are particularly important for patients: courage (or fortitude), wisdom (especially prudence), humor, hope, truthfulness, and faithfulness to the task of healing, whether through long-suffering endurance or through attack and resistance. In spite of this agreement, the assessment of what constitutes a virtue will be culturally conditioned and will likely reflect the biases of dominant groups in a culture.

KAREN LEBACQZ (1995)
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SEE ALSO: *Beneficence; Care; Conscience, Rights of; Death; Healing; Law and Morality; Maternal-Fetal Relationship; Narrative; Pain and Suffering; Patients' Responsibilities: Duties of Patients; Professional-Patient Relationship; Trust; Virtue and Character*

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PATIENTS' RIGHTS

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I. Origin and Nature of Patients' Rights
II. Mental Patients' Rights

I. ORIGIN AND NATURE OF PATIENTS'RIGHTS

In most industrialized countries it is taken for granted that citizens have a right to medical care, but there is much less recognition of rights in medical care. In the United States, in contrast, concentration has historically been on rights that individuals may exercise in the medical-care context, whereas only in the mid-1990s has discussion begun to focus on rights to medical care (or at least the right to medical insurance). From "informed consent" to the "right to abortion" to the "right to die," patients' rights have become both a political slogan and a part of broader political agendas.

Although initially the trend toward recognizing patients' rights concentrated on the institutional setting in which medical care was delivered, and focused on issues such as natural childbirth and informed consent, by the 1990s the trend was visible throughout the healthcare system in the United States and was spreading internationally.

The doctor–patient relationship has historically been described as based on trust rather than on the monetary considerations evident in the more typical business transaction. Nevertheless, increased expectations and increased cost have contributed to patients' views of themselves as "consumers," and by the 1980s hospitals began considering themselves private businesses. U.S. courts and legislatures had previously moved to protect the weaker party from abuses of power in areas formerly unregulated, such as landlord–tenant, seller–buyer, creditor–debtor, employer–employee, police–suspect, and warden–prisoner relationships. The law has now also come to the aid of patients asserting their rights in medical situations.

The recognition of patients' rights flows from two fundamental premises: (1) The healthcare consumer possesses certain interests, many of which may properly be described as rights, that are not automatically forfeited by entering into a relationship with a physician or a healthcare facility; and (2) many physicians and healthcare facilities fail to recognize the existence of these interests and rights, fail to provide for their protection or assertion, and frequently limit their exercise without recourse (Annas and Healey).

History

In 1969, the Joint Commission on Accreditation of Hospitals (JCAH)—a private, voluntary accreditation organization composed of members from the American Hospital Association (AHA) and the American Medical College of Surgeons—issued its proposals for revisions in its standards. The National Welfare Rights Organization (NWRO), a grass-roots consumer organization spawned during the activist 1960s, responded in June 1970 by drafting a document containing twenty-six demands; this was the first comprehensive statement of "patients' rights" from the consumers' perspective. Included were provisions for such things as grievance procedures, community representation on hospital governing boards, nondiscrimination on the basis of source of payment, restrictions on transfers, provisions on privacy and confidentiality, and prompt attention to patients' requests for nursing assistance (Silver). After months of negotiation, a number of these items were specifically written into the revised standards of the JCAH. By the late 1980s, issues of access to care, of respect and dignity, privacy and confidentiality, consent, refusal of treatment, and patient transfer to another facility were specifically addressed in a new section of their accreditation manual called "Rights and Responsibilities of Patients" (Annas, 1989).

In late 1972, the American Hospital Association adopted a Patient Bill of Rights based on the premise that "[the] traditional physician–patient relationship takes on a new dimension when care is rendered within an organizational structure … the institution itself also has a responsibility to the patient." The text of the AHA bill of patient rights called for acknowledgment of the rights to (1) respectful care; (2) current medical information; (3) information requisite for informed consent; (4) refusal of treatment; (5) privacy; (6) confidentiality; (7) response to requests for service; (8) information on other institutions touching on the patient's care; (9) refusal of participation in research projects; (10) continuity of care; (11) examination and explanation of financial charges; and (12) knowledge of hospital regulations. In 1992, items on access to medical records and use of advance directives were added. Although the listing remains vague and incomplete, and there is no enforcement mechanism, it moves in the direction of more adequately informing patients of their rights.

Between 1974 and 1988, many states, including Arizona, California, Illinois, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, New Hampshire, New York, Pennsylvania, Rhode Island, and Vermont, adopted a patients' bill of rights by regulation or statute (Annas, 1989). All fifty states have adopted some form of advance healthcare directive document, such as a living will or durable power of attorney, in which people can express their wishes regarding medical care should they become incompetent. Both former President Nixon and Jacqueline Kennedy Onassis used such documents in 1994.

The American Medical Association (AMA), probably because of its traditional paternalistic philosophy, did not seriously consider adopting its own version of the patients' bill of rights until 1989. Five of the six provisions of its proposal—the rights of patients to access information in the medical record and to make treatment decisions and the rights to respect, to confidentiality, and to continuity of care—seem to have been uncontroversial. The bill of rights was rejected by the AMA House of Delegates, however, because of its sixth provision: "The patient has the right to essential health [medical] care." In the absence of some national healthcare program, or unless the patient has a preexisting relationship with a physician or insurance program or is experiencing an emergency medical condition, there is no "right to medical care" in the United States (although opinion polls taken since 1948 show that most physicians and Americans believe this right either exists or should exist).

International Scope of the Movement

Although "rights talk" is uniquely American (as are the Bill of Rights and Declaration of Independence), the patients' rights movement should not be viewed as unique to any one country. In 1975, for example, the Parliamentary Assembly of the Council of Europe submitted a draft recommendation to its sixteen member-nations recommending that all necessary action be taken to ensure that the sick can receive relief from their suffering and that people can prepare adequately for death; that commissions be established to study the issue of euthanasia; and that physicians be impressed "that the sick have a right to full information, if they request it, on their illness and the proposed treatment, and to take action to see that special information is given when entering hospitals as regards the routine, procedures and medical equipment of the institution." By 1990, work on a European Declaration of the Rights of Patients was well under way (Westerhall and Phillips; Leenen et al.). In 1991, a national conference on patients' rights was held in Japan, and at the impetus of tort lawyers and some physicians, a trend toward recognizing patients' rights is developing in that country as well.

The worldwide trend toward recognizing human rights in health should be viewed in context of the worldwide trend toward recognizing human rights in general. Recognition of rights to bodily integrity in general, for example, translates into a right to refuse treatment in the medical context. In this regard documents such as the Nuremberg Code (1947), the United Nations Universal Declaration of Human Rights (1948), and the United Nations International Covenant on Civil and Political Rights (1966) should be viewed as foundational (Annas and Grodin; Sieghart).

Patients' Rights in Context

Historian Paul Starr discusses the patents' rights movement in the United States as part of the "generalization of rights," distinguishing the movement to recognize healthcare as a basic human right (still unfulfilled) from the movement to work for rights in healthcare. In his words, "The new health care rights movement went beyond traditional demands for more medical care and challenged the distribution of power and expertise" (p. 389). Grass-roots consumer organizations in some states, such as Oregon, have begun to influence health policy, as have activist groups such as ACT-UP. Courts, of course, have contributed greatly to this trend, especially through decisions defining the doctrine of informed consent and by upholding treatment refusals as an individual's right to the exercise of liberty. But no one should have to go to court to have rights vindicated. Some have suggested the establishment of ethics committees to help patients enforce their rights, but such committees usually represent institutional interests more than the rights of individual patients (Annas, 1993). There is a need for an effective enforcement mechanism and an efficient dispute-resolution mechanism. Institutional and professional interests have made agreement on these issues difficult, and legal requirements to adopt such mechanisms may be needed.

One effective method of protecting patients' rights would be the establishment, either by the government under a national healthcare system or by health-insurance plans, of a patients' rights advocate program. The advocate should have the authority, under the direction of the patient, to exercise the patient's rights and powers on behalf of the patient. Such individuals could operate at the institutional level, but they are more likely to be effective in health plans, multi-institutional settings, and, of course, under any national health plan (Annas and Healey).

GEORGE J. ANNAS (1995)
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SEE ALSO: *Abortion: Contemporary Ethical and Legal Aspects; Abortion: Legal and Regulatory Issues; Abuse, Interpersonal; Access to Healthcare; Autonomy; Confidentiality; Conscience, Rights of; Disability: Legal Issues; Ethics: Normative Ethical Theories; Feminism; Genetic Discrimination; Human Rights; Informed Consent; Law and Bioethics; Law and Morality; Privacy and Confidentiality in Research; Privacy in Healthcare; Race and Racism;* and other *Patients' Rights* subentries

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II. MENTAL PATIENTS' RIGHTS

The strength of a society's commitment to justice and humanity can often be assessed by examining its treatment of its most vulnerable and/or disliked citizens. Few individuals have been as disliked, feared, persecuted, or stigmatized as have the mentally ill. Briefly reviewing the treatment of the mentally ill can provide a useful perspective in addressing present issues in mental patients' rights.

This article will examine mental patients' rights, including legal rights (judicial decisions, legislative and administrative enactments); human wants (basic human rights and entitlements); and clinical needs (the mental-health view of the right of every citizen to be free of the pain and limitations of mental illness).

In the United States, the mentally ill have historically experienced deprivation of many rights enjoyed by other citizens. Since colonial times there has been essentially a two-tier system distinguishing the treatment of the rich from that of the poor. The insane rich were usually kept at home—or more recently, in private institutions—and concealed from society to protect the reputation of their families, while the insane poor were left to the care of local communities. If the insane poor were seen as harmlessly deranged, society's main fear was that they would become public charges and drain the community's resources. To prevent this from happening, the mentally ill were often subjected to whipping and banishment, forced to wander from village to village. If they refused to leave their home community, their "treatment" frequently was incarceration in the local jail or poorhouse (Deutsch).

During the nineteenth century "moral treatment" was brought to America by a Quaker clergyman, the Rev. Thomas Scattergood. Great success, as high as 90 percent improvement in conditions, was reported by its early practitioners. The treatment was accomplished by removing patients from their family and community and placing them in a peaceful rural retreat—the asylum—where, under the absolute control of the physician, they lived a highly disciplined existence and engaged in useful employment (Rothman). "Moral treatment" represented an improvement in the conditions under which the mentally ill were treated. While still deprived of the legal and civil rights enjoyed by other citizens, they were at least given humane and hopeful treatment. This improvement, however, did not last long. By the end of the nineteenth century, as the result of a large influx of immigrants and a growing population of chronic patients, the asylums became overcrowded and inadequately staffed. Overcrowding and disorder created justification for mechanical restraints and punishments that grew in usage and severity; hospitals became human warehouses instead of treatment centers.

The failings and increasing harshness of public asylums did not lead to their dismantlement. Loose commitment laws facilitated the expulsion of the mentally ill from an increasingly urban society less willing to tolerate them. Efforts to improve conditions were sporadic, and progress was slow and uneven. Despite numerous books and exposés, including Clifford Beers's *A Mind That Found Itself* (1930), Albert Deutsch's *The Shame of the States* (1948), and Mary Jane Ward's *The Snake Pit* (1946, later made into a movie), the period of incarceration without adequate treatment continued well into the first half of the twentieth century.

By the mid-1950s, the mental-health community began to express its discontent with the situation in state mental hospitals. The resident population soared to 550,000, and approximately 40 percent of hospital beds were in state and county mental hospitals. The president of the American Psychiatric Association declared in 1958, "I do not see how any reasonably objective view of our mental hospitals today can fail to conclude that they are bankrupt beyond remedy" (Solomon, p. 7).

Public concern about the plight of the nation's mentally ill led Congress to establish the Joint Commission on Mental Illness and Health in 1955. The commission advocated the goal of community-based mental-healthcare accessible and responsive to the needs of all citizens. Community mental-health centers would provide the mentally ill with treatment close to their homes and jobs, and would reduce the need for prolonged or repeated hospitalization. As the result of the development of psychotropic medicine (medications that therapeutically affect an individual's mood or cognitive thoughts), expansion of community-based care, increased public concern about civil rights, and some greater tolerance of alternative behaviors, the population of the hospitalized mentally ill dropped to 220,000 during the 1960s and 1970s. This process of deinstitutionalization, however, did not always proceed smoothly. Frequently, patient discharges from hospitals occurred precipitously and without adequate aftercare. In addition, communities protested that they were becoming "dumping grounds" for patients unprepared for the demands of community living and for whom no adequate support system had been established (*Stone v. Miller,* 1974).

Despite the increased willingness of the public to support improved care for the mentally ill within their home communities, the plight of those treated in large state hospitals was still characterized by dehumanization, inadequate facilities, and insufficient staff. Such conditions provoked a flurry of lawsuits during the 1960s and 1970s, which led to increased attention to the rights of the mentally ill. These cases fit into three broad categories: the right to treatment; the right to refuse treatment; and the right to be placed in the least restrictive alternative. A fourth right, the right to liberty, represented by the U.S. Supreme Court's *O'Connor v. Donaldson* decision (1975), has aspects that encompass the three other categories.

Right to Treatment and Right to Liberty

During the 1960s, mental-health litigation reflected the increased activism of many civil-rights attorneys who turned their attention to mental patients' rights. In a parallel development, courts that had previously refused to rule on matters of medical treatment began, during the same period, to question whether conditions that would enable treatment to occur actually existed in facilities to which the mentally ill were committed. The concept of a right to treatment was first enunciated by Morton Birnbaum, who wrote the following in an *American Bar Association Journal* article:

> The fact that a person has a mental ailment is not a crime. Therefore, if anyone is voluntarily restrained of his liberty because of mental ailment, the state owes a duty to provide him reasonable medical attention. If medical attention reasonably adjusted to the needs is not given, the person is not a patient, but … virtually a prisoner. (Birnbaum, p. 499)

As a result of such thinking, a number of lawsuits were filed under the rationale of a constitutional right to treatment. Facilities in which widespread abuses and violation of clinical and legal rights were common were excellent targets for such litigation. Such was the situation that existed in certain hospitals in 1971, when the *Wyatt v. Stickney* lawsuit was brought against the Alabama Mental Health System. It was established during the trial that the state legislature had seriously underfunded Parlow and Bryce hospitals, leading to severe understaffing, deterioration in services and facilities, and limitation on treatment and basic care for the patients there. As a result of the rights violations described in the trial, the judge promulgated minimum standards for nearly every aspect of institutional care and a detailed program for implementation.

The minimum standards promulgated by the court include the following: a provision against institutional peonage; a number of protections to ensure a humane psychological environment; minimum staffing standards; provision for a human-rights committee at each institution; detailed physical standards; minimum nutritional requirements; a provision for individualized evaluations of patients, habilitation plans, and programs; minimum staff/patient ratios; and a requirement that every mentally impaired person has a right to the least restrictive setting necessary for treatment (*Wyatt v. Stickney,* 1971).

The courts have felt justified in moving into the vacuum caused by a lack of national standards to assure the treatment rights of involuntarily committed psychiatric patients. In the *O'Connor* decision, for example, the Supreme Court dismissed as "unpersuasive" the argument that the court should not be involved, noting: "Where treatment is the sole asserted ground for depriving a person of liberty it is plainly unacceptable to suggest that courts are powerless to determine whether the asserted ground is present" (*O'Connor v. Donaldson,* 1975, p. 574, n. 10). In other cases, such as *Wyatt v. Stickney,* the judges have consulted with various professional organizations, taken expert testimony, and come up with what they considered minimum standards. These standards tend to be more of the mortar-and-brick and staff-to-patient-ratio variety than to pertain directly to the quality of treatment. The basis behind the right-to-treatment issues as reflected in *Wyatt* and other cases is the expectation that if a psychiatric patient is to be involuntarily confined in order to be treated, then the facility in which he or she is placed should at least have the minimum capacity to deliver such treatment as will assure the patient's recovery and release. To do other than this is to "warehouse" patients and thus violate their constitutional right to liberty. The limited holding of the Supreme Court's *O'Connor* decision emphasized this point: "A state cannot constitutionally confine without *more* [emphasis added], a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends" (*O'Connor v. Donaldson,* 1975, p. 576).

Changing Perspectives on Patient-Physician Relationships

The Supreme Court's decision in *O'Connor v. Donaldson* reflects an evolving philosophy about the rights of the mentally ill in relation to society and to mental-health practitioners. For hundreds of years, many concerned with care and treatment of the mentally ill believed that their condition categorically prevents them from accurately perceiving reality and making reasoned judgments. Therefore it was considered the state's duty, according to the principle of *parens patria* (the state acting as a good parent to the nation's citizens) to take care of such afflicted individuals, and to prevent them under the state's police power from harming themselves or others, or disturbing the peace and safety of the community (Fowlkes).

Consistent with these commitment perspectives has been the psychiatric view that life and health or physical and emotional well-being are at the pinnacle of any hierarchy of values and should be maintained at any cost—even if the cost is a considerable loss of liberty for the individual whose health is at stake (Kopolow, 1976). A corollary to this position is the belief that mental illness is a disease of processes that impairs an individual's judgment and capacity for responsible action in relation to self and others. In refusing hospitalization and treatment, therefore, the patient's wishes might very well be discounted and viewed as symptoms of his or her mental illness (Sadoff and Kopolow).

A countervailing philosophy was reflected in the civil-liberties perspective and shared by a growing number of lawyers and mental-health professionals concerned with human rights. This view maintains that although a person's physical and mental health are important they are not necessarily of the highest value, and that freedom of the individual to place a higher value on other things should be respected. Those espousing this view maintain that what is called "mental illness" is not a process that necessarily interferes with or invalidates a person's will or lessens responsibility for his or her behavior (Szasz). Even psychotic individuals should have their wish to live at home rather than in a state mental hospital taken into consideration by the judges and psychiatrists who determine their fate.

Increasingly, states have abandoned the *parens patria* doctrine as being intrusive into the lives of individuals and have begun to utilize a more limited criterion of dangerousness as the justification for the use of "police power" for commitment. The *O'Connor* court seemed to sanction a definition of dangerousness as applied to civil commitment when it declared:

> Of course, even if there is no foreseeable risk of self injury or suicide, a person is literally dangerous to himself if for physical or other reasons he is helpless to avoid the hazards of freedom either through his own efforts or with the aid of willing family members or friends. (*O'Connor v. Donaldson,* 1975, p. 574, n. 9)

As a result of such court decisions, the test for commitment in many states now requires that the person be harmful to self or others by reason of mental illness and that no less restrictive alternative exists (Stone).

Initially, right-to-treatment decisions such as *Wyatt v. Stickney* and the right-to-liberty case of *O'Connor v. Donaldson* were welcomed by some mental-health professionals who viewed litigation as a potentially effective means for obtaining the release of patients who were receiving only custodial care or should not have been institutionalized in the first place. Others considered litigation as an intrusion into clinical practices that would produce great disruption in the mental-health system and no long-term benefit for patient care. While this debate continues, it does seem clear that litigation did focus public attention on the plight of the hospitalized mentally ill and, at least in the short term, resulted in pressure on legislatures to increase mental-health appropriations in order to avoid litigation or to avert increased court intervention.

Traditionally, the decisions about therapies and medical procedures have been within the domain of the treating professional responsible for the patient. In many states, patients who were hospitalized involuntarily were considered incompetent to make decisions on their own behalf. As a result of these medical and legal perspectives, patients frequently were denied the rights of other citizens when they were hospitalized. They were not permitted to vote; often they could not make phone calls or correspond without censorship of their mail. Additionally, they were not told what was happening to them or the consequences of the treatment imposed on them.

In the past, patients within an institution experienced a double limitation on their rights—one created by their disabilities and the other by the inherent organization of an institutional system. Even now, the prevailing atmosphere in many hospitals and especially psychiatric facilities perpetuates dependency and helplessness (Goffman).

While the actual disabilities that require institutional care limit a patient somewhat, the prejudging of his or her capacities by the staff may constitute an even greater obstacle. Even at the most enlightened institution, there will inevitably be a strain between the needs of the individual to live a life free of outside control and the institution's need to deliver care efficiently and effectively. Within a mental-health institution or any long-term-care facility, such organizational factors can be dehumanizing and promote frustration, regimentation, and despair. In addition, the stigmatization of mentally ill patients throughout history has seriously hampered attempts to protect their rights, meet their clinical needs, and advance their basic human wants.

Right to Refuse Treatment

The right to refuse treatment in many ways encompasses virtually all other rights of patients and raises fundamental questions as to the extent of control that can be exerted by a treater over a person who may not wish to participate in treatment. The issues raised by this right include the right to privacy, personal sovereignty, inviolability of one's thoughts, freedom from harm, freedom from cruel and unusual punishment, and the issue of the least restrictive alternatives to institutionalization (Perlin, 1979).

From the legal perspective, the right to refuse treatment arises from a composite of postulated constitutional sources including the constitutional right to freedom from harm and the constitutional right to privacy. While the courts and legislatures in recent years have been active in assuring patients the right to refuse such intervention as electroconvulsive therapy and psychosurgery, they have been slower to recognize the right to refuse psychotropic medication (Clayton).

Many individuals with mental illness wish to avoid psychotropic medication because of the potential side effects, which range from merely unpleasant (dry mouth, tiredness, blurry vision) to permanent and disfiguring (tardive dyskinesia, involuntary muscle movement). In addition, some mentally ill patients refuse medication not for the side effects but because the medication works well and therefore forces them to surrender the positive defensive adaptation of the psychotic state. Such adaptations may include an increased sense of importance and power, an ability to shut out problems that exist in the real world, and the support offered by hospitals and physicians (Appelbaum, 1988).

In various jurisdictions, including Massachusetts (*Rogers v. Okin,* 1979), New York (*Rivers v. Katz,* 1986), New Jersey (*Rennie v. Klein,* 1978), and the nation (*Washington v. Harper,* 1990), mental-health attorneys have sought to expand and clarify issues related to the right to refuse treatment, especially medication. Among the issues examined have been questions such as the right to protect all mental processes (thoughts, feelings, beliefs) from governmental interference; the right to protect autonomy over one's own body; the effectiveness of involuntary treatment versus voluntary treatment; and the questions of whether the potential benefits of drug treatment are worth the risks and who should be permitted to make this decision (Perlin, 1979).

The courts in the cases cited above sought to establish various procedures to protect patient autonomy and decision making in refusing antipsychotic medication. While these court decisions and subsequent legislative statutes have attempted to make the right to refuse treatment a legal and clinical reality, recent studies have revealed serious practical complications in applying these principles. One such study examined the assumption by the courts that patients' refusals of treatment are based on autonomous decision making. The study concluded that for most patients the decision to refuse psychotropic medication is a manifestation of their illness and does not reflect autonomous functioning or consistent beliefs about mental illness or its treatment (Schwartz et al.).

A study done by Paul Appelbaum noted that while refusal of treatment was not uncommon, ultimately most of the patients received treatment during their hospitalization (1988). Some clinicians have studied the cost of implementing court-mandated protection programs in the wake of the *Rogers* decision. On the basis of the studies' results, these clinicians have concluded that from the economic perspective, such programs are not cost-effective (Schouten and Gutheil). Furthermore, some authors have noted that the right to refuse treatment may infringe on the constitutionally based right to treatment for involuntarily committed mental patients (Blais). Thus the battle continues to be fought. On one side is concern for patients' autonomy and for protection from intrusive and potentially dangerous procedures. On the other side is concern for the clinical needs of patients and the necessity of interventions that can restore them to mental and physical freedom. The future evolution of this right will need to take into consideration not only legal and psychiatric perspectives but also the reality of the consequences of court intervention.

Right to the Least Restrictive Alternative to Hospitalization

A third important right that has received increasing judicial and psychiatric attention is the right to the least restrictive alternative to hospitalization. Many mental-health departments have seen deinstitutionalization as an effective way to reduce the cost of mental-healthcare; unfortunately, clinical services have not always followed patients to their communities.

The trend toward community-based services (least restrictive alternative to hospitalization) was initially heralded as the answer to improved quality and more responsive services. However, it has only partially addressed the need to protect mental patients' rights in the community. In place of the neglect by large institutions, many ex-patients now suffer from the despotic control of boardinghouse managers; in place of "voluntary work with token rewards," they now face long hours of inactivity; in place of even rudimentary treatment plans, they now receive larger doses of tranquilizers administered by untrained persons. These patients also face the continuing threat that unless they conform and follow the rules, they will be rehospitalized (Kopolow, 1979). While community-based services are less restrictive than institutional care, services are only as good as a community is willing to make them.

In the case of *Dixon v. Weinberger* (1974), Judge Aubrey Robinson ruled that patients in the District of Columbia have a statutory right to treatment in the least restrictive alternative to institutionalization. Responsibility was placed on the District of Columbia and the federal government to prepare a plan to identify and transfer patients to newly created community facilities. It is significant to note that twenty years later, the court's orders still have not been fully implemented. This case clearly shows the limitation of the courts in establishing rights when a community is resistant to, or incapable of, compliance. Another important judicial decision that has relevance to least restrictive treatment is *O'Connor v. Donaldson.* In this decision, the court acknowledged that states have a legitimate interest in providing care and assistance to patients, but it also declared that the patients' preferences should be recognized as well:

> The mere presence of mental illness does not disqualify a person from preferring his home to the comforts of an institution. Moreover, while the States may arguably confine a person to save him from harm, incarceration is rarely if ever a necessary condition for raising the standards of those capable of surviving safely in freedom. (*O'Connor v. Donaldson,* 1975, p. 575)

The court's movement toward a standard of ability to survive and the expectation that the least drastic means of treatment will have to be used put increased pressure on communities to develop an adequate range of services. To have such a range of services, however, requires commitment of resources that, as the *Dixon* case so clearly pointed out, may be slow in coming. The right to the least restrictive alternative will become meaningful only when communities invest adequate resources to develop such alternatives and provide mechanisms such as patient advocates to protect and advance patients' rights within the community or within an institution.

Advocacy

Advocacy has many meanings, depending on the interests and priorities of the various groups using it: mental-health professionals, consumers, attorneys, citizens' organizations. In its classic sense it means "to summon to one's assistance, defending, or calling to one's aid." The present-day connotation of conflict or antagonism is not inherent in the basic concept of advocacy, but results from the manner in which some advocates pursue their duties.

The mentally ill, as noted previously, suffer from prejudice and stigmatization that make it difficult for them to advocate their own causes. In addition to these factors, the complexity of the support and treatment programs and the need for change agents in what is essentially a conservative system make the need for advocates especially important. Advocacy, as related to patients' rights, is the responsibility of many individuals and professionals, including lawyers, psychiatrists, social workers, and concerned citizens. While it is obvious that it is the responsibility of the legal profession to advocate for legal rights of patients, the term also has other useful meanings within the mental-health service delivery system. After pure legal rights have been established and attorneys are available to patients to ensure their protection, other issues remain that cannot and should not be resolved through the legal system. Such issues, including staff attitudes, environmental conditions, and alternative treatment services, which influence the quality of the day-to-day life of mental patients, can be more effectively dealt with through administrative and legislative actions.

It is clear that no one approach or even one professional group can perform all the necessary tasks of mental-health advocacy. Advocacy functions can be divided into three broad categories:

1. Education and training of hospital staff regarding the nature of patients' rights and the best way to assure their protection.
2. Establishment of procedures to allow the speedy resolution of problems, questions, or disagreements that may or may not be legal rights. Such procedures would enable quick and efficient resolution outside the courtroom of legal and nonlegal rights issues.
3. While functions (1) and (2) can be properly handled by appropriate state agencies, a final category requires the use of independent outside lawyers and agencies: provision for independent and readily available legal support when it is necessary to litigate for protection of patients' rights after internal procedures have failed.

A major controversy in advocacy is whether the predominant emphasis should be on internal or external rights-protection programs. An external advocacy program system would be implemented by individuals who are totally independent of the mental-health system. An internal advocacy program would be implemented by employees of the service system. Arguments for external programs relate to the concept that the advocate is ultimately loyal and responsible to the client. An advocate who is an employee of a department or agency of state government may have divided loyalty. An alternative perspective is that not all state employees are equally subject to that conflict—for example, someone working in an independent section or agency of the state government.

Internal rights-protection or advocacy programs, however, frequently tend to be highly efficient in solving complaints about daily living and in planning for future patients'-rights needs. They have easier access to patient records, can participate in program policy development, have a more collegial relationship with administrators that engenders trust and greater cooperation, and have the ability to identify problems to be corrected without outside pressures or publicity. Unfortunately, such programs suffer from the double danger of co-optation and replacement at the discretion of administrators.

An external advocacy program can use persuasion, and when persuasion fails, litigation is always a backup position. Such a program can bypass administrative changes for quick action; however, court cases may move slowly. Therefore, while external advocacy may have a limited range of action, it nonetheless can be powerful and decisive in producing change in a system now receptive to patients' rights protection. This analysis of internal and external advocacy programs clearly illustrates a patient's need for the availability of both programs. Such comprehensive advocacy programs can go far in assuring that patients'-rights concerns do not become mere rhetoric or window dressing, but are permitted to make substantive changes necessary to create a more responsible mental-health system.

Conclusion

In answering the question "What rights do mental patients have?" it is important to go beyond judicial decisions, administrative actions, or legislative statutes, and look at the status of the mentally ill in American society. The rights of mental patients have historically been disregarded and denied. The mentally ill were frequently viewed as incompetent to make decisions, and society's concern was to place them in institutions where they would cause neither themselves nor others harm and where they might receive treatment for their conditions.

The patients'-rights movement, made up of civil-rights attorneys, enlightened mental-health professionals, and former patients, has waged a struggle in courts, in legislatures, and in local communities to stop patient abuse, end stigmatization, increase needed community services, and empower patients to exert their full civil rights. Major patients'-rights litigation in the areas of right to treatment, right to refuse treatment, right to least restrictive alternatives, and right to liberty have led to increased recognition of the existence of these rights. But it is clear, when one examines the plight of the mentally ill down through history, that "something else" is needed if there is to be no recurrence of the cycle of abuse, exposé, improvement, neglect, and abuse again.

This "something else" that can safeguard patients' rights is the advocate. Mental patients already have extensive rights under the Constitution. The problem is not simply granting or recognizing rights but protecting them. Only through the continuing efforts of the advocates will the mentally ill truly have the rights enjoyed by other citizens. In the case of patients, as in the case of other citizens, "the price of freedom is eternal vigilance." The advocate provides the vigilance that helps assure that the legal rights, human wants, and clinical needs of the mentally ill are protected and promoted.

LOUIS E. KOPOLOW (1995)
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SEE ALSO: *Autonomy; Coercion; Competence; Informed Consent: Issues of Consent in Mental Healthcare; Institutionalization and Deinstitutionalization; Mental Health Services; Mental Illness: Conceptions of Mental Illness; Mental Institutions, Commitment to; Paternalism; Professional-Patient Relationship;* and other *Patients' Rights* subentries

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PEDIATRICS, ADOLESCENTS

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Adolescents, defined as young people between the ages of thirteen and eighteen, have much more autonomy and much more extensive rights to make their own choices about healthcare than their parents did when they were adolescents. Constitutional and other law on reproductive issues and the development of the rights of privacy and of confidentiality also affect adolescents’ rights to seek or to refuse healthcare. Until the ratification in 1971 of the Twenty-Sixth Amendment to the U.S. Constitution, which gave eighteen-year-olds the right to vote in federal elections, a “minor” was anyone under the age of twenty-one. Almost all states then changed their laws to make eighteen the age of majority.

Consent to Medical Treatment

Under the common law of England, from which the American legal system evolved, children were, in effect, possessions of their fathers. Until 1772, a mother had no right to her eldest son’s custody after his father’s death if her husband had chosen to make a will, leaving the boy to another man. Because women could not own property, mothers had the right to custody only of their daughters and their noninheriting younger sons. Even into the twentieth century, fathers retained rights to control their children to the point of brutality. Before 1903 nowhere in the United States was child abuse a crime, because it interfered with the father’s right to discipline his children in any way he saw fit. The reporting of child abuse was not mandated until the 1960s. In the context of medical care, the father’s total authority was recognized by allowing him to sue a physician who had provided nonemergency medical treatment to a minor—even completely successful treatment—if the father’s consent had not been obtained.

Beginning in the 1960s, however, epidemics of sexually transmitted infections (STIs) in adolescents were worsened because the teenagers would not seek medical care if their parents would find out they had been infected. Not only did they remain untreated, they spread the infections to sex partners. Physicians all over the country and the American Medical Association itself began to lobby state legislators to enact statutes permitting minors to receive treatment for STIs in confidence. By the end of the 1960s all states had such statutes and thereafter also added statutes permitting confidential treatment for drug or alcohol abuse problems.

At the same time, about half of the states also enacted general minor consent statutes. Although the ages vary from fourteen to sixteen, these statutes allow a minor who has attained that age to consent to general medical or surgical care, although since 1973 and the Supreme Court's decision in *Roe v. Wade,* many states have enacted exceptions to this consent related to abortion. Even in states that do not have general consent statutes, courts apply what is known as the "mature minor rule" and hold that a physician is not liable for failing to obtain parental consent to provide medical or surgical services to an adolescent as long as the adolescent is as capable of giving informed consent as an adult would have been.

Therefore, whether a particular minor can consent to a particular medical intervention depends not only on the age and maturity of the adolescent but also on the severity of the condition and the risks of the proposed treatment. Most physicians would be perfectly willing to treat an adolescent for an earache without involving parents, but most, if not all, would not consider treating the same teenager for leukemia without her parents' involvement.

These conflicts rarely involve illness sufficiently severe to require hospitalization, however, because minors are insured, if at all, as dependents in their parents' health insurance plans. A hospital will not permit a nonemergency admission unless the parent agrees to pay or to have their insurance do so. If the physician has not obtained parental consent to a nonemergency procedure, the parent does not have to pay the bill.

In an emergency, parental consent is not required, no matter how young the child, if the parent cannot immediately be found. If a four-year-old falls at preschool and is brought to the emergency department or to his physician's office, if his parents are called but cannot be located, and if the physician proceeds to suture the child's cut, parents cannot thereafter object. In fact, it might be regarded as malpractice to allow an injured child to be denied care because his parent could not be reached.

Parental consent is also not required if the minor is emancipated. Minors are emancipated if they are married or in the military, and in most (but not all) states they are considered emancipated if they do not live with their parents and are self-supporting. Most states also consider a teenage mother to be emancipated, and in some states a pregnant minor is emancipated.

Refusal of Medical Treatment

If an adolescent is able to consent to a particular medical intervention, she is equally able to refuse it even if her parents wish her to have it. These situations usually involve non-life-threatening illnesses.

In no state may a minor execute a legally binding living will (a directive that describes patient preferences in certain medical situations, such as the use of a respirator, to be invoked if the patient is not able to express his or her wishes at the time the decision must be made) or durable power of attorney (a directive that appoints a specific person as the patient's agent to make decisions on the patient's behalf when the patient cannot do so). This does not mean, however, that the young person's views should not be considered. When an adolescent, or even a younger child, has a terminal illness, and there is no realistic hope of improvement, even if parents want to try "one more thing," if the patient wants to change the goal to palliative care, the physician should support the patient's wishes. (Palliative care is that which seeks to alleviate symptoms produced by a life-threatening disease or its treatment and to maintain the patient' quality of life when the medical condition is not remediable.)

Where lifesaving treatment is likely to be successful, but the adolescent does not wish to have it, courts in most states will not allow the patient to refuse. Examples of this situation have involved adolescents who have expressed the desire to refuse blood transfusions for religious reasons. Although a few judges have determined that the teenager had realistically assessed the situation and could give an informed refusal (e.g., *In re E.G.* [1990]), most others, on essentially identical facts, have simply stated that minors may not refuse lifesaving treatment (e.g., *In re Application of Long Island Jewish Medical Center,* [1990], *Novak v. Cobb County-Kennestone Hospital Authority,* [1996]).

Parents, of course, may not refuse lifesaving therapies for their children on religious or other grounds. Furthermore, if a child dies when reasonable medical care more probably than not would have saved the child, the parents may be successfully prosecuted for manslaughter or even murder (*Commonwealth of Pennsylvania v. Nixon* [2000]).

The "refusal of treatment" may, of course, involve many issues other than legal ones. An adolescent can very easily be so uncooperative that treatment is, for all practical purposes, impossible and he may either threaten to or actually run away.

Confidentiality

If an adolescent is deemed by a physician to be capable of giving informed consent and the adolescent's parent is not involved, the patient is entitled to the same degree of confidentiality that an adult patient would have. If the physician does not involve a parent before the treatment is given, the patient will understandably assume that the care is confidential. If the physician then notifies a parent, the patient's trust in all medical personnel is likely to be destroyed. In some cases, particularly those involving sexual behavior, parents may reject and evict their child when they learn the information, and some of these young people have been driven to suicide (Remafedi, 1999).

In some situations, such as treatment for STIs or for alcohol or drug abuse problems, state statutes mandate confidentiality. Some, in fact, specifically forbid billing parents in these circumstances, lest the parent find out about the treatment from the bill.

The most difficult issue about intrafamily confidentiality in the care of adolescents today involves those who have HIV disease. Although in normal situations parents would be included in decision making when an adolescent has a very serious and perhaps fatal disease, AIDS is likely to engender parental reactions that may be adverse to the patient's medical care—the adolescent may be expelled from the family home and left to live on the streets or be subjected to emotional and physical abuse if remaining at home. While all authorities agree that the patient should be encouraged to include parents in decision making about the disease, there is increasing agreement that if the adolescent is able to consent to testing and counseling, she should be promised confidentiality. This assumes, of course, that medications can be provided free or at very low cost, because health insurance is usually in the parent's name and notice to parents would be given of payments to pharmacies.

AIDS clinics have ample evidence suggesting that adolescents will not come for testing, much less treatment, if they are not assured of confidentiality. Long-term follow-up studies indicate that teenagers whose parents do not know that they are HIV positive fare as well as those whose parents are involved (Kipke and Hein).

The reverse issue in confidentiality occurs when a parent knows the adolescent's diagnosis and does not wish the adolescent to know. The physician's duty is to the patient, not to the patient's parent, so the physician may disregard the parent's request if she deems it in the patient's best interest. In no case, even if the physician is willing to accede to the parent's request, may she lie to her patient, so questions must be answered truthfully even if this leads to the patient's discovery of the diagnosis.

Although this is usually a question of ethics, in some cases there may be legal consequences to the physician for failing to make sure the patient understands the implications of his disease, including the risk of transmission to others. For example, if an adolescent has HIV/AIDS, and the parent is in denial that the adolescent is sexually active, protection of others requires that the patient understands the disease, its ramifications for others, and how to prevent infection through safe-sex practices.

In situations where requests for information come from outsiders, the adolescent patient's rights to privacy and confidentiality are as extensive as those of an adult. A school principal without permission from a parent to obtain medical information about a student has no more right to that information than does the student's neighbor.

Contraception

Contrary to the belief that adolescents are more sexually active than they used to be, the American teenage childbearing rate was 96 per 1,000 girls aged fifteen to nineteen in the late 1950s but fell to 49 per 1,000 by 2000. American girls who are sexually active are much more likely to become pregnant than their European counterparts. The percentage who are sexually active is about the same, but the pregnancy rate is much higher—the U.S. rate is four times higher than Germany's, six times higher than France's, and eight times higher than that of the Netherlands. A study conducted in 2000 by Harold Leitenberg and Heidi Saltzman found that 77 percent of American females and 85 percent of males had had intercourse by age nineteen.

In the 1965 case *Griswold v. Connecticut,* the U.S. Supreme Court held that married couples have a right to privacy that encompasses their decisions about whether to have children. State laws that made dissemination of information about or prescription of birth control a crime were found to be unconstitutional. This right was expanded to unmarried adults in 1972 (*Eisenstat v. Baird*) and in 1977 to minors (*Carey v. Population Services*).

In 1970 Congress enacted Title X (Family Planning Services) of the Public Health Services Act. This established federally funded family planning services and required that they be provided without regard to religion, creed, age, marital status, or number of pre-existing pregnancies, regardless of outcome. In 1978 the act was amended specifically to include teenagers. Attempts during the administration of Ronald Reagan to require parental notification if a girl received services were held unconstitutional. By statute, in federally funded clinics, services are confidential. There is, however, no obligation on a physician in private practice or an institution that does not receive federal family planning funds to provide contraceptives to anyone of any age.

Many adolescents go directly to family planning clinics instead of their customary healthcare provider because they do not trust their physicians or nurse practitioners to keep their confidences. Thus if an unrelated illness arises where it may be important to know whether an adolescent is taking birth control pills, the physician whom she does not trust is most unlikely to get a truthful answer.

Sexual Abuse

If a very young adolescent (under age fourteen) seeks contraceptives, sexual abuse should be considered but not assumed. After all, asking for contraceptives in and of itself requires some degree of maturity. Many very young girls may well be involved in exploitive relationships with older men; this constitutes statutory rape as well as abuse. In most states the statutory rape statute provides an age differential beneath which the relationship is presumed consensual and above which it constitutes a crime. In most states the differential is five years, so if a fifteen-year-old girl is having a relationship with a nineteen-year-old boy, it is not a crime, but if he is twenty-five, it is. In the mid-1980s the California attorney general issued an order that all sexual activity by children under fourteen had to be reported as sex abuse, and reports were to be made by anyone who had knowledge that a child under fourteen had a sexually transmitted disease or had asked for birth control. In a 1986 case (*Planned Parenthood Affiliates of California v. Van de Kamp*), this order was struck down by the California Court of Appeals as invasive of the minor's rights of privacy.

Abortion

When the Supreme Court decided *Roe v. Wade* in January 1973, all the plaintiffs were adult women. Many state legislatures responded to the decision by enacting laws requiring consent to abortion by a married woman's husband and consent by a parent to a minor's abortion. The Supreme Court quickly declared unconstitutional any requirement of a husband's consent (*Planned Parenthood Association of Missouri v. Danforth*) but in subsequent decisions permitted states to restrict a minor's right to consent (*Planned Parenthood Association of Kansas City v. Ashcroft*. Since the Ashcroft case in 1983, a state may require parental consent as long as it also provides a "bypass" procedure whereby the young woman may apply to a judge to find her "sufficiently mature" to consent to the procedure. The judge's role is to determine the girl's maturity: The judge's personal opinion of abortion is supposed to be irrelevant. In some states, almost no young women are found "too immature"; in others most girls, even those weeks from their eighteenth birthdays, are routinely turned down. In an article published in the *Minnesota Law Review* in 2001, Nicole A. Saharsky noted that of the twenty-three states allowing a juvenile to be sentenced to death when convicted of murder, eighteen are also among the most restrictive in limiting the decisions of young women of exactly the same age to have abortions on the grounds that they are too immature. (If there is no state statute, the young woman's right to consent to abortion is the same as her right to consent to any other medical procedure.)

Of course, if a young woman is "too immature" to make this decision, she is altogether likely to be too immature to care for the baby she will have in a few months. It should be remembered that an adolescent mother, no matter how young, has the authority to surrender her baby for adoption, even if her parents strenuously object. Her parents, conversely, have never been given the right to surrender the infant for adoption over her objections. A teenage mother, no matter how young, has the same responsibilities and decision-making authority for her baby as she would if she were thirty. With the exception of a very few states, the teenage mother's parents have no duty to provide for her baby and in some states, because she is emancipated by childbirth, they may refuse further support for her as well, and evict her and the baby from the household (*A.N. v. S.M., Sr.* [2000]).

Since 1998 there have been several cases in which a girl lied about her age to obtain an abortion, and her parents, upon discovering the situation later, sued the physician who performed it. All of the girls were sixteen or seventeen and claimed to be eighteen. In each case, the suit was unsuccessful, because the consent statutes do not impose a duty on abortion providers to verify the patient's age. The cases *Jackson v. A Woman's Choice* and *McGlothin v. Bristol Obstetrics* held that the girls were "mature minors."

If parents have the right to refuse to permit their daughter to have an abortion, do they have the right to require her to have one if they think she is too young to have a baby? Logically, if she is too immature to say yes, she is also too immature to say no. There are very few cases on the subject, but in all instances the courts held that a girl has the right to refuse. None of those cases, however, came from states with parental consent statutes. There is only one case that can be located in which a physician, without telling his minor patient that she was pregnant, performed an abortion at the behest of the patient's mother and lied to the girl about the procedure. Years later she found out the truth and sued the physician. In 1995 the Texas Supreme Court, in *Powers v. Floyd,* ruled that the physician had not violated the girl's rights. The court held that although the state law had changed by the time the girl discovered the truth, at the time of the abortion, the girl could not refuse abortion because she equally could not consent.

Mental Health Issues

Adolescence is a period during which many serious psychiatric disorders such as schizophrenia begin to surface. Parents, confronted with "normal" rebellious behavior by their teenager, may think he or she has suddenly become mentally ill.

CONSENT TO TREATMENT. The issue of the young person's right to seek mental health treatment is unlikely to involve private psychotherapy, because the parent can refuse to pay the bill and in most cases a young person cannot afford it. A more practical question involves an adolescent's right of access to a community mental-health facility, a drug treatment center, or a counseling center for troubled adolescents. Community mental-health centers are probably covered by the normal rules of minor consent that apply to other medical treatment, because those institutions, most of which receive federal funds, must be careful to comply with requirements of proper licenses and credentials for all staff.

In some cases, however, treatment may be offered by caregivers without formal medical credentials. In drug rehabilitation centers, for example, many of the personnel may be former drug addicts without formal mental health training. Although this may be a viable method of treating addiction, it complicates the issue of the legal right of the adolescent to seek care. All statutes granting adolescents specific authority to consent to medical treatment, and all cases in which these issues have been decided, have dealt with the rights of young people to receive treatment from physicians, nurses, and other healthcare providers who fall within the boundaries of "mainstream medicine." Minor treatment statutes quite specifically refer to treatment given by physicians. Although there are no cases on the point, it is unlikely that courts would extend these rights of consent to encompass an unemancipated minor's right to seek treatment from a chiropractor; it is even more unlikely that a court would hold that an adolescent's right to consent to care would apply to situations in which the minor would choose to consult an alternative healer such as a naturopath. Parents in many cases have been found guilty of child neglect if they refused treatment from physicians and took their children to alternative healers, so it is most improbable that young people have the right to go to the same practitioners on their own. Drug rehabilitation clinics not directed by physicians and nurses and places where therapy is provided by persons outside the credentialed healthcare system undoubtedly would be held to fall into the same category.

REFUSAL OF TREATMENT. Many forms of behavior that may seem perfectly rational to an adolescent can be interpreted by a parent to be sufficiently abnormal to warrant psychiatric intervention, at least on an outpatient basis. By definition, this discussion involves those minors who would generally be considered "normal neurotics" in adult psychiatry. Such adolescents are functional and are not engaging in criminal or dangerous antisocial behavior. They have not engaged in definitive delinquent behavior and are not dangerous to themselves or others. They may be defiant at home, missing school for a few days but not becoming dropouts, refusing to dress as their parents think appropriate, or engaging in equally distressing but non-dangerous activities.

As discussed above, if minors have the right to consent to treatment, a court would probably hold that they have the right to refuse it. More to the point, however, as a fact of psychiatric practice, although it might be possible to subdue a teenager physically in order to remove his or her appendix, it is absolutely impossible to carry out any form of effective psychotherapy on an unwilling patient. The patient will simply refuse to discuss anything. At least one court has held that a school system violates the minor's right of privacy if it sets up a system of routine psychological evaluations in the absence of any behavior that indicates serious emotional disturbance that may require treatment.

CONFIDENTIALITY AND PSYCHIATRIC TREATMENT. What is the psychiatrist's obligation of confidentiality to the adolescent patient? When confidentiality issues arise because schools or other outside entities such as insurance companies or employers want information, the minor's confidentiality protection is as extensive as that of an adult patient. The conflicts arise when the patient's parent is the party who wants the information.

Because young children are almost never treated except in the context of family therapy, this problem rarely, if ever arises, but it does arise often with adolescents. The parent–child relationship may be genuinely adversarial, the parent may be terrified that the adolescent will disclose family secrets or tell the mental health professional about abuse, or the parent may just want to know whether, for example, her daughter is sexually active. Increasingly, as well, when parents are divorced and a child is in therapy, there are attempts to "get" the other parent or to attempt to change custody based on what the adolescent has told the psychiatrist.

Several cases from the 1990s and early 2000s (including *Abrams v. Jones* [2000] and *In re Daniel C. H. v. Daniel O. H.* [1990]) have held that a parent does not have the right to access his child's psychiatric records over the objection of either the adolescent patient or the mental health professional who believes that such disclosures are not in the patient's best interests.

INPATIENT TREATMENT. There are two distinct standards for commitment of adult patients to psychiatric institutions. Involuntary commitment of adults is reserved for those persons who are "dangerous to themselves or others" or are considered "gravely mentally disabled." For the latter, the legal definition covers patients who, as the result of mental illness, cannot provide the necessities of life—food, clothing, shelter, and medical care—for themselves. Voluntary commitment occurs when the patient and the patient's physician agree that treatment would be beneficial.

Minors of any age fall into an altogether different category. By statute many states allow "voluntary" commitment of children by their parents. Minors who are committed as "voluntary" patients at their parents' behest have fewer legal protections than adult patients do. Adult voluntary patients in a psychiatric hospital can leave at will unless, after arrival at the hospital, they are deemed to fall within one of the categories applied to involuntary patients ("dangerous" or "disabled"), at which point a judge must hold a hearing and the patient must be civilly committed or allowed to leave. Involuntary patients, on the other hand, have a right to a judicial hearing at the time of admission to the hospital and the right to release when they are no longer dangerous to themselves or others. Most states, however, stipulate that minors may not leave a psychiatric hospital without the approval of their parents. If parents choose not to have their child released, the patient cannot legally leave the hospital. Thus, on a standard of reasonable due process of law, hospitalized minors are in a far more restricted legal position than adults.

The case law indicates that there are many situations in which abusive parents have sought to incarcerate their children in psychiatric hospitals for reasons having nothing to do with the children's condition. In the 1960s, for example, some male adolescents were confined to hospitals for months or years because they refused to cut their hair. In many cases, it has become clear that adolescents have been committed to psychiatric hospitals without any serious attempt by admitting psychiatrists to discover whether the young people are really mentally ill.

If a child or adolescent has conflicts with a parent, society apparently concludes that the young person, not the parent, is the one with the problem. This is not necessarily true. In particular, as many judicial decisions have indicated, a parent cannot be assumed to have the best interests of a child at heart when commitment proceedings are undertaken.

In the early 1970s, several cases held that children do have certain minimal rights of due process before being committed to a psychiatric institution, and a right to be released from a hospital or an institution for the mentally handicapped on constitutional grounds if they have been denied a fair hearing and representation by counsel. As a result of these decisions, many states enacted statutes stipulating that younger children (under the age of thirteen or fourteen) could be admitted "voluntarily" to psychiatric hospitals by their parents, but minors over the statutory age had a right to a hearing, counsel, and due process, either at the minor's request or automatically. Where those statutes exist, the rights conferred by them are enforceable in the state courts under state constitutional rights of due process.

In 1979, however, the U.S. Supreme Court in *Parham v. J. R.* held that if a state legislature did not choose to enact such a statute, a minor's federal constitutional rights were not violated by "voluntary" admission to a mental hospital by a parent, even if the minor was not free to leave the institution thereafter. The court held that to protect minors from abuses of parental authority, the decision to admit had to be reviewed by a "neutral fact finder," but the fact finder could be a staff physician, "so long as he or she is free to evaluate independently the child's mental and emotional condition and need for treatment." After that decision, no more states enacted due process statutes for minor mental patients. In those states that have not enacted statutes providing for judicial intervention in a minor's commitment, the young person has no right to be evaluated by an independent psychiatrist or to consult a lawyer and may even be denied the right to contact a grandparent or other relative for help.

As press reports in 1991 indicated, some profit-making psychiatric hospitals admitted any adolescent patient whose parents sought his or her admission. Some of these hospitals paid bounties to high school guidance counselors to persuade parents that their children needed hospitalization and then, after the unsuspecting parents admitted them, refused to release the patients for weeks or months. The possibility of abuse of this population is a very serious one, because once hospitalized, the patients can be totally isolated from outside contact. State legislators and judges have been unwilling to deal with the problems of bad-faith actions by either parents or physicians.

An increasingly important problem today involves the rights of young people whose parents have had them admitted to an alcohol or drug treatment facility. The courts in at least two states have held that because these institutions do not claim to be "mental (psychiatric) hospitals," any rights to judicial intervention the minor may have under state law if admitted to a psychiatric hospital do not apply, and that the courts will not question the parent's right to admit the adolescent, even in the absence of an institutional definition of "addiction" to which the adolescent presumably conforms (*R. J. D. v. The Vaughn Clinic* [1990], *Department of Health and Rehabilitative Services v. Straight* [1986]). Thus a minor unjustly confined in a psychiatric hospital or addiction facility may have no recourse to, or even a right to contact, outside help of any sort. By contrast, if the parent wishes to turn for help to the juvenile court system and have the child declared "unmanageable" for precisely the same behavior, the child has a presumption of innocence, the right to counsel, and the right to a full hearing.

Participation in Research

In 1974 Congress passed the National Research Act, establishing the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Congress mandated that the commission study the problems of biomedical research and report to the Secretary of Health, Education, and Welfare (now the Secretary of Health and Human Services) on what ethical principles should be applied in research funded by or performed under the direction of the federal government. The Commission was also specifically mandated to consider the ethical and regulatory issues involved in research on a variety of "special populations" deemed particularly vulnerable, including children. The Commission issued significant studies and regulatory recommendations on each of the groups. Most of the recommendations are now federal regulations.

In general, research on minors is permissible if it involves no greater than minimal risk (defined as "the probability and magnitude of physical or psychological harm that is normally encountered in the daily lives, or in the routine medical or psychological examination, of healthy children"); or, when greater risk is involved, if there is likely to be a direct benefit to the young person. Parental permission is required for research on most preadolescent children. The Commission's recommendations and the final regulations permit adolescents to participate in some research projects without parental consent. If the local institutional review board (IRB) determines that a research protocol is designed for a subject population for which parental or guardian permission is not a reasonable requirement, the researcher may include adolescents as subjects without parental involvement. Any waiver of parental permission must be accompanied by the IRB's acceptance of a substitute mechanism for the protection of adolescent subjects or a finding that they are not being placed at any risk. The discretion afforded to the IRB by the regulations for protecting the rights and welfare of the human subjects of all ages in the institution of which it is a part make it extremely unlikely that research that could endanger an adolescent would ever be approved. It is most improbable that any IRB would waive parental permission for adolescent participation in any project that included a serious risk of even minimal harm.

The three following types of research normally involve adolescents who participate without parental consent:

1. Research in which adolescence is relevant. For example, a researcher might wish to question pregnant teenagers coming to a prenatal clinic about their knowledge of contraception at the time they became pregnant.
2. Research in which adolescence is irrelevant. For example, a researcher might wish to draw small amounts of blood from volunteers, and a sixteen-year-old, seeing the poster, volunteers.
3. Research that involves an attempt to recruit subjects from all age groups. For example, an epidemiologist might wish to do a community survey about knowledge of HIV infection, and some of the people she approaches in the local shopping mall are adolescents.

It is likely that an IRB would approve these studies as suitable for adolescent consent without parental involvement. There is a fourth type of research, however, that normally requires parental involvement:

(4) Research that is not related to the patient's age but that involves investigational therapy. If an adolescent patient has a disease for which the patient's physician-researcher wishes to administer such therapy, parental permission would almost certainly be sought. Investigational therapies that involve risk (and most do, at least to the same degree that comparable standard treatment does) are reserved for the treatment of serious illness.

It is most unlikely that a physician would be caring for an adolescent ill with the sort of serious condition on which this type of research is done without involvement of parents. It is most unlikely that an IRB would approve this even if the investigator wished to deal with the adolescent patient alone.

Research in schools involving "normal educational practices" is usually exempt from requirements of either IRB review or parental permission. This type of research might, for example, compare two methods of teaching multiplication and has been held to carry no risk of harm. Before passage of the Family Educational Rights and Privacy Act

(FERPA) in 1992 and the Protection of of Pupil Rights Amendment (PPRA) of 2002, school-based surveys of children or psychological research involving children were also considered to be of no risk as long as the children were not individually identifiable. Under the 2002 Protection of Pupil Rights Amendment; however, parents may inspect instructional materials to be used in any surveys or evaluations sponsored or funded by the U.S. Department of Education. Schools also are required to adopt policies in conjunction with parents about surveys sponsored by other entities. Under the amendment and regulations to carry it out (as published by the Department of Education), written parental consent is now mandatory before minor students are required to participate in any federally supported in-class survey that would reveal information concerning:

1. political affiliation;
2. mental and psychological problems potentially embarrassing to the student or the student's family;
3. sex behavior and attitudes;
4. illegal, antisocial, self-incriminating, and demeaning behavior;
5. critical appraisals of other individuals with whom respondents have close family relationships;
6. legally recognized privileged or analogous relationships such as those of lawyers, physicians, and ministers; or
7. income.

If a student may refuse to participate, parental consent is apparently not required. If any research is funded by or is to be submitted to any agency of the federal government or if the institution in which the research is being conducted has agreed to evaluate all research (regardless of funding source) by federal standards, the participants must be advised that they may refuse to participate without penalty or loss of benefits.

Although the National Commission's recommendations included a provision that even small children should have the right to refuse to participate in any studies from which they will not derive benefit, the final regulations on research on children did not include this provision. By the time adolescents can make a decision to participate in research, they can certainly can make a decision to refuse.

ANGELA RODDEY HOLDER (1995)
REVISED BY AUTHOR

SEE ALSO: *Abortion: Contemporary Ethical and Legal Aspects; Autonomy; Care; Children; Coercion; Competence; Confidentiality; Family and Family Medicine; Infanticide; Informed Consent; Paternalism; Pediatrics, Overview of Ethical Issues in; Sexual Behavior, Social Control of; Students as Research Subjects*

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PEDIATRICS, INTENSIVE CARE IN

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While sickness and death are an inevitable part of the human condition, they are never expected in childhood. Even though the number of pediatric intensive care unit (ICU) beds is only a small fraction of the number of adult ICU beds, the practice of pediatric intensive care medicine raises a disproportionate number of complex and unresolved ethical issues, including those related to decision making for critically ill children as well as issues related to end-of-life care in this setting.

Informed Consent

Children in the intensive care unit often have diminished capacity to participate in decision making, either on the basis of their age, their illness, or a combination of both. Although these children are noncompetent in terms of their capacity to give informed consent, they differ from noncompetent adults in several important ways. For example, most of the important legal cases involving noncompetent adults have concerned patients who were never expected to regain competency, that is, adults with chronic and usually progressive medical problems. Children are different, because in most cases their competency and decision making-capacity is expected to recover and grow. Therefore, with adults the emphasis is on respecting their *former* autonomy; with children the challenge is to faithfully preserve options for their *future* autonomy.

CHILDREN NOT ABLE TO PARTICIPATE IN DECISION MAKING. Children in the intensive care unit are often very ill, and many require high levels of analgesia and sedation to tolerate life-sustaining treatments such as mechanical ventilation. In addition, from the newborn period through early childhood, even healthy children are not able to participate in decisions about their medical care. For all these patients, parents are generally viewed as their surrogate decision makers. Up until the nineteenth century or so, children were seen essentially as the "property" of their parents, and parents were seen as having a "right" to make these medical decisions. Although this is no longer the case, the presumption in favor of parental decision making is based upon several persuasive considerations:

1. Parents have strong emotional bonds to their children and are powerfully motivated to make decisions that are in the best interests of their children;
2. An assumption is made that children will grow up to espouse many of the same values as their parents, therefore parental decisions are more likely to resemble the kinds of decisions that children will make when they become competent;
3. Parents will usually have to shoulder and live with the consequences of the decisions that are made on behalf of their children (including financial obligations), so they should have some say in making those decisions; and
4. Parents are held responsible for most of the nonmedical decisions that need to be made on behalf of the child (housing, food, schooling, etc.), so they should have responsibility for the medical decisions as well.

An interesting and largely unresolved question is how to balance the interests of the child against the interests of the family as a whole when these are in conflict. Consider, for example, a child who has sustained severe brain injury following an accident, and the family is given the option of either withdrawing life support and allowing the child to die or continuing with treatment that will likely lead to survival of the child with severe disabilities. Is it legitimate for the parents to factor the interests of the family as a whole into their decision, and to consider the impact (psychological, financial, spiritual, etc.) that raising a severely disabled child will have on other members of the family? The traditional view has been that only the best interests of the child should be considered. Yet families with children are profoundly interdependent, and parents often have responsibility for fairly balancing the interests of one family member against another, such as in the way that financial resources are distributed for various needs, projects, and interests. Because parents are rarely required to fully account for the reasons behind their decisions about life-sustaining treatments, it is likely that these potential conflicts are operative but remain unarticulated and unexplored in many of these situations.

CHILDREN ABLE TO "ASSENT" TO MEDICAL TREATMENT. The concept of "assent" to treatment for pediatric patients was first proposed by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in the 1970s. Based upon knowledge of normal childhood development, this commission proposed that children between the ages of seven and fourteen should be asked for their assent to medical treatment. Above the age of fourteen, they suggested, children should generally be presumed to have full decision-making capacity. In an article published in 1998 in the *American Journal of Law and Medicine,* Leonard H. Glantz observed that this "rule of sevens" has also appeared in legal decisions, with the view that below the age of seven a child is irrebuttably decisionally incapacitated, from seven to fourteen years there is a rebuttable presumption of decisional incapacity, and for those between fourteen years and the age of majority there is a rebuttable presumption of decisional capacity.

The American Academy of Pediatrics (AAP) extended this concept in 1995, claiming that the entire "doctrine of 'informed consent' has only limited *direct* application in pediatrics. Only **patients** who have appropriate decisional capacity and legal empowerment can give their **informed consent** to medical care. In all other situations, parents or their surrogates provide **informed permission** for diagnosis and treatment of children with the **assent** of the child whenever appropriate" (bold and italics in original) (Kohrman et al., p. 314).

In its definition of the term, the AAP said that "assent" should include at least the following elements:

1. Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition;

> 2. Telling the patient what he or she can expect with tests and treatment(s);
> 3. Making a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy);
> 4. Soliciting an expression of the patient's willingness to accept the proposed care. (Kohrman et al., p. 315)

Regarding this final point, the AAP added: "no one should solicit a patient's views without intending to weigh them seriously. In situations in which the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived" (Kohrman et al., p. 316).

"EMANCIPATED" AND "MATURE" MINORS. Two legal categories that give special status to patients under the age of majority also need to be mentioned (Holder). Emancipated minors fall into a legal category that grants certain individuals under the age of majority all of the rights of an adult to consent to medical care. State laws vary, but most states specify by statute the conditions under which a minor is considered emancipated. Generally, minors are emancipated when they are married, are parents, or are on active duty in the armed forces. In some jurisdictions minors are emancipated when they are above a certain age (e.g., sixteen years), are not financially supported by their parents, and are either not subject to parental control or their parents have consented to their emancipation (note that runaways would therefore not generally be considered emancipated).

Many states have either statutory or case law for the treatment of "mature minors." Mature minors are not emancipated, but they may nevertheless have the legal power to consent to some forms of medical treatment. Although the mature minor concept provides legal protection to physicians who treat adolescents, the patient's parents are not financially responsible for treatment rendered without their consent.

Conflicts among Clinicians, Patients, and Patients' Parents

Just as adolescents may have the capacity to participate in their decision making, they are also well known to have the capacity for (what most adults regard as) irrational behavior. Billy Best, for example, was a sixteen-year-old patient diagnosed with Hodgkin's disease in 1994. He and his parents were told he had an 80 to 90 percent chance of cure with chemotherapy and low-dose radiation. Although he reportedly had only "minor" side effects from the chemotherapy (including hair loss, nausea, and fatigue), after several months he refused treatment and ran away from home. This situation was resolved only when his clinical team chose to honor his refusal of treatment while still monitoring him for evidence of cancer.

Clinicians and parents have not always refrained from imposing standard treatment, however. In New York in 1991, for example, a fifteen-year-old was diagnosed with an anterior mediastinal tumor. The patient's father had died of carcinoma of the lung four months earlier. Based largely upon his phobia of needles, the patient refused to undergo diagnostic surgery. His mother asked the court for an order directing the child to submit to surgery. The court found that surgery was urgently required and ordered the sheriff's department to take him to the hospital, restrain him if necessary, and supervise him while he was in the hospital.

These two cases illustrate the kinds of problems that arise in the gray area of late adolescence, when patients do not yet have the nearly unqualified rights of adults to refuse medical therapy, yet parents no longer have the authority to mandate their children's treatment. The best recommendation that can be made is for clinicians to attempt to persuade adolescents regarding the optimal approach to their care. When these recommendations are refused, however, clinicians must decide whether this refusal is reasonable, all things considered, or whether it is in the patient's best interest to seek a court order imposing the standard therapy. When in doubt, the bias should be toward potentially life-prolonging treatment, because this is the path that is least likely to foreclose options for the patient as she matures into a fully functioning autonomous adult.

End-of-Life Care

Just as pediatric intensivists need to have coherent strategies and plans for managing patients with clinical syndromes such as acute respiratory or renal failure, so they need to have a systematic approach to caring for children who are dying. The most important components of this approach relate to the "mechanics" of withdrawing life support and to the provision of sedation and analgesia.

WITHDRAWAL OF LIFE-SUSTAINING TREATMENTS. Although pediatric ICUs have a much lower mortality rate than most adult ICUs, they are similar in that an increasing proportion of deaths follow the withdrawal of life-sustaining treatment. One survey of adult ICUs found that 90 percent of the deaths followed a decision to limit therapy (Prendergast and Luce). Similarly, a study of more than 100 consecutive deaths in three Boston pediatric ICUs found that about two-thirds of the deaths followed the withdrawal of life-sustaining treatment (Burns et al.). In the Boston study, the treatment withdrawn in all cases was mechanical ventilation, reflecting that the cause of death in children in the ICU is very often related to respiratory failure, in contrast to adults where the proximate causes of death are more diverse.

SEDATION AND ANALGESIA AT THE END OF LIFE. Current ethical and legal guidelines place importance upon the intentions of clinicians in administering analgesics and sedatives at the end of life. Specifically, clinicians should administer doses that are intended to relieve pain and suffering but that are not intended to directly cause death. Because intentions are essentially subjective and private, the only ways to infer the nature of an individual's intentions are by self-report and by an analysis of his or her actions. Accordingly, documentation of one's intentions in the patient's chart is an important part of providing end-of-life care. For example, when a clinician administers morphine in small doses every ten or twenty minutes, it is plausible to conclude that the clinician intends to make the patient comfortable and not to directly cause the patient's death. On the other hand, when a clinician administers a large dose of morphine to a patient who is not profoundly tolerant, it is difficult not to conclude that the clinician did in fact intend the death of the patient (Truog et al., 2001).

Although ethical and legal guidelines require that sedatives and analgesics be administered in doses based on the patient's comfort, they provide little advice about what to do when the clinician and the family disagree about whether or not the patient is comfortable. Consider a patient who is near death and having "agonal" respirations. The family may find these very distressing, despite reassurances from the clinicians that the patient is unconscious and not experiencing any pain or suffering. Should the physician administer additional opioid to the patient, with the intention of making the patient appear more peaceful for the benefit of the family? Although controversial, many pediatric intensivists would do so, on the ethical grounds that doing so may be of great benefit to the family members in terms of how they remember the child's death, while the potential for this action to harm the patient is small.

TERMINAL EXTUBATION VERSUS TERMINAL WEAN. A systematic approach to ventilator withdrawal at the end of life was first proposed in the early 1980s, with this approach involving a gradual reduction in the ventilator settings over several hours. Since then, there has been an ongoing debate regarding the best method of withdrawing mechanical ventilation.

One recommended approach, commonly referred to as "terminal extubation," involves the removal of the endotracheal tube, usually following the intravenous administration of sedatives and/or analgesics. The second technique, known as a "terminal wean," is performed by gradually reducing the amount of supplemental oxygen the patient is receiving and/or the rate at which the ventilator is providing breaths to the patient, leading to the progressive development of hypoxemia and hypercarbia. In the latter technique there is considerable variability in the pace of the process, with some completing the wean over several minutes and others stretching it over several days (Truog et al., 2001).

The preferred approach varies widely. A 1992 survey of critical-care physicians found that 33 percent preferred terminal weaning, 13 percent preferred extubation, and the remainder used both. These preferences were correlated with specialty: surgeons and anesthesiologists were more likely to use terminal weaning, whereas internists and pediatricians were more likely to use extubation (Faber-Langendoen).

The principle advantage of the terminal wean is that patients do not develop any signs of upper airway obstruction during the withdrawal of ventilation. They therefore do not develop distress from either stridor or oral secretions, and if the wean is performed slowly with the administration of sedatives and analgesics, they do not develop symptoms of acute air hunger. These advantages not only promote the comfort of the patient but also reduce the anxiety of the family and caregivers.

Another cited advantage of terminal weans is that they are perceived to diminish the moral burden of the family and caregivers, presumably because the terminal wean is perceived as being less "active" than terminal extubation. Whether this is an advantage or disadvantage remains controversial. There is a risk that terminal weans—particularly those in which the wean is prolonged over several days—may be perceived by families as bona fide attempts to have the patient successfully survive separation from the ventilator, even when this is not the expectation or intent of the clinicians. Terminal weans therefore should not be adopted as a means of avoiding difficult conversations with families about the patient's condition and prognosis.

In contrast to terminal weans, the principle advantages of terminal extubations are that they do not prolong the dying process and that they allow the patient to be free of an "unnatural" endotracheal tube. The process of terminal extubation also is morally transparent; the intentions of the clinicians are clear, and the process cannot be confused with a therapeutic wean.

Despite the tendency for clinicians to use only one of these approaches based upon their specialty training, the relative advantages and disadvantages of each suggest that both approaches have a role in end-of-life care, and that the technique used should be tailored to the needs of the patient, rather than just the preferences of the clinician.

PARALYTIC AGENTS. Neuromuscular blocking agents (NMBAs) are required occasionally for the management of critically ill patients, primarily to facilitate the use of nonphysiologic ventilatory modes such as high-frequency oscillation. When a decision is made to withdraw ventilator support from a patient who is paralyzed by these agents, there is a question as to whether the effects of the medication need to be reversed or allowed to wear off before the ventilator is withdrawn.

Neuromuscular blocking agents possess no sedative or analgesic activity and can provide no comfort to the patient when they are administered at the time of withdrawal of life support. Clinicians cannot plausibly maintain that their intention in administering these agents in these circumstances is to benefit the patient. Indeed, unless the patient is also treated with adequate sedation and analgesia, the NMBAs may mask the signs of acute air hunger associated with ventilator withdrawal, leaving the patient to endure the agony of suffocation in silence and isolation. While it is true that families may be distressed while observing a dying family member, the best way to relieve their suffering is by reassuring them of the patient's comfort through the use of adequate sedation and analgesia, rather than by simply paralyzing the patient (Truog et al., 2000).

PRACTICING PROCEDURES ON THE NEWLY DECEASED. Practicing procedures on newly deceased patients has been a source of controversy between physicians and society dating back at least to the Middle Ages. This is an especially relevant issue for pediatric critical-care medicine, where practitioners have an important obligation to practice and teach resuscitation procedures.

Some have argued that it is ethically justifiable to perform practice procedures on the newly dead without permission from the family because these procedures cannot harm the deceased, because there is a substantial societal benefit to be gained, and because families could not realistically be expected to discuss consent at such a difficult time (Orlowski, Kanoti, and Mehlman). Moreover, a study showed that 39 percent of training programs in emergency and critical-care medicine use newly dead patients to teach various resuscitation procedures (for example, endotracheal intubation, central line placement, and pericardiocentesis). Few of these programs obtain either verbal or written consent from the families (Burns, Reardon, and Truog).

Despite the frequency of this practice without consent, some have argued that teaching procedures on newly deceased patients is ethical only when permission is first obtained from the family. Unquestionably, newly dead patients offer opportunities to practice resuscitation techniques that are difficult or impossible to learn in other ways without exposing living patients to additional risk. While seeking permission from family members to practice resuscitation procedures may generate additional stress at a time when the clinicians are most concerned with reducing it, they argue that this does not justify practicing without consent (Burns, Reardon, and Truog).

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SEE ALSO: *Adolescents; Autonomy; Beneficence; Children; Competence; Grief and Bereavement; Infants; Information Disclosure; Informed Consent; Life, Quality of; Life Sustaining Treatment and Euthanasia; Moral Status; Palliative Care and Hospice; Surrogate Decision Making*

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PEDIATRICS, OVERVIEW OF ETHICAL ISSUES IN

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Pediatric ethics is a branch of bioethics that analyzes moral aspects of decisions made relating to the healthcare of children. Several matters distinguish pediatric from adult ethics, including issues of consent, confidentiality, genetic testing, end-of-life care, and justice.

Consent: Making Medical Decisions for Children

Decision making for children is a unique and challenging process. Adults generally make their own medical decisions through the process of informed consent, in which a competent adult capable of sufficient understanding is given adequate, clear information about the proposed intervention and granted the autonomy to make choices. Most children have not reached the developmental stage at which they can ethically or legally give informed consent. To further complicate matters, many parties may be involved in the decision-making process, including the patient, parents, family members, nurses, doctors, social workers, clergy, and the courts.

Beneficence is the foundation of decision making for children. This principle encourages identification of the child’s best interest through a shared decision-making process involving the clinician, patient, and parents. Each member of this triad brings information that helps identify the child’s best interest. The clinician provides a thorough understanding of the available medical evidence regarding the condition along with a repertoire of clinical knowledge and experience. The parents bring their intimate familiarity with the child and the family. As the child’s primary caregivers, parents give informed consent by proxy (otherwise known as “informed permission”) because they are usually best able to determine the child’s best interest. Physicians have the responsibility to ensure that parental motivations are based on the child’s needs rather than the parents’ wishes. All of the tenets of informed consent apply to informed permission; however, the adult parents are the ones who ultimately make the decision instead of the child patient.

Children gradually develop the ability to understand a diagnosis and treatment plan as they approach adulthood. Hence, the older child’s opinions deserve serious consideration and can be quite enlightening in the effort to identify the child’s best interest. Although these older children may be legally unable to give informed consent, they may still express assent, which empowers them to the extent of their developmental abilities. Thus, the ideal decision-making scenario is a shared process: The physician provides information and recommendations, the parents give informed permission, and the patient gives assent to interventions in her best interest.

Confidentiality: Adolescent Issues

As part of the process of individuation, adolescents desire more privacy in their personal lives. At the same time, they are encountering increasingly complex and dangerous health issues. Not infrequently, issues of confidentiality arise within the physician/patient/parent triad, and management can be quite delicate in terms of the limits of confidentiality and the circumstances under which disclosure must occur. Although the specifics vary from state to state, the legal community gives adolescents who demonstrate some degree of maturity the discretion to make healthcare decisions for themselves and without the involvement of their parents regarding issues such as substance abuse, sexually transmitted diseases, pregnancy, contraception, and mental health. Variously known as emancipated minors, mature minors, or medically emancipated minors, some subgroups of adolescents are considered capable of providing informed consent for all forms of care by virtue of their life experiences, which may include financial independence, pregnancy, homelessness, or marriage. Because statutes governing adolescents vary, physicians should become familiar with the laws in their communities. In all cases, the primary duty of the physician is to optimize the adolescent's care by advocating for his best interest.

LIMITS OF CONFIDENTIALITY. All clinical interactions are by nature confidential. Because the adolescent is the patient, in most instances he or she must give permission to share information with parents or others. At the outset, the physician should establish an independent relationship with the adolescent, explaining to the patient and the parents both the breadth and the limits of confidentiality. In the event that the life of the patient or anyone else is in peril or the patient is being abused, the physician is mandated both ethically and legally to disclose this information to appropriate authorities. A critical role of the physician is to facilitate communication between the adolescent patient and the parents. Under most circumstances, the adolescent should be encouraged to involve the parents in her healthcare because they can ideally provide support on a continual basis. Conversely, the physician should also encourage the parents to embrace the adolescent's emerging sense of independence. Confidentiality in the physician–adolescent patient relationship must be a priority in the physician's effort to be a confidant and caregiver and to ultimately act in the patient's best interest.

Genetic Testing in Children

Genetic testing in children is generally more complex than other pediatric testing because the results have implications for other family members as well. Patients with certain genetic diagnoses, and their families, may suffer financial, psychological, or interpersonal prejudices that are not easily foreseeable. In spite of the awesome wealth of information the human genome can supply, both nature and nurture influence the health outcomes of any given person; and this form of testing runs the risk of assuming genetic determinism—exaggerating the genetic influences while devaluing the environmental ones. Deciding when to undertake a genetic evaluation in pediatrics can be a challenge. As with other medical decisions for children, physicians should use beneficence as their guide.

NEWBORN GENETIC SCREENING. Every state requires that newborns undergo screening to detect a number of metabolic and inherited conditions that can threaten the health of the child. The screening procedure reflects society's obligation to optimize health by detecting and treating particular infant or early childhood conditions. Theoretically, screening tests are carefully chosen to satisfy a number of criteria. Tests must be sensitive enough to identify cases among masses of screened newborns, specific enough to avoid the anxiety that comes from a multitude of falsely positive tests, and widely available. In addition, effective preventive or treatment interventions must be available that significantly alter the morbidity and mortality of the condition. Perhaps the most important criterion is that the test must provide a clear benefit for the child.

SCREENING CHILDREN FOR GENETIC DISEASES OF ADULTHOOD. Huntington's disease, breast cancer, and polycystic kidney disease are just a few of the exploding number of adult diseases for which genetic tests are available and can be performed in childhood or even in utero. Theoretically, identifying a predilection to such disease may lead to preemptive intervention to decrease the morbidity and mortality of the disease; but this supposition has not been confirmed in practice. Physicians faced with requests for this type of pediatric testing must proceed with great caution. The psychological and social impact of this information can be much greater than anticipated and may lead to discrimination by employers, insurers, and others. Performing these tests while remaining committed to the child's best interests can be troublesome. By definition, these tests detect diseases of adulthood; so if there is no intervention during childhood that can significantly alter the natural history of the disease, the testing may not be in the child's best interest. The testing may best be deferred until the child reaches adulthood and can make his own autonomous choice. Physicians faced with requests for genetic testing should keep all of these issues in mind when determining if testing is in the best interests of the child.

End-of-Life Issues

Caring for dying children is one of the most challenging responsibilities in pediatrics. The emotions engendered by anticipation of a child's death have a powerful impact on families and caregivers and may sometimes be an obstacle to the appropriate care of the child. Again, beneficence must guide any decisions at the end of life. Through a shared decision-making process, the clinician should obtain informed permission from the parents as well as patient assent, when possible, to optimize these interests. Careful, continual evaluation is critical so that when the burdens of treatment outweigh the benefits, the treatment plan can be appropriately modified.

WITHHOLDING AND WITHDRAWING SUPPORT. Clinicians and families often struggle at the point when they realize that neither the current interventions nor additional ones will alter the child's progression toward death. The inevitability of death then challenges the family and the healthcare team to change the goals from cure to palliation. Parents often fear that they would be taking an active role in hastening death by withholding or withdrawing support. Physicians must be prepared to help the family understand that palliation is not equivalent to giving up but instead part of the continuum of respect and consideration for the child. Parents and clinicians may feel that withholding support is somehow preferable to withdrawing support already in place. This distinction between not initiating an intervention and removal of an intervention is not ethically meaningful. Viewed in light of the changing goals of treatment and the child's best interest, either can be ethically sound.

Justice: The Example of Childhood Immunizations

The issue of immunizing infants and children highlights the role of justice in pediatric ethics. Parents frequently question the need for the immunizations recommended for their children. To address their concerns, the physician must know the risks and benefits of immunizations in order to identify the best interest of the child. Immunizations are generally intramuscular, painful injections; and the current immunization schedule recommends that the patient receive as many as four or five injections during one visit. Each vaccination has established side effects, and parents need to be aware of these. The list of available immunizations continues to change and grow and so do recent claims about vague associations between these vaccinations and diseases of unclear origin. Such claims have not been substantiated by careful medical research, yet the theories are still widely publicized and accessible.

Parents may be hesitant to immunize their children against diseases such as diphtheria and polio when the child's risk of contracting the disease is exceedingly low in the United States. Because of vaccine effectiveness, these diseases are currently uncommon. In past decades, however, these diseases affected thousands of American children and still overwhelm many in underprivileged societies. Countries such as Russia, whose established immunization programs have been compromised by political strife, are now experiencing epidemics of diseases that were previously under control. These events reinforce the idea that widespread vaccination confers immunity to the population as a whole and is likely the reason for the low prevalence of these devastating diseases in the United States. Nonetheless, humans live in a world community. Travel around the world is fairly easy, and transient and immigrant populations with different histories of disease exposure live throughout the United States.

Still, parents may argue that in a society with relatively low disease prevalence, their child should not be subjected to the pain, side effects, and inconvenience of immunization in order to protect the society at large; therefore, immunization is not in the child's best interest. Yet the American medical community continues to recommend routine vaccine administration. The ethical justification for this position requires a more comprehensive view of a child's best interest and includes consideration of the principle of justice. Just as there are limits to confidentiality, there are limits to pursuing the individual child's best interests. In the case of immunizations, justice imposes such a limitation. Broadly speaking, the principle of justice suggests that all members of a society must bear both the burdens and the benefits of coexistence. By not immunizing their children, parents may put their own children at only a small individual risk. But if the numbers of unimmunized American children grow, the entire population is at increased risk. Justice challenges the absolute sovereignty of the beneficence paradigm by suggesting that the child's best interest may be balanced by the needs of society, particularly when a particular action, or in this case inaction, puts the society in peril. In the case of immunizations, the child has the potential to benefit directly and also contributes to a safer society. These benefits outweigh the individual risk to the child. Optimal care for children goes beyond addressing the needs and interests of individual patients.

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SEE ALSO: *Autonomy; Beneficence; Care; Children; Competence; Confidentiality; Family and Family Medicine; Infants; Informed Consent; Research Policy: Risk and Vulnerable Groups; Surrogate Decision Making*

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PEDIATRICS, PUBLIC HEALTH ISSUES IN

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Public health and medicine represent separate and complementary approaches to the protection of health. While medicine focuses primarily on the health of individuals, public health concentrates on the health of populations. Government assumes primary responsibility for public health. Laws governing the water and food supply, controls on air pollution, legislative efforts to protect children from tobacco, mandatory immunization statutes, and the treatment of persons with sexually transmitted diseases, tuberculosis, or other communicable diseases are examples of how government may regulate environmental conditions and administer interventions that positively affect the health of a population.

Nearly every public health measure has the potential to impinge upon individual freedom. Balancing individual freedoms with the protection of a population's health represents perhaps the most important ethical issue related to public health and children. Compulsory immunization statutes illustrate these tradeoffs and the ethical issues surrounding public health interventions.

Compulsory Immunization and Children

Childhood immunization programs have been identified as one of the most effective health interventions of the twentieth century. The immunization of children effectively reduces the incidence of childhood disease. Alternatively, outbreaks of disease frequently occur when immunization rates fall (Rogers, Pilgrim, Gust, et al.). Disease prevention may be accomplished directly through the protection offered to vaccinated individuals and indirectly through a phenomenon known as *herd immunity,* in which unvaccinated individuals are protected from disease because they are surrounded by vaccinated individuals who neither contract nor spread the agent in question.

Immunization differs from most medical interventions in that it is administered to healthy individuals "to prevent diseases that often do not pose an immediate threat to the individual" (Wilson and Marcuse, p. 161). For childhood immunization programs to be successful, either parents must willingly agree to have their children vaccinated or immunization must be coerced. While some parents may object to immunization on religious or philosophical grounds, others may believe that immunization poses a risk to their children that is not justified by its benefits.

The government's authority in the public health arena arises primarily from its constitutionally sanctioned "police power" to protect the public's health, welfare, and safety (Dover). What is the ethical basis for the exercise of these police powers? In *On Liberty,* John Stuart Mill argued that "The only purpose for which power can rightfully be exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant" (p. 13).

Mill's justification for interfering with the freedom of an individual has become known as the "harm principle." Philosopher Joel Feinberg has further refined the principle by arguing that to be justified, restriction of an individual's freedom must be effective at preventing the harm in question and no option that would be less intrusive to individual liberty would be equally effective at preventing the harm.

Public health authorities may therefore be justified in interfering with parental decisions regarding immunization in two situations. First, intervention may be justified under the *parens patriae* doctrine. Under this doctrine, states have the authority to protect and care for those who cannot care for themselves and may intervene when there is evidence that parental actions or decisions are likely to harm a child. Second, intervention may be justified as an exercise of government's police powers when immunization is necessary to protect the health of the population.

Parental Refusals and the Best Interests of Children

Parents who refuse immunization on behalf of their children may have valid and important reasons for doing so. While most mandatory vaccines are effective and safe, a small possibility of adverse reactions exists. A parent might reasonably conclude that refusing the pertussis vaccine is in the best interests of a child living in a community with a high immunization rate. In such a community, the prevalence of pertussis is sufficiently low that an unimmunized child would be unlikely to contract pertussis and, therefore, could be safely spared any possible risks associated with the vaccine. In fact, it has been argued that "any successful immunization program will inevitably create a situation, as the disease becomes rare, where the individual parent's choice is at odds with society's needs" (Anderson and May, p. 415).

The *parens patriae* doctrine recognizes that society has an obligation to ensure that the basic needs of its most vulnerable members are met. In general, parental decisions should be accepted unless they clearly fall outside the range of what would be a reasonable decision concerning the child's best interest. In those rare cases where the decision of a parent places the child at substantial risk of serious harm, state agencies may be obligated to intervene and provide the necessary immunization over the parents' objections. For example, where a child has sustained a deep and contaminated puncture wound, the state might justifiably override a parent's refusal of tetanus immunization.

In these cases, the state acts in loco parentis, in the place of the parents. While this role of the state has been recognized as constitutionally valid in the United States, courts have closely examined such actions, showing reluctance to require medical treatment over the objection of parents "except where immediate action is necessary or where the potential for harm is rather serious" (Wing, p. 32). With the exception of an epidemic, the *parens patriae* doctrine rarely provides sufficient justification for interference with parental decisions regarding immunization with most vaccines.

Community Interests and Public Health

The harm principle justifies an exercise of the state's police powers when an individual's action puts others at risk of harm. Parents who choose not to immunize their children increase the potential for harm to other persons in three important ways (Veatch). First, immunized individuals are harmed by the cost of medical care for those who choose not to immunize their children and whose children then contract preventable disease. Second, should an unimmunized child contract disease, they pose a potential threat to other unimmunized children. Finally, even in a fully immunized population, a small percentage of vaccinated individuals will remain susceptible to disease. These individuals derive important benefit from herd immunity and may be harmed by contracting disease from those who remain unvaccinated.

A parent's refusal to vaccinate a child also raises an important question of justice referred to as the problem of "free riders" (Veatch; Rogers et al.). When immunization rates are high and disease rates low, the risks of immunization may exceed or equal the risks of contracting disease. Some parents may rationally decide not to immunize their children, taking advantage of the benefit created by the participation of others in the immunization program. These individuals act unfairly to others in the community, reaping the benefits of an immunization program without sharing any of the risks.

Compulsory immunization laws in the United States have repeatedly been upheld as a reasonable exercise of the state's police power even in the absence of an epidemic, and even where these laws conflict with the religious beliefs of individuals (Dover).

When others are placed at substantial risk of serious harm, an individual's range of choices may be restricted. However, serious harm can be averted in most situations without compulsory immunization. Under the harm principle, compulsory immunization is clearly justifiable when widespread use of an effective vaccine could limit an epidemic. In all likelihood, however, compulsory immunization would be unnecessary under such conditions since it would clearly be in the self-interest of individuals to receive the vaccine both for themselves and their children. A noncompulsory immunization program would probably bring about a result similar to a compulsory program without infringing on liberties. Indeed, immunization rates in several countries without compulsory immunization laws suggest that self-interest in combination with effective education and public relations campaigns may be sufficient to achieve protection of most individuals within a population (Noah). On the other hand, in a highly immunized population, the risk posed by a small number of unimmunized children is not significant enough to justify state action (Ross and Aspinwall).

Justice and Public Health Interventions

Most vaccines carry a small but measurable risk. At a population level, the risk of currently accepted vaccines is almost always justified by the benefit of widespread immunization to the population. With the polio vaccine, for example, one person will suffer vaccine-induced paralytic disease per million people vaccinated, as opposed to some 5,000 people developing paralytic disease per million unvaccinated people. Yet there remains the problem that an occasional individual will bear significant burden for the benefit that is provided to the rest of the population by an immunization program.

Given the unequal sharing of the burdens associated with vaccine programs, it seems fair and reasonable that those who are protected by the immunization program be asked to bear some of the burden of those few who are injured by the program (Gelfand; Anderson and May; Rogers et al.). A tax-based system of compensation for vaccine-related injuries and expenses can easily be justified.

A similar argument can be made concerning the costs of the vaccine program itself. Since all individuals in the community, even those refusing to participate through immunization, benefit from the immunization program, the costs of the immunization program should be born by the public. The full series of childhood immunizations costs more than $500 and is not always covered by insurance. Charging individuals the cost of vaccines has a negative effect on immunization rates by offering a financial disincentive to vaccinate. At the same time, it allows "free riders" to avoid the financial costs of a program that benefits them. For those reasons, a strong argument can be made to fund immunization programs for all citizens through a tax-based system into which all citizens contribute (Diekema and Marcuse).

Public health interventions benefit all citizens. The harm principle justifies restrictions on individual liberty when individual decisions or actions put others at risk, when harm can be prevented by restricting individual liberty, and when no less restrictive alternative would be equally effective at preventing the harm. Justice requires that the burdens and benefits of public health intervention be shared equally across the population.

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SEE ALSO: *Abuse, Interpersonal; Autonomy; Beneficence; Blood Transfusion; Children; Healthcare Resources, Allocation of; Health Screening and Testing in the Public Health Context; Infants; Informed Consent*

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PHARMACEUTICAL INDUSTRY

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In the public media and in discussions of healthcare ethics significant questions have been raised about some of the practices of the pharmaceutical industry in the early years of the twenty-first century. The increase in expenditures for medications in the United States appears to be one of the reasons for this attention. The expansion of direct-to-consumer advertising of prescription drugs, particularly on television, and the manner in which industry sales representatives relate to physicians are among the other factors that have focused attention on the industry.

Pharmaceutical companies are in the healthcare business. It therefore is not surprising that much of the interest in the ethics of the industry relates to the potential impact of company practices on the quality and cost of healthcare, access to healthcare, and the integrity of healthcare professionals. This entry discusses some of the major and recurring issues in studies of and commentaries on ethics and the pharmaceutical industry.

Relationships between Industry Representatives and Healthcare Professionals

Representatives of the pharmaceutical industry relate to healthcare professionals in a variety of ways, including personal visits with physicians, exhibits at professional meetings, industry-sponsored education on products, financial support for nonindustry educational programs, and employment of professionals as consultants. The general ethical concerns related to these relationships are whether the interactions are in the best interests of patients and the way the relationships should be managed or structured to prevent a negative impact on healthcare.

It has long been recognized in business ethics that when gifts are given by vendors or suppliers to purchasers, there is a serious risk of undermining the objectivity of the purchasers. Most corporate codes of ethics limit the kinds of gifts that may be offered and accepted to those of minimal or nominal value. Although physicians may not be purchasers as that term sometimes is understood, their decisions are directly related to the purchase of pharmaceutical products. As could be expected, therefore, the issue of gift giving has received particular attention in the context of efforts to prevent or limit inappropriate industry influence on healthcare professionals.

Studies consistently report that the acceptance of gifts or samples from pharmaceutical representatives is associated with the rapid prescription of a new drug, the prescription of fewer generic drugs, the use of more newer medications, and formulary requests for medications (Wazana). Although some healthcare professionals state that gifts and personal relationships do not influence their professional judgment about what is best for patients, research raises serious doubt about the validity of that assertion.

The responsibility to avoid practices that result in unnecessary conflicts of interest rests with both the industry and healthcare professionals. Professional healthcare providers have a responsibility to prevent other interests from compromising their ability to exercise independent objective judgment in their work, in other words, a responsibility to subordinate other interests to their commitment to provide good medical care. A pharmaceutical company, as a healthcare business, has a responsibility to interact with physicians and other healthcare professionals only in ways that do not lead to harm of patients or undermine the professionalism of medical practice.

By 2002 healthcare professionals, healthcare organizations, the pharmaceutical industry, and the federal government had begun major efforts to reform the interactions of company representatives with physicians in response to the concerns that have been identified here. Many hospitals developed policies clarifying and restricting the activities of industry representatives while on the hospital campus. The American Medical Association (AMA) undertook a major initiative to communicate its ethical guidelines on gifts to physicians, and the Ethics and Human Rights Committee of the American College of Physicians, and the American Society of Internal Medicine issued a position paper titled "Physician-Industry Relations" (Coyle). The industry trade association, the Pharmaceutical Research and Manufacturers of America (PhRMA), published its voluntary "Code on Interactions with Healthcare Professionals" (Pharmaceutical Research and Manufacturers of America). The U.S. Department of Health and Human Services (2002) drafted standards for pharmaceutical companies, the first of this kind, for marketing products to healthcare professionals.

Although there were differences among these efforts, they all were designed to limit abuses without prohibiting all interaction between the industry and healthcare professionals. There is a widespread belief that continued interactions are valuable and benefit patients, especially through the information that is provided to healthcare professionals by the industry about new products and the risks and benefits of these products. It remains to be seen whether these reforms will prevent undue industry influence on doctors' prescribing behavior.

It also remains to be seen whether a system that permits drug companies to function as a significant source of physician education despite the fact that those companies have an organizational self-interest in selling their drugs (especially their most profitable drugs) will continue to be accepted as reasonable and ethically supportable. For many observers it is irresponsible to expect unbiased information about their own products from drug companies. Although pharmaceutical companies have an interest in promoting good healthcare, their marketing practices are designed to sell their products.

Industry Sponsorship of Research

Another issue that has received significant attention in healthcare ethics is sponsorship of medical research by the pharmaceutical industry. As in the issue of the relationship between doctors and the pharmaceutical industry, the concern is whether the nature of the relationship undermines professionalism and scientific objectivity, a concern expressed most frequently about clinical trials. The way a trial is designed and/or the relationship of the clinical researcher to the sponsor may result in research that is neither good science nor in the public interest.

Much attention has been paid to financial conflicts of interest that result from the relationship of investigators to the companies that manufacture the medication and/or sponsor their research. When investigators are paid consultants to or regularly receive speaker honoraria from a company, when they have significant personal funds invested in company stock, or when the research compensation arrangement is such that they personally benefit significantly, their scientific and professional objectivity and independence may be compromised. In these situations there is an incentive to avoid reporting findings that make it less likely that the company will do well selling the product or continue to hire the investigator.

Ethical reflection on conflicts of interest has indicated that in most instances actual conflicts of interest are unrecognized and/or unintentional. That is, professionals do not choose deliberately to go against their primary responsibility. Instead, the nature of the context inclines one to other interests, often without conscious awareness. Most efforts to prevent or mitigate the potential negative effects of conflicts of interest therefore go beyond appeals to individual ethical integrity. Policies, procedures, and other safeguards have to be put in place.

One response to the growing concern about the financial interest of investigators was a decision made by several major medical journals in 2001 to revise and strengthen their policies regarding financial disclosure by authors. Authors are required to disclose the sponsorship of their studies and any relevant financial associations. Editors can use that information in making decisions about publication and to inform readers of potential bias if an article is published.

Another response to concern about conflicts of interest was a task force report approved in 2001 by the Executive Council of the Association of American Medical Colleges (AAMC). The AAMC Taskforce on Financial Conflicts of Interest in Clinical Research developed guidelines for medical school policies on financial conflicts of interest. In addition to requirements for reporting and monitoring, the task force recommended that institutional policies assume that an individual who has a significant financial interest in a study involving human subjects should not do that research. This assumption may be overcome in individual cases, but the researcher should have to persuade an institutional committee that his or her involvement is in the best interests of the subjects.

Although most of the emphasis has been on the responsibility of investigators to avoid conflicts of interest, there is a concomitant responsibility on the part of companies that sponsor research to avoid such conflicts. Companies have a responsibility to ensure that trials assessing the safety and efficacy of their medications are scientifically sound. They can do this by adopting policies and practices designed to prevent obstacles to the independence and objectivity of investigators. In addition to avoiding conflicts of interest for the investigators, companies need to avoid the other reported threats to scientific independence, such as industry control over or delay of publication of study results. The ethical burden of doing good research falls on both the sponsors and the clinical investigators.

Direct-to-Consumer Advertising of Prescription Drugs

At the beginning of the twenty-first century the only countries that permitted direct-to-consumer (DTC) advertising of prescription drugs were the United States and New Zealand. In 1997 the U.S. Food and Drug Administration (FDA) adopted more permissive rules on mass media advertising of prescription drugs, and in the following years DTC advertising increased significantly in the United States. The 1997 regulations permitted advertisements for prescription drugs without detailed medical information on risks and side effects. The question of whether such advertising is ethically and socially responsible is widely debated.

The Institute of Medicine (1998) described problems with healthcare quality as including underuse (failure to provide proven effective medicine), overuse (unnecessary interventions or treatments not indicated by symptoms), and misuse (interventions causing preventable complications). The primary criticism of DTC advertising of prescription drugs is that it may contribute to overuse or misuse because patients demand and sometimes get prescriptions for medications that are not appropriate in their circumstances. This leads to poor-quality care. The unnecessary use of brand-name drugs also leads to unjustified increases in healthcare costs with all the implications for healthcare access that follow from rises in those costs. The primary ethical argument for DTC advertising is that it improves the quality of healthcare because patients, through their informed questions about specific medications, assist physicians in avoiding underuse or misuse. In addition, some argue that it gives patients a much more active role in their healthcare.

Other concerns have been raised about the impact of DTC advertising. One is whether such advertising more commonly contributes to valuable interaction or puts an undue strain on the patient–physician relationship. There is also serious concern about whether specific advertisements educate consumers or mislead them and oversimplify. There is also the question of whether in a culture in which such advertising is common the result will be a heightened expectation that physicians can and should prescribe pills to cure all ills.

One study found that prescription drugs that were advertised heavily accounted for a significant proportion of the increase in pharmaceutical spending in the year studied. The same study found that the number of prescriptions for the most heavily advertised drugs grew at a rate several times higher than that of prescriptions for other drugs (National Institute for Health Care Management). This study did not try to determine whether the public health benefited from or was harmed by the growth in prescriptions of the heavily advertised drugs. There appears to be evidence that DTC advertising leads to increased use of the drugs advertised in most cases, but it is not clear whether that use is medically appropriate and cost-effective and how the patient–doctor relationship is affected.

The controversy about whether DTC advertising is good for public health and healthcare is related to other questions about the nature of a good healthcare system. Those who advocate a more rigorous evidence-based foundation for decisions about medical treatment are not likely to welcome the influence of popular marketing tactics and techniques or that of patients who expect to get specific brand-name medications. The same thing is true of those who are seeking the most effective allocation of limited healthcare resources. In contrast, those who believe that patients are best served by a consumer-driven model of healthcare are likely to welcome the contribution of advertising to consumer initiative in interactions with professionals.

Many healthcare professionals have not accepted the claim that DTC advertising contributes to improved patient care. Patients who demand a particular brand-name drug are not necessarily better-informed patients. Some advertising does not even indicate the condition or symptoms a medication is designed to address; little if any of it describers the success rate of a drug or the necessary duration of use. Furthermore, there is often no independent evidence that a more expensive brand-name product (the type that typically is advertised) is sufficiently superior to generic medications to justify the use of limited healthcare resources.

The basic question may be whether medicines are enough like other commodities that it is appropriate to advertise them in a similar manner. One major difference is that unlike consumer products, they have to be prescribed by a licensed professional. If the objective of DTC prescription drug advertising is a better-informed public, the informational nature of the marketing will be of central importance. If the objective is to contribute to improvement in the quality of healthcare, the advertising will be designed to prevent misuse and overuse as well as underuse.

Other Issues

Whereas the three issues discussed above have received the most attention in the literature on healthcare ethics, several other questions have been raised about the practices and standards of the pharmaceutical industry. Three additional concerns are noted below as examples of those issues.

MISUSE OF THE PATENT SYSTEM. Pharmaceutical companies have been accused of "gaming the drug patent system." (*New York Times*) The concern here is that drug companies are using questionable methods to extend the life of their most profitable patents. At least some of those methods are legal, taking advantage of existing interpretations of the law. One such method is to sue a generic company for infringing on patents for packaging or dosing schedules. Those suits automatically delay the introduction of the generic version into the marketplace for thirty months even if the suit is frivolous. Extending patent life may prove financially beneficial to the company but may be detrimental to public health by increasing healthcare costs and placing an unnecessary burden on available healthcare resources. The question is whether this is an ethically defensible practice for a health-related business even when it is legal.

PRICING. A related issue concerns pricing. The effort at the beginning of the twenty-first century to extend Medicare benefits to cover prescription drugs was driven in large part by the high cost of prescription drugs for many citizens over age sixty-five. The fact that the same drugs can be purchased in a neighboring country at a much lower price raises the question of whether the price in the United States is unnecessarily high. In addition, because the prices of pharmaceuticals are different for group purchasers from what they are in retail pharmacies, those who must purchase their prescription drugs at a local retail pharmacy pay the highest prices. This is a part of the bigger issue of equitable access to healthcare in the United States, but it also raises a serious question for the pharmaceutical industry: What constitutes fair pricing for prescription medicines?

RESEACH AND DEVELOPMENT. Pharmaceutical companies also have also been challenged in terms of their research and development agenda. There are two parts to this criticism: (1) that many of the drugs being developed are "me-too" medications, or prescription drugs that are slightly different formulations of existing drugs; and (2) that the new medications developed by the (multinational) industry are more likely to be lifestyle drugs for the wealthy world than drugs for serious diseases commonly found in poorer countries. Research programs in pharmaceutical companies on male impotence (Silverstein) and on baldness, for example, may have many more resources put into them than research programs on malaria. Because the industry both is a for-profit industry and accounts for a significant part of international efforts to meet the real healthcare needs of people, what is a responsible agenda for research and development?

Conclusion

A review of some of the ethical concerns about the pharmaceutical industry must focus on criticisms and questions related to industry practices. This focus does not deny that the industry has made significant contributions to public health through the development and marketing of important medications.

The concept of the stakeholder has come to occupy a central place in reflection on business ethics. Businesses have responsibilities to various stakeholders: all those who are affected significantly by company decisions and practices, including employees, investors, customers, suppliers, and the larger community. Although it is not always possible to satisfy the concerns and legitimate interests of all stakeholders all the time, it is not satisfactory to say that a company has only one key responsibility: to benefit the shareholders. Making the right decisions and keeping priorities straight when there have to be trade-offs in regard to different stakeholders is the hard work of business ethics.

Establishing the right priorities among stakeholder interests depends somewhat on the nature of the industry. Businesses in the healthcare industry, whether for-profit or not-for-profit, have a high-priority responsibility to protect public health and the integrity of the healthcare system. When specific practices of a health-related business appear to be placing the public health at unnecessary risk or to be undermining the public commitment to a good healthcare system, it is reasonable to question the ethical appropriateness of those practices. The variety and seriousness of the questions asked about practices of the pharmaceutical industry appear to indicate that for many people some industry practices mean unnecessarily risks for health and healthcare despite the industry's contributions to healthcare.

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SEE ALSO: *Advertising; Commercialism in Scientific Research; Corporate Compliance; Pharmaceutics, Issues in Prescribing*

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PHARMACEUTICS, ISSUES IN PRESCRIBING

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During much of the fourth quarter of the twentieth century, discussions of ethics in prescribing tended to focus on the physician–patient relationship, the quality of patient care, and on patient rights. By the turn of the century, another set of considerations began receiving consistent attention in the United States: issues raised for the prescribing clinician by some healthcare business practices. Most of the ethical issues related to prescribing decisions and behavior fit into one of these two, sometimes overlapping, categories.

Prescribing and the Clinician-Patient Relationship

In the traditional medical model of rational prescribing, the patient presents challenging symptoms that the physician investigates and then diagnoses a disease. Based on this diagnosis, the appropriate drug and/or non-drug treatment is prescribed. Emphasis is placed on accurate diagnosis and application of pharmacologic principles, which govern the use of safe and effective drugs to treat a disease (O'Hagan).

The prescribing of medication, which occurs in most physician–patient encounters, does not, however, always occur through the application of this rational model. Many prescriptions are written on the basis of careful diagnosis and assessment, but sometimes other factors are involved as well.

Patients often expect prescriptions. A friend or a family member may have experienced some benefit from a medication given for a similar symptom. Direct-to-consumer advertising has raised patient expectations, both that prescribed medications are needed and that they will be beneficial. The public is led to accept the principle that there is a pill for every ill (Morgan and Weintraub; O'Hagan). The physician is expected to "do something" for the patient. Patients may feel confident that something concrete has been offered when given a prescription. Regardless of how trivial the complaint may be, the patient's sick role is legitimated by a prescription. It validates the doctor visit and allows future visits for vague symptoms (Stimson; O'Hagan). It is quite possible, however, that physicians may be overestimating the extent to which patients actually desire medications (Frølund).

Physicians are regularly exposed to education and marketing that highlights the use of medications in patient care. Physicians frequently have little time to spend speaking with patients about non-drug regimens, which may contribute to the frequency of prescription writing. Many physicians, like many patients, expect that something will be done in a patient–doctor encounter. Prescribing is a common way for the physician to intervene. It also allays the physician concern that the patient may be unhappy if not given a prescription and go elsewhere for the medicine believed to be necessary (Schwartz, Soumerai, and Avorn).

Some have suggested that a prescription may even help the physician define the disease in situations where the diagnosis is uncertain (O'Hagan). "I prescribe an antibiotic, therefore the patient has a bacterial infection." Or "I prescribe a tranquilizer, so the symptoms must be due to anxiety." Reimbursement requirements of insurers may reinforce this attitude, since often a diagnosis is expected even if the physician is uncertain.

Clearly, it is more difficult not to prescribe than to prescribe. Medicines are generally viewed as good, and prescribing as a beneficent act. Nevertheless, there are some developments in American medicine in the beginning of the twenty-first century that place more emphasis on the risks associated with medications and on the importance of prescribing medications only when there is a good medical reason for do so. The Institute of Medicine in 1998 identified misuse (interventions causing preventable complications) and overuse (unnecessary interventions or treatment for clearly inappropriate indications) as healthcare quality problems, in addition to under-use (failure to provide proven effective interventions). The movement toward "evidence-based" healthcare, which stresses the importance of having a foundation in medical experience and research for interventions, discourages treatment that cannot be supported scientifically. The growing recognition of the risks of "polypharmacy" means that more emphasis is being placed on the harm done by multiple medications and their interactions (Colley and Lucas).

These and related developments have supported the efforts of some physicians (and others in healthcare) to highlight the ethical importance of avoiding unnecessary prescribing.

Placebos

The question of whether, or when, the prescribing of placebos is ethically acceptable has received considerable attention at least since the 1970s. Placebos can relieve symptoms and they are one way that physicians can please patients who expect a medication without prescribing unnecessary drugs. The use of placebos might appear, therefore, to benefit patients without much risk of harm (Schwartz et al.). The major objection to the use of placebos is based on the conviction that, however well they might work, prescribing placebos is a deception of patients and is a basic violation of their right to be informed about the diagnosis and the treatment (Bok). Long-term placebo treatment might divert attention from the cause of a patient's complaints, possibly resulting in a serious medical problem going unrecognized and untreated. In addition, the patient may lose trust in the physician upon recognizing the deception (Schwartz et al.).

The use of placebos received renewed attention near the end of the twentieth century in the United States with the movement to improve the management of patient pain. The use of placebos in response to patient request for pain relief became a focus of special concern. For many, prescribing placebos for pain relief is, in effect, a refusal to accept the patient's own perception of pain and was incompatible with a pain management program based on taking patient reports of pain seriously. Some hospitals developed policies prohibiting the use of placebos for symptoms of pain or for all treatment purposes, permitting placebos only as part of a clinical study approved by an institutional review board (IRB).

Healthcare Business Practices and the Writing of Prescriptions

As discussed above, some of the enduring concerns about ethics in prescribing focus on the quality of patient care and on the nature of the clinician–patient relationship. A commitment to professional competence and to professional integrity requires that these concerns continue to receive careful attention. In recent years, however, there has been a growing concern about another aspect of ethics in prescribing: the potential impact of different healthcare business practices on prescribing decisions and behavior. The practices of pharmaceutical companies and of health insurance plans are of particular interest in this regard.

Pharmaceutical companies invest heavily in marketing and most heavily of all in marketing to physicians (Johnson; Relman and Angell). Drug company representatives visit physician offices regularly and frequently, bringing information on their company's products, free samples, and gifts for the physician and staff. The sales representatives often have information on the physician's individual prescribing habits and are prepared to influence specific prescribing decisions (Kowalczyk).

As studies have demonstrated, physician prescribing is often affected by interactions with drug company representatives (Wazana). Drug companies market their products to provide patients with good and needed medicines, but they are also highly focused on profit and on market share. Physicians acquire some useful and important information from sales representatives, but they are at some risk of compromising their professional judgment by participating in these interactions. To protect the quality of healthcare, it is important to minimize the influence of (potentially) biased information and the influence of the personal interactions with sales representatives.

Influences can be present even when they are not recognized, when the individual is not aware of what is affecting a particular decision or action. Some physicians have decided that the best way of interacting with drug company representatives is not to see them at all (Griffith). While much of the concern about physician relationships with drug companies has been focused on the acceptance of gifts (American Medical Association; Coyle), the issue is more extensive than that. Marketing and objective education simply may be two quite different things.

The acceptance of free samples of medicines is also being questioned by some bioethicists. These medications are often used for patients with limited resources or to test whether a particular medication is effective for a specific patient. Once started, however, a medication is often difficult to change, even when it may not be the best for the patient or when the cost cannot be justified. Free samples are especially problematic when the sales representative rather then the physician decides which medications will be provided as samples.

Ethical challenges in prescribing are also raised by healthcare insurance industry practices. The use of formularies and a tiered schedule of pharmacy co-pays are two such practices. Healthcare plans publish lists of covered and of recommended medications for specific symptoms or diagnoses and provide physicians with clinical guidelines for recommended treatment. The insured are often charged different co-pays for different medications (for example, a lower out-of-pocket cost for generics, higher for recommended brand drugs, and highest for nonrecommended brand-name drugs).

Insurance plans are seeking to control costs through these practices. They are encouraging the use of the lowest cost medications or treatments appropriate. Physicians are free to prescribe whatever they think best, but they risk being identified as providers who are not following the plan's guidelines. In addition, their prescribing decisions have a direct impact on the patient's personal pharmacy expenses.

These practices raise the question of the clinicians' responsibility in regard to the cost of the medications they prescribe. Many physicians, at least until recently, have not routinely considered the cost when making medication decisions. In fact, based on the belief that the physician's responsibility is to do what is best for the individual patient under care, it has often been considered inappropriate to allow the cost of the treatment to play a significant role in the recommendation for medical treatment. This understanding of the meaning of patient advocacy was widely challenged at the beginning of the twenty-first century.

In a statement that has received considerable attention and support, James Sabin argued that physicians do have an ethical responsibility to act as stewards of society's healthcare resources. "As a clinician I believe it is ethically mandatory to recommend the least costly treatment unless I have substantial evidence that a more costly intervention is likely to yield a superior outcome" (Sabin, p. 859). If a physician's responsibility to patients includes taking cost into account, it makes good ethical sense to conform to an insurer's practice that promotes lower cost medications, whenever that "substantial evidence" of a more expensive medication being more effective does not exist.

Wise use of available medical resources is one rationale for physician attention to the cost of the medications prescribed. Another reason is respect for the patient role in making informed consent decisions. If patient out-of-pocket expenses are greater for one medication than another (because of lack of healthcare insurance coverage or because of a tiered co-pay system), the patient needs to know, in advance, the relative difference in price. The patient needs to know, as well, the prescriber's rationale for recommending a higher-cost drug, when that is the case. Without both pieces of information, the patient does not have all the information necessary to determine whether to consent to the recommended treatment.

Some cost-driven insurance company practices support (or are compatible with) high-quality prescribing decisions and some do not. The physician needs to distinguish between the two and act to protect the patients' best interests and their own professional integrity. Knowledge of the general costs of the medications that one prescribes is, it seems, an essential component of responsible practice.

The ethical considerations related to prescribing treatment, especially prescribing medications, can be expected to receive continuing attention—and perhaps significantly increased attention—in the early part of the twenty-first century.

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SEE ALSO: *Addiction and Dependence; Conflict of Interest; Informed Consent; Life, Quality of; Placebo; Pharmaceutical Industry; Psychopharmacology*

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PHYSICIAN-ASSISTED SUICIDE

SEE *Life Sustaining Treatment and Euthanasia: I. Ethical Aspects of*

PLACEBO

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The terms *placebo* and *placebo effect* are quite difficult to define. Most commonsense definitions contain serious inconsistencies. For example, one commonly hears placebo defined as an “inert remedy”; but if a placebo were totally inert, there would be no point in giving it.

In Latin, *placebo* means “I shall please,” but the effects of a placebo can be either positive or negative (the term *nocebo,* roughly meaning “I shall harm,” is sometimes used to designate negative effects). Adolf Grünbaum emphasized that whether or not a remedy is a placebo is always relative to some biomedical theory. A sugar pill is a placebo for a migraine only because the biomedical theory agreed upon by all discussants denies any pharmacologic efficacy of small amounts of oral glucose in altering the pain of vascular headache.

Some find it useful to locate the species “placebo” under the genus “nonspecific therapy,” by which they mean a therapy that strengthens the general resistance of the organism to disease of many sorts (as opposed to a therapy that removes the specific cause of a single disease or class of diseases). But the latter term may be as hard to define precisely as placebo is. Moreover, there may be an unspoken assumption that nonspecific therapies are synonymous with “therapies that operate through psychological rather than biological mechanisms.” But this is clearly false; some psychological therapies may be very specific for certain diseases according to established psychiatric theories, and some biological therapies, notably diet and exercise, seem to be good candidates for “nonspecific” status.

For purposes of ethical analysis, placebo effect may be defined generally as the change in a patient’s condition that results from the symbolic aspects of the encounter with a healer or with a healing setting, and not from the pharmacological or physiological properties of any remedy used. The term *symbolic* alludes not only to the psychological processes that occur within the patient but also to the social and cultural belief systems that form a background to the patient’s thoughts and feelings and that give meaning to the healing process. A placebo, then, is a remedy administered either for purposes of eliciting the placebo effect or as a control in an experimental situation. Virtually any modality, including surgery and psychotherapy, can function as a placebo; the term is not confined to pills, capsules, or injections.

The practical goal of defining placebo effect as precisely as possible is to distinguish the changes it produces in the patient’s condition from changes produced by other causes. In treatment, the two factors likely to be confused with placebo effects are the pharmacological or physiological effects of the therapy employed and the natural history of the illness. For example, if a patient with gastritis visits a physician, who recommends antacids, and the patient improves, the relief could have come from the pharmacological properties of the antacids, the natural tendency of gastritis to heal over time, the soothing symbolic effects of the physician consultation, or some combination of the three. The two-group design in a controlled experimental trial (“active” treatment versus placebo) allows the investigator to distinguish pharmacological or physiological effects from the placebo effects and the natural history of the illness. It does not allow a distinction to be made between natural history and placebo effects.

It is also helpful to distinguish a pure placebo, thought to have no pharmacological potency under any circumstances whatever, from an impure placebo, which has pharmacological potency under some circumstances. Common examples of impure placebos are vitamins administered to patients who have no documented deficiency and antibiotics administered to patients who have viral illnesses (which do not respond to antibiotics). In today’s medical practice, impure placebos are probably used much more commonly than pure placebos.

Scientific Controversies

A number of works published in 2001 showed the controversy surrounding the science of the placebo effect. A careful meta-analysis of 114 randomized controlled trials concluded that the placebo effect does not exist in that context, and changes previously attributed to the placebo effect resulted from either natural history or random variation (Hróbjartsson and Gøtzsche). Other scientists reported further evidence that placebo effects in pain are mediated by endorphin release in the brain (Amanzio et al.) and that alteration in dopamine release in response to placebo therapy for Parkinson’s disease can be detected by positron emission tomographic imaging of the brain (de la Fuente-Fernández et al.). The results of a conference on “The Science of the Placebo” sponsored by the U.S. National Institutes of Health (NIH) were published (Guess et al.), and the NIH announced that research programs would for the first time be devoted specifically to studying the mechanisms and extent of placebo effects. Readers were thus led to various conclusions: that the placebo effect is a myth; that scientists understand better how it works; and that further research into its mechanisms will be fruitful. The majority view appears to be that the "myth" dismissal is premature and that more study is needed.

At the biochemical and cellular level, placebo effects may induce organ changes via the release of catecholamines, endorphins, or immunoactive cells; all three have been shown to be very sensitive to a patient's psychological or emotional state. At the social and psychological level, one must identify aspects of the setting or of the human interaction that cause the patient to perceive the situation as a healing one, thereby releasing whatever biochemically active substances might be involved. It appears safe to claim that a positive change in the patient's health status is most likely to occur when at least three things happen: the patient receives a satisfying explanation of the illness and treatment, the patient feels cared for and supported, and the patient feels an enhanced sense of mastery and control over symptoms.

During the 1990s and early 2000s, the ethics of placebo-controlled trials has been both challenged (Rothman and Michels) and defended (Miller and Brody). Besides the ethical questions concerning whether it is permissible to deprive research subjects of an effective standard treatment, some researchers have questioned how much scientific benefit is added by the use of a placebo control as opposed to an active-treatment control (Freedman, Weijer, and Glass). Systematic reviews have claimed that at least for selected conditions, such as depression, studies conducted without placebo controls might be scientifically suboptimal (Walsh et al.).

Ethical Issues

In the traditional use of placebos, a pharmacologically inert pill might be administered to a patient under circumstances that encourage the belief that a powerful drug is being given. Many patients—the average of one-third is often cited, though this conceals a wide variation among different settings—will experience some degree of positive response (White, Tursky, and Schwartz). This traditional use is ethically questionable because the patient is deceived. Therefore, an ethical analysis of placebo use might proceed with two questions. First, is deception necessary to produce the patient benefit promised by the placebo effect? Second, are there nondeceptive uses of placebos?

If one wishes to use placebo effects for the benefit of patients, one can simply work to enhance those aspects of the patient encounter that have been scientifically correlated with symptom improvement. One can show care, offer explanations, and enhance perceived mastery and control in many ways that require no deception whatever. Because, in the traditional use of placebos, the deception is justified by appeal to patients' benefit (Rawlinson), it is important to see that in almost all patient encounters, a nondeceptive alternative can produce the same result. Moreover, Sissela Bok argued, in her 1978 book, *Lying,* that the defender of the deception entailed in the traditional use of placebos makes two miscalculations: ignoring possible short-term harm (e.g., missing a diagnosis of serious disease because a placebo has temporarily relieved the patient's complaints) and failing to see how apparently trivial acts build up into collectively undesirable practices (e.g., overreliance on medication).

One may conclude that the traditional use of placebos in therapy can be justified only by very unusual circumstances (in which the use of a dummy pill is the only way to encourage the desired psychological state, for instance). By contrast, because reassuring patients and offering explanations and emotional support are part and parcel of good clinical care, one may argue that a physician has a positive ethical duty to try to enhance the placebo effect in every patient encounter (Connelly).

Counterarguments in defense of the traditional use focus on the claim that the deception is apparent rather than real (Spiro). It might be argued, for example, that if one gives the patient a placebo and says, "There, this will make you feel a lot better," one has not really lied. The increasing scientific interest in the placebo *effect* has triggered a resurgence of interest in administering *placebos* to patients, and some have claimed that placebo administration can be combined with respect for patients' rights and with appropriate informed consent (Brown). Perhaps the best reply to these counterarguments was put forth in a 1903 article by Richard C. Cabot: "A true impression, not certain words literally true," (Cabot, p. 345) is what the physician is obligated to promote in the patient. Most efforts at "informed consent" for placebo therapy still seem to rely on some element of equivocation, assuming that if the patient fully understood the pharmacologically inert nature of the remedy, no meaningful placebo effect would result.

Placebos may be employed in ways that do not entail deception and may therefore be fully licit. When placebos are used in controlled studies, it is generally possible to obtain a fully informed consent. It is also possible to use placebos in the therapy of individual patients in a way that avoids deception. One formal procedure for doing so has been termed the "N of 1 Trial," because it is basically a double-blind, controlled research trial performed on a single, informed subject (Guyatt et al.).

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SEE ALSO: *AIDS: Healthcare and Research Issues; Healing; Informed Consent; Pharmaceutics, Issues in Prescribing; Research Methodology; Research, Unethical*

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POPULATION ETHICS

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I. Elements of Population Ethics: A. Definition of Population Ethics
I. Elements of Population Ethics: B. Is There a Population Problem?
I. Elements of Population Ethics: C. History of Population Theories
II. Normative Approaches
III. Religious Traditions: A. Introduction
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I. ELEMENTS OF POPULATION ETHICS: A. DEFINITION OF POPULATION ETHICS

Population studies deal with fertility, mortality, and migration. Fertility refers to human reproduction, mortality to death, and migration to the movement of people from one region to another. The articles on population ethics and population policies in this *Encyclopedia* take up only those aspects of fertility and migration with close links to healthcare and the life sciences, that is, to bioethics.

Population ethics has two main foundations: moral principles and factual information. Moral principles come from religious traditions, philosophy, declarations of human rights, and other sources. Factual information derives from careful analysis of what is happening or has happened in a given place or situation. Judgments about the ethics of population policies require the application of moral principles to cases based on solid, factual information. Vague principles or a poor understanding of how population programs really operate lead to questionable judgments about population ethics.

The articles on normative approaches and on religious traditions show similarities and differences in the moral principles applied to population policies. One major normative framework, accepted in principle by most countries, includes the universal statements on human rights developed by the United Nations. By endorsing and defining rights such as life, liberty, and welfare, the United Nations has established ethical standards applicable to all social programs, including those dealing with population. The major religious traditions of the world also have their own perspectives on fertility control and migration. Many of these are fully compatible with U.N. statements on human rights, but some are not. The main conflicts over population ethics arise when governments, most of which have officially accepted U.N. standards on human rights, violate those rights in their own population programs.

The articles on population policies apply moral principles to strategies used in fertility control, health standards required in that field, ethical issues in programs involving migration and refugees, and the work of donor agencies dealing with fertility control and migration and refugees. Strategies of fertility control can range from the application of force to information campaigns aimed at voluntary changes in attitudes and behavior. They include compulsion, which has been used to force China's one-child-per-couple policy; strong persuasion, such as the application of heavy government and community pressure on potential users of fertility control; financial incentives and disincentives given to users, field workers, and communities; and educational or information campaigns aimed at promoting greater acceptance of fertility control. The ethical issues are most serious with the use of compulsion and least serious, though still significant, with information campaigns.

Debates over whether rapid population growth poses problems for human societies also show the need for clear moral principles and solid factual understanding. Advocates enter those debates with different principles and factual information.

The moral principles guiding discussions about population problems include preventing environmental pollution (Ehrlich and Ehrlich); keeping population size within the carrying capacity of the world (Hardin); and promoting economic growth (World Bank). Each principle leads to a different focus on factual information. Those concerned with pollution analyze data about global warming, acid rain, and depletion of the ozone layer. Those proposing to keep population size within the carrying capacity of the world look, for example, at figures on population density. Students of economic growth consider the many links between birthrate and economic development, including relationships among fertility, education, and healthcare. Because each concern leads to a different meaning of a population problem and a different selection of information, it is difficult to compare one problem definition with another.

Two research practices have held back the development of an adequate factual base for population ethics. One practice begins with conclusions and then selects only those facts consistent with them. Analysts claiming that rapid population growth has had negative consequences for economic development often cite facts supporting that conclusion and leave out contrary evidence (World Bank). Those claiming benefits from rapid population growth do the same (Simon).

The second practice involves assigning more or less weight to population conditions than objective research would support. Some advocates of fertility control claim that rapid population growth has caused starvation and political instability in the developing countries. Such simple interpretations overlook the many other influences leading to those conditions, such as the lack of food in poor countries, corruption among political leaders, and ethnic conflicts.

The strategies countries use to control fertility have provoked the sharpest debates about population ethics. China and India have used outright coercion to promote sterilization or abortion. In China, women found to be pregnant with unauthorized children have been forced to undergo abortions (Aird). Between 1975 and 1977, police in some parts of India rounded up eligible men and required them to be sterilized (Gwatkin). Indonesia's use of strong community pressures to increase use of contraceptives has also been controversial. To gain new users the Indonesian government has relied on such methods as repeated visits to eligible women from village heads, family-planning workers, and members of Acceptors Clubs; pressure to accept intrauterine devices during "safaris" attended by prominent public officials; and promoting a positive image of small families.

Those defending coercion and heavy social pressures argue that countries such as China, India, and Indonesia require vigorous methods of fertility control to curb swelling populations. Voluntary methods, they say, will work too slowly to prevent damage to the economy and create impossible demands for a nation's schools and other public services. Critics respond that applying force and heavy pressure violates human rights and disregards international agreements on fertility control, such as the 1974 World Population Plan of Action (United Nations).

Policies on migration and refugees also raise questions of ethics. Under what conditions, if any, do residents of one country have the right to enter another? Are the moral claims of potential migrants stronger when they are facing starvation, persecution, or violence? Do countries have the right to bar or expel immigrants they see as harmful to their national interest, as the United States did with Haitian immigrants in the early 1990s? What obligations, if any, does a government have to undocumented aliens within its borders? Can it deny them healthcare services regularly available to its own citizens? What kinds of aid should donor agencies, such as the World Food Program or the International Committee for the Red Cross, provide to migrants, refugees, and displaced persons? And how should that aid be distributed?

Issues of medical risks and proper standards of healthcare arise in fertility control as well as migration and refugee programs. Family-planning programs sometimes put more emphasis on achieving numerical targets for clients than on safeguarding the freedom and health of users. Field workers may promote medically unsafe methods of fertility control, fail to disclose the risks of a given method, or be unavailable to deal with the side effects that do occur. Or they may insert the subdermal contraceptive Norplant and then refuse to remove it at the client's request (Ubinig). Fertility-control programs also differ in the health support they provide to users, such as local clinics to deal with minor problems or hospitals to handle serious complications.

Questions about standards for healthcare also arise in programs for refugees. Program managers often have to decide whether refugees should be sent back to countries from which they fled, where they may be tortured, imprisoned, or killed. If they are kept in camps, what should be done to prevent the high rates of illness sometimes seen in those settings? Possible preventive measures include providing adequate food, safe water, suitable shelter, sanitation, immunization of vulnerable groups, and a primary healthcare system.

International donor agencies, such as the World Bank, the United Nations Population Fund, and the U.S. Agency for International Development, also face moral choices in their assistance to fertility-control programs. Among those choices are whether donors should support programs known or thought to involve coercion, such as that in China; whether those organizations funding a variety of projects, such as the World Bank, should put pressure on countries to initiate fertility-control programs as a precondition for other aid; and how far and in what ways they should ensure that recipients of their funds provide honest explanations of methods to clients and adequate health support for complications or side effects.

In migration and refugee programs, ethical principles affect decisions about who receives assistance and who does not. Are those decisions based mainly on the health and welfare needs of those to be served or on other criteria, such as racial or ethnic politics? This question is particularly salient in countries where the government controls donor access to areas in which its political opponents want to be evacuated. Donors must likewise make moral choices in designing programs for migrants or refugees. In interventions for disaster relief, they must often choose between strategies providing rapid action by outsiders, such as building homes, or slower methods of educating residents in how to become more self-sufficient (Parker). Instead of constructing new homes after an earthquake, donors might show community members how to build their own homes using earthquake-resistant methods of construction. The result could be greater self-sufficiency and better protection against future disasters.

Population ethics thus involves the application of moral principles to what are often complex empirical situations. Its greatest challenges are to select principles that are broadly applicable to population issues, rather than those that advance some specific interest, and to explore their implications with an adequate factual understanding of the circumstances involved.

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SEE ALSO: *Abortion; Aging and the Aged; Autonomy; Behavior Control; Environmental Ethics; Ethics: Normative Ethical Theories; Fertility Control; Future Generations, Reproductive Technologies and Obligations to; Life, Quality of; Natural Law; Population Policies, Strategies for Fertility Control in; Race and Racism; Women, Historical and Cross-Cultural Perspectives;* and other *Population Ethics* subentries

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I. ELEMENTS OF POPULATION ETHICS: B. IS THERE A POPULATION PROBLEM?

Policy analysts, the popular press, and scholars often speak of "the population problem." This phrase usually means that the existence of too many people on the planet will cause difficulties or even catastrophes for individuals, couples, countries, or the world. It can also mean that a country or region has too few people for its economic, social, or political welfare.

The first definition argues that rapid population growth, large population size, or high population density can bring widespread poverty, famine, air pollution, poor public health, drought, more children than can be educated in national school systems, overcrowded cities, or other serious harms. Under the second definition, too few people can reduce a country's population below the number that the government wants, decrease the size of the labor force, change the size and mix of ethnic groups in ways that can cause conflict, or create a population with few young and many old people. In either case the location of the problem can be the world, geographic regions such as sub-Saharan Africa, single countries, cities, or other regions within a country.

Those stating that there is a population problem base their assertions on three elements: perceived threats to social, moral, or political values; factual evidence; and theories explaining how population creates the conditions that threaten values. Much of the confusion in discussion of population problems arises from ambiguity or disagreement about these three elements.

Every statement of a population problem explicitly or implicitly expresses concern about values such as preventing famine, having an adequate number of workers and jobs, and giving couples the opportunity to determine their family size. Whether the concern is with too many or too few people, those stating that there is a problem always mention or allude to some moral, social, or political value. They also directly cite factual evidence to support their case or imply that this evidence exists. The evidence may be quantitative, such as figures on the relationship between population size and the number of teachers and schools in a country, or qualitative, such as the judgments of political scientists on a country's strength in foreign affairs, or a combination of the two. And every claim that there is a population problem involves a theory or conceptual scheme showing the links between too many or too few people and indicators of the values at stake in the discussion. Economic theories, for example, may try to show how, specifically, rapid population growth has created or will create unemployment.

Confusion about whether there is a population problem arises when analysts are vague about the values advanced or threatened by population size; omit relevant factual evidence; or use theories that have little validity. Advocates are vague about values advanced or threatened when they state that there is a population problem without indicating the social, moral, or political goods affected by population size. Some writers simply take it for granted that the world is now too crowded and go on to say what should be done about it. Omitting relevant factual evidence leads to charges of bias in statements about population problems. So does the use of theories that aim more at making the case for a problem than at objectively weighing the influence of population conditions.

Whether or not there is a population problem is critical to the ethics of population control. If rapid or limited population growth, population size, and population density do indeed cause serious damage, societies and governments will have some ethical justification for trying to change those conditions. If, on the other hand, pronouncements about population problems fail to state the values affected, are selective in their choice of factual evidence, or rely on dubious theories, the ethical justification for policies to deal with those problems will be tenuous.

The following discussion illustrates the complexity of making statements about population problems by comparing four approaches: those of Paul and Anne Ehrlich, the World Bank, the U.S. National Academy of Sciences, and Julian Simon. It reviews the values at stake in each approach, the completeness of the factual evidence cited, and the theories invoked to link population conditions to outcomes reflecting the values of concern.

Approaches to the Population Problem

In *The Population Bomb* Paul Ehrlich made this statement about population growth:

> The battle to feed all of humanity is over. In the 1970s and 1980s millions of people will starve to death.… Although many lives could be saved through dramatic programs to "stretch" the carrying capacity of the earth by increasing food production and providing for more equitable distribution of whatever food is available … these programs will only provide a stay of execution unless they are accompanied by determined and successful efforts at population control. (p. xi)

During the 1970s and 1980s, high birthrates did not produce the levels of starvation Ehrlich predicted, in part because of the Green Revolution, which led to much higher food production than in the 1960s. Nonetheless, in their 1990 book *The Population Explosion* Paul and Anne Ehrlich continued to argue that the human race would face starvation and widespread disease unless societies immediately controlled their birthrates.

> Human inaction has already condemned hundreds of millions more people to premature deaths from hunger and disease. The population connection must be made in the public mind. Action to end the population explosion *humanely* and start a gradual population *decline* must become a top item on the human agenda: the human birthrate must be lowered to slightly below the human deathrate as soon as possible. (pp. 22–23)

The authors blame overpopulation for starvation in Africa, homelessness and drug abuse in the United States, global warming, holes in the atmosphere's ozone layer, fires in tropical forests, sewage-blighted beaches, and drought-stricken farm fields.

The World Bank has taken a different approach to the population problem. The *World Development Report 1984* (World Bank) acknowledges that the evidence on this subject is complex but concludes that "population growth at the rapid rates common in most of the developing world slows development" (p. 105). This statement echoes the remarks of the Bank's president in the foreword: "What governments and their peoples do today to influence our demographic future will set the terms for development strategy well into the next century" (p. iii). In the World Bank's view, high fertility and rapid population growth bring on a problem by creating conditions, such as lower-quality education, that block economic development.

In 1971 the National Academy of Sciences (NAS) claimed that rapid population growth causes serious harm to economic development in sixteen ways. It holds down growth in per capita income; leads to unemployment and underemployment; creates mass poverty; distorts international trade; aggravates political, religious, linguistic, and ethnic conflicts; retards the mental and physical development of children; and has other negative consequences.

Fifteen years later the NAS (National Research Council, 1986) issued a report that backs away from the earlier conclusions. According to that report, slower population growth may benefit developing countries, but there is little evidence for judging whether its impact will be large or small. Furthermore, the results of population growth will depend not only on numbers of people but also on the effectiveness of government administration, social institutions, and the resources of specific countries. Thus, over a decade and a half the NAS shifted from a negative to a more neutral assessment of the impact of demographic growth.

Julian Simon (1990) gives a much more optimistic view of population growth than do the Ehrlichs, the World Bank, and the NAS. He first questions what he calls myths about population and resources. For example, while some say that the food situation in developing countries is worsening, Simon holds that per capita food production has been increasing about 1 percent each year. Responding to arguments that higher population growth means lower per capita economic growth, Simon states: "Empirical studies find no statistical correlation between countries' population growth and their per capita economic growth, either over the long run or in recent decades" (p. 45). Simon also offers evidence challenging statements that the world is running out of natural resources and raw materials and that energy is becoming more scarce.

Simon argues that having additional children improves productivity in the more developed countries and raises the standard of living in less developed countries. Over a period of thirty to seventy years in the more developed countries, each additional person contributes to increased knowledge and technical progress by "inventing, adapting, and diffusing new productive knowledge" (p. 48). Over the same time period in the less developed countries, more children lead to more work done by parents, stimulate agricultural and industrial investment, and bring other benefits. Simon calls people "the ultimate resource" and holds that population growth increases that resource.

The four approaches have different notions of how population growth affects economies and societies. The Ehrlichs are consistently gloomy about the impact of population growth on human societies. The World Bank is seriously concerned about its effects, and generally negative in its conclusions, but willing to consider different points of view and some evidence challenging its position. Like the World Bank, the NAS focuses on population growth and economic development, but comes to very different conclusions in its 1971 and 1986 reports. Simon plays down the harms and underscores the advantages of population growth for economic development and social welfare.

Values, Evidence, and Theories

The statements just reviewed show the difficulty of having a coherent discussion about "the population problem." The main reason is that the authors are concerned about different values, do not use all available factual evidence, and base their conclusions on different conceptual schemes and theories.

For Paul and Anne Ehrlich, central values include avoiding starvation, protecting the environment, preserving the world's resources, and maintaining public health: "*The Population Explosion* is being written as ominous changes in the life support systems of civilization become more evident daily. It is being written in a world where hunger is rife and the prospects of famine and plague ever more imminent" (p. 10). The World Bank shows greater concern with promoting economic growth, providing the world with adequate food supplies, having public services such as health and education, and protecting the environment. Both reports of the NAS address similar values. The values guiding Julian Simon's work include showing the benefits of population growth for human welfare and economic development; removing or reducing popular fears about population growth and the availability of resources; and convincing the public that "life on earth is getting better, not worse" (p. 21).

What evidence do these writers use, and how representative is that evidence of all that was available? In *The Population Bomb,* Paul Ehrlich does not try to be objective. He opens his first chapter with these words:

> I have understood the population explosion intellectually for a long time. I came to understand it emotionally one stinking hot night in Delhi a few years ago. My wife and daughter and I were returning to our hotel in an ancient taxi. The seats were hopping with fleas. The only functional gear was third. As we crawled through the city we entered a crowded slum area. The temperature was well over 100, and the air was a haze of dust and smoke. The streets seemed alive with people. People eating, people washing, people sleeping. People visiting, arguing, and screaming.… People defecating and urinating. People clinging to buses. People herding animals. People, people, people, people. (p. 5)

Ehrlich goes on to specify the nature of the problem, summarize what is being done to deal with it, state what needs to be done, and tell readers what they can do to help. The book makes its case more by an appeal to the moral and political concerns of its readers than by presenting factual evidence.

The Population Explosion has a more scholarly tone, but still limits the findings presented to those that would be widely interpreted as supporting the authors' claims about overpopulation. It has chapters on shortages of food in developing countries; the difficulties facing agriculture; greenhouse warming, acid rain, and other damages to Earth's ecosystems; and urban air pollution, crowding, and hazards to public health. The Ehrlichs adduce no evidence challenging or qualifying their conclusions. They conclude with a chapter showing what readers can do to stop the population explosion.

Like the Ehrlichs, Simon gives a one-sided presentation of his findings. He contrasts popular views of bad news about population with the "unpublicized, good-news truth" (p. 42) deriving from his own analysis. He summarizes commonly cited statements, such as that the food situation in developing countries is growing worse, and then offers his own view under the heading of *fact.* Instead of presenting a balanced summary of research findings, he tries to attack the popular belief with as many findings as he can assemble that will be widely interpreted as contrary.

The World Bank (1984) admits that judging the evidence about the consequences of population growth is not easy and summarizes some conflicting views on that subject. But it does not mention dozens of cross-national studies that contradict its main conclusion, including work by Simon Kuznets (1974) and Ester Boserup (1965, 1981). This research shows no relationship between the rates of growth of population size and the growth rates of per capita income. Nor does the Bank's report explore the possibility, put forth by Boserup and Simon, that population size, population growth rate, and population density contribute to technological progress. According to one reviewer, "the Report can be evaluated from two different perspectives: as a position paper making the best case for a point of view; or as a summary of current knowledge. It is clearly much more successful as the first than as the second" (Lee, p. 129).

The two reports by the NAS are also mainly concerned with economic growth, but they differ in their approach to the studies they cite. The 1971 report selects evidence that supports its conclusions about the negative consequences of population growth and neglects research whose findings challenge or contradict those conclusions. The 1986 study is much better balanced in its coverage of the evidence and more cautious in arriving at conclusions. The authors draw a clear distinction, for example, between conditions caused by population growth and those only associated with such growth.

The four approaches also differ in their use of theories and conceptual schemes. In *The Population Bomb,* Paul Ehrlich has no social-scientific theory; he argues almost entirely by assertion. He assumes that the connections between population growth and conditions such as starvation are evident and therefore need no conceptual or theoretical justification. As is the case with their choice of evidence, in *The Population Explosion* Paul and Anne Ehrlich select only those conceptual frameworks showing the negative consequences of population growth. The World Bank recognizes the diversity of theories about the impact of population growth, but chooses a model that eliminates the possibility of any positive effects, such as those mentioned by Julian Simon. The 1971 NAS report also relies heavily on conceptual models showing the harms done by population growth. The 1986 NAS report applies concepts and theories allowing for a fairer evaluation of the relationships between population growth and economic development.

Much of the debate about whether there is a population problem and what it means stems from the different values and concerns behind statements of problems; selective use of evidence; and choosing theories to support preestablished conclusions rather than to arrive at impartial conclusions. Until analysts remove the ideology and biases commonly found in discussions about population problems, the confusion will continue.

The Population Problem: Where and When?

Most discussions of the population problem focus on the world at large or regions such as developing countries. It is also possible to examine the impact of population growth, size, and density on single countries. This is the focus of the work done by the Population Division of the Department of International Economic and Social Affairs (DIESA) of the United Nations (Chamie). The Population Division assumes that, whatever the impact of population size, density, and growth across the world, single countries will have different views on what those concepts mean to them. Since the mid-1970s DIESA has maintained the Population Policy Data Bank to assess the perceptions and policies of governments regarding fertility.

At the end of the 1980s, 44 percent of U.N. member countries reported that their fertility levels were too high and 12 percent that they were too low (Chamie). If one defines a population problem as a government's perception that its fertility is either too high or too low, then 56 percent of U.N. member countries had a problem. The response to that problem depended on whether the governments thought that their fertility was too high or too low.

The first group, usually in countries with low per capita incomes, often set up programs of birth control. Countries reporting that their fertility is too low, such as France, Greece, Hungary, and Switzerland, adopt financial incentives and other policies to encourage more births (McIntosh). Singapore has been unusual in shifting from the perception that it would have too many people to its current view that it requires higher fertility. These differing perspectives show the importance of asking where and why population is a problem. While many studies focus on the world or on developing countries, the research done by DIESA underscores the importance of opinions and policies in single nations.

The single countries mentioned show agreement on the definition of a population problem. The value of most concern is the government's perception of whether it has too many, too few, or the right number of people. This may be a limited way of defining a population problem, but it does have a consistent point of reference: the views of the government. The evidence used is also the same: the information collected for the Population Policy Data Bank. Conceptual frameworks and theories differ about the reasons for governments' perceptions of a population problem and about why they do or do not take action on population issues. But consistency in the value behind the data and in the evidence used makes it much easier to compare definitions of population problems than in the four approaches outlined earlier.

Another critical question about population growth, size, and density is how they will affect the future. Paul Ehrlich's *The Population Bomb* and William and Paul Paddock's *Famine 1975* (1967) show that confident predictions of disasters are often wrong. But that experience does not mean students of population problems should stop looking to the future. Instead, they should make their predictions but be modest enough to indicate that, because they do not know everything that will happen between the time of writing and the time of the predicted event, they may be mistaken about the predicted events.

A related question concerns the obligations of the present generation to future ones. Do people living now have a duty to preserve the world so that future societies and individuals will have the resources and health conditions currently available? There is no simple answer. Over time, serious problems, such as the pollution of London a century ago, have been resolved and new problems, such as the depletion of water supplies in some regions, have arisen.

Two principles can help reflection on this topic. First, U.N. organizations and governments should pay explicit attention to the long-term consequences of population policies. Rather than taking a passive stance in debates on this topic, they should encourage and, if necessary, subsidize research on how population growth, population size, and population density affect the future. Second, the present generation has no right to adopt or accept population policies likely to damage the health and welfare of future generations. These might include actions leading to widespread environmental pollution, deforestation, and poor conditions of public health.

Recommendations

How can students of population policy reduce the bias now seen in many discussions of population problems and provide a solid basis for comparing different statements of those problems?

First, commentators should explicitly state the geographic focus of their analysis. Is it the universe? All the countries in the world? Some region of the world, such as sub-Saharan Africa or South America? A single country? Regions within a single country, such as cities or rural areas? Or some combination of those options, such as a country as a whole and its urban and rural areas? Given the great differences in population, economic, social, and political conditions across nations, specifying the geographic focus would immediately help observers to see similarities and differences across the territory covered. Tables such as those in the World Bank's annual *World Development Report* would be helpful for that purpose.

Second, those discussing population problems should indicate the moral, social, or political values of concern in their analysis. This recommendation should apply whether the observer claims that the region being analyzed has too many, too few, or an adequate number of people. Values often found, explicitly or implicitly, in such analyses include promoting economic growth; preserving the environment; preventing a decline in the region's population; increasing the size of the dominant ethnic group or changing the sizes of ethnic minorities; and maintaining the availability of schools and other social services for the region's inhabitants.

Third, scholarly analyses of population problems should use all relevant evidence rather than just studies that support the author's point of view. Discussions of population growth and economic development should make full use of the numerous cross-national comparisons on that subject. When, as often happens, the sources of evidence lead to different conclusions, that situation should be mentioned.

Fourth, those discussing population problems should specify the theories or conceptual frameworks guiding their analysis. It is particularly important to indicate how population conditions, such as growth rates and size, influence conditions such as economic growth or the availability of schools. Many publications have used conceptual models that attribute more influence to population than it deserves, partly because other relevant influences are not considered. Such is the case with the 1971 NAS study on the consequences of rapid population growth. By using a more thorough conceptual framework and considering a broader range of evidence, the 1986 NAS study in effect retracts many of the conclusions in the 1971 report.

Fifth, conclusions should be based on the results of careful conceptual or theoretical analysis and the weight of the evidence rather than on a priori judgments by the authors. Following this recommendation will often mean reporting contradictory or inconsistent evidence and arriving at qualified judgments. The greatest single source of confusion in present statements on population problems is a strong ideological bias in writing. This bias has led to vagueness about the values at stake, use of incomplete theories and conceptual schemes, citation only of those parts of the evidence consistent with the authors' preconceptions, and conclusions based more on ideology than on a fair assessment of the evidence.

Sixth, policy recommendations in statements about population problems should be based on the evidence presented rather than on the personal preferences of the authors or the donors who have supported them. For example, after a lengthy discussion of the links between population growth and economic development, the 1986 NAS report suggests that governments should establish family-planning programs. This recommendation has little to do with the main lines of the report, which says nothing about family planning. This practice is intellectually misleading, for it suggests that the policy suggestions flow directly from the scholarly analysis, which in this case they do not.

Conclusions

Is there a population problem? When the focus is on single countries, when the source of information is the Population Policy Data Bank maintained by the United Nations, and when the definition of the population problem is the government's opinion on whether it has too many, too few, or the right number of people, it is possible to answer that question. But when the focus is on the world as a whole, and authors are concerned with different values, use different theories and sources of evidence, and become advocates for a particular point of view, there is and can be no answer.

To have more comparable notions of population problems, authors must clearly identify the geographical region they are discussing; indicate the values of concern to them; use all available evidence; apply theories or conceptual schemes that consider all relevant influences; weigh the evidence objectively; and draw only those conclusions supported by their analysis. The ideological discourse seen in current discussions of population problems must give way to scholarly analysis. When these criteria are met, more accurate, less biased, and more comparable discussions of population problems will be available.

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SEE ALSO: *Abortion; Aging and the Aged: Life Expectancy and Life Span; Children; Climate Change; Endangered Species and Biodiversity; Environmental Ethics; Epidemics; Fertility Control; Genetics and Environment in Human Health; Hazardous Wastes and Toxic Substances; International Health; Life, Quality of;* and other *Population Ethics* subentries

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I. ELEMENTS OF POPULATION ETHICS: C. HISTORY OF POPULATION THEORIES

Ancient and Medieval Theories

Like most general theories of Western civilization, those concerning population evolved first in ancient Greece. Both policies and their conceptual frameworks varied in their details, but there was much consistency from one city-state to another. The typical pronatalist policies were intended not to induce a growth in numbers but to prevent their decline (Stangeland, chap. 1; Hutchinson, chap. 2). In the ideal city-state that Plato pictured in *Laws,* the population was to be kept stable at 5,040 (the product of 1 × 2 × 3 × 4 × 5 × 6 × 7) by encouraging or inhibiting fertility or by infanticide. If the population grew much beyond this optimum, the community was to establish colonies. To neglect measures that would keep the population more or less fixed, according to Aristotle, would “bring certain poverty on the citizens, and poverty is the cause of sedition and evil” (*Politics,* 2.9).

Greek thought on population, in sum, was characterized by an overriding concern with policy, and thus a relative indifference to empirical or conceptual analysis. Policy was to be applied, moreover, to aggregates ridiculously small by present-day standards. And whether the meaning of *population* was in accord with the modern sense is often not clear; in most instances the term may have referred only to citizens, thus omitting females, children, slaves, and aliens.

In its far larger arena, Rome's policy was more consistently pronatalist. As imperial hegemony spread from Italy throughout the Mediterranean basin and beyond, the center was troubled by moral decay, the dissolution of the family, and a slower growth of population. Successive pronatalist measures culminated in three enactments under Augustus (63 B.C.E.–14 C.E.), which punished celibacy and adultery and rewarded prolific couples (Stangeland, pp. 30–38). Since they had little apparent effect, the laws were repeatedly amended and finally repealed under Constantine (ca. 288–337).

As the empire gradually disintegrated, many came to believe that the end of the world was imminent, and various sects offered competing dogmas appropriate to the apocalypse. The early Christian church gradually developed its own doctrine with a compromise between libertine and ascetic, but emphasizing the latter (Noonan). Catholic thought reached its apogee in the *Summa Theologica* of Thomas Aquinas (ca. 1224–1274). For him, a marriage between Christians is not merely a means of obeying the injunction to replenish the earth but also a spiritual bond, a sacrament. The function of intercourse is procreation (Bourke).

Early Modern Theory

The dominant theme of the early modern period was the view that population growth is precarious and has to be fostered. Just as the mercantilist state hoarded gold, so it hoarded people, and for the same reason—to increase its economic, political, and military power. If rapid population growth resulted in what was termed "overcrowding," the mercantilist solution was to ship the surplus to colonies, where the settlers and their progeny could continue to aggrandize the state's power in another quarter of the globe.

Modern demography began with the efforts of mercantilist states to keep track of their populations (Glass). William Petty (1623–1687) was the first exponent of what he called "political arithmetic." John Graunt (1620–1674) constructed the first crude life table. Gregory King (1648–1712) calculated population estimates based on local enumerations, which he corrected for technical errors. On the Continent, Johann Peter Süssmilch (1707–1767) used Protestant parish records to estimate Prussia's fertility and mortality. Richard Cantillon (ca. 1680–1734) held that internal migration, deaths, and especially marriages (and therefore births) varied according to the prevailing standard of living and the structure of the demand for labor. François Quesnay (1694–1774), who founded what was later called physiocratic thought, analyzed the implicit bounds to population growth.

The philosophes of eighteenth-century France varied greatly on many issues, but most also found reason to favor policies stimulating population growth. Charles-Louis de Secondat, Baron Montesquieu (1689–1755), believed that the entire world had undergone depopulation and recommended pronatalist decrees. According to Voltaire (1694–1778), a nation is fortunate if its population increases by as much as 5 percent per century. Louis de St.-Just (1767–1794) held that one can usually depend on nature "never to have more children than teats," but to keep the balance in the other direction requires the state's assistance. By this notion of an equitable family law, as inspired by Jean-Jacques Rousseau (1712–1778), marriages should be encouraged by state loans, and a couple that remained childless after several years ought to be forcibly separated.

The two utopians that Thomas Robert Malthus opposed in the first edition of his *Essay on the Principle of Population,* William Godwin (1756–1836) and Marie-Jean Caritat, Marquis de Condorcet (1743–1794), focused their attention on the wholly rational age they discerned just over the horizon. According to them, in a world from which diseases had been wholly eliminated, the span of life would have no assignable upper limit. People would devote themselves to more important tasks than, in Condorcet's words, "the puerile idea of filling the earth with useless and unhappy beings."

Malthus

Malthus summarized or contravened earlier ideas so effectively that, for more than a century and a half, subsequent theorists have generally taken him as a benchmark. Unfortunately, many references to "Malthusian" thought are based, at best, on the first edition of *Essay on the Principle of Population* rather than on the much enlarged and thoroughly revised later editions—or, at worst, on a total misunderstanding of what he stood for (Petersen, 1979, chap. 4).

Thomas Robert Malthus (1766–1834) was a professor at the newly founded East India College, occupying Britain's first chair in the new discipline of political economy. He spent much of his life collecting data on the relation between population and its social, economic, and natural environments, bringing his theory into accord with these facts and adjusting it to criticism. There were seven editions of the *Essay* in all.

According to the principle of population as expounded in the *Essay,* population, "when unchecked," doubles once every generation. Among "irrational animals" this potential is realized, and its "superabundant effects are repressed afterwards by want of room or nourishment." But rational human beings can consider the consequences of their reproductive potential and curb their natural drive. With humans, thus, there are two types of control of population growth: "preventive checks," the chaste postponement of marriage, and "positive checks," the deaths resulting from too large a population relative to its subsistence. Tension between numbers and food can have a beneficial effect: A man who postpones marrying until he is able to support a family is goaded by his sex drive to work hard, thus contributing to social progress. For this reason Malthus opposed contraceptives, for their use permits individual sexual gratification with no benefit to society.

Through the successive editions of the *Essay,* Malthus increasingly stressed the negative correlation between station in life and size of family. This, in his view, was the principal clue to solving what later became known as "the population problem." In order to bring the lower classes up to the self-control and social responsibility exercised by those with more money and education, Malthus asserted, the poor should be given more money and education. "The principal circumstances" that induce prospective parents to have fewer children are "liberty, security of property, the diffusion of knowledge, and a taste for the comforts of life." Those that tend to increase procreation are "despotism and ignorance." The thesis that upward mobility into the middle class effects a decline in fertility, though it is far less familiar than that relating population growth to food, is in retrospect Malthus's most important contribution.

For many decades Malthus's reputation was far below that of lesser social analysts. Recently it has become apparent that much of present-day demography was at least partly stimulated by Malthus and that those who denounced him as a false prophet had typically begun by misrepresenting his ideas.

Population Optima

Most of the populations that Malthus discussed tended to grow too rapidly relative to the available resources, and he recommended institutional checks to their fertility. But the extraordinarily rapid growth of the American colonies, whose population was doubling every twenty-five years, he held to be of great benefit. In other words, each country has an optimum size and rate of growth, depending on the social and economic conditions. Malthus neither used the term *optimum* nor developed the concept beyond an implicit statement, but he planted the seed of the theory. Malthus's principle that the population tends to increase by a geometrical ratio and food by an arithmetical ratio can be reformulated as a law of diminishing returns. If to a fixed acreage of land more and more labor is added, return per person may first rise but then will decline as the work force increases beyond its most efficient size. The first definition of "the optimum" was based on this schema: It is that population which under given conditions produces the highest per capita economic return.

Soon, however, the optimum came to mean simply "the best population," with each analyst furnishing a particular yardstick of what is "good." By this route the theory of population optimum could be regarded as a version of social choice theory, with a wide variety of open questions (Dasgupta). Should the population be related to the present institutional structure or to some supposed future ("socialism," for instance)? Should the criterion of "good" be economic welfare, military strength, the conservation of resources, or some combination of these? This conundrum is aggravated by the fact that optima vary greatly, according to the goal that society sets. And should the standard relate exclusively to the number of people or also to their age structure, rate of growth, level of skill, and other characteristics that affect how efficiently the society can operate?

Obviously, no judgment concerning "the optimum" can be very precise. Whether a country of western Europe, say, is underpopulated or overpopulated is less a demographic-economic measurement than a more or less arbitrary opinion. The norm can be applied meaningfully only at the extremes. The colonies that became the United States were definitely underpopulated, as Malthus pointed out. And in some of today's less developed countries, by the judgment of most demographers, the rapidly growing populations impede a rise in the people's well-being.

Migration

We are all born and we all die, but only some of us move from one place to another. Unlike fertility and mortality, migration is not a biological process. Indeed, many determinants of migration are political: Movements are subsidized, restricted, or forced, and the status of migrants in their new homeland depends on the state's laws on aliens. If we conceive of migration following the usual definition—as the relatively permanent movement of persons over a significant distance—the specifications "permanent" and "significant" must be set by more or less arbitrary criteria. Partly for this reason, migration statistics are generally imprecise and subject to capricious interpretation.

Migration changes the size of population and the rate of growth in the two areas involved, but usually not in the simple fashion that common sense suggests. Most migrants are young adults, and their movement changes the age structure, and thus the birth and death rates, in both areas. Given a sedentary population and a stimulus to emigrate, typically some leave and some do not. There is self-selection by age, sex, family status, and occupation, as well as possibly by intelligence, mental health, and independence of character. Since migration is not unitary, it cannot be analyzed in supracultural terms but must be differentiated even at the most abstract level with respect to the social conditions obtaining. Generalizations about migration, thus, developed mostly outside of standard population theories.

Demographic Transition

The number of people in the world is increasing at an unprecedented rate to unprecedented totals, and the basic reason is no mystery: Mortality has fallen sharply, and in many areas fertility has not. As originally formulated (e.g., Landry), this so-called demographic transition was conceived as taking place in three broad stages: (1) preindustrial societies, with high fertility more or less balanced by high mortality and a consequent low natural increase; (2) societies in transition, with continuing high fertility but declining mortality and a consequent rapid natural increase; and (3) modern societies, with both fertility and mortality stabilized at low levels and a consequent more or less static population. In its barest form this theory is one of the best-documented generalizations in the social sciences.

Collapsing the whole of human history into these three demographic types means, of course, that not only details but also important distinctions are passed over. When actual populations are reconstituted, so simplistic a theory often proves to be less a guide to research or policy than an invitation to misunderstanding. And this has been so concerning each of the three stages (Chesnais).

It is assumed that the mortality of primitive peoples was high relative to that in advanced societies, but estimates of the longevity in ancient times can hardly be very precise. Whether or not preindustrial peoples were warlike, lived in a favorable climate, developed cultural norms promoting cleanliness, and so on certainly influenced their death rates. And the usual formula—that since the mortality of primitive humans was high, their fertility must have been close to the physiological maximum if the group was to survive—is also questionable. From an early survey of contemporary primitive cultures, Alexander Carr-Saunders (1922) concluded that *all* of them included customs intended to restrict the increase of population. There is no reason a priori to postulate that all prehistoric peoples reproduced like unthinking animals, incurring the cost of a subsequent unnecessarily high mortality.

In stage two, the first steps toward a modern industrial society bring about a decline in mortality—but also often, contrary to the theory, a rise in fertility. Improved health can result in greater physiological ability to reproduce. Whatever means had been used to reduce population growth, such as infanticide in Tokugawa Japan, may not survive modernization. If the age at marriage had been set well past puberty, as in early modern western Europe, the institutions bolstering this norm often became less effective. Religious practices or taboos unintentionally inhibiting fertility, such as the one prohibiting the remarriage of widows in Hindu India, may dissipate. Most remarkably, family-planning programs can result in a rise in fertility, for if women are able to depend on controls later in their reproductive life, many begin childbearing at an earlier age. In short, the effect of modernization is partly to increase fertility and partly to decrease it (Heer).

Moreover, the early analysts of the demographic transition failed to forecast the decline of mortality in less-developed countries. Over the past two centuries or so, as the main advances were applied in medicine, surgery, public sanitation, agriculture, and nutrition, Western populations gradually improved in health and longevity. During the last several decades, however, some of the most recent techniques have been transferred to areas lacking most prior scientific controls; peoples cared for until recently by witch doctors acquired access to antibiotics. In Ceylon (now Sri Lanka), to take one striking example, the estimated expectation of life at birth increased from forty-three years in 1946 to fifty-two in 1947; the gain achieved in this one year had taken half a century in most Western countries.

Efforts to Reduce Fertility

Because of the continuing high fertility and the sharp decline of mortality in less-developed countries, their populations have grown at rates high enough to stimulate widespread control measures. Some of these programs have been successful, but many have achieved far less than their proponents hoped they would, in part because none has an appropriate theory underlying it.

Is a large and rapidly growing population indeed a problem? Leaders of the independence movements of pre-1940 European colonies held that their countries' poverty derived not from excessive procreation but from imperial misrule, and this view often persisted after independence. The very slow start of India's programs to check its population growth, for instance, was due in part to Jawaharlal Nehru's initial ambivalence. Among those who accept the thesis that too many people can impede modernization, proponents have often advocated *either* birth control *or* industrialization, as though one or the other were the sole relevant factor.

The theories underlying birth-control programs, often implicit rather than spelled out in papers, reports, or books, can be summed up in the following propositions:

1. *Elements of "traditional" society constitute the principal impediment to the spread of contraception.* But, as we have noted, most traditional cultures include antinatalist tendencies and, on the other hand, modern nationalism is often strongly pronatalist.
2. *The most important variable in any program is the contraceptive means to be used.* But the history of the West suggests that, given the will to reduce fertility, people will make effective use of whatever means are available to them—coitus interruptus and illegal abortion in France, postponed marriage or nonmarriage in Ireland, and so on.
3. *The agency through which contraception can be most effectively disseminated is the state.* But this contradicts, again, the history of the decline of Western fertility, where officialdom typically opposed the private neo-Malthusian leagues and their successors.
4. *Population policy can be equated essentially with family policy: That is, zero population growth can be realized by inducing each pair of parents to have an average of only two children.* But the rate of growth depends also on the proportion of the population that is of childbearing age, and in less-developed countries that is generally very high.
5. *It is so important that the population crisis be solved that policy-oriented action and knowledge-oriented research must be collapsed into a single operation.* This procedure violates the scientific canon that truth can be effectively sought only in a setting made as value-free as possible. As a consequence, field workers and analysts are encouraged to accept spurious results as valid, for it is very difficult to ascertain the actual sentiments and behavior patterns of respondents.

In sum, the many attempts to reduce fertility in less-developed countries have typically been made with little regard to what had been learned from the prior decline in family size in the industrial West. Perhaps the best link between the two is the wealth-flow theory, so designated by John Caldwell. The crucial factor is whether children are productively useful to their parents and care for them in their old age; if so, as in African cultures he studied, the incentive is to procreate to the maximum feasible. If, however, parents incur net costs for the long-term care and education of their children, who generally contribute little to household finances, the inevitable tendency is to reduce the number brought into the world. By concentrating on the family budget, Caldwell (1982) was able to elucidate both the historical decline of fertility in the West and the partial success of family-planning programs in less-developed countries.

Theories of Population in Totalitarian Countries

A focus on economic or cultural factors can mean that political influences on fertility are bypassed. More generally, theories developed in the democratic West are in many respects ill suited to analyze such past totalitarian societies as the Soviet Union and Nazi Germany. Though their cultures differed greatly, these two countries had certain features in common, many of which related to population theory and its application.

1. The Nazi party and the Communist party were defined as omnipotent, able to cope with any increase in population. According to the first Soviet delegate to the U.N. Population Commission, "I would consider it barbaric for the Commission to contemplate a limitation of marriages or of legitimate births, and this for any country whatsoever, at any period whatsoever. With an adequate social organization it is possible to face any increase in population" (quoted by Sauvy, vol. 1, p. 174; cf. Petersen, 1988).
2. Population theory had the same purpose as any other science—to bolster the power of the party in power (Besemeres). In particular, the need of the totalitarian state for labor was reflected in theories on how to maintain a high rate of population growth and in such applications as family subsidies.
3. Efforts to stimulate the birthrate, however, were hampered by the ruling party's hostility to the family, which by its legal and emotional links between generations helps to maintain a traditional opposition to radically new ideas and practices. Both Nazi Germany and the Soviet Union tried to establish institutions that could replace the family, such as brothels in which SS men could impregnate young women certified as racially pure, or the Soviet children's homes in which the state could convert orphans and the offspring of political dissidents into reliable instruments of the Communist party. But such substitutes never produced a large enough crop,

and policy toward the family therefore vacillated in both countries.

4. The need for a high fertility was enhanced by the recklessness with which sectors of the population designated as hostile or inferior were killed off. The terror most closely associated with the Nazis was the mass slaughter of Jews, based on the outpouring of writings on *Rassenkunde* (race science). More often Communists defined their victims as class enemies (though antagonism to ethnic minorities was also a constant element of Soviet life), but the difference was not fundamental: The slaughter began in different sectors of the population and was sometimes concentrated there, but in both cases it spread to the whole society (Hilberg; Conquest).
5. Totalitarian ideology was based on what in German is called *Stufenlehre,* a doctrine of stages. All analysis, all planning, began not in the empirical present but in the inevitable perfect future, homogenized into a "classless" (*Judenfrei,* "Jewless") sameness. The road to this paradise could be seen clearly only by the Nazi party and the Communist party, whose function was to move the rest of the population toward its destiny. The ruthless terror that was often needed was warranted, thus, by the glorious community that would ensue.

Conclusions

Intellectual history includes few population theories in the narrow sense; most theories were developed as usually minor adjuncts to systematic statements about the society or the economy. Even this thin conceptual framework, however, may have profound ethical implications, for long before anything scientific was known about the determinants and consequences of population growth, statesmen, theologians, and scholars proposed—and their societies sometimes adopted as policies—rules of behavior allegedly suitable to their environment.

Until the modern era, the usual policy orientation was pronatalist, for it was generally assumed both that more people were better than fewer and that realizing a faster growth required state aid. Though not the first to take a contrary position, Malthus was by far the most important. Paradoxically, the greatly increased concern with policy in recent decades has not been accompanied by a more precise definition of goals. The judgment of whether a population is too large or too small obviously depends on a reasonably precise designation of the optimum, which has remained perhaps the most controversial concept in demography.

In past times, tyrants and conquering armies slaughtered many aliens, variously defined, but the combination of ruthless nationalism with scientific means of disposing of "inferior" sectors of the population is an innovation of the twentieth century. Partly because of a reaction against totalitarian genocide, demographers have given less systematic attention than warranted to such population characteristics as health or skill, though in many contexts these may be more important than mere numbers.

In recent decades the most striking characteristic of demography has been the attempt to dispense with theory in the solution of population problems widely recognized as critical. The substitution of "concern" for competence has not led, however, to many successes. In spite of the proliferation of antinatalist programs in less-developed countries and of the numbers of potential parents who accept the contraceptives made available, the world's population continues to grow at a rapid rate.

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SEE ALSO: *Eugenics; Family and Family Medicine; Fertility Control; Infanticide; International Health; Public Health; Sustainable Development; Women, Historical and Cross-Cultural Perspectives;* and other *Population Ethics* subentries

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II. NORMATIVE APPROACHES

Population policies raise profound questions of ethics. Is China justified in using coercion to enforce its policy of one child per couple? Is it legitimate for government officials and community peers in Indonesia to apply strong pressure to promote birth control? Should U.S. judges be free to require the insertion of Norplant, a long-lasting, subdermal contraceptive, when sentencing women they consider unfit to be mothers (Feringa et al.)? Do the wealthiest nations of the world have a moral obligation to accept refugees from poor countries?

Answers to such questions require ethical principles applicable to population policies across all countries and cultures. Principles that reflect the standards of only one country or region, such as the United States or Europe, may not persuade leaders and peoples of other countries.

Three schools of thought have guided debates on these principles. The first argues that government programs of any kind must respect human rights as stated in the Universal Declaration of Human Rights adopted by the United Nations in 1948; the International Covenant on Economic, Social, and Cultural Rights (1976); the International Covenant on Civil and Political Rights (1976); and many related U.N. statements (Nickel; Claude and Weston). A second school holds that the morality of population interventions must be determined by the country that carries them out, for it has the problem and best understands how to deal with it. This school accepts no universal standards of human rights. It considers attempts by others to impose such standards to be infringements on national sovereignty. The third school recognizes some or all of the human rights affirmed by the United Nations, but claims that when population growth or density create desperate economic or social problems for a country, its government has the right to limit individual reproductive freedom for the common good.

This article develops a framework of ethical principles based on the Universal Declaration of Human Rights, later U.N. statements on human rights, and regional declarations on the same subject, particularly the European Convention on Human Rights. It then applies those principles to population policies. It concludes by contrasting this approach with another ethical framework known as "stepladder ethics."

Five Key Principles

Ethical evaluation of population policies requires five principles to guide decisions as well as criteria for determining when one principle can be sacrificed for another.

Life heads the list, for without it people cannot benefit from the other four principles. Article 3 of the Universal Declaration of Human Rights states: "Everyone has the right to life, liberty and security of person." The International Covenant on Civil and Political Rights is more specific: "Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life" (Part III, Article 6).

Life means not only being alive, but enjoying good health and having reasonable security against the actions of others that cause death, illness, severe pain, or disability. Policies on fertility control, migration, and refugees threaten this principle when they take no action to assist people facing starvation or slaughter and when they create incentives for female infanticide (Aird; Brown and Shue). Policies endanger health when they promote methods of fertility control, such as sterilizations, oral contraceptives, the intrauterine device (IUD), or injections, that can pose grave risks to physical well-being. Among such risks are cardiovascular diseases, tubal infertility, pelvic inflammatory disease, and septic abortion (National Research Council, 1989; Schearer). Fertility-control programs may also damage the health of users when they overlook sexually transmitted diseases, such as gonorrhea, or other reproductive-tract infections, including genital herpes, chancroid, genital warts, vaginal infections, and infections of the upper reproductive tract (Dixon-Mueller and Wasserheit).

Freedom is the capacity and opportunity to make reflective choices and to act on those choices. Freedom requires knowledge about the choices available, such as options for fertility control or migration; a chance to make choices without coercion or strong pressure from others; awareness that one is making choices and of the issues at stake in each; and the possibility of taking action to carry out the choices made (Warwick, 1982, 1990; Veatch). Restrictions on any of these conditions, such as ignorance of options, decisions made while an individual is being tortured, or barriers to acting on choices made, void or limit freedom.

U.N. statements strongly endorse freedom. According to the Universal Declaration, everyone has the right to freedom of thought, conscience, and religion (Article 18); freedom of opinion and expression (Article 19); freedom of peaceful assembly and association (Article 20); freedom from slavery and servitude (Article 4); and freedom from arbitrary interference with privacy, family, home, or correspondence (Article 12). Both the International Covenant on Economic, Social, and Cultural Rights and the International Covenant on Civil and Political Rights open with this statement: “All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social, and cultural development” (Part I, Article 1, in both covenants). In the World Population Plan of Action developed at the World Population Conference in 1974, delegates agreed to the following statement on reproductive freedom: “All couples and individuals have the basic right to decide freely and responsibly the number and spacing of their children and to have the information, education, and means to do so …” (World Population Conference, p. 7).

Welfare means a standard of living adequate to provide food, clothing, housing, healthcare, and education. Affirmed in Articles 25 and 26 of the Universal Declaration, this standard was both repeated and broadened in the International Covenant on Economic, Social, and Cultural Rights. That statement spoke specifically about the right to continuous improvement in living conditions; the steps needed to protect the right to be free from hunger; the right of everyone to the highest attainable standard of physical and mental health; the widest possible protection and assistance for the family; special protection for mothers before and after childbirth; and protection of children and young persons from social and economic exploitation, including work that threatens their lives or is harmful to their morals and health. The World Population Plan of Action of 1974 also explicitly tied population policies to human welfare: “The principal aim of social, economic, and cultural development, of which population goals and policies are integral parts, is to improve levels of living and the quality of life of the people” (World Population Conference, p. 7). Population programs, therefore, should not aim only to raise or lower fertility, reduce mortality, or control migration, but to be instruments for promoting human welfare.

Fairness refers to an equitable distribution of the benefits and harms from population policies. It does not require an equal distribution of benefits and harms, but it does demand that one individual or group should not receive disproportionate advantages or disadvantages from a given policy. The Universal Declaration strongly endorses fairness in Article 1: “All human beings are born free and equal in dignity and rights.” Article 2 continues: “Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status.” The 1967 U.N. Protocol Relating to the Status of Refugees established principles for determining fairness in refugee and immigration policies.

In 1972, Ugandan President Idi Amin Dada ordered the expulsion of between 40,000 and 50,000 Asians living in Uganda. His action is an extreme example of the unfairness seen when the costs of population policy are borne by a single ethnic group. India’s use of coercion to promote sterilization among beggars and other poor people between 1975 and 1977 was another case of unfair policy implementation (Gwatkin). Other examples include the testing only in low-income areas of contraceptives designed for all women (Holmes et al.), and failing to tell uneducated candidates for sterilization how this operation is carried out, what it means for fertility, and what medical risks and side effects accompany it. In each of these cases the political, economic, social, and medical harms of population interventions fall more heavily on one group than another.

Truth telling requires accurate information about population policies and avoiding lies, misrepresentations, distortions, and evasions about their content, implementation, and consequences. Though truth telling is not explicitly stated in U.N. declarations of human rights, it is a prerequisite for the other four principles cited. Lies about policies of fertility control, migration, and refugees can jeopardize human life when they involve fatal risks, such as death from infections or from being shot in enemy territory. They limit freedom by depriving individuals of the knowledge necessary to make an informed choice, such as information about the side effects of sterilization. Lies harm welfare when they cause risk to one’s income, education, or job prospects, and they violate fairness when they are more likely to be told to one group, such as the poor or an ethnic minority, than to others.

Life, freedom, welfare, fairness, and truth telling can conflict with each other. Faced with what they see as excessive population growth, government officials may claim that the common welfare demands restrictions on reproductive freedom and allows distortions of the truth, such as not disclosing the medical risks of contraceptives, in order to make birth control seem attractive. Also citing the national interest, political leaders may decide to exterminate members of a specific religion, such as Jews in German territory during World War II; expel an entire ethnic group from the country, as happened in Uganda; or put severe limits on the entry of immigrants they define as hostile to the national interest, as happened when the U.S. government used ships to block the entry of Haitian refugees in the early 1990s. All three policies subordinate fairness toward religious and ethnic groups to local definitions of the common welfare. Are such policies justified, or are there some principles that cannot be sacrificed to promote others?

The Universal Declaration puts no relative weights on the many rights it endorses. However, later agreements do set priorities among rights. In Article 15, the European Convention on Human Rights states that even in national emergencies, governments cannot use murder, torture, degrading punishments, slavery, or servitude. These rights thus hold the highest rank. Nothing, including government concerns about the damage due to population growth, can override them. The International Covenant on Civil and Political Rights, drafted after the European Convention, accepts all the rights that the Convention declares immune to being overridden and adds others, particularly freedom of thought, conscience, and religion. Henry Shue (1980) and James Nickel (1987) suggest comparable criteria for weighing human rights while Sissela Bok (1978) discusses the value of truth telling and the conditions under which it may be suspended.

Application to Population Interventions

The viability of any framework of population ethics depends on its ability to illuminate right and wrong in specific policies, strategies, and sets of actions. Policies set the directions for population interventions, strategies show the broad plans for following those directions, and actions indicate what happens in the field, whether intended or not. The ethics of the three are not necessarily the same. Policies may be stated in humane terms and yet be accompanied by strategies that are coercive. Strategies can be expressed in benign language but, through deliberate initiatives or neglect, lead to field actions that compromise truth, limit freedom, damage human welfare, and in extreme cases, threaten life. Ethical analysis must pay close attention not only to official statements of policies and strategies, but also to how the programs they generate are carried out.

The five ethical principles will now be applied to three examples of interventions begun by population policies. In each case the aim will be to lay out the key principle or principles involved and to indicate how apparent tensions among principles might be resolved.

THE "POPULATION PROBLEM." Population policies usually begin with some notion of a problem. For strong advocates of fertility control, such as Paul Ehrlich and Anne Ehrlich (1990), the problem is captured in phrases such as "the population bomb" or "the population explosion." According to others, particularly Julian Simon (1981), population growth brings many benefits to society, including the stimulation of human creativity. And for some, fertility, migration, and refugees are complex phenomena that must be carefully studied and that may produce no catchwords that draw public attention.

Any definition of a population problem, or a statement that there is none, must be governed by the principle of truth telling. Those claiming a problem exists should indicate the good promoted or the evil created by fertility, migration, and refugees. What, precisely, has population done to make it qualify as a problem or a nonproblem?

Statements of a problem should also give a fair summary of the evidence bearing on the subject and its limitations. If the findings are drawn from simulations, or cover a small sample of the countries in the world, those points should be disclosed. Scholars violate truth telling when they say or imply that simulations done through a hypothetical model of reality are equivalent to data on what people or organizations actually do. Further, when scholars who write on population work for or are funded by organizations promoting or trying to prevent action on population, such as the World Bank or a right-to-life committee, can it be determined whether they have remained objective or have taken on the advocacy role of their sponsors? If scholars have merged research and advocacy, do they indicate where research stops and advocacy begins? Truth telling requires that all relevant information be presented, even when it may harm one's active endorsement of a policy.

Claims that a problem exists must next show the specific connection between research evidence and the good or evil that makes it a problem. That connection often proves elusive. Data showing that the poorest nations of the world have the highest fertility and the wealthiest nations the lowest fertility may seem to establish a link between population growth and economic development. Indeed, such data are commonly used to support claims of a "population bomb." Yet many studies have failed to show that rapid population growth holds back economic development in the industrialized or developing countries, and a few suggest that it may have advantages (Boserup; National Research Council, 1986). To meet the standard of truth telling, scholars should not, as often happens, cite only those studies that support the view of a population problem to which they subscribe and omit contrary evidence.

USING COERCION. China has used coercion to force some of its citizens to limit fertility. *Coercion* means using or threatening to use physical force or severe deprivation in order to make people do things they would not normally do. Governments apply physical force when they order armed police or military officers to take citizens against their will to clinics that perform abortion or sterilization, or when they credibly threaten with torture couples who have more than two children. They use severe deprivation when they require that poor citizens be sterilized before they can obtain a job or receive food supplies necessary for their own and their family's welfare; warn that parents with more than a certain number of children will be put in prison or have their houses demolished; or use other threats that carry serious risks to life, health, and welfare.

China has relied on coercion to carry out its one-child-per-couple policy (Aird). The Chinese government claims that its policies are voluntary, but its pressure on field workers to meet their targets, particularly in cities, has led to coercive implementation. According to Tyrene White: "Beijing's penetration to the household is awesome. In 1979 mobilization campaigns for 'voluntary' sterilizations, abortions, and adoption of contraceptive measures were widespread, and the fine line between persuasion and coercion was crossed frequently" (p. 315). Two other scholars comment: "During 1979 and in some subsequent years, in some urban areas and provinces, women pregnant with a second or higher order child were required to abort the pregnancies. Instances of mandatory sterilization were also reported" (Hardee-Cleaveland and Banister, p. 275).

China's use of coercion and heavy pressures to reduce fertility has, from indications, led to female infanticide and adoption (Johansson and Nygren). In traditional China, men had the basic duty of continuing the descent line of their fathers by having a son. This boy could carry on the family name, support his parents in their old age, and inherit their property. Failure to have a son showed ingratitude to one's ancestors and discredited men in their own communities. This tradition has continued to the present. If a man's only child is a daughter, he and his neighbors may feel that he has not fulfilled one of his most basic duties in life. Yet a successful one-child policy would mean that many males could not have a son. Demographic analysis strongly suggests a clash between a couple's normal desire to keep and raise their daughters and the limits on having sons imposed by the country's policies on fertility control.

Terence Hull (1990) shows that in 1987 the sex ratios in China—the number of males per 100 females—were nearly 111, compared to an earlier reference norm of 106. Using comparable data, Sten Johansson and Ola Nygren (1991) estimate that from 1985 through 1987 the average number of missing girls (those normally expected to be in the population but, in fact, missing from it) was about 500,000 per year or 1,500,000 for those three years alone. These authors and others writing about the many millions of missing girls in China attribute this phenomenon to the one-child-per-couple policy. They offer four possible explanations: infanticide caused by deliberate actions of the parents or neglect leading to fatal illnesses; a higher proportion of abortions for female than male babies; births not properly registered with the authorities, usually because they were beyond the local quota for couples; and the practice of offering female children for adoption. The evidence offered by Johansson and Nygren suggests the presence of excess female infant deaths, whether from infanticide or other reasons; unregistered babies; and female adoption.

China's coercive policies show the severe tensions between limiting population for the common good and life, freedom, and fairness. If, in response to the one-child norm, Chinese couples have used female infanticide to raise their chances of having a son, compulsion clashes with the infant girl's right to life. Government officials may say that they never intended to encourage infanticide, but that statement does not absolve them of responsibility for the deaths that take place. A full ethical analysis of policies must take account not only of official declarations and intentions, but also of the actions to which they lead. If, as seems to be the case, the policy of one child per couple has led to infanticide, by U.N. standards of human rights this sacrifice of life cannot be justified by the argument that China's overpopulation demands stringent control of fertility. In social policies, life holds such a high value that it cannot be traded off for even the most compelling public claims.

Coercive policies also put unjustifiable limits on human freedom. Unlike life, freedom can be and often is restricted for the common good. Laws, tax regulations, and many other policies indicate what individuals and groups must and must not do. But forcing citizens to undergo sterilizations or abortions that they do not want, as has happened in China, violates the principles of liberty and human dignity endorsed in all U.N. declarations of human rights. The moral question is not whether individuals should be totally free to set their family size—which they are not in any country or culture—but whether some limits on reproductive choice violate human rights. Using force to promote small family sizes does violate those rights.

China's population interventions further raise the question of fairness. Policies leading directly or indirectly to female infanticide, the abortion of female children, or female adoption put a far heavier burden on girls than boys. Abortion and infanticide mean that, through the decisions of their parents, girls stand a lower chance than boys of being born or of surviving to be adults. With adoption, young girls survive but do not have the same opportunity as male children to be raised by their parents. All three outcomes violate fairness by providing more benefits to boys than to girls and more harms to girls than to boys.

INADEQUATE MEDICAL SUPPORT. Fertility control programs in low-income countries sometimes lead to a conflict between efficiency in delivering services and healthcare for those receiving the services. To raise efficiency, program managers may insist that field workers meet the targets set for them and threaten with severe punishments those who do not comply. During India's birth-control campaign between 1975 and 1977, which relied heavily on forced sterilization, the Chief Secretary of the state of Uttar Pradesh sent this telegraph to his subordinates: "… Failure to achieve monthly targets will not only result in the stoppage of salaries but also suspension and severest penalties. Galvanise entire administrative machinery forthwith and continue to report daily progress by … wireless to me and secretary to Chief Minister" (Gwatkin, p. 41).

Managers and staff working under such pressures often provide little or no health support for those receiving their services. In India during the period mentioned, hundreds of men died from infections that developed after hastily performed sterilizations with no medical follow-up (Gwatkin, p. 47). Other health hazards caused by fertility-control methods include severe, and sometimes fatal, upper reproductive-tract infections among women not properly screened for the intrauterine device; medical complications produced by using the Dalkon shield and high-dose oral contraceptives in developing countries when their risks were well-known in the United States and Europe; reproductive-tract infections among thousands of women in poor countries; and disruptions of the menstrual cycle, heavy bleeding or spotting, weight gain, depression, headaches, dizziness, fatigue, bloating, or loss of libido among women using the injectable contraceptive Depo-Provera (National Research Council, 1989; Schearer).

Ethical Responsibilities of Fertility-Control Programs

Given these risks to life and health, officials responsible for fertility-control programs face three questions of ethics. The first question concerns the amount of information about the hazards of a particular method that should be disclosed by program staff to their clients. With heavy pressure from their superiors to meet their targets, field workers often emphasize the benefits of a method and conceal its risks. This practice violates the principle of freedom, which requires that clients have reasonable information about risks and benefits to make an informed choice about fertility control. Even when clients cannot grasp sophisticated explanations of medical hazards, they can be told what is at stake in language that they understand. When the risks not disclosed are serious, clients may also face threats to their life, their health, or their welfare.

The second ethical question concerns the adequacy of health services to deal with the hazards created by methods of fertility control. Some argue that, given the severity of the population problem, governments are morally justified in operating fertility-control services well ahead of health-support services. Others, particularly groups supporting the rights of women in family-planning programs, claim that this strategy not only violates human rights but produces a backlash against birth control. Clients who have not been told of any possible side effects or complications from the methods offered and who then suffer poor health can retaliate in many ways. They may discontinue the methods they have started, accept a method but not use it, start rumors about the physical dangers of birth control, stay away from family-planning clinics and field workers, enlist religious leaders or political parties to make fertility control a political issue, vote against the government in the next election, or, if they are truly angry, riot against the government in power. Many of these reactions followed India's use of coercion between 1975 and 1977.

The third ethical question is fairness in the distribution of medical harms and benefits among individuals and groups. This issue arises in the testing as well as the distribution of fertility-control methods. Beginning with the contraceptive pill, whose main evaluation was carried out in Puerto Rico, drug companies have often tested new methods of fertility control on poor individuals in developing countries. Government regulations on testing in those countries have been far less strict than in the United States. Moreover, the low-income individuals chosen for the testing asked few questions about what was being done and were unlikely to mount political protests or begin lawsuits to receive compensation for damage to their health. During the distribution of fertility-control methods, poor individuals in many countries likewise have received less adequate explanations and suffered more health hazards than those with higher incomes. As one example, for many years the U.S. government, citing health risks, banned the domestic use of the injectable contraceptive Depo-Provera. But it saw no problem including Depo-Provera as part of the contraceptive services in poor nations supported by U.S. foreign aid.

Four ethical guidelines help to resolve these conflicts. First, no program should knowingly threaten the life of its clients by using methods that can cause death or by failing to provide health services. If, as happened in India, sterilized males apply animal dung to areas of pain, and if that folk remedy proves fatal, fertility-control programs must take all possible steps to prevent its use.

Second, programs must offer healthcare for all users of methods with serious medical risks. In its villages, Indonesia has developed a simple system of healthcare often located in the home of the village head or another resident. Should clients show symptoms that cannot be treated there, they are referred to the nearest health clinic or hospital.

Third, clients must be told, in words they understand, about the risks as well as the benefits of fertility-control methods. To deny potential users information about risks unjustifiably limits their freedom of choice. Explanations need not be elaborate to be accurate, but they must be given.

Fourth, the distribution of risks and benefits from fertility-control programs should be fair, though not necessarily equal. Poor persons should not be the main candidates on whom fertility-control methods are tested, nor should some groups of citizens receive adequate health support while others receive little or none.

To promote user freedom and welfare, program designers and field workers can be trained to adopt the standards of quality suggested by Judith Bruce (1990). Quality care requires technical competence that gives accurate information to users in language they understand; informed consent that shows sensitivity to concerns about modesty among women and girls; pain management; and continuous rather than one-time service to clients. Instead of aiming only to avoid violations of human rights, which might attain that goal but result in mediocre care, staff can be taught to seek high client satisfaction with fertility-control services.

Stepladder Ethics: A Contrast

Ethical principles based on internationally accepted standards of human rights contrast sharply with the stepladder ethics proposed by Bernard Berelson and Jonathan Lieberson (1979). Berelson was president of the Population Council, a visible center of research, training, and advocacy on population policy, and Lieberson was a philosopher who served as adviser to the Population Council and taught at Columbia University. These two authors commanded attention and respect, and their article was the first and last systematic analysis of ethics to appear in *Population and Development Review*, the leading journal on population policy.

Berelson and Lieberson offered this pivotal statement about population ethics: "Employ less severe measures where possible and only ascend to harsher measures if the problem at hand, as a matter of (established) fact, is clearly grave enough to warrant it" (p. 596). They continued: "… The degree of coercive policy brought into play should be proportional to the degree of seriousness of the present problem and should be introduced only after less coercive means have been exhausted. Thus overt violence or other potentially injurious coercion is not to be used before noninjurious coercion has been exhausted" (p. 602). Their moral stepladder involves beginning with voluntary policies and, if they fail, moving up the scale of pressure on people to the point justified by the seriousness of the population problem. They do not mention fertility-control measures involving threats to life, but, by their logic, governments facing exceptionally severe problems from population growth would be allowed to use those methods as well.

The authors state that they are writing out of a Western, individualistic mode, and recognize that other countries draw ethical principles from different philosophical and political traditions. They do not mention U.N. declarations on human rights, or the widely varying views of the world's religions on methods of fertility control. They apply their Western code to the strategies adopted by countries whose local standards are very different from their own. Leaders in countries populated by Catholics, Buddhists, and Muslims, for instance, might vigorously challenge the principle of allowing governments to use any form of coercion in limiting fertility. Stepladder ethics provides no means of developing cross-national ethical principles whose morality derives mainly from religion or from assumptions that differ from those of the authors, including human rights.

Stepladder ethics thus differs greatly from principles based on universally accepted human rights. Norms such as life, freedom, fairness, and welfare provide a basis for developing ethical guidelines for population policies that apply to every society. Like all ethical principles, those norms need clear definition and are often violated in practice, but they open the way for discussion among persons from diverse political systems and religious traditions and beliefs.

Conclusions

To be applicable to the hundreds of countries and cultures across the world, population ethics must be based on widely shared norms. Principles drawing on the assumptions of a single society or culture will often be rejected by those from other backgrounds. Moreover, to be viable in helping decisions about population policies, the principles chosen should have priorities assigned to them. They must be able to answer one of the most challenging questions in ethics: Is it morally acceptable to sacrifice one principle, such as life, for another, such as the common welfare?

This entry proposes four principles based on international declarations of human rights: life, freedom, welfare, and fairness. It adds truth telling as a fifth principle valuable in itself and necessary in reaching the other four. When these principles clash, life receives first priority. In contrast to stepladder ethics, which grants no human rights, the ethical framework proposed here bans any method of population control with serious risks of death or those relying on torture, slavery, servitude, or other degrading punishments.

If adopted, this ethical framework would have the same advantages and limitations as all universal codes of human rights. The main advantage is that it can be used to educate policymakers and field workers on what is and is not morally acceptable in population programs. When a program violates its standards, U.N. organizations, including the Commission on Human Rights, or private groups, such as Amnesty International, could document the abuses of human rights and demand more humane policies or practices. As has already happened, universal codes can also stimulate geographic regions, such as Europe and Latin America, or major religions to examine human rights from other perspectives. S. M. Haider (1978) and his associates, for example, found many parallels and some differences between Islamic teaching and the Universal Declaration of Human Rights.

The key drawback to this framework is that, like other declarations of human rights, it might be viewed as noble in the abstract but unworkable in practice. Critics could say that it embodies foreign rather than national standards and takes no account of the difficulties with population control that face an overcrowded nation. Even so, it would give local and international advocates of human rights criteria that could be used to develop political and moral pressure to end abuses such as forced sterilization and abortion. And it would avoid the charge, leveled against stepladder ethics, that its ethical standards derive from one country or region, such as the West.

A normative framework based on internationally accepted standards of human rights offers no simple answers to the complex ethical difficulties found in population programs. It does, however, provide a foundation for discussing morality among those who hold widely different views about politics, religion, ethics, and culture. Without that foundation there will never be any serious analysis or lasting agreement about what should and should not be done in population policies and programs.

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SEE ALSO: *Abortion; Adoption; Coercion; Embryo and Fetus: Religious Perspectives; Eugenics and Religious Law; Genetic Testing and Screening; Infanticide; Feminism; Fertility Control; Freedom and Free Will; Harm; Infanticide; Informed Consent; Justice; Life; Natural Law; Race and Racism; Rights, Human; Sexism;* and other *Population Ethics* subentries

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III. RELIGIOUS TRADITIONS: A. INTRODUCTION

How and to what extent religion influences population policies and the practices of individuals, couples, and larger groups is a very complex question. Although specific religious teachings about marriage, ideal family size, and the permissibility of birth control or abortion would seem to bear on reproductive decision making, the actual effects of these religious beliefs and teachings are not easily assessed. Explicitly pronatalist doctrines that espouse the value of having many children and oppose birth limitation sometimes have little effect on reproductive behaviors or policies, while other aspects of religion, seemingly remote from reproductive decision making, may have powerful demographic effects.

Until recently, most major religions stressed marriage as a religiously sanctified state and were pronatalist in outlook; such teachings reflected the perilous demographic circumstances in which these religions were formed. Although Eastern Orthodox Christianity and most Protestant denominations have come to accept the use of contraception for family planning, other major traditions have concretized traditional religious pronatalism in specific beliefs that discourage the use of birth control. Roman Catholicism continues to prohibit contraception and sterilization; Orthodox Judaism forbids use of the condom or any male methods that prevent insemination. Classical Islam, Hinduism, and Confucianism, while more permissive regarding use of birth control, share the traditional religious bias in favor of marriage and large families. Although abortion has played an important role in societies that have undergone population stabilization, no historical religious tradition favors the use of abortion for purposes of limiting the size of the family.

Other features of religious practice and teaching would seem to have a strong pronatalist effect. Many traditions stress the importance of offspring, especially sons, in carrying out vital religious rituals and in maintaining family continuity. The *Rigveda* (VI.61.l), Hinduism's foundational sacred text, terms a son a *rnachyuta,* one who removes the moral debts of a father and spares him from hell. Recent studies suggest that preference for sons leads couples in India to continue building their family until they have a son

(Arnold, Choe, and Roy; Vlassoff). In Judaism, key rituals emphasize the importance of children, especially male offspring: a son's *bris,* or circumcision ceremony, is a major source of religious joy; children play an important part in the Passover service; and the *kaddish* rite for the dead is ideally performed by a surviving son.

In African tribal societies, veneration of the ancestors is a central religious activity. Whatever immortality awaits the individual after death depends on survivors' continued performance of family rites. Individuals without progeny are viewed as pitiful figures who may become marauding spirits after death (Molnos). Since ancestors profoundly affect the circumstances of the living, family prosperity and health require the existence of an ample number of descendants to maintain the family cult. In contrast to Western views, popular opinion in some African societies favors providing a scarce, lifesaving medical therapy to a bachelor over a family man (Kilner). This reflects the belief that an individual's religious and social significance is not established until he or she founds a family.

In addition to formal teachings, the whole tapestry of a religion's beliefs, its "bioethical sensibility" (Green), must be taken into account in understanding its bearing on demographic behaviors. Thus, although Judaism is historically pronatalist, it also tends to privilege women's interests in reproductive matters. This has led Jewish women to be among the most enthusiastic acceptors of female birth control measures. Popular religious beliefs, as opposed to formal teaching, must also be factored into thinking about reproductive behavior. Orthodox Islam, for example, does not actively prohibit the use of birth control, and most Muslims live under governments with official family planning programs (Omran). But popular attitudes about kismet, or fate, and the idea that Allah appoints each couple the children they have contribute to a widespread reluctance to adopt family-planning methods (Fagley; Knodel, Gray, Sriwatchacharin, et al.). In Africa and elsewhere, popular beliefs about reincarnation or the existence of "souls in heaven" awaiting birth contribute to a reluctance to employ birth control.

Teachings and practices regarding women are another significant aspect of religion that contributes to high birthrates. There is a growing body of evidence that women's autonomy is a key factor in promoting the practice of birth limitation (Dharmalingam and Morgan; Hindin). As a result, those aspects of religious belief and practice that reduce women's autonomy can contribute significantly to high fertility and population growth. Many features of traditional religions have this effect. For example, Hinduism regards women as of lower karmic status, able to effect spiritual ascent by having children and fulfilling family duties. In different ways, most other traditional religions echo these beliefs, removing women from the central sphere of political and religious life and locating whatever spiritual fulfillment that is available to them in the home (Ruether; Carmody).

Multiple demographic consequences follow from this history of marginalization of women and treatment of them as "second-class" religious citizens. Early marriage is associated with larger completed family size. Religious values that encourage child marriage, as in India, or that discourage women's education and career preparation before marriage are therefore major contributors to higher birthrates. The existence of highly differentiated social roles for men and women also may lead to larger completed family size, since sons and daughters are less "interchangeable" in terms of their ability to fulfill parental needs (Johnson and Burton). When religiously influenced values consign women to the home, their social, economic, and spiritual value comes to depend on their reproductive success. In polygynous African tribal societies, a woman's standing among her co-wives depends on the number of her children. Her material well-being also depends on the number of progeny she has to help her with home-based economic tasks and agriculture (Molnos). Although the consequences of religious teachings and institutional practices about gender have not been measured, they may be among the most important and persistent religious influences on fertility.

These beliefs and practices affect fertility through the behavior of individuals and couples. At the institutional and policy levels, religion can affect population through its impact on national and international family-planning programs. During the early 1970s, the Roman Catholic Church's opposition to contraception made it difficult for the governments of some Latin American nations to mount family-planning programs (McCoy). This opposition was vigorously expressed by the offical Vatican representative at the 1994 Cairo Conference on Population (Martino) and continues to influence Vatican responses to the population policies of the United Nations and other national and international bodies. Opposition to abortion by Roman Catholic and evangelical Christian groups has repeatedly led conservative U.S. administrations to deny support for international family-planning programs that offer abortion services or counseling. This was shown most recently at a December 2002 Bangkok Conference on Population when the administration of George W. Bush sought to strike from the conference's document endorsements of "reproductive health services" and "reproductive rights" because these can include abortion and abortion counseling in nations where this procedure is legal (Dao). In contrast to these oppositional positions, some religious pronouncements on behalf of responsible parenthood by religious leaders in Islamic countries may have contributed to the success of family-planning programs. On balance, it is not clear how much difference religious involvement in population policy or programs makes. For example, official Roman Catholic opposition to birth control and abortion has had little or no effect on altering the very low birthrates in Catholic countries such as Austria, Ireland, or Italy.

Whatever the influence of religion at the level of national policies, there is considerable evidence that explicit religious teachings about birth control or family size are only one of many factors that play a role in couples' reproductive decision making. Decades ago, sociologists noted that socioeconomic modernization is normally accompanied by a "demographic" transition—from the high birthrates of agricultural and traditional societies to the lower birthrates and family-planning practices of urbanized societies (United Nations). Once economic and social modernization begins, this demographic transition occurs regardless of the religious basis of the society, casting doubt on the importance of religion in reproductive behavior.

Demographers and social scientists have tried to determine the precise role played by religious, economic, or social factors in reproductive decision making, and the relative importance of these factors in influencing demographic behaviors. Three main hypotheses about the religion-fertility relationship have been advanced and variously tested by use of survey data or historical case studies (Johnson). The "characteristic" hypothesis stresses that socio-economic determinants are the primary causal factors in behavioral change, often eclipsing specific religious teachings about family size. For example, Joseph Chamie's 1981 study of fertility and religion in Lebanon shows that whatever their traditions teach, educated, urban, middle-class Catholic or Muslim couples make similar decisions about family size and reproduction; and lower-income, agricultural families have higher birthrates, regardless of their creed. In both cases, social and economic circumstances are determinative. The impact of purely religious doctrine on fertility appears significant only while a society is going through economic and social transition, when such doctrine may delay acceptance of birth control.

A second, "minority-group status" hypothesis holds that if a religious group is a minority and holds strong pronatalist views that are heightened by opportunities for group reinforcement, there may be some independent impact of religious teachings on fertility (Kennedy; Day; Williams and Zimmer). Studies of Mormons in the United States, for example, suggest that a pronatalism deeply rooted in Mormon theology and family values, and heightened by intragroup reinforcements, contributes to higher birthrates among Mormons than would be expected among groups of similar social and economic standing (Heaton and Calkins; Heaton).

Only the third, "particularistic theology" hypothesis sees religious belief as an independent causal variable affecting fertility. This hypothesis has drawn some support from studies of demographic patterns widely separated in time or geographical location (Brown and Guinnane; Knodel, et al.; Sanders).

Taken together there is good reason to believe that while religious teachings and doctrines have some direct influence on reproductive behavior and population growth rates, this influence is probably less than the amount of attention given inside and outside religious communities to specific teachings on marriage, birth control, or abortion would suggest. Furthermore, among religious teachings, those less directly related to reproductive decision making, especially the religiously sanctioned subordination of women, may have the most powerful impact on fertility.

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SEE ALSO: *Authority in Religious Traditions; Eugenics; Family and Family Medicine; Feminism; Fertility Control; Infanticide; International Health; Public Health; Sustainable Development; Women, Historical and Cross-Cultural Perspectives;* and other *Population Ethics* subentries

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III. RELIGIOUS TRADITIONS: B. ISLAMIC PERSPECTIVES

Population issues in Islam are the product of the interplay of faith and experience, Muslim belief and local social realities. Like Islam itself, in which unity of faith has been expressed by a diversity of practice, so the application of Islam to population issues has been conditioned by local circumstances and customs as well as personal piety. Understanding the issue of population control in Islam requires an appreciation both of the history of Islamic thought and practice and of its implementation in Muslim countries today.

The impact of Islam on population policies reflects the continuous interaction of religious teaching, local cultural traditions, and national politics. The diverse results of that interaction lead to great variation in the population policies of Muslim countries. Thus the government's approach to fertility control in Indonesia and Egypt differs greatly from that in Saudi Arabia and Iran. The first two have long had active fertility-control programs supported by senior Islamic officials. Saudi Arabia has no active family-planning program. Iran, for religious and political reasons, discontinued its family-planning program after the country's revolution in 1979 (Ross). However, in 1992, responding to severe economic and social conditions, including a rapid population growth, Iran reinstated its program with the approval of the religious leaders (*ulama*).

Muslim attitudes toward population control are influenced by beliefs and values concerning the nature and purpose of society, the family, marriage, procreation, and child rearing; they also reflect responses to several centuries of Western influence and dominance. The locus of Muslim norms and ethical standards is the Shari'a, Islamic law, which constitutes the blueprint for the ideal Islamic society. Shari'a consists of those rules and institutions that God has revealed in the Qur'an. In the early centuries of Islam, pious scholars in various Muslim capitals attempted to delineate God's law for the community. They produced a body of law that combined God's word with human interpretation and application of that word. The difference between the divine component of the law and human interpretations or applications of it has provided the rationale for legal change.

Islamic law is based upon four sources: the Qur'an, which Muslims believe is the literal and perfect word of God; the Sunnah, or example of the Prophet Muhammad; analogical reasoning; and the consensus of the community. Islamic law constitutes a comprehensive ideal that provides guidelines for personal and social life, a Muslim's duties to God (worship), and duties to society (social transactions). Jurists also recognized a number of subsidiary sources. Among the most relevant utilized for social and legal reform is public welfare. Sunni and Shi'ite Islam, the two major groups or traditions within the Islamic community, have a number of law schools, or schools of legal thought. Their laws, while in general agreement, nevertheless include a diversity of orientations, rules, and methods.

Muslim family law, covering marriage, divorce, and inheritance, has long been considered the heart of the Shari'a, an especially sacrosanct component of Islamic law. Historically, the family has been regarded as the basis of Muslim society. As the nucleus of the Islamic community, it is where the next generation receives its religious, social, and cultural training. In modern times, Muslim families, like those in much of the world, have undergone significant change. This is especially clear in the shift from extended to nuclear families as well as in greater educational and employment opportunities for women. These changes have been the subject of continued debate and legal reform.

Reforms in family or gender issues, from family law to population policies, have been widespread and the subject of controversy. During the latter part of the twentieth century, after Muslim nations had gained their independence from European colonial powers, many continued to look to the West for their models or paradigms of development. Political, economic, legal, and social changes were Western-inspired or -oriented, as were modern Muslim elites. As a result, social change, like political and legal reform, has often been judged both in terms of its relationship to the Islamic tradition and its law and within the context of reactions to Western influence, if not hegemony, in the Muslim world.

Marriage and the Family

Marriage in Islam is a sacred contract, though not a sacrament, between two individuals and also between their families (Esposito). Sexuality in Islam is centered on marriage and the family. The married state is the norm—indeed, the ideal—for all Muslims, prescribed by Islamic law and embodied in the life of Muhammad, the exemplar of Muslim life. Celibacy, while permitted if necessary, is not regarded as an ideal. Though procreation and the formation of the family are among the primary purposes of marriage, Muslim jurists from early in Islamic history permitted contraception to limit the size of a family.

Islamic teachings on methods of fertility control depend on the method used. While open to the use of coitus interruptus and methods of contraception such as the pill, many Muslim scholars oppose any form of abortion; others accept it only to save the life of the mother during the first 120 days of pregnancy. Though some Islamic jurists accept sterilization to avoid having more children, most oppose this method unless it is a medical treatment.

Contraception

In contrast to the Christian and Jewish traditions, from earliest times the Islamic tradition showed acceptance of family planning and contraception. From the tenth to the twentieth centuries, the vast majority of legal scholars and all the major schools of law accepted coitus interruptus between a husband and wife. Early acceptance of birth control was built on a combination of sacred texts, biological knowledge, and reason (Musallam, 1978). The Qur'an contains no clear or explicit text regarding birth control. However, the traditions (*hadith*) of the Prophet do. Though some *hadith* forbid birth control, the majority permit it. Muslim jurists were able to construct an argument based on *hadith* and the biological knowledge of the times to declare birth control by means of coitus interruptus as licit. They argued that such means do not limit or counter God's power because they are not foolproof. Thus, if God wanted a woman to become pregnant, his will could and would prevail despite the practice of coitus interruptus.

The prominent religious scholar al-Ghazālī (d. 1111) is representative of the majority of Sunni Muslim jurists who accepted the use of contraception through coitus interruptus. For Ghazali, coitus interruptus was not only licit but also permissible, regardless of the need to practice it, because there was no explicit text in the Qur'an or Sunnah against it, nor was there clear judicial precedent based on an explicit text:

> We have ruled out its [coitus interruptus] … prohibition because, to establish prohibition, one has to have a text [from the Qur'an or Sunnah] or resort to analogous reasoning based on a precedence for which a text is available. In this case … there is neither a text nor a precedent for analogical reasoning. (Omran, p. 80)

The vast majority of Sunni and Shi'ite jurists believed that birth control through the use of coitus interruptus was permissible. However, because it deprived a woman of her right to children and to sexual satisfaction, her consent was required.

Despite the historical record of jurists regarding the permissibility of contraception, some scholars, such as Ibn Hazm (d. 1064), and local religious leaders viewed contraception as prohibited by Islam because they regarded increase in the number of Muslims as a Prophetic (Muhammad's) command. Though the Qur'an has no text that forbids contraception, critics of contraception interpret it to construct and legitimate their case. Among the major arguments offered are that it (1) constitutes infanticide, which is expressly forbidden by the Qur'an; (2) is contrary to belief in God's power and in divine providence, articulated in the Qur'an's teaching that God is the all-powerful creator and ruler or overseer of the world, and that he determines and controls the destiny of all (81: 29 and 11: 6); (3) ignores the Qur'anic mandate to trust or rely on God; and (4) ignores the necessary connection between marriage and procreation, the primary purpose of marriage.

In modern times, many Muslims, reacting to the impact of Western colonialism and imperialism, have argued that by diminishing the number of Muslims, contraception undermines the power of the Muslim community. More specifically, they charge that birth-control campaigns and programs are part of a Western conspiracy to limit development in the Muslim world and thus subdue Islam.

Modern Islamic Thought

The adoption of Western-inspired legal systems in many Muslim countries in the nineteenth and twentieth centuries limited the scope of Islamic law and the prestige and authority of religious scholars. However, because of the centrality of the family in Muslim society, in most countries family-law and family-planning issues continued to be strongly influenced by Islamic law and ethics. Consciousness of and concern over the implications of a population explosion in areas with limited and shrinking resources, the battle against poverty and illiteracy, urbanization, education and changing expectations, and the development of modern methods of contraception have made the issues of fertility control more prominent and contentious in Muslim societies. Government-sponsored family-planning programs and policies have become common in Muslim countries such as Indonesia, Egypt, Iran, and Bangladesh. Government intervention and implementation of such programs have met with mixed success. In many Muslim countries, when governments introduced fertility-control programs, they often looked to Islamic religious leaders to legitimate their programs and to mobilize popular support. Even when they did not support fertility control, Islamic scholars, viewing it as subject to Islamic law and as a critical area of social intervention, felt it was necessary for them to give moral guidance to Muslim believers.

Legal scholars have generally provided an Islamic rationale for various modern methods to control population growth. Modern Sunni and Shi'ite jurists, such as Lebanon's Sheikh Muhammad M. Shamsuddin, employing the legal principle of reasoning by analogy, have argued that since birth control in the form of coitus interruptus has been accepted for so long in Islam, then by analogy other, more modern forms of birth control that achieve the same effect are acceptable (Omran). Both individual jurists and assemblies of religious scholars have issued *fatwas* (formal legal opinions) that have endorsed contraception and in turn not only have informed the consciences of individual Muslims but also have been employed by governments from Egypt to Indonesia to support their birth-control policies and programs.

On the basis of the clear legal precedent of the acceptance of contraception in the form of coitus interruptus, modern jurists have argued for the permissibility of modern chemical and mechanical forms of birth control, such as the diaphragm, the contraceptive pill, and IUDs. Egypt's Sheikh M. S. Madkour, for example, citing the opinions of early jurists, wrote:

> We may say that the first mechanical method known as coitus interruptus, *al-azl* in Arabic, used by our ancestors to prevent pregnancy, corresponds to the device used these days by women and known as the diaphragm or ring to block the uterine aperture, or to another device used by men, the condom. Both are designed to prevent the semen from reaching the ovum and fertilizing it. The second method … for temporary contraception [is] … the contraceptive pill. Under this heading may also be included the injectables much advertised and supposed to be effective for several months … [and] every other beneficial drug which may be discovered by the medical profession for this purpose. The third … is the [IUD], … which … prevents the fertilized egg from attaching itself to the uterine wall, and the uterus expels it instead. (Omran, p. 81)

Sheikh Tantawi, the mufti of Egypt, senior official consultant on Islamic law, in his 1988 *fatwa* recognized several reasons for practicing contraception. Couples may wish to postpone or space the birth of children for financial reasons; others may wish to do so in order to provide a separate room for a son and daughter; even those who are well off but already have three children may wish to avoid another birth because they live in an overpopulated country (Omran).

Jurists have found many licit reasons for couples to practice contraception: to avoid pregnancy due to health risks to the wife or children resulting from repeated pregnancies, transmission of hereditary or infectious diseases, or genetic risks of inbreeding; economic hardship; to better provide for children's education; and even to preserve a wife's beauty (Omran).

Muslim jurists have addressed infertility within the context of family planning. They have tended to show the same openness and flexibility in their treatment of infertility. Thus, chemical and surgical treatment, as well as artificial insemination between a husband and wife, are permitted. Insemination of a wife with her husband's sperm or in vitro fertilization is allowed. However, procedures that involve someone other than a spouse, such as inseminating a woman with sperm from a man who is not her husband, are forbidden. Children who result from such procedures are regarded as illegitimate.

Sterilization and Abortion

As is the case with contraception, there is no clear text of the Qur'an or Sunnah that forbids sterilization. Although some diversity of opinion exists, the majority of jurists have maintained that sterilization for purposes of contraception, as opposed to its use for medical treatment, is forbidden. Whatever the debate among scholars, local Islamic leaders have tended to oppose sterilization. In recent years, a number of Sunni and Shi'ite jurists have called for a reconsideration of the legality of sterilization (Omran).

Abortion is a far more complex and contentious matter. There is a consensus among religious authorities that abortion after 120 days, when the fetus becomes "ensouled" and thus is a person, is absolutely prohibited except to save the mother's life. While many if not most jurists allow abortion as a means of contraception within 120 days of conception, this scholarly and theoretical position stands in sharp contrast with actual practice—abortion is condemned by most religious leaders and omitted from public-sector programs.

Religion, Government, and Population Issues

During the post–World War II period, governments in the Muslim world, faced with rapid population growth, cited religious, demographic, and nationalist reasons for instituting family-planning programs. Some utilized the prestige and authority of the religious establishment to legitimate family-planning policies. In Egypt, the government has often looked to the leadership and scholars of Cairo's al-Azhar University, a historic and authoritative international center of Islamic learning, for support. *Fatwas* obtained from experts (muftis) in Islamic law have played a prominent role in legitimating population policies throughout the Muslim world. However, differences often exist between official religious decrees and the more conservative responses of local religious leaders and popular beliefs. Since there is no organized church or hierarchy in Islam, and no clear text from revelation or consensus of scholars exists, local religious leaders and their followers are free to hold a variety of opinions.

Islam has legitimated and reinforced traditional pronatalist beliefs and practices in areas where social conditions have made large families desirable. Agricultural and pastoral societies have regarded large families as providing a source of labor, insurance against the loss of help due to high mortality or marriage, and social security in old age. Poverty, illiteracy, lack of educational and employment opportunities, and high mortality often foster and promote a belief in the necessity of a large family. Thus, many Muslims have been raised in a social context in which a primary emphasis on procreation in marriage and large families has been the traditional ideal and norm, a custom reinforced by the preaching and teaching of local religious leaders.

Local beliefs, attitudes, and values have reinforced high fertility rates. Values such as early marriage for women and emphasis on fertility and large families, in particular the importance of having a male child, pressure a young wife to gain the status of motherhood to "prove herself." Women also want to avoid the stigma of infertility and with it the possibility of divorce or of the husband taking a second wife. The importance of motherhood is reflected in the common practice in many Arab countries, once a woman has given birth to a male child, to call her by the name of that firstborn male child, that is, "mother of.…"

Government-sponsored programs have varied considerably in their impact and effectiveness. Moderate-to-high contraceptive prevalence rates were indicated in 1994 for Turkey (63%), Tunisia (50%), Indonesia (50%), Algeria (36%), and Egypt (47%). Muslim countries with low rates reported in 1990 include Somalia (0%), Saudi Arabia (1%), Afghanistan (2%), and Yemen (2%) (Ross et al.). Bangladesh's poor performance has been attributed to a "population control battlefield" between contending religious and social forces (Hartmann); Indonesia, on the other hand, has been identified as a family-planning success story. Since the 1970s, Indonesia has used a carrot-and-stick approach of incentives and state pressure. This policy, combined with socioeconomic changes such as reduced infant mortality, increased educational levels, and rural-to-urban migration, has led to a significant decline in fertility (Hartmann).

Initially, many local religious leaders opposed family-planning programs on moral grounds and because they believed that growth in population was necessary in order to spread Islam. Efforts by the government, early in the program, to consult with religious leaders, and the government's decision to exclude sterilization and abortion from the program, helped counter the opposition.

The role and influence of religious leaders has varied and can often prove significant. The influence of Islam on people's acceptance or rejection of government-sponsored fertility-control programs depends not only on moral teachings of a religious tradition but also on how those teachings are interpreted to local people by religious leaders. If, as in Indonesia, many of those leaders support the program and use occasions such as marriage ceremonies to suggest the value of family planning, acceptance will typically be greater than if those leaders tell believers that using contraceptives to limit birth violates Islamic teaching. Postrevolution Shi'ite Iran provides a unique example of religious leaders, the *ulama,* functioning as both the executors and the formulators or legislators of new *fatwas* on family planning.

The Egyptian government has addressed the population question since the beginning of the rule of Gamal Abdel Nasser in 1952. Because of religious sensibilities, the government moved slowly, employing only the pill. Religious officials, from the government-appointed mufti of Egypt to the rector of the state-supported al-Azhar University, issued a series of *fatwas* endorsing the use of contraceptives. However, many think the religious establishment has been coopted by the government. Thus, while Nasser and his successors could marshal the support of the religious establishment, local religious leaders continued to condemn contraception as immoral as well as contrary to Islam, and reinforced traditional emphasis on procreation and acceptance of the will of God, as did other opinion makers, such as midwives.

Like many other countries, Egypt has utilized a centralized, top-down approach, bypassing or ignoring local and regional realities. In 1953, Nasser was concerned that Egypt's population would leap to 44 million (Warwick, 1982). However, little was done about fertility control until the mid-1960s.

In Lebanon, religious sectarianism and communalism have both determined and limited the success of government policy. Lebanon was created as a confessional state whose delicate balance was based upon a system of proportional representation: Maronite Christians were dominant, followed by Sunni and Shi'ite Muslims and Druze. However, tensions between Christians and Muslims were exacerbated by the socioeconomic dominance and advancement of the Maronites, who had a lower fertility rate than the Muslims. By the mid-1970s, social realities proved explosive, and civil war broke out. The Shi'ite community, the poorest and most disenfranchised, had grown, and constituted one-third of Lebanon's population.

Given the precarious balance of power and social tensions, the Lebanese government for more than two decades shied away from any official promotion of family planning. However, while contraceptives remained illegal, the government indirectly supported private family-planning projects (Warwick, 1982).

Conclusion

Islam has a well-established body of teaching on fertility control that is closely linked to its views on marriage and the family. The interpretation of these teachings varies from country to country. The openness of individual Muslims to fertility control depends on many variables, including interpretations by local religious leaders of how it should be regarded by Muslims. Countries differ greatly in the extent to which Islamic religious leaders cooperate with government-sponsored fertility-control programs.

Much of the Muslim world faces rapid population growth in a situation of limited resources. Containment or reversal of this trend remains hampered by widespread poverty, illiteracy, and debates about the morality of birth control. In this struggle, the criticisms of local religious leaders combine with voices of many militant Muslims who attack government-sponsored family-planning programs and Western aid as a conspiracy to limit the size of the Muslim community in order to contain and dominate it more effectively.

JOHN L. ESPOSITO

SEE ALSO: *Abortion; Adoption; Coercion; Embryo and Fetus: Religious Perspectives; Eugenics and Religious Law; Feminism; Fertility Control; Freedom and Free Will; Genetic Testing and Screening; Harm; Infanticide; Informed Consent; Islam, Bioethics in; Justice; Life; Natural Law; Race and Racism; Rights, Human; Sexism; Women, Historical and Cross-Cultural Perspectives;* and other *Population Ethics* subentries

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III. RELIGIOUS TRADITIONS: C. JEWISH PERSPECTIVES

Pronatalism is the contemporary word describing the classic Jewish tradition regarding fertility. To begin with the religious component of the Jewish culture, procreation is counted as a positive *mitzvah* (a commandment or virtue), given pride of place at the top of rabbinic formulations of Bible commandments. *P'ru ur'vu* ("Be fruitful and multiply," or better, "Be fruitful and increase"—more arithmetic than geometric) in the first chapter of Genesis is a general blessing to other creatures; for humans, it is a behavioral imperative to reproduce. Bible commentators explain this difference in terms of the human differential: The command mode is needed because humankind, created in the image of God, might seek to devote itself entirely to the spiritual and intellectual, and might neglect the material and physical. Accordingly, Scripture thus negates the antiprocreative or celibate views of some cultures. Alternatively, the commandment addresses the fact that only humans are aware of the consequences of sexual activity; they might seek to avoid the attendant responsibilities of procreation while indulging the sexual drive.

On another level, a rabbinic Bible commentary observes that, throughout the first chapter of Genesis, the seal of approval—the announcement that "the Lord saw that it was good"—is repeated for each element of creation. But after Adam was created, "the Lord said, 'It is not good that man [Adam] should be alone.'" Only that which can endure is good; if humankind does not procreate, it will not endure.

Nor will God himself endure, according to the Talmud, without us to acknowledge him: "Not to engage in procreation," we are told, "is to diminish the Divine image." That is why the verse "for in the image of God has He created man" (Gen. 9: 6) is followed immediately by the reaffirmation of Genesis 9: 7, "Be fruitful and increase" (*Yevamot* 63b). More to the point, when the later verse (Gen. 17: 7) introduces the Lord who will be "thy God and [that] of thy 'descendants after thee,'" the Talmud asks, "If there are no 'descendants after thee,' upon whom will the Divine Presence rest? Upon sticks and stones?" (*Yevamot* 64a). Without human progeny and continuity, there is no one to worship God. Without the physical body, there is no soul.

The biblical commandment is, as usual, spelled out in its details in *Mishnah* and *Gemara,* the two components of the Talmud, setting forth the *halakah,* the definitive legal ruling as formulated by the Codes. The *halakah* of "be fruitful" requires that a couple replace itself, that is, give birth to at least a son and a daughter. Having several sons or several daughters still does not fulfill the commandment. Yet, after the fact, the Talmud counts "grandchildren like children," so that parents with progeny of just one gender can be reassured that their children's children will help them measure up. Actually, even two children of different genders are only the bare minimum; in Maimonides' codification, the effort to procreate must continue. In *Tosafot,* authoritative critical commentaries from medieval France printed on the margin of the Talmud, the fear is expressed that letting the minimum number suffice could result in ethnic extinction (*Bava Batra* 60b). Infant mortality, as well as the possibility that the offspring may not live to adulthood or not reproduce, requires that more than one son and one daughter be conceived and born.

The duty to go far beyond the minimum has its rationale in the rabbinic dimension of the procreative *mitzvah,* where it is called, in brief, *la-shevet* or *la-erev.* (Deriving legal teaching from biblical books other than the Pentateuch is termed "rabbinic"; only the Five Books of Moses are the source of law called "biblical.") The biblical support for the first, *la-shevet,* is Isaiah (45: 18): "Not for void did He create the world, but for habitation [*la-shevet*] did He form it." The second, *la-erev,* comes from Ecclesiastes (11: 6): "In the morning sow thy seed, and in the evening [*la-erev*] do not withhold thy hand [from sowing], for you know not which will succeed, this or that, or whether they shall both alike be good." These verses strongly suggest a moral imperative to continue beyond the minimum.

The broader dimension of the *mitzvah* is very much an operative part thereof. To illustrate its legal implications, a Sefer Torah (scroll) belonging to an individual requires special care and may not ordinarily be sold for its proceeds. There are two exceptions: It may be sold (1) to finance tuition for the study of Torah, and (2) to dower a bride and thus enable her to marry and procreate. What if she already has a son and daughter? The power of the rabbinic extension of the *mitzvah* is now seen in the ruling that a Sefer Torah may be sold to finance the remarriage of that woman, so that she may fulfill *la-shevet* or *la-erev.*

The traditional pronatalist stance is vividly evident in modern-day rabbinic rulings with respect to reproductive technology. Just as illness or pathology are the targets of Judaism's mandate to heal, whereby Sabbath and dietary laws—and the rest of the Torah—are to be set aside to allow healing procedures to do their work, so barrenness and infertility are seen as pathological states to be overcome by aggressive therapies that may also supersede ritual laws. This equation of barrenness with illness means that fertility problems are to be overcome by such exigencies as in vitro or in utero fertilization, even artificial insemination or gestation by a host mother, for cases in which usual (or "natural") conception and birth are not possible. The principle of the primacy of fertility as a desideratum in a pronatalist tradition is given concrete form by the contemporary application of these legal provisions.

Another technical detail of Jewish law places the *mitzvah* (commandment) of procreation on the man rather than on the woman, though of course both are needed for procreation and both share in the *mitzvah* (virtue). This position may have its basis in the theoretical permissibility of polygamy or polygyny, whereby a man could marry more than one wife, but both paternity and maternity would still be known. The husband has to "worry about" the mitzvah's accomplishment. An actual sex-role difference derives from the "Be fruitful and increase" of Genesis, which goes on to say "Fill the earth and conquer it." The male is the conqueror, the aggressive one; the female, as the more passive, should not have to "go seeking in the marketplace" (*Yevamot* 65a). If that observation is rooted in anthropology, an explanation based more on ethics is offered by a Bible commentator of the twentieth century, Rabbi Meir Simcha HaKohen (d. 1921): Both the pain and the risk of childbearing are borne by the woman, not the man. Since the Torah's "ways are ways of pleasantness, and all its paths are peace" (Prov. 3: 17), the Torah could not in fairness command a woman to undergo pain and assume risk; this must be her choice and it becomes her virtue. For the man, exposed to neither pain nor risk, there is both the command and the responsibility to heed the command (*Meshekh Hokhmah* to Gen. 1: 28).

The discussion of what is and what is not a commandment refers to the formulations of the Sinai Covenant, which did in most cases reaffirm the pre-Sinai imperatives of Genesis, and as such applies only to the covenanted Jewish community. What of the rest of the world? A system called "the Seven Commandments of the Children of Noah" was discerned by the Talmudic sages; it is derived from God's charge to Noah after the flood and applied to his descendants in the world at large. These commandments include basic moral imperatives against murder, incest, cruelty to animals, and a directive to establish general law and order. Hence, the Sinai legislation cannot be imposed on mankind in its specifics. Many Jewish teachers see the thrust of *la-shevet* as generally applicable, for that biblical verse holds forth the *telos,* or ultimate end, of the earth, that it be inhabited and populated.

Attitudes toward procreation among Jews were not, of course, shaped by the law alone. Pronatalism partakes of the personal and cultural: In the face of all God's promises, Abraham protests to God (Gen. 15: 2): "What canst Thou give me, seeing that I go childless?" The anguish of the barren woman is a recurrent theme in the Bible and beyond. On the other hand, fecundity is the most cherished blessing, exemplified idyllically in the Psalmist image (Ps. 128) of one "whose wife is a fruitful vine" and whose "children are as olive plants around the table" and whose ultimate satisfaction is the sight of "children [born] to thy children."

The natural impulse was buttressed by a national one. Historical circumstances of frequent massacres and forced conversions, with their resulting decimation of Jewish communities, added the impulse to compensate for losses to an existing instinct to procreate. The yearning for offspring was deepened, addressing positively the need to replenish depleted ranks. This contrasts to the response of despair reflected in an antiprocreative stance taken by some Christian sects in the face of evil. The Gnostics in the first century, the Manichees in the fifth century, and the Cathars in the twelfth century are among the groups that taught and lived by the belief that procreation is to be avoided in a world of evil unredeemed. Apprehensiveness about the eventual well-being of offspring, the Talmud teaches, should not be a reason for not bearing children. This was King Hezekiah's worry, to which the response of Isaiah (38: 1–10) is understood to mean: "The secrets of God are none of your business. You fulfill your duty [of procreation]" (*Berakhot* 10a).

In the post-Holocaust days, both the individual and the Jewish collectivity have been encouraged to make up for the physical losses of that tragic period. Nonetheless, realization of this impulse or teaching has not been evident across the board. In fact, the Jewish birthrate in the United States and other developed nations in recent decades was lower than, or as low as, that of the rest of the population. Upward socioeconomic mobility, and an increased pursuit of secular education and professional opportunity, has kept the birthrate down in assimilated families. Jews have, in fact, been visibly active in the movement for zero population growth, advancing a cause they consider ecologically necessary. Reform and, to a greater extent, Conservative Jews generally answer to the influence of Judaic tradition alongside social considerations, while Orthodox families register the highest rates of reproduction.

Contraception and Abortion

Sentiments toward procreation go hand in hand with views and practices of contraception and abortion. The *halakah* of contraception includes both the problem of method—whether or not a particular means completes the sexual union, or is not onanistic—and of motive—whether medical reasons or convenience are determinant. Contraception is clearly permitted where medically indicated, with even the less preferable methods. For nonmedical reasons, only methods such as rhythm or the pill may be used, providing the motive is acceptable. The preferable methods, such as the pill or Norplant, are not occlusive and not onanistic because sperm has an unimpeded trajectory. Coitus interruptus and the use of condoms are the least acceptable methods. But where AIDS, for example, is a threat, the condom's prophylactic properties take precedence, on the Talmudic principle that "[avoiding] danger is more serious than [avoiding] transgression" (*Chulin* 10a). This clear, medical permission means, incidentally, that in marital relations contraception is to be preferred over sexual abstinence.

Medical reasons are essentially what govern resort to abortion. The distinction is made between murder and killing of the fetus: If abortion were murder, it could only be considered if the life of the mother were at stake; as killing, or taking of only a potential human life, it can be considered to save her health or well-being, emotional as well as physical. As with contraception and pronatalism, Orthodoxy takes a less liberal position on abortion in theory and in practice than do the Conservative and Reform alignments.

The voluminous Responsa (formal replies to queries by rabbinic authorities) on these subjects are addressed to the individual couples and to their queries in deed. Global questions are also addressed, such as population control for ethical reasons as a concern for humanity and for available resources. The counsel of one rabbinic authority invoked the notion of "lifeboat ethics," whereby the lifeboat in which we all find ourselves, like Noah's Ark according to a Talmudic observation, must be kept from sinking as a result of overpopulation. The solicitude in halakic legislation for the welfare of existing children and their mother, before adding to one's family, was also invoked to argue for ecological responsibility.

Birthrate and the State of Israel

Advocacy of world population limitation is not contradicted by efforts to raise the Jewish birthrate. To the extent that growth globally threatens human well-being and Earth's ecology, it is an imperative concern for us all. But the Jewish people, constituting less than 1 percent of the world's population, would not adversely affect that picture even if their numbers doubled. Replacing Jewish losses would not upset the geophysical numerical balance; it would merely keep Judaism alive. Other minorities should similarly be allowed to maintain their existing numbers. Jewish aspirations, as reflected in synagogue liturgy, are not to become predominant in the world, but merely to "preserve the remnant of Israel."

That liturgical phrase refers, of course, to the People of Israel, but the State of Israel reflects similar concerns. At least one reason for the state's establishment in 1948 was demographic. When Palestine was ruled by British mandate, a "white paper" was issued that severely limited immigration by Jews, even hapless Holocaust survivors and internees of Europe's displaced-person camps. Whatever else sovereignty and independence provide, here they were necessary primarily to remove quotas and barriers to Jewish immigration.

After Israel was founded under the sponsorship of the United Nations and Jewish refugees were admitted, interior population growth was encouraged. The Hebrew word for immigration is *aliyah,* or ascendance to the Land of Israel. Now a new term was coined—*aliyah penimit,* or internal immigration—to refer to new births in Israel, encouraged as a patriotic act to build the nation and its defenses. Also, since the very raison d'etre of the establishment of the state was as a restored homeland and a haven of refuge, the Law of Return was promulgated. It called for the "ingathering of the exiles," inviting Jews to be rehabilitated in their ancestral home, and granting them automatic citizenship upon their arrival.

The politics of population power have been evident not only in control of the disputed territories of Judea and Samaria (West Bank) but also in Israel proper and in the peace efforts begun in 1993. Nationalists express the concern that a disproportionate increase in the Arab birthrate or Arab immigration could effectively dissipate the Jewish character of the world's only Jewish state. On the other hand, during the early 1990s, massive absorption of Jews from the former Soviet Union and from Ethiopia took place; this influx demonstrated the profound demographic and cultural, as well as political, consequences of population factors.

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SEE ALSO: *Abortion; Adoption; Coercion; Embryo and Fetus: Religious Perspectives; Eugenics and Religious Law; Feminism; Fertility Control; Freedom and Free Will; Genetic Testing and Screening; Harm; Infanticide; Informed Consent; Judaism, Bioethics in; Justice; Life; Natural Law; Race and Racism; Rights, Human; Sexism; Women, Historical and Cross-Cultural Perspectives;* and other *Population Ethics* subentries

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III. RELIGIOUS TRADITIONS: D. ROMAN CATHOLIC PERSPECTIVES

Roman Catholic teaching on population is a complex blend of theological beliefs, ethical norms, and empirical judgments. The distinctive characteristic of Roman Catholic doctrine is the sustained and significant place its teaching on contraception has held in its population position. Indeed, the detailed discussion of contraception in Catholic moral theology at times conveys the impression that this one issue constitutes the whole Catholic position on population ethics.

It is necessary, therefore, to distinguish two related but not identical moral questions in Catholic theological ethics: the morality of contraception and the teaching on population policy. John Noonan's classic work on contraception identifies moments in the history of the tradition when demographic trends affected the official teaching of the church, but it points out that these instances do not stand out as major determinants in the development of Catholic doctrine on contraception (Noonan). Noonan's analysis illustrates the complexity of the Catholic response to falling birthrates in the late Roman Empire, in the medieval period, and again in the nineteenth century. During those periods the Catholic position criticized the idea of restraining population growth but did not assert that procreation of children should be fostered without regard to other values. The balancing factors in the Catholic position are the linking of procreation to education and the high status accorded virginity in Catholic life.

It is possible, therefore, to trace a relationship between contraception and population policy throughout Catholic teaching; yet until the twentieth century, the dominant idea is the prohibition of contraceptive and other birth-limiting practices, with the population issue treated as a minor theme. Even in Pius XI's encyclical *Casti Connubii* (1930), which Noonan describes as "a small summa on Christian marriage" (p. 426), the population issue receives only indirect reference. A systematic treatment of the morality of population policy as a distinct issue in its own right is not evident in Catholic thought until the time of Pius XII (Hollenbach). Beginning with Pius XII's address to the Italian Association of Catholic Midwives in 1951 and continuing through the teachings of Popes John XXIII and Paul VI, Vatican II, the Synod of Bishops (1971), and John Paul II, one can find an articulated ethical doctrine on population policy. The ethical teaching responds to two dimensions of the contemporary population debate: first, intensification of the debate about the relationship of population and resources; second, the move by governments and international institutions to design policies to affect demographic trends.

It is possible to distinguish in the Catholic teaching two species of moral analysis: One focuses on the context of population policy; the other, on the content of the procreative act. David Hollenbach distinguishes these two dimensions as the public and private aspects of Catholic teaching.

Population Policy

The public dimension is found generally in the social teaching of the church; the principal documents relating to population policy are *Gaudium et Spes* (1965) (Gremillion), *Populorum Progressio* (Paul VI, 1967), and the interventions of the Holy See on the occasions of international conferences about population, resources, and the environment. These documents manifest a social, structural analysis of the population issue, seeking to place demographic variables within a broadly defined socioeconomic context. The tenor and style of analysis is exemplified in Paul VI's message for the 1974 U.N. Population Year. The Pope's message argues for a broadly based approach to demographic problems with the category of social justice used as a principal theme (Paul VI, 1974a). This perspective is reaffirmed in the Holy See's intervention at the 1984 U.N. Population Conference (Schotte).

The main presupposition of all these statements is that the population problem is one strand of a larger fabric involving questions of political, economic, and social structure at the national and international levels. While acknowledging the existence of a population problem, this view asserts that it is morally wrong and practically ineffective to isolate population as a single factor, seeking to reduce population growth without simultaneously making those political and economic changes that will achieve a more equitable distribution of wealth and resources within nations and among nations (Rich; Paul VI, 1974a, 1974b).

The ethical categories used in analyzing the social aspect of the population problem are drawn from Catholic social teaching developed principally in the papal documents from 1891 to 1991 (Calvez and Perrin; Gremillion; Pavan; O'Brien and Shannon). The foundation of the argument is that the human person, endowed with the gifts of reason and free will, possesses a unique dignity or status in the world. The person, in Christian thought, is regarded as the pinnacle of God's creative action; the uniqueness of the person is argued in Catholic thought in both philosophical and theological terms. The dignity of the person is the source of a spectrum of rights and duties articulated as claims upon and responsibilities toward other persons and society as a whole. The distinguishing mark of the Catholic theory of rights, setting it apart from a classical, liberal argument, is the assertion of the social nature of the person. Society and state are necessary and natural institutions that are presupposed and required for full human development.

The strong social orientation of Catholic political philosophy holds that the way in which society, state, and subordinate social institutions are designed and structured is a moral question of the first order. Society and state are not self-justifying; they exist for the purpose of achieving the common good, defined as the protection and promotion of the rights and duties of each person in the society (Gremillion).

The central category used in evaluating the organization of social structures and institutions is social justice. This concept has roots in medieval Catholic teaching, but it has been developed and refined in the social encyclicals *Quadragesimo Anno* (1931) (O'Brien and Shannon) and *Mater et Magistra* (John XXIII, 1961), as well as in the third synodal document, "Justice in the World" (1971), and in the social teaching of John Paul II (O'Brien and Shannon). As social justice is used in these documents, it measures the role of key social institutions in procuring a fair distribution of wealth and resources nationally and internationally. In *Pacem in Terris,* the normative framework for assessing social institutions is expanded beyond justice to include truth, freedom, and charity (John XXIII, 1963).

The articulation of these categories in Catholic social teaching manifests two stages of development, both pertinent to a population ethic. The social teaching of the period from 1891 through the 1930s focuses on the nation as the unit of analysis; social justice principally means justice within the nation.

Beginning with Pius XII and continuing through John Paul II, the scope of analysis is broadened to focus on the international community. This move from assessing justice within the nation to justice among nations can be charted in the emergence of key concepts. John XXIII (1961) is the first to discuss the international common good as a standard for measuring national policies. The implication of this idea is that an adequate assessment of a state's policy must be calculated in terms of its impact on other states and peoples as well as upon its own citizens. For transnational questions like population and food policy, such a category of analysis opens a whole new set of questions. A similar expansion of a traditional category is found in "Justice in the World" in its discussion of international social justice (Gremillion). The concept explicitly addresses the structures through which states relate to each other in political and economic affairs. John Paul II develops the notion of solidarity as the ethical category that can direct the increasing interdependence of world politics and economics (O'Brien and Shannon).

At both the national and international levels, the categories of common good, social justice, and freedom of choice for individuals and families in society are used to define the population question. Among social institutions, the family, based on the covenant of marriage, holds a unique place in Catholic thought (Hollenbach). It is regarded as the basic cell or unit of society and the Catholic

Church. In the social hierarchy, reaching from the person through the state to the international community, no other association, save the Catholic Church itself, is accorded such status. The demands of the common good and the requirements of social justice are articulated in terms of providing the family and its members with those conditions of life that satisfy basic human needs, protect personal dignity, and allow human development through the exercise of rights and responsibilities in society.

High on the list of inviolable rights is that of marrying and having a family (Hollenbach). To protect this right and other such rights for each person, Catholic social teaching establishes two parameters: Positively, it calls upon the society to guarantee a basic minimum of material welfare, and negatively, it prohibits the state from any significant interference in the exercise of these rights. To summarize the public dimension of Catholic teaching, it accords primary attention to the context of the population question, focusing on the requirements of social justice that should be met as the first step in dealing with the relationship of resources and people. These requirements in specific form include questions of international trade, development assistance, agricultural reform, foreign-investment policies, consumption patterns, and the structure of social relationships within nations. In addition to these contextual issues in the population debate, Catholic teaching also includes a private dimension as regards the content of the procreative relationship.

The Teaching on Contraception

In contrast to the public teaching that focuses on societal structures, the tradition concerning private matters focuses upon the nature of the conjugal relationship and specifically upon the morality of the conjugal act. The principal issue involves analyzing permissible means of preventing contraception. The private aspect of the tradition is rooted in the extensive Catholic teaching on contraception, which has developed in very complex and detailed fashion since the second century (Noonan).

The modern expression of the private issues of the tradition is found in Pius XI's *Casti Connubii* (1930), Pius XII's *Address to the Italian Catholic Union of Midwives* (1954), Paul VI's *Humanae Vitae* (1968), and John Paul II's *Familiaris Consortio* (1982). The principal private issues in the tradition include the morality of abortion, contraception, and sterilization; in the official teaching, all are rejected as means of preventing conception of birth. The only sanctioned means of limiting conception is some form of natural family planning, that is, one that excludes contraceptives. In contrast to the discussion among theologians on the public tradition, there is a very significant division between the official teaching on contraception and an analysis of contraception by theologians (Hoyt; Curran). While official teaching forbids all forms of contraception, many prominent theologians hold for the legitimacy of contraceptive techniques and the use of sterilization under specified conditions.

Population Policy and the Teaching on Contraception

The private dimension of the tradition on population policy has public implications; it seeks to prevent any public policy that would either constrain or induce individuals to procure an abortion or to use contraceptives or would prevent them from choosing to have children. There are themes of coherence and consistency between the public and private aspects of the Catholic tradition: Both are concerned with the procreative process as a sacred dimension of human relationships; both seek to preserve maximum freedom for the couple to determine when to exercise procreative rights; both stress that society and the state exist to serve their members, and the relationship of the state to citizens is articulated in terms of social justice and personal freedom.

Having acknowledged these elements of continuity, it is equally important to illustrate the tension that prevails between the public and private dimensions of Catholic teaching on population policy. The tension can be analyzed by examining two principal texts: *Populorum Progressio,* representing the public dimension, and *Humanae Vitae,* representing the private one (Paul VI, 1967, 1968). These texts, in turn, must be assessed in light of the teaching of John Paul II on population policy. Paragraph 37 of *Populorum Progressio* is a carefully articulated and expansive statement of Catholic teaching on population policy (Gremillion). The passage contains the following elements: (1) an acknowledgment that a population problem exists in the world; (2) an affirmation that governments have a right and competency to deal with the problem; (3) a prescription that governmental action must be in accord with the moral law. This specific treatment of population policy is couched in the context of Paul VI's most detailed statement of the need for international reform in the political and economic order. Hence, the paragraph presupposes that the social justice requirements are being addressed, and in that context the paragraph speaks to the question of measures to restrict population growth.

This passage is the clearest statement in Catholic teaching affirming the right of governments to intervene in the population question; left undefined, however, is the permissible scope of governmental intervention. The phrase that renders the policy ambiguous is that public intervention must be "in conformity with the moral law." In this area of public policy, what measures fall within the moral law? One way to clarify and specify the public tradition is to use *Humanae Vitae* as the guide for interpreting the moral law. The principal argument of the encyclical is that the moral law requires each and every act of intercourse to be open to procreation. A supporting reason offered for this position is that any compromise on this point opens the way to unregulated governmental intrusion into the sacred domain of family life (Gremillion). Presumably, then, the conjunction of *Humanae Vitae* and *Populorum Progressio* would limit the scope of governmental intervention to supporting and fostering only that means of population restraint approved in *Humanae Vitae*.

This is a restrictive reading of the texts; another view would stress the distinction between public and private dimensions of Catholic moral teaching as the key to interpreting Catholic teaching on population policy. This distinction is crucial in recognizing the different ethical norms used in Catholic thought for personal and social morality. A characteristic feature of Catholic social teaching is its sense of the multiple levels of society (Murray). The state is distinguished from society, and voluntary associations are distinguished from the state. Each principal part of the societal fabric is regarded as having a specific, limited role to play.

Two corollaries flow from this carefully delineated perspective on society. First, there is the recognition that personal conceptions of morality cannot be directly translated into requirements of social morality or public policy; to attempt to do so ignores the distinct nature of social and institutional relationships in society and thereby "makes wreckage not only of public policy but also of morality itself" (Murray, p. 286). Second, a recognition of two related but distinct levels of moral discourse—public and private—yields the jurisprudential distinction of moral law and civil law (Murray). While every human action and all human relationships fall under the moral law, only those that have a demonstrable effect on the public order and are open to state regulation without sacrificing other proportionately significant values are to be included under civil law or public policy. Since Catholic theology recognizes distinctions between public and private morality and between civil and moral law, it is possible for Catholic teaching to oppose an action or policy on moral grounds but not be inevitably committed to seek legal or political means to prevent its implementation.

The use of these distinctions between public and private morality and between civil and moral law could yield a more flexible reading of *Populorum Progressio*. First, such a reading would accent the state's right to intervene in the population question. Second, it would then treat the *Humanae Vitae* argument as being principally applicable in the area of personal morality and not an adequate framework for examining population policy. Third, it would acknowledge the disputed character of *Humanae Vitae* in the Catholic community, even as a norm of personal morality. The purpose of bringing to light the opposing Catholic views on papal teaching regarding contraception (as expressed in *Humanae Vitae*) would simply be to acknowledge that, when such dispute exists within the Catholic community, there is strong reason not to seek to make such a norm a standard of public policy in a pluralistic world. Finally, while not interjecting the specific prescriptions of *Humanae Vitae* into public debate, such a Catholic stance could still speak to the limits of permissible state intervention on population questions. The criteria for setting limits could be drawn from the human-rights standards of the public ethic in the tradition, including a stance against abortion (on human-rights grounds), protection of the person from coercion regarding procreative practice (particularly regarding sterilization), and a respect for religious and moral pluralism as a guide for governmental action.

This broadly designed "public" approach to population policy, one cast in terms of human rights and social justice, is defensible in terms of principles of Catholic moral theology. It is not, however, the direction Pope John Paul II has set for the church's approach to population questions since his election to the papacy in 1978. His approach has been to tie the public and private dimensions of policy more tightly together, thereby raising the visibility and role of the teaching on contraception in the overall direction of policy. The impact of John Paul's leadership can be found in his own teaching and in the positions the Holy See has taken in international conferences on population-related issues.

Teaching of John Paul II

John Paul's influence can be summarized in terms of four contributions. First, in his encyclical on Catholic moral theology *Veritatis Splendor* (1993), the pope reaffirmed the structure of moral argument that sustains traditional Catholic teaching, not only on abortion but also on sterilization and contraception. The encyclical did not break new ground on these issues, but the effect of it has been a call for greater restraint on theological dissent from the teaching on contraception and sterilization. The scope of *Veritatis Splendor* is much broader than specific issues of sexual morality; its influence on population policy lies in its resistance to an interpretation of Catholic teaching that would treat contraception as an internal issue of church discipline but not a position to be espoused in public policy. Prior to the encyclical, the pope's thinking was made clear in the Holy See's intervention at the 1984 U.N. Conference on Population at Mexico City. The Vatican's statement affirmed "that the Catholic Church has always rejected contraception as being morally illicit. That position has not changed but has been reaffirmed with new vigor" (Schotte, p. 207).

Second, the weight given to the private dimension of Catholic teaching does not, however, mean that John Paul II has forsaken the broader public dimensions of the teaching on population policy. Indeed, the second dimension of his contribution to population policy in the church has been to expand and develop the social justice theme espoused by Paul VI and the 1971 Synod of Bishops. John Paul's contribution is found in a series of encyclical letters, from *Redemptor Hominis* (1979) through *Centesimus Annus* (1991). In his social teaching, John Paul develops a moral vision rooted in human rights, including both political and economic rights, and shaped by principles of social justice and solidarity. The papal teaching takes the international community as the unit of analysis, and John Paul II argues that a broadly defined notion of human, economic, and social development should be the context for examining population questions. John Paul II substantially extends Paul VI's critique of international institutions and practices in the socioeconomic order. Like his predecessor, John Paul II primarily emphasizes deep and extensive changes in international economic policies as the response to demographic pressures. In *Sollicitudo Rei Socialis,* he argues that "one must denounce the existence of economic, financial and social mechanisms which … often function almost automatically, thus accentuating the situation of wealth for some and poverty for the rest" (O'Brien and Shannon, p. 404). In the same encyclical, John Paul II cites the need "for a solidarity which will take up interdependence and transfer it to the moral plane" (p. 411). In subsequent teaching, he explicates some of the policy demands of solidarity as they affect international distribution, problems of the Third World debt, and protection of human rights within nations and through the work of international institutions.

Third, a dimension of Catholic teaching which holds a prominent place in the pontificate of John Paul II is the relationship of migration and population. The teaching and the practice of the church both testify to a deep concern for the welfare of migrants and refugees. At the level of the Holy See, in the structure of national episcopal conferences, and in the work of dioceses and religious orders, the pastoral care of migrants and refugees holds a substantial place in the ministry of the church.

This ministry is supported by Catholic teaching on migration. The perspective on the right of the person to emigrate and immigrate is based on Catholic teaching on human rights and on the moral structure of the international order. The right of the person to emigrate places upon the international community, and states within it, the responsibility for developing fair policies regarding immigration. Catholic teaching does not assert an unlimited duty to receive migrants and refugees, but it does not specify particular limits either. The emphasis of the teaching falls on a duty of international solidarity that then must find expression in international and national policies regarding migrants and refugees. In John Paul II's teaching, "the state's task is to ensure that immigrant families do not lack what it ordinarily guarantees its own citizens as well as to protect them from any attempt at marginalization, intolerance or racism …" (John Paul II, 1994, p. 718).

This expansive conception of the duty of states to be open to the movement of populations when they are driven by war, famine, economic necessity, or human-rights violations provides another social instrumentality, along with the teaching on social justice, to complement the Vatican's restrictive policy regarding the limitation of population.

In summary, there is substantial continuity between Paul VI and John Paul II on the public dimensions of population policy. The public argument about human rights and social justice remains the context in which population policy is addressed. Within that context, however, there is a difference in the way John Paul II relates the public and private dimensions of Catholic teaching.

This is the fourth aspect of his teaching, and it does not point toward more active Catholic engagement concerning population issues. Paul VI had acknowledged the objective dimensions of demographic problems, and the duty of governments to address these; John Paul II places the emphasis in a different direction. He also acknowledges that population growth can create "difficulties for development," but his concern is principally about the abuses public agencies commit in pursuit of population policies (O'Brien and Shannon). There is undoubtedly a need for the multiple concerns expressed by the pope himself and by the Holy See in its 1984 intervention at Mexico City. The values and principles stressed in the Holy See's intervention at the Mexico City conference and reiterated in 1994 by Pope John Paul II in preparation for the U.N. Population Conference at Cairo—protection of the rights of the person and the family, resistance to conditioning economic assistance on the basis of population targets, restraints on the role of the state—are necessary for an ethically sound population policy. But there is less positive encouragement or guidance for the state or international agencies to take responsibility for population issues. The principal guidance for public authorities is to reject abortion, sterilization, and contraception in the implementation of population policy. These restrictions are matched with a statement of the duty states have to create conditions within which parents can make responsible choices about family size (e.g., John Paul II, 1994).

Clearly, any Catholic policy will oppose abortion because of the deeply held conviction that a human life is at stake, and it will be deeply suspicious of state intervention in any decisions and choices about procreation that are basic to the dignity and freedom of married couples. The question of whether all forms of contraception would have to be explicitly opposed, save that described in Catholic thought as “natural family planning,” is what lay implicit in Paul VI’s statement of 1967. John Paul’s response is decisively in the direction of treating abortion, sterilization, and contraception in similar fashion; although different in nature, all three are to be opposed in population policy.

The basic lines of Catholic policy, in both its public and private dimensions, have been firmly set for centuries. The policy combines a powerful vision of economic justice and human rights with a comprehensive resistance to most specific measures of population limitation. At the level of implementation, does the policy framework allow for or manifest any differentiation? Two possibilities exist: at the level of pastoral care and the level of principles and rules of conduct.

The pastoral level involves the advice, counsel, and direction provided by the ministers of the church to Catholics as guidance for conscience. The pastoral level also involves the degree of activism that marks Catholic life on population issues at national and local levels of the church. The other possibility for differentiation would involve an attempt to change the basic principles of Catholic teaching in its public or private dimensions.

In his history of the teaching on contraception, John Noonan illustrates the fact that some difference has often marked the church’s life between what has been prohibited at the level of principle and how distinctions were made to accommodate the specific conditions in the lives of individuals. In the years since *Humanae Vitae* (1968) was issued, substantial differences have existed between the principles of the encyclical and the choices individuals have made, often with advice from theologians or pastors. John Paul II has been vigorous in his attempt to close this gap. While pastoral practice undoubtedly affects the population issue, its primary impact is felt not at the level of church policy or involvement in the public debate on population issues but in the lives of individuals.

In terms of the principles of Catholic population policy, it is useful to compare the universal teaching and the role of the church within nations. It is clear that the church ministers in nations with very different approaches to population policy, some close to Catholic principles and others in direct opposition to either the public or private dimensions of Catholic teaching. It is also clear that in the period since the Second Vatican Council, there has been greater possibility in Catholic polity for national episcopal conferences to take initiatives in applying the church’s teaching to specific local circumstances. Examples of this include Latin American hierarchies addressing human rights and economic justice, and the hierarchy of the United States engaging the issues of nuclear deterrence and economic policy.

Population policy, however, is not an area where much latitude exists for national or local voices. The Holy See, through its teaching office and its diplomatic engagement, is clearly the primary and predominant voice on population issues. National hierarchies may coexist with governmental programs that differ from Catholic teaching, but they seldom seek to challenge or change the principles of Catholic teaching to meet their local situations. Examples of national teaching that do seem to press for some change in the understanding or application of the teaching (particularly in its private dimensions) are recognized as rare exceptions. Such is the case of the Indonesian bishops who issued a statement in 1968 and then were required to provide clarification of their position in 1972 (Indonesian Bishops, 1972). The normal practice for episcopal conferences is to take the Holy See’s principles as the premise of their position and then try to relate these principles to the broader policy debate in their own countries; this has been the policy followed by the U.S. bishops in their 1973 and 1994 statements on the population question (National Conference; U.S. Cardinals).

In the 1984 U.N. Conference on Population in Mexico City and in the preparatory debate leading to the 1994 Cairo conference, John Paul II has forcefully reasserted the papal role as the decisive voice on population issues. His position of tightly integrating the public and private dimensions of the teaching, and seeking to shape global policy in both areas, sets the standard for any other voice in the Catholic Church. No Catholic policy would forsake either the socioeconomic principles of justice or its opposition to abortion as a method of population limitation. The effect of John Paul II’s leadership is to reaffirm these dimensions and to diminish the likelihood that any distinction will be made in the policy debate between the public and private dimensions of Catholic teaching (John Paul II, 1994).

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SEE ALSO: *Abortion; Adoption; Christianity, Bioethics in; Coercion; Embryo and Fetus: Religious Perspectives; Eugenics and Religious Law; Feminism; Fertility Control; Freedom and Free Will; Genetic Testing and Screening; Harm; Infanticide; Informed Consent; Justice; Life; Natural Law; Race and Racism; Rights, Human; Sexism; Women, Historical and Cross-Cultural Perspectives;* and other *Population Ethics* subentries

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III. RELIGIOUS TRADITIONS: E. EASTERN ORTHODOX CHRISTIAN PERSPECTIVES

Population questions have not received a great deal of treatment in Orthodox theology or ethics. What little has been written comes out of other, related interests. Even in patristic times, population concerns usually appeared within the framework of discussion on Christian marriage and attendant issues, the most important of which was the place of procreation as a purpose, or even as *the* purpose, of marriage. The fourth-century writings of Saint John Chrysostom, for example, suggest that the purpose of marriage is in part determined by population considerations.

Recent Literature

The relevant Eastern Orthodox literature on the contemporary situation may be divided into two periods.

FIRST PERIOD: 1933-1969. During this time, Orthodox thinking discounted the threat of overpopulation, which was either ignored or seen as a dubious argument to support birth control. If it was taken seriously, it was perceived to be a false issue, unsupported by the evidence. This position aimed to undercut support for conception control, especially in regard to maintaining the strength of ethnic groups. Many traditionally Orthodox countries (e.g., Greece, Bulgaria, Romania, Serbia) were experiencing a reduced birthrate, which was often perceived as putting them at a political and military disadvantage in relation to neighboring countries. Hence, their interest was in increasing rather than decreasing their populations.

The first important work of this period appeared in 1933: Seraphim G. Papakostas's *To zetema tes teknogonias: To demographihon problema apo Christianikes apopseos* (The question of the procreation of children: The demographic problem from a Christian viewpoint), which places birth control and population concerns within family ethics. The population issue appears under the rubric "The Arguments of the Supporters [of birth control]," where the author holds that arguments drawn from the threat of overpopulation, financial considerations, the improvement of conditions of life for both individual and nation, and other such positions are inadequate to justify the practice of birth control. After discussing the relationship between population and cultivated land, Papakostas concludes that "the means of support are increasing faster than the population" (p. 53). Numerous factors contribute to overpopulation, he argues, and all must be functioning in order for it to occur. His conclusion is that "the danger of overpopulation is non-existent" (p. 57).

In 1937 the Holy Synod of the Church of Greece, its highest governing body, issued an encyclical against the practice of birth control that reflected Papakostas's views. (Papakostas was very likely the author of the encyclical.) Although the document treats birth control almost without reference to the population issue, the encyclical does characterize birth control as an agent of "permanent harm to the Greek Nation because of the reduction of the population."

A similar treatment of the subject, written by the *hegoumenos* (abbot) of one of the monasteries of Athos, Gabriel Dionysiatou, was published in 1957. In this work, *Malthousianismos: To englema tes genoktonias* (Malthusianism: The crime of genocide), concern with overpopulation is believed to be unwarranted. The author, however, does not foresee the progress of technology and the resulting increase of agricultural productivity and distribution. The study is based on the view that the primary purpose of marriage is the procreation of children.

SECOND PERIOD: 1970 TO THE PRESENT. The second period of the treatment of the population issue, beginning in 1970, continues to deal with its relationship to birth control. A significant number of writers now feel that birth control is not the unmitigated evil described in the previous period. Most have adopted their view not because of population issues but through a rejection of Augustinian understandings of sin and "concupiscence" and a more Eastern patristic understanding of the purposes of marriage. While the Western patristic approach drew moral teaching primarily from natural law, the Eastern view was based on a Trinitarian approach that emphasized the interpersonal dimensions of marriage.

Of great importance is Alexander Stavropoulos's *He ekklesia tes Hellados enanti tou problematos tes technogonias* (The Church of Greece and the question of the procreation of children), published in 1977. Using textual analysis, Stavropoulos shows that both Papkostas's work and the encyclical of 1937 were based not on patristic sources but on Western prototypes. As a result of Stavropoulos's work, the encyclical ceased to be considered an authoritative text for Orthodox theological and ethical reflection. Efforts were made to include the issue of conception control in the themes of a forthcoming Great and Holy Council of the Orthodox church, but eventually it was dropped.

Some Orthodox writers treat the issue on the basis of theological grounds without reference to population concerns (Meyendorff; Constantelos, 1975; Zapheiris, 1974, 1991; Harakas, 1982). During this period a revival of patristic thought and method in theology, emphasizing the importance of the interpersonal dimensions of Eastern Orthodox Christianity, has been instrumental in changing the attitude toward ethical issues as well. These theological developments focus on the human dimensions of Orthodox Trinitarian theological perspectives, since the doctrine of the Holy Trinity as "three persons in unity" is seen as paradigmatic for human beings, in that the goal of human life is growth toward Godlikeness.

Several new treatments of birth control in relation to population issues have appeared in this period. The debate now focuses on the actual (or the mistakenly perceived) danger of overpopulation. In *The Sacrament of Love,* Paul Evdokimov (1985) makes explicit reference to the danger of overpopulation as an argument for the use of birth control.

Similarly, Nicon Patrinacos (1975) deals with ethnic demographic implications, placing the population issue in historical perspective. Explaining the traditional emphasis on the procreative dimension of marriage, he notes: "As with all societies and nations of [the Byzantine] era, numbers were extremely important to the survival of the country and nation" (p. 3). He comments that many factors explain Orthodox emphasis on population increase: high infant mortality; population depletion resulting from frequent wars; and lack of adequate sanitary conditions, medical care, and food. Unlike the writers of the pre-1970 period, Patrinacos is convinced of the reality and dangers of the population explosion. Rather than discounting it, he takes it as one of the chief elements of his moral reasoning. He condemns as evasive and morally irresponsible those positions that ignore the issues created by overpopulation. He is convinced that "unlimited reproduction of our own kind has reached the point of impoverishing rather than enriching humanity" (p. 46).

Patrinacos holds that the command God gave to Adam and Eve to multiply and populate the Earth has been realized. The church must now provide new guidance: "Birth control is, in more than half of today's world, as important and as urgent as feeding the millions of starving. More births would mean more hunger, more pain, more deaths" (p. 48).

The revival of the patristic mind-set in Orthodox theology, with its emphasis on both divine and human relationality, makes untenable the older argument that the only or primary purpose of marriage is procreation. The theology of marriage has come to focus on the interpersonal unity and relationship of spouses. Studies by Megas Farantos (1983), Paul Evdokimov (1985), Haralambos Hatzopoulos (1990), Chrysostom Zapheiris (1991), W. Basil Zion (1992), and Stanley Harakas (1992), among others, reject the previous approach as not reflective of authentic Eastern Orthodox perspectives, and approve conception control within marriage. Some of these writers connect conception control to population issues.

Nicholas Bougatsos's 1994 work, *He rhythmise tes teknogonias: Orthodoxos kai Hellenike apopse* (The regulation of childbearing: Orthodox and Hellenic view), discounts the issue of overpopulation for Greece and Europe in general (it does not deal with population issues in the Third World). Nevertheless, Bougatsos argues that for theological reasons, different approaches to the issue of conception control are ethically possible. These may include the practice of birth control by spouses for a number of reasons, among them the enhancement of interpersonal relations and growth in the unity of Christian marriage.

A Population Agenda for Orthodox Christian Ethics

The crucial differences between the earlier and later aspects of this discussion are traceable both to theological outlooks and to concern with issues of population. The foundations now exist for the development of an Orthodox population ethic, which might include a number of elements.

THEOLOGICAL APPROPRIATENESS OF POPULATION CONCERNS. It is true that "the Fathers of the Church were … uninterested in the economic implications of population growth … and early Christian writers can, indeed, hardly be considered to have had a population policy" (Callahan, p. 187). However, contemporary Orthodox ethics is concerned with population as both an imperative of present existential realities and a demand of the implications of the faith. Orthodox ethics cannot ignore the implications of the fact that there has been an enormous increase in the rate of world population growth, especially in the Third World. It cannot limit its teachings on conception control to the geographical areas where its members reside. Humanity must "maintain some balance between [its] numbers and the finite dimensions of this planet" (Freedman, p. 18).

THEOLOGY OF HUMAN DOMINION OVER THE EARTH. Theological anthropology has ecological and population implications. Traditionally, political implications have been discerned in humanity's creation in the image of God by finding parallels between the kingship of God and that of political leaders. The same doctrine requires human responsibility for creation, including ecological and population dimensions. Further, the dominion of humanity over the environment is an appropriate aspect of the Orthodox doctrine of divine providence in conjunction with the doctrine of "synergy," which calls for the cooperation of the human with the divine. Orthodox ethicists (e.g., Demetropoulos) have expressed some renewed interest in this approach.

ETHICAL DOCTRINE OF PHILANTHROPY. One of the chief theological and ethical categories of Eastern Christianity is *philanthropia,* a concept that transcends mere charity and includes the heartfelt identification of God, the church, and the individual Christian with all of humanity. *Philanthropia*, long a fruitful concept for Eastern Orthodox thought and life (Constantelos, 1968), has implications for population issues.

FERTILITY GUIDELINES. Orthodox personal ethics and the ethics of marriage and family have not adequately elucidated the implications of population realities. Both church leaders and scholars tend to leave such issues to "private conscience" or the "guidance of father confessors," although public teaching on the matter is now more widespread than it was earlier (Harakas, 1982; Meyendorff).

JUSTICE AND DISTRIBUTION POLICIES. The Orthodox churches tend to focus on national cultures and heritages. This is a result of their strong "incarnational" emphasis, based on the theological teaching in regard to the second person of the Holy Trinity, the Son, who took on full human nature and lived on Earth. The divine, as fully present in the created human reality of the one person Jesus Christ, becomes a model for all creation and relationships. Sacraments, icons, and church architecture are religious examples of this modeling in that in and through them the divine is made significant. Relationships, both formal and informal, are also imbued with the divine. Among these, marriage and marital relationships are thus understood incarnationally.

Global perspectives focusing on structural injustices, especially as they relate to population concerns, are equally incarnational concerns. The Orthodox Christian conscience has always had a universal dimension. Orthodox anthropology does not permit the view that equitable food distribution policies are utopian, nor that population concerns are limited to a single nation or region (Patrinacos).

AN ECUMENICAL APPROACH. Concern for population problems must be a shared endeavor. This may come closest to the original intent of Orthodox involvement in the ecumenical movement, the original justification of which was based on interchurch cooperation toward the solution of social problems. The ecumenical approach, however, must go beyond church cooperation and include collaboration with local and international agencies concerned with hunger and population problems.

POLICY AND PRACTICE. The recent direction in Orthodox thought has been to become more deeply involved in social issues. If this increased social involvement is to be put into practice seriously, Orthodox leaders will seek practical policy changes. For example, if birth control is to be considered by the Orthodox to be "one of the more effective means by which a balancing between eaters and food to be eaten, consumers and goods, and services and labor" can occur (Patrinacos, p. 48), this implies a commitment to a positive emphasis on conception control, coupled with sex education founded on a deeply considered theology of marriage. In addition, the Orthodox church must develop acceptable practices to influence national and international policymaking, legislation, corporate decision making, and public opinion. Serious concern with population issues necessarily requires what has been called "eco-tactics" (De Bell)—what used to be called in Orthodox history "whispering in the ear of the Emperor in the name of Christ."

In conclusion, both the imperatives and the potentials for involvement by the Orthodox church in population concerns are found within its tradition.

STANLEY S. HARAKAS (1995)

SEE ALSO: *Abortion; Adoption; Christianity, Bioethics in; Coercion; Eastern Orthodox Christianity, Bioethics in; Embryo and Fetus: Religious Perspectives; Eugenics and Religious Law; Feminism; Fertility Control; Freedom and Free Will; Genetic Testing and Screening; Harm; Infanticide; Informed Consent; Justice; Life; Natural Law; Race and Racism; Rights, Human; Sexism; Women, Historical and Cross-Cultural Perspectives;* and other *Population Ethics* subentries

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III. RELIGIOUS TRADITIONS: F. PROTESTANT PERSPECTIVES

Protestantism generally includes all Christian movements, denominations, and sects whose histories can be traced to or related to the sixteenth-century Reformers, especially Martin Luther and John Calvin. Hundreds of such Christian bodies exist worldwide. They represent very diverse theological orientations and forms of church discipline. It is possible to characterize a "mainstream" position on many theological and ethical issues held by major denominational families associated with the World Council of Churches (WCC), including Anglicanism (or Episcopalianism), Lutheranism, Presbyterianism, Methodism, Congregationalism, and various national united churches, such as the United Church of Canada and the Church of North India. Many other Protestant bodies, such as the Assemblies of God, Southern Baptists, and Jehovah's Witnesses are outside such a consensus. Even within the so-called mainline churches sharp differences exist. On many issues, some Protestants take positions completely at odds with others even within their own denominations while finding themselves in agreement with persons in other denominations or even with non-Christians. In recent years, there has been a sharp increase in numbers of Protestants in traditionally Roman Catholic Latin America, in Africa, and in parts of Asia. At the same time, there has been a marked falling off of active participation in the churches in such traditionally Protestant countries as Sweden and the United Kingdom.

It is therefore difficult to generalize about any one Protestant position on population ethics. This article focuses primarily on the mainstream churches and theologians for three reasons. First, these bodies represent the main currents of Protestant Christian history. Second, these bodies have taken the most explicit positions on population issues. Third, theologians representing these bodies present us with the clearest connections between distinctively Protestant theological emphases and ethical applications.

Early Protestant Thought on Population

The Reformers did not have theories about population as such, although their views on human sexual relations and procreation are relevant to discussions about methods of limiting population growth. Both Luther and Calvin understood sexual relations within marriage as a morally acceptable outlet for sexual drives quite apart from the purpose of procreation. Both, especially Calvin, also viewed sexual relations within marriage as an expression of loving companionship between a husband and wife (Fagley). Early Protestantism coincided in time with the decimation of Europe's population through the plague and the Hundred Years' War, so discussions of population during that period—which were mostly by secular writers—emphasized the need for population growth, not limitation. In contrast, Robert Malthus, whose demographic theories, published in 1798, first expressed alarm over excessive population growth rates, was a Protestant clergyman. His views derived more from economic thought than from Protestant theology, but the laissez-faire economic theories that exerted primary influence upon him may themselves have been encouraged by individualistic aspects of Protestant thought, especially the heightened importance of the "calling" each person has from God and the demand that each person respond, through faith, to God's grace (Weber).

Population issues were not intrinsically important to nineteenth-century Protestant thought except at three points. First, Malthus's pessimistic views of population growth were countered by various Protestant divines who considered them an impious reflection on the goodness of God's providence (Hutchinson). Second, in Anglo-Saxon countries, attitudes toward sexual relations during the Victorian era were often repressive. This gave rise to some rejection of contraceptive methods of birth control early in the twentieth century. Third, the nativist movement in North America, which sought to inhibit immigration from Roman Catholic countries, arose almost exclusively among Protestants. That movement exerted influence on subsequent anti-immigration legislation until the mid-twentieth century.

Theological Support for Family Planning

Protestant support for planned parenthood dates from early in the twentieth century. The early American movement in support of family planning and use of artificial methods of birth control, exemplified especially by Margaret Sanger (1883–1966, founder of Planned Parenthood), was more secular and humanist than Protestant, but it began to attract a serious following among Protestant thinkers and churches. The Lambeth Council of worldwide Anglicanism declared in 1930 that contraceptive methods could be justified when there is "a clearly felt moral obligation to limit or avoid parenthood and where there is a morally sound reason for avoiding complete abstinence" (Noonan, p. 125). During the thirty years thereafter, a strong consensus developed among mainline denominations and theologians in support of that position.

The preeminent Protestant theologian of that period, Karl Barth, wrote, "There is agreement to-day among all serious Christian moralists … that although the choice for or against generation and conception is not a matter for human caprice, it should not be left to chance and therefore lack the character of true decision, but must always be a matter of free obedience and therefore free consideration and decision" (Barth, p. 273). Artificial means of contraception must not, he wrote, be considered evil "just because they are so manifestly artificial" (Barth, p. 275). Dietrich Bonhoeffer, another European theologian of the midcentury, wrote, "It would not be right for blind impulse simply to run its course as it pleases and then to go on to claim to be particularly pleasing in the eyes of God; responsible reason must have a share in this decision" (p. 177). While Bonhoeffer strongly opposed abortion, on the grounds that in the pregnancy "God certainly intended to create a human being" (p. 176), he explicitly related support for planned parenthood to rapid population growth rates, which concerned him.

Barth's and Bonhoeffer's views are ultimately grounded in their respective views of creation. God's purposes for human life can be supported or obstructed by events in the natural order, including human interventions. When couples have children for which they are not prepared, this falls outside God's life-giving intentions. The same can be said of whole societies or of the world in general: Too rapid population growth can diminish the possibilities for humanity to find its God-intended fulfillment in the created order. Barth, therefore, did not limit his ethical perspective on family planning to decisions by individual couples about what is right for them. There was also the question of what was best for society as a whole. Humankind, in his view, is no longer under the divine command of Genesis 1, "Be fruitful, and multiply."

A leading American liberal theologian, Albert C. Knudson, expressed typical American Protestant thought in insisting (1) that procreation is not the only purpose of sexual intercourse; (2) that "there is nothing in the use of contraceptives that is inconsistent with a sincere faith in Divine Providence," since there is no religious duty to let nature run its own course; and (3) that the general improvement in the standard of living requires lowering the rate of population growth (pp. 209–210).

The first two of these points have been so generally characteristic of mainline Protestant thought and official denominational statements that one is hard pressed to find exceptions. The third has been in some dispute.

The Evolution of Protestant Views in the Twentieth Century

We may broadly characterize three main periods in the middle to later twentieth-century Protestant church teaching on population matters.

The first period, roughly from the Lambeth statement of 1930 to the late 1960s, emphasized the companionate, love-enhancing possibilities of sexual intercourse within the bonds of marriage while deemphasizing the moral obligation of married couples to have children. Contraception was generally accepted as a morally legitimate means toward the end of expressing love within marriage for its own sake. Birth control, or "planned parenthood," was, however, considered mainly within the family unit. Couples should be able to have as many children as they wish: no more, no less. Since the real issue was whether people could decide to limit their family size by conscious decision and employing contraceptive means, the net effect of such teaching was to encourage a diminishing birth rate. But during this period comparatively little attention was given to the world population growth rate.

The second period, coinciding with the emergence of the environmental movement in the late 1960s and 1970s and the publication of neo-Malthusian literature on the "population explosion," found Protestant teaching focusing primarily on the dangers of population growth and a corresponding moral responsibility by societies to find ways to limit it. Many of the mainline church declarations date from this period, with revisions added in subsequent years.

The third period, beginning in the late 1970s and corresponding to the growth of the liberation theology movement (the movement that began in the 1960s and that emphasizes freedom from external oppression as a central theme of Christian faith), witnessed greater criticism of neo-Malthusianism as a way to avoid social justice issues in the distribution of the world's resources. There was less inclination to treat population growth rates themselves as the primary problem. During this period, the mainline denominations continued to affirm the importance of family planning and to recognize the morality of the use of contraceptive measures of birth control. But there was a growing tendency to consider population limitation as a by-product of increased social justice and economic prosperity rather than the reverse.

In the United States, this period also witnessed the rise of evangelical Christian movements critical of mainline denominations and of what was taken to be their laxness in sexual morality and family values. Evangelicals often deemphasized the population issue while reemphasizing the restriction of sexual intercourse to marriage and strongly opposing abortion. Evangelicals, as a force in U.S. politics, played a role in the decision by the administration of President Ronald Reagan to oppose the United Nations Fund for Population Activities at the Second World Conference on Population (Mexico City, 1984) and to withdraw funding from the International Planned Parenthood Federation.

Official Positions of Mainline Protestant Churches

Official statements by mainline denominations illustrate the continuing importance of views developed in each of these three periods.

Among the mainline denominations, the United Methodist Church developed what may be the most systematic position on population ethics. The principal outlines of its position were adopted in 1972 as part of a broader declaration of social principles. Subsequent revisions did not substantially modify this position, although various resolutions adopted by the denomination's General Conference show the influence of the third period of Protestant thinking. In its 1992 form the United Methodist statement cites the strains on food, mineral, and water supplies by growing populations and asserts, "People have the duty to consider the impact on the total world community of their decisions regarding childbearing, and should have access to information and appropriate means to limit their fertility, including voluntary sterilization" (p. 40). A 1980 resolution by that denomination adds a theological rationale: "Our goal in history is that everyone may have the conditions of existence necessary for the fulfillment of God's intentions for humanity. Our context in history is the preciousness of life and the love of God and all creation" (p. 345).

The United Methodists have also dealt at length with questions related to the migration of populations. While stopping short of supporting unlimited movement across national borders, the Methodist statement reminds its readers of biblical support for strangers and sojourners, and calls upon the leaders of all nations "to welcome generous numbers of persons and families dislocated by natural disasters, war, political turmoil, repression, persecution, discrimination, or economic hardship" (p. 510). This document also calls upon governments "to alleviate conditions and change internal politics that create a momentum for the migration of people over the world" while seeking "protection of the basic human rights of immigrants … for both documented and undocumented, permanent or transient refugees or immigrants" (pp. 509–510).

Another mainline denomination, the Presbyterian Church in the U.S.A. (and its predecessor denominations), advocated voluntary planned parenthood and population limitation as early as 1965. In that year, the General Assembly of the United Presbyterian Church in the United States of America (UPCUSA; one of the predecessor communions) called upon the United States to "assist countries who request help in the development of programs of voluntary planned parenthood as a practical and humane means of controlling fertility and population growth." In 1971, that body came to "recognize that reliance on individual desires and private decisions to effect voluntary [birth] control, however well supported by information and means, will not be sufficient to provide the necessary limitation of population growth unless there is a radical and rapid change in the attitudes and desires." This document challenged "the assumption that couples have the freedom to have as many children as they can support," asserting that "we can no longer justify bringing into existence as many children as we desire." In 1984, the Presbyterian General Assembly again voiced its awareness "of the increasing size of the world's population and conscious[ness] of the potential consequences of unlimited growth, of resource limitations, of insufficient public responses, and of unmet population needs." It called "upon the U.S. government to participate fully in the International Conference [on population] and to give generous and continuing financial and logistical support to United Nations programs designed to address specific population needs."

The American Baptist Churches adopted a policy statement in 1976 supporting "efforts to develop programs which encourage family planning in an environment of free individual choice." Subsequent declarations emphasized social and economic justice without much specific application to population questions. A 1988 resolution indicated the denomination's internal divisions on the abortion question while opposing abortion "as a means of avoiding responsibility for conception" or "as a primary means of birth control" (1988, p. 9).

The Friends Committee on National Legislation (FCNL) has long supported family planning, but that position receives comparatively little emphasis in statements adopted during what I have characterized as the third period in the evolution of Protestant views on population. A lengthy 1987 statement on a variety of social-political-economic issues, for instance, merely repeats the FCNL's "support for safe and non-coercive family planning as one element of an effective national population policy" (p. 5).

The same 1987 statement does, however, contain a much lengthier section dealing with immigration and refugees. That section expresses the belief that "the world should evolve toward a global community whose people can choose freely where they wish to live and work" (p. 6). The FCNL's "long-range ideal" is, therefore, "a world of open borders that ensures both asylum for refugees escaping oppression and freedom to migrate for those who hope to improve their living conditions" (p. 6). Such a world would require "a more equitable distribution of the world's wealth, more respect for human rights, and greater tolerance of differences than exist at present" (p. 6).

The Unitarian Universalist Association continues to support family planning as a response to "the crush of overpopulation" that "is frequently associated with increasing the pollution of the water, air, soil, and ozone shield, and further depleting the earth's finite resources" as well as being a factor in "aggressive and destructive behavior." This denomination, like the other mainline churches, supports full access to contraception while going further than most in its direct support for "the right to choose abortion" (p. 56).

This sampling of denominational statements on population-related issues in the latter third of the twentieth century suggests no diminution of commitment to planned parenthood and the full rights of access to contraceptive technologies. At the same time, churches devoted less attention to population issues during the 1980s and 1990s and seemed more reluctant to grant full moral legitimation to abortion.

Protestant denominational statements do not generally enjoy the authoritative status of Roman Catholic papal encyclicals, though they do reflect deliberation by official bodies. When the official statements are seriously inconsistent with the deeper convictions of members, mechanisms are usually present to enact changes. That fact itself reflects a deep historic theme in most Protestant theology: God has immediate access to every believer. Consequently, the views of every church member, when expressed in good faith, must be taken seriously. Not surprisingly, therefore, Protestant viewpoints on population policy and other issues can change without threat to the basic body of shared doctrine. It is more difficult to ascertain the extent to which denominational statements on such issues reflect nontheological sociocultural influences. But the deliberative process of decision making in Protestant churches generally affords ample opportunity, over time, for purely secular influences to be criticized on the basis of shared faith traditions.

Protestant Positions into the Twenty-first Century

Projecting the future of Protestant views on population, there seems little prospect that the basic commitments to planned parenthood will change during the period ahead. The amount of emphasis given to the issue may well vary, however, with perceptions of the effects of population growth rates and patterns of migration. Protestant churches worldwide will doubtless continue to reflect a wide variety of views on these and other subjects. Historically, however, Protestant views on such issues have tended to be framed in response to empirical problems and opportunities. Evidence mounts that the churches will increasingly have to respond to global environmental problems, and the continuing growth of world population will remain a significant factor in that (Nash). The churches' response to population migration may be even more interesting as the world moves into the twenty-first century. Toward the end of the twentieth century, ethnic nationalism was felt as a major political force in some parts of the world, such as the Middle East, the former Yugoslavia, and the former Soviet Union. Nevertheless, the growing integration of global economics, increased facilities for communication and transportation, and the conclusion of the Cold War between the United States and the Soviet Union all point toward greater pressure on the increasing irrelevance of national boundaries. While addressing problems related to population growth, religious bodies may find it equally necessary to respond to archaic restrictions of movement.

J. PHILIP WOGAMAN (1995)

SEE ALSO: *Abortion; Adoption; Christianity, Bioethics in; Coercion; Eastern Orthodox Christianity, Bioethics in; Embryo and Fetus: Religious Perspectives; Eugenics and Religious Law; Feminism; Fertility Control; Freedom and Free Will; Genetic Testing and Screening; Harm; Infanticide; Informed Consent; Justice; Life; Natural Law; Race and Racism; Rights, Human; Sexism; Women, Historical and Cross-Cultural Perspectives;* and other *Population Ethics* subentries

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[*Note: Official declarations on population-related issues by Protestant and ecumenical church bodies are rarely available in libraries or in trade publication form. They generally can be obtained from denominational or ecumenical offices.*]

III. RELIGIOUS TRADITIONS: G. HINDU PERSPECTIVES

Hinduism includes a complex array of teachings related directly and indirectly to population dynamics (fertility, mortality, and migration) and to the ethics of population-related behavior. Its rich heritage spans millennia and embraces diverse populations. Hindus are found in many world regions, both within and beyond South Asia, its area of origin. Hinduism is the predominant religious tradition of India (for a general overview, see Hiltebeitel). It is practiced in one form or another by about 80 percent of the approximately 800 million people living there. Another 20 million Hindus live in nations other than India, including Fiji, Indonesia, Singapore, Guyana, Trinidad, Canada, the United States, and the United Kingdom. Diaspora Hindu communities increased in number and prominence in the United States beginning in the late 1960s, when the law was changed to allow immigration of educated professionals. The construction of major Hindu temples in such cities as Pittsburgh, Chicago, New York, and Washington, D.C., demonstrates the vitality of this international growth.

Basic Hindu teachings on population-related ethics and behavior will have different impacts depending on the context in which Hinduism is practiced. Within a particular locality, socioeconomic class, caste, and ethnicity are associated with differences in awareness of and adherence to Hindu religious teachings. Moreover, social resistance to certain aspects of orthodox Hindu religious teachings is being voiced around the world, particularly by ethnic minorities and women's groups.

This article first considers key aspects of Hindu religious teachings. It then focuses on Hindu values in India and how they contribute to demographic practices and outcomes. Last, it offers some observations on how members of Hindu communities in the United States are revising Hindu values related to population.

Hindu Teachings Related to Population

Several key teachings of Hinduism relate to population dynamics and have implications for how governments might formulate policy. A primary value is on *ahimsa* (this word combines the prefix *a,* "non," with *himsa,* "harm," thus meaning "nonviolence" or "nonkilling"). A well-known source of Hindu teachings on proper behavior, *The Laws of Manu* (Doniger and Smith), describes the model of four life stages (*ashramas*): student, householder, celibate, forest dweller. Manu's guidelines about marriage stipulate that the best form involves the father giving a virgin daughter, implying that the marriage is arranged by the parents of the bride and groom. Repeated statements in *The Laws of Manu* emphasize the importance for a woman of bearing offspring, especially sons. Other popular classical Hindu myths, such as in the epic *Mahabharata,* contain messages relevant to population. One is that the world is overpopulated, and that renunciation of the world is a valid means for release from personal, familial, and other worldly attachments. Celibacy is honored as reflecting a high level of self-control and spiritual attainment. Teachings about celibacy are linked with a strongly enunciated value on premarital chastity for females.

It is likely that these general teachings are known to Hindus throughout India and across most social divisions. It is also likely that links between people's knowledge of Hinduism and their population practices vary markedly across regions because India's demography differs dramatically by region and class (see Miller, 1981). Fertility is much higher in the northern plains than in the south and east. Mortality is more gender-differentiated in the northern plains, with excess female mortality, and is less severely skewed by gender in the south and east.

Thus we are confronted with a puzzle: Basic Hindu teachings are espoused by India's Hindu population more or less equally, but Hindu demography does not present a smooth pattern. We must therefore assume a loose linkage between Hindu teachings and demographic outcomes such as fertility rates and child survival by gender. In other words, as an explanatory variable affecting population dynamics, Hindu teachings are partial at most.

Population Issues in India

FERTILITY. Reproduction should, according to Hindu cultural norms, take place only within marriage. Stigma is attached to a premarital pregnancy, a situation that may bring serious consequences to the persons involved. A high premium is placed on marriage as a universal life stage through which, ideally, everyone should pass. As a householder, one marries, has children, and raises them. Reproduction is the primary goal of marriage. For Hindu women, the key to auspiciousness (a highly desired status for women that implies the opposite of stigma) involves being married, being devoted to one's husband, and bearing sons. All these values are clearly pronatal.

Hindu values support the bearing of children within marriage, and they emphasize the bearing of sons. Sons provide social security for their aged parents. The social security function of sons is especially marked in the northern Indian kinship system, which is followed strictly by Hindus and Jains. North Indian kinship rules stipulate that a daughter must marry a man from outside her natal village while a married son remains with his parents and brings a bride into his family. Another primary value of Hindus is to have a son light one's funeral pyre; a daughter cannot perform this task. The Sanskrit word for "hell" is *put*; the word for son, *putra,* means "the one who saves his ancestors from hell" (May and Heer, p. 200). Given mortality rates of the mid-1960s, demographers estimated that in order for a man to have a son who would be alive when he was sixty-five years old, his wife would have to bear seven children. Preference for male children operates to promote fertility and also plays a role in excess female mortality and indirect fertility reduction as discussed below. Desire for sons prompts families to keep trying until they have one, and then to have a second or third son as well.

The pervasiveness of the Hindu teachings on the value of having sons may be regionally variable in terms of intensity. Social surveys across the nation reveal that a stated preference for sons is stronger in the northern region than in the south and east (Dyson and Moore). This difference arises because socioeconomic factors such as the gender division of labor, marriage and kinship patterns, and the costs of marriage operate to affect the level of son preference (Miller, 1981; Dyson and Moore).

Other important fertility-reducing factors related to Hindu beliefs include ritually determined rules for sexual abstinence that limit the frequency of intercourse. One study found a total of 120 days mentioned for abstention (Nag). Such rules may be linked to a lower frequency of intercourse among Hindus than among Muslims, since the latter do not have such ritually proscribed days. Also important are the positive value placed on male self-control, including control of sexuality, and male anxiety about semen loss (Bottero). No one knows how much of an effect these conditions might have on the frequency of intercourse or actual reproductive rates, but one could posit at least some impact on both compared with non-Hindu populations.

Hindu views concerning widowhood may also lower fertility, since widows should not remarry and therefore should not reproduce (Mandelbaum). Restrictions on widow remarriage most significantly decreases fertility when women are widowed at a young age, as they often are in India.

Direct methods of fertility control, such as condoms, birth-control pills, or sterilization, are not antithetical to Hindu teaching since sexual intercourse is not seen solely as a means to achieve pregnancy. In contrast with this fairly liberal understanding, the famous leader of the independence movement and national hero, Mohandas Gandhi, supported abstinence as the only appropriate contraceptive.

Abortion for sociomedical reasons has long been legally allowed in India, except in the predominantly Muslim state of Kashmir (Chandrasekhar). In spite of legal provisions for abortion, safe services are lacking (Dixon-Mueller). This situation reflects the political priorities of the central and state governments more than religious doctrine.

Sex-selective abortion, a practice begun in the 1980s, is done almost exclusively to abort female fetuses. One study of a large number of hospital births in the Ludhiana area of the state of Punjab in northwestern India found that after 1983, when sex-selection became possible through amniocentesis, the sex ratio at birth rose from a normal of 105 boys per 100 girls to 117 boys per 100 girls in 1989 (Sachar et al.). Many feminist activists in India wish to maintain a woman's right to seek an abortion while striving to ban sex-selective abortion. The debate on prenatal sex selection in the public media in India has been largely secular.

MORTALITY. India is well known for its gender bias in survival of males and females. Hindu teachings that favor males provide the ideological justification for better treatment of males than females. But it is not possible to explain the scarcity of females relative to males in the Indian population solely on Hinduism. North India and neighboring Pakistan, which is predominantly Muslim, have similar gender patterns in mortality. Recent demographic data on China reveal substantial differences in mortality rates between males and females there as well. Economic, political, and social factors are important in explaining this phenomenon.

In the northern plains of India, son preference is linked with behavior termed "daughter neglect" (Miller, 1981, 1987). This neglect, which takes the form of biased allocations of food, medical care, and psychological attention, can be fatal. It skews the sex ratio among children as well as in the general population. In northern India, census data from the first part of the twentieth century indicated that unbalanced juvenile sex ratios favoring boys characterized all major religious groups in the area: Sikhs, Hindus, Muslims, and Jains. Son preference interacts with daughter neglect to create excess female child mortality. The indirect fertility-reducing effect of excess female child mortality is clear: If daughters experience higher mortality than sons, then the number of future childbearers is reduced in comparison with what would be the case without excess female child mortality. In such a demographic regime, the ratio of living sons to daughters is maintained over time, as brides are brought in from other villages and regions to marry sons; thus, no "shortage" of brides to produce future sons is perceived or experienced.

Hindu beliefs seem implicated in the high mortality rates of widows, which are caused by general neglect and nutritional deprivation (Chen and Drèze). More extremely, the low value placed on a woman once her husband has died relates to the uncommon practice of *sati,* the suicide of a Hindu widow on the funeral pyre of her husband. In general, the value of female self-sacrifice is long-standing in Hinduism, and it supports socialization patterns of girls that train them in self-denial of food and other resources.

MIGRATION. According to traditional Hindu teaching, migration beyond the boundaries of India was grounds for outcasting. Since the late nineteenth century, however, the rate of migration of Hindus outside of India has increased substantially (Madhavan), and anxiety about "outcasting" appears to be nonexistent among migrants. With international migration, Hindu traditions are being reshaped in local contexts.

The United States

In the United States, most Hindus are middle or upper class (Helweg and Helweg), although large populations, especially in New York City and New Jersey, are less well off. Among this employed and generally well-educated population, fertility rates are low, infant and child mortality rates are low, and longevity is high.

The value placed on having a son among the Hindu population of the United States is an important but unresearched question. Undocumented sources indicate numerous cases of demand for prenatal sex determination, in order to keep male fetuses, by South Asian immigrants in the United States and Canada. As of 1994, U.S. law prohibits abortion based on the sex of the fetus, but people circumvent this rule. They may have a test done ostensibly to reveal genetic abnormalities in the fetus and, in the process, find out its sex. If the fetus is female, they go to another doctor and present a story about genetic abnormalities in their family that cannot be proved or disproved because the relatives who are claimed to have the genetic problems are in South Asia. On this basis, the couple requests an abortion.

Within the teachings of Hinduism, nothing specifically argues against sex-selective abortion per se, since traditional teachings do not address the topic of abortion from a gender-specific perspective. This issue will pose a challenge for contemporary theologians and ethicists working within the Hindu tradition.

Another issue being quietly contested in the everyday lives of Hindus and Jains in the United States is premarital chastity. In opposition to the more liberal sexual mores among the general population, many Hindu and Jain parents apply pressures on their children, especially daughters, to maintain their virginity before marriage. Depending on how conservative the family is, more or less intergenerational conflict ensues.

Many Hindu and Jain communities have started Sunday schools (never a tradition in India) and summer camps where religious values are instilled in young children and teenagers. Such values include premarital chastity. At the same time, marked liberalizing changes are being made in some Hindu rituals in the United States, as a response to lowered fertility rates (many Hindu families have only one child) and an interest in treating daughters the same as sons. In the early 1990s, the Hindu-Jain temple of Pittsburgh held its first *upanayana* (sacred thread) ceremony for girls. Several liberal-minded leaders promoted this reform of Hindu tradition, which restricts the *upanayana* ceremony to boys of the upper castes.

The Challenge of Change

Neither Hinduism nor population dynamics is static. Contemporary movements in Hinduism range from conservative trends that could be termed fundamentalist to more liberal tendencies among some migrant communities. The greatest challenges to the study of the relationship between Hindu teachings and population lie in the following directions: the links that individuals make in their thinking between Hindu tenets and their own demographic practices; the reactions of Hindu theologians to new questions such as sex-selective abortion; and governments' policies in dealing with such problems as population growth and excess female mortality within a moral framework that would be acceptable to Hindu constituents.

BARBARA D. MILLER (1995)

SEE ALSO: *Abortion; Adoption; Coercion; Embryo and Fetus: Religious Perspectives; Eugenics and Religious Law; Feminism; Fertility Control; Freedom and Free Will; Genetic Testing and Screening; Harm; Hinduism, Bioethics in; Infanticide; Informed Consent; Justice; Life; Natural Law; Race and Racism; Rights, Human; Sexism; Women, Historical and Cross-Cultural Perspectives;* and other *Population Ethics* subentries

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III. RELIGIOUS TRADITIONS: H. BUDDHIST PERSPECTIVES

Buddhism is a dominant cultural force in most parts of Asia. Theravada Buddhism, also known under the name of Hinayana or "Small Vehicle," prevails in such Southeast Asian countries as Sri Lanka, Thailand, Burma, Cambodia, and Laos; its sister sect, Mahayana Buddhism, or "Great Vehicle," is currently found in Tibet, Japan, Taiwan, and Korea. This article focuses on Theravada Buddhism, especially as practiced in Thailand.

Though Therevadins have their own sacred literature that distinguishes them from the rest of Buddhism, they do share certain central beliefs with other Buddhists. Among these beliefs are those concerned with *samasara, karma,* and *nirvana,* which are the key concepts of all forms of Buddhism. *Samasara* refers to the round of existence, or the cycle of rebirth, in which all beings revolve according to their *karma.* This perpetual cycle comprises three realms of rebirth, namely, the realm of desire (*kamaloka*), the realm of forms (*rupaloka*), and the formless realm (*arupaloka*). These realms have thirty-one subspheres containing different forms of life, such as humans (*manussa*); animals (*tirachan*); ghosts or unhappy departed beings with deformed bodies (*peta*); spirits or wandering ghostly beings (*bhuta*); hell-beings or tortured beings (*niraya*); titans (*asura*); and gods (*deva*). The realm of desire consists of the higher spheres of gods; the middle spheres, of sentient beings, humans, and animals; and the lower spheres, of ghosts, spirits, and hell-beings. The celestial realm of forms and the formless realm are the abodes of the most refined and subtle beings (*brahman*). Despite differences in life span, beings in all realms are subject to death and rebirth.

Karma means intentional, mental, verbal, or physical action and its result (*vipaka*). The sequence of actions, or deeds, and their effects, known as the law of *karma,* act both as the natural law of cause and effect (operating in the physical realm) and as the moral law (governing the moral sphere that regulates the movement of beings between rebirths). Rebirths of all beings are the natural results of their own deeds, good or bad, and not “rewards” or “punishment” imposed by a supernatural, omniscient ruling power. All beings reap what they sowed in the past, and all will be reborn according to the nature of their present deeds—they are “heirs” to their actions. When a being dies, the karmic result, acting as the individual life-force, passes to other lives, endlessly exalting or degrading successive rebirths. This life-force will become completely inactivated only with the cessation of craving (*tanha*), the inherent force of karmic action. Such cessation is referred to as nirvana and can be achieved through following the Middle Path (*Majima Patipada*) consisting of wisdom (*panna*), morality (*sila*), and concentration (*samadhi*).

Buddhist Concepts in Population Growth and Control

There is no fixed number for population in *samasara* existence. It is in a state of flux, with continual migration of beings from one realm to the others regulated by the law of *karma* and continuously readjusted to the nature and the quality of *samasara* dwellers. An increase of population in one realm means a decrease of population in others, and vice versa. Human rebirth is considered incomparably precious because the human realm is the only place where there is enough suffering to motivate humans to seek ways to transcend misery and enough freedom to act on their aspirations. In the higher and lower spheres, by contrast, beings are fully reaping the karmic results, good and bad: The gods are too absorbed in the blissful state to find ways out of *samasara* existence while animals, ghosts, spirits, and hell-beings are in irremediable misery and have little freedom to do either good or evil. These suffering beings will gain the precious human rebirth only when the results of bad *karma* that led to their lower rebirths are exhausted. When this happens, the results of their previous good actions performed when they were human will lead them to better rebirths and, sooner or later, to the human level again.

From this view, an increase in the human population is desirable for it means more beings will have the rare human opportunity to transcend suffering. In theory, then, Buddhists should welcome population growth. But the fact that increasing numbers of Buddhists use contraceptives in countries such as Thailand, where 98 percent of the population is Buddhist, seems to indicate a different position. Family planning has been quite successful in both urban and rural areas of Thailand. Apart from the contributing factors of the economy, social change, and education, there are some Buddhist tenets that may account for the low fertility rate. The most important one is the emphasis on the quality of human life concomitant with the high value it gives to human rebirth.

In the Buddhist perspective, the rare human rebirth is meaningless if there is no quality in it. The value of life does not depend on its duration but on its quality. For life to be worth living, it should be lived with the ultimate purpose of attaining *nirvana*, the final emancipation. This goal, however, like all spiritual progress, cannot be achieved without a certain degree of material and economic security. Below the level of subsistence, human life lacks real meaning because it consists only of hunger, illness, and unrelieved misery. This emphasis on material necessities was made by the Buddha as a necessary condition for a truly enlightened, meaningful life. The Buddha himself once refused to preach to a starving man until his hunger had first been appeased. He also recommended that monks who lead the life of renunciation depend on the lay community for food, shelter, and clothing.

This emphasis on life’s material necessities is an important part of the Buddhist perspectives on population control and thus needs to be considered together with the Buddhist endorsement of human rebirth. That is, human rebirth, though desirable, needs adequate supporting conditions (*upatthambhaka*) to enable it to be worthwhile. Since famine is one of the most powerful forces (*upapilaka*) working against spiritual development, Buddhism does not approve of population growth disproportionate to a society’s available resources of food. Because of this, Buddhists in Thailand and other countries do not attribute large family size to good *karma.* Unlike the Hindu householder, who believes he must have sons to perform the prescribed rituals for him after his death, Buddhist parents are not anxious to have sons to be ordained as monks. Although ordination is considered a meritorious act that will ensure good rebirth after death, many other means of receiving merit are also available, including offering food to monks, listening to sermons, and building or repairing temples.

The lack of anxiety for sons or large families supports the practice of family planning among Thai Buddhists. Unlike abortion, which is still socially unacceptable in Thailand and not as widely practiced as it is in Japan, birth control is believed by Thai Buddhists to be in line with Buddhist teachings concerning marriage and family life. Though the Buddha considered celibate life superior to married life, he did not advise it for all his followers. Realizing that all humans were at different stages of spiritual evolution, he did not commend the same codes of conduct to all. To his lay followers who could not lead the austere life of monks and nuns, he recommended marriage but stressed spiritual progress, and not procreation, as its main goal. For those with children he devised a code of discipline, emphasizing responsible childbearing and child rearing.

For Thai Buddhists birth control, unlike abortion, does not transgress the Buddhist precept of nonkilling, nor does it interfere with the working of the law of *karma.* In Buddhist understanding, conception begins only when three factors merge: the coitus of the parents, the woman's generative capability, and the presence of the *gandhabba,* the karmic life force of one who has died. By preventing pregnancy, birth control makes human rebirth more difficult but it does not interfere with the operation of the law of *karma.*

From the Buddhist viewpoint, the fruition of good or bad *karma* requires the right supporting conditions; without them the karmic life-force cannot express itself. Only beings who are fully qualified for human rebirth can be reborn in the human realm. Under unfavorable physical conditions a being, though possessing the good *karma* to be reborn as a human being, must dwell in his or her sphere waiting until the opportune moment. Buddhism does not oblige parents to open the gate of human rebirth to all beings with good *karma* by having as many children as they can. The Buddhist concept of *karma* assigns to each person sole responsibility for his or her own life. According to the Buddhist analysis of human nature, one's sexual life is the outcome of the urge to satisfy one's sexual craving. Whether sexual activity produces children or not is a matter to be decided by the couples themselves. The autonomy of individuals to choose their own destiny and to be responsible for their own actions is a crucial element in Buddhist population ethics.

Self-restraint and the control of the senses and passions are recommended as important forms of population control and to prevent the sexual indulgence that widespread use of artificial means of birth control may lead to. Following this teaching, many Buddhists in Thailand, Sri Lanka, and Burma have contributed to population control by practicing sexual continence, leading celibate lives as monks or nuns, and using contraceptives.

PINIT RATANAKUL (1995)

SEE ALSO: *Abortion; Adoption; Buddhism, Bioethics in; Coercion; Embryo and Fetus, Religious Perspectives; Eugenics and Religious Law; Feminism; Fertility Control; Freedom and Free Will; Genetic Testing and Screening; Harm; Hinduism, Bioethics in; Infanticide; Informed Consent; Justice; Life; Natural Law; Race and Racism; Rights, Human; Sexism; Women, Historical and Cross-Cultural Perspectives;* and other *Population Ethics* subentries

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POPULATION POLICIES, DEMOGRAPHIC ASPECTS OF

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Population projections made in the 1950s predicted the large expansion in human numbers that subsequently occurred in the second half of the twentieth century. When these projections were first published they led to widespread concern about the potential adverse consequences of rapid population growth for human welfare and the environment, especially in the poor countries of Asia, Latin America and Africa where growth was expected to be most rapid. As a result, in the 1960s and 1970s funding and technical assistance expanded enormously for developing country governments that were willing to take action. Efforts by these governments to curb rapid population growth focused on reducing high birth rates through the implementation of voluntary family planning programs. These programs aimed to provide information about and access to contraception to permit women and men to take control of their reproductive lives and avoid unwanted childbearing. Only rarely, most notably in China, has coercion been used. Newly available contraceptive methods, such as the pill and intrauterine device (IUD), greatly facilitated the delivery of family planning services. Successful implementation of such programs in a few countries in the early 1960s (for example, in Taiwan and Korea) encouraged other governments to follow this approach.

Rationale for Family Planning Programs

The choice of voluntary family planning programs as the principal policy instrument is based largely on the documentation of a substantial unsatisfied demand for contraception. In surveys, large proportions of married women in the developing world report that they do not want a pregnancy at the time of the interview. Some of these women want no more children because they have already achieved their desired family size, while others want to wait before having the next pregnancy. A substantial proportion of these women (more than one-half in some countries) risk pregnancy by not practicing effective contraception (including sterilization) and, as a result, unintended pregnancies are common. In the mid-1990s, 36 percent of all pregnancies in the developing world were unplanned and 20 percent ended in abortion (Alan Guttmacher Institute).

Why do apparently motivated individuals fail to practice contraception? The answer lies in a mixture of social and health service-related reasons. In the past, a lack of access to services or information was a dominant obstacle. But access in the geographic sense has improved with the widespread implementation of family planning programs and the expansion of the role of private-sector providers. These efforts have not eliminated all unmet need, however, because many service points still offer too few methods and little if any information, or they are otherwise deficient in quality. In addition, other factors—such as fear of side effects of contraceptive methods and overt or suspected disapproval of husbands/partners and other family members—are significant barriers to use in many societies.

The existence of this unmet need for contraception was first documented in the 1960s, and it convinced policymakers that family planning programs were needed and would be acceptable and effective. The health and human rights benefits of family planning and reproductive health programs have provided additional rationales for this policy approach, which was endorsed at the 1994 United Nations International Conference on Population and Development. The Programme of Action adopted by the participating governments encourages the expansion of reproductive health and family planning programs as a means to improve women's reproductive freedom and health. Coercion of any kind is strongly opposed.

Demographic Impact

Over the past three decades large changes in reproductive behavior have occurred in most of the developing world. Around 1960, only a tiny fraction of couples practiced contraception, and knowledge of methods was very limited. In contrast, contraceptive knowledge is now widespread and more than one-half of married women in the developing world are current users of contraception. The large majority of these current users rely on modern methods, including male and female sterilization, the IUD, and the pill.

As a consequence of this widespread adoption of contraception, birth rates have declined sharply. In the past, fertility was high and relatively stable at over 6 births per woman. Since a precipitous decline began in the 1960s, the fertility of the developing world has been reduced by almost one-half, reaching 3.1 births per woman in the years from 1995 to 2000 (United Nations). The largest fertility declines occurred in Asia (–52%) and Latin America (–55%) and the smallest in sub-Saharan Africa (–15%). On average, the pace of change in reproductive behavior in the developing world has been faster than was the case in Europe and North America in the late-nineteenth and early-twentieth centuries.

A key factor contributing to this rise in contraception has been the diffusion of information about and access to contraceptive methods, aided by a rapid expansion of family planning programs. Experiments have provided the most direct and convincing evidence of the value of well-designed family planning services. An example of a large and influential experiment is the one conducted in the Matlab district of rural Bangladesh (Cleland et al.). When this experiment began in the late 1970s, Bangladesh was one of the poorest and least developed countries, and there was considerable skepticism that reproductive behavior could be changed in such a setting. Comprehensive family planning and reproductive health services were provided in the treatment area of the experiment. A wide choice of methods was offered, the quality of referral and follow-up was improved, and a cadre of well-trained women replaced the traditional birth attendants as service providers. The results of these improvements in the quality of services were immediate and pronounced with contraceptive use rising sharply. No such change was observed in the comparison area. The differences between these two areas in contraceptive use and birth rates have been maintained over time. The success of the Matlab experiment demonstrated that appropriately designed services can reduce unmet need for contraception even in very traditional settings with low levels of development.

Despite the undoubtedly crucial role of family planning programs, they are not the only or even the principal cause of changes in reproductive behavior in the developing world. Instead, socioeconomic change is considered by most analysts to be the dominant driving force of the fertility transition. As traditional agricultural societies are transformed into modern industrial ones the cost of children (e.g., for education) and a decline in their value (e.g., for labor and old-age security) to parents leads to declines in desired family size. In addition, with fewer children dying at young ages, fewer births are needed to ensure the survival of the number of children that parents desire. A rise in human development and, in particular, improvements in health and education, appear to be the principal determinants of progress through the fertility transition (Jejeebhoy; Sen; Cleland). In fact, it is possible for poor populations to reach low fertility levels, provided literacy and life expectancy are high. Well-known examples of this occurred in Sri Lanka and the state of Kerala in India.

The primary role of family planning programs is and has been to reduce unintended births by assisting couples with the implementation of their preferences for smaller families through contraception and abortion. Family planning programs have accelerated fertility transitions, so that, on average, these transitions have occurred about a decade earlier than they would have without the programs. Because small changes in fertility have relatively large effects on long term population growth this acceleration of fertility decline attributable to programs probably has reduced the eventual population size of the developing world by a few billion (Bongaarts, 1997).

Demographic Causes of Future Population Growth

Despite recent fertility declines, population growth continues at a rapid pace throughout most of the developing world. According to United Nations projections, the expected increase in population of the developing world as a whole between 2000 and 2050 (from 4.87 to 8.14 billion) is about the same as the historically unprecedented increase that occurred between 1950 and 2000 (from 1.71 to 4.87). This future growth can be attributed to three demographic factors (Bongaarts, 1994).

First, the past decline still leaves average fertility about 50 percent above the two-child level per woman needed to bring about population stabilization. With more than two surviving children per woman, every generation is larger than the preceding one and as long as that is the case population growth will continue. High fertility can in turn be attributed to two distinct underlying causes: unwanted childbearing and a desired family size above two surviving children. Many couples continue to want large numbers of children, partly because of fears of child mortality and partly because of the need for a sufficient number of surviving children to assist them in family enterprises and support them in old age. In most developing countries, the completed family size desired by women still exceeds two children; in some areas, such as sub-Saharan Africa, desired family size is typically above four children.

Second, declines in death rates—historically the main cause of population growth—will almost certainly continue. Higher standards of living, better nutrition, greater investments in sanitation and clean water supplies, expanded access to health services, and wider application of public health measures such as immunization, will insure longer and healthier lives in most countries. The exceptions will be mostly in sub-Saharan African countries, where the AIDS epidemic is severest.

The third growth factor is what demographers call *population momentum.* This refers to the tendency for a population to keep growing even if fertility could immediately be brought to the replacement level of 2.1 births per woman with constant mortality and zero migration. Due to a young population age structure, the largest generation of adolescents in history will enter the childbearing years in the first decade of the twenty-first century. Even if each of these young women has only two children they will produce more than enough births to maintain population growth over the next few decades.

Population momentum is the most important of these three factors, contributing about one-half of projected future growth. Further large increases in the population of the developing world are therefore virtually certain.

Future Policy Options

To be effective, population policies should address all these sources of continuing growth, except declining mortality, by implementing several strategies.

REDUCE UNINTENDED PREGNANCIES BY EXPANDING HIGH QUALITY FAMILY PLANNING SERVICES. Unintended pregnancies occur when women and men who want to avoid pregnancy do not practice effective fertility regulation. Offering individuals and couples appropriate services is a priority of many governments in the developing world. Despite considerable progress over the last several decades, the coverage and quality of family planning services remain less than satisfactory in many countries. In addition, some countries have imposed demographic and provider targets on family planning programs, thus actively interfering with trust between clients and providers. To ensure that family planning programs appropriately assist individuals in reaching personal fertility goals, family planning should be a strictly voluntary service linked with other reproductive health services. The quality of most existing programs can be improved by extending services to under served areas, broadening the choice of methods available, (including safe pregnancy termination where it is legal), improving information exchanges between client and provider, promoting empathetic client/provider relationships, assuring the technical competence of providers, including men in programs, adding service elements to address related health problems, such as diagnosis and treatment of sexually transmitted diseases and treatment following unsafe abortion, and increasing public awareness of the value of and means available for fertility regulation, responsible/safe sex, and the location of services.

REDUCE HIGH DESIRED FERTILITY BY CREATING FAVORABLE CONDITIONS FOR SMALL FAMILIES. Even if unintended fertility could be reduced or eliminated, a desire for large families remains a key cause of population growth in many countries. Several social and economic measures have substantial effects on desired family size:

Increase Educational Attainment, Especially Among Girls. Mass education changes the value placed on large families and encourages parents to invest in fewer “higher quality” children. Higher levels of education are also associated with the spread of nontraditional roles and values, including less gender-restricted behaviors. Educated women want (and have) fewer children with higher survival rates.

Improve Child Health and Survival. No developing country has had a sustained fertility decline without a prior substantial decline in child mortality. A high child death rate discourages investments in children’s health and education and encourages high fertility by requiring excess births to insure that at least the desired number of children will survive to adulthood.

Improve Women’s Status and Provide Them with Economic Prospects and Social Identities Apart from Motherhood. Improvements in the economic, social, and legal status of girls and women is likely to increase their bargaining power over family reproductive and productive decisions. Increased women’s autonomy reduces the dominance of husbands and other household members, the societal preference for males, and the value of children as insurance against adversity and as securers of women’s social positions.

CURB THE MOMENTUM OF POPULATION GROWTH. While a young age structure—the key demographic cause of population momentum—is not amenable to modification, an option to reduce momentum is available that has received little attention in past policy debates. Further reductions in population growth can be achieved if the average age at which women begin childbearing rises (by delaying the first birth) and through wider spacing between births. Young women often have little choice about whether or not to have sexual relations, when or whom to marry, and whether to defer childbearing. Governments that wish to encourage later childbearing have several options at their disposal. Legislation to raise the age at marriage has been moderately effective in a few countries. However, legislation has the drawback that it forces rather than encourages changes in marriage customs. Indirect approaches are likely to be more effective. A greater investment in the education of girls, particularly at the secondary level, is the most obvious example. The longer girls stay in school, the later they marry and the greater the delay in childbearing. Delaying the onset of childbearing will therefore not only reduce population momentum, it also significantly improves individual welfare.

Well-designed population policies are broad in scope, socially desirable, and ethically sound. Mutually reinforcing investments in family planning, reproductive health, and a range of socioeconomic measures operate beneficially at both the macro and micro levels: The same measures that slow population growth increase productivity, and improve individual health and welfare.

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SEE ALSO: *Fertility Control; International Health; Population Ethics; Population Policies, Strategies for Fertility Control*

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POPULATION POLICIES, MIGRATION AND REFUGEES IN

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Global migration is as old as history, but its significance has waxed and waned over the centuries. In the late twentieth century, political, economic, and social factors have brought it once more to prominence; a 1993 United Nations Population Fund report asserted that migration “could become the human crisis of our age.”

What accounts for the contemporary significance of global migration? For one thing, the world no longer contains politically unincorporated territories, so that every instance of migration is not only a move from some nation or other; it is a move to some nation or other. Nations are sovereign states whose recognized rights include the right to control their borders—the right, therefore, to decide who may enter their territory. Thus a decision to migrate to some place is a decision that, politically if not morally, is not for an individual alone to make; it requires the consent of the receiving country. In some cases, even the decision to migrate from a place has been taken out of the hands of the individual; some nations, that is, have claimed the authority to decide who may leave as well as who may enter.

There are further reasons for the increased significance and magnitude of international migration: explosive, uneven population growth in different nations; large disparities in economic wealth and economic development between countries; special interdependencies between particular countries; and advances in transportation and communications systems. Not surprisingly, people tend to move from crowded, poor countries to less crowded, richer ones where economic and other opportunities are better. The desire to migrate may be fostered by television and other mass media, which arouse awareness of opportunities in faraway places; the ability to migrate may be aided by transportation systems that make relocation easier. It has been said that the question is not why people migrate but why they do not migrate more often, given conditions in many “sending” countries and the basic economic principle that resources flow to optimal locations. Migration always involves both “push” factors that give people reason to want to leave a place and “pull” factors that attract them to someplace else.

International migration raises fundamental ethical questions about the moral significance of national boundaries and social communities, the nature and extent of human rights, and the circumstances in which people have moral obligations to aid others or to accept them into their communities. It also raises a host of empirical questions about the effects of migration on both sending and receiving countries and about the extent to which migration can be controlled. On the basis of our current knowledge, it cannot be said that the empirical questions are any more tractable than the ethical ones. Both the facts about migration, and the relevant moral principles, are highly controversial.

A Framework for Migration Issues

It seems a safe assumption that, other things being equal, most people would rather remain in their native countries than begin anew in a strange land. But other things are not always equal. The contemporary world is organized into nation-states possessing very different characteristics, a situation creating disequilibrium. Countries that are relatively rich, safe, or politically free tend to attract people—either as permanent residents or as temporary workers—from countries not possessing these features. Not only do individuals in such circumstances have reason to migrate, but the countries from which they come may view emigration as a way to relieve political or economic pressures. Moreover, receiving countries often have powerful economic interests in acquiring foreign labor. Disentangling the various interests at stake—between sending and receiving countries, and between different groups and classes within each—is a complex task.

The pressure point in contemporary discussions of migration centers primarily on its effects on receiving countries. It is perhaps a truism that if too many people come to those countries, they will eventually cease to be attractive either to their original inhabitants or to anyone else. But the question is how many are too many, and why? How should a receiving country decide which of those seeking entry ought to be admitted?

These questions are misleading if they suggest that an immigration policy is simply a way of implementing charity or beneficence. Immigrants, legal and illegal, serve important interests of receiving countries, or of significant groups within them. We can organize the issues at stake by elaborating four considerations appropriate to formulating an immigration policy—leaving aside, for the moment, the perspective of sending countries. First, what is at stake for those seeking entry? Second, is immigration the only way their needs can be met? Third, what costs and benefits—economic, social, cultural—are at stake for the receiving country as a whole and for particular groups within it? Should these costs and benefits be weighed differently depending on who bears them? Fourth, do receiving countries sometimes have moral obligations to accept potential immigrants—on the basis of past actions, a special relationship with the sending country, or general humanitarian grounds? We can begin to address this fourth question only after the first three have been explored.

Refugees, Immigrants, and Migrants

The first two considerations—what is at stake for those seeking entry, and the extent to which migration is the only way their needs can be met—are captured in the way different categories of people who migrate are usually described. The basic distinction is between refugees and immigrants.

According to the 1951 Convention Relating to the Status of Refugees and the 1967 Protocol Relating to the Status of Refugees, the definition accepted by the United Nations says a refugee is a person who, "owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it" (Article 1.A.2, in Goodwin-Gill, p. 253). Essentially this definition has been in force since shortly after World War II, in response to the upheavals surrounding that conflict.

The meaning of *immigrant* or *migrant* has traditionally been understood by contrast to refugees: Those who migrate are not fleeing political persecution. The difference between migrants and immigrants, furthermore, is not a formal one; but based on common usage, we may say that migrants relocate temporarily, or travel back and forth between their home country and another, while immigrants relocate permanently.

The suggestion is typically that immigrants move for economic betterment, with the implication that they are "pulled" rather than "pushed." But this implication, although often reasonable, is sometimes highly misleading. Even to speak of economic betterment misleadingly suggests an acceptable baseline from which one aims to improve; but many who migrate for economic reasons find themselves in desperate circumstances—as desperate, sometimes, as those of political refugees. The causes of migration may be natural disaster, external aggression, civil war, or internal oppression, all of which can severely affect even those who do not suffer direct political persecution. Furthermore, it may be that those who wish to migrate cannot be helped where they are. Recognizing these problems and the possible bias in the U.N. definition, the Organization of African Unity (OAU) in its 1969 Convention added the following to the definition of a refugee: "every person who, owing to external aggression, occupation, foreign domination or events seriously disturbing public order in either part or the whole of his country of origin or nationality, is compelled to leave his place of habitual residence in order to seek refuge in another place outside his country of origin or nationality" (Article I, Section 2). Thus, for example, "environmental refugees" may be forced to flee their homeland because of deforestation resulting from trading practices and the import strategies of rich countries or international institutions. The OAU definition accommodates the truth that in today's world—as Aristide Zolberg, Astri Suhrke, and Sergio Aguayo argue—"The causes of life-threatening conditions in the developing world stem from an interpenetration of national and transnational, or global, processes" (p. 33).

Why does it matter how we define *refugee*? The reason is that the term has special legal, moral, and emotional force; to be counted a refugee is to be treated as having a compelling claim to admission, whereas potential immigrants have a much weaker claim, in part because of the assumption that their needs can be met without relocation. Many countries are bound by international agreements forbidding *refoulement,* the forcible return of a refugee to his or her country. To exclude from the definition extremely pressing claims that do not result directly from persecution has a powerful influence on the lives and well-being of millions of people.

The definition of a refugee can be manipulated in other ways. Thus, although the United States helped draft the 1951 Convention Relating to the Status of Refugees, it did not ratify it, and adopted the U.N. definition only in the Refugee Act of 1980. Until that time, ideological considerations played a large part in U.S. policy; priority was given to those fleeing "Communist or Communist-dominated" societies. Even since 1980, ideological considerations have continued to influence U.S. refugee admissions. Of course, many of those seeking to migrate—for example, Mexicans to the United States, Turks to Germany—are not in desperate straits. They are poor compared to most people in the receiving countries, but they do not usually come from the poorest stratum of their own society; the poorest lack the physical, emotional, and economic resources to uproot themselves from their homes and begin again. What is at stake for these potential immigrants? A better life, a decent life—a life that most of those in the receiving countries would consider much superior to what is available in the sending countries, but one that it is in no way inappropriate to aim for. The life left behind, then, is not desperate, but it may not be acceptable either.

Costs and Benefits to Receiving Countries

No one would oppose immigration unless he or she believed it presented significant drawbacks or costs. Those who favor stricter limits on the number of immigrants, or stricter conditions of entry, typically argue that at certain levels (often current levels), immigration carries significant economic, social, or cultural costs. Sometimes the concern is primarily with those who enter illegally, either because it is believed that the flow of illegal immigrants inflates the number of outsiders to unacceptable limits, or because as illegal immigrants they pose special problems not posed by those admitted through legal channels.

A central debate concerns the effects of immigrant labor on jobs for natives. In the United States, the debate takes the following form: Some who wish to restrict immigration believe that immigrant labor displaces the worst-off native citizen groups and depresses wages (Briggs). Immigrants, it is said, will work for wages that citizens, possessing the elevated standards prevalent in more developed societies, find unacceptable. Illegal immigrants make things even worse, these critics argue, because they are fearful and thus willing to accept whatever they can get. Proponents of immigration argue, on the other hand, that immigrants do work that citizens consider too menial, such as domestic work and hard agricultural labor. In addition, they say, because the labor market is not a zero-sum game and because immigrants are also consumers, they often stimulate the economy, thereby creating new jobs (Simon).

It is extremely difficult to sort out the various issues implicit in these claims and to derive conclusions with any degree of certainty. Immigration has multiple effects, and unequivocal conclusions about these effects lack plausibility. Most economists seem to agree that immigration increases aggregate national wealth, but that some displacement of low-skilled workers and depression of their wages do occur. For obvious reasons, the welfare of low-income citizens should be of special concern: Policies that make the worst-off even worse off are difficult to justify. But economists disagree about the magnitude of these problems, and many argue that in some occupations, immigrants and citizens do not compete.

In any case, it is easy to see how foreign labor serves business interests. This is especially true in industries dominated by undocumented migrant labor—those that are part of the "informal economy"—where workers' docility and fear are easy to exploit. In some industries, like the garment industry in the United States, women, who sometimes do "home work," are particularly at risk (Fernandez-Kelly and Garcia).

Another issue that is partly economic and partly social concerns the extent to which immigrants burden a society's social services and, particularly because of language deficiencies and cultural differences, its educational institutions. Even if new immigrants do utilize such services disproportionately—and this remains a point of controversy—they also contribute significantly to a nation's tax base. Some argue, furthermore, that countries with low population growth, like the United States and the nations of western Europe, will need immigrants to help pay for programs such as Medicare and Social Security for older citizens. In the United States, these costs and benefits cannot be easily weighed against each other, since for the most part social services are funded locally, and local jurisdictions are not reimbursed proportionately for the services they render. The countries of western Europe may face different and greater problems because of their more comprehensive social support systems.

Perhaps the most complex "costs" that immigration is said to impose are social and cultural. Several issues are relevant. For one thing, immigration sometimes produces conflict among ethnic groups. In part, this can arise because low-income native-born groups regard the newcomers—accurately or inaccurately—as competing for jobs and resources. But it may also occur when immigrants constitute "middleman minorities," a role played historically in many countries by Jews, Asian Indians, and Chinese (Portes and Rumbaut). Conflict of this kind exists today in the United States, for example, between African Americans and the Korean merchants who own shops in their communities.

Some critics argue that too many immigrants may threaten a society's distinctive way of life, diluting or destroying its identity and its institutions. This is a difficult criticism to assess, in part because the values said to be at stake are elusive and vague. Historically, immigrants have often been viewed with suspicion and fear (Higham), and sometimes the concern about culture amounts to no more than veiled xenophobia or racism. The immigration policies of many countries, such as the United States and Australia, have during extended periods excluded or severely limited the entry of non-northern European or nonwhite immigrants (Jones). When immigrant groups consist partly or largely of nonwhite peoples, as they often do today, it is difficult to avoid the suspicion that claims of cultural integrity contain a racial component.

Let us suppose that these attitudes do not exhaust the concern about cultural integrity. Then we are faced with difficult questions about what a culture is and how immigrant groups mix or assimilate into it, or do not (Gordon). It may be argued that the worry about cultural integrity rests on a misconception about culture. A culture is not an unchanging entity that is threatened by, and too inflexible to accommodate, influences from without or within. Especially in the contemporary world, cultures change. We can imagine radical, unacceptable changes that render the old culture unrecognizable; but the burden of proof is on the critic to show that immigrant groups cause such transformations.

In the United States, immigrant groups have shown a remarkable capacity to assimilate into the dominant culture. Historically, the nations of western Europe have had less experience with immigration than the United States; partly for that reason, the citizens of such a nation do not see themselves as part of a "melting pot," a "salad," or a "nation of immigrants," as Americans often do. Apart from this matter of self-conception, these societies are ethnically less heterogeneous than the United States. But one cannot conclude from this alone that they have more to fear from immigration.

Costs and Benefits to Sending Countries

Just as costs and benefits to receiving countries are controversial, so are those to sending countries. "Out-migration" serves to reduce economic and population pressures, but it can also cause "brain drain"—loss of some of the most productive members of a society—and it can reduce the pressure for needed social, economic, and political reforms. On the other hand, some countries, such as the Philippines and El Salvador, now earn more from remittances sent home by migrants than from any export. Thus migration can produce important benefits to sending countries and to families within them.

But as important as these issues are, the central point of controversy today concerns the impact of migration on receiving countries. This is not unconnected with the fact that the moral and legal right to leave a place is generally accepted; debate centers on the right to enter. Thus, even if overall a decline in emigration benefited a sending country, few would endorse prohibitions against leaving. Thus the hard core of the argument—about what people or nations have the right to do or to prevent, about what strictures on mobility ought to be implemented—concerns the point of entry, not the point of exit. If immigration today is more imminently pressing than emigration, then the problems it poses—that is, problems in receiving countries—will be the engine that drives new approaches and policies. At the same time, as the world becomes increasingly interdependent economically, as well as in every other way, it is clear that there can be no "solution" to immigration that is not at the same time a solution to emigration. If people are to stop coming to the developed countries, conditions in their home countries will have to become more attractive. Policies are needed to weaken both the pulls and the pushes of migration.

Migration and Morality

Uncertainties about the effects of migration on sending and receiving countries and on particular groups within them; a sense that to a large extent these phenomena exemplify forces beyond our control; the legacy of political realism, according to which ethical considerations do not and should not operate in international relations—all of these may contribute to the view that moral questions have no place at all in discussions of migration.

But such questions cannot be avoided. In the case of refugees and others not officially designated as such but who are equally desperate, migration confronts us with clashes between the claims of some individuals both to survive and to attain basic levels of health and well-being, on the one hand, and the claims of nations, or individuals within them, to exclude these people from such basic goods by refusing them entry, on the other hand. Even when the needs of those seeking entry are not quite so stark, migration poses difficult questions about the relationship between rich and poor—both individuals and countries—and the nature of the moral ties between them. Do rich countries have an obligation to aid poor countries, either by accepting immigrants or by some other means? On what basis could such a moral obligation stand? And how far does it extend?

According to a commonly held view, nations have the right to prevent the entry of whomever they wish. But this claim needs further analysis. It may be uncontroversial that nations have the *legal* right to refuse entry to noncitizens and thus may use whatever criteria they like to decide admissions. Even this claim is somewhat misleading, however, because nations bound by agreements forbidding *refoulement* may not ordinarily expel refugees even if they have entered illegally. But refusing admission to those who have not yet entered does not constitute a violation of international law.

Yet a legal right is not a moral right, nor is it equivalent to what is morally right. Consider the well-known case of the *St. Louis.* In June 1939, the United States turned away a German vessel carrying more than 900 Jews fleeing Nazi Germany. They had been promised, then denied, visas by Cuba; proceeding up the U.S. coast, they requested refuge from the American government. These "boat people" were not inside U.S. territorial waters, and in any case, international agreements regarding refugees had not yet been established; thus there is no doubt that the United States was within its legal rights in refusing the refugees' appeal. But did it have a moral right to refuse their request? Or did it, on the contrary, have a moral obligation to provide at least a temporary haven?

Some people may shy away from speaking in terms of rights and obligations in this context. But few today would deny that the United States ought to have taken in the refugees, or that it was wrong and reprehensible for it to have refused. The moral principle underlying such a judgment might be expressed thus: If a person or a nation can prevent a great harm at little or no cost to itself, it is wrong not to do so.

This principle fits the case under discussion because taking in the St. Louis passengers, whose lives hung in the balance, would have had no adverse effects on the United States. The issues confronting us today, however, raise two kinds of questions not raised by this example. First, in most cases, those seeking entry are not as desperate as were the refugees from Nazi Germany. It might be argued that what is at issue in such cases is not preventing a great harm but providing a good, and that people are not obviously worthy of blame if they choose not to provide that good.

In any case, it is the second question raised by contemporary migration that more seriously challenges the relevance of the principle that one ought to act if one can do so with little or no cost to oneself. The great number of people who might be inclined to migrate—and who might be encouraged to do so if they were aware that others have been admitted—calls into question the assumption that migration imposes no costs on countries that open their doors, or on particular groups or individuals within them. Debate continues about the economic, social, and cultural costs of migration. Some hold that the costs of migration at current levels are not significant, while others claim that it has adverse effects on the well-being of groups in the resident population. Thus, two critical empirical questions are at what point migration brings harm to groups in the receiving country, and which groups there are affected. The crucial moral question is whether and to what extent people in receiving countries should bear the costs of accommodating immigrants.

Haves and Have-Nots

Why, morally, should people in receiving countries bear any costs to promote immigration? Two kinds of reasons can be offered. First, it might be argued that it is wrong or indecent for some to have so much while others have so little, even if the haves are in no way responsible for the plight of the have-nots. Second, it can be argued that the haves owe something because they bear some responsibility for the situation of the have-nots, perhaps in virtue of some prior or current relationship between them. Let us consider these two kinds of reasons in turn.

From a moral point of view, the global distribution of wealth and poverty as it affects individuals is largely arbitrary. Whether one happens to be born in Sweden or Pakistan, Australia or Somalia, is a matter of chance, but it makes all the difference to a person's life prospects. What follows morally from this fact? There is little consensus. To some, it seems obvious that radical inequalities are unfair or otherwise unacceptable to the extent that they are undeserved. On this view, since people in rich countries are lucky to have been born there and those in poor countries are unlucky, and since these chance occurrences have much to do with how people fare in the world, something ought to be done to redistribute wealth from rich to poor. The same conclusion regarding the need for redistribution might be based not on the arbitrariness of birthplace but on a principle of humanitarianism or benevolence: Those who can help people in dire need ought to do so. Migration is one way to achieve redistribution. Whether and in what circumstances it is preferable to other approaches, such as humanitarian or development assistance to poor countries, will depend on a variety of factors.

But others draw no such conclusion from the moral arbitrariness of nationality. In part, their refusal may flow from the conviction that this line of thinking "proves too much": Not only does one not deserve to be born in a rich country, but one does not deserve to be born to rich parents, or to be endowed with superior genes. Taken to its logical conclusion, the critics say, this argument removes the grounds for all systems of rewards and punishments, and would mark the end of a free society. For this or other reasons, such critics insist that although it might be decent or nice or admirable for rich countries to share their wealth, the fact that birthplace is arbitrary implies no moral obligation to do so; and poor people or poor countries who do not receive such benefits have no cause for complaint.

Disagreement about what follows from the moral arbitrariness of nationality goes to the deepest questions about moral responsibility and social justice. Progress toward resolving these questions, if it can be achieved at all, is impossible without extensive and detailed argument. But there is another rationale for the conclusion that rich countries ought to make some sacrifices for the well-being of immigrants from poor countries—a rationale that does not depend on the moral arbitrariness of birthplace or on simple humanitarianism. This is the view that rich countries owe something to poor countries on the basis of past or present actions and relationships. For example, in 1974 the U.N. General Assembly's Declaration on the Establishment of a New International Economic Order argued that rich countries have "underdeveloped" poor countries: that it is because of colonialism and exploitation, at least in part, that there are now radical disparities in wealth and well-being among nations, and that poor countries are poorer than they would have been had there been no interaction. If this is true, then poor countries are owed something by way of reparations or compensation, not simply in virtue of benevolence.

There are several problems with such claims. Even if one agrees that rich countries did mistreat poor countries in various ways, it is difficult to know what the victims of such exploitation and harm would be like today in the absence of these actions. Without knowledge of this kind, it is almost impossible to decide what reparations or compensation are owed. Moreover, it is possible that in the absence of colonialism, some developing countries would not exist and would be even worse off than they are today. And some, such as Singapore, have fared well despite a colonial legacy.

An obligation may rest more specifically on a particular relationship between countries. For example, acceptance by the United States of large numbers of refugees and immigrants from Vietnam can be viewed as acknowledgment of the moral import of U.S. involvement in Vietnam and the U.S. debt to the Vietnamese people. American relations with Mexico fit this principle as well, although in a less extreme form. Mexican labor was crucial to the growth of many American industries, and recruitment of Mexican labor by U.S. mining and railroad companies and by agricultural growers dates to the middle of the nineteenth century. European countries' use of "guest workers" can be understood similarly to generate obligations: Having brought workers to one's country when they were deemed necessary, one is not free to sever the relationship after the "guests" have set down roots.

Beyond "Us" and "Them"

Whether on grounds of the moral arbitrariness of nationality, general humanitarianism, or compensatory justice, it seems clear that developed countries, which tend to be the recipients of immigrants and refugees, have moral obligations to developing countries. To what extent such obligations are best fulfilled through migration requires further investigation: In some cases it will make more sense to move resources to people than to move people to resources.

More fundamental questions remain, however. How extensive are these moral obligations? How much ought people in rich countries to sacrifice, if that is necessary, to raise the welfare of poor and oppressed people to tolerable levels? It is clear that no general answers can be given to these questions. In part, the answers depend on how obligations to those outside one's country are to be weighed against obligations to those within. Does one not, it may be asked, owe more to the poor within one's own society than to those elsewhere? And is it not likely that serious commitment to fulfilling obligations to our fellow nationals will strain our resources and therefore our virtue as it is?

Perhaps we can find part of an answer to this question by addressing the concerns of those who view claims about the moral obligations of rich countries to poor countries as misplaced or pointless, because they believe that national policies are not based on such considerations, or even that they should not be. Obviously the foregoing discussion rejects this view. Nevertheless, it is important to see—both because it is true and because it may motivate those unmoved by considerations of morality—that "self-interest rightly understood," in Alexis de Tocqueville's phrase, may also serve to support policies that reduce global inequalities.

In what ways? With international economic interdependence ever increasing—and telecommunications and transportation systems rendering the world of the haves more accessible both psychologically and physically to the have-nots—in the long run, rich countries will be unable to keep their privileges to themselves without employing methods that are repellent, and perhaps ineffective. One might go further and say that the same factors that render the world more interdependent and the North more visible and immediate to the South also render the South more visible and immediate to the North. And so it will become more difficult for those in the North to maintain their humanity while denying their connections with distant strangers of whose suffering they are aware. The reasons that we have duties to those within our community, and that our well-being depends on the well-being of other members of our community, still stand. But the boundaries of our community now may have to be enlarged.

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SEE ALSO: *Immigration, Ethical and Health Issues of; Population Ethics; Race and Racism; Rights, Human; Warfare: Public Health and War*

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POPULATION POLICIES, STRATEGIES FOR FERTILITY CONTROL IN

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Population wide fertility control has a history of both success and failure. That history has been fraught with ethical dilemmas rooted in issues of autonomy, responsibility, choice, community, the significance of reproduction, and the meaning of life, among many others, that have occurred in the context of a wide range of practical policies designed to limit or sometimes increase human reproduction.

Many early cultures, both Western and non-Western, have been aware of population pressures and have made attempts to prevent excessive population growth. However, the contemporary history of fertility control, responding to the economist Thomas Malthus's 1798 warnings, began in earnest in the mid-1960s, when some of the world's most populous nations, especially India and China, became aware of skyrocketing growth rates. From the mid-nineteenth century on, death rates had begun to decline. Developments in public sanitation, immunization, antibiotics, and medical technology began to reduce infant and child mortality and lengthen the average life span. Average family size in many cultures increased, and more offspring survived to reproductive age. In the latter half of the twentieth century, the world's population doubled in two generations, increasing from 3 billion in 1960 to 6 billion in 1999, and estimates of the population in 2050 ranged from 9 billion to 12 billion.

Despite these estimates of uncontrolled growth, in the early years of the twenty-first century global population growth rates began to decline, particularly in Europe, where by 2003 at least fourteen countries had below-replacement rates (that is, below 2.1 children per woman), in some cases well below that number. Average fertility rates in the less developed countries also fell, declining from 6.0 in the late 1960s, when fears of a "population explosion" were coming to the fore, to about 2.9 in 2003. Disputes over population policies and strategies for fertility control have continued to rage, although they have been tempered in the developed countries in recent years by the mistaken popular perception in which declining growth rates are conflated with declining growth. Despite declining fertility rates, absolute population growth remains high as a result of both above-replacement birthrates in many populous parts of the world and enormous population momentum.

Ethical Issues in Population-Control Programs and Policies

The ethical issues raised by population-control programs are of two principal kinds: those concerned with specific means for controlling population growth and those which challenge the objective of limiting human fertility. The earlier population-control programs have been more vulnerable to criticism about the means used for limiting fertility; contemporary policies raise questions about the overall objectives of fertility control.

EARLY PROGRAMS: INDIA AND CHINA. In 1975, concerned by the prospect of uncontrolled population growth in an already very poor country, India launched a vigorous population-control program that encouraged vasectomy, a comparatively simple and inexpensive method for permanent fertility control. The program in India employed a broad system of incentives and penalties to secure cooperation. Its critics often focused on the violations of individual rights and procreative liberty it seemed to involve, especially when nonvoluntary or semivoluntary means were used to elicit consent, for example, "bribing" men with transistor radios, middle-of-the-night roundups coupled with fines, denial of benefits and wages, denial of educational opportunities, and other penalties. Hostility to the sterilization program was so substantial that it contributed to the downfall of Indira Gandhi's government in 1976, and the program essentially was dropped without an effective replacement.

In China concern with population growth also began in the mid-1960s, but it was not until 1979 that that country instituted an effective, if controversial, population-control program. Dubbed the "one-child" policy, that program introduced a system of birth limitations that were imposed in both urban areas and, less effectively, rural areas: With some exceptions couples were permitted to have only a single child. The few exceptions were made for couples whose first child died or was disabled and in some rural areas if the first child was a girl or the couple were members of a non-Han minority group. The one-child policy was imposed by means of a system of birth permits and local supervision of the menstrual cycles of village women, separate residences for young couples in different cities, delayed marriage ages, and the required use of indwelling contraceptives (especially the intrauterine device [IUD]) and required or forced abortion for supernumerary pregnancies.

Observers outside China typically identified two principal moral problems in the one-child policy: the sometimes draconian means by which regulations and penalties were imposed and the consequences for females in a culture with strong preferences for male offspring, including selective female abortion, female infanticide, and female abandonment and out-adoption. Although China has permitted considerable relaxation of the one-child policy—in particular, couples in which both the husband and the wife are only children are now allowed two children and couples who are able to pay a fine for a second child are often permitted to do so—but the one-child policy is still officially in force.

Although India's and China's population-control programs appear to have involved similar ethical abuses, including mandatory contraception and severe penalties for extranumerary children, there is a substantial ethical difference between them. India's system was a *targeted* system that worked by profiling categories of individuals on whom pressure for nonreproduction was to be put and was satisfied when a preset proportion of "acceptors" complied. China's policy, in contrast, has been imposed in a comparatively egalitarian way: The few exceptions aside, China's policy stipulated that at least in principle *all* couples were limited to having only one child. While China's policy was not easy to impose, especially at the outset, and the total fertility rate did not drop below 2 children per woman until 1990, the policy was egalitarian in intent. However, outside critics, in their haste to expose excesses such as forced abortion and female abandonment, typically have failed to notice the ethical conundrum at the center of China's policy: Although it is the most restrictive coercive population-limitation policy in any country, it is also the most fair.

Population policies in the developed world typically but not always have stressed voluntary fertility reduction. Zero population growth (ZPG) became a rallying cry as well as the name of an influential organization and an international family-planning movement dedicated to encouraging couples to have only two children; indeed, average family size in the United States and other developed nations declined dramatically to just above the replacement level. There has been some concern in the United States about manipulative and coercive fertility-control programs that have been suggested, recommended, or put into practice for various minority groups (for example, sterilization programs for Puerto Rican and Native American women that involved inadequate consent and proposals for bonuses or bribes to encourage black women on welfare to accept Norplant), but in general the developed nations have proceeded through the stages of the demographic transition, going from high birthrates and death rates, to high birthrates and low death rates, to low birthrates and low death rates at which population growth again stabilizes, largely as a result of voluntary fertility control.

DEVELOPMENT-BASED POLICIES. After denouncing abuses in policies such as those of India and China as well as other nations that attempted to limit population growth by nonvoluntary means, international attention turned to the pronounced association between more developed economies and lower fertility rates. With the once-a-decade United Nations Conference on Population and Development that was held in 1994 in Cairo, population policy began to shift toward encouraging development, which was understood as involving both macroeconomic changes such as moving from agrarian to industrial economies, improving infrastructure, and shifting the balance of trade to greater proportions of export commodities as well as changes in social agendas, especially more education for girls and improved economic status for women. With that shift would come the benefits of a modern consumer society, it was argued, with its advanced healthcare, social security policies, and other institutions, and people no longer would need to have many children to provide farm labor, foraging, or care and economic support in their old age.

The effort in the new development-based policies was understood as being aimed at stimulating mechanisms that would bring about the demographic transition in countries that had not undergone it, and so birthrates would drop, as death rates already had, and population growth would "level out" at a low, steady, globally supportable rate of about 2.1 children per woman. Because women in underdeveloped countries with high birthrates routinely reported having on average about two more children than they wanted, changes in the economic environment would make it possible for them to reduce fertility to accord with their desires.

Development-based fertility-lowering policies counted among their ethical advantages the fact that people in advanced industrial nations were willing to share a lifestyle—higher development with low fertility and small family size—that had brought them material advantages and were willing to foot much of the bill. Developed societies offered better nutrition, better healthcare, better infant and child survival rates, better education, better jobs, longer life spans, and better security in old age; those advantages were to be made possible for developing countries as well, and in the process fertility rates would decrease. Development-based population policies also seemed to have another moral advantage: They were aimed not at directly controlling population or restricting individuals' fertility but at changing people's background circumstances for the better, thus allowing them to choose to have fewer children. Thus, they seemed to have the moral advantage of favoring individual choice rather than manipulation (as in the Indian vasectomy-targeting scheme) or coercion (as in China's one-child policy).

However, development-based strategies for fertility reduction have raised at least three moral dilemmas. First, they function by disrupting existing cultures, changing traditional agrarian lifestyles into wage-labor ones, often leading rural villagers into the cities and the life of the urban poor and in the process changing gender roles, parent–child relationships, and community structures. Second, they move resources from developed countries into the economic restructuring of less-developed, high-fertility countries, not always in efficient ways, and in doing so often bring with them alien cultural and economic values.

Third, those models may have counterproductive results: Even if they reduce fertility, they may increase consumption, thus undercutting the Malthusian argument for population control. They exacerbate rather than reduce the so-called tragedy of the commons, in which individuals in economic competition exploit resources for their own self-interest and thus make communal restraint impossible. In terms of global resources and environmental impact, the original Malthusian rationale for population control, China's success with its one-child policy, for example, will be negated if all those single children want refrigerators and cars.

REPRODUCTIVE-HEALTH MODELS. Currently favored in programs in many countries, reproductive-health models of fertility control attempt to avoid many of the ethical problems associated with the early population-control programs and the development model. They avoid the targeting of "acceptors," instead attempting to provide access to contraception and reproductive healthcare to everyone; avoid birth ceilings and after-the-fact penalties for excess births; and do not attempt to change existing cultures' economic patterns, occupational roles, domestic relationships, and community structures.

Instead, the reproductive-health model attempts to provide women with full-range reproductive healthcare, including access not only to modern contraception but also to disease prevention; prenatal, perinatal, and postnatal healthcare; and other forms of healthcare and education that affect reproduction. They are designed to satisfy unmet needs for contraception rather than to force conception on unwilling users, keeping in mind that women in less developed, high-fertility societies routinely say that they would have wanted on average about two children fewer than they have. Many of these programs also seek to extend reproductive healthcare to men, including the provision of male contraception and the prevention of sexually transmitted diseases. Many programs that provide reproductive healthcare in less developed nations have been inventive in devising new, more effective forms of healthcare delivery: In Bangladesh, for example, healthcare workers are aware that village women may have difficulty reaching public clinics or may be prevented from visiting them and have developed systems of home delivery of contraceptives and other forms of reproductive healthcare.

Although reproductive-health models of fertility control have avoided many of the ethical problems of earlier programs, they have had other problems. Some nations with conservative administrations, including the United States, have refused to support programs that provide safe abortion services even when those services are recognized by local providers as essential to reproductive healthcare. Other points of dispute that have been raised primarily by the Catholic Church include the provision of condoms for disease prevention as well as contraception and the supplying of contraception and other reproductive-health services to unmarried adolescents and women. Those issues differ from the ethical dilemmas raised by the earlier programs in that they are politically freighted, occurring at the intersection of conservative political and religious thinking with progressive public-health-oriented concerns. Some view the fact that reproductive-health programs may involve contraception, abortion, and the provision of services to unmarried persons as an issue of troubling moral significance; for others there seems to be no moral problem.

Ethical Issues Concerning Fertility Encouragement

The most thoroughly explored issues in fertility theory involve global population growth and ways to control it without violating individual reproductive rights. In some parts of the world, however, including Europe and Japan, fertility rates have declined so dramatically that they are well below the replacement rate. Some of the apparent decline is an artifact of later-onset childbearing and longer child-spacing intervals, but some of it is real. Subreplacement societies are "graying," it often is said, and social security, health insurance, and other social systems are being stressed as very low birthrates coupled with much longer average life spans have produced comparatively few children but many elderly people.

The ethical issues that arise in this context involve fertility encouragement, usually in preference to more liberal immigration policies, and what measures a society may or should take to increase birthrates, if any, and for what reasons. It is becoming fashionable to speak of "population collapse," associating the prediction of population decline, particularly in Europe, with predicted economic collapse.

Some countries offer bonuses, generous maternity and paternity leave, and/or child support for having a baby.

Some engage in public advertising that promotes childbearing: “Sterben die Deutschen aus?” (“Are the Germans dying out?”) asked one German subway poster. Although none of these programs repeat ethical abuses such as the requirement the former dictator Nicolae Ceausesçlu imposed on Romanian women that they bear at least five children, some attempt to influence individual reproductive behavior in many of the same ways in which advertising attempts to influence consumer choice.

The ethical issue here is whether individuals’ reproductive lives should be influenced in the same ways and by the same means that manufacturers sell automobiles or laundry soap. There is also the question of whether public-service advertising to increase fertility is ethically analogous to public-service advertising to decrease fertility, as in “stop at one or two” billboards in Vietnam, soap operas favoring small family size in China, and similar measures in many other countries.

Averting “population collapse” is not the only motivation for a state, ethnic group, or religious group to encourage fertility increase. Many earlier societies and some contemporary ones, such as early Maoist China and contemporary Iraq, have encouraged high fertility as a source of military might and/or productive power: More children mean more soldiers and workers. Some religious groups have encouraged high fertility to, as detractors see it, increase denominational strength. It might be considered appropriate for some groups that have suffered genocide or other calamities to practice high fertility to recover their demographic strength. Examples include Armenians after their expulsion by the Turks, Jews after the Holocaust, African Americans after slavery, and New World Amerindians after European contact, when indigenous groups in North, Central, and South America were reduced not so much by warfare but by epidemics of European diseases such as measles, typhus, yellow fever, and smallpox that in many areas killed 80 to 90 percent of the population or resulted in complete extinction. In what sense a group may or should attempt to regain its earlier population size, when and how compensatory population gain should be measured, and what impact it may have on other groups inhabiting the same region are issues that invite further discussion.

Ethical Issues Concerning Technology in Fertility Control

New reproductive technologies play a major role in issues involving fertility control, especially new forms of contraception and pregnancy interruption. Three pose particularly complex ethical issues.

MALE CONTRACEPTION. With the exception of India’s vasectomy program, virtually all programs for fertility control have focused on women. While a wide variety of modern contraceptive methods have been developed for women, until recently sexually active males had only three methods for controlling their contribution to reproduction: withdrawal, condoms, and vasectomy. A number of modern male contraceptive methods are under development, including vas-blocking methods, heat-based methods, and hormonal methods, and several can be expected to reach the market soon.

These methods raise a variety of ethical issues. Are different degrees of control over whether conception can occur appropriate to non-abstinent males and females? At least in areas where women have free access to it, female-controlled contraception has given women veto power over their own reproduction, something that is often held to be appropriate because reproduction occurs within women’s bodies. Should males also have veto power over reproduction even though it does not affect them physically in the same way? Might the development of effective long-acting but reversible methods of male contraception herald an ethically problematic change in male/female reproductive roles, especially in roles that often are considered essential to female identity?

POSTCONCEPTION CONTRACEPTION. Among the various methods of female contraception, some function by preventing conception and others function by preventing implantation or interrupting an early pregnancy. Generating particularly vigorous ethical controversy have been “morning after” contraceptive modalities, not only “emergency contraception” that is effective for up to 120 hours but in particular abortifacient methods that interrupt pregnancy at up to seven weeks of gestation.

As with reproductive-health programs for fertility control, the problems here are the subject of political dispute, involving disagreements between those who oppose abortion altogether and those who do not or who find moral issues of abortion appropriately resolved privately or overridden by other moral concerns. Another issue posed by postconception technologies involves the timing of decisions about pregnancy: Should those decisions be made before conception, when one is not yet pregnant—that is, should they deal with a condition not yet established—or is there a moral and epistemological advantage to allowing conception and pregnancy to occur and then deciding whether to continue it? Opponents of abortion would insist on the former; the latter might be supported on the grounds that it gives the woman or couple a more realistic opportunity for full-fledged consent: Once pregnancy has begun, she can understand more fully the step she is taking, including the changes it brings about in her body, and then decide whether she wants to continue. Although this issue may seem bizarre to Western theorists of reproduction, it is pressing in countries, such as Soviet-era and post-Soviet Russia, in which abortion has been a principal method of fertility control. The total induced abortion rate for Moscow is about 6 (though for Russia as a whole it is 2.5) and decisions about pregnancy continuation often are made after rather than before the fact.

LONG-ACTING CONTRACEPTION. The ethical implications of the difference between short-acting, "time-of-need" contraceptive modalities such as the condom; the diaphragm; spermicidal foams, gels, and sponges; and other forms that require use at the time of sexual exposure as distinct from long-acting modalities that have a contraceptive effect over an extended period, such as the IUD, the subdermal implant, and the depot injection, also have been explored inadequately. The central theoretical difference involves the degree of user cooperation required to prevent conception. Short-acting, time-of-need modalities require user awareness and cooperation each time, every time, as do nontechnological methods of contraception such as withdrawal and the "rhythm method" of scheduled abstinence. In contrast, true long-acting contraception requires no user cooperation beyond the initial emplacement. This difference is obscured, however, by a variety of technologies that have a long-term chemical effect but require repeated dosing, such as oral contraceptives ("the pill"), as well as by permanent or difficult-to-reverse methods such as tubal ligation, quinacrine sterilization, and vasectomy.

The ethical issue that arises here concerns whether it is morally appropriate to "reverse the default" in human reproductive biology. Currently, sexual contact between a fertile male and a fertile female may permit conception *unless that is prevented;* if the default were reversed by having long-acting, indwelling but reversible contraception in place and if everybody used it, sexual contact would not permit conception *unless that were chosen.* The consequences of such a reversal for fertility control are potentially enormous: If everybody did it all the time—that is, used long-acting, reversible contraception except when he or she wanted to have a child—fertility rates would decline dramatically without a violation of reproductive rights.

Societal Interests in Fertility

The issue of societal interests in individual fertility has a greater scope than any of the issues discussed above. Society in general—that is, the global population as a whole—is composed of individual human beings, all of whom are the product of reproductive activity between earlier human beings: their parents, the providers of the male and female gametes involved. A very small proportion of this reproductive activity, at least in the developed world, involves artificial reproductive technologies such as in vitro fertilization, embryo storage and transfer, surrogacy, and cloning, and some involves arrangements between nonheterosexual couples, but most reproductive behavior takes place between a man and a woman, whose reproductive roles are influenced by the wide range of cultural settings in which their conjunction occurs.

The overarching ethical question is what weight the interests of their society or society in general should be given over people's personal choices about reproduction. Should concern about global population growth take precedence over individual reproductive behavior? Should the risks of population decline take priority over individual choice? Are pressures for increased fertility more or less defensible than pressures for fertility limitation? These larger issues invite extended exploration.

Population control measures are motivated principally by the Malthusian specter of global crowding, which traditionally is formulated as the threat that a population will outrun the carrying capacity of its site, that is, will consume more than can be replaced in its environment and thus eventually will exhaust its resources and die. The urgency of global fertility control often is underestimated by those who confuse declining growth rates with declining growth: Growth rates are falling in virtually all areas of the world, but as a result of immense population momentum in the latter decades of the twentieth century, total global population is still increasing rapidly. Nevertheless, the Malthusian specter does not answer the question of whether it is better to have fewer people with a higher standard of living or more people in far more modest circumstances. What should be the aim of population control?

As the philosopher Derek Parfit has discussed, different future scenarios may involve fewer people with a higher quality of life or more people with a lower quality of life, but as long as the quality of life is not so low that life is not worth living, it is not easy to say why a larger population of less fortunate people is not preferable to a smaller population of people with a higher quality of life. Parfit entertains what he calls the "repugnant conclusion" that for a large population with a high quality of life there always could be a much larger population with a much lower quality of life, a life barely worth living, but that such a future would be better.

Similarly, fewer people consuming more is not obviously better in terms of global environmental impact than more people consuming less and also is not obviously morally preferable to the opposite situation, assuming that the effect on environmental sustainability is equal. This philosophical puzzle raises deep cultural, political, and religious questions and perhaps will be the central challenge for theorists of fertility control in the future.

MARGARET PABST BATTIN

SEE ALSO: *Abortion; Autonomy; Eugenics; Eugenics and Religious Law; Family and Family Medicine; Feminism; Race and Racism; Sexism; Sustainable Development; Women, Historical and Cross-Cultural Perspectives*

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PRINCIPLISM

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Since the mid-1970s, American bioethicists have tended to justify their proposed solutions to the moral problems arising in medical care and health policy by appealing to fairly abstract moral principles, such as respect for autonomy or beneficence, rather than to a particular moral tradition, such as a religion, or to a complex, philosophically articulated moral theory, such as consequentialism or deontology. This method has come to be called principlism, a label originally meant to be derogatory, but since embraced by its defenders.

Tom Beauchamp and James Childress present the canonical account of this method in their *Principles of Biomedical Ethics,* where they suggest that four principles—respect for autonomy, nonmaleficence, beneficence, and justice—provide the proper justificatory framework for bioethics. Because both Beauchamp and Childress were working at the Kennedy Institute of Ethics at Georgetown University in Washington, DC, while they were writing their book, principlism is sometimes called the "Georgetown approach" to bioethics.

A second, related source for principlism is the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, with which both Beauchamp and Childress worked quite closely during the period they were drafting their book. The commissioners describe their method in what is known as the *Belmont Report* (after the location of a retreat held in 1976), where they present the set of principles that they relied upon to justify their policy recommendations. These principles more or less coincide with Beauchamp and Childress's, though the commissioners treat nonmaleficence as a subprinciple of beneficence.

Why Principles?

Moral thought can occur at several different levels of abstraction. Most concretely, there are the *judgments* people make in particular cases, when they say "this is the right thing to do here." Sometimes people justify these judgments by appealing to *rules* that offer general guidance about how to act in certain types of situations, such as "make only sincere promises" or "do not tell a lie." People can in turn justify a rule by showing how it falls under an even more general *principle* that links it with many other rules; not lying and making only sincere promises, for example, can both be seen as cases of respecting the autonomy of the persons one encounters. Finally, a *moral theory* is an attempt to systematize and justify a set of principles that applies comprehensively to all of the moral issues that people are confronted with.

Clinical bioethicists are in the business of making moral judgments when they help health professionals make decisions at the bedside, and many different kinds of bioethicists often help to formulate policies—a special kind of rule—to guide health professionals in their research and practice. It might seem that these judgments and policies are fully justified only to the extent that they are grounded in an ethical theory. The problem, however, is that philosophers have been unable to agree on what moral theory is best. Some, such as Beauchamp, favor consequentialist theories that take the promotion of the welfare of sentient beings as the fundamental aim of morality; others, such as Childress, favor versions of deontology, where certain types of actions are categorically proscribed no matter what the consequences; others favor yet other flavors of moral theory. This lack of consensus might seem to make the resolution of bioethical problems impossible, because it seems that bioethicists with different theoretical affinities will endorse different principles, different rules, and ultimately different concrete judgments.

But the commissioners discovered in their deliberations—a point that Beauchamp and Childress argue for more extensively—that despite differences at the level of theory, they could agree at the level of principles. The different theories converge on the same set of principles. The commissioners could thus appeal to members of this set to justify their policy recommendations, even while they differed on the principles' fundamental justification; though no one theory was satisfactory to all of them, each of them could turn to their preferred theory to defend the principles. Principlism is thus a practical response to the intractable debates found in moral philosophy: Because bioethicists deal with real-world problems, they should sidestep these academic debates by remaining one step down in the justificatory ladder.

The Four Principles

The first of Beauchamp and Childress's principles requires *respect for autonomy.* Autonomy is a controversial philosophical concept, but Beauchamp and Childress treat it largely in terms of autonomous choices or the intentional choices of agents who understand what they are undertaking and who are free from undue influences on their decisions. The principle of respect for autonomy requires others not to intervene when someone has made an autonomous choice, even if it is a choice that is thought to be imprudent or foolish. This principle, then, usually rules out health professionals' paternalistically interfering with the decision making of competent adults.

Beauchamp and Childress also argue that respecting autonomy requires that people take positive steps to promote and protect the capacity of agents to act autonomously. Health professionals are thus sometimes required to increase the options available to a patient or to work hard to make sure that patients are able to understand the decisions that confront them.

The most important bioethical rule to fall under the principle of respect for autonomy is the requirement for the informed consent of patients before health professionals intervene in their bodies. Health professionals must disclose to a patient the various possible courses of treatment for her condition and their likely outcomes; they must ensure that the patient understands this information; and they must let the patient make the decision for herself, so that she directs her medical care in light of her own values and preferences. By following the rules for informed consent, health professionals first enable a patient to make an autonomous choice, and then respect that choice by following the treatment directions she issues. Of course, the requirement for informed consent applies only to competent patients, because only they can make the autonomous choices that the principle requires others to respect.

Beauchamp and Childress's second principle is one of *nonmaleficence,* the requirement that health professionals not intentionally harm their patients. This principle encodes the ancient medical dictum, *primum non nocere* (above all do no harm). Because there are many different kinds of harm, the principle of nonmaleficence supports many different rules, such as: "Do not intentionally kill a patient," and "do not intentionally cause a patient unnecessary pain or suffering." This principle could, for example, require that treatment of a patient cease when it becomes a burden to her, even if that cessation hastens her death. This principle also plays an important role in research ethics, for it prohibits experimentation that is likely to harm subjects, even when they consent to it.

Whereas Beauchamp and Childress's second principle is largely negative, in that it prohibits a class of actions, their third principle, that of *beneficence,* is positive: It requires health professionals to act for the benefit of their patients, where "benefit" is construed with the same latitude that was used to interpret "harm" in the principle of nonmaleficence. The principle of beneficence requires health professionals to advocate on behalf of their patients in order to ensure that they receive appropriate care. It also mandates paternalistic intervention when, because of age, disability, or disease, a patient lacks the capacities for autonomous choice.

Beauchamp and Childress's fourth principle is the principle of *justice,* which they take to include distributive, criminal, and rectificatory forms of justice. The distributive version of this principle is especially relevant in bioethical issues having to do with the morality of institutions, where it requires that the benefits and burdens of the institution be shared fairly. This principle might require, for example, that the state provide a certain level of healthcare to all of its citizens. It also plays a significant role in evaluating the ethical dimension of a scheme for rationing scarce resources (such as organs for transplant or beds in an intensive care unit).

Beauchamp and Childress intend that each of these four principles be taken as only prima facie binding: The directives that flow from them are to be followed only when they do not clash with those arising from a different principle. Otherwise, a suitable resolution of the conflicting directives must be crafted.

Consider, for example, the question of what health professionals should do when they discover that a patient infected with the human immunodeficiency virus (HIV) is having unprotected sex with partners who are ignorant of his condition. First, respect for the patient's autonomy supports a policy of medical confidentiality, requiring health professionals not to reveal to others private information discovered in the course of caring for patients. According to this policy, health professionals should do nothing to warn the sexual partners of their HIV-positive patient, as doing so would violate his confidentiality. Second, if there is evidence that public disclosure of the patient's condition would harm him economically, socially, psychologically, or physically, the principle of nonmaleficence would also urge against interfering with his activities. Third, however, the principle of beneficence requires health professionals to benefit others by preventing harm to them, suggesting that they should warn the patient's sexual partners of their risk of infection. Finally, if the patient is intentionally trying to infect his partners with the disease, his behavior is criminal, and the principle of justice will require health professionals to notify the police; even if he is not intentionally trying to infect his patients, justice requires that everyone take responsibility for the public health, and so health professionals would have to alert public health authorities of his activity.

In this example, the four principles pull in two opposing directions. To resolve this conflict, note that the two principles discouraging health professionals from interfering with the patient's activities—respect for autonomy and nonmaleficence—also suggest that he should not be sexually active with partners who are ignorant of his infection: Respecting their autonomy requires that he give them the information they need to decide for themselves whether to be involved with him, and the principle of nonmaleficence requires that he not harm them by exposing them to possible infection. Accordingly, the moral requirement that health professionals protect third parties overrides their prima facie duties of noninterference. Principlism supports health professionals' duty to warn the unsuspecting sexual partners of the HIV-positive patient.

Criticisms

Critics have attacked the version of principlism Beauchamp and Childress developed in the first three editions of their book from opposite directions. On the one hand, K. Danner Clouser and Bernard Gert criticize Beauchamp and Childress for their failure to give a systematic organization to their principles. Because the principles are not justified by means of a single moral theory, Clouser and Gert worry that they offer no real guidance in cases where the principles clash. How can bioethicists justify choosing to favor the directions of one principle over those of another? In the situation explored above, for example, bioethicists might seem to be arbitrarily siding with the directive flowing from the principles of beneficence and justice, as opposed to that flowing from the principles of respect for autonomy and nonmaleficence.

On the other hand, Albert R. Jonsen and Stephen Toulmin argue that the move from specific cases to more general principles is of no help. Like Clouser and Gert, they think that the principles do not by themselves give sufficient guidance for bioethicists to resolve the problems that confront them. But unlike Clouser and Gert, Jonsen and Toulmin oppose developing a moral theory to integrate the principles, for Jonsen's experience on the National Commission helped him to realize that philosophical disagreement over moral theory is an inevitable consequence of any such attempt. Instead, Jonsen and Toulmin contend that bioethical problems are best resolved casuistically—not by appeal to principles but by reasoning analogically from settled cases to new situations. So, in the example above, bioethicists might argue that the case, *Tarasoff, Vitaly v. The Regents of the University of California,* which established the duty of psychiatrists to warn the potential victims of their violent patients, is sufficiently similar to the case of an HIV-positive patient whose sexual partners are ignorant of his condition to establish that health professionals have a similar duty to warn.

Beauchamp and Childress respond to both Clouser and Gert's and Jonsen and Toulmin's criticisms in the fourth and fifth editions of their book. Beauchamp and Childress agree that the four principles are, by themselves, too abstract to provide much guidance in particular cases. So they incorporate Jonsen and Toulmin's casuistical insight by suggesting that the use of the principles will first involve "specifying" them in light of the situation at hand and other similar cases. Beauchamp and Childress respond to Clouser and Gert's criticism that they resolve conflicts between principles arbitrarily by saying that the specified versions of the principles can be "balanced" against one another to produce a final verdict in a manner akin to the "reflective equilibrium" that John Rawls described in his 1971 book, *A Theory of Justice.* That is, the proposed resolution of a bioethical problem is to be tested against other established moral principles, previously established cases, and empirical facts; if there is a lack of fit, then the principles are to be specified differently or rebalanced until there is mutual confirmation among all the relevant moral data.

In the case explored above, for example, before the conflicting principles were balanced, the principle of respect for autonomy was first specified to a rule requiring medical confidentiality; the principle of justice was specified in terms of the criminal justice protection against intentional bodily harm and the public health policy of preventing infectious disease; and so on. A full principlist justification of health professionals' duty to warn the sexual partners of their HIV-positive patients would show this requirement to be in reflective equilibrium with other limits to confidentiality, responses to other sexually transmitted diseases, and privacy rights in matters of sexuality.

Common Morality

In the fourth and fifth editions of their book, Beauchamp and Childress also introduce a new justification for their principlist methodology. Whereas in the earlier editions they justified their choice of principles in terms of the convergence of ethical theories on them, they now contended that the principles offer a "common morality" theory. This approach "takes its basic premises directly from the morality shared in common by the members of a society—that is, unphilosophical common sense and tradition" (Beauchamp and Childress, p. 100). The four principles are supposed to make explicit what is implicit in common morality as it applies to bioethics.

The earlier justification of the principles in terms of theory convergence has some affinity with this later common-morality justification because Beauchamp and Childress see the aim of ethical theory as systematizing and unifying the various facets of common morality. They take the incapacity of philosophers to agree on which ethical theory is best as a sign that each successfully captures some of common morality, but neglects other parts of it. Indeed, the common-morality justification of principlism improves on the convergence justification in at least one respect. Beauchamp and Childress devote most of their effort to establishing the convergence of only two theories—consequentialism and deontology—on their principles; but there are many other moral theories, some of which are given more attention in the later editions of their book, all of which should be shown to converge on the principles if this justification of principlism is to be successful.

The common-morality justification of principlism, however, leaves Beauchamp and Childress open to other objections. Why accept that these four principles fully characterize common morality as it applies to bioethics? Ronald Dworkin, for example, argues in a 1993 book that a commitment to a nonparochial version of the sanctity of life has as much of a place in common morality as any of the other four principles, but it is not accepted by Beauchamp and Childress as a guide for bioethical decision making.

H. Tristram Engelhardt Jr., in contrast, thinks that principlist approaches to bioethics are ideological, in that they allow bioethicists to force their own private moral outlook on others even while they pretend to be making judgments and formulating policies that are objective and fair to all. Engelhardt is skeptical about there being such a thing as *common* morality, holding instead that there are many different substantive moralities, no one of which should be used to solve bioethical problems that affect those in communities structured by different moral outlooks. He offers instead a libertarian approach to bioethics in which the rules governing the delivery of healthcare are justified only when patients and healthcare providers consent to them.

Perhaps Beauchamp and Childress's best reply to the criticism that they fail to take pluralism seriously would be for them to replace the common-morality justification of the principles with one modeled on the notion of an *overlapping consensus* that Rawls develops in his 1993 book, *Political Liberalism.* Rawls recognizes that people subscribe to conflicting moral outlooks, but he thinks that, at least at a basic level, policy problems can be solved by appealing to what people who disagree about the deep moral questions would nonetheless accept as the reasonable terms for their cooperation. Rawls thus appeals to *hypothetical* consent, instead of Engelhardt's appeal to *actual* consent. Similarly Beauchamp and Childress's four principles can be seen as what reasonable people would agree to as the fair terms for the provision of healthcare, despite their differing views on other moral questions. Many different moral doctrines would thus overlap by including a common commitment to the four principles as the appropriate norms for bioethics. Unlike Beauchamp and Childress's appeal to common morality or to the convergence of ethical theories on the principles, this alternative justification of them is based on the overlap of various moral outlooks, be they ethical theories, religions, or popular social movements.

Though the foundations of the principlist approach remain contested, it is likely to continue as the primary method used by American bioethicists. This is because principlism allows bioethicists to appeal to generally accepted norms to justify their resolutions of the problems they face, without requiring them to enter into abstruse philosophical debates about how best to understand morality.

DONALD C. AINSLIE

SEE ALSO: *Autonomy; Beneficence; Casuistry; Communitarianism and Bioethics; Confidentiality; Consensus, Role and Authority of; Contractiarianism in Bioethics; Ethics; Information Disclosure, Ethical Issues of; Justice*

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PRISONERS AS RESEARCH SUBJECTS

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Since the 1980s, virtually no prisoners in the United States have been used in biomedical experimentation that does not benefit prisoners as individuals or as a class. A principal reason is that ethical reflection on this topic in the 1970s not only decisively affected public policy but also shaped an enduring moral consensus in society.

A crucial year in that process was 1976. The Federal Bureau of Prisons announced an indefinite moratorium on nontherapeutic biomedical experimentation conducted in any federal prison. That same year, the board of directors of the American Correctional Association—the professional organization of U.S. prison officials at all levels of government—officially adopted a statement urging responsible bodies at federal, state, and local levels to eliminate the use of prisoners as subjects of medical pharmacological experimentation.

Most important, the U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (National Commission) recommended to the secretary of the Department of Health, Education and Welfare (now the Department of Health and Human Services, DHHS) that a moratorium on approving and funding prisoner experimentation be declared until certain specified minimum standards had been met by any prison allowing experimentation on inmates. The work of the National Commission deserves special attention because it was pivotal, at a critical moment in the 1970s, in articulating connections between moral principles and public policies concerning prisoner experimentation (U.S. National Commission, 1976a, 1976b).

Some debate continued over government regulations implementing the National Commission's recommendations, but by the 1980s, experimentation that was not therapeutic for the individual prisoner or prisoners as a class had virtually come to an end. With the crucial help of the National Commission, American society had reached a moral consensus already achieved by the rest of the world.

Practices

Such a consensus did not always exist. Rulers in ancient Persia permitted physicians to use prisoners as experimental subjects. Rome tested poisons on prisoners. European physicians in the eighteenth century used prisoners in experiments, exposing them—sometimes through injections—to venereal disease, cancers, typhoid, and scarlet fever.

In the United States, prisoners were used for experimentation from at least 1914, when white male convicts in Mississippi were used in pellagra experiments. During World War II, prisoner experimentation assumed a morally favorable aura when prisoners, to show their patriotism, signed up in large numbers for experimental studies. After reviewing this experimentation, several state commissions encouraged the use of prisoners (Beecher).

The American Medical Association (AMA) underscored the degree to which participation in medical experimentation was viewed as morally admirable. It adopted a resolution disapproving of the practice of permitting prisoners convicted of murder, rape, arson, kidnapping, treason, or other heinous crimes to participate in medical experimentation. They were not considered sufficiently virtuous to be part of such a noble enterprise (Katz).

After World War II, when it became known that Nazi physicians had used concentration camp prisoners in medical experiments that mutilated and killed their subjects—innocent Jewish citizens of all ages—Europe found the use of any incarcerated persons in experimentation morally repugnant. An early draft of the Declaration of Helsinki included the following provision: "Persons retained in prisons, penitentiaries, or reformatories—being 'captive groups'—should not be used as subjects of experiment; nor persons incapable of giving consent because of age, mental incapacity, or being in a position in which they are incapable of exercising the power of free choice" (U.S. National Commission, 1976a, essay 16, p. 4).

However, the provision was deleted from the final version of the 1964 Declaration, reportedly because of pressure from the United States. Not only did the United States have an extended history of approving prisoner experimentation, but during the post-World War II years there was a substantial increase in biomedical experiments, including those using prisoners.

The federal government funded a wide variety of biomedical and behavioral experiments using prisoners, including numerous studies on infectious diseases, and the Atomic Energy Commission (later absorbed by the Department of Energy) conducted experiments involving radiation of male prisoners' genitals. From 1970 to 1975, five of the six government agencies that supported experimentation—all within the Public Health Service of the Department of Health, Education and Welfare—used prisoners in 125 biomedical studies and 19 behavioral research projects (U.S. National Commission, 1976b).

The greatest use of prisoners was in initial tests of drugs, performed primarily by private drug companies. In 1962, following the thalidomide tragedy, the U.S. Congress passed legislation requiring that before drugs were released for therapeutic use, their safety and efficacy must be tested on humans. To ensure an increased and steady supply of experimental subjects, pharmaceutical companies built facilities within prisons.

Prisoners became the principal subjects in the United States for testing new drugs. By 1975, according to a survey conducted by the Pharmaceutical Manufacturers Association (whose members develop most of the prescription drugs in the United States), at least 3,600 U.S. prisoners were the first humans on whom the safety of new drugs was tested. Prisoners in the United States were even being used to test drugs for researchers in other countries.

Principles

When the National Commission conducted its deliberations on prisoners, the Department of Health, Education and Welfare was already on record as being enthusiastic about the advantage of using prisoners in research. The president of the Pharmaceutical Manufacturers Association testified before the National Commission that his organization believed there were few alternatives to using prisoners in drug tests. Given that factual assumption, the moral argument was made that the good of society required the use of prisoners.

In its *Report and Recommendations* the National Commission moved beyond the moral appeal to the good of society by challenging the factual assumption that prisoners were necessary for at least initial drug trials. The commission found several drug-testing programs in the United States that successfully used healthy, nonincarcerated volunteers (U.S. National Commission, 1976b). Thus prisoners were not essential for biomedical experimentation. Having established that empirical fact, the National Commission then devoted considerable attention to two of the three ethical principles it said should govern experimentation with human subjects.

RESPECT FOR PERSONS. According to the National Commission, the fundamental moral principle of respect for persons includes respect for their dignity and autonomy. Experimentation with autonomous persons demands obtaining their consent to participate. The basic principle of respect for persons thus justifies the bioethical guideline of informed consent. Debates arising from the moral principle of respect for persons revolve around whether prisoners can provide a sufficiently voluntary consent to participate in experimentation.

One line of reasoning argues that prisoners obviously are competent to volunteer for experiments. After all, conviction for a crime presupposes that the citizen has been found sufficiently competent to be held accountable for his or her acts. Also, the citizen who enters prison has had certain rights legally recognized, such as the right to sue for freedom of worship and even to obtain compensation for injuries sustained in prison jobs (McDonald).

According to this line of thinking, prison inmates participate in remunerated occupations that put them at some risk. No one challenges the capacity of prisoners to volunteer for these tasks—for example, stamping license plates in prison factories. Why should there be moral outrage at prisoners' choosing (they are permitted to refuse) to participate in medical experiments that admittedly provide financial inducements but also may do less physical harm?

Those who oppose prisoner experimentation argue that the relationship of persons to their bodies is very different from their relationship to their productive goods; the former comprises their relationship to themselves. There is a distinction between activities in which impinging on a person's body is accidental or unavoidable, as in a job, and those in which it is the very purpose of the activity, as in experimentation (Fried). The argument runs that since consent to a job is different from consent to experimentation, prisoners may be sufficiently free to consent to prison jobs but not sufficiently free to consent to experimentation.

Among those who cite the principle of free and informed consent as part of their opposition to the use of prisoners in experimentation, some argue that prisoners cannot in principle give a sufficiently free consent (American Civil Liberties Union). Others who oppose the use of prisoners in experimentation admit that in principle it might be possible for an inmate in some ideal correctional institution to give a sufficiently free and informed consent. However, they argue that in fact either the structure or the administration of the penal system in the Unted States makes it impossible for prisoners to give a sufficiently free consent to experimentation.

This argument relies on analyses of the basic structure of American prisons made by historians and sociologists. According to historians, the coercive structure of the American prison and its powerful impact on the attitudes of prisoners are not accidental. After the 1820s, foreign officials came to the United States to observe the unique lengths to which the country went in creating new institutions called *penitentiaries.* They were designed not only to incarcerate criminals but also to shape their behavior and their character (Rothman).

Those opposed to prisoner participation in experimentation argue that medical experiments cannot remain unaffected by the social environment of what sociologist Erving Goffman calls a "total institution," such as a penitentiary. In a total institution a single authority tightly controls the entire space and time of each person within it, including a series of abasements, degradations, and humiliations designed to convince inmates to accept the single authority's view of them. In such institutions the entire social environment is designed to elicit cooperation with the central authority. It is argued that in total institutions even the attractive and beneficial features of an activity such as experimentation can overcome the inmates' ability to give a sufficiently free consent (Goffman).

The National Commission's investigations revealed that in U.S. prisons there appeared to be limited alternatives to experimentation among available prison activities. Other activities were not conducted in comparably secure surroundings, and there appeared to be a paucity of meaningful, alternative ways for prisoners to express any altruism they might have. Most importantly, no other prison activity paid comparably. The National Commission learned of differences in payment between experimentation and other prison activities that ranged to well over ten to one. Not surprisingly, surveys showed that 70 percent of prisoner research subjects volunteered primarily for the money (Arnold et al.).

Ethicists who served on the National Commission, or as staff and consultants, have subsequently emphasized that the commission believed prisoners were able to consent to experimentation under some conceivable conditions. However, the actual and likely conditions of American prisons raised genuine questions concerning prisoners' being able to give sufficiently free and informed consent. A distinction between coercion and manipulation of a prisoner's consent may be useful, although even a manipulated consent to participation in experimentation may be impermissible (Beauchamp and Childress; Faden et al.).

JUSTICE. A significant contribution of the National Commission was making not only respect for persons but also justice central to ethical considerations of prisoner experimentation. A few voices defended the use of prisoners as a form of reparative justice. Prisoners, they said, have committed crimes against society, and it is inherently appropriate, as an act of reparation for those crimes, for prisoners to serve society by being used in research. Opponents of prisoner experimentation responded that society, through its legal system, had already pronounced sentence on prisoners for whatever crime they committed, and medical experimentation should not be considered a form of punishment.

The National Commission brushed past discussions of reparation to questions raised by comparative justice. The essence of comparative justice is that like cases or classes are to be treated alike, and different cases or classes are to be treated differently (Feinberg). Problems of remuneration immediately came to the fore. Considerations of justice would require paying prisoners participating in experiments the same as free volunteers. However, the amounts would be so much greater than remuneration otherwise available in prison that the payments could become so irresistible as to be coercive. Thus, in its final report, the National Commission included suggestions that researchers pay the same rate for prisoners to participate in experiments as they did for nonincarcerated volunteers; however, individual prisoners would receive the same amount they received for other prison jobs. The excess would go into a fund for the general benefit of prisoners, or into escrow accounts paid to each participant at the time of his or her release from prison (Branson).

Comparative justice leads in biomedical ethics to considerations of the selection of subjects for experimentation. With respect to nontherapeutic experimentation in particular, risks and benefits should be distributed equitably among classes and groups of experimental subjects. The implications of comparative justice specifically for the gender and race of prisoners selected for experimentation received some attention from the National Commission. It heard testimony from black prisoners that they did not have equal opportunity to participate in experiments. Better-educated whites were disproportionately enrolled in prisoner experimentation. In its report the National Commission also noted that less research was conducted in women's prisons than in men's.

More fundamental were concerns about the justice of selecting prisoners at all for research benefiting society generally. A principal moral concern was that prisoners bore a disproportionate share of the burdens of research benefiting society as a whole—for example, initial drug trials on humans.

Comparative justice refers not only to similarities but also to differences between groups. Unequal treatment—for example, permitting free subjects, but not prisoners, to participate in experimentation—can be justified when individuals or groups are different in relevant respects. Prison populations are significantly different from the free society.

Prisoners live in an institutional environment that is more coercive than that of free-living volunteers, and prisoners are less likely to receive equivalent healthcare. They also receive a minuscule percentage of the financial benefits given to free research subjects.

That prisoners are considered to be in so many relevant respects different from, and unequal to, the rest of society is a principal reason they are considered to be treated justly if they do not participate in research that does not benefit them directly.

Policies

In 1976, the National Commission recommended that research involving prisoners that posed more than minimal risk, that was not studying the process of incarceration, and that did not directly improve the health or well-being of individual prisoners should not be conducted unless the reasons for the research were compelling and "a high degree of voluntariness on the part of the prospective participants and openness on the part of the institution(s) to be involved would characterize the conduct of the research." The National Commission included a long list of acceptable prison conditions. Showing its concern for justice, the commission also said that research would have to satisfy "conditions of equity" (1976b, p. 16).

In 1978, the DHHS published final regulations on research involving prisoners that were more restrictive than the recommendations of the National Commission. The department threw up its hands at trying to find prisons that met the commission's conditions of openness, and prohibited research on prisoners that did not benefit them as individuals or as a class ("Additional DHHS Protections,").

DHHS limited research involving prisoners to: (1) studies, involving no more than minimal risk or inconvenience, of the possible causes, effects, and processes of incarceration and criminal behavior; (2) studies of prisons as institutional structures, or of prisoners as incarcerated persons; (3) research on particular conditions affecting prisoners as a class; and (4) research involving a therapy likely to benefit the prisoner subject. Minimal risk was defined as risk normally encountered by nonprisoners ("Additional DHHS Protections").

The Federal Bureau of Prisons has maintained a policy that is even more restrictive. It prohibits biomedical research and drug testing on its inmates unless an individual, sick federal prisoner could benefit directly from an experimental therapy. Even then, a federal prisoner can be enrolled in a relevant clinical trial only if the responsible physician recommends it, the experiment has been approved by the DHHS, the prisoner consents, and the medical director of the Federal Bureau of Prisons approves the individual case.

The U.S. Food and Drug Administration (FDA), which has authority over private drug companies, announced regulations in 1980 that were essentially the same as those of DHHS. But in 1981 the FDA "stayed indefinitely" its proposed regulations concerning use of prisoners. As a result, as of 1993, no regulations were in place that would prevent private drug companies from arranging with somewhat less than half the state prisons of the United States to resume using prisoners as subjects of initial drug trials (Penslar).

However, drug companies have evidently taken to heart the view expressed in the FDA's proposed regulations that sponsors of research could never establish a compelling need to use prisoners ("Protection of Human Subjects"). Ethical discussion, most notably that of the National Commission, not only affected public policy. It also created a persistent moral consensus in society that prisoners should not be used in experimentation that does not specifically benefit them as individuals or as a class.

ROY BRANSON (1995)
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SEE ALSO: *Autonomy; Bioethics, African American Perspectives; Coercion; Eugenics: Historical Aspects; Freedom and Free Will; Holocaust; Informed Consent: Consent Issues in Human Research; Justice; Minorities as Research Subjects; Research, Human: Historical Aspects; Research, Unethical; Rights, Human; Utilitarianism and Bioethics*

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PRISONERS, HEALTHCARE ISSUES OF

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“It is but just that the public be required to care for the prisoner, who cannot, by reason of the deprivation of his liberty, care for himself” (*Spicer v. Williamson,* 1926).

Because of incarceration, the legal context of providing medical, dental, and mental health services is different in prisons and jails from that in the outside community. In no other setting are such services constitutionally guaranteed. Drawing upon the prohibition against “cruel and unusual punishment” in the Eighth Amendment to the Constitution (and the Due Process Clauses of the Fifth and Fourteenth Amendments for juveniles, pre-trial detainees, and federal prisoners), the courts require that institutions with custody of human beings provide for their basic necessities, including healthcare.

It was not always so. Historically, the correctional system in the United States has been largely protected from public scrutiny. Prisons were built far from population centers, and courts adopted a “hands off” doctrine regarding their administration (*Procunier v. Martinez,* 1974). Early cases in the 1970s, however, revealed horrendous medical conditions in which inmates were used without supervision to perform medical care on their fellows, including pulling teeth, suturing, and surgery. Dramatic instances were illustrated in which prisoners died neglected, covered in maggots, and lying in their own filth (*Newman v. Alabama,* 1974).

The present legal framework was established in the 1976 landmark decision of *Estelle v. Gamble,* in which the Supreme Court ruled that prisoners have a right to be free of “deliberate indifference to their serious health care needs.” Although there has been some fine-tuning, the legal landscape has remained largely unchanged since that ruling.

In the hundreds of published cases following *Estelle v. Gamble,* three basic rights have emerged: the right to access to care, the right to care that is ordered, and the right to a professional medical judgment (Rold, 2001). The failure of correctional officials to honor these rights has resulted in protracted litigation, the awarding of damages and attorneys' fees, and the issuance of injunctions regarding the delivery of healthcare services.

To provide for constitutional care and to protect themselves from litigation, correctional administrators must adopt procedures to protect inmates' basic rights, including a functioning sick call system that uses properly trained healthcare staff, a means of addressing medical emergencies, a priority system so that those most in need of care receive it first, the development and maintenance of adequate medical records, liaison with outside resources for specialist and hospital care when needed, a system for staff development and training, and an ongoing effort at quality improvement. Jail wardens and prison superintendents and their chief medical officers must develop policies and procedures for meeting the special needs of disabled, elderly, and mentally ill inmates, as well as those with HIV infection and AIDS, and to preserve the confidentiality of medical information.

The Eighth Amendment

The Eighth Amendment, forbidding cruel and unusual punishment, presents a relatively narrow standard of liability. The Eighth Amendment does not render prison officials or staff liable in federal cases for malpractice or accidents, nor does it resolve professional disputes about the best choice of treatment. It does require, however, that sufficient resources be made available to protect the three basic rights.

While the constitutional standard does not require that an express intent to inflict pain be shown (*Wilson v. Seiter,* 1991), it does include an inquiry into the defendants' state of mind. A violation of the Eighth Amendment requires a "subjective" showing of "deliberate indifference." It is not enough that the defendant should have known or ought to have understood the danger to the inmate. The defendant must know of and disregard a substantial risk (*Farmer v. Brennan,* 1994). Such knowledge, however, can be inferred from the surrounding facts where the failure to respond to a clear risk is reckless.

In general, cost considerations are not valid defenses to a violation of the Eighth Amendment. Corrections officials must diagnose and treat illness and eradicate conditions of confinement that expose inmates to communicable disease and other identifiable health threats (*Jones v. Diamond,* 1981). Indeed, correctional facilities have been ordered to pay for the cost of medical procedures for indigent inmates, such as an otherwise legal abortion, where the inmate was precluded by incarceration from any option other than carrying her fetus to term (*Monmouth County Correctional Institute Inmates v. Lanzano,* 1987). The Eighth Amendment does not afford inmates priority in the allocation of scarce medical resources, such as organ transplants; but it does require access to such resources for serious conditions on the basis of the same ethical and medical considerations for similarly situated patients who are not incarcerated (see Statement, United Network for Organ Sharing, 2001). Finally, the increasingly common practice of contracting with private healthcare corporations to provide healthcare services does not shield the correctional agency from fulfilling the constitutionally required dimensions of healthcare. The private contractor is likewise brought within the aegis of the Eighth Amendment (*West v. Atkins,* 1989).

THE RIGHT TO ACCESS TO CARE. The right to access to care is fundamental: When access is denied or delayed, the health staff does not know which patients need immediate attention and which patients need care that can wait. "A well-monitored and well-run access system is the best way to protect prisoners from unnecessary harm and suffering and, concomitantly, to protect prison officials from liability for denying access to needed medical care" (Winner).

The right to access to care includes access to both emergency and routine care. All institutions, of whatever size, must have the capacity to cope with emergencies and to provide for sick call. Access to specialists and to in-patient hospital treatment, where warranted by the patient's condition, are also guaranteed by the Eighth Amendment.

THE RIGHT TO CARE THAT IS ORDERED. Generally, courts assume that care would not have been ordered if it were not needed. Thus, once a healthcare professional orders treatment for a serious condition, the courts will protect, as a matter of constitutional law, the patient's right to receive that treatment without undue delay. The easiest way for an institution to lose a lawsuit is to fail to provide inmate patients with the care that its own staff has ordered.

THE RIGHT TO A PROFESSIONAL MEDICAL JUDGMENT. In general, the courts will not determine which of two equally efficacious treatment modalities should be chosen. The adjudication of constitutional claims is not the business of "second guessing" healthcare professionals. Rather, the courts seek to: "ensure that decisions concerning the nature and timing of medical care are made by medical personnel, using equipment designed for medical use, in locations conducive to medical functions, and for reasons that are purely medical" (Neisser).

By ensuring that professional judgment is actually exercised, however, the federal courts have not only protected the sphere of discretion surrounding medical practitioners' treatment and diagnostic decisions, but they have often enhanced it. At issue in a typical injunctive case are such matters as staffing, physical facilities, transportation, and sick call and follow-up procedures. When a court orders relief in these areas, it is assuring that the raw materials from which responsible professional judgment is formed and carried out are available to practitioners.

"Serious Medical Needs"

The Constitution requires that correctional officials provide medical care only for "serious medical needs." Generally, a medical need is "serious" if it "has been diagnosed by a physician as mandating treatment or … is so obvious that even a lay person would easily recognize the necessity for a doctor's attention" (*Duran v. Anaya,* 1986; *Ramos v. Lamm,* 1980). Conditions are also considered to be "serious" if they "cause pain, discomfort, or threat to good health" (*Dean v. Coughlin,* 1985). A condition need not be life-threatening to be deemed "serious," and many treatment plans that are labeled "elective" nevertheless are deemed "serious" within the meaning of *Estelle v. Gamble* (1976).

In general, courts consider three factors in determining whether correctional officials are being deliberately indifferent to "serious medical needs": (1) the amenability of the patient's condition to treatment; (2) the consequences to the patient if treatment does not occur; and (3) the likelihood of a favorable outcome. Within this mix, the court may also consider the length of the patient's anticipated incarceration. It is one thing to decline the provision of dentures or an artificial limb to an inmate with a three-day jail sentence. It is quite another to withhold such adjuncts to a patient serving twenty years to life (Rold, 1997).

The Role of Standards and Accreditation

Compliance with national standards and accreditation, while not dispositive on the outcome of litigation, are frequently regarded favorably by the courts. In the Arizona prison litigation (which ultimately reached the Supreme Court on the unrelated issue of inmates' claims of denial of access to the courts), experts for both sides relied on standards of the National Commission on Correctional Health Care in their testimony, the defendant prison officials' expert stating that "[t]here are no correctional health care standards that are more stringent or more difficult to fulfill than the National Commission on Correctional Health Care standards" (*Casey v. Lewis,* 1993) The standards of the National Commission on Correctional Health are the only national standards devoted solely to healthcare delivery in corrections. They have been updated periodically as the standard of care evolves. The American Correctional Association (1990) and the Joint Commission on Accreditation of Health Care Organizations (2000) also have standards and accredit correctional facilities. The American Public Health Association (1986) also has detailed standards for prison and jail healthcare, although it does not accredit. While meeting standards is not a guarantee that a lawsuit against a correctional facility will fail, compliance with standards and facility accreditation have been noted by courts in the granting of summary judgment to defendants in individual prisoner damages cases (*Williams v. Ceorlock,* 1998; *Tumath v. County of Alameda,* 1996).

Confidentiality

Inmates have a constitutional right to privacy in their medical diagnoses and other healthcare records and information. That right is not violated by the reporting of medical findings in the ordinary course of prison medical care operations or probably even to prison and jail executives with a reason to know, but the "[c]asual, unjustified dissemination of confidential medical information to non-medical staff and other prisoners" is unconstitutional (*Woods v. White,* 1998; *Doe v. Coughlin,* 1988). "[T]he gratuitous disclosure of an inmate's confidential medical information as humor or gossip. . . is not reasonably related to a legitimate penological interest." (*Powell v. Schriver,* 1999).

In contrast, there are also occasions when a provider may have not only a prerogative, but a duty, to report or disclose confidential medical information to third parties. If a concrete risk to an identifiable person is revealed, and "disclosure is essential to avert danger," the revelation of a patient's private communication may be essential to protect peril to innocent persons. In such cases, however, disclosure must be done "discretely" and in a way that preserves the privacy of the patient "to the fullest extent compatible with the prevention of the threatened danger." (*Tarasoff v. Regents of the University of California,* 1976).

Informed Consent and the Right to Refuse Treatment

A mentally competent adult has the right to be informed of proposed medical treatment (and its likely benefits and risks) and the right to refuse medical treatment, including the direction that life-saving or other extraordinary measures be withdrawn in terminal cases (*Cruzan v. Missouri Department of Health,* 1990). As Judge Cardozo stated in the 1914

Schloendorff v. Society of New York Hospitals ruling: “Every human being of adult years and sound mind has a right to determine what shall be done with his own body.” This right generally extends to prisoners as well (*White v. Napoleon,* 1990). On the other hand, in some cases life-sustaining care may be imposed. In *Commissioner of Corrections v. Myer* (1979), the court balanced the inmate patient’s objections to treatment with the state’s interest in orderly prison administration and ordered resumption of dialysis despite the patient’s refusal. Temporary, forced administration of antipsychotic drugs over a prisoner’s objection has also been allowed if preceded by administrative protections, including an impartial hearing that finds that the patient has a “mental disorder,” is “gravely disabled,” and “pose[s] a likelihood of serious harm to self or others” (*Washington v. Harper,* 1990).

Profound ethical issues can be presented, most acutely in the case of mentally ill inmates facing execution:

> [T]he determination of whether an inmate is “competent for execution” should be made by an independent expert and not by any health care professional regularly in the employ of … the correctional institution …. This requirement does not diminish the responsibility of correctional health care personnel to treat any mental illness of death row inmates. (National Commission on Correctional Health Care, p. 75)

While the courts continue to explore this issue, the availability of an ethical advisory board for consultation with individual correctional systems is strongly recommended.

The right to refuse is, of course, the obverse of the right to informed consent, and each depends upon the genuine observance of the other (*White v. Napoleon,* 1990). Because of the environment, there are “reason[s] to be leery of refusals of care in prisons” (Anno), because the institutional environment often clouds issues of informed consent, making it difficult to distinguish between refusal of care by the staff. It is important in corrections to take steps to determine if a refusal of care is genuine. Some investigation of an inmate who does not appear for treatment should occur if the appointment were for a serious condition and a lapse in treatment might result in deterioration or a poor outcome.

Ethical Considerations

Correctional healthcare providers work in a “medically alien setting” (Wishart and Dubler). The mission of medical care is to diagnose, comfort, or cure; the goal of a prison or jail is to confine, to punish, and, ideally, to reform. There is an inevitable tension between these two purposes, because correctional facilities are “inherently coercive institutions that for security reasons must exercise nearly total control over their residents lives and the activities within their confines” (*West v. Atkins,* 1988). This setting affects the way healthcare is practiced by professionals within institutions.

In addition to constitutional mandates and the range of medical/ethical problems complicated by the prison context, there is a series of ethical dilemmas peculiar to correctional settings, even though healthcare providers in correctional settings are bound by the same guidelines as their colleagues who work in more conventional medical spaces. They must promote the welfare of patients, advocate their medical needs, inform them about their diagnoses and prognoses, and protect their privacy. Providers in correctional settings, however, also face ethical challenges for which there are no parallels in the outside world because the prison setting exerts a continual pressure on professional judgment (Anno and Dubler).

Providers may be asked to act as impartial arbiters of potentially explosive or violent situations, to witness forced transfers, or to supervise punishment. It is assumed that their presence will prevent violence or that their skill and special status will render searches less painful and intrusive and the punishment less destructive. Acquiescing to these requests, however, may destroy the provider’s ability to act independently as the patient’s advocate. Such participation violates the particular provider–patient relationship, and by extension, relationships with other inmates (Anno and Dubler).

“No individual, however skilled and compassionate a doctor, can maintain a normal doctor-patient relationship with a man who the next day he may acquiesce in subjecting to solitary confinement” (Brazer). Other assignments that tend to undermine the provider–patient relationship include collecting forensic information for prosecutors, using restraints for nonmedical purposes, agreeing to endorse a “special diet” that is actually a nutritionally adequate yet inedible punishment, permitting a medical note about an inmate’s noncompliance with a care plan or follow-up appointment to be used to trigger disciplinary action, agreeing to monitor a hunger strike, certifying that a prisoner has been successfully executed, or helping to determine whether an inmate is “competent” and sufficiently mentally intact and aware for execution.

Deciding how to respond to requests for such assistance is a difficult and complex task. The institutional pressures for provider participation may be enormous, yet many scholars and commentators have argued, consistent with comprehensive standards published by the National Commission on Correctional Health Care (2003) and by the American Public Health Association (1986), that if professional ethics would prohibit an action in a community setting, they prohibit it in a correctional setting as well.

Inmates are not passive in the process of receiving healthcare. The need for a medical note to obtain an assignment excuse and the lack of available common over-the-counter medications all encourage heavy use of the medical service. Prisoners, who are largely poor and did not have adequate access to medical, mental health, and dental care before incarceration, tend to have more significant health problems than a matched-age cohort. Prisoners may also view medical service personnel as more humane and caring than the rest of the prison staff and for this reason seek to spend inordinate amounts of time in their presence. Such use of the medical service to meet "nonmedical" needs, although perhaps a rational coping strategy in a dehumanizing environment, may elicit hostility from the medical staff (Wishart and Dubler). In short, correctional rules issued for administrative reasons (and not because of legal, medical, or ethical imperatives) continue to influence and challenge those who work in healthcare "inside the walls."

Conclusion

"No serious student of American correctional history can deny that litigation has provided the impetus for reform of medical practice in prisons and jails" (Nathan). Yet, as resources become increasingly scarce, government officials are constantly faced with doing more with less. Voluntary adoption of community and ethical standards and accreditation are a less tortuous road to reform, and, in the long run, are likely to be more successful and less divisive.

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SEE ALSO: *Coercion; Conflict of Interest; Death Penalty; Divided Loyalties in Mental Healthcare; Freedom and Free Will; Research Policy: Risk and Vulnerable Groups*

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PRIVACY AND CONFIDENTIALITY IN RESEARCH

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When people seek the help of healthcare providers, and thus become patients, they exchange some of their privacy for the chance to be healed, diagnosed, and protected from illness. Healthcare providers in turn promise to keep patients' private information confidential by sharing it only with those whose knowledge stands to benefit the patient, unless higher duties require that the promise be broken, or the patient has consented to other uses of the information. When private information is shared not for treatment purposes but in research, the exchange is necessarily different: Research subjects (even those who are also patients) are not the same as patients, and researchers are not the same as persons offering treatment (even if they are also clinicians). The research context may alter not only what information individuals consider private and the extent to which they are willing to share it, but also the potential harms and wrongs that may result from breaches of privacy and confidentiality.

Issues of privacy and confidentiality in human-subjects research can arise in three contexts. First, patient care can give rise to research questions, as when researchers wish to use data from patients' medical records or contact health providers for the names of patients with specific health problems to ask them to participate in research projects. Second, human subjects of biomedical, behavioral, or social science research, as well as persons and groups who may not be research subjects, can be affected in a variety of ways that implicate privacy and confidentiality by the gathering or the use of information for research purposes. Finally, clinical research involving subjects who are also patients has its own particular risks to privacy and confidentiality, as when the media and the public claim a special interest in the first patient-subjects to receive a novel research intervention. In all of these circumstances we must examine the disclosure, sharing, and publication of information, and the interests of researcher, subject, and others, as well as the legal, policy, and practical protections that are available to preserve subjects' privacy and the confidentiality of their private information.

Privacy, as a right belonging to persons, and confidentiality, as an attribute of data that arises from a promise made by healthcare providers or researchers, can readily be seen as intimately related to the moral principles of autonomy, respect for persons, and beneficence, and to the requirement of informed consent. In the United States, federally funded research is governed by consolidated regulations for the protection of human subjects, known as the Common Rule, which require that all research collecting identifiable private information about living individuals be reviewed by an institutional review board. This review must minimize the risks that research poses to subjects, determine that the risks are reasonable in relation to anticipated benefits, ensure that informed consent is obtained, and, "when appropriate," require "adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data." The required informed consent includes "a statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained" ("Federal Policy for the Protection of Human Subjects").

According to the Common Rule, if confidentiality is promised by researchers, they must be able to provide it; but confidentiality need not be promised, so long as subjects are informed that confidentiality is not offered and can freely choose to participate based on that knowledge. The *ethical baseline* thus provided by the Common Rule must then be supplemented by professional codes and other guidelines, as well as by existing federal, state, or local privacy laws (Annas, 2001; Symposium).

Privacy and Professional Codes

Many professional codes discuss the ethics of research and scholarly publication; the attention each gives to privacy and confidentiality necessarily varies, with each such code generally combining an aspirational morality with a particularized professional focus. For example, the Council for International Organizations of Medical Sciences' *International Guidelines for Ethical Review of Epidemiological Studies* (1991) contains an extensive discussion of confidentiality protection in large data sets, and its *International Ethical Guidelines* *for Biomedical Research Involving Human Subjects* (2002) includes a confidentiality provision addressing a broad range of data types, sources, uses, and risks of harm. In contrast, the World Medical Association's *Declaration of Helsinki* (2000) includes only a statement of the importance of respecting "the privacy of the subject [and] the confidentiality of the patient's information"; and the Nuremberg Code (Germany [Territory Under Allied Occupation …], 1949), devoted to the subject's right to consent, does not mention privacy or confidentiality at all.

PRIVACY AND HIPAA. In the United States, regulations implementing federal legislation designed to improve access to health insurance, the Health Insurance Portability and Accountability Act (HIPAA), may have considerable impact on privacy and confidentiality in research using health information. HIPAA's data privacy regulations apply to a specific set of users (*covered entities*) who generate and maintain personally identifiable health information. This group of users is not coextensive with federally funded researchers, and crosses professional boundaries; thus, HIPAA's privacy rule may have broader application in human subjects research than the federal regulations (Department of Health and Human Services [DHHS]).

In very general terms, the privacy rule's application to research means that personally identifiable health information may not be created or used for research by covered entities and their business associates unless the research subject has specifically authorized the use, the authorization requirement has been waived by a HIPAA privacy board or an institutional review board, or the use falls under a limited set of exceptions (Office of Civil Rights). In many respects, the privacy rule in research conceptually parallels the privacy and confidentiality concerns of institutional review boards and of federal research oversight agencies like the Office for Human Research Protections.

The HIPAA privacy rule may prove extremely helpful in addressing confidentiality problems in health research using large data sets (Barnes and Krauss; Durham). However, HIPAA's focused attention on personally identifiable health information in research may diminish attention to other types of risks to privacy and confidentiality that are posed by research but not considered by HIPAA, such as risks to groups, dignitary harms, or risks arising from interactions themselves, rather than from the resulting data. Because implementation of the HIPAA privacy rule is so new, whether and how it affects overall perspectives on research privacy remains to be seen (Annas, 2002; Kulynych and Korn).

Becoming a Research Subject

Usually, research subjects are enrolled in a study after giving their informed consent to participation. However, subjects in studies that examine information about which there is considered to be a lesser expectation of privacy (e.g., large-scale record abstraction that collects no identifying information, or studies observing public behavior) may never know that they have been the subjects of research. In fact, pursuant to the Common Rule, such studies may be exempted from review by an institutional review board. Violations of privacy may occur in such studies. For example, some subjects may not want researchers to read their records even though only aggregate data are recorded; and some subjects may feel wronged if they know their behavior is being observed for research purposes, even though many strangers who are not researchers observe the same behavior. However, the balance of benefits and harms is generally considered to warrant exempting such studies both from full consideration by an institutional review board and from the informed-consent requirements that would alert subjects to participation (Capron).

In addition, according to the Common Rule, some studies reviewed by institutional review boards may be considered appropriate for waiver or alteration of informed consent requirements. Factors used in determining whether waiving the informed consent requirement is acceptable include the magnitude and likelihood of the risks of harm to subjects in the study, and whether obtaining individual consent is considered impracticable. Large-scale database research that involves no direct contact with subjects, but in which researchers plan to retain information that identifies subjects in order to link, for example, information from a cancer registry to medical and other records and to stored tissue specimens presents an increasingly common scenario throughout the world. Investigators reason that they have no interest in the identities or characteristics of individual subjects, but need identifiers in order to gather, link, and analyze aggregate data. Seeking consent may be considered impracticable because of the cost and difficulty of reaching potential subjects, or because too many negative responses would result in a nonrepresentative sample, thus adversely affecting the validity of any findings. Confidentiality protections in such studies depend on ethically sensitive oversight and robust data security measures. (Berman; Bruppacher and Kaiser; Leufkens; Truter).

As in the case of research that is exempted from the informed consent requirement, research for which the consent requirement is waived may result in privacy violations if subjects would not wish investigators to see and use their personal information, even if only to link data sets. Breaches of confidentiality are of course also possible, but the risk may be lowered if adequate data security plans are in place, and identifying and potentially identifying information is destroyed as soon as it is no longer needed. Perhaps more basic, however, is the question whether sample validity overrides individuals' privacy interests in, at the very least, knowing that they are subjects. With the growth of large-scale research of this type, it is increasingly common to seek subjects' general consent to the prospective collection of data and specimens to be stored for future research (Annas, 2000; National Bioethics Advisory Commission, 1999).

All research requiring access to patients' medical records raises confidentiality concerns when the investigator is not also either a healthcare provider or other person with legitimate reason to inspect medical records. Perhaps the most significant concerns arise when patients are contacted to solicit their research participation by non-provider researchers using contact and diagnosis information they have obtained from medical records without patients' knowledge or permission. A variety of ways of balancing harms and benefits, and of reducing risks to confidentiality, are available to investigators and healthcare providers concerned about the interests of patients who are in the process of becoming research subjects (National Bioethics Advisory Commission, 2001; Office for Human Research Protections; Veatch).

The fact of study participation is generally treated as confidential information; this is especially important when the category of subjects or the purpose of the research carries potential social stigma (e.g., studies of HIV-positive patients, familial mental illness, genetic disease, or drug abuse). Inclusion in the subject pool may be enough to warrant confidentiality protection for potential subjects who decline to participate. Persons approached to participate in some studies may not want others to know that they fall into a category appropriate for inclusion. Others may be concerned that their participation may signal the existence of desirable information about them to employers, insurers, treating health professionals, or other authorities, placing the confidentiality of collected data at particular risk (Melton and Gray).

Privacy and the Researcher-Subject Relationship

Once enrolled, the subject is asked to disclose private information to a researcher. Such disclosure can take place in a variety of ways, from giving up tissue samples to answering extensive questions about personal history and psychology. The subject's judgment regarding the privacy of such information is highly dependent upon the circumstances. Someone enrolled in an addiction-control program may have little difficulty discussing alcohol consumption with health professionals in that program, but may have some hesitation about discussing it with a researcher collecting epidemiological information on the health of the person's county of residence, and even more when it is requested as part of a survey about the effects of television on perceptions about violence. Collection of genetic information may be of particular concern to subjects, because of heightened public awareness of how such information may be regarded and used (Sankar).

Sometimes revealing personal information (e.g., giving a blood sample, disclosing personal habits, recounting a past experience, or discussing physical limitations) can cause psychological or physical distress. According to the Common Rule, subjects must be informed when the research may be painful or address sensitive topics. Subjects must also be informed of their rights to refuse to answer individual questions and to terminate participation in the research at any time ("Federal Policy for the Protection of Human Subjects").

Interview studies raise an additional privacy concern when the information sought concerns persons other than the subject. For example, much survey research asks questions about the habits and activities of the subject's family, household, and associates. Some questions may concern sensitive topics or disfavored or illegal conduct. Although persons other than the subject are not named, they may be identifiable through naming of the relationship to the subject. In at least some such instances, these *secondary subjects* are research subjects in every respect, and their consent for participation should be sought unless criteria for waiver of consent are met (Botkin). Even if they are not identifiable, they may be wronged, simply because information about them is revealed without their consent or knowledge (Capron). It is likewise possible for some people or groups to become unexpected subjects if collection of information from them about study subjects incidentally reveals important information about the informants—as when studies of medical technologies or practices uncover information about healthcare providers who were not initially considered subjects (King, Henderson, and Stein; Veatch).

A similar concern can arise when others are asked to provide information about study subjects. In long-term studies, some subjects may become decisionally incapacitated, and investigators may turn to others, perhaps family members or institutional caregivers, to provide needed data.

This violation of subjects' privacy can be avoided by dropping these subjects from the study, or ameliorated by anticipating the problem and discussing with all subjects the designation of appropriate proxies should that become necessary (National Bioethics Advisory Commission, 1998).

The Promise of Confidentiality

The promise of confidentiality given by researchers to subjects extends not only to the information actually collected but also to whatever information the researcher encounters in the course of the data collection, regardless of whether that information is recorded. Thus, for example, when medical records are abstracted, information read by researchers as part of the abstraction process must be kept confidential, and information conveyed but not used in interviews similarly must not be divulged. Research projects that make use of record abstractors or interviewers generally require them to sign pledges of confidentiality promising that they will discuss no information outside the research project.

The information collected in human-subjects research needs protection not only from careless disclosure but also from intentional disclosure to those with a particular interest in the data. For example, study results may be offered as evidence in civil or criminal litigation, and both plaintiffs and defendants may seek to challenge the research by reexamining the data used or even by reinterviewing subjects. Criminal or social services authorities may seek access to study data that could inform them of ongoing violations. Health insurers may want to know whether those they insure have been tested for HIV or genetic disorders (Holder; Lansing; Symposium; Wing;Yolles et al.) In order to protect subjects from court-ordered disclosure of identifying information in civil, criminal, administrative, or other legal proceedings, federal certificates of confidentiality are available for human-subjects research that collects sensitive information which, if disclosed, could have adverse consequences for subjects or damage their financial standing, employability, insurability, or reputation. Certificates of confidentiality must be applied for by the investigator, and do not prevent voluntary disclosures by investigators; nonetheless, they can offer considerable protection for subjects (Office of Extramural Research).

Certificates of confidentiality have been expanded from their original focus on criminal justice questions, alcohol and drug use, and mental health, to encompass a broad range of research collecting sensitive information, including genetic information, information about sexual attitudes and preferences, information about sexually transmitted disease, behavioral research, and information about environmental or occupational exposures where litigation may be an issue. They preclude only the release of information that would identify specific individual research subjects and connect their identities with their data (Reatig). The concept of a researcher–subject privilege is not well established in the law, but courts that have considered requests for research data have generally required a strong showing of necessity and the deletion of all information that could lead to identification of subjects, even when the subjects' identities are a critical part of the request.

Confidential or Anonymous?

One way to ensure that confidentiality is not breached is to ensure that the information collected in research is anonymous—that is, that no information that could identify subjects is recorded or retained. Confidentiality can be preserved without anonymity by stripping collected data of identifying information but substituting a subject identification code and creating a secured *linkage file* that contains information connecting the subject's name and/or other identifying information to the code. The complexities of confidentiality protection can be considerable, especially in large projects, conducted at multiple sites that collect and manipulate data in hard copy or electronic formats, or both. Many different means of protecting confidentiality for different types of data have been devised (Berman; Schiedermayer).

Anonymous research virtually eliminates the risk of breaching confidentiality. However, anonymity may not be practicable or desirable. Researchers may wish to recontact subjects for a follow-up study, or may be conducting a long-term study that requires multiple contacts. Researchers may also wish to retain identifiers for subjects' benefit: Studies may collect health information, such as blood pressure or blood cholesterol levels, that subjects have been promised as an inducement to participation, or investigators may feel the need to inform subjects of potentially dangerous health situations that data collection may uncover. Finally, anonymity may too readily be considered a justification for not seeking participants' consent in studies that can be conducted without their knowledge (Bok).

Giving up anonymity in order to protect subjects' other interests can be highly problematic. HIV research provides an excellent example. Because of the stigma associated with the possibility of membership in an at-risk population and the difficulty in obtaining consents in sufficient numbers, some epidemiological researchers have conducted anonymous studies of the percentage of persons testing HIV-positive in large populations in order to obtain basic information about the spread of the disease. This makes it impossible to identify persons found to test positive, so that they can be counseled and treated. In effect, it precludes offering research subjects the opportunity to become patients.

Similar problems can arise in other research. For example, survey research that includes questions about family violence may uncover instances of recent or ongoing child abuse, but if survey answers have been rendered anonymous, even information gathered in *live* telephone or computer-assisted interviews may have insufficient detail to be reported to social services authorities, no matter how detailed the account of abuse given to investigators (King, Henderson, and Stein). How the tensions between public health goals in collecting data and protection and benefit for research subjects are addressed and resolved in such instances reflects continually shifting balances between the perceived need for epidemiological study, prospects for therapeutic intervention, and societal responses to particular health issues.

The Problem of Unexpected Information

Some researchers resist the idea of anonymous studies out of a felt obligation to offer information, counseling, and treatment to subjects found by the research to be in need of health services (Bayer et al.). But similar concerns can arise in confidential research as well. Studies using *gene-trolling* technologies like microarray techniques, which can quickly search a DNA sample for a wide range of disease-associated genes, can uncover potentially important health information that is unrelated to the stated goals of the research, thus surprising subjects who consented to research on one health problem with information about another (Berman; Collins). Additional challenges to privacy and confidentiality arise when the unexpected information has health implications for close relatives of the subject, who have not consented to participation and may know nothing about it. And if the research was conducted under a consent waiver, investigators may face the prospect of contacting people who have been involuntary subjects to give them bad news arising from their research participation.

Because the information derived from genetic research can have implications that go beyond those for subjects and their families, unexpected information may prove problematic for communities as well (Beskow; Rothstein). Even expected information may raise important concerns. The privacy interests of communities and groups may be directly and deliberately implicated by large-scale genetic research seeking information about the relationships between genetic characteristics and health outcomes, and both individual subjects and investigators may be ill-equipped to address and assess these risks of harm (Annas, 2000; Collins; Greely).

New Uses for Old Data

Data-sharing problems arise when researchers seek access to previously collected information. Researchers may seek to abstract information from the medical records of both currently and formerly hospitalized patients, or to perform additional tests on samples of blood or tissue obtained for diagnostic purposes. Study subjects may be approached by other researchers, or the data collected about them may be sought for new research uses. Stored research data may even yield information that is thought to be of therapeutic usefulness (Medical Research Council; Tribe).

Each of these examples raises one or more of several recurring problems: Is the new use one that was contemplated in the original consent? Is it one that the person would or would not be likely to find objectionable? Can the person be contacted for a new consent? If not, is proceeding without consent appropriate? If contact is necessary or desirable, does such a contact in itself constitute an unacceptable breach of confidentiality? The use of medical records and blood and tissue specimens for research has been addressed in a variety of ways, including: By asking patients at the time of hospital admission to give blanket consent to confidential or anonymous use of record data; by simply advising patients that such research may be undertaken with the approval of an institutional review board; by permitting researchers to contact patients for consent to specific uses, including long-term storage of identified or anonymized specimens for specified or unspecified research uses; and by using the treating physician to screen researchers' requests. Each of these solutions provides a different moral balance between the burden on researchers and the wrongs, harms, and benefits to subjects (Appelbaum et al.; National Bioethics Advisory Commission, 1999).

Where stored data have a potential therapeutic use, the situation is even more sensitive. A subject who participates in blood and tissue studies does not thereby consent to be contacted with a request to become a bone marrow donor for a specific patient. Such a contact could place considerable pressure on some subjects; others may want to have the opportunity to help, and may feel guilt at not having been afforded it. The temptation to compromise on privacy and confidentiality may be strong here. However, the argument that the needs of the patient should outweigh the privacy interests of a potential donor has not been embraced by the courts that have heard such cases (Davis, 1983; Lansing). As a result, this situation has been addressed, like the use of treatment information for research purposes, by asking research subjects whether they agree to be contacted later should a specific therapeutic need arise.

Publicity, Privacy, and Voice in Research

Publicity is most notably a problem for participants in innovative clinical trials, such as the first recipients of organ transplants, the first subjects to receive a novel intervention or vaccine for HIV infection, or the first subjects to experience an adverse event in a human gene transfer trial. The invasions of privacy threatened by the public interest in the lives of persons suffering from exotic diseases and undergoing unprecedented treatments may constitute civil wrongs if the media cannot claim First Amendment protection (Tribe).

The civil right to privacy is encompassed by several distinct courses of action, including the rights of private persons to be free from intrusion upon their solitude, to keep private information from being made public, and to prevent the publication of true information that places them in a *false light* (Warren and Brandeis). American society has changed greatly since this understanding of privacy was first outlined in law; yet finding a balance between protecting private information and sharing it remains a profound challenge (Goldman). Indeed, public interest in medical research is such that patient–subjects in clinical trials in high-profile emerging fields like gene transfer research are routinely informed that complete protection of their privacy may not be possible in the face of media interest.

A related threat to privacy and confidentiality is posed by the emphasis on narrative in research and teaching. Publication of research results is permitted, in professional and international codes and regulations, either when the subject has consented or when identifying information has been deleted or altered so as to preclude identification of the subject by readers and audiences, so long as the data are not misrepresented thereby (International Committee of Medical Journal Editors).

In many circumstances, such as in ethnographic research and increasingly in bioethics generally, it may not be possible to disguise case studies and other narratives adequately and still use them pedagogically (Davis, 1991). Well-known cases cannot be disguised at all. The scholarly community and the public have learned much from widespread discussion of Baby Fae, Barney Clark, Jesse Gelsinger, and many others, but not without costs to them and their families. And in less famous cases, even when a stripping of details is sufficient to disguise a patient–subject for a scholarly audience without misrepresenting the data, it may not be sufficient to disguise that person from family, associates, and treating health professionals who may chance to read a publication.

Finally, recognition of the subject by others may not constitute the only or the greatest wrong. Recognizing oneself in a public depiction can produce shame even when no one else knows. Although issues of consent and deception may be entangled with privacy and confidentiality in narrative research (Allen), subjects may be wronged and harmed regardless of whether the depiction is perceived to be accurate or distorted, and whether or not they have consented to the publication (King, Henderson, and Stein).

Some researchers address this complex problem by developing long-term collaborative relationships with subjects. Collaboration can reduce the exclusive control the researcher has over the story by including the subject's voice, but is not always possible, helpful, or desirable. Indeed, the ethics of telling stories has become a primary issue for bioethics itself (Chambers; Davis, 1991). As the problem of privacy and confidentiality in research shows, even in the face of the imperative to increase knowledge, it is important to consider whether some new knowledge is worth sacrificing privacy or confidentiality, and whether some knowledge comes at too great a cost to the rights and interests of those from whom we learn.

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SEE ALSO: *AIDS: Healthcare and Research Issues; Confidentiality; Informed Consent: Consent Issues in Human Research; Law and Bioethics; Privacy in Healthcare; Research, Unethical; Research Ethics Committees; Research Methodology; Research Policy*

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PRIVACY IN HEALTHCARE

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Privacy is a rich concept with a major role in the assessment of healthcare practices, policies, and law. It has become increasingly commonplace to ascribe important health-related privacy interests to individuals, families, and institutions and then to criticize public and private sector failures to protect those interests.

Privacy and Health Services

The word *privacy* has four major usages, corresponding to four distinct forms, dimensions, or conceptions of privacy: physical privacy, informational privacy, proprietary privacy, and decisional privacy. Issues relating to all four pervade healthcare.

PHYSICAL PRIVACY. Under one popular usage of the term, *privacy* denotes freedom from contact with other people. The desire for limited physical accessibility—for seclusion and solitude conducive to peace of mind and intimacy—is a desire for privacy in this first sense. Members of the general public regard many social, business, and governmental contacts as privacy intrusions. These include door-to-door, street corner, telephone, and mail solicitation; some forms of sexual harassment; beeper and cellular telephone monitoring; and employers' performance, polygraph, drug, and alcohol testing. Common governmental practices are controversial for their threats to physical privacy, especially the use in foreign intelligence gathering and domestic surveillance of high-powered binoculars, concealed tape recorders, cameras, wiretaps, and thermal imaging. The loss of physical privacy is sometimes a concern when criminal-justice officials rely on body-cavity searches, prison-cell searches, and electronic monitoring of probationers; or when the police operate "checkpoints" to detect violations of curfew, seat-belt, drug, and drunk-driving laws.

Complete physical privacy is inconsistent with the demands of modern healthcare. The modern delivery of health services presupposes that patients and medical professionals mutually accept nudity, touching, and observation as unavoidable aspects of examination, treatment, surgery, and hospitalization. Typical patients willingly sacrifice the desire for bodily concealment and seclusion for a chance at better health. Yet patients often expect their physicians, nurses, and other caretakers to guard assiduously against unnecessary bodily exposure or contact. The examination gowns and pajamas worn by patients respond to the expectation of privacy, as well as the need for warmth.

Hospital patients—and their lawyers—have sometimes characterized unauthorized medical treatments as invasions of privacy, along with the bedside presence of inessential medical attendants, spectators, or cameras. The desire for physical privacy may lead patients who have a choice to select single over shared hospital rooms. Because for many Americans bodily exposure to persons of the opposite sex is a more significant loss of privacy than same-sex exposures, the desire for physical privacy has led some patients to prefer physicians or nurses of their own sex. Norms of quietude surrounding hospitals reflect the sentiment that patients have heightened physical and psychological needs for solitude and peace of mind.

INFORMATIONAL PRIVACY. Under a second popular usage, *privacy* is synonymous with secrecy, confidentiality, data protection, or anonymity. It requires limits on the accessibility of personal information. The expectations of privacy surrounding health information are especially high, but not unique. Significant expectations of privacy exist also for information related to employment, education, Social Security numbers, criminal arrest, library use, video rentals, motor vehicle registration, taxes, consumer credit, and banking.

Informational privacy concerns in the healthcare setting have traditionally focused on the confidentiality of the physician–patient relationship and on limiting access to medical and insurance records. The willingness of patients to speak openly about physical and mental health concerns depends, in part, on expectations of professional confidentiality. The administrative demands of managed care interject faceless decision makers into the context of physician care at a cost to privacy. Proposals for governmentally or institutionally mandated testing, reporting, and identification raise other informational privacy concerns. The public health community recognizes the potential threat to privacy and other important interests posed by nonanonymous AIDS testing or reporting and mandatory medical insurance identification cards.

Informational privacy in healthcare is not solely a matter of safeguarding information about individuals. By virtue of genetic ties, family members may share health conditions or predispositions. Progress by researchers toward the goal of mapping and sequencing the human genome has heightened ethical concerns about possible family, as opposed to individual, privacy interests in the information coded in a person's genetic materials (Powers).

Informational privacy requires appropriate forms of secrecy, sometimes defined as intentional concealment of fact (Bok); and confidentiality, defined as selective disclosure of fact to authorized persons (Allen, 1988). In institutional settings security requires mechanisms capable of limiting access to information, such as locked office doors and file cabinets. The security of health data shared on computers may require user identification passwords and encoding. In addition to security, concern about privacy of information overlaps with concern about what are sometimes called "fair information" practices. These include maintaining accurate information in confidence. The accuracy and security of information contained in health, insurance, adoption, and gene-research records potentially bears on the quality of healthcare and therefore holds special importance.

Managed care, the AIDS epidemic, and the Human Genome Project spawned numerous proposals for federal and state regulations governing health information. The federal government responded with the Health Insurance Portability and Accountability Act of 1996 (HIPAA). HIPAA included provisions encouraging uniform electronic transfer of medical information and required modern safeguards to protect both the security and confidentiality of medical data. HIPPA's initial privacy standards went into effect in April 2001 and did not preempt stronger state law privacy standards.

HIPAA covers government and private health plans, healthcare clearinghouses, and many healthcare-related service providers, such as firms that take care of patient billing. These firms must adopt privacy policies and inform patients of their privacy rights. They must also train staff to respect privacy and designate a privacy officer charged with privacy oversight responsibilities.

HIPAA requires special protections for individually identifiable health information disclosed orally, on paper, or electronically. Patients must be given notice of their privacy rights, access to their medical records, and a right to limit disclosures to third parties, subject to certain exceptions. For example, patients do not have the right under HIPAA to veto access to their medical records by public health officials, researchers, the courts, or emergency medical personnel or in certain other situations. Only psychotherapy notes used and created by psychotherapists are accorded a higher level of protection. Patients do have rights against the unauthorized disclosure of their medical information to third parties for employment personnel or marketing purposes. Although HIPAA does not authorize patients to sue for violations, it places enforcement powers in the hands of the Department of Health and Human Services, which may seek civil penalties and criminal punishments up to $250,000 and ten years in prison for the most egregious knowing violations of the statute.

PROPRIETARY PRIVACY. Concerns relating to the appropriation and ownership of human personality are increasingly framed as privacy concerns. Under a third usage, privacy can mean the appropriation of a repository of personal identity. These concerns have emerged in healthcare and health-research-related domains. According to American common law now recognized in a majority of states, to appropriate a person's name, likeness, or identity is a way of invading that person's privacy. Following this precedent, patients photographed without their consent may object to publication on privacy grounds. Moreover, because a person's genes are widely believed to be biologic keys to personal identity and sources of health information that should be properly controlled by the individual, a person whose DNA is appropriated without consent may likewise object on privacy grounds. In the 1990s, when the U.S. military first required active duty service members to undergo tissue sampling for possible future DNA testing in the

1990s, service members raised privacy objections that led the Department of Defense to strengthen safeguards against breaches of its DNA data banking system. After the Burlington Northern Santa Fe Railroad conducted secret DNA testing on employees to determine genetic predisposition to carpal tunnel syndrome, the company entered into a settlement with the Equal Employment Opportunity Commission in May 2002, agreeing to pay $2.2 million to affected workers.

DECISIONAL PRIVACY. Individuals, families, and domestic partners typically define some decisions as personal decisions and certain conduct as intimate conduct. Under its fourth usage, privacy denotes autonomous choices about the personal and intimate matters that constitute private lives. Decisional privacy signifies the ability to make one's own decisions and to act on those decisions, free from governmental or other unwanted interference. Decisional privacy concerns in the health context relate to responsibility for important decisions about treatment, the termination of treatment, and the allocation of scarce medical resources. Legal and ethical disagreements about who has the "right to decide" or the "right to choose" sometimes have turned collaborating patients, physicians, nurses, hospitals, families, researchers, and lawmakers into competitors and litigants.

In the United States, conceptions of decisional privacy have come to dominate discussions of government regulation of abortion and the treatment of patients who are severely disabled, terminally ill, or in a persistent vegetative state. In the context of so-called surrogate motherhood, privacy for infertile couples has meant the freedom to make legally enforceable agreements to procreate with the assistance of third parties. Gay men and lesbians invoke the ideal of privacy in their quest for the freedom to engage in consensual adult sexual relationships and marriage, free from the fear of criminal prosecution and legally sanctioned discrimination. Parents sometimes invoke "family privacy" to mean the freedom of heads of households to decide how those for whom they are responsible will be reared, educated, and medically assisted. Invocations to respect privacy accompany defenses of limited government and autonomous decision making respecting heterosexual sex, contraception, midwifery, women's prenatal conduct, use of experimental medical remedies, psychotropic drug therapy, organ sales and transplants, hunger striking, prostitution, and pornography.

Theories about Privacy

Theorists from disciplines that include philosophy, bioethics, and law have offered accounts of the meaning and value of privacy. Some of these accounts, though by no means all of them, have been prompted by a desire to clarify the assumptions and aims of health-related law and public policy.

DEFINITIONS OF PRIVACY. Contemporary theorists actively debate how precisely to define, value, and protect privacy (Cohen; Schoeman, 1992; Inness; Wacks; Allen, 1988). Although many acknowledge that privacy is used in distinguishable physical, informational, proprietary, and decisional senses, no single definition of privacy in any of its senses has gained universal acceptance. Nor has any theory of the value of privacy gained universal acceptance.

Scholars disagree about how to approach defining privacy (Allen, 1988). Some say privacy should be defined as a value or moral claim (Inness), others as a fact or a legal right (Gavison). Some say that definitions of privacy should prescribe ideal uses of the term (Gavison), others that definitions should describe actual usage (Allen, 1988). Debates over the definition of privacy may seem arcane. Yet the outcome of the debates bears importantly on the framing of ethical and legal issues raised by healthcare. For example, some theorists contend that the popular privacy arguments for abortion rights are unsound because they confuse privacy with liberty, autonomy, or freedom.

Proposed definitions of privacy range from the very expansive "being let alone," popularized by Louis Brandeis and Samuel Warren in an 1890 *Harvard Law Review* article, to Alan F. Westin's more specific "claim of individuals, groups or institutions to determine for themselves when, how, and to what extent information about them is communicated to others" (p. 7). Many definitions characterize privacy in its physical and informational senses as denoting conditions of restricted access to persons, their mental states, or information about them (Allen, 1988). According to Ruth Gavison, "[i]n perfect privacy no one has information about X, no one pays attention to X, and no one has physical access to X" (p. 428). So conceived, privacy functions as an umbrella concept, encompassing a family of concepts each of which denotes a form of limited access to others. There is disagreement about the composition of the privacy family's membership list. The list, however, arguably includes seclusion, solitude, anonymity, confidentiality, modesty, intimacy, reserve, and secrecy.

The debate over the relationship between the concepts of privacy and secrecy exemplifies the bewildering extent of disagreement about how to define privacy and related concepts. Although some scholars view secrecy as a form of privacy, others view privacy as a form of secrecy (Friedrich). Still others view them as distinct concepts. In a 1984 book titled *Secrets,* Sissela Bok argued that privacy and secrecy are wholly distinct concepts—the former referring to limited physical and information access, the latter to intentional concealment of information.

A number of definitions of privacy instead emphasize control, whether control over information or control over avenues of observation and physical contact (Fried; Westin). In the media-saturated and bureaucracy-dependent society of the United States, it is perhaps unsurprising that one scholar has suggested that privacy involves the possession of undocumented information (Parent, 1983a, 1983b). Other legal and moral theorists stress privacy as a social practice with normative functions (Inness). Jeffrey H. Reiman links privacy to the formation of individuality and personhood: "Privacy is a social ritual by means of which an individual's moral title to his own existence is conferred" (p. 39).

THE DECISIONAL PRIVACY CONTROVERSY. Perhaps the greatest source of definitional disagreement surrounding the concept of privacy has related to the decisional usage of privacy. Decisional privacy has been defined as control over intimate aspects of personal identity. In the United States, aspects of the human body, sex, reproduction, marriage, and family are generally considered as numbering among the intimacies of personal identity. The U.S. Supreme Court popularized the decisional usage of privacy in the 1960s, 1970s, and 1980s by characterizing laws restricting birth control, abortion, end-of-life medical decision making, marriage, and parental authority as burdening the right to privacy. Decisional privacy rights in the law presuppose a private sphere of conduct immune from state or federal regulation. Some scholars emphasize the ideal of privacy as the ideal of limited government (Rubenfeld).

Many theorists insist that privacy in the decisional sense is not properly understood as a sense of privacy at all (Gavison; Parent, 1983; McCloskey; Ely). They raise several arguments. First, they argue, as an aspect of liberty, freedom, or autonomy, decisional privacy stands apart from paradigmatic forms of privacy, such as seclusion, solitude, and anonymity. Second, if one speaks of "decisional" privacy, one loses the ability to treat privacy and liberty as distinct concepts. Confused, ambiguous uses of the concept of privacy in the U.S. Supreme Court's first contraception and abortion cases helped to raise this widespread objection.

Defenders of the decisional usage of the term *privacy* counter that decisional privacy is worthy of the name (DeCew, 1987). They emphasize that although decisional privacy denotes aspects of liberty, freedom, and autonomy, it denotes aspects of these that pertain to deeply felt conceptions of a private life beyond legitimate social involvement. Controversial or not, using "privacy" to denote a domain outside of legitimate social concern has become an entrenched practice in the United States.

THE PUBLIC AND THE PRIVATE IN POLITICAL THOUGHT. Linkage with the Greco-Roman heritage of Western law and political theory may provide a degree of historic and etymological validity to the controversial practice of referring to freedom from interference with personal life as "privacy." The decisional usage of privacy has origins in classical antiquity's distinction between private and public spheres.

The Greeks distinguished the "public" sphere of the polis, or city-state, from the "private" sphere of the *oikos,* or household. The Romans similarly distinguished *res publicae,* concerns of the community, from *res privatae,* concerns of individuals and families. The ancients celebrated the public sphere as the sphere of political freedom for citizens. The public realm was the sector in which select men—free men with property whose economic virtue had earned them citizenship and the right to participate in collective governance—could truly flourish. By contrast, the private realm was the sector of mundane economic and biologic necessity. Wives, children, and slaves populated the private economic sphere, living as subordinates and ancillaries to autonomous male caretakers.

The post-Enlightenment Western liberal tradition inherited the premise that social life ought to be organized into public and private spheres (Arendt; Habermas). It also inherited the premise that the private sphere is properly constituted by the home, the family, and intimate association. Nevertheless, whereas ancient thought tolerated the private and celebrated the public, modern liberal thought often reflects an opposing tendency: It tolerates the public as pervasive and necessary for collective welfare but celebrates the private as an essential expression of personal identity, freedom, and responsibility.

The political concept of a limited, tolerant government—elaborated by the English philosopher John Locke (1632–1704) and Thomas Jefferson as a requirement of natural rights, and by the nineteenth-century English philosopher and economist John Stuart Mill and the eighteenth-century Scottish economist Adam Smith as a requirement of utility—entails a nongovernmental, private sphere of autonomous individuals, families, and voluntary associations. Mill emphasized the importance of government tolerance, arguing that government is not well situated to assess the utility of "self-regarding" acts that potentially harm only the actors themselves. Self-regarding conduct "neither violates any specific duty to the public, nor occasions any perceptible hurt to any assignable individual except himself" (Mill, p. 80). It is, in other words, conduct that is restricted to an individual's own body and property and that may offend others but imposes no risk of significant harm on others. The contractarian political tradition of American democratic liberalism requires tolerance for religious minorities, political dissenters, and unpopular lifestyles. The ideal of tolerance is arguably the ultimate foundation of the case for sexual privacy for homosexuals and women seeking abortions (Richards).

The ideal of a private sphere free of government and other outside interference has currency, despite the reality that in the United States and other Western democracies, virtually every aspect of nominally private life is a focus of direct or indirect government regulation (Cohen). Marriage is considered a private relationship, yet governments require licenses and medical tests, impose age limits, and prohibit polygamous, incestuous, and same-sex marriages. Procreation and child rearing are considered private, but government child-abuse and neglect laws regulate, if at times inadequately, how parents, and possibly even pregnant women, must exercise their responsibilities. The ideal of a private sphere can be no more than an ideal of the ability of ordinary citizens to make choices that are relatively free of the most direct forms of governmental interference and constraint.

The worthiness of this ideal has been called into question in the United States, where problems of domestic and other private sector violence suggest a need for more rather than less involvement in the traditionally "private" spheres (Allen, 2003; Morris; MacKinnon). In addition, the ideal of a private sphere has been the ideal of a sphere of negative as opposed to positive freedom. The right to privacy in the context of contraception and abortion has meant a negative right against government decision making respecting procreation, not a positive right to governmental programs designed to make contraception and abortion services available to those who cannot afford to pay. Critics blame the emphasis on privacy and negative freedom for the failure of legal efforts to secure government funding of abortions for women who are poor.

ETHICAL VALUES. Physical and informational privacy practices serve to limit observation and disclosure deemed inimical to well-being. Psychologists have long emphasized the unhealthful effects of depriving individuals of opportunities for socially defined modes of privacy (Schneider). Many philosophers maintain that respecting physical, informational, and decisional privacy is paramount for respect for human dignity and personhood, moral autonomy, and workable community life (Schoeman, 1992; Allen, 1988; Kupfer; DeCew, 1986; Feinberg; Benn). Lawyers view the moral value of privacy as the basis of moral rights deserving legal protection (Greenawalt; Fried; Westin).

Scholarly disagreement about how best to characterize the ethical value of privacy is fundamental (Inness). One axis of disagreement concerns whether privacy denotes a value or a state of affairs. A second axis of disagreement concerns whether privacy, presumed to denote a state of affairs, refers to a state of affairs with necessary moral legitimacy or merely contingent moral legitimacy. A third axis of disagreement concerns whether the value of privacy, presumed to denote a state of affairs with only contingent moral legitimacy, should be measured against relevant consequentialist criteria, such as promoting aggregate happiness or efficiency; or deontological criteria, such as respect for personhood, personal identity, or humanity.

From the consequentialist perspective, privacy has value to the extent that it is useful in promoting, for example, aggregate happiness or the diverse interests of individuals, groups, or government. In this vein, scholars commonly argue that privacy has value because it functions to create or enhance human personhood in ways that promote liberal social and political institutions. Privacy practices promote individuality and the formation of self-concept presupposed by democratic self-government. Some accounts stress the utilitarian value to society of restraining government power in the spheres of what John Stuart Mill called "self-regarding" actions.

Scholars also argue that privacy has instrumental value relative to its role in creating and enhancing relationships. The traditional argument is that only in isolation from others can desirable forms of intimacy and friendship flourish; only if individuals and families can seclude themselves from others can the potentially stifling and emotionally explosive social demands of group life be abated. In reply, it is argued that privacy practices have facilitated both the mistreatment of women and children and the disregard for the ideal of aggregate as opposed to individual responsibility. The ethical challenge posed by these criticisms is to describe social arrangements that vigorously protect states of physical and informational privacy in the name of individuality, creativity, family, and free association, but that avoid the subordination and alienation often associated with modern Western liberal societies.

Scholars sometimes explain what they regard as the value of privacy by reference to the importance of personhood and personal dignity to individuals. These arguments draw connections between limited physical and informational access and/or the ability to make important decisions for oneself and the very idea of rational moral autonomy. In his contribution to the 1971 book, *Privacy,* Stanley I. Benn argued, for example, that the principle of respect for persons provides a moral reason for not interfering with personal privacy. David A. J. Richards, in his 1986 book, *Toleration and the Constitution,* argued, by appeal to the "social contract" metaphor, for legal privacy protections, stressing the fundamental value of government toleration of the choices individuals make for themselves pertaining to procreation, sexuality, and religion.

Privacy in the United States

The United States has a wealth of state and federal law protecting privacy. Recent federal law has increased legal safeguards for health information privacy at a time when Americans are increasingly open about formerly sensitive health matters.

CULTURAL AND HISTORICAL DIMENSIONS. Focusing on physical and informational privacy, anthropologist Barrington Moore observed in his 1984 book, *Privacy,* that both the desire for privacy and the ability to satisfy it are unequally distributed among and within human societies. Although some cultures do not emphasize privacy at all, privacy protection practices are found in virtually every human culture (Moore; Altman; Westin). Strikingly, what is treated as private can vary significantly from society to society (Pennock and Chapman). In one culture, defecation and sexual intercourse may be performed openly without embarrassment or shame; in another they are deeply private. One culture shields religious rites in secrecy, whereas another performs them on the commons. Female breasts and breastfeeding require concealment for modesty's sake in one place, but not another. Nuclear family problems are personal information in one society, but they are freely shared with leaders of one's tribe or village elsewhere.

The protection of personal privacy is among the most important public issues in the Western nations of the world (Flaherty; Schwartz and Reidenberg). These nations have in common large, well-developed bureaucracies and advanced information technologies (Bennett). Categories of data that western Europeans and North Americans deem personal include health information, criminal convictions, disciplinary measures, religious beliefs, political opinions, racial origin, trade union membership, sexual life, and intimate private life (Nugter).

U.S. culture is dominated by widely shared aspirations for lifestyles that afford frequent opportunities for privacy and intimacy. In families and friendships, though accountability for sensitive health information is the rule rather than the exception. Partners, kin, and friends rely on one another for health-related advice, comfort and care (Allen, 2003). Although the "taste" for privacy is strong in the United States, it competes with the principle of a "public right to know" reflected in the practices of government and the media. Commercial, professional, and personal relationships of many kinds presuppose a high degree of self-disclosure and physical contact. As a consequence, the United States is not a country in which expectations of physical or informational privacy are easily satisfied.

American culture was not always dominated by articulated concern for privacy. Nor have deeply private lifestyles often been the norm. According to David H. Flaherty, Colonial lifestyle "left little room for privacy or nonconformity even among the free and the affluent" (Flaherty, p. 172). Concerns for physical and informational privacy achieved prominence as public issues for the first time in the nineteenth century, when a sharp increase in technology and industrialization had begun to transform the agrarian and mercantile culture to one of urban capitalism, and when the courts and legislatures began to expressly regulate marriage and family life (Garrow).

According to Alan Westin, nuclear family lifestyles, mobility in work and residence, and the decline of religious authority meant "greater situations of physical and psychological privacy" for mid- and late-nineteenth-century Americans (p. 21). Nevertheless, at about the same time that some middle-class and wealthy Americans were enjoying more privacy than ever before, a number of factors appear to have increased Americans' privacy-related anxieties. The simultaneous growth of crowded cities, the closing of the western frontier, the invention of commercial photography, and the rise of mass circulation newspapers may explain the emergence during the late nineteenth century of public concern about lost privacy (Allen and Mack; Copple).

The development in the early twentieth century of a social welfare bureaucracy and surveillance technologies may have further increased concerns about privacy. Indeed, the Supreme Court's first pronouncement about the right to privacy came in a dissenting opinion in *Olmstead v. United States* (1928), a case that validated telephonic eavesdropping by government. But the development of powerful computers capable of storing personal data appears to have spawned another, larger wave of concern about privacy in the 1960s and 1970s, the decades of origin for many of the major federal privacy laws that were in force in the early twenty-first century (Miller; Turkington and Allen). Finally, the rhetorical success of legal claims based on the "right to privacy" after 1965 in Supreme Court contraception and abortion cases spawned additional interest in fending off interference with choices people make respecting their bodies, healthcare, families, and lifestyles.

LEGAL DIMENSIONS. Near ubiquitous recognition of the importance of privacy is suggested by the language of key international human-rights documents. Privacy is mentioned, for example, in the Universal Declaration of Human

Rights, adopted by the United Nations General Assembly in 1948. Article 12 provides that "No one shall be subjected to arbitrary interference with his privacy, family, home, or correspondence, nor to attacks upon his honor and reputation" and that "Everyone has the right to the protection of the law against such interference or attacks" (Henkin et al., p. 144). In fact, the law of most modern legal systems prohibits, at least officially, physical privacy invasions and assaults on honor of the sort identified by Article 12. Western nations typically regulate several forms of physical, informational, and decisional privacy. Access to health-related information is limited by statute in most industrialized nations and the European Union (Nugter).

Great Britain and the United States share a common legal heritage and protect many of the same forms of privacy. Yet courts and legislatures in the United States have been more willing than their English counterparts to multiply the number of specific privacy protections. The reasons for this difference are unclear, although one explanation may be greater concerns in Britain about creating rights of uncertain application (Wacks). In the United States privacy interests are protected, often expressly, by tort law, the Constitution, and numerous federal and state statutes.

Tort law. The first privacy rights to be recognized expressly in United States law were rights of physical and informational privacy. The express right to privacy first came into existence through the common-law process of judicial recognition. Endorsed by Louis Brandeis and Samuel Warren in a famous 1890 *Harvard Law Review* article stressing the importance of freedom from unwanted publicity, the invasion of privacy tort was officially adopted by the Georgia Supreme Court in *Pavesich v. New England Life Insurance Company* (1905). Many other state courts eventually followed suit.

By 1960, William Prosser could identify, not one, but four common-law privacy rights recognized by courts in the United States. Today, most states have adopted one or more of Prosser's four privacy rights through their courts or legislatures. The influential *Restatement of the Law Second: Torts 2d* (American Law Institute), a summary and exposition of developments in personal injury law, embraced Prosser's analysis. In states that have adopted Prosser's analysis, a person may bring a privacy-invasion lawsuit claiming highly offensive conduct consisting of either:

1. interference with seclusion, solitude, and anonymity;
2. publication of embarrassing private facts;
3. publicity placing a person in a false light; or
4. appropriation of name, likeness, or identity.

In addition, most states permit privacy-invasion-related claims involving unauthorized publicity; breach of confidence or secrecy; and unfair business practices involving misappropriation, trade secret, trade name, and copyright violations. Plaintiffs have alleged invasion of privacy in cases related to health services. An Oregon physician was sued for disclosing the identity of an adult adoptee's birth mother. A New Yorker whose photograph appeared in a newspaper accompanying a story about an AIDS treatment facility sued the publisher.

Constitutional law. Although the U.S. Constitution makes no express mention of the term *privacy* itself, the constitutional law of the United States protects physical, informational, and decisional privacy interests. The First Amendment, the guarantor of freedom of speech and association, protects the physical and informational privacy concerns of exclusive clubs or political groups. In effect, the Supreme Court has held that the Fourth Amendment guarantees a right of physical privacy when it limits warrantless search and seizure, and that the Fifth Amendment guarantees a right of informational privacy when it limits compulsory disclosure and self-incrimination. Although the Supreme Court has never held as much, some judges and lawyers maintain that the Ninth Amendment, which provides that the "enumeration in the Constitution, of certain rights, shall not be construed to deny or disparage others retained by the people," implies decisional privacy rights. The Supreme Court has established First and Fourteenth Amendment limits on government record keeping and access to personal information. In *Whalen v. Roe* (1977), a major Supreme Court case involving a data bank of prescription drug users maintained by New York officials, the Court held that the First and Fourteenth Amendments require states seeking to deter drug abuse to implement confidentiality safeguards.

The U.S. Supreme Court and many lower courts have held that the Constitution protects decisional privacy respecting aspects of health, reproduction, sex, and family life, deriving this brand of privacy from what the court has termed the *penumbra* of the Bill of Rights and the Fourteenth Amendment. The Fourteenth Amendment, which provides that no state may deprive a person of liberty without due process, is the most frequently cited basis of the decisional privacy right protecting autonomous decision making respecting contraception, abortion, and the termination of medical treatment. *Griswold v. Connecticut* (1965) and *Roe v. Wade* (1973) established the right to contraception and abortion. The privacy doctrine that originated in the *Griswold* and *Roe* cases has come under repeated attack from critics who stress the absence of a textual basis for reproductive privacy rights. Some critics have urged that gender equality and equal protection of the laws, rather than privacy and liberty, are the core values served by reproductive rights.

In *Planned Parenthood of Southeast Pennsylvania v. Casey* (1992), the Supreme Court affirmed the essential holding of *Roe v. Wade,* reiterating the Fourteenth Amendment as protection for reproductive privacy. The Court backed away, however, from *Griswold*'s and *Roe*'s characterization of the right to privacy as a "fundamental" right that cannot be breached except where there is a truly "compelling" governmental interest. *Cruzan v. Director, Missouri Department of Health* (1990) recognized an adult patient's privacy right—not her parents'—to terminate life-sustaining medical treatment. Yet *Cruzan* and *Casey* applied weaker standards of review than *Roe v. Wade.* Abortion restrictions "rationally related" to a "legitimate state interest" that do not "unduly burden" the woman's constitutional right to privacy are valid. And restrictions on the right to refuse treatment that reasonably relate to a legitimate state interest are also valid.

Statutory law. The U.S. Congress enacted a number of federal statutes after 1970 to protect informational and physical privacy interests. The Privacy Act (1974), the Freedom of Information Act (1974), the Family and Educational Privacy Act (1974), the Right to Financial Privacy Act (1978), and Title V of the Financial Services Modernization Act (2001) protect information privacy by limiting access to personal information held in government, school, and bank records. The federal Employee Polygraph Protection Act protects workers from potentially incriminating self-disclosure in the workplace by limiting use of the lie-detector test. The Electronic Communications Privacy Act (1986) and other major federal statutes protect against intrusive searches using electronic surveillance, wiretapping, and other unauthorized access to telephones or computers. Proposed federal privacy statutes would limit access to genetic information about individuals. HIPAA requires the maintenance of the confidentiality and security of health-related information, including genetic health information.

State statutes in virtually every state address concerns about the privacy of information related to medical care, criminal histories, and adoption. Newer state statutory regulations include the decisional privacy protections of Virginia's Natural Death Act and Pennsylvania's Confidentiality of HIV-Related Information statute. Recently, state constitutions in Montana, California, and Florida have been amended or interpreted to require physical, informational, and decisional privacy protections. For example, in a pre-*Casey* decision, the Florida high court held that the state constitution protects decisional privacy to the same degree as *Roe v. Wade.*

Patients' privacy rights. One of the most important areas of health law is the broad field of patients' rights. Discussions of patients' rights include the physical, informational, and decisional privacy rights recognized under tort, constitutional, and statutory law. A Patients' Bill of Rights that would include privacy protections emerged as a policy initiative during the presidency of George W. Bush.

The oldest American legal case decided by reference to rights of privacy, *DeMay v. Roberts* (1881), vindicated interests in physical privacy and modesty. A Michigan husband and wife successfully sued a physician who permitted an "unprofessional young, unmarried man" to enter their home and help deliver their baby. A century later a married couple in Maine brought *Knight v. Penobscot Bay Medical Center* (1980), a similar, though unsuccessful, lawsuit claiming that a hospital violated the couple's privacy by permitting a layperson, the spouse of a nurse, to observe delivery of their child through a glass partition from a distance of 12 feet. The issue of whether women should be able to choose who is present at the birth of their children—including whether delivery is undertaken with the aid of a midwife, nurse practitioner, or physician—is clearly both a physical and a decisional privacy issue.

All patients generally may share the obstetrical patient's sense that adequate privacy is lacking in hospitals where well-intentioned medical, administrative, and support staff move freely in and out of (even nominally "private") inpatient wards. The feeling that one's privacy has been invaded may be especially acute in busy, crowded public hospitals serving low-income patients or in any hospital where groups of several physicians, interns, and medical students simultaneously conduct physical examinations and discussions at one's bedside. Some men and women report feeling their privacy invaded by having to share a room in an intensive-care unit with a person of the opposite sex. The law is unclear about the extent to which medical resources or the general written consent to treatment patients give upon admission to hospitals eliminates legitimate expectations of physical and informational privacy. Specific waivers of legal privacy claims may give patients clear notice of the privacy losses associated with treatment in teaching and research hospitals, but arguably they do not eliminate hospitals' ethical obligations to respect privacy to the extent possible.

Moral outrage over the discovery that healthcare providers have recorded, filmed, or photographed a patient for scholarly or research purposes occasionally results in litigation. Respect for privacy would appear to dictate obtaining prior consent to the publication of graphic images of a person, particularly if the person is identifiable in an image or is named in connection with its publication.

The legal importance of obtaining prior informed consent was underscored by the holding of the California court in a highly publicized case, *Moore v. Regents of University of California* (1990). John Moore brought a multimillion-dollar lawsuit when he discovered that University of California medical researchers who treated him for hairy cell leukemia had failed to disclose that "certain blood products and blood components were of great value in a number of commercial and scientific efforts." Moore's right to privacy claims were based on the notion that exploitation of his blood for commercial purposes was a highly offensive appropriation of a person's name, likeness, or identity compensable as an invasion of privacy under state tort law. According to the California court, a patient has a right to know the medical purpose of treatment and the treating physician's personal economic stake; otherwise treatment is battery, presumably no better than sterilizing a fertile woman or performing a cesarean section on a cancer patient without her consent.

As noted earlier, abortion, physician-assisted suicide, and the right to die are approached in the United States as patient privacy issues. Opponents of laws prohibiting abortions say that state and federal regulations should not prevent women from acting on their own decisions about whether to terminate pregnancy through medical abortion. On the other hand, it is also argued on privacy grounds that women should not be forced or counseled to abort for any reason, including where they are seropositive for the virus that causes AIDS. "Privacy" can signify freedom to choose the circumstances of death for oneself, a family member, or an intimate friend. It means the absence of criminal laws and bureaucratic procedures that constrain the choice to accelerate the death of a person who is terminally ill or to refuse artificial nutrition and hydration to preserve life in a person in a persistent vegetative state. The right to privacy may also prove to be the ethical refuge of supporters of physician-assisted suicide of nonterminally ill, fully competent adults. In *Vacco v. Quill* (1996) and *Washington v. Glucksberg* (1996), however, the U.S. Supreme Court ruled that states may outlaw physician-assisted suicide.

The privacy implications of nonvoluntary and routine AIDS testing of obstetrical patients, surgical patients, and newborns have been of great interest to public authorities and private healthcare providers for two reasons. First, nonconsensual testing is a prima facie denial of decisional privacy or autonomy. Some individuals prefer not to be tested and forced to confront the specter of terminal illness. And while this precise concern has never applied to newborns, newborn testing can reveal the HIV status of birth mothers. Second, where medical or insurance providers breach the confidentiality of an HIV- or AIDS-infected person, far-ranging implications for private lives and employment can follow because of prejudice and discrimination. In this context, policy analysts often assert that the individual interest in privacy is outweighed by societal interests, including the societal interest in controlling the spread of deadly disease through inappropriate handling of contaminated blood and other tissues. But societal interests do not always outweigh individual privacy rights.

The federal courts have upheld the mandatory AIDS-testing policies of the U.S. military and the nation's prisons. In *Glover v. Eastern Nebraska Community Office of Retardation* (1989), however, a federal court struck down a state requirement that all persons working closely with mentally retarded clients disclose their HIV and hepatitis B status and undergo periodic HIV and hepatitis B blood testing. Against the argument that persons working in highly regulated state agencies have lower expectations of privacy, the court stressed that constitutional values do not permit mandatory testing where the risk of disease transmission is extremely low. A similar weighing of the costs of testing against its benefits in view of the low risk of transmission may explain government reluctance to mandate AIDS testing for all dentists, physicians, and other healthcare providers who come in close contact with patients.

Conclusion

Privacy is likely to have an important role in bioethical discussions for some time. The English political philosopher James Fitzjames Stephen wrote in 1873 that "conduct which can be described as indecent is always in one way or another a violation of privacy" (p. 160). These words capture a truth about the broad usage the term *privacy* enjoys in the health field. Patients and those who care about them consider a diverse spectrum of "indecencies," ranging from maltreatment and breach of confidentiality to interference with decision making, as "invasions of privacy." Accordingly, the ethics, law, and politics of privacy have made what may be an indelible mark on the future of healthcare and health research.

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SEE ALSO: *Confidentiality; Privacy and Confidentiality in Research*

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PRIVATE OWNERSHIP OF INVENTIONS

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As a historical matter, the Western tradition of protecting intellectual property has been justified by the argument for rights in tangible property put forth by the English philosopher John Locke (1632–1704): namely, that the individual who adds labor to a natural object should have rights in that object (Gordon). In the United States today, however, intellectual property rights are justified primarily on instrumental economic grounds, as a mechanism for inducing individuals to generate inventions that are expensive to create but easily copied once created. Because intellectual property protection prevents others from copying the invention, the inventor can capture as private value at least some portion of the social value represented by the invention. Although intellectual property encompasses patents, copyrights, and trade secrecy, patents represent the strongest form of intellectual property. Unlike a copyright, a patent protects the underlying idea behind the invention and not simply the particular expression the idea might take. Unlike trade secrecy, which protects only against misappropriation of the invention, patent protection also operates against those who may come up with the invention independently.

Public Funding and the Bayh-Dole Act

The most prominent alternative to intellectual property protection has been public funding. In the United States, public funding of science became particularly robust after World War II. By the turn of the twenty-first century, federal agencies such as the National Institutes of Health (NIH) were funding tens of billions of dollars of basic biomedical research each year. Although some of this research is performed intramurally, most of it is conducted extramurally, in university laboratories.

Until 1980, most federally funded research conducted in universities was put into the public domain. In 1979, for example, universities received only 264 patents (Mowery et al.). This figure has increased dramatically with the passage of the Bayh-Dole Act of 1980, which explicitly encourages university patenting. In 2000, universities received 3,764 patents. The rationale behind Bayh-Dole is not the conventional argument that patents are necessary to induce invention: In the case of federally funded invention, public funding has already provided the necessary invention incentive. Rather, the theory is that patent protection, coupled with exclusive licensing, is necessary to stimulate development of university research into commercially viable products.

As a consequence of Bayh-Dole, and the nearly simultaneous liberalization of patentability standards following the creation of a specialized patent appellate court in 1982, basic, or "upstream," biomedical research has increasingly become the subject of both university and private firm patents. Even when universities or private firms do not seek patents, they often impose proprietary restrictions on transfer of research tools, particularly research tools that are hard to replicate independently (NIH).

Impact of Proprietary Claims

For a number of reasons, these proprietary claims threaten to impede biomedical research. Most obviously, patents or other proprietary claims on upstream discoveries hinder subsequent research by permitting owners to charge a greater than competitive price. This feature of proprietary claims is particularly troubling for biomedical research given that researchers in nonprofit institutions, who are crucial to the progress of research, often cannot afford to pay large licensing fees. Upstream patents may also hinder biomedical research when a single broad patent gives a firm monopoly control over a significant new area of scientific territory. A monopolist is unlikely to see all of the different applications of its broadly enabling patent. One response to this argument, that the profit-seeking owner of a pioneer patent will find it in its interest to license the discovery to as many follow-on improvers as possible, is belied by historical examples in many industries, including the electrical lighting, radio, automobile, and aircraft industries (Merges and Nelson). The transaction costs that arise when people are bargaining under conditions of imperfect information with current or potential scientific and commercial rivals are likely to be quite high (Rai). Transaction costs can also mount quickly when the basic research discoveries necessary for subsequent work are owned not just by one entity but by a number of different entities (Heller and Eisenberg). Notably, because under the patent law an initial broad patent on a pioneering discovery does not preclude a proliferation of upstream patents related to that discovery, the problems of broad patent scope and proliferating patent rights held by multiple owners can arise simultaneously.

Efforts and Arguments against Proprietary Claims

Various private and public sector efforts have attempted to mitigate the negative impact on research of broad and/or numerous proprietary rights. Developments in patent case law suggest, for example, that broad biotechnology patents will be struck down (*Regents of the University of California v. Eli Lilly & Co.*). In addition, federal funding agencies such as the NIH have urged universities to refrain from patenting, or at least licensing exclusively, research tools that are likely to be broadly enabling (NIH). In certain cases, actions by the private and public sector that have put genomic data into the public domain have also preempted the possible proliferation of proprietary rights on that data (SNP Consortium; NHGRI).

Another set of arguments concerns the impact of private ownership of inventions on stakeholders other than researchers. Some have argued that those who contribute the raw material for development of commercially successful inventions should, as a matter of equity, receive some portion of the commercial proceeds that proprietary rights on these inventions provide (Boyle). At a minimum, the sources of the raw material should be informed of the commercial intentions of those who use their material. These arguments have been made on behalf of patients with particular diseases who contribute genetic material for research (Palmer). Similar arguments have also been made on behalf of less-developed nations that are sources of commercially promising biological diversity or traditional knowledge. In the case of less-developed nations, the 1992 Convention on Biological Diversity specifically asserts that genetic resources belong to nation-states as an element of national sovereignty (Rosendal). Various contractual mechanisms are now being used to ensure the sharing of short- and long-term benefits between developed and developing countries (Reid et al.).

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SEE ALSO: *Conflict of Interest; Patenting Organisms and Basic Research; Profit and Commercialism; Technology*

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PROFESSIONAL-PATIENT RELATIONSHIP

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I. Historical Perspectives
II. Sociological Perspectives
III. Ethical Issues

I. HISTORICAL PERSPECTIVES

The following article is a reprint of the first-edition article "Therapeutic Relationship: History of the Relationship" by the same author, with only minor changes.

We give the name "therapeutic relationship" to the link established between an individual (the patient) and another individual or group (the healers), with the aim of curing or relieving the disease suffered by the former. Our problem is to describe as exactly as possible the various forms this relationship has assumed throughout history.

The Empirico-Magical Stage

Ever since records have existed concerning the treatment of the sick, we may distinguish the following four chief forms: (1) the spontaneous or instinctive, (2) the empirical, (3) the magico-religious, and (4) the scientific. In all periods of history, all of these forms have had their practitioners. The mother who holds her feverish child on her lap, embracing it to protect it from the cold air, illustrates the first form, *spontaneous* or *instinctive* help. The second form, *empirical* help, consists in using a remedy because it has provided some relief in similar cases—that is, without asking why the remedy has those particular healing qualities. Medicine owes some very important discoveries to therapeutic empiricism. The treatment of wounds from firearms, discovered by chance by Ambrosio Paré (c. 1510–1590); the introduction of quinine into the Western world; and Edward Jenner's vaccination against smallpox are three superb examples.

Generically speaking, in *magico-religious* treatment both healer and patient believe that the cure is due to the action of "supernatural" or "divine" powers available for the purpose. In some cases the curative effectiveness of these powers depends on "who" uses them (medicine man, shaman, witch doctor, etc.); in others, on "how" they are applied (magic ritual); and in others, upon "where" the cure takes place (in localities "singled out" or "favored" for their healing powers—some shrine, island, or spring).

Since scientific treatment in the strict sense began in Greece in the fifth century B.C., we can definitely state that from the origin of the human race and for many thousand years thereafter, the therapeutic relationship was empirico-magical in character, with either the "empirical" or the "magical" element of the healing process dominant, according to circumstances. It is known that in the most highly developed pre-Hellenic cultures of ancient Egypt, China, and India, a form of medicine existed in which strictly "magical" or magico-religious elements were minor compared with the empirical and theoretical. However, a careful study of these three methods of understanding and practicing the care of the sick would reveal to some extent attitudes of the doctor that can only be called "magical" and that, above all, show a lack of principles capable of initiating a way toward purely "scientific" medicine.

The Ancient Scientific Stage

As Aristotle taught, treatment of the sick is scientific ("technical") in the strictest sense when it depends on the knowledge of why it is being done, what is being done, and by what means it takes effect (in other words, what is the disease, what remedy is being used, and by what therapeutic procedure is it administered). Thus the healer's ability to cure does not depend on the agent who applies the remedy, nor on the ceremony accompanying its application, nor on the privileged place where the cure takes place—that is, not on a magical "who," "how," or "where," but on a series of "whats" concerning the illness and its remedy.

Taking as their starting point the most important cosmological idea of the pre-Socratic philosophers—the idea of *physis,* or "nature"—the group of physicians, the Aesclepiades, known as Hippocratics, originated the technical concept of illness a century before Aristotle formulated the conceptual definitions just mentioned. Consequently, a doctor would try to cure a patient or to alleviate the patient's pain in the rational or scientifically definitive knowledge of the "nature" of humans, of illness in general, of the special disease he was treating, and of the remedy being used—while at the same time having the knowledge and skill to perform everything required by the treatment. This is not to say that Hippocratic medicine—apart from its inevitable deficiencies—was free from some serious errors and superstitious practice but to affirm that it already contained various principles: the notion of *physis* as the basis of all technical knowledge, the concept of medicine as *téchne iatriké,* the idea of a method of knowing whose first rule is the attentive sensory examination of the patient's body—as a result of which defects and errors would be gradually corrected.

From Hippocrates to Galen (A.D. 130?–200?)—while the ancient view of technical medicine remained in force—the therapeutic relationship can be described under four heads.

BASIS OF THE THERAPEUTIC RELATIONSHIP. Ideally considered, this basis is *philanthropia,* the "love of man," because, according to a famous saying, "Where there is love of man, *philanthropia,* there is love of the art [of healing], *philotechnia*" (Hippocrates, *Praeceptiones,* L.IX, 258). Of course, this saying belongs to a later, post-Stoic period; but the study of much earlier medical texts, such as the *Epidemias,* gives grounds for the belief that the Hippocratics, as they were called, practiced *philanthropia* before the word was invented. In any case, the "love of man" of ancient Greece was the same as "love of nature," of the divine *physis,* as is specifically and individually realized in the name given to the subject in question: *physiophilia.* It is not necessary to add that less noble interests, such as love of money and thirst for fame, in practice often obscured this ethical and technical ideal of "physiological philanthropy" as the basis of the therapeutic relationship.

DIAGNOSTIC ASPECT OF THE RELATIONSHIP. As scientific and effective "knowledge" was the first premise of the technical concept of medicine, the therapeutic relationship required—as it has of doctors since—that the Greek physician should reach a diagnosis by rational means. During the period in the history of medicine here called "ancient scientific," this diagnostic activity appears to have consisted of (1) a fourfold desire to discover whether the illness is determined by an insuperable and necessary cause (*kat'ananken*) or by some controllable contingency (*katà tychen*); to identify the typical form (*tropos, eidos*) of the suffering; to determine its causes, both remote and immediate (*aitia, prophasis*); and to establish a well-founded prognosis; (2) a series of exploratory maneuvers (*anamnesis*, study of the surroundings, examination of the patient's body by means of sight, touch, hearing, smell, and taste); and (3) adequate inductive reasoning (*logismos*).

CURATIVE ASPECT OF THE RELATIONSHIP. After some deliberation, the therapeutic activity of the Greek doctor was subjected to the following rules: (1) to help the patient, or at least to do no harm to the patient (Hippocrates, *Epidemias,* I, L.II, 634); (2) to refrain from interfering if the illness were incurable and inevitably mortal, because in that case the doctor, by intervening, would commit the sin of *hybris,* or rebellion against an edict of the divine and sovereign *physis;* and (3) insofar as possible, to attack the cause of the disease therapeutically. Diet, drugs, surgery, and to a lesser degree "psychotherapy" were the four great healing methods of ancient medicine.

ETHICAL AND SOCIAL ASPECTS OF THE THERAPEUTIC RELATIONSHIP. One must avoid the common error of seeing the oath contained in the *Corpus Hippocraticum* as the ethical code of Greek medicine; in all probability it was not in force outside the Pythagorean order (Edelstein). However, it is possible to trace the outline of the medical ethics and social medicine of the ancient Greeks:

1. The doctor's duties to the patient: to help or not to harm, to abstain from the impossible, to adjust the fees to the patient's income.
2. Duties toward other doctors: The ideal principle of regarding colleagues as brothers (Hippocrates, *Praeceptiones,* 4, IX, 258) was very infrequently infringed by the competitiveness of which doctors of antiquity are so often accused (Edelstein).
3. Duties toward self: A doctor should give attention to personal appearance and behave in a manner that would be called "beautiful and good" (Hippocrates, *Medicus,* L, IX, 204). To serve nature through the application of professional skill (Hippocrates, *Epidemias,* I, L.11, 636) should be the physician's paramount principle.
4. Duties to society: Though clearly stated by Plato (*Republic, Laws*), these are given much less importance in strictly medical writings; in any case (Plato, the Hippocratic treatise *On Diet*), it is certain that there was "medicine for the rich" and "medicine for the poor" in the ancient world.

Christianity and the Therapeutic Relationship

The propagation of Christianity was not motivated by the need to reform the conduct of doctor toward patient, insofar as this conduct could be held as technical, but because the medical technique prevailing at the time had been created by pagans. Because the Christian concept of love was relatively new, Christ's religious message influenced both the problem and the form taken by the therapeutic relationship in various ways.

Could the pagan medical technique have been accepted without more ado by Christians? Out of excessively vehement opposition to paganism, some of them—Tatian the Assyrian and Tertullian, for instance—gave a negative answer to this question. But the good sense of others prevailed in the end; and thus, from the fourth century to the increasingly strong anti-Galenism of the sixteenth and seventeenth centuries, the medicine of Christian peoples (e.g., in Byzantium and medieval Europe) showed a progressive intellectual effort to relate the art of healing, inherited from ancient Greece and culminating in the work of Galen, to the Christian worldview.

One can note the novelty of the Christian concept of love and its decisive effect on the form taken by the therapeutic relationship. When this was the direct, pure expression of the evangelical message—in other words, before Constantine's edict led to the primitive Christian communities' becoming involved with the civil power—there were two chief features of its structure.

IDEAL BASIS OF THE THERAPEUTIC RELATIONSHIP. We are no longer facing love of *physis* or universal "nature," as individualized in the sick person; rather, we are confronting his or her unique persona as a "neighbor" (parable of the good Samaritan). Moreover, in helping an ailing neighbor, one is helping Christ (Matt. 25: 39–40).

THE THERAPEUTIC RELATIONSHIP AS HELP. Herein lie the most significant new developments in primitive or pre-Constantinian Christianity.

1. In the assistance given to the sick person there should be no "natural limits," thus putting an end to the Hellenic imperative to refrain from therapy in cases of "necessarily" mortal or incurable disease. Here, although there is no place for therapeutic technique, the patient can always be helped by spiritual advice.
2. The egalitarian nature of treatment: No difference should be made between Greeks and barbarians, free people and slaves, friends and enemies.
3. The necessity of giving free help: Within a community governed by the principle that possessions are shared (see the texts of Acts of the Apostles), the basic motive of help for the sick was charity, not only on the part of the doctor but also on the part of other people (widows acting as nurses and, later, "deaconesses"). The Greek doctor would give free treatment in exchange for some favor received or to acquire prestige in the town (Hippocrates, *Praeceptiones,* L.IX, 258); the Christian doctor should give help free, on principle.

4. Such practices of the Christian religion as prayer and extreme unction were incorporated into the care of the sick.

The Medieval Scientific Stage

After Constantine's Edict of Milan (C.E. 312), the links between Christianity and the civil power became increasingly strong, and this gave rise to public awareness that the Christian life, such as was led outside the new conventual communities, was losing at least some of its original purity. This is shown by a brief examination of the two main politicosocial forms of Christianity, during the historical period that we call the Middle Ages, in the Byzantine Empire and medieval Europe. Exigencies of space allow no more than a mention of the third great cultural ambit of the Middle Ages: the world of Islam.

THERAPEUTIC RELATIONSHIP IN BYZANTIUM. The theocratic fusion between the Christian religion and civil power has never been stronger than in the Byzantine Empire; never has religious error or heresy been more methodically and sternly treated as "political crime." From this are derived the two main characteristics of the therapeutic relationship in Byzantine society: its doctrinal basis and its importance as help. The doctrinal basis of the therapeutic relationship in the Byzantine world was essentially the result of a juxtaposition that never turned out well. On the ethical plane, Byzantine medicine went on accepting and proclaiming the Christian concept of helping the sick; on the technical plane it accepted in principle everything described by the Greeks as "practical," and refused to acknowledge (as pagan and evil) the basic "theoretic" concepts of Hippocratic-Galenic medicine—for example, the notion of *physis* as "divine" and the denial or negation of a personal, spiritual God, creator of the world and transcending it. The doctors of Byzantium did not succeed in connecting the dogmas of their Christian faith with the scientific and philosophic basis of Hellenic *téchne iatriké.*

The most important contribution made by Byzantine Christianity to medical care was the creation of hospitals to treat poor invalids; among them was the famous "hospital city" of Caesarea, founded about the year 370. (Earlier institutions did not strictly deserve the name "hospitals.") In those institutions there were specialists, male and female nurses, surgeons, assistant doctors (*parabalani*), and servants. Charity was the ruling principle in their activity, but that did not prevent the distinction between "medicine for the rich" and "medicine for the poor" from being clearly observed in Byzantium. And finally, we must mention the magical and pseudoreligious cures, which particularly attracted poorer patients.

THE THERAPEUTIC RELATIONSHIP IN MEDIEVAL EUROPE. The historical period we call the Middle Ages covers the millennium between the invasion of Rome by the Germanic races and the conquest of Constantinople by the Turks in 1453, and is far from uniform in character—suffice it to compare the life in a feudal castle in the ninth century with that of a Flemish or Italian town in the fifteenth. It is shown also by the gradual changes in the therapeutic relationship throughout this period.

Doctrinal basis of the therapeutic relationship. Two chief aspects must be distinguished—the technical and the ethical. Until the School of Salerno became famous (in the eleventh and twelfth centuries) and the Scholastic medicine of the thirteenth to fifteenth centuries was flourishing, medieval medicine hardly deserves the term *technical* or *scientific* in the strict sense. Mainly practiced by monks ("monastic medicine") either inside or outside monasteries, it was based solely on a certain amount of experience and the extremely scanty remains of ancient learning that had survived the destruction of the Roman Empire.

There was a marked change at the beginning of the twelfth century: Secular doctors with professional degrees became more common; from the time of Roger of Sicily in 1140, Greco-Arab learning began to spread from Salerno, or from Toledo, and became truly "technical" medicine, an authentic *ars medica.* By means of the intellectual resources provided by the theology and philosophy of the period, the Scholastic European doctors of the thirteenth and fourteenth centuries achieved something not attained by Byzantine medicine; they systematically adapted Hippocratic and Galenic thought to the needs of the Christian faith.

From the ethical point of view, medieval medicine continued to base itself ideally on the Christian concept of aid for the needy and sick—ideally because in practice the pressure of economic interest was not uncommon, nor, sometimes, free from corruption.

Diagnostic aspect of the therapeutic relationship. Though it had become impoverished and schematized in comparison with that of ancient Greece, the diagnostic relationship between doctor and patient—examination and establishment of "genus" and "species" of the affliction observed—remained much the same. Two techniques gained prominence and were gradually perfected: examination of the urine (*uroscopia*) and taking of the pulse. There were also two doctrinal guidelines to help the doctor pass from clinical experience to reasoning, treatises that systematically described the different species of disease (*de passionibus, de* *affectionibus*) and the didactic descriptions of individual cases of disease (*consilia*).

Curative aspect of the therapeutic relationship. From a technical standpoint the Middle Ages added little that was new to the treatment of the sick as taught by Greek and Arab doctors. Diet, the use of drugs, surgery, and "psychotherapy"—with a Christian orientation— remained the principal methods of treatment. As to theory, the chief concept of Galenic therapy, the "symptom" (*endeixis*), became latinized and scholasticized under the name of *insinuatio agendi.* On the other hand, the problem arose of how to harmonize "technical" requirements derived from the Galenic concept of symptoms with the "moral" rules imposed by the Christian idea of the person: the bond between *ars* and *caritas.* However, medieval physicians did not succeed in solving this delicate human problem coherently or systematically.

Ethical and social aspects of the therapeutic relationship. As to principles and ideals, medieval medical ethics are as faithfully Christian as the society to which they belong; but individual and social realization of this sincere Christianity was very different from that prevailing in pre-Constantine communities. Four reasons contribute to this:

1. The avarice of many clerical and secular doctors: "Doctor, do not be afraid of asking good fees from the rich," wrote Lanfranc in the eleventh century.
2. The growing interference of the civil power in regulating doctors' duties by means of ordinances—relating not only to the healer's technical behavior but also sometimes to his religious conduct—infringement of which was punished.
3. The frequent critico-burlesque attitude of society toward the doctor's greed for gain or lack of skill (John of Salisbury's *Metalogicus* and Petrarch's *Invectivae*).
4. The marked difference between "medicine for the rich" and "medicine for the poor"—in monasteries, the distance separating the *infirmarium* from the *hospitale pauperum*; in cities, the even greater gap between the treatment of those in power—politicians or churchmen, nearly all of whom had their own private doctors—and the almost purely religious treatment given to the unfortunates in hospital beds. Not everything in the Christian Middle Ages was in fact Christian.

Modern Scientific Stage: Christian Modernity

It is a platitude to say that the "modern world" began with the Renaissance or even in the fifteenth century. However, a thorough study of the various characteristics of this modernity—greater knowledge of classical antiquity, importance of worldly matters, new conceptions of science, rationalization of life, awareness of historical progress—clearly shows the roots of all these developments to be present in the transition from the thirteenth to the fourteenth century, when the voluntarism and nominalism of Franciscan thought (e.g., William of Occam, 1285?–1349?) began to influence European culture. When human freedom (and hence human creative ability) was seen as a person's chief similarity to God, the idea of "natural" and "necessary" limitations to human scientific and technical capacity with regard to the cosmos disappeared in principle, and the human mind began to entertain the idea of "indefinite progress." Science and modern techniques took their first steps, in the belief that knowledge of the sensible world consisted in creating abstract symbols—they would soon be called mathematical symbols—by means of which the external world could be understood and dominated. Many years had to pass, however, for these germinal concepts to be converted into strong, widespread social customs. Only in the secularized society of the eighteenth through the twentieth century would a great tree grow from the tiny seed of the fourteenth century.

Two periods must be distinguished in the history of the modern Euro-American world: In the first, from the fifteenth to the second half of the eighteenth century, by far the largest proportion of society was still nominally Christian, although the form of religion, whether Catholic or Protestant, was growing away from that of the Middle Ages; in the second, the nineteenth and twentieth centuries, society was becoming secularized.

BASIS OF THE THERAPEUTIC RELATIONSHIP. Whether Catholic or Protestant, modern Christian doctors still saw the injunction to give charitable help to those in need as the basic ideal of healing activity: They thought of Theophrastus Paracelsus, they remembered the ritual oath taken by newly graduated French doctors in front of the altar of Notre Dame. But the diversity of religions in Europe and America, and the growing esteem both for the reality of worldly values and for increasing civil power, led to two new features in this ideal: (1) greater respect for the personal religious life of the patient; and (2) an increasing and sharper separation between the spiritual and material worlds, the latter being known and governed by the beginnings of modern science and the technology founded upon it. Two examples of this spiritual–material separation will suffice: Hermann Boerhaave's teaching of the distinction between the mind and the body (*De distinctione mentis a corpore*) and Friedrich

Hoffmann's significant anthropological contrast between the physical (*cor corporale*) and the spiritual (*cor spirituale*).

DIAGNOSTIC ASPECT OF THE THERAPEUTIC RELATIONSHIP. The principle of understanding nature in order to master it (Francis Bacon, René Descartes) gained strength in modern society and led to the physician's concern to make diagnoses that were objectively correct. Very briefly, the following are the chief characteristics of the diagnostic aspect of the therapeutic relationship during this period:

1. Understanding of the disease being treated became more individualized, as was very clear in the form taken by case histories (Giovanni Battista Montanus, Boerhaave, etc.).
2. Numerical measurement gradually began to figure in examinations, leading to the first use of instruments such as watches and thermometers.
3. Diagnosis was increasingly used to guess at the existence of an anatomic lesion, which could be proved by an autopsy (Giovanni Maria Lancisi and Hippolyte Albertini, Hermann Boerhaave, Giovanni Battista Morgagni).
4. A more lively and objective interest was evinced in the influence of the social environment on the disease (Paracelsus, Bernardino Ramazzini, Johann Peter Frank).

CURATIVE ASPECT OF THE RELATIONSHIP. The spread and strength of the modern scientific mentality required a doctor who wished to keep up with the times to validate by experimentation the efficacy of the available remedies. On the other hand, awareness of human power over natural phenomena demanded a constant increase in the number and curative scope of those remedies. Paracelsus thought that every natural substance could be an efficacious medicament, if convenient means of using it could be discovered; God had disposed the world thus when it was created, and this the inquiring and inventive intelligence of the doctor should be able to make plain. Consequently, doctors no longer saw themselves as "servants of nature by means of their skill," as in ancient Greece but also during the Middle Ages in a Christian interpretation of the words as the true "collaborators of God." Whether Paracelsists or not, the most eminent doctors of the fifteenth to eighteenth centuries made use more or less consciously of this concept of therapeutic activity. But at the same time there was increasing distrust of the healing qualities assumed to belong to many of the remedies traditional practice had recommended.

The main therapeutic methods were still the four employed in Hippocratic medicine: diet (adapted to new ways of life), cure by drugs (enriched by various new medicines), surgery (whose technique had advanced considerably, from Ambrosio Paré to William Cheselden, Percival Pott, and Hunter), and, on a distinctly lower plane, psychotherapy, whose later triumph was unconsciously heralded by Franz Anton Mesmer at the end of the eighteenth century. The separation of healers into "doctors" (or "physicians") and "surgeons" was daily becoming more clear.

ETHICAL AND SOCIAL ASPECTS OF THE PROFESSIONAL-PATIENT RELATIONSHIP. Since both doctor and patient were Christians, it was natural for doctors to find their ethical principles in those of the Christian life; but at the same time, since the creation and rational order of the world had gained greater stature as explanations of the world, it was also natural for the form in which these principles were individually and socially realized to change to some extent. There should have been, and indeed there was, a relationship between religion and medicine that was both theoretical and practical. As religion was concerned with the life of the spirit and medicine with the life of the body (or what human knowledge tells us about the cosmos), the scientist and the physician did their best to discover and establish points of direct communication between those two worlds. In regard to theory, such communication was guaranteed by the "harmony" between Holy Writ and science, for example, in Francisco Valles's *Sacra philosophia* (sixteenth century) and Friedrich Hoffmann's *Dissertatio theologico-medica* (eighteenth century). Naturally, such communication and the bridge establishing it had to take a different form on the practical level. There the communication gave rise to "medical deontology," a collection of ethical precepts that were to be respected in the healer's technical activity. Examples of both early and mature forms of them are found in certain parts of the *Quaestiones medico-legales* of Paulo Zacchia (1621–1635) and the *Embriologia sacra* of Francesco Emmanuel Cangiamilla (1758).

Between the fifteenth and the seventeenth centuries, and therefore during the ancien régime, the bourgeois structure of society in Europe and America was being developed, and three distinct strata began to emerge: the "upper classes" (aristocrats, magnates of church and state, rich merchants), the "middle classes" (artisans, officials, and members of various professions), and the "lower classes" (laborers, the poor). Parallel strata could be observed in medical care. Ill persons of the upper classes were looked after in their luxurious homes and had a monopoly on more expensive treatments (one need only think of the distribution of quinine in the seventeenth century). The lower classes still went to hospitals for the poor, although during the eighteenth century those were altered or completely rebuilt on a larger scale. But the care of the sick inside those hospitals was far from acceptable (as to dirt, parasites, smell), as can be seen from denunciations by some socially and philanthropically sensitive doctors, like James René Tenon in 1788 and Howard in 1789. Nor was the medical care of the middle classes entirely satisfactory.

Modern Scientific Stage: Secularized Modernity

The process of secularizing society advanced at progressive speed during the nineteenth and twentieth centuries. Certainly there were still many Christians in the cities of Europe and America, but their individual and social style of living, their habits, were affected by this secularization; and it was in the eighteenth century that distinct groups came to be known as “intellectuals” and “aristocrats,” and later (from the second half of the nineteenth century) a class came to be known as “proletarian.”

Combined with this increasing secularization of behavior, we find that in the nineteenth century, life was becoming more technical, and in consequence of the industrial revolution an urban proletariat made its appearance. Submissive at first, the proletariat afterward organized itself as the “workers’ movement” and asserted its rights more effectively, so that in one way or another it has decisively contributed to shaping the social scene of the twentieth century. How was the therapeutic relationship to be interpreted in this secularized world, part bourgeois, part proletarian?

DOCTRINAL BASIS OF THE RELATIONSHIP. As had been the case ever since Hippocratic medicine, the doctrinal basis of this relationship had two essential aspects, one ethical, the other scientific or technical. First, from an ethical standpoint, the ideal motive of medical care of the sick was “philanthropy,” the feelings and the rules of conduct in which Christian charity was secularized. But modern philanthropy was radically different from the Hippocratic form (which had as its ultimate goal the divine *physis,* or universal nature), in that it was concerned with the “individual persona” of the patient—although the doctor’s theory of humanity might not be formally “personalist.” During the nineteenth and twentieth centuries many doctors have been “naturalist” in theory (in their scientific concept of human nature) and “personalist” in practice (in their therapeutic relation with the patient). Not until Marxist socialism did there appear a philanthropy based on the notions of “social or civil nature” and “state of nature.” Second, from a scientific point of view, the ideal basis of medical care was the concept of medicine as the application of pure natural science. “Medicine should be natural science—in other words, what the second half of the nineteenth century understood as natural science—or it will be nothing” was the oracular saying of Hermann Helmholtz. The sick person was *scientifically* considered as a fragment of the cosmos, acted on by biological evolution and governed by the laws of physics and chemistry. Scientifically, because in practice nearly all doctors obeyed the rule of Joseph Frédéric Bérard and Gluber: *Guérir parfois, soulager souvent, consoler toujours* (heal sometimes, relieve often, always console). This does not, of course, preclude the usual corruption of the medical profession—desire for gain, thirst for social prestige—often contaminating that philanthropic and scientific ideal.

DIAGNOSTIC ASPECT OF THE RELATIONSHIP. The diagnostic relationship with the patient now conformed to the following principles:

1. The patient was seen, above all, as an individual, capable of being rationally understood.
2. This understanding was increased by means of the instrumental aids to clinical examination (stethoscope, sphygmograph, ophthalmoscope, chemical analysis, X rays, etc.).
3. The disease was scientifically understood by applying rules that were anatomoclinical (diagnosis of anatomical lesions), physiopathological (diagnosis of disorders typical of the functional and material processes of life), or etiopathological (diagnosis of external causes, microbes, poison, etc., of the disease process); or the doctor could try to coordinate these three approaches.
4. Neurosis, whose frequency increased from the second half of the nineteenth century as a result of industrial civilization, was understood by natural scientific medicine by reference to anatomoclinical (Jean-Martin Charcot) or physiopathological rules (German practice since Friedrich Frerichs and Ludwig Traube).
5. To sum up, the diagnosis was, or tried to be, *at the same time* natural-scientific and individualist.

CURATIVE ASPECT OF THE RELATIONSHIP. When medicine was considered as applied natural science, the doctor’s powers of healing (by experimental pharmacology, surgery enhanced by the development of anesthesia and antisepsis, synthesis of new drugs, serum therapy, vaccination, etc.) were progressively and wonderfully increased. Moreover, giving broad social expression to what was merely a slight and theoretical germ at the end of the thirteenth century and the beginning of the fourteenth, doctors freed themselves from the Hellenic concept of “natural force” (*ananke physeos*) and began to think of humans as not being, in principle, subject to diseases that were mortal or incurable “of necessity.” What could not be cured today might well be curable tomorrow. In fact, the doctor ceased being “the servant of nature by means of skill” and became instead nature’s “guardian, master, and sculptor.”

Alongside dietetics, now scientifically regulated, increasingly rich therapy by drugs, and increasingly effective surgery, the psychotherapeutic element in treatment was acquiring more importance through several different methods and interpretations. In the history of this renewed importance of psychotherapy, the most distinguished names are those of the Englishmen Daniel Tuke, Alfred John Carpenter, and Hughes Bennet; the Frenchmen Jean-Martin Charcot and Bernheim; and, above all, Sigmund Freud, whose work had already reached maturity at the start of World War I in 1914.

ETHICAL AND SOCIAL ASPECTS OF THE RELATIONSHIP. Something has already been said about medical ethics in the society of the nineteenth and twentieth centuries. Like the society to which it belonged, this ethics became more secular, as is shown by the attempts to codify it, beginning with Percival’s in 1803. From an ethical and social point of view, medical care was a service purchased at different prices or given free to the poor in hospitals supported by charity and inspired by the new philanthropy. The poor received medical care as a gift.

The sick were cared for in three different ambits.

1. *Hospitals* were supported by charity, the state, the municipality, or the church. Here the patient was one of two things in relation to the doctor: either an object that could be scientifically understood and modified, combined with a human being who was unknown and indifferent (if the doctor was a cold and matter-of-fact person), or an object that could be scientifically understood and modified, combined with a person suffering and in need of compassion (if the doctor was a person of feeling and carried out the rule of Bérard and Gluber).
2. *The patient’s own home.* The patient visited at home was an object that could be scientifically understood and modified, combined with a well-known person—a friend.
3. *The doctor’s private consulting room.* Here the patient was, according to circumstances, an object that could be scientifically understood and modified, combined with a person to whom the therapist was indifferent (purely “scientific” doctors); an object that could be understood and modified, combined with a person who paid the fee asked (doctors dominated by desire for gain); or an object that could be understood and modified, combined with a friend in need of compassion (generous, sympathetic doctors).

These three ambits, with certain exceptions, correspond to the three strata into which the bourgeois and proletarian society of the age are divided, and to the three socioeconomic methods of providing medical care: “medicine for the rich” (private consulting rooms for specialists), “medicine for the middle classes” (attendance in their homes), and “medicine for the poor and proletarians” (charitable hospitals). The injustice of this social organization of medicine becomes flagrant and untenable when the proletariat becomes conscious of its right to health and proper medical care, and when, one may add, medical treatment is both efficient and expensive.

Since the second half of the nineteenth century there has been a visible rebellion against this injustice with its politicosocial and clinical aspects. Since Turner Thackrah in 1831, Sir Edwin Chadwick in 1842, and Louis René Villermé in 1840, some doctors have denounced the terrible effects of industrial poverty on health; and workers’ movements have included the right to put an end to this painful and unjustifiable situation in their programs for social reform. The great vogue of Friendly Societies in the United Kingdom between 1800 and 1875, the institution of the *zemstvo* system in tsarist Russia in 1867 after the liberation of the serfs, and the creation of *Krankenkassen* in Germany by Otto von Bismarck (1882–1884) are examples of the first medical results of the proletarian rebellion.

Among the clinical results of this rebellion may be counted the increase in neurotic forms of illness, which in some cases were direct consequences of social injustice and maladjustment. The “introduction of the subject in medicine” (von Weizsäcker’s term), that is, the methodical study of the patient as an individual, both in diagnosis and treatment (penetration of hospitals by Freudian psychoanalysis and psychosomatic medicine) and in social pathology and medical sociology (Grotjahn and various English authors), constitutes the response of scientific medicine to the clinical rebellion of the sick against the medical care of the nineteenth century.

To the layperson as well as to the doctor of today, the present period begins with World War I. From that point on, the historian of yesterday must defer to the chronicler of the present day.

PEDRO LAÍN ENTRALGO (1995)
TRANSLATED BY FRANCES PARTRIDGE

SEE ALSO: *Beneficence; Care; Compassionate Love; Confidentiality; Healing; Hospital, Medieval and Renaissance History; Information Disclosure, Ethical Issues of; Informed Consent: History of Informed Consent; Medical Ethics, History of Europe; Medicine, Anthropology of; Medicine, Art of; Medicine, Philosophy of; Medicine, Profession of; Medicine, Sociology of; Nursing, Profession of; Trust; Virtue and Character;* and other *Professional-Patient Relationship* subentries

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II. SOCIOLOGICAL PERSPECTIVES

The purposes of this article are to provide a sociological perspective of the doctor–patient relationship by sketching the models of it as they have been developed by sociology, and to summarize contemporary sociological analysis. Both are essential for understanding the issues surrounding the therapeutic relationship today.

No other aspect of medicine has attracted more sociological analysis than the medical professional–patient relationship. From a classic view of the relation between doctor and patient “as a pure person-to-person relation” (Sigerist), the full range of psychosocial and sociocultural influences has been studied. Many of the most distinguished sociologists have used this particular problem to illustrate theories of the field. At the same time, the changing facts of technology, organization, and cost were charted as the necessary context for understanding the changes in professional–patient encounters.

There are also distinctive regional-cultural interpretations of the therapeutic relationship. European sociologists consistently have emphasized the significance of power (Foucault). This perspective makes the human body, and hence the patient, the passive recipient of pathology, and sees the professional as an agent of the state (Rosen). David Armstrong, a British medical sociologist, has pointed out that in Britain, not until about 1970 was the importance of the “inherently problematic … [aspects of the] … doctor–patient relationship” recognized (Armstrong; Interdepartmental Committee on Medical Schools). Not until the Todd Report was history taking described as “a great deal more … than simply asking a series of prescribed questions and checking the accuracy of the answers” (Great Britain). Essentially, Foucault viewed the clinical examination as a technique of surveillance. Beginning in the eighteenth century, such surveillance invoked a disciplinary power and required that the body (and hence the patient) be a discrete (passive) object. The change signaled by the Todd Report suggests “the beginnings of the fabrication of patient subjectivity” or, more simply, the activation of the patient (Armstrong).

Americans, on the other hand, have been preoccupied largely with the analysis of medicine as a profession, placing emphasis upon the role of the physician as a professional with resultant claims to autonomy and dominance (Freidson, 1970b). Initially, this perspective placed the patient in a primarily passive role. The American approach, however, has been to construct models that separate each role according to its structure—its reciprocal privileges and obligations—and its function for the society, defining the doctor as the legitimizer of illness and thereby the agent of social control, and the patient as an involuntary deviant who is allowed temporary exemptions from normal social expectations but is required to resume his or her place as soon as possible. Americans have assumed that within the framework of cultural expectations, behavior in these roles is voluntary. Europeans have directed their concern mainly to questions about how the rights and obligations of doctor and patient are inherent and controlled by the state.

These distinctive frames of reference for the analysis of medical relationships are reflected in very different systems for the delivery of health care. European nations, in both financing and service organization, have constructed systems that provide universal access to healthcare. Whether by a government-run national health service (the British model) or by national health insurance (the government guarantees the payment of fees for service by an essentially independent profession), the goal is to provide healthcare as a fundamental right for all citizens. The United States, virtually alone among modern industrialized nations—South Africa is its only companion state—has not guaranteed this right for the sick nor established the obligations of the caregiver, choosing instead to rely primarily on an implicit contract between the medical profession and the society. The latter arrangement, on the premises of individualism, claims that the doctor–patient relationship is sacred, based on the privileges of the professional to autonomy and the patient's right to choose his or her doctor. The alternative approach is based on the premise that in the therapeutic relationship, the behavior of the individuals—and their rights—depends upon social controls vested in the state. "Models," the Americans choose to call their explanations, signifying the fullness and reciprocity of the interaction between doctor and patient.

However, the intellectual distance between the continents has steadily grown smaller. When one traces the full history, the American and European interpretations can be seen gradually to converge. The starting point is in the 1930s, with all the major theories of sociological thought applied to the therapeutic relationship. Although the healing art is older than—and practiced by others than—the physician, the doctor's role has been the centerpiece. Other helping roles—the nurse, social worker, and various "allied health professionals"—have received attention (Aiken), but historically it is the therapist as a professional in modern society who has most interested the sociologist, and medicine is seen as the archetypal profession.

The result has been a changing portrait of both doctor and patient—from a dominantly psychological perspective to a sharp turn when Talcott Parsons introduced the social-system frame of reference (Parsons), shifting the analysis to the social roles of therapist and client, instilled in each individual by agents of socialization like the family and schools. The idea was that the qualities of patienthood were part of social development. We learn what to expect of physicians and how to behave as patients. Such roles were interpreted as "functional" components fashioned to maintain the society. Within this framework, the doctor's achieved high level of expertise is described as essential to modern scientific healthcare, and as a consequence, medical education is spotlighted. The medical school is seen as the principal source of attitudes and values as well as of training in skills and knowledge. That approach enhances the physician's image of awesome technological accomplishment and heroic personal attributes, while the patient is relegated to a subordinate, fragile state in which the only requirements are to be motivated to get well and to consult the physician toward that end.

The reaction to this approach, beginning in the 1960s, changed the role images dramatically: Complex bureaucratic forces were elevated to predominance over the voluntaristic choices of individuals (Starr). The "monopoly of dominance" replaced "technological achievement" as the more popular view of the doctor; the patient came to be viewed as "exploited" by the physician as much as or more than he or she was victimized by the primarily organic forces of illness. The doctor and patient became antagonists, each from a separate world, and their adversarial relationship was described as a "clash of perspectives" instead of a balanced, interdependent system.

In this changing approach, sociological thought has run parallel to the public's attitude toward the medical profession. The sociologists' picture of the physician, at first cautious and respectful, reflected the peak of public prestige and trust that allocated to doctors the privilege of virtually complete autonomy as "high priests in the temples of science" (Churchill). That pedestal was not an easy resting place, however. Physicians became the objects of public exhortation, government regulation, and legal attack.

The implications of the ethical standards by which physicians are judged are profound. After centuries of struggle to win the right to take risks, under conditions of uncertainty (Sigerist; Fox, 1957), in the "best interests of their patients," doctors now find themselves confronted by a fresh demand for accountability. The responsibility that was once assumed in trust is increasingly subject to the formal controls either of state-run systems or of various forms of peer review and medical audit. The added pressure of changing definitions of both the onset of life and its termination, stimulated by new technologies, has intensified the challenge to social values (Fox, 1979).

The therapeutic relationship is also responding to changes in the age profile, particularly of the populations of the United States and other modern industrial nations, and altered patterns of illness and disability. The challenge for physicians increasingly has become less a matter of cure and more of maintaining function (Mechanic, 1985).

At the same time, the sciences basic to medical practice—represented by modern molecular biology, genetics, and the neurosciences, together with computer-related technologies—have produced what has been called a "paradigmatic leap" that must profoundly affect the basic human relations of medical practice (Marston and Jones). As medical knowledge and technology have expanded, public expectations of physicians' expertise and caring have become higher than ever before, complicated by patient needs for a more active, sharing role in therapy.

The development of sociological interpretation of the therapeutic relationship must be viewed as an expansion rather than a linear growth. It is not possible to say that the models have emerged successively, each more valid than its predecessor. The theories represented are still hypothetical. We present them in historical order.

The System Model

FUNCTIONALISM. As applied to both biology and sociology, functional theory proposes that the relationships between the basic elements, whether chemical and physiological or social roles and institutions, are arranged in systems rather than as sums of their parts. Also basic in this conception is that the system is inherently driven toward equilibrium, a homeostatic balance that is reasserted whenever an intervention or change occurs. This dynamic toward balance and stability is the source of the term *functionalism.* It is assumed that living processes, including but not limited to the social, are dominated by relationships that function to maintain or reassert stability to the whole. Thus the terms *system, function,* and *equilibrium* are often used interchangeably: Functionalist theory is system theory.

Although not the first functionalist in social thought, Lawrence J. Henderson pioneered the application of an equilibrium model to the doctor–patient relationship (Henderson, 1935). This he did only in midcareer, after having established himself as an outstanding biological scientist by translating Willard Gibbs's model of physicochemical systems for use in the study of blood physiology. Known as the formulator of the acid-base equilibrium, he applied his functional model with simultaneous equations to explain the quantitative relationship of eight variables of the blood.

Functionalism in physics, chemistry, and biology replaced the linear, cause-and-effect positivism dominant in the nineteenth century. The introduction of this theoretical framework and its mathematical proofs had produced revolutionary effects in biology, and Henderson believed they would be duplicated in social science. The essence of his reasoning was expressed as follows:

> Because every factor interacts in a social system, because everything, every property, every relation, is therefore in a state of mutual dependence with everything else, ordinary cause-and-effect analysis of events is rarely possible. In fact, it must be regarded as one of the two great sources of error in sociological work (Henderson, 1970, p. 29).

Henderson's application of the functionalist model to social systems produced a limited conception, and his model was mechanical and simplistic. As a result, his achievement in social science was mainly that of the seminal teacher: to inspire and challenge colleagues and students to take his model further.

Henderson's was soon followed by other interpretations of the social-system model. Illustrations and applications of the theory were drawn from all the major social institutions, especially the industrial and educational, but the doctor–patient relationship remained important. The major functional analysts of the therapeutic relationship, their illustrative examples, and their special contributions to knowledge are listed in Table 1.

Talcott Parsons, more than any other, carried forward the discussion of the doctor–patient relationship as a social system, giving it full expression as part of sociological theory. He argued that human social relationships can be described as patterns rooted in cultural expectation about the social roles of group members; that the fundamental process of behavior is communication; and that the integrity of the system is maintained by homeostasis, defined as a dynamic force that reacts to any change or intervention by reasserting a balance in the system that enables it to perform its intended function.

Parsons conceived of the doctor–patient relationship as a social-role interaction in which the sick role is voluntary; for instance, a person can be ill—say, with a cold—but choose not to be "sick," a status that invokes privileges and obligations determined by the cultural expectations of the society. The sick role is a form of social deviance that must be controlled to prevent the abuse of the dependency of illness. The professional role combines healing the patient and social control as the agent of the society. Accordingly, the sick role is temporary, undesirable, and socially disruptive. The professional is a technical expert who legitimizes the claim to illness and is responsible for returning the sick person to his or her normal role in society.

Criticisms of Parsons's views are of two distinct types. One is intellectual, challenging his theoretical premises and argument (Freidson, 1970a). The other is political, interpreting the work of both Henderson and Parsons as a conservative political response to the historical events of the early 1930s, particularly the Great Depression and the rise of communism (Gouldner).

The theoretical criticism of the model focuses on Parsons's emphasis on the asymmetry of the therapeutic situation—that is, the professional dominance versus the client's dependence—and in the distancing effect of that asymmetry. Parsons is interpreted as a defender of the technical elitism of the modern physician. His patients must be "controlled," lest they take advantage of the privileges of the sick role to prolong dependency; his physicians must be "protected" from emotional overinvolvement with their patients. The consequences, the criticism asserts, are not just to explain a role asymmetry based upon the achieved technical expertise of the professional, but also to categorize and label the roles so that the passive, dependent patient and the expert doctor become hardened stereotypes.

The continuous development of functionalist interpretations of the therapeutic relationship was broken abruptly

TABLE 1

Functional Models of the Doctor–Patient Relationship, Illustrative Cases, and Effects on the Field, 1930–1965

Models	*Illustrative Examples*	*Effects on the Field*
Lawrence J. Henderson 1935	Cancer patient: socioemotional determinants of system process	Established legitimacy of medical relationship as a subject of scientific inquiry
Talcott Parsons 1951	Institutional case: the profession a social system	Contributed to general theory of social behavior
Florence Kluckhohn, John Spiegel 1954	Psychiatric patients, studied according to cultural value orientation	Contributed to general theory of behavior, combining sociological with psychoanalytic concepts: transactional theory
William Caudill 1958	The hospitalized mental patient	Applied social-system theory to analysis of mental hospital; conceived hospital as a functional social system
Thomas Szasz, Marc Hollender 1956	Acute, ambulatory, and chronic diseases, to illustrate behavioral implication of biological symptoms	Operationalized role theory in medical terms; articulated system theory for education of physicians and to improve clinical practice
Michael Balint 1957	Ambulatory patient of general practitioner	Expanded biomedical model (in Great Britain) to include socioemotional; broke down mind-body dualism.
Samuel W. Bloom 1963	Diabetes, mental illness, and multiproblem patient to illustrate sociocultural determinants	Applied functional theory to health care in historical/ developmental terms
Kenneth Arrow 1963	The medical-care market	Adapted Pareto to general economic theory by conceptualizing optimum equilibrium as a theorem of competitive systems
Edward Suchman 1965	A population of “seriously ill” patients: a survey	Operationalized social-system explanation of health-services utilization

SOURCE: Adapted from Bloom and Speedling, 1989, p. 115.

in the 1960s with the appearance of studies that emphasized the structural, situational determinants and directly challenged the validity of the functional.

STRUCTURAL CONFLICT THEORY. Eliot Freidson is the major spokesman for the application of the structural conflict theory to the professional–patient relationship. The therapeutic interaction, he argued, is most effectively analyzed as a clash of perspectives. “The professional expects patients to accept what he recommends on his terms; patients seek services in their own terms. In that each seeks to gain his own terms, there is conflict” (Freidson, 1961, p. 171). The patient, in this formulation, is assumed to be governed by an interpersonal order equal in complexity to that of the professional. The asymmetry of Parsons’s model underscoring the physician’s technical expertise is discarded. The patient responds largely on the basis of current experience and sources of influence, not as a result of deeply embedded beliefs and expectation derived from long-term cultural socialization. Between doctor and patient, negotiation, not persuasion, occurs. The critical factor is structure, not function—the structural social positions based on the separate statuses and interests of the client and the professional. The deviance of the sick role, within this framework, becomes more central and more complex than in Parsons. A distinctive influence is assigned to stigma. For example, mental illness and sexually transmitted diseases, Freidson argues, are perceived by society on a variable scale of deviance and stigmatized accordingly; they are not lumped together as diseases that are beyond the control of the patient.

Freidson's critique of Parsons was very specific. First, the Parsons model sees the doctor–patient relationship from too limited a perspective, most essentially that of the physician; it does not pay attention to the varying expectations of all members of the "role-set," including the patients (or, more inclusively, their lay associates as well) and the nurses and other persons involved in the process of treatment. Second, expectations are presented by Parsons as though they are the primary influence on actual behavior; they are only an ideal standard against which actual behavior is judged. Third, influence does not inhere in the expectation but in the position of the person holding it; only from the structure of the situation and the limits imposed by it can one weigh the possibility of an expectation's being met. Fourth and most important, the functional model ignores the necessity of conflict in human relationships. Insofar as each person, the professional and the patient, seeks to gain his or her own terms from the other, there is conflict.

This approach spawned a succession of studies about the therapeutic situation. The major examples are listed in Table 2. Through these studies, the view of the patient was transformed. Fully equal to the physician, the patient might behave passively, influenced either by personality or by the structure of the situation. Nevertheless, the patient role was no longer inherently subordinate by virtue of the physician's technical expertise or of the patient's lack of adequate knowledge.

Neo-Marxism, Bureaucracy, and the Politics of Health

The high point of structural conflict theory occurred with the 1970 publication by Freidson of the second of his two books about the medical profession. Marxist critiques followed by Howard Waitzkin and Barbara Waterman in 1974 and by Vicente Navarro in 1975.

The new Marxism built its argument on the classic conception that social behavior is essentially organized according to principles of social stratification or social class, based on materialistic determinants, and inevitably dominated by one class, leading to monopolistic control of resources and markets by the dominant class and to the exploitation of subordinate groups for profit or gain of the more powerful class. Waitzkin illustrated what he called the "micropolitics" of the doctor–patient relationship, using the following types of cases: (1) a young worker with occupationally caused sterility; (2) neonatal death attributable to neglect caused by poverty and racial discrimination; (3) an elderly man burdened by costs of technically oriented medicine. Waitzkin analyzed more than 300 taped doctor–patient interviews in an effort to demonstrate that medicine, like other social institutions, functions as part of the "ideologic state apparatus," with the doctor as the agent of ideology and social control. The micropolitics of the doctor–patient relationship, he argued, revealed contradictions that no current political system resolves (Waitzkin).

The boundaries between this view and that of the earlier structuralists were not as sharp as the demarcations with functionalism. Nevertheless, there are important differences. In Freidson, for example, there is no hint of patient exploitation. Nor does the drive among doctors for "professional autonomy and dominance," as described by the structuralists, mean anything similar to the Marxist description of the physician as a self-interested manager of health resources. What neo-Marxists like Waitzkin added to forecast subsequent trends was the analysis of how both doctor and patient have become captives of monopolistic trends in the healthcare industries.

The focus of the 1980s was on the same monopolistic big business, but with a different interpretation. Paul Starr (1982), for example, argued that rational behavior leads to large-scale privatization and the absorption of healthcare into the marketplace. He described the corporatization of the healthcare system of the United States in five dimensions:

1. Change in the type of ownership and control, shifting from nonprofit and governmental service organizations, especially hospitals, to for-profit healthcare companies.
2. Horizontal integration, the decline of freestanding institutions and the consequent shift in the locus of control from community boards to regional and national healthcare corporations.
3. Diversification and corporate restructuring, the shift from single-unit organizations operating in one market to conglomerates involved in a variety of healthcare markets.
4. Vertical integration, the shift from a single level of care organizations, like acute-care hospitals, to organizations that embrace the various phases and levels of care, such as health maintenance organizations (HMOs).
5. Industry concentration, the increasing concentration of control of health services in regional markets and the nation as a whole.

The implications of these trends, it was argued, are to depersonalize the therapeutic relationship and to change the nature of the social roles. The doctor, increasingly a salaried

TABLE 2

Models of the Doctor–Patient Relationship, Their Illustrative Cases, and Effects on the Field: Structuralism (Conflict Theory, Labeling), 1960–1975

Models	*Illustrative Examples*	*Effects on the Field*
Erwin Goffman 1961	Hospitalized mental patients	General theory of structured deviance; labeling; social stigma. Concepts: total institution, moral career of patients
Eliot Freidson 1961, 1970b	Health-care institutions; HMOs; the medical profession	General theory of conflict behavior determined by situational factors; clash of perspectives mediated by negotiation; professional autonomy and monopoly; patient networks
David Mechanic 1962	Illness behavior in various contexts	A multivariate theory: synthesized social psychological with situational variables; designed to operationalize for research; problem-oriented. Based on Volkart and W.I. Thomas. Health behavior as coping
Julius A. Roth 1963	Hospitalized tuberculosis patients	General theory: management of illness by normative timetables; institutional organization of illness response
Thomas Szasz 1964	Disabled patients, mental and physical	Critique of functionalism; contribution to deviance and labeling theory
Thomas Scheff 1966	Hospitalized mental patients	General theory of social deviance; labeling

SOURCE: Adapted from Bloom and Speedling, 1989, pp. 122–123

employee instead of an individual entrepreneur, is losing autonomy and, in effect, is becoming proletarianized. The patient, as a result of pressures to join large healthcare organizations, cannot freely choose a doctor or join with the doctor in certain decisions because cost control by the organization intervenes.

Such interpretations were buttressed by the increase in large-scale organizations for the delivery of healthcare, but the interest of scholars in psychosocial factors in therapeutic encounters continued to be strong. Compliance, the extent to which patients follow the recommendations of their therapists, for example, remained an important problem independent of the organizational framework for healthcare. Marshall Becker and Lois Maimon (1982) described a "health belief model" that made individual motivations and beliefs about the validity of treatment methods the central factors of health behavior. Attempts to quantify the sociobehavioral determinants of compliance preoccupied many researchers during the next two decades. The physician, at the same time, has been scrutinized in comparable empirical and quantitative detail as a "decision-maker" (Elstein et al.).

This quantitative trend is reflected in the training and assessment of medical students and residents. With the increasing orientation toward the use of measurements of clinical reasoning and behavior, didactic teaching and memorization are being replaced by problem-based learning and experiential learning situations such as simulations of clinical cases, called standardized patient (SP) methods (Woodward and Gerard). The goal of these efforts to change how physicians are trained is to create a more patient-oriented approach and, at the same time, influence doctors to become active, lifelong learners in order to maintain effectiveness under conditions of rapidly advancing basic medical sciences (Marston and Jones).

The Nonmedical Healing Professions

The history of the healing professions has been dominated by medicine. Although nurses, public-health workers, dentists, and social workers have been major contributors to the health of individuals and communities, their professional status and power have always been less than those of physicians. However, dramatic changes have expanded the need for the care of health and disease, challenging the monopoly of doctors. Constantly advancing technology applied to diagnosis and treatment, the increase in life expectancy and consequent growth of the elderly population, and changed patterns of illness and disability have forced physicians to depend on partnerships with members of other healing professions.

Nursing is the outstanding case in point. Nurses, although much more numerous than physicians (four nurses for every doctor), increasingly professionalized (over 100,000 have master's or doctorate degrees), and performing tasks in health settings previously restricted to physicians, continue to struggle for release from the view, argued by Freidson, that, following precedents established by Florence Nightingale more than a century ago, "All nursing work flowed from the doctor's orders … [so that] nursing became a formal part of the doctor's work, a technical trade.… Nursing thus was defined as a subordinate part of the technical division of labor surrounding medicine" (Freidson, 1970b, p. 61). There is some evidence that success in this struggle is at last being achieved.

Advanced-practice nurses, for example, are registered nurses with specialty training, usually at the master's degree level, in primary care (i.e., nurse practitioners and nurse-midwives) or acute care of in-patients (i.e., clinical nurse specialists). Mary Mundinger writes:

> The practice of nurse practitioners has been evaluated since 1965 when the role was developed by Henry Silver, M.D., and Loretta Ford, R.N. When measures of diagnostic certainty, management competence, or comprehensiveness, quality, and cost are used, virtually every study indicates that the primary care provided by nurse practitioners is equivalent or superior to that provided by physicians.… Over the past few years, state legislatures have broadened the authority of nurse practitioners to receive direct payment and write prescriptions, and the barriers to independence have fallen. As a result, nurse practitioners can establish independent practices that parallel those of primary care physicians (either solo or health maintenance organizations), or they can establish collaborative practices in which doctors and nurses care for patients together. (Mundinger, p. 211)

Initiatives from private foundations and the government have encouraged the professionalization of nursing and the other healing occupations, rewarding the creation of both educational and healthcare reforms that foster the creation of teams working together as equals. Nevertheless, these other professions remain in the shadow of medicine. As a consequence, nurses, probably the highest-status members of the paramedicals, earn an average of less than a third of physicians' incomes; their training, except for the 5 percent who have earned higher degrees, is considerably shorter and less rigorous; and nursing is almost totally a women's profession, a fact that, regrettable though it is, remains a classic indicator of low occupational status.

However, as indicated by the testimony of Mary Mundinger above, the status of nursing as a profession has changed. Increasingly, nurses are both trained in and responsible for the complex knowledge and technical aspects of patient care. In 1960, 83 percent of new graduates were trained in hospitals, the rest in colleges and universities. By 1980, those figures had reversed.

We are witnessing, therefore, a historical development in nursing reminiscent of the changes that occurred in medicine in the 1910s. Like medicine in the post-Flexner era (1910 and following), nursing is seeking to increase its professionalism by extending its training in close association with the university. Included is new emphasis on biomedical science and research.

The value implications of these changes are of particular concern. Professionalism for nurses tends to emphasize intellectual and technical skills in an occupation whose major function has been as much the ministering of nurturant and humane care as technical prowess.

For the patient, the options seem to narrow as knowledge and technical skill increase. Whereas once it seemed reasonable to expect physicians to combine technical expertise with emotional sensitivity and skill, and nurses to complement them in both, now the patient gains equality and independence but with increasing emotional distance from caregivers.

Under the current conditions of healthcare, social workers would seem to have a strategic role. They are, after all, uniquely trained in the skills of interpersonal relations, and professionally are intended to function as the patient's advocate for well-being, both within the period of illness and in preparation for the recovery period. Yet, here, too, the pressures for professional status take an ironic toll. A trend toward private practice with fee-for-service financial rewards attracts social workers toward professional status on the medical model and away from the team model in which their function is to balance the technical with the social.

The same value dilemma confronts all the healing professions. A polarization has developed between two orientations, one centered on the *what* of healthcare and the other on the *how*. The former has been called a reductionistic approach, emphasizing biomedical knowledge and technology; the latter is the "social ecology" or "humanistic" approach.

The values of these two approaches are significantly different. The more traditional, reductionistic approach is dominated by faith that all problems of health and illness have rational solutions, and by a dedication to competence in practice and to a community of science that transcends personal interest. Patient, societal, and ethical issues are seen as matters of opinion not susceptible to rational discourse (Pellegrino; Fox, 1979).

The approach of social ecology, on the other hand, rests on a very different set of values. The social and behavioral sciences and even the humanities are here as pertinent as the biological sciences; students are selected on the basis of social concern and interest in people and their problems; emphasis is on caring as much as on curing. The community, not the university hospital, is the proper locus for the education of health professionals.

Although one can say that neither of these approaches has sought or gained exclusive dominance, their differences are important enough to generate partisan claims from each about the failures of the past, the needs of the future, and the implications for patients and society. Both the value of modern science and the critical need for enlightened social and ethical orientations can be found in the way national commissions are addressing the problems of today's healing professions (Marston and Jones).

Summary and Conclusions

The definition of the professions is the foundation of sociological analysis of the professional–patient relationship. Uniquely among modern occupations, a profession has been seen as an activity that requires extensive training based upon a continuously developing knowledge base coupled with the application of such knowledge for the general welfare of society. Therefore, although the rewards of professional life have been substantial, it is assumed that the professional is not free to exploit such skills and knowledge for personal gain alone, as other entrepreneurs may—the so-called principle of *caveat emptor* (let the buyer beware). On the contrary, the professional is granted unusual privileges involving access especially to the personal and biological privacy of patients, but only on an implicit contractual premise that such professional rights will conform to general rules of the welfare of society.

Medicine has been the primary subject of such analysis because it is seen as the archetype of professions. Virtually every person needs the help of healing occupations; the other classic professions, the law and the clergy, are not so ubiquitous. Therefore, a large sociological literature grew out of the study of medicine as a profession. However, the practice of medicine has changed radically in modern times and continues to change. Research in the biomedical sciences is usually considered the major driving force of this transformation, but changes in the social organization of the delivery of health services, the application side of the medical profession, have been no less dramatic.

In the wake of both the bioetchnological and application developments, new ethical issues have appeared and earlier ones have deepened. Bioethics as a separate discipline has grown significantly, very likely as a direct consequence of these changes. Sociology, meanwhile, has spawned its own forms of interest in medical ethics. In part, sociologists have followed the tradition of individualism, which interprets behavior as a social psychological process determined by the values individuals learn and carry with them into social encounters. A different perspective emphasizes the material technologies and organizational constraints that dominate the therapeutic relationship. For example, the bureaucratization of medicine has advanced, creating a situation in which both doctor and patient meet less as individuals than as members of groups. The resulting formalization has altered the emotional quality of the exchange and the nature of responsibility and accountability for those involved therein.

Conventional wisdom has suggested that the ethical problems of current therapeutic relationships are driven mainly by technical imperatives. Sociologists, in the main, however, have argued that bioethics is determined by the value context in which medical technology must be managed, not by the intrinsic qualities of the technology. The dilemmas—the extension of life at the sacrifice of quality of life, the increased efficiency of neonatology at the cost of disability—are seen as only part of the current medicoethical challenge. Equally important is the unequal access to the benefits of technological advancement for populations that are disadvantaged by poverty, by race, or by other sources of discrimination.

Pressures are increasing for comprehensive entitlement to medical care but, as in the past, the chances for such change remain in doubt. As analysts have noted, the proportion of national income that will be invested in healthcare is both a value judgment and a product of the political process. As a result, David Mechanic writes:

> When faced with competing claims on national resources, government finds it easier to restrain growth in programs affecting the poor and disabled, who constitute relatively weak constituencies, than to reduce subsidies shared by large, articulate, and sophisticated segments of the larger American public.…The imminent risk we face is not a deterioration in medical care overall, but more a continuing erosion of access and appropriate care for our most unfortunate populations.…

> Between 1976 and 1984 the proportion of poor and near poor covered by the Medicaid program decreased from 65 to 52 percent. (Mechanic, 1985, p. 454)

In the pluralistic society that America epitomizes, attitudes have become polarized. At one extreme are those who view the system as basically sound and strongly support the conventional structure of medicine. At the other extreme are those "who view the delivery system as so flawed in its structure and priorities and so dominated by special interests that only major reorganization offers any promise of an equitable and effective delivery system in the future" (Mechanic, 1985, p. 190).

The struggle between these polar opposites will be strongly affected by the values that are basic to American thinking and that inevitably must be reconciled in the policy decisions that will be made. The trend at this time appears to be toward universal health insurance. The methods reinforce organizational development that fosters large corporate structures. Those who cling to the right to choose one's personal doctor, and believe that no healthcare system can function effectively otherwise, feel they have been put on the defensive against pressures for cost-effectiveness, even rationing, but nevertheless persevere in a time-honored American belief in individualism.

The contributions of sociologists, if they follow the patterns of the period since the 1940s, will continue to focus on the microrelations of medicine, especially the doctor–patient relationship (Stacey). They will also explore the ethics of human research, and issues of public policy such as equality of access to care and the role of the professions in determining the availability of medical and healthcare services (Sorenson and Swazey).

Renée Fox lists the primary values of American society as follows: individualism, contractual relations, veracity, the fair allocation of scarce resources, and the principle of benevolence. Individualism, for Fox, is "the primary value-complex on which the intellectual and moral edifice of bioethics rests" (Fox and Swazey, p. 352). It starts with a belief in the importance, uniqueness, dignity, and sovereignty of the individual. From this flows the assumption that every person has certain individual rights. Autonomy, self-determination, and privacy are fundamental. In addition, individuals are entitled to the opportunity to find, develop, and realize themselves and their self-interests. They are entitled to be and do as they see fit, so long as they do not violate the comparable rights of others.

Can these values be reconciled with the changes in modern American society, especially those that foster large organizational structures? Sociologists will certainly devote themselves to such questions, and include the fate of microrelations such as the professional–patient relationship.

SAMUEL W. BLOOM (1995)

SEE ALSO: *Autonomy; Beneficence; Care; Competence; Conscience, Rights of; Healing; Managed Care; Medical Codes and Oaths; Medicine, Anthropology of; Medicine, Profession of; Medicine, Sociology of; Nursing as a Profession; Patients' Rights; Profession and Professional Ethics;* and other *Professional-Patient Relationship* subentries

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III. ETHICAL ISSUES

Until recently in the history of healthcare, writing about and reflection on ethical issues in the health professional–patient relationship have focused primarily on the interactions and expectations of two individuals: a professional (traditionally, a physician) and a patient. The relationship usually is between a patient and a wide range of health professionals. Today, several basic ethical values, moral duties and rights, and virtues continue to be relevant to their interaction. The emphasis in this section of the entry is on concrete questions related to morality. Thus, enduring normative ethical foundations of the relationship as well as issues that have become relevant because of changes in the character of the relationship and the institutional settings in which it takes place will be discussed. In normative ethics, basic questions include, "What types of acts are morally right (or wrong)?" and "What are the morally praiseworthy (or blameworthy) virtues of the individuals or groups involved?"

Conduct, Virtue, and Context in the Professional–Patient Relationship

Normative ethical judgments about a relationship can be made on the basis of whether right conduct is exhibited by the parties toward each other, and whether praiseworthy character traits and dispositions (virtues) that ought to manifest themselves within the relationship are present. The context in which the relationship takes place also has moral relevance. Ethical issues can arise from any of the three.

CONDUCT-RELATED ISSUES. Issues related to morally right conduct in a relationship are understood through an examination of moral obligations and rights in the relationship. Today some of the most fundamental have been developed into general categories called *principles.* Several key principles that ought to be present in the professional–patient relationship are described later in this section.

VIRTUE-RELATED ISSUES. A second area of ethical issues is understood through an examination of the good or praiseworthy habits and dispositions of the parties in the relationship. Here the focus is less on the things people *do* and more on the types of people they *are.* Just as we can engage in reflection about ethical principles that help to elucidate right from wrong conduct, so can we make reasoned judgments about the character traits and attitudes that people ought to exhibit in a relationship. For example, we expect a person with virtue to be more disposed to honor another's values and to try to create a better community than would a person who lacks it. On this basis alone it is justifiable to place expectations of virtue on certain relationships. Some of the most basic virtues that have bearing on the professional–patient relationship also are discussed later in this section.

CONTEXTUAL CONSIDERATIONS. Issues involving judgments about the conduct and virtues that are morally appropriate may vary according to the larger social and institutional context in which the relationship takes place. One needs to assess, for example, the special peculiarities of the way in which the relationship was formed, the genesis of explicit or implicit expectations of the parties, the utility and function of the relationship, and the role of society's expectations.

A consideration of several dominant models that have been proposed to characterize this relationship will aid in the reader's understanding of the ethical issues discussed in this article.

Moral Models of the Relationship

Robert Veatch was one of the first contemporary bioethicists to seriously consider that various moral models exist. He offered four models of the physician–patient relationship: the *priestly model,* an explicitly paternalistic and value-laden approach in which the physician assumes competence not only for medical facts but also for naming and interpreting value dimensions of healthcare decisions on the patient's behalf; the *engineering model,* in which the physician acts as a scientist dealing with facts divorced from questions of value; the *collegial model,* in which physician and patient become *pals* assuming equality through mutual trust and loyalty; and the *contractual model,* which entails a mutual understanding of benefits and responsibilities incumbent on each person involved (Veatch, 1972).

In 1992, Ezekial Emanuel and Linda Emanuel, two physician bioethicists, also presented four models with some parallels, but set the context as one in which each model demonstrates the tension between patients's autonomy and their health as well as among various physician and patient values: In the *paternalistic model,* the physician independently acts on behalf of the patient's well-being; at the opposite pole, in the *informative model,* the patient receives all information and the physician serves as a technical expert only; in the *interpretive model,* the patient's life is viewed as a specific story or *narrative* from which a mutual understanding of appropriate goals and interventions are derived; and in the *deliberative model,* the physician, who provides the relevant information to the patient, also acts as a combined teacher-friend to empower the patient in ways that are consistent with the patient's health-related values.

Sheri Smith was among the first to distinguish models of the nurse–patient relationship, though others have followed. In the *surrogate mother* model, the nurse is morally obliged to assume ultimate responsibility for the well-being and care of an essentially passive patient; the *technician* model characterizes the nurse's responsibility as limited to competently applying technical knowledge and skills to meet the patient's needs; and the *contracted clinician* model defines the nurse's responsibility by the values and rights of the patient and assumes that the patient is capable of determining her or his own best interests (Smith).

In spite of important differences, the similarities among all three models are more important. They point to a progression over time from traditional paternalism to more mutuality and shared decision making. Several models support the idea of the professional as a patient (or client) advocate. The advocacy idea suggests that a patient's health-related rights must be protected and the health professional is in a unique—or at least opportune—position to protect these rights. Lively debate continues for and against adopting the advocacy idea as the central moral role of the health professional in relation to the patient (Bandman and Bandman).

U.S. law places the professional–patient relationship in the class of fiduciary relationships. In fiduciary relationships "each [person] must repose trust and confidence in the other and must exercise a corresponding degree of fairness and good faith," because the two persons cannot expect to have all of the usual facts that would allow them to contract as equals (Garner, p. 640). This law is used by the legal profession to help hold physicians (and, to varying degrees, other health professionals) accountable for the fact that they have the greater measure of power within the relationship and may not be able to equalize that power merely by disclosing relevant information to patients or their families. Trust is the bridge to the success of the relationship, and the burden is on the professional not only to engender the patient's trust but also to build a solid foundation of trustworthiness upon which the patient can depend.

The following discussion provides the reader with some basic components of ethical thought common to all of the models.

Ethical Principles in the Professional-Patient Relationship

Several ethical principles are relevant in an analysis of the professional–patient relationship and provide insight into its ethical foundations. Among the most important are respect for persons, nonmaleficence, beneficence, veracity, autonomy, and justice.

RESPECT FOR PERSONS. Respect for persons, highlighting the dignity of the patient as a person, is found in the preambles of most professional codes of ethics, mission statements of healthcare organizations, and patients's rights documents, as well as many other ethics writings. The principle assumes that persons have inherent or essential worth simply because they are human beings. Diverse philosophical, religious, and scientific understandings of the nature of persons provide a wide base upon which the health professions can ground this ideal (Lammers and Verhey). But the principle also presents challenges to health professionals: One is to discern categories of beings that are persons; another is to discern practical direction from such a general ideal. For example, two health professionals may agree on a Judeo-Christian-Islamic interpretation that all persons have worth or dignity because they are equally children of God. They may follow the influential notion of the philosopher Immanuel Kant (1724–1804) that persons must be treated as ends and not as means to ends, yet the two may differ in their positions regarding the moral status of the fetus and come to different conclusions about whether a life-saving liver transplant should be given to a person who has an acute alcohol addiction. In spite of its difficulties, however, this principle makes a signal contribution to the understanding of the professional–patient relationship by counseling professionals against making hasty or arbitrary distinctions.

NONMALEFICENCE. The maxim to do no harm, *primum non nocere,* often is cited as the first ethical principle of medical practice. Its meaning and usefulness can be gleaned from the serious thought given to the concept in deontological (duty-oriented) approaches to moral philosophy. W. D. Ross argues that it is our stringent duty to inflict no harm intentionally, because to live in any other type of society would make each of us too vulnerable. This duty, he adds, is not covered by the duty to prevent or remove existing harm, or to do good (Ross).

The duty of nonmaleficence places the professional on alert that society reasonably expects him or her not to be an agent of harm. Debate about physician-assisted dying, euthanasia, and abortion often focuses on the interpretation of harm and the physician's, pharmacist's, nurse's or other health professional's role in participating in activities that cause harm. Discussion of maleficence must take into account that some types of harm are necessary in the name of a patient's greater good: For example, the patient undergoes the harm of the surgical knife in order to have the pathology removed.

BENEFICENCE. The principle of beneficence delineates conduct directed to the welfare of others and is pivotal in the understanding of the professional–patient relationship. Since its inception, the relationship has had its grounding in the idea that the professional's ethical priority is to further the welfare of a patient. Other worthy goals, such as furthering the knowledge about disease and its cure, or earning a just wage, or maintaining the efficiency or financial solvency of the institution, must take a lesser position on the scale of priorities.

Taken in combination with the principle of respect for persons, the principle of beneficence highlights that health professionals have a moral obligation to provide optimum care to all kinds of patients with whom they are in a professional relationship, assuming that the patient's problem lends itself to healthcare intervention and the professional is competent to treat the patient's type of condition. Therefore, the principle is put to the test when the professional is prejudiced against persons of a certain ethnicity, age, gender, religious conviction, sexual orientation, or any other characteristic, and therefore finds it difficult to give a full measure of attention to members of such groups. A health professional also may judge an individual patient *undesirable* on the basis of poor personal hygiene, irritating personality traits, or lifestyle choices. In each case, the health professional must regard the patient in the relationship as worthy of treatment however great a gulf exists between their respective values. If their differences create so great a barrier on the part of the professional that it prevents good care, he or she must attempt to assure that the patient receives it from someone else. In short, the health professional must focus on the person's needs whether the patient be model citizen or thief, old or young, man or woman, likable or not.

VERACITY. Philosophers may treat the principle of truth telling as a separate principle. More often today, however, it is conceived as derived from respect for persons (Veatch, 2003). However, treating it as a derived principle in this case only strengthens it since it is derived from such a fundamental moral premise of healthcare.

Given the moral stringency of truth telling, an interesting ethical quandary arises when it falls to the professional to convey bad news to patients and families. Health professionals long have believed that patients want professionals to help them maintain hope in the face of catastrophe. In 1932, Nicolai Hartman noted that for centuries this was interpreted as requiring the professional to protect patients from the truth at times, engaging, if necessary, in a *benevolent lie* and bearing responsibility for having breached the patient's moral expectation that veracity would be honored.

Today this belief has shifted, at least in some major subcultures of North America and Europe where the belief is that hope is enhanced by the patient's ability to take control of important life events. In other words, the fostering of hope is not dependent solely on whether the truth is shared directly with the patient. More determinative is the role of veracity in maintaining a patient's exercise of autonomy and capability to actively participate in decisions. This interpretation, however, does not necessarily lead to professional conduct consistent with it. For example, Nicholas Christakis observed that physicians tend to convey information about a poor prognosis in a way that avoids giving the worst aspects and conforms to what the physician believes the patient's expectations are.

AUTONOMY AND SELF-DETERMINATION. In the tradition of medical ethics, discussion regarding autonomy did not focus on patient autonomy but on the professional's autonomy, the assumption being that freedom from impingement by others on his or her clinical judgment and practice was a key means to acting beneficently on behalf of the patient's best interests. However, there are numerous government regulations and other controls within healthcare today that restrict professional autonomy, causing thoughtful health professionals to worry whether they will be able to honor basic professional tenets of the professional–patient relationship.

By the beginning of the twentieth century the historical roots of libertarianism in the United States, first introduced as a political theory under the influence of such British thinkers as John Locke (1632–1704) and John Stuart Mill (1806–1873), had begun to seriously influence the character of the professional–patient relationship in the direction of honoring the patient's agency in healthcare decisions. Although related to the idea that the patient should have access to *the truth* in accordance with the principle of veracity, autonomy goes beyond that aspect.

The principle of autonomy provided a social groundwork for the introduction of the idea of patients' rights within the relationship. Applied to the patient's situation the principle evolved from being viewed as the patient's prerogative to refuse treatment to the negative right to refuse it, and finally to the positive right to play a central role in determining the course of treatment. For example, the increased emphasis on informed consent as the brokering chip in the relationship places a major focus on the patient's role as an active agent in treatment decisions. Today informed consent modes range from explicit or presumed consent in special situations to the more commonly discussed explicit consent. Moreover, in 1990 the U.S. Congress passed the Patient Self-Determination Act, which took the idea of patient autonomy as a right more deeply into the legal and life-span arenas. The law was a legislative mandate that patients have an opportunity to express their wishes about potential treatments in critical situations. This form of advance consent was buttressed through numerous cases and laws affirming use of living wills, durable power of attorney and other surrogate/proxy or substituted judgment mechanisms that are effective when the patient is unable to express his or her wishes on the spot.

In spite of the central role of patient autonomy in bioethics discourse and the medical-legal aspects of health professions' practice, lively discussion about its appropriate moral limits is growing (Schneierman).

For example, new attention is being devoted to tensions that develop when there is a serious disjuncture between the patient's expressed wishes and the professional's judgment of how best to carry out the professional obligations of beneficence and nonmaleficence. In other words, under what conditions is it morally permissible for the physician or other professional to go against the patient's informed preferences (hard paternalism) or not seek the patient's input (soft paternalism)?

The weight of moral opinion today supports at least four areas of paternalistic conduct. In the first instance the conduct is justified when the professional knows for a certainty that the intervention will harm the patient. (How *harm* is defined becomes extremely important. For instance, if death is judged an unacceptable harm the professional may engage in a kind of vitalism that imposes additional suffering on a dying patient). A second situation exists when the intervention being sought goes beyond or against the public moral mandate of medicine and the other health professions. Third, professionals need not be held hostage to patient wishes that will be of no benefit whatsoever to the patient even if it does no harm. The idea of futility, though imperfectly developed to date, is an attempt to provide criteria for setting boundaries that will prevent these potential misuses of healthcare. And fourth, a request by a patient that the professional engage in a clinically indicated and legally sanctioned option that is morally repugnant to the professional may cause moral distress for the professional and can be denied. In this case, although he or she is not morally obligated to personally participate in the intervention, the patient must be placed in the hands of another competent professional who can more sympathetically assess the patient's informed wishes.

Two critical concerns are being raised regarding the centrality of patient autonomy in the professional–patient relationship. The first addresses an increased awareness of the importance of diversity by professionals In order to meet the moral mandates of cultural sensitivity and cultural competence, the professional must have a deep understanding of how various cultures conceptualize individual, family and clan roles in regards to decision making (Hyun). In some groups the professional's insistence on the patient's individual informed consent is morally and socially antithetical to healing or other appropriate reasons for seeking out professional attention. A second concern arises in instances of high medical/clinical uncertainty. The professional's disposition to shared decision making often falters, likely due to a fear that an admission of uncertainty will undermine the patient's or family's confidence or create additional stress for them (Parascandola, Hawkins, and Danis). Both of these concerns warrant careful attention and research.

JUSTICE. The principle of justice, stated simply, is that each should get his or her due. What is *due* must be derived from the high moral standards of healthcare and the information available about what will create the most benefit. At the level of the professional–patient relationship, this has several implications. First, its relationship to beneficence is apparent: The patient can expect to be treated fairly. Persons seeking treatment should not be given advantage on the basis of arbitrary favoritism or be left out on the basis of arbitrary dislike. The rules will be applied consistently, taking into account legitimate departures from the norm. For instance, a procedural rule of first come, first served will be applied except in cases where greater need morally requires that the rule be flexible enough to allow for valid exceptions.

The principle of justice raises important ethical issues related to the allocation of scarce resources. Health professionals abide by a duty of beneficence, but that duty does not entail the prerogative of automatically providing a disproportionate amount of a scarce resource to any one person, even if that person's need could warrant receiving all of it. The resulting allocation may have a relatively deleterious effect on one or more other patients because their optimum benefits are compromised. For example, a nursing shortage on a unit may require the nurses to make difficult (though not arbitrary) decisions about patient-care priorities.

Compensation for harm also derives from our understanding of what justice requires. A patient who is harmed in the relationship through, say, professional error, has a right to know that the harm has occurred and may wish to seek compensation for the harm.

Serious barriers to justice often arise outside of the relationship. Societal discrimination against patients on the basis of race, ethnicity, religion, sex, and age are well documented, and continue to contribute to serious disparities in the distribution of U.S. healthcare benefits and burdens in spite of legislation designed to prevent them (Garner). Other barriers are imposed by today's bureaucratic context of healthcare: institutional mechanisms and societal arrangements designed to foster efficiency, profit, or other goals, but not the patient's well-being (Stein). The relationship does not stand in isolation from these influences, all of which have profound effects on it.

The health professional who is committed to upholding the profession's moral ideals must work not only to preserve justice within the relationship directly but also to remove barriers to it on a broader scale so that the appropriate ends of healthcare can be realized.

Conflicts among Principles

As illustrated by the issue of paternalism in truth-telling situations and the compromise of beneficence in situations of scarce resources, conflicts among this set of general principles inevitably arise in everyday professional–patient relationship situations. In actual situations, professionals usually can use the basic moral ideas imbedded in the principles as guides to set priorities consistent with the values of healthcare, the professions's moral codes and standards, and patients's informed preferences. At the same time, not all conflicts can be resolved and sometimes principles seem to remove us a step further from the immediacy of the situation.

Virtue in the Professional-Patient relationship

Cognizant of the limitations in an ethics based entirely on conduct, Aristotle in *Nichomachean Ethics* suggested the alternative of a focus on *virtues* by those who are decision-makers so that they approach moral conflict in the right frame of mind and heart. A life of moral virtue is characterized by dispositions and attitudes that can be cultivated into habits of preparedness that enable a person to act in ways that further the good of a relationship or community. Aristotle also underscored the importance of the person's desire to become a good person, which in turn requires knowledge of ultimate goods and ends. Aristotle did not divorce virtue from the realm of feelings and emotions, suggesting instead that acts arising out of various dispositions will give pleasure and that, at the same time, ethical action resulting from a virtuous disposition requires the exercise of reason.

Since the late twentieth century, several leading ethicists have led a lively re-examination of the virtues that should be expressed by health professionals. Notable among them are Edmund Pellegrino and David Thomasma who propose that the contemporary reappraisal is not an attempt to demean the emphasis on rights-and-duty-based ethics, “but a recognition that rights and duties notwithstanding, their moral effectiveness still turns on dispositions and character traits of our fellow men and women” (Pellegrino and Thomasma, p. 113).

A challenge throughout the ages has been to identify dispositions that the professional should cultivate so as to further the good and proper ends of healthcare. Many virtues have been proposed, among them benevolence and kindliness, compassion, integrity, honesty, fairness, conscientiousness, fidelity beyond duty, and humility.

These virtues are as appropriate in today's professional–patient relationship as they have always been. However, some things about the relationship are understood differently today than in the past, and our understanding of human relationships in general continues to undergo new evaluation. It is not surprising that our understanding of the virtues also continues to evolve. The following two illustrations of this evolution by no means exhaust the important work that is being conducted in this area.

BENEVOLENCE AND CONSIDERATIONS OF TRUST. The traditional professional virtue of benevolence or kindness has enjoyed a long history in the writings on the professional–patient relationship. This character trait evokes pictures of a physician, midwife, or nurse sitting quietly at the bedside, reassuring a patient, an image consistent with a period in which the professional was viewed as a kindly person who used the limited technologies available to minister to the clinical and emotional needs of a trusting, mostly passive patient. Today the notion of benevolence must be refined to adapt to a relationship in which patients are active participants in the interaction, suggesting that kindness met by blind trust taken alone are not adequate ingredients for the tasks of this relationship to be accomplished. At the very least an adequate notion of professional benevolence today must include an examination of how the professional's trustworthiness figures in the professional–patient relationship.

For example, traditionally confidentiality focused on the physician's duty. To the extent that the physician had cultivated a benevolent disposition toward the patient, the duty would come more naturally. Today the moral focus has shifted to the patient, particularly to his or her right to expect confidentiality. Only trustworthiness based on the professional's authentic commitment to respecting the patient's rights and dignity assures the patient that he or she is in the hands of a benevolent professional.

Benevolence as traditionally understood is challenged further by a revitalized emphasis on professionalism in the medical profession. In this broader conceptualization benevolence commitments explicitly include competence, honesty, confidentiality, maintenance of appropriate boundaries, improvement of the quality of and access to care, and management of conflicts of interest, to name some. Moreover, a rise in the literature on such dimensions of the physician's moral role as that of dealing positively with professionals' errors (Kohn et al.) and fatigue (Gaba and Howard) are expanding the scope of what benevolence entails today.

COMPASSION AND CONSIDERATIONS OF CARING. Compassion also has long been viewed as a virtue that should characterize the professional–patient relationship. Compassion often has been interpreted according to its etymological root, "to suffer with." Theories vary about what, exactly, this means in the healthcare context, but one central theme is that healing is enhanced when professionals exhibit a disposition and ability to sympathize deeply with the patient's plight. The cultivation of this disposition leads the professional to recognize that the key issue is not only "Have I done my duty?" (e.g., truth telling) but also "Have I been sensitive to the effect my approach will have?" (e.g., how, when, by whom, and where this information should be disclosed). The central notion of *caring* in the professional–patient relationship sheds light on important ways in which the virtue of compassion might manifest itself in the everyday work of professionals. Among contemporary bioethicists Warren Reich makes an important contribution to the understanding of compassion by relating different modes of compassion to different phases of a patient's suffering. Care in the relationship between health professional and patient also has been seen as an activity that reflects an attitude of sensitivity to the patient's deepest values and concerns.

Anne Bishop and John Scudder propose that "Being compassionate is not something that human beings can achieve by an act of will. It is possible, however, to be open to compassion, to be situated so that compassion is likely to be evoked…" (p. 81). They conclude that professionals who do not feel compassion but have a deep desire to show caring (i.e., *feel called to care*) can actually express care by a focus on fostering the patient's well-being as well as a commitment to full participation in being an excellent practitioner. In some current approaches to professional care, compassion or other virtues are not invoked at all; rather the emphasis turns exclusively to conduct and behaviors that various professions describe as *caring behaviors* with the goal of incorporating them into an assessment of measurable outcomes in patient management (Galt). This latter approach diverges dramatically from the traditional and most contemporary research on the role of care and its relationship to compassion in the larger ethical context of the professional–patient relationship. There have also been serious caveats raised about a professional ethic based primarily on the concept of care.

Aware of problems created by sexism, and that caring and the care-giving role are associated with women, social devaluation of professions that promote care as a centerpiece of their identity could follow to the patient's detriment (Nelson). Therefore, when a health professional expresses care to a patient he or she may also appear to condone injustices that derive from being in a society that devalues women in a care-giving role (Condon). At the same time, recipients of care may be forced into stereotyped roles of *dependency*. Eva Feder Kittay calls for a reassessment of the dichotomy often viewed as existing between caregiver and care receiver. Clearly, the role of care and its relationship to compassion warrants continued attention.

Existential Dimensions of the Patient's Experience: Implications for the Professional-Patient Relationship

The existential dimensions of the patient's experience also deserve consideration in the relationship. *Existential,* as used here, refers to the human quest for meaning in the face of our limitations, among them illness and death. Especially significant are new insights regarding the health professional's role in exploring the existential meaning of illness for a patient.

One aspect of the exploration has focused on the professional's desire and ability to individualize the patient's situation and story: Respect in the relationship rests on a premise that health professionals are called into a particular relationship with patients because of the importance of the illness experience to the patient, and the medium of that relationship is the patient's story (Purtilo and Haddad). The notion of patients's *patterns* is the term used by Margaret Newman to describe what has value—is meaningful—in a patient's life. The professional's skill in helping the patient recognize aspects of him- or herself that the person may not even be conscious of is the professional's act of *pattern recognition.* The professional, acting as facilitator, can show how the pieces fit. Once identified, professional and patient can work together toward mutually agreed upon health goals. Bishop and Scudder capture the essence of the professional's position in this task as being a *caring presence,* a "personal presence that assures others of another's concern for their well-being" (Bishop and Scudder, p. 41).

Narratives, the patient's and the professional's, are the professional's means of gaining insight into the existential complexities of the professional–patient relationship (Greenhalgh and Horwitz). Sociologist Arthur W. Frank, drawing partially on his own illness experiences (from *patienthood* to *survivorship* roles), powerfully illustrates how the moral responsibility of survivorship is to reconstruct, *put back together,* a life that had been altered by interventions and professional interactions. Through that process the wounded also becomes healer, but the process requires the mutual effort of professional and patient. When the professional, through narrative, shows to the patient a personality with emotions, likes and dislikes, fears and dreams, hopes and faults, the patient has a greater opportunity to understand that there is a *person* in the professional role, not just a bundle of competencies and technical skills. The patient becomes more trusting that his or her own personality has a chance of being taken seriously (Purtilo).

Howard Brody, a physician bioethicist, notes that the challenge does not lie only in the professional's desire and willingness to hear and respect the patient's story. Even those who are so disposed may meet barriers because both professional and patient believe that the professional holds the key to knowing the *real problem* (i.e., the medical problem). The power differential built into the structure of the relationship means that the professional is believed to be empowered to impute the *real* meaning of the patient's story. A concentrated effort must be made to overcome such a barrier (Brody). Merging from such thinking and reflection on the existential aspects of the relationship and its key members are new materials for refining their encounter, new ethical dimensions to build on the traditional foundations of moral obligations, rights, and virtues. The healing quest will be for the discovery of the patient's lost or changed self, not just for removal of a disease that resides in that person, and the recognition that in the deepest sense each party is affected by the relationship.

Mechanisms for Resolving Ethical Conflict in the Professional-Patient Relationship

Ethical issues in the professional–patient relationship are receiving more attention in the everyday environments of healthcare. Inevitably, differences in judgment, even deeply held differences, arise between professional and patient (or the patient's family). *Conflict* does not always denote a feeling of animosity. Often it signals a frustration shared by all involved in not knowing the best way to proceed.

There are several mechanisms designed to assist patients in such situations. First, the patient representative or patient ombudsperson is an employee of the provider institution who is charged with being available to patients and their families when dissatisfaction or questions arise. This advocate may learn that a patient or family believes that the patient is being harmed by receiving substandard treatment. While not all such situations involve ethical issues, many do. The advocate may act as a direct liaison between the parties or may refer the issue to one of the other mechanisms designed to provide assistance.

Second, ethics consultants are being hired by many major hospitals. Their charge is to deal with ethical issues regarding patient-care decisions. Depending on the institution, the ethics consultation service may be accessed by the physician, nurse or other professional, patient, or patient's family. Usually the consultant meets with all the relevant parties to help them identify the ethical issues involved, reason about the issues, and make recommendations for how to weigh conflicting priorities. The consultant does not make the final decision, which is correctly left to be decided within the professional–patient relationship.

Third, clinical ethics committees are present in many healthcare environments. Usually multidisciplinary, they function in a manner similar to the ethics consultant. Sometimes an ethics consultant will be called first, and if he or she thinks that the issue merits further deliberation by several different disciplines and personalities, may call the ethics committee together.

Everyone would agree that whenever possible, prevention is the best approach to moral conflict in a professional or institutional setting. The professional's diligence in communication, technical competence, and caring are keys to conflict prevention, as well as powerful instruments for resolution of conflict when it does occur in the professional–patient relationship.

RUTH B. PURTILO (1995)
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SEE ALSO: *Authority; Autonomy; Beneficence; Care; Compassionate Love; Confidentiality; Conflict of Interest; Informed Consent; Justice; Medical Codes and Oaths; Medicine, Art of; Narrative; Paternalism; Profession and Professional Ethics; Rights, Human; Trust; Virtue and Character;* and other *Professional-Patient Relationship* subentries

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PROFESSION AND PROFESSIONAL ETHICS

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Among any society's most important institutions are the social structures by which the society controls the use of specialized knowledge and skills. This is particularly true when highly valued aspects of human life depend on such expertise, and all the more so if acquiring such expertise requires lengthy theoretical education and intensive training in its practical application under the supervision of those already expert, thus rendering the knowledge and skill in its application unavoidably exclusive.

Social control over the use of such knowledge and skills is important because the members of the expert group could use their exclusive expertise solely for their own benefit or even hold society hostage to their expertise. But those who might exert such control, if they are outside the expert group, cannot depend on their understanding of this expertise precisely because they lack the relevant knowledge and practical training. How, then, can a society control the use of important, specialized expertise and render those outside the expert group secure so that they will be able to enjoy the values that depend on it? One of the most important social structures developed to this end is the institution of profession.

In many people's minds, it is by publicly taking an oath that a person becomes a professional and acquires specifically professional obligations; and indeed the term *profession* does come to us from the Latin *professio* that comes in turn from the Greek verb *prophaino,* "to declare publicly." But it is not the oath that classically concludes professional training that creates professionals or produces their special obligations. It is in their presenting themselves to others as possessors and practitioners of a profession's expertise that they *declare publicly* that they are members of a profession and accept its ethical commitments as their own. The oath that many new professionals take is rather a reminder to those beginning professional practice that important ethical commitments go with it and a public assurance to the larger community by the new practitioners that they understand and accept this reality.

In the minds of many mature professionals, it was not the formal oath nor any other public activity that made them professionals, but rather their personal sense of vocation, of a calling or of being called, to this way of life. There is something truly admirable in this view of profession because professional practice is ethically challenging enough that only those with a deep sense of personal ethical commitment will manage its challenges well. But it would be a serious mistake to put all the focus on the person of the committed professional and none on the important social systems in which such a person functions. First, the content of the ethic of each profession—that is, the ethic that the committed professional is called to practice—is the content of an ongoing dialogue between the profession as a whole and the larger community within which it practices. Second, every professional's practice is necessarily practice in conjunction with someone served, frequently a capable, independent decision maker and always someone whose well-being is not fully defined by the values of the profession. The vocation or calling of the committed professional is precisely a social vocation, a calling to ethical relationships with those served in the context of the whole profession's proper relationship to the larger community.

The practice of specialized expertise and the special moral commitments associated with professional practice are what most differentiate a profession from other occupations. All the ways in which people spend their time earning a living involve skills and knowledge of value to others and involve relationships with others that have ethical significance, at a minimum the prohibition of coercion and the requirement that people honor their contracts that characterizes marketplace relationships. But the analysis just offered indicates that specifically professional practice involves a particular combination of institutionalized expertise and special ethical obligations over and above the obligations of the marketplace. It is these characteristics taken together that differentiate professions from other occupations.

The Key Features of a Profession

A few social philosophers and a large number of sociologists, following Émile Durkheim (1858–1917), a Frenchman, and Talcott Parsons (1902–1979), an American, have studied the institution of profession in depth and have attempted to identify its essential elements. This is not easy because so many groups have been eager to appropriate the title of profession in order to enjoy the social rewards that go with it. In addition, the terms *profession* and *professional* have both normative and descriptive uses in ordinary discourse. Nevertheless, by looking for common features among the most obvious examples of this institution, such as medicine, law, and dentistry, a useful listing of characteristic features is possible.

IMPORTANT AND EXCLUSIVE EXPERTISE. For an occupational group to be a profession, it must provide its clients with something the larger community judges extremely valuable, either because of its intrinsic value or because it is a necessary precondition of any person's achievement of valued goals, or both. Health and the preservation of life, to take two commonly identified goals of the health professions, are held by almost everyone to be values of the highest order, either as intrinsic values or as necessary preconditions of people's achievement of whatever else they value. In a similar way, security of one's property and person against the errors of others and against the adverse workings of government and the legal system, as one defensible description of the goal of the legal profession, is also widely valued as a precondition of achieving whatever other goals one has.

The expertise of a profession has both cognitive (theoretical and factual) and practical (the fruits of experiential learning) components that are of sufficient subtlety and complexity that only persons who have been specifically and extensively educated in them, by persons already expert, can be depended upon to bring about the relevant benefits for those whom the occupation serves. In the practical division of a society's labors, this makes possession of such expertise exclusive to a relatively small group.

Moreover, for the same reason, only persons fully educated in both knowledge and practice of a profession's expertise can be relied on to judge correctly the need for expert intervention in a given situation or to judge the quality of such an intervention as it is being carried out. Such judgments by those not so trained are not dependable. Because of the importance of what is at stake, it is not sufficient to judge the performance solely on the basis of its long-term outcomes, even when the nonexpert can accomplish such a judgment unaided. Long-term outcomes will not be known for some time, and the risk of negative consequences in the meantime, in a matter of great importance, is too great.

The expertise of a profession involves not only specialized and complex knowledge, both theoretical and practical, but also the application of this knowledge. This is the reason that mastery of a profession's expertise requires experiential as well as cognitive education. This is also why the members of a profession are said to "practice" its expertise. A profession is not made up simply of experts; it is made up of practitioners of a body of expertise.

INTERNAL AND EXTERNAL RECOGNITION. A profession, as an occupational group made exclusive by reason of its particular body of expertise, is also characterized by a set of internal relationships of which the most important is a mutual recognition of expertise on the part of its members. These internal relationships may remain informal or may become quite formal, as when a community of experts who mutually recognize each other's expertise establishes a formal organization. The expression "the profession of medicine" thus refers most properly to all those expert in the practice of medicine, mutually recognized as such by one another, within whatever geographic limits are relevant. This same expression is also used, however, to refer either to the chief national organization of such persons, the American Medical Association (AMA), or to some larger set of associations, including the AMA, to which physicians would likely belong. Nevertheless, it is not the formal character of association among experts, but the fact of their mutual recognition of expertise, that is most important here. Other expressions—for example, "organized medicine"—are available to refer to formally constituted groups.

The expertise of a profession is also recognized by the members of the larger community. This recognition may remain quite informal, or the external recognition of a profession's expertise may be expressed in formal actions of the larger community, such as certification, licensure, and so on, that confer formal authority in matters of the profession's expertise to an organized group of professionals. A group may be given, for example, exclusive authority to determine the degree of expertise needed by those who intend to practice it and to test the expertise of those who wish to do so. Such authorization often includes a grant of exclusive authority to train and certify new members of the profession as well. But, as with internal recognition, it is the reality of the community's recognition of the group's expertise that is essential to the character of a profession, not the degree to which it has been formalized.

AUTONOMY IN MATTERS OF EXPERT PRACTICE. Because the activity of a profession is so valued by those it serves, and because proper performance and dependable judgments about performance depend upon expertise that is unavoidably exclusive and therefore not available to the ordinary person, those served by a profession routinely grant its members extensive autonomy in the performance of the profession's practice. The term *autonomy* has a number of important uses in moral discourse and often appears when issues in bioethics are under discussion. Here, however, this term refers specifically to the acceptance by others of professionals' judgments as determinative on any matter that is within the range of the relevant profession's expertise. Such autonomy can characterize three kinds of judgments by professionals.

First, such according of autonomy depends on the assumption that each member of the expert community possesses the relevant professional expertise and is therefore a dependable provider of its benefits. Professional autonomy here extends to three arenas of professional practice: (1) determining the specific needs of the person seeking services in matters within the range of the profession's expertise; (2) determining the likely outcomes of various courses of action that might be undertaken in response to these needs; and (3) judging which of the possible courses of action is most likely to best meet these needs.

Consider, for example, the encounter between a physician or a dentist and a patient. The patient often accepts without question the doctor's judgments regarding these three things: (1) the nature of the patient's present condition and of the patient's need for care, if any (diagnosis); (2) the possible courses of action that might be undertaken in response and their likely outcomes (prognosis); and (3) the likelihood that one of these courses of action will meet the patient's needs better than the others (treatment recommendation).

In addition to these items, professionals also make judgments about the intermediate, instrumental steps involved in carrying out the chosen course of action. But these judgments can be and frequently are relegated to another party, such as a technician. Such a person, while capable of making judgments about properly applying instrumental actions already identified as needed, is not necessarily capable of dependably judging the need for these actions or which of the possible actions will best meet the need.

Although those who seek professional services ordinarily grant autonomy of this sort to the professional, they do not ordinarily do so simply on the basis of their individual judgments of the expertise of the individual professional. Instead they make their judgments on the basis of a more complex set of factors including the community's (external) recognition of the professional group's expertise and the professional group's (internal) recognition of the expertise of the particular professional. Thus, even though this grant of professional autonomy ordinarily takes place principally in the interaction of an individual in need and a particular professional, its full meaning can be understood only against the social background of the institution of profession.

A second kind of judgment sometimes accorded autonomy by the larger community concerns the various features of the situation in which the encounter between professional and the person seeking professional services takes place. Professionals often seek and the larger community and individuals seeking professional service often grant professionals considerable additional autonomy in determining the immediate circumstances of their practice.

The extent of this aspect of professional autonomy depends on answers to two questions: What aspects of the immediate circumstances of practice significantly affect the quality of professional performance? And what additional factors do members of the profession also prefer to control, either for their convenience or out of a conviction, possibly unexamined or even mistaken, that they affect the quality of professional performance?

For example, physicians, not their patients, typically control much of the daily routine of medical practice. In the marketplace, this control could easily be explained as the producers' control of the product they offer. But physicians ordinarily justify such preferred patterns on the grounds that they maximize their service to their patients. Patients in turn typically change their daily schedules accordingly even if they are doubtful that the inconveniences they accept are in fact the only way that physicians can best serve all of their patients.

Third, professionals' ability to make dependable judgments for their clients is also conditioned by other, still more remote situational factors over which professionals may seek, and the larger community may grant, some measure of control. To an even greater degree than autonomy in making practice judgments and in controlling the immediate circumstances of practice, autonomy of this third kind is ordinarily granted not to individual members of a profession but to organized groups of professionals.

For example, physicians' opposition to health insurance programs in the middle of the twentieth century and their later opposition to federally funded healthcare programs for the needy were efforts to preserve the medical community's then-preferred economic structure for healthcare distribution, namely, the fee-for-service marketplace. At one time, physicians also exercised almost total control over hospitals in the United States. They believed that their preferred economic and institutional arrangements for hospitals were the best way to produce healthcare for their patients. For a number of years, the larger community accepted this rationale and granted physicians a great deal of control of healthcare economics and healthcare institutions, with dramatic changes in this regard coming only in the last decade of the twentieth century. Regarding these changes, however, note that the lessening of physicians' control of these aspects of healthcare has not entailed any lessening of the professional autonomy of physicians in matters central to their expertise, the first category of professional autonomy discussed above.

THE OBLIGATIONS OF PROFESSIONS AND PROFESSIONALS. The final and, for present purposes, the most important feature of the institution of profession is that membership in a profession implies the acceptance by its members of a set of ethical standards of professional practice. Contrasting what may be termed a "normative" picture of a profession with what may be termed a "commercial" picture may make this point clear.

According to the commercial picture, practicing a profession is no different in principle from selling one's wares in the marketplace. The professional has a product to sell and makes the appropriate and needed agreements with interested purchasers. Beyond some fundamental obligation not to coerce, cheat, or defraud others, the professional would have no other obligations to anyone except those voluntarily undertaken with specific individuals or groups. According to the commercial picture, in other words, there are no specifically professional values or obligations in any profession. There is nothing to which a person is obligated precisely because she is a professional.

Some commentators consider the commercial picture to be an accurate description of what professions are like, whereas others maintain that professionals or the community at large would be better off if professions conformed to this view more thoroughly (Sade; Kuskey). But recall that all professional groups have a corner on some valuable form of knowledge within a society. Wherever this is the case, there is power—power to control the knowledge itself and, especially, power over the aspects of human life that depend upon this knowledge. Now compare how various powerful groups are dealt with in U.S. society. Contrast professionals with politicians, for example.

Experience has taught that politicians will be tempted to misuse their power. Consequently, Americans want to keep a close eye on them. This is arguably one reason why Americans accept without too much complaint the terribly inefficient system of periodic reelection, to take one example—the system enables the populace to keep close watch over those with political power. This may also be why Americans tolerate the excesses of a free press, because a free press means that it will be that much harder for politicians to misuse their power.

But the professions, though they do face some measure of regulation through licensing boards and the like, are subjected to remarkably little oversight in U.S. society. In fact, even when there is regulation, professions are generally regulated by their own members, not the larger community. How does the community assure itself that the power of the professions will not be misused? The answer is: by means of the institutions of professional obligation.

When a person enters a profession, he undertakes obligations, obligations whose content has been worked out and is continually being affirmed or adjusted through an ongoing dialogue between the expert group and the larger community. In other words, there are conventional obligations, over and above obligations incurred in other human relationships, that both individuals and groups have simply because they are members of a profession. Professions and professionals have obligations, and the content of these obligations for each profession comprise the "professional ethics" of that profession. In this way, the way in which a profession functions within the larger community is inherently normative. That is, the institution of profession is such that for each profession there are ethical standards that apply both to the actions of the whole professional group and to the actions of each member of the profession.

The Chief Categories of Professional Norms

Although most professions have articulated a code of ethics or other statement of the norms of their professional practice, such statements are never complete or fully authoritative. They are, at best, good partial representations of the content of the profession's norms and obligations. The full content of these norms is the fruit of an ongoing dialogue between the expert group and the larger community, on whose recognition of expertise and grant of professional autonomy the expert group depends for its status as a profession. Therefore, the effort to answer such questions as "What professional norms apply to this situation?" and "What is a member of this profession obligated to do in this situation?" must include asking what the larger community understands those norms and obligations to be, rather than looking only at the views of the professional group or some organization(s) within it.

Determining a profession's norms is therefore a much subtler enterprise than it might seem. Even the well-known moral categories of autonomy, beneficence, maleficence, and justice are only a useful starting point. Another way to examine a profession's norms is in terms of nine categories of professional obligation that have been identified from studies of numerous professional groups (Ozar and Sokol). Each of these categories provides a set of questions about a profession's norms for use in personal reflection on one's obligations, in scholarly study, and in professional ethics education.

Briefly stated, the nine categories of questions about professional obligation are:

1. Who is (are) this profession's chief client(s)?
2. What are the central values of this profession?
3. What is the ideal relationship between a member of this profession and a client?
4. What sacrifices are required of members of this profession and in what respects do the obligations of this profession take priority over other morally relevant considerations affecting its members?
5. What are the norms of competence for this profession?
6. What is the ideal relationship between the members of this profession and co-professionals?
7. What is the ideal relationship between the members of this profession and the larger community?
8. What ought the members of this profession do to make access to the profession's services available to everyone who needs them?
9. What are the members of this profession obligated to do to preserve the integrity of their commitment to its values and to educate others about them?

THE CHIEF CLIENT. Every profession has a chief client or clients, which is a category or categories of persons whose well-being the profession and its members are chiefly committed to serving. (The English language does not have a satisfactory generic noun to refer to the person or class of persons whom a profession serves. *Beneficiary* is etymologically correct but is clumsy and typically associated with trusts or insurance. *Client* is too commercial in its connotations, but it seems better than any other term for present purposes.)

For some professions, the identification of the chief client seems quite easy. Surely, one might say, the chief client of a physician and a nurse, for example, is the patient. But who is the chief client of a lawyer? Is it simply the party whose case the lawyer represents or to whom the lawyer gives advice? Lawyers are told and they announce in their self-descriptions and codes of conduct that they have obligations to the whole justice system; therefore, there are things that they as professionals may not ethically do, even if doing them would advance the situation of the party they represent or advise. So it appears that the answer to the question about the chief client of the legal profession is complex, involving not only the persons lawyers represent or advise but also the whole justice system and/or perhaps the whole larger community served by that system.

Once this sort of complexity about the chief client is noticed, even those cases that initially appear simple prove more complex. The physician and the nurse must attend not only to the patient before them, for example, but also to those in the waiting room or to the other patients on the hospital unit, and so on. In fact, they have some obligations to all the patients in the institution where they work, or to all their patients of record if they are in private practice. They also have significant obligations to the public as a whole; for example, they are obligated to practice with caution so as not to spread infection from patients they are caring for either to themselves or to other patients.

In all cases, this question about the chief client is one of the first questions that must be asked if a particular profession's obligations are to become clear: Whom does the profession principally serve?

THE CENTRAL VALUES OF THE PROFESSION. Every profession is focused only on certain aspects of the well-being of its clients. The professions' rhetoric to the contrary, no professional group is expected by the larger community to be expert in their clients' whole well-being or to secure for its clients everything that is of value to them. There is, rather, a certain set of values that are the focus of each profession's expertise, and it is the job and obligation of that profession to work to secure these values for its clients. These values can be called the profession's central values.

Most professions are committed to pursuing more than one central value for clients. For example, whatever other values are central for a given profession, the value of client autonomy is ordinarily a central value as well. Efficiency in the use of resources may have a similar standing. In any case, if there is more than one central value for a given profession, the question can then be asked whether these values are all equal in rank, or whether the members of the profession are committed to choosing them in some ranked order when they cannot all be realized at once.

For example, the values proposed as the central values that the dental profession is committed to pursuing for its patients, in order of decreasing importance, are: life and general health; oral health (understood as appropriate and pain-free oral functioning); patient autonomy (i.e., patient control), whenever practicable, over what happens to her body; preferred patterns of dental practice; aesthetic considerations; and efficiency in the use of resources (Ozar and Sokol).

Every profession needs to ask and answer the question: What are its central values? What specific aspects of human well-being is it the task of each member of this profession to secure for clients? And if there are more than one, which takes precedence?

THE IDEAL RELATIONSHIP BETWEEN PROFESSIONAL AND CLIENT. The point of the relationship between a professional and a client is to bring about certain values for the client that cannot be achieved without the expertise of the professional. To achieve this, the professional and the client must both make a number of judgments and choices about the professional's interventions. This third category of professional norms addresses the proper roles of the professional and the client as they make these judgments and choices.

At least four general models of such relationships can be distinguished:

1. In a "commercial model," only the minimal morality of the marketplace governs. In other words, neither party has any obligations beyond a general prohibition on coercion and fraud, unless and until individuals freely contract together to be obligated toward each other in specific additional ways.
2. In a "guild model," the emphasis is on the professional's expertise and the client's lack of it, so that the professional alone is the active member in all judgments and choices about professional services for the client.
3. In an "agent model," the expertise of the professional is simply placed at the service of the values and goals of the client without interference by any competing goals or values, including values to which the profession is committed from the start.
4. In an "interactive model," both parties have irreplaceable contributions to make in the decision-making process. The professional offers expertise to help meet the client's needs and has a commitment to the profession's central values, and the client brings his own values and priorities as well as the value of his self-determination. Ideally, the two parties judge together what professional interventions will most benefit the client and choose together to carry them out.

In addition, because the ideal relationship is described in regard to fully functioning adults, a profession's norms must also include how its members are to interact with clients who are not capable of full participation in decision making about professional interventions. Such clients might include children, the developmentally disabled, and persons whose capacity to participate is diminished by fear, illness, or other conditions.

SACRIFICE AND THE RELATIVE PRIORITY OF THE CLIENT'S WELL-BEING. Most sociologists who study professions mention "commitment to service" or "commitment to the public" as one of the characteristic features of a profession. Similarly, most professional organizations' codes of ethics and other self-descriptions give clients' best interests or service to the public a prominent place. But these expressions are subject to many different interpretations with significantly different implications for actual practice.

Consider, for example, what could be called a "minimalist" interpretation of this general norm. According to this interpretation, a professional would have an obligation to consider the well-being of the client as only one of the professional's most important concerns. This is called a minimalist interpretation because if any less consideration than this were given, the client's well-being could not be said to have any priority at all for the professional.

On the other hand, according to a "maximalist" interpretation, the professional has an obligation to place the well-being of clients ahead of every other consideration, both the professional's own interests and all other obligations or concerns that the professional might have.

It is doubtful that either of these interpretations accurately represents what the larger community wants or understands in this matter. Professional obligation almost certainly requires that members of a profession accept certain sacrifices of other interests in the interest of their clients. On the other hand, even if it were only for the sake of assuring a continued supply of professionals to meet its needs in the future, the larger community certainly would not actually require the commitment of a member of any profession to be absolute or to impose the utmost of sacrifices for the sake of the client's well-being in all circumstances. The actual content of professional obligation in this respect lies somewhere in the middle.

Each professional group therefore has, as an element of its obligations worked out over time in dialogue with the larger community, an obligation to accept certain kinds of sacrifices, certain degrees of risk in certain matters, and so on. For health professionals there is a degree of risk of infection, accepted in order to serve their clients. In other professions it may be primarily a risk of financial loss, social loss, or criticism. In any case, it should be a part of reflection on every profession's ethics and a part of all professional ethics education to raise this issue and to try to identify the kinds and degrees of risk that are part of that profession's obligations.

COMPETENCE. Every professional is obligated both to acquire and to maintain the expertise needed to undertake her professional tasks, and every professional is obligated to undertake only those tasks that are within her competence.

Competence is probably the most obvious category of professional obligation. It is also the easiest to describe in a general way. For if a professional fails to apply his expertise, or fails to obtain the expertise for undertaking some task, these failures directly contradict both the point of being an expert and the very foundation of the larger community's award of decision-making power to the professional in the first place.

But determining what counts as competence on the part of a member of a given profession, both in general and in relation to specific tasks, is a complex matter. In practice, and almost of necessity, detailed judgments about requisite expertise are left to those who are expert—to the profession itself. But the larger community usually requires that explanations be given regarding the general reasoning involved. In particular, the community should understand the risk–benefit judgments involved in every determination of minimal competence. For as the level of competence identified as the minimum acceptable in some matter is raised, the relative availability of that level of expertise to the profession's clients will fall, and these trade-offs should be made in dialogue with the larger community, not unilaterally by members of the profession alone.

IDEAL RELATIONSHIPS BETWEEN CO-PROFESSIONALS. Each profession also has norms, mostly implicit and unexamined, concerning the proper relationship among members of the same profession in various matters and also among members of different professions when they are dealing with the same client. Some elements of the proper relationship between a family practitioner and a renal specialist, for example, are not matters of etiquette, but they bear directly on the medical profession's ability to achieve its proper ends. The same is true of relationships between physicians and nurses, dentists and dental hygienists, dentists and physicians, and so on, when they are caring for the same patient, and between architects and engineers when serving the same client.

Some aspects of these relationships are dictated by each professional's obligation not to practice beyond her competence and so to seek assistance from other professionals when a particular matter requires expertise that the first professional does not possess. But other aspects of co-professional relationships are also governed by professional norms, though they are rarely explicit. For example, how should co-professionals communicate with a client about their differing recommendations for the client when these differences derive not from differing interpretations of the facts, but from differing philosophies of practice within their different professions or from their professions' different or differently ranked central values?

THE RELATIONSHIP BETWEEN THE PROFESSION AND THE LARGER COMMUNITY. The activities of every profession also involve diverse relationships between the profession as a group, or its individual members, and persons who are neither co-professionals nor clients. These relationships may involve the larger community as a whole, various significant subgroups, or specific individuals. Every profession, precisely because it is permitted to be self-regulating, for example, owes the larger community the effort needed to carry out this task conscientiously. This includes providing and monitoring educational programs and institutions in which new members of the profession receive their formation as professionals; monitoring the collective activities of members of the profession in their various professional organizations to make sure that these organizations act in ways consistent with the other professional obligations of the members; and having measures in place to monitor and correct incompetent or other professionally inappropriate practice on the part of individual members of the group.

Each profession has an educational obligation to the larger community. The reason is that both through actions of its individual members and through collective actions, every profession functions as the principal educator of the community regarding those elements of the profession's expertise that the lay community needs to understand in order to function effectively in ordinary life. Thus, for example, the health professions have obligations regarding public education in matters of ordinary health self-care and hygiene; and the engineering and scientific professions have obligations to educate regarding safety practices that the lay community needs to know in daily life.

A more subtle kind of obligation in relation to the larger community has to do with the content of key value concepts that become part of the public culture and play crucial roles in people's private lives and especially in public policy, but whose content is significantly influenced by the members of a profession or of a group of professions. For example, the engineering professions have a powerful formative influence on the culturally dominant notions of safety and physical risk; the health professions are more responsible than any other group for educating the public about what it means to be healthy; and so on. This is an area of professional obligation to the larger community that has received little attention but is of continuing ethical significance.

ACCESS TO PROFESSIONAL SERVICES. Professional services are distributed within a society by a complex system of economic, legal, and social structures. These structures principally determine who in the society will have access to the services of the professions when they need them. But because every professional is committed to the values that are central to his profession, no professional can consistently be indifferent when a significant number of people in the society need professional assistance to achieve these values and their need remains unmet.

There is, however, no single best answer to the question, "What ought I do when the society's distribution system leaves people in need of my profession's services without access to them?" Individual professionals will respond to this aspect of their professional obligation in different ways. For some it will involve pro bono or charity service of one sort or another. For others it will involve advocacy for changes in the distribution system or for publicly funded programs to provide services for the underserved. Others may focus on the value judgments being made by public decision makers who are arguably giving too low a priority to the kinds of well-being the profession provides. But in any case, access to the profession's services on the part of those in the society who need them is a matter that deserves special notice and explicit attention in the articulation of every profession's ethic.

INTEGRITY AND EDUCATION. Finally, there is that very subtle component of conduct by which a person communicates to others what she stands for, not only in the person's acts themselves but also in how these acts are chosen and in how the person presents herself to others in carrying them out. The two words that seem to communicate the core of this concern are *integrity* and *education,* especially when the two words are paired.

Each profession stands for, or "professes," certain values that it is committed to bringing about both for its clients individually and for the community at large. But a professional's personal priorities may communicate a different set of values, even though the professional's choices of interventions for clients and his efforts to secure appropriate relationships with clients all conform to accepted standards. Concern with this kind of communication to their patients and to the general public, for example, motivates some health professionals to establish in their personal lives patterns of healthy living consonant with what they say to their patients. Failure to attend to this element of professional commitment also makes illegal personal activities on the part of lawyers somehow doubly wrong.

Professionals may be obligated, then, to do some things and to refrain from doing others in order to remain true to the values that their profession stands for and thereby to educate others in these values by their own example.

There are undoubtedly other useful ways of dividing the general topic of professional obligation besides these nine categories. The point is that conceptual tools such as the key features of the institution of profession and the principal categories of professional obligation can assist professionals in determining their own obligations in general and in particular cases, and can assist scholars and educators of professional ethics to gain a clearer understanding of professional practice and of the ethical standards that apply to it.

Alternative Views of Profession

The account just given explains the institution of profession in terms of its function in society, as a means by which a society secures the benefits of specialized expertise for its members and prevents or at least limits its misuse by those who possess it. Like every account of a thing's function, this account is both descriptive and normative. It describes how professions and their members act, at least for the most part, and it identifies sets of standards by which their successes and failures to act in those ways are to be judged.

The principal alternative ways of explaining the institution of profession can be described under four headings: historical, critical functionalist, radical democratic, and personalist. Each of these approaches separates the descriptive and normative elements that are interwoven in a functionalist account, with the first and second stressing the descriptive elements and the third and fourth the normative elements.

Historical explanations of the institution of profession identify, through historical study, a developmental pattern that brings an occupational group to the point of being considered a profession. This pattern is then used normatively to determine whether particular occupational groups qualify as professions and what patterns of conduct by these groups conform or do not conform to the pattern. Some historical studies of professions do not purport to explain the institution of profession, of course, but simply tell part of its story without attempting to draw normative conclusions. Historical explanations may depend, at least initially, on some functionalist account of profession or on the selection of certain occupations, in their contemporary form or otherwise, as endpoints or at least markers of the developmental process being studied. But once a developmental explanation has been formulated, it can then be offered to replace functionalist accounts on the grounds that these are excessively idealized and are not adequately descriptive of the current or historical conduct of relevant groups. For example, the medical profession in the mid-twentieth century has been described as the product of a process of monopolization, or gradual acquisition of control by an exclusive group over a segment of market activity over the years (Berlant). The institution of profession generally has been described as a specialized mechanism for maintaining economic power and class-based status and dominance (Larson).

Some critics of the professions formulate a functionalist account of the institution for themselves, or accept someone else's, and then use its normative content to critique current patterns of conduct of individuals and organizations within a particular profession or across the professions generally (Freidson). Other functionalist critics argue that currently accepted functionalist accounts are so idealized—that is, pay so little attention to the gap between what is described as the profession's function and the profession's actual conduct—that they leave unchallenged actual or potential harm to the community by the professions or at least do not call upon the professions strongly enough to correct their inadequacies for the community's sake. Therefore, an alternative account of the function of professions and professionals is proposed, and its implications for professional conduct are identified (Kultgen).

Radical democratic critics of the institution of profession believe that any society that accepts this institution makes a profound mistake. It is central to the institution of profession that the possession of expertise is a basis of power and that one element of that power is a grant of autonomy to those possessed of it. By institutionalizing deep inequalities of power and autonomy in this way, these critics argue, a society makes the achievement of genuine democracy almost impossible. According to the radical democrat, the failures in conduct pointed out by functionalist critics and the developmental patterns leading to monopoly and to other forms of economic and class-based inequality that the historical critics point out are not historically contingent events but the inevitable outcomes of the inherently undemocratic constitution of the institution of profession. For these thinkers the solution, on which the well-being of the human community depends, is to do away with the institution of profession and all other institutions grounded on undemocratic premises (Illich, 1973, 1976).

The personalist explanation of profession identifies the individual professional's act of personal commitment upon entering a profession as the basis of everything morally significant about the institution of profession. As centuries ago a solemn vow initiated a person's membership into a profession—a vestige of which remains, for example, in the ceremony in which new physicians speak the Hippocratic Oath—so today the act of personal commitment by each member of a profession is what brings the profession continually into being and gives it its character. The contents of a profession's norms are determined by the contents of these personal acts of commitment; and the professional who falls short in conduct fails above all to honor her own commitment to serve others, rather than failing to follow a norm created and sustained principally, according to the account proposed here, by the mutual effort of the profession and the community at large (Pellegrino; Pellegrino and Thomasma).

Each of these approaches stresses a feature of the institution of profession that standard functionalist accounts are held to overlook or underestimate: the developmental patterns by which professions and professionals are formed; the extent to which professions' and professionals' actual conduct falls short of the functionalist's proposed norms; the undemocratic character of exclusive expertise; and the centrality of the act of commitment by which a person becomes a professional. More complex functionalist accounts could incorporate much that is stressed in these other approaches, as more complex versions of each of them could incorporate emphases and concerns from the others. From the point of view of understanding professions as they exist, in other words, each of these approaches teaches something of importance and all deserve careful study.

Changing Times, Changing Standards, Changing Concepts

It is not only the conduct of individuals and groups, as measured by professional norms, that can fall short of what ought to be. Professional norms themselves can fall short of what they ought to be, particularly when important characteristics of a society undergo change. There was a time, for example, when the general level of education in the United States may well have justified an ethics in which the ideal patient–practitioner relationship for physicians and dentists conformed to the guild model rather than the interactive model, whereas the latter has become normative for these professions in the years since the 1970s.

A profession's norms and the institution of profession itself are human constructs and, like all things of human making, they can fall short of their intended goals, and the goals themselves can change with changing times. When norms and institutions are no longer able to do the tasks that a society needs them to do, then the society is justified in trying to change them. But social structures such as professions are inherently conservative, in the root sense of that word; they exist to preserve a mode of acting or of organizing conduct that has proven fruitful, and they preserve it by forming in their participants strong habits of perceiving, judging, and acting in ways that support it.

So when times and expectations change, or people's values or abilities change, or the surrounding social institutions change, then it is important to reexamine the relevant norms and institutions to see if they are still appropriate and to change them if they are not, even if this involves a major transformation of a particular profession's norms across many of the nine categories. One of the weaknesses of functionalist accounts of the institution of profession in the minds of critics is that such accounts seem to say that whatever is the case is what ought to be the case. But, like the other four approaches, the functionalist account is simply a conceptual tool whose purpose is to help a society understand what it has when it has a particular profession with a particular set of norms so that the society can then make a judgment on whether that is the profession that ought to exist.

In an analogous way, the new professional enters a profession whose norms are already in place. This does not mean that these norms cannot be changed, but they achieve their content by means of an ongoing dialogue between the profession and the larger community, and they change their content in the same way. So the new professional cannot create the contents of his professional obligations out of whole cloth. Yet, even in the individual case, the norms of the profession are not the ultimate determiners of right and wrong. If these norms are in conflict with one another or with other important moral considerations, or if they are severely defective in some way, then the professional must form his own conscience to decide how to act. Situations arise in which conscientious disobedience of a professional norm is what a person's moral judgment requires when all things about a situation are considered.

By what standards should a society judge a profession's norms when their adequacy to the society's needs is in question? By what standard should the institution of profession itself be judged? By what standard should the individual professional form her own conscience when conflict or severe doubt about the adequacy of a professional norm in a particular case suggests that conscientious disobedience may be the correct path? Surely not by the norms of the profession, because these are precisely what are being challenged when such questions arise. It is to the deeper values and standards of human conduct and social life that individuals must turn at such times, for it is upon them that the norms of professions rest for their moral force in the first place.

As is true for many other human institutions, if the institution of profession did not exist, it or something like it would need to be invented in order for people to live together effectively. For no one person can master all the knowledge and skills on which the achievement of so many important values in human life depend. But, like other human institutions, the institution of profession as a whole, and each individual profession, and each normative feature of each profession, requires regular ethical scrutiny to make sure it continues to fulfill the purposes for which it was made. One of the principal roles of the field of bioethics and its practitioners is to provide the members of the health professions and the larger community with effective conceptual tools to employ in this scrutiny.

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SEE ALSO: *Care; Compassionate Love; Competency; Confidentiality; Conflict of Interest; Divided Loyalties in Mental Healthcare; Impaired Professionals; Information Disclosure, Ethical Issues of; Informed Consent; Medicine, Profession of; Professional-Patient Relationship; Nursing, Profession of; Teams, Healthcare; Psychiatry, Abuses of; Sexual Ethics and Professional Standards*

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PROFIT AND COMMERCIALISM

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The practice of medicine is clearly a profession, as usually defined. In some senses it is also a business. However, the extent to which the professional behavior of physicians ought to be influenced by business considerations is a matter of debate (Veatch). A more general but closely related question is the degree to which business values should control the healthcare system (Gray).

Physicians in private practice must generate income to pay their costs and earn a livelihood. In this sense, profit (the excess of gross revenues over costs) is as economically important in the fee-for-service practice of medicine as it is in the conduct of a business. But some have carried the analogy further and have maintained that the payment of a fee is an essential part of the professional relation between physicians and patients, because this relation is in effect a commercial contract between the supplier of a service (the physician) and the purchaser of a service (the patient). Although the service is professional, and therefore involves more constraints and responsibilities for the supplier than does an ordinary market transaction, this interpretation of medical practice effectively blurs most of the distinctions between medicine and business (Sade). This argument further asserts that physicians may choose to offer their services to indigent patients gratis or at reduced rates, but their professional status does not require them to do so. Nor are physicians required to ignore or minimize their own economic interests when making professional decisions, provided their treatment is medically appropriate (Engelhardt and Rie).

Opposed to this point of view is the perhaps more traditional interpretation that regards medical practice primarily as a ministering function—a commitment to serve the needs of patients without concern for self-interest (Relman, 1992). According to this interpretation, profit may be an economic necessity in fee-for-service practice, in the aggregate if not in each individual case, but a de facto contract binding all physicians establishes an overriding obligation to serve those in need of medical care regardless of their ability to pay. Furthermore, fee for service is not considered to be a critical, or even an important, feature of professional practice. In this view, the contract between doctor and patient is basically ethical, not commercial, and is seen as part of a broader commitment that physicians make to society in exchange for licensure, authority, and the many other benefits bestowed on them by the state.

Although there has always been an uneasy tension between these two perspectives, until recently the traditional view of the ethical obligations of the medical profession generally prevailed. Most people considered medical care to be a social good, not an economic commodity, and most physicians and medical professional organizations acted as if they agreed. For example, the version of the American Medical Association's (AMA) ethical code prevailing from 1957 to 1980 said: "The practice of medicine should not be commercialized nor treated as a commodity in trade" (AMA Judicial Council, 1969, p. 28). Advertising was discouraged, and physicians were advised to limit the source of their professional incomes to services to patients rendered by them or under their supervision (AMA Judicial Council, 1969).

A similar view of the role of hospitals as essentially not-for-profit social institutions was widely accepted. Although many small proprietary hospitals existed in the early part of the twentieth century, until fairly recently virtually all hospitals larger than seventy-five beds were public or private, not-for-profit institutions that considered their primary mission to be public service. Most of the private, not-for-profit (voluntary) hospitals admitted patients—particularly those who were acutely or seriously ill—without regard to income, and many accepted less than full payment from patients with limited means. They sometimes operated at a deficit and depended on philanthropy, public contributions, or other non-patient-derived income to continue operation. The public hospitals, of course, were tax supported and were not expected to meet their expenses from patient revenues.

Beginning in the late 1960s, however, a new commercial spirit began to permeate the healthcare system (Relman, 1980; Gray). It started with the hospitals but soon spread rapidly to virtually every other part of the system. In response to the growing opportunities for profit resulting from the expansion of government-supported health insurance through Medicare and Medicaid in the 1960s and employment-based private health insurance, large chains of investor-owned hospitals sprang up in many communities. Other types of for-profit medical facilities and services soon followed, attracted by the seemingly unlimited opportunities for financial gain. Today about 15 percent of all private general hospitals and the majority of private nursing homes, psychiatric hospitals, and free-standing ambulatory care and diagnostic facilities are owned by for-profit corporations. When the Clinton administration's proposals for health insurance reform failed in 1994, for-profit companies selling managed care insurance quickly filled the breach. By the beginning of the twenty-first century, the great majority of private health insurance plans were owned by investor-owned companies. So were most private indemnity health insurance companies, and most healthcare management and consulting services. Together with the new and rapidly-growing biotechnology companies and the traditional pharmaceutical and medical supplies and equipment industries, these for-profit businesses constitute a vast commercial network with a pervasive and powerful influence on the U.S. healthcare system. In no other country is so much of the healthcare delivery and insurance system operated by investor-owned corporations, and in no other country does private business have so large a stake in healthcare policy.

Even the not-for-profit voluntary hospitals have become infused with the entrepreneurial spirit. Overexpansion of hospital capacity and competition from investor-owned healthcare facilities, both in-patient and ambulatory, forced voluntary hospitals to become more competitive. Private managed care insurance and federal insurance programs have pressured the not-for-profit hospitals to accept lower payments. As a result, their marketing and advertising efforts, and their preoccupation with the generation of revenue, are almost indistinguishable from those of their investor-owned competitors. Care of the indigent, once considered a prime responsibility of voluntary as well as public hospitals, has been increasingly shifted to public institutions. Pressures to control costs have led to reductions in hospital staff and shortened lengths of stay, which may adversely affect quality of care.

Practitioners first began to feel economic pressures in the decade of the 1980s, and these pressures have increased since then, forcing them, like the hospitals, into more entrepreneurial behavior. The numbers of competing specialists have grown rapidly, while available fee-for-service patients have become more scarce and insurance companies have shifted from unquestioning payment of the doctor's bill to increasingly stringent efforts to control expenses through capitated and discounted payment, and through managed care. Medicare fees are also being reduced. To protect their income, many physicians began to act like competing businesspeople seeking more customers and more ways to deliver profitable services (Relman, 1988). Physicians have also become interested in opportunities to increase their revenues through partnership in, or ownership of, healthcare facilities and through financial arrangements with companies supplying the drugs, devices, or diagnostic services they prescribe for their patients. In many parts of the United States, practicing physicians refer their patients to free-standing diagnostic or ambulatory surgery facilities in which the physicians hold financial interest—a practice called *self-referral.*

In 1975 the U.S. Supreme Court declared that the reach of antitrust law extended to the professions (*Goldfarb v. Virginia State Bar,* 1975), and shortly thereafter the AMA was legally enjoined from interfering with the advertising and marketing practices in which increasing numbers of physicians were engaged. In response to the growing view that healthcare was a competitive marketplace and physicians were essentially small independent entrepreneurs, the AMA retreated in the 1980s from its earlier proscriptions against commercialization. Its 1982 revised ethical code says nothing about the distinction between medical practice and trade; instead, there is a statement that competition is "not only ethical but is encouraged" (AMA Judicial Council, 1982, p. 22). Advertising was sanctioned provided it was not misleading, and the earlier restriction on sources of professional income was removed. Self-referral and other kinds of economic interests by physicians in the medical products they prescribe were said to be ethical, provided the financial interest was disclosed to patients and did not influence medical judgment. The most recent AMA position (AMA, 1998, p. 121) puts additional restraints on self-referral, but does not prohibit it altogether.

Ethical issues aside, does the commercialization of the healthcare system bestow any special benefit on patients or on society in general? In most sectors of the economy, free market competition among suppliers of goods and services helps to control prices and encourages quality. Although suppliers promote consumption through marketing and advertising, the cost-conscious choices of consumers largely determine the number of units purchased and the total expenditures allotted to each product. Goods and services are distributed primarily according to consumers' desires, their judgments about price and quality, and their ability to pay—all of which is believed to serve useful social purposes.

But the healthcare sector is quite different from most other parts of the economy, and the consequences of market competition are not the same. Consumers (patients) can make relatively few independent and informed purchasing decisions because they must rely so heavily on advice from their physicians. And because of third-party payment, neither the consumer nor the provider of services (the physician) is much constrained by cost. Physicians largely determine the distribution and use of services. Professional judgment of the patient's medical needs is the primary consideration, but the economic benefits to the physician and the healthcare institution also play a role, particularly when the medical needs are optional or uncertain. Therefore, when healthcare that is paid on a fee-for-service basis becomes commercialized, competition serves not to limit but to increase expenditures, because providers have greater economic incentives to offer their services to patients who are, for the most part, dependent and unresisting consumers. Profit motives thus intensify inflation in a healthcare system unless it has effective cost-control mechanisms.

On the other hand, when payment for medical services is made in advance, as in HMOs and other kinds of prepaid managed care, economic incentives tend to force physicians and hospitals to reduce, rather than increase, their allocation of elective services to patients. In such a system insurers and providers profit most when medical expenditures are kept to a minimum. Commercialization of managed care thus raises concerns about cutting corners and underserving patients' needs, just as the commercialization of fee-for-service care raises concerns about excessive and unnecessary services. In both cases, there is the risk that the profit motive may influence professional judgment and make it more difficult for physicians to act in the best interests of their patients.

Furthermore, a commercialized healthcare system has little concern for the needs of the uninsured and the underinsured. Unless government intervenes, those without means to pay are denied access to all but emergency care. The steadily rising number of uninsured and underinsured patients testifies to the social indifference of a profit-oriented medical marketplace and to the inability of tax-supported institutions to accept the growing burden of the medically indigent. It is currently estimated that about 15 percent of the U.S. population has no medical insurance and that at least as many are seriously underinsured. Efforts by providers of medical care to remain economically viable may require them not only to restrict charity but also to promote profitable services, which may not be those most needed by the community.

Proponents of commercialization in healthcare argue that it rewards innovation and technological development. They say that one of the benefits of an expanding medical marketplace is stimulation of applied research and development, leading to the more rapid introduction and dissemination of useful new products. However, there is no reason to believe that the pace of worthwhile innovation would be significantly slowed in a system that encouraged research and development but allowed industry to market only properly tested new products, and restrained entrepreneurialism in the delivery of medical care. The current dominance of the United States in the development of new medical technology is probably the result more of substantial public support of medical research than of the commercialization of the healthcare system.

Avocates of for-profit healthcare also claim that market competition and commercial incentives improve the quality and efficiency of medical services. What little data there are on comparative quality seem to suggest the opposite. For example, studies of the quality of care in investor-owned hospitals (Devereaux et al.), kidney dialysis centers (Garg et al.) and nursing homes (Harrington et al.) show serious deficiencies in comparison with similar but not-for-profit facilities. The efficiency of medical care, on the one hand, is hard to define and measure. Some suggest that efficiency means the delivery of medically acceptable care at lower cost to the payer, but there simply aren't any good studies that would allow comparison of for-profit and not-for-profit services by that kind of measure. However, administrative and total costs in for-profit hospitals have been reported to be higher than in their not-for-profit counterparts (Woolhandler and Himmelstein).

In short, defenders of commercialism in healthcare have no firm empirical support for their arguments. Instead, their position is largely based on the assumption that market incentives will improve services in healthcare, just as they are supposed to do in ordinary commerce. However, as already noted, there is reason to question that assumption. This issue has been hotly debated ever since the introduction of managed care. Those who believe that the era of the "corporate practice of medicine" has arrived assert that old-fashioned medical professionalism is becoming obsolete (Robinson), but there are still influential voices defending the traditional ethical values (Freidson).

It remains to be seen whether commercialism in medicine will continue to grow and ultimately dominate the U.S. healthcare system. Those who believe medical care is a business like any other regard such an outcome as desirable and necessary for the achievement of optimal efficiency. On the other hand, those who believe medical care is primarily a social rather than an economic good hope that the present trend toward commercialism will be resisted and in the long run reversed. They believe the ultimate solution of the healthcare problems in the United States will be found through social action and community responsibility.

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SEE ALSO: *Advertising; Commercialism in Scientific Research; Economic Concepts in Healthcare; Health Insurance; Healthcare Institutions; Managed Care; Pharmaceutical Industry*

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PSYCHIATRY, ABUSES OF

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Abuse of psychiatry conjures up a situation in which a psychiatrist acts improperly, causing a patient to experience some sort of harm. The concept is more complex than it appears to be at first sight. This article examines psychiatric abuse in an effort to determine its accurate meaning so that steps can be taken to eliminate or prevent it.

Historical Background

Evidence has emerged of such practices as the abuse of psychiatry for political purposes in the former Soviet Union (Bloch and Reddaway, 1977, 1984), a similar pattern in Cuba designed to suppress political dissent (Brown and Lago), the deployment of psychiatric knowledge in torture and interrogation in Northern Ireland in 1971 (Bloch, 1990), and pursuit of financial profit as a priority in Japanese private psychiatric hospitals (Harding). The tragic perversion of psychiatry during the Nazi era, in which tens of thousands of chronic psychiatric and mentally retarded patients were gassed to death, and similar numbers were sterilized, is the most gross instance of abuse (Burleigh; Müller-Hill).

Commentary on psychiatric abuse has also referred to its prevalence elsewhere particularly in the United States and South Africa. But, as will become evident in the section on definition, care must be taken to distinguish between intentional misapplication of psychiatric knowledge, skills, and technology and inadequate or negligent practice. In the South African case, the policy of apartheid involved massive inequity in the provision of mental health services, with blacks allocated substantially lesser resources compared with whites despite equivalent need. On the other hand, the allegation of the misuse of psychiatry to squelch black political activism never had any basis (Bloch, 1984).

In the United States, discriminatory practices have also occurred but due to economic rather than explicitly political forces. With millions of Americans unable to afford health insurance and inadequate budgets for public psychiatric services, the result has been substandard care in state mental hospitals, particularly for minority groups and the poor (frequently the same population) (Green and Bloch; Torrey).

The abuse of psychiatry for political or other purposes in the United States has been sporadic, the examples of the poet Ezra Pound (1885–1972) and General Edwin Walker (1909–1993) being especially well known. In the case of Pound, psychiatry was recruited to deal with a politically sensitive situation. A celebrated poet, indicted for treason following his pro-Axis broadcasts in Italy during World War II, Pound faced possible execution. Although the evidence was equivocal, Pound was judged incompetent to stand trial on grounds of insanity and transferred to St. Elizabeth's Psychiatric Hospital where he spent the next thirteen years. The indictment was later dismissed and Pound released. Whether psychiatry was misused to extricate the U.S. government from a quandary or Pound was deluded and this accounted for his wartime behavior remains a baffling issue. Suffice to say, the case demonstrates the vulnerability of psychiatry to political exploitation.

Similar factors prevailed in the case of Edwin Walker, a decorated major general in the American army who adopted an extreme right-wing position during the civil rights campaigns of the 1950s and the 1960s. His competence became a matter of dispute after he had been charged with offenses related to his activism. Although declared competent to stand trial (the case was later dismissed for technical reasons), the possibility of the government's recourse to psychiatry to deal more conveniently with a *troublemaker* cannot be ruled out (Stone).

A final comment in this brief historical context concerns criticism of psychiatry for its patronizing attitude toward women. The dramatic case of Mrs. E. P. W. Packard in 1860 illustrates how prejudice may undermine clinical judgment. Upon the insistence of her husband, a fundamentalist clergyman, that she harbored dangerous religious beliefs, Mrs. Packard was committed to a mental hospital, where she remained confined for three years. Upon her release, she launched a campaign against the expression of opinions as a basis for psychiatric detention (Musto).

Over a century later in 1972, Phyllis Chesler was among the first to argue that psychiatry's view of women was so distorted as to impair its objectivity. Other feminist perspectives followed (e.g., Showalter; Luepnitz). According to this view, a male-dominated profession too readily regards women not conforming to stereotypic roles as psychologically suspect, even disturbed. Freud's contribution to gender psychology has no doubt been influential in the maintenance of such attitudes.

Definitions

Psychiatric abuse can be defined according to specified criteria and differentiated from other undesirable activities, which are best termed *malpractice. Abuse* refers to the intentional, improper application of the knowledge, skills, and technology of psychiatry for a purpose other than serving the patient's interests or to harm, in diverse ways, people who do not warrant psychiatric status in the first instance. Abuse is invariably perpetrated by psychiatrists (and other mental health professionals) in collaboration with other persons or agencies, such as a state security service or political authority and, then, usually as part of a totalitarian system.

Such institutional abuse is always unethical in that the protagonist intentionally carries out an act in the knowledge that the act is intrinsically wrong (whether or not it turns out to harm), explicitly violating professional ethics. A psychiatrist who acts in this way, claiming that he is obliged to follow the orders of superiors and in that sense is heteronymous, is inexcusably rejecting a responsibility to ensure that regulations serve good, not bad, professional goals. In these circumstances, even if psychiatrists covertly seek to ameliorate the welfare of the patient, claiming that this is the sole means to maintain an ethical stance, their behavior, by virtue of colluding in an abusive practice, becomes an inherent part of the abuse.

Reference to institutional abuse, on which this article focuses, does not negate the possibility of individual psychiatrists abusing one or more of their own patients. A similar ethical violation takes place in both cases, psychiatrists in the latter exploiting patients to meet their personal needs on the pretext that the practice applied is clinically indicated. A clear-cut example is sexual involvement, but other forms of abuse of power intrinsic to the psychiatrist–patient relationship, such as financial and religious, are relevant here. This sort of abuse may mar any doctor–patient relationship, but the not uncommon situation in psychiatric treatment of an excessively vulnerable patient seeking comfort from an ostensibly all-caring professional is arguably more conducive to its occurrence than in other medical spheres.

Abuse can also be perpetrated by a psychiatrist in conjunction with, or acceding to, attempts by lay people to exploit the discipline for nonmedical purposes. Consider this example: A husband who knows that his wife is not mentally ill, but is determined to gain custody over their children in an impending legal tussle, persuades a psychiatrist to commit her to a mental hospital. His interests are other than the welfare of his wife; he desires to wield power over her for his own purposes and recruits the psychiatrist as an accessory (Robitscher).

Malpractice is distinguishable from abuse with respect to intent. Although the term is used in diverse ways, an alternative remains elusive; *inadequate practice* comes closest in meaning. A psychiatrist who does not set out to use knowledge, skills, or technology improperly but who deploys these in an unskilled fashion is engaging in malpractice. An example is prescribing psychotropic drugs for patients upon the request of nursing staff, who claim they are otherwise unable to manage “difficult behavior,” in cases where patients do not need such medication. Psychiatrists do not pervert their science in these circumstances but fail to adhere to a standard of practice that requires the application of drugs only when clinically indicated. Malpractice should be differentiated from “errors in clinical judgment” when that judgment has been made in good faith. Psychiatrists, like any other professionals, are prone to err on occasion. Although the consequences may simulate the effects of malpractice, malpractice is not actually carried out.

The Vulnerability of Psychiatry to Abuse

Abuse is more common in psychiatry than elsewhere in medicine, probably because it is inherently more vulnerable to it in at least three respects: (1) its boundaries remain ill-defined; (2) diagnosis is often made in the absence of objective criteria; and (3) the psychiatrist is granted immense power by society to determine the fate of other people, even to the extent of detaining them in hospital or imposing treatment on them.

The lack of a well-demarcated conceptual boundary in psychiatry leads to a correspondingly ill-defined role for its practitioners. Debate has long continued among psychiatrists themselves, and in the wider community, as to what constitutes their legitimate role (Dyer). Attitudes vary considerably, even to the point of contradiction. The following views, expressed by former presidents of the American Psychiatric Association, reflect this diversity. In 1969 Ewald Busse argued for a limited role whereby psychiatrists restrict their focus to the suffering patient, and services are accordingly confined to reducing pain and discomfort. In 1970 his colleague Raymond Waggoner had a much wider perspective, calling upon the profession to pursue “fundamental social goals,” and for psychiatrists to be visionaries.

Definitions of health and ill health are pertinent to the above positions. Thus, a *visionary* outlook brings psychiatrists into the domain of social policy. Their potential participation in a context beyond hospital and clinic is boundless, leading to professional judgements, ostensibly derived from expertise, on social issues like unemployment, racism, poverty, torture, religious cults, child-rearing practices, sexual expression, and indigenous rights. Psychiatrists may assume roles, including those of social commentator, political activist and lobbyist, that extend well beyond the traditional role of clinician.

Whatever the role adopted, psychiatrists are buffeted by the demands of multiple loyalties. They are caught ineluctably between responsibilities to patients and to society, the latter potentially including, among others, a patient’s family, an employer, the courts, prison officials, and military authorities. In these circumstances they have to weigh the interests of patients against those of social agencies. In so doing, they may be subject to such intense pressure as to subordinate themselves to social forces, and so neglect their obligation to patients.

Psychiatry’s role is more clear-cut when limited to an exclusively medical function. But this depends on the psychiatrist’s ability to conduct diagnostic assessments that are relatively objective and value-free—for example, in the case of a person with a brain disorder like Alzheimer’s Disease. This brings us to the second feature of psychiatry that contributes to its vulnerability to abuse, lack of objective criteria in clinical evaluation.

Although psychiatry has evolved as a scientific discipline for over a century and a half, including progress in classification, the discipline still faces the key question of what constitutes mental illness (Fulford, 1989). No satisfactory criteria exist to define precisely many of the conditions with which psychiatry deals. Compared with those in other medical fields, many currently used psychiatric diagnoses derive from clinical observation alone, and lack identifiable pathophysiological correlates. Objective tests to confirm the presence of a psychiatric condition are rare.

Moreover, in the diagnostic task psychiatrists rely in uncomfortably large measure on social criteria and value judgments. As the British sociologist Kathleen Jones reminds us, society would not be able to determine what was normal if it failed to designate certain acts and certain people as abnormal or antisocial. William Fulford and Walter Reich have contributed handsomely to the question of what constitutes a mental disorder by dissecting the complex process psychiatrists use to determine whether a diagnosis should be applied to a specific constellation of mental or behavioral features. Fulford (1999) stresses the place of values in clinical practice overall, positing that diagnoses in both physical and psychological medicine are an admixture of the factual and the evaluative. For him the concept of mental illness is on the same logical platform as the concept of physical illness.

Reich makes explicit the vulnerability of the diagnostic process in psychiatry to error given its reliance on subjective criteria, the intrusion of bias and prejudice and shifting criteria leading to inconsistency and frequent change. Consider the illustrative diagnostic controversies which buttress Reich's contentions: the deletion of homosexuality as a condition following a poll of members of the American Psychiatric Association in 1973; intense debates over whether a concept like attention-deficit hyperactivity in children or in adults is valid; and the question of whether antisocial personality disorder is a valid disorder of personality functioning or mere social deviance (and therefore belongs within the sphere of crime and delinquency). Many more examples could be added to this list.

In the context of an ill-defined professional framework and the vague criteria for diagnosis, the psychiatrist is sanctioned by law to manage the situation in which a person suffers or is suspected of suffering from mental illness that may require enforced hospitalization and/or treatment to protect a person's welfare or that of others (Peele and Chodoff). This is an awesome responsibility in that a person may be deprived of his liberty, lose basic civil rights, and be subject to a range of legal regulations.

Although commitment statutes in many jurisdictions, particularly those pertaining to determining the risk of dangerousness to self and/or others, have been rigorously scrutinized, a disconcerting uncertainty persists as to what constitute relevant criteria. Psychiatrists are caught in a dilemma of having to arrive at a judgment about a person's clinical needs and protecting her civil rights at the same time. The civil libertarian would insist that an inalienable right to liberty should be guaranteed above all other considerations whereas those with a paternalistic outlook would aver that society, through its legally sanctioned agents, has an obligation periodically to take measures, undesirable as they may be, to protect patient, society, or both from harm.

Soviet Psychiatric Abuse

In summary, ill-defined boundaries, the subjective basis of assessment, and the authority to treat a person involuntarily combine to make psychiatry especially vulnerable to abuse. The most clear-cut illustration of this was the use of psychiatry in the former Soviet Union to suppress political, religious, and other forms of dissent. These practices have been analyzed at length by several observers (Bloch and Reddaway 1977, 1984; see also Bukovsky; Plyushch).

Soviet psychiatry's boundaries were drawn in such a way that made the entire discipline subordinate to the pervasive influence, overt and covert, of the Soviet state and, more particularly, of the Communist Party. The monolithic form of the administrative structure, with power wielded by a small, compliant group of psychiatrists, allowed a political authority to mould the functions of all Soviet psychiatrists. Even if professional boundaries had been clearer, the totalitarian nature of the Soviet state prevented psychiatrists from functioning autonomously. The fact that boundaries were blurred made it all the easier for the state to exert control and influence the profession in terms of its ideology. The Soviet government's avowal that the interests of society were as pertinent as those of the individual paved the way for the principle of respect for autonomy to be undermined.

The Soviet abuse is a blatant reminder that psychiatrists may function in a state whose interests do not serve those of the society. The corollary is obvious—psychiatrists must act independently with regard to ethical standards.

The lack of objective criteria for diagnostic evaluation permitted the evolution of an idiosyncratic taxonomic scheme in Soviet psychiatry for virtually four decades. Andrei Snezhnevsky rapidly ascended to the pinnacle of the psychiatric establishment during the 1950s, and from that impregnable position launched a unique classificatory system of mental illness. A crucial result was the profound shift in the way schizophrenia was conceptualized. Snezhnevsky advanced several claims, among them the notion that since the illness could be present in a person showing minimal features, schizophrenia was much more common than previously thought. A form of the illness, *sluggish schizophrenia,* named thus because of its slow progression, accounted for the wider limits placed on the use of the diagnosis. When suppression of dissent by psychiatric means escalated in the 1960s, the label *sluggish schizophrenia,* was commonly applied to political, religious, and other dissidents whom the state wished to disempower and punish (Reich; Bloch and Reddaway, 1977).

Although this framework was not originally devised to curb dissent, the vagueness of its concepts enabled application of a disease label to people whom psychiatrists elsewhere would have regarded as normal, mildly eccentric or, at worst, *neurotic.*

The inadequacy of criteria to appraise the risk of harm of a person to himself and/or to others makes psychiatry open to the improper use of its sanction to detain. As an element of the Soviet pattern, the notion of "social danger" was promulgated. In a letter to the Western press in 1973 (Guardian), the psychiatric establishment, fending off allegations that psychiatry was being misused, asserted that in a proportion of patients, their disease process could result in antisocial activity, including "disturbances of public order, dissemination of slander, and manifestations of aggressive intentions." They commented further on the "seeming normality" of these patients when they committed dangerous acts. Aggression in the mentally ill leading to self-harm or harm to others was conflated with disturbance of public order and slander. Well-documented cases of dissenters in Soviet hospitals pointed to an obvious conclusion: Psychiatrists there had broadened the concept of dangerousness in an ethically dubious way.

Chinese Abuse

The allegation of the systematic, political abuse of psychiatry in China, comparable to what occurred in the former Soviet Union, has been widely debated since Robin Munro, a Research Fellow in the University of London and formerly an observer of the human rights situation in China employed by Human Rights Watch, produced a report detailing most methodically its prevalence and procedures (Munro, 2001; Dangerous Minds).

According to Munro, a small number of political dissenters were arrested as *enemies of the state,* diagnosed with a major psychiatric disorder and then compulsorily hospitalized as far back as the 1950s. Having stumbled across evidence of this practice in 1989 in a Chinese textbook on legal aspects of psychiatry, Munro scrutinized the *official* psychiatric literature—books and journals in the main—only to find repeated references to *political* patients. In one series of forensic psychiatric assessments, no less than one in five related to *counterrevolutionary behavior.*

The Cultural Revolution from 1966 to 1976 saw further ethical disarray in psychiatry. On the one hand, genuine patients forced by the Red Guards into confessing that they were truly counterrevolutionary, were thereupon promptly imprisoned or even executed. Conversely, genuine political dissidents were dispatched to institutions for the criminally insane. As one prominent forensic psychiatrist, Zheng Zhanpei, put it in 1988, the turmoil within Chinese psychiatry "… had to do with the particular historical circumstances of the time" (Munro, 2002, p.102). Munro provides extracts from Chinese psychiatric publications during this turbulent period which reveal just how politicized the profession became. For instance, mental illness was seen as being bound up with the class struggle and, given the tussle between the proletariat and capitalist positions, most patients had a bourgeois outlook.

Following the Cultural Revolution, the Soviet pattern of abuse returned but became more prominent in the late 1990s in association with the state-led campaign to stamp out the religious Falun Gong movement. As the pressure began to mount against the movement's members, so a proportion of them were falsely detained in general psychiatric hospitals under the rubric of a newly devised psychiatric condition with the bizarre title of "evil cult-induced mental disorder."

The response of Western psychiatrists to Munro's findings and conclusions have differed substantially, ranging from total incredulity that any country would be silly enough to repeat the Soviet saga and thus earn universal disapproval and condemnation to a solid conviction that the allegations are well-founded.

The Royal College of Psychiatrists for instance resolved at its 2001 Annual General Meeting to call on the World Psychiatric Association to organize a fact-finding visit to China.

How prominent Western figures in psychiatry have arrived at their conclusions, one way or the other, is difficult to fathom. Alan Stone, Professor of Law and Psychiatry at Harvard University, sharply criticizes Munro's research and regards Chinese psychiatrists as more victims than victimizers. It is relevant here that Stone remains adamant that Soviet psychiatrists also did not misuse their knowledge and skills to curb dissent. Sing Lee, and Arthur Kleinman, a distinguished anthropologist and psychiatrist, also at Harvard, similarly argue that "… there is simply no evidence of systematic abuse of mental hospitals for reasons of political oppression by the profession as a whole" (p.124) although they do concede that some psychiatrists are more open to "abusive practices" (p.124) when under police or Communist Party pressure.

Among psychiatrists who contend that abuse almost certainly has taken place and continues are Jim Birley, past President of the Royal College of Psychiatrists, who opines thus: "There is certainly a strong case, more than a suspicion, that psychiatry is once again being used for political purposes" (p. 147); and Sunny Lu and Viviana Galli, two American psychiatrists, who have provided a detailed account of the role of Chinese psychiatrists in dealing with the Falun Gong specifically. The latter conclude that the psychiatric gambit is part of a "… comprehensive and brutal campaign to *eradicate* Falun Gong" (p. 129).

Western psychiatrists and human rights organizations had to toil long and hard before the abuse of psychiatry ceased in the former Soviet Union. The toll of suffering was tragically high as thousands of dissenters were victimized through psychiatry. In the case of the Chinese allegations, a similar delay should not ensue.

Preventing Abuse

Legislation, professional self-regulation, establishment of watchdog committees, and adherence to appropriate codes of ethics are complementary means to deal with and prevent psychiatric abuse. Legislation has the potential to safeguard patients's civil rights, hold psychiatrists accountable, and specifically define their functions. Such mental health laws promote patients's rights and protect them from abusive psychiatry, and set requirements of practice whose transgression is tantamount to illegal conduct (e.g., Mental Health Act, 1986).

Peer review and quality assurance may help identify ethically suspect judgments or actions. Many national associations of psychiatrists have procedures to discipline members who violate principles of clinical care: informal warning, reprimand, suspension, or expulsion (see for example, Royal Australian and New Zealand College of Psychiatrists). The Royal College of Psychiatrists in Britain and the American Psychiatric Association have developed procedures to investigate abuse.

As a professional collective, psychiatrists, both nationally and internationally, need to maintain vigilance when governmental or nongovernmental entities try to exploit them to apply their knowledge and skills for purposes other than serving the interests of patients and the community at large. Psychiatrists operating in totalitarian states may not be in an equivalent position without jeopardizing their professional or personal interests. For instance, Semyon Gluzman and Anatoly Koryagin experienced years of incarceration for condemning the misuse of psychiatry in the former Soviet Union.

As part of their ethics, psychiatrists have an obligation to protest against the misuse of their profession wherever and whenever it occurs. Such action points to a political role psychiatrists may be required to play.

Finally, psychiatrists need to familiarize themselves with, and adhere to, relevant ethical codes, from the Oath of Hippocrates which stipulates that the doctor will "keep [the sick] from harm and injustice," to their own national and international codes, many of which affirm that they should never use their professional authority to maltreat people. The 1998 ethical code of the Royal Australian and New Zealand College of Psychiatrists explicitly covers abuse by incorporating the principle that "Psychiatrists shall not allow the misuse of their professional knowledge and skills." A series of annotations follows which deal with such issues as never diagnosing a person as mentally ill solely on the basis of political, religious, ideological, moral, or philosophical belief; the impermissibility of using nonconformity with a society's prevailing values as the determining factor in diagnosis; and the unacceptability of participation in torture and executions.

Conclusion

The history of psychiatry has been dreadfully tarnished by the occurrence of gross abuses, the Soviet and Nazi cases being especially prominent. Attention to such cases has led to greater ethical sensitivity among psychiatrists and beyond. Although this may serve as a safeguard against abuse now and in the future, both the profession and society need to maintain a vigorous defense against any malignant force that is tempted to exploit psychiatry and thus jeopardize its integrity.

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SEE ALSO: *Autonomy; Coercion; Deep Brain Stimulation; Electroconvulsive Therapy; Holocaust; Informed Consent: Issues of Consent in Mental Healthcare; Insanity and Insanity Defense; Institutionalization and Deinstitutionalization; Mental Illness: Conception of Mental Illness; Mental Illness: Cultural Perspectives; Mental Institutions, Commitment to; Mistakes, Medical; Paternalism; Patients' Rights; Psychosurgery, Medical and Historical Aspects of; Race and Racism; Technology; Women, Historical and Cross-Cultural Perspectives*

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PSYCHOANALYSIS AND DYNAMIC THERAPIES

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The term *psychoanalysis,* in its narrow sense refers to a method of psychological therapy originally developed by Sigmund Freud around the turn of the twentieth century and now practiced by analysts trained in the intellectual and clinical tradition that has followed Freud. The earliest psychoanalytic investigations led to revolutionary discoveries about the working of the mind, and therefore the term *psychoanalysis* refers also, in a broader sense, to the accumulated body of findings and theories about human mental functioning that have resulted from clinical psychoanalysis, and that are available to guide psychoanalysts in continuing their work.

The issue of the ethical implications of psychoanalysis was not one that greatly preoccupied Freud. He considered ethics to be the reflection of the cultural super-ego at a given moment in history, a "therapeutic attempt" to come to terms with human aggression (1930), and would no doubt have regarded the present concern with bioethics in this light. An examination of its principles and practices may help to show how current ethical reflection is relevant to psychoanalysis.

Clinical psychoanalysis is used as a treatment for a variety of psychological conditions, including both specific symptoms and more general personality problems. The treatment involves individual meetings with an analyst, several times per week, over a period of several years. The patient usually lies on a couch and is instructed to say whatever comes to mind (a technique called free association), including symptoms, life events, memories, fantasies, dreams, physical sensations, and feelings about the analyst. The analyst listens to this material, and eventually interprets it as revealing conflicts between emotional forces ("dynamic" conflicts) of which the patient had previously been unconscious. Feelings about the analyst, called transference feelings, are particularly important for this purpose, since these feelings are unconsciously transferred onto the analyst from significant persons in the patient's past, and can be used to interpret and rework current conflicts derived from these past relationships.

Psychoanalytic theory has been continually revised and expanded since its inception. Its earliest form was codified in Freud's major work, *The Interpretation of Dreams* (1900). In this volume he presented the topographic theory, which emphasized the division of the mind into conscious and unconscious realms, and explained not only neurotic symptoms but also normal phenomena, such as dreams and slips of the tongue, as the results of unconscious wishes breaking through, in disguised and distorted form, into consciousness. Psychoanalytic techniques, such as free association and the use of the couch, were intended to maximize the possibility of such breakthroughs. In this way, unconscious wishes could be interpreted and made conscious, and the symptoms resulting from those wishes could be relieved.

Dreams, errors, and symptoms remain useful sources of interpretable material for the modern analyst, but topographic theory has been subsumed by later theoretical developments. Freud's 1923 work "The Ego and the Id" presented a structural theory, in which the mind includes three agencies: the id, ego, and superego. Each agency has wishes and directions of its own, and they often come into conflict with each other. Neurotic symptoms, as well as character traits, are interpreted as the results of conflicts among these structures, and the goal of analysis is to strengthen the ego, the structure responsible for resolving conflicts within the mind and negotiating compromises between internal wishes and external reality.

Structural theory forms the core of a theoretical tradition known as "ego psychology," one of the dominant schools of thought in modern psychoanalysis, along with object-relations theory and self psychology. Object-relations theory places greater emphasis on the effects of early relationships, most importantly with the mother. It holds that pathological early relationships are internalized and unconsciously repeated, causing problems in later relationships. Self psychology emphasizes the role of early trauma and parental failure in preventing the establishment of a stable and coherent self. Proponents of these theories hold that they are more serviceable than structural theory for the treatment of seriously disturbed patients, those whose pathological early lives prevented the formation of stable mental structures.

The applicability of clinical psychoanalysis is limited by a number of practical and psychological factors. There are many patients for whom psychoanalytic ideas and insights might be useful, but who cannot be treated with clinical psychoanalysis because they cannot afford the time or money required, because they are interested only in more limited treatment for well-circumscribed problems, or because they do not have the necessary psychological resources, such as curiosity about the mind, access to dreams and fantasies, and an ability to tolerate frustration. The term *dynamic therapies* refers to a variety of psychotherapeutic techniques that have evolved for use in these situations.

The dynamic therapies, which are now considered the treatment of choice in some situations, are similar to psychoanalysis in that they involve regular meetings between patient and therapist in which talking is the primary therapeutic activity, an effort is made to understand the unconscious origins of the patient's problems, the patient's relationship to the therapist is used as an important source of information and a vehicle for change, and the practitioner is guided by psychoanalytic ideas about the working of the mind, including the idea that psychological problems are caused by "dynamic" conflict between unconscious forces. The dynamic therapies differ from psychoanalysis in that they are usually less intensive and involve less frequent meetings, the patient usually sits in a chair facing the therapist, the overall duration of the treatment may be shorter, the treatment may be focused on more specific goals, and the therapist is more likely to use techniques that offer emotional support to the patient as well as exploration of the unconscious. To the extent that the dynamic therapies are derivatives of psychoanalysis, similar considerations of ethics and values apply to both. This article will focus on ethical and value-related issues in psychoanalysis, with the understanding that similar considerations apply to the other dynamic therapies.

Training and Practice

Freud was trained as a neurologist, but most medical psychoanalysts have been psychiatrists. Freud believed that a medical background was not necessary for analysts (1926), and in Europe it has been common for nonphysicians to become analysts. In the United States analysis was for many years seen primarily as a subspecialty of psychiatry, but recently some nonphysicians have been admitted to analytic training.

Training in psychoanalysis begins after the completion of professional school and specialty training, and includes classroom education, a personal analysis of the trainee, and the treatment of several analytic cases under the supervision of senior analysts. Becoming a psychoanalyst involves not only mastering theory and technique but also becoming a member of a nonmedical profession, and accepting that profession's ethical judgments. The psychoanalytic profession's formal organization, the International Psychoanalytical Association, and its component associations, articulate and enforce ethical standards for the profession, as well as standards for training and procedures for certifying the skills of psychoanalysts. However, these bodies have no legal authority and cannot prevent nonmembers from calling themselves psychoanalysts.

The field of psychotherapy is much less organized and regulated. Individuals from many different professional backgrounds are free to call themselves therapists. Those individuals may be answerable to the standards of their own professions, but there is no overarching set of standards for training or ethical practice in psychotherapy.

Clinical Theory Versus Theory of the Mind

Over the decades, psychoanalysis has evolved two related but quite different bodies of theory. The first, "clinical theory," is a set of ideas about how the process of psychoanalysis works and a set of principles about how the analyst should behave. The second, comprising ideas about the working of the human mind that have resulted from psychoanalytic investigations in the past, might be broadly termed a psychoanalytic "theory of the mind"; this body of theory includes ideas about normal development, about the nature and origins of psychopathology, and about the structure and functioning of the mind (a branch of theory termed *metapsychology*). For the purpose of ethical analysis, these two bodies of theory present quite different challenges. Psychoanalytic clinical theory strives to remain value-neutral, while the psychoanalytic theory of the mind embodies a host of value-laden assumptions about normality and deviance, health and sickness, and the relationship of the individual to society, many of which have been challenged by critics of psychoanalysis.

Freud argued that psychoanalysis was a scientific method of investigation, and therefore neutral with respect to values (1927). The assertion that clinical analysis is value-neutral is related to the tenet in clinical theory that the analyst is guided by the principles of abstinence (Freud, 1915a) and neutrality (Freud, 1919; LaPlanche and Pontalis). The principle of abstinence enjoins the analyst from indulging in any kind of gratification (for patient or analyst) other than the satisfactions of analysis itself; sexual contact between analyst and patient, extra-analytic friendship, and nonanalytic emotional support are all proscribed.

The principle of neutrality dictates, in terms of structural theory, that the analyst should occupy a position equidistant from the competing forces in the mind (Freud, 1946), analyzing the conflict between them but not trying to influence the outcome of that conflict. In lay terms, the principle of neutrality means that the analyst should not try to influence the patient to adopt any particular set of values, or to conduct his or her life in any particular way; the analyst's job is only to analyze conflicts and remove inhibitions. Neurotic inhibitions limit the patient's freedom, and their successful removal liberates the patient to live however he or she chooses.

The Limits of Neutrality

The attitude of neutrality is not easy to adopt or to maintain. It requires that the analyst first become aware of his or her own values and preferences, unconscious as well as conscious, and then exert a constant and vigilant self-discipline, in order not to let these personal values influence the conduct of analysis. Much of the analyst's lengthy training, especially the personal analysis that he or she must undergo, is directed toward this end. However, it can be argued that absolute neutrality is not possible, even with a thorough personal analysis and a consistent adherence to the principle. The process of psychoanalysis necessarily embodies certain values, both in its selection of patients and in the ideals that inhere in the process itself.

The analyst can adopt the attitude of neutrality only if certain preconditions are met in the patient. Patient and analyst must have a common view of reality, at least in a broad way, for the analyst will probably find it impossible to remain neutral with respect to frankly psychotic ideas. Similarly, if the patient's illness is of the type that produces serious danger to the patient or others, the analyst may be unable to remain neutral with respect to that danger, and may instead intervene to protect the values of life and health, concluding that these medical and therapeutic values take precedence over analytic goals in this situation. In order to adopt an attitude of neutrality, the analyst must also believe that the patient possesses an adequately sound moral character; if the analyst believes the patient to be an evil person, neutrality will be impossible. It is part of the individual analyst's clinical and ethical responsibility to become aware of the kinds of patients with whom he or she has particular difficulty. Thus, some of the preconditions in the selection of patients for analysis embody value-laden assumptions that limit the scope of the principle of neutrality.

Moreover, the process of analysis itself can be seen to embody certain values that are not universally held and deviate from absolute neutrality (Michels and Oldham). Psychoanalysis assumes that insight is a goal worth pursuing; that it is always better to know things, especially about oneself, than not to know them; and that greater knowledge will ultimately lead to decreased suffering. This is a common belief, but by no means an unquestionable one; indeed, the Greek drama on which Freud based much of his theory of the mind, Sophocles's *Oedipus Rex,* primarily concerns the question whether knowledge or insight is an unmitigated good.

Clinical analysis also embodies the value of individuality; it is a process in which an individual patient spends a great deal of time, energy, and money exploring his or her individual mind and personal history in order, ultimately, to achieve greater individual happiness. This is not to say that relationships with others are neglected, or that the individual is encouraged to promote his or her welfare at the expense of others. However, to members of other cultures, especially non-Western ones, the idea of devoting so much attention to the individual alone, rather than as a member of the group, would seem strange and inappropriate. Thus the principle of neutrality, while central in clinical theory, is limited in its scope; the process requires that patient and analyst share certain value-laden assumptions about the perception of reality, about morally acceptable behavior, and about the importance of individuality and insight.

Limitations on the Analyst's Role

The principles of abstinence and neutrality dictate that the analyst may not assume other roles in the patient's life. As noted above, nonprofessional contacts, such as sexual, social, or business relationships, or exchanging gifts with patients, are inconsistent with analytic abstinence. Certain other professional functions, which might well be beneficial, are still proscribed because they are inconsistent with neutrality, and therefore are not analytic. For example, advising the patient on life decisions or on how to manage relationships with important others, as one might do in a supportive psychotherapy, would constitute a deviation from analytic neutrality. Similarly, certain assessment or advocacy functions, such as testifying on a patient's behalf in a legal proceeding, would violate the analytic role. In certain circumstances, such violations are inescapable or necessary; if an analytic patient becomes suicidally depressed, the analyst may have to intervene in a nonabstinent and nonneutral fashion. However, such a situation is best understood not as an exception to the principles of analysis but as a point at which other values, such as preserving life, override the importance of analysis, and the analyst chooses temporarily to suspend analysis in order to serve other goals.

The Analyst's Obligations

In the broadest sense, the analyst's primary obligation is to give good treatment. In practice, this means ensuring that he or she is well-trained; that his or her skills remain current and consistent with professional standards, by keeping up with the analytic literature and being involved with professional associations; selecting patients for analysis carefully, to be sure that they have the psychological resources necessary for analysis, and that there is no more appropriate treatment for each patient's condition; and conducting the analysis under the guidance of the principles of neutrality and abstinence. By adhering to these guidelines, the analyst will fulfill most of his or her ethical obligations. However, certain obligations deserve particular notice.

COUNTERTRANSFERENCE. Just as the patient in a successful analysis predictably develops intense transference feelings about the analyst, the analyst predictably develops intense feelings about the patient, which are called countertransference. These feelings may be positive or negative, and their specific content will be determined both by the nature of the patient's transference and by the analyst's own history and unconscious dynamics. In any case, countertransference feelings, especially unconscious ones, constitute the most serious challenge to analytic neutrality.

The ability to recognize and manage countertransference feelings is both an essential goal of analytic training and supervision, and an ongoing ethical obligation for the practicing analyst.

SEXUAL MISCONDUCT. A very common variety of transference and countertransference involves erotic attraction between patient and analyst. The analyst is under a strict ethical obligation to strive to recognize the transferential origin of this attraction and, in any event, to refrain from acting on it (Freud, 1915a). Sexual contact between doctor and patient is prohibited in general medicine, as stated in the Hippocratic Oath, and in psychiatry, but there are additional reasons for this rule in psychoanalysis. In general medicine and psychiatry, the patient is in a dependent position, and the chance that the patient's needs could be exploited for the doctor's sexual satisfaction is so great that the American Medical Association (AMA) has seen fit to ban sex between physicians and their current patients (Council on Ethical and Judicial Affairs). In 1993 the American Psychiatric Association (APA) went further and stated in their *Principles of Medical Ethics: With Annotations Especially Applicable to Psychiatry* that "Sexual activity with a current or former patient is unethical" (p. 4).

In psychoanalysis, the same argument about dependency and exploitation applies, but another and more encompassing argument exists as well. The conduct of psychoanalysis rests on the proposition that the treatment is conducted in words only, not in action; the patient is free to say or imagine anything, because no action will ensue. If this principle is violated and the patient and analyst act on their erotic attraction to each other, either during or long after the analysis, the credibility of the treatment itself is seriously damaged, and the interests of those who might benefit from analysis in the future are thus harmed. Accordingly, the American Psychoanalytic Association, recognizing that the unconscious is timeless (Freud, 1915b), absolutely prohibits sexual contact between analyst and patient, with no special exemption for a postanalytic relationship (1983).

CONFIDENTIALITY. The analyst's obligation to respect the patient's confidentiality derives not specifically from the principles of clinical psychoanalysis but from the general principle of confidentiality recognized in both physician–patient and therapist–client relationships. However, the principle assumes special importance in psychoanalysis, since the analyst specifically instructs the patient to hold no information back, and thereby acquires the obligation to treat the patient's communications with full respect for privacy.

Psychoanalysis and Social Values: Common Criticisms

CRITICISMS OF THE THEORY OF THE MIND. Many of the value-laden assumptions embodied in the psychoanalytic theory of the mind have been attacked as promoting negative stereotypes and producing destructive social consequences. For example, feminist critics have argued that the psychoanalytic theory of female development and psychology offers a negative view of women as psychologically inferior to men. The argument is based on Freud's early position that women do not experience castration anxiety in the same way men do, and are therefore less likely to develop a rigorous superego. This criticism is generally accurate with respect to Freud's original theory, which was very much a product of the culture in which he lived and his personal predilections. However, psychoanalytic ideas about female psychology and social roles have been extensively revised since that time, with the result that current psychoanalytic theorizing on the subject offers a much fuller, more positive, and more nuanced view of both male and female development and psychology.

Similarly, spokespersons for the gay community have argued that psychoanalysis treats gays unfairly and advances a biased view that homosexuality is invariably a pathological outcome of disturbed development. This criticism could only be directed at organized psychoanalysis after Freud, since Freud himself argued strongly that homosexuality need not be considered a form of pathology (1905). Debate on the subject has been intense over the last decades, involving such questions as whether homosexuality has significant concurrence with certain forms of psychopathology, especially narcissistic disorders; whether the psychopathology seen in homosexuals can be understood as a result of familial and social condemnation of biologically determined orientation; whether heterosexuality can or should be a goal of analytic treatment; and whether homosexuals are acceptable candidates for training as analysts. As far as the American Psychoanalytic Association is involved, the issue has been formally settled by a position statement affirming that "same-gender sexual orientation cannot be assumed to represent a deficit in personality development or the expression of psychopathology," and disavowing "efforts to 'convert' or 'repair' an individual's sexual orientation" (American Psychoanalytic Association, 2000; for the history of this debate, see also Bayer).

Another important criticism of psychoanalysis, deriving largely from the circumstances of Freud's personality and culture, is that it is hostile to religion. Freud himself made clear his belief that religion was nothing more than a cultural neurosis (1927). For many years, psychoanalysis and religion saw each other as enemies, but in recent decades this situation has changed. Analysts have come to recognize religion as an important domain of human mental activity, not to be lightly dismissed, and theologians have become increasingly interested in the use of psychoanalytic insights in their thinking and pastoral practice.

The concept of "psychic reality" is both a central tenet of psychoanalytic theory and a source of some important criticisms of that theory. The concept appeared when Freud revised his theory about the role of childhood seduction in causing neurosis; at first, he believed his patients' frequent stories of being sexually abused as children were historically accurate, but later he came to appreciate the psychological importance of fantasies and wishes as capable of producing neurosis even in the absence of actual seduction. Critics have argued that psychoanalytic theory went too far in this direction, presenting a view in which all memories of childhood sexual abuse were dismissed as fantasies, and that this development was responsible for long-standing and widespread denial, until recently, of the extent of actual sexual abuse of children.

Finally, psychoanalysis has been criticized by the antipsychiatry movement as a form of mind control. Spokespeople for this movement are opposed to all psychiatric practice as a tool of social control that imposes on patients a view of reality acceptable to the politically powerful. As a particularly influential form of psychiatric treatment, these critics argue, psychoanalysis is very effective in imposing the analyst's view of reality on the unsuspecting patient. Whether this general criticism is valid or not, the behavior it describes is clearly inconsistent with analytic neutrality and good analytic practice.

CRITICISMS OF CLINICAL THEORY AND PRACTICE. Various ethical objections have been raised against clinical psychoanalysis, concerning both its status as a form of treatment and the effects it has on individuals and on society.

Critics have argued that it is impossible for a patient to give informed consent to analysis, since the patient cannot possibly appreciate beforehand what an exploration of the unconscious will involve. This situation is analogous to other investigative procedures in medicine, in which neither patient nor doctor can know beforehand what will be found, and the patient can be informed only as to the risks and potential benefits of the procedure itself, with the understanding that the findings cannot be predicted. In clinical analysis, the patient's act of giving consent is ongoing throughout the treatment. Opponents of psychoanalysis, including many prominent psychiatrists, have argued extensively that it is unethical to offer a treatment, like psychoanalytic therapy, the value of which has not been demonstrated in controlled statistical studies, when other treatments are available that have been shown by such studies to be effective (Klerman). However, the vast majority of treatments and practices in clinical medicine have not yet been proven effective in this rigorous fashion. The fact that psychoanalysis still awaits such proof requires only that the prospective patient be informed of what is known about the treatment's effectiveness, and of other treatments that might be available.

A related issue arises from a concerted attack on psychoanalysis as science (see, for example, the work of Adolf Grunbaum) that has worked against the support of psychoanalytic treatment in a climate of managed care and health maintenance organizations (HMOs) (Gunderson and Gabbard). One aspect of this problem is the difficulty of research for the purpose of empirical validation in a situation that "allows the presence of no third person" (Freud, 1926). Indeed, some early studies may have crossed the line later to be laid down by committees on experimentation with human subjects (Wallerstein). But the negative effects of outside observers on therapy may have been overestimated (Busch et al.), and comparative studies of dynamic and other therapies for specific disorders seem to promise new support for their effectiveness (Barber and Crits-Christoph).

With respect to the effects of analysis, critics have argued that it discourages spontaneity, encourages dependence and self-centeredness, excuses evil or criminal behavior, and medicalizes human relationships. For the most part, these criticisms describe expectable complications and distortions of the analytic process, or inappropriate applications of analytic principles outside of analytic treatment, rather than the process of analysis as it should be conducted.

The idea that analysis discourages spontaneity by requiring that the patient substitute thought for action presents a common and analyzable distortion of the process. While it is true that analysis requires substituting thought for action during the analytic hour, it does not follow that the patient is expected to behave this way outside the hour. In fact, an inhibition of spontaneity outside of analysis would usually be seen as a manifestation of obsessional pathology, in which thought is substituted for action, or as an enactment of the transference, and in any case as an indication for further analytic work. Similarly, the idea that the focus on oneself required in the analytic hour should extend to the rest of life is a miscarriage of analysis, requiring interpretation and correction.

The argument that analysis encourages dependency results from the fact that a dependent transference toward the analyst commonly develops, since the patient's relationship to important others in the past will often have been a dependent one, or that the experience of a dependent time of life is remembered when regression occurs in the analysis. However, analysis itself neither encourages nor discourages dependency; it encourages only the emergence and resolution of the transference, whatever its content may be. If the patient is reluctant to relinquish this dependent posture, that development is an interpretable distortion. Some varieties of dynamic therapy, in contrast, may encourage dependency as the cost of attaining important therapeutic goals.

Debates about the insanity defense in criminal proceedings have often involved a misapplication of the psychoanalytic principle of neutrality. Critics argue that by trying to make all behavior understandable in terms of the interplay of unconscious forces, psychoanalysis has removed the sense of personal responsibility for behavior. However, as described above, the principle of neutrality is employed only in a very specific setting, the psychoanalytic hour, and only with a well-selected population and for a specific limited purpose. Analysts do not encourage the adoption of an attitude of neutrality outside of clinical psychoanalysis (Gaylin).

The argument that psychoanalysis tends inappropriately to medicalize problems in human life and relationships is based partly on a peculiar historical association between analysis and medicine. Freud was a physician, as were his earliest disciples, but the psychoanalytic movement in Europe rapidly expanded to include nonmedical practitioners. In the United States, analysis has been dominated by the medical profession, though the 1991 decision of the American Psychoanalytic Association to approve full training for nonmedical candidates presages a significant increase in the proportion and influence of nonmedical analysts in the United States. The distinction between prescribing analysis and conducting analysis may be useful in elucidating the proper relationship between medicine and analysis. The act of prescribing psychoanalysis as the treatment of choice for a particular patient is a medical act, since it requires diagnosing the patient's problem and knowing the possible alternative treatments; but the act of conducting the analysis, while it requires good clinical judgment, does not require medical knowledge or training.

Finally, psychotherapeutic practices have come under scrutiny because of a widespread feeling that medicine in general and psychiatry in particular have paid insufficient attention to the real needs and sensitivities of patients as individual human beings. This feeling has been articulated in part by advocacy groups like the National Alliance for the Mentally Ill (NAMI), but has also been evidenced in independent critiques of the profession by writers who have claimed that it is out of its depth and "omits the moral dimension of living" (Lomas) or that it is in disorder and desperately needs a "culture of responsibility" (Luhrmann). Such manifestations of the moral and social preoccupations of the current cultural epoch can only be welcomed; they represent challenges that it is in everyone's interest to meet openly and honestly.

PUBLIC-HEALTH ISSUES. Some criticisms of psychoanalysis contend that it is a luxury for the rich, is suitable only for a tiny minority of the most prosperous and least disturbed members of society, and consumes a vast amount of medical resources that could be put to better use meeting the needs of the poor and the seriously mentally ill. Psychoanalysts offer several rebuttals. First, it is not true that the problems of psychoanalytic patients are trivial; while analysis does require certain particular psychological strengths, patients in analysis can be seriously impaired and genuinely suffering in many ways, and analysis can provide significant relief to them. Second, the benefits of psychoanalysis extend well beyond the patients who are treated with full analysis. Many other forms of treatment, including the dynamic therapies and even pharmacotherapy and general medical treatment, can be rendered more effective if the practitioner understands and makes use of psychoanalytic insights about human motivation. Finally, analysts recognize that few individuals can afford to pay a standard psychiatric fee several times per week over many years, and many analysts are willing to reduce their fees to enable a wider range of people to benefit from psychoanalytic treatment. These financial problems could be mitigated if systems of reimbursement paid fairly for cognitive and interpersonal services in comparison with surgical and invasive procedures. But such decisions are usually governed by political and economic concerns rather than by ethical imperatives.

Conclusion

Until the 1960s, psychoanalysis was the dominant theory and psychoanalytically derived therapies were the most common treatment in the mental health professions. Since then the dominance has waned, partly as a result of economic forces leading to the development of briefer treatments, and partly as the result of the rise of biological psychiatry and the development of effective pharmacologic treatments. In recent decades only a small fraction of psychiatrists have chosen to become psychoanalysts, and only a small fraction of patients are treated with full psychoanalysis. However, the influence of analytic theories and findings continues to be felt throughout the fields of psychiatry, psychotherapy, and medicine. It is likely that there will remain a population of patients who have problems of sufficient breadth and depth, and who can support its financial costs, who will choose psychoanalysis and its related therapies as their treatments of choice.

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SEE ALSO: *Behavior Control; Behaviorism; Behavior Modification Therapies; Freedom and Free Will; Mental Health; Mental Illness; Psychiatry, Abuses of*

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PSYCHOPHARMACOLOGY

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Psychopharmacology is the study of drugs used to treat disturbances in mood, behavior, and mental functioning across a broad range of illnesses and conditions. While many drugs used in general medicine (e.g., antihypertensives, hormonal therapies) can cause behavioral changes or psychological symptoms, psychopharmacologic agents are used specifically for their behavioral or mental effects. The classes of psychopharmacologic medications include the following: antipsychotics, antidepressants, antianxiety agents, and mood stabilizers. There are numerous ethical issues in psychopharmacology. This entry focuses on issues related to consent to treatment, the inclusion of severely mentally ill persons in psychopharmacologic research, involuntary outpatient treatment, and the cost of newer psychotropic medications.

The main classes of psychopharmacologic agents, which are antipsychotics, antidepressants, antianxiety agents, and mood stabilizers, are discussed below. Under each category, the U.S. Food and Drug Administration (FDA) approved drugs as well as their therapeutic and adverse effects are described. Cognitive enhancers (e.g., donepezil or Aricept), used to treat Alzheimer disease, are not included in this entry.

Antipsychotics

As the first effective medications to be introduced into treatment of psychosis, antipsychotic drugs revolutionized the treatment of schizophrenia and other severe psychiatric disorders. Prior to the introduction of the first antipsychotic (i.e., chlorpromazine [Thorazine]) in 1952, the principal treatment for a person with schizophrenia was long-term hospitalization. Often this hospitalization was aimed primarily at protecting society from patients with mental illness. The arrival of antipsychotic medications that could actually reduce psychiatric symptoms heralded a new era in the history of mental healthcare. Over the ensuing years, care for schizophrenia and other psychotic disorders changed from a largely custodial, institution-based system to a more community-based model emphasizing treatment and rehabilitation of individuals with psychiatric disorders (Grob).

Although they have been used to treat a variety of psychiatric conditions, antipsychotic drugs are primarily intended for psychotic disorders, the best example being schizophrenia. Schizophrenia affects approximately 1 percent of the population worldwide, and the vast majority of patients receive antipsychotic medication. Antipsychotics are especially useful in treating the hallucinations (perceptual disturbances such as hearing voices or seeing things), delusions (fixed false beliefs), and disorganized behavior. In addition antipsychotics can reduce the associated agitation, hostility, and unsafe behaviors that frequently impact the quality of life of patients, family members, and caregivers of persons with schizophrenia. Antipsychotic medications can reduce the symptoms of schizophrenia but do not cure the underlying illness, so a person who stops taking his medications is likely to have a relapse. In addition symptoms such as social withdrawal, loss of motivation, reduced emotional expression, and slowed thinking often persist, despite the use of antipsychotics.

There are different types of antipsychotics, each with a distinct chemical structure. With the advent of a newer generation of antipsychotics beginning in the late 1980s, drugs are now categorized as either *conventional* or *atypical*. The conventional agents were the only drugs available for treating schizophrenia for the first thirty-five years of the pharmacologic treatment era.

Conventional antipsychotics block receptors for a chemical messenger called dopamine in certain areas of the brain that are believed to mediate psychotic behavior. Hence increased dopamine activity is believed to be associated with psychosis, whereas blocking dopamine is believed to reduce psychosis. At the same time, blocking dopamine in other areas of the brain can produce uncomfortable muscular symptoms (stiffness, rigidity, tremor, restlessness) as well as abnormal breast milk production and sexual dysfunction.

The newer atypical antipsychotics may be of greater clinical benefit compared to the conventional antipsychotics. These atypical antipsychotics have fewer side effects and are better tolerated by patients. Patients may be more likely to take the newer medications regularly (Dolder et al.) and these medications may facilitate improved emotional expression, motivation, and social interaction in patients with schizophrenia.

ADVERSE EFFECTS. In the short term, dopamine receptors in brain regions responsible for involuntary movement system often produces rigidity, tremor, slowing of movement, and an unpleasant feeling of muscular restlessness. Over the long term, a substantial proportion of patients treated with conventional antipsychotics develop tardive dyskinesia, a potentially irreversible neurological disorder of involuntary movements of the mouth, face, neck, and body. The condition can be quite incapacitating, and there is currently no effective treatment. Each additional year of antipsychotic exposure increases a person's chance of developing tardive dyskinesia. Elderly patients are particularly at risk for this condition, especially if there is a pre-existing movement disorder such as drug induced parkinsonism (Jeste et al., 1999b; 1999a).

The newer antipsychotics have been found to be much less likely to induce abnormal movements including tardive dyskinesia. To that end, clozapine (Clozaril), the first atypical agent to become available in the United States, is recommended for patients who either have not responded to other antipsychotic medications or have developed severe abnormal movements or tardive dyskinesia while taking other agents. The use of Clozaril has been limited by other unpleasant adverse effects such as excessive sedation, weight gain, low blood pressure, cognitive clouding, blurred vision, hypersalivation, and increased risk of seizures. In addition Clozaril has a rare tendency to cause a drop in the white blood cell count, which can be potentially life-threatening. For that reason, any patient who begins treatment with Clozaril is required to have a blood test every week to monitor his or her white blood cell count.

In the late 1990s and early 2000s, five other atypical antipsychotics were approved by the FDA: risperidone (Risperdal), olanzapine (Zyprexa), quetiapine (Seroquel), ziprasidone (Geodon), and aripiprazole (Abilify). Each agent has a somewhat unique side effect profile. Some of the newer agents have been found to be associated with metabolic changes such as weight gain, development of diabetes and lipid abnormalities, and risk for serious cardiac arrhythmia. Additional experience with the newer agents over the coming years will provide a better knowledge base regarding their more serious side effects.

Antidepressants

The arrival of antidepressant drugs closely followed that of antipsychotics, and eventually paved the way for a new approach to the treatment of depression. Like the antipsychotics, antidepressants have contributed to reduced hospitalization and a move to a more rehabilitative model of treatment. The tricyclic antidepressants (TCAs), named for their three-ring chemical structure, were found to block the reuptake of the chemical messengers (i.e., neurotransmitters) norepinephrine and serotonin at the junction between nerve cells. Ordinarily unused neurotransmitter substance is taken back into the cell to be reused, a process known as reuptake (Stahl). By blocking reuptake, tricyclic antidepressant agents were found to make more neurotransmitters available to the nerve cell. A second class of antidepressants blocks monoamine oxidase, the enzyme that degrades both norepinephrine and serotonin; drugs belonging to this class became known as monoamine oxidase inhibitors (MAOIs).

Despite the therapeutic effects of these drugs, their use is complicated by adverse effects. Like the conventional antipsychotics, these agents frequently produce sedation, hypotension, and anticholinergic effects. These side effects can be particularly problematic for older individuals who may be cognitively impaired and at risk for falls. In addition these agents can be lethal in overdose, as they cause serious cardiac arrhythmias. Nevertheless clinical experience with these medications ultimately led to the current prevailing theory of depression as a deficiency in certain neurotransmitters in predisposed individuals.

The introduction of fluoxetine (Prozac) in 1985 was arguably the single most influential development in contemporary treatment of depression. As the first in a family of new antidepressants, Prozac revolutionized the treatment of psychiatric illness. Because of its significantly improved side effect profile, Prozac provided a more convenient treatment alternative for patients. With the improved safety and tolerability of antidepressants beginning with Prozac, depression has come to be understood even by the lay public as a treatable medical condition frequently compared to diabetes or hypertension. This has been a critical step in destigmatizing depression as a mental illness. Moreover it has made possible improved recognition and treatment of depression as well as other psychiatric disorders in the United States and worldwide.

The newer family of antidepressants ushered in by Prozac became known as selective serotonin reuptake inhibitors (SSRIs). In contrast to the TCAs and MAOIs that act on both serotonin and norepinephrine, SSRIs primarily increase the availability of serotonin. The SSRIs have fewer side effects than the older antidepressants, are easier for physicians to dose, and do not have the risk of heart conduction problems that TCAs have, nor do the SSRIs require special dietary restrictions like the MAOIs. Although they were developed for the treatment of depression, SSRIs have become widely used for the treatment of various conditions including certain anxiety disorders, eating disorders, and disorders of impulse control.

There are five other SSRIs currently available in the United States: sertraline (Zoloft), paroxetine (Paxil), citalopram (Celexa), and fluvoxamine (Luvox), and escitalopram (Lexapro). All are FDA approved for depression with the exception of Luvox, which is indicated for obsessive-compulsive disorder. All SSRIs are equally effective for the treatment of depression and the choice of an agent is largely dependent on other effects (see below). The availability of different agents allows clinicians to customize treatment to some extent. For example a patient with prominent apathy and fatigue may benefit from an antidepressant that is activating, such as Prozac. Conversely a patient with severe insomnia and anxiety may be better served by an agent that is more sedating, such as Paxil.

Since the arrival of SSRIs, several newer antidepressants have been developed with unique mechanisms of action. Venlafaxine (Effexor), nefazodone (Serzone), bupropion (Wellbutrin), and mirtazapine (Remeron) are antidepressants that were designed with the benefit of even more recent pharmacological knowledge. Effexor is an agent that exerts its effect on different neurotransmitters according to the dosage selected by the clinician. At lower doses, its effect is mediated primarily via increasing serotonin, whereas at higher doses of the drug, norepinephrine and dopamine effects predominate. Lower doses tend to be appropriate for milder depressive states and higher doses for more severe disorders.

ADVERSE EFFECTS. Adverse effects of antidepressants can be problematic. The TCAs tend to produce dry mouth, constipation, and sedation, but the sedative effect can be used to treat the insomnia that frequently accompanies depression. In cases of overdose, MAOIs and TCAs can produce dangerous cardiac arrhythmias. MAOIs can also produce serious blood pressure elevations if they are combined with certain other drugs or tyramine-rich foods such as aged cheese or meats. Patients on MAOIs must adhere to strict dietary guidelines in order to prevent problems.

The SSRI antidepressants produce a characteristic spectrum of adverse effects including nausea, diarrhea, weight loss, headache, insomnia, agitation, and fatigue. Many of these effects resolve within 2 to 3 weeks of treatment, and patients are generally advised to continue taking their medication to see if the unwanted effects dissipate over time. These compounds can also cause sexual side effects such as reduced sexual interest as well as difficulty in achieving orgasm. Other less common effects include tremor, rash, and easy bruising. Although they tend to be relatively safe in overdose, SSRIs can produce serious adverse effects if combined with other serotonin-containing drugs (i.e., serotonin syndrome). Serotonin syndrome is characterized by symptoms such as confusion, tremors, sweating, fever, and incoordination. It may become potentially life threatening if not recognized and appropriately treated.

Other non-SSRI antidepressants have somewhat unique side effects. The side effects of Effexor are similar to those of an SSRI at lower doses, and it causes an increase in blood pressure in a small percentage of patients. Serzone tends to be sedating and many patients prefer to take it at bedtime, especially if they have insomnia. It can interact with many commonly used medications including certain antihistamines, antibiotics, and anti-fungal agents, causing potentially dangerous cardiac arrhythmias. Wellbutrin is a stimulant-like agent that can produce agitation and insomnia in susceptible individuals. It has the potential to increase the risk for seizures in a small percentage of patients. It is the antidepressant least likely to cause weight gain and sexual dysfunction and has been successfully used to improve sexual function in some patients. Remeron is sedating and can also produce significant weight gain. It tends to be prescribed at bedtime for patients with insomnia.

Antianxiety agents

Antianxiety drugs are used to treat primary anxiety disorders such as panic attacks, phobias, obsessive-compulsive disorder (OCD), and post-traumatic stress disorder (PTSD), as well as anxiety that accompanies depression. In addition these medications are used to treat anxiety associated with various emergency medical conditions (e.g., myocardial infarction). Alcohol is the oldest antianxiety agent. Medical use of anxiolytics began with barbiturates and propanediols, drugs with sedative and anxiety-reducing effects, but these agents also slowed thinking and decreased alertness.

In the late 1960s, benzodiazepines were introduced as drugs that reduced anxiety but preserved cognitive function and physical activity. These drugs include diazepam (Valium), lorazepam (Ativan), and alprazolam (Xanax). Benzodiazepines are believed to stimulate another neurotransmitter, gamma aminobutyric acid (GABA), which plays an inhibitory role in brain function, lessening arousal and anxiety. Benzodiazepines are safer compared to the earlier antianxiety drugs. Nevertheless they do have significant cognitive and sedating effects that limit their use. Moreover benzodiazepines produce tolerance and withdrawal symptoms, which defines them as potential drugs of abuse. Their effects tend to dissipate over time, leading to the need for increases in dosage and increased potential for toxicity.

Scientists have searched for antianxiety drugs that do not produce tolerance or addiction. Currently the SSRI antidepressants are the preferred agents for treating anxiety disorders including panic attacks, phobias, and OCD. They have been found to reduce effectively symptoms of anxiety and do not lead to dependence syndromes. However these agents often require several weeks before beginning to exert therapeutic effects. They are not useful for emergency situations, but rather, for ongoing management and prevention of recurrent distressing symptoms. Buspirone (Buspar) is another agent that affects serotonin and was developed for the treatment of anxiety disorders. Like the SSRIs, it has a role in maintenance treatment rather than for acute intervention in anxiety disorders. Benzodiazepines continue to be the most frequently used agents for acute anxiety because of their immediate effects.

ADVERSE EFFECTS. The adverse effects of SSRIs have been described in the previous section. Regarding benzodiazepines, several side effects are generally extensions of their therapeutic effects: sedation, impaired cognitive or motor performance, tolerance, and physical dependency (addiction); the sedative effects impair driving and attention to mechanical tasks. However untreated anxiety or insomnia can produce serious problems in these same areas. Thus clinicians must carefully weigh the risks and benefits of prescribing benzodiazepines. Their safety profile is better compared to that of barbiturates. Nevertheless physical addiction can occur, and if abruptly discontinued, a withdrawal state can result.

Benzodiazepine withdrawal is rather similar to withdrawal from alcohol. It is characterized by anxiety, restlessness, agitation, and insomnia, as well as increased heart rate, sweating, tremors, and blood pressure elevation. An example of a withdrawal reaction is the so-called “rebound insomnia” associated with the discontinuation of short-acting benzodiazepines (e.g., triazolam) as a sleep-aid. In more severe cases, withdrawal from benzodiazepines can lead to a seizure. This syndrome typically develops two or three days after abrupt cessation of benzodiazepines, especially shorter-acting agents such as Xanax. It is characterized by an acute confusional state with fluctuating level of consciousness, disorientation, hallucinations, paranoia, agitation, and often seizures. Without appropriate medical management, this syndrome can be life threatening. During short-term, low-dose therapy, the risk is low; however patients with prior drug abuse or alcoholism are at an increased risk for these problems as are patients who take higher doses over longer periods of time.

Mood Stabilizers

Mood stabilizing agents are primarily indicated for the treatment of bipolar disorder, previously known as manic-depressive illness. Bipolar disorder is typically characterized by alternating episodes of depression and mania. Whereas depression is a state of low mood, hopelessness, low motivation and energy, and slowed activity, mania is a state of elevated or euphoric mood, increased energy, inflated self-esteem, racing thoughts, and a tendency to become involved in excessive, often unrealistic, and even unnecessarily risky activities. Like other psychiatric disorders, there are various forms of bipolar disorder. Some patients experience primarily depressive episodes with only occasional manias, while other patients may experience almost continuous mania, with very little depression. Whatever form the disorder takes, mood stabilizing agents are intended to reduce the frequency and severity of the mood episodes, and thereby reduce functional impairment.

The first mood stabilizer was lithium carbonate, a naturally occurring salt introduced into clinical use in the 1960s. For many years it was the preferred treatment for bipolar disorder, although its mechanism of action has never been well understood. It is effective for both depression and mania and has been shown to reduce the risk of suicide in patients with bipolar disorder. It has a variety of toxic side effects that limit its tolerability (see below). In addition, lithium has a very narrow therapeutic range, in terms of blood levels, below which it may be ineffective and above which it causes toxic side effects. A number of commonly prescribed medications can interact with lithium and increase its serum level. Therefore any patient taking lithium requires regular monitoring of serum levels in order to maintain safety and efficacy with this drug.

Because of its side effects and safety issues, today fewer patients are being treated with lithium as other options have become available. Most of the other mood stabilizers are anticonvulsants initially developed for seizure control. Carbamazepine (Tegretol) and valproate (Depakote) were the earliest drugs of this class. Depakote has become the first-line medication for bipolar disorder, particularly for patients who have rapid cycling of moods or episodes with combined symptoms of depression and mania (i.e., mixed episodes). Although they have been well studied and demonstrated to be effective, similar to lithium, both of these agents have side effects and potential for toxicity (although not as narrow a margin for toxicity as that of lithium). Several newer anticonvulsants have therefore been studied and introduced for mood stabilization. These include gabapentin (Neurontin), lamotrigine (Lamictal), topiramate (Topamax), and oxcarbazepine (Trileptal). Although they appear to be better tolerated overall, the efficacy of these newer agents is not yet as well established as that of the older mood stabilizers.

ADVERSE EFFECTS. Lithium is associated with numerous side effects including cognitive slowing, gastrointestinal upset, weight gain, tremor, excessive thirst and urination, acne, and rash. Long-term use of lithium is known to be particularly toxic to the thyroid and kidneys. When the level of lithium in the serum becomes high, patients develop signs of neurological toxicity, such as slurred speech, impairment in gait and coordination, worsening tremor, and sedation.

Lithium toxicity is considered a medical emergency requiring hospitalization, intravenous hydration, and often hemodialysis to prevent irreversible kidney failure.

The most common early side effects of Depakote are sedation and gastrointestinal upset, both of which tend to subside or decrease within a few weeks. Other reported side effects include weight gain, dizziness, tremor, and hair loss. Depakote frequently induces an elevation in the liver enzymes, which is usually benign, but requires monitoring because of the rare possibility of liver toxicity. Depakote may also lower serum platelets. Tegretol too can be toxic to the liver and bone marrow and therefore requires serum monitoring. It also produces sedation and dizziness, as well as cognitive slowing. In rare instances, it is associated with the development of a severe allergic reaction involving the skin. Elevation of Tegretol levels beyond a certain level can produce neurotoxicity with coordination and gait impairment, and abnormal eye movements. Tegretol has a tendency to reduce the levels of other medications, such as oral contraceptives.

Side effects of the newer anticonvulsants include sedation and dizziness. Lamictal is associated with the development of a life-threatening rash in rare cases. Topimax is associated with weight loss and cognitive slowing.

Ethical Dilemmas in Psychopharmacology

CONSENT TO TREATMENT. A principal ethical dilemma of treating people with mental illnesses is that many patients are impaired by their condition, but need to make an informed choice as to their treatment and its risks and benefits. For example, antipsychotic drugs may be prescribed to a psychotic patient who is paranoid, especially about drugs he is asked to take. The prescriber faces the dilemma of determining how reasonable the patient's ability is to accept or refuse treatment for an illness that impairs his ability to process reality, leading him to suspect all those who try to help him, and even to constitute a risk to self or others.

A basic tenant of medical care is that a competent patient has the right to refuse treatment of any kind. Unfortunately, determining competency can be difficult, and state laws have not clearly defined competency in regard to psychotic disorders. One study demonstrated that the most severely psychotic patients refused treatment more frequently than did patients who are less symptomatic (Marder et al.). For patients who are a danger to themselves (e.g., refusing to eat) or to others (e.g., attacking feared persecutors), both common sense and state statutes permit temporary involuntary medication treatment. However when a patient who is very ill and hospitalized for a mental illness refuses medications, but is not a danger to herself or others, it can be very difficult to provide optimal care. Many physicians involve the family in this decision, but this approach poses risks too. From the perspective of the paranoid patient, an alliance between a doctor and the family may make the patient even more suspicious of the physician. Often the psychiatrist is forced to involve the court system in determining whether a patient is competent to refuse treatment. Although a judge may allow involuntary treatment, these competency hearings may delay decision making for weeks, and are expensive for both the patient and the treating physician or facility.

CONSENT TO PARTICIPATE IN PSYCHOPHARMACOLOGIC RESEARCH. Conducting research on new psychopharmacologic treatments poses ethical dilemmas. For serious mental illnesses such as schizophrenia, current treatment is beneficial in reducing the symptoms, but many patients continue to have significant impairments. Improved treatments are needed, especially for the patients with the most severe psychopathology. In addition to knowing whether the new treatments will help those patients with the most severe symptoms, research into the new treatments needs to include the full range of patients. A critical component of conducting ethical research is obtaining informed consent from potential research subjects. Often those patients with the most severe psychopathology also have the greatest impairment in their ability to provide informed consent to be a research subject (Kim et al.).

Informed consent includes four key components: understanding, appreciating, reasoning, and expressing a choice. Patients with schizophrenia are more likely to have impairments with one or more of these four areas of decision making. At the same time, it is important to emphasize that having a psychiatric illness is by no means synonymous with having impaired decision-making capacity to consent for research. In studies of the decisional abilities of patients with schizophrenia, for example, the majority of non-hospitalized patients have not been found to be impaired on measures of their capacity to consent (Jeste et al., 2003).

Including patients with severe mental illness in studies of new medications, when the patient's ability to give informed consent to be a research volunteer is impaired due to the illness, is a major ethical challenge. In 1998, the National Bioethics Advisory Commission (NBAC) issued a report entitled "research involving persons with mental disorders that may affect decision making capacity." This report recommended additional special protections for research that involved persons with mental disorders. Critics of the NBAC report have expressed concern that the report's recommended additional special protections, specifically a proposed moratorium on research studies that posed greater than minimal risk until a new “special standing panel” or “national IRB” could review each study, which could impede important biomedical research, including neuroimagning and genetic linkage studies (Shore and Hyman). Another criticism of the NBAC report was that many medical illnesses, not just mental illnesses, can impair a person’s decision-making capacity. By focusing on persons with psychiatric disorders, the NBAC report’s recommendations risk increasing the stigma associated with mental illnesses (Appelbaum). One area of current research focuses on ways to enhance the process of informed consent so patients with more severe psychopathology can participate in research. As new potential treatments for schizophrenia become available, a key question will be finding ethical ways of determining whether these medications help the most severely ill patients.

SPECIAL POPULATIONS: ELDERLY PATIENTS. Certain segments of mentally ill populations are at a particularly high risk of problems with decisional capacity. These include children, elderly persons, and non-English speaking ethnic minority groups. Below one such group—that is, elderly patients with serious mental illnesses in need of pharmacotherapy—is considered.

It is anticipated that the numbers of older persons with psychiatric disorders will increase substantially within the next three decades (Jeste et al., 1999a). Yet most investigations of the efficacy and safety of pharmacologic treatments for these illnesses have focused on younger adults. Hence there will be a need for a marked growth of geriatric psychopharmacologic research in the immediate future. As mentioned above, an important issue in intervention research is ensuring that the patient has adequate decision-making capacity for participation in such research. Older psychiatric patients are at a risk of lacking decisional capacity by virtue of their aging-associated cognitive deficits and physical comorbidity, which are compounded by complex medication regimens. At the same time it is critical to stress that considerable heterogeneity exists among older persons with mental illnesses. Moreover the capacity to consent may vary from one protocol to another. It is clear that empirical research into assessing and possibly improving decisional capacity is needed in older people with severe mental illness.

One model of a multidisciplinary collaboration that is necessary for facilitating such research is the Bioethics Unit of an Intervention Research Center (Jeste et al., 2003). This Unit was developed in the last half of the 1990s. It includes geriatric psychiatrists, psychologists, bioethicists, lawyers, and most importantly, a Community Advisory Board comprised of patient participants in research, their family members, patient advocates, and mental health workers in the community not affiliated with the research team. The members of the Bioethics Unit have conducted several studies of decisional capacity and of ways to improve the process of giving information to the research participants by educational means (e.g., repeating the information) or by use of techniques such as PowerPoint slide presentation of the consent material (Dunn et al.; Palmer et al.). As of mid-2003, those investigations suggest that older individuals with psychotic disorders vary considerably in their decisional capacity, and many (but not all) subjects are fully capable of consenting to research projects. Additionally the patients’s comprehension of the consent material can be improved significantly through repetition and user-friendly presentation of the information. It thus appears that, even in older seriously mentally ill individuals, decisional capacity for a given research protocol is not necessarily an unmodifiable trait, but can be enhanced with improvements in consenting procedures. Research at the Bioethics Unit has also demonstrated that the Community Advisory Board is very helpful in ensuring community equipoise—for example, the community’s perspective of the relative risk: benefit ratio of a research protocol.

INVOLUNTARY TREATMENT. One of the most controversial areas in psychiatry is involuntary outpatient treatment. The field of psychiatry has long held that benevolent coercion is necessary to treat some people with serious mental illnesses such as schizophrenia and bipolar disorder, and most experts would agree that involuntary treatment for a person who is imminently suicidal or homicidal is justified. However it is much less clear whether a person with a serious mental illness who stops his medications and decompensates, becoming homeless or requiring rehospitalization, may be treated against his or her will to prevent this decompensation. In the early-twenty-first century, there are many people with serious mental illnesses who are unable or unwilling to receive outpatient mental health treatment, and some of these patients end up being homeless, incarcerated, or hospitalized multiple times. Involuntary outpatient treatment has been advocated as a means to improve the mental healthcare of these patients (Swartz et al.; Torrey and Zdanowicz).

Most states have provisions for involuntary outpatient treatment, which is usually court-ordered. This involuntary outpatient treatment is often used for patients who are being released from a psychiatric hospital and have a past record of stopping their medications, decompensating, and being rehospitalized. Depending on the particular state, this involuntary treatment may or may not include forced administration of medications. Proponents of involuntary outpatient treatment argue that it can help a patient to remain compliant with treatment (or face re-hospitalization), and at the same time, force the mental health systems to provide a patient with needed treatment. Opponents of involuntary outpatient treatment argue that it unnecessarily restricts the rights of people with mental illnesses, and that improved access to comprehensive outpatient services can accomplish the same goals as involuntary outpatient treatment (Allen and Smith).

DRUG THERAPY AND RESOURCE ALLOCATION. Since the mid-1990s the cost of pharmaceuticals has received increasing attention. Pharmaceutical costs are currently the fastest rising component of healthcare costs; between 1987 and 1996 per capita spending on psychotropic medications increased by 254 percent, while spending on all mental health and substance abuse treatments only increased by 30 percent (Zuvekas). This increase has many causes, including an increasing awareness and acceptance of treatment for mental illnesses, and a large number of newer psychiatric medications that have fewer side effects and may be more effective, but are significantly more expensive. For example there are five new *atypical* antipsychotic medications that have been introduced in the past decade. These medications have fewer short-term and long-term side effects, but cost much more than the older antipsychotic medications. The newer medications cost approximately $300 to $400 per month. This compares with about $15 to $50 per month for the older antipsychotic medications. There is some evidence that over one to two years the atypical antipsychotic medications are *cost neutral* due to lower rates of relapse and fewer psychiatric hospitalizations (Csernansky and Schuchart). Similarly the newer antidepressants are also more expensive (at $80 to $90 per month) than the older antidepressants ($10 to $15 per month). It should be kept in mind that the recent increase in cost of medications is not restricted to psychiatric medications; lipid lowering agents cost $70 to $90 per month, Viagra runs $8 to $9 per pill and common triple-drug treatments for HIV can cost $1000 to $1250 per month (drugstore.com).

Optimistically a balancing of the needs of the patient, the government's ability to pay, and market forces may provide the optimal solution. From a clinical and ethical perspective, it is necessary to ensure that patients who would benefit from a new psychotropic drug should not be denied that medication. However people without prescription drug benefits as part of their healthcare insurance are often unable to afford to pay for their medications and many state Medicaid plans and private insurance companies have created medication formularies that restrict the medications which a patient can receive. Many psychiatrists, patients, and patient advocates believe that these restrictions on which medications can be used to treat a serious mental illness could cause an exacerbation of symptoms and may require more intensive, institutional-based care in the future, ultimately resulting in greater cost. Among the important issues that arise in the debate over the cost of newer psychiatric medications include: Who decides whether a new medication, which is safer but more expensive, should be used: the patient, the physician, the insurance company, or the government?

Conclusion

Psychopharmacologic medications have undergone a major transformation since the mid-1990s. In 2003, medications have fewer side effects, are easier to take, and may be more effective. On the other hand, these medications are significantly more expensive. The development of these newer medications has highlighted the challenge of ethically studying new treatments for people with serious mental illness. In addition these new medications have not solved the longstanding dilemma of consent for psychotropic medication treatment or administering psychiatric treatment involuntarily. Finally weighing the cost versus benefit of these newer (more expensive) medications has been receiving growing attention.

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SEE ALSO: *Behavior Control; Health Insurance; Life, Quality of; Mental Health; Mental Illness; Patients' Responsibilities; Pharmaceutics, Issues in Prescribing; Profit and Commercialism; Psychiatry, Abuses of*

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PSYCHOSURGERY, ETHICAL ASPECTS OF

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As long as patients with problems of feeling, thinking, and behavior are assumed to be capable of making a free and informed decision on the question of a brain operation intended to improve some aspect of their mental state, there is no logical reason to object to such treatment. Ethical and legal problems regarding psychosurgery should arise primarily because of issues relating to consent to treatment, about which there certainly can be argument.

The Peculiar Case of Psychosurgery

The peculiar problem of psychosurgery arises in part because the brain, which is the instrument of consent, is also understood to be the source of the disability that requires cure. In itself, this is scarcely an objection. Perhaps no one gives a second thought to the specific justification for obtaining consent to the removal of a brain tumor, even if the patient is confused and a proxy consent is necessary. In contrast, it is plausible that much of the hesitation and obstruction that attend discussions of consent to psychosurgery are based upon an unwillingness to view mental illness in the same way as physical illness. Frequently, equality of treatment is denied for all sorts of psychological illness compared with physical illness, as can be seen in numerous health insurance policies. With respect to psychosurgery, there is concern that informed consent must depend upon the adequate function of a large part or wide area of the brain, and there is a valid fear that such function is liable to be absent in those to whom the operation is offered.

Even more aptly, it may be supposed that the effect to be abolished is a prime source of virtue, so that if leukotomy (the cutting of the white matter in the brain; also known as lobotomy) abates guilt it may also impair admirable features of the personality. While there can be sympathy with some of these concerns, they are judgmental questions for which practical answers can be demanded. They ought not to operate as presumptive justifications for refusing practical treatment to anyone. Sometimes there are practical problems in ensuring that the consent of a particular patient to a particular procedure is genuinely free. Nevertheless, psychosurgery attracted enough hostile comment from various quarters to lead to the creation in the United States of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research to look into this topic and related issues after "Widespread expression of public and congressional concern … including allegations that these procedures were … being used for 'Social Control' of dissidents and violence-prone individuals and … were performed disproportionately on members of minority populations" (HEW, p. 53242). Thus, the ethical issues of psychosurgery must be considered against a historical background of success.

The commission demonstrated that there was no substance to the claims being made. For example, only 100 procedures meeting the definition of psychosurgery were being performed annually in the United States in the years leading up to 1977 (when the commission issued its report on psychosurgery). It also determined that no significant psychological deficits were attributable to the psychosurgery undertaken; that the treatment was efficacious in more than half of the case studies; that there was no evidence that the procedure had been used for psychosocial control; and that only a few operations were conducted on minority or disadvantaged populations. Correspondence with the most active psychosurgeons in the United States revealed that out of 600 patients, only one was black, two were Asian, and six were Hispanic Americans. Between 1970 and 1980 only seven operations were reported to have been performed on children, and only three prisoners underwent psychosurgery. In fact, psychosurgery was largely limited to middle-class individuals. In a 1988 study, English investigators E. S. Hussain, H. Freeman, and R. A. C. Jones showed that psychosurgery provided valuable benefits for a selected small group within a cohort of patients from a defined population, particularly those with depression, agoraphobia, obsessional neurosis, and certain aspects of schizophrenia. Such findings show that the ethical aspects of psychosurgery have to do with the conditions under which it is offered, not with the inherent nature of the procedure.

Axioms and Rules

In psychiatric practice, there are some common axioms and some derivative rules. The following may apply to psychosurgery (Merskey, 1991):

1. Ordinarily, medical advice is just advice, and the patient is not obliged to follow it. Even the imposition of treatment to save life (e.g., a surgical operation for kidney disease or cancer) is ethically and legally permissible only if the patient consents.
2. Children and others in a condition that precludes them from deciding rationally may have decisions made for them by people, usually their next of kin, who have appropriate concern for their interests and welfare.
3. Special care is needed when decisions are made for children and other incompetent persons. Careful scrutiny of the status and motives of the person who makes the decision for the patient is necessary. Given that care, treatment can be ethically undertaken.
4. Ethical actions may or may not be sanctioned by law. The legality of a physician's conduct is a separate issue from its ethical basis.
5. Coercive treatments for the benefit of a third party are unethical, and healthcare professionals should not use behavior modification, drugs, or lobotomy against an individual's wishes to prevent that person from hurting someone else.
6. Likewise, coercive treatment for the benefit of society rather than the patient is repugnant to ethical physicians.
7. Patients may consent to treatment that benefits either themselves or others, but there are peculiar difficulties in confirming the presence of free consent in some circumstances, particularly with prisoners.

Overall, the critical issue for the physician is to recognize whether the problem receiving attention is one that is seen by the patient as needing treatment or whether it is seen by others as requiring treatment in the patient's interest. The relationship of physicians to patients is principally based on an implicit contract that the physician will care for the patient provided that the physician is not expected to violate the legal and ethical interests of other people in order to provide that care (Merskey, 1986). Given these presuppositions, the issues surrounding brain surgery can be considered with and without consent in mind.

Brain Surgery with Consent

The easiest case in which to accept the validity of leukotomy is the relief of severe depression. While leukotomy and related operations such as cingulotomy (destruction of a part of the medial portion of the cerebral hemispheres) are now rarely required for this purpose, a patient with this protracted and life-threatening condition may wish to undergo a surgical operation with relatively small risk in order to relieve the condition. Prior to the introduction of physical methods of treatment, there was a high death rate in patients with severe depression (Huston and Locher).

When leukotomy was more common in the 1950s and 1960s, a written agreement might not have been obtained—schizophrenic patients are notoriously unwilling to sign documents—but the patient was not actively opposed. Relatives would support the procedure, and, at least in Britain, the relatives' consent was accepted as legally sufficient. A large number of chronic schizophrenic patients in some countries were submitted to bilateral standard leukotomy operations under the above conditions. If operations failed to relieve fully the schizophrenic illness, at least they reduced agitation or aggressive outbursts and produced a more manageable state in some extremely disturbed patients. Was this process used for "social control?" The available options included locked or padded rooms and physical restraint. Though most psychiatrists did not regard these options favorably, leukotomy operations were not necessarily undertaken to provide otherwise unattainable control but rather to provide the patient with a quieter and easier life. If the patient did not object, and if he or she was substantially disturbed and likely to benefit from the operation, there could be no reasonable objection to such treatment, given the consent of those most likely to have the patient's best interests at heart. It remains the case that such treatment is still appropriate in the same circumstances.

Although the numbers of brain operations for depression, anxiety, and obsessive-compulsive disorder decreased in the 1970s and remained low in the 1980s and the 1990s, their accuracy was much enhanced by the use of stereotactic surgery for movement disorders (especially Parkinson's disease), intractable pain (usually cancer), and the modern developments from leukotomy. Such surgery, undertaken with the help of a fixed framework attached to the cranium, radiological control through magnetic resonance imaging, and radiofrequency ablation of the chosen area, has provided very acceptable results for a number of patients with depression, anxiety, and obsessive-compulsive disorders.

Four related operations stand out as having been the most successful and as having been usefully employed since the 1970s in the treatment of depression, anxiety, and obsessive-compulsive disorder: subcaudate trachtotomy, the implantation of pellets of radioactive yttrium below the head of the caudate nucleus to destroy the neighboring tissue over some six to eight weeks; cingulotomy, the bilateral destruction of the cingulate gyrus; anterior capsulotomy, ablation of the anterior limb of the internal capsule; and limbic leukotomy, in which lesions are placed in the orbito-fronto thalmic and limbic circuits. In 2001 Robert P. Feldman, Ronald L. Alterman, and James T. Gooderich detailed success rates and complications with these methods and described their neuroanatomical bases and physiological implications. In 1997 P. Sachdev and J. Sachdev concisely reviewed psychiatric considerations and the social setting.

With the improvements in technique and results, the discussion of ethical issues appears to have been reduced to a minimum. Only a few centers are known to perform these operations in Australia and New Zealand, Canada, Sweden, the United Kingdom, and the United States. In their 1988 book, *Physical Treatments in Psychiatry,* Leslie G. Kiloh, J. Sydney Smith, and Gordon F. Johnson observed that in 854 stereotactic operations the operative mortality rate was 0.1 percent, the rate for epilepsy was 0.4 percent, marked personality change affected 0.4 percent of patients, and mild personality change affected 3 percent. With a complication rate of this order, and results generally in which 50 percent of patients get considerable benefit and the majority get some benefit, the operations present a rate of risk that is highly acceptable for most individuals who have suffered from disabling chronic depression, anxiety, or obsessive-compulsive disorder for many years. Of the four operations, anterior capsulotomy appears to have the best results overall.

In addition to the treatment of depression and schizophrenia, stereotactic neurosurgical operations—especially amygdalotomy (the amygdala being the gray matter of the brain's frontal lobe)—have been used for the control of aggression, which may be directed against the patient's own self or at others (Kiloh et al.). Also, such an operation was sometimes considered for a number of chronic self-mutilators. The availability and relatively specific effect of serotonin reuptake inhibitor drugs have eased the symptoms of many patients who were prone to self-damage. That medication might produce such a radical change in self-harm means that a surgical operation when medication fails can be seen as a logical and reasonable effort to modify an aberrant portion of the brain. Many patients with such tendencies are not intellectually retarded and have no organic brain damage. Nevertheless, although most of them can respond to antidepressant medication, others need more radical treatment, suggesting that psychosurgery still has a role to play for a few patients.

Psychosurgery for individuals who are dangerous only to others but who might be willing to consent is the most difficult issue in this field. If the patient can consent, one might ask why the person should not be allowed the treatment? This problem is exemplified by the 1973 case of *Kaimowitz v. Department of Mental Health.* A patient who had behaved aggressively, but was a prisoner, consented to treatment but was refused it on the grounds that his consent in prison could not be truly free. The patient, who had spent eighteen years in prison for murder, had satisfied an "informed consent" review committee comprising a law professor, a priest, and an accountant that he wanted the operation. A suit was brought by an attorney, Kaimowitz, and others belonging to a medical committee for human rights who had never consulted the prisoner. The lawyer appointed by the courts to represent the prisoner thought that the prisoner desperately wanted the operation. Coincidentally, the prisoner's appointed lawyer satisfied the court that his client was held unconstitutionally as a prisoner. He went free, but the discussion continued on the question of whether as a prisoner he had given free informed consent to psychiatric surgery. The court held that he could not have. Once the prisoner was released, he changed his mind about wanting the operation. According to Robert A. Burt (1975), imprisonment and medical surveillance at least contributed to the prisoner's consent without any attempt having been made by physicians to press the prisoner to agree. Some commentators have argued that no prisoner's consent should be accepted for psychosurgery if its purpose is to alter the type of behavior that caused imprisonment. To guard against the possibility that a prisoner might be deprived of the right to medical care, some framework should be contemplated that would provide for exceptions. Exceptions would include independent professional examination of the individual's motives as well as separation of the question of release from the outcome of the operation.

Incompetent Patients

Certain incompetent patients might undergo surgery provided that it can be demonstrated that the action is not against their wishes. This would apply particularly to schizophrenic patients, who might accept a surgical operation but would never be able to comprehend or fill out a form requiring them to indicate informed consent. Patients should not undergo surgery if they give the merest hint of refusal.

Children with significant brain damage may benefit from psychosurgery, not so much to treat epilepsy caused by the brain damage as for the reduction of aggressive behavior against either themselves or others (Balasubramaniam and Kanaka). If the interests of the child are paramount, then the child should not be deprived of the possibility of beneficial surgery, even though the child is either unable to consent or appears hostile to almost any physical intervention by nursing staff or attendants. This would apply both to patients who gravely damage themselves—and sometimes have been kept for weeks or months in canvas clothing to protect themselves from such injury—and to patients who, while retarded and clearly incompetent, attack others if allowed the minimum opportunity for human contact. Such a patient also may benefit if a paternalistic approach to treatment is recognized, acknowledged, and followed.

Nevertheless, there is no justification for the forcible use of psychosurgery with individuals who are thought to be political prisoners by the family, the patient's proxies, the treating doctor, or indeed any rational contemporary.

In summary, psychosurgery should never be forced, but it might be performed on noncompetent individuals or prisoners without their formal consent, subject to stringent safeguards that require extensive consideration.

HAROLD MERSKEY (1995)
REVISED BY AUTHOR

SEE ALSO: *Autonomy; Coercion; Deep Brain Stimulation; Electroconvulsive Therapy; Holocaust; Informed Consent: Issues of Consent in Mental Healthcare; Insanity and Insanity Defense; Institutionalization and Deinstitutionalization; Mental Illness: Conception of Mental Illness; Mental Illness: Cultural Perspectives; Mental Institutions, Commitment to; Mistakes, Medical; Narrative; Paternalism; Patients' Rights; Psychiatry, Abuses of; Psychosurgery, Medical and Historical Aspects of; Race and Racism; Technology; Women, Historical and Cross-Cultural Perspectives*

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PSYCHOSURGERY, MEDICAL AND HISTORICAL ASPECTS OF

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Psychosurgery is the surgical removal or destruction of brain tissue with the intent of normalizing behavior in otherwise disabling psychiatric disorders. The patients selected for treatment generally have certain types of symptoms rather than being a part of entire nosological groups or diagnostic categories. Examples of such symptoms include phobias, anxieties, depressions, obsessive compulsions, and affective components of schizophrenia—behaviors that include, but are not limited to, incapacitating alterations in mood with loss of interest in usually pleasurable activities; persistent and irrational fear of an object, activity, or situation; or feelings of apprehension or dread about the future. Routine neurosurgical procedures are employed, including cutting, burning, or irradiation of brain tissue. Neurosurgical procedures for psychosurgical purposes are performed in the absence of definable, structural brain changes such as tumors, vascular malformations, or post-traumatic scarring. Surgical intervention in the brain for the purpose of treating a structural lesion, or other definable pathology such as an epileptic focus or tumor, would not be considered psychosurgery even if the procedure resulted in some behavioral alteration. Regarding pain relieving procedures employing some of these techniques, there is no clear consensus. Such procedures clearly are designed to alter the perception of pain, thereby altering the behavioral response to that pain. Pain relieving procedures have not been included in most discussions of psychosurgery unless they are specifically oriented toward altering an emotional or affective disorder associated with the pain.

Mechanisms

The best results of treating psychiatric disease by neurosurgical interventions follow destruction of some part of the frontal lobes or their connections to other brain structures. The limbic system—that portion of the brain including the white-matter fiber tracts (consisting of nerve fibers covered with myelin and hence white in appearance) of the corpus callosum (connecting the two hemispheres of the brain), the cingulate, the fornicate, and the angulate gyri, and the amygdala and hippocampus of the temporal lobes, as well as the deeper nuclei (consisting of cell bodies or gray matter), the thalamus, and the hypothalamus—is now generally accepted to control behavior and the emotions. While the relationship of these structures to behavior and emotions is accepted, the specific functions of the various segments have not been identified with any certainty. The present state of knowledge about the physiological mechanisms for the control of normal emotions, to say nothing of the mechanisms involved in affective disorders, can only be characterized as rudimentary and empirical. Hence, there is no pathophysiological rationale for selecting targets for psychosurgical procedures. There is no good answer at present to the question of how these treatments work. It is, therefore, of critical importance to prospectively evaluate outcomes of treatment in relation to the initial patient symptoms.

The Development of Psychosurgery

Psychosurgery began in the 1930s in the Yale University laboratory of neurophysiologist John Fulton. Based on a growing background of knowledge from animal experiments using selective destruction of frontal lobe areas, combined with behavioral training from a number of laboratories, and on a specific observation from Ivan Pavlov (1928) concerning the production of neurotic behavior in dogs presented with confusing reinforcement symbols, he and his colleague Carlyle Jacobsen conducted behavioral experiments on two chimpanzees trained to solve complex problems in order to obtain food rewards. When frustrated with attempts to obtain food, they became agitated and aggressive. Fulton and Jacobsen then performed frontal lobectomies, literally cutting out the anterior frontal lobes of the brain, and noted that the animals became immune to frustration, although they performed assigned tests slightly less well.

Fulton and Jacobsen reported their observations at a 1935 London neuroscience meeting (Fulton and Jacobsen; see also Fulton, 1942, 1951). In attendance was a noted Portuguese neuroscientist, Egas Moniz, who, with his neurosurgical colleague Almeida Lima, performed the first procedures in humans a few months thereafter. The initial operation involved placing two holes through the skull three centimeters from the midline over the frontal area, with injection of alcohol to destroy the brain substance. In subsequent operations a wire loop was used to cut the frontal lobe connections. Thus they modified the Fulton procedure, performing only a frontal lobotomy or, as Moniz termed it, a *leukotomy* (cutting of the white matter). Moniz was awarded the 1949 Nobel Prize for his discovery of the therapeutic value of prefrontal leukotomy in certain psychoses.

Neuropsychiatrist Walter Freeman of the United States also attended the London conference. He and his neurosurgical colleague James Watts introduced psychosurgery to the United States. They pioneered the *lobotomy,* in which frontal lobe connections to the surrounding brain were severed initially by an open neurosurgical approach called *craniotomy,* using suction to sever the fibers. The demographics of the over 600 patients reported on by Freeman and Watts are not easily summarized. Many were institutionalized but many others were cared for at home and referred by their psychiatrists. The majority were women. All of these patients were considered disabled by their illness. However, Freeman felt the procedure was too costly, being primarily governmentally funded through the state-run mental institutions, and required too much skill to use on a broad scale to empty the wards of the large mental institutions. Freeman was very much a community psychiatrist and saw it as his mission to empty the back wards of state mental hospitals.

Around 1945, Freeman introduced a procedure described by the Italian neurosurgeon Amarro Fiamberti, in which the surgeon introduced a sharp probe (originally an ice pick) through the roof of the eye socket (orbit) into the frontal lobe white matter and oscillated it back and forth, thus severing the nerve fibers; this was called a *transorbital lobotomy* (Freeman and Watts). Watts, who performed the traditional procedure, felt Fiamberti's procedure violated any sense of neurosurgical dignity. The so-called "ice pick lobotomy" could easily be performed, and it is estimated that by 1955 over 40,000 had been done in the United States. Freeman, a nonsurgeon, alone performed or supervised over 3,500 operations in 19 states and 10 foreign countries (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research). The indications were broad, including almost any patient confined to an institution, predominantly schizophrenics. While as effective as open craniotomy, the procedure was undertaken at a much greater risk of immediate complications resulting in neurologic sequelae, such as paralysis or epilepsy. Long-term psychological results were often associated with intellectual and emotional changes, such as a withdrawn and flattened affect. However, more patients were able to be discharged from the institutions because of the procedure than previously had been possible (Mettler; Tow; Petrie).

With the introduction of the drug chlorpromazine in 1952, use of psychopharmacologic agents (drugs designed to treat the symptoms of psychiatric illness) ended the era of lobotomies. Chlorpromazine resulted in the sedation of agitated patients and alleviation of psychotic behaviors, such that patients could be managed better both in and out of institutions. In the 1960s, with the advent of antidepressant medication, the number of psychosurgical procedures declined even further. Although they were performed far less frequently, they continued to be used from time to time because of their demonstrated beneficial effects in many intractable patients who were not helped by traditional therapy.

In 1947, Ernest Spiegel and Henry Wycis introduced a technique for precisely locating points or targets within the human brain, thereby allowing destruction of specific tissue with minimal disruption of the surrounding brain (Spiegel and Wycis). This technique, still the technique of choice, is called *stereotaxic surgery.* Stereotaxis employs precise calculation of locations within the brain using internal, radiographically determined reference points, thus allowing placement of a probe or beam of radiation with great accuracy. At about the same time, John Fulton reasoned that an optimum site of a lesion to treat psychiatric illness should be located in one quadrant of the frontal lobe and could be quite small. Stereotaxic surgery ushered in the modern era of psychosurgery by making possible treatment of psychiatric disease through very small, precisely located lesions.

As knowledge of the limbic structures became more precise, neurosurgeons began directing their efforts to cutting selected fiber tracts that connected the frontal lobes with specific limbic structures by using stereotaxis. Although surgeons could not specify how destruction of small brain areas worked to alleviate the symptoms of psychiatric disease, it did work. Complications from surgery declined significantly. The safety and efficacy of psychosurgery improved greatly. Stereotaxic psychosurgical technique gained in popularity by the late 1960s, when mental-health professionals recognized that the medications used to treat psychic disease did not help everyone and often had significant side effects.

Psychosurgery suffered a dramatic decline in the United States, similar to that coinciding with the advent of psychotropic medication, beginning in the 1970s. Those who viewed psychosurgery as mutilation of the brain leveled much criticism at those who were performing the procedures. The most vocal opponent was Peter Breggin (Breggin, 1972). Trained in a tradition that denied the authenticity of mental illness as a disease, he argued vehemently that all surgical treatments mutilated the brain and destroyed function. No scientific data were presented to substantiate his claims, but they did serve to raise public awareness about psychosurgery. The case against psychosurgery was aided by the speculation of Vernon Mark and Frank Ervin that the techniques might be helpful in controlling criminal or violent behavior, thereby raising the specter of political control (Mark and Ervin).

The debate generated a politically stressful environment, with the most vocal groups being against the treatment. There developed a desire on the part of American psychiatrists and neurosurgeons to avoid controversy over this form of treatment. The result was a dramatic decline in the use of psychosurgery techniques. Between 1949 and 1952, approximately 5,000 lobotomies were performed each year in the United States, largely by itinerant physicians lacking neurosurgical training. The commission established by Congress to investigate psychosurgery estimated that in 1971 and 1972, 140 neurosurgeons had performed a total of approximately 400 to 500 operations a year (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research). In 1987, Harvard University neurosurgeon Thomas Ballantine reported on a group of 474 psychosurgical patients treated over the previous twenty-five years (about 18 per year); most procedures had occurred in the late 1960s and early 1970s (Ballantine and Giriunas). More specific reports from which the current incidence of psychosurgical procedures in the United States might be calculated are lacking.

Current Safety and Effectiveness

Psychosurgery, in spite of declining frequency due to nonmedical reasons, benefited from the more precise definition and understanding of the types of patients who were likely to be helped by this surgery. This process occurred simultaneously with the development of psychosurgery, as psychiatry made advances in the understanding of mental illness. One important consideration is consent to treatment. Informed consent for mentally ill patients may be possible if the impairment does not extend to rendering the patient “incompetent” in the legal sense. But whether a mentally ill or incarcerated person can ever give a voluntary informed consent is doubtful, as mental competence and autonomy are such arbitrary notions. The integrity of the physician is the most effective guarantee of a patient’s rights.

Currently, in selecting who should be treated, an appropriate psychiatric diagnosis revealing symptoms amenable to relief by psychosurgery is required. Appropriate candidates include chronically and severely depressed individuals with a preexisting history of obsessive-compulsive personality traits; chronically anxious patients whose psychic pain is incapacitating; and increasingly incapacitating obsessive-compulsive neuroses associated with depression. All other treatments deemed appropriate for the diagnosis, including the use of appropriate doses of psychopharmacologic medication, should be tried before psychosurgery is contemplated. Incapacity produced by the illness should be disabling and persistent. There should be no contraindications, either physical or mental, to the performance of the procedure.

Technique

Modern stereotaxic psychosurgery consists of producing lesions by heating electrodes in the target areas to coagulate the tissue or, more recently, by the destruction of a target area by focused radiation utilizing either a linear accelerator radiation source or a focusable cobalt radiation source known as the gamma knife. Either technique requires fixing a head frame to the patient’s skull with pins, inserted under local anesthesia. Some type of imaging—magnetic resonance scanning, computed tomographic scanning, or the introduction of air into the fluid space of the brain for contrast and using radiographs (ventriculography)—defines the target within the brain. When heat is used, the surgeon places a burr hole through the skull over the target area and introduces a probe into the target. A radio frequency current is applied to the probe and the lesion is produced. The production of the lesion is painless. The radiation lesion technique requires no opening of the skull. The patient is transported to the instrument used and is exposed to a focused beam of radiation. This also is painless. Following the production of the lesion, the patient is returned to the hospital room and usually discharged the following day. The onset of the effects of the heat lesion is virtually immediate, while the radiation may take as long as six months to produce the final result. Both lesions are irreversible.

Targets

Primarily four areas of the limbic system are currently utilized as targets. The procedures, named for the target areas, are cingulotomy, subcaudate tractotomy, limbic leukotomy, and amygdalotomy. Cingulotomy places the lesion in the cingulate gyrus of the brain, located on the inside of the frontal lobes. One or both of these structures may be lesioned, primarily for relief of depression and/or obsession; the procedure has a reported 75 percent recovered or markedly improved result in depression and 56 percent in obsession. Subcaudate tractotomy is performed just below the nucleus of the brain, called the caudate nucleus, in the white-matter fiber tracts connecting with frontal lobe structures. The primary indications for this procedure are depression, anxiety, and obsession; it has a recovered or improved rate of 68 percent for depression, 63 percent for anxiety, and 53 percent for obsession. Limbic leukotomy is a lesion placed in the white-matter tracts of the frontal lobe connecting to the nucleus called the thalamus. This lesion has been used for depression, anxiety, and obsession, with recovery or improvement in 61 percent for depression, 63 percent for anxiety, and 84 percent for obsession. Amygdalotomy places a lesion in the amygdaloid nucleus of cell bodies located in the temporal lobe and integrally connected to the limbic system structures. Unlike the other targets, amygdalotomy is used primarily for aggression, with a 76 percent markedly improved or recovered outcome (Maxwell).

Complications

The incidence of complications for each procedure is extremely low when compared with the morbidity and mortality of the old frontal leukotomy of Freeman and Watts (Mettler; Tow; Petrie). Significant neurologic complications, such as paralysis or epilepsy, and psychological complications, such as persistent behavioral or personality changes, occur in much less than 1 percent of cases (Ballantine and Giriunas).

The one aspect of the old frontal lobotomy that has remained in the minds of those caring for these patients is the generally placid affect, loss of initiative, and decline in intellectual function that was frequently seen. Reports of neuropsychological studies of patients undergoing modern psychosurgical procedures have indicated no significant damage to higher brain functions such as recognizable personality. Relief of disabling and intractable behavioral symptoms is followed by impressively improved overall function with preservation of personality (Mindus and Jenike; Bridges). However, neuropsychological instruments designed to measure cognition may not be sensitive enough to detect subtle emotional impairments. Currently available methods of testing support the conclusion that limited procedures such as cingulotomy, subcaudate tractotomy, limbic leukotomy, and amygdalotomy result in minimal intellectual and cognitive changes for the patient while reducing disabling symptoms such as depression.

Issues of Patient Selection

In the 1970s, amid concern about violence in the ghettos, some political activists, black and white, made accusations that psychosurgery was being used as a tool of the establishment to exercise political and social control, specifically of minorities and women (Mason; Carver). These accusations arose from publicity regarding proposed but never undertaken research projects, to be supported by federal funds, that focused on the psychosurgical treatment of irrational and spontaneously violent behavior arising from epilepsy in the limbic system. In addition, the issue of social control and racism in the application of psychosurgery became public when, with the establishment in Los Angeles of a Center for the Prevention of Violence, one of the researchers who had proposed a study of psychosurgery and violence joined the staff. At about this time, reports of psychosurgery performed on black patients in Mississippi were published (Andy and Jurko). These were institutionalized, severely disturbed, mentally retarded children; the neurosurgeon defended the practice on the basis that the psychosurgery was indicated medically as a treatment of last resort, and that the preponderance of black patients reflected the composition of the total patient group and not prejudice. There were those in the psychiatric community who felt that the levels of psychiatric care, the availability of qualified staff, and the availability of alternative treatment in this facility were below even minimal standards, thus calling into question the use of psychosurgery. The possibility of de facto racism existed.

No reliable evidence to support charges of intentional racism in the use of psychosurgery has been presented. There is no case of a responsible individual or group claiming that psychosurgery has actually been used for purposes of political action, social control, or acting out of personal prejudices against minority groups or women. However, there are no reliable data with respect to the incidence of psychosurgery performed on whites or blacks, males or females; such reports as are available give no support to the charge that minority groups of any category have been subjected to operations specifically on the basis of membership in such a group.

With respect to legally committed or otherwise involuntarily institutionalized patients, the issue of valid or proxy consent is a difficult one. However, it is generally acknowledged that there are some patients in this category who may benefit from psychosurgical procedures. As issues of autonomy versus community are studied and elaborated, new ethical grounds for consent in this population should arise (Beauchamp et al.).

Recent Developments

Since the mid-1990s, the use of functional neurosurgery to access the cingulate gyrus, subcaudate tractotomy, limbic leukotomy, and anterior capsulotomy targets has seen a renaissance of interest (Christie; Lichterman; Snaith). Although efficacy continues to be estimated at 30 to 70 percent of persons treated, depending on diagnosis, the difficulty of evaluating the efficacy of such procedures cannot be overemphasized and researchers have placed an emphasis on developing methods to better assess efficacy (Binder and Iskandar). Several factors have made these determinations difficult. Most reports have been long-term retrospective analyses using methods that did not remain constant over the period studied. Most evaluations since the mid-1990s describe shorter follow-up periods but are prospective in design, and feature more well-defined diagnostic populations, but suffer from the problem that the persons selecting the patients and performing the outcomes analysis also selected the persons to be treated. Estimates of outcomes have been difficult to compare between studies. The most difficult problem has been determining appropriate control groups. A randomized, double blind, prospective study of surgical versus non-surgical treatments is definitely needed. The ability to perform such a procedure is constrained by the ethics of withholding treatment in the population of persons selected for treatment, the practical difficulty of identifying controls with severe disease who are not surgical candidates, and the ethics of sham open neurosurgical procedures, which carry significant risk. In the absence of such studies, the best current evidence of efficacy remains in the pre- and post-operative evaluation of individuals.

With the increased interest in psychosurgical procedures, now more favorably referred to as functional neurosurgery for psychiatric disorders, clinical practice guidelines have been developed to assist physicians who are contemplating surgical intervention for their patients (March et al.). Such guidelines identify the availability of surgical therapy for psychiatric disorders and the make explicit the order of treatment. The guidelines help referring psychiatrists with selection criteria and indications. Obsessive-compulsive disorders, treatment resistant affective disorders, and anxiety were the accepted indications for surgical treatment in the early 2000s. Personality disorders and psychotic disorders are relative contraindications.

Several technical advances have contributed to the increasing interest in these procedures. More precise delineation of the anatomical substrate of psychiatric disorders has been progressing, for example the relationship of the amygdala to human fear (Adolphs et al.). Researchers have compared the activation of certain structures during obsessive-compulsive states to resting states using imaging techniques, and similar studies have been done for psychosis and bipolar disorder. Such information begins to confirm that the targets selected for functional neurosurgery are indeed related to the diseases being treated. Such information is also teaching that surgical destruction of brain target areas may not be the only way to affect these anatomical locations. Surgical interventions that might augment nervous system function such as electrical stimulation, implantation of mini-pumps or drug-secreting capsules, transplantation cells, and implantation of genetically modified vectors for gene delivery are all being explored. Researchers have also performed deep brain electrical stimulation for obsessive-compulsive disorder and Tourette's syndrome.

Conclusion

There is substantial evidence that twenty-first century stereotaxic techniques, involving smaller, more discrete lesions in the brain, avoid the unwanted outcomes seen in many patients treated by earlier psychosurgical procedures. In addition, there is sufficient evidence that certain procedures do offer potential benefit to the patient who has failed to respond to other known therapies. These procedures do not appear to produce adverse psychological changes.

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SEE ALSO: *Autonomy; Coercion; Deep Brain Stimulation; Electroconvulsive Therapy; Holocaust; Informed Consent: Issues of Consent in Mental Healthcare; Insanity and Insanity Defense; Institutionalization and Deinstitutionalization; Mental Illness: Conception of Mental Illness; Mental Illness: Cultural Perspectives; Mental Institutions, Commitment to; Mistakes, Medical; Narrative; Paternalism; Patients' Rights; Psychiatry, Abuses of; Psychosurgery, Ethical Aspects of; Race and Racism; Technology; Women, Historical and Cross-Cultural Perspectives*

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PUBLIC HEALTH

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I. Determinants
II. History
III. Philosophy
IV. Methods

I. DETERMINANTS

The current preoccupation with medical science and its application as the primary determinant of health derives largely from the enormously successful experience with applying microbiology in the battle against ill health. Identification of specific microorganisms as agents of epidemic communicable diseases, and means of controlling them, aroused expectations of finding “magic bullets” for most of humanity's ills. Further discoveries, such as insulin for diabetes and chemicals effective against certain forms of cancer, have encouraged the notion. Using the term *health provider* to mean a physician epitomizes this view.

However, dependence on medicine as the source of health tends to obscure far more fundamental influences on health. For millennia it has been evident that living conditions and the response to them largely determine people's health. Therefore, people have sought to extend life and improve health not only as individuals but also through communal efforts in the societies of which they are a part. These social efforts to enhance the health of whole populations have come to be called public health, "what we, as a society, do collectively to assure the conditions in which people can be healthy" (Institute of Medicine, p. 1). In modern times, government plays the leading role in this endeavor, supplemented by other endeavors organized to advance the health of the public. Making medical services available to people is only one way in which modern industrialized societies address health challenges; other measures include assuring a healthful environment and encouraging healthful behavior by individuals. To carry out its mission, public health must establish effective linkage with other efforts for social advancement, particularly in welfare and education.

Public health measures its progress by the health status of the population it serves. Thus, knowing the determinants of the public's health (which is also known as public health) is essential to the field.

Advances in Health, 1800–2000

The period since 1800 has brought the most spectacular health improvement in human history. From the time of the hunter-gatherers thousands of years ago until the industrial revolution around 1800, Mark Cohen estimates that life expectancy at birth ranged consistently between twenty and fifty years, most commonly about twenty-five to thirty years (Cohen). At the end of the twentieth century, life expectancy exceeds sixty-five years in most parts of the world and seventy-five years in western Europe, North America, and Japan.

In the United States, for example, life expectancy was only forty-seven years when the twentieth century began. By the late 1980s it had reached seventy-five years, according to the National Center for Health Statistics (1990). To a considerable extent that advance was due to declining infant mortality, from more than 100 per 1,000 in 1900 to less than 10 per 1,000 in the late 1980s, and to the control of communicable diseases, which take their major toll during the early years of life. Since 1960, however, relatively greater extension of life has occurred in the later years. From 1900 to 1960 life expectancy at birth increased twenty-two years, but only one-tenth of that expansion came after age sixty-five. Since 1960, on the other hand, more than half of the five years gained in life expectancy at birth have come beyond age sixty-five.

Table 1 lists specific diseases, and their trends, that have affected residents of the United States since 1900. Medical students in the early 1900s learned about pneumonia as "the old man's friend" and tuberculosis as "the captain of the men of death." Heart disease at the start of the century largely came from rheumatic fever, whereas now atherosclerosis accounts overwhelmingly for heart disease. Population aging considerably influences death rates from cancer and heart disease. Even when adjusted for age, however, cancer mortality has been increasing, mainly because of the twentieth-century epidemic of lung cancer. A rare form of the disease in 1900, respiratory cancer increased to constitute about one-tenth of all cancer deaths in 1950 and almost one-third as the century closed. Other measures of health status, such as survival to age sixty-five, reveal the role of violence and injury in certain human populations, such as young males in the United States.

Historical Determinants of Health

Health may be viewed as the human side of a dynamic equilibrium between the organism and its environment; that interface is the place where health is mainly determined.

The genetic structure with which humans enter the world will generally allow survival for about eighty-five years, according to James Fries (1980). In some people, of course, hereditary abnormalities interfere with and/or shorten life, while others live more than eighty-five years in reasonably good health. Beyond these biological influences, since food and oxygen are the most critical elements for human life and since oxygen is only rarely inadequate, nutrition constitutes a paramount factor in health. From earliest times to the present, inadequate food has been a major threat to health. In fact, society has evolved largely to supply enough food for people—for example, through migration and the development of agriculture.

Not infrequently, however, huge numbers of people have been trapped in starvation through ecological and social catastrophes—both in ancient times and more recently, as in the Irish potato blight of the late 1840s and in slavery in the United States, and now in certain African nations and among the homeless in America. Moreover, beyond gross lack of calories, deficiencies of vitamins and

TABLE 1

Crude Death Rates per 100,000, Selected Causes, U.S. Registration Area, 1900–1988

Cause of Death	*1900*	*1920*	*1940*	*1970*	*1980*	*1988*
Pneumonia	153	82	25	31	24	32
Tuberculosis	94	113	46	3	1	1
Diphtheria	40	15	1			
Organic heart disease	123	151	296	362	336	312
Cancer	64	83	125	163	184	199
Diabetes	11	16	27	19	15	16

SOURCE: Linder, Forrest E., and Grove, Robert D., 1943; Stieglitz, Edward J., 1945; U.S. Bureau of the Census, 1990.

other micronutrients cause incalculable damage to health—incalculable because scurvy, rickets, and pellagra may be only the most striking clinical manifestations of severe damage to health.

Industrialization, even though it has improved the standard of living in many respects, has also precipitated some devastating health events. In the early 1800s, when people flocked from the countryside to factory towns and cities in search of a better life, they found crowded housing, gross lack of sanitation, and exhausting work (even for children), as well as food deficiencies. These living conditions produced the "crowd" diseases, epidemics spread by intestinal and respiratory discharges that debilitated many people and caused high mortality. Though all segments of society were affected, the poor suffered then, as throughout history, most severely from the adverse conditions.

While medical science has helped in overcoming the communicable disease epidemics since 1800, other factors have been even more important. John and Sonja McKinley have estimated that at most 3.5 percent of the total decline in mortality (from influenza, pneumonia, diphtheria, whooping cough, and poliomyelitis) since 1900 could be ascribed to medical measures (McKinley and McKinley). Thomas McKeown has demonstrated that medical science barely affected the decline of tuberculosis (McKeown).

During the twentieth century a constellation of noncommunicable diseases, led by cardiovascular disease and cancer, has supplanted the epidemic communicable diseases as the foremost health problem in industrialized countries (despite the current public attention to AIDS); and increasingly such noncommunicable diseases are affecting the rest of the world. Again, the circumstances of life and the way people behave in them are the major determinants. For example, the first to indulge in excessive calories, fats, cigarettes, and physical inactivity were affluent men, and accordingly they suffered consequent ischemic heart disease first. Poor men—for example, blacks in the United States—only later had considerable access to those relevant factors; their epidemic of ischemic heart disease came later and is persisting longer.

Major Current Influences on Health

Epidemiological studies have delineated key factors in the rise and the start of the decline of twentieth-century noncommunicable diseases. Most noteworthy, in 1964 an advisory committee to the U.S. surgeon general summarized the growing evidence that "Cigarette smoking is causally related to lung cancer in men … the most important of the causes of chronic bronchitis in the United States … [and is associated with] … a higher death rate from coronary artery disease …" (U.S. Surgeon General's Advisory Committee, pp. 31–32).

Studying a sample of the Alameda County, California, population, Nedra Belloc and Lester Breslow demonstrated the strong relationship of seven health practices to health status and subsequent total mortality: eating moderately, sleeping seven to eight hours, using alcohol moderately if at all, not smoking, eating breakfast, not snacking, and having at least moderate physical activity (Belloc and Breslow). Men who followed all seven health practices enjoyed physical health equal to that of men thirty years younger who reported two or fewer. Forty-five-year-old men who followed none to three of the health practices had a longevity of sixty-seven years; four to five, seventy-three years; and six to seven, seventy-eight years, thus yielding an advantage of eleven years, depending upon health behavior. Lisa Berkman and Lester Breslow reported further that the extent of one's social network likewise substantially predicted physical health status and mortality (Berkman and Breslow). A 1974 official Canadian document, the LaLonde Report, proposed a health field concept. According to the latter, four broad elements comprise the health field: human biology, environment, and lifestyle, and healthcare organization. Further, the LaLonde Report asserted that “Improvements in the [social as well as physical] environment and an abatement in the level of risks imposed upon themselves by individuals, taken together, constitute the most promising ways by which further advances can be made.”

The growing emphasis on the way people live as an important health factor in the industrial (and postindustrial) world must be considered carefully in relation to social responsibility for lifestyle. Otherwise, that emphasis can properly be termed “victim blaming.” A 1952 report to the president of the United States, *Building America’s Health,* noted that “Recognition of the significance of individual responsibility for health does not discharge the obligation of a society which is interested in the health of its citizenry. Such recognition, in fact, increases social responsibility for health” (President’s Commission on Health Needs of the Nation, vol. 1, p. 2). As the Ottawa Charter for Health Promotion stated, “Health promotion is the process of enabling people to increase control over and to improve their health. … [It] … demands coordinated action by all concerned: by governments, by health and other social and economic sectors, by non-governmental and voluntary organizations, by local authorities, by industry, and by the media” (International World Health Organization Conference, p. 1).

As it becomes clear that we are able to raise life expectancy to some sort of biological limit, it may well be that public health rather than gross national product (GNP) will constitute the criterion for national success. Using public health as a standard for this success would help illuminate how GNP masks the staggering toll of ill health found among low-income or very poor Americans, many of whom, like American Indians or African Americans, have been disproportionately disadvantaged for generations. Achieving that reorientation of values will require a new approach to the food, alcohol, tobacco, medical, and other industries whose products and services are pertinent to health. Health ethics now entails concern for issues beyond matters in which the physician–patient relationship predominates. How to deal effectively with the “right” to addict young people throughout the world to tobacco and to expose others to one’s intoxicated behavior, and similar public-health issues, are coming to the fore. Social action reflecting experience and thought concerning such questions will determine health in the future, just as assuring safe water and milk determined health in the past.

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SEE ALSO: *Hazardous Wastes and Toxic Substances; Health and Disease: History of Concepts; Health Screening and Testing in the Public Health Context; Injury and Injury Control; Lifestyles and Public Health; Public Health Law; Sexual Behavior, Social Control of; Warfare: Public Health and War;* and other *Public Health* subentries

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II. HISTORY

Public health may be defined as the collective action by a community or society to protect and promote the health and welfare of its members. In a world where sickness and accidents were attributed to spirits, the welfare of the tribe and its individual members depended upon paying proper homage to the spiritual realm. Since public-health measures are based upon the level of existing medical knowledge or prevailing assumptions, the observance of taboos and rituals by early tribal societies represents a form of public health. The origins of modern public health lie in efforts to prevent pestilential diseases, but in the past centuries public health has broadened its aims and now applies the findings of social and scientific fields to promoting physical and mental well-being.

Public health in its modern sense arose as a phenomenon of urbanization. As towns and cities emerged, communal living created special problems relating to food, water, sanitation, and disease. In an urban environment, the responsibility for providing safe food and water and disposing of garbage and human wastes could no longer be left to individual initiative, and what were essentially public-health regulations appeared. Both health and aesthetics supplied the motive for these early sanitary regulations, since foul odors were associated with the miasmic theory of disease, a belief that some obnoxious gaseous substance was the cause of epidemic disease.

The classical civilizations evolved relatively sophisticated public health measures. In the second millennium B.C.E. the Minoans developed elaborate plumbing systems that included flush toilets. The great Roman aqueducts that were built between 312 B.C.E. and about 100 C.E., sections of which still survive, are familiar to all; but what is not so well known is that the Roman water systems, at least the one for Rome, differentiated between water for common use and that for drinking. The decline of the Western Roman Empire meant a return to a rural society, and it was not until the rise of towns and cities in the medieval period that public-health measures were reinstituted. The need to live within the town walls for safety intensified crowding and its concomitant sanitary and health problems. In the medieval period fear of two horrible diseases, leprosy and bubonic plague (the Black Death), was responsible for the practice of isolating the sick and instituting quarantines to keep the sickness at bay. Victims of leprosy were literally read out of society, and the first quarantine laws appeared in 1348 in response to the spread of the Black Death.

The late Renaissance and early modern period witnessed two developments that helped pave the way for the institutionalization of public health. The first of these was the concept of mercantilism, which, among other factors, counted population as a source of a nation's wealth. The second was the development of what was termed political arithmetic. Morbidity and mortality statistics are basic to understanding the health of a population and to determining health policy. Two Englishmen, William Petty (1623–1687) and John Graunt (1620–1674), were among the first to recognize this need. They urged the collection of statistics pertaining to health and social matters in order to promote a more healthy and productive population. The astronomer Edmund Halley in 1693 published a life expectancy table that made possible the first life insurance company. Later, life and industrial insurance companies in the United States were to play a role in promoting public health.

John Locke (1632–1704) in 1690 published his classic treatise, *Essay on Human Understanding,* in which he asserted that human beings were the product of their environment. By applying intelligence to social problems and creating a better society, it would be possible to improve humankind. The French philosophers Denis Diderot, Jean Le Rond d'Alembert, Voltaire, and Jean-Jacques Rousseau carried the idea even further by assuming the perfectibility of humanity. Joining this assumption to the mercantilist principle that a growing and healthy population strengthened the power of the state, the "benevolent despots" of the eighteenth century sought to impose public-health measures by fiat. This form of public health, in which administrators issued decrees relating to health and sanitation, was called "medical police" or medical policy; and its leading exponent was Johann Peter Frank, whose six-volume *Complete System of Medical Policy* (1779–1817) dealt with virtually all aspects of public health, from sanitation to the health of workers.

In Britain, the Civil War and the Glorious Revolution of 1688 had made the British people suspicious of the central government; consequently, much administration was kept at the local level. As in the United States, the major impulse for public-health reform came in the nineteenth century and was led by middle-class reformers motivated by a mixture of Christian benevolence, humanitarianism, and rationalism. The dislocations resulting from economic changes in the eighteenth and early nineteenth centuries created a large impoverished class and led to efforts by humanitarians to reduce the enormous mortality among infants, to alleviate the suffering of prisoners and the insane, and to fight against widespread alcoholism among the working class.

By the early nineteenth century, the industrial revolution was drawing thousands of workers from rural areas into crowded city slums, compounding the growing urban sanitary problems. In Britain, the harsh conditions of the poorly paid men, women, and children working long hours in the newly spawned factories and mills came to the attention of several humane individuals, and, under the leadership of Lord Ashley, a series of factory acts was enacted. The first of these, passed in 1833, restricted the working hours of children below the age of eighteen to twelve per day and sixty-nine per week. In the legislative battle for this law, parliamentary hearings drew attention to the atrocious living conditions of the workers and their high rates of sickness and death. The hearings also showed that the excessive use of alcohol and opium was a means of escape for workers condemned to lifelong toil in a brutalizing environment.

Meanwhile, the physicians C. Turner Thackrah, James Philips Kay, Thomas Southwood Smith, and Neil Arnott were drawing attention to the need for health reform. They were fortunate in enlisting Edwin Chadwick (1801–1890) in their cause. Chadwick was a single-minded reformer who dedicated himself to promoting the welfare of the working class. His investigations and reports on behalf of government commissions, culminating in his report for the Health of Towns Commission, were largely responsible for the passage of the Public Health Act of 1848. This measure marks the first step in the institutionalization of public health in the West.

In France the work of Louis René Villerme (1782–1863) roughly paralleled that of Chadwick. Like the latter, his morbidity and mortality statistics demonstrated the close correlation between health and living standards, and led the French government to establish a national public-health advisory committee in 1848. The committee, which included professionals such as physicians, chemists, pharmacists, and veterinarians, was purely an advisory body. Although it dealt with a wide range of public-health issues, from epidemics to industrial health, it was devoid of all powers, and the successive French governments did little to strengthen it during the rest of the century.

The industrial revolution and its concomitant problems arrived late in the United States, but by 1800 cities were beginning to establish temporary boards of health. The chief impetus for these early health agencies came from a series of yellow fever epidemics that struck port cities from South Carolina to New England in the years from 1793 to 1806. These boards were appointed whenever yellow fever threatened or was present. With medical opinion divided as to whether the disease was an imported contagion or the result of a miasma arising from foul, putrefying substances or some other source, the health officials played safe by promptly quarantining incoming vessels and instituting large-scale sanitary programs. Privies were cleaned, dead animals removed from the streets, stagnant pools drained, and slaughterers, tanners, and other members of the "noxious" trades required to cleanse their premises. After 1806 the danger from yellow fever in the region north of Norfolk, Virginia, receded, and health boards virtually disappeared. The appearance in 1832 of the first of three great epidemic waves of Asiatic cholera that swept through the United States revived these temporary boards, but generally they functioned only in times of emergencies.

By the 1830s and 1840s, American cities were beginning to experience the worst aspects of the industrial revolution. Rural Americans and immigrants flooded into urban areas that were ill prepared to handle the influx. Housing and sanitary conditions deteriorated, and morbidity and mortality rose. The movement to remedy these conditions was initiated largely by physicians, most notably by Benjamin W. McCready, whose 1837 essay drew attention to the deplorable health conditions in the workplace and the slums housing the workers, and by John H. Griscom, whose 1845 report, *The Sanitary Condition of the Laboring Population of New York,* laid the basis for establishing the first effective municipal health department in the United States. In other cities, too, physicians led the reform movement: Wilson Jewell in Philadelphia, Edwin Miller Snow in Providence, Edward Jarvis in Boston, and Edward H. Barton and J. C. Simmonds in New Orleans.

The outstanding layman in the early health movement was Lemuel Shattuck of Boston, who pioneered in the collection of vital statistics and promoted sanitary reform. The success of the early reformers in drawing public attention to the need for action led in the 1850s and 1860s to the appearance of civic sanitary organizations and agencies such as the New York Association for Improving the Condition of the Poor. As in England, the public health movement was both a humanitarian and a moral crusade. A few reformers emphasized improving the morals of the poor, but most recognized that immorality and intemperance were closely associated with the crowded and brutally degraded living conditions of the poor.

In 1857, an abortive attempt was made to unite the health reformers at the national level when Wilson Jewell of Philadelphia summoned a national quarantine convention. The original purpose was to respond to the danger from yellow fever, a disease still ravaging southern ports and threatening the Mississippi Valley. In the first meeting the delegates generally agreed on the necessity to standardize state quarantine laws, but many of them felt that the real need was complete sanitary reform. In the following three annual meetings, sentiment among the delegates swung in favor of a program affecting all areas of community health. At the 1860 meeting a resolution was passed suggesting that the delegates form a national health association. The outbreak of the Civil War ended these hopes, and a national organization awaited the postwar years.

Although the Civil War temporarily set back a nationwide organization of public health leaders, it stimulated the health movement. Wartime experiences in army camps and hospitals demonstrated the value of cleanliness and proper food and housing. In addition, the U.S. Sanitary Commission, a civilian body given official status at the outset of the war, introduced thousands of Union soldiers to the principles of personal and public hygiene. Leading members of this commission also played a key role in establishing the New York Metropolitan Board of Health in 1866, an agency that set the pattern for municipal health departments throughout the United States. Four years later, the Massachusetts State Board of Health, the first effective state health agency, came into existence. The founding of the American Public Health Association in 1872 indicated that the institutionalization of public health in the United States was under way.

Until the 1870s, the only action by the federal government relating to health had been the creation of the U.S. Marine Hospital Service in 1798. Although designed to provide medical care for sick sailors, for much of the nineteenth century it served primarily as a form of political patronage. Two yellow fever epidemics, one in 1873 and a major one in 1878 that spread far up the Mississippi River Valley, resulted in the federal government's briefly moving into the area of public health. Responding to widespread alarm, in 1879 Congress established the National Board of Health. The board was given little authority and limited funds, and was expected to act primarily in an advisory capacity. It immediately encountered strong opposition from the U.S. Marine Hospital Service, which was seeking to expand into the health area, and from state and municipal health officials reluctant to surrender any of their authority. The board performed quite well, promoting scientific health studies, assisting local health boards, and encouraging standardization of local quarantine laws. Nonetheless, political pressure led to its demise in 1883. During the nineteenth century Congress voted substantial funds to promote the health of domestic animals and fowls but virtually nothing for human health.

The Progressive movement at the turn of the century promoted political reform, economic efficiency, and social justice and, in the process, gave an impetus to U.S. public health. By the early twentieth century, public health in all developed countries was both professionalized and institutionalized. The bacteriological revolution had provided a new basis for action by health authorities, shifting the emphasis away from sanitation and environmental considerations and toward utilizing the newly developed antitoxins and vaccines to cure and prevent the great epidemic disorders of earlier years. Advances in technology and improvements in civic administration enabled health departments to spin off to separate agencies many former responsibilities, such as street cleaning and garbage removal, inspecting housing, and supervising water supplies and sewage removal. Their place was taken by new concerns: maternal and child care, the health of schoolchildren, the development of laboratory techniques for diagnostic purposes, and the health of people in rural areas. The major gains during the first forty years of the twentieth century were the elimination or drastic reduction of smallpox, measles, diphtheria, scarlet fever, tuberculosis, and other killer diseases.

Until the bacteriological revolution and the advances in basic sciences in the last decades of the nineteenth century, the medical profession, particularly in the United States, was viewed with considerable skepticism. In an effort to improve their status, physicians took an active role in the early public-health movement, and in England and on the Continent they gained control of it. The institutionalization of public health in the United States, however, assumed a different form, in part because the American Public Health Association from its founding in 1872 included sanitary engineers, bacteriologists, and other nonphysician members. In the early twentieth century, as public health moved into the area of school, maternal, and child health, health officials recognized the inadequacy of the medical care available to the lower-income groups and began establishing clinics. The medical profession by this time had gained control of hospitals and medical education, and dominated medical care. Recognizing that clinics represented a threat to the lucrative fee system, the American Medical Association used its political power to force public-health agencies out of direct healthcare. Health departments in general were restricted to supplying free vaccines to physicians, referring patients screened by public-health doctors or nurses, gathering statistics, and dealing with community health problems.

As the great killer diseases of former times were brought under control in the first forty years of the twentieth century, health authorities began turning their attention to chronic and constitutional disorders and to the long-neglected area of occupational hazards. Although the danger from miasmas had been dismissed, the post–World War II period saw a rising concern over the environment. The thousands of new chemicals polluting the air and water presented subtle but potentially serious dangers to health, and radiation introduced still another possible threat. In addition, stimulated in part by the psychiatric problems uncovered during the war years, public health was broadened to include community mental health.

The development of sulfa drugs and antibiotics in the World War II period seemed to have ended contagious diseases as major public-health problems. Even venereal disorders appeared to be in full retreat by the 1950s. Within another decade the situation began to change. The success of the new "miracle drugs"—such as penicillin—in curing venereal disorders led physicians to prescribe antibiotics for almost every form of infection, whether the cause was bacterial or viral. The result was the rapid creation of resistant strains of pathogenic organisms. The emergence of resistant forms of syphilis and gonorrhea coincided with the sexual revolution of the 1960s and contributed notably to a sharp rise in the incidence of venereal diseases. Since the 1970s new or newly diagnosed disorders such as genital herpes, Legionnaire's disease, Lyme disease, and acquired immunodeficiency syndrome (AIDS) have appeared, further confirming that infectious diseases remain a serious public-health threat.

Of the above disorders, AIDS best epitomizes the interrelationship between the social and biological factors in defining and dealing with disease. In the U.S., public fears aroused by the rising incidence of AIDS have led to the ostracizing of its victims, demands that physicians and health workers be tested, and pressure upon Congress to divert funds from other medical research to investigate AIDS. The public reaction to this new and fatal disorder has antecedents going far back in history. Bubonic plague, smallpox, yellow fever, and Asiatic cholera all evoked a similar response. In the nineteenth century, Asiatic cholera victims were not infrequently dumped from river boats and left to die on the banks. AIDS bears an additional burden because it is equated with sexual immorality, a venereal disorder compounded by its association with homosexuality. Since the eighteenth century any disease associated with sexual activity has been equated with immorality. As late as 1897 Howard Kelly of Johns Hopkins objected in the American Medical Association's annual meeting to a discussion of "the hygiene of the sexual act," on the grounds that the subject "was attended with filth."

AIDS also illustrates the perennial question of the rights of the individual versus those of society. When, as was true for most of history, epidemic diseases were strange, inexplicable occurrences, isolating or casting out the sick or effectively quarantining an infected area was taken for granted. Pesthouses in the colonial period were designed more to protect the town than to provide care for the sick. When inoculation for smallpox was introduced into the United States in 1721, the early laws forbade its use on the justifiable grounds that it would spread the disease. In the nineteenth century, laws requiring vaccination were bitterly opposed by many citizens, with antivaccination societies flourishing in a number of areas.

Public-health regulations by their nature are designed to restrict certain activities on the part of individuals. The 1867 annual report of the New York City Health Board declared: "The Health Department of a great commercial district which encounters no obstacles and meets no opposition, may safely be declared unworthy of public confidence." The vast majority of health regulations affect private property or place an extra cost on individuals or businesses; hence they have invariably led to protests. In New York and New Orleans, when health officials designated certain buildings as hospitals during yellow fever epidemics, mobs rioted and burned them to the ground. During an 1894 smallpox epidemic in Milwaukee, the Health Department sought to isolate cases and vaccinate all individuals in the infected areas. The result was rioting and the dismissal of the health officer. Health officers are government officials subject to political pressures; they must always seek a balance between what needs to be done and what can be done.

Limiting the right of individuals to practice medicine, requiring vaccinations, setting standards for food processing, and requiring physical examinations for food handlers, or establishing sanitary regulations with respect to housing or other property is an assertion that the community's health transcends individual or property rights. Laws requiring physicians to report contagious diseases have always raised strong objections from the medical profession, whether they involved reporting yellow fever in the eighteenth and nineteenth centuries or venereal disease in the twentieth century. When the New York City Health Department issued an order requiring the reporting of tuberculosis cases, the city's medical societies were outraged and appealed to the state legislature to restrict the powers of the Board of Health. In contrast, when on several occasions the New York City Board of Health ordered the evacuation of many blocks during the early yellow fever outbreaks, no one objected, nor were any protests made in 1907 when the New York City Health Department decided that in the interest of public welfare Mary Mallon (Typhoid Mary) should be kept on North Brother Island in the East River, where she remained until her death in 1938. Since medical experiments on the poor had long been taken for granted, neither physicians nor laymen, black or white, objected to the 1932 Tuskegee syphilis experiment, funded by the U.S. Public Health Service and designed to study the course of untreated syphilis in blacks.

The latter decades of the twentieth century have seen an increasing sensitivity to individual rights. The most obvious example is the deinstitutionalization of the mentally sick, who now constitute a large portion of the homeless. The question arises of whether individuals, the homeless in particular, have the right to refuse treatment for mental illness or contagious disorders. The presence in the community of cases of tuberculosis and other communicable diseases represents a threat both to the individual concerned and to the citizens at large. The main issue—as alcoholism, drug addiction, and smoking illustrate—is not whether the government should regulate individual conduct but the degree to which it does so.

As the United States moves toward revising its healthcare system, decisions must be made as to the role of public-health agencies. Maternal and child care for the lowest income groups and preventive medicine have traditionally been in the domain of public health. At present the vaccination of children is left to private medicine or state and local authorities, with the result that thousands of children remain unprotected. These responsibilities should, and probably will, be of major concern in a comprehensive healthcare system. In devising a new health system, will public-health departments expand their work in these areas or surrender them? Or should public health be incorporated into a comprehensive healthcare system? Whatever the case, serious thought must be given to formulating any major changes in the nation's healthcare system.

JOHN DUFFY (1995)

SEE ALSO: *Coercion; Environmental Health; Hazardous Wastes and Toxic Substances; Health and Disease: History of Concepts; Health Screening and Testing in the Public Health Context; Injury and Injury Control; Lifestyles and Public Health; Public Health Law; Sexual Behavior, Social Control of; Warfare: Public Health and War;* and other *Public Health* subentries

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III. PHILOSOPHY

Public health is the prevention of disease and premature death through organized community effort. While this community effort is often led by government, many nongovernment and quasi-public institutions play key roles in promoting the public's health. Public health as an idea is one of the most influential of our time, and has been an important force in changing the shape of the modern world and enlarging government's scope, if not its size, since the middle of the nineteenth century. The general idea that government and communities can systematically discover, anticipate, and relieve disease and social distress through collective choice and organization is relatively new in human history. It involves the complex and related developments of collections and analysis of statistics, the understanding of variations in disease patterns in human societies (usually called epidemiology), and government of sufficient scale and capacity to exploit these findings.

Public health's focus on populations and communities is its most distinctive feature and the primary source of its philosophical interest. The community perspective produces a way of thinking about disease and early death and their prevention, that often runs counter to the categories and assumptions of much of modern bioethics and other disciplines as well. Public health as an organized practice views disease and premature death from the standpoint of the community and its capacity for self-examination, reorganization, and modification. The community perspective, far from neglecting the welfare of individuals, strengthens society's ability to discover the causes of disease in individuals, and society's capacity to devise flexible and rapid means for controlling disease and preventable death. Bioethics has been interested mainly in the intersection of the worlds of public health and the individual and his or her autonomy, and far less in public health as a method, seeing this as falling outside its sphere into the world of practice, and into the realm of contingency, experience, and practical action (Dewey).

Considerations for a Philosophy of Public Health

Public health as a method bears a strong resemblance to pragmatism, with its emphasis on probabilistic and fallibilistic ways of knowing, on exploiting experience and action, and on the centrality of knowing and acting in the context of communities, institutions, and practices (Bernstein; Rorty). While it is true that public health has many roots in utilitarianism (the English reformer E. H. Chadwick was once a literary secretary to Jeremy Bentham), public health came of age in the United States and Europe during the late nineteenth century and the early decades of the twentieth century, when the causes and methods for preventing many deadly diseases were discovered.

At the same time, philosophy and the social sciences began to revolt against the formalism of previous centuries (Dewey), and in both the United States and Europe, in philosophy and the social sciences, the search for fundamental truths gave way to empiricism and pragmatism, to a greater stress on the parallels between social science and philosophy, and to courses of action guided by both results and experience (Feffer; Anderson). After World War II there was in the United States a marked retreat to the earlier formalism with the rise of analytic philosophy and the return to social contract ideas, factors in the tendency of bioethics and philosophy to ignore the more pragmatic way of public health. This is not to say that public health as an organized practice needs no further philosophical elaboration or justification, or that it can ignore questions about the limits of health policy in restricting liberty or the coherence of public health's use of the idea of the common good. It is simply to say that public health does not need first to be translated into utilitarianism or contract theory to become a social philosophy.

A philosophy of public health must accomplish four things. First, it must give a central place to the unique approach and method of public health, with its distinctive emphasis on community, and on the central role of the scientific method in formulating courses of action for social improvement. Second, a philosophy of public health must give priority to prevention, and must challenge and revise explanations for health problems with the community perspective, which is essential to effective prevention. Third, a philosophy of public health must set out and defend an adequate definition of the common good, taking into account public health's pursuit of the common well-being—measured in terms of rates of disease and early death—as the object of group or common action. Fourth, while the philosophy of public health must acknowledge the claims of individual autonomy and justify actions that limit liberty and autonomy, it must do so in a way that leaves the community perspective and the common good intact.

Health by Design: The Idea of Prevention

Prevention is the major focus in public health, and it involves as a minimum the imaginative redesign of social environments and communities to better promote health and safety, as well as the replacement of older models of the problems that need to be solved. A major part of the battle in public health, especially in applying public-health methods to modern problems of chronic disease, injury, and alcohol and other drug problems, is to redescribe these problems in terms of the community perspective, countering the individualism, so widely prevalent in much of philosophy and social science, that serves as a powerful obstacle to effective prevention.

Two recent examples make this point. In the case of alcohol, since the 1970s there has been a shift away from purely individual or agent-focused explanations for alcohol problems, based on the capacities, dispositions, and motivations of individuals who drink, and subsequently experience problems, factors like "loss of control" over drinking. With the public-health perspective, the focus is on the exposure of whole societies to alcohol, on the varying levels of total consumption among groups, and on such factors as price, hours of sale, and age limits in causing rates of problems. This approach does not seek so much to explain alcoholism (why some people drink addictively) but why rates of alcoholism rise or fall among communities, or over time (Moore and Gerstein).

In a similar way, highway safety since the early 1960s has witnessed a shift from individual capacities ("driver error," "driver negligence," "failure to yield the right-of-way," and factors beyond the control of agents, such as "acts of God") toward such factors as the exposure of drivers to highway hazards, miles driven annually, types of roads driven on, and the safe or unsafe character of the automobile. Exposure is a key variable in this redescription and often results in counterintuitive insights. For example, researchers have noted that "driver education programs" in the United States probably raise the level of death and injury because they expose more young people to the hazards of driving at an early age.

Public health has many similarities to modern applied systems theory and the policy sciences, with their stress on nonreductionism, on policy or systems knowledge rather than disciplinary knowledge, on systems-level (community-level) analysis, and on promoting change through novel interventions with high leverage potential, often deployed at places located far from the primary cause of the problems.

It is common to find public-health specialists, in their attempt to fashion new means of reducing disease, speaking of "agents," "hosts," and "environments," translating individual descriptions of problems into community descriptions. According to the interpretation of William Haddon, Jr., this framework's "agents" are "exchanges" of hazardous chemicals, ionizing sources, drugs, or kinetic energy, suffered by individual "hosts." The environment is the larger social and physical terrain of hazardous agents and hosts. The purpose of this strange language is to provoke new ways of thinking about old problems, and to give public-health designers free play in their imaginative search for new and innovative ways of reducing dangers, ways that are both effective and ultimately politically feasible. All three elements—hosts, agents, and environment—are potential targets for change and modification, with no priority given any one (Haddon).

This search for new societal arrangements is often expressed as the search for "conditions" that promote health or prevent disease, a point found in the Institute of Medicine's report *The Future of Public Health,* and its definition of the mission of public health: "the fulfillment of society's interest in assuring the conditions in which people can be healthy" (Institute of Medicine).

In one way or another, public health concerns collective choice. Public health is about how much alcohol is permitted in society (per capita consumption levels), about the frequency of highway crashes, about the number of drownings in a state or nation, and about the changes in environment, legislation, and public attitudes that will directly affect those statistics. This emphasis on social organization and social arrangements in public health does not reduce public health to a species of social causation. For example, to use the link between general consumption levels and occurrence rates of cirrhosis is not to say that society causes specific individuals to drink heavily or alcoholically. It is to say that because we have learned through scientific studies that society, through alcohol policy, can influence the levels and kinds of problems in society, it is accurate to say that society influences these problems, and can and should seek, within the context of democratic discussion and debate, to sharply reduce them.

Public Health and the Common Good

In the public-health view, the common good in public health means the good of individuals taken together as a group, as communities, or in terms of aggregate health and safety; this aggregate health, expressed as so many thousands of lives saved, is the object of organized government or community effort. The common good does not mean that each individual has the same or identical good in health and safety, or even the same interests. An individual with a genetic predisposition for colon cancer does not have the same interest in health and safety as another who lacks such genetic makeup. Yet both can be said to have a common interest in measures to promote health and safety and to reduce general risks to health and safety that all face, including risks from cancer. This is another way of saying that individuals can face threats to health and safety alone and in groups, using group efforts to reduce those threats.

The common good expressed in aggregate terms does not refer to a good that is separate from, and set over against, the good of the individuals who constitute a group at risk. It is rather that the good of the group is jointly consumed, producing a common benefit of thousands of lives saved and many thousands more who will avoid injury or disease. This common benefit of lives saved (and avoidance of disease) is taken as the expression of the common good and is the object or purpose of collective or common action.

For most public-health problems, the aggregate savings in lives is far smaller than the number of individuals at risk and whose liberty is to be limited. Put another way, and for most public-health problems, the group that benefits from protections is a much smaller subset of the group that is at risk. Thus, all who are at risk and whose liberty is limited by public-health legislation do not benefit; the benefit accrues for an unknown and unaccountable minority of the larger at-risk group. Because this good is expressed in the form of statistical lives, it is viewed as a savings for the community. Thus, it is not wrong to think of public-health measures as undertaken by a community for the sake of a common good, that is, the thousands whose lives will actually be saved. The slogan for public health should not be "The life you save may be your own," but rather, "The lives we save together may include your own."

Geoffrey Rose refers to the fact that communities benefit more from public health than individuals as the "prevention paradox" (Rose). The prevention paradox states that most modern public-health risks are sufficiently low and widely distributed—indeed, they often stem from mass behavior like driving automobiles, drinking, smoking—and that despite the fact that millions engage in the activity, savings in lives will measure only in the tens of thousands in any period.

Public Health and Autonomy

Some have used John Stuart Mill's famous point in *On Liberty* that only individuals can know their own good (Mill, 1975) to criticize many public-health measures—such as laws that require people to wear seat belts in automobiles and helmets when riding motorcycles, and requiring fluoride in the water supply—as paternalistic. These laws threaten the autonomy of individuals, and also threaten to usher in an era of vast, paternal, preventive government. Ronald Dworkin argues that "laws that promote the common interest insult no man … while laws that constrain one man, on the grounds that he is incompetent to judge are profoundly insulting" (Dworkin, 1977, p. 263). Dworkin is here arguing that seat-belt laws or higher taxes on alcohol are not in the common interest, and are therefore insulting. Unlike Mill, he believes that the class of these kinds of laws and restrictions is actually quite small.

Those who support public-health restrictions on individual liberty, but who wish to avoid a strong paternalist position, can do so in basically two ways. They can argue that public-health measures are only mildly paternalistic. This is the "weak paternalism" thesis (Dworkin, 1972; Feinberg). In this view, public-health measures are not strongly intrusive, and they save thousands of lives. Most philosophers today seem to embrace this view. The second and more controversial view is that public-health interventions are not at all paternalistic (Beauchamp, 1988) because the good produced is not a private or individual good, but rather a common good produced by common action. In this view, the citizen sees himself or herself as living in a world in which common action, after public and democratic discussion, often promotes public health, and while individuals may potentially benefit from these actions, the community or the common good will assuredly benefit.

The differences between these two basically supportive perspectives on most public-health legislation cannot easily be reconciled, but their differences should not be exaggerated. Both sides agree that any restriction on liberty and autonomy needs justification. The only disagreement is over who is benefiting from this restriction and whether the good is private or common.

In the public-health perspective, the conception of autonomy is one of a basic autonomy, not an absolute autonomy. A basic autonomy can be overridden on evidence that restrictions are minimal, acceptable, and will produce a substantial savings in lives. The guardians of basic autonomy are the democratic process and elected officials, such as legislators or chief executives. This makes many nervous, yet the long history of the struggle for public-health legislation is, on balance, reassuring. Because most public-health legislation necessitates the burdens placed on large numbers of individuals, including powerful interests, to benefit small numbers of individuals, the political path to successful public-health legislation is strewn with political roadblocks that are likely powerful deterrents to overzealous public-health activists. This emphasis on relying on the processes of democratic communities reflects the pragmatism of public health as philosophy, and its interest in political theory. Also, Richard Flathman, a political theorist, notes that governments rarely promote the good of a single individual (Flathman).

Public Health and Social Justice

An enduring theme in public health is the attempt to persuade democratic bodies to legislate rules for economic production and distribution that are safer and more benign. Community public-health interests frequently oppose powerful, well-organized entities such as corporations and interest groups. Public health as an interest of the community often causes deep conflict among elected officials, who are also strongly enjoined to promote economic prosperity.

The struggle for the common health and safety is further complicated by the fact that the redistribution of the burdens of health and safety protection is on behalf of "statistical lives." Thus the struggle of public health has many resemblances to the struggle for social justice in society (Beauchamp, 1976) in that they both work on behalf of the less numerous and less powerful against the power of the market and its masters. The idea of social justice influences public health, for instance, as it battles the human immunodeficiency virus (HIV) epidemic, to modify its traditional methods of fighting epidemics (Bayer), using new weapons like confidentiality and privacy to fight societal discrimination and prejudice toward the victims of the widespread epidemic.

Democracy, Public Discussion, and Public Health

Much of public health is concerned with providing and/or regulating information and education. These activities typically encounter far fewer ethical conflicts than does legislation that limits individual liberty or property in order to promote health and safety. Yet even here the distinctive footprint of public health as a social practice can be detected. Progress against cigarette smoking has been made in the United States during the decades after World War II not so much through regulating or banning smoking as through communicating the discovery by public-health researchers of the links between smoking and disease. The subsequent public discussion and controversies surrounding a series of reports by U.S. surgeons general (and also by health officials in other nations) widely publicized the links between smoking and lung cancer and heart disease. The further publicity surrounding the role of tobacco in public policy and other related controversies produced a growing awareness of smoking as a social problem. This publicity, coupled with the ban on television advertising of cigarettes, produced sharp declines in smoking rates (Warner), in advance of more recent and controversial moves to ban smoking in public areas.

Here again, the unique emphasis in public health is to use the discovery of threats to the common health as part of the "hubbub" of democracy. Such controversy can be used to affect public opinion and discussion (including a growing social disapproval of smoking) as principal forces for promoting change in individual and mass behavior (Beauchamp, 1988). Public dialogue, in turn, moves public health into the new territories of promoting more information and speech and of countering advertising's role in limiting information.

Conclusion

The idea of public health as philosophy involves the elaboration of its core ideas of promoting fallibilistic and probabilistic ways of knowing, of learning from experience and action, of imaginatively proposing new designs to social environments to promote health and safety, and, above all, of focusing on prevention and community approaches everywhere possible. While public health proponents have been successful in ensuring that their methods are central to the study of health problems, working closely with scientists studying disease from an epidemiological perspective (and in the future from a more molecular and genetic perspective), they have been less successful in having public health's group approach accepted as philosophy. While it is true that public health is one of those "second languages" of community (Bellah et al.), it has yet to be widely appreciated among philosophers and social scientists as a distinctive method with a distinctive philosophical perspective on common health problems, one that bears a strong resemblance to pragmatist perspectives on action and experience.

Finally, as health reform has increasingly dominated the public agenda in the United States, it is likely that public-health lessons will be more widely appreciated for two reasons: to prevent disease and reduce the burden and costs of illness, and, equally important, to remind the larger society that medicine and public health alike promote a common good, a lesson that is central to public health's distinguished history.

DAN E. BEAUCHAMP (1995)

SEE ALSO: *Autonomy; Coercion; Eugenics; Genetic Testing and Screening; Hazardous Wastes and Toxic Substances; Health and Disease: History of Concepts; Health Screening and Testing in the Public Health Context; Injury and Injury Control; Lifestyles and Public Health; Public Health Law; Sexual Behavior, Social Control of; Warfare: Public Health and War;* and other *Public Health* subentries

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IV. METHODS

Epidemiology is basic to modern public health. It provides, for example, the rational basis for health planning, the justification for allocating funding, and the basis for deciding whether or not to introduce or change preventive health policies. Finally, it plays a fundamental role in making decisions concerning optimal treatment regimens through its involvement in the clinical evaluation process.

Epidemiology is distinct from medical science in that epidemiology's focus is on population health, opposed to medicine's focus on the individual patient. While medicine seeks to heal the individual who, by virtue of being susceptible, becomes ill, epidemiology seeks to identify the underlying cause that results in illness among those who are susceptible. With an underlying cause identified, it becomes possible to intervene at the source of the chain of events that leads to illness among people who are susceptible. Removal of the cause can directly result in preventing those who are susceptible from being exposed to it in the first place and thereby from becoming ill.

Epidemiology focuses on large numbers of people comprising populations or communities. It is a quantitative (as opposed to a qualitative) science whose methods are heavily dependent on the application of biostatistical principles and on advances in biostatistical methods. As with other quantitative sciences, epidemiology requires the counting, classification, and analysis of sizable amounts of data. In order to derive meaning from large amounts of data, statistical techniques are used to produce various kinds of summaries. These techniques are known as biostatistics in the health and/or biological sciences.

Through the early 1940s, prior to the advent of antibiotics at the time of World War II, epidemiologists were occupied almost exclusively with controlling infectious diseases. Success resulted in better control of infectious diseases; improved living standards, especially in developed countries; and increased life expectancy of the population. Consequently, epidemiology expanded from its preoccupation with infectious diseases to include noninfectious diseases.

The notion that noninfectious and, by extension, chronic diseases can be prevented by eliminating their causes, analogous to the prevention of infectious diseases, is a relatively new concept. Hence, the modern role of epidemiology, from the public health perspective, is to identify appropriate interventions for consideration by policymakers for controlling disease at the source and thereby promoting health in the community.

The linking of epidemiology and biostatistics has become a hallmark of modern epidemiology in both its research and its practice areas of activity. Research in epidemiology tends to embrace activities of an experimental nature, while the practice domain tends to focus on disease surveillance and monitoring activities. Regardless of the domain, biostatistics provides the analytic tools used in epidemiology.

Scientific discovery in the laboratory should ultimately have practical application at the bedside. Results of epidemiologic investigations made on a population or on clearly defined subgroups of the population ought to benefit individuals. Because the results of population-based research are couched in terms of probabilities, the application of epidemiologic studies to the individual is not direct. Nevertheless, the identification of risk factor information in the absence of a biologically identified cause of a disease has been instrumental for prevention programs. Furthermore, physicians can apply probabilities in deciding therapeutic options.

The Scope of Epidemiologic Activity

Epidemiologic studies are necessary to provide both valid and reliable data not only concerning the distribution of diseases in populations, but also on the impact of social, economic, environmental, and other factors on the health of populations. In addition, epidemiologic data are often fundamental in making future projections of disease burden, crucial for planning purposes.

Concerning professional ethics, in the physician–patient "medical" relationship, the physician assumes a patient advocacy role; epidemiologists, on the other hand, assume a population/community advocacy role. Ethical guidelines that have been developed for medicine therefore have little relevance to epidemiology. Obligations assumed under these two different models must be explicit for trust to exist between professionals and the public.

Since the 1960s, epidemiology has undergone dramatic growth, paralleling to some extent the growth and development of computers. In North America, for example, the sex distribution and training of epidemiologists has changed over this period. Previously, epidemiologists were predominantly male, but today about half, especially those engaged in research, are women. Also, about half of today's epidemiologists were never trained as physicians.

The absolute numbers of epidemiologists have grown exponentially and the development of advanced computer technology has enabled epidemiologists to work with and share increasingly larger databases and to apply sophisticated multivariate statistical adjustment techniques via the use of computer software. But while technology has led to important advances in epidemiology, the complex issues of ensuring both integrity in science and ethical conduct among scientists have yet to be adequately addressed. There is increasing recognition of the need for guidelines to ensure professional accountability to the public in whose service epidemiologists work.

Classical epidemiology—as distinct from clinical evaluation—is primarily an observational science; it studies the events of daily life among the members of the various subgroups that comprise a community. Unlike controlled experiments, epidemiologic research measures events associated with populations whose lifestyles, work habits, and other characteristics have evolved outside the epidemiologist's control. Because uncontrollable and unknown risk factors can impact study outcomes radically, they must be accounted for if demonstrated contrasts, comparisons, and differences are attributed to these. Epidemiologic methods include various approaches for ensuring appropriate analysis of observational events. Professional epidemiologists are cognizant of the strengths, weaknesses, and limitations of the various methodologic options in light of the complexities associated with the conduct of uncontrolled experiments.

The closest epidemiology comes to the conduct of a controlled experiment is in the randomized controlled trial (RCT). However, RCTs can be justified only on the basis of substantial preexisting information concerning the intervention of interest (e.g., a particular therapy). Preexisting information usually is derived from the conduct of studies utilizing designs that are nonexperimental in nature (i.e., from the realm of natural experiments). Only where justification exists can human beings be subjected to random allocation in a clinical trial. Natural experiments in observational research include descriptive, ecological, retrospective case-control, and prospective cohort designs.

Diseases associated with aging, including cancer, diabetes, and cardiovascular diseases, have required greater attention. Because epidemiology provides the methodology for rational approaches to interventions, epidemiology is fundamental to disease prevention. Interventions based on epidemiological studies have taken the form of health promotion programs, such as campaigns for smoking cessation, no drinking and driving, and condom use in sexual intercourse. The onset in 1981 of the acquired immunodeficiency syndrome (AIDS) pandemic, however, reminded epidemiologists that infectious diseases are not necessarily a thing of the past.

With escalating healthcare costs in Canada, the United States, and elsewhere, epidemiology is playing a major role through providing the evaluative methodology for assessing cost-effective interventions for rational healthcare planning. Epidemiologists establish health goals by assessing health status indicators for a population; they identify target levels for reduced morbidity, disability, and mortality. These activities have implications for resource allocation which bear directly on the ethical principle of distributive justice. Indeed, numerous jurisdictions are attempting to identify those illnesses for which free health coverage should be provided by the "state" based on prevailing population values. Epidemiology assists in these determinations through expertise in survey methodology, health-status indicators, and disease classification.

From the foregoing, it is clear that epidemiology plays a major role in health-policy decisions, which involve, among others, substantial financial resources. "Health" is big business. Concerns arose during the 1980s about the possible influence of individuals and/or groups whose vested interests could bias outcome(s), motivated by financial profit and/or professional prestige. Conflicting-interest issues have been of concern not only in the interpretation of epidemiologic studies in favor of any one interest group's position but even in limiting or blocking the potential to conduct the best possible epidemiologic study for addressing a health concern.

The legal aspects—in terms of civil, administrative, and criminal law—are profound. With utilitarian goals in mind (i.e., doing the greatest good for the largest number of people), the courts usually have invoked the collective good over individual freedoms (e.g., in legislation concerning vaccination, quarantine, seat belts, and smoke-free public indoor environments in both Canada and the United States).

In general, governments prefer that professions regulate themselves. Professional organizations are expected to do what is necessary to minimize scientific misconduct and ensure professional etiquette among employers, sponsors, colleagues, and clients.

A Historic and Ongoing Concern: Privacy

Any epidemiologic investigation conducted under the auspices of an institution (e.g., a university, hospital, or government office) is likely to be subjected to ethical review by a committee. The committee usually comprises members of various disciplines as well as a lay representative.

Not only can ethics review committees examine the nature of the question to be addressed by the investigation, but they also may determine the appropriateness of the methods being proposed. Generally, however, the main focus tends to be on the possible harms versus benefits to those who will participate in the study; that is, with issues of privacy, informed consent, and confidentiality, and most important, that none of the procedures expected of the subjects/participants will cause them harm.

Scientific peer review concentrates on the aptness of the proposed scientific research methods, including the scientific relevance of the proposed research question, assessment of potential bias and confounding, adequacy of the proposed size of the study and associated statistical power, and recognized limitations impacting on the interpretation of the study. These two distinct but related areas of concern are seldom brought to the attention of a single expert other than the principal investigator, and perhaps also his or her research team. Without the support of both groups, the proposal usually cannot proceed into action.

Because the data epidemiologists rely on can be personally sensitive, governments have enacted privacy legislation to protect its citizens. Only with special permission from the custodians of these data bases can epidemiologists gain access—usually controlled—to the data banks essential to the conduct of health research. Some agencies also impose an oath of secrecy on the researcher.

One protection that researchers are expected to exercise (in their publication of results from access to health records in the public domain) is the anonymity of all persons studied. In addition, the identification of small areas or groups of people must be avoided also to ensure anonymity and thereby the protection of individual privacy. Individual or group stigmatization is to be avoided. Any infringement of the public trust could have repercussions, including legal penalties to the researcher involved. Furthermore, the epidemiologic research enterprise could be placed in jeopardy by engendering a loss of trust in research by the very communities whose support (both financial and possibly also participatory) is needed for investigation purposes.

Professional training, in conjunction with well-publicized guidelines, is likely to minimize any risk of infringement. In addition, the epidemiologist has an obligation not only to respect the right to privacy of personal data, but to ensure that co-workers are equally vigilant. “Whistleblowing” also must be encouraged and those doing so must be protected from any form of reprisal. Most professional ethics guidelines/codes require that attention be drawn to the person who elects to perform contrary to normative standards of professional practice.

In 1991, European Community government officials developed a set of proposals concerning rights to privacy. Unfortunately, if enacted, these proposals could serve to make it virtually impossible to conduct epidemiologic research that depends on access to these data banks. The proposals ensure that personal information provided for one purpose cannot be used for another purpose without prior consent. Similar legislative proposals were mounted in the United States in the mid-1970s, but were defeated. Hence, epidemiologists and biostatisticians worldwide have a duty to remain vigilant of legislative proposals that might, directly or indirectly, adversely impact research for the public’s health. They must be organized enough to provide input to such legislative proposals. Ultimately, it is the public-health interest that must prevail.

Current Issues

ETHICS GUIDELINES. The first stated need for guidelines on the ethical conduct of epidemiologists was printed in 1985. Despite considerable debate within the profession in North America, through 1987, little movement was made. It was at the International Epidemiological Association’s (IEA) 1987 XIth Scientific Meeting in Helsinki, Finland, that the proposal to develop guidelines was adopted. By 1990, further discussion had advanced the thinking on this subject and a first draft of IEA guidelines was published.

A milestone conference on the subject of ethics in epidemiology had stimulated the discussion in 1989. The conference had been organized by the United States’ Industrial Epidemiology Forum. The organizers had compiled a set of ethics guidelines and a commentary; these subsequently were published in the conference proceedings in

1991. Since then, the Council for International Organizations of Medical Sciences (CIOMS) has published *International Guidelines for Ethical Review of Epidemiological Studies* together with a compendium conference proceedings which contributed to the development of these guidelines. In addition, CIOMS published *International Ethical Guidelines for Biomedical Research Involving Human Subjects.* (CIOMS, 1991, 1993).

In November 1991, the American College of Epidemiology was accorded the leadership role among the North American epidemiology bodies to further ethics initiatives in this region of the world. Other groups of epidemiologists with specialty interests are contributing to this process (e.g., environmental epidemiologists).

The Industrial Epidemiology Forum's Guidelines, modeled on those developed some years earlier by the International Statistical Institute, are organized as follows:

I. *Obligations to the subjects of research*
  - to protect their welfare, ensuring no physical or mental harm through their participation;
  - to obtain their informed consent, ensuring the fullest possible understanding of any risks and benefits associated with participation;
  - to protect their privacy, ensuring no stigmatization resulting from information provided through their participation;
  - to maintain confidential information, ensuring the privacy of the participant.

II. *Obligations to society*
  - to avoid conflicting interests, recognizing that vested interests could bias research in ways that fail to serve the goal of seeking truth;
  - to avoid partiality by openly recognizing one's biases;
  - to widen the scope of epidemiology by teaching its methods to interested candidates;
  - to pursue responsibilities with due diligence;
  - to maintain public confidence in the profession by ensuring that both the strengths as well as the limitations of the profession are disclosed.

III. *Obligations to funders and employers*
  - to specify obligations, ensuring that the values and principles to which epidemiologists are expected to abide are clearly understood;
  - to protect privileged information, respecting the need of employers and providers of information to have reasonable time to assess the implications of research utilizing their data to their interests prior to disseminating the results from such a study.

IV. *Obligations to colleagues*
  - to report methods and results for wider peer review;
  - to confront unacceptable behavior and conditions, ensuring ethical conduct in support of the public interest;
  - to communicate ethical requirements, thereby ensuring accountability of the profession to the public.

Loreen Herwaldt (1993) has extended the guidelines set forth by the Industrial Epidemiology Forum by identifying principles having special relevance to hospital infection control officers and clinical practice.

While guidelines, commentaries, and case studies are recognized as essential to ethical conduct, they are insufficient. They must be taught, learned, discussed, challenged, and revised in light of case studies, if they are to affect behavior. Finally, mechanisms for dealing with allegations of breaches of conduct need to be established with remedies that serve to mitigate any wrongs.

CONFLICTING INTERESTS. Objectivity is required both on the part of the epidemiologist who is proposing a research project or submitting a manuscript for publication and on the part of the scientific peer review committee members. A conflict of interest arises when a reviewer has a vested interest in the subject under review that can either positively or negatively impact on the review decision. When a reviewer has a conflict of interest—whether at the scientific approval stage, the ethics review stage, or the publication stage—this must be declared and such reviewer's comments should be considered in this light in any final decision.

Reviewers have an obligation never to use, or to discuss with others, the ideas conveyed in a proposalmanuscript without full attribution to the person who proposed them. To do otherwise would misappropriate the intellectual property of another. In addition, if the reviewer is in a position to execute another's proposal, whether funded or not, such work should not proceed without the prior written permission of the person whose idea it was.

SCREENING FOR DISEASE AND HIV ANTIBODY. As a means of secondary prevention, early detection of disease through screening programs is well recognized. The AIDS pandemic, however, has presented new challenges well documented by Ronald Bayer and his colleagues, whose concern has been more with the stigmatization of individuals or groups. Access to test results by, for example, employers, landlords, or insurance companies has been of concern to infected people who fear job or housing loss and noninsurability. In research involving sexual practices, for example, the investigator requires special legal protection not only to render data inaccessible under subpoena but also to disclose such issues as the sexual abuse of children to child welfare authorities. Since valid responses must be obtained from persons volunteering for research if epidemiologic studies are to be useful, the right to privacy by the person being studied has to be secured in order for the person to participate honestly in the study.

In its initial years, testing for the human immunodeficiency virus (HIV) antibody was intended (together with self-exclusion) to secure the safety of the donated blood supply. Shortly thereafter, however, there were mandates for the testing of population subgroups believed to be at high risk of infection. It was postulated that the HIV antibody test could separate those truly positive from those truly negative, after which one could identify or physically separate the positives from the negatives. (The Cuban model, applied since early in the epidemic, has required that all persons found to be HIV-antibody positive be confined to a common residence and thus be barred from associating with persons who are not HIV-antibody positive.) Unfortunately, no test provides 100 percent sensitivity and specificity for HIV antibody or any other test. Furthermore, a "window period" exists between time of exposure and infection with HIV and the actual development of antibody. This window period can range from about three weeks to several months during which time the individual would test negative when in fact he or she could transmit the virus. This example demonstrates how epidemiology can assist in the rational presentation of facts, thus preventing misinterpretation by the media and/or lobby groups not fully informed of the scientific facts and how to interpret them.

NOTIFICATION. When special subgroups are identified for a study, the results of that study should be provided to the participants. Specifically, in occupational cohort studies, it is recommended in the United States that study participants be informed of any exposure to health risks uncovered through the study. The question that remains relates to the welfare of other workers who may be exposed to similar risk factors and who therefore could be at the same level of risk as those workers who were actually studied. If the cohort study that initially identified the risk was well-designed, it might be possible to extrapolate the research findings to other subgroups at risk in similar occupations, as well as to former employees. These latter two potentially at-risk groups are not currently included in the United States' National Institute for Occupational Safety and Health (NIOSH) guidelines.

Technologies continue to grow for determining individual susceptibility to illness that arises from workplace exposure to hazardous substances. If employers were privy to such information, they could exclude a job applicant on the grounds of wishing to protect the individual and at the same time to protect themselves from potential litigation. The tension arises between the obligation for full disclosure by the job applicant/worker on the one hand, and the obligation of the employer to provide a safe workplace. Some employers have argued that to render a workplace safe could be economically impractical. The controversy continues. Women, for example, face restrictions on employment in certain industries for fear by employers of liability—based on the existing body of knowledge about exposure to certain substances during pregnancy—if pregnancy should result in any abnormality at birth.

One mechanism for disseminating information involves community participation at all stages of a study, from hypothesis formulation through proposal development, review, conduct, analysis, write-up, and interpretation. In this way, community values are integrated into the research. Some occupational health studies have succeeded simply by establishing steering committees. These include not only scientists but also labor and management. Government involvement on a steering committee may also be appropriate.

WOMEN AND MINORITIES. The U.S. National Institutes of Health has stated that research has focused disproportionately on white male subjects (Dresser). Results from studies on males are generalized to other population subgroups (i.e., to women and racial minorities) when the results, in fact, may not be generalizable. Such inferences may not only be misleading for the health of women and minorities but also could create harm through the potentially inappropriate application of findings from studies on white males to other groups in the United States. Therefore, it has now been mandated in the United States that women and minorities be included in all research programs whenever possible (NIH/ADAMHA).

It is difficult to quarrel with the concerns and remedies noted above. However, epidemiology is undertaken in populations not only where the problem to be investigated arises but also in populations that are large enough to satisfy statistical considerations. That is, access to exposed populations is what motivates and justifies epidemiologists to design and conduct a study. Statistical power is a function of the prevalence of exposure in a population. If a large enough number of women or minorities is not exposed to a given agent (e.g., chemical or pathogen) of interest, then their inclusion in studies could be unproductive, consequently wasting resources. Clearly, the researcher must be cognizant of the limits to which inferences can be drawn from any study; it is up to those formulating policy, however, to provide the incentives needed to encourage and enable the address of researchable questions of relevance to groups other than white males.

Assessment to Date and Future Directions

Only recently have ethics guidelines been drafted for epidemiologists, whereas statisticians had broached the subject and developed guidelines in the 1980s. Physicians have been concerned with professional standards of practice in North America since the late nineteenth century. Although epidemiologists indeed may be entering the ethics discussion later than their counterparts, the relative recency of the profession must, of course, be considered. In their favor, epidemiologists are making efforts not only to develop ethics guidelines but also to integrate ethics into their teaching programs and into continuing professional education more generally. Ultimately, the expectation is that grass-roots involvement will maximize the likelihood of adherence to guidelines; the greater accountability of the profession to the public in whose interest epidemiology functions will be more assured.

Of growing concern are issues of self-interest and conflicting interests that sometimes take precedence over the public interest. Greater attention is being given to the consequences of research for destructive purposes through possible harm to the ecosystem and the advancement of militarism. Unless the professions are conversant with the principles of ethics, technological advances will continue to outstrip the ability of professions to respond; the professions' role will continue to be one manifesting a reactive as opposed to a proactive position.

COLIN L. SOSKOLNE (1995)
BIBLIOGRAPHY REVISED

SEE ALSO: *AIDS: Public Health Issues; Coercion; Conflict of Interest; Economic Concepts in Healthcare; Epidemics; Information Disclosure, Ethical Aspects of; Informed Consent; Minorities as Research Subjects; Occupational Safety and Health; Privacy and Confidentiality in Research; Profession and Professional Ethics; Public Policy and Bioethics; Research, Unethical; Technology; Whistleblowing;* and other *Public Health* subentries

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PUBLIC HEALTH LAW

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I. The Law of Public Health

II. Legal Moralism and Public Health

I. THE LAW OF PUBLIC HEALTH

Public health law is used to regulate activities and facilities to protect human health and establish institutions and programs that advance health and well-being. Its development has long been informed by the shared political and philosophical beliefs that provide a reason for government generally: to advance the common good and protect people's health, safety, and welfare. Public health law has changed over the years to reflect technological, scientific, and medical advances and respond to new threats and hazards. Societal and legal developments continue to create new ethical problems and challenges.

Historical Background

In the eighteenth and nineteenth centuries public health was largely a matter of protecting the public against communicable diseases and preventing epidemics. Concerns about food and waste sanitation, health and safety in the workplace, and other issues arose late in the nineteenth century and the early twentieth century. As a result of recurring epidemics of cholera, yellow fever, smallpox, typhus, typhoid, dysentery, diphtheria, and scarlet fever, states and municipalities created boards of health to protect people against disease (Rosen).

Because little was known about the causes of disease, quarantine—the separation of persons who could infect others—became, in the absence of immunization and other preventive measures, the primary mode of control. As the understanding of the bacterial cause and spread of disease grew, other preventive measures followed, including the control of food handlers to prevent typhoid carriers from working in food establishments, the prevention of persons with tuberculosis from working as teachers or nursemaids, and the prohibition of industrial work in the home to prevent the dissemination of tuberculosis through homemade clothing. Other regulations forbade spitting in public places and carrying soiled laundry on public conveyances such as the subway system in New York (Rosen).

The basis for early state and local legislation was the state's police power to protect people's safety, health, and welfare. The police power constitutes the reason for the establishment of state governments: to advance the public good and protect people from one another. This is a broad and inherent power because it is part of the social contract (Bentham, 1969a, 1969b).

The police power was relied on long before public health became a concern. For example, in 1837 the courts relied on police power to support a state law authorizing the construction of a second bridge across the Charles River that interfered with an alleged earlier franchise held by the owners of an old bridge (*Proprietors of Charles River Bridge v. Proprietors of Warren Bridge*). In 1851 the courts relied on police power to uphold state legislation limiting an owner's use of his property in Boston Harbor because that use would interfere with navigation (*Commonwealth v. Alger*). In 1876 the police power provided the basis for a state law to regulate grain elevator charges (*Munn v. Illinois*).

The broad thrust of police power to advance and protect community interests was developed further in early public health cases that upheld state regulation of retail liquor sales over the objection that that regulation interfered with the use of private property (*Crowley v. Christiansen*). In those early cases the claims of public interest under the police power overcame the assertion of private property interests protected under constitutional due process. Later cases involving the discriminatory regulation of laundries in wood-frame buildings (*Yick Wo v. Hopkins*) and the establishment of a quarantine district in a way that included and burdened a larger number of Chinese immigrants (*Jew Ho v. Williamson*) firmly applied the police power to protect public health, safety, and morals while upholding individual interests protected by the Fourteenth Amendment of the U.S. Constitution.

In the twentieth century public health law in the United States increasingly dealt with the resolution of tensions between the exercise of state police power and the protection of personal liberties through the due process clause of the Fourteenth Amendment and other parts of the Bill of Rights. In the landmark case *Jacobson v. Massachusetts* in 1905 the U.S. Supreme Court upheld the city of Cambridge and the state of Massachusetts in exercising the police power to compel Jacobson to undergo a smallpox vaccination not for his own protection but to prevent him from infecting others if he became infected in a smallpox epidemic. Jacobson argued that the law denied him due process and the equal protection of the law. The Court upheld the state's exercise of the police power by applying a standard of reasonableness that followed the utilitarian principle of the greatest protection for society at the least cost to the individual. Thus, the state's chosen method of control (vaccination) was adopted to achieve the end sought (an end to the epidemic) and was seen by the Court as a reasonable price to be paid by the individual in those circumstances (Bentham, 1969b).

In cases in which the exercise of police power allegedly violated property rights other analytic approaches were applied. In some of those cases reliance on constitutional principles was not articulated because the common law had long dealt with inappropriate uses of private property. For example, it is a well-established legal principle that citizens have a right to enjoin or abate a nuisance: A condition that is unwholesome or filthy and adversely affects neighboring property owners. The ancient principle of *sic utere tuo ut alienum non laedas* ("use your property so as not to hurt another") often was applied in private disputes and cited in constitutional decisions. States and municipalities began to designate such conditions as abatable nuisances, and public authorities could prohibit or abate them. Some conditions that were considered nuisances were referred to in *Commonwealth v. Alger* (1851), including warehouses for the storage of gunpowder near habitations or highways, wooden buildings of excessive height in populous neighborhoods and similar structures not covered with incombustible materials, buildings used as hospitals for contagious diseases, the use of buildings to carry on noxious or offensive trades, and the raising of a dam that caused stagnant waters emitting dangerous fumes to spread over meadows near inhabited villages.

A contemporary listing would include garbage dumps, sites for the disposal of hazardous wastes, paint spray plants, and fat-rendering plants. In *Mugler v. Kansas* (1887) the defendant was enjoined from using his property to operate a brewery, a proscribed use. The equitable rule of *sic utere* also calls for a balancing of equities, that is, a balancing of the benefit denied to the defendant against the benefit derived by the community in stopping undesirable uses of the property.

Public Health Law and the Eugenics Movement

The father of eugenics was Sir Francis Galton (1822–1911), a cousin of Charles Darwin who self-identified as a philosopher of natural science. One of his works was titled "Genius, an Inquiry into Its Laws and Consequences" (Pickens). Galton's work reflected the worst aspects of nineteenth-century Enlightenment thought, including the fundamental error that acquired characteristics can be transmitted by heredity. Eugenicists believed that the human race could be improved and social ills eliminated through selective procreation to eliminate defective germplasm from the national genetic germ pool.

Between 1900 and 1970 some 100 statutes based on eugenic theory were adopted by state legislatures to improve the nation through selective mating and to eradicate disease, crime, poverty, and other social ills by preventing the reproduction of socially deviant individuals. In the late nineteenth century and early twentieth century people worried about the future health of a growing and diverse population and held Malthusian fears about the adverse impact of overpopulation. That message was carried in the *American Journal of Eugenics,* which was published in July 1907 until 1910, and by two other journals, both publications of the American Eugenics Society, namely *Eugenics: A Journal of Race Betterment* from October 1929 to February 1931 and *Eugenical News* published from January 1916, continuing publication until December 1953 (Lombardo). The eugenics movement coincided with the development of the twentieth-century interest in broader public health protection, but it contributed to racial divisions and undermined the scientifically sound genetic research of the twentieth century.

The American eugenics movement was championed by the Eugenics Record Office of Cold Spring Harbor, Long Island, which collaborated with other groups that objected to the large numbers of immigrants from central and eastern Europe between 1880 and 1924. It supported the Immigrant Restriction (Johnson-Reed) Act of 1924 (Chase), which restricted immigration by Russian and Polish Jews, Italians, and other central Europeans, who were said to have a greater number of inborn undesirable qualities, including insanity, feeblemindedness, dependency, criminal behavior, deformities, and tuberculosis, than did the older Nordic and Anglo-Saxon stock. The act imposed severe immigration quotas to maintain the national racial and ethnic balance. A misguided effort of the Progressive Era, it applied so-called scientific approaches to manage the ills of society. Endorsing a form of social Darwinism, it extolled the Anglo-Saxon heritage and encouraged prejudice against inferior races and persons of color because the unlimited immigration of those groups would dilute the native stock with defective germplasm. Its "quarantine mentality" sought to separate the healthy from the ill or abnormal (Markel, Kühl).

The work of Charles B. Davenport and the Eugenics Record Office was supported by prominent citizens and some members of Congress who relied on pseudo-scientific charts, tables, and graphs illustrating the genetic inferiority of those immigrants. The organization favored the sterilization of hereditary paupers, criminals, the feebleminded, tuberculars, the shiftless, and ne'er-do-wells (Chase). At the turn of the century states began enacting involuntary sterilization laws to deal with idiots and imbecile children, hereditary criminals, and other genetically defective persons as well as sexual perverts, drug fiends, drunkards, epileptics, and others considered ill or degenerate. By 1931 about thirty states had enacted compulsory sterilization laws that covered mostly the "insane" and "feebleminded" and frequently "epileptics." Those laws were applied in the sentencing process and in institutional treatment and covered recent immigrants and others who were functionally illiterate or did poorly on intelligence tests. Although most of those laws were not enforced in all the states, by January 1935 some 20,000 people in the United States had been sterilized involuntarily, mostly in California. The California law was not repealed until 1979 (Hubbard and Wald). Nineteen states had laws that permitted the sterilization of mentally retarded persons without a clear definition of that category (Reilly).

In 1927 Justice Oliver Wendel Holmes wrote the opinion in *Buck v. Bell,* a case that has influenced law and genetics for many years. The opinion concluded with the assertion, "Three generations of imbeciles are enough." The case involved a law in Massachusetts that authorized the involuntary sterilization of feebleminded persons in state institutions. Carrie Buck was ordered sterilized because she was the feebleminded daughter of a feebleminded mother and had given birth in the institution to a feebleminded daughter. The sentence was carried out shortly after the decision in 1927. Subsequent investigation seemed to show that none of the three generations of women involved in the case were feebleminded (Gaylord). Never overruled, the decision was discredited by *Skinner v. Oklahoma,* which invalidated a law that provided for the sterilization of repeat offenders convicted of crimes of "moral turpitude."

The history of the eugenics movement was recalled by opponents of the U.S. Human Genome Project who compared it with the outrages of the Nazi holocaust, which used racist theories to justify compulsory sterilization and the murder of six million persons who were viewed as subhuman (Caplan). Citing *Buck v. Bell,* American opponents of the Human Genome Project also relied on other instances of involuntary sterilization, such as the cases that arose out of abuses in the U.S. sickle cell anemia program in the 1970s. Another instance of misguided medicine cited in the context of racist eugenics is the so-called Tuskegee Institute Study, which involved the intentional failure for many years to treat African Americans in Macon County, Alabama, who were suffering from syphilis (Duster; King; Hubbard and Wald).

Scholarly writings opposing the Human Genome Project and other genetic research do not assert that those projects attempt to advance eugenic principles but insist that in a racist society genetic investigation will exacerbate existing racial divisions and that even if such projects yield medically useful results, they will be used to benefit the dominant group rather than groups that have been discriminated against. In the course of mapping and sequencing the human genome, correlations will emerge between genetic characteristics and race or ethnicity that will be misused. Those writers also believe that genetic studies overemphasize genetic factors in human development and downplay the importance of environmental influences.

The only beneficial aspect of eugenics was personified by Margaret Sanger. Born in 1879, Sanger became a feminist activist as well as a socialist. After 1911 she pursued her interest in sex education and women's health. Sanger believed that frequent and unwanted pregnancies, sometimes including miscarriages and self-induced abortion, burdened women's lives, personal development, and freedom. Some of her books on female sexuality, social hygiene, and venereal disease were seized by postal authorities as obscene, and her career frequently was interrupted by arrests and imprisonment on obscenity charges. Later, focusing on the development of family-planning and birth control clinics, she argued that prenatal care and the limitation of pregnancies would result in healthier babies as well as healthier and more fulfilled women.

The idea that sex need not lead to conception and that women freed of the burdens of unwanted pregnancies could enjoy sex ran afoul of the 1873 federal Comstock law and state obscenity laws. In 1914 her books on birth control and contraception led to her indictment for violating postal obscenity laws. Sanger later continued her efforts at birth control advocacy by founding the American Birth Control League and connected those efforts with a part of the nativist U.S. eugenics movement that sought birth control for persons with mental or physical genetically transmitted defects, seeking the forced sterilization of mentally incompetent persons. Although Sanger did not advocate positive eugenics or limitations on population growth based on race, ethnicity, or class, her reputation was damaged by the growing development of race-based eugenics.

In 1936 the ruling by the U.S. Court of Appeals in *U.S. v. One Package of Japanese Pessaries* that physicians were exempted from the ban on the importation of birth control materials supported Sanger's efforts. Though ahead of her time, she never gained public funding for birth control as a public health measure. In 1939 the American Birth Control League and Sanger's Birth Control Clinical Research Bureau became the Birth Control Federation of America, which in 1942 became the Planned Parenthood Federation of America. The words *birth control* were considered too radical to be included in the name of the organization.

In 1952 Sanger and others founded the International Planned Parenthood Federation (IPPF) to address global overpopulation. She believed that reducing the number of unwanted children would make it easier to allocate economic and social resources. Sanger worked with the American and British medical establishments to develop an effective and inexpensive female contraceptive. That was accomplished in the 1950s when Gregory Pincus developed an effective anovulant, the birth control pill; Sanger had helped secure funding for this effort. Sanger died in 1966, soon after the Supreme Court's 1965 decision in *Griswold v. Connecticut,* which allowed the use of birth control information by unmarried and married couples.

Although the legislation it spawned remained on the books, by the 1930s and 1940s the eugenics movement no longer fit the economic and political changes in society and in scientific attitudes. The simplistic view that heredity would produce copies of earlier generations and their acquired characteristics unaffected by nurture and environment was abandoned. Moreover, the search for the perfect contraceptive was successful at a time when the pressures that created the eugenics movement had abated. At the beginning of the 1940s birth control research and eugenics in both Britain and in America gave way to the pressing concerns of World War II and the needs of the Third World (Soloway).

Expansion of Public Health Law

With the entry of the federal government into public health in the twentieth century, public health law expanded and there were significant changes in the exercise of governmental powers and the tasks assigned to public health law. The federal government has no plenary police powers (it lacks the power to provide for health, safety, and welfare), yet it plays a major role in the creation and execution of public health policies through the exercise of the powers delegated to it by the states under Article I of the U.S. Constitution. Those powers include the power to regulate interstate and foreign commerce and to tax and spend for the general welfare. The Food, Drug, and Cosmetic Act enacted in 1938 demonstrates the use of the federal commerce power in the regulation of public health. Congress not only regulates trade in and the interstate transport of food, drugs, and cosmetics but also authorizes the U.S. Food and Drug Administration (FDA) to set standards for and monitor the quality of that merchandise. Through the FDA the federal government also regulates the safety and efficacy of drugs and pharmaceuticals with a detailed mechanism of administrative controls, including the power to adopt standards to inspect pharmacies and supervise food and drug regulation. Interstate commerce regulation also includes the control of harmful emissions from automobile engines, showing that interstate commerce controls affecting public health may be designated environmental controls even though their primary purpose is the advancement of public health. To exercise the commerce power the federal government usually acts directly through a federal agency such as the FDA or the U.S. Environmental Protection Agency (EPA).

Taxing and spending power represents a less direct exercise of federal powers. An early example of the use of that power in public health was the 1944 Hill Burton Hospital Construction Program, under which the federal government grants funds to a state or municipality for hospital construction programs and nonprofit community hospitals (Grad, 1990). As a condition of the grant the state or local government must comply with federal regulations, including facility and personnel requirements, and provide free services for indigent persons. Another ongoing grant-in-aid program is the program under Subchapter II of the Federal Water Pollution Control Act Amendments of 1972 for the construction of public waste-treatment works by states and municipalities. This program has helped clean up waterways and develop improved sewers in cities. Grant-in-aid programs have been used widely to support infrastructure developments to advance public health. Under those programs the federal government requires states to pass regulations and carry out construction, enforcement, and compliance activities to meet the conditions of a grant.

Federal public health activities under the commerce power are analogous to state exercise of the police power in that they command and control certain activities. Like exercises of state police power, they must meet the constitutional requirements of due process and equal protection. Their philosophical basis is largely utilitarian, seeking a balance between the public interest and the protection of private entrepreneurial interests in development and property. Federal public health activities under the taxing and spending power may advance similar concerns, but to the extent that they involve the distribution of federal funds, other concerns, such as those relating to fairness in distribution, also play a role. John Rawls argues that if the principle of equal liberty is met, as well as that of equality of opportunity, the difference principle permits inequalities in the distribution of social and economic goods if those inequalities will benefit everyone, especially the least advantaged (Rawls). Distribution formulas for the sharing of federal funds by responding to areas with greater needs satisfy that formulation.

Relationship between State and Federal Public Health Law

The relationship between state and federal public health law is not a simple hierarchical one. Although under Article VI, Section 2, of the U.S. Constitution federal law is the supreme law of the land, in cases of conflict between federal and state law, federal law trumps state law only if Congress has the jurisdiction to pass such a law. In the case of public health law, federal jurisdiction generally is defined by the interstate commerce power. In the past the federal commerce power generally was viewed as broad enough to cover virtually any law Congress decided to pass. However, a series of close decisions by the Supreme Court has limited congressional power to subjects that are clearly related to interstate commerce. The Court has invalidated laws involving gun control and violence against women. Other decisions have addressed the issue of whether the federal exercise of regulatory power was sufficiently related to the area of interstate commerce. This stringent limitation on federal power and correlative limitations on state judicial power were enhanced by decisions interpreting the reach of states' Eleventh Amendment immunity from lawsuits. In another effort to increase state powers the Court has held that although an activity may be federally regulated, Congress lacks the power to subject nonconsenting states to private suits for damages and other relief in state courts. Thus, under the Americans with Disabilities Act the Court held that the Eleventh Amendment limits private actions by state employees for damages under the federal law. The Court also has held that the Constitution does not permit private lawsuits to recover damages from nonconsenting states for the violation of federal rights even when the suits are brought in state courts (*Alden v. Maine*). Those cases indicate that the subject matter of public health does not change the Court's rules concerning the protection of states' rights.

Major Public Health Approaches

There are two major approaches to the protection of public health. The first and older one uses regulatory enforcement programs that range from epidemiological controls and protection against unwholesome living conditions to the identification and removal of poisons in the environment. Included are protection of the food and water supplies and protection against hazards and poisons in the workplace. Programs to protect the public against hazards from the generation of nuclear energy and efforts to prevent the destruction of the stratospheric ozone layer by the dissemination of hydrofluorocarbons and other destructive gases are included in this area.

Although public health regulation and enforcement have grown enormously, that expansion has been exceeded by the second area of public health protection: public health services. The government provides services to advance the health of the public, including the provision of well-baby clinics, family-planning clinics, community mental health programs, and government-sponsored research institutions that provide special services.

Both regulatory enforcement programs and service programs must meet constitutional requirements. In general, equal protection under the Fourteenth Amendment specifies that the same degree of fairness apply in the provisions of benefits and services as applies in the imposition of obligations and duties. As a result government agencies carefully consider allocation factors in the distribution of services to determine how priorities should be set between public health and other needs and determine the priority of certain health-related needs. Finally, institutions often must determine specific allocations among individuals with different health and other needs (Rawls). Political considerations such as pressure from physicians and other service providers or from consumers also have an effect on the process.

In addition to direct service programs, Medicare and Medicaid, both of which were established in 1965, pay or reimburse medical costs. Medicare is an offshoot of Social Security. Focused on the reimbursement of fees for service, it subsidizes the healthcare costs of Social Security recipients, primarily the disabled and persons age sixty-five and older. Initially paid for by employer and employee contributions, Medicare became an entitlement program because employees had secured contractual rights to social insurance through their contributions. Medicaid is a federal grant-in-aid program financed by federal and state contributions to provide medical care for "medically indigent" persons whose family income level is so low that they cannot pay for their own medical care. Both Medicare and Medicaid are managed federally by the Health Care Financing Administration.

Government involvement is dominant in these programs; because the government reimburses medical providers for services rendered, it is directly involved in regulating the quality of those services. Medicaid may be viewed as a welfare program that takes the place of earlier provision of care for the poor through charitable or public institutions. Medicare, based on contractual entitlements, was created with the expectation that employees would die soon after reaching the retirement age of sixty-five. However, the increasing longevity of the covered population and the substantial increase in the cost of health services have led to persistent political criticism. Such programs are not novel. State financing of healthcare costs began in Germany in the late nineteenth century, and many European nations, including Great Britain, the Netherlands, the Scandinavian countries, and Austria, have continued to provide healthcare even though their gross national products and industrial bases are considerably smaller than those of the United States.

In the United States there is no right to healthcare or to treatment under federal or state law except insofar as specific reimbursement provisions have been provided by law. There is no constitutional entitlement to healthcare. However, a number of writers have suggested an egalitarian right to healthcare, claiming that everyone who has an equal need for healthcare services or resources must have equal access to them. This sometimes has been asserted as a corollary of a general egalitarian welfare right that requires the distribution of resources to assure that everyone's lifetime net welfare is equal (Buchanan; Veatch). This expansion of welfare rights, including the right to healthcare, last failed to become part of American law during the second term of the Clinton adminstration when the universal health insurance proposal by the committee headed by First Lady Hillary Clinton was not adopted. However, in June of 2003, new efforts were underway to include "universal" health insurance as part of the law had not as of 1994 become part of American law. Any such proposal would be rejected by those who hold the so-called libertarian point of view, which regards as inappropriate all social ordering that does not rely on the allocation of goods and services through market processes (Buchanan; Nozick).

It is difficult to formulate a single philosophical basis for federal involvement in the multiplicity of public health programs. Twentieth-century federal public health programs were based on detailed programmatic legislation that not only established new rules of law but also created new governmental structures to manage the new areas of governmental control (Grad, 1985). Those new structures are exemplified by the FDA, the EPA, and agencies that manage social insurance programs such as Medicare and Medicaid. In every instance the agency is given broad rule-making powers that must be exercised in accordance with the general purposes of the statute. In statutes intended to protect society against toxic substances and hazardous waste the general purpose may be "to protect health and the environment."

In regard to such legislative instructions one might refer to the principle *sic utere* or to the broader principle of preventing harm to others, but that would not be historically or analytically correct because those principles were intended to govern persons in their private relationships or their relationships within a relatively small community. Modern public health programs, in contrast, address broader national or even global problems. Moreover, the emphasis of earlier approaches was generally on preventing harm, whereas modern programmatic legislation often seeks to advance public benefits. The utilitarian rationale of protecting the health interests of the public at the lowest possible cost to the individual seems the most appropriate. The purposes of public health programs are legislatively defined. Legislation is political and therefore majoritarian in its nature, unlike the judicially established bases for protection under common law articulated by judges and intended primarily to resolve individual disputes.

Public Health and AIDS

The emergence of AIDS in the 1980s demonstrated the tension between the protection of individual rights and the enforcement of broadly applicable police-power measures to protect public health. Another significant challenge was the threat of a multidrug-resistant form of tuberculosis in the late 1980s and 1990s. Communicable diseases generally are reportable under health codes, and those reports to a health department are normally protective of the patient's privacy. Special confidentiality protections are particularly applicable to reports of sexually transmitted diseases and, in earlier times, tuberculosis. Special privacy protections originated in the protection of patients against stigma because a report of certain diseases was regarded as a social disgrace. The knowledge that the report of a communicable disease might result in stigmatization and discrimination was undesirable from the point of view of public health because patients were less likely to seek treatment if their confidentiality was breached.

When AIDS emerged in 1981, most other communicable diseases no longer represented major public health problems, and the history of reports to health departments and the possibility of contact investigations to trace potentially exposed persons, particularly in the area of sexually transmitted diseases, had been forgotten. Constitutional protection of privacy as a part of due process had developed earlier in the context of the right of a pregnant woman to choose to terminate her pregnancy. Privacy protections and related protections of personal autonomy are asserted to protect against the disclosure of human immunodeficiency virus (HIV) status even though AIDS is now a reportable disease in all the states.

Because transmission of HIV was associated first with homosexual intercourse and later with intravenous drug use, there were compelling reasons to protect the identity of persons who were HIV-positive. Privacy protections also interfered with giving notice of exposure and risk to persons who had been exposed because that information, unless disclosed voluntarily, inevitably would breach the patient's confidentiality. Patient privacy continued to have broad legal protection, and the tension between the protection of individual privacy and the need for public information in order to protect the public health is a continuing one, even though there is today in 2003 both greater tolerance of what had earlier been considered deviant sexual behavior. Many more persons freely acknowledge their sexual preferences and "come out of the closet." At the same time, the medical and public view of HIV/AIDS has changed in view of the decline in HIV morbidity and mortality during the late 1990s, attributable to combination antiretroviral therapy. This decline appears to have ended, and in 2003 new outbreaks of primary and secondary syphilis among men who have sex with men and increases in newly diagnosed human immunodeficiency virus (HIV) infections among such men and among heterosexuals have been increasing. As a result there are new concerns that HIV incidence may be increasing. Earlier programs focused on prevention efforts targeted at persons at risk for becoming infected with HIV and on programs to reduce sexual and drug using risk behavior. More recent efforts are focused in 2003 on prevention efforts for persons living with HIV. During 1981 to 2001, an estimated 1.3 to 1.4 million persons in the United States were infected with HIV, and 816,149 cases of AIDS and 467,910 deaths were reported to CDC. During the late 1990s, after the introduction of combination antiretroviral therapy, the number of new AIDS cases and deaths among adults and adolescents declined substantially. The annual number of incident AIDS cases and deaths have remained stable since 1998, at approximately 40,000 and 16,000, respectively. The number of children in whom AIDS attributed to perinatal HIV transmission was diagnosed peaked in 1992 at 954 and declined 89 percent to 101 in 2001. (Morbidity and Mortality Weekly Report, 2003).

The *Morbidity and Mortality Weekly Report* (2003) notes that since early 1990 an estimated 40,000 new HIV infections have occurred annually in the United States and the number of persons living with HIV continues to increase. Of an estimated 850,000 to 950,000 persons living with HIV an estimated 180,000 to 280,000 (25%) are unaware of their serostatus. The report points to new and faster tests for HIV which create a new prospect for expanding testing, identification, and treatment of HIV infections. Thus, testing and more information will be used to reduce the number of HIV infections by working with persons diagnosed with HIV and their partners. There will consequently be increased emphasis on partner notification (Morbidity and Mortality Weekly Report; CDC; HIV/AIDS Surveilance Report, 2001).

It is notable that the new program returns to the earlier methods applied to deal with sexually transmitted diseases (STDs) such as routine screening, identification of new cases, partner notification, and prevention services for those who are infected. The change in approach is a reversal of earlier emphasis on privacy where for sometime a New York physician who diagnosed a patient as HIV positive could, but was not under any legal compulsion, to inform the patient's spouse or other sexual partners.

Because persons who are HIV-positive and have a defective immune system are more likely to contract tuberculosis than are others, the recurrence of tuberculosis in a multidrug-resistant form creates a situation in which the disclosure of a patient's affliction with tuberculosis may be regarded, often erroneously, as an indication of positive HIV status, aggravating the problem of maintaining confidentiality. Privacy is now an aspect of personhood, and protection against the invasion of privacy—in this case the invasion of informational privacy—is constitutionally granted by the Fifth Amendment (Tribe). Ethical protection of privacy is based on privacy as an aspect of personhood that is protectable to the same extent that a person's physical integrity is. Violations of privacy are ethically justifiable only if disclosure serves a greater good. Thus, whether a patient's HIV status should be disclosed to others depends on the need of those persons to know and the uses and benefits that may result from the disclosure (Bayer).

Public Health and Bioterrorism

The use of passenger aircraft as guided missiles to destroy the World Trade Center on September 11, 2001, did not change the task of public health but created an urgent need to plan for disasters. Terrorists target civilian populations, and the means and the impact are likely to be unexpected, deeply hurtful, and unrestrained by humane concerns. Civilian populations in dense urban centers are vulnerable because in those areas disease and terror spread readily.

Bioterrorism involves the use of pathogens—disease-causing organisms such as bacteria and viral agents—as weapons to attack civilian populations and armies to weaken their health and resistance. Pathogens may be spread by using advanced technology, but simple devices such as giving smallpox-contaminated blankets to Native Americans during the French and Indian Wars of 1763 can serve the same purpose. During World War II and the Cold War period virtually all the major powers worked to develop biological weapons (Evans et al.).

Before September 11, 2001, public health commentators thought that a significant bioterrorist attack was not likely. Because it was impossible to predict the nature and extent of an attack, preparations could be both costly and inadequate. After a simulation by the U.S. Department of Justice at the request of Congress in Denver in May 2000 in which a hypothetical terrorist sprayed airborne plague bacteria at a concert, a survey of hospital emergency departments showed that as few as 50 casualties could not be well served. The simulation called attention to the infrastructure weaknesses of many public health systems, noting inadequacies of capacity, underfunding, and inability to recognize a new epidemic.

Although bioterrorism events such as the anthrax cases in 2001 may be small-scale, a bioterrorism attack could leave hundreds of thousands dead or incapacitated. In the anthrax event, which involved contaminated letters and resulted in five deaths, it took several days for the first case to be diagnosed. Only later was it recognized that one form of respiratory anthrax could be released from sealed envelopes. The old notion that physicians are the first line of defense for public health was proved again because only physicians know to diagnose diseases, determine who has been exposed and to what agent, and determine who will have to be quarantined.

The period immediately after a bioterrorist attack is crucial for saving lives and managing public panic. An adequate response at the local level is essential, and local agencies must be equipped for an effective response. Although the federal government plans to spend billions of dollars to increase the stockpile of antibiotics and vaccines and develop protection and treatments against bioterrorism agents, funds are needed for infrastructure improvements of state and especially local public health departments to put those materials to use. In addition to stockpiling vaccines and medications, more needs to be done to enable local health agencies to function and respond in the first twelve hours after an attack. Aside from bioterrorism readiness, the capacity for full local responses also will upgrade the public healthcare system because if a local public healthcare system were more fully integrated, it could respond more effectively to bioterrorism, or to such unexpected developments as the emergence of new highly communicable and potentially deadly disease, SARS (severe acute respiratory syndrome).

The threat of bioterrorism by itself may cause major disruptions. Past experiences with bioterrorism show the need for infrastructure changes to facilitate immediate responses. Those responses require the ability to provide the public with accurate and consistent information. Public health must use its long experience in addressing and responding to naturally occurring infectious diseases in large populations to deal with the challenges of bioterrorism, but this may be difficult to undertake in view of other demands on the system. Agencies must be capable of responding both to actual illnesses of exposed persons and to psychogenic casualties and also must be aware of the likelihood of injury to healthcare workers. Because bioterrorism is a crime, law enforcement agencies may be involved. Teamwork is needed with a cross section of public health professions, and public health physicians must learn to recognize diseases that may be related to bioterrorism. The Centers for Disease Control and Prevention's (CDC) National Electronic Disease Surveillance System project provides funds to help states develop electronic modalities to speed reporting.

An immediate response is essential to address events that cause large numbers of casualties, but states also must have an independent ability to cope with smaller-scale events during the first twelve to forty-eight hours after a bioterrorism attack. State and local agencies must develop plans to prevent the spread of infection from bioterrorism agents. Guidance is provided by the CDC in the "Model State Emergency Powers Act" and "Smallpox Plan and Guidelines" to deal with the complex challenges of controlling communicable disease initiated by bioterrorism.

Planning is necessary for the stockpiling of antibiotics as well as to deal with the economic impact of bioterrorism, which is likely to be very high. The economic impact of the release of a Category 1 agent might range from $500 million to $26.2 billion per 100,000 persons exposed, depending on the agent. Public health agencies must ensure that future means and projections are adequate to respond to the risks involved and that adequate information and a capacity for a quick response are available.

Smallpox is a very effective agent for bioterrorism because in nonimmune persons the mortality rate can approach 30 percent and because person-to-person airborne transmission may occur rapidly. There is no effective antiviral therapy against smallpox because the disease effectively was eradicated by 1977 through a World Health Organization program. Serious viral diseases occur in specific locations, and physicians outside their normal locales are likely to mistake them for other local ailments. Other diagnostic difficulties arise because those cultures may be hard to culture from humans and may pose risks to laboratory personnel. Few practitioners have ever seen a case of smallpox, and cases are likely to be mistaken for more common diseases. There is also substantial resistance to smallpox immunization because of possible adverse reactions that have received broad publicity even though they occur very infrequently. Immunization is possible for smallpox, but there are few immunization strategies for other viral diseases. Viral agents as weapons of mass destruction pose major risks because they are highly contagious in susceptible populations and have a high rate of fatality (Bronze et al.).

Because pathogens used for bioterrorism may be spread without being observed immediately, infectious agents may not be discovered until it is too late to respond. Detectors that consist of electronic chips that can detect pathogens through the use of antibodies or DNA are being developed, and an important question will be to determine where to place those devices, which apply a new and expensive technology (Casgrande).

Bioterrorism is analogous to what has been referred to as ecoterrorism, which uses existing industrial and ecological hazards against populations near atomic power plants or other plants that use or store dangerous substances. Attacks on such plants that result in the release of hazardous substances may equal or exceed the consequences of bioterrorism (Prenders and Thomas). The consequences of accidental releases of hazardous substances in Bhopal, India, have made people aware of the potential of intentional releases through acts of terrorism.

Conclusion

Public health law is a developing field that is based on established principles and legal tradition yet is contemporary and responsive to current needs. Based on the police power of the state and federal powers delegated under the U.S. Constitution, public health law has experienced a significant expansion through its inclusion of fields such as the law of mental health, the law of occupational health and safety, major aspects of environmental law, and the growing area of legal developments related to genetic disease. Although the domain of public health law has expanded, it has retained its essential purpose of advancing the public good at the least cost to individual freedom.

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SEE ALSO: *AIDS: Public Health Issues; Bioterrorism; Coercion; Conscience, Rights of; Environmental Policy and Law; Epidemics; Eugenics; Health Screening and Testing in the Public Health Context; Paternalism; Public Health*

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II. LEGAL MORALISM AND PUBLIC HEALTH

Modern public health, which uses organized community effort, law, and regulation to save lives and prevent disease, has long been entangled with legal moralism, which uses the same measures to protect society against behavior that is viewed in some quarters as "offensive, degrading, vicious, sinful, corrupt, or otherwise immoral" (Schur and Bedau, p. 1). "Morals offenses" have "included mainly sex offenses, such as adultery, fornication, sodomy, incest and prostitution, but also a miscellany of nonsexual offenses" (Feinberg). Legal moralism has cultural and religious origins, but its deepest roots are in purity rituals codified in religious and secular codes (Douglas). Purity rituals are avoidance rituals designed to make the environment and the community safe from the threat of uncleanness and contamination and to promote social order. These codes governed diet, sexual conduct, bodily cleanliness, and avoidance of contamination.

In its most expansive expression legal moralism is the belief that these behavioral codes, regulations, and legal proscriptions are foundational to a social order. To the moralist, drug taking, vice, crime, and sexual promiscuity not only harm the self and others but also threaten, through contagion and example, to loosen the bonds that hold society together. It is the connection between the proscribed conduct or practice and the theories about how the spread of this conduct threatens social order that so often results in the confusion of public health and moralism. Because moralism is often expressed in terms of public-health theories of contagion, it has proved difficult to separate the two modes of thought.

The belief that immorality is contagious also often includes the belief that immorality causes disease. Barbara Gutmann Rosenkrantz's authoritative history of public health in Massachusetts cites a review of Lemuel Shattuck's 1850 report on the health of the state, noting that the "sanitary movement does not merely relate to the lives and health of the community; it is also a means of moral reform.… The ultimate connection between filth and vice has been noted by all writers upon this subject" (Rosenkrantz, p. 2).

Moralism in public health arises when society or groups in society respond to a health crisis more by voicing objections to a social practice or to a group engaged in that practice than by rationally assessing the dangers of disease and the best ways to prevent its spread. The parallels between theories of disease causation found in public health and legal moralism are often challenged and overturned by scientific theories of disease causation. While public-health campaigns and officials have often addressed problems moralistically in the past, the long-term trend indicates a separation of the two ways of thinking. Moralism has also suffered attacks from religious groups that emphasize social justice or inwardness more than adherence to religious rules. Finally, moralism is challenged by the modern and postmodern tolerance of a wider range of sexual expression and by the spreading support for political liberties and rights of privacy for all citizens, even those accused of immoral practices.

Moralism's most potent threat to public health comes from the ways in which epidemics and moral dissolution are believed to be inextricably tied together. This entanglement makes the victims of new outbreaks of certain diseases seem a threat to society itself. It also leads to powerful drives to stigmatize and shame the epidemic's victims, in the use of legislation and regulation to invoke shame and public denunciation for a category of persons or in what have been called "status degradation ceremonies" (Garfinkel). The current struggle in the fight against acquired immunodeficiency syndrome (AIDS) is the best-known contemporary example of the confusion between moralism and public health. Thus, the purpose of the policies of the United States in incarcerating prostitutes during World War I was not just to prevent the spread of syphilis and venereal disease but also to shame and punish a class of individuals and to close and solidify the ranks of a nation going to war (Brandt). This moral campaign of imprisonment took priority over the use of new medical treatments for syphilis and gonorrhea, which, while still primitive, were surely more effective.

Modern public-health problems, especially those of a contagious or epidemic nature, provide a constant temptation for legislators, health officials, and the public to confuse the ends of preventing harm to individuals and communities and of proscribing immorality. Yet it would be wrong to conclude that all proscriptions of a practice or behavior are tantamount to moralism. Moralism and social disapproval are not the same thing, even though the latter may be an echo of the former. Social disapproval or even indignation about a practice remains a potent ally of many public-health campaigns.

Public Health and Alcohol Policy

Legal moralism has played a prominent role in alcohol policy, particularly in movements to prohibit all drinking in the United States, in England, and in the Nordic countries. The history of alcohol policy, more than that of most public-health problems, reveals the difficulty in separating health issues from moralizing claims. It also reveals how some of the ways we seek to avoid moralism can be counter to science and to the health and safety of the public.

In the United States, Prohibition, or the outlaw of the manufacture and sale of alcoholic beverages, was enforced from 1917 until 1933. The Prohibition movement is a fascinating intermingling of progressive and scientific thinking, moralism, and religious fundamentalism. For example, the Progressive period in U.S. history (roughly 1890 to 1920) was not just a period when the states began to expand their powers over child labor, over the working conditions of adults, or of assuring safe food and water by strengthening the regulatory power of the states over private property; it was also a period that witnessed the rise of movements to protect the decency and purity of the public through antipornography legislation, crackdowns on prostitution (especially during World War I), and American Prohibition (Brandt). There is little doubt that the various reform movements that culminated in the passage of the Prohibition amendment brought to the nation's attention a social problem (drunkenness, the saloon, and an overly powerful liquor interest) that demanded state and federal legislation. Also, the record shows clearly that the results of Prohibition, measured solely in public-health terms, were sharply reduced overall consumption of alcohol and related steep declines in serious public-health problems like cirrhosis, admittance to public hospitals for alcohol-related disorders, and the like (Moore and Gerstein; Beauchamp).

The strong secular and progressive side to the movement for Prohibition saw the saloon as a great social problem, one that undermined the public health and safety and promoted domestic violence and crimes against women. Both the movements for women's suffrage and the movement against slavery frequently were headed by leaders who also advocated Prohibition. Yet this began to change in the last decade of the nineteenth century. The women's movement had focused its energies on winning suffrage, and the movement against slavery had long since been replaced by Reconstruction. During the concluding decades of the agitation for Prohibition, the first two decades of the twentieth century, support for Prohibition came primarily from Protestant churches; national Prohibition's justification shifted more and more toward the moralistic claim that drink was the root of most of society's evil. (Moralism is often characterized by inflated claims of the evils or dangers from a substance or a practice, even in very small quantities or isolated and scattered acts.) The intertwining of moralism and public policy, especially for alcohol and drug taking, seems more common in nations where fundamentalist forms of Protestantism that stress adherence to religiously sanctioned behaviors are widespread, or in Muslim nations, where similar fundamentalism obtains; Catholic societies have never had successful Prohibition movements (although temperance movements are found in Ireland).

The backlash to Prohibition produced theories of alcoholism that sought both to deny its moralistic forebears and to establish a new and scientific theory of causation, called the disease concept of alcoholism. This was the belief that alcoholism was caused by an inability to control drinking. In parallel fashion, and also to separate itself from a discredited past, the new alcoholism movement denied the public-health benefits of Prohibition, and as late as the 1960s leading national experts claimed that Prohibition caused people to drink more. The links between what a society drinks generally and the level of alcohol problems were viewed as part of a neoprohibitionist agenda.

The attempt to purge society of moralistic remnants of Prohibition has often been met with surprises. For example, there were strong drives to prohibit alcohol in Norway, Sweden, and Finland during the 1920s and 1930s. Only Sweden avoided Prohibition, in a narrow national referendum vote. In Finland, during the late 1960s and 1970s, the drive to eliminate the rural remnants of their national prohibition legislation of the 1930s led to a sharp relaxation of drinking laws throughout society and the elimination of prohibition in rural areas. The experts believed that restrictions actually encouraged drinking of distilled beverages in unsocialized ways and that by eliminating prohibition, drinking would actually decrease. Yet the measures to liberalize drinking were followed by steep increases in drinking rates and associated problems such as public drunkenness (Beauchamp). Subsequently, state authorities and their advisers retreated from a too-uncritical relaxation of drinking legislation, shifting the justification for alcohol policy more toward a public-health model that accepted limits on all drinking as a necessary part of a sound policy and as not necessarily moralistic.

Western democracies during the 1970s and 1980s witnessed declines in drinking rates, attributed by experts to a growing cultural conservatism and a widening awareness of the public-health consequences of heavy drinking and high levels of per capita consumption. This new period was likely also solidified by the fact that heavy drinking became socially and even morally undesirable, just as smoking became morally undesirable. While drunkenness and addiction were still viewed less punitively, the public began to register its strong disapproval of heavy drinking, especially when it posed risks to others, such as in drinking and driving, or any drinking at all by teenagers. More broadly, the era when drinking itself was not seen as the problem was replaced with a period in which all drinking remains somewhat under a public-health cloud. The evidence that some forms of drinking might promote a healthier heart has caused that cloud to lift only a little.

Smoking and Public Health

At the turn of the twentieth century, smoking was treated as morally offensive. Churches proscribed cigarette smoking and urged public action. But the long-term popularity of smoking spread too quickly, and the campaign was eventually abandoned. Soon smoking was regarded as cosmopolitan and modern. Cigarette smoking rates grew and became widely and culturally approved (Warner). In the 1950s epidemiological studies appeared in the United States and England noting the link between smoking and lung cancer and the possible links with heart disease. The U.S. Surgeon General issued a widely discussed report compiling very strong and extensive research suggesting that smoking was one of the most lethal hazards of our times.

The social climate against smoking began to turn in the late 1960s and 1970s. Antismoking sentiment rose, and cigarette advertising on television was banned. The risks of smoking for third parties was noted. Communities and entire states began to legislate against smoking in public places. Higher taxes on cigarette smoking were advocated. Smoking rates in most industrial societies fell, but most impressively in the United States. This sharp decline is not only due to the extensive public discussion devoted to the hazards of smoking but also to the growing sense of social and even moral disapproval of smoking by the larger society. This social disapproval was sometimes seen as a resurgence of moralism. But there is scant evidence that the strong current of disapproval against smoking adds up to moralism.

Moralism and the AIDS Epidemic

As Allan Brandt notes, the battle against venereal diseases in the first decades of the twentieth century and the rise of AIDS more recently give evidence that moralism remains a powerful element in the social construction of society's definition of these diseases. Early in the twentieth century, syphilis was a symbol of a "society characterized by a corrupt sexuality. Venereal disease has typically been used as a symbol of pollution and contamination, [and of] … a decaying social order. Venereal disease makes clear the persistent association of disease with dirt and uncleanness as well" (Brandt, p. 5).

The most serious challenge to modern public health by legal moralism entered with the AIDS epidemic and HIV-related diseases. Because anal sex and frequent sex with multiple partners heightens the risk of transmission of the HIV virus and because intravenous drug use also seriously elevates the risk of infection from contaminated needles, legislation that seeks to regulate these behaviors—which are widely proscribed in many states—is always open to the charge of moralism.

Early in the epidemic in the United States, bathhouses frequented by homosexual patrons became targets of public-health regulations. Many in the gay community charged that the measures were aimed less at fighting the epidemic than at proscribing homosexuality. These advocates argued, quite plausibly, that the regulations would have little impact on the course of the epidemic in San Francisco or New York, the two cities where conflicts primarily arose. This was because the bathhouses were the site of only a fraction of the proscribed behaviors. Advocates also argued that city officials and state public-health authorities had caved in to political pressures (Bayer, 1991b).

The same charge of moralism and discrimination was also brought when public-health officials attempted to introduce methods of identifying the sexual partners of those who were AIDS victims, or when state medical societies sought legislation to make AIDS and HIV diseases reportable to state health authorities (Bayer, 1991b). (All states require private physicians to report certain communicable diseases to state health officials.) Ronald Bayer, in his book *Private Acts, Social Consequences* (1991b), has provided the best chronicle of the clash between public-health legislation and the civil libertarians defending AIDS victims. As Bayer says, "These two abstractions, liberty and communal welfare, are always in a state of tension in public health policy" (1991b, p. 16).

It is likely, however, that the AIDS epidemic has permanently altered the landscape of public-health policy, and not just in the United States. No longer will it be possible to easily equate public health only with the use of powers to restrict power and liberty to promote the public health or to see the realms of public health and individual liberty as radically distinct. The growing awareness is that a sound public-health policy requires more than restrictions on liberty and property to promote the communal welfare. It also may require the expansion of private liberties and rights for groups suffering social discrimination based on moralism.

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SEE ALSO: *Abortion; AIDS; Body; Cloning; Conflict of Interest; Death, Definition and Determination of; Embryo and Fetus; Fertility Control; Informed Consent: Legal and Ethical Issues of Consent in Healthcare; Law and Morality; Life Sustaining Treatment and Euthanasia; Maternal-Fetal Relationship; Public Health; Sexual Behavior, Social Control of;* and other *Public Health Law* subentry

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PUBLIC POLICY AND BIOETHICS

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There are at least two ways of understanding the relation of public policy to bioethics. The first, focusing on public policy *in* bioethics, involves the public laws (both statutory and case law), policies, regulations, and guidelines that bear on ethical aspects of medical practice and healthcare. These are public in the sense that they emanate from some publicly accountable governmental process, as opposed to private or professional policy; in addition, nonpublic institutions such as hospitals can adopt their own policies to conform to public policy. In this sense, legal requirements to obtain informed consent for treatment, federal regulations requiring approval of a research protocol by an institution's human subjects committee, and the lack in the United States of any governmental means of ensuring universal access to healthcare for all citizens represent public policy bearing on ethical aspects of medical and research practice.

When the relation of public policy to bioethics is understood in this way, the question arises as to the extent to which bioethics issues have been and should be matters of explicit public policy. Physician–patient relations, for example, may be taken to be a largely private matter to be worked out by physicians and patients outside of the public sphere, as they were to a great extent in the early part of the twentieth century, or to be a matter of professional concern by physicians in professional settings, but not the subject of and regulated by public policy. Alternatively, such issues might be seen, as they increasingly were in the United States in the 1970s and 1980s, as an appropriate concern of public policy. Thus, public policy in bioethics includes what governments choose not to do, as well as what they do, in bioethics.

The second understanding of the relation of public policy to bioethics focuses on public-policy bodies that have been influential in shaping bioethics, public policy on bioethics issues, and healthcare practice. Understood in this way, the subject is the manner and extent to which bodies in the United States, such as the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereafter President's Commission) or the National Bioethics Advisory Commission (NBAC), or international bodies, such as the United Nations Educational, Scientific and Cultural Organization (UNESCO) or the World Health Organization (WHO), have shaped bioethics and medicine. Why have the United States and many other countries frequently turned to such bodies in the development of public policy in bioethics? How have such bodies functioned? What has been their impact?

This entry addresses both of these understandings of the relation between public policy and bioethics. A general thesis of this entry is that bioethics and public policy have influenced one another. The field of bioethics has helped shape and has been shaped by both public policy in bioethics and a variety of public policymaking institutions in bioethics.

The Relation between Substantive Public Policy and Bioethics

As bioethics in the United States and elsewhere during the 1970s and 1980s became an area of great public and professional concern, many standard bioethical issues began to be addressed, not just in classrooms or between doctors and patients, but also in explicit public debates and policies. One of the most prominent examples, cardiopulmonary resuscitation (CPR), illustrates a relatively common pattern of this development of public policy on important bioethics issues. First, a new technology was developed; in this case and not atypically, it was a form of life-sustaining treatment. Originally the technology was developed for and applied in a relatively narrow range of cases in which there was clear expected benefit: saving otherwise healthy people who had suffered unexpected cardiac or respiratory arrest. CPR later came to be used in a wider range of cases, including many patients for whom its expected success and benefit were questionable. The reason for the wider use was that the conditions under which CPR was applied precluded taking time to make thoughtful decisions about whether to employ it once a patient was in need of it.

Reports of widely varied practices, including some that were ethically problematic at best and certainly did not represent sound general practice, led many hospitals to develop formal policies concerning resuscitation. In particular, the general interest in "do not resuscitate" (DNR) orders led to scholarly studies of the use of CPR and of DNR orders. Public bodies such as the President's Commission addressed the issue and developed recommendations about institutional policies, and the Joint Commission on Accreditation of Healthcare Institutions required institutions to have a policy regarding DNR orders. In this case, a public-policy response to an identified and significant ethical problem in medical practice led to both a public and a professional policy response.

In other cases, public-policy initiatives have sought to increase the use of a practice generally deemed desirable. For example, the U.S. Patient Self-Determination Act of 1991 was intended to increase the use and effectiveness of advance directives by requiring institutions receiving federal funds both to inform patients at admission of their rights under state law to use advance directives, and to have policies in place for implementing them.

Public policy regarding life-sustaining treatment and the care of the dying reflects as well as any issue the mutual interaction and development of bioethics scholarship and public policy. The Karen Ann Quinlan case first focused public attention in the United States on issues of life-sustaining treatment. In the landmark *Quinlan* ruling in 1976, the New Jersey Supreme Court held that an incompetent patient retained a right to refuse life-sustaining medical care, a right that could be exercised by a surrogate, in this case a parent, acting for the patient. The next fifteen years were filled with intense activity on these issues in both the public-policy and scholarly arenas of bioethics. In addition to books on the topic, many articles appeared in bioethics journals such as the *Hastings Center Report* and in medical journals such as the *New England Journal of Medicine;* at the same time, state courts around the country were addressing many legal cases concerned with life-sustaining treatment and the care of the dying. Other public-policy bodies issued extensive studies, such as the President's Commission's report *Deciding to Forego Life-Sustaining Treatment* (1983a), and briefer policy statements on the subject came from professional bodies such as the American Medical Association (AMA). The President's Commission's report drew explicitly on a wide range of bioethics scholarly work on life-sustaining treatment decisions, as well as on closely related legal scholarship and healthcare research. Court decisions frequently appealed not only to legal scholarship but also to the growing bioethics literature.

The bioethics literature on life-sustaining treatment issues was influenced by these court cases in two important ways. First, the attention many of these legal cases received served as a relatively direct stimulus for much bioethics commentary and analysis of the arguments made in the opinions. Because there was generally little specific statutory law constraining the judicial rulings, they often appealed in part to explicitly ethical arguments. Second, and at a deeper level, the President's Commission's report and many legal decisions greatly influenced debates on life-sustaining treatment and played a major role in the degree and nature of the consensus that emerged during the 1980s. This was true especially for specific issues such as the moral importance of differences between stopping and not starting life-sustaining treatment and between ordinary and extraordinary treatment, as well as on broader issues such as the nature and importance of the moral values of individual autonomy and well-being in guiding life-sustaining treatment decisions. The issue of forgoing life-sustaining nutrition and hydration is a particularly good illustration. Here, the debate in the bioethics literature began, not coincidentally, at about the same time that nutrition and hydration cases were being brought to a number of courts. Because the bioethics literature and the court decisions are best understood as profoundly interdependent parts of a single debate on which significant consensus was emerging, the bioethics literature and the court decisions were unlikely to veer in sharply conflicting directions on the permissibility of forgoing nutrition and hydration.

From its inception, bioethics has had a micro focus, especially on individual doctor–patient issues, and a macro focus on ethical issues in health policy, especially justice in healthcare. The micro issues were predominant in bioethics during the 1970s and much of the 1980s, and will, no doubt, continue to be important. But as health-policy debates in the United States focus on access to healthcare, containment of healthcare costs, and rationing of healthcare, the macro focus of bioethics is likely to become increasingly prominent. On these macroethical issues in health policy, the profound interaction of bioethics and public policy is even more evident. Unlike many doctor–patient issues, which could to a significant extent be worked out between individual doctors and patients, questions of justice in healthcare can be adequately addressed only at an institutional and policy level. Bioethics scholarship on these questions of justice that hopes to influence public policy and practice must address questions about the design of social, political, and professional institutions and practices. These are public-policy issues at their very core, which means that more profound mutual influences between bioethics and public policy can be expected in the future.

The Role of Public Policymaking Bodies in Bioethics: U.S. Commissions and Efforts

In the United States and throughout much of the rest of the world, public policy bodies have been established in bioethics to study and issue reports on bioethics issues. These public commissions have varied considerably in their nature, roles, and effectiveness.

THE NATIONAL COMMISSION. In 1974 the U.S. Congress established the U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (hereafter National Commission). Two important factors led to the creation of this first public, national body to shape bioethics thinking and practice in the United States.

First, the character of biomedical research had changed significantly in the preceding three decades. Before World War II, such research was carried out largely in small-scale therapeutic settings in which researchers tended to be well known to and trusted by their patients/subjects and the surrounding community. During and following the war, however, the scale of this research expanded greatly as public expectations about the potential benefits of medical research grew. Biomedical researchers increasingly were distinct from clinicians caring for patients, and the unknown investigator replaced the well-known and trusted clinician.

Second, public concern with research abuses had increased. The shocking abuses of human subjects by Nazi doctors during World War II had earlier drawn public attention to these issues. In 1966 a member of the faculty of Harvard Medical School, Henry K. Beecher, published an article in the *New England Journal of Medicine,* detailing twenty-three instances of published research in which the treatment of human subjects was at best ethically problematic. Around the same time some especially egregious cases of research abuse received wide public attention, such as the Tuskegee Syphilis Study, in which African-American men infected with syphilis were left untreated in order to study the natural course of the disease.

The National Commission's work has shaped law, federal regulatory oversight, and institutional oversight of research practice. The National Commission consisted of eleven commissioners and a professional staff. The commission held public hearings, sponsored a wide range of studies and scholarly papers, and eventually issued reports on the use of different groups of human subjects—children, prisoners, the mentally infirm, and fetuses—in research. The legislation establishing the National Commission required the secretary of the U.S. Department of Health, Education, and Welfare (forerunner of the Department of Health and Human Services) to implement the National Commission's recommendations or offer a public justification for not doing so. In some cases, the commission's reports led to the virtual elimination of research with particular classes of subjects, such as prisoners, whereas in other cases, they led to the development of special rules for the involvement of particular classes of subjects, such as children. The final report of the National Commission—the *Belmont Report* (1978a)—had a great impact on bioethics because it addressed the moral principles that underlay the various reports on particular aspects of research. Here, the principles of respect for persons, beneficence, and justice were enunciated; these same principles later figured prominently in Tom L. Beauchamp and James F. Childress's *Principles of Biomedical Ethics* (first published in 1979), probably the most widely read and influential scholarly work in bioethics.

The National Commission stressed the moral principle of respect for persons and the implications of this principle: that subjects should be enrolled in research only with their free and informed consent and with their confidentiality properly protected. The work of the National Commission continues to form the ethical basis for the federal government's regulatory oversight of research involving the use of human subjects, carried out by the Office for Human Research Protections within the Department of Health and Human Services (HHS).

THE PRESIDENT'S COMMISSION. When the National Commission concluded its work in 1979, the Congress established the President's Commission with a substantially broader mandate. During the four years of its existence, this commission issued ten book-length reports on a wide variety of topics in bioethics, including the definition of death, the compensation of injured research subjects, genetic screening and counseling, genetic engineering, informed consent in medical treatment, decisions about life-sustaining treatment, access to healthcare, whistle-blowing in research, and protection of research subjects. Like the National Commission, the President's Commission had public commissioners and a full-time professional staff representing a wide variety of academic disciplines.

Because of the diverse nature of the topics addressed by the President's Commission, its reports had different kinds of impacts on bioethics. For example, *Defining Death* (1981) contributed to the adoption of a uniform brain-death standard for death by the great majority of the states; here, the impact was a relatively discrete piece of legislation. On the other hand, the report on informed consent, *Making Health Care Decisions* (1982), had a more diffuse, though no less important, impact in advancing the ideal that physicians and patients share decisions about treatment; here, medical education and the professional ethos for physician–patient relations were affected. *Securing Access to Health Care* (1983b) focused on the ethical problems represented by the more than 20 million Americans who were without health insurance. This report had relatively less immediate impact than many others because massive government expenditures were necessary to solve the problem at a time when the political ideology of the new presidential administration was to reduce, not expand, government social programs. Ten years after it was issued, however, it was clear that this report contributed to the public and political recognition in the United States of the ethical problem of access to healthcare and to understanding the ethical case for government action.

Deciding to Forego Life-Sustaining Treatment (1983a) was almost certainly the commission's most influential report, for several reasons. Following the *Quinlan* decision in 1976, both public and professional attention to this area steadily increased. In addition, new and more widely disseminated life-sustaining medical technology meant that both professionals and the public had had more personal experience with these difficult decisions; individual professionals, healthcare institutions, and the public were uncertain about what was ethically acceptable and desirable practice in this area. Finally, implementation of the commission's recommendations did not require major new government expenditures. The commission's recommendations centered on patients' or their surrogates' rights to weigh the benefits and burdens of any available treatment, including the alternative of no treatment, according to the patient's values, and to accept or refuse treatment. The report criticized and offered alternative language for some distinctions that until then had had an important influence on the bioethics literature and on practice, such as the differences between not starting and stopping a life-sustaining treatment and between ordinary and extraordinary treatment.

The report filled a vacuum: Hospitals, courts, and others sorely needed guidance about ethically acceptable practice. The fact that this report, like the others, was issued by a presidential commission gave its recommendations an unmatched authoritativeness.

NATIONAL BIOETHICS ADVISORY COMMISSION. After a lengthy hiatus in which the United States lacked any national bioethics commission, in 1996 President Bill Clinton established the National Bioethics Advisory Commission (NBAC). Its initial work plan was interrupted by the cloning of the sheep Dolly and the president's request for a report within ninety days on the ethical, social, and legal issues of cloning. This illustrates one role that public commissions sometimes play: responding in a rapid, but measured and reasoned, way to developments in biotechnology that raise serious ethical concerns. The commission recommended that there be a moratorium on any reproductive cloning, largely based on concerns about safety, to allow time for a public debate and a later revisiting of the issue.

A later report of NBAC addressed a different but related issue—embryonic stem cell research. This was another instance of using a public commission to address an extremely controversial issue in the hopes of achieving a more reasoned debate of the issues and a position that might gain some consensus among parties with widely differing views. One focus of the NBAC report was whether federal funding of this research should be permitted. The commission sought a compromise position by making a distinction in the sources of the stem cells and recommended permitting that funding when the cells were derived from cadaveric tissue or from embryos left over from in vitro fertilization (IVF), but rejected funding of research using cells derived from embryos created for the purposes of research by IVF or by means of somatic cell nuclear transfer. While some found the compromise position appealing, it failed to create any consensus that could guide public policy, in particular on public funding of this research. It was another illustration, along with an earlier fetal tissue study and a failed attempt to establish a national bioethics commission in the late 1980s that foundered on disputes about abortion, of the difficulty of using public commissions to address deeply controversial issues, especially in the United States those that involve the moral status of embryos and fetuses.

As had the earlier U.S. public commissions, NBAC also produced several reports on ethical issues in research, including research with mentally impaired subjects, research in developing countries, and a study of the overall regulatory process of research. This work reflected continuing concern with protecting human subjects in research as well as new concerns such as the potential for exploitation of subjects in the increasingly common research being done in developing countries by investigators from the developed world.

PRESIDENT'S COUNCIL ON BIOETHICS. The charter of NBAC expired in October 2001, and in November 2001 President George W. Bush appointed the President's Council on Bioethics. Through early 2003, the council had produced only one report, *Human Cloning and Human Dignity: An Ethical Inquiry* (2002), which featured special attention to the stem cell research debate. Interestingly, in the case of therapeutic cloning and stem cell research, the council was charged to advise the president on an issue on which he had already taken a formal position, which illustrates the political tensions that these public bodies can sometimes face. There was also considerable controversy about whether the membership of the council was overly slanted in a particular political and ideological direction.

OTHER PUBLIC OR QUASI-PUBLIC BODIES. In the United States, besides the national bioethics commissions, a number of other public or quasi-public bodies have also have entered these frays. Several states, including New Jersey and New York, established bioethics commissions. In addition, many government bodies and commissions with a broader medical or health policy agenda have had one or more bioethicists among their members and have included bioethics issues as a part of their broader concerns. For example, the Task Force on Organ Transplantation of the HHS addressed ethical issues in the procurement and distribution of scarce organs for transplantation, although the ethical issues were not the main focus of its work. The Institute of Medicine within the National Academy of Sciences has done many studies on and issued reports concerning a wide array of bioethics issues as well as broader health and public policy issues that have bioethical components. Furthermore, many other government organizations and studies whose main focus is not ethical issues typically now include some discussion of the ethical aspects of their work.

A striking example of the extent to which bioethics in the United States has become an accepted part of the public realm is the Human Genome Project. This $15 billion, fifteen-year project to map and sequence the complete human genome or genetic code gave the ethical implications of government-sponsored research an unprecedented role. At the time the project was being debated in Congress, there was considerable concern about its ethical, social, and legal ramifications. James Watson, the first director of the National Center for Human Genome Research (now known as the National Human Genome Research Institute) at the National Institutes of Health, committed the center to spending at least 3 percent of its total budget on research into and public and professional education concerning these legal and bioethical issues, and in fact it has ended up spending more. The genome project's Ethical, Legal and Social Implications (ELSI) Research Program has supported a wide range of studies and projects aimed at the general public as well as the academic, research, and public-policy communities.

A last important manifestation of public-policy bodies in bioethics in the United States has been the formation of grassroots citizen groups in a number of states to address bioethics issues. Such groups have often treated issues of health policy, especially how to set priorities among healthcare services with a view to allocating limited funds in government health insurance programs, such as Medicaid. The widely publicized prioritization of healthcare services in the state Medicaid program in Oregon made use of such citizen groups.

International Activity

The United States is hardly alone in turning to government bodies to address issues of bioethics. Indeed, while the United States had no national government bioethics commissions between 1983 and 1996, countries throughout the world established them during and after this period. Nearly every country in northern and western Europe, as well as a number of eastern European countries, now has a national bioethics commission. Such commissions also exist in a number of countries in the Americas and in Asia and Oceania.

These national bioethics commissions have varied greatly—in their form and membership, in the scope of issues addressed, and in their general effectiveness. For example, the Danish Council of Ethics, established by the Danish Parliament in 1988, has followed a populist model, with largely lay members, and has pursued broad educational efforts. In France, the National Consultative Ethics Committee for Health and Life Sciences has followed a more elite model with scholarly and professional members, high public and professional prestige, and more direct attempts to determine government policy. In Great Britain, government-sponsored groups have addressed ethical policy issues in reports comparable in scope and detail with those of the U.S. commissions. The Nuffield Council on Bioethics in Great Britain has established expert panels that have produced major reports of high quality on a wide range of subjects including genetic screening, use of human tissue, mental disorders and genetics, genetically modified crops, stem cell therapy, research in developing countries, patenting DNA, and behavior genetics.

Although there is no international bioethics commission as such, both the United Nations (U.N.), through two of its agencies, and the Council of Europe have created bodies that have been active in bioethics. UNESCO has an International Bioethics Committee that has addressed many bioethics issues and that developed the Universal Declaration on the Human Genome and Human Rights (1997), following up the earlier general U.N. Universal Declaration of Human Rights. The World Health Organization has been active on such issues as resource allocation and genetics, with special emphasis on developing countries. In 1982 the International Association of Bioethics was formed to foster international interchange among scholars and practitioners in bioethics. Most non-U.S. efforts, however, have been at a national level so that they can reflect a particular society's historical, political, legal, and cultural traditions.

Membership and Authority Issues

The use of governmental bodies to address public policy in bioethics raises political and ethical questions of membership, function, decision-making methods, and the authority of their recommendations. With regard to membership, there has often been an attempt to balance two concerns: first, that members have relevant expertise on the issues the body will address and that the body be representative of the relevant professions and disciplines; second, that members represent their communities in such areas as gender, minority status, and political affiliation. Statutes establishing these bodies often mandate the areas from which members must be drawn.

The membership question is related to the proper function of these bodies and the authority of their recommendations. If these bodies were to provide only the highest-level expertise on the issues of concern, the case for representativeness would be weak, though even then the question of who had expertise in bioethics, and the nature of their expertise, would be more contentious than in most areas of scientific medicine. That has not generally been their sole function, however. They have been viewed as combining such expertise with the role of addressing what public policy should be in a particular area. This latter role is by its very nature a more political role, requiring representation of groups that have a substantial stake or interest in the policy question at issue, both on ethical grounds and because the group's recommendations must be able to be "sold" in the political arena.

The difficulty of using governmental bodies to address deeply divisive ethical and political issues is illustrated in the United States by the task force established to address the use of fetal tissue in research. Its recommendations to permit limited use of fetal tissue essentially were ignored in the late 1980s by the first Bush administration because the use of fetal tissue was so closely related to the politically contentious issue of abortion. "Right to life" groups feared any use of fetal tissue could increase or appear to condone abortions. The attempt by the U.S. Congress in the late 1980s to establish a biomedical ethics advisory committee to its Biomedical Ethics Board also failed in large part because of political struggles over abortion.

Representativeness in membership is desirable to ensure that concerns and points of view of significant groups are taken account of for pragmatic reasons, so those groups will support instead of block acceptance and implementation of the recommendations, and for ethical reasons, so those most affected by the recommended policies have some input into what the policies will be. At the same time, powerful professional groups, such as physicians, as well as corporate interests, such as pharmaceutical firms, often have a substantial stake in the policy outcomes. When those interest groups have important or dominant roles within bioethics commissions, they can shape and control the debates, the policy alternatives considered, and the recommendations that emerge. Thus, in the membership of public-policy bioethics bodies, as well as in the policy process more broadly, representation for affected groups must be balanced with preventing powerful professional groups from controlling and distorting the policy process.

For several reasons, the authority of the recommendations of these public-policy bioethics bodies is more problematic than those of analogous scientific bodies. First, the nature and even the existence of expertise in ethics generally, and bioethics in particular, is contested to a greater extent than in scientific medicine. Many people believe that ethical claims express attitudes or feelings and cannot be shown in principle, much less in practice, to be true or false in the manner that claims about empirical matters of fact can be. By contrast, a consensus conference on the appropriate treatment of pulmonary hypertension or breast cancer may be controversial and involve ethical or value issues, but it is usually thought that expertise in the medical aspects of these treatment issues is not problematic to the extent that bioethics expertise is.

Second, appeals to authority are widely acknowledged to be out of place in ethical reasoning—it is the strength of the arguments, not who makes them, that should be persuasive. Because public bodies such as the President's Commission or NBAC typically lack any enforcement powers for their recommendations, their impact ultimately should, and does, lie in their ability to persuade others who do have the authority to pass legislation, render court decisions, and make institutional policies, of the wisdom of their recommendations. This has led many such bodies to see their task as articulating and advancing an emerging consensus on the issues addressed. The President's Commission put great efforts into reaching consensus and had only one dissent, from a single commissioner, in all of its reports. Moreover, all such bodies will give some weight to arriving at consensus, and as in the more overtly political process, reaching consensus sometimes requires that ethically problematic but politically necessary compromises be made, especially regarding policy recommendations.

Some would argue that the main purpose of such bodies is to sharply delineate the ethical issues, conflicts, and choices. The President's Council for Bioethics, for example, sees its role as providing a deep exploration and delineation of the issues, but not blurring or sidestepping them in the interests of compromise and consensus. Pragmatic or political compromise, according to this view, should be left to the overtly political process. In this way the ethics body can speak more unequivocally to the ethical issues and not compromise or cut and trim the ethical arguments where it is politically expedient to do so. On the other hand, this approach may make the body less effective than it might otherwise be in influencing policy.

Another issue that has received some attention concerning these public bodies is the methodology they do or should employ in their deliberations and in arriving at policy positions. In their 1988 book, *The Abuse of Casuistry,* Albert R. Jonsen and Stephen E. Toulmin argued that when members of the National Commission addressed concrete cases, they were generally able to arrive at consensus, even when they disagreed strongly on the more general moral principles or theories that underlay their consensus. Jonsen and Toulmin contrasted the experience of the National Commission with what is sometimes called principlism, in which bioethics, and applied or practical ethics more generally, are seen as beginning with moral principles or theories that are applied in a relatively mechanical, deductive fashion to particular cases or policy choices.

Because providing justification for concrete moral judgments involves appeal to moral principles or reasons of often substantial generality, public-policy bodies such as bioethics commissions should, and in fact often do, work back and forth between concrete cases and more general moral principles. The aim should be to develop a position on the particular ethical and policy issue that is backed by the most plausible, coherent reasons. This can often be a great challenge when political pressures to reach a publicly acceptable compromise conflict with the policy backed by the best ethical reasons.

Conclusion

Bioethics issues have come to receive prominent attention in public policy, and bioethics scholarship has strongly influenced public policy in healthcare. At the same time, public policy in the form of legal decisions and public-policy bodies deeply influenced the development of both the field and scholarship of bioethics during the last decades of the twentieth century. As bioethics comes to focus more on broader issues of health policy in coming years, this mutual interaction and influence between public policy and bioethics can only be expected to increase.

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SEE ALSO: *Communitarianism and Bioethics; Consensus, Role and Authority of; Death, Definition and Determination of; Embryo and Fetus, Embryonic Stem Cell Research; Environmental Policy and Law; Ethics, Social and Political Theories; Fertility Control, Legal and Regulatory Issues; Health Policy in International Perspective; Health Policy in the United States; Informed Consent; Injury and Injury Control; Law and Bioethics; Law and Morality; Maternal-Fetal Relationship: Legal and Regulatory Issues; Medical Ethics, History of the Americas: United States in the Twentieth Century; Organ and Tissue Procurement; Patients' Rights; Privacy in Healthcare; Public Health Law; Research Policy; Social Medicine*

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RACE AND RACISM

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In the biomedical sciences of the United States and in their wider cultural context, ideas about race and gender play a prominent but unacknowledged role. Despite their apparent universality, these concepts vary over time and place. Different beliefs about them and their social consequences are found across cultures past and present. Both are, in fact, cultural constructions, one or another culture's folk theories of human biological variation. The great variability found in racial and gender notions is indicative of their local cultural construction.

Biological and behavioral assertions concerning race are without empirical validity. After decades of research, largely in anthropology, the social and cultural bases of racial conceptions have become clear (American Anthropological Association; American Association of Physical Anthropologists). Race is a folk-culture concept. While many, perhaps most, cultures of the world do not hold racial theories, such theories are important to consider in discussions of biomedicine and biomedical ethics, especially in the United States. Here, we find that admittedly folk ideas of race and ethnicity serve as the formal basis for government practice, policy and research (Office of Management and Budget). Given the demonstrable negative social, psychological, and health results of the perpetuation of the invidious distinctions represented by racial (and gender) conceptions, and the antipathy generated by their stereotypes, the continued use of such identities in biomedical work can be said to represent serious ethical, as well as biomedical research, problems.

Historical Constructions of Race

Race is one of a number of popular cultural conceptions about human variability. The Western concept was developed in its present scientific and related lay versions largely in the nineteenth century (Barkan; Gossett; Naroll and Naroll; Stocking). At its most abstract level, race is an explanation for observed human variation; people differ in appearance because they belong to different races. Behavior is also implicated; people behave differently because they belong to different races. Racism is a set of negative beliefs held by individuals or groups with respect to a population thought to be biologically distinct. Such beliefs about fundamental biological differences came late to the Western world, but not as a result of scientific progress.

The ancients—whether the civilizations of Nubia and Egypt or the later Minoan, Mesopotamian, Greek, and Roman civilizations—held no beliefs about essential human biological or racial differences. There was recognition that people differed in appearance, language, custom, and even ethics (MacIntyre), but such differences were not considered reflections of immutable, biological differences among humans. Nor could there have existed assertions that biology determined behavior, for most of these civilizations were composed of a variety of physical and cultural types in various stages of assimilation to a titular ethnic identity (e.g., Sherwin-White). Were this not the case, the ancient empires could not have expanded their numbers through the recruitment of physically and culturally different peoples, for they would have thought them fundamentally different and nonassimilable.

An important step in the development of the notion of race is to be found in the work of the Swedish botanist and taxonomist Carolus Linnaeus (1707–1778). Linnaeus built upon earlier notions of *species,* distinct groups of living things that cannot interbreed. Linnaeus proposed a classification comprising six human *groups*; he did not use the term *race.* These human groups were understood as neither pure nor (biologically) stable; they were not represented as distinct species. Such an assertion would have been contradicted at the time by considerable evidence of interbreeding of Europeans and other groups. Such empirical evidence was later ignored in the West.

The French naturalist and founder of invertebrate paleontology George Louis Buffon (1707–1788) introduced the term *race* into the biological literature in 1749. The term then did not refer to distinct human groups with separate origins or biologies (Montagu). Buffon's and Linnaeus's early reflections on human difference regarded such differences, correctly, as representing variations of a single species.

In the eighteenth and nineteenth centuries, English and German philosophy and science began the construction of ideas of fundamental, incommensurate biological differences dividing human groups (Barkan; Boas; Gould). While evolutionist views of monogenesis (a theory of a single origin of all humans) replaced polygenesis (a theory of multiple, separate origins) and creationist views (those based on religious beliefs and not on investigations of the natural world) in Europe, nineteenth-century theories were largely alike in expressing racist sentiments, though the sentiments were not recognized as such. Triumphant nineteenth-century evolutionism fitted well in racist science.

Monogenecists assigned to non-Europeans fates of early separation from a "main" line of Europeans. JeanBaptiste Lamarck (1744–1829) suggested that differences among human groups around the world were to be attributed to the inheritance of acquired characteristics. He implicated the role of the environment in evolutionary change, although he misconstrued the mechanism of biological change.

Non-Europeans, and many eastern and southern Europeans, were believed to have a common origin by many western European scholars, but were seen as less evolved. Some were said to be little different than nonhuman primates (Barkan; Stocking). And some ethnic groups of western Europe created racial alliances. English historians of the nineteenth century repeatedly referred to the "rational and freedom-loving" character of the English as racial traits of the Anglo-Saxon, believed to be a branch of the "German race" (Gossett). As with the Nazi *race science* of the next century, the notion of the German race excluded most people commonly regarded in the United States as belonging to a "white race" (e.g., the French and other circum-Mediterranean people, Celtic ethnics, the Slavic people) as well as people from what are commonly regarded as other "races" in U.S. ideology—Asians, Africans, and Native Americans.

In England, Sir Francis Galton (1822–1911), the father of statistical manipulation, lent both ideas and methods to racial theories. He coined the term *eugenics,* and conceived of this new "science" as a program of "racial" improvement. The idea of group biological improvement was carried to horrendous extremes by Nazi "hygienists." Galton's work on head size and intelligence lent credence to later racist work in the United States as well, such as that of physician Robert Bean of Virginia. His work, in 1906, purportedly showed that parts of the brain were of different sizes in "Whites and Negroes" (in Gould). He also claimed to have found measurable differences in males and females and between higher and lower classes. His interpretations and biased readings, soon disproved (Gould), showed the affinity of the ideas of racism, sexism, and elitism in the United States that are also apparent in English science.

Sir Cyril Burt, dean of twentieth-century educational psychology in England, studied twins during the first half of the twentieth century. He purported to show that twins raised apart had the same IQ. It appears he sought scientific proof for the English folk notion that nature determined human abilities such as intelligence. As a consequence, his views were widely received for decades and influenced the establishment of national examinations. The examinations were used to limit the educational opportunities of millions of young people in Britain. In the 1970s, it was discovered that the late scientist had, in fact, fabricated most of his data. He had also fabricated his long-time research assistants, who supposedly collected most of the data, as well as his coauthors (Gould). The advocates of nature over nurture suffered a heavy blow when this key body of literature was discredited.

In the United States, a multicultural society usually referred to as *multiracial,* Burt's elitist arguments were converted to racist (and sexist) theories by his students, psychologists such as Hans Jurgen Eysenck and Jensen (Gould), as well as others (Fausto-Sterling). Research aimed at showing that African-Americans and other "minorities" were intrinsically less intelligent than the generic "White race." Within each group, moreover, women were said to be less capable than men. Many flaws appear in this sort of research. One of the major problems is the fact that social labels, such as White and Black, were used to make genetic arguments; the arguments were flimsy because they regularly excluded from consideration profound differences in the social and educational experience of the members of the various social categories. This was done in order to arrive at (prejudged) conclusions of inborn racial differences.

A similar idea concerning mental illness was developed in German psychiatry in the mid-1800s. The leader of nineteenth-century German psychiatry, Wilhelm Griesinger, adopted a biological definition of mental disorders. His dictum was that "mind diseases are brain diseases" (Gilman). The idea that mental illness was based in biology and not social environment was actually borrowed from German philosophy, which in turn had taken the idea from popular German culture. Griesinger passed on this popular prejudice in his psychiatric science to a follower, Emile Kraepelin. Kraepelin became the twentieth century's father of biological psychiatry and the creator of a racially based "comparative psychiatry" (Gaines, 1992a; Gilman). This influential figure made the case for the biological basis of major mental diseases such as schizophrenia. His ideas were greatly influential on Nazi and contemporary U.S. biological psychiatry (Barkan; Gaines, 1992c; Gilman).

The Nazi "race science" of the 1930s reverted to nineteenth-century polygenesis to explain differences among racial groups and to assert its group's alleged superiority (Montagu). Some Germans were likewise seen as unfit; they were the disabled, the mentally ill, and the homosexual. In contemporary German society, popular and medical beliefs still express the model of mental illness that considers the mentally ill to be biologically different from "normal" people (Townsend).

As is evident, both English and German cultures exhibit biological theories of human difference. A brief historical look suggests that the ideas of these two cultures are related. In both systems, differences are held to be intrinsic and groups are hierarchically ranked, allegedly in terms of abilities. In the relatively isolated society of England, the Germanic notion of inherent differences and similarities based upon shared "blood" was doubtless introduced by invading Germanic tribes in the fifth century. The idea remained but was applied to internal social differences within England. This focus transformed the theory of difference based upon blood into the English notion of "breeding" that was and is applied to members of the British (which includes the Celtic peoples) social system. It produced Britain's rigid class systems wherein abilities are said to be differentially inherited by those differing in breeding. This conception of inborn qualities then serves to justify the respective social positions of society's members.

The Critique of Scientific Racism

Evolutionists explained the increasing knowledge of human diversity in biological terms (Barkan; Gossett). The allegedly different developmental levels of various societies were said to indicate inferior inborn abilities in the societies' people compared with the usual apex of evolution found in (western) Europe. Eastern Europe, not a direct heir to the Renaissance, has been considered marginal in much of western European thought and totally alien and inferior in Germanic thought. History tells us, however, that Europe was the last of the world's areas to develop the hallmarks of civilization, hallmarks largely borrowed from others who were later alleged to be less evolved than (western) Europeans.

ANTHROPOLOGICAL ARGUMENTS. Racist evolutionist ideas, and many not evolutionist, permeated much of medicine, psychology, biology, and other sciences in Europe and the United States at the beginning of the twentieth century. Among the first to lead a concentrated and protracted attack on scientific racism was Franz Boas (1858–1942). A German immigrant, Boas was the foremost anthropologist of his time and the founder of U.S. anthropology. Among many other things, Boas's research demonstrated the plasticity of the human form and the overlap in measurements (anthropometry) of anatomical features previously asserted to be unique to specific racial groups. These findings flatly contradicted the conceptions of races as stable, unchanging, and distinct physical types. Time has continued to enhance our understanding of the enormous plasticity of human biology, a biology so changeable that it has produced all the variations in the human form found in the world in less than 180,000 years.

Boas himself demonstrated how rapidly biology can change, as well as the nonempirical basis of racial differences, by showing that very different anthropometric readings could be obtained from the children of immigrants to the United States when compared with their parents. The cause was the change in environmental factors, especially nutrition. These measurements indicated, according to the current, specific racial measurement norms, that people in the same family appeared to belong to completely different racial groups (Boas).

Boas also advanced fatal arguments against notions of the relatedness of race to behavior. He showed that so-called races did not exhibit distinct religious, linguistic, or general cultural patterns. People of a variety of races spoke the same language and practiced the same religion. And members of the same race spoke different languages, held different religious beliefs, and otherwise exhibited distinct cultures. Race could not be shown to determine even major forms of human behavior (Boas; Stocking). Many of the positions advanced by Boas remain the most powerful antiracist arguments. It is remarkable that he began his assault on scientific racism before 1910, a time when blatantly racist statements were common in science and in the White House (see Brandt, 1985).

Evolutionary schemes were soon generally recognized as based on biased conjecture. There were no empirical bases for the evolutionary stages of Karl Marx, Herbert Spencer, Edward Tylor, or any of the other evolutionary theorists. Boas replaced evolutionist theorizing with the study of the historical diffusion of cultural traits. Historical diffusionism based its arguments on empirical evidence from all the branches of anthropology, physical anthropology, linguistics, archaeology, and sociocultural anthropology as well as from history. Such evidence was used to demonstrate that the current cultural (or physical) features or organization of any group were a result of contact and borrowing from other groups it had encountered. Of less influence in cultural change were innovation and creativity. Cultural arrangements, then, had more to do with a particular history of contact than with innate abilities related to alleged evolutionary stages. This understanding replaced a notion of the evolution of a single human general culture with an understanding of particular cultures' histories.

Evolutionists rank people and cultures from low to high, worst to best. Implicit in evolutionist thinking is the idea of progress, the idea that things are changing for the better. Evolution and progress are unrelated in fact and must be kept separate. Evolutionary change is simply descent with modification; there is no implication of improvement or superiority of later social or biological forms over earlier ones.

But evolutionists depicted some groups, such as Africans, as being near the apes because the groups were perceived as different. They were said to resemble nonhuman primates, such as chimpanzees and apes, who were described as having thick lips, curly hair, and dark skin. This representation has persisted despite the fact that nonhuman primates actually have straight hair covering their rather white skin and are totally lacking lips. That is, nonhuman primates exhibit precisely the characteristics claimed by Europeans as indicative of their own racial superiority.

While racism is still common, though less so than earlier in the twentieth century in the United States, evolutionist notions containing the idea of progress persist. A counter to these ideas is one of Boas's most enduring contributions: his articulation of the notion of *cultural relativism,* which is not a theory but a descriptive reaction to wide experience with other cultures. While evolutionists ranked people and cultures, anthropologists after Boas came to see them in relative terms; cultures were not better or worse than one another, they were simply different. One could not judge a culture using values from another; cultures must be evaluated using internal, not external, criteria. Relativism has become a central tenet of anthropology, the science of culture.

Biomedical sciences often evidence not the relativism of Boas but the hierarchical evaluative thinking indicative of evolutionism. An implicit ranking system appeared in medicine and persists in notions of defects afflicting groups of people. Historians of medicine show that this idea was disseminated by medicine's association of specific illness states with specific ethnic groups (called races) and/or genders (Chesler; Gilman; Pernick). This was but one of many techniques for the pathologization of often fictitious differences.

Difference from an implicit standard, that is, Anglo, male, adult (Gaines, 1992a; Gilman), in medical and psychiatric thought has been represented as problematic, dangerous, exceptional, pathological, defective, weak, vulnerable, and/or requiring "special" treatment (Gaines, 1992a; Osborne and Feit). Ultimately, the idea communicated is that culturally defined "others"—in the United States, non-European ethnics, women, and children—are simply, and inherently, "not normal" (Ehrenreich and English; Gilman).

One significant problem with the theories about natural racial groups is the fact that the precise number of them has never been agreed upon. Throughout the last century and a half, enumerations of groups said to constitute races fluctuated from author to author. Indeed, the number of racial groups is still changing. A recent example is the creation, starting in the early 1980s, of a Hispanic race.

The dynamics of the numbers of races should not be surprising given that the boundaries created to distinguish among the various groups have no empirical bases. Such discriminations are everywhere the arbitrary choice of an author (Gould; UNESCO; Stocking). The lack of fixed criteria for differentiation is reflected in the changes over time in racial labels of individuals in modern health statistical records (Hahn), in local and personal history (Domínguez), and in the ever-changing number of races, a number that varies somewhere between one race and three hundred. The correct number is one.

THE HETEROGENEITY OF RACE. Analyses of biogenetic differences of human groups lead to the recognition of a great variety of characteristics, most of which are shared in various proportions. Local configurations of traits (height, color, etc.) produce a huge number of distinguishable groups. On the African continent, there are about one thousand biologically distinguishable groups, as opposed to races

(Hiernaux). Human groups are not divisible into groups that exhibit unique, nonoverlapping physiological characteristics. Differences in biology are always local differences that are characteristic of a local inbreeding population. What is seen as normal human biology also changes from culture to culture (see Kuriyama, in Leslie and Young). Just as the cultural elements exhibited by individuals of ethnic groups vary, so does the biology of members of so-called races.

The central problem for racial classifications is that there exist no intrinsically significant human features. Cultures have selected specific features as worthy of concern and hence as criteria of inclusion or exclusion. The selection of any one trait—such as skin, hair, or eye color, body hair, height, weight, religion, or place of birth—as a criterion of group exclusion or inclusion is, by definition, arbitrary. The selected characteristics represent historical attributions of meaning in local cultural contexts, not the expression of universal human nature or physical characteristics.

Racial Theories in the United States

Most observers in the United States, whether lay or scientific, believe that observation of racial differences and racial antipathy has existed since time immemorial, being an understandable outcome of the encounter of dissimilar social groups. However, this is understandable only in a specific cultural context and is not an accurate rendering of the history of cultural contact.

The deleterious effect of racism on perception and cognition is obvious if the ancestry of U.S. racial groups is examined. Misrepresentations appear in scientific research as well as the popular media. The two—research and media—engage in a kind of cultural conversation that confirms the reality of race. An objective look at the ancestry of members of the major groups in the United States reveals race as a fatal conceptual problem in public health and medical research.

In the United States, most people labeled by self and others as Native Americans are biologically part European; in many cases, they are largely so. Many such individuals also have West African ancestry. Virtually all American "blacks," or African-Americans, are biologically part European. In many if not most cases, more of their ancestors came from Europe than from West Africa. Quite commonly, African-Americans also have Native American ancestry (Blu; Domínguez; Gaines, "Medical/Psychiatric Knowledge," in Gaines, 1992a; Hallowell; Naroll and Naroll; Watts).

All classificatory whites claiming multigenerational descent in the South can be shown to have West African ancestry and, very likely, Native American ancestry (Domínguez; Hallowell; Naroll and Naroll). This is not surprising since most of the colonists who settled in the U.S. South were single males. The relatively few unmarried females were generally of lower status and in long-term bond service. Without Native American and African women, European males in the South could not have had offspring. In the move westward into what was northern Mexico, where the Spanish had settled with Native Americans a century before the English came to the East Coast, one finds again that those "Americans" who went were primarily males from the South and the East. For this reason, the descendants of these early settlers in the West (settlers who were themselves illegal immigrants because this was northern Mexico) are today of mixed ancestry, although this is not publicly known.

Another distortion relates directly to Latinos, Mexicans, and other groups of "Hispanics." Latinos are descendants of western European, Native American, and West African peoples. This mixture is what the term *la raza* means: a "race" born of a mixture of elements. Because many Mexicans are actually Indians or partly so, the difference between Native Americans (many of whom are Spanish-speaking) and Hispanics is often only nationality, a matter of sociolegal definition and not biology. In other instances, Hispanics have no Native American ancestry but do have West African along with their western European ancestry. In many Latino groups (such as those of Venezuela and Puerto Rico), West African ancestry is virtually universal.

Despite the very definition of Latino as people of mixed cultural and biological ancestry, this language group has been homogenized in the scientific literature and, in the 1980s, became a discrete biological group, a "race" (Gaines, "Medical/Psychiatric Knowledge," in Gaines, 1992a; Hahn). In reality, the groups seen as discrete in the United States—white, African-American, Native American, and Latino—are not at all biologically distinct. Indeed, individuals in any of the categories may embody the same mixture of ancestors as do individuals in the others. The difference in the group to which one is assigned depends not on biology but on local context and social history. These groups represent social categories that are unstable and without common biogenetic content.

VARIABLE RACIAL CRITERIA. In considering the referents of the term *race,* no fixed criterion exists even within the United States. Many nonbiological criteria are used to identify races. The term is applied, for example, to people from a region or geographical direction, one usually designated from the perspective of Europe (e.g., Asians/Orientals). Another referent of this cultural term *race* is a specific continental location (e.g., African, [Native] American). A new basis for a racial group has also emerged quite recently—language. Hispanic, a new racial identity in the United States, may be attributed on the basis only of a surname; here language is biologized.

Putative skin color is commonly used as a marker of race, for example, white, red, black, brown, yellow. This use of color-as-race continues despite the fact that Asians run the gamut in complexion from white to black, as in southern India. The same range of skin color is found among people labeled black or white in the United States. The lack of real color "lines" produces cases of people who are black but look white or the reverse, as well as many other oddities. In such instances, it is social history (i.e., knowledge of ancestry) that produces assignment to an allegedly biological category.

A final criterion of race in the United States is religion. Judaism is employed to demarcate an allegedly biologically distinct group. But it is clear that Jews conform to the local physiological characteristics of the communities in which they reside (e.g., Germany, Poland, Russia, England, Scandinavia, Spain, France). The Jews in the United States represent a (fictional) biological group created by religious intolerance.

If a cultural approach has some predictive value, one can anticipate that the antipathy of U.S. people toward Arabs in the 1980s and 1990s will likely result in the social construction of yet another historically unknown race—Muslims. (The British have used the term *Wogs.*) Some indication of this process may be seen in the descriptions of the 1990s conflict in the former Yugoslavia. The U.S. media described the conflict as between "Muslims, Serbs, and Croats," although the Muslims were themselves either Serbs or Croats whose ancestors converted to Islam.

Because racism clearly influences cognition, perception, and affect (emotion), it could well appear in psychiatric classifications as a specific disorder. Rather than a condition of professional psychiatric concern, racism and its twin, sexism, instead appear as significant implicit elements in psychiatric (mis)diagnosis and (mis)treatment (Adebimpe; Chesler; Good).

The erroneous views of race found in the United States encode several distinct ideas: (1) a fixed number of distinct biological populations, or races, exist in nature; (2) races have distinctive physical, mental, and/or behavioral characteristics; (3) racial characteristics (physical and behavioral) are naturally reproduced over time; and (4) specific group characteristics—physical, mental, and often moral—are hierarchically ranked, that is, some groups are superior to others (Boas; Gould; Stocking; Montagu). These assumptions, however, are not the only extant racial views of human difference.

Cultural Systems of Racial Classification Beyond the United States

Some writers have argued that capitalism, with a need for cheap labor and for justifying expropriation of land and resources, provided the political context and motivation that drove science to create a defensible basis in biology for immoral acts such as slavery and genocide (Rex and Mason). Certainly, Europeans' encounters with Native Americans and imported West Africans affected their constructions of human difference (Gossett). However, it appears more likely that racial views are a form of *ethnobiology,* a cultural classificatory theory about the nature of human variability (Gaines, 1992a), because some racial ideologies predate capitalism. As well, various capitalist countries exhibit distinctive notions of race. Their differing views have resulted in very different treatment of those designated as belonging to different races.

RACE IN EUROPE. Both English and German science and society produced biological constructions of affinity and difference (Gaines, 1992a). Those who are alike share a common "blood" in Germany and "breeding" in England. Those of the same blood constitute a "race." This German belief is a kind of biological essentialism. It is a much more exclusive notion of race than that found in the United States. It is in reality a kind of ancient kinship theory, a theory of a coherent, related descent group (Gaines, 1992a) that later merged with evolutionist ideas. As such, it is much narrower than U.S. notions. In contemporary Germany, the cultural system of group membership based upon descent from a common ancestor continues. It determines social identity as well as citizenship and suitability to hold political office, for non-Germans cannot hold office or become citizens.

The same system of social classification is found in Alsace, the culturally Germanic northeastern province of France. The biological German system exists alongside a very different, French cultural system that determines ethnic identity by other means. It accords in-group identity to those sharing French civilization and culture. Membership is primarily based on language, not appearance or place of birth (Gaines, 1992a). The term *race* in France thus refers to people who share a particular language and civilization. Both can be acquired, but the latter only by means of the former. Anyone can become French; being French is a linguistic existential state, not a biological one as in the case of the German system.

The so-called racist groups of France may be seen as *culturalists*; their targets are not races but culturally distinct groups, such as unassimilated Muslims. French-speaking sub-Saharan Africans are not targets of the French racism.

North Africans have been historically white even though their complexions run the gamut from black to pale. The conflicts in France thus cannot be based upon race, though they are reported as such in the U.S. media where cultural differences are always interpreted as "racial differences."

RACE IN JAPAN AND SOUTH AFRICA. In Japan, a modern, industrial, and scientific society, a conception of human races exists that differs from that of the United States. Japanese sciences hold, and offer evidence to support, that the Japanese are a race distinct from Koreans, Chinese, the indigenous Ainu people, and the outcast Eta group (DeVos and Wagatsuma). In contrast, U.S. science and society hold that all these people from the East constitute a single biological race, along with South Asians, Indonesians, Filipinos, and others. These people do not evidence a common language, culture, or physical appearance, so the U.S. cultural system converts a geographical designation of people, borrowed from Europe, into an "Asian race."

In South Africa, there exists yet another system that classifies "racial groups." There, before the official collapse of apartheid, a sociolegal system was in place that distinguished four groups: Black, White, Asian, and Coloured. All people with ancestry in more than one of the first three groups were categorized as Coloured. Chinese were Asian, but Japanese were White. Each group historically has had different rights and privileges (see Schwartz, in Gaines, 1992a). All have equal status, at least legally, in the new South Africa.

In the United States, unlike South Africa, science and society ignore mixed ancestry and label individuals as wholly belonging to the least prestigious group of his or her parents, that is, to one exclusive category or another. In medical research, epidemiological studies, and clinical practice, people of mixed ancestry—that is, most Americans—are treated as if they had no ancestry except (West) African, Native American, Asian, or European. Designations are assumed to refer to homogeneous, distinct biological groups. If "admixture" is noted, researchers tend to ignore European ancestry and focus on genetic "vulnerabilities" deriving only from the subject's putative "minority" ancestry (Duster; Gaines, 1985; Wailoo).

In the United States, virtually all people called black or African-American, a term coined by anthropologist Melville Herskovits, would be classified in South Africa as Coloured because of their mixed ancestry (West African, western European, Native American). Indeed, all U.S. residents who claim long lines of U.S. antecedents would be likewise classified because they too have mixed ancestry. The same would hold true for most Native Americans and Latinos. Ironically then, the major U.S. racial groups, those with major antipathies and conflicts enduring over centuries based on their racial differences, all would be classified in South Africa as belonging to the same racial group—Coloured.

Race as a Key Variable in Biomedical Research and Practice

The ideas of race enumerated above underlie almost all medical and psychiatric research in the United States that pertains to group differences other than age or sex (Gaines, 1992a; Hahn; Robbins and Regier; Osborne and Feit). Remarkably, these beliefs concerning the existence or homogeneity of human populations called "races" have not the slightest scientific (or logical) basis; no empirical evidence has ever existed for the differentiation of humanity into broad racial groups (Gould; Montagu; UNESCO, 1969). In reality, thousands of biologically distinct human groups exist (Hiernaux, 1970; Montagu; Naroll and Naroll; Watts).

Assertions of the biological bases of differences among races are used to justify caste systems; that is, the results of oppression, discrimination, and poverty are commonly used to justify further discrimination and prejudice (Boas; DeVos and Wagatsuma; Naroll and Naroll; Thomas and Sillen). As is shown below, medical research, theory, and practice often play this same role in U.S. society and thereby serve as "scientific" justification for the persistence of popular conceptions of racial difference and of racism (Brandt, 1985; Gilman; Duster).

Racial groups are mental constructs. As mental constructs they cannot evidence medical conditions. Yet "one of the most common methodological blunders in scientific studies of the significance of racial differences in the United States is the tacit acceptance of this phantasmic notion of race as the basis for establishing research samples" (Harris, 1968, p. 264). Given this, it can be noted that a folk medicine, or *ethnomedicine,* is largely a creation of cultural beliefs. Its practices serve to reinforce and even justify those beliefs. Such is precisely the nature of medical research on group differences in the United States. This supportive role may be seen in research on afflictions said to appear only in certain populations.

THE MYTH OF RACE-SPECIFIC DISEASES. In biology or psychology, research science is used to reach conclusions that are in fact a priori assumptions; "prejudice not … documentation dictates conclusions" (Gould, p. 80). In today's medical and scientific community, expressed ideas concerning ethnic and gender inferiority are largely implicit.

They are replaced in the medical literature by vague assertions such as vulnerability, susceptibility, tendency, increased risk, and difference. One aspect of this discourse that constructs and maintains racial difference concerns "race-specific diseases." Since it is believed that races are distinct groups with their own biologies, it stands to reason that they would exhibit particular diseases. Sickle-cell anemia is a case in point.

At the beginning of the twentieth century, sickle-cell anemia was found originally through laboratory analysis of the blood of five patients—two European-Americans, two *mulattos* (in the parlance of the time, persons of mixed European and West African ancestry, but very largely the former), and one Negro (who doubtless was also part European). The findings were reported in the medical literature, however, as a condition found only in Negroes (Wailoo). In fact, this condition has existed in most world populations including the Mediterranean, Middle Eastern, Indian, Filipino, and South American. Instructively, the condition is not found among people in eastern, southern, or central Africa. Rather, it is found largely in West Africa, the ancestral area of most people in the Americas with African ancestry. Clearly, the condition is not a "racial disease" but rather a characteristic of some local populations.

Tay-Sachs disease is said to be a Jewish disease. In fact, it is a disorder found in a specific local population of the eastern Mediterranean from which some Jews, as well as Arabs, came. Jews not from this area, and not descended from people who were, have no risk of developing the disorder. The same is true of the so-called Portuguese disease, a degenerative, fatal neurological disease said to afflict Portuguese people. The afflicted are in reality descended from a single person (one Joseph) who carried the gene causing the disease. It is purely by chance that the antecedent person was Portuguese. Unrelated Portuguese are not at risk for developing the disease. In Tay-Sachs and the Portuguese diseases, specific sites of affliction are generalized to all in the racial category of the afflicted. "Local biologies" (Gaines, 1992a) are ignored in favor of "racial" ones.

The medical assertion that certain diseases are peculiar to specific races is without merit. The fiction is maintained through a number of techniques. Findings in a single person of a racial group are regularly generalized to all members of that putative group (Brandt, 1978; Wailoo); a part is made to stand for a whole. For example, a clinical finding that Indians in Britain required lower therapeutic levels of certain psychotropic medications became the basis for research comparing "Asians" and "Caucasians" (Lin et al., 1990; Lin et al., 1986; Mendoza et al.).

Tendencies discerned in research are commonly reinterpreted to suggest significant differences in research on hypertensive medications; "diuretics are best for 'blacks' and beta-blockers for 'whites.'" Since members in neither group have common ancestry in the United States, such stereotypes can limit diagnosis of problems to groups "known" to be afflicted; others are then overlooked, misdiagnosed, or considered to be exceptions. As such, they do not challenge the stereotype, though logically such exceptions should call into question the very notion of racial distinctiveness.

Despite the absence of any scientific basis, the idea of race represents the basic population variable, aside from age and sex, on which inquiries focus and in terms of which results are interpreted and recommendations made. The huge body of literature on race-specific problems and racial comparisons are actually of unknown scientific value, though they represent a rich corpus for cultural study.

As long as medical science continues in its archaic racial folk beliefs, its claims to objective, acultural, and disinterested status in the health field are seriously compromised. Because these and gender beliefs are purely popular, modern medical sciences appear as cultural medicines, ethnomedicines, albeit professional ones (Gaines, 1992c; Hahn and Gaines). The validity of racial conceptions has been challenged and its use compromised. The continued use of racial conceptions in biomedical research and practice looms as a central conceptual and methodological problem in the biomedical sciences.

CONSEQUENCES OF RACIAL BELIEFS. Common to intentional and unintentional discriminatory motivations is the unstated theory that ancestry in nonwhite groups "taints" the individual, not only determining identity but also causing disease. This is the implicit pathologization of perceived "difference" typical in research on high blood pressure and diabetes as well as a variety of other conditions (Cowie et al.; Harris, 1991; Jones and Rice). Affliction is attributed to the fact that the individuals are "minority," by which is meant biologically different and therefore "defective."

Considering the study of diabetes in African-Americans more closely, it is found that while no risk factors and very few cases of diabetes exist in West Africa, individuals classified as African-Americans are still commonly said to be at "high risk" for developing the disease because of their "racial or ethnic ancestry." The presence of diabetes in these populations has other probable causes that are normally overlooked in research. They are (1) the European genetic background of the African-Americans; (2) poverty and related poor nutrition caused by discrimination; and (3) the high animal-fat content of the dominant northern European diet.

Racial thinking leads researchers to ignore oppression, racism, and discrimination—all of which can implicate the researchers themselves—as well as other cultural and biological factors. Research is confined to allegedly biological problems existing as defects within the afflicted. The real biogenetic makeup of individuals goes unanalyzed while their social identity is blamed for their illness.

Research on the treatments of choice and treatment recommendations in U.S. biomedicine demonstrates that medical and psychiatric diagnoses and therapeutic choices are often made on the basis of patients' social identity, be it race, class, or gender rather than objective need (Brandt, 1985; Ehrenreich and English; Gilman; Good; Lindenbaum and Lock; Osborne and Feit). Historically, this includes the differential use of anesthesia; the poor didn't need it but the wealthy did, as they were more delicate! (Pernick).

The form of intervention in psychiatry, pharmacotherapy, and psychotherapy is today heavily dependent on racial and/or sexual stereotypes rather than on empirical psychiatric signs or symptoms (Katz; Gaines, 1982, 1992a, 1992c; Littlewood). Blacks and Hispanics are often seen as belonging to that group of patients termed *psychologically unsophisticated* or *not psychologically minded* (e.g., Leff; MacKinnon and Michels; Sudack). Psychopharmacotherapy is seen as more "appropriate" for such patients than forms of "talk" therapy.

It should be recalled that U.S. psychiatry in the nineteenth century "found" that psychiatric disorders afflicted black slaves who otherwise "unaccountably" ran away from their masters. This is a historical version of a biological psychiatry and posits that all conditions are biological and will ultimately yield to somatic interventions. Environment, in this view, can be discounted or its consideration delayed until suspected "biological components" can be studied.

In medical research, behavior is also related to race. Medical researchers often choose research topics that implicate behaviors judged as immoral or incautious when dealing with minority populations, for example, number of sex partners, unwed mothers, and drug addiction (Gaines, 1985; Osborne and Feit). In this way, medical research also becomes moral research and supports blame-the-victim thinking.

In the psychiatric literature, neo-evolutionist racial theories lurk behind some assertions. Certain groups, such as the English, are said to be more evolved and psychologically normal (see Leff). In this view, somatization is allegedly less evolved and is characteristic of less developed "traditional" or "primitive" societies. The position inserts a cultural view of emotion and thought into a not-too-implicit neo-evolutionist scheme.

In the West, emotions are believed to be natural, universal, and distinct from cognition. But anthropological research has shown that specific emotions are not universal nor are they naturally distinct from cognitive or bodily states and functions (see Good et al., Lutz, Obeyesekere, Schieffelin, in Kleinman and Good). While highly valued in a very few cultures, psychologization of distress is not "natural," but rather a learned, shared, and transmitted cultural approach (Kleinman). Psychologization is not found in many areas of Europe itself, for example, the Mediterranean and eastern Europe (Gaines, 1992c; Gaines and Farmer; see Good et al. in Kleinman and Good), or in China, Japan, or India (Kleinman and Good; Leslie and Young).

Research on racial differences provides the scientific bases for the maintenance of popular and scientific racial ideology in the United States. This ideology clearly leads to differential evaluation of social actors in medical and nonmedical contexts. As such, biomedical practices can be said to contribute to the social problems caused by racism. These problems include unequal access and poor medical outcomes (Good). The use of racial categories in biomedical research and practice, then, may be seen to breach the medical profession's own primary ethical injunction "to do no harm."

GENES, RACE, AND VIOLENCE. Biomedicine conceives of its domain as the discovery and manipulation of nature (see Gordon, in Lock and Gordon). Its wider culture perceives nature as something to be dominated and controlled (Pike). Ideas of nature, as well as those of difference and inferiority that are encoded in racial and gender identities, greatly affect practice and research in U.S. biomedical sciences. Classes of people believed to be closer to nature are seen as requiring control and guidance, even domination. Such people—among them women, children, non-Anglo or non-Germanic European ethnics (e.g., French, Italian, Spanish, Celtic, and Slavic people), Africans and their descendants, Native Americans, Hispanics, Pacific Islanders—are, in the United States, rather widely believed to be emotional, and therefore dangerous, unpredictable, and wild. Comments about "natural abilities" (intuitive, musical, irrational, fierce, shrewd) or characteristics of particular groups indicate their closeness to nature; they, like animals, are thought to be dominated by instinct and irrationality, not by "reason," a European cultural and masculine virtue (Chesler; Fausto-Sterling; Kleinman and Good; Pike).

The imputation of wildness, impulsiveness, and irrationality is doubtless a culturally constituted defensive projection of aggression that actually exists in the dominant group (Gilman; Pike). It is used to justify control, domination, and even extermination, as with Africans and Native

Americans in the United States and non-German ethnics and the disabled in World War II Germany.

A similar logic appears in contemporary U.S. society. Urban violence, born of repression, discrimination, violence, and poverty, is recast as "genetic predispositions to violence or criminality" in individuals and the groups to which they are ascribed, especially after periods of civil unrest. However, rather obvious examples of genetic predispositions toward criminality and violence in the dominant group are regularly ignored as are centuries of clear provocations of African-Americans.

If researchers were indeed interested in a dispassionate evaluation of genetic components of violence and criminality, it would be appropriate to study people descended from generations of individuals all of whom have committed crimes of a serious nature. In the United States, such a population would be the many immigrants from Russia or Germany, as well as their offspring. Another group of subjects would be the descendants of slave traders and owners. Mass murderers and serial killers in the United States and Europe are virtually always white; their relatives would be suitable subjects of biological research on white criminality. These data might suggest some genetic basis for the inheritance of violent tendencies, if one were to think in racial terms. But researchers on violence and its causes regularly ignore such evidence. It appears that violence and criminality are possible genetic predispositions only when they appear in individuals belonging to specific low-status racial groups.

RACE AND CLINICAL STUDIES. That racial groups are considered unequally in U.S. biomedical science and society is clearly demonstrated by the infamous and tragic Tuskegee syphilis study. In 1932, the U.S. Public Health Service (PHS) began a prospective study of syphilis infection among four hundred rural Alabamans who were black male sharecroppers. The researchers asserted that the study could be a "natural experiment" because it was assumed (for racist reasons) that "such people" were all infected and would not seek treatment for their condition (Brandt, 1978). For these reasons, the PHS argued that it could observe the natural history of syphilis infection in these black men. As it happened, the subjects, who had been unknowingly selected, began to seek treatment almost immediately.

Rather than provide healthcare, the PHS initiated a vast conspiracy to prevent the subjects from receiving care from any source. It conspired with local and state health officials, clinics and hospitals, and the U.S. Army, in which some of the men had enlisted, to prevent disclosure to the subjects of their diagnosis and to prevent treatment of their affliction.

Despite the fact that the natural experimental premise was invalidated in short order, this horrendous project continued over four decades until 1972, when public outcries finally stopped it. Until that time, however, the study was often reported in the medical literature without raising ethical concerns about informed consent, the sometimes fatal use of these human subjects, or the conspiracy to prevent them from receiving efficacious treatments (Brandt, 1978, 1985).

Aside from specific research projects that indicate differential concern for specific groups in the United States, "minorities" in day-to-day medical settings are often underdiagnosed for problems that could be treated (e.g., heart disease) and overdiagnosed for others. For example, blacks are regularly misdiagnosed with schizophrenia. These misdiagnoses lead to confinement and inappropriate pharmacological regimens. Loss of freedom and improper use of powerful psychotropic medications may themselves lead to chronicity in the illnesses that are left untreated, illnesses that led the patient to the attention of health professionals in the first place (see Adebimpe; Mukherjee et al.; Bell and Mehta; Good). This is one means by which medicine creates chronicity of particular disorders as well as increases in the reported incidence of these disorders in a specific population. The circular logic is completed by the subsequent tendency to diagnose in an individual a disorder that is reported as "common" in members of his or her racial or ethnic group.

It is important for a full understanding of the role of racial classifications in the biomedical field to see it as part of a cultural system. This allows for the recognition of both the clearly concerned altruistic practitioners and researchers and the profoundly troubling aspects of racial thought in biomedical practices. In this view, the problems of racial thinking may be seen to arise frequently from the use of popular racial notions by force of tradition—tradition in the Weberian sense, wherein it is one source of authority for human action (Weber). The use of racial categories is thus not necessarily racist.

Conclusions

The U.S. version of human biology is a folk biology that assumes that social categories—"races"—are reflections of nature rather than culture. As a result, biomedical work, as well as public healthcare, is conducted and interpreted in these terms. In clinical practice in U.S. medicine, every patient record begins with three basic bits of information thought to be of critical importance: age, race, and gender (e.g., "A thirty-seven-year-old black female presented with

…”). This is a significant part of the discourse of medicine that reconfirms the cultural conceptions that race, age, and sex are natural and empirical realities that make a difference.

Specific forms of communalism, such as racism and sexism, are intrinsic to U.S. society. As a result, they are fundamentally part of its medical institutions, because U.S. medicine is a reflection of the culture that created it. Culturally specific prejudice makes U.S. biomedicine an expression of a particular culture and its history. That culture has held and still expresses empirically problematic and ultimately unethical conceptualizations of human variation. However, neither contemporary medicine nor society remains monocultural; different ethnic and gender voices are being heard advocating what may be seen as more cultural and therefore humane and equal medical-research concerns and treatment. In many scientific fields, the lessons learned from the Nazi atrocities—as well as the inclusion of Jews, African-Americans, and women into collegial relations—has helped to reduce scientific racism and sexism since the 1950s (Barkan). Trends of pluralism begun then continue and expand.

Modern biomedical thought in the United States appears to lag in its understanding of the bases of human differences. The basis is culture, not biology. Even though racial terms are now often exchanged for ethnic ones, the problems persist in biomedicine and related sciences. Ethnicity has a cultural referent, and race has a putatively biological one. The two terms are incommensurate and cannot be used interchangeably.

Intentionally or unintentionally, biomedicine conserves, employs, and disseminates racial and gender-biased conceptions in its theory and practice. Such actions may be seen to derive both from habit and from nefarious intent. Comparisons are at the heart of science. U.S. science, along with U.S. popular society, has always thought that comparisons of black versus white or other races are the more or less “natural” ones to make in a “multiracial” society. Some others yet seek to show one group’s superiority over others.

Biomedical enterprises will surely be subject to increasing ethical and practical criticism in the future “both from without and within its cultural tradition by those it fails to serve and those it serves to fail” (Gaines, 1992c). The growing understanding of the cultural biases of the professional medicines (and sciences) of the world suggests that medicines, like their particular medical ethics, reflect local cultural realities. A pluralistic medicine is needed in a multicultural country such as the United States. In such a country, a single medical voice may easily lead to, if not generate, bioethical conflicts. A medicine without cultural understandings, unreflective of its own cultural foundations, is inadequate, and an inadequate medicine cannot be of great help in a multicultural society.

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SEE ALSO: *Bioethics, African-American Perspectives; Biology, Philosophy of; Eugenics; Feminism; Genetic Discrimination; Genetics and Racial Minorities; Genetics and Human Self-Understanding; Holocaust; Human Dignity; Human Nature; Mental Illness: Conceptions of Mental Illness; Minorities as Research Subjects; Psychiatry, Abuses of; Sexism; Women, Historical and Cross-Cultural Perspectives*

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REHABILITATION MEDICINE

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Rehabilitation medicine encompasses medical, psychosocial, and vocational interventions provided to persons who have experienced some type of functional impairment. Individuals receiving rehabilitation services may have been born with a disabling condition, such as cerebral palsy, spina bifida, muscular dystrophy, or mental retardation; or they may have acquired disability from stroke, spinal cord injury, polio, amputation, cardiovascular disease, acquired immune deficiency syndrome (AIDS), or traumatic brain injury. They may receive rehabilitation treatments at a traditional acute-care hospital, at a hospital specializing in rehabilitation, or at a post-acute facility, sometimes called a *transitional* or *independent living* facility. Increasingly, individuals receive rehabilitation services in their homes through home health agencies or visiting nurses (DeLisa).

Consumers of rehabilitation medicine, especially if their disabilities are acquired rather than congenital, invariably experience intense feelings of anger, rage, helplessness, and worthlessness (Gunther, 1971). Ethical problems arise from the way disability disrupts one's capacity to make autonomous choices and decisions and to develop and sustain meaningful social relationships. The transformation of a self that experiences profound alienation resulting from a disability to a self that can productively engage the world is the ultimate challenge of rehabilitation and prompts many of its ethical considerations.

Certain aspects of contemporary rehabilitation medicine derive from treatment strategies, dating back to the 1920s, for managing job-related injuries. A series of developments associated with World War II, however, shaped rehabilitation medicine as it is known today. Widespread use of penicillin resulted in the survival of seriously injured soldiers. The resultant crowding of nursing homes and chronic-care facilities created an imperative to return wartime casualties either to the front or to meaningful civilian life. President Franklin Roosevelt, himself no stranger to rehabilitation, wrote to Secretary of War Henry Stimson in

1944 that "No overseas casualty [shall] be discharged from the armed forces until he [*sic*] has received the maximum benefit of hospitalization and convalescent facilities, which must include physical and psychological rehabilitation, vocational guidance, prevocational training and resocialization." Toward the war's end, financier Bernard Baruch and physicians who included Howard Rusk and Henry Kessler established Veterans Administration hospitals that would translate the war experience of rehabilitation into civilian life. Their vision evolved into the comprehensive multidisciplinary approach of rehabilitation that is known today (Berkowitz).

Admission to a rehabilitation facility, typically a few weeks or months after acute hospitalization, anticipates that the individual is medically stable and not at serious risk of a life-threatening episode. Most important, patients admitted to rehabilitation facilities are deemed to have sufficient capacity and "rehabilitation potential" to engage in various therapeutic programs aimed at restoring as much functional ability as possible (Purtilo, 1992). Absence of rehabilitation potential may result in the individual's admission to a long-term-care facility.

Contemporary rehabilitation interventions focus on reducing the disabling effects of physical impairments (e.g., poor motor control, loss of sensorimotor skills, muscle weakness, loss of sensation, paralysis, loss of bowel and bladder control); cognitive impairments (e.g., poor concentration, memory, attention, insight, information processing, problem solving); or behavioral impairments (e.g., emotional disorganization, poor emotional expression, inability to engage in goal-directed behavior, poor interpersonal skills). Because the patient's impairments often appear in combinations or clusters, rehabilitation medicine involves an array of specialized therapies and services to assist patients in overcoming their often multiple functional limitations (Keith).

In acute rehabilitation hospitals, treatments are typically provided by a specially designated team of professionals that, depending on the nature and extent of the patient's impairments, may include a physiatrist (a physician who specializes in physical medicine and rehabilitation), a rehabilitation nurse, a physical therapist, an occupational therapist, a specialist in communicative disorders, a recreational therapist, a psychologist, a social-service specialist, a spiritual adviser, an orthotistprosthetist, a vocational rehabilitation counselor, and perhaps a rehabilitation engineer (Lyth). Length of stay for rehabilitation patients varies according to medical need and the extent of health insurance. Stroke patients commonly spend two to six weeks in acute rehabilitation (Parfenchuck et al.); persons with serious brain injury may spend one to four months (Cope and Hall); and persons with spinal cord injury may spend three to five months (Apple).

Bioethical Issues

Because the scope of rehabilitation medicine is so broad, and because other entries will focus on bioethical aspects of disability that either follow from or are independent of an individual's formal stay in an in-patient rehabilitation facility, this entry will discuss certain bioethical aspects of rehabilitation medicine as they derive from the provider-patient relationship. Examining how rehabilitation relationships form and evolve illuminates how bioethical ideals such as autonomy, nonmaleficence, beneficence, and justice occur in the context of treating persons with serious disability. The provider-patient models whose bioethical ramifications will be discussed below are the contractual, paternal, educational, and empowering models.

THE CONTRACTUAL MODEL. The contractual model usually refers to the clinician and the patient developing a mutual understanding and accord on the nature of and need for treatment, its probable benefits and risks, and so forth. Informed consent is central in such discussions; the provider of services assumes certain contractual responsibilities to inform and secure consent to treat the patient, while the patient's consent implies an agreement to the conditions of treatment, including reasonable compliance with the treatment program, remunerating the provider, and so on (Caplan et al.).

The rehabilitation patient's engagement in treatment is not passive, as it would be in an acute, surgical scenario. Active and eventually self-directed, it focuses on learning and performing a variety of functional tasks, such as walking, dressing, toileting, and bathing. Nevertheless, the contractual model in acute rehabilitation is immediately qualified by the fact that many rehabilitation patients have sustained organic impairments that substantially interfere with their cognitive ability to make autonomous decisions. Some patients may not be able to concentrate on, understand, evaluate, or process information well enough to make choices and decisions congruent with their welfare. Or the patient may be psychologically devastated by the onset of disability and unwilling to participate in therapy. Certain rehabilitation patients may experience serious cognitive disorganization accompanied by frightened, anxious feelings and regression to childlike levels of behavior, especially with respect to managing their feelings and impulses (Rosenthal).

Although rehabilitation is defined as elective treatment, many patients do not elect it at all. The onset of a disability like stroke, spinal cord injury, or brain injury can be so abrupt and severe that many rehabilitation patients begin to comprehend the nature and extent of their disability only *after* they have been medically stabilized and referred to the rehabilitation environment. There the patient, confronted with the functional challenges that the disability has imposed, may begin to try to make sense out of what has happened and to deal with the fact that some of his or her life expectations may have to be modified. To the extent that patients are cognitively or psychologically unable to manage these situations, their capacity to make autonomous choices is problematic (Purtilo, 1988). Furthermore, the individual who is discharged directly from an acute hospital to a rehabilitation facility, and only then begins to realize his or her circumstances, has not voluntarily assumed the promissory role that is implicit in the contractual model. To view such a patient's subsequent resistance to or noncompliance with the rehabilitation effort as a violation of a contractual agreement overlooks the fact that the patient may never have reflected on or consented to rehabilitation in the first place.

In sum, the contractual model's presumption of an autonomous self who can voluntarily and insightfully contemplate, assume, and fulfill a variety of promises and obligations is hardly congruent with the reality of the acute rehabilitation environment for many patients. From what has been implied above, a more probable model of care, at least in the early stages of recovery from a neurological event, is the one that will be examined next: the paternalistic model.

THE PATERNALISTIC MODEL. Paternalism has been defined as "the interference with a person's liberty of action justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced" (Dworkin, p. 65). Once the prevailing model in provider-patient relationships, paternalism has since 1970 come under increasing fire, both from the patient-rights' movement and in the literature of bioethics. Compelling legal justifications for paternalism now condone overriding a patient's decision only when the decision would pose serious harm to the patient or to identifiable others (Jonsen et al.). In acute rehabilitation, justified paternalism is usually predicated on the patient's impaired cognition or psychological disorganization. As Arthur Caplan observed, "If it is true that time is essential in allowing patients to accommodate to the reality of severe impairment, then this would seem … at least for some patients in some settings, to allow for the presence of paternalistic medical care" (1988, p. 315).

Paternalism in acute rehabilitation frequently appears when patients resist complying with their therapeutic program. Patients may object to the time at which they must rise in the morning to begin therapy, the nature and intensity of their therapies, their diet, the kinds of medications they require, the aesthetics of their hospital room, the personalities of other patients in their room, the date of discharge, or the discharge site. Alternatively, some rehabilitation patients will insist on engaging in activities that pose harm to them, such as trying to walk unassisted despite poor balance or muscle weakness.

Paternalistic interventions in certain instances—such as refusing to comply with a clinically depressed, suicidal patient's request for privacy—are easily justified. Paternalism cannot serve as the preferred provider-patient relationship, however, for at least three reasons. First, justifying a paternalistic intervention in rehabilitation on the basis of a patient's cognitive or psychological impairment requires an objective determination of that impairment. If the rehabilitation patient exhibits profoundly impaired memory, extreme confusion, or very poor judgment, he or she has a doubtful claim to self-determination. Yet providers may disagree on which of the patient's decisions are sufficiently problematic to justify a paternalistic decision. Richard Wanlass and his colleagues showed that rehabilitation clinicians do not consistently or reliably apply the labels "mild," "moderate," and "severe" to cognitively impaired patients; Vivian Auerbach and John Banja found that considerable discrepancy exists among physicians, mental-health professionals, and lawyers in distinguishing competent from incompetent decisions made by persons with traumatic brain injury; and Bruce Caplan noted a marked disparity between patient and provider ratings of the patient's mood. In cases of considerable professional disagreement about a patient's "competence" to make decisions or the severity of a patient's cognitive impairment or mood disorder, it is not possible to justify overriding the patient's decision *on those bases.*

A second reason for rejecting a thoroughgoing paternalism in rehabilitation is that providers with paternalistic attitudes risk misinterpreting resistance to therapy as "noncompliant" or "unmanageable." Whatever their therapeutic value, such attitudes and behaviors may indicate the provider's need to be in control (McKnight). When patients resist the provider's ministrations, the provider may become angry or exhibit behaviors destructive to the therapeutic relationship (Gunther, 1987). What may appear to be noncompliant patient behaviors may in fact be the patient's attempt to assert himself or herself, an attempt that perhaps ought to be applauded as an expression of the patient's striving for independence rather than discouraged as inappropriate behavior.

A third reason for rejecting paternalism is that it ultimately runs counter to the rehabilitation ideal of independence. If the goal of rehabilitation is to help the person's movement toward functional independence, then patients ought to begin learning how to assume control of their lives in the rehabilitation environment. Consequently, the rehabilitationist who excludes the patient's input or interest in defining goals and making decisions is stifling the very behavior and attitude he or she is supposed to be cultivating. Indeed, because a profound change in one's bodily image and functional capacity can so seriously affect one's self-image and identity, the ultimate goal of rehabilitation may well be to bring patients to accept themselves as persons with disability and empower them with the necessary will and information to engage the world on somewhat new terms (Banja).

THE EDUCATIONAL MODEL. Empowerment depends in part on various kinds of information the patient will need to function as autonomously as possible. Newly disabled persons require information on and training in managing their activities of daily living (e.g., bathing, grooming, feeding, toileting, and so on); they may also need to learn about creative recreational opportunities, financial planning, social skills training, problem solving, accessing community resources, sexual enjoyment, using community transportation, assertiveness, and perhaps vocational planning or training. Patients should also learn about their rights as rehabilitation consumers before and after rehabilitation discharge: that they have the right to request reasonable changes in the personnel of their teams; that disclosures of otherwise confidential information may occur, for example, to family members or third-party payers; how rehabilitation termination is decided and what evidence is used to determine the nature and length of the rehabilitation; and how they are protected by legislation, such as the Americans with Disabilities Act (Caplan et al.).

Providing this information responds to the same ethical principles requiring that information be imparted to an individual about to undergo surgery. In the latter case, information is treatment-specific, while in the former, the information addresses a host of functional issues. But whereas consent to surgical procedures pertains only to the intervention at issue, consent to rehabilitation reflects a disabled person's willingness to manage his or her life. If no effort is made to stimulate the rehabilitation patient's will to use that information or to be autonomous, then the rehabilitation effort may ultimately fail. Rehabilitation providers not only must convey important information but also must seek to deepen the patient's appreciation of its value and encourage the patient to use it.

THE EMPOWERMENT MODEL. Able-bodied persons frequently confess to being uncomfortable around and having negative feelings toward individuals with disability. Persons with disability are therefore often isolated, deprived, discriminated against, and generally assigned to dependent roles. Ironically, even public programs presumed to assist persons with disability toward autonomy and independence sometimes foster dependency (McKnight). Persons who receive services from such programs frequently complain of feeling dehumanized, subservient, devalued, and ostracized. Studies of the psychodynamic aspects of relationships among program personnel and clients suggest that program staff may develop a narcissistic feeling of authority from these relationships that is threatened by their clients' acting independently (Mullins). Consequently, it is not surprising that such programs may be perceived by clients as unhealthy.

According to the empowerment model, which is moored in principles of social justice, the goal of rehabilitation is to facilitate the rehabilitation consumer's access to social goods. Necessary elements of this access involve social attitudes and measures that aim at equalizing opportunity. Because persons with disability face limitations on normal functioning, justice theorists like Norman Daniels (1985) argue that a society ought to assume certain duties to make up for the fact that an unequal distribution of disabilities among citizens unfairly handicaps the disabled person's attempts to satisfy his or her life needs. Legislation such as the Americans with Disabilities Act, which calls for reforms in hiring practices, barrier-free architecture, handicapped-accessible public transportation, and the implementation of communication devices in business operations for employees who are speech- or hearing-impaired, is highly responsive to the goal of empowerment.

The robust sense of autonomy explicit in the empowerment model transcends clinical objectives that stop at restoring functional ability. In seeking to enhance the individual's power to control his or her life, the empowerment model aims at liberating the individual's self by respecting and advocating the individual's right to his or her choices, preferences, and decisions. From a therapeutic standpoint, therefore, the provider may have to honor the patient's preferences even if they contradict the therapist's, allow the patient to take reasonable decision-making risks, and be prepared to assist when the patient fails. Most important, the therapist must provide the patient with the tools necessary to seize, maintain, and enjoy control of his or her life.

Because many rehabilitation patients are depressed and despondent over the onset of their disability, various empowering models or strategies have been formulated by mental-health professionals (O'Hara and Harrell). A key ethical challenge for the therapist is determining when patients are reasonably ready or "competent" to gainsay therapeutic recommendations, or when patients can "reasonably" assume the risks inherent in the enjoyment of their moral and constitutional liberties and freedoms (Purtilo, 1988).

Meeting this kind of challenge requires an acute sensitivity on the therapist's part in judging when certain types of paternalistic interventions are warranted versus when patients may assume control and responsibility. While the empowerment model may not object to vesting decision-making authority in the provider at the beginning of rehabilitation, in ideal cases that power is increasingly channeled to the consumer as rehabilitation discharge nears. The goal is for patients to realize their right to engage the world on their terms and to enjoy the self-esteem and dignity of risk that derives from doing so (O'Hara and Harrell).

Familial and Social Obligations

Families play a critical role during the rehabilitation process, not only supporting their loved ones but also learning how to accommodate their needs after rehabilitation discharge. The nature and extent of familial duty that occurs by virtue of a member's becoming disabled is nevertheless problematic. Overwhelmed by the financial and personal toll that caring for someone with serious disability poses, families may feel that the burdens imposed on them by the individual's care needs are unreasonable. If the family defaults, does an individual's misfortune in sustaining a disability impose special obligations on society? The extent to which the disabled person's family assumes the responsibilities of care depends on the family's love, sense of values, and willingness to sacrifice, rather than on legal or constitutional mandates (Callahan). If both family and society repudiate a duty to care for the person with disability, then the rehabilitation itself is jeopardized.

The future of allocating rehabilitation services requires a moral consensus about what disability within human life means and whether and to what extent society has a duty to accommodate the needs of persons with disability. Because such a consensus about disability does not yet exist in contemporary American society, rehabilitation medicine is available largely on the basis of the ability to pay (Brody). Shrinking financial resources may preclude the provision of rehabilitation resources to those who desperately need but cannot afford them. Although condoning such a situation in an egalitarian society seems ethically repugnant (Purtilo, 1992), a marked reluctance, if not downright hostility, exists toward imposing social obligations—such as increased tax revenues—to improve care for persons with disabilities. In the face of moral arguments that the burdens resulting from disability should be lightened by spreading them as widely and equitably as possible, libertarians counter that because "I am not my brother's keeper," others' disability and its rehabilitation are not their concern (Will).

To the extent, however, that able-bodied persons accept the idea of valid social roles for persons with disabilities, social stigmas that have interfered with the latter's participation in mainstream American life may diminish. The implementation of the Americans with Disabilities Act may facilitate this change in attitude because it insists that greater opportunities be made available for persons with disability to enter the economic mainstream of American life. Furthermore, demographic projections indicate an astonishing rate of growth among elderly persons in the United States, many of whom will require rehabilitation services at some point in their lives. To the extent that they can influence the political will, access to rehabilitation resources may expand rather than shrink through legislative enactments.

If moral arguments are not sufficient to justify the allocation of rehabilitation services, certain purely material considerations might compel an examination of the merits of rehabilitation medicine. Extensive research indicates that the social costs of disability without rehabilitation are staggering (Brooks; Davidoff et al.). Reimbursement for rehabilitation services might be straightforward and noncontroversial, then, simply because of its cost-effectiveness.

Appeals to self-interest may also sustain an interest in rehabilitation's merit. As medical technology and improved lifestyle choices result in increased longevity, the need for rehabilitation services will doubtless increase. To the extent that living longer increases the probability of a disabling neurological or musculoskeletal impairment, Americans might seek to protect their own access to rehabilitation services by advocating an entitlement to such access for everyone else.

In any case, rehabilitation's objective of securing independence for its consumers fits admirably into an egalitarian culture's sociopolitical aspirations. Independence for persons with disability is the same thing as independence for the able-bodied: the ability to enjoy life as a chooser of ends and to participate in a just and democratic society. Much to its credit, and perhaps more than any other medical specialty, the ethos of rehabilitation medicine embodies these cherished ideals of individual freedom and liberty.

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SEE ALSO: *Autonomy; Beneficence; Care; Chronic Illness and Chronic Care; Competence; Disability; Family and Family Medicine; Healthcare Resources, Allocation of: Microallocation; Informed Consent; Life, Quality of; Long-Term Care; Professional-Patient Relationship; Teams, Healthcare*

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REPRODUCTIVE TECHNOLOGIES

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I. Introduction
II. Sex Selection
III. Fertility Drugs
IV. Legal and Regulatory Issues
V. Gamete Donation
VI. Contract Pregnancy
VII. Sperm, Ova, and Embryos
VIII. Ethical Issues
IX. In Vitro Fertilization and Embryo Transfer

I. INTRODUCTION

The development of effective and imaginative approaches to the management of human infertility has focused public attention on the techniques themselves and on their ethical and legal implications. Although differing widely in their complexity, these methods have one characteristic in common: the separation of human reproduction from the act of coitus. An understanding of these reproductive technologies is essential to an overall consideration of the ethical issues surrounding them.

Artificial Insemination

Artificial insemination involves the mechanical placement of spermatozoa into the female reproductive tract. Inseminations are separated into two broad categories: those using the semen of the husband or designated partner (AIH) and those employing semen of a third party, or donor insemination (DI). Because the ethical and moral issues surrounding AIH and DI take on different dimensions, each will be considered separately.

AIH constitutes effective treatment when, for whatever reason, the male partner is unable to ejaculate within the vagina. Some males are unable to ejaculate during coitus but can ejaculate through masturbation or the use of vibratory stimuli. Certain anatomical abnormalities result in faulty semen placement. Hypospadias, a penile abnormality in which the opening of the urethra is located a distance from the tip of the glans penis, causes the ejaculate to be deposited at the periphery of the vagina even when the penis is well within. Retrograde ejaculation is a condition usually caused by a complication of prostatic surgery resulting in the formation of a channel that causes the ejaculate to be directed away from the penis and retrograded into the bladder. After ejaculation, semen for artificial insemination can be recovered from the bladder by catheterization.

Normal vaginal intercourse may be precluded by congenital or acquired vaginal abnormalities. In rare cases, the vagina is constricted as the result of in utero exposure to the hormone diethylstilbestrol (DES) or possibly by past trauma. Psychological problems in the male or female or both may interfere with normal coital exchange.

In recent years, AIH has been recommended when the semen displays deficiencies in numbers of sperm or their ability to move. Laboratory techniques have been developed to separate and concentrate the most active spermatozoa. These are then introduced into the uterine cavity, closer to the site of fertilization. Intrauterine insemination has been successful in cases of male infertility and in couples with unexplained infertility (Guzick et al.).

TECHNIQUES OF OBTAINING SEMEN. Semen for use in artificial insemination is usually obtained by masturbation. An alternate possibility is intercourse using a plastic condom. Coitus interruptus is not recommended, as the first portion of the ejaculate, which contains the majority of active, motile spermatozoa, is sometimes lost. In cases of obstruction of the vas deferens, which serves as the conduit for spermatozoa, spermatozoa can be obtained surgically from the epididymis, the storage depot for spermatozoa. Specimens so retrieved have been used successfully for in vitro fertilization.

TIMING OF THE INSEMINATION. Placement of spermatozoa should be timed to coincide with the twelve hours immediately preceding ovulation. Approximately twenty-four hours before ovulation, increased levels of luteinizing hormone can be detected in the urine, using a color indicator to predict ovulation. The day-to-day development of the egg-containing ovarian follicle can be monitored with pelvic ultrasound. To enhance the accuracy of ovulation timing still further while causing the release of additional eggs for fertilization, the use of human gonadotropins to induce ovulation has become increasingly popular.

INSEMINATION AND SEX SELECTION. Insemination has also been used with limited success for sex selection. Laboratory methods have been suggested to separate the X-chromosome-bearing (female-producing) from the Y-chromosome-bearing (male-producing) spermatozoa. Success rates in the production of male offspring in the 80 percent range are claimed (van Kooij and van Oost). Such techniques are useful in animal husbandry but do not yield a consistently satisfactory success rate in humans. Sex selection would be useful to avoid a sex-linked genetic disease. Sex preselection based solely on preference for a boy or a girl has much wider social implications.

DONOR INSEMINATION. Donor insemination was mentioned as a method of treating infertility in the nineteenth century. As DI has become more widely used, the legal climate has become more favorable and the status of the offspring much less uncertain. With this has come awareness of the importance of careful counseling and the use of appropriate permission forms. There has not yet been a case in U.S. law in which the anonymous sperm donor has been assigned parental responsibility.

The clinical indications for donor insemination are related mainly to deficiencies in the semen. The most clear-cut cases are those in which the male partner suffers from azoospermia (absence of spermatozoa). Indications have been extended to include those in whom some spermatozoa are present but the quality of the specimen is poor. Known hereditary disorders in the male partner, such as Huntington's disease, Tay-Sachs disease, or hemophilia, are also indications for DI.

In vitro fertilization (IVF) has widened the possibility of conception with severely deficient semen. Donor insemination is sometimes used in IVF when there is failure of fertilization using the male partner's specimen.

EVALUATION OF THE COUPLE FOR DONOR INSEMINATION. A couple considering donor insemination should be thoroughly counseled. If either partner has reservations, it is wise to accept these at face value and encourage consideration of other options, including adoption. The man's fertility should be thoroughly evaluated, and efforts made to correct any abnormalities. The woman also should be thoroughly evaluated for factors that might contribute to infertility. Both partners are usually required to review and sign a detailed informed-consent form.

SELECTION AND SCREENING OF DONORS. Unless he expresses willingness to be identified, the donor is anonymous. Occasionally there is a request that a close relative (usually a brother or even a father) be used. In such cases, the couple should be encouraged to consider carefully the potential for future familial conflicts. Analysis of donor semen should meet the normal standards for fertility (ASRM, 2002). The donor should be in excellent health and be screened for any family history of genetic disorders. Serologic tests for syphilis and serum hepatitis B antigen are obtained initially and after six months. The genitalia are cultured for gonorrhea and chlamydia. An initial screening for the AIDS virus antibodies is performed and repeated after six months because the antibody test for AIDS may not turn positive until several months after infection. Most centers now use frozen semen exclusively. If a donor is providing repeated specimens, periodic reevaluation of his health status is essential. Clinics should maintain records of pregnancies and set a limit on the number of pregnancies any one donor may produce. To decrease the possibility of consanguinity (procreation between close relatives, such as siblings or first cousins) in a given population, an arbitrary limit of ten or fewer pregnancies is recommended.

It is important to maintain confidential donor records, including all of the information on the screening procedures, so that it is available in the future in case it is needed for medical reasons.

TECHNIQUE OF INSEMINATION. The standard insemination involves placing the specimen, thawed if it has been frozen, into the cervical canal by means of a small, flexible tube (cannula). As the vaginal speculum is removed, the remainder of the specimen is placed in the vagina, at the outer cervical canal. The patient remains supine for twenty minutes or so. The specimen may be held in place with a cervical cap, which is removed four to six hours after insemination. For intrauterine insemination, a plastic cannula is passed through the opening of the cervix into the uterine cavity, where the concentrated, pretreated (i.e., washed) spermatozoa are deposited.

CRYOPRESERVATION OF SEMEN. Since the first successful insemination with freeze-stored semen in 1953, this technique has had a significant impact on clinical practice. In the 1970s, formal semen banks were established, largely to address the needs for long-term preservation of the specimens of men who had undergone vasectomy. Semen also is preserved prior to chemotherapy or radiation, which might result in sterility. Although there is no formal reporting system, information accumulated over the years has failed to uncover an increased incidence of genetic defects among the offspring resulting from insemination with cryopreserved semen.

The response of spermatozoa to cryopreservation is unpredictable and varies on an individual basis. Some specimens freeze well and others do not. The pregnancy rate is lower overall with frozen semen. The only reliable way to determine whether a specimen is suitable for cryopreservation is to cryopreserve it, thaw it, and evaluate the impact of the procedure on the quality of sperm motility. Specimens are usually stored in individual straws or small vials so that fractions may be thawed while the remainder is preserved for future use. The Ethics Committee of the American Society for Reproductive Medicine (formerly the American Fertility Society, AFS) has determined that cryopreservation of human semen is ethically and medically acceptable (ASRM, 2002). Most programs use only cryopreserved semen for donor insemination.

In Vitro Fertilization

In vitro fertilization and embryo transfer (IVF-ET) is increasingly common in infertility practice. Initially used exclusively in women with damaged fallopian tubes, the indications for IVF-ET have been extended to include male factor infertility and cases in which no cause for the infertility can be uncovered. Much as artificial insemination separates procreation from the coital act, in vitro fertilization separates fertilization from the normal maternal environment, allowing the initial phases of development to occur outside the reproductive tract, followed by transfer of the embryo into the uterus. The first successful in vitro fertilization was carried out in a normally ovulating woman whose tubes had been surgically removed. A single egg (ovum, oocyte) was obtained by aspiration at the time of laparoscopy. The procedure required general anesthesia and involved placing a telescope through the umbilicus for visualization of the pelvic structures. The oocyte was fertilized in vitro and transferred to the uterus after two days.

In later developments, the ovaries were stimulated with human urinary gonadotropins to induce development of several follicles, each containing an ovum, in a given cycle. This approach is now standard. Follicular development is followed by means of blood estrogen levels, and the size of the growing follicles is measured by ultrasound. When the follicles are judged ready for ovulation, a second hormone, human chorionic gonadotropin, is administered to induce ovulation. This causes further development of the follicles and the maturing of oocytes within them. The oocytes complete their first division in a process referred to as meiosis, releasing half their complement of chromosomes in a small, round structure, the first polar body. The maternal chromosomes are now ready for the second meiotic division, which occurs after the ovum has been penetrated by the spermatozoa. Within two to three hours of the expected time of ovulation, the oocytes are aspirated from their follicles.

In the early phases of IVF development, this was carried out with the aid of the laparoscope. The oocytes were obtained by needle aspiration. Today, ova are obtained by ultrasound-guided transvaginal aspiration. This procedure can be done without general anesthesia, and the overall approach to in vitro fertilization is greatly simplified.

Another major clinical problem in the early phases of IVF development was that occasionally a patient would ovulate before the oocytes could be obtained, and the cycle would have to be canceled. Analogues of the gonadotropin-releasing hormone are now used to prevent this. These analogues are capable of blocking the release of the patient's pituitary gonadotropins, and the ovaries can be brought under the complete control of exogenously administered hormones. The number of follicles that develop varies from patient to patient, and even in the same patient from one cycle to the next. By and large, the aim is to obtain as many oocytes as possible in a given treatment cycle, especially if the couple has selected cryopreservation as a possible option.

IVF treatment is both physically and emotionally demanding. Several visits for hormone determinations and ultrasound are required. Ovum recovery, although relatively safe, is not without complications. Rarely ovarian infection occurs, which can further compromise the fertility status of the patient. This point is particularly pertinent when oocytes are being obtained for donation.

A freshly ejaculated semen specimen is obtained for insemination. The ova are placed in individual containers and mixed with spermatozoa that have been prepared by separating them from the semen and incubating them in a solution designed to enhance their fertilizability. The inseminated ova are cultured for approximately twenty-four hours and then inspected for evidence of fertilization.

Much has been learned about human fertilization through in vitro fertilization. When it is removed from the woman's body, the ovum is surrounded by layers of small, loosely packed cells, the cumulus oophorus. An inner layer of more densely arranged cells, the corona radiata, immediately surrounds the oocyte. These cells interface with the zona pellucida, a translucent protein shell that immediately surrounds the egg. Penetration past these barriers is accomplished through a sequence of interactions between spermatozoa and the ovum and its layers (Kopf and Gerton). When the spermatozoon reaches the zona pellucida, a series of chemical communications occurs. These condition the spermatozoon so that it can penetrate through the zona pellucida. Once past the zona, the spermatozoon attaches to the egg membrane and is then incorporated into the egg cytoplasm, the tail along with the head. The head is then transformed into a pronucleus. The second polar body is released and the nucleus of the egg is transformed into a pronucleus. The pronuclei then join and the chromosomes are intermingled in preparation for the first cell division. Twenty-four hours after insemination, there are two pronuclei and two polar bodies. This constitutes evidence that the penetration has been successful and fertilization is in process. After three days, the embryo has developed to the eight-to sixteen-cell stage and is ready for transfer into the uterus. Transfer is sometimes delayed until day five or six to allow growth to the blastocyst stage.

EMBRYO TRANSFER. The dividing embryos are incorporated into the end of a catheter that is then passed through the cervical opening into the uterine cavity, where they are discharged. The pregnancy rate is progressively improved if more than one embryo is transferred. If more than three are transferred, there is a greatly increased possibility of multiple pregnancy. Twins are not usually a problem, but triplets or more greatly increase the possibility of fetal loss. Therefore, in many IVF programs no more than two fertilized oocytes are transferred in women under age thirty-five and three in the older group. The availability of cryopreservation has made such decisions easier.

Moral Status of the Embryo

The issue of when meaningful human life begins is pivotal in any discussion of IVF. The fertilization process is a complex series of events. The spermatozoon must be exposed to the environment of the female reproductive tract for a period of time before it acquires the ability to penetrate the layers surrounding the recently ovulated oocyte. This process, referred to as *capacitation,* takes between one and two hours in the human. It is reproduced in vitro in the fluids used for sperm preparation. The series of events involving penetration through the zona pellucida requires complex chemical communication between sperm and egg. After the spermatozoon has penetrated into the cytoplasm, completion of fertilization, although increasingly probable, is not assured.

The events that follow, including the formation and subsequent fusion of the pronuclei, occupy more than twenty-four hours. In the natural sequence of events, the conceptus remains in the fallopian tube for approximately three days. At the eight-to-sixteen-cell stage, it is transported into the uterus. There it develops into a fluid-filled structure, the blastocyst, that attaches to the uterine lining, or endometrium, on the sixth to seventh day after fertilization. The blastocyst is incorporated into the endometrium and invades blood vessels. Development occurs rapidly thereafter, but it is not until the fourteenth day that it develops unique characteristics. This coincides with the formation of the primitive streak, a linear region that can be identified on the early embryonic disk; it signals the beginning of the development of a distinct category of cells. Until this point, there is the potential for division into identical twins. Each of the individual cells in the early conceptus has the potential to develop into a complete adult. On or about day five or six, specialized cells, the trophoblasts, are formed. They provide the point of attachment for the placenta and are essential to the nourishment of the growing embryo. The Ethics Committee of the American Society for Reproductive Medicine applies the term *pre-embryo* to the conceptus through the first two weeks of gestation (AFS). It takes the position that the moral status of the pre-embryo is different from that of either the unfertilized eggs and spermatozoa or the later stages in embryonic development.

Cryopreservation of Pre-embryos

Techniques for freeze-preserving pre-embryos have contributed to the success of human in vitro fertilization and embryo transfer. The incidence of multiple pregnancy, which increases dramatically if more than two to three pre-embryos are transferred, can be reduced with the availability of cryopreservation. Pre-embryos not transferred during the treatment cycle can be used in subsequent spontaneous ovulation cycles. When pregnancy occurs in the initial treatment cycle and pre-embryos have been cryopreserved, a number of future options must be considered. These issues should be reviewed and decisions made before the pre-embryos are frozen. Patients whose response to stimulation clearly indicates that more than three oocytes will be recovered should consider the freezing option well in advance of ovum recovery. Those who for whatever reason, including deeply felt moral reservations, choose not to cryopreserve may wish to have sperm added to no more than three oocytes and have all of the fertilized specimens transferred. Remaining ova can be disposed of in their unfertilized state. Another alternative short of cryopreservation is to fertilize all available ova and select only the best of the resulting pre-embryos, as determined by their appearance and rate of cell division, for replacement, discarding the remainder.

The standard consent form should contain a detailed description of the possibilities to consider if a decision is made to cryopreserve human pre-embryos. As far as is known, cryopreservation of human pre-embryos is not associated with adverse fetal effects. Generally it is agreed that the pre-embryos will be frozen and stored for use in subsequent cycles. Unforeseen situations can occur, such as failure of equipment, although backup freezer systems and liquid-nitrogen holding facilities are usually available in the event of such an occurrence.

In most major centers, the disposition of unused frozen pre-embryos is reviewed in advance of cryopreservation. Handling of these pre-embryos is subject to the couple's joint disposition. They agree that if one partner is unwilling or unable to assume responsibility for the fertilized eggs, the responsibility reverts to the other partner. If that person is not willing or able to assume ownership, the hospital or clinic usually reserves the right to dispose of the pre-embryos in accordance with policies in existence at the time.

Micromanipulation of Oocytes and Embryos In Vitro

Instruments have been developed to allow manipulation of gametes and pre-embryos under magnification. These techniques of micromanipulation have been used extensively in laboratory mammals. More recently they have been applied to human eggs, spermatozoa, and pre-embryos. When the oocyte is not penetrated by spermatozoa that are otherwise apparently normal, micromanipulation can be used to insert a spermatozoon mechanically through the zona pellucida directly into the oocyte itself, a technique known as intracytoplasmic sperm insertion (ICSI). In males with a congenitally obstructed vas deferens, sperm may be recovered directly from the epididymis and used for ICSI. Pregnancies that would otherwise be impossible can occur as a result of these procedures. Because abnormalities in the semen and vas obstruction may be associated with genetic risk factors, these should be considered before proceeding with ICSI (Dohle et al.).

Micromanipulation has been extended to pre-embryos. It has been suggested that the second polar body, the cell that is released from the ovum at the time it is penetrated by the spermatozoon, be removed for chromosome analysis in an effort to determine whether the embryo is genetically normal. This approach could be used in couples at risk of genetic abnormalities and would avoid the onus of a decision to terminate the pregnancy later on. Individual cells have been removed from the embryo for analysis without apparent harm (Tarin and Handyside). Other possibilities may eventually emerge, including the removal and storage of individual cells as clones of the embryo that is transferred. Some of these approaches have not yet attained clinical practicality, but they raise moral, ethical, and legal issues that it would be wise to address now.

Gamete Intrafallopian Tube Transfer

The procedure referred to as gamete intrafallopian tube transfer (GIFT) involves the transfer of freshly recovered ova and conditioned spermatozoa into the fallopian tubes. Thus, fertilization actually occurs in vivo. GIFT is not applicable to all infertility patients. Those with damaged or absent fallopian tubes are obviously not candidates. GIFT has been recommended for couples with unexplained infertility and women with extratubal disease, such as pelvic adhesions or endometriosis. Although fertilization occurs within the fallopian tube, GIFT is certainly assisted reproductive technology and is clearly separated from the coital act. When more than four ova are recovered at the time of a GIFT procedure, one or more are usually fertilized in vitro and cryopreserved for transfer in subsequent cycles. Transfer of the ova and spermatozoa into the fallopian tubes is usually carried out by means of laparoscopy. The success rate following GIFT is now surpassed by that of in vitro fertilization (SART/ASRM). In most centers, GIFT is now largely supplanted by IVF.

Surrogate Gestational Mothers

Human in vitro fertilization has opened the possibility that the resulting pre-embryos can be transferred to a woman other than the woman providing the oocytes. The second woman, referred to variously as a surrogate carrier, a womb mother, a placental mother, or a surrogate gestational mother, provides the gestational but not the genetic component of that pregnancy. Usually arrangements are made for the couple whose egg and sperm produced the embryo to adopt the newborn.

In another type of surrogacy, a husband's spermatozoa are used to inseminate a woman other than his wife. This surrogate mother carries the gestation to term. Agreement is reached before the procedure is carried out that the contracting couple will have custody of the resulting child.

In everyday infertility practice, there are circumstances that seem to justify these procedures. Consider a woman who was born without a uterus but with normal, functioning ovaries. Her husband is normally fertile. The patient's sister had a tubal sterilization after three pregnancies and is healthy in every way. The patient's sister's husband is entirely in agreement with the patient's sister's desire to act as a gestational surrogate mother. Oocytes are obtained from the patient, they are fertilized with her husband's spermatozoa, and the pre-embryos are transferred to her sister's uterus. In this situation we are virtually 100 percent confident that the pregnancy resulted from the procedure and is not an accidental result of coitus between the surrogate and her husband. The offspring is the genetic product of the husband and wife and has no direct genetic relationship to the patient's sister.

Other cases involve the use of a surrogate mother who contributes 50 percent of the chromosomal makeup of the offspring; this represents a more complex situation. The birth mother, who clearly is genetically related to the offspring, will be giving up her newborn child (hers in terms of both birth process and genetics). Indications for the use of a surrogate gestational mother include any condition in which there are functioning ovaries but an absent or nonfunctioning uterus. The uterus may be congenitally absent or may have been removed because of disease; it may be nonfunctional as a result of in utero DES exposure. A surrogate carrier may also be considered if pregnancy is ill-advised for reasons of maternal health. Another issue concerns responsibility for the child in the event that the child is abnormal or damaged as a result of premature birth or birth trauma. There are also issues of the health status and behavior of the surrogate gestational mother during pregnancy. One must consider the impact of drugs or alcohol and the possibility of transmission of diseases. Finally, there is the matter of payment to the surrogate gestational mother. The possibility for exploitation certainly exists.

Oocyte Donation

The clinical indications for the use of donor ova usually are rather straightforward. They include premature menopause and the inability of the wife to produce genetically normal oocytes. On the surface, the ethical issues surrounding the use of donor oocytes should be no different from those involved in the use of donor semen. They are compounded, however, by the risks involved in obtaining oocytes compared with obtaining a semen specimen. For example, ovarian infection could occur following ovum retrieval, which could result in permanent sterility (Tureck et al.). In addition to the cost of the procedures, which is usually borne by the couple requiring the oocytes, there is also the question of payment to the donor for her time, pain, and suffering.

In contrast to spermatozoa, oocytes are difficult to cryopreserve; hence, menstrual cycle coordination between the recipient and the donor is required. Alternatively, donor oocytes may be fertilized with the husband's sperm, and the pre-embryos cryopreserved for future transfer. Sources of donor oocytes include the excess eggs from patients undergoing IVF, oocytes obtained incidental to an operative procedure such as a sterilization, or a specific donation by a relative or close friend. Increasingly, the source of the eggs is a paid "volunteer" (ASRM Ethics Committee). The availability of this technology allows pregnancy in women who are well past the ordinary childbearing age (Sauer, Paulson, and Lobo).

In an effort to improve oocyte quality, cytoplasmic transfer between human oocytes, that is, ooplasm donation, has been attempted. The procedure involves aspirating cytoplasm, the portion of the egg surrounding but not including the nucleus, from a donor egg and injecting it into a recipient egg. Recipient oocytes were deemed to be of poor quality or were recovered from women in their late reproductive years or who previously had a failed IVF cycle. Not unlike some of the early approaches to IVF, the procedure was carried out with minimal basic research background, although in limited studies the technique was found not to impair successful fertilization and cell division in the mouse. Unfortunately, children born as a result of this technique have now exhibited traces of mitochondrial DNA from the donor egg. This foreign cytoplasmic DNA may result in untoward consequences in the future and, defects that are transmitted might be heritable and therefore could be observed in the next generation. Until and unless the safety and efficiency of this approach is established in suitable animal models, this effort to rejuvenate deficient oocytes must be approached with extreme caution.

Conclusion

The techniques employed in what is known as the *new assisted reproductive technologies* are varied and challenging. They range in complexity from seemingly straightforward artificial insemination to micromanipulation of ova, spermatozoa, and pre-embryos—and perhaps, in the future, to treatment of genetic disease by gene insertion in vitro. Just as the techniques vary, so do the ethical issues surrounding them. In no other field is there a greater opportunity for interaction among the physician-scientist, ethicist, moral theologian, social scientist, and legal scholar.

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REVISED BY AUTHOR

SEE ALSO: *Abortion; Adoption; Christianity, Bioethics in; Cloning; Embryo and Fetus; Fetal Research; Genetic Testing and Screening: Reproductive Genetic Testing; Maternal-Fetal Relationship; Moral Status; Transhumanism and Posthumanism; Women, Contemporary Issues of;* and other *Reproductive Technologies* subentries

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II. SEX SELECTION

Sex selection or sex selection techniques usually refer to methods that can be used to help ensure that children are of a specific sex.

Traditional and Scientific Techniques

INFANTICIDE. The simplest, most effective and most morally problematic form of sex selection is infanticide. Before the development of modern techniques the only way to determine the sex of offspring was to kill infants of the undesired sex after birth. This method has been practiced in many areas and at many times in human history.

While some people argue that infanticide can be morally acceptable (Tooley), such support is usually in cases where the individual would have a life that was not worth living. It is implausible to suppose that sex alone could ever be a condition that makes a life not worth living. Therefore even if we accept that there can be justified instances of infanticide we are not committed to permitting infanticide for the purposes of selecting sex.

PRENATAL DIAGNOSIS AND ABORTION. The first genetic testing technologies emerged in the 1950s. They provided the possibility of determining the sex of the fetus in utero (Bubeck).

The development of ultrasound during the 1970s further opened up the possibilities for determining the sex of offspring. It enabled parents to determine the sex of their child in utero and then abort the fetus if it was not of the desired sex. This practice is prevalent in India, China and other countries where a high value is placed upon the first child being male.

PREIMPLANTATION GENETIC DIAGNOSIS AND EMBRYO SELECTION. Preimplantation Genetic Diagnosis (PGD) was developed primarily so that embryos could be tested for genetic abnormalities before implantation. While the intention was to provide a technique for avoiding genetic diseases, it can also be used for determining the sex of the embryo. While PGD does not involve aborting a fetus growing in utero, it can involve discarding unwanted embryos. Some legislative bodies draw a distinction between techniques that are requested for medical as opposed to nonmedical reasons (see The Ethics Committee of the American Society of Reproductive Medicine). The implication is that a technique may be acceptable for a medical reason (PGD for avoiding genetic disease) but unacceptable for nonmedical reasons (PGD for determining the sex of the child). PGD is, next to infanticide, the most effective method of sex selection with an effectiveness of nearly 100 percent.

SPERM SORTING. Rather than determining the sex of a child after it has become an embryo or fetus, sperm sorting techniques attempt to ensure that sperm is sorted by whether they are X chromosome bearing (female) or Y chromosome bearing (male). If this is done successfully then the sperm can be used in artificial insemination or in vitro fertilization (IVF) to help ensure that any resulting child will be of the desired sex.

Sperm swim up or swim through techniques have been in development for some time but have not proved to be effective. More recently greater success rates have been achieved using flow cytometry. Recent figures on the effectiveness of this technique rate have evaluated it as 88 percent effective for determining X chromosome bearing sperm and 73 percent effective for determining Y chromosome bearing sperm. (Microsort.com)

Successful sperm sorting techniques have a number of advantages over other sex selection methods. They are less expensive in that, instead of invasive and potentially harmful techniques such as ultrasound and abortion or PGD and IVF, they involve relatively noninvasive Assisted Insemination. For those who believe that there is something morally significant about aborting a fetus or discarding unwanted embryos, sperm sorting is morally less problematic than PGD or selective abortion.

While these techniques are not likely to become very cheap in the foreseeable future they are already at a cost that could be born by most parents wanting to access this service. For those needing selection services in order to prevent a genetic disease that is carried by the X or Y chromosome, the techniques provide an attractive alternative to other forms of treatment.

Motives for Determining the Sex of the Child

There are a number of reasons why people might want to determine the sex of their child. These reasons range widely in the ethical difficulties that they present.

SOCIAL VERSUS MEDICAL REASONS. At the least problematic end of the spectrum is the intention to determine the sex of offspring so as to avoid the transmission of sex-linked disease. Sperm sorting for this reason is, arguably, morally unproblematic. PGD might also be justifiably used for this reason. Even ultrasound followed by abortion has a morally strong case to support it. However the greatest demand for these technologies comes from those who want to determine the sex of a child for so-called *social reasons.*

SOCIAL REASONS. Social reasons are reasons for wanting sex selection that do not aim at avoiding disease. John Robertson (2001) thinks that there are two different types of social reason, which, together, constitute the most significant demand for sex selection services. First, there are those who want a child of a particular sex because they already have a number of children of one sex or because they are only having two children and have a preference for one of each sex. A second group is those who have a strong preference for their first child being of a particular sex. The first scenario is often referred to as a *family balancing* reason and is often viewed as less morally problematic than valuing male children more highly.

Ethical Issues Raised by These Technologies

It is vital that the ethical issues raised by sex selection techniques are carefully considered because they are, essentially, techniques that select for particular genes.

Because couples or individuals, typically, request these techniques, the historical worries about eugenics have tended not to be raised in this context. However in contexts where there is a widely held view about the relative worth of a specific sex whether sex selection is a form of eugenics is much less clear. It is because of considerations such as these that Mary Anne Warren coined the term *Gendercide* for the systematic way in which female embryos, fetuses and children are killed and neglected in some parts of the world.

PROCREATIVE AUTONOMY. The main argument for open access to sex selection services is the interest that individuals have in exercising their reproductive autonomy. One key advocate of extending reproductive autonomy to sex selection is Robertson (1994) who borrows from English philosopher and economist John Stuart Mill's (1806–1873) harm principle. Mill theorized that the only reason a society has for restricting the liberty of individuals is if the exercise of that liberty would result in physical harm to others. A key freedom in western democracies is the liberty to make choices about procreation. The level of harm that is required for us to interfere with procreative autonomy is ordinarily very high. Even if there were some harms to others that result from the use of sex selection technologies, they would not be as serious as the harm that would be required to constrain this important liberty. Therefore we should not restrict access to sex selection services.

A second important defense of autonomy comes from German philosopher Immanuel Kant (1724–1804). He argued that persons must always be treated as ends in themselves and never as a means only. There are a number of reasons upon which Kant based his opinion but very significant among them is the status of human beings as project pursuers. It is the ability of persons to pursue projects that bestows value upon these projects. The wish to have children is an important component of the life projects of many people. Not only do people wish to have children they can also desire that those children be of a specific sex. Thus blocking access to sex selection services is a severe limitation upon the interests of individuals who want a child of a specific sex.

Restricting access to sex selection technologies may frustrate more than just the desire to have a child of specific sex. Robertson (2001) argues that in cases where the sex of a child will be the deciding factor in whether that child is born, selection techniques are necessary for parents to exercise their reproductive autonomy.

RESPECTING CHILDREN AS PERSONS. While Kantian considerations about how we should treat persons can count in favor of sex selection technologies, the same considerations can also be used to argue against them. When parents wish to use sex selection services they do so because they have a preference about what kind of child they want to have. If they use a sex selection technology and have a child the child's sex has been determined to satisfy an end of the parents and the child has been used as an instrument to bring about this end.

There are a number of responses to this argument. A child is either male or female and all sex selection does is to remove the randomness from the natural process. Children are born a specific sex and removing the randomness from this process does not violate them. A possible counter to this argument is to insist that children have the right to an *open future* (Feinberg). An open future means that a child has the right to its own liberties or conceptions of the good that are not intentionally limited by decisions and preferences of others. In the context of sex selection this would derive to the right to have one's sex determined by a random process. In other words, while most of us know that our sex resulted from no human action, persons whose sex has been selected will know that they are a specific gender because of a parental preference.

A second response is to think carefully about what the Kantian theory demands. Kant requires us to treat persons as ends in themselves and never as a means only. In actuality, it would be impossible to never use other persons as a means because it implies that employing the assistance of another to achieve any end negates the personhood of that other. Kantian theory directs us to only use persons for our own ends when this does not violate their status as persons. So while it may be that parents who use sex selection techniques are using their children as a means it is not obvious that this in consistent with respecting their children as persons. Furthermore it is not clear that "wanting to have a child of a specific sex" for your own reasons is any different from *wanting to have a child* for your own reasons.

SEX-RATIO IMBALANCES. A major objection to the widespread introduction of sex selection is that it might result in a significant imbalance of male to female sex ratios. A preference about the value of having male children or a male first child could result in many more male babies being born.

In the Western world there is little reason to be concerned about sex ratio imbalances. Research in the United States and the United Kingdom on the preferences of those requesting sex selection services indicates that there was a slight preference for girls over boys (Lui and Rose). A majority of people wishing to access these services in the West do so for family balancing reasons.

However there are good reasons for worrying about sex ratio balance in parts of the world where male children are more highly valued.

IMPLICATIONS OF SEX SELECTION FOR COUNTRIES OR CULTURES WHERE SONS ARE VALUED MORE HIGHLY. In some parts of the world there is a significant imbalance in the sex ratios. By comparing the sex ratio of North America and Europe to that of Asia and North Africa there are more than 50 million fewer women in China than there should be. When the sub-Saharan ratio is used (where beliefs about the relative importance of women are more similar to Europe and America) there are 44 million in China, 37 million in India and over 100 million world-wide fewer women than there should be (Sen).

The differences in sex ratios are not due solely to sex selection; they are also a result of factors such as poor diet, limited access to healthcare and other environmental factors.

There is every reason to suppose that the introduction of new sex selection services will increase this imbalance. In 1993 ultrasound machines constituted 20 percent of the total Indian market in medical technology (Miller). Sperm sorting technologies could potentially become readily affordable and they are likely to result in an increase in the number of male babies born.

A society having a balanced sex ratio can be considered to be a public good. It is an indicator that there is equity between the sexes in terms of access to healthcare, education, nutrition and wealth. Barbara Miller has suggested that in India sex ratio imbalances correlate with high levels of intersocietal warfare, the frequency of violence, and violence towards women.

THE IMPLICATIONS FOR WOMEN OF A BAN ON SEX SELECTION. While there is a likelihood that better access to sex selection services in India and China will increase the selection of male offspring, it is important to bear in mind the implications of banning access to these technologies. Without access to pre-conception methods of sex selection women may be forced or coerced into aborting fetuses if they are female. There is also the likelihood that some female neonates will be neglected when that child might have been preconception selected as male. The arguments are counterbalanced to some extent by the fact that the increased use of these technologies might make it easier for these practices to continue and will do little to rectify the value system which makes them possible.

IS THE MOTIVATION SEXIST? OR ARE SOME REASONS MORALLY ACCEPTABLE? On one level it is hard to deny that sex selection is sexist because it is a practice that involves acting on a preference to have a child of a determinate sex. This implies that having a child of a particular sex is in some way better, according to the person with that preference. If a person did not believe that having a child of a specific sex would be better, they would have no reason for wanting a child of a specific sex.

The problem with this analysis is that it implies that any preference that has sex as a distinguishing feature is sexist. This is absurd because it implies that a heterosexual woman who has a preference for cohabitating with a man is sexist. Sexism is the making of morally relevant discriminations on the basis of morally irrelevant features. On this view if parents want to have a female child because they already have a male child and will only have two children, their preference is not sexist; the preference is not based upon believing that there is anything inherently more valuable about male children.

While there are some reasons for wanting to select the sex of a child that are sexist and therefore morally unacceptable, whether society should stop people from acting upon these reasons is another question.

Some justifications people give for their actions are so immoral that we might consider them *illegitimate* reasons—or reasons that are immoral to the extent that a liberal democracy does not need to respect their legitimacy. Profoundly sexist beliefs fall into the class of reasons that we might consider to be illegitimate.

However if a couple wishes to select the sex of their child for sexist reasons it is unclear whether allowing them access to sex selection services will make things any worse or perpetuate sexism. Failing to allow the couple access to these services may not do anything to change their beliefs about the relative worth of male and female children.

GROWING TECHNOLOGIZATION OF REPRODUCTION. Sex selection technologies are part of the growing trend towards the technologization of reproduction. Reproduction used to occur only naturally and within the context of a family unit. Care and concern in parenting has always been the province of traditional family units and technologization of reproduction might be a threat to this important human institution.

While the values that surround nurturing our children are of great value and ought not be placed at risk, it is unfair to single out sex selection technologies. If the growing technologization of reproduction is a serious problem then the response ought to be to place restrictions on all new reproductive technologies.

That there is a broad spectrum of technologization of reproductive services must be considered. At one end are the relatively low-tech practices of artificial insemination and at the other technologies such as PGD. Sex selection by sperm sorting is closer to the low-tech end of the spectrum and therefore does not have the same potential to technologize reproduction as do technologies like PGD.

INAPPROPRIATE USE OF MEDICAL TECHNOLOGY. Sex selection for social reasons is not a healthcare need. We can plausibly think of infertility as constituting a healthcare need because it is a deviation from a capacity that people of childbearing age usually have. But the capacity to determine sex is over and above normal human capacity. Sex selection is more like cosmetic surgery or other services that can be provided by physicians. Given that there are morally problematic reasons for wanting these services, reproductive specialists need to consider whether this is an appropriate use of their resources and expertise (see Dresser). The concern regarding the appropriate use of medical resources can be partially addressed if sex selection services are privately funded and do not result in any person not receiving treatment for a medical condition. However the issue of whether sex selection services are something that the medical profession ought to be using its knowledge and skill to provide is more difficult to resolve.

THE WELFARE OF THE SEX SELECTED CHILD. A major objection to sex selection technologies is that they may result in harm to children. There are a number of ways in which harm may result.

First, if a sex selection technique is used and fails, the child that results may be neglected or be psychologically harmed by the knowledge that he or she is not the sex that the parents wanted. This consideration can be also be used as an argument for sex selection technologies. If a child will be harmed if he or she is not of the desired sex, then it is better to ensure that the parents have a child of the sex that they want.

Second, if parents have strong views about the way in which children of a certain sex ought to be raised, a child of the undesired sex may be born into an overly restrictive environment.

Third, sex selection techniques can carry risks to the child that may result. At this point in time there is no evidence to suggest that there are harms to children born after sperm sorting interventions. PGD may carry some risks to resulting children. When PGD is used to predict disease the benefit may offset the risk of the technique, but when it is used in selecting sex, determining the value of the benefit in relation to the risk is more problematic.

Sex selection techniques present a broad range of ethical issues. Many objections can be turned into arguments for sex selection. However, some reasons for wanting sex selection are undoubtedly unethical. Moreover, the consequences of sex selection may justify regulation, if not prohibition.

JOHN MCMILLAN

SEE ALSO: *Abortion; Adoption; Christianity, Bioethics in; Cloning; Embryo and Fetus; Family and Family Medicine; Feminism; Fetal Research; Genetic Counseling; Genetic Testing and Screening: Reproductive Genetic Testing; Judaism, Bioethics in; Maternal-Fetal Relationship; Moral Status; Population Ethics; Sexism; Transhumanism and Posthumanism; Women, Contemporary Issues of;* and other *Reproductive Technologies* subentries

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III. FERTILITY DRUGS

The diagnosis and treatment of infertility in humans is a complex matter. The trend has been to regard infertility as a problem that a couple faces, not an issue that rests with the man or the woman alone. Infertility is generally defined as the inability to achieve a pregnancy after one year of unprotected intercourse (Office of Technology and Assessment). There are a number of approaches to the treatment of infertility, one of which is the use of fertility drugs. Some aspects of these drugs, however, are ethically troublesome or controversial.

The causes of infertility in men are much less understood than the causes in women. Historically, the inability to become pregnant and have a healthy child has been viewed

TABLE 1

Summary of Drugs Used to Stimulate Ovulation

Drug Name	Use	Side Effects
Clomiphene citrate	Mildest drug used to induce ovulation	Headaches, blurred vision Hot flashes Enlarged ovaries Abdominal discomfort Rarely, ovarian hyperstimulation syndrome Dry, thick cervical mucus Luteal phase defect Slightly increased risk of miscarriage Increased risk of multiple births Increased ovarian cancer risk?
Pituitary gonadotropins (FSH and LH)	Strongest drugs used to induce ovulation	Redness/swelling at injection site Mood swings, depression Enlarged ovaries Abdominal distention/pain Ovarian hyperstimulation syndrome (may be severe) Increased risk of ectopic pregnancy Increased risk of miscarriage Increased risk of prematurity Increased risk of multiple births Increased ovarian cancer risk?
Human chorionic gonadotropin (hCG)	Spurs release of oocytes	False positive pregnancy test if given late in cycle
Gonadotropin-releasing hormone (GnRH)	Induces ovulation in cases of certain hormone deficiencies	Redness, swelling at catheter site Headaches, nausea Slight risk of ovarian hyperstimulation syndrome Slight risk of multiple births
GnRH analogs	Disrupts normal cycling to allow greater control over ovarian stimulation	Hot flashes Vaginal dryness, painful intercourse Insomnia, mood swings Bone loss (with lengthy use)

SOURCE: Table reprinted with permission from The New York State Task Force on Life and the Law, Assisted Reproduction, 1998, pp. 43–44.

as a woman's problem, and initial attempts to treat infertility were (and often still are) aimed at the woman—even in the absence of the most basic assessments of the presence of viable sperm in the man. In a 1998 report, the American Society for Reproductive Medicine, the main professional association for infertility specialists in the United States, stated that: "Prior to embarking on a course of induction of ovulation with exogenous gonadotropins (originating outside of the ovaries or testes), other fertility factors should be defined and treated as required. Screening tests for these factors should include at least one semen analysis and a hysterosalpingogram (radiography of the uterus and oviducts using a contrast medium) or laparoscopy and hysteroscopy" (p. 2).

Given that one of the earliest and most basic elements in the initiation of a pregnancy is the formation of an embryo as a result of fertilization of an oocyte (egg) in a woman, infertility problems are often traced to ovulatory problems—that is, any biological or structural impairments in the ability to ovulate or release one or more oocytes during the menstrual cycle. Implantation, the process of attachment of the early embryo to the uterine wall, is also a crucial step in the development of a pregnancy, but implantation problems are not well understood, and thus not treated with drug therapy.

There are a number of reasons why a clinician might want to provoke increased ovulatory activity in the female (at her request), including: (1) to increase the likelihood that fertilization will take place naturally, or *in vivo* (in the body of the woman), as a result of usual intercourse or artificial insemination; and (2) to aspirate (remove by suction) oocytes from the woman for donation to another infertile woman, for research, or for attempts to create embryos via *in vitro* fertilization (IVF) for donation, research, or transfer back to the uterus for possible implantation, pregnancy, and birth (National Advisory Board on Ethics in Reproduction).

A Brief History of Fertility Drug Development

Drug therapy to treat infertility in women started in the 1930s, when the relationship between the normal menstrual cycle and ovarian and pituitary function began to be understood. It was discovered that "the pituitary gonadotropin follicle stimulating hormone (FSH) and luteinizing hormone (LH) stimulate follicle growth in the ovary producing estrogen, and this influenced endometrial growth in the uterus" (Leibowitz and Hoffman, p. 203). This led to scientific efforts to obtain gonadotropin extracts. Serum from pregnant mares was the source of the first manufactured gonadotropin (PMG, or pregnant mare gonadotropin), an approach that was eventually abandoned because of the threat of allergic response in humans injected with animal protein (Lunenfeld). Human menopausal gonadotropins (HMGs) were developed in the 1950s using extracts from postmenopausal women.

Since the 1960s, a series of drugs have been discovered, synthesized, and developed to promote or provoke ovulatory activity in women. These drugs are generally labeled *fertility drugs,* and the basic types are reviewed in Table 1. Fertility drugs for men are those that promote and enhance ejaculatory activity (e.g., Viagra), although there are no drug remedies for oligospermia (low sperm count) and azoospermia (no sperm in the semen). More recently, for women, naturally occurring agents to stimulate fertility are being replaced by synthetic agents that are highly purified and designed to reduce side effects.

Economic Considerations

There are economic considerations involved in the use of fertility drugs because, in most U.S. states, patients must pay for these drugs themselves (in the absence of third party reimbursement). In fact, it has often been suggested that cost influences the choice of infertility treatment. Drug therapy alone may cost as much as 3,000, which is still considerably cheaper than cycles of *in vitro* fertilization, which, as of 2002, costs between $8,000 and $10,000 per cycle (Jain et. al.). In addition, there are global economic issues that influence the delivery of this care. Drugs to treat infertility have historically been considerably cheaper in Mexico, for example, and individuals or couples may travel outside of the United States to have their prescriptions filled at a lower cost (Kutteh).

Risks and Ethical Issues

There are two distinct steps in drug regimens to stimulate ovulation. The first step is to promote the actual development of oocytes within the ovarian follicles. The second is to administer drugs that provoke the release of oocytes for purposes of retrieval or natural transit through the fallopian tube. The hazards associated with drug use for this purpose include: (1) the likelihood that a large number of follicles may form and rupture at once, which increases the chances that a number of oocytes may be fertilized, resulting in a multiple birth; and (2) the likelihood that ovulation in large numbers will increase the chances of an ectopic pregnancy (a pregnancy that takes place outside of the uterus, often in the fallopian tube). Ectopic pregnancies are life threatening and considered an adverse event in pregnancy management or infertility treatment. Even in a controlled situation, ovarian stimulation entails both known and theoretical risks.

Ovarian hyperstimulation syndrome (OHSS) is a potential complication of ovarian stimulation with exogenous gonadotropins. OHSS can be classified as mild, moderate, or severe (ASRM, 1998). The pathophysiology of this syndrome is not well understood, but it seems to be caused by "increased capillary permeability, which allows major fluid shifts from the intravascular compartment to the extravascular space within the follicle and ovary" (Gianaroli et al., p. 175). Physical symptoms that OHSS might be occurring include: a weight gain of one to two pounds or more daily after human chorionic gonadotropin (hGC) has been administered, severe abdominal pain, nausea, vomiting, or diarrhea (Leibowitz and Hoffman, p. 208). In addition, a concentration of red blood cells can lead to thromboembolic events, electrolyte imbalance, oliguria (low production of urine), shock, or death in 1 percent of women (Miller and Hoffman). It is important to note that ovarian stimulation is sometimes provided by physicians who are not infertility specialists (Dresser), and thus may not have the depth of expertise to judge the dosage of these powerful drugs. They may also not have a sonogram available to view developing follicles.

There has been considerable controversy about a possible relationship between cancer and infertility treatment. However, according to *Pharmacotherapy, A Pathophysiologic Approach* (2002), by Joseph Dipiro et al., "an association between fertility agents and the risk of breast and ovarian cancers has not been confirmed and more studies are needed to clarify any link between infertility treatment and ovarian cancer." (p. 1440).

Multiple Births

At first glance, a multiple birth might be regarded as a welcome event by those who are seeking to remedy the problem of infertility and build their families. Multiple births have been a consistent outcome of infertility treatment using drugs to induce ovulation, and also as a result of *in vitro* fertilization. An increase in the incidence of twins, triplets, and higher multiple births over that observed in the normal pregnant population has been a steady feature of IVF since the birth of the first IVF baby, Louise Brown, in 1978. It has been observed that many infertile couples are delighted on learning that they will be the parents of twins, partly because they can have two children without having to undergo infertility treatment twice. But there are hazards associated with multiple gestation and births, especially when the pregnancy results in the birth of super-multiples (quadruplets or above). The primary hazard associated with multiple gestation and birth is premature birth. The low birthweight of premature babies poses a significant risk to these infants.

The incidence of triplet or higher-order multiples has gone up from 29 per 100,000 live births in 1971 to 174 per 100,000 live births in 1997 (U.S. Centers for Disease Control, 2000). Of these, it is believed that approximately 20 percent are spontaneously conceived, with the remaining 80 percent evenly split between conception by ovarian stimulation and conception by other assisted-reproductive technologies (ARTs). A more recent study of state-specific use of assisted reproductive technologies in 1996 and 1998 indicates that the use of ART is increasing in most states, and that more than half of the infants born as a result are multiple births (U.S. Centers for Disease Control, 2002).

Except in the case of spontaneous twinning, high order multiple births can be minimized in the course of infertility treatment. If a clinician notes that in a given cycle a large number of follicles are maturing, the woman or the couple can be so advised and skip intercourse until the next cycle. Another possibility is to transfer only a small number of embryos back to the uterus for possible implantation in the process of IVF. The United Kingdom, for example, limits the number of transferred embryos to two (Human Fertilisation and Embryology Authority).

Clincally and ethically, the most controversial strategy for avoiding multiple births is reducing the number of fetuses in utero after the pregnancy is underway, which provides more space for a smaller number of fetuses to grow and develop. Although reducing the number of fetuses in utero is not objectionable to some, it can be particularly traumatic for a couple who have been trying to conceive to then be faced with the choice of whether or not to remove some of the fetuses. From a clinical standpoint, multifetal-pregnancy reduction poses serious risks, including the loss of the entire pregnancy. The risk of pregnancy loss increases with the number of fetuses (Alexander; Evans). It is therefore preferable to avoid or prevent the development of a high-order multiple pregnancy in the first place through transfer of only a small number of embryos via IVF, or through the careful monitoring of maturing follicles occurring as a result of ovulation induction (White and Leuthner).

In conclusion, the overriding ethical objective in the use of fertility drugs is to facilitate fertility without causing harm. From a clinical standpoint, this is a balancing act based on careful physical assessment of the couple (and primarily the woman) involved. Ethical practice in this area also involves careful counseling to ensure that the risks are understood and that careful choices are made. The goal of achieving pregnancy and birth must be balanced against the likely health and well-being of children who are born, as well as the ongoing physical and emotional health of the woman and family. To this end, fertility drugs cannot be used carelessly, and pregnancy and number of births alone, particularly in the case of supermultiples, cannot be the sole objectives.

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SEE ALSO: *Abortion; Adoption; Christianity, Bioethics in; Cloning; Embryo and Fetus; Feminism; Fetal Research; Genetic Counseling; Genetic Testing and Screening: Reproductive Genetic Testing; Islam, Bioethics in; Judaism, Bioethics in; Maternal-Fetal Relationship; Moral Status; Population Ethics; Sexism; Transhumanism and Posthumanism; Women, Contemporary Issues of;* and other *Reproductive Technologies* subentries

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IV. LEGAL AND REGULATORY ISSUES

Reproductive freedom is not a simple concept. Encompassing far more than abortion, it also includes the choice of whether and with whom to procreate, how many times to procreate, and by what means. It includes the choice of the social context (e.g., marital, communal, or solitary) in which the reproduction takes place and, to some extent, the characteristics of the children people will have (gender, presence or absence of certain disease). It is grounded, for some moral philosophers, in self-determination, individual welfare, and equality of expectation and opportunity (Brock).

Noncoital reproduction, that is, reproduction achieved despite the absence of sexual intercourse, allows single, homosexual, and infertile people to start and rear families. Often, it entails such controversial techniques as extracorporeal maintenance of an embryo, screening and storage of gametes, or the reproductive assistance of men and women who do not plan to maintain a relationship with the child they help to conceive or gestate.

Thus, new reproductive technologies enable individuals to exercise more reproductive choices. This, in turn, invites exploration of the depths of cultural relativism and the meaning of genetic linkage; the preference for the heterosexual couple as the paradigm for family life; the role of the state as the regulator versus facilitator of individual aspirations; and the role of the state and the professional as the gatekeeper to the technologies that permit people to circumvent infertility or conventional forms of procreation.

Under U.S. law, states can outlaw or regulate certain aspects of reproductive technologies. Areas for possible state intervention include protection of the extracorporeal embryo; protection of patients (and their resulting children) who seek to use reproductive technologies; regulation of contract (i.e., *surrogate*) motherhood; definition of family forms and familial relationships in light of gamete transfers and use of contract birth mothers; and limitation on commercialization of the techniques. But the extent to which states can ban or regulate noncoital reproduction depends on the extent to which procreation is protected by state and federal constitutions, and the extent to which ancillary practices, such as payment for gametes or services of a contract mother, are viewed as part of the act of procreation or as independent acts of commercial negotiation.

In the United States, the more zealously procreation is guarded by constitutional guarantees and the more broadly the definition of procreation is drawn, the more compelling and narrowly drawn must be state efforts to restrict use of noncoital procreation. Those restrictions, when they exist, will be manifested in both common law and statutory law, usually with regard to the fields of contracts, property, or family law. Because the details of such law vary tremendously from state to state, this article focuses primarily on the overarching constitutional issues that limit state policymaking and lawmaking in this field, and compares national responses.

Is There an Affirmative Right to Procreate?

The right to procreate, that is, the right to bear or beget a child, appears to be one of the rights implied by the U.S. Constitution. It is grounded in both individual liberty (*Skinner v. Oklahoma,* 1942) and the integrity of the family unit (*Meyer v. Nebraska,* 1923), and is viewed as a "fundamental right" (*Griswold v. Connecticut,* 1965), one that is essential to notions of liberty and justice (*Eisenstadt v. Baird,* 1972).

The U.S. Supreme court has not explicitly considered whether there is a positive right to procreate—that is, whether every individual has a right to actually bear or beget a child and thereby has a claim on the community for necessary assistance in this endeavor. It has, however, considered a wide range of related issues, including the right of a state to interfere with procreative ability by forcible sterilization (*Skinner v. Oklahoma,* 1942), the right of individuals to prevent conception or to terminate a pregnancy (*Roe v. Wade,* 1973; *Webster v. Reproductive Services,* 1989; *Planned Parenthood v. Casey,* 1992), and the right of individuals to rear children in nontraditional family groups (*Moore v. City of East Cleveland, Ohio,* 1977).

Since the 1942 *Skinner* decision, lower courts have accepted the notion that states may not forcibly sterilize selected individuals unless such a policy can withstand strict constitutional scrutiny. The basis for requiring this level of scrutiny is the assertion that the "right to have offspring," like the right to marry, is a "fundamental," "basic liberty." Further, the *Skinner* and *Eisenstadt* decisions arguably hold that the right to use contraception or to be free of unwarranted sterilization is an aspect of individual, rather than marital, privacy. As stated in *Eisenstadt:* "If the right to privacy means anything, it is the right of the individual, married or single, to be free of unwarranted government intrusion into matters so fundamentally affecting a person as the decision to bear or beget a child" (*Eisenstadt v. Baird,* 1972).

But the right to privacy is no longer the primary justification for abortion rights, or, by extension, reproductive rights. The 1992 *Planned Parenthood v. Casey* decision specifically based its opinion on "liberty" (rather than privacy) rights, and concluded that abortion remains protected from state efforts to prohibit abortion. The emphasis on "liberty" language changes the focus of abortion rights from one of limitations on governmental power (as discussed in "privacy"-based decisions) to one of individual control of one's person. The opinion attempts to explain why abortion is an essential "liberty" for women because it permits control of one's body and one's personal destiny.

Justice Antonin Scalia's dissent mocks this attempt. After reciting the list of phrases used elsewhere by his colleagues, such as "a person's most basic decision," "a most personal and intimate choice," "originat[ing] within the zone of conscience and belief," "too intimate and personal for state interference," Scalia complains that "the same adjectives can be applied to many forms of conduct that this Court … has held are not entitled to constitutional protection—because, like abortion, they are forms of conduct that have long been criminalized in American society. Those adjectives might be applied, for example, to homosexual sodomy, polygamy, adult incest, and suicide" (p. 785).

Scalia's dissent highlights the potentially far-reaching implications of what the plurality has written regarding the fundamental importance of controlling one's fertility. The *Casey* plurality opinion lays out an argument for reexamining the 1879 *Reynolds v. U.S.* decision (upholding the power of the state to outlaw polygamous marriage) and the 1986 *Bowers v. Hardwick* decision (upholding the power of the state to criminalize homosexual behavior), a task critical to determining if states can restrict noncoital reproduction to married couples. It also lays the groundwork for cases sure to arise concerning prenatal diagnosis, sex selection, cloning, and (ultimately) parthenogenesis.

What Can States Do To Regulate Reproductive Technologies?

Even assuming that constitutional protection for procreation remains grounded in a fundamental rights analysis, possibilities remain for areas of state regulation of who may use noncoital reproduction and how they may proceed. First, many aspects of noncoital reproduction arguably do not amount to *procreation,* and therefore are more amenable to state control. Donor gametes and surrogacy do not permit an infertile person to procreate; rather, they allow fertile persons to reproduce without partners or to bypass the infertility of their partners.

Artificial insemination by donor (AID), for example, can be used by single or lesbian women who want to become pregnant but who find the thought of sexual intercourse with a man distasteful. Almost half the states in the United States have statutory language governing AID that appears to ignore the possibility of such a use, leaving the legal status of the donor-father unclear (U.S. Congress, Office of Technology Assessment [OTA], 1988b). Canada and France have also had national commissions recommend that single and lesbian women be barred from using donor insemination in order to conceive (Liu; McLean). Because such women could physically procreate without donor insemination, albeit with great discomfort, it can be argued that such restrictions do not impinge upon a fundamental right to procreate and are therefore potentially tolerable.

Of course, the restrictions would still be subject to challenges based on the unequal treatment of single or lesbian women as compared with the married, heterosexual population. AID for a married couple in which the husband is infertile is also nothing more than a medical alternative to the social solution of adultery; the AID itself does not enable the infertile man to procreate. Nevertheless, in Canada, France, and much of the United States, this form of AID is viewed as therapeutic, seemingly because the *unit* of infertility (i.e., the *patient*) is seen as a monogamous, married, heterosexual couple, not as an unmarried individual.

In typical surrogacy arrangements, in which the husband is fertile and the wife infertile, the surrogacy arrangement, like AID, does not permit the infertile wife to procreate, nor is the fertile husband unable to procreate without resorting to surrogacy. Rather, surrogacy allows the husband to procreate without committing adultery and with some assurance, as in the AID scenario, that the couple will be able to retain exclusive custody of the resulting child. As with AID, such a use of contract motherhood is viewed as therapeutic by many. While even this use of surrogacy has engendered opposition ranging from criminalization to mere unenforceability in countries such as Australia, Canada, England, and France, and in some portions of the United States, it has never encountered the same degree of approbation as the so-called surrogacy of convenience, in which a rearing mother finds it useful to hire someone else to carry the child (Liu; McLean).

Indeed, much of the debate surrounding the most famous surrogacy case in the United States, *Baby M* (1988), focused on whether the rearing mother had declined to become pregnant due to career concerns and undue worry about her health, or rather due to legitimate concern that pregnancy would seriously worsen her multiple sclerosis. This debate exemplifies the increased willingness of the American public to regulate or ban surrogacy when it is not perceived as a cure for a medical problem such as infertility, a sentiment reflected in the constitutional analysis that permits greater state regulation where the right to procreate is not directly implicated.

Egg donation to a woman who cannot ovulate but who can carry to term does not technically allow the recipient to procreate, as she will not *reproduce* in the genetic sense. But it does allow her to experience pregnancy and childbirth, which for women are intimately associated with genetic procreation. In terms of both biological significance (gestation is, of course, a biological activity) and emotional impact, this would seem to be close to procreation, even in its more narrow definition. Thus, it is difficult to categorize this activity in terms of whether it allows an infertile person to *procreate.*

Despite this fact, there is considerable hesitation about permitting egg donation. Whereas sperm donation is widely accepted, egg donation entails significantly more medical discomfort and even risk on the part of the donor. This in turn raises the specter, at least in the United States, of increased payments for the donation. For some, such payments represent an undue incentive to undergo medical risks, as well as an unacceptable commercialization of human gametes. Nevertheless, at least in California, there is a thriving egg donation practice.

Even those aspects of noncoital reproduction that clearly involve procreation can be regulated or banned, if there is a sufficiently compelling state interest. It is true that artificial insemination by husband (AIH), and in vitro fertilization (IVF) using a couple's own gametes (whether or not a contract mother is hired to carry the child to term), permit an otherwise infertile man or woman to procreate genetically. By bypassing the fallopian tube defect or permitting intrauterine insemination of the husband's concentrated semen, these techniques actually help infertile individuals to participate in the act of reproduction. But a compelling state interest in the protection of embryos and fetuses, for example, could justify significant restraints on even AIH and IVF.

Is There a Compelling State *Interest* in Embryos and Fetuses?

The most likely claim for a compelling state purpose to outlaw or regulate IVF is that of protection for the extracorporeal embryo, whether or not accompanied by a contract with a gestational surrogate.

The *Webster v. Reproductive Services* (1989) and *Planned Parenthood v. Casey* (1992) decisions indicate that the U.S. Supreme Court is now quite tolerant of symbolic legislative statements concerning the sanctity of embryonic life and of significant restrictions on the exercise of constitutionally protected rights, such as abortion, in the name of protecting these early life forms. It seems likely that the court would uphold state statutes, such as the one in Louisiana that regulates management of extracorporeal embryos. Such restrictions may include prohibiting nontherapeutic experimentation on the embryo, embryo discard, and unnecessary creation of *surplus* embryos for the purpose of experimentation. It might also attempt to regulate transfer of embryos. By declaring that life begins at conception, as was done in the Missouri statute upheld in Webster, and by equating the rights of embryos to the rights of children, states could demand that embryo transfers be viewed as adoptions.

This was the approach taken by the trial court in the case of *Davis v. Davis* (1992), a Tennessee divorce case that struggled with determining the legal status of several frozen embryos that were left over from unsuccessful IVF treatments and became the subject of a divorce dispute. Characterizing the question as one of child custody, and viewing the embryos as children, the trial court then awarded custody to the parent whose actions would be in the best interests of the embryos. By assuming that embryos have "interests," and then defining one of those interests as an interest in being born, the trial court awarded the embryos to the wife, who intended to have them implanted in her womb in the hope of bringing them to term.

By contrast, the appellate court backed away from the characterization of the embryos as *children* and the resulting "best interests" analysis. Without ever explicitly calling the embryos property, the court proceeded to treat them as property held jointly by the couple, and thereby concluded that disposition of the embryos must be by agreement because each party had an equal property interest in them.

The Tennessee Supreme Court reviewed available models for disposition of the embryos when unanticipated contingencies arise. Those models range from a rule requiring, at one extreme, that all embryos be used by the gamete-providers or be donated for uterine transfer (such as is required under an as yet unchallenged Louisiana statute), and, at the other extreme, that any unused embryos be automatically discarded. The Tennessee Supreme Court, when it considered the *Davis* case, was aware of the *Planned Parenthood v. Casey* (1992) decision, which reiterated the *Roe* (1973) holding that a state may express an "interest" in a fetus. Unfortunately, like *Roe, Planned Parenthood v. Casey* fails to identify what this interest might be or why it arises, leaving the *Davis* court with little guidance on how to extend the state interest argument to nonabortion settings.

Numerous commentators have struggled to identify this state interest (Joyce; Tooley). Many begin with the premise that a sufficiently detailed biological understanding of embryo potential will yield an answer:

> [E]very living individual being with the natural potential, as a whole, for knowing, willing, desiring, and relating to others in a self-reflective way is a person. But the human zygote is a living individual (or more than one such individual) with the natural potential, as a whole, to act in these ways. Therefore the human zygote is an actual person with great potential.… (Joyce, p. 169)

But others argue that the genetic blueprint of a person cannot be entitled to the same moral standing as that of the person himself or herself, because any inherent "right" to live is premised on the idea that it is in the "interest" of the entity to continue existing (Tooley). Where, as with a zygote, there is no self-concept, there can be no "interest" in continuing to exist, no "desire" to continue to exist, and therefore no "right" to continue to exist.

Such an argument refutes the *Davis* trial court's treatment of the frozen embryos as children with an interest in being brought to term. But the appellate court's assumption that they must therefore be treated as property is equally unjustified. Society may choose nonetheless to grant rights to the zygote or fetus, for any number of reasons, if such steps do not unduly impinge on another liberty recognized by society, such as the liberty of men and women to control their reproductive futures.

In fact, Justice John Paul Stevens takes on this issue in his concurring opinion in *Planned Parenthood v. Casey:*

> Identifying the State's interests—which the States rarely articulate with any precision—makes clear that the interest in protecting potential life is not grounded in the Constitution. It is, instead, an indirect interest supported by both humanitarian and pragmatic concerns. Many of our citizens believe that any abortion reflects an unacceptable disrespect for potential human life and that the performance of more than a million abortions each year is intolerable; many find third-trimester abortions performed when the fetus is approaching personhood particularly offensive. The State has a legitimate interest in minimizing such offense.… These are the kinds of concerns that comprise the State's interest in potential human life. (*Planned Parenthood v. Casey,* 1992, 120 L. Ed. 2d 674 at p. 739)

Struggling with the task of expressing a state interest in embryonic life without unduly impinging upon the reproductive rights of adult men and women, the Tennessee Supreme Court in the *Davis* case concluded that embryos are neither children nor property, but occupy an intermediate status based on their potential for development. This, in turn, would not convey a right to be born under either state or federal constitutional law but would demand some protections. These include implantation where possible, freedom from unnecessary creation or destruction, and dignified management.

The Tennessee court's characterization of an intermediate status for embryos is the most intriguing part of the opinion, as it did not present a coherent theory of that status and its implications. There are, of course, models of intermediate property status. Animals, for example, are treated as property with no "right to life," but at the same time are protected from cruel and painful treatment by their owners. Works of art may be owned, but "moral rights" possessed by the artist in some jurisdictions prohibit defacing or destroying the art. Land may be owned subject to numerous restrictions on use that would permanently destroy some publicly valued attribute. Which, if any, of these models describes the intermediate status held by the embryos? And on what basis? This is indeed the key question left totally unanswered by the Tennessee court. As it stands, though the opinion gives some narrow, nearly regulatory guidance to IVF clinics, it offers little to those wondering in general whether other restraints on embryo creation and management are in order.

Other countries have struggled with the same dilemma. Most often, as in England and Australia, the compromise solution is chosen, in which limited experimentation is permitted on unavoidably abandoned embryos. Deliberate creation of embryos for the purpose of experimentation is frowned upon. Occasionally a stricter view is adopted, as in Germany, where embryo experimentation is simply banned. Generally, however, where embryos are to be created in order to permit implantation and gestation, even extracorporeal maintenance or embryo freezing is tolerated (U.S. Congress, OTA, 1988b; Liu; McLean).

What is the State Interest in the Children Conceived Noncoitally?

Related to state interest in the protection of extracorporeal embryos is its interest in protecting the children born following noncoital conception. This takes its most frequent form in suggestions for limiting use of these technologies to married couples, on the theory that being born into a single-parent home is harmful to a child. On this basis, almost two-thirds of physicians surveyed in 1987 and a number of states either explicitly or implicitly deny artificial insemination services to unmarried women (U.S. Congress, OTA, 1988a, 1988b).

While some may deplore this practice, the fact that unmarried persons are not considered a "suspect" class in constitutional jurisprudence (i.e., they are not considered a class in need of special protection from discriminatory legislation because they are fully able to use the political system to protect their interests), means that such discriminatory practices are largely immune to constitutional challenge as an abridgment of their right to equal protection of the laws. Unless procreation, and specifically the use of artificial insemination, is viewed as a fundamental right, such persons will be limited to challenges under state and federal civil rights statutes in their pursuit of equal access to these technologies.

To the extent that the right to procreate implies a right to create a family, constitutional law from the nineteenth century remains unchallenged in its support for criminalization of family forms, such as polygamy, that fly in the face of Western European tradition. While there have been twentieth-century cases in support of broadening the definition of *family,* there has not yet been any case in which the right to marry is extended beyond a heterosexual couple. Thus, whatever the right to privacy entails, it does not appear to guarantee the right to form familial relationships that achieve the same legal recognition as that bestowed by marriage.

Generally, current interpretations of constitutional law appear to support the assertion that for married couples there is a right to privacy embedded in the wording and history of the constitution and that such privacy extends to reproductive decision making free from unwarranted governmental intrusion. While case law suggests that individuals are entitled to this privacy in equal measure, judicial hostility to claims of a right by homosexuals to marry or engage in sexual activity (*Bowers v. Hardwick,* 1986), by minors to have unrestricted access to abortion (*Hodgeson v. Minnesota,* 1990), and by physicians to give full information concerning abortion (*Rust v. Sullivan,* 1991) suggest limitations on Supreme Court extension of this right.

Indeed, much of the state activity concerning contract motherhood has been directed at protecting the children conceived through these arrangements. In the event a surrogate changes her mind, a custody dispute can break out between the birth mother and the genetic father. Reluctant to extend parental status to the adopting mother without terminating the parental status of the birth mother, but also determined to see the child placed in the safest home, courts have been in a quandary. Most often the solution has been to refuse to use the contract as the basis for a custody decision, and instead to rely on traditional family notions of child welfare. Next, courts have generally refused to terminate the birth mother's status as a presumptive legal parent. But despite these findings, most courts also award custody to the genetic father and his wife, as it is this couple who is usually better able financially and socially to convince the court that they can provide a secure home for the baby (U.S. Congress, OTA, 1988b; McLean).

Other Concerns Regarding Contract Motherhood

Another state interest in surrogacy stems from the fact that the contracts typically entail promises by the contract mother to refrain from certain behaviors such as drinking, smoking, or the use of illicit drugs, as well as affirmative promises to follow prescribed prenatal care regimes and to undergo prenatal testing for fetal health. Enforcing such contract promises raises constitutional issues, requiring a relinquishment of significant autonomy on the part of the contract mother. This is particularly true with regard to promises to follow prescribed medical care, which may entail submission to invasive tests and even surgery, in the case of cesarean sections.

Surrogacy also raises the specter that the hiring couple might gain what amounts to a property interest in the body of the contract mother. This is particularly true where gestational surrogacy is employed, and the child the contract mother is carrying is genetically related to the hiring parents but not to her. At least one court has been known to issue a "prenatal adoption" order, in which the hiring husband and wife were declared the legal parents of the fetus still within the gestational mother's body (*Smith v. Jones,* 1988). In such a case, the hiring parents would have a legally recognized interest in the development of the fetus. Indeed, as parents they might have a legal duty to protect the fetus from harm, as has been confirmed by cases that hold pregnant women criminally liable for behaviors that threaten fetal health. How to protect fetuses while not compromising the physical integrity and legal autonomy of the gestational mother poses a significant constitutional challenge.

Gestational surrogacy also raises fundamental questions about the definition of parenthood, particularly of motherhood. While the law has consistently given preference to biological parents over nonbiological parents, with specific exceptions carved out for adoption and AID, it has never before been forced to consider the definition of *biological.* As of the mid-1990s, only one state has considered the problem. In California, a dispute developed between a couple (the Calverts) whose gametes had been used to conceive a child who was subsequently brought to term by a hired gestational contract mother named Anna Johnson. The trial and appellate courts both concluded that the genetic relationship, which defines "natural" parent for men, would define the "natural" parent for women. The two lower courts specifically rejected the notion that gestation is a biological relationship formed by the indisputable fusing of maternal and fetal well-being during the nine months of pregnancy that could equally well form the basis for defining the "natural" mother.

California's lower court decisions in *Johnson v. Calvert* (1991), stating that a gestational mother is no more than a foster parent to her own child, are almost without precedent worldwide. Only Israel, bound by unique aspects of religious identity law, has adopted a genetic definition of motherhood. Every other country that has examined the problem—including the United Kingdom, Germany, Switzerland, Bulgaria, and even South Africa with its race-conscious legal structure—has concluded that the woman who gives birth is the child's mother.

The California Supreme Court's 1993 opinion on *Johnson v. Calvert* declined to find either the genetic or the gestational mother to be the definitive "natural" parent. Instead, it chose to view either relationship as a presumptive form of natural parenthood. Then it specifically declined the invitation to have the law reflect what had actually happened, that is, the birth of a child with two biological mothers, one gestational and the other genetic. Agreeing that acknowledging more than one natural mother would be, as the trial court stated, a "recipe for crazymaking," the California Supreme Court said that whichever of the two biologically related women had been the intended mother would then be declared the "natural" mother. It continued by stating that in the event that the gestational and genetic mothers are not the same person, and that the intended mother is neither the genetic nor gestational parent, she would nonetheless be considered the "natural" mother. Thus the court avoided what is at base the most interesting question raised by the use of reproductive technologies: the possibility of declaring more than one woman to be a "natural" parent of a child. To do so, of course, would require escaping the confines of the heterosexual couple as the paradigm for a family and acknowledging that some people become parents by virtue of genetic connection, others by gestational connection, and still others by contract—whether a marital contract with a genetic or gestational parent, or a reproductive technology contract that creates relationships with children conceived with donor gametes or carried to term by contract mothers.

What is the State Interest in Access to Quality Services?

A final and overarching area of state interest lies in consumer access and protection. Only a handful of states have legislation mandating insurance coverage for the most expensive of these technologies, IVF. Those states, including Arkansas, Hawaii, Maryland, Massachusetts, Texas, and Wisconsin, have responded to political pressure from organized medicine as well as from infertility support groups. But no state has yet asserted that insurance coverage is required by virtue of the fact that procreation is a fundamental right that may, for some people, be exercised only when using an expensive technology. Indeed, in the context of abortion services, the Supreme Court has made clear that states may forbid Medicaid or other public funding of such services, although they are clearly linked to the exercise of a fundamental right. In fact, the *Webster* decision upheld a state prohibition on the use of public facilities for abortion services, even when no public funds are used.

Where IVF and other reproductive technology services are being provided, however, the state may well choose to regulate them for the sake of protecting patients from unscrupulous practices. These may include misleading advertising, inadequate facilities, insufficiently trained personnel, and negligent screening of gamete donors for genetic and infectious diseases that might be transmitted to recipients. Even in the exercise of a fundamental right, the state may enforce regulations designed to protect the patient.

Another consumer issue involves the regulation of commercialization of reproductive technologies. Although sperm donation has continued apace in countries where no payment is permitted, most commentators agree that the availability of donor gametes and contract mothers in the United States would be severely reduced if commercialization were prohibited. Nonetheless, even when viewing access to reproductive technologies as an exercise of freedom to procreate, several state courts have concluded that there is ample state authority to prohibit commercialization (*Doe v. Kelley,* 1981; *Baby M,* 1988). The basis for this conclusion can vary. One line of argument, focusing on surrogacy, characterizes it either as baby-selling or the sale of parental rights, both of which traditionally have been forbidden despite significant libertarian arguments in favor of free markets for both. These prohibitions on selling children or parental rights would easily extend to prohibitions on the sale of embryos, if embryos are characterized as children. Prohibitions on the sale of semen and ova probably could be justified on the same basis as the current prohibitions on organ sales, despite the same line of libertarian arguments.

Other arguments in favor of prohibiting commercialization focus on the effect such activities have on public morals, on the creation of property interests in the bodies of others, and on the fear that the creation of an industry surrounding the sale of gametes, embryos, and reproductive services will create a class of professional breeders. A 1987 survey of surrogacy brokers by the OTA revealed significant discrepancies in economic and educational backgrounds of those who hire contract mothers and those who work as contract mothers (U.S. Congress, OTA, 1988a), leading to the conclusion that the two groups would be unlikely to wield equal bargaining power during the preconception contract negotiations or during postbirth custody disputes.

All of these arguments would probably fail if subjected to the strict scrutiny brought to bear on state interference with a fundamental right. But the reluctance of U.S. courts to view commercialization of reproductive services as an expression of procreative freedom reduces the degree of scrutiny to which state restrictions are subjected. Any rational state purpose will suffice if the restriction interferes with a privilege rather than a fundamental right.

Conclusion

The legal and regulatory issues surrounding reproductive technologies concern the ability of a government to ban or restrict noncoital reproduction because it may harm embryos, children, consumers, or public morals. Where governments choose not to ban the practice, they may wish to regulate it, for example, by limiting what types of prospective parents may use it, which adults will be related to the resulting children, and what kinds of ancillary practices—such as research or commercialization—will be permitted. In the United States, the details of such regulation are a function of state legislation and the resolution of novel cases by the courts. But the federal Constitution places significant limits on how far such legislation or judicial lawmaking may interfere with the opportunity of individuals to exercise procreative choice.

R. ALTA CHARO (1995)
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SEE ALSO: *Abortion; Adoption; Cloning; Embryo and Fetus; Feminism; Fetal Research; Genetic Counseling; Genetic Testing and Screening: Reproductive Genetic Testing; Healthcare Resources, Allocation of: Microallocation; Law and Bioethics; Maternal-Fetal Relationship; Moral Status; Population Ethics; Sexism; Transhumanism and Posthumanism; Women, Contemporary Issues of;* and other *Reproductive Technologies* subentries

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V. GAMETE DONATION

Gamete donation is a procedure that enables those who wish to have children, but who cannot produce or use their own gametes (sperm or eggs), to use gametes provided by others in attempts to procreate. Those at risk of transmitting serious genetic disease to their children and those without a sexual partner (of the opposite sex) may also use the gametes of others to attempt to have children. Sperm donation is carried out by inserting sperm provided by a donor directly into a woman's reproductive tract. Egg (oocyte) donation involves merging eggs extracted from a donor with sperm in a laboratory dish by (*in vitro* fertilization [IVF]) and transferring some of the resulting embryos to a woman's uterus.

While the use of gamete donation has stimulated amazement and curiosity, it has also created significant ethical and public-policy questions. Concerns have been raised about whether this practice might radically alter understandings of marriage, procreation, and parenthood; whether it objectifies and commodifies gamete donors and the offspring who emerge from such procedures; and whether it harms donors, recipients, or the resulting children. There is also a rising concern about whether the procedures associated with gamete donation should be subject to greater oversight and regulation. Egg donation, in particular, is poised to expand in novel directions that will raise ethical and public-policy issues never before considered.

The use of the term *donation* in connection with the provision of gametes is seen as self-contradictory by some, since sperm and egg donors in many instances do not donate their gametes, but are financially remunerated for them. However, since this term is in common usage and is understood to cover both unpaid and paid suppliers, its use will be retained here.

The History of Gamete Donation

Pregnancy following sperm donation was mentioned in Western literature as early as 1790, when the Scottish surgeon John Hunter was said to have artificially inseminated a woman in London. J. Marion Sims, a New York doctor, is believed to have carried out the first sperm insemination in the United States in 1866. The practice was usually kept secret, however, because it was considered shameful and unnatural to introduce the sperm of a man other than her husband into the body of a woman. The first confirmed case of sperm donation took place in the United States in 1884, when William Pancoast, a physician in Philadelphia, inseminated a woman using sperm from a medical student. In 1953, scientists demonstrated that human sperm could be frozen and thawed for insemination to produce a normal child, paving the way for the first commercial sperm bank, which was opened in 1970 in Minnesota. By 1993 it was estimated that more than 80,000 women were undergoing the procedure each year, resulting in approximately 30,000 pregnancies annually.

Oocyte donation was first reported in 1983 in Australia. Since then, use of this procedure has grown rapidly. In 1987 it was reported to be available at 17 programs in the United States; in 1993 there were 135 known programs, and in 1998 this number had doubled to 260 programs. In 1998, a total of 5,273 egg-donation cycles were initiated, with 4,783 transfers of donated eggs to recipients, for a delivery rate per transfer of 41.2 percent (Society for Assisted Reproductive Technology).

The Practice of Sperm Donation

Sperm donation is usually performed in a medical setting by a physician using sperm acquired from an anonymous donor. It is also practiced in private contexts by those who do not want professional supervision, although this is considered extremely unsafe as the donor has not been screened for infectious diseases that might affect the woman or the resulting child. This private practice employs sperm from a known or anonymous donor using common household implements. There are three major sources of sperm: large sperm banks that ship frozen specimens nationwide, regional sperm banks with a more local distribution area, and pools of donors retained by individual practitioners.

As long as physicians could use friends, colleagues, and informal networks to acquire sperm, supply was not a problem. When these sources became insufficient in the 1980s, medical students were given a modest financial incentive to *donate* sperm. Payment represented closure of the transaction, and donor anonymity was guaranteed (Daniels). Donors today are primarily young single males students who are found by word of mouth and through advertising in college and local newspapers, in magazines, and on the Internet. Sperm banks attempt to recruit a pool of donors exhibiting a variety of physical, mental, and ethnic characteristics. Donors are matched with recipients on the basis of physical and other features as far as possible, while a few sperm banks specialize, offering sperm from donors of high academic or athletic ability.

Practice guidelines of the American Society of Reproductive Medicine (ASRM; formerly the American Fertility Society) recommend that sperm donors undergo medical screening that includes testing for infectious and sexually transmitted diseases. Until the 1980s most insemination with donated sperm was performed with fresh sperm, which were only sometimes tested for venereal disease. That changed dramatically in 1988 when the Centers for Disease Control, concerned about the transmission of AIDS, called for donors to be tested for HIV antibodies at the time of donation and again after their sperm had been frozen for six months before their gametes could be used. This rule was designed to reduce the risk of transmitting HIV through sperm from infected donors who did not have detectable antibodies at the time of donation. Practitioners now only use frozen sperm.

Meanwhile, according to ASRM recommendations, the recipient is also screened medically and tested for cystic fibrosis carrier status. Her partner is clinically evaluated and tested for HIV antibodies, and both are to be offered psychological counseling.

In the United States, sperm donors are paid for their time and expenses, with payment in 1998 ranging from $35 to $50 per unit. The Human Fertilisation and Embryology Authority (HFEA) of the United Kingdom currently allows a fee of U.S.$23 per donation, but it is moving toward completely phasing out payments to gamete donors. Sperm donors are not paid in New Zealand, Sweden, and France.

The Practice of Egg Donation

Egg donation is a more complex, onerous, and risky procedure than sperm donation—both for donor and recipient. Both must follow drug regimens to stimulate the production of multiple eggs and the donor must undergo an intrusive egg-recovery procedure. Consequently, egg donation is necessarily offered under medical auspices through *in vitro* fertilization (IVF) programs affiliated with academic medical centers, community hospitals, and private practices.

Egg donors must undergo the same drug regimens and egg-recovery procedures as women who undergo IVF. An average of thirteen eggs is collected from each donor, and up to twenty-five eggs have been reported extracted at one time. These eggs are fertilized with sperm *in vitro*. Some of the resulting embryos are then inserted into the uterus of the recipient, who has been injected with drugs to prepare her uterus to accept embryos. The remaining embryos may be frozen for later use by the recipient, donated to medical research, donated to others, or discarded.

Egg donation involves medical risks to the donor of varying degrees of severity. As a consequence of the use of fertility drugs, 1 percent of donors experience ovarian hyperstimulation syndrome (OHSS), which can lead to kidney or liver failure, cardiorespiratory dysfunction, or stroke, among other effects. In addition, 10 to 20 percent of donors experience moderately severe hyperstimulation syndrome, while approximately one-third are affected by milder forms of this syndrome. According to some studies, there is an association between the use of ovulation-stimulating drugs and ovarian cancer. Laparoscopy, which is used to extract eggs from donors, also carries minor risks. Even when there are no complications, the procedure is highly uncomfortable and time-consuming. Recipients of donated eggs, studies suggest, are at increased risk of pregnancy-related complications such as preeclampsia, diabetes mellitus, and anemia, as well as HIV infection.

When egg donation began, it was usual to acquire eggs from anonymous donors who were undergoing IVF and were willing to part with spare eggs. As the practice grew in the late 1980s, and as more donors were needed, infertility specialists sought eggs from known donors who were relatives or friends of recipients and were willing to contribute eggs out of a spirit of altruism. To meet the ever-increasing demand for eggs, they then moved to married women under thirty-five years of age who were not known to the recipient couple, and who had already had as many children as they wanted. Such women, it was reasoned, had exhibited that they were fertile and they were less likely than childless women to attempt to claim the resulting children in the future. Some of these women received financial compensation. Gradually, practitioners realized that they achieved better results using the eggs of young women and began to advertise for college women to serve as donors, for these women were presumed to be healthy, fertile, and in need of extra funds. Donated eggs are now derived primarily from healthy young women who are specifically recruited for this purpose, followed by relatives or friends of the prospective parents, and lastly from infertility patients undergoing IVF who agree to donate extra eggs to others.

Guidelines of the ASRM and the national advisory board on ethics in reproduction (NABER), a private body that is independent of practitioners and that has developed standards for egg donation, recommend medical screening of recipients and psychological evaluation of both recipients and their partners. They also call for medical screening of donors and a genetic evaluation based largely on the donor's stated medical history. Whether HIV antibodies might be transmitted by the donor to the recipient cannot be resolved in egg donation by direct testing of eggs because donated eggs cannot currently be frozen and quarantined for the 180 days required for retesting for HIV antibodies. However, recipients of donated eggs can have the resulting embryos frozen and used six months later if the egg donor tests negative for HIV antibodies at that time. The disadvantage of this is that freezing embryos lessens the chances of successful embryo implantation. Psychological counseling is also recommended for the donor and her partner by both the ASRM and NABER.

Clinics in the United States vary greatly in how much information they offer to recipients about donors. At many programs, matches are made by physicians and nurses on the model of anonymous sperm donation. Recipients are informed about the donor's physical characteristics and given some additional nonidentifying information, and donors usually learn nothing about the recipients. At some centers, brokers recruit and screen donors for a fee. Recipient couples choose an anonymous donor from a list of candidates provided by these brokers. At still other centers, information is provided to donors and recipients about one another and they are urged to meet, a practice known as *open donation* that echoes a growing trend toward *open adoption.*

The cost of egg donation combined with *in vitro* fertilization in the United States rose from about $9,000 per attempt in 1991 to about $20,000 in 2001 (not including donor payment). Donors in the United States are reported to have been paid amounts ranging from $1,500 to $10,000. Some are said to have been offered $50,000 and $100,000. Egg donors in England are currently paid the equivalent of $23 and, as with sperm donation, such payments are to be phased out.

Ethical Issues

Ethical issues raised by the practice of gamete donation tend to fall into two major categories. There are those that focus on underlying conceptual questions, such as whether gamete donation is, in principle, ethically acceptable, and whether this procedure might radically alter understandings of procreation, marriage, and parenthood. Other questions are more oriented toward the consequences of gamete donation, such as its safety; its possible psychological import for donors, recipients, and children; and whether adequate informed consent has been obtained.

Procreation and the Marital Relationship

The use of gamete donation has sparked powerful philosophical differences that center on two features of procreation that many deem essential: it is exclusive and it is embodied. There was a public uproar in 1909 when it was revealed that sperm donation had been carried out by a physician some twenty-five years earlier, and the practice was condemned as a form of mechanical adultery. Some secular and religious critics voice similar concerns today, holding that the use of reproductive materials provided by individuals outside the marital relationship intrudes upon the exclusive union between spouses that is normative in marriage, and is therefore wrong. "There is, generally, strong rabbinic opinion that AID [artificial insemination by donor] should be condemned as 'an act of hideousness' or 'an abomination' or 'human stud farming'" (Rosner, p. 133). Such critics of third-party gamete donation believe that procreative acts that take place in a context other than marital fidelity are diminished and distorted. However, other commentators, including some within the Jewish tradition, accept gamete donation, maintaining that the exclusive relationship between husband and wife remains unchanged when gametes from a third party are used to achieve fertilization (Mackler). Thus, some members of a Church of England working party declared that this procedure is ethically acceptable because "there is no offence against the married partner, there is no breaking of the relationship of physical fidelity, and there is no relationship with a person outside of marriage" (Church of England, p. 57).

The other feature of procreation of special concern to critics of gamete donation, that it is embodied, is undeniably set aside in gamete donation—no act of sexual union takes place between those who will be the rearing parents of the resulting child. Many natural-law theorists hold that it is wrong to replace sexual intercourse with methods of assisted reproduction, particularly when they involve third parties, for to do so wrongly separates the procreative and unitive or loving ends of sexual intercourse. The Roman Catholic Church, in particular, rejects gamete donation because it is thought to erode the unity of body and spirit in the procreative process (Congregation for the Doctrine of the Faith). The Protestant theologian Paul Ramsey (1913–1988) once declared that an ethic that regards "procreation as an aspect of biological nature to be subjected merely to the requirements of *technical* control while saying that the unitive purpose is the free, human, personal end of the matter pays disrespect to the nature of human parenthood" (p. 33). The use of gametes derived from third parties outside a marriage is prohibited in Islamic law, as this risks inadvertent consanguinity ("being of the same blood") dilutes the purity of the family line, and could create confusion about the identity of a child's genetic parents and about a child's heritage (Serour).

Proponents of gamete donation respond that to insist on physical union between man and woman in procreation is to derive ethical norms too simply and narrowly from the usual physical structure of human reproduction. Furthermore, it is to ignore that the use of donated gametes can uphold, rather than violate, the loving dimension of the relation between marital partners and lead to responsible parenthood (Laurtizen, pp. 9–12). It is sufficient that love and procreation are held together within the marital relationship as a whole.

Feminist scholars, in particular, have expressed concern about the metaphorical disembodiment that gamete donation can entail for women. Some of those who have donated gametes maintain that they are not treated as whole persons, but are divided into unrelated parts, each of which is subjected to manipulation in order to produce a child. A woman's body can thus be treated as "a field to be seeded, ploughed, and ultimately harvested for the fruit of the womb" (Raymond, pp. 61–62). Supporters of gamete donation and assisted reproduction respond that neither current ethical analysis nor public policy views women as "fetal containers" (Robertson, pp. 192, 228–229). While they acknowledge that the legitimate needs and interests of women must be recognized, they argue that new technologies such as gamete donation expand the freedom of women and assure them a large measure of control over their reproductive lives.

Parenthood and Family Relationships

Those who challenge the use of donated gametes argue that in a world where the rearing mother or father is no longer the biological source of gametes, there is no obvious answer to the question who are the "real" parents of the child. They argue that the use of third-party gametes thus vitiates lines of kinship and descent that situate individuals within particular and extended familial relationships (Meilaender). Further, when gamete donation is used to enable single women to have babies with donor sperm, and when postmenopausal women to give birth to children using donated eggs, traditional notions of the family are confounded (Cahill).

A second line of argument presented by these critics is that those who engender a biological relationship to a child, as do gamete donors, bear responsibility for the well-being of children who result. It is wrong, they maintain, for men and women to provide their gametes to couples and then leave without concern for the child who emerges. (O'Donovan). Some argue forcefully that sperm donation, in particular, institutionalizes the socially problematic phenomenon of paternal abandonment (Callahan).

Those in the opposite camp respond that while the biological connection is important to parenthood, it is not essential. In adoption, for example, the biological relationship between parent and child is sundered, and yet the practice is well accepted. It is also acceptable, therefore, to allow such separation in gamete donation. If those using gamete donation will provide a stable and caring environment in which the welfare of the child is a central focus, as is presumptively the case in adoption, there is no reason to adjudge gamete donation wrong. In this view, nurturing is of greater significance to parenthood than biological rootedness. Thus, while proponents recognize that gamete donation challenges traditional understandings of the family, they accept this as reflecting contemporary social realities (Robertson, pp. 121–122). Critics respond that this procedure is distinct from adoption, for it amounts to intentional preconception abandonment of future children by donors, as opposed to giving up already born biological children out of necessity (Cahill). Moreover, they maintain that the biological connection of children with their parents and extended family is a significant factor affecting their sense of self that ought not be disregarded.

The use of gamete donation to enable older women to have children has come under special scrutiny, not only because it raises issues of safety for mature women and the children they might bring into the world, but also because of concerns about its impact on the family. Some commentators maintain that egg donation is making biological limitations of aging irrelevant, and this, in turn, is confounding traditional notions of the family as women old enough to be grandmothers give birth to babies. Yet others observe that men have been known to father children in their mature years without criticism, and that there is no reason that the same should not be true of women. Older parents, they argue, may stretch the usual concept of the family, but they do not destroy it. Even so, the risks of egg donation and pregnancy for older women and their children can be serious. NABER and the New York State Task Force on Life and the Law recommend caution about the use of egg donation in women of relatively advanced reproductive age, maintaining that the risks to the woman and the best interests of resulting children must be considered.

Secrecy and Anonymity

Whether it is wrong to keep the use of gamete donation secret has become a pressing ethical, social, and psychological issue. Secrecy in gamete donation is said to place a lie at the center of family life, and therefore to be destructive. Studies show that any lifetime secrets impose a burden on the family members and have a detrimental psychological and social impact on the resulting children. The risk of unexpected disclosure of the circumstances of a child's conception hangs over the family that has concealed this information. Some psychologists maintain that it is important to the healthy development of children that they know their biological origins (Baran and PanNor; Nachtigall). They believe that disclosure of the participation of a gamete donor in the conception of a child improves, rather than weakens, family relationships. Moreover, in a world in which genetic information is of increasing importance, children who do not know of a source of some of their genes are denied information that might be important to their health. The primary reason for concealing this information is that the children who spring from gamete donation might be stigmatized as different. Such stigmatization is decreasing, however, in a world in which families are more often composed of members of varying biological origins.

If secrecy were abjured in families, it would be necessary either that rearing parents and the resulting children at maturity know the identity of their gamete donor, or else have a certain amount of information about him or her that could lead to identification if all involved are amenable to this. Yet identifying donors has been controversial. Perhaps the oldest argument against doing so is that potential donors would be fearful of having a child born with the assistance of their gametes later appear at the front door, or that they might be held responsible for the support of such a child. Many donors would therefore decide against donating, which would diminish the pool of available donors. In addition, recipients fear that donors would seek them out and either claim the children or attach themselves to the children (Cohen, 1996). This is of particular concern when relatives are gamete donors. Coercion within families could surface, as could bad feelings if donation were followed by an adverse outcome.

For such reasons, the identity of those who donate gametes is generally not revealed to recipients. The Ethics Committee of the American Fertility Society formally embraced the principle of anonymity of sperm donors in 1994 in order to encourage men to donate and to safeguard them from unwittingly becoming responsible for the support of the resulting children.

Enthusiasm for maintaining anonymity, however, appears to be diminishing. Surveys indicate that donors are increasingly willing to be contacted after a child born of their gametes turns eighteen if they have assurance that they will have no financial or familial obligation to the child. NABER has proposed that egg donation centers move toward a policy of offering both known and confidential donors to those seeking eggs, and that donors be required to provide information about their medical history and genetic health. Children born of donated gametes would be given access to this information at the age of eighteen, if they so requested, and donors would have the option of providing either relevant identifying or nonidentifying information to them. NABER has also recommended that a centrally coordinated network of registries be established in the United States that would keep records about donors in either identifiable or coded form, depending on the choice of the donor (National Advisory Board on Ethics in Reproduction, pp. 290–291, 300).

Commodification of Procreation and Children

There is growing concern that egg donation, in particular, is being left adrift amidst a stream of commerce, and that procreation is being commodified. The current marketing of egg donation, critics contend, relegates human beings to the status of commercial objects and their gametes to that of products. Some see the current practice of paying significant sums to egg donors as coming uncomfortably close to baby buying, and they maintain that this flies in the face of the accepted view of children as individuals endowed with an underlying dignity. Several commentators observe that gametes, as the means of making new life possible, are not negligible body products that ought to be bought and sold in the open market (Lauritzen; Radin; Cohen, 1999; Shanley). Moreover, they argue, to offer large sums of money to egg donors amounts to a form of undue inducement that can vitiate the voluntary decision of donors to donate eggs. Some feminists argue that poor women, in particular, should not be enticed to turn their reproductive capacities into a commodity.

Defenders of paying women for their eggs outright maintain that women have the right to sell "products" of their bodies if they so choose. State intervention to prohibit the sale of eggs, in their view, would violate the individual liberty interests of such women. Moreover, prohibiting payment to donors would only compound the problems of those who are less well off by depriving them of a source of income (Harris). It is not the sale of human eggs that is wrong, in their view, but the fact that a bidding war for them has emerged with no industry-wide standards that set a fair price. The most prudent social policy would be to regulate the market for human eggs to ensure that egg donors receive appropriate pay for their time and endeavors. (Resnik).

Several review groups that have addressed this question advocate financially reimbursing gamete donors only for their time and inconvenience. Their primary justification for this approach is that it upholds human dignity and avoids undue inducement of women to donate their eggs. It is fair and reasonable, they maintain, to compensate donors for their expenses, travel, lost wages, and, to some extent, the risks that they incur in going through the donation procedure (National Advisory Board on Ethics in Reproduction, 1996; New York State Task Force on Life and the Law, 1998; Ethics Committee of the American Society of Reproductive Medicine, 2000). The ASRM suggests that appropriate compensation for egg donors would amount to $5,000, and that amounts up to $10,000 might be justifiable. It is inappropriate to offer larger amounts to potential egg donors, the society holds.

Oversight

Some legal commentators maintain that individuals have a constitutionally protected right to reproduce, a right that extends from coital reproduction to such methods of assisted reproduction as gamete donation. The use of gamete donation should thus be a matter of individual decision, and the state should play only a limited regulatory role to ensure safety and prohibit uses that would substantially harm others (Andrews; Ethics Committee of the American Fertility Society, 1994, p. S13; Robertson, pp. 41, 119–123). Others agree that individuals have a right to reproduce coitally that lies in a sphere protected from most state intrusion, but they reject the view that methods of assisted reproduction clearly fall under the aegis of this right. They are concerned about the use of gamete donation without sufficient regard for the interests and health of donors, recipients, and the resulting children. Some have therefore recommended that there be national standards and a federal regulatory system governing this and other forms of assisted reproduction (Rao; Massie; Cohen, 1997).

Yet no federal laws govern the procedures of gamete donation in the United States, and no review of novel assisted-reproductive techniques is required by federal regulation. IVF clinics that practice gamete donation are not required to set up institutional review boards or to review innovative treatments under the regulations of the Department of Health and Human Services. The Clinical Laboratory Improvement Amendments of 1988 covers only the laboratory analysis of sperm for purposes of quality control. The Food and Drug Administration requires registration, but not licensure, of sperm banks, although it has indicated that plans to develop guidelines for screening donated sperm to prevent transmission of communicable diseases. Under the Fertility Clinic Success Rate and Certification Act of 1992, data regarding clinic-specific pregnancy and delivery success rates for assisted-reproductive procedures, including oocyte donation, are collected and published by the Centers for Disease Control along with various professional societies (Society for Assisted Reproductive Technology). This produces useful information, but does not regulate procedures of gamete donation. Thus, there is a dearth of federal oversight of the methods and materials used for sperm and egg donation.

There is some state law regulating sperm donation but the vast majority of states do not require sperm banks to be licensed. There is almost no state law regarding egg donation. Judicial holdings in this area have been limited and have focused on deciding who should serve as the rearing parents of children born of gamete donation. In the private sector, a voluntary association of tissue providers, the American Association of Tissue Banks, has developed detailed standards for sperm donor screening, the ASRM has published practice guidelines for egg and sperm donation, and NABER has developed recommendations for egg donation. However, these guidelines do not have the force of law and offer no mechanism for surveillance or enforcement.

Commentators and review groups observe that in a market-driven environment that has been blighted by occasional scandals and misrepresentations, there is a compelling need to provide oversight of the use of gamete donation and other methods of assisted reproduction in the United States (Annas; ISLAT Working Group; National Advisory Board on Ethics in Reproduction; Cohen, 2002; New York State Task Force on Life and the Law). NABER, in 1996, called for a national regulatory body to license and monitor the quality of services of infertility centers and proposed that in the interim a task force composed of practitioners, outside experts from various disciplines, and lay persons should develop uniform intercenter policies to inform and safeguard donors, recipients, and resulting children (National Advisory Board). It also recommended numerous changes in professional guidelines and standards, as well as state and federal law. In addition, in 1998, the New York State Task Force on Life and the Law identified major problems in the provision of gamete donation and drafted guidelines and model consent forms to improve information given to donors and recipients. It, too, offered detailed recommendations for changes in professional standards that would provide some degree of uniformity in practice, and it proposed changes in state law to protect those involved in gamete donation and the children born of these procedures. Also in 1998, the ISLAT (Institute for Science, Law and Technology) Working Group recommended a federal law that would set a minimum standard for the provision of assisted-reproductive technologies and urged that noncompliance should result in criminal or civil liability. Few of these proposals have been adopted.

There are now at least twenty legal jurisdictions around the world that have enacted legislation regarding the uses of the new reproductive technologies. Countries that allow gamete donation combine the prohibition of certain procedures with licensing requirements to limit who may perform reproductive procedures. The use of eggs from donors, for instance, is prohibited by law in Germany, Norway, Sweden, Switzerland, and Japan. Countries that have adopted uniform standards for the infertility industry, such as the United Kingdom and Australia, began by appointing a commission or committee to study the issues and make legislative recommendations, and they then acted upon those recommendations.

Future Directions

Demand for donated eggs will increase in the future, not only to accommodate ever greater numbers of couples and individuals seeking to have children, but also to bolster new areas of research. Investigative programs, such as those in basic human embryology, embryonic stem cells, cloning, and cryopreservation of human eggs, will require large quantities of human eggs before they can proceed. Other sources of human eggs, in addition to living donors, are therefore under investigation for both clinical and research uses.

Researchers have begun to delve into the possibility of using fetal eggs, derived from aborted fetuses and matured *in vitro*, for clinical egg donation programs. Some have prophesied that this could lead to the development of *egg farms,* in which some of the thousands of eggs in a young woman's ovaries that would otherwise fall by the wayside could be salvaged to increase the number of eggs available for personal use or the use of others (Gosden, p. 152). It is not yet known whether the early female eggs, which normally are subject to a high degree of degeneration, can develop into mature eggs capable of giving rise to a normal fetus after fertilization. Moreover, an aborted fetus could be the carrier of a metabolic or genetic disorder that could manifest itself in the resulting child. If such eggs were used to overcome infertility, this would raise concern about the psychological well-being of the resulting children, who might experience harm either from being told that their genetic mother was an aborted fetus or from not being told of this. Since there is currently no compelling need to use fetal oocytes, the ASRM has recommended that this avenue of investigation not be pursued (Ethics Committee of the American Society of Reproductive Medicine, 1997, pp. 6S–7S).

Frozen, stored ovaries are another possible source of human eggs for clinical use. A slice of ovary contains thousands of immature eggs, and ovarian tissue could be removed during surgery for ovarian cyst or endometriosis, or during prophylactic surgery for ovarian cancer. Freezing and storing ovarian tissue currently appears more promising than freezing mature eggs. Moreover, storage of ovarian tissue is relatively easy. This is an experimental procedure that is under development and, consequently, there has been little comment about its safety or its import for the interests of the resulting children.

Because women are currently the sole source of eggs that can be used to create human embryos, and because there is a paucity of eggs for research, women will increasingly be called upon to provide eggs for investigative purposes. This raises significant ethical questions. Women asked to contribute eggs to stem-cell research or research cloning, for instance, would receive neither health benefits to themselves nor the satisfaction of assisting in the birth of a child to others (Baylis). Their primary motivations for undergoing egg donation procedures in such cases would either be the satisfaction of assisting medical science or the prospect of financial reward. If such research were carried out in the public sector under current federal guidelines for stem-cell research that had been extended beyond current restrictions on the sources of such lines, women would be barred from receiving financial compensation for their endeavors and risks in donating eggs. They would provide eggs solely to assist medical research. Thus they would constitute human subjects participating in nontherapeutic investigations that expose them to more than minimal risk, and the Common Rule requiring full, written, informed consent would apply. However, it is clear, commentators have observed, that the common rule for informed consent is currently not being adhered to in either federally or privately funded research when deriving eggs from women to create embryos from which stem cell lines are developed. Therefore, they argue that to protect the voluntary choice and health of women, fully informed consent should be rigorously sought in the future from women whose eggs are used in scientific research, no matter who provides those eggs or what the source of funding for that research.

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SEE ALSO: *Abortion; Adoption; Cloning; Embryo and Fetus; Feminism; Fetal Research; Genetic Counseling; Genetic Testing and Screening: Reproductive Genetic Testing; Healthcare Resources, Allocation of: Microallocation; Law and Bioethics; Maternal-Fetal Relationship; Moral Status; Population Ethics; Sexism; Transhumanism and Posthumanism; Women, Contemporary Issues of;* and other *Reproductive Technologies* subentries

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VI. CONTRACT PREGNANCY

Contract pregnancy, often also called *surrogate motherhood,* consists of a complex set of practices in which women employ their distinctive reproductive powers to give birth to children on the understanding that others will take on the responsibilities and prerogatives involved in the rearing of the children. The controversies surrounding such practices extend even to issues of labeling. Women who provide their ova as well as their abilities to gestate and deliver babies to this enterprise are sometimes referred to as *full surrogates,* as contrasted with *partial surrogates,* who gestate and give birth to children conceived in vitro, typically with the gametes of the commissioning man or couple. For reasons of clarity, the phrase *genetic-gestational* is used in this entry to refer to those women who have agreed to provide both their gametes and their wombs; *gestational* alone indicates those women whose role is to sustain and deliver a child to whom they are not genetically related. More significantly, some writers have argued that referring to women who have carried a fetus to term and delivered a child as *surrogates* slights their status as mothers, and prejudices the discussion of disputes concerning parental status between the birthgiver and the commissioning party in favor of the couple or individual who secured the birthgiver's services. For this reason the term *contract pregnancy,* coined by Laura Purdy, is adopted here, although it should be noted that not all such arrangements are explicitly contractual. The understandings under which women act may well be highly formal arrangements, brokered by intermediaries and involving payment, but they may also be quite informal, with no intermediaries or compensation.

Apart from matters of nomenclature, controversies concerning contract pregnancy have, in practice, revolved around disputes concerning the enforceability of agreements when one (or more) of the parties involved has undergone a change of heart, namely: contract birthgivers who find themselves no longer willing to relinquish custody of the children they have borne, or commissioning parties who have changed their minds about wanting to parent the child born of the arrangement they initiated. In theory, the chief disagreement concerns the conditions that confer parental responsibility—that is, how the elements of gestation, genetics, desire, and intention should be weighed when their customary connections have been purposefully sundered. Other disagreements arise over whether women or children are harmed or wronged by contract pregnancy, whether contract pregnancy involves the commodification of children or of the parent–child relationship, and whether desires on the part of adults to rear children to whom they are in some way biologically related ought to be honored in light of the needs of existing children who lack parents. It has also been suggested that contract pregnancy offers important reproductive options to people who have not previously enjoyed them—women who have undergone hysterectomies and gay men, for example—and that by expanding the ways in which families can grow (and, in principle, the ways in which people can be related to each other), contract pregnancy can add important value to human lives.

Disputes about Motherhood

The incidence of contract pregnancy is not centrally monitored, but empirical studies by Helena Ragone (1994) suggest that most such arrangements prove satisfactory, at least to the adults who are centrally involved. Nevertheless, three prominent court cases exemplify the deeply unsettling controversies that can arise when the strands of motherhood are pulled apart and the affected parties disagree about how to weave them together again. The first two cases discussed below involve a dispute between the commissioning parties and the birthgivers, in a genetic-gestational contract pregnancy and a gestational pregnancy, respectively; the third case involves a disagreement between the man and the woman who constituted the commissioning party.

IN THE MATTER OF BABY M. Contract pregnancy became a matter of public concern as a result of the *Baby M* case, probably the most notorious of contract pregnancy disputes. A 1985 agreement between Mary Beth Whitehead and David Stern, providing that Whitehead should, for financial considerations, conceive, bear, and then surrender their child to the sole custody of Stern, led to the birth of Melissa Stern. The contract was voided on appeal to the New Jersey Supreme Court in 1988, after a drawn-out dispute between Whitehead and the Sterns that featured Whitehead fleeing with the child from New Jersey to Florida. Whitehead was recognized as the child's legal mother, contracts of the sort in question being found contrary to New Jersey public policy and law. Custody, however, was awarded to Stern and his wife, Elizabeth Stern, on a determination that the "best interests of the child" would thus be served. Whitehead was granted visitation rights.

JOHNSON V. CALVERT. Anna Johnson agreed to be implanted with an embryo created from the gametes of Crispina and Mark Calvert on the understanding that the Calverts would rear the ensuing child. In September 1990, before the birth of the child, Johnson challenged the contract. The Supreme Court of California upheld the lower court's ruling in favor of the Calverts, on the grounds that while both "genetic consanguinity" and giving birth are legally recognized means of establishing a mother–child relationship, "when the two means do not coincide in one woman, she who intended to procreate the child—that is, she who intended to bring about the birth of a child that she intended to raise as her own—is the natural mother under California law." Johnson's visitation rights were terminated.

IN RE MARRIAGE OF BUZZANCA. Luanne and John Buzzanca arranged for an unnamed woman to gestate an embryo donated by third parties and agreed to rear the resulting child. Just prior to the child's birth, John Buzzanca filed for divorce, maintaining that he had no parental responsibilities to Jaycee, the child to be carried to term on his estranged wife's behalf. The trial court, accepting the stipulation that the birthgiver was not Jaycee's mother and reasoning that the Buzzancas' lack of a genetic tie to the child ruled them out as well, concluded that Jaycee "had no lawful parents." The appeals court disagreed, ruling in a 1998 decision that "the intent to parent as expressed in the surrogacy contract" established Luanne and John as Jaycee's legal mother and father, and finding John Buzzanca responsible for her support.

Three Analytical Clusters

These cases illustrate various forms of disputes about who counts as a parent, and in virtue of what considerations. Given the deep significance for many people of biological connections to their children, bioethicists have been quite concerned to resolve these matters, and a variety of approaches have been explored. These approaches may be grouped under three headings, according to whose interests are deemed most crucial. The first cluster centers on the *adult parties* involved as competent makers of contracts. These analyses address themselves with the features the contracts should have in order to avoid moral and practical problems. The second cluster focuses especially on the position of *women* in these arrangements, with particular attention to the woman who accepts the commission. These approaches portray women as operating in what is in general a hostile social environment and are skeptical that women's interests will be reliably served or protected by contract pregnancy. The third cluster centers particularly on the claims that the *children* born of these arrangements should be able to make against their parents, drawing on the notion that children have a moral stake in how the responsibilities of the adults who brought them into being are assigned.

Contracts and Commodification

A clearly argued version of the first model provided in a 1988 article by Bonnie Steinbock, contends that there is no sufficient reason to outlaw contract pregnancy or hold such contracts unenforceable. Steinbock maintains that these arrangements ought to be seen as a prenatal version of adoption. Among the safeguards she proposes is that a birthgiver ought to be allowed an opportunity after giving birth to change her mind about surrendering custody of the child to the commissioning party, just as a new mother is allowed to reconsider whether she will give up her child for adoption.

The most significant challenge to contract pregnancy, as Steinbock sees it—the concern that such practices involve a mother's relinquishing her standing as a parent for money—could be obviated by mandating that any payment be for "risk, sacrifice and discomfort" (Steinbock, p. 49) involved in pregnancy, and hence would be made even if the pregnancy ended in a stillbirth. Should the mother change her mind about giving up her child, she would not, however, be entitled to any remuneration for those sacrifices.

With commodification thus deflected as a criticism of contract pregnancy, none of the other concerns Steinbock surveys—for example, potential emotional damage to the mother or the child as a result of their involvement in these arrangements—strike her as sufficient to justify state action against the practice. While the possibility that some women will undergo a change of heart cannot be dismissed, it would be intolerably paternalistic for the state to refuse to allow women to make contractual agreements they believe to be in their own best interests because of concerns that they were too prone to mistake what those interests are. Nor is there any reason to believe that any distress suffered by children would be so intense as to make it reasonable for them to wish that they had never been born via these arrangements (which, of course, are the only possible arrangements that would have led to the birth of precisely those children).

Steinbock does not explicitly discuss gestational contract pregnancy, so it is not clear whether such cases would be understood along the lines of her prenatal adoption model, nor whether gestational birthgivers who change their minds would be able to retain any claim to parental standing they might have, losing merely the money that had been agreed upon. This suggests one difficulty with an approach to contract pregnancy that attempts to adapt standing models of assigning parental rights and duties, such as adoption, to resolve contractual disputes. It seems unlikely that any account of contract pregnancy that does not explicitly grapple with what it is that makes a woman a mother in the first place (in the sense of conferring parental responsibilities and prerogatives upon her) will be altogether satisfactory.

Nor is it clear just how a contract pregnancy that includes substantial economic transactions can be insulated from the concern that what is bought and sold is the baby, rather than the gestational services. Steinbock insists that payment be made even in cases in which the pregnant woman loses the child, thereby underscoring the claim that the money is not a quid pro quo for the infant. In a 1990 article, however, Elizabeth S. Anderson argues that commercial surrogacy devalues children insofar as it regards maternal connections to children as commodities to be exchanged and trivializes a woman's own evolving perspective on her pregnancy by providing her with fiscal incentives for severing whatever emotional links to the child she may develop. If the argument that any payment is solely for inconvenience and risk were to stand against Anderson's points, it would seem that the payment should be made regardless of whether the birthgiver is willing to relinquish her parental relationship to the child. She has, after all, faced risk and inconvenience to bring into the world a child to whom the contracting party has a parental relation. That such an arrangement would severely diminish the attractiveness of the contract pregnancy in the first place strongly suggests that the payment cannot be regarded as mere compensation for the birthgiver's trouble. The whole point of the arrangement is that the child should be given up at birth, rather than becoming a part of the birthgiver's family. So it seems that the would-be parents are paying for more than the birthgiver's inconvenience and risk. Their incentive for paying rests on the assurance that they will have custody of the born child.

Women, Exploitation, and Altruism

The issue of turning children or parental relationships into commodities is a serious challenge to the moral and legal propriety of contract pregnancy. Janice Raymond, however, points out in a 1990 article that even when money does not change hands—an arrangement she calls "altruistic surrogacy"—coercive forces are present in society in general and in families in particular that can influence women to act against their own better judgment and interests. Her argument thus serves as a significant instance of the second, woman-focused model of analysis. While the point has often been made that women who are potential contract birthgivers are likely to be less socially powerful than the men or couples who seek to reproduce through their agency, Raymond focuses on expectations of feminine—and particularly maternal—altruism that cut across class distinctions and are in her view among the most powerful of the forces that oppress women. While not denying that "women can give freely," Raymond insists on the sociological complexity of "gift giving," arguing in particular that the connections between altruism and femininity can distort individual choice and reinforce unjust patterns of social status. She ties these cautions about altruism to a broader criticism of contract pregnancy. The practice depicts women as "reproductive conduits," "incidental incubator(s) detached from the total fabric of social, affective and moral meanings associated with procreation" (Raymond, p. 11).

Do concerns of this kind constitute reasons to forbid or restrict women's freedom to enter into such contracts as a matter of law? This depends in part on whether women are able to resist coercive or manipulative pressures that may well be more present in altruistic than commercial contexts, and whether altruistic forms of surrogacy can be conceptualized in ways that do not support, and in fact undermine, objectionable connections between women and altruism. By the same token, whether contract birthgivers are mere "reproductive conduits" may hinge on whether contract pregnancy can be absorbed into the social, affective, and moral fabric to which Raymond alludes—perhaps by revaluing brightening and motherhood in ways that are themselves less prone to reinforce women's subordination. While such refiguring of social meanings seem latent possibilities within the practice of contract pregnancy, it is unclear whether or to what extent they are being realized in individual cases. Nevertheless, Elizabeth F. S. Roberts's ethnographic research, published in 1998, suggests that at least some contract birthgivers are indeed engaged in forging their own, new understandings of what it is to bear a child. These understandings may in turn help destabilize traditional understandings of family and motherhood that have been oppressive for women.

Children and Parenthood

Focusing on the moral role of children in contract pregnancy arrangements, James Lindemann Nelson and Hilde Lindemann Nelson have argued that parental responsibilities arise from parents' causal relation to their children. Because parents have brought about their children's existence, and because their children's existence is initially one of vulnerability and dependence, parents are responsible for their children's well-being. If they cannot fulfill their responsibility, they may give up the child for adoption, but they may not deliberately create a situation in which they put it out of their power to look after their children. Their responsibility cannot be relinquished solely as a matter of agreements between adults that are prompted by their own interests. Nelson and Nelson further argue that because biological ties with children are seen as precisely the justification for such practices as contract pregnancy, it is only fair to assume that children too will have an interest in relationships with those to whom they are connected by ties of biology.

As with Steinbock's position, the implications of this position for cases of gestational surrogacy are unclear, and the situation might seem to be even more murky in cases where the commissioning couple are neither the genetic nor the gestational parents, as in *Buzzanca.* What kind of causal involvement with the child's emergence into the world is sufficient to establish at least a presumptive set of moral responsibilities? Further, the position at least leaves open the question why a person whose causal involvement is sufficient to ground such responsibilities cannot discharge them simply by taking steps to ascertain that the parties to whom she will relinquish her responsibilities are likely to be good parents. Regarding this latter question, a distinction between prediction and performance might be invoked. The acts of another can only be predicted, but one can exercise substantial amounts of control over one's own performance. May one divest oneself of the ability to see to it that the needs of a child for whom one is responsible will reliably be met? What constitutes a good enough reason to relinquish one's moral responsibilities to one's offspring? Setting aside concerns about commodification, concerns about exploitation of women, and concerns about the deep distress occasioned by a change of mind, it remains to be asked whether an altruistically motivated interest in helping others to procreate is sufficient to initiate human reproduction with the intent not to participate in raising the resulting children. Two further questions remain as well: Is it justifiable to ask someone else to put herself at the personal and moral risk involved with contract pregnancy in order to have or expand a family? Is it important that biologically linked children could not otherwise be brought into the family?

Reassembling Motherhood

Insofar as questions of this sort can be answered empirically, there seems reason to believe that contract pregnancy has afforded a way for infertile people longing to have children of their own to meet women who are gratified by the opportunity to help them realize their goal. That this process sometimes backfires rather spectacularly, as in the *Baby M, Johnson v. Calvert,* and *Buzzanca* cases, would not seem a decisive reason to regard the process as immoral or so flawed as to outlaw it. The enterprise is attended by moral risks, however, even in the majority of cases in which everyone walks away feeling satisfied. Giving birth by contract cuts the connections among the genetic, gestational, and intentional elements that constitute motherhood, yet there is no settled, reflective consensus regarding what kind of comparative priority such elements should have when they are sundered. The popularity of such contracts certainly puts force behind a particular answer to the priority question—it strongly privileges the intentional. Given that a rollback toward an answer more influenced by genetic or gestational elements is unlikely in the absence of a showing of serious harm, those concerned about contract pregnancy might consider how the moral risks of this practice might be minimized, and how such pregnancies might achieve moral gains that go beyond the gratification of private impulses.

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SEE ALSO: *Abortion; Adoption; Cloning; Conflict of Interest; Contractarianism and Bioethics; Embryo and Fetus; Feminism; Fetal Research; Genetic Counseling; Genetic Testing and Screening: Reproductive Genetic Testing; Healthcare Resources, Allocation of: Microallocation; Law and Bioethics; Maternal-Fetal Relationship; Moral Status; Population Ethics; Public Policy and Bioethics; Sexism; Transhumanism and Posthumanism; Women, Contemporary Issues of;* and other *Reproductive Technologies* subentries

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VII. SPERM, OVA, AND EMBRYOS

The technical ability to freeze sperm, embryos, and eventually ova for long periods and then thaw them without destroying their biologic potential offers several new reproductive options for both fertile and infertile individuals. It makes the donation of eggs, sperm, or embryos to treat infertility a more efficient and safe procedure. It also allows individuals and couples to preserve sperm, eggs, and embryos to protect against future reductions in gametic viability due to age, disease, or occupational exposure, and permits posthumous reproduction to occur.

As with any technological deviation from the natural mode of conception, these techniques raise both medical questions of safety and efficacy and ethical, legal, and social questions about prohibition, restriction, or regulation of these practices. Once cryopreservation is medically established as safe and effective, its ethical, legal, and social acceptability depends on a general acceptance of noncoital and assisted means of reproduction, with specific issues relating to the particular technique in question.

Sperm

Cryopreservation of sperm is now well established medically and socially as a commercial enterprise. Sperm banking occurs as an aspect of infertility practice, or as an option for men who foresee damage to their gametes as a result of disease or occupational exposure. In the former case, a commercial sperm bank recruits sperm providers, screens them medically and socially, and usually pays them a fee for their sperm (technically they are vendors rather than donors of sperm though the latter word is commonly used to describe their role). The sperm is then distributed to doctors or others who practice artificial insemination with donor sperm, who in turn resell or distribute it to recipients.

A main legal and ethical issue with regard to this practice is the duty of the sperm bank to screen sperm donors and their sperm for infectious diseases, including the human immunodeficiency virus (HIV). Guidelines of the American Fertility Society, the main professional organization of physicians treating infertility, now recommend that donated sperm be screened for HIV diseases. Because there may be a six-month gap before HIV transmission shows up on antibody screening tests, screening requires that the donated sperm be quarantined for six months so that a second test can be performed on a sample to ensure that it is not HIV-infected. Failure to screen in this way is unethical and could make the sperm bank legally liable for transmission of HIV to recipients and offspring.

There are no laws that restrict to whom sperm banks may sell their sperm, and in the United States, the buying and selling of sperm is not generally covered by federal or state laws against selling organs, though several European countries prohibit the practice. Thus a bank could sell sperm to a single woman or representative organizations for use in inseminating single women. Despite fears that a bank or physician who provides sperm to an unmarried woman could be held liable for financial support of a child born as a result, no such legal liability has yet been imposed. While some persons find artificial insemination of single women to be unethical, and the practice is prohibited in some countries, it can allow women who otherwise could not bear children to reproduce, and unmarried women who are committed to reproduction in this way have been shown to be able childrearers.

Commercial sperm banks also provide service to individuals or couples who wish to store sperm for later use because of treatment of disease, occupational exposure, or fear of later impotence. Because no legislation specifically applies to this practice, its legal status would depend upon basic contract law. The depositor would be entitled to keep the sperm in the bank and retrieve it under conditions specified in the contract of deposit. Thus sperm could be released to the depositor or to his designee posthumously, if that is envisaged, and the bank would perhaps have no obligation to maintain the sperm past a specified time if failure to pay storage charges should occur. Clear specification of rights and duties in the original contract is essential. While posthumous release of stored sperm to the appropriate designee could lead to the birth of a child without a rearing father, this situation is similar to the insemination of an unmarried woman and should be treated similarly.

Whether a child born posthumously will be able to share in a deceased's estate is a matter of state inheritance law that does not affect the ethical, legal, or social acceptability of the practice.

The bank would, of course, have a legal duty to return the correct sperm to the depositor. At least one case has arisen in which the bank returned the wrong sperm, which led to the birth of a child who was not of the same race as the depositor. In such instances, suits for damages are likely to be successful. An important issue will concern damages, because there is no way to establish that in fact the lost gametes would have implanted and produced a child. In addition, some states regulate the operation of sperm banks as medical or clinical laboratories to protect the health and safety of consumers of their services.

Many of the issues that arise with commercial sperm banks would also apply to physicians who recruit sperm donors directly. They too would have ethical and legal duties of reasonable care to assure that donors have been tested for genetic and infectious disease. They would also be free to inseminate single women and use sperm posthumously, if that is the clear intention of the parties.

Ova

The ability to freeze and then successfully thaw ova has not yet been developed, due to the larger size of the ovum and the great amount of fluid in it. Once this ability is developed, egg banking will occur.

Frozen ova have less ethical significance than frozen embryos. Once the technical ability to freeze and thaw ova safely is developed, they will play an important role in enabling women to initiate pregnancies through in vitro fertilization (IVF), which involves hormonal stimulation of the ovaries to produce ova, often many more than are needed for fertilization at that time; freezing the extra ova will minimize the need for additional cycles of egg retrieval. Rather than inseminate all eggs retrieved in a cycle of IVF treatment, many couples will prefer to freeze extra eggs, which can then be thawed and inseminated for later attempts at pregnancy. Cryopreservation of ova, rather than embryos, may thus become the preferred method of storage.

Once ova freezing and banking begins, the same issues that currently arise with cryopreservation of sperm will occur. Commercial ova banks, which may be associated with sperm and embryo banks or exist independently, will be established. No doubt such banks will both buy or procure eggs from women and then resell them to doctors and couples in need of an egg donation. The main issues will then concern what the precise arrangement is between the donor and the bank concerning subsequent use, whether the bank will be responsible for genetic and infectious disease screening, and whether the bank will be responsible for any rearing costs of offspring.

With eggs that have been frozen for subsequent use in initiating pregnancy in an infertile couple, the agreement between the woman or couple and the storage facility will be of paramount importance. The depositor of the eggs will be the owner and will control release or discard of cryopreserved ova within the limits of the storage facility's policies. Thus the contract between the depositor and the facility would largely control deposits of eggs prior to disease treatment or occupational exposure or to use then or at a later time. As long as the depositor has paid storage charges, she would be entitled to have the eggs stored, to expect reasonable care to be taken in their maintenance, and to have the eggs released, transferred, or discarded as directed. Posthumous release and use of stored eggs should be as acceptable as posthumous release and use of stored sperm. As with sperm banking, failure of payment could lead to the bank taking the eggs out of storage, but it would not be entitled to transfer them to other persons in lieu of payment unless there were a specific agreement to that effect. Professional or even legislative regulation of ova banking to ensure standards of health and safety can also be expected.

Embryos

Cryopreservation of embryos (sometimes referred to as preimplantation embryos or *pre-embryos*) is now a well-established adjunct to IVF programs. Standard IVF treatment often produces more eggs than can be safely fertilized and placed in the uterus at one time. Rather than fertilize only the number of eggs that could be safely transferred or fertilize all retrieved eggs and discard the surplus, cryopreservation allows all eggs to be fertilized, a safe number such as two or three placed in the uterus, and the rest frozen for later use. At a later time, the frozen embryos can be thawed and placed in the uterus, donated to others, or discarded. Although the success rate is not as great as with fresh embryos, the pregnancy rate of both fresh and frozen embryos from a single egg-retrieval cycle is 15 to 20 percent greater than the rate from use of fresh embryos alone. Until the ability to freeze and thaw ova is developed, the excess eggs retrieved in a cycle of IVF treatment are likely to be inseminated and then cryopreserved for use during a later cycle.

The main issues that arise with cryopreservation of embryos concern the ethical and legal status of embryos and the locus of dispositional authority over frozen embryos. While some persons have argued that embryos are persons or moral subjects with all the rights of persons, and others claim that embryos are merely tissue with no special status or rights, a wide ethical and legal consensus in the United States, Europe, and Australia views embryos as "deserving of special respect, though not the respect due persons." As a result, embryos may be created, frozen, donated, and even discarded or used in research when there is a valid need to treat infertility or pursue a legitimate scientific goal and rules concerning consent of the gamete providers and institutional review board approval have been followed.

With regard to dispositional authority over frozen embryos, it is now well established that the couple providing the gametes has dispositional authority within the limits of state law and the conditions of storage set by the IVF program or storage facility. If they agree to have embryos created from their gametes cryopreserved, they are *owners* of the embryos and may decide on any disposition of frozen embryos that their agreement with the storage facility and applicable statutes permit.

Since the frozen gametes are the joint property of the persons providing the gametes, their joint consent is needed for disposition until they relinquish or transfer their dispositional authority to others. To maximize their control over embryos and to introduce administrative efficiency into the operation of embryo banking, they should also give written directions at the time of storage for disposition of frozen embryos in the future if the providers have died, divorced, are unavailable for decision, or are unable to agree between themselves on disposition.

In such cases, the IVF program or embryo bank should be able to rely on this prior agreement in decisions concerning stored embryos. This will give advance control to the parties and clear directions to the bank and minimize costly disputes about what to do with stored embryos. Although no court has yet been faced with a case directly involving a disputed contract, there have been cases recognizing the right of the depositing couple to remove their frozen embryo from a bank against the bank's wishes. There is also legal authority recognizing the validity of such advance contracts for disposition in case disputes arise.

The *Davis v. Davis* case (1992) illustrates the wisdom of giving effect to the prior agreement. A couple had frozen seven embryos pursuant to their efforts to have children via IVF. They subsequently decided to divorce but could not agree on disposition of the frozen embryos. The husband opposed thawing them and using them to start pregnancy, while the wife insisted that she or another person have them placed in her. The Tennessee Supreme Court finally resolved this issue by ruling that an agreement between the parties for disposition in the case of divorce would have been binding, and that in the absence of such an agreement, the relative burdens and benefits of a particular solution must be examined. In that case if the party wishing to retain the embryos had other means of obtaining embryos, such as by going through IVF again with a new partner, that party's wish to have children could still be satisfied without foisting unwanted parenthood on the party who wished that the embryos not be used. On the other hand, if there was no other way for that party to be reasonably able to produce embryos, so that the existing embryos were the last resort or chance to have offspring, then they should be entitled to use them. In that case, fairness would require that the objecting party not have to provide child support. In the facts presented to it, the court ruled in favor of the husband, who did not want frozen embryos implanted after divorce, because the wife had alternative ways to reproduce.

Ethical and legal codes for assisted reproduction in other countries have not yet addressed the problem that arose in the *Davis* case. A country could take the position that all embryos must be preserved, or that provision of gametes for IVF is a commitment to have all resulting embryos placed in the uterus. However, the American preference to have the parties control disposition in the case of divorce or disposition by prior agreement might also be recognized, for it maximizes the procreative liberty of the parties directly involved.

The authority of the gamete providers over the disposition of frozen embryos can be limited by law or the policies of the banks or facilities where frozen embryos are stored. For example, some European countries (Spain and Germany) prohibit embryo discard and research, while others (Great Britain, for example) limit the period of storage to a maximum of ten years or the reproductive life of the woman, whichever is longer. While U.S. legislation on these issues is largely absent, the Ethics Committee of the American Fertility Society (1986) has recommended a similar maximum period of storage, and individual embryo banks and programs for religious or administrative reasons have imposed limitations on dispositions that involve discard, donation, or release of frozen embryos to other programs. As long as the storage facility makes clear its restrictions on disposition of frozen embryos, it may impose these restrictions on couples who request storage of embryos at that facility.

Conclusion

Cryopreservation of sperm, ova, and embryos offers individuals options to extend or enhance their reproductive ability and should presumptively be recognized as adjuncts of their procreative liberty. If this view is accepted, principles of informed consent and contract will inform and regulate most of the transactions and activities that occur with cryopreserved gametes and embryos. In some cases legislation to protect the parties' wishes and ensure the health and viability of stored gametes and embryos may also be desirable.

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SEE ALSO: *Abortion; Adoption; Cloning; Embryo and Fetus; Feminism; Fetal Research; Genetic Counseling; Genetic Testing and Screening: Reproductive Genetic Testing; Healthcare Resources, Allocation of: Microallocation; Law and Bioethics; Maternal-Fetal Relationship; Moral Status; Organ And Tissue Procurement: Ethical and Legal Issues Regarding Living Donors; Population Ethics; Sexism; Transhumanism and Posthumanism; Women, Contemporary Issues of;* and other *Reproductive Technologies* subentries

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VIII. ETHICAL ISSUES

The introduction of in vitro fertilization (IVF) in 1978 sparked anew an intense ethical debate about the use of innovative reproductive technologies that had raged a decade earlier. Questions were raised about whether these technologies would harm children and parents and alter people's understanding of the meaning of procreation, family, and parenthood. Gradually the controversy subsided as healthy children were born from these procedures; committees in at least eight countries issued statements indicating that they considered the use of IVF ethically acceptable in principle (Walters). Arguably, one reason for this readiness to embrace IVF and other new reproductive techniques was that they enabled couples to create offspring in a way that seemed an extension of the natural way of procreating. Although IVF involved joining sperm and ovum in a glass dish, the resulting embryo, once implanted, went through a natural period of gestation that culminated in the birth of a child. A second reason was that these technologies, with the exception of artificial insemination by donor, allowed people to have children who were genetically their own. Louise Brown, the first child created through IVF, resulted from the union of the gametes of her biological parents. Third, the children born of these new means of reproduction were born into traditionally structured families. These techniques were assumed to have been developed for use by married couples who, with the new baby, would form what was ordinarily defined as a nuclear family.

In the 1990s, these rationales for accepting novel reproductive technologies are being challenged by medical advances and a changing social environment. Human intervention in the procreative process has become more frequent, more complex, and more highly technological. Oocytes can be removed surgically from one woman and, after fertilization, transferred to another in the procedure of oocyte donation. Women can lend their wombs to others for the incubation of children who have no genetic connection to such "surrogates." Embryos created in vitro can be cryopreserved and stored for use in future years by their genetic parents or by others. Consequently, it is difficult to argue that such innovative measures are mere extensions of the natural way of reproducing. Parthenogenesis (stimulating an unfertilized egg to develop and produce offspring by mechanical or chemical means), cloning (deriving genetically identical organisms from a single cell or very early embryo), and ectogenesis (maintaining the fetus completely outside the body) are on the horizon. Furthermore, third, fourth, and fifth parties, such as oocyte donors, surrogate mothers, and (some suggest) even fetuses and cadavers, are joining sperm donors to assist those who are childless to have offspring. New forms of assisted reproduction are increasingly being used to create children who are not tied to those who will raise them by biological or hereditary links. Finally, these technologies are no longer used almost exclusively to create traditional nuclear families. Unmarried heterosexual and homosexual couples and single women and men now have greater access to them. Such scientific and social changes give new emphasis to the older unresolved ethical questions about the uses of these technologies and raise new questions. Ethical questions raised by the use of the new reproductive technologies The initial ethical question created by these technologies is whether they ought to be used at all. Different religious traditions vary tremendously in their judgments about the licitness of the use of these novel techniques. The Roman Catholic church declared the use of new reproductive technologies morally unacceptable (Catholic Church) because they separate the procreative, life-giving aspects of human intercourse from the unitive, lovemaking aspects, and these, according to Catholic teachings, are morally inseparable in every sexual act. The creation of a child should involve the convergence of the spiritual and physical love of the parents; fertilization outside the body is "deprived of the meanings and the values which are expressed in the language of the body and in the union of human persons" (Catholic Church, p. 28).

Certain other religious groups, such as the Lutheran, Anglican, Jewish, Eastern Orthodox, and Islamic, view some of these methods as ethically acceptable because God has encouraged human procreation (Lutheran Church; Episcopal Church; Feldman; Harakas; Rahman). According to these bodies, it is sufficient that love and procreation are held together within the whole marital relationship; each act of sexual intercourse need not be open to the possibility of conception. Still other religious groups hold that there is no necessary moral connection between conjugal sexual intercourse and openness to procreation, and consequently they accept the use of the new reproductive technologies with few qualifications (Smith; Simmons; General Conference). In Hindu thought, for instance, although there is no authoritative teaching on this subject, the mythologies of ancestors appear to allow IVF, oocyte donation, embryo implantation, and surrogacy (Desai).

Feminists, too, are split about the use of the new reproductive technologies. Some argue that these novel methods define and limit women in ways that demean them, for example, as "fetal containers." They maintain that the desire of many women, both fertile and infertile, for children is, in large part, socially constructed (Bartholet, 1992; Williams). The cultural imperative to have children drives infertile women to undergo physically, emotionally, and financially costly treatment. They are thrust into the hands of a predominantly male medical establishment that uses women as "living laboratories" whose body parts they manipulate without regard to the consequences (Rowland). Male experts sever what was once a continuous process of gestation and childbirth for women into discrete parts, thereby fragmenting motherhood (Corea).

In contrast, other feminists argue that the new reproductive technologies enhance the status of women by providing them with an increased range of options. By circumventing infertility and providing women with alternative means of reproducing, these technologies extend reproductive choices and freedoms (Jaggar; Andrews; Macklin, 1994). In their view, the charge that surrogacy exploits women is paternalistic because it questions women's ability to know their own interests and to make informed, voluntary, and competent decisions (Macklin, 1990); women have the ability and right to control their bodies and to make autonomous choices about their participation in such practices, these feminists argue.

Some people recommend adoption over the use of the new reproductive technologies because they view the latter as physically and emotionally debilitating and unlikely to succeed, whereas adoption, while not easy, provides a home and family for children in need (Bartholet, 1993). Yet adoption is a second choice for many infertile couples because of its perceived drawbacks. These include the declining number of healthy children available for adoption, the long and emotionally draining wait, the expense, and the difficult and often frustrating system with which adoptive parents must deal (Lauritzen). Although the use of assisted reproduction presents some of the same problems as adoption, it offers what some infertile couples consider distinct advantages: It allows them to have children who are genetically related to at least one of them and (except in the case of surrogacy) makes the experience of pregnancy and birth available to the woman. The desire to reproduce through lines of kinship and to connect to future generations exerts a powerful influence, as does the hope of experiencing the range of fulfilling events associated with pregnancy and childbirth (Overall).

Individual Choice, Substantial Harm, and Community Values

A central issue in the debate about the use of reproductive technologies concerns the scope that should be given to individual discretion over their use. Some philosophical commentators, emphasizing personal autonomy, enunciate a broad moral right to reproduce by means of these technologies (Bayles; Brock). They borrow from legal discussions of the right to reproduce, which some legal theorists take to include the liberty to use methods of assisted reproduction (Robertson, 1986; Elias and Annas, 1987). To limit individual choice about noncoital means of reproduction, the state must show that the use of specific reproductive technologies threatens substantial harm to participants and the children born to them (Robertson, 1988). The philosophers influenced by such legal positions maintain that individuals have great leeway in their choice of whether to procreate, with whom, and by what means. They have a right to enter into contractual arrangements giving them access to these technologies and to utilize third parties in their reproductive efforts. Those who take this approach concede that substantial adverse effects on others, particularly the children, would justify restricting individual use of assisted reproduction.

Since the primary reason for accepting these innovative methods is to bring children into the world, a major consideration in assessing them is whether or not they harm these children. Critics contend that these techniques may cause social and psychological problems to the resulting children because of confusion they engender over divided biological parentage and the social stigmatization to which they may be subjected (Callahan, 1988). John Robertson responds that this criticism is logically incoherent. When the alternative is nonexistence, he argues, it is better for the children to have been born—even though they may experience some harm from the means used to bring them into the world—than never to have existed at all (Robertson, 1986). In most cases, the difficulties they face are not so great as to render life a complete loss.

There are several problems with this influential response. One is that it justifies allowing almost any harm to occur to children born as a result of the use of these techniques in that it can almost always be said they are better off alive. Moreover, this argument presupposes that these children are waiting in a world of nonexistence to be summoned into existence and that they would be harmed by not being born. Since children do not exist at all prior to their arrival in this world, there are no children who could be harmed by not being born. When we say that it is better for a child to have been born, we do not compare that child's current existence with a previous one. Instead, we make an after-the-fact judgment that life is a good for an already existing child, even though that child may have suffered some harm from the technology used to bring him or her into the world. Critics of the use of the new reproductive technologies, however, make a before-the-fact judgment about children who do not exist, but who might. They maintain that it would be wrong to bring children into the world if they would suffer certain substantial harms as a result of the methods by which they are created. This is a logically coherent claim that justifies considering whether the new reproductive technologies severely damage children born as a result of their use.

The criterion of avoiding substantial harm, while valid, may provide inadequate ethical constraints on various ways of employing the new reproductive arrangements. The criterion is derived from a position that especially prizes individuality, liberty, and autonomy—quite possibly at the cost of values that are served by the building of families and communities, and by accounting for the common good (Cahill). Taking respect for individual freedom as the primary value, according to Allen Verhey, runs the danger of reducing the value of persons to their capacities for rational choice and denying the significance of the communities that shape them. People are not just autonomous individuals, they are also members of communities, some of which are not of their own choosing. Freedom is insufficient for an account of the good life in the family. Thus, it may be morally legitimate to recommend limits to individual choice about assisted reproductive techniques, not only to protect the children born of these methods but also to uphold basic community values. What is at issue, he suggests, is what kind of society we are and want to become (Verhey).

Ethical Issues Related to the Introduction of Third Parties

The introduction of third parties into procreative acts, according to some critics, imperils the very character of society by threatening the nuclear family, the basic building block of U.S. society (Callahan, 1988). Religious commentators and groups, in particular, have expressed concern about the effect of the use of gamete donors and surrogates on the relation between married couples within the nuclear family. Richard McCormick, a Roman Catholic theologian, argues that when procreation takes place in a context other than marriage (as when single women use artificial insemination by donor, for example) and another's body is used to achieve conception (as in the case of surrogacy, for example), total dedication to one's spouse is made more difficult; in Roman Catholic terminology, it also violates "the marriage covenant wherein exclusive, nontransferable, inalienable rights to each other's person and generative acts are exchanged" (Ethics Committee, 1986, p. 82).

In Islamic law, artificial insemination by donor is rejected on grounds that the use of the sperm of a man other than the marriage partner confuses lineage and might also constitute a form of adultery because a third party enters into the procreative aspect of the marital relation. The practice is highly controversial in the Jewish religion because (1) some consider it a form of adultery; (2) some take the resulting child to be illegitimate; and (3) if the donor is unknown, the practice might eventually result in incestuous marriage between siblings. Most other religious groups that have commented on surrogacy also reject it because it depersonalizes motherhood and risks subjecting surrogates and procreation itself to commercial exploitation. Such practices will lead people to regard children as products who, in Oliver O'Donovan's terms, are "made" rather than "begotten."

Those who wish to counter concerns about adultery distinguish between adultery and the use of a gamete or womb contributed by a third party to assist a married couple to have a child. A necessary element of adultery, they contend, is sexual intercourse; neither gamete donation nor surrogacy involves sexual contact between the recipient and the donor. Moreover, unlike adultery, no element of unfaithfulness need inhere in participation in gamete donation. Indeed, a couple may participate in gamete donation just because they have a strong commitment to their marriage, rather than out of disdain for it (Lauritzen). When only one parent can contribute genetically to the procreation of a child, but both can nourish and nurture a child, this argument runs, it is ethically acceptable for them to have a child by means of third-party collaboration.

The use of third parties in the provision of the new reproductive technologies leads to confused notions of parentage, critics note, since it severs the connection between the conceptive, gestational, and rearing components of parenthood. It can be difficult to predict who will be declared the rearing parent in different reproductive scenarios, despite the fact that they embrace the same set of facts. For instance, in IVF followed by embryo transfer, the woman who gestates an embryo provided by someone else is considered the mother of the resulting child, but in artificial insemination by donor she is not. Those who respond to this criticism, in attempting to develop a consistent ethical basis for awarding the accolade of parenthood, give priority either to the interests of the children born of these technologies or to those of their adult progenitors.

Those who view the interests of the children as of prime importance argue that genetic connections should constrain the freedom to choose parental status in that biological kinship relations are important to children's development and self-identity (Callahan, 1988). Purposefully to break the link between procreation and rearing, these commentators maintain, harms children born of these procedures because it obscures their identity within a family lineage. Indeed, it has been argued that the biological relationship between gamete donors and the children who result from their contributions carries an obligation for donors to support and nurture those children (Callahan, 1992). Respondents observe that it is not considered wrong to separate the genetic and rearing components of parenthood in such well-established arrangements as adoption, stepparenting, blended families, and extended kin relationships. This precedent suggests that, although the genetic relation may be important, it is not essential to parenthood.

Caring for and raising a child are of greater significance for parenthood than providing the genetic material or gestational environment, according to this view. Consequently, the rearing parent should have moral priority over the genetic parent in the interests of the child (Lauritzen). Others focus on the interests of the parents when the choice is between the genetic and the gestational mother, and they contend that the gestational mother should prevail because of her greater physical and emotional contribution and the risks of childbearing (Elias and Annas, 1986).

Parents who are not the biological progenitors of the children they raise and those who provide them with gametes often fear social stigmatization. This raises the question of whether anonymity and secrecy should be used to envelop all who participate in the use of the new reproductive technologies for their own protection. Anonymity has to do with concealing the identity of the donor; secrecy has to do with concealing the fact that recipients have participated in gamete donation. The practice of artificial insemination by donor has historically been carried out in secrecy with anonymous donors to protect family and donor privacy; oocyte donation, which began with openness about the identity of donors, is moving in that direction as well. The major argument against this development takes the interests of the children as primary and contends that since the personal and social identity of children is dependent on their biological origins, they ought to know about their genetic parents (National Bioethics Consultative Committee). Several countries that accept this argument have adopted regulations allowing children, when they reach maturity, to gain access to whatever information is available about donors who contributed to their birth.

Technologies of assisted reproduction, especially those involving third parties, facilitate the creation of models of family that depart significantly from the traditional nuclear family. As single persons, homosexual couples, and unmarried heterosexual couples increasingly gain access to these technologies, both religious and secular bodies express concern about weakening mutual commitment within the family and about the welfare of the resulting children. Sherman Elias and George Annas observe that "it seems disingenuous to argue on the one hand that the primary justification for noncoital reproduction is the anguish an infertile married couple suffers because of the inability to have a `traditional family,' and then use the breakup of the traditional family unit itself as the primary justification for unmarried individuals to have access to these techniques" (1986, p. 67). The Warnock Report, developed by a commission of inquiry into the use of artificial means of reproduction in Great Britain in 1984, concluded that "the interests of the child dictate that it should be born into a home where there is a loving, stable, heterosexual relationship and that, therefore, the deliberate creation of a child for a woman who is not a partner in such a relationship is morally wrong" (p. 11).

Some psychologists claim that children who grow up in these nontraditional families will suffer psychological and social damage because they will lack role models of both genders and may consequently develop an impaired view of sexuality and procreation (McGuire and Alexander). Moreover, they argue, two parents are better able than one to cope with the demands of childrearing. Other studies have been used to vindicate the opposite conclusions (McGuire and Alexander). Since few studies have been carried out on the consequences for children of atypical family arrangements that emerge when the new reproductive technologies are employed, it is difficult to provide any clear evidence to support or undermine these opposing contentions. A further concern voiced is that using new reproductive technologies to assist single people and homosexual couples to have children involves a misuse of medical capabilities because these methods are not being employed to overcome a medical problem but to circumvent biological limits to parenthood.

To others, however, the use of new methods of assisted reproduction by single people and homosexual couples mirrors the reality that U.S. society has begun to move away from the nuclear family (Glover). They see the inclusion of homosexual parents within the meaning of family as a move toward greater equality in a society in which those who are homosexual suffer from prejudice and discrimination. If single people and homosexual couples can offer to a child an environment that is compatible with a good start in life, the *Glover Report to the European Commission* maintains, they ought to have access to these techniques, but it is appropriate for those providing them to make some inquiries before proceeding (Glover). The Royal Commission on New Reproductive Technologies of Canada approved of allowing infertility clinics to provide single heterosexual and lesbian women access to donor insemination on grounds that no reliable evidence could be found that the environment in families formed by these gamete recipients is any better or any worse for the children than in families formed by heterosexual couples (Canada, Royal Commission on New Reproductive Technologies).

Ethical Issues Related to Commodification

A concern of special ethical significance is that the introduction of third parties into some of the new reproductive techniques carries with it the danger of commodification of human beings, their bodies, and their bodily products. Giving payment of any sort to surrogates and gamete donors, some argue, risks making them and the children produced with their assistance fungible objects of market exchange, alienating them from their personhood in a way that diminishes the value of human beings (Radin). Third parties who assist others to reproduce should be viewed as donors of a priceless gift for which they ought to be repaid in gratitude, but not in money.

Others argue that persons have a right to do what they choose with their bodies and that when they choose to be paid, their reimbursement should be commensurate with their services (Robertson, 1988). The value of respect for persons is not diminished by using surrogates and gamete donors for the reproductive purposes of others if those third parties are fully informed about the procedure in which they participate and are not coerced into participating—even when they are paid (Harris). There is a presumption on all sides that third parties should not be specifically compensated for their gametes, wombs, or babies. Several groups that have considered the matter, though, such as the Warnock Committee in Great Britain (Warnock) and the Waller Committee in Australia (Victoria), allow third-party payment for out-of-pocket and medical expenses. The American Fertility Society goes further when it maintains that gamete donors should be paid for their direct and indirect expenses, inconvenience, time, risk, and discomfort (Ethics Committee, 1990). It would be unfair and exploitive not to pay donors for their time and effort, John Robertson argues (1988).

Offering large amounts of money to third parties incommensurate with the degree of effort and service that these persons provide may diminish the voluntariness of their choice to participate in assisted reproduction, particularly when they have limited financial means. There is concern that a new economic underclass might develop that would earn its living by providing body parts and products for the reproductive purposes of those who are better off economically. This would violate the principle of distributive justice, which requires that society's benefits and burdens be parceled out equitably among different groups (Macklin, 1994). However, if poor women and men have voluntarily and knowingly accepted their role in these reproductive projects, it could be seen as unjustifiably paternalistic to deny them the opportunity to earn money. The possibility of exploitation of the poor must be weighed "against a possible step toward their liberation through economic gain" from a new source of income connected to innovative methods of reproduction (Radin).

Ethical Issues Related to the Uses of Embryos, Fetuses, and Cadavers

When the process of fertilization is external, the embryo becomes accessible to many forms of intervention. During the brief extracorporeal, in vitro period, embryos can be frozen, treated, implanted, experimented on, discarded, or donated. Theoretically, embryos that result from IVF could be cryopreserved for generations, so that a woman could give birth to her genetic uncle, siblings could be born to different sets of parents, or one sibling could be born to another. A 1993 experiment in which human embryos were split reawakened concerns about these sorts of possibilities, which had remained dormant since a mid-1970s controversy about cloning human beings (National Advisory Board). (Cloning, either by transplanting the nucleus from a differentiated cell into an unfertilized egg from which the nucleus has been removed or by splitting an embryo at an early stage when its cells are still undifferentiated, results in individuals who are genetically identical to the original from which they are cloned.)

Advocates of embryo splitting view it as a way of obtaining greater numbers of embryos for implantation in order to enhance the chances of pregnancy for those who are infertile (Robertson, 1994). Critics claim that cloning in any form negates what we view as valuable about human beings, their individuality and uniqueness. It risks treating children as fungible products to be manipulated at will, rather than as unique, self-determining individuals. These critics maintain that twinning that occurs in nature is an unavoidable accident that does not involve manipulation of one child-to-be to produce a duplicate (McCormick, 1994). Defenders of cloning respond that the similarity of identical twins does not diminish their uniqueness or their sense of selfhood. In any case, cloned individuals would not be identical in that the genome does not fully determine a person's identity. Environmental factors, such as family upbringing and the historical context, weigh heavily in influencing the expression of genes (National Advisory Board).

It is the potential for abuse of cloning that disturbs most critics. The possibility of cryopreserving cloned embryos suggests the option of implanting cloned embryos and bringing them to term should their already-born twin need a tissue or organ transplant. In another scenario, embryos derived from parents who are likely to produce "ideal specimens" would be cloned and sold on a "black market." Critics condemn such potential applications of cloning because they diminish the value of embryos and of human beings by treating them as objects available for any use by others (National Advisory Board). They are concerned that the deep desire of the infertile for children, in combination with scientific zeal and market forces, will create strong pressure to clone embryos without a view to the ethical considerations involved. In 1993 scientists in the United Kingdom announced the possibility of using for infertility treatment eggs and ovaries taken from aborted fetuses (Carroll and Gosden). The eggs could be fertilized in vitro and then transferred into infertile women who lack viable eggs; the ovaries could be transplanted directly into women to mature and produce eggs.

This would help meet the shortage of oocytes for those who lack their own. Such uses of aborted fetuses, however, are highly contentious and strike some as grotesque. Many who object to abortion on ethical grounds maintain that this procedure, like other forms of fetal tissue use, would encourage the practice. Moreover, it seems self-contradictory for a woman to consent to abortion and at the same time consent to become a grandmother. Children created by this procedure, it could be argued, would know little about their genetic heritage or about their mother, other than that she was a dead fetus, and would therefore be at risk of both psychological and social harm.

Female cadavers provide another potential source of oocytes for those who are infertile. It has been proposed that women consider donating their ovaries for use by others after their death, much as individuals donate organs such as kidneys and livers (Seibel). It may soon be possible to collect immature eggs from cadavers, mature and fertilize them in vitro, and then transfer them into infertile women. This procedure would have an advantage over the use of eggs from aborted fetuses in that the recipient would be able to learn the medical and genetic history of the adult donor. An argument for this practice is that it would allow the continuation of the family's biological heritage and serve to console the grieving family because some aspect of their deceased relative will have been preserved. Postmortem recovery of eggs would be done with the consent of the donor and would therefore respect individual rights and allow freedom of choice for individuals and their close relatives.

This proposal is grounded in an analogy between organ and gamete donation. Yet gamete donation is different in that it involves the provision of an essential factor for bringing a child into existence; it is not life-saving but life-giving. The interests of the resulting children, consequently, provide a major consideration to be taken into account in determining whether such procedures ought to be pursued. The difficulty noted earlier in connection with the introduction of third parties arises in this instance as well.

Children develop their identity and self-understanding, in part, through their relationships with their biological parents. Consequently, they might face serious psychological and social harm if one of their biological parents were a cadaver. Indeed, this concern amounts to a central social concern as well, in that the prospect of using gametes derived from the newly dead in order to create children endangers our perception of the respect due to the dead human body and our view of procreation as ideally grounded in an interpersonal relationship between living persons.

Ethical Issues Related to Access and Justice

Although those able to procreate naturally can decide whether and when to do so, the choice to reproduce among those who need medical assistance to do so is more limited. In part, this is because they enter a healthcare system in which providers have responsibilities both to candidates for infertility treatment and to the resulting child, because they are assisting in the creation of a new human being. Although physicians have a special obligation to respect the autonomy and freedom of those who are candidates for treatment, they are not obligated to provide them with all treatments that they request (Chervenak and McCullough). As one of several groups of gatekeepers of the new reproductive technologies, some physicians use a medicalindications criterion to bar access to these technologies to some patients, as when, for example, the physical risk of pregnancy is too great. Yet many physicians find that they cannot easily separate medical indications from indications that are psychological, social, and ethical. Questions requiring judgments that go beyond those that are strictly medical arise in many situations. These questions include possible treatment for candidates who wish to create "designer babies" of a certain sex, intelligence, and/or race; couples who want to use a surrogate mother for frivolous reasons related to personal convenience; infertile single women who request access to both oocyte and sperm donation in lieu of adoption; women of advanced reproductive age who want to have children despite the risk to their own health; and couples who appear severely dysfunctional and prone to violence and child abuse. Physicians are not usually trained to address ethical questions that arise in such situations. Because physicians have personal and professional biases and are part of a largely unregulated and profitable infertility industry, it might be appropriate to assign the gatekeeper role to a specially trained group of professionals who are not physicians. Another possibility is to utilize guidelines for the use of the new reproductive technologies prepared by physician professional associations, institutional ethics committees, private-sector ethics boards, public ethics commissions, and state and national regulatory agencies; such guidelines should address not only medical but social, psychological, and ethical issues (Cohen, 1994; Fletcher).

Public-policymakers and private healthcare insurance regulators also affect who gains access to the new reproductive technologies. If they define infertility treatment as a response to a disease rather than to a social need, a case for financial support of the new reproductive technologies can be made. Because infertility is a physical condition that impairs normal function, many commentators regard it as something like a disease, the victims of which are in need of help from medical science (Overall). However, it can also be argued that since reproductive technologies do not correct the condition causing infertility, they do not constitute medical treatment for a disease. Yet many well-accepted treatments do not correct the underlying condition but only its symptoms or disabilities. Given the importance to many people of having a biological child and the fact that normal functioning allows this, the claim has been made that infertility should be treated as a disease on a par with other physical impairments. Historically, the *barren* woman or man has not been accorded sympathy; the availability of infertility treatment might disarm similar current discriminatory attitudes toward those who are infertile.

Even if infertility were defined as a disease, however, this would not indicate that its treatment would be ethically mandatory. The U.S. healthcare system does not have infinite resources and cannot provide everyone with every desired or desirable health service. Should the new reproductive technologies be subject to more severe criteria for funding than are set for other medical techniques? Because infertility is a physical dysfunction with significant effects on the life plans of those it affects, it can be contended that a just society should include reproductive technologies among the range of treatments covered. The opposing argument is that the costs of such treatment and its relatively low likelihood of success do not justify its inclusion.

A related issue arises from the fact that only a limited range of people—those with greater financial resources—benefit from the new reproductive technologies. Access depends on economic factors, culture, race, and social class. Those in the United States who are poor have little access to specialty services such as infertility clinics because public and private insurers provide limited coverage. If poor people participate at all in the use of these technologies, they do so as surrogates or occasionally as oocyte donors. Thus, the use of new reproductive technologies has potential for creating further unjust schisms in our society between rich and poor and between one subculture and another. As long as IVF services and gametes are in short supply, questions will arise about how to select candidates from among those who seek access to the new methods of assisted reproduction. Those persons who are infertile or who carry a serious genetic disease may have a greater first claim than those who are not infertile but who wish to use these methods to select the features of their children or as a matter of personal convenience.

This is because the need of the former is a more basic need, directly related to the goal of remedying a difficulty in normal species functioning. A more refined set of rationing priorities would take account of such factors as the number of children an individual or a couple already has; whether they have a support system in place to assist them to care for a child adequately; and the greater medical risk to certain recipients of treatment, such as women of advanced reproductive age. These considerations would be grounded in the interests of the potential children and of their would-be parents, as well as in the need to distribute the number of children among couples in an equitable way.

Conclusion

Behind many of the ethical issues raised by the new reproductive technologies lie difficult questions about the importance of genetic parenthood, the nuclear family, and the welfare of children, as well as the role that society should play in overseeing the creation of its citizens. Perplexity about how to resolve these questions is due, in part, to the speed with which these technologies are being developed. There is a growing concern that they are being created too rapidly, before the old technologies, such as artificial insemination, have been integrated into the ethical and social fabric. As the rate of reproductive change accelerates, the ability to provide ethical safeguards for the creation and use of the new reproductive technologies diminishes. This may be the most persuasive reason to provide some form of direction and regulation of the new reproductive technologies that incorporates defensible ethical limits to their use.

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SEE ALSO: *Abortion; Adoption; Cloning; Embryo and Fetus; Eugenics; Feminism; Fetal Research; Fertility Control; Genetic Counseling; Genetic Testing and Screening: Reproductive Genetic Testing; Healthcare Resources, Allocation of: Microallocation; Law and Bioethics; Maternal-Fetal Relationship; Moral Status; Organ and Tissue Procurement: Ethical and Legal Issues Regarding Living Donors; Population Ethics; Sexism; Transhumanism and Posthumanism; Women, Contemporary Issues of;* and other *Reproductive Technologies* subentries

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IX. IN VITRO FERTILIZATION AND EMBRYO TRANSFER

In in vitro fertilization (IVF), a woman’s ovaries are stimulated with fertility drugs to produce multiple eggs. The physician monitors the woman’s response by examining urine samples, blood samples, and ultrasound imaging. After giving her an injection to control the timing of the egg release, the physician retrieves the eggs in one of two ways. In a laparoscopy, done under general anesthesia, the surgeon aspirates the woman’s eggs through a hollow needle inserted into the abdomen, guided by a narrow optical instrument called a laparoscope. In the more recently developed transvaginal aspiration, done with local anesthesia, the physician inserts the needle through the woman’s vagina, guided by ultrasound.

After they are retrieved, the eggs are placed in separate glass dishes and combined with prepared spermatozoa from the woman’s partner or a donor. The dishes are placed for twelve to eighteen hours in an incubator designed to mimic the temperature and conditions of the body. If a single spermatozoon penetrates an egg, IVF has occurred.

A fertilized egg subdivides into cells over a period of forty-eight to seventy-two hours. Microscopic in size, it is generally called a pre-embryo or an embryo after it has divided into two or more cells. When the embryos have divided into four to sixteen cells, they are placed in a hollow needle (catheter) that is inserted into the woman’s vagina. The embryo or embryos are released into the woman’s uterus in the procedure known as embryo transfer. Implantation in the uterine wall, if it takes place, will occur within days after transfer; a pregnancy is detectable about two weeks after the transfer.

In established IVF clinics, the odds that a continuing pregnancy and birth will occur after embryo transfer are 20 to 30 percent. Because problems can arise at all stages of IVF, such as the inability to retrieve eggs or secure fertilization, the odds are less if they are calculated from the time fertility drugs are first given. Data from several national registries indicate a delivery rate of 9 to 13 percent if calculated from the starting point of hormonal stimulation (Cohen, 1991). The birthrates tend to cluster among clinics, so that some clinics account for a large percentage of the total births while others have few or no deliveries (Medical Research International). Tens of thousands of embryo transfers are carried out each year internationally, and thousands of babies have been born. Clinicians reported over 12,000 deliveries following IVF in one five-year period (1985–1990), and in one country (the United States) alone (Medical Research International).

Present and Future Variations

The first birth following IVF occurred in England in 1978 (Steptoe and Edwards). The technique was originally designed to circumvent blocked or damaged fallopian tubes in women trying to become pregnant. During the late 1970s and early 1980s, physicians combined the male partner’s sperm and the female partner’s eggs and transferred the embryos shortly after fertilization. If the couple had a large number of embryos, physicians either transferred all at once, which created the risk of a multiple pregnancy, or disposed of extra embryos, which wasted the embryos and was morally problematic.

The start of embryo freezing in the early 1980s has given physicians greater control over the number of embryos transferred at once. Two to four embryos are transferred in the first IVF cycle and the remaining embryos, if any, are frozen for later thawing and transfer. Embryo freezing saves the woman from the hormonal stimulation of repeated start-up IVF cycles, and it allows embryo transfer when the woman’s body has returned to a more natural state. By enabling the transfer of a small number of embryos at once, it reduces the odds of a multiple pregnancy and the subsequent risk this poses to the woman and the fetuses. Controlled transfer of embryos is arguably less morally problematic than the selective abortion of fetuses in a large multiple pregnancy. The birth of the first infant to have been frozen as an embryo took place in Australia in 1984. Embryo freezing is now a routine option in IVF.

Another variation that has increased the flexibility of IVF is the use of donated sperm, eggs, and embryos to circumvent fertility problems such as low sperm count in the male partner, lack of ovulation in the female partner, or lack of fertilization with the couple's own eggs and sperm, or to help couples at high risk avoid passing on a serious genetic disorder to their children. Sperm and embryo donation are more straightforward than egg donation, which is complicated by the need to synchronize the menstrual cycles of the donor and recipient. Women are either paid for their services in donating eggs or they donate in the course of their own medical treatment. In addition, some women donate eggs for their sisters or other close relatives. Donation of eggs or sperm raises questions about, among other things, confidentiality of medical records, the child's sense of identity, and the psychological well-being of the donor.

The embryos in IVF can be transferred to a surrogate if the genetic mother does not have a uterus or cannot carry a child to term for other reasons. Although the surrogate is usually unrelated, there have been instances of embryo transfer to the sister or even the mother of a woman who cannot carry a fetus to term. In the latter case, the surrogate is the child's gestational mother and genetic grandmother.

Sperm microinjection is another technique used in connection with IVF. If the male partner has low sperm count or poor sperm quality, a healthy spermatozoon can be manually inserted into the egg with special microinstruments. This alternative to sperm donation allows the transfer of embryos genetically related to the couple. This and other microsurgical procedures remain experimental and infrequent.

Another procedure for IVF is the examination of sperm, eggs, and embryos for chromosomal and genetic abnormalities. Preimplantation diagnosis has been conducted on an experimental basis in the United States, Britain, and other European countries. It is being developed for couples at high risk for passing to their children a genetic disorder such as cystic fibrosis or Tay-Sachs disease but who will not terminate a pregnancy and are therefore not candidates for prenatal screening.

Preimplantation diagnosis includes polar-body analysis (analyzing the DNA of the first polar body of the human egg), trophectoderm biopsy (examining extra-embryonic cells surrounding the inner cell mass), and embryo biopsy (removing a single cell from a four- or eight-cell embryo). It also includes chromosomal analysis to select only female embryos for transfer to couples who are at high risk for passing on a sex-linked disease, such as hemophilia, to male children. Pregnancies and births have been reported following embryo biopsy and sex preselection. Many variables remain to be worked out in preimplantation diagnosis, and physicians urge caution before expanding it in the IVF setting (Trounson). Correcting genetic flaws after they have been diagnosed is a distant, though foreseeable, possibility (Verlinksy et al.).

Ethical Issues in IVF

A recurring and unresolved issue in IVF involves the status of the embryo (McCormick). The Ethics Advisory Board, set up by the U.S. Department of Health, Education and Welfare, and later disbanded without its recommendations' being acted on, issued a report in 1979 stating that "The human embryo is entitled to profound respect, but this respect does not necessarily encompass the full legal and moral rights attributed to persons" (U.S. Department of Health, Education and Welfare, p. 107). The Warnock Commission issued a report in Britain in 1984 that also accorded the embryo a "special status," though not the same status "as a living child or adult" (Warnock).

The notion that the embryo is an entity with a special status deserving special respect is contested by those who regard the embryo as fully a human being from the moment of conception. An instruction issued by the Vatican concluded that the "human being must be respected—as a person—from the very first instant of his existence" (Catholic Church; Shannon and Cahill). The unique genetic makeup of the embryo, among other things, is given as evidence of its individuality.

Beliefs about the embryo's status are central to conclusions about what in IVF is permissible and what is not. Some observers who regard the embryo as a human being believe IVF is ethically acceptable provided all embryos are transferred and given a chance to survive. Others believe external fertilization is always immoral. If the embryo is regarded as a human being, it has "full human rights," including the right not to be experimented upon without its consent (Ramsey, 1972a, 1972b). Even if one regards IVF as no longer experimental, the conclusion of immorality still extends to IVF's variations, which begin as experimental procedures posing the risk of higher-than-normal embryo loss.

If, on the other hand, the embryo is regarded as only potentially a human, fewer ethical strictures on IVF techniques apply. The Ethics Advisory Board concluded that IVF was ethically acceptable for married couples and that research on human embryos was acceptable provided the research was designed to establish IVF safety, would yield "important scientific information," complied with federal laws protecting research subjects, and proceeded only with the consent of tissue donors. No research was to take place beyond the fourteenth day after fertilization. After fourteen days, the embryo begins to develop an embryonic disk or "primitive streak" and is no longer capable of spontaneous twinning, which means it is on the way to becoming a single individual.

IVF has been criticized as a fundamentally dehumanizing technique that takes place in a laboratory, involves the scientist as a third party, is geared to the production of human beings, and is aimed at conquering nature and producing a "quality" child (Kass). The language of IVF and its business and marketing overtones contribute to a situation in which tissues and children are treated as commodities to be produced and in which intimacy is devalued (Lauritzen). The Vatican instruction concluded that IVF is unnatural because the sperm are secured by masturbation and the union takes place outside the body. Tissue donation is especially illicit, as it is "contrary to the unity of marriage, [and] to the dignity of the spouses" (Catholic Church).

Some feminists have expanded on this theme by criticizing laboratory conception as an intervention that divides reproduction—once a continuous process taking place naturally within the woman's body—into discrete and impersonal parts subject to a male-dominated medical profession (Arditti et al.). They argue that in IVF, women are perennial research subjects in an unending set of techniques that have significant emotional costs (Williams); that IVF benefits men and compromises women; and that it curtails women's autonomy and magnifies gender-based power differences in society (Wikler). Other feminists support IVF if it is bounded by feminist ethics and if it builds women's control over reproduction rather than taking it away (Sherwin).

IVF's variations challenge notions of the family, the interests of the potential child, the distribution of societal resources, and the rights of prospective parents. Tissue donation from relatives creates new biological if not legal relationships—for example, when a sister donates an egg to a sister for IVF or a brother donates sperm for his brother's IVF attempt. Embryo freezing creates the prospect of some embryos being stored indefinitely or transferred in a later generation, possibly endangering the resulting child's sense of identity. It also sets the stage for custody disputes and conflicts over the disposition of unwanted embryos (*Davis v. Davis,* 1992).

Embryo diagnosis for genetic defects raises safety questions for the embryo and potential child. Conceivably, it will lead to screening for many genetic problems and not just the life-threatening disorders envisioned now. On the one hand, discarding embryos after tests reveal a genetic abnormality might be less morally contentious than aborting pregnancies, at least for those who believe the embryo has a lesser status than a fetus. On the other hand, discarding "defective" embryos may blunt societal sensibilities and invite fertile couples into the costly and uncertain IVF procedure. The ability to preselect embryos according to sex raises concerns that the technique will be used for nonmedical reasons to give couples a child of their preferred gender, which may be male (Wertz and Fletcher).

IVF is highly selective in the people it can help. An expensive procedure covered by few insurance companies, it is available primarily to affluent couples. Critics question the wisdom of directing scarce resources to an elective and costly procedure with low odds of success (Callahan). Others advise paying more attention to preventing infertility in the first place (Blank). Aggressive marketing of IVF, including marketing that distorts success rates to make them seem greater than they actually are, arguably creates needs by making couples feel they ought to try IVF because it is there to try and by interfering with alternatives such as adoption or stopping efforts to conceive.

Concerns about the support of IVF and embryo research have been integrated into formal policy in a number of countries (Knoppers and LeBris). For example, the British Human Embryology and Fertilisation Act of 1990 created a licensing authority to conduct on-site visits to clinics in which human embryos are manipulated, review research proposals, and ensure that quality control is maintained in the laboratories (Morgan and Lee). A restrictive law in Germany, by contrast, makes criminal a range of techniques not therapeutic for the embryo, including sex preselection for nonmedical reasons ("German Embryo Protection Act"). Among the international documents relating to embryo manipulations are a recommendation from the Parliamentary Assembly of the Council of Europe that the Council of Ministers provide a "framework of principles" governing embryo and fetal research ("Parliamentary Assembly"), and a set of principles relating to IVF and its variations ("Council of Europe").

Fifteen states in the United States mention embryos in their statutes, but legislators passed most laws with abortion and fetuses in mind rather than IVF and embryos. Some of these laws would presumably make embryo research illegal, but their constitutionality has not been tested (Robertson). In 1989 the U.S. Supreme Court reviewed Missouri's abortion statute but declined to address the constitutionality of the statute's preamble that "the life of each human being begins at conception" (*Webster v. Reproductive Health Services*). This definition of personhood appears to contradict the Court's abortion rulings, but by leaving it untouched, the Court left the embryo's legal status unclear.

Several states have passed laws mandating insurance coverage for IVF under certain conditions (U.S. Congress, Office of Technology Assessment). The federal government does not fund proposals involving human embryos; by law, research must be reviewed by an ethics board ("Protection of Human Subjects"), but no board has replaced the Ethics Advisory Board, which was disbanded in 1979. This has led to a de facto funding moratorium.

Conclusion

Prior to and in the years following the first successful use of IVF, critics argued that it challenged the sanctity of marriage and family, posed the threat of psychological and physical harm to unborn children, involved the immoral destruction of human embryos, made women experimental pawns in research in which men asserted control over reproduction, and introduced the senseless creation of people in an era of overpopulation. It was also said to admit no clear stopping point, use scarce medical resources, and amount to an elective technique that did not cure infertility.

Supporters argued that IVF would spare couples the psychological trauma of infertility, meet the needs of tens of thousands of women with blocked fallopian tubes, lead to knowledge that would help ensure healthy children, and preserve the family by bringing children to couples who truly want them. They responded to criticism by saying IVF was no more unnatural than cesarean births, should not be diminished merely because it did not cure infertility, posed no apparent risks to children, and was not immoral, in that embryos were only potential human beings.

Today, basic IVF has shifted from experimental to standard medical practice. It is widely available, is regarded as safe, and is the only viable way women with blocked fallopian tubes can conceive a baby genetically related to them. New technical additions ensure, however, that external fertilization will remain at center stage in the ongoing bioethics debate over reproductive technologies.

The lasting unanswered questions relate to the high value placed on genetic parenthood, equitable access to techniques across race and class, the impact of laboratory conception on women's control over reproduction, and whether priority ought to be placed on conception in a time when discussions are directed to ways of reducing the gap in medical services available to richer and poorer citizens.

Perhaps most significant, however, is the matter of the limits to be placed on reproductive technologies. It appears that the scope of refinements is nearly endless. Should substantive and procedural limits be placed by government on any of IVF's variations? If so, which, and why? Understanding the reasons for placing limits is as important as understanding the reasons laboratory conception is pursued with such intensity in the first place.

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SEE ALSO: *Abortion; Adoption; Cloning; Embryo and Fetus; Feminism; Fetal Research; Genetic Counseling; Genetic Testing and Screening: Reproductive Genetic Testing; Healthcare Resources, Allocation of: Microallocation; Law and Bioethics; Maternal-Fetal Relationship; Moral Status; Population Ethics; Sexism; Transhumanism and Posthumanism; Women, Contemporary Issues of;* and other *Reproductive Technologies* subentries

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REPROGENETICS

SEE *Gene Therapy; Genetics and Human Behavior; Genetic Testing and Screening*

RESEARCH ETHICS COMMITTEES

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The World Medical Association’s Declaration of Helsinki (2000) and the Council for International Organizations of Medical Sciences’ *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (hereafter, CIOMS *International Ethical Guidelines*) (2002) establish as the international standard for biomedical research involving human subjects this requirement: “All proposals to conduct research involving human subjects must be submitted for review of their scientific merit and ethical acceptability to one or more scientific review and ethical review committees.… The investigator must obtain their approval or clearance before undertaking the research” (CIOMS, Guideline 2). In most of the world this committee is called the research ethics committee (REC). In the United States, federal law assigns to the committee the name institutional review board (IRB), and the authority and responsibility for approving or disapproving proposals to conduct research involving human subjects ("IRB Review of Research").

History

The Nuremberg Code (1949) and the original Declaration of Helsinki (1964) made no mention of committee review; these documents placed on the investigator all responsibility for safeguarding the rights and welfare of research subjects. The first mention of committee review in an international document was in the Tokyo revision of the Declaration of Helsinki (1975).

In the United States, the first federal document requiring committee review was issued on November 17, 1953. Titled "Group Consideration for Clinical Research Procedures Deviating from Accepted Medical Practice or Involving Unusual Hazard," its guidelines applied only to research conducted at the newly opened Clinical Center at the National Institutes of Health (Lipsett, Fletcher, and Secundy). Very little is known about peer review in other institutions in the 1950s other than that it existed in at least some medical schools. In 1961 and again in 1962, questionnaires were sent to departments of medicine at U.S. universities. Approximately one-third of those responding reported that they had committees, and one-quarter either had or were developing procedural documents (Curran).

On February 8, 1966, the surgeon general of the U.S. Public Health Service (USPHS) issued the first federal policy statement requiring research institutions to establish the committees that subsequently came to be known as RECs (Curran). This policy required recipients of USPHS grants in support of research involving human subjects to specify that

> the grantee institution will provide prior review of the judgment of the principal investigator or program director by a committee of his institutional associates. This review shall assure an independent determination: (1) Of the rights and welfare of the … individuals involved, (2) Of the appropriateness of the methods used to secure informed consent, and (3) Of the risks and potential medical benefits of the investigation.

The evolution of the federal government's charges to the committee and of its recognition of the need for diversity of committee membership was reflected in several revisions of its policy between 1966 and 1969 (Veatch; Levine, 1986); these will be further discussed below.

Purpose

The purpose of the REC is to ensure that research involving human subjects is designed to conform to relevant ethical standards. Historically, the REC's primary focus was on safeguarding the rights and welfare of individual research subjects, concentrating on the plans for informed consent and the assessment of risks and anticipated benefits. In 1978 the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (hereafter, National Commission) added a requirement that the REC ensure equitableness in the selection of research subjects (Levine, 1986). The National Commission was concerned primarily with protecting vulnerable subjects from bearing a disproportionately large share of the burdens of research. Subsequently, as participation in some types of research became perceived as a benefit, RECs also assumed responsibility for ensuring disadvantaged persons equitable access to such benefits (Levine, 1994).

A source of continuing controversy is whether the REC has an obligation to approve or disapprove the scientific design of research protocols (Levine, 1986). Those who argue that they do or should have such an obligation point out that the leading ethical codes establish a requirement for good scientific design. Moreover, these observers argue, the REC's obligation to determine that risks to subjects are reasonable in relation to anticipated benefits necessarily relies on a prior determination that the scientific design is adequate, for if it is not, there will be no benefits and any risk must be considered unreasonable.

Opponents to assigning such an obligation to the REC, while conceding these two points, argue that the REC is not designed to make expert judgments about the adequacy of scientific design. RECs are generally competent to appraise the value of the science—what the Nuremberg Code calls "the humanitarian importance of the problem to be solved"—but not the validity of the methods or the results (Freedman; Veatch). In general, responsibility for assessment of scientific validity is, and ought to be, delegated to committees designed to have such competence—such as scientific review committees either within the institution or at funding agencies such as the National Institutes of Health (Levine, 1986; IOM).

Membership

The surgeon general's 1966 memo called for prior review by "a committee of [the investigator's] associates," what was commonly called "peer review." As of 1968, 73 percent of committees were limited in membership to immediate peer groups: scientists and physicians (Curran).

On May 1, 1969, USPHS guidelines were revised to indicate that a committee constituted exclusively of biomedical scientists would be inadequate to perform the functions now expected of it: "The membership should possess … competencies necessary in the judgment as to the acceptability of the research in terms of institutional regulations, relevant law, standards of professional practice and community acceptance."

Regulations of the U.S. Department of Health and Human Services (DHHS), first promulgated in 1974 and since revised several times, maintain the spirit of the 1969 policy and in addition require gender diversity; at least one nonscientist (e.g., lawyer, ethicist, member of the clergy); and at least one member who is not affiliated with the institution (commonly and incorrectly called a "community representative"). Persons having conflicting interests are to be excluded; this concern is also reflected in the CIOMS *International Ethical Guidelines*' requirement for "review committees independent of the research team."

According to Robert M. Veatch (1975), the REC is an intermediate case between two models of the review committee: The "interdisciplinary professional review model," made up of diverse professionals such as doctors, lawyers, scientists, and clergy, brings professional expertise to the review process, while the "jury model … reflects the common sense of the reasonable person." In the jury model "expertise relevant to the case at hand is not only not necessary, it often disqualifies one from serving on the jury" (Veatch, p. 31). Veatch conceded that in order to perform all of its functions, the REC requires both professional and jury skills. He argued, however, that the presence of professionals makes it more difficult for the REC to be responsive to the informational needs of the reasonable person or to be adept at anticipating community acceptance.

John A. Robertson (1979) recommended correcting the "structural bias" of professional domination by introducing a "subject surrogate," an expert advocate for the subjects' interests. DHHS regulations require that if an REC "regularly reviews research that involves a vulnerable category of subjects … consideration shall be given to the inclusion of … [persons who know] about and [are] experienced in working with these subjects" (IRB Membership). For research involving prisoners, the regulations require that at least one member of the REC be either a prisoner or a prisoner representative. There is unresolved controversy over whether persons with AIDS should be appointed to serve on all RECs that review research in the field of HIV infection (Levine, Dubler, and Levine).

In the United States the Institute of Medicine (IOM) endorsed the recommendation of the National Bioethics Advisory Commission (NBAC) that "at least 25 percent of [the IRB's] membership should be reserved for unaffiliated [with the institution] members and those who can provide nonscientific perspectives" (IOM, p. 96). The IOM further expressed its support for the current trends in the United States to enhance the education of REC members and to certify them as competent by independent agencies.

Locale

In the United States the first RECs were established in the institutions where research was conducted. The 1966 surgeon general's policy statement required a committee of "institutional associates." In 1971 the Food and Drug Administration (FDA) promulgated regulations that required committee review only when regulated research was conducted in institutions; hence their name, institutional review committee. Regulations proposed in 1973 by the Department of Health, Education, and Welfare, forerunner of DHHS, also reflected a local setting in their term "organizational review board." In 1974 the National Research Act established a statutory requirement for review by a committee to which it assigned the name "institutional review board," a compromise between the two names then extant.

RECs are required to comply with federal regulations when reviewing activities involving FDA-regulated "test articles," such as investigational drugs and devices, and when reviewing research supported by federal funds. Moreover, all institutions that receive federal research grants and contracts are required to file "statements of assurance" of compliance with federal regulations. In these assurances virtually all institutions voluntarily promise to apply the principles of federal regulations to all research they conduct, regardless of the source of funding (Levine, 1986; IOM).

These points notwithstanding, each REC has a decidedly local character. Most have local names, such as "human investigation committee" or "committee for the protection of human subjects." Each is appointed by its own institution, and each makes its own interpretation of the requirements of federal regulations. For example, at one university, medical students are forbidden to serve as research subjects, whereas at another, involvement of medical students as research subjects is sometimes required as a condition of approval (Levine, 1986).

In its 1978 report, the National Commission recommended that RECs should be "located in institutions where research … is conducted. Compared to the possible alternatives of a regional or national review … local committees have the advantage of greater familiarity with the actual conditions" (U.S. National Commission, pp. 1–2). The

National Commission envisioned the local REC as an ally of the investigator in safeguarding the rights and welfare of research subjects, as well as a contributor to the education of both the research community and the public.

The FDA's change in regulations in 1981 to require REC review of all regulated research, regardless of where it was done, created a problem for the many physicians who were conducting investigations in their private offices; many of these physicians had no ready access to RECs. In response, private corporations developed noninstitutional review boards (NRBs) (Herman). Although there are reasons to question the validity of reviews by NRBs, they appear to be performing satisfactorily (Levine and Lasagna).

In 1986 the FDA began to waive the requirement for local REC review of some protocols designed to evaluate, or to make available for therapeutic purposes, investigational new drugs, particularly those intended for the treatment of HIV infection. In such cases RECs were offered the option of accepting review by a national committee as fulfilling the regulatory requirement for REC review. Such practices have caused some commentators to question the strength of the government's commitment to the principle of local review (Levine and Lasagna).

Internationally, there is much less commitment to the importance of local review. The CIOMS *International Ethical Guidelines* require REC approval for all research involving human subjects and recognize the validity of review at "the institutional, local, regional or national, and in some cases, at the international level." In many European countries, RECs are regional (McNeill).

Several commentators have expressed concern that in the United States the local institution has too much power in protection of human research subjects. Robertson, for example, warned about "the danger … that research institutions will use [RECs] to protect themselves and researchers rather than subjects" (1979); others point to the close associations between RECs and risk-management offices in many institutions as evidence that RECs are being used in this manner.

Criticisms

Before 1962, "a general skepticism toward the development of ethical guidelines, codes, or sets of procedures concerning the conduct of research" prevailed in the medical research community (Curran, p. 408). In the 1970s several biomedical scientists were harshly critical of the REC system, claiming that it tended to stifle creativity and impede progress (Levine, 1986); survey research, however, showed that only 25 percent of biomedical researchers agreed with the statement that "The review … is an unwarranted intrusion on the investigator's autonomy—at least to some extent" (U.S. National Commission, p. 75). Behavioral and social scientists were considerably less accepting of review, claiming that their research activities were much less likely than those of the biomedical scientist to harm subjects. Some argued that because all they did was talk with subjects, review was an unconstitutional constraint on their freedom of speech (Levine, 1986). With the passage of time, most social and behavioral scientists have recognized the value of the REC's review of work in their fields; they have protested, however, that much of the review of social and behavioral research is unsatisfactory because RECs, in general, tend to inappropriately apply rules and procedures that were designed for the "biomedical model" (IOM).

According to Peter C. Williams (1984), RECs do an inadequate job of ensuring that risks will be reasonable in relation to anticipated benefits. This is inevitable for three reasons:

1. Federal regulations on this standard are written in vague language, in contrast to the clearer direction provided for protecting subjects' rights. Moreover, because the regulations permit consideration of the long-range effects of applying knowledge as benefits but not as risks, they create a bias in favor of approval.
2. The membership of the committee, dominated as it is by professionals, is likely to place a higher value than laypersons would on the benefit of developing new knowledge.
3. Groups confronted with choices involving risks may be either more or less cautious or "risk aversive" than the average of individuals within the group; this is known as the *risky shift* or *group polarization phenomenon.* Williams (1984) and Veatch (1975) have argued that in the context of RECs, the groups are likely to be more tolerant of higher levels of risk than would be the individuals who comprise the groups.

Several commentators have proposed that RECs could enhance their effectiveness by sending members to the sites of the actual conduct of research to verify compliance with protocol requirements (Robertson, 1979) or to supervise consent negotiations (Robertson, 1982). Others respond that while such activities should be done when there are reasons to suspect problems in specific protocols, routine monitoring activities might be detrimental to the successful functioning of the committee by eroding its support within the institution (Levine, 1986). The Institute of Medicine concurs with the NBAC's proposal that the REC should engage in routine monitoring of the actual conduct of research, concentrating its efforts on research projects that present to subjects relatively high levels of risks (IOM).

Evaluation

Critics of the REC system claim that there is little or no objective evidence that REC review prevents the conduct of inadequate research. For example, a national survey of RECs revealed that the rate of rejection of protocols is less than 1 in 1,000 (National Commission). Supporters of the system respond that the actual rejection rate is much higher if one includes protocols withdrawn because investigators refuse to modify them as required by RECs. Moreover, rejection rates may be a poor indicator of the REC's quality; protocols may be improved in anticipation of the REC's requirements, and investigators, fearing rejection, may decide not to submit proposals they think might be rejected.

It is very difficult to evaluate the REC's performance objectively; satisfactory subjective evaluations can be made only by experienced REC members and administrators (Levine, 1986). In his excellent theoretical analysis of RECs, published in 1981, Jerry L. Mashaw concluded:

> If [the REC] is to do its core job well, we must live with its inevitable incompetence at other tasks. Moreover, we must also live with the rather vague regulatory standards and with the continuing inability of the federal funding agencies to know for sure whether [RECs] are functioning effectively. If we would have wise judges and paternalistic [skilled in protecting subjects' rights and welfare interests] professionals, we can neither specifically direct nor objectively evaluate their behavior. (Mashaw, p. 22)

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SEE ALSO: *Aging and the Aged: Healthcare and Research Issues; AIDS: Healthcare and Research Issues; Autoexperimentation; Children: Healthcare and Research Issues; Commercialism in Scientific Research; Conflict of Interest; Embryo and Fetus: Embryo Research; Empirical Methods in Bioethics; Genetics and Human Behavior: Scientific and Research Issues; Holocaust; Infants: Public Policy and Legal Issues; Informed Consent: Consent Issues in Human Research; Mentally Ill and Mentally Disabled Persons: Research Issues; Military Personnel as Research Subjects; Minorities as Research Subjects; Pediatrics, Overview of Ethical Issues in; Prisoners as Research Subjects; Race and Racism; Research, Human: Historical Aspects; Research Methodology; Research, Multinational; Research Policy; Research, Unethical; Responsibility; Scientific Publishing; Sexism; Students as Research Subjects; Virtue and Character*

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RESEARCH, HUMAN: HISTORICAL ASPECTS

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In Western civilization, the idea of human experimentation, of evaluating the efficacy of a new drug or procedure by outcomes, is an ancient one. It is discussed in the writings of Greek and Roman physicians and in Arab medical treatises. Scholars like Avicenna (980–1037) insisted that "the experimentation must be done with the human body, for testing a drug on a lion or a horse might not prove anything about its effect on man" (Bull, p. 221). But records of how often ancient physicians conducted experiments, with what agents, and on which subjects, are very thin. The most frequently cited cases involve testing the efficacy of poisons on condemned prisoners, but the extent to which other human research was carried on remains obscure.

Experimentation was frequent enough to inspire a discussion of the ethical maxims that should guide would-be investigators. Moses Maimonides (1135–1204), the noted Jewish physician and philosopher, instructed colleagues always to treat patients as ends in themselves, not as means for learning new truths. Roger Bacon (1214–1294) excused the inconsistencies in therapeutic practices on the following grounds:

> It is exceedingly difficult and dangerous to perform operations on the human body. The operative and practical sciences which do their work on insensate bodies can multiply their experiments till they get rid of deficiency and errors, but a physician cannot do this because of the nobility of the material in which he works; for that body demands that no error be made in operating upon it, and so experience [the experimental method] is so difficult in medicine. (quoted in Bull, p. 222)

Human Experimentation in Early Modern Western History

Human experimentation made its first significant impact on medical practice through the work of the English country physician Edward Jenner (1749–1823). Observing that dairy farmers who had contracted the pox from swine or cows seemed to be immune to the more virulent smallpox, Jenner set out to retrieve material from their pustules, inject the material into another person, and see whether the recipient could then resist challenges from smallpox materials. The procedure promised to be less dangerous than the more standard one of inoculating people with small amounts of smallpox that had been introduced into Europe and America from the Ottoman Empire in the first half of the eighteenth century.

In November 1789, Jenner inoculated his son, then about a year old, with swinepox. When this intervention proved ineffective against a challenge of smallpox, Jenner tried cowpox several months later with another subject. As he recalled: "The more accurately to observe the progress of the infection, I selected a healthy boy, about eight years old, for the purpose of inoculation for the cow-pox. The matter … was inserted … into the arm of the boy by means of two incisions" (Jenner, pp. 164–165). A week later Jenner injected him with smallpox, and noted that he evinced no reaction. The cowpox had rendered him immune to smallpox. One cannot know whether the boy was a willing or unwilling subject or how much he understood of the experiment. But this was not an interaction between strangers. The boy was from the neighborhood, Mr. Jenner was a gentleman of standing, and the experiment did have potential therapeutic benefit for the subject.

For most of the nineteenth century, human experimentation throughout western Europe and the United States was a cottage industry, with individual physicians trying out one or another remedy on neighbors or relatives or on themselves. One German physician, Johann Jorg (1779–1856), swallowed varying doses of seventeen different drugs in order to analyze their effects. Another, Sir James Young Simpson (1811–1870), an Edinburgh obstetrician who was searching for an anesthesia superior to ether, in November 1847 inhaled chloroform and awoke to find himself lying flat on the floor (Howard-Jones). Perhaps the most extraordinary self-experiment was conducted by Werner Forssman. In 1929 he passed a catheter, guided by radiography, into the right ventricle of his heart, thereby demonstrating the feasibility and the safety of the procedure.

The most unusual nineteenth-century human experiment was conducted by the American physician William Beaumont (1785–1853) on Alexis St. Martin. A stomach wound suffered by St. Martin healed in such a way as to leave Beaumont access to the stomach and the opportunity to study the action of gastric juices. To carry on this research, which was very important to the new field of physiology, Beaumont had St. Martin sign an agreement, not so much a consent form as an apprenticeship contract. Under its terms, St. Martin bound himself to "serve, abide, and continue with the said William Beaumont … [as] his covenant servant," and in return for board, lodging, and $150 a year, he agreed "to assist and promote by all means in his power such philosophical or medical experiments as the said William shall direct or cause to be made on or in the stomach of him" (Beaumont, pp. xii–xiii).

The most brilliant human experiments of the nineteenth century were conducted by Louis Pasteur (1822–1895), who demonstrated an acute sensitivity to the ethics of his investigations. Even as he conducted his animal research to identify an antidote to rabies, he worried about the time when it would be necessary to test the product on a human being. "I have already several cases of dogs immunized after rabic bites," he wrote in 1884. "I take two dogs: I have them bitten by a mad dog. I vaccinate the one and I leave the other without treatment. The latter dies of rabies: the former withstands it." Nevertheless, Pasteur continued, "I have not yet dared to attempt anything on man, in spite of my confidence in the result.… I must wait first till I have got a whole crowd of successful results on animals.… But, however I should multiply my cases of protection of dogs, I think that my hand will shake when I have to go on to man" (Vallery-Radot, pp. 404–405).

The fateful moment came some nine months later when his help was sought by a mother whose nine-year-old son, Joseph Meister, had just been severely bitten by what was probably a mad dog. Pasteur agonized as to whether to carry out what would be the first human trial of his rabies inoculation. He consulted with two medical colleagues, had them examine the boy, and at their urging and on the grounds that "the death of the child appeared inevitable, I resolved, though not without great anxiety, to try the method which had proved consistently successful on the dogs." With great anxiety he administered twelve inoculations to the boy, and only weeks later did he become confident of the efficacy of his approach and the "future health of Joseph Meister" (Vallery-Radot, pp. 414–417).

Claude Bernard (1813–1878), professor of medicine at the College of France, not only conducted ground-breaking research in physiology, but also composed an astute treatise on the methods and ethics of experimentation. "Morals do not forbid making experiments on one's neighbor or one's self," Bernard argued in 1865. Rather, "the principle of medical and surgical morality consists in never performing on man an experiment which might be harmful to him to any extent, even though the result might be highly advantageous to science, i.e., to the health of others." To be sure, Bernard did allow some exceptions; he sanctioned experimentation on dying patients and on criminals about to be executed, on the grounds that "they involve no suffering of harm to the subject of the experiment." But he made clear that scientific progress did not justify violating the well-being of any individual (Bernard, p. 101).

Anglo-American common law recognized both the vital role of human experimentation and the need for physicians to obtain the patient's consent. As one English commentator explained in 1830: "By experiments we are not to be understood as speaking of the wild and dangerous practices of rash and ignorant practitioners … but of deliberate acts of men from considerable knowledge and undoubted talent, differing from those prescribed by the ordinary rules of practice, for which they have good reason … to believe will be attended with benefit to the patient, although the novelty of the undertaking does not leave the result altogether free of doubt." The researcher who had the subject's consent was "answerable neither in damages to the individual, nor on a criminal proceeding. But if the practitioner performs his experiment without giving such information to, and obtaining the consent of this patient, he is liable to compensate in damages any injury which may arise from his adopting a new method of treatment" (Howard-Jones, p. 1430). In short, the law distinguished carefully between quackery and innovation, and—provided the investigator had the subject's agreement—research was a legitimate and protected activity.

With the new understanding of germ theory in the 1890s and the growing professionalization of medical training in the next several decades, the amount of human experimentation increased and the intimate link between investigator and subject weakened. Typically, physicians administered a new drug to a group of hospitalized patients and compared their rates of recovery with past rates or with those of other patients who did not have the drug. (Truly random and blinded clinical trials, wherein a variety of patient characteristics were carefully matched and where researchers were kept purposely ignorant of which patient received the new drug, did not come into practice until the 1950s.) Thus, German physicians tested antidiphtheria serum on thirty hospitalized patients and reported that only six died, compared to the previous year at the same hospital when twenty-one of thirty-two patients died (Bull). In Canada, Frederick G. Banting and Charles Best experimented with insulin therapy on diabetic patients who faced imminent death, and interpreted their recovery as clear proof of the treatment's efficacy (Bliss). So too, George R. Minot and William P. Murphy tested the value of liver preparations against pernicious anemia by administering them to forty-five patients in remission and found that they all remained healthy so long as they took the treatment; the normal relapse rate was one-third, and three patients who on their own accord stopped treatment relapsed (Bull). It is doubtful if many of these subjects were fully informed about the nature of the trial or formally consented to participate. They were, however, likely to be willing subjects since they were in acute distress or danger and the research had therapeutic potential.

As medicine became more scientific, some researchers did skirt the boundaries of ethical behavior in experimentation, making medical progress—rather than the subject's welfare—the goal of the research. Probably the most famous experiment in this zone of ambiguity was the yellow-fever work of Walter Reed (1851–1902). When he began his experiments, mosquitoes had been identified as crucial to transmission but their precise role was unclear. To understand more about the process, Reed began a series of human experiments in which, in time-honored tradition, the members of the research team were the first subjects (Bean). It soon became apparent that larger numbers of volunteers were needed and no sooner was the decision reached than a soldier happened by. "You still fooling with mosquitoes?" he asked one of the doctors. "Yes," the doctor replied. "Will you take a bite?" "Sure, I ain't scared of 'em," responded the man. And in this way, "the first indubitable case of yellow fever … to be produced experimentally" occurred (Bean, pp. 131, 147).

After one fellow investigator, Jesse William Lazear, died of yellow fever from purposeful bites, the other members, including Reed himself, decided "not to tempt fate by trying any more [infections] upon ourselves." Instead, Reed asked American servicemen to volunteer, and some did. He also recruited Spanish workers, drawing up a contract with them: "The undersigned understands perfectly well that in the case of the development of yellow fever in him, that he endangers his life to a certain extent but it being entirely impossible for him to avoid the infection during his stay on this island he prefers to take the chance of contracting it intentionally in the belief that he will receive … the greatest care and most skillful medical service." Volunteers received $100 in gold, and those who actually contracted yellow fever received a bonus of an additional $100, which, in the event of their death, went to their heirs (Bean, pp. 134, 147). Although twenty-five volunteers became ill, none died.

Reed's contract was a step along the way to more formal arrangements with human subjects, complete with enticements to undertake a hazardous assignment. But the contract was also misleading, distorting in subtle ways the risks and benefits of the research. Yellow fever was said to endanger life only "to a certain extent"; the likelihood that the disease might prove fatal was unmentioned. And on the other hand, the prospect of otherwise contracting yellow fever was presented as an absolute certainty, an exaggeration that aimed to promote recruitment.

Some human experiments in the pre-World War II period in the United States and elsewhere used incompetent and institutionalized populations for their studies. The Russian physician V. V. Smidovich (publishing in 1901 under the pseudonym Vikentii Veresaev) cited more than a dozen experiments, most of them conducted in Germany, in which unknowing patients were inoculated with microorganisms of syphilis and gonorrhea (Veresaev). George Sternberg, the Surgeon General of the United States in 1895 (and a collaborator of Walter Reed), conducted experiments "upon unvaccinated children in some of the orphan asylums in … Brooklyn" (Sternberg and Reed, pp. 57–69). Alfred Hess and colleagues deliberately withheld orange juice from infants at the Hebrew Infant Asylum of New York City until they developed symptoms of scurvy (Lederer). In 1937, when Joseph Stokes of the Department of Pediatrics at the University of Pennsylvania School of Medicine sought to analyze the effects of "intramuscular vaccination of human beings … with active virus of human influenza," he used as his study population the residents of two large state institutions for the retarded (Stokes et al., pp. 237–243). There are also many examples of investigators using prisoners as research subjects. In 1914, for example, Joseph Goldwater and G. H. Wheeler of the U.S. Public Health Service (PHS) conducted experiments to understand the causes of pellagra on convicts in Mississippi prisons.

One of the few instances of an individual investigator being taken to task for the ethics of his research involved Hideyo Noguchi (1876–1928) of the Rockefeller Institute for Medical Research. He was investigating whether a substance he called luetin, an extract from the causative agent of syphilis, could be used to diagnose syphilis; through the cooperation of fifteen New York physicians, he used 400 subjects, most of them inmates in mental hospitals and orphan asylums and patients in public hospitals. Before administering luetin to them, Noguchi and some of the physicians did first test the material on themselves, with no ill effects. But no one, including Noguchi, informed the subjects about the experiment or obtained their permission to do the tests.

Noguchi's work was actively criticized by the most vocal opponents of human experimentation during those years, the antivivisectionists. They were convinced that a disregard for the welfare of animals would inevitably promote a disregard for the welfare of humans. As one of them phrased it: "Are the helpless people in our hospitals and asylums to be treated as so much material for scientific experimentation, irrespective of age or consent?" (Lederer, p. 336). Despite their opposition, such experiments as Noguchi's did not lead to prosecutions, corrective legislation, or formal professional codes. The profession and the wider public were not especially concerned with the issue, perhaps because the practice was still relatively uncommon and mostly affected disadvantaged populations.

Research at War

The transforming event in the conduct of human experimentation in the United States was World War II. Between 1941 and 1945, practically every aspect of American research with human subjects changed. What were once occasional and ad hoc efforts by individual practitioners now became well-coordinated, extensive, federally funded team ventures. At the same time, medical experiments that once had the aim of benefiting their subjects were now frequently superseded by experiments whose aim was to benefit others, specifically soldiers who were vulnerable to the disease. Further, researchers and subjects were far more likely to be strangers to each other, with no sense of shared purpose or objective. Finally, and perhaps most importantly, the common understanding that experimentation required the agreement of the subjects, however casual the request or general the approval, was superseded by a sense of urgency so strong that it paid scant attention to the issue of consent.

In the summer of 1941, President Franklin Roosevelt created the Office of Scientific Research and Development (OSRD) to oversee the work of two parallel committees, one devoted to weapons research, the other—the Committee on Medical Research (CMR)—to combat the health problems that threatened the combat efficiency of American soldiers. Thus began what one participant called "a novel experiment in American medicine, for planned and coordinated medical research had never been essayed on such a scale" (Keefer, p. 62). Over the course of World War II, the CMR recommended some 600 research proposals, many of them involving human subjects, to the OSRD for funding. The OSRD, in turn, contracted with investigators at some 135 universities, hospitals, research institutes, and industrial firms. The accomplishments of the CMR effort required two volumes to summarize (the title, *Advances in Military Medicine,* did not do justice to the scope of the investigations); and the list of publications that resulted from its grants took up seventy-five pages (Andrus). All told, the CMR expended some $25 million. In fact, the work of the CMR was so important that it supplied not only the organizational model but also the intellectual justification for creating, in the postwar period, the National Institutes of Health.

The CMR's major concerns were dysentery, influenza, malaria, wounds, venereal diseases, and physical hardships (including sleep deprivation and exposure to frigid temperatures). To create effective antidotes required skill, luck, and numerous trials with human subjects, and the CMR oversaw the effort with extraordinary diligence. Dysentery, for example, proliferated under the filth and deprivation endemic to battlefield conditions, and no effective inoculations or antidotes existed. With CMR support, investigators undertook laboratory research and then, requiring sites for testing their therapies, turned to custodial institutions where dysentery was often rampant (OSRD, 1944b). Among the most important subjects for the dysentery research were the residents of the Ohio Soldiers and Sailors Orphanage in Xenia, Ohio; the Dixon, Illinois, institution for the retarded; and the New Jersey State Colony for the Feeble-Minded. The residents were injected with experimental vaccines or potentially therapeutic agents, some of which produced a degree of protection against the bacteria but, as evidenced by fever and soreness, were too toxic for common use.

Probably the most pressing medical problem the CMR faced immediately after Pearl Harbor was malaria, "an enemy even more to be feared than the Japanese" (Andrus, vol. 1, p. xlix). Not only was the disease debilitating and deadly, but the Japanese controlled the supply of quinine, one of the few known effective antidotes. Since malaria was not readily found in the United States, researchers chose to infect residents of state mental hospitals and prisons. A sixty-bed clinical unit was established at the Manteno, Illinois, State Hospital; the subjects were psychotic, backward patients who were purposefully infected with malaria through blood transfusions and then given antimalarial therapies (OSRD, 1944a). With the cooperation of the commissioner of corrections of Illinois and the warden at Stateville Prison (better known as Joliet), one floor of the prison hospital was turned over to the University of Chicago to carry out malaria research and some 500 inmates volunteered to act as subjects. Whether these prisoners were truly capable of consenting to research was not addressed by the researchers, the CMR, or prison officials. Almost all the press commentary was congratulatory, praising the wonderful contributions the inmates were making to the war effort.

In similar fashion, the CMR supported teams that tested anti-influenza preparations on residents of state facilities for the retarded (Pennhurst, Pennsylvania) and the mentally ill (Michigan's Ypsilanti State Hospital). The investigators administered the vaccine to the residents and then, three or six months later, purposefully infected them with influenza (Henle). When a few of the preparations appeared to provide protection, the Office of the Surgeon General of the U.S. Army arranged for the vaccine to be tested by enrollees in the Army Specialized Training Program at eight universities and a ninth unit made up of students from five New York medical and dental colleges.

Because the first widespread use of human subjects in medical research for nontherapeutic purposes occurred under wartime conditions, attention to the consent of the subject appeared less relevant. At a time when the social value attached to consent gave way before the necessity of a military draft and obedience to commanders' orders, medical researchers did not hesitate to use the incompetent as subjects of human experimentation. One part of the war machine conscripted a soldier, another part conscripted a human subject, and the same principles held for both. In effect, wartime promoted teleological as opposed to deontological ethics; "the greatest good for the greatest number" was the most compelling precept to justify sending some men to be killed so that others might live. This same ethic seemed to justify using institutionalized retarded or mentally ill persons in human research.

Human Research and the War Against Disease

The two decades following the close of World War II witnessed an extraordinary expansion of human experimentation in medical research. Long after peace returned, many of the investigators continued to follow wartime rules, this time thinking in terms of the Cold War and the war against disease. The utilitarian justifications that had flourished under conditions of combat and conscription persisted, in disregard of principles of consent and voluntary participation.

The driving force in post-World War II research in the United States was the National Institutes of Health (NIH). Created in 1930 as an outgrowth of the research laboratory of the U.S. Public Health Service, the NIH assumed its extraordinary prominence as the successor agency to the Committee on Medical Research (Swain). In 1945, its appropriations totaled $700,000. By 1955, the figure had climbed to $36 million, and by 1970, $1.5 billion, a sum that allowed it to award some 11,000 grants, about one-third requiring experiments on humans. In expending these funds, the NIH administered an intramural research program at its own Clinical Center, along with an extramural program that funded outside investigators.

The Clinical Center assured its subjects that it put their well-being first. "The welfare of the patient takes precedence over every other consideration" (NIH, 1953a). In 1954, a Clinical Research Committee was established to develop principles and to deal with problems that might arise in research with normal, healthy volunteers. Still, the relationship between investigator and subject was casual to a fault, leaving it up to the investigator to decide what information, if any, was to be shared with the subject. Generally, the researchers did not divulge very much information, fearful that they would discourage patients from participating. No formal policies or procedures applied to researchers working in other institutions on studies supported by NIH funds.

The laxity of procedural protections pointed to the enormous intellectual and emotional investment in research and to the conviction that the laboratory would yield answers to the mysteries of disease. Indeed, this faith was so great that the NIH would not establish guidelines to govern the extramural research it supported. By 1965, the extramural program was the single most important source of research grants for universities and medical schools, by the NIH's own estimate, supporting between 1,500 and 2,000 research projects involving human research. Nevertheless, grant provisions included no stipulations about the ethical conduct of human experimentation and the universities did not fill the gap. In the early 1960s, only nine of fifty-two American departments of medicine had a formal procedure for approving research involving human subjects and only five more indicated that they favored this approach or planned to institute such procedures (Frankel).

One might have expected much greater attention to the ethics of human experimentation in the immediate postwar period in light of the shadow cast by the trial of the German doctors at Nuremberg. The atrocities that the Nazis committed—putting subjects to death by long immersion in subfreezing water, deprivation of oxygen to learn the limits of bodily endurance, or deliberate infection by lethal organisms in order to study the effects of drugs and vaccines—might have sparked a commitment in the United States to a more rigorous regulation of research. (Japanese physicians also conducted experiments on prisoners of war and captive populations, but their research was never subjected to the same judicial scrutiny.) So too, the American research efforts during the war might have raised questions of their own and stimulated closer oversight.

The Nuremberg Code of 1946 itself might have served as a model for American guidelines on research with human subjects. Its provisions certainly were relevant to the medical research conducted in the United States. “The voluntary consent of the human subject is absolutely essential,” the code declared. “This means that the person involved should have legal capacity to give consent.” By this principle, the mentally disabled and children were not suitable subjects for research—a principle that American researchers did not respect. Moreover, according to the Nuremberg Code, the research subject “should be so situated as to be able to exercise free power of choice” (Germany [Territory Under …], p. 181), which rendered at least questionable the American practice of using prisoners as research subjects. The Nuremberg Code also stated that human subjects “should have sufficient knowledge and comprehension of the elements of the subject matter involved as to make an understanding and enlightened decision” (Germany [Territory Under …], p. 181), thus ruling out the American practice of using the mentally disabled as subjects.

Nevertheless, with a few exceptions, neither the Code nor these specific practices received sustained analysis before the early 1970s. Only a handful of articles in medical or popular journals addressed the relevance of Nuremberg for the ethics of human experimentation in the United States. Perhaps this silence reflected an eagerness to repress the memory of the atrocities. More likely, the events described at Nuremberg were not perceived by most Americans as relevant to their own practices. From their perspective, the Code had nothing to do with science and everything to do with Nazis. The guilty parties were seen less as doctors than as Hitler’s henchmen (Proctor).

In the period 1945–1965, several American as well as world medical organizations did produce guidelines for human experimentation that expanded upon the Nuremberg Code. Most of these efforts, however, commanded little attention and had minimal impact on institutional practices whether in Europe or in the United States (Ladimer and Newman). The American Medical Association, for example, framed a research code that called for the voluntary consent of the human subject, but it said nothing about what information the researchers were obliged to share, whether it was ethical to conduct research on incompetent patients, or how the research process should be monitored (Requirements for Experiments on Human Beings). In general, investigators could do as they wished in the laboratory, limited only by what their consciences defined as proper conduct and by broad, generally unsanctioned statements of ethical principle.

The World Medical Association in 1964 issued the Helsinki Declaration, stating general principles for human experimentation, and has revised that document four times. The declaration is modeled on the Nuremberg Code, requiring qualified investigators and the consent of subjects. The 1975 revision recommended review of research by an independent committee (Annas and Grodin).

How researchers exercised discretion was the subject of a groundbreaking article by Henry Beecher, professor of anesthesia at Harvard Medical School, published in June 1966 in the *New England Journal of Medicine.* His analysis, “Ethics and Clinical Research,” contained brief descriptions of twenty-two examples of investigators who risked “the health or the life of their subjects,” without informing them of the dangers or obtaining their permission. In one case, investigators purposefully withheld penicillin from servicemen with streptococcal infections in order to study alternative means for preventing complications. The men were totally unaware that they were part of an experiment, let alone at risk of contracting rheumatic fever, which twenty-five of them did. Beecher’s conclusion was that “unethical or questionably ethical procedures are not uncommon” among researchers. Although he did not provide footnotes for the examples or name the investigators, he did note that “the troubling practices” came from “leading medical schools, university hospitals, private hospitals, governmental military departments … government institutes (the National Institutes of Health), Veterans Administration Hospitals, and industry” (Beecher).

Two of the cases that Beecher cited were especially important in provoking public indignation over the conduct of human research. One case involved investigators who fed live hepatitis virus to the residents of Willowbrook, a New York State institution for the retarded, in order to study the etiology of the disease and attempt to create a protective vaccine against it. The other case involved physicians injecting live cancer cells into twenty-two elderly and senile hospitalized patients at the Brooklyn Jewish Chronic Disease hospital without telling them that the cells were cancerous, in order to study the body’s immunological responses.

Another case that sparked fierce public and political reactions in the early 1970s was the Tuskegee research of the U.S. Public Health Service. Its investigators had been visiting Macon County, Alabama, since the mid-1930s to examine, but not to treat, a group of blacks who were suffering from secondary syphilis. Whatever rationalizations the PHS could muster for not treating blacks in the 1930s, when treatment was of questionable efficacy and very complicated to administer, it could hardly defend instructing draft boards not to conscript the subjects for fear that they might receive treatment in the army. Worse yet, it could not justify its unwillingness to give the subjects a trial of penicillin after 1945 (Jones).

During the 1950s and 1960s, not only individual investigators but government agencies conducted research that often ignored the consent of the subjects and placed some of them at risk. Many of these projects involved the testing of radiation on humans. Part of the motivation was to better understand human physiology; even more important, however, was the aim of bolstering the national defense by learning about the possible impact of radiation on fighting forces. Accordingly, inmates at the Oregon State Prison were subjects in experiments to examine the effects on sperm production of exposing their testicles to X-rays. Although the prisoners were told some of the risks, they were not informed that the radiation might cause cancer. So too, terminally ill patients at the Cincinnati General Hospital underwent whole-body radiation, in research supported by the U.S. Department of Defense, not so much to measure its effects against cancer but to learn about the dangers radiation posed to military personnel. During this period, the Central Intelligence Agency also conducted research on unknowing subjects with drugs and with psychiatric techniques in an effort to improve interrogation and brainwashing methods. It was not until the 1980s that parts of this record became public, and not until 1994 that the full dimensions of these research projects were known.

Regulating Human Experimentation

The cases cited by Beecher and publicized in the press over the period 1966 to 1973 produced critical changes in policy by the leadership of the NIH and the U.S. Food and Drug Administration (FDA). Both agencies were especially sensitive to congressional pressures and feared that criticisms of researchers' conduct could lead to severe budget cuts. They also recognized that the traditional bedrock of research ethics, the belief that investigators were like physicians and should therefore be trusted to protect the well-being of their subjects, did not hold. To the contrary, there was a conflict of interest between investigator and subject: One wanted knowledge, the other wanted cure or well-being.

Under the press of politics and this new recognition, the NIH and the FDA altered their procedures. The fact that authority was centralized in these two agencies, which were at once subordinate to Congress and superordinate to the research community, guaranteed their ability to impose new regulations. Indeed, this fact helps explain why the regulation of human experimentation came first and more extensively to the United States than to other developed countries (Rothman, 1991).

Accordingly, in February 1966, and then in revised form in July 1966, the NIH promulgated through its parent body, the PHS, guidelines covering all federally funded research involving human experimentation. The order of July 1, 1966, decentralized the regulatory apparatus, assigning "responsibility to the institution receiving the grant for obtaining and keeping documentary evidence of informed patient consent." It then mandated "review of the judgment of the investigator by a committee of institutional associates not directly associated with the project." Finally it defined, albeit very broadly, the standards that were to guide the committee: "This review must address itself to the rights and welfare of the individual, the methods used to obtain informed consent, and the risks and potential benefits of the investigation" (Commission on Health Science and Society, pp. 211–212). In this way and for the first time, decisions traditionally left to the conscience of individual physicians came under collective surveillance.

The new set of rules was not as intrusive as some investigators feared, or as protective as some advocates preferred. At its core was the superintendence of the peer review committee, known as the Institutional Review Board (IRB), through which fellow researchers approved the investigator's procedures. With the creation of the IRB, the clinical investigator could no longer decide unilaterally whether the planned intervention was ethical, but had to answer formally to colleagues operating under federal guidelines. The events in and around 1966 accomplished what the Nuremberg trials had not: They moved medical experimentation into the public domain and revealed the consequences of leaving decisions about clinical research exclusively to the individual investigator.

The NIH response focused attention more on the review process than on the process of securing informed consent. Although it recognized the importance of the principle of consent, it remained skeptical about the ultimate feasibility of the procedure. Truly informed consent by the subject seemed impossible to achieve ostensibly because laypeople would not be able to understand the risks and benefits inherent in a complex research protocol. In effect, the NIH leadership was unwilling to abandon altogether the notion that doctors should protect patients and to substitute instead a thoroughgoing commitment to the idea that patients could and should protect themselves. Its goal was to ensure that harm was not done to the subjects, not that subjects were given every opportunity and incentive to express their own wishes (Frankel).

The FDA was also forced to grapple with the problems raised by human experimentation in clinical research. With a self-definition that included a commitment not only to sound scientific research (like the NIH) but to consumer protection as well, the FDA did attempt to expand the prerogatives of the consumer—in this context, the human subject. Rather than emulate the NIH precedent and invigorate peer review, it looked to give new meaning and import to the process of consent.

In the wake of the reactions set off by Beecher's article, the FDA, on August 30, 1966, issued a "Statement on Policy Concerning Consent for the Use of Investigational New Drugs on Humans." Distinguishing between therapeutic and nontherapeutic research, in accord with various international codes like the Helsinki Declaration, it now prohibited all nontherapeutic research unless the subjects gave consent. When the research involved "patients under treatment," and had therapeutic potential, consent was to be obtained except in what the FDA labeled the "exceptional cases," where consent was not feasible or not in the patient's best interest. "Not feasible" meant that the doctor could not communicate with the patient (its example was when the patient was in a coma); and "not in the best interest" meant that consent would "seriously affect the patient's disease status" (its example here was the physician who did not want to divulge a diagnosis of cancer) (Curran, pp. 558–569).

In addition, the FDA, unlike the NIH, spelled out the meaning of consent. To give consent, the person had to have the ability to exercise choice and to have a "fair explanation" of the procedure, including an understanding of the experiment's purpose and duration, "all inconveniences and hazards reasonably to be expected," what a controlled trial was (and the possibility of the use of placebos), and any existing alternative forms of therapy available (Curran, pp. 558–569).

The FDA regulations represented a new stage in the balance of authority between researcher and subject. The blanket insistence on consent for all nontherapeutic research would have prohibited many of the World War II experiments and eliminated most of the cases on Beecher's roll. The FDA's definitions of consent went well beyond the vague NIH stipulations, imparting real significance to the process. To be sure, ambiguities remained. The FDA still confused research and treatment, and its clauses governing therapeutic investigations afforded substantial discretion to the doctor-researcher. But authority tilted away from the individual investigator and leaned, instead, toward colleagues and the human subjects themselves.

The publicity given to the abuses in human experimentation, and the idea that a fundamental conflict of interest characterized the relationship between the researcher and the subject, had an extraordinary impact on those outside of medicine, drawing philosophers, lawyers, and social scientists into a deeper concern about ethical issues in medicine. Human experimentation, for example, sparked the interest in medicine of Princeton University's professor of Christian ethics, Paul Ramsey. Ethical problems in medicine "are by no means technical problems on which only the expert (in this case, the physician) can have an opinion," Ramsey declared, and his first case in point was human experimentation. He worried that the thirst for more information was so great that it could lead investigators to violate the sanctity of the person. To counter the threat, Ramsey had two general strategies. The first was to make medical ethics the subject of public discussion. We can no longer "go on assuming that what can be done has to be done or should be.… These questions are now completely in the public forum, no longer the province of scientific experts alone" (Ramsey, p. 1). Second, and more specifically, Ramsey embraced the idea of consent; consent, in his formulation, was to human experimentation what a system of checks and balances was to executive authority, that is, the necessary limitation on the exercise of power. "Man's capacity to become joint adventurers in a common cause makes the consensual relationship possible; man's propensity to overreach his joint adventurer even in a good cause makes consent necessary.… No man is good enough to experiment upon another without his consent" (Ramsey, pp. 5–7).

Commissioning Ethics

The U.S. Congress soon joined the growing ranks of those concerned with human experimentation and medical ethics. In 1973, it created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, whose charge was to recommend to federal agencies regulations to protect the rights and welfare of subjects of research. The idea for such a commission was first fueled by an awareness of the awesome power of new medical technologies, but it gained congressional passage in the wake of newly uncovered abuses in human experimentation, most notably the Tuskegee syphilis studies.

The U.S. National Commission for the Protection of Human Subjects was composed of eleven members drawn from "the general public and from individuals in the fields of medicine, law, ethics, theology, biological science, physical science, social science, philosophy, humanities, health administration, government, and public affairs." The length of the roster and the stipulation that no more than five of the members could be researchers indicated how determined Congress was to have human experimentation brought under the scrutiny of outsiders. Senator Edward Kennedy, who chaired the hearings that led to the creation of the commission, repeatedly emphasized this point: Policy had to emanate "not just from the medical profession, but from ethicists, the theologians, philosophers, and many other disciplines." A prominent social scientist, Bernard Barber, predicted, altogether accurately, that the commission "would transform a fundamental moral problem from a condition of relative professional neglect and occasional journalistic scandal to a condition of continuing public and professional visibility and legitimacy.… For the proper regulation of the powerful professions of modern society, we need a combination of insiders and outsiders, of professionals and citizens" (Commission on Health Science and Society, part IV, pp. 1264–1265).

Although the National Commission was temporary rather than permanent, and advisory (to the Secretary of Health, Education, and Welfare), without any enforcement powers of its own, most of its recommendations became regulatory law, tightening still further the governance of human experimentation. It endorsed the supervisory role of the IRBs and successfully recommended special protection for research on such vulnerable populations as prisoners, mentally disabled persons, and children. It recommended that an Ethical Advisory Board be established within the Department of Health and Human Services to deal with difficult cases as they arose. This board was inaugurated in 1977 but expired in 1980, leaving a gap in the commission's plan for oversight of research ethics. However, the Office for Protection from Research Risks at NIH exercised vigilance over institutional compliance with research regulations. Finally, the commission issued the Belmont Report, a statement of the ethical principles that should govern research, namely, respect for autonomy, beneficence, and justice. This document not only had an influence on research ethics but on the emerging discipline of bioethics (U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research).

Conclusion

In the United States, and to a growing degree in other developed countries, many of the earlier practices that had raised such troubling ethical considerations have been resolved. Oversight of research has been accomplished without stifling it, and without violating the prerogatives of research subjects. Almost everyone who has served on IRBs, or who has analyzed the transformation that their presence has secured on medical experimentation, will testify to their salutary impact. To be sure, the formal composition and decentralized character of these bodies seem to invite a kind of back-scratching, mechanistic review of colleagues' protocols, without the kind of adversarial procedures that would reveal every risk in every procedure. Similarly, IRB review of consent forms and procedures rarely takes the concern from the committee room onto the hospital floor to inquire about the full extent of the understanding of subjects who consent to participate. Nevertheless, IRBs do require investigators to be accountable for the character and severity of risks they are prepared to let others run, knowing that their institutional reputation may be harmed if they minimize or distort it. This responsibility unquestionably has changed investigators' behavior, and social expectations of them. To be sure, abuses may still occur. IRBs must be ready to minimize the amount of risk involved in certain protocols so as to enable researcher-colleagues to pursue their investigations. But they happen considerably less often now that IRB regulation is a fact of life. Scientific progress and ethical behavior turn out to be compatible goals.

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SEE ALSO: *Aging and the Aged: Healthcare and Research Issues; AIDS: Healthcare and Research Issues; Autoexperimentation; Autonomy; Children: Healthcare and Research Issues; Coercion; Commercialism in Scientific Research; Embryo and Fetus: Embryo Research; Empirical Methods in Bioethics; Freedom and Free Will; Genetics and Human Behavior: Scientific and Research Issues; Holocaust; Infants: Public Policy and Legal Issues; Informed Consent: Consent Issues in Human Research; Mentally Ill and Mentally Disabled Persons: Research Issues; Military Personnel as Research Subjects; Minorities as Research Subjects; Paternalism; Pediatrics, Overview of Ethical Issues in; Public Policy and Bioethics; Prisoners as Research Subjects; Race and Racism; Research, Human: Historical Aspects; Research Methodology; Research, Multinational; Research, Unethical; Responsibility; Scientific Publishing; Sexism; Students as Research Subjects; Virtue and Character;* and other *Research Policy* subentries

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RESEARCH METHODOLOGY

• • •

I. Conceptual Issues
II. Clinical Trials
III. Subjects

I. CONCEPTUAL ISSUES

Research in medicine, in the biomedical sciences, and in science in general is defined as "studious inquiry or examination; *esp*: investigation or experimentation aimed at the discovery and interpretation of facts, revision of accepted theories or laws in the light of new facts, or practical application of such new or revised theories or laws" (Merriam-Webster, p. 992). The U.S. federal government's Common Rule for human-subject investigation (CR) echoes Webster's definition; according to the CR, "*Research* means a systematic investigation, including research development, testing, and evaluation, designed to contribute to generalizable knowledge" (Code of Federal Regulations, sec. 102). Research can refer to investigations that involve intentional manipulation of the objects studied, frequently termed *experimental* studies, as well as those inquiries that collect data generated by naturally occurring events, or *observational* studies. This entry focuses on the burdens and benefits scientific research has on human subjects (or perhaps better, on trial participants) and on society, as well as on laboratory animals. Research methodology comprises those general principles and designs used to describe valid and effective inquiries into nature, which includes humans. Research methodology has philosophical, scientific, and social dimensions.

General Aspects of Research Methodology

Beginning with Plato and Aristotle, philosophers have proposed a number of different though quite general approaches to scientific method. Philosophers René Descartes (1596–1650) and Francis Bacon (1561–1626) wrote on the subject in the seventeenth century, but the study of scientific method received its most systematic treatments in the work of the nineteenth-century philosophers and scientists William Whewell, Stanley Jevons (1835–1882, and John Stuart Mill (1806–1873), who forcefully re-presented the methods of agreement, difference, concomitant variation, and others that continue to influence contemporary philosophers; frequently these are referred to as Mill's Methods. Philosophers of science have continued to stimulate the imagination of practicing scientists. Since the early 1960s, Sir Karl Popper's *falsificationist* approach, T. S. Kuhn's account of revolutionary scientific changes as *paradigm shifts,* and the latter's criticisms of traditional rational and gradualist methodology have been cited in a number of scientific research articles.

Research methodology also involves more specific scientific components, including the analysis of different laboratory methodologies (e.g., molecular approaches and pure culture techniques); the utility of various *animal models* of diseases; and the characterization and assessment of the strengths of distinct study designs, ranging from the report of an individual case to the randomized controlled clinical trial (RCT). These scientific components may involve a considerable amount of sophisticated mathematical and statistical analysis. In this entry, both the philosophical and the scientific dimensions of research methodology will be pursued in the context of questions that they raise for bioethics.

A final major aspect of research methodology is the important *social* dimension of systematic empirical investigations. For the purposes of this entry, the term signifys the ethical, legal, political, and religious aspects of research methodology. More specifically, this rubric treats various moral implications of scientific investigation, including vulnerable or hitherto ignored subject populations (e.g., the disabled and women), from both descriptive and normative perspectives, as well as significant interactions among the philosophical, scientific, and social themes.

The Scope of Research

BIOMEDICAL AND BEHAVIORAL INVESTIGATIONS. Biomedical research (generally understood as also including behavioral research in the psychological and social sciences) covers a broad array of disciplines. The term *biomedical* is itself intended to bridge the gap between the more fundamental, *pure,* or *basic* sciences, such as physiology and biochemistry, and the more *applied* sciences, such as pathology and pharmacology. This interpretation, however, leaves the more *clinical* sciences, such as anesthesiology and medicine, less connected with the meaning of science than is appropriate. Better, perhaps, to follow a more expansive definition as found in *Merriam-Webster's Tenth Collegiate*

Dictionary, which gives as one definition of biomedical: "Of, relating to, or involving biological, medical, and physical science" (Merriam-Webster, p. 115). *Dorland's Medical Dictionary* (28th edition) offers as its preferred meaning "biological and medical" (Dorland, p. 199). In accordance with this expanded characterization of the term, virtually all of the natural, behavioral, and social sciences, as well as engineering, can be conceived of as biomedical sciences if the intent is to place them in the service of advancing generalizable knowledge in the domains of medicine and healthcare.

BASIC SCIENCE AND CLINICAL SCIENCE. A common division is found in the departmental organization in medical schools distinguishing between basic sciences, such as microbiology (but also including more applied sciences such as pharmacology), and the clinical sciences such as medicine and oncology, whose practitioners spend much of their time and effort working with patients. It must not be forgotten that studies employing systems ranging from in vitro (*test tube*) inquiries through research on bacterial viruses to animal-model investigations comprise the bulk of research in the biomedical sciences. Preliminary research on new drug therapies, as well as investigations into human immunodeficiency virus (HIV) pathophysiology, falls into this category. In addition, in recent years there has been heightened awareness of the ethical problems generated by the use of animals in biomedical research, and thus it is appropriate to comment briefly on this basic science dimension of research methodology.

In 1976 an important study investigated the type of research that led to the ten most important advances in the treatment of cardiovascular and pulmonary diseases (Comroe and Dripps). The investigators used a broad definition of *clinically oriented* research; studies involving animals, tissues, or cells (including cell fragments) were included in the definition if the author mentioned a possible clinical application even briefly. In spite of this expansive definition, some 41 percent of key articles involved in the development of these ten clinically relevant advances were not clinically oriented; that is, they reported on basic science research. This finding suggests that supporting only *targeted* or *mission-oriented* research is likely to have adverse effects on clinical research advances.

Another intensive investigation, conducted in 1985 by the National Research Council's Committee on Models for Biomedical Research, examined the nature of research methodology in the biomedical sciences and underscored the intimate and reciprocal relationship between research generally characterized as clinical and research generally characterized as basic. This report introduced the general notion of a *biomatrix,* which was defined as a "complex body, or matrix, of interrelated biological knowledge built from studies of many kinds of organisms, biological preparations, and biological processes at various levels" (National Research Council, p. 2). Within such a multidimensional matrix, biomedical research involves *many-many modeling* in which analogous features at various levels of aggregation (e.g., molecules, cells, and organs) are related to each other across various species. The committee suggested that an "investigator considers some problem of interest—a disease process, some normal physiological function, or any other aspect of biology or medicine. The problem is analyzed into its component parts, and for each part and at each level, the matrix of biological knowledge is searched for analogous phenomena.… Although it is possible to view the processes involved in interpreting data in the language of [simple] one-to-one modeling, the investigator is actually modelling back and forth onto the matrix of biological knowledge" (National Research Council, p. 67). The study conducted by Julius Comroe and Robert Dripps, as well as the council's report, thus indicate that clinically relevant advances emerge from research sources beyond those involving human subjects.

Before innovations can be tested on humans, ethical codes and governmental regulation require research involving chemical, cell-fragment, cell, tissue, and intact-animal-model systems. The Nuremberg Code (1947–1948), for example, recommends that human experimentation should be based on the results of animal experimentation. The Declaration of Helsinki (1964, most recently revised in 2000) requires that "medical research involving human subjects must conform to generally accepted scientific principles, be based on a thorough knowledge of the scientific literature, other relevant sources of information, and on adequate laboratory and, where appropriate, animal experimentation" (World Medical Association). These requirements are based on the belief that such inquiries will assist in identifying interventions that are both safer and more effective by the time they are finally applied to human subjects. In the biomedical sciences, including studies involving human subjects, biological diversity and the number of systems that strongly interact in living organisms create considerable complexity. Researchers must often pay special attention to ensuring the (near) identity of the organisms under investigation, except for those differences that are the focus of the scientist's inquiry.

Biomedical investigations involving virtually identical laboratory organisms can yield precise and often nonstatistical results that can then be utilized in more variable human populations. As is discussed in the section below on various study designs, human variability of both genetic and environmental sources will typically require the extensive use of statistical methodologies to uncover generalizable knowledge that is clinically applicable. In more rigidly controllable laboratory experiments—for example, in the rapidly advancing area of molecular genetics—biomedical scientists can often employ the classical methods of experimental inquiry, referred to earlier as Mill's Methods. These methods can be thought of as attempting to discover the causal structure of the world, and in their application scientists endeavor to identify and compensate for possible confounding factors that, if ignored, can lead to mistaken inferences about causes and effects. Thus all natural scientists attempt to compensate for interfering and extraneous factors, frequently by setting up a control comparison or a control group. Such controls are a direct implementation of what Mill termed the *method of difference* and Claude Bernard (1813–1878), the notable nineteenth-century French scientist and methodologist, the *method of comparative experimentation.*

The method of difference may be stated in a form similar to that in which Mill presented it. Suppose that in Case 1 some phenomenon occurs, and in Case 2, that is identical with Case 1 *except for one factor,* the phenomenon does *not* occur. Then the single difference between the two cases is the effect of that phenomenon, or the cause of that phenomenon, or an indispensable part of the cause of that phenomenon. (See Mill, p. 256, for his original language).

Claude Bernard judged that this focus on only one difference was far too stringent and reformulated the experimental idea as his method of comparative experimentation:

> Physiological phenomena are so complex that we could never experiment at all rigorously on living animals if we necessarily had to define all the other changes we might cause in the organism on which we were operating. But fortunately it is enough for us completely to isolate the one phenomenon on which our studies are brought to bear, separating it by means of comparative experimentation from all surrounding complications. Comparative experimentation reaches this goal by adding to a similar organism, used for comparison, all our experimental changes save one, the very one which we intend to disengage. (p. 127–128)

Bernard referred to comparative experimentation as "the true foundation of experimental medicine."

General Ethical Issues Associated with Research on Human Subjects

The principal ethical controversies in biomedical (including behavioral and social) research have emerged from studies involving human subjects. Before discussing the general ethical requirements of studies involving human subjects, however, it is important to describe briefly the often contentious debate about the terms used to distinguish between different kinds of standard medical practice and research, among them *therapeutic research, nontherapeutic research, innovative treatments,* and *experimentation.*

TERMINOLOGICAL CONSIDERATIONS. It is a fundamental tenet of medical ethics that the well-being of human subjects should be protected. This tenet, together with another general ethical principle frequently associated with the name of philosopher Immanuel Kant (1724–1804), to treat oneself or another human being always as an end and never merely or only as a means, requires that a human research subject be expected to obtain some direct benefit from the investigation, or, if not, to waive such benefit on the basis of a free and informed consent. (This Kantian injunction is sometimes characterized as a principle of *respect for persons.*) The need to clarify the therapeutic/nontherapeutic distinction in the light of such principles should be evident.

Thoughtful scholars have generally agreed about the difficulty of drawing a clear distinction between research and accepted practice, but have differed about the usefulness of various terms proposed to assist with this task. Some find the distinction between therapeutic and nontherapeutic experimentation *crucial,* whereas others find it is better phrased as one between beneficial and nonbeneficial experimentation. Tom Beauchamp and James Childress urge caution with the use of the closely related term therapeutic research since "attaching the favorable term *therapeutic* to research can be dangerous, because it suggests *justified intervention* in the care of particular patients and may create a misconception" (p. 320). Robert Levine, an authority on research involving human subjects, contends that the expressions therapeutic research, nontherapeutic research, and experimentation (in human subject contexts) are "unacceptable" and "illogical" (p. 8). The problem arises in part because it is fairly common that a diagnostic and therapeutic plan involve some variation from the textbook norm, and because it is in only rare cases that biomedical research conveys absolutely no benefit on its subjects.

Levine suggests that we employ the term *nonvalidated practices* as a more encompassing term for innovative therapies, acknowledging that it is the uncertainty associated with variation in the outcomes of diagnostic and therapeutic maneuvers that is the principal issue. This suggestion seems to have been accepted in much of the recent literature, though frequently the narrower term *nonvalidated therapy* is also employed. Though no definitive algorithm can be provided that will unambiguously differentiate the various inquiries and activities discussed in the preceding paragraph, the general proposal that appears to emerge from the discussion involves three elements. First, the intent of the investigator is critical in determining whether the intervention (or the withholding of an intervention) is to be characterized as primarily beneficial to the subjects or as contributing to generalizable knowledge. A surgeon employing a novel suturing technique in an attempt to save a patient from bleeding to death does not evidence any intent of beginning a research project to evaluate a new operative technique. Second, the degree of variation from standard practice figures in this determination, and this may depend as well on the degree of possible harm that the intervention entails. Even small variations associated with significant harm are more likely to be seen as nonvalidated in contrast to small variations with minor adverse consequences. For example, a physician may believe that he or she must try a powerful immunosuppressive drug, usually used only in the case of potential organ-transplant rejection, to help a patient suffering with severe rheumatoid arthritis. The dangers associated with such drugs and the departure from their normal use argues that this would be a nonvalidated practice. Finally, there is the element of uncertainty, the degree of likelihood of a particular outcome or set of outcomes. These include both anticipated and unintended effects (side effects). Again, the example just cited of the immunosuppressive drug would be relevant here because of the difficulty of anticipating the effects of powerful drugs on systems as complex as the immune system.

For interventions from which the researcher intends to produce new general knowledge, that represent significant departures from accepted practice, and about which there is reasonable uncertainty regarding consequences, including intended outcomes, it would seem mandatory that the researchers develop a formal research protocol to be assessed by an appropriate institutional review board (IRB). Such a multidimensional *sliding scale,* possibly with thresholds that could be specified in particular areas of clinical investigation, may be the best possible mechanism for determining whether to require IRB review in this complex area.

ETHICAL REQUIREMENTS FOR RESEARCH ON HUMAN SUBJECTS. As noted in the preceding section, general principles requiring free and informed consent and a net balance of benefits over harms for the individual subject (unless this is waived by the subject in the interests of greater social benefits) will be assumed in all research contexts, and the present section will examine additional details regarding these requirements. Furthermore, however, in order both to safeguard research subjects and ensure that the resources used will generate valuable knowledge, a research study must conform to scientifically validated principles of design. To begin with, a prospective research project must be evaluated in terms of the risks of harm—physical, psychological, and social—to the subject(s), as well as in terms of the benefits that are likely to accrue to participants. Only studies in which the expected benefits outweigh the expected harms are morally permissible. Further, there must be no alternative and less risky means for the subject to obtain the anticipated benefits. Subjects must be selected equitably, with special sensitivity to the problems faced by vulnerable populations, such as children, prisoners, pregnant women, mentally disabled persons, or educationally disadvantaged persons. In recent years the practice of *community consultation* has developed, which involves meetings with representatives of the at-large subject community (e.g., HIV-infected individuals) to "assure a suitable balancing of the relevant values [such as respect for persons, individual beneficence and justice] in the design and conduct of a clinical trial" (Levine et al., p. 10).

An investigator must also obtain the legally effective informed consent of the subject or of the subject's legally authorized representative. Such consent must be voluntary and not obtained by coercive measures. The consent must be informed; this means that the investigator must specify the purposes of the research and how long the subject is expected to participate and provide a nontechnical description (in terms readily understandable to the subject) of any procedures to be followed, as well as a designation of procedures considered untested or experimental. The subject must also be provided with a description of any reasonable foreseeable risks or discomforts as well as reasonably anticipated benefits. Alternative procedures or courses of treatment that may be advantageous to the participant must be disclosed. Subjects are also to be provided with a statement about the extent of confidentiality of their records and, for research involving more than minimal risk, an explanation of what, if any, compensation or treatments will be available in the event of injury. According to the CR, subjects must be informed about whom to contact for answers about any questions or injuries that may arise in the course of or as a consequence of the research. They are to be told that their participation is voluntary and that they may refuse to participate or may withdraw from participation without any penalty or loss of benefits to which they would normally be entitled. Should the investigator come to believe in the course of the research that harm to the patient has become likely, the patient should be so informed and withdrawn from the project. The above requirements underscore the point that informed consent should not be conceived of only as a one-time event, but is best construed as an ongoing process involving clinical investigators and trial participants.

In certain types of behavioral and social-science research, investigators have maintained that scientifically valid conclusions can be obtained only if the subjects are kept uninformed or even deliberately deceived about the nature of the research. In a well-known example of this type of research, Stanley Milgram's studies on obedience to authority, subjects were falsely told they were causing pain to another human as part of a learning experiment. A majority of subjects proceeded to escalate the level of fictiously inflicted pain to *agonizing* levels on the instructions of the investigator. Subsequently, when the subjects were informed about this feature of themselves as part of the debriefing, they experienced severe, and in some cases, prolonged anxiety reactions (Milgram, 1963). Milgram defended his study against criticism and reported that most of the subjects had a positive view of their participation (Milgram, 1964).

The ethics of such studies continue to be controversial. Levine notes that he himself chairs an IRB that occasionally approves deceptive studies but generally disapproves of deception (Levine). Various guidelines regarding deceptive research methods have been published, such as those by the American Psychological Association, which can be viewed on their website. In response to many unethical research practices, ranging from Nazi atrocities before and during World War II to well-documented cases in the United States, the U.S. government has mandated a set of formal procedures to ensure compliance with ethical requisites. Institutions involved in research on human subjects are required to have their investigations reviewed and approved by IRBs whose composition, procedures, and record-keeping requirements are well-defined in law and governmental regulations. It should be noted, however, that the determination by a duly constituted IRB of the satisfaction of these ethical requirements does not in all cases resolve all ethical and practical stresses generated by research on human subjects. A number of authors have discerned a deeply rooted dilemma that the physician as healer and the physician as researcher confront in a search for generalizable knowledge employing human subjects. This dilemma has its source partly in the respect-for-persons principle cited above and partly in the ethical principle that the physician should do what is best for his or her patient. The dilemma is also most clearly evident in the context of the RCT but can also arise in less stringent research designs, which it will be necessary to discuss before turning to an account of this troublesome research predicament.

Study Designs

THE SPECTRUM OF STUDY DESIGNS IN BIOMEDICAL AND BEHAVIORAL RESEARCH. Diverse research designs guide research in the biomedical, behavioral, and clinical sciences. Since this topic can easily become quite technical and mathematically abstruse, this entry presents only a general introduction to this subject. (For specialized information including indications when, and why, one design is preferable to another, see works on clinical epidemiology and monographs devoted to specific research designs, e.g., Feinstein,; Fletcher et al.; Hulley, et al.; Lilienfeld and Lilienfeld; and Sackett et al.)

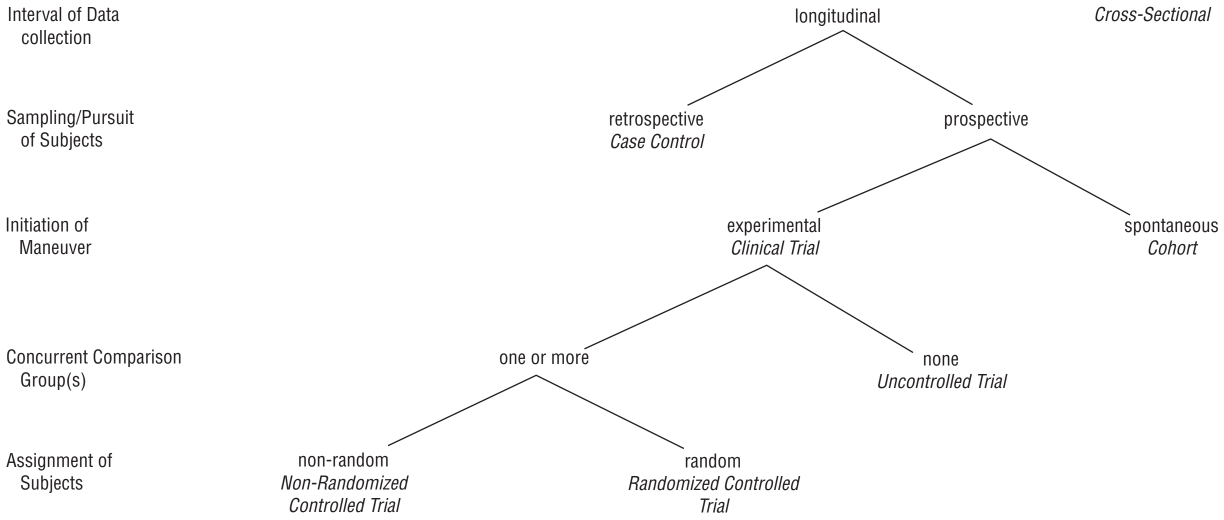
The chart depicted in Figure 1 can be used as a guide to the various research designs found in clinical research. (This figure is based in part on Lilienfeld and Lilienfeld, p. 192, and in part on Fletcher et al., p. 193.) To these designs should also be added the *case report* and the *case series,* in which a biomedically interesting individual's (or small group of similar individuals's) situation is described. Some writers characterize the case report or case series as another design; others view such a small series as conductible using any of the designs described in the chart below. (The use of small numbers of subjects in any trial design, however, raises concerns that errors of interpretation are likely because of chance events. Problems generated by chance events in biomedical research are analyzed using the tools of mathematical statistics.)

The *interval of data collection* refers to the period of time during which data are collected. If one or more populations are studied over a period of time, the study is described as a *longitudinal* one. Alternatively, we may wish to collect information within one time slice, yielding a *cross-sectional* study. Moving to the next line, the investigator may collect data by looking back in time—for example, inquiring (or reviewing chart records) to learn whether the population was exposed to a specific agent. At least one control group is assembled to provide a comparison, again retrospectively. This *case control* design is the type of approach that Arthur Herbst and his colleagues employed in his pioneering inquiry into the causes of vaginal cancer in daughters of mothers who had been given diethylstilbestrol (DES), a synthetic estrogen believed to help prevent miscarriages, during their pregnancies. The case-control type of study is generally thought to be open to a number of potential errors, termed *biases.* Potentially confounding elements therefore need to be monitored carefully.

If the putative active difference between the comparison groups, such as the administration of a new drug, is intentionally introduced by the investigators, a study is characterized as *experimental.* If the suspected active difference occurs by accident or is chosen by the subjects—for example, a subject's decision to begin cigarette smoking or to

FIGURE 1

The Epidemiological Study: Various Research Designs (in italics) Used to Establish Causation in Medicine


Interval of Data collection
longitudinal
Cross-Sectional
Sampling/Pursuit of Subjects
retrospective
Case Control
prospective
Initiation of Maneuver
experimental
Clinical Trial
spontaneous
Cohort
Concurrent Comparison Group(s)
one or more
none
Uncontrolled Trial
Assignment of Subjects
non-random
Non-Randomized Controlled Trial
random
Randomized Controlled Trial

SOURCE: Based in part on Lilienfeld and Lilienfield, 1980, p. 192 and in part on Fletcher et al., 1982, p. 193.

reduce blood cholesterol by diet—the investigation is termed a *cohort* study. A longitudinal prospective experimental study is a clinical trial, but such trials may or may not involve a comparison control group. Good examples of uncontrolled types of clinical trials are Phase I and Phase II investigations of new drugs, though occasionally a Phase II investigation may involve randomized controls (see Byar et al.). Phase I studies look at the metabolism and toxicity of new drugs, often in normal subjects, and Phase II inquiries test for preliminary efficacy of a drug or a procedure. The terms Phase I and Phase II were introduced in 1977 by the U.S. Food and Drug Administration (FDA). (For details of the procedures by which toxicity and efficacy of interventions are evaluated, see Gilman et al., chapter 68.)

A Phase III investigation is almost always a RCT. Randomization refers to the process of assigning a patient to one rather than another treatment (or to the control group) by the flip of a coin or a more mathematically sophisticated but analogous procedure of using a table of random numbers. The RCT refers to that form of investigation that involves (1) one or more treatment groups and a control group that will typically receive a placebo (an inert substance) or the standard therapy (i.e., the traditionally accepted therapy); (2) randomized assignment of patients to the two or more groups (possibly after stratification or subgrouping based on known factors that will make a difference) sometimes referred to as *arms* of the trial; and (3) often a single- or double-blind design in which the assignments of the agents or procedures being tested are not known to the patients (single-blind) or possibly also to the treating health professionals (double-blind). (In place of the word *blind,* some accounts use the word *masked.*) In one unusual exception to that rule, the trial of the anti-HIV drug didanosine, or ddI, the whole experimental cohort were given ddI; these subjects were compared with *historical,* or retrospectively identified, control subjects (Waldholz; FDA).

Considerable debate has occurred about the methodological value and the ethical significance of randomization in controlled clinical trials. Various types of studies described above differ in their *strength,* that is, their ability to detect what is actually causing the changes that are being observed. The case series is traditionally the weakest of the research designs; other designs, in order of increasing strength, are the case-controlled study, the cohort study, and the RCT. The principal reason for the increase in design strength is the decrease in the likelihood of bias, or lack of comparability of the matched populations, as one moves from case series through to the RCT.

There are many types of bias, and some of them are quite subtle (Sackett). A major source of bias is selection or susceptibility bias, in which the groups compared have distinctly different outcome probabilities (more specifically, different prognostic likelihoods for the study's endpoint). This type of bias can occur within the study, or it can arise as part of the selection process and affect the generalizability of a study's results. In this type of situation, unrepresentative individuals are selected, and subgroups drawn from the unrepresentative class are then assigned to the arms of the study. An example of this type of bias would occur if only the sickest patients in a study were given the new drug and the better-off patients were assigned standard therapy (or a placebo). Another source of noncomparability is performance bias, in which the interventions in the trial are not reasonably equal. An example would be if the patients receiving the new drug were monitored much more closely and treated for concurrent health problems with no such monitoring and treatment being provided to the control group. A third type of bias is *confounding* bias, in which another, unsuspected causal variable *travels along* with the putative causal variable and actually accounts for the outcome. This could occur in a study to determine the effects of alcohol consumption on lung function, if alcohol drinkers were also much more likely to be smokers and the effect of smoking was not considered by the investigators. Other significant types of bias are detection or measurement bias, where the outcome event is detected differently in the comparison groups—for example, if the test group received MRIs and the control group standard X rays—and transfer bias, in which subject dropouts or reassignments may yield differences in outcome. The arguments for randomization in clinical investigations typically cite the ability of randomized assignment to decrease the likelihood of bias because, many maintain, randomizing will average together, and thus cancel out, factors that are not suspected by the investigators to affect the outcome.

RCTs can generate potential conflicts of interest between the roles of the physician as healer and physician as investigator, including questions about the suitability of placebo controls and its possible resolution using the concept of *clinical equipoise.*

META-ANALYSIS. Human variability, based on both genetics and environment, requires the extensive use of statistical methodologies to uncover generalizable, clinically applicable knowledge. This is in contrast to laboratory investigations in which virtually identical organisms yield cleaner and often *deterministic* results. Besides the variability of the subjects studied, many sources of bias such as the ones described can also lead to incorrect research conclusions.

Under these circumstances, researchers have turned increasingly to a method of clinical trial pooling and interpretation that seems to provide a better means of inferring correct conclusions from repeated clinical investigations. This methodology, known as meta-analysis, uses a set of formal statistical techniques to aggregate a group of separate but similar studies. In contrast to the widely employed scientific practice of summing up such studies qualitatively in a review article, meta-analysis purports to fulfill this summarizing function quantitatively and thus more precisely and objectively. Meta-analysis has been practiced for many years in a variety of scientific disciplines, from physics to the biomedical and the behavioral sciences, but only since the early 1980s has it had a major impact in the clinical arena, particularly in the areas of cardiovascular disease and obstetrics and gynecology (Chalmers et al., 1989; Mann).

Simple introductions as well as accessible authoritative accounts of the methodology are available. (See Mann, for an introduction, and Friedman et al, pp. 310–316, for a more comprehensive overview.) The technique remains controversial even as its use in biomedicine escalates exponentially.

EVIDENCE-BASED MEDICINE. Many of the issues reviewed above coalesce in what is termed *evidence-based medicine* (EBM), which is both a critical methodological approach as well as a kind of social movement. EBM had its origins in the 1980s discipline of clinical epidemiology, and developed rapidly in Canada, the United Kingdom, and then the United States and other countries in the 1990s. Initially EBM saw itself as representing a kind of Kuhnian paradigm shift, urging the replacement of the received view of medical evidence—seen as a combination of clinical expertise and basic science—with evidence based mainly on rigorously evaluated empirical clinical trials. (Haynes). More recently, EBM advocates have taken a more nuanced position on this replacement view though the distinction is still evident in EBMs databases (Haynes). EBM provides evaluations and clinician guidance through its literature, various websites, and electronically available systematic reviews including the Cochrane collaboration. EBM provides grades of recommendation from A (excellent) to D (poor) based on studies's empirical strengths following a detailed assessment protocol based on five *levels* of study types, several of which have sublevels. The levels range from the best (a systematic review with homogenous RCTs as the main element) to the worst (expert opinion without explicit critical appraisal, or essentially based on physiology, whether bench research or general principles). The specifics of these grades, the levels on which they are based, and the definitions of the concepts involved (such as *homogeneity*) can be obtained at <http://minerva.minervation.com/cebm/>. EBM has not gone uncriticized, both from without and within the movement. One of its founders, Brian Haynes, laments the fact that EBM itself has not, and probably ethically cannot, be subject to its own highest standards of evaluation: a series of homogeneous RCTs in which EBM is utilized as an intervention but is not employed in the control groups of patients (Haynes).

Conclusion

This entry has reviewed a number of conceptual issues associated with current research methodology in the biomedical sciences. It contains a review of research in the basic sciences, such as biochemistry and microbiology, but has concentrated on the clinical sciences, such as medicine, oncology, and virology, since it is in the latter that ethical issues affecting human subjects arise. Scientific research on humans takes place in the context of a complex web of ethical and legal requirements, and the interplay between methodological and ethical/legal components of research has been examined. Ethical and regulatory principles (primarily as affecting U.S. research) have been presented, and several conceptual issues regarding scientific inquiry have been outlined, including different types of research designs. This entry is limited to an introduction to these issues, which become very technical in their details; references to further reading have been provided.

Although scientific methodology has a venerable history, many current issues are of much more recent vintage. In point of fact, the RCT is essentially a post-World War II invention, and the discipline of meta-analysis is a creature of the late 1980s and 1990s. New issues will continue to arise as better methodologies and improved safeguards for human subjects are sought, and the reader is urged to consult on-line bibliographic services, such as the bioethics database at the U.S. National Library of Medicine, in addition to references provided in this entry, to keep up to date with a continuously evolving subject.

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SEE ALSO: *Aging and the Aged: Healthcare and Research Issues; AIDS: Healthcare and Research Issues; Autoexperimentation; Autonomy; Children: Healthcare and Research Issues; Commercialism in Scientific Research; Embryo and Fetus: Embryo Research; Empirical Methods in Bioethics; Genetics and Human Behavior: Scientific and Research Issues; Holocaust; Infants: Public Policy and Legal Issues; Informed Consent: Consent Issues in Human Research; Mentally Ill and Mentally Disabled Persons: Research Issues; Military Personnel as Research Subjects; Minorities as Research Subjects; Pediatrics, Overview of Ethical Issues in; Prisoners as Research Subjects; Race and Racism; Research, Human, Historical Aspects; Research, Multinational; Research Policy; Research, Unethical; Responsibility; Scientific Publishing; Sexism; Students as Research Subjects; Virtue and Character;* and other *Research Methodology* subentries

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II. CLINICAL TRIALS

In the last half of the twentieth century, clinical trial methodology fundamentally transformed the nature of biomedical research. During this period, investigators developed ways to avoid certain biases in research design and to adapt methods of statistical analysis to empirical research. The story of biomedical research's progressive sophistication, however, does not begin in clinics or hospitals, but in a cornfield. Ronald A. Fisher (1890–1962), the famous British statistician, biologist, and geneticist, devised methods for testing hypotheses on how to improve crops (Gigerenzer et al.). By dividing fields into two or more groups, making them as similar as possible in composition and treatment, Fisher hoped to isolate the effects of one feature on the individuals studied. For example, would a fertilizer given to some of the corn improve yield? The resulting differences between groups could then be expressed as probabilities about whether outcomes were due to chance or their different treatment. By studying more individuals for longer periods, confidence levels increase that variations between group outcomes were due to their different treatment.

In the late 1940s, Fisher and others began to adapt and refine these pioneering principles for use with human research, and in 1948 clinical trial methodology was systematically launched into medicine with the testing of streptomycin to treat tuberculosis (Concato, Shah, and Horwitz). Since that time, investigators have used clinical trial methods to evaluate virtually everything affecting patients, including: therapies, diagnostic techniques, prevention of illnesses, vaccines, counseling, health delivery systems, and even the benefits of classical music, pets, and humor on health. In one study, for example, people were divided into large groups; some got a daily aspirin and others a placebo (an inert substance). This helped ensure that groups were treated alike even down to the number of pills that they were given. The group receiving aspirin suffered fewer heart attacks (Steering Committee). Like methods developed in agricultural research, the goal of clinical trial methodology is to compose and treat groups as similarly as possible except for the one feature under study. Investigators attempt to identify other features that are likely to affect outcomes and stratify or distribute individuals with those features equally between groups. For example, the healthiest individuals (whether people, pigs, or parsnips) should be stratified equally among the groups because health often affects outcomes.

To help further ensure that groups are similar, investigators generally use another method, randomization (nonhuman choice), such as, charts of random numbers, to assign individuals to groups. For example, suppose that investigators want to study the influence of caffeine upon alertness. They know other things affect alertness, such as people's interest in the subject or their intelligence, and the investigators try to stratify people with these variables equally between groups. But the investigators also know that many additional features affect alertness, such as people's sleeping, eating, or television-watching habits. Unable to identify all such variables or distribute people with similar features equally between groups, the investigators try to minimize the impact of these "nuisance" variables and achieve uniform groups through randomization. Even simple random methods, such as flipping a coin to determine group assignments, help ensure that people with distinctive features that could affect results do not cluster in one group. The larger the groups, the more likely that randomization will produce similar groups. The goal of randomization is to combat bias in group assignments by distributing individual characteristics whose effects are unknown equally among the study arms to minimize their influence. In human studies, randomized clinical trials (RCTs) use random assignment to eliminate, through equal distribution, the effects of variables such as nutritional habits, beliefs, attitudes, behavior, ancestry, and education in correlating the variable under investigation with its observed effects. Nonrandomized trials generally seem second best because of the risk of bias in the formation of the groups.

Investigators use other methods in addition to randomization and stratification to make groups similar and to eliminate bias. In single-blind studies, subjects do not know their group assignment, thereby minimizing the effects of their beliefs and expectations about the different modes of treatment. For unbiased results, the subjects should be treated so similarly that they cannot know which treatment they receive. Investigators' subconscious beliefs, preferences, or attitudes may also affect how they take care of individuals or evaluate outcomes. Believing one medicine works best, for example, may affect their estimates of how individuals respond. To combat such biases, investigators may use double-blind designs in which the group assignments are kept from subjects, their clinicians and investigators until after the trial so that clinicians' or investigators' own views will not contaminate the study's results.

Impartial studies can expose bias, prejudice, the flaws of common wisdom, the errors of standard practice, and the harms or benefits of established treatments. For example, in the 1940s and early 1950s doctors believed that giving copious amounts of oxygen to premature infants prevented death and brain damage. By 1953 this common wisdom was being challenged by clinical trials, and by 1954 the link between the lavish use of oxygen and blindness from retrolental fibroplasia was clearly established (Silverman). Other studies uncovered previously unforeseen adverse drug reactions. For example, systematic testing of commonly used antibiotics showed that premature infants receiving sulfisoxazole (gantrisin) had a much higher incidence of death and retardation than other groups. Further investigation revealed that premature infants could not metabolize and detoxify bilirubin, thus causing kernicterus, or neurological damage to the brain (Behrman and Vaughan).

Clinical trials also account for many treatment advances. In three decades of continual evaluation of alternative therapies through clinical trials, childhood leukemia went from a uniformly fatal disease to an often-curable illness. RCTs also demonstrated that coronary artery bypass surgery was ineffective for many of the diseases for which it had been widely used.

In a controlled clinical trial (CCT), investigators compare the outcomes for patients getting one treatment with those who do not. This allows investigators to separate the treatment's effects from other influences. The U.S. Department of Health and Human Services (HHS) cites five kinds of control groups distinguished, in part, upon whether the comparison involves a historical control group (in which patients' outcomes are compared with records from past patients) or a concurrent control group (in which patients' outcomes are compared with patients currently being treated):

1. placebo concurrent control;
2. dose comparison, concurrent control;
3. no treatment concurrent control;
4. active treatment concurrent control; and
5. historical control.

Investigators often regard the double-blind RCT with a concurrent control group getting a placebo as the "gold standard" because it offers the greatest assurances that differences between groups have not been distorted by people's different diagnosis criteria, treatments, observations, measurements, or expectations (Ellenberg and Temple; Temple and Ellenberg).

Gaining General Acceptance: An Example Involving Breast Cancer

Enrolling patients in clinical trials involved fundamental shifts in how to think about patient–doctor relationships. Consequently, it was one thing to work out a good methodology and another to find clinicians and patients willing to participate in CCTs. For example, by 1968, 70 percent of women with breast cancer had radical mastectomy, which entails removing the breast, lymph nodes, and chest wall muscles on the affected side. Many clinicians believed this gave women their best chance of a "cure" (defined as surviving five years or longer), at no real loss, because in their view, the breast of an older woman was entirely expendable (Lerner). Beginning in the 1970s, these views changed gradually, but many clinicians clung to these beliefs into the 1990s, long after information gained from a series of RCTs showed radical mastectomy as unnecessarily mutilating and disabling. Ultimately, these trials established that removal of only the tumor or the breast, with or without radiation therapy, resulted in survival comparable to that achieved with the radical mastectomy (Fisher). Follow-up studies done twenty-five years later confirmed that there is no advantage to the more mutilating surgery (Fisher et al.).

Getting clinicians to agree to participate and women to enroll in CCTs or RCTs in the 1970s and 1980s was a crucial step to discrediting radical mastectomies. Investigators had to persuade skeptical physicians who believed that the radical mastectomy was necessary to give their patients the best chance of survival. Many clinicians asserted that they had a "therapeutic obligation" or duty to pick what they viewed as the best therapy for their patients. Some were so convinced radical mastectomy was best that they did not inform women of other options, let alone enroll them in RCTs; others did not want to communicate the uncertainties about which therapies were best or feared that informed consent would destroy trust in the doctor–patient relationship (Taylor, Margolese, and Soskolne).

Such paternalistic attitudes increasingly troubled both investigators (how did clinicians know what was best?) and women (do they not have a say about what is best for them?). Women were learning about the controversies over treatment options swirling in the medical literature at the same time that informed-consent policy took root. Consequently, investigators and clinicians had to make room for good informed consent and choice. In response, therapeutic research became an increasingly cooperative venture among doctors, patients, and investigators (Kopelman, 1994; Fisher).

Increasingly, patients and clinicians saw the advantages of participation in multi-institutional research using the same protocols. These large trials proved to have many research advantages, because they can involve many patients and get results quickly, and because they can help neutralize biases that result from distinctive groups of people who use certain institutions. In addition, large trials can even result in improved care for all groups and better fulfillment of consent requirements. This is because these cooperative studies are often designed by experts and include quality-control provisions. In addition, they are also reviewed for approval by many agencies. Moreover, expert panelists review data and stop the trials if early results show clear advantages to some assignments.

By the 1990s, great progress in treating cancer resulted, in part, from doctors' willingness to enroll patients in clinical trials and patients' willingness to participate. Patients often acted from altruism to help the next generation of patients, just as the last generation had helped them. Clinical trials, by this time, were also seen as a way to get good care, leading many people to be eager to enroll and disappointed if they were excluded. Largely gone were the sweeping general denunciations of the 1970s and 1980s when critics claimed an inherent incompatibility existed between these research methods on the one hand and doctors' duties to protect patients, patient's rights and welfare, and good patient–doctor relationships on the other (Fried; Gifford; Marquis; Wikler).

An Imperfect Consensus with Enduring Issues

For clinical trials to be morally acceptable, a consensus exists that they must meet the following conditions:

1. The study is important.
2. Patients or their representatives give informed consent including knowledge of all alternatives, of their right to withdraw at any time, and of clinicians' and investigators' conflicts of interest.
3. Physicians and investigators place the well-being of the patients ahead of research interests.
4. The study has gained appropriate approval from institutional review boards or research ethics committees.
5. A data safety monitoring panel will end studies if it is demonstrated that one or more of the study arms prove better than others and will report significant new findings to doctors or patients.
6. The uncertainty principle or null hypothesis is justified, meaning that the arms of the study are "equally good."

Before a trial begins, then, investigators must do a comprehensive review of the literature to show that all treatments being given and compared have a therapeutic success rate that is acceptably high for all arms, and that it is uncertain whether any one of the treatments being tested is better than any of the others. In addition, it must be shown that no study arm provides what is known to be inferior care (HHS; Beauchamp and Childress; Concato, Shah, and Horwitz; Emanuel, Wendler, and Grady; WMA).

Serious questions exist about implementing these assumptions. Patients have legitimate preferences about how they want to be treated, and doctors have responsibilities to try to give patients the best care to meet their individual needs, goals, and desires. Controlled trials restrict people's choices and limit the ways therapies can be adapted for them by the methodologies of stratification, randomization, inflexible interventions, eligibility requirements, and single-blind or double-blind study designs. Some of these concerns are discussed below.

PHYSICIANS' ROLES AS CLINICIANS AND AS SCIENTISTS. When physicians enroll patients in clinical trials, they help patients collectively by gaining knowledge but may lose flexibility in tailoring treatments for individual patients. This can create a conflict between doctors' roles as scientists dedicated to conducting the best studies to gain knowledge, and as healers dedicated to adapting treatments to each patient's needs, goals, and values. To address this potential conflict, most agree that physicians should not enroll a patient in a clinical trial if they have reason to believe a patient might, thereby, obtain inferior care (Byar et al.; Chalmers, Block, and Lee; Kopelman, 1986; WMA; Ellenberg; Levine, Dubler, and Levine; Shaw and Chalmers; Zelen, 1990; Emanuel, Wendler, and Grady).

Although agreement exists that doctors should not enroll patients in studies in which they get inferior care, substantive disagreements remain about when arms of studies are considered equally good. One controversy concerns what values to employ in deciding if treatments are "equally good." Investigators tend to measure equality among treatments in terms of easily quantified outcomes such as survival after cancer treatments or reduction of blood pressure. Patients and some clinicians, however, also consider how treatments affect the quality of patients' lives and whether patients think the treatment makes them feel better (Levine, Dubler, and Levine). Views, therefore, about what treatments are equally good differ when people regard different things as relevant benefits and burdens. Hence nausea, hair loss, sexual impotence, weakness, extra costs, inconvenience, or more hospital visits may be more important outcomes from a patient's perspective than from an investigator's perspective in determining when treatments are equally good.

Another controversy that involves how to use the uncertainty principle may be called "the problem of clinician preference," or, should conscientious clinicians with any preference at all for one treatment arm enroll their patients in a clinical trial? Some argue that clinicians have a duty to provide what they believe to be the best available care for patients; consequently, as long as physicians have any preference about which treatment is best for their patients, they should not enroll their patients in clinical trials (Fried; Gifford; Waldenstrom). It is rare that clinicians have no preference whatsoever about what is best for their patients, especially for the treatment of serious illnesses where the outcomes, conveniences, risks, and possible benefits are different. Moreover, if asked, patients will often have preferences even if the clinicians do not, and this could break the tie for doctors. Consequently, these critics find trials, especially RCTs, generally unethical.

In his 1987 article, "Equipoise and the Ethics of Clinical Research," philosopher Benjamin Freedman tried to solve the problem of clinician preference by distinguishing between "theoretical equipoise" and "clinical equipoise." Theoretical equipoise is an epistemic (cognitive) state in which the evidence is exactly balanced, meaning that treatments are of equal value. Clinical equipoise, in contrast, is that state in which the community of expert clinicians is undecided as to the preferred treatment for the given population as determined by the study's eligibility criteria; the study should be designed to disturb clinical equipoise and to terminate when it is achieved. Freedman argued that clinical equipoise is a better way to understand that treatments are equally useful for a particular group and, thus, that the uncertainty principle has been reached. To decide equipoise, then, the focus should not be on the treatment that the particular clinician prefers, but on what the community of clinicians believes to be equally good treatments for some condition given their respective benefits and burdens. A clinician may have a preference for one treatment but respect colleagues with different views. Thus, as the trial begins, treatments (including any placebo arm) must be in clinical equipoise, or be regarded as having equal merit by the community of experts in treating some condition for a certain group. Disagreements should be expected in a rapidly advancing field such as medicine, and it is these disagreements that help explain why trials are important. Exceptions are sometimes made to this policy of requirement equipose if there is no more than minimal risk of harm to the subjects, such as testing the efficacy of nose drops in the common cold.

This solution presupposes agreement or justification about who should be in the community of expert clinicians deciding which treatments are equally good and whether their views adequately represent those of the potential patients. Disputes arise over this, however (Kopelman, 1994). Some people disvalue the views of any but the most acclaimed clinical investigators. Others contend that many perspectives, including those of investigators, clinicians, and patient advocates, represent patients' sometimes differing values. Increasingly, clinical trials are moving out of the academic centers and into private doctors' offices. Clinicians often find such arrangements professionally fulfilling, but they can also be financially lucrative when drug companies, who typically sponsor these studies, offer monetary incentives to enroll patients. In contrast to academic medical centers, little oversight or accountability exists in private offices, argued Jason E. Klein and Alan R. Fleischman in 2002; but more opportunity exists for patients to misunderstand that they are being enrolled in research programs not necessarily designed for their benefit. Klein and Fleischman argued that financial incentives to clinicians should be limited, patients should have an independent resource to answer their questions, and doctors should be required to disclose potential conflicts of interest. Arguably, in both the academic and private practice settings where there are genuine risks, the treating physician should not be the investigator.

STARTING TRIALS. Disagreements can erupt about the overall benefits of the new treatments or investigational new drugs when compared with standard care or to a placebo. To justify the time, energy, risks, and expense of testing a new therapy for some condition by means of a CCT or RCT, investigators must produce preliminary evidence of its safety, efficacy, and proper dose. Some knowledgeable people are likely to be more impressed with these findings than others, especially for serious diseases with no established treatments (Levine, Dubler, and Levine). Consequently, they disagree about if or when trials should begin. In addition, resources are limited so not all good studies can be funded. These funding choices depend not only upon the merits of the study but also on political and social interests because funding for studies is limited and often comes from tax revenues.

PLACEBO-CONTROLLED RCTS. One of the most persistent controversies concerns the use of the placebo arm in a controlled trial. A placebo is used because people's beliefs and expectations can influence how they react. Suppose there are two groups, and persons in one group get a red pill with specific activity. People sometimes react to getting pills. If one group gets a red pill, and if the two groups are being treated exactly the same, then arguably, the other group should also get a red pill, although without the same active preparation. The red pill might be a sugar pill. As noted, placebo-controlled RCTs are widely regarded as the gold standard for assessing the safety and efficacy of therapies.

A knotty problem exists over whether placebos should be used when there is a proven and effective treatment. Defenders of the use of a placebo arm in such cases cite its enormous methodological advantages in evaluating treatments and justify its use as long as subjects are not made worse off (Varmus and Satcher; Temple and Ellenberg). In one case, for example, investigators wanted to study the safety and efficacy of mood disorder medications adopted long ago without rigorous testing. Some of these drugs have a good track record of abating serious symptoms including suicidal ideation. Disputes arose over whether these drugs should be tested against a placebo because beliefs and expectations affect mood disorders. A distinguished panel of experts could not reach consensus and concluded: "Research is needed on the ethical conduct of studies to limit risks of medication-free intervals and facilitate poststudy treatment. Patients must fully understand the risks and lack of individualized treatment involved in research" (Charney et al., p. 262). Yet obtaining consent for what can be risky studies from such patients may also be problematic because their illnesses often disturb their thought processes.

Perhaps the most contentious debate so far concerned using placebo-controlled trials to study perinatal transmission of HIV/AIDS when a proven and effective therapy existed (Angell; Temple and Ellenberg; Ellenberg and Temple; Lurie and Wolfe). The funding was from rich countries where, because proven and effective therapies were the standard of care, the studies could not be done. Some argued these studies were immoral because the stakes were life and death (Angell; Lurie and Wolfe); others said that the studies were needed and that these poor people were made no worse off by being given local standards of care (Temple and Ellenberg; Ellenberg and Temple; Varmus and Satcher). They maintained this was the most efficient way to obtain urgently needed information to fight the HIV/AIDS epidemic.

In 2000 the influential World Medical Association (WMA) took a stand. It issued a new draft of the Declaration of Helsinki stating that placebos should not be used if there was a proven and accepted treatment. This put the declaration on a collision course with the U.S. Food and Drug Administration (FDA), which often requires the use of placebo despite the existence of a proven and accepted treatment. Defenders also point out that if placebos are not permitted, trials may have to be a great deal larger and therefore more costly.

One possible middle ground is to consider the harm of not having the treatment. If there is only a minor risk of harm, such as minor discomfort or inconvenience to being denied the proven and effective treatment, then studies might be permitted. As potential harms to those on the placebo arm increase, it should become more difficult to approve the study, even with consent from subjects or their representatives.

An entirely different set of concerns exists, challenging the placebo as the gold standard.In their 2001 article, "Is the Placebo Powerless?" Asbjorn Hrobjartsson and Peter Gotzsche questioned whether the placebo is really as powerful as claimed. The placebo itself, they pointed out, was adopted without testing. They conducted a meta-analysis comparing placebo with no treatment arms, finding that in many cases, there was no difference between them at all. They wrote, "We found little difference in general that placebos have powerful clinical affects. Although placebos had no significant affects on objective or binary outcomes, they had possible small benefits in studies with continuous subjective outcomes and for treatments of pain. Outside the setting of clinical trials, there is no justification for the use of placebos" (Hrobjartsson and Gotzsche, p. 1594). In a 2000 article, John Concato and colleagues also raised doubts about the ascendancy of the placebo-controlled RCT when compared to all other methods. They argued that even observational studies can, when carefully done, control bias as well as an RCT.

Kenneth J. Rothman and Karin B. Michaels, in a 1994 article titled "The Continuing Unethical Use of Placebo Controls," concluded that the FDA's insistence upon viewing the placebo as the gold standard not only has moral problems but also is essentially a political decision. The FDA scientists argued that the placebo-controlled studies make it easier to show statistical significance with smaller numbers of subjects; but larger studies would reduce statistical variability. Unfortunately, this is expensive. Concato and colleagues also objected, stating that it is the drug companies that benefit from the FDA policy of fostering small CCTs and RCTs given that such studies are less costly; it is the patients who bear the burdens of this policy because they are denied proven and effective treatments.

Yet another challenge to the use of placebos as the gold standard comes from those who study complementary and alternative medicines (CAMs). RCTs and CCTs try to eliminate nuisance variables, and they include in this category people's different hopes and beliefs. There is little doubt, however, that these are powerful forces in people's lives. Some argue that research that eliminates hope and belief has limited utility, just because mental attitude is so powerful. In 2002 Kenneth J. Schaffner argued that the study of CAMs "…might lead us to question"

> a standard research design methodology that priorities randomized clinical trials and objective measures of health … and think about the arguments of [the American philosopher Thomas] Kuhn and the disunity of science proponents, and about varying local methodologies … [with their] different evidential standards … CAM can help make us realize both that the influence of the belief systems may have powerful effects on health and that discerning these effects may require a realization of these Procrustean standards. (Schaffner 2002, p. 12)

ENDING TRIALS. The goal of a study is to learn whether different treatments are equally good for certain conditions. But justification for claiming to know something is a matter of degree, and there can be substantial disagreements about where to draw the line for the purpose of saying that it is known that treatments are or are not equally good. Investigators should adopt rules about when to stop at the outset of a study. Although investigators generally do not release preliminary data, there are some exceptions. A data safety monitoring panel is often charged with monitoring the data and deciding if trials should be ended early because people in one arm of the study are doing far worse than others. For example, azidothymidine (AZT) was first tested against a placebo in a double-blind RCT to see if it helped patients with AIDS. Doctors and nurses believed they knew from the abatement of symptoms, which patients were getting AZT and which were getting a placebo. After several months, 16 of the 137 patients in the placebo arm died, whereas only 1 of the 145 patients receiving AZT died. The trial was ended and all received AZT (Beauchamp and Childress).

Deciding when to stop a trial is not an entirely scientific choice but is also a moral decision. Investigators, panels, and journal editors typically require a probability of at most 0.05 (five chances in a hundred) that the observed results between groups occurred by chance, as a ground for holding that *sufficient evidence* exists to say they *know* that the groups are different. Although the 0.05 standard is a reasonable and well-established convention, it should not be misunderstood. As Daniel Wikler (1981) and Loretta M. Kopelman (1986, 1994) have argued, it is at best a moral trade-off between continuing the study so long that some people receive obviously suboptimal care and stopping so early that some people are harmed because insufficiently verified treatments are adopted or discredited. Some will draw that line differently, especially when treatments are tested for serious illnesses with few other means of treatment, as in AIDS research (Kopelman, 1994).

INFORMED CONSENT AND RESEARCH INTEGRITY. For people to enroll in studies, they or their guardians must give informed consent, meaning authorization that is competent, adequately informed, and voluntary. Assuming that people are competent to give consent and do so voluntarily, what do they need to know to give informed consent for clinical studies?

Generally they must be told about the study's nature, purpose, duration, procedures, and foreseeable risks and benefits. Moreover, they need to know about any alternative treatments, inconveniences, additional costs, and extra procedures or hospitalizations resulting from enrollment. They must also be told of their right to withdraw from the study at any time should they agree to participate (U.S. 45 CFR 46.116). If the study design includes different groups, randomization, or placebos, for example, prospective subjects need to be informed. Consent for therapy or research requires giving people all information that a reasonable person would want to know in order to make a choice.

These widely recognized consent requirements create tensions in relation to the research goals of clinical trials. For example, suppose in testing treatments, one study arm uses surgery with medical management resulting in a faster recovery if there are no complications, and the other study arm uses medical management alone, with fewer risks but a slower recovery. If distinctive groups have special preferences, such as the elderly preferring medical management and the young surgery, then the study of the different treatment results could be biased through self-selection.

Thus, there is a difficulty that may be called "the problem of subject preference": How can people's preferences be accommodated while preserving the scientific integrity of the CCT or RCT? Some criticize regulations on informed-consent doctrine as unrealistic, too individualistic, and shortsighted because they give too much weight to individual choice and make it hard to conduct good studies (Tobias; Zelen, 1979, 1990). Physicians and healthcare professionals, they argue, have a duty to take proper care of patients but are not typically required to educate them about these technical and complex matters; patients should get good treatment given by conscientious professionals, but patients do not need to know how, when, or why investigators evaluate their treatments. Most patients cannot understand the investigation's complexities, they argue, and would be harmed by learning of the uncertainties about what care is best or that they are being studied. Investigators should be free to design the best possible trials consistent with good care, they argue, and the current understanding of patients' rights disrupts clinical trials, thereby slowing medical progress. If people have only the right to good care and not the right to refuse to be enrolled in a study, it would be easier for investigators to conduct research and minimize problems of bias introduced by people's preferences. For example, Marvin Zelen devised schemas in which patients give their consent for a treatment without knowing that the treatment was selected by a random method and/or that they are in a study; other designs prerandomize people to group assignments before consent is sought (Zelen, 1979, 1990).

Such paternalism, in general, and Zelen's designs in particular, has garnered legal and moral criticism (Ellenberg, 1984, 1992; Kopelman, 1986, 1994). It not only denies people self-determination, but, without pertinent information, people do not have means to protect their own well-being. The doctrine of informed consent developed because many patients and activists wanted impartial information and participation in choices about their care, especially when they will be serving as research subjects. For example, statistician Susan S. Ellenberg criticized Zelen's prerandomization schemas in which patients are assigned to groups before consent is sought. She argued that this threatens impartiality in gaining consent, risking that the informational sessions will be shaped to enhance the benefits and minimize the risks of each individual assignment (Ellenberg, 1984, 1992).

On the other hand, others are skeptical that most subjects give genuine informed consent to research (Tobias; Wikler; Zelen, 1979). Most patients, they claim, do not understand the benefits or burdens of their treatment options, let alone the scientifically rigorous methodology used in testing. A related criticism is that investigators do not tell the patients, and most patients do not understand, that at some point in the trial it may become increasingly apparent that some groups are getting suboptimal care (Wikler). Investigators, they argue, put medical advances ahead of subject-patient rights and welfare because those rights typically violate physicians' duties to their patients (Fried; Gifford; Marquis; Wikler). Some support for this view comes from a study that George Annas reports was conducted by the FDA, which carried out spot checks on 1,000 investigations; the FDA found that investigators did not seek informed consent in 213 studies, did not follow their approved research protocol in 364 investigations, and failed to report adverse reactions for 140 test subjects. Unfortunately, the FDA results square with others, reports Annas (Annas).

In contrast to these two positions implying that one must choose between good trials and good informed consent, other commentators argue that clinical trials, including RCTs, can be cooperative ventures between patients and investigators (Freedman; Kopelman 1986, 1994; Levine, Dubler, and Levine; Levine, 1986). They believe that investigators and patients should work together with candor, respect, and trust about the goals and means of the research, and view consent as an on-going process. They maintain that with proper consent some studies (but not all) are morally justifiable. Subjects may *have* to be regarded as partners in a cooperative venture, however, if investigators expect people to enroll and cooperate. People can defeat trials if they do not identify with the investigators' goals. In one case, investigators were testing whether patients infected with HIV who were not yet showing symptoms of AIDS would benefit from AZT. At the end of the trial, researchers estimated that 9 percent of the patients in the placebo arm had been taking AZT. If more patients in the placebo group had secretly taken AZT, investigators might have judged a beneficial drug ineffective and refused to release it for this use (Merigan). These patients, facing a life-threatening disease, found a way to get the drug they believed useful and inadvertently jeopardized a clinical trial and the welfare of future patients. Poor cooperation results when the subjects fail to identify with the goals of the study, do not understand its importance, or are asked to risk too much in terms of health and convenience (Spilker).

PROTECTION OR ACCESS. During the period from the 1970s to the early twenty-first century, patients and physicians have gone from being wary of participating in CCTs and RCTs to seeking access to them. Studies were increasingly seen as opportunities for good care rather than as dangerous projects from which vulnerable people should be protected (Dresser; Kopelman, 1994). For example, AZT, the first effective drug to treat AIDS, was initially tested for safety and efficacy against a placebo in a double-blind RCT, as has been mentioned. Until the early 1990s, many biomedical research study populations excluded people of color, women, and children in order to “protect” what were considered to be these more vulnerable populations. Advocates argued that this was unfair because enrollment in trials often provides people the only or best available access to adequate or promising care. For example, children with AIDS initially could not get AZT because only adults could be enrolled in studies. Even after some studies showed that AZT was beneficial for treatment of adults, regulations initially forbade its prescription for children because it had not been tested with them (Pizzo). Moreover, a study excluding people of color, females, and children focuses upon a narrow range of the patient population (adult white males), making it uncertain whether the results of a study apply to other groups. There may be differences among groups; if there are, variations might be due to nature, nurture, or a combination of both. A study on depression, for example, conducted exclusively with white men, leaves uncertainty as to whether the results would be the same for other groups who have different social standing, burdens, genes, or physiologies.

More flexible eligibility requirements, advocates argue, would give all groups access to new treatments and would also yield results that more accurately reflect the entire patient population. Opponents respond that this would tend to make it harder to ensure that groups are comparable unless they have more subjects in the group. This would, of course, make the studies more costly. Despite these objections, policies were adopted to address unequal access and to revise eligibility criteria that excluded groups simply to save money and hold down the cost of trials, especially when studies were supported by tax dollars.

Patient-advocacy groups also demanded more access to preliminary information about the safety and efficacy of different modes of care. They wanted less secrecy regarding early trends, especially in cases in which patients have few treatment options for serious diseases. Many patients with severe or chronic diseases, or their families, have learned to follow closely relevant research, and they want greater access to promising new treatments.

These proposals generated a variety of responses (Byar et al.; Levine, Dubler, and Levine; Merigan; Schaffner, 1986; “Expanded Availability,” 1990). For example, programs now make some investigational new treatments more available by means of expanded access or a “parallel track” (“Expanded Availability”). In the past, there was a single way, or *track,* for patients to get certain investigational new treatments, namely, participating in the study as a subject. Some people were excluded because they lived too far from the study site(s) or because of age, gender, or prognosis (Dresser; Kopelman, 1994). New programs expanded access or offered a parallel track to make it possible for some patients who are not subjects to have investigational new treatments. Patients with HIV-related diseases, for example, can sometimes obtain investigational new treatments even though they are not enrolled as trial subjects. Some investigators recommend this approach when there are no therapeutic alternatives, when the investigational new treatments are being tested, when there is some evidence of their efficacy, when there are no unreasonable risks for the patient, and when the patient cannot participate in the clinical trial (Byar et al.). This solution presupposes that there is agreement about who should make these verdicts. Community representation on panels that make these decisions may be reassuring to groups advocating more openness.

These and other proposals allow greater flexibility but also may make it harder to conduct and interpret the results (Ellenberg; Merigan). For example, if patients can get the investigational new treatment without enrolling in a clinical trial, some may refuse to participate in the study. Thus, even if these proposed changes are adopted, tensions still exist between individual and collective interests in conducting trials.

Conclusion

The CCT and RCT methodologies are powerful ways to combat the effects of bias. By using these methods, bias can be minimized, but it can never be entirely eradicated. People’s beliefs, hopes, duties, prejudices, values, or interests can create biases in their choices about what studies to fund, when to begin and end studies, what measures will be used, how groups are established, and how results are interpreted.

When people consider the adoption of procedures such as copious amounts of oxygen for premature infants (later found to cause blindness), a high premium is placed on protection of the public from someone's idea of *promising* new treatments; when they think of drugs that have proved to help sustain or improve people's lives, however, a high premium is placed on early access. Who should decide the optimal degree of testing or protection needed in order to establish the safety and efficacy of drugs before they are available? This question of access versus protection is a social and moral decision, not just a scientific matter. It is not unlike the decision about how much inspection of foods or buildings is necessary in order to protect the public. When the stakes are high, as in fatal or chronically degenerative diseases with no promising treatments, the disputes about when to begin or end trials are sometimes a tangle of scientific, moral, social, political, statistical, and medical problems.

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SEE ALSO: *Aging and the Aged: Healthcare and Research Issues; AIDS: Healthcare and Research Issues; Autoexperimentation; Children: Healthcare and Research Issues; Commercialism in Scientific Research; Embryo and Fetus: Embryo Research; Empirical Methods in Bioethics; Genetics and Human Behavior: Scientific and Research Issues; Holocaust; Infants: Public Policy and Legal Issues; Informed Consent: Consent Issues in Human Research; Mentally Ill and Mentally Disabled Persons: Research Issues; Military Personnel as Research Subjects; Minorities as Research Subjects; Pediatrics, Overview of Ethical Issues in; Prisoners as Research Subjects; Race and Racism; Research, Human: Historical Aspects; Research, Multinational; Research Policy; Research, Unethical; Responsibility; Scientific Publishing; Sexism; Students as Research Subjects; Virtue and Character;* and other *Research Methodology* subentries

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III. SUBJECTS

Selecting individuals to participate in research involves not only scientific decisions about appropriate entry criteria but also ethical decisions about the distribution of benefits and burdens. In *The Belmont Report* (1979), the U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research cited three ethical principles as the foundation of research ethics. The first, respect for persons, and the second, beneficence, have been analyzed more often and in greater depth than the third, justice. Investigators, regulators, and institutional review boards (IRBs) are accustomed to applying the principle of beneficence by examining the risk-benefit ratio and applying the principle of respect for persons by examining informed consent. But the third principle—the selection of subjects as a matter of justice—has often been considered last and in only one of its aspects, the protection of vulnerable groups from exploitation as subjects.

This situation is changing as persons and groups previously excluded from research on grounds of vulnerability seek access to what they perceive as research benefits, primarily the opportunity to try new drugs for serious and life-threatening illnesses. However, the concept of vulnerability is itself coming under greater scrutiny as being ill-defined and too broad. In his 2001 paper, *Vulnerability in Research Subjects,* Kenneth Kipnis proposed a new taxonomy of vulnerability, which he defined as limitations on the ability to provide informed consent. He outlined six types of vulnerability, based on characteristics of the individual or society:

1. cognitive: the ability to understand information and make decisions;
2. juridic: being under the legal authority of someone such as a prison warden;
3. deferential: customary obedience to medical or other authority;
4. medical: having an illness for which there is no treatment;
5. allocational: poverty or educational deprivation; and
6. infrastructure: limits of the research setting to carry out the protocol.

According to the U.S. National Commission, justice is relevant to the selection of subjects at two levels: the social and the individual. At the individual level, “researchers [should] exhibit fairness: thus, they should not offer potentially beneficial research only to some patients who are in their favor or select only ‘undesirable’ persons for risky research” (U.S. National Commission, p. 7). At the social level, “distinctions [should] be drawn between classes of subjects that ought, and ought not, to participate in any particular kind of research, based on the ability of members of that class to bear burdens and on the appropriateness of placing further burdens on already burdened persons” (U.S. National Commission, p. 7). Specifically, on the grounds of social justice, classes of subjects should be ranked (e.g., adults before children) and some classes of potential subjects (e.g., prisoners and the institutionalized mentally infirm) should be selected only under certain conditions and should perhaps not be selected at all.

Very few philosophers or other scholars have proposed standards by which to establish priorities in the selection of subjects. Hans Jonas (1970) proposed a “descending order of permissibility” for the “conscription” of subjects. In his view, researchers themselves should be the first to test a new therapy, in that they can best understand the risks and benefits. Believing that very sick or dying patients are particularly vulnerable to researchers’ invitations, Jonas opposed using them in research not directly related to their care.

Another approach has been to assert an obligation to participate in biomedical research. Arthur L. Caplan (1984) argued that research is a form of voluntary social cooperation that generates obligations of fairness and reciprocity. If a competent individual voluntarily seeks care in a hospital or institution that conducts biomedical research, he or she benefits from research and should share in its costs (i.e., participate). This obligation is a general one, not an obligation to volunteer for the first available trial or any particular trial.

Selecting the Least Vulnerable

Underlying these different views is the assumption that research is risky or at least burdensome. If this is true, subjects should be selected in a way that protects those whose social, demographic, or economic characteristics make them particularly vulnerable to coercion and exploitation. Volunteering for research is seen as either a duty to be discharged or an altruistic act to be applauded. This emphasis on protecting vulnerable persons is understandable given the signal event in the modern history of clinical research ethics—the cruel and often fatal experiments performed on unconsenting prisoners by Nazi doctors in World War II (Caplan, 1992). Public opinion in the United States also was shaped by the revelations of unethical experiments such as the Tuskegee Syphilis Study of poor black sharecroppers (Jones), the Willowbrook hepatitis B studies at an institution for mentally retarded children (Rothman, 1982), and the Jewish Chronic Disease Hospital studies in which live cancer cells were injected into uninformed elderly patients (Katz, Capron, and Glass). The most influential single article was one by Henry Knowles Beecher, a respected anesthesiologist, published in the *New England Journal of Medicine* in 1966; it described a series of studies at major research institutions that placed subjects at risk and in which the researchers failed to obtain informed consent (Rothman, 1991).

The view of research as inherently risky and of research subjects as inherently needing protection began to change in the early 1980s, but the pendulum may be swinging back to a more cautious view in the light of rare but highly publicized deaths of research subjects. In September 1999 Jesse Gelsinger, eighteen years old, died in a gene transfer. Ellen Roche and Hoiyan Wan, both young “normal, healthy volunteers,” died in trials at Johns Hopkins University and the University of Rochester, respectively (Steinbrook, 2002a, 2002b). Research studies at several prominent medical centers were shut down temporarily after deficiencies in their procedures were identified.

The actual risk in most research studies is generally considered to be quite low, but there are no recent data. The

U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982) asked three large research institutions to summarize their experience with research-related injuries. Each group found a very low incidence of adverse effects. In one institution, out of more than 8,000 subjects involved in 157 protocols, only three adverse effects were reported, including two headaches after spinal taps. The definition of "adverse effect" is vague, however, especially among sick people, and it is possible that many adverse effects are not reported because they are deemed unrelated to the research study.

Sharing the Benefits of Research

The benefits side of the equation has assumed greater weight in individual decision making. Patients and advocacy groups are demanding more autonomy and less paternalism in the selection of subjects. Desperately ill patients forcefully argue that they are willing to trade a higher level of risk for the potential benefits of promising new procedures, devices, or drugs. Advocates for women and children point out that the typical exclusion or underrepresentation of these populations in clinical trials means that the drugs, when approved, will be prescribed for them with little direct data about dosage, efficacy, or side effects. These trends have been spurred by the vigorous, sometimes confrontational, efforts of persons with acquired immunodeficiency syndrome (AIDS). This advocacy also has stressed the inclusion of groups with poor access to trials, mainly women and minorities (C. Levine, 1988, 1993).

Increased emphasis on women's health issues has provided some information on subject recruitment. Examining the inclusion of women in clinical trials, the U.S. General Accounting Office reviewed the practices of the National Institutes of Health (NIH) and the Food and Drug Administration (FDA) (Nadel; U.S. General Accounting Office, 1992). In both instances women were found to be underrepresented. The FDA review found that women were represented in every clinical trial of the fifty-three drugs approved by the FDA in the previous three and a half years. For more than 60 percent of the drugs, however, the proportion of women in the trial was less than the proportion of women with the relevant disease. Women were particularly underrepresented in trials of cardiovascular drugs, even though cardiovascular disease is the leading cause of death in women.

In arguing for wider inclusion criteria in clinical trials, patient advocates and some clinicians have noted that in the interest of good medical care, drugs should be tested on the populations that will use them. This belief runs counter to the more traditional research view of subject selection, which focuses on testing drugs in a small, homogeneous population in order to detect differences in efficacy and side effects as rapidly as possible.

Even with broadened inclusion criteria, not all patients who want access to promising new agents can be enrolled in clinical trials because they fail to meet the inclusion criteria, they live too far from a research center, or the trials are already closed. Several other mechanisms have been developed, such as the "parallel track," in which qualified patients who cannot enroll in clinical trials may obtain a promising drug through their physician ("Expanded Availability," 1992). Community-based research, especially in cancer and AIDS, also has made clinical trials more accessible to patients.

The NIH has formalized the movement toward broader selection of subjects by mandating that its research grant recipients include appropriate numbers of women and minorities (Kirschstein). The 1993 NIH Revitalization Act (Pub. L. 103–43) extended the revised NIH policy by requiring the NIH director to ensure that women and members of minority groups are included in each federally funded project. The director may waive the requirement if the inclusion is inappropriate for health reasons, the purpose of the research, or any other circumstance. Cost, however, is not considered a permissible reason to fail to include women and members of minority groups.

This trend has limits, however. The inclusion of pregnant women in clinical trials is still controversial unless the trial is specifically designed to benefit the fetus, such as trials to prevent maternal–fetal transmission of the human immunodeficiency virus (HIV), which is associated with AIDS. Some of the objections to including pregnant women rely on ethical concerns about, for example, placing a fetus, who cannot consent, at risk. Most of the concerns are based on fears of legal liability should the fetus be born with an injury that might be attributed to the investigational drug. Other subject groups for which protection is still deemed essential include children (Levine, 1991), prisoners, and mentally ill persons. Still other groups sometimes cited as vulnerable include elderly people, military personnel, pharmaceutical company employees, and medical students. Although for these individuals some conditions and some protocols might be coercive, in general they can make choices voluntarily. Special procedures have been set up in some instances to ensure voluntariness (see, e.g., Winter, on the U.S. Department of Defense).

From the societal perspective, equitable selection of subjects means that the groups bearing the burdens of research should also share in its benefits. Opponents of research in prisons argue that the fruits of the research—newly approved drugs—are rarely available in that setting. Similarly, although many drug trials have been carried out in Third World countries, these nations are often so poor or so lacking in healthcare services that they cannot afford to provide the tested drugs to their citizens.

More recently, representatives of Third World countries and of poorly served communities in the United States have been demanding a greater role in the distribution of benefits (Lurie et al.; U.S. National Commission on AIDS; Thomas and Quinn). Their agreement to participate in clinical drug trials is sometimes conditioned on a promise from trial sponsors to provide something of benefit to the population—the drug, if it proves efficacious, or the health infrastructure needed to deliver the therapy. Efficacy trials for vaccines, which require thousands of subjects, cannot be conducted without the goodwill and participation of a community's leaders. Community consultation, in which investigators and community spokespersons collaborate on the design and implementation of a trial, is becoming a frequent strategy for ensuring that the concerns of the pool of potential subjects and their representatives are addressed.

Recognizing the importance of social justice in the distribution of burdens and benefits, the Council for International Organizations of Medical Sciences (CIOMS) guidelines for international research state:

> Before undertaking research in a population or community with limited resources, the sponsor and the investigator must make every effort to ensure that:
>
> - the research is responsive to the health needs and the priorities of the population or community in which it is to be carried out; and
> - any intervention or product developed, or knowledge generated, will be made reasonably available for the benefit of that population or community. (CIOMS, p. 19)

Principal 19 of the World Medical Association's most recent restatement of the Declaration of Helsinki (1964, revised 2000) states: "Medical research is only justified if there is a reasonable likelihood that the populations in which the research is carried out stand to benefit from the results of the research."

The equitable selection of subjects now includes an assessment of both the need for protecting vulnerable individuals and groups and the importance of allowing them maximum choice in making the ultimate decision to participate. In the future, even more emphasis will be placed on the equitable distribution of the benefits of research.

CAROL LEVINE
THOMAS W. OGLETREE (1995)
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SEE ALSO: *Aging and the Aged: Healthcare and Research Issues; AIDS: Healthcare and Research Issues; Autoexperimentation; Autonomy; Children: Healthcare and Research Issues; Coercion; Commercialism in Scientific Research; Embryo and Fetus: Embryo Research; Empirical Methods in Bioethics; Freedom and Free Will; Genetics and Human Behavior: Scientific and Research Issues; Holocaust; Infants: Public Policy and Legal Issues; Informed Consent: Consent Issues in Human Research; Mentally Ill and Mentally Disabled Persons: Research Issues; Military Personnel as Research Subjects; Minorities as Research Subjects; Paternalism; Pediatrics, Overview of Ethical Issues in; Public Policy and Bioethics; Prisoners as Research Subjects; Race and Racism; Research, Human: Historical Aspects; Research Methodology; Research, Multinational; Research, Unethical; Responsibility; Scientific Publishing; Sexism; Students as Research Subjects; Virtue and Character;* and other *Research Policy* subentries

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RESEARCH, MULTINATIONAL

• • •

The term *multinational research* refers to biomedical, epidemiological, or social science research that involves investigators and subjects from more than one nation. The type of multinational research that has raised the most ethical concerns is that in which the investigators or sponsors are from an industrialized country and the research is conducted in a developing country (the "host" country). Two chief ethical concerns have dominated this type of research in the past. The first concern is that research subjects in the host country might be vulnerable by virtue of their low educational level or lack of familiarity with modern scientific concepts and, therefore, open to exploitation in some manner. The second concern is that the cultural norms and practices in the industrialized and host countries may differ, leading to the question of which to adhere to when such norms and practices conflict.

More recently, a third ethical concern has become prominent: the level of care and treatment provided to research subjects during a clinical trial. Should it be identical to what subjects in the industrialized, sponsoring country would receive in a similar trial? Or can a lower level of care be justified based on affordability and a less well-developed infrastructure in resource-poor countries? These latter questions have been prompted primarily by HIV/AIDS research conducted in countries in Africa and Asia. A fourth concern has also risen to prominence in recent years: What, if anything, is owed to trial participants, to the community, or to the host country as a whole when a biomedical research project results in a successful product?

Two trends bring concern about biomedical research ethics in a multinational context to the fore. The first is a vast increase in the number of studies conducted in developing countries and sponsored by the pharmaceutical industry or by governmental agencies of industrialized countries (Brennan; U.S. Department of Health and Human Services). The second trend is the growing gap in the burden of disease between industrialized and developing countries, a result in part of the AIDS epidemic but also stemming from the lack of affordable treatments for diseases such as malaria and tuberculosis in resource-poor countries (Michaud, Murray, and Bloom).

Although the chief ethical concerns of the past continue to require vigilance in the ethical review and conduct of multinational research, the two more recent concerns have generated considerable controversy. A clinical trial conducted in Thailand and other developing countries, aimed at finding an affordable and appropriate treatment to prevent the transmission of HIV/AIDS from pregnant women to their infants, led to fierce debates in leading medical and bioethics journals (Angell; Lurie and Wolfe; Varmus and Satcher; Annas and Grodin, 1998; Crouch and Arras; Lie; Schüklenk). The controversy went beyond the debates in academic journals, leading eventually to a prolonged process to revise two of the leading international ethical guidelines for research: the World Medical Association's Declaration of Helsinki and the *International Ethical Guidelines for Biomedical Research Involving Human Subjects,* prepared by the Council for International Organizations of Medical Sciences (CIOMS) in conjunction with the World Health Organization.

International Research Guidelines and Recommendations

The first international code of ethics for research involving human subjects, the Nuremberg Code, was drafted in 1947 at the Nuremberg Doctors' Trial in response to the atrocities committed by physicians in Nazi Germany in experiments they conducted on inmates of concentration camps (Annas and Grodin, 1992). The purpose of the code was both to acknowledge the importance of research involving human beings and to provide a set of universally applicable rules for protecting human subjects of research from violations of their rights and welfare. The first principle of the Nuremberg Code is: "The voluntary consent of the human subject is absolutely essential." This requires that the subject "be able to exercise free power of choice, without … any element of force, fraud, deceit, duress … or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision." Other principles in the Nuremberg Code require that the proposed research be meaningful and essential, that it be based on prior animal experiments, and that it "avoid all unnecessary physical and mental suffering and injury."

The Declaration of Helsinki, first promulgated by the World Medical Association (WMA) in 1964, with relatively minor revisions in 1975, 1983, 1989, and 1996, adapted and expanded the principles of the Nuremberg Code to apply more readily to clinical research in the medical setting. Until the revision in 2000, the Declaration of Helsinki did not address the special features of research sponsored by industrialized countries and carried out in developing countries. However, the controversy that surrounded the trial to test an affordable drug to prevent maternal-to-child transmission of HIV/AIDS produced a subsequent, related controversy over a provision in the Declaration of Helsinki itself.

Critics of the HIV/AIDS trial in developing countries argued that the trial design was unethical because some of the pregnant women were given a placebo, an inactive substance, thereby withholding from them a treatment proven to be effective in reducing the transmission of HIV/AIDS in the United States. These critics also contended that the trial violated the following provision in the Declaration of Helsinki: "In any medical study, every patient—including those of a control group, if any—should be assured of the best proven diagnostic and therapeutic method. This does not exclude the use of inert placebo in studies where no proven diagnostic or therapeutic method exists" (WMA, II, 3). Whereas critics of the placebo-controlled trials cited the Declaration of Helsinki in support of their contention that the trials were unethical (Lurie and Wolfe), defenders of the trials argued that the Declaration of Helsinki was in need of revision (Levine).

The WMA embarked on a process to revise the declaration, a process that took place over a two-year period and was itself fraught with controversy. In an effort to make the process transparent and democratic, the WMA posted a draft of the revised version on its web site and invited comments. As a consequence of many comments that found the draft unsatisfactory primarily because it weakened the provision requiring that a control group be given "the best proven diagnostic and therapeutic method," the WMA appointed a new drafting committee whose members reinstated the original requirement in slightly different words: "The benefits, risks, burdens and effectiveness of a new method should be tested against those of the best current prophylactic, diagnostic, and therapeutic methods. This does not exclude the use of placebo, or no treatment, in studies where no proven prophylactic, diagnostic or therapeutic method exists" (WMA, paragraph 29).

The newly revised draft was posted on the WMA web site, once again with an invitation for comments. In October 2000 the WMA adopted the second revised version at its meeting in Edinburgh, Scotland. But that did not end the controversy. A substantial number of influential spokespersons from the research community, the pharmaceutical industry, and U.S. federal agencies that sponsor research objected that adherence to this provision would prevent important research from going forward that could benefit developing countries. In an attempt to compromise between these opposing factions, the WMA issued the following clarification in 2001:

> The WMA is concerned that paragraph 29 of the revised Declaration of Helsinki (October 2000) has led to diverse interpretations and possible confusion. It hereby reaffirms its position that extreme care must be taken in making use of a placebo-controlled trial and that in general this methodology should only be used in the absence of existing proven therapy. However, a placebo-controlled trial may be ethically acceptable, even if proven therapy is available, under the following circumstances:
>
> - Where for compelling and scientifically sound methodological reasons its use is necessary to determine the efficacy or safety of a prophylactic, diagnostic or therapeutic method; or
> - Where a prophylactic, diagnostic, or therapeutic method is being investigated for a minor condition and the patients who receive placebo will not be subject to any additional risk of serious or irreversible harm.…

This clarification did not lay the controversy to rest. Defenders of placebo-controlled trials conducted in developing countries would cite what they consider “compelling and scientifically sound methodological reasons” for using placebo controls. Critics of such trials would then question whether the reasons provided were scientifically compelling and would propose instead a trial design comparing the experimental treatment with a treatment currently and widely used in the industrialized country sponsoring the research. The debate appears intractable, with each side comprising researchers, bioethicists, governmental spokespersons, and others from both developing and industrialized countries.

The same controversial clinical trials that prompted revision of the Declaration of Helsinki created a need to undertake a review and revision of the CIOMS *International Ethical Guidelines,* which were first published in 1993. In part because the CIOMS guidelines were promulgated with the purpose of applying the standards of the Declaration of Helsinki in developing countries, but also because the rapidly increasing amount of multinational research called for a reassessment of the 1993 guidelines, a multistage process was undertaken for the CIOMS revisions.

Predictably, the same debate that arose among defenders and opponents of placebo-controlled trials in the revision of the Declaration of Helsinki surfaced among drafters, members of an appointed steering committee, and commentators who responded to a posting of drafts on the CIOMS web site. The controversial guideline that emerged from this process departs significantly from the strict requirement in the Declaration of Helsinki; it permits clinical trials “in which the comparator is other than the best current intervention, such as placebo or no treatment or a local remedy” (CIOMS, Guideline 11). The justification for withholding the best current intervention is that it “cannot be used as comparator because its use as comparator would not yield scientifically reliable results that would be relevant to the health needs of the study population” (CIOMS, Guideline 11). Critics of this position argue that it is unethical to use placebos when doing so can lead to serious or irreversible harm to subjects in the control group.

Other studies of multinational research were launched at about the same time. The U.S. National Bioethics Advisory Commission (NBAC) launched an international project and in 2001 issued a final report, *Ethical and Policy Issues in International Research.* This report contains a recommendation on the same controversial point:

> Researchers and sponsors should design clinical trials that provide members of any control group with an established effective treatment, whether or not such treatment is available in the host country. Any study that would not provide the control group with an established effective treatment should include a justification for using an alternative design. Ethics review committees must assess the justification provided, including the risks to participants, and the overall ethical acceptability of the research design. (NBAC, Recommendation 2.2)

This recommendation sets up a strong presumption to provide an “established effective treatment” to the control group. But it also contains an escape hatch, allowing the proposal of an alternative trial design, which must be approved by an ethics review committee.

The Nuffield Council on Bioethics in the United Kingdom issued a report on multinational research one year after publication of the NBAC report. The Nuffield report's recommendation on level of care provided to a control group is also less stringent than the requirements in the 2000 Declaration of Helsinki:

> Wherever appropriate, participants in the control group should be offered a universal standard of care for the disease being studied. Where it is not appropriate to offer a universal standard of care, the minimum standard of care that should be offered to the control group is the best intervention available for that disease as part of the national public health system. (Nuffield Council, paragraph 7.29)

This unresolved controversy about what should be provided to a control group gives rise to a series of philosophical questions about ethical guidelines: When reasonable people disagree on key provisions, what should be done? Should the controversy be resolved in favor of the position held by the majority? Should it be resolved in favor of the more influential party to the dispute? Or should there be no guideline at all on points of major contention among reasonable persons of good will? On the one hand, if a published ethical guideline is systematically violated, it leads to disrespect for or cynicism about the guidelines as a whole. This is the contention of critics of the paragraph in the Declaration of Helsinki requiring that a control group receive "the best current treatment." On the other hand, if a guideline is published and held by some to be exploitative of research subjects in developing countries, it creates a general skepticism concerning the ethical conduct of multinational research. This is the view of defenders of the paragraph requiring the "best current treatment" for the control group in studies in developing countries.

Understanding the Controversy

Opponents on both sides of this controversy are committed to finding appropriate and affordable diagnostic, prophylactic, and therapeutic methods for populations in developing countries. Both sides believe that to be ethical, research must be responsive to the health needs of the population where the research is conducted. That is where their agreement ends.

The chief difference between the two sides from an ethical perspective concerns the obligation to research subjects enrolled in a clinical trial. A study with the identical design of the maternal-to-child transmission study carried out in Thailand could not have been conducted in the United States for both moral and practical reasons. Morally, women outside the trial in the United States had access to an effective treatment, so they would be made worse off if they participated in the trial. Practically, many would obtain the effective treatment from other sources, undermining the study. In contrast, women in the trials in developing countries had limited or no access to a preventive treatment for their infants outside the trial, so those in the placebo group would not be made worse off by participating in the trial. Defenders of the placebo controls contended that women in the control group received the "standard of care" in their country. Critics argued that they could have been provided with the effective treatment, which could then have been compared to the experimental treatment.

As the Thai studies demonstrate, what appears to be a straightforward debate about obligations to research subjects in a clinical trial turns in part into a debate over research methodology. Defenders of the placebo-controlled trials argue that the research question to be addressed is: "In cases where there is no standard treatment whatsoever, is the experimental treatment better than nothing?" To answer that question, the only appropriate research design is one that uses a placebo control. Moreover, some test placebo against standard treatments in the United States because they can make the case that the treatment may not be any better than placebo and it is important to find that out. Critics of these placebo-controlled trials argue that a different research question is meaningful and could be addressed: "Is the experimental drug as good, or almost as good, as the best current treatment used in the United States?" The first group argues that an answer to the latter question is not responsive to the needs of the developing country. The second group replies that given a large enough number of subjects, the use of appropriate statistical tools, and a research design comparing the experimental and the proven treatments, a research question relevant to the developing country can be formulated and answered.

Thus a resolution to this ethical controversy turns, in part, on a methodological issue in the design and conduct of clinical trials. Because researchers and methodologists can be found on both sides of the debate, there is little hope that this type of controversy can be resolved by rational means unless the risks of harm are low.

Providing Posttrial Benefits in Developing Countries

The 2000 version of the Declaration of Helsinki added two new provisions that were not included in the revision issued only four years earlier. These new paragraphs reflect the widely acknowledged fact that much past research conducted in developing countries failed to produce subsequent benefits to the populations of the countries in which the research was carried out; the benefits of biomedical research typically accrued to the populations in industrialized countries. This imbalance violates the principle of distributive justice, which calls for an equitable distribution of the benefits and burdens of research. Paragraph 19 of the declaration addresses this point: "Medical research is only justified if there is a reasonable likelihood that the populations in which the research is carried out stand to benefit from the results of the research." And paragraph 30 states: "At the conclusion of the study, every patient entered into the study should be assured of access to the best proven prophylactic, diagnostic and therapeutic methods identified by the study."

Both of these newly added provisions are a response to criticisms that have been leveled against past research sponsored by industrialized countries or industry in which any resulting benefits of the research have accrued to the sponsoring country but not to the population from which the research subjects were drawn. Paragraph 19 of the 2000 declaration seeks to ensure that research is not carried out on inhabitants of developing countries solely for the benefit of inhabitants of wealthy, industrialized countries. Paragraph 30 seeks to ensure that the sponsoring country or industry does not simply pull out when the study is concluded, abandoning research subjects who still need a treatment that has been demonstrated to be effective.

Although these situations might very well occur when research is conducted wholly within an industrialized country, the lack of access to affordable treatments outside a research study is much more prevalent in resource-poor countries. This has been especially true of medications to treat HIV/AIDS. By the year 2000, virtually all pregnant women in the United States had access to effective treatments to prevent HIV transmission to their infants, but those treatments remained out of reach for most inhabitants of most developing countries (Joint United Nations Programme on HIV/AIDS, 2002). Effective treatments to prevent progression of HIV infection into symptomatic AIDS is also available to large numbers of people in industrialized countries, but here again, only a small minority of people in developing countries can afford the cost of these drugs, which remain too expensive for purchase by the ministries of health, as well. (Brazil has been an exception, as the government made a commitment to provide treatments for HIV/AIDS to its entire infected population.)

The requirement that research be responsive to the health needs of the population of the country in which the research is conducted has been a feature of the CIOMS guidelines, which were promulgated specifically with developing countries in mind. The 2002 revision of the guidelines reiterates a requirement in the 1993 version that the research be responsive to the health needs and priorities of the community in which it is carried out. The 2002 revision goes considerably further than the 1993 version by elevating a key provision to the status of a guideline instead of being relegated to the commentary under a guideline:

> *Guideline 10: Research in populations and communities with limited resources*
>
> Before undertaking research in a population or community with limited resources, the sponsor and the investigator must make every effort to ensure that:
>
> - the research is responsive to the health needs and the priorities of the population or community in which it is to be carried out; and
> - any intervention or product developed, or knowledge generated, will be made reasonably available for the benefit of that population or community.

Although the term *reasonably available* has been criticized as being too vague, the guideline nevertheless establishes a presumption for sponsoring countries or industry to seek to ensure access to successful products developed in the course of research conducted in developing countries. The reports of both the NBAC and the Nuffield Council on Bioethics address this issue, but their recommendations permit a failure to ensure access if researchers provide sufficient justification to a research ethics committee.

Preventing Exploitation

The ongoing controversy over what should be provided to a control group and the acceptability of placebo controls, along with the question of posttrial obligations to research subjects, the community, and the country in which the research takes place, have overtaken the main ethical concerns of the past regarding multinational research. Yet those past concerns have not disappeared. The need to prevent exploitation of research subjects is an ethical requirement everywhere, but it becomes more problematic in settings where subjects are illiterate or semiliterate, and where they are unfamiliar with the concepts of modern science as well as the purpose and conduct of biomedical research. Two mechanisms exist to aid in protecting research subjects from violations of their rights and welfare: prior ethical review of research protocols by an independent committee; and an adequate process for obtaining voluntary, informed consent from individual subjects. Problem exist with regard to the effectiveness of both of these mechanisms in developing countries.

PRIOR ETHICAL REVIEW. The first and most obvious shortcoming is the absence of ethical review committees in many developing countries and in the institutions within those countries (such committees are termed institutional review boards [IRBs] in the United States, research ethics boards [REBs] in Canada, and other names elsewhere). Even where such committees exist, they may be newly established and therefore inexperienced. Even committees that are not recently established may lack adequate education and training for their members. Or they may be staffed with researchers or institutional officials who have a conflict of interest regarding the research to be reviewed. In the poorest countries, institutions lack the resources to make photocopies of the protocols to be reviewed by all the members, and time spent on committee work means loss of income from clinical work for which they would otherwise be paid.

Recent guidelines and reports acknowledge these shortcomings and propose that they be remedied through efforts to build capacity for local or national ethical review in developing countries. For example, a guidance document issued by the Joint United Nations Programme on HIV/AIDS (UNAIDS) contains the following point, titled "Capacity building": "Strategies should be implemented to build capacity in host countries and communities so that they can practise meaningful self-determination in vaccine development, can ensure the scientific and ethical conduct of vaccine development, and can function as equal partners with sponsors and others in a collaborative process" (UNAIDS, p. 15). Although the guideline specifically addresses vaccine research, a similar point appears in many other documents.

The revised version of the CIOMS guidelines issued in 2002 elevates to the level of a guideline the obligation of sponsors of research to engage in building capacity for ethical review (in the 1993 CIOMS guidelines, the obligation appeared under a commentary):

> *Guideline 20: Strengthening capacity for ethical and scientific review and biomedical research*
>
> Many countries lack the capacity to assess or ensure the scientific quality or ethical acceptability of biomedical research proposed or carried out in their jurisdictions. In externally sponsored collaborative research, sponsors and investigators have an ethical obligation to ensure that biomedical research projects for which they are responsible in such countries contribute effectively to national or local capacity to design and conduct biomedical research, and to provide scientific and ethical review and monitoring of such research.

The obligation of sponsoring countries and agencies to build capacity for ethical review of research is included as a recommendation in both the NBAC and Nuffield reports. The NBAC report states:

> Recommendation 5.7: Where applicable, U.S. sponsors and researchers should assist in building the capacity of ethics review committees in developing countries to conduct scientific and ethical review of international collaborative research.

INFORMED CONSENT. The second mechanism designed to prevent exploitation of research subjects is the requirement for voluntary, informed consent from each prospective research subject. All ethical guidelines for research include this requirement, which can pose special problems in multinational research in countries in which customs, traditions, and even the concept of a person vary considerably from those that predominate in the North America and Europe. In some developing countries a substantial portion of the population is illiterate or semiliterate. It is clear that the practice of requiring written, signed consent documents when the research subjects are illiterate is inappropriate. For semiliterate subjects, a written consent document may be appropriate, especially because family members whom the subject may wish to involve in the consent process may be literate.

It is important to distinguish between the requirement that a written document be provided to a prospective subject and the requirement that the subject sign the document. In some countries, the meaning of signing a document is quite different from what it is in North America or Western Europe. Even when the need for individual, informed consent is fully accepted, if the country has a history of oppressive regimes, or if people are fearful, based on their experience, that a signed document might be used against them in some manner, it is appropriate for the research ethics committee to waive the requirement of a signature on a consent document (NBAC).

One challenge for researchers who conduct clinical trials in developing countries is how to deal with practices that depart from the requirements of informed consent in the United States and other industrialized countries. These practices include withholding diagnoses from patients who become research subjects (Sugarman et al.; Kass and Hyder) and not disclosing key elements that comply with the substantive ethical standard of informed consent, such as the use of placebo controls, the process of randomizing subjects into different groups in a clinical trial, and the expected efficacy (or lack of efficacy) of a method being tested (Sugarman et al.). Even if the custom of routinely withholding complete information from patients with certain diseases might be defended in ordinary medical practice, it poses a severe challenge to the need to adhere strictly to the ethical standard of disclosure required for research involving human subjects. Potential subjects cannot make an informed decision to participate without knowing that they may not receive a proven treatment that will benefit them. To enroll individuals who are not provided with these key items of information deviates from the substantive ethical standard of disclosure required for adequate informed consent.

A different problem arises when research subjects are unacquainted with the concepts and methods of modern science or biomedical research. These problems are addressed in NBAC's 2001 report, *Ethical and Policy Issues in International Research,* which contains several recommendations on informed consent. Recommendation 3.2 urges researchers to seek creative ways of presenting information, for example, by means of analogies readily understood by the population:

> Researchers should develop culturally appropriate ways to disclose information that is necessary for adherence to the substantive ethical standard of informed consent, with particular attention to disclosures relating to diagnosis and risk, research design, and possible post-trial benefits. Researchers should describe in their protocols and justify to the ethics review committee(s) the procedures they plan to use for disclosing such information to participants. (NBAC, p. 40)

It is not sufficient simply to present the information. An important component of the process is determining whether the prospective subjects adequately understand what they have been told. To this end, NBAC has two recommendations:

> Recommendation 3.4: Researchers should develop procedures to ensure that potential participants do, in fact, understand the information provided in the consent process and should describe those procedures in their research protocols.

and

> Recommendation 3.5: Researchers should consult with community representatives to develop innovative and effective means to communicate all necessary information in a manner that is understandable to potential participants. When community representatives will not be involved, the protocol presented to the ethics review committee should justify why such involvement is not possible or relevant. (NBAC, p. 42)

Some have considered it problematic in cross-cultural contexts to require that informed consent be obtained from each individual recruited as a research subject. This has been described as "philosophically and practically difficult" (Christakis and Levine, p. 1783). The problem is characterized as one in which some cultures lack the individualistic concept of a person to which the Western world adheres, so the question of how to apply the respect for persons principle becomes problematic. Debate on this point is illustrated in the following two positions.

The first holds that researchers should adhere to local customs and traditions regarding individual informed consent, and that it is ethical imperialism to insist on Western requirements in other cultures (Newton). The second maintains the opposite view that individual informed consent is a requirement that should not be eliminated or altered: "We see no convincing arguments for a general policy of dispensing with, or substantially modifying, the researcher's obligation to obtain first-person consent in biomedical research conducted in Africa" (IJsselmuiden and Faden, p. 883).

The Nuffield Council on Bioethics report addresses the tension between respect for culture and respect for persons:

> [W]e cannot avoid the responsibility of taking a view when the two aspects of respect—respect for culture and respect for persons—come into conflict with one another. We are of the view that the fundamental principle of respect for persons requires that participants who have the capacity to consent to research should never be subjected to research without such consent. (Nuffield Council, paragraph 6.22)

Those who would subordinate the respect for persons principle to other considerations have not identified a competing ethical principle that deserves a higher ranking. The unstated assumption that respect for cultural tradition may outrank respect for persons construes respect for cultural tradition as an ethical principle on a par with the following three widely acknowledged principles: respect for persons, beneficence, and justice (National Commission). Although an ethical obligation to be culturally sensitive should be honored, a limit is reached when a cultural practice violates an internationally accepted principle of research ethics.

A different sort of problem arises when it is necessary to obtain permission from a community leader or tribal chief in order to enter the community to embark on research. That requirement has to be respected, but it is no different, in principle, from the need in Western culture to obtain permission from the head of a workplace or a school principal to enter the premises to conduct research. Permission from a tribal chief or village leader may be required but should not serve as a substitute for individual informed consent obtained from each potential subject. The NBAC report contains the following recommendation:

> Where culture or custom requires that permission of a community representative be granted before researchers may approach potential research participants, researchers should be sensitive to such local requirements. However, in no case may permission from a community representative or council replace the requirement of a competent individual's voluntary informed consent. (NBAC, p. 43)

Considerably more problematic is the need to obtain individual informed consent from women in cultures in which the husband or father of an adult woman normally grants permission for her participation in activities outside the home. NBAC's recommendation on this point calls for a presumption to treat men and woman equally in the informed-consent process but allows for a loophole:

> Researchers should use the same procedures in the informed-consent process for women and men. However, ethics review committees may accept a consent process in which a woman's individual consent to participate in research is supplemented by permission from a man if all of the following conditions are met:
>
> a. it would be impossible to conduct the research without obtaining such supplemental permission; and
>
> b. failure to conduct this research could deny its potential benefits to women in the host country; and
>
> c. measures to respect the woman's autonomy to consent to research are undertaken to the greatest extent possible.
>
> In no case may a competent adult woman be enrolled in research solely upon the consent of another person; her individual consent is always required. (NBAC, p. 45)

Here, as in other recommendations, NBAC leaves the ultimate decision on controversial matters to the discretion of the ethics review committee. The Nuffield Council's recommendation on this point is also somewhat flexible.

Unlike the NBAC and Nuffield recommendations, the CIOMS 2002 guidelines do not permit a departure from the need to obtain individual informed consent from the woman only. The commentary under Guideline 16 states:

> [O]nly the informed consent of the woman herself is required for her participation. In no case should the permission of a spouse or partner replace the requirement of individual informed consent. If women wish to consult with their husbands or partners or seek voluntarily to obtain their permission before deciding to enroll in research, that is not only ethically permissible but in some contexts highly desirable. A strict requirement of authorization of spouse or partner, however, violates the substantive principle of respect for persons.

In this, as in other areas of multinational research, what some people take to be ethical imperialism, others consider proper adherence to universally applicable ethical standards.

INDUCEMENTS. In avoiding exploitation when research is conducted in developing countries, there are two important considerations: whether inducements are offered for participation and whether such inducements are undue, that is, so attractive as to diminish voluntariness on the part of subjects who are invited to enroll. When medical treatment is an inevitable part or accompaniment of clinical research, this may provide a strong inducement to enrollment for people without access to medical care. The Nuffield Council report noted that this need not amount to exploitation. The report stated, however, that "when participants are ill and do not have alternative ways of receiving treatment, the possibility for exploitation is greater" (Nuffield Council, paragraph 6.29). The report urged that special care should be taken in determining the type and amount of additional healthcare that may be offered to participants as an inducement.

The NBAC report addresses this concern, distinguishing between, on the one hand, an inducement that may exist because participants receive beneficial clinical care and, on the other hand, the different circumstance that arises out of the "therapeutic misconception"—the belief that the purpose of a clinical trial is to benefit the individual patient rather than to gather data for the purpose of contributing to scientific knowledge. This misconception is widespread even among research subjects in industrialized countries and may be considerably greater in developing countries where people are unfamiliar with scientific research and view medical researchers as healers in whom they place great trust. The NBAC report recommends the following: "Researchers working in developing countries should indicate in their research protocols how they would minimize the likelihood that potential participants will believe mistakenly that the purpose of the research is solely to administer treatment rather than to contribute to scientific knowledge" (NBAC, p. 48).

Guideline 7 of the 2002 CIOMS document permits both monetary payments to subjects as an inducement to participate in research and the provision of free medical services. CIOMS cautions that the monetary payments should not be so great or the medical services so extensive that they induce people to participate against their better judgment. Any payments or provision of medical services should be approved by an ethical review committee.

Crossing National Boundaries: Ethical Standards and Procedural Variations

Different views exist regarding how conflicts between Western cultural conceptions and norms and those of non-Western cultures should be resolved. This raises the question of how ethical standards should be arrived at and whose standards should be adopted. The 1993 CIOMS guidelines included in Guideline 15 a provision intended to prevent exploitation, titled "Obligations of sponsoring and host countries" in externally sponsored research. This guideline required scientific and ethical review of proposed research "according to the standards of the country of the sponsoring agency, and the ethical standards applied should be no less exacting than they would be in the case of research carried out in that country." This provision prompted the criticism that the guidelines reflected a "Western bias" because of "the assumption that the circumstances … in the developed world are the norm. Thus, the developed world is envisioned as more advanced, not only technologically but also morally" (Christakis and Levine, p. 1781).

This criticism is not shared by the many developing countries that by 2002 had enacted laws or adopted ethical guidelines governing research (NBAC). Most provisions in these regulations and guidelines replicate the CIOMS guidelines and the Declaration of Helsinki. All require that informed consent be obtained from each individual research subject, yet, as outlined in these regulations and guidelines, certain procedures for obtaining consent may diverge from the requirement for written, signed informed-consent forms that is included in the U.S. regulations.

Guidelines issued by the Medical Research Council of South Africa in 1993 include two rules regarding informed consent: (1) research subjects should know that they are taking part in research; and (2) research involving subjects should be carried out only with their consent. Yet these guidelines also say: "It can be proper for research involving less than minimal risk and which is easily comprehended to proceed on the basis of oral consent given after an oral description of what is involved." Similarly, the guidelines issued in 2000 by the Indian Council of Medical Research require that informed consent be obtained from each individual subject. But the guidelines also say that the nature and form of the consent may depend on a number of different factors.

The NBAC international report (2001) makes a useful distinction between substantive and procedural ethical requirement in research. Substantive ethical requirements are those embodied in the fundamental principles of bioethics stated in the *Belmont Report:* respect for persons, beneficence, and justice (National Commission). These substantive requirements are the ones that constitute ethical *standards,* and they should be applied universally. Examples are the requirement to obtain informed consent individually from each adult participant and the need to disclose complete information about the research maneuvers to be performed and the expected risks of those interventions. Procedural requirements, on the other hand, may vary according to cultural and other differences in multinational research. Examples include the requirement that informed-consent documents be signed, and the composition of ethical review committees and their rules of procedure. Attention to the distinction between substantive and procedural ethical requirements shows that the same ethical standards can be applied across national borders, while permitting differences in specific procedures in order to respect cultural variations.

Ethical codes and international guidelines are not likely to resolve all questions or conflicts that may arise in proposing, reviewing, and conducting multinational research. Any differences in judgments made by two or more committees that review a research protocol will have to be negotiated. On some points, codes and guidelines may be insufficiently specific. In other respects, provisions in codes or guidelines that address the same point may vary in minor or even major respects. An example of an unresolved conflict is the difference in existing guidelines and recommendations on the use of placebo controls and the level of care and treatment to be provided to research subjects during and after a clinical trial. As long as unresolved differences remain among parties committed to conducting such research according to the highest ethical standards, it is open to question whether ethical codes or guidelines should attempt to settle the conflict by imposing an unequivocal rule.

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SEE ALSO: *AIDS: Healthcare and Research Issues; Anthropology and Bioethics; Epidemics; Human Rights; Informed Consent: Consent Issues in Human Research; International Health; Patenting Organisms and Basic Research; Pharmaceutical Industry; Placebo; Research, Human: Historical Aspects; Research Policy; Scientific Publishing*

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RESEARCH POLICY

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I. General Background
II. Risk and Vulnerable Groups
III. Subjects

I. GENERAL BACKGROUND

Since the 1960s the challenges of human research have received increasing attention and have caused a great deal of concern. In 1966 Professor Henry Beecher captured the attention and aroused the ire of the academic research community in the United States with the disclosure of what he considered unethical research practices at some premier research facilities. Beecher initiated a cycle of disclosure and reaction that has characterized the country’s approach to ensuring the well-being of participants in research for more than four decades (Papworth).

Early Criticisms of Research Procedures

Beecher’s article came at a time when public investment in research and development, particularly in biomedicine and technology, was growing at an unprecedented rate and the prospects for medicine and the future of biotechnology appeared limitless. The boom in private, corporate-sponsored clinical trials had not yet materialized but was not beyond people’s imagination. The disturbing events at the Jewish Chronic Diseases Hospital in New York (Katz), in which a physician scientist injected live cancer cells into unwitting recipients, had been noted by Dr. James Shannon, at that time the director of the National Institutes of Health.

Prompted by that disclosure, in 1966 Shannon moved to require for the first time a mechanism for peer review of proposed scientific research by individuals that was concerned primarily with the well-being and safety of research subjects. However, much of the scientific community remained oblivious or insensitive to the apparent disregard for the safety and the rights of subjects in the research practices of that period. For the first time the scientific community began to realize that scientists could not be allowed on their own to determine how they would conduct experimental studies on other human beings.

The First Cycle of Regulations

Beecher’s article and the monumental work subsequently published by Jay Katz just as the U.S. Public Health Service syphilis study in rural Alabama came to light (Tuskegee Syphilis Study Ad Hoc Advisory Panel) evoked strong emotional reactions among scientists, the public, and government regulators. That scientists working for the government could intentionally, for research purposes, allow poor African-American men to live with untreated syphilis for thirty years after the discovery of safe, effective treatment was appalling. Studies of the transmission of hepatitis in institutionalized children at the Willowbrook School (see Katz) underscored the need for special societal and legal protections of those incapable of protecting their own interests, including children. Many people called for new government regulations to protect the safety of research subjects, and the government responded. Within two years Congress passed the National Research Act of 1974, establishing the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research and laying a course for regulatory action. The act required the U.S. Department of Health, Education and Welfare, the predecessor of the Department of Health and Human Services (DHHS), to codify its policy for the protection of human subjects in the form of regulations.

Almost immediately the perception of scientists and physicians who worked in human research was altered. Activities that once were held in the highest esteem, conducted by individuals who were trusted and respected as much as anyone in society, suddenly were cast in an unflattering light as potential sources of injury and harm from which individuals needed protection despite the potential benefit to humankind of those activities.

The National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research, which conducted its deliberations over a period of several years before it was disbanded in the late 1970s, attempted to define a set of fundamental ethical principles underlying the responsible conduct of human research first for the general population and subsequently for special populations that were deemed to need special protections, notably children, prisoners, pregnant women, and fetuses. The Commission also recognized the special challenges posed by research involving individuals with mental illnesses and impaired decision-making capability, many of whom were institutionalized at the time of the its discussions.

The Commission did not state a preference for any particular philosophy or ideology, although traditional Western values of individual autonomy and justice were reflected prominently in its Belmont Report. The justification of human experimentation and the attendant exposure of individuals to uncertain risks for little or no direct benefit, but for the benefit of science and society is fundamentally utilitarian. At the time of the Commission's work, feminism, consumerism, and communitarian ethics were not yet part of mainstream thinking and thus were not reflected prominently in the debate. The lack of universality of ethical principles across cultures may limit the generalizability of the Commission's recommendations.

Today most parties to the human research process in the U.S. are at least aware of the commission's Belmont Report and are able to name the principles of respect for persons, beneficence, and justice discussed therein (National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research 1979), but this is a relatively recent development resulting primarily from the requirements imposed by the National Institutes of Health (NIH) that all individuals who participate in human research receive *training* in research ethics and regulatory requirements (National Institutes of Health). The fact that members of the research community would seek training in the responsible conduct of human research only as a condition of receiving funding from a federal agency is an unfortunate commentary on the way in which the research community establishes priorities. This pattern of behavior is what many critics and scholars of the human research process have come to expect and has not been lost on legislators.

The bioethicist Carol Levine once said that human research ethics were "born in scandal and reared in protectionism." That quip often is repeated because it resonates with current perceptions of reality. That statement captures the continuing cycle of disclosure and reaction that has characterized regulatory activities at the federal level, beginning with the amendment of the Public Health Service Act in 1974 and the subsequent promulgation of revised regulations by the DHHS for the protection of human subjects in 1981 (Code of Federal Regulations, Title 45, Part 46).

Although frequently cited as a framework for the ethical conduct of human research, those regulations do not constitute a set of ethical principles. The regulations are a set of rules established under the Public Health Service Act that attempt to operationalize the ethical principles set forth in the Belmont Report. They establish the minimum necessary requirements for implementing and maintaining a system for the protection of human subjects in research, including formal requirements for the establishment and operations of institutional review boards and the processes for obtaining and documenting informed consent, as recommended by the National Commission in 1978.

The DHHS expended considerable effort in crafting those regulations so that they would allow enough flexibility to encompass the wide variety of biomedical, behavioral, and social research it supported. The regulations reflected a well-intended effort to ensure that the ethical principles delineated in the Belmont Report would be applied in a uniform and appropriate manner by all recipients of federal research funds. Unfortunately, the DHHS was unable to establish a uniform set of regulations governing the oversight of all human research under its jurisdiction, most notably excluding privately sponsored clinical trials of new drugs, devices, and biologics performed under the regulatory authority of the U.S. Food and Drug Administration (FDA), which operates under a separate statutory authority, the Food Drug and Cosmetic Act of 1972. Those studies are covered by separate regulations (Code of Federal Regulations, Title 21, Parts 50 and 56) that are substantially similar to but more narrowly focused on clinical investigation than are the Public Health Service regulations. The lack of a uniform oversight process and standards has probably contributed to inconsistent and ineffective implementation and noncompliance with the regulations. This situation has been and is likely to continue to be a source of confusion and frustration to individual investigators, sponsors, institutions, and review boards that attempt in good faith to comply with the requirements of the often overlapping regulations and oversight processes that apply to their activities.

The Common Rule

The situation in the DHHS is compounded in other federal agencies. In 1991 sixteen agencies adopted 45 CFR 46 Subpart A, the main body of the DHHS's regulations, as signatories to the common Federal Policy on Protection of Human Subjects in Biomedical and Behavioral Research, informally known as the Common Rule. Many of those agencies, including the National Bioethics Advisory Commission (2001c), had noted previously that it had taken a full decade for some of the federal agencies to sign on to those important regulations, yet not all federal agencies have done that, including some that engage in or support human research. Those that have adopted the Common Rule do not always agree fully on the interpretation and application of the regulations and some continue to impose specific additional regulatory and administrative requirements of their own. Thus, research entities and individuals have been left to reconcile the differences as best they can, often with little specific guidance, support, and cooperation from the various federal agencies involved in the support and oversight of human research activities.

Both investigators and institutions, including their review boards, have complained that the complexity and inflexibility of the regulations have made it difficult for them to comply. Although these are contributing factors, there are more likely explanations for the widespread noncompliance discovered when the former Office for Protection from Research Risks (OPRR) began a series of not-for-cause site visits to major research institutions across the country in the late 1990s. The 1998 reports from the Office of Inspector General offered insight into the nature of the problems in the system by noting that institutional review boards "review too much too quickly, with too little expertise" (p. 5). The report also notes the inadequacy of resources provided to support their work.

Problems in the Implementation of the Regulations

Apparently, while implementing the requirements of the regulations, institutions that received research support failed to invest adequately in robust programs for the protection of human subjects despite dramatic growth in their research budgets and their assurances to the government that they would do so.

At most of those institutions funds to support programs for human research protection were allocated to so-called indirect costs as an administrative activity. Within the indirect cost pool the allocation for administration and facilities costs had been capped by the federal Office for Management and Budget (OMB) at 26 percent of the direct costs of research after some institutions had been discovered using those funds for unallowable expenses. As healthcare reform began to affect the flow of clinical revenues that could be used to subsidize research activities, funding for programs for human research protection were marginalized further and in many cases minimized. The overriding goal seemed to be to achieve regulatory compliance at the lowest possible cost. Accordingly, many institutions relied heavily on volunteers (or "conscripts") and part-time personnel, many of whom had little or no formal training in research ethics or regulatory affairs, to fulfill those important responsibilities.

Although it is easy to lay the blame for this situation on the research institutions, that would be unfair. From the outset research institutions, which did not ask for those regulations, considered the required implementation of programs for human research protection an unfunded or at least underfunded federal mandate. The dramatic growth in corporate-sponsored clinical trials that rely heavily on those programs, which was only beginning when the regulations first were adopted, may warrant the consideration of a mechanism through which industry can offset the associated costs at arm's length from the review and approval process as part of a comprehensive funding scheme for human research oversight.

However, without knowledge of the actual costs associated with implementing and maintaining effective programs for the protection of human research subjects, the allocation of appropriate funding for those programs is unlikely if not impossible. Few credible attempts have been made to measure those variables since the 1970s. The little information that is available regarding those costs reflects at best an estimate of what was being expended to support programs of questionable efficacy. Because there is no well-established approach to measuring efficacy, it is unlikely that a rational formula for supporting those programs will emerge in the near future despite the pressing need to develop one.

Public and Private Reports

The current state of dissatisfaction and anxiety that affects almost everyone in the human research enterprise is not a new phenomenon. Almost immediately after the adoption of the DHHS's regulations for the protection of human subjects in 1981, the first of what was to become a long series of reports on the challenges of human studies was issued in 1982 by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. In the same year a report was issued by the Council for International Organizations of Medical Sciences (CIOMS). That report was followed in 1993 by the report of the President's Advisory Committee on Human Radiation Experiments, several reports from the National Bioethics Advisory Commission (1998, 1999, 2001a, b, and c), the General Accounting Office (1996, 2000, 2001), the Office of Inspector General of the DHHS (1998–2001), the recently disbanded National Human Research Protections

Advisory Committee (2001), and the Institute of Medicine (1994, 2002). Many private organizations have issued reports or guidelines, including the Association of American Universities (2001), the Association of American Medical Colleges (2001), the American Association of University Professors (2001), the American Academy of Pharmaceutical Physicians (2001), the American Medical Association (2000), the American Society for Gene Therapy (2000), the American Society of Clinical Oncology (2002), and the Association of Clinical Research Professionals (2001).

This array of reports covers ethics, regulatory affairs, financial relationships, conflicts of interests, and the responsible conduct of research. Generally, all the reports recognize and emphasize the dependence of human research on the willingness of individuals to participate voluntarily as subjects, acknowledging the key role that trust plays in the relationship between investigators and subjects. They acknowledge the fact that past and present events have undermined that sense of trust and that steps must be taken to rebuild and maintain it. They all offer recommendations, most of which are consistent or at least compatible, yet most observers agree that little progress has been made since the 1970s in implementing those recommendations apart from the adoption of the regulations and the implementation of institutional review boards and informed consent as the "twin pillars" of protection for human subjects. Some people think that those recommendations afford more of an impediment to research than effective protections for human subjects. Many are perplexed that it seems so hard for the scientific community and the government to do what is morally and legally appropriate when doing so is clearly in the interest of science and society.

The Ethical Issues in Human Research

There is no simple solution to this problem, which involves a complex interplay of ethics, economics, and expediency in a system affected by people, politics, and profits. The most fundamental issue is the moral dilemma inherent in human research: In all cases of human experimentation individuals are subject to risks for the benefit of science and society. Human research is an endeavor that exploits some individuals for a greater good, but that exploitation is considered acceptable and even justifiable as long as participation is voluntary and informed and the research is conducted within the well-established ethical framework of respect for persons, beneficence, and justice.

Human research entails a dynamic tension between the interests of those who do research and the interests of those on whom research is done. Can science and society justifiably place their own interests above the interests, rights, and well-being of research subjects? More correctly, should the interests of science and society prevail over those of individual subjects? Even if one identified compelling circumstances in which it would be ethically permissible to do that, those cases probably would be rare. However, it is tempting and easy to allow the pursuit of knowledge, the lure of fame and fortune, advantage in the marketplace, and the chance of academic promotion to color one's judgment and influence one's conduct.

The events the past three decades in which subjects have been harmed and misconduct revealed have shown that not all scientists, institutions, and sponsors are immune to temptation. Breaches of responsible conduct may go unnoticed and unreported, but when they are serious and are discovered and criticized, they evoke a host of reactions, including sorrow, anger, indignation, and defensiveness. The consequences of those breaches are far-reaching and long-lasting, leaving no party untouched. The corrective actions that follow may provide long-term benefits but are painful and costly in both human and financial terms.

The Deaths of Jesse Gelsinger and Ellen Roche

No two cases more aptly illustrate these points than the deaths of Jesse Gelsinger at the University of Pennsylvania in 1999 and Ellen Roche at Johns Hopkins University Medical Center in 2001. Gelsinger, suffering from a genetic metabloic disorder, died in a gene-transfer study just days after receiving an infusion of a corrected gene attached to a virus intended to introduce the new gene into his liver cells. Roche was a normal healthy young woman participating in a study of the mechanisms of airway responsiveness, a study that required inhalation of a chemical that blocked certain pathways of nerve transmission. The second case has been described (Steinbrook) and analyzed (Kreiger and De Pasquale) extensively. The death of Jesse Gelsinger was a critical event because it catalyzed a coalescence of will in the government and public to face the problems of human research directly, particularly the potential impact of financial relationships and conflicts of interests on the well-being of research participants (Shalala).

The Roche case eventually may have an even more far-reaching impact. It is particularly relevant because it involves a failure to protect research participants adequately not only at the level of an individual study but also at the level of an institutional system as judged not only by government regulators but also by an external evaluating committee of peers selected by the institution. In this case attention was focused not just on an individual's untimely death, the failings of a single investigator, the shortcomings of an institutional review board, and a deficient institutional system for the protection of human subjects: The focus ultimately became the culture of the institution and more generally the culture of science as it relates to the responsible conduct of human research. The message here is the need to move beyond a culture of compliance to a culture of conscience in science (Koski, 2003a).

Resistance to Change

Since the Renaissance the pursuit of knowledge through science has been regarded as a noble profession. Recognizing the importance of the pursuit of truth in science, one might expect scientists to be intolerant of those among them who fail to respect truth or undermine the integrity of science. However, in this regard perception and reality sometimes diverge. Statements of ethical principles and codes of conduct have done much to guide the scientific community, along with the medical profession, in the pursuit of truth, but some members of those professions betray the truth. When a profession is willing to tolerate rather than hold accountable those whose behavior violates the principles and traditions of the profession, the credibility of the principles on which the profession is established are undermined. *Pseudoaccountability,* a term coined by a Jerome Kasirer, results in a profession that traverses the road of good intentions but does not arrive at its destination.

Accounts of Beecher's efforts to publish in the medical literature his concerns about the ethics of research studies conducted in the early 1960s suggest that that was not an easy task. Initial rejections finally gave way to an agreement with the editor of the *New England Journal of Medicine* to publish the paper only after Beecher agreed to limit the number of cases to a small fraction of those about which he was concerned and to withhold identification of the investigators and their institutions. As a respected physician, scientist, and professor at Harvard Medical School Beecher demonstrated courage and integrity in attempting to bring those issues before his peers, but many in the scientific community did not receive his paper enthusiastically.

One can only wonder how human research might be different today if the scientific community at that time had responded with a concerted effort to achieve a higher standard of conduct, promoted integrity with an expectation that all who engage in research involving other human beings would act in accordance with the highest ethical standards, and shown a willingness to hold accountable those who did not live up to those standards. If the scientific community rather than the government had taken action to ensure the well-being of research participants not because it was required to do so by regulations but out of concern for the integrity of science, the continuing pursuit of knowledge, and an earnest desire and commitment to prevent harm to fellow human beings while honoring the rights of others, there might not be regulations on the books requiring them to do so.

Laws and regulations are one way in which a society attempts to influence the behaviors of its citizens. Regulations may be used to prescribe certain actions and prohibit others. However, regulations can be a double-edged sword.

In a 2003 article published in the *Emory Law Journal* Robert Gatter discusses the normative and expressive functions of the law in the context of regulations that address continuing concerns about financial conflicts of interest in human research. Many laws are not directed toward criminal activity, but seek to establish a recognized norm of conduct, and to do so by expressing the normative message through regulations and guidance. The regulations for the protection of human subjects in research are analogous to those involving financial conflict in that they are intended to establish a norm of conduct for investigators and institutions through the expression and application of the ethical principles delineated in the Belmont Report. Laws, however, do not always achieve their desired goals, particularly if the regulated community is resistant to acceptance of the normative standard and the implementation or enforcement provisions make it unlikely that noncompliance will be discovered or punished. As Gatter points out, regulations can evoke "juridification," by which those who are subject to regulations try to find ways to avoid or circumvent them rather than embrace them. Although scientists and physicians may be no less hostile to regulation of their activities than are others, one might expect them to more readily accept such regulation in light of their codes of professional conduct that already express values compatible with those embodied in the regulations.

Since the 1970s researchers have worked within a regulatory framework in which the regulated parties too frequently have viewed the requirements of the regulations as unnecessarily complicated, costly, and onerous administrative impediments to their research activities. That viewpoint, which seems to contrast markedly with the values that society traditionally associates with scientists and the pursuit of knowledge, may reflect changes in the culture of science that occurred in the second half of twentieth century or may indicate significant juridification, to use Gatter's terminology, of the human research community in response to the imposition of regulations by the government in response to a limited number of high-profile breaches of responsible conduct.

There is no question that the American system for the responsible conduct of human research and the protection of human subjects is undergoing dramatic change. It may be far more difficult to effect cultural change that requires behavioral changes consistent with acceptance of fundamental values than it is to overcome and reverse the juridification that has occurred in response to failures in the normative and expressive functions of the applicable law and regulations.

New Initiatives

The death of Jesse Gelsinger launched a new cycle of reform in human research and the protection of the human subjects. Although the initial calls were for more stringent regulations and penalties, the DHHS, with strong leadership from the former secretary, Donna Shalala, has taken a different course. In June 2000 the department established a new Office for Human Research Protections (OHRP), replacing the Office for Protection for Research Risks. The new office was placed within the office of the secretary to give it the visibility and autonomy necessary to lead a major remodeling effort to improve the performance and effectiveness of the national system for the protection of human subjects in research. The strategy and approach taken by the DHHS were outlined in September 2000 in testimony delivered before the House Oversight Committee on Veterans Affairs (Koski, 2000).

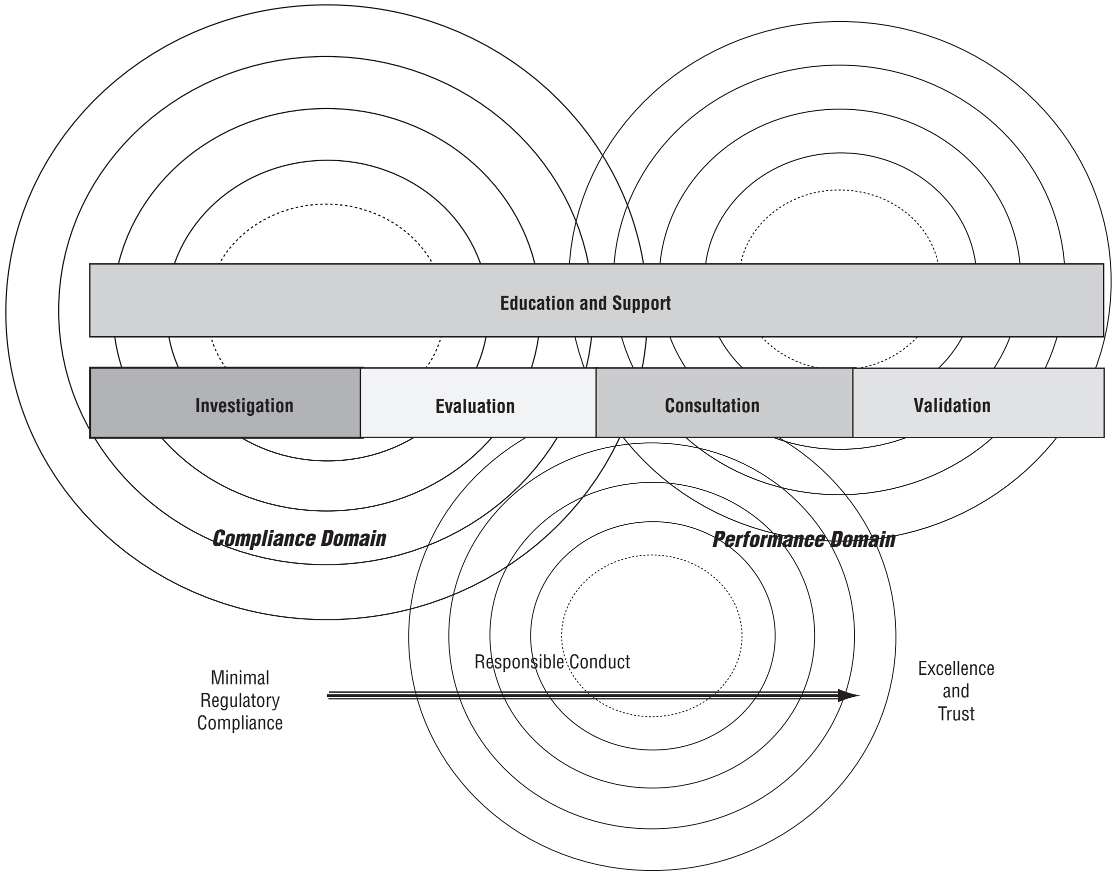
Those initiatives mark a shift from a reactive, compliance-focused approach to the oversight of human research toward a proactive model focused on the prevention of harm. Recognizing the widely varying and sometimes idiosyncratic behavior of local institutional review boards, the new approach emphasizes education and support as the umbrella under which activities aimed at improving performance are conducted (Figure 1). The goal of current efforts is to move from an approach focused on achieving regulatory compliance to one that attempts to achieve excellence and trust. In this model activities to ensure the well-being of research participants are conducted in two primary domains: the compliance domain and the performance domain. The compliance domain includes both for-cause investigations and not-for-cause evaluations. Both types of compliance oversight activities are intended to ensure accountability and fall generally into the class of quality control and quality assurance processes. In this model the identification of deficiencies should be focused on system failures in an attempt to strengthen processes rather than use punishment or sanctions except in cases of gross negligence or willful disregard for regulatory requirements, thus avoiding the counterproductive impact of a reactive, juridifying approach to regulatory enforcement. Traditionally, these activities have been conducted primarily by government oversight agencies or parties acting on their behalf. Activities within the performance domain generally are classified as quality improvement activities, including continuous quality improvement, largely in the form of consultation and feedback on actual performance. Objective validation processes such as accreditation of institutions or programs and professional certification of individuals provide empirical evidence of proficiency and recognition of excellence. Education and support are overarching activities that work to improve the effectiveness and efficiency of the system. Realization of positive results and appropriate validation of excellence provide incentives to shift resources toward the performance domain. Ultimately, prevention of harm to human participants through responsible conduct builds trust and promotes public confidence in the research process, enhancing voluntary participation in research. Those activities are focused on improving, measuring, and validating the performance of the system in its entirety, utilizing proven continuous quality improvement methods to achieve those goals (Institute of Medicine, 2002).

In the past the government generally waited until it received a complaint from an outside source or a report from one of the institutions under its regulatory authority to initiate an investigation into the circumstances of an event. Those for-cause investigations, many of which were conducted through correspondence alone, were the mainstay of the OPRR's oversight activities. The bulk of its resources were dedicated to review, negotiation, and approval of assurances, documents submitted by entities receiving federal support for research to satisfy regulatory requirements that such a document be filed as a condition of receiving support. Too often those were empty assurances, paper commitments insufficiently backed by substantive actions and resources.

The creation of the OHRP added significant new resources to the office and a reorganization plan that redirected those resources toward enhanced educational programs and the development and implementation of a new quality improvement program through which the office provides consultation and support for institutions that seek to improve their programs for human research protection.

FIGURE 1

An Outcome-Focused Systems Approach to Responsible Conduct of Human Research



SOURCE: Author.

To a large extent that redistribution of resources was made possible by a dramatic simplification of the assurance process. Rather than continue the long-standing practice of negotiating and processing multiple types of assurances and interagency agreements, the office adopted a single standardized federal assurance that could be utilized by all participating federal agencies and was consistent with the original intent of the Common Rule. Significant progress is being made toward establishing a more effective system for the protection of human subjects in research (Koski, 2003b) despite the fact that the regulations adopted since the 1970s remain essentially unchanged. In large measure this progress is a direct result of a renewed willingness in the research community to adopt a more proactive, responsible approach toward the conduct of its activities. Whether this progress continues will be a principal determinant of the nature and scope of future regulatory actions in the area of human research.

GREG KOSKI

SEE ALSO: *Aging and the Aged: Healthcare and Research Issues; AIDS: Healthcare and Research Issues; Autoexperimentation; Autonomy; Children: Healthcare and Research Issues; Commercialism in Scientific Research; Embryo and Fetus: Embryo Research; Empirical Methods in Bioethics; Genetics and Human Behavior: Scientific and Research Issues; Holocaust; Infants: Public Policy and Legal Issues; Informed Consent: Consent Issues in Human Research; Law and Bioethics; Mentally Ill and Mentally Disabled Persons: Research Issues; Military Personnel as Research Subjects; Minorities as Research Subjects; Paternalism; Pediatrics,* *Overview of Ethical Issues in; Public Policy and Bioethics; Prisoners as Research Subjects; Race and Racism; Research, Human: Historical Aspects; Research Methodology; Research, Multinational; Research, Unethical; Responsibility; Scientific Publishing; Sexism; Students as Research Subjects; Virtue and Character;* and other *Research Policy* subentries

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II. RISK AND VULNERABLE GROUPS

There are two groups of people considered to be vulnerable research subjects. First, people lacking capacity to give informed consent are vulnerable because they depend on others to protect them, such as young children and adults impaired by trauma, illness, retardation, or dementia. Second, people who are likely to be coerced or manipulated are vulnerable because fear, ignorance, or pressure may account for their agreement to participate. Institutionalized persons, prisoners, members of the military, students, hospital staff, laboratory assistants, and pharmaceutical personnel are frequently cited as vulnerable to coercion or manipulation (U.S. Public Health Service; CIOMS). In addition, the indigent, uninsured, or desperate may be unduly tempted into study participation that they would otherwise reject by financial remuneration. Insofar as participation of vulnerable subjects is problematic, enrolling them in research protocols often requires special justification and safeguards (CIOMS; "Protection of Human Subjects," 45 C.F.R. 46).

Dilemmas of Inclusion vs. Exclusion

It is important to include all segments of society in research, including vulnerable people, so that everyone benefits from research studies. Yet dangers exist in both too many and in too few protections. When too few protections exist, vulnerable people may be exploited. When too many protections exist, however, it is hard to conduct research with vulnerable populations; consequently there is little information about how to diagnose, treat or understand their conditions. Without good research information, people from these groups become neglected. Doctors must then choose between using only modalities that have been tested on the group in question and risk undertreating these subjects, or using untested interventions and risk adverse effects. There are several ways to address this apparent dilemma, and many guidelines adopt some combination of them.

First, all research guidelines require studies to have a strict review by boards known by various names: institutional review boards (IRBs), research ethics committees (RECs), or ethical review committees (ERCs). These boards have discretion to disapprove or approve studies or to adopt suitable additional protections for studies with all or some vulnerable subjects. These committees should be sensitive to various forms of vulnerability (cognitive, environmental, institutional, deferential, medical, economic and social) and respond with appropriate and situationally-appropriate restrictions. The National Bioethics Advisory Commission (NBAC), which carefully distinguishes these different forms of vulnerability, relies upon review board discretion to protect vulnerable subjects because it is flexible (NBAC). But this option has been undermined by high-profile revelations of poor oversight or compliance by some of these review boards. Moreover, confidence in these boards varies according to people's perceptions of whether they represent the interests of vulnerable populations or are seen as favoring the research enterprise or commercial interests.

Second, others favor another approach with special regulatory requirements that must be met before enrolling some or all vulnerable subjects. Such regulations generally exist for infants, children, pregnant women, and prisoners. But critics argue that expanding regulations for other groups could become unwieldy since many, perhaps even most, people may be perceived as vulnerable in some situations (NBAC). If special regulations existed for all or most groups of people who might be vulnerable, it could become unreasonably difficult to approve or conduct research. Moreover, some competent persons, such as pregnant women, object to special restrictions placed upon their freedom of choice.

Third, some guidelines limit risk when subjects are deemed vulnerable. The Food and Drug Administration (FDA, 1997, 4.8.14) stipulates that, when people cannot give consent for trials that do not directly benefit them, risks must be low and other considerations must be fulfilled (i.e., the study cannot be conducted with consenting subjects, consent is obtained from subjects' legal representatives, IRB approval is gained, the negative impact on the subjects is minimized and low, and the study is not illegal). The Council for International Organizations of Medical Science (CIOMS) limits the risk of harm to vulnerable subjects to a "minimal risk," unless the study offers direct benefit to subjects; in some cases a minor increase over minimal risk is permitted in order to study vulnerable people's disorders or conditions. Critics argue that this policy unreasonably restricts people's choices and opportunities, especially when the vulnerable people are competent adults. As noted, NBAC objects to this proliferation of regulations and maintains that once review boards put safeguards in place, vulnerable subjects should be enrolled in studies on the same basis as other subjects.

While these research approaches suggest some similar ways to protect vulnerable people, the moral and policy issues differ greatly for those who are not legally competent and those who are. NBAC describes these two groups' vulnerability as "intrinsic" and "situational," respectively, and CIOMS refers to them as "absolute" and "relative." Yet this language is misleading. First, many children and legally incompetent adults have the capacity to participate in some tasks but not others, so they are neither "absolutely" nor "intrinsically" incompetent; if they have the capacity to assent, which refers to their permission and is a notion different from legal consent, it generally should be sought for research participation. Second, it is misleading to call people either absolutely or intrinsically incapacitated when, for many members of these groups, capacity fluctuates or it grows, as it does for most for children. Third, legally competent persons may view additional protections and restrictions as unjustified paternalism that places obstacles in their path to gain participation in research on the same basis as others; they deny that their situation or relations make them vulnerable. Because the issues are so different for the two groups, their policy options are discussed separately.

Competent Adults Vulnerable to Coercion and Manipulation

There has been some consensus, at least in theory, about how to protect the rights and welfare of competent adults who are vulnerable to coercion or manipulation. First, since the right to consent is grounded in its utility, fairness, and the right of self-determination, studies should be reviewed to ensure that consent is voluntary and that the risks of research are not unfairly distributed to vulnerable groups (CIOMS; "Protection of Human Subjects," 45 C.F.R. 46). This evaluation should be conducted by IRBs, RECs, or ERCs. Review boards bear a heavy responsibility in recognizing when competent persons may be vulnerable and need additional protection as research subjects. The views of reviewers, however, may differ from those of the potential subjects. One remedy is to assemble a group of prospective subjects and conduct a group consultation to learn their views.

Second, most review boards, investigators, and bioethicists agree that the greater the vulnerability and risk to competent adults, the more specific protections should be adopted; where it is difficult to supervise the voluntariness of vulnerable people's consent, it may be necessary to adopt special regulatory protection. For example, because prisoners live in settings that are inherently coercive and because of past abuses, most guidelines provide additional protections for this population (CIOMS; U.S. "Protection of Human Subjects," 45 C.F.R. 46 Subpart C). In general, research guidelines limit the risk of harm to prisoners to a minimal risk unless the study offers direct benefit to the prisoner subjects (individually or as a class) and requires demonstrated utility, special safeguards, experts' approval, and authorization from the U.S. Secretary of Health and Human Services. In some cases a minor increase over minimal risk is permitted to study their disorders or conditions. These restrictions make biomedical research with prisoners difficult to justify, because there are no diseases unique to them as a class. Given their extraordinary living conditions, however, social or behavioral studies might gain approval.

A third area of general agreement about protecting vulnerable competent adults from coercion or manipulation concerns the importance of avoiding interference with people's self-determination or unjustified paternalism. There is less consensus, however, on how to do this. Competent people may resent paternalistic restrictions of their liberties because someone views them as potentially vulnerable. People may deeply object to being denied options open to others, such as innovative or subsidized care for their illnesses in research programs. Impoverished people, including students, may willingly volunteer for risky studies that pay well. They may argue that if firefighters or fighter pilots receive high pay for taking risks, civilians, too, should have the choice to obtain high pay for taking research risks. They may object to the views of some that payment, other than expenses and tokens, constitutes undue influence and should be prohibited (CIOMS).

DISPUTES ABOUT INCLUDING WOMEN. Perhaps the greatest sustained debate has been over limiting the research options for women of childbearing years or women who are pregnant. One dilemma, as noted, is that if some group is excluded from studies, then it is hard to provide good treatment options for them. Pregnant women have diseases and conditions that need study for their own sakes as well as for the sake of their fetuses. At issue is who makes the decision, the woman herself or others.

In many but not all guidelines, women of childbearing years and especially pregnant woman are listed as "vulnerable" and sometimes denied opportunities open to others. In its instructions to the IRB, for example, the U.S. federal regulations state that: "When some or all of the subjects are likely to be vulnerable to coercion or undue influence such as children, prisoners, pregnant women, mentally disabled persons, or economically or educationally disadvantaged persons, additional safeguards have been included in the study to protect the rights and welfare of these subjects" (U.S. "Protection of Human Subjects," 45 CFR 46.111[b]). The U.S. Public Health Service's "Consultation on International Collaborative Human Immunodeficiency Virus" also includes pregnant and nursing women on their list of possibly vulnerable groups. The goal of these guidelines is to protect the fetuses, newborns, and pregnant and nursing women from research risk. Such policies are controversial since there is no uniform agreement about how to rank duties to protect the women and her fetus and duties to also honor women's rights of self-determination.

Many regulations view pregnant women and those of childbearing years as "vulnerable" and favor more regulatory protections, even if they restrict women's options. These restrictions include limiting the array of studies in which they can participate to those designed to benefit them or their fetus, or those having low risk and requiring their husbands' consent as well as their own. In the United States, for example, research with pregnant women designed to benefit the fetus requires the consent of the father (unless he is unavailable, incompetent, or incapacitated, or the pregnancy resulted from rape or incest). (U.S. CFR 45 46.203 [e]).

Pregnant women's illnesses need to be studied, and it is not in their interests if regulations make this difficult. For example, without research pregnant women are denied the benefits of learning about how drugs affect them as a group. Second, participation in research may be a woman's only or best means to gain access to subsidized care or to investigational drugs or therapy, so restrictions deny them options or direct benefit that are available to others. It may be an unfair denial of benefits to rule that women cannot be considered as subjects. Third, it seems unfair that men of reproductive age are not similarly excluded from drug studies; yet many drugs cause changes in male germ cells that are mutagenic.

A consensus is developing that where there is a conflict between the health needs of the mother and that of the fetus, the mother should be at liberty to resolve the conflict herself (CIOMS; U.S. 45 C.F.R. 46 Subpart B). Restrictions to protect the fetus sometimes rest upon poorly founded assumptions about what might cause harm to the fetus. Informed consent from any woman, however, presupposes that she is informed of the likely harms or benefits, including those that effect her fetus. Pregnancy and nursing make women neither incapable of consent, like children, nor vulnerable to coercion or manipulation, like students and prisoners.

CIOMS does not automatically include women as vulnerable subjects, separating guidelines for vulnerable groups and those for women. It states that vulnerable subjects are those "incapable of protecting their own interests … they may have insufficient power, intelligence, education, resources, or other needed attributes to protect their own interests" (CIOMS, Guideline 13). For vulnerable persons or groups, CIOMS limits the risk of harm to a minimal risk unless the study offers direct benefit to them; in some cases a minor increase over minimal risk is permitted to study vulnerable people's disorders or conditions. In Guideline 16, CIOMS states, "Investigators, sponsors or ethical review committees should not exclude women of reproductive age from biomedical research. The potential for becoming pregnant during a study should not, in itself, be used as a reason for precluding or limiting participation." In CIOMS's commentary on these guidelines, the committee notes that the general presumption should be to include women and that past practices of excluding them is unjust, but that "it must be acknowledged that in some parts of the world women are vulnerable to neglect or harm because of …social conditioning to submit to authority.…" CIOMS also takes a stand on seeking consent from husbands: "In research involving women of reproductive age, whether pregnant or non-pregnant, only the informed consent of the woman herself is required for her participation. In no case should the permission of a spouse or partner replace the requirement of individual informed consent … A strict requirement of authorization of spouse or partner, however, violates the substantive principle of respect for persons." Thus, CIOMS favors women's rights of self-determination and their needs to have drugs and other interventions tested on them. NBAC agrees, and even goes beyond CIOMS, arguing that once review boards put safeguards in place, women and other potentially vulnerable subjects should be enrolled in studies on the same basis as other subjects.

Thus, when vulnerable people are competent, disagreements abound concerning what specific restrictions on their choices are fair, promote their well-being, and respect their self-determination. Too little protection risks their exploitation; too much protection risks unjustified paternalism.

Before limiting the liberty of competent people, reviewers and researchers should use community consultation with members of the potentially vulnerable group to consider if they want such protection, if the probability and magnitude of harm warrants constraints, and if the restrictions are the least invasive to secure their well-being.

People Lacking Capacity to Give Consent

As with the competent people, the ethical basis for research policy with persons lacking capacity to give informed consent concerns promoting their self-determination, fair treatment, and well-being. There are four important policy options that were adopted in the twentieth century, and each offers different approaches to ranking what is fair, most protective of incompetent people's well-being, and most respectful of whatever self-determination they have or may develop. These four policies represent different regulative ideals because they rank these primary values differently, and because they offer different authority principles (stating who decides) and guidance principles (substantive directions about how decisions should be made). The remaining discussion will focus on these options.

THE "SURROGATE" OR "LIBERTARIAN" SOLUTION. The oldest policy adopts no special regulatory protection for people lacking the capacity to consent, and allows the same sort of research with them as with other subjects, if their legal guardians consent. Since guardians have the authority to choose the mode of care, religion, and schooling for their dependents, then, according to this view, guardians should determine whether their charges participate in research.

Critics argue that guardians have no authority to volunteer another for studies that are hazardous or that do not hold out benefit for them (Ramsey; Levine; Kopelman, 1989). Guardians have authority insofar as they promote the well-being of those under their care and prevent, remove, or minimize harms to them. They have discretion about how to do this. In nonresearch settings guardians can allow their children or wards to participate in dangerous activities, such as football, presumably because in their judgement there are also direct benefits to them. This differs from volunteering them for risky research, however, when there are no direct benefits to compensate for the risks and where others benefit from that information. Volunteering to put oneself in harm's way to gain knowledge may be morally admirable. But volunteering to put another in harm's way is not admirable, and violates the guardian's protective role. Critics argue that allowing guardians to enroll their charges in potentially harmful experiments wrongs the charges, sets a dangerous precedent, and has a brutalizing effect upon society.

THE "NO CONSENT-NO RESEARCH" OR "NUREMBERG" SOLUTION. Another policy forbids enrolling people as research subjects without their consent. This view is maintained in the first international research statement, the Nuremberg Code. Its first principle states, "The voluntary consent of the human subject is absolutely essential." It goes on to define consent—in a way that has become fairly standard—as requiring legal capacity, free choice, and understanding of "the nature, duration, and purpose of the experiment; the methods and means by which it is conducted; all inconveniences and hazards reasonably to be expected; any effects upon his health or person which may possibly come from participation in the research" (Germany Military Tribunals).

Composed at the end of World War II, the Nuremberg Code stands as an international response to the horrible, involuntary medical studies done by Nazi physicians in which many unwilling subjects and prisoners were killed or permanently maimed (Proctor). It is uncertain if it was intended as a comprehensive code for research (McCormick). If it is taken as a general policy, however, subjects who lack capacity to give informed consent cannot serve as research subjects.

Critics argue that this policy would cripple evidenced-based medicine for people who cannot give consent, turning them into "therapeutic orphans" (Shirkey; McCormick; Levine). Children, retarded persons, and those incapacitated by mental illness have unique medical problems; thus, studies with normal adult volunteers may be inapplicable. Normal adults cannot serve as subjects in studies comparing treatments for schizophrenia, bipolar illness, or lung disease in premature infants. To test the safety and efficacy of many standard, innovative, or investigational treatments for distinctive groups, and give them due consideration, some members of the groups have to be subjects in controlled testing.

THE "NO CONSENT-ONLY THERAPY" SOLUTION. A third policy permits persons who lack the capacity to give informed consent to be enrolled as research subjects if the studies are therapeutic and offer at least as much direct benefit to subjects as other alternatives, and if guardians consent. This view was represented in the next major international code for research to follow the Nuremberg Code, the World Medical Assembly's Declaration of Helsinki, written in 1964 and revised in 1975, 1983, and 1989. (The Declaration's 2000 revision abandoned the "no consent-only therapy" stance after many years.)

This policy option distinguishes *clinical* or *therapeutic research* (studies seeking generalizable knowledge and intending to provide medically acceptable therapy for the individual) from *nontherapeutic biomedical research* (studies seeking generalizable knowledge and not intended as therapy to benefit the individual directly). Therapeutic studies attempt to benefit the person through prevention, diagnosis, or treatment of disease. Thus, drawing the line at therapeutic research for people who lack capacity to give informed consent seems to defenders to be a good solution to the problem of when to permit incompetent people to serve as subjects (Ramsey).

One difficulty with this third option concerns the difficulty of classifying studies as therapeutic or nontherapeutic in a way that is not arbitrary or misleading. Therapeutic studies often have features that are not a part of routine therapy, such as extra tests, inflexible research protocols, and additional hospitalizations, or visits to the doctor. If these nontherapeutic features increase costs, risks, or inconvenience to the patient, classifying the study as therapeutic may be arbitrary and misleading. Moreover, this classification can be misleading if people assume therapeutic studies are always safe or beneficial. They may have a “therapeutic misconception” based on such labels. Labeling something as “therapeutic” may mask risk, inconvenience, costs, or nonbeneficial features, creating an inappropriate bias for participation.

A second problem is that it seems unreasonable to prohibit important low-risk research especially when it offers nontherapeutic direct benefits to subjects or allows progress for these groups. Subjects would be neither harmed nor wronged if they gained from the experience, liked participating, and were not at risk of harm. Children may enjoy and learn from participating in nontherapeutic studies in which they are asked to do such things as stack similar blocks or identify animals from sounds they make. Yet these nontherapeutic studies could be important for establishing criteria of normal vision and hearing. Adults who are not legally competent may also enjoy and learn from serving as research subjects in nontherapeutic studies. For example, they might like an outing to a research facility, meeting the investigators or learning about the study. In addition, they can benefit indirectly from nontherapeutic studies.

Because this option rules out even low-risk studies it seriously impedes medical progress for these groups including the formation of standards about children’s typical growth and development. Such standards presuppose carefully tested criteria distinguishing people with developmental delays or impairments from those with normal growth and development. Establishing such norms requires collecting and analyzing data on the growth and development of large numbers of healthy children. Such safe but important research, however, is forbidden under this policy because it is not therapeutic. Even though these studies establishing norms for growth and development are safe, they are nontherapeutic because they are designed not to benefit the subjects directly but to gain generalizable knowledge. If children stack blocks at play, it is not research; if people test views about how they stack blocks, it is research but may be no more burdensome to the child. Thus, when nontherapeutic studies are needed to promote the well-being of incompetent people as a *group,* and involve little or no risk of harm or inconvenience to them, it is hard to understand how critics can make the case that the subjects are always harmed or wronged by participation.

This option also prohibits epidemiological studies and the investigation of the natural history of disease when there are no therapies. These are among the most important methods for collecting information, so this policy is flawed.

The initial justification for excluding persons who lack the capacity to give informed consent from nontherapeutic research was to honor their rights and protect their welfare. Safe, nontherapeutic research, however, seems neither unfair nor a violation of the rights or welfare of people who lack the capacity to give consent. Failing to do safe but important studies might be unfair and violate their rights and welfare, since it fails to consider all their needs. The Declaration of Helsinki (2000) now permits nontherapeutic studies with guardians’ consent and if other subjects cannot be used; no upper level of risk is given unlike the next option.

THE “RISK-BENEFIT” OR “U.S. FEDERAL REGULATION” SOLUTION. A fourth approach allows research on procedures or interventions with incompetent persons when the research holds out direct benefit to them or does not place them at unwarranted risk of harm, discomfort, or inconvenience. Defenders of the fourth option should clarify what risk is unwarranted. This policy uses risk assessment to set priorities between the social utility of encouraging studies and the protection of people’s rights of self-determination and well-being. To try to set priorities between the social utility of such studies and respect and protection of incompetent people, this option stipulates that the greater the risk, the more rigorous and elaborate the procedural protection and consent requirements. The U.S. federal regulations (U.S. “Protection of Human Subjects,” 45 CFR 46 Subpart D) reflect this fourth policy option in the codes for research with children adopted and those proposed (in 1978 but never adopted) for institutionalized people with mental impairment or retardation. The Council for International Organizations of Medical Science has adopted a similar standard (CIOMS). Under this fourth option, therapy is one of the intended direct benefits that should be taken into account in a risk analysis. Whenever possible, the incompetent persons should give their assent to participate. Assent means affirmative agreement, not just lack of objection.

There are advantages to focusing directly upon the likely benefits and harms of procedures or interventions being studied. First, there are benefits other than therapy that may play a role in deciding if it is reasonable to serve as a subject. A safe, nontherapeutic study that increases a child's understanding of a sibling's chronic illness, for example, might have important lessons about empathy for the child. Those giving consent need to know, of course, the nature and magnitude of the intended benefits (such as education or therapy) or risks of harms associated with the study. Second, calling something "therapeutic" can create the unwarranted idea that participating in the study is in a person's best interest. Risk assessment can reveal hazards, inconveniences, and costs in therapeutic studies that some reasonable people would prefer to avoid.

Using a likely-harms-to-benefits calculation, the U.S. regulations specify four categories of research for children (U.S. "Protection of Human Subjects," 45 CFR 46 Subpart D). IRBs can approve research that they judge to be in the first three categories, and all three generally require the child's assent, if possible, parental approval, and other safeguards such as minimizing risks of harm, having competent investigators and suitable background studies. The first category permits studies with no greater than a minimal risk; the second allows studies with higher risks as long as they are likely to have at least as much direct benefit to subjects as other available therapies; the third category allows research involving a minor increase over minimal risk and no likelihood of direct benefit to each individual subjects, if it is likely to yield vitally important knowledge about the children's disorder or condition. U.S. policy is unique in allowing studies having more than a minor increase over a minimal risk and that do not hold out benefit for the subjects but approval is needed from the federal government. As in the case of the guidelines for prisoners cited earlier, procedural safeguards increase with risk.

There are no final guidelines in the United States for research on those institutionalized as mentally infirm, but there is a proposal about how to treat those institutionalized with impairments like mental illness, senility, psychosis, mental retardation, or emotional disturbances (U.S. Department of Health, Education and Welfare, 1978a, 1978b). It is similar to that proposed for children, except that it allows incompetent adults more authority to decline to participate in studies. The consent or assent of those institutionalized with such impairments must be sought. Those who refuse may not be enrolled in any study that does not hold out direct benefit, without authorization from the courts. CIOMS has a policy that permits enrolling incompetent adults if the study has no more than a minimal risk, others cannot be subjects, the consent of the person or the permission of a responsible family member is obtained, and the research goal is to study the person's disorder or to benefit them.

Unfortunately, this fourth, popular policy option has difficulties. Key terms are either undefined or have vague definitions, permitting broad interpretations about what risks of harm are warranted and what constitutes a benefit. For example, the pivotal concepts of "minimal risk" and "a minor increase over a minimal risk" are problematic (Kopelman, 1989; 2000). The regulations state "'minimal risks' means that the probability and magnitude of harm or discomfort anticipated in the proposed research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests" (U.S. "Protection of Human Subjects," 45 CFR 46 102 I). Many other countries and organizations have adopted a similar definition (Kopelman, 2000).

The first part of the definition is vague because daily risks include dangers from drive-by shootings, playing in traffic, flying in airplanes, terrorists attacks, and weapons of mass destruction. Can one know the nature, probability, and magnitude of these "everyday" hazards well enough to serve as a baseline to estimate research risk? And if one can, what reason exists for regarding them as a morally justifiable baseline? It seems easier to determine whether asking a four-year-old to stack blocks is a minimal-risk study than to determine the nature, probability, and magnitude of whatever risks people normally encounter in their daily lives. Moreover, it is unclear if it is the "everyday risks" refer to those some encounter (called the relative standard) or all of us encounter (called the absolute standard). It is also unclear why everyday risks should be a proper baseline to determine that research risk is minimal. Some people have terrible risks in their daily life, but it would seem unfair to use that to justify higher-risk studies for them than for other people.

The second disjunctive of the definition seems to set a standard for physical interventions that have a minimal risk, especially if it is understood as referring to the routine examinations of healthy persons. The test is whether the risk in the research activity is like that of a routine examination. Accordingly, review boards may not approve *as minimal risk* research such procedures as X rays, bronchoscopy, spinal taps, or cardiac catheterization because they are not part of routine examinations, at least for healthy persons. Review boards, however, can approve studies that have a minor increase over minimal risk, and some of these procedures have been approved as having a minor increase over a minimal risk if their goal is to study a child's "disorder or condition." The terms "minor increase over minimal risk" and "condition" are undefined and vague with no definition for the crucial upper limit of risk that can be approved by review boards, considerable variation exists in how they are understood (NBAC; Kopelman, 2000; 2002).

Finally, this definition of "minimal risk" offers little guidance about how to assess *psychosocial risks* such as invasion of privacy, breach of confidentiality, labeling, and stigmatization. In routine visits, doctors and nurses ordinarily encounter discussions of family abuse, sexual orientation, and diagnoses that could affect reputations or the ability to get jobs or insurance.

Without clear standards for risk assessment, how effective are these guidelines? A 1981 survey of pediatric department chairs and pediatric research directors (Janofsky and Starfield) found considerable differences of opinion about whether procedures such as venipuncture, arterial puncture, and gastric and intestinal intubation are hazardous. For example, most regarded arterial puncture to have a "greater than minimal risk"; but between 8 and 24 percent thought it had less than a minimal risk, depending on the child's age. An editorial in the *Journal of Pediatrics* found such variation "cause for concern" and said that better standards of risk assessment are needed (Lascari). Two decades later, similar concerns remain (NBAC; Kopelman, 2000, 2002).

In short, this fourth policy is vague and open to very different interpretations. For example, in 1992 the National Institutes of Health appointed a nine-member review board to assess whether a study of the safety and efficacy of synthetic growth hormone (hGH) was in compliance with federal research guidelines. Eighty children whose adult height was projected to be at or below the first percentile would participate with their parents' consent. The children would receive injections three times a week for four to seven years (600 to 1,100 injections), half getting hGH and, for comparison, the other half receiving salt water, an ineffective placebo. Neither the doctors, the parents, nor the children would know who got water and who got the growth hormone. Each year all the children would come to the National Institutes of Health to undergo a variety of tests, including physicals, X rays, nude photographs, and psychological evaluations. Of the nine panelists, a majority held there was a minor increase over minimal risk, but this risk was offset by the health benefits of being in the study. Two others judged there was no benefit to offset the risks, inconvenience, and discomfort to those getting water rather than hGH, but the study was important enough to be justified. One panelist (this author) argued that a study of a terrible disease might justify these risks for the group getting hundreds of water injections; but shortness is no disease, and so the risk is unwarranted.

If there is any consensus that the fourth approach represented by the U.S. rules and others is the best way to set priorities between the need to protect the rights and welfare of people who lack the capacity to give informed consent with the need to encourage research, it may mask different understandings of what constitutes an acceptable risk of likely-harms-to-benefits ratio. There is a lively debate in the literature about how to clarify these thresholds and, not surprisingly, some favor more restrictive definitions than others (NBAC; Kopelman, 2002).

Conclusion

IRBs, ERCs, and RECs should continue to play an important role in protecting vulnerable subjects while making it possible to continue important research, but there are sharp differences about whether additional regulatory protections are needed (NBAC). Without safeguards, vulnerable subjects risk exploitation. Excessive restrictions, however, have dangers as well. They can thwart the advance of knowledge needed to improve medical care for the groups they seek to protect. Where potential subjects are capable of giving legal consent but are vulnerable to pressure or manipulation, their consent should be monitored to see if it is coerced or manipulated, and regulations should be sought only when they can be justified. There is general agreement that competent adults should serve as research subjects whenever possible, and that when people who lack capacity to give consent are enrolled as subjects in biomedical research, the study should be related to their healthcare needs. The guardian's consent should be obtained; and, if possible, the assent or permission of the person lacking capacity to consent should also be sought. Since there are difficulties with each of the four policies regarding subjects lacking capacity to give informed consent, IRBs, ERCs, and RECs will have to consider issues of utility, fairness, and protection without entirely satisfactory guidance.

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SEE ALSO: *Aging and the Aged: Healthcare and Research Issues; AIDS: Healthcare and Research Issues; Autoexperimentation; Autonomy; Children: Healthcare and Research Issues; Coercion; Commercialism in Scientific Research; Embryo* *and Fetus: Embryo Research; Empirical Methods in Bioethics; Freedom and Free Will; Genetics and Human Behavior: Scientific and Research Issues; Holocaust; Infants: Public Policy and Legal Issues; Informed Consent: Consent Issues in Human Research; Mentally Ill and Mentally Disabled Persons: Research Issues; Military Personnel as Research Subjects; Minorities as Research Subjects; Paternalism; Pediatrics, Overview of Ethical Issues in; Public Policy and Bioethics; Prisoners as Research Subjects; Race and Racism; Research, Human: Historical Aspects; Research Methodology; Research, Multinational; Research, Unethical; Responsibility; Scientific Publishing; Sexism; Students as Research Subjects; Virtue and Character;* and other *Research Policy* subentries

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III. SUBJECTS

Selecting individuals to participate in research involves not only scientific decisions about appropriate entry criteria but also ethical decisions about the distribution of benefits and burdens. The U.S. National Commission on the Protection of Human Subjects of Biomedical and Behavioral Research (U.S. National Commission) cited three ethical principles as the foundation of research ethics. The first, respect for persons, and the second, beneficence, have been analyzed more often and in greater depth than the third, justice. Investigators, regulators, and institutional review boards (IRBs) are accustomed to applying the principle of beneficence by examining the risk-benefit ratio and applying the principle of respect for persons by examining informed consent. But the third principle—the selection of subjects as a matter of justice—has often been considered last and in only one of its aspects, the protection of vulnerable groups from exploitation as subjects. This situation is changing as persons and groups previously excluded from research on grounds of vulnerability seek access to what they perceive as research benefits, primarily the opportunity to try new drugs for serious and life-threatening illnesses.

According to the U.S. National Commission, justice is relevant to the selection of subjects at two levels: the social and the individual. At the individual level, "researchers [should] exhibit fairness: thus, they should not offer potentially beneficial research only to some patients who are in their favor or select only 'undesirable' persons for risky research" (p. 7). At the social level, "distinctions [should] be drawn between classes of subjects that ought, and ought not, to participate in any particular kind of research, based on the ability of members of that class to bear burdens and on the appropriateness of placing further burdens on already burdened persons" (U.S. National Commission, p. 7). Specifically, on the grounds of social justice, classes of subjects should be ranked (e.g., adults before children) and some classes of potential subjects (e.g., prisoners and the institutionalized mentally infirm) should be selected only under certain conditions and perhaps not at all.

Very few philosophers or other scholars have proposed standards by which to establish priorities in the selection of subjects. Hans Jonas proposed a "descending order of permissibility" for the "conscription" of subjects. In his view, researchers themselves should be the first to test a new therapy, in that they can best understand the risks and benefits. Believing that very sick or dying patients are particularly vulnerable to researchers' invitations, Jonas opposed using them in research not directly related to their care.

Another approach has been to assert an obligation to participate in biomedical research. Arthur Caplan (1984) argued that research is a form of voluntary social cooperation that generates obligations of fairness and reciprocity. If a competent individual voluntarily seeks care in a hospital or institution that conducts biomedical research, he or she benefits from research and should share in its costs (i.e., participate). This obligation is a general one, not an obligation to volunteer for the first available trial or any particular trial.

Selecting the Least Vulnerable

Underlying these different views is the assumption that research is risky or at least burdensome. If this is true, subjects should be selected in a way that protects those whose social, demographic, or economic characteristics make them particularly vulnerable to coercion and exploitation. Volunteering for research is seen as either a duty to be discharged or an altruistic act to be applauded. This emphasis on protecting vulnerable persons is understandable, given the signal event in the modern history of clinical research ethics—the cruel and often fatal experiments performed on unconsenting prisoners by Nazi doctors in World War II (Caplan, 1992). Public opinion in the United States also was shaped by the revelations of unethical experiments such as the Tuskegee Syphilis Study of poor black sharecroppers (Jones), the Willowbrook hepatitis B studies at an institution for mentally retarded children (Rothman, 1982), and the Jewish Chronic Disease Hospital studies in which live cancer cells were injected into uninformed elderly patients (Katz et al.). The most influential single article was one by Henry Knowles Beecher, a respected anesthesiologist, in the *New England Journal of Medicine;* it described a series of studies at major research institutions that placed subjects at risk and failed to obtain informed consent (Beecher; Rothman, 1991).

The view of research as inherently risky and of research subjects as inherently needing protection began to change in the early 1980s. Why? First, consider research at the level of individuals. The empirical question of the actual risk in most research studies has been answered: quite low. The U.S. President's Commission for the Study of Ethical Problems in Biomedical and Behavioral Research asked three large research institutions to summarize their experience with research-related injuries (U.S. President's Commission). Each group found a very low incidence of adverse effects. In one institution, out of more than 8,000 subjects involved in 157 protocols, only three adverse effects were reported, including two headaches after spinal taps. Some of these reassuring results may be due to the vigilance of IRBs and investigators in reducing the likelihood of risk in designing and implementing studies. While risk is always an element that subjects should consider when deciding whether to enter a study, it is often no longer the paramount issue.

Sharing the Benefits of Research

Even more important, the benefits side of the equation has assumed greater weight in individual decision making. Patients and advocacy groups are demanding more autonomy and less paternalism in the selection of subjects. Desperately ill patients forcefully argue that they are willing to trade a higher level of risk for the potential benefits of promising new procedures, devices, or drugs. Advocates for women and children point out that the typical exclusion or underrepresentation of these populations in clinical trials means that the drugs, when approved, will be prescribed for them with little direct data about dosage, efficacy, or side effects. These trends have been spurred by the vigorous, sometimes confrontational, efforts of persons with the acquired immunodeficiency syndrome (AIDS). This advocacy also has stressed the inclusion of groups with poor access to trials, mainly women and minorities (C. Levine, 1988, 1993). Increased emphasis on women's health issues has provided some information on subject recruitment. Examining the inclusion of women in clinical trials, the U.S. General Accounting Office reviewed the practices of the National Institutes of Health (NIH) and the Food and Drug Administration (FDA) (Nadel; U.S. General Accounting Office). In both instances women were found to be underrepresented. The FDA review found that women were represented in every clinical trial of the fifty-three drugs approved by the FDA in the previous three and a half years. However, for more than 60 percent of the drugs, the proportion of women in the trial was less than the proportion of women with the relevant disease. Women were particularly underrepresented in trials of cardiovascular drugs, even though cardiovascular disease is the leading cause of death in women.

In arguing for wider inclusion criteria in clinical trials, patient advocates and some clinicians have noted that in the interest of good medical care, drugs should be tested on the populations that will use them. This belief runs counter to the more traditional research view of subject selection, which focuses on testing drugs in a small, homogeneous population in order to detect differences in efficacy and side effects as rapidly as possible.

Even with broadened inclusion criteria, not all patients who want access to promising new agents can be enrolled in clinical trials because they fail to meet the inclusion criteria, they live too far from a research center, or the trials are already closed. Several other mechanisms have been developed, such as the "parallel track," in which qualified patients who cannot enroll in clinical trials may obtain a promising drug through their physician ("Expanded Availability"). Community-based research, especially in cancer and AIDS, also has made clinical trials more accessible to patients.

The NIH has formalized the movement toward broader selection of subjects by mandating that its research grant recipients include appropriate numbers of women and minorities (Kirschstein). The 1993 NIH Revitalization Act (P.L. 103–43) extended the revised NIH policy by requiring the NIH director to ensure that women and members of minority groups are included in each federally funded project. The director may waive the requirement if the inclusion is inappropriate for health reasons, the purpose of the research, or any other circumstance. Cost, however, is not a permissible reason to fail to include women and members of minority groups.

This trend has limits, however. The inclusion of pregnant women in clinical trials is still controversial unless the trial is specifically designed to benefit the fetus, such as trials to prevent maternal-fetal transmission of the human immunodeficiency virus (HIV), which is associated with AIDS. Some of the objections to including pregnant women rely on ethical concerns about, for example, placing at risk a fetus, who cannot consent. Most of the concerns are based on fears of legal liability should the fetus be born with an injury that might be attributed to the investigational drug. Other subject groups for which protection is still deemed essential include children (Levine, 1991) and prisoners and mentally ill persons. Still other groups sometimes cited as vulnerable include elderly people, military personnel, pharmaceutical company employees, and medical students. Although some conditions and some protocols might be coercive, in general these individuals can make choices voluntarily. Special procedures have been set up in some instances to ensure voluntariness (see, e.g., Winter, on the U.S. Department of Defense).

From the societal perspective, equitable selection of subjects means that the groups bearing the burdens of research should also share in its benefits. Opponents of research in prisons argue that the fruits of the research—newly approved drugs—are rarely available in that setting. Similarly, although many drug trials have been carried out in Third World countries, these nations are often so poor or so lacking in healthcare services that they cannot afford to provide the tested drugs to their citizens.

More recently, representatives of Third World countries and of poorly served communities in the United States have been demanding a greater role in the distribution of benefits (Lurie et al.; National Commission on AIDS; Thomas and Quinn). Their agreement to participate in clinical drug trials is sometimes conditioned on a promise from trial sponsors to provide something of benefit to the population—the drug, if it proves efficacious, or the health infrastructure needed to deliver the therapy. Efficacy trials for vaccines, which require thousands of subjects, cannot be conducted without the goodwill and participation of a community's leaders. Community consultation, in which investigators and community spokespersons collaborate on the design and implementation of a trial, is becoming a frequent strategy for ensuring that the concerns of the pool of potential subjects and their representatives are addressed.

Recognizing the importance of social justice in the distribution of burdens and benefits, the World Health Organization (WHO) and the Council for International Organizations of Medical Sciences (CIOMS) guidelines for international research state:

> Before undertaking research involving subjects in underdeveloped communities, whether in developed or developing countries, the investigator must ensure that:
>
> - persons in underdeveloped communities ordinarily will not be involved in research that might equally well be carried out in developed communities;
> - the research is relevant to the health needs and responsive to the priorities of the community. (WHO-CIOMS)

The commentary on this guideline states: "If any product is to be developed, such as a new therapeutic agent, clear understandings should be reached about whether and how the product, once developed, will be made available to members of the community in which the research was conducted" (WHO-CIOMS, pp. 38–39).

The equitable selection of subjects now includes an assessment of both the need for protecting vulnerable individuals and groups and the importance of allowing them maximum choice in making the ultimate decision to participate. In the future, even more emphasis will be placed on the equitable distribution of the benefits of research.

CAROL LEVINE (1995)
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SEE ALSO: *Aging and the Aged: Healthcare and Research Issues; AIDS: Healthcare and Research Issues; Autoexperimentation; Children: Healthcare and Research Issues; Commercialism in Scientific Research; Embryo and Fetus: Embryo Research; Empirical Methods in Bioethics; Genetics and Human Behavior: Scientific and Research Issues; Holocaust; Infants: Public Policy and Legal Issues; Informed Consent: Consent Issues in Human Research; Mentally Ill and Mentally Disabled Persons: Research Issues; Military Personnel as Research Subjects; Minorities as Research Subjects; Pediatrics, Overview of Ethical Issues in; Prisoners as Research Subjects; Race and Racism; Research, Human: Historical Aspects; Research, Multinational; Research Policy; Research, Unethical; Responsibility; Scientific Publishing; Sexism; Students as Research Subjects; Virtue and Character;* other *Research Methodology* subentries

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RESEARCH, UNETHICAL

• • •

Unethical research is a concept inevitably relative to accepted views concerning research’s ethical requirements. For Claude Bernard, an early French exponent of the scientific method in medicine who felt that the principle underlying medical morality requires that persons not be harmed, paradigm cases of unethical research are studies that offer their subjects risks that exceed their potential benefits. The Nuremberg Tribunal, by stating in its first principle of ethical research that the subject’s free consent is absolutely essential, added as paradigmatic cases of unethical research those studies performed upon unconsenting persons (Germany [Territory Under Allied Occupation, …]). U.S. regulations that require an equitable selection of research subjects imply that a study that is otherwise ethical (e.g., a study with an acceptable risk-benefit ratio and whose subjects have freely consented) becomes unethical when it unfairly draws its research population from persons disadvantaged by reason of race, religion, or dependency, among others (“Federal Policy”).

Examples of Unethical Research

Whichever ethical requirement may be chosen, the history of human research offers grim examples of its violation. During World War II, German researchers performed a large number of experiments in concentration camps and elsewhere. Subject-victims of Nazi research were predominantly Jews, but also included Romanies (Gypsies), prisoners of war, political prisoners, and others (Germany [Territory Under Allied Occupation …]; Caplan). Nazi experimental atrocities included investigation of quicker and more efficient means of inducing sexual sterilization (including clandestine radiation dosing and unanesthetized male and female castration) and death (an area of study Leo Alexander

[1949] termed “thanatology,” which includes studies of techniques for undetectable individual assassination—i.e., murder that mimics natural death—as well as mass murder). Among the best-known cases were the hypothermia experiments, which investigated mechanisms of death by freezing and means of preventing it. These studies, motivated by the loss of German pilots over the North Sea, included immersing prisoners in freezing water and observing freezing’s lethal physiological pathways.

Beginning in 1932, the U. S. Public Health Service funded a study of the natural progression of untreated syphilis in black men. Four hundred subject-victims were studied, along with 200 uninfected control subjects. The study, whose first published scientific paper appeared in 1936, continued until a newspaper account of it appeared in 1972. Its subject-victims were uninformed or misinformed about the purpose of the study, as well as its associated interventions. For example, participants were told that painful lumbar punctures were given as treatment, when in fact treatment for syphilis was withheld even after the discovery of penicillin (Brandt; Jones).

Numerous other examples of unethical research may be cited, though they have received far less attention. A New Zealand study on women that began in 1966 and was active for at least ten years had macabre similarities to the Tuskegee study. It concerned the natural history of untreated cervical carcinoma in situ (i.e., cancer that had not spread), and as in Tuskegee, its subject-victims were both uninformed and had treatment withheld for the study’s duration (Paul). Parallel to the Nazi studies during World War II were those conducted by Japan. They included experimental attacks with biological weapons on at least eleven Chinese cities, and studies conducted on subject-victims that included efforts to induce gas gangrene by exploding fragmentation bombs near the exposed limbs and buttocks of 3,000 prisoners of war who were housed at a detention center known as Unit 731 (McNeill; Williams and Wallace).

Much unethical research comes to light only many years after its conduct, as is true of unethical military research conducted by the United States during and immediately following World War II. At that time, over 60,000 U.S. servicemen were involuntarily enrolled in studies involving exposure to chemical warfare agents (mustard gas and lewisite); at least 4,000 of them were exposed to high concentrations in field experiments and test chambers (Institute of Medicine).

Information about experiments on human radiation response supported by the U.S. government beginning in 1945 came to public attention in 1993. In one study, conducted from 1945 to 1947, eighteen patients considered to be terminally ill were injected with high doses of plutonium to determine how long it is retained in the human body. Military secrecy surrounding atomic energy precluded informed consent. Rather than telling subject-victims they would receive an injection of radioactive plutonium, the investigators told subjects they would receive a “product.” Experiments on intellectually handicapped teenagers in a Massachusetts institution involved feeding the subjects very small amounts of radioactive iron and calcium to study the body’s absorption of these materials. While the radiation exposure in these studies was low and unlikely to result in harm, the subject-victims were all incompetent, and their parents, who consented on their behalf, were simply asked by the institution to agree to “nutritional experiments.” In reaction to news accounts of these and other studies, orders were issued in 1993 to declassify documents relating to unethical exposure of U.S. service personnel and citizens to radiation from atomic-weapons testing after World War II; in 1994 President Bill Clinton appointed a panel to guide a federal investigation into the radiation studies (Mann).

Several themes emerge from the known examples of unethical research. Such studies are likely to be done using disenfranchised or disadvantaged populations as subjects. In the absence of public outcry, unethical research may continue for many years, despite the fact that readers of the scientific literature in many cases have had access to all the facts they need to expose unethical practice (see Beecher). The larger and more egregious studies are especially likely to have been motivated by national security concerns and funded by the military.

Use of Data from Unethical Research

Very early sources reflect differing views on the permissibility of making medical or other use of information derived from unethical practices. The Babylonian Talmud (Shabbat 67b) states that the prohibition on Amorite practices (pagan sorcery) does not forbid actions done for the sake of healing, and it cites several cases of permitted incantations and sympathetic magic. Robert Burton quotes Paracelsus’s *De occulta philosophia* to similar effect: “It matters not whether it be God or the Devil, Angels or unclean Spirits cure him, so that he be eased” (Burton, 1628, p. 7). By contrast, Thomas Aquinas prohibits “inquiring of demons concerning the future.” Even if demons should know scientific truths, he writes, it is improper to “enter into fellowship” with them in this way (Aquinas).

A large variety of empirical and ethical arguments have been marshaled to oppose the use of data from unethical research. Empirical arguments, which depend upon the facts of particular cases, question the scientific reliability of such data. For example, Robert Berger, through a close analysis of the Nazi hypothermia data, claims that even by then-current scientific standards, the information is unreliable. He describes incomplete and contradictory data reporting, the absence of a controlling scientific protocol, and the control of the research program by scientifically untrained personnel (including Heinrich Himmler, Commander of the SS). In fact, the principal investigator, Sigmund Rascher, had a previous record of deception and was arrested in 1944 and charged with crimes that included scientific fraud. Some commentators argue that such data may be used, but only when the information is exceptionally reliable and useful. Most or all instances known of data gathered unethically, however, fail to meet this test (see Schafer).

Ethical arguments opposing use of the data are especially numerous. From a consequentialist point of view, unethical studies should be "punished" by "non-use," to discourage future investigators tempted to resort to unethical research practices. Other theories of punishment may be appealed to as well: As a matter of justice, it is argued that unethical investigators should not be rewarded by having the data from their studies used. By expunging the records of unethical research, the society of scientists expresses its solemn condemnation of the methods employed to acquire it; failing to do so would make science complicit with the research studies. Appropriate symbolism may call for the "burial" of this data, as it calls for the burial of the subject-victims from whom the data was derived (see Caplan; Martin; Post).

Rebuttals of these ethical arguments are equally numerous, relying upon the premise that data from unethical research studies may be valuable in principle: Any coincidence between "good science" and "good ethics," these writers argue, is only contingently true. As a practical matter, it is argued, the most serious instances of unethical research could not have been deterred by the punishment of non-use; some of the most heinous research studies were commissioned by governments, especially national security apparatuses. Punishment should be visited upon the investigators who engaged in unethical research; by withholding the use of data, current patients whose care might have been improved by use of that data are made to bear the brunt. Arguments from complicity are rejected because there is no causal connection between the prior acquisition of the data and its current use (the Nazis did not gather information about hypothermia in anticipation of its use by Canadian researchers a generation later); and because the current use of the data, far from being a continuation of the Nazi project, is for humanitarian purposes antithetical to the original Nazi intentions. In that way, the symbolism associated with the use of these data is seen to have a positive, redemptive value, while retaining the data's possible value to science and society (Freedman; Greene).

The debate about the use of data from unethical studies should distinguish the different ways scientific results can be used. Three different meanings for data use have been suggested: reference to data, for example, by scientific publication or citation, to serve as grounding for a scientific argument; reliance upon data in establishing or validating a practice, scientific or technological (including clinical); and using data as suggestive of further areas for inquiry (Freedman). This last meaning, while the most common in practice, has been the least debated; it is unlikely that data, once disclosed, could fail to be used in this way.

Much debate has centered on the first meaning, use of data through publication or citation. Kristine Moe found that the Nazi hypothermia studies had been referenced at least forty-five times in the medical literature (Moe). The *New England Journal of Medicine,* among other publications, has taken the position that it will not publish studies considered unethical by its editor; moreover, it will allow references to unethical research only in articles that focus on ethical condemnation of the research in question (Ingelfinger). Robert J. Levine has argued that a preferable stance would permit the publication of scientifically sound but ethically questionable research, while requiring the simultaneous publication of editorial discussion of the ethical issues raised (Levine).

Use of data in the second sense, as grounding scientific or ethical practices, was central to a 1988 controversy. While considering air pollution regulations on phosgene, a chemical used in plastics manufacture and a component of pesticides, the U. S. Environmental Protection Agency (EPA) withdrew an analysis that made reference to data derived from Nazi experiments after some EPA scientists circulated a protest letter (Sun). Phosgene was a component of some chemical weapons, and the Nazis had studied the response of French prisoners to various levels of phosgene exposure. EPA officials, while recognizing scientific and technical flaws in the data's collection and reporting, held the data to be useful additions to the existing animal toxicology information. Nazi data is often said not to be generalizable to a normal population because it was derived from prisoners under horrible conditions of privation. However, even this aspect of the data was applicable because the EPA's recommendations were designed to minimize risk to those most physiologically vulnerable. Those opposed to use of the data presented arguments based on both fact and value. The data were said to be valueless because of their omission of consideration of vital variables like sex and weight of subject-victims. In addition, some agency scientists felt that data derived from this source, however valuable, should never be used.

In the majority of cases, the scientific value and impact of unethical research has been modest. Ethically, however, the Nazi, Tuskegee, and other studies have loomed large in raising both public awareness and ethical standards for the conduct of research. Unethical research has found its main use in ethics.

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SEE ALSO: *Animal Welfare and Rights: Ethical Perspectives on the Treatment and Status of Animals; Bias, Research; Bioterrorism; Children: Healthcare and Research Issues; Commercialism in Scientific Research; Competence; Conflict of Interest; Embryo and Fetus: Embryo Research; Embryo and Fetus: Embryonic Stem Cell Research; Harm; Holocaust; Informed Consent: Consent Issues in Research; Mentally Ill and Mentally Disabled Persons: Research Issues; Military Personnel as Research Subjects; Minorities as Research Subjects; Moral Status; Prisoners as Research Subjects; Race and Racism; Research Policy; Sexism; Surrogate Decision-Making; Transhumanism and Posthumanism*

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RESPONSIBILITY

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Responsibility has emerged as a central ethical category, directing attention to human beings as moral actors. It highlights the importance for ethical understanding of self-conscious moral commitments, discretion in moral judgment, personal strengths necessary to effective action, a wise use of the power and authority of societal offices, and accountability to oneself and to fellow human beings, perhaps also to God, for moral judgment and action. Discussions of responsibility do not displace systematic treatments of moral principles, laws, and rules; neither do they set aside critical studies of values worthy of promotion in human affairs. They recast these inquiries in terms of the personal lives and social roles of human beings.

Themes associated with responsibility have long been prominent in philosophical and religious discourse, though in different conceptual forms. Especially important are accounts of the moral and intellectual virtues, of moral character, and of the obedient or resolute wills of the upright (Aristotle; Aquinas; Calvin; Kant; cf. Cohen). Also relevant are themes elaborated in conceptions of moral law, including natural law; in notions of the orders of nature or creation; in interpretations of divine commandments and ordinances; and in treatments of God's covenant with Israel, or of the Christian idea of a new covenant in Jesus Christ (Aristotle; Aquinas; Brunner; Häring). Contemporary accounts of responsibility weave these classic themes together in ways that take account of modern social realities, and that utilize theories of action provided by the human sciences.

In regard to modern realities, the concept of responsibility corresponds to social complexity, which routinely generates problems with more features than any system of moral rules can encompass. It fits well with advanced technologies and high levels of specialization, where expert knowledge and skill are indispensable to moral judgment. Responsibility takes account of open spaces within democratic and free-market settings for individuals and groups to follow independent initiatives in the pursuit of cherished social goals. It accords with modern social theory, which conceives of social institutions—the state, business enterprises, special-interest associations, even families and religious bodies—as the constructions of autonomous individuals contracting for mutual advantage. Finally, responsibility can accommodate reflections on the moral ambiguities of the social and organizational contexts that structure human activity. In respect to each of these characteristics, themes relating to responsibility take on considerable importance.

The concept of responsibility enjoys prominence, then, because it can draw together a wide range of ethical ideas in a fashion pertinent to contemporary social existence. For some thinkers it serves as the unifying principle of a comprehensive ethical theory (cf. Niebuhr; Jonsen). Responsibility virtually becomes the first principle of ethics, so that the admonition "Be responsible!" conveys all that needs to be said about the moral life (Jonsen; cf. Glatzer). The theoretical task is to unfold the dimensions of responsibility in their bearing on personal and social processes.

The dimensions of responsibility appear both in the personal lives of individuals and in the roles, positions, and offices that order social institutions. All of these dimensions may not be explicit in a particular ethical theory, though most enter into discussion at some point. For religious thinkers, responsibility includes relationship to God, which uncovers a theological basis for ethical understanding.

Duties

At the most elementary level, responsible persons are those who recognize and carry out their duties. Duties define the moral requisites of human social existence: what we normally must do, no matter what else we might hope to accomplish, and what we normally may not do, regardless of our larger objectives. Moral duties can be qualified or set aside only when exceptional steps are necessary to secure the values they are designed to protect. Thus, medical procedures normally may not be performed without a patient's informed consent, even if the patient's life is at risk. However, in a medical emergency, they may be performed without consent, provided the patient is unable to respond and there is no one present with authority to decide on his or her behalf.

Duties are formulated as laws, regulations, and rules, perhaps in conjunction with underlying moral principles. Responsible persons abide by moral principles in their personal lives. They pay special attention to principles and rules linked to their social roles: parent, spouse, physician, research scientist, junior executive at a medical center, senator. They support collective efforts to uphold moral standards that order human activities in institutional contexts (cf. Beauchamp and Childress). For those who are religious, moral duties may derive their ultimate authority from divine purposes.

Tasks

Within the constraints of moral principles and rules, responsibility consists in the reliable performance of assumed or assigned tasks. We may speak of our tasks as our responsibilities. Responsible persons know what needs to be done, they appreciate its significance, they proceed on their own, they get the job done, and they do it well (Jonsen).

Some tasks are broad and open-ended: sustaining a good marriage; bearing and nurturing children; promoting the public good as a citizen, public servant, or professional. Others are specialized, such as the practice of pediatric medicine. Some may be narrowly focused, for example, the execution of insurance claims. Even specialized tasks lack clear limits. When do physicians know enough to be confident that they are providing optimal care for their patients? When have they done enough to promote life, health, and healing? Responsible persons maintain standards of excellence in relation to expectations associated with their social roles. Those who are religious may further connect their tasks with a vocation to serve a wider, divine purpose in all areas of their lives.

General Well-being

In conjunction with explicit moral commitments and role-determined assignments, responsible persons strive for just, fair, and good conditions where they live and work. They seek to bring about and maintain states of affairs that favor human well-being, perhaps the well-being of all creatures. Similarly, they resist and, where possible, seek to change circumstances that do harm to fellow human beings, even to other living creatures. They strive to improve the execution of tasks, and to see that basic moral imperatives are honored in everyday social interactions. Those who are religious may be sustained in their quest for a greater good by their hope in the promises of God.

Thus, a physician's responsibility does not end with patient care or with professional relationships wherein standards of quality care are maintained. It includes a public interest in the healthcare system as a whole, and in its ability to provide appropriate services for all people. More broadly, it embraces the promotion of human health in basic life patterns.

Commitment

Responsibility is about personal commitment. It expresses human care about the moral life (cf. Fingarette). Those who are responsible claim their duties and tasks as their own, as ways of acting that are internal to who they have become and are becoming (Gustafson; cf. Jonsen).

Classic ethical theories dealt with commitment either in terms of moral virtues (Aristotle; Aquinas) or in terms of the resolute will (Calvin; Kant; cf. Novak). Moral virtues are habits, stable ways of acting that accord with the good. They derive their energy from passions that have been *perfected* through disciplined practice, until an actor is disposed to do the good as a kind of *second nature.* In terms of normative content, the central moral virtue is justice, the disposition to grant to each person what he or she is due.

In Judaism and in Reformed Protestant thought, the basic commitment to do the good has been defined not as habit or disposition but as volition, a self-conscious determination to do one's duty in all things. Here the aim is not to shape the passions but to control them. Immanuel Kant gave these latter traditions philosophical form by speaking of the unqualified value of the "good will," that is, the will ever ready to do what the moral law commands (Kant).

Modern psychological theories generally set aside accounts of the self that isolate discrete virtues or particular psychic functions, such as the will. They portray the self as a complex, dynamic process in which a centered unity can be only a relative achievement (cf. Wallwork). Post-Freudian thinkers place special emphasis on the formative power of human relationships in these complex dynamics (cf. Erikson; Winnicott; Kohut; Chodorow). Thus, our moral commitments are integral to the relational bonds that form and sustain us as human beings. We come to understand these commitments through our life stories, including both family stories and the stories of communities to which we belong. It is by means of narrative that we apprehend and claim our moral identities (Taylor; Ricoeur).

Psychological perspectives substantially inform ethical discussions of responsibility (cf. Fingarette; Rouner; Wallwork; Taylor). They render more intelligible seemingly irrational features of human behavior: individuals acting in socially inappropriate ways or in ways that work against their self-conscious purposes (cf. Fingarette). They help us grasp dynamics that leave some persons virtually incapable of consistent care for the good, and hence unable to respond to concrete situations with moral sensitivity. In other instances, persons may profess moral concern, yet find themselves internally torn, deeply ambivalent, or emotionally empty. They lack focused energy to carry out the good they claim to honor.

In classic thought, such cases either revealed bad habits, called vices (Aristotle; Aquinas), or they represented the bondage of the will to sinful inclinations (Augustine; Calvin; Luther; cf. Kant). Modern perspectives introduce notions of pathology to account for this "irresponsible" behavior. They offer neither moral admonition nor judgment but therapy, a supportive relationship wherein a skilled professional helps a patient gain insight into the internal conflicts that impel him or her to destructive behavior. Therapy provides resources for self-discovery that open the way to mature moral concern (cf. Fingarette; Wallwork). Through processes of self-discovery we reconnect with values and relationships that give identity and significance to human life.

Moral commitment involves social roles and offices. Responsible persons incorporate into their personal identities moral principles and values that are linked to positions they occupy. Social roles, like social institutions, are invariably marred by moral ambiguities. They gain their moral import from the fact that despite their ambiguity, they serve a greater good, at least by minimizing harm. Responsible actors seek to advance the moral promise of their offices while resisting their morally questionable tendencies.

Strength

Responsibility presumes that we have the personal strengths and the requisite skills to carry out our duties and to perform our tasks. Classic traditions of moral virtue and volition focus on distinctively moral strengths. In volitional approaches, the pivotal strength is willpower, the determination to control any fears, desires, even natural inclinations, that might distract us from our duty. Those who are religious seek divine support for moral rectitude.

In theories of virtue, moral strength derives from an ability to harness the passions in the service of purposive activity (Aristotle; Aquinas). On the one hand, responsibility requires personal toughness, perseverance, courage. These strengths stem from a natural, organic combativeness that through practice has been shaped into a virtue. If we lack such strength, the pressures, threats, and risks common to social existence will force us to shrink from the proper performance of basic tasks and duties. For example, a physician might remain silent after witnessing a senior colleague's failure to observe minimal professional standards in practice. Although the physician cares about standards, he or she cannot bear the stresses of a formal complaint. Courage equips us to follow through on our commitments, even those that entail danger.

On the other hand, responsibility requires self-control, the ability to restrain our wants, desires, and feelings when they dispose us to betray our commitments. Here, too, we develop self-control or temperance through practice. We learn to shape our wants and desires to accord with the larger good toward which we aspire. Without self-control we are unreliable. Our desires continually override good judgment, perhaps even impelling us to harmful actions (cf. Aristotle; Aquinas).

Because of an attraction to a patient, a psychiatrist violates sexual boundaries that define professional relationships. A research scientist falsifies research data or makes improper use of the findings of others in order to advance his or her career. In the interest of increased income, a specialist in internal medicine proposes medical procedures of dubious merit to a dying patient. Responsibility requires the discipline to restrain our wants for the sake of our moral integrity.

Modern psychological theories deal with similar phenomena, although with greater emphasis on the complex dynamics, including interpersonal relationships, that figure so prominently in our makeup. As a result, moral strengths appear less as matters of personal accomplishment and more as functions of self-formation in relationships. As inherently social beings, we derive both courage and self-control from human bonds that cohere with our moral purposes (cf. Kohut; Chodorow; Rouner; Glatzer).

Personal strengths are not limited to emotional resources or volitional restraints. They embrace intellectual capacities, general and specialized knowledge, competence in oral and written communication, self-confidence, self-esteem, the mastery of skills crucial to typical tasks, physical strength and agility, energy, stamina, and manual dexterity.

We may not associate all of these elements with the moral life, yet they profoundly affect a person's ability to act. The responsible life includes, therefore, a commitment to cultivate native talents and abilities, and to devise ways of mitigating disabilities. Similarly, social responsibility requires policies that enhance human potential for effectiveness: opportunities for education and advanced training; specialized equipment and physical arrangements for persons hampered by "handicapping conditions"; nondiscriminatory practices regarding race, gender, ethnic origin, age, religious identification, and sexual orientation.

Responsibility for personal strengths includes self-care and discipline in holding personal and professional commitments to manageable levels. Mistakes, indiscretions, intemperate and abusive behavior, even addictive and self-destructive patterns, are more likely when we habitually overextend ourselves. Personal strengths are indispensable to the good we are disposed to do. They also allow us to broaden our moral commitments, perhaps to assume leadership in promoting the common good.

Power

The human capacity to act derives from social offices and positions as well as from personal strengths (cf. Brunner; Bonhoeffer). Responsible persons are attentive to power dynamics that operate in their interactions with colleagues, associates, and employees, as well as with patients, clients, customers, and users of services. They resist abuses of power in these interactions and draw upon the resources of their offices to promote justice and the common good. They model fairness and concern for general well-being in their own activities; they commend similar practices by others.

Judgment

Responsibility involves sound judgment about the good to be done in concrete situations. Our ability to judge depends upon stable moral commitments and personal strengths to act on those commitments. It is affected by the perceptions of those to whom we are closely related, and also by interests that structure our business, professional, and political activities. Yet judgment is still a distinct skill, a "practical intellectual virtue" cultivated through practice (Aristotle; Aquinas).

Moral judgment operates in a number of ways, all of which involve the creative imagination and accumulated practical wisdom of morally mature individuals. It consists in the interpretation and application to concrete cases of laws, regulations, and rules that define moral duties (cf. Ramsey). These regulations may be borne by the common culture or the culture of professional practice; they may also be codified in public law or in the operating procedures of complex organizations, such as hospitals. The task is to discern what is at stake in these regulations so that they can appropriately inform particular moral judgments. Interpretation generally leads to a search for principles that disclose what is morally at stake in various regulations, for example, the claim that these regulations protect conditions essential to human existence and well-being.

By their very nature, principles, laws, and rules are abstract. It is not uncommon, therefore, to confront cases that are not adequately covered by existing regulations. Moral judgment may then consist in the construction of new rules that can inform our responses to these problem cases. The new rules may represent reformulations or extensions of familiar standards. They may consist of novel directives derived from elemental moral principles. The goal is to furnish stable guidelines for dealing with an emerging class of cases in the context of changing social circumstances. Bioethics continually confronts such challenges as it responds to enlarged technical capacities within biomedical practice.

Some cases are sufficiently distinct that they are best treated as exceptions to the rules. Moral judgment then entails adapting the rules to take account of variables that define the exception. Through experience, we learn to distinguish genuine exceptions from sets of cases that expose problems with existing rules. For the latter, we must rethink the rules, devising fresh formulations suited to the new cases.

In many life contexts, such as biomedical practice, we regularly deal with so many specific variables that general principles and rules cease to prove helpful as guides to moral judgment. Especially important are cases where conflicting values and disvalues are likely to result from any conceivable course of action, such as the treatment of the terminally ill or experiments with promising medical procedures that invariably have negative side effects. Practical wisdom for handling such cases emerges through experience accumulated in the treatment of similar cases. By evaluating a significant number of cases, we increase our ability to isolate variables pertinent for assessing each new case. This pattern of moral judgment is continuous with classic traditions of casuistry, or case reasoning. Casuistry locates moral judgment in the comparative study of recognizable classes of cases that require human decision and action (cf. Jonsen and Toulmin). Medical centers now institutionalize casuistic thinking through case conferences and regular consultations with specialists and advisers.

Responsiveness

H. Richard Niebuhr dramatizes the social matrix of action. We act in response to actions upon us and in anticipation of further responses to our own actions in ongoing social interactions. In this interactive framework, moral judgment involves responsiveness, self-conscious attempts to draw upon the perceptions and experiences of others in our own deliberations (cf. Gilligan). Responsiveness is best realized in conversation among representative actors in a situation. The conversation is not primarily an occasion for debate, in which the stronger positions defeat the weaker until the most cogent prevails. Its purpose is to facilitate vision. It may confirm widely held judgments, yet it may uncover matters that have been concealed, clarify phenomena that have been obscured, and bring to awareness considerations previously passed over.

Responsiveness begins with the attempt to understand what is going on. It does not presume that the morally important issues in a situation are obvious. Through conversation we surface the pivotal issues and construct ways of portraying them to ourselves and others. Historical studies and social analyses inform these efforts. The account we provide of the situation sets the stage for a consideration of appropriate responses.

Responsive judgments are guided by the notion of what is *fitting*. The fitting action may be largely self-evident once we have grasped what is morally at stake in a situation. Yet it may emerge only gradually, through the thoughtful balancing of multiple variables with their negative and positive features. Moral imagination and discernment are as important to this balancing process as are conceptual precision and logical rigor. The reasoning involved, moreover, is often more akin to weaving a tapestry than to forging a chain. Various strands of thinking supplement, complement, and perhaps clash with one another within a complete configuration. A fitting response is integral to that configuration. It consists of the most promising means of negotiating multiple considerations. For Niebuhr, fitting actions are also responses to God, the center of values that bestows authority on all values.

Responsiveness gains moral urgency from the partial, even distorted, nature of all human viewpoints. Biases rooted in special interests plague our most sincere efforts to promote justice. For example, a white male medical establishment gave lower priority to breast cancer than to prostate cancer. In studying heart disease, it focused on male rather than female subjects. Exalting scientific advances and technical achievements, the U.S. healthcare system institutionalizes almost unlimited care for those with comprehensive health coverage while failing to offer basic care for the poor. Other biases—racial, ethnic, religious—have distorted biomedical practices from time to time. We overcome socially mediated biases by responsiveness to the voices of those previously left out of the conversation.

Responsiveness is not merely a personal trait. It can be incorporated into professional, organizational, and institutional practices. We can create contexts for exchanges of views among peers, colleagues, coworkers, support staff, and volunteers. We can regularly seek information from those who receive medical services: patients, clients, consumers, constituents. Within a particular organization, these exchanges promote collaboration on common projects, facilitate coordination among interrelated activities, and enhance both quality and efficiency in performance. As a dimension of responsibility, responsiveness contributes to good management. Similarly, professionals routinely respond to peer judgments through associations, convocations, conferences, and publications, as well as through regular consultations and case conferences. Ideally, they also elicit the active participation of clients to whom they offer their services.

Responsiveness in moral judgment is especially pertinent to the formation of public policy, such as debates about healthcare reform. These debates begin with attempts to interpret “what is going on” and move to proposals for the “fitting” response (Niebuhr). In the United States, controversial policy issues are rarely resolved by a new public consensus on the proper treatment of pressing social problems. Practical accomplishments require compromise. To gain support for new directions in policy, public actors accommodate the special interests of competing groups. In so doing, they consent to measures that fall short of their larger goals. The search for acceptable compromises is crucial to public responsibility.

Accountability

Responsibility embraces accountability for judgments and actions (cf. Jonsen). Because our actions affect the lives of fellow human beings, we have to answer to others for what we do. We must be able to give an account of our intentions and of their moral bases that is credible within the relevant conversational context, whether it be familial, communal, professional, or public. Responsible persons seek feedback from others because they are conscientious about quality performance. Structures of accountability may be formalized in well-defined review processes, including disciplinary hearings, and civil and criminal actions. Yet they also operate in everyday human interactions.

The morally committed have a strong sense of accountability to self. Conscience names the dynamism whereby we answer to ourselves for our fidelity to our commitments. If we violate our own normative standards, we feel guilt. If others have been disadvantaged or harmed by our actions, we recognize a need to apologize, perhaps to make restitution. In religious contexts, accountability involves answering to God as the source and ground of the moral life. We confess our failures, seek forgiveness, and pray for strength to renew our commitments.

Responsibility includes a readiness to hold others accountable for their actions, in the interest of the common good. It will not suffice to be conscientious only about our own actions. Because substantive moral commitments are requisite to human existence and well-being, we must hold one another accountable to those commitments. Accountability is especially important for professionals, who alone are adequately equipped to assess the performances of peers. Likewise, we are obliged to promote mutual accountability in the organizational and communal contexts in which we normally live and work; this includes support for appropriate disciplinary hearings and criminal proceedings.

The notion of accountability directs us to revisit all of the dimensions of responsibility, though with a focus on our obligation to nurture, model, encourage, cultivate, and teach responsibility to fellow human beings, especially the children, youth, and young adults of a coming generation.

THOMAS W. OGLETREE (1995)

SEE ALSO: *Care; Compassionate Love; Communitarianism and Bioethics; Freedom and Free Will; Holocaust; Lifestyles and Public Health; Paternalism; Profession and Professional Ethics*

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RIGHT TO DIE, POLICY AND LAW

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Prior to World War II, death came naturally or accidentally. There was little that doctors could do to forestall it. With the development and application of a variety of drugs and devices, this slowly began to change in the 1950s and 1960s. In addition to the improved medical capabilities, public attitudes toward the respective roles of physicians and patients in making decisions about whether to deploy medical technology also began to shift. In the 1950s and 1960s, influenced by the civil rights and the consumer rights movements, the public gradually shifted the almost sole responsibility for deciding whether and how to treat patients from physicians' hands to the hands of patients or their families.

The Development of Patient Autonomy

Autonomy—or as it is sometimes referred to, self-determination—is the core value that has driven the development of the right to die, as well as the more fundamental right to refuse medical treatment out of which the right to die has grown. Legal recognition of the right of patients to make decisions about the medical care they do and do not wish to receive has deep historical roots. However, the right to make medical decisions is itself of relatively recent vintage, perhaps because until recently there was not a great deal in the way of medical treatment to choose from and certainly not much that was efficacious. Before the last decades of the twentieth century, there was not so much a right of patients to choose but a right to veto what the doctor proposed.

As medical capability has gradually increased, so have efforts aimed at increasing the role of patients in making decisions about whether and how to employ that capability. Autonomy has had a long struggle to dislodge the longstanding dominance of medical paternalism in the doctor-patient relationship. By the last quarter of the twentieth century, patient autonomy had become the prevalent value in law, public policy, and bioethics. However, there remains a considerable gap between theory and actual clinical practice (Solomon, et al.).

Another important trend that has affected the shift in medical decision making is the role of law in society in general. Prior to the twentieth century, law played a much more limited role in resolving controversies among private citizens and lawsuits by patients against physicians were exceedingly rare. These few lawsuits fell into two groups: claims based on an allegation of negligent medical practice, and claims of nonconsensual treatment amounting to a civil battery. Ultimately, these two themes were merged in the 1950s and 1960s in the development of the concept of informed consent to medical treatment.

Originally, the law of battery played the more significant role. Although mostly thought of as a protection against conduct involving violence against another person (and in fact it does provide such protection), battery provides a legal remedy for an intentional, nonconsensual touching of another person that results in either harm or offense. Out of the law of battery developed a right to refuse medical treatment. The relationship between the two is clear: the converse of the right not to be touched—in a medical context, treated—without consent, is a right to refuse treatment. Viewed from a broader perspective, the law of battery could be seen as creating a right of individual autonomy or self-determination, and certainly there is significant judicial authority to support that view.

Prior to the 1970s, the right to refuse treatment existed more in form than in substance. In clinical medical practice, although it is unlikely that physicians frequently forced treatment on unwilling patients, the instances in which they did were of the sort—emergencies, patients lacking in decision-making capacity—that any legal challenged was unlikely to arise. In most instances, the situation was such that either the patient recovered and in retrospect no longer objected to the treatment or the patient died or was otherwise unable to pursue a legal remedy.

The Era of Passively Hastening Death

The two trends— of medicine's increasing ability to stave off death if not provide complete cure, and the increasing recognition of patient autonomy —collided in the Karen Ann Quinlan case in 1975 (*In re Quinlan,*). It is virtually certain that such collisions occurred before the *Quinlan* case, but none of these clinical cases metamorphosed into legal cases with the attendant public visibility of *Quinlan* (Filene).

Karen Ann Quinlan, a twenty-one-year old woman, stopped breathing and was taken to the hospital by emergency medical personnel. Doctors were able—through a variety of medical means that were not available only a decade earlier—to resuscitate her. She was then placed on a ventilator. Because of prolonged oxygen deprivation before she was resuscitated, Quinlan suffered severe brain damage and was ultimately diagnosed as being in a persistent vegetative state, a condition in which her brain stem was still alive and maintained her so-called vegetative functions (digestion, metabolism, etc.), but in which the remainder of her brain had died and along with it the higher brain functions such as awareness and cognition.

When Quinlan's prognosis became clear to her parents, they concluded that Karen would not want to be kept alive in this twilight state in which her corporeal existence was maintained but in which she could no longer, think, feel, perceive, or have any contact with other people or her environment. Therefore, after seeking additional medical consultation and religious counseling, they requested that her doctors discontinue the ventilator that was keeping her alive, and that she be allowed to die naturally.

The doctors, however, refused. They refused because they believed it was contrary to the ethics of the medical profession to do so. The treating physicians and several of the qualified experts who testified in the case asserted that removal from the respirator would not conform to medical practices, standards, and traditions. The physicians also refused because they were concerned that they could be subject to liability for criminal homicide if they did so. In effect, the doctors issued an invitation to Quinlan's parents to sue, which they accepted by filing an action for a declaratory judgment—not a case seeking monetary damages against the doctor, but a case requesting the court to declare that Karen had the right to have life-sustaining medical treatment removed, which would, it was thought, inevitably lead to her death.

The trial court refused to issue such an order, and the Quinlan family appealed to the New Jersey Supreme Court. Although the court's opinion is confused and important portions of it were superseded by later decisions, it did grapple with a number of fundamental ethical and legal issues in an unprecedented way. It prescribed procedures for making end-of-life decisions that did not routinely require judicial supervision, and it endowed physicians and patients' close family members with substantial discretion to carry out what they believed to be the patients' wishes about forgoing treatment.

The *Quinlan* decision, despite its shortcomings, can be said to be the foundation on which an entire body of law and public policy have been erected concerning end-of-life decision making. This case ushered in what in retrospect should be called the era of passively hastening death because, along with similar cases that followed in its wake for the next fifteen years or more, it established the right of terminally ill and permanently unconscious patients to have their deaths hastened passively, that is by having life-sustaining medical treatment withheld or withdrawn.

The Consensus about Forgoing Life-Sustaining Treatment

The *Quinlan* case was a catalyst to the development of law and policy about the termination of end-of-life medical treatment. It spurred state legislatures to adopt advance directive legislation intended to head off similar litigation. Federal and state commissions were appointed to study and make recommendations on these issues. Other landmark cases were litigated in other states; in the quarter century following *Quinlan,* courts in half the states decided more than one hundred similar cases—and within a decade, a remarkably uniform body of law and policy had emerged.

Each element of this consensus fed the others. Court cases spurred legislative action. Government commissions relied on important court cases and legislation as guidance for their deliberations and recommendations. Further court cases adopted the recommendations of the commissions. Although there are some important exceptions, taken together, these cases, statutes, and commission reports constitute a consistent consensus about how end-of-life decisions should be made.

Although Congress and the United States Supreme Court have played some role in its development, the legal components of this consensus have been almost exclusively state appellate judicial cases and state legislation. By the time the Supreme Court issued its first and only ruling in a case involving the passive hastening of death—the *Cruzan* case in 1990—the consensus was largely developed based on state law. The *Cruzan* ruling did little more than put the Supreme Court's imprimatur on a number of features of the existing consensus.

In the wake of *Cruzan,* Congress enacted the Patient Self-Determination Act (PSDA) in the same year. This law required institutional providers of healthcare to provide patients with information about their decision-making rights—including the right to make an advance directive. However, the Act was entirely procedural in nature; it did not establish any new rights, but only required that patients be told about their already-existing rights under *state* law.

COMPETENT PATIENTS. The centerpiece of the consensus on end-of-life decision making is the unanimous agreement that competent patients have a legal right to refuse treatment. So well established is this right that its existence has been largely assumed by both courts and legislatures. Although no court has ever said that this right is absolute, the manner in which courts increasingly discuss and apply it strongly suggests that they are headed toward that conclusion. In addition to the strong support in law-making institutions, the consensus of the public, of policy makers, of bioethicists, and the healthcare professions also supports a strong right to refuse medical treatment for competent patients.

LEGAL SOURCES OF THE RIGHT. Although in the *Quinlan* decision the New Jersey Supreme Court predicated the right to refuse treatment on a federal constitutional right of privacy, few other courts have based rulings on the right to privacy. It has become clear that this is a particularly weak basis for the right. Later courts have tended to ground the right in the common law—specifically, in the right to be free from unwanted interferences with bodily integrity protected by the law of battery. The United States Supreme Court, when addressing this issue in the *Cruzan* case, stated that the "logic of" a series of earlier cases decided by the Supreme Court suggests that there is a constitutional basis for such a right, but assumed this logic without actually holding that such a right exists. Presumably, this right is grounded in the protection of liberty contained in the Fourteenth Amendment to the United States Constitution, rather than the discredited right of privacy cited in *Quinlan.*

Regardless of the particular constitutional provision in which this right is grounded, the right is one that may only be asserted against individuals or institutions acting as agents of a state or federal governmental entity, and not against private individuals or institutions. Thus, the broadest and firmest legal basis for the right to refuse treatment is state law—state common law, state statutes, and state constitutional provisions—because it usually accords protections against actions taken by private individuals and institutions as well those taken by agents of the state.

HOW ABSOLUTE IS THE RIGHT? It can be said with absolute certainty that no legal right is absolute. In cases predating the *Quinlan* decision—mostly involving the refusal of blood transfusions by members of the Jehovah's Witness religion—judges readily gave lip service to the right to refuse treatment but exhibited an enormous reluctance to match words with deeds, and exhibited a high degree of creativity in evading the full implications of the right. They did so by finding patients incompetent who might not have been, declaring emergencies on flimsy evidence, and insisting that the state had a strong interest in children having two living parents.

With the passage of time, these efforts to evade the full force of a competent patient's strong right to refuse treatment have substantially dissipated if not disappeared. In a series of legal cases beginning in the late 1980s, courts—especially the Florida Supreme Court (*Wons v. Public Health Trust; In re Dubreuil*), but others too—began gradually to enforce a full-blown right to refuse treatment when Jehovah's Witnesses refused blood transfusions. No longer did judges find patients incompetent primarily because they refused treatment, nor find an emergency to exist simply because a physician says the patient would probably die without a blood transfusion. Courts also recognized that parents of minor children have no obligation to avoid risk-taking behavior simply because they are parents of minor children (*Fosmire v Nicoleau*).

This change in attitude is probably accounted for primarily by the fallout from *Quinlan* and cases like it. As courts increasingly strengthened the right of terminally ill or permanently unconscious *incompetent* patients to refuse treatment, it became increasingly difficult, if not impossible, to justify denying that right to fully competent patients. It is significant that although the objection to medical treatment in the Jehovah's Witness cases was based on religious belief, the decisions themselves were generally grounded on a common-law right to refuse treatment applicable to all, regardless of religious belief.

A parallel trend beginning in the mid 1980s involved non-religious refusers of treatment who also were not terminally ill or permanently unconscious. In a handful of cases beginning in the mid-1980s, permanently disabled, competent patients began to raise the question of whether they had a right to refuse life-sustaining medical treatment. In the landmark *Bouvia* case in California, the court held that a woman in her 30s, a victim of cerebral palsy, had a right not to be force fed by medical procedures even if the refusal led to her death (*Bouvia v. Superior Court*). In three cases in Georgia (*State v. McAfee*), Nevada (*McKay v. Bergsted*), and California (*Thor v. Superior Court*), the highest courts in those states held that quadriplegic accident victims who were being kept alive by ventilators had the right to refuse further treatment and thus die. In all four of these cases, if treatment were continued the individuals were likely, with adequate nursing care, to have a relatively long life expectancy and to remain mentally intact.

Thus, it was not just the patients who were as close to death as they could be while still alive who had the right to refuse treatment and allow nature to take its course, but also patients whose prospects for a meaningful existence were virtually certain.

INCOMPETENT PATIENTS' RIGHT TO REFUSE TREATMENT. A core point of the *Quinlan* decision, which has become a cornerstone of the consensus on end-of-life decision making, is that incompetent patients, as well as competent patients, have a right to refuse medical treatment. *Quinlan* and subsequent cases raised two subsidiary issues. The first was whether the termination of life support would raise the prospect of legal liability for criminal homicide on the part of those who terminated treatment. The second was whether or not there were any limits on the right to refuse treatment.

Lack of criminal liability. In the development of the consensus in the courts, in public policy—most notably by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (President's Commission)—and in bioethics, there has been a unanimous assertion that forgoing life-sustaining treatment that results in a patient's death does not constitute a crime as long as there is proper authorization for the termination of treatment, either from the patient, from someone legally authorized to speak for the patient, or from a court.

There are a number of explanations offered in support of this conclusion. One is that when treatment is withheld or withdrawn, there is no *intent* to kill but rather to relieve suffering. Thus there cannot be liability for homicide or aiding suicide because each of these crimes requires intent. Another is that the *cause* of death is not the conduct of the party who withholds or withdraws treatment (or who authorizes the termination), but the patient's underlying illness or injury. It can be asserted that the patient is not killed, but rather is allowed to die when life-sustaining treatment is forgone.

A third explanation is that when life-sustaining treatment is forgone, there is no liability for assisted suicide because the kind of act required for assisting—"affirmative, assertive, proximate, direct conduct such as furnishing a gun, poison, knife or other instrumentality" (*Bouvia v Superior Court,* p. 306)—does not exist. This explanation is less successful if the crime to be charged is homicide because an omission to act when there is a duty to do so, as might be the case when the actor is a physician or other healthcare professional, will support liability for homicide equally well as an act would (*Barber v. Superior Court*).

The fourth explanation given is that there is no criminal liability because the patient is exercising the legal right to refuse treatment. It is clear that this is not an explanation at all but a restatement of the question. Nonetheless, it is probably the best explanation. No liability, either criminal or civil, should arise as a result of a patient's death from forgoing life-sustaining treatment if this occurs in the exercise of a legal right to refuse treatment either by the patient or someone with legal authority to speak on his behalf. To conclude otherwise would be, in effect, to eliminate the right itself.

Limits on incompetents' rights: countervailing state interests. That there is a legal right of incompetent patients to forgo treatment does not mean that there are no limitations on that right. The courts have identified a number of countervailing societal interests that, in theory at least, may be invoked in opposition to the forgoing of treatment. These interests, recited in virtually every legal opinion on forgoing life-sustaining treatment, are:

1. the preservation of life;
2. the prevention of suicide;
3. the protection of third parties;
4. the ethical integrity of the medical profession.

In practice, these societal interests have not been accorded significant weight if the patient is terminally ill or permanently unconscious (or if the patient is competent). As to the preservation of life, the prevailing legal view is that of the New Jersey Supreme Court in *Quinlan*: "the State's interest … weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims."

The prevention of suicide is not a significant matter because of the virtually unanimous view that the forgoing of life-sustaining treatment is not suicide. However, in instances in which a person is very seriously disabled but not terminally ill or permanently unconscious, some courts are more reluctant to permit the forgoing of life support unless there is clear and convincing evidence of the patient's refusal of treatment in circumstances such as these, prior to losing decision making capacity (*Martin v. Martin*; *In re Edna M.F. v. Eisenberg*; *Wendland v. Wendland*).

As previously mentioned, one of the ways that courts found to circumvent the right of Jehovah's Witnesses to refuse blood transfusions was to invoke the societal interest in the protection of the children of these patients. In the case of minor children, however, the view is beginning to prevail that even though it is desirable for them to have not just one but two living parents, many other children do not, and in any event, to impose medical treatment on an individual in furtherance of this interest is to deny that person the choice of which risks to take, a choice assigned to adults—even those with minor children—in virtually all other circumstances. The interests of other close family members are just too attenuated to prevail in the face of the strong right of individuals to make their own medical choices.

Likewise, the judicial view is virtually unanimous that the forgoing of life-sustaining treatment does not offend the ethical integrity of the healthcare professions because these professions no longer hold the belief, if they ever did, that the sole goal of treatment is cure. In cases where cure is impossible or even highly unlikely, "the prevailing ethical practice seems to be to recognize that the dying are more often in need of comfort than treatment" (*Superintendent of Belchertown State School v. Saikewicz,* p. 426). And, returning to basics, "if the doctrines of informed consent and right of privacy have as their foundations the right to bodily integrity … and control of one's own fate, then those rights are superior to the institutional considerations" (*Superintendent of Belchertown State School v. Saikewicz,* p. 427).

Decision making procedures for incompetent patients. A central issue in *Quinlan* was the issue of how the right to refuse treatment is to be exercised when the patient is literally incapable of doing so. The two extremes that the court had available were to require that all such decisions be reviewed by a court, or that they take place in the privacy of the doctor-patient-family relationship without any oversight. Rather than choosing either extreme, the court settled on a middle ground: decisions to forgo life-sustaining treatment were ordinarily to be made in the privacy of the clinical setting without judicial involvement. However, to provide some safeguards against inappropriate decisions, the court mandated that the decision receive approval by a multidisciplinary ethics committee. This was a novel approach adopted from a law review article written by a physician just one year earlier (Teel).

One serious difficulty with this approach was the assumption that hospitals had ethics committees when in fact very few did. However, by mandating the use of an ethics committee, the court set in motion a movement for most healthcare institutions to create them. Another problem was the fact that, although the committee was labeled an ethics committee, the role the court assigned to it was to confirm the patient's prognosis, a medical function for which such a multi-disciplinary committee was unsuited. The more fundamental criticism, however, was that ethics committees had no clear moral authority to make or even review decisions about forgoing life-sustaining treatment.

As a consequence of these difficulties, no other court or legislature mandated the use of ethics committees in end-of-life decision making. In the *Saikewicz* case, decided just a year after *Quinlan,* the Massachusetts Supreme Judicial Court required that such decisions always be made by courts, because

> questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any other group purporting to represent the "morality and conscience of our society," no matter how highly motivated or impressively constituted. (*Superintendent of Belchertown State School v. Saikewicz,* p. 435)

However, practical—and some philosophical—considerations ultimately won out. No other law-making body concurred in this position and within just two years, the Massachusetts court itself backed away from it. Requiring judicial review of all decisions to forgo life-sustaining treatment is too cumbersome, slow, and time-consuming. More fundamentally, it creates a tremendous intrusion by instruments of the state into the very private process of dying.

Thus, after a very heated debate, a consensus developed that all procedural aspects of the decision making process—the determination of whether or not the patient lacks decision making capacity, the designation of a surrogate decision maker, and any review of the decision about forgoing treatment—should ordinarily be made in the clinical setting. An ethics committee may play a role if the parties choose to have it do so, but it is not legally mandated. And in situations in which there is intractable disagreement among participants in the decision-making process about administering or forgoing treatment, or if there is a serious conflict of interest, the courts are available to adjudicate the issue.

Decision making standards for incompetent patients. One of the central tenets of the consensus concerns the standard by which a surrogate may make a decision for a patient who lacks decision-making capacity. In theory, surrogates could be empowered to exercise complete discretion—to make whatever decision they wish, for whatever reason they wish. Rather than according such unfettered discretion, courts have sought guidance from the values in which medical decision making is grounded, the primary one being autonomy. When competent patients make medical decisions for themselves, they are guided by their own values and goals. On the assumption that decision making for incompetent patients should be similarly guided, the courts have invoked autonomy as the guiding principle for decision making by surrogates as well.

The difficulty, of course, is that when the patient lacks decision-making capacity—and in many instances lacks even rudimentary communication capacity—the patient's values and goals cannot be determined contemporaneously. To honor and implement autonomy, the courts have mandated that surrogates attempt to determine what the patient would have decided if the patient were capable of deciding. Some believe, however, that this is an elusive and ultimately futile search and that for individuals for whom autonomy is lost, decision making must be based on other values (Dresser; Harmon).

The predominant standard that has evolved and been adopted is referred to as the *substituted judgment* standard. It requires the surrogate to determine what the patient would have wanted had the patient actually given thought to the matter—in other words, the patient's *probable* wishes.

A small number of courts (most notably, the New York Court of Appeals) reject the substituted judgment standard altogether and insist that decision making for patients who lack decision-making capacity must be made on the basis of their *actual* wishes, that the evidence adduced to establish their wishes be clear and convincing, and that the statements made by the patient have been uttered under "solemn" circumstances and not merely be casual or offhand remarks, such as those made in reaction to the treatment of another (*In re Westchester County Medical Ctr.* [O'Connor]). Those adhering to this standard are preoccupied by the possibility of an erroneous decision to allow a patient to die—that is, a decision that does not reflect the patient's own wishes—and that in the case of uncertainty, it is better to err on the side of keeping the patient alive.

The opposing view recognizes that prolonging life can entail undesired effects as well, as expressed by U.S. Supreme Court Justice William Brennan in a dissenting opinion in the *Cruzan* case:

> Dying is personal. And it is profound. For many, the thought of an ignoble end, steeped in decay, is abhorrent. A quiet, proud death, bodily integrity intact, is a matter of extreme consequence.… Such conditions are, for many, humiliating to contemplate, as is visiting a prolonged and anguished vigil on one's parents, spouse, and children. A long, drawn-out death can have a debilitating effect on family members.… For some, the idea of being remembered in their persistent vegetative states rather than as they were before their illness or accident may be very disturbing.

Sentiments such as these have motivated other courts and the President's Commission to permit surrogates to forgo life-sustaining treatment in the absence of any information concerning the wishes of the patient, on the basis of the *best interests* standard. These authorities take the position that while autonomy is the predominant value, it is not the only one, and that when autonomy cannot be effectuated because of ignorance of the patient's wishes, the patient's *welfare* must govern instead. In such a case, the surrogate is obligated to do what is best for the patient, which entails a weighing of the benefits of continued treatment against its burdens. If the burdens predominate, the surrogate may authorize the termination of treatment (*Barber v. Superior Court; In re Conroy*).

Family members as surrogates for incompetent patients. An important corollary of the views that decisions about life-sustaining treatment should ordinarily be made in the clinical setting without outside supervision, and that the patient's own views should govern decision making, is the presumption that close family members are the appropriate persons to speak for the patient. When a decision needs to be made whether to administer or forgo life-sustaining medical treatment, physicians should turn to close family members, who have moral and legal authorization to decide for the patient, even if they have not been appointed as guardians by a court or designated by the patient to be their spokesperson. This presumption is based on the belief that close family members best know the patient's actual or probable wishes (substituted judgment) and when they do not are most likely to act for the patient's welfare (best interests).

Advance directives in decision making for incompetent patients. Because of the centrality of the patient's wishes in decision making and the inability to ascertain those wishes in precisely the instances in which that information is most needed, the use of advance directives in end-of-life decision making has taken on a very high degree of importance. An advance directive is a device by which competent individuals make their wishes known about treatment if, at some future time, they should lack decision-making capacity. This is best done through a formal written instrument which either gives instructions about future medical treatment (referred to as a *living will*), appoints another person (*agent* or *proxy*) to make such decisions (referred to as a *health care power of attorney*), or both.

In the wake of the *Quinlan* and similar judicial decisions, it became readily apparent that it would be useful, if not essential, for individuals to have an advance directive. In 1976, the same year that *Quinlan* was decided, California became the first state to enact legislation to provide a firm legal basis to assure the validity of advance directives. For many years, there was some uncertainty about the validity of an advance directive without such legislation. By the end of the twentieth century, however, every state had enacted some type of advance directive legislation.

Some uncertainty continues to surround the use of advance directives. Advance directive statutes can be very limiting. Perhaps the most restrictive requirement is that before an advance directive becomes effective, the patient must be in a *terminal condition* or *permanently unconscious.* However, some individuals may wish to engage in advance healthcare planning for other conditions that they find particularly troublesome, such as dementia. It is still open to question in law, at least in some states, as to whether such "nonconforming" advance directives are legally enforceable.

The theory of healthcare decision making, based as it is on individual autonomy, would seem to allow individuals to issue instructions—especially instructions to forgo life-sustaining treatment, such as feeding tubes—to cover such situations. However, a highly defensible position, as stated more or less explicitly in the statutes themselves, is that the statutes do not create legal rights to refuse (or consent) to healthcare, but merely provide a mechanism for doing so. The Uniform Health Care Decisions Act, a model law drafted by the National Council of Commissioners on Uniform State Laws, lacks the restrictions found in most advance directive statutes, but must be adopted in an individual state before it has the force of law, and so far it has not been.

Perhaps the largest obstacle to the efficacy of advance directives—to which the previously-mentioned PSDA was seen as a solution—is that most people do not have them, either out of ignorance of what they are or of their importance, or because of an aversion to planning for death, exhibited also by the failure of many people to buy life insurance or write wills.

Forgoing Artificial Nutrition and Hydration

In the *Quinlan* case, the legal question was whether Karen Quinlan could be allowed to die from the withdrawal of the ventilator that was keeping her alive. After the New Jersey Supreme Court answered this question in the affirmative, and her physicians gradually withdrew her ventilatory support, she continued breathing on her own, contrary to the medical assumption on which the case had been decided. Thereafter, she was kept alive by a feeding tube, raising the question of whether her parents could authorize the termination of the feeding tube as well.

Because they did not seek to do so, this question remained unanswered until 1983, when it arose in the California case of *Barber v. Superior Court.* In this case, physicians were subjected to criminal prosecution for the termination of a feeding tube from a patient diagnosed, like Quinlan, as being in a persistent vegetative state. This case, for the first time in a judicial forum, raised the question of whether it is permissible to withhold or withdraw nutrition and hydration. It is also the first of only two criminal prosecutions that have ever occurred for forgoing life-sustaining treatment with the consent of someone legally authorized to make such decisions for the patient.

Opponents of permitting the forgoing of nutrition and hydration usually raise two major objections. First, nutrition and hydration is not a medical procedure but basic sustenance, and thus should not be treated the same as, for example, a ventilator. In this view, one is no more morally entitled to remove nutrition and hydration from an incompetent patient than from a young child who cannot provide itself with nourishment. Perhaps the best legal rejoinder to this claim was issued in the *Cruzan* case by U.S. Supreme Court Justice Sandra Day O'Connor, who addressed the question by declining to answer it. Rather than entering into the debate about whether nutrition and hydration provided by a feeding tube was or was not a form of medical treatment, she observed that regardless of how it is characterized, when provided to an unwilling patient it constitutes a restraint on individual liberty. Since it is certainly contrary to individual autonomy to force feed a competent patient, it is contrary to the individual autonomy of an incompetent patient as well, when the patient's surrogate refuses it based on the patient's previously expressed wishes.

The second objection is that death resulting from the forgoing of nutrition and hydration amounts to killing, rather than letting nature take its course, and is therefore unlawful and immoral. The standard rejoinder to this is that there is no difference between termination of nutrition and hydration and other treatments. When a ventilator is terminated, the patient dies because his injury or illness prevents him from breathing and that is the cause of death. Similarly, feeding tubes are placed in, and only removed from, patients whose injury or illness prevents them from eating in the ordinary way, and thus it is the injury or illness, rather than the actions of the individual who removes the feeding tube, which is the cause of death.

Actively Hastening Death

The distinction between passively and actively hastening death has been central to the development of the consensus about end-of-life decision making. The former is equated with forgoing life-sustaining treatment, which includes both withholding treatment not yet begun and withdrawing treatment that is in progress. Actively hastening death consists of both active euthanasia (sometimes referred to as mercy killing) and assisted suicide. Active euthanasia is the direct ending of a human life, by a lethal injection, for example, whereas assisted suicide is defined as giving another the means by which that person ends his or her own life, such as providing a prescription for a lethal dose of medication which the person then ingests. Both legal and ethical thought have, for the most part, drawn a bright line between passively and actively hastening death, holding the former to be both morally and legally licit and condemning the latter as killing, and thus immoral and illegal.

The reasons for viewing passively hastening death as not constituting a crime were previously discussed. By contrast, when death is actively hastened—whether by the patient with assistance from another (assisted suicide) or directly by another (active euthanasia)—it is usually said that criminal liability cannot be avoided because all of the elements of a crime—act, intent, causation, consequence—are present. In the case of active euthanasia, to wit, the actor commits an *act,* with the *intent* of bringing about the patient's death, which is the *cause* of the patient's *death.*

From a legal, political, and policy perspective, this reasoning has been essential to the development of the consensus. It was simply not possible politically for legislatures or courts to have characterized forgoing life-sustaining treatment as killing and then to have attempted somehow to permit it. It was far simpler and more palatable to the public and to judges themselves to legitimate passively hastening death by denying that it was killing. Similarly, it would simply have been too great a leap from existing mores to legitimate actively hastening death, had any judge or legislator even wished to do so, because it involves practices that traditionally have been viewed as killing, even when done with merciful motives.

With the passage of time and increasing clamor for the legalization of actively hastening death—or at least for the legalization of suicide assisted by a physician—the weaknesses in the reasoning used to distinguish passively and actively hastening death have gradually become more apparent. Nonetheless, with a few exceptions both in the United States and other countries, legal barriers to actively hastening death remain.

Beyond the Consensus: The Legalization of Actively Hastening Death

Although the bright line between passively and actively hastening death is part of the bedrock on which the ethical, legal, and policy consensus about forgoing life-sustaining treatment has been grounded, it has not been immune from challenge. These challenges have come in writings by ethicists, in litigation, and in legislation.

It has occasionally been asserted that a physician is prohibited by law and ethics from undertaking an act that would end a patient's life because it constitutes killing, but is permitted to omit treating a patient because he or she is merely allowing nature to take its course and the patient to die. Both the courts and public policy makers (President's Commission) have been quick to correct this misunderstanding. Certainly taking an affirmative act to end the patient's life, such as giving the patient a lethal injection, is a legal wrong; omitting is also a legal wrong if there is a duty to act, and a physician is under a duty to treat unless excused from doing so by the patient, the patient's surrogate, or a court. Thus the categorical distinction between wrongness of acting and rightness of omitting is fallacious.

The same is true of withholding and withdrawing treatment. It has sometimes been thought that withdrawing treatment is a wrong because it involves an act, but withholding treatment is legally and ethically acceptable because it involves an omission. Again, if there is a duty to act, withholding is a legal wrong, unless properly excused. However, withdrawing treatment, even though it involves an act, is not considered killing because, unlike the administration of a lethal substance to the patient, withdrawing treatment merely allows nature to take its course. On policy grounds, the distinction between withdrawing and withholding is an especially pernicious one, because permitting treatment to be withheld but not withdrawn would discourage physicians from trying to treat some patients thought to be hopelessly ill out of fear that once started, treatment could not later be stopped, even if it were ineffective in reversing the patient's condition.

While the weaknesses in the reasoning that supports passively hastening death but rejects actively hastening death have long been apparent (Rachels), they have been papered over by the courts and justified by policy analysts when this has seemed necessary to achieve what some see as the desirable result of not legitimating actively hastening death. Some recognize the desirability of permitting actively hastening death in individual cases but oppose legalization, preferring to leave it to the private actions of doctors and patients, and to allow the legal system to exercise discretion in not prosecuting those truly merciful cases that come to its attention. The difficulty with this approach is that because the legal outcome for those who provide assistance or engage in mercy killing is so uncertain and so potentially serious, few will be willing to take the chance. Consequently, actively hastened death will not, in fact, be available to those whose conditions may warrant it, or else will be available on an arbitrary basis.

Apart from those who see actively hastening death as killing and condemn all killing as wrong, the primary concern seems to be a practical one. If actively hastening death becomes legally acceptable, there will be no way to draw lines to confine it to those for whom it might be appropriate, on both policy and ethical grounds, and it will become susceptible to widespread abuse through incremental extensions of existing accepted practices. For instance, if physician-assisted suicide becomes legal, what reasoning can confine actively hastening death to those who can self-administer the instrumentality of death? There will be individuals whose claims to actively hastening death are equally high, but who are no longer able to end their own life and thus must have someone end it for them. If actively hastening death is then extended to this group, there will be individuals who lose their decision-making capacity before being able to have their lives ended. Should not, in the name of equity, individuals be allowed to execute an advance directive requesting that their deaths be actively hastened when they are no longer able to do so themselves, and when they meet the conditions specified in the advance directive? And if this becomes permissible, then surely an actively-hastened death will be permissible for individuals whose wishes were never committed to paper but can be intuited by relatives using the substituted judgment standard. And if such evidence is lacking, then perhaps the best interests standard should be applied to permit an actively hastened death as it sometimes is to allow for passively hastened death. While this may not be the bottom of the proverbial slippery slope, it is far enough to demonstrate to many the lack of wisdom of ever stepping onto the slope by legitimating any form of actively-hastened death.

Proponents of taking the first step, however, believe first that it is merely a logical extension of the same process that recognized the legality and ethicality of passively-hastened death. Further, they believe that taking one step, or even more than one, does not necessarily entail a commitment to taking the next step. Experience and policy considerations may suggest limitations even where logic might dictate otherwise. Finally, proponents point to the inequity of permitting the terminally ill who depend on life-sustaining medical treatment to have their lives ended, but not permitting the same merciful release from suffering to the terminally ill who may have an equal claim but who happen not to be dependent on life-sustaining medical treatment.

Legalization of Physician-Assisted Suicide

Events began to overtake logic in the 1990s in the United States. Efforts to legalize physician-assisted suicide through voter initiatives took place in five states; all but one failed to win passage. Oregon voters approved a ballot initiative in 1994, which did not go into effect until 1997 because of efforts to overturn it in the courts and through a second voter initiative. Bills have been introduced into the legislatures of many states to legalize physician-assisted suicide, but none received very much support until 2002 when the Hawaii legislature narrowly defeated such an effort.

Several lawsuits have been filed seeking to declare unconstitutional state laws making assisted suicide a crime. Lower federal courts invalidated such laws in Washington state and New York state, at least when the person seeking assistance in dying was competent and terminally ill, and when the person rendering the assistance was a licensed physician. The two cases, *Washington v. Glucksberg* and *Vacco v. Quill,* were reversed by the United States Supreme Court in 1997. The Court held that there is no federal constitutional right to physician-assisted suicide—that states are constitutionally permitted to make assisted suicide a crime, but it is also constitutionally permissible for a state to legalize physician-assisted suicide, as Oregon had done.

All of the discussion of legalizing actively hastening death in the 1990s took place against the backdrop of the activities of Dr. Jack Kevorkian, a retired physician who publicly announced that he would aid individuals in ending their lives. He publicized many of his cases—totaling well in excess of one hundred until he was imprisoned in 1999. The high visibility of his activities was taken as a defiant invitation to legal authorities to file criminal charges against him on several occasions, but none were successful until he went beyond aiding patients' deaths and administered a lethal substance to a terminally ill man and then gave a videotape of the event to a national television network, where it was publicly broadcast. He was then indicted for murder, tried, and convicted.

Another important component in discussions of legalizing actively hastening death has been the experience with the open practice of active euthanasia in the Netherlands since the early 1970s. Until 2001, voluntary active euthanasia by physicians for competent terminally ill patients has been formally illegal, but actively practiced and not prosecuted by the authorities—if the physician complied with guidelines proposed by the Minister of Justice and the Secretary of Health—and supported by the Royal Dutch Medical Association. In that year, the Netherlands formally legalized voluntary active euthanasia along lines quite similar to the informal practice that had previously prevailed.

Dr. Kevorkian's activities were widely viewed as highly irresponsible by both supporters and opponents of the legalization of actively hastening death. Nonetheless, most admit that his activities—as well as the developments in the Netherlands—did have the consequence of helping to open public debate on this issue. One of the undoubtedly salutary consequences of the public debate has been an acknowledgement and realization that the medical profession has been laggard in providing adequate palliative care—especially pain relief—to terminally ill individuals, and that there has been inadequate education of physicians about these issues. In the view of many, improvements in these areas are not only necessary to relieve the suffering of the dying, but they may also go a long way in derailing the legalization of actively hastening death. Others, however, see these two approaches as complementary, rather than working in opposition to each other.

THE OREGON EXPERIENCE WITH PHYSICIAN-ASSISTED SUICIDE. Physician-assisted suicide was legalized by a voter initiative in Oregon in 1994 and went into effect in November 1997. The law does not actually refer to physician-assisted suicide; the title of the law is the Oregon Death with Dignity Act, but in fact physician-assisted suicide—or, as some prefer to call it, physician aid-in-dying—is the practice that is made legal. The law permits a competent terminally ill patient to have a physician prescribe a lethal dose of medication for the patient to self-administer; it does not permit the physician or anyone else to administer the medication (active euthanasia).

In the first four years of its operation, 140 (2001: 44; 2000: 39; 1999: 33; 1998: 24) people obtained lethal prescriptions from their doctors and 89 (2001: 19; 2000: 27; 1999: 27; 1998: 16) used them to end their lives. The remainder died without using the prescriptions. The death rate for those using a lethal prescription varied between six and nine per ten thousand, which is in the same range as the death rate of individuals who die otherwise. Most patients suffered from cancer. The three most commonly mentioned reasons that patients wanted to end their lives were loss of autonomy, a decreasing ability to participate in activities that made life enjoyable, and losing control of bodily functions. The overwhelming proportion of patients died at home.

Fears that people who would avail themselves of physician-assisted suicide would do so because of lack of alternatives were not borne out by experience. More than three-fourths of patients were also enrolled in a hospice care program, and all had some form of health insurance. Likewise, patients who used physician-assisted suicide were similar in terms of age and race to those who died without using it. Patients who used physician-assisted suicide were also better educated. However, more women died in this manner than men with comparable disease, and those who died in this way were more likely to be divorced and possibly not have as good family support systems (Oregon Department of Human Services).

Opponents of the legalization of physician-assisted suicide in Oregon have mounted several efforts to have the law invalidated. The first was a lawsuit challenging the constitutionality of the law, which delayed its implementation for three years. While this lawsuit was pending, opponents were able to put an initiative to overturn the original legalization on the Oregon ballot in 1997. Although the original approval was by a 51 percent to 49 percent margin, Oregon voters underscored their approval of the physician-assisted suicide legalization by refusing to repeal the law by a 60 percent to 40 percent margin. However, shortly after the law went into effect, the director of the federal Drug Enforcement Administration (DEA) ruled that it was a violation of the federal controlled substances act for doctors to use controlled substances in the implementation of the Oregon law. This was quickly reversed by the U.S. Attorney General Janet Reno. Bills were then introduced in two sessions of Congress to prevent the use of controlled substances in physician-assisted suicide, but neither was enacted. With a change of administration in 2000, Attorney General John Ashcroft reversed the policy of the former Attorney General and banned the use of controlled substances in physician-assisted suicide. A lawsuit was then filed to prevent implementation of the Attorney General's order, and a federal court ruled that the order was illegal and could not be implemented.

Beyond the Consensus: Autonomy Turned Upside Down

Although patient autonomy is the foundation on which the consensus around end-of-life decision making has been built, autonomy has encountered a serious challenge in the form of so-called futility cases. These cases reverse the usual right-to-die cases. In those cases, competent patients or family members have determined that further treatment is unwarranted and challenged physicians who have wanted to continue to provide treatment. In futility cases, physicians and other healthcare professionals conclude that further treatment is unwarranted, but are met by resistance from competent patients—or, more likely, family members of incompetent patients—who insist that treatment be continued. Despite the raft of literature on this subject, there has been very little contribution to resolution of this debate by either courts or legislatures. Most likely, situations of this sort are eventually resolved in the clinical setting either by the patient's death, for the patients involved are usually very critically ill, or by a realization by family members over time that further treatment will not improve the patient's condition.

Future Challenges for Policy Makers, Legislators, and Health Professionals

The consensus about forgoing life-sustaining treatment has become well-accepted in public policy, law, and clinical practice. Despite the fact that half of the states have not yet experienced a major legal case, it does not seem likely that these states will make major changes in the consensus.

The same sort of stability is not likely to exist with respect to actively hastening death. Coming decades are likely to witness continuing challenges to the prohibition on assisted suicide in the courts, in state legislatures, and through ballot initiatives. Acceptance in law is likely to be very gradual, if it occurs at all. However, the influence of the movement to legalize actively hastening death will continue to be felt in improved efforts at providing alternatives in the form of hospice care, palliative care, and the more judicious use of pain relief medications, even if they might hasten death.

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SEE ALSO: *Autonomy; Christianity, Bioethics in; Competence; Conscience, Rights of; Death; Death, Definition and Determination of; Dementia; Harm; Homicide; Informed Consent; Islam, Bioethics in; Judaism, Bioethics in; Law and Bioethics; Law and Morality; Life, Quality of; Medical Ethics, History of Europe, Contemporary Period: The Benelux Countries; Medical Codes and Oaths; Pain and Suffering; Palliative Care and Hospice; Patients' Rights; Professional-Patient Relationship; Suicide; Virtue and Character*

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SCIENCE, PHILOSOPHY OF

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Philosophy of science as an autonomous subject is a product of the twentieth century. Its development stemmed from the great intellectual challenges of the quantum and relativity theories, but philosophical issues surrounding such theories as psychoanalysis, evolutionary theory, Marxist and capitalist economics, the ethics of human experimentation, and the enormously increased importance of science as an intellectual endeavor led to a great expansion of the field.

Work within philosophy of science tends to fall into two approaches. The first sees science as a testing ground for traditional philosophical problems. Chief among these traditional problems is this: Can we have any knowledge that is certain and in terms of which all other knowledge in the area can be justified (*foundationalism*), or are all claims to knowledge uncertain (*fallibilism*)? Within the realm of things that can be known by empirical investigation, it would seem that science has the best claim to secure knowledge. Philosophers of science have thus devoted a considerable amount of time to what kinds of scientific methods are effective in producing such reliable knowledge. On the other hand, many philosophers, especially in recent times, have denied that science does actually produce a privileged body of knowledge, and have argued that all scientific knowledge is a product of its historical and social context.

The second approach to philosophy of science focuses on issues that are peculiar to individual sciences. Of particular interest here is the possibility of reducing biology to chemistry or physics, and of reducing some of the social sciences, especially psychology, to biology. If these reductionist projects were to be successful, then issues that currently appear to be peculiarly biological, such as the question of what makes something a living organism, would turn out to be merely a question of degrees of complexity, and not specifically biological at all. In addition, the moral issues that pertain to humans and animals because of their psychological characteristics would be approached very differently if psychological properties were considered to be unreal or merely disguised biological properties. These differences between the sciences are crucial. For example, a great deal of medical research cannot enjoy the unlimited freedom of laboratory experimentation that is characteristic of physics simply because of the ethical constraints its subjects require. Moreover, the variability of its subjects makes universal laws hard to formulate in biology, in distinction to, for example, astronomy.

Predecessors to Contemporary Viewpoints

It was the logical positivists and logical empiricists of the Vienna Circle (1923–1936) and the Berlin school (1928–1933) who succeeded in placing scientific issues near the heart of the philosophical enterprise. (A classic, albeit sententious, presentation of the logical positivists' views can be found in A. J. Ayer's *Language, Truth and Logic,* 1946.) For philosophers such as Moritz Schlick, Rudolf Carnap, Hans Reichenbach, and Carl Hempel, all of whom had a scientific education, the task was to provide a foundation for genuine knowledge, and this foundation was to be as secure as the best science of the time. The logical positivists were squarely within the empiricist tradition, which holds that all genuine knowledge must be reducible in principle to knowledge obtainable by empirical methods, and ultimately to that obtainable through the human sensory apparatus. To this empiricist view they added a deep concern with language resulting from developments in logic in the late nineteenth and early twentieth centuries. Although the most famous manifestation of their approach was the attempt to eliminate metaphysical claims through the verificationist criterion of meaning (which asserts that a sentence is factually significant to a given individual if and only if he knows what observations would lead him to accept that proposition as true or to reject it as false), their true legacy has been the view that it is by means of logical analyses of philosophical concepts that genuine understanding is achieved. It is no exaggeration to say that philosophy of science since 1950 has been primarily engaged in a struggle to decide which elements of the positivist monolith to retain, and what should be the replacement approaches for those parts that have been rejected.

Falsificationism

An important alternative to the positivist program has been the falsificationist approach of Karl Popper. Although his *Logik der Forschung* was published in 1934, its impact was muted until the expanded English translation appeared in 1959 as *The Logic of Scientific Discovery.* Popper set himself the task of providing a criterion that would distinguish between genuine scientific hypotheses and pseudoscientific statements. A key belief driving Popper's work was his view that the traditional problem of induction could not be solved. Most generally, inductive inference involves reasoning from what has been observed to what has not been observed, a characterization that covers inferences from the past to the future, from observed data to the existence of directly unobservable microentities such as prions, and from finite data sets to the universal hypotheses that represent scientific laws and general theories. Justifying inductive inferences was a serious problem for logical positivism, because the verificationist criterion ruled out all universal scientific theories and laws as meaningless, simply because no amount of finite data could conclusively verify these general claims. Popper instead proposed the demarcation criterion that a statement or theory was scientific only if it was falsifiable; that is, it must be possible to state in advance a set of possible observations which, if observed, would result in the statement or theory being rejected. Theories such as astrology and psychoanalysis were, according to Popper, branded as pseudoscientific on the basis of this criterion because they traditionally accommodated themselves to fit any observations whatsoever. To refuse to relinquish a theory in the face of recalcitrant data is a characteristic feature of scientific irrationality. Popper's brand of falsificationism is comprehensive, for it requires that even reports of observations be falsifiable. Thus, in contrast to the positivists' foundationalism, which is grounded in an empirical base that is certain, falsificationism is a deeply fallibilist position, within which claims to certainty are relinquished at all levels of generality.

Popper was well aware of a point often made by the French philosopher Pierre Duhem: In order to draw out testable predictions from scientific hypotheses, one ordinarily needs to assume the truth of various background assumptions and theories (Duhem). Thus, if the prediction turns out to be false, the force of the falsification could be deflected away from the principal hypothesis onto the background assumptions. Hence the need in the above specification of falsificationism to state *in advance* what would result in the hypothesis being rejected.

Although this strategy removes the force of Duhem's criticism that there are no crucial experiments that can conclusively decide between competing theories, it moves the emphasis away from a method of testing that is based only on logic and empirical data to one where a (human) decision plays a central role, and this introduces a characteristically conventional element into the picture. Falsificationism is primarily a normative methodology, for it prescribes and proscribes courses of action with respect to scientific hypotheses. As historical and sociological studies of science have become increasingly influential, there has been a concomitant emphasis on the need for methodological theories to be descriptively accurate of what scientists do and have done. It is easy to find cases where historically important episodes of science do not fit the falsificationist model, ones where scientists refused to abandon theories in the face of clear counter evidence. The difficult task is to articulate when this furthers broad scientific ends, rather than just narrow personal motives. But to reject falsificationism merely because it is not descriptively accurate of everything done in the name of science would be as misguided as the attempt to turn ethics into a purely descriptive enterprise.

Thomas Kuhn's Work

One of the best known alternatives to the positivist approach is Thomas Kuhn's. Ironically, Kuhn's seminal work *The Structure of Scientific Revolutions* (1996) was originally published in the positivists' *International Encyclopedia of Unified Science* (Kuhn, 1955). Kuhn's strategy was to use the history of science as a proving ground for methodological positions in the philosophy of science. This history, Kuhn claimed, could be divided into two distinct types of periods. There were long stretches of normal science punctuated by brief periods of revolutionary science. To illuminate both kinds of science, Kuhn introduced the concept of a scientific paradigm. This concept, in its mature characterization, consists of four components. First, there are the symbolic generalizations, those fundamental laws and principles of a science that underpin all theoretical work in the field, such as the laws of genetic replication or the principle of natural selection of species. Second is the metaphysical component of the paradigm, within which the fundamental kinds of things constituting the subject matter of the science are specified, such as atomistic or field-theoretic assumptions in physics, or a commitment to specifically mental properties, as opposed to material properties, in psychology. Third, there are the value commitments. These not only concern what constitutes an acceptable piece of evidence in the science, but what the appropriate goals are for a science, and what the ethical standards are to which one should adhere. Thus, double-blind studies will be considered the standard methodology for drug trials. Fourth, there are the exemplars, those quintessential successes that a scientific field can point to as evidence for the fruitfulness of the first three elements, as, for instance, Newtonian mechanics could point to its success in predicting the existence of the planet Neptune.

Normal science, then, is science conducted entirely within the framework of a single paradigm, whereas revolutionary science consists in the development of a competing paradigm and the process of a scientific community's transfer of allegiance to the new paradigm. A seemingly inescapable consequence of paradigm change in periods of revolutionary science, and one that is deeply disturbing to many, is that the process of change is determined by neither rational argument nor empirical evidence. Because a change in paradigm necessarily involves a change in at least one of the four components already described, there will inevitably be fundamental differences of opinion about whether the old or the new component is preferable, and the remaining three components will frequently not provide a large enough common ground to resolve the dispute in an impartial way. In this way, paradigms are, to use Kuhn's term, incommensurable. There is then a deep difference between Kuhn on the one hand and both Popper and the positivists on the other.

Equally important is the distinction between internal and external descriptions of science. Within both the positivists' and Popper's approaches, the way in which science proceeds ought to be appraised only in terms of influences that are purely internal to the science at hand, including the construction of theories, the invention of new experimental apparatus, and the verification or falsification of hypotheses by empirical data. Any interference by nonscientific factors, such as economic considerations, political pressure, and religious prohibitions, are to be condemned as illegitimate influences to be resisted in practice, and ignored in writing the history of the science. In contrast, Kuhn holds that not only are such influences usually present and causally effective in propelling or impeding the elaboration of a paradigm, but they are frequently important in fixing the values component of a paradigm. Thus, the religious opposition to research on fetal tissue derived from deliberate abortions, the political pressure to direct funds in molecular biology toward acquired immunodeficiency syndrome (AIDS) research, and the decision to allocate significant financial resources to the Human Genome Project are all part of an externalist appraisal of the scientific research concerned. Inseparable from this externalist approach is the shift in emphasis from scientific theories as logical entities whose existence and appraisal are objective matters, and the truth or falsity of which is something to be discovered, to a position where the opinions of a community of scientists are primary, and acceptance of a paradigm is determined by a consensus in that community rather than by the paradigm's truth or falsity. Coupled with the inclusion of externalist factors, this leads naturally toward a focus on the sociology of science, rather than its philosophy as traditionally conceived.

Some further consequences of the Kuhnian approach are worth mentioning. Because of the incommensurability of paradigms, revolutions lead to schisms in the path of science, with a resulting loss of the notion of scientific progress. Comparative judgments of the kind "Paradigm A is superior to Paradigm B" can no longer be made on a uniform scale of comparison, and what remains is technological progress without any necessary concomitant progress toward the truth. Consequently, what has come to be known as the Whig view of the history of science, which sees the development of science as an uninterrupted triumphal march to the peak of contemporary success, has to be abandoned in favor of a contextually sympathetic interpretation of previous theoretical traditions. Finally, if Kuhn is correct, there is no longer anything peculiarly privileged in the scientific enterprise. The development of art, architecture, music, and so forth can all be characterized in terms of paradigms, normal practice, and revolutionary changes, a feature that has not escaped Kuhn's critics.

Contemporary Work in the Field

Perhaps the most important consequence of the collapse of the positivists' domination in the philosophy of science has been the splintering of the field into a number of subsets. One principal division is between those who continue to hold that there are general principles underlying various scientific methods, and those for whom only local, context-specific approaches are feasible. Certain areas of science still seem to be amenable to the first approach. The nature of scientific explanation is a topic of perennial interest, with various causal and unification approaches (Salmon) serving as the chief contenders to replace Carl Hempel's logical model. How scientific hypotheses and theories are confirmed is the subject of another area of research (Achinstein), with computer-assisted diagnostic procedures in medicine forming a small but important proving ground for inference procedures. There is considerable current interest in causal inference, particularly of the kind used in epidemiology (Pearl). Despite these successes, issues related to the autonomy of particular sciences have increasingly come to the fore. The positivists' orientation towards reducing all sciences to physics, at least in principle, has been replaced by a recognition that at least in practice, and perhaps even in principle, this reduction cannot be carried out. There is now a "philosophy of X" for almost every science, from economics to geology. In particular, the philosophy of biology and the philosophy of medicine are well established subfields with their own problems and methods. Accompanying this trend has been a reduced emphasis on grand unifying theories in favor of local models that capture, albeit imperfectly, the structure of specific systems (Humphreys). This latter approach works well for biological models, within which the sheer number and complexity of the influences on a system and the importance of its historical evolution render simple general theories inadequate.

A second primary division is between those for whom normative, objective, and a priori characterizations of science are desirable and attainable, and those who maintain that such characterizations are inevitably descriptively inaccurate and unrevealing of the true nature of science. Within this latter orientation lie contemporary naturalistic and cognitive approaches to philosophical issues. Philosophers using these methods hold that scientific knowledge from areas such as psychology and evolutionary biology shed more light on why certain methods are successful than can more traditional a priori approaches. For example, instead of specifying a priori the inferences that an ideal reasoner should make in deciding which course of action is appropriate in some clinical setting, a naturalist will investigate the heuristics that underlie reasoning used in clinical practice (Gigerenzer, Todd, and ABC Research Group).

Another dispute is between those who hold that many objects of scientific investigation, such as various psychiatric disorders, are social constructions, and those who hold that there is an objective reality that science investigates (Hacking). Much of this work is interesting and legitimate, but the rejection of traditional norms of rationality has led in certain quarters to a denial that science has any claim to superior methods of investigating the world. The so-called "science wars" between those who seek to maintain the epistemological superiority of science and those who wish to undermine it are an extreme, albeit avoidable (Koertge) consequence of this division.

All of the threads described have made formulating a satisfactory account of scientific progress less easy than it was in earlier periods, especially within the philosophy of biology. The piecemeal framework of models, the attacks on both the rationality of scientific appraisal and the objectivity of reality, the autonomy of multiple sciences—all have made a defense of progress towards a unified scientific account of the world more difficult than one might wish. Nevertheless, mere complexity and locality does not preclude science from accurately describing an objective reality in a systematic and rational fashion.

Summary

Philosophy of science and bioethics share a common concern. Each must draw a line between the prescriptive and the descriptive, between what is rational and justified on the one hand, and what is merely popular opinion and prejudice on the other. Both Galileo and Ignaz Semmelweiss were victims of such antiscientific attacks, the first for advocating the correct theory of the solar system, the second for discovering the mode of transmission of childbed fever. It is thus essential to have some clear distinction between fact and opinion, between the rational evaluation of a hypothesis or ethical view and its mere acceptance, between what is ethically justified and the way individuals happen to act. To use a specific example, it is essential to distinguish between what science can do to allow premature babies to survive and how one can evaluate the quality of life they might expect. This, if nothing else, is why the apparently dry and abstract issues of the foundations of knowledge, of internal and external influences on science, and of fact versus convention bear directly upon matters of more immediate concern.

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SEE ALSO: *Biology, Philosophy of; Research Bias; Research Methodology*

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SCIENTIFIC PUBLISHING

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During the late 1970s and the 1980s, an ethics of scientific publication began to evolve. Competition among scientists for academic rewards and research funds, the continued fragmentation and commercialization of science, and reports of scientific misconduct, as well as increasing governmental and legal interference with the inner workings of the scientific community led many within that community to perceive a need for reforms to guide both the conduct of science and the dissemination of scientific information. Journal editors, universities, professional associations, funding agencies, and governments have taken active roles in debating and setting ethical standards and editorial policies for the dissemination of scientific information. In 1978, a self-appointed group of editors, the International Committee of Medical Journal Editors (ICMJE), representing leading general medical journals, met in Vancouver, British Columbia, to set technical guidelines for the submission of manuscripts. These guidelines, the Uniform Requirements for the Submission of Manuscripts to Biomedical Journals, have evolved to include statements for the ethical conduct of authors, editors, and peer reviewers. While the ICMJE statements set international standards for biomedical publishing, the number of journals that adhere to them is unknown (ICMJE, 1991, 1993b). This entry presents an overview of the major ethical issues in biomedical and scientific publishing.

Editorial and Peer Review

The prestige and influence of biomedical journal publication are closely related to the quality control and selection process that precedes publication. Thus, the essential tasks of medical editing are the selection and improvement of articles submitted for publication. These tasks are generally accomplished through processes of editorial review (evaluation by the journal's editorial staff) and peer review (evaluation by experts in a given field who are considered the authors' "peers"). These two processes may overlap, particularly when an editor is also an expert in a manuscript's topic, but editorial review usually focuses on the appropriateness, clarity, and priority of articles for the journal's readership. Peer reviewers are selected by the editor to assess the quality of an article's scientific and technical content and to offer advice about publication. Since decisions regarding rejection, revision, or acceptance are made solely by the editor, the term *referee* exaggerates a reviewer's advisory role and should be avoided.

Peer review was first used for biomedical publications by the Royal Societies of London and Edinburgh in the eighteenth century, but evolved haphazardly; it was not employed regularly until after World War II (Lock). Two striking aspects of peer review are that it is based almost entirely on uncompensated, voluntary labor and that the peer review system itself has only recently come under scientific scrutiny (Lock; "Guarding the Guardians,"; Rennie and Flanagin, 1994b). Journals follow differing policies about revealing reviewers' identities to authors and authors' identities to reviewers (Lock; "Guarding the Guardians,"; Rennie and Flanagin, 1994b). Some editors believe that disclosure of reviewer identities to authors decreases the potential for bias, while others believe such disclosure leads to less critical reviews. Many biomedical journals do not attempt to remove the identities of authors or their institutions from submitted manuscripts; studies have shown that author identities may be discerned by reviewers from the paper's content or from bibliographic citations, especially in narrow subspecialties (Lock). On the other hand, these same journals do not reveal the identities of peer reviewers to authors. While most editors are impressed by the care and objectivity usually reflected in reviewer comments and recommendations, the anonymous review of papers whose authors are known obviously involves potential for abuse. To maintain integrity in the peer review process, reviewers are expected to disclose any conflicts of interest involved in their review, and editors are expected to be alert to any signs of bias that may interfere with an objective evaluation of the merits of the paper.

Maintaining the confidentiality of an author's work before publication is an important ethical principle in scientific publishing. Most journals inform peer reviewers that the information in unpublished manuscripts is privileged and should be kept confidential, and also require manuscripts to be either returned to the editorial office or destroyed after review. However, maintaining confidentiality depends on an honesty among editors, authors, and reviewers that is nearly impossible to guarantee. Conscious or unconscious intellectual theft by peer reviewers may occur but cannot be measured. Journal editors have a particular responsibility to maintain strict confidentiality about the peer review process, editorial decisions, and all manuscript submissions.

How well do the processes of editorial and peer review work? Many persons involved in publishing recognize the improved quality of articles that have been revised after review, and this has been clearly demonstrated with regard to improvements of study designs and statistical methods ("Guarding the Guardians,"; Rennie and Flanagin, 1994b). Nevertheless, both editorial and peer review are based on human judgments that carry the potential for bias and error.

One form of publication bias is the tendency for papers with statistically significant "positive" results (for example, those showing that a new treatment works better) to be published in favor of papers with statistically nonsignificant "negative" results (for example, those showing that a new treatment does not have any effect or does not work any better than other treatments). Studies have shown that such publication bias exists, but its extent is unknown and controversial ("Guarding the Guardians,"; Rennie and Flanagin, 1992, 1994b). Prepublication bias (the tendency of authors not to submit negative results for publication because the findings are incomplete or nonsignificant or because funding runs out) and postpublication bias (bias in the reception and interpretation of published research data by researchers, funding agencies, editors, and the media) may be more substantial problems. All of these forms of bias can lead to inappropriate medical policies and treatment decisions, especially with new or controversial therapies. Hence, the evaluation of scientific results should be based on their quality and importance, not on their direction.

Authorship

Despite the fact that university promotion committees evince some shift in the emphasis from the quantity to the quality of publication, academic pressures to publish remain. In many academic circles, achievement is still measured by the length of an individual's bibliography. As a result, authorship of an article published in a peer-reviewed scientific journal carries considerable merit, and consequently, considerable responsibility (Rennie and Flanagin, 1994a).

During the past several decades, the meaning of authorship has become diluted as the number of names appearing in scientific article bylines has grown. Authors have justified lengthy bylines by the increasing specialization of science and the need for collaboration among many subspecialists. But the once-accepted practices of adding the names of a department chair or laboratory chief to the end of bylines (guest authorship), and hiring someone to write up a paper without credit (ghost authorship), have caused many editors to adopt formal policies to curtail inflated bylines (Huth, 1986a, 1986b; Lundberg and Flanagin; Rennie and Flanagin, 1994a) and limit the number of names that can appear in a byline without formal justification.

In 1985, the ICMJE recommended that only those persons who have participated sufficiently to take public responsibility for the work should be authors and that "authorship credit should be based solely on substantial contributions to (a) conception and design, or analysis and interpretation of data; (b) drafting the article or revising it critically for important intellectual content; and (c) final approval of the version to be published" (ICMJE, 1991). Each of these criteria must be met by each person listed in the byline, and the authors must state that they meet these criteria in the cover letter accompanying each submitted manuscript. In the latter half of the 1980s, a number of medical journals, including the *Annals of Internal Medicine* and the *Journal of the American Medical Association* (JAMA), began requiring authors to sign authorship statements based on the ICMJE criteria. Anyone who does not meet these conditions but has contributed or assisted significantly can be recognized in an acknowledgment within the article, if he or she has given written permission to be so named (ICMJE, 1993b).

Group authorship results when investigators from many different institutions or participants in study groups, consensus conferences, or working groups prepare reports of their works. Frequently these groups comprise hundreds of investigators, technicians, and specialists. While it is conceivable that each of these individuals contributed critical time and information to the overall work, it is unlikely that each meets the ICMJE authorship criteria. In these cases, those participants who do meet the authorship criteria can be listed with the name of the study group in the byline. Those participants who do not qualify for authorship are then listed in a group box or in an acknowledgment. If all of the participants do meet the criteria for authorship, then the group name can be listed as the sole byline, with the individuals composing the group named in a separate box or the acknowledgment.

Unlike the definition of authorship, there are no established standards for order of authorship, although a number have been proposed, ranging from alphabetical listings to mathematical formulas for determining individual contribution levels and ranking. Many editors agree that authors should be listed according to how much they contributed, with the author who contributed the most listed first and the author who dontributed least listed last (Huth, 1986a, 1986b; Riesenberg and Lundberg). In addition, a number of publications and indexes limit the number of names to be published in a reference list to three, six, or ten. But there is still no consensus on the order of authorship, mostly because there are no widely accepted objective measures of individual coauthors' contribution levels. Editors recommend that authors determine the order of authorship before writing their papers, or before beginning their study, with an agreement to reevaluate the order later if necessary. Editors also recommend that authors solve disagreements over order among themselves, since the authors are in the best position to determine levels of contribution (Riesenberg and Lundberg; ICMJE, 1991).

Duplicate Publication

Another result of the pressures to publish and a driving force behind the need for ethical standards in scientific publication is the practice of duplicate publication. Also known as multiple, dual, or redundant publication, duplicate publication is the simultaneous or subsequent publication of the same article or major parts of an article—methods, results and data, discussion, conclusions, and graphic or illustrative material—in two or more journals or other media, including electronic journals and databases, without notifying the editors (Huth, 1986a, 1986b; ICMJE, 1993b; Iverson et al.). The types of duplicate publication range from selfplagiarism (publishing two or more identical articles or large parts of an article in different journals without citing each article in the texts and references lists) to "salami slicing" (dividing up different parts of the same study for publication in different journals) to sequential publication (reporting follow-up of the same study with additional subjects but without new results). Word-for-word duplication is uncommon, as duplicators usually attempt to alter or disguise the similarities.

Duplicate publication should be distinguished from secondary publication, in which an article or abbreviated version is subsequently republished, in the same or another language, with the consent of both editors. The secondary article should include a footnote on the title page, informing all readers that the information was published previously, and a complete citation to the primary article. Duplicate publication may violate copyright law, and it is unethical for an author to submit duplicate papers to different journals without notifying the editors. By doing so, authors clutter the literature with redundant information; waste the valuable time and resources of editors, reviewers, and readers; and prevent other authors from publishing their work because of limited journal space. To discourage such practices, many scientific journals state in their instructions for authors that they will only consider papers that have not been previously published or submitted to other journals, and some journals will publish notices of duplicate publication, publicly admonishing those authors who publish duplicate articles in violation of the journal's written policies (Iverson et al.).

Conflicts of Interest

Reflecting the increasing commercialization of science and the public doubts about researchers' once hallowed and rarely questioned integrity, financial conflicts of interest are now recognized as another ethical problem for authors and editors. During the 1980s, the public's trust of the scientific community diminished as a result of a number of public scandals and government investigations of biomedical researchers' ties to drugs with potential public health benefits and high financial rewards for stockholders and manufacturers (Relman; Lundberg and Flanagin; U.S. Congress). These cases have generally involved researchers being biased by their direct but undisclosed financial interests, such as stock ownership and paid consultancies. However, there are several other potential sources of author bias: funds from granting agencies, any research or material support, employment, money paid for expert testimony, and honoraria paid for public speaking.

Recognizing that not all financial interests will bias an author, editors disagree over how to handle these financial interests. Most journals publish an author's source of funding or material support, but that is usually because the funding institution requires that it be published. Some journals require authors to disclose all financial interests relevant to the work reported in their submitted manuscripts. If a manuscript is subsequently accepted for publication, the editors of these journals will determine whether it is necessary to publish such financial interests. In this manner, readers can judge for themselves the author's potential for bias from a financial interest just as they can judge an author's potential for intellectual bias based on his or her previously published works or specialty status (Rennie et al.). In 1990, the *New England Journal of Medicine* instituted a stringent policy prohibiting anyone with relevant financial interests from publishing editorials or review articles in that journal. Critics have argued that such prohibition is scientific censorship.

In 1989, the American Federation for Clinical Research and the Association of American Medical Colleges recommended full disclosure of all relevant financial interests and the possible divestiture of any stock or equity in a company that makes a product the researcher is studying (U.S. Congress). The Editorial Policy Committee of the Council of Biology Editors (CBE) recommends that authors disclose all relevant financial interests to the editors at the time of manuscript submission, and that editors disclose authors' financial interests to reviewers and readers when appropriate (CBE). There is no consensus among editors for the need and extent of such disclosure. In 1993, however, the ICMJE approved a statement that all participants in the peer review and publication process disclose any conflicting interests (ICMJE, 1993a). Some journals with disclosure policies have applied the basic principles of disclosure to everyone in the editorial process, including editors, editorial board members, and in some cases, reviewers (Relman; Rennie et al.).

Fraudulent Publication Resulting from Scientific Misconduct

The publication of a fraudulent article remains the most serious transgression of the ethics of scientific publication. The once generally accepted view that scientific misconduct was rare and committed by a few deviants has been replaced by a view, unsubstantiated, that it is more common and can involve respected scientists from leading institutions. Scientific misconduct has been defined as plagiarism (presenting another's ideas without attribution), fabrication (presenting data or facts that do not exist), falsification (changing or selecting certain data to obtain a desired result, misrepresenting evidence or facts, or misrepresenting authorship), or other serious deviations from accepted practice in the proposing, conducting, or reporting of research (U.S. Department of Health and Human Services). Policy makers have disagreed over the merits of including the phrase *deviations from accepted practice* in the definition. Some argue that the phrase is too vague and thus open to misinterpretation and overuse (Committee on Science); others argue that it must be included to address misconduct that would not technically be considered plagiarism, fabrication, or falsification. Examples of such deviations include misuse or theft of privileged information by a reviewer or editor, submitting a paper listing several coauthors who are unaware that they are named as coauthors, misrepresenting publication status of articles in a bibliography, or failing to perform funded research while filing reports stating that such work has been done (U.S. Department of Health and Human Services).

Variations in the definition of fraud have caused some confusion, but most editors acknowledge a major difference between fraud and unintentional errors. Although unprofessional and in some cases unethical, the following usually are not considered fraudulent: errors in study design or application of methods, inappropriate use or interpretation of statistics, faulty interpretation or overgeneralization of study results, failure to cite relevant literature or studies, duplicate publication or fragmentary reporting of results, prepublication release of information, publication bias, failure to disclose intellectual or financial conflicts of interests, or violations of experimentation rules protecting humans or animals.

Plagiarism is probably more commonly acknowledged, since it is easier to detect and prove. Detecting and proving falsification or fabrication of data in a published article is not so easy, and it carries grave ethical and legal consequences for editors, authors, institutions, and funding agencies. While an editor has a duty to see that questions of fraud are appropriately and confidentially pursued, the Association of American Medical Colleges, the National Academy of Sciences, and the ICMJE recommend that primary responsibility for investigating cases of suspected fraud rests with the author's institution or funding agency (Association of American Medical Colleges; Committee on Science; ICMJE, 1991). If it is determined that a fraudulent paper has been published, the journal should print—in a timely manner—a retraction, written by the author(s) or an appropriate representative of the institution. Since the validity of any previous work by the author of a fraudulent paper cannot be assumed, the editor must ask the institution to verify the validity of any of the author's articles previously published in the journal or to retract them (ICMJE, 1991).

Protecting Patient Rights

The two major issues regarding patient rights in medical publishing are requirements for the ethical conduct of published research and the protection of patient confidentiality. A now well-established principle followed by all credible medical journals is that reports of experimental investigations of human or animal subjects must include a statement that the research project has been approved by an appropriate institutional review board (IRB). For investigators not covered by a formal ethics review board, the report should state that the researchers have followed the principles of the Declaration of Helsinki (World Medical Association), which includes requirements for freely given informed consent and for the review of the research protocol by a committee independent of the investigator and the sponsor. Many journals also require an additional statement of the manner in which informed consent was obtained from human subjects, since informed consent is a central tenet for ethical research.

Many editors now agree that journal publication should protect patient confidentiality. For example, placing a black bar over the eyes in a facial photograph does not effectively disguise identity. Patients may also be identified from detailed case descriptions. In 1991, the ICMJE published expanded guidelines for the protection of patients' right to anonymity (ICMJE, 1991). These guidelines state that identifying information should be avoided unless it is essential for scientific purposes; informed consent should be obtained for the publication of identifying descriptions or photographs; changing patient data should not be used as a way of securing anonymity; and journals should publish editorial policies to preserve patient confidentiality (ICMJE, 1991).

One problematic area regarding patient anonymity is the publication of pedigrees from genetics research, since the family as a whole or individual family members can sometimes be identified from pedigree information. Following the ICMJE guidelines, identifying information should be deleted if possible, but pedigree data should not be altered. Pedigree publication is complicated by the fact that a large number of family members may be involved, not all of whom may have given consent for, or even be aware of, the collection of family data. A requirement for informed consent for publication from each individual member of a large pedigree may be impossible to meet, particularly if family members disagree about publication. Whether some kind of group consent would be ethically permissible, or whether identifiable pedigrees should not be published without the consent of each individual family member, remains an unsettled issue.

Release of Information

Scientific journals play a major role in informing the public, as well as health professionals, about biomedical developments. This function involves a balance between the timely release of information and the adequate evaluation of the quality of the information. Conflicts sometimes occur between scientists, who want rapid dissemination of new or controversial research findings; editors, who as gatekeepers want to make sure that only accurate and valid scientific information is released; and the news media, which compete with each other to be the first to publicize new scientific information. The process of scientific publication after peer review takes time. Some investigators have chosen to short-circuit this traditional process by announcing results at a news conference rather than waiting for a paper to be evaluated by a scientific journal. Advocates for a particular disease (acquired immunodeficiency syndrome [AIDS], for example) have also pressed for faster release of research results. Even if well-intended, such attempts to bypass careful evaluation and publication may result in the dissemination of misinformation (Angell and Kassirer).

In 1969, Franz Ingelfinger, then editor of the *New England Journal of Medicine,* promulgated a policy (subsequently known as the *Ingelfinger rule*) that manuscripts would be considered for publication only if their substance had not been submitted or reported elsewhere. Other journals adopted similar policies to discourage both duplicate publication and the public dissemination of results before peer review and publication. Such policies have been criticized as self-serving on the part of journals, but they usually exempt presentations at scientific meetings (including published abstracts and media coverage from such meetings) and the rare situations when an appropriate public health authority determines that there is an immediate need for dissemination. Some medical journals also ask news media to observe a press embargo for a brief period to allow physician subscribers to read and evaluate information before their patients begin seeing it in the media.

Copyright

Copyright protection covers text and illustrative material—whether in print or electronic (digital) format. U.S. copyright law provides that the creator of a written work, the author, owns all legal rights to that work for his or her life span plus fifty years, unless the author transfers those rights to another party. Two exceptions to individual copyright ownership are works prepared by employees of the U.S. government and works made for hire, in which an individual, either by an employment mandate or by contract, agrees in writing that all work prepared within the scope of employment or contract is the property of the employer or contractor (*Copyright Law of the United States of America*). Different countries have different copyright laws, but the Universal Copyright and Berne Conventions protect works published and distributed in other countries.

Most journals require authors to transfer copyright to their publishers before publication, giving the publisher exclusive rights to the work after publication. Therefore, anyone who wishes to reprint or adapt from an article (in part or whole) must receive written permission to do so from the publisher. However, certain uses of a published work without permission from the owner—such as photocopying for teaching, scholarship, or research purposes—may not be an infringement of copyright under the provisions of "fair use." Fair use can be difficult to justify in court and must take into account the following factors: (1) the purpose of the use, including whether it is educational or commercial; (2) the nature of the copyrighted work; (3) the amount of the copyrighted work to be used; and (4) the effect of use on the potential marketability or value of the copyrighted work (*Copyright Law of the United States of America*).

Rights to Unpublished Data

Unlike rights to copyrighted work, rights to unpublished data are difficult to define, and most ethical dilemmas concern access to rather than ownership of such information. Unpublished scientific data include written and electronic laboratory notes, experimental materials, project records and observations, databases, descriptions of methods and processes, analyses, and illustrative material. Traditionally, unpublished scientific data have been owned by their creators—the scientific investigators—and most scientists believe they have a duty to share data with their peers and, when appropriate, with the public. Any data reported in a published article become the property of the publisher, but rights to relevant, supportive data not reported in a published article (sometimes called raw data) are not transferred to the publisher. Problems arise when investigators, institutions, the government, and the public compete for control of and access to the same data. For example, who should have first rights to publication of research data: the principal investigator, the coinvestigators, or the institution that funded the research? Legally, the investigator controls access to unpublished data, except under the following circumstances: (1) the investigator is an employee of an organization that claims rights to any work conducted by its employees; (2) the investigator is under federal contract or has received a federal grant to perform the work; or (3) a court decides that public interest in the data outweighs the interest of the owner (CBE). Government or industrial sponsorship of research may impose specific restrictions on data control and sharing, particularly when such data are proprietary or commercial. This area of law will continue to evolve as electronic technology makes data ownership and access more difficult to define and control by narrow standards and laws.

While it is generally agreed that data must be kept in an accessible format for a reasonable period of time, no standard has been universally accepted, because different types of data from different specialties require various modes and spaces for storage, which can be prohibitively expensive. Some institutions have recommended three or five years, and longer periods for data that support publications (Committee on Science). The National Research Council Committee on National Statistics recommends and many journals require that editors have access to data during the peer review process, which means that the data must be maintained until publication (CBE). Some journals require authors to provide data to editors for their evaluation if requested, but this requirement does not have a time limit. Some journals require authors to send their data to national or international storage centers at the time of publication.

Disputes over who has rights to use scientific data have caused ethical dilemmas for editors. For example, what should an editor do with a manuscript from an author that reports an analysis of unpublished data originally collected and analyzed by another author? The ICMJE and the Committee on National Statistics recommend that editors consider such secondary analyses on their scientific merit as long as full credit and appropriate citations are given to the original data collections (ICMJE, 1991; CBE). Other open questions concern the nature of sharing data, which is a vital part of the scientific enterprise. Should there be restrictions on the access, use, and citation of unpublished works by other authors and investigators? Most scientists and editors would argue that such restrictions would stifle scientific exchange. But what about access to unpublished data by those outside the scientific community, such as representatives of the media, the courts, and people with commercial interests? Many of these questions are currently under debate, and whether or not access will be widened or restricted is difficult to predict.

Advertising

Advertisements for pharmaceutical products and medical/laboratory devices provide major financial support for biomedical publications. Advertising income is essential for many large biomedical publications since their costs would not be met by subscription revenue. Whether this situation represents one aspect of the success of the free enterprise system or a major ethical problem for editors is a matter of controversy.

To protect a journal's integrity and credibility, complete separation between advertising and editorial decisions is essential, and advertisers should have no influence on editorial content. Advertisements, including advertorials, should have a distinct appearance or labeling so that readers can readily distinguish them from editorial content, and ads for a product should not be placed adjacent to editorial material dealing with the product or disorders for which it might be used (Rennie). Publication of industry-sponsored journal supplements is problematic, since the supplement's editorial content may be selected or influenced by the sponsor to favor their products, and the review process may not be as rigorous or as independent as it is for the journal's regularly published issues.

The accuracy of advertisements in medical publications is more controversial. The purpose of advertisements is promotional, and studies have shown that the prescribing behavior of physicians is indeed influenced by advertisements. Because of their effect on the health of the public, advertisements for drugs and medical devices are regulated by a government health agency in many countries. In the United States, this responsibility lies with the Food and Drug Administration (FDA), which reviews and approves marketing and *labeling* (the package insert that describes the indications and side effects of a drug) but does not routinely review or approve advertisements prior to their dissemination. However, the FDA does review advertisements after publication and can require companies to withdraw or publicly correct ads that it determines to be inaccurate or misleading.

The standards by which print advertisements should be judged and the method of enforcing standards remain unsettled. Some have recommended the development of multidisciplinary review boards, such as the Canadian Pharmaceutical Advertising Advisory Board, to review and approve medical advertisements before their dissemination.

Enforcement of Ethical Standards

The enforcement of ethical standards in scientific publishing is a responsibility shared among authors, institutions, funding organizations, peer reviewers, and editors. Authors are primarily responsible for upholding the scientific commitment to a search for truth, accepting responsibility and credit for the work that bears their names, and fully disclosing any conflicts of interest. Institutions where research is performed and organizations that fund research share the main responsibility for ensuring that studies are designed and conducted ethically, and also for investigating and sanctioning allegations of misconduct. Peer reviewers are charged with performing objective and timely appraisals of papers submitted for publication, while maintaining strict confidentiality and disclosing their own conflicts of interest. Editors should exercise sound judgment and objectivity in selecting papers for publication, maintaining vigilance for any ethical problems, and ensuring that authors, reviewers, and institutions fulfill their responsibilities. Clear ethical standards and implementation policies are certainly desirable, and editors have taken the lead in setting standards and policies (U.S. Congress). Yet the ethics of scientific publication is based on trust, and obsessive "policing" of the research community and the publication enterprise could be counterproductive. Persistent emphasis on the importance of maintaining ethical standards in the entire research process, from initial research ideas to their eventual publication, should be an expectation shared by all involved in that process. However, defining and enforcing such standards will be an even greater challenge as the electronic revolution extends the traditional boundaries of authorship and scientific publication.

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SEE ALSO: *Advertising; Bias, Research; Commercialism in Scientific Research; Conflict of Interest; Research, Unethical*

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SEXISM

• • •

Sexism is the failure to give equal weight to women's interests. It is the antithesis of feminism, a moral, political, and social movement that seeks justice for women. Sexism is important because it undermines the welfare of one-half of the human population and is a major source of women's oppression.

Each of these terms—interests, justice, welfare, oppression—is theory-laden, suggesting a particular way of understanding the origins and remedies for wrongful sex- and gender-based distinctions. This entry is eclectic but relies primarily on the liberal language of rights and interests.

Women have two kinds of rights, the ones shared with men by virtue of their common humanity, and the ones required by virtue of their differences from men. Sexism fails to recognize these rights by assuming, on the basis of inadequate evidence, that there are morally relevant differences between women and men, or by overlooking morally relevant differences that call for different treatment.

Medical treatment of heart disease in women is an example of both kinds of sexism. On the one hand, ignoring contrary evidence, practitioners have assumed that heart disease is not a women's problem. On the other, they have refused to take seriously the possibility that heart disease might manifest itself differently in women than in men. Consequently, heart disease in women is underdiagnosed, treatments are geared toward men's needs, and women needlessly suffer and die more often than men.

Although sexism can be a result of inattention, or a deliberate policy of subordinating women's interests to those of men or children, it may also result from historically embedded social institutions that naturalize assumptions about gender. A key assumption is that biology determines women's nature, whereas men construct themselves. Woman's inherent function is to nurture children and men. Women therefore do not elicit the respect due to rational persons with legitimate life-plans of their own; their interests are relatively unimportant, and may be subordinated to others with which they come in conflict. The consequences range from abortion, infanticide, and starvation for female Indian children, to more subtle but still significant losses for Western women. Among these are lack of representation in positions of public power and prestige, longer hours of work for less pay, lack of sexual or reproductive freedom, less advanced healthcare, and less leisure, pleasure, and financial and physical security.

No thoughtful person wants to be seen as sexist. But because of widespread negativism about feminism, many people believe that there is neutral territory between the two. However, where women's interests are affected there is either a (feminist) commitment to count them equally or there is a (sexist) discounting of those interests. Neutrality can exist where gender is not at issue or where it is difficult to determine whether sexism is at work.

Oppression, Discrimination, Sexism

Oppression is the systematic and unjust subordination of some people by others. Sexism is a major source of women's oppression. Oppression may be based on superior power, without any attempt at justification. However, it is usually predicated on the alleged inferiority of a class of people, such as women, the poor, people of color, the elderly, homosexuals, or adherents of certain religions. In principle, recognizing the wrong of one kind of oppression implies recognizing the wrong of other types, but in practice these connections are often ignored.

Because many mainstream thinkers (consciously or unconsciously) accept sexist assumptions, they are unconvinced of women's oppression, and they doubt evidence alleged to support the claim that such oppression exists. Even when the facts (e.g., women's lesser wealth) are undisputed, they are attributed to the consequences of women's inferiority, their autonomous choices, or to social necessity.

Feminists respond by arguing that these defenses are mere rationalizations, and that there are systematic and interlocking patterns of sex and gender relationships that disadvantage women. Sexism leads to the high valuation of qualities associated with men but not women. Also, pervasive patterns of gender socialization affect women's capacities (such as strength or mathematical achievement) and mean that women's choices may not be as autonomous as they seem. Moreover, many of women's disadvantages are rooted in the sexist failure to recognize the special rights that need to be granted because of the differences between women and men. Social and political arrangements allegedly based on necessity are essential only for men's convenience. Relegating women to inferior positions is therefore unjustified, and constitutes oppression.

Discrimination is an effective tool for creating and maintaining oppression. Discrimination can be used descriptively or normatively. Descriptive discrimination among concepts and entities is essential for thought and language. Such distinctions are usually considered to reflect the world, and are thus *natural.* However, categories may depend on choices about what characteristics count for inclusion and so morally significant groupings may instead be constructed (e.g., race). Normatively, discrimination always implies wrongful treatment of members of a group. The constructed nature of some descriptive groupings may facilitate the creation of normative ones. Thus, for example, conceptualizing the class of potentially pregnant women may make it easier to discriminate against them in the workplace or in medical research.

Recognizing Sexism

Sometimes it can be difficult to determine whether a decision or policy is sexist or feminist. For example, selective abortion of female fetuses is often cited as a paradigm case of sexism. But different contexts can render the same act sexist or feminist. Aborting a female because of the belief that boys are superior to girls is sexist; aborting a female to prevent a girl's suffering can be feminist.

In addition, it is important to distinguish between legal and moral contexts. Because motivation is difficult to determine in legal contexts, sexism in law is most successfully rooted out by a focus on disparate impact. Moral investigation, however, can and must delve further into motivation and intention.

Is it sexist to abort female fetuses to ensure that there are both male and female children in a family? If "balance" is a pretext for ensuring the birth of a boy to secure the alleged social benefits only he can provide (e.g., continuation of the family name), then it promotes and maintains a sexist world. But what if the decision to abort is based on the reasonable belief that social pressures generally lead girls and boys to develop somewhat differently (no matter what the family environment), and that raising them is likely to be an equally desirable, but different, experience?

Baseline Assumptions

Evaluating whether assumptions that underlie decisions are sexist can be challenging. For example, it would be sexist to exclude women from drug trials because they are different from men in relevant ways, but not because they are alike in those ways. But which assumption is it reasonable to start with in the absence of knowledge? Assuming that the sexes are alike could be just another instance of taking males as the norm, without paying attention to ways that females might be different. Assuming they are different could be just another instance of the belief that females have more in common with the females of other species than with male humans. A similar quandary arises for race.

Inquiry suggests that women are harmed by their exclusion from clinical trials because such exclusion can result in poorer healthcare. Do cholesterol-lowering drugs or aspirin prevent heart disease in women? Nobody knows because the original research was done in men, and only at the very end of the twentieth century did the relevant studies begin for women.

Digging into the history and culture of medicine reinforces this conclusion. In the past, women were not admitted to most medical schools because they were considered fit only for nursing or midwifery. Harvard University began accepting women only in 1945, when World War II had reduced the number of male applicants; women could not exceed 6 percent of each class until the 1970s. Sue Rosser and Eileen Nechas and Denise Foley were pioneers in documenting obstacles facing women in medicine in the twentieth century. Adriane Fugh-Berman describes a dispiriting range of problems she encountered at a leading medical school. Among them were medical disinterest in women's bodies (breasts were discarded on the first day of anatomy class) and welfare (students were taught that women can have a satisfactory sex life without orgasms). Some professors did not see women students as equals and refused to teach them certain procedures or topics (sexually transmitted diseases). Male students compounded the hostile environment by harassing and threatening with rape the members of a women's study group. A survey of recent literature on problems women encounter in medicine shows that there is still much room for progress.

In 2003 women still experience substantial sexism as consumers of healthcare, as the aforementioned example of heart disease shows. Stereotypes about women's nature (irrational, focused on reproduction) may continue to lead healthcare researchers and providers to sometimes dismiss what women say about their symptoms (e.g., in women with AIDS, or menstrual pain). It may also encourage the development of procedures that put women disproportionately at risk in what should be joint ventures with men (contraception, infertility treatment). More generally, until the end of the twentieth century, researchers emphasized conditions that affect men, ignoring such complaints as dysmenorrhea, incontinence in the elderly, and nutrition in postmenopausal women. At the same time, medicine has also tended to inappropriately medicalize the bodily experiences connected with reproduction: menstruation, pregnancy, childbirth, and menopause. Medicine has also promoted and reinforced the assumption that only women —not men or society at large—are responsible for babies's health.

Is there any evidence to suggest that women's exclusion from research (and the failure to analyze studies they did participate in by sex) is a result of concern for women? No. It appears that women have been excluded either for researchers's convenience or due to concern about harm to possible offspring (or concern about liability for such harm). Men have been assumed to lack hormonal cycles that would confound study results; women however, engender the opposite assumption. But men appear to have their own hormonal cycles, and if women's cycles affect outcomes, being excluded harms the latter. Also, some researchers have had easier access to male populations (the military, prisons). But ease of access does not justify ignorance about the medical care of women. Excluding women because of possible pregnancy accepts the stereotypes that women are ignorant about their bodies, and careless about the welfare of fetuses; the exclusion of women also ignores the evidence that sperm are affected by exposure to toxins. Non-sexist drug trials would thus regard women and men as equally likely to risk harm to offspring. Both would therefore need to be warned against reproduction, and both sexes ought to be trusted to heed those warnings to the same degree. Abandoning women for such sexist reasons is especially unjust when research is publicly funded. It follows that women should be included in experimentation, and that results should be analyzed by sex. Excluding women from health studies could be seen as a feminist position only when there are excellent reasons for believing that to include women would create more harm than good for women as a class.

In conclusion, the concept of sexism points to the ways that women's interests are systematically discounted in comparison with those of men. Sexism is a kind of discrimination that oppresses women as a class. Groundless stereotyped assumptions about women and the unjust failure to take seriously both the ways that women resemble men and the ways that the two sexes differ play a central role in sexism. Women have been seriously harmed by sexism in medicine, and only in the last decades of the twentieth century have the women's health movement and practitioners in the field of women's health begun to rectify this wrong. Bioethics, which, among other tasks, critiques the healthcare system, was itself quite blind to sexism in healthcare until the 1990s; sexism in bioethics remains a serious problem, as overtly feminist bioethics literature is marginal.

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SEE ALSO: *Abuse, Interpersonal: Abuse between Domestic Partners; Access to Healthcare; Circumcision, Female Circumcision; Feminism; Fertility Control; Healthcare Delivery; Healthcare Resources, Allocation of; Maternal-Fetal Relationship; Medical Ethics, History of South and East Asia: China, Contemporary China; Medicine, Profession of; Mental Illness: Conceptions of Mental Illness; Metaphor and Analogy; Moral Status; Nursing, Profession of; Paternalism; Population Policies; Professional-Patient Relationship; Race and Racism; Reproductive Technologies; Research Methodology; Research Policy; Sexual Ethics; Sexual Ethics and Professional Standards; Women as Health Professionals; Women, Historical and Cross-Cultural Perspectives*

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SEXUAL BEHAVIOR, SOCIAL CONTROL OF

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The twentieth century witnessed an explosion of knowledge about the physiology, psychology, and sociology of human sexuality, thanks to the revolution in public acceptability of discourse about sexual conduct and the freeing of scholarly interest that followed the trailblazing works published in the late Victorian era by Richard von Krafft–Ebing (1939 [1886]), Havelock Ellis (1901), and Sigmund Freud (1955a [1895], 1955b [1905]). However, controversy still rages over the basic issue of how sexual behavior is molded, encouraged, and discouraged by social customs and practices. Are males naturally more aggressive in seeking sexual contact than females, or is this a product of social patriarchy? Is homosexuality caused primarily by biological factors, or is it largely caused by social experiences during formative stages of the child's development? Is cultural permissiveness responsible for the dramatic increase in reports of sexual harassment and abuse, or are changing mores encouraging victims to name parents, doctors, and priests who were in the past able to hide their misconduct under a cloak of respectability?

The answers to these questions are not only empirical, they are also ethical and political. Allegedly scientific beliefs about the *naturalness* of certain sexual acts often reflect unacknowledged cultural biases, and thoughts and theories affect the behavior they label, characterize, and implicitly valorize or demean. As feminists and historians such as Michel Foucault (1990) have pointed out, the neutral scientific language of medicine is no guarantor of the moral innocuousness of theories about gender and sexual behavior; to the contrary, claims of scientific objectivity about these topics are apt to be all the more dangerous morally for pretending to be value-free.

Theories of sexual behavior cannot avoid assumptions about power and domination that too frequently perpetuate injustices. Thus, sexologist Alfred Kinsey's claim that males are naturally more aggressive in initiating sex (Kinsey, Pomeroy, and Martin) is not merely the objective scientific statement it purports to be, but a statement that supports the power of men over women in society. Anyone who is concerned about power and justice needs continually to scrutinize and critique so-called scientific claims about human sexuality by attending to how they perpetuate social stereotypes that are not universal and, by assigning more value to the experiences of certain people (e.g., white heterosexual males), help to empower some and disempower others. One would expect social ethicists to be sensitized to these issues, but the most influential recent theorists of justice (e.g., John Rawls, Ronald Dworkin, Robert Nozick, Michael Walzer) scarcely even mention gender justice, much less consider sexual roles a central matter for ethical scrutiny (see Susan Okin's 1989 work). One reason for this neglect is the traditional public/private dichotomy that assigns sexual behavior to a private arena outside the concerns of the social theorist. Employment of this dichotomy in the past to keep cases of domestic rape and child abuse out of American courts, on the grounds that they occur within a zone of privacy protected from public scrutiny, shows that it is scarcely an ethically neutral matter for a social scientist to point out how individuals' sexual lives are influenced by a social ethos that makes such distinctions.

Essentialism and Constructionism

Theories about human sexual behavior in its social context range along a continuum stretching from essentialism (or naturalism) on the one hand to social construction theory on the other.

Essentialism attributes certain sexual and gender behaviors to the unchanging nature of the human species. According to this perspective, what is natural is *good*; what is social is *artificial* and tends to be *bad* insofar as it inhibits realization of the proper natural end of sexual conduct, be it erotic pleasure or procreation. Thomistic natural-law theory is explicitly essentialist in identifying procreation as the natural end of human sexuality, but modern sexologists assume essentialism in contending that a wide variety of pleasurable erotic acts are no less natural than heterosexual intercourse. Kinsey, for example, uses an essentialist argument when he draws on the sexual behavior of other mammals, "primitive" cultures, and human physiological capacities to contend that masturbation and homosexual acts are natural expressions of sexuality and, hence, irrationally condemned and punished by society. Kinsey also employs essentialist arguments, citing mammalian data, in support of such dubious contentions as that male extramarital coitus is more natural than female extramarital coitus (Kinsey, Pomeroy, Martin et al.; Irvine). American sexologists William Masters and Virginia Johnson assume essentialism in viewing sex exclusively in terms of physiological responses unencumbered by social and psychological factors. It is not an issue for Masters and Johnson that the socialization of Western women has discouraged female sexuality; rather the woman's naturally superior sexual responsiveness to the male, as evidenced by her capacity for multiple orgasms, is what counts for them (Irvine). What is missing in the sexologist's essentialist view of culture as an impediment is any acknowledgement of the multiple ways cultures give meaning to sexual behaviors and structure sexual and gender relationships beyond physiological responses.

According to social constructionists, sexual behavior and gender roles are products of a specific history, culture, and set of social institutions. French social scientist Émile Durkheim succinctly expressed the constructionist emphasis on the primacy of culture over biology when he argued, at the end of the nineteenth century, that if an adolescent did not have cultural concepts to identify sexual desires, he or she might feel a vague urge but not know what it was, much less how to act on it (Durkheim; Wallwork, 1972, 1984). A second main feature of the social constructionist approach involves situating sexual role behavior within the prevailing economic and political system, with its male-dominated hierarchies of status and power. The constructionist perspective encourages exploration of the ways in which widespread cultural beliefs about sexual behavior (and the research projects they inspire) serve to perpetuate a patriarchal vision of human nature, social institutions, gender, and sex roles. Constructionists note with concern that the focus in research has more often than not been on the male sexual experience; Masters and Johnson's research, for example, limits sexuality to genitally-oriented orgasm (Masters and Johnson). Feminist critics Alice Rossi (1973) and Leonore Tiefer (1978) complain that research focusing on genital physiology as the standard of sexual involvement evidences a "phallic fallacy" that implicitly devalues the pregenital or nongenital sexual experiences of women, such as the emotionally intense erotic feelings associated with looking at the beloved or anticipating a reunion with him or her.

The obvious strength of social constructionist theory is that it is able to account for the considerable diversity of sexual behavior and the meanings associated with such behavior cross-culturally, and to link these meanings to other role relationships. The power of society to mold human sexuality is evident in how nonerotic body parts—for example, crushed feet among the Chinese of a former era, the naked foot and even shoes in medieval Europe, and hair—have been eroticized by different peoples at different times (Stoller). The power of social custom is also obvious when one contrasts the negative conception of homosexuality in the Judeo-Christian West with its positive evaluation among Melanesian societies and certain African tribes. Among the Sambia in the New Guinea highlands, boys from prepuberty to their mid-teens are expected to engage in oral-genital sexuality with the older teenage males with whom they live as a prerequisite to becoming heterosexual adult males (Herdt and Stoller). Because Sambians believe semen is essential for males to grow and mature physically, the ingestion of semen is deemed essential to becoming an adult heterosexual male and to fathering children.

Even within the same society, there are fads and fashions of sexual behavior. For instance, since the 1960s there has been a dramatic increase in oral-genital behavior in the United States (Janus and Janus; Walsh). Among contemporary males in the West, premature ejaculation is defined as a dysfunction for which medical treatment is often sought; but in many developing countries males are expected to reach orgasms quickly (in fifteen to twenty seconds in the East Bay society in Melanesia, for example) and those who take a "long time" are ridiculed (Reiss).

But it would be a mistake to assume from the considerable evidence for the importance of the elaborate cultural ideas, stimulants, and norms that surround the biologically limited range of sexual behaviors of which the human body is capable that social constructionists are winning the battle with essentialists. In fact, the nature–nurture pendulum, which swung back and forth several times in the twentieth century, was swinging back again toward the nature pole as the century ended. During the 1980s, 1990s, and 2000s, biological explanations have been on the ascendancy in many scientific circles. Sociobiologists challenge the constructionist assumption that most sexual behavior is determined by culture, arguing instead that certain basic mammalian and primate traits that lie beneath the social surface determine the configuration of human sexual behavior (Wilson). At the same time, the biologizing of psychology is well underway, as physiological models and research strategies are held to offer the best route to understanding traditional subjects of psychological inquiry such as mental illness and sexual orientation.

Interactionist Model

The most plausible position on the essentialism-constructionism debate would appear to be that the biological factors in sexual desire, such as genes and hormones, do not act alone but instead interact with environmental factors, such as visual or auditory erotic stimuli, the significance of which depends in turn upon the individual's subjective erotic sensitivities, identities, fantasies, cognitive schemata, and behavioral patterns. These subjective factors, which lead some people to be excited by depictions of sadomasochistic acts and others not, are themselves influenced by the way a unique individual with certain inherited strengths and vulnerabilities interacts with significant others and specific sociocultural environments during the various psychosexual, ego-social, and cognitive stages of development. Biological factors certainly play a role; for example, testosterone appears to influence the intensity of sexual desire. But biological factors do not invariably cause sexual motives or behavior, for testosterone is itself highly responsive to environmental stimuli. Nurture, psychological development, subjective fantasies and beliefs, erotic stimuli, moral and aesthetic standards, social roles and expectations, and ego strengths and weaknesses all mold the range of the individual's sexual potentialities in certain directions rather than others. This molding is clear from the inability of biologists and sociobiologists, who study determinants that have operated within the species for thousands of years, to explain changes in sexual customs within a single generation or variations in sexual customs that occur in the same gender cross-culturally. Unfortunately, researchers have not yet developed a theoretical model sufficiently complex and nuanced to integrate and assign proper weight to all the multiple factors, including the individual's self-control, that influence human sexual behavior. The sociological point of view adopted here, which falls at the constructivist end of the essentialism-constructionism continuum, remains one among several plausible selective perspectives on social control of sexual behavior. Others are history, anthropology, ethnography, psychoanalysis, and social psychology.

Social Control Requirements

Sexual behavior, defined broadly as any action or reaction involving erotic arousal or genital responses, is viewed by most sociologists as sufficiently problematic to require some degree of social control. One explanation often proffered for this social-control requirement, whether as controlled permission or regulated prohibition, is that at some point in the distant past human beings lost the preformed automatic sexual instincts of the lower animals—that is, the sexual control that is in nature—and came to depend upon culture and social institutions to guide the varied reproductive and nonreproductive behaviors that are considered sexual. The loss of preformed instinctual patterns of sexual behavior, by freeing human beings from the comparatively rigid behavior patterns of other animals, helped to create the great adaptability of the human species to its changing environment. It also meant, with the human female's loss of the periodic estrus of other mammals, that the human female and male were potentially capable of sex at any time. Sexual motives came to pervade virtually all aspects of human life in a way that is uniquely characteristic of the species. At the same time, because the sexual drive differs from instinctual needs like respiration, thirst, and hunger, which must be gratified for the individual organism's survival, sexual desire was modified by subtle psychological and social influences.

Social control of sexual behavior has been necessitated in all social units—from the family to the clan, tribe, local community, and state—in part by the serious threats to social stability and maintenance of group life over time created by the potential for sex on demand all the year round. One such threat is incest, which is inimical to the group's evolutionary survival as well as to the psychological well-being and functioning of those who might be victimized by it. Another serious social consequence of sex on demand is the likelihood of children, which every society has a stake in limiting, assigning to families peacefully, and raising, educating, and training to be law-abiding, productive contributors. Still another consequence of sexual behavior that has required its social control is its potential for either reinforcing or disrupting existing roles and status hierarchies by creating strong new social bonds. Any rape or seduction of young girls or boys, or any adulterous relation, is liable to spark violence or some other disruption of the existing social order.

Societies attempt to handle another crucial consequence of sexual liaisons—the transmission of family and communal property, prestige, and power—by means of legalized sexual union in marriage and the begetting of *legitimate children.* Any dramatic increase in the number of illegitimate children and abandoned wives strains the system of distributing limited economic resources, shifting some of the burden from the family onto the rest of the community. The perpetuation of a society's religious ideals, moral norms, and laws is also intertwined with the monitoring of sexual conduct, since the way sexual conduct is controlled is often paradigmatic of the way the society expects individuals to pursue other moral and spiritual goals (Stone). The well-known sexual asceticism of the Puritan, for instance, was only one part of a lifestyle that affected every aspect of the Puritan's life, just as the idealization of female virginity affects every aspect of the life of the traditional Southern Italian villager (Parsons).

IDEALS AND TABOOS. Social control of sexual behavior is exercised most obviously by widely shared, explicit ideals of sexual behavior that form the basis for taboos against inappropriate conduct. Taboos are backed by social punishments ranging from mild disapproval and loss of status to ostracism, imprisonment, and death. Within Judaism, Christianity, and Islam, the standard-of-standards has been heterosexual intercourse in the context of marriage. Accordingly, masturbation, homosexuality, and extramarital sexuality have been condemned and often severely punished. Among the Greeks during the classical period, pederasty was idealized as the purest form of love, but it was also hedged about by rigid taboos. The accepted sexual relationship was limited to an older free man and a pubescent free boy. Oral and anal intercourse were unacceptable, and if a boy allowed himself to be penetrated anally, he lost his rights to citizenship. For the Greek male, what was important was not whether one's partner was male or female, but whether one was dominant or submissive (Foucault).

SOCIAL ROLES. In addition to the values and norms shared throughout a culture, social control is also maintained by the basic institutions of society, especially the family, religion, schools, medicine, and law. An institution is defined sociologically as a stable cluster of values, norms, statuses, and roles that develop around a basic need of society. An important function of an institution is to socialize developing individuals through inculcation of social roles, which are social actions that take account of social expectations. A person's role is not simply what he or she habitually does (for this may not be socially significant), nor even what he or she is expected to do, if an expectation is only what one might predict from past actions. The role is what is expected of him or her, in the sense of what is approved or required, by, say, fashion, tradition, charismatic authority, or standards of rationality.

Gender roles, which indicate how males and females are expected to behave, significantly influence sexual behavior. In Western culture, the expectation has been that the woman is more passive and receptive, and more attuned to emotional connections, than the male, who is expected to be more aggressive, autonomous, and focused on power. Such gender roles have an effect on sexual conduct, independent of explicit sexual standards. For example, rape is strongly disapproved of in contemporary culture, yet date rape is disturbingly frequent, in part because males are socialized to dominate women in many social situations involving power. Hence, if a male's charm and powers of psychological persuasion fail in a sexual situation, coercion remains as a last resort. Here, as in most sexual acts, erotic desire is only one of several motivations that enter into the behavior. In addition, the need to maintain the male-dominant role identity and the propensity for males in Western societies to turn anger at frustration into aggression and violence are equally powerful motives.

Recently, sociologists have applied *script theory* to sexual behavior in order to account for the more specific patterns that enable participants to make reasonably good guesses about the sequence of events probable in an otherwise loosely structured social situation (Gagnon and Simon; Laumann, Gagnon, Michael, et al.; McKinney and Sprecher). Scripts are mental schemas that enable participants to jointly structure the interaction so that uncertainty is systematically reduced and cooperation enhanced. Sexual scripts enable participants to decode novel situations by reading the meaning of certain actions and to organize the situation into sequences of specifically sexual interactions (e.g., nonverbal courtship behaviors signaling availability, like smiling, gazing, hair flipping, the "opening line," leaning close, and the proverbial invitation to see one's etchings). However, research on conflicts between the sexes in dating and marriage also shows that scripting is far from perfect, that the sexes often miscue each other or are dissatisfied in predictable ways—say, with the male's excessive sexual demands or emotional constriction, or the woman's unresponsiveness or moodiness.

HEALTH CONCERNS. Empirical beliefs—especially medically sanctioned ones—about the consequences of various sexual practices on the individual's health also play a significant role in the social control of sexual behavior. In classical Greece, for example, physicians recommended sexual moderation to prevent the excessive loss of life force in the too-frequent ejaculation of semen. In ancient China, somewhat similar beliefs about the consequences of excessive semen loss led to the cultivation of special techniques of intercourse without ejaculation in order to conserve the *yang* (the positive, light, masculine principle whose interaction with *yin*—the negative, dark, feminine principle—was believed to influence the destiny of creatures and things). And, of course, Western doctors have for centuries warned that masturbation would bring about some dreaded disease, disfigurement, or insanity. By the turn of the twenty-first century, fear of AIDS had dramatically changed sexual behavior, primarily by altering beliefs about the risks of unprotected sexual intercourse (Laumann, et al.). Viagra has altered time-honored myths about impotence, while offering hope for continuing sexual relations into old age. It is one of Foucault's main contentions that medical beliefs, precisely because they are so important to patients, provide physicians with power that historically often has been used to dominate and control unjustly (Foucault).

It is easy to be impressed by the ideals, moral rules, and prudential teachings that are set forth so impressively in explicit doctrine by leading social authorities. But these action guides are not always reinforced by other cultures or even by other institutions in the same cultural context. Complex societies are not systematic cultural ensembles, despite the beliefs of sociological functionalists like Émile Durkheim and Talcott Parsons. Illicit sexual cultures—like red-light districts or the houses of prostitution that flourished in medieval Europe (Ariès and Bejin)—exist side by side with licit sexual cultures, counterbalancing and correcting excessive asceticism, and on some points canceling out the influence of the licit culture. A complex interrelationship often exists between these cultures, so there is often plenty of room for compromises and loopholes. Moreover, the different social-status groups and classes of the same society usually have different sexual cultures. For example, libertine elites concentrated around courts (as in ancient Egypt, classical Greece and Rome, imperial China, India, and Japan) have surrounded themselves with a rich panoply of erotic art, pornographic literature, artificial physical stimuli, toys, and partners not encouraged among lower social ranks (Stone). Consider, too, how Roman Catholic bishops have tolerated the sexual abuse of children and adolescents by priests in flagrant violation of the church's explicit moral teachings (see, for example, the work of the *Boston Globe* Investigative Staff).

Control and Permissiveness

The so-called sexual revolution that occurred in the post–World War II epoch is sometimes viewed—erroneously—as releasing the individual from the constraining pressures of social control. But the new permissiveness is more accurately perceived as substituting new and, in some instances, somewhat different social standards, controls, and permissions for older ones. The most important contemporary cultural standards focus less on the legitimation of sex by marriage and more on the goods of sensual pleasure, intimacy, the autonomy of the parties (violated in the case of rape and harassment), and the basic equality of partners. Some salient features of the sexual revolution are the greater explicit public acknowledgment of sexuality (for example, in films, advertisements, soap operas, talk shows, and advice columns); the availability of cheap and reliable contraception, particularly birth control pills, which have for the first time in history released women from the fear of unwanted pregnancies; the increased availability of erotic stimulants (e.g., adult magazines, pornographic videos, explicit Internet sites); the rise of feminism and correlative decline in social inequality between the sexes; the increased acceptance or tolerance of sexual behaviors that were formerly disapproved, like masturbation, homosexuality, extramarital sexual affairs, and oral-genital sex; and the increase in teenage sexual conduct and at younger ages (Michael, Gagnon, Laumann, et al.; Laumann and Michael). Around the turn of the twenty-first century, there also emerged a recreational ideology, which holds that the purpose of sexual activity is not procreation or even mutual affection, but physical pleasure.

Although these changes reflect a certain permissiveness, there is evidence that men and women today have higher expectations, demands, and worries about their sexual performance (McKinney and Sprecher; Janus and Janus). The liberating views of sexologists have brought in their train new demands for mutual orgasm and standards of erotic performance that not all couples are capable of realizing at all times. Anger about date rape on university campuses and sexual harassment in the workplace has given rise in the United States to explicit policies, sometimes accompanied by detailed lists of *do's* and *don'ts,* designed to make sure there is willing and verbal consent to each individual sexual act, for example, kissing, fondling of breasts, touching of genitals, intercourse. New policies, grievance procedures, and punishments are proliferating to prevent and punish sexual harassment and rape (Gross). Some professional ethics codes (for example, the new Principles and Standards of the American Psychoanalytic Association) prohibit sexual relations of any sort between professionals and clients, even in situations of mutual consent years after the professional relationship has ended, on the grounds that a misuse of professional authority is likely to have coerced the subordinate in the relationship (Dewald and Clark).

The permissiveness associated with the sexual revolution also coexists with the continuation of strong cultural constraints on frank interpersonal communication about sexual behavior that has disturbing implications for preventing unwanted pregnancies and venereal diseases and for containment of the AIDS epidemic. Western society has a long history of prudishness about sexual topics that stretches back several millennia into the biblical period, when writers of the Hebrew Bible and Christian New Testament used euphemisms like "flesh," "loin," "thigh," "side," and "feet" (for penis), "lewdness" (for female genitals), and "one flesh" (for intercourse) in lieu of explicit sexual terms (Baab). Despite the new sexual permissiveness, and research showing that, for example, 9 percent of American school children have initiated sexual intercourse before age thirteen, that 53.1 percent of students in grades nine through twelve have had sexual intercourse, and that 17.8 percent of high school students have had sexual intercourse with four or more sexual partners (Centers for Disease Control), parents continue to find it difficult to talk with their children in a knowledgeable way about sexual behavior. In a 1987 national survey, 69 percent of adult Americans viewed premarital coitus as "always wrong" for fourteen- to sixteen-year-olds (Davis and Smith). Research suggests that many adolescents perceive their parents as not very well informed about sex and as negative, rigid, and conservative in their attitudes toward sexuality (Metts and Cupach). Although adolescents tell researchers they would like to learn more about sex from their parents, their perceptions as well as the reported attitudes of many parents discourage open communication.

The difficulty parents have communicating information about sex is also found among many professionals charged with conveying information about sex to children, such as schoolteachers, clergy, and physicians. Research shows that adolescents learn most of their information about sexuality, such as petting and sexual intercourse, from same-sex peers, who are often ill-informed about contraception or the prevention of sexually transmitted diseases. However, some studies indicate that some sex education programs are able to convey factual information about anatomical and physiological aspects of sexuality, and to influence understanding of the risks of sexual behaviors (Orbuch; Metts and Cupach). Unfortunately, most teenagers remain unprepared for their first sexual encounters. Much remains to be done in communicating information about how to avoid unwanted pregnancies and infection by the human immunodeficiency virus (HIV) that causes AIDS.

Constraints on open discussion of sexual desires and practices is one factor in the high rates of unwanted sexual contact. Research shows that young men remain reluctant to declare their desire for sexual intercourse to a new date, while young women are less than open about their reluctance. Discussion of contraceptive measures is apparently still difficult for couples who have not had coitus, despite the threat of AIDS (Reiss). The culture of sexual permissiveness is thus riddled with constraints on forthright discussion of choosing among alternative sexual options. To help counter these constraints, healthcare professions need improved educational programs on human sexuality, more training in public health, and opportunities to cultivate skills of communicating with patients as knowledgeable allies and responsible agents, not as passive recipients of authoritative information and advice.

A peculiar problem with many attempts to control sexual behavior is that the constraints and repressions designed to foster licit or safe sex often themselves contribute to the flourishing of illicit or unsafe sexual behavior, which becomes all the more alluring, exciting, and frequent precisely because it is prohibited. The firmest social controls of sexual behavior appear to be those that acknowledge the unique value of sexual desires, fantasies, and actions in human life in a spirit of tolerance toward nonharmful illicit wishes and behaviors, even as actual conduct is directed toward goals that are compatible with the best interests of the individuals involved and the groups of which they are a part.

ERNEST WALLWORK (1995)
REVISED BY AUTHOR

SEE ALSO: *Coercion; Confidentiality; Epidemics; Homosexuality; Sexual Ethics; Sexual Ethics and Professional Standards; Sexual Identity; Sexuality, Legal Approaches to; Public Health Law*

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SEXUAL ETHICS

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Insofar as bioethics is concerned with human bodily health, it has an interest in the way health is influenced by and contributes to sexual functioning. There is a sense, then, in which bioethics includes sexual ethics, or at least some of the key questions of sexual ethics, such as the meaning of human sexuality and the causes and effects of sexual attitudes, orientations, and activities. Concepts of the human person—of desire and obligation, disease and dysfunction, even of justice and purity—can be found overlapping in various bioethical and sexual ethical theories. Like bioethics generally, sexual ethics considers standards for intervention in physical processes, rights of individuals to self-determination, ideals for human flourishing, and the importance of social context for the interpretation and regulation of sexual behavior. Bioethics specifically incorporates issues surrounding contraception and abortion, artificial reproduction, sexually transmitted diseases, sexual paraphilias, gendered roles and sexual conduct of the medical professionals, and sex research, counseling, and therapy. All of these issues are importantly shaped by moral traditions, so that health professionals frequently find themselves called upon to deal with questions of sexual ethics.

Historically, medicine has interacted with philosophy and religion in shaping and rationalizing the sexual ethical norms of a given culture. Medical opinion often simply reflects and conserves the accepted beliefs and mores of a society, but sometimes it is also a force for change. In either case, its influence can be powerful. For example, from the Hippocratic corpus in ancient Greece to the writings of the physician Galen in the second century C.E., medical recommendations regarding sexual discipline echoed and reinforced the ambivalence of Greek and Roman philosophers regarding human sexual activity. Galen's theories retained considerable power all the way into the European Renaissance. The interpretation of syphilis as a disease rather than a divine punishment came in the fifteenth century as the result of medical writings in response to a high incidence of the disease among the socially powerful. In nineteenth century western Europe and North America, medical writers were enormously influential in shaping norms regarding such matters as masturbation (physicians believed it would lead to insanity), homosexuality (newly identified with perversions that medicine must diagnose and treat), contraception (considered unhealthy because it fostered sexual excess and loss of physical power), and gender roles (promoted on the basis of medical assessments of women's capacity for sexual desire). Today sex counseling and therapy communicate, however implicitly, normative ethical assumptions. Indeed, so great has been the influence of the medical profession on moral attitudes toward sexual options that critics warn of the "tyranny of experts," referring not to moral philosophers or religious teachers but to scientists and physicians.

The history of sexual ethics provides a helpful perspective for understanding current ethical questions regarding human sexuality. This article focuses on Western philosophical, scientific-medical, and religious traditions of sexual ethics and on the contemporary issues that trouble the heirs of these traditions. A historical overview of sexual ethics is not without its difficulties, however, as critical studies have shown (Brown; Foucault, 1978; Fout; Plaskow).

First of all, while it is possible to find a recorded history of laws, codes, and other guides to moral action regarding sexual behavior, it is almost impossible to determine what real people actually believed and did in the distant past. Or at least the historical research has barely begun. Second, ethical theory regarding sex (e.g., what is to be valued, what goals are worth pursuing, what reasons justify certain sexual attitudes, activities, and relationships) is predominantly theory formulated by an elite group of men. Women's experiences, beliefs, and values are largely unrecorded and, until recently, have been almost wholly inaccessible. The same is true of men who do not belong to a dominant class. Third, what we do find through historical research is necessarily subject to interpretation. It makes a difference, for example, whether one is looking for historical evaluations of human sexual desire or historical silences about sexual abuse of women. Finally, if one takes seriously the social construction of gender and sexuality, it is not clear that any kind of coherent historical narrative is possible. All of these difficulties notwithstanding, it is possible to survey (with appropriate caution) a Western normative and theoretical history regarding sex and to gain from the richness of varying contemporary interpretations. Central strands of this history can be traced to classical Greek and Roman antiquity, Judaism, and early and later developments in Christianity.

Ancient Greece and Rome

GENERAL ATTITUDES AND PRACTICE. Ancient Greece and Rome shared a general acceptance of sex as a natural part of life. Both were permissive regarding the sexual behavior of men. In Athens, for example, the only clear proscriptions applicable to citizen-class men were in incest, bigamy, and adultery (insofar as it violated the property of another man). The focus of sexual concern in the two cultures was significantly different, however. For the Greeks, adult male love of adolescent boys occupied a great deal of public attention, whereas the Romans focused public concern on heterosexual marriage as the foundation of social life.

Marriage for both Greeks and Romans was monogamous. In Greece, however, no sexual ethic confined sex to marriage. Marriage as the expected pattern for citizen-class individuals was based not on the affective bond between husband and wife but on what were considered natural gender roles regarding procreation and service to the city. Male human nature was generally assumed to be bisexual, and the polyerotic needs of men were taken for granted. Concubinage, male and female prostitution, and the sexual use of slaves were commonly accepted. In practice, much of this was true in ancient Rome as well, even though ideals of marital fidelity became much more important. The development of marriage as a social institution was, however, considered a central achievement of Roman civilization. This included a growing appreciation of the importance of affective ties between wives and husbands.

Greece and Rome were male-dominated societies, and for citizens a gendered double standard prevailed in regard to sexual morality. Both Greek and Roman brides, but not bridegrooms, were expected to be virgins. In Greece, the only women who were given some equal status with men were a special class of artistically and educationally sophisticated prostitutes, the *hetaerae.* Generally women were considered intellectually inferior to men. In addition, Greek husbands and wives were unequal in age (wives were much younger) and in education. Wives had no public life, though they were given the power and responsibility of managing the home. In the Roman household, on the contrary, the husband retained power and could rule with an entirely free hand. Here the ideal of the *patria potestas* reached fulfillment. Mutual fidelity was much praised, but in fact absolute fidelity was required of wives while husbands could consort freely with slaves or prostitutes. Although by the first century C.E., women in Rome had achieved considerable economic and political freedom, they could not practice the sexual freedom traditionally granted to men.

Homosexuality was accepted in both Greek and Roman antiquity. Especially for the Greeks, however, it was less a matter of some men being sexually attracted only to men (or, more likely, boys) than a matter of men generally being attracted to beautiful individuals, whether male or female. Desire was of greater interest, as both possibility and problem, than its object; and desire was not essentially differentiated according to the gender of its object. Greek men were expected to marry, in order to produce an heir. Yet love and friendship, and sometimes sex, between men could be of a higher order than anything possible within marriage (for gender equality obtained between men, despite differences in age). Same-sex relations were not thereby wholly unproblematic, however, as cultural cautions against male passivity attested. Moreover, the ethos tended not to support a positive evaluation of sexual relationships between women. Lesbian relations were often judged negatively because they counted as adultery (since women belonged to their husbands) or because a cultural preoccupation with male sexual desire made sex between women appear unnatural.

In both Greece and Rome, abortion and infanticide were common. Concern about the need to limit population influenced Greek sexual practices at various times, whereas efforts to improve a low birthrate in imperial Rome led to legal incentives to marry and to procreate. Divorce was more readily available in ancient Greece than in Rome, but eventually both cultures provided for it and for the resulting economic needs of divorced women; in Greece, husbands continued to administer their former wives' dowries, while in Rome a woman took her dowry with her.

Scholars today tend to dispute the belief that the last years of the Roman Empire saw a great weakening of sexual norms, a sexual dissipation at the heart of a general moral decline. The favored historical reading is now the opposite: that general suspicion of sexuality grew, and normative restrictions of sexual activity increased. In part, this was the result of the gradual influence of philosophical theories that questioned the value of sexual activity and emphasized the dangers in its consequences.

GREEK AND ROMAN PHILOSOPHICAL APPRAISALS. Michel Foucault's influential history of Graeco-Roman theory regarding sex identifies two problems that preoccupied philosophers: the natural force of sexual desire, with its consequent tendency to excess, and the power relations involved in the seemingly necessary active/passive roles in sexual activity (Foucault, 1986, 1988). The first problem contributed to the formulation of an ideal of self-mastery within an aesthetics of existence. Self-mastery could be achieved through a regimen that included diet, exercise, and various practices of self-discipline. The second problem yielded criteria for love and sex between men and boys. Active and passive roles were not a problem in adult male relations with women or with slaves, for the inferior passive role was considered natural to women, including wives, and to servants or slaves. This was a problem, however, for citizen-class boys, who must come to be equal with men. The solution, according to some philosophers (e.g., Demosthenes), was to regulate the age of boy lovers and the circumstances and goals of their liaisons with men. Others (e.g., Plato) preferred transcending and eliminating physical sex in erotic relations between men and boys.

The aspects of Greek and Roman thought about sex that were to have the most influence on subsequent Western theory included a distrust of sexual desire and a judgment of the inferior status of sexual pleasure, along with the inferior status of the body in relation to the soul. While sex was not considered evil, it was considered dangerous—not only in its excess but also in its natural violence (orgasm was sometimes described as a form of epileptic seizure); in its expenditure of virile energy (it was thought to have a weakening effect); and in its association with death (nature's provision for immortality through procreation made sex a reminder of mortality) (Foucault, 1986).

The Pythagoreans in the sixth century B.C.E. advocated purity of the body for the sake of cultivating the soul. The force of their position was felt in the later thinking of Socrates and Plato. Although Plato moved away from a general hostility to bodily pleasure, he made a careful distinction between lower and higher pleasures (in, for example, the *Republic, Phaedo, Symposium,* and *Philebus*): Sexual pleasure was a lower form of pleasure, and self-mastery required domination over its demands. Plato advocated unleashing, not restraining, the power of eros for the sake of uniting the human spirit with the highest truth, goodness, and beauty. Insofar as bodily pleasures could be taken into this pursuit, there was no objection to them. But Plato thought that sexual intercourse diminished the power of eros for the contemplation and love of higher realities and that it even compromised the possibility of tenderness and respect in individual relationships of love (*Phaedrus*).

Aristotle, too, distinguished lower and higher pleasures, placing pleasures of touch at the bottom of the scale, characteristic as they are of the animal part of human nature (*Nicomachean Ethics*). Aristotle, more this-worldly than Plato, advocated moderation rather than transcendence. However, for Aristotle the highest forms of friendship and love, and of happiness in the contemplation of the life of one's friend, seemed to have no room for the incorporation of sexual activity or even for Platonic eros. Aristotle never conceived of the possibility of equality or mutuality in relationships between women and men, and he opposed the design for this that Plato had offered in the *Republic* and *Laws.*

Of all Graeco-Roman philosophies, Stoicism probably had the greatest impact on later developments in Western thought about sex. Musonius Rufus, Epictetus, Seneca, and Marcus Aurelius, for example, taught strong doctrines of the power of the human will to regulate emotion and of the desirability of such regulation for the sake of inner peace. Sexual desire, like the passions of fear and anger, was in itself irrational, disruptive, liable to excess. It needed to be moderated if not eliminated. It ought never to be indulged in for its own sake but only insofar as it served a rational purpose. Procreation was that purpose. Hence, even in marriage sexual intercourse was considered morally good only when engaged in for the sake of procreation.

With the later Stoics came what Foucault calls the "conjugalization" of sexual relations (1988, p. 166). That is, the norm governing sexual activity was now "no sex outside of marriage," derived from what others have called the "procreative" norm. Marriage was considered a natural duty, excused only in special circumstances such as when an individual undertook the responsibilities of life as a philosopher. The good effects of marriage included progeny and the companionship of husband and wife. It became the context for self-control and the fashioning of the virtuous life. Plutarch (in *Dialogue on Love*) took the position that marriage, not homosexual relationships, was the primary locus for erotic love and for friendship.

Overall, the Graeco-Roman legacy to Western sexual ethics holds little of the sexual permissiveness that characterized ancient Greece. The dominant themes carried through to later traditions were skepticism and control. This may have been due to the failure of almost all Greek and Roman thinkers to integrate sexuality into their best insights into human relationships. Whether such an integration is possible in principle has been at least a tacit question for other traditions.

The Jewish Tradition

Earliest Jewish moral codes were simple and without systematic theological underpinnings. Like other ancient Near Eastern legislation, they prescribed marriage laws and prohibited rape, adultery, and certain forms of prostitution. In contrast with neighboring religions, the Jews believed in a God who is beyond sexuality but whose plan for creation makes marriage and fertility holy and the subject of a religious duty (Gen. 2:24). At the heart of Judaism's tradition of sexual morality is a religious injunction to marry. The command to marry holds within it a command to procreate, and it assumes a patriarchal model for marriage and family. These two aspects of the tradition—the duty to procreate and its patriarchal context—account for many of its specific sexual regulations.

While the core of the imperative to marry is the command to procreate, marriage was considered a duty also because it conduced to the holiness of the partners. Holiness referred to more than the channeling of sexual desire, though it meant that also; it included the companionship and mutual fulfillment of spouses. In fact, monogamous lifelong marriage was considered the ideal context for sexuality, and in time it became the custom and not only an ideal. Yet the command to procreate historically stood in tension with the value given to the marriage relationship. Thus while the laws of *onah,* of marital rights and duties, aimed to make sex a nurturant of love (Lamm), polygamy, concubinage, and divorce and remarriage were long accepted as solutions to a childless marriage. Only in the eleventh century C.E. was polygamy finally banned (much later in the East), and it was only in the twelfth century that Maimonides explicitly condemned concubinage (Novak, 1992).

Judaism has traditionally shown a concern for the "improper emission of seed" (appealing to interpretations of Gen. 38:9). Included in this concern have been proscriptions of masturbation and homosexual acts. The latter in particular have been considered unnatural (Lev. 18:22, 20:13), failing in responsibility for procreation, beneath the dignity of humanly meaningful sexual intercourse, indicative of uncontrolled (and hence morally evil) sexual desire, and a threat to the stability of heterosexual marriage and the patriarchal family. Lesbian relations were not regulated by biblical law, and in rabbinic literature were treated far less seriously than male homosexuality.

Throughout the Jewish tradition there has been a marked difference in the treatment of women's and men's sexuality (Plaskow). In part, this was because of women's subordinate role in the family and in society. The regulation and control of women's sexuality was considered necessary to the stability and the continuity of the family. Premarital sex, extramarital sex, and even rape were legally different for women than for men. In the biblical period, husbands but not wives could initiate divorce (Deut. 24:1–4), although later rabbinic law made it possible for either to do so. Adultery was understood as violating the property rights of a husband and could be punished by the death of both parties. Women's actions and dress were regulated in order to restrict their potential for luring men into illicit sex. The laws of onah required men to respect the sexual needs of their wives; but the laws of *niddah* (menstrual purity) had the symbolic consequence, however unintended, of associating women with defilement.

The perspective on sex, in all the branches of Judaism, has been an enduringly positive one, yet not without ambivalence. The sexual instinct was considered a gift from God, but it could still be called by the rabbis the "evil impulse" (*yetzer hara*) (Plaskow). The tradition was not immune from the suspicion regarding sex that, with the rise of Stoic philosophies and the advent of certain religious movements from the East, permeated all Middle Eastern cultures. Interpretations of the relation between sexuality and the sacred have not been univocal, as evidenced in differences between mainstream Jewish thinking and kabbalistic mysticism. Hence, some issues of sexual ethics have not been resolved once and for all. Contemporary developments in the Jewish tradition include growing pluralism regarding questions of premarital sex, contraception, abortion, gender equality, and homosexuality (Borowitz; Feldman; Plaskow; Biale; Posner). Current conflicts involve the interpretation of traditional values, the analysis of contemporary situations, and the incorporation of hitherto unrepresented perspectives, in particular those of heterosexual women and of gays and lesbians.

Christian Traditions

Like other religious and cultural traditions, the teachings of Christianity regarding sex are complex and subject to multiple influences, and they have changed and developed through succeeding generations. Christianity does not begin with a systematic code of ethics. The teachings of Jesus and his followers, as recorded in the New Testament, provide a central focus for the moral life of Christians in the command to love God and neighbor. Beyond that, the New Testament offers grounds for a sexual ethic that (1) values marriage and procreation on the one hand, and singleness and celibacy on the other; (2) gives as much or more importance to internal attitudes and thoughts as to external actions; and (3) affirms a sacred symbolic meaning for sexual intercourse, yet both subordinates it to other human values and finds in it a possibility for evil. As for unanimity on more specific sexual rules, this is difficult to find in the beginnings of a religion whose founder taught as an itinerant prophet and whose sacred texts were formulated in "the more tense world" of particular disciples, a group of wandering preachers (Brown, pp. 42–43).

EARLY INFLUENCES ON CHRISTIAN UNDERSTANDINGS OF SEX. Christianity emerged in the late Hellenistic age, when even Judaism was influenced by the dualistic anthropologies of Stoic philosophy and Gnostic religions. Unlike the Greek and Roman philosophies of the time, Christianity's main concern was not the art of self-mastery and not the preservation of the city or the empire. Unlike major strands of Judaism at the time, its focus was less on the solidarity and continuity of life in this world than on the continuity between this world and a life to come. Yet early Christian writers were profoundly influenced both by Judaism and by Graeco-Roman philosophy. With Judaism they shared a theistic approach to morality, an affirmation of creation as the context of marriage and procreation, and an ideal of single-hearted love. With the Stoics they shared a suspicion of bodily passion and a respect for reason as a guide to the moral life. With the Greeks, Romans, and Jews, Christian thinkers assumed and reinforced views of women as inferior to men (despite some signs of commitment to gender equality in the beginnings of Christianity as a movement). As Christianity struggled for its own identity, issues of sexual conduct were important, but there was no immediate agreement on how they should be resolved.

Gnosticism was a series of religious movements that deeply affected formulations of Christian sexual ethics for the first three centuries C.E. (Noonan). For example, some Gnostics taught that marriage was evil or at least useless, primarily because the procreation of children was a vehicle for forces of evil. This belief led to two extreme positions—one in opposition to all sexual intercourse, and hence in favor of celibacy, and the other in favor of any form of sexual intercourse so long as it was not procreative. Neither of these positions prevailed in what became orthodox Christianity.

What did prevail in Christian moral teaching was a doctrine that incorporated an affirmation of sex as good (because part of creation) but seriously flawed (because the force of sexual passion as such cannot be controlled by reason). The Stoic position that sexual intercourse can be brought under the rule of reason not by subduing it but by giving it a rational purpose (procreation) made great sense to early Christian thinkers. The connection made between sexual intercourse and procreation was not the same as the Jewish affirmation of the importance of fecundity, but it was in harmony with it. Christian teaching could thus both affirm procreation as the central rationale for sexual union and advocate celibacy as a praiseworthy option (indeed, the ideal) for Christians who could choose it.

With the adoption of the Stoic norm for sexual intercourse, the direction of Christian sexual ethics was set for centuries to come. A sexual ethic that concerned itself primarily with affirming the good of procreation, and thereby the good of otherwise evil tendencies, was reinforced by the continued appearance of antagonists who played the same role the Gnostics had played. No sooner had Gnosticism begun to wane than, in the third century, Manichaeanism emerged. It was largely in response to Manichaeanism that Saint Augustine formulated his sexual ethic, an ethic that continued and went beyond the Stoic elements incorporated by Clement of Alexandria, Origen, Ambrose, and Jerome.

THE SEXUAL ETHICS OF SAINT AUGUSTINE AND ITS LEGACY. Against the Manichaeans Augustine argued in favor of the goodness of marriage and procreation, though he shared with them a negative view of sexual desire as in itself an evil passion. Because evil was for Augustine, however, a privation of right order (something missing in what was otherwise basically good), he thought at first that it was possible to reorder sexual desire according to right reason, to integrate its meaning into a right and whole love of God and neighbor. This reordering could be done only when sexual intercourse was within heterosexual marriage and for the purpose of procreation (*On the Good of Marriage,* 6). Intercourse within marriage but without a procreative purpose was, according to Augustine, sinful, though not necessarily mortally so. Marriage, on the other hand, had a threefold purpose: not only the good of children but also the goods of fidelity between spouses (as opposed to adultery) and the indissolubility of the union (as opposed to divorce).

In his later writings against the Pelagians (*Marriage and Concupiscence*), Augustine tried to clarify the place of disordered sexual desire in a theology of original sin. Although for Augustine the original sin of Adam and Eve was a sin of the spirit (a sin of prideful disobedience), its effects were most acutely present in the conflict between sexual desire and reasoned love of higher goods. Moreover, this loss of integrity in affectivity was passed from one generation to another through the mode of procreation—sexual intercourse. In this debate Augustine argued that there is some evil in all sexual intercourse, even when it is within marriage and for the sake of procreation. Most of those who followed Augustine disagreed with this, but his basic formulation of a procreative ethic held sway in Christian moral teaching for centuries.

Some early Christian writers (e.g., John Chrysostom) emphasized the Pauline purpose for marriage—marriage as a remedy for incontinence. Such a position hardly served to foster a more optimistic view of sex, but it did offer a possibility for moral goodness in sexual intercourse without a direct relation to procreation. However, from the sixth to the eleventh century, it was Augustine's rationale that was codified in penitentials (manuals for confessors, providing lists of sins and their prescribed penances) with detailed prohibitions against adultery, fornication, oral and anal sex, contraception, and even certain positions for sexual intercourse if they were thought to be departures from the procreative norm. Gratian's great collection of canon law in the twelfth century contained rigorous regulations based on the principle that all sexual activity is evil unless it is between husband and wife and for the sake of procreation. A few voices (e.g., Abelard and John Damascene) maintained that concupiscence (sexual passionate desire) does not make sexual pleasure evil in itself, and that intercourse in marriage can be justified by the simple intention to avoid fornication.

Overall, the Christian tradition in the first half of its history developed a consistently negative view of sex, despite the fact that Augustine and most of those who followed him were neither anti-body nor anti-marriage. The statement that this tradition was negative must be a qualified claim, of course, for it was silent or vacillating on many questions of sexuality (e.g., on the question of homosexuality); and there is little evidence that Christians in general were influenced by the more severe sexual attitudes of their leaders (Boswell). The direction and tone that the early centuries gave to the tradition's future, however, were unmistakable. What these leaders were concerned about was freedom from bondage to desires that seemingly could not in themselves lead to God. In a quest for transformation of the body along with the spirit, even procreation did not appear very important. Hence, regulation of sexual activity and even the importance of the family were often overshadowed by the ideal of celibacy. As Peter Brown's 1988 massive study has shown, sexual renunciation served both eros and unselfish love, and it suited a worldview that broke boundaries with this world without rejecting it as evil.

THE TEACHING OF AQUINAS. Thomas Aquinas wrote in the thirteenth century, when rigorism already prevailed in Christian teaching and church discipline. His remarkable synthesis of Christian theology did not offer much that was innovative in the area of sexual ethics. Yet the clarity of what he brought forward made his contribution significant for the generations that followed. He taught that sexual desire is not intrinsically evil, since no spontaneous bodily or emotional inclination is evil in itself; only when there is an evil moral choice is an action morally evil. Consequent upon original sin, however, there is in human nature a certain loss of order among natural human inclinations. Sexual passion is marked by this disorder, but it is not morally evil except insofar as its disorder is freely chosen.

Aquinas offered two rationales for the procreative norm the tradition had so far affirmed. One was the Augustinian argument that sexual pleasure, in the fallen human person, hinders the best working of the mind. It must be brought into some accord with reason by having an overriding value as its goal. No less an end than procreation can justify it (*Summa theologiae,* I-II.34.1, ad 1). But second, reason does not merely provide a good purpose for sexual pleasure. It discovers this purpose through the anatomy and biological function of sexual organs (*Summa theologiae* II-II.154.11; *Summa contra Gentiles* III.122.4, 5). Hence, the norm of reason in sexual behavior requires not only the conscious intention to procreate but also the accurate and unimpeded (i.e., noncontraceptive) physical process whereby procreation is possible.

From the procreative norm there followed other specific moral rules. Many of them were aimed at the well-being of offspring that could result from sexual intercourse. For example, Aquinas argued against fornication, adultery, and divorce on the grounds that children would be deprived of a good context for their rearing. He considered sexual acts other than heterosexual intercourse to be immoral because they could not be procreative. Aquinas's treatment of marriage contained only hints of new insight regarding the relation of sexual intercourse to marital love. He offered a theory of love that had room for a positive incorporation of sexual union (*Summa theologiae* II-II.26.11), and he suggested that marriage might be the basis of a maximum form of friendship (*Summa contra Gentiles* III.123).

Though what had crystallized in the Middle Ages canonically and theologically would continue to influence Christian moral teaching into the indefinite future, the fifteenth century marked the beginning of significant change. Finding some grounds for opposing the prevailing Augustinian sexual ethic in both Albert the Great and in the general (if not the specifically sexual) ethics of Aquinas, writers (e.g., Denis the Carthusian and Martin LeMaistre) began to talk of the integration of spiritual love and sexual pleasure, and the intrinsic good of sexual pleasure as the opposite of the pain of its lack. This did not reverse the Augustinian tradition, but it weakened it. The effects of these new theories were felt in the controversies of the Reformation.

PROTESTANT TEACHINGS ON SEX. Questions of sexual behavior played an important role in the Protestant Reformation beginning in the sixteenth century. Clerical celibacy, for example, was challenged not just in its scandalous nonobservance but also as a Christian ideal. Marriage and family replaced it among the reformers as the center of sexual gravity in the Christian life. Martin Luther and John Calvin were both deeply influenced by the Augustinian tradition regarding original sin and its consequences for human sexuality. Yet both developed a position on marriage that was not dependent on a procreative ethic. Like most of the Christian tradition, they affirmed marriage and human sexuality as part of the divine plan for creation, and therefore good. But they shared Augustine's pessimistic view of fallen human nature and its disordered sex drive. Luther was convinced, however, that the necessary remedy for disordered desire was marriage (*On the Estate of Marriage*). And so the issue was joined over a key element in Christian sexual ethics. Luther, of course, was not the first to advocate marriage as the cure for unruly sexual desire, but he took on the whole of the tradition in a way that no one else had. He challenged theory and practice, offering not only an alternative justification for marriage but also a view of the human person that demanded marriage for almost all Christians.

According to Luther, sexual pleasure itself in one sense needed no justification. The desire for it was simply a fact of life. It remained, like all the givens in creation, a good so long as it was channeled through marriage into the meaningful whole of life, which included the good of offspring. What there was in sex that detracted from the knowledge and worship of God was sinful, but it had simply to be forgiven, as did the inevitable sinful elements in all human activity. After 1523, Luther shifted his emphasis from marriage as a "hospital for the incurables" to marriage as a school for character. It was within the secular, nonsacramental institution of marriage and family that individuals learned obedience to God and developed the important human virtues. The structure of the family was hierarchical, husband having authority over wife, parents over children.

Calvin, too, saw marriage as a corrective to otherwise disordered desires. He expanded the notion of marriage as the context for human flourishing by maintaining that the greatest good of marriage and sex was the society that is formed between husband and wife (*Commentary on Genesis*). Calvin was more optimistic than Luther about the possibility of controlling sexual desire, though he, too, believed that whatever fault remained in it was "covered over" by marriage and forgiven by God (*Institutes of the Christian Religion,* 2.8.44). Like earlier writers, he worried that marriage as a remedy for incontinence could nonetheless in itself offer provocation to uncontrolled passion.

As part of their teaching on marriage, Luther and Calvin opposed premarital and extramarital sex and homosexual relations. So concerned was Luther to provide some institutionally tempering form to sexual desire that he once voiced an opinion favoring bigamy over adultery. Both Luther and Calvin were opposed to divorce, though its possibility was admitted in a situation of adultery or impotence.

MODERN ROMAN CATHOLIC DEVELOPMENTS. During and after the Roman Catholic Counterreformation, from the late sixteenth century on, new developments alternated with the reassertion of the Augustinian ethic. The Council of Trent (1545–1563) was the first ecumenical council to address the role of love in marriage, but it also reaffirmed the primacy of procreation and reemphasized the superiority of celibacy. In the seventeenth century, Jansenism, a morally austere and ultimately heretical movement, reacted against what it considered a dangerous lowering of sexual standards and brought back the Augustinian connection between sex, concupiscence, and original sin. Alphonsus Liguori in the eighteenth century gave impetus to a manualist tradition (the development and proliferation of moral manuals designed primarily to assist confessors) that attempted to integrate the Pauline purpose of marriage (as a remedy for incontinence) with the procreative purpose. Nineteenth-century moral manuals focused on "sins of impurity," choices of any sexual pleasure apart from procreative marital intercourse. Then came the twentieth century, with the rise of Catholic theological interest in personalism and the move by the Protestant churches to accept birth control.

In 1930, Pope Pius XI responded to the Anglican approval of contraception by reaffirming the procreative ethic (*Casti connubii*). But he also gave approval to the use of the rhythm method for restricting procreation. Moral theologians began to move cautiously in the direction of allowing sexual intercourse in marriage without a procreative intent and for the purpose of fostering marital union. The change in Roman Catholic moral theology from the 1950s to the 1970s was dramatic. The wedge introduced between procreation and sexual intercourse by the acceptance of the rhythm method joined with new understandings of the totality of the human person to support a radically new concern for sex as an expression and cause of married love. The effects of this theological reflection were striking in the 1965 Second Vatican Council teaching that the love essential to marriage is uniquely expressed and perfected in the act of sexual intercourse (*Gaudium et spes,* 49). Although the Council still held that marriage is by its very nature ordered to the procreation of children, it no longer ranked what the tradition considered the basic ends of marriage, offspring and spousal union, as primary and secondary.

In 1968, Pope Paul VI insisted that contraception is immoral (*Humanae vitae*). Rather than settling the issue for Roman Catholics, however, this occasioned intense conflict. The majority of moral theologians disagreed with the papal teaching, even though a distinction between nonprocreative and antiprocreative behavior mediated the dispute for some. Since then, many of the specific moral rules governing sexuality in the Catholic tradition have come under serious question. Official teachings have sustained past injunctions, though some modifications have been made in order to accommodate pastoral responses to second marriages, homosexual orientation (but not sexual activity), and individual conscience decisions regarding contraception. Among moral theologians there has been serious debate (and by the 1990s, marked pluralism) regarding premarital sex, homosexual acts, remarriage after divorce, infertility therapies, gender roles, and clerical celibacy (Curran and McCormick).

POST-REFORMATION PROTESTANTISM. Twentieth-century Protestant sexual ethics developed even more dramatically than Roman Catholic sexual ethics. After the Reformation, Protestant theologians and church leaders continued to affirm heterosexual marriage as the only acceptable context for sexual activity. Except for the differences regarding celibacy and divorce, sexual norms in Protestantism looked much the same as those in the Catholic tradition. Nineteenth-century Protestantism shared and contributed to the cultural pressures of Victorianism. But in the twentieth century, Protestant thinking was deeply affected by biblical and historical studies that questioned the foundations of Christian sexual ethics, by psychological theories that challenged traditional views, and by the voiced experience of church members.

It is difficult to trace one clear line of development in twentieth-century Protestant sexual ethics, or even as clear a dialectic as may be found in Roman Catholicism. The fact that Protestantism in general was from the beginning less dependent on a procreative ethic allowed it almost unanimously to accept contraception as a means to responsible parenting. Overall, Protestant sexual ethics has moved to integrate an understanding of the human person, male and female, into a theology of marriage that no longer deprecates sexual desire as self-centered and dangerous. It continues to struggle with issues of gendered hierarchy in the family, and with what are often called “alternative lifestyles,” such as the cohabitation of unmarried heterosexuals and the sexual partnerships of gays and lesbians. For the most part, the ideal context for sexual intercourse is still seen to be heterosexual marriage, but many Protestant theologians accept premarital sex and homosexual partnerships with general norms of noncoercion, basic equality, and so on. Every mainline Protestant church in the 1990s has task forces working particularly on questions of homosexuality, professional (including clergy) sexual ethics, and sex education. Traditional positions have either changed or are open and conflicted.

Modern Sexology: Philosophical, Medical, Social Scientific

The contemporary shaking of the foundations of Western sexual ethics, religious and secular, is traceable to many factors. These quite obviously include the rapid development of reproductive technologies, none more important than the many forms of contraception. But there have been other factors as well, such as changes in economic structures under capitalism and in social structures following major shifts of population to urban centers. Of important influence, too, has been the rise of the modern women’s movement and of movements for gay and lesbian civil rights. Along with these developments, as both cause and effect, there have been significant contributions from disciplines such as history, psychology, anthropology, sociology, and medicine. Philosophy has generally followed these changes, though in the late twentieth century it, too, has contributed to cultural alterations in perspectives on sex.

PHILOSOPHICAL DEVELOPMENTS. As surveyors of the history of philosophy note, philosophers have not paid much attention to sex. They have written a great deal on love but have left sexual behavior largely to religion, poetry, medicine, or the law (Baker and Elliston; Soble). After the Greeks and Romans, and medieval thinkers such as Thomas Aquinas whose work is philosophical as well as theological, there is not much to be found in the field regarding sexuality until the twentieth century. Some exceptions to this are the sparse eighteenth-century writings on sex and gender by David Hume, Jean-Jacques Rousseau, Immanuel Kant, Mary Wollstonecraft, and Johann Gottlieb Fichte, and the nineteenth-century writings of Arthur Schopenhauer, Karl Marx, Friedrich Engels, John Stuart Mill, and Friedrich Nietzsche. Most of these writers reinforced the norm of heterosexual procreative sex within marriage. Hume, for example, in his "Of Polygamy and Divorce" (1742), insisted that all arguments finally lead to a recommendation of "our present European practices with regard to marriage." Rousseau's La Nouvelle Héloïse (1761) deplored the faults of conventional marriage but strongly opposed divorce and marital infidelity. Kant defended traditional sexual mores, although in his *Lectures on Ethics* (1781) he introduced a justification for marriage not in terms of procreation but of altruistic love, arguing that only a mutual commitment in marriage can save sexual desire from making a sexual partner into a mere means to one's own pleasure. Schopenhauer viewed sexual love as subjectively for pleasure, though objectively for procreation; his strong naturalism paved the way for a more radical theory of sex as an instinct without ethical norms (*The Metaphysics of Sexual Love,* 1844).

Philosophers in these centuries came down on both sides of the question of gender equality. Fichte, for example, asserted an essentially passive nature for women, who, if they were to be equal with men, would have to renounce their femininity (*The Science of Rights,* 1796). But Mary Wollstonecraft in her "A Vindication of the Rights of Women" (1792), and Mill in his "The Subjection of Women" (1869), offered strong challenges to the traditional inequality of gender roles in society. Marx and Engels critiqued bourgeois marriage as a relationship of economic domination (e.g., in their *The Origin of the Family, Private Property and the State,* first published by Engels in 1884). Schopenhauer, reacting to feminist agendas, advocated polygamy on the basis of a theory of male needs and female instrumental response (*On Women,* 1848). Nietzsche, like Schopenhauer, moved away from traditional ethical norms but also reinforced a view of the solely procreative value of women (*Thus Spake Zarathustra,* 1892).

Twentieth-century European philosophers attempted to construct new meanings for human sexuality in the light of new philosophical theories of freedom and interpersonal love. Jean-Paul Sartre analyzed sexuality as an ontological paradigm for human conflict (*Being and Nothingness,* 1943); Maurice Merleau-Ponty tried to challenge this and to go beyond it (*The Phenomenology of Perception,* 1945); Simone de Beauvoir fueled a feminist movement with a stark and revealing analysis of sexism and its influence on the meaning of both gender and sex (*The Second Sex,* 1949). With the exception of Bertrand Russell (*Marriage and Morals,* 1929), it was not until the late 1960s that British and American philosophers began to turn their attention to sexual ethics. Then, however, key essays by analytic philosophers began to appear on issues such as sexual desire, gender, marriage, adultery, homosexuality, abortion, sexual perversion, rape, pornography, and sexual abuse (Baker and Elliston; Shelp; Soble). All of these efforts were profoundly influenced by nineteenth- and twentieth-century contributions from other disciplines.

FREUD AND PSYCHOANALYSIS. The emergence of psychoanalytic theory brought with it new perceptions of the meaning and role of sexuality in the life of individuals. Whatever the final validity of Sigmund Freud's insights, they burst upon the world with a force that all but swept away the foundations of traditional sexual morality. Augustine's and Luther's assertions about the indomitability of sexual desire found support in Freud's theory, but now the power of sexual need was not the result of sin but a natural drive, centrally constitutive of the human personality (*Three Essays on the Theory of Sexuality,* 1905). Past efforts to order sexuality according to rational purposes could now be understood as repression. After Freud, when sex went awry, it was a matter of psychological illness, not moral evil. Taboos needed demythologizing, and freedom might be attained not through forgiveness but through medical treatment.

Yet psychoanalytic theory raised as many questions as it answered. Freud argued for liberation from sexual taboos and from the hypocrisy and sickness they caused, but he nonetheless maintained the need for sexual restraint. His theory of sublimation called for a discipline and channeling of the sexual instinct if the individual and society were to progress (*Civilization and Its Discontents,* 1930). The concern for sexual norms therefore remained, and Freud's own recommendations were in many ways quite traditional. But new work had clearly been cut out for thinkers in both secular and religious traditions.

SCIENCE, SOCIAL SCIENCE, AND MEDICINE. Freud was not the only force in nineteenth- and twentieth-century scientific and social thought that shaped changes in Western sexual mores. Biological studies of the human reproductive process offered new perspectives on male and female roles in sex and procreation. Animal research showed that higher forms of animals masturbate, perform sexual acts with members of the same sex, and generally engage in many sexual behaviors that were previously assumed to be unnatural for humans because they were unnatural for animals. Anthropologists found significant variations in the sexual behavior of human cultural groups, so that traditional notions of human nature seemed even more questionable. Surveys of sexual activities in Western society revealed massive discrepancies between accepted sexual norms and actual behavior, undercutting consequential arguments for some of the norms (e.g., the fact that 95% of the male population in the United States engaged in autoerotic acts made it difficult to support a prohibition against masturbation on grounds that it leads to insanity).

Modern sexology, then, has incorporated the work not only of sexual psychology but also of biology, anthropology, ethnology, and sociology—the research and the theories of individuals like Richard von KrafftEbing, Havelock Ellis, Magnus Hirschfield, Alfred Kinsey, Margaret Mead, William Masters, and Virginia Johnson. The results have not all been toward greater liberty in sexual behavior, but they have shared a tendency to secularize and medicalize human sexuality. In theory, sex has become less an ethical or even an aesthetic problem than a health problem. In practice, experts of all kinds—physicians, counselors, psychiatrists, social workers, teachers—provide guidance; and the guidance can at least appear to carry moral weight. An example of the intertwining of science, the medical professions, and morality is clear in the long efforts to define and identify sexual deviance or perversion—from Krafft-Ebing in the nineteenth century to the debates in the American Psychiatric Association in the 1970s and 1980s over the classification of homosexuality as a disease.

LESSONS OF HISTORY. Historians, too, have played an important role in the weakening of traditional sexual ethical norms. The very disclosure that sexual prescriptions have a history has revealed the contingency of their sources and foundations. To see, for example, that a procreative ethic rose as much from Stoic philosophies as from the Bible has allowed many Christians to question its validity. Feminist retrievals of elements in the Western tradition have led to critiques of taboo moralities and a consequent need for reconstruction. In an effort to make sense of present beliefs, historians have searched for the roots and developments of these beliefs, and the result has seldom been a reinforcement of the original rationales (Foucault, 1978; Boswell).

But it is not only the history of ideas that has had an impact on contemporary sexual ethics. It is also the historical excavation of the moral attitudes and actual practices of peoples of the past, and an identification of the shifting centers of influence on the sexual mores of different times and places (D'Emilio and Freedman; Peiss and Simmons; Fout). Sometimes referred to as a history of sexuality rather than a history of theories about sexuality or of institutionalized norms for sexuality, this is a task that is barely under way, and it has strong critics. Yet it has already had an impact on, for example, understandings of homosexuality and what can be called the politics of sex. This kind of history also attempts to provide narratives, describing shifts like the one in the United States from family-centered procreative sexual mores to romantic notions of emotional intimacy to a commercialization of sex and its idealization as the central source of human happiness (D'Emilio and Freedman). The history of sexuality and of sexual ethics, no less than the analysis of contemporary sexual norms, thus becomes subject to interpretation.

Interpretive Theories: Sex, Morality, and History

No one may have been more influential in determining current questions about the history of sexuality and sexual ethics than the French philosopher Michel Foucault. His ideas permeate much of the work of other sexual historians as well as philosophers and theologians. Yet his is not the only formative study in the history of sexual ethics, and his conclusions have provoked both positive and negative responses.

MICHEL FOUCAULT: A HISTORY OF DESIRE. Foucault originally planned to write a history of what he called "the experience of sexuality" in modern Western culture. In the course of his work, he became convinced that what was needed was a history of desire, or of the desiring subject. At the heart of this conviction was the premise that sexuality is not an ahistorical constant. Neither is sex a natural given, a biological referent that simply expresses itself in different experiences of sexuality shaped historically by changing moral norms. Sexuality is, rather, a transfer point for relations of power—between women and men, parents and children, teachers and students, clergy and laity, and so forth. Power in this sense is diffused through a field of multiple "force relations immanent in the sphere in which they operate" (Foucault, 1978, p. 92). In other words, sex is not a "stubborn drive" that requires the control of power. Power produces and constitutes sexual desire much more than it ever represses it. Power determines, shapes, and deploys sexuality, and sexuality determines the meaning of sex (Foucault, 1978).

Foucault denied, then, the "repressive hypothesis" as an explanation of the eighteenth- and nineteenth-century Western experience of sexuality. That is, he denied that the Victorian era had been an era of sexual repression and socially enforced silence about sex. He argued, rather, that it had been a time of an expanding deployment of sexuality and a veritable explosion of discourse about sexuality. The questions that interested him were not "Why are we repressed?" but "Why do we say that we are repressed?" and within this, not "Why was sex associated with sin for such a long time?" but "Why do we burden ourselves today with so much guilt for having made sex a sin?" (Foucault, 1978, pp. 8–9). Since the key to these questions was, Foucault thought, to be found in a study of discourse, he began with an examination of what he considered a Western impulse to discover the "truth" about sex. This, in his view, included a striking Western compulsion to self-examination and self-reporting regarding sexual experience, whether in the discourses of religion, medicine, psychiatry, or criminal justice.

To make sense of the connections between power, sexuality, and truth in the modern period, Foucault revised his project to include a study of the variations on sexual themes in other historical periods. His move to the past began with his thesis that a forerunner of modern discourse on sex was the seventeenth-century Christian ecclesiastical emphasis on confession. To put this in perspective, he undertook studies of pagan antiquity and of Christianity prior to the seventeenth century. Thus, volumes 2 and 3 of his *History of Sexuality* address the sexual mores of the fourth-century B.C.E. Greeks and the first- and second-century C.E. Romans (1990 and 1988, respectively). His unpublished fourth volume (*The Confessions of the Flesh*) examine developments within Christianity. The contrasts (and, as it turned out, the continuities) between the different historical periods shed some light on each period and on the overall Western pursuit of the kind of knowledge that promised power in relation to sex, what Foucault called the scientia sexualis.

Foucault came to the conclusion that the sexual morality of the Greeks and Romans did not differ essentially from Christian sexual morality in terms of specific prescriptions. He rejected the commonly held view that the essential contrast between sexual ethics in antiquity and in early Christianity lies in the permissiveness of Graeco-Roman societies as distinguished from the strict sexual rules of the Christians, or in an ancient positive attitude toward sex as distinguished from a negative Christian assessment. Both traditions, he argued, contained prohibitions against incest, a preference for marital fidelity, a model of male superiority, caution regarding same-sex relations, respect for austerity, a positive regard for sexual abstinence, fears of male loss of strength through sexual activity, and hopes of access to special truths through sexual discipline. Nor were these basic prescriptions very different from what could be found in post-seventeenth-century Western society.

Yet there were clear discontinuities, even ruptures, between these historical periods. The reasons for moral solicitude regarding sexuality were different. In Foucault's reading, the ancients were concerned with health, beauty, and freedom, while Christians sought purity of heart before God, and bourgeois moderns aimed at their own self-idealization. The Greeks valued self-mastery; Christians struggled for self-understanding; and modern Western individuals scrutinized their feelings in order to secure compliance with standards of normality. Eroticism was channeled toward boys for the Greeks, women for the Christians, and a centrifugal movement in many directions for the Victorian and post-Victorian middle class. The Greeks feared the enslavement of the mind by the body; Christians dreaded the chaotic power of corrupted passion; post-nineteenth century persons feared deviance and its consequent shame. Sexual morality was an aesthetic ideal, a personal choice, for an elite in antiquity; it became a universal ethical obligation under Christianity; and it was exacted as a social requirement under the power of the family and the management of the modern professional.

Foucault's study of the history of sexuality left open a question with which he had become preoccupied: How did contemporary Western culture come to believe that sexuality was the key to individual identity? How did sex become more important than love, and almost more important than life? He exposed the lack of freedom in past constructs of sexuality, and he critiqued past formulations of sexual prescriptions. But his presentation of current strategies for sexual liberation yielded no less skeptical a judgment. It suggested, rather, that however historically relative sexual ethics may be, moral solicitude regarding sexuality is not entirely a mistake.

CATHARINE MACKINNON: A HISTORY OF GENDERED VIOLENCE. Many Western feminists have shared Foucault's convictions that sexuality is socially constructed and the body is a site of power. Like Foucault, they have exposed continuing roles of medicine, education, and psychology in determining post-eighteenth-century sexual mores. With Foucault, they have emphasized discourse as a key to identifying underlying forces that link power, sexuality, and identity. But feminists fault Foucault for not extending his analytics of power to gender. Legal scholar Catharine MacKinnon, for example, opposes a Foucaultian history of desire on the grounds that the unacknowledged desiring subject is male. A history of sexuality that emphasizes sexual desire and change misses the enduring aspects of history—the unrelenting sexual abuse of women. History, then, remains silent regarding sexual exploitation, harassment, battery, and rape. Without attention to these unchanging experiences of women, MacKinnon argues, there can be no accurate analysis of sex and power.

A feminist theory of sexuality, according to MacKinnon, "locates sexuality within a theory of gender inequality" (1989, p. 127). It is a mistake, therefore, to adopt the stance that what sex needs is socially constructed freedom, that all sex can be good—healthy, appropriate, pleasurable, to be approved and expressed—if only it is liberated from ideologies of allowed/not allowed. Since sexuality is socially constructed not by a diffuse multiplicity of powers (in Foucault's sense) but by hegemonic male power, it is culturally determined as violent toward women. Pornography is a means through which this social construction is achieved.

Although not all feminists share MacKinnon's radical critique of historical and contemporary sexual understandings and practices, there is significant agreement that sexuality needs norms, and that past and present norms require gender analysis and critique. From this standpoint, a Foucaultian treatment of male discourse regarding sexuality perpetuates a view of sexuality as eroticized dominance and submission; it fails to expose this conflict as gendered.

EVOLUTIONARY INTERPRETATIONS. Foucault and MacKinnon represent interpretations of the history of sexuality and sexual ethics that deny any progress. They refuse to applaud advances in understandings of sexuality or to sanctify the present as enlightened and free. To some extent, they even reject notions of change in history—Foucault arguing for different, but not causally connected, historical perspectives; and MacKinnon focusing on similarities across time and cultures—indeed, a failure to change. Others, however, have charted an evolutionary process across the Western history of ideas about sex and the moral norms that should govern it. Those who believe that contemporary sexual revolutions have liberated persons and their sexual possibilities belong in this category. So do those who acknowledge the significance of advances in biology and psychology and call for appropriate adjustments in philosophical and theological ethics. Thoughtful commentators do not necessarily conclude that there has been real progress, though they identify evolutionary changes (Green; Shelp; Soble).

Richard Posner belongs to this latter group, offering what he calls an "economic theory of sexuality." That is, he relies heavily on economic analysis both to describe the practice of sex and to evaluate legal and ethical norms in its regard. There are, he argues, three stages in the evolution of sexual morality. These stages correlate with the status of women in a given society (Posner). In the first stage, women's occupation is that of "simple breeder." When this is the case, companionate marriage is an unlikely possibility, and practices that are considered "immoral" are likely to flourish (e.g., prostitution, adultery, homosexual liaisons).

The second stage begins when women's occupations expand to include "child rearer and husband's companion." Here, companionate marriage is a possibility, and because of this, "immoral" practices that endanger it are vehemently condemned. When companionate marriage is idealized as the only possibility for everyone, societies become puritanical in their efforts to promote and protect it. In the third stage, women's roles are enlarged to include "market employment." Marriages will be fewer, but where they exist, they will be companionate. Other forms of sexual relationship, previously considered immoral, no longer appear to be either immoral or abnormal. This stage characterizes some Western societies more than others—notably, according to Posner, contemporary Sweden.

A very different kind of evolutionary theory can be found in the philosopher Paul Ricoeur's 1967 analysis of the symbolism of evil in Western history. In this analysis, the Greco-Hebraic history of the consciousness of evil has three moments or stages: defilement, sin, and guilt. The sense of defilement is a pre-ethical, irrational, quasi-material sense of something that infects by contact. Sin is a sense of betrayal, of rupture in a relationship. And guilt is the subjective side of sin, a consciousness that the breakdown of a relationship is the result of an evil use of freedom. According to Ricoeur, sexual morality has appeared historically paradigmatic of the experience of defilement. This association has not been left behind; there remains in the implicit consciousness of the West an inarticulable but persistent connection between sexuality and evil. The result is that ethical wisdom regarding sexuality has remained far behind other developments in Western ethics, even though there has been a significant demythologizing of sex.

Contemporary Ethical Reconstruction

The turn to history may have relativized much of traditional sexual ethics, but the motivation for the turn is more complicated. Given all the factors that have helped to weaken traditional sexual norms, ethical reflection has been left with very little anchorage. Science and medicine help, but they sometimes add to human suffering experienced in relation to sex. Philosophy and religion find their traditions struggling for relevance, for clarity, for reasonable guidance and more than reasoned inspiration. The turn to history has been an effort to find a truth that continues to be elusive.

And history, like other disciplinary efforts, has probably both helped and heightened the need for the quest.

Contemporary efforts in sexual ethics recognize multiple meanings for human sexuality—pleasure, reproduction, communication, love, conflict, social stability, and so on. Most of those who labor at sexual ethics recognize the need to guide sexual behavior in ways that preserve its potential for good and restrict its potential for evil. Safety, nonviolence, equality, autonomy, mutuality, and truthfulness are generally acknowledged as required for minimal human justice in sexual relationships. Many think that care, responsibility, commitment, love, and fidelity are also required, or at least included as goals. With social construction no longer ignored, the politics of sex has become an ethical matter for persons and societies, institutions and professions. New questions press regarding the ways in which humanity is to reproduce itself and the responsibilities it has for its offspring. In all of this, sexual ethics asks, How is it appropriate—helpful and not harmful, creative and not destructive—to live and to relate to one another as sexual beings?

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BIBLIOGRAPHY REVISED

SEE ALSO: *Autonomy; Body; Care; Coercion; Compassionate Love; Confidentiality; Emotions; Epidemics; Eugenics; Feminism; Freedom and Free Will; Homosexuality; Natural Law; Sexual Ethics; Sexual Ethics and Professional Standards; Sexual Identity; Sexuality, Legal Approaches to*

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SEXUAL ETHICS AND PROFESSIONAL STANDARDS

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The Hippocratic oath gives early expression to a general prohibition against professionals taking advantage of the vulnerability of clients or patients and their families to enter into sexual relations: “Whatever house I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves” (Verhey, p. 72). The prohibition was reiterated for mental-health professionals by Sigmund Freud (Schoener et al.). From these roots grows a general prohibition against professional-client sexual relations, including relations between teacher and student, supervisor and supervised, clergy and parishioner, therapist and client, and physician and patient. In some professions, the taboo has been so strong that sexuality is the problem professionals “don’t talk about” (Rassieur) or “the problem with no name” (Davidson).

Yet some famous therapists (e.g., Carl Jung) have been notorious for having sexual relations with their clients (Schoener et al.). Studies of various professions indicate a rate of sexual contact between professionals and clients or patients of between 5 and 11 percent (Schoener et al.; Bonavoglia). The phenomenon has become sufficiently widespread to be called a “national disgrace” (Pope and Bouhoutsos) and an “epidemic” (Rutter).

In the ten years following the publication of *Betrayal* (Freeman and Roy), which described one woman’s successful lawsuit over sexual misconduct by a psychiatrist, over $7 million was paid out in legal claims. In the face of revelations of misconduct, professional societies began to insert clear prohibitions into their codes: “sexual intimacies with clients are unethical” (American Psychological Association); “the social worker should under no circumstances engage in sexual activities with clients” (National Association of Social Workers); “sexual relations between analyst and patient are antithetic to treatment and unacceptable under any circumstance” (American Psychoanalytic Association). Even in the controversial field of sex therapy, direct sexual contact between therapist and client is discouraged; sexual surrogates are used instead (Masters et al.).

Several jurisdictions have enacted laws making it a felony for a psychotherapist (including clergy) to have sexual contact with a client, and at least one holds the therapist’s employer liable if the employer knew or should have known of a history of sexual abuse (Bonavoglia; for statutes, see Schoener et al.). Sexual contact is variously defined, but generally includes not only sexual intercourse but also intimate touching and other sexualizing of the relationship.

The prohibition against professional-client sexual contact rests on three foundations: the likelihood of great harm from the sexual contact, the responsibility of the professional to work for the good of the client, and the vulnerability of the client and the power gap between client and professional, which raises questions even in the absence of demonstrable harm.

There is growing consensus that significant harm is done to patients or clients who enter sexual relations with professionals in whom they have vested trust: “[T]he balance of the empirical findings is heavily weighted in the direction of serious harm resulting to almost all patients sexually involved with their therapists” (Pope and Bouhoutsos, p. 63). A few therapists have argued for the beneficial effects of sexual relations between therapist and client (Shepard; Schoener et al.), but their data have been challenged (Pope and Bouhoutsos; Schoener et al.). Studies of women who have had sexual relations with their gynecologists, psychotherapists, and clergy all point to deleterious consequences including loss of trust, poor self-concept, loss of confidence in one’s judgment, and difficulty establishing subsequent relationships (Pope and Bouhoutsos). Several commentators have noted the similarities to incest because of the power of the professional and have argued that the consequences are as deleterious as those of incest (e.g., Fortune, 1989). Others note that women who enter relations with therapists often have a history of sexual abuse, and thus are being revictimized (Rutter; Pope and Bouhoutsos).

Sexual contact between professional and client thus subverts the legitimate goal of the profession—the healing or making whole of one who is wounded and vulnerable (Verhey). There is both exploitation of the client for benefit of the professional and a failure to provide the services implied by the professional role.

However, harm and failure to help are not the only ethical issues at stake. Several commentators argue that the power of the professional is morally relevant (Lebacqz; Lebacqz and Barton). Professionals may hold several types of power: Asclepian power—the power of professional training; charismatic power—the power of personal magnetism and authority; social power—the power of the role and its authority (Brody). By contrast, the client lacks the power of the role and of its associated training. In addition, female clients facing male professionals generally lack the social power that men have in a sexist context (Lebacqz; Lebacqz and Barton). Clients are vulnerable.

The vulnerability of clients and the power of professionals mean that professionals can take advantage of clients. Sexual relations between professional and client are therefore an abuse of professional power—an illegitimate use of that power for the professional's own ends instead of for the ends of healing the client (Lebacqz and Barton; Schoener et al.; Rutter; Fortune, 1989).

Moreover, the vulnerability of patients or clients and the power gap between client and professional may compromise the freedom needed to give truly informed consent for sexual intimacies (Pope and Bouhoutsos; Lebacqz and Barton). The psychotherapeutic notion of transference (redirecting childhood feelings toward a new object) suggests a special vulnerability that may literally paralyze patients, making them unable to resist a therapist's advances (Freeman and Roy). Noting special vulnerabilities in the sexual arena, Karen Lebacqz and Ronald Barton (1991) propose that sexual intimacies differ from other acts to which patients, clients, and parishioners might continue to consent.

Some argue that vulnerability does not end when therapy ends and that there should be a prohibition on posttherapy sexual contact (Schoener et al.; Rutter). John C. Gonsiorek and Laura S. Brown proposed that sexual relations posttherapy should never be permitted where there was significant transference or where the client was severely disturbed, but might be permitted after two years with former clients who were not disturbed and showed little transference (Gonsiorek and Brown). Such a proposal raises difficult issues regarding who would make this judgment, but it reflects a clear principle that the base for determining whether sexual relations are permissible is the relative power and vulnerability of professional and client. Sexual contact might not be wrong where the power gap is minimized. Although few codes of professional ethics address the posttherapy issue, in 1993, the American Psychiatric Association explicitly addressed it: "Sexual activity with a current or former patient is unethical" (APA).

In a similar vein, Lebacqz and Barton (1991) argue that romantic or sexual relations might be acceptable under circumstances where the power of professional and client is relatively equal and the relationship is under public scrutiny—for example, when clergy date parishioners with whom they are not involved in a pastoral counseling relationship and members of the church are informed.

All commentators agree, however, that "sexualizing … therapy is a betrayal of a trusting relationship" (Pope and Bouhoutsos, p. 54) and that no sexual relationship should be permitted where there is a counseling or therapeutic relationship involved (Pope and Bouhoutsos; Fortune, 1989; Rutter). The professional-client relationship that involves psychotherapy or particular vulnerability on the part of the client is a "forbidden zone" for sexuality (Rutter).

Professional-client sexual contact must be addressed on institutional, not just personal, levels. Professional societies and supporting organizations such as churches are complicit when they fail to punish offenders, try to cover up the problem, blame the victim, and otherwise minimize the issue (Fortune, 1989; Bonavoglia). Underreporting is a significant issue: 65 percent of therapists in one study had seen clients who were sexually abused by a previous therapist; they judged that abuse harmful in 87 percent of cases but reported it in only 8 percent (Schoener et al.). Peter Rutter acknowledges the reluctance of men to blow the whistle on each other (Rutter). Gary Richard Schoener notes that the professional literature "documents more in the way of inaction than of active and creative study leading toward solutions" (Schoener et al.). Professional misconduct damages the profession and institutions as well as individuals (Fortune, 1989). Lack of internal regulation within the professions has led some U.S. state legislatures (e.g., Minnesota) to pass laws that hold institutions as well as individuals responsible for sexual misconduct of professionals (Lebacqz and Barton).

Underlying social and cultural patterns—sexism, the eroticization of domination, and the maldistribution of power in society—are causal factors (Lebacqz and Barton; Rutter). Since Phyllis Chesler's early feminist exposé of therapy in *Women and Madness* (1972), feminists have paid attention to the ways in which traditional therapy often reinforces passive and self-destructive behaviors for women, including behaviors that would make women likely victims of sexual abuse. Dynamics of sexual contact cannot be understood without recognizing sex-role patterning and power imbalances in the general culture (Schoener et al.; Lebacqz and Barton; Brown and Bohn,). Evidence indicates, for example, that male clients may not experience the sexualizing of relationships to be as harmful as female clients do (Pope and Bouhoutsos). Such gender differences may reflect social patterning of male and female sexuality, in which men gain and women lose power when entering a sexual relationship. There is also evidence that women therapists do not engage in sexual contact with clients as frequently as male therapists do, and that they judge it more harmful (Schoener et al.).

The traditional prohibition against sexual contact between professionals and their clients continues to be reaffirmed in spite of arguments and practices to the contrary. An adequate ethical framework requires attention not only to professional responsibility, harm, and power imbalances but also to institutional structures and to cultural dynamics of sexuality and power.

KAREN LEBACQZ (1995)
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SEE ALSO: *Coercion; Confidentiality; Epidemics; Medicine, Profession of; Nursing, Profession of; Profession and Professional Ethics; Sexual Behavior, Social Control of; Sexual Ethics; Sexual Identity; Sexuality, Legal Approaches to; Public Health Law*

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SEXUAL IDENTITY

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Because some terms are deeply embroiled in controversial debates, the task of defining them itself becomes controversial. So it is with the term *sexual identity.* Providing any definition immediately situates the definer within a particular perspective. One important perspective, which has served as the backdrop of much contemporary discussion, claims that the term refers to the distinct biological types of *male* and *female.* This "traditionalist" definition of sexual identity has sometimes been associated with one or more of the following additional positions: that certain specific and "complementary" psychological attributes and social roles, specifically those of *masculinity* and *femininity,* correspond to each of these distinct biological types; that a "natural" sexual attraction exists between these two biological types; that this attraction is most naturally satisfied through the act of intercourse; and that the act of intercourse, while naturally motivated by attraction, should also be motivated by other concerns, most importantly by love and by the desire to have children within the context of marriage.

These claims have been challenged over the last few decades by feminists, by those advocating various forms of sexual liberation, by gays and lesbians, and by scholars. All of these challenges raise questions about what is meant by *sexual identity.* Some of the positions developed in response to the traditionalist set of views have themselves been challenged. For the sake of clarity, one can group the challenges and counterchallenges around the following set of questions:

1. The sex question: Are there really two distinct biological types, *male* and *female*?
2. The gender question: How should one think about the relationship between biology and psychological attributes and forms of behavior?
3. The sexuality question: What constitutes sexual desire? What are the various ways in which it can be characterized?
4. The sexual ethics question: How ought one think about sexual practices? Which, if any, should be condoned, which prohibited, and why?

The Sex Question

Over the past few decades, many have rejected the claim that there exist two sexes without gradations. Some feminists have argued that, biologically, it is more useful to think of many of the physical characteristics associated with sexual difference as manifested across the human species in a range of degrees, rather than as being associated exclusively with either sex. They claim that only a social desire to emphasize difference has caused us to think of such variations in stark, bipolar ways. Thus, for example, though one often thinks of men as physically bigger than women, many individual women are taller, heavier, longer limbed, and so forth, than many men. Similarly, while one tends to think of women and men as possessing very distinctive hormones, in actuality the situation is more complex. For example, the hormones estrogen and androgen are often thought of as the "female" and "male" hormones, respectively, suggesting that women have one and men the other. In reality, both hormones are found in both women and men, and after menopause, women often exhibit a lower ratio of estrogen to androgen than do men of a comparable age (Spanier). These feminists argue that many of the striking differences we see are at least partially the consequence of social pressures exerted on women and men to manifest such differences. Thus women are encouraged to remove body hair and to buy shoes that make their feet look as small as possible.

Some cultural historians claim that the view of men and women as possessing sharply differentiated bodies has developed only within the last few centuries. Thomas Laqueur, for example, points out that prior to the eighteenth century, women's bodies were thought of as less developed versions of men's bodies. In this *one-sex* view, the vagina was not thought of as different from the male penis but, rather, as an inverted form of it. But during the eighteenth century there emerged a view of *the two-sex body,* that is, of female and male bodies being fundamentally different. With this new development, organs that had previously been referred to by the same name were given separate names. Thus, what had previously been *the testicles* now became differentiated into *the testicles* and *the ovaries.* Others that previously had no name were given names, for example, the vagina. Even parts of the body remote from reproductive functions, such as the skeleton and the nervous system, began to be depicted as distinctive for women and men.

Recent research in biology suggests that differentiating the male from the female is no simple task. Various indicators of maleness and femaleness are individually sometimes ambiguous. Even when all of the indicators are clear, they do not necessarily cohere. For example, within contemporary science the standard distinguishing criterion has been taken to be the presence or absence of the Y chromosome. Most people possess two sets of chromosomes, one from each parent; females are understood to be those with two X chromosomes and males those with one X chromosome and one Y chromosome. However, there are problems with any neat application of this criterion. Some individuals inherit only one X chromosome but no Y chromosome. Or a piece of a Y chromosome may become attached to an X chromosome, producing an individual with an XXY pattern.

Even those individuals who possess a standard XX or XY pattern may exhibit characteristics that would incline many not to identify them by their chromosomal pattern. An XY individual may have testes that do not secrete the male hormone testosterone, or may have cells that are not sensitive to testosterone. That person will end up looking more like a female than a male (Lowenstein). There are also XY individuals who look female at birth and are raised as girls, but who develop masculine bodily features at adolescence. There are XX people whose adrenal glands secrete large amounts of male hormones. One consequence is clitoral enlargement, causing them to be taken for boys at birth. As adults they may also possess increased muscle mass and hairiness (Lowenstein). In short, recent scientific research has supported the point that even the biological distinction between male and female is not always clear-cut.

The Gender Question

Until the emergence of the second wave of feminism in the 1960s, the term *gender* was used primarily to indicate differences between female and male forms within language. Differences between women and men were commonly indicated by the term *sex,* as in the phrase "the battle of the sexes." Feminists, however, began to use the term *gender* to refer to what they argued were socially constructed differences between women and men. It was felt that the term *sex,* when applied to differences between women and men, suggested that such differences were biological in origin. A new term was needed to refer to differences that were a product of society.

Studies done within the social sciences pointed to the great differences among societies in expectations of what was appropriate behavior for men and women. For example, the anthropologist Michelle Zimbalist Rosaldo noted that there are some societies where women trade or garden, and others where men do; some where men are prudish or flirtatious, and others where women are (Rosaldo, Lamphere, and Bamberger). Psychologists and other social scientists stressed the importance of socialization in structuring an individual's sense of self. Thus, John Money and Anke Ehrhardt (1972) asserted that when children were assigned a gender at birth that did not match their chromosomal sex, it was most likely that their adult sense of self would conform to their assigned gender rather than to their chromosomal sex.

The term *gender* has been very useful in encouraging a greater recognition of the social construction of differences between women and men. Increasingly, however, scholars have been raising questions about how gender should be understood, and particularly how its relationship to sex should be interpreted. Using the term *sex* to describe biological differences, and *gender* to describe socially constructed ones—what R. W. Connell calls the "two realms model"—ignores the fact that biological distinctions are themselves social constructions, at least in part. That modern biology, for example, interprets the penis as an organ distinct from the vagina is a social construction, more a consequence of changing cultural metaphors than of new scientific evidence (Laqueur). The notion of a "pre-social sexed body" (Heyes) which is identifiable in purely biological terms, then, has lost much of its appeal. As a result, the distinction between gender and sex based on the categories of the social and the biological respectively has also lost its force and theorists are struggling with what Connell calls "an additive conception of sex and gender." As she explains, "our new model begins with the observation that human bodies are active players in social lives. They are neither biological machines producing social effects mechanically, nor blank pages on which cultural messages are written" (Connell, p. 463).

Another problem with emphasizing the difference between sex and gender is that the relationship between psychological traits and biological phenomena is still often understood to be that the former follows from the latter. While *gender* emphasizes that many psychological traits are social constructions, it does not necessarily undermine the view that such traits follow from biological differences. All it adds is that the path from biology to psychology proceeds by way of social construction.

Any model that claims that psychology follows from biology has problems accounting for those individuals whose socialization deviates from the norm. In other words, to the extent that gender is still viewed as tied to sex, there remains the problem of explaining the phenomena of girls who grow up exhibiting "masculine" psychological traits and boys who grow up with a "feminine" sense of self. The most striking examples of such cases are transsexuals, people who experience a dramatic misalignment between their physical features and their internalized sense of self. Such people frequently desire physical restructuring of their bodies to bring the physical and the psychic into alignment.

The term *gender* may still suggest, as did the term *sex,* that people's psychic lives and behavior are necessarily unified, that it is appropriate to talk about a male or a female identity. One suggestion has been that we talk about *gender* be used not to describe individual identity, but to describe acts or performances all humans play out (Butler). Such a model allows one to move the focus of *gender* from the individual to the activity. This type of shift is consistent with an overall tendency on the part of many contemporary scholars to think of gender as a type of social coding that is applied not only to behavior but also to psychic stances and to bodies. A further aspect of this notion of social coding is suggested by Jan Clausen, who describes her experience when she changed from a committed lesbian to a woman involved in a long-term exclusive relationship with a man. Clausen claims that "the notion of sexual identity … implies some expectation about the future" (pp. 97–98); the inclusive approach—that which covers behavior, psychology and the materiality of the body—thus extends over time as well.

The Sexuality Question

At least since the 1890s in industrialized Western countries, one paradigm of sexuality has been dominant: that which describes genital-to-genital intercourse between one male and one female as "normal," and as "abnormal" or "perverse," sexual practices that fall outside that paradigm. "Perverse" practices in this paradigm include but are not limited to the following: voyeurism; exhibitionism; incest (sex between close relatives); oral sex; anal sex; sex with children (pedophilia); sex involving more than two persons; sex between humans and animals (zoophilia); sex with oneself (masturbation); sex involving the use of visual images (pornography); sex with a corpse (necrophilia); sex involving heightening sexual pleasure by dressing in garments associated with the opposite sex (transvestism); sex associated with the giving or experiencing of pain or humiliation (sadomasochism); sex strongly associated with a particular object or part of the body (fetishism); and sex between members of the same sex (homosexuality).

Homosexuality has, in particular, been the subject of much attention and debate. The stigmatizing label *homosexual* has been used to negatively characterize certain individuals since the late nineteenth century (Weeks, 1989); laws have been enacted against homosexuality and people have been jailed for practicing it (e.g., the English playwright Oscar Wilde). During the twentieth century, medical doctors and other scientific specialists have depicted it as a pathology and, as with other pathologies (but not accepted practices), have searched for causes (Bayer).

Much debate has centered on the question of whether homosexuality is a product of genetic inheritance or some other biological trait, or is a consequence of socialization. During the 1960s and 1970s, homosexual men (who increasingly adopted the label *gay*) and homosexual women (lesbians) began to form political organizations to resist the laws, practices, and beliefs that stigmatized them. They argued that homosexuality was not a perversion or a pathology to be outlawed or cured, but a difference in preference or *orientation* that should be tolerated within a free and open society. Since the 1960s, the American psychiatric community has moved away from a description of homosexuality as pathology. In December 1973, the board of trustees of the American Psychiatric Association moved to delete the category *homosexuality* as necessarily a pathology from the second edition of the *Diagnostic and Statistical Manual of Psychiatric Disorders,* retaining the term *ego dystonic homosexuality* to cover those not comfortable with their sexual orientation. In yet another revision, any specific reference to homosexuality was removed altogether, but the term *sexual orientation distress* was retained to permit treatment of those disturbed about their sexuality (Bayer).

More recently, there has been a good deal of interest in studying the possible biological origins or causes of homosexuality. There are two major explanatory pictures, both of which have been variously received with skepticism and approval. The first is the anatomical approach, which claims that one can (or should be able to) find structural differences between heterosexuals and homosexuals. Simon LeVay, for instance, published a study in 1991 showing that the interstitial nuclei of the anterior hypothalamus (INAH) of homosexual men was on average significantly smaller than those of heterosexual men (Murphy). Other candidates for anatomical explanations include the anterior commissure and the suprachiasmatic nucleus (Hamer, 1993). None of these studies have been met with unmixed approval. Some criticisms of the anatomical approach include the claim that sexual orientation is far too complex a phenomenon to be mapped to a single (and seemingly simple) physical cause, concern over the size of the sample pools, and even the attempt to "explain" homosexuality at all (Murphy).

The other possible explanatory story is that of the so-called gay gene. In 1993, Dean Hamer and a team of scientists concluded a study of the genetic make-up of gay men and their family members (most importantly brothers who were also gay) and announced that "our data indicate a statistically significant correlation between the inheritance of genetic markers on chromosomal region Xq28 and sexual orientation in a group of homosexual males" (Hamer, Hu, Magnuson, et al., p. 321). This study has also been criticized: for instance, the demographic homogeneity (and size) of the subject pool has led some to question whether the correlation is really genetic or merely environmental (Kaplan). This concern is made even more problematic by the fact that a precise causal connection between the possession of specific genetic markers and homosexual orientation is still lacking (Murphy). Most disturbing about any attempt to establish a biological link to homosexuality, according to some theorists, is the very fact that alternative sexual orientations are *in need of* explanation. In other words, the research itself may imply that there is something abnormal, or indeed perverse, about such orientations and thus, something that needs "curing" (Kaplan).

Other questions have been added to the debate, among them whether homosexuality describes a particular kind of person or, more appropriately, a specific type of activity. Social historians have pointed out that the category "the homosexual" was constructed in the latter part of the nineteenth century to depict a specific type of person, followed shortly by the construction of "the heterosexual" (Katz; Halperin). Prior to the creation of "the homosexual," people who engaged in acts one would label as homosexual were not necessarily seen to require a special label. This is at least partially a consequence of the fact that the sex of one's partner has not always been viewed as an overriding feature of the sex act. For example, within many Native American societies, certain men, "the berdache," took on many of the tasks and characteristics associated with women. These men would have sex with other men. However, what was seen as distinguishing the sexual practices of the berdache was not that they had sex with other men but that they took the passive role in sex. Their male partners were not distinguished from men who had sex only with women (Williams). The same distinction between active and passive (or dominant and submissive) is believed by many to be the primary form of categorization of sexuality in ancient Greece (Stein; Kaplan). For such reasons, Eve Sedgwick has observed that, given the many dimensions along which genital activity can be described, it is quite amazing that the sex of object choice has emerged as central during the twentieth century, and has come to define what is meant by "sexual orientation" (Sedgwick).

The Sexual Ethics Question

Just as matters of individual sexual identity have been oversimplified into a single male-female dichotomy, the many varieties of sexual behavior have often been reduced to a simple distinction between normality and perversion.

The condemnation of homosexuality and other deviant sexual activities and "perversions" leads to a discussion of sexual ethics and to the question of alternative sexual paradigms. A paradigm is an exemplary instance that serves as a standard. A sexual paradigm is an example of sexual activity that is taken as a standard for "normal" sexual behavior. The most obvious sexual paradigm is heterosexual genital-to-genital intercourse, but in order to employ this paradigm as a norm, one needs to specify not only the overt activity but the aims and desires of the participants. Is the purpose of sexual intercourse, for example, to produce children? Or to produce pleasure? Or to express love? Or to mark a "conquest"? One can further distinguish between minimalist and murky paradigms of sexuality: minimalist accounts tend to define sexuality as a simple, straightforward desire, while murky accounts dig deeper in order to find hidden or unconscious desires. Thomas Nagel, for example, introduces the minimalist notion of "unadorned sexual intercourse," although he adds that such behavior, "unadorned," may well be perverse, and that a typical sexual encounter involves a complex of communicative gestures. Janice Moulton defines sexuality simply as the desire for physical contact, although she then provides a rich discussion of its many associated meanings. Alan Goldman isolates what he calls "plain sex," which he defines as "a desire for contact with another's body," and rejects accounts that try to define sexuality in terms of any further goal or purpose.

On the murky side, there is the lasting legacy of Plato's *Symposium* and its various discussions of eros. In particular, there is Aristophanes' famous tale about the divine fission of individual human beings out of complete wholes, according to which sexual desire is nothing less than the impossible desire to join together with "one's other half" and become "complete once again," and Socrates' much more effete conception of eros as the love of Beauty as such. Two thousand years of Christian theology have attempted both to chastise and to spiritualize sexuality, and the Tantric traditions of India and Tibet have refined sexuality into a spiritual road to enlightenment. In the twentieth century, Sigmund Freud and Carl Jung profoundly deepened conceptions of sexuality, which is, in their accounts, no mere desire but a focus for the darkest and most explosive secrets of the psyche.

THE REPRODUCTIVE PARADIGM. Biologically, sexuality can be defined in terms of a very specific genetic process, although even that has its ambiguities and confusions. This biological definition and its implied reproductive paradigm play an enormous role in contemporary conceptions of sexuality. Whatever embellishments, variations, and alternatives humans and some other vertebrates have evolved or invented, heterosexual intercourse remains something of an "original text" in our sexual hermeneutics. It can be rejected, refuted, even reviled, but it must, first of all, be taken account of.

One might distinguish here, in line with a three-thousand-year-old moral tradition, between an individual's purpose and what one might call *nature's purpose.* Until the end of the nineteenth century, when teleology or the purposiveness of nature was taken seriously, this phrase could be interpreted literally. In the twenty-first century, in the wake of increasingly antiteleological conceptions of evolution, the phrase *nature's purpose* must be taken as, at best, shorthand for a complex set of causal processes that are themselves the result of chance and natural selection. Even so, one might distinguish between the various drives and desires favored by natural selection because they increase the likelihood of a more adaptive genotype (what Richard Dawkins calls "the selfish gene"), and the more or less conscious and sometimes articulate desires of an adult human being. But humans are not, like most creatures, mere sexual pawns of cunning nature. Some teenagers may not know of the various consequences and the significance of sexual activity, but for most adults this knowledge is profound, if not extensive, and sexuality may never be free of those associations. But whether or not this is the hidden purpose of *all* sexual desire and activity, it is clearly the conscious and conscientious choice of *some* sexual activity. Building a family is not, for most people, the only purpose of sexual activity; but by having sexual intercourse, it is possible to have children. Whatever creative alternatives may be dreamed up by medicine, one undeniable aspect of sexuality is, and will be, its traditional role in procreation.

The view that sexuality and sexual desire are really aimed at reproduction, even if the sexual participants desire only to perform a particular activity without thinking of the consequences, tends to lead from the minimalist view of sexuality to various murky views. The self-evident desires are no longer taken at face value, and a deeper biological (or theological) narrative, which may not be self-evident to the participants, comes into play. Thus the psychological consequences of thousands or millions of years of evolution manifest themselves in desires that may seem straightforward. Or, behind seemingly simple sexual desire lurks the secret of God's creation and the biblical injunction to be fruitful and multiply. But what links all the murky views is that sexuality does have a purpose or purposes, however they are to be explained, and these purposes are typically not self-evident. According to the minimalist views, sex is best understood as "plain" or "unembellished"; the murky views, on the other hand, insist that sex so understood is not understood at all.

The target of many, if not most, of the minimalist accounts is the restricted reproduction of the procreative paradigm of sexual activity. For two thousand years, the harsher side of Biblical commentary and the Christian theological tradition has insisted that sex is primarily, if not solely, procreative. In this view, the pleasures and desires associated with sexual activity not only are inessential but also are to be minimized. Emphasizing pleasure to the exclusion of the possibility of reproduction—for example, using contraception or engaging in activity that cannot result in impregnation—is forbidden. Essential to sexuality, in the reproductive paradigm, are male ejaculation, female receptivity, fertility, and conception.

THE PLEASURE PARADIGM. In opposition to the reproductive model, with all of its strict prohibitions and limitations, and its suggestions of deep biological drives and purposes, the attractiveness of what one can call the pleasure paradigm is unmistakable. The availability of improved birth control methods since the 1960s has contributed greatly to its appeal. Sex is for pleasure, and what is desired is pleasure. There is nothing murky about this. Indeed, to many people the pleasure paradigm is self-evident. Accordingly, the restrictions on sexuality that limit and direct it toward heterosexual intercourse drop away, and in effect, anything that feels good is acceptable. Of course, one might well object that pleasure is not in itself sexual, and so one might want to circumscribe pleasures that are sexual from those that are not. But, for the defender of the pleasure paradigm, this requirement comes later. First comes the liberation from the restrictions of the reproductive model. Homosexuality, autosexuality, even bestiality seem to be normal on the pleasure paradigm. Heterosexual intercourse is but one of many activities serving the paradigm, and however many couples may continue to prefer it, it does not have any special claim to normality. According to this paradigm, good sex is that which provides maximum mutual pleasure; bad or mediocre sex is that which fails to satisfy either or both partners.

Once the reproduction model has been rejected, there are no longer the restrictions on either the objects or the obvious aims of sexual activity, but neither is it the case that "anything goes." Homosexuality is no longer a perversion of sex, but rape certainly will be. Almost any sexual activity between consenting adults is acceptable, but forcing sex on a person is not. Sexual activities that will not result in conception are no longer secondary, and sex that is conscientiously prevented from resulting in undesired conception becomes the norm. Masturbation becomes part of the paradigm of acceptable sexuality, even though its lacks the dimension of shared sexual enjoyment. The appeal of the paradigm and the cornerstone of most contemporary sexual ethics is the idea that sex ought to be pleasurable and, within moral but not particularly sexual bounds, unrestricted.

We might call the pleasure paradigm the *Freudian* model of sexuality, in order to pay homage to the person most responsible for its contemporary dominance. Sigmund Freud, in his *Three Contributions to the Theory of Sex,* argued that sexuality should be conceived as enjoyable for its own sake, not as a means to further ends, whether natural or divine. But the centrality of Freud here also suggests that the pleasure paradigm may not be so simple and self-evident as originally suggested: Freud is one of the great contemporary architects of "deep," if not labyrinthine, accounts of the psyche and of sexuality in particular. And so, for him and for us, pleasure and satisfaction are not to be construed so straightforwardly. Pleasure, as Aristotle noted more than two millennia ago, is not just a sensation. It is the "bloom" on successful activity. It accompanies but does not constitute satisfaction. But the difficult question is, Satisfaction of what? And here Freud's theory moves from an apparently minimalist physiological model to an extremely murky deep psychology.

In Freud's early theories, the pleasure paradigm rested on a male-dominated biological foundation, a *discharge* model in which sexual pleasure has its origins in the release of tension (catharsis). But the tensions released in sexual behavior are not merely physiological; they also arise from complexes of ego needs and identifications with various sexual "objects," usually (but not always) other people. Thus Freud distinguished between mere physical gratification and *physical satisfaction.*

The pleasure paradigm, for all of its seeming simplicity, invites murky interpretations. What is it that is enjoyed? What is it that is satisfied? A sensation is not pleasant in itself but in terms of its context, as a love bite on the shoulder by one's lover or a nasty passerby, respectively, makes evident. Indeed, even orgasm is not pleasant in itself, however often that might be fallaciously supposed; an orgasm in an inappropriate context is typically an extremely unpleasant experience. And so the pleasure Freud postulates is no simple release of tension but the satisfaction, often symbolic and indirect, of some of the murkiest of hidden and forbidden desires.

THE METAPHYSICAL PARADIGM. Some of these desires and motives are so profound that they deserve to be called *metaphysical.* Freud's discussion of the Oedipus complex sometimes takes on these ontological overtones, and Jung's various archetype theories surely do. But perhaps the most basic of all metaphysical paradigms of sexuality goes back (at least) to the fable told by Aristophanes in Plato's *Symposium,* and the idea that the gods split what we now call human beings out of complete wholes, with sexual desire being the desire to reunify the divided halves. One need not literally accept the more consciously absurd aspects of the story to appreciate the deep insight captured in the idea of "two out of one" or "merged selves" that Plato's Aristophanes suggested.

Sexual activity is an expression of a profound desire that has very little to do with merely physiological need or satisfaction, and the metaphysical paradigm is, accordingly, very much a part of the contemporary conceptions of romantic love and the idea that two people were "made for each other."

Indeed, despite the prevalence of the pleasure model in much of the current literature, there can be little doubt that much more is usually demanded of sexuality than mere pleasure, even mutual pleasure. People demand *meaningful* relationships. The metaphysical model provides this sense of *meaning.* Pleasure, according to the metaphysical model, is no longer the purpose of sex, although it will surely appear as its accompaniment. But sex without love, no matter how enjoyable, is to be rejected on this paradigm. Even if it is not "perverse" or "immoral," "plain sex" will be meaningless, and the meaning of a relationship is primary in the metaphysical model.

THE COMMUNICATION PARADIGM. Sex is often "meaningful" without love, however, although sometimes those "meanings" are demeaning, as in a sadomasochistic relationship. What is one to say of the many varieties of sexual activity that are aimed neither at reproduction, nor at pure pleasure, nor at expressions of romantic love and togetherness? What of those relationships that seem to thrive on domination and pain? What does it say about current paradigms of love that sadomasochistic relationships are now celebrated and preferred by some of our more avant-garde social visionaries? And what of those many tender encounters that, nonetheless, make no pretenses of love?

To explain such aspects of sexuality, a fourth paradigm is in order: sex as communication, as a physical form of expression of one's emotions and attitudes toward other people. It is a language, for the most part a body language, whose vocabulary consists of touches, gestures, and physical positions. It may be an expression of domination and submission; it may be an expression of respect, fear, tenderness, anger, admiration, worship, concern, or (of course) love. In the 1940s Jean-Paul Sartre defended a truncated version of this model in his classic *Being and Nothingness.* He interpreted all sexuality as the expression of conflict, a war for domination and freedom. But what is communicated in sex is rarely this alone, nor is sex plausibly always an expression of conflict. Nevertheless, Sartre forces us to see something that the defenders of the pleasure and metaphysical paradigms of sex prefer not to see: that sexual relationships, even normal, fully consensual sexual relationships, are not always innocent or loving. Sex is a medium for all sorts of emotions, some of them manipulative and even malicious.

The communication paradigm shifts the emphasis in sexuality from the more physical and sensual aspects of reproduction and pleasure to interpersonal roles and attitudes, and from expressions of love alone to expressions of all emotions and attitudes. Thus Sartre's model is clearly a communication model, but it is, like Sartre's view of emotions in general, too narrow, emphasizing only the more conflict-ridden and competitive interpersonal attitudes—one of which, he thinks, is love. In this view, certain sexual activities are visibly more expressive of domination and submission, or equality and respect, or resentment and fear, or shyness and timidity. According to the communication model, these nonverbal expressions are essential to sexuality, its very purpose and content. This does not mean, however, that other sexual aspects need be excluded. The intention to impregnate a woman, for example, may be an expression of male domination and conquest, as described in several of Norman Mailer's novels. Pleasure is an important aspect of the communication model, but pleasure for its own sake is not: pleasure—both the giving and the receiving of it, as well as the sharing of it—is vital to the communication of many emotions. But pain may be important as well, and inflicting small amounts of pain, as well as enduring moderate discomfort, is familiar as a means of expression in sex. What distinguishes the communication paradigm from the three more traditional ones is its emphasis on expression of interpersonal emotions and attitudes. These expressions are recognized by the other paradigms, but not as essential and primary.

IMPLICATIONS OF THE VARIOUS SEXUAL PARADIGMS. It is evident that the answers to such questions as "What is normal sex?" and "What is perverse?" are immensely complicated. On a strict reproduction paradigm of sexuality, normal sex is whatever minimal genital activity is necessary to promote conception. All else is either irrelevant or immoral. In fact, of course, the reproduction paradigm is usually defended within the moral institution of marriage, and rarely defended without some reference to both love and mutual pleasure. On the pleasure paradigm, by contrast, whatever gives pleasure (to consenting adults) is normal and acceptable. Perversions of this paradigm provide pain instead of pleasure, ignore the pleasure of the other person, or produce pleasure in a manner that is, in the longer run, harmful. On the metaphysical paradigm, normality is sex as an expression of mutual meaningfulness, such as mutual love. On the communication paradigm, what is normal becomes extremely complex, for one must view the emotions being expressed and the entire psyches of the people involved to make any intelligent judgment.

Human sexuality seems particularly appropriate for expressing the tender feelings of love and affection, but there are circumstances under which this is absolutely inappropriate (for example, with children); and all too often sexual activity that claims the expression of love as its aim may actually be an avoidance of intimacy. Indeed, the common context of sexual activity— two people alone, attending only to one another—is particularly conducive to intimate communication. But if we take two-party sex as our paradigm, then multiple-party sex, insofar as it confuses the communication becomes perversion. Moreover, masturbation, while not exactly perverse, would surely be less than wholly sexual, just as talking to oneself is less than a whole conversation. And perhaps, any form of deceit would be perverse, just as lying is a "perversion" of verbal communication.

Conclusion: The Problem of Normality

So long as biological specification and sexual intercourse alone define sexuality, *normality,* as opposed to *perversion,* seems to be easily defined. Males are equipped with certain obvious features, and females are differently equipped with equally obvious sexual features; *normal* sex is intercourse between male and female. But as more is learned about the complexities of chromosome configuration and the biology of sex, the distinction between male and female becomes increasingly difficult. And as soon as one adds the essential concerns of psychology and the many worlds of cultural norms, practices, and paradigms to the unfolding medical complications, the traditional view of *normality* becomes a Pandora's box of problems.

This confusion extends to the task of defining a *normal* model of sexuality. Of the various cases and models considered in this article, not a single one would be accepted as *normal* in every society and by everyone. Moreover, a pure instance of an ideal type or paradigm is probably nowhere to be found; not even the most pious proponent of a religiously oriented reproductive view would deny the desirability of love, pleasure, and emotional expression in sex, nor would the most enthusiastic hedonist deny the desirability of reproduction on at least some occasions, and perhaps of love and communication as well. And when these four paradigms of sexuality are integrated with the matrix of possibilities that are to be found in the various combinations of gender identity and sexual orientation (and, in the most extreme cases, transsexual biological operations), the result is an enormous number of sexual lifestyles, desires, and activities, every one of which would be insisted upon as *normal,* at least according to some people.

How does one decide what is normal and what is not? In one sense, *normal* simply means *statistically predominant,* and there are still many people who would insist that this is a proper definition. But it is clear that, in ethical contexts, *normal* also means *morally correct.* But in an area where most behavior is private, and involves only consenting adults and a great many individual differences, the relevance of statistics is easily challenged. Furthermore, what is statistically predominant in one portion of a population may be relatively rare and considered *perverted* in another. If sexual normality includes subjective preferences and psychological as well as biological considerations, then any definition of sexual normality will give priority to certain preferences and paradigms over others. But which ones? The traditional religious standards? The more modern "anything goes between consenting adults" attitude? The current "local standards" criterion of the courts, which assumes that it can be made clear how large or small a domain—a home, a town, or a state—is "local"?

The problem of normality thus becomes a dilemma. It begins with a built-in ambiguity between the statistically dominant and what ethically ought to be. The first is ascertained easily enough, assuming either truthful informants or extremely intrusive investigators; but the second, the quest for a sexual ethics, arises from within diverse psychological, cultural, and personal settings that presuppose many of the norms and attitudes that are to be investigated.

The result of these complexities should not be the abandonment of a search for ethical norms or the rejection of the concepts of normality and perversion. What emerges instead is an extremely complex matrix of considerations to be taken into account, in which tolerance is a wise approach and mutual understanding is the desirable outcome. In other words, what is needed in the examination of sexual identity is not just a good deal of medicine, biology, social psychology, and anthropology. It is also a good deal of appreciation for diversity and complexity. It is with this appreciation for diversity and complexity that the contemporary quest can proceed.

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SEE ALSO: *Body; Gender Identity; Genetic Discrimination; Homosexuality; Human Nature; Sexual Ethics*

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SEXUALITY, LEGAL APPROACHES TO

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This entry discusses law's relationship to sexuality from an American perspective, although the framework suggested here may lend itself to application in other cultural contexts.

Sexual Status and Sexual Conduct

From the point of view of American law, sexuality has two dimensions: status and conduct. Sexuality as status, in law as in the culture at large, contains two primary alternatives—heterosexuality and homosexuality—although recent efforts on the part of those claiming bisexual status to make political alliance with gay and lesbian activists may presage increased legal recognition of this third alternative. Sexuality as conduct also has two principle aspects. The first encompasses explicitly sexual acts, of which intercourse is perhaps the paradigmatic example. Law prohibits intercourse, and sometimes other sexual activity, in a wide variety of situations, either when one of the parties has not consented or is unable to consent, or when the intercourse or other activity, although consensual, offends norms of public decency. Child sexual abuse, sexual assault and rape, statutory rape (intercourse with a woman, or in a few states with an individual, who is considered too young to provide meaningful assent), and incest are uniformly prohibited. Prostitution—the buying and selling of sex—is authorized only in Nevada. Sodomy, both homosexual and heterosexual, is unlawful in a large minority of states. Sex before marriage and outside of marriage is still prohibited in some states, although enforcement of these prohibitions is virtually nonexistent because of the disconnect between the law and prevailing cultural attitudes.

Law also regulates sexual intercourse by controlling or limiting postcoital choices. State limits on access to abortion, a hotly contested issue ultimately adjudicated by the U.S. Supreme Court in *Planned Parenthood of Southeastern Pennsylvania v. Casey* (1992), illustrates one such regulatory measure. Similarly, adult use of contraception remains constitutionally protected, while access to particular contraceptive techniques is regulated on health grounds. President Bill Clinton's reversal in 1993 of the first Bush administration's opposition to the introduction of RU-486, a "morning-after pill" and early abortifacient, provides a dramatic example of the interplay between public policies and medicine. Meanwhile, contraceptive freedom has not been extended to minors, and contraception remains regulated in the nation's high schools (Miller, Turner, and Moses).

In other contexts, law precludes procreation as a consequence of intercourse. The eugenics movement in the United States in the 1920s and 1930s produced laws compelling the sterilization of certain classes of criminals and those with mental disabilities or illness. Although no longer enforced, these laws remain on the books in several states and never have been held unconstitutional. Today, most if not all states provide a mechanism by which those legally responsible for sexually active people determined to be mentally incompetent can petition the state to authorize sterilization or contraception.

The second aspect of sexuality as conduct encompasses sexual displays the law views as expressing or arousing sexual receptivity or interest and thereby offending norms of public decency or order. The sexual displays regulated by law vary in character; they include solicitation, public nudity, and provocative dressing, as well as all forms of pornography. In this arena, too, enforcement is by no means uniform, and constitutional freedoms of speech and expression have created uncertainty with regard to the legitimacy of regulation.

Law's Multiple Relationships to Legal Status and Conduct

Law's relationship to sexuality in part constitutes law's account of what is permissible in the sexual arena—which behaviors are to be encouraged and which are to be discouraged. Legislative statutes help establish guidelines for behavior, while judges determine the constitutionality of the statutory law. This relationship between law and sexuality is importantly shaped, however, by the fact that law's authority is actually invoked in sexual matters by public agencies or private parties in only a small fraction of the possible cases.

The gap between the laws as written and as enforced has a variety of origins. For example, sometimes those who might initiate action against a violator do not know that the law offers them protection. Sometimes the enforcement of legal norms governing private sexual behavior is simply impractical; for example, sodomy, unlike public nudity, seldom comes to the attention of law enforcement personnel. Often, police and prosecutors make conscious decisions not to investigate or prosecute certain offenses for a variety of reasons, including the difficulty or the costliness of prosecution, the behavior of the victim, and the nature of the statute that has been broken (e.g., laws against adultery and premarital sexual contact). Or it may be because enforcing officers are dubious of the regulation or its particular application. Many rape prosecutions, especially those involving parties who are not strangers, founder for one or more of these reasons. Those who have argued that specific victims of pornography should be allowed to bring civil actions against pornographers and distributors of pornography base their argument, in part, on the reluctance of public authorities to take appropriate action (MacKinnon, 1987).

Those who urge giving private parties greater responsibility for or authority to initiate legal action must also realize that individuals are often unwilling or unable to invoke the law even when they understand that a law has been violated. For example, the trauma of childhood sexual abuse often results in the repression of memory (Ernsdorff and Loftus, 1993). If the memory ever surfaces, it may be long after the statute of limitations has passed. Potential claimants may be fearful of retribution on the part of the one they accuse; this is often true for sexual-harassment claimants and battered women who charge their abusers with physical and sexual violence. They may be anxious about the financial and emotional costs involved in testifying. They may fear having their credibility challenged or their character impugned and may see participation in the legal system as just another opportunity to be victimized. Finally, claimants in some circumstances may be able to resolve the situation without using the formal legal system.

If the law's relationship to sexuality is influenced by the limited nature of actual legal interventions in sexual matters, it is equally influenced by limited public understanding of the legal norms governing sexuality. How social actors perceive law's application to their own or others' sexual status or conduct may derive from actual individual or institutional knowledge of the law or of enforcement practices; but it may equally derive from impressions gleaned from a limited number of personal experiences or from stories emphasized by the media. Generalizations, often derived from limited information, then guide an individual's interaction with the legal system around sexual matters—setting standards for personal conduct, governing expectations about how the system will respond to legal violations, and providing the initiative for involvement in political efforts to change the law or replace its agents.

Given this multilayered relationship between law and sexuality, it is important to appreciate what law does and does not do, as well as how laws are implemented, what they say, and what people understand the law to be.

The Tools of Regulation

In regulating sexuality, the legal system draws on a variety of cultural authorities and principles. The two principal sources of authority guiding legal regulation of sexuality have been morality and medical science. Morals derive from either secular ethical precepts or religion, both of which are complicated by America's religious diversity and the political struggles over the separation of church and state. But when moral and religious precepts are broadly accepted and secularized within society, they become a legitimate basis for legal intervention. The law justifies its intervention by appealing to the secularized form of the moral mandate: to public decency or public order; to the value of life or the state's practical interest in heterosexual unions; to the "degeneracy" of certain sexual practices. When social consensus around a moral issue begins to erode, the link between particular moral notions and their specific religious underpinnings becomes exposed again, and law's endorsement of one side of the debate can be challenged as an improper conflation of church and state. This challenge to the moral basis of law has been most dramatic in the debates regarding abortion and homosexual marriage.

The issues involved in law's reliance on medical science have a different quality, because the concerns here are perceived to be those of knowledge rather than faith. In areas involving sexuality, medical science has provided the law with an understanding of what is necessary to protect public health and welfare and with guidelines concerning sexual status and conduct. In addressing the fundamental issue of sexual identity, medical science has drawn and redrawn the lines between aspects of sexuality that depend upon genetic programming, aspects that are the product of physical or mental disease or malfunction, and aspects that are the product of willed or chosen conduct. Changes in the medical understanding of homosexuality, for example, have in turn been central to legal debates about regulating homosexual relationships and activity. In the abortion arena, the law has looked to medicine for a scientific ruling about the beginning of human life.

The problems inherent in the relationship between law and medical science have two interrelated sources. First, medical science does not stand still, and the law often lags behind the newest research. Compulsory sterilization laws provide a dramatic example. The genetic "science" on which these laws were based has been discredited, and yet not all such laws have been repealed. Second, medical science is not as value-free as the deferential legal community often assumes; many shifts in the medical understanding of sexuality reflect shifts in values more than they do real advances in knowledge.

What of the legal principles governing the regulation of sexuality? Several of those legitimizing interventions have already been spelled out: maintaining public order, decency, health, and welfare. These laws fall within the traditional *police power* of the state. Another traditional basis for governmental intervention has been to encourage forms of association and sexuality that promote the state's conception of its interests. Matrimony and childbearing and child rearing within matrimonial relationships are the clearest historical examples. Nevertheless, the concepts of public order, decency, health, and welfare, and indeed of the state's interests, are malleable enough to serve the modern vision of social and family life.

The legal principles limiting regulation of sexuality have traditionally been those of privacy and autonomy, especially those forms of autonomy protected by the First Amendment. Both of these principles reflect a constitutional order that sees government as a threat to liberty; both are prepared to accord some cultural space to sexual activity and expression that deviate from widely held cultural norms to guard against the erosion of liberty.

In the shift from the nineteenth-century Victorian vision to the modern vision, the principles of privacy and autonomy have been pressed into service in new contexts while their hold over other arenas has been challenged. The privacy accorded family life was an important bulwark to the patriarchal authority of the male head of household, but it no longer serves to shield family members from charges of sexual abuse. Instead, privacy now provides the foundation for the constitutional protection given to both abortion and contraception, and efforts are being made to have sodomy statutes ruled unconstitutional on similar grounds.

Since the 1970s, the champions of the modern vision of social and family life have invoked the legal principle of equality. Equality has provided a basis for the abolition of old intrafamilial immunities and has supported the exposure of family abuses. Equality has translated the private pain of sexual harassment in the workplace into a public claim of discrimination when the job itself or other workplace privileges are conditioned on consent to sexual activity, or when the harassment creates a hostile working environment (MacKinnon, 1979; *Burlington Industries, Inc. v. Ellerth,* 1998; *Oncale v. Sundowner Offshore Services, Inc.,* 1998).

Equality has also offered a new analysis of pornography. Whereas previous regulation of pornography depended on the "obscenity" that made it offensive to norms of public decency, the new analysis emphasizes the role pornography plays in endorsing and promoting the sexual objectification of women that denies women equal status in society (MacKinnon, 1987, 1993). This characterization more properly represents what is at stake in regulating pornography. By the mid-1990s, however, none of the municipal ordinances based on it had survived constitutional scrutiny. The violation of women's right to be free of discrimination must still be weighed against the First Amendment freedoms of pornographers, distributors, and users; in this balance, pornography opponents have not prevailed. Importantly, women themselves are divided on this issue; many see the proliferation of pornography as enabling a liberating sexuality for women and support the First Amendment protection of pornography, whereas others remain concerned that pornography fosters male dominance and female subjugation (Strossen, 1993).

Finally, equality is frequently offered by advocates as a basis for outlawing differential treatment on the basis of sexual identity and for providing a protected sphere in which gay and lesbian people can enjoy both privacy and autonomy in their experience of their sexuality (Mohr, "Sexual Orientation and the Law"). This argument has made limited headway within the legal system. While most courts continue to uphold state statutes restricting marriage to opposite-sex couples, a few courts have taken positions favorable to same-sex marriage. In its 1999 decision in *Baker v. State of Vermont,* the Vermont Supreme Court held that "the State is constitutionally required to extend to same-sex couples the common benefits and protections that flow from marriage under Vermont law." The court carefully noted that its decision did not entitle same-sex couples to a marriage license but merely ordered the state legislature to either allow same-sex marriage licenses or "establish an alternative legal status to marriage for same-sex couples."

The controversial *Baker* decision has led some legal commentators to wonder about the futures of traditional and same-sex marriage. Some have speculated that if courts find marriage benefits constitutionally required, then they will likely find the title and status of marriage constitutionally required as well, ultimately leading to legalized same-sex marriages (Duncan). While the issue of legalized same-sex marriages remains unresolved, Hawaii's courts, like Vermont's, have taken steps toward legalizing same-sex marriage, finding the state's same-sex marriage ban to be a form of sex discrimination and directing the state legislature to resolve the issue accordingly (*Baehr v. Lewin,* 1993; *Baehr v. Miike,* 1998). The legal developments in Vermont and Hawaii have been controversial nationally in part because many states fear that the U.S. Constitution's full faith and credit clause (found in Article 4) will require them to recognize same-sex marriages, with potential positive and negative consequences for children, parents, families, social structures, and social values (Gushiken).

Conclusion

In matters relating to sexuality, the law attempts to strike a delicate balance between the impetus to regulate and the impetus to stay government's hand, while always remaining aware of shifting cultural values. Issues resolved in the direction of regulation in one era may be revisited and resolved in the direction of abstention in another. In the decades to come, it seems likely that the most contested territory is going to involve, first, the extent to which regulation of sexuality will be directed toward achieving the egalitarian vision of social and family life, freeing women and children from sexual exploitation and abuse, and second, the extent to which law will be persuaded to lift the burden of regulation currently imposed on homosexual conduct and give equal protection to those who claim homosexual status.

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SEE ALSO: *Sexism; Sexual Behavior, Social Control of; Sexual Ethics; Sexual Ethics and Professional Standards; Sexual Identity*

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SIKHISM, BIOETHICS IN

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Origins and Teachings

Sikhism began with Guru Nanak (1469–1539 C.E.), who was born a Hindu in the Punjab, which is still home for the vast majority of Sikhs. The word *Sikh* means *learner* or *disciple,* and today the community numbers approximately 16 million. Nanak was the first of ten personal Gurus. Following the death in 1708 of the tenth Guru, Gobind

Singh, the function of the Guru passed to the scripture and to the community. For this reason the Adi Granth (the Sikh scripture) is particularly venerated by the community.

In the North India of Nanak's day, a popular mode of religion among ordinary people was worship of a God of grace, immanent in all creation and never incarnated as a person or as an idol. This was the Sant Tradition and Nanak provided in his teachings its clearest statement. The presence of God is known through the *nam* (divine Name), mystically manifested in the beauty and order of the world around us, and one's duty is to meditate on the *nam*. This may be done by repeating a particular word or mantra, by singing hymns, or by silently meditating. In so doing one grows ever nearer to God, eventually achieving a condition of perfect union. In this union the cycle of transmigration (movement of the soul, at the death of the body, into a new body) is finally ended.

Those who accepted these teachings from Nanak were the first Sikhs. A line of successor Gurus followed him, the same divine spirit believed to inhabit each of them. The first four successors continued Nanak's teachings concerning the divine Name and, in 1603–1604 Arjan, the fifth Guru, collected their hymns and his own into a scripture, adding to it the works of other members of the Sant Tradition. During the time of the sixth Guru, Hargobind, the community attracted the attention of the Moghuls, at that time the rulers of northern India. By this time the community had grown noticeably large and the Moghuls were becoming suspicious of its increasing numbers. This danger receded, but it returned in the time of the ninth Guru, Tegh Behadur, who was executed by the Moghuls in 1675.

The Foundation of the Khalsa

In 1699 Tegh Bahadur's son and successor, Gobind Singh, inaugurated the Khalsa, a new order loyal Sikhs were summoned to join. Membership in the Khalsa was by an initiation ceremony and by a lifelong vow to maintain certain outward symbols, particularly uncut hair. Emphasis on the centrality of the divine Name was retained, but in place of the strictly inward faith taught by Guru Nanak, the tenth Guru created an organization that proclaimed the identify of his followers to all.

The inauguration of the Khalsa was crucial because it laid down for members an explicit code, or Rahit. Tradition records that the Guru promulgated all that the modern Khalsa observes today. In fact, many of the individual items of the Rahit can be traced to experiences that follow the actual foundation. The essential nature of the Khalsa, however, remains unaffected. Gobind Singh summoned loyal Sikhs to join his Khalsa; the Khalsa Sikh was to be known by certain outward features. These conspicuously included the obligation to bear arms and to retain uncut hair. Men were to add Singh ("Lion") to their name and women were to add Kaur ("Princess").

Ranjit Singh, the Singh Sabha, and Modern History

The eighteenth century, a time of much turbulence in the Punjab, was followed by a settled period during the early nineteenth century. Under Maharaja Ranjit Singh, who became ruler of the central Punjab in 1801, strong government was introduced and during the next twenty-five years, the boundaries were enlarged in three directions. In the southeast, where the British advanced against Ranjit Singh, the border was drawn along the Satluj river, leaving many Sikhs in British territory or in the territory of their client states. Amritsar was not the capital city, but it was confirmed as the principal religious center. Ranjit Singh gilded the two upper storeys of its main temple, converting it into the famous Golden Temple.

His death in 1839 has been interpreted as marking the beginning of a steep decline in Sikh fortunes. In 1849, following two wars, the British annexed the Punjab. In 1873, however, the Singh Sabha (Singh Society) was founded and under its influence, the Sikh community was revived and reshaped. In 1920 the Singh Sabha was taken over by the more radical Akali movement, which was dedicated to the liberation of the gurdwaras (temples). With the partition of India in 1947, the Punjab was divided and the Sikhs in Pakistan moved across to the Indian area. Since then many Sikhs have claimed greater Punjab autonomy. The Indian army assault on the Golden Temple in 1984 led to decade-long demands by many Sikhs for Khalistan, a completely independent state. By 1993, however, these demands had subsided.

The Singh Sabha and the Rahit

The dominant concern of the Singh Sabha reformers was to demonstrate that Sikhs formed an entirely distinct faith and that, in particular, they should not be confused with the Hindus. Special concern focused on the question of how a Sikh should behave. The intention was to show that the ways of the Sikh were emphatically not the ways of the other groups in India.

This required a restatement of the Rahit. According to tradition, Guru Gobind Singh had promulgated the Rahit in all its details, but by the late nineteenth century it had become impossible to determine his words with precision. The Rahit had been recorded for Sikhs in a number of Rahit-namas (Rahit manuals), none of which was entirely satisfactory. Those present at the founding of the Khalsa in 1699 would know what was required of them, and likewise those who associated with the Guru until his death in 1708. Most of the eighteenth century was, however, charged with warfare and persecution, and Sikhs had little time to record the Rahit that had been delivered to them. Ignorant or mischievous people might have corrupted the received Rahit, and the Rahit-namas could only be trusted after a scrupulous hand excised those portions that misled readers and restored those parts that had been lost.

The Singh Sabha leaders made unsuccessful attempts to produce an authentic Rahit-nama. Eventually, however, an acceptable version, Sikh Rahit Maryada, was issued in 1950, and appeals to this written authority are possible. The Sikhs have no clergy and so the publication of an authoritative text was truly significant. The question of orthodoxy, however, remains. Sikh Rahit Maryada represents the Khalsa version of orthodoxy, that is, the insistence on uncut hair; there is no doubt that since the days of the Singh Sabha, this has been the dominant style. There are, however, Sikhs who do not observe this version, preferring to venerate the Gurus and scripture while cutting their hair. They do not observe the Rahit, yet still insist that they are Sikhs. It is here that Sikh identity becomes difficult to define and with it, the whole question of what constitutes Sikhism. The remainder of this article describes Khalsa Sikhism, but it is important to remember that many who call themselves Sikhs are not members of the Khalsa. This applies particularly to Sikhs living outside India.

Khalsa Regulations

Members of the Khalsa are identified by what are called the Five Ks (uncut hair, a comb, a steel wrist-band, a sword or dagger, and shorts). Smoking and intoxicants are firmly banned, the latter largely ignored but the former strictly maintained. Khalsa Sikhs are insistent on the right to carry a sword, a feature that enhances their reputation for violence. This reputation is greatly exaggerated. The Sikh should draw the sword (or use arms) only defensively, only when the cause is just, and only when all other methods have failed.

In Sikhism the key term when discussing ethical and moral issues is *seva* (service). Little guidance is given regarding health, disease, and the environment other than the most general principles. The objective is simply a life of personal righteousness, largely undefined. *Seva* is primarily considered a duty toward the gurdwara, and consists of obligations performed for the Guru on its holy ground. These include service in the *langar*, the free refectory that all gurdwaras are required to maintain, symbolizing the equality of all people. The concept is, however, further interpreted to mean genuine concern for the needs of others. According to Sikh Rahit Maryada, every Sikh is required to devote his or her entire life to the welfare of others.

In general, Sikhs are directed to see themselves as distinct from other faiths, particularly from all forms of Hindu tradition. This is the case with funerals, which involve a simple rite. Cremation follows death but all who assemble are required to restrict their lamenting. The corpse is dressed in clean garments, complete with the Five Ks, and the ceremony is conducted while hymns are sung. Such practices as laying the corpse on the floor or breaking the skull are sternly forbidden. Specific ethical injunctions are comparatively rare in Sikh Rahit Maryada, although those that are mentioned are clearly intended to be mandatory. The emphasis is, instead, placed on the duty of the individual Sikh to live a worthy life as circumstances of time and place dictate.

With two exceptions, matters of bioethical concern are not spelled out. Sikhs are left to determine them in the light of their religious faith. One exception is that female infanticide is strictly prohibited. This reflects an earlier period in Punjab history. The second exception is that, strictly speaking, initiated Khalsa members should not eat from the same dish as an uninitiated Sikh or one who has renounced the faith. All other issues, such as abortion, birth control, suicide, and euthanasia, are left to the individual or the family to decide.

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SEE ALSO: *Death: Eastern Thought; Eugenics and Religious Law: Hinduism and Buddhism; Hinduism, Bioethics in; Jainism, Bioethics in; Medical Ethics, History of South and East Asia: India; Population Ethics, Religious Traditions: Hindu Perspectives*

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SMOKING

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From the time when the native peoples of the Americas introduced Europeans to tobacco until the second decade of the twentieth century smoking and other forms of tobacco use focused on questions of production, commerce, and morality rather than on questions of medicine (U.S. Department of Health and Human Services, 1992). The first public policy issues concerning tobacco centered on its role as an important cash crop and a potential source of tax revenue. Medical questions about tobacco use did not materialize because until the 1920s there were no scientific grounds for supposing that smoking endangers the health of smokers. Half a century passed before epidemiologists began to make a case for the dangers of environmental tobacco smoke (ETS) to nonsmokers. Smoking and other forms of tobacco use provide a vivid illustration of how ethical considerations can change over time as scientific evidence and the social, political, and economic dimensions of an issue change.

Scientists began to build the case for the dangers of smoking when A. C. Broders (1920) published an article correlating tobacco use with lip cancer. Subsequent studies repeatedly linked tobacco use, in particular smoking, with a variety of diseases, primarily lung cancer and respiratory diseases. Evidence was derived from epidemiological studies, typically retrospective laboratory studies, and findings at autopsy. In 1957 based on the findings of a federally sponsored study group on smoking and health the U.S. Public Health Service (USPHS) concluded that there was a causal link between smoking and lung cancer (U.S. Department of Health, Education, and Welfare). The USPHS also affirmed a causal link between smoking and numerous other cancers, as well as other diseases in 1964, when Surgeon General Luther Terry issued an advisory report titled *Smoking and Health* (U.S. Department of Health, Education and Welfare).

Since 1964 a wealth of research has demonstrated the deleterious effects of tobacco use on health. Both government and private agencies have been instrumental in publicizing and documenting research findings and their implications, most efficiently through their websites. For example, the Centers for Disease Control and Prevention (CDC) lists all the surgeon general's reports on tobacco and health from 1964 to 2001. These reports summarize the state of research and education on tobacco use at the time of each report. Research articles, tobacco industry documents, tobacco control guideline programs, and educational materials can be accessed through the CDC's site. Other websites—the Agency for Healthcare Research and Quality (AHRQ), the U.S. Department of Health and Human Services (USDHHS), the National Library of Medicine, and the National Institutes of Health (including the National Cancer Institute), as well as private foundations such as the American Cancer Society and the American Lung Association—all provide access to research and educational materials for laypersons and professionals. The importance of tobacco use and exposure as a health risk is demonstrated further in the USDHHS document *Healthy People 2010* (2000a), which cites morbidity and mortality related to tobacco use and ETS as one of the leading indicators of the health of the American people for the next ten years.

Reflection on some of the facts gives one a sense of the ethical and policy problems posed by smoking. Approximately 440,000 deaths in the United States are due to smoking and diseases related to tobacco use (American Lung Association, 2002). Exposure to ETS (also known as passive smoking) increases the risk of cancer in people who have never smoked (Hackshaw et al.). Tobacco use has become a serious pediatric health issue, but in spite of regulation, children and adolescents continue to be able to obtain tobacco products (U.S. Department of Health and Human Services, 2000b). Control of the risks and diseases related to tobacco use has been hampered by continuing efforts by the tobacco industry to promote and market its products without constraints (U.S. Department of Health and Human Services, 2000b; Ong and Glatz).

The negative health effects of tobacco use are widely known and may be widely acknowledged even though individuals may not change their behavior on the basis of that knowledge. The reasons for the lack of behavioral change are many and complex (U.S. Department of Health and Human Services, 2000b). The ethical issues are also complex and have evolved over time and as a result of political and legal factors. Major ethical issues related to smoking and other tobacco use are: (1) the protection of nonsmokers from the effects of ETS; (2) the protection of children from an addictive product; (3) the scientific integrity of tobacco industry research; and (4) corporate integrity in marketing tobacco products.

In the past ethical arguments about smoking focused on issues of autonomy, paternalism, and societal harm. Smoking as an individual choice was juxtaposed against the restriction of individual smoking behavior as a consideration in protecting the individual from himself or herself and protecting society from smokers. Today the moral issues associated with tobacco use have moved away from individual autonomy and individual values because of the recognition of the significant public health implications of smoking. However, the earlier ethical arguments regarding smoking and tobacco use will be reviewed here to gain a historical perspective.

Ethics and Restrictive Policies: Autonomy, Paternalism, and Societal Harm

Before the harmful effects of ETS were demonstrated, the health risks of smoking suggested that at least some restrictive policies designed to protect smokers from themselves could be ethically justified. Knowledge of the risks that smokers impose on nonsmokers could support public policies designed to keep smokers from exposing nonsmokers to ETS or imposing on nonsmokers the medical costs of smoking. In addition to these two considerations the promotion of health has served as a third impetus for a restrictive policy. For example, in 1992 the Joint Commission on the Accreditation of Health Care Organizations (JCAHO), the chief hospital accreditation agency in the United States, required hospitals to forbid smoking within their premises by 1994 as a condition of accreditation (Center for Disease Control Chronology of Significant Developments). Robert Goodin (1989) used these considerations to develop a vigorous case for a public policy aimed at a total ban on smoking. Today bans on smoking in public places are common and often complement state tobacco control programs that have been shown to be effective, at least in one instance, in reducing the mortality from heart disease attributed to smoking (Fichtenberg and Glantz).

Restrictive social policies that attempt to protect an individual from harming himself or herself have been viewed as paternalistic. At least since John Stuart Mill's (1859) *On Liberty* antipaternalistic sentiment has been widespread in the English-speaking philosophical community, with Joel Feinberg being one of its leading contemporary voices. Feinberg has emphatically rejected legal paternalism, the doctrine that "[i]t is always a good reason in support of a prohibition that it is necessary to prevent harm (physical, psychological, or economic) to the actor himself" (Feinberg, p. xvii). Despite an absence of consensus on what constitutes a competent choice, factors such as coercion, ignorance, mental impairment, and addiction serve as grounds for challenging the competence of a choice. The rejection of restrictive smoking policies on the basis of their paternalistic nature and curtailment of individual autonomy thus was considered a viable moral argument until the addictive properties of nicotine and the extent of children's tobacco use became known. The case for smoking as simply another autonomous value choice became difficult to make for an addictive substance whose use often began in childhood or adolescence.

Ethics and the Public's Health: Protecting Children and Nonsmokers

Although a moral argument based on the freedom to exercise individual autonomy could be made for not restricting competent adults from engaging in tobacco-related behaviors that are detrimental to their health, that argument fails because of the propensity of adult smokers to begin smoking in childhood or adolescence and the known effects of active and passive smoke on nonsmokers, children, and fetuses. According to a 1994 surgeon general's report, most first-time smoking occurs before graduation from high school, and the younger a child is when he or she begins smoking, the greater are the negative health effects (U.S. Department of Health and Human Services, 1994). Smoking and ETS are associated with decreased fetal growth during pregnancy and respiratory problems in school-age children who were exposed to smoke during early development (American Academy of Pediatrics). Children exposed to passive smoke are more likely to develop respiratory and middle-ear problems (Cook and Strachan).

Maternal smoking has been associated with sudden infant death syndrome, and passive smoke has been associated with an increase in hospital admissions among children with cystic fibrosis (Cook and Strachan). Because of these and other significant health risks to children and adolescents, the American Academy of Pediatrics has identified the reduction of children's exposure to both active and passive smoke as a primary goal of preventive health (American Academy of Pediatrics Committee on Substance Abuse).

The moral obligation to protect a vulnerable population is heightened by the dangers of tobacco to children in all stages of development and the fact that those risks are preventable. Although children potentially may be harmed by actively smoking or by their parents' smoking, children are also at risk from ETS outside the home.

The harm from ETS in all age groups is well established. The increased risks of respiratory and heart diseases and the role of passive smoke as an irritant were summarized in a 1986 surgeon general's report (U.S. Department of Health and Human Services, 1986). More recent meta-analyses of epidemiological studies have continued to affirm ETS as a cause of lung cancer (Hackshaw et al.) and have provided further evidence of the negative cardiac effects associated with ETS (He et al.). The continuing confirmation through scientific evidence of the detrimental health effects of passive smoking and the recognition of nicotine as addicting have moved smoking from the realm of personal value choice to the realm of public health.

The ethics involved in public health issues may differ in some respects from those involved in clinical medicine in that obligations to society as a whole may be different from or conflict with obligations to an individual patient. Although some conflicts between the rights of society and the rights of individuals may entail controversy, the overwhelming scientific evidence for the detrimental effects of tobacco has effectively eliminated controversy and promoted consensus among health professionals. The evidence justifies the imposition of restrictions such as workplace bans and restrictions on smoking in public places, whereas the lack of a total ban allows adult individuals to make the choice to smoke. Rather than being viewed as restrictions on personal liberty or intolerance of diverse values, those restrictions can be seen as analogous to the imposition of speed limits to protect the public's safety on highways. Occasional challenges to the scientific evidence still appear, but it is recognized increasingly that one reason for the public's (and some health professionals') delay in accepting the scientific evidence regarding the negative effects of smoking was an active campaign by the tobacco industry to market tobacco use aggressively and discredit scientific evidence about its negative health effects (Ong and Glantz).

Scientific Integrity and Corporate Morality

Since the 1990s confidential tobacco industry documents have become public as a result of litigation and increased public knowledge about the health effects of active tobacco use and ETS. Those documents demonstrate the efforts of the tobacco industry to publicly deny its own research results confirming the dangers of ETS, alter data to support its desired conclusions, and discredit legitimate scientists whose work demonstrated negative effects of ETS (Barnes et al.). Elisa K. Ong and Stanton A. Glantz describe how between 1993 and 1998 lawyers and marketing firms employed by Philip Morris directed a campaign to distort epidemiological standards with contrived concepts of *sound science* in order to attack legitimate scientific evidence on the negative health effects of tobacco use. Because further regulation of the tobacco industry appeared inevitable, the industry's goal was to raise the standards for scientific proof of harm so that legitimate studies demonstrating harm could never reach those standards and thus could be dismissed as *junk science* (Ong and Glantz).

The campaign was insidious but lost its force when epidemiological organizations refused to agree to some of the statistical standards being pushed by the tobacco industry (Ong and Glantz). This example of the tobacco industry's unethical attempts to manipulate public opinion is only one of many. Policies related to the sale of tobacco to foreign countries also raise difficult issues, including the promotion of cigarettes to children or to people who lack adequate information about the risks of smoking. Vigorous opposition by tobacco companies to efforts to inform Third World consumers about the effects of smoking and attempts to manipulate those efforts have exacerbated the problem (Emri, Bagci, Karakoca, Baris). Corporate morality leading to conflicts of interest and potential harm to individuals remains an unresolved problem.

Legal Regulation of the Tobacco Industry

All defensible theories of just laws recognize the harmfulness of a conduct to others as a good reason for regulating that conduct (Feinberg). In the environment of recognized health risks and the deceptive marketing practices of the tobacco industry lawsuits and regulations have become increasingly common.

Historically, legal decisions and regulations have been decided for and against both the tobacco industry and consumers. For example, the Federal Cigarette Labeling and Advertising Act of 1965 required the warning label that is familiar today but at the same time prohibited warning labels on cigarette advertisements for a period of three years (Center for Disease Control). The Controlled Substance Act of 1970, regulating addictive substances; the Consumer Product Safety Act of 1972, regulating hazardous substances; and the Toxic Substances Control Act of 1976, regulating injurious chemicals, specifically excluded tobacco from their lists of hazardous or addictive substances (Center for Disease Control). Other notable regulations include policies and laws in 1973, 1987, and 1989 to segregate and then ban smoking on domestic airline flights and bans on smoking in government workplaces in 1987, 1994, and 1997 (Center for Disease Control). The CDC website provides a summary of the numerous government regulations pertaining to tobacco since the early twentieth century (Center for Disease Control).

Over the years legal battles by individuals against the tobacco industry were fought with varying degrees of success, but eventually more consumers began to prevail in the courts. Although most disputes were heard in lower courts, two cases involving state laws, cigarette advertising, and injury or potential injury reached the U.S. Supreme Court and resulted in rulings that were partially favorable to each side (*Thomas Cipollone*; *Lorillard Tobacco Company*). In a third case, a victory for the tobacco industry, the U.S. Supreme Court ruled that the U.S. Food and Drug Administration did not have the authority to regulate tobacco products as it did other drugs.

By the mid-1990s four individual states had sued the tobacco industry to obtain reimbursement for healthcare costs related to tobacco use. In an effort to avoid more lawsuits the six major tobacco companies entered into an agreement with the attorney generals and representatives of the remaining forty-six states, along with U.S. territories and the District of Columbia. This so-called Master Settlement provides billions of dollars in payments to states from the tobacco industry beginning in June 2000 and extending over the following twenty-five years (Wilson). In addition to settlement payments, provisions of the Master Settlement include the prevention of industry targeting of children and adolescents in advertising, the regulation of tobacco industry lobbying, and public access to industry records and research (Wilson).

Since the last two decades of the twentieth century the changes in the ways in which the public thinks about and uses tobacco have been sweeping. The moral considerations of individual personal choice and freedom in smoking have become issues of public health, the protection of children, the integrity of science and scientists, and the morality of corporations. On January 27, 2003, Philip Morris changed its name to Altria Group, Inc., to demonstrate, it claimed, "To better clarify its identity as the owner of both food and tobacco companies that manage some of the world's most successful brands" (according to <http://www.philipmorris.com>). However, the moral tensions between the industry and the public continue. What the industry changes will mean in the long term remains to be seen.

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SEE ALSO: *Addiction and Dependence; Advertising; Alcohol and Other Drugs in a Public Health Context; Alcoholism; Behavior Modification Therapies; Freedom and Free Will; Genetics and Human Behavior; Harm; Harmful Substances, Legal Control of; Hazardous Wastes and Toxic Substances; Human Dignity; Life, Quality of; Maternal-Fetal Relationship; Patients' Responsibilities; Race and Racism; Responsibility*

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SOCIAL MEDICINE

• • •

Throughout most of medical history the physician's role has been seen predominantly as a personal one in which, for the most part, the one-to-one patient–physician relationship is the one that is considered in medical ethical principles. Although the shocking evidence of physician participation in genocidal activities during World War II led to new ethical statements, such as the Declaration of Geneva, that place physicians' behavior in a social context, such statements nevertheless largely remain codifications of the ethical behavior of a physician toward a particular patient.

Origin and Meaning of Social Medicine

Enlargement of the role of the physician to include social and community aspects of disease prevention, diagnosis, and treatment is of relatively recent development, and is referred to as *social medicine.* Many definitions of social medicine have been attempted, the more generally accepted ones reflecting the relationship of social factors to disease and death. Today there is a general consensus that social medicine represents the study of the medical needs of society and the interaction of medicine and society, along with the practice of inclusion of social factors in public health, preventive medicine, and the clinical examination and treatment of patients.

The concept grew from a variety of experiences over the centuries. In seventeenth-century London, weekly "Bills of Mortality" listing the previous week's deaths began to be published. Incomplete and inaccurate as they were, they inspired John Graunt (1620–1674) and, later, Edwin Chadwick (1800–1890) to relate social and economic circumstances to death rates.

Similarly, in Italy, Bernardino Ramazzini (1633–1714) documented the relationship of disease to a series of occupations. In the nineteenth century, these inchoate efforts came together into social-policy constructs. In Austria, Johann

Peter Frank (1745–1821) published a monumental six-volume work on medical policy as a governmental endeavor—to ensure clean water and sewage disposal, for example, and to promote other regulatory efforts for the benefit of society. Chadwick, in Britain, urged government to take responsibility under the Poor Laws to protect the health of the growing population impoverished by increasing industrialization (Chadwick).

The industrial revolution fostered turmoil throughout Europe and increased the awareness of social causation of disease and death as it brought about far-reaching changes in the lives of working people. Friedrich Engels's study, *The Condition of the Working Class in England in 1844,* described the relationship of diseases such as tuberculosis, typhoid, and typhus to malnutrition, inadequate housing, contaminated water supplies, and overcrowding (Engels; Waitzkin).

The early nineteenth century therefore saw the beginning of a transformation of the physician's role (Rosen, 1974). As physicians increasingly recognized the impact of social factors on their patients' health, they saw that helping individual patients made it necessary to assess and respond to the social aspects of their lives along with everything else that might cause or prolong their patients' illnesses.

The term *social medicine* was first used in 1846 to mean "all those aspects of medicine that affect society" (Guérin, p. 203), but its popularization in Europe is usually attributed to Rudolf Virchow (1821–1902; see Erwin Heinz Ackerknecht's 1953 work, and George A. Silver's 1987 work). Virchow, who later became a highly respected pathologist (known by his colleagues as the "Pope of Medicine"), was an early exponent of the importance of social factors as contributors to disease. In 1847, at the Prussian government's request, Virchow investigated a severe typhus epidemic in rural Upper Silesia. In his report he recommended a series of dramatic economic, political, and social changes that included increased employment, better wages, local autonomy in government, agricultural cooperatives, and a more progressive tax structure. He described disease causation as multifactorial, including the conditions of people's lives. To be effective, he argued, a healthcare system must go beyond treating pathological problems in individual patients, and health professionals therefore must take responsibility for political action. In a radical medical-political newspaper he edited, the masthead read: "The physician is the natural attorney of (advocate for) the poor." Virchow insisted that "medicine is a social science, and politics nothing but medicine on a grand scale" (Silver, 1987, p. 85).

Early on, social medicine was basically an approach to medical practice; proponents recognized the effects of social conditions and took them into consideration in dealing with illness in patients. During the first half of the twentieth century, when Alfred Grotjahn published his *Soziale Pathologie* (1912) and René Sand his *Vers la Médecine Sociale* (1952), social medicine became more than an aspect of medical practice. These works, among others, established the importance and perhaps even the predominance of social factors in disease causation, maintenance, and remission. A whole new field of scholarly study emerged that understood health, disease, and the role of medicine in these terms. Beyond the traditional ethic of a physician's responsibility to a patient or to other physicians, social medicine, which was concerned with the relationship between health and the conditions of society, imposed an added discipline of responsibility to society (Grotjahn; Sand).

The discipline was further refined by John Ryle, professor of medicine at Cambridge University, who included social factors in the analysis of the varied responses of patients to illness. Since individual responses were influenced by the patient's family, work, and economic circumstances, he regarded the study and clinical application of these factors as part of the practice of social medicine (Galdston; Ryle). Ryle wrote that social medicine

> embodies the idea of medicine applied to the service of man as socius, as fellow or comrade, with a view to a better understanding and more durable assistance of all his main and contributory troubles which are inimical to active health.… It embodies also the idea of medicine applied in the service of societas, or the community of man with a view to lowering the incidence of all the preventable diseases and raising the general level of human fitness.

As it became clear that many of the causative agents of disease were social in nature, social medicine embraced not only what is usually called *preventive medicine*—that is, advice on the prevention of illness provided to individuals and families within medical practice—but also what is usually called *public health*—efforts to prevent disease in whole communities. For health and disease, an interface was seen to exist between society and medicine, not just between the doctor and a patient. The family itself, the home, the workplace, the environment, and various other social conditions played a part in whether or not people became sick, how long they remained sick, whether they recovered, and even whether medical care and other healthcare services were available.

Social medicine ranges from the doctor's use of social factors in making a better diagnosis or offering better treatment (that is, an approach to clinical problems) as well as providing preventive medicine, to helping the medical profession recognize social factors that are *pathological* or *therapeutic* in society (that is, an approach to public health). In its contemporary interpretation, social medicine also means influencing the doctor's frame of mind as a professional, so he or she will recognize the need to modify social factors (in effect, an approach to social reform).

Social medicine therefore includes four components:

1. *medical care*: treatment of the individual patient (or family) to provide comfort and hope, ease symptoms, and, when possible, prolong satisfying and productive life or even "cure" the disease;
2. *preventive medicine*: guidance for the individual patient (or family) in promoting health and preventing disease;
3. *public health*: advocacy and action for health promotion and disease prevention in the community; and
4. *social well-being* (as used in the definition of "health" in the Constitution of the World Health Organization), including amelioration of hunger, homelessness, unemployment, poverty, and hopelessness.

Social medicine in action attempts to

1. ensure equitable access to an effective and efficient medical-care system;
2. encourage preventive medicine by, for example, educating practitioners;
3. support extensive public-health activities; and
4. increase resources and services to improve social well-being.

Social Medicine as an Ethical Model

Physicians engaged in the field of social medicine must concern themselves with a wide variety of problems, disciplines, and factors that encompass what are conventionally understood to be outside the proper concerns of the medical profession. Once the physician recognizes a person as a social creature, the whole range of a patient's needs becomes relevant. Traditionally, physicians have rarely seen themselves as responsible for intervention to correct a social situation outside the family that might be contributing to the patient's illness or obstructing recovery. A socially-oriented medical profession may need to take vigorous action in its patients' interest to promote improved housing, nutrition, and educational opportunities or to combat racism, discriminatory practices, or the inequities and inadequacies of the medical delivery system and its distribution or availability.

Social medicine holds that the physician has an ethical responsibility to take steps to change pathogenic situations to protect society, of which the particular patient for whom he or she bears responsibility is a part. In such circumstances, the practice of social medicine may place a physician in serious opposition to many powerful forces in society, not excluding the majority membership of his or her own profession. A physician may thereby incur social and professional opprobrium. This was the fate of playwright Henrik Ibsen's Dr. Stockmann, described by his community as an "enemy of the people" because he questioned the safety of the town's springs, the source of its prosperity (Ibsen).

Even in milder efforts, physicians who undertake the practice of social medicine may face resistance in utilizing their professional role to ameliorate pathogenic social situations such as inadequate nutrition or malnutrition; accidents and disease that befall those who live in inadequate housing; unsafe working conditions; environmental hazards or decayed neighborhoods; and polluted air and water. Again, since many of these factors are the result of neglect commonly visited upon the poor, the physician who seeks to modify such situations may find it necessary to engage in social movements that attempt to mitigate or eliminate poverty and to encourage poor people to take action on their own. The physician may be forced to take a political position, even initiate political action, in pursuing this end, just as those who do not act or who oppose such actions are taking political positions.

The remainder of this article will cover specific aspects of social medicine. These aspects—environmental and occupational health, medical-care systems, responsibility of the profession, and medical education—illustrate the range of the field and its relevance to current issues.

Environmental and Occupational Health

When a physician, as a responsible practitioner of social medicine, recognizes the potent and often baleful influence of industry on the health not only of its workers but of the community in which it is located, community education and further action may be indicated. There is increasing recognition of the environmental origins of cancer, for example, including the role of carcinogens in the workplace. Some workplaces are hazardous by the nature of the job; in others, accidents—commonly the result of inadequate safety measures or careless disregard for safety standards—result in thousands of deaths and millions of injuries. Further, in an unfortunately large number of instances, the effluent of factories poisons rivers, lakes, and air, contributing to chronic morbidity and increased mortality among the workers and in the community.

The physician with social concern may find both political action and educational efforts unwelcome in a community torn between its need for the jobs provided by the industrial presence and fear of the industry's lethal qualities. In some communities, the answer has been to keep the lethal factory rather than accept unemployment, poverty, and starvation without it. Doctors and communities must begin to deal with a novel ethical conflict: How to modify the paradox of democratic capitalism—the need to restrain the profit motive in order to protect the community from destructive exploitation.

These actions include something more than professional response. The requirements for social change and political action (e.g., nutrition for the children of the poor or occupational safety measures) also demand that the physician act as citizen. In some situations the physician may very well be torn between social concern and his or her livelihood. The physician who works for an industry whose work processes are unsafe or pathogenic may jeopardize his or her job by taking a stand against the employer or the industry of which the employer is a part. Yet failing to take a stand makes him or her complicit and endangers the lives of countless others. A physician cannot be expected ethically to remain silent when the work situation is likely to produce trauma or disease.

Some employed physicians are expected to minimize reports of injury or disease in order to reduce the employer's financial commitment. That is the "job," as the employer sees it, for which the physician was hired. But is the physician's job to put first the interests of the employer who pays his or her salary, or the interests of the patient?

The dilemma of dual responsibility is most vividly apparent in wartime. In addition to the medical oath the physician may have taken at the completion of medical school, on entering military service the physician, like all military officers, must agree to obey military orders. These orders, for example, usually require the military physician to return wounded military personnel to action as quickly as possible. The decision as to which patient to treat first may therefore be determined by which one can be returned to duty most quickly rather than by the urgency of each patient's individual need for medical care. In an extreme case, the military physician would be expected to let a seriously wounded soldier die in order to save the life of one less seriously wounded who was able to return more quickly to battle. And if there were enemy wounded who were more urgently in need of care, when would their turn be?

Medical-Care Systems

In its scholarly manifestation, social medicine initiates studies on a nation's economic and social systems' influence on the structure and function of its healthcare system. Studies and procedures of healthcare in individual countries and cross-national comparisons are an important part of the analytic work of social medicine (Allende; Cochrane; Navarro; Roemer; Sidel and Sidel, 1982, 1983; Waitzkin).

The ethical imperative that arises from this work invites agitation for change and improvement in the structure of the medical-care system to improve its functioning. To that end the results of social medicine studies may generate promotion of the values and methods observed in other national systems, toward better access and improved quality in meeting the needs of the poor and the geographically isolated, and of marginally self-supporting workers. At the turn of the twenty-first century, for example, the inflation of medical costs resulting from disorganization and inequities bankrupted many families and barred adequate access to medical care for many others. What is the physician's role in this situation?

If access to medical care is dependent upon ability to pay, and many people are unable to obtain care for lack of funds, is the physician ethically obliged to oppose ability to pay as a condition for service? Of whom, if anyone, should the physician ethically demand payment? Should physicians demand that medical care be free to everyone at the time of service? When ability to pay interferes with access to medical care, does not the profit motive operate against the best interests of the patient and the ethical principles of the physician?

Newspaper reports and medical journal articles offer accounts of unequal medical treatment by race or gender. Blacks receive fewer advanced technological studies than whites for the same conditions (Kahn, Pearson, Harrison, et al.; Kjellstrand; Wenneker and Epstein); women receive less intensive studies and procedures for heart disease than men (Ayanian and Epstein; Kjellstrand). Ethical principles require reversal of such situations, and social medicine studies and principles guide physicians in taking action (Perkins; Hurowitz).

Evidence accumulates that, with the increase of managed care as a method of cost control in medicine, physicians are urged to limit expenditures by reducing services or narrowing access to expensive studies, hospitalization, or medications. Physicians in medical groups under managed-care controls are offered incentives to conform with such regulations or may be punished financially for not complying.

Official reports as well as media accounts about the scandalous treatment of elderly people confined to nursing homes is another example in point. The profit motive too often leads not only to cutting corners on services and allowing short weights in food or supplies, but to making substitutions of less qualified staff, eliminating necessary services, and waiving safety and protective measures for the helpless inhabitants. Aside from the corrupt financial dealings it encourages in such cases, profit-making often prevents and obstructs both the best care and the provision of alternatives to institutional care. Physicians cannot insulate themselves morally from the mistreatment of elderly people in nursing homes nor from the exploitation of patients through the entrepreneurial mechanics of the pharmaceutical drug industry.

Is it part of the ethics of social medicine to condemn investment in drug industry stocks, in private proprietary hospitals, and in a variety of entrepreneurial enterprises such as laboratories, radiological centers, and other diagnostic and treatment modalities to which they refer their patients? The U.S. Congress and the American Medical Association have strongly condemned "self-dealing" of this nature.

Responsibility of the Profession

In addition to the question of the individual physician's ethics in financial dealings that may compromise patients' best interests, there is the associated question of the physician's responsibility for taking action when he or she observes any unethical or unprofessional behavior on the part of a colleague. If a physician knows first-hand about the poor quality of a particular nursing home, even if his or her particular patient is not affected by it, is the physician required to take steps to correct the situation? Legal steps? Professional steps? Or, more narrowly, if the physician knows of colleagues who do not or cannot adequately carry out their obligations as physicians because of incompetence or because of lack of training, illness, or addiction, what should be done about it? Social medicine holds that there is an ethical responsibility to call attention to these facts even if they do not cause risk to the physician's particular patients.

The physician as social medicine practitioner is asked to make a difficult choice, as a citizen and as a doctor. Social medicine as an ethical model imposes an obligation on the physician to serve his or her individual patient by serving all patients. And, as a member of a profession, the physician must act not only as an individual but as representative of that profession, adopting an advocacy role for the groups in society that require special attention and care. The profession is being asked to act toward society as the individual physician is asked in traditional ethical statements to act toward an individual patient.

Finally, the ethical physician has a responsibility to inform and educate the community on the social nature of health and illness. An educated and knowledgeable constituency is required to provide the necessary support for the political social action. Discussing the dangers of smoking, for example, is hardly enough. Physicians ought also to discuss the economics of the tobacco industry and suggest that steps need be taken to cushion workers from unemployment if the tobacco industry is diminished or eliminated. Moreover, if there is an industrial hazard that needs correction, physicians ought to advise not only on the danger but on means for correcting it.

It is clear, nonetheless, that for physicians to discharge social medical responsibilities in complex areas, they need to see themselves as part of a group larger than the medical profession alone. In 1956, Theodore Fox described the "Greater Medical Profession" and urged "converting the medical empire into a commonwealth" (Fox). To respond ethically to social needs is to recognize the contribution of all health workers and to act in concert with others in the health field and outside it. In doing this the physician may wish to join with others in professionally oriented groups—such as the American Public Health Association, the International Physicians for the Prevention of Nuclear War, Physicians for Human Rights, and Physicians for Social Responsibility.

Social Medicine in Medical Education

Medical education should include not only the technical, laboratory, and clinical models of what a physician can do, must know, and be able to deal with; it should also give the future physician the tools to recognize the social circumstances—industrial, neighborhood, legislative, administrative—that play a part in the production of disease or that influence medical care. Exposure to social medicine as an important component of medical education, along with the example of role models and the fact that faculty members have such interests, will influence students' and later practicing physicians' ideas as to what their responsibilities are and how these responsibilities can be discharged (Silver, 1973).

Although departments of social medicine had long existed in medical schools and hospitals in other countries, it was not until the 1950s that Ephraim Bluestone and Martin Cherkasky organized the first department of social medicine in a U.S. medical institution, Montefiore Medical Center in New York City (Levenson). Other institutions such as Harvard Medical School, the University of North Carolina College of Medicine, and the Albert Einstein College of Medicine later adopted the term in department names or titles of professorships, but the pace of this development in the United States has languished.

Conclusion

Early medical ethics was largely restricted to the concept of a physician–patient dyad. Social relationships of pathogenic factors were unknown or ignored. By the beginning of the twenty-first century, it had become clear that the social aspects of the prevention, causation, maintenance, or cure of disease cannot be adequately dealt with solely in the one-to-one relationship. Expanded notions of the physician's responsibility based on social factors ought to be included in modern medical ethics statements. The physician should learn to recognize and articulate social demands for change in situations that are harmful to patients and to the community, and not simply deal with problems as they arise in his or her patients.

To this end, physicians must know more about the social situations in which disease occurs or which contribute to disease; they must adopt an advocacy role in pursuing change, and join with other health workers in ensuring appropriate social action for correction. In addition to oaths and declarations in which physicians bind themselves to serve individual patients honorably and ethically, service to society must also be required of physicians. Social medicine deserves an integral place within a more traditional medical ethics. Unfortunately, issues of social medicine are often assigned low priority in medical education and in medical practice.

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SEE ALSO: *AIDS: Public Health Issues; Conflict of Interest; Epidemics; Eugenics: Historical Aspects; Genetics and Environment in Human Health; Healthcare Resources, Allocation of; Health Screening and Testing in the Public Health Context; Medical Education; Medicine, Anthropology of; Medicine, Sociology of; Occupational Safety and Health; Population Ethics: Elements of Population Ethics; Public Health; Race and Racism; Responsibility; Sexism; Warfare: Medicine and War; Whistleblowing*

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SOCIAL WORK IN HEALTHCARE

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Social workers have played a vital role in healthcare settings since the early twentieth century. Social work was introduced to medical settings in the United States by Dr. Richard C. Cabot in 1905. Cabot, a professor of both clinical medicine and social ethics at Harvard University, was instrumental in adding social workers to his clinic staff at Massachusetts General Hospital. Under the direction of their first department head, Ida Cannon, these social workers helped patients and their families cope with illness, disease, disability, and hospitalization by focusing particularly on their psychosocial needs, including their emotional reaction and adaptation (Rossen).

Over time, social work's function and influence in healthcare settings have expanded significantly (Miller and Rehr). In addition to assisting hospitalized patients and their families, social workers provide genetic counseling, hospice services, psychotherapy and counseling in mental-health agencies, and treatment of people with eating disorders and substance abuse problems. These opportunities exist in hospitals, neighborhood health and family planning clinics, psychiatric institutions, community mental-health centers, nursing homes, rehabilitation centers, and other long-term care facilities. Social workers' specialized role is to help patients and their families cope with illness and disability.

Many social workers in healthcare settings provide patients and their families with counseling, and information about and referral to needed resources (e.g., home healthcare, financial assistance, nursing home placement). Social workers are also skilled in organizing and facilitating support groups for various populations, such as cancer patients, rape victims, and parents of seriously impaired infants. They work to enhance the availability of community-based resources (e.g., healthcare clinics in low-income neighborhoods or residential programs for children with AIDS), advocate on behalf of individual patients who are in need of services, and advocate to ensure that important public policy issues related to healthcare are addressed (e.g., funding for lead screening or guidelines concerning involuntary commitment of mentally ill individuals to psychiatric hospitals).

Social workers typically function as part of an interdisciplinary team, which may include physicians, nurses, nutritionists, rehabilitation staff, clergy, and healthcare administrators. On occasion, they facilitate the process through which healthcare professionals negotiate differences of opinion or conflict among themselves concerning specific ethical issues. Social workers' skilled use of mediation techniques can help to resolve disagreements that sometimes arise in healthcare settings. Their sensitivity to ethnic and cultural diversity can be particularly helpful when there is a clash between patients' and families' ethnically or culturally based values and prevailing ethical norms, policies, and healthcare practices (e.g., concerning the use of mood-altering medication, autopsy, or blood transfusion).

Bioethical issues in healthcare settings present social workers with complex challenges (Reamer, 1985, 1987). Some of these ethical issues pertain to specific medical conditions. Examples include ethical dilemmas related to a family's decision about withdrawal of a patient's life support, abortion following a rape, organ transplantation, the use of restraints with a noncompliant psychiatric patient, or a patient's decision to refuse neuroleptic medication. When such issues arise, social workers often serve as important intermediaries in relationships among patients, their families, and healthcare professionals. In these instances, social workers help patients and their families make difficult personal decisions, facilitate communication among members of the healthcare team, advocate on a patient's or family's behalf, or raise policy issues that need to be addressed by a hospital, nursing home, or rehabilitation center.

Other bioethical issues concern the nature of relationships and transactions between social workers and patients or their families. For example, social workers in healthcare settings must be familiar with privacy and confidentiality norms that govern relationships with patients and families. They must also be sensitive to complex ethical issues involving patients' right to self-determination, informed consent procedures, truth telling, professional paternalism, and whistleblowing (Loewenberg and Dolgoff; Reamer, 1990).

In particular, social workers can clarify differences among the ethical obligations that guide various professions. For example, social workers in a healthcare setting can help clarify the ethical responsibilities of various professionals when staff suspect child abuse or that a patient with AIDS poses a threat to a third party.

Healthcare social workers are also involved in discussion and formulation of the ethical aspects of healthcare policy and administration. This may take several forms. Social workers may participate as members of institutional ethics committees (IECs) that discuss ethically complex cases and policies. They may have a particularly valuable perspective because of their extensive contact with patients and their families and can, therefore, contribute to discussions about, for example, resuscitation guidelines, patients' right to refuse treatment, advance directives, organ transplantation, treatment of severely impaired infants, and the privacy rights of AIDS patients. Similarly, social workers are active participants on institutional review boards (IRBs) that examine a variety of ethical issues in research on human subjects.

In addition, social workers may be involved in discussions about the ethical aspects of healthcare financing mechanisms and cost-containment measures. They may also propose ways to advocate on patients' behalf or to advocate for policy reform that may provide a more just allocation of scarce healthcare resources at the local, national, or international level. An example is social workers' participation on a hospital committee to assess the pressure to limit care provided to, and hasten discharge of, psychiatric patients covered under *managed care* programs operated by private insurers. In these instances, social workers may help identify the psychosocial consequences of various strategies to allocate limited healthcare resources.

As a profession, social work has its formal origins in nineteenth-century concern about the poor, and is an outgrowth of the pioneering work of charity organization societies and settlement houses, primarily in England and the United States (Brieland; Leiby). Thus, social workers are inclined to be attentive to the needs of low-income, culturally diverse, and oppressed patients and families.

Although contemporary social workers provide services to individuals and families at all points on the socioeconomic spectrum, the profession continues to have an abiding concern for the disadvantaged. As a result, social workers in healthcare settings are alert to ethical issues that involve such populations as low-income patients, abused children and elders, women, refugees and immigrants, substance abusers, ethnic minorities, and gay or lesbian individuals. Concern about such vulnerable groups—for example, with respect to their access to healthcare, their privacy rights, or discrimination against them by healthcare providers—is one of social work's principal hallmarks. Social workers may advocate for individual patients and families whose rights are threatened or who are victims of institutional abuse or discrimination. They also may advocate for public policy that will enhance protection of the rights of these populations.

Like all healthcare professionals, in order to participate fully in discussions of bioethical issues and dilemmas, social workers need specialized knowledge and training. First, they need to be familiar with the history, language, concepts, and theories of bioethics, particularly as they have evolved since the early 1970s. Second, social workers should be knowledgeable about formal mechanisms that can help healthcare professionals monitor and address bioethical issues. These include phenomena such as IECs, IRBs, utilization review and quality assurance committees, informed consent procedures, and advance directives. It is also useful for social workers to be acquainted with relevant codes of ethics and legal considerations (statutes and case law) related to patients' rights and healthcare professionals' obligations.

Finally, social workers should be familiar with the various schools of thought that pertain to ethical decision making and ethical theory. This can be particularly useful when social workers are involved in discussion of cases with professional ethicists, for example, when a decision must be made about when and how to tell a fragile, terminally ill patient the truth about his or her diagnosis, or to disclose confidential information, against a patient's wishes, in order to protect a third party. This training may be offered as part of agency-based in-service education, professional conferences, or undergraduate and graduate social work education.

Especially since the early 1970s, social workers have been aware of the diverse and complex bioethical issues involved in healthcare, whether it involves acute or chronic, inpatient or outpatient, or medical, rehabilitative, nursing, or psychiatric care. Social workers' growing awareness of, and enhanced expertise in addressing, bioethical issues helps to ensure the protection of patients' and families' rights and the soundness of ethical decisions made in healthcare settings.

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SEE ALSO: *Bioethics Education: Other Health Professions; Clinical Ethics: Institutional Ethics Committees; Confidentiality; Family and Family Medicine; Informed Consent:*

Meaning and Elements of Informed Consent; Palliative Care and Hospice; Paternalism; Privacy in Healthcare; Teams, Healthcare; Whistleblowing

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SPORTS, BIOETHICS OF

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The use of banned substances (doping), genetic enhancement, and gender issues are three topics central to the discussion of bioethics in sports.

Doping in Sport

Prior to the inception of the World Anti-Doping Agency (WADA) in 1999 and the World Anti-Doping Code (2003), banned substances and practices in organized sport were identified by the International Olympic Comittee (IOC). In its *International Olympic Charter against Doping in Sport* (1990), the IOC declared that "the use of doping agents in sport is both unhealthy and contrary to the ethics of sport, and that it is necessary to protect the physical and spiritual health of athletes, the values of fair play and of competition, the integrity and unity of sport, and the rights of those who take part in it at whatever level." This charter contains a list of substances and practices that are banned from the Olympic Games. The use of these banned substances and practices is referred to as *doping.* However, the IOC lacked a clear ethical framework that could justify the banning of these items by showing them to be relevantly different from permitted substances and practices.

Each of the IOC's reasons for banning certain substances and practices can be found in more developed forms in the literature of the philosophy and ethics in sport. These include arguments against cheating, unfair advantage, and harm,as well as the ideas that doping perverts the nature of sport and that doping is dehumanizing. The basis for a potential coherent and enforceable ban on doping in sport derives from a view of the intrinsic goods of sport.

THE INADQUACY OF CURRENT ARGUMENTS TO SUPPORT BANS. There are four arguments that are generally proposed to justify banning drugs in sport. All of them have some merit, though none of them provide a sufficient justification for banning doping.

Cheating and unfairness. The argument that doping amounts to cheating was used by Justice Charles Dubin of the Canadian Royal Commission, which was established by the Canadian Federal Government after the Ben Johnson scandal during the 1988 Seoul Olympics. The *Dubin Report* states that the most vigorous opponents of cheating in sport are those who insist that sports must be conducted in accordance with the rules. The moral disapprobation of doping is thus seen as coming from the fact that doping is cheating.

The major problem with this position is that an activity only becomes cheating once there is a rule prohibiting it. So while the fact that doping is cheating may well provide a reason for enforcing the rules against doping, and while the fact that doping is cheating may give other athletes a reason to have an extremely negative attitude towards those who dope, there is not yet a clearly argued reason for creating the rule banning doping in the first place.

There are alternative interpretations of this argument. One is that there is something in the concept of *cheating* that implies a notion of *unfair advantage* of one competitor over another. The use of certain substances and practices falls into this category. However, for this view to justify banning a substance, the notion of unfair advantage must be independent of the rules of sport (unlike cheating). In other words, if *unfair advantage* turns out to be just rule-breaking, then it cannot do the work that the concept of "cheating as rule-breaking" could not do. This raises a variety of philosophically interesting questions: What is cheating? Why is cheating wrong? And, independent of the answer to these questions, *Why should doping been banned?* From a bioethics perspective, it will not do to say simply that one should not dope because it is banned. What is significant is the justification for banning it in the first place.

The argument that doping is unfair suffers from a similar weakness. The simplest idea of fairness is one connected to adherence to the rules: an action is unfair if it is against the rules. An alternative notion of fairness is independent of the rules of sport. But this notion would have to show how doping was inherently unfair, even if the contestants agreed that all could do it, and even if the rules of the game permitted it. Thus, the concept of unfair advantage is no better justification for banning a substance than cheating is.

The concepts of cheating and unfair advantage would have to exist independently outside of sport in order to be brought to bear to evaluate sport. For example, the concepts of cruelty or brutality, which are moral evaluations, have been used to ban sports such as bare-knuckle boxing. It may well have been the case that bare-knuckle bouts were free of cheating and quite fair, they were, however, brutal and cruel, and on these grounds they were banned. Unless the concepts of cheating and unfair advantage can similarly be grounded outside of sport, they will be unavailable to justify or criticise the rules of sport.

Harm to the athlete. The second most commonly cited argument used to justify the ban on doping is that it is harmful. Doping is viewed as being: (1) harmful to users, (2) harmful to other athletes, (3) harmful to society, and (4) harmful to the sports community. However, these arguments cannot be expected to provide a general justification for prohibiting doping, but must be addressed sport by sport and substance by substance.

The argument that a ban is justified because doping is harmful to the user assumes that a particular substance or pracice is harmful, and that potential users need to be protected from the substance or practice. Anabolic steroids provide a good example of such a substance. The assertion that medically supervised steroid use harms the user is, at the turn of the twenty-first century, scientifically unproven. Much of the evidence concerning harm is derived from anecdotal testimony of athletes using very high doses in uncontrolled conditions, and the medical evidence from controlled low-dose studies tends to show minimal harm. Society's abhorrence of the practice has prevented the gathering of hard scientific evidence, because such research has yet to be approved by ethics committees. Autologous blood-doping has not been shown to have adverse side-effects at all.

There are two elements to the charge of harm to the user of a substance: the bad effects of the substance, and the causal linkage of these effects to doping. It has not been scientifically proven just what the "bad effects" from doping are. For the sake of argument, however, one can grant that steroids do indeed harm their users (not an implausible assumption). It would then be necessary to address each particular steroid on its own merits, rather than formulated a general argument against doping.

It can also be argued that the desire to protect competent adults from the consequences of their own actions is paternalistic. Paternalism has both acceptable and unacceptable forms. For example, some would argue that banning doping for minors is acceptable, but that banning doping for adults is unacceptable.There are, however, instances where certain practices are banned for adults, such as banning driving without seatbelts. The question thus becomes whether banning steroids, and other substances and practices, is acceptable paternalism?

Much of the thrust of modern bioethics has been directed against medical paternalism. It may be argued that to ban steroids solely to protect competent adults is to treat those adults athletes as children who are unable to make choices that directly impact their lives. This position is generally inconsistent with the nature of high-performance sport, in which athletes are constantly pushing their limits.

Some would argue that it is inconsistent, and even hypocritical, for the governing bodies of sports to attempt to justify a ban by appealing to the athlete's well-being. There are many training practices, and indeed many sports, that carry a far greater likelihood of harm to the athlete than does the controlled use of steroids. If the reason for banning doping in sport really were a concern for the health and well-being of athletes, then many other practices (and many sports) should also be banned.

One might argue that the risks incurred by the nature of the sport (e.g., brain damage from having one's head pummelled in boxing) are different from the risks that are incurred from practices that have nothing to do with competition in the sport per se (e.g., liver damage from steroid use). The basis of this argument might be tied to a distinction between the *external good* and the *internal good* that are derived from participation in a sport. Internal goods (skill, strategy, self-fulfillment, etc.) are gained from participation in the activity itself, while external goods (fame, prestige, money, etc.) are gained from societal recognition of success. Some might argue that the only way one can gain these internal goods is to take the risks involved in participation. However, this distinction is invalid if the justification for the ban is that a substance harms the user, because the athlete can be harmed in either case (i.e., both brain damage and liver damage are harmful).

There is little evidence to suggest that banning doping will protect athletes. As long as a subculture exists that believes that doping brings benefits—and that it is an occupational hazard of highlevel competitive sport—athletes will continue to use these substances in clandestine, unsanitary, and uncontrolled ways. Only a change in values will end such use, and this will only happen after a logically consistent position for the ban has been put forward (presumably, a ban would be intended as part of a larger process aimed at producing just such a change in values).

Harm to other athletes. It is also argued that steroids should be banned because of the harm their use causes to other athletes. ("Others" are usually deemed to be "clean," or nondoping, athletes.) This is called the *coercion* argument, and it is more difficult to dismiss quickly. The same liberal tradition that prohibits paternalistic interventions permits interventions designed to prevent harm to others. What must be determined is how great the harm is to other athletes, and how severe the limitation on personal action is.

In order to assess this argument one needs to consider whether or not the potential coercion of clean athletes outweighs the infringement on the liberties of athletes caused when a substance or practice is banned. Clean athletes are harmed, so the argument goes, because the dopers "up the ante." If some competitors are using steroids, then all competitors who wish to compete at their level will need to take steroids or other substances to keep up. This argument has some merits, but it is still incomplete, for elite-level sport is already highly coercive. If full-time training, altitude training, or diet control are shown to produce better results, then everyone is forced to adopt these measures to keep up. The feeling that somehow steroid use is worse than longer or more specialized training just raises the question of *why* it is worse. Why can't an athlete accept two "raises of the ante" but not accept a third, or even an unlimited number?

The answer to this question relies on a demand for consistency. There must be some reason why a particular practice is banned, and that reason cannot be merely that it raises the ante too high. This is a qualitative question, not a quantitative one, that necessarily requires an explanation for banning a substance on its own merits.

On the other hand, the coercion argument has merit if it can be shown that doping is irrelevant to a particular view of what is important to sport. If sports and sporting contests are about testing skills, then it can be argued that the improved performance that comes with doping is irrelevant to that test of skill (especially when one bears in mind that if some athletes dope, others will be forced to dope in order to keep up, thus obviating the original advantage that came with doping). If doping is irrelevant to sport, the athletes can shun it as being unnecessarily coercive.

Harm to society. This position says that doping harms others in society, especially children who see athletes as role models. If children see athletes having no respect for the rules of the games they play, there will be an undermining of respect for rules, and for law in general. This argument only works if doping is against the rules, however, and so cannot function as a justification for banning doping in the first place.

Athletic drug use is also seen as part of a wider social problem of drug use. The argument here is that if children see athletes using drugs to attain sporting success, then other drugs may be seen as a viable means to other ends. The limitation of this argument is that there are many things that are considered appropriate for adults but not for children. Alcohol and cigarettes are obvious examples, as is sex, but, in North America at least, these substances or activities are not banned for adults simply because they would be bad for children.

A further response to the suggestion that athletes should be role models—and, in particular, *moral* role models—is to ask why. People expect widely varying things of their public figures. No one seriously expects musicians or actors and actresses to be moral role models, so why should athletes be singled out for special treatment? Why should more be expected from athletes than from other public figures?

Some philosophers have argued that sport is one of the very first areas young people experience, and one of the first in which they hope to gain excellence. From a societal perspective, if the heros and heroines of young people are morally despicable, then they will exert a negative influence. Young people will not separate the athletic abilities of their heroes or heroines from the quality of their personal lives, especially when fame and glamour surround such persons. The achievement of excellence in athletics comes prior to, and will greatly influence, the achievement of excellence in adult arenas such as business, academia, and politics. Perhaps for these reasons people are more concerned about the moral image of athletes than of other public figures.

What is it about drug use in sport that people find morally repugnant? No one else is prevented from using cold remedies, even if they drive public transportation, or from using caffeine as a stimulant to work harder. So it is not even the case that athletes are asked to meet the standards every one else meets, but rather, at least in regard to substance use, they must meet more rigorous standards.

Harm to the sport community. One other group that is potentially harmed is the sports-watching public. These people will be harmed, the argument goes, if they are being cheated—if they expect to see dope-free athletes battling it out in fair competition and are denied this form of entertainment. This harm can be removed in other ways than through banning steroid use, however. One could, for example, remove the expectation that athletes be dope-free. The feeling of being cheated is dependent on the idea that what was expected was a particular type of competition. However, this means asking people to settle for less than what they really want. They might, therefore, suffer other harms, such as the loss of the chance to watch doping-free competition. Of course, this does not address the question of why people value doping-free competition.

HARM CAUSED BY BANS. Because any bans that are imposed need to be enforced, there are potential harms caused by the bans themselves. Enforcement of bans on substances or practices designed to help one train, rather than improve one's performance on the day of competition, requires year-round, random, unannounced, out-of-competition testing. This is an intrusion into the private lives of athletes. Thus, athletes are harmed by being required to consent to such testing procedures (and to give out constant updated information on their whereabouts) in order to be eligible for competition.

One aspect of the harm caused by bans is abstract. Any time one's choices are restricted, one has been harmed. One could argue that the athlete is harmed when deprived of the chance to dope in order to improve performance. On the other hand, the spectator is harmed when deprived of the chance to watch doping-free sport. There is, however, a more direct harm. If one bans drugs or practices, one must necessarily take steps to enforce that ban. Despite the number of positive tests during a competition, the only effective way to test for banned substances is to introduce random, unannounced, out-of-competition testing. This is because some substances, such as anabolic steroids, can be discontinued before competition, and still retain their effects and also because of the prevalence of masking agents and urine substitution using catheters. The demand that athletes be prepared to submit to urine (or blood) testing at any time is considered by some to be a serious breach of their civil and human rights. It could also be argued, however, that such interference is just part of the price of being in sports—no one is forced to become an athlete, let alone an elite athlete.

Many who discuss this topic suggest that "sport is different," that it is not "real life," but "only a game." They argue that, because of this difference, the limitations imposed by the requirements of consent do not apply. The suggestion is that participation in high-performance sport is a privilege, not a right. Therefore, athletes are not deprived of their rights if they are deemed ineligible because they will not submit to a drug test, because they do not have a right to participate in the first place. The serious consequences of this argument is that it would allow the imposition of any rules, no matter how absurd.

Further, this argument is unclear. It may mean that no person has the right to be selected for a national team or for financial support. This is certainly true, but it is also true that there is some obligation to select the best available people for national teams and, barring income tests, for financial support as well. It could then be argued that the "best available person" means the best person available who abides by the rules of the game. However the rules of sport are not arbitrary, and they are open to moral scrutiny. If the format of the drug test is unacceptable on the moral grounds that it invades privacy, then it is also unacceptable for there to be a rule of eligibility that requires it. Sport may well be different, but nothing is so special or different that it can escape all moral scrutiny.

Perversion of sport. The concepts of cheating and unfairness and of harm are moral concepts. Cheating and unfairness presuppose a set of rules, so logically these concepts cannot be used to justify a rule. The concepts of cheating and unfairness are are thus *inside* sport. The arguments related to harm utilize a principle found outside of sport and applied to it, thus working from the outside in.

In contrast, arguments related to the perversion of sport do not operate from moral principles, but from metaphysical ones. What the arguments seek to show is that there is some feature of sport, which, if properly understood, would be demonstrably incompatible with doping. Thus, doping should be banned because it is somehow antithetical to the true nature of sport.

Part of the problem when dealing with this question is that sport is socially constructed, and there is no obvious reason why it could not be constructed to include doping. A view of sport which places at its center the testing of sporting skills, with sporting skills defined by the nature of the game concerned, suggests that doping is not so much antithetical to sport, but rather irrelevant to it (Schneider and Butcher, 1994). Doping is irrelevant to sport because it does not improve skill, but merely provides a competitive advantage over those who do not dope. But a prerequisite for this justification is that it must come from the athletes themselves, not from sport administrators.

Unnaturalness and dehumanization. It is also argued that doping should be banned because it is either unnatural or dehumanizing. The unnaturalness argument does not get very far for two reasons. The first is that it is not clear what would count as *unnatural.* The second is that it is inconsistent. Some things designated unnatural are permitted (e.g., spiked shoes) while certain natural substances (e.g., testosterone) are banned.

The dehumanization argument is interesting but incomplete. There is no agreed upon conception of what it is to be human. Without this it is difficult to see why some practices should count as dehumanizing. We also have a problem with consistency. Some practices, such as psycho-doping (the mental manipulation of athletes using the techniques of operant conditioning) are not banned, whereas the re-injection of one's own blood is banned.

An Alternative Approach

A two-tiered approach has been proposed that could justifiably prohibit doping in sport. This approach tries to show: (1) why athletes should not want to dope, and (2) why the community should support doping-free sport.

WHY ATHLETES SHOULD NOT WANT TO DOPE. Sports are practices that provide the opportunity for individuals to acquire and demonstrate skills. A well-executed back-hand volley is a demonstration of skill because of the kinds of things that are necessary to win at tennis. The shot is difficult and effective, and it is just this sort of manifestation of skill that makes participating in sport so worthwhile. The joy of sport comes from acquiring the goods that are internal to sport, the goods that come with the mastery and demonstration of skill. If this joy is the primary reason for participation in sport, then doping is irrelevant to the internal goods of sport.

Every sport is a sort of game, a game where obstacles have been artificially created to prevent one from readily achieving the object of the game. Skill is demonstrated in the overcoming of those obstacles, within the limits provided by the rules of the game. What makes sport interesting and worthwhile is the mastery of skill, and its demonstration in a fair contest with equally skilled opponents. Doping does not help one to acquire sporting skills, but simply provides a competitive advantage over those who do not dope.

Further, as long as one's competitors do not dope, there is no reason for any athlete to dope, even if the risks are minimal and the probabilities of harm are small. Because there is no game-productive reason for doping, athletes would be wise to avoid it as an unnecessary risk.

Finally, the coercive effect of doping is such that if athletes believe that a good number of their opponents dope, they will feel compelled to dope in order to keep up. But this has the effect of removing the competitive advantage that those who first doped soughtto gain. Doping is only an advantage—in terms of *winning*—if you dope and your opponent does not. That advantage is lost if everyone dopes.

These arguments point the way to a method of avoiding the invasion of privacy caused by the enforcement of bans. If athletes want doping-free sport, they will also want to be assured that the competition is fair. Athletes, then, would be in the position to request the enforcement of the rules of self-limitation that they themselves have rationally and prudently chosen.

WHY THE COMMUNITY SHOULD SUPPORT DOPING-FREE SPORT. The sporting community, both participants and fans, is in a position to defend a view of human excellence that can put limits on the pursuit of performance excellence in sport. Given that in most countries amateur sport is publicly funded, the community can promote a view of sporting excellence that places it within the context of a complete, and excellent, human life. So, despite the fact that excellence in certain sports (i.e. boxing and downhill skiing) requires running dreadful risks, society is in a position to limit those risks because it does not want to promote downhill speed over long and healthy lives. The message from those who support sport should be that an athlete's sporting life is only a part of his or her entire life. While excellence in sport is a worthy pursuit, it should not be pursued at the expense of one's health and well-being. Because amateur sport is publicly funded, the community is in a position to put limits on its support, limits that come from the desire to promote human excellence across a complete lifetime.

Genetic Enhancement in Sport and Bioethics

Gene transfer technology will revolutionize the way people view illness and health, and it will also transform the way we diseases are treated and prevented. While this work is still in the research phase, the most imminent applications of gene transfer research to sport performance include muscle growth factors and oxygen transport and utilization.

CONCEPTUAL ISSUES. The primary challenge in gene transfer technology is in drawing the line between therapy and enhancement. The standard approach in sport has been that therapy (repair to bring one back to *normal*) has been permitted, but enhancement (going beyond *normal*) has been banned. This approach does not fit neatly with current medical practice and thinking. For example, in many forms of prevention, the body's normal responses to disease are enhanced to enable a person to avoid infection or illness. Some muscle-repair therapies may have the effect of making the muscle stronger than it was before the injury, thus enhancing performance.

The wording used in a particular ban or regulatory list needs careful consideration. It is easy to be either too specific (thus missing a significant new development) or too general (thus encompassing a variety of acceptable uses of technology). Because of the relation of sport to society, the language used in the World Anti-Doping Code attempts to deal with the development of genetic technology. This code addresses the use and impact of gene transfer technology in sport, while acknowledging that sport operates in a social context. In regard to genetic enhancement, even if sport organizations decided that enhancements should not be permitted, if it became standard medical and social practice to enhance memory and mental acuity, or to enhance muscle growth and strength in the elderly, it would be extremely difficult for sport to stand apart in opposition. There are many areas where enhancement is not only accepted, but encouraged, valued, and highly rewarded (e.g., cosmetic surgery) and even sport—some drug use is permissible in baseball in North America, for instance. If it is socially acceptable in some settings, why not in sport?

The World Anti-Doping Agency (WADA) attempted to initiate discussion on the development of some core agreements by hosting a conference on genetic enhancement and sport at the Banbury Centre in New York in February 2002. WADA has the opportunity to influence and shape the discussion, and to define and direct policy, before gene transfer technologies become available for general use.

OBJECTIONS TO GENE TRANSFER TECHNOLOGY FOR PERFORMANCE ENHANCEMENT. Despite a lack of clarity in exactly what is meant by *treatment* and *enhancement,* it is generally agreed that enhancement for sport purposes is unacceptable. However, within medicine and science this is a very complicated issue, partly because the technology is in the early stages of development. It is difficult for medical scientists to state, in the abstract, that enhancement for sport is unacceptable. This position is thus far more appropriate as a statement from the sport community. Scientifically, it would certainly be unacceptable when the technology is in this immature state.

There is strong agreement that action is required on this issue, and that this action will be complex and multifaceted. It should include: (1) ongoing cooperation between the research and sport community, (2) communication between the sport community and regulatory bodies for review and regulation of research and biotechnology, (3) inclusion of wording covering gene transfer technology in the World Anti-Doping Code, (4) research into detection mechanisms, (5) ongoing discussions between the sport community and the medical and scientific communities concerning standards of practice, (6) ongoing discussions between the sport community and the biotech and pharmaceutical industries, (7) education of athletes, the professions (especially medicine), industry, governments, and the public.

UNDISCOVERED COUNTRY. A number of themes and issues related to genetic therapy and genetic information have yet to be discussed in the sport context. The first of these is *genetic design,* which involves "designing" babies for specific (athletic) traits. The second of these issues is *germ-line,* or heritable, therapy. Other uses of genetic technology include *in vitro* genetic screening, which, in principle, makes it possible to screen embryos for genetic characteristics, and then implant into the womb only those with the "desirable" genetic makeup. It is not known if it will be possible to do this for genes associated with traits that predispose to greater athletic performance, but such a possibility raises numerous ethical questions.

There is also the possibility of genetic screening *in vivo,* where genetic screening techniques could be used (as a form of potential aptitude testing) to determine which children or young people were most likely to benefit from specialized sport training. There has been no comprehensive discussions of the acceptability of these procedures for sport purposes, nor of the privacy issues associated with this genetic information.

REGULATION AND REVIEW. Research on the human applications of gene transfer technology is highly regulated and reviewed at local and national levels in the United States, and, to some extent, by similar mechanisms in other nations. However, review and regulation vary by jurisdiction and nation. The research is currently highly sophisticated and expensive.

There are gaps in regulation in regard to sport applications. For example, a study would not be likely to be described as having the purpose of exploring the enhancement of sport performance, though it could have that effect. The prospective regulation of gene transfer technology for sport purposes must be multifaceted and include: (1) regulation of research, (2) regulation of professional medical practice, and (3) regulation of athletes and support staff.

TESTING. There is general agreement in the sport community that the possibility of testing requires the development of more efficient methods for detection of genetic modification or of the physiological effects of genetic modification. Testing may well be difficult, and it may raise additional ethical issues, but it involves technical issues that are soluble by improved research and technology development. Testing could be aimed at both the primary genetic modification and at secondary indicators. The incorporation of *markers,* or tags, into foreign therapeutic genes to make them more readily detectable may help in detection programs, though this would be contrary to best principles of drug design, in which only therapeutic efficacy should be relevant.

RESEARCH AND EDUCATION. There needs to be increased research and development in the areas of *in vivo* gene and vector detection and the identification of the physiological effects of genetic modification, along with careful and constant ethical review. General education, as part of social change, is viewed as essential. Education should be values-based and target-specific. Researchers need to be educated on the potential uses of their research for sport enhancement purposes—and why this would be harmful to sport and athletes. Biotech companies need to be educated on the potential uses of their products and processes, and on their role (and self-interest) in avoiding misuse. The professions (particularly medicine) need to be educated on standards of professional practice and distinctions between therapy and enhancement. Finally, athletes need to be educated on the values of sport and the side effects and hazards of gene transfer technology.

Bioethics, Sport, and Gender

Many elite-level sports require pushing human limits, and thus present high risks of injuries. Generally speaking, elite-level training can produce fit, but not necessarily healthy, athletes. The results of the pressure to can be different for men and women, however. Three issues in particular—disordered eating, amenorrhea, and osteoporosis—are commonly referred to as *the female athlete-triad.* These problems surface most often in sports such as gymnastics, where victory is the result of judging. In such cases, the physical requirements and resulting risks are directly caused by decisions about what counts as excellent sport. The judging criteria for these sports need to be tailored so as to minimize the health risks they impose on the athletes.

Women athletes have a much higher prevalence of disordered eating than men. Women athletes have, at various times, faced different body-type ideals, but the greatest tension is that between the traditional ideal athlete and the traditional ideal woman. This reflects the higher level of eating disorders among women in the general population, a result of unattainable ideals among many women regarding their bodies. Thus, this problem is partly cultural, and medical control may not be the best, and is certainly not the only, way of addressing the issue.

Historically, some medical authorities have viewed menstruation, pregnancy, menopause, body size, and some feminine behaviors as diseases. For the female athlete the situation becomes even more complicated, because she can be classified as even more abnormal when reproductive changes are evaluated in the context of the traditional male sports arena. If a normal healthy woman is considered unhealthy because the model of the ideal healthy adult is based on being male, then the female athlete starts out as an unhealthy adult simply because she is a woman. If the female athlete then shows signs of becoming masculine through excellence in sports, this only increases her "abnormality." Following this kind of medical classification, when a woman bleeds, she is ill, yet if she does not bleed she is also ill. Pregnancy, then, theoretically constituting a state of health for the traditional ideal woman, should not be treated as disease.

Serious charges of irresponsibility can occur when the relationship between women athletes and their fetuses are characterised as adversarial. Some countries (e.g., Canada, the United States, Australia) have begun to imprison women for endangering their fetuses (Sherwin). Most pregnant women athletes face, at the very least, moral pressure based on the view that simultaneously being pregnant and participating in sport is socially unacceptable. However, genuine harm to the fetus may occur with participation in sport (e.g., through oxygen deprivation). This is a problem best dealt with through education, however, not through prohibition and criminal penalties.

The classification of the reproductive aspects of women's lives as illnesses has led to wide-scale paternalistic medical management of women under claims of beneficence (Sherwin). In sport, these so-called illnesses have been part of the basis for excluding women. Certainly, serious complications requiring medical interventions can occur with any aspect of a female athlete's reproductive life or life-cycle changes. The physical and emotional pain experienced by older women athletes during menopause has always been a fact. Sport physicians, however, who are predominately male, had to learn to take their female patients seriously before they could recognize that this pain was real, and not just "in their heads." There are instances where the label of illness or disease is appropriate, but it is important that this does not lead to harming women athletes from a policy perspective (e.g., banning them from participation, rather than educating them about coping with their illness and participating in sport).

The Logic of Gender Verification and Transsexualism

Having entirely separate sports for men and women inevitably leads to the question of the logic of gender verification. If there are to be separate sporting events for women, it must be possible to exclude any men that may wish, for whatever reason, to compete in these events. This means that there must be a rule of eligibility that excludes men. (Conversely, if there is such a rule, the question arises of whether there should also be such a rule excluding women from men's events, even if the women believed they would inevitably lose.) This requires a test of gender that can be applied fairly to any potential participant. There are at least three methods of applying any such test. The first would be to test all contestants, the second would be to test random contestants, and the third would be to test targeted individuals.

It is not beyond the realm of imagination, however, that a money-hungry promoter might decide to enter men in a women's event. A male may even, with good intentions, choose to enter a women's event (such as synchronized swimming) as a form of protest against gender discrimination. Without a test to decide just who is eligible, women's events could be forced to accept participants who were quite obviously and unashamedly male, but who professed to be female.

There is a great deal of debate about how sex roles and gender are established. One school of thought takes the position that *sex* refers to biological characteristics and *gender* to socially learned characteristics. The standard practice in the Olympic Games has been to have medical experts verify gender. But, by delegating gender verification to medical experts, the sport community (and society in general) has given great power to medical experts on an issue that is in dispute by researchers.

One famous case that illustrates the conceptual and moral issues of gender verification is that of Renée Richards. Richards was previously a male elite-level tennis player who underwent what is commonly termed a "sex-change operation." The U.S. Women's Tennis Federation wanted to exclude a player who was genetically male, and they therefore introduced the requirement that players take a chromosomal test known as the Barr Test. Richards refused, and went to court to demand the right to participate in women's events. In court she was deemed to be female on the basis of the medical evidence. In the media, this story played as an example of a courageous individual fighting for personal rights against an intransigent and uncaring system, though there are, of course, other ways of viewing the story.

What makes a woman a woman? Is it chromosomes, genitalia, a way of life or set of roles, or a medical record? It is not clear why medical evidence of surgery and psychology should outweigh chromosomal evidence, nor is it clear why any one answer should be taken as categorically overriding any other. Some women argue that any gender or sex test is demeaning (especially visual confirmation of the "correct" genitalia) and discriminatory if it is not also applied to men. Clearly the use of any test, given the complexity of human sex and gender, may lead to anomalies and surprises. Yet many women wish to have sporting competitions that exclude men. One thing that does seem to become clear when faced with the complexity of this issue is that women athletes themselves should be the guardians and decision makers concerning women's sport. The best result will be one that arises through discussion, debate, and consensus.

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SEE ALSO: *Addiction and Dependence; Conflict of Interest; Cybernetics; Enhancement Uses of Medical Technology; Harmful Substances, Legal Control of; Human Dignity; Transhumanism and Posthumanism*

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STUDENTS AS RESEARCH SUBJECTS

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Why does it matter if research subjects are students? Three answers surface immediately: first, students might be children; second, students might be in school; and third, students might be engaged in learning. None of these answers is always true, but they are true often enough to deserve consideration in research plans involving students as research subjects. Research involving students, be they minors or adults, should be conducted in accord with ethical principles and applicable regulations to protect students from potential coercion and harm. Paradoxically, these regulations and ethical codes send conflicting signals: The regulations carve out certain kinds of education research as being exempt from the umbrella of regulatory protection, while various ethical statements, disciplinary codes, and guidance—most notably from the American Educational Research Association—single out students as deserving careful treatment (Office for Human Research Protections; Strike, Anderson, Curren, et al.; American Psychological Association; American Sociological Association).

Primary and Secondary Education Students

The vast majority of students in primary and secondary schools have yet to reach adult maturity, legally and developmentally. Given the ethical principle of respect for persons, from which arises the practice of informed consent, research involving young students raises the question of students' abilities to make voluntary, competent and informed decisions about whether or not to participate in proposed research. Human development and experience affect the level of student understanding of research participation. Language and literacy skills affect students' ability to receive and interpret relevant information, much less appreciate the implications of what the consequences of participation could be. Children are generally less familiar than adults with key concepts relevant to research participation and risk, such as confidentiality, experimental trials, or the estimated probability of a particular outcome. Such cognitive tools are essential to grasping a specific research activity and the involvement of research subjects. As they develop and learn, students gradually become more like adults in their capacity to truly understand what involvement in research entails (Bruzzese and Fisher). Some education systems set standards regarding what students should know and be able to do in science at various grade levels, as illustrated by the American Association for the Advancement of Science and the National Research Council. Such standards may provide useful guidance regarding what prospective young research subjects should be expected to understand about participation in research.

Young students also vary significantly from adults in their perceptions and assessments of risks and benefits. Their abilities to make practical judgments are less well developed than those of adults. They may attach very different values to specific harms and benefits, and most concern themselves with short-term consequences. A typical sixth grader views the sacrifice involved in giving up math class to participate in research differently from how an adult would understand it. Children and adolescents also have their own views about common forms of research compensation such as money or material goods. Young people's faculties of moral judgment, including the reasons they use to justify practical decisions, also vary from adults in patterned ways (Bebeau, Rest, and Narvaez).

Students' voluntary decision-making is also shaped by various influences. Very young children are strongly affected by their parents and other significant adults, while adolescents become more susceptible to their friends' and peers' value orientations and pressures as adult influences wane (Steinberg, Brown, and Dornbusch) These influences obviously bear upon how researchers should construct the circumstances in which students are asked to participate in research.

Parents, Guardians, and School Officials

These developmental considerations lead ethicists and some federal agency regulations to view the agreeable young person as providing *assent,* that is, an affirmative expression of willingness to participate voluntarily in research. U. S. federal regulations generally require assent from minors and supplement that requirement with the *permission* of a parent or guardian. Requirements are less rigidly established in other countries, and practices vary widely. Permission is construed according to standard criteria for informed consent with respect to the parent or guardian's decision on behalf of the student.

Permission generally provides an appropriate mechanism for protecting the autonomy, interests and welfare of the young student, but it may also present challenges. If permission comes from the parents, the research team needs twice the number of affirmative responses to its request for participation. Parents often are not as easy to contact as students, and research suggests that some parents do not give permission for their children to participate in research not because they object, but simply because they don't get around to signing and returning a consent form (Singer). Other parents have reservations about a research team's overtures that are unrelated to any concerns about their children's welfare; they may be embarrassed to reveal their lack of literacy skills, or believe that signing a form reflects a legal concession, or even fear that their signature somehow puts them in jeopardy. Some parents have interests contrary to the students whose welfare they are expected to protect; they may worry that their child's responses to a research survey may embarrass or incriminate the parents. On the other side, students' hesitation about participation may stem from apprehensions about what their parents may find out about sensitive survey questions or how they answered them.

Other adults have a role in protecting prospective student research subjects, which may lead to tension over who has authority to permit student participation in research. School officials are responsible for students' welfare and directly supervise students' school day activities. Since proposed research activities may disrupt normal school life, researchers are generally obliged to obtain school officials' permission to carry out research with students as research subjects. Researchers might also view school officials as appropriate sources for permission to involve students in research. This view is contestable, however, as conflicts arise about parents having control over, or at least a say in, what happens to their children in schools. In the United States, federal laws—most notably the *Family Educational Rights and Privacy Act* and the *Protection of Pupil Rights Amendment*—and state and local laws and policies reflect efforts to prescribe when parents must be consulted before researchers may collect data about students through school records, surveys, or other means. Since federal regulations do allow for waiver or alteration of elements of consent or documentation of consent under certain conditions, researchers sometimes request such waivers, particularly for large scale surveys where the researchers point to the low level of risk involved and the difficulties of securing adequate unbiased samples if active parental permission is required. For some parents, however, it is the sensitivity of survey topics and the potential invasion of privacy that concerns them, not the degree of risk involved.

The School Site

The question of who has authority over what happens to students in schools also raises the issue of the convenience of conducting research with students in schools. Most primary and secondary schooling is compulsory in affluent countries; consequently, researchers can expect to find in schools large and fairly representative samples of young people, neatly segregated by age, under adult supervision, engaged in activities not of their own choosing, and legally required to stay. The opportunities for relatively inexpensive and efficient data collection are obvious. Thus some research efforts seek to involve populations of students as research subjects not because the research objective is focused on understanding education or the lives of students per se, but rather because students in schools offer a convenient way to study a wide variety of phenomena concerning youth. This approach may be viewed by some as a form of exploitation that could be unwelcome and disruptive to the educational process. Frequently students are surveyed about their health and development, extracurricular activities, and perceptions of themselves and society, for reasons unrelated to their educations. Research studies focused on areas outside of education may detract from the school's pursuit of its educational mission, and may pose risks for students by asking for sensitive information about criminal, antisocial, or private behavior.

Education Research and Practice

Education research involves students for the specific purpose of studying the formal and informal processes of learning. Such research projects raise their own set of important ethical concerns, particularly when they involve educational practice and practitioners. Some of these concerns resemble those raised in clinical trials of therapeutic medical interventions.

Education research may involve the educational equivalent of the *therapeutic misconception*: the mistaken belief that the nature of the subject's involvement in research in designed to improve that subject's welfare, rather than in developing generalizable knowledge (Appelbaum, Roth, Lidz, et al.). Students, parents, and researchers may all fall prey to the *educational misconception,* especially in the context of educational practice.

Education researchers often involve teachers or other practitioners in data collection or as co-researchers, and the dual roles of researcher and practitioner sometimes conflict (Hammack), as they do in biomedical research (Koski). What should a practitioner/investigator do in a classroom situation where pursuing a research question comes at the expense of delivering an important lesson? What if one uncovers sensitive information about the students that an educator would not otherwise have known? If a practitioner/investigator discovers that a student cheated on a test, should he or she, as an educator, discipline the student and alter the grade, or, as a researcher, protect the research subject from harm? Note that in such circumstances the protective research device of confidentiality is rendered useless, because the person who collects the information is the selfsame person as the one from whom the potentially harmful information is supposed to be kept.

Education research also raises issues of justice or fairness with regard to the selection of research objectives and selected student populations. Should the focus be on research that will benefit the largest possible number of students, with current level of success in the middle range? Or should the focus be on those students who possess the potential to improve the most from better educational interventions, even if they are already doing relatively well? And what of those students who are currently doing relatively poorly in the current educational system, whose level of achievement may be the most difficult to improve? Do students of one ethnic or linguistic minority deserve more attention than students of another, because their numbers in the education system are larger? Such questions of beneficence and justice are reflected in any research project proposing a selective sample of students, and are framed by deeply held cultural beliefs about the importance of education as a vehicle for equality of opportunity and social mobility.

Education research frequently involves the evaluation of interventions delivered at a collective level in classrooms and schools. Reducing class size, changing teacher behavior, altering curricula, attaching high stakes to test performance, and reforming school culture are all educational interventions that can only be accomplished and studied at a group level. In a study where classrooms or schools are randomly assigned to an innovative approach (treatment) or to the standard educational practice (control), by the time the results are available, students may have outgrown the opportunity to benefit from the more effective intervention if they did not receive it during the study. Individual students and their guardians may be able to decline to have the data about them collected or included in research analyses, and sometimes accommodations such as classroom re-assignment can be made to enable students to opt out of a research study. In many cases, though, if a student or guardian wants to avoid the student's participation in a research evaluation of an educational practice at a participating school, the options may be severely constrained or costly. Such collective decisions about the involvement of students as research subjects must face the challenge of striking a reasonable balance between majority will and minority freedoms (Oakes)

The use of qualitative methods and the involvement of practitioners in many education research studies significantly transform the relations and ethical orientations among researchers, practitioners, and students. Qualitative research strategies in education characteristically intertwine the prescriptive and descriptive dimensions, place research activities in specific moral and political frameworks, and recognize the essential contributions of the "insider" subjects' perspectives, abandoning disinterested stances in favor of "advocacy" positions (Howe and Moses). Likewise, practitioner/investigators often find themselves sharing control over the nature, objectives, and credit for research projects with their colleagues and students, making the relationships among the participants more egalitarian, changeable, and complex (Zeni). In such cases the ethical responsibilities shift accordingly.

Tertiary Education Students

Undergraduate and graduate students generally have the background knowledge, literacy skills, and abilities to appreciate potential harms and benefits at a level resembling those of adults. Indeed, nearly all are adults, removing the need for parental permission for the vast majority of tertiary education students. The typical college student also has relatively good health, more flexible schedule commitments, few or no dependents, limited financial resources, considerable disposable time, and openness to new experiences. More than fifteen million students attend degree-granting tertiary education institutions in the United States, where they are easily accessible to academic researchers. Tertiary education students are prime candidates for research involvement.

DEPARTMENTAL SUBJECT POOLS. Academic researchers, most notably psychologists, have capitalized on the ready availability of students, often their own students. The vast majority of findings in human studies by psychologists come from research involving students as research subjects (Chastain and Landrum). In order to avoid the coercive situation of faculty asking their students to participate in their own research, many institutions set up departmental subject pools (DSPs) through which they arrange for students to participate in faculty research projects.

The practical arrangements of DSPs vary. Some are entirely voluntary, while others are attached to course selection—usually introductory psychology or other lower-division social science courses—and are either required of students or award extra credit for the course. Most DSPs allow students other options, such as writing a paper, as an alternative to participation in research. The ethical rationale generally put forward for this practice is that the DSP arrangements for research participation provide an educational benefit to the research subjects while efficiently supplying sufficient numbers of research subjects to enable faculty to carry out a more robust research agenda of valuable studies.

Some DSPs are ethically better than others, depending on specific features of the DSP, including the following:

- Clear, timely information is provided to prospective students.
- Investigators demonstrate respect for research subjects through their conduct.
- Student participation in the system is efficient and non-punitive.
- Students choose from a variety of research studies.
- Research studies are appropriate for a sample population of college students.
- Research studies are generally low in risk.
- Subject participation is structured to provide educational consent and debriefing experiences.
- A variety of alternatives to participation in research are offered, involving comparable

educational value, time commitment, and enjoyment (Sieber).

The 2002 revision of the American Psychological Association's ethical code reaffirms its previous position on students as research subjects, allowing DSPs if students have alternative options: "8.04 Client/Patient, Student, and Subordinate Research Participants (b) when research participation is a course requirement or an opportunity for extra credit, the prospective participant is given the choice of equitable alternative activities" (American Psychological Association).

There are reasons for skepticism about whether DSPs are ethical at all, unless they are entirely voluntary. Given the imbalances in power, authority, and autonomy inherent in the relationship between teacher and student, complete voluntariness may not be possible. Whatever degree of latitude DSPs permit in student choice of research projects or alternatives, required participation still reflects researchers' use of their control over students' educational choices to induce them to participate.

The claim that DSP participation represents a genuinely beneficial and authentic educational experience is open to objection. DSPs present students with consent situations that do not reflect the ideal of voluntary participation: Outside of DSPs, research subjects are either volunteers or are offered compensation in forms they value. Extraordinary briefing or debriefing experiences may provide students with better understanding of the substance of a particular research project, but to the extent that they succeed in this regard they also provide a distorted picture of the educational benefits of the typical non-DSP research subject's experience. It is also difficult to accept the idea that well-designed debriefing exercises will overcome the inherent differences in the educational potential of the research subject's actual experience of participation in a given research study. If the goal throughout is really supposed to be educational, it seems a more effective approach would be for faculty to involve their students in mock research activities specifically designed to demonstrate key features of research subject participation connected to the rest of the course's curricular content. In sum, the rationale for DSPs may be said to represent the institutionalization of the educational misconception. What is especially intriguing in this regard is the fact that the educational value of research subject participation in DSPs is seldom even assessed, and few if any rigorous research studies have been conducted comparing the educational effectiveness of research participation to the frequently utilized alternative educational options. Some educational institutions have taken steps to eliminate DSPs or impose additional oversight procedures to ensure that when and if they are permitted, they are closely scrutinized. For some, recruitment of students through broad-based appeals to the general public is considered preferable both ethically and scientifically, as a less selected population of subjects may enhance the generalizability of study results.

STUDENTS IN GRADUATE OR PROFESSIONAL TRAINING. Outside of DSPs, students sometimes participate in research studies related to their field of study, some of which focus on their regular education and training. These studies present challenges resembling those discussed above with regard to primary and secondary school practitioner researchers, with respect to the general issues of possible coercion, the educational misconception, and the inherent limits of confidentiality protections. What is different, however, is that the researcher/subject relationship has grown in some ways: The student research subject is now an adult, and the researcher is now someone whose authority over the student has taken on a different shade. For example, graduate or medical students may view the investigator as an important mentor and career influence, in addition to whatever control the investigator might possess over students' grades, recommendations, teaching or research assignments, and opportunities for postdoctoral work or residency programs. Even if the researcher wishes the students to view a decision to participate as a research subject as entirely voluntary, the students may see themselves as having no choice.

At the same time, academic faculty may view participation in research as an obligation students should accept as a function of their having chosen to pursue a profession in which research plays an integral part. Where faculty are doing research to evaluate the effectiveness of their educational practices, they may feel that students have an obligation to contribute to improving those practices, because the students are benefiting from lessons drawn from studying previous students' experiences (Dubois). At the same time, faculty may be conscious of the importance of providing role models of researchers who treat their subjects with the utmost respect, and must therefore solicit their voluntary consent (Henry and Wright). Hans Jonas argued that those persons who are most knowledgeable, committed, and autonomous should be the first to participate as research subjects, which presumably implies that graduate and medical students should be the first to volunteer for such studies, after the faculty themselves. This argument construes the idea of autonomy more broadly, in the sense that while the student may feel pressured to volunteer for a study at the given moment, the student has chosen to pursue a highly-rewarded profession in which research—with its incumbent risks and sacrifices for human subjects such as themselves—plays an important role. To the extent that a student's autonomy is limited by the personal and professional circumstances of their participation, Jonas's presumption may not be true.

Conclusion

Students' decisions to participate in research may be affected by various influences, incentives, rewards, or compensation, and yet the pressure of these factors does not always rise to the level of undue influence or coercion. Students occupy a wide range of locations along the spectrum of opportunities for participation in research, ranging from invitation to attraction to enticement to pressure to force. Some influences may be altered, while others are endemic to the student's natural condition. As long as investigators and institutions are cognizant of and responsive in the design and execution of their studies to the special situations that arise in research involving students, they can reduce the likelihood that additional social and regulatory limits to their work will be imposed. Unless society is willing to forego all research in which students are the research subjects, the challenges of enlisting students as research subjects under circumstances of mixed voluntariness will continue.

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SEE ALSO: *Informed Consent, Consent Issues In Human Research; Research Policy, Subject Selection; Military Personnel as Research Subjects; Minorities as Research Subjects; Prisoners as Research Subjects; Research, Unethical*

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SUICIDE

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Philosophical issues concerning suicide arise in a wide range of contemporary end-of-life dilemmas: the withdrawal or withholding of medical treatment; involuntary treatment; high-risk, experimental, and unconventional treatment; euthanasia, assistance, and physician assistance in suicide; requests for maximal treatment; and many others. Although suicide is often popularly understood in a narrower sense of active, pathological self-killing, traditionally abhorred, the underlying issue most broadly conceived concerns the role that individuals may play in bringing about their own deaths.

Two focal issues concerning suicide are evident in these broader dilemmas. First, should suicide be recognized as a right, and if so, under what conditions? On this first question rest the foundations for various applications of the "right to die," as well as a variety of other issues in high-risk and self-sacrificial behavior.

Second, what should the role of other persons be toward those intending suicide? On this second question rest practical, legal, and public-policy issues in suicide prevention and suicide assistance. Both focal issues concerning suicide raise larger questions about the nature of choices to die and the relevance of mental illness, about the role of the state, about conceptual issues in determining what actions are to be counted as suicide, about the role of religious belief concerning suicide, about the possibility of an autonomous choice of suicide, and about the moral status of suicide.

The Incidence of Suicide

The United States exhibits a rate of reported suicide—10.7 per 100,000 year (year 2000 figures)—that falls approximately midway between societies in which reported suicide rates are extremely low, such as the Islamic countries, and those in which reported rates are extremely high, for example, Hungary. In the United States, there are almost 30,000 reported suicides per year and twenty-five times that many reported attempts; it is the eleventh highest cause of death for the U.S. population as a whole, ahead of homicide, the fourteenth highest. This means that, as John L. McIntosh points out, more Americans kill themselves than are killed by others.

Suicide rates are approximately equivalent across socioeconomic groups. Suicide rates are four times higher for males than females, but attempted suicide rates are four times higher for females than males. Attempt rates for whites and blacks are equivalent; rates of death by suicide are twice as high for whites. Suicide is the third leading cause of death for fifteen- to twenty-four-year-olds. For white males, suicide rates increase with age, rising to a peak of 61.7 per 100,000 in the age range eighty-four to eighty-nine; for women, suicide rates peak in midlife and decline thereafter; and elderly black women have the lowest rate of all adult groups, with those eighty-five and above showing the lowest risk (0.04 per 100,000, a rate based on such a low number of deaths that it is considered unreliable). In the United States, suicide rates declined throughout the 1990s and early 2000s—possibly due, among other factors, to the increased availability of antidepressant medications. Nevertheless, the number of deaths remains high. On average, one person commits suicide in the United States every eighteen minutes.

There are no reliable estimates of the number of unreported suicides, particularly those in medical situations involving terminal illness, the very cases that raise the most pressing current ethical issues. Suicide statistics, including those just cited, primarily reflect suicide in the narrower sense of active, pathological self-killing, whereas deaths brought about by refusal of treatment, by self-sacrifice or voluntary martyrdom, by high-risk behavior, or by self-deliverance in terminal illness are rarely described or reported as suicides. Rates of physician-assisted suicide where legal are quite low: In the Netherlands, where both voluntary active euthanasia and physician-assisted suicide are legal, the former comprises approximately 2.4 percent of the total annual mortality and the latter approximately 0.2 percent, figures fairly constant over the sixteen-year period, 1985 to 2001, for which reliable data is available. In Oregon, where physician-assisted suicide has been legal since 1997 under Measure 16, the Oregon Death with Dignity Act, 125 patients used lethal prescriptions provided legally by their physicians during the first five years of the act, representing less than 0.1 percent of the total annual deaths in the state.

Scientific Models of Suicide

Contemporary scientific understandings of the nature of suicide, primarily in the narrower sense, tend to fall into three groups: the "medical" model; the "cry-for-help," "suicidal career," or "strategic" model; and the "sociogenic" model.

THE MEDICAL MODEL. This model, heavily influential throughout most of the twentieth century, has understood suicide in terms of *disease:* If suicide is not itself a disease, then it is the product of disease, usually mental illness. Suicide is understood as largely involuntary and nondeliberative, the outcome of factors over which the individual has little or no control; it is something that "happens" to the victim. Studies of the incidence of mental illness in suicide often tacitly appeal to this model by attempting to show that mental illness—usually depression, less frequently other mental disorders—is always or almost always present in suicide. This invites the inference that the mental illness or depression "caused" the suicide.

More recent work presupposing the medical model has focused on biological factors associated with suicide, exploring among other findings decreases of serotonin in spinal fluid; drug challenges with fenfluramine; twin studies and other avenues of detecting heritable genetic patterns in families with multiple suicides; and environmental and disease exposures during pregnancy. While work to date remains provisional and in any case establishes correlations rather than causes, it nevertheless points to biological factors that may play a role in suicide.

THE CRY-FOR-HELP MODEL. A second model, developed in the pioneering work of Edwin S. Shneidman and Norman L. Farberow in the 1950s, understands suicide as a communicative strategy: It is a cry for help, an attempt to seek aid in altering one's social environment. Thus it is primarily *dyadic,* making reference to some second person (or less frequently, an institution or other entity) central in the suicidal person's life. In this view, it is the suicidal gesture that is clinically central; the completed suicide is an attempt that is (often unintentionally) fatal. While the cry for help is manipulative in character, it is also often quite effective in mobilizing family, community, or medical resources to assist in helping change the circumstances of the attempter's life, at least temporarily. Later theorists have developed related models that also interpret suicide attempts as strategic: The concept of *suicidal careers* interprets an individual's repeated suicide threats and attempts as a method of negotiating the world, though—as for the American poet Sylvia Plath (1932–1963)—an attempt in such a "career" may prove fatal.

THE SOCIOGENIC MODEL. Originally developed by the French sociologist Émile Durkheim (1858–1917) in his landmark work *Suicide* (1897), the sociogenic model sees suicide as the product of social forces varying with the type of social organization within which the individual lives. "It is not mere metaphor," Durkheim wrote, "to say of each human society that it has a greater or lesser aptitude for suicide, … a collective inclination for the act, quite its own, and the source of all individual inclination, rather than their result" (p. 299). In societies in which individuals are very highly integrated into the society and their behavior is rigorously governed by social codes and customs, suicide tends to occur primarily when it is institutionalized and required by the society (as, for example, in the Hindu practice of *sati,* or voluntary widow-burning); this is termed *altruistic* suicide. In societies in which individuals are very loosely integrated into the society, suicide is *egoistic,* almost entirely self-referential. In still other societies, Durkheim claimed, individuals are neither over- nor underintegrated, but the society itself fails to provide adequate regulation of its members; this situation results in *anomic* suicide, typical of modern industrial society. In Western societies of this sort, institutionalized suicide has been extremely rare but not unknown, confining itself to highly structured situations: the sea captain who was expected to "go down with his ship" and the Prussian army officer who was expected to kill himself if he was unable to pay his gambling debts.

Like the medical model, the sociogenic model considers suicide to be "caused," but it identifies the causes as social forces rather than individual psychopathology. Like the cry-for-help model, the sociogenic model sees suicide as a responsive strategy, but the responses are not so much matters of individual communication as conformity to social structures and reaction to the social roles a society creates.

Prediction and Prevention

Two principal strategies are employed to recognize the prospective suicide *before* the attempt: the identification of verbal and behavioral clues and the description of social, psychological, and other variables associated with suicide. Suicide prevention includes alerting families, professionals (especially those likely to have contact with suicidal individuals, such as schoolteachers), and the public generally to the symptoms of an approaching suicide attempt. They are trained to recognize and take seriously both direct warnings (e.g., "I feel like killing myself") and indirect warnings (e.g., "I probably won't be seeing you anymore") and behavior (e.g., giving away one's favorite possessions). They are also encouraged to be especially sensitive to these symptoms in those at highest risk, especially in males, those who are older, live alone, are alcoholic, have negative interactions with important others, are isolated, have poor or rigid coping skills, are less willing to seek professional help, have low religiosity, and have a history of previous suicide attempts—the last of these being a particularly at-risk group. Prevention strategies take a vast range of forms, from the *befriending* techniques developed by the Samaritans in England and the crisis *hot lines* widely used in the United States to involuntary commitment to a mental institution. Prevention strategies also include *postvention,* or post-occurrence intervention, for the survivors—spouse, parents, children, or important others—of a person whose suicide attempt was fatal, because such survivors are themselves at much higher risk of suicide, especially during the first year following the death.

These models of suicide and the associated forms of prediction and prevention are ubiquitous in contemporary medical and psychiatric practice. Yet although suicide has been treated largely as a medical or psychiatric matter, the conceptual, epistemological, and ethical problems it raises have reemerged in two central contexts: that of right-to-die issues in terminal illness and that of political phenomena such as self-sacrifice and suicide terrorism.

Conceptual Issues

The term *suicide* carries extremely negative connotations. There is little agreement, however, on a formal definition. Some authors count all cases of voluntary, intentional self-killing as suicide; others include only cases in which the individual's primary intention is to end his or her life. Still others recognize that much of what is usually termed suicide neither is wholly voluntary nor involves a genuine intention to die, such as suicides associated with depression or other mental illness. Many writers exclude cases of self-inflicted death that, while voluntary and intentional, appear aimed to benefit others or to serve some purpose or principle—for instance, the Greek philosopher Socrates (c. 470–399 B.C.E.), who drank the hemlock; Captain Lawrence Oates (1880–1912), thean English explorer who, after falling ill during the return trip from an expedition to the South Pole, deliberately walked out into a blizzard to allow his fellow explorers to continue without him; or the Buddhist monk Thich Quang Duc, who immolated himself in the streets of Saigon in June 1963 to protest the Diem regime during the Vietnam war. These cases are usually not called suicide, but *self-sacrifice* or *martyrdom,* terms with strongly positive connotations.

However, attempts to differentiate these positive cases from negative ones often seem to reflect moral judgments, not genuine conceptual differences. Conceptual and linguistic framing of a practice plays a substantial role in social policies; for example, supporters of physician-assisted suicide often use the term *aid-in-dying* as well as earlier euphemisms such as *self-deliverance* to avoid the negative connotations of *suicide,* while opponents insist on the more negative term *suicide.* The term suicide is not used in Oregon's Death with Dignity Act to describe the practice it makes legal, and indeed the statute stipulates: "Actions taken in accordance with this Act shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law" (Section 3.14). In contrast, the U.S. Supreme Court cases *Washington v. Glucksberg* and *Vacco v. Quill* (decided jointly in 1997) expressly considered the issue as one involving "suicide." Similarly, Palestinian militants attacking Israeli civilians have been called *suicide bombers* by their targets and by the Western press, but they are called *martyrs* by their supporters and those who recruit them for this role.

Cases of death from self-caused accident, self-neglect, chronic self-destructive behavior, victim-precipitated homicide, high-risk adventure, refusal of lifesaving medical treatment, and self-administered euthanasia—all of which share many features with suicide but are not usually termed such—cause still further conceptual difficulty. Consequently, some authors claim that it is not possible to reach a rigorous formal definition of suicide, and prefer a *criterial* or operational approach to characterizing the term, noting its varied, shifting, and often inconsistent range of uses. Nevertheless, conceptual issues surrounding the definition of suicide are of considerable practical importance in policy formation, affecting, for instance, coroners' practices in identifying causes of death, insurance disclaimers, psychiatric protocols, religious prohibitions, codes of medical ethics, and laws prohibiting or permitting assistance in suicide.

Suicide in the Western Tradition

Much of the extremely diverse discussion of suicide in the history of Western thought has been directed to ethical issues. The Greek philosopher Plato (c. 428–c. 348 B.C.E.) acknowledged Athenian burial restrictions—the suicide was to be buried apart from other citizens, with the hand severed and buried separately—and in the *Phaedo,* he also reported the Pythagorean view that suicide is categorically wrong. But Plato also accepted suicide under various conditions, including shame, extreme distress, poverty, unavoidable misfortune, and "external compulsions" of the sort that had been imposed on his teacher Socrates by the Athenian court when it condemned him to drink the hemlock. In the *Republic* and the *Laws,* respectively, Plato obliquely insisted that the person suffering from chronic, incapacitating illness or uncontrollable criminal impulses ought to allow his life to end or cause it to do so. Plato's pupil, the Greek philosopher

Aristotle (384–322 B.C.E.) held more generally that suicide is wrong, claiming that it is "cowardly" and "treats the state unjustly." The Greek and Roman Stoics, in contrast, recommended suicide as the responsible, appropriate act of the wise man, not to be undertaken in emotional distress, but as an expression of principle, duty, or responsible control of the end of one's own life, as exemplified by Cato the Younger (95–46 B.C.E.), Lucretia (sixth century B.C.E.), and Seneca (c. 4 B.C.E.–65 C.E.).

Although Old Testament texts describe individual cases of suicide (Abimilech, Samson, Saul and his armor-bearer, Ahithophel, and Zimri), nowhere do they express general disapproval of suicide. The Greek-influenced Jewish general Josephus (c. 37–c. 100 C.E.), however, rejected it as an option for his defeated army, and clear prohibitions of suicide appear in Judaism by the time of the Talmud during the first several centuries C.E., often appealing to Genesis 9:5, "For your lifeblood I will demand satisfaction." The New Testament does not specifically condemn suicide, and mentions only one case: the self-hanging of Judas Iscariot after the betrayal of Jesus. There is evident disagreement among the early church fathers about the permissibility of suicide, especially in one specific circumstance: Eusebius of Caesarea (c. 260–c. 339), Ambrose (339–397), Jerome (c. 347–c. 419), and others all considered whether a virgin may kill herself in order to avoid violation.

While Christian values clearly include patience, endurance, hope, and submission to the sovereignty of God, values that militate against suicide, they also stress willingness to sacrifice one's life, especially in martyrdom, and absence of the fear of death. Some early Christians (e.g., the Circumcellions, a subsect of the rigorist Donatists) apparently practiced suicide as an act of religious zeal. Suicide committed immediately after confession and absolution, they believed, permitted earlier entrance to heaven. Rejecting such reasoning, Augustine (354–430) asserted that suicide violates the commandment "Thou shalt not kill" and is a greater sin than any that could be avoided by suicide. Whether he was simply clarifying earlier elements of Christian faith or articulating a new position remains a matter of contemporary dispute. In any case, it is clear that with this assertion the Christian opposition to suicide became unanimous and absolute.

This view of suicide as morally and religiously wrong intensified during the Christian Middle Ages. Thomas Aquinas (c. 1225–1274) argued that suicide is contrary to the natural law of self-preservation, injures the community, and usurps God's judgment "over the passage from this life to a more blessed one" (*Summa theologiae* 2a 2ae q64 a5). By the High Middle Ages the suicide of Judas, often viewed earlier as appropriate atonement for the betrayal of Jesus, was seen as a sin worse than the betrayal itself. Enlightenment writers began to question these views. The English statesman Thomas More (1478–1535) incorporated euthanatic suicide in his *Utopia* (1516). In his *Biathanatos* (1608, published posthumously in 1647), the English poet John Donne (1572–1631) treated suicide as morally praiseworthy when done for the glory of God—as he claimed was the case for Christ. The Scottish philosopher and historian David Hume (1711–1776) mocked the medieval arguments, justifying suicide on autonomist, consequentialist, and beneficent grounds.

Later thinkers such as the French writer Madame de Staël (Anne-Louise-Germaine, née Necker, the baroness Staël-Holstein, 1766–1817) and the German philosopher Arthur Schopenhauer (1788–1860) construed suicide as a matter of human right—although Mme. De Staë subsequently reversed her position. Throughout this period, other thinkers insisted that suicide was morally, legally, and religiously wrong: Among them, the English evangelist and founder of methodism John Wesley (1703–1791) said that suicide attempters should be hanged, and the English jurist William Blackstone (1723–1780) described suicide as an offense against both God and the King. The German philosopher Immanuel Kant (1724–1804) used the wrongness of suicide as a specimen of the moral conclusions the categorical imperative could demonstrate. In contrast, the Romantics tended to glorify suicide, and the German philosopher Friedrich Nietzsche (1844–1900) insisted that "suicide is man's right and privilege" (Nietzsche, p. 210).

Although religious moralists have continued to assert that divine commandment categorically prohibits suicide, that suicide repudiates God's gift of life, that suicide ruptures covenantal relationships with other persons, and that suicide defeats the believer's obligation to endure suffering in the image of Christ, the volatile discussion of the moral issues in suicide among more secular thinkers ended fairly abruptly at the close of the nineteenth century. This was due in part to Émile Durkheim's insistence (1897) that suicide is a function of social organization, and also to the views of psychological and psychiatric theorists, developing from the French physician Jean Esquirol (1772–1840) to the Austrian neurologist Sigmund Freud (1856–1939), that suicide is a product of mental illness. These new "scientific" views reinterpreted suicide as the product of involuntary conditions for which the individual could not be held morally responsible. The ethical issues, which presuppose choice, reemerged only in the later part of the twentieth century, stimulated primarily by discussions in bioethics of terminal illness and other dilemmas at the end of life.

Suicide and Martyrdom in Religious Traditions

The major monotheisms, Judaism, Christianity, and Islam, all repudiate suicide, though in each martyrdom is recognized and venerated. Judaism rejects suicide but venerates the suicides at Masada, where in May of the year 73 C.E. some 960 Jews trapped in a fortress built on a high rock plateau killed themselves rather than be taken prisoner by the Romans, and accepts *kiddush hashem,* self-destruction to avoid spiritual defilement. At least since the time of Augustine, Christianity has clearly rejected suicide but accepts and venerates martyrdom to avoid apostasy and to testify to one's faith. Islam also categorically prohibits suicide but at the same time defends and expects martyrdom to defend the faith. Yet whether the distinction between suicide and martyrdom falls in the same place for Judaism, Christianity, and Islam is not clear. Judaism appears to accept self-killing to avoid defilement or apostasy; Christianity teaches passive submission to death when the faith is threatened but also celebrates the voluntary embrace of death in such circumstances; some Islamic fundamentalists support the political use of *suicide bombing,* viewing it as consistent with Islam and its teachings of jihad, or *holy war,* though others view this as a corruption of Islamic doctrine. Thus while all three traditions revere those who die for the faith as martyrs and all three traditions formally repudiate suicide, at least by that name, the practices they accept may be quite different: Christians would not accept the mass suicide at Masada; Jews do not use the suicide-bombing techniques of their Islamic neighbors in Palestine; and Muslims do not extol the passive submission to death of the Christian martyrs, appealing on Koranic grounds to a more active self-sacrificial defense of the faith.

Non-Western Religious and Cultural Views of Suicide

Many other world religions hold the view that suicide is prima facie wrong, but that there are certain exceptions. Still others encourage or require suicide in specific circumstances. Known as *institutionalized suicide,* such practices have included the *sati* of a Hindu widow, who was expected to immolate herself on her husband's funeral pyre; the seppuku or hara-kiri (suicide by disembowelment) of traditional Japanese nobility out of loyalty to a leader or because of infractions of honor; and, in traditional cultures from South America to Africa to China, the apparently voluntary submission to sacrifice by a king's retainers at the time of his funeral in order to accompany him into the next world. Eskimo, Native American, and some traditional Japanese cultures have practiced voluntary abandonment of the elderly, a practice closely related to suicide, in which the elderly are left to die, with their consent, on ice floes, on mountaintops, or beside trails.

In addition, some religious cultures have held comparatively positive views of suicide, at least in certain circumstances. The Vikings recognized violent death, including suicide, as guaranteeing entrance to Valhalla (the central hall of the afterlife). Some Pacific Islands cultures regarded suicide as favorably as death in battle and preferable to death by other means. The Jains, and perhaps other groups within traditional Hinduism, honored deliberate self-starvation as the ultimate asceticism and also recognized religiously motivated suicide by throwing oneself off a cliff. On Mangareva, members of a traditional Pacific Islands culture also practiced suicide by throwing themselves from a cliff, but in this culture not only was the practice largely restricted to women, but a special location on the cliff was reserved for noble women and a different location assigned to commoners. The Maya held that a special place in heaven was reserved for those who killed themselves by hanging (though other methods of suicide were considered disgraceful), and they recognized a goddess of suicide, Ixtab. Many other pre-Columbian peoples in the western hemisphere engaged in apparently voluntary ritual self-sacrifice, notably the Aztec practice of heart sacrifice, which was generally characterized at least during some historical periods by enhanced status and social approval. The view that suicide is intrinsically and without exception wrong is associated most strongly with post-Augustinian Christianity of the medieval period, surviving into the present; this absolutist view is not by and large characteristic of other cultures.

Contemporary Ethical Issues

Is suicide *morally* wrong? Both historical and contemporary discussions in the Western tradition exhibit certain central features. Consequentialist arguments tend to focus on the damaging effects a person's suicide can have on family, friends, coworkers, or society as a whole. But, as a few earlier thinkers saw, such consequentialist views would also recommend or require suicide when the interests of the individual or others would be served by suicide. Deontological theorists in the Western tradition have tended to treat suicide as intrinsically wrong, but, except for Kant, are typically unable to produce support for such claims that is independent of religious assumptions. Contemporary ethical argument has focused on such issues as whether hedonic calculus of self-interest—weighing pleasures and pains, or benefits against harms—in which others are not affected, provides an adequate basis for an individual's choice about suicide; whether life has intrinsic value sufficient to preclude choices of suicide; and whether any ethical theory can show that it would be wrong, rather than merely imprudent, for the ordinary, nonsuicidal person, not driven by circumstances or acting on principle, to end her life.

Epistemological Issues

Closely tied to conceptual issues, the central epistemological issues raised by suicide involve the kinds of knowledge available to those who contemplate killing themselves. The issue of what, if anything, can be known to occur after death has, in the West, generally been regarded as a religious issue, answerable only as a matter of faith; few philosophical writers have discussed it directly, despite its clear relation to theory of mind. Some writers have argued that because we cannot have antecedent knowledge of what death involves, we cannot knowingly and voluntarily choose our own deaths; suicide is therefore always irrational. Others, rejecting this argument, instead attempt to establish conditions for the rationality of suicide. Others consider whether death is always an evil for the person involved, and whether death is appropriately conceptualized as the cessation of life. Still other writers examine psychological and situational constraints on decision making concerning suicide. For instance, the depressed, suicidal individual is described as seeing only a narrowed range of possible future outcomes in the current dilemma, the victim of a kind of *tunnel vision* constricted by depression. The possibility of preemptive suicide in the face of deteriorative mental conditions such as Alzheimer's disease is characterized as a problem of having to use the very mind that may already be deteriorating to decide whether to bear deterioration or die to avoid it.

Public-Policy Issues

It is often, though uncritically, assumed that if a person's suicide is *rational,* it ought not to be interfered with or prohibited. This assumption, however, raises policy issues about the role of the state and other institutions in the prevention of suicide.

RIGHTS AND THE PREVENTION OF SUICIDE. In the West, both church and state have historically assumed roles in the control of suicide. In most European countries, ecclesiastical and civil law imposed burial restrictions on the suicide as well as additional penalties, including forfeiture of property, on the suicide's family. European attitudes and legal sanctions concerning suicide were translated into colonial societies as well, for example in India, Africa, and various Pacific Islands. In England, suicide remained a felony until 1961, and in Canada until 1971. Suicide has been decriminalized in most of the United States and in England, primarily to facilitate psychiatric treatment of suicide attempters and to mitigate the impact on surviving family members; in most U.S. states, however, assisting another person's suicide is a violation of statutory law, case law, or recognized common law. In Germany assisting a suicide is not illegal, provided the person whose death it will be is competent and acting voluntarily; in the Netherlands, physician-assisted suicide is legal under the same guidelines as voluntary active euthanasia: In Switzerland, assisted suicide is legal if it is done without self-interest on the part of the assister; and in Belgium, physician-performed voluntary active euthanasia is legal but physician-assisted suicide is not. Ongoing ferment characterizes the legal status of physician-assisted suicide in many countries.

Building on Shneidman and Farberow's early work, suicide-prevention strategies have been enhanced by considerable advances in the epidemiological study of suicide, in the identification of risk factors, and in forms of clinical treatment. Suicide-prevention professionals welcome increased funding for education and prevention measures targeted at youth and other populations at high risk of suicide. Nevertheless, philosophers are increasingly alert to the more general theoretical issues these strategies raise, for example, the effect of high false-positive rates on the right to avoid unjustified coercion. Restrictions to prevent suicide—such as involuntary incarceration in a mental hospital or suicide precautions in an institutional setting—typically limit liberty, but because the predictive measures of suicide risk that are available are neither perfectly reliable nor perfectly sensitive, they identify some fraction of persons as potential suicides who would not in fact kill themselves and fail to identify others who actually will. There are two distinct issues here. First, how great an infringement of the liberty of those erroneously identified is to be permitted in the interests of preventing suicide by those correctly identified? Second and more generally, can restrictive measures for preventing suicide be justified at all, even for those who will actually go on to commit suicide? Civil rights theorists are generally disturbed by the first of these problems, libertarians by the second.

Although U.S. law does not prohibit suicide, suicide has not been recognized as a right. There has been considerable pressure from right-to-die groups in favor of recognizing a broad right to self-determination in terminal illness not only by refusal of life-prolonging treatment but also by bringing about one's own death. In the *Washington v. Glucksberg* and *Vacco v. Quill* cases, the U.S. Supreme Court ruled unanimously that there was no constitutional right to assisted suicide, though the Court's ruling did not prohibit states from establishing laws that would legalize it. Cases such as these, however, tend to conflate the notion of a negative right to assistance in suicide, which would prohibit interference when a willing physician wished to provide assistance to a patient, with the far more controversial notion of a positive right to assistance in suicide—something that would give patients a claim to be provided with help from physicians when they sought it.

Other rights issues raised by suicide include, for example, freedom of expression. When Hemlock Society president Derek Humphry's *Final Exit*—a book addressed to the terminally ill that provided explicit instructions on how to commit suicide, including lethal drug dosages—was published in the United States in 1991 and sold over half a million copies, its publication was protected on the grounds of freedom of expression; yet in several other countries, including France and Australia, *Final Exit* was banned. More recent controversy surrounds web sites that provide explicit how-to information about suicide, including how to do so using readily available materials, and internet chat rooms that encourage or dare visitors to kill themselves.

PHYSICIAN-ASSISTED SUICIDE. Although issues of the permissibility of suicide generally have been the focus of sustained historical discussion, contemporary public-policy debate tends to focus on a narrower, specific issue: that of physician-assisted suicide, usually coupled with the question of voluntary active euthanasia. There are two principal arguments advanced for the legalization of these practices. First, claims about autonomy appeal to a conception of individuals as entitled to control as much as possible the course of their own dying. To restrict the right to die to the mere right to refuse unwanted medical treatment and so be *allowed* to die, this argument holds, is an indefensible truncation of the more basic right to choose one's death in accordance with one's own values. Thus, advance directives, such as living wills and durable powers of attorney, "do not resuscitate" (DNR) orders, and other mechanisms for withholding or withdrawing treatment, are inadequate to protect fundamental rights. Second, arguments for the legalization of physician-assisted suicide, usually together with arguments for voluntary euthanasia, involve an appeal to what is variously understood as mercy or nonmaleficence. Because not all terminal pain can be controlled and because suffering encompasses an even broader, less controllable range than pain, it is argued, it is defensible for a person who is in irremediable pain or suffering to choose death if there is no other way to avoid it.

Two principal arguments form the basis of the opposition to legalization of these practices. The first is that killing (in both suicide and euthanasia) is simply morally wrong, and hence wrong for doctors to facilitate or perform. The second argument is that legalization would invite a "slippery slope" leading to involuntary killing. The slippery slope argument contends, among other things, that permitting assistance in suicide or the performance of euthanasia would make killing "too easy," so that doctors would turn to it for reasons of bias, greed, impatience, or frustration with a patient who was not doing well; that it would set a dangerous model for disturbed younger persons who were not terminally ill; and that, in a society marked by prejudice against the elderly, the disabled, racial minorities, and many others, and motivated by cost considerations in a system that does not guarantee equitable care, "choices" of death that were not really voluntary would be imposed on vulnerable persons. Suicide in these circumstances would become a matter of social expectation or imperative. The counterargument for legalization replies that more open attitudes toward suicide would reduce psychopathology by allowing more effective counseling, and that by bringing practices that have always gone on in secrecy out into the open—and hence under adequate control—legalization would provide the most substantial protection for genuine patient choice.

Data from the Netherlands, where physician-assisted suicide and voluntary active euthanasia have been legally tolerated since the mid-1980s and are now legal, and from Oregon, where physician-assisted suicide became legal in 1997, do not support claims about a slippery slope, though full legalization is comparatively recent in both. In both only a very small fraction of patients who die actually die with physician assistance. Most are patients with cancer: 75 percent in the Netherlands, 79 percent in Oregon. Even so, of patients with cancer, the vast majority of those who die in either the Netherlands or Oregon do not die with this form of assistance. There is no evidence of disparate impact on groups of patients understood as vulnerable—the elderly, the poor, people with disabilities or with developmental delays, and others, although prior to the development of the protease inhibitors, was high for people with AIDS. Pain has not been the central issue; rather, most patients who have elected physician assistance in dying have done so, according to family members, physicians, and hospice caregivers, to avoid deterioration and loss of control over their circumstances. In Oregon, for example, the most frequently reported concerns by patients who died in 2001 included loss of autonomy (94%), decreasing ability to participate in activities that make life enjoyable (76%), and loss of control of bodily functions (53%); inadequate pain control and the financial implications of treatment were mentioned by just 6 percent each.

Particularly relevant to public-policy discussions is the contention of some contemporary writers that suicide will become "the preferred way of death" because it allows control over the time, place, and circumstances of dying. Others claim that as pain control in terminal illness improves, interest in physician-assisted euthanatic suicide will disappear. These may seem to be mere predictive claims. But in the technologically developed nations, where the epidemiologic transition in causes of death now means that the majority of the population will not die of parasitic and infectious disease, as was the case in all societies until the middle of the nineteenth century and is still the case in many less developed nations, but will die of late-life degenerative diseases with prolonged downhill courses, these claims may seem to harbor quite different normative visions of the roles people may—and should—play in their own deaths. One now faces a death that is comparatively predictable and prolonged, often perceived as burdensome to oneself and to those one loves.

Several particularly contentious issues have been raised in view of these facts. One concerns the question of whether a person can have a "duty to die." Some theorists have argued that as the burdens and costs of terminal care increase, both to the patient and to the family, a person becomes obligated to end his life; other commentators find this claim repugnant, an example of the kind of thinking that would fuel a slide down the slippery slope. Resolution of this issue rests on whether an individual's preferences and personal sense of concern for and obligation to family or others can be disentangled from social expectations about costs and savings.

Another issue of growing philosophical concern is that of suicide in old age, for reasons of old age alone rather than illness that accompanies old age. Despite extensive discussion among the Stoics of this matter—they held it to be a reasonable choice—and despite the prospects of vastly extended life expectancies of people in advanced industrial societies, such matters as preemptive suicide to avoid the deterioration of old age have been very little discussed.

Nor has the issue of altruistic suicide, not only in order to spare healthcare costs or other burdens for family members or others, but also in situations such as political protest and military strategy, received adequate philosophical analysis. In situations in which individuals committing suicide believe themselves to be acting for the common good, even at extreme personal sacrifice, is suicide—though it might be labeled with such euphemisms as martyrdom or heroism—morally acceptable or even praiseworthy? Such issues will form the basis for some of the many ethical challenges concerning suicide to be faced in future years.

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SEE ALSO: *Aging and the Aged: Old Age; Autonomy; Death; Dementia; Emotions; Human Rights; Life, Quality of; Life Sustaining Treatment and Euthanasia; Medical Codes and Oaths; Medical Ethics, History of Europe; Mental Illness: Conceptions of Mental Illness; Mental Institutions, Commitment to; Natural Law; Pain and Suffering; Pastoral Care and Healthcare Chaplaincy*

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SURROGACY

SEE *Reproductive Technologies: VI. Contract Pregnancy*

SURROGATE DECISION-MAKING

• • •

It is well established in medical ethics, practice, and law that the informed consent of competent patients must be secured before treatment. However, patients frequently are unable to participate in decision making about their treatment because of the effects of the illness, treatment, or underlying condition. This is especially common when patients are critically ill or near death, but it can happen at any time in the course of treatment. More specifically, patients who cannot make their own decisions are those who have been found to be incompetent to make a particular treatment choice; the determination of competence sorts patients into those whose treatment choices must be respected even if others disagree with them and those for whom decision-making authority will be transferred to another person.

When someone else must make decisions for a patient, a possible alternative is for their physicians to do that; when decisions are routine and uncontroversial, this is often what happens. However, when decisions have significant consequences for the patient, it is common practice to seek a surrogate or proxy to take the patient's place in decision making with the patient's physician.

The practice of and requirement for informed consent with competent patients are based on two central moral values: self-determination and patient well-being. Self-determination is the interest of ordinary persons in making important decisions about their lives for themselves and according to their own values; informed consent respects patients' self-determination. Patients' well-being is served by informed consent because the consent process allows a patient to decide which alternative treatment, including the alternative of no treatment, will best serve his or her values and life plans; the practice of informed consent usually, though not always, results in decisions that serve the patient's well-being. These two values can support the practice of surrogate decision making when a patient is not able to take part in decision making. The surrogate can be the person the patient authorized or would authorize to decide for him or her and can reflect the patient's values and life plans.

This entry examines in more detail how surrogate decision making can serve a patient's self-determination and well-being by considering two central issues: Who should be selected to be a patient's surrogate? and By what standards should a surrogate make decisions about a patient's care? (Buchanan and Brock). The entry then briefly considers some controversies about surrogate decision-making.

Selection of a Surrogate

Who should be selected to be a patient's surrogate? If the goal is to serve a patient's self-determination when that patient is unable to take part in decision making, it is appropriate to select the person whom the patient wanted or would want to act as a surrogate. If the goal is to serve the patient's well-being, it is appropriate to select a person who will be well positioned to represent the patient's interests and values. Sometimes the patient will have authorized another individual explicitly to act as his or her surrogate through an advance directive. In most states in the United States a durable power of attorney for healthcare (DPAHC) allows a patient to legally designate a surrogate to make healthcare decisions for him or her in the case of the patient's incompetence. Many other countries also have procedures for designating a surrogate. Ethically, there is a strong presumption that the surrogate should be the person whom the patient selected.

Most patients who become incompetent, however, do not have an advance directive to select a surrogate. In that case the surrogate should be the person whom the patient would have wanted to serve as a surrogate. In most cases it will be clear who that is: either a close family member or a friend who cares about the patient and knows the patient's values and wishes (Brock). When it is clear who the patient would have wanted to be the surrogate, there is a strong presumption that that is who should be selected. In the absence of a DPAHC or guardianship, many states in the United States have statutes authorizing a family member to make healthcare decisions for an incompetent patient; these statutes often list the order of the family members in terms of their relationship to the patient who should be selected. This presumption that a close family member should be the surrogate when the patient has not chosen one explicitly is justified by the fact that a close family member is the person whom most patients would want to be the surrogate. A close family member also usually will be most concerned to secure what is best for the patient and usually will know the patient best and thus be in the best position to represent the patient's wishes and values in decision making.

In cases where it is clear that the patient would have wanted someone besides the closest family member to be the surrogate, however—for example, because of conflict with or estrangement from that family member—that other person should be selected. In other cases there may be conflict between family members over who should serve as the surrogate. In either case it often is possible to resolve the question of who should be surrogate informally with the healthcare team or within the family. If those attempts fail, the healthcare team can have the responsibility to utilize the courts to attempt to obtain an appropriate surrogate for the patient.

In some cases there is no appropriate person available and willing to serve as the patient's surrogate. This typically occurs when no family members or friends can be located, or located in time, to make the necessary decisions. Different healthcare institutions have different procedures and practices for these cases. Relatively routine and uncontroversial decisions often are made by the healthcare team. For more consequential or controversial decisions, such as the patient's resuscitation status or the withdrawing or withholding of life-sustaining treatment, practice varies. Some institutions allow such decisions to be made by the healthcare team after consultation with others, such as the chief of service or an ethics committee. Others go to court to have a legally authorized surrogate appointed for the patient. It is important that healthcare institutions have clear procedures to follow when patients lack a natural surrogate so that decision making is not paralyzed but can proceed appropriately.

Standards for Surrogate Decision Making

What standards should surrogates employ in making decisions for incompetent patients? As in the selection of a surrogate, the standards for surrogate decision making should support the values of patient self-determination and well-being that underlie all treatment decision making. Viewed from this perspective, there are three ordered principles to guide surrogate decision-making. They are ordered in the sense that the first should be applied when possible; if that cannot be done, the second should be used, and if the second cannot be applied, the third should be used. This ordering means that the three principles should be understood as applying in different circumstances rather than as competing for application in the same circumstances.

The first principle is the advance directives principle, according to which decisions should be made in accordance with the patient's advance directive when one exists with instructions that relate to the decision at hand. The advance directive might be either a so-called treatment directive such as a living will with specific instructions about treatment the patient does or does not want in specific circumstances (whereas advance directives typically are used to decline treatment, they also can be used to indicate what treatment the patient wants) or a DPAHC that names a surrogate but also includes instructions about the patient's treatment wishes for the surrogate. Despite great efforts at the end of the twentieth century to increase the use of advance directives, most patients do not have one when they are incompetent to make their own decisions. Moreover, the instructions in advance directives are often so vague—for example, "if I am terminally ill no extraordinary measures should be applied"—that it is unclear what their implications are for the specific treatment decision at hand. As a result there usually will not be an advance directive available that clearly and decisively states the patient's wishes regarding the treatment choice in question.

When the advance directives principle cannot be applied for these or other reasons, the substituted judgment principle should be used. This instructs the surrogate to attempt to make the decision the patient would have made if he or she had been competent in the circumstances that obtain. More informally, it tells the surrogate to use his or her knowledge of the patient and the patient's values, wishes, and concerns to try to determine what the patient would have wanted. Even in the absence of explicit instructions from the patient, a surrogate often will know the patient well enough to have considerable evidence about what the patient would have wanted. However, some caution is needed when there has not been a prior explicit discussion between the patient and the surrogate about treatment because a number of studies have shown that family members frequently are mistaken in their judgments about patients' wishes, and physicians tend to do even less well in predicting patients' wishes in the absence of explicit prior discussions (Seckler et al.).

One of the most important functions of the substituted judgment principle is to emphasize that surrogates' role is not to determine what they would want in the circumstances if they were the patient or what they want for the patient but what the patient would want for himself or herself. An important responsibility of healthcare providers in working with surrogates is to help them understand their appropriate role however much what they might want for themselves differs from what the patient would want.

When there is no surrogate available who knows the patient well or, more specifically, has knowledge of the patient bearing on the treatment choice at hand, the best interests principle should be employed. That principle instructs the surrogate to attempt to make the choice that best serves the patient's interests. In practice this generally entails making the choice that most reasonable persons would make in the circumstances. This standard is justified because in the cases in which it is used the surrogate does not have knowledge about how the patient might differ from most reasonable persons in respects that are relevant to the decision to be made.

In actual practice decision-making circumstances cannot be characterized as neatly as they have been in this discussion of these three principles. For example, sometimes an advance directive may give some, but not decisive, guidance, and so the surrogate must interpret it by using substituted judgment reasoning. In other cases, there may be no advance directive and a surrogate may have only incomplete knowledge of the patient's likely wishes; in this case substituted judgment reasoning must be supplemented by best interests reasoning to arrive at a treatment choice. The relative weight that should be given in these cases to advance directives versus substituted judgment reasoning or to substituted judgment versus best interests depends on the particular circumstances of the case and how decisive or indeterminate the prior principle is for the choice and thus to the extent to which the subordinate principle must be used to supplement it.

Controversies about Surrogate Decision Making

One of the main controversies in surrogate decision making concerns the degree of discretion surrogates should have in making decisions for incompetent patients. It is not possible to be precise about this and there will be disagreement in particular cases, but the standards for surrogate choice make it clear that surrogate discretion should not be unlimited. More specifically, surrogates should make decisions that are reasonably in accordance with the appropriate principle or standard for decision; "reasonable accord," however, does not mean that others, such as the healthcare providers, must always be convinced that a surrogate is making the best choice. The important point is that it is a mistake for healthcare providers to believe that they must do whatever the surrogate wants no matter how unreasonable that choice appears to be. The law reflects such limits as well; for example, DPAHCs typically do not give surrogates the authority to make choices that conflict with the patient's known wishes or fundamental interests.

A second controversy concerns conflicts between advance directives or substituted judgment standards and the best interests standard (Dworkin). Defenders of the best interests standard (Dresser) argue that an incompetent patient's prior wishes, especially when the patient is no longer aware of or identifies with them, should not be followed when they are in conflict with the current interests of the patient. An example would be a patient with pneumonia who needs antibiotics, is demented, and can no longer recognize friends or family members but enjoys his or her existence watching television and previously said that he or she would want no life-sustaining treatment in those circumstances. Here the patient's previous wishes expressed when the patient was competent appear to be in conflict with the patient's current interests. There is no consensus about how these conflicts should be resolved, although they are probably relatively uncommon.

A third controversy concerns whether and to what extent the interests of others justifiably can override the wishes or interests of the patient (Hardwig). Especially when patients are very near death, decisions about treatment may have little impact on their interests but a considerable impact on others, such as family members. Some have argued that in this case the standard patient-centered model for decision making should be set aside to recognize the needs and interests of family members.

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SEE ALSO: *Advance Directives and Advance Care Planning; Autonomy; Beneficence; Cancer, Ethical Issues Related to Diagnosis and Treatment; Care; Clinical Ethics: Clinical Ethics Consultation; Compassionate Love; Competence; Death; Dementia; Ethics: Normative Ethical Theories; Informed Consent; Life Sustaining Treatment and Euthanasia; Medical Futility; Mentally Disabled and Mentally Ill Persons; Palliative Care and Hospice; Pediatrics, Adolescents; Pediatrics, Intensive Care in; Right to Die: Policy and Law*

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SURVEILLANCE

SEE *Confidentiality*

SUSTAINABLE DEVELOPMENT

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The idea of sustainable development dominates late-twentieth-century discussions of environment and development policy. It is a key term in international treaties, covenants, and programs and is being written into the constitutions of nation-states. An immense literature has gathered around it (Marien). Even those who reject the term must define their views in reference to it. In spite of this influence, serious empirical, conceptual, and normative problems must be addressed if the term is to serve as a comprehensive framework for efforts to sustain the biosphere and advance human fulfillment, economic security, and social justice throughout the world.

The Appeal of Sustainable Development

If the peoples of the world are to cooperate in solving their economic, social, and environmental problems, they must share a common understanding of the relationships among these problems and a common vision of a sustainable and just future. The economic expansion that began in the West several centuries ago has spread to embrace the world, transforming all societies in its wake and creating a global economic system and attendant monoculture with powerful human and environmental impacts. Given the dominance of this system, there needs to be a comprehensive policy framework to guide it—even if the framework adopted is critical of the system itself and seeks to redirect or even dismantle it.

Sustainable development is an appealing candidate for this office. "The key element of sustainable development is the recognition that economic and environmental goals are inextricably linked" (National Commission on the Environment, p. 2). This premise, bolstered by empirical claims that poverty and environmental degradation feed one another and that conservation need not constrain development nor development result in environmental degradation, has obvious political advantages. It allows persons with conflicting positions in the environment-development debate to search for common ground without appearing to compromise their positions. New coalitions of nongovernmental organizations (NGOs) concerned for justice, population, environment, and development issues have formed under the flag of sustainable development. Business leaders have come forward to propose new business-to-business and business-to-government partnerships in the name of sustainable development (International Chamber of Commerce; Schmidheiny). In addition, sustainable development has broad moral appeal among those motivated by concern for present as well as future generations, since it purports to be the name for a process and a future state in which everyone and the environment as a whole will benefit.

"Sustainable" qualifies the idea of development. After World War II it was widely assumed that economic development would lead to greater freedom, justice, and security for the world's peoples. When environmental issues first appeared on the international agenda at the Stockholm Conference on the Human Environment in 1972, the debate was whether—and how—concerns for environment and equity could be reconciled with economic development. In succeeding years, as economic development strategies failed to close the gap between rich and poor, within or between nations, and studies showed growth in world population and consumption approaching Earth's biophysical limits, questions were raised about whether the theory of development could serve either human or environmental needs and whether it did not need to be modified to include ecological, political, social, cultural, and spiritual considerations.

By 1992, for most participants at the World Conference on Environment and Development (UNCED) held at Rio de Janeiro, these issues appeared settled. The principal agreement of the conference, *Agenda 21,* affirms that "integration of environment and development … will lead to the fulfillment of basic needs, improved living standards for all, better protected and managed ecosystems and a safer, more prosperous future. No nation can achieve this on its own; but together we can—in a global partnership for sustainable development" (United Nations, p. 15).

This entry analyzes why the concept of sustainable development occupies the center of thought on development and environment policy, how it is being defined, what criticisms are being raised about it, and what kind of work is needed if the concept truly is to meet the needs of the planet.

Sustainable development nicely expresses the progressive evolutionary worldview that emerged in the West in the late nineteenth century, with all the presumed objective support of the natural sciences, and the positive attitude toward social change often associated with it (Esteva). This progressivist ideology recognizes the problems posed by the interactions of population growth, resource use, and environmental degradation but is guardedly optimistic about the capacities of modern societies to solve those problems, given public understanding, technological and structural improvements in keeping with sound scientific research, and strong political leadership. As the Stockholm Declaration affirmed: "[T]he capability of man to improve the environment increases with each passing day" (Weston et al., p. 344).

The discourse of sustainable development thus occupies a middle-of-the-road position between those perspectives that take an uncritically optimistic attitude toward growth and technological change and those that predict the inevitability of global collapse. It also confirms the liberal insistence that the meaning of the goal of human development, fulfillment, or quality of life be stated in purely formal terms so that individuals and groups have the opportunity to define it for themselves (Kidd).

The Meaning of Sustainable Development

Mainstream thinking on sustainable development views it as a form of societal change that adds the objective or constraint of resource sustainability to the traditional development objective of meeting basic human needs (Lélé). "Mainstream thinking" refers to those ideological frameworks typical of international environmental agencies such as the United Nations Environment Programme (UNEP); international development agencies, including the World Bank; research organizations such as the International Institute for Environment and Development; and NGOs such as the Washington-based Global Tomorrow Coalition.

The concept of resource sustainability originated in the late nineteenth century in the context of renewable resources such as forests or fisheries, where it informed such ideas as *maximum sustainable yield.* When the language of *sustainable development* came into international usage with the publication by the International Union for the Conservation of Nature and Natural Resources (IUCN), UNEP, and the World Wildlife Fund (WWF) of the *World Conservation Strategy* in 1980, this original meaning was retained but broadened to include the maintenance of ecosystem *carrying capacity* and the management and conservation of all living resources as a necessary prerequisite to development. Thus a clear line of intellectual (and often institutional and professional) descent runs from Gifford Pinchot, the first director of the U.S. Forest Service, and other turn-of-the-century advocates of the *resource conservation ethic* in Europe and the United States, to contemporary mainstream thought on sustainable development. Pinchot's utilitarian notion that "conservation … stands for development … the use of natural resources … for the greatest number for the longest time" remains at the root of contemporary thinking on sustainable development (Pinchot, pp. 42–48).

It is possible to interpret *sustainable development* literally to mean sustaining indefinitely the process of economic growth, change, or development. But this viewpoint is not representative of the U.N. World Commission on Environment and Development, chaired by Gro Harlem Brundtland, prime minister of Norway, the group most responsible for marshaling the data, argument, and political influence necessary to put the term on the agenda of international debate. In the commission's view, although a new era of more efficient technological and economic growth is needed in order to break the link of poverty and environmental degradation, "ultimate limits [to usable resources] exist" and indefinite economic expansion is therefore impossible (World Commission on Environment and Development, pp. 8–9).

Nonetheless, like the goal of equity, the prerequisite of ecological sustainability is often either downplayed or presumed, as in the classic definition offered by the World Commission on Environment and Development: "Sustainable development is development that meets the needs of the present without compromising the ability of future generations to meet their own needs" (World Commission on Environment and Development, p. 43). Ecological sustainability is more likely to be mentioned in a list of *requirements* of sustainable development, such as those composed by the organizers of the Ottawa Conference on Conservation and Development in 1986 (Jacobs and Munro):

- integration of conservation and development
- satisfaction of basic human needs
- achievement of equity and social justice
- provision for social self-determination and cultural diversity
- maintenance of ecological integrity

Issues of Sustainable Development

For many critics, sustainable development lacks clarity of definition, including criteria for and examples of successful achievement (Yanarella and Levine). As early as 1984, UNEP Executive Director Mostafa K. Tolba lamented that sustainable development had become "an article of faith, a shibboleth; often used, but little explained" (Lélé, p. 607). A recent survey of the literature on sustainable development found that "case studies are surprisingly few and often hard to come by" (Slocombe et al.). It is notable that the second version of the *World Conservation Strategy, Caring for the Earth,* acknowledges the ambiguity of the term, and places its emphasis on "building a sustainable society" (IUCN, UNEP, WWF, 1991).

For other critics, the concept of sustainable development is all too clear and fundamentally mistaken. Negative critiques of sustainable development cluster around its (1) empirical accuracy; (2) idea of justice; (3) idea of sustainability; (4) economic assumptions; (5) view of science; and (6) metaphorical and spiritual assumptions.

EMPIRICAL ACCURACY. The empirical basis of sustainable development thinking is criticized both for its analysis of the problems of poverty and environmental degradation and for its proposed solutions to them. Thijs de la Court and Richard B. Norgaard (1988a), among others, argue that mainstream thinking typically ignores the two major factors responsible for both of these problems—the shift of local economies to production of exports for the world market and the adoption by traditional societies of the values of Western urban and capitalist society. Thus global free trade, the solution often offered by sustainable development proponents as the way to greater integration of the local community into the world economic system, will only intensify the problems, lending support to massive, hierarchically managed, capital-intensive industrial projects—dams, plantations, factories, urban settlements—that destroy the diversity and integrity of human communities and environments alike (Sachs). Nor will most of the other policies typically promoted in the name of sustainable development be of much help: more scientific data, more efficient technology, improved managerial capabilities, and more effective environmental education. Much more fundamental and difficult actions are necessary, such as community control of the economy, land reform, changes in cultural values, and reductions in the consumption of industrial commodities and in birthrates (Lélé).

SOCIAL JUSTICE. Most pronouncements on sustainable development hold that social justice, especially in the form of equity between wealthy and poor nations, is essential to the process. Critics contend that these ideas are seldom explicated in any detail, however. The issue of population stabilization is generally avoided, conflicting claims of intragenerational versus intergenerational equity are not addressed, and fundamental civil and political rights are seldom mentioned. In keeping with traditional development theory, there is abstract emphasis on meeting *basic human needs* and, in recent years, *participation of all stakeholders,* but it is seldom clear what these needs are, which ones should have priority, what kind of participation is required, or how sustainable development will result in greater justice or environmental protection.

These questions have become especially acute in the sphere of gender. One of the primary challenges to mainstream thinking on sustainable development has come from the international women's movement through organizations such as INSTRAW (United Nations International Research and Training Institute for the Advancement of Women) and ecofeminist theoretical perspectives, such as those of Vandana Shiva and Maria Mies (Braidotti et al.). Within the women's movement there is widespread recognition of the deep-seated patriarchal assumptions in development discourse and the connections between the destruction of nature and the exploitation of women and other marginal groups in the development process. Mainstream sustainable development theory does little to change this. *Agenda 21,* the blueprint for sustainable development adopted by the United Nations Conference on Environment and Development in 1992, retains a patriarchal orientation, evident in its failure to recognize the special role of "subdominants"—women, people of color, children, native and indigenous people—in each of its seven major themes (Warren). In order to address this problem, the Women's Environmental and Development Organization (WEDO) and other organizations have argued for the need for women to gain control over natural resources and the benefits that are derived from them and for recognition of women's special knowledge and skills in environmental care.

IDEA OF SUSTAINABILITY. Environmental ethicists and scientific ecologists are critical of the idea of sustainable development because of its reductionist approach to environmental values. Discussions of sustainable development typically assume that what needs to be sustained is human use, especially human agricultural use and industrial production. Yet instrumental value is only one of the many environmental values that need to be sustained in the complex interplay of human enjoyment, respect, use, and care of nature, and there is empirical evidence that single-minded pursuit of instrumental value through such policies, for example, as "maximum sustainable yield" seldom succeeds (Ludwig et al.). *Agenda 21* is criticized for its exclusive concentration on the need to sustain the environment for human use. Chapter 15, for example, argues that the primary reason for preserving biodiversity is that it provides a potential source of genetic materials for biotechnological development (Sagoff). This emphasis reflects a strong anthropocentric value orientation, explicit in Principle 1 of the Rio Declaration on Environment and Development: "Human beings are at the centre of concerns for sustainable development" (United Nations, p. 9).

In an unprecedented policy decision in 1991, the Ecological Society of America challenged the widely held assumption that what ought to be sustained is human use of the biosphere. It set the goal of a "sustainable biosphere" as its priority for research in ecology in the closing decade of the twentieth century, thus implying that the biosphere has value in and for itself and that above all else this is the value that must be sustained (Risser et al.).

Failure to recognize that nature has value of its own (as well as for the sake of humans) has serious practical consequences. Not only does it inhibit acceptance of the idea of sustainable development by many environmental and religious groups whose traditions embrace a more generous understanding of nature's values, but it eliminates consideration of those meanings of sustainability having to do with the way life nourishes life—with sustenance. Certain methods of subsistence agriculture, for example, built up over many generations, especially by women, simultaneously nourish human communities and the soil, yet fail to receive public recognition and support (Shiva).

ECONOMIC ASSUMPTIONS. Criticisms of the economic analysis and prescriptions of sustainable development thinking have been suggested above and may be summarized under two primary headings. First, and most generally, are those criticisms that find in the idea of sustainable development only another example of the triumph of *homo economicus* in modern society. There is a prevalent assumption that sustainable development is equivalent to sustainable *economic* development. Thus economists at the International Institute for Environment and Development argue in circular fashion that their "sustainability paradigm," a version of the "conventional economic paradigm, illustrated by utilitarian benefit-cost analysis," if modified to allow for the concept of intergenerational equity, is preferable to the "bioethics paradigm" that recognizes intrinsic values in nature, because, among other things, the latter "inhibits [economic] development" (Turner and Pearce, p. 2).

The second sort of criticism concentrates on the failure of sustainable development thinking to challenge the assumption that economic growth can break the link between poverty and environmental degradation. Although the Brundtland commission recognized "ultimate limits," it nonetheless recommended a five- to tenfold increase in global economic productivity to reduce poverty and provide the resources for environmental protection (World Commission on Environment and Development). Ecological economists such as Herman Daly point out the biophysical impossibility of such growth and the need to arrest, or even reduce, the total "throughput" or flow of matter-energy, from natural sources, through the human economy, and back to nature's sinks. They believe that a strict distinction should be made between *growth,* defined as "quantitative expansion in the scale of the physical dimensions of the economic system," which cannot be sustained indefinitely, and *development,* defined as the "qualitative change of a physically nongrowing economic system in dynamic equilibrium with the environment," which can be so sustained (Daly and Cobb, p. 71). In their view, limited progress can be made in arresting economic growth by enforcing accepted maxims of sound economics, for example, increased resource efficiency and environmental accounting to show how income is actually a drawdown of natural capital or stock resources. Such measures alone, however, will be insufficient without redistribution of wealth and income between nations and classes, as well as population stabilization.

VIEW OF SCIENCE. Mainstream sustainable development thinking is dominated by the policy languages of science, economics, and law. Typical of such discourse is the view that science can provide a value-neutral definition of sustainability acceptable to persons with widely differing value perspectives (Brooks). But critics point to hidden norms in scientific methodology that support the status quo and are inconsistent with the personal and political transformations needed for justice and care of Earth. Moreover, only a very narrow range of considerations can be scientifically determined, thereby effectively eliminating challenges to established value judgments. In addition, the use of *risk analysis* focuses on involuntary costs that ecological changes may impose on society rather than on what should be the most important concern: the altering of ecosystems that risk-free business-as-usual will effectuate (Sagoff). Donald Ludwig, Ray Hilborn, and Carl Walters (1993) argue that the history of resource exploitation teaches the necessity of action before scientific consensus is achieved and that while science can help recognize problems, it cannot provide solutions. They caution that spending money on more scientific research is often a way to avoid addressing problems of population growth and excessive use of resources.

METAPHORICAL AND SPIRITUAL ASSUMPTIONS. Some critics consider the concept of *development* a dangerous mystification of history and do not believe adding the adjective *sustainable* appreciably alters the difficulty. Biologically speaking, *development* means progress from earlier to later, or from simpler to more complex, stages in the growth of an organism. In post-World War II development discourse, it was used as a metaphor for the transition of traditional societies into modern industrial societies (leading to distinctions between "underdeveloped," "developing," and "developed" societies). Used in this way, the metaphor implies a step forward in a linear progression, a natural, organic flowering, rather than a deliberate, culturally specific invention. It also implies that the most modern nations, such as the United States, are the most civilized and therefore models to imitate. Adding *sustainable* to *development* only confirms these biological connotations and hence strengthens its potential to obscure differences among cultures and the drawbacks of modernization.

But more than a misplaced analogy is at issue. *Development* is a powerful secular religion, in the words of Peter Berger, "the focus of redemptive hopes and expectations" (Berger, p. 17). Viewed in these terms, *development* means more than an improvement in material living standards. Development as religion means that human fulfillment is to be found in activities that improve material living conditions, for oneself and for others. Development as religion is a messianic mission to bring the fruits of material progress to the world, and it is questionable whether the idea of *sustainable development* substantially changes this. To depart from the religion of development would require defining the ends of development in terms of qualitative, as well as quantitative, goods—goods such as truth, beauty, freedom, friendship, humility, simplicity. Not only are such moral and spiritual goods the most worthy ends of human life; they may be the only way to empower persons to reduce their consumption, limit their procreation, and live sustainable lives (Goulet, 1990).

The Future of Sustainable Development

Given the value placed upon unthrottled economic growth in industrial and nonindustrial societies alike, acceptance of the goal of sustainable development, even in a weak sense, is a remarkable and positive step (Marien). Moreover, acceptance of the idea of sustainable development in international circles and by the government, business, and NGO leadership of many nations, north and south, means that there now exists an opportunity for dialogue and new social compacts between diverse political constituencies. It is possible to argue, therefore, that the idea of sustainable development offers a realistic way of effecting a potentially radical transformation in global environment and development policy. The question is whether (1) these diverse constituencies can be engaged in a process of mutual inquiry, criticism, and discussion that will lead, step by step, toward improvements in the empirical, conceptual, and normative adequacy of the idea and in meaningful attempts to embody it in practice; and (2) an international political constituency, uniting mainstream and marginal groups and actors, can be mobilized to challenge the entrenched powers that will inevitably be threatened by changes in policy. There is also the question of whether these things can happen quickly enough, before disillusionment sets in and a fragile consensus is shattered. There are several ways of advancing this kind of agenda over the next decade. Empirical understanding of sustainable development will improve with a more issue-driven and democratically structured scientific approach that recognizes the uncertainty of facts, conflicts in values, and the urgency of decisions. Such an approach needs to be transdisciplinary and practically focused on the dynamics responsible for poverty, injustice, and environmental degradation and on how these dynamics may be changed without economic growth through resource depletion. It requires analyses of factors such as human motivation and ownership patterns, neglected in most studies to date. Studies of alternative development policies in the Indian state of Kerala present good examples (Franke and Chasin).

Empirical adequacy also will improve through initiatives such as those now underway to design quantitative "indicators" of sustainability (Trzyna), especially those indexes that can challenge, and eventually replace, the Gross National Product (GNP) as the measure of economic and social well-being. For example, Daly and Cobb (1989) propose an Index of Sustainable Economic Welfare that measures not only levels of consumption but also income distribution, natural resource depletion, and environmental damage. Macroeconomic criteria and indicators of sustainability have been proposed in areas such as population stability, greenhouse gases, soil degradation, and preservation of natural ecosystems (Ayres). Specific moral and material incentives to meet these criteria are also being developed (Goulet, 1989).

The conceptual and normative adequacy of the idea of sustainable development will improve as it is expanded to include the full range of moral and public policy criteria necessary to sustain the biosphere and advance human fulfillment, economic security, and social justice throughout the world (Corson). Such a redefinition of the goals of sustainable development will need to include (1) development conceived primarily as improvement in the quality of human life; (2) sustainability conceived as the sustainability of Earth's biosphere, with protection and restoration of ecosystems and biodiversity and sustainable use of renewable resources contributing to that end; (3) the transition to a steady-state global economy by reducing consumption among affluent classes while at the same time promoting economic growth in poor communities to meet basic human needs and provide the resources necessary for environmental protection; (4) redistribution of wealth and income between rich and poor nations; (5) population stabilization and eventual reduction to more optimal levels; (6) guarantees of basic human rights, including environmental rights, to all persons, with special attention to the empowerment of women and children; (7) new nondominating and nonreductionsitic ways of producing and transmitting knowledge of the environment and sustainable livelihood; and (8) freedom for local cultures, Western and non-Western, to pursue a variety of alternative visions and strategies of sustainable development.

The philosophy of sustainable development will also improve as discussion moves beyond the confines of economics and resource management into larger multidisciplinary and public arenas. Most mainstream thought on sustainable development has taken place without the benefit of philosophy, theology, the arts, or humanities and with only limited benefit from scientific ecology. Yet intellectual leaders in these fields, from diverse cultures and faiths throughout the world, have been trying to understand the meaning of just, participatory, and sustainable ways of life for several decades (Engel and Engel). Citizens also have substantial contributions to make to an enlarged understanding of sustainable development, as the peoples' alternative treaties signed at the NGO-led Global Forum at Rio de Janiero demonstrate (Rome et al.).

Nowhere is the challenge to mainstream sustainable development thinking more difficult—or more fateful—than in the area of comprehensive spiritual values and morals. In 1987 the U.N. Commission on Environment and Development concluded that "human survival and well-being could depend on success in elevating sustainable development to a global ethic" (World Commission on Environment and Development, p. 308). Faced with the prospect that the mainstream interpretation of sustainable development might well become a global ethic, critics argue for what they believe to be more adequate understandings of human nature and destiny, calling instead for "authentic development," "just, participatory ecodevelopment," or simply "good life." Sustainable development need not be anthropocentric or androcentric; it may be theocentric or coevolutionary (Norgaard, 1988b), a human activity that nourishes and perpetuates the historical fulfillment of the whole community of life on Earth.

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SEE ALSO: *Endangered Species and Biodiversity; Environmental Ethics; Environmental Health; Environmental Policy and Law; Population Ethics; Population Policies; Technology*

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Stephen G. Post
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TEAMS, HEALTHCARE

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A healthcare team is two or more health professionals (and, when appropriate, other lay or professional people) who apply their complementary professional skills to accomplish an agreed-upon goal. Coordinated, comprehensive patient care is the primary goal of most teams. Other goals may include education of health professionals, patients, or families; community outreach; advocacy; abuse prevention; family support; institutional planning; networking; and utilization review in hospitals. The team approach to patient care has been viewed as a means of building and maintaining staff morale, improving the status of a given profession (for example, nurses and allied health professionals may become team collaborators with the physician rather than working under the physician), or improving institutional efficiency.

Some teams are ongoing, such as a psychiatric care team, home visit team, ventilator patient care team, child development team, or rehabilitation team. Such teams may be responsible for following the person throughout the entire process of healthcare interventions, including diagnosis, goal setting and planning, implementation, evaluation, follow-up, and modification of goals for the patient. Other teams form around an event (for example, a disaster plan team or organ transplant team), or focus on a single function, such as discharge planning or the initiation of renal dialysis. Some teams are undisciplinary; others are multidisciplinary, and may include lay people.

Though taken for granted today, a team approach to healthcare has appeared only recently in many places where Western medicine is practiced. The development of team approaches in the United States reflects the history of that development in North America and Europe as well. In the first period, between World War I and World War II, a multiprofessional approach appeared that later developed into the team model. Major sources of impetus included the proliferation of medical specialties, an increase in expensive, complex technological interventions, and the ensuing challenge of providing a coordinated and comprehensive approach to patient care management. A second period of development occurred between the 1950s and the 1980s, when teamwork became the norm: healthcare became increasingly hospital-based, enabling a large corps of health professionals in one place to minister to the patient. In addition, new professional groups were generated in the belief that healthcare should be attentive to patients' social as well as physical well-being. The third period, which continues to the present, has focused on the appropriate goals and functions of the healthcare team and evaluation of the team's effectiveness (Brown).

Ethical issues regarding teams arise in four major areas: challenges arising from the team metaphor itself; the locus of authority for team decisions; the role of the patient as team member; and mechanisms for fostering morally supportable team decisions.

The Team Metaphor

It is generally agreed that the healthcare team idea and rhetoric arose from assumptions about sports teams and military teams (Nagi; Erde). This metaphor is not completely fitting because the healthcare team is not in competition with another team. However, it is fitting insofar as members experience their affiliation as entailing *team loyalty,* a moral obligation to other members and to the team itself. They may believe that they have voluntarily committed themselves to a type of social contract requiring a member not only to perform maximally but also to protect team secrets, thereby promoting a tendency for cover-ups or protection of weaker members. In the military team, obedience to and trust in the leader is an absolute.

A troubling ethical conflict arises when the member's moral obligation of faithfulness to other team members or "captain" does battle with moral obligations to the patient. This may manifest itself in questions of whether to cover up negligence or a serious mistake by some or all of the team. Overall, holding peers morally accountable for incompetence or unethical behavior may be made more difficult by the team ideal. Therefore, teams must foster rules that require and reward faithfulness to patient well-being, and balance and value of team membership with that of maintaining high ethical standards.

Feminist analyses of bureaucratic structures and bioethical issues highlight a related ethical challenge. The team metaphor entails assumptions about relationships, rules, and "plays" that often exclude women from full participation because their childhood and later socialization did not prepare them for this "game" and its insiders' rhetoric. Noteworthy is the sports or military team ethos of ignoring the personal characteristics of fellow team members (within limits), provided each person is technically well suited to carry out assigned functions. Many women find it almost impossible to function effectively with team members whom they judge as morally deplorable, no matter the latter's technical skills; for such women, the relationships among and integrity of team members is as important as the external goal (Harragan).

Sometimes a further breakdown of communication and effectiveness accrues because of the team leader's allegiance to scientific rigor and specificity at the expense of subjective attentiveness to caring. Since many team leaders are physicians, on multidisciplinary teams the problems may become interpreted as pointing to serious differences in orientation between physicians and other healthcare professionals (addressed in the next section). Whatever its cause, marginalization of some team members results in team dysfunction.

Locus of Authority for Decision Making

Roles involve ongoing features and conduct appropriate to a situation, and create expectations in the self and others regarding that conduct. Each role has an identity and boundaries, giving rise to the question of whose role carries the authority for team decision making (Rothberg). The challenge applies to both unidisciplinary and multidisciplinary teams but is highlighted in multidisciplinary ones, particularly those involving physicians and other health professionals. Traditionally the physician was the person in authority by virtue of his or her office. The team metaphor reinforces the nonmovable locus of authority vested in one who holds such office (for example, *captain*).

At the same time, the team metaphor created expectations of more equality among members based on competence to provide input. Each member becomes an authority on the basis of professional expertise instead of office, and should be in a position to provide leadership at such time as expertise indicates it. In ethical decisions regarding patient care, the question of authority must be viewed in terms of who should have the morally authoritative voice. Technical expertise does not automatically entail ethical expertise. In both types of decision-making situations, the locus of authority is movable.

Clarification of role identity and boundaries helps to create reasonable expectations and mitigate this type of conflict regarding locus of authority (and concomitant locus of accountability) regarding team decisions (Green). A further complication arises, however, because teams usually have several members. A critical question regarding such collective decision making is whether team decisions are the sum of individual members, with accountability allocated only to the individuals, or whether a team itself can be regarded as a moral agent (Pellegrino). Lively debate continues regarding this topic (Abramson; Newton; Green).

Sometimes teams have difficulty coming to consensus about the appropriate course of action. The moral responsibility of the team members is to assure that further role clarification, further attempts at consensus building, and other collective decision-making mechanisms are instrumental only to maximizing patient well-being (or any other appropriate goal of teamwork). Negotiation strategies must be built into the team process so that the authority of any one or several members, or even the team as a whole, does not govern at the cost of the competent, compassionate decision geared to the appropriate ends of that team's activities.

The Patient as Team Member

There is much discussion about whether and in what respect patients/clients and their families are members of healthcare teams. The doctrine of informed consent and its underlying legal and ethical underpinnings dictate that patients and families should have input into decisions affecting themselves and their loved ones. At the same time, much of the team's work proceeds without direct involvement of patients and families. Some have argued that a primary care orientation places the patient as focus and arbiter of the care, and that present team practices fall short of that essential condition (Smith and Churchill). Others argue that conceptually a primary care approach is consistent with the goals of good teamwork (Barnard).

Moral Education for Teams

The team ideal provides a widely used model for effective and efficient patient care. Ethical issues are an inherent part of clinical decision making. In preparation for facing ethical issues the team can (1) develop a common moral language for discussion of the issues; (2) engage in cognitive and practical training in how to articulate feelings about pertinent ethical issues; (3) clarify values to uncover key interests among team members; (4) participate in common experiences upon which to base workable policies; and (5) refine a decision-making method for the team to use (Thomasma).

It appears that team approaches to a wide variety of healthcare issues and events will continue to develop and grow. The emergence of ethics committees as a type of team approach focusing explicitly on ethical decisions should help further in these deliberations.

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TECHNOLOGY

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I. History of Medical Technology
II. Philosophy of Medical Technology

I. HISTORY OF MEDICAL TECHNOLOGY

Medical technologies are objects, directed by procedures, that are applied against the hazards of illness. The object is the tangible dimension of technology. The procedure is the focused and standardized plan that guides the use of the object according to defined purposes.

Some medical technologies are more object-embedded. In them the tangible portion is the principal functional component. The X ray, artificial kidney, and penicillin are examples. Others technologies are more procedure-embedded. Their main function is to organize facts, individuals, and/or other technologies. Examples are the medical record, hospital, and surgical procedures. Indeed, the common synonym for the surgical procedure, the operation, connotes actions that are related as parts in a series.

It is important to distinguish technologies from another medium through which actions are taken in medicine—techniques. Medical techniques are procedures mediated through the human senses rather than through objects. Examples are percussion, pulse-feeling, and psychoanalysis. This perspective on medical technology will be used in this entry.

Technology, Nature, and Ethics

The works of the Hippocratic corpus, a group of essays on medical theory and therapy written between the fifth and third centuries B.C.E., analyze the relation between nature and the agents of the medical art, from the viewpoints of effectiveness and ethics.

The ancient Greek concepts of health and illness were based on a theory postulating four humors or basic elements of the body: blood, phlegm, yellow bile, and black bile. In health, these were in a stable equilibrium. Illness occurred when one or more of these humors increased or decreased and thus changed their proportional relation. This change caused an instability of the equilibrium state synonymous with health, and the breakdown produced illness. Nature—the force that inclined the humors toward remaining in or returning to the proportional relations of the healthful state—was viewed as the most powerful agent of healing. The purpose of the medical art was to assist nature to reestablish the proportional relationship of health among the humors.

Works in the Hippocratic corpus cautioned physicians against misapplying medical means. Such behavior constituted an offense that could harm both the patient and the reputation of medicine. In the essay "The Art," the following observation is made:

> For in cases where we may have the mastery through the means afforded by a natural constitution or by an art, there we may be craftsmen, but nowhere else. Whenever therefore a man suffers from an ill which is too strong for the means at the disposal of medicine, he surely must not even expect that it can be overcome by medicine. (Hippocrates, 1923a, p. 203)

To exceed the rational limits of the means of medicine was to commit the sin of hubris.

The technology of Greek doctors was relatively simple. They used ointments, compresses, bandages, surgical instruments, simple and compound drugs, and bloodletting in moderation. They used the techniques of history taking, visual observation, and palpation to learn the circumstances of illness, and prescribed diets, bathing, and exercise to maintain health and combat illness.

The Greeks also recognized that the manner in which physicians dressed, approached the bedside, and discussed illness with a patient could influence their success at healing by producing help and avoiding harm, and thus had an ethical meaning. Accordingly, attention to the effects of the physician as a person on the patient as a person became a significant aspect of Greek medical practice. The physician is told "to have at his command a certain ready wit, as dourness is repulsive both to the healthy and the sick." When coming into the sickroom, doctors should consider their "manner of sitting, reserve, arrangement of dress, decisive utterance, brevity of speech." The doctor was to perform all duties "calmly and adroitly, concealing most things from the patient while you are attending him," lest such revelations cause the patient to take "a turn for the worse" (Hippocrates, 1923b, pp. 291–299).

The Hippocratic Greek physicians recognized that appropriate applications of technology required a searching analysis of its capabilities, of the ethical canons that should guide its use, and of the relation between technology and nature in treating patients. Consideration of these three factors was the significant contribution of Greek civilization to the use of medical technology.

Anatomy and Specialization

The content of the technologies used in medical practice did not change appreciably for two thousand years. Indeed, the Hippocratic works and other Greek texts, in Latin translations, formed the core of medical learning in Europe through the Middle Ages.

As the sixteenth century began, however, a growing interest in firsthand exploration of nature, and learning and questioning the authority of tradition, created what we call the Renaissance, generating a perspective that would eventually exert a profound influence on the development and use of technology in medicine. Although the study of the structural composition of the body through anatomic dissection was thwarted by cultural, social, and religious constraints against dismemberment, Renaissance scientific and artistic interest in the body's physical makeup overcame these restrictions and encouraged its exploration.

The leading figure in this movement was Andreas Vesalius, a physician and professor at Padua, who in 1543 published *De humani corporis fabrica.* In it the structure of the body was analyzed in detail and portrayed through illustrations that were far in advance of any previous work. Its illustrations, the work of a still unknown Renaissance artist, were startling in their beauty and detail. In contrast, the typical anatomical illustrations of the day were inaccurate and crude outlines, with organs drawn in more as symbols than as representations. Vesalius corrected over two hundred errors in the work that had been the standard, authoritative text in use for almost fifteen hundred years. Written by the Greek doctor Galen in the second century, it reflected typical restrictions on human dissection, for its content was based on animal dissection (mainly pigs and apes) extrapolated to human structure.

Vesalius' book, devoted to the normal anatomy of the body, fostered within medicine an interest in bodily structure, particularly in the changes it underwent when attacked by illness. During the next two hundred years, physicians examined bodies and wrote texts commenting on the pathological transformation of anatomic structure. These efforts were brought together in a 1761 text by the Italian physician Giovanni Battista Morgagni, *The Seats and Causes of Diseases Investigated by Anatomy.* The work's principal objective was to demonstrate that the symptoms of illness in the living were determined by the structural changes produced within the body by disease. Morgagni demonstrated this relation through a tripartite analysis of cases. Typically, he began by reporting on the clinical course of an illness experienced by a patient who eventually died. This was followed by the autopsy findings. Then came a synthetic commentary in which he connected clinical and autopsy results.

Morgagni asserted that through anatomic examination, particular diseases could be recognized by their telltale footprints on the landscape of the body. As the title of Morgagni's work suggests, the author believed that diseases had "seats" in the body, and that they were expressed through characteristic disruptions of the body's fabric in discernible sites. This perspective ran directly counter to that prevailing under the humoral theory of illness, dominant since Hippocratic times.

Anatomy, beginning in the sixteenth century, when it departed from this whole-body perspective, focused the doctor's vision on the search for sites in the body where a change in structure had occurred. The leading question for anatomists and the physicians who adopted their outlook was *Where is the disease?* This question and viewpoint paved the way for the modern specialization of medicine, beginning in the nineteenth century and undergirded by a new technology. It justified a retreat by the doctor from patients as individuals to aspects of their anatomy, giving rise to the practice of having different physicians for the eyes, heart, kidneys, and other organs and organ systems.

Technology and the Nineteenth Century

With the anatomic ideology firmly established, the nineteenth century became one of the great centuries for medicine, a time of significant advance and change fueled largely by technologic innovation.

The transformation of diagnosis by technology was one of the century's most important features. The symbol and initiator of this change was a simple instrument used to enhance the conduction of sound, the stethoscope. Its transforming effect was as much caused by the new relationship it generated between physicians and patients as by the new information it provided. Before the stethoscope, the evidence that physicians acquired about illness came mostly from two sources: the visual inspection of the motions and surface of the body, and the story told by the patient of the events, sensations, and feelings that accompanied the illness. It was this encounter with the life of the patient that was at once enlightening, troubling, and engaging for physicians.

The patient's story provided significant diagnostic evidence that often determined the doctor's judgment. But physicians expressed concern about the authenticity of this evidence, which usually could not be confirmed. Who could know if a patient really heard a buzzing in the ears? Diagnosis was prone to the distortions of memory and whim. For all of its evidentiary faults, however, the narrative of the patient's journey through illness connected the doctor with the life of the patient.

The stethoscope challenged the place of the narrative of illness. It was introduced into practice through 1819 treatise (*De l'auscultation médiate*), written by the inventor of the stethoscope, the French physician René Laennec. Laennec claimed that physicians who placed their ear to one end of the foot-long wooden tube that was the first stethoscope and the other end to the chest of a patient, would hear sounds generated by the heart and lungs indicative of health or disease within them. He demonstrated through autopsy evidence that a particular sound perceived in the chest corresponded to a particular lesion within its anatomic structure. He asserted that his technology enabled physicians to diagnose illness not only precisely but often without the help of other symptoms. Doctors need depend on no one else. They could be scientifically self-reliant. The findings of their own senses, extended by a simple instrument, were adequate to reach diagnostic judgments.

This technological advance reduced the significance of the patient's narrative. Why should physicians painstakingly acquire this story and its subjective and unverifiable verbal evidence, if they could use more objective sonic evidence they gathered themselves? With the stethoscope, physicians stepped back from the lives of patients. They began to engage patients through the anatomic and physiologic signs detected by their instruments.

Other simple technologies to extend the doctor's senses into the body, such as the ophthalmoscope (1850), the clinical thermometer (1867), and the sphygmomanometer (1896), were introduced during the nineteenth century. By the century's end physicians had become skillful diagnosticians, seekers of physical clues they used to deduce the source of their patients' troubles. The doctor's black bag contained the technologies to explore the body physically and to obtain evidence that greatly improved diagnostic accuracy. It was, in fact, through witnessing great skill in the analysis of physical evidence by one of his instructors, Joseph Bell, that a physician-in-training, Arthur Conan Doyle, was led to create the fictional character Sherlock Holmes.

Still, therapy remained limited. In the 1860 address to the Massachusetts Medical Society, Oliver Wendell Holmes, Harvard professor of anatomy, proclaimed: "I firmly believe that if the whole materia medica, *as now used,* could be sunk to the bottom of the sea, it would be all the better for mankind,—and all the worse for the fishes" (Holmes, p. 203).

The only major bright spot to emerge in the nineteenth century on the therapeutic side of medicine was in surgery. Radical change in the ability of surgeons to perform the dangerous and delicate work of cutting into the body occurred through two separate innovations, one introduced in 1846 and the other in 1867. At the beginning of the nineteenth century, pain had become so inseparably linked with surgical incision that several reports of an anesthetic effect produced by nitrous oxide and ether were disregarded by practitioners. Surgical pain was dealt with by efforts to shorten its presence. Techniques of rapid surgery were developed, with some surgeons capable of detaching a limb in minutes. The conclusive demonstration (in a surgical procedure for a tumor of the neck) at the Massachusetts General Hospital in 1846 of the ability to control operative pain through use of ether, was made by the American Dentist William Morton, who administered the ether. It ameliorated the trauma of surgery for patient and surgeon alike, but cutting into the cavity of the body still was limited by infection.

To control infection, insight was needed into the causal role of bacteria. Joseph Lister, a British surgeon, wrote a paper in 1867 in which he described eleven operations on compound fractures of the limbs in which nine patients recovered without amputation, one required it, and one died. These startling results were made possible by treating the operating space—wound, instruments, surgeon's hands, and air—with the antiseptic carbolic acid. In 1882, the German scientist Robert Koch published a paper that proved through rigorous experiments the causal link between the tubercle bacillus and tuberculosis—a disease that at the time was responsible for about one out of seven deaths in Europe. This essay established the pivotal role played by bacteria in infection. It not only gave further impetus to the practice of antiseptic surgery and liberated surgeons, no longer thwarted by pain or infection, to perform extensive operations within the body cavity. It also produced a new workshop for surgery and all of medicine—the hospital.

The Technologies of Twentieth-Century Medicine

The origins of the hospital reside in military hospitals put up by Roman soldiers on their routes of march, and hospices established early in the history of Christianity to care for the homeless, travelers, orphans, the hungry, and the sick. These multiple activities gradually became divided among separate institutions, one of which was the hospital. It flourished greatly through the medieval period but began a decline afterward, due to diminished church support of its activities.

By the nineteenth century the hospital's medical role was restricted. It was a place for those who could not afford either to call a physician or surgeon to the house for treatment or to employ servants to administer needed bedside care at home. There were two kinds of medicine: home care for the well-to-do and hospital care for the indigent. Hospitals were dangerous places. Infections could rage through them, killing large numbers of patients and making work there dangerous for staff. Hospitals were also feared for the moral dangers said to be posed to women and children by the rough patients they housed.

New technologies transformed the hospital medically and socially. Surgery could no longer be done on kitchen tables at home: it required an antiseptic environment, sterilized instruments, and a staff of skilled nurses for the aftercare of patients undergoing more extensive procedures than were possible in the past.

As the twentieth century dawned, diagnosis and therapy of nonsurgical disease could not be readily done in the home with technology carried in a doctor's bag. diagnostic technology now entered a new phase of development. The simple instruments to extend the senses of the physicians were being replaced by sensing machines too large and expensive to be housed anywhere but in hospitals.

This new technology automatically recorded the data of illness, leaving the reading of its results to the doctor. The X ray, discovered in 1895; the ward laboratory, with its microscopes and chemical tests of the body fluids, which came together as a hospital space in the early 1900s; and the electrocardiograph, introduced in 1906, all converted medical diagnosis from a personal act to a scientific event. The physician leaning over the bedside, at least physically connected to the patient through the stethoscope and similar technologies, became an increasingly anachronistic image as the twentieth century wore on. The physician holding an X ray up to light, studying it, was more in keeping with physicians' growing self-image as scientists. Where was the patient? There was less need for personal medical encounters; the best evidence available to medicine was increasingly not what the patient said, nor what the physician sensed, but what the pictorial or graphic image reported.

As it entered this new technologic phase, medicine required a location within which patients, the increasingly specialized medical staff, and technology could be brought together. The hospital became that place. Its success was dramatic. While there were about four hundred hospitals in the United States in 1875, by 1909 the number grew to over four thousand, and by 1929 surpassed six thousand. No longer shunned but sought by communities, the hospital became the workshop of medicine. By the mid-twentieth century not only patients and technology but also doctors' offices were placed in hospitals. Home care and the house call, no longer adequate as means to apply new medical knowledge, were disappearing as the hospital, perhaps the quintessential technology of the twentieth century to organize medical care, enfolded medicine.

Several other innovations critical to the functions of hospitals and medicine were in place by the mid-twentieth century. One—having integrative influence like the hospital—was the technology of organizing the data of medicine—the medical record. It was fundamentally reformed in the 1920s by the work of the American College of Surgeons (Reiser, 1991). In an era of growing specialization, not only among physicians but also among nurses and the technical experts needed to run the hospital and its machines (there were over two hundred separate healthcare specializations by the mid 1970s), communication was of great importance. How to learn what each had done? Through the record, which was the main agent of synthesis in medicine. In its pages the thoughts and actions of a diverse staff were recorded.

But for all its integrative significance, the medical record remains a problem. It shows the results of the information explosion. These data literally burst the confines of the chart. Hundred-page records abound. They contain the details of medical care, but their order often makes following the course of an illness, or locating a particular bit of information, difficult and frustrating. Innovations such as the unit record (having all hospital encounters of a patient recorded in a single place rather than dispersed through separate charts in each clinic); the problem-oriented record (ordering medical data problems—physical, psychologic, or social—rather than by data source, such as putting laboratory data in one place, X-ray data in another); and the computerized record have yet to solve the problem of what to do with the avalanche of technologic evidence.

Another critical innovation available by mid-century was antibiotics. The mass production of penicillin in 1944 (it had been discovered by Alexander Fleming in 1928) inaugurated the antibiotic era in medicine. Antibiotic drugs flowed from the laboratories of the pharmaceutical industry, finally breaking the hold of bacterial illness. Penicillin was called a wonder drug when it was introduced. Given the drug, a patient gravely ill with meningitis or pneumonia would be up and about and home in a week. Not only was it fast-acting and fully curative, but it was safe and cheap. It was commonly thought that penicillin would be the first innovation of a pharmaceutical revolution to produce not only antibacterial drugs but also drugs to deal as effectively with other human ailments. However, the symbol of medicine in the second half of the twentieth century would not be penicillin but a machine that made its debut in the mid-1950s.

The artificial respirator had a long history, dating back to the mid-nineteenth century, when rudimentary forerunners were fashioned to deal mainly with the respiratory crisis of drowning. A tank respirator introduced by Philip Drinker and Charles McKhann in 1929, which used negative-pressure techniques to secure respiration, became the "iron lung" that sustained victims of poliomyelitis. Its effectiveness was variable, and its use was complicated. But by the mid-1950s, using new machines based on positive-pressure technology, clinicians had a far better means of dealing with diseases and accidents that threatened lives through respiratory failure.

Initially, this machine was intended to assist critically ill persons by temporarily sustaining a vital physiologic function and giving them time to recover. For the first time in medical history, physicians acquired a technology that, allied to other advances in nursing, monitoring, and drug therapy, and all brought together by an integrative technique of care embodied in the intensive care unit (ICU), permitted the long-term sustenance of desperately ill people who had no chance of recovery. Now families and medical staff waited by ICU beds, where the main signs of life were not manifest in the expressions or movements of the patient but in the mechanical sounds, motions, and readouts of the new machinery of rescue.

Ethical Issues in Applying Medical Technologies

As families and medical staff assimilated the consequences of the life-support technology represented by the artificial respirator that could prolong dying or life without cognition, they reached out to the ethical traditions of religion, medicine, and society for help (Pius XII, pp. 501–504). Physicians particularly began to see that the ethical problems to be solved in these crises were as great as or greater than the technical problems of treatment. How to decide whether in a hopeless case to remove the technology that maintained the person's life? On what values should this judgment be based, and who should decide?

Other machines developed in this period posed a similar mix of ethical and technical issues. The artificial kidney was created as a device for acute, intermittent dialysis by Willem Kolff in The Netherlands in 1944. However, it was introduced as a clinically usable machine in the early 1960s in Seattle, Washington, by Belding Schribner. He added an arteriovenous shunt that allowed long-term access to it and made continuing hemodialysis possible. The limited number of machines and personnel to run them led to moral agonizing over developing criteria for selection. Someone had to choose which of the thousands of individuals in the United States having chronic renal failure and able to benefit from dialysis would gain access to a technology that could save their lives. Thirteen years after the machine's introduction, American society decided how to resolve this crisis. In 1973, U.S. congressional legislation provided funds to provide dialysis to all who required it.

Technologies such as the artificial kidney and the respirator have been criticized as offering expensive but partial solutions to fundamental problems of biologic breakdown. The American physician Lewis Thomas calls them "halfway technologies," because they represent only a partial (halfway) understanding of a biologic puzzle that, once solved, will do away with the expense and the disadvantages of such therapies (Thomas, p. 37).

The extraordinary and growing expense of the healthcare system that followed the development of such technologies may be reduced when biomedical research produces comprehensive biologic answers to problems such as organ failure. But in the twentieth century, we have acquired few such complete technologies. One group, already mentioned, is penicillin and other antibiotics, which offer total solutions, that also are inexpensive and rapidly acting, to the problems of bacterial infection. A second generic complete technology is the vaccine. Those invented to prevent smallpox (first introduced in the eighteenth century) and poliomyelitis (developed in the mid-1950s) have in the twentieth century eradicated the first disease and almost wholly contained the second.

The emerging field of genetic research promises fundamental solutions to a host of disorders, with the prospect of their early detection and correction. Finally, the growing ability to visualize the basic structures of the body through endoscopes and computer-driven imaging machines such as the MRI and PET scans provides diagnostic knowledge facilitating the use of therapeutic technologies that promise complete cures. Indeed, genetic and imaging technologies have taken the anatomic concept of illness to its ultimate terminus. To the question "Where is the disease?" the answer now can be "In this particular gene!"

Conclusion

Technologies, history shows, can be imperative: We may be impelled to use the capacities they provide us without adequate reflection on whether they will lead to the humane goals of medical care. The ancient Greeks understood this issue. They recognized that technologic means must be used in consonance with articulated, ethically informed ends. Their example remains worth following.

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SEE ALSO: *Artificial Hearts and Cardiac Assist Devices; Artificial Nutrition and Hydration; Cybernetics; Dialysis, Kidney; Deep Brain Stimulation; DNR; Electroconvulsive Therapy; Enhancement Uses of Medical Technology; Fertility Control: Medical Aspects; Genetic Testing and Screening; Life Sustaining Treatment and Euthanasia; Organ Transplants, Medical Overview; Pediatrics, Intensive Care in;*

Psychosurgery, Medical and Historical Aspects of; Reproductive Technologies; Tissue Banking and Transplantation, Ethical Issues in; Transhumanism and Posthumanism; Virtue and Character; and other *Technology* subentries

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II. PHILOSOPHY OF MEDICAL TECHNOLOGY

Philosophy of technology aspires to comprehensive reflection on the making and using of artifacts. Medicine is increasingly defined not just by the character of its human interactions (physician—patient relationships) or professional expertise (knowledge of illness and related therapies) or its end (health), but also by the type and character of its instruments (from stethoscope to high-tech imaging devices) and the construction of special human-artifact interactions (synthetic drugs, prosthetic devices). Indeed, the physician-patient relationship, medical knowledge, and the concept of health are all affected by technological change. There is even debate about whether the term *artifact* should include nonmaterial as well as material human constructions, in which case all of the above might well be interpreted as technologies. From either perspective, medicine and the issues of bioethics fall within the purview of the philosophy of technology.

Historical Development

Philosophy of technology as a distinct discipline originated with the publication of Ernst Kapp’s *Grundlinien einer Philosophie der Technik* (1877), the first book to be entitled a “philosophy of technology.” A left-wing Hegelian contemporary of Karl Marx, whose thought includes important analyses of human-machine systems, Kapp left Germany in the mid-1800s to become a pioneer and “hydrotherapist” on the central Texas frontier. Returning to Europe two decades later, he elaborated a general theory of technology as “organ projection”—from the hammer as extension of the fist to railway and telegraph as extensions of the circulatory and nervous systems—thereby promoting analysis of the philosophical-anthropological foundations of technology.

Another major formative figure was Friedrich Dessauer, whose *Philosophie der Technik* (1927) and *Streit um die Technik* (1956) reflect his experience as the inventor of deep penetration X-ray therapy. For Dessauer the philosophical core of technology is the act of invention, for which he sought to provide a Kantian analysis of transcendental preconditions. Dessauer’s argument that the fact inventions work shows how inventors depend on insight into a supernatural realm of “pre-established solutions” to technical problems raises basic epistemological and metaphysical issues.

José Ortega y Gasset and Martin Heidegger, two major philosophers of the twentieth century, also contributed texts dedicated to the theme of technology. Ortega's "Meditación de la técnica" (1939) presents technical activity as a means for realizing some supernatural human self-conception, and modern technology as generalized knowledge of how to create such means. Ortega thus pushes anthropological reflection to new depths. Heidegger's "Die Frage nach der Technik" (1954) argues that both traditional technics or craft and modern technology are forms of truth, revealing different aspects of Being. Modern technology in particular is a "challenging" and "setting-upon" that reveals Being as "resource"—that is, the world as a reservoir of materials subject to indefinite human manipulations. In this argument Heidegger likewise carries epistemological and metaphysical reflection well beyond Kantian terms.

Lewis Mumford, Jacques Ellul, Herbert Marcuse, Jürgen Habermas, and Michel Foucault have made further contributions to the development of philosophy of technology from the perspective of social theory. Mumford (1934) focuses attention on technological materials and processes as major elements in the historical development of modern civilization. Ellul (1954) argues that the pursuit of technical efficiency is the defining characteristic of the contemporary world, which constitutes a milieu distinct from the natural and social milieus that preceded it. For Ellul, just as the Hebrew-Christian tradition once demythologized the two earlier milieus, now it called upon to demythologize technology.

Marcuse (1964) and Habermas (1968) have debated the character of technology as ideology. Foucault (1988) views all technologies and sciences as masking power manipulations, and develops a special analysis of technologies as historical transformations and determinations of the self. Such ideas exercise continuing influence in debates over the extent to which technology is properly conceived as an autonomous determinant of human affairs (see Winner, 1986) or as a social construction (see Feenberg). Such debates in turn influence fundamental orientations with regard to practical questions about the assessment and control of technology that find expression in such applied fields as medical ethics, environmental ethics, engineering ethics, and computer ethics.

Ortega and Heidegger are leading figures in the Continental or phenomenological tradition in the philosophy of technology. Further analyses of phenomenological inspiration can be found in the work of Don Ihde (1979) on human-technics interactions and of Albert Borgmann (1984) on the political-cultural implications of contemporary technological formations.

A different, equally strong tradition in the philosophy of technology is constituted by Anglo-American analytic reflection on artificial intelligence (AI). Here questions center on the extent to which brains are computers and thinking processes can be modeled (see, e.g., Simon; Dreyfus). In contrast to the phenomenological tradition, the Anglo-American analysis of AI exhibits considerable interactions with biomedical theory of neurological processes and, to a lesser extent, with biomedical practice.

Theoretical Perspectives

Throughout its diverse strands, philosophy of technology, like philosophy generally, includes theoretical and practical issues, from epistemology and metaphysics to ethics and politics, all of which can helpfully inform bioethics. Comprehensive understanding nevertheless grows out of partial understandings. The making and using of artifacts involve not only the artifacts themselves but also technological knowledge, technological activity, and technological volition. Theoretical analyses can thus conveniently be described by referencing tendencies to interpret technology in one of four primary forms.

TECHNOLOGY AS OBJECT. The theory that identifies technology with particular artifacts, such as tools, machines, electronic devices, or consumer products, is the commonsense view. Initially it involves a classification of artifacts into different types, according to their own internal structures, different kinds of human engagement, impacts on the environment, or other factors. Mumford, for instance, distinguishes utilities (roads, electric power networks), tools (artifacts under immediate human power and guidance), machines (nonhuman power with immediate human guidance), and automatons (nonhuman power and no immediate human guidance).

Taking a different tack, Borgmann argues a distinction between things and devices. An example of a thing, in Borgmann's special sense, is a traditional fireplace, which engages a variety of human activities ranging from cutting wood to cooking food, functions in a clearly understandable manner, and is an explicit center of daily life. By contrast, a device, such as a heat pump, simply makes available some commodity (hot and cold air) by nonobvious processes and disappears into a background of quotidian activities. The device is a special instance of what Heidegger called a "resource."

Ihde, in a different but equally provocative manner, distinguishes embodiment and hermeneutic relations between humans and their instruments. Embodiment relations experience the world through instruments, as exemplified by eyeglasses, which disappear into and become an unconscious part of the experience of seeing. In hermeneutic relations, by contrast, the instrument itself—for instance, a camera—becomes part of the world with which one engages; a user consciously focuses on the operation and interpretation of this instrument. Both Borgmann's and Ihde's distinctions obviously provide frameworks within which to interpret the myriad tools and instruments of high-technology medicine.

TECHNOLOGY AS KNOWLEDGE. Etymologically, however, the word *technology* implies not objects but "knowledge of techne," or craft skill. Epistemological analyses of such knowledge distinguish between knowing how (intuitive skill) and knowing that (propositional knowledge). The transition from premodern technics to modern technology can thus be argued as defined by the development of propositional knowledge about techne through the unification of technics and science.

This theory of modern technology as applied science is particularly influential among scientists and engineers, and has been given detailed philosophical exposition by Mario Bunge (1967). For Bunge, modern technology develops when the rules of prescientific crafts, originally discovered by trial-and-error methods, are replaced by the "grounded rules" or technological theories. Technological theories can be formulated by applying either the content or the method of science to technical practices. The former application takes preexisting scientific knowledge (e.g., fluid dynamics) and adapts it under certain boundary conditions to formulate an engineering science (aerodynamics). The latter uses the methods of science to formulate distinctive engineering analyses of human-machine interactions, such as operations research and decision theory.

Medicine can readily be incorporated within such an epistemological analysis. Prior to the nineteenth century, most medical practice relied on rule-of-thumb experience. But twentieth-century medicine has involved the progressive grounding of medical practice in the sciences of anatomy and physiology as well as the development of such distinctive fields as epidemiology and biomedical engineering. Indeed, José Sanmartín (1987), for instance, analyzes genetic engineering exactly as an embedding of techniques in scientific theory.

TECHNOLOGY AS ACTIVITY. The transformation of some technics (such as medicine) into an applied science is not, however, simply an epistemic event. As Foucault (1963) argues, for example, modern medicine "is made possible as a form of knowledge" by the reorganization of hospitals and new kinds of medical practices. This emphasis on technology as activity or a complex of activities is characteristic of social theory. Ellul's "characterology of technique" and analysis of the central role played by the rational pursuit of technical efficiency in the economy, the state, and what he terms "human techniques" (ranging from education to medicine) is another case in point, as are the Marxist and neo-Marxist analyses of Marcuse, Habermas, and Andrew Feenberg.

The emphasis on technology as activity has roots in Max Weber's observation that there are techniques of every conceivable human activity—from artistic production and performance to mass manufacturing and bureaucratic organization—even education, politics, and religion. One classic problem for social theorists is to explain the character and limits of *technicalization*—that is, the movement from traditional societies, in which techniques are situated within and delimited by nontechnical values, to modern societies, in which techniques are increasingly evaluated solely in technical terms. In traditional societies, for example, animals can be eaten only if butchered in a ritually prescribed manner; in modern societies animal slaughter is largely subject to calculations of efficiency.

Efficiency can also be conceived in economic terms and applied at micro or macro levels. The former is typical of analyses internal to business corporations (including hospitals and clinics); the latter, of social assessments of technology. In regard to technology assessments especially, there arise questions of the limits of technicalization and possible alternative forms of technical institutions (see Feenberg), as well as of responsible agency and risk.

TECHNOLOGY AS VOLITION. A fourth element in the interrelationship of knowledge, object, and activity is that of volition. The human activity of making and using artifacts depends not only on knowledge but also on volition. Indeed, it can be argued that volition is even more important in this respect than knowledge, that is, that human action can be ignorant but not unwilled.

The philosophical analysis of volition distinguishes between volition in the weaker senses of wishing, hoping, longing, and desiring, and the stronger or more decisive intending and affirming. Volition in the second or stronger senses is constituted by self-reflective identification with some particular wish, hope, or desire that takes on the character of a project. Ortega, Mumford, and Frederick Ferré (1988) argue that technology is essentially a matter of volition in one or more of these senses. According to Ferré, for instance, technology is grounded in "the urge to live and to thrive." For Ortega, technology is based in the willed attempt at a worldly realization of some specific self-image. For Mumford, technology in a distinctive sense emerges when human beings subordinate their traditional polytechnical activities of craft, religious ritual, and poetry to the monotechnical pursuit of physical power—something that first happened about five thousand years ago in Egypt, with the construction of the pyramids by means of large, rigid, hierarchical social organizations that he terms "megamachines."

Defining technology in terms of volition makes possible the perception of broad historical continuities more than does a focus on the elements of knowledge or object or even activity. It is inherently more believable that the *will* to fly was coeval with human existence than that technical knowledge of how to fly, flying machines, or the human performance of flying or flying-like actions have existed from time immemorial. Such an approach once again has immediate implications for the interpretation of medicine. If medicine is interpreted primarily as grounded in volition, then it is inherently more believable that there exists a fundamental continuity between premodern and modern medicines.

Nevertheless, one of the most sustained critiques of modern medicine is precisely that as volition, it is fundamentally different from all previous kinds of medicine. Ivan Illich's *Medical Nemesis* (1976) argues that modern medicine arises from a basic "social commitment to provide all citizens with almost unlimited outputs." Indeed, the nemesis of rising iatrogenic disease is a direct result of "our contemporary hygienic hubris," which can be reversed only "through a recovery of the will to self-care." In the 1990s, however, Illich becomes critical of the idea of self-care when it serves as an ideological support for what has been termed "health fascism."

Practical Perspectives

Not theoretical analysis, however, but ethical and political concerns predominate in philosophy of technology. Ethics has from its beginnings in the West involved at least marginal considerations of technology. Aristotle's *Nicomachean Ethics,* for instance, in passing identifies *techne* as an intellectual virtue. More than two thousand years later Immanuel Kant distinguished moral and technical imperatives. But in line with such marginal attention, from Plato and Aristotle to the Renaissance, technology was widely accepted as properly subject to ethical constraints. From the Renaissance to the Enlightenment, by contrast, traditional restraints were effectively replaced with an ethical commitment to the unfettered pursuit of technology for what Francis Bacon called "the relief of man's estate." It is precisely this modern commitment, along with its subsequent questioning in response to a series of increasingly prominent problems, that frames the contemporary prominence of ethical issues in the philosophy of technology.

ALIENATION. Historically, the first problem of modern technology involved the industrial revolution and alienation. At the basis of modern technological making lies a belief that the world as it is given does not provide a suitable home for human beings; humanity must construct a home for itself. The problem is that human beings do not immediately find themselves at home in the worlds they technologically create. The resulting alienation is especially problematic to the extent that it is grounded in attempts to overcome alienation.

The two most extensive critiques of technological alienation are Romanticism and socialism. The Romantic critique, an early version of which appears in Jean-Jacques Rousseau's *Discourse on the Sciences and the Arts* (1750), focuses on how technology alienates the individual from feelings and sentiments, as manifested in relationships with nature, the past, or other human beings. This is caused, according to the Romantic argument, by a one-sided development of rationality. Romanticism thus perceives technology as an extension of reason and proposes to enclose it within a larger affective life.

By contrast, in the socialist critique of alienation, Marx, like Kapp, explicitly conceives technology as a human organ projection. Marx thus focuses on the separation of human beings from control over the tools and products of their labor, as manifested in an economy based on money and the "fetishism of commodities." In response, socialism argues for a comprehensive restructuring of society to promote worker control of the means of production.

In biomedical practice the use of technological instruments and rationalized systems of diagnosis raises the issue of alienation in the form of questions about the depersonalization of healthcare techniques and organizations. Responses can exhibit characteristically Romantic or socialist features. Exemplifying Romanticism are proposals to situate diagnostic techniques within a more humanistic framework, perhaps one of beautiful buildings and a pleasant environment. Exemplifying a socialist response might be arguments for the promotion of patient autonomy by granting patients more direct control over their own healthcare institutions.

WARFARE. A second ethical problem has centered on technology and war. There are two basic theories about the relationship between war and technology: First, technological weapons make war so horrible that it becomes unthinkable; rational self-interest leads to deterrence of their use. Second, human beings will always tend to miscalculate their self-interests and go to war; weapons production must therefore be limited, and a higher ideal of global human unity promoted.

Prior to World War I, naive versions of the first theory largely supported the pursuit of technology. The trauma of the war contributed to pessimistic criticisms of technological civilization and led to emphasis on the second theory. This pessimistic critique, coupled with idealist attempts at world government, failed to avoid World War II and a technological practice of genocide, the invention and use of the atomic bomb, and a subsequent Cold War spread of nuclear weapons. As a result, much more sophisticated versions of deterrence policy were developed in alliance with management and decision theories. Advanced technological weapons development projects also stimulated science and technology policy and management studies, while the practice of nuclear deterrence was subject to extended moral criticism. One of the more idealistic criticisms argues that human unity and peace, which in the past could remain as moral exhortations, have now become necessities, lest human beings obliterate themselves from the face of the planet. In this argument the rational self-interest of the first theory appears to merge with the idealism of the second.

Prospects for social and genetic engineering call forth similar arguments between pragmatic deterrence management and idealistic delimination. The progressive refinements of conditioning techniques and sophisticated drug therapies create behavior-control technologies of immense potential power. Developments in recombinant DNA technology and the Human Genome Project offer opportunities to extend this power to the biological creation of human life. As Sanmartín has pointed out, this attack on the vagaries of human nature can be seen as developing new technologies for the prevention of “social diseases” such as war.

TECHNOLOGY AND SOCIAL CHANGE. Concerns about the relatively specific issues of alienation and warfare have been complemented by more general analyses of the causal relations and patterns of interaction that obtain between technology and social change. Such analyses include bottom-up case studies of changes related to bureaucracy, urbanization, work (from mass production to automation to customized production), leisure and mobility, secularization, communications (from telephone and radio to television and computer), and medical technologies, as well as top-down theoretical reflections on the same dimensions of social life and on the social order as a whole. Within both approaches it is common to find descriptions of disorder between technology and society brought about by technological change along with arguments for addressing such disorder by means of some intellectual and/or volitional adaptations.

In the period between the two world wars, for instance, William F. Ogburn’s *Social Change* (1922) described a “cultural lag” between technological development and social adaptation across a variety of indicators, and argued for a more intelligent appropriation of technology. A decade later Henri Bergson’s *Two Sources of Morality and Religion* (1932) argued that the vices of industrial civilization as a whole could be corrected only by what he termed a “supplement of soul” that is at once ascetic (against luxuries) and charitable (for eliminating inequalities).

To stress the need for intellectual or rational adaptations is no doubt more characteristic of advanced industrial society, with its concomitant large-scale educational institutions and activities. The kind of piecemeal social engineering advocated by John Dewey and Karl Popper, and the many theories of economic rationality from Pareto efficiency to risk-benefit analysis, and of postindustrial organization from Daniel Bell to Habermas, likewise advocate effective increases in the rational control of modern technology. By contrast, a follower of Bergson such as Ellul argues that technology has become a kind of totalitarian milieu that requires comprehensive demythologizing. Others suggest the need for expansions of affective sensibility. Some theories of postmodern culture exhibit certain affinities with this approach.

With regard to increasing rationality, Kristin Shrader-Frechette (1991) has drawn an explicit parallel between the requirements of informed consent in the practice of medically risky procedures and the general societal adaptation to technological change. With regard to affective responses to technological change, the work of Illich is illustrative.

POLLUTION AND THE ENVIRONMENTAL CRISIS. Perhaps even more demanding of attention than warfare, and adding a new dimension to analyses of technological change, are problems associated with environmental pollution and global climate transformation. The environmental crisis has obvious and fundamental impacts on human health and safety, and thereby on biomedicine. Indeed, outside medical ethics, perhaps the single most intensively explored area of applied philosophy is that of environmental ethics.

Beyond intensified self-interest, environmental change has engendered the new science of ecology and extended ethical concern both temporally (for future generations) and ontologically (for nonhuman entities). As analyzed by Hans Jonas (1979), this extension is grounded in “the altered nature of human action” brought about by the “novel powers” of modern technology. Although all human life requires some technical activity, not until the advent of modern scientific technology did the technical power to create become so explosive as to be capable of fundamentally transforming nature and the future of the human condition. On the basis of this power there arises what Jonas terms an “imperative of responsibility” to “ensure a future.”

Jonas explicitly argues the application of this principle of responsibility in the field of bioethics. Applications might also be adumbrated for other discussions in environmental ethics, such as those that distinguish shallow versus deep ecology movements and argue the rights of nature understood as wilderness. Could one not, for instance, distinguish a shallow versus a deep bioethics? Would it not be possible to argue, against excessive medical intervention, a defense of wildness in biology?

ENGINEERING ETHICS. A second well-developed field of applied ethics with potential implications for the medical dimensions of bioethics is that of engineering ethics (see Martin and Schinzinger). Here a basic shift has taken place in the interpretation of the primary responsibility of the professional engineer—from loyalty to a company or client (patterned after the ethics of the medical and legal professions) to responsibility to public health, safety, and welfare. Could this shift, resting on a recognition of engineering as social experimentation, have implications for new understandings of professional medical obligation? Is it not the case that technological medicine is, as much as the treatment of individual patients, to some extent a social experiment? If so, then the engineering ethics defense of the rights and role of the whistle-blower might well have analogous applications in the biomedical field.

COMPUTERS AND INFORMATION TECHNOLOGY. A third well-developed area of applied ethics deals with computers. One defining book in this field was written by a computer scientist (see Weizenbaum) and based on Mumford's philosophical anthropology of the human as a polyvalent being for whom calculating is only a very small part of thinking and a limited dimension of technics. Key issues in the philosophical analysis of computers concern the degree to which human thinking can be modeled by computers and the extent to which human beings should properly rely on computer programs, especially in areas such as weapons. Subsequent development, as summarized by Deborah Johnson (1985), has emphasized issues of individual privacy and corporate security, the formulation of ethical codes for computer professionals, and liabilities for the malfunctioning of computer programs. The computerization of medical practice calls for the application of such reflection to many aspects of high-tech medical diagnosis and treatment.

DEVELOPMENT AND DIVERSITY. The ambiguities of technology in developing countries, together with reassessments of the impacts of advanced technological transformations in relation to women and ethnic minorities, especially in the United States and Europe, raise new issues regarding the abilities of scientific technology to accommodate true diversity. On the one side, there are questions of equity. In advanced technological countries, technological power and affluence are not equally shared between men and women and among different ethnic communities. Nor does there appear to be equality of opportunity among advanced and developing countries. On the other side, technological development tends to set up national and international economic orders that homogenize personal and world cultures. Distinctions among markets and ways of life are subsumed within the financial structures of transnational corporations and global communications systems. This paradox of inequity and homogenization poses a fundamental challenge to both reflection and action.

Attempts to address this challenge can be found in the alternative technology movement, arguments regarding the ethics and politics of development, and in diverse feminist contributions to the philosophy of technology (as collected, for instance, in Rothschild). Feminist critiques of technology, for instance, emphasize both the need for equity and the threats of homogenization. Technologies of the workplace are to a large extent sexually differentiated; those of the home are designed and used in ways that confirm masculine and feminine roles. But technological culture creates images of androgynous liberation while medical procedures diminish the experiences of gendered bodies. In the face of this paradox, what some feminists argue is the need for a new theory and practice of technology itself, a truly alternative technology, one that transforms both its masculine biases and its characteristically modern commitments. The ideals and pursuit of alternative medicines can be interpreted as concrete attempts to achieve such a goal.

Conclusion

Successive technological problems have provoked a series of ethical analyses and moral responses. Reflections on these problems and their emerging responses, because they have been focused on a particular technology, have tended to remain isolated from each other and untested by generalization. Philosophies of technology that have attempted to bridge such particularities, and that include a substantial role for bioethics, can be found in the work of Jonas, Sanmartín, Gilbert Hottois (1990), and Friedrich Rapp (1990).

Complementing such work, problems addressed by the varied discussions of practice have been approached from within a variety of ethical frameworks, among which are natural-law theory, deontologism, and consequentialism. With natural-law theory, one tends to assess technological change in terms of its harmony with some given lawful order perceived in nature. With deontological theory the emphasis is on evaluating the rightfulness and wrongfulness of technological change in accord with some inner criteria of the action. With consequentialism there is an effort to look to the goodness or badness of future results that flow from some particular technology. Each such ethical framework can exhibit selective affinities with different basic theoretical conceptions of technology.

Environmental ethics, for instance, tends to be distinguished by criticisms of technologies that do not harmonize with preexisting natural order. The emphasis here is easily placed on human activity, with nonhuman realities taking on special moral significance. Computer ethics, by contrast, tends to put forth deontological principles about the wrongness, for instance, of the invasion of privacy. Such an ethics emphasizes human intention or volition with respect to technology. Finally, technology policy studies are likely to stress the evaluation of technologies in terms of results, and thus to call attention to the physical consequences of technological decisions. Here the issue of risk becomes a special challenge to the accepted cost-benefit calculus typical of consequentialist analysis.

The suggestive character of such relationships points toward the need for a more systematic pursuit of the philosophy of technology in ways that integrate epistemological, metaphysical, ethical, and political analyses. They also indicate the opportunities for more extended interactions between general philosophies of technology and the issues of biomedical ethics, interactions that have the potential for deepening and increasing the fruitfulness of both.

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SEE ALSO: *Human Dignity; Human Nature; Medicine, Philosophy of; Natural Law; Posthumanism and Transhumanism; Virtue and Character;* and other *Technology* subentries

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TISSUE BANKING AND TRANSPLANTATION, ETHICAL ISSUES IN

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Although the transplantation of solid organs such as kidneys and hearts is familiar to the general public, knowledge about transplants of tissues such as bone, skin, veins, and heart valves is only beginning to be disseminated broadly. In the first decade of the twenty-first century the tissue transplant industry grew rapidly as tissue transplantation became a standard treatment option for thousands of patients. Spurred by technological developments and new clinical applications, the transplantation of human tissue grew from a $20 million industry in the early 1990s to one that was approaching $1 billion. In 1994 an estimated 6,000 persons were tissue donors upon death; by 1999 that number had grown to 20,000, more than tripling.

The great majority of cadaveric organs come from brain-dead, heart-beating donors who are maintained on ventilators, of whom there are an estimated 10,000 to 20,000 each year. The pool of potential tissue donors is in the hundreds of thousands because tissue can be retrieved up to 24 hours after death, assuming that the donor is medically suitable and meets generally applied age criteria. With tissue from one donor going to as many as 50 to 100 recipients, the number of tissue transplants dwarfs that of organ transplants. It is estimated that there were more than 850,000 tissue transplants in 2002. The immunological properties of most tissue are reduced greatly or eliminated in the processing of tissue. Therefore, unlike recipients of solid organs, tissue recipients are not required to take antirejection drugs for the rest of their lives.

With this growth in transplantation have come changes in organization, financing, and regulation, and those changes have led to unique ethical concerns. Those concerns arise in great measure from the stark contrast between the selfless gift of human tissue by donor families and the commercial forces at play as tissue passes down a complex chain of distribution from donor to recipients.

This entry describes the history, organization, technological developments, clinical applications, and regulation of the tissue industry and then dicusses the ethical issues that have emerged. It is concerned solely with the transplantation of tissues that come as gifts from families whose members have died recently. Other human tissues also may be used for medical and research purposes, including gametes (sperm and eggs), tissue discarded during surgery, blood and blood products, and cell lines grown in laboratories. The collection, distribution, financial implications, regulation, and ethical issues raised by those tissues are different from those which apply to tissues transplanted from newly dead donors to recipients.

History

Although many human tissues can be transplanted, including corneas, heart valves, veins, and skin, the most common type of transplant by far involves musculoskeletal tissue. Legend has it that Saints Cosmos and Damian performed the first transplant (a leg) in 287 C.E., but the first documented successful transplantation of musculoskeletal tissue was performed by the Scottish surgeon William Macewan in 1881. In 1908 the U.S. surgeon Eric Lexer reported transplanting an entire knee joint. Although Inclan established a surgical bone bank (storing bone from living patients) in Cuba in 1942, the U.S. Navy Tissue Bank in Bethesda, Maryland, established in 1949, was the first modern tissue bank. The Navy Tissue Bank recovered and preserved tissues to treat injured servicemen and servicewomen and advanced the science of tissue banking through research programs.

Tissue banks have always attempted to provide tissues needed by surgeons in the form in which they can be used best. The organization and operation of tissue banks have changed in response to changes in practice and demand. In the 1960s and 1970s many hospitals maintained their own surgical discard bone banks, storing primarily femoral heads that were removed during hip replacement surgery. Advances in orthopedic surgery, especially the treatment of primary large bone (e.g., femur, humerus) cancers by replacing entire bones with those obtained from cadavers, increased the need for more sophisticated tissue banking. In the 1980s, local tissue banks began to proliferate and a few regional tissue banks were established. Over time banks began to distribute outside their traditional service areas. Currently, many U.S.

tissue banks have allocation systems that return high-demand tissue to the area that provided the donation and distribute other tissue throughout the country. Some tissue banks distribute tissue to other countries.

Clinical and Organizational Developments

As the proportion of older patients in the United States has grown, there has been a dramatic increase in the types of tissues used for joint replacement surgery, which often requires transplanted bone in combination with a metallic prosthesis. There also has been a major increase in spinal fusion surgery. Some reports estimate that more than 200,000 patients in the United States have received cadaveric bone for spinal surgery. Enhanced techniques for limb salvage surgery in cancer patients have increased the demand for large tissue grafts. Sports medicine uses increasing amounts of *soft tissues,* primarily patellar and Achilles tendons, to repair damaged knee ligaments.

The 1990s saw the development of proprietary processing technologies, patented tissue configurations, and advanced processing systems that result in tissue grafts with very specific dimensions and shapes designed by biomechanical engineers that are used primarily in spinal fusion surgery and sports medicine. These and other developments have resulted in the need to hire new and different kinds of personnel, the move by tissue banks to affiliate with traditional competitors to gain access to new technologies, the elimination of smaller tissue banks, and the consolidation of tissue banks. They also have facilitated the entry into the field of for-profit companies. In 1992 Grafton® demineralized bone matrix (DBM) was introduced by the for-profit company Osteotech. Grafton® and similar DBM products are made from demineralized cortical bone combined with various types of carriers that are designed to function as defect fillers or as adjuncts to traditional bone-grafting techniques to promote bone healing. This type of tissue originally was designed for use in dental and periodontic applications but now is being used broadly in orthopedics and neurosurgery. By 2000 at least five other DBM products were on the market, usually codeveloped and promoted by a nonprofit tissue bank and a for-profit device partner.

Another development that has spawned controversy has been the use of tissue for enhancement purposes. Deep layers of skin can be processed into an acellular form that can be used by plastic surgeons to reconstruct deep dermal defects and scars as well as to smooth out wrinkles and temporarily “puff up” lips. Despite the debate that this use of donated tissue has generated, the industry reports that this type of surgery accounts for only a minuscule proportion of tissue transplants.

By the 1990s larger tissue banks, most of which are nonprofit organizations, were moving toward a more traditional medical device–pharmaceutical sales and marketing system, using professionally trained sales representatives or agents to promote their tissue and services, developing advertisements and brochures, and implementing controversial market-driven practices such as consignment, discounting, and bundling. Nonprofit tissue banks also have entered into relationships with orthopedic and medical device companies, sometimes allowing a device company to process, package, market, and sell the tissue. These activities and relationships have blurred the line between an altruisitic gift and the distribution of a medical device and created ethical challenges relating to the handling of the gift. In 1996 the American Association of Tissue Banks (AATB) adopted a set of principles intended to provide guidance in the growing commercialization of tissue, Ethical Guidelines for Commercial Advertising and Activities.

Regulation and Safety

Although tissue safety is not the only medical and ethical issue in which regulation may come into play, it is a crucial one. The avoidance of potential infection has always been of paramount importance. This is not a simple task because transplant tissue is removed from a dead body that may have been exposed to bacteria, viruses, and other pathogens before death or during the decomposition process. Until the late 1980s processing techniques primarily entailed sterilization, which was felt by many to be mandatory despite concerns that sterilization techniques damage the biological and/or biomechanical properties of tissue.

In the late 1980s the construction of pharmaceutical-grade processing facilities allowed *aseptic processing,* which eliminated the need for sterilization of tissues while maintaining the biomechanical and biological properties of tissue. *Clean room* technology provides an environment with 10 to 100 microorganisms per cubic foot of air. In comparison, a standard operating room, normally the “cleanest” place any patient will enter, provides an environment with 1,000 to 10,000 microorganisms per cubic foot. As tissue transplantation becomes an increasingly integral part of modern medical treatment, processors must strike a balance between the goals of maximal tissue safety and viability.

Regulation of organ transplantation began in the mid-1980s with the passage of the National Organ Transplantation Act and other legislation that initiated federal influence on and regulation of organ procurement and transplantation policy and practice. A national Organ Procurement and Transplantation Network (OPTN) was created at government expense to set organ transplantation policy and gather data on organ transplantation events. The transplant community formed the United Network of Organ Sharing (UNOS), which obtained the OPTN contract. None of this authority, however, has been extended to tissue transplant practices. In addition, organ procurement organizations (OPOs) were given the authority to operate within a designated territory by the Health Care Financing Administration (HCFA, now the Centers for Medicare and Medicaid Services, or CMS), which also provided for financial reimbursement for the costs associated with kidney transplantation. Tissue banks, in contrast, were not and still are not compensated directly by the federal government for their operations, and there are no governmental regulations or guidelines that govern the organization of tissue banks.

Despite their safety risks, tissue banks were subject to very little federal regulation until the 1990s. In 1976 the AATB was founded as scientific nonprofit peer group organization to address issues of donor criteria and recovery and processing systems with an eye toward maintaining quality and safety. In the mid-1980s it established standards for acceptable norms of technical and ethical performance, including a program of inspection and accreditation. However, the AATB is strictly voluntary. In 2002 it listed 73 accredited banks among the estimated 100-plus banks in the United States. Among the unaccredited banks are some of the largest tissue processors. Only a handful of states have any type of tissue bank regulation.

A seminal event occurred in 1991 with the report of the transmission of human immunodeficiency virus (HIV) from an organ and tissue donor who had tested negatively for the antibody to HIV. This focused the public's attention on the potential for disease transmission, especially the need for more rigorous donor screening. In 2001 safety issues resurfaced. The Federal Drug Administration (FDA) and the Centers for Disease Control (CDC) reported several cases of infection, possibly caused by donor tissue in recipients, including one that resulted in the death of the patient. In 2002 the CDC issued a report documenting fifty-four tissue infections that had occurred over several years, noting, however, that out of an estimated 650,000 annual tissue transplants, bacterial infection was a rare complication. Later in 2002 there were reports involving six organ and tissue recipients who contracted hepatitis C from an organ and tissue donor, and several organ recipients who were infected with West Nile virus, including a number who died. Creutzfeldt-Jakob disease, the human variant of mad cow disease, looms as a potential hazard, and new testing regimens to screen out potential donors with these diseases are awaited by the tissue banking and surgical communities.

FDA regulation of tissue banking began in earnest in 1993 with the Interim Rule for Banked Human Tissue, which was intended to require infectious disease testing, donor screening, and record keeping. Among the things required were extensive interviews about a potential donor's sexual history, use of illegal drugs, and other exposure to infectious diseases. This rule was finalized in 1997 and resulted in in-depth training of tissue bank and hospital staff and a lengthy interview (between thirty and sixty minutes) with a grieving family member. During that time the FDA also began routinely inspecting tissue banks, suggesting changes, and conducting mandatory recalls at large tissue banks that remained out of compliance. It is anticipated that additional FDA regulations for good tissue banking practices will be issued in 2004.

In 1997 the Centers for Medicare and Medicaid Services (CMS) established regulations that changed the system of organ and tissue donation dramatically. The Conditions of Participation (CoP) required that all hospital deaths be reported to the OPO that serves the hospital and that all those deaths be evaluated as potential donors. The results of the CoPs were most notable among tissue banks, which often experienced an increase of over 50 percent in their tissue donors.

Ethical Issues

As tissue transplantation has gained visibility, it has attracted the attention of critics. In April 2000 the *Orange Country Register* ran a series of articles titled "The Body Brokers." With provocative headlines such as "Assembly Line" and "Skin Merchants," the newspaper raised concern that the tissue industry was commodifying the human body, making outrageous profits, and irresponsibly allocating skin for "cosmetic" purposes. According to those and other allegations, the industry was violating the trust of grieving families that altruistically had donated tissue. The tissue industry replied that those allegations were inflammatory and inaccurate. However, press coverage brought the the industry to public attention. Several senators approached the secretary of the U.S. Department of Health and Human Services (DHHS), Donna Shalala, who asked the DHHS's inspector general to investigate. Out of that investigation came two thorough 2001 reports, *Oversight of Tissue Banking* and *Informed Consent in Tissue Donation: Expectations and Realities.*

As was mentioned above, the ethical issues of tissue banking arise largely from the apparent contrast between the way society views the source of human tissue and the industrial and commercial aspects of tissue processing and distribution. Like organs, tissue comes as an altruistic gift from grieving families. The notion of altruistic donation has been the bedrock of the ways in which organs and tissues are obtained. The National Organ Transplant Act specifically prohibited the sale of human organs and tissues, allowing only reasonable charges for the costs of retrieval, processing, and the like. Whereas some would argue that financial incentives and even outright payment should be allowed to increase the supply of organs, the law continues to recognize only altruistic donation.

Commerce is not absent from organ transplantation, however. Surgeons, hospitals, OPOs, and pharmaceutical companies, among others, make money from their participation in the transplantation process. However, with tissue transplantation, commodification and commercialization are much more evident. Unlike organs, which remain identifiable as organs in their relatively brief journey from donor to recipient, many tissue forms are highly processed and machined into forms that no longer resemble the bones or skin from which they were derived. Tissue forms are packaged much like pharmaceutical products and medical devices and can be stored for distribution years later. As they pass down the chain of distribution from donor to recipients, for-profit companies enter into the process. Many of those companies have invested capital to develop new processes for which they hold patents.

Unlike organs, tissue is rarely lifesaving, with skin for severe burn victims being the major exception. Instead, tissues are used to treat medical and surgical illnesses that are debilitating but not necessarily life-threatening. Sometimes tissue products are employed for cosmetic or enhancement purposes.

In summary, the chain of distribution of tissue from donor to recipient involves multiple players, including organ procurement organizations, nonprofit and for-profit tissue banks, and publicly held companies that process and distribute tissue. Tissue often is changed from its original form into packaged grafts that may sit on shelves to be distributed months or years later. Value is thus added to tissue as it passes along the chain of distribution. Sometimes donated tissue can be used for enhancement rather than saving lives or the treatment of serious medical and surgical conditions.

These characteristics make the commodification and commercialization of tissue much more evident than those of solid organs and, most important, present a stark contrast to the altruistic gifts of grieving families that make the entire enterprise possible. This contrast forms the basis for much of the criticism of the tissue industry. For example, if the families that selflessly donate do not make money, why should others? Another criticism is that families would not want their gifts used for cosmetic purposes.

Two potential solutions to these problems are not acceptable in the current legal and cultural context. On the one hand, society could abandon altruism and allow families to sell tissue at its fair market value. On the other hand, financial incentives could be eliminated from the processing and distribution of tissue. The first solution would eliminate the traditional basis of organ and tissue procurement: the gift. The second would bring an increasingly successful and desired clinical intervention to a halt.

Informed Consent

As a more realistic alternative many have suggested a rigorous informed consent process. If families were informed about the commodification and commercial aspects of their gifts, they would have the freedom not to give them. This would avoid the abandonment of both altruism and the market forces that have allowed the tissue industry to flourish. Although this suggestion has great merit, it also has several limitations.

First, the informed consent model does not fit the situation perfectly. People think of informed consent as the principle governing the decision of patients to consent to treatment or that of research subjects to consent to research. With tissue donation, the patient is dead and no treatment or research is involved. The decision to donate generally is made by a family member. Second, the request is made under less than ideal conditions: The family is in the middle of a crisis, and the request most often is made by a stranger, frequently over the telephone. In these circumstances the ability and willingness of the family to receive and process large amounts of information are limited. Third, issues involving the financial aspects of donation are complicated and to some extent dependent on the political views of the requestor and the family member. Is it possible, for example, to give a robust description of the structure and function of the tissue transplant industry in the context in which the request is made? Even if one attempted to do that, what words and tone should be used? Should the difference between for-profit and not-for-profit organizations be explained? Should the realities of the market economy be presented? Should those realities be praised or criticized, and in what balance? Words such as *for profit* and *making money* used out of context can be provocative and even manipulative. However, avoiding a discussion of these issues might allow people to naïvely imagine that their gifts of tissue make their way to grateful recipients without money changing hands or acting as an incentive.

Some things are known about what families want to be told. In 2000 the University of Florida Tissue Bank released the results of two telephone surveys of 507 persons who had been offered the option of tissue donation at the death of a family member. Among those who donated, 86 percent said they had enough time to make a decision, whereas 73 percent of nondonors said they did not. Twenty-eight percent of donors and 36 percent of nondonors said they did not receive enough information. Thirty-five percent of donors and 43 percent of nondonors said it would have been helpful to know that recovered tissue is "sent to companies" and in that group10 percent of donors said that knowing would have made a difference in their decisions. Forty-one percent of donors and 49 percent of nondonors said they would have wanted to know costs are associated with recovery, preparation, distribution, and surgery, including salaries, materials, shipping, and administration. Nineteen percent of donors said that knowing those facts would have made a difference in their decisions. Forty-eight percent of donors and 24 percent of nondonors said that profits should be permitted.

Donor families that have written on the subject point out that not all donor families think alike and acknowledge their ambivalence about their right to information versus their ability to process information in the middle of a tragedy.

After interviewing 30 organizations involved in tissue recovery and receiving more than 50 responses to a questionnaire from donor families, the inspector general of the DHHS concluded that the expectations of altruistic motives among donor families are the foundation of tissue banking. The report, *Informed Consent in Tissue Banking: Expectations and Realities,* said that, among other things:

- Large-scale financial operations may overshadow the underlying altruistic nature of tissue donation.
- After processing, tissue and products containing tissue often are marketed and sold as a medical supply rather than as a donation.
- Some tissues, particularly skin, may be processed into products that are used for cosmetic puposes.

The inspector general concluded that the special nature of tissue and the way in which it is made available call for steps beyond those which apply to most other businesses and philanthropic enterprises. He called for the HHS Division of Transplantation to identify principles and guidelines that should underpin consent requests; make suggestions about the type, format, and content of written information that should be shared with families; make recommendations about training tissue bank staff and external requestors; and make recommendations about ways to evaluate the effectiveness of requestors. He also called on the tissue industry to give written materials to families at the time of a request or in the days immediately afterward, including a copy of the consent form, a full description of the uses to which donated tissue may be put, and a list of other companies and entities with which the bank has relationships, and to indicate clearly on all tissue packaging and marketing materials that the contents are derived from donated human tissue. Finally, the report called for the tissue banking industry to explore a process for public disclosure of tissue banks' financing and research into what types and how much financial information would be useful for families and to consider the impact of that disclosure on the rate of donation.

The report also asked the tissue banking industry to work with groups representing the interests of donor families. The most prominent of those groups is the National Donor Family Council of the National Kidney Foundation. The council is an organization of over 8,000 donor families whose mission is to nurture and protect the interests of donor families as well as to promote donation. In 2000 the Donor Family Council issued a report titled *Informed Consent Policy for Tissue Donation* that called for full disclosure of the facts, including the ways in which tissue is recovered, processed, stored, and distributed. The report also said that families should have the right to restrict use of the tissue they donate. It did not mention financial issues.

In response to those suggestions the transplant community has begun to strengthen the process of informed consent. Many tissue banks now offer informational brochures to donor families that more clearly outline the specifics of donation, including the fact that tissue may be processed into many forms and sizes and may be stored for extended periods and the fact that for-profit companies may be involved in the processing. Education for tissue requestors also has been expanded. Tissue banks routinely offer donor families follow-up information, including copies of the consent form. The AATB, the Association of Organ Procurement Organizations (AOPO), and the Eye Bank Association of America (EBAA) established guidelines for obtaining informed consent on tissue donation that formed the basis of many recovery agencies' consent policies. In addition, the AOPO established suggested guidelines for its members to use in selecting a tissue processor or tissue banking partner.

Many commentators think that the inherent limitations of those recommendations call for other mechanisms to protect potential donors and the integrity of the industry. One of those mechanisms is public education. If the general public better understood the way tissue is altered and the financial realities of tissue processing and distribution, there would be less need to place the burden for sharing that information only at the moment of the actual request. The inspector general, for example, recommended that the tissue banking industry work with groups representing donor families to explore a process for disclosure of tissue banks' financing, including knowledge about the sources of tissue banks' funding and other entities with which tissue banks have financial arrangements. Proposed legislation in California would mandate that families be given information about the involvement of for-profit companies and the possibility of cosmetic uses of tissue and be given the option to "opt out" of those scenarios.

Many states have passed laws that may further change the landscape as it relates to obtaining consent. Known as designated donation or first person consent, those laws give individuals an opportunity to declare their intention (or consent) to donate upon death and do not allow the next of kin to override that declaration. These laws present an entirely new set of challenges for OPOs, tissue banks, and eye banks: If an individual has declared his or her desire to "be an organ donor," does that necessarily refer to any body part that can be transplanted? Did that person receive full information about tissue donation so that the decision to donate was fully informed? What if the family objects strongly? Should the recovery agency move forward without regard for their feelings?

Good Stewardship

In the essay "The Gift and the Market" Courtney Campbell argues against the industrial perception of tissue banking, emphasizing instead that the tissue industry should "act in accordance with a model of 'stewardship of the gift'" (Campbell, p. 207). The acceptance of the gift of tissue, he writes, involves harmony between donor and recipient in regard to the meaning of the gift, the intention for its use, and the relationship of giver and recipient. Others also have emphasized this point. For example, Helen Leslie and Scott Bottenfield from LifeNet, one of the United States' leading tissue banks, in the essay "Donation, Banking and Transplantation of Allograft Tissues" note that "it is only through the humanitarian actions of donors and donor families—people helping people, the noblest of principles—that tissue transplantation is made possible" (Leslie and Bottomfield, p. 281). Stewardship mediates the relationship of the donor to the recipient. It provides a moral connection between the gift and the use of the gift and establishes a framework for enhancing the value of the gift as long as the intent of the donor is respected and the benefits of the gift are directed toward the larger community, not claimed solely as proprietary interests by tissue bankers, processors, and distributors.

Good stewardship in the context of human tissue for transplantation means that the industry should take collective responsibility by doing the following:

- Minimizing commodification by insisting that all packaged tissue prominently reveal its origin as an altruistic gift;
- Adopting nationwide rules for the just allocation and distribution of tissues, for example, making sure that purely cosmetic uses of tissue occur only after more worthy needs are met;
- Working to make tissue as safe as possible;
- Making sure that all tissue recovery is done by nonprofit organizations whose finances are publicly known;
- Maintaining a publicly accessible national database against which potential problems can be assessed rationally; and
- Providing a public forum for discussion and debate of controversial issues.

Although the industry has begun to adopt some of these aspects of good stewardship, there is much room for improvement and it remains to be seen how active a role the federal government will assume in pushing for these important moral and social goals.

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SEE ALSO: *Human Dignity; Organ and Tissue Procurement; Organ Transplants, Medical Overview of; Organ Transplants, Sociocultural Aspects of*

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TRANSHUMANISM AND POSTHUMANISM

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At one time or another, most people have dreamed of having the ability to fly (without technological assistance), of never having to have to age or die, or of having bodies and minds that transcend human limitations. Yet in the end people move on with their lives, trying to learn to deal with the realities of finitude and mortality. This is necessary, given the lack of means to significantly alter biological constraints. Yet new technologies may soon begin to enable people to transcend such limitations. With such technologies, however, come questions about the appropriateness of actually pursuing and employing them to experience greatly extended longevity—perhaps even some form of physical immortality—and to re-engineer the human body to expand its functional capacity. Transhumanism and posthumanism are worldviews, or philosophies, that strongly favor an affirmative reply to these questions and that look forward to the day when *homo sapiens* have been replaced by biologically and technologically superior beings.

Transhumanism has been defined as "the intellectual and cultural movement that affirms the possibility and desirability of fundamentally improving the human condition through applied reason, especially by using technology to eliminate aging and greatly enhance human intellectual, physical, and psychological capacities" (Bostrum, 1999). A posthuman would no longer be a human being, having been so significantly altered as to no longer represent the human species. Underlying this worldview is a core belief that the human species in its current form does not represent the end of our development, but rather its beginning (Bostrom, 1999).

The tools transhumanists would use to achieve their ends include genetic manipulation, nanotechnology, cybernetics, pharmacological enhancement, and computer simulation. The most ambitious—and controversial—transhumanist vision involves the concept of *mind uploading.* According to proponents, advances in computing and neurotechnologies will, within several decades, enable individuals to completely read the synaptic connections of the human brain, enabling an exact replica of the brain to exist and function inside a computer. This simulation could then "live" in whatever mechanical body-form it desired (Kurzweil). In his book *The Enchanted Loom* (1981), Richard Jastrow speculated about this future time: "At last, the human brain, ensconced in a computer, has been liberated from the weakness of the mortal flesh.… It is in control of its own destiny.… Housed in indestructible lattices of silicon, and no longer constrained in its span of years, … such a life could live forever" (p.166–167).

Origins of Transhumanism

While the terms *transhumanism* and *posthumanism* are very recent in creation, the ideas they represent are anything but new. The underlying philosophical ideals are fully those of the Enlightenment, imbued with a healthy dose of postmodern relativism. From the Enlightenment comes a fully reductionistic view of human life characteristic of that movement's materialistic empiricism. In *L'Homme Machine (Man a Machine),* written in 1748, the French physician and philosopher Julien Offray de la Mettrie wrote that humans "are, at bottom only animals and machines," while the Marquis de Condorcet, another French Enlightenment philosopher, wrote in 1794 that "no bounds have been fixed to the improvement of faculties … the perfectibility of man is unlimited." These eighteenth century ideas could be easily updated to recent transhumanist writings, such as Bart Kosko's *The Fuzzy Future* (1999), in which he proclaims: "Biology is not destiny. It was never more than tendency. It was just nature's first quick and dirty way to compute with meat. Chips are destiny" (p. 256). Consider also Kevin Warwick's declaration, written in 2000, "I was born human. But this was an accident of fate—a condition merely of time and place. I believe it's something we have the power to change" (p. 145). Derived from other Enlightenment ideals is a fierce libertarianism, supported by a postmodern moral skepticism, that proclaims that each individual is the final arbiter of what is right and appropriate for his or her life or body. One also sees a precedent for transhumanist thinking in Frederick Nietzche's thoughts on the will to power and the *ubermensche* (superman), particularly in *Thus Spake Zarathustra,* "man is something to be overcome"(p. 12).

As a named movement, transhumanism started in the 1980s with the writings of a futurist known as FM-2030, with the term *transhuman* being a shorthand for *transitional human* (Bostrom, 1999). Transhumans were "the earliest manifestation of new evolutionary beings, on their way to becoming posthumans" (FM-2030). Within the first years of the 1990s, a whole series of groups emerged embracing transhumanist ideology, including the Extropians, the Transtopians, and the Singularitarians, the latter group anticipating and working to bring about the technological "Singularity" predicted by Vernor Vinge. Writing in 1993, Vinge predicted that the exponential increase in scientific and technical knowledge, coupled with feedback loops from artificial intelligence systems, would soon lead to a massive destabilization and transformation of all social structures, technical devices, and human beings, who would be transformed into superior beings. While the Singularity is the most extreme of the transhumanist visions, the idea that humankind should engineer the next phase of its own evolution, and that human beings should be augmented and altered, even to the point of losing their humanity, has captured the thinking of numerous faculty and leaders in the engineering and scientific establishment. This can no better be illustrated than the National Science Foundation's (NSF) proposed plan for converging several technologies, including nanotechnology, biotechnologies, information technologies, and cognitive technologies (such as cybernetics and neurotechnologies) for the expressed purpose of improving human performance (Roco and Bainbridge).

Fundamentals of Transhumanism and Posthumanism

The first assertion of transhumanist thinking is a rejection of the assumption that human nature is a constant (Bostrom, 1999). There is nothing sacrosanct about *nature* in general, or about *human nature* in particular. Criticisms of attempts to modify nature as "playing God" or as the ultimate human hubris are therefore rejected as inappropriate.

Katherine Hayles, in her book *How We Became Posthuman* (1999), describes four characteristic posthuman, or transhuman, assumptions. First, information patterns are more important or essential to the nature of being than any "material instantiation, so that embodiment in a biological substrate is seen as an accident of history rather than an inevitability of life" (p. 2). Second, consciousness is an epiphenomenon. There is no immaterial soul. Third, the body is simply a prosthesis, albeit the first one we learn to use and manipulate. Consequently, replacing or enhancing human function with other prostheses is only a natural extension of our fundamental relationship with our begotten bodies. Lastly, the posthuman views the human being as capable of being "seamlessly articulated with intelligent machines. In the posthuman, there are no essential differences or absolute demarcations between bodily existence and computer simulation, cybernetic mechanism and biological organism, robot technology and human goals" (p. 3).

Ethical Issues

One of the first significant ethical issues relating to transhumanism and posthumanism is the question of enhancement or augmentation: should human beings augment or enhance themselves and future generations? This is not a simple question to answer, though humans have made a practice of augmenting and enhancing themselves throughout recorded history. This is the nature and explicit goal of all tool use and education. Yet there are some implicit boundaries that transhumanist modifications challenge.

As an example, consider correction of vision. The use of glasses or contact lenses to correct vision is an example of a commonly employed augmentation. Yet this intervention is only correcting a deficiency, returning the individuals function to species-normal levels. It is thus a healing intervention more than an enhancement. What becomes problematic for some is when the augmentation or enhancement in question potentially exceeds the function that could be achieved by the finest specimens of *homo sapiens* trained in the most rigorous fashion. People accept the use of some enhancing technologies, such as telescopy or microscopy, which may be used for a time, and for a specific purpose, but cannot become a permanent fixture of the human being. They remain tools, rather than becoming attributes. Thus it is acceptable to use a computer or personal digital assistant (PDA), which can be separated from the user, but permanently enhancing the brain with cybernetic connections or brain implants seems to many to cross a boundary that should not be violated. Why is this so?

Two criticisms of such permanent enhancements are that: (1) they are unnatural; and (2) they engage people in activities that should be the sole purview of the deity—"Playing God" is a frequent aspersion thrown at enhancement technologies. While these are both legitimate concerns, the rhetoric used in the critique typically misses the point, which is a concern about the appropriateness, personal and social consequences, and wisdom of pursuing the proposed modifications and are thus generally dismissed as irrelevant by transhumanists (without addressing the genuine issues).

Transhumanists dismiss the claim of *unnatural* because most of what human beings do with any technology is *unnatural,* yet these uses are accepted as benefits, not harms. As to the second argument, many, if not most, transhumanists are agnostic or atheists, and thus engaging in a supposed Promethean rebellion against the gods is not to them a legitimate concern. The issue is one of great concern to theists, however, though the way the argument is commonly expressed comes close to violating their own basic theological tenants. Can God be so easily dethroned? Can the creature really act outside the permissive will of the creator? Further, many theologians assert that part of the *Imago Dei,* the "image of God," that humankind is said to bear, is the creative impulse.

The real issue of concern to those who object to or are wary of transhumanist goals is that human beings are engaging in activities that may have a profound impact on the individuals involved, as well as on the surrounding environment, without balancing forces or divine wisdom that might minimize possible negative consequences of such activities. From the environmental, or naturalist, perspective, the changes are occurring too swiftly and too dramatically for ecosystems or individual creatures to evolve appropriate safeguards or counterbalances. From the more theistic perspective, these changes are occurring without proper understanding and respect for God's initial designs and plan, and certainly without God's foresight or wisdom. In the end, both arguments are expressing concern for the great harm that these interventions could potentially induce, calling into question activities that presuppose a significant degree of knowledge, foresight, and wisdom that may, and most likely will, be lacking. Hubris, therefore, not ingenuity or even a passion for change, is the fundamental problem.

For others, however, even if such enhancements would not be tried until there was careful prospective evaluation for, and protections against, undesirable consequences, any intervention intended to move function beyond species-normal levels would be rejected. This leads to the next series of concerns: the social consequences of transhumanism. The pursuit of transhumanist goals could lead to individuals and communities possessing significant differences in the type and extent of biotechnological modifications. One consequence of these disparities will be the likelihood of discrimination—against both the enhanced and the unenhanced, as each community may feel threatened by the other. Claims of unfair competitive advantage are probable, potentially leading to attempts at restrictive legislation. Yet it is doubtful such restrictions would find sufficient consensus to be passed, let alone prevent the enhancements from taking place. According to Freeman Dyson, a British physicist and educator, "the artificial improvement of human beings will come, one way or another, whether we like it or not, as soon as the progress of biological understanding makes it possible. When people are offered technical means to improve themselves and their children, no matter what they conceive improvement to mean, the offer will be accepted.… The technology of improvement may be hindered or delayed by regulation, but it cannot be permanently suppressed.… It will be seen by millions of citizens as liberation from past constraints and injustices. Their freedom to choose cannot be permanently denied" (p. 205–206). Particularly powerful—especially in the United States, which is predicated upon the right to life, liberty, and the pursuit of happiness—is the argument posed by the transhumanist Anders Sandberg that freedom to pursue enhancing technologies is a fundamental matter of the right to life.

One likely consequence of this is that multiple communities will develop that adhere to certain values and agreed-upon levels of technological modification. But as some groups may choose lesser degrees of enhancement they may run the risk of becoming ghettoized or restricted from other goods of the larger society that they may still desire. While some transhumanists are quite clear that they do not wish to force their desires for enhancement onto others (Bostrom, 1999), as a group, or even as individual scholars, they have not satisfactorily resolved how tolerance will be maintained both within and outside their communities of choice. In fact, some transhumanists already display belligerent attitudes against skeptics and dissenters (Dvorsky; Smith; Shropshire).

This fact itself acknowledges one of the fundamental flaws of transhumanist, or any other, utopian thinking: the failure to understand the darkness, the fears, and the unpredictability of each human heart. The lesson of the twentieth century, such as the experience with eugenics, fascism, and communism, should have been to beware the power of utopian dreams to enslave, destroy, and demean, rather than provide the promised justice, freedom, and human flourishing. Now the transhumanists offer yet another form of human contrivance to provide salvation for all. This time the faustian bargain is with technology—what John McDermott, a professor emeritus in labor studies at the State University of New York at Old Westbury, has referred to as "the opiate of the intellectuals"—rather than with economic or political systems.

Technology is not inherently evil, and has in fact been the source of much good (as well as harm). It is but a tool, and as a tool must be carefully examined and carefully used. Transforming ourselves into our tools in the hopes of achieving immortality is an illusion. Decay cannot be forestalled indefinitely. If one must change the underlying substrate of the body to "live," then it is really something else that exists, not the original being, and death will still need to be confronted. Extended life may be achieved, but at what social cost? How will people deal with greatly enhanced life spans? What will be the impact on economic structures, the workforce, and reproduction? These questions are all, as yet, unanswered by the transhumanists and the Converging Technologies project of the NSF. While it is doubtful that consensus could ever be reached on enhancing or augmenting technologies, humankind must engage prospectively in a full and open dialogue concerning the coming technologies and their implications.

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SEE ALSO: *Cybernetics; Enhancement Uses of Medical Technology; Nanotechnology*

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TRIAGE

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Triage is the medical assessment of patients to establish their priority for treatment. When medical resources are limited and immediate treatment of all patients is impossible, patients are *sorted* in order to use the resources most effectively. The process of triage was first developed and refined in military medicine, and later extended to disaster and emergency medicine.

In recent years, it has become common to use the term *triage* in a wide variety of contexts where decisions are made about allocating scarce medical resources. However, triage should not be confused with more general expressions such as *allocation* or *rationing* (Childress). Triage is a process of screening patients on the basis of their immediate medical needs and the likelihood of medical success in treating those needs. Unlike the everyday practice of allocating medical resources, triage usually takes place in urgent circumstances, requiring quick decisions about the critical care of a pool of patients. Generally, these decisions are controlled by a mixture of utilitarian and egalitarian considerations.

History

Baron Dominique Jean Larrey, Napoleon's chief medical officer, is credited with organizing the first deliberate plan for classifying military casualties (Hinds, 1975). Larrey was proud of his success in treating battle casualties despite severe scarcity of medical resources. He insisted that those who were most seriously wounded be treated first, regardless of rank (Larrey). Although there is no record of Larrey's using the term *triage,* his plan for sorting casualties significantly influenced later military medicine.

The practice of systematically sorting battle casualties first became common during World War I. It was also at this time that the term *triage* entered British and U.S. military medicine from the French (Lynch, Ford, and Weed). Originally, *triage* (from the French verb *trier,* "to sort") referred to the process of sorting agricultural products such as wool and coffee. In military medicine, *triage* was first used both for the process of prioritizing casualty treatment and for the place where such screening occurred. At the *poste de triage* (casualty clearing station), casualties were assessed for the severity of their wounds and the need for rapid evacuation to hospitals in the rear. The emphasis was on determining need for immediate treatment and the feasibility of transport.

The following triage categories have become standard, even though terminology may vary:

1. *Minimal.* Those whose injuries are slight and require little or no professional care.
2. *Immediate.* Those whose injuries, such as airway obstruction or hemorrhaging, require immediate medical treatment for survival.
3. *Delayed.* Those whose injuries, such as burns or closed fractures of bones, require significant professional attention that can be delayed for some period of time without significant increase in the likelihood of death or disability.
4. *Expectant.* Those whose injuries are so extensive that there is little or no hope of survival, given the available medical resources.

First priority is given to those in the immediate group. Next, as time and resources permit, care is given to the delayed group. Little, beyond minimal efforts to provide comfort care, is given to those in the expectant category. Active euthanasia for expectant casualties has been considered but is almost never mentioned in triage proposals (British Medical Association, 1988). Those in the minimal group are sent to more distant treatment facilities or left to take care of themselves until all other medical needs are met.

From the beginning, the expressed reasons for such sorting were a blend of utilitarian and egalitarian considerations. Larrey stressed equality of care for casualties sorted into the same categories. On the other hand, one early text on military medicine advised, "The greatest good of the greatest number must be the rule" (Keen, p. 13). Over the years, it also became clear that the utilitarian principle could be interpreted in different ways. The most obvious meaning was that of limited medical utility: The good to be sought was saving the greatest number of casualties' lives.

But the principle could also be construed to mean doing the greatest good for the military effort. When interpreted this way, triage could produce very different priorities. For example, it was sometimes proposed that priority be given to the least injured in order to return them quickly to battle (Lee). An oft-cited example of the second use of the utilitarian principle for triage occurred during World War II (Beecher). Commanders of U.S. forces in North Africa had to decide how to use their extremely limited supply of penicillin. The choice was between battle casualties with infected wounds and soldiers with gonorrhea. The decision was made to give priority to those with venereal disease, on the grounds that they could most quickly be returned to battle preparedness. A similar decision was made in Great Britain to favor members of bomber crews who had contracted venereal disease, because they were deemed most valuable to the continuation of the war effort (Hinds, 1975).

As military triage has evolved during the twentieth century, the goal of maintaining fighting strength has increasingly become the dominant, stated goal. In the words of surgeons Gilbert W. Beebe and Michael E. DeBakey, "Traditionally, the military value of surgery lies in the salvage of battle casualties. This is not merely a matter of saving life; it is primarily one of returning the wounded to duty, and the earlier the better" (p. 216).

The nuclear weapons used at the end of World War II introduced unprecedented destructive power. In the nuclear age, triage plans have had to include the possibility of overwhelming numbers of hopelessly injured civilians. In earlier days, it was not uncommon to plan for 1,000 or 2,000 casualties from a single battle. Now, triage planners must consider the likelihood that a single nuclear weapon could produce a hundred times as many casualties or more. At the same time a single blast could destroy much of a community's medical capacity. Such probabilities have led some analysts to wonder if triage would be a realistic expectation following a nuclear attack (British Medical Association, 1983).

Triage has moved from military into civilian medicine in two prominent areas: the care of disaster victims and the operation of hospital emergency departments. In both areas, the categories and many of the strategies of military medicine have been adopted.

The necessity of triage in hospital emergency departments is due, in part, to the fact that a number of patients needing immediate emergency care may arrive almost simultaneously and temporarily overwhelm the hospital's emergency resources (Kipnis). More often, however, the need for triage in hospital emergency departments stems from the fact that the majority of patients are waiting for routine care and do not have emergent conditions. Thus, screening patients to determine which ones need immediate treatment has become increasingly important. Emergency-department triage is often conducted by specially-educated nurses using elaborate methods of scoring for severity of injury or illness (Purnell; Wiebe and Rosen; Grossman).

Ethical Issues

The traditional ethic of medicine obligates healthcare professionals to protect the interests of patients as individuals and to treat people equally on the basis of their medical needs. These same commitments to fidelity and equality have, at times, been prescribed for the treatment of war casualties. For example, the Geneva Conventions call for medical treatment of all casualties of war strictly on the basis of medical criteria, without regard for any other considerations (International Committee of the Red Cross; Baker and Strosberg). However, this principle of equal treatment based solely on medical needs and the likelihood of medical success has competed with utilitarian considerations in military medicine. In such triage, healthcare professionals have sometimes thought of patients as aggregates and given priority to goals such as preserving military strength; loyalty to the individual patient has, at times, been set aside in order to accomplish the most good or prevent the most harm. The good that might have been accomplished for one has been weighed against what the same amount of effort and resources could do for others. The tension between keeping faith with the individual patient and the utilitarian goal of seeking the greatest good for the greatest number is the primary ethical issue arising from triage.

Triage generates a number of additional ethical questions. To what extent are the utilitarian goals of military or disaster triage appropriate in the more common circumstances of allocating everyday medical care, such as beds in an intensive care unit? If some casualties of war or disaster are categorized as hopeless, what care, if any, should they be accorded? Should their care include active euthanasia? Should healthcare professionals join in the triage planning for nuclear war if they are morally opposed to the policies that include the possibility of such war (Leaning, 1988)? What new issues arise for triage in a time of global terrorism (Kipnis)?

Triage is a permanent feature of contemporary medical care in military, disaster, and emergency settings. As medical research continues to produce new and costly therapies, it will continue to be tempting to import the widely accepted principles of triage for decisions about who gets what care. Indeed, whenever conditions of scarcity necessitate difficult decisions about the distribution of burdens and benefits, the language and tenets of medical triage may present an apparently attractive model. This is true for issues as far from medical care as world hunger and population control (Hardin; Hinds, 1976). The moral wisdom of appropriating the lessons of medical triage for such diverse social problems is doubtful and should be carefully questioned. Otherwise, utilitarian considerations often associated with triage may dominate issues better addressed in terms of loyalty, personal autonomy, or distributive justice (Baker and Strosberg).

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SEE ALSO: *Healthcare Resources, Allocation Of: Microallocation; Justice; Warfare: Medicine and War*

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TRUST

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Trust Between Patients and Providers

Trust between patients and providers is a central topic for bioethics. Consider the trust (or distrust) involved when someone contemplates major surgery: First of all, there is the relation between the surgeon and patient. The patient needs from the physician both a high level of competence (both judgment and skill) and a concern for the patient's well-being. For healthcare professionals to behave in a responsible or trustworthy way requires both technical competence and moral concern—specifically, a concern to achieve a good outcome in the matter covered, which is sometimes called "fiduciary responsibility," the responsibility of a person who has been entrusted in some way. The moral and technical components of professional responsibility have led sociologist Bernard Barber to speak of these as two "senses" of trust. However, if the patient trusts the surgeon, it is not in two senses; the patient trusts the surgeon simply to provide a good, or perhaps the best, outcome for the patient. To fulfill that trust, the surgeon needs to be both morally concerned for the patient's well-being (or at least health outcome) and technically competent.

Because the exercise of professional responsibility characteristically draws on a body of specialized knowledge that is brought to bear on the promotion or preservation of another's welfare, to trust someone to fulfill a professional responsibility is to trust that person to perform in a way that someone outside that profession cannot entirely specify, predict, or often even recognize. In drawing attention to this point, Trudy Govier says that trust is "open-ended." The point is not captured in the frequent suggestion that trust is necessary because the trusting party cannot control or monitor the trusted party's performance. It would do the patient little good to have full prescience of all the events in the operation, or even the ability to guide the surgeon's hand, unless the patient also happened to be a surgeon. Although a typical patient might be able to recognize some acts of gross malpractice, such as being stitched up with foreign bodies left inside, the patient would not know the implications of most of what he or she saw and would have no idea of how to improve the surgeon's performance. For this reason, from the point of view of the patient, there are no good alternatives to having trustworthy professionals. There are no good alternatives in these circumstances because the patient must rely on the discretion of the practitioner.

Philosophers like John Ladd and legal theorists like Joel Handler have drawn attention to the role of discretion in many areas of professional practice. They have argued that because of the role of discretion, the criteria for morally responsible practice cannot be specified in terms of rules or rights alone. The centrality of discretion makes it all the more difficult to separate competence (having adequate knowledge and skill) and moral elements (exercising sufficient concern for the client's well-being) in the professional's behavior.

The provider—in this case the surgeon—also must trust the patient. At a minimum, the surgeon depends on the patient to disclose all information relevant to the case so as to minimize the risks of unexpected events in the operating room. If the patient disappoints the surgeon and does not disclose all relevant information, the negative consequence for the surgeon is, at most, to impair the surgeon's professional performance. The disappointment does not carry a risk of death or disability for the surgeon. The difference in the severity of risk is one of the many aspects of a trust relationship that is counted as a difference of power in that relationship. The lesser severity of consequence for the provider—in this case the surgeon—can obscure the mutuality of trust in the patient-provider relationship.

When the provider is a nurse or physical therapist rather than a surgeon, the provider's central tasks often require an understanding of the patient's experiences, hopes, and fears. Although some nursing, such as the work of the surgical nurse who assists in the operating room, does not depend on an understanding of the patient's experience, most nursing does. Postsurgical nursing care is a good example. This care typically includes motivating the patient to do things such as coughing and breathing deeply in order to reduce the risk of postoperative lung infection. These acts are often quite uncomfortable. Such nursing requires an understanding of the individual patient's state of mind and the ability to motivate the patient—the ability to inspire confidence and hope in patients.

CHANGING THE STANDARDS OF THE PATIENT-PROVIDER RELATIONSHIP. When sociologist Talcott Parsons put forward his influential theory that professionals function as trustees, or in a "fiduciary" capacity, the standard for the so-called fiduciary aspects of the relationship between patients and physicians was that the provider furthered the patient's well-being by being entrusted to make medical decisions in the best interests of that patient.

The doctrine of informed consent for medical procedures was adopted only gradually over the next two decades as a check on provider discretion. This doctrine has been implemented to require informed consent only for a very circumscribed set of procedures. To treat competent persons against their will is considered battery, in legal terms. Therefore, there is a foundation in law for the prohibition of forced or nonconsensual treatment of all types. In practice, however, information is often given only for major procedures, and practitioners tend to assume consent for lesser interventions, including most medical tests. Although patient-oriented practitioners will offer an explanation of why they are ordering a particular test, others will explain only when explicitly asked. For procedures other than surgery, formal requests for consent are rare unless there is a significant risk of death or severe disability from the procedure.

Furthermore, most patients are well informed only about the risk of death or significant permanent injury in circumstances in which informed consent is legally or institutionally mandated. Significant risk—such as becoming temporarily psychotic as a result of the trauma of open-heart surgery, as a result of intensive-care procedures, or from the sleep deprivation that often results from those procedures—is rarely disclosed to patients. The rationale for not telling a patient about to have bypass surgery or enter intensive care is that the risk will seem so shocking that the patient will refuse needed care.

Although the standard of informed consent is enforced by law and institutional practice only for certain risks of major procedures, the U.S. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (President's Commission) has urged that the informed-consent standard be replaced by another, more comprehensive standard, the standard of *shared decision making.*

The President's Commission's 1982 report, *Making Health Care Decisions,* advocated such a shift, which would presumably apply to most significant healthcare decisions. The rule of informed consent requires only the recognition of the patient's right of veto over the alternatives that the provider has presented to the patient. In contrast, shared decision making requires participation of the patient in setting the goals and methods of care and, therefore, in formulating the alternatives to be considered. This participation requires that patients and practitioners engage in complex communication, which the practitioners have a fiduciary responsibility to foster. This new standard is particularly appropriate for a pluralistic society, in which the responsible provider may have an idea of the patient's good that is significantly different from the patient's own idea.

The responsibility to foster shared decision making requires significant skill on the part of medical professionals in understanding patients of diverse backgrounds and in fostering communication with them in difficult circumstances—circumstances in which their communication may be compromised by fear and pain as well as by a lack of medical knowledge. Although some physicians, notably primary-care providers, have sought the skills to fulfill the responsibility to foster such communication, this responsibility is not one that medical education prepares physicians to accept.

IMPLEMENTING THE FIDUCIARY STANDARD. Ironically, although the fiduciary responsibility in healthcare has often been viewed primarily as the responsibility of physicians, as was noted above, it is other classes of providers, especially nurses, who are educated in a way that prepares them to understand patients' experience. Although there is much to recommend the new fiduciary standard in healthcare, its realization requires either a major change in medical education or a change in the relations among members of the healthcare team, so that those who are prepared to oversee and foster shared decision making have the authority to do so. Without such changes, the trust that one's healthcare will be shaped by one's own priorities and concerns is not well founded.

In many cases, distrust of either individual providers or medical institutions has been warranted, especially for women, people of color, and the poor, whose experience has often been discounted or who have been viewed as less rational or less competent than white males. Annette Dula argues that historical events, from the Tuskegee syphilis study to the experience with screening for sickle-cell carrier trait, confirm that trust of the healthcare system on the part of African-Americans is often not warranted (Dula, 1992). The problem is one of the need not only for assurance but also for evidence that the former conditions no longer prevail.

Many poor or uninsured people have not even had a significant patient-provider relationship; when they are able to obtain healthcare, it is often with a provider whom they see in only a single clinical encounter. It is therefore impossible to establish a trusting relationship that would serve the patient's health interest. If society is obliged to provide decent healthcare for its citizens, this failure of the healthcare system is a betrayal of trust not by individual providers but by society and its healthcare institutions.

Trust and Family Members

Trust among family members is at least as important an issue for healthcare as is trust in the provider-patient relationship. The trustworthiness of parents and guardians to decide the care of children and other dependent family members is widely discussed, and trust among family members is beginning to receive more attention in connection with the writing of living wills and health proxy statements. The issues of the competence of family members to give various forms of care or to make technical decisions, and the sufficiency of their concern for the patient's well-being, parallel those issues for providers. The matter is further complicated by the phenomenon of psychological denial that interferes with decision making about the healthcare of a person who is important in one's own life. Denial, as well as incompetence or lack of commitment to the patient's welfare, may compromise a person's decisions or care when the health or life of a close friend or relative is gravely threatened. Therefore, warranted trust in family members to provide or decide one's care requires confidence not only in their competence and in their concern for one's well-being but also in their psychological ability to come to terms with the situation.

Other Areas of Trust in Healthcare

There is also the question of the public's trust in a class of professionals, which is distinct from the question of the public's concern that, should they become clients of these professionals, their interests will be well served. For example, Sissela Bok (1978) has examined the concern about the trustworthiness of lawyers, not by their clients but by the public. Of particular concern is lawyers' commitment to keep the crimes of their clients confidential, even certain ongoing or planned crimes. The public believes that lawyers should not violate usual ethical norms for the sake of their clients' interests. The corresponding issue in healthcare is the fear that providers will, in protecting patient confidentiality, put the public health or the safety of individuals at undue risk. The question of ethical criteria for breaking confidentiality is regularly discussed, especially in the case of a sexually transmitted disease or a patient intent on harming another person. However, there is no widespread public concern that healthcare providers may be going so far in protecting patient confidentiality that they are derelict in protecting the public.

In addition to the public's trust of providers, the trust or distrust of medical technology is often a significant factor. The risk is particularly salient in the case of artificial organs, joints, and other body parts. In place of the components of competence and concern of a trusted provider, the qualities required of a technology to warrant trust are its performance (it performs the function it was designed to perform) and its relative safety (it is relatively unlikely to cause accidents or to have other injurious side effects). Of course, with such life-critical technologies as artificial organs, the performance issue is itself a safety issue.

There are many aspects of the healthcare system on which patients rely but which most rarely consider. Many people become fully aware of their trust only when that trust is disappointed. A case in point is the discovery that research misconduct occurred in a major breast cancer study. The belated revelation of misconduct made patients aware of their trust in medical research.

The Morality of Trust

Although Sissela Bok has discussed trust as a moral resource since the 1970s, the question of the morality of trust relationships—the question of the circumstances under which, from a moral point of view, one ought to trust—was not explicitly discussed until Annette Baier's 1986 essay, "Trust and Anti-Trust." Two earlier essays were important in laying the foundation for this major turn in the discussion. In 1984, Ian Hacking provided a devastating assessment of the use of game theory to understand moral questions, such as the Prisoner's Dilemma, which will be discussed below. Baier herself argued in 1985 for broadening the focus in ethics from obligations and moral rules to the subject of who ought, as a moral matter, to be trusted and when. As Kathryn Addelson points out, Baier's change of focus establishes a general perspective on ethical legitimacy that is shared by all—both the powerful and those whom society labels *deviant*—rather than privileging the perspective of those who make, instill, and enforce moral rules.

Baier's general account of the morality of trust illuminates the strong relation between the trustworthy and the true. A trust relationship, according to Baier, is decent to the extent that it stands the test of disclosure of the premises of each party's trust (Baier, 1986). For example, if one party trusts the other to perform as needed only because the truster believes the trusted is too timid or unimaginative to do otherwise, disclosure of these premises will tend to insult the trusted party and give him or her an incentive to prove the truster wrong. Similarly, if the trusted party fulfills the truster's expectations only through fear of detection and punishment, disclosure of these premises may lead the truster to suspect that the trusted would betray the trust, given an anonymous opportunity to do so.

Although explicit discussion of moral trustworthiness is relatively recent, both professional ethics and the philosophy of technology have given considerable attention to the concept of responsibility. Since being trustworthy is key to acting responsibly in a professional capacity, or to being a responsible person if one considers responsibility a virtue, the literature on responsibility provides at least an implicit discussion of many aspects of the morality of trust, much of which is relevant to the subject of trust in healthcare.

Conceptual Relationships

Trust involves both confidence and reliance. Annette Baier (1986) argues that if we lack other options, we may continue to rely on something even when we no longer trust it. Similarly, we may have confidence in something, or confidence in our expectations concerning it, without relying on it. To rely only on what we can trust is a fortunate circumstance.

Niklas Luhmann (1988) urges a different distinction between confidence and trust, suggesting that *trust* be used only when the truster has considered the alternatives to trusting. Such use is incompatible with unconscious trust, a phenomenon to which Baier draws attention. Luhmann's discussion of the distinction between trust and confidence highlights the element of risk in trusting. Risk or vulnerability does characterize situations in which trust is necessary, in contrast to situations in which one's control of the outcome makes trust unnecessary. However, the element of risk taking in trust is captured in the notion of reliance when trust is understood as confident reliance. Being vulnerable in one's reliance does not require that one have considered the alternatives, if any, to such reliance.

Although one often trusts people, their intentions and goodwill, there is also trust in mere circumstances or events: One may trust that a taxi will come along shortly, even if no taxi has been ordered, without believing anything about another person's reliability in providing a taxi.

The risk taken in trusting does leave the truster liable to disappointment (or worse), whether that trust is of persons or events. But only when trust is in other people, and not merely in the events involving them, can one be let down by them. Suppose that a person is awakened every weekday by another person's calling for a neighbor. If the first person has come to rely on being awakened, but one day the other person does not come for the neighbor or does so quietly, the first person's expectations will be disappointed. But the person will not have been disappointed or let down by the one who usually picks up the neighbor. To be disappointed by another person, that person must at least be aware of doing or not doing the act in question. Here the person doing the calling for the neighbor is not aware of waking up the first party, much less of being trusted to do it. As Baier mentions (1986), it is possible for there to be trust of which the trusted person is unaware, and so one might let down another without being aware of letting that person down.

Niklas Luhmann (1979) has shown how trust simplifies human life by endowing some expectations with assurance. To consider all possible disappointments, defections, and betrayals by those on whom we rely, the possible consequences of those disappointments, and any actions that one might take to prevent those disappointments or change their effect is prohibitively costly in terms of time and energy. Trust reduces that burden.

The Literature on Trust

Sociologists like Bernard Barber and Luhmann (1979, 1988) have written on many facets of the notion of trust, and legal theorists have reflected on the distinct, though related, notion of a legal trust. Until the 1980s, however, the explicit attention given to the common notion of trust, or confident reliance, in Anglo-American philosophy was largely in relation to such questions as how the "prisoners" in the so-called Prisoner's Dilemma might solve their problem of assurance with regard to one another's behavior so as to cooperate in achieving a mutually beneficial outcome. (In the Prisoner's Dilemma, each of two prisoners will receive a light sentence if neither confesses to a crime, and a more severe sentence if both confess; but if one confesses and the other does not, the latter will be freed, but the former will receive the most severe sentence of all. Without assurance about each other's behavior, and in spite of knowing that both would be better off if neither confesses, both are likely to confess and be less well off.)

Recent literature on trust has examined trust in a variety of different social circumstances, involving a wide range of objects and systems, persons in a wide variety of roles, and matters in which they might be trusted or distrusted. For example, some writers focus on cases of the breakdown of trust in war, under the influence of the Mafia, or in some other extreme situation. Differences in the domain of application of the notion of trust lead to an unusually wide range of estimates of its character and importance. They also lead to disparate distinctions between trust and such notions as reliance, faith, vulnerability, and confidence, as well as to different conclusions about the moral value and the moral risks associated with trust.

Those who write about trust in a market context often take economic rationality—according to which each person simply seeks to maximize his or her goals by the most efficient means—as their model. They then often regard trust as a way of coping with *imperfect rationality,* understood as uncertainty about the facts or about one another's behavior, and how to estimate the consequences for the achievement of one's goals. The economic model of rationality is not readily applicable in considerations of ethics because it was designed to avoid consideration of values other than efficiency, and it treats moral considerations as nonobjective *personal preferences.* Where a market context is assumed, the relatively minor risk of being a "sucker" is likely to be mentioned as a barrier to trust. (See, for example, Dasgupta.) In discussions of trust among family members or between nations (Bok, 1990a), much more is recognized to be at stake.

Feminists like Trudy Govier argue that attention to trust relationships will bring attention to other relationships, such as those between parents and children, that have been neglected when contracts are the focus of attention. Such relationships, however, together with the features of trust that are prominent in them, continue to be ignored in much of the literature on trust. For example, Geoffrey Hawthorn mentions a parent's nonegotistic motives toward his or her child, only to turn immediately to "more ordinary" instances of nonegoistic motives.

Bernard Williams, who begins his own essay with a discussion of the Prisoner's Dilemma, argues that the problem of how nonegoistic motivation is to be encouraged and legitimated does not have a general solution. He argues that the problem of trust or cooperation is not one that can be solved in a general way at the level of decision theory, social psychology, or the general theory of social institutions. To ensure cooperation in a given situation requires an understanding of the ways in which the people in that situation are motivated. Williams believes that solutions to the problem of cooperation are found only for particular historically shaped societies, rather than for society in general. He argues that investigating the sorts of combinations of motivations that make sense in that society might lead to a general perspective on the problems of cooperation in such a society.

However, as he says, "there is no one problem of cooperation: the problem is always how a given set of people cooperate" (p. 13). Those whose cooperation is of the greatest interest in bioethics are patients, their families, the healthcare providers, and the policymakers who shape the healthcare system.

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SEE ALSO: *Beneficence; Care; Confidentiality; Family and Family Medicine; Health and Disease: The Experience of Health and Illness; Informed Consent; Malpractice, Medical; Patients' Responsibilities; Patients' Rights; Privacy and Confidentiality in Research; Privacy in Healthcare; Teams, Healthcare; Virtue and Character*

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UTILITARIANISM AND BIOETHICS

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In bioethics the influence of utilitarianism as an applied ethical theory is widely felt, both positively and negatively. On almost all substantive issues in the area, utilitarianism anchors one of the contending positions. Yet, it is the object of fierce criticism, nearly always to do with the challenges it poses to ordinary or conventional morality, especially in cases involving the taking of life, and to the distinctions that are supposed to carry the weight of that morality.

Classical Utilitarianism

Classical or act-utilitarianism is the view that an act is right if its consequences are at least as good as those of any alternative. In this form the view is consequentialist, welfarist, aggregative, maximizing, and impersonal, and the principle of utility that it endorses what might be called the utilitarian goal.

The view is consequentialist, in that it holds that acts are right or wrong solely in virtue of the goodness or badness of their actual consequences. This view is sometimes called act-consequentialism, or, here, for reasons of brevity, simply consequentialism. It is matters to do with consequentialism, and the conflicts that consequentialist thinking is supposed to engender with ordinary morality in bioethics (and elsewhere), that has made the present topic one of note in contemporary bioethics. The view is welfarist, in that rightness is made a function of goodness, and goodness is understood as referring certainly to human welfare but also, perhaps, to animal welfare as well. The view is impersonal and aggregative, in that rightness is determined by considering, impersonally, the increases and diminutions in well-being of all those affected by the act and summing those increases and diminutions across persons. The view is a maximizing one: One concrete formulation of the principle of utility, framed in the light of welfarist considerations is "Always maximize net desire-satisfaction."

The act-utilitarian goal, understood in the light of the above characterization, then, is to maximize (human) welfare. The crucial question to which this goal gives rise is how best to go about achieving it, and some contemporary act-utilitarians have come to think that the best way of going about maximizing (human) welfare overall may be to forego trying to maximize it on each occasion. It is this insight, in some form or other, that has spurred the most important developments in act-utilitarianism today—developments, however, that have not for the most part featured in bioethics, where the utilitarianism discussed and criticized remains classical or act-utilitarianism, with its embedded consequentialism.

Act-Utilitarianism v. Moral Intuition: The Opposition View

What has driven and continues to drive much of the opposition to act-utilitarianism has been the thought that some alternative view can better account for a number of our moral intuitions. Our moral intuitions, it is said, frown upon murdering or torturing someone, upon enslaving people or using them as means, upon acting in certain contexts and so using people in certain ways for mere marginal increases in utility, all of which act-utilitarianism is supposed to license. It is supposed to license these things because of its constituent consequentialism: If such acts were to have better consequences than the actual consequences of any alternative, then the act-utilitarian would be compelled to call such acts right. And this, allegedly, conflicts with our moral intuitions or ordinary moral convictions or what some people think of as commonsense morality.

This is familiar territory in past debates over utilitarianism generally, though it is no more settled for all that, and it raises directly the question of whether our moral intuitions have probative force in ethics. This is an important issue in its own right, separate from the fate of any form of utilitarianism, but far too broad and complex an issue to be gone into in any detail here. For those inclined to the view that moral intuitions do have probative force in ethics and utilitarianism can be rejected if it produces clashes with those intuitions, the problem has been to make it appear that certain of our intuitions are more secure than others—so secure, in fact, that we believe them to be more *correct* or *true* than any normative ethical theory that contended otherwise could be. Obviously those who adopt this line need to identify which these crucial intuitions are, and various ways of doing this have been suggested. Today reflective equilibrium methodologies are perhaps the preferred way, though some relatively straightforward intuitionists still survive, as do some who seek for the preferred intuitions or convictions in their religion. Even with the back and forth movement between intuition and principle that reflective equilibrium methodologies involve, however, it is clear that some intuitions survive and remain intact. Thus, in *A Theory of Justice,* Rawls appears to think that, if a moral/political theory gave the result that slavery was justified, that would be enough to demand from us amendment and/or abandonment of the theory. His intuition on this score needs no revision. Other writers privilege other of their moral intuitions either about particular acts or classes of acts. Of course the more people that are found, whether in our own or another culture, to differ over these crucial intuitions, the more difficulty there is in selecting just which the crucial ones are. Thus reflective equilibrium methodologists on the one hand and straightforward intuitionists on the other seek ways to discount variation in these crucial intuitions, or, at the very least, to reduce the scope and depth of variations.

The Taking of Life: A Prime Example

Whatever the scope and depth of variations, however, the assumption that certain intuitions survive critical scrutiny has been the springboard from which assaults upon act-utilitarianism have nearly always begun. In cases involving the taking of life, this has been especially true, so that, for example, the topics of abortion, infanticide, euthanasia, suicide, and physician-assisted suicide have become battlegrounds for the playing out of certain kinds of consequentialist reasoning over intending and causing or bringing about death. Of course, other issues in bioethics have been contentious between consequentialists and their opponents, and those involving genetic engineering and therapeutic cloning promise to become intense in the near future; but it is the cases of taking life that have pressed upon the opponents of consequentialism. Four points may be used to illustrate the clash:

(1) Can a genuine distinction be drawn between intending death and merely foreseeing death as a side-effect of one's act and, if such a distinction can be drawn, whether it can be used to mark off moral differences between cases? This issue haunts the taking-life cases; it has been one of the main bones of contention over the viability of the doctrine of double effect; and it is, when allied with a whole array of concerns having to do with whether the act/omission, acting/refraining, and active/passive distinctions are morally significant ones, part of the killing/letting die debate. On the whole, consequentialists attack the moral significance of these distinctions. Thus with a patient who has required ever larger doses of a pain-killer, a physician now proposes to administer the minimum dosage necessary to relieve pain, in the knowledge, however, that the drug at that dosage will prove fatal or at least hasten death. Is the doctor's act permissible? According to some it is permissible, since the physician intends the relief of pain, not death, and only foresees as a side effect of the act that death will ensue or be hastened. Were the doctor to intend the death, either as end or as means, the act would be, not tantamount to, but in fact murder. In this way, then, some want to distinguish morally between the doctor's intentionally killing the patient and his knowingly bringing about the patient's death. Consequentialists, on the whole, have doubts that any such moral distinction can be drawn on this basis: In both cases, the patient ends up dead as the result of causal steps that the doctor takes. Suppose the doctor chooses to administer the drug and knowingly brings about the patient's death: What is one to say about this *bringing about*? One cannot say that it was the result of negligence or recklessness or of accident or mistake. In fact the death is in part the result of choice or decision on the part of the doctor, and it is an integral part of the case that the doctor is a causal agent in the patient's death. Certainly the choice or decision by the doctor to administer the drug cannot be ignored in describing what happened in the patient's case, since that choice or decision in part determines what happened to the patient. This

is true, moreover, even if it is true that the patient's death forms no part of the doctor's intention. It is simply false that the only way morality can be injected into the doctor's case is through what is intended; for that fails to take account of the fact that the patient's death is brought about by the doctor, in the sense described. Unplugging ventilators and turning off machines, among other acts, are all things that the doctor does, in the course of bringing about the patient's death. (The causal account requires complication in a case involving an omission; but the injection of morphine is not an omission.)

(2) In this regard, withdrawing treatment or food and hydration is something the doctor does as well. It is sometimes held that a doctor may not permissibly supply the means of death to a competent, informed patient who is terminally ill, who has voluntarily requested the doctor's assistance in dying, and whose request has survived depression therapy. Yet the very same doctor, it is held, may withdraw food and hydration if, for example, the patient makes a valid refusal of further treatment. Not all withdrawal cases take this form, since things other than food and hydration can be withdrawn from a patient's treatment; but consequentialists on the whole have difficulty in seeing what the morally relevant differences are between these cases. The doctor can supply a pill and produce death, he can withdraw feeding tubes and produce death; how can one be permissible and the other impermissible? Causally he appears to be a factor in the patient's death in both cases. Nor will the consequentialist allow the case to be made out to be one in which, by his valid refusal of further treatment, the patient is to be regarded as the sole actor present, as if the doctor who will withdraw feeding tubes were not there and did not act. The patient's autonomous, voluntary decision to forego further treatment is not the only morally or causally relevant fact to the situation: Death is only produced if the doctor withdraws feeding tubes. Notice, importantly, that the case cannot be reduced to one in which it is claimed that the patient is *permitted* or *allowed* by the doctor to die and that it is the underlying disease which kills him, which is what is usually claimed in the cases of omissions; for in the withdrawal of feeding tubes, it is starvation, not the patient's underlying condition, that kills him. What one causes in the world is relevant to the issue of one's moral responsibility. One may want the doctor to take seriously the autonomous, voluntary decision of the patient to refuse further treatment, but this does not settle the issue of whether withdrawing feeding tubes helped cause death by starvation. Withdrawal of feeding tubes is not an alternative to physician-assisted suicide, so far as causality is concerned: In both cases, the doctor takes an essential step in the production of death.

(3) In the withdrawal case, if the doctor does not withdraw feeding tubes, then he fails to honor the patient's right to refuse treatment, but if he fails to provide the pill, there is no violation of the patient's right to refuse further treatment. Nor does a right to refuse treatment entail a right to be provided with the means of death. So why is there not a moral difference between the withdrawal and pill cases, in that not prescribing the pill does not violate the patient's rights, whereas not withdrawing the feeding tubes does. But this lands the opponent of consequentialism with another problem: While to insist upon one's right to refuse treatment is one way of committing suicide, taking the pill is another way of committing suicide. Why, if suicide is permissible, is one way of committing suicide, the doctor withdrawing feeding tubes, more acceptable than another way of committing suicide, the doctor supplying a pill that the patient takes? It is necessary to identify some reason to think that, if suicide is morally permissible for terminally ill patients, having a doctor withdraw feeding tubes is acceptable but having the doctor provide a pill is not, when both are seen by the patient and by the rest of society as means of committing suicide. If one refuses to allow that suicide is permissible in such cases, then there will be no moral difference between the withdrawal and the pill cases and so the one cannot be used by way of contrast to the other. Of course, in the withdrawal case, those who want to find a difference between it and the pill case may point to the fact that the law allows the doctor to withdraw feeding tubes but not, for example, the patient's son to withdraw those tubes. But it would be a mistake to treat this as if it were identical with the claim that, if the son withdraws the tubes, the withdrawal causes death, whereas if the doctor withdraws them, the withdrawal *does not cause* death. In either case the cause of death is starvation through the removal of feeding tubes; it is just that the law frowns upon the son's act in a way that it does not the doctor's act, in the relevant circumstances.

(4) There is an issue that intersects this discussion of alleged moral differences between cases that turns the debate in another direction. Consequentialists on the whole accept a quality of life view of the value of a life. The value of a life is a function of its quality, and quality of life is a function of a life's content. In this regard, some lives lack the scope and capacities for richness of life that confer on other lives untold blessings, and this regard for content can reach the desperate levels involved in the cases of anencephalic infants and those in a

> permanently vegetative state, where even the very capacities for having a rich life are impaired or missing. The result is that such lives are judged on a quality of life view to be deficient in quality, with the result that their value is less than the lives of ordinary humans. This view enrages some people, for whom the thought that all lives are equally valuable, whatever their quality, is a stance or intuition or principle that is paramount and to remain unchallenged. This view is difficult in some ways to credit; for there are some lives so deficient in quality that one would not wish to live them and would not wish those lives on even enemies. To be fully in the progressive grip of amyotrophic lateral sclerosis is to have a life the quality of which seems progressively to plummet; indeed, some of those condemned to such lives often ask for relief from them through the earlier discussed examples of physician-assisted suicide. It is not society who is judging their lives adversely that prompts them to seek help; they themselves so judge their lives. It seems hard, therefore, to think of such lives on all fours with ordinary ones, and the quality of life view of the value of life reflects this fact.

It doubtless strikes some as repugnant and offensive to think of human lives as of different values. The old view would have been that all human lives were equally valuable in the eyes of God, but today this view cannot be assumed to be prevalent in all medical contexts, even when it could be agreed that people ought to base value claims about lives on the assumption of God's existence, religious tenets, or the like. So what is to replace God in this claim about lives? One can make assumptions about, say, equal worth being apart from value, but are these more than assumptions? And does society not use quality of life judgments about lives all the time in hospitals and medical settings, to decide all kinds of issues, from who gets what resource to how much of it they get? And there all the while, of course, is the plain fact that the content of some lives inspires an overwhelming sense of tragedy, of what lives once were or could have been but of what they have become. How can this sense of tragedy and dire outcome represent equal value?

Of course, in many lives, say, where certain physical handicaps are present, there does not exist this sense of overwhelming tragedy, and people cope very well with misfortune. But where a life begins to plummet disastrously in quality, equal value appears harder to defend. Unequal value, however, implies that some are at greater risk than others: If one could save either a life of very high quality or a life of very low quality; if in hospitals medical intervention is likely to produce in one case a life of ordinary dimensions and in another a life of radically reduced dimensions, and a doctor can only make one such intervention; which life should be choosen?

R. G. FREY

SEE ALSO: *Autonomy; Care; Casuistry; Communitarianism and Bioethics; Consensus; Contractarianism and Bioethics; Emotions; Ethics: Normative Ethical Theories; Human Rights; Obligation and Supererogation*

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V

VALUE AND HEALTHCARE

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Bioethics is concerned with values insofar as they are identical to universal or objective goods (benefits) and evils (harms). There is a use of *value* such that it refers to whatever any person happens to value, but this sense of value has no normative implications. What *value* refers to in this sense is completely determined by empirical research; it is a purely descriptive sense. There is a related sense of *value* such that it refers to what a large number of people value. This is the sense that seems to be important in economics. Economically speaking, something has value or is valuable if there are many people who value it, it can be transferred from one person to another, and there is not enough of it for all of the people who value it. How valuable something is on this understanding is also a completely empirical matter with no normative implications. However, there is another sense of *valuable* where what is valuable is what leads to less harms being suffered or more benefits gained, regardless of whether or not people are aware of this. This is an instrumental sense of *valuable,* and is objective. Modern healthcare, as a whole, is valuable in this sense, but some kinds of healthcare are not valuable, even though misinformed people value them.

Basic Values

Whether something has instrumental value is determined by whether it leads to a decrease in universal or objective evils or an increase in universal or objective goods. These goods and evils are the basic values because all other values in a normative sense are derived from them. Positive basic values have been called intrinsic goods, and negative basic values, intrinsic evils, but the phrases *intrinsic goods* and *intrinsic evils* are misleading, as they suggest that whether something is an intrinsic good or evil is independent of the attitudes of rational persons. However, an account of basic values that does not relate them to the attitudes of rational persons cannot explain why all rational persons avoid evils and do not avoid goods.

The following definition of basic evils (harms) and basic goods (benefits) acknowledges the necessary connection between basic values and rationality. “In the absence of reasons, evils or harms are what all rational persons avoid, and goods or benefits are what no rational person gives up or avoids” (Gert, 1998, ch. 4, p. 92). On this account of the basic values, there are five basic evils: death (permanent loss of consciousness), pain (including mental pains and other unpleasant feelings), disability (including loss of physical, mental, or volitional abilities), loss of freedom (including loss of freedom from being acted on as well as the freedom to act), and loss of pleasure (including loss of sources of pleasure). There are four basic goods: consciousness, ability, freedom, and pleasure.

These basic values are central to healthcare. Healthcare is primarily concerned with the prevention and cure of maladies, and with the relief of the symptoms of maladies that cannot be cured. Maladies, which include both diseases and injuries, have as an essential feature, that a person with a malady is suffering one of the basic harms, or has a significantly increased risk of suffering one of them (Gert, 1997, ch. 5). It is almost a truism that healthcare is primarily concerned with preventing, as far as possible, death, pain, and disability. Although not mentioned quite so commonly, healthcare is also concerned with treating those conditions of persons that would result in their suffering a loss of freedom or pleasure. Those in healthcare might rank the basic values differently from people outside of healthcare;

physicians generally rank preventing evils as more important than promoting goods, and view death as the worst evil. However, no one in healthcare would challenge any of the items on the list of basic goods and evils, that is, the basic values.

Values and Rationality

Given that the definition of good and evils is based on the actions of rational persons, it may seem as if, without empirical research, nothing could be said about what counts as evils or harms, or what counts as goods or benefits. However, such research is impossible to carry out, for it requires examining what *all* rational persons avoid and do not avoid. A list of the basic goods and basic evils has already been provided, however, so there is a seeming inconsistency. It is important to clarify the definition so as to remove this problem. To say "In the absence of reasons, evils or harms are what all rational persons avoid, and goods or benefits are what no rational person gives up or avoids," means "In the absence of reasons, evils or harms are what all rational persons, *insofar as they are acting rationally,* avoid, and goods or benefits are what no rational person, *insofar as he is acting rationally,* gives up or avoids." Almost all rational persons sometimes act irrationally. This happens when they are in a very frightening situation or are overcome by some other strong emotion. What they happen to avoid or not avoid at these times is not relevant to the account of objective values.

Making clear that basic values are determined only by the behavior of rational persons insofar as they are acting rationally introduces a new problem. How is it determined that a person is acting rationally? This is a crucial question. Most philosophers, as well as most economists and political scientists, answer this question by providing a formal answer, one that has no universal or objective content. With various modifications, the standard answer to the question "What is it to act rationally?" is "It is to act in a way that maximizes the overall satisfaction of your desires." On the formal account of rationality under consideration, persons are acting rationally if and only if their actions are consistent with maximizing the satisfaction of their desires, regardless of the content of those desires.

On this account of rationality, there is no particular kind of thing that all rational persons act to avoid and not avoid, and thus there are no basic values or objective goods and evils. There are only values in a sense that has no normative implications. It might be thought that, at least, pleasure and pain would remain as goods and evils, but this is not so. The formal answer cannot restrict itself to persons who are not suffering from mental disorders. When people with serious mental disorders are included, it is not true that all persons acting rationally, defined as acting in a way that maximizes the overall satisfaction of their desires, act to avoid pain and act so as not to avoid pleasure, even in the absence of reasons. The maximizing satisfaction account of rationality results in values being defined as whatever people value. So defined, values have no normative implications. People determine for themselves what is good or evil and so pain and disabilities can be goods to some people, and pleasure and abilities, evils to them.

The Inadequacy of Formal Accounts of Rationality

Many attempts have been made to handle this problem, none of them satisfactory. Insofar as rationality is defined in purely formal terms with no limit on content, it loses its normative implications. It will always be possible to come up with an example that will categorize someone as acting rationally when no one would ever recommend that any person for whom they are concerned act in that way. For example, suppose a person's desire to kill himself in the most painful possible way is stronger than all of his other desires put altogether, even after full consideration. On the maximum satisfaction of desire view, he would be acting rationally to consult *Consumer Reports,* read biology books, etc., in order to achieve his goal. Once this consequence of the maximum satisfaction of desire view is made explicit, it is clear that this account of rationality has no normative force. Given this sense of rationality, it makes perfectly good sense to ask, "Why should I act rationally?" Many people would respond that on some occasions you should not act rationally.

In the normative sense of rationality, the one with which philosophers are properly concerned, no persons who are regarded as a moral agents, i.e., who are held responsible for their actions, would ever recommend to anyone for whom they were concerned, including themselves, that they ever act irrationally. They would never seriously ask, "Why shouldn't I act irrationally?" If it makes perfectly good sense to ask, "Why shouldn't I act irrationally?" then it is not important to determine whether rationality supports morality or anything else. The normative sense of rationality, like the normative sense of values, evils (harms) and goods (benefits), requires that there be universal agreement among moral agents on what kinds of things are harms and what kinds are benefits. All persons who are regarded as responsible for their behavior agree that they would always recommend to anyone for whom they were concerned, including themselves, that they act rationally and they would never recommend acting irrationally.

This agreement is what allows for clear counter-examples to all of the formal definitions of rationality. Everyone agrees that death, pain, disability, loss of freedom and loss of pleasure are evils. In the absence of reasons, all of us would recommend to anyone for whom we are concerned that he act in such a way as to avoid these harms. Likewise, in the absence of reasons, all of us would recommend to anyone for whom we are concerned that she not act so as to avoid the goods of consciousness, ability, freedom, or pleasure. Indeed, if, in the absence of reasons, persons do not act so as to avoid any of these harms or act to avoid any of these goods, they are regarded as acting irrationally. If they act in these ways for an extended period of time, they would be classified by the *Diagnostic and Statistical Manual of Mental Disorders,* fourth edition (*DSM IV*) as suffering from a mental disorder. Having objective values (objective goods and evils), and having an account of rationality with content necessarily go together. Healthcare presupposes these objective values. Medicine aims at avoiding and relieving the basic evils that are the result of a condition of the person being treated.

Reasons

As pointed out in the previous paragraph, people are regarded as acting irrationally if, in the absence of reasons, they do not avoid the evils and do avoid the goods. This correctly suggests that the primary function of a reason is to make some otherwise irrational action rational. Since irrational actions are those in which, in the absence of reasons, a person does not act to avoid an evil or acts to avoid a good, reasons must be facts about avoiding evils or gaining goods. Only such facts can make it rational not to avoid an evil or to avoid a good. It is rational to amputate my right arm if that is necessary to avoid the spread of a cancer that will kill me. It is not rational to amputate my right arm simply because I want to do so, or because I correctly believe that doing so will make me asymmetrical. If desires are taken as reasons that can make an otherwise irrational action rational, then it could be perfectly rational not to avoid an evil or to avoid a good simply because of a desire to do so.

All reasons must involve one or more of these basic goods or evils that are involved in the account of an irrational action. Of course, not all reasons will be adequate to make all otherwise irrational actions rational. An adequate reason must be one that involves a good or an evil that is viewed by a significant number of otherwise rational persons as compensating for the evil suffered. Otherwise rational persons are persons who, in the absence of reasons, avoid evils and do not avoid goods. Rational people can, within limits, differ in their rankings of the goods and evils. What one person regards as an adequate reason for not avoiding a given evil, another person might not. But there are limits. It is irrational to commit suicide to avoid going to the dentist. However, it is not irrational to commit suicide when suffering from an incurable illness that is sufficiently painful or disabling. Although rational persons can, within limits, differ on which good counts as better and which evil counts as worse, they do not disagree on what counts as an evil or as a good. There is complete agreement on the basic values even though there is limited disagreement concerning their ranking.

Healthcare and Values

Healthcare is primarily concerned with preventing or treating those conditions of persons that cause or significantly increase the risk of death, pain, and disability and, to a lesser extent, the loss of freedom and pleasure. Healthcare is less involved with gaining any of the goods, but still has some concern with these matters. Those in healthcare might have a unique ranking of values, with the avoidance of death, pain, and disability, being ranked higher than they might be by people not in healthcare. However, English philosopher Thomas Hobbes (1588–1679), who was primarily concerned with politics, not with healthcare, also took death, pain, and disability to be of primary importance. Indeed, like many doctors, Hobbes seemed to view death as the worst of the evils. When the rankings of individual healthcare practitioners are not the same as the rankings of their patients, patients need not accept the rankings of their healthcare practitioners. On the contrary, healthcare practitioners must accept the rational rankings of their patients, for it is the patients that will actually be suffering the evils.

In addition to the basic values, there are also moral values. Moral values are the moral virtues, such as kindness, fairness, trustworthiness, and honesty. Moral values, like the basic goods and evils, are objective values. Kindness, fairness, trustworthiness, and honesty, are traits of character that all impartial rational persons want everyone to have because having these traits of character increase the probability that less harm will be suffered by all people affected. Indeed, a trait of character counts as a moral virtue only if its general practice increases the probability that less harm will be suffered than its not being generally practiced. There are other virtues of character such as courage, prudence, and temperance that all rational persons want for themselves because they increase the probability that the person himself, or those he cares for, will suffer less harm and gain greater benefits. These are personal virtues and although they are necessary in order to have the moral virtues, they are, as Hobbes and German philosopher Immanuel Kant (1724–1804) pointed out, traits of character that make immoral persons even more dangerous.

It should now be clear that there are no unique values in healthcare, either unique basic values or unique moral values. Since the moral values in healthcare cannot conflict with the moral values in the rest of life, it is not even plausible that there are any unique moral values in healthcare. There are duties that are unique to those in health case, but there are duties that are unique to those in every profession. But none of these duties exempt those in healthcare from the requirements of common morality. As in any profession, a physician may have duties that are in conflict with some other moral rule, but in all of these cases they must be willing for everyone to know that everyone is allowed to violate this other moral rule in circumstances with the same morally relevant features.

Although it may seem that some values such as kindness take on more importance in healthcare, there is no unique ranking of moral values. There are no moral values that are unique to healthcare. The importance of recognizing that there are no values, including moral values, that are unique to healthcare is that it makes clear that, as long as two persons know the facts of a situation equally well, it makes no difference to the validity of their judgments whether or not one is a practitioner of healthcare and the other not. Of course, those involved in healthcare usually know more of the relevant facts better than someone not involved in healthcare. However, the relevant facts should be made available to people outside the field as well as to those within. The advantages in moral evaluation and moral decision making about healthcare matters that those in healthcare have over those not in healthcare, in addition to greater knowledge of the facts, is greater experience and practice. These are not insignificant advantages.

Ethical Relativism

Anthropologists investigating a society previously unknown to them are very wary of criticizing any aspect of that society, even when that aspect involves a harmful practice. At one time, this reluctance to criticize was based upon a kind of naïve ethical relativism. They believed that each society had its own morality, but they believed that their own morality required tolerance, which they took to require that they not judge any practice in another society on the basis of their own moral standards. They did not even care whether the harmful practice was based on false beliefs about the empirical world. That the people of that society, or more commonly the dominant group in that society, accepted a certain practice, was all that was important. For various reasons, these views changed. Partly this was due to a great increase in the number of women anthropologists, and the widespread practice of female circumcision or genital mutilation in many societies being studied by anthropologists. However, even though many anthropologists now consider the practice of female circumcision to be immoral, they do not thereby immediately criticize that practice and try to get the society to stop practicing it. The reason for this is that they realize that this practice is tied into many other beliefs and practices, so that it is not clear how this practice can be changed or eliminated without doing greater harm to the people of that society.

Realization that objective evaluation of a society's practices is legitimate should lead to a more careful examination of the complex interrelationships between the practices in that society. It is not appropriate to criticize a practice and attempt to change or eliminate it until reasonably sure that changing or eliminating that practice will not result in even worse consequences. Caution is in order before trying to get a society to change or eliminate any of its practices. This is true not only of the practices of other societies, but also of a person's own society. Nonetheless, when encountering a harmful practice, it is now recognized that it is morally acceptable to try to find out what can be done to lessen the amount of harm, without causing even greater harm. A harmful practice should always give rise to an investigation about what can be done to change or eliminate that practice without resulting in greater harms. Anthropologists came to realize that the basic harms were universal. They also understood that a practice could be recognized as harmful even though it might not yet be known how to eliminate that harm without causing even greater harms.

Relativism and Unique Values in Healthcare

If healthcare is thought to have unique values, then people outside of healthcare, e.g., philosophers, might be in a position like those anthropologists who held ethical relativism. Evaluation by outsiders who did not share these unique values would be inappropriate. However, if healthcare shares the same values as all other areas of life, then all that outsiders need to know is what the facts are. However, similar to the situations of anthropologists, knowing all the facts is not an easy matter. Consider the following example; a philosopher claims, with some justification, that the process of providing information as practiced by the overwhelming number of doctors, is not adequate. On an ideal or philosophical level, a patient ought to be provided with all of the information that any rational person in that situation would want to know. This would include not only any significant risks and benefits of the proposed treatment, of alternative treatments, and of no treatment at all, it would also include information about which hospitals and doctors are most successful in providing those treatments.

Everyone agrees that patients are deprived of some freedom to make rational decisions if they are not supplied with all of this information. Thus the current practice of not providing this information is a harmful practice. In the absence of adequate justification, it would seem that this failure to provide all of this information is not morally acceptable. However, it does not follow that this practice should be changed and that doctors should be required to provide all of this information. It might be that, unless many other practices are also changed, requiring doctors to provide all of that information will require so much time, with so little change in outcome, that the costs, human as well as financial, make it undesirable to require physicians to provide that information. Perhaps healthcare practitioners already know that. But if we know that a practice is harmful, we should be trying to see if something can be done to change that practice without thereby causing even more harm. There should be consideration of other methods of providing this kind of information to patients.

Summary

Healthcare accepts the same basic and moral values that are accepted by all rational persons. Death, pain, disability, loss of freedom and loss of pleasure, due to conditions of person, are the focus of healthcare. Those in health case might rank the basic values differently, they may even rank the moral values differently, but even if they do, it is quite likely not a uniform difference. It is only that more individuals in healthcare might rank avoiding death higher than avoiding pain than most people not in healthcare. Sometimes, however, as in end of life care, these differences in rankings can be very important. Although there are no unique values in healthcare, there is a unique experience. Those who are healthcare practitioners know more about what actually happens and how different practices are related to one another. Anyone not in healthcare who has not studied what actually goes on in healthcare should, like anthropologists confronting a new society, be very wary of suggesting changes in the way healthcare is practiced, even when confronted with what seem like clear cases of harmful practices. But those in healthcare should recognize that when all the facts are known and appreciated, the rankings of values by those in healthcare do not have any privileged status, rather the rankings of those who will suffer the evils carry the most weight.

BERNARD GERT

SEE ALSO: *Autonomy; Care; Casuistry; Communitarianism and Bioethics; Compassionate Love; Consensus, Role and Authority of; Contractarianism and Bioethics; Emotions; Freedom and Free Will; Human Rights; Obligation and Supererogation; Principalism; Utilitarianism and Bioethics; Value and Valuation; Virtue and Character*

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VALUE AND VALUATION

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Though values are integral to human experience, it is only in modern societies that they have gained an explicit place in ethics. In traditional societies, values generally operate as components of the common culture that are taken for granted. Their moral discourse focuses on the rules that define primary human obligations and on notions of moral excellence. Values first acquire ethical importance where individuals have wide choices about how they are to live their lives. These choices lead to a plurality of value perspectives whose competing claims may appear to express little more than subjective preferences. The challenge to ethics, then, is to devise ways of assessing values critically in relation to normative moral discourse.

In European civilizations, wide value choices were first opened up by the rise of capitalism and of liberal democratic states. In this context, value considerations are never far removed from market dynamics or from basic principles of human liberty. Although class and status factors bar many from the benefits of these modern social formations, their impact on human life remains pervasive, compelling us for the sake of social order to accommodate various value orientations.

The Concept of Values

We take note of the realities in our world that matter to us. Values are concepts we use to explain how and why various realities matter. Values are not to be confused with concrete goods. They are ideas, images, notions. Values attract us. We aspire after the good they articulate. We expect to find our own good in relation to what they offer.

Because values are linked to realities we experience, they have an objective reference. They disclose features in our everyday world to which we attach special importance. Positive values are balanced by disvalues. Disvalues express what we consider undesirable, harmful, or unworthy about particular phenomena. They identify realities that we resist or strive to avoid. Virtually everything we experience has valuative significance: objects, states of affairs, activities, processes, performances, relational networks, and so on.

Values are linked to acts of valuation (Scheler). For every value that appears, there is a corresponding valuative orientation (Husserl). This orientation may not be fully self-conscious; still less is it an expression of critical judgment. It is, nonetheless, the subjective basis for the appearance of values. Without valuing subjects, there can be no such thing as values.

In an elemental sense, values are disclosed by feelings (Ricoeur). Explicit value language comes later, if at all. How do I know that health is good? I know because I feel good when I am healthy. The positive feeling signals the presence of value. How do I know that a performance of Shakespeare's *Hamlet* is good? Even an informed aesthetic judgment has an affective basis: I was moved by it. In being moved, I apprehend value. My primal awareness of value becomes explicit as I identify the features in a phenomenon that draw me to it. Human languages furnish a rich vocabulary for conversations about values.

The correlation between values and valuative acts does not imply that values are purely subjective or that they are merely secondary embellishments of empirical fact. On the contrary, the notion of an empirical reality devoid of all valuative meaning is itself an abstraction. As our perceptions disclose an object's reality, so our affections disclose its worth (Ricoeur). By means of perceptions and affections, we apprehend facets of the realities we encounter. Apart from corresponding acts of consciousness, however, nothing whatever can appear.

Values and Human Needs

Values are intimately related to human needs and desires (Niebuhr; Ogletree; Ricoeur). We value realities that satisfy basic needs and fulfill deeply felt aspirations. We associate disvalues with realities that threaten or diminish human well-being. Human well-being is only part of the story. With a growing environmental consciousness, value discussions embrace nonhuman life forms as well, perhaps creaturely well-being as a whole. Human life then gains its value within a natural world that has intrinsic worth. Religious communities honor a world-transcending center of values from which all lesser values derive their significance.

There are as many kinds of values as there are regions of experience where we distinguish good or bad, better or worse, beneficial or harmful: sensory values, organic values, personal values, interpersonal values, social values, cultural values, and spiritual values (Scheler). Social values can be differentiated into economic, political, legal, associational, and familial subsets. Cultural values embrace religious, moral, cognitive, and aesthetic interests (Parsons). The formal value types all contain values and disvalues. Notions of creaturely well-being are implied if not stated.

Value Issues in Biomedical Practice

Virtually all kinds of values figure in biomedical practice. Organic values are basic: life, health, vigor, bodily integrity. The purpose of medicine is to save lives and to promote healing. Yet the ill and injured are never merely "patients," organisms suffering treatable maladies; they are persons with dignity who have their own life plans (May, 1991; Ramsey). Personal values, therefore, qualify organic values. Patients as persons may in no case be subjected to medical procedures without informed consent. Ideally, they participate actively in their own healing.

Organic values are inherently problematic. Our impulses press us to strive for life, strength, and agility. Yet these strivings are limited by our vulnerability to illness, injury, disability, and, finally, certain death. Modern medicine inclines us to define the limits of organic life not as natural features of finitude but as problems to be solved. This tendency requires us to make value judgments about the boundaries of medical intervention. Medical practices inattentive to these boundaries can deprive the dying of the personal space they need to achieve closure in their life pilgrimages.

At this point, organic values are qualified by more encompassing value commitments. Such commitments can help us to accept life's limits, acknowledge goods more noble than our own survival, and endure sufferings and disappointments with grace and wisdom. Life, death, health, and illness are never purely physiological; they are moral and spiritual as well. Healthcare must also have moral and spiritual as well as physiological dimensions (Cousins; May, 1991; Nelson and Rohricht).

Professional and economic values intersect medical practice in similar ways. Physicians have specialized knowledge that equips them to provide socially valued services. They enjoy social status as professionals who maintain standards for medical practice. In this role, they are public guarantors of prized social values (May, 1983). Physicians in the United States offer services for fees, primarily through third-party payments. Accordingly, medical practice is also a market transaction, and physicians are businesspeople with economic interests. The stake in economic values qualifies professional devotion to patient well-being.

The organization of healthcare profoundly conditions its operative values. Modern medicine requires sophisticated technologies affordable only to large medical centers. These institutions, usually constituted as corporations, dominate medical practice in the United States. The technologies they use are typically produced and supplied by global corporations. The income they receive derives largely from corporate employee-benefit plans and from insurance firms that service them. Health-related industries have become a major component of the economy, perhaps inappropriately overriding the legitimate claims of other social goods. Powerful economic and political interests support the continued growth of medical enterprises with little regard for wider social ramifications.

Because the desire for quality medical services is urgent, intense public debate surrounds federal policies that bear upon the organization, regulation, and funding of healthcare. The struggle is to determine appropriate government roles for the oversight and financing of biomedical activities. In this struggle, conflicting political values intersect healthcare practices as public actors respond to constituent interests. Similar sociocultural analyses could be directed to the roles played in the healthcare system by values resident in families, religious communities, research institutes, medical colleges, the legal system, the media, and the arts. Ethical studies of the intersection between biomedical practices and social processes uncover a volatile mix of conflict-laden value issues.

Fluidity of Values

Values are not only pervasive but also fluid. Any concrete experience harbors many values and disvalues, none of which is definitive or self-contained. Illness can be a physical malady, a ruthless disruption of personal plans, an economic disaster, an opportunity for self-discovery, a moment of human bonding, an occasion for medical virtuosity, or a case study in biomedical research (May, 1991). Each of these meanings captures some of the values that belong to a particular experience. As attention shifts, one set of values continually flows into another.

Our terminology for values is similarly fluid. The word *health* can be used descriptively; it also identifies an important value. *Justice* can designate a basic moral principle; it can refer equally to a value worthy of promotion in social arrangements. The term *objective* may characterize "value-free" inquiry, but it also designates a cognitive value.

Because of their fluidity, values resist schematic classification. Attempts to construct comprehensive value schemes do, however, have heuristic significance. They heighten awareness of the range of our valuative connections with our world, and they stimulate reflections on what belongs to human well-being (Hartmann; Perry; Scheler).

Moral Values

Within the value field, we can isolate a subset of moral values. Moral values cluster around personal identity, interpersonal relationships, and the makeup of groups, associations, social institutions, whole societies, and even the global community (Scheler). Numerous values—dignity, integrity, mutual respect, loyalty, friendship, social cohesion, fairness, stability, effectiveness, inclusiveness—are moral in import. Anthropocentric values are supplemented and corrected by the moral claims of animals and, more broadly, by the moral claims of the environment, a self-sustaining ecosystem. Even religious devotion to the divine life has moral dimensions, for the faithful are obliged to honor God as the final bearer of value.

Moral values enjoy precedence within the value field because they identify the basic loci of all valuing experience—that is, valuing subjects in relationship. Where moral values are secure, we can cultivate a wide array of values. Where moral values are in danger, all values are at risk.

Even so, in our responses to concrete cases we regularly rank some nonmoral values above specifically moral ones. Faced with a health emergency, our regard for life itself, an organic value, surpasses normal preoccupations with human dignity, a moral value. We do what we can to save a life! At the same time, we know that life as such is but one value among many. Prolonging human life can never, therefore, be the primary goal.

Similarly, human beings can often best advance their own good through value commitments that transcend specifically moral considerations. Cognitive, aesthetic, and especially spiritual values finally stand *higher* than moral values in most value schemes because they bestow significance on existence in its travail and woe. Yet these values still require for their realization valuing subjects who are bearers of moral value.

We normally discuss moral values in terms of rights and duties. Rights identify claims that others properly make on us. These claims intersect our value-oriented projects and disclose our duties. A physician's professional judgment about a course of therapy is subject to the patient's informed consent. The abortion debate hinges on differing assessments of fetal rights against a pregnant woman's right to choose.

Duties consist of obligations and prohibitions. Obligations specify what we must do no matter what else we might also hope to accomplish. Hospital emergency rooms must treat seriously injured persons regardless of whether they can pay, offering such care as a part of normal operations. Prohibitions specify what we must not do regardless of larger objectives. We must not use human beings as research subjects without their consent no matter how important the research may be.

It is for the sake of moral values that basic rights and duties are binding. We may set such mandates aside only when extraordinary measures are required to safeguard the values they protect. For the sake of human dignity, physicians are normally obliged to do all they reasonably can to sustain the lives of their patients. Precisely for the sake of human dignity, however, this obligation loses its force when further medical interventions would only prolong the dying process.

Values and Human Action

Value awareness gains practical importance in terms of action (Ricoeur). We adopt courses of action that promise results favoring our prized values; we act to inhibit developments that endanger our values. Values guide decision making, disposing us to choose one course of action over another. We justify our decisions in terms of the values they are designed to promote.

Matters do not always turn out as we expect. We may lack the skill, the power, the influence, or the knowledge to achieve our objectives. In medical practice, few surprises follow the skilled application of routine therapies proven to be effective for treating particular ills. Physicians do not stay within safe territory, however. They regularly confront medical problems that they cannot diagnose with confidence and for which there are no known clinical responses with assured results. Medical outcomes frequently fall short of human hopes. They include side effects whose disvalues outweigh desired values. "Side effects" belong to action consequences even when they do not reflect our intentions.

When our actions affect the actions of others, uncertainty increases. Other people may not react as we expect. They may misunderstand our intentions or respond carelessly. We may misread their value commitments. Perhaps the relevant network of human interactions is so vast and complex that it surpasses what we can grasp. Here, too, the outcomes may not fit our values. Prediction is most reliable for highly routine actions with widely understood purposes. It is least reliable for novel initiatives, such as new directions in policy.

Because we cannot fully control or predict the consequences of our actions, the fit between actions and values is inexact. This inexactness carries over into value assessments. We may readily name the values that attach to desired outcomes. Before we can evaluate a course of action, however, we have to consider the uncertainties. We have to weigh the disvalues that could accompany significant miscalculations. Considerations of value differ from discussions of duty by virtue of the inexact fit between values and action. Duty refers not to the likely outcomes of actions but to actions as such, which are largely in our power. It specifies ground rules that order human activity. In general, we may pursue a larger vision of the good only within constraints set by these ground rules. In its early stages, biomedical ethics properly gave precedence to the delineation of basic moral duties.

The fit between values, action, and action consequences remains close enough, however, that values must figure in the ethical examination of action. I am accountable to myself and others not simply for the conformity of my actions to rules that define my duties but also for values and disvalues that reside in the results of my actions. In decision making, I project the likely outcomes of actions I am considering and I weigh probabilities that qualify my projections. I also bring into view risks of unpleasant surprises. Practical reflection on values depends on substantial knowledge of the social dynamics that structure action.

Values in Society and Culture

In traditional societies, the most crucial value issues are largely settled. To be viable, a society requires a shared set of reasonably cohesive values. This shared value cluster composes the society's moral identity. It is expressed in many ways within the common culture: public rituals, speeches, novels, paintings, school textbooks, standard histories, and scholarly investigations.

Modern societies with market economies and liberal democracies are not able to sustain comprehensive value syntheses. At best, they promote what John Rawls calls a "thin" theory of the good—that is, elemental goods that all are presumed to need and want whatever else they might also desire (Rawls). Within the framework of basic goods, such societies host a multiplicity of concrete value orientations, reflecting the diverse priorities of individuals and groups within the society. Some question whether we can sustain even a "thin" theory of the good without a widely shared, substantive value synthesis fostered in basic social institutions (MacIntyre). The disintegration of traditional cultural values tends to undermine interest in the common good. Private preoccupations with individual advantage and "interest group" politics then displaces public discourse about the good of the society as a whole. Likewise, political battles are fought without the restraints of civility necessary to social order. Value theory becomes urgent when basic values are in dispute. Its task is not only to advance critical investigations of persistent value disputes but also to show how various value streams within a pluralistic society can contribute to the good of all.

Critical Reflection on Values

The scrutiny of values has four crucial layers: (1) the reflective identification of our operative values; (2) assessments of the fit between these operative values and considered judgments about creaturely well-being; (3) analyses of value relations in order to identify compatible and incompatible values sets; and (4) imaginative constructions of value syntheses capable of ordering life priorities in personal, communal, and social contexts.

The investigation of values begins with description. We seek to become self-conscious about the values we prize, taking note of value commitments ingrained in stable life patterns and ongoing institutional involvements. The descriptive task is informed by historical studies of normative traditions and of social developments leading to current practices. As we make our operative values explicit, we are often stimulated to reorder our priorities. We recognize that existing arrangements do not reflect our convictions about what matters most in life.

The relation that values have to basic human needs suggests a second step in value studies. British utilitarians and American pragmatists sought to test our presumptive values by empirical investigations (Bentham; Dewey). Their aim was to discover life practices and value attachments that truly accord with primary human needs. Much human-science research functions as value inquiry of this sort, shedding light on value patterns that tend to promote human well-being in contrast to those that finally prove dysfunctional. Historical, philosophical, and theological reflections can also inform such inquiry. For ethics, the challenge is to clarify the contributions empirical studies can make to the critical assessment of values and to incorporate those contributions into constructive philosophical and religious thought. The third step is an analysis of value relations. Not all values are compatible with one another, at least not in practical terms. We cannot both affirm free speech and shield people from all offensive public expressions. We cannot protect the environment without constraining market freedoms. Likewise, we cannot guarantee everyone healthcare that fully utilizes the most advanced medical technologies while also controlling aggregate healthcare costs. Critical thought examines values in terms of their fit with one another. It dramatizes the necessity of choices among different sets of values. We bypass some values and endure relative disvalues for the sake of value combinations that reflect considered priorities. The crucial step in the critical study of values is the imaginative construction of coherent value syntheses capable of guiding action. Because modern societies harbor a multiplicity of value perspectives, attempts to determine value priorities take place in several contexts.

Individuals develop a mature moral identity by clarifying the connections and priorities that order personally cherished values. Value syntheses are no less vital for families, special-interest associations, and religious bodies. These collectives gain moral, and perhaps religious, identity through shared value commitments. Organizations that give concrete form to economic, legal, political, and cultural institutions are themselves more effective when they make their defining values explicit.

Coherent sets of values are not easily achieved or sustained. They enjoy the greatest authority when they emerge as critical appropriations and transformations of normative value traditions within contemporary life settings. Because of the complexity of experience, value syntheses can never fully overcome areas of ambivalence or wholly resolve internal strains. Within limits, we can accommodate value conflicts that we acknowledge and honor. Such conflicts may even stimulate creativity. Within comprehensive value syntheses, value priorities normally run in two contrary directions. Elemental sensory, organic, and economic values enjoy priority over higher political, cultural, and spiritual values in the sense that they furnish the conditions necessary to the appearance of the higher values. Political, cultural, and spiritual values enjoy priority over more basic sensory, organic, and economic values in the sense that they bestow meaning and significance on the more elemental values. Moral values play the mediating role because they identify the loci of value experience. These contrasting modes of priority can shed light on concrete values conflicts.

Public Value Syntheses

A basic value of modern societies is the protection of private spaces for people to pursue diverse visions of the good. Social cohesion rests, then, on minimal agreements that allow individuals and groups to live together in their diversity. In the United States, the prevailing value synthesis combines liberal democratic principles and principles of free-market capitalism. Enduring controversies concern the nature and extent of appropriate government intervention in market processes. Less clearly articulated are images of a greater national community embracing many races, cultures, and religions. The latter images are countered by persisting patterns of racism, ethnocentrism, and religious intolerance.

In biomedical ethics, the most urgent challenge is to form a public value synthesis that can guide healthcare reform. Though difficult disputes remain, there is considerable agreement that a good system will guarantee basic care for all, maintain acceptable standards of quality, foster an active partnership between patients and physicians, take account of the defining values of those who give and receive care, sustain advanced biomedical research, hold total costs to manageable levels, and protect contexts for personal preferences and individual initiatives in delivering and receiving care. These values—especially the contention that all people must have access to basic medical services—all have important moral dimensions.

Any workable system will include value trade-offs. It will require a reexamination of standards of quality care, a balance between healthcare needs and other social goods, and a workable mix of economic incentives and government regulations that maintains discipline within the system while allowing space for individual initiatives. Any system will also confront limits. Moral creativity requires imaginative responses to limits in the promotion of creaturely well-being.

Because of the subtleties involved, bioethics cannot easily incorporate notions of value and valuation into deliberations about basic human duties. Yet values pervade human experience. They even shape our perceptions of the obligations and prohibitions that set constraints on our actions. As we examine more comprehensively the moral issues that reside in biomedical practice, the more we will discover the necessity of systematic value assessments. Critical value studies will tend as well to force a shift in the dominant structure of moral reasoning, from the linear logic of the syllogism to the more nuanced process of weaving multiple value considerations together into an illuminating pattern of moral understanding. While the resulting judgments may appear less precise and decisive, they will probably be more true to life.

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SEE ALSO: *Animal Welfare and Rights: Ethical Perspectives on the Treatment and Status of Animals; Healthcare Resources, Allocation of; Health and Disease; Medicine, Art of; Research Methodology: Conceptual Issues*

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VETERINARY ETHICS

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Veterinary medicine, as the distinctive medical discipline we know today, emerged during the nineteenth century as an adjunct to agriculture. Animals were valued for the food or fiber they provided or for the work they performed, and the veterinarian's role in society was to keep the animals healthy so they could serve people's needs. Even after anticruelty laws had become widespread by the late 1800s, and the horse doctor became the dog doctor with the growth of companion animal practice in the mid-twentieth century, the veterinarian's ethic remained unexamined and substantive ethical issues officially unacknowledged.

Unlike medical doctors, whose engaging of ethical issues can be traced back to Hippocrates, veterinarians did not have a historic tradition of professional ethics to draw on. Until the late 1970s, the field of veterinary ethics focused primarily on issues of business etiquette and professional relations. The Code of Ethics of the American Veterinary Medical Association (AVMA) addressed such areas as referrals to other veterinarians and whether it was "ethical" to have a large insert for one's practice in the Yellow Pages. Social changes, such as the emergence of the animal-welfare/rights movement and its impact on public consciousness, helped catalyze consideration of the complex of ethical concerns that face the veterinarian.

Two people acted as gadflies to the profession in this important period: Michael W. Fox, a veterinarian with the Humane Society of the United States, and Bernard E. Rollin, a philosopher at Colorado State University. Fox and Rollin published articles in influential journals (Fox, 1983b; Rollin, 1978, 1983) that pointed out the need for systematic examination of the ethical concerns of the veterinary profession. Fox also wrote letters to the *Journal of the AVMA* on this theme (Fox, 1983a). In 1978, Rollin inaugurated the first regular, required, full-term course in veterinary ethics at the Colorado State University College of Veterinary Medicine. Both Fox and Rollin wrote books on animal welfare and rights. Rollin, in addition, had taught and published in human medical ethics, and he was sensitive to the differences between the problems of human medical ethics and those of veterinary medical ethics. In particular, owing to his extensive work in the moral status of animals, Rollin was aware that veterinary medicine had not yet addressed its moral obligation to animals. By the end of the 1980s, veterinary interest in the ethics of the profession had developed enough to warrant publication of a textbook on the subject by Jerrold Tannenbaum of Tufts University (1989).

The Veterinary Oath and Its Moral Dilemmas

When the veterinarian graduates from veterinary school, he or she is administered the veterinarian's oath, which includes a promise "to use my scientific knowledge and skills for the benefit of society through the protection of animal health, the relief of animal suffering, the conservation of livestock resources, the promotion of public health, and the advancement of medical knowledge" (see the Appendix, Volume 5). The veterinarian is immediately faced with a fundamental ethical dilemma: to whom does he or she owe primary loyalty, the owner or the animal? In a 1978 article, Rollin used the examples of a pediatrician and a car mechanic to illustrate the two possible choices. When the repairs on a car are more costly than the car's value, the owner can simply tell the mechanic to "junk" it or not do the repairs; there is no such choice in a necessary surgery or treatment of a child (Rollin, 1978). The pediatrician is ethically (and legally) obligated to act as advocate of the child's well-being. On the other hand, the basic current legal status of animals is that they are property, although their sentient qualities have been the basis of limited protection provided by so-called welfare laws (in the United States, primarily local anticruelty ordinances and federal laboratory animal laws).

In addition to the responsibilities they have to the animal and the owner, veterinarians must weigh practice judgments in light of the needs of society in general ("public health"), peers, and themselves as well. As the oath also states, "I will practice my profession conscientiously, with dignity, and in keeping with the principles of veterinary medical ethics. I accept as a lifelong obligation the continual improvement of my professional knowledge and competence" (Appendix, Volume 5). In the face of often conflicting interests of animal, owner, society, profession, and self, the individual veterinarian is often presented with situations that require complex ethical judgments (Rollin, 1988). The traditional minimalistic animal ethics proscribing cruelty, from which anticruelty laws derived, are not adequate to mid-twentieth-century uses of animals such as confinement agriculture or testing and research, which were not matters of cruelty yet caused significant suffering in pursuit of profit and scientific knowledge (Rollin, 1981). In seeking a new animal ethic, society began to apply the notion of rights, which protect human nature from being submerged for the sake of general welfare, to animals in order to protect their fundamental interests as dictated by their nature (or "telos"). The veterinarian came to be considered a natural animal advocate. As society elevated to the status of animals by applying a rights ethic, the status and effectualness of the veterinarian began to increase (Rollin, 1983).

Laboratory-Animal Legislation: Effect on the Profession

One area—laboratory-animal medicine—has had its ethical obligations to animals articulated by law because of societal concern for animal welfare. Before the 1985 Amendment to the Animal Welfare Act, which originated as a Colorado state bill written by Rollin and others, and the National Institutes of Health Reauthorization Act of 1985, which turned animal use "guidelines" into regulations, researchers enjoyed carte blanche in the use of animals. The pursuit of knowledge, or "advancement of medical knowledge," had completely trumped consideration of animal pain, suffering, or distress, and laboratory-animal veterinarians were relegated to the role of keeping animals in good enough shape to serve their research purposes. The legislation that was passed in 1985, as well as the original Animal Welfare Act of 1966 and other amendments to that act, was a direct result of societal response to well-publicized atrocities in research and testing activities and the correlative demand for assurance that animals' interests were protected.

Laboratory-animal veterinarians, because of animal-protective legislation, now fulfill the most unambiguous role of all veterinarians regarding animal well-being: They are obligated by law to act as animal advocates, to assure that pain and suffering do not occur or are minimized by proper medication, that proper animal care is provided, and that humane euthanasia is performed. The veterinarians are aided by Institutional Animal Care and Use Committees, which review research or testing protocols for humane considerations before studies may commence and provide regular monitoring of facilities.

Small-Animal-Practice Concerns

Although the role of the veterinarian has been defined by society in law for the laboratory-animal veterinarian, this has not occurred in other areas of veterinary medicine in which owner interest and animal interest may conflict. The small-animal veterinarian is often faced with ethical decisions based on these conflicts. Examples include cosmetic or behavior-altering surgery and orthodontic intervention for cosmetic reasons. In general, these procedures could be considered in the interests of the animal only if the animal were afflicted with a condition that was causing or was likely to cause it pain or distress. Dewclaw removal—dewclaws can catch and tear when dogs run through rough terrain—or repair of malocclusions like base-narrow lower canines, in which the offending tooth or teeth can drive into the upper palate, can easily be justified as in the animal's interest. Cosmetic surgery that causes the animal to conform to standards of style (e.g., ear cropping) or surgery that is used to curb "objectionable" behavior (e.g., declawing of cats, devocalizing of dogs) can be viewed as causing pain and distress to the animal for frivolous human reasons. Likewise, straightening teeth that are functional to provide a perfect bite for the show dog could be considered unnecessary.

Many veterinarians refuse to do purely cosmetic surgery, and consequently they lose clients. Other small-animal veterinarians believe they owe their major loyalty to the owner. They may argue that providing the service of cosmetic surgery enhances the animal's value, emotional as well as monetary, to the owner. Still other veterinarians will provide behavior-altering surgeries, such as declawing, after first pursuing, with an owner, honest attempts at retraining or other options. They may justify their actions by saying that the owner would otherwise get rid of the pet or that they are fostering the continuation of a rewarding relationship for both pet and owner.

Surgically neutering (spaying or castrating) dogs and cats to prevent sexual behaviors and overpopulation of pets is well accepted by North American society, but (especially for dogs) is largely rejected in other countries in favor of owner responsibility in administering contraceptives and controlling pets. Many small-animal veterinarians readily neuter cats and dogs, assuming that the discomfort of the surgery is of less import than the enhancement of the desirability of the pet to the owner (the elimination of objectionable sexual behavior, for instance) and the elimination of the chance of unwanted pregnancies; in addition, there are health advantages to neutering.

Some Equine-Practice Concerns

The equine veterinarian is under similar tension, only more so. Lameness is the most frequent complaint of horse owners, as the horse's usefulness requires a smooth and efficient gait. The equine veterinarian is often pressured to provide painkilling medication or surgery to cut the nerves to the feet of race or performance horses because of lameness. In some respects this is a compassionate action, as the animal is rendered fully or relatively free of pain. However, there are cases in which eliminating painful sensations may cause the animal to use and seriously injure a limb. Pressures to administer performance-enhancing drugs, or to look the other way when objectionable training techniques may be used, may be severe for equine veterinarians. Veterinarians may also be called on to perform purely cosmetic surgery, such as tail docking or tail "breaking" for an artificially high tail carriage. Unfortunately, horses are generally of little entertainment or economic value if they do not "go sound," or conform to an ideal of beauty.

A Look at Food-Animal Medicine

Food-animal veterinarians have always been placed in a position of tension between the interests of animals and the interests of producers. In traditional agriculture, which prevailed as an "extensive" (as opposed to "intensive") endeavor until the mid-twentieth century, the tension was mitigated to some extent because producers generally did well economically only if they provided for the health and welfare of their individual animals. With the rise of confinement agriculture, however, new considerations have entered into the picture, and producers can prosper—in fact, may make the most profits—even if numerous individual animals suffer from poor health or die. For instance, feedlots may utilize diets that cause digestive and liver disease in a certain percentage of animals, but that loss will be more than compensated economically by the weight gain in the remaining animals. Furthermore, the use of antibiotics, vaccines, growth promoters, etc., have permitted selectivity in meeting animal needs and the separation of economic productivity from animal well-being. Animals can thus suffer in areas not related to economic productivity, yet producers can do well. Since the advent of intensive agriculture, veterinary concern for individual animals has tended to be replaced by a "herd health" philosophy to serve the livestock industry.

In confinement operations, a certain death loss is expected from the animals, whether from contagious or so-called production diseases, which are caused by handling, artificial environments, selective breeding, population density, or nutrition in the operation. Veterinary care in confinement operations usually covers only animals that are expected to recover without costing more in money and labor than the animals' market value. In sheep feedlots, a common daily chore is picking up dead or moribund animals. Discovering which animals are sick, separating them from their group, and treating or euthanizing them is often considered too expensive to support. In complete confinement houses for swine, animals are fed antibiotics because respiratory disease is so prevalent owing to high ammonia levels. To combat fighting in tight quarters among feeder pigs, their tails are amputated so the animals cannot wound each other by tail biting. Mastitis and footrot in dairy cattle are production diseases caused by the enforcement of high milk yields while the cattle are maintained on dirt lots. The average dairy cow is worn out and culled in four or five years, less than half of the expected useful lifetime fifty years ago.

Agrarian values of husbandry have been abandoned in much of present-day agriculture, affecting how the veterinarian may conduct his or her profession, because whereas a small farmer once maintained a modest lifestyle by caring for a few individual animals, a corporation now looks at profit margin only. Even in the more traditional agricultural activity of cattle ranching, economic considerations militate against veterinarians' controlling the pain of such activities as branding, dehorning, and castration. Thus the modern food-animal veterinarian faces a variety of conflicts arising out of tension between economic considerations on the one hand and animal health and welfare considerations on the other.

The Veterinarian and Euthanasia

Even if the veterinarian's inclination is to act as an animal advocate, he or she may be thwarted by the owner's wishes, because of the legal status of animals as chattel or property. Occasionally a veterinarian is faced with a situation in which a pet is suffering without hope of recovery, as in terminal cancer, but where euthanasia is not an option because an owner refuses to authorize it. Many veterinarians quietly euthanize such animals as a humane act in spite of its illegality; but a more direct approach, utilized by veterinarians who often deal with death and the consequent grief of owners, is to discuss the inevitable with clients beforehand and exercise a humane ethic by requesting the clients to agree to euthanasia if certain clinical signs, like unremitting pain or inability to eat, arise.

A more common delay of euthanasia occurs when a food animal is kept alive despite suffering to maximize income. This scenario is most often seen in large, commercial operations, where, for instance, a sow with a fractured leg or a cow with a cancerous eye could be kept alive without expensive treatment until parturition or weaning of offspring. It is interesting to note that the laboratory-animal veterinarian is required by law to euthanize when faced with hopeless animal suffering, while the private practitioner is hamstrung by laws of private property in situations that do not constitute cruelty under the law.

The most obvious and rewarding use of euthanasia—killing without causing pain or distress—is to end an animal's suffering due to unremitting illness or fatal injury. However, there are other uses of euthanasia, such as end points for research, humane slaughter for meat, and humane killing of unwanted pets by pounds, shelters, or veterinarians. The AVMA Panel on Euthanasia periodically updates and publishes its report on euthanasia. The report examines methods of killing and labels as unacceptable those that cause animals to suffer. For instance, the report accepts an overdose of anesthetic, which causes an animal to become unconscious before dying, but condemns an overdose of paralytic drug, which causes motor and respiratory paralysis and suffocation in an alert animal.

Many small-animal veterinarians are confronted with requests for "convenience" euthanasia—euthanasia of healthy pets for owners who have rejected the implied contract of care they incurred when they acquired the pet. Some veterinarians avoid these ethical dilemmas by refusing categorically to perform any "convenience" euthanasia, even though they know that the owner may choose a nonhumane alternative, such as abandonment. Others accept such animals on the condition that they be allowed to find a home for the animal as an alternative to euthanasia; this route obviously requires time, effort, and probably expense on the part of the veterinarians but helps to satisfy their obligation to the animal.

Accepting an animal for euthanasia, and then not performing it, however, is a breach of contract and indefensible on legal grounds. One interesting dilemma that has challenged equine veterinarians is insurance companies' requirement that expensive horses be euthanized if they are rendered unfit by accident or illness for an insured purpose (e.g., racing, breeding, or showing) even if these animals are otherwise capable of a pain-free, or even useful, existence. When enormous sums of money are at stake, consideration of the animal's interests tends to disappear.

Veterinarians and Anticruelty Laws

Animal cruelty laws are notoriously lax. Most allow conviction only in cases of purposeful abuse, and in any case generally result in insignificant fines. However, the veterinarian may be able to make a difference in the lives of animals by reporting and testifying in animal abuse cases. Reporting a client for battering his dog or starving his horses or other stock, when all efforts at education and persuasion are exhausted, may be the only means of protecting animals. In taking a stand as an animal advocate, the veterinarian may experience a loss of clientele and income, thereby placing personal interest in conflict with animal and client interests.

The Veterinarian's Obligation to Society

The veterinarian's obligation to society can also be the occasion for conflicts relating to self or business interests. The most straightforward example may be the protection of society from contaminated animal-source foods. Hormonal and medicinal additives to feed, or treatments of individual animals with medications, can result in residues in meat and milk. These products, if allowed for food animals, have government-mandated withdrawal times before slaughter or milking. Sometimes products used in animal production are not approved for any food animal administration. Yet because of poor planning, inattention to withdrawal times, or attempt to defraud, producers may send contaminated animals or their products to market. The underlying motive is usually profit. If a veterinarian discovers that a producer is feeding an illegal additive, or if, for example, a heifer is sent to slaughter before the withdrawal time of the penicillin she was given, the food-animal veterinarian has a public-health obligation—an obligation to society—to report the client despite professional confidentiality concerns. The loss of one client may be the least of the financial impact of such an ethical choice; other potential or actual clients may avoid association with the veterinarian because of fear of also being turned in, as some illegal practices in the food-animal industry may be widespread, especially in a given region.

The laboratory-animal veterinarian's career can be seen as a service to society, in that he or she provides clinical support or scientific information for the advancement of scientific knowledge. Despite his or her legal mandate as animal advocate, the veterinarian may experience personal conflict in areas of pain or disease research; for example, studies that involve the most animal suffering may also provide the most useful information for the betterment of humans and animals alike. The laboratory-animal veterinarian must also come to grips with the fact that virtually all of his or her patients will be killed at the end of a study.

The zoo or wildlife veterinarian serves societal interests in areas of animal conservation and wildlife management. Incarceration, as in a zoo, is not generally in individual animals' interests, but captive breeding programs may be needed to preserve a valued species. Similarly, situations may arise in which a disease is introduced into study animals to determine pathophysiology or treatment for that species or similar groups. The use of wild animals in research, especially when capture is a part of the research design, has been severely criticized by animal welfare and rights groups because of unacceptably high numbers of "stress" losses of animals used in the studies.

Policing the Profession: Obligations to Peers

The veterinarian, like practitioners in other professions, may have to take an ethical or legal stand regarding the practices of his or her peers—as, for example, when one gives testimony in a malpractice suit. Certainly a person's choice in business practices and commitment to medical standards indicate the quality of his or her moral fiber and loyalty to the profession. It is not unusual for veterinarians to sever professional or personal ties with other veterinarians over professional standards, although it is rare for them to make allegations of malpractice or business malfeasance of other veterinarians. This course is largely left to state boards of veterinary medicine, which respond to complaints by the public. Reluctance to speak out against professional misconduct by other veterinarians is not unique to this profession. A certain degree of prudence must be exercised by professionals to avoid unfairly slandering a colleague without knowing the entire story; for instance, a client's account of a veterinarian's actions may be biased and medically naïve. Many veterinarians also believe that exposing misconduct puts the entire profession in a bad light, even if the public would likely have a positive regard for "policing the ranks." Veterinarians, like other professionals, are allowed a fair amount of leeway in regulating themselves, since they are presumed to know the issues better than laypeople. Failure to self-police can result in loss of autonomy, with rules initiated and governed by people who know little about the profession, such as legislators.

The Veterinarian's Obligation to Self and Personal Values

The veterinarian's obligation to self is best fulfilled by examination of and adherence to his or her professional and personal values. Some veterinarians believe the veterinarian's only or major loyalty should be to the animal. Most veterinarians probably enter the profession with a desire to protect animal health and relieve animal suffering, without an understanding of competing interests. A fuzzy or unexamined ethic may lead to compromising professional decisions. Veterinary schools have responded to the need for ethical training in their curricula, with the understanding that veterinary students need intellectual tools to examine their own ethics throughout their professional lives.

Veterinary Ethics Today

The profession is by no means monolithic in its attitudes, but the AVMA and other veterinary organizations have gradually begun to take official positions on animal issues. A number of practitioners' organizations, including the American Society of Laboratory Animal Practitioners, the American Association of Bovine Practitioners, the American Association of Equine Practitioners, and some state veterinary organizations, have taken animal-welfare positions or have held symposia or meetings pertaining to issues of concern to them. Advocacy groups, such as the Association of Veterinarians for Animal Rights, have emerged. The Animal Welfare Committee of the AVMA has encouraged the association to take published positions on a variety of companion animal, exhibit and performance animal, research animal, and agricultural animal issues. Although some positions are weak and tentative (mainly on agricultural issues), many are specifically protective (e.g., condemning use of the steel-jawed trap and recommending to the American Kennel Club and breed associations that ear cropping be dropped from standards and that dogs with cropped ears be prohibited from showing). The AVMA also sponsors an annual Animal Welfare Forum, in which veterinary educators, animal advocates, philosophers, and others examine the need for animal-welfare reform within the profession.

Given that the formal articulation and organized study of veterinary ethical issues are new, the field has made a good deal of progress. In the future, we can expect the emergence of more sophisticated treatments of many of the issues we have articulated. With society's expectations that the veterinarian serve as mandated animal advocate (as evidenced by the aforementioned laboratory-animal laws), veterinarians will doubtless be in the forefront of emerging social concerns about animal use and treatment.

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SEE ALSO: *Animal Research; Animal Welfare and Rights: Pet and Companion Animals; Care; Cloning: Scientific Background; Harm; Research, Unethical; Value and Valuation*

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VIRTUE AND CHARACTER

• • •

"Virtue" is the translation of the ancient Greek *arete*, which meant any kind of excellence. Inanimate objects could have *arete*, since they were assumed to have a *telos*, that is, a purpose. Thus, the *arete* of a knife would be its sharpness. Animals could also have *arete*; for example, the strength of an ox was seen as its virtue. Though an animal could possess *arete*, the Greeks assumed natural potentialities in men and women to be virtues requiring enhancement through habits of skill. Therefore, Aristotle defined virtue as "'a kind of second nature' that disposes us not only to do the right thing rightly but also to gain pleasure from what we do" (Aristotle, 1105b25–30).

Because there are many things that "our nature" as humans inclines us to do, Aristotle argues, there can be many human virtues. How particular virtues are constituted can vary with different understandings of "human nature" and the different social roles and their correlative skills. Yet the virtues, according to Aristotle, are distinguished from the arts, since in the latter excellence lies in results. In contrast, for the virtues it matters not only that an act itself is of a certain kind, but also that the agent "has certain characteristics as he performs it; first of all, he must know what he is doing; secondly, he must choose to act the way he does, and he must choose it for its own sake; and in the third place, the act must spring from a firm and unchangeable character" (Aristotle, 1105a25–30).

The word *hexis*, which Aristotle uses for "character," is the same word that denotes the habitual dispositions constitutive of the virtues. Character, therefore, indicates the stability that is necessary so that the various virtues are acquired in a lasting way. Character is not simply the sum of the individual virtues; rather, it names the pattern of thought and action that provides a continuity sufficient for humans to claim their lives as their own (Kupperman). However, the material form associated with character may vary from one society to another. Therefore any definition of virtue, the virtues, and character can be misleading because it can conceal the differences between various accounts of the nature and kinds of virtues as well as character.

The Role of Virtue in Recent Moral Philosophy

Ancient philosophers as well as Christian theologians, though offering quite different accounts of the virtues, assumed that any account of the well-lived life had to take virtue into consideration. Modern moral philosophy, in contrast, treats virtues—if it treats them at all—as secondary to an ethics based on principles and rules. The attempt to secure an account of morality that is not as subject to variations as an ethics of virtue certainly contributed to this displacement of virtues. The first edition of the *Encyclopedia of Bioethics*, for example, had no entry on virtue or character.

In his widely used and influential introduction to philosophical ethics, William Frankena manifests the approach to ethics that simply assumed that considerations of virtue were secondary. According to Frankena, ethical theory should be concerned primarily with justifying moral terms and clarifying the differences between appeals to duty and consequences. The virtues, to the extent they were discussed by theorists such as Frankena, were understood as supplements to the determination of right and wrong action. The virtues in such a theory were seen more as the motivational component in more basic principles, such as benevolence and justice. As Frankena put it,

> We know that we should cultivate two virtues, a disposition to be beneficial (i.e., benevolence) and a disposition to treat people equally (justice as a trait). But the point of acquiring these virtues is not further guidance or instructions; the function of the virtues in an ethics of duty is not to tell us what to do, but to insure that we will do it willingly in whatever situation we may face. (Frankena, p. 67)

Frankena's understanding of the nature and role of the virtues drew on the commonsense view that in order to know what kind of person one ought to be, one needs to know what kind of behavior is good or bad. Unless one knows what constitutes acts of truth-telling or lying, one has no way to specify what the virtue of truthfulness or honesty might entail. Ethical theories were assumed to be aids to help people make good decisions on the basis of well-justified principles or rules. Virtues were secondary for that endeavor.

This account of ethics seemed particularly well suited to the emerging field of bioethics. It was assumed that the task of medical ethics was to help physicians and other healthcare providers make decisions about difficult cases created by the technological power of modern medicine. Whether a patient could be disconnected from a respirator was analyzed in terms of the difference between such basic rules as "do no harm" and "always act that the greatest good for the greatest number be done." The case orientation of medical decision making seemed ideally suited to the case orientation of ethical theory exemplified by Frankena.

In their influential book, *Principles of Biomedical Ethics*, Tom L. Beauchamp and James F. Childress retain the structure of ethics articulated by Frankena. Their account of biomedical ethics revolves around the normative alternatives of utilitarian and deontological theories and the principles of autonomy, nonmaleficence, beneficence, and justice. Each of these fundamental principles has correlative primary virtues—that is, respect for autonomy, nonmalevolence, benevolence, and justice—but these "virtues" play no central role. Beauchamp and Childress justify leaving an account of virtue to the last chapter by saying that there are no good arguments for "making judgments about persons independent of judgments about acts or … making virtue primary or sufficient for the moral life" (p. 265).

Both philosophers (Pincoffs) and theologians (Hauerwas) have challenged the assumption that ethics in general and biomedical ethics in particular should be focused primarily on decisions and principles. It is a mistake, they argue, to separate questions of the rightness or goodness of an action from the character of the agent. To relegate the virtues to the motivation for action mistakenly assumes that the description of an action can be abstracted from the character of the agent. To abstract actions from the agent's perspective fails to account for why the agent should confront this or that situation and under what description. Those who defended the importance of virtue for ethics argued, following Aristotle, that *how* one does *what* one does is as important as what one does.

The renewed interest in the nature and significance of virtue ethics has been stimulated by the work of Alasdair MacIntyre, in particular his book *After Virtue* (1984). MacIntyre's defense of an Aristotelian virtue theory was but a part of his challenge to the presuppositions of modern moral theory. MacIntyre attacked what he called "the Enlightenment project," the attempt to ground universal ethical principles in rationality qua rationality—for example, Kant's categorical imperative (Kant). MacIntyre agrees that principles and rules are important for ethics, but he rejects any attempt to justify those principles or rules that abstracts them from their rootedness in the historical particularities of concrete communities. The narratives that make such communities morally coherent focuses attention on the virtues correlative to those narratives. For the Greeks, for example, the *Odyssey* acted as the central moral text for the display of the heroic virtues. To separate ethics from its dependence on such narratives is to lose the corresponding significance of the virtues.

MacIntyre's defense of an ethics of virtue is part of his challenge to the attempt to secure agreement among people who share nothing besides the necessity to cooperate in the interest of survival. Enlightenment theories of ethics, MacIntyre argues, falsely assume that an ahistorical ethics is possible; a historical approach tries to justify ethical principles from anyone's (that is, any rational individual's) point of view.

Renewed interest in the ethics of virtue has accompanied a renewed appreciation of the importance of community in ethics. Those commentators who emphasize the importance of community presume that morally worthy political societies are constituted by goods that shape the participants in those societies to want the right things rightly. Therefore ethics, particularly an ethics of virtue, cannot be separated from accounts of politics. Such a politics cannot be reduced to the struggle for power but, rather, is about the constitution of a community's habits for the production of a certain kind of people—that is, people who have the requisite virtues to sustain such a community.

Bioethics and the Ethics of Virtue

In the past the practice of medicine was thought to be part of the tradition of the virtues. As Gary Ferngren and Darrel Amundsen observe, "If health was, for most Greeks, the greatest of the virtues, it is not surprising that they devoted a great deal of attention to preserving it. As an essential component of *arete*, physical culture was an important part of the life of what the Greeks called *kalos kagathos*, the cultivated gentleman, who represented in classical times the ideal of the human personality" (p. 7). It should not be surprising, therefore, that not only was health seen as an analogue of virtue but medicine was understood as an activity that by its very nature was virtuous. In medical ethics, the "ethics of virtue" approach tends to focus on the doctor-patient relationship. The trust, care, and compassion that seem so essential to a therapeutic relationship are virtues intrinsic to medical care. Medicine requires attention to technical knowledge and skill, which are virtues in themselves; however, the physician must also have a capacity—compassion—to feel something of patients' experience of their illness and their perception of what is worthwhile (Pellegrino). Not only compassion but also honesty, fidelity, courage, justice, temperance, magnanimity, prudence, and wisdom are required of the physician.

> Not every one of these virtues is required in every decision. What we expect of the virtuous physician is that he will exhibit them when they are required and that he will be so habitually disposed to do so that we can depend upon it. He will place the good of the patient above his own and seek that good unless its pursuit imposes an injustice upon him, or his family, or requires a violation of his own conscience. (Pellegrino, p. 246)

The importance of virtue for medical ethics has been challenged most forcefully by Robert Veatch. According to Veatch, there is no uncontested virtue ethic. The Greeks had one set of virtues, the Christians another, the Stoics another; and there is no rational way to resolve the differences among them. This is a particularly acute problem because modern medicine must be practiced as "stranger medicine," that is,

> medicine that is practiced among people who are essentially strangers. It would include medicine that is practiced on an emergency basis in emergency rooms in large cities. It would also include care delivered in a clinic setting or in an HMO that does not have physician continuity, most medicine in student health services, VA Hospitals, care from consulting specialists, and the medicine in the military as well as care that is delivered by private practice general practitioners to patients who are mobile enough not to establish long-term relationships with their physicians. (Veatch, p. 338)

Virtue theory is not suited to such medicine, Veatch argues, because "there is no reasonable basis for assuming that the stranger with whom one is randomly paired in the emergency room will hold the same theory of virtue as one's self" (p. 339). The ethics of "stranger medicine" is best construed, Veatch contends, on the presumption that the relationship between doctor and patient is contractual. Such a relationship is best characterized by impersonal principles rather than in terms of virtue. The virtues make sense only within and to particular communities, and therefore only within a "sectarian" form of medicine.

Veatch's argument exemplifies what Alasdair MacIntyre calls the Enlightenment project. Yet MacIntyre would not dispute the descriptive power of Veatch's characterization of modern medicine. He thinks medicine is increasingly becoming a form of technological competence, bureaucratically institutionalized and governed by impersonal ethical norms. MacIntyre simply wishes to challenge the presumption that this is a moral advance. Put more strongly, MacIntyre challenges the presumption that such a medicine and the morality that underlies it can be justified in the terms Veatch offers. In particular, he asks, how can one account for the trust that seems a necessary component of the doctor-patient relationship without relying on an ethic of virtue?

Contrary to Veatch, James Drane and others argue that medicine does not exist within a relationship between strangers, but in fact depends on trust and confidence, if not friendship, between doctor and patient. Ethics, they hold, is not based on principles external to medical care and then applied to medicine; rather, medicine is itself one of the essential practices characteristic of good societies. Medicine thus understood does not need so much to be supplemented by ethical considerations based on a lawlike paradigm of principles and rules; on the contrary, medical care becomes one of the last examples left in liberal cultures of what the practice of virtue actually looks like. Those who work from an ethics of virtue do not come to medicine with general principles justified in other contexts, to be applied now to "medical quandaries"; rather, they see medicine itself as an exemplification of virtuous practices. Here medicine is understood in the Aristotelian sense, as an activity—that is, as a form of behavior that produces a result intrinsic to the behavior itself (Aristotle). In MacIntyre's language, medicine is a practice in which the goods internal to the practice extend our powers in a manner that we are habituated in excellence (MacIntyre). Put simply, the practice of medicine is a form of cooperative human activity that makes us more than we otherwise could be.

MacIntyre's account of practice and Aristotle's account of activity remind us that the kinds of behavior that produce virtue are those done in and for themselves. Thus virtue is not acquired by a series of acts—even if such acts would be characterized as courageous, just, or patient—if they are done in a manner that does not render the person performing the actions just. As Aristotle says, "Acts are called just and self-controlled when they are the kinds of acts which a just and self-controlled man would perform; but the just and self-controlled man is not he who performs these acts, but he who also performs them in the way that the just and self-controlled men do" (1105B5–9).

There is an inherently circular character to this account of the virtues that cannot be avoided. We can become just only by imitating just people, but such "imitation" cannot be simply the copying of their external actions. Becoming virtuous requires apprenticeship to a master; in this way the virtues are acquired through the kind of training necessary to ensure that they will not easily be lost. How such masters are located depends on a social order that is morally coherent, so that such people exhibit what everyone knows to be good. Medicine, because it remains a craft that requires apprenticeship, exemplifies how virtue can and should be taught.

William F. May suggests that the very meaning of a profession implies that one who practices it is the kind of person who can be held accountable for the goods, and corresponding virtues, of that profession. Medicine as a profession functions well to the extent that medical training forms the character of those who are being initiated into that practice. This does not imply that those who have gone through medical training will be virtuous in other aspects of their lives; it does imply, however, that as physicians they will exhibit the virtues necessary to practice medicine.

In *Becoming a Good Doctor: The Place of Virtue and Character in Medical Ethics*, James Drane suggests that the character of the doctor is part of the therapeutic relationship, and that there is a structure to the doctor-patient relationship that is based on the patient's trust that the physician will do what is necessary to help the patient heal. The physician's task, Drane argues, is not to cure illness but to care for patients, and such care depends on the character of the physician. Drane, in contrast to Robert Veatch, argues that medicine must remain a virtuous practice if it is to be sustained in modern societies. Paul Ramsey's insistence that the focus of medicine is not the curing of illness but the care of patients "as persons," can be interpreted as an account of medicine commensurate with an emphasis on the virtues. The particular character of the judgments clinicians must make about each patient is not unlike Aristotle's description of practical wisdom, or *phronesis*. According to Aristotle, ethics deals with those matters that can be other; a virtuous person not only must act rightly but also must do so "at the right time, toward the right objects, toward the right people, for the right reasons, and in the right manner" (1106B20–23). Similarly, physicians must know when to qualify what is usually done in light of the differences a particular patient presents. From this perspective, medicine is the training of virtuous people so they are able to make skilled but fallible judgments under conditions of uncertainty. The increasing recognition of the narrative character of medical knowledge (Hunter) reinforces this emphasis on virtue and character. That the disease entities used for diagnosis are implicit narratives means medicine is an intrinsically interpretative practice that must always be practiced under conditions of uncertainty. Accordingly, patient and physician alike bring virtues (and vices) to their interaction that are necessary for sustaining therapeutic relationships.

Continuing Problems for an Ethics of Virtue

To construe medicine as a virtue tradition establishes an agenda of issues for investigation in medical ethics. How are the virtues differentiated? Are there some virtues peculiar to medicine? How are different virtues related to one another? How is the difference between being a person of virtue and character, and the possession of the individual virtues, to be understood? Can a person possess virtues necessary for the practice of medicine without being virtuous? Can a person be courageous without being just?

Such questions have been central to the discussion of the virtues in classical ethical theory. For example, Aristotle maintained that none of the individual virtues could be rightly acquired unless they were acquired in the way that the person of practical wisdom would acquire them. Yet one could not be a person of practical wisdom unless one possessed individual virtues such as courage and temperance. Aristotle did not think the circular character of his account was problematic because he assumed that the kind of habituation commensurate with being "well brought up" is the way we were initiated into the "circle."

Yet in what sense the virtues are habits remains a complex question that involves the question of how the virtues are individuated. For Aristotle some of the virtues are "qualities" that qualify the emotions, but not all the virtues are like courage and temperance in that respect. Aristotle's resort to the artificial device of the "mean" for locating the various virtues has caused more problems than it has resolved. These matters are made even more complex by the importance Aristotle gives to friendship in the *Nicomachean Ethics*, where it is treated as a virtue even though it is not a quality but a relation.

The Christian appropriation of the virtues did little to resolve these complex issues. For Saint Augustine the virtues of the pagans were only "splendid vices" insofar as they were divorced from the worship of God. In "Of the Morals of the Catholic Church," Augustine redescribed the fourfold division of the virtues as four forms of love:

> that temperance is love giving itself entirely to that which is loved; fortitude is love readily bearing all things for the loved object; justice is love serving only the loved object, and therefore ruling rightly; prudence is love distinguishing with sagacity between what hinders it and what helps it. The object of this love is not anything, but only God, the chief good, the highest wisdom, the perfect harmony. So we may express the definition thus, that temperance is love keeping itself entire and uncorrupt for God; fortitude is love bearing everything readily for the sake of God; justice is love serving God only, and therefore ruling well all else, as subject to man; prudence is love making a right distinction between what helps it toward God and what might hinder it. (p. 115)

Thomas Aquinas, influenced profoundly by Augustine and Aristotle, provided an extraordinary account of the virtues that in many ways remains unsurpassed. According to Aquinas, charity, understood as friendship with God, is the form of all the virtues. Therefore, like Augustine, he maintained that there can be no true virtue without charity (Aquinas). Unlike Augustine, however, Aquinas grounded the virtues in an Aristotelian account of human activity, habits, and passions. For Aquinas, therefore, the virtues are dispositions or skills necessary for human flourishing.

Aquinas's account of the virtues does present some difficulties, however. Even though he followed Augustine's (and Plato's) account of the four "cardinal" virtues—prudence, courage, temperance, and justice—neither he nor Augustine successfully argued why these four should be primary. (Aristotle does not single out these four as primary.) Indeed, it is clear from Aquinas's account that he thought of the cardinal virtues as general descriptions that required more specification through other virtues, such as truthfulness, gentleness, friendship, and magnanimity.

These issues obviously bear on medicine considered as part of the virtue tradition. Are there virtues peculiar to the practice of medicine that require particular cultivation by those who would be doctors? If the virtues are interdependent, can a bad person be a good doctor? Or, put more positively, do the virtues required to be a good doctor at least set one on the way to being a good person? If the Christian claim that the "natural virtues" must be formed by the theological virtues of faith, hope, and charity is correct, does that mean that medicine as a virtue requires theological warrant?

Some of these questions have not been explored with the kind of systematic rigor they deserve. MacIntyre, however, suggests some promising directions. For example, he has argued that practices are not sufficient in themselves to sustain a full account of the individual virtues, their interrelations, or their role in areas such as medicine. Practices must be understood within the context of those goods necessary for the display of a whole human life and within a tradition that makes the goods that shape that life intelligible (MacIntyre). Those initiated into the practice of medicine, for example, might well have their moral life distorted if medicine as a virtue was not located within a tradition that placed the goods that medicine serves within an overriding hierarchy of goods and corresponding virtues. Yet what such a hierarchy would actually consist of remains to be spelled out.

These matters are made more complex to the extent that those who stand in virtue traditions cannot draw on the distinction between the moral realm and the nonmoral realm so characteristic of Kantian inspired moral theory. Once distinctions between the moral and the nonmoral are questioned, strong distinctions between deontological ethics, consequential ethics, and the "ethics of virtue" are equally questionable. L. Gregory Jones and Richard Vance argue, for example, that to assume that the virtues are an alternative to an ethics of principles and rules simply reproduces the assumption that there is a distinct realm called "ethics" that can be separated from the practices of particular communities. It was this assumption that led to the disappearance of virtue from modern moral theory.

For example, Aristotle thought that how a person laughed said much about his or her character. Therefore, what we consider matters of personal style and/or etiquette were considered morally significant by the ancients. For the virtues to encompass such matters as part of human character makes problematic the distinction so crucial to modernity—that is, the distinction between public and private morality. Thus, from such a perspective, what physicians do in their "private time" may well prove important for how they conduct themselves morally as physicians.

Equally troubling is the role *luck* plays in an ethics of virtue. For example, Aristotle thought that a lack of physical beauty made it difficult for a person to be happy: "For a man is scarcely happy if he is very ugly to look at, or of low-birth, or solitary and childless" (1099A35–37). Modern egalitarian sensibilities find it offensive to think that luck might play a role in our being virtuous (Card), yet the Greeks thought it unavoidable for any account of the virtuous and happy life. Indeed, as Martha Nussbaum has argued, the very strength the virtues provide create a "fragility" that cannot be avoided. Illness may well be considered part of a person's "luck" that limits the ability to live virtuously. Medicine may thus be understood as the practice that can help restore a person to virtue.

How medicine and an ethics of virtue are understood differs greatly from one historical period to another as well as from one community to another. To the extent that medicine can no longer be sustained as a guild, perhaps it should no longer be construed in the language of the virtues. As Mark Wartofsky asks, "How is benevolence, as a distinctively *medical* virtue, to be interpreted in those forms of the practice where the individual patient is literally seen not as a person but only through the mediation of the records, laboratory reports, or a monitoring of data in a computer network?" (p. 194).

Yet many continue to argue that any treatment of medicine that makes the virtues of both physician and patient secondary cannot be a medicine anyone should desire or morally support. Truthfulness, for example, is a virtue intrinsic to the care of patients; without it, whatever care is given, even if it is effective in the short run, cannot sustain a morally healthy relationship between patient and physician. Good medicine requires communication and participation by the patient that can be secured only by the physician's telling the patient the truth as well as the patient's demanding truthful speech. Without such truthful communication, the patient, as Plato argued, is reduced to the status of a slave (Drane). Ironically, in the name of freedom, the kind of medicine Veatch envisioned looks like a medicine fit for slaves—admittedly an odd conclusion since Veatch assumes that a contractual relation between physician and patient is the condition for a free exchange. Moreover, even Veatch continues to assume that truth-telling is a virtue necessary for medicine to survive as a practice between strangers.

For his part, Drane raises issues at the heart of any account of the virtues as well as of medicine as a virtue tradition. If it is true that truthfulness is a virtue intrinsic to the practice of medicine, can that virtue conflict with, for example, the virtue of benevolence? Plato and Aristotle assumed the unity of the virtues. Accordingly, the virtues would not conflict with one another if they were rightly oriented to a life of happiness. Aquinas held that the virtues might conflict during the time we are "wayfarers," but not in heaven. Drane resolves the possibility of such conflict by suggesting that medicine requires the truth to be spoken, but benevolently. One may doubt, however, whether this attractive suggestion resolves all questions about the conflict among the virtues, particularly in medical care.

If medicine is to be construed in the tradition of the virtues, the virtues and character of patients must be considered. The very term *patient* suggests a necessary virtue that is closely associated with Christian accounts of the virtues. If we must learn to live our lives patiently, then illness may appear in quite a different light than it does in those accounts of the moral life that have no patience with patience. For example, if suffering is thought to be an occasion to learn better how to be patient, then a medicine of care may be sustainable even when cure cannot be accomplished.

Karen Lebacqz suggests that the circumstances in which patients find themselves, especially the circumstance of pain and helplessness, can invite them to become accepting and obedient. These traits, which may appear virtuous, may just as likely be vices if they are not shaped by fortitude, prudence, and hope. Lebacqz suggests that these virtues are particularly relevant to the condition of being a "patient," because they provide the skills necessary to respond to illness in a "fitting" manner. No *one* way of expressing these virtues suits all patients; yet they do provide the conditions for our learning the tasks required in health and illness.

Questions of virtue also relate to issues of justice in the distribution of healthcare. For if the patient can ask medicine to supply any need abstracted from a community of virtue, then there seems no way to limit in a moral way the demands for medical care. In such a situation, those who have more economic and social power can command more than is due medically, since medicine seems committed to meeting needs irrespective of the habits that created those needs. Liberal political theory has often tried to show how a just society is possible without just people; a "medicine of strangers" may result in a maldistributed medicine.

Conclusion

There is no consensus about the nature of virtue and/or the virtues that a good person should possess. That should not be surprising: the attempt to introduce the virtues into bioethics has gone hand in hand with an emphasis on the inevitable historical character of ethical reflection. If, as MacIntyre has argued, the virtues can be described only in relation to a particular tradition and narrative, then the very assumption that a universal account of ethics—and in particular, of medical ethics—is problematic. Yet the very character of medicine as a practice whose purpose is care for the ill remains one of the richest resources for those committed to an account of the moral life in the language of the virtues.

STANLEY M. HAUERWAS (1995)

SEE ALSO: *Beneficence; Care; Compassionate Love; Ethics: Normative Ethical Theories; Justice; Medicine, Art of; Narrative; Patients' Responsibilities: Virtues of Patients; Trust*

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W

WARFARE

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I. Introduction
II. Medicine and War
III. Public Health and War
IV. Chemical and Biological Weapons

I. INTRODUCTION

In the immortal words of General William Tecumseh Sherman, one of its better known practitioners, “war is hell.” Rather than diminishing with the cessation of the superpower rivalry that dominated the international scene for nearly half a century, the incidence of warfare is increasing. As the twenty-first century began over three dozen wars were being fought around the globe, like an insidious disease with no cure is in sight.

Types of War

Warfare is generally understood as armed conflict, often prolonged, between nations or parts of nations. Civil wars are fought between sections of the population within a nation. When an armed group engages in military action against its government, the war is an insurrection or a revolution, sometimes called a war of national liberation.

Despite its abhorrent character, nations routinely prepare for armed conflict, defensively, most claim. Some actively institute it for reasons their leaders deem necessary.

After the September 11, 2001, bombings of the World Trade Center and Pentagon, a new kind of war emerged, a war against terrorism. This turned out initially to be military action by the United States and its allies against the Taliban rulers of Afghanistan and against the international organization believed to be responsible for the September 11th attacks. It was followed shortly by Israeli forces invading Palestinian cities in an attempt to stop terrorist suicide bombings.

The point of all warfare, whether international, civil, revolutionary, or against terrorism, is to cause enough damage—human, physical, psychological, social, economic—that the other side gives up, surrenders, ceases to resist, or sometimes ceases to exist as a viable society. Throughout history the tactics of warfare have always included, sometimes reluctantly, sometimes not, but whenever deemed necessary, the deliberate targeting of enemy civilians. Contemporary military tactics emphasize creating severe damage to the enemy with as little loss of life on one’s own side as possible.

Weapons of War

Over the centuries ever newer and more destructive means of waging war have been designed and produced. Contemporary wars are waged with highly sophisticated and lethal weapons by those societies that have sufficient technological and economic resources. The most deadly of these are the so-called weapons of mass destruction—nuclear, chemical, and biological weapons.

NUCLEAR WEAPONS. First used by the United States on the Japanese cities of Hiroshima and Nagasaki at the end of World War II, nuclear weapons can destroy an entire urban area in one blast. Thousands of them, capable of leveling cities of potentially hostile countries, are deployed by the United States, Russia, Great Britain, France, China, Israel, India, and Pakistan. A one-megaton hydrogen bomb, a medium-sized nuclear weapon, would instantly destroy everything within a radius of a mile and a half of where it explodes. Every building in that radius would disintegrate, and all living creatures would die in a fraction of a second, and disappear. Within a three-mile radius, the heat would be so severe that anything exposed to it would burst into flames. As far as eight miles away people would suffer second-degree burns. As much as one-third of the population of a city of 1 million people would be killed or wounded by the blast and fire of such a bomb.

Smaller weapons, sometimes called mininukes or bunker busters, are designed to destroy underground targets. These bombs also create a huge crater above the target and spew radioactive dust for miles around the center. These smaller nuclear weapons are considered "usable" by military planners, by contrast with the larger city-destroying weapons whose value consists primarily in deterrence.

CHEMICAL AND BIOLOGICAL WEAPONS. Chemical weapons, first used by both sides in World War I in the form of poison gas, were later employed by Italy against Ethiopia in the 1930s, by the United States in South Vietnam in the 1960s, and by Iraq against Iran in the 1980s. In the twenty-first century the most advanced chemical warfare agent is binary nerve gas, which consists of two chemicals of relatively low toxicity that mix when their containing munition is fired. At that point they produce a lethal gas that is odorless and can be absorbed through the skin and eyes as well as by inhalation. The gas attacks the central nervous system, and those exposed to even low concentrations of it experience sweating and vomiting, followed by paralysis, respiratory failure, and then death.

Biological weapons spread viruses that cause diseases such as anthrax, botulism, plague, and smallpox, diseases that are usually accompanied by high fevers and deadly internal bleeding. Other viruses are designed to attack the lungs, brain, spinal cord, or heart. Once dispersed, these diseases can easily spread throughout a concentrated population, causing incurable illness, panic, and death.

Because it can also be used to manufacture benign agricultural and medicinal products, the equipment for manufacturing chemical or biological weapons is considered, in military terminology, "dual use." A pharmaceutical plant making civilian medical products might become a military target because it could also be used to make weapons for warfare.

The 1975 Biological Weapons Convention prohibited the development, production, and stockpiling of such weapons. But because they are relatively easy and cheap to produce—they have been called "a poor person's nuke"—less developed countries may consider them affordable weapons of mass destruction.

CONVENTIONAL WEAPONS. Conventional weapons include supersonic aircraft, swift ships and silent submarines, precision-guided munitions, remote-controlled pilot-less aircraft, rapid all-terrain vehicles for ground troops, land mines impervious to detection, visual aids for seeing in the dark, space-based sensors to pinpoint enemy targets, assault rifles that fire dozens of rounds a second, handheld grenade and rocket launchers, and shoulder-fired antiaircraft missile launchers.

SPACE-BASED WEAPONS. Space-based lasers and antimissile systems are being developed by the United States to give what military planners call full-spectrum dominance—control of land, sea, air, and outer space.

Ethical Frameworks

War involves the inflicting of pain and suffering, and the deliberate killing of other human beings, often on a large scale. It also inflicts serious emotional trauma on those who do the killing. Because warfare is so terrible, so contrary to the best inclinations of the human character, but because it is also a fact of national and international life, concerned persons through the ages have attempted to provide ethical frameworks with which to evaluate it.

Three such frameworks are traditionally presented, with a fourth added since the middle of the twentieth century. The first, often called the realist position, is the belief that a war must be prosecuted to a successful conclusion using all available means. The second, pacifism, maintains that all killing is wrong, that war is so inhumane that no one should take part in it. The third, and most widely held, is the just war theory, which maintains that, although war is regrettable, it is sometimes necessary and should be fought under specific ethical guidelines. The fourth, relatively new since Mohandas Gandhi (1869–1948) introduced it in waging India's war of national liberation against the British, involves active nonviolence as an effective alternative to the organized killing of warfare.

REALIST APPROACH. Realism is based on the belief that the end justifies the means, necessity knows no law, that if a war must be fought it should be fought totally. This meant, according to the nineteenth-century German theoretician Carl von Clausewitz in his influential book *On War* (1832), that an enemy's military power must be destroyed, and that the country must be conquered in such a way that it cannot produce a new military power. Even the will of the enemy must be destroyed. Whatever means are necessary should be used to force the other side into submission.

The realist approach was epitomized in World War II when the Allies waged what came to be called “total war” against Germany and Japan, insisting on nothing short of unconditional surrender. Earlier President Franklin D. Roosevelt had decried the German bombing of the cities of Warsaw, Poland; Coventry and London, England; and Rotterdam, the Netherlands, calling these campaigns ruthless and shocking to the conscience of humanity. But in pursuit of the goal of unconditional surrender, the United States itself used saturation bombing on cities in Germany and Japan, culminating in the atomic bombing of Hiroshima and Nagasaki.

Those countries that possess nuclear weapons in the twenty-first century have steadily maintained their will to use them if their security is severely threatened, if deterrence fails, regardless of the consequences.

Contemporary warfare tends to absolutize one’s country and the cause for which it is fighting: “My country, right or wrong”; “we’re good, they’re evil”; or, as President George W. Bush put it in launching the war on terrorism, “you’re either with us or you’re with the terrorists.” Given the patriotic fervor that arises when a nation finds itself at war, the vast majority of a country’s political, academic, and even religious leaders tend to support the war. Rare are the instances of religious officials questioning whether the war is right, rarer still those who put forward the great ideals of peace and common humanity as an alternative to fighting and killing.

PACIFISM. Pacifism, refusal to take part in war on religious or humanitarian grounds, is based on the belief that the deliberate taking of human life is wrong. The belief might be religious (e.g., “Thou shalt not kill,” “Love your enemies”), or it could be a conviction that all human life is valuable, and that deliberately terminating it, even an enemy in warfare, violates the integrity of the human condition. A pacifist’s refusal to take part in war is recognized by law in some countries as conscientious objection to military service. Where such refusal is not legal, pacifists suffer the consequences—often imprisonment, and sometimes even death.

JUST WAR THEORY. The just war position is based on the conviction that violence is sometimes necessary to stop aggression or to secure the legitimate goals of one’s country. The phrase *just war* was coined by the Greek philosopher Aristotle in the fourth century B.C.E. to describe military action undertaken to enslave those designed by nature for servitude but who resisted their proper place in the social scale. The term’s classical formulation in Western philosophy began, however, with the Christian theologian Augustine of Hippo in the fifth century C.E.

Augustine was convinced that humanity, corrupted by sin, was prone to violence. Although loving one’s enemies was the Christian ideal and peace the goal, it was inevitable that human cruelty and desire for power would emerge. When this happened, Augustine maintained, force must be used to counteract it. But the intention must always be to restore peace.

The just war theory was later codified under two headings. The first, *jus ad bellum,* was the right to go to war. This could happen only when there was a just cause, and when going to war was a last resort. It also had to be ordered by the proper authority, responsible for the common good of the society. The damage to be inflicted must be proportionate to the good expected by taking up arms.

The second heading, *jus in bello,* concerned ethically proper conduct during a war. This involved two important restrictions: using only those military means that are sufficient to accomplish the goal (sometimes called the principal of proportionality) and a prohibition both on executing hostages and prisoners and on attacking nonmilitary targets (the principle of discrimination).

Governments in modern times have tended to reduce the *jus ad bellum* argument to having a just cause for war, expressed as a serious threat to national integrity or security. Although the Charter of the United Nations declares that all war is illegal, Article 51 allows nations to go to war in self-defense, with every nation free to define self-defense as it sees fit, including the maintenance of access to sufficient natural resources such as water or oil.

Modern weapons assure that some if not many noncombatants will be killed. The *jus in bello* part of the just war theory is increasingly focused not on avoiding such killing, but on preventing public revulsion over it. Political expediency demands that civilians not be considered as direct targets but, in military terminology, as collateral damage, regrettable side effects. Restricting the news media’s access to areas of combat and limiting the media only to information derived from military briefings are ways of keeping civilian casualties from arousing negative public opinion.

ACTIVE NONVIOLENCE. Gandhi, leading the people of India in their struggle for independence against Great Britain in what would otherwise have been a war of revolution or national liberation, introduced a new tactic—active, positive, organized nonviolent resistance. For the most part the Indian war of independence disavowed armed conflict in favor of a disciplined nonviolent movement by large numbers of Indian people. This new kind of war took several decades but resulted in freedom from the British and the creation of the modern nation of India.

Gandhi's tactics were taken up in the late 1950s and 1960s by the American clergyman Martin Luther King Jr. in the struggle for the civil rights of African Americans. It has also been used in other parts of the world, such as in the liberation of South Africa from the oppression of apartheid.

Gandhian nonviolence presents a whole other range of possibilities different from the pacifist refusal to take part in war. A determination to use nonviolent means to resolve international conflicts could involve a nonviolent defense force in which people would be trained in ways of resisting an aggressor through noncooperation and direct, unarmed confrontation. In his 1971 book, *The Politics of Nonviolent Action,* peace researcher Gene Sharp identified more than 146 specific techniques of nonviolent action, ranging from general strikes and boycotts to nonpayment of taxes.

Active nonviolence offers for many a fruitful alternative to the ethical positions of realism, pacifism, and the just war. It does not aim simply at achieving a more effective national defense, but also at establishing a system of human and international relationships that would eventually do away with the need for war altogether. Active nonviolence seeks to address the underlying causes of war by working for the establishment of social justice, environmental protection, and the defense of human rights.

Personal Responsibility

In the reality of the contemporary world, where warfare remains an ongoing possibility, each individual is involved in some way. Wars are made possible not only by political leaders who launch them and military personnel who fight them but also by those who design and produce the weapons, those who arouse citizen support, those who pay for war through their taxes, and those who form a chorus of patriotic approval.

Once a decision has been made for whatever reason to go to war, leaders try to mobilize popular support through communication verging on propaganda, by attempting to withhold negative information, and by discouraging public debate. It is hard to resist the groundswell of nationalistic fervor, hard to find the truth, and hard to see what is really going on, what are the causes, and where real justice lies. Hence the importance of looking at these issues ahead of time, getting information about international trouble spots and likely scenarios before hostilities break out, assessing it all according to what one knows and believes, and exploring realistic nonviolent alternatives.

Warfare is a troubling, vexing question. In the end, each person must make a decision about approving of, participating in, or supporting a war based on one's own personal integrity, which is to say, one's conscience.

GERARD VANDERHAAR

SEE ALSO: *Bioterrorism; Conscience, Rights of;* and other *Warfare* subentries

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II. MEDICINE AND WAR

Ethical conflicts occur whenever medicine and war intersect. This entry discusses four general types of ethical conflict: (1) conflict between the military obligation of physicians and other medical personnel to provide care to members of the military force in which they are serving and the medical obligation to serve others, such as members of opposing military forces and civilians, who need their care; (2) conflict between the obligation of military medical personnel to "conserve the fighting strength" and the medical obligation to respond to the special needs or rights of individual military personnel under their care even if that response hinders the fighting strength; (3) conflict between the combatant and noncombatant roles of medical personnel; and (4) conflict between the national obligation to serve one's country through service in a military force and the international obligation to prevent war or prevent specific actions by the military force of one's country.

The history of physicians' involvement with military forces is a long one. Homer praised the efforts of the sons of Asclepios to provide surgical care before the gates of Troy, and Hippocrates, recognizing that the battleground was an important training ground for surgeons, urged that "he who would become a surgeon should join an army and follow it" (Vastyan, 1978, p. 1695).

However, physicians and other medical personnel had relatively little aid to offer to military casualties until the eighteenth century. Since that time developments in military weaponry and concurrent advances in medical technology and techniques for the evacuation of casualties have made the deployment of medical resources increasingly important to armies and their commanders. To the armies of the czar, for example, Peter the Great brought the *feldsher,* modeled after the *feldscherer* (field barber-surgeon) of the Prussian armies. In the New World deplorable medical care during the American Revolution caused political conflicts over the management of hospitals and healthcare for soldiers. The increase in the number of military casualties during the wars of the nineteenth century and the extraordinary increase in military and civilian casualties during those of the twentieth century, together with dramatic improvements in the ability to treat casualties successfully, led to changes in the types of ethical issues that arise in the context of war and an increase in their number.

Military Obligations Versus Medical Obligations

As a member of the military forces of a nation a military physician is charged with protecting the strength of that force. As a member of the medical profession, however, a physician generally is obligated to care for all the sick and wounded who need his or her services and to set priorities for providing those services on the basis of the urgency of medical need and the effectiveness of medical care.

Hippocrates, often called the father of medicine, apparently rejected the principle that physicians have an obligation in war to succor "enemies" as well as "friends." The evidence for this appears in Plutarch's *Lives* in a reference to "Hippocrates' reply when the Great King of Persia consulted him, with the promise of a fee of many talents, namely, that he would never put his skill at the service of Barbarians who were enemies of Greece" (Plutarch, p. 373).

Just before the start of the U.S. Civil War the American Medical Association (AMA) selected as the model for a commemorative stone carving for the Washington Monument, then being built in the District of Columbia, the painting *Hippocrates Refuses the Gifts of Artaxerxes,* portraying Hippocrates's dismissal of the emissaries of the king of Persia. The inscription the AMA selected was *Vincit Amor Patriae,* "Love of Country Prevails" (Stacey).

In a time of "unjustifiable and monstrous rebellion," a phrase used by one of its leaders, the AMA probably intended by its use of the painting and the inscription to applaud the refusal to provide medical services for enemies. Indeed, no evidence can be found that in the pre–Civil War United States there was a great deal of sympathy for even-handed medical care in time of war (Sidel, 1991b).

PHYSICIANS AS IMPARTIAL HEALERS. A physician's responsibility to treat those in medical need on both sides did not burn itself into public or medical consciousness until the late 1860s, in the aftermath of the Crimean War and the U.S. Civil War. Leadership in increasing the new consciousness was assumed by the nonphysicians Florence Nightingale, who served as a nurse in Turkey and the Crimea from 1854 to 1856, and Dorothea Dix, whose work in bringing humane care to mental patients in the United States led President Abraham Lincoln to invite her to organize the U.S. Army Nursing Corps and become the first superintendent of nurses in the U.S. Army.

Henri Dunant, a Swiss banker who was an eyewitness at the Battle of Solferino in 1859, organized medical services for the Austrian and French wounded. In 1864 he helped initiate an international conference in Geneva that led to the founding of the International Red Cross and its national affiliates. The conference adopted a Convention for the Amelioration of the Condition of the Wounded and Sick in Armed Forces in the Field. Fourteen signatory nations pledged to regard the sick and wounded, as well as personnel, facilities, and transportation for their care, as neutrals on the battlefield. For his efforts Dunant was awarded the first Nobel Peace Prize.

Two contemporaneous events in the United States influenced future codifications and applications of international law and their bearing on medicine. Francis Lieber, a German-born philosopher, lawyer, and historian, was commissioned by the Union forces to draft a code of conduct for armies in the field. The resultant Lieber Code was promulgated in May 1863 as General Order No. 100 by the Union Army. Closely related to that development was the 1865 trial of Captain Henry Wirz, a physician who served as the commandant of the infamous Confederate prison at Andersonville, Georgia. Wirz was charged with a series of offenses involving inhumane treatment of the prisoners under his charge. His plea that "superior orders" mitigated the negligence of duty with which he was charged was disallowed, and Wirz was convicted and sentenced to be hanged.

During the eighty years after the first Geneva treaty on the treatment of war casualties three other related international agreements were negotiated in the Hague and in Geneva. The Convention for the Amelioration of the Wounded, Sick, and Shipwrecked Members of Armed Forces at Sea dealt with the care of casualties of naval warfare. The Convention Relative to the Treatment of Prisoners of War regulated the treatment and repatriation of prisoners. The Convention Relative to the Protection of Civilian Persons in Time of War prohibited deportation, the taking of hostages, torture, and discrimination in treatment. Those three agreements, along with the original Geneva accord, were codified in a single formal document in Geneva in 1949; together they are called the Geneva Conventions. Agreed to at that time by sixty nations, the 1949 conventions were declared binding on all nations according to "customary law, the usages established among civilized people … the laws of humanity, and the dictates of the public conscience" (Geneva Conventions of 1949).

Under the conventions medical personnel are singled out for certain specific protections by an explicit separation of the healing role from the wounding role. Medical personnel and treatment facilities are designated as immune from attack, and captured medical personnel are to be repatriated promptly. In return for that treatment, specific obligations are required of medical personnel:

1. Because they are regarded as noncombatants, medical personnel are forbidden to engage in or be parties to acts of war.
2. The wounded and sick—soldier and civilian, friend and foe—must be respected, protected, treated humanely, and cared for by the belligerents.
3. The wounded and sick must not be left without medical assistance, and only urgent medical reasons authorize any priority in the order of their treatment.
4. Medical aid must be dispensed solely on medical grounds, "without distinctions founded on sex, race, nationality, religion, political opinions, or any other similar criteria."
5. Medical personnel shall exercise no physical or moral coercion against protected persons (civilians), in particular to obtain information from them or from third parties.

Those duties are imposed clearly with no exceptions and are given priority over all other considerations. Thus, the Geneva Conventions formalized the recognition that although professional expertise merits special privileges, it incurs very specific legal as well as moral obligations (Vastyan, 1978). That special role of physicians has been incorporated in the public expectations and the ethical training of doctors in most societies. It also is embedded in the World Medical Association's Declaration of Geneva, which is administered as a "modern Hippocratic Oath" to graduating classes at many medical schools.

There is, however, evidence of deviation from those principles. An example of the erosion of the principle of equal medical care for "enemies" occurred in the United States during the Cold War. The medical society of Maryland and the AMA refused to criticize a Maryland psychiatrist who testified voluntarily before the Un-American Activities Committee of the U.S. House of Representatives in 1960 about information he had obtained while treating an employee of the National Security Agency (NSA). His patient, together with another NSA employee with whom the patient allegedly had had a sexual relationship, later defected to the Soviet Union. The psychiatrist, clearly without his patient's permission, provided to the committee information given to him by that patient, and the material was leaked to the press by the committee. In response to a petition by a group of Maryland psychiatrists and other physicians asking that the psychiatrist be censured, the medical society stated that "the interests of the nation transcend those of the individual" (Sidel, 1961).

Obligations to Enhance Military Strength Versus Personnel Needs

Military physicians must accept priorities different from those of their civilian colleagues (Vastyan, 1974). The primary role of a military physician is expressed in the motto of the U.S. Army Medical Department: "To conserve the fighting strength" (Bellamy). In describing that role, a faculty member of the Academy of Health Sciences at Fort Sam Houston in 1988 cited as "the clear objective of all health service support operations" the goal stated in 1866 by a veteran of the Army of the Potomac in the Civil War: "[to] strengthen the hands of the commanding general by keeping his Army in the most vigorous health, thus rendering it, in the highest degree, efficient for enduring fatigue and privitation [sic], and for fighting" (Rubenstein, p. 145).

Principles of triage that are unacceptable in civilian practice may be required in war, such as placing emphasis on patching up the lightly wounded so that they can be sent back to battle. For example, "overevacuation" (the presumed excessive transfer of personnel to a safe area rather than back to the military operation) is cited as "one of the cardinal sins of military medicine" (Bellamy). Violation of patient confidentiality, which is unacceptable in civilian practice, may be required. Medical personnel may be required to administer experimental drugs or immunizations to troops without their free and informed consent (Annas).

Combatant Versus Noncombatant Roles for Medical Personnel

Perhaps the most dramatic attempt to meld these conflicting obligations was made by the Knights Hospitallers of Saint John of Jerusalem, a religious order founded in the eleventh century. With a sworn fealty to "our Lords the Sick," the knights defended their hospitals against "enemies of the Faith," becoming the first organized military medical officers. They were "warring physicians who could strike the enemy mighty blows, and yet later bind up the wounds of that same enemy along with those of their own comrades" (Vastyan, 1978, pp. 1695–1696).

A more recent example of the erosion of the distinction between combatant and noncombatant roles was demonstrated in a U.S. Army exhibit at the 1967 AMA convention. It was titled "Medicine as a Weapon" and featured a photograph of a Green Beret (Special Forces) aidman handing medicine to a Vietnamese peasant (Liberman et al.). Dr. Peter Bourne, who had been an army physician working with the Special Forces in Vietnam, wrote that the primary task of Special Forces medics was "to seek and destroy the enemy and only incidentally to take care of the medical needs of others on the patrol" (Liberman et al., p. 303).

In 1967 Howard Levy, a dermatologist drafted into the U.S. Army Medical Department as a captain, refused to obey an order to train Special Forces aidmen in dermatological skills. He refused specifically on the grounds that the aidmen were being trained predominantly for a combat role and that cross-training in medical techniques would erode the distinction between combatants and noncombatants. Levy was charged with one of the most serious breaches of the Uniform Code of Military Justice: willfully disobeying a lawful order. Tried by a general court-martial in 1967, Levy admitted his disobedience, saying that he had acted in accordance with his ethical principles. The physicians who testified for the defense "argued that the political use of medicine by the Special Forces jeopardized the entire tradition of the noncombatant status of medicine" (Langer, p. 1349). They agreed with Levy that physicians are responsible for even the secondary ethical implications of their acts and that they must not only act ethically but also anticipate that those to whom they teach medicine will act ethically as well. Although Levy was a medical officer, the court-martial panel did not include a physician. Levy was given a dishonorable discharge and sentenced to three years of hard labor in a military prison. His appeals were not successful (Glasser; Langer).

Inside or outside the armed forces medical personnel may be involved in war-related research and development such as work on biological weapons or the radiation effects of nuclear weapons. In that work it is said to have been common practice to concentrate physicians into "principally or primarily defensive operations" (Rosebury). However, work on weapons and their effects can never be exclusively defensive, and at times the distinction is arbitrary. The question arises whether there is a special ethical duty for physicians, because of their medical obligation to "do no harm," to refuse to participate in such work or whether in non-patient-care situations physicians only share the ethical duties of all human beings (Sidel, 1991a).

The noncombatant role of a physician in military service is ambiguous even if frank combatant activities are eschewed. Military physicians, like all members of the armed forces, are limited by the threat of military discipline in the extent to which they can protest publicly against what they consider an unjust war. The issue of what is a just war has been debated for more than two millennia (Seabury and Codevilla; Walzer). It generally is thought that there are two elements in a just war: *jus ad bellum* (when is it just to go to war?) and *jus in bello* (what methods may be used in a just war?). Among the elements required for *jus ad bellum* are a just grievance and the exhaustion of all means short of war to settle that grievance. Among the elements required for *jus in bello* are the protection of noncombatants and the proportionality of force, including avoiding the use of weapons of mass destruction such as chemical, biological, and nuclear weapons and the massive bombing of cities. Membership in the armed forces, even in a noncombatant role, usually requires self-censorship of public doubts about the justness of a war in which the armed forces are engaged.

In 2003 the United States, with the support of the United Kingdom, initiated an attack on Iraq that those countries alleged was permissible under international law as a "preventive" or "preemptive" war. The action was not approved specifically by the Security Council of the United Nations. Many lawyers and physicians argued that because there had been no attack or imminent attack on the United States, the requirements for *jus ad bellum* had not been met and the "collateral damage" to civilians caused by the attack exceeded the ethical test of *jus in bello.* Although there were protests from Physicians for Social Responsibility and other medical groups, U.S. service members, including medical personnel, evinced no public protest.

The U.S. military used depleted uranium as a casing for armor-piercing shells in the 1991 Gulf War, its actions in Kosovo and Afghanistan, and the 2003 Gulf War. Uranium is both toxic and radioactive, and its use is seen by many experts as a violation of the United Nations Charter, the Geneva Conventions, the Conventional Weapons Convention, and the Hague Conventions. There was no public protest by military physicians.

In addition, medical personnel, like other people, may consider themselves pacifists. "Absolute pacifism" opposes the use of any force against another human being even in self-defense against a direct personal attack. The argument underlying this position for many of its adherents is that the use of force can be ended only when all people refuse to use it and that acceptance of one's own injury or even death is preferable to the use of force against another person. More limited forms of pacifism, such as "nuclear pacifism," hold that the use of certain weapons of mass destruction in war is never justified no matter how great the provocation or how terrible the consequences of failure to use them. It has been suggested ("maternal pacifism") that because of their nurturing roles women have a special responsibility to oppose the use of force (Ruddick).

When a group is threatened with genocide, which the Nazis attempted in World War II, many who otherwise might adopt a pacifist or limited pacifist position believe that force may be justified. Their shift in position is based on the threat to the survival of the group, a threat that makes the pacifist argument that current failure to resist will lead to a future diminution in violence seem untenable.

There is considerable debate whether physicians, because of a special dedication to the preservation of life and health, have a special obligation to serve or to refuse to serve in a military effort. That position is made more complex by the physician's role as a military noncombatant. Many military forces permit physicians, like other military personnel, to claim conscientious objector status. In the United States conscientious objection is defined as "a firm, fixed, and sincere objection by reason of religious training and belief to: (1) participation in war in any form; or (2) the bearing of arms." Religious training and belief is defined as "belief in an external power or being or deeply held moral or ethical belief to which all else is subordinate and … which has the power or force to affect moral well-being" (U.S. Department of Defense). A person who claims conscientious objector status must convince a military hearing officer that the objection is sincere.

Obligations to Serve in War Versus Obligations to Prevent War

As wars kill an increasing percentage of civilians with so-called conventional weapons and as threats of the use of weapons of mass destruction continue, what form of service is appropriate for an ethical physician? One response was suggested in the late 1930s by John A. Ryle, then Regius Professor of Physic at the University of Cambridge:

> It is everywhere a recognized and humane principle that prevention should be preferred to cure. By withholding service from the Armed Forces before and during war, by declining to examine and inoculate recruits, by refusing sanitary advice and the training and command of ambulances, clearing stations, medical transport, and hospitals, the doctors could so cripple the efficiency of the staff and aggravate the difficulties of campaign and so damage the morale of the troops that war would become almost unthinkable (p. 8).

During the Vietnam War more than 300 American medical students and young physicians brought Ryle's vision a step closer to reality by signing the following pledge:

> In the name of freedom the U.S. is waging an unjustifiable war in Viet Nam and is causing incalculable suffering. It is the goal of the medical profession to prevent and relieve human suffering. My effort to pursue this goal is meaningless in the context of the war. Therefore, I refuse to serve in the Armed Forces in Viet Nam; and so that I may exercise my profession with conscience and dignity, I intend to seek means to serve my country which are compatible with the preservation and enrichment of life (Liberman et al., p. 306).

Ryle's vision is a variation on that of Aristophanes in his comedy *The Lysistrata,* which was written in 411 B.C.E., just before the probable time of Hippocrates's refusal to treat the Persians (circa 400 B.C.E.). The title character, an Athenian woman, ends the second Peloponnesian War by organizing the wives of the soldiers of both Athens and Sparta to refuse sexual intercourse with their husbands while the war lasts. The Athenians and Spartans make peace quickly and go home with their wives (Aristophanes).

Some physicians and other medical personnel have refused to support war by serving in the armed forces. In one of the most dramatic examples Yolanda Huet-Vaughn, a captain in the U.S. Army Medical Service Reserve, refused active duty in the Persian Gulf. In her statement she explained her actions:

> I am refusing orders to be an accomplice in what I consider an immoral, inhumane and unconstitutional act, namely an offensive military mobilization in the Middle East. My oath as a citizen-soldier to defend the Constitution, my oath as a physician to preserve human life and prevent disease, and my responsibility as a human being to the preservation of this planet, would be violated if I cooperate (Sidel, 1991b, p. 102).

The reasons Huet-Vaughn gave for her action were quite different from the reasons given by Levy. Levy refused to obey an order that he believed required him to perform a specific act that would violate the Geneva Conventions; Huet-Vaughn refused to obey an order that she believed required her to support a particular war that she felt to be unjust and destructive to the goals of medicine and humanity.

One of the questions Huet-Vaughn's action raises is whether physicians have a special ethical responsibility, in view of their obligation to protect the health and lives of their patients and the people in their communities, to refuse to support a war they believe will cause major destruction to the health and environment of both combatants and noncombatants (Geiger; Sidel, 1991b). If a physician considers service in support of a particular war unethical on the grounds of sworn fealty to medical ethics, may—or must—that doctor refuse to serve even if that objection does not meet the criteria for formal conscientious objector status? Is there an ethical difference if the service is required by the society—as in a "doctor draft"—or if the service obligation has been entered into voluntarily in return for military support of medical training or for other reasons? Is military service a voluntary obligation if enlistment, as it is for many poor and minority people, is prodded by lack of educational or employment opportunities or, as for many doctors, by the cost of medical education or specialty training that in other societies is provided at public expense?

Although few physicians are willing or able to take an action such as that taken by Huet-Vaughn, other actions are available to oppose acts of war that are considered unjust, oppose a specific war, or oppose war in general. One is acceptance of a service alternative consistent with an ethical obligation to care for the wounded or maimed without simultaneously supporting a war effort. Opportunities for service in an international medical corps such as Médecins du Monde and Médecins sans Frontieres are limited, but U.S. physicians may wish to demand that their nation redirect some of the billions of dollars it spends annually on preparation for war to the United Nations or the World Health Organization to help fund an international medical service to treat the casualties of war.

Other physicians may work, as individuals and particularly in groups, to help prevent war by contributing to public and professional understanding of the nature of modern war, the risks of weapons of mass destruction, and the nature and effectiveness of alternatives to war. Among the groups organized for that purpose are the International Physicians for the Prevention of Nuclear War, whose U.S. affiliate is Physicians for Social Responsibility. If the world is to survive, physicians may need to consider new forms of national service and contribute in a broader sense to their nations and their planet (1986).

In the broader context of medical ethics it is widely accepted that opposition to war does not permit an ethical physician to refuse medical care to victims of war he or she is in a position to serve and that that care does not presume the physician's support of the war being fought. Ethical dilemmas arise when a physician actively supports the war effort through membership in a military medical service or by assigning priority to patient care on the basis of military demands rather than patient needs. These issues and those associated with the role of the physician in peacemaking and peacekeeping, which often are distorted by the fervor that may accompany war and preparation for war, require dispassionate analysis and action in times of peace.

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SEE ALSO: *Care; Conflict of Interest; Conscience; Justice; Medical Codes and Oaths: Ethical Analysis; Obligation and Supererogation; Profession and Professional Ethics; Prisoners, Healthcare Issues of; Triage;* and other *Warfare* subentries

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III. PUBLIC HEALTH AND WAR

During the twentieth century, an estimated 110 million people lost their lives as a result of armed conflicts (WHO). If one includes the major episodes of "collective violence," such as the Stalinist terror of the 1930s and the famine associated with the Great Leap Forward in China (1958–1960), this figure reaches 191 million (Rummel), with approximately 60 percent of these deaths occurring among noncombatants.

Since the Second World War, approximately 190 armed conflicts have occurred affecting ninety-two countries (WHO; Federation of American Scientists). Most occurred in Asia, Africa, and Latin America; however, since 1990, four European conflicts—Chechnya, Azerbaijan, Georgia, and the former Yugoslavia—have caused more than 350,000 deaths. Some wars are still fought primarily between competing armies, such as the Iran-Iraq conflict (1980–1988), in which an estimated 450,000 military personnel died (Sivard), but the vast majority now take place within states.

Civilian populations have increasingly been the intentional targets of military actions, as can be seen in the shelling of urban centers during the conflicts in Bosnia and Herzegovina, Chechnya, Angola, Lebanon, and Somalia. In addition, modern weapons such as napalm, cluster bombs, and land mines do not discriminate between combatants and innocent civilians. In Mozambique the antigovernment forces killed approximately 100,000 civilians in 1986 and 1987 alone (Ugalde, Zwi, and Richards) and between 5 million and 6 million people were either internally displaced or fled to neighboring countries.

Since World War II there have been numerous episodes of massive human rights atrocities and genocide that defy the traditional characteristics of armed warfare. Examples include Pol Pot's killing fields in Cambodia; the Guatemalan government action against indigenous Mayan communities; the use of chemical and biological weapons against the Kurds in Halabja, Iraq; the genocide against Tutsis in Rwanda; and the civilian massacres following the referendum on independence in East Timor.

Public Health Impact of War

DIRECT IMPACT. The direct public health consequences of war include death, injury, sexual assault, disability, and psychological stress. Measuring the impact and hidden costs of conflict is complex for a variety of reasons. Even where huge numbers of people are involved, agreement on the magnitude of impact varies. Estimates of the number of victims of the Rwandan genocide are still imprecise and vary from 500,000 to one million (Murray, King, Lopez, et al.). Particularly high civilian death rates have been reported in Angola, Ethiopia, Liberia, Mozambique, Rwanda, Somalia, Southern Sudan, El Salvador, Guatemala, Afghanistan, Cambodia, Tajikistan, and Bosnia and Herzegovina (Zwi and Ugalde; Toole, Galson, and Brady).

Rape is increasingly recognized as a feature of internal wars, and it has been present in many different types of conflicts. In some conflicts, rape has been used systematically as an attempt to undermine opposing groups. In the former Yugoslavia, for example, estimates of the number of rape survivors have ranged from 10,000 to 60,000 (Swiss and Giller).

Estimates of mine-related disabilities are also sobering: 36,000 in Cambodia (one in every 236 persons in that nation has lost at least one limb), 20,000 in Angola, 8,000 in Mozambique, and 15,000 in Uganda. The costs are both physical and social and affect all age groups. Between February 1991 and February 1992, approximately 75 percent of the land-mine injuries treated worldwide were in children five to fifteen years old (Toole, Waldman, and Zwi).

Immeasurable psychological trauma has been caused by widespread human-rights abuses, including detention, torture, and forced displacement (institutionalized in the former Yugoslavia as "ethnic cleansing"). The extent of mental health "trauma" experienced during and in the aftermath of war and conflict is controversial, with some analysts identifying significant proportions of affected populations suffering from post-traumatic stress disorder, while others argue that this term and the response to it medicalizes an essentially social phenomenon.

INDIRECT IMPACT. The indirect public health consequences of war have been mediated by hunger, mass migration, and collapsed health services, especially in impoverished developing countries where basic services and food reserves are already inadequate. The intentional use of food deprivation as a weapon has become increasingly common (MacCrae and Zwi). For example, armed factions on all sides have obstructed food-aid deliveries in southern Sudan, resulting in mass hunger and, during 1993, death rates up to fifteen times those reported in nonfamine times. In 1992 widespread looting and banditry deprived millions of Somalis of much-needed food aid.

At the end of 2002 there were more than 15 million refugees worldwide, and an additional 22 million people internally displaced in their own countries (U.S. Committee for Refugees). Crude death rates (the number of deaths per 1,000 population per month) among refugees and internally displaced persons have ranged between five and twenty-five times baseline rates. Most deaths have been caused by preventable conditions such as malnutrition, diarrhea, pneumonia, measles, and malaria (Toole, Waldman, and Zwi). High death rates reflect the prolonged period of deprivation suffered prior to displacement, the often inadequate response to humanitarian crises by the international community, and problems of gaining access to provide relief assistance to war-affected communities. More than 50,000 refugees from Rwanda died within one month of fleeing into eastern Zaire in 1994, representing a death rate more than 25 times higher than the baseline rate in Rwanda (Goma Epidemiology Group).

Health facilities have been intentionally destroyed by armed factions in Afghanistan, Angola, Bosnia, Mozambique, and other war-stricken countries. In addition, the high costs of both maintaining military forces and treating the wounded have often led to insufficient funding for basic health services. In the Bosnian province of Zenica, for example, the proportion of surgical cases related to war injuries rose from 22 percent to 78 percent between April and November 1993, resulting in the cessation of almost all preventive health services (Toole, Galson, and Brady).

Perhaps the most significant consequence of war on public health relates to the tremendous cost of preparing for war. Military budgets throughout both the industrialized and developing worlds have diverted precious resources from public health and other social development programs. For example, in April 2002 the U.S. Congress approved $85 billion to fund the initial stages of the war in Iraq. In comparison, the total global expenditure on the fight against HIV/AIDS in low- and middle-income countries was $1.5 billion in 2001. Moreover, the destruction of environmental resources, such as water sources, agricultural land, livestock, and housing has had a major impact on public health in numerous countries affected by war.

Ethical Issues

Modern warfare has increasingly involved flagrant violations of the Geneva Conventions related to the protection of civilian persons in time of war (ICRC). Ethnic cleansing, detention of civilians, summary executions, and torture are clearly illegal under international law. The unrestricted ability of combatants to target civilians is fostered by the officially sanctioned international arms trade. The International Committee of the Red Cross (ICRC), the custodian of the Geneva Conventions, has often been deprived of access to civilians in countries such as Somalia, Sudan, and Bosnia and Herzegovina. Further, providing humanitarian assistance has become more dangerous. Between 1985 and 1998, over 380 deaths occurred among humanitarian workers (Sheil et al.).

Although violations of human rights law and international humanitarian law are crimes, the legal systems for punishing the perpetrators and compensating the victims are grossly inadequate. To date, international tribunals have been established to prosecute war criminals from the former Yugoslavia and from Rwanda. While these courts help to move the punishment of war criminals from theory to practice, they have been very slow to act and very expensive to implement. The establishment of an International Court of Justice is another step towards strengthening what has, in many respects, been a legal system without law enforcement capability.

International public opinion has increasingly supported the use of force by the United Nations to ensure delivery of humanitarian aid in situations either where governance has completely collapsed (e.g., Somalia and Liberia) or where governments consciously hinder access by relief agencies (e.g., Sudan and Bosnia and Herzegovina). However, there are no clear guidelines that might promote a consistent deployment of force to achieve humanitarian objectives (Dewey). The U.N. Charter prohibits interference in the affairs of a sovereign nation, thereby giving more weight to the rights of the state than to individual citizens.

Two contradictory examples from 1992 illustrate the ethical dilemmas inherent in the use of force to save lives from hunger and disease. In Bosnia and Herzegovina, European soldiers deployed to ensure the safe delivery of humanitarian supplies were powerless to prevent flagrant abuses of human rights committed in their presence (Jean). In contrast, the international armed contingent dispatched to Somalia in late 1992 to ensure the safe delivery of relief supplies eventually became a party to the internal conflict. This led to battles between U.N. troops and one local armed faction in heavily populated areas of the capital, Mogadishu, with high civilian casualty rates (Brauman). Thus, well-motivated intervention by the international community may inadvertently increase the risks to the intended beneficiaries.

Once access to an affected area is assured, health personnel have a critical role to play in accurately documenting the public health impact of war on civilian populations, thereby acting as effective advocates for a prompt and adequate response. Relief programs may pose a difficult choice for health workers: between the provision of individual curative care and the implementation of more effective, community-based programs such as childhood immunization.

Conclusions

Modern warfare has exacted a devastating toll on civilian populations. High mortality, morbidity, and disability rates have resulted directly from traumatic injuries and indirectly from hunger and mass displacement. Since the end of the Cold War, the potential for a more unified and coherent "international community" has emerged. The United Nations has a responsibility to carefully monitor the public health consequences of evolving conflicts and to apply aggressive diplomacy early to seek solutions. When conflicting parties obstruct access to civilians by relief agencies, the world needs to respond in a consistent and effective manner, and clearer guidelines on the use of force to deliver humanitarian aid in conflict settings need to be developed.

Relief programs will be more effective if they reflect the real needs of affected populations, rather than the availability of surplus commodities in donor countries. With a proper and timely scientific assessment of public health needs and careful monitoring of health and nutrition trends, those who are suffering are more likely to receive the aid they require. Primary prevention is the basic strategy of public health; consequently, in war settings, public health practitioners need to recognize that primary prevention means stopping the violence, as well as actively exploring methods for promoting sustainable peace.

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SEE ALSO: *Bioterrorism; Epidemics; Healthcare Resources, Allocation of; Health Policy; Public Health;* and other *Warfare* subentries

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IV. CHEMICAL AND BIOLOGICAL WEAPONS

The development, production, storage, transfer, use, and destruction (demilitarization) of chemical and biological weapons (CBW) pose a number of ethical issues. First, those weapons, like nuclear weapons, are largely indiscriminate in their effects and are generally more effective against vulnerable noncombatants than against combatants; they therefore are known as weapons of mass destruction, and their use generally is considered a violation of the proportionality principle of a just war. Second, CBW, also like nuclear weapons, are the subject of intensive international arms-control efforts involving problems of definition, verification, and enforcement. Third, biomedical scientists and physicians may be called on to participate in research and development on more effective CBW as well as on methods for defense against them and the treatment of their victims.

Chemical Weapons

Chemical weapons (CW), which have been known since antiquity, are designed to inflict direct chemical injury on their targets, in contrast to explosive or incendiary weapons, which produce their effects through blast or heat. In the siege of Plataea in 429 B.C.E., for example, the Spartans placed enormous cauldrons of pitch, sulfur, and burning charcoal outside the city walls to harass the defenders. Although nations that signed the 1899 Hague Declaration promised not to use CW, during World War I those weapons, including in descending order of use tear gas, chlorine gas, phosgene, and mustard gas, were employed. Overall, 125,000 tons of CW were used during World War I, resulting in 1.3 million casualties. One-quarter of all casualties in the American Expeditionary Force in France were caused by them (Harris and Paxman; Sidel and Goldwyn; Sidel, 1989; United Nations; World Health Organization).

In 1925 twenty-eight nations negotiated the Geneva Protocol for the “prohibition of the use in war of asphyxiating poisonous or other gases and of all analogous liquids, materials or devices and of bacteriological methods of warfare” (Wright, p. 368). In fact, however, the protocol prohibited only the use, not the development, production, testing, or stockpiling, of those weapons. Furthermore, many of the nations that ratified the protocol reserved the right to use those weapons in retaliation, and the protocol became in effect a “no first use” treaty with no verification or enforcement provisions. The United States was one of the initial signers, but the Senate did not ratify the treaty until 1975 (Sidel, 1989; Wright).

Despite the protocol, the use of CW continued. Italy used mustard gas during its invasion of Abyssinia (Ethiopia), and Japan used mustard and tear gases in its invasion of China. Germany, with its advanced dye and pesticide industries, developed acetylcholinesterase inhibitors known as nerve gases, and the United States and Britain stockpiled CW during World War II; transportation and storage accidents caused casualties (Infield), but there was no direct military use. After World War II CW were used by Egypt in Yemen, mustard and nerve gases were used in the Iran-Iraq war in the 1980s, and Iraq used CW against Kurdish villages in its territory. CW stockpiles and production facilities in Iraq were ordered destroyed by the United Nations after the 1991 Persian Gulf War. The United States and Russia are known to have maintained CW stockpiles, and a number of other countries have stockpiles or facilities for rapid CW production (Harris and Paxman; Sidel, 1989).

Troops can be protected against those weapons for limited periods through the use of gas masks and impenetrable garments. That protective gear, however, reduces the efficiency of troops by as much as 50 percent and damages morale, and so the use or threat of use of CW may continue to be considered effective against troops. Civilian populations, in contrast, cannot be protected adequately. Israel, for example, provides every civilian with a gas mask and a self-injectable syringe filled with atropine, a temporary antidote to nerve gas. However, that protection is inadequate against weapons, such as mustard gas, that attack the skin and against longer-term exposure to nerve gas. Furthermore, poorly trained civilians are likely to injure themselves with equipment such as self-injectable syringes (Amitai et al.).

The production of CW has been associated with serious accidents to workers and high levels of pollution in the production sites and nearby communities. Tests of mustard gas, nerve agents, and psychochemicals, including lysergic acid diethylamide (LSD), during and after World War II involved thousands of military personnel, many of whom later claimed disabilities from the exposure. The records of participation and effects are so poor that only a small fraction of those who participated can be identified. Even the destruction of the weapons is dangerous because toxic ash is produced by their incineration (Sidel, 1993).

A Chemical Weapons Convention (CWC) that prohibits the development, production, storage, and transfer of those weapons and calls for their demilitarization was approved by the United Nations General Assembly in 1992. The Organization for the Prohibition of Chemical Weapons (OPCW), which is responsible for ensuring the implementation of the CWC, was established in the Hague after the entry into force of the CWC in 1997. By 2003 a total of 151 “states parties” (nations) had ratified or acceded to the BWC. The First Review Conference of the States Parties to the CWC was held in the Hague in April 2003, and Kofi Annan, secretary general of the United Nations, urged that “membership in the CWC be extended to all nations in the world and that enough funds be provided to accelerate complete chemical disarmament.”

In the 1960s and 1970s the United States used both tear gas and herbicides in Vietnam. Although most nations that are parties to the Geneva Protocol considered tear gas and herbicides to be CW and thus prohibited under the provisions of the protocol, the United States until recently rejected that interpretation (Sidel and Goldwyn; Sidel, 1989). Many countries use tear gas to quell civil disorders (Hu et al.). The signatories to the CWC have agreed not to use riot-control agents or herbicides as weapons of war.

In 2002 Russia used derivatives of fentanyl, a potent opium-based narcotic, to subdue Chechen rebels who had occupied a theater in Moscow and taken 800 hostages. Although Russia formally considered the chemical agent “nonlethal” and its use permissible under the CWC, a total of 117 people died as a result of its use (“Russia Names Moscow Siege Gas”).

In 1984 members of a cult in Oregon intentionally contaminated the salad bars in local restaurants with salmonella bacteria. More than 700 people became ill, but there were no reported deaths. In 2001, shortly after the attack on the World Trade Center, anthrax spores were disseminated through the U.S. mail. Approximately twenty people became ill, and five people died.

Biological Weapons

Biological weapons (BW) depend for their effects on the ability of microorganisms to infect and multiply in the attacked organism. In this regard they differ from toxins, which, as biological products used as chemicals, are covered under CW as well as BW treaties. BW are very hard to defend against and are not as controllable and predictable in their use as are CW (Harris and Paxman; Geissler, 1986; Sidel and Goldwyn; Sidel, 1989; United Nations; World Health Organization, 1970).

The effects of BW were characterized officially by a U.S. government agency in 1959: “Biological warfare is the intentional use of living organisms or their toxic products to cause death, disability, or damage in man, animals, or plants. The target is man, either by causing sickness or death or through limitation of his food supplies or other agricultural resources.… Biological warfare has been aptly described as public health in reverse” (U.S. Department of Health, Education, and Welfare).

BW have been known since antiquity. Persia, Greece, and Rome used diseased corpses to contaminate sources of drinking water. In 1347 Mongols besieging the walled city of Caffa (now called Feodosiya), a seaport on the east coast of the Crimea, began to die of the plague. The attackers threw the corpses into the besieged city; the defenders, who were Genoans, fled back to Genoa and carried the plague farther into Europe. During the French and Indian Wars Lord Jeffrey Amherst, commander of the British forces at Fort Pitt, gave tribal emissaries blankets in which smallpox victims had slept (Harris and Paxman; Geissler).

During World War I Germany is alleged to have used the equine disease glanders against the cavalries of eastern

European countries (Harris and Paxman, p. 74). According to testimony at the Nuremberg trials, prisoners in German concentration camps were infected during tests of BW. Great Britain and the United States, fearing that the Germans would use BW in World War II, developed their own BW. The British tested anthrax spores on Gruinard Island off the coast of Scotland; the island remained uninhabitable for decades. The United States developed anthrax spores, botulism toxin, and other agents as BW but did not use them (Bernstein).

In the 1930s Japanese troops dropped rice and wheat mixed with plague-carrying fleas from planes, resulting in plague in areas of China that previously had been free of it. During World War II Japanese laboratories conducted extensive experiments on prisoners of war, using a wide variety of organisms selected for possible use as BW, including anthrax, plague, gas gangrene, encephalitis, typhus, typhoid, hemorrhagic fever, cholera, smallpox, and tularemia (Wright). Unlike the Soviet Union, which in 1949 prosecuted twelve people who had been involved in that work, the United States never prosecuted any of the participants. Instead, U.S. researchers met with Japanese biological warfare experts in Tokyo and urged that the experts be "spared embarrassment" so that the United States could benefit from their knowledge (Powell; Williams and Wallace).

DIFFICULTIES OF SURVEILLANCE. After World War II the development of BW continued. None of the numerous allegations of BW use have been substantiated or even investigated fully, but it is known that extensive BW testing was done. In the 1950s and 1960s, for example, the University of Utah conducted secret large-scale field tests of BW, including tularemia, Rocky Mountain spotted fever, plague, and Q fever, at the U.S. Army Dugway Proving Ground. In 1950 U.S. Navy ships released as simulants (materials believed to be nonpathogenic that mimic the spread of BW) large quantities of bacteria in the San Francisco Bay area to test the efficiency of their dispersal. Some analysts attributed subsequent infections and deaths to one of those organisms. During the 1950s and 1960s the United States conducted 239 top-secret open-air disseminations of simulants, involving areas such as the New York City subways and Washington National Airport (Cole). The U.S. military developed a large infrastructure of laboratories, test facilities, and production plants related to BW. By the end of the 1960s the United States had stockpiles of at least ten biological and toxin weapons (Geissler). A 1979 outbreak of pulmonary anthrax in the Soviet Union is said to have been caused by accidental release from a Soviet BW factory. Recent disclosures by Russian scientists indicate extensive environmental contamination and medical problems caused by CW production ("Russian Experts Say Many Died Making Chemical Weapons").

In 1969 the Nixon administration, with the concurrence of the U.S. Defense Department, which declared that BW lacked "military usefulness," unconditionally renounced the development, production, stockpiling, and use of BW and announced that the United States would dismantle its BW program unilaterally. In 1972 the Soviet Union, which had urged a more comprehensive treaty that would include restrictions on CW, ended its opposition to a separate BW treaty. The United States, the Soviet Union, and other nations negotiated the Convention on the Prohibition of the Development, Prevention and Stockpiling of Bacteriological (Biological) and Toxin Weapons and on Their Destruction (BWC). The BWC prohibits, except for "prophylactic, protective and other peaceful purposes," the development or acquisition of biological agents or toxins as well as weapons carrying them and means of their production, stockpiling, transfer, and delivery. The U.S. Senate ratified the BWC in 1975, the same year it ratified the Geneva Protocol of 1925. As of 1987, 110 nations had ratified the BWC and an additional 25 had signed but not yet ratified it (Wright).

Invoking the specter of new biological weapons and unproven allegations of aggressive BW programs in other countries, the Reagan administration initiated intensive efforts to conduct "defensive research," which is permitted under the BWC. The budget for the U.S. Army Biological Defense Research Program (BDRP), which sponsors programs in a wide variety of academic, commercial, and government laboratories, increased dramatically during the 1980s. Much of that research work is medical in nature, including the development of immunizations and treatments against organisms that might be used as BW (Piller and Yamamoto; Wright).

Although research on and the development of new BW are outlawed by the BWC, it is possible that they will occur in the future. Novel dangers lie in new genetic technologies that permit the development of genetically altered organisms that are not known in nature. Stable, tailor-made organisms used as BW could travel long distances and still be infectious, rapidly infiltrate a population, cause debilitating effects very quickly, and be resistant to antibiotic treatment (Piller and Yamamoto).

Ethical Issues for Biomedical Scientists

Biologists, chemists, biomedical scientists, and physicians have played important roles in CBW research and development. Fritz Haber, who was awarded the 1918 Nobel Prize in chemistry for his synthesis of ammonia, is known as the father of Germany's chemical weapons program in World War I. In his speech accepting the Nobel Prize Haber declared poison gas "a higher form of killing" (Harris and Paxman, 1982). By contrast, during the Crimean War the British government consulted the noted physicist Michael Faraday on the feasibility of developing poison gases; Faraday responded that it was entirely feasible but that it was inhumane and he would have nothing to do with it (Russell).

Many scientists who explicitly acknowledge the ethical conflicts involved in work on weapons argue that a higher ethical principle—the imperative of defending one's country or helping to curb what is perceived as evil or destructive—permits or even requires participation in such work. Dr. Theodor Rosebury, who worked on BW during World War II, based his participation on his belief that crisis circumstances that were expected to last for only a limited time required that he act as he did. "We were fighting a fire, and it seemed necessary to risk getting dirty as well as burnt," he later wrote (Rosebury, 1963). Rosebury refused to participate in BW work after the end of the war (Rosebury, 1949).

Other scientists resolved their ethical dilemma by arguing that their work on weapons was designed to reduce the devastation of war. For example, while working on "nonlethal" CBW in the 1960s Dr. Knut Krieger argued that his research would lead to decreased fatalities: "If we do indeed succeed in creating incapacitating systems and are able to substitute incapacitation for death it appears to me that, next to stopping war, this would be an important step forward" (Reid).

Relevant ethical concerns about "defensive research" on BW by biomedical scientists include issues of content, safety, context, and locus (Lappé).

CONTENT. The Japanese laboratory established in 1933 to develop BW was called the Epidemic Prevention Laboratory. One of its activities was supplying vaccines for troops bound for Manchuria, but its major work was developing and testing BW (Powell). Military forces today could conduct research on the offensive use of BW under the cover of defensive research because offensive and defensive research are joined inextricably in at least some phases of the work (Huxsoll et al.). In the parts of the work in which offensive and defensive efforts are parallel new forms of organisms may be found or developed that would be more effective as biological weapons. The possibility that offensive work on BW is being done in the United States under the cover of defensive work has been denied by the leaders of the BDRP, who point out the areas in which the two types of research diverge (Huxsoll et al.). Critics nonetheless raise questions about the ambiguity of BDRP research, arguing that "these efforts are highly ambiguous, provocative and strongly suggestive of offensive goals" (Jacobson and Rosenberg; Piller and Yamamoto; Wright).

SAFETY. Many analysts believe that CW or BW research, even if it is truly defensive in intent, may be dangerous to surrounding communities if toxic materials or virulent infectious organisms are released accidentally.

CONTEXT. CW or BW research, even if it is defensive in intent, can be viewed by a potential military adversary as an attempt to develop protection for a nation's military forces or noncombatants against weapons that that nation might wish to use for offensive purposes, thus permitting that nation to protect its own personnel in a CW or BW first strike. In fact, the military justification for preparing altered organisms is that they are needed for the preparation of defenses. It is therefore impossible for adversaries to determine whether a nation's defensive efforts are part of preparations for the offensive use of weapons.

LOCUS. Fears in this area usually are based on military sponsorship of defensive BW research. Even if that research is relatively open, other nations may view with suspicion the intense interest of military forces rather than civilian medical researchers in vaccines and treatments against specific organisms. Those fears can feed a continuing BW arms race.

More generally, concern has been expressed about the militarization of genetic engineering and biology in general. Characterization of biological weapons as "public health in reverse" therefore may have an even broader and more sinister meaning: The entire field of biology, along with and aspects of it such as the use of human genome research to design weapons to target specific groups, may be in danger of military use for destructive ends (Piller and Yamamoto; Wright). The imprisonment of a chemist by the Russian government and the revocation of his university diploma for publishing an article describing the development of new, highly toxic CW illustrate the restrictions that are placed on scientists who do CBW research (Janowski).

Ethical Issues for Physicians

The first question that arises is whether it is constructive to view certain ethical responsibilities as unique to the physician's social role. Theodor Rosebury described the response to physician participation in work on BW during World War II: "There was much quiet but searching discussion among us regarding the place of doctors in such work … a certain delicacy concentrated most of the physicians into principally or primarily defensive operations." Rosebury went on to point out that the modifiers *principally* and *primarily* are needed "because military operations can never be exclusively defensive" (Rosebury, 1963). What is seen as the special responsibility of physicians is based largely on an ethical responsibility not to use the power of the physician to do harm (*primum non nocere*). Although the Hippocratic oath seems to apply to the relationship of the physician to an individual patient, its meaning has been broadened by many to proscribe physician participation in actions harmful to nonpatients.

In regard to research on offensive weapons of war there seems to be a consensus that physicians participate in such research at their ethical peril even if their country demands it or they think it useful for deterrence or other preventive purposes. However, because of the ambiguity of defensive work on BW, the dilemma for the physician is not easily resolved even for those who believe that defensive efforts are ethically permissible.

Some proponents of defensive research on BW have argued that it is entirely ethical—that in fact it is obligatory—that physicians work on it. According to this perspective, not only will defenses be needed if such weapons are used against the United States, that work also may be useful in developing protection against naturally occurring diseases (Crozier; Huxsoll et al.; Orient). Other analysts believe that it is unethical for physicians to play a role in military-sponsored BW research because it has a strong potential for intensifying a BW arms race and helping to militarize the science of biology, thus increasing the risk of the use of BW and the destructiveness of their effects if they are used (Jacobson and Rosenberg; Nass, 1991; Sidel, 1991).

The question is: Where on the slippery slope of participation in preparing for the use of BW should physicians draw the line? If physicians engage in civilian-sponsored research on disease control that carries an obligation to report all findings in the open literature even if the research may have implications for BW, that participation, most analysts agree, cannot be faulted on ethical grounds. However, when physicians engage in military-sponsored research in which the openness of reporting is equivocal and the purposes are ambiguous, it is difficult to distinguish their work ethically from work on the development of weapons.

As was noted above, the BWC prohibits any "development, production, stockpiling, transfer or acquisition of biological agents or toxins" except for "prophylactic, protective and other peaceful purposes." The responsibility for government-sponsored medical research for prophylactic, protective, and other peaceful purposes in the United States lies largely with the National Institutes of Health (NIH) and the Centers for Disease Control (CDC). The NIH or the CDC therefore might be given the responsibility and the resources for medical research of this type. The U. S. Army still may want to conduct nonmedical research and development on defense against BW, such as work on detectors, protective clothing, and other barriers to the spread of organisms. Under this proposed division of effort that research is less likely to be seen as offensive, provoke a BW race, pervert the science of biology, and involve physicians (Sidel, 1989).

A different type of ethical issue related to CBW arose during the Persian Gulf War in 1991. The United States provided protective measures such as immunization against botulinum toxin and anthrax for its military forces. Despite the fact that some of those measures were experimental, no informed consent procedures were used and compliance often was required. Furthermore, the measures were made available to military forces but not to noncombatants in the area (Annas; Howe and Martin).

In addition to the ethical dilemmas involved in these decisions it may be unethical for physicians to ignore the issues involved in CBW. One of the greatest dangers of those weapons may be the apathy of the medical profession toward them. The fact that BW are the weapons with which physicians may become engaged and the ones about which they have specialized knowledge gives physicians a special responsibility not only to refuse to work on them but also actively to work to reduce the threat of their development or use.

Conclusion

Physicians and biomedical scientists should support methods for international epidemiological surveillance to detect the use of BW and investigate incidents in which use has been alleged after an unexplained disease outbreak (Geissler, 1986; Nass, 1992a, 1992b) and support the Vaccines for Peace Programme for the control of "dual-threat" agents (Geissler and Woodall). Support also might be given for measures to strengthen the BWC through the introduction of the verification proposals that were put forth at the 1991 BWC Review Conference (Falk; Rosenberg and Burck; Rosenberg). With regard to chemical weapons, biomedical scientists and physicians might support effective implementation of the 1993 CWC (Smithson).

More broadly, physicians may wish to explore the connection between CBW and nuclear weapons. It has been argued that by refusing to reduce their vast stockpiles of nuclear weapons substantially and refusing to agree to verifiable cessation of nuclear weapons testing and production, the nuclear powers provoke nonnuclear powers to contemplate the development and production of CBW for deterrence against nuclear weapons. The U.S. Defense Intelligence Agency reported that “third world nations view chemical weapons as an attractive and inexpensive alternative to nuclear weapons” (U.S. General Accounting Office; Zilinskas, 1990a, 1990b). There is much that physicians can do, for example, through the International Physicians for the Prevention of Nuclear War, the organization that received the 1985 Nobel Peace Prize, and its affiliates in many countries to reduce the provocation and proliferation of weapons of mass destruction caused by the continuing nuclear arms race.

Individual physicians and scientists can add to the awareness of the dangers of CBW by signing the pledge sponsored by the Council for Responsible Genetics “not to engage knowingly in research and teaching that will further development of chemical and biological warfare agents.” U.S. physicians also may wish to support legislation to transfer all medical aspects of biological defense from the military to the NIH or the CDC. Physicians may help awaken the medical profession to the dangers of CBW and nuclear weapons by adding a clause to the oath taken by medical students upon graduation from medical school, similar to the oath for medical students in the former Soviet Union, requiring them “to struggle tirelessly for peace and for the prevention of nuclear war” (Cassel et al., p. 652). The clause might be worded as follows: “Recognizing that nuclear, chemical, and biological arms are weapons of indiscriminate mass destruction and threaten the health of all humanity, I will refuse to play any role that might increase the risk of use of such weapons and will, as part of my professional responsibility, work actively for peace and for the prevention of their use.”

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SEE ALSO: *Bioterrorism; Conflict of Interest; Harm; Military Personnel as Research Subjects; Prisoners as Research Subjects; Research, Unethical;* and other *Warfare* subentries

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WHISTLEBLOWING IN HEALTHCARE

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The term *whistleblowing* is a metaphor, apparently derived from a referee's use of a whistle to call a foul in a sporting event. It refers to a disclosure made by a member or former member of an organization about some practice within the organization. Whistleblowing can be internal (disclosure to someone in higher authority in the organization) or external (disclosure to outside persons or organizations such as government agencies, public-interest groups, or the news media). The term is most commonly used to describe disclosure to persons outside the organization, and it is external whistleblowing that is the focus of discussion here.

The whistleblower is a person, usually willing to be identified publicly, who makes an unauthorized disclosure regarding some action or practice within the organization that the person judges to be ethically wrong or unacceptably dangerous. Whistleblowing takes place in business, in government, and in the professions. In healthcare, the most common example in the ethics literature is whistleblowing by nurses about physician behavior. With increased attention being given to ethical issues throughout the healthcare organization, it can be expected that, in the future, the examples of potentially justified whistleblowing in healthcare will be focused nearly as frequently on the business side of the organization as on the clinical side.

Whistleblowing is unauthorized disclosure. As such, it almost always involves activity that management considers disloyal to the organization. In addition, organizations and individuals can be harmed, perhaps in an irreparable manner, by public accusations. Retractions or corrections of false or unfair allegations seldom receive the same degree of public attention as the initial accusations. These considerations of disloyalty and harm have led many ethicists to stress the conditions that must be met before individuals should feel justified in blowing the whistle. It is also important to recognize, however, that the organization has a responsibility to prevent the need for whistleblowing and to treat the whistleblower fairly.

Responsible Whistleblowing

Even when potential whistleblowers are motivated by a desire to protect other individuals or society in general, they need to be careful lest they do more harm than good. Ethical or responsible whistleblowing is usually understood to mean that all of the following conditions are met:

(1) The person has clear evidence that the organization or someone in the organization is engaged in activity that is seriously wrong or that has a high potential for doing serious harm.

(2) The charge to be made by the whistleblower is accurate and accusations against any individuals are able to be substantiated.

(3) The wrongdoing or the danger to be disclosed must be serious enough to justify risking the harm that will likely result to the organization and to some individuals once the public disclosure is made.

(4) Reasonable attempts to prevent the wrong through internal consultation and reporting have been made and have failed. Potential whistleblowers should attempt to use methods of reporting within the organization before going outside, in spite of the frustrations and delays internal mechanisms can sometimes cause. (It should be recognized, however, that in some situations internal efforts to prevent the wrong are not feasible or would simply lead to an effective cover-up.)

(5) There is a reasonable possibility that the disclosure will help prevent or mitigate the harm or wrong or that the disclosure will lesson the likelihood that similar actions will occur in the future. (This condition should not be interpreted too rigidly. In many cases, it is exceedingly difficult to calculate the potential consequences that may result from acting. Furthermore, it may sometimes be legitimate just to call attention to the reality in order to have a better-informed public.)

When these conditions are all met, blowing the whistle might best be considered an ethical responsibility, not just an ethically permissible act; all employees have some responsibility to protect the public from serious harm when possible.

The Organization: Prevention and Protection

While much of the discussion of whistleblowing in the ethics literature has focused on the responsibility of the potential whistleblower, there is also a need to recognize the responsibilities of management. Many healthcare organizations now have corporate compliance programs that have mechanisms for internal reporting of suspected wrongdoing (including anonymous reporting to the compliance officer). However, unless and until employees and medical staff see that changes are made when concerns are raised internally, they will still be faced with the question of whether to go public. Management is in a weak position to claim that an employee should not blow the whistle out of loyalty to the organization if management does not adequately attend to reported problems. One of the key reasons why some nurses believe they have a responsibility to blow the whistle publicly on physician behavior is that their experience is that internal complaints have led to no changes at all.

In addition to following up quickly and with thorough investigations when staff report what they perceive to be serious wrongdoing, management can take other steps to prevent staff from concluding that they have no alternative but to blow the whistle. Those who make internal reports or complaints should be protected from any recrimination or discipline, as long as they make the report in good faith (which should be assumed until proven otherwise). Trying to protect the organization from doing harm should be rewarded, not penalized.

Organizations also have a responsibility to deal fairly with employees who do blow the whistle. In the history of whistleblowing in business, a common outcome has been the firing of whistleblowers. This has been the case, even when there was evidence that the whistleblower did, in fact, expose a serious wrongdoing that was not being addressed internally. It is difficult, if not impossible, to justify ethically the firing of an employee because the person blew the whistle on actions that seriously threaten the public good after making reasonable internal attempts to achieve a change. The ethical healthcare organization recognizes that loyalty to the public good takes priority over loyalty to the employer.

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SEE ALSO: *Conscience; Conscience, Rights of; Malpractice, Medical; Mistakes, Medical; Pharmaceutical Industry; Profession and Professional Ethics; Responsibility; Virtue and Character*

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WOMEN AS HEALTH PROFESSIONALS, CONTEMPORARY ISSUES OF

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After three decades of increasing numbers of women entering previously male-dominated health professions, few academic health centers have what might be considered a "critical mass" of women full professors, much less women leaders. A brief status report on women in academic medicine introduces a discussion of recent research on why gender differences in the advancement of professionals persist. For instance, no matter how complex the technical requirements of a woman's occupation, Western culture expects her to be more nurturing and emotionally accessible than a man. At the same time, it places a low value on caretaking roles, in terms of both prestige and financial remuneration. Forward-looking institutional strategies to enhance the development of women health professionals target features of the work culture that may be "simply the norm" but that disadvantages women. The concluding section of this entry attempts responses to the questions: Is the increasing number of women entering medicine and other health professions mitigating the impact of gender? And how is gender diversity changing the profession?

Status Report on Women in Academic Medical Centers

Of all the health profession schools, the most extensive data is available on medical schools (and they are largest in terms of budget and size); therefore, this statistical report centers on women in academic medicine. Most trends and findings cited would apply as well to other health professions that were male-dominated until recently.

In 2001 women constituted 45 percent of U.S. medical students, 39 percent of dental students, and 41 percent of osteopathic students (by comparison, women are 55% of enrollees in four-year colleges/universities). The number of men applying to medical school has been declining faster than the number of women. For instance, between 1995 and 2001, the number of men applying to medical school declined by 33 percent, compared to 17 percent for women. If this rate of change continues, by 2005, half of first-year medical students nationally will be women.

The proportion of full-time medical school women faculty in 2001 was 28 percent (in dental schools, 25%, and in osteopathic schools, 39%). The proportion of medical school instructors who are women has been steadily increasing and is now 46 percent, but only 12 percent of full professors are women.

With regard to the proportion of men and women faculty at each rank, these proportions have remained remarkably stable, especially at the full professor rank (Bickel, 2001). For instance, in 2001, 10.9 percent of all women faculty and 30.9 percent of all men faculty were full professors; in the mid-1980s, these proportions were 9.9 percent and 31.5 percent, respectively.

In 2001, 14 percent of tenured medical school faculty (all ranks) were women. Between 1995 and 2001, the percent of women with tenure actually dropped from 14 percent to 12 percent, about the same proportional decline as the percent of men tenured (32% to 28%) (Bickel, 2001). Data from the Association of American Medical College's Faculty Roster System also reveal that the average annual rate of women faculty attrition (9.1%) exceeds that of men (7.7%) (Yamagata).

With regard to academic administrative roles, in 2001 women chaired approximately 214 departments (91 basic science and 123 clinical departments [including interim and acting chairs]), which is about 8 percent of all medical school chairs. This total constitutes an average of just 1.7 per medical school, and at least 20 of 125 medical schools have no women chairs (most of these have never had one). The specialties with the largest number of women chairs are microbiology, pathology, anesthesiology, family medicine, obstetrics/gynecology, and pediatrics (Bickel, Clark, and Lawson).

By 2002 the number of women assistant, associate, and senior associate deans at American medical schools totaled approximately 422 (an average of three per school); three schools had no woman in a decanal position. As of July 2002, women held deanships at eight of the 125 U.S. medical schools (two were interim positions). In osteopathic schools, women held three of nineteen deanships and in dental schools, none.

Continuing Disadvantages Related to Professional Opportunities

Numerous studies from the late 1990s and early 2000s have elucidated continuing gender differences in professional opportunities and advancement. Although these areas are highly interrelated, the findings are presented below under five headings: specialty choice, sexism and mental models of gender, acquiring mentoring, practice-related areas of career disadvantage, and the intersection of gender and ethnicity.

SPECIALTY CHOICE. The specialty choices of women physicians have changed little despite their large increases in numbers, with comparatively few women entering surgery and most subspecialties. Why are women not distributing more evenly across specialties? The weight of tradition from earlier eras when women physicians were restricted to treating women and children (Bickel, 2000) explains in part why high proportions of women physicians continue to enter obstetrics and gynecology, pediatrics, general internal medicine, and family practice. But the paucity of women entering surgery also points to characteristics of the field, including hours that may preclude having a healthy family or personal life, and a lack of positive role models (Biermann). Women who enter training, however, do not drop out of surgical residencies at a higher rate than men. The American College of Surgeons' analysis of the 1993 entering cohort found that male and female U.S. and Canadian graduates had the same attrition rate from surgical residencies (Kwakwa and Jonasson). The largest study of women physicians (U.S. medical school graduates between 1950 and 1989) found that women surgeons are less likely (43%) to have children than nonsurgeons (71%) but reported a higher level of satisfaction with their specialty than nonsurgeons (Frank, Brownstein et al., 1998).

Thus, the more prestigious (and better paid) *curing* specialties continue to be male dominated (Bickel, 1988). One issue of equity related to women physicians' concentration in what might be termed the *caring* specialties is that listening and counseling skills are sometimes viewed as qualities inherent in women rather than acknowledged as technical proficiencies that deserve recognition and recompense.

SEXISM AND MENTAL MODELS OF GENDER. Harassment and sexism continue to detract from the education and opportunities of women health professionals. Even medical school department chairs admit to witnessing inappropriate sexual behavior including pressuring women to participate in sexual relationships (Yedidia and Bickel). Almost half of American women physicians believe they have been harassed during their careers, and most cite medical school as the location. In this national study, harassment was associated with depression, suicide attempts, and a desire to switch specialties (Frank, Brogan, and Schiffman). Abused students are more likely to lack confidence in their clinical skills and in their ability to give compassionate care (Kassebaum and Cutler; Schuchert).

As troublesome as overt sexual harassment continues to be, subtler forms of bias pose a much larger challenge to women's development as professionals. U.S. society associates decisiveness, rationality, and ambition with men, and gentleness, empathy, and nurturance with women (Tong). Such stereotypes, however, deny individuals the opportunity to be appraised positively on the basis of their unique traits. Indeed, men or women who act "against type" tend to be dismissed or marginalized. The "feminine" man who displays more sensitivity or emotion than is culturally normative risks derision; the assertive woman is perceived as "uncaring" and "unfeminine."

These widely shared schemas about males and females also include expectations about their professional competence (Valian). Medical school department chairs confirm that lack of recognition and respect of women in routine interactions was prevalent (Yedidia and Bickel). Women report feeling "invisible" and frequently having their contributions at meetings ascribed to men (Valian). Both men and women asked to rate works of art, articles, and curricula vitae give lower ratings when they believe they are rating the work of a woman (Valian, 1998). An analysis of peer-review scores for postdoctoral fellowship applications revealed that women applicants had to be 2.5 times more productive than the average man to receive the same competence score (Wenneras and Wold). Students judge women faculty who are not nurturing much more harshly than they do men professors who are not nurturing (Sandler, Silverberg, and Hall).

Thus, without being conscious of their "mental models" of gender, both men and women still tend to devalue women's work and to allow women a narrower band of assertive behavior (Valian). Under such conditions, women cannot realize their full potential, nor can they care for their patients with maximum effectiveness. "Mental models" persist in part because individuals, especially dominant personalities, tend to ignore information that runs counter to their stereotypes (Fiske). Features common to clinical medicine, such as time pressures, stress, and cognitive complexity, also stimulate stereotyping and "application error" (i.e., inappropriate application of epidemiological data to all group members) (Geiger). Nonetheless, most scientists and physicians appear to believe that they work in a meritocracy and that they are not influenced by stereotypes (Bickel, 1997). Some even conclude that women are advantaged compared to men. Apparently, while individual men do not feel powerful, power is so deeply woven into their lives that it is most invisible to those who are most empowered (Kimmel). Equity demands, however, that health professionals accept responsibility for unlearning whatever stereotypes interfere with their evaluations of patients, students, and colleagues.

ACQUIRING MENTORING. While most studies find that women faculty are as likely as men to have a mentor, women gain less benefit from the mentor relationship. One internal medicine department found that mentors more actively encouraged men than women protégés to participate in professional activities outside the institution and that women were three times more likely than men to report a mentor taking credit for their work—an unethical practice rarely discussed (Fried, Francomano, and MacDonald). Women cardiologists report their mentors to be less helpful with career planning than men do and more commonly noted that their mentor was actually a negative role model (19% of women versus 8% of men) (Limacher, Zaher, and Wolf).

These challenges in obtaining mentoring are particularly unfortunate because, for a variety of reasons, women have a greater need for mentoring than men do (Bickel, 2000).

Not only does Western culture tend to devalue women's work, women tend to be more modest than men about their achievements; they are less apt than men to see themselves as qualified for top positions even when their credentials are equivalent or superior (Austin). Moreover, women's informal networks are less extensive and less likely to include colleagues or higher-ranking people from previous institutions (Hitchcock et al.). Without the "social capital" and essential information that grow out of developmental relationships, women remain isolated. And isolation further reduces their capacity for risk-taking, often translating into a reluctance to pursue professional goals or a protective response such as niche work or perfectionism (the obverse strategy of identifying a hot topic) (Etzkowitz, Kemelgor, and Uzzi). It is significant that women experience isolation at work whereas for male health professionals work tends to be highly social and socializing. This paradox is compounded when similarly isolated women are appointed as tokens to committees and pointed to as *role models* (i.e., expected to be *solutions* to a *problem*). If women seek affiliation through a women's group, they may be labeled as needy, lesbian, or *rabble-rousers.*

Many men have difficulty effectively mentoring women because of lack of experience with career-oriented women or because they find it easier to relate to women in social than in professional roles. A contemporary approach to mentoring builds on the recognition that styles and advice that worked for the mentor may not work for a protégé (Thomas) and that advice applicable even five years earlier may no longer be helpful. Thus, many chairs and senior faculty could use assistance in techniques of active listening, avoiding assumptions, and providing supportive feedback that also stimulates the protégé's professional growth (Bickel et al, 2002).

PRACTICE-RELATED AREAS OF CAREER DISADVANTAGE. A large national study conducted in 2000 found that compared with men, women physicians have more patients with complex psychosocial problems. Women physicians also have substantially less control of their work than men—in term of patient volume, selecting physicians for referrals, and office scheduling. Women physicians also have more patients with complex psychosocial problems, adding to their time and energy requirements, in an era when physicians are being pressured to see more patients in fewer minutes. Time spent with patients is time not spent with students, writing grants, or on their many other responsibilities. Thus, it is not surprising that women were 1.6 times more likely to report burnout than men, with the odds of burnout by women increasing by at least 12 percent for each additional five hours worked per week over forty hours. This study also found a $22,000 gap in income between men and women, after controlling for age, specialty, practice type, time in current practice, uninsured status of patients, region, hours worked, and other variables (McMurray, 2000). A 1998 survey of board-certified internists in Pennsylvania found that women earned 14 percent less per hour than their male counterparts, even after adjustment for demographic, training, practice, and family characteristics (Ness et al.).

Junior faculty have been hardest hit by imperatives in academic medicine to increase clinical loads; these imperatives disproportionately affect women (67% of women are instructors or assistant professors compared to 44% of men). Women faculty have less "protected" time for research and fewer academic resources than men (Carr et al.). In addition to pressures to simultaneously complete fellowship, start a practice and a research program, and take on heavy service and administrative responsibilities, most young faculty members are raising young children. Women physicians are actually more likely to be married (and less likely to be divorced) than women in the general population (Frank et al., 1997). And about 85 percent of women physicians have children, compared to 83 percent of the general population (Potee, Gerber, and Hall, 1999).

While family-leave policies at academic medical centers are now commonplace, they rarely allow for more than three months of leave and require women to use up annual and sick leave. Some schools have introduced less-than-full-time options; in many cases, however, users sacrifice benefits and the flexibility to return to the tenure track (Socolar et al.). Even when flexible policies exist, individuals who take advantage of the flexibility allowed may be labeled "uncommitted." Thus, the relationship between medicine and parenthood can be characterized as uneasy and not well-tolerated, especially in academic careers.

Moreover, family-related decisions can escalate into moral dilemmas. The traditional obligation of physicians to set patients' needs above their own sometimes confronts physician-parents (and especially couples who are both in practice) with difficult choices between the needs of patients and those of their own children. How are they to decide when a patient must take priority over their children? While such dilemmas are common because of the lack of easily available child care, they are rarely discussed. The profession would benefit from opportunities for practitioners who are also family caretakers to dialogue about the ethics of family responsibilities as related to the ethics of medicine. Even more helpful would be institutional approaches to improving and supporting flexibility for those with family responsibilities, such as on-site day care, emergency or sick child care, and nonpunitive leave policies. All of these features are much more readily available in Canada, Britian, and Australia than in the United States (McMurray et al., 2002).

THE INTERSECTION OF GENDER AND ETHNICITY. In 2001 the 125 U.S. medical schools had a total of 1,199 African-American women faculty (4% of all female faculty); smaller numbers of Native Americans, Mexican Americans, and Puerto Rican women added up to an additional 4 percent of women faculty. A higher proportion of women faculty than men faculty are underrepresented minorities.

Faculty from ethnic minorities are no more likely to attain senior rank than are women (Palepu et al.; Fang et al.; Bright, Duefield, and Stone). Both women and minorities face stigmatization and prejudice and difficulties in obtaining career-advancing mentoring. Thus women ethnic minorities experience "double jeopardy." A study of African-American women physicians found that the majority cited racial discrimination as a major obstacle during medical school and residency and in practice. In addition they perceived gender discrimination to be a greater obstacle than did non-African-American women physicians (More).

Psychologists have described the *just world* bias: That is, people want to believe that, in the absence of special treatment, individuals generally get what they deserve and deserve what they get; they adjust their perceptions of performance to match the outcomes they observe (Valian). If women, particularly women of color, are underrepresented in positions of greatest prominence, the most psychologically convenient explanation is that they lack the necessary qualifications or commitment. Thus, women of color must frequently overcome assumptions that they owe their positions to affirmative action rather than professional qualifications. At the same time, minority women encounter severe *surplus visibility,* that is, their mistakes are more readily noticed and they are less likely to be given a "second chance."

Compounding all of the above extra challenges, minority female physicians are also at highest risk for institutional service obligations (Menges and Exum), including committee work, student counseling, and patient care (Menges and Exum; Levinson and Weiner). Thus, while increasing the number of ethnic minorities progressing in academic medicine presents different challenges than increasing women, the challenges overlap, for instance, in overcoming unconscious bias related to "what a leader looks like" (Bickel, 1997).

Forward-Looking Institutional Approaches

Most approaches to improve the advancement of women have attempted to "fix" or "equip" women with skills that they are perceived to lack and to add temporal flexibility to policies. While these efforts are necessary, organizational development experts concluded that such narrow approaches can have only limited success (Ely and Meyerson).

The research findings summarized above clearly raise fundamental questions about organizational culture and the ways in which work is organized. What is wrong with U.S. health systems that women have such a hard time succeeding in them? The faculty tenure system offers a striking example; it is a forced march in the early years, allowing a slower pace later on. Most women would prefer the opposite timing, allowing them more flexibility while their children are young. The most clinically productive decade for women physicians begins at age fifty.

Another example of organizational disadvantage is medicine's overvaluation of heroic individualism, with the largely invisible work of preventing crises and maintaining relationships going unrewarded. Because women tend to be doing the less visible, collaborative, relational work, their contributions remain underrecognized (Etzkowitz, Kemelgor, and Uzzi).

Thus strategies to promote women must target features of the work culture that may be "simply the norm" but that disadvantage women (Ely and Meyerson). For instance, new models of cooperation are needed to recognize and reward contributions of all members of the team. And these models must avoid expectations that women will do the "relationship" work; dialogue between the sexes is required to achieve the facilitating of *caring* and *leading* on the part of both women and men.

Much of the process by which disadvantage is created and reinforced occurs at the department level (e.g., recruitment, mentoring, access to resources). Thus, department heads are key, and one avenue to stimulate their cooperation is to emphasis diversity issues in departmental reviews (Etzkowitz, Kemelgor, and Uzzi).

The most comprehensive analysis to date of initiatives to develop women medical school faculty (Morahan et al.) found that exemplary schools focus on improvements not specific to women: heightening department chairs' focus on faculty development needs, preparing educational materials on promotion and tenure procedures, improving parental-leave policies, allowing temporary stops on the tenure probationary clock and a less than full-time interval without permanent penalty, and conducting exit interviews with departing faculty. These schools regularly evaluate their initiatives by comparing recruitment, retention, and promotion of women and men faculty and by conducting faculty satisfaction and salary equity studies. Surveying faculty about their career development experiences and their perceptions of the environment, comparing the responses of men and women, and presenting the results to faculty and administrators are particularly useful strategies.

Initiatives to develop women and to improve the work culture do not lower standards or disadvantage men. Interventions on behalf of women tend to improve the environment for men as well. When the Department of Medicine at Johns Hopkins University evaluated its interventions to increase the number of women succeeding in the department (Fried et al.), the proportion of women expecting to remain in academic medicine increased by 66 percent and the proportion of men increased by 57 percent.

With regard to ensuring that students and junior faculty obtain the mentoring they need, institutions find themselves challenged by the increasing heterogeneity of new entrants, not only in terms of gender but also with regard to ethnicity, age, values, and previous life experience. In order to competently mentor students unlike themselves, the relatively homogeneous senior faculty would benefit from opportunities to improve listening and feedback skills and to overcome engrained models of gender and race. Another strategy to increase positive emphasis on mentoring is to evaluate faculty on how well they meet this responsibility. For instance, just as promotions committees count first authorships in major journals, some schools are also now counting *last* authorships with mentees as first authors (Grady-Weliky, Kettyle, and Hundert). Other schools now require that on each faculty member's annual evaluation, senior faculty list their protégés; trainees and junior faculty are asked to name their mentors and role models. An increasing number of schools and individual departments offer programs that facilitate mentor/protégé pairings; another positive strategy is mentor-of-the-year awards (Bickel, 2000).

Medical schools' approaches to eliminating sex discrimination and harassment have included sporadically distributed informational resources and occasional educational programs; by and large the effectiveness of such efforts has not been evaluated. Medical educators' increasing emphasis on professionalism in general shows more promise in drawing positive attention to responsible physicians' attitudes and behaviors (Epstein and Hundert; Wear and Bickel). However, more attention to barriers created by mental models of gender and race would strengthen most professionalism initiatives. Likewise, programs designed to improve patient communication skills should include assistance in overcoming gender stereotypes.

Finally, there are encouraging trends in medical education toward problem-based learning and toward the incorporation of women's health into the curriculum. Both require interdisciplinary bridges and teamwork, actually furthering a sense of community within academic medical centers. And adding a focus on women's health also frequently incorporates a more holistic and community orientation into the curriculum (Donoghue, Hoffman, and Magrane).

Conclusion

Gender differences in professional and leadership opportunities persist, yet perceptions of these continuing inequalities are not widespread. The number of women entering the health professions, and even becoming faculty, actually obscures the work that remains—part of which is persuading many that academic medicine still greatly favors the development of men. Actually, many male physicians and medical students are concluding not only that equal opportunity has been won but also that women tend to have an "affirmative action" advantage. Many young women entering medicine, surrounded by women peers and unaware of their predecessors' struggles, are assuming that women may be freely choosing to reap fewer rewards than men for their work but that they themselves will not have to settle for less (McCorduck and Ramsey). Thus, impetus for change is lacking, as the women who are not realizing their potential tend to be invisible or to disappear.

Is the increasing number of women entering medicine and other health professions mitigating the impact of gender? Recent studies comparing the careers of men and women consistently show that increases in the number of women is *not* reducing gender disparities in advancement nor the power of mental models of gender. Reducing the power of gender stereotypes in medicine is a moral imperative because healthcare professionals have a duty to ensure that perceptual bias does not interfere either with the best possible patient care or with clinicians' responsibilities as role models for and teachers of students of both genders. Healthcare professionals' effectiveness depends in large part on their sensitivities to others, that is, their ability to "hear" and "see" individual patients.

Is gender diversity changing the medical profession? Too many diverse forces (e.g., technological, economic, political) are shaping modern medicine to link any one change to the increasing numbers of women providers, especially given the extent to which men and women share characteristics. But the primary difficulty in answering this question is that too few women have achieved leadership positions to allow comparison with the records of their male predecessors.

That the health professions are not realizing the full value of their investment in women is not only an injustice, it is also evidence of poor stewardship. These careers involve considerable personal and public resources, but the leadership potential of most women continues to be wasted. This is a collective loss—all the more unaffordable given the leadership challenges facing the health professions. It is highly likely that women leaders can make a positive difference: "Women have lived in *embedded* roles, roles intimately interwoven into the warp and woof of the social context … serving as links between other roles, between generations, between institutions, between the public and private domains.… Consequently women are no newcomers to the complications generated by interdependence and diversity" (Lipman-Blumen, p. 289).

Gender equity will always be an elusive concept and goal; for one thing, women are as different from each other as men are from each other. Nonetheless, leaders owe it to future generations of trainees and patients to create an environment of equal opportunity—where assumptions and judgments about individuals' competencies and preferences are not colored by their sex, where women's goals and traits are as valued as men's, and where nonpunitive options facilitate the combining of professional and family responsibilities. The future of the health professions is inextricably linked to the development of its women professionals.

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SEE ALSO: *Alternative Therapies: Social History; Care; Compassionate Love; Feminism; Sexism; Sexual Ethics and Professional Standards*

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WOMEN AS HEALTH PROFESSIONALS, HISTORICAL ISSUES OF

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Historically, women's roles in healthcare were primarily as caretakers and nurturers; as wives, mothers, and nurses; and in their responsibility for children, the sick, the aged, and the disabled. When instrumental healing roles became more technical and financially lucrative, women met resistance to their assumption of those roles. This attitude often was based on mistrust of their capacities and the departure their work in healthcare represented from their more traditional roles, especially because they might compete with men.

Early History of Women in Healthcare

Women have always been healers as well as caretakers; they have acted as pharmacists, physicians, nurses, herbalists, abortionists, counselors, midwives, and *sagae* or "wise women." They also have been called witches. In the physician role, however, society rarely permitted them to perform in the same capacities and positions as men.

THE ANCIENT WORLD. Early Egyptian steles refer to a chief woman physician, Peseshet, and in 1500 B.C.E. women studied in the Egyptian medical school in Heliopolis. In the Chinese record in 1000 B.C.E. female physicians were in positions that encompassed activities other than traditional midwifery and herb gathering. There also were medical roles for women in the Greek and Roman civilizations. In Rome physicians were often slaves or freed slaves; it is likely that many were women. Women who entered medicine were frequently members of medical families and practiced together with their family members. The physician husband of a second-century woman physician wrote for his wife's epitaph, "You guided straight the rudder of life in our home and raised high our common fame in healing—though you were a woman you were not behind me in skill" (Anderson and Zinsser, p. 61).

Throughout history women have been special attendants to other women, assisting with labor and delivery, providing advice on the functions and disorders of their bodies, and tending newborns. Because childbirth was considered a normal rather than a pathological process, it was not thought to be part of medicine. Soranus of Ephesus, a first-century C.E. physician practicing in Rome, believed that women were divinely appointed to care for sick women and children. Among the criteria he delineated for those practicing medicine, inluding women, were literacy, an understanding of anatomy, a sense of patient responsibility, and ethical concerns, particularly in regard to confidentiality.

During the first few centuries of the spread of Christianity, women ordained as deaconesses by bishops with the consent of the congregation appear to have played a significant role in healthcare. Although little is known about their work, many of those deaconesses became the first parish workers and district nurses (Shryock, 1959). Among those women were Saint Monica, the mother of Saint Augustine, and Fabiola, who founded a hospital at Ostia in Italy in 398 C.E.

After the fall of the Roman Empire, medicine continued along two paths: monastic medicine, which lost touch with older traditions, and Arabic medicine, which developed in Persia and transmitted the heritage of Greek medicine to Europe. Arabic medicine produced notable practitioners and hospitals run by male and female "nurses." During the Crusades women staffed infirmaries and clinics in Jerusalem and along the European routes to the Holy Land.

THE MIDDLE AGES. Medical scholarship flourished in the ninth century at the University of Salerno in Italy and continued to develop through the tenth and eleventh centuries (Corner). At that time women apparently studied medicine at the university. Although little is known about most of those early women physicians, eleventh-century records reveal the existence of Trotula, a woman faculty member at Salerno who is said to have written important texts on obstetrics and gynecology and to have headed a department of women's diseases. Her most important work, *De Passionibus Mulierum,* remained the major reference on that subject for several centuries. The authorship of this and other works was attributed to her husband or to other male colleagues (Corner; Achterberg). Trotula suggested that infertility could be attributed to the male as well as the female. In cooperation with the "Ladies of Salerno," a group of women physicians, Trotula established the first center of medicine that was not under Church control.

The M.D. degree was first awarded in 1180, apparently only to men. One of the notable figures of the twelfth century was Hildegard of Bingen, a scientific scholar, abbess, writer, composer, and political adviser to kings and to the pope. She wrote two medical textbooks, *Liber Simplicis Medicinae* and *Liber Compositae Medicinae,* presumably for use by the nurses who were in charge of the infirmaries at Benedictine monasteries. Her textbooks described a number of diseases, including their courses, symptoms, and treatment, as well as scientific data on the pulsation of blood and the regulation of vital activities by the nervous system. Hildegard's writings also demonstrated an understanding of normal and abnormal psychology.

In the medieval period affluent women were active in medicine, particularly in Italy, where the universities were accessible to them. In 1390 Dorotea Bocchi earned a degree in medicine from the University of Bologna and followed her father as a lecturer in medicine at that university. In 1423 Constanza Calenda, the daughter of the dean of the medical faculty at Salerno, lectured on medicine at the university in Naples. Women also were qualified and permitted to practice medicine in France, England, and Germany. They generally were limited in practice to specifically defined roles, including bleeding, administering herbs and medicines, and reducing fractures, as well as practicing midwifery. As early as 1292, however, women in Paris worked as "barber surgeons," practicing what was known of surgery. Until 1694 widows automatically were allowed to continue practicing if their specific form of medicine had been their husbands' field.

From the thirteenth to the seventeenth centuries the number of physicians was low, and the role of women healers was particularly important in meeting the healthcare needs of the population. During that period women practiced as physicians, surgeons, bone setters, eye healers, and midwives. It generally was believed that women were better suited for the treatment of women's diseases.

During the fifteenth century women obtained higher degrees by presenting medical theses, and during the fifteenth century and the early part of the sixteenth century women began to excel in innovative techniques and made important contributions to medicine. They served kings, royal families, and even armies in Europe.

Although it is assumed that the number of women in medicine was small, their healthcare work in the Middle Ages caused enough concern that by 1220 the University of Paris succeeded in preventing them from gaining admission to medical school. In 1485 Charles VIII of France decreed that women could not work as surgeons.

By the fourteenth century the licensing of physicians was well established, although women rarely were allowed to sit for licensing examinations. In 1322 university-trained male physicians brought a suit against Jacoba Felicie de

Almania in France, claiming that in practicing without appropriate training and licensing, she endangered patients. Patients testified to her skill; Jacoba argued that she was both physician and nurse to her patients. She also emphasized that many women would not seek treatment for their illnesses if they had to see a male physician. Because she did not have the correct university degree, she not only was barred from medicine but also was excommunicated from the Church. Women who practiced outside their licensed specialities, for example, midwives who functioned as physicians, also were condemned.

THE RENAISSANCE AND AFTERWARD. By the end of the fifteenth century, as medicine became an academic discipline and a more established profession in several centers in Europe, the movement to exclude women from the formal practice of medicine gained momentum. That movement coincided with the ideology of misogyny as it was articulated by Heinrich Kraemer and James Sprenger in *The Malleus Maleficarum* (1486), a treatise on identifying and dealing with witches. Witch-hunting capitalized on the widespread belief in the spiritual and mental inferiority of women, a belief that was fueled by the Church. Even when active witch-hunts subsided, their effects remained. Women were effectively eliminated from performing medical roles other than traditional caretaking and midwifery.

Before the sixteenth century it was not possible for a man to be a midwife; it was a capital offense in some places. As medicine and surgery were differentiated from each other in the fifteenth and sixteenth centuries, some male barber surgeons began to practice midwifery. By the late fifteenth century licensing examinations were given, generally by a doctor and a midwife. Increasingly, concern was expressed by physicians and the laity about whether midwives were knowledgeable enough to recognize when it was appropriate to call for a consultation with male physicians and surgeons.

The sixteenth to eighteenth centuries produced several outstanding female midwives, including Louyse Bourgeois, who in 1609 became the first midwife to publish a work on obstetrics, a book that became the basic text for midwifery in Europe. Nonetheless, with the invention of the obstetrical forceps in the seventeenth century by the Chamberlens, a family of male midwives and barber surgeons, obstetrics was pushed closer to the realm of the male practitioner. In 1634 Peter Chamberlen III attempted to establish a corporation of midwives in England with himself as the governor, a move that was resented by female midwives. Increasingly, men began to participate and compete in that profession, particularly in serving the upper classes. By the eighteenth century men controlled all areas of medicine except midwifery and nursing, and even in those areas women increasingly were required to practice only under male supervision.

By the beginning of the seventeenth century women were denied access to medical training and then prohibited from belonging to professional associations. University training was required, and women were not admitted to universities. Despite exclusion from formal training and practice, women continued to provide for the healthcare needs of family members and others in the community, especially the poor, who had no other access to healthcare.

Women in Early American Medicine

In colonial North America the healing role of women was critical to survival, and many women assumed medical roles. Ann Hutchinson, the early seventeenth-century dissident religious leader, worked as a general practitioner and midwife. Because there were relatively few university-trained physicians and no medical schools in the colonies, medicine was practiced by those who appeared to be particularly talented, and an apprenticeship system began to evolve. Two women listed as physicians in Boston in the seventeenth century later were denounced as witches, and no other woman practiced medicine in Boston until Harriot Hunt, after apprenticeship training, opened a medical office in 1835.

Eighteenth-century American medicine had no unified concept of medical care; a variety of views of practice and training offered various programs of study and concepts of healing. In that setting the role of women was extensive and complex because the medical care of families was frequently the responsibility of women.

Most women practitioners were midwives. Many went to Europe to train, as the first school for midwives in the English colonies was not started until 1762. The early training of midwives was based on the assumption that most obstetrical practice would remain in the hands of women. This did not occur in colonial North America, although it was the case in many parts of Europe.

In 1765 John Morgan founded the first university-connected, so-called regular American medical school at the University of Pennsylvania. Its formal, scientifically based curriculum departed from the almost exclusive apprenticeship training that existed in the colonies and was more reflective of European standards of that time. By excluding women, it began a tradition of barring them from formal medical training and forcing them into “irregular” training. Many women without diplomas, however, set up flourishing practices. They were trained in the homeopathic, eclectic, or “irregular” traditions, which tended to be less prestigious.

Women in Nineteenth-Century Medicine

In 1847 Elizabeth Blackwell became the first woman to be admitted to a "regular" medical school in the United States; she graduated first in her class at Geneva (New York) Medical School in 1849. The New York State Medical Association promptly censured the school, and when her sister, Emily Blackwell, applied a few years later, she was rejected. Emily subsequently received an M.D. from Western Reserve Medical College in Cleveland after her acceptance to Rush Medical College in Chicago had been rescinded in response to pressure from the state medical society.

Ann Preston began her medical studies in 1847 as an apprentice to a Quaker physician. After two years she applied to and was rejected by four medical schools. In 1850 she established the first regular women's medical college in the world, the Women's Medical College of Pennsylvania. She and her students recalled their experiences at the Pennsylvania Hospital: "We entered in a body, amidst jeerings, groaning, whistlings, and stamping of feet by the men students. On leaving the hospital, we were actually stoned by those so-called gentlemen" (Alsop, pp. 54–55). This account was corroborated by the *Evening Bulletin* of Philadelphia.

In 1847 Harriot K. Hunt, who earlier had established an irregular practice in Boston despite her lack of an M.D. degree, applied to Harvard Medical School. Although supported by the dean, Oliver Wendell Holmes, she was rejected for admission. After hearing about Elizabeth Blackwell's acceptance, she again applied for admission and was accepted. However, she was denied a seat when the all-male class threatened to leave if women or blacks were admitted. Not until almost a hundred years later, in 1946, did Harvard Medical School begin to admit women.

By 1850 two additional all-female medical colleges were founded, one in Boston and one in Cincinnati. Both were "irregular" schools. The Boston Female Medical College was designed primarily to prevent male midwifery, which its founder, Dr. Samuel Gregory, felt trespassed on female delicacy. The school was founded in 1848 and offered a medical degree by 1853, but it was always financially troubled and did not have a good reputation. In 1856 it changed its name to the New England Female Medical College and began to recruit new faculty members, including Marie Zakrzewska, who helped develop a pioneering clinical training program. In 1873 the school merged with Boston University.

In 1855 the National Eclectic Medical Association formally approved the education of women in medicine, and in 1870 it became the first medical society to accept women as members. Traditional medical societies, however, continued to be closed to women. In his 1871 American Medical Association (AMA) presidential address Alfred Stille criticized female physicians for being women who seek to rival men, who "aim toward a higher type than their own" (Ehrenreich and English, p. 26). Negative attitudes toward the presence of women in medicine appeared to be supported by accumulating "scientific" evidence that supposedly supported the inferior status of women on biological grounds, including the idea that their brain capacity was less than men's. A book published in 1873 by Edward Hammond Clarke fueled the controversy: In *Sex in Education: or, A Fair Chance for the Girls* he stated, "Higher education for women produces monstrous brains and puny bodies" (Clarke, p. 41). It echoed Charles Meigs's 1847 statement, "She [woman] has a head almost too small for the intellect but just big enough for love."

The debate about women's intellectual capacity induced Harvard Medical School to offer the Boylston Medical Prize in 1874 for the best paper on the topic "Do women require mental and bodily rest during menstruation and to what extent?" The winning research was submitted by Mary Putnam Jacobi. When the judges discovered the sex of the author, they hesitated about awarding the prize but finally did so (Walsh). Putnam Jacobi had found, contrary to prevailing views, that the majority of women in her sample did not suffer incapacity. Her study was followed by several others, all with similar findings. Despite such work and evidence, the barriers to women did not fall.

Even women who managed to obtain medical training were refused admittance to medical societies, and hospitals denied them appointments. Female physicians in the United States began to open their own hospitals and clinics. In 1857 Elizabeth and Emily Blackwell founded the New York Infirmary for Women, where they cared largely for indigent women, and in 1865 the Women's Medical College of the New York Infirmary opened. Paternalistic attitudes coupled with the difficulty women had in obtaining hospital privileges led Marie Zakrzewska in 1862 to found the New England Hospital for Women, owned and operated entirely by women.

The role of women in medicine, including the productivity and lifestyle of female physicians, continued to be debated vigorously. In 1881 Rachel Bodley, dean of the Women's Medical College of Pennsylvania, surveyed the 244 living graduates of the school and found that despite persistent beliefs to the contrary, the overwhelming majority were in active practice. Those who had married reported that their profession had had no adverse effect on their marriages and that marriage had not interfered with their work.

By the end of the nineteenth century women physicians were being accepted into many medical societies. The Massachusetts Medical Society admitted women in 1884, and the AMA seated a woman delegate in 1876 but did not accept women formally until 1915 (Morantz-Sanchez, 1985). Women physicians began to form their own associations. There were several attempts to build a national organization of women physicians, beginning in 1867. The *Women's Medical Journal* was started in 1872. In 1915 the National Women's Medical Association was founded. It was renamed the American Medical Women's Association (AMWA) in 1919 and was condemned by many male physicians. To alleviate people's fears the AMWA required that its members also join the AMA, and it held its meetings together with that organization.

Female separatism was a double-edged sword. Although it gave women a special place in the care of women and children, it also was used to exclude women from more extensive roles in medical education and from the increasing influence and prestige of the profession.

Financial contributions from women philanthropists (such as M. Carey Thomas, Mary Elizabeth Garrett, Mary Gwinn, and Elizabeth King) forced the Johns Hopkins Medical School in 1889 to accept women on the same terms that it used for accepting men. However, this did not result in large numbers of women being admitted and did not appear to increase the number of appointments of women to faculty and leadership positions (Walsh).

Following Johns Hopkins's lead, however, 75 percent of other, already existing medical schools began to accept women as students. By 1894 over 66 percent of women medical students were enrolled in regular medical schools (Walsh). The student body at Tufts Medical School was 42 percent female. Women also received a disproportionate number of the academic honors in their graduating classes.

Women Physicians in Europe and Canada

In 1859 the American Elizabeth Blackwell was placed on the British Medical Register; in the following year the British Medical Association ruled that persons with foreign medical degrees could not practice in Great Britain. In 1865 Elizabeth Garrett Anderson became the first woman to qualify to practice medicine in that country. She did that by passing the apothecaries' examination; the regulations of that guild did not exclude women. The rules were changed shortly afterward. In France, although women were allowed to study at the Faculty of Medicine in Paris, they could not become interns and thus could not complete their training.

The Royal College of Physicians in Edinburgh attempted to exclude Sophia Jex-Blake in 1869 by stating that a single woman could not attend medical school. Jex-Blake organized a group of seven women, and together they completed the first year of training. Attacks on female students from male peers, however, prompted some public support from people who were outraged that these "indelicate and ungentlemanly" men would be seeing female patients. Four years later the university won a lawsuit allowing it to refuse to grant degrees to women. Women in other European countries also experienced hostile and even violent attacks by their male peers.

The first continental European university to accept women was the University of Zurich in 1865. By the 1870s other Swiss universities had followed its lead. In Russia women were allowed to attend medical schools in 1872, partly because a number of Russian women already had studied medicine in Zurich. Negative attitudes toward women were fueled by the assassination of Czar Alexander II by a woman. After that event, from 1881 through 1905, universities in Russia were closed to women.

Many of the women who graduated from medical schools in those countries were from middle-class or upper-class backgrounds. Often they had fathers or other family members in medicine; they entered the profession to join the family practice.

The first woman doctor to practice medicine in Canada, James Barry, a graduate of the University of Edinburgh, was a British Army medical officer who became inspector general of hospitals in Canada in 1857. She was able to practice because she was thought to be a man. After her death Dr. Barry was discovered to have been a woman (Hacker).

Nineteenth-Century Midwifery

There was considerable opposition to the practice of midwifery by women in the mid-nineteenth century, particularly in the United States. In 1820 John Ware, a Boston physician, is said to have written *Remarks on the Employment of Females as Practitioners of Midwifery,* in which he raised objections that were based on his view of women's moral qualities. He stated: "Where the responsibility in scenes of distress and danger does not fall upon them when there is someone on whom they can lean, in whose skill and judgement they have entire confidence, they retain their collection and presence of mind; but where they become the principal agents, the feelings of sympathy are too powerful for the cool exercise of judgment" (p. 7).

In addition, economic and class issues played a role in women's exclusion from medicine. Midwives came primarily from working-class, rural, and poor backgrounds. They charged less than physicians did for their services and were more likely to care for the poor. With the beginning of obstetrics as a medical discipline, physicians feared economic competition from midwives.

Some physicians objected to midwives on the basis of the allegedly lower quality of healthcare they provided. However, in the 1840s two physicians, Oliver Wendell Holmes and Ignaz Semmelweiss, reported on the spread of puerperal sepsis (childbirth infection). Semmelweiss found that there was a lower incidence of it in women who were assisted in delivery by midwives. He deduced that because medical students and physicians did not wash their hands when they moved from the autopsy room to the delivery room, they spread disease. The warnings of both doctors were ignored by most of the medical profession, and controversy continued about the adequacy of midwives.

By the turn of the twentieth century about 50 percent of all babies in the United States were delivered by midwives. Midwives were held responsible for childbirth illness and puerperal sepsis, as well as neonatal ophthalmia (inflammation of the eyes generally related to maternal gonorrhea), because it was believed by many people, especially in the medical profession, that they were not sufficiently trained to prevent those illnesses. Under mounting pressure, many states began to pass laws forbidding midwifery, many of which remain in effect.

Evolution of Nursing in the Nineteenth Century

The practice of nursing was sponsored primarily by the Church until the mid-eighteenth century, when the London Infirmary appointed a lay nurse. Nursing was seen as a low-status occupation; records show long working hours and low pay. Dickens's novel *Martin Chuzzlewit* (1844) focused attention on the quality of the nursing care given by pardoned criminals, aging prostitutes, and other women of questionable morality and interest who functioned as nurses.

At the time of the Crimean War Florence Nightingale responded to the need for nursing reform and established military and then civilian nursing. In 1860 she founded a school for nurses in London that had a rigorous curriculum and specific guidelines for nursing as a profession. She met opposition from the medical profession, many of whose members felt that "nurses are in much the same position as housemaids and need little teaching beyond poultice-making and the enforcement of cleanliness and attention to the patient's wants" (Dolan, p. 230).

The first nursing schools recruited upper-class women who were "refugees from the enforced leisure of Victorian ladyhood" (Ehrenreich and English, p. 34). Despite their aristocratic image, nursing schools began to attract more women from working-class and lower-middle-class homes. Those advocating the nursing profession saw the nurse as the embodiment of Victorian femininity and nursing as a natural vocation for women, second only to motherhood. Nightingale viewed women as instinctive nurses, not physicians: "They have only tried to be men, and they have succeeded only in being third-rate men" (Ehrenreich and English, p. 36).

Women in Twentieth-Century Medicine

By the beginning of the twentieth century women were seeking admission to medical schools in increasing numbers. Because of an oversupply of physicians, however, salaries and prestige were diminishing. Some people blamed the situation on the "feminization" of the profession, and many schools began to decrease the number of women they accepted. Women also had more difficulty obtaining internships and residencies. Because all but one of the female institutions (the Women's Medical College of Pennsylvania) had consolidated or closed, many women had nowhere to train.

The conviction that women were not able to perform effectively as physicians and the belief that women would be damaged by pursuing a difficult career intensified. Women physicians seemed to be unable to develop a consolidated and effective strategy to resist that negative attitude. In 1905 Dr. F. W. Van Dyke, the president of the Oregon State Medical Society, stated, "Hard study killed sexual desire in women, took away their beauty, brought on hysteria, neurasthenia, dyspepsia, astigmatism and dysmenorrhea. Educated women could not bear children with ease because study arrested the development of the pelvis at the same time it increased the size of the child's brain and therefore its head. This caused extensive suffering in childbirth" (Bullough and Voght, pp. 74–75).

At that time academic medical schools were developing formal medical curricula. Proprietary medical schools also were increasing in number. The education they provided was focused primarily on an apprenticeship model, and there was little monitoring of the quality of the education. Because of the oversupply of doctors produced by those two systems, with consequent competition for patients as well as a lack of mechanisms to assess quality and monitor performance, the AMA asked the Carnegie Foundation to investigate the condition of medicine and make recommendations for dealing with the situation. The foundation commissioned Abraham Flexner, a schoolteacher with no medical expertise, to perform the study. In his 1910 report Flexner stated: “Medical education is now, in the United States and Canada, open to women upon practically the same terms as men. If all institutions do not receive women, so many do, that no woman desiring an education in medicine is under any disability in finding a school to which she may gain admittance. Now that women are freely admitted to the medical profession, it is clear that they show a decreasing inclination to enter it” (Flexner, pp. 178–179, 296).

Flexner’s report concluded that medical education required higher standards for training and provided an important impetus for establishing medicine as an academic discipline. It resulted in the closing of many medical schools, especially the proprietary ones; unfortunately, because women continued to have difficulty gaining admission to many of the university-affiliated and more prestigious medical schools, the schools that were closed were the ones that traditionally had admitted substantial numbers of women and members of minority groups. This had the effect of lowering the numbers of women physicians in the United States.

Women physicians gained some status as a result of their patriotism during World War I, when the AMWA campaigned to have women physicians commissioned on the same basis as men. Although that effort was rejected by the government, the AMWA urged women physicians to contribute to the war effort. Fifty-five women physicians practiced medicine by signing specific contracts with the military. They received neither military status nor benefits (Walsh). At Johns Hopkins the percentage of women medical students dropped from 33 percent in 1896 to 10 percent in 1916. At the University of Michigan the percentage of women medical students dropped from 25 percent in 1890 to 3 percent in 1910 (Walsh).

The number of female physicians in the United States continued to be low until the 1970s. Other countries continued to report greater percentages of female physicians. In 1965, for example, women accounted for 7 percent of all U.S. physicians. The Soviet Union reported 65 percent female physicians; Poland, 30 percent; the Philippines, 25 percent; the German Federal Republic, 20 percent; Italy, 19 percent; the United Kingdom and Denmark, 16 percent; and Japan, 9 percent (Lopate).

Medicine was viewed as a male profession in the United States more than it was in most other countries. Some scholars hypothesize that this occurred because medicine had higher prestige and income than did many other professions and therefore interested men more. Others believe that the dominance of men adds prestige and that men demand better compensation. The reasons for the gender stereotyping of professions, however, is complex and has cultural as well as political determinants. Many areas of work are sex-role-stereotyped. This occurs because of the perception that men or women are better at certain functions. For example, in the United States women were considered to be more suited to caretaking roles and men were considered to be better in more instrumental and technological activities. Thus, although medicine presents a melding of these stereotypes, women were not considered capable of performing in the increasingly technological aspects of the field. Even in a revolutionary society such as Cuba, where these stereotypes are disparaged, there is a persistence of traditional roles for women in healthcare; 30 to 40 percent of Cuban physicians are women, but virtually all nurses and midwives are women.

In the United States the choice of a specialty and the specific positions held by women in their fields of expertise reveal a pattern that has held since women began to be admitted to medical schools. In the 1970s the fact that women would assume primary care roles was used as an argument for increasing their numbers in medical schools. This has proved to be correct. Women characteristically have entered primary care fields including pediatrics, internal medicine, family practice, and obstetrics and gynecology, as well as psychiatry, pathology, and some medical subspecialties. There has been more diversification in the choice of medical specialties for women in recent years, but the numbers in the higher-paid technically oriented surgical fields continue to be low. (Accreditation Council on Graduate Medical Education).

In the United States and other countries academic and administrative appointments as well as other decision-making positions are held almost exclusively by men, whereas the majority of women physicians tend to be involved in direct patient care. Women continue to constitute almost 30 percent of full-time medical school faculty, but they are concentrated in the lower academic ranks and do not advance at the same rate as do their male colleagues (Bickel).

In countries where women have made significant progress in terms of their influence in the healthcare fields changes have occurred most often in times of war, physician shortages, or major cultural reorganization. In Russia midwives proved to be effective as doctors in the Russo-Turkish War of 1870, beginning the influx of women into medical schools. However, after the 1917 revolution, as the prestige of medicine declined, women were admitted in greater numbers. By 1940, 62 percent of Soviet physicians were women, and by 1970, that number had risen to 72 percent. As in the United States and other countries, however, Russian women held a disproportionately small number of senior positions. The *feldschers* (semiprofessional health workers) in the Soviet Union were primarily women.

The rise of female health professionals in China occurred along with the reorganization of the medical-care system and of Chinese society under the People's Republic after 1949. About half of Chinese physicians were women. In the countryside "barefoot doctors" (peasants, primarily women, with basic medical training) provided medical care without leaving their regular work to meet the needs of fellow workers (Sidel and Sidel).

Women's Evolving Role in Healthcare

The blurring of roles and the overlapping of areas of function in a healthcare have raised important questions about roles and responsibilities, for example, among primary care physicians, physician's assistants, and nurse practitioners as well as among psychologists, psychiatrists, psychiatric social workers, and psychiatric nurses. In the United States economic factors rather than specific expertise, experience, or skills have become important determinants of decisions about which practitioners will provide care. Less well trained practitioners may be favored by payers because their services are less costly. Many of these healthcare providers are women. There are few objective guidelines for determining the scope of practice. For example, in providing routine physical examinations, obstetrical care, anesthesia, psychotherapy, and minor medical and surgical procedures, professionals of varied backgrounds and training may provide similar services. There are insufficient data assessing the outcomes of this practice.

Since 1945 there has been more regulation of medical practice in the United States, and healthcare increasingly has been paid for or subsidized by governments and/or private insurance companies. Health maintenance organizations and other managed-care models have evolved. With this has come a diminution in physicians' authority and, more recently, income. At the same time there have been fewer white men applying to medical school and more women and minority group members; as a result, almost 50 percent of medical students are women and increasing numbers are from minority groups (Lorber).

The demands of work and family life as well as the nature of the process of attaining medical leadership positions continue to result in the presence of few women in major healthcare policy decision-making positions. As a result, less has changed and women have had less of an impact on practice, research, and education in medicine than was predicted in the 1970s, when the demographic shift began. There has been evidence of some changes in practice with the increase in the number of women physicians; for example, some preventive tests are more likely to be performed depending on the sex of the patient and the physician, and there are differences in practice styles related to gender. Most of the changes in the practice patterns of physicians appear to be related more to economics and political factors than to gender. However, the development of a focus on women's health and an emphasis on gender biology, including an expansion of research in this area, have been fueled largely by women physicians and scientists and by the women's movement, beginning in the 1960s. This has been important for women's health and represents a substantial contribution by women to medicine.

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SEE ALSO: *Alternative Therapies: Social History; Care; Feminism; Medical Education; Nursing, Profession of; Paternalism; Sexism*

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WOMEN, HISTORICAL AND CROSS-CULTURAL PERSPECTIVES

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A central problem of women's history is that women have been defined by men using concepts and terms based on men's experiences. Such androcentric thought pervades all domains of knowledge. Scholarship in women's studies, developed largely since the late 1960s across a broad range of disciplines, shows that attitudes, customs, laws, and institutions affecting women are grounded in religious and functionalist perspectives according to which "woman" is said to have been created from and after man; has been identified with her sexuality and defined by her sexual function; and has been confined to roles and relationships that are extensions of her reproductive capacity. Alongside this history stands a centuries-old feminist critique that challenges as self-serving and often misogynist the assumptions and intentions of the religions, philosophies, sciences, and familial and political institutions that have shaped the experiences of women in most eras and cultures. Moreover, both the definition of women and its critique reflect a Eurocentric bias that today is the subject of much criticism. This entry summarizes the scholarship produced since the mid-1970s by historians of women, reflecting their collective efforts to compensate for ahistorical assumptions and to constitute a written record both more inclusive of the experiences of women and more open to differences of perspective. It assumes that the history of women requires consideration of moral and ethical as well as social, economic, and political issues.

Women Defined

From ancient times it has been customary to define "woman," in relationship to man, as a limited and contingent part of a dimorphic species. Western cultures have placed heavy constraints on female lives, sometimes justifying these constraints by attributing to women, such as Pandora and Eve, responsibility for human misfortunes resulting from their allegedly weaker self-control or greater lasciviousness. Despite the existence of exceptional women in myth and history, most women in most historical societies have been confined to positions of dependency. Ultimately, whether on the basis of their capacity for pregnancy and resulting physical vulnerability or the use of women's fertility in forging relationships of social and economic value, women, like children, have been denied an independent voice. Seen as "lesser men" by the fathers of Western philosophy, women have been viewed as "Other," as not-man, through a discourse in which human being was embodied in the male sex (Beauvoir).

Deprived of political power and identified with sexual temptation, women have been subject to myriad laws and customs that have at once prescribed and enforced their secondary status. Men have termed women "the sex"; defined them primarily in terms of their sexuality; and, as masters of family and public power, created and staffed the institutions that control female sexuality. In the early fifteenth century, the Italian-born French author Christine de Pizan (1364–ca. 1430) challenged the prevailing androcentric definition of her sex, declaring that the evil attributed to women by learned men existed in men's minds and that, if permitted education, women would become as virtuous and capable as men.

Resistance and rebellion by individual women have a long history; and organized protest, termed *feminism* only since the 1890s, is traceable through a history that is continuous for at least two centuries. However, the condition of women has only occasionally been viewed as a general problem of social justice. The *woman question,* as it was phrased in the nineteenth century, was debated as a political, social, and economic, but rarely as a moral issue; women's rights and responsibilities were discussed as matters of expediency. In the great democratic revolutions of the late eighteenth century, the "inalienable rights of man" were not extended to women. Men, as heads of traditional patriarchal families, continued to speak for their dependents, women as well as children. While some Enlightenment philosophers, most notably Theodore von Hippel (1741–1796), had admitted the abstract equality of all human beings, and others, such as the Marquis de Condorcet (1743–1794), advocated women's accession to equal education and to full civic rights, social arrangements nevertheless made it expedient to ignore their claims. Ultimately, most efforts to improve women's status and condition have been justified on grounds of expediency: if women vote, said the suffragists of 1915, war would be less likely; if mothers earned fathers' wages, said the feminists of 1985, fewer children would live in poverty.

Most matters related to women, then, whether intellectual constructs or social institutions, whether constraining or enlarging women's options, whether produced by misogynists or feminists, have rested on utilitarian grounds. Woman, first of all as an individual human being, was rarely the subject of thought or decision; woman as wife and mother or potential mother has been the ideal type. Even for suffragist leaders of the nineteenth and twentieth centuries, the resort to arguments of expediency over considerations of justice or ethics has itself been an expedient (Kraditor). By the 1990s, however, following two decades of reexamination of all domains of knowledge by scholars in women's studies, feminist theorists began to challenge arguments based on expediency (while sometimes using them as well) and to demand a voice in the discourse through which both knowledge and social institutions are established. Noting injustice in the treatment of women, and the absence of concern about women at the center of most modern and contemporary philosophical systems, they criticize ethical theory itself as a hegemonic expression of the values of a dominant class or gender (Walker).

It is simpler, and historically has been more effective, to argue the needs of women in terms of their differences from men—their needs as wives and mothers, their concerns with nurturant values, their familial and social responsibilities. Women often do speak "in a different voice," reflecting different moral concerns and material circumstances (Gilligan). Women have been and remain deeply divided over their own definition of self: as individuals entitled to, and now demanding, equality of treatment with men; or as persons with gender-specific differences and resulting relationships with families, friends, and communities to whom they bear responsibilities that limit individual autonomy and rights. "Equal rights feminists" have been challenged for basing their claims on an abstract concept of personhood that denies female specificity. Rather than buttressing the claims of individualism based in nineteenth-century liberal philosophy (Fox-Genovese; Pateman), they should, according to this view, emphasize the need for men as well as women to acknowledge their dependence on and debts to the communities that are essential to their existence.

Furthermore, through failure to emphasize female differences, women may continue to be measured through a single, male-constructed lens that ignores or denigrates female-specific experiences. Yet woman along with man should be the measure of all things—and the universalizing of human experience based only on consideration of dominant cultures should be avoided. Awareness of the dimensions of this "equality vs. difference" question is critical to understanding a wide range of historical and contemporary issues regarding the status of women. Can gender-specific needs of individuals such as pregnant women be acknowledged in law that also supports equality of treatment for all individuals? Can employment preferences be granted to men if, historically, most women have not pursued a given occupation? How should a history grounded in gender distinctions be interpreted (Scott)?

Scholars today recognize that neither "man" nor "woman" has a single, fixed meaning; cross-cultural and international differences defy simple definition. The concept of separate spheres of human activity labeled public and private, political and personal, society and family, however, has a long history; the reality of women's lives was obscured by these universalizing categories of analysis often used by philosophers, politicians, and professors. In the early twenty-first century, historians of women have firmly established the historicity of women, a critical first task. Women's lives, as well as their consciousness, vary, not only by era but also by class, race, age, marital status, region, religion, education, and a host of factors peculiar to individual circumstances. Implicit in this work is a political message: that changes over time past make future change conceivable. Also implicit is an accusation of injustice against a system of societal arrangements that has suppressed women, for the questions raised in this scholarship deal often with omissions, silences, and double standards. This form of scholarship elicits new knowledge and conjectures about human possibilities.

Women in Traditional Western Societies

As the story has been reconstructed, women in history have become increasingly visible (Bridenthal et al.). New anthropological studies suggest that women may have enjoyed greater equity with men in prehistorical times (Sanday). Agrarian economies with relatively little differentiation of tasks allowed for more egalitarian relationships within families; families themselves constituted societies, and participation was not dichotomized by gender, or sex roles. The classical world, with its more advanced economies, and greater wealth and militarism, vested both property rights and citizenship only in men, as heads of households. Separated into family and polity, society became a male world of civic virtue. Relegated to the household, women became men's property, and a double standard of sexuality was constructed to assure female subjection to patriarchal family interests. A woman's honor, and that of her family, was identified with her chastity. The virtue of a woman, said Aristotle, was to obey. Differentiation by class allowed some variation of roles for women; but Plato's philosopher queens aside, no women could claim equal treatment in regard to property, citizenship, marriage, criminal law, or access to social institutions. Women existed to reproduce and to serve men's needs; rights in their progeny were assigned to men.

INFLUENCE OF CHRISTIANITY. The spread of Christianity brought new possibilities for women: for some, a role in spreading the new religion; for all, a promise of spiritual equality. Christianity created new opportunities for women's voices to be heard, especially by instituting marriage laws requiring consent and establishing, in some instances, inheritance and property rights for women. Monasteries and convents, while providing shelter for the destitute, also offered education and alternative careers for a small, often highborn, minority. The high Middle Ages saw the foundation of the first universities in the Western world, beginning in 1088 with Bologna, whose famous twelfth-century legal scholar, Gratian, incorporated into his influential study Aristotle's dualistic view of women as passive and men as active, in law as well as reproductive physiology.

This Aristotelian dualism was also advanced by the work of Thomas Aquinas in the thirteenth century; he combined his reading of Aristotle with the Christian view of creation to assert that woman was a "defective and misbegotten" man, assigned by nature to the work of procreation. The rebirth of learning thus gave new life to the hoary tradition of defining women as not-men and for men, in terms of qualities they lacked and services they provided. Renaissance thinkers transmitted across the ages classical Greece's sharp distinction between polity and household. The literature of courtly love notwithstanding, as dynastic power was reconstituted in bureaucratic and political structures, the separation of public and private arenas of human activity increased; and relative to aristocratic men, upper-class women faced new restrictions. Growth of the market economy, however, probably had a more liberating effect on rural and urban women of other classes.

Neither the Renaissance nor the Reformation, both considered watersheds in European history, brought reformed ideas about women to the fore. The advent of Protestantism meant the closing of nunneries that had allowed some women, notably those who could offer a dowry to the church, agency outside marriage. It also deprived all classes of women of the succor of the Virgin Mary and female saints. However, Protestantism did provide some literate women as well as men direct access to the word of God in the Bible. By ending clerical celibacy, it opened opportunities to ministers' wives, and ultimately, especially in the dissenting sects, it allowed women wider participation in church affairs. In the Counterreformation, some Catholic laywomen formed communities through which they provided social services for the poor, ill, and orphaned. Nuns continued to serve as teachers, nurses, and social workers. But Catholics and Protestants alike, following the biblical injunction of Paul, taught women silence in public and subjection to men in private.

URBAN VS. RURAL EXPERIENCE. Controversy over the effects of the Renaissance and Reformation on women's lives continues to fuel debate among historians of women. In an increasingly complex society, generalizations fail to satisfy: some women prospered, enjoyed education by leading humanist scholars such as Erasmus, and wielded power on behalf of dynastic lines. Urban craftsmen's wives shared in domestic production and local marketing of goods, and helped to manage artisanal workshops. City women developed professions of their own, largely in the healing arts, midwifery, and retail establishments, especially those purveying food. But most wage-earning women worked as domestic servants, frequently for a decade before marriage and sometimes for their entire lives; "maid" had become synonymous with "female servant."

However, most women, like most men, lived in rural settings, where all members of the household pooled their labor in a family economy organized to produce the goods and services essential to supporting and reproducing themselves. They lived within households and made essential contributions to the economic survival of their families. Labor needs over the family's life cycle determined the status, residence, and welfare of most people (Tilly and Scott). Only after centuries-long structural changes in agriculture and industry, in company with a demographic shift that reduced both mortality and fertility, did the employment of female productive capacity generate public debate over a "woman question." Ultimately it was a shift in the location of women's traditional work—especially making cloth and garments—from the household into the factory, and the ensuring restructuring of (especially married) women's economic contribution to the family, that created the conditions for feminist debate. Only then did the question "Should a woman work?" or "Should she have a 'right to work'?" make sense.

EFFECTS OF POLITICAL AND SCIENTIFIC DEVELOPMENTS. In addition to religious reformation and the expansion of commerce and trade, other major trends in the early modern period led to new institutions and novel ideas that affected women's lives and challenged traditional views of women's "nature." Political centralization and the rise of science also meant change in women's lives. According to one recent interpretation, the great witchcraft persecution of the sixteenth and seventeenth centuries reflected not only religious and gender conflict but also efforts to legitimize political authority by exercising new forms of social control over individual behavior (Larner). Because women's relative physical and economic weaknesses made their recourse to magic power seem plausible, and because their alleged sexual insatiability predisposed them to temptation by the devil, 80 percent of the victims of witch-hunts were female—often older, single, eccentric women lacking male protection.

Ultimately science disproved many misogynist notions about the female body. However, despite studies in embryology challenging the Aristotelian view of women's passivity in reproduction that also buttressed attitudes and customs denying them agency in society, only in the late nineteenth and early twentieth centuries were such classical and false assumptions finally displaced by scientific knowledge.

Although by the eighteenth century the economic, political, and intellectual structures that maintained traditional attitudes and institutionalized age-old practices toward women were subject to a multitude of challenges, time-honored patterns persisted. Just as in the thirteenth century Thomas Aquinas had recapitulated Aristotle, so the influential eighteenth-century philosopher Jean-Jacques Rousseau reinforced belief in woman's role as the helpmate of man. Like Adam's Eve, Rousseau's Sophie, the ideal wife of his ideal citizen, Émile, was created to serve, support, and console the chief actor on the human stage, the man to whom she was legally subject. The Napoleonic Code of 1804, and similar codes of law subsequently promulgated across Europe, required married women to obey their husbands. Voices that demanded inclusion of civil rights for women along with the "Rights of Man"—Condorcet in France, von Hippel in Germany, Mary Wollstonecraft in England—were silenced as the Age of Reason gave way to an Age of Steel. Men alone wrote and signed the new "social contract"; as "natural" dependents, women could not aspire to citizenship.

And yet women increasingly did claim civil rights. Despite the negative examples of Wollstonecraft (dead after childbirth and infamous more for her unconventional lifestyle than for her contributions to radical philosophy), Marie Antoinette, Olympe de Gouges (author of *The Declaration of the Rights of Woman and the Female Citizen,* 1791), and Jeanne Manon Roland (dead on the Jacobins' guillotine, ostensibly for having violated the boundaries of conventional femininity), and despite increasingly restrictive legal codes and an ideology of domesticity that won widespread support across class lines, new philosophic currents, based in the Enlightenment concept of human perfectibility, generated the first organized movements for women's rights.

Women in Transforming Societies

Inspired by the French Revolution, women in the nineteenth century began to form groups through which collectively to advocate improved treatment of their sex. By the mid-nineteenth century, organized groups we now call *feminist* were formed in France, England, the United States, Prussia, and even Russia, to challenge women's subject status. The new protest took place in the context of economic as well as political transformation in western and central Europe and the United States. Revolutionary changes in methods of agriculture and transportation, and the rise of an enlarged market economy, industrialization, and urbanization brought profound alteration to family structures and relationships. More young people, including women, could claim and find opportunities for social and geographic mobility and economic independence.

Especially for women, however, escape from the confines of the patriarchal family brought new vulnerabilities (Tilly and Scott, 1978). With female wages far below subsistence levels, a woman alone required assistance, and might trade sex for survival, risking dismissal from employment for her "loose morals" or extreme deprivation if deserted by her male partner.

Social reformers responded, purportedly in women's defense. Not all protesters and reformers called for *equality* for women; few, if any, entertained ideas of identical rights and responsibilities for both sexes. Utopian schemes for the total reconstruction of society aside, debate over the status of women most often focused on ways to "protect" them: to shelter traditional women's work from the intrusion of men; to safeguard women (along with children) from unsafe conditions and/or excessive hours of labor; to secure for women rights to inherited property, their own earnings, and custody of their persons as well as some share in legal authority over their children in cases of divorce. Divorce itself, largely illegal or difficult to obtain before the twentieth century, was one of many reform issues about which women themselves differed, often on the basis of class, religion, or ethnicity.

DEFINING FEMINISM. Emphasis by historians on the woman-suffrage movement, which began as a minority concern within women's groups in the mid-nineteenth century and peaked near the beginning of the twentieth, has obscured not only the larger concerns of women activists but also deep differences within feminist movements. Campaigns for "equal rights," grounded in the assumptions of liberal individualism, became dominant to a greater extent in England and the United States than elsewhere. Contemporary English-language dictionaries tend to define feminism as a movement toward political, social, educational, economic, and legal rights for women equal to those of men. This has been termed *individualistic* feminism (Offen).

The feminisms of continental Europe in that earlier era, as well as later women's movements in Third World countries, reflected a closer association with the social question—that is, with issues of class and nation—and with family relationships and community ties. This constitutes a *relational* form of feminism. Socialist feminists, while cognizant of women's needs for education and encouragement to participate fully in political struggles in support of class goals, declined to envision as their purpose access to equal—and equally exploitative—conditions with working-class men. Others, including Catholic feminists in large numbers, insisted on improvement of women's status in order to enhance their performance in traditional women's roles and relationships. In some countries, notably the United States, a "century of struggle" for women's rights grew out of religious ferment and the recognition that no subjected person, woman or slave, could be fully responsible to God as a moral being. Nineteenth-century equal-rights feminism and the concurrent movement for "protective legislation" offered contrasting answers to the "woman question."

EQUAL BUT DIFFERENT. Differentiation between "individualistic" and "relational" forms of feminism heightens current debate over the definition of feminism. It also parallels a major controversy among feminist theorists that cuts to the heart of moral issues regarding women. Must arguments undergirding a political movement on behalf of women—the various forms of feminism—be grounded in the assumption that human beings are identical? If so, equal-rights law can be used to deny pregnant women special insurance and employment benefits. Equality so defined may demand identity of treatment.

Alternatively, to emphasize women's particularity, to focus on sexual differences, may invite legislation (and buttress attitudes) restricting women's options in the guise of acknowledging their special needs. Precisely this argument was long used to justify labor laws that denied many excellent employment opportunities to all women because they required occasional work during evening hours or involved physically demanding tasks. More recently, women workers in potentially hazardous industries have faced coerced sterilization or loss of employment on grounds of their capacity for reproduction. But to deny that women on the basis of their sex constitute a special class can also deprive them of support they may need—for example, in pregnancy. It can even, some argue, destroy the very basis for a political movement in their name and interest.

This "difference versus equality" debate, often in inchoate form, has led to extended conflict over definitions of feminism and feminist demands. It also raises fundamental issues regarding individual rights, family responsibilities, and the prerogatives of government. In the nineteenth century, reformers called for legislative action to ameliorate the worst abuses of industrialization and urbanization. Reformers ranged from British industrialists who wanted to improve the quality of the labor force to French Social Catholics who sought to base solutions to societal problems on Christian principles to Prussia's "Iron Chancellor" Otto von Bismarck, who schemed to reduce the threat of socialist revolution. Whether impelled by religious, philanthropic, political, or economic motives, they shared the recognition that such innovations increased governmental powers over persons' lives. They also found that they could succeed, against strongly held liberal tenets favoring laissez-faire practice, by exposing the physical, and allegedly moral, dangers to female (and young) persons posed by the new working and living conditions. Working women rarely spoke for themselves in these debates, and even feminist voices, largely from the middle class, were little heeded.

Beginning in the 1840s with the first laws limiting women's night work, every policy of the interventionist states, acting in lieu of a patriarchal family to regulate female behavior, extended the premise that women needed special consideration and that men must provide them with protection, even against themselves. The nineteenth-century debate over short hours and the twentieth-century controversy over state regulation of reproduction share the assumption that adult women, as individual citizens, cannot or should not be empowered to make decisions affecting their own persons. Whether arguing against a woman's working outside the home at night, on behalf of keeping her husband home from the cabaret, or championing limits on abortion, advocates of restrictive legislation link women's rights with those of others: husband, child, family, state.

Similar arguments may be employed on occasion in support of male-specific measures such as military conscription, which subordinates individual freedom to national security. Such denial of personal autonomy, however, remains the exception for men and, moreover, often brings with it rights of citizenship. Women, on the other hand, are assumed to serve the interests of others at all times, and rarely gain comparable advantage. Historically, legislation concerning women has not distinguished among them by race, ethnicity, or class, by marital status, age, preference, or capacity, assuming marriage and motherhood to be the overriding obligation and destiny of all women, and conflating childbearing with child rearing. As historians have highlighted in recent books, the interests of women and their calls for "freedom" may even be seen as at odds with those of the family. This, of course, is true especially of the type of family associated primarily with the white, Western world (Bell and Offen; Degler); studies of the African-American family in the United States, and of extended families in other cultures, stress their function as sources of strength as well (Jones).

The history of women in the twentieth century reveals the centrality of the "woman question" to the social, economic, and political concerns of many nations. During wars and revolutions, traditional notions of *women's place* and struggles over woman suffrage have been eclipsed by calls for female labor and patriotic support. Apparent feminist advances, however, have frequently led to the reinstitution of traditional norms. Following both world wars, women were summarily discharged from good-paying jobs or offered less skilled and less rewarding employment. However, structural changes in commerce and industry have escalated demand for female workers, especially in clerical, teaching, and other service occupations dominated by women; expansion of educational opportunities has augmented female literacy and professional expertise; advances in public health, nutrition, and medicine have continued to increase female life expectancy and decrease infant mortality; and new technologies have reduced the need for labor-intensive household chores. All of these changes tend to free many women for long periods of productive activity outside the family. As more and more countries have been swept into the global economy and information network, women's movements, often linked (and sometimes subordinated) to nationalism, have appeared around the world. Along with efforts to improve women's health and education, Third World feminists are challenging double standards in law and culture as well as such practices as clitoridectomy, marriage by capture, and sati (Johnson-Odim and Strobel).

Unlike earlier waves of feminist protest, the mid-twentieth-century rebirth of feminism called into action sufficient numbers of educated and strategically placed women and their male supporters to successfully challenge many social priorities and institutional structures. Though feminists are sometimes wrongly perceived as a *special interest* group reflecting only the needs and desires of middle-class white women in developed nations, their pressure, especially since the 1970s, has achieved significant change in legal status, medical treatment, and workplace conditions of benefit to all women. It has opened to women professions long monopolized by men, including medicine, law, the ministry, and the professoriate, whose collective powers of definition long buttressed gender biases. In some cases, most notably medicine, this represents a restoration to women of roles they held prior to the institution of professional schools and licensure, from which they were excluded. As healthcare providers, women today often challenge the gender distinction between male doctors who *cure* and female nurses who *care.* Women's health centers tend to stress women's need to question conventional medical procedures and to encourage women to assume an active role in determining their own treatment (Jaggar).

Women Challenging Epistemology

Modeled on the *self-help* agencies for women's health that first developed in the late 1960s and influenced medical practice, this new women's liberation movement has flourished in the academy, especially in the United States but increasingly in Europe and in some instances in Africa, Asia, and Latin America. The field of women's studies, which began as a search for feminist foremothers and a female past lost to history, has expanded across the disciplines to question old methodologies, ask new questions, identify new sources, reinterpret received wisdom, develop new female perspectives, and challenge the very construction of knowledge—not only about the *nature* of women but also about all the constructs in the natural and social sciences based on androcentric experience. Grounded in advocacy for the rights of women to equality in education, culture, and society, it is a form of moral as well as scientific inquiry.

Among the earliest paradigms developed from the new scholarship in women's studies was the *social construction of feminity.* Whether psychologists rereading Sigmund Freud, sociologists reinterpreting Erik Erikson, or historians rediscovering Heinrich Kramer and James Sprenger's notorious late-fifteenth-century handbook on witchcraft, these scholars found in the sciences as well as the humanities a pervasive confusion of description with prescription. Proceeding from male-imposed definitions of female nature and proscriptions limiting female behavior as old as written records of humankind, men as philosophers, preachers, physicians, politicians, patriarchs, and professors had labeled unconventional women abnormal, criminal, ill, even pathological—or, alternatively, not "real women." The *eternal feminine* of Western mythology falsely universalized descriptions of an idealized (implicitly) white woman (Spelman; Chaudhuri and Strobel).

Historical and cross-cultural studies that belie many such interpretations have now been done. The new women's history, increasingly inclusive of women of color and international perspectives (Offen et al.; Johnson-Odim and Strobel), lays bare the many consequences of the absence of female voices and agency, and the fundamental ways in which justice has been denied to half the human species. Women's history tells a tale of misconceptions, biases, and injustices that have oppressed women and limited their freedom of choice—and, hence, their moral responsibility. It also reveals the many and differing contributions, perceptions, and struggles that constitute the female past. Although this historical perspective faces challenges, sometimes by groups of women who remain dependent on traditional sex roles for economic support and social recognition, it nevertheless offers the potential for transformation of benefit to all (Jaggar). It rests, moreover, on the principles of justice.

To the extent that ethical considerations require attribution of personhood and personal agency to every human being, ethical behavior toward women calls for disclosure and discussion of the full record of women in history. It demands that women be defined by their particular positions within specific and changing contexts and allowed choices reflecting the full range of their human attributes. It calls for major societal change. Inspired by new knowledge and the new feminisms, women have begun as never before to speak in their own voices and to claim equality despite their differences—envisioning difference without hierarchy. The "woman question," as posed by women today, can no longer be answered in terms of expediency. The ground has shifted: in the new world, women stand along with men as individuals endowed equally, if perhaps differently, with moral rights and moral responsibilities.

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BIBLIOGRAPHY REVISED

SEE ALSO: *Biology, Philosophy of; Body: Cultural and Religious Perspectives; Care; Circumcision, Female Circumcision; Environmental Ethics: Ecofeminism; Ethics: Social and Political Theories; Feminism; Human Rights; Paternalism; Sexism; Social Control of Sexual Behavior*

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X

XENOTRANSPLANTATION

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Xenotransplantation is the transplantation of living cells, tissues, or organs between members of different species. In the human clinical context, xenotransplantation refers to the use of living biological material from any nonhuman species in human recipients for therapeutic purposes. The practice began with attempts to develop whole animal organs as "spare parts" to replace failing human organs. Current efforts also involve cellular applications.

Xenotransplantation is currently experimental. However, some applications have progressed to clinical trials in humans and could become available therapeutic options in the early twenty-first century. Decisions about such trials must draw on areas in which science currently offers inexact guidance, raising interrelated issues of ethics and social policy. Forging consensus on appropriate public policy is multinational in scope, often pits different stakeholders against each other, and has triggered heated debate among scientists, ethicists, and the public. In this respect, the issues raised by the exercise of social policymaking for xenotransplantation provide a good case study for more general discussions of how biomedical technology should be developed and implemented.

Organ transplantation has been hailed as one of the most remarkable achievements in medical history. The original kidney transplant successes of the mid-1950s were between genetically identical human twins, whose immune systems would not recognize each other's organs as genetically foreign (and therefore would not reject them). Soon thereafter, kidneys for transplantation were obtained from non-twin siblings, from unrelated living donors, and, finally, from cadavers. These transplants between members of the same species are known as *allotransplants,* and apart from the rare identical twin transplants, all require some form of manipulation of the recipients' immune systems to prevent rejection of the donated organ.

Medical advances, particularly the discovery of powerful new immunosuppressive drugs, have greatly increased the number of transplants performed worldwide. Today, where facilities and expertise are available, it is fairly routine to transplant kidneys, hearts, livers, lungs, and other organs and tissues between human beings. However, this very success has created a disparity between the demand and supply of organs. As a result, thousands of patients die every year while waiting to receive a suitable organ for transplant. The situation is particularly severe in developing countries. Were xenotransplantation to become an effective and inexpensive method of addressing end-stage organ failure, however, the same social and economic issues that limit the ability to maintain transplant programs in developing countries today will hinder efforts to develop and maintain xenotransplantation programs. Basic healthcare needs (such as vaccination, basic diagnostics, and drugs) and accessible clean water will compete with any advanced technology for limited healthcare dollars.

Allotransplantation raised important ethical issues, many of which continue to be debated (Dossetor and Daar). While xenotransplantation raises similar issues, especially in terms of equity of access and diversion of resources, it also raises issues pertaining to human rights, animal welfare, and public health risks.

Xenotransplantation Defined

While consensus is not universal, xenotransplantation is defined as "any procedure that involves the transplantation, implantation, or infusion into a human recipient of either

TABLE 1

Summary of Clinical Organ Xenotransplantation during the 1960s, 1970s and 1980s

Organ	Year	Source Animal	Number	Investigator
Kidney	1964	Chimpanzee	12	Reemtsma
	1964	Monkey	1	Reemtsma
	1964	Baboon	1	Hitchcock
	1964	Baboon	6	Starzl
	1964	Chimpanzee	1	Hume
	1964	Chimpanzee	3	Traeger
	1965	Chimpanzee	2	Goldsmith
	1966	Chimpanzee	1	Cortesini
Heart	1964	Chimpanzee	1	Hardy
	1968	Sheep	1	Cooley
	1968	Pig	1	Ross
	1968	Pig	1	Ross
	1969	Chimpanzee	1	Marion
	1977	Baboon	1	Barnard
	1977	Chimpanzee	1	Barnard
	1984	Baboon	1	Bailey
Liver	1966	Chimpanzee	1	Starzl
	1969	Chimpanzee	2	Starzl
	1969	Baboon	1	Bertoye
	1970	Baboon	1	Leger
	1970	Baboon	1	Marion
	1971	Baboon	1	Poyet
	1971	Baboon	1	Motin
	1974	Chimpanzee	1	Starzl

SOURCE: Council of Europe Working Party on Xenotransplantation. Report on the State of the Art in the Field of Xenotransplantation, February 21, 2003.

(a) live cells, tissues, or organs from a nonhuman animal source; or (b) human body fluids, cells, tissues, or organs that have had *ex vivo* contact with live nonhuman animal cells, tissues, or organs." This is the definition adopted by the U.S. Public Health Services, and the Council of Europe has a similar one. This definition would include transplantation of an animal heart into a patient with heart failure, implantation of pancreatic islets for people with diabetes, circulation of blood from a patient with acute liver failure through a nonhuman liver or a device containing nonhuman liver cells, or the treatment of burn patients using human skin cells that have been grown *ex vivo* (outside the body) over a layer of mouse feeder cells. The transplantation of inert animal tissue (such as pig heart valves) does not fall under this definition.

Scientific and Clinical State of the Art: Continuing Challenges

Tables 1 and 2 summarize the attempts at clinical xenotransplantation since the 1960s. With the exception of the inexplicable survival for nine months of a kidney transplanted from a chimpanzee into a human recipient in the 1960s, all whole-organ xenotransplants have failed rapidly, despite massive immunosuppression of the human recipients. In contrast, a number of preclinical trials of cellular therapies have shown enough promise to justify progressing to clinical trials. These include neural-cell transplants to treat disorders such as Parkinson's disease, intractable epilepsy, and other degenerative neurologic diseases (Fink et al.). There have also been attempts at perfusing the blood of patients in acute liver failure *ex vivo* through nonhuman animal livers until a human liver becomes available or the patient recovers (Chari et al). However, as of April 2003, no xenotransplantation application has demonstrated a high enough level of efficacy in clinical trials to allow progression to general clinical adoption.

HYPERACUTE REJECTION. The initial technical obstacle to xenotransplantation is the phenomenon of *hyperacute rejection,* which occurs when tissue is transplanted between two distant (discordant) species, for example between pigs and humans. Hyperacute rejection is swifter and more severe than the acute rejection response usually seen in transplants between individuals of the same species. Xenotransplant rejection responses are, however, also less severe in transplants between members of closely related (concordant) species, such as between rats and mice. A carbohydrate

TABLE 2

Summary of Clinical Trials on Organ and Cell Xenotransplantation during the 1990s

	Graft	Indication	Number	Country	Presently including patients
Organ transplantation	Pig heart	Heart failure, bridging procedure	1	Poland	No
	Baboon liver	Hepatitis B with liver failure	2	USA	No
	Pig liver	Liver failure, bridging procedure	1	USA	No
Cellular grafts	Neonatal bovine cromaffine cells	Pain	more than 100	Poland, Czech Republic, Switzerland & USA	No?
	Encapsulated transgenic hamster cells	ALS	6	Switzerland	No?
	Fetal porcine neurons	Parkinson	21	USA	Yes
		Huntington	12	USA	Yes
		Epilepsy	3	USA	Yes
		Stroke	3	USA	Yes
	Fetal porcine islets	Diabetes	10	Sweden	No
	Neonatal porcine islets	Diabetes	6	New Zealand	No
	Fetal rabbit islets	Diabetes	Several 100	Russia	Yes
	Baboon bone marrow	HIV	1	USA	No

SOURCE: Council of Europe Working Party on Xenotransplantation. Report on the State of the Art in the Field of Xenotransplantation, February 21, 2003.

molecule known as Gal alpha-1, 3 Gal (alpha-gal) is present on all cells of most mammalian species, including pigs, which at present are considered the most likely source-animal species. Humans and closely related old-world primates such as chimpanzees lack alpha-gal, but have naturally occurring antibodies that recognize it as foreign. In hyperacute rejection these antibodies would react against the alpha-gal on pig cells, causing the blood to clot (thrombosis) and the transplanted organ to die within minutes.

Activation of complement, a substance found in blood, is part of normal defense mechanism against foreign tissue or microbes. The presence of chemical substances that inactivate complement when its work is done normally prevents thrombosis. These complement factor regulatory proteins (CRPs) are species-specific. Thus one of the scientific responses to the challenge of hyperacute rejection has been to create transgenic pigs in which the genes for various human CRPs have been incorporated into the pig's genome, and thus prevent thrombosis. Experiments in which tissue from these transgenic pigs was transplanted into nonhuman primates have shown better graft survival rates than using tissue from unmodified pigs, raising hopes that similar improved results would be reproduced in human recipients.

Another genetic approach to dealing with hyperacute rejection has aimed to alter the expression of the alpha-gal molecule on pig tissue either by inserting genes that result in carbohydrate remodeling (Sandrin et al.,1995); by a reduction in expression of alpha-gal (Sharma et al.); or by "knocking out" (removing) the gene for the enzyme that is involved in making alpha-gal (Tearle et al). A double knockout pig, (a pig in which both copies of the gene have been deleted from its genome) was announced in 2002 (Phelps et al.). Others have focused on reducing the massive inflammatory responses.

OTHER IMMUNOLOGICAL CHALLENGES. Hyperacute rejection is only one challenge facing xenotransplantation. Even if hyperacute rejection can be avoided, progressive phases of rejection would follow, including acute vascular rejection, cellular rejection, and chronic rejection.

Related research focuses on attempts to manipulate the immune system of higher animals in ways that would make it "tolerate" one, or a few, foreign antigens without paralyzing the whole immune system. Should immunological tolerance be achieved in humans, it would become possible to transplant organs without administering the large doses of powerful immunosuppressive drugs that leave the recipients vulnerable to dangerous infections.

PHYSIOLOGICAL BARRIERS. Physiological barriers may also stand in the way of successful xenotransplantation. For example, there is serious doubt that a pig liver will be able to sustain a human being for long. The liver is not only a detoxifying and storage organ, it is the main factory in the body for the manufacture of a large number of crucial molecules, including proteins such as albumin and clotting factors. Many of these are species-specific and will function inadequately in humans (Hammer and Thein), and some may also evoke immune reactions. In contrast, porcine insulin has successfully treated human diabetics; thus porcine pancreatic islet transplantation may offer human diabetics hope for a cure.

Xenogeneic Infections

Another reason for caution is that infections not normally encountered in humans might be transmitted from source animals to human recipients. In addition to the risk to the recipient, there is a theoretical risk that an infected recipient could transmit the infection to others. Of particular concern in this regard are infectious agents such as retroviruses that result in persistent infections and remain clinically quiescent for long periods before causing identifiable disease. During that "silent" period they can be transmitted from person to person, infecting many people before the danger is recognized.

In the past, animal viruses, such as Nipah virus and avian influenza, have been known to infect humans, resulting in outbreaks of disease of limited scope and duration (CDC, 1998, 1999). Of even greater concern is evidence that viruses once restricted to a nonhuman host species may infect and adapt to humans as a host species, as is theorized to have occurred with the HIV/AIDS pandemic (Hahn et al.). There is some controversy about whether nonhuman primates are more likely than other species to transmit dangerous infections to humans (Chapman et al). In response to widespread concern, the U.S. Food and Drug Administration produced an advisory in April 1999 against the use of primates as source animals pending adequate demonstration of safety.

Exogenous infection (infections from agents passed among animals by contagion) can theoretically be controlled by eliminating them from the source animals. More uncertainty exists about the significance of endogenous retroviruses, which exist as part of the genetic material of humans, nonhuman primates, pigs, mice, and perhaps all animals. Endogenous retroviruses are passed from one animal to another through inheritance. Unable to cause active infection in the host animal, many can produce a virus capable of causing infection in cells from other species in the laboratory. Thus, living biological material devoid of recognized microbes has an innate infectious potential of uncertain significance for xenotransplantation. Specifically, both pigs and nonhuman primates have been shown to have endogenous retroviruses that can infect human cells in the laboratory.

Since the pig is the most likely source animal for human clinical xenotransplants, endogenous retroviruses of pigs have become a major focus of research. Porcine endogenous retroviruses (PERV) exist in the genomes of all pigs. Several variants of PERV have been characterized that vary in their infectivity. It would be difficult, but perhaps possible, to eliminate PERV through breeding or genetic manipulations (Patience et al.; Stoye).

In animal experiments, short-lived (but nonclinically obvious) replicative infections have been documented (van der Laan et al.), and PERV can be transmitted from pig cells to human cells when they are cultured together in the laboratory (Patience et al.; Wilson et al.), but there is currently no convincing evidence that PERV can cause infections leading to disease in humans.This does not, of course, exclude the possibility that it may be capable of doing so given the right circumstances.

HUMAN PATIENTS PREVIOUSLY EXPOSED TO PIG TISSUE. In the past decade or so a small but significant number of patients have been exposed to various experimental forms of xenotransplantation. Several studies of these patients have found no evidence of PERV infection, despite evidence that many of those exposed exhibited "microchimerism" (they had small numbers of pig cells in their bodies which provided ongoing exposure to PERV). While many scientists do not consider that these studies conclusively establish the absence of infectious disease risk associated with xenotransplantation, they are reassuring to some extent.

Ethical, Social and Economic Issues

Research and development costs for any major new technology, including xenotransplantation, can be high. If xenotransplantation progresses from experimentation into clinical practice, the final cost is uncertain. Even beyond the development costs, many factors will contribute to the expense of a clinical xenotransplantation program, including rearing specific infection-free source animals, laboratory tests for early diagnosis of infection, specialized staff, and maintaining monitoring and surveillance regimes. Costs will also be determined by companies owning intellectual property rights to the technologies employed, the size of the market, and so on. Whether this cost will exceed the current costs of medication and extended hospital care for patients awaiting allotransplants is uncertain. It seems likely, however, that xenotransplantation, like allotransplantation, would initially benefit only a privileged few.

It has been argued that xenotransplantation efforts could be justified only if large numbers of patients could benefit at reasonable cost and with no significant diversion of resources from the healthcare system. In this light, efforts to develop applications of porcine pancreatic islets for functional cure of type I diabetes mellitus are the most easily justified. While many applications of xenotransplantation research would benefit relatively few patients, diabetes mellitus affects a large number of people and poses substantial costs to society, both in terms of economics and in years of productive life lost.

PRECAUTIONARY PRINCIPLE VERSUS RISK-BENEFIT ANALYSIS. It is possible that the public may eventually benefit indirectly from successful widespread xenotransplantation due to a decrease in the societal burdens of healthcare costs and years of productive lives lost due to chronic diseases. The public may, however, also be put at risk of infections. As a result, although the extent of the risk is not clear, many nations have regulations that would allow xenotransplant clinical trials only when using husbandry methods that eliminate exogenous infectious agents from source animals prior to transplantation, and ensuring ongoing monitoring of receipients.

As long as uncertainty about the risk to society exists, different constituencies will perceive the same scientific data on public risk in different ways. Those basing their public-policy decisions on traditional risk-benefit analysis would tend to favor patients, perhaps at the expense of the public. Many clinicians and scientists in the transplant community do this instinctively, emphasizing the benefits in terms of a moral imperative to ameliorate suffering and save lives. This attitude is reflected by the Institute of Medicine's statement that "our own humanity is diminished if, in order to protect ourselves, we turn away from others whose suffering is both clearly visible … and … devastating in … impact … we are morally obliged, not only as individuals but as a community, to accept some risk to ourselves to save our fellow human beings from more certain harm" (Institute of Medicine, p. 71). On the other hand, those who would base decisions on the "precautionary principle" (of which there are several versions) would tend to pay more attention to the public interest, perhaps at the expense of needy patients (Daar; 2001).

The precautionary principle originated in environmental risk discourse, but has been adopted into health-policy discussions partly because of the history of infections with agents that cause AIDS, mad cow disease, and so on. It is easy to misunderstand, misquote, and misuse this concept, as there is no single definition. There are two well-known formulations. The first, from Article 15 of the United Nation's 1992 Rio Declaration on Environment and Development, states: "In order to protect the environment, the precautionary approach shall be widely applied by States according to their capabilities. Where there are threats of serious or irreversible damage, lack of full scientific certainty shall not be used as a reason for postponing cost-effective measures to prevent environmental degradation." The second, the so-called Wingspread Declaration, states: "When an activity raises threats of harm to human health or the environment, precautionary measures should be taken, even if some cause-and-effect relationships are not established scientifically."

As can be expected, the precautionary principle has become a subject of intense scholarly debate and ethical analysis (Saner). Some have argued that to be true to itself the precautionary approach requires risk-risk analysis, which would suggest an alternative formulation for the principle along the lines that "Public health and environmental policies should attempt to minimize net risks to public health and the environment based on the best available scientific information and their net anticipated cost to society" (Goklany, p. 1075).

ANIMAL ISSUES. The great British reformer Jeremy Bentham, a key figure in the development of utilitarian ethics, was also one of the earliest advocates for the humane treatment of animals. In 1780 he asked two fundamental questions: (1) "The question is not can they reason? nor can they talk? but can they suffer?" and (2) "What insuperable line prevents us from extending moral regard to animals?"

Since Bentham's time, it has become widely recognized that all vertebrates essentially perceive pain in the same way. Some argue that animals can also suffer. Animals reared in stressful conditions in captivity experience fear, boredom, isolation, and separation anxiety. Recent evidence indicates that the great apes are capable of using language, including human words (BBC), and also exhibit forms of culture. The emotional repertoire of nonhuman primates, according to ethologists Jane Goodall and Dian Fossey, includes love, sorrow and jealousy. These attributes have led some to argue that such animals are more than just sentient beings, and that they possess intrinsic value. If so, then they must have rights. To some, ignoring these rights is a form of speciesism, a term analogous to racism, and a growing minority are embracing this view.

The awareness of such qualities of animal life raises serious questions: What is it in humans that bestows on us the right of killing an animal for our own self interest? Is it our complex use of language and tools? Is it our rationality, intentionality, consciousness, conscience, or empathy? Immanuel Kant argued that all nonhuman animals can be regarded as means to ends, and that only humans, who are "rational beings," have the intrinsic right to be considered as ends in themselves. If capacity for rational thought is the basis of intrinsic rights, some have questioned whether we are justified in using organs taken from a nonhuman primate but not those taken from an anencephalic, or severely retarded, human. Philosophic justifications for the prohibition against killing incapacitated humans for such purposes have referenced their memories, if any, their potential to grow and form lasting relationships, their capacity to be mourned for long periods, and the effect that using their organs would have on relationships between humans. Others justify this distinction based on religious or metaphysical notions of the inherent elevation of humans above other creatures. These views are not convincing to many animal rights advocates, however.

NONHUMAN PRIMATES AND PIGS. Nonhuman primates are biologically close to humans, and many humans feel an emotional attachment to them. They are a concordant species, and would therefore be easier to use as sources for xenotransplantation (from an immunological and physiological perspective) than pigs, which are a discordant species. However, there are several arguments against using them for such purposes. First, the microorganisms they harbor may more easily infect and be pathogenic in humans than would be the case with pigs. Humans have a long history of contact with the pig, and the resultant physical proximity has only rarely led to the acquisition of serious infections. Second, it is not possible to raise primates under the husbandry conditions that currently allow for the production of pig herds from which exogenous infectious agents of concern have been excluded (specific-pathogen-free pigs). Third, some primate species (e.g. the chimpanzee) are endangered. While the baboon exists in large numbers and is considered a pest in some parts of the world, it breeds slowly (and it is currently impossible to rear specific-pathogen-free baboons). Thus, a consensus to exclude nonhuman primates as source animals for xenotransplantation has emerged.

There are laws to protect research animals in many countries. Sensible guidelines include the 3 Rs of Russell and Burch (1959); namely to "reduce, replace, and refine"—to which we might now add "respect and reconsider." There are increased efforts underway to look for alternatives to animal use.

GENETIC MANIPULATION OF ANIMALS FOR HUMAN PURPOSES. The recently acquired power to manipulate the genomes of animals, including the ability to produce "double knockouts" and to clone these over several generations raises an important ethical question: Where do we draw the line? The Kennedy Report (1997) and other similar reports have concluded that the current extent of manipulating the pig's genome to incorporate human genes or other manipulations of the same magnitude raise little ethical concern provided the pig "recognizably remains a pig." Today, on balance, a case has been made that it is ethically acceptable to use pig organs, but not organs from nonhuman primates, for human xenotransplantation. At this stage of development a larger consensus exists on the importance of attending to "animal welfare" than to "animal rights."

RELIGIOUS PERSPECTIVES ON XENOTRANSPLANTATION. The views of different religions concerning xenotransplantation largely depend on the manner in which these religions consider animals and how they should be treated. From the religious perspective, it would be important that a xenotransplant not tamper with the human personality or the individual's freedom, and ability, and eligibility to bear responsibility. Minimally, all religions consider that humans have stewardship responsibilities to minimize the pain and suffering of animals being used for the benefit of humans.

Within the three major monotheistic religions (Judaism, Christianity and Islam), human beings have canonically been considered unique, with the rest of creation existing to serve humankind. The Old Testament, the first five chapters of which are canonical to both Jews and Christians, declares: "Man was made in God's image and has dominion over all other creatures and all the earth" (Genesis 1:26). In both Judaism and Islam the imperative to preserve human life overcomes many religious prohibitions.

The pig is considered to be ritually unclean in both Islam and Judaism, and it is not surprising that authorities in these two religions have been asked if the pig can be used as a source animal for organs. In Islam, the conclusion of the majority seems to be that this would not be a barrier to xenotransplantation, based on the Shariah principle that need and necessity can allow that which is forbidden—and that, in any case, the prohibition is only to eating pig tissue. F. Rosner, a physician and scholar of Jewish medical ethics, has come to the same conclusion with regard to Judaism. There is, however, a minority opinion in Islam that pigs, because they are ritually unclean, cannot be used as source animals.

A number of thoughtful Christian commentators have written about xenotransplantation. On the whole, these are generally accepting, while emphasizing that animal suffering should be minimized. The Catholic Church addressed xenotransplantation as far back as 1956, and in 2000 Pope John Paul II restated its permissive position:

> It is not my intention to explore in detail the problems connected with this form of intervention. I would merely recall that already in 1956 Pope Pius XII raised the question of their legitimacy. He did so when commenting on the scientific possibility, then being presaged, of transplanting animal corneas to humans. His response in still enlightening for us today: in principle, he stated, for a xenotransplant to be licit, the transplanted organ must not impair the integrity of the psychological or genetic identity of the person receiving it; and there must also be a proven biological possibility that the transplant will be successful and will not expose the recipient to inordinate risk. (Transplantation Society)

Some Christian arguments against xenotransplantation have focused on the themes of "playing God" and "interfering with creation." These arguments have less emphasis in Judaism and Islam.

Hinduism, Buddhism, and some Animist traditions have not drawn such a sharp theological distinction between humans and other animals, seeing all as part of a hierarchy of creatures, with indistinct borders between them. Other religions supportive of xenotransplantation include Baha'i and Sikhism. Those that have religious concerns about xenotransplantation include Buddhism, Hinduism and Native American faiths (Council of Europe).

REGULATORY CHALLENGES. The uncertain potential for introducing xenogeneic pathogens has influenced many countries to develop specific policies that incorporate very stringent safety standards for clinical xenotransplantation. Some countries have initiated moratoria, while others have allowed limited and tightly monitored clinical trials. Several countries have developed policies that advocate caution with xenotransplantation clinical trials, requiring that they occur only with regulatory oversight and involve stringent standards for animal husbandry, particularly for screening and surveillance for infectious diseases. (Bloom; Tibbel; OECD).

The Council of Europe, the European Agency for Evaluation of Medicinal Products, and the United Kingdom Xenotransplantation Interim Regulatory Authority (UKXIRA, 2003) are developing specific policies on at least certain kinds of xenotransplants that incorporate the concepts of safety built around pre-xenotransplantation screening to prevent transmission of infection and post-transplantation surveillance to maximize the probability of early recognition and containment of any infections introduced through xenotransplantation. Further, the European Union has advocated multinational efforts toward consensus development and collaborative work to minimize threats from emerging infections in general.

Multinational organizations have recognized infectious disease issues associated with xenotransplantation as policy issues that transcend national boundaries. The World Health Organization (WHO) has produced recommendations for addressing and harmonizing issues related to infection control, monitoring, sharing of scientific information, consent, and human rights. Both the WHO and the Organization for Economic Co-operation and Development (OECD) have recommended that member states develop regulatory frameworks for xenotransplantation clinical trials, and they have taken leadership roles that encourage international collaborative efforts to minimize infectious risks and actively discourage expatriate xenotransplantation experiments in countries with poor regulatory environments.

Some professional societies were early critics of efforts to bring xenotransplantation clinical trials under special regulatory oversight. In recent years, however, most professional societies have been active advocates for clinical trials under regulatory oversight with stringent husbandry and infection surveillance standards. Many professionals working in xenotransplantation are concerned about "xenotourism" (the migration of patients across geopolitical boundaries to obtain unregulated xenotransplantation "therapies"). These patients may undergo risky procedures without adequate understanding, and they may bring unrecognized infections back to their home communities. Further, professionals who conduct expatriate xenotransplantation clinical trials potentially endanger the ability of the field to move forward in a systematic way. In an effort to discourage such practices, the International Xenotransplantation Society has adopted a rule that reports of such experiments will not be accepted for presentation at its meetings or for publication in its journals.

MANAGING POTENTIAL CONFLICTS OF INTEREST. The increasing participation of private interests in biomedical research is an important trend. One of the key catalysts of this change in the United States was the passage in 1980 of the Bayh-Dole act, which transferred intellectual property rights to researchers funded by federal research monies. In addition, universities in many countries must now attract more private funding to function in a very competitive environment. As a result, companies and investigators with potential conflicts of interest (COI) are testing increasingly powerful experimental therapeutic interventions.

Identifying ways to deal with potential COI while introducing innovative therapies is a complex issue and a constant source of ethical tension. Many would argue that full disclosure of financial and other COI by both institutions and investigators is adequate to manage such COI. Others have argued that disclosure alone may not suffice, and that even a pilot trial should not be conducted if an institution has a major financial interest in the outcome (Emanuel and Steiner). The Institute of Medicine has observed that "Clinical trials with cellular xenotransplants are already under way, and a real danger exists that the commercial applications of xenotransplant technology will outstrip both the research base and the national capacity to address special issues raised by xenotransplantation, including the risk of disease transmission" (Executive Summary, p. 4).

TIMING OF CLINICAL INTRODUCTION OF XENOTRANSPLANTATION OF WHOLE ORGANS. Although small-scale experimental clinical xenotransplantation of cells and xenotransplantation involving *ex vivo* contact of human living cells with living nonhuman animal cells is underway in some countries, the question of when it would be prudent to translate laboratory successes into clinical trials remains open. The accepted standard is that before clinical trials are attempted in humans, preclinical research should provide proof of the principle hypothesis adequate to anticipate that humans may benefit from the experiment. lec. However, no consensus has been reached on what would constitute adequate graft survival in animal experiments to justify clinical trials. Attempts to define this crucial criterion have ranged from a median survival time of a minimum of three months to the suggestion that, although it is likely that hyperacute rejection can be prevented, xenotransplants should be delayed until there is a better understanding of acute vascular and cellular responses (Cooper et al.).

EPIDEMIOLOGICAL SURVEILLANCE AND POST-TRANSPLANT PATIENT MONITORING. In the past, infections transferred across species boundaries (e.g. HIV-AIDS, parvoviruses, SARS coronavirus) have spread globally. The development of international surveillance for xenotransplantation-associated infections has been proposed as a way to assist countries to manage risks associated with infections introduced through xenotransplantation performed within and beyond their borders (Rhonchi). Such recommendations raise concerns for many people. The concept of lifelong international surveillance of xenotransplant recipients is fraught with ethical complexities. International consensus has not been achieved on the definition of xenotransplantation, on what constitutes a xenogeneic infection or disease, on what events should be reported and by what methods, or on which individuals should constitute the population under surveillance. Whether a surveillance system should only report transmission of xenogeneic infections from recipients to their contacts, or should go further to collect information on the contacts themselves, is a source of controversy. All proposed national policies for monitoring xenotransplantation recipients are intrusive. Most advise against unprotected sex, donation of blood or other biological materials, and for education of intimate contacts. Some go further to require the consent of intimate partners for xenotransplantation, active surveillance of intimate contacts as well as xenotransplant recipients, and pre-transplantation agreements to avoid procreation post-xenotransplantation.

PATIENT-PHYSICIAN RELATIONSHIPS AND CONSENT. The perceived potential for xenotransplantation to benefit an individual while putting the larger community at risk complicates both the patient-physician relationship and the issue of informed consent. The Helsinki Declaration on Ethical Principles for Medical Research Involving Human Subjects states that, in medical research on human subjects, considerations related to the well-being of the human subject should take precedence over the interests of science and society. Xenotransplantation clinical trials present situations that may place the interests of recipients and the greater good of society at odds. If a doctor is required to think of the public interest rather than merely the interests of the immediate patient, the traditional role of the physician as patient advocate is altered. At best, this will create confusion, since the physicians must weigh the responsibility to individual patients against the public good. At worst, the doctor-patient relationship itself could become one of antagonism rather than of trust (Daar, 1997).

The current informed-consent requirements for patients who might receive xenotransplants exceed those required in most other research settings. A major question on which there is no consensus at present is the problem of what to do if a patient changes her or his mind about intrusive follow-up monitoring and the waiver or curtailment of confidentiality rights previously agreed to. Informed consent is not usually legally binding on the patient, who retains a right to withdraw participation at any point in the investigational process.

Given the expectations of lifelong follow-up for initial xenotransplant recipients, a different kind of consent has been discussed (Daar 1999). A specific legal contract might provide enforceability of pre-transplant agreements for lifelong monitoring. Unlike the traditional consent form, such a contract would allow specific curtailment of the patient's rights (the traditional consent procedure does not, in all cases, require that a document be signed; more often than not, the signed form protects the doctor more than the patient). Such a legal contract would be a radical departure from current accepted norms, since it would directly conflict with the present emphasis on the primacy of respect for the autonomy of the research subject. Thus, these issues are fraught with controversy.

MODELS TO BUILD ON. Are there any precedents in which a patient can decide in advance what medical treatment she or he would want to receive in the future? Both "advance directives" and the so-called "Ulysses contract" fall into this category.

Advance directives are used in medicine as a means by which patients declare their wishes in anticipation of a future day when they may not be competent to make decisions. Such an instrument has been used, for example, to establish the point at which a patient desires a "do not resuscitate" status. It could be adapted to allow a mentally competent xenotransplantation recipient to make provision for intrusive post-transplant medical monitoring (with its attendant curtailment of certain rights), to continue if the recipient changes her or his mind-a situation that might occur, if, for example, the graft fails but monitoring must continue in order to protect public health.

This would be more akin to a "Ulysses contract." In Greek, mythology Ulysses was a strong, good man. He knew he would sail near the Sirens, whose enchanting songs would overcome him and cause his ship to be destroyed. He ordered his sailors to plug their ears, and, wanting to hear the songs, had himself tied to the mast of the ship, ordering his companions not to release him regardless of his subsequent demands. A Ulysses contract, then, is used for patients who are likely to experience periods of incompetence in the future, such as patients with psychiatric disorders characterized by alternating periods of therapy-induced competence and incompetence. While they are in a competent state, they can specify treatment decisions for future occasions. In the xenotransplant setting, such a binding advance directive signed by the recipient prior to the xenotransplantation could, theoretically, be used to forcibly investigate, treat, or even confine a recipient who fails to meet responsibilities to the public agreed to prior to the procedure (Daar 1999). A Ulysses contract usually assumes that the subject is so affected as to have their *true* judgment subordinated by some other pressure, while in this instance the xenotransplantation recipient may merely have changed her or his mind about cooperating with intrusive surveillance. Discussion of these options has raised concerns about the possibility of unacceptably eroding the human rights of research participants on the basis of hypothesis and fear rather than established or proximate risk.

PUBLIC ENGAGEMENT AND PUBLIC CONSENT. Some people have argued that since the public is going to be exposed to some level of risk of xenogeneic infections, the public must be consulted, and must consent, before xenotransplantation clinical trials proceed. Many national reports recommend that the public must in some way be consulted before proceeding with xenotransplantation. It is, however, difficult to define what would constitute *public consent.* Further, efforts at public education can easily merge over into propaganda, since the opinions formed by non-experts are completely dependent on the nature and presentation of the information they receive.

While some have advocated a moratorium pending public consent (Bach et al.) there are significant problems with adopting a moratorium. The majority of researchers and clinicians appear to be opposed to this position, mainly because moratoria remove from public discourse the very issues that ought to be addressed. Most researchers and clinicians would encourage increased capacity to evaluate the potential social consequences as the technology develops. Significantly, there have been no serious calls for reduction in xenotransplantation research.

Canada has undertaken a major public engagement exercise consisting of a series of forums involving education, discussion, and *citizen juries.* A subsequent report of the Canadian Public Health Association has recommended that Canada not proceed with xenotransplantation involving humans until several critical issues are addressed. It recommends, among other steps, that further efforts be made to inform and educate the public; that additional preclinical research be carried out; and that the risks and probability of benefit from clinical trials be more fully defined. It also calls for the development of legislation and regulations to cover all aspects of xenotransplantation clinical trials, concluding that there is a continuing need to involve the public in discussions about the future of xenotransplantation. This approach, however, has been criticized as being vulnerable to biases introduced by the information presented to the public (Wright). Nevertheless, this particular exercise reflects the current uncertainties surrounding xenotransplantation.

Conclusion

Xenotransplantation currently describes a multifaceted array of experimental biotechnological approaches to disease amelioration, some of which have progressed to small-scale clinical trials. The theoretical risk of infections spreading from source animal to recipient and then to contacts and the public has triggered debates on issues of science and on how biomedical technology should be developed, regulated and implemented. The specific ethical dilemmas discussed in the context of xenotransplantation reflect areas of ethical conflict and uncertainty relevant to other aspects of community life. These include the rights of the minority in the face of concern by the majority; conflicting values around decision making in the face of uncertain collective risk; the relative rights of humans and nonhuman animals; the relative value of safety versus of hope for progress; and the rights of, and appropriate protections afforded to, human subjects of research.

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SEE ALSO: *Animal Research: Law and Policy; Organ and Tissue Procurement; Organ Transplants; Tissue Banking and Transplantation, Ethical Issues in; Transhumanism and Posthumanism*

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APPENDIX I

CODES, OATHS, AND DIRECTIVES RELATED TO BIOETHICS

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REVISED FROM THE WORK FOR THE 2ND EDITION OF THE
ENCYCLOPEDIA OF BIOETHICS, DONE BY
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NATURE AND ROLE OF CODES AND OTHER ETHICS DIRECTIVES

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The earliest extant documents regulating the practice of medicine are records of Egyptian laws from the sixteenth century B.C.E. and the Babylonian Code of Hammurabi, dated about 2000 B.C.E. These legal documents included guidance on what fees could be charged, what constituted competent medical care, the conditions under which a physician could be held accountable for malpractice, and what sanctions would apply. The first significant statement on medical *morality,* however, is the Hippocratic Oath (fourth century B.C.E.). Although the Oath's historical role has been critiqued by scholars such as Robert Baker, the Oath continues to play an important symbolic role in Western medical ethics.

With the notable exception of religious precepts being brought to bear on the conduct of physicians, most medical ethics documents written prior to World War II were professionally generated, that is, they were developed by physicians for physicians. Since the mid-1900s, however, a complex set of factors has challenged the professional authority of the medical profession.

The atrocities committed by Nazi physician–researchers, which led to the Nuremberg Code (Germany, 1949), and infamous cases of abuse of research subjects in the United States, such as the Tuskegee syphilis study, began to undermine trust in the profession. The various rights movements of the 1960s and 1970s and the anti-Vietnam War movement emphasized individual liberty and contributed to a general willingness to challenge authoritative traditions. At the same time, the dramatic increase in scientific knowledge and the development and use of medical technology powerfully increased the ability of health-care professionals to affect the course of people's lives and deaths. These factors, among others, contributed to an increased emphasis on respect for the autonomy and self-determination of individuals seeking health care.

With these changes came a proliferation of bioethics documents pertaining to research on human subjects, to health professionals other than physicians, and to health-care institutions. Furthermore, growing concerns over the alleged mistreatment of research animals and claims that the use of animals for any research purpose is immoral, coupled with concerns for the protection of the environment, resulted in bioethics directives that extend well beyond human medical practice. Concurrent with the increased diversity in the focus of bioethics documents, the authorship of such documents has diversified as well. Professional organizations no longer monopolize the formulation of directives governing professional behavior; religious organizations, institutions, and government agencies, for example, also set moral or legal standards for clinicians and researchers.

The resulting array of bioethics documents may be divided into three fundamental types: (1) professionally generated documents that govern behavior within the profession; (2) documents that set standards of behavior for professionals but are generated outside the profession; and (3) documents that specify values and standards of behavior for persons who are not members of a profession.

Documents Generated by and for a Profession

Although controversy exists over precisely what constitutes a profession, professions may be distinguished from occupations on several grounds (see, e.g., Barber, 1963; Greenwood, 1982; Kultgen, 1988). Professions involve a specialized body of knowledge and skill that requires lengthy education and training to acquire and provides a service to clients and to society. Once a field has achieved professional status, a trained practitioner is considered a professional regardless of employment status. Another characteristic of professions is their claim to be autonomous and self-regulating; however, with the freedom and power of self-regulation comes a concurrent obligation to establish and enforce standards of ethical behavior. Indeed, some have argued that the existence of a professional ethic is the hallmark of a profession (see, e.g., Barber, 1963; Newton, 1988; Campbell, 1982).

Professionally generated ethics documents may take the form of prayers, oaths, or codes. Prayers, such as that once attributed to the Jewish physician-philosopher Moses Maimonides, express gratitude to a deity and ask for divine assistance in developing one's skills and meeting one's responsibilities. Oaths are vows taken by individuals entering a profession to uphold specified obligations. They were frequently employed in ancient times; more recent examples include the Declaration of Geneva (World Medical Association, 1983, 1994) and the Solemn Oath of a Physician of Russia (1993), among others. In contrast to the personal, interactive nature of prayers and oaths, codes, which are often accompanied by more detailed "interpretive statements," are collective summaries of the moral ideals and conduct that are expected of the professional.

ROLES OF PROFESSIONAL ETHICS DIRECTIVES. The importance to an emerging profession of producing its own ethics directives indicates a primary role of such documents. They help to define and legitimate a profession as well as to maintain, promote, and protect its prestige. Simultaneously, the documents function as a promise to society that the profession will maintain specified standards of practice in return for the power and autonomy that society is being asked to grant the profession.

Protection of the unity, integrity, and power of the profession, which appears to be a primary goal of the rules of etiquette governing the relationship between professionals, is a "quasi-moral" role of professional ethics documents. Although maintenance of a profession has a limited moral component in that its existence promotes the well-being of society, it especially serves the interests of those within the profession who stand to lose the monopoly on their practice should society lose faith in them. In contrast, the explicitly moral role of professional ethics documents lies in the articulation of both ideal and minimal standards of character and conduct for the professional. Both the moral and some of the "quasi-moral" guidelines form the content of the profession's promise to society and serve as a guide for determining when sanctions should be brought to bear against a member of the profession.

THE NATURE OF PROFESSIONAL CODES. In professionally generated codes, the same guideline may simultaneously help to fulfill both categories of function.

"Quasi-moral" guidelines. In addition to having an ethic, professions are characterized by the possession and practice of a specialized body of knowledge. Consequently, frequently articulated requirements include: competency to practice; restriction of professional status to those who have undergone specific educational and training programs; keeping one's knowledge current; and working to advance the existing knowledge in one's field through research (see, e.g., American Nurses' Association, 1985; Canadian Nurses Association, 1991; American Dental Association, 1994; American Psychological Association, 1992; and American Chiropractic Association, 1992).

Such requirements serve a dual purpose—to maintain the profession and to serve society's well-being. By maintaining a specialized body of knowledge, the profession ensures a monopoly in providing its services. At the same time, restricting the practice of a profession to those who are qualified and requiring that they keep their skills and knowledge current are essential elements in fulfilling society's mandate to the profession: to provide a specialized service competently and safely.

Rules of professional etiquette, such as prohibitions on criticizing colleagues in the presence of clients, the proper procedures for consultation, and the process for the adjudication of disputes, constitute another characteristic of professional ethics documents. Thomas Percival's *Medical Ethics* (1803), originally commissioned to address conflicts among physicians, surgeons, and apothecaries at Manchester Infirmary, epitomizes this characteristic. Like the competency requirements, rules governing intraprofessional behavior serve the dual purpose of maintaining the profession and serving the well-being of society. Regarding the former, public criticism of colleagues could, as Percival noted, undermine the credibility of the professional and might ultimately damage the reputation of the profession. Professionally generated documents require that questions one practitioner has about another's competence or conduct be brought to the attention of the appropriate authorities, but none to my knowledge explicitly states that the client be advised of the concern. The presumption seems to be that this arrangement, at least in most cases, will protect the client from incompetent practice at the same time as it safeguards the reputation of the professional.

In addition, rules that foster harmony between members of a profession presumably promote not only the self-interest of the profession(als) but also the well-being of society. Rules of etiquette help to maintain the unity of the profession and promote teamwork, two factors that are widely perceived to optimize the quality of patient care (see, e.g., American Chiropractic Association, 1992).

Similarly, rules governing professionals' association with practitioners outside of the profession serve multiple functions. The American Medical Association, for example, proscribes the association of its physicians with "nonscientific practitioners" but permits its physicians to refer patients to nonphysician practitioners provided the referrals are believed to benefit the patients and the services "will be performed competently and in accordance with accepted scientific standards and legal requirements." In part, such rules protect the standing of a profession by not allowing a competing practice to infringe upon its professional monopoly. But if the competing practice truly is "quackery," the rules may also protect the professional's clients from harm.

Many codes include guidelines on the setting of fees as well as prohibitions of fee-splitting, deceptive advertising, and misrepresenting one's professional qualifications (see, e.g., American Dental Association, 1994; American Psychological Association, 1992). Once again, the dual purpose of protecting the profession and safeguarding its clients is evident. With regard to deceptive practices, the prohibition benefits both the consumer and the profession. Over time, deceptive practices undermine the credibility of the profession, resulting in diminished status and externally imposed sanctions. The setting of fees promotes the interests of professionals by allowing them the discretion to set fees in return for the expertise over which they hold a monopoly. However, professional codes also may admonish the professional to take into account the client's ability to pay when setting the fee in a particular case (see, e.g., Canadian Medical Association, 1990a, 1990b; International Chiropractors Association, 1990).

A common component of the "quasi-moral" elements of professional ethics codes is a description of the procedures for reviewing, adjudicating, and, if necessary, sanctioning alleged violations of professional conduct (see, e.g., American Chiropractic Association, 1992; American Psychiatric Association, 1989). There are several reasons for this often lengthy discussion. Allegations of moral impropriety can harm the reputation of the accused as well as the profession. Consequently, every effort must be made to ensure due process and the fair treatment of all parties. In addition, the potentially explosive nature of such allegations and the serious consequences if they are proved true set the stage for vehement denial and rebuttal by the professional accused. It is not unreasonable for the professional organization to protect itself, the process, and any victims, by making the rules clear in advance.

Moral guidelines. Professional ethics is best understood as a subset of ethics in general, although this might be disputed by some. The moral dictates of professional ethics documents ought to relate general moral values, duties, and virtues to the unique situations encountered in professional practice. A professional ethic cannot make a practitioner ethical; it can only hope to inform and guide a previously existing moral conscience. Lisa Newton (1988) has distinguished between the internal and external aspects of ethics in professional practice. The internal aspect is ontologically prior to the external; it is the personal conscience that each professional brings to the professional enterprise. The external aspect consists of the publicly specified moral requirements of the profession, that is, those elements of professional morality that are addressed in the profession's ethics documents. Despite the potential conflict between the internal and external aspects, both of them are important.

The external aspect may prompt professionals to reflect critically on their personal moral beliefs and values, a process that helps practitioners refine their internal ethic. The internal ethic then guides professionals when they encounter the myriad situations and conflicts of duty to which ethics documents can only allude. However, since only the external aspect is accessible to public scrutiny, the remainder of this section will explore that aspect in more detail.

The moral guidelines of ethics documents generally involve three elements: (1) values; (2) duties; and (3) virtues.

1. At the center of the professional ethic lies the value that the profession perceives to be the primary good, or its objective. Professional ethics documents often identify this value explicitly and include a pledge to promote it as their means of serving the public interest. Some professional organizations focus on general values, citing the benefit, well-being, or greatest good of their clients as the fundamental value to be pursued (see, e.g., National Federation of Societies for Clinical Social Work, 1987; American Chiropractic Association, 1992). Although including values in ethics documents helps provide a touchstone for guiding conduct when duties that are specified conflict, a problem can arise when it is the profession that articulates the value central to the client-provider relationship. An individual's well-being generally involves all aspects of his or her life, and practitioners, who might be qualified to assess and advance more specific goods, such as health, can claim no particular expertise in judging what constitutes a client's total well-being (Veatch, 1991).

Even the professional organizations that cite the health of clients as the central value encounter difficulties (see, e.g., International Council of Nurses, 1973; American Pharmaceutical Association, 1981; World Medical Association, 1983). In this case, the problem arises because a client's real goal is usually total well-being. Even if the practitioner can claim expertise in "health," it is still only one factor in the client's overall welfare. The Canadian Nurses Association (1991) takes particular care to avoid this difficulty by admonishing nurses to respect the "individual needs and values" of their clients; this injunction appears to recognize the client as the expert in judging what is in his or her own best interests.

2. The moral duties articulated in professional ethics documents may be broad (such as respecting the dignity and self-determination of one's clients) or specific (such as maintaining client confidentiality or not engaging in sexual relations with a client). The more general duties permit a certain amount of interpretation in their implementation by the individual practitioner, whereas the more specific ones

establish particular minimum standards for professional behavior.

There are, of course, gray areas, such as the duty of confidentiality. The duty to keep professional confidences secret is found in almost every professional ethic since the Hippocratic Oath. Yet exceptions to the general rule can be found. Until 1980, for example, the American Medical Association's "Principles of Medical Ethics" included an exception clause that permitted the disclosure of confidential information not only when required by law but also when "necessary in order to protect the welfare of the individual or of the community." Although most professional ethics documents allow for at least limited disclosure to ensure the safety of third parties, disclosure without consent for the benefit of the patient is suspect and subsequently has been dropped from the AMA "Principles of Medical Ethics." Also, although it is generally acceptable to disclose patient information when consulting with colleagues, there are rules governing such disclosure.

The presence of guidelines on safeguarding and disposing of written and computerized patient records emphasizes how seriously the duty to keep confidences is viewed by professions (see, e.g., British Medical Association, 1988; International Chiropractors Association, 1990). Although some discretion is permitted, the rules governing confidentiality still have the force of minimum requisite standards rather than ideals.

Some professional documents are organized around the distinction between ideal and minimalist standards (see, e.g., American Psychological Association, 1992, American College of Radiology, 1991). They begin with a set of general guidelines that are admittedly broad and explicitly not subject to sanction by the professional organization. These ideals are followed by the minimal rules of professional conduct, violations of which may be punishable by the organization.

3. Traditionally, philosophers have argued that moral behavior is governed primarily in one of two ways. Moral obligations, ideal or minimalist, may be specified, as in the documents just discussed. Alternatively, moral guidelines may focus on the character of the individual, with the assumption that moral behavior will flow naturally from a moral person.

Although the Prayer of Moses Maimonides is concerned primarily with specifying the virtues of a moral physician (Purtilo, 1977), many other professional ethics documents incorporate both basic standards of conduct and specific character traits, such as honesty, compassion, and integrity.

Even though a good or virtuous character may help a professional respond morally to a complex dilemma (in which, for example, specific duties conflict), the possession of a good character does not ensure morally right conduct. The moral character of an individual does, however, affect the way others perceive him or her. One is apt to have more regard for persons who act morally from good motives than for those who act morally simply because the rules require them to do so. Arguably a professional of good character is more trustworthy than one of poor character, and trust is an extremely important element in the relationship between client and professional.

DIFFICULTIES WITH PROFESSIONAL CODES. Professionally generated ethics documents are subject to a number of criticisms.

Monopoly and self-regulation. The most serious problems stem from the profession's power as an autonomous and self-regulating entity. The profession's monopoly on both setting and enforcing rules of conduct raises charges of elitism and opens the door to abuse of power. The presumption is that only professionals can know what constitutes ethical conduct for professionals and thus that they are the only ones who can evaluate the technical and moral quality of the services rendered.

It is true that professionals have been trained in a specialized body of knowledge that is not generally available to the layperson. That knowledge and professional judgment is part of the reason that society grants power and respect to a profession. However, professionals are neither uniquely nor the best equipped to make moral decisions (Veatch, 1973). Even if professionals were able to determine a client's best interest, they would have no special expertise in determining whether, for example, the client's interest, the client's rights, or the interests of society should take moral precedence in a given case.

Competing ethics. Historically, prayers, oaths, and certain codes have incorporated appeals to deities and/or the precepts of a broader religious or philosophical ethic into the professional mandate. Ludwig Edelstein (1943), for example, has argued that the Hippocratic Oath involves an application of Pythagorean principles to medicine. Some modern professional documents, such as the *Health Care Ethics Guide of the Catholic Health Association of Canada* (1991) and the *Islamic Code of Medical Ethics* (Islamic Organization of Medical Sciences, 1981), also explicitly place professional practice in the context of a larger ethic.

The generation of a professional ethic by modern secular professional organizations makes those organizations the functional equivalent of a religious or philosophical system and places them in direct competition with those systems, at least in their claim to know what is morally right in professional practice. In short, what the profession determines to be ethical is so, regardless of whether clients or other individuals in society agree. Of course, as illustrated by the variations between the codes authored by, for example, the medical associations of different countries (see Appendix, Section II), even secular professional ethics are influenced by the underlying values of the societies in which they are written. Furthermore, professional ethics are evolutionary and specific changes can be brought to bear from outside the profession. The significant moderation, if not obliteration, of traditional medical paternalism by societal demands for information and "informed consent" in decision making is one example of this point.

Self-policing. The self-policing of professionals raises a similar problem. If the profession does not find a practitioner to be at fault in an alleged ethics violation, there is no recourse to a general moral standard. Despite the requirement of many codes that unethical behavior by a colleague be reported, professionals may have a vested interest in not reporting or condemning violations by colleagues for fear of reprisal. They also may be deterred by the recognition that "everyone makes mistakes" and that they might be in a similar position in the future. An example of the closing of professional ranks appears in the American Academy of Orthopaedic *Surgeons' Guide to the Ethical Practice of Orthopaedic Surgery* (A.A.O.S., 1992, pp. 4–5, 9). Allegations raised by a professional against a colleague are investigated confidentially, and allegations brought by a patient, which admittedly are explicitly outside the auspices of the academy, are forwarded directly to the practitioner with a letter "urging him or her to contact the patient about the concern."

Although abuses of power can and do occur, mechanisms exist to limit them. International professional organizations, such as the World Medical Association, have arisen in part in an effort to forestall idiosyncratic, immoral practices of the sort that occurred in Nazi medicine. In addition, requiring that professionals report suspected violations, as well as maintaining, to the extent possible, the confidentiality of individuals who report them, and protecting such individuals from reprisal, helps to ensure that professionals will not be absolved of their responsibilities.

Business interests. Another criticism of professional codes is their excessive concern with nonmoral "business" interests, such as etiquette, fees, advertising, and the like, and the use of such measures to enhance professional prestige and prosperity. However, although such concerns are not specifically moral, they do have a moral component and their presence in an ethics document can thereby be justified. Furthermore, although the potential for abuse exists, the same type of safeguards outlined above apply here as well.

Inadequate education. A persistent criticism of professional codes is that professionals themselves know very little about the content of their own codes. A survey of physicians revealed that most knew little or nothing about the contents of the AMA's Code of Medical Ethics. Few ethics educators in medical school incorporate the Code as a text in their courses. Michael Davis, an expert on professional codes of ethics at the Illinois Institute of Technology, agrees that a certain hostility to code ethics has existed in medicine for the last few decades. This can be contrasted to engineering, which generally is more receptive to code ethics, especially in the pedagogy of professional ethics. In the pre-electronic era, one could argue professional codes were inaccessible documents that gathered dust on library shelves. With the advent of the internet, however, this kind of complaint is hardly justified. Many of the professional codes in this newly revised appendix are easily accessible online and the AMA's Code of Medical Ethics is available completely online for no fee.

Generality. The remaining concerns with professional ethics documents are directed at the vagueness, conflicts, and idealism found in them. Many of the guidelines found in professional codes are intentionally vague. No document can or should pretend to foresee all eventualities and eliminate the need for individual discretion. In addition, ethics statements are "consensus documents." They reflect the general values and obligations held by most of the profession's members. The more specific such statements become, the more likely it is that there will be disagreement and loss of support for the moral authority of the document. For this reason, professional organizations address the more controversial topics in bioethics in separate documents that do not require ratification by the entire membership (Gass, 1978).

Similarly, resolutions to all conflicts of duty cannot be specified. The professional must rely on the values underlying the ethic, as well as his or her own conscience as informed by virtue, to determine the correct action when multiple duties conflict. Ethics codes may idealize the profession by suggesting that all professionals consistently possess all the virtues, uphold all the ideals, and reason through conflicts flawlessly. Holding professionals to such standards is, of course, unreasonable and may even be detrimental by undermining the motivation of those professionals who cannot, but feel they must, satisfy such expectations. Nevertheless, ideals serve as guides, as something to aspire to; if one aims high, one may land close to the goal.

As long as the difficulties with professionally generated ethics documents are recognized and accounted for both within and outside the profession, it seems that the documents do provide a standard by which questionable professional behavior can be judged. In addition, they are useful tools for generating professional awareness of the need for ethical discourse, which in turn helps to inform the internal ethic of individual practitioners.

Documents Directed Toward a Profession, but Generated Outside It

This category encompasses all bioethics documents that have direct implications for professional behavior, yet are authored by an “extraprofessional” group. The term “extraprofessional” refers to individuals who, in a specified setting, are not engaged in professional practice. Most commonly such documents are authored by an entity representing the public at large, such as a state licensing agency or other government body; a group within a field such as health care but outside of the profession(s) addressed; or a group representing a religious or philosophical ethic.

THE NATURE AND ROLES OF “EXTRAPROFESSIONAL” ETHICS DIRECTIVES. Typically, documents generated outside of a profession serve two main functions, either independently or concurrently. The first purpose is to regulate professional practice, thereby helping to limit the professional authority discussed in the previous section and addressing some of its potential abuses. Laws, regulations, and judicial decisions governing informed consent, advance directives, and research practices are examples of outside controls placed on professional practice.

Directives from outside professional organizations, such as the American Hospital Association’s Patient’s Bill of Rights (1973, 1992) serve a similar purpose. Rights documents are complex because they pertain not only to the individuals whose rights are being enumerated but also to the persons who are obliged to respect those rights. The American Hospital Association is, in effect, issuing guidelines governing ethical behavior for all individuals working at the facility, although in several instances the duties of physicians are singled out.

Extraprofessional documents that seek to regulate professional behavior tend to be minimalistic. Whereas professionally generated statements frequently articulate the ideals of character and behavior to which professionals should aspire, externally imposed standards are often generated in response to professional indiscretion and are designed to specify the limits to the range of acceptable professional conduct.

The second principal function of extraprofessional ethics statements is to focus attention on a broader ethic of which professional ethics is perceived by the authoring group to be a subset. Such documents derive norms for ethical practice from the values underlying a whole ethic or world view, rather than from the values underlying a specific profession. Whereas secular associations of health care professionals generally derive their ethical principles from the values of the profession, such as the health and well-being of clients, bioethics directives generated by religious bodies derive standards of practice from the values of the religion.

For example, the *Ethical and Religious Directives for Catholic Health Facilities* (United States Catholic Conference, 1975) outlines the practices that may and may not take place in Catholic facilities. Although many of the directives correspond directly to precepts already adhered to by healthcare practitioners, other directives, such as those concerning abortion and sterilization, reflect distinctly Catholic values and teaching. Although the directives are addressed to institutions, their force applies to the institutions’ employees, including the professionals.

Other examples of religious or philosophical ethics being brought to bear on professional practice include the application of Jewish law to medical practice, for instance, to ascertain the moral licitness of neurological criteria for determining death, and the admonition of the old Oath of Soviet Physicians (1971) to follow the principles of communist morality in all of one’s actions.

Documents that explicitly locate professional ethics within a religious or philosophical ethic tend to be idealistic in the same way that many professionally generated documents are. The goal is to provide a moral framework for professional practice. In contrast to the policing function of other extraprofessional documents, these documents attempt to define an ideal standard at which to aim.

Although some of the obligations articulated in extraprofessional documents—for example, those emphasizing duties to clients or to society—parallel those articulated in professionally generated statements, others specify the duties of professionals to an organization, institution, government, or other authority. In such cases, conflicts between the values and duties perceived by a profession and those articulated by the extraprofessional group are likely to arise.

Researchers, for example, might perceive their professional mandate to be the expansion of scientific knowledge, either generally or with the goal of aiding a specific population, such as persons with Alzheimer’s disease, that might potentially benefit from the information acquired. They might further believe that the best means of advancing those goals is to violate an externally imposed ban on human fetal tissue transplantation research. Or nurses might believe that their professional mandate to care for the well-being of their client requires the violation of an institutional policy. In such cases, professionals face potential legal, monetary, or moral sanctions, on the one hand, or the loss of personal and/or professional integrity, on the other.

Such conflicts illustrate the more global problem of reconciling competing values in a pluralistic society (cf. Veatch and Mason, 1987). Professionals who simultaneously subscribe to a general religious or philosophical ethic—such as Catholicism, Islam, or libertarianism—and are members of a professional organization, or employees of an institution, that does not explicitly reflect that ethic are apt to find themselves in an untenable situation if personal values and professional duties conflict.

Some professionally generated documents attempt to address such conflicts by proscribing practices forbidden by law and by allowing, within certain confines, practitioners to withdraw from practices they find morally objectionable. The American Nurses' Association (1985) cautions its members that "neither physicians' orders nor the employing agency's policies relieve the nurse of accountability for actions taken and judgments made," implying that the precepts of the profession may outweigh the requirements of an institutional obligation. The Canadian Nurses Association (1991) advises that "prospective employers be informed of the provisions of [its] Code so that realistic and ethical expectations may be established at the beginning of the nurse-employer relationship."

Although such provisions may be of some assistance, their value may be limited by other provisions of the code. For example, a professional's right to withdraw from practices he or she deems morally offensive is conditional upon ensuring that the client is not abandoned, that is, the fundamental professional duty to care for the client ultimately takes precedence over one's personal ethic. Furthermore, even if a professional's personal morality were compatible with those of the professional association and the employing institution, the professional may still encounter conflict when a client with different values and beliefs requests a service deemed morally offensive by the professional.

Documents Directed Toward "Nonprofessionals"

The term "nonprofessional" here refers to two groups: (1) clients, for instance, patients or research subjects, and (2) persons engaged in nonprofessional work, such as orderlies, hospital volunteers, or laboratory assistants. Since these groups do not have a self-imposed ethic other than a broad, societal one, bioethics directives pertaining to them usually are generated outside of the group by the same sources that apply to professionals. The implications, however, are rather different.

DIRECTIVES PERTAINING TO CLIENTS. Rights statements are directed at two distinct groups, those who hold rights and those who must respect them. Most of the rights documents in bioethics are not generated by individuals specifically representing the holders of the rights. For example, although groups advocating for health-care consumers helped to precipitate its establishment, the American Hospital Association's Patient's Bill of Rights (1973, 1992) was written by individuals representing member hospitals. Although the intention of protecting the interests of patients is admirable, it is not clear that the authoring group has any special expertise in determining what the rights of hospital patients actually are or should be. Similarly, the American Medical Association's Fundamental Elements of the Physician-Patient Relationship is a professionally generated document that outlines patients' rights to information, confidentiality, continuity of care, and so forth. Again, in one sense, this document sets forth the obligation of physicians to advance these rights (as such it is subject to the discussion in the first section), but in another sense, it claims authority for knowing what rights patients have, a task for which physicians are not necessarily the best suited.

In addition, rights documents, which presumably are intended to protect the rights-bearer, increasingly are accompanied by statements of the responsibilities of the rights-bearer. The American Medical Association, for example, includes among the responsibilities of patients the provision of accurate and complete information and compliance with the treatment plan and instructions of those responsible for the patient's care. It is not clear in any of the documents that issue joint statements of rights and responsibilities whether respect for the rights identified is contingent upon fulfillment of the specified responsibilities. Also not clear is why the authoring body has the moral authority to specify the responsibilities of those not members of the group.

Other bioethics documents affecting patients or research subjects are regulatory and/or governmental. Judicial and legislative actions as well as regulatory agencies and advisory bodies that represent the general populace are the closest the recipients of professional services come to a self-generated ethic. Even here, however, controversy arises over the extent to which patients and research subjects should be protected from others (and themselves). In the United States, the debates over access to experimental drugs by seriously ill patients and silicone implants by women seeking breast augmentation exemplify the dilemma.

Religious and broad philosophical ethics also affect individuals in this category. Usually individuals have elected to follow the precepts of a particular ethic in their overall existence and bring that ethic into whatever situation they encounter. As noted earlier, difficulties arise when one encounters a competing ethic. A traditional example is the difficulty faced by a Jehovah's Witness who refuses a potentially life-saving blood transfusion. On a larger scale, the imposition of one culture's beliefs upon another—for example, through regulations attached to financial assistance—poses the same problem.

DIRECTIVES PERTAINING TO NONPROFESSIONAL WORKERS. The final documents to be discussed are those that articulate standards for nonprofessional workers. Rights documents and other statements directed at institutions set minimal standards for all personnel, insofar as they apply, not just for professionals. Ethics directives that pertain to nonprofessionals tend to be minimalistic. They set guidelines protecting basic concerns such as respect, privacy, and competence, but unlike their professional counterparts, the job descriptions of nonprofessionals do not include a unique ethical mandate.

Nonprofessionals, like their professional counterparts, may be subject to certain duties to the institution or organization employing them. Similarly, nonprofessional workers are subject to moral standards articulated by legal and governmental bodies, as well as those stemming from religious or philosophical worldviews. The problem of conflicting duties arising from multiple moral authorities affects nonprofessionals, but not to the same degree as it plagues professionals. The conflicts faced by the nonprofessional are more analogous to those faced by any human being when the demands of law or one's employer conflict with a broader ethic that is perceived to be more fundamental. This is not to imply that these conflicts are any less difficult to resolve, only that their nature is different.

Conclusion

The number and diversity of bioethics documents reflect the pluralism of our world. When the ideologies expressed in these documents clash, controversy and conflicts may arise. In such cases, it is to be hoped that the documents will provide a basis for dialogue between the disagreeing parties. Ethical dialogue can promote understanding and a resolution to the conflict, as well as an ongoing assessment of the precepts in question relative to their underlying ideologies.

CAROL MASON SPICER (1995)

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INTRODUCTION TO THE CODES, OATHS, AND DIRECTIVES

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The bioethics documents included in this Appendix are divided into six sections as listed in the table of contents. The first section contains documents that outline the health-related rights of individuals or address topics that are designed to implement such rights. The remaining sections contain directives that address the responsibilities of professionals, many of which can be understood as correlates of the rights of the individuals under their care or supervision.

The appendix for the third edition of the *Encyclopedia of Bioethics* has been substantially updated through online searches using the Google search engine. The internet has made many of these documents vastly more accessible. The careful researcher should use this appendix in tandem with his own online research. Frequently, these documents have their latest versions online.

Credits for the documents that appear in the Appendix can be found at the end of the Appendix.

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SECTION I.

DIRECTIVES ON HEALTH-RELATED RIGHTS AND PATIENT RESPONSIBILITIES

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Constitution of the World Health Organization [1948]

Universal Declaration of Human Rights, General Assembly of the United Nations [1948]

Declaration of the Rights of the Child, General Assembly of the United Nations [1959]

Declaration on the Rights of Mentally Retarded Persons, General Assembly of the United Nations [1971]

A Patient's Bill of Rights, American Hospital Association [1973, revised 1992]

Declaration of Lisbon on the Rights of the Patient, World Medical Association [1981]

Declaration on Physician Independence and Professional Freedom, World Medical Association [1986]

Fundamental Elements of the Patient-Physician Relationship, American Medical Association [1990, updated 1993, 2001]

Patient Responsibilities, American Medical Association [1993, updated 2001]

Patient Rights, Joint Commission on Accreditation of Healthcare Organizations [1994]

The use of rights language has emerged in recent decades as a strong feature of contemporary bioethics documents. Although the language of rights cannot embrace all that must be said in bioethics, this collection of directives on health-related rights and patient responsibilities heads the Appendix both because it reinforces the common doctrine that all health care is patient-centered and because rights language has become typical of the period on which this edition is reporting.

Most of the documents in this section outline the health-related rights of specific groups of individuals, such as children, mentally retarded persons, and patients. Two documents, however, address topics that are designed to implement these rights. The World Medical Association's Declaration on Physician Independence and Professional Freedom addresses the importance of physicians' professional freedom to support patient rights. The American Medical Association (AMA) perceives patient rights and the corresponding patient responsibilities to be two elements of a mutually respectful alliance between patients and physicians. The AMA's directive on patient responsibilities elaborates upon the view expressed in the AMA's patient rights document, Fundamental Elements of the Patient-Physician Relationship, that "patients share with physicians the responsibility for their own health care."

CONSTITUTION OF THE WORLD HEALTH ORGANIZATION

1948

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Originally adopted by the International Health Conference held in New York in June-July 1946 and signed by the representatives of sixty-one nations, the following statement is found in the Preamble to the Constitution of the World Health Organization, established in 1948. Especially significant elements are the controversial definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"and the recognition of health as a fundamental human right.

The States Parties to this Constitution declare, in conformity with the Charter of the United Nations, that the following principles are basic to the happiness, harmonious relations and security of all peoples:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

The health of all peoples is fundamental to the attainment of peace and security and is dependent upon the fullest co-operation of individuals and States.

The achievement of any State in the promotion and protection of health is of value to all. Unequal development in different countries in the promotion of health and control of disease, especially communicable disease, is a common danger.

Healthy development of the child is of basic importance; the ability to live harmoniously in a changing total environment is essential to such development.

The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.

Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people.

Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.

Accepting these principles, and for the purpose of co-operation among themselves and with others to promote and protect the health of all peoples, the Contracting parties agree to the present Constitution and hereby establish the World Health Organization as a specialized agency within the terms of Article 57 of the Charter of the United Nations.

UNIVERSAL DECLARATION OF HUMAN RIGHTS

General Assembly of the United Nations

1948

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Adopted in 1948 by the General Assembly of the United Nations, the Universal Declaration of Human Rights is, as stated in its preamble, "a common standard of achievement for all peoples in all nations, to the end that every individual and every organ of society . . . shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance. . . . "

Article five should be compared to article seven of the International Covenant on Civil and Political Rights (Section IV). Article 25 directly pertains to health and healthcare.

ARTICLE 1

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

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ARTICLE 3

Everyone has the right to life, liberty and the security of person.

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ARTICLE 5

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

• • •

ARTICLE 16

1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
2. Marriage shall be entered into only with the free and full consent of the intending spouses.
3. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

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ARTICLE 25

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

DECLARATION OF THE RIGHTS OF THE CHILD

General Assembly of the United Nations

1959

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Adopted unanimously by the General Assembly of the United Nations on November 20, 1959, the Declaration of the Rights of the Child emphasizes the physical, mental, and moral health and development of children.

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"Whereas the child by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth.

• • •

The General Assembly

"Proclaims this Declaration of the Rights of the Child to the end that he may have a happy childhood and enjoy for his own good and for the good of society the rights and freedoms herein set forth, and calls upon parents, upon men and women as individuals, and upon voluntary organizations, local authorities and national Governments to recognize these rights and strive for their observance by legislative and other measures progressively taken in accordance with the following principles:

PRINCIPLE 1

"The child shall enjoy all the rights set forth in this Declaration. Every child, without any exception whatsoever, shall be entitled to these rights, without distinction or discrimination on account of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, whether of himself or of his family.

PRINCIPLE 2

"The child shall enjoy special protection, and shall be given opportunities and facilities, by law and by other means, to enable him to develop physically, mentally, morally, spiritually and socially in a healthy and normal manner and in conditions of freedom and dignity. In the enactment of laws for this purpose, the best interests of the child shall be the paramount considerations.

PRINCIPLE 3

"The child shall be entitled from his birth to a name and a nationality.

PRINCIPLE 4

"The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided both to him and to his mother, including adequate pre-natal and post-natal care. The child shall have the right to adequate nutrition, housing, recreation and medical services.

PRINCIPLE 5

“The child who is physically, mentally or socially handicapped shall be given the special treatment, education and care required by his particular condition.

PRINCIPLE 6

“The child, for the full and harmonious development of his personality, needs love and understanding. He shall, wherever possible, grow up in the care and under the responsibility of his parents, and, in any case, in an atmosphere of affection and of moral and material security; a child of tender years shall not, save in exceptional circumstances, be separated from his mother. Society and the public authorities shall have the duty to extend particular care to children without a family and to those without adequate means of support. Payment of State and other assistance towards the maintenance of children of large families is desirable.

PRINCIPLE 7

“The child is entitled to receive education, which shall be free and compulsory, at least in the elementary stages. He shall be given an education which will promote his general culture, and enable him, on a basis of equal opportunity, to develop his abilities, his individual judgement, and his sense of moral and social responsibility, and to become a useful member of society.

“The best interests of the child shall be the guiding principle of those responsible for his education and guidance; that responsibility lies in the first place with his parents.

“The child shall have full opportunity for play and recreation, which should be directed to the same purposes as education; society and the public authorities shall endeavour to promote the enjoyment of this right.

PRINCIPLE 8

“The child shall in all circumstances be among the first to receive protection and relief.

PRINCIPLE 9

“The child shall be protected against all forms of neglect, cruelty and exploitation. He shall not be the subject of traffic, in any form.

“The child shall not be admitted to employment before an appropriate minimum age; he shall in no case be caused or permitted to engage in any occupation or employment which would prejudice his health or education, or interfere with his physical, mental or moral development.

PRINCIPLE 10

“The child shall be protected from practices which may foster racial, religious and any other form of discrimination. He shall be brought up in a spirit of understanding, tolerance, friendship among peoples, peace and universal brotherhood, and in full consciousness that his energy and talents should be devoted to the service of his fellow men.”

DECLARATION ON THE RIGHTS OF MENTALLY RETARDED PERSONS

General Assembly of the United Nations

1971

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The following Declaration on the Rights of Mentally Retarded Persons was adopted by the General Assembly of the United Nations on December 20, 1971. It is a revised and amended version of the Declaration of General and Special Rights of the Mentally Retarded that was adopted in 1968 by the International League of Societies for the Mentally Handicapped.

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1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.
2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.
3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.
4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.
5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.
6. The mentally retarded person has a right to protection from exploitation, abuse and degrading

treatment. If prosecuted for any offence, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.

7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

A PATIENT'S BILL OF RIGHTS

American Hospital Association

1973, REVISED 1992

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In 1973, the American Hospital Association's House of Delegates adopted A Patient's Bill of Rights, which was influential in the development of similar documents in other parts of the world. The first revision of the document, and the only one to date, was approved in 1992. Some of the most notable changes from the 1973 document include: (1) deletion of the "therapeutic privilege" clause that permitted information regarding a patient's condition to be disclosed to family, rather than to the patient, when it was "not medically advisable to give such information to the patient"; (2) addition of the right to execute advance directives; (3) addition of a clause indicating that otherwise confidential information may be released when permitted or required by law for the benefit of third parties; (4) addition of the patients' right to review their medical records; (5) addition of the clarification that a patient's right to expect a hospital to reasonably respond to requests for care and services is limited to those that are "appropriate and medically indicated"; and (6) addition of a list of patient responsibilities.

Introduction

Effective health care requires collaboration between patients and physicians and other health care professionals. Open and honest communication, respect for personal and professional values, and sensitivity to differences are integral to optimal patient care. As the setting for the provision of health services, hospitals must provide a foundation for understanding and respecting the rights and responsibilities of patients, their families, physicians, and other caregivers. Hospitals must ensure a health care ethic that respects the role of patients in decision making about treatment choices and other aspects of their care. Hospitals must be sensitive to cultural, racial, linguistic, religious, age, gender, and other differences as well as the needs of persons with disabilities.

The American Hospital Association presents A Patient's Bill of Rights with the expectation that it will contribute to more effective patient care and be supported by the hospital on behalf of the institution, its medical staff, employees, and patients. The American Hospital Association encourages health care institutions to tailor this bill of rights to their patient community by translating and/or simplifying the language of this bill of rights as may be necessary to ensure that patients and their families understand their rights and responsibilities.

Bill of Rights*

1. The patient has the right to considerate and respectful care.
2. The patient has the right to and is encouraged to obtain from physicians and other direct caregivers relevant, current, and understandable information concerning diagnosis, treatment, and prognosis.

   Except in emergencies when the patient lacks decision-making capacity and the need for treatment is urgent, the patient is entitled to the opportunity to discuss and request information related to the specific procedures and/or treatments, the risks involved, the possible length of recuperation, and the medically reasonable alternatives and their accompanying risks and benefits.

   Patients have the right to know the identity of physicians, nurses, and others involved in their care, as well as when those involved are students, residents, or other trainees. The patient also has the right to know the immediate and long-term financial implications of treatment choices, insofar as they are known.
3. The patient has the right to make decisions about the plan of care prior to and during the course of treatment and to refuse a recommended treatment or plan of care to the extent permitted by law and hospital policy and to be informed of the medical consequences of this action. In case of such refusal, the patient is entitled to other appropriate care and services that the hospital provides or transfer to another hospital. The hospital should notify patients of any policy that might affect patient choice within the institution.
4. The patient has the right to have an advance directive (such as a living will, health care proxy, or durable power of attorney for health care) concerning treatment or designating a surrogate decision

maker with the expectation that the hospital will honor the intent of that directive to the extent permitted by law and hospital policy. Health care institutions must advise patients of their rights under state law and hospital policy to make informed medical choices, ask if the patient has an advance directive, and include that information in patient records. The patient has the right to timely information about hospital policy that may limit its ability to implement fully a legally valid advance directive.

5. The patient has the right to every consideration of privacy. Case discussion, consultation, examination, and treatment should be conducted so as to protect each patient's privacy.
6. The patient has the right to expect that all communications and records pertaining to his/her care will be treated as confidential by the hospital, except in cases such as suspected abuse and public health hazards when reporting is permitted or required by law. The patient has the right to expect that the hospital will emphasize the confidentiality of this information when it releases it to any other parties entitled to review information in these records.
7. The patient has the right to review the records pertaining to his/her medical care and to have the information explained or interpreted as necessary, except when restricted by law.
8. The patient has the right to expect that, within its capacity and policies, a hospital will make reasonable response to the request of a patient for appropriate and medically indicated care and services. The hospital must provide evaluation, service, and/or referral as indicated by the urgency of the case. When medically appropriate and legally permissible, or when a patient has so requested, a patient may be transferred to another facility. The institution to which the patient is to be transferred must first have accepted the patient for transfer. The patient must also have the benefit of complete information and explanation concerning the need for, risks, benefits, and alternatives to such a transfer.
9. The patient has the right to ask and to be informed of the existence of business relationships among the hospital, educational institutions, other health care providers, or payers that may influence the patient's treatment and care.
10. The patient has the right to consent to or decline to participate in proposed research studies or human experimentation affecting care and treatment or requiring direct patient involvement, and to have those studies fully explained prior to consent. A patient who declines to participate in research or experimentation is entitled to the most effective care that the hospital can otherwise provide.
11. The patient has the right to expect reasonable continuity of care when appropriate and to be informed by physicians and other caregivers of available and realistic patient care options when hospital care is no longer appropriate.
12. The patient has the right to be informed of hospital policies and practices that relate to patient care, treatment, and responsibilities. The patient has the right to be informed of available resources for resolving disputes, grievances, and conflicts, such as ethics committees, patient representatives, or other mechanisms available in the institution. The patient has the right to be informed of the hospital's charges for services and available payment methods.

The collaborative nature of health care requires that patients, or their families/surrogates, participate in their care. The effectiveness of care and patient satisfaction with the course of treatment depend, in part, on the patient fulfilling certain responsibilities. Patients are responsible for providing information about past illnesses, hospitalizations, medications, and other matters related to health status. To participate effectively in decision making, patients must be encouraged to take responsibility for requesting additional information or clarification about their health status or treatment when they do not fully understand information and instructions. Patients are also responsible for ensuring that the health care institution has a copy of their written advance directive if they have one. Patients are responsible for informing their physicians and other caregivers if they anticipate problems in following prescribed treatment.

Patients should also be aware of the hospital's obligation to be reasonably efficient and equitable in providing care to other patients and the community. The hospital's rules and regulations are designed to help the hospital meet this obligation. Patients and their families are responsible for making reasonable accommodations to the needs of the hospital, other patients, medical staff, and hospital employees. Patients are responsible for providing necessary information for insurance claims and for working with the hospital to make payment arrangements, when necessary.

A person's health depends on much more than health care services. Patients are responsible for recognizing the impact of their life-style on their personal health.

Conclusion

Hospitals have many functions to perform, including the enhancement of health status, health promotion, and the prevention and treatment of injury and disease; the immediate and ongoing care and rehabilitation of patients; the education of health professionals, patients, and the community; and research. All these activities must be conducted with an overriding concern for the values and dignity of patients.

**These rights can be exercised on the patient's behalf by a designated surrogate or proxy decision maker if the patient lacks decision-making capacity, is legally incompetent, or is a minor.*

DECLARATION OF LISBON ON THE RIGHTS OF THE PATIENT

World Medical Association

1981, 1995

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Whereas most of the early documents on patients' rights, such as the American Hospital Association's A Patient's Bill of Rights, focus on the rights of individuals within healthcare facilities (hospitals, nursing homes), the Declaration of Lisbon, adopted in 1981 by the 34th World Medical Assembly at Lisbon, is an international statement of the rights of patients in general. In conjunction with the International Code of Medical Ethics (Section II), it illustrates the relatively recent emphasis placed on "the rights of patients" in addition to the traditional "duties of physicians." Physicians not only "ought" to behave in certain ways, but patients also are entitled to have them do so. The Declaration of Lisbon was amended by the 47th General Assembly in Bali, Indonesia in September, 1995. This most recent version provides much more detail regarding the nature of the rights patients possess, particularly rights to quality information and health education.

Preamble

The relationship between physicians, their patients and broader society has undergone significant changes in recent times. While a physician should always act according to his/her conscience, and always in the best interests of the patient, equal effort must be made to guarantee patient autonomy and justice. The following Declaration represents some of the principal rights of the patient which the medical profession endorses and promotes. Physicians and other persons or bodies involved in the provision of health care have a joint responsibility to recognize and uphold these rights. Whenever legislation, government action or any other administration or institution denies patients these rights, physicians should pursue appropriate means to assure or to restore them.

In the context of biomedical research involving human subjects—including non therapeutic biomedical research—the subject is entitled to the same rights and consideration as any patient in a normal therapeutic situation.

Principles

1. Right to medical care of good quality
    a. Every person is entitled without discrimination to appropriate medical care.
    b. Every patient has the right to be cared for by a physician whom he/she knows to be free to make clinical and ethical judgements without any outside interference.
    c. The patient shall always be treated in accordance with his/her best interests. The treatment applied shall be in accordance with generally approved medical principles.
    d. Quality assurance always should be a part of health care. Physicians, in particular, should accept responsibility for being guardians of the quality of medical services.
    e. In circumstances where a choice must be made between potential patients for a particular treatment which is in limited supply, all such patients are entitled to a fair selection procedure for that treatment. That choice must be based on medical criteria and made without discrimination.
    f. The patient has the right of continuity of health care. The physician has an obligation to cooperate in the coordination of medically indicated care with other health care providers treating the patient. The physician may not discontinue treatment of a patient as long as further treatment is medically indicated, without giving the patient reasonable assistance and sufficient opportunity to make alternative arrangements for care.
2. Right to freedom of choice
    a. The patient has the right to choose freely and change his/her physician and hospital or health service institution, regardless of whether they are based in the private or public sector.
    b. The patient has the right to ask for the opinion of another physician at any stage.
3. Right to self-determination
    a. The patient has the right to self-determination, to make free decisions regarding himself/herself. The physician will inform the patient of the consequences of his/her decisions.
    b. A mentally competent adult patient has the right to give or withhold consent to any diagnostic

procedure or therapy. The patient has the right to the information necessary to make his/her decisions. The patient should understand clearly what is the purpose of any test or treatment, what the results would imply, and what would be the implications of withholding consent.

   c. The patient has the right to refuse to participate in research or the teaching of medicine.

4. The unconscious patient
   a. If the patient is unconscious or otherwise unable to express his/her will, informed consent must be obtained whenever possible, from a legally entitled representative where legally relevant.
   b. If a legally entitled representative is not available, but a medical intervention is urgently needed, consent of the patient may be presumed, unless it is obvious and beyond any doubt on the basis of the patient's previous firm expression or conviction that he/she would refuse consent to the intervention in that situation.
   c. However, physicians should always try to save the life of a patient unconscious due to a suicide attempt.
5. The legally incompetent patient
   a. If a patient is a minor or otherwise legally incompetent the consent of a legally entitled representative, where legally relevant, is required. Nevertheless the patient must be involved in the decision making to the fullest extent allowed by his/her capacity.
   b. If the legally incompetent patient can make rational decisions, his/her decisions must be respected, and he/she has the right to forbid the disclosure of information to his/her legally entitled representative.
   c. If the patient's legally entitled representative, or a person authorized by the patient, forbids treatment which is, in the opinion of the physician, in the patient's best interest, the physician should challenge this decision in the relevant legal or other institution. In case of emergency, the physician will act in the patient's best interest.
6. Procedures against the patient's will
   a. Diagnostic procedures or treatment against the patient's will can be carried out only in exceptional cases, if specifically permitted by law and conforming to the principles of medical ethics.
7. Right to information
   a. The patient has the right to receive information about himself/herself recorded in any of his/her medical records, and to be fully informed about his/her health status including the medical facts about his/her condition. However, confidential information in the patient's records about a third party should not be given to the patient without the consent of that third party.
   b. Exceptionally, information may be withheld from the patient when there is good reason to believe that this information would create a serious hazard to his/her life or health.
   c. Information must be given in a way appropriate to the local culture and in such a way that the patient can understand.
   d. The patient has the right not to be informed on his/her explicit request, unless required for the protection of another person's life.
   e. The patient has the right to choose who, if anyone, should be informed on his/her behalf.
8. Right to confidentiality
   a. All identifiable information about a patient's health status, medical condition, diagnosis, prognosis and treatment and all other information of a personal kind, must be kept confidential, even after death. Exceptionally, descendants may have a right of access to information that would inform them of their health risks.
   b. Confidential information can only be disclosed if the patient gives explicit consent or if expressly provided for in the law. Information can be disclosed to other health care providers only on a strictly "need to know" basis unless the patient has given explicit consent.
   c. All identifiable patient data must be protected. The protection of the data must be appropriate to the manner of its storage. Human substances from which identifiable data can be derived must be likewise protected.
9. Right to health education
   a. Every person has the right to health education that will assist him/her in making informed choices about personal health and about the available health services. The education should include information about healthy lifestyles and about methods of prevention and early detection of illnesses. The personal responsibility of everybody for his/her own health should be stressed. Physicians have an obligation to participate actively in educational efforts.
10. Right to dignity
   a. The patient's dignity and right to privacy shall be respected at all times in medical care and teaching, as shall his/her culture and values.
   b. The patient is entitled to relief of his/her suffering according to the current state of knowledge.

   c. The patient is entitled to humane terminal care and to be provided with all available assistance in making dying as dignified and comfortable as possible.

11. Right to religious assistance
    a. The patient has the right to receive or to decline spiritual and moral comfort including the help of a minister of his/her chosen religion.

DECLARATION ON PHYSICIAN INDEPENDENCE AND PROFESSIONAL FREEDOM

World Medical Association

1986

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Adopted in 1986 by the 38th World Medical Assembly at Rancho Mirage, California, this declaration elaborates on section (b) of the 1981 Declaration of Lisbon. Of interest is the declaration's assertion of the need for professional independence in order to ensure the rights of patients and to fulfill professional obligations to them. The document emphasizes concern over conflicts of interest in the area of cost containment and asserts that physicians must advocate for their individual patients.

The World Medical Association, Inc., recognizing the importance of the physician's independence and professional freedom, hereby adopts the following declaration of principles:

Physicians must recognize and support the rights of their patients, particularly as set forth in the World Medical Association Declaration of Lisbon (1981).

Physicians must have the professional freedom to care for their patients without interference. The exercise of the physician's professional judgement and discretion in making clinical and ethical decisions in the care and treatment of patients must be preserved and protected.

Physicians must have the professional independence to represent and defend the health needs of patients against all who would deny or restrict needed care for those who are sick or injured.

Within the context of their medical practice and the care of their patients, physicians should not be expected to administer governmental or social priorities in the allocation of scarce health resources. To do so would be to create a conflict of interest with the physician's obligation to his patients, and would effectively destroy the physician's professional independence, upon which the patient relies.

While physicians must be conscious of the cost of medical treatment and actively participate in cost containment efforts within medicine, it is the physician's primary obligation to represent the interests of the sick and injured against demands by society for cost containment that would endanger patients' health and perhaps patients' life.

By providing independence and professional freedom for physicians to practice medicine, a community assures the best possible health care for its citizens, which in turn contributes to a strong and secure society.

FUNDAMENTAL ELEMENTS OF THE PATIENT-PHYSICIAN RELATIONSHIP

American Medical Association

1990, UPDATED 1993

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This document, which constitutes one part of the American Medical Association's complete code of ethics, extends the rights language introduced in the 1980 Principles of Medical Ethics (Section II) to a separate statement listing the specific rights of patients. The opening paragraph of the Fundamental Elements also mentions the responsibilities of patients. Points of particular interest include: (1) Right #4 on confidentiality, which contains the therapeutic privilege exception dropped from the Principles of Medical Ethics in 1980 and still not restored to the principles themselves; (2) Right #5 on continuity of care, which implies that treatment may be discontinued, without making alternative arrangements for care, when further treatment is not "medically indicated"; and (3) Right #6, which establishes a basic right to adequate health care, but explicitly does not guarantee the fulfillment of such a right.

From ancient times, physicians have recognized that the health and well-being of patients depends upon a collaborative effort between physician and patient. Patients share with physicians the responsibility for their own health care. The patient-physician relationship is of greatest benefit to patients when they bring medical problems to the attention of their physicians in a timely fashion, provide information about their medical condition to the best of their ability, and work with their physicians in a mutually respectful alliance. Physicians can best contribute to this alliance by serving as their patients' advocate and by fostering these rights:

1. The patient has the right to receive information from physicians and to discuss the benefits, risks,

and costs of appropriate treatment alternatives. Patients should receive guidance from their physicians as to the optimal course of action. Patients are also entitled to obtain copies or summaries of their medical records, to have their questions answered, to be advised of potential conflicts of interest that their physicians might have, and to receive independent professional opinions.

2. The patient has the right to make decisions regarding the health care that is recommended by his or her physician. Accordingly, patients may accept or refuse any recommended medical treatment.
3. The patient has the right to courtesy, respect, dignity, responsiveness, and timely attention to his or her needs.
4. The patient has the right to confidentiality. The physician should not reveal confidential communications or information without the consent of the patient, unless provided for by law or by the need to protect the welfare of the individual or the public interest.
5. The patient has the right to continuity of health care. The physician has an obligation to cooperate in the coordination of medically indicated care with other health care providers treating the patient. The physician may not discontinue treatment of a patient as long as further treatment is medically indicated, without giving the patient reasonable assistance and sufficient opportunity to make alternative arrangements for care.
6. The patient has a basic right to have available adequate health care. Physicians, along with the rest of society, should continue to work toward this goal. Fulfillment of this right is dependent on society providing resources so that no patient is deprived of necessary care because of an inability to pay for the care. Physicians should continue their traditional assumption of a part of the responsibility for the medical care of those who cannot afford essential health care. Physicians should advocate for patients in dealing with third parties when appropriate.

PATIENT RESPONSIBILITIES

American Medical Association

1993, UPDATED 1998, 2000 AND 2001

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The American Medical Association's (AMA) Patient Responsibilities draws upon the recognition, articulated in the preceding Fundamental Elements of the Patient-Physician Relationship, that successful medical care depends upon a collaborative effort between physicians and patients. Originally published in July 1993 as Report 52 in the AMA Code of Medical Ethics: Reports of the Council on Ethical and Judicial Affairs, Patient Responsibilities expands upon the Fundamental Elements document by specifying the responsibilities of patients for their own health care. It has been updated three times since its creation in 1993.

The background section of the original report states: "Like patients' rights, patients' responsibilities are derived from the principle of autonomy. . . . With that exercise of self-governance and free choice comes a number of responsibilities." The list of those patient responsibilities follows.

1. Good communication is essential to a successful physician-patient relationship. To the extent possible, patients have a responsibility to be truthful and to express their concerns clearly to their physicians.
2. Patients have a responsibility to provide a complete medical history, to the extent possible, including information about past illnesses, medications, hospitalizations, family history of illness and other matters relating to present health.
3. Patients have a responsibility to request information or clarification about their health status or treatment when they do not fully understand what has been described.
4. Once patients and physicians agree upon the goals of therapy, patients have a responsibility to cooperate with the treatment plan and to keep their agreed-upon appointments. Compliance with physician instructions is often essential to public and individual safety. Patients also have a responsibility to disclose whether previously agreed upon treatments are being followed and to indicate when they would like to reconsider the treatment plan.
5. Patients generally have a responsibility to meet their financial obligations with regard to medical care or to discuss financial hardships with their physicians. Patients should be cognizant of the costs associated with using a limited resource like health care and try to use medical resources judiciously.
6. Patients should discuss end of life decisions with their physicians and make their wishes known. Such a discussion might also include writing an advance directive.
7. Patients should be committed to health maintenance through health-enhancing behavior. Illness can often be prevented by a healthy lifestyle, and patients must take personal responsibility when they are able to avert the development of disease.
8. Patients should also have an active interest in the effects of their conduct on others and refrain from behavior that unreasonably places the health of others at risk. Patients should inquire as to the

means and likelihood of infectious disease transmission and act upon that information which can best prevent further transmission.

9. Participation in medical education is to the mutual benefit of patients and the health care system. Patients are encouraged to participate in medical education by accepting care, under appropriate supervision, from medical students, residents, and other trainees. Consistent with the process of informed consent, the patient or the patient's surrogate decision maker is always free to refuse care from any member of the health care team.
10. Patients should discuss organ donation with their physicians and, if donation is desired, make applicable provisions. Patients who are part of an organ allocation system and await needed transplant should not try to go outside of or manipulate the system. A fair system of allocation should be answered with public trust and an awareness of limited resources.
11. Patients should not initiate or participate in fraudulent health care and should report illegal or unethical behavior by providers to the appropriate medical societies, licensing boards, or law enforcement authorities.

PATIENT RIGHTS

Joint Commission on Accreditation of Healthcare Organizations

1994

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Patient Rights is a section of the Joint Commission on Accreditation of Healthcare Organizations' (JCAHO) Accreditation Manual for Hospitals, 1994. Although many healthcare organizations demonstrate their recognition and support of patient/client rights by issuing lists of those rights, no list can assure that the rights are respected. The standards on patient rights included in JCAHO's Accreditation Manual are designed to reflect the implementation, as well as the existence, of institutional policies and procedures for the exercise and protection of a specified set of patient rights.

The scoring of the standards in this chapter will reflect evidence of the implementation of policies and procedures as well as the existence of such policies and procedures.

RI.1 The organization supports the rights of each patient.

RI.1.1 Organizational policies and procedures describe the mechanisms by which the following rights are protected and exercised:

Intent of RI.1 and RI.1.1

The policies and procedures that guide the organization's interaction with and care of the patient demonstrate its recognition and support of patient rights.

No listing of patient rights can assure the respect of those rights. It is the intent of these standards that the organization's interaction with and care of the patient reflect concern and respect for the rights of the patient.

The organization's policies and procedures describe the mechanisms or processes established to support the following patient rights:

- Reasonable access to care;
- Considerate (and respectful) care that respects the patient's personal value and belief systems;
- Informed participation in decisions regarding his/her care;
- Participation in the consideration of ethical issues that arise in the provision of his or her care;
- Personal privacy and confidentiality of information;
- Designation of a representative decision maker in the event that the patient is incapable of understanding a proposed treatment or procedure or is unable to communicate his/her wishes regarding care.

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RI.1.1.1 [Organizational policies and procedures describe the mechanisms by which the following rights are protected and exercised:] The right of the patient to the hospital's reasonable response to his/her requests and needs for treatment or service, within the hospital's capacity, its stated mission, and applicable law and regulation;

Intent of RI.1.1.1

In response to the patient's request and need, the organization provides care that is within its capacity, its stated mission and philosophy, and applicable law and regulation. When the organization cannot meet the request or need for care because of a conflict with its mission or philosophy or incapacity to meet the patient's needs or requests, the patient may be transferred to another facility when medically permissible. Such a transfer is made only after the patient has received complete information and explanation concerning the need for and alternatives to such a transfer. The transfer must be acceptable to the receiving organization.

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RI.1.1.2 [Organizational policies and procedures describe the mechanisms by which the following rights are protected and exercised:] The right of the patient to considerate and respectful care;

RI1.1.2.1 The care of the patient includes consideration of the psychosocial, spiritual, and cultural variables that influence the perceptions of illness.

Intent of RI.1.1.2 and RI.1.1.2.1

The provision of patient care reflects consideration of the patient as an individual with personal values and a belief system that impact his/her attitude toward and response to the care provided by the organization. The organizational policies and procedures that guide patient care include recognition of the psychosocial, spiritual, and cultural values that affect the patient's response to the care given. Organizational policies and procedures allow the patient to express spiritual beliefs and cultural practices that do not harm others or interfere with the planned course of medical therapy for the patient.

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RI.1.1.2.2 The care of the dying patient optimizes the comfort and dignity of the patient through

RI.1.1.2.2.1 treating primary and secondary symptoms that respond to treatment as desired by the patient or surrogate decision maker;

RI.1.1.2.2.2 effectively managing pain; and

RI.1.1.2.2.3 acknowledging the psychosocial and spiritual concerns of the patient and the family regarding dying and the expression of grief by the patient and family.

NOTE: *The term dying is used to refer to an incurable and irreversible condition such that death is imminent. Imminent is seen as impending or about to happen.*

Intent of RI.1.1.2.2 Through RI.1.1.2.2.3

All hospital staff are sensitized to the needs of the dying patient in an acute care hospital. Support for the psychological, social, emotional, and spiritual needs of the patient and family demonstrates respect for the patient's values, religion, and philosophy. The goal of respectful, responsive care of the dying patient is to optimize the patient's comfort and dignity by providing appropriate treatment for primary and secondary symptoms as desired by the patient or surrogate decision maker, responding to the psychosocial, emotional, and spiritual concerns of the patient and family, and managing pain aggressively. (The management of pain is appropriate for all patients, not just dying patients. Guidelines such as those published by the Agency for Health Care Policy and Research for Acute Pain Management reflect the state of knowledge on effective and appropriate care for all patients experiencing acute pain.)

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RI.1.1.3 [Organizational policies and procedures describe the mechanisms by which the following rights are protected and exercised:]The right of the patient, in collaboration with his/her physician, to make decisions involving his/her health care, including

RI.1.1.3.1 the right of the patient to accept medical care or to refuse treatment to the extent permitted by law and to be informed of the medical consequences of such refusal, and

RI.1.1.3.2 the right of the patient to formulate advance directives and appoint a surrogate to make health care decisions on his/her behalf to the extent permitted by law.

RI.1.1.3.2.1 The organization has in place a mechanism to ascertain the existence of and assist in the development of advance directives at the time of the patient's admission.

RI.1.1.3.2.2 The provision of care is not conditioned on the existence of an advance directive.

RI.1.1.3.2.3 Any advance directive(s) is in the patient's medical record and is reviewed periodically with the patient or surrogate decision maker.

Intent of RI.1.1.3 Through RI.1.1.3.2.3

The quality of patient care is enhanced when the patient's preferences are incorporated into plans for care. The process by which care and treatment decisions are made elicit respect and incorporate the patient's preferences. Sound medical judgment is provided to the patient or the patient's surrogate decision maker for informed decision making.

In hospitals providing services to neonate, child, and adolescent patients, a mechanisms exists that is designed to coordinate and facilitate the family's and/or guardian's involvement in decision making throughout the course of treatment. The patient is responsible for providing, to the best of his/her knowledge, accurate and complete information about present complaints, past illnesses, hospitalizations, medications, advance directives, and other matters relevant to his/her health or care. The patient is also responsible for reporting whether he/she clearly comprehends a contemplated course of action and what is expected of him/her.

The hospital ascertains the existence of advance directives, and health care professionals and surrogate decision makers honor them within the limits of the law and the organization's mission and philosophy. An advance directive is a document a person uses to give directions about future medical care or to designate another person to give directions about medical care should he/she lose decision-making capacity. Advance directives may include living wills, durable powers of attorney, or similar documents and contain the patient's preferences.

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RI.1.1.4 [Organizational policies and procedures describe the mechanisms by which the following rights are protected and exercised:] The right of the patient to the information necessary to enable him/her to make treatment decisions that reflect his/her wishes;

RI.1.1.4.1 A policy on informed decision making is developed by the medical staff and governing body and is consistent with any legal requirements.

Intent of RI.1.1.4 and RI.1.1.4.1

The patient is given clear, concise explanation of his/her condition and of any proposed treatment(s) or procedure(s), the potential benefit(s) and the potential drawback(s) of the proposed treatment(s) or procedure(s), problems related to recuperation, and the likelihood of success. Information is also provided regarding any significant alternative treatment(s) or procedure(s).

This information includes the identity of the physician or other practitioner who has primary responsibility for the patient's care and the identity and professional status of individuals responsible for authorizing and performing procedures or treatments. The information also includes the existence of any professional relationship among individuals treating the patient, as well as the relationship to any other health care or educational institutions involved in his/her care.

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RI.1.1.5 [Organizational policies and procedures describe the mechanisms by which the following rights are protected and exercised:] The right of the patient to information, at the time of admission, about the hospital's

RI.1.1.5.1 patient rights policy(ies), and

RI.1.1.5.2 mechanism designed for the initiation, review, and, when possible, resolution of patient complaints concerning the quality of care;

Intent of RI.1.1.5 through RI.1.1.5.2

The organization assists the patient in exercising his/her rights by informing the patient of those rights during the admission process. The information is given to the patient or his/her representative in a form that is understandable to the patient (for example, in a language that is understood by the patient).

The patient has the right, without recrimination, to voice complaints regarding the care received, and to have those complaints reviewed and, when possible, resolved. This right, and the mechanism(s) established by the organization to assist the patient in exercising this right, are explained to the patient during the admission process.

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RI.1.1.6 [Organizational policies and procedures describe the mechanisms by which the following rights are protected and exercised:] The right of the patient or the patient's designated representative to participate in the consideration of ethical issues that arise in the care of the patient;

RI.1.1.6.1 The organization has in place a mechanism(s) for the consideration of ethical issues arising in the care of patients and to provide education to caregivers and patients on ethical issues in health care.

Intent of RI.1.1.6 and RI.1.1.6.1

Health care professionals provide patient care within an ethical framework established by their profession, the hospital, and the law. The health care professional has an obligation to respect the views of the patient or the patient's designated representative when ethical issues arise during the patient's care. Moreover, the hospital has an obligation to involve the patient or the patient's representative in the organizational mechanism for considering such issues. Such mechanisms may include community programs, education programs for patients or their representatives, and education programs for staff members. The hospital also has an obligation to provide education on important ethical issues in health care to caregivers, care recipients, and the community.

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RI.1.1.7 [Organizational policies and procedures describe the mechanisms by which the following rights are protected and exercised:] The right of the patient to be informed of any human experimentation or other research/educational projects affecting his/her care or treatment;

Intent of RI.1.1.7

The patient has the right to know of any experimental, research, or educational activities involved in his/her treatment: the patient also has the right to refuse to participate in any such activity.

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RI.1.1.8 [Organizational policies and procedures describe the mechanisms by which the following rights are protected and exercised:] The right of the patient, within the limits of law, to personal privacy and confidentiality of information; and

RI.1.1.8.1 The patient and/or the patient's legally designated representative has access to the information contained in the patient's medical record, within the limits of the law.

Intent of RI.1.1.8 and RI.1.1.8.1

The patient has the following rights:

- To be interviewed, examined, and treated in surroundings designed to give reasonable visual and auditory privacy;
- To have access to his/her medical record and to have his/her medical record read only by individuals directly involved in his/her care, or by individuals monitoring the quality of the patient's care, or by individuals authorized by law or regulation (other individuals may read the medical record only with the patient's written consent or that of a legally authorized or designated representative); and
- To request a transfer to a different room if another patient or a visitor in the room is unreasonably disturbing him/her and if another room equally suitable for his/her care needs is available.

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RI.1.1.9 [Organizational policies and procedures describe the mechanisms by which the following rights are protected and exercised:] The right of the patient's guardian, next of kin, or a legally authorized responsible person to exercise, to the extent permitted by law, the rights delineated on behalf of the patient if the patient has been adjudicated incompetent in accordance with the law, is found by his/her physician to be medically incapable of understanding the proposed treatment or procedure, is unable to communicate his/her wishes regarding treatment, or is a minor.

Intent of RI.1.1.9

Although the patient is recognized as having the right to participate in his/her care and treatment to the fullest extent possible, there are circumstances under which the patient may be unable to do so. In these situations, the patient's rights are to be exercised by the patient's designated representative or other legally authorized person.

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RI.2 There are hospital-wide policies on the withholding of resuscitative services from patients and the forgoing or withdrawing of life-sustaining treatment.

Intent of RI.2

No single set of policies can anticipate the varied situations in which the difficult decisions about withholding resuscitative services or forgoing or withdrawing life-sustaining treatment will need to be made. However, organizations can develop the framework for a decision-making process. Such a framework would include policies designed to assist the organization in identifying its position on the initiation of resuscitative services and the use and removal of life-sustaining treatment. Policies of this nature need to conform to the legal requirements of the organization's jurisdiction.

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RI.2.1 The policies are developed in consultation with the medical staff, nursing staff, and other appropriate bodies and are adopted by the medical staff and approved by the governing body.

Intent of RI.2.1

Organizational policies that provide a framework for the decision-making process for withholding resuscitative services or forgoing or withdrawing life-sustaining treatment offer guidance to health professionals on the ethical and legal issues involved in such decisions and decrease the uncertainty about the practices permitted by the organization. It is vital that the policies guiding such decisions be formally adopted by the organization's medical staff and approved by the governing body in order to assure that the process is consistent and that there is accountability for the decisions made.

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RI.2.2 The policies describe

RI.2.2.1 the mechanism(s) for reaching decisions about the withholding of resuscitative services from individual patients or forgoing or withdrawing of life-sustaining treatment;

RI.2.2.2 the mechanism(s) for resolving conflicts in decision making, should they arise; and

RI.2.2.3 the roles of physicians and, when applicable, of nursing personnel, other appropriate staff, and family members in decisions to withhold resuscitative services or forgo or withdraw life-sustaining treatment.

Intent of RI.2.2 through RI.2.2.3

Organizational policies regarding the withholding of resuscitative services or the forgoing or withdrawing of life-sustaining treatment outline a process for reaching such decisions. This process protects the decision-making rights of the patient or his/her designated representative; decreases staff uncertainty about practices permitted by the organization; clarifies the roles and duties, and therefore the accountability, of health professionals; and reduces arbitrary decision-making procedures.

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RI.2.3 The policies include provisions designed to assure that the rights of patients are respected.

Intent of RI.2.3

Organizational policies regarding the withholding of resuscitative services or the forgoing or withdrawing of life-sustaining treatment empower the patient or designated representative to make such decisions and assure that such decisions made by a patient or designated representative explicitly affirm the patient's responsibility for such decision making.

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RI.2.4 The policies include the requirement that appropriate orders be written by the physician primarily responsible for the patient and that documentation be made in the patient's medical record if life-sustaining treatment is to be withdrawn or resuscitative services are to be withheld.

Intent of RI.2.4

Decisions regarding the withholding of resuscitative services or the withdrawal of life-sustaining treatment are communicated to all health professionals involved in the patient's treatment to assure that the decision is implemented.

NOTE: This does not mean that for all deaths in which resuscitative services were not utilized there must be an order to withhold resuscitative services.

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RI.2.5 The policies address the use of advance directives in patient care to the extent permitted by law.

Intent of RI.2.5

The organization is expected to use any advance directives prepared by the patient and known to the organization in the decision-making process surrounding the consideration of the withholding of resuscitative services or the initiation or withdrawal of life-sustaining treatment, to the extent permitted by law and supported by the organization's mission and philosophy.

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SECTION II.

ETHICAL DIRECTIVES FOR THE PRACTICE OF MEDICINE

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1. Fourth century B.C.E.–Early twentieth century C.E.

Oath of Hippocrates (Fourth Century B.C.E.)
Oath of Initiation (Caraka Samhita) (First Century C.E.?)
Oath of Asaph (Third Century-Seventh Century C.E.?)
Advice to a Physician, Advice of Haly Abbas (Ahwazi) (Tenth Century C.E.)
The 17 Rules of Enjuin (For Disciples of Our School) (Sixteenth Century C.E.)
Five Commandments and Ten Requirements (1617)
A Physician's Ethical Duties from Kholasah al Hekmah (1770)
Daily Prayer of a Physician ("Prayer of Moses Maimonides") (1793?)
Code of Ethics, American Medical Association (1847)
Venezuelan Code of Medical Ethics, National Academy of Medicine (1918)

2. Mid-twentieth century–2003

Declaration of Geneva, World Medical Association (1948, amended 1968, 1983, 1994)
International Code of Medical Ethics, World Medical Association (1949, amended 1968, 1983))
Principles of Medical Ethics (1957), American Medical Association
Principles of Medical Ethics (2001), American Medical Association
Current Opinions of the Council on Ethical and Judicial Affairs, American Medical Association (2002)
Declaration of Professional Responsibility: Medicine's Social Contract with Humanity (2001), American Medical Association [2001]
Charter on Medical Professionalism (2002), American Board of Internal Medicine Foundation, Amercian College of Physicians—American Society of Internal Medicine Foundation, and European Foundation of Internal Medicine [2002]
The Moral and Technical Competence of the Ophthalmologist, American Academy of Ophthalmology (1995)
Code of Ethics, American Osteopathic Association (1998)
Code of Ethics and Guide to the Ethical Behaviour of Physicians, Canadian Medical Association (1996)
Code of Ethics and Guide to the Ethical Behaviour of Physicians, New Zealand Medical Association (2002)
Code of Ethics of the Chilean Medical Association, Chilean Medical Association (1983)
Code of Medical Ethics, Brazil, Federal Council of Medicine (1988)
European Code of Medical Ethics, Conférence Internationale des Ordres et des Organismes d' Attributions Similaires (1987)
Code of Ethics for Doctors, Norwegian Medical Association (amended 2000)
Final Report Concerning Brain Death and Organ Transplantation, Japan Medical Association (1988)
Summary of the Report on Information from Doctors and Consent of Patients, Japan Medical Association (1991)
Oath of Soviet Physicians (1971)
Solemn Oath of a Physician of Russia (1992)
Regulations on Criteria for Medical Ethics and Their Implementation, Ministry of Health, People's Republic of China (1988)
Ethical and Religious Directives for Catholic Health Facilities, United States Catholic Conference (1971, revised 2001)
Health Care Ethics Guide, Catholic Health Association of Canada (1991)
The Oath of a Muslim Physician, Islamic Medical Association of North America (1977)
Islamic Code of Medical Ethics, Kuwait Document, Islamic Organization for Medical Sciences (1981)

I. Fourth Century B.C.E.–Early Twentieth Century C.E.

The ethical directives for the practice of medicine included in this section are organized in two primary groups: (1) codes, oaths, prayers, and other directives from the fourth century B.C.E. through the early-twentieth century; and (2) directives from the mid-twentieth century through 2003. Documents in the first group are arranged in chronological order; those in the second group are arranged chronologically within thematic clusters, for example, by issuing body, area of the world, and philosophical or religious tradition.

Some of the documents in this section address not only physicians but also healthcare institutions and the health professions in general; they are included in this section because many medical ethics codes historically have applied not only to physicians but also to the practice of health care more generally. Ethical directives for medical specialties generally have not been included in this Appendix, due to space constraints.

OATH OF HIPPOCRATES

FOURTH CENTURY B.C.E.

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Attributed to Hippocrates, the oath, which exemplifies the Pythagorean school rather than Greek thought in general, differs from other, more scientific, writings in the Hippocratic corpus. Written later than some of the other treatises in the corpus, the Oath of Hippocrates is one of the earliest and most important statements on medical ethics. Not only has the oath provided the foundation for many succeeding medical oaths, such as the Declaration of Geneva, but it is still administered to the graduating students of many medical schools, either in its original form or in an altered version.

I swear by Apollo Physician and Asclepius and Hygieia and Panaceia and all the gods and goddesses, making them my witnesses, that I will fulfil according to my ability and judgment this oath and this covenant:

To hold him who has taught me this art as equal to my parents and to live my life in partnership with him, and if he is in need of money to give him a share of mine, and to regard his offspring as equal to my brothers in male lineage and to teach them this art—if they desire to learn it—without fee and covenant; to give a share of precepts and oral instruction and all the other learning to my sons and to the sons of him who has instructed me and to pupils who have signed the covenant and have taken an oath according to the medical law, but to no one else.

I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice.

I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect. Similarly I will not give to a woman an abortive remedy. In purity and holiness I will guard my life and my art.

I will not use the knife, not even on sufferers from stone, but will withdraw in favor of such men as are engaged in this work.

Whatever houses I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves.

What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about.

If I fulfil this oath and do not violate it, may it be granted to me to enjoy life and art, being honored with fame among all men for all time to come; if I transgress it and swear falsely, may the opposite of all this be my lot.

OATH OF INITIATION (CARAKA SAMHITA)

FIRST CENTURY C.E.?

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This ancient Indian oath for medical students appears in the Caraka Samhita (or, Charaka Samhita), a medical text written around the first century C.E. by the Indian physician Caraka. Unlike the Hippocratic Oath, which exemplifies only one, minority, school of ancient Greek thought, the Oath of the Caraka Samhita reflects concepts and beliefs found throughout ancient nonmedical Indian literature. The oath contains several uniquely Hindu elements, including the requirements to lead the life of a celibate, eat no meat, and carry no arms.

1. The teacher then should instruct the disciple in the presence of the sacred fire, Brahmanas [Brahmins] and physicians.
2. [saying] “Thou shalt lead the life of a celibate, grow thy hair and beard, speak only the truth, eat no meat, eat only pure articles of food, be free from envy and carry no arms.
3. There shall be nothing that thou should not do at my behest except hating the king, causing another’s

death, or committing an act of great unrighteousness or acts leading to calamity.

4. Thou shalt dedicate thyself to me and regard me as thy chief. Thou shalt be subject to me and conduct thyself for ever for my welfare and pleasure. Thou shalt serve and dwell with me like a son or a slave or a supplicant. Thou shalt behave and act without arrogance, with care and attention and with undistracted mind, humility, constant reflection and ungrudging obedience. Acting either at my behest or otherwise, thou shalt conduct thyself for the achievement of thy teacher's purposes alone, to the best of thy abilities.
5. If thou desirest success, wealth and fame as a physician and heaven after death, thou shalt pray for the welfare of all creatures beginning with the cows and Brahmanas.
6. Day and night, however thou mayest be engaged, thou shalt endeavour for the relief of patients with all thy heart and soul. Thou shalt not desert or injure thy patient for the sake of thy life or thy living. Thou shalt not commit adultery even in thought. Even so, thou shalt not covet others' possessions. Thou shalt be modest in thy attire and appearance. Thou shouldst not be a drunkard or a sinful man nor shouldst thou associate with the abettors of crimes. Thou shouldst speak words that are gentle, pure and righteous, pleasing, worthy, true, wholesome, and moderate. Thy behaviour must be in consideration of time and place and heedful of past experience. Thou shalt act always with a view to the acquisition of knowledge and fullness of equipment.
7. No persons, who are hated by the king or who are haters of the king or who are hated by the public or who are haters of the public, shall receive treatment. Similarly, those who are extremely abnormal, wicked, and of miserable character and conduct, those who have not vindicated their honour, those who are on the point of death, and similarly women who are unattended by their husbands or guardians shall not receive treatment.
8. No offering of presents by a woman without the behest of her husband or guardian shall be accepted by thee. While entering the patient's house, thou shalt be accompanied by a man who is known to the patient and who has his permission to enter; and thou shalt be well-clad, bent of head, self-possessed, and conduct thyself only after repeated consideration. Thou shalt thus properly make thy entry. Having entered, thy speech, mind, intellect and senses shall be entirely devoted to no other thought than that of being helpful to the patient and of things concerning only him. The peculiar customs of the patient's household shall not be made public. Even knowing that the patient's span of life has come to its close, it shall not be mentioned by thee there, where if so done, it would cause shock to the patient or to others.

   Though possessed of knowledge one should not boast very much of one's knowledge. Most people are offended by the boastfulness of even those who are otherwise good and authoritative.
9. There is no limit at all to the Science of Life, Medicine. So thou shouldst apply thyself to it with diligence. This is how thou shouldst act. Also thou shouldst learn the skill of practice from another without carping. The entire world is the teacher to the intelligent and the foe to the unintelligent. Hence, knowing this well, thou shouldst listen and act according to the words of instruction of even an unfriendly person, when his words are worthy and of a kind as to bring to you fame, long life, strength and prosperity."
10. Thereafter the teacher should say this—"Thou shouldst conduct thyself properly with the gods, sacred fire, Brahmanas, the guru, the aged, the scholars and the preceptors. If thou has conducted thyself well with them, the precious stones, the grains and the gods become well disposed towards thee. If thou shouldst conduct thyself otherwise, they become unfavorable to thee." To the teacher that has spoken thus, the disciple should say, "Amen."

OATH OF ASAPH

THIRD CENTURY–SEVENTH CENTURY C.E.?

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The Oath of Asaph appears at the end of the Book of Asaph the Physician (Sefer Asaph ha-Rofe), which is the oldest Hebrew medical text. It was written by Asaph Judaeus, also known as Asaph ben Berachyahu, a Hebrew physician from Syria or Mesopotamia, who lived sometime between the third and seventh centuries C.E., probably in the sixth century. The oath, which in part resembles the Oath of Hippocrates, was taken by medical students when they received their diplomas.

And this is the oath adminstered by Asaph, the son of Berachyahu, and by Jochanan, the son of Zabda, to their disciples; and they adjured them in these words: Take heed that ye kill not any man with the sap of a root; and ye shall not dispense a potion to a woman with child by adultery to cause her to miscarry; and ye shall not lust after beautiful women to commit adultery with them; and ye shall not disclose secrets confided unto you; and ye shall take no bribes to cause injury and to kill; and ye shall not harden your hearts against the poor and the needy, but heal them; and ye shall not call good evil or evil good; and ye shall not walk in the way of sorcerers to cast spells, to enchant and to bewitch with intent to separate a man from the wife of his bosom or woman from the husband of her youth.

And ye shall not covet wealth or bribes to abet depraved sexual commerce.

And ye shall not make use of any manner of idol-worship to heal thereby, nor trust in the healing powers of any form of their worship. But rather must ye abhor and detest and hate all their worshippers and those that trust in them and cause others to trust in them, for all of them are but vanity and of no avail, for they are naught; and they are demons. Their own carcasses they cannot save; how, then, shall they save the living?

And now, put your trust in the Lord your God, the God of truth, the living God, for He doth kill and make alive, smite and heal. He doth teach man understanding and also to do good. He smiteth in righteousness and justice and healeth in mercy and lovingkindness. No crafty device can be concealed from Him, for naught is hidden from His sight.

He causeth healing plants to grow and doth implant in the hearts of sages skill to heal by His manifold mercies and to declare marvels to the multitude, that all that live may know that He made them, and that beside Him there is none to save. For the peoples trust in their idols to succour them from their afflictions, but they will not save them in their distress, for their hope and their trust are in the Dead. Therefore it is fitting that ye keep apart from them and hold aloof from all the abominations of their idols and cleave unto the name of the Lord God of all flesh. And every living creature is in His hand to kill and to make alive; and there is none to deliver from His hand.

Be ye mindful of Him at all times and seek Him in truth uprightness and rectitude that ye may prosper in all that ye do; then He will cause you to prosper and ye shall be praised by all men. And the peoples will leave their gods and their idols and will yearn to serve the Lord even as ye do, for they will perceive that they have put their trust in a thing of naught and that their labour is in vain; (otherwise) when they cry unto the Lord, He will not save them.

As for you, be strong and let not your hands slacken, for there is a reward for your labours. God is with you when ye are with Him. If ye will keep His covenant and walk in His statutes to cleave unto them, ye shall be as saints in the sight of all men, and they shall say: “Happy is the people that is in such a case; happy is that people whose God is the Lord.”

And their disciples answered them and said: All that ye have instructed us and commanded us, that will we do, for it is a commandment of the Torah, and it behooves us to perform it with all our heart and all our soul and all our might: to do and to obey and to turn neither to the right nor to the left. And they blessed them in the name of the Highest God, the Lord of Heaven and earth.

And they admonished them yet again and said unto them: Behold, the Lord God and His saints and His Torah be witness unto you that ye shall fear Him, turning not aside from His commandments, but walking uprightly in His statutes. Incline not to covetousness and aid not the evildoers to shed innocent blood. Neither shall ye mix poisons for a man or a woman to slay his friend therewith; nor shall ye reveal which roots be poisonous or give them into the hand of any man, or be persuaded to do evil. Ye shall not cause the shedding of blood by any manner of medical treatment. Take heed that ye do not cause a malady to any man; and ye shall not cause any man injury by hastening to cut through flesh and blood with an iron instrument or by branding, but shall first observe twice and thrice and only then shall ye give your counsel.

Let not a spirit of haughtiness cause you to lift up your eyes and your hearts in pride. Wreak not the vengeance of hatred on a sick man; and alter not your prescriptions for them that do hate the Lord our God, but keep his ordinances and commandments and walk in all His ways that ye may find favour in His sight. Be ye pure and faithful and upright.

Thus did Asaph and Jochanan instruct and adjure their disciples.

ADVICE TO A PHYSICIAN

Advice of Haly Abbas (Ahwazi)

TENTH CENTURY C.E.

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A leading Persian figure in medicine and medical ethics, Haly Abbas (Ahwazi), who died in 994 C.E., devoted the first chapter of his work Liber Regius (Kamel Al Sanaah al Tibbia) to the ethics of medicine. An excerpt of his ethical admonition follows.

The first advice is to worship God and obey his commands; then be humble toward your teacher and endeavor to hold him in esteem, to serve and show gratitude to him, to hold him equally dear as you do your parents, and to share your possessions with him as with your parents.

Be kind to the children of your teachers and if one of them wants to study medicine you are to teach him without any remuneration.

You are to prohibit the unsuited and undeserving from studying medicine.

A physician is to prudently treat his patients with food and medicine out of good and spiritual motives, not for the sake of gain. He should never prescribe or use a harmful drug or abortifacient.

A physician should be chaste, pious, religious, well-spoken, and graceful, and must avoid any kind of sinfulness or impurity. He should not look upon women with lust and never go to their home except to visit a patient.

A physician should respect confidences and protect the patient's secrets. In protecting a patient's secrets, he must be more insistent than the patient himself. A physician should follow the Hippocratic counsels. He must be kind, compassionate, merciful and benevolent, and give himself unstintingly to the treatment of patients, especially the poor. He must never expect remuneration from the poor but rather provide them free medicine. If it is not impossible, he must visit them graciously whenever it is necessary, day or night, especially when they suffer from an acute disease, because the patient's condition changes very quickly with this kind of disease.

It is not proper for a physician to live luxuriously and become involved in pleasure-seeking. He must not drink alcohol because it injures the brain. He must study medical books constantly and never grow tired of research. He has to learn what he is studying and repeat and memorize what is necessary. He has to study in his youth because it is easier to memorize the subject at this age than in old age, which is the mother of oblivion.

A medical student should be constantly present in the hospital so as to study disease processes and complications under the learned professor and proficient physicians.

To be a learned and skillful physician, he has to follow this advice, develop an upright character and never hesitate to put this advice into practice so as to make his work effective, to win the patient's trust, and to receive the benefit of the patient's friendship and gratitude.

The Almighty God knows better than all.…

THE 17 RULES OF ENJUIN (FOR DISCIPLES OF OUR SCHOOL)

SIXTEENTH CENTURY C.E.

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The 17 Rules of Enjuin were developed for students by practitioners of the Ri-shu school, an approach to disease that was practiced in sixteenth-century Japan. The text reflects the priestly role of the physician and emphasizes the idea, also found in the Hippocratic Oath, that medical knowledge should not be disclosed outside of the school.

1. Each person should follow the path designated by Heaven (Buddha, the Gods).
2. You should always be kind to people. You should always be devoted to loving people.
3. The teaching of Medicine should be restricted to selected persons.
4. You should not tell others what you are taught, regarding treatments without permission.
5. You should not establish association with doctors who do not belong to this school.
6. All the successors and descendants of the disciples of this school shall follow the teachers' ways.
7. If any disciples cease the practice of Medicine, or, if successors are not found at the death of the disciple, all the medical books of this school should be returned to the School of Enjuin.
8. You should not kill living creatures, nor should you admire hunting or fishing.
9. In our school, teaching about poisons is prohibited, nor should you receive instructions about poisons from other physicians. Moreover, you should not give abortives to the people.
10. You should rescue even such patients as you dislike or hate. You should do virtuous acts, but in such a way that they do not become known to people. To do good deeds secretly is a mark of virtue.
11. You should not exhibit avarice and you must not strain to become famous. You should not rebuke or reprove a patient, even if he does not present you with money or goods in gratitude.
12. You should be delighted if, after treating a patient without success, the patient receives medicine from another physician, and is cured.
13. You should not speak ill of other physicians.
14. You should not tell what you have learned from the time you enter a woman's room, and, moreover, you should not have obscene or immoral feelings when examining a woman.

15. Proper or not, you should not tell others what you have learned in lectures, or what you have learned about prescribing medicine.
16. You should not like undue extravagance. If you like such living, your avarice will increase, and you will lose the ability to be kind to others.
17. If you do not keep the rules and regulations of this school, then you will be cancelled as a disciple. In more severe cases, the punishment will be greater.

FIVE COMMANDMENTS AND TEN REQUIREMENTS

1617

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The Five Commandments and Ten Requirements of physicians constitute the most comprehensive statement on medical ethics in China. They were written by Chen Shih-kung, an early-seventeenth-century Chinese physician, and appear in his work An Orthodox Manual of Surgery.

Five Commandments

1. Physicians should be ever ready to respond to any calls of patients, high or low, rich or poor. They should treat them equally and care not for financial reward. Thus their profession will become prosperous naturally day by day and conscience will remain intact.
2. Physicians may visit a lady, widow or nun only in the presence of an attendant but not alone. The secret diseases of female patients should be examined with a right attitude, and should not be revealed to anybody, not even to the physician's own wife.
3. Physicians should not ask patients to send pearl, amber or other valuable substances to their home for preparing medicament. If necessary, patients should be instructed how to mix the prescriptions themselves in order to avoid suspicion. It is also not proper to admire things which patients possess.
4. Physicians should not leave the office for excursion and drinking. Patients should be examined punctually and personally. Prescriptions should be made according to the medical formulary, otherwise a dispute may arise.
5. Prostitutes should be treated just like patients from a good family and gratuitous services should not be given to the poor ones. Mocking should not be indulged for this brings loss of dignity. After examination physicians should leave the house immediately. If the case improves, drugs may be sent but physicians should not visit them again for lewd reward.

Ten Requirements

1. A physician or surgeon must first know the principles of the learned. He must study all the ancient standard medical books ceaselessly day and night, and understand them thoroughly so that the principles enlighten his eyes and are impressed on his heart. Then he will not make any mistake in the clinic.
2. Drugs must be carefully selected and prepared according to the refining process of Lei Kung. Remedies should be prepared according to the pharmaceutical formulae but may be altered to suit the patient's condition. Decoctions and powders should be freely made. Pills and distilled medicine should be prepared in advance. The older the plaster is the more effective it will be. Tampons become more effective on standing. Don't spare valuable drugs; their use is eventually advantageous.
3. A physician should not be arrogant and insult other physicians in the same district. He should be modest and careful towards his colleagues; respect his seniors, help his juniors, learn from his superiors and yield to the arrogant. Thus there will be no slander and hatred. Harmony will be esteemed by all.
4. The managing of a family is just like the curing of a disease. If the constitution of a man is not well cared for and becomes over-exhausted, diseases will attack him. Mild ones will weaken his physique, while serious ones may result in death. Similarly, if the foundation of the family is not firmly established and extravagance be indulged in, reserves will gradually drain away and poverty will come.
5. Man receives his fate from Heaven. He should not be ungrateful to the Heavenly decree. Professional gains should be approved by the conscience and conform to the Heavenly will. If the gain is made according to the Heavenly will, natural affinity takes place. If not, offspring will be condemned. Is it not better to make light of professional gain in order to avoid the evil retribution?
6. Gifts, except in the case of weddings, funerals and for the consolation of the sick, should be simple. One dish of fish and one of vegetable will suffice for a meal. This is not only to reduce expenses but also

to save provisions. The virtue of a man lies not in grasping but rather in economy.

7. Medicine should be given free to the poor. Extra financial help should be extended to the destitute patients, if possible. Without food, medicine alone can not relieve the distress of a patient.
8. Savings should be invested in real estate but not in curios and unnecessary luxuries. The physician should also not join the drinking club and the gambling house which would hinder his practice. Hatred and slander can thus be avoided.
9. Office and dispensary should be fully equipped with necessary apparatus. The physician should improve his knowledge by studying medical books, old and new, and reading current publications. This really is the fundamental duty of a physician.
10. A physician should be ready to respond to the call of government officials with respect and sincerity. He should inform them of the cause of the disease and prescribe accordingly. After healing he should not seek for a complimentary tablet [a wooden board inscribed with complimentary words, hung in the physician's office for propaganda] or plead excuse for another's difficulty. A person who respects the law should not associate with officials.

A PHYSICIAN'S ETHICAL DUTIES

From Kholasah al Hekmah

1770

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In 1770 C.E.*, during Persia's Islamic era, Mohamad Hosin Aghili of Shiraz wrote the work Kholasah al Hekmah. The first chapter of that work contains a list of ethical duties for the physician, which are printed here in condensed form.*

1. A physician must not be conceited; he should know that the actual healer is God.
2. He should praise his teachers and professor and return thanks to them for their kindnesses.
3. He should never slander another physician. The fault of others should occasion the recognition of his own fault, not be the occasion for pride and conceit.
4. He must speak to patients with civility and good humor and never get angry at the misbehavior and insults of patients.
5. He must protect the patients' secrets and not betray them, especially to those the patients do not want to know.
6. In the case of the transmission of disease, the physician must not turn the second patient against the first.
7. He must be energetic in studying diseases and drugs and earnest in the diagnosis and treatment of a patient or disease.
8. He must never be tenacious in his opinion, and continue in his fault or mistake but, if it is possible, he is to consult with proficient physicians and ascertain the facts.
9. If someone mentions a useless or wrong idea, he must not turn it down definitely but say politely, "Maybe it is true in some cases but, in my opinion, in this case it is more probably such and such."
10. If a prior physician has a better knowledge of a patient or disease, he has to encourage the patient to return to the first physician.
11. If he is not successful in the treatment of a case or if he has found the patient did not have confidence in his work or that the patient would like to refer to another physician, it is better to offer an excuse and ask him to consult another physician.
12. He must not be prejudiced against any method of treatment and never continue any wrong practice.
13. In the treatment of disease, he must begin with simple medicine and not recommend any drug as long as the nature of the disease is resistant to it and it would not be effective.
14. If a patient has several diseases, first of all he has to cure the main disease which may be the cause of complications.
15. He should never recommend any kind of fatal, harmful or enfeebling drugs; he has to know that as a physician he has to do what is conducive to the patient's temperament, and temperament itself is an efficient corrector and protector of the body, not fatal or destructive.
16. He must not be proud of his class or his family and must not regard others with contempt.
17. He must not withhold medical knowledge; he should teach it to everyone in medicine without any discrimination between poor or rich, noble or slave.
18. He must not hold his students or his patients under his obligation.
19. He must be content, grateful, generous and magnanimous, and never be covetous, greedy, ravenous or jealous.
20. He must never covet another's property. If someone offers him a present while he himself is in need of it, he must not accept it.
21. He must never claim that he can cure an impoverished patient who has gone to many

physicians, and should not jeopardize his own reputation.

22. He should never be gluttonous and become involved in pleasure-seeking, buffoonery, drinking, and other sins.
23. He must not look upon women with lust but must look at them as he looks at his daughter, sister, or mother.

DAILY PRAYER OF A PHYSICIAN ("PRAYER OF MOSES MAIMONIDES")

1793?

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Although there is considerable debate about this prayer's true authorship, it was first attributed to Moses Maimonides, a twelfth-century Jewish physician in Egypt. Many now believe it was in fact authored by Marcus Herz, a German physician, pupil of Immanuel Kant, and physician to Moses Mendelssohn. The prayer first appeared in print in 1793 as "Tägliches Gebet eines Arztes bevor er seine Kranken besucht—Aus der hebräischen Handschrift eines berühmten jüdischen Arztes in Egypten aus dem zwölften Jahrhundert" ("Daily prayer of a physician before he visits his patients—From the Hebrew manuscript of a renowned Jewish physician in Egypt from the twelfth century"). The Prayer of Moses Maimonides and the Oath of Hippocrates are probably the best known of the older statements on medical ethics.

Almighty God, Thou has created the human body with infinite wisdom. Ten thousand times ten thousand organs hast Thou combined in it that act unceasingly and harmoniously to preserve the whole in all its beauty—the body which is the envelope of the immortal soul. They are ever acting in perfect order, agreement and accord. Yet, when the frailty of matter or the unbridling of passions deranges this order or interrupts this accord, then forces clash and the body crumbles into the primal dust from which it came. Thou sendest to man diseases as beneficent messengers to foretell approaching danger and to urge him to avert it.

Thou has blest Thine earth, Thy rivers and Thy mountains with healing substances; they enable Thy creatures to alleviate their sufferings and to heal their illnesses. Thou hast endowed man with the wisdom to relieve the suffering of his brother, to recognize his disorders, to extract the healing substances, to discover their powers and to prepare and to apply them to suit every ill. In Thine Eternal Providence Thou hast chosen me to watch over the life and health of Thy creatures. I am now about to apply myself to the duties of my profession. Support me, Almighty God, in these great labors that they may benefit mankind, for without Thy help not even the least thing will succeed.

Inspire me with love for my art and for Thy creatures. Do not allow thirst for profit, ambition for renown and admiration, to interfere with my profession, for these are the enemies of truth and of love for mankind and they can lead astray in the great task of attending to the welfare of Thy creatures. Preserve the strength of my body and of my soul that they ever be ready to cheerfully help and support rich and poor, good and bad, enemy as well as friend. In the sufferer let me see only the human being. Illumine my mind that it recognize what presents itself and that it may comprehend what is absent or hidden. Let it not fail to see what is visible, but do not permit it to arrogate to itself the power to see what cannot be seen, for delicate and indefinite are the bounds of the great art of caring for the lives and health of Thy creatures. Let me never be absent-minded. May no strange thoughts divert my attention at the bedside of the sick, or disturb my mind in its silent labors, for great and sacred are the thoughtful deliberations required to preserve the lives and health of Thy creatures.

Grant that my patients have confidence in me and my art and follow my directions and my counsel. Remove from their midst all charlatans and the whole host of officious relatives and know-all nurses, cruel people who arrogantly frustrate the wisest purposes of our art and often lead Thy creatures to their death.

Should those who are wiser than I wish to improve and instruct me, let my soul gratefully follow their guidance; for vast is the extent of our art. Should conceited fools, however, censure me, then let love for my profession steel me against them, so that I remain steadfast without regard for age, for reputation, or for honor, because surrender would bring to Thy creatures sickness and death.

Imbue my soul with gentleness and calmness when older colleagues, proud of their age, wish to displace me or to scorn me or disdainfully to teach me. May even this be of advantage to me, for they know many things of which I am ignorant, but let not their arrogance give me pain. For they are old and old age is not master of the passions. I also hope to attain old age upon this earth, before Thee, Almighty God!

Let me be contented in everything except in the great science of my profession. Never allow the thought to arise in me that I have attained to sufficient knowledge, but vouchsafe to me the strength, the leisure and the ambition ever to extend my knowledge. For art is great, but the mind of man is ever expanding.

Almighty God! Thou has chosen me in Thy mercy to watch over the life and death of Thy creatures. I now apply myself to my profession. Support me in this great task so that it may benefit mankind, for without Thy help not even the least thing will succeed.

CODE OF ETHICS

American Medical Association

1847

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The American Medical Association's (AMA) first code of ethics can be understood only in light of the work in medical ethics done by Thomas Percival, an eighteenth-century English physician. Percival wrote the first comprehensive modern statement of medical ethics in response to a request from the trustees of the Manchester Infirmary to draw up a "scheme of professional conduct relative to hospitals and other medical charities" that would resolve conflicts among infirmary physicians and prevent future conflicts. In 1794, after three years of writing and revising, Percival privately distributed a book titled Medical Ethics. Finally published in 1803, Percival's Medical Ethics served for many years as a model for the ethics codes of medical societies in both England and the United States.

When the AMA was founded in 1847, its first tasks were to establish standards for medical education and to formulate a code of ethics. Because most of the existing American codes of medical ethics relied heavily on Thomas Percival's work, the AMA followed suit, frequently preserving Percival's wording. The code of 1847, adopted by both the AMA and the New York Academy of Medicine, is excerpted below.

Chapter I. OF THE DUTIES OF PHYSICIANS TO THEIR PATIENTS, AND OF THE OBLIGATIONS OF PATIENTS TO THEIR PHYSICIANS

Art. I—*Duties of Physicians to Their Patients*

1. A physician should not only be ever ready to obey the calls of the sick, but his mind ought also to be imbued with the greatness of his mission, and of the responsibility he habitually incurs in its discharge. Those obligations are the more deep and enduring, because there is no tribunal other than his own conscience, to adjudge penalties for carelessness or neglect. Physicians should, therefore, minister to the sick with due impressions of the importance of their office; reflecting that the ease, the health, and the lives of those committed to their charge, depend on their skill, attention and fidelity. They should study, also, in their deportment, so to unite tenderness with firmness, and condescension with authority, as to inspire the minds of their patients with gratitude, respect and confidence.
2. Every case committed to the charge of a physician should be treated with attention, steadiness and humanity. Reasonable indulgence should be granted to the mental imbecility and caprices of the sick. Secrecy and delicacy, when required by peculiar circumstances, should be strictly observed; and the familiar and confidential intercourse to which physicians are admitted in their professional visits, should be used with discretion, and with the most scrupulous regard to fidelity and honor. The obligation of secrecy extends beyond the period of professional services;—none of the privacies of personal and domestic life, no infirmity of disposition or flaw of character observed during professional attendance, should ever be divulged by him except when he is imperatively required to do so. The force and necessity of this obligation are indeed so great, that professional men have, under certain circumstances, been protected in their observance of secrecy by courts of justice.
3. Frequent visits to the sick are in general requisite, since they enable the physician to arrive at a more perfect knowledge of the disease,—to meet promptly every change which may occur, and also tend to preserve the confidence of the patient. But unnecessary visits are to be avoided, as they give useless anxiety to the patient, tend to diminish the authority of the physician, and render him liable to be suspected of interested motives.
4. A physician should not be forward to make gloomy prognostications, because they savor of empiricism, by magnifying the importance of his services in the treatment or cure of the disease. But he should not fail, on proper occasions, to give to the friends of the patient timely notice of danger, when it really occurs; and even to the patient himself, if absolutely necessary. This office, however, is so peculiarly alarming when executed by him, that it ought to be declined whenever it can be assigned to any other person of sufficient judgment and delicacy. For, the physician should be the minister of hope and comfort to the sick; that, by such cordials to the drooping spirit, he may smooth the bed of death, revive expiring life, and counteract the depressing influence of those maladies which often disturb the tranquility of the most resigned, in their last moments. The life of a sick person can be shortened not only by the acts, but also by the words or the manner of a physician. It is, therefore, a sacred duty to guard himself carefully in this respect, and to avoid all things which have a tendency to discourage the patient and to depress his spirits.

5. A physician ought not to abandon a patient because the case is deemed incurable; for his attendance may continue to be highly useful to the patient, and comforting to the relatives around him, even to the last period of a fatal malady, by alleviating pain and other symptoms, and by soothing mental anguish. To decline attendance, under such circumstances, would be sacrificing to fanciful delicacy and mistaken liberality, that moral duty, which is independent of, and far superior to all pecuniary consideration.
6. Consultations should be promoted in difficult or protracted cases, as they give rise to confidence, energy, and more enlarged views in practice.
7. The opportunity which a physician not unfrequently enjoys of promoting and strengthening the good resolutions of his patients, suffering under the consequences of vicious conduct, ought never to be neglected. His counsels, or even remonstrances, will give satisfaction, not offence, if they be proffered with politeness, and evince a genuine love of virtue, accompanied by a sincere interest in the welfare of the person to whom they are addressed.

Art. II—*Obligations of Patients to their Physicians*

1. The members of the medical profession, upon whom are enjoined the performance of so many important and arduous duties towards the community, and who are required to make so many sacrifices of comfort, ease, and health, for the welfare of those who avail themselves of their services, certainly have a right to expect and require, that their patients should entertain a just sense of the duties which they owe to their medical attendants.
2. The first duty of a patient is, to select as his medical adviser one who has received a regular professional education. In no trade or occupation do mankind rely on the skill of an untaught artist; and in medicine, confessedly the most difficult and intricate of the sciences, the world ought not to suppose that knowledge is intuitive.
3. Patients should prefer a physician whose habits of life are regular, and who is not devoted to company, pleasure, or to any pursuit incompatible with his professional obligations. A patient should also confide the care of himself and family, as much as possible, to one physician, for a medical man who has become acquainted with the peculiarities of constitution, habits, and predispositions, of those he attends, is more likely to be successful in his treatment than one who does not possess that knowledge.

   A patient who has thus selected his physician, should always apply for advice in whatever may appear to him trivial cases, for the most fatal results often supervene on the slightest accidents. It is of still more importance that he should apply for assistance in the forming stage of violent diseases; it is to a neglect of this precept that medicine owes much of the uncertainty and imperfection with which it has been reproached.
4. Patients should faithfully and unreservedly communicate to their physician the supposed cause of their disease. This is the more important, as many diseases of a mental origin simulate those depending on external causes, and yet are only to be cured by ministering to the mind diseased. A patient should never be afraid of thus making his physician his friend and adviser; he should always bear in mind that a medical man is under the strongest obligations of secrecy. Even the female sex should never allow feelings of shame and delicacy to prevent their disclosing the seat, symptoms and causes of complaints peculiar to them. However commendable a modest reserve may be in the common occurrences of life, its strict observance in medicine is often attended with the most serious consequences, and a patient may sink under a painful and loathsome disease, which might have been readily prevented had timely intimation been given to the physician.
5. A patient should never weary his physician with a tedious detail of events or matters not appertaining to his disease. Even as relates to his actual symptoms, he will convey much more real information by giving clear answers to interrogatories, than by the most minute account of his own framing. Neither should he obtrude the details of his business nor the history of his family concerns.
6. The obedience of a patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them. A failure in one particular may render an otherwise judicious treatment dangerous, and even fatal. This remark is equally applicable to diet, drink, and exercise. As patients become convalescent, they are very apt to suppose that the rules prescribed for them may be disregarded, and the consequence, but too often, is a relapse. Patients should never allow themselves to be persuaded to take any medicine whatever, that may be recommended to them by the self-constituted doctors and doctoresses, who are so frequently met with, and who pretend to possess infallible remedies for the cure of every disease. However simple some of their prescriptions may

appear to be, it often happens that they are productive of much mischief, and in all cases they are injurious, by contravening the plan of treatment adopted by the physician.

7. A patient should, if possible, avoid even the friendly visits of a physician who is not attending him—and when he does receive them, he should never converse on the subject of his disease, as an observation may be made, without any intention of interference, which may destroy his confidence in the course he is pursuing, and induce him to neglect the directions prescribed to him. A patient should never send for a consulting physician without the express consent of his own medical attendant. It is of great importance that physicians should act in concert; for, although their modes of treatment may be attended with equal success when employed singly, yet conjointly they are very likely to be productive of disastrous results.
8. When a patient wishes to dismiss his physician, justice and common courtesy require that he should declare his reasons for so doing.
9. Patients should always, when practicable, send for their physician in the morning, before his usual hour of going out; for, by being early aware of the visits he has to pay during the day, the physician is able to apportion his time in such a manner as to prevent an interference of engagements. Patients should also avoid calling on their medical adviser unnecessarily during the hours devoted to meals or sleep. They should always be in readiness to receive the visits of their physician, as the detention of a few minutes is often of serious inconvenience to him.
10. A patient should, after his recovery, entertain a just and enduring sense of the value of the services rendered him by his physician; for these are of such a character, that no mere pecuniary acknowledgment can repay or cancel them.

Chapter II. OF THE DUTIES OF PHYSICIANS TO EACH OTHER AND TO THE PROFESSION AT LARGE

Art. I—*Duties for the support of professional character*

1. Every individual, on entering the profession, as he becomes thereby entitled to all its privileges and immunities, incurs an obligation to exert his best abilities to maintain its dignity and honor, to exalt its standing, and to extend the bounds of its usefulness. He should therefore observe strictly, such laws as are instituted for the government of its members;—should avoid all contumelious and sarcastic remarks relative to the faculty, as a body; and while, by unwearied diligence, he resorts to every honorable means of enriching the science, he should entertain a due respect for his seniors, who have, by their labors, brought it to the elevated condition in which he finds it.
2. There is no profession, from the members of which greater purity of character and a higher standard of moral excellence are required, than the medical; and to attain such eminence, is a duty every physician owes alike to his profession, and to his patients. It is due to the latter, as without it he cannot command their respect and confidence; and to both, because no scientific attainments can compensate for the want of correct moral principles. It is also incumbent upon the faculty to be temperate in all things, for the practice of physic requires the unremitting exercise of a clear and vigorous understanding; and, on emergencies for which no professional man should be unprepared, a steady hand, an acute eye, and an unclouded head, may be essential to the well-being, and even life, of a fellow creature.
3. It is derogatory to the dignity of the profession, to resort to public advertisements or private cards or handbills, inviting the attention of individuals affected with particular diseases—publicly offering advice and medicine to the poor gratis, or promising radical cures; or to publish cases and operations in the daily prints, or suffer such publications to be made;—to invite laymen to be present at operations—to boast of cures and remedies—to adduce certificates of skill and success, or to perform any other similar acts. These are the ordinary practices of empirics, and are highly reprehensible in a regular physician.
4. Equally derogatory to professional character is it, for a physician to hold a patient for any surgical instrument, or medicine; or to dispense a secret nostrum, whether it be the composition or exclusive property of himself or of others. For, if such nostrum be of real efficacy, any concealment regarding it is inconsistent with beneficence and professional liberality; and, if mystery alone give it value and importance, such craft implies either disgraceful ignorance, or fraudulent avarice. It is also reprehensible for physicians to give certificates attesting the efficacy of patent or secret medicines, or in any way to promote the use of them.

Art. II—*Professional services of Physicians to each other*

1. All practitioners of medicine, their wives, and their children while under the paternal care, are entitled to the gratuitous services of any one or more of the faculty residing near them, whose assistance may be desired. A physician afflicted with disease is usually

an incompetent judge of his own case; and the natural anxiety and solicitude which he experiences at the sickness of a wife, a child, or any one who by the ties of consanguinity is rendered peculiarly dear to him, tend to obscure his judgment, and produce timidity and irresolution in his practice. Under such circumstances, medical men are peculiarly dependent upon each other, and kind offices and professional aid should always be cheerfully and gratuitously afforded. Visits ought not, however, to be obtruded officiously; as such unasked civility may give rise to embarrassment, or interfere with that choice on which confidence depends. But, if a distant member of the faculty, whose circumstances are affluent, request attendance, and an honorarium be offered, it should not be declined; for no pecuniary obligation ought to be imposed, which the party receiving it would wish not to incur.

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Art. IV—*Of the duties of Physicians in regard to consultations*

1. A regular medical education furnishes the only presumptive evidence of professional abilities and acquirements, and ought to be the only acknowledged right of an individual to the exercise and honors of his profession. Nevertheless, as in consultations, the good of the patient is the sole object in view, and this is often dependent on personal confidence, no intelligent regular practitioner, who has a license to practice from some medical board of known and acknowledged respectability, recognised by this association, and who is in good moral and professional standing in the place in which he resides, should be fastidiously excluded from fellowship, or his aid refused in consultation when it is requested by the patient. But no one can be considered as a regular practitioner, or fit associate in consultation, whose practice is based on an exclusive dogma, to the rejection of the accumulated experience of the profession, and of the aids actually furnished by anatomy, physiology, pathology, and organic chemistry.
2. In consultations, no rivalship or jealousy should be indulged; candor, probity, and all due respect, should be exercised towards the physician having charge of the case.
3. In consultations, the attending physician should be the first to propose the necessary questions to the sick; after which the consulting physician should have the opportunity to make such farther inquiries of the patient as may be necessary to satisfy him of the true character of the case. Both physicians should then retire to a private place for deliberation; and the one first in attendance should communicate the directions agreed upon to the patient or his friends, as well as any opinions which it may be thought proper to express. But no statement or discussion of it should take place before the patient or his friends, except in the presence of all the faculty attending, and by their common consent; and no opinions or prognostications should be delivered, which are not the result of previous deliberation and concurrence.
4. In consultations, the physician in attendance should deliver his opinion first; and when there are several consulting, they should deliver their opinions in the order in which they have been called in. No decision, however, should restrain the attending physician from making such variations in the mode of treatment, as any subsequent unexpected change in the character of the case may demand. But such variation and the reasons for it ought to be carefully detailed at the next meeting in consultation. The same privilege belongs also to the consulting physician if he is sent for in an emergency, when the regular attendant is out of the way, and similar explanations must be made by him, at the next consultation.

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7. All discussions in consultation should be held as secret and confidential. Neither by words nor manner should any of the parties to a consultation assert or insinuate, that any part of the treatment pursued did not receive his assent. The responsibility must be equally divided between the medical attendants—they must equally share the credit of success as well as the blame of failure.
8. Should an irreconcilable diversity of opinion occur when several physicians are called upon to consult together, the opinion of the majority should be considered as decisive; but if the numbers be equal on each side, then the decision should rest with the attending physician. It may, moreover, sometimes happen, that two physicians cannot agree in their views of the nature of a case, and the treatment to be pursued. This is a circumstance much to be deplored, and should always be avoided, if possible, by mutual concessions, as far as they can be justified by a conscientious regard for the dictates of judgment. But in the event of its occurrence, a third physician should, if practicable, be called to act as umpire; and if circumstances prevent the adoption of this course, it must be left to the patient to select

the physician in whom he is most willing to confide. But as every physician relies upon the rectitude of his judgment, he should, when left in the minority, politely and consistently retire from any further deliberation in the consultation, or participation in the management of the case.

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10. A physician who is called upon to consult, should observe the most honorable and scrupulous regard for the character and standing of the practitioner in attendance: the practice of the latter, if necessary, should be justified as far as it can be, consistently with a conscientious regard for truth, and no hint or insinuation should be thrown out, which could impair the confidence reposed in him, or affect his reputation. The consulting physician should also carefully refrain from any of those extraordinary attentions or assiduities, which are too often practiced by the dishonest for the base purpose of gaining applause, or ingratiating themselves into the favor of families and individuals.

Art. V—*Duties of Physicians in cases of interference*

1. Medicine is a liberal profession, and those admitted into its ranks should found their expectations of practice upon the extent of their qualifications, not on intrigue or artifice.
2. A physician in his intercourse with a patient under the care of another practitioner, should observe the strictest caution and reserve. No meddling inquiries should be made; no disingenuous hints given relative to the nature and treatment of his disorder; nor any course of conduct pursued that may directly or indirectly tend to diminish the trust reposed in the physician employed.
3. The same circumspection and reserve should be observed, when, from motives of business or friendship, a physician is prompted to visit an individual who is under the direction of another practitioner. Indeed, such visits should be avoided, except under peculiar circumstances; and when they are made, no particular inquiries should be instituted relative to the nature of the disease, or the remedies employed, but the topics of conversation should be as foreign to the case as circumstances will admit.

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Art. VI—*Of differences between Physicians*

1. Diversity of opinion, and opposition of interest, may, in the medical, as in other professions, sometimes occasion controversy and even contention. Whenever such cases unfortunately occur, and cannot be immediately terminated, they should be referred to the arbitration of a sufficient number of physicians, or a court-medical.

   As peculiar reserve must be maintained by physicians towards the public, in regard to professional matters, and as there exist numerous points in medical ethics and etiquette through which the feelings of medical men may be painfully assailed in their intercourse with each other, and which cannot be understood or appreciated by general society, neither the subject-matter of such differences nor the adjudication of the arbitrators should be made public, as publicity in a case of this nature may be personally injurious to the individuals concerned, and can hardly fail to bring discredit on the faculty.

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Chapter III. OF THE DUTIES OF THE PROFESSION TO THE PUBLIC, AND OF THE OBLIGATIONS OF THE PUBLIC TO THE PROFESSION

Art. I—*Duties of the profession to the public*

1. As good citizens, it is the duty of physicians to be ever vigilant for the welfare of the community, and to bear their part in sustaining its institutions and burdens: they should also be ever ready to give counsel to the public in relation to matters especially appertaining to their profession, as on subjects of medical police, public hygiene, and legal medicine. It is their province to enlighten the public in regard to quarantine regulations,—the location, arrangement, and dietaries of hospitals, asylums, schools, prisons, and similar institutions,—in relation to the medical police of towns, as drainage, ventilation, &c.,—and in regard to measures for the prevention of epidemic and contagious diseases; and when pestilence prevails, it is their duty to face the danger, and to continue their labors for the alleviation of the suffering, even at the jeopardy of their own lives.
2. Medical men should also be always ready, when called on by the legally constituted authorities, to enlighten coroners' inquests and courts of justice, on subjects strictly medical,—such as involve questions relating to sanity, legitimacy, murder by poisons or other violent means, and in regard to the various other subjects embraced in the science of Medical Jurisprudence. But in these cases, and especially where they are required to make a post-mortem examination, it is just, in consequence of the time,

labor and skill required, and the responsibility and risk they incur, that the public should award them a proper honorarium.

3. There is no profession, by the members of which, eleemosynary services are more liberally dispensed, than the medical; but justice requires that some limits should be placed to the performance of such good offices. Poverty, professional brotherhood, and certain public duties referred to in section 1 of this chapter, should always be recognised as presenting valid claims for gratuitous services; but neither institutions endowed by the public or by rich individuals, societies for mutual benefit, for the insurance of lives or for analogous purposes, nor any profession or occupation, can be admitted to possess such privilege. Nor can it be justly expected of physicians to furnish certificates of inability to serve on juries, to perform militia duty, or to testify to the state of health of persons wishing to insure their lives, obtain pensions, or the like, without a pecuniary acknowledgment. But to individuals in indigent circumstances, such professional services should always be cheerfully and freely accorded.
4. It is the duty of physicians, who are frequent witnesses of the enormities committed by quackery, and the injury to health and even destruction of life caused by the use of quack medicines, to enlighten the public on these subjects, to expose the injuries sustained by the unwary from the devices and pretensions of artful empirics and impostors. Physicians ought to use all the influence which they may possess, as professors in Colleges of Pharmacy, and by exercising their option in regard to the shops to which their prescriptions shall be sent, to discourage druggists and apothecaries from vending quack or secret medicines, or from being in any way engaged in their manufacture and sale.

Art. II—*Obligations of the public to Physicians*

1. The benefits accruing to the public directly and indirectly from the active and unwearied beneficence of the profession, are so numerous and important, that physicians are justly entitled to the utmost consideration and respect from the community. The public ought likewise to entertain a just appreciation of medical qualifications;—to make a proper discrimination between true science and the assumption of ignorance and empiricism,—to afford every encouragement and facility for the acquisition of medical education,—and no longer to allow the statute books to exhibit the anomaly of exacting knowledge from physicians, under liability to heavy penalties, and of making them obnoxious to punishment for resorting to the only means of obtaining it.

VENEZUELAN CODE OF MEDICAL ETHICS

National Academy of Medicine

1918

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The Venezuelan Code, first promulgated by the National Academy of Medicine of Venezuela in 1918, was largely the work of Dr. Luis Razetti and for this reason is sometimes called the "Razetti Code." It served as a model for other Latin American codes of medical ethics (Colombia, 1919; Peru, 1922). The Sixth Latin American Medical Congress, meeting in Havana in 1922, recommended that the Venezuelan Code (slightly revised in 1922) serve to unify medical ethical concerns in Latin America. The First Brazilian Medical Congress, held in Rio de Janeiro in 1931, was similarly influenced by the Venezuelan Code.

The Venezuelan Code of 1918 includes many elements characteristic of the codes of its day, with heavy emphasis on the protection of the dignity of the profession, the maintenance of high standards of competence and training, duties toward patients (even regarding their health habits), the rendering of professional services to other doctors, obligations regarding substitute physicians and consultants, professional discipline, fees, and the like.

There are several interesting features in the Venezuelan Code that deserve comparison with other codes:

1. *The code insists that there are "rules of medical deontology" that apply to the entire "medical guild"—physicians, surgeons, pharmacists, dentists, obstetricians, interns, and nurses.*
2. *It places emphasis on physicians' virtues and qualities of character—circumspection, honesty, honor, good faith, respect, and so forth—that serve as a basis for those practices of etiquette that support the honorable practice of medicine.*
3. *The code prohibits abortion and premature childbirth (morally and legally), except "for a therapeutic purpose in cases indicated by medical science"; but it permits embryotomy if the mother's life is in danger and no alternative medical skills are available.*
4. *The excerpt below contains an interesting and detailed set of instructions on "medical confidentiality." It combines a strong affirmation of the moral obligation of health professionals to observe confidentiality with many attenuations of that obligation in the interests of the public welfare.*

Chapter IX. On Medical Confidentiality

Article 68. Medical confidentiality is a duty inherent in the very nature of the medical profession; the public interest, the personal security of the ill, the honor of families, respect for the physician, and the dignity of the art require confidentiality. Doctors, surgeons, dentists, pharmacists, and midwives as well as interns and nurses are morally obligated to safeguard privacy of information in everything they see, hear, or discover in the practice of their profession or outside of their services and which should not be divulged.

Article 69. Confidential information may be of two forms: that which is explicitly confidential—formal, documentary information confided by the client—and that which is implicitly confidential, which is private due to the nature of things, which nobody imposes, and which governs the relations of clients with medical professionals. Both forms are inviolable, except for legally specified cases.

Article 70. Medical professionals are prohibited from revealing professionally privileged information except in those cases established by medical ethics. A revelation is an act which causes the disclosed fact to change from a private to a publicly known fact. It is not necessary to publish such a fact to make it a revealed one: it suffices to confide it to a single person.

Article 71. Professionally confidential information belongs to the client. Professionals do not incur any responsibility if they reveal the private information received by them when they are authorized to do so by the patient in complete freedom and with a knowledge of the consequences by the person or persons who have confided in them, provided always that such revelation causes no harm to a third party.

Article 72. A medical person incurs no responsibility when he reveals private information in the following cases:

1. When in his capacity as a medical expert he acts as a physician for an insurance company giving it information concerning the health of the applicant sent to him for examination; or when he is commissioned by a proper authority to identify the physical or mental health of a person; or when he has been designated to perform autopsies or give medico–legal expert knowledge of any kind, as in civil or criminal cases; or when he acts as a doctor of public health or for the city; and in general when he performs the functions of a medical expert.
2. When the treating physician declares certain diseases infectious and contagious before a health authority; and when he issues death certificates.

In any of the cases included in (1), the medical professional may be exempt from the charge of ignoring the right of privacy of a person who is the object of his examination if said person is his client at the time or if the declaration has to do with previous conditions for which the same doctor was privately consulted.

Article 73. The physician shall preserve utmost secrecy if he happens to detect a venereal disease in a married woman. Not only should he refrain from informing her of the nature of the disease but he should be very careful not to let suspicion fall on the husband as responsible for the contagion. Consequently, he shall not issue any certification or make any disclosure even if the husband gives his consent.

Article 74. If a physician knows that one of his patients in a contagious period of a venereal disease plans to be married, he shall take pains to dissuade his patient from doing so, availing himself of all possible means. If the patient ignores his advice and insists on going ahead with his plan to marry, the physician is authorized without incurring responsibility not only to give the information the bride's family asks for, but also to prevent the marriage without the bridegroom's prior consultation or authorization.

Article 75. The doctor who knows that a healthy wet-nurse is nursing a syphilitic child should warn the child's parents that they are obligated to inform the nurse. If they refuse to do so, the doctor without naming the disease will impose on the nurse the necessity of immediately ceasing to nurse the child, and he should arrange to have her remain in the house for the time needed to make sure that she has not caught the disease. If the parents do not give their consent and insist that the wet-nurse continue to nurse the child, the doctor shall offer the necessary arguments, and if they nevertheless persist he shall inform the nurse of the risk she runs of contracting a contagious disease if she continues to nurse the child.

Article 76. The doctor can without failing in his duty denounce crimes of which he may have knowledge in the exercise of his profession, in accord with article 470 of the [Venezuelan] Penal Code.

Article 77. When it is a matter of making an accusation in court in order to avoid a legal violation the doctor is permitted to disclose private information.

Article 78. When a doctor is brought before a court as a witness to testify to certain facts known to him, he may refuse to disclose professionally private facts about which he is being interrogated, but which he considers privileged.

Article 79. When a doctor finds himself obliged to claim his fees legally, he should limit himself to stating the number of visits and consultations, specifying the days and nights, the number of operations he has performed, specifying the major and minor ones, the number of trips made outside the city to attend the patient, indicating the distance and time involved in travel in each visit, etc., but in no case should he reveal the nature of the operations performed, nor the details of the care that was given to the patient. The explanation of these circumstances, if necessary, shall be referred by the doctor to the medical experts so designated by the court.

Article 80. The doctor should not answer questions concerning the nature of his patient's disease; however, he is authorized not only to tell the prognosis of the case to those closest to the patient but also the diagnosis if on occasion he considers it necessary, in view of his professional responsibility or the best treatment of his patient.…

2. Mid-Twentieth Century–2003

DECLARATION OF GENEVA

World Medical Association

1948, AMENDED 1968, 1983, 1994

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The Declaration of Geneva was adopted by the second General Assembly of the World Medical Association (WMA) at Geneva in 1948, and subsequently amended by the twenty-second World Medical Assembly at Sydney in 1968, the thirty-fifth World Medical Assembly at Venice in 1983, and the 46th WMA Assembly at Stockholm in 1994. The declaration, which was one of the first and most important actions of the WMA, is a declaration of physicians' dedication to the humanitarian goals of medicine, a pledge that was especially important in view of the medical crimes that had just been committed in Nazi Germany. The Declaration of Geneva was intended to update the Oath of Hippocrates, which was no longer suited to modern conditions. Of interest is the fact that the WMA considered this short declaration to be a more significant statement of medical ethics than the succeeding International Code of Medical Ethics.

Only a few changes have been made in the declaration since 1948. In 1968, the phrase "even after the patient has died" was added to the confidentiality clause. In the 1983 version, which follows, the sentence regarding respect for human life was modified. Prior to 1983, it read, "I will maintain the utmost respect for human life from the time of conception.…" Finally, the 1994 version amended sexist language and added a broader range of impermissible categories of discrimination.

At the time of being admitted as a member of the medical profession:

I solemnly pledge myself to consecrate my life to the service of humanity;

I will give to my teachers the respect and gratitude which is their due;

I will practice my profession with conscience and dignity;

The health of my patient will be my first consideration;

I will respect the secrets which are confided in me, even after the patient has died;

I will maintain by all the means in my power, the honor and the noble traditions of the medical profession;

My colleagues will be my sisters and brothers;

I will not permit considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, or social standing to intervene between my duty and my patient;

I will maintain the utmost respect for human life from its beginning even under threat and I will not use my medical knowledge contrary to the laws of humanity;

I make these promises solemnly, freely and upon my honor.

INTERNATIONAL CODE OF MEDICAL ETHICS

World Medical Association

1949, AMENDED 1968, 1983

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The International Code of Medical Ethics was adopted by the third General Assembly of the World Medical Association (WMA) at London in 1949, and amended in 1968 by the twenty-second World Medical Assembly at Sydney and in 1983 by the thirty-fifth World Medical Assembly at Venice. The code, which was modeled after the Declaration of Geneva and the medical ethics codes of most modern countries, states the most general principles of ethical medical practice.

The original draft of the code included the statement, "Therapeutic abortion may only be performed if the conscience of the doctors and the national laws permit," which was deleted from the adopted version because of its controversial nature. In addition, the words "from conception" were deleted from the statement regarding the doctor's obligation to preserve human life.

The 1983 version of the code, which is still current, reflects several changes from the version originally adopted. There are numerous changes in language, for example, the phrase "A physician shall … " replaces "A doctor must.…" Substantive changes include the addition of the paragraphs on providing competent medical service; on honesty and exposing physicians deficient in character; and on respecting rights *and safeguarding confidences. Also, as in the Declaration of Geneva, the duty of confidentiality is extended to "even after the patient has died." Under practices deemed unethical, collaboration "in any form of medical service in which the doctor does not have professional independence" has been deleted, but the importance of professional independence is emphasized elsewhere in the text.*

Duties of Physicians in General

A physician shall always maintain the highest standards of professional conduct.

A physician shall not permit motives of profit to influence the free and independent exercise of professional judgement on behalf of patients.

A physician shall, in all types of medical practice, be dedicated to providing competent medical service in full technical and moral independence, with compassion and respect for human dignity.

A physician shall deal honestly with patients and colleagues, and strive to expose those physicians deficient in character or competence, or who engage in fraud or deception.

The following practices are deemed to be unethical conduct:

a) Self-advertising by physicians, unless permitted by the laws of the country and the Code of Ethics of the National Medical Association.
b) Paying or receiving any fee or any other consideration solely to procure the referral of a patient or for prescribing or referring a patient to any source.

A physician shall respect the rights of patients, of colleagues, and of other health professionals, and shall safeguard patient confidences.

A physician shall act only in the patient's interest when providing medical care which might have the effect of weakening the physical and mental condition of the patient.

A physician shall use great caution in divulging discoveries or new techniques or treatment through non-professional channels.

A physician shall certify only that which he has personally verified.

Duties of Physicians to the Sick

A physician shall always bear in mind the obligation of preserving human life.

A physician shall owe his patients complete loyalty and all the resources of his science. Whenever an examination or treatment is beyond the physician's capacity he should summon another physician who has the necessary ability.

A physician shall preserve absolute confidentiality on all he knows about his patient even after the patient has died.

A physician shall give emergency care as a humanitarian duty unless he is assured that others are willing and able to give such care.

Duties of Physicians to Each Other

A physician shall behave towards his colleagues as he would have them behave towards him.

A physician shall not entice patients from his colleagues.

A physician shall observe the principles of the "Declaration of Geneva" approved by the World Medical Association.

PRINCIPLES OF MEDICAL ETHICS (1957)

American Medical Association

1957

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Until 1957, the American Medical Association's (AMA) Code of Ethics was basically that adopted in 1847, although there were revisions in 1903, 1912, and 1947. A major change in the code's format occurred in 1957 when the Principles of Medical Ethics printed here were adopted. The ten principles, which replaced the forty-eight sections of the older code, were intended as expressions of the fundamental concepts and requirements of the older code, unencumbered by easily outdated practical codifications. Of note are the therapeutic-privilege exception to the confidentiality clause in Section 9—confidences may be disclosed if "necessary in order to protect the welfare of the individual"—and Section 10, which highlights the tension between physicians' duties to patients and those to society.

PREAMBLE. These principles are intended to aid physicians individually and collectively in maintaining a high level of ethical conduct. They are not laws but standards by which a physician may determine the propriety of his conduct in his relationship with patients, with colleagues, with members of allied professions, and with the public.

SECTION 1. The principal objective of the medical profession is to render service to humanity with full respect for the dignity of man. Physicians should merit the confidence of patients entrusted to their care, rendering to each a full measure of service and devotion.

SECTION 2. Physicians should strive continually to improve medical knowledge and skill, and should make available to their patients and colleagues the benefits of their professional attainments.

SECTION 3. A physician should practice a method of healing founded on a scientific basis; and he should not voluntarily associate professionally with anyone who violates this principle.

SECTION 4. The medical profession should safeguard the public and itself against physicians deficient in moral character or professional competence. Physicians should observe all laws, uphold the dignity and honor of the profession and accept its self-imposed disciplines. They should expose, without hesitation, illegal or unethical conduct of fellow members of the profession.

SECTION 5. A physician may choose whom he will serve. In an emergency, however, he should render service to the best of his ability. Having undertaken the care of a patient, he may not neglect him; and unless he has been discharged he may discontinue his services only after giving adequate notice. He should not solicit patients.

SECTION 6. A physician should not dispose of his services under terms or conditions which tend to interfere with or impair the free and complete exercise of his medical judgment and skill or tend to cause a deterioration of the quality of medical care.

SECTION 7. In the practice of medicine a physician should limit the source of his professional income to medical services actually rendered by him, or under his supervision, to his patients. His fee should be commensurate with the services rendered and the patient's ability to pay. He should neither pay nor receive a commission for referral of patients. Drugs, remedies or appliances may be dispensed or supplied by the physician provided it is in the best interests of the patient.

SECTION 8. A physician should seek consultation upon request; in doubtful or difficult cases; or whenever it appears that the quality of medical service may be enhanced thereby.

SECTION 9. A physician may not reveal the confidences entrusted to him in the course of medical attendance, or the deficiencies he may observe in the character of patients, unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the community.

SECTION 10. The honored ideals of the medical professional imply that the responsibilities of the physician extend not only to the individual, but also to society where these responsibilities deserve his interest and participation in activities which have the purpose of improving both the health and the well-being of the individual and the community.

PRINCIPLES OF MEDICAL ETHICS (2001)

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The AMA adopted a new set of principles in 2001. Two completely new principles were added to the 1980 principle, making nine the total number of principles. The two new principles reinforce the primacy of the physician's responsibility to the patient and also introduce the idea of a physician's commitment to health care access for all people.

The medical profession has long subscribed to a body of ethical statements developed primarily for the benefit of the patient. As a member of this profession, a physician must recognize responsibility to patients first and foremost, as well as to society, to other health professionals, and to self. The following Principles adopted by the American Medical Association are not laws, but standards of conduct which define the essentials of honorable behavior for the physician.

<http://www.ama-assn.org/ama/pub/category/2512.html>

Principles of Medical Ethics

I. A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights.

II. A physician shall uphold the standards of professionalism, be honest in all professional interactions, and strive to report physicians deficient in character or competence, or engaging in fraud or deception, to appropriate entities.

III. A physician shall respect the law and also recognize a responsibility to seek changes in those requirements which are contrary to the best interests of the patient.

IV. A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy within the constraints of the law.

V. A physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, make relevant information available to patients, colleagues, and the public, obtain consultation, and use the talents of other health professionals when indicated.

VI. A physician shall, in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical care.

VII. A physician shall recognize a responsibility to participate in activities contributing to the improvement of the community and the betterment of public health.

VIII. A physician shall, while caring for a patient, regard responsibility to the patient as paramount.

IX. A physician shall support access to medical care for all people.

Adopted June 1957; revised June 1980; revised June 2001

CURRENT OPINIONS OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS

American Medical Association

2002

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The 2002 revision of the Current Opinions of the Council on Ethical and Judicial Affairs, "reflects the application of the Principles of Medical Ethics to more than 175 specific ethical issues in medicine, including health care rationing, genetic testing, withdrawal of life-sustaining treatment, and family violence." A complete list of topics of the Current Opinions and the text of selected opinions follow; the annotations of court opinions and pertinent medical, ethical, and legal literature that follow many of the opinions are not included. (For full text opinions, go to www.ama-assn.org/ceja).

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2.00 · Opinions on Social Policy Issues

2.01 **ABORTION.** The Principles of Medical Ethics of the AMA do not prohibit a physician from performing an abortion in accordance with good medical practice and under circumstances that do not violate the law. (III, IV)

Issued prior to April 1977.

2.015 **MANDATORY PARENTAL CONSENT TO ABORTION.** Physicians should ascertain the law in their state on parental involvement to ensure that their procedures are consistent with their legal obligations.

Physicians should strongly encourage minors to discuss their pregnancy with their parents. Physicians should explain how parental involvement can be helpful and that parents are generally very understanding and supportive. If a minor expresses concerns about parental involvement, the physician should ensure that the minor's reluctance is not based on any misperceptions about the likely consequences of parental involvement.

Physicians should not feel or be compelled to require minors to involve their parents before deciding whether to undergo an abortion. The patient—even an adolescent—generally must decide whether, on balance, parental involvement is advisable. Accordingly, minors should ultimately be allowed to decide whether parental involvement is appropriate. Physicians should explain under what circumstances (e.g., life-threatening, emergency) the minor's confidentiality will need to be abrogated.

Physicians should try to ensure that minor patients have made an informed decision after giving careful consideration to the issues involved. They should encourage their minor patients to consult alternative sources if parents are not going to be involved in the abortion decision. Minors should be urged to seek the advice and counsel of those adults in whom they have confidence, including professional counselors, relatives, friends, teachers, or the clergy. (III, IV)

Issued June 1994 based on the report "Mandatory Parental Consent to Abortion," issued June 1992. (JAMA. 1993; 269: 82–86)

2.02 **ABUSE OF CHILDREN, ELDERLY PERSONS, AND OTHERS AT RISK.** The following are guidelines for detecting and treating family violence:

Due to the prevalence and medical consequences of family violence, physicians should routinely inquire about physical, sexual, and psychological abuse as part of the medical history. Physicians must also consider abuse in the differential diagnosis for a number of medical complaints, particularly when treating women.

Physicians who are likely to have the opportunity to detect abuse in the course of their work have an obligation to familiarize themselves with protocols for diagnosing and treating abuse and with community resources for battered women, children, and elderly persons.

Physicians also have a duty to be aware of societal misconceptions about abuse and prevent these from affecting the diagnosis and management of abuse. Such misconceptions include the belief that abuse is a rare occurrence; that abuse does not occur in "normal" families; that abuse is a private problem best resolved without outside interference; and that victims are responsible for the abuse.

In order to improve physician knowledge of family violence, physicians must be better trained to identify signs of abuse and to work cooperatively with the range of community services currently involved. Hospitals should require additional training for those physicians who are likely to see victims of abuse. Comprehensive training on family violence should be required in medical school curricula and in residency programs for specialties in which family violence is likely to be encountered.

The following are guidelines for the reporting of abuse:

> Laws that require the reporting of cases of suspected abuse of children and elderly persons often create a difficult dilemma for the physician. The parties involved, both the suspected offenders and the victims, will often plead with the physician that the matter be kept confidential and not be disclosed or reported for investigation by public authorities.
>
> Children who have been seriously injured, apparently by their parents, may nevertheless try to protect their parents by saying that the injuries were caused by an accident, such as a fall. The reason may stem from the natural parent-child relationship or fear of further punishment. Even institutionalized elderly patients who have been physically maltreated may be concerned that disclosure of what has occurred might lead to further and more drastic maltreatment by those responsible.
>
> The physician should comply with the laws requiring reporting of suspected cases of abuse of spouses, children, elderly persons, and others.
>
> Public officials concerned with the welfare of children and elderly persons have expressed the opinion that the incidence of physical violence to these persons is rapidly increasing and that a very substantial percentage of such cases is unreported by hospital personnel and physicians. A child or elderly person brought to a physician with a suspicious injury is the patient whose interests require the protection of law in a particular situation, even though the physician may also provide services from time to time to parents or other members of the family.
>
> The obligation to comply with statutory requirements is clearly stated in the Principles of Medical Ethics. Absent such legal requirement, for mentally competent, adult victims of abuse, physicians should not report to state authorities without the consent of the patient. Physicians, however, do have an ethical obligation to intervene. Actions should include, but would not be limited to: suggesting the possibility of abuse with the adult patient, discussing the safety mechanisms available to the adult patient (e.g., reporting to the police or appropriate state authority), making available to the adult patient a list of community and legal resources, providing ongoing support, and documenting the situation for future reference. Physicians must discuss possible interventions and the problem of family violence with adult patients in privacy and safety. (I, III)
>
> Issued December 1982.
>
> Updated June 1994 based on the report “Physicians and Family Violence: Ethical Considerations,” adopted December 1991 (JAMA. 1992; 267: 3190–93); updated June 1996; and updated June 2000 based on the report “Domestic Violence Intervention,” adopted June 1998.

2.03 **ALLOCATION OF LIMITED MEDICAL RESOURCES.** A physician has a duty to do all that he or she can for the benefit of the individual patient. Policies for allocating limited resources have the potential to limit the ability of physicians to fulfill this obligation to patients. Physicians have a responsibility to participate and to contribute their professional expertise in order to safeguard the interests of patients in decisions made at the societal level regarding the allocation or rationing of health resources.

Decisions regarding the allocation of limited medical resources among patients should consider only ethically appropriate criteria relating to medical need. These criteria include likelihood of benefit, urgency of need, change in quality of life, duration of benefit, and, in some cases, the amount of resources required for successful treatment. In general, only very substantial differences among patients are ethically relevant; the greater the disparities, the more justified the use of these criteria becomes. In making quality of life judgments, patients should first be prioritized so that death or extremely poor outcomes are avoided; then, patients should be prioritized according to change in quality of life, but only when there are very substantial differences among patients

Nonmedical criteria, such as ability to pay, age, social worth, perceived obstacles to treatment, patient contribution to illness, or past use of resources should not be considered.

Allocation decisions should respect the individuality of patients and the particulars of individual cases as much as possible. When very substantial differences do not exist among potential recipients of treatment on the basis of the appropriate criteria defined above, a “first-come-first-served” approach or some other equal opportunity mechanism should be employed to make final allocation decisions. Though there are several ethically acceptable strategies for- implementing these criteria, no single strategy is ethically mandated. Acceptable approaches include a three-tiered system, a minimal threshold approach, and a weighted formula. Decision-making mechanisms should be objective, flexible, and consistent to ensure that all patients are treated equally.

The treating physician must remain a patient advocate and therefore should not make allocation decisions. Patients denied access to resources have the right to be informed of the reasoning behind the decision. The allocation procedures of institutions controlling scarce resources should be disclosed to the public as well as subject to regular peer review from the medical profession. (1, VII)

Issued March 1981.

Updated June 1994 based on the report "Ethical Considerations in the Allocation of Organs and Other Scarce Medical Resources Among Patients," issued June 1993. (Archive of Internal Medicine 1995; 155: 29–40).

2.035 **FUTILE CARE.** Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients. Patients should not be given treatments simply because they demand them. Denial of treatment should be justified by reliance on openly stated ethical principles and acceptable standards of care, as defined in Opinion 2.03, "Allocation of Limited Medical Resources," and Opinion 2.095, "The Provision of Adequate Health Care," not on the concept of "futility," which cannot be meaningfully defined. (I, IV)

Issued June 1994.

2.06 **CAPITAL PUNISHMENT.** An individual's opinion on capital punishment is the personal moral decision of the individual. A physician, as a member of a profession dedicated to preserving life when there is hope of doing so, should not be a participant in a legally authorized execution. Physician participation in execution is defined generally as actions which would fall into one or more of the following categories: (1) an action which would directly cause the death of the condemned; (2) an action which would assist, supervise, or contribute to the ability of another individual to directly cause the death of the condemned; (3) an action which could automatically cause an execution to be carried out on a condemned prisoner.

Physician participation in an execution includes, but is not limited to, the following actions: prescribing or administering tranquilizers and other psychotropic agents and medications that are part of the execution procedure; monitoring vital signs on site or remotely (including monitoring electrocardiograms); attending or observing an execution as a physician; and rendering of technical advice regarding execution.

In the case where the method of execution is lethal injection, the following actions by the physician would also constitute physician participation in execution: selecting injection sites; starting intravenous lines as a port for a lethal injection device; prescribing, preparing, administering, or supervising injection drugs or their doses or types; inspecting, testing, or maintaining lethal injection devices; and consulting with or supervising lethal injection personnel.

The following actions do not constitute physician participation in execution: (1) testifying as to medical history and diagnoses or mental state as they relate to competence to stand trial, testifying as to relevant medical evidence during trial, testifying as to medical aspects of aggravating or mitigating circumstances during the penalty phase of a capital case, or testifying as to medical diagnoses as they relate to the legal assessment of competence for execution; (2) certifying death, provided that the condemned has been declared dead by another person; (3) witnessing an execution in a totally nonprofessional capacity; (4) witnessing an execution at the specific voluntary request of the condemned person, provided that the physician observes the execution in a nonprofessional capacity; and (5) relieving the acute suffering of a condemned person while awaiting execution, including providing tranquilizers at the specific voluntary request of the condemned person to help relieve pain or anxiety in anticipation of the execution.

Physicians should not determine legal competence to be executed. A physician's medical opinion should be merely one aspect of the information taken into account by a legal decision maker such as a judge or hearing officer. When a condemned prisoner has been declared incompetent to be executed, physicians should not treat the prisoner for the purpose of restoring competence unless a commutation order is issued before treatment begins. The task of re-evaluating the prisoner should be performed by an independent physician examiner. If the incompetent prisoner is undergoing extreme suffering as a result of psychosis or any other illness, medical intervention intended to mitigate the level of suffering is ethically permissible. No physician should be compelled to participate in the process of establishing a prisoner's competence or be involved with treatment of an incompetent, condemned prisoner if such activity is contrary to the physician's personal beliefs. Under those circumstances, physicians should be permitted to transfer care of the prisoner to another physician.

Organ donation by condemned prisoners is permissible only if (1) the decision to donate was made before the prisoner's conviction, (2) the donated tissue is harvested after the prisoner has been pronounced dead and the body removed from the death chamber, and (3) physicians do not provide advice on modifying the method of execution for any individual to facilitate donation. (I)

Issued July 1980.

Updated June 1994 based on the report "Physician Participation in Capital Punishment," adopted December 1992, (JAMA. 1993; 270: 365–368); updated June 1996 based on the report "Physician Participation in Capital Punishment: Evaluations of Prisoner Competence to be Executed; Treatment to Restore Competence to be Executed," adopted in June 1995; Updated December 1999; and Updated June 2000 based on the report "Defining Physician Participation in State Executions," adopted June 1998.

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2.077 **ETHICAL CONSIDERATIONS IN INTERNATIONAL RESEARCH.** Physicians, either in their role as investigators or as decision-makers involved in the deliberations related to the funding or the review of research, hold an ethical obligation to ensure the protection of research participants. When the research is to be conducted in countries with differing cultural traditions, health care systems, and ethical standards, and in particular in countries with developing economies and with limited health care resources, U.S. physicians should respect the following guidelines:

(1) First and foremost, physicians involved in clinical research that will be carried out internationally should be satisfied that a proposed research design has been developed according to a sound scientific design. Therefore, investigators must ascertain that there is genuine uncertainty within the clinical community about the comparative merits of the experimental treatment and the one to be offered as a control in the population among which the study is to be undertaken. In some instances, a three-pronged protocol, which offers the standard treatment in use in the U.S., a treatment that meets a level of care that is attainable and sustainable by the host country, and a placebo (see Opinion 2.075, "Surgical 'Placebo' Controls"), may be the best method to evaluate the safety and efficacy of a treatment in a given population. When U.S. investigators participate in international research they must obtain approval for such protocols from U.S. Institutional Review Boards (IRBs).

(2) IRBs, which are responsible for ensuring the protection of research participants, must determine that risks have been minimized and that the protocol's ratio of risks to benefits is favorable to participants. In evaluating the risks and benefits that a protocol presents to a population, IRBs should obtain relevant input from representatives from the host country and from the research population. It is also appropriate for IRBs to consider the harm that is likely to result from forgoing the research.

(3) Also, IRBs are required to protect the welfare of individual participants. This can best be achieved by assuring that a suitable informed consent process is in place. Therefore, IRBs should ensure that individual potential participants will be informed of the nature of the research endeavor and that their voluntary consent will be sought. IRBs should recognize that, in some instances, information will be meaningful only if it is communicated in ways that are consistent with local customs.

(4) Overall, to ensure that the research does not exploit the population from which participants are recruited, IRBs should ensure that the research corresponds to a medical need in the region where it is undertaken. Furthermore, they should foster research with the potential for lasting benefits, especially when it is undertaken among populations that are severely deficient in health care resources. This can be achieved by facilitating the development of a health care infrastructure that will be of use during and beyond the conduct of the research. Additionally, physicians conducting studies must encourage research sponsors to continue to provide beneficial study interventions to all study participants at the conclusion of the study. (I, IV, VII, VIII, IX)

Issued December 2001 based on the report "Ethical Considerations in International Research," adopted June 2001.

2.09 **COSTS.** While physicians should be conscious of costs and not provide or prescribe unnecessary services, concern for the quality of care the patient receives should be the physician's first consideration. This does not preclude the physician, individually or through medical or other organizations, from participating in policy-making with respect to social issues affecting health care. (I, VII)

Issued March 1981.

Updated June 1994 and June 1998.

2.095 THE PROVISION OF ADEQUATE HEALTH CARE. Because society has an obligation to make access to an adequate level of health care available to all of its members regardless of ability to pay, physicians should contribute their expertise at a policy-making level to help achieve this goal. In determining whether particular procedures or treatments should be included in the adequate level of health care, the following ethical principles should be considered: (1) degree of benefit (the difference in outcome between treatment and no treatment), (2) likelihood of benefit, (3) duration of benefit, (4) cost, and (5) number of people who will benefit (referring to the fact that a treatment may benefit the patient and others who come into contact with the patient, as with a vaccination or antimicrobial drug).

Ethical principles require that the ethical criteria be combined with a fair process to determine the adequate level of health care. Among the many possible alternative processes, the Council recommends the following two:

(1) Democratic decision making with broad public input at both the developmental and final approval stages can be used to develop the package of benefits. With this approach, enforcement of anti-discrimination laws will be necessary to ensure that the interests of minorities and historically disadvantaged groups are protected.

(2) Equal opportunity mechanisms can also be used to determine the package of health care benefits. After applying the five ethical criteria listed above, it will be possible to designate some kinds of care as either clearly basic or clearly discretionary. However, for care that is not clearly basic or discretionary, a random selection or other equal consideration mechanism may be used to determine which kinds of care will be included in the basic benefits package.

The mechanism for providing an adequate level of health care should ensure that the health care benefits for the poor and disadvantaged will not be eroded over time. There should also be ongoing monitoring for variations in care that cannot be explained on medical grounds with special attention to evidence of discriminatory impact on historically disadvantaged groups. Finally, adjustment of the adequate level over time should be made to ensure continued and broad public acceptance.

Issued June 1994 based on the report "Ethical Issues in Health System Reform: The Provision of Adequate Health Care," issued December 1993. (JAMA. 1994; 272)

2.10 FETAL RESEARCH GUIDELINES. The following guidelines are offered as aids to physicians when they are engaged in fetal research:

(1) Physicians may participate in fetal research when their activities are part of a competently designed program, under accepted standards of scientific research, to produce data which are scientifically valid and significant.

(2) If appropriate, properly performed clinical studies on animals and nongravid humans should precede any particular fetal research project.

(3) In fetal research projects, the investigator should demonstrate the same care and concern for the fetus as a physician providing fetal care or treatment in a non-research setting.

(4) All valid federal or state legal requirements should be followed.

(5) There should be no monetary payment to obtain any fetal material for fetal research projects.

(6) Competent peer review committees, review boards, or advisory boards should be available, when appropriate, to protect against the possible abuses that could arise in such research.

(7) Research on the so called "dead fetus," macerated fetal material, fetal cells, fetal tissue, or fetal organs should be in accord with state laws on autopsy and state laws on organ transplantation or anatomical gifts.

(8) In fetal research primarily for treatment of the fetus:
  A. Voluntary and informed consent, in writing, should be given by the gravid woman, acting in the best interest of the fetus.
  B. Alternative treatment or methods of care, if any, should be carefully evaluated and fully explained. If simpler and safer treatment is available, it should be pursued.

(9) In research primarily for treatment of the gravid female:
  A. Voluntary and informed consent, in writing, should be given by the patient.
  B. Alternative treatment or methods of care should be carefully evaluated and fully explained to the patient. If simpler and safer treatment is available, it should be pursued.
  C. If possible, the risk to the fetus should be the least possible, consistent with the gravid female's need for treatment.

(10) In fetal research involving a fetus in utero, primarily for the accumulation of scientific knowledge:

  A. Voluntary and informed consent, in writing, should be given by the gravid woman under circumstances in which a prudent and informed adult would reasonably be expected to give such consent.
  B. The risk to the fetus imposed by the research should be the least possible.
  C. The purpose of research is the production of data and knowledge which are scientifically significant and which cannot otherwise be obtained.
  D. In this area of research, it is especially important to emphasize that care and concern for the fetus should be demonstrated. (I, III, V)

Issued March 1980.

Updated June 1994.

2.11 **GENE THERAPY**. Gene therapy involves the replacement or modification of a genetic variant to restore or enhance cellular function or to improve the reaction of non-genetic therapies.

Two types of gene therapy have been identified: (1) somatic cell therapy, in which human cells other than germ cells are genetically altered, and (2) germ line therapy, in which a replacement gene is integrated into the genome of human gametes or their precursors, resulting in expression of the new gene in the patient's offspring and subsequent generations. The fundamental difference between germ line therapy and somatic cell therapy is that germ line therapy affects the welfare of subsequent generations and may be associated with increased risk and the potential for unpredictable and irreversible results. Because of the far-reaching implications of germ line therapy, it is appropriate to limit genetic intervention to somatic cells at this time.

The goal of both somatic cell and germ line therapy is to alleviate human suffering and disease by remedying disorders for which available therapies are not satisfactory. This goal should be pursued only within the ethical tradition of medicine, which gives primacy to the welfare of the patient whose safety and well-being must be vigorously protected. To the extent possible, experience with animal studies must be sufficient to assure the effectiveness and safety of the techniques used, and the predictability of the results.

Moreover, genetic manipulation generally should be utilized only for therapeutic purposes. Efforts to enhance "desirable" characteristics through the insertion of a modified or additional gene, or efforts to "improve" complex human traits"the eugenic development of offspring"are contrary not only to the ethical tradition of medicine, but also to the egalitarian values of our society. Because of the potential for abuse, genetic manipulation to affect non-disease traits may never be acceptable and perhaps should never be pursued. If it is ever allowed, at least three conditions would have to be met before it could be deemed ethically acceptable: (1) there would have to be a clear and meaningful benefit to the person, (2) there would have to be no trade-off with other characteristics or traits, and (3) all citizens would have to have equal access to the genetic technology, irrespective of income or other socioeconomic characteristics. These criteria should be viewed as a minimal, not an exhaustive, test of the ethical propriety of non-disease-related genetic intervention. As genetic technology and knowledge of the human genome develop further, additional guidelines may be required.

As gene therapy becomes feasible for a variety of human disorders, there are several practical factors to consider to ensure safe application of this technology in society. First, any gene therapy research should meet the Council's guidelines on clinical investigation (Opinion 2.07) and investigators must adhere to the standards of medical practice and professional responsibility. The proposed procedure must be fully discussed with the patient and the written informed consent of the patient or the patient's legal representative must be voluntary.

Investigators must be thorough in their attempts to eliminate any unwanted viral agents from the viral vector containing the corrective gene. The potential for adverse effects of the viral delivery system must be disclosed to the patient. The effectiveness of gene therapy must be evaluated fully, including the determination of the natural history of the disease and follow-up examination of subsequent generations. Gene therapy should be pursued only after the availablity or effectiveness of other possible therapies is found to be insufficient. These considerations should be reviewed, as appropriate, as procedures and scientific information develop. (I, V)

Issued December 1988.

Updated June 1994 based on the report "Prenatal Genetic Screening," adopted December 1992 (Arch Fam Med. 1994; 2: 633–642), and updated June 1996.

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2.147 **HUMAN CLONING.** "Somatic cell nuclear transfer" is the process in which the nucleus of a somatic cell of an organism is transferred into an enucleated oocyte. "Human cloning" is the application of somatic nuclear transfer technology to the creation of a human being that shares all of its nuclear genes with the person donating the implanted nucleus.

In order to clarify the many existing misconceptions about human cloning, physicians should help educate the public about the intrinsic limits of human cloning as well as the current ethical and legal protections that would prevent abuses of human cloning. These include the following: (1) using human cloning as an approach to terminal illness or mortality is a concept based on the mistaken notion that one's genotype largely determines one's individuality. A clone-child created via human cloning would not be identical to his or her clone-parent. (2) Current ethical and legal standards hold that under no circumstances should human cloning occur without an individual's permission. (3) Current ethical and legal standards hold that a human clone would be entitled to the same rights, freedoms, and protections as every other individual in society. The fact that a human clone's nuclear genes would derive from a single individual rather than two parents would not change his or her moral standing.

Physicians have an ethical obligation to consider the harms and benefits of new medical procedures and technologies. Physicians should not participate in human cloning at this time because further investigation and discussion regarding the harms and benefits of human cloning is required. Concerns include: (1) unknown physical harms introduced by cloning. Somatic cell nuclear transfer has not yet been refined and its long-term safety has not yet been proven. The risk of producing individuals with genetic anomalies gives rise to an obligation to seek better understanding of—and potential medical therapies for—the unforeseen medical consequences that could stem from human cloning. (2) Psychosocial harms introduced by cloning, including violations of privacy and autonomy. Human cloning risks limiting, at least psychologically, the seemingly unlimited potential of new human beings and thus creating enormous pressures on the clone-child to live up to expectations based on the life of the clone-parent. (3) The impact of human cloning on familial and societal relations. The family unit may be altered with the introduction of cloning, and more thought is required on a societal level regarding how to construct familial relations. (4) Potential effects on the gene pool. Like other interventions that can change individuals' reproductive patterns and the resulting genetic characteristics of a population, human cloning has the potential to be used in a eugenic or discriminatory fashion—practices that are incompatible with the ethical norms of medical practice. Moreover, human cloning could alter irreversibly the gene pool and exacerbate genetic problems that arise from deleterious genetic mutations, resulting in harms to future generations.

Two potentially realistic and possibly appropriate medical uses of human cloning are for assisting individuals or couples to reproduce and for the generation of tissues when the donor is not harmed or sacrificed. Given the unresolved issues regarding cloning identified above, the medical profession should not undertake human cloning at this time and pursue alternative approaches that raise fewer ethical concerns.

Because cloning technology is not limited to the United States, physicians should help establish international guidelines governing human cloning. (V)

Issued December 1999 based of the report "The Ethics of Human Cloning," adopted June 1999.

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2.17 **QUALITY OF LIFE.** In the making of decisions for the treatment of seriously disabled newborns or of other persons who are severely disabled by injury or illness, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life, as defined by the patient's interests and values, is a factor to be considered in determining what is best for the individual. It is permissible to consider quality of life when deciding about life-sustaining treatment in accordance with opinions 2.20, 2.215, and 2.22 (I, III, IV)

Issued March 1981.

Updated June 1994.

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2.19 **UNNECESSARY SERVICES.** Physicians should not provide, prescribe, or seek compensation for services that are known to be unnecessary. (II, VII)

Issued prior to April 1977.

Updated June 1996.

2.20 **WITHHOLDING OR WITHDRAWING LIFE-SUSTAINING MEDICAL TREATMENT.** The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail. The principle of patient autonomy requires that physicians respect the decision to forego life-sustaining treatment of a patient who possesses decision-making capacity. Life-sustaining treatment is any treatment that serves to prolong life without reversing the underlying medical condition. Life-sustaining treatment may include, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration.

There is no ethical distinction between withdrawing and withholding life-sustaining treatment.

A competent, adult patient may, in advance, formulate and provide a valid consent to the withholding or withdrawal of life-support systems in the event that injury or illness renders that individual incompetent to make such a decision. A patient may also appoint a surrogate decision maker in accordance with state law.

If the patient receiving life-sustaining treatment is incompetent, a surrogate decision maker should be identified. Without an advance directive that designates a proxy, the patient's family should become the surrogate decision maker. Family includes persons with whom the patient is closely associated. In the case when there is no person closely associated with the patient, but there are persons who both care about the patient and have sufficient relevant knowledge of the patient, such persons may be appropriate surrogates. Physicians should provide all relevant medical information and explain to surrogate decision makers that decisions regarding withholding or withdrawing life-sustaining treatment should be based on substituted judgment (what the patient would have decided) when there is evidence of the patient's preferences and values. In making a substituted judgment, decision makers may consider the patient's advance directive (if any); the patient's values about life and the way it should be lived; and the patient's attitudes towards sickness, suffering, medical procedures, and death. If there is not adequate evidence of the incompetent patient's preferences and values, the decision should be based on the best interests of the patient (what outcome would most likely promote the patient's well-being).

Though the surrogate's decision for the incompetent patient should almost always be accepted by the physician, there are four situations that may require either institutional or judicial review and/or intervention in the decision-making process: (1) there is no available family member willing to be the patient's surrogate decision maker, (2) there is a dispute among family members and there is no decision maker designated in an advance directive, (3) a health care provider believes that the family's decision is clearly not what the patient would have decided if competent, and (4) a health care provider believes that the decision is not a decision that could reasonably be judged to be in the patient's best interests. When there are disputes among family members or between family and health care providers, the use of ethics committees specifically designed to facilitate sound decision making is recommended before resorting to the courts.

When a permanently unconscious patient was never competent or had not left any evidence of previous preferences or values, since there is no objective way to ascertain the best interests of the patient, the surrogate's decision should not be challenged as long as the decision is based on the decision maker's true concern for what would be best for the patient.

Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care. This includes providing effective palliative treatment even though it may foreseeably hasten death.

Even if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or best interests analysis. (I, III, IV, V)

Issued December 1984 as Opinion 2.18, Withholding or Withdrawing Life-Prolonging Medical Treatment, and Opinion 2.19, Withholding or Withdrawing Life-Prolonging Medical Treatment—Patients' Preferences. In 1989, these Opinions were renumbered 2.20 and 2.21, respectively.

Updated June 1994 based on the reports "Decisions Near the End of Life" and "Decisions to Forego Life-Sustaining Treatment for Incompetent Patients," both adopted June 1991 (Decisions Near the End of Life. JAMA. 1992; 267: 2229–2233), and updated June 1996. [In March 1981, the Council on Ethical and Judicial Affairs issued Opinion 2.11, Terminal Illness. The Opinion was renumbered 2.15 in 1984 and was deleted in 1986.]

2.21 **EUTHANASIA.** Euthanasia is the administration of a lethal agent by another person to a patient for the purpose of relieving the patient's intolerable and incurable suffering.

It is understandable, though tragic, that some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life. However, permitting physicians to engage in euthanasia would ultimately cause more harm than good. Euthanasia is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks.

The involvement of physicians in euthanasia heightens the significance of its ethical prohibition. The physician who performs euthanasia assumes unique responsibility for the act of ending the patient's life. Euthanasia could also readily be extended to incompetent patients and other vulnerable populations.

Instead of engaging in euthanasia, physicians must aggressively respond to the needs of patients at the end of life. Patients should not be abandoned once it is determined that cure is impossible. Patients near the end of life must continue to receive emotional support, comfort care, adequate pain control, respect for patient autonomy, and good communication. (I, IV)

Issued June 1994 based on the report "Decisions Near the End of Life," adopted June 1991 (JAMA. 1992; 267: 2229–2233).

Updated June 1996.

2.211 **PHYSICIAN ASSISTED SUICIDE**. Physician-assisted suicide occurs when a physician facilitates a patient's death by providing the necessary means and/or information to enable the patient to perform the life-ending act (e.g., the physician provides sleeping pills and information about the lethal dose, while aware that the patient may commit suicide).

It is understandable, though tragic, that some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life. However, allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks.

Instead of participating in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Patients should not be abandoned once it is determined that cure is impossible. Multidisciplinary interventions should be sought including specialty consultation, hospice care, pastoral support, family counseling, and other modalities. Patients near the end of life must continue to receive emotional support, comfort care, adequate pain control, respect for patient autonomy, and good communication. (I, IV)

Issued June 1994 based on the reports "Decisions Near the End of Life," adopted June 1991, and "Physician-Assisted Suicide," adopted December 1993 (JAMA. 1992; 267: 2229–33).

Updated June 1996.

2.215 **TREATMENT DECISIONS FOR SERIOUSLY ILL NEWBORNS**. The primary consideration for decisions regarding life-sustaining treatment for seriously ill newborns should be what is best for the newborn. Factors that should be weighed are (1) the chance that therapy will succeed, (2) the risks involved with treatment and nontreatment, (3) the degree to which the therapy, if successful, will extend life, (4) the pain and discomfort associated with the therapy, and (5) the anticipated quality of life for the newborn with and without treatment.

Care must be taken to evaluate the newborn's expected quality of life from the child's perspective. Life-sustaining treatment may be withheld or withdrawn from a newborn when the pain and suffering expected to be endured by the child will overwhelm any potential for joy during his or her life. When an infant suffers extreme neurological damage, and is consequently not capable of experiencing either suffering or joy a decision may be made to withhold or withdraw life-sustaining treatment. When life-sustaining treatment is withheld or withdrawn, comfort care must not be discontinued.

When an infant's prognosis is largely uncertain, as is often the case with extremely premature newborns, all life-sustaining and life-enhancing treatment should be initiated. Decisions about life-sustaining treatment should be made once the prognosis becomes more certain. It is not necessary to attain absolute or near absolute prognostic certainty before life-sustaining treatment is withdrawn, since this goal is often unattainable and risks unnecessarily prolonging the infant's suffering.

Physicians must provide full information to parents of seriously ill newborns regarding the nature of treatments, therapeutic options and expected prognosis with and without therapy, so that parents can make informed decisions for their children about life-sustaining treatment. Counseling services and an opportunity to talk with persons who have had to make similar decisions should be available to parents. Ethics committees or infant review committees should also be utilized to facilitate parental decisionmaking. These committees should help mediate resolutions of conflicts that may arise among parents, physicians and others involved in the care of the infant. These committees should also be responsible for referring cases to the appropriate public agencies when it is concluded that the parents' decision is not a decision that could reasonably be judged to be in the best interests of the infant. (I, III, IV, V)

Issued June 1994 based on the report "Treatment Decisions for Seriously Ill Newborns," issued June 1992.

2.22 **DO-NOT-RESUSCITATE ORDERS.** Efforts should be made to resuscitate patients who suffer cardiac or respiratory arrest except when circumstances indicate that cardiopulmonary resuscitation (CPR) would be inappropriate or not in accord with the desires or best interests of the patient.

Patients at risk of cardiac or respiratory failure should be encouraged to express in advance their preferences regarding the use of CPR and this should be documented in the patient's medical record. These discussions should include a description of the procedures encompassed by CPR and, when possible, should occur in an outpatient setting when general treatment preferences are discussed, or as early as possible during hospitalization. The physician has an ethical obligation to honor the resuscitation preferences expressed by the patient. Physicians should not permit their personal value judgments about qualify of life to obstruct the implementation of a patient's preferences regarding the use of CPR.

If a patient is incapable of rendering a decision regarding the use of CPR, a decision may be made by a surrogate decisionmaker, based upon the previously expressed preferences of the patient or, if such preferences are unknown, in accordance with the patient's best interests.

If, in the judgment of the attending physician, it would be inappropriate to pursue CPR, the attending physician may enter a do-not-resuscitate order into the patient's record. Resuscitative efforts should be considered inappropriate by the attending physician only if they cannot be expected either to restore cardiac or respiratory function to the patient or to meet established ethical criteria, as defined in the Principles of Medical Ethics and Opinions 2.03 and 2.095. When there is adequate time to do so, the physician must first inform the patient, or the incompetent patient's surrogate, of the content of the DNR order, as well as the basis for its implementation. The physician also should be prepared to discuss appropriate alternatives, such as obtaining a second opinion (e.g., consulting a bioethics committee) or arranging for transfer of care to another physician.

Do-Not-Resuscitate orders, as well as the basis for their implementation, should be entered by the attending physician in the patient's medical record.

DNR orders only preclude resuscitative efforts in the event of cardiopulmonary arrest and should not influence other therapeutic interventions that may be appropriate for the patient. (I, IV)

Issued March 1992 based on the report "Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders," issued December 1990. (JAMA. 1991; 265: 1868–1871)

Updated June 1994.

2.23 **HIV TESTING.** HIV testing is appropriate and should be encouraged for diagnosis and treatment of HIV infection or of medical conditions that may be affected by HIV. Treatment may prolong the lives of those with AIDS and prolong the symptom-free period in those with an asymptomatic HIV infection. Wider testing is imperative to ensure that individuals in need of treatment are identified and treated.

Physicians should ensure that HIV testing is conducted in a way that respects patient autonomy and assures patient confidentiality as much as possible.

The physician should secure the patient's informed consent specific for HIV testing before testing is performed. Because of the need for pretest counseling and the potential consequences of an HIV test on an individual's job, housing, insurability, and social relationships, the consent should be specific for HIV testing. Consent for HIV testing cannot be inferred from a general consent to treatment.

When a health care provider is at risk for HIV infection because of the occurrence of puncture injury or mucosal contact with potentially infected bodily fluids, it is acceptable to test the patient for HIV infection even if the patient refuses consent. When testing without consent is performed in accordance with the law, the patient should be given the customary pretest counseling.

The confidentiality of the results of HIV testing must be maintained as much as possible and the limits of a patient's confidentiality should be known to the patient before consent is given.

Exceptions to confidentiality are appropriate when necessary to protect the public health or when necessary to protect individuals, including health care workers, who are endangered by persons infected with HIV. If a physician knows that a seropositive individual is endangering a third party, the physician should, within the constraints of the law, (1) attempt to persuade the infected patient to cease endangering the third party; (2) if persuasion fails, notify authorities; and (3) if the authorities take no action, notify the endangered third party.

In order to limit the public spread of HIV infection, physicians should encourage voluntary testing of patients at risk for infection.

It is unethical to deny treatment to HIV-infected individuals because they are HIV seropositive or because they are unwilling to undergo HIV testing, except in the instance where knowledge of the patient's HIV status is vital to the appropriate treatment of the patient. When a patient refuses to be tested after being informed of the physician's medical opinion, the physician may transfer the patient to a second physician who is willing to manage the patient's care in accordance with the patient's preferences about testing. (I, IV)

Issued March 1992 based on the report "Ethical Issues Involved in the Growing AIDS Crisis," issued December 1987. (JAMA. 1988; 259: 1360–1361)

Updated June 1994.

3.00 · Opinions on Interprofessional Relations

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3.02 **NURSES.** The primary bond between the practices of medicine and nursing is mutual ethical concern for patients. One of the duties in providing reasonable care is fulfilled by a nurse who carries out the orders of the attending physician. Where orders appear to the nurse to be in error or contrary to customary medical and nursing practice, the physician has an ethical obligation to hear the nurse's concern and explain those orders to the nurse involved. The ethical physician should neither expect nor insist that nurses follow orders contrary to standards of good medical and nursing practice. In emergencies, when prompt action is necessary and the physician is not immediately available, a nurse may be justified in acting contrary to the physician's standing orders for the safety of the patient. Such occurrences should not be considered to be a breakdown in professional relations. (IV, V)

Issued June 1983

Updated June 1994.

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3.08 **SEXUAL HARASSMENT AND EXPLOITATION BETWEEN MEDICAL SUPERVISORS AND TRAINEES.** Sexual harassment may be defined as sexual advances, requests for sexual favors, and other verbal or physical conduct of a sexual nature when (1) such conduct interferes with an individual's work or academic performance or creates an intimidating, hostile, or offensive work or academic environment or (2) accepting or rejecting such conduct affects or may be perceived to affect employment decisions or academic evaluations concerning the individual. Sexual harassment is unethical.

Sexual relationships between medical supervisors and their medical trainees raise concerns because of inherent inequalities in the status and power that medical supervisors wield in relation to medical trainees and may adversely affect patient care. Sexual relationships between a medical trainee and a supervisor even when consensual are not acceptable regardless of the degree of supervision in any given situation. The supervisory role should be eliminated if the parties involved wish to pursue their relationship. (II, IV, VII)

Issued March 1992 based on the report "Sexual Harassment and Exploitation Between Medical Supervisors and Trainees," issued June 1989.

Updated June 1994

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5.00 · Opinions on Confidentiality, Advertising, and Communications Media Relations

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5.015 **DIRECT-TO-CONSUMER ADVERTISEMENTS OF PRESCRIPTION DRUGS.** The medical profession needs to take an active role in ensuring that proper advertising guidelines are enforced and that the care patients receive is not compromised as a result of direct-to-consumer advertising. Since the Food and Drug Administration (FDA) has a critical role in determining future directions of direct-to-consumer advertising of prescription drugs, physicians should work to ensure that the FDA remains committed to advertising standards that protect patients' health and safety. Moreover, physicians should encourage and engage in studies regarding the effect of direct-to-consumer advertising on patient health and medical care. Such studies should examine whether direct-to-consumer advertising improves the communication of health information; enhances the patient–physician relationship; and contains accurate and reasonable information on risks, precautions, adverse reactions, and costs.

Physicians must maintain professional standards of informed consent when prescribing. When a patient comes to a physician with a request for a drug he or she has seen advertised, the physician and the patient should engage in a dialogue that would assess and enhance the patient's understanding of the treatment. Although physicians should not be biased against drugs that are advertised, physicians should resist commercially induced pressure to prescribe drugs that may not be indicated. Physicians should deny requests for inappropriate prescriptions and educate patients as to why certain advertised drugs may not be suitable treatment options, providing, when available, information on the cost effectiveness of different options.

Physicians must remain vigilant to assure that direct-to-consumer advertising does not promote false expectations. Physicians should be concerned about advertisements that do not enhance consumer education; do not convey a clear, accurate, and responsible health education message; do not refer patients to their physicians for more information; do not identify the target population at risk; and fail to discourage consumer self-diagnosis and self-treatment. Physicians may choose to report these concerns directly to the pharmaceutical company that sponsored the advertisement.

To assist the FDA in enforcing existing law and tracking the effects of direct-to-consumer advertising, physicians should, whenever reasonably possible, report to them advertisements that: (1) do not provide a fair and balanced discussion of the use of the drug product for the disease, disorder, or condition; (2) do not clearly explain warnings, precautions, and potential adverse reactions associated with the drug product; (3) do not present summary information in language that can be understood by the consumer; (4) do not comply with applicable FDA rules, regulations, policies, and guidelines as provided by the FDA; or (5) do not provide collateral materials to educate both physicians and consumers. (II, III)

Issued June 1999 based on the report "Direct-to-Consumer Advertisement of Prescription Drugs," adopted December 1998 (Food and Drug Law Journal. 2000; 55: 119–24).

5.045 **FILMING PATIENTS IN HEALTH CARE SETTINGS.** The use of any medium to film, videotape, or otherwise record (hereafter film) patient interactions with their health care providers requires the utmost respect for the privacy and confidentiality of the patient. The following guidelines are offered to assure that the rights of the patient are protected. These guidelines specifically address filming with the intent of broadcast for public viewing, and do not address other uses such as in medical education, forensic or diagnostic filming, or the use of security cameras. (1) Educating the public about the health care system should be encouraged, and filming of patients may be one way to accomplish this. This educational objective is not severely compromised by filming only patients who can consent; when patients cannot consent, dramatic reenactments utilizing actors should be considered instead of violating patient privacy. (2) Filming patients without consent is a violation of the patient's privacy. Consent is therefore an ethical requirement for both initial filming and subsequent broadcast for public viewing. Because filming cannot benefit a patient medically, and moreover has the potential of causing harm to the patient, it is appropriate to limit filming to instances where the party being filmed can explicitly consent. Consent by a surrogate decision-maker is not an ethically appropriate substitute for consent by the patient because the role of surrogates is to make medically necessary decisions in the best interest of the patient. A possible exception exists when the person in question is permanently or indefinitely incompetent (e.g., permanent vegetative state or minor child). In such circumstances, if a parent or legal guardian provides consent, filming may occur. (a) Patients should have the right to have filming stopped upon request at any time and the film crew removed from the area. Also, persons involved in the direct medical care of the patient who feel that the filming may jeopardize patient care should request that the film crew be removed from the patient care area. (b) The initial granting of consent does not preclude the patient from withdrawing consent at a later time. After filming has occurred, patients who have been filmed should have the opportunity to rescind their consent up until a reasonable time period before broadcast for public viewing. The consent process should include a full disclosure of whether the tape will be destroyed if consent is rescinded, and the degree to which the patient is allowed to view and edit the final footage before broadcast for public viewing. (c) Due to the potential conflict of interest, informed consent should be obtained by a disinterested third party, and not a member of the film crew or production team. (3) Information obtained in the course of filming medical encounters between patients and physicians is confidential. Persons who are not members of the health care team, but who may be present for filming purposes, must demonstrate that they understand the confidential nature of the information and are committed to respecting it. Where possible, it is desirable for stationary cameras or health care professionals to perform the filming.

Physicians, as advocates for their patients, should not allow financial or promotional benefit to the health care institution to influence their advice to patients regarding participation in filming. Because physician compensation for participation in filming may cause an undue influence to recruit patients, physicians should not be compensated directly. To protect the best interests of patients, physicians should participate in institutional review of requests to film. (I, IV, VII, VIII)

Issued December 2001 based on the report "Filming Patients in Health Care Settings," adopted June 2001.

5.05 **CONFIDENTIALITY.** The information disclosed to a physician during the course of the relationship between physician and patient is confidential to the greatest possible degree. The patient should feel free to make a full disclosure of information to the physician in order that the physician may most effectively provide needed services. The patient should be able to make this disclosure with the knowledge that the patient will respect the confidential nature of the communication. The physician should not reveal confidential communications or information without the express consent of the patient, unless required to do so by law.

The obligation to safeguard patient confidences is subject to 2certain exceptions which are ethically and legally justified because of overriding social considerations. Where a patient threatens to inflict serious bodily harm to another person or to him or herself and there is a reasonable probability that the patient may carry out the threat, the physician should take reasonable precautions for the protection of the intended victim, including notification of law enforcement authorities. Also, communicable diseases, gun shot and knife wounds should be reported as required by applicable statutes or ordinances. (IV)

Issued December 1983.

Updated June 1994.

5.055 **CONFIDENTIAL CARE FOR MINORS.** Physicians who treat minors have an ethical duty to promote the autonomy of minor patients by involving them in the medical decision-making process to a degree commensurate with their abilities.

When minors request confidential services, physicians should encourage them to involve their parents. This includes making efforts to obtain the minor's reasons for not involving their parents and correcting misconceptions that may be motivating their objections.

Where the law does not require otherwise, physicians should permit a competent minor to consent to medical care and should not notify parents without the patient's consent. Depending on the seriousness of the decision, competence may be evaluated by physicians for most minors. When necessary, experts in adolescent medicine or child psychological development should be consulted. Use of the courts for competence determinations should be made only as a last resort.

When an immature minor requests contraceptive services, pregnancy-related care (including pregnancy testing, prenatal and postnatal care, and delivery services), or treatment for sexually transmitted disease, drug and alcohol abuse, or mental illness, physicians must recognize that requiring parental involvement may be counterproductive to the health of the patient. Physicians should encourage parental involvement in these situations. However, if the minor continues to object, his or her wishes ordinarily should be respected. If the physician is uncomfortable with providing services without parental involvement, and alternative confidential services are available, the minor may be referred to those services. In cases when the physician believes that without parental involvement and guidance, the minor will face a serious health threat, and there is reason to believe that the parents will be helpful and understanding, disclosing the problem to the parents is ethically justified. When the physician does breach confidentiality to the parents, he or she must discuss the reasons for the breach with the minor prior to the disclosure.

For minors who are mature enough to be unaccompanied by their parents for their examination, confidentiality of information disclosed during an exam, interview, or in counseling should be maintained. Such information may be disclosed to parents when the patient consents to disclosure. Confidentiality may be justifiably breached in situations for which confidentiality for adults may be breached, according to Opinion 5.05, "Confidentiality." In addition, confidentiality for immature minors may be ethically breached when necessary to enable the parent to make an informed decision about treatment for the minor or when such a breach is necessary to avert serious harm to the minor. (IV)

Issued June 1994 based on the report "Confidential Care for Minors," adopted June 1992.

Updated June 1996.

5.07 **CONFIDENTIALITY: COMPUTERS.** The utmost effort and care must be taken to protect the confidentiality of all medical records, including computerized medical records.

The guidelines below are offered to assist physicians and computer service organizations in maintaining the confidentiality of information in medical records when that information is stored in computerized data bases:

(1) Confidential medical information should be entered into the computer-based patient record only by authorized personnel. Additions to the record should be time and date stamped, and the person making the additions should be identified in the record.

(2) The patient and physician should be advised about the existence of computerized data bases in which medical information concerning the patient is stored. Such information should be communicated to the physician and patient prior to the physician's release of the medical information to the entity or entities maintaining the computer data bases. All individuals and organizations with some form of access to the computerized data bases, and the level of access permitted, should be specifically identified in advance. Full disclosure of this information to the patient is necessary in obtaining informed consent to treatment. Patient data should be assigned a security level appropriate for the data's degree of sensitivity, which should be used to control who has access to the information.

(3) The physician and patient should be notified of the distribution of all reports reflecting identifiable patient data prior to distribution of the reports by the computer facility. There should be approval by the patient and notification of the physician prior to the release of patient–identifiable clinical and administrative data to individuals or organizations external to the medical care environment. Such information should not be released without the express permission of the patient.

(4) The dissemination of confidential medical data should be limited to only those individuals or agencies with a bona fide use for the data. Only the data necessary for the bona fide use should be released. Patient identifiers should be omitted when appropriate. Release of confidential medical information from the data base should be confined to the specific purpose for which the information is requested and limited to the specific time frame requested. All such organizations or individuals should be advised that authorized release of data to them does not authorize their further release of the data to additional individuals or organizations, or subsequent use of the data for other purposes.

(5) Procedures for adding to or changing data on the computerized data base should indicate individuals authorized to make changes, time periods in which changes take place, and those individuals who will be informed about changes in the data from the medical records.

(6) Procedures for purging the computerized data base of archaic or inaccurate data should be established and the patient and physician should be notified before and after the data has been purged. There should be no mixing of a physician's computerized patient records with those of other computer service bureau clients. In addition, procedures should be developed to protect against inadvertent mixing of individual reports or segments thereof.

(7) The computerized medical data base should be on-line to the computer terminal only when authorized computer programs requiring the medical data are being used. Individuals and organizations external to the clinical facility should not be provided on-line access to a computerized data base containing identifiable data from medical records concerning patients. Access to the computerized data base should be controlled through security measures such as passwords, encryption (encoding) of information, and scannable badges or other user identification.

(8) Back-up systems and other mechanisms should be in place to prevent data loss and downtime as a result of hardware or software failure.

(9) Security:

  (a) Stringent security procedures should be in place to prevent unauthorized access to computer-based patient records. Personnel audit procedures should be developed to establish a record in the event of unauthorized disclosure of medical data. Terminated or former employees in the data processing environment should have no access to data from the medical records concerning patients.

  (b) Upon termination of computer services for a physician, those computer files maintained for the physician should be physically turned over to the physician. They may be destroyed (erased) only if it is established that the physician has another copy (in some form). In the event of file erasure, the computer service bureau should verify in writing to the physician that the erasure has taken place. (IV) Issued prior to April 1977; Updated June 1994 and June 1998.

5.09 **CONFIDENTIALITY: INDUSTRY-EMPLOYED PHYSICIANS AND INDEPENDENT MEDICAL EXAMINERS.** Where a physician's services are limited to performing an isolated assessment of an individual's health or disability for an employer, business, or insurer, the information obtained by the physician as a result of such examinations is confidential and should not be communicated to a third party without the individual's prior written consent, unless required by law. If the individual authorized the release of medical information to an employer or a potential employer, the physician should release only that information which is reasonably relevant to the employer's decision regarding that individual's ability to perform the work required by the job.

When a physician renders treatment to an employee with a work-related illness or injury, the release of medical information to the employer as to the treatment provided may be subject to the provisions of worker's compensation laws. The physician must comply with the requirements of such laws, if applicable. However, the physician may not otherwise discuss the employee's health condition with the employer without the employee's consent or, in the event of the employee's incapacity, the appropriate proxy's consent.

Whenever statistical information about employees' health is released, all employee identities should be deleted. (IV)

Issued July 1983.

Updated June 1994; updated June 1996; updated December 1999 based on the report "Patient–Physician Relationship in the Context of Work-Related and Independent Medical Examinations," adopted June 1999.

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6.00 • Opinions on Fees and Charges

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6.11 **COMPETITION.** Competition between and among physicians and other health care practitioners on the basis of competitive factors such as quality of services, skill, experience, miscellaneous conveniences offered to patients, credit terms, fees charged, etc., is not only ethical but is encouraged. Ethical medical practice thrives best under free market conditions when prospective patients have adequate information and opportunity to choose freely between and among competing physicians and alternate systems of medical care. (VII)

Issued July 1983.

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8.00 • Opinions on Practice Matters

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8.0315 **MANAGING CONFLICTS OF INTEREST IN THE CONDUCT OF CLINICAL TRIALS.** As the biotechnology and pharmaceutical industries continue to expand research activities and funding of clinical trials, and as increasing numbers of physicians both within and outside academic health centers become involved in partnerships with industry to perform these activities, greater safeguards against conflicts of interest are needed to ensure the integrity of the research and to protect the welfare of human subjects. Physicians should be mindful of the conflicting roles of investigator and clinician and of the financial conflicts of interest that arise from incentives to conduct trials and to recruit subjects. In particular, physicians involved in clinical research should heed the following guidelines: (1) Physicians should agree to participate as investigators in clinical trials only when it relates to their scope of practice and area of medical expertise. They should have adequate training in the conduct of research and should participate only in protocols which they are satisfied are scientifically sound. (2) Physicians should be familiar with the ethics of research, and should agree to participate in trials only if they are satisfied that an Institutional Review Board has reviewed the protocol, that the research does not impose undue risks upon research subjects, and that the research conforms to government regulations. (3) When a physician has treated or continues to treat a patient who is eligible to enroll as a subject in a clinical trial that the physician is conducting, the informed consent process must differentiate between the physician's roles as clinician and investigator. This is best achieved when someone other than the treating physician obtains the participant's informed consent to participate in the trial. This individual should be protected from the pressures of financial incentives, as described in the following section. (4) Any financial compensation received from trial sponsors must be commensurate with the efforts of the physician performing the research. Financial compensation should be at fair market value and the rate of compensation per patient should not vary according to the volume of subjects enrolled by the physician, and should meet other existing legal requirements. Furthermore, according to Opinion 6.03, “Fee Splitting: Referral to Health Care Facilities,” it is unethical for physicians to accept payment solely for referring patients to research studies. (5) Physicians should ensure that protocols include provisions for the funding of subjects’ medical care in the event of complications associated with the research. Also, a physician should not bill a third-party payor when he or she has received funds from a sponsor to cover the additional expenses related to conducting the trial. (6) The nature and source of funding and financial incentives offered to the investigators must be disclosed to a potential participant as part of the informed consent process. Disclosure to participants also should include information on uncertainties that may exist regarding funding of treatment for possible complications that may arise during the course of the trial. Physicians should ensure that such disclosure is included in any written informed consent. (7) When entering into a contract to perform research, physicians should ensure themselves that the presentation or publication of results will not be unduly delayed or otherwise obstructed by the sponsoring company. (II, V)

Issued June 2001 based on the report “Managing Conflicts of Interest in the Conduct of Clinical Trials,” adopted December 2000 (JAMA. 2002; 287: 78–84).

8.061 **GIFTS TO INDUSTRY FROM PHYSICIANS**. Many gifts given to physicians by companies in the pharmaceutical, device, and medical equipment industries serve an important and socially beneficial function. For example, companies have long provided funds for educational seminars and conferences. However, there has been growing concern about certain gifts from industry to physicians. Some gifts that reflect customary practices of industry may not be consistent with the Principles of Medical Ethics. To avoid the acceptance of inappropriate gifts, physicians should observe the following guidelines: (1) Any gifts accepted by physicians individually should primarily entail a benefit to patients and should not be of substantial value. Accordingly, textbooks, modest meals, and other gifts are appropriate if they serve a genuine educational function. Cash payments should not be accepted. The use of drug samples for personal or family use is permissible as long as these practices do not interfere with patient access to drug samples. It would not be acceptable for non-retired physicians to request free pharmaceuticals for personal use or use by family members. (2) Individual gifts of minimal value are permissible as long as the gifts are related to the physician’s work (e.g., pens and notepads). (3) The Council on Ethical and Judicial Affairs defines a legitimate “conference” or “meeting” as any activity, held at an appropriate location, where (a) the gathering is primarily dedicated, in both time and effort, to promoting objective scientific and educational activities and discourse (one or more educational presentation(s) should be the highlight of the gathering), and (b) the main incentive for bringing attendees together is to further their knowledge on the topic(s) being presented. An appropriate disclosure of financial support or conflict of interest should be made. (4) Subsidies to underwrite the costs of continuing medical education conferences or professional meetings can contribute to the improvement of patient care and therefore are permissible. Since the giving of a subsidy directly to a physician by a company’s representative may create a relationship that could influence the use of the company’s products, any subsidy should be accepted by the conference’s sponsor who in turn can use the money to reduce the conference’s registration fee. Payments to defray the costs of a conference should not be accepted directly from the company by the physicians attending the conference. (5) Subsidies from industry should not be accepted directly or indirectly to pay for the costs of travel, lodging, or other personal expenses of physicians attending conferences or meetings, nor should subsidies be accepted to compensate for the physicians’ time. Subsidies for hospitality should not be accepted outside of modest meals or social events held as a part of a conference or meeting. It is appropriate for faculty at conferences or meetings to accept reasonable honoraria and to accept reimbursement for reasonable travel, lodging, and meal expenses. It is also appropriate for consultants who provide genuine services to receive reasonable compensation and to accept reimbursement for reasonable travel, lodging, and meal expenses. Token consulting or advisory arrangements cannot be used to justify the compensation of physicians for their time or their travel, lodging, and other out-of-pocket expenses. (6) Scholarship or other special funds to permit medical students, residents, and fellows to attend carefully selected educational conferences may be permissible as long as the selection of students, residents, or fellows who will receive the funds is made by the academic or training institution. Carefully selected educational conferences are generally defined as the major educational, scientific or policy-making meetings of national, regional, or specialty medical associations. (7) No gifts should be accepted if there are strings attached. For example, physicians should not accept gifts if they are given in relation to the physician's prescribing practices. In addition, when companies underwrite medical conferences or lectures other than their own, responsibility for and control over the selection of content, faculty, educational methods, and materials should belong to the organizers of the conferences or lectures. (II)

Issued June 1992 based on the report "Gifts to Physicians from Industry," adopted December 1990 (JAMA. 1991; 265: 501)

Updated June 1996 and June 1998.

8.08 **INFORMED CONSENT.** The patient's right of self-decision can be effectively exercised only if the patient possesses enough information to enable an intelligent choice. The patient should make his or her own determination on treatment. The physician's obligation is to present the medical facts accurately to the patient or to the individual responsible for the patient's care and to make recommendations for management in accordance with good medical practice. The physician has an ethical obligation to help the patient make choices from among the therapeutic alternatives consistent with good medical practice. Informed consent is a basic social policy for which exceptions are permitted: (1) where the patient is unconscious or otherwise incapable of consenting and harm from failure to treat is imminent; or (2) when risk-disclosure poses such a serious psychological threat of detriment to the patient as to be medically contraindicated. Social policy does not accept the paternalistic view that the physician may remain silent because divulgence might prompt the patient to forego needed therapy. Rational, informed patients should not be expected to act uniformly, even under similar circumstances, in agreeing to or refusing treatment. (I, II, III, IV, V)

Issued March 1981.

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8.11 **NEGLECT OF PATIENT.** Physicians are free to choose whom they will serve. The physician should, however, respond to the best of his or her ability in cases of emergency where first aid treatment is essential. Once having undertaken a case, the physician should not neglect the patient. (I, VI)

Issued prior to April 1977.

Updated June 1996.

8.12 **PATIENT INFORMATION.** It is a fundamental ethical requirement that a physician should at all times deal honestly and openly with patients. Patients have a right to know their past and present medical status and to be free of any mistaken beliefs concerning their conditions. Situations occasionally occur in which a patient suffers significant medical complications that may have resulted from the physician's mistake or judgment. In these situations, the physician is ethically required to inform the patient of all the facts necessary to ensure understanding of what has occurred. Only through full disclosure is a patient able to make informed decisions regarding future medical care.

Ethical responsibility includes informing patients of changes in their diagnoses resulting from retrospective review of test results or any other information. This obligation holds even though the patient's medical treatment or therapeutic options may not be altered by the new information.

Concern regarding legal liability which might result following truthful disclosure should not affect the physician's honesty with a patient. (I, II, III, IV)

Issued March 1981.

Updated June 1994.

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8.14 **SEXUAL MISCONDUCT IN THE PRACTICE OF MEDICINE.** Sexual contact that occurs concurrent with the physician–patient relationship constitutes sexual misconduct. Sexual or romantic interactions between physicians and patients detract from the goals of the physician–patient relationship, may exploit the vulnerability of the patient, may obscure the physician's objective judgment concerning the patient's health care, and ultimately may be detrimental to the patient's well-being.

If a physician has reason to believe that non-sexual contact with a patient may be perceived as or may lead to sexual conduct, then he or she should avoid the non-sexual contact. At a minimum, a physician's ethical duties include terminating the physician–patient relationship before initiating a dating, romantic, or sexual relationship with a patient.

Sexual or romantic relationships between a physician and a former patient may be unduly influenced by the previous physician–patient relationship. Sexual or romantic relationships with former patients are unethical if the physician uses or exploits trust, knowledge, emotions, or influence derived from the previous professional relationship. (I, II, IV)

Issued December 1986.

Updated March 1992 based on the report "Sexual Misconduct in the Practice of Medicine," issued December 1990. (JAMA. 1991; 266: 2741–2745)

8.15 **SUBSTANCE ABUSE.** It is unethical for a physician to practice medicine while under the influence of a controlled substance, alcohol, or other chemical agents which impair the ability to practice medicine. (I)

Issued December 1986.

8.181 **PERFORMING PROCEDURES ON THE NEWLY DECEASED FOR TRAINING PURPOSES.** Physicians should work to develop institutional policies that address the practice of performing procedures on the newly deceased for purposes of training. Any such policy should ensure that the interests of all the parties involved are respected under established and clear ethical guidelines. Such policies should consider rights of patients and their families, benefits to trainees and society, as well as potential harm to the ethical sensitivities of trainees, and risks to staff, the institution, and the profession associated with performing procedures on the newly deceased without consent. The following considerations should be addressed before medical trainees perform procedures on the newly deceased:

(1) The teaching of life-saving skills should be the culmination of a structured training sequence, rather than relying on random opportunities. Training should be performed under close supervision, in a manner and environment that takes into account the wishes and values of all involved parties.

(2) Physicians should inquire whether the deceased individual had expressed preferences regarding handling of the body or procedures performed after death. In the absence of previously expressed preferences, physicians should obtain permission from the family before performing such procedures. When reasonable efforts to discover previously expressed preferences of the deceased or to find someone with authority to grant permission for the procedure have failed, physicians must not perform procedures for training purposes on the newly deceased patient.

In the event post-mortem procedures are undertaken on the newly deceased, they must be recorded in the medical record. (I, V)

Issued December 2001 based on the report "Performing Procedures on the Newly Deceased for Training Purposes," adopted June 2001.

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9.00 • Opinions on Professional Rights and Responsibilities

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9.031 **REPORTING IMPAIRED, INCOMPETENT, OR UNETHICAL COLLEAGUES.** Physicians have an ethical obligation to report impaired, incompetent, and unethical colleagues in accordance with the legal requirements in each state and assisted by the following guidelines:

Impairment. Impairment should be reported to the hospital's in-house impairment program, if available. Otherwise, either the chief of an appropriate clinical service or the chief of the hospital staff should be alerted. Reports may also be made directly to an external impaired physician program. Practicing physicians who do not have hospital privileges should be reported directly to an impaired physician program, such as those run by medical societies, when appropriate. If none of these steps would facilitate the entrance of the impaired physician into an impairment program, then the impaired physician should be reported directly to the state licensing board.

Incompetence. Initial reports of incompetence should be made to the appropriate clinical authority who would be empowered to assess the potential impact on patient welfare and to facilitate remedial action. The hospital peer review body should be notified where appropriate. Incompetence which poses an immediate threat to the health of patients should be reported directly to the state licensing board. Incompetence by physicians without a hospital affiliation should be reported to the local or state medical society and/or the state licensing or disciplinary board.

Unethical conduct. With the exception of incompetence or impairment, unethical behavior should be reported in accordance with the following guidelines:

Unethical conduct that threatens patient care or welfare should be reported to the appropriate authority for a particular clinical service. Unethical behavior which violates state licensing provisions should be reported to the state licensing board or impaired physician programs, when appropriate. Unethical conduct which violates criminal statutes must be reported to the appropriate law enforcement authorities. All other unethical conduct should be reported to the local or state medical society.

Where the inappropriate behavior of a physician continues despite the initial report(s), the reporting physician should report to a higher or additional authority. The person or body receiving the initial report should notify the reporting physician when appropriate action has been taken. Physicians who receive reports of inappropriate behavior have an ethical duty to critically and objectively evaluate the reported information and to assure that identified deficiencies are either remedied or further reported to a higher or additional authority. Anonymous reports should receive appropriate review and confidential investigation. Physicians who are under scrutiny or charge should be protected by the rules of confidentiality until such charges are proven or until the physician is exonerated. (II)

Issued March 1992 based on the report "Reporting Impaired, Incompetent, or Unethical Colleagues," adopted December 1991 (J Miss St Med Assoc. 1992; 33: 176–77).

Updated June 1994 and June 1996.

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9.035 **GENDER DISCRIMINATION IN THE MEDICAL PROFESSION.** Physician leaders in medical schools and other medical institutions should take immediate steps to increase the number of women in leadership positions as such positions become open. There is already a large enough pool of female physicians to provide strong candidates for such positions. Also, adjustments should be made to ensure that all physicians are equitably compensated for their work. Women and men in the same specialty with the same experience and doing the same work should be paid the same compensation.

Physicians in the workplace should actively develop the following: (1) Retraining or other programs which facilitate the reentry of physicians who take time away from their careers to have a family; (2) On-site child care services for dependent children; (3) Policies providing job security for physicians who are temporarily not in practice due to pregnancy or family obligations.

Physicians in the academic medical setting should strive to promote the following: (1) Extension of tenure decisions through "stop the clock" programs, relaxation of the seven year rule, or part-time appointments that would give faculty members longer to achieve standards for promotion and tenure; (2) More reasonable guidelines regarding the appropriate quantity and timing of published material needed for promotion or tenure that would emphasize quality over quantity and that would encourage the pursuit of careers based on individual talent rather than tenure standards that undervalue teaching ability and overvalue research; (3) Fair distribution of teaching, clinical, research, administrative responsibilities, and access to tenure tracks between men and women. Also, physicians in academic institutions should consider formally structuring the mentoring process, possibly matching students or faculty with advisors through a fair and visible system.

Where such policies do not exist or have not been followed, all medical workplaces and institutions should create strict policies to deal with sexual harassment. Grievance committees should have broad representation of both sexes and other groups. Such committees should have the power to enforce harassment policies and be accessible to those persons they are meant to serve.

Grantors of research funds and editors of scientific or medical journals should consider blind peer review of grant proposals and articles for publication to help prevent bias. However, grantors and editors will be able to consider the author's identity and give it appropriate weight. (II, VII)

Issued June 1994 based on the report "Gender Discrimination in the Medical Profession," issued June 1993. (Women's Health Issues. 1994; 4:1–11)

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9.045 **PHYSICIANS WITH DISRUPTIVE BEHAVIOR.** This Opinion is limited to the conduct of individual physicians and does not refer to physicians acting as a collective, which is considered separately in Opinion 9.025, "Collective Action and Patient Advocacy." (1) Personal conduct, whether verbal or physical, that negatively affects or that potentially may negatively affect patient care constitutes disruptive behavior. (This includes but is not limited to conduct that interferes with one's ability to work with other members of the health care team.) However, criticism that is offered in good faith with the aim of improving patient care should not be construed as disruptive behavior. (2)

Each medical staff should develop and adopt bylaw provisions or policies for intervening in situations where a physician's behavior is identified as disruptive. The medical staff bylaw provisions or policies should contain procedural safeguards that protect due process. Physicians exhibiting disruptive behavior should be referred to a medical staff wellness—or equivalent—committee. (3) In developing policies that address physicians with disruptive behavior, attention should be paid to the following elements: (a) Clearly stating principal objectives in terms that ensure high standards of patient care and promote a professional practice and work environment. (b) Describing the behavior or types of behavior that will prompt intervention. (c) Providing a channel through which disruptive behavior can be reported and appropriately recorded. A single incident may not be sufficient for action, but each individual report may help identify a pattern that requires intervention. (d) Establishing a process to review or verify reports of disruptive behavior. (e) Establishing a process to notify a physician whose behavior is disruptive that a report has been made, and providing the physician with an opportunity to respond to the report. (f) Including means of monitoring whether a physician's disruptive conduct improves after intervention. (g) Providing for evaluative and corrective actions that are commensurate with the behavior, such as self-correction and structured rehabilitation. Suspension of responsibilities or privileges should be a mechanism of final resort. Additionally, institutions should consider whether the reporting requirements of Opinion 9.031, "Reporting Impaired, Incompetent, or Unethical Colleagues," apply in particular cases. (h) Identifying which individuals will be involved in the various stages of the process, from reviewing reports to notifying physicians and monitoring conduct after intervention. (i) Providing clear guidelines for the protection of confidentiality. (j) Ensuring that individuals who report physicians with disruptive behavior are duly protected. (I, II, VIII)

Issued December 2000 based on the report "Physicians With Disruptive Behavior," adopted June 2000.

9.065 **CARING FOR THE POOR.** Each physician has an obligation to share in providing care to the indigent. The measure of what constitutes an appropriate contribution may vary with circumstances such as community characteristics, geographic location, the nature of the physician's practice and specialty, and other conditions. All physicians should work to ensure that the needs of the poor in their communities are met. Caring for the poor should be a regular part of the physician's practice schedule.

In the poorest communities, it may not be possible to meet the needs of the indigent for physicians' services by relying solely on local physicians. The local physicians should be able to turn for assistance to their colleagues in prosperous communities, particularly those in close proximity.

Physicians are meeting their obligation, and are encouraged to continue to do so, in a number of ways such as seeing indigent patients in their offices at no cost or at reduced cost, serving at freestanding or hospital clinics that treat the poor, and participating in government programs that provide health care to the poor. Physicians can also volunteer their services at weekend clinics for the poor and at shelters for battered women or the homeless.

In addition to meeting their obligations to care for the indigent, physicians can devote their energy, knowledge, and prestige to designing and lobbying at all levels for better programs to provide care for the poor. (I, VII)

Issued June 1994 based on the report "Caring for the Poor," issued December 1992. (JAMA. 1993; 269: 2533–2537)

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9.115 **ETHICS CONSULTATIONS.** Ethics consultations may be called to clarify ethical issues without reference to a particular case, facilitate discussion of an ethical dilemma in a particular case, or resolve an ethical dispute. The consultation mechanism may be through an ethics committee, a subset of the committee, individual consultants, or consultation teams. The following guidelines are offered with respect to these services: (1) All hospitals and other health care institutions should provide access to ethics consultation services. Health care facilities without ethics committees or consultation services should develop flexible, efficient mechanisms of ethics review that divide the burden of committee functioning among collaborating health care facilities. (2) Institutions offering ethics consultation services must appreciate the complexity of the task, recognizing the potential for harm as well as benefit, and act responsibly. This includes true institutional support for the service. (3) Ethics consultation services require a serious investment of time and effort by the individuals involved. Members should include either individuals with extensive formal training and experience in clinical ethics or individuals who have made a substantial commitment over several years to gain sufficient knowledge, skills, and understanding of the complexity of clinical ethics. A wide variety of background training is preferable, including such fields as philosophy, religion, medicine, and law. (4) Explicit structural standards should be developed and consistently followed. These should include developing a clear description of the consultation service's role and determining which types of cases will be addressed, how the cases will be referred to the service, whether the service will provide recommendations or simply function as a forum for discussion, and whether recommendations are binding or advisory. (5) Explicit procedural standards should be developed and consistently followed. These should include establishing who must be involved in the consultation process and how notification, informed consent, confidentiality and case write-ups will be handled. (6) In general, patient and staff informed consent may be presumed for ethics consultation. However, patients and families should be given the opportunity, not to participate in discussions either formally, through the institutional process, or informally. (7) In those cases where the patient or family has chosen not to participate in the consultation process, the final recommendations of the consultant(s) should be tempered. (8) In general, ethics consultation services, like social services, should be financed by the institution. (9) A consultation service should be careful not to take on more than it can handle, ie, the complexity of the role should correspond to the level of sophistication of the service and the resources it has available. As a result, some services may offer only information and education, others a forum for discussion but not advice, others might serve a mediation role, and some might handle even administrative or organizational ethics issues. (IV, V)

Issued June 1998 based on the report "Ethics Consultation," adopted December 1997.

9.121 **RACIAL DISPARITIES IN HEALTH CARE**. Disparities in medical care based on immutable characteristics such as race must be avoided. Whether such disparities in health care are caused by treatment decisions, differences in income and education, sociocultural factors, or failures by the medical profession, they are unjustifiable and must be eliminated. Physicians should examine their own practices to ensure that racial prejudice does not affect clinical judgment in medical care. (I, IV)

Issued March 1992 based on the report "Black-White Disparities in Health Care," issued December 1989. (JAMA. 1990; 263: 2344–2346)

Updated June 1994.

9.122 **GENDER DISPARITIES IN HEALTH CARE**. A patient's gender plays an appropriate role in medical decisionmaking when biological differences between the sexes are considered. However, some data suggest that gender bias may be playing a role in medical decisionmaking. Social attitudes, including stereotypes, prejudices and other evaluations based on gender role expectations may play themselves out in a variety of subtle ways. Physicians must ensure that gender is not used inappropriately as a consideration in clinical decisionmaking. Physicians should examine their practices and attitudes for influence of social or cultural biases which could be inadvertently affecting the delivery of medical care.

Research on health problems that affect both genders should include male and female subjects, and results of medical research done solely on males should not be generalized to females without evidence that results apply to both sexes. Medicine and society in general should ensure that resources for medical research should be distributed in a manner which promotes the health of both sexes to the greatest extent possible. (I, IV)

Issued March 1992 based on the report "Gender Disparities in Clinical Decisionmaking," issued December 1990. (JAMA. 1991; 266: 559–562)

Updated June 1994.

9.13 **PHYSICIANS AND INFECTIOUS DISEASES**. A physician who knows that he or she has an infectious disease, which if contracted by the patient would pose a significant risk to the patient, should not engage in any activity that creates a significant risk of transmission of that disease to the patient. The precautions taken to prevent the transmission of a contagious disease to a patient should be appropriate to the seriousness of the disease and must be particularly stringent in the case of a disease that is potentially fatal. (I, IV)

Issued August 1989.

Updated June 1996 and June 1999.

9.131 **HIV-INFECTED PATIENTS AND PHYSICIANS**. A physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is seropositive for HIV. Persons who are seropositive should not be subjected to discrimination based on fear or prejudice.

When physicians are unable to provide the services required by an HIV-infected patient, they should make appropriate referrals to those physicians or facilities equipped to provide such services.

A physician who knows that he or she is seropositive should not engage in any activity that creates a significant risk of transmission of the disease to others. A physician who has HIV disease or who is seropositive should consult colleagues as to which activities the physician can pursue without creating a risk to patients. (I, II, IV)

Issued March 1992 based on the report "Ethical Issues in the Growing AIDS Crisis," adopted December 1987 (JAMA. 1988; 259: 1360–1361).

Updated June 1996 and June 1998.

E-10.01 **FUNDAMENTAL ELEMENTS OF THE PATIENT-PHYSICIAN RELATIONSHIP.** From ancient times, physicians have recognized that the health and well-being of patients depends upon a collaborative effort between physician and patient. Patients share with physicians the responsibility for their own health care. The patient–physician relationship is of greatest benefit to patients when they bring medical problems to the attention of their physicians in a timely fashion, provide information about their medical condition to the best of their ability, and work with their physicians in a mutually respectful alliance. Physicians can best contribute to this alliance by serving as their patients' advocate and by fostering these rights:

(1) The patient has the right to receive information from physicians and to discuss the benefits, risks, and costs of appropriate treatment alternatives. Patients should receive guidance from their physicians as to the optimal course of action. Patients are also entitled to obtain copies or summaries of their medical records, to have their questions answered, to be advised of potential conflicts of interest that their physicians might have, and to receive independent professional opinions.

(2) The patient has the right to make decisions regarding the health care that is recommended by his or her physician. Accordingly, patients may accept or refuse any recommended medical treatment.

(3) The patient has the right to courtesy, respect, dignity, responsiveness, and timely attention to his or her needs.

(4) The patient has the right to confidentiality. The physician should not reveal confidential communications or information without the consent of the patient, unless provided for by law or by the need to protect the welfare of the individual or the public interest.

(5) The patient has the right to continuity of health care. The physician has an obligation to cooperate in the coordination of medically indicated care with other health care providers treating the patient. The physician may not discontinue treatment of a patient as long as further treatment is medically indicated, without giving the patient reasonable assistance and sufficient opportunity to make alternative arrangements for care.

(6) The patient has a basic right to have available adequate health care. Physicians, along with the rest of society, should continue to work toward this goal. Fulfillment of this right is dependent on society providing resources so that no patient is deprived of necessary care because of an inability to pay for the care. Physicians should continue their traditional assumption of a part of the responsibility for the medical care of those who cannot afford essential health care. Physicians should advocate for patients in dealing with third parties when appropriate.

Issued June 1992 based on the report, "Fundamental Elements of the Patient-Physician Relationship," adopted June 1990; Updated 1993.

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E10.015 **THE PATIENT-PHYSICIAN RELATIONSHIP.** The practice of medicine, and its embodiment in the clinical encounter between a patient and a physician, is fundamentally a moral activity that arises from the imperative to care for patients and to alleviate suffering.

A patient–physician relationship exists when a physician serves a patient's medical needs, generally by mutual consent between physician and patient (or surrogate). In some instances the agreement is implied, such as in emergency care or when physicians provide services at the request of the treating physician. In rare instances, treatment without consent may be provided under court order (see Opinion 2.065). Nevertheless, the physician's obligations to the patient remain intact.

The relationship between patient and physician is based on trust and gives rise to physicians' ethical obligations to place patients' welfare above their own self-interest and above obligations to other groups, and to advocate for their patients' welfare.

Within the patient-physician relationship, a physician is ethically required to use sound medical judgment, holding the best interests of the patient as paramount.

Issued December 2001 based on the report "The Patient–Physician Relationship," adopted June 2001.

DECLARATION OF PROFESSIONAL RESPONSIBILITY MEDICINE'S SOCIAL CONTRACT WITH HUMANITY

American Medical Association

2001

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This declaration was drafted by members of the Ethics Standards Group at the American Medical Association and approved by the House of Delegates of the AMA in December of 2001. Although the Declaration was drafted in part as a response to the attacks on September 11, 2001, the language of the Declaration is broad enough to be used for the world community of physicians. In addition to traditional exhortations of respecting human life and preserving confidentiality, the Declaration also states that physicians should better educate the public about health threats as well as take a more directly political role to reduce human suffering.

<http://www.ama-assn.org/ama/pub/category/7491.html>

Preamble

Never in the history of human civilization has the well being of each individual been so inextricably linked to that of every other. Plagues and pandemics respect no national borders in a world of global commerce and travel. Wars and acts of terrorism enlist innocents as combatants and mark civilians as targets. Advances in medical science and genetics, while promising great good, may also be harnessed as agents of evil. The unprecedented scope and immediacy of these universal challenges demand concerted action and response by all. As physicians, we are bound in our response by a common heritage of caring for the sick and the suffering. Through the centuries, individual physicians have fulfilled this obligation by applying their skills and knowledge competently, selflessly and at times heroically. Today, our profession must reaffirm its historical commitment to combat natural and man-made assaults on the health and well being of humankind. Only by acting together across geographic and ideological divides can we overcome such powerful threats. Humanity is our patient.

Declaration

We, the members of the world community of physicians, solemnly commit ourselves to:

I. Respect human life and the dignity of every individual.
II. Refrain from supporting or committing crimes against humanity and condemn all such acts.
III. Treat the sick and injured with competence and compassion and without prejudice.
IV. Apply our knowledge and skills when needed, though doing so may put us at risk.
V. Protect the privacy and confidentiality of those for whom we care and breach that confidence only when keeping it would seriously threaten their health and safety or that of others.
VI. Work freely with colleagues to discover, develop, and promote advances in medicine and public health that ameliorate suffering and contribute to human well-being.
VII. Educate the public and polity about present and future threats to the health of humanity.
VIII. Advocate for social, economic, educational, and political changes that ameliorate suffering and contribute to human well-being.
IX. Teach and mentor those who follow us for they are the future of our caring profession.

We make these promises solemnly, freely, and upon our personal and professional honor.

CHARTER ON MEDICAL PROFESSIONALISM

ABIM Foundation, ACP–ASIM Foundation, and European Federation of Internal Medicine

2002

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Unlike the AMA's Declaration of Professional Responsibility, which is drafted in the style of an oath, the Charter on Medical Professionalism *reads more like a contract between medicine and society. The Charter outlines three principles and ten responsibilities that physicians should abide. The Charter mentions traditional ethical duties of physicians (confidentiality, avoiding sexual misconduct), as well as newer ethical duties, such as managing conflicts of interest.*

Preamble

Professionalism is the basis of medicine's contract with society. It demands placing the interests of patients above those of the physician, setting and maintaining standards of competence and integrity, and providing expert advice to society on matters of health. The principles and responsibilities of medical professionalism must be clearly understood by both the profession and society. Essential to this contract is public trust in physicians, which depends on the integrity of both individual physicians and the whole profession.

At present, the medical profession is confronted by an explosion of technology, changing market forces, problems in health care delivery, bioterrorism, and globalization. As a result, physicians find it increasingly difficult to meet their responsibilities to patients and society. In these circumstances, reaffirming the fundamental and universal principles and values of medical professionalism, which remain ideals to be pursued by all physicians, becomes all the more important.

The medical profession everywhere is embedded in diverse cultures and national traditions, but its members share the role of healer, which has roots extending back to Hippocrates. Indeed, the medical profession must contend with complicated political, legal, and market forces. Moreover, there are wide variations in medical delivery and practice through which any general principles may be expressed in both complex and subtle ways. Despite these differences, common themes emerge and form the basis of this charter in the form of three fundamental principles and as a set of definitive professional responsibilities.

Fundamental Principles

Principle of primacy of patient welfare. This principle is based on a dedication to serving the interest of the patient. Altruism contributes to the trust that is central to the physician-patient relationship. Market forces, societal pressures, and administrative exigencies must not compromise this principle.

Principle of patient autonomy. Physicians must have respect for patient autonomy. Physicians must be honest with their patients and empower them to make informed decisions about their treatment. Patients' decisions about their care must be paramount, as long as those decisions are in keeping with ethical practice and do not lead to demands for inappropriate care.

Principle of social justice. The medical profession must promote justice in the health care system, including the fair distribution of health care resources. Physicians should work actively to eliminate discrimination in health care, whether based on race, gender, socioeconomic status, ethnicity, religion, or any other social category.

A Set of Professional Responsibilities

Commitment to professional competence. Physicians must be committed to lifelong learning and be responsible for maintaining the medical knowledge and clinical and team skills necessary for the provision of quality care. More broadly, the profession as a whole must strive to see that all of its members are competent and must ensure that appropriate mechanisms are available for physicians to accomplish this goal.

Commitment to honesty with patients. Physicians must ensure that patients are completely and honestly informed before the patient has consented to treatment and after treatment has occurred. This expectation does not mean that patients should be involved in every minute decision about medical care; rather, they must be empowered to decide on the course of therapy. Physicians should also acknowledge that in health care, medical errors that injure patients do sometimes occur. Whenever patients are injured as a consequence of medical care, patients should be informed promptly because failure to do so seriously compromises patient and societal trust. Reporting and analyzing medical mistakes provide the basis for appropriate prevention and improvement strategies and for appropriate compensation to injured parties.

Commitment to patient confidentiality. Earning the trust and confidence of patients requires that appropriate confidentiality safeguards be applied to disclosure of patient information. This commitment extends to discussions with persons acting on a patient's behalf when obtaining the patient's own consent is not feasible. Fulfilling the commitment to confidentiality is more pressing now than ever before, given the widespread use of electronic information systems for compiling patient data and an increasing availability of genetic information. Physicians recognize, however, that their commitment to patient confidentiality must occasionally yield to overriding considerations in the public interest (for example, when patients endanger others).

Commitment to maintaining appropriate relations with patients. Given the inherent vulnerability and dependency of patients, certain relationships between physicians and patients must be avoided. In particular, physicians should never exploit patients for any sexual advantage, personal financial gain, or other private purpose.

Commitment to improving quality of care. Physicians must be dedicated to continuous improvement in the quality of health care. This commitment entails not only maintaining clinical competence but also working collaboratively with other professionals to reduce medical error, increase patient safety, minimize overuse of health care resources, and optimize the outcomes of care. Physicians must actively participate in the development of better measures of quality of care and the application of quality measures to assess routinely the performance of all individuals, institutions, and systems responsible for health care delivery. Physicians, both individually and through their professional associations, must take responsibility for assisting in the creation and implementation of mechanisms designed to encourage continuous improvement in the quality of care.

Commitment to improving access to care. Medical professionalism demands that the objective of all health care systems be the availability of a uniform and adequate standard of care. Physicians must individually and collectively strive to reduce barriers to equitable health care. Within each system, the physician should work to eliminate barriers to access based on education, laws, finances, geography, and social discrimination. A commitment to equity entails the promotion of public health and preventive medicine, as well as public advocacy on the part of each physician, without concern for the self-interest of the physician or the profession.

Commitment to a just distribution of finite resources. While meeting the needs of individual patients, physicians are required to provide health care that is based on the wise and cost-effective management of limited clinical resources. They should be committed to working with other physicians, hospitals, and payers to develop guidelines for cost-effective care. The physician's professional responsibility for appropriate allocation of resources requires scrupulous avoidance of superfluous tests and procedures. The provision of unnecessary services not only exposes one's patients to avoidable harm and expense but also diminishes the resources available for others.

Commitment to scientific knowledge. Much of medicine's contract with society is based on the integrity and appropriate use of scientific knowledge and technology. Physicians have a duty to uphold scientific standards, to promote research, and to create new knowledge and ensure its appropriate use. The profession is responsible for the integrity of this knowledge, which is based on scientific evidence and physician experience.

Commitment to maintaining trust by managing conflicts of interest. Medical professionals and their organizations have many opportunities to compromise their professional responsibilities by pursuing private gain or personal advantage. Such compromises are especially threatening in the pursuit of personal or organizational interactions with for-profit industries, including medical equipment manufacturers, insurance companies, and pharmaceutical firms. Physicians have an obligation to recognize, disclose to the general public, and deal with conflicts of interest that arise in the course of their professional duties and activities. Relationships between industry and opinion leaders should be disclosed, especially when the latter determine the criteria for conducting and reporting clinical trials, writing editorials or therapeutic guidelines, or serving as editors of scientific journals.

Commitment to professional responsibilities. As members of a profession, physicians are expected to work collaboratively to maximize patient care, be respectful of one another, and participate in the processes of self-regulation, including remediation and discipline of members who have failed to meet professional standards. The profession should also define and organize the educational and standard-setting process for current and future members. Physicians have both individual and collective obligations to participate in these processes. These obligations include engaging in internal assessment and accepting external scrutiny of all aspects of their professional performance.

Summary

The practice of medicine in the modern era is beset with unprecedented challenges in virtually all cultures and societies. These challenges center on increasing disparities among the legitimate needs of patients, the available resources to meet those needs, the increasing dependence on market forces to transform health care systems, and the temptation for physicians to forsake their traditional commitment to the primacy of patients' interests. To maintain the fidelity of medicine's social contract during this turbulent time, we believe that physicians must reaffirm their active dedication to the principles of professionalism, which entails not only their personal commitment to the welfare of their patients but also collective efforts to improve the health care system for the welfare of society. This Charter on Medical Professionalism is intended to encourage such dedication and to promote an action agenda for the profession of medicine that is universal in scope and purpose.

THE MORAL AND TECHNICAL COMPETENCE OF THE OPHTHALMOLOGIST

American Academy of Ophthalmology

1991, REVISED 1999

The following Moral and Technial Competence material augments the AAO's Code of Ethics, which can be at http://www.aao.org/aao/member/ethics/code_ethics.cfm.

<http://www.aao.org/aao/member/ethics/moral_competence.cfm>

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Information Statement

Introduction

The overall purpose of developing ophthalmologic competency is to improve the physician–patient relationship and the medical care that accompanies that relationship. Competent ophthalmologic practice requires both moral and technical capacities. Moral capacities are demonstrated by 1) appreciation of clinical ethical problems, 2) practicing as an agent of the patient, and 3) facilitating a caring relationship with the patient. Technical capacities are comprised of the knowledge and skills required to practice medicine, and especially ophthalmology, according to current standards of care.

Background

The American Academy of Ophthalmology is dedicated to providing ophthalmologists with information and education necessary for the optimal care of the public. The quality of such care is based on competence achieved through training and continuing education. The Academy's Code of Ethics, which serves as a standard of exemplary professional conduct, requires that an ophthalmologist be competent by virtue of specific training and experience (Rule 1). However, the Rules of the Code specify neither the components of competence nor the capacities of which it is comprised. Competence for medical (ophthalmologic) practice does not occur in the abstract. Physician competence exists for the purpose of advancing the best interests of the patient as a person—with sensitivity, and with respect for and understanding of their sovereignty needs and wants.

Bioethicists generally agree that "moral" and "ethical" values are equivalent; these words are used synonymously here. Moral (and ethical) capacities are those which preserve, protect and advance the best interests of the patient through the practice (a process) of applying knowledge, skills and attitudes which resolve the human conflicts and dilemmas of clinical and scientific endeavor on principled bases.

Ophthalmologic Competence

Ophthalmologic competence is comprised of both moral and technical capacities; both are necessary to establish ophthalmologic competence. Ophthalmologic competence is thus a continuing process of self-development; of acquiring and refining the knowledge, skills, values, and expectations to provide quality patient care.

This acquisition process, of necessity, must proceed along two paths:

1. An outer-directed process of study and instruction into the vocabulary, concepts, case studies, negotiation strategies, and so on, that concern moral and technical capacities, and
2. An inner-directed process of personal experience and insight that integrates personal and professional development and moral and technical capacities.

Moral Competence

Moral competence follows from understanding the purpose of medical care and calls upon the physician to practice moral discernment, moral agency, and caring in relationships.

Moral discernment is the ability to confront, discuss, and resolve the ethical considerations in a clinical encounter. In particular, it is the ability to:

- Use the vocabulary and concepts of ethical and moral reasoning to place a moral dilemma in perspective;
- Respect the cultural, social, personal beliefs, expectations, and values that the patient brings to the therapeutic setting;
- Respect the patient's chosen lifestyle and acknowledge the conditions and events that have helped to shape that lifestyle;
- Confront one's own beliefs, expectations, and values when faced with different perspectives; and
- Reflect on the causes and consequences of one's ethical decisions.

Moral Agency is the ability to act on behalf of the patient; to act with respect for social, religious, and cultural differences that may exist between physician and patient. It is the ability to:

- Consider the possible consequences of one's actions and to act to affect consequences that are in accord with one's values and those of the patient;
- Resolve differences on the basis of principle, rather than power;
- Provide medical care that is both professionally appropriate and socially responsible;
- Genuinely engage the patient as a fellow human being; and
- Keep the confidences of the patient.

A caring and healing relationship between physician and patient is the foundation of medical care. Such a relationship is characterized by ability to:

- Acknowledge the patient's right to self-determination in the process of participating in his or her own care;
- Avoid conflicts of interests in one's own personal, professional, and financial relationships with patients, colleagues, and other members of the health care community;
- Provide the patient complete, accurate, and timely information about treatment options in the best spirit of informed consent;
- Share one's weaknesses and limits as well as one's strengths and virtues; and
- Strive for the experience of compassion through progressively deeper understandings of others' behavior.

Technical Competence

Technical competence consists of the knowledge and skills necessary to diagnose and treat disease and disability according to the precepts of medical science and especially of ophthalmology, and to assist in the maintenance of health.

In particular, technical competence consists of the ability to:

- Apply principles of ophthalmic care;
- Differentiate normal and pathological anatomy and physiology of the eyes and visual system;
- Understand the relationships between ophthalmic and systemic health and disease;
- Perform skills intrinsic to medicine in general and to ophthalmology in particular;
- Provide necessary and sufficient medical care;
- Develop, critique, and present appropriate therapeutic options;
- Provide timely, complete, and accurate documentation about patient care; and communicate appropriately with other members of the medical community and the health care system;
- Acknowledge one's limitations in skill and knowledge; and
- Make a commitment, through study, instruction, and experience, to keep one's medical skills and knowledge current.

We acknowledge the importance of these moral commitments and technical capacities to the education, practice and credentialing of ophthalmologists. Further, the curriculum of ophthalmology should specifically address each of these two competencies and the two paths to developing them and should be defined further for purposes of assessment and accountability.

Approved by: Ethics Committee, January 1991

Revised and Approved by: Secretariat for Ophthalmic Practice & Services, February 1999

CODE OF ETHICS

American Osteopathic Association

REVISED 1985, 1998, 2003

<http://www.aoa-net.org/MembersOnly/code.htm>

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The 1965 revision of the American Osteopathic Association's (AOA) Code of Ethics appeared in the Appendix to the first edition of this encyclopedia. The 1985 revision of the AOA code contained standards that address the osteopathic physician's responsibilities to other healthcare providers, to patients, and to society. The code serves as a guide to all AOA members; wording that denotes masculine or feminine gender has been changed to include both men and women in the latest 1998 version. The more significant changes between the 1965 and 1985 revisions included: (1) addition of the nondiscrimination clause in Section 3; (2) elimination of the earlier ban on advertising, as required by law; (3) elimination of the previous requirement that degrees be acquired only from institutions sanctioned by the AOA; and (4) elimination of the prohibition on publicly commenting on the professional services of other physicians. For the 1998 version, two new sections on sexual misconduct and sexual harassment have been added. The 2003 revision adds a section on the ethics of receiving gifts.

The American Osteopathic Association has formulated this Code to guide its member physicians in their professional lives. The standards presented are designed to address the osteopathic physician's ethical and professional responsibilities to patients, to society, to the AOA, to others involved in health care and to self.

Further, the American Osteopathic Association has adopted the position that physicians should play a major role in the development and instruction of medical ethics.

SECTION 1. The physician shall keep in confidence whatever she/he may learn about a patient in the discharge of professional duties. Information shall be divulged by the physician when required by law or when authorized by the patient.

SECTION 2. The physician shall give a candid account of the patient's condition to the patient or to those responsible for the patient's care.

SECTION 3. A physician–patient relationship must be founded on mutual trust, cooperation, and respect. The patient, therefore, must have complete freedom to choose her/his physician. The physician must have complete freedom to choose patients whom she/he will serve. However, the physician should not refuse to accept patients because of the patient's race, creed, color, sex, national origin or handicap. In emergencies, a physician should make her/his services available.

SECTION 4. A physician is never justified in abandoning a patient. The physician shall give due notice to a patient or to those responsible for the patient's care when she/he withdraws from the case so that another physician may be engaged.

SECTION 5. A physician shall practice in accordance with the body of systematized and scientific knowledge related to the healing arts. A physician shall maintain competence in such systemized and scientific knowledge through study and clinical applications.

SECTION 6. The osteopathic medical profession has an obligation to society to maintain its high standards and, therefore, to continuously regulate itself. A substantial part of such regulation is due to the efforts and influence of the recognized local, state and national associations representing the osteopathic medical profession. A physician should maintain membership in and actively support such associations and abide by their rules and regulations.

SECTION 7. Under the law a physician may advertise, but no physician shall advertise or solicit patients directly or indirectly through the use of matters or activities which are false or misleading.

SECTION 8. A physician shall not hold forth or indicate possession of any degree recognized as the basis for licensure to practice the healing arts unless she/he is actually licensed on the basis of that degree in the state in which she/he practices. A physician shall designate her/his osteopathic school of practice in all professional uses of her/his name. Indications of specialty practice, membership in professional societies, and related matters shall be governed by rules promulgated by the American Osteopathic Association.

SECTION 9. A physician should not hesitate to seek consultation whenever she/he believes it advisable for the care of the patient.

SECTION 10. In any dispute between or among physicians involving ethical or organizational matters, the matter in controversy should first be referred to the appropriate arbitrating bodies of the profession.

SECTION 11. In any dispute between or among physicians regarding the diagnosis and treatment of a patient, the attending physician has the responsibility for final decisions, consistent with any applicable osteopathic hospital rules or regulations.

SECTION 12. Any fee charged by a physician shall compensate the physician for services actually rendered. There shall be no division of professional fees for referrals of patients.

SECTION 13. A physician shall respect the law. When necessary a physician shall attempt to formulate the law by all proper means in order to improve patient care and public health.

SECTION 14. In addition to adhering to the foregoing ethical standards, a physician shall recognize a responsibility to participate in community activities and services.

SECTION 15. It is considered sexual misconduct for a physician to have sexual contact with any current patient whom the physician has interviewed and/or upon whom a medical or surgical procedure has been performed.

SECTION 16. Sexual harassment by a physician is considered unethical. Sexual harassment is defined as physical or verbal intimation of a sexual nature involving a colleague or subordinate in the workplace or academic setting, when such conduct creates an unreasonable, intimidating, hostile or offensive workplace or academic setting.

SECTION 17. The use of a product of service based solely on the receipt of a gift shall be deemed unethical.

CODE OF ETHICS AND GUIDE TO THE ETHICAL BEHAVIOUR OF PHYSICIANS

Canadian Medical Association

REVISED 1990, 1996

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Most recently revised by the Canadian Medical Association (CMA) in 1996, the CMA Code of Ethics and Guide to the Ethical Behaviour of Physicians delineate standards of ethical behavior for Canadian physicians. The code offers six general responsibilities; the rest of the code pertains to the physician–patient relationship, communication, consent, confidentiality, clinical research, professional fees and responsibility to onself.

<http://www.cma.ca/cma/common/displayPage.do?pageId=/staticContent/HTML/N0/l2/where_we_stand/1996/10–15.htm>

Preface

The Canadian Medical Association accepts the responsibility for delineating the standard of ethical behaviour expected of Canadian physicians and has developed and approved this Code of Ethics as a guide for physicians.

The Code is an ethical document. Its sources are the traditional codes of medical ethics such as the Hippocratic Oath, as well as developments in human rights and recent bioethical discussion. Legislation and court decisions may also influence medical ethics. Physicians should be aware of the legal and regulatory requirements for medical practice in their jurisdiction. However, the Code may set out different standards of behaviour than does the law.

The Code has been prepared by physicians for physicians. It is based on the fundamental ethical principles of medicine, especially compassion, beneficence, non-maleficence, respect for persons and justice. It interprets these principles with respect to the responsibilities of physicians to individual patients, family and significant others, colleagues, other health professionals, and society.

The Code is not, and cannot be, exhaustive. Its statements are general in nature, to be interpreted and applied in particular situations. Specific ethical issues such as abortion, transplantation and euthanasia are not mentioned; they are treated in appropriate detail in CMA policy statements.

Physicians may experience conflict between different ethical principles, between ethical and legal or regulatory requirements, or between their own ethical convictions and the demands of patients, proxy decision makers, other health professionals, employers or other involved parties. Training in ethical analysis and decision making during undergraduate, postgraduate and continuing medical education is recommended for physicians to develop the knowledge, skills and attitudes needed to deal with these conflicts. Consultation with colleagues, licensing authorities, ethicists, ethics committees or others who have expertise in these matters is also recommended.

The Code applies to physicians, including residents, and medical students.

General Responsibilities

1. Consider first the well-being of the patient.
2. Treat all patients with respect; do not exploit them for personal advantage.
3. Provide for appropriate care for your patient, including physical comfort and spiritual and psychosocial support even when cure is no longer possible.
4. Practise the art and science of medicine competently and without impairment.
5. Engage in lifelong learning to maintain and improve your professional knowledge, skills and attitudes.
6. Recognize your limitations and the competence of others and when indicated, recommend that additional opinions and services be sought.

Responsibilities to the Patient

Initiating and Dissolving a Patient-Physician Relationship

7. In providing medical service, do not discriminate against any patient on such grounds as age, gender, marital status, medical condition, national or ethnic origin, physical or mental disability, political affiliation, race, religion, sexual orientation, or socioeconomic status. This does not abrogate the physician's right to refuse to accept a patient for legitimate reasons.
8. Inform your patient when your personal morality would influence the recommendation or practice of any medical procedure that the patient needs or wants.
9. Provide whatever appropriate assistance you can to any person with an urgent need for medical care.
10. Having accepted professional responsibility for a patient, continue to provide services until they are no longer required or wanted; until another suitable physician has assumed responsibility for the patient;

or until the patient has been given adequate notice that you intend to terminate the relationship.

11. Limit treatment of yourself or members of your immediate family to minor or emergency services and only when another physician is not readily available; there should be no fee for such treatment.

Communication, Decision Making and Consent

12. Provide your patients with the information they need to make informed decisions about their medical care, and answer their questions to the best of your ability.
13. Make every reasonable effort to communicate with your patients in such a way that information exchanged is understood.
14. Recommend only those diagnostic and therapeutic procedures that you consider to be beneficial to your patient or to others. If a procedure is recommended for the benefit of others, as for example in matters of public health, inform your patient of this fact and proceed only with explicit informed consent or where required by law.
15. Respect the right of a competent patient to accept or reject any medical care recommended.
16. Recognize the need to balance the developing competency of children and the role of families in medical decision-making.
17. Respect your patient's reasonable request for a second opinion from a physician of the patient's choice.
18. Ascertain wherever possible and recognize your patient's wishes about the initiation, continuation or cessation of life-sustaining treatment.
19. Respect the intentions of an incompetent patient as they were expressed (e.g., through an advance directive or proxy designation) before the patient became incompetent.
20. When the intentions of an incompetent patient are unknown and when no appropriate proxy is available, render such treatment as you believe to be in accordance with the patient's values or, if these are unknown, the patient's best interests.
21. Be considerate of the patient's family and significant others and cooperate with them in the patient's interest.

Confidentiality

22. Respect the patient's right to confidentiality except when this right conflicts with your responsibility to the law, or when the maintenance of confidentiality would result in a significant risk of substantial harm to others or to the patient if the patient is incompetent; in such cases, take all reasonable steps to inform the patient that confidentiality will be breached.
23. When acting on behalf of a third party, take reasonable steps to ensure that the patient understands the nature and extent of your responsibility to the third party.
24. Upon a patient's request, provide the patient or a third party with a copy of his or her medical record, unless there is a compelling reason to believe that information contained in the record will result in substantial harm to the patient or others.

Clinical Research

25. Ensure that any research in which you participate is evaluated both scientifically and ethically, is approved by a responsible committee and is sufficiently planned and supervised that research subjects are unlikely to suffer disproportionate harm.
26. Inform the potential research subject, or proxy, about the purpose of the study, its source of funding, the nature and relative probability of harms and benefits, and the nature of your participation.
27. Before proceeding with the study, obtain the informed consent of the subject, or proxy, and advise prospective subjects that they have the right to decline or withdraw from the study at any time, without prejudice to their ongoing care.

Professional Fees

28. In determining professional fees to patients, consider both the nature of the service provided and the ability of the patient to pay, and be prepared to discuss the fee with the patient.

Responsibilities to Society

29. Recognize that community, society and the environment are important factors in the health of individual patients.
30. Accept a share of the profession's responsibility to society in matters relating to public health, health education, environmental protection, legislation affecting the health or well-being of the community, and the need for testimony at judicial proceedings.
31. Recognize the responsibility of physicians to promote fair access to health care resources.
32. Use health care resources prudently.

33. Refuse to participate in or support practices that violate basic human rights.
34. Recognize a responsibility to give the generally held opinions of the profession when interpreting scientific knowledge to the public; when presenting an opinion that is contrary to the generally held opinion of the profession, so indicate.

Responsibilities to the Profession

35. Recognize that the self-regulation of the profession is a privilege and that each physician has a continuing responsibility to merit this privilege.
36. Teach and be taught.
37. Avoid impugning the reputation of colleagues for personal motives; however, report to the appropriate authority any unprofessional conduct by colleagues.
38. Be willing to participate in peer review of other physicians and to undergo review by your peers.
39. Enter into associations only if you can maintain your professional integrity.
40. Avoid promoting, as a member of the medical profession, any service (except your own) or product for personal gain.
41. Do not keep secret from colleagues the diagnostic or therapeutic agents and procedures that you employ.
42. Collaborate with other physicians and health professionals in the care of patients and the functioning and improvement of health services.

Responsibilities to Oneself

43. Seek help from colleagues and appropriately qualified professionals for personal problems that adversely affect your service to patients, society or the profession.

CODE OF ETHICS AND GUIDE TO THE ETHICAL BEHAVIOUR OF PHYSICIANS

New Zealand Medical Association

1989, LAST AMENDED 2002

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The current New Zealand Medical Association (NZMA) Code of Ethics, which includes a Guide to the Ethical Behaviour of Physicians, was adopted in 1989, amended in December 1992, and last amended in March of 2002. There is great similarity, both in structure and content, between the NZMA code and the preceding code and guide of the Canadian Medical Association. The section of the NZMA entitled "Responsibilities to the Profession" and portions of the section entitled "Responsibilities to Society," not printed here, repeat some of the prescriptions of the Canadian code.

<http://www.nzma.org.nz/about/ethics.html>

Code of Ethics

All medical practitioners, including those who may not be engaged directly in clinical practice, will acknowledge and accept the following Principles of Ethical Behaviour:

1. Consider the health and well-being of the patient to be your first priority.
2. Respect the rights of the patient.
3. Respect the patient's autonomy and freedom of choice.
4. Avoid exploiting the patient in any manner.
5. Protect the patient's private information throughout his/her lifetime and following death, unless there are overriding public interest considerations at stake, or a patient's own safety requires a breach of confidentiality.
6. Strive to improve your knowledge and skills so that the best possible advice and treatment can be offered to the patient.
7. Adhere to the scientific basis for medical practice while acknowledging the limits of current knowledge.
8. Honour the profession and its traditions in the ways that best serve the interests of the patient.
9. Recognise your own limitations and the special skills of others in the prevention and treatment of disease.
10. Accept a responsibility for assisting in the allocation of limited resources to maximise medical benefit across the community.
11. Accept a responsibility for advocating for adequate resourcing of medical services.

Recommendations

Given the complexities of doctor–patient relationships, and the increasing difficulties brought about by the need for rationing of resources and direct intervention of third-party providers of funding, no set of guidelines can cover all situations. The following set of recommendations is designed to convey an overall pattern of professional behaviour consistent with the principles set out above in the Code of Ethics.

Responsibilities to the Patient

1. Doctors should ensure that all conduct in the practice of their profession is above reproach. Exploitation of any patient, whether it be physical, sexual, emotional, or financial, is unacceptable and the trust embodied in the doctor–patient relationship must be respected.
2. Doctors, like a number of other professionals, are involved in relationships in which there is a potential imbalance of power. Sexual relationships between doctors and their patients and students fall within this category. The NZMA is mindful of Medical Council policy in relation to sexual relationships with present and former patients, and expects doctors to be familiar with this. The NZMA considers that a sexual relationship with a current patient is unethical and that, in most instances, sexual relations with a former patient would be regarded as unethical, particularly where exploitation of patient vulnerability occurs. It is acknowledged that in some cases the patient–doctor relationship may be brief, minor in nature, or in the distant past. In such circumstances and where the sexual relationship has developed from social contact away from the professional environment, impropriety would not necessarily be inferred. Any complaints about a sexual relationship with a former patient need to be considered on an individual basis before being condemned as unethical.
3. Doctors should practise the science and art of medicine to the best of their ability in full moral independence, with compassion and respect for human dignity.
4. Doctors should ensure that every patient receives appropriate investigation into their complaint or condition, including adequate collation of information for optimal management.
5. Doctors should ensure that information is recorded accurately and is securely maintained.
6. Doctors should seek to improve their standards of medical care through continuing self education and thoughtful interaction with appropriate colleagues.
7. Doctors have the right, except in an emergency, to refuse to care for a particular patient. In any situation which is not an emergency, doctors may withdraw from or decline to provide care as long as an alternative source of care is available and that the appropriate avenue for securing this is known to the patient. Where a doctor does withdraw care from a patient, reasonable notice should be given.
8. When a patient is accepted for care, doctors will render medical service to that person without discrimination (as defined by the Human Rights Act).
9. Doctors should ensure that continuity of care is available in relation to all patients, whether seen urgently or unexpectedly, or within a long-term contractual setting, and should establish appropriate arrangements to cover absence from practice or hours off duty, informing patients of these.
10. Doctors should ensure that patients are involved, within the limits of their capacities, in understanding the nature of their problems, the range of possible solutions, as well as the likely benefits, risks, and costs, and shall assist them in making informed choices.
11. Doctors should recognise the right of patients to choose their doctors freely.
12. Doctors should recognise their own professional limitations and, when indicated, recommend to patients that additional opinions and services be obtained, and accept a patient's right to request other opinions. In making a referral to another health professional, so far as practical, the doctor shall have a basis for confidence in the competence of that practitioner.
13. Doctors should accept the right of a patient to be referred for further management in situations where there is a moral or clinical disagreement about the most appropriate course to take.
14. Doctors should keep in confidence information derived from a patient, or from a colleague regarding a patient, and divulge it only with the permission of the patient except when the law requires otherwise, or in those unusual circumstances when it is clearly in the patient's best interests or there is an overriding public good. Patients should be made aware of the information sharing which enables the delivery of good quality medical care. Where a patient expressly limits possession of particular information to one practitioner, this must ordinarily be respected. Patients should be made aware in advance, if possible, where there are limits to the confidentiality which can be provided. When it is necessary to divulge confidential patient information this must be done only to the proper authorities, and a record kept of when reporting occurred and its significance.
15. Doctors should recommend only those diagnostic procedures which seem necessary to assist in the care of the patient and only that treatment which seems necessary for the well-being of the patient.
16. When requested or when need is apparent, doctors should provide patients with information required to enable them to receive benefits to which they may be entitled.
17. Doctors shall accept those obligations to patients which are imposed by statutory provisions and the

codes of the Privacy Commissioner, the Human Rights Commissioner and the Health and Disability Commissioner, and the requirements of the Medical Council of New Zealand.

18. Doctors have a duty to explain to patients the role of doctors, patients and citizens generally in advancing medical knowledge, given that medical knowledge evolves in the light of ongoing research.
19. Doctors should accept that autonomy of patients remains important in childhood, chronic illness, ageing, and in the process of dying.
20. Doctors should bear in mind always the obligation of preserving life wherever possible and justifiable, while allowing death to occur with dignity and comfort when it appears to be inevitable. Doctors should be prepared to discuss and contribute to the content of advance directives and give effect to them. In the case of conflicts concerning management, doctors should consult widely within the profession and, if indicated, with ethicists and legal authorities.
21. In relation to transplantation and requests for organ donation, doctors should accept that when death of the brain has occurred, the cellular life of the body may be supported if some parts of the body might be used to prolong or improve the health of others. They shall recognise their responsibilities to the donor of organs that will be transplanted by disclosing fully to the donor or relatives the intent and purpose of the procedure. In the case of a living donor, the risks of the donation procedures must be fully explained. Doctors will ensure that the determination of the time of death of any donor patient is made by doctors who are in no way concerned with the transplant procedure or associated with the proposed recipient in a way that might exert any influence upon any decisions made.
22. Doctors have a responsibility to ensure that all people in their employ are fully aware of the appropriate actions to be taken in cases of medical emergency. It is strongly recommended that these procedures be included in a written policy document.

Professional Responsibilities

23. Doctors have both a right and a responsibility to maintain their own health and well-being at a standard that ensures that they are fit to practise.
24. Doctors should seek guidance and assistance from colleagues and professional or healthcare organisations whenever they are unable to function in a competent, safe and ethical manner.
25. Doctors have a general responsibility for the safety of patients and shall therefore take appropriate steps to ensure unsafe or unethical practices on the part of colleagues are curtailed and/or reported to relevant authorities without delay.
26. Doctors should make available to their colleagues, on the request of patients, a report or summary of their findings and treatment relating to that patient.
27. Doctors should recognise that an established relationship between doctor and patient has a value which dictates that this should not be disturbed without compelling reasons. Disruption of such a relationship should, wherever possible, be discussed in advance with an independent colleague.
28. Doctors should avoid impugning the reputations of other doctors with colleagues, patients or other persons.
29. Doctors should accept a share of the profession’s responsibility toward society in matters relating to the health and safety of the public, health promotion and education, and legislation affecting the health or well-being of the community.
30. Doctors should not countenance, condone or participate in the practice of torture or other forms of cruel, inhuman, or degrading procedures, whatever the offence of which the victim of such procedures is suspected, accused or guilty.
31. Doctors should recognise the responsibility to assist courts, commissioners, commissions, and disciplinary bodies, in arriving at just decisions. In all circumstances doctors shall certify only that which has been personally verified when they are testifying as to circumstances of fact.
32. Doctors should not allow their standing as medical professionals to be used inappropriately in the endorsement of commercial products. When doctors are acting as agents for, or have a financial or other interest in, commercial organisations, their interest must be declared to patients.
33. Doctors should not use secret remedies.
34. Advances and innovative approaches to medical practice should be subject to review and promulgation through professional channels and medical scientific literature. Doctors should accept responsibility for providing the public with carefully considered, generally accepted opinions when presenting scientific knowledge. In presenting any personal opinion contrary to a generally held viewpoint of the profession, doctors must indicate that such is the case, and present information fairly.
35. Doctors should accept that their professional reputation must be based upon their ability, technical skills and integrity. Doctors should advertise professional services or make professional

announcements only in circumstances where the primary purpose of any notification is factual presentation of information reasonably needed by any person wishing to make an informed decision about the appropriateness and availability of services that may meet his or her medical needs. Any such announcement or advertisement must be demonstrably true in all respects and contain no testimonial material or endorsement of clinical skills. Qualifications not recognised by appropriate New Zealand statutory bodies should not be quoted.

36. Doctors should exercise careful judgement before accepting any gift, hospitality or gratuity which could be interpreted as an inducement to use or endorse any product, equipment or policy. In all cases of doubt, advice should be sought from relevant professional organisations.

Research

37. Before initiating or participating in any clinical research, doctors must assure themselves that the particular investigation is justified in the light of previous research and knowledge. Any proposed study should reasonably be expected to provide the answers to the questions raised. All studies involving patients should be subject to the scrutiny of an Ethics Committee before initiation. It is often appropriate to establish a committee independent of the primary investigators, initiators and funders of a trial to oversee ongoing ethical issues, including the evaluation of emerging results according to stated clinical, ethical and scientific criteria.
38. Doctors must be assured that the planning and conduct of any particular study is such that it minimises the risk of harm to participants. In comparative studies, the patient and control groups must receive the best available treatment.
39. Patient consent for participating in clinical research (or permission of those authorised to act on their behalf) should be obtained in writing only after a full written explanation of the purpose of that research has been made, and any foreseeable health hazards outlined. Opportunity must be given for questioning and withdrawal. When indicated, an explanation of the theory and justification for double-blind procedures should be given. Acceptance or refusal to participate in a clinical study must never interfere with the doctor–patient relationship or access to appropriate treatment. No degree of coercion is acceptable.
40. Boundaries between formalised clinical research and various types of innovation have become blurred to an increasing extent. Doctors retain the right to recommend, and any patient has the right to receive, any new drug or treatment which, in the doctor's considered judgement, offers hope of saving life, re-establishing health or alleviating suffering. Doctors are advised to document carefully the basis for any such decisions and also record the patient's perception and basis for a decision. In all such cases the doctors must fully inform the patient about the drug or treatment, including the fact that such treatment is new or unorthodox, if that is so.
41. In situations where a doctor is undertaking an innovative or unusual procedure on his or her own initiative, it is wise to consult colleagues. This recommendation applies particularly in relation to care of the dying.
42. It is the duty of doctors to ensure that the first communication of research results be through recognised scientific channels, including journals and meetings of professional bodies, to ensure appropriate peer review. Participants in the research should also be informed of the results as soon as is practicable after completion.
43. Doctors should not participate in clinical research involving control by the funder over the release of information or results, and must retain the right to publish or otherwise release any findings they have made. Any dispute or ethical issue which may arise in the course of research should be considered openly, e.g. by consultation with the Ethics Committee of the NZMA and/or Regional Ethics Committees.

Teaching

44. Clinical teaching is the basis on which sound clinical practice is based. It is the duty of doctors to share information and promote education within the profession. Education of colleagues and medical students should be regarded as a responsibility for all doctors.
45. Teaching involving direct patient contact must be undertaken with sensitivity, compassion, respect for privacy, and, whenever possible, with the consent of the patient, guardian or appropriate agent. Particular sensitivity is required when patients are disabled or disempowered, e.g. children. If teaching involves a patient in a permanent vegetative state, the teacher should, if at all possible, consult with a nursing or medical colleague and a relative before commencing the session.
46. Wherever possible, patients should be given sufficient information on the form and content of the teaching, and adequate time for consideration,

before consenting or declining to participate in clinical teaching. Refusal by a patient to participate in a study or teaching session must not interfere with other aspects of the doctor–patient relationship or access to appropriate treatment.

47. Patients' understanding of, or perspective on, their medical problems may be influenced by involvement in clinical teaching. Doctors must be sensitive to this possibility and ensure that information is provided in an unbiased manner, and that any questions receive adequate answers. It may be appropriate for the doctor to return later to address these issues.

Medicine and Commerce

48. Commercial interests of an employer, health provider, or doctor must not interfere with the free exercise of clinical judgement in determining the best ways of meeting the needs of individual patients or the community, nor with the capacities of individual doctors to co-operate with other health providers in the interests of their patients, nor compromise standards of care in order to meet financial or commercial targets.
49. Where potential conflict arises between the best interests of particular patients and commercial or rationing prerogatives, doctors have a duty to explain the issues and dilemmas to their patients. Doctors shall state quite clearly what their intentions are and why they advocate particular patterns of diagnosis, treatment or resource use. Rationing of resources must be open to public scrutiny and points of conflict identified and presented in a rational, non-biased manner to the public.
50. Doctors who provide capital towards health services in the private sector are entitled to expect a reasonable return on investment. Where there may be a conflict of interests, the circumstances should be disclosed and open to scrutiny.
51. Like all professionals, doctors have the right to fair recompense for the use of their skills and experience. However, motives of profit must not be permitted to influence professional judgement on behalf of patients.
52. Doctors should insist that any contracts into which they enter, including those involving patients, be written in clear language such that all parties have a clear understanding of the intentions and rules.
53. Doctors who find themselves in a potentially controversial contractual or commercial situation should seek the advice of a suitable colleague or organisation.

CODE OF ETHICS OF THE CHILEAN MEDICAL ASSOCIATION

Chilean Medical Association

1983

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Approved by the Honorable General Council in November 1983, the Code of Ethics of the Chilean Medical Association sets moral standards for the conduct of members of the association and "should only be used by and for physicians." Articles of particular note include: (1) article 25, which proscribes physician participation in torture; (2) article 26, which permits abortion only for therapeutic reasons and, along with articles 27–28, reflects the prevalence of Catholicism in Chile; (3) articles 27 and 28, which pertain to euthanasia and death with dignity; and (4) article 44, which provides for a patient or the patient's family to request a review board to investigate the clinical findings and recommendations of the attending physician.

Declaration of Principles

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A respect for life and the human person is the basic foundation for the professional practice of medicine.

The ethical principles that govern the conduct of physicians oblige them to protect the human being from pain, suffering, and death without any discrimination.

Decorum, dignity, honesty, and moral integrity, as imperative norms in the life of a doctor, are attributes the medical community deems fundamental in its professional practice.

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Title I

General Resolutions

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ARTICLE 10. Doctor-patient confidentiality is both a right and an obligation of the profession. With respect to any patient this is imperative, even when the patient is no longer under a particular physician's care.

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If a patient communicates to a physician the intent to commit a crime, such communication is not protected by the right and duty of doctor–patient confidentiality, and the physician must reveal any information necessary for the prevention of a crime or to protect any person(s) in danger.

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Title II

On the Duties of the Doctor toward Patients

ARTICLE 13. The physician must attend to the needs of any person requiring his or her services and, in the absence of another colleague able to care for the patient, may not deny such attention.

ARTICLE 14. Physicians may not, under any circumstances, directly or indirectly reveal facts, data, or information that they have learned or that have been revealed to them in the course of their professional work, except by judicial order, or by freely expressed authorization by a patient who is of legal age and of sound mind.

Doctor-patient confidentiality is an objective right of the patient that the physician must absolutely respect as a natural right, based neither on promise nor on pact. Doctor-patient confidentiality includes the patient's name.

ARTICLE 15. In cases where it may be therapeutically necessary to have recourse to treatments involving known risk or serious disfiguring of the patient, the physician may not act without the express and informed consent of the patient or responsible family members when the patient is a minor or otherwise unable to make such decisions.

In emergency situations or in the absence of responsible family members and without the possibility of communication with them, or in the event that there be no next of kin, the physician may proceed without the above-mentioned authorization and without prejudice, after attempting to obtain the concurring opinion of another colleague in the treatment.

ARTICLE 16. No physician may participate or advise in any transaction involving the transplantation of organs if said transaction involves monetary gain.

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ARTICLE 22. Scientific biomedical research on human beings is necessary; however, it is acceptable only when it does not involve serious health risks. It should always be carried out under direct medical supervision.

Its design and development should follow a strict protocol and be subject to scientific and ethical review. The patient or subject of the research must be informed of both potential risks and benefits, must give consent, and must reserve the right to abstain from any part of or withdraw from the study at any time.

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ARTICLE 25. A physician shall not support or participate in the practice of torture or the infliction of any other cruel, inhumane, or degrading procedures, regardless of the offense(s) of which the victim of such procedures is accused or guilty, and regardless of the beliefs or motivation of the accused or guilty victim of such procedures, including armed conflict or civil war.

A physician must not provide any rationale, instrument, substance, or knowledge expertise that would facilitate the practice of torture or other forms of cruel, inhumane, or degrading treatment, or for the purpose of diminishing the victim's capacity to resist such treatment.

A physician must not be present before, during, or after any procedure in which torture or other forms of cruel, inhumane, or degrading treatment are used as a threat.

ARTICLE 26. A physician must respect human life from the moment of conception. Abortion may be performed only under the following circumstances:

a) it is performed for therapeutic reasons;
b) the decision is approved in writing by two physicians chosen for their competence;
c) the procedure is carried out by a specialist in the field.

If a physician considers that it is against his or her convictions to perform an abortion, he or she must withdraw, permitting the patient to continue medical care with another qualified physician.

ARTICLE 27. A physician must not under any circumstances deliberately end the life of a patient. No authority may order or permit a physician to do so. Furthermore, no patient or person responsible for making decisions for the patient may request this of a physician.

ARTICLE 28. Every person has the right to die with dignity. Thus, diagnostic and therapeutic procedures must be proportionate to the results that can be hoped for from such procedures.

A physician must relieve a patient's pain and suffering even though this may involve the risk of shortening the patient's life.

In the event of an imminent and inevitable death, were routine life support interrupted, a physician may in good faith make the decision to withhold any treatment that would prolong a precarious and painful condition. In a case where the patient is proven to be brain dead, the physician is authorized to withhold any and all types of treatment.

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Title III

On Physicians' Relationship with Colleagues

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ARTICLE 44. Any and all physicians must consult with one or more colleagues whenever the making of a diagnosis, the type of illness, or treatment requires such collaboration.

A patient or patient's family, with the knowledge of the attending physician, may ask that a Review Board be arranged if they deem it necessary.

It is a moral duty of the attending physician to accept the collaboration of colleagues convened on the Review Board, who shall examine the patient in the presence of the attending physician and one after the other, except in special cases. The findings of the Board shall be discussed among the attending and collaborating physicians before the Chief Physician makes them known to the patient or to the patient's family.

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CODE OF MEDICAL ETHICS, BRAZIL

Federal Council of Medicine

1988

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Brazil's Federal Council of Medicine approved the current Code of Medical Ethics in January 1988, rescinding the 1965 Code of Medical Ethics and the 1984 Brazilian Code of Medical Deontology. The preamble states that the code "contains the ethical standards governing physicians"; that "organizations delivering medical services are subject to the standards in this code"; and, interestingly, that "those who violate this code are subject to disciplinary action as stated by law." Other interesting features of the code include: (1) statements regarding occupational health and the natural environment (articles 12, 13); (2) the right of physicians to strike (article 24); and (3) the requirement that protocols for medical research be submitted to an independent committee for approval and monitoring (article 127).

Chapter I

Basic Principles

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ART. 6 – The physician shall have utmost respect for human life, always acting in the interest of the patient. He/she will never use his/her knowledge to inflict physical or moral suffering, to end the life of an individual, or to allow cover-ups against his dignity and integrity.

ART. 7 – The physician shall practice his/her profession with ample autonomy and is not forced to provide professional services to an individual against his/her will, except in the absence of another physician, in emergency cases, or when his refusal could cause irreversible damage to the patient.

ART. 8 – The physician may not, under any circumstance or pretext, renounce his professional freedom and shall disallow any restriction or imposition that could harm the efficacy and appropriateness of his/her work.

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ART. 11 – The physician shall keep information, obtained during the practice of his profession, confidential. The same applies to his/her work with businesses, except in cases when such information damages or poses a risk to the health of an employee, or the community.

ART. 12 – The physician shall promote an appropriate working environment for the individual, and the elimination, or control, of risks inherent in his/her work.

ART. 13 – The physician shall inform competent authorities of any forms of pollution and deterioration of the environment, that pose a risk to health and life.

ART. 14 – The physician shall promote the improvement of health conditions and medical service standards, and take part in responsibilities in relation to public health, health education, and health legislation.

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Chapter II

Rights of the Physician

The physician has the right to:

ART. 20 – Practice Medicine without being discriminated against in terms of religion, race, sex, nationality, color, sexual choice, social status, political opinion, or for any other reason.

ART. 21 – Recommend adequate procedures to the patient, observing regularly accepted practice and respecting legal standards in force in the country.

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ART. 24 – Suspend his/her activities, individually or collectively, when the public or private institution for which he/she works, does not offer minimal conditions for the practice of his/her profession, or does not pay accordingly, except in conditions of urgency and emergency. This decision shall be communicated immediately to the Regional Council of Medicine.

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ART. 27 – When employed, dedicate the time and professional experience recommended for the performance of his/her duties, to the patient, avoiding excessive workloads or consultations that could harm the patient.

ART. 28 – Refuse to perform medical practices, although allowed by law, that are contrary to his/her conscience.

Chapter III

Professional Responsibility

The physician is forbidden:

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ART. 40 – Not to inform the individual about working conditions that could pose a risk to his/her health. These facts must be communicated to those in charge, the authorities, and the Regional Council of Medicine.

ART. 41 – Not to inform the patient about social, environmental, or professional implications of his/her illness.

ART. 42 – To practice or recommend medical procedures, not necessary or forbidden by local law.

ART. 43 – Not to abide by specific legislation on organ or tissue transplants, sterilization, artificial insemination, and abortion.

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Chapter IV

Human Rights

The physician is forbidden:

ART. 46 – To perform any medical procedure without previous explanation and consent of the patient or his/her legal representative, except in cases of imminent threat to life.

ART. 47 – To discriminate against a human being in any way or under any pretext.

ART. 48 – To exercise his/her authority in such a way that it limits the right of the patient to decide freely for him/herself or on his/her well-being.

ART. 49 – To participate in the practice of torture, or any other degrading procedures, that are inhuman or cruel; to be an accomplice in these kinds of practices, and not to denounce them when they come to his/her knowledge.

ART. 50 – To provide means, instruments, substances, or knowledge that facilitate the practice of torture or other kinds of degrading, inhuman, and cruel procedures, in relation to the individual.

ART. 51 – To force-feed any person on a hunger strike, who is considered capable, physically and mentally, of making perfect judgement of possible complications from this attitude. In these cases, the physician shall inform the individual of possible complications from prolonged lack of nutrition and treat him/her if there is imminent danger to life.

ART. 52 – To use any process that might change the personality or conscience of an individual, to decrease his/her physical or mental resistance during a police investigation or of any other kind.

ART. 53 – Not to respect the interest and integrity of an individual, by treating him/her in any institution where the person is being kept against his/her will.

Any procedures damaging the personality or physical or mental health of an individual, while under the care of a physician, shall compel the physician in charge to denounce this fact to the competent authorities and to the Regional Council of Medicine.

ART. 54 – To provide means, instruments, substances, knowledge, or to participate in any way, in the execution of a death penalty.

ART. 55 – To use the profession to corrupt customs or to commit or favor crime.

Chapter V

Relation with Patients and Family Members

The physician is forbidden:

ART. 56 – To disregard the right of the patient to decide freely about the performance of diagnostic or therapeutic practices, except in cases of imminent loss of life.

ART. 57 – Not to use all available diagnostic and treatment means within his/her reach in favor of the patient.

ART. 58 – Not to treat a patient, looking for his/her professional care, in an emergency, when there are no other physicians or medical services available.

ART. 59 – Not to inform the patient of the diagnosis, prognosis, risks and objectives of treatment, except when direct communication may be harmful to the patient. In this case, communication shall take place with the legal representative of the patient.

ART. 60 – To exaggerate the seriousness of a diagnosis or prognosis, to complicate treatment, or to exceed the number of visits, consultations, or any other medical procedures.

ART. 61 – To abandon a patient under his/her care.

§1 – Under circumstances, that in his/her view are harmful to the doctor–patient relationship or that interfere with full professional performance, a physician has the right to renounce treatment, as long as this fact is previously communicated to the patient or his/her legal representative, with the assurance of continuity of care and supplying all necessary information to the substituting physician.

§2 – Except in cases of just cause, communicated to the patient or his/her family members, the physician may not abandon the patient for having a chronic or incurable disease. The physician shall continue to treat him/her, even if only to alleviate physical or psychological suffering.

ART. 62 – To prescribe treatment or other procedures without examining the patient directly, except in emergency cases or the impossibility of performing such an examination. In this case, the examination shall be performed as soon as possible.

ART. 63 – Not to respect the modesty of any individual in his/her professional care.

ART. 64 – To oppose the realization of a medical inquiry requested by the patient or his legal representative.

ART. 65 – To take advantage of the doctor–patient relationship to obtain physical, emotional, financial, or political advantages.

ART. 66 – To use, in any case, means to shorten the life of a patient, even if requested to do so, by the patient or his legal representative.

ART. 67 – Not to respect the right of the patient to decide freely on a contraceptive or conceptive method. The physician shall always explain indication, reliability, and reversibility, as well as the risk of each method.

ART. 68 – To practice artificial insemination, without total consent by the participants, with the procedure duly explained.

ART. 69 – Not to maintain medical records for each patient.

ART. 70 – To deny the patient access to his/her medical records, clinical or similar records, as well as not to provide explanations necessary for their understanding, except when this incurs risks for the patient or third parties.

ART. 71 – Not to provide a medical opinion to the patient, upon referral or transfer for the continuity of care, or upon release, if requested to do so.

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Chapter IX

Medical Confidentiality

The physician is forbidden:

ART. 102 – To reveal the fact that he is aware of information received during the practice of his/her profession, except for just cause, legal duty, or express authorization by the patient.

This is maintained:

a) Even if the fact is public knowledge or if the patient is deceased.
b) When testifying. In this instance, the physician shall present him/herself and declare his/her constraint.

ART. 103 – To reveal a professional secret relating to a minor, including to his/her parents or legal representatives, as long as the minor is capable of resolving his/her problem by his/her own means, except when the lack of revelation could imply damage to the patient.

ART. 104 – To make reference to identifiable clinical cases, exhibit patients or their photographs in professional announcements or during medical programs on radio, television or movies, as well as in articles, interviews or newspaper reports, magazines or other publications not specific to Medicine.

ART. 105 – To reveal confidential information obtained during the medical exam of workers, including upon demand by directors of businesses or institutions, except if silence poses a risk to the health of workers or the community.

ART. 106 – To provide insurance companies with any information about the circumstances of the death of his/her patient, beyond that contained in the death certificate, except by express authorization of the legal representative or heir.

ART. 107 – Not to inform his/her assistants and not to promote the respect of professional secrecy, as required by law.

ART. 108 – To facilitate the handling and knowledge of medical records, forms, and other kinds of medical observations, subject to professional secrecy, by persons not obligated by this commitment.

ART. 109 – Not to maintain professional secrecy when recovering professional fees by judicial or extra-judicial means.

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Chapter XII

Medical Research

The physician is forbidden:

ART. 122 – To participate in any type of experiment with human beings with warlike, political, racial, or eugenic reasons.

ART. 123 – To perform research on an individual, without his/her express consent in writing, after having had the nature and consequence of research duly explained.

If the patient is not in condition to give his/her consent, research shall only be performed, in his/her own benefit, after express authorization by his/her legal representative.

ART. 124 – To use any type of experimental treatment, not approved for use in the country, without due authorization by competent authorities and without the consent of the patient or his legal representative, duly informed of the situation and possible consequences.

ART. 125 – To promote medical research in the community without knowledge by the community and with a purpose not directed at public health, in consideration of local characteristics.

ART. 126 – To obtain personal advantages or have any commercial interest or to renounce his/her professional independence in relation to medical research financing entities in which he/she participates.

ART. 127 – To perform medical research on individuals without having submitted the protocol for approval and monitoring of a commission not subject to any entity related to the researcher.

ART. 128 – To perform medical research on volunteers, healthy or not, who have a direct or indirect relation of dependency or subordination with the researcher.

ART. 129 – To perform or participate in medical research in which there is a need to suspend or to stop using recognized treatment, thereby harming the patient.

ART. 130 – To perform experiments with new clinical or surgical treatment on incurable or terminal patients, without reasonable hope for positive effects, imposing additional suffering.

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EUROPEAN CODE OF MEDICAL ETHICS

Conférence Internationale des Ordres et des Organismes d'Attributions Similaies

1987

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Drafted in January 1987 by the Conférence Internationale des Ordres et des Organismes d'Attributions Similaires, this European Code of Medical Ethics represents one effort to articulate medical ethics guidelines for the European Community. The code represents a guide for the countries involved, each of which must decide whether further action at a national level is warranted. The twelve participating countries and their representative bodies include: Belgium, Conseil National de l'Ordre des Médecins Belges; Denmark, Danish Medical Association and National Board of Health; Spain, Consejo General de Colegios Oficiales de Medicos; France, Conseil National de l'Ordre des Médecins Français; Luxembourg, Collège Médical; Ireland, Medical Council; Italy, Federazione Nazionale degli Ordini dei Medici; The Netherlands, Koninklijke Nederlandsche Maatschappij tot Bevordering der Geneeskunst; Portugal, Ordem dos Medicos; Germany, Bundesärztekammer; United Kingdom, General Medical Council; and observer for Sweden, Association Médicale Suédoise.

This guide is intended to influence the professional conduct of doctors, in whatever branch of practice, in their contacts with patients, with society and between themselves. The guide also refers to the privileged position of doctors, upon which good medical practice depends. The Conference has recommended to its constituent regulatory bodies in each member state of the European Communities that they take such measures as may be necessary to ensure that their national requirements relating to the duties and privileges of doctors vis-à-vis their patients and society and in their professional relationships conform with the principles set out in this guide, and that there is provision within their legal systems for the effective enforcement of these principles.

ARTICLE 1

The doctor's vocation is to safeguard man's physical and mental health and relieve his suffering, while respecting human life and dignity with no discrimination on the grounds of age, race, religion, nationality, social status, political opinions or any other, whether in peace time or in war time.

Undertakings by the Doctor

ARTICLE 2

A doctor engaging in medical practice undertakes to give priority to the medical interests of the patient. The doctor may use his professional knowledge only to improve or maintain the health of those who place their trust in him; in no circumstances may he act to their detriment.

ARTICLE 3

A doctor engaging in medical practice must refrain from imposing on a patient his personal philosophical, moral or political opinions.

Enlightened Consent

ARTICLE 4

Except in an emergency, a doctor will explain to the patient the effects and the expected consequences of treatment. He will obtain the patient's consent, particularly when his proposed medical interventions present a serious risk.

The doctor may not substitute his own definition of the quality of life for that of his patient.

Moral and Technical Independence

ARTICLE 5

Both when given advice and when giving treatment, a doctor must make best use of his complete professional freedom and the technical and moral circumstances which permit him to act in complete independence.

The patient should be informed if these conditions are not met.

ARTICLE 6

When a doctor is working for a private or public authority or when he is acting on behalf of a third party, be it an individual or institution, he must also inform the patient of this.

Professional Confidentiality

ARTICLE 7

The doctor is necessarily the patient's confidant. He must guarantee to him complete confidentiality of all the information which he may have acquired and of the investigations which he may have undertaken in the course of his contacts with him.

The death of a patient does not absolve a doctor from the rule of professional secrecy.

ARTICLE 8

A doctor must respect the privacy of his patients and take all necessary steps to prevent the disclosure of anything which he may have learned in the course of his professional practice.

Where national law provides for exceptions to the principles of confidentiality, the doctor should be able to consult the Medical Council or equivalent professional authority.

ARTICLE 9

Doctors may not collaborate in the establishment of electronic medical data banks which could imperil or diminish the right of the patient to the safely protected confidentiality of his privacy. A nominated doctor should be responsible for ethical supervision and control of each computerised medical data bank.

Medical data banks must have no links with other data banks.

Standards of Medical Care

ARTICLE 10

The doctor must have access to all the resources of medical knowledge in order to utilise them as necessary for the benefit of his patient.

ARTICLE 11

He should not lay claim to a competence which he does not possess.

ARTICLE 12

He must call upon a more experienced colleague in any case which requires an examination or method of treatment beyond his own competence.

Care of the Terminally Ill

ARTICLE 13

While the practice of medicine must in all circumstances constantly respect the life, the moral autonomy and the free choice of the patient, the doctor may, in the case of an incurable and terminal illness, alleviate the physical and mental suffering of the patient by restricting his intervention to such treatment as is appropriate to preserve, so far as possible, the quality of a life which is drawing to its close.

It is essential to assist the dying patient right to the end and to take such action as will permit the patient to retain his dignity.

Removal of Organs

ARTICLE 14

In a case where it is impossible to reverse the terminal processes leading to the cessation of a patient's vital functions, doctors will establish that death has occurred, taking account of the most recent scientific data.

At least two doctors, acting individually, should take meticulous steps to verify that this situation has occurred, and record their findings in writing.

They should be independent of the team which is to carry out the transplantation and must, in all respects, give priority to the care of the dying patient.

ARTICLE 15

Doctors removing an organ for transplantation may give particular treatment designed to maintain the condition of that organ.

ARTICLE 16

Doctors removing organs for transplantation and those carrying out transplantations should take all practicable steps to ensure that the donor had not expressed opposition or left instructions to this effect either in writing or with his family.

Reproduction

ARTICLE 17

The doctor will furnish the patient, on request, with all relevant information on the subjects of reproduction and contraception.

ARTICLE 18

It is ethical for a doctor, by reason of his own beliefs, to refuse to intervene in the processes of reproduction or termination of pregnancy, and to suggest to the patients concerned that they consult other doctors.

Experimentation on Humans

ARTICLE 19

Progress in the field of medicine is based on research which must finally lead to experiments which have a direct bearing on humans.

ARTICLE 20

Details of all proposed experimentation involving patients must first be submitted to an ethical committee which is independent of the research team for opinions and advice.

ARTICLE 21

The free and informed consent of any person who is to be involved in a research project must be obtained after he has first been sufficiently informed of the aims, methods and expected benefits as well as the risks and potential problems, and of his right not to take part in experiments (or other research) and to withdraw from participation at any time.

Torture and Inhuman Treatment

ARTICLE 22

A doctor must never attend, take part in or carry out acts of torture or other kinds of cruel, inhuman or degrading treatment whatever the crime, accusation against, beliefs or motives of the victim or of those who commit these deeds, whatever the situation, including cases of civil or armed conflict.

ARTICLE 23

A doctor must never use his knowledge, his competence or his skills for the purpose of facilitating the use of torture or any other cruel, inhuman or degrading procedure for the purpose of weakening the resistance of a victim of these methods.

The Doctor and Society

ARTICLE 24

In order to accomplish his humanitarian duties, every doctor has the right to legal protection of his professional independence and his standing in society, in times of peace as in times of war.

ARTICLE 25

It is the duty of a doctor, whether acting alone or in conjunction with other doctors, to draw the attention of society to any deficiencies in the quality of health care or in the professional independence of doctors.

ARTICLE 26

Doctors must be involved in the development and the implementation of all collective measures designed to improve the prevention, diagnosis and treatment of disease. In particular, they must provide a medical contribution to the organisation of rescue services, particularly in the event of public disaster.

ARTICLE 27

They must participate, so far as their competence and available facilities permit, in constant improvement of the quality of care through research and continual refinement of methods of treatment, in accordance with advances in medical knowledge.

Relationships with Professional Colleagues

ARTICLE 28

The rules of professional etiquette were introduced in the interest of patients. They were designed to prevent patients becoming the victims of dishonest manoeuvres between doctors. The latter may, on the other hand, legitimately rely on their colleagues to adhere to the standards of conduct to which the profession as a whole subscribes.

ARTICLE 29

A doctor has a duty to inform the competent professional regulatory authorities of any lapses of which he may be aware on the part of his colleagues from the rules of medical ethics and good professional practice.

Publication of Findings

ARTICLE 30

It is the duty of a doctor to publish, initially in professional journals, any discoveries that he may have made or conclusions that he may have drawn from his scientific studies relevant to diagnosis or treatment. He must submit his findings in the appropriate form for review by his colleagues before releasing them to the lay public.

ARTICLE 31

Any exploitation or advertisement of a medical success to the profit of an individual or of a group or of an institution is contrary to medical ethics.

Continuity of Care

ARTICLE 32

A doctor, whatever his specialty, is obliged by his humanitarian duty to give emergency treatment to any patient in immediate danger, unless he is satisfied that other doctors will provide this care and are capable of doing so.

ARTICLE 33

The doctor who agrees to give care to a patient undertakes to ensure continuity of care when necessary with the help of assistants, locums or colleagues.

Freedom of Choice

ARTICLE 34

Freedom of choice constitutes a fundamental principle of the patient–doctor relationship. The doctor must respect, and make sure that others respect, the patient's freedom of choice of doctors.

The doctor, for his part, may refuse to treat a particular patient, unless the patient is in immediate danger.

Withdrawal of Services

ARTICLE 35

When a doctor decides to participate in an organised, collective withdrawal of services, he is not absolved of his ethical responsibilities vis-à-vis his patients to whom he must guarantee emergency services and such care as is required by those currently being treated.

Fees

ARTICLE 36

In fixing his fees, the doctor will take account, in the absence of any contract or of individual or collective agreement, of the importance of the service which has been given, any special circumstances in a particular case, his own competence and the financial situation of the patient.

CODE OF ETHICS FOR DOCTORS

Norwegian Medical Association

AMENDED 1992, 2000

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Adopted in 1961 and most recently amended in 2000, the Norwegian Medical Association's Code of Ethics for Doctors is interesting in its freedom from the governmental intrusions that characterize U.S. codes. Other provisions of interest include the right to withhold information from patients (I, §3) and the admonition that physicians should take care of their own health (II, §3). Excerpts from the Norwegian code follow.

Adopted by the Representative Body in 1961 and subsequently amended, most recently in 2000.

<http://www.legeforeningen.no/index.db2?id=297>

I. General Provisions

§ 1. A doctor shall protect human health. A doctor shall cure, alleviate and console. A doctor shall help the ill to regain their health and the healthy to preserve theirs. A doctor shall base his practice on respect for fundamental human rights, and on truth and justice in relation to patients and to society.

§ 2. A doctor shall safeguard the interests and integrity of the individual patient. The patient shall be treated with compassion, care and respect. Cooperation with the patient should be based on mutual trust and where possible on informed consent.

§ 3. A patient is entitled to information on his or her condition and treatment and normally to access to the information in the patient's case sheet. The patient shall be informed to the extent he or she wishes. Information which may be thought to be particularly difficult to bear, shall be given with care.

§ 4. A doctor shall maintain confidentiality and exercise discretion in respect of information he or she obtains in his or her medical capacity. The ethical obligation to maintain professional secrecy and discretion may extend further than the statutory obligation. The giving of information must be grounded in the patient's implicit or explicit consent or in a statute.

§ 5. A doctor must when a patient's life is ending show respect for the patient's right of self-determination. Active euthanasia, i.e. measures intended to hasten a patient's death, must not be engaged in. A doctor must not help a patient to commit suicide. To terminate or to refrain from initiating treatment which is of no avail is not considered active euthanasia.

§ 6. When a patient is in urgent need of medical assistance, this shall be provided as soon as possible. The obligation to provide immediate assistance ceases to apply if the doctor has ascertained that another doctor is providing assistance.

A doctor can refuse to treat a patient provided the patient has reasonable access to treatment by another doctor.

§ 7. A doctor must not exploit a patient sexually, financially, religiously or in any other way. A patient's consent does not absolve the doctor of responsibility. A doctor must not enter into sexual relations with a person whose doctor he or she is.

§ 8. A doctor shall in his or her practice have due regard for his or her patient's financial circumstances and not charge unreasonable fees.

§ 9. In examinations and treatment a doctor shall only employ methods indicated by sound medical practice. Methods which expose the patient to unnecessary risk shall not be employed. If a doctor does not possess the skill a method calls for, he or she shall ensure that the patient receives other competent treatment.

A doctor must not use or recommend methods which lack foundations in scientific research or sufficient medical experience. A doctor must not allow him- or herself to be pressed into using medical methods which he or she regards as professionally incorrect.

When new methods are being tried out, regard for the patient on whom they are being tried shall be the primary concern.

§ 10. A doctor shall maintain and constantly seek to renew his or her knowledge.

A doctor should according to his or her competence contribute to the development and mediation of medical knowledge.

§ 11. A doctor should according to his or her ability contribute to objective information to the public and the authorities on medical matters. A doctor who pronounces on medical matters to the media should ensure that he or she will be able to check the form in which the pronouncements are made public.

§ 12. A doctor shall in his or her practice have due regard for the national economy. Unnecessary or excessively costly methods must not be employed.

A doctor must contribute to the distribution of medical resources in accordance with generally accepted ethical norms. A doctor must in no way seek to provide individual patients or groups with unjustified advantages, whether financial, in respect of priorities, or otherwise. A doctor must give notice of insufficient resources in his or her area of responsibility.

II. Rules Governing the Relations of Doctors with Their Colleagues and Collaborators

§ 1. A doctor must show respect for colleagues and collaborators, and assist, advise and guide them.

§ 2. A doctor who sees signs of professional or ethical failings in a colleague or collaborator should first take the matter up directly with the person concerned. The approach should be tactful, especially towards students or doctors in training.

If this does not have the desired effect, the doctor should take the matter up with the person's administrative superior, bodies of the Norwegian Medical Association, or the competent health authority.

A doctor who sees signs of illness or abuse of intoxicants in a colleague or collaborator should offer his/her assistance.

§ 3. A doctor should take care of his own health and seek help if it fails.

§ 4. A doctor should take care not to criticise colleagues and collaborators in the presence of patients and their relatives, but must always keep the patient's interests in view.

§ 5. Public and other debates between colleagues on medical questions and health policy issues must be conducted in an objective manner.

§ 6. The referring and referring back of patients between colleagues must be based on professional medical criteria and the patient's need for continuous health services.

§ 7. Doctors must communicate with one another openly and trustfully. Exchanges of information between doctors concerning patients must take place sufficiently quickly and cover what is professionally necessary.

§ 8. Practice with regard to referrals must not be governed by personal financial interests.

III. Advertisements and Other Information Concerning Medical Services

§ 1. Advertisements and other information concerning medical services may only state:

- the location, opening hours, and administration of the business,

- the type of practice, and the speciality (cf. § 2 below) and title (cf. § 3 below) of the practitioner,
- the diagnostic and therapeutic methods used, and
- the fees charged.

The information must reflect generally medically accepted and/or scientifically documented diagnosis of indications and/or methods. The information must contain nothing incorrect or misleading to the public.

Advertisements or other information may make no mention of possible or expected results of specific services, or of the quality of the services. No formulations may be used which could give the public the impression that by failing to avail oneself of the services advertised, one is placing one's own or other persons' somatic, mental or social health at risk.

The overall presentation of the advertisement or other information concerning medical services must accord with the intentions indicated in the above.

Commercial advertisements of medical services must state the name of a or the medically responsible doctor. That doctor is considered responsible for compliance with the provisions in this Chapter.

§ 2. A doctor who is not an approved specialist may only advertise general practice. An approved specialist may advertise his or her specialty on its own or together with "general practice". A specialty in a particular disease may only be advertised with the permission of the Council.

§ 3. A doctor may only use such titles and designations as his or her education and position entitle him to. He or she may not use titles and designations which may give an erroneous impression of his or her qualifications and work.

§ 4. A doctor may not advertise medicines or medical consumer goods. Mention in professional medical contexts in articles, lectures and the like, not made for gain, is not regarded as advertising.

IV. Rules Governing the Issuing by Doctors of Medical Certificates and Other Certified Documents

§ 1. A medical certificate is a declaration by a doctor concerning a person's state of health. Medical certificates comprise such documents as completed forms for the use of the National Insurance authorities, certificates for various purposes, and statements of expert opinion.

§ 2. A doctor shall not issue a medical certificate if he/she is in doubt as to his/her competence. If a doctor does not find objective grounds for issuing a certificate, a certificate shall not be issued.

§ 3. A doctor shall base his/her certificates on the necessary information and on examinations that are sufficiently extensive for the purpose.

§ 4. A medical certificate shall convey sufficient information for its purpose and be objective and neutral in its wording. Relevant information must not be withheld or distorted. A certificate shall not contain more information than necessary for its purpose. When medical documents intended for other purposes are attached to medical certificates, special care must be taken to observe professional secrecy.

§ 5. A medical certificate must clearly show to whom it is addressed, its purpose, the doctor's relation to the person concerned, and what the doctor's knowledge concerning the person is based on. Written certificates must be drawn up as separate documents and dated and signed.

§ 6. The person to whom a medical certificate relates is generally entitled to be informed of the contents of the certificate.

Regulations of the Council for Medical Ethics and the Divisional Medical Ethics Committees

Adopted by the Representative Body in 1997.

§ 1. The Council for Medical Ethics and the Divisional medical ethics committees are the Norwegian Medical Association's special bodies for dealing with ethical questions.

§ 2. The Council for Medical Ethics is the Association's highest competent body in matters concerning medical ethics. The Council's decisions are binding on members of the Association, and decisions in individual cases can not be reviewed by other bodies.

§ 3. The Council's main task is to advise members of the Association, its central bodies, and society on questions of medical ethics. The Council reports on matters of principle relating to questions of medical ethics, and deals with complaints against doctors on the basis of the Code of Ethics for Doctors.

The Council does not deal with matters relating to professional aspects of medical work or normally with cases undergoing public legal or administrative treatment.

§ 4. The Council consists of a chairperson, a deputy chairperson, and three other members, and is elected by the Representative Body for terms of four calendar years. Two deputy members are also elected, to step in in the event of lasting absence. The Central Board nominates persons for membership of the Council. The chairperson and deputy chairperson are elected separately. Members of the Central Board can not be members of the Council.

One of the Medical Association's lawyers serves as secretary to the Council.

§ 5. Each Division of the Norwegian Medical Association shall have a medical ethics committee of four members, and a deputy member who shall step in in the event of lasting absence, cf. §11 of the Bylaws of the Medical Association. The committees shall concern themselves with questions of medical ethics in cooperation with the Council, and deal with complaints at divisional level.

§ 6. Matters may be brought before the Council and the committees by individuals, organizations, or Medical Association bodies. The Council and the committees may also themselves bring matters up.

If a complaint appears to be due to a doctor's health problem, an offer of assistance should be made as mentioned in §12 of the Medical Association's Bylaws.

§ 7. The Council and the committees shall always consider first whether or not a matter falls within their scope, and can in that connection consider whether to send it from the committee to the Council or vice versa. Matters which raise important questions of principle are dealt with by the Council.

Cases of doubt as to which Divisional committee ought to handle a case are decided by the Council.

Decisions by medical ethics committees can be appealed to the Council within four weeks after receipt of notification of the decision.

The Council and the committees shall keep minutes of their proceedings. Committees shall send copies of all their minutes to the Council. The Council shall send a copy of its minutes to the committee concerned.

§ 8. When a matter has been brought before the Council or a committee, the person or persons concerned shall be entitled to comment. They can demand to present a verbal account of the matter at a meeting. If the case concerns a complaint, the complainant is entitled to comment on the reply given by the person complained against.

Members of the Medical Association are obliged to testify before the Council or a medical ethics committee. If no testimony has been received within the time limit, the matter can be decided on the basis of the information available.

Any person is entitled to assistance by a lawyer and/or a colleague in matters brought before the Council or a medical ethics committee.

§ 9. Parties in cases before the Council or a committee may submit reasoned requests that members whom they consider disqualified shall withdraw during the handling of the case. A Council or committee member may also request permission to step down if he/she believes that he/she is disqualified. Such questions are decided by the Council or by the committee concerned.

§ 10. For a decision by the Council or by a committee to be valid, it must be adopted with at least three votes in favour.

§ 11. A decision by the Council or a committee shall be made known to the persons concerned as soon as possible. The Council can decide to publish a decision, formulated so as to ensure anonymity, in the Journal of the Norwegian Medical Association.

§ 12. If the Council or a committee is of the opinion that a doctor has contravened the Code of Ethics, it can express its disapproval or reprimand the doctor. It may require that the doctor apologise for and/or discontinue the matter complained of.

If the Council finds that a doctor has committed such a serious contravention of the Code of Ethics for Doctors that he/she should be expelled from the Medical Association, the case and the expulsion proposal shall be sent to the Central Board. The expulsion can also be proposed of a doctor who refuses to comply with a Council decision.

FINAL REPORT CONCERNING BRAIN DEATH AND ORGAN TRANSPLANTATION

Japan Medical Association

1988

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Traditional religious and cultural values surrounding death and dying inform the Japanese public's reluctance to accept brain-based criteria for determining death and the subsequent harvesting of organs for transplantation. Generally, the medical profession has been more amenable to the use of brain criteria for determining death. In 1988, the Bioethics Council of the Japan Medical Association issued its Final Report Concerning Brain Death and Organ Transplantation. The report recognizes the legitimacy of brain criteria for determining death, in addition to the traditional cardiac criteria. However, it also includes a clause that emphasizes the need to consider the wishes of the patient and/or the patient's family and to obtain their consent when using brain criteria to determine death. This compromise position permits the introduction of brain criteria for death while not offending those individuals who oppose it.

1. Definition of Death

   In addition to cardiac death heretofore, death of the brain (irreversible loss of brain function) can be considered as the state of death of the individual human being.
2. Brain Death Determination Criteria

   With the criteria of the Research Group of the Ministry of Health (Kazuo Takeuchi, Group Leader) as minimum required criteria, fundamental particulars should be determined by the ethics committees of university hospitals, etc., and determination should be carried out with certainty and circumspection according to these criteria in such a manner that no doubt remains.
3. Respecting the Wishes of the Patient Himself and His Family

   It is considered appropriate under present circumstances to carry out the determination of death resulting from brain death upon giving serious consideration to the wishes of the patient himself and his family and obtaining their consent.
4. Justifiability of the Determination of Death Resulting from Brain Death

   Together with being generally recognized by the Japan Medical Association and others, it is considered that the determination of death as a result of brain death is socially and legally justifiable when the consent on the part of the patient has been obtained and determination has been carried out by physicians in a reliable manner according to appropriate methods.
5. Time of Death as a Result of the Determination of Brain Death

   In regard to the time of a death as a result of a determination of brain death, it can be considered to be (1) the time when determination of brain death was first made or (2) the time of confirmation of brain death six or more hours subsequent to that. The time of death indicated on the death certificate can be either (1) or (2) above; however, as a precaution in case of disputes over inheritance after death, the other of the two should be recorded in the records of the patient's treatment.
6. Organ Transplantation

   The transplantation of organs is to be carried out in accordance with the guidelines established by the Japan Transplantation Association once the organ donor, organ recipient and the families involved have received thorough explanations and their consent given through their own free will has been obtained.

SUMMARY OF THE REPORT ON INFORMATION FROM DOCTORS AND CONSENT OF PATIENTS

Japan Medical Association

1991

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In 1951, the Japan Medical Association (JMA) issued a Physician's Code of Ethics, which is of historic interest for its emphasis on the Confucian concept of jin, "loving kindness," in the practice of medicine. Medicine is considered a jin-jyutsu, "humanitarian art." Traditionally, in Japanese medical practice, the combination of jin with the concept of shinrai-kankei, "fiduciary relationship," which is a positive value between people, correlated with a tendency for patients to trust and adhere to professional advice without question and a predilection toward medical paternalism. Since the 1960s, a gradual trend has emerged in Japan toward reassessing the nature of the patient–physician relationship. Exposure to contemporary Western bioethics and greater recognition of patients' rights is reflected in a movement among Japanese medical professionals to redefine the formerly paternalistic fiduciary relationship in light of a new emphasis on shared information and decision making with their patients. Although the JMA has never technically rescinded its 1951 code, the code has been superseded in practice by more recent documents from the JMA Bioethics Council that reflect the trend away from medical paternalism. One such document is the 1991 Summary of the Report on Information from Doctors and Consent of Patients, which follows.

1. The Definition of Informed Consent

   In strict terms, informed consent refers to the system of determining of the selection of medical procedures, which is carried out once the physician, as obliged, provides the patient with thorough explanations regarding feasible procedures within the course of medical treatment activities.

   Informed consent is a concept which originated in U.S.A. as the principal statement of the rights of a patient and came to incorporate a specific content as a result of courtroom judicial precedents and so forth in connection with mishaps during medical treatment.

   It would seem necessary in the case of Japan, however, to examine its content independently and thereupon, with the opportunity offered by the informed consent, proceed with the structuring of a new relationship between physician and patient in the context of medical treatment.
2. The Relationship between the Physician's Explanation and Patient's Consent

   As a general rule, the patient's consent is obtained on the occasion of direct or indirect invasions of the patient's body; carrying out such invasions without consent could, legally speaking, entail the possible occurrence of problems of the criminal infliction of bodily harm or those of civil justice involving injury compensation.

Thus, the consent of the patient is premised on explanations by the physician; the physician must provide thorough explanations to the patient necessary to allow the patient to make judgments or selections.

3. The Current Meaning of Informed Consent

In Japan up to the present, there has been a tendency on the part of the patient to leave everything up to the physician. However, more and more we are seeing an increase in the comprehension of patients relating to medical treatments, changes in the structure of present-day illnesses, together with subdivision and specialization taking place in treatment methods, resulting in an increased emphasis on the frank and open interaction between physician and patient. There has also been a deeper concern for the problem of informed consent.

At this point, instead of simply adopting the American style of informed consent intact, it is more reasonable that we should embrace one which is relevant to our own society, one which sufficiently takes into account the sentiments of the people, the history of medical treatment, cultural background, the character of the nation and so forth.

4. Specific Content of Informed Consent and Its Configuration

THE PHYSICIAN'S EXPLANATION AND THE PATIENT'S CONSENT

The physician's explanations to the patient must be expressed in words which are easily understood, allowing effortless comprehension by the patient, with the minimum use of specialized terminology.

The patient's consent indicates that the patient has comprehended, is satisfied with and consents to the procedures which the physician proposes to take.

5. The Physician's Obligation to Explain and Its Limits

Explanations within the limits indicated below can be considered necessary under normal circumstances:

1. The disease name and its present condition>
2. Proposed treatment methods for the disease
3. The degree of risk involved in such treatment methods (the presence and extent of risk)
4. Other possible choices of treatment methods and their relative advantages and disadvantages.
5. Prognosis, that is, future assumptions relating to the patient's illness

Emergencies or cases in which the patient does not have the capacity to make judgments him or herself regarding consent after having been given explanations can be cited as exceptions to the general rule.

Cases in which the patient does not have the capacity to make judgments regarding consent after having been given explanations require that explanations be provided to the most appropriate next of kin and the patient's consent received by proxy. However, since the procedures in question are directed specifically to the patient, the inclinations of the patient should be taken into consideration when it is recognized that the patient does have judgmental capacity, though it may be impaired.

6. Informed Consent in Routine Diagnoses and Treatment

(1) Notification of Cancer

The following should be given thorough consideration as prior conditions upon the notification of cancer:

1. The purpose of notification must be explicit.
2. The family of the patient must be receptive.
3. Physician or others in the practice of medicine must have a satisfactory relationship with the family of the patient.
4. Mental care and support of the patient must be possible subsequent to notification.

(2) Living Wills

When a patient in terminal treatment has prepared a living will in advance and there is no hope of recovery, it is considered reasonable to respect the wishes of the patient not to engage in life-prolonging procedures, when such have been clearly stated.

(3) Others

If there is a necessity for blood transfusions in a patient who refuses such for religious reasons, the patient should be persuaded and then consent for transfusions obtained. However, if the patient persistently refuses, the will of the patient should be respected even though the outcome of not doing so would be disadvantageous to the patient. In such cases, it is considered that the physician does not assume any legal liability.

When the patient is a child, transfusions given contrary to the will of the parent can be considered permissible, even though the parent, as a follower of a religion, has refused such, since the child and the child's parents are fundamentally separate beings.

7. Informed Consent in Medical and Treatment Education

It cannot be denied that concern regarding informed consent among young physicians is lacking. It is of extreme importance that instruction regarding informed consent be promoted in the future both prior to graduation and thereafter through continuing education.

OATH OF SOVIET PHYSICIANS

1971

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On 26 March 1971, the Presidium of the Supreme Soviet approved the text of the oath and ordered that all physicians and graduating medical students take the oath, sign a copy of it, and abide by it. The ruling went into effect on June 1, 1971. Distinctive features of this oath are: (1) dedication to preventive medicine; (2) commitment to the principles of communist morality; and (3) responsibility to the people and the Soviet government. The Soviet oath should be compared to the 1988 Regulations on Criteria for Medical Ethics and Their Implementation, issued by the Ministry of Health, People's Republic of China, and included in this section.

Having received the high title of physician and beginning a career in the healing arts, I solemnly swear:

to dedicate all my knowledge and all my strength to the care and improvement of human health, to treatment and prevention of disease, and to work conscientiously wherever the interests of the society will require it;

to be always ready to administer medical aid, to treat the patient with care and interest, and to keep professional secrets;

to constantly improve my medical knowledge and diagnostic and therapeutic skill, and to further medical science and the practice of medicine by my own work;

to turn, if the interests of my patients will require it, to my professional colleagues for advice and consultation, and to never refuse myself to give advice or help;

to keep and to develop the beneficial traditions of medicine in my country, to conduct all my actions according to the principles of the Communistic morale, to always keep in mind the high calling of the Soviet physician, and the high responsibility I have to my people and to the Soviet government.

I swear to be faithful to this Oath all my life long.

SOLEMN OATH OF A PHYSICIAN OF RUSSIA

1992

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Approved by the Minister of Health and the Minister of Higher Education of the Russian Federation, this oath, which replaces the preceding Oath of Soviet Physicians, was first published in 1992. It is interesting to note the similarities between the new Russian oath and the Hippocratic Oath, indicating a conscious return to the Hippocratic tradition. While the Soviet oath bound physicians to the principles of communist morality and explicitly recognized their duty to the people and the Soviet state, the new oath focuses on the well-being of the individual patient.

In the presence of my Teachers and colleagues in the great science of doctoring, accepting with deep gratitude the rights of a physician granted to me

I SOLEMNLY PROMISE:

- to regard him who has taught me the art of doctoring as equal to my parents and to help him in his affairs and if he is in need;
- to impart any precepts, oral instruction, and all other learning to my pupils who are bound by the obligation of medical law but to no one else;
- I will conduct my life and my art purely and chastely, being charitable and not causing people harm;
- I will never deny medical assistance to anyone and will render it with equal diligence and patience to a patient of any means, nationality, religion, and conviction;
- no matter what house I may enter, I will go there for the benefit of the patient, remaining free of all intentional injustice and mischief, especially sexual relations;
- to prescribe dietetic measures and medical treatment for the patient's benefit according to my abilities and judgment, refraining from causing them any harm or injustice;
- I will never use my knowledge and skill to the detriment of anyone's health, even my enemy's;
- I will never give anyone a fatal drug if asked nor show ways to carry out such intentions;
- whatever I may see and hear during treatment or outside of treatment concerning a person's life, which should not be divulged, I will keep to myself, regarding such matters as secret;

- I promise to continue my study of the art of doctoring and do everything in my power to promote its advancement, reporting all my discoveries to the scientific world;
- I promise not to engage in the manufacture or sale of secret remedies;
- I promise to be just to my fellow doctors and not to insult their persons; however, if it is required for the benefit of a patient, I will speak the truth openly and impartially;
- in important cases I promise to seek the advice of doctors who are more versed and experienced than I; when I myself am summoned for consultation, I will acknowledge their merit and efforts according to my conscience.

If I fulfill this Oath without violating it, let me be given happiness in my life and art. If I transgress it and give a false Oath, let the opposite be my lot.

REGULATIONS ON CRITERIA FOR MEDICAL ETHICS AND THEIR IMPLEMENTATION

Ministry of Health, People's Republic of China

1988

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The following regulations on medical ethics for healthcare providers were issued in December 1988 by the Ministry of Health of the People's Republic of China. The mention of socialist values in Article 1 may be compared to the statement regarding principles of communist morality found in the 1971 Soviet oath, which appears earlier in this section. It is notable, however, that these regulations do not mention responsibility to the State as did the Soviet oath. Also of note are the strong emphasis on education in medical ethics and the explicit application of the criteria to all healthcare workers.

Article 1. The purpose of the criteria is to strengthen the development of a society based on socialist values, to improve the quality of professional ethics of health-care workers and to promote health services.

Article 2. Medical ethics, which is also called professional ethics of health-care workers, guides the value system the health-care workers should have, covering all aspects from doctor–patient relationships to doctor–doctor relationships. The criteria for medical ethics form the code of conduct for health-care workers in their medical practice.

Article 3. The criteria for medical ethics include the following:

1. Heal the wounded, rescue the dying, and practice socialist humanitarianism. Keep the interests of the patient in your mind and try every means possible to relieve patient suffering.
2. Show respect to the patient's dignity and rights and treat all patients alike, whatever their nationality, race, sex, occupation, social position and economic status is.
3. Services should be provided in a civil, dignified, amiable, sympathetic, kind-hearted and courteous way.
4. Be honest in performing medical practice and conscious in observing medical discipline and law. Do not seek personal benefits through medical practice.
5. Keep the secrets related to the patient's illness and practice protective health-care service. In no case is one allowed to reveal the patient's health secret or compromise privacy.
6. Learn from other doctors and work together in cooperation. Handle professional relations between colleagues correctly.
7. Be rigorous in learning and practicing medicine and work hard to improve knowledge, ability, skills and service.

Article 4. Education in medical ethics is mandated for the implementation of these regulations and for supporting medical-ethical attitudes. Therefore, good control and assessment of medical ethics has to be introduced.

Article 5. Education on medical ethics and the promotion of medical ethics must be a part of managing and evaluating hospitals. Good and poor performance of working groups have to be judged and assessed according to these standards.

Article 6. Education in medical ethics should be conducted positively and unremittingly through linking theories with practice aiming to achieve actual and concrete results. It should be the rule to educate new health-care workers in medical ethics before they start their service; in no case are they allowed to practice before they get such an education.

Article 7. Every hospital should work out rules and regulations for the evaluation of medical ethics and should have a particular department to carry out the evaluation, regularly and irregularly. The results of the evaluation should be kept in record files.

Article 8. The evaluation of medical ethics should include self-evaluation, social evaluation, department evaluation and higher-level evaluation. Social evaluation is of particular importance and the opinions of the patients and public should be considered and health service should be offered under the surveillance of the masses.

Article 9. The result of the evaluation should be considered as an important standard in employment, promotion, payment and the hiring of health-care workers.

Article 10. Practice the rewarding of the best and the punishment of the worst. Those who observe medical ethics criteria should be rewarded and those who fail to observe criteria of medical ethics should be criticized and punished accordingly.

Article 11. These criteria are suitable for all health-care workers, including doctors, nurses, technicians and health-care administrators at all levels in all hospitals and clinics.

Article 12. Provincial health-care offices may work out detailed rules for the implementation of these criteria.

Article 13. These criteria become valid on the date they are issued.

ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH FACILITIES

United States Conference of Catholic Bishops

1971, REVISED 1975; 2001

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The Catholic Church has published directives on medical ethics in several parts of the world, principally, though not exclusively, for use in its hospitals. These directives are considered binding not only on institutions but also on individuals: The medical staff, patients, and employees, regardless of their religion, are frequently expected to abide by such a code.

In the United States, a set of Ethical and Religious Directives for Catholic Hospitals *was published in 1949 and revised in 1954. The directives printed here were originally approved as the national code by the U.S. Conference of Catholic Bishops and the United States Catholic Conference in 1971 and were revised in 1975 and again in 2001. Most distinctive are the directives on abortion, hysterectomy, sterilization, and artificial insemination.*

<http://www.nccbuscc.org/bishops/directives.htm>

Preamble

Health care in the United States is marked by extraordinary change. Not only is there continuing change in clinical practice due to technological advances, but the health care system in the United States is being challenged by both institutional and social factors as well. At the same time, there are a number of developments within the Catholic Church affecting the ecclesial mission of health care. Among these are significant changes in religious orders and congregations, the increased involvement of lay men and women, a heightened awareness of the Church's social role in the world, and developments in moral theology since the Second Vatican Council. A contemporary understanding of the Catholic health care ministry must take into account the new challenges presented by transitions both in the Church and in American society.

Throughout the centuries, with the aid of other sciences, a body of moral principles has emerged that expresses the Church's teaching on medical and moral matters and has proven to be pertinent and applicable to the ever-changing circumstances of health care and its delivery. In response to today's challenges, these same moral principles of Catholic teaching provide the rationale and direction for this revision of the *Ethical and Religious Directives for Catholic Health Care Services.*

These Directives presuppose our statement *Health and Health Care* published in 1981.[1] There we presented the theological principles that guide the Church's vision of health care, called for all Catholics to share in the healing mission of the Church, expressed our full commitment to the health care ministry, and offered encouragement to all those who are involved in it. Now, with American health care facing even more dramatic changes, we reaffirm the Church's commitment to health care ministry and the distinctive Catholic identity of the Church's institutional health care services.[2] The purpose of these *Ethical and Religious Directives* then is twofold: first, to reaffirm the ethical standards of behavior in health care that flow from the Church's teaching about the dignity of the human person; second, to provide authoritative guidance on certain moral issues that face Catholic health care today.

The *Ethical and Religious Directives* are concerned primarily with institutionally based Catholic health care services. They address the sponsors, trustees, administrators, chaplains, physicians, health care personnel, and patients or residents of these institutions and services. Since they express the Church's moral teaching, these Directives also will be helpful to Catholic professionals engaged in health care services in other settings. The moral teachings that we profess here flow principally from the natural law, understood in the light of the revelation Christ has entrusted to his Church. From this source the Church has derived its understanding of the nature of the human person, of human acts, and of the goals that shape human activity.

The Directives have been refined through an extensive process of consultation with bishops, theologians, sponsors, administrators, physicians, and other health care providers. While providing standards and guidance, the Directives do not cover in detail all of the complex issues that confront Catholic health care today. Moreover, the Directives will be reviewed periodically by the United States Conference of Catholic Bishops (formerly the National Conference of Catholic Bishops), in the light of authoritative church teaching, in order to address new insights from theological and medical research or new requirements of public policy.

The Directives begin with a general introduction that presents a theological basis for the Catholic health care ministry. Each of the six parts that follow is divided into two sections. The first section is in expository form; it serves as an introduction and provides the context in which concrete issues can be discussed from the perspective of the Catholic faith. The second section is in prescriptive form; the directives promote and protect the truths of the Catholic faith as those truths are brought to bear on concrete issues in health care.

General Introduction

The Church has always sought to embody our Savior's concern for the sick. The gospel accounts of Jesus' ministry draw special attention to his acts of healing: he cleansed a man with leprosy (Mt 8:1–4; Mk 1:40–42); he gave sight to two people who were blind (Mt 20:29–34; Mk 10:46–52); he enabled one who was mute to speak (Lk 11:14); he cured a woman who was hemorrhaging (Mt 9:20–22; Mk 5:25–34); and he brought a young girl back to life (Mt 9:18, 23–25; Mk 5:35–42). Indeed, the Gospels are replete with examples of how the Lord cured every kind of ailment and disease (Mt 9:35). In the account of Matthew, Jesus' mission fulfilled the prophecy of Isaiah: "He took away our infirmities and bore our diseases" (Mt 8:17; cf. Is 53:4).

Jesus' healing mission went further than caring only for physical affliction. He touched people at the deepest level of their existence; he sought their physical, mental, and spiritual healing (Jn 6:35, 11:25–27). He "came so that they might have life and have it more abundantly" (Jn 10:10).

The mystery of Christ casts light on every facet of Catholic health care: to see Christian love as the animating principle of health care; to see healing and compassion as a continuation of Christ's mission; to see suffering as a participation in the redemptive power of Christ's passion, death, and resurrection; and to see death, transformed by the resurrection, as an opportunity for a final act of communion with Christ.

For the Christian, our encounter with suffering and death can take on a positive and distinctive meaning through the redemptive power of Jesus' suffering and death. As St. Paul says, we are "always carrying about in the body the dying of Jesus, so that the life of Jesus may also be manifested in our body" (2 Cor 4:10). This truth does not lessen the pain and fear, but gives confidence and grace for bearing suffering rather than being overwhelmed by it. Catholic health care ministry bears witness to the truth that, for those who are in Christ, suffering and death are the birth pangs of the new creation. "God himself will always be with them [as their God]. He will wipe every tear from their eyes, and there shall be no more death or mourning, wailing or pain, [for] the old order has passed away" (Rev 21:3–4).

In faithful imitation of Jesus Christ, the Church has served the sick, suffering, and dying in various ways throughout history. The zealous service of individuals and communities has provided shelter for the traveler; infirmaries for the sick; and homes for children, adults, and the elderly.[3] In the United States, the many religious communities as well as dioceses that sponsor and staff this country's Catholic health care institutions and services have established an effective Catholic presence in health care. Modeling their efforts on the gospel parable of the Good Samaritan, these communities of women and men have exemplified authentic neighborliness to those in need (Lk 10:25–37). The Church seeks to ensure that the service offered in the past will be continued into the future.

While many religious communities continue their commitment to the health care ministry, lay Catholics increasingly have stepped forward to collaborate in this ministry. Inspired by the example of Christ and mandated by the Second Vatican Council, lay faithful are invited to a broader and more intense field of ministries than in the past.[4] By virtue of their Baptism, lay faithful are called to participate actively in the Church's life and mission.[5] Their participation and leadership in the health care ministry, through new forms of sponsorship and governance of institutional Catholic health care, are essential for the Church to continue her ministry of healing and compassion. They are joined in the Church's health care mission by many men and women who are not Catholic.

Catholic health care expresses the healing ministry of Christ in a specific way within the local church. Here the diocesan bishop exercises responsibilities that are rooted in his office as pastor, teacher, and priest. As the center of unity in the diocese and coordinator of ministries in the local church, the diocesan bishop fosters the mission of Catholic health care in a way that promotes collaboration among health care leaders, providers, medical professionals, theologians, and other specialists. As pastor, the diocesan bishop is in a unique position to encourage the faithful to greater responsibility in the healing ministry of the Church. As teacher, the diocesan bishop ensures the moral and religious identity of the health care ministry in whatever setting it is carried out in the diocese. As priest, the diocesan bishop oversees the sacramental care of the sick. These responsibilities will require that Catholic health care providers and the diocesan bishop engage in ongoing communication on ethical and pastoral matters that require his attention.

In a time of new medical discoveries, rapid technological developments, and social change, what is new can either be an opportunity for genuine advancement in human culture, or it can lead to policies and actions that are contrary to the true dignity and vocation of the human person. In consultation with medical professionals, church leaders review these developments, judge them according to the principles of right reason and the ultimate standard of revealed truth, and offer authoritative teaching and guidance about the moral and pastoral responsibilities entailed by the Christian faith.[6] While the Church cannot furnish a ready answer to every moral dilemma, there are many questions about which she provides normative guidance and direction. In the absence of a determination by the magisterium, but never contrary to church teaching, the guidance of approved authors can offer appropriate guidance for ethical decision making.

Created in God's image and likeness, the human family shares in the dominion that Christ manifested in his healing ministry. This sharing involves a stewardship over all material creation (Gn 1:26) that should neither abuse nor squander nature's resources. Through science the human race comes to understand God's wonderful work; and through technology it must conserve, protect, and perfect nature in harmony with God's purposes. Health care professionals pursue a special vocation to share in carrying forth God's life-giving and healing work.

The dialogue between medical science and Christian faith has for its primary purpose the common good of all human persons. It presupposes that science and faith do not contradict each other. Both are grounded in respect for truth and freedom. As new knowledge and new technologies expand, each person must form a correct conscience based on the moral norms for proper health care.

Part One

THE SOCIAL RESPONSIBILITY OF CATHOLIC HEALTH CARE SERVICES

INTRODUCTION

Their embrace of Christ's healing mission has led institutionally based Catholic health care services in the United States to become an integral part of the nation's health care system. Today, this complex health care system confronts a range of economic, technological, social, and moral challenges. The response of Catholic health care institutions and services to these challenges is guided by normative principles that inform the Church's healing ministry.

First, Catholic health care ministry is rooted in a commitment to promote and defend human dignity; this is the foundation of its concern to respect the sacredness of every human life from the moment of conception until death. The first right of the human person, the right to life, entails a right to the means for the proper development of life, such as adequate health care.[7]

Second, the biblical mandate to care for the poor requires us to express this in concrete action at all levels of Catholic health care. This mandate prompts us to work to ensure that our country's health care delivery system provides adequate health care for the poor. In Catholic institutions, particular attention should be given to the health care needs of the poor, the uninsured, and the underinsured.[8]

Third, Catholic health care ministry seeks to contribute to the common good. The common good is realized when economic, political, and social conditions ensure protection for the fundamental rights of all individuals and enable all to fulfill their common purpose and reach their common goals.[9]

Fourth, Catholic health care ministry exercises responsible stewardship of available health care resources. A just health care system will be concerned both with promoting equity of care—to assure that the right of each person to basic health care is respected—and with promoting the good health of all in the community. The responsible stewardship of health care resources can be accomplished best in dialogue with people from all levels of society, in accordance with the principle of subsidiarity and with respect for the moral principles that guide institutions and persons.

Fifth, within a pluralistic society, Catholic health care services will encounter requests for medical procedures contrary to the moral teachings of the Church. Catholic health care does not offend the rights of individual conscience by refusing to provide or permit medical procedures that are judged morally wrong by the teaching authority of the Church.

DIRECTIVES

1. A Catholic institutional health care service is a community that provides health care to those in need of it. This service must be animated by the Gospel of Jesus Christ and guided by the moral tradition of the Church.

2. Catholic health care should be marked by a spirit of mutual respect among care-givers that disposes them to deal with those it serves and their families with the compassion of Christ, sensitive to their vulnerability at a time of special need.
3. In accord with its mission, Catholic health care should distinguish itself by service to and advocacy for those people whose social condition puts them at the margins of our society and makes them particularly vulnerable to discrimination: the poor; the uninsured and the underinsured; children and the unborn; single parents; the elderly; those with incurable diseases and chemical dependencies; racial minorities; immigrants and refugees. In particular, the person with mental or physical disabilities, regardless of the cause or severity, must be treated as a unique person of incomparable worth, with the same right to life and to adequate health care as all other persons.
4. A Catholic health care institution, especially a teaching hospital, will promote medical research consistent with its mission of providing health care and with concern for the responsible stewardship of health care resources. Such medical research must adhere to Catholic moral principles.
5. Catholic health care services must adopt these Directives as policy, require adherence to them within the institution as a condition for medical privileges and employment, and provide appropriate instruction regarding the Directives for administration, medical and nursing staff, and other personnel.
6. A Catholic health care organization should be a responsible steward of the health care resources available to it. Collaboration with other health care providers, in ways that do not compromise Catholic social and moral teaching, can be an effective means of such stewardship.[10]
7. A Catholic health care institution must treat its employees respectfully and justly. This responsibility includes: equal employment opportunities for anyone qualified for the task, irrespective of a person's race, sex, age, national origin, or disability; a workplace that promotes employee participation; a work environment that ensures employee safety and well-being; just compensation and benefits; and recognition of the rights of employees to organize and bargain collectively without prejudice to the common good.
8. Catholic health care institutions have a unique relationship to both the Church and the wider community they serve. Because of the ecclesial nature of this relationship, the relevant requirements of canon law will be observed with regard to the foundation of a new Catholic health care institution; the substantial revision of the mission of an institution; and the sale, sponsorship transfer, or closure of an existing institution.
9. Employees of a Catholic health care institution must respect and uphold the religious mission of the institution and adhere to these Directives. They should maintain professional standards and promote the institution's commitment to human dignity and the common good.

Part Two

THE PASTORAL AND SPIRITUAL RESPONSIBILITY OF CATHOLIC HEALTH CARE

INTRODUCTION

The dignity of human life flows from creation in the image of God (Gn 1:26), from redemption by Jesus Christ (Eph 1:10; 1 Tm 2:4–6), and from our common destiny to share a life with God beyond all corruption (1 Cor 15:42–57). Catholic health care has the responsibility to treat those in need in a way that respects the human dignity and eternal destiny of all. The words of Christ have provided inspiration for Catholic health care: "I was ill and you cared for me" (Mt 25:36). The care provided assists those in need to experience their own dignity and value, especially when these are obscured by the burdens of illness or the anxiety of imminent death.

Since a Catholic health care institution is a community of healing and compassion, the care offered is not limited to the treatment of a disease or bodily ailment but embraces the physical, psychological, social, and spiritual dimensions of the human person. The medical expertise offered through Catholic health care is combined with other forms of care to promote health and relieve human suffering. For this reason, Catholic health care extends to the spiritual nature of the person. "Without health of the spirit, high technology focused strictly on the body offers limited hope for healing the whole person."[11] Directed to spiritual needs that are often appreciated more deeply during times of illness, pastoral care is an integral part of Catholic health care. Pastoral care encompasses the full range of spiritual services, including a listening presence; help in dealing with powerlessness, pain, and alienation; and assistance in recognizing and responding to God's will with greater joy and peace. It should be acknowledged, of course, that technological advances in medicine have reduced the length of hospital stays dramatically. It follows, therefore, that the pastoral care of patients, especially administration of the sacraments, will be provided more often than not at the parish level, both before and after one's hospitalization. For this reason, it is essential that there be very cordial and cooperative relationships between the personnel of pastoral care departments and the local clergy and ministers of care.

Priests, deacons, religious, and laity exercise diverse but complementary roles in this pastoral care. Since many areas of pastoral care call upon the creative response of these pastoral care-givers to the particular needs of patients or residents, the following directives address only a limited number of specific pastoral activities.

DIRECTIVES

10. A Catholic health care organization should provide pastoral care to minister to the religious and spiritual needs of all those it serves. Pastoral care personnel—clergy, religious, and lay alike—should have appropriate professional preparation, including an understanding of these Directives.
11. Pastoral care personnel should work in close collaboration with local parishes and community clergy. Appropriate pastoral services and/or referrals should be available to all in keeping with their religious beliefs or affiliation.
12. For Catholic patients or residents, provision for the sacraments is an especially important part of Catholic health care ministry. Every effort should be made to have priests assigned to hospitals and health care institutions to celebrate the Eucharist and provide the sacraments to patients and staff.
13. Particular care should be taken to provide and to publicize opportunities for patients or residents to receive the sacrament of Penance.
14. Properly prepared lay Catholics can be appointed to serve as extraordinary ministers of Holy Communion, in accordance with canon law and the policies of the local diocese. They should assist pastoral care personnel—clergy, religious, and laity—by providing supportive visits, advising patients regarding the availability of priests for the sacrament of Penance, and distributing Holy Communion to the faithful who request it.
15. Responsive to a patient's desires and condition, all involved in pastoral care should facilitate the availability of priests to provide the sacrament of Anointing of the Sick, recognizing that through this sacrament Christ provides grace and support to those who are seriously ill or weakened by advanced age. Normally, the sacrament is celebrated when the sick person is fully conscious. It may be conferred upon the sick who have lost consciousness or the use of reason, if there is reason to believe that they would have asked for the sacrament while in control of their faculties.
16. All Catholics who are capable of receiving Communion should receive Viaticum when they are in danger of death, while still in full possession of their faculties.[12]
17. Except in cases of emergency (i.e., danger of death), any request for Baptism made by adults or for infants should be referred to the chaplain of the institution. Newly born infants in danger of death, including those miscarried, should be baptized if this is possible.[13] In case of emergency, if a priest or a deacon is not available, anyone can validly baptize.[14] In the case of emergency Baptism, the chaplain or the director of pastoral care is to be notified.
18. When a Catholic who has been baptized but not yet confirmed is in danger of death, any priest may confirm the person.[15]
19. A record of the conferral of Baptism or Confirmation should be sent to the parish in which the institution is located and posted in its Baptism/Confirmation registers.
20. Catholic discipline generally reserves the reception of the sacraments to Catholics. In accord with canon 844, §3, Catholic ministers may administer the sacraments of Eucharist, Penance, and Anointing of the Sick to members of the oriental churches that do not have full communion with the Catholic Church, or of other churches that in the judgment of the Holy See are in the same condition as the oriental churches, if such persons ask for the sacraments on their own and are properly disposed.

    With regard to other Christians not in full communion with the Catholic Church, when the danger of death or other grave necessity is present, the four conditions of canon 844, §4, also must be present, namely, they cannot approach a minister of their own community; they ask for the sacraments on their own; they manifest Catholic faith in these sacraments; and they are properly disposed. The diocesan bishop has the responsibility to oversee this pastoral practice.
21. The appointment of priests and deacons to the pastoral care staff of a Catholic institution must have the explicit approval or confirmation of the local bishop in collaboration with the administration of the institution. The appointment of the director of the pastoral care staff should be made in consultation with the diocesan bishop.
22. For the sake of appropriate ecumenical and interfaith relations, a diocesan policy should be developed with regard to the appointment of non-Catholic members to the pastoral care staff of a Catholic health care institution. The director of pastoral care at a Catholic institution should be a Catholic; any exception to this norm should be approved by the diocesan bishop.

Part Three

THE PROFESSIONAL-PATIENT RELATIONSHIP

INTRODUCTION

A person in need of health care and the professional health care provider who accepts that person as a patient enter into a relationship that requires, among other things, mutual respect, trust, honesty, and appropriate confidentiality. The resulting free exchange of information must avoid manipulation, intimidation, or condescension. Such a relationship enables the patient to disclose personal information needed for effective care and permits the health care provider to use his or her professional competence most effectively to maintain or restore the patient's health. Neither the health care professional nor the patient acts independently of the other; both participate in the healing process.

Today, a patient often receives health care from a team of providers, especially in the setting of the modern acute-care hospital. But the resulting multiplication of relationships does not alter the personal character of the interaction between health care providers and the patient. The relationship of the person seeking health care and the professionals providing that care is an important part of the foundation on which diagnosis and care are provided. Diagnosis and care, therefore, entail a series of decisions with ethical as well as medical dimensions. The health care professional has the knowledge and experience to pursue the goals of healing, the maintenance of health, and the compassionate care of the dying, taking into account the patient's convictions and spiritual needs, and the moral responsibilities of all concerned. The person in need of health care depends on the skill of the health care provider to assist in preserving life and promoting health of body, mind, and spirit. The patient, in turn, has a responsibility to use these physical and mental resources in the service of moral and spiritual goals to the best of his or her ability.

When the health care professional and the patient use institutional Catholic health care, they also accept its public commitment to the Church's understanding of and witness to the dignity of the human person. The Church's moral teaching on health care nurtures a truly interpersonal professional-patient relationship. This professional–patient relationship is never separated, then, from the Catholic identity of the health care institution. The faith that inspires Catholic health care guides medical decisions in ways that fully respect the dignity of the person and the relationship with the health care professional.

DIRECTIVES

23. The inherent dignity of the human person must be respected and protected regardless of the nature of the person's health problem or social status. The respect for human dignity extends to all persons who are served by Catholic health care.
24. In compliance with federal law, a Catholic health care institution will make available to patients information about their rights, under the laws of their state, to make an advance directive for their medical treatment. The institution, however, will not honor an advance directive that is contrary to Catholic teaching. If the advance directive conflicts with Catholic teaching, an explanation should be provided as to why the directive cannot be honored.
25. Each person may identify in advance a representative to make health care decisions as his or her surrogate in the event that the person loses the capacity to make health care decisions. Decisions by the designated surrogate should be faithful to Catholic moral principles and to the person's intentions and values, or if the person's intentions are unknown, to the person's best interests. In the event that an advance directive is not executed, those who are in a position to know best the patient's wishes—usually family members and loved ones—should participate in the treatment decisions for the person who has lost the capacity to make health care decisions.
26. The free and informed consent of the person or the person's surrogate is required for medical treatments and procedures, except in an emergency situation when consent cannot be obtained and there is no indication that the patient would refuse consent to the treatment.
27. Free and informed consent requires that the person or the person's surrogate receive all reasonable information about the essential nature of the proposed treatment and its benefits; its risks, side-effects, consequences, and cost; and any reasonable and morally legitimate alternatives, including no treatment at all.
28. Each person or the person's surrogate should have access to medical and moral information and counseling so as to be able to form his or her conscience. The free and informed health care decision of the person or the person's surrogate is to be followed so long as it does not contradict Catholic principles.
29. All persons served by Catholic health care have the right and duty to protect and preserve their bodily and functional integrity.[16] The functional integrity of the person may be sacrificed to maintain the health or life of the person when no other morally permissible means is available.[17]
30. The transplantation of organs from living donors is morally permissible when such a donation will not sacrifice or seriously impair any essential bodily function and the anticipated benefit to the recipient

is proportionate to the harm done to the donor. Furthermore, the freedom of the prospective donor must be respected, and economic advantages should not accrue to the donor.

31. No one should be the subject of medical or genetic experimentation, even if it is therapeutic, unless the person or surrogate first has given free and informed consent. In instances of nontherapeutic experimentation, the surrogate can give this consent only if the experiment entails no significant risk to the person's well-being. Moreover, the greater the person's incompetency and vulnerability, the greater the reasons must be to perform any medical experimentation, especially nontherapeutic.
32. While every person is obliged to use ordinary means to preserve his or her health, no person should be obliged to submit to a health care procedure that the person has judged, with a free and informed conscience, not to provide a reasonable hope of benefit without imposing excessive risks and burdens on the patient or excessive expense to family or community.[18]
33. The well-being of the whole person must be taken into account in deciding about any therapeutic intervention or use of technology. Therapeutic procedures that are likely to cause harm or undesirable side-effects can be justified only by a proportionate benefit to the patient.
34. Health care providers are to respect each person's privacy and confidentiality regarding information related to the person's diagnosis, treatment, and care.
35. Health care professionals should be educated to recognize the symptoms of abuse and violence and are obliged to report cases of abuse to the proper authorities in accordance with local statutes.
36. Compassionate and understanding care should be given to a person who is the victim of sexual assault. Health care providers should cooperate with law enforcement officials and offer the person psychological and spiritual support as well as accurate medical information. A female who has been raped should be able to defend herself against a potential conception from the sexual assault. If, after appropriate testing, there is no evidence that conception has occurred already, she may be treated with medications that would prevent ovulation, sperm capacitation, or fertilization. It is not permissible, however, to initiate or to recommend treatments that have as their purpose or direct effect the removal, destruction, or interference with the implantation of a fertilized ovum.[19]
37. An ethics committee or some alternate form of ethical consultation should be available to assist by advising on particular ethical situations, by offering educational opportunities, and by reviewing and recommending policies. To these ends, there should be appropriate standards for medical ethical consultation within a particular diocese that will respect the diocesan bishop's pastoral responsibility as well as assist members of ethics committees to be familiar with Catholic medical ethics and, in particular, these Directives.

Part Four

ISSUES IN CARE FOR THE BEGINNING OF LIFE

INTRODUCTION

The Church's commitment to human dignity inspires an abiding concern for the sanctity of human life from its very beginning, and with the dignity of marriage and of the marriage act by which human life is transmitted. The Church cannot approve medical practices that undermine the biological, psychological, and moral bonds on which the strength of marriage and the family depends.

Catholic health care ministry witnesses to the sanctity of life "from the moment of conception until death."[20] The Church's defense of life encompasses the unborn and the care of women and their children during and after pregnancy. The Church's commitment to life is seen in its willingness to collaborate with others to alleviate the causes of the high infant mortality rate and to provide adequate health care to mothers and their children before and after birth.

The Church has the deepest respect for the family, for the marriage covenant, and for the love that binds a married couple together. This includes respect for the marriage act by which husband and wife express their love and cooperate with God in the creation of a new human being. The Second Vatican Council affirms:

> This love is an eminently human one.… It involves the good of the whole person.… The actions within marriage by which the couple are united intimately and chastely are noble and worthy ones. Expressed in a manner which is truly human, these actions signify and promote that mutual self-giving by which spouses enrich each other with a joyful and a thankful will.[21]
>
> Marriage and conjugal love are by their nature ordained toward the begetting and educating of children. Children are really the supreme gift of marriage and contribute very substantially to the welfare of their parents.… Parents should regard as their proper mission the task of transmitting human life and educating those to whom it has been

> transmitted.… They are thereby cooperators with the love of God the Creator, and are, so to speak, the interpreters of that love.[22]

For legitimate reasons of responsible parenthood, married couples may limit the number of their children by natural means. The Church cannot approve contraceptive interventions that "either in anticipation of the marital act, or in its accomplishment or in the development of its natural consequences, have the purpose, whether as an end or a means, to render procreation impossible."[23] Such interventions violate "the inseparable connection, willed by God…between the two meanings of the conjugal act: the unitive and procreative meaning."[24]

With the advance of the biological and medical sciences, society has at its disposal new technologies for responding to the problem of infertility. While we rejoice in the potential for good inherent in many of these technologies, we cannot assume that what is technically possible is always morally right. Reproductive technologies that substitute for the marriage act are not consistent with human dignity. Just as the marriage act is joined naturally to procreation, so procreation is joined naturally to the marriage act. As Pope John XXIII observed:

> The transmission of human life is entrusted by nature to a personal and conscious act and as such is subject to all the holy laws of God: the immutable and inviolable laws which must be recognized and observed. For this reason, one cannot use means and follow methods which could be licit in the transmission of the life of plants and animals.[25]

Because the moral law is rooted in the whole of human nature, human persons, through intelligent reflection on their own spiritual destiny, can discover and cooperate in the plan of the Creator.[26]

Directives

38. When the marital act of sexual intercourse is not able to attain its procreative purpose, assistance that does not separate the unitive and procreative ends of the act, and does not substitute for the marital act itself, may be used to help married couples conceive.[27]
39. Those techniques of assisted conception that respect the unitive and procreative meanings of sexual intercourse and do not involve the destruction of human embryos, or their deliberate generation in such numbers that it is clearly envisaged that all cannot implant and some are simply being used to maximize the chances of others implanting, may be used as therapies for infertility.
40. Heterologous fertilization (that is, any technique used to achieve conception by the use of gametes coming from at least one donor other than the spouses) is prohibited because it is contrary to the covenant of marriage, the unity of the spouses, and the dignity proper to parents and the child.[28]
41. Homologous artificial fertilization (that is, any technique used to achieve conception using the gametes of the two spouses joined in marriage) is prohibited when it separates procreation from the marital act in its unitive significance (e.g., any technique used to achieve extra-corporeal conception).[29]
42. Because of the dignity of the child and of marriage, and because of the uniqueness of the mother–child relationship, participation in contracts or arrangements for surrogate motherhood is not permitted. Moreover, the commercialization of such surrogacy denigrates the dignity of women, especially the poor.[30]
43. A Catholic health care institution that provides treatment for infertility should offer not only technical assistance to infertile couples but also should help couples pursue other solutions (e.g., counseling, adoption).
44. A Catholic health care institution should provide prenatal, obstetric, and postnatal services for mothers and their children in a manner consonant with its mission.
45. Abortion (that is, the directly intended termination of pregnancy before viability or the directly intended destruction of a viable fetus) is never permitted. Every procedure whose sole immediate effect is the termination of pregnancy before viability is an abortion, which, in its moral context, includes the interval between conception and implantation of the embryo. Catholic health care institutions are not to provide abortion services, even based upon the principle of material cooperation. In this context, Catholic health care institutions need to be concerned about the danger of scandal in any association with abortion providers.
46. Catholic health care providers should be ready to offer compassionate physical, psychological, moral, and spiritual care to those persons who have suffered from the trauma of abortion.
47. Operations, treatments, and medications that have as their direct purpose the cure of a proportionately serious pathological condition of a pregnant woman are permitted when they cannot be safely postponed until the unborn child is viable, even if they will result in the death of the unborn child.

48. In case of extrauterine pregnancy, no intervention is morally licit which constitutes a direct abortion.[31]
49. For a proportionate reason, labor may be induced after the fetus is viable.
50. Prenatal diagnosis is permitted when the procedure does not threaten the life or physical integrity of the unborn child or the mother and does not subject them to disproportionate risks; when the diagnosis can provide information to guide preventative care for the mother or pre- or postnatal care for the child; and when the parents, or at least the mother, give free and informed consent. Prenatal diagnosis is not permitted when undertaken with the intention of aborting an unborn child with a serious defect.[32]
51. Nontherapeutic experiments on a living embryo or fetus are not permitted, even with the consent of the parents. Therapeutic experiments are permitted for a proportionate reason with the free and informed consent of the parents or, if the father cannot be contacted, at least of the mother. Medical research that will not harm the life or physical integrity of an unborn child is permitted with parental consent.[33]
52. Catholic health institutions may not promote or condone contraceptive practices but should provide, for married couples and the medical staff who counsel them, instruction both about the Church’s teaching on responsible parenthood and in methods of natural family planning.
53. Direct sterilization of either men or women, whether permanent or temporary, is not permitted in a Catholic health care institution. Procedures that induce sterility are permitted when their direct effect is the cure or alleviation of a present and serious pathology and a simpler treatment is not available.[34]
54. Genetic counseling may be provided in order to promote responsible parenthood and to prepare for the proper treatment and care of children with genetic defects, in accordance with Catholic moral teaching and the intrinsic rights and obligations of married couples regarding the transmission of life.

Part Five

ISSUES IN CARE FOR THE DYING

INTRODUCTION

Christ’s redemption and saving grace embrace the whole person, especially in his or her illness, suffering, and death.[35] The Catholic health care ministry faces the reality of death with the confidence of faith. In the face of death—for many, a time when hope seems lost—the Church witnesses to her belief that God has created each person for eternal life.[36]

Above all, as a witness to its faith, a Catholic health care institution will be a community of respect, love, and support to patients or residents and their families as they face the reality of death. What is hardest to face is the process of dying itself, especially the dependency, the helplessness, and the pain that so often accompany terminal illness. One of the primary purposes of medicine in caring for the dying is the relief of pain and the suffering caused by it. Effective management of pain in all its forms is critical in the appropriate care of the dying.

The truth that life is a precious gift from God has profound implications for the question of stewardship over human life. We are not the owners of our lives and, hence, do not have absolute power over life. We have a duty to preserve our life and to use it for the glory of God, but the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome. Suicide and euthanasia are never morally acceptable options.

The task of medicine is to care even when it cannot cure. Physicians and their patients must evaluate the use of the technology at their disposal. Reflection on the innate dignity of human life in all its dimensions and on the purpose of medical care is indispensable for formulating a true moral judgment about the use of technology to maintain life. The use of life-sustaining technology is judged in light of the Christian meaning of life, suffering, and death. Only in this way are two extremes avoided: on the one hand, an insistence on useless or burdensome technology even when a patient may legitimately wish to forgo it and, on the other hand, the withdrawal of technology with the intention of causing death.[37]

Some state Catholic conferences, individual bishops, and the USCCB Committee on Pro-Life Activities (formerly an NCCB committee) have addressed the moral issues concerning medically assisted hydration and nutrition. The bishops are guided by the Church’s teaching forbidding euthanasia, which is “an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated.”[38] These statements agree that hydration and nutrition are not morally obligatory either when they bring no comfort to a person who is imminently dying or when they cannot be assimilated by a person’s body. The USCCB Committee on Pro-Life Activities’ report, in addition, points out the necessary distinctions between questions already resolved by the magisterium and those requiring further reflection, as, for example, the morality of withdrawing medically assisted hydration and nutrition from a person who is in the condition that is recognized by physicians as the “persistent vegetative state” (PVS).[39]

DIRECTIVES

55. Catholic health care institutions offering care to persons in danger of death from illness, accident, advanced age, or similar condition should provide them with appropriate opportunities to prepare for death. Persons in danger of death should be provided with whatever information is necessary to help them understand their condition and have the opportunity to discuss their condition with their family members and care providers. They should also be offered the appropriate medical information that would make it possible to address the morally legitimate choices available to them. They should be provided the spiritual support as well as the opportunity to receive the sacraments in order to prepare well for death.
56. A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community.[40]
57. A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community.[41]
58. There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient.
59. The free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless it is contrary to Catholic moral teaching.
60. Euthanasia is an action or omission that of itself or by intention causes death in order to alleviate suffering. Catholic health care institutions may never condone or participate in euthanasia or assisted suicide in any way. Dying patients who request euthanasia should receive loving care, psychological and spiritual support, and appropriate remedies for pain and other symptoms so that they can live with dignity until the time of natural death.[42]
61. Patients should be kept as free of pain as possible so that they may die comfortably and with dignity, and in the place where they wish to die. Since a person has the right to prepare for his or her death while fully conscious, he or she should not be deprived of consciousness without a compelling reason. Medicines capable of alleviating or suppressing pain may be given to a dying person, even if this therapy may indirectly shorten the person's life so long as the intent is not to hasten death. Patients experiencing suffering that cannot be alleviated should be helped to appreciate the Christian understanding of redemptive suffering.
62. The determination of death should be made by the physician or competent medical authority in accordance with responsible and commonly accepted scientific criteria.
63. Catholic health care institutions should encourage and provide the means whereby those who wish to do so may arrange for the donation of their organs and bodily tissue, for ethically legitimate purposes, so that they may be used for donation and research after death.
64. Such organs should not be removed until it has been medically determined that the patient has died. In order to prevent any conflict of interest, the physician who determines death should not be a member of the transplant team.
65. use of tissue or organs from an infant may be permitted after death has been determined and with the informed consent of the parents or guardians.
66. Catholic health care institutions should not make use of human tissue obtained by direct abortions even for research and therapeutic purposes.[43]

Part Six

FORMING NEW PARTNERSHIPS WITH HEALTH CARE ORGANIZATIONS AND PROVIDERS

INTRODUCTION

Until recently, most health care providers enjoyed a degree of independence from one another. In ever-increasing ways, Catholic health care providers have become involved with other health care organizations and providers. For instance, many Catholic health care systems and institutions share in the joint purchase of technology and services with other local facilities or physicians' groups. Another phenomenon is the growing number of Catholic health care systems and institutions joining or co-sponsoring integrated delivery networks or managed care organizations in order to contract with insurers and other health care payers. In some instances, Catholic health care systems sponsor a health care plan or health maintenance organization. In many dioceses, new partnerships will result in a decrease in the number of health care providers, at times leaving the Catholic institution as the sole provider of health care services. At whatever level, new partnerships forge a variety of interwoven relationships: between the various institutional partners, between health care providers and the community, between physicians and health care services, and between health care services and payers.

On the one hand, new partnerships can be viewed as opportunities for Catholic health care institutions and services to witness to their religious and ethical commitments and so influence the healing profession. For example, new partnerships can help to implement the Church's social teaching. New partnerships can be opportunities to realign the local delivery system in order to provide a continuum of health care to the community; they can witness to a responsible stewardship of limited health care resources; and they can be opportunities to provide to poor and vulnerable persons a more equitable access to basic care.

On the other hand, new partnerships can pose serious challenges to the viability of the identity of Catholic health care institutions and services, and their ability to implement these Directives in a consistent way, especially when partnerships are formed with those who do not share Catholic moral principles. The risk of scandal cannot be underestimated when partnerships are not built upon common values and moral principles. Partnership opportunities for some Catholic health care providers may even threaten the continued existence of other Catholic institutions and services, particularly when partnerships are driven by financial considerations alone. Because of the potential dangers involved in the new partnerships that are emerging, an increased collaboration among Catholic-sponsored health care institutions is essential and should be sought before other forms of partnerships.

The significant challenges that new partnerships may pose, however, do not necessarily preclude their possibility on moral grounds. The potential dangers require that new partnerships undergo systematic and objective moral analysis, which takes into account the various factors that often pressure institutions and services into new partnerships that can diminish the autonomy and ministry of the Catholic partner. The following directives are offered to assist institutionally based Catholic health care services in this process of analysis. To this end, the United States Conference of Catholic Bishops has established the Ad Hoc Committee on Health Care Issues and the Church as a resource for bishops and health care leaders.

This new edition of the *Ethical and Religious Directives* omits the appendix concerning cooperation, which was contained in the 1995 edition. Experience has shown that the brief articulation of the principles of cooperation that was presented there did not sufficiently forestall certain possible misinterpretations and in practice gave rise to problems in concrete applications of the principles. Reliable theological experts should be consulted in interpreting and applying the principles governing cooperation, with the proviso that, as a rule, Catholic partners should avoid entering into partnerships that would involve them in cooperation with the wrongdoing of other providers.

DIRECTIVES

67. Decisions that may lead to serious consequences for the identity or reputation of Catholic health care services, or entail the high risk of scandal, should be made in consultation with the diocesan bishop or his health care liaison.
68. Any partnership that will affect the mission or religious and ethical identity of Catholic health care institutional services must respect church teaching and discipline. Diocesan bishops and other church authorities should be involved as such partnerships are developed, and the diocesan bishop should give the appropriate authorization before they are completed. The diocesan bishop's approval is required for partnerships sponsored by institutions subject to his governing authority; for partnerships sponsored by religious institutes of pontifical right, his *nihil obstat* should be obtained.
69. If a Catholic health care organization is considering entering into an arrangement with another organization that may be involved in activities judged morally wrong by the Church, participation in such activities, must be limited to what is in accord with the moral principles governing cooperation.
70. Catholic health care organizations are not permitted to engage in immediate material cooperation in actions that are intrinsically immoral, such as abortion, euthanasia, assisted suicide, and direct sterilization.[44]
71. The possibility of scandal must be considered when applying the principles governing cooperation.[45] Cooperation, which in all other respects is morally licit, may need to be refused because of the scandal that might be caused. Scandal can sometimes be avoided by an appropriate explanation of what is in fact being done at the health care facility under Catholic auspices. The diocesan bishop has final responsibility for assessing and addressing issues of scandal, considering not only the circumstances in his local diocese but also the regional and national implications of his decision.[46]
72. The Catholic partner in an arrangement has the responsibility periodically to assess whether the binding agreement is being observed and implemented in a way that is consistent with Catholic teaching.

Conclusion

Sickness speaks to us of our limitations and human frailty. It can take the form of infirmity resulting from the simple passing of years or injury from the exuberance of youthful energy. It can be temporary or chronic, debilitating, and even terminal. Yet the follower of Jesus faces illness and the consequences of the human condition aware that our Lord always shows compassion toward the infirm.

Jesus not only taught his disciples to be compassionate, but he also told them who should be the special object of their compassion. The parable of the feast with its humble guests was preceded by the instruction: "When you hold a banquet, invite the poor, the crippled, the lame, the blind" (Lk 14:13). These were people whom Jesus healed and loved.

Catholic health care is a response to the challenge of Jesus to go and do likewise. Catholic health care services rejoice in the challenge to be Christ's healing compassion in the world and see their ministry not only as an effort to restore and preserve health but also as a spiritual service and a sign of that final healing that will one day bring about the new creation that is the ultimate fruit of Jesus' ministry and God's love for us.

Notes

1. National Conference of Catholic Bishops, *Health and Health Care: A Pastoral Letter of the American Catholic Bishops* (Washington, D.C.: United States Catholic Conference, 1981).
2. Health care services under Catholic auspices are carried out in a variety of institutional settings (e.g., hospitals, clinics, out-patient facilities, urgent care centers, hospices, nursing homes, and parishes). Depending on the context, these Directives will employ the terms "institution" and/or "services" in order to encompass the variety of settings in which Catholic health care is provided.
3. *Health and Health Care,* p. 5.
4. Second Vatican Ecumenical Council, *Decree on the Apostolate of the Laity (Apostolicam Actuositatem)* (1965), no. 1.
5. Pope John Paul II, Post-Synodal Apostolic Exhortation, *On the Vocation and the Mission of the Lay Faithful in the Church and in the World (Christifideles Laici)* (Washington, D.C.: United States Catholic Conference, 1988), no. 29.
6. As examples, see Congregation for the Doctrine of the Faith, *Declaration on Procured Abortion* (1974); Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (1980); Congregation for the Doctrine of the Faith, *Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day (Donum Vitae)* (Washington, D.C.: United States Catholic Conference, 1987).
7. Pope John XXIII, Encyclical Letter, *Peace on Earth (Pacem in Terris)* (Washington, D.C.: United States Catholic Conference, 1963), no. 11; *Health and Health Care,* pp. 5, 17–18; *Catechism of the Catholic Church,* 2nd ed. (Washington, D.C.: United States Catholic Conference, 2000), no. 2211.
8. Pope John Paul II, *On Social Concern, Encyclical Letter on the Occasion of the Twentieth Anniversary of "Populorum Progressio" (Sollicitudo Rei Socialis)* (Washington, D.C.: United States Catholic Conference, 1988), no. 43.
9. National Conference of Catholic Bishops, *Economic Justice for All: Pastoral Letter on Catholic Social Teaching and the U.S. Economy* (Washington, D.C.: United States Catholic Conference, 1986), no. 80.
10. The duty of responsible stewardship demands responsible collaboration. But in collaborative efforts, Catholic institutionally based health care services must be attentive to occasions when the policies and practices of other institutions are not compatible with the Church's authoritative moral teaching. At such times, Catholic health care institutions should determine whether or to what degree collaboration would be morally permissible. To make that judgment, the governing boards of Catholic institutions should adhere to the moral principles on cooperation. See Part Six.
11. *Health and Health Care,* p. 12.
12. Cf. *Code of Canon Law,* cc. 921–923.
13. Cf. ibid., c. 867, § 2, and c. 871.
14. To confer Baptism in an emergency, one must have the proper intention (to do what the Church intends by Baptism) and pour water on the head of the person to be baptized, meanwhile pronouncing the words: "I baptize you in the name of the Father, and of the Son, and of the Holy Spirit."
15. Cf. c. 883, 3.
16. For example, while the donation of a kidney represents loss of biological integrity, such a donation does not compromise functional integrity since human beings are capable of functioning with only one kidney.
17. Cf. directive 53.
18. *Declaration on Euthanasia,* Part IV; cf. also directives 56–57.
19. It is recommended that a sexually assaulted woman be advised of the ethical restrictions that prevent

Catholic hospitals from using abortifacient procedures; cf. Pennsylvania Catholic Conference, "Guidelines for Catholic Hospitals Treating Victims of Sexual Assault," *Origins* 22 (1993): 810.

20. Pope John Paul II, "Address of October 29, 1983, to the 35th General Assembly of the World Medical Association," *Acta Apostolicae Sedis* 76 (1984): 390.
21. Second Vatican Ecumenical Council, "Pastoral Constitution on the Church in the Modern World" (*Gaudium et Spes*) (1965), no. 49.
22. Ibid., no. 50.
23. Pope Paul VI, Encyclical Letter, *On the Regulation of Birth (Humanae Vitae)* (Washington, D.C.: United States Catholic Conference, 1968), no. 14.
24. Ibid., no. 12.
25. Pope John XXIII, Encyclical Letter, *Mater et Magistra* (1961), no. 193, quoted in Congregation for the Doctrine of the Faith, *Donum Vitae,* no. 4.
26. Pope John Paul II, Encyclical Letter, *The Splendor of Truth (Veritatis Splendor)* (Washington, D.C.: United States Catholic Conference, 1993), no. 50.
27. "Homologous artificial insemination within marriage cannot be admitted except for those cases in which the technical means is not a substitute for the conjugal act but serves to facilitate and to help so that the act attains its natural purpose" (*Donum Vitae,* Part II, B, no. 6; cf. also Part I, nos. 1, 6).
28. Ibid., Part II, A, no. 2.
29. "Artificial insemination as a substitute for the conjugal act is prohibited by reason of the voluntarily achieved dissociation of the two meanings of the conjugal act. Masturbation, through which the sperm is normally obtained, is another sign of this dissociation: even when it is done for the purpose of procreation, the act remains deprived of its unitive meaning: 'It lacks the sexual relationship called for by the moral order, namely, the relationship which realizes "the full sense of mutual self-giving and human procreation in the context of true love"'" (*Donum Vitae,* Part II, B, no. 6).
30. Ibid., Part II, A, no. 3.
31. Cf. directive 45.
32. *Donum Vitae,* Part I, no. 2.
33. Cf. ibid., no. 4.
34. Cf. Congregation for the Doctrine of the Faith, "Responses on Uterine Isolation and Related Matters," July 31, 1993, *Origins* 24 (1994): 211–212.
35. Pope John Paul II, Apostolic Letter, *On the Christian Meaning of Human Suffering (Salvifici Doloris)* (Washington, D.C.: United States Catholic Conference, 1984), nos. 25–27.
36. National Conference of Catholic Bishops, *Order of Christian Funerals* (Collegeville, Minn.: The Liturgical Press, 1989), no. 1.
37. *Declaration on Euthanasia.*
38. Ibid., Part II, p. 4.
39. Committee for Pro-Life Activities, National Conference of Catholic Bishops, *Nutrition and Hydration: Moral and Pastoral Reflections* (Washington, D.C.: United States Catholic Conference, 1992). On the importance of consulting authoritative teaching in the formation of conscience and in taking moral decisions, see *Veritatis Splendor,* nos. 63–64.
40. *Declaration on Euthanasia,* Part IV.
41. Ibid.
42. Cf. ibid.
43. *Donum Vitae,* Part I, no. 4.
44. While there are many acts of varying moral gravity that can be identified as intrinsically evil, in the context of contemporary health care the most pressing concerns are currently abortion, euthanasia, assisted suicide, and direct sterilization. See Pope John Paul II's *Ad Limina* Address to the bishops of Texas, Oklahoma, and Arkansas (Region X), in *Origins* 28 (1998): 283. See also "Reply of the Sacred Congregation for the Doctrine of the Faith on Sterilization in Catholic Hospitals" (*Quaecumque Sterilizatio*), March 13, 1975, *Origins* 10 (1976): 33–35: "Any cooperation institutionally approved or tolerated in actions which are in themselves, that is, by their nature and condition, directed to a contraceptive end…is absolutely forbidden. For the official approbation of direct sterilization and, a *fortiori,* its management and execution in accord with hospital regulations, is a matter which, in the objective order, is by its very nature (or intrinsically) evil." This directive supersedes the "Commentary on the Reply of the Sacred Congregation for the Doctrine of the Faith on Sterilization in Catholic Hospitals" published by the National Conference of Catholic Bishops on September 15, 1977 in *Origins* 11 (1977): 399–400.
45. See *Catechism of the Catholic Church*: "Scandal is an attitude or behavior which leads another to do evil" (no. 2284); "Anyone who uses the power at his disposal in such a way that it leads others to do wrong becomes guilty of scandal and responsible for the evil that he has directly or indirectly encouraged" (no. 2287).
46. See "The Pastoral Role of the Diocesan Bishop in Catholic Health Care Ministry," *Origins* 26 (1997): 703.

HEALTH ETHICS GUIDE

Catholic Health Association of Canada

2000

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The full introduction to the "Health Ethics Guide" includes a summary of the basic principles that shape Catholic medical ethics. This 2000 "Health Guide" replaces the 1991 "Health Care Ethics Guide."

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The Catholic Health Organization

The ministry of Catholic organizations is one of the visible expressions of the ministry of Christ. As creatures of body and spirit, we need visible, tangible human institutions to assist us to live as a believing community bearing witness to the Good News as expressed in the Catholic faith. Catholic organizations fulfil this important role by being present to people at the critical points where life can be fostered, where people are born and die, where they learn and are taught, where they are cured and healed, and where they are assisted when in trouble. Catholics see this concrete involvement as a sacramental presence, an encounter with Christ.

Catholic health organizations have a distinct spiritual vision and culture that directs them to attend to the needs of the poor and vulnerable with compassion and dignity. It is that vision which defines the quality of their relationship with those in need of care.

Our distinctive vocation in Christian health care is not so much to heal better or more efficiently than anyone else; it is to bring comfort to people by giving them an experience that will strengthen their confidence in life. The ultimate goal of our care is to give those who are ill, through our care, a reason to hope. (Joseph Cardinal Bernadin, "What Makes a Hospital Catholic—A Response," *America,* Vol. 174, no. 15 (May 4, 1996), 9.)

Among the tangible signs that should identify Catholic organizations are the following: Catholic sponsorship and management; quality care; proper stewardship of resources for the community served; a culture that supports Christian ethical values and spiritual beliefs; recognition by the bishop of the diocese as an integral part of the apostolate; promotion of spiritual/religious care; mission and values integration; just working conditions; the availability of the sacraments, and the prominence of various Christian symbols.

The work of Catholic health organizations is a particular expression of the healing ministry of Christ. The physical, emotional and spiritual healing experienced by those cared for within these organizations is a sign of the presence and compassion of Christ the healer. Such organizations offer a privileged opportunity to provide the best possible care in a manner and atmosphere fully inspired by the gospel.

The basic orientation of Catholic health organizations and their personnel is respect for the dignity of every person and concern for the total well-being of persons receiving care. These organizations affirm the importance of family, friends and the community in the promotion of health. They also strive to provide for their personnel a milieu that is conducive to personal fulfillment.

As part of the history of health care institutions in Canada, religiously-based organizations have earned their rightful place in our country through their pioneering efforts, often undertaken in very demanding circumstances. Such centres continue to make a distinctive contribution to health care in Canada.

Ethical Reflection and Decision-Making

To witness to the teachings and values of Jesus Christ requires sound moral reflection and judgement. This is especially true in our technological world where there is an ever-increasing danger of reducing persons to objects. Judgements of what is right or wrong are ethical or moral decisions. Especially when rights, duties, or values appear to conflict, ethical reflection and discernment can assist everyone concerned.

The quality of ethical decisions depends not merely on abstract reasoning, but also on the lived faith, prudence and virtue of the decision-maker. The Catholic moral tradition is the fruit of an on-going dialogue between our understanding of human nature and our experience of God as revealed in Jesus Christ. It develops through prayer, study, reflection and the recognition of the Holy Spirit at work through various sources. Such sources include health and social service providers, the experience of the Christian community, moral theologians, ethicists, pastoral care workers, the local bishop, church teachings, and especially Sacred Scripture. No source of knowledge pertinent to the issue at hand should be neglected in the making of moral decisions.

The Catholic moral tradition presents a number of theological foundations that guide ethical reflection. These include a belief in the presence of God in human experience;

the conviction that all of creation is to be regarded as a gift of God's love; an awareness that we have a responsibility to work to eliminate sickness and suffering; an acknowledgement that, at times, there can be growth through suffering; and the recognition that the moral dimension of human existence requires that we act from an informed conscience.

The local bishop has the responsibility to provide leadership and to collaborate with the mission of Catholic organizations. In fulfilling his role as the primary teacher and pastor of the community, with the assistance of specialists in different disciplines, he has the task to ensure that the teaching of the church is reflected faithfully in the context of rapidly developing medical advances and of the increasing complexity of the human sciences. In order to truly respect dignity, promote justice and foster trust, the church must itself witness to these values.

Since the Christian moral tradition is a living tradition, our formulations of it are necessarily the product of a grasp of reality that is constantly being refined, of historically conditioned attitudes, and of limited philosophical concepts and language. At any given time in history, a particular formulation is only more or less adequate. Continued faithfulness to this living tradition presupposes growth in understanding of moral principles and their implications. It is also important to remember that Catholic teaching maintains a hierarchy of truths and values. This means that specific teachings have varying degrees of importance concerning one's faith and moral life.

The tradition is not always clear or unanimous concerning all moral issues. In such cases, it is the teaching of the Catholic Church that obligations are not to be imposed unless they are certain. Thus, in moral questions debated by moral theologians in the church, Catholic tradition upholds a person's liberty to follow those opinions that seem to be consistent with the wishes of the person receiving care and with the best standards of good care.

Christian Moral Values

Christian ethical reasoning is based upon a world view contained in the gospel as interpreted by the church. This world view gives rise to values and principles that direct ethical decision-making and that enable us to respond to the call to respect dignity, promote justice and foster trust.

Two fundamental values underlie the discussion of values in this guide.

1. DIGNITY OF EVERY HUMAN PERSON – All persons possess an intrinsic dignity and worth that is independent of what any other person thinks or says about them. (*Pastoral Constitution of the Church in the Modern World, Vatican Council II: Constitutions, Decrees, Declarations,* Austin Flannery (ed.), New York, American Press, 1996, nos. 27, 29.) The basis for this dignity, in the Judeo-Christian tradition, is the belief that every human being is made in the image of God.

2. THE INTERCONNECTEDNESS OF EVERY HUMAN BEING — Human persons are social beings and cannot live or develop their potential outside of human relationships and community. (Ibid., nos. 12, 25.) This fundamental value affirms the interconnectedness of every human being with all persons, with all of creation, and with God. From these two fundamental values flow a number of related values.

3. STEWARDSHIP AND CREATIVITY – The scriptures present a view of creation as both gift and responsibility. We share a responsibility to respect, protect and care for all of creation and for ourselves. We are to use our own free and intelligent creativity to fashion a better world while respecting its true nature, appreciating its benefits and accepting its limitations.

4. RESPECT FOR HUMAN LIFE – Human life is sacred and inviolable in all of its phases and in every situation. (*Pontificia Academia Pro Vita, Final Declaration, 5th General Assembly* (February 24–27) 1999, no. 1.) Human life is a gift of God's love and the basis for all other human goods. Nevertheless, human bodily life is not an absolute good but is subordinated to the good of the whole person.

5. THE COMMON GOOD – Every individual has a duty to share in promoting the well-being of the community as well as a right to benefit from being a member of the community. Respect for human freedom necessitates that society seeks to enable men and women to assume responsibility for their own lives, and to encourage them to cooperate with each other in pursuit of the common good—the building of a just and compassionate social order in which true human growth for all persons is encouraged. By extension, the common good includes environmental concerns that have a direct relationship to the good of individuals and of society.

6. CHARITY OR SOLIDARITY – Charity is the Christian virtue urging us to respond to the needs of others. Solidarity (which includes empathy and compassion for others) is a contemporary way to express our interconnectedness to all human beings and our obligation to respond with love to their needs. This response is even more explicitly articulated in church teaching which exhorts individuals, organizations and those who develop public policy to a preferential option for the poor and marginalized.

Christian Moral Principles

1. **TOTALITY AND INTEGRITY** – All our physical and psychological functions are to be developed, used, and cared for to protect our human dignity. Therefore, no human function can ever be sacrificed except for the saving or better functioning of the whole person. Basic human capacities may not be sacrificed if more harm than good would result to that person.

2. **DOUBLE EFFECT** – When an action may have both beneficial and harmful consequences, such as pain relief treatment for a terminally ill person—treatment that might shorten life—the action may be pursued if the following conditions are fulfilled: (i) the directly intended object of the act must not be intrinsically evil, i.e. contrary to one's fundamental commitment to God, neighbour or oneself; (ii) the intention of the agent must be to achieve the beneficial effects and to avoid the harmful effects as far as possible (i.e. the harmful effects should not be wanted, but only allowed); (iii) the foreseen beneficial effects are not achieved by means of the foreseen harmful effects; rather, the beneficial effects are inextricably and unavoidably linked to the harmful effects; (iv) the foreseen beneficial effects must be equal to or greater than the foreseen harmful effects.

3. **LEGITIMATE COOPERATION** – This principle applies to situations where an action involves more than one person, and sometimes when the persons have different intentions. It is unethical to cooperate formally with an immoral act, i.e. directly to intend the evil act itself. But sometimes it may be an ethical duty to cooperate materially with an immoral act, i.e. one does not intend the evil effects, but only the good effects, when only in this way can a greater harm be prevented. Two provisions must be considered, namely, (1) the cooperation is not immediate and, (2) the degree of cooperation and the danger of scandal is taken into account. (Refer to Appendix II, "The Principle of Legitimate Cooperation")

4. **SUBSIDIARITY** – According to this principle, decisions should be taken as close to the grass roots as possible. As applied to health needs, the principle suggests that the first responsibility for meeting these needs resides with the free and competent individual. Individuals, however, are not self-sufficient. They can achieve health and obtain health care only with the help of the community. The responsibility of fulfilling those needs that the individual cannot achieve alone must be assumed by larger or more complex groups, e.g. community organizations and different levels of government. (Refer to John Paul II, *Centesimus Annus,* no. 12)

5. **FREE AND INFORMED DECISION-MAKING** – The person receiving care is the primary decision-maker. No service or treatment is to be provided without his or her free and informed consent. For those not capable of making an informed decision, a proxy shall act for the person in accordance with their personal care directives. If an advance health care directive is inapplicable or unavailable, a proxy shall act for the person in accordance with their known needs, values and wishes. In emergency situations where the person receiving care is not capable of making an informed decision and a proxy is unavailable, the care provider may act in the proxy's stead.

6. **CONFIDENTIALITY** – Respect for the dignity of persons insists that persons receiving care be treated with trust, honesty and confidentiality. This includes privacy of personal information and freedom from unnecessary intrusions by others.

In this introductory section of the guide, we have highlighted the values and ethical principles of the Christian tradition that direct our efforts to enter into relationships that respect dignity, promote justice and foster truth. In the remainder of the guide we apply these values and ethical principles to seven key areas related to care in the fields of health and social services.

The Communal Nature of Care

INTRODUCTORY COMMENTS

Health and social service organizations operate in societies that are organized into complex networks of social groups, from the smallest family to local, national, international and global systems. These different social structures are contemporary expressions of the basic and diverse social needs of all persons. The interconnectedness of all human beings is a fundamental value.

While each person is unique, no one could exist for long or fulfil their potential apart from the human community. The community gives people opportunities to provide and obtain resources such as food, clothing, shelter and culture that are required to live a truly human life. Through sharing and communicating with others in community persons grow in knowledge and love. They achieve human fulfillment by serving others, since each one receives from and contributes in some way to the individual personal development of others. Indeed, every society in a certain sense is "personal," so that the person is the beginning, the subject and the aim of every social institution. (*Pastoral Constitution of the Church in the Modern Work, Vatican Council II: Constitutions, Decrees, Declarations,* Austin Flannery (ed.), New York, American Press, 1996, no. 25.)

The individual and social needs of people always must be kept in balance within a social order "founded on truth, built on justice, and animated by love.… Every social group must take account of the needs and legitimate aspirations of other groups, and even of the general welfare of the entire human family." (Ibid., no. 26.) This is achieved through cooperative activity and through social structures that seek to guarantee equity and to overcome domination of one group by another. Through such an approach, individuals and groups contribute to the well-being of others and receive from others what is needed to meet their own particular needs.

Christian tradition uses the images of the human body and of the family to emphasize that human beings function often as organs of the greater civil society, united by common ends and using common means. Every person shares responsibility for our society and society has a responsibility for each of its members. As Christians, we also live in society as members of a community of faith. The faith life of the Christian community is shaped by our baptismal call to share God's life and to work for the common good of all peoples. The fundamental law of this community is such that love of self, love of neighbour and love of God should not be separated.

Health care and social support are two of the responsibilities and benefits of society. *It is therefore necessary that (governments) give wholehearted and careful attention to the social as well as to the economic progress of the citizens, and to the development […] of such essential services as […] housing, public health, education […]* (John XXIII, *Pacem in Terris,* April 11, 1963, no. 63.)

Catholic health and social service organizations function in civil society with a particular identity and mission. The specific way in which this mission is carried out distinguishes the service of Catholic care providers. This service is designated as "ministry" because it is motivated by the gospel and is part of an enduring faith tradition. Such an understanding of ministry challenges any system which might treat a person merely as a case, number or statistic. All those who are engaged in this ministry seek to create a community of compassion. They are dedicated to the care of persons in need, especially the most vulnerable, to the promotion of health in all its dimensions, and to forming healing relationships.

In society at large, Catholic health and social service organizations are a voice expressing a vision of life based on the moral and religious values of the Roman Catholic tradition. The care provided by these organizations is one expression within the local church of the healing ministry of Jesus Christ.

The Dignity of the Human Person

INTRODUCTORY COMMENTS

A fundamental value underlying ethics in health care and social services is respect for the dignity of each human person. This value aspires to protect the multiple interests of the person—from bodily to psychological to spiritual to cultural integrity. This respect for the dignity of each human person has been acknowledged and enshrined in the United Nations' *Universal Declaration of Human Rights.*

Human dignity is based on the physiological, psychological, social and spiritual uniqueness of being a person. Persons are created with intelligence and free will, with a moral consciousness and a potential for self-fulfillment. They possess the radical capacity to know, to love, to choose freely and to determine the direction of their lives. Each person is irreplaceable, with an intrinsic value and purpose in life. All persons are equal in dignity and, therefore, are to be treated with equal respect.

Our Christian faith holds that all persons are created in the image and likeness of God, and are called to know, love and be in communion with God, with all other persons and creation for all eternity. We believe that God became human in Jesus Christ, enabling all human beings to share the dignity of being daughters or sons of God, sisters or brothers of Jesus Christ.

Respect is due to every person. In light of gospel values, differences of age, sex, race, religion, social and cultural background, health status, sexual orientation, intelligence, economic status, employment, or other qualitative distinctions do not take away from the dignity shared by all persons, whether or not they are aware of their dignity.

Human Reproduction

INTRODUCTORY COMMENTS

Human sexuality is a personal aspect of our identity that gives beauty, pleasure, power and mystery to our lives.

Because we are created in the image and likeness of God, human sexuality is good in all its dimensions: physical, psychological, spiritual and social.

Human sexuality has an interpersonal purpose. It is rooted in our basic human need to love and be loved, to live and grow through human relationships, to preserve and perpetuate society. The wonders of sexuality and birth are best shared in the family setting, and should be supported by instruction in both the parish and school.

Human sexuality is meant to nurture and sustain a woman's and a man's free gift of themselves in a permanent, loving and fruitful commitment of marriage. For Christians, this covenant of human love is a symbol of that faithful love existing between Christ and the church.

The love between a woman and a man is experienced in a unique way and completed through the marital act of sexual intercourse. This act can deepen the union of love, enabling the couple to share with God in the creation of human life. Men and women are called to be responsible stewards of God's gifts, always treating each other with loving respect. The unitive and procreative aspects of sexual intercourse are not to be separated.

Responsible parenthood requires that decisions about having children be made in a prayerful and discerning manner, considering what is most loving and life-giving and what is best for the overall welfare of the family.

Christianity looks upon the beginnings of human life with particular wonder and reverence. Catholic health care providers, therefore, are to surround obstetrical and perinatal care with an atmosphere respectful of human life, mindful of the parents' special circumstances and needs.

Organ and Tissue Donation and Transplantation

INTRODUCTORY COMMENTS

Human beings live and grow in mutual dependence with other members of the human community. Advances in medicine have made organ, blood and other tissue transplants a way to improve health and to give new life to countless people. Organ and tissue donation is an expression of respect for the dignity of persons, solidarity with other members of the human community, and charity in response to the needs and suffering of others.

From a Christian perspective, as members of the human community, we are co-creators and stewards of God's creation. We are to use our gifts to benefit ourselves, other individuals and the common good. In honouring the sacredness of every human life, Christians are encouraged to be generous in their response to God's call to love through the self-giving that comes from volunteering to be an organ donor. (John Paul II, *Evangelium Vitae,* no. 86.)

In applying its ethical principles to the issue of organ and tissue donation and transplantation, the church teaches that transplanting organs and tissues from a dead person to a living person, and transplanting organs and tissues from a living person to another, are ethically acceptable, provided that the following criteria are met: there is a serious need on the part of the recipient that cannot usually be fulfilled in any other way; the functional integrity of the living donor as a human person is not impaired; the risk taken by the living donor as an act of charity is proportionate to the good resulting for the recipient; the donor's and the recipient's consent are free and informed.

Many Catholic health care organizations provide a crucial link in the donation and transplantation of organs and tissues. They have a responsibility to provide this service with respect. Health care professionals are ideally suited for promoting organ donation and for educating the public about the subject.

Schools, parishes and community organizations should highlight the merits of organ and tissue donation and transplantation. Such activities would help to bring this issue into peoples' homes and encourage them to express their wishes to family and care providers.

Care of the Dying Person

INTRODUCTORY COMMENTS

Because of the inherent dignity and value of the person, all human beings are to be respected at every stage of life.

Sickness, suffering and dying are an inevitable part of human experience. Although the harshness of these realities can be eased by medical and psychological advances, nonetheless, they are a reminder of the limits of human existence and they lead human beings to ask more profound questions about the meaning of life and the mystery of death.

Dying can be a time of deeper self-awareness and not merely an inevitable process to which persons must passively submit. It can be a time in which persons freely and consciously affirm the meaning of their lives. It can also be an occasion of profound reconciliation with family and friends. In the time between the diagnosis of a terminal illness and death many losses occur which affect both the dying person and family members. These losses may be physical, psychological, social, or spiritual in nature. Grief is an important dimension of the dying process. Spiritual and religious care, therefore, is an essential element of care for those who are dying.

As Christians, what may seem meaningless takes on new meaning when we walk with Jesus Christ in faith through his life, death and resurrection. Death is the end of life on earth and the beginning of an eternal life with God. This conviction has moved Christians throughout history to regard death with awe and profound respect. When suffering and sickness do occur, they can have a positive meaning in a person's life. They do not represent a punishment or curse. On the contrary, accepted as a means of drawing closer to Christ, they can be an aid to spiritual growth.

Advances in science and technology are dramatically improving our ability to cure illness, ease suffering and prolong life. Concerted efforts must be taken to alleviate sickness and suffering.

These advances also raise new ethical questions concerning end-of-life care, particularly around life-sustaining treatment. There are occasions when prolonging life by artificial means places onerous burdens on dying persons and their families. In the face of such issues, it is necessary to maintain a balance between two important obligations. We are obliged not to intentionally kill someone; assisted suicide and euthanasia are not acceptable options. At the same time, we are not obliged to use life-sustaining procedures which would impose burdens out of proportion with the benefits to be gained from such procedures.

Catholic health and social service organizations, along with local parish communities, should surround dying persons and their families with all the care resources available.

Research on Human Subjects

INTRODUCTORY COMMENTS

Research in the human sciences provides significant benefits for the human community. New knowledge and understanding in health care, the social sciences and technology help alleviate human suffering, improve treatments for illnesses and enhance health status. The findings of research involving human subjects can offer creative solutions and hope for research subjects, particular groups and society as a whole. The participation of individuals in research studies, as investigators or as subjects, is an affirmation of solidarity with others. The way research is carried out must always respect the dignity and integrity of the persons involved and serve the common good.

Our Christian faith gives us an increased awareness of solidarity with others and challenges us to exercise leadership through participation in research. As co-creators with God, we are to use our gifts of intelligence and freedom to improve our bodies and to develop health care and social services that will benefit humankind, including medical technologies, methodologies and basic sciences.

Catholic health and social service organizations, as well as educational institutions engaged in research involving human subjects, have a responsibility to communicate and foster a respectful ethical attitude toward such research.

Governance and Administration

INTRODUCTORY COMMENTS

Catholic health and social service organizations are communities of service, united through collaborative activities and inspired by Roman Catholic moral principles for the purpose of providing an optimum level of care for those who are sick or in need, and promoting a healthy society. At the same time, they are occupational communities providing for personnel a means of personal and professional fulfillment and a means of earning a living.

To meet these obligations, the organization is called upon to act as a moral community by addressing the ethical dimension of decisions related to governance and administration, and by striving for effective communication and consultation with all members of the organization.

As a community of service that receives funds from the public to carry out its mission, the organization acts to meet obligations that correspond to its several roles:

- as an agency commissioned to provide services to the public;
- as a human community of service expressing solidarity with those in need of care;
- as a Christian community acting as a careful steward of God's gifts;
- as a church community committed to a preferential option for those who are poor and marginalized.

Work is a dimension of a person's creativity; it provides a community and a sense of meaning and purpose. As a community of work, the organization seeks to create an atmosphere within which work is viewed as more than an economic function. The personnel, in turn, are expected to carry out the mission of the organization. In their life and work personnel are guided by personal values that go beyond their role as employees. Personnel should be treated accordingly.

THE OATH OF A MUSLIM PHYSICIAN

Islamic Medical Association of North America

1977

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Adopted in 1977 by the Islamic Medical Association of North America, the Oath of a Muslim Physician is a composite drawn from the historical and contemporary writings of Muslim physicians.

Praise be to Allah (God), the Teacher, the Unique, Majesty of the heavens, the Exalted, the Glorious, Glory be to Him, the Eternal Being Who created the Universe and all the creatures within, and the only Being Who containeth the infinity and the eternity. We serve no other god besides Thee and regard idolatry as an abominable injustice.

Give us the strength to be truthful, honest, modest, merciful and objective.

Give us the fortitude to admit our mistakes, to amend our ways and to forgive the wrongs of others.

Give us the wisdom to comfort and counsel all towards peace and harmony.

Give us the understanding that ours is a profession sacred that deals with your most precious gifts of life and intellect.

Therefore, make us worthy of this favoured station with honor, dignity and piety so that we may devote our lives in serving mankind, poor or rich, literate or illiterate, Muslim or non-Muslim, black or white with patience and tolerance with virtue and reverance, with knowledge and vigilance, with Thy love in our hearts and compassion for Thy servants, Thy most precious creation.

Hereby we take this oath in Thy name, the Creator of all the Heavens and the earth and follow Thy counsel as Thou hast revealed to Prophet Mohammad (pbuh).

"Whoever killeth a human being, not in lieu of another human being nor because of mischief on earth, it is as if he hath killed all mankind. And if he saveth a human life, he hath saved the life of all mankind." (Qur'an v/35)

ISLAMIC CODE OF MEDICAL ETHICS KUWAIT DOCUMENT

Islamic Organization for Medical Sciences

1981

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The First International Conference on Islamic Medicine, held in Kuwait in January 1981, endorsed this Islamic Code of Medical Ethics with the hope that every Muslim doctor would "find in it the guiding light to maintain his professional behaviour within the boundaries of Islamic teachings." As do other Muslim medical ethics texts, the code draws on passages from the Qur'an and demonstrates an explicitly religious tone, more so even than most contemporary Judaeo-Christian medical ethics directives. The code includes an oath for physicians.

<http://www.islamset.com/ethics/code/cont2.html>

The Oath of the Doctor

I swear by God…The Great

To regard God in carrying out my profession

To protect human life in all stages and under all circumstances, doing my utmost to rescue it from death, malady, pain and anxiety…

To keep people's dignity, cover their privacies and lock up their secrets…

To be, all the way, an instrument of God's mercy, extending my medical care to near and far, virtuous and sinner and friend and enemy…

To strive in the pursuit of knowledge and harnessing it for the benefit but not the harm of Mankind…

To revere my teacher, teach my junior, and be brother to members of the Medical Profession joined in piety and charity…

To live my Faith in private and in public, avoiding whatever blemishes me in the eyes of God, His apostle and my fellow Faithful.

And may God be witness to this Oath.

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Definition of Medical Profession

- "THERAPEUSIS" is a noble Profession. God honoured it by making it the miracle of Jesus son of Mary. Abraham enumerating his Lord's gifts upon him included "and if I fall ill He cures me."

- Like all aspects of knowledge, medical knowledge is part of the knowledge of God "who taught man what man never knew." The study of Medicine entails the revealing of God's signs in His creation. 'And in yourselves…do you not see?' The practice of Medicine brings God's mercy unto His subjects. Medical practice is therefore an act of worship and charity on top of being a career to make a living.
- But God's mercy is as accessible to all people including good and evil, virtuous and vicious and friend and foe—as are the rays of His sun, the comfort of His breeze, the coolness of His water and the bounty of His provision. And upon this basis must the medical profession operate, along the single track of God's mercy, never adversive and never punitive, never taking justice as its goal but mercy, under whatever situations and circumstances.
- In this respect the medical profession is unique. It shall never yield to social pressures motivated by enmity or feud be it personal, political or military. Enlightened statesmanship will do good by preserving the integrity of the medical profession and protecting its position beyond enmity or hostility.
- The provision of medical practice is a religious dictate upon the community, 'Fardh Kifaya,' that can be satisfied on behalf of the community by some citizens taking up medicine. It is the duty of the state to ensure the needs of the nation to doctors in the various needed specialities. In Islam, this is a duty that the ruler owes the nation.
- Need may arise to import from afar such medical expertise that is not locally available. It is the duty of the State to satisfy this need.
- It also behoves the State to recruit suitable candidates from the nation's youth to be trained as doctors. An ensuing duty therefore is to establish relevant schools, faculties, clinics, hospitals and institutions that are adequately equipped and manned to fulfill that purpose.
- "Medicine" is a religious necessity for society. In religious terms, whatever is necessary to satisfy that "necessity" automatically acquires the status of a "necessity." Exceptions shall therefore be made from certain general rules of jurisprudence for the sake of making medical education possible. One such example is the intimate inspection of the human body whether alive or dead, without in any way compromising the respect befitting the human body in life and death, and always in a climate of piety and awareness of the presence of God.
- The preservation of man's life should embrace also the utmost regard to his dignity, feelings, tenderness and the privacy of his sentiments and body parts. A patient is entitled to full attention, care and feeling of security while with his doctor. The doctor's privilege of being exempted from some general rules is only coupled with more responsibility and duty that he should carry out in conscientiousness and excellence in observing God, "excellence that entails that you worship God as if you see Him. For even though you don't see Him, He sees you."

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Characters of the Physician

- The physician should be amongst those who believe in God, fulfill His rights, are aware of His greatness, obedient to His orders, refraining from His prohibitions, and observing Him in secret and in public.
- The physician should be endowed with wisdom and graceful admonition. He should be cheering not dispiriting, smiling and not frowning, loving and not hateful, tolerant and not edgy. He should never succumb to a grudge or fall short of clemency. He should be an instrument of God's justice, forgiveness and not punishment, coverage and not exposure.
- He should be so tranquil as never to be rash even when he is right…chaste of words even when joking…tame of voice and not noisy or loud, neat and trim and not shabby or unkempt…conducive of trust and inspiring of respect…well mannered in his dealings with the poor or rich, modest or great…in perfect control of his composure…and never compromising his dignity, however modest and forebearing.
- The physician should firmly know that "life" is God's…awarded only by Him…and that "Death" is the conclusion of one life and the beginning of another. Death is a solid truth…and it is the end of all but God. In his profession the Physician is a soldier for "Life" only…defending and preserving it as best as it can be, to the best of his ability.
- The Physician should offer the good example by caring for his own health. It is not befitting for him that his "do's" and "don'ts" are not observed primarily by himself. He should not turn his back on the lessons of medical progress, because he will never convince his patients unless they see the evidence of his own conviction…God addresses us in the Qoran by saying "and make not your own hands throw you into destruction." The Prophet

says "your body has a right on you"…and the known dictum is "no harm or harming in Islam."

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- The role of Physician is that of a catalyst through whom God, the Creator, works to preserve life and health. He is merely an instrument of God in alleviating people's illness. For being so designated the Physician should be grateful and forever seeking God's help. He should be modest, free from arrogance and pride and never fall into boasting or hint at self glorification through speech, writing or direct or subtle advertisement.
- The Physician should strive to keep abreast of scientific progress and innovation. His zeal or complacency and knowledge or ignorance, directly bear on the health and well-being of his patients. Responsibility for others should limit his freedom to expend his time. As the poor and needy have a recognized right in the money of the capable, so the patients own a share of the Doctor's time spent in study and in following the progress of medicine.
- The Physician should also know that the pursuit of knowledge has a double indication in Islam. Apart from the applied therapeutic aspect, pursuit of knowledge is in itself worship, according to the Qoranic guidance: "And say…My Lord…advance me in knowledge." and: "Among His worshippers…the learned fear Him most"…and: "God will raise up the ranks of those of you who believed and those who have been given knowledge."

Doctor-Doctor Relationship

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- Physicians are jointly responsible for the health care of the Nation…and complement one another through the variety of their medical specialization be they preventive or therapeutic, in the private sector or in State employment…all abiding by the ethics and rules of their profession.

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Doctor-Patient Relationship

- For the sake of the patient the Doctor was…and not the other way round. Health is the goal and medical care is the means…the "patient" is master and the "Doctor" is at his service. As the Prophet says "The strongest should follow the pace of the weakest…for he is the one to be considered in deciding the pace of travel." Rules, schedules, time-tables and services should be so manipulated as to revolve around the patient and comply with his welfare and comfort as the top and overriding priority…other considerations coming next.

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- The sphere of a Doctor's charity, nicety, tolerance and patience should be large enough to encompass the patient's relatives, friends and those who care for or worry about him…but without of course compromising the dictates of "Professional Secrecy".
- Health is a basic human necessity and is not a matter of luxury. It follows that the Medical Profession is unique in that the client is not denied the service even if he cannot afford the fee. Medical legislature should ensure medical help to all needy of it, by issuing and executing the necessary laws and regulations.

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Professional Secrecy

Keeping other persons' secrets is decreed on all the Faithful…the more so if these were Doctors, for people willfully disclose their secrets and feelings to their doctors, confident of the time old heritage of Professional Secrecy, that the medical profession embraced since the dawn of history. The Prophet (peace be upon Him) described the three signs of the hypocrite as: "He lies when he speaks, he breaks his promise and he betrays when confided in." The Doctor shall put the seal of confidentiality on all information acquired by him through sight, hearing or deduction. Islamic spirit also requires that the items of the Law should stress the right of the patient to protect his secrets that he confides to his Doctor. A breach thereof would be detrimental to the practice of medicine, beside precluding several categories of patients from seeking medical help.

Doctor's Role During War

- Since the earliest battles of Islam it was decreed that the wounded is protected by his wound and the captive by his captivity. The faithful are praised in the Qoran as: "they offer food—dear as it is—to the needy, orphan or captive, (saying) we feed you for the sake of God without seeking any reward or gratitude from you." The Prophet (peace be upon Him) said to his companions: "I entrust the captives to your charity”…and they did…even giving them priority over themselves in the best of the food they shared. It is of interest to note that this was thirteen centuries prior to the Geneva Convention and the Red Cross.

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- The Medical Profession shall not permit its technical, scientific or other resources to be utilized in any sort of harm or destruction or infliction upon man of physical, psychological, moral or other damage…regardless of all political or military considerations.

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Responsibility and Liability

- The Practice of Medicine is lawful only to persons suitably educated, trained and qualified, fulfilling the criteria spelt out in the Law. A clear guidance is the Prophet’s tradition: “*Who-so-ever treats people without knowledge of medicine, becomes liable*”.
- With the availability of medical specialization, problem cases shall be referred to the relevant specialist. “*Each one is better suited to cope with what he was meant for*”.
- In managing a medical case the Doctor shall do what he can to the best of his ability. If he does, without negligence, taking the measures and precautions expected from his equals then he is not to blame or punish even of the results were not satisfactory.
- The Doctor is the patient’s agent on his body. The acceptance by the patient of a Doctor to treat him is considered an acceptance of any line of treatment the Doctor prescribes.
- If treatment entails surgical interference the initial acceptance referred to should be documented in writing, for the sake of protecting the Doctor against possible eventualities. If the patient declines or refuses the Doctor’s prescribed plan of treatment, this refusal should also be documented by writing, witnesses, or patient’s signature as the situation warrants or permits.
- When fear is the obstacle preventing the patient from consent, the Doctor may help his patient with a medicine such as a tranquilliser to free his patient from fear but without abolishing or suppressing his consciousness, so that the patient is able to make his choice in calmness and tranquillity. By far the best method to achieve this is the poise of the Doctor himself and his personality, kindness, patience and the proper use of the spoken word.
- In situations where urgent and immediate surgical or other interference is necessary to save life, the Doctor should go ahead according to the Islamic rule’ ‘necessities override prohibitions‘. His position shall be safe and secure whatever the result achieved, on condition that he has followed established medical methodology in a correct way. The “bad” inherent in not saving the patient outweighs the presumptive ‘good’ in leaving him to his self-destructive decision. The Islamic rule proclaims that “warding off” the ‘bad’ takes priority over bringing about the ‘good’.

The Prophetic guidance is “Help your brother when he is right and when he is wrong”. When concurring with helping a brother if right but surprised at helping him when wrong, the Prophet answered his companions: “Forbid him from being wrong…for this is the help he is in need of”.

The Sanctity of Human Life

- “On that account we decreed for the Children of Israel that whoever kills a human soul for other than manslaughter or corruption in the land, it shall be as if he killed all mankind, and who-so-ever saves the life of one, it shall be as if he saved the life of all mankind.” 5–32
- Human Life is sacred…and should not be willfully taken except upon the indications specified in Islamic Jurisprudence, all of which are outside the domain of the Medical Profession.
- A Doctor shall not take away life even when motivated by mercy. This is prohibited because this is not one of the legitimate indications for killing. Direct guidance in this respect is given by the Prophet’s tradition: “In old times there was a man with an ailment that taxed his endurance. He cut his wrist with a knife and bled to death. God was displeased and said ‘My subject hastened his end…I deny him paradise.’”

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- The sanctity of human Life covers all its stages including intrauterine life of the embryo and fetus. This shall not be compromised by the Doctor save for the absolute medical necessity recognised by Islamic Jurisprudence.

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- In his defence of Life, however, the Doctor is well advised to realize his limit and not transgress it. If it is scientifically certain that life cannot be restored, then it is futile to diligently keep on the vegetative state of the patient by heroic means of animation or preserve him by deep-freezing or other artificial methods. It is the process of life that the Doctor aims to maintain and not the process of dying. In any case, the Doctor shall not take a positive measure to terminate the patient's life.

- To declare a person dead is a grave responsibility that ultimately rests with the Doctor. He shall appreciate the seriousness of his verdict and pass it in all honesty and only when sure of it. He may dispel any trace of doubt by seeking counsel and resorting to modern scientific gear.
- The Doctor shall do his best that what remains of the life of an incurable patient will be spent under good care, moral support and freedom from pain and misery.
- The Doctor shall comply with the patient's right to know his illness. The Doctor's particular way of answering should however be tailored to the particular patient in question. It is the Doctor's duty to thoroughly study the psychological acumen of his patient. He shall never fall short of suitable vocabulary if the situation warrants the deletion of frightening nomenclature or coinage of new names, expressions or descriptions.
- In all cases the Doctor should have the ability to bolster his patient's faith and endow him with tranquility and peace of mind.

Doctor and Society

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- The Medical Profession shall take it as duty to combat such health-destructive habits as smoking, uncleanliness, etc.

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The combat and prevention of environmental pollution falls under this category.

The Doctor and Biomedical Advances

<http://www.islamset.com/ethics/code/cont2.html>

There is no censorship in Islam on scientific research, be it academic to reveal the signs of God in His creation, or applied aiming at the solution of a particular problem.

Freedom of scientific research shall not entail the subjugation of Man, telling him, harming him or subjecting him to definite or probable harm, with holding his therapeutic needs, defrauding him or exploiting his material need.

Freedom of scientific research shall not entail cruelty to animals, or their torture. Suitable protocols should be laid upon for the uncruel handling of experimental animals during experimentation.

The methodology of scientific research and the applications resultant thereof, shall not entail the commission of sin prohibited by Islam such as fornication, confounding of genealogy, deformity or tampering with the essence of the human personality, its freedom and eligibility to bear responsibility.

The Medical Profession has the right- and owes the duty of effective participation in the formulation and issuing of religious verdict concerning the lawfulness or otherwise of the unprecedented outcomes of current and future advances in biological science. The verdict should be reached in togetherness between Muslim specialists in jurisprudence and Muslim specialists in biosciences. Single-sided opinions have always suffered from lack of comprehension of technical or legal aspects.

The guiding rule in unprecedented matters falling under no extant text or law, is the Islamic dictum: "Wherever welfare is found, there exists the statute of God".

The individual patient is the collective responsibility of society, that has to ensure his health needs by any means inflicting no harm on others. This comprises the donation of body fluids or organs such as blood transfusion to the bleeding or a kidney transplant to the patient with bilateral irreparable renal damage. This is another 'Fardh Kifaya', a duty that donors fulfil on behalf of society. Apart from the technical procedure, the onus of public education falls on the medical Profession, which should also draw the procedural, organizational and technical regulations and the policy of priorities.

Organ donation shall never be the outcome of compulsion, family embarrassment, social or other pressure, or exploitation of financial need.

Donation shall not entail the exposure of the donor to harm.

The Medical Profession bears the greatest portion of responsibility for laying down the laws, rules and regulations organizing organ donation during life or after death by a statement in the donor's will or the consent of his family; as well as the establishment of tissue and organ banks for tissues amenable to storage. Cooperation with similar banks abroad is to be established on the basis of reciprocal aid.

On Medical Education

In planning the making of a Doctor, a principal goal is to make him a living example of all that God loves, free from all that God hates, well saturated with the love of God, of people and of knowledge.

The Medical Teacher owes his students the provision of the good example, adequate teaching, sound guidance and continual care in and out of classes and before and after graduation.

Medical Education picks from all trees without refractoriness or prejudice. Yet it has to be protected and purified from every positive activity towards atheism or infidelity.

Medical Education is neither passive nor authoritarian. It aims at sparking mental activity, fostering observation, analysis and reasoning, development of independent thought and the evolvement of fresh questions. The Qoran blamed those who said: " As such we have found our fathers and we will follow on their footsteps" an attitude which is only conductive to stagnation and arrest of progress.

"Faith" is remedial, a healer, a conqueror of stress and a procurer of cure. The training of the Doctor should prepare him to bolster "Faith" and avail the patient of its unlimited blessings.

Medical school curricula should include the teaching of matters of jurisprudence and worship pertaining to or influenced by various health aspects and problems.

Medical School curricula should familiarise the student with the medical and other scientific heritage of the era of Islamic civilization, the factors underlying the rise of Muslim civilization, those that lead to its eclipse, and the way(s) to its revival.

Medical school curricula should emphasize that medicine is worship both as an approach to belief by contemplation on the signs of God, as well as from the applied aspect by helping Man in distress.

Medical school curricula should comprise the teaching and study of this "Islamic Code of Medical Ethics".

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SECTION III.

ETHICAL DIRECTIVES FOR OTHER HEALTH-CARE PROFESSIONS

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Code for Nurses, International Council of Nurses [1973, reaffirmed 1989; revised 2002]

Code for Nurses with Interpretive Statements, American Nurses' Association [1950, revised 1976, 1985, 2001]

Code of Ethics for Nursing, Canadian Nurses Association [1985, revised 1991]

Code of Ethics, American Chiropractic Association [1994–1995]

Principles of Ethics and Code of Professional Conduct with Advisory Opinions, American Dental Association [revised to June 2002]

Code of Ethics for the Profession of Dietetics, American Dietetic Association [1987, revised 1999]

Code of Ethics, American Association of Pastoral Counselors [last amended 1994]

Guidelines for the Chaplain's Role in Bioethics, College of Chaplains, American Protestant Health Association [1992]

Code of Ethics, American Pharmacists Association [1969, amended 1975, revised 1981, 1994]

Statement of Professional Standards: Codes of Ethics for Pharmacists, Fédération Internationale Pharmaceutique [1988, revised 1997]

Code of Ethics and Guide for Professional Conduct, American Physical Therapy Association [1981, last amended 1991]

Occupational Therapy Code of Ethics, American Occupational Therapy Association [1988, revised 2000]

Code of Ethics of the Physician Assistant Profession, American Academy of Physician Assistants [1983, amended 1985, reaffirmed 1990]

Ethical Principles of Psychologists and Code of Conduct, American Psychological Association [1992]

Code of Ethics, National Association of Social Workers [1979, revised 1990, 1996, 1999]

Code of Ethics, American College of Healthcare Executives [amended 1990]

Ethical Conduct for Health Care Institutions, American Hospital Association [1992]

This section demonstrates the great number and diversity of ethical directives for healthcare professionals other than physicians. The section opens with several codes of ethics for nurses, followed by ethics directives for other professional groups from chiropractors and dentists to social workers and hospital administrators.

Most of the documents in this section represent professional organizations in the United States.

CODE FOR NURSES

International Council of Nurses

1973, REAFFIRMED 1989, REVISED 2000

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The International Council of Nurses first adopted an international code of ethics for nurses in 1953 and revised it in 1965. In 1973, the council adopted a new code, which was reaffirmed in 1989, and revised in 2000. The text of the International Code for Nurses follows.

<http://www.icn.ch/icncode.pdf>

Preamble

Nurses have four fundamental responsibilities: to promote health, to prevent illness, to restore health and to alleviate suffering. The need for nursing is universal.

Inherent in nursing is respect for human rights, including the right to life, to dignity and to be treated with respect. Nursing care is unrestricted by considerations of age, colour, creed, culture, disability or illness, gender, nationality, politics, race or social status.

Nurses render health services to the individual, the family and the community and co-ordinate their services with those of related groups.

THE CODE

The *ICN Code of Ethics for Nurses* has four principal elements that outline the standards of ethical conduct.

Elements of the Code

1. Nurses and people

The nurse's primary professional responsibility is to people requiring nursing care.

In providing care, the nurse promotes an environment in which the human rights, values, customs and spiritual beliefs of the individual, family and community are respected.

The nurse ensures that the individual receives sufficient information on which to base consent for care and related treatment.

The nurse holds in confidence personal information and uses judgement in sharing this information.

The nurse shares with society the responsibility for initiating and supporting action to meet the health and social needs of the public, in particular those of vulnerable populations.

The nurse also shares responsibility to sustain and protect the natural environment from depletion, pollution, degradation and destruction.

2. Nurses and practice

The nurse carries personal responsibility and accountability for nursing practice, and for maintaining competence by continual learning.

The nurse maintains a standard of personal health such that the ability to provide care is not compromised.

The nurse uses judgement regarding individual competence when accepting and delegating responsibility.

The nurse at all times maintains standards of personal conduct which reflect well on the profession and enhance public confidence.

The nurse, in providing care, ensures that use of technology and scientific advances are compatible with the safety, dignity and rights of people.

3. Nurses and the profession

The nurse assumes the major role in determining and implementing acceptable standards of clinical nursing practice, management, research and education.

The nurse is active in developing a core of research-based professional knowledge.

The nurse, acting through the professional organisation, participates in creating and maintaining equitable social and economic working conditions in nursing.

4. Nurses and co-workers

The nurse sustains a co-operative relationship with co-workers in nursing and other fields.

The nurse takes appropriate action to safeguard individuals when their care is endangered by a co-worker or any other person.

Suggestions for use of the ICN Code of Ethics for Nurses

The *ICN Code of Ethics for Nurses* is a guide for action based on social values and needs. It will have meaning only as a living document if applied to the realities of nursing and health care in a changing society.

To achieve its purpose the *Code* must be understood, internalised and used by nurses in all aspects of their work. It must be available to students and nurses throughout their study and work lives.

Applying the Elements of the ICN Code of Ethics for Nurses

The four elements of the *ICN Code of Ethics for Nurses*: nurses and people, nurses and practice, nurses and co-workers, and nurses and the profession, give a framework for the standards of conduct. The following chart will assist nurses to translate the standards into action. Nurses and nursing students can therefore:

- Study the standards under each element of the *Code.*
- Reflect on what each standard means to you. Think about how you can apply ethics in your nursing domain: practice, education, research or management.
- Discuss the *Code* with co-workers and others.
- Use a specific example from experience to identify ethical dilemmas and standards of conduct as outlined in the *Code.* Identify how you would resolve the dilemma.
- Work in groups to clarify ethical decision making and reach a consensus on standards of ethical conduct.
- Collaborate with your national nurses' association, co-workers, and others in the continuous application of ethical standards in nursing practice, education, management and research.

CODE FOR NURSES WITH INTERPRETIVE STATEMENTS

American Nurses' Association

1950, REVISED 1976, 1985, 2001

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The 1985 Code for Nurses is a revised version of the code adopted by the American Nurses' Association (ANA) in 1950. The eleven-point code and the accompanying interpretive statements provide a framework for ethical decision making that includes several noteworthy aspects: (1) It identifies the values and beliefs that undergird the ethical standards; (2) it encompasses a breadth of social and professional concerns; (3) it manifests an awareness of the ethical implications of shifting professional roles and of the complexity of modern health care; and (4) it goes beyond prescriptive statements regarding personal and professional conduct by advocating a sense of accountability to the client.

Although the text of the code remains essentially unchanged from the 1976 revision, both the organization and the text of the interpretive statements have been modified somewhat. Among the changes: (1) The discussion of human dignity following point 1 is expanded and includes specific statements that "the nurse does not act deliberately to terminate the life of any person," but that nurses may provide symptomatic intervention to dying clients "even when the interventions entail substantial risks of hastening death"; and (2) a statement under point 11 in the 1976 code, that "quality health care is mandated as a right to all citizens," has been deleted. The 2001 ANA Code for Nurses and the text of selected interpretive statements are at <http://www.nursingworld.org/ethics/code/ethicscode150.htm>.

CODE OF ETHICS FOR NURSING

Canadian Nurses Association

1985, REVISED 1991

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The introductory sections of the Canadian Nurses Association (CNA) code suggest a sophisticated view of the role of codes. For example, the code "provides clear direction for avoiding ethical violations," that is, "the neglect of moral obligation," but it cannot resolve "ethical dilemmas," in which there are "ethical reasons both for and against a particular course of action." The code also cannot relieve the "ethical distress" that occurs "when nurses experience the imposition of practices that provoke feelings of guilt, concern or distaste." The CNA code is unique in its explicit organization around values, which "express broad ideals of nursing"; obligations, which are "moral norms that have their basis in nursing values"; and limitations, which "describe exceptional circumstances in which a value or obligation cannot be applied."

Preamble

Nursing practice can be defined generally as a "dynamic, caring, helping relationship in which the nurse assists the client to achieve and maintain optimal health." Nurses in clinical practice, education, administration and research share the common goal of maintaining competent care and improving nursing practice. "Nurses direct their energies toward the promotion, maintenance and restoration of health, the prevention of illness, the alleviation of suffering and the ensuring of a peaceful death when life can no longer be sustained."

The nurse, by entering the profession, is committed to moral norms of conduct and assumes a professional commitment to health and the well-being of clients. As citizens, nurses continue to be bound by the moral and legal norms shared by all other participants in society. As individuals, nurses have a right to choose to live by their own values (their personal ethics) as long as those values do not compromise care of their clients.

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Ethical Problems

Situations often arise that present ethical problems for nurses in their practice. These situations tend to fall into three categories:

(a) Ethical violations involve the neglect of moral obligation; for example, a nurse who neglects to provide competent care to a client because of personal inconvenience has ethically failed the client.
(b) Ethical dilemmas arise where ethical reasons both for and against a particular course of action are present and one option must be selected. For example, a client who is likely to refuse some appropriate form of health care presents the nurse with an ethical dilemma. In this case, substantial moral reasons may be offered on behalf of several opposing options.
(c) Ethical distress occurs when nurses experience the imposition of practices that provoke feelings of guilt, concern or distaste. Such feelings may occur when nurses are ethically obliged to provide particular types of care despite their personal disagreement or discomfort with the course of treatment prescribed. For example, a nurse may think that continuing to tube feed an irreversibly unresponsive person is contrary to that client's well-being, but nonetheless is required to do so because that view is not shared by other caregivers.

This Code provides clear direction for avoiding ethical violations. When a course of action is mandated by the Code, and there exists no opposing ethical principle, ethical conduct requires that course of action.

This Code cannot serve the same function for all ethical dilemmas or for ethical distress. There is room within the profession of nursing for conscientious disagreement among nurses. The resolution of any dilemma often depends upon the specific circumstances of the case in question, and no particular resolution may be definitive of good nursing practice. Resolution may also depend upon the relative weight of the opposing principles, a matter about which reasonable people may disagree.

The Code cannot relieve ethical distress but it may serve as a guide for nurses to weigh and consider their responsibilities in the particular situation. Inevitably, nurses must reconcile their actions with their consciences in caring for clients.

The Code tries to provide guidance for those nurses who face ethical problems. Proper consideration of the Code should lead to better decision-making when ethical problems are encountered.

It should be noted that many problems or situations seen as ethical in nature are problems of miscommunication, failure of trust or management dilemmas in disguise. There is, therefore, a distinct need to clarify whether the problem is an ethical one or one of another sort.

Elements of the Code

This Code contains different elements designed to help the nurse in its interpretation. The values and obligations are presented by topic and not in order of importance. There is intentional variation in the normative terminology used in the Code (the nurse should or must) to indicate differences in the moral force of the statements; the term should indicates a moral preference, while must indicates an obligation. A number of distinctions between ethics and morals may be found in the literature. Since no distinction has been uniformly adopted by writers on ethics, these terms are used interchangeably in this Code.

- Values express broad ideals of nursing. They establish correct directions for nursing. In the absence of a conflict of ethics, the fact that a particular action promotes a value of nursing may be decisive in some specific instances. Nursing behaviour can always be appraised in terms of values: How closely did the behaviour approach the value? How widely did it deviate from the value? The values expressed in this Code must be adhered to by all nurses in their practice. Because they are so broad, however, values may not give specific guidance in difficult instances.
- Obligations are moral norms that have their basis in nursing values. However, obligations provide more specific direction for conduct than do values; obligations spell out what a value requires under particular circumstances.
- Limitations describe exceptional circumstances in which a value or obligation cannot be applied.

> Limitations have been included separately to emphasize that, in the ordinary run of events, the values and obligations will be decisive.

It is also important to emphasize that even when a value or obligation must be limited, it nonetheless carries moral weight. For example, a nurse who is compelled to testify in a court of law on confidential matters is still subject to the values and obligations of confidentiality. While the requirement to testify is a justified limitation upon confidentiality, in other respects confidentiality must be observed. The nurse must only reveal that confidential information that is pertinent to the case at hand, and such revelation must take place within the appropriate context. The general obligation to preserve the client's confidences remains despite particular limiting circumstances.

Rights and Responsibilities

Clients possess both legal and moral rights. These serve as one foundation for the responsibilities of nurses. However, for several reasons this Code emphasizes the obligations of nurses, rather than the rights of clients. Because the rights of clients do not depend upon professional acceptance of those rights, it would be presumptuous for a profession to claim to define the rights of clients. Emphasizing the rights of clients may also seem unduly legalistic and restrictive, ignoring the fact that sometimes ethics require nurses to go beyond the letter of the law. (For one example, see Value II, Obligation 3.) Finally, because it is sometimes beyond the power of a nurse to secure the rights of a client—an achievement that requires the cooperative and scrupulous efforts of all members of the health care team—it is better for a professional code of nursing to emphasize the responsibilities of nurses rather than to detail the entitlements of clients.

Nurses, too, possess legal and moral rights, as persons and as professionals. It is beyond the scope of this Code to address the personal rights of nurses. However, to the extent that conditions of employment have an impact on the establishment of ethical nursing, this Code must deal with that issue.

The satisfaction of some ethical responsibilities requires action taken by the nursing profession as a whole. The fourth section of the Code contains values and obligations concerned with those collective responsibilities of nursing; this section is particularly addressed to professional associations. Ethical reflection must be ongoing and its facilitation is a continuing responsibility of the Canadian Nurses Association.

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Clients

VALUE I: RESPECT FOR NEEDS AND VALUES OF CLIENTS

Value

A nurse treats clients with respect for their individual needs and values.

Obligations

1. The client's perceived best interests must be a prime concern of the nurse.
2. Factors such as the client's race, religion or absence thereof, ethnic origin, social or marital status, sex or sexual orientation, age, or health status must not be permitted to compromise the nurse's commitment to that client's care.
3. The expectations and normal life patterns of clients are acknowledged. Individualized programs of nursing care are designed to accommodate the psychological, social, cultural and spiritual needs of clients, as well as their biological needs.
4. The nurse does more than respond to the requests of clients; the nurse accepts an affirmative obligation within the context of health care to aid clients in their expression of needs and values, including their right to live at risk.
5. Recognizing the client's membership in a family and a community, the nurse, with the client's consent, should attempt to facilitate the participation of significant others in the care of the client.

VALUE II: RESPECT FOR CLIENT CHOICE

Value

Based upon respect for clients and regard for their right to control their own care, nursing care reflects respect for the right of choice held by clients.

Obligations

1. The competent client's consent is an essential precondition to the provision of health care. Nurses bear the primary responsibility to inform clients about the nursing care available to them.
2. Consent may be signified in many different ways. Verbal permission and knowledgeable cooperation are the usual forms by which clients consent to

nursing care. In each case, however, a valid consent represents the free choice of the competent client to undergo that care.

3. Consent, properly understood, is the process by which a client becomes an active participant in care. All clients should be aided in becoming active participants in their care to the maximum extent that circumstances permit. Professional ethics may require of the nurse actions that exceed the legal requirements of consent. For example, although a child may be legally incompetent to consent, nurses should nevertheless attempt to inform and involve the child.
4. Force, coercion and manipulative tactics must not be employed in the obtaining of consent.
5. Illness or other factors may compromise the client's capacity for self-direction. Nurses have a continuing obligation to value autonomy in such clients; for example, by creatively providing clients with opportunities for choices within their capabilities, the nurse helps them to maintain or regain some degree of autonomy.
6. Whenever information is provided to a client, this must be done in a truthful, understandable and sensitive way. The nurse must proceed with an awareness of the individual client's needs, interests and values.
7. Nurses have a responsibility to assess the understanding of clients about their care and to provide information and explanation when in possession of the knowledge required to respond accurately. When the client's questions require information beyond that known to the nurse, the client must be informed of that fact and assisted to obtain the information from a health care practitioner who is in possession of the required facts.

VALUE III: CONFIDENTIALITY

Value

The nurse holds confidential all information about a client learned in the health care setting.

Obligations

1. The rights of persons to control the amount of personal information revealed applies with special force in the health care setting. It is, broadly speaking, up to clients to determine who shall be told of their condition, and in what detail.
2. In describing professional confidentiality to a client, its boundaries should be revealed:
    (a) Competent care requires that other members of a team of health personnel have access to or be provided with the relevant details of a client's condition.
    (b) In addition, discussions of the client's care may be required for the purpose of teaching or quality assurance. In this case, special care must be taken to protect the client's anonymity.

    Whenever possible, the client should be informed of these necessities at the onset of care.
3. An affirmative duty exists to institute and maintain practices that protect client confidentiality—for example, by limiting access to records or by choosing the most secure method of communicating client information.
4. Nurses have a responsibility to intervene if other participants in the health care delivery system fail to respect the confidentiality of client information.

Limitations

The nurse is not morally obligated to maintain confidentiality when the failure to disclose information will place the client or third parties in danger. Generally, legal requirements or privileges to disclose are morally justified by these same criteria. In facing such a situation, the first concern of the nurse must be the safety of the client or the third party.

Even when the nurse is confronted with the necessity to disclose, confidentiality should be preserved to the maximum possible extent. Both the amount of information disclosed and the number of people to whom disclosure is made should be restricted to the minimum necessary to prevent the feared harm.

VALUE IV: DIGNITY OF CLIENTS

Value

The nurse is guided by consideration for the dignity of clients.

Obligations

1. Nursing care must be done with consideration for the personal modesty of clients.
2. A nurse's conduct at all times should acknowledge the client as a person. For example, discussion of care in the presence of the client should actively involve or include that client.
3. Nurses have a responsibility to intervene when other participants in the health delivery system fail to respect any aspect of client dignity.

4. As ways of dealing with death and the dying process change, nursing is challenged to find new ways to preserve human values, autonomy and dignity. In assisting the dying client, measures must be taken to afford the client as much comfort, dignity and freedom from anxiety and pain as possible. Special consideration must be given to the need of the client's family or significant others to cope with their loss.

VALUE V: COMPETENT NURSING CARE

Value

The nurse provides competent care to clients.

Obligations

1. Nurses should engage in continuing education and in the upgrading of knowledge and skills relevant to their area of practice, that is, clinical practice, education, research or administration.
2. In seeking or accepting employment, nurses must accurately state their area of competence as well as limitations.
3. Nurses assigned to work outside an area of present competence must seek to do what, under the circumstances, is in the best interests of their clients. The nurse manager on duty, or others, must be informed of the situation at the earliest possible moment so that protective measures can be instituted. As a temporary measure, the safety and welfare of clients may be better served by the best efforts of the nurse under the circumstances than by no nursing care at all. Nurse managers are obligated to support nurses who are placed in such difficult situations and to make every effort to remedy the problem.
4. When called upon outside an employment setting to provide emergency care, nurses fulfil their obligations by providing the best care that circumstances, experience and education permit.

Limitations

A nurse is not ethically obliged to provide requested care when compliance would involve a violation of her or his moral beliefs. When that request falls within recognized forms of health care, however, the client must be referred to a health care practitioner who is willing to provide the service. Nurses who have or are likely to encounter such situations are morally obligated to seek to arrange conditions of employment so that the care of clients will not be jeopardized.

Nursing Roles and Relationships

VALUE VI: NURSING PRACTICE, EDUCATION, RESEARCH AND ADMINISTRATION

Value

The nurse maintains trust in nurses and nursing.

Obligations

1. Nurses accepting professional employment must ascertain to the best of their ability that conditions will permit the provision of care consistent with the values and obligations of the Code. Prospective employers should be informed of the provisions of the Code so that realistic and ethical expectations may be established at the beginning of the nurse–employer relationship.
2. Nurse managers, educators and peers are morally obligated to provide timely and accurate feedback to nurses, nurse managers, students of nursing and nurse educators. Objective performance appraisal is essential to the growth of nurses and is required by a concern for present and future clients.
3. Nurse managers bear special ethical responsibilities that flow from a concern for present and future clients. The nurse manager must seek to ensure that the competencies of personnel are used efficiently. Working within available resources, the nurse manager must seek to ensure the welfare of clients. When competent care is threatened due to inadequate resources or for some other reason, the nurse manager must act to minimize the present danger and to prevent future harm.
4. Student–teacher and student-client encounters are essential elements of nursing education. These encounters must be conducted in accordance with ethical nursing practices. The nurse educator is obligated to treat students of nursing with respect and honesty and to provide fair guidance in developing nursing competence. The nurse educator should ensure that students of nursing are acquainted with and comply with the provisions of the Code. Student–client encounters must be conducted with client consent and require special attention to the dignity of the client.
5. Research is necessary to the development of the profession of nursing. Nurses should be acquainted with advances in research, so that established results may be incorporated into clinical practice, education and administration. The individual nurse's competencies may also be used to promote, to

engage in or to assist health care research designed to enhance the health and welfare of clients.

The conduct of research must conform to ethical practice. The self-direction of clients takes on added importance in this context. Further direction is provided in the Canadian Nurses Association publication Ethical Guidelines for Nursing Research Involving Human Subjects.

VALUE VII: COOPERATION IN HEALTH CARE

Value

The nurse recognizes the contribution and expertise of colleagues from nursing and other disciplines as essential to excellent health care.

Obligations

1. The nurse functions as a member of the health care team.
2. The nurse should participate in the assessment, planning, implementation and evaluation of comprehensive programs of care for individual clients and client groups. The scope of a nurse's responsibility should be based upon education and experience, as well as legal considerations of licensure or registration.
3. The nurse accepts responsibility to work with colleagues and other health care professionals, with nursing interest groups and through professional nurses' associations to secure excellent care for clients.

VALUE VIII: PROTECTING CLIENTS FROM INCOMPETENCE

Value

The nurse takes steps to ensure that the client receives competent and ethical care.

Obligations

1. The first consideration of the nurse who suspects incompetence or unethical conduct must be the welfare of present clients or potential harm to future clients. Subject to that principle, the following must be considered:
    - (a) The nurse is obliged to ascertain the facts of the situation before deciding upon the appropriate course of action.
    - (b) Relationships in the health care team should not be disrupted unnecessarily. If a situation can be resolved without peril to present or future clients by direct discussion with the colleague suspected of providing incompetent or unethical care, that discussion should be done.
    - (c) Institutional mechanisms for reporting incidents or risks of incompetent or unethical care must be followed.
    - (d) The nurse must report any reportable offence stipulated in provincial or territorial professional nursing legislation.
    - (e) It is unethical for a nurse to participate in efforts to deceive or mislead clients about the cause of alleged harm or injury resulting from unethical or incompetent conduct.
2. Guidance on activities that may be delegated by nurses to assistants and other health care workers is found in legislation and policy statements. When functions are delegated, the nurse should be satisfied about the competence of those who will be fulfilling these functions. The nurse has a duty to provide continuing supervision in such a case.
3. The nurse who attempts to protect clients or colleagues threatened by incompetent or unethical conduct may be placed in a difficult position. Colleagues and professional associations are morally obliged to support nurses who fulfil their ethical obligations under the Code.

VALUE IX: CONDITIONS OF EMPLOYMENT

Value

Conditions of employment should contribute in a positive way to client care and the professional satisfaction of nurses.

Obligations

1. Nurses accepting professional employment must ascertain, to the best of their ability, that employment conditions will permit provision of care consistent with the values and obligations of the Code.
2. Nurse managers must seek to ensure that the agencies where they are employed comply with all pertinent provincial or territorial legislation.
3. Nurse managers must seek to ensure the welfare of clients and nurses. When competent care is threatened due to inadequate resources or for some other reason, the nurse manager should act to minimize the present danger and to prevent future harm.

4. Nurse managers must seek to foster environments and conditions of employment that promote excellent care for clients and a good worklife for nurses.
5. Structures should exist in the work environment that provide nurses with means of recourse if conditions that promote a good worklife are absent.

VALUE X: JOB ACTION

Value

Job action by nurses is directed toward securing conditions of employment that enable safe and appropriate care for clients and contribute to the professional satisfaction of nurses.

Obligations

1. In the final analysis, the improvement of conditions of nursing employment is often to the advantage of clients. Over the short term, however, there is a danger that action directed toward this goal could work to the detriment of clients. In view of their ethical responsibility to current as well as future clients, nurses must respect the following principles:
    - (a) The safety of clients is the first concern in planning and implementing any job action.
    - (b) Individuals and groups of nurses participating in job actions share the ethical commitment to the safety of clients. However, their responsibilities may lead them to express this commitment in different but equally appropriate ways.
    - (c) Clients whose safety requires ongoing or emergency nursing care are entitled to have those needs satisfied throughout the duration of any job action. Individuals and groups of nurses participating in job actions have a duty through coordination and communication to take steps to ensure the safety of clients.
    - (d) Members of the public are entitled to know of the steps taken to ensure the safety of clients.

Nursing Ethics and Society

VALUE XI: ADVOCACY OF THE INTERESTS OF CLIENTS, THE COMMUNITY AND SOCIETY

Value

The nurse advocates the interests of clients.

Obligations

1. Advocating the interests of individual clients and groups of clients includes helping them to gain access to good health care. For example, by providing information to clients privately or publicly, the nurse enables them to satisfy their rights to health care.
2. When speaking in a public forum or in court, the nurse owes the public the same duties of accurate and relevant information as are owed to clients within the employment setting.

VALUE XII: REPRESENTING NURSING VALUES AND ETHICS

Value

The nurse represents the values and ethics of nursing before colleagues and others.

Obligations

1. Nurses serving on committees concerned with health care or research should see their role as including the vigorous representation of nursing's professional ethics.
2. Many public issues include health as a major component. Involvement in public activities may give the nurse the opportunity to further the objectives of nursing as well as to fulfil the duties of a citizen.

The Nursing Profession

VALUE XIII: RESPONSIBILITIES OF PROFESSIONAL NURSES' ASSOCIATIONS

Value

Professional nurses' organizations are responsible for clarifying, securing and sustaining ethical nursing conduct. The fulfillment of these tasks requires that professional nurses' organizations remain responsive to the rights, needs and legitimate interests of clients and nurses.

Obligations

1. Sustained communication and cooperation between the Canadian Nurses Association, provincial or territorial associations and other organizations of

nurses are essential steps toward securing ethical nursing conduct.

2. Activities of professional nurses' associations must at all times reflect a prime concern for excellent client care.
3. Professional nurses's associations should represent nursing interests and perspectives before nonnursing bodies, including legislatures, employers, the professional organizations of other health disciplines and the public communication media.
4. Professional nurses' associations should provide and encourage organizational structures that facilitate ethical nursing conduct.
    (a) Education in the ethical aspects of nursing should be available to nurses throughout their careers. Nurses' associations should actively support or develop structures to enhance sensitivity to, and application of, norms of ethical nursing conduct. Associations should also promote the development and dissemination of knowledge about ethical decision-making through nursing research.
    (b) Changing circumstances call for ongoing review of this Code. Supplementation of the Code may be necessary to address special situations. Professional associations should consider the ethics of nursing on a regular and continuing basis and be prepared to provide assistance to those concerned with its implementation.

CODE OF ETHICS

American Chiropractic Association

1994–1995

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The current, 1994–1995 American Chiropractic Association (ACA) code differs significantly from an earlier, 1973 version. The current code rests on a single fundamental principle, "The greatest good for the patient," whereas the 1973 code also cited the Golden Rule—do unto others as you would have them do unto you—as a fundamental principle. In addition, the structure and language of the current code is much more modern than that of the 1973 code, which strongly resembled the American Medical Association Code of Medical Ethics of 1847 (see Section II) in the wording and ordering of its articles and subsections.

The 1994–1995 code is divided into four sections. Although the final section on "Administrative Procedures" is not printed below, it is noteworthy that two-thirds of the code is devoted to that section, which discusses the reporting and reviewing of alleged ethics violations.

Preamble

This Code of Ethics is based upon the fundamental principle that the ultimate end and object of the chiropractor's professional services and effort should be:

"The greatest good for the patient."

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A. Responsibility to the Patient

A(1) Doctors of chiropractic should hold themselves ready at all times to respond to the call of those needing their professional services, although they are free to accept or reject a particular patient except in an emergency.

A(2) Doctors of chiropractic should attend their patients as often as they consider necessary to ensure the well-being of their patients.

A(3) Having once undertaken to serve a patient, doctors of chiropractic should not neglect the patient. Doctors of chiropractic should take reasonable steps to protect their patients prior to withdrawing their professional services; such steps shall include: due notice to them allowing a reasonable time for obtaining professional services of others and delivering to their patients all papers and documents in compliance with A(5) of this Code of Ethics.

A(4) Doctors of chiropractic should be honest and endeavor to practice with the highest degree of professional competency and honesty in the proper care of their patients.

A(5) Doctors of chiropractic should comply with a patient's authorization to provide records, or copies of such records, to those whom the patient designates as authorized to inspect or receive all or part of such records. A reasonable charge may be made for the cost of duplicating records.

A(6) Subject to the foregoing Section A(5), doctors of chiropractic should preserve and protect the patient's confidences and records, except as the patient directs or consents or the law requires otherwise. They should not discuss a patient's history, symptoms, diagnosis, or treatment with any third party until they have received the written consent of the patient or the patient's personal representative. They should not exploit the trust and dependency of their patients.

A(7) Doctors of chiropractic owe loyalty, compassion and respect to their patients. Their clinical judgment and practice should be objective and exercised solely for the patient's benefit.

A(8) Doctors of chiropractic should recognize and respect the right of every person to free choice of chiropractors or other health care providers and to the right to change such choice at will.

A(9) Doctors of chiropractic are entitled to receive proper and reasonable compensation for their professional services commensurate with the value of the services they have rendered taking into consideration their experience, time required, reputation and the nature of the condition involved. Doctors of chiropractic should terminate a professional relationship when it becomes reasonably clear that the patient is not benefiting from it. Doctors of chiropractic should support and participate in proper activities designed to enable access to necessary chiropractic care on the part of persons unable to pay such reasonable fees.

A(10) Doctors of chiropractic should maintain the highest standards of professional and personal conduct, and should refrain from all illegal conduct.

A(11) Doctors of chiropractic should be ready to consult and seek the talents of other health care professionals when such consultation would benefit their patients or when their patients express a desire for such consultation.

A(12) Doctors of chiropractic should employ their best good faith efforts that the patient possesses enough information to enable an intelligent choice in regard to proposed chiropractic treatment. The patient should make his or her own determination on such treatment.

A(13) Doctors of chiropractic should utilize only those laboratory and X-ray procedures, and such devices or nutritional products that are in the best interest of the patient and not in conflict with state statute or administrative rulings.

B. Responsibility to the Public

B(1) Doctors of chiropractic should act as members of a learned profession dedicated to the promotion of health, the prevention of illness and the alleviation of suffering.

B(2) Doctors of chiropractic should observe and comply with all laws, decisions and regulations of state governmental agencies and cooperate with the pertinent activities and policies of associations legally authorized to regulate or assist in the regulation of the chiropractic profession.

B(3) Doctors of chiropractic should comport themselves as responsible citizens in the public affairs of their local community, state and nation in order to improve law, administrative procedures and public policies that pertain to chiropractic and the system of health care delivery. Doctors of chiropractic should stand ready to take the initiative in the proposal and development of measures to benefit the general public health and well-being, and should cooperate in the administration and enforcement of such measures and programs to the extent consistent with law.

B(4) Doctors of chiropractic may advertise but should exercise utmost care that such advertising is relevant to health awareness, is accurate, truthful, not misleading or false or deceptive, and scrupulously accurate in representing the chiropractor's professional status and area of special competence. Communications to the public should not appeal primarily to an individual's anxiety or create unjustified expectations of results. Doctors of chiropractic should conform to all applicable state laws, regulations and judicial decisions in connection with professional advertising.

B(5) Doctors of chiropractic should continually strive to improve their skill and competency by keeping abreast of current developments contained in the health and scientific literature, and by participating in continuing chiropractic educational programs and utilizing other appropriate means.

B(6) Doctors of chiropractic may testify either as experts or when their patients are involved in court cases, workers' compensation proceedings or in other similar administrative proceedings in personal injury or related cases.

B(7) The chiropractic profession should address itself to improvements in licensing procedures consistent with the development of the profession and of relevant advances in science.

B(8) Doctors of chiropractic who are public officers should not engage in activities which are, or may be reasonably perceived to be in conflict with their official duties.

B(9) Doctors of chiropractic should protect the public and reputation of the chiropractic profession by bringing to the attention of the appropriate public or private organization the actions of chiropractors who engage in deception, fraud or dishonesty, or otherwise engage in conduct inconsistent with this Code of Ethics or relevant provisions of applicable law or regulations within their states.

C. Responsibility to the Profession

C(1) Doctors of chiropractic should assist in maintaining the integrity, competency and highest standards of the chiropractic profession.

C(2) Doctors of chiropractic should by their behavior, avoid even the appearance of professional impropriety and should recognize that their public behavior may have an impact on the ability of the profession to serve the public. Doctors of chiropractic should promote public confidence in the chiropractic profession.

C(3) As teachers, doctors of chiropractic should recognize their obligation to help others acquire knowledge and skill in the practice of the profession. They should maintain high standards of scholarship, education, training and objectivity in the accurate and full dissemination of information and ideas.

C(4) Doctors of chiropractic should attempt to promote and maintain cordial relationships with other members of the chiropractic profession and other professions in an effort to promote information advantageous to the public's health and well-being.

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PRINCIPLES OF ETHICS AND CODE OF PROFESSIONAL CONDUCT WITH ADVISORY OPINIONS

American Dental Association

REVISED TO JUNE 2002

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Although most of the topics addressed in the 1994 American Dental Association code are the same as those found twenty years ago in the 1974 version, the organization and details of the code have been modified. The twenty-two sections of the 1974 code have been reduced to five main principles (which have been preserved in the latest 2002 version), and many of the remaining original sections now appear as subsections, which constitute the "code of professional conduct." The subsections are denoted as "advisory opinions." Some notable changes in content include the specification that dentists cannot ethically deny treatment to individuals who are HIV seropositive; addition of the obligation to safeguard the confidentiality of patient records; and removal of the former prohibition on advertising.

<http://www.ada.org/prof/prac/law/code/index.html>

I. Introduction

The dental profession holds a special position of trust within society. As a consequence, society affords the profession certain privileges that are not available to members of the public-at-large. In return, the profession makes a commitment to society that its members will adhere to high ethical standards of conduct. These standards are embodied in the *ADA Principles of Ethics and Code of Professional Conduct* (*ADA Code*). The *ADA Code* is, in effect, a written expression of the obligations arising from the implied contract between the dental profession and society.

Members of the ADA voluntarily agree to abide by the *ADA Code* as a condition of membership in the Association.

They recognize that continued public trust in the dental profession is based on the commitment of individual dentists to high ethical standards of conduct.

The *ADA Code* has three main components: The Principles of Ethics, the Code of Professional Conduct and the Advisory Opinions.

The Principles of Ethics are the aspirational goals of the profession. They provide guidance and offer justification for the *Code of Professional Conduct* and the *Advisory Opinions.* There are five fundamental principles that form the foundation of the *ADA Code*: patient autonomy, nonmaleficence, beneficence, justice and veracity. Principles can overlap each other as well as compete with each other for priority. More than one principle can justify a given element of the *Code of Professional Conduct.* Principles may at times need to be balanced against each other, but, otherwise, they are the profession's firm guideposts.

The *Code of Professional Conduct* is an expression of specific types of conduct that are either required or prohibited. The *Code of Professional Conduct* is a product of the ADA's legislative system. All elements of the *Code of Professional Conduct* result from resolutions that are adopted by the ADA's House of Delegates. The *Code of Professional Conduct* is binding on members of the ADA, and violations may result in disciplinary action.

The Advisory Opinions are interpretations that apply the *Code of Professional Conduct* to specific fact situations. They are adopted by the ADA's Council on Ethics, Bylaws and Judicial Affairs to provide guidance to the membership on how the Council might interpret the *Code of Professional Conduct* in a disciplinary proceeding.

The *ADA Code* is an evolving document and by its very nature cannot be a complete articulation of all ethical obligations. The *ADA Code* is the result of an on-going dialogue between the dental profession and society, and as such, is subject to continuous review.

Although ethics and the law are closely related, they are not the same. Ethical obligations may—and often do—exceed legal duties. In resolving any ethical problem not explicitly covered by the *ADA Code,* dentists should consider the ethical principles, the patient's needs and interests, and any applicable laws.

II. Preamble

The American Dental Association calls upon dentists to follow high ethical standards which have the benefit of the patient as their primary goal. Recognition of this goal, and of the education and training of a dentist, has resulted in society affording to the profession the privilege and obligation of self-government.

The Association believes that dentists should possess not only knowledge, skill and technical competence but also those traits of character that foster adherence to ethical principles. Qualities of compassion, kindness, integrity, fairness and charity complement the ethical practice of dentistry and help to define the true professional.

The ethical dentist strives to do that which is right and good. The *ADA Code* is an instrument to help the dentist in this quest.

III. Principles, Code of Professional Conduct And Advisory Opinions

The *Code of Professional Conduct* is organized into five sections. Each section falls under the Principle of Ethics that predominately applies to it. Advisory Opinions follow the section of the Code that they interpret.

Section 1—Principle: Patient Autonomy

("Self-governance"). The dentist has a duty to respect the patient's rights to self-determination and confidentiality.

This principle expresses the concept that professionals have a duty to treat the patient according to the patient's desires, within the bounds of accepted treatment, and to protect the patient's confidentiality. Under this principle, the dentist's primary obligations include involving patients in treatment decisions in a meaningful way, with due consideration being given to the patient's needs, desires and abilities, and safeguarding the patient's privacy.

Code of Professional Conduct

1.A. PATIENT INVOLVEMENT

The dentist should inform the patient of the proposed treatment, and any reasonable alternatives, in a manner that allows the patient to become involved in treatment decisions.

1.B. PATIENT RECORDS

Dentists are obliged to safeguard the confidentiality of patient records. Dentists shall maintain patient records in a manner consistent with the protection of the welfare of the patient. Upon request of a patient or another dental practitioner, dentists shall provide any information that will be beneficial for the future treatment of that patient.

Advisory Opinions

1.B.1.COPIES OF RECORDS. A dentist has the ethical obligation on request of either the patient or the patient's new dentist to furnish, either gratuitously or for nominal cost, such dental records or copies or summaries of them, including dental X-rays or copies of them, as will be beneficial for the future treatment of that patient. This obligation exists whether or not the patient's account is paid in full.

1.B.2. CONFIDENTIALITY OF PATIENT RECORDS. The dominant theme in Code Section l-B is the protection of the confidentiality of a patient's records. The statement in this section that relevant information in the records should be released to another dental practitioner assumes that the dentist requesting the information is the patient's present dentist. The former dentist should be free to provide the present dentist with relevant information from the patient's records. This may often be required for the protection of both the patient and the present dentist. There may be circumstances where the former dentist has an ethical obligation to inform the present dentist of certain facts. Dentists should be aware, however, that the laws of the various jurisdictions in the United States are not uniform, and some confidentiality laws appear to prohibit the transfer of pertinent information, such as HIV seropositivity. Absent certain knowledge that the laws of the dentist's jurisdiction permit the forwarding of this information, a dentist should obtain the patient's written permission before forwarding health records which contain information of a sensitive nature, such as HIV seropositivity, chemical dependency or sexual preference. If it is necessary for a treating dentist to consult with another dentist or physician with respect to the patient, and the circumstances do not permit the patient to remain anonymous, the treating dentist should seek the permission of the patient prior to the release of data from the patient's records to the consulting practitioner. If the patient refuses, the treating dentist should then contemplate obtaining legal advice regarding the termination of the dentist/patient relationship.

Section 2—Principle: Nonmaleficence

Principle: Nonmaleficence

("Do no harm"). The dentist has a duty to refrain from harming the patient.

This principle expresses the concept that professionals have a duty to protect the patient from harm. Under this principle, the dentist's primary obligations include keeping knowledge and skills current, knowing one's own limitations and when to refer to a specialist or other professional, and knowing when and under what circumstances delegation of patient care to auxiliaries is appropriate.

Code of Professional Conduct

2.A. EDUCATION.

The privilege of dentists to be accorded professional status rests primarily in the knowledge, skill and experience with which they serve their patients and society. All dentists, therefore, have the obligation of keeping their knowledge and skill current.

2.B. CONSULTATION AND REFERRAL

Dentists shall be obliged to seek consultation, if possible, whenever the welfare of patients will be safeguarded or advanced by utilizing those who have special skills, knowledge, and experience. When patients visit or are referred to specialists or consulting dentists for consultation:

1. The specialists or consulting dentists upon completion of their care shall return the patient, unless the patient expressly reveals a different preference, to the referring dentist, or, if none, to the dentist of record for future care.
2. The specialists shall be obliged when there is no referring dentist and upon a completion of their treatment to inform patients when there is a need for further dental care.

Advisory Opinion

2.B.1. SECOND OPINIONS. A dentist who has a patient referred by a third party* for a "second opinion" regarding a diagnosis or treatment plan recommended by the patient's treating dentist should render the requested second opinion in accordance with this Code of Ethics. In the interest of the patient being afforded quality care, the dentist rendering the second opinion should not have a vested interest in the ensuing recommendation.

2.C. USE OF AUXILIARY PERSONNEL.

Dentists shall be obliged to protect the health of their patients by only assigning to qualified auxiliaries those duties which can be legally delegated. Dentists shall be further obliged to prescribe and supervise the patient care provided by all auxiliary personnel working under their direction.

2.D. PERSONAL IMPAIRMENT.

It is unethical for a dentist to practice while abusing controlled substances, alcohol or other chemical agents which impair the ability to practice. All dentists have an ethical obligation to urge chemically impaired colleagues to seek treatment. Dentists with first-hand knowledge that a colleague is practicing dentistry when so impaired have an ethical responsibility to report such evidence to the professional assistance committee of a dental society.

Advisory Opinion

2.D.1. ABILITY TO PRACTICE. A dentist who contracts any disease or becomes impaired in any way that might endanger patients or dental staff shall, with consultation and advice from a qualified physician or other authority, limit the activities of practice to those areas that do not endanger patients or dental staff. A dentist who has been advised to limit the activities of his or her practice should monitor the aforementioned disease or impairment and make additional limitations to the activities of the dentist's practice, as indicated.

2.E. POSTEXPOSURE, BLOODBORNE PATHOGENS

All dentists, regardless of their bloodborne pathogen status, have an ethical obligation to immediately inform any patient who may have been exposed to blood or other potentially infectious material in the dental office of the need for post exposure evaluation and follow-up and to immediately refer the patient to a qualified health care practitioner who can provide postexposure services. The dentist's ethical obligation in the event of an exposure incident extends to providing information concerning the dentist's own bloodborne pathogen status to the evaluating health care practitioner, if the dentist is the source individual, and to submitting to testing that will assist in the evaluation of the patient. If a staff member or other third person is the source individual, the dentist should encourage that person to cooperate as needed for the patient's evaluation.

2.F. PATIENT ABANDONMENT

Once a dentist has undertaken a course of treatment, the dentist should not discontinue that treatment without giving the patient adequate notice and the opportunity to obtain the services of another dentist. Care should be taken that the patient's oral health is not jeopardized in the process.

*A third party is any party to a dental prepayment contract that may collect premiums, assume financial risks, pay claims, and/or provide administrative services.

Section 3—Principle: Beneficence

Principle: Beneficence

("Do good"). The dentist has a duty to promote the patient's welfare.

This principle expresses the concept that professionals have a duty to act for the benefit of others. Under this principle, the dentist's primary obligation is service to the patient and the public-at-large. The most important aspect of this obligation is the competent and timely delivery of dental care within the bounds of clinical circumstances presented by the patient, with due consideration being given to the needs, desires and values of the patient. The same ethical considerations apply whether the dentist engages in fee-for-service, managed care or some other practice arrangement. Dentists may choose to enter into contracts governing the provision of care to a group of patients; however, contract obligations do not excuse dentists from their ethical duty to put the patient's welfare first.

Code of Professional Conduct

3.A. COMMUNITY SERVICE.

Since dentists have an obligation to use their skills, knowledge and experience for the improvement of the dental health of the public and are encouraged to be leaders in their community, dentists in such service shall conduct themselves in such a manner as to maintain or elevate the esteem of the profession.

3.B. GOVERNMENT OF A PROFESSION.

Every profession owes society the responsibility to regulate itself. Such regulation is achieved largely through the influence of the professional societies. All dentists, therefore, have the dual obligation of making themselves a part of a professional society and of observing its rules of ethics.

3.C. RESEARCH AND DEVELOPMENT.

Dentists have the obligation of making the results and benefits of their investigative efforts available to all when they are useful in safeguarding or promoting the health of the public.

3.D. PATENTS AND COPYRIGHTS.

Patents and copyrights may be secured by dentists provided that such patents and copyrights shall not be used to restrict research or practice.

3.E. ABUSE AND NEGLECT

Dentists shall be obliged to become familiar with the signs of abuse and neglect and to report suspected cases to the proper authorities, consistent with state laws.

Advisory Opinion

3.E.1. REPORTING ABUSE AND NEGLECT

Advisory Opinion

3.E.1. REPORTING ABUSE AND NEGLECT The public and the profession are best served by dentists who are familiar with identifying the signs of abuse and neglect and knowledgeable about the appropriate intervention resources for all populations.

A dentist's ethical obligation to identify and report the signs of abuse and neglect is, at a minimum, to be consistent with a dentist's legal obligation in the jurisdiction where the dentist practices. Dentists, therefore, are ethically obliged to identify and report suspected cases of abuse and neglect to the same extent as they are legally obliged to do so in the jurisdiction where they practice. Dentists have a concurrent ethical obligation to respect an adult patient's right to self-determination and confidentiality and to promote the welfare of all patients. Care should be exercised to respect the wishes of an adult patient who asks that a suspected case of abuse and/or neglect not be reported, where such a report is not mandated by law. With the patient's permission, other possible solutions may be sought.

Dentists should be aware that jurisdictional laws vary in their definitions of abuse and neglect, in their reporting requirements and the extent to which immunity is granted to good faith reporters. The variances may raise potential legal and other risks that should be considered, while keeping in mind the duty to put the welfare of the patient first. Therefore a dentist's ethical obligation to identify and report suspected cases of abuse and neglect can vary from one jurisdiction to another.

Dentists are ethically obligated to keep current their knowledge of both identifying abuse and neglect and reporting it in the jurisdiction(s) where they practice.

Section 4—Principle: Justice

Principle: Justice

("Fairness"). The dentist has a duty to treat people fairly.

This principle expresses the concept that professionals have a duty to be fair in their dealings with patients, colleagues and society. Under this principle, the dentist's primary obligations include dealing with people justly and delivering dental care without prejudice. In its broadest sense, this principle expresses the concept that the dental profession should actively seek allies throughout society on specific activities that will help improve access to care for all.

Code of Professional Conduct

4.A. PATIENT SELECTION.

While dentists, in serving the public, may exercise reasonable discretion in selecting patients for their practices, dentists shall not refuse to accept patients into their practice or deny dental service to patients because of the patient's race, creed, color, sex or national origin.

Advisory Opinion

4.A.1. HIV POSITIVE PATIENTS. A dentist has the general obligation to provide care to those in need. A decision not to provide treatment to an individual because the individual has AIDS or is HIV seropositive, based solely on that fact, is unethical. Decisions with regard to the type of dental treatment provided or referrals made or suggested, in such instances should be made on the same basis as they are made with other patients, that is, whether the individual dentist believes he or she has need of another's skills, knowledge, equipment or experience and whether the dentist believes, after consultation with the patient's physician if appropriate, the patient's health status would be significantly compromised by the provision of dental treatment.

4.B. EMERGENCY SERVICE.

Dentists shall be obliged to make reasonable arrangements for the emergency care of their patients of record. Dentists shall be obliged when consulted in an emergency by patients not of record to make reasonable arrangements for emergency care. If treatment is provided, the dentist, upon completion of treatment, is obliged to return the patient to his or her regular dentist unless the patient expressly reveals a different preference.

4.C. JUSTIFIABLE CRITICISM.

Dentists shall be obliged to report to the appropriate reviewing agency as determined by the local component or constituent society instances of gross or continual faulty treatment by other dentists. Patients should be informed of their present oral health status without disparaging comment about prior services. Dentists issuing a public statement with respect to the profession shall have a reasonable basis to believe that the comments made are true.

Advisory Opinion

4.C.1. MEANING OF "JUSTIFIABLE." A dentist's duty to the public imposes a responsibility to report instances of gross or continual faulty treatment. However, the heading of this section is "Justifiable Criticism." Therefore, when informing a patient of the status of his or her oral health, the dentist should exercise care that the comments made are justifiable. For example, a difference of opinion as to preferred treatment should not be communicated to the patient in a manner which would imply mistreatment. There will necessarily be cases where it will be difficult to determine whether the comments made are justifiable. Therefore, this section is phrased to address the discretion of dentists and advises against disparaging statements against another dentist. However, it should be noted that, where comments are made which are obviously not supportable and therefore unjustified, such comments can be the basis for the institution of a disciplinary proceeding against the dentist making such statements.

4.D. EXPERT TESTIMONY.

Dentists may provide expert testimony when that testimony is essential to a just and fair disposition of a judicial or administrative action.

Advisory Opinion

4.D.1. CONTINGENT FEES. It is unethical for a dentist to agree to a fee contingent upon the favorable outcome of the litigation in exchange for testifying as a dental expert.

4.E. REBATES AND SPLIT FEES.

Dentists shall not accept or tender “rebates” or “split fees.”

Section 5—Principle: Veracity

Principle: Veracity

(“Truthfulness”). The dentist has a duty to communicate truthfully.

This principle expresses the concept that professionals have a duty to be honest and trustworthy in their dealings with people. Under this principle, the dentist’s primary obligations include respecting the position of trust inherent in the dentist-patient relationship, communicating truthfully and without deception, and maintaining intellectual integrity.

Code of Professional Conduct

5.A. REPRESENTATION OF CARE.

Dentists shall not represent the care being rendered to their patients in a false or misleading manner.

Advisory Opinions

5.A.1. DENTAL AMALGAM AND OTHER RESTORATIVE MATERIALS. Based on available scientific data the ADA has determined that the removal of amalgam restorations from the non-allergic patient for the alleged purpose of removing toxic substances from the body, when such treatment is performed solely at the recommendation or suggestion of the dentist, is improper and unethical. The same principle of veracity applies to the dentist’s recommendation concerning the removal of any dental restorative material.

5.A.2. UNSUBSTANTIATED REPRESENTATIONS. A dentist who represents that dental treatment or diagnostic techniques recommended or performed by the dentist has the capacity to diagnose, cure or alleviate diseases, infections or other conditions, when such representations are not based upon accepted scientific knowledge or research, is acting unethically.

5.B. REPRESENTATION OF FEES.

Dentists shall not represent the fees being charged for providing care in a false or misleading manner.

Advisory Opinions

5.B.1. WAIVER OF COPAYMENT. A dentist who accepts a third party* payment under a copayment plan as payment in full without disclosing to the third party* that the patient’s payment portion will not be collected, is engaged in overbilling. The essence of this ethical impropriety is deception and misrepresentation; an overbilling dentist makes it appear to the third party* that the charge to the patient for services rendered is higher than it actually is.

5.B.2. OVERBILLING. It is unethical for a dentist to increase a fee to a patient solely because the patient is covered under a dental benefits plan.

5.B.3. FEE DIFFERENTIAL. Payments accepted by a dentist under a governmentally funded program, a component or constituent dental society sponsored access program, or a participating agreement entered into under a program of a third party* shall not be considered as evidence of overbilling in determining whether a charge to a patient, or to another third party* in behalf of a patient not covered under any of the aforecited programs constitutes overbilling under this section of the Code.

5.B.4. TREATMENT DATES. A dentist who submits a claim form to a third party* reporting incorrect treatment dates for the purpose of assisting a patient in obtaining benefits under a dental plan, which benefits would otherwise be disallowed, is engaged in making an unethical, false or misleading representation to such third party.*

5.B.5. DENTAL PROCEDURES. A dentist who incorrectly describes on a third party* claim form a dental procedure in order to receive a greater payment or reimbursement or incorrectly makes a non-covered procedure appear to be a covered procedure on such a claim form is engaged in making an unethical, false or misleading representation to such third party.*

5.B.6. UNNECESSARY SERVICES. A dentist who recommends and performs unnecessary dental services or procedures is engaged in unethical conduct.

5.C. DISCLOSURE OF CONFLICT OF INTEREST.

A dentist who presents educational or scientific information in an article, seminar or other program shall disclose to the readers or participants any monetary or other special interest the dentist may have with a company whose products are promoted or endorsed in the presentation. Disclosure shall be made in any promotional material and in the presentation itself.

5.D. DEVICES AND THERAPEUTIC METHODS.

Except for formal investigative studies, dentists shall be obliged to prescribe, dispense, or promote only those devices, drugs and other agents whose complete formulae are available to the dental profession. Dentists shall have the further obligation of not holding out as exclusive any device, agent, method or technique if that representation would be false or misleading in any material respect.

Advisory Opinions

H5.D.1. REPORTING ADVERSE REACTIONS. A dentist who suspects the occurrence of an adverse reaction to a drug or dental device has an obligation to communicate that information to the broader medical and dental community, including, in the case of a serious adverse event, the Food and Drug Administration (FDA).

5.D.2 MARKETING OR SALE OF PRODUCTS OR PROCEDURES Dentists who, in the regular conduct of their practices, engage in or employ auxiliaries in the marketing or sale of products or procedures to their patients must take care not to exploit the trust inherent in the dentist-patient relationship for their own financial gain. Dentists should not induce their patients to purchase products or undergo procedures by misrepresenting the product's value, the necessity of the procedure or the dentist's professional expertise in recommending the product or procedure.

In the case of a health-related product, it is not enough for the dentist to rely on the manufacturer's or distributor's representations about the product's safety and efficacy. The dentist has an independent obligation to inquire into the truth and accuracy of such claims and verify that they are founded on accepted scientific knowledge or research.

Dentists should disclose to their patients all relevant information the patient needs to make an informed purchase decision, including whether the product is available elsewhere and whether there are any financial incentives for the dentist to recommend the product that would not be evident to the patient.

5.E. PROFESSIONAL ANNOUNCEMENT.

In order to properly serve the public, dentists should represent themselves in a manner that contributes to the esteem of the profession. Dentists should not misrepresent their training and competence in any way that would be false or misleading in any material respect.**

5.F. ADVERTISING.

Although any dentist may advertise, no dentist shall advertise or solicit patients in any form of communication in a manner that is false or misleading in any material respect.**

Advisory Opinions

5.F.1. ARTICLES AND NEWSLETTERS. If a dental health article, message or newsletter is published under a dentist's byline to the public without making truthful disclosure of the source and authorship or is designed to give rise to questionable expectations for the purpose of inducing the public to utilize the services of the sponsoring dentist, the dentist is engaged in making a false or misleading representation to the public in a material respect.

5.F.2. EXAMPLES OF "FALSE OR MISLEADING." The following examples are set forth to provide insight into the meaning of the term "false or misleading in a material respect." These examples are not meant to be all-inclusive. Rather, by restating the concept in alternative language and giving general examples, it is hoped that the membership will gain a better understanding of the term. With this in mind, statements shall be avoided which would: a) contain a material misrepresentation of fact, b) omit a fact necessary to make the statement considered as a whole not materially misleading, c) be intended or be likely to create an unjustified expectation about results the dentist can achieve, and d) contain a material, objective representation, whether express or implied, that the advertised services are superior in quality to those of other dentists, if that representation is not subject to reasonable substantiation.

Subjective statements about the quality of dental services can also raise ethical concerns. In particular, statements of opinion may be misleading if they are not honestly held, if they misrepresent the qualifications of the holder, or the basis of the opinion, or if the patient reasonably interprets them as implied statements of fact. Such statements will be evaluated on a case by case basis, considering how patients are likely to respond to the impression made by the advertisement as a whole. The fundamental issue is whether the advertisement, taken as a whole, is false or misleading in a material respect.

5.F.3. UNEARNED, NONHEALTH DEGREES. A dentist may use the title Doctor or Dentist, DDS, DMD or any additional earned, advanced academic degrees in health service areas in an announcement to the public. The announcement of an unearned academic degree may be misleading because of the likelihood that it will indicate to the public the attainment of specialty or diplomate status. For purposes of this advisory opinion, an unearned academic degree is one which is awarded by an educational institution not accredited by a generally recognized accrediting body or is an honorary degree.

The use of a nonhealth degree in an announcement to the public may be a representation which is misleading because the public is likely to assume that any degree announced is related to the qualifications of the dentist as a practitioner.

Some organizations grant dentists fellowship status as a token of membership in the organization or some other form of voluntary association. The use of such fellowships in advertising to the general public may be misleading because of the likelihood that it will indicate to the public attainment of education or skill in the field of dentistry.

Generally, unearned or nonhealth degrees and fellowships that designate association, rather than attainment, should be limited to scientific papers and curriculum vitae. In all instances, state law should be consulted. In any review by the council of the use of designations in advertising to the public, the council will apply the standard of whether the use of such is false or misleading in a material respect.

5.F.4. REFERRAL SERVICES. There are two basic types of referral services for dental care: not-for-profit and the commercial. The not-for-profit is commonly organized by dental societies or community services. It is open to all qualified practitioners in the area served. A fee is sometimes charged the practitioner to be listed with the service. A fee for such referral services is for the purpose of covering the expenses of the service and has no relation to the number of patients referred. In contrast, some commercial referral services restrict access to the referral service to a limited number of dentists in a particular geographic area. Prospective patients calling the service may be referred to a single subscribing dentist in the geographic area and the respective dentist billed for each patient referred. Commercial referral services often advertise to the public stressing that there is no charge for use of the service and the patient may not be informed of the referral fee paid by the dentist. There is a connotation to such advertisements that the referral that is being made is in the nature of a public service. A dentist is allowed to pay for any advertising permitted by the *Code,* but is generally not permitted to make payments to another person or entity for the referral of a patient for professional services. While the particular facts and circumstances relating to an individual commercial referral service will vary, the council believes that the aspects outlined above for commercial referral services violate the *Code* in that it constitutes advertising which is false or misleading in a material respect and violate the prohibitions in the *Code* against fee splitting.

5.F.5. INFECTIOUS DISEASE TEST RESULTS An advertisement or other communication intended to solicit patients which omits a material fact or facts necessary to put the information conveyed in the advertisement in a proper context can be misleading in a material respect. A dental practice should not seek to attract patients on the basis of partial truths which create a false impression.

For example, an advertisement to the public of HIV negative test results, without conveying additional information that will clarify the scientific significance of this fact contains a misleading omission. A dentist could satisfy his or her obligation under this advisory opinion to convey additional information by clearly stating in the advertisement or other communication: “This negative HIV test cannot guarantee that I am currently free of HIV.”

5.G. NAME OF PRACTICE.

Since the name under which a dentist conducts his or her practice may be a factor in the selection process of the patient, the use of a trade name or an assumed name that is false or misleading in any material respect is unethical. Use of the name of a dentist no longer actively associated with the practice may be continued for a period not to exceed one year.**

Advisory Opinion

5.G.1. DENTIST LEAVING PRACTICE. Dentists leaving a practice who authorize continued use of their names should receive competent advice on the legal implications of this action. With permission of a departing dentist, his or her name may be used for more than one year, if, after the one year grace period has expired, prominent notice is provided to the public through such mediums as a sign at the office and a short statement on stationery and business cards that the departing dentist has retired from the practice.

5.H. ANNOUNCEMENT OF SPECIALIZATION AND LIMITATION OF PRACTICE.

This section and Section 5-I are designed to help the public make an informed selection between the practitioner who has completed an accredited program beyond the dental degree and a practitioner who has not completed such a program. The special areas of dental practice approved by the American Dental Association and the designation for ethical specialty announcement and limitation of practice are: dental public health, endodontics, oral and maxillofacial pathology, oral and maxillofacial radiology, oral and maxillofacial surgery, orthodontics and dentofacial orthopedics, pediatric dentistry, periodontics and prosthodontics. Dentists who choose to announce specialization should use "specialist in" or "practice limited to" and shall limit their practice exclusively to the announced special area(s) of dental practice, provided at the time of the announcement such dentists have met in each approved specialty for which they announce the existing educational requirements and standards set forth by the American Dental Association. Dentists who use their eligibility to announce as specialists to make the public believe that specialty services rendered in the dental office are being rendered by qualified specialists when such is not the case are engaged in unethical conduct. The burden of responsibility is on specialists to avoid any inference that general practitioners who are associated with specialists are qualified to announce themselves as specialists.

GENERAL STANDARDS.

The following are included within the standards of the American Dental Association for determining the education, experience and other appropriate requirements for announcing specialization and limitation of practice:

1. The special area(s) of dental practice and an appropriate certifying board must be approved by the American Dental Association.
2. Dentists who announce as specialists must have successfully completed an educational program accredited by the Commission on Dental Accreditation, two or more years in length, as specified by the Council on Dental Education and Licensure, or be diplomates of an American Dental Association recognized certifying board.

   The scope of the individual specialist's practice shall be governed by the educational standards for the specialty in which the specialist is announcing.
3. The practice carried on by dentists who announce as specialists shall be limited exclusively to the special area(s) of dental practices announced by the dentist.

STANDARDS FOR MULTIPLE-SPECIALTY ANNOUNCEMENTS.

Educational criteria for announcement by dentists in additional recognized specialty areas are the successful completion of an educational program accredited by the Commission on Dental Accreditation in each area for which the dentist wishes to announce. Dentists who completed their advanced education in programs listed by the Council on Dental Education and Licensure prior to the initiation of the accreditation process in 1967 and who are currently ethically announcing as specialists in a recognized area may announce in additional areas provided they are educationally qualified or are certified diplomates in each area for which they wish to announce. Documentation of successful completion of the educational program(s) must be submitted to the appropriate constituent society. The documentation must assure that the duration of the program(s) is a minimum of two years except for oral and maxillofacial surgery which must have been a minimum of three years in duration.**

Advisory Opinions

5.H.1. DUAL DEGREED DENTISTS. Nothing in Section 5-H shall be interpreted to prohibit a dual degreed dentist who practices medicine or osteopathy under a valid state license from announcing to the public as a dental specialist provided the dentist meets the educational, experience and other standards set forth in the *Code* for specialty announcement and further providing that the announcement is truthful and not materially misleading.

5.H.2. SPECIALIST ANNOUNCEMENT OF CREDENTIALS IN NON-SPECIALTY INTEREST AREAS. A dentist who is qualified to announce specialization under this section may not announce to the public that he or she is certified or a diplomate or otherwise similarly credentialed in an area of dentistry not recognized as a specialty area by the American Dental Association unless:

1. The organization granting the credential grants certification or diplomate status based on the following: a) the dentist's successful completion of a formal, full-time advanced education program (graduate or postgraduate level) of at least 12 months' duration; and b) the dentist's training and experience; and c) successful completion of an oral and written examination based on psychometric principles; and

2. The announcement includes the following language: [Name of announced area of dental practice] is not recognized as a specialty area by the American Dental Association.

Nothing in this advisory opinion affects the right of a properly qualified dentist to announce specialization in an ADA-recognized specialty area(s) as provided for under Section 5.H of this *Code* or the responsibility of such dentist to limit his or her practice exclusively to the special area(s) of dental practice announced. Specialists shall not announce their credentials in a manner that implies specialization in a non-specialty interest area.

See also: Report of the Council on Ethics, Bylaws and Judicial Affairs on Advisory Opinion 5.H.2. Specialist Announcement of Credentials in Non-Specialty Interest Areas

5.I. GENERAL PRACTITIONER ANNOUNCEMENT OF SERVICES.

General dentists who wish to announce the services available in their practices are permitted to announce the availability of those services so long as they avoid any communications that express or imply specialization. General dentists shall also state that the services are being provided by general dentists. No dentist shall announce available services in any way that would be false or misleading in any material respect.**

Advisory Opinions

5. I.1. GENERAL PRACTITIONER ANNOUNCEMENT OF CREDENTIALS IN NON-SPECIALTY INTEREST AREAS A general dentist may not announce to the public that he or she is certified or a diplomate or otherwise similarly credentialed in an area of dentistry not recognized as a specialty area by the American Dental Association unless:

1. The organization granting the credential grants certification or diplomate status based on the following: a) the dentist's successful completion of a formal, full-time advanced education program (graduate or postgraduate level) of at least 12 months duration; and b) the dentist's training and experience; and c) successful completion of an oral and written examination based on psychometric principles;
2. The dentist discloses that he or she is a general dentist; and
3. The announcement includes the following language: [Name of announced area of dental practice] is not recognized as a specialty area by the American Dental Association.

5.I.2. CREDENTIALS IN GENERAL DENTISTRY. General dentists may announce fellowships or other credentials earned in the area of general dentistry so long as they avoid any communications that express or imply specialization and the announcement includes the disclaimer that the dentist is a general dentist. The use of abbreviations to designate credentials shall be avoided when such use would lead the reasonable person to believe that the designation represents an academic degree, when such is not the case.

See also: Report of the ADA Council on Ethics, Bylaws and Judicial Affairs On Advisory Opinion 5.I.2. Credentials in General Dentistry

*A third party is any party to a dental prepayment contract that may collect premiums, assume financial risks, pay claims and/or provide administrative services.

**Advertising, solicitation of patients or business or other promotional activities by dentists or dental care delivery organizations shall not be considered unethical or improper, except for those promotional activities which are false or misleading in any material respect. Notwithstanding any *ADA Principles of Ethics and Code of Professional Conduct* or other standards of dentist conduct which may be differently worded, this shall be the sole standard for determining the ethical propriety of such promotional activities. Any provision of an ADA constituent or component society's code of ethics or other standard of dentist conduct relating to dentists' or dental care delivery organizations' advertising, solicitation, or other promotional activities which is worded differently from the above standard shall be deemed to be in conflict with the *ADA Principles of Ethics and Code of Professional Conduct.*

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CODE OF ETHICS FOR THE PROFESSION OF DIETETICS

American Dietetic Association

1987, REVISED 1999

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The current Code of Ethics for the Profession of Dietetics was adopted by the American Dietetic Association (ADA) in 1999. Whereas most professional codes apply only to members of the authoring organization, the ADA code applies both to members of the ADA and to nonmembers who are credentialed as "registered dieticians" (RDs) or "dietetic *technicians, registered" (DTRs) by the Commission on Dietetic Registration, the ADA's credentialing agency. Certain provisions, however, apply only to one group or the other. The code is supplemented by a detailed Consideration of Ethics Issues which outlines how ethics cases will be handled.*

<http://www.eatright.org/adacode.html>

Principles

1. The dietetics practitioner conducts himself/herself with honesty, integrity, and fairness.
2. The dietetics practitioner practices dietetics based on scientific principles and current information.
3. The dietetics practitioner presents substantiated information and interprets controversial information without personal bias, recognizing that legitimate differences of opinion exist.
4. The dietetics practitioner assumes responsibility and accountability for personal competence in practice, continually striving to increase professional knowledge and skills and to apply them in practice.
5. The dietetics practitioner recognizes and exercises professional judgment within the limits of his/her qualifications and collaborates with others, seeks counsel, or makes referrals as appropriate.
6. The dietetics practitioner provides sufficient information to enable clients and others to make their own informed decisions.
7. The dietetics practitioner protects confidential information and makes full disclosure about any limitations on his/her ability to guarantee full confidentiality.
8. The dietetics practitioner provides professional services with objectivity and with respect for the unique needs and values of individuals.
9. The dietetics practitioner provides professional services in a manner that is sensitive to cultural differences and does not discriminate against others on the basis of race, ethnicity, creed, religion, disability, sex, age, sexual orientation, or national origin.
10. The dietetics practitioner does not engage in sexual harassment in connection with professional practice.
11. The dietetics practitioner provides objective evaluations of performance for employees and coworkers, candidates for employment, students, professional association memberships, awards, or scholarships. The dietetics practitioner makes all reasonable effort to avoid bias in any kind of professional evaluation of others.
12. The dietetics practitioner is alert to situations that might cause a conflict of interest or have the appearance of a conflict. The dietetics practitioner provides full disclosure when a real or potential conflict of interest arises.
13. The dietetics practitioner who wishes to inform the public and colleagues of his/her services does so by using factual information. The dietetics practitioner does not advertise in a false or misleading manner.
14. The dietetics practitioner promotes or endorses products in a manner that is neither false nor misleading.
15. The dietetics practitioner permits the use of his/her name for the purpose of certifying that dietetics services have been rendered only if he/she has provided or supervised the provision of those services.
16. The dietetics practitioner accurately presents professional qualifications and credentials.
    a. The dietetics practitioner uses Commission on Dietetic Registration awarded credentials ("RD" or "Registered Dietitian"; "DTR" or "Dietetic Technician, Registered"; "CSP" or "Certified Specialist in Pediatric Nutrition"; "CSR" or "Certified Specialist in Renal Nutrition"; and "FADA" or "Fellow of The American Dietetic Association") only when the credential is current and authorized by the Commission on Dietetic Registration. The dietetics practitioner provides accurate information and complies with all requirements of the Commission on Dietetic Registration program in which he/she is seeking initial or continued credentials from the Commission on Dietetic Registration.
    b. The dietetics practitioner is subject to disciplinary action for aiding another person in violating any Commission on Dietetic Registration requirements or aiding another person in representing himself/herself as Commission on Dietetic Registration credentialed when he/she is not.
17. The dietetics practitioner withdraws from professional practice under the following circumstances:
    a. The dietetics practitioner has engaged in any substance abuse that could affect his/her practice;
    b. The dietetics practitioner has been adjudged by a court to be mentally incompetent;
    c. The dietetics practitioner has an emotional or mental disability that affects his/her practice in a manner that could harm the client or others.
18. The dietetics practitioner complies with all applicable laws and regulations concerning the profession and is subject to disciplinary action under the following circumstances:
    a. The dietetics practitioner has been convicted of a crime under the laws of the United States which is a felony or a misdemeanor, an essential

element of which is dishonesty, and which is related to the practice of the profession.
  - b. The dietetics practitioner has been disciplined by a state, and at least one of the grounds for the discipline is the same or substantially equivalent to these principles.
  - c. The dietetics practitioner has committed an act of misfeasance or malfeasance which is directly related to the practice of the profession as determined by a court of competent jurisdiction, a licensing board, or an agency of a governmental body.

19. The dietetics practitioner supports and promotes high standards of professional practice. The dietetics practitioner accepts the obligation to protect clients, the public, and the profession by upholding the Code of Ethics for the Profession of Dietetics and by reporting alleged violations of the Code through the defined review process of The American Dietetic Association and its credentialing agency, the Commission on Dietetic Registration.

CODE OF ETHICS

American Association of Pastoral Counselors

LAST AMENDED 1994

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Amended in 1994, the current Code of Ethics of the American Association of Pastoral Counselors contains many of the same elements as other professional codes, for example, statements pertaining to confidentiality, professional qualifications, and the welfare of the individuals they serve. In addition, the code contains aspects unique to the profession, such as avoiding the imposition of one's personal theology on clients and maintaining a responsible association with one's faith group.

Principle I – Prologue

As members of the American Association of Pastoral Counselors, we are committed to the various theologies, traditions, and values of our faith communities and to the dignity and worth of each individual. We are dedicated to advancing the welfare of those who seek our assistance and to the maintenance of high standards of professional conduct and competence. We are accountable for our ministry whatever its setting. This accountability is expressed in relationships to clients, colleagues, students, our faith communities, and through the acceptance and practice of the principles and procedures of this Code of Ethics.

In order to uphold our standards, as members of AAPC we covenant to accept the following foundational premises:

A. To maintain responsible association with the faith group in which we have ecclesiastical standing.
B. To avoid discriminating against or refusing employment, educational opportunity or professional assistance to anyone on the basis of race, gender, sexual orientation, religion, or national origin.
C. To remain abreast of new developments in the field through both educational activities and clinical experience. We agree at all levels of membership to continue post-graduate education and professional growth including supervision, consultation, and active participation in the meetings and affairs of the Association.
D. To seek out and engage in collegial relationships, recognizing that isolation can lead to a loss of perspective and judgement.
E. To manage our personal lives in a healthful fashion and to seek appropriate assistance for our own personal problems or conflicts.
F. To diagnose or provide treatment only for those problems or issues that are within the reasonable boundaries of our competence.
G. To establish and maintain appropriate professional relationship boundaries.

Principle II – Professional Practices

In all professional matters members of AAPC maintain practices that protect the public and advance the profession.

A. We use our knowledge and professional associations for the benefit of the people we serve and not to secure unfair personal advantage.
B. We clearly represent our level of membership and limit our practice to that level.
C. Fees and financial arrangements, as with all contractual matters, are always discussed without hesitation or equivocation at the onset and are established in a straight-forward, professional manner.
D. We are prepared to render service to individuals and communities in crisis without regard to financial remuneration when necessary.
E. We neither receive nor pay a commission for referral of a client.
F. We conduct our practice, agency, regional and Association fiscal affairs with due regard to recognized business and accounting procedures.
G. Upon the transfer of a pastoral counseling practice or the sale of real, personal, tangible or intangible property or assets used in such practice, the privacy

and well being of the client shall be of primary concern.

1. Client names and records shall be excluded from the transfer or sale.
2. Any fees paid shall be for services rendered, consultation, equipment, real estate, and the name and logo of the counseling agency.

H. We are careful to represent facts truthfully to clients, referral sources, and third party payors regarding credentials and services rendered. We shall correct any misrepresentation of our professional qualifications or affiliations.

I. We do not malign colleagues or other professionals.

Principle III – Client Relationships

It is the responsibility of members of AAPC to maintain relationships with clients on a professional basis.

A. We do not abandon or neglect clients. If we are unable, or unwilling for appropriate reasons, to provide professional help or continue a professional relationship, every reasonable effort is made to arrange for continuation of treatment with another professional.

B. We make only realistic statements regarding the pastoral counseling process and its outcome.

C. We show sensitive regard for the moral, social, and religious standards of clients and communities. We avoid imposing our beliefs on others, although we may express them when appropriate in the pastoral counseling process.

D. Counseling relationships are continued only so long as it is reasonably clear that the clients are benefiting from the relationship.

E. We recognize the trust placed in and unique power of the therapeutic relationship. While acknowledging the complexity of some pastoral relationships, we avoid exploiting the trust and dependency of clients. We avoid those dual relationships with clients (e.g., business or close personal relationships) which could impair our professional judgement, compromise the integrity of the treatment, and/or use the relationship for our own gain.

F. We do not engage in harassment, abusive words or actions, or exploitative coercion of clients or former clients.

G. All forms of sexual behavior or harassment with clients are unethical, even when a client invites or consents to such behavior or involvement. Sexual behavior is defined as, but not limited to, all forms of overt and covert seductive speech, gestures, and behavior as well as physical contact of a sexual nature; harassment is defined as but not limited to, repeated comments, gestures or physical contacts of a sexual nature.

H. We recognize that the therapist/client relationship involves a power imbalance, the residual effects of which are operative following the termination of the therapy relationship. Therefore, all sexual behavior or harassment as defined in Principle III, G with former clients is unethical.

Principle IV – Confidentiality

As members of AAPC we respect the integrity and protect the welfare of all persons with whom we are working and have an obligation to safeguard information about them that has been obtained in the course of the counseling process.

A. All records kept on a client are stored or disposed of in a manner that assures security and confidentiality.

B. We treat all communications from clients with professional confidence.

C. Except in those situations where the identity of the client is necessary to the understanding of the case, we use only the first names of our clients when engaged in supervision or consultation. It is our responsibility to convey the importance of confidentiality to the supervisor/consultant; this is particularly important when the supervision is shared by other professionals, as in a supervisory group.

D. We do not disclose client confidences to anyone, except: as mandated by law; to prevent a clear and immediate danger to someone; in the course of a civil, criminal or disciplinary action arising from the counseling where the pastoral counselor is a defendant; for purposes of supervision or consultation; or by previously obtained written permission. In cases involving more than one person (as client) written permission must be obtained from all legally accountable persons who have been present during the counseling before any disclosure can be made.

E. We obtain informed written consent of clients before audio and/or video tape recording or permitting third party observation of their sessions.

F. We do not use these standards of confidentiality to avoid intervention when it is necessary, e.g., when there is evidence of abuse of minors, the elderly, the disabled, the physically or mentally incompetent.

G. When current or former clients are referred to in a publication, while teaching or in a public presentation, their identity is thoroughly disguised.

H. We as members of AAPC agree that as an express condition of our membership in the Association,

Association ethics communications, files, investigative reports, and related records are strictly confidential and waive their right to use same in a court of law to advance any claim against another member. Any member seeking such records for such purpose shall be subject to disciplinary action for attempting to violate the confidentiality requirements of the organization. This policy is intended to promote pastoral and confessional communications without legal consequences and to protect potential privacy and confidentiality interests of third parties.

Principle V – Supervisee, Student & Employee Relationships

As members of AAPC we have an ethical concern for the integrity and welfare of our supervisees, students and employees. These relationships are maintained on a professional and confidential basis. We recognize our influential position with regard to both current and former supervisees, students and employees, and avoid exploiting their trust and dependency. We make every effort to avoid dual relationships with such persons that could impair our judgement or increase the risk of personal and/or financial exploitation.

A. We do not engage in ongoing counseling relationships with current supervisees, students and employees.
B. We do not engage in sexual or other harassment of supervisees, students, employees, research subjects or colleagues.
C. All forms of sexual behavior, as defined in Principle III.G, with our supervisees, students, research subjects and employees (except in employee situations involving domestic partners) are unethical.
D. We advise our students, supervisees, and employees against offering or engaging in, or holding themselves out as competent to engage in, professional services beyond their training, level of experience and competence.
E. We do not harass or dismiss an employee who has acted in a reasonable, responsible and ethical manner to protect, or intervene on behalf of, a client or other member of the public or another employee.

Principle VI – Interprofessional Relationships

As members of AAPC we relate to and cooperate with other professional persons in our community and beyond. We are part of a network of health care professionals and are expected to develop and maintain interdisciplinary and interprofessional relationships.

A. We do not offer ongoing clinical services to persons currently receiving treatment from another professional without prior knowledge of and in consultation with the other professional, with the clients' informed consent. Soliciting such clients is unethical.
B. We exercise care and interprofessional courtesy when approached for services by persons who claim or appear to have inappropriately terminated treatment with another professional.

Principle VII – Advertising

Any advertising by or for a member of AAPC, including announcements, public statements and promotional activities, is undertaken with the purpose of helping the public make informed judgements and choices.

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GUIDELINES FOR THE CHAPLAINS' ROLE IN BIOETHICS

College of Chaplains, American Protestant Health Association

1992

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This document differs from codes of ethics in its focus on the role of chaplains in clinical settings, particularly within healthcare institutions. Certified chaplains are recognized to be essential members of the healthcare team; they help to identify and integrate the spiritual and moral perspectives of patients with those of other healthcare disciplines to form a holistic approach to bioethics.

<http://www.professionalchaplains.org/stage/index.html>

Introduction

Advances in medical science and technology, the evolution of integrated delivery systems, and the changing economics of health care present benefits and ethical dilemmas. Ethical conflicts can arise in the clinical setting and at the organizational level. The obligations of health care organizations include provision of a forum for ethical reflection, a deliberate process for ethics consultation, and persons trained in ethics consultation.

Health care ethics committees may serve three functions: (1) education, (2) consultation, and (3) review and recommendation of institutional policies and procedures. Health care organizations that have a formal health care ethics committee often include a certified Chaplain on that committee. As members of health care ethics committees, Chaplains play a crucial role in health care ethics reflection. Chaplains may be of assistance to health care ethics committees as they discuss the questions of philosophy, theology, spirituality, human values, and morals which are integral to ethical questions.

While some Chaplains have education and/or training in ethics, their roles as Chaplains differ from those of ethicists. Chaplains identify and clarify the patient's spiritual and moral perspectives as essential ingredients in the process of health care ethics reflection. Integration of these perspectives with those of other health care disciplines fosters a holistic approach to health care ethics.

These Guidelines provide primary principles for the effective inclusion of pastoral/spiritual care in the process of health care ethics reflection. While each health care institution has a particular context within which ethical reflection is done, these Guidelines are generally applicable to a variety of health care settings. The Guidelines emphasize pastoral/spiritual care's unique perspective as integral to the ethical reflection process of a health care organization.

Principle I

The health care organization includes a certified chaplain on its health care ethics committee.

INTERPRETATION – *A certified Chaplain can make unique contributions to a health care ethics committee. Certified Chaplains have theological education on at least the master's level or its equivalent that includes formal training in pastoral theology and clinical pastoral education.*

Guideline 1

Chaplains offer pastoral/spiritual care to health care ethics committee members and to medical and health care professionals involved in health care ethics discussion and consultation.

Guideline 2

Chaplains serve as resource persons to religious/faith group leaders and to the health care ethics committee concerning the spiritual and value dimensions and values of illness and health even if patients or their families have no apparent religious affiliation.

Principle II

Chaplains develop a continuing education plan for themselves and their colleagues that addresses health care ethics theories and approaches related to the spiritual, religious, cultural, and philosophical values represented in persons served by their health care institutions, thus, contributing to the institution's education program.

INTERPRETATION – *Certified Chaplains commit to yearly continuing education for themselves in order to maintain certification and serve as resource persons in their organizations' educational programs in health care ethics.*

Guideline 1

The Chaplain seeks continuing education in health care ethics and ethics consultation in order to achieve a working knowledge of basic principles, ethical decision-making, current issues, and developing trends.

Guideline 2

Chaplains participate in and serve as resource persons to the organization's health care ethics education program to patients, staff, and community with the goal of providing a forum for discussion of various spiritual and religious perspectives on health care ethics issues.

Guideline 3

Chaplains are included in peer review as the multi-disciplinary team seeks to teach health care ethics theories, principles, and options that apply in specific situations.

Guideline 4

Chaplains contribute as resource persons and speakers in the organization's education programs for patients, health care professionals, and the community.

Guideline 5

Chaplains bring expertise in spiritual, theological, ethical, and moral values to the multi-disciplinary team in the clinical setting.

Guideline 6

Chaplains bring expertise in spiritual, theological, ethical, and moral values to the multi-disciplinary reflection and discourse on ethical issues, dilemmas, case studies, and retrospective reviews.

Principle III

Chaplains participate in the health care ethics consultation services of the facility or organization.

INTERPRETATION – *A health care ethics committee may provide the service of consultation to physicians, nurses, administration, patients, and families. Consultation does not take the place of or interfere with the patient-physician relationship. Consultation helps clarify ethical options through reflective discussion in the context of health care ethics principles and good medical practice.*

Guideline 1

The Chaplain's role is to maintain contact with the patient and/or the patient's decision-maker(s) during the ethics consultation process.

- The Chaplain may serve as a resource to the health care ethics consultation process, helping to interpret the process and facilitate the patient and the patient's decision-maker's understanding of and participation in the consultation process.

Guideline 2

The Chaplain may assist in facilitating group process.

- The Chaplain may facilitate and be a resource in supporting group process, i.e., consultative process, staff and patient decision-makers' concerns, etc.

Guideline 3

The Chaplain clarifies theological beliefs and values that influence decision-making.

- The Chaplain's function is to identify spiritual, moral, religious, cultural, and philosophical values which influence decisions.
- The Chaplain provides validation and recognition of the importance of personal beliefs, which will help individuals trust the consultation process.
- The Chaplain serves as an advocate for the spiritual values and religious beliefs held by the patient, even when those values and beliefs are not those of the Chaplain.
- The Chaplain assures that the religious, cultural, and philosophic values of the patient are considered during discussion of appropriate medical treatment, even when those values and beliefs are other than those of the Chaplain.

Guideline 4

The Chaplain provides pastoral care to those involved in the health care ethics consultation process.

- Chaplains may provide continuing support to the patient, family, and staff during and following the consultation process.

Guideline 5

The Chaplain serves as liaison with the patient's own clergy.

- The Chaplain is the liaison with the religious community. The Chaplain develops programs and strategies to develop positive relationships with community clergy and other designated religious representatives who visit congregants and may be involved in the decision-making process.
- The Chaplain provides consultations, referrals, professional resources, and educational opportunities for community clergy.
- The Chaplain facilitates the pastoral ministry and the role of community clergy in the decision-making process for their congregants who are patients.

Principle IV

Chaplains assist the health care organization in its review and recommendation of policies that have health care ethics implications in the services provided by the organization.

INTERPRETATION – *Health care ethics committees are usually responsible for reviewing existing or proposed policies and procedures for the organization, medical staff, nursing staff, etc. As members of the health care ethics committee, Chaplains offer input from their discipline of pastoral/spiritual care.*

Guideline 1

Chaplains serve as resource persons for understanding and interpreting faith communities, religious traditions, and belief systems as they might relate to or be affected by proposed policies and procedures.

Guideline 2

Chaplains serve as resource person to staff who have spiritual and religious concerns which arise in the implementation of policies and procedures with ethical implications.

Principle V

Chaplains provide pastoral and spiritual care to those involved in the ethical reflection process.

INTERPRETATION – *The ministry of Chaplains includes a wide repertoire of services including pastoral presence, pastoral conversation, pastoral/spiritual care, and pastoral counseling. Experiencing such services, patients, families, health care staff, and employees feel affirmed, understood, and supported in their particular predicament and in their right to have a particular ethical perspective. Those involved in the process can be enabled to explore the relationships of the physical issues of health and illness, psychological dimensions of the situation, i.e., anxiety, fear, trust, etc., and the spiritual issues, i.e., meaning, hope, ultimate concern, and God's presence. Issues vary greatly from person to person depending upon the situation and belief system of the individual. Pastoral/spiritual care offers support for all involved and creates an atmosphere of sensitivity and trust in the context of health care ethics decision-making.*

Guideline 1

Chaplains offer religious resources and support from the patient's and family's faith system and community as appropriate.

Guideline 2

Chaplains facilitate the ministry of community clergy and faith group leaders for the purpose of offering support and the opportunity for patients and families to explore the values, beliefs, and meaning inherent in the patient's situation.

Principle VI

Chaplains provide specific evaluation of the process of ethical reflection from a spiritual perspective as well as from a clinical perspective.

INTERPRETATION – *Evaluation of the health care ethics reflection process utilized in a case consultation, policy review, or educational event is an important part of quality improvement. Each discipline, including pastoral/spiritual care, has its own perspective and responsibility to contribute to the evaluation process.*

Guideline 1

Chaplains have the responsibility to be advocates for patients, families, and health care staff in behalf of their particular spiritual values. The role of the Chaplain is to help ensure that the health care ethics reflection process is as attentive, respectful, and inclusive of patients' values and wishes as possible.

Guideline 2

Pastoral intervention in the health care ethics process is evaluated regularly through peer review and input from a clinically trained and experienced ethicist. The health care organization provides opportunities and encouragement for Chaplains to attend and participate in regional and/or national health care ethics workshops, conferences, and other educational events.

Principle VII

Chaplains provide for alternate coverage of the chaplain's role in the health care ethics reflection process when it is appropriate for the chaplain designated to exclude her/himself.

INTERPRETATION – *The Chaplain charged with the responsibility to serve on the health care ethics committee or to participate in the consultation service may withdraw from participation so that objectivity and professionalism can be maintained in the process.*

Guideline 1

If the Chaplain does not have adequate knowledge about an issue, particularly a patient's or family's spiritual perspective, the Chaplain seeks consultation or makes an appropriate referral.

Guideline 2

If the Chaplain has a personal relationship with one or more of the significant parties involved in the case being reviewed, designating another certified Chaplain to participate in the ethics process maintains objective and professional integrity.

Guideline 3

Chaplains are familiar with the process for health care ethics consultation in their organizations. When patients with whom they have pastoral relationships are brought to the attention of the health care ethics service for consultation or for education purposes, other pastoral care staff persons or community clergy can be involved when and to the degree appropriate. In this process, confidentiality is maintained.

PRINCIPLE VIII

Chaplains in administrative and managerial roles assist in the identification and consideration of values in matters of the health care organization.

INTERPRETATION – *Organizational values and ethics reflect consistency at all levels and in all services of the health care organization. The certified Chaplain who is in an administrative position and/or works at a managerial level has knowledge and experience of health care ethics, organizational ethics, and spiritual values related to the organization.*

Guideline 1

Chaplains bring expertise in spiritual dimensions, theological considerations, ethical issues, and moral values to the administrative and managerial teams.

Guideline 2

Chaplains with managerial/administrative responsibilities serve as resource persons to the administrators, board members, owners, etc. concerning the exploration of the spiritual dimensions, theological considerations, ethical issues, and moral values of the health care organization.

Conclusion

Spiritual and religious dimensions of health care ethics issues and dilemmas must be considered and included in the process of health care ethics reflection. The Association of Professional Chaplains provides resources and a Bioethics Committee to assist members of the APC as well as other health care providers to facilitate, promote, enhance, and strengthen the role of Chaplains in this important endeavor.

Approved by the Board of Directors 10/2000

CODE OF ETHICS

American Pharmacists Association

1969, AMENDED 1975, REVISED 1981, 1994

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The current code of the American Pharmacists Association (APhA) was approved in 1969, amended in 1975 and 1981, and last revised in 1994. Since the 1969 code, the Association has introduced gender-neutral language and removed the prohibition on advertising. The name of the organization was changed from American Pharmaceutical Association in 2003.

<http://www.aphanet.org/>

Preamble

Pharmacists are health professionals who assist individuals in making the best use of medications. This Code, prepared and supported by pharmacists, is intended to state publicly the principles that form the fundamental basis of the roles and responsibilities of pharmacists. These principles, based on moral obligations and virtues, are established to guide pharmacists in relationships with patients, health professionals, and society.

I. A pharmacist respects the covenantal relationship between the patient and pharmacist.

Considering the patient-pharmacist relationship as a covenant means that a pharmacist has moral obligations in response to the gift of trust received from society. In return for this gift, a pharmacist promises to help individuals achieve optimum benefit from their medications, to be committed to their welfare, and to maintain their trust.

II. A pharmacist promotes the good of every patient in a caring, compassionate, and confidential manner.

A pharmacist places concern for the well-being of the patient at the center of professional practice. In doing so, a pharmacist considers needs stated by the patient as well as those defined by health science. A pharmacist is dedicated to protecting the dignity of the patient. With a caring attitude and a compassionate spirit, a pharmacist focuses on serving the patient in a private and confidential manner.

III. A pharmacist respects the autonomy and dignity of each patient.

A pharmacist promotes the right of self-determination and recognizes individual self-worth by encouraging patients to participate in decisions about their health. A pharmacist communicates with patients in terms that are understandable. In all cases, a pharmacist respects personal and cultural differences among patients.

IV. A pharmacist acts with honesty and integrity in professional relationships.

A pharmacist has a duty to tell the truth and to act with conviction of conscience. A pharmacist avoids discriminatory practices, behavior or work conditions that impair professional judgment, and actions that compromise dedication to the best interests of patients.

V. A pharmacist maintains professional competence.

A pharmacist has a duty to maintain knowledge and abilities as new medications, devices, and technologies become available and as health information advances.

VI. A pharmacist respects the values and abilities of colleagues and other health professionals.

When appropriate, a pharmacist asks for the consultation of colleagues or other health professionals or refers the patient. A pharmacist acknowledges that colleagues and other health professionals may differ in the beliefs and values they apply to the care of the patient.

VII. A pharmacist serves individual, community, and societal needs.

The primary obligation of a pharmacist is to individual patients. However, the obligations of a pharmacist may at times extend beyond the individual to the community and society. In these situations, the pharmacist recognizes the responsibilities that accompany these obligations and acts accordingly.

VIII. A pharmacist seeks justice in the distribution of health resources.

When health resources are allocated, a pharmacist is fair and equitable, balancing the needs of patients and society.

* adopted by the membership of the American Pharmaceutical Association October 27, 1994.

STATEMENT OF PROFESSIONAL STANDARDS: CODE OF ETHICS FOR PHARMACISTS

Fédération Internationale Pharmaceutique

1988, REVISED 1997

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In 1988, the Fédération Internationale Pharmaceutique adopted sixteen guidelines for ethical behavior by pharmacists. The guidelines, which are deliberately broad so that nations may adapt them in creating their own ethics codes, mention several topics of particular note: (1) the independence of the profession, extending to the refusal to dispense medications, including prescriptions, if it serves the patient's health; (2) the role of pharmacists as health educators; and (3) respect for the freedom of choice of patients. A more recent statement was adopted by the Council of the International Pharmaceutical Federation (FIP) at its Council meeting in Vancouver on 5th September 1997.

<http://www.fip.org/pdf/codeeth.pdf>

Introduction:

A profession is identified by the willingness of individual practitioners to comply with ethical and professional standards which exceed minimum legal requirements.

Pharmacists are health professionals who help people to maintain good health, to avoid ill health and, where appropriate, to acquire and make the best use of their medicines. The role of the pharmacist has changed significantly in the last twenty years. Whilst the fundamental ethical principles remain essentially the same, this Code of Ethics has been redrafted to reaffirm and state publicly the principles that form the basis of the roles and responsibilities of pharmacists. These principles, based on moral obligations and values, are established to enable national pharmaceutical organisations through their Codes of Ethics to guide pharmacists in their relationships with patients, other health professionals, and society generally.

Pharmacists seek to act with fairness and equity in the allocation of health resources available to them.

Principles:

In the practice of their profession:

1. **The pharmacist's prime responsibility is the good of the individual.**

   Obligations:

   –to be objective,

   –to put the good of the individual before personal or commercial interests (including financial interest),

   –to promote the individual's right of access to safe and effective treatment.

2. **The pharmacist shows the same dedication to all.**

   Obligations:

   –to show respect for life and human dignity,

   –to not discriminate between people,

   –to strive to treat and inform each individual according to personal circumstances.

3. **The pharmacist respects the individual's right to freedom of choice of treatment.**

   Obligation:

   –to ensure that where the pharmacist is involved in developing care and treatment plans, this is done in consultation with the individual.

4. **The pharmacist respects and safeguards the individual's right to confidentiality.**

   Obligation:

   –to not disseminate information, which identifies the individual, without informed consent or due cause.

5. **The pharmacist cooperates with colleagues and other professionals and respects their values and abilities.**

   Obligation:

   –to cooperate with colleagues, and other professionals and agencies in efforts to promote good health and treat and prevent ill health.

6. **The pharmacist acts with honesty and integrity in professional relationships.**

   Obligations:

   –to act with conviction of conscience,

   –to avoid practices, behaviour or work conditions that could impair professional judgement.

7. **The pharmacist serves the needs of the individual, the community and society.**

   Obligation:

   –to recognise the responsibilities associated with serving the needs of the individual on the one hand and society at large on the other.

8. **The pharmacist maintains and develops professional knowledge and skills.**

   Obligation:

   –to ensure competency in each pharmaceutical service provided, by continually updating knowledge and skills.

9. **The pharmacist ensures continuity of care in the event of labour disputes, pharmacy closure or conflict with personal moral beliefs.**

   Obligation:

   –to refer the patient to another pharmacist.

   –To ensure that when a pharmacy closes, the patients are informed of the pharmacy to which their records, if held, have been transferred.

CODE OF ETHICS AND GUIDE FOR PROFESSIONAL CONDUCT

American Physical Therapy Association

1981, LAST AMENDED 1991

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The American Physical Therapy Association Code of Ethics articulates eleven ethical principles for the physical therapy profession, which are developed further in the Guide for Professional Conduct. The eleven principles are printed here.

<http://www.apta.org/PT_Practice/ethics_pt/code_ethics>

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Preamble

This Code of Ethics of the American Physical Therapy Association sets forth principles for the ethical practice of physical therapy. All physical therapists are responsible for maintaining and promoting ethical practice. To this end, the physical therapist shall act in the best interest of the patient/client. This Code of Ethics shall be binding on all physical therapists.

Principle 1

A physical therapist shall respect the rights and dignity of all individuals and shall provide compassionate care.

Principle 2

A physical therapist shall act in a trustworthy manner towards patients/clients, and in all other aspects of physical therapy practice.

Principle 3

A physical therapist shall comply with laws and regulations governing physical therapy and shall strive to effect changes that benefit patients/clients.

Principle 4

A physical therapist shall exercise sound professional judgment.

Principle 5

A physical therapist shall achieve and maintain professional competence.

Principle 6

A physical therapist shall maintain and promote high standards for physical therapy practice, education and research.

Principle 7

A physical therapist shall seek only such remuneration as is deserved and reasonable for physical therapy services.

Principle 8

A physical therapist shall provide and make available accurate and relevant information to patients/clients about their care and to the public about physical therapy services.

Principle 9

A physical therapist shall protect the public and the profession from unethical, incompetent, and illegal acts.

Principle 10

A physical therapist shall endeavor to address the health needs of society.

Priniciple 11

A physical therapist shall respect the rights, knowledge, and skills of colleagues and other health care professionals.

OCCUPATIONAL THERAPY CODE OF ETHICS

American Occupational Therapy Association

1988, REVISED 2000

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The Occupational Therapy Code of Ethics, revised in 2000, updates the 1988 Code. Although the code is enforceable only with respect to members of the association, it is interesting because it expressly applies to all "occupational therapy personnel," including therapists, assistants, and students.

http://www.aota.org/general/coe.asp

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The American Occupational Therapy Association and its component members are committed to furthering people's ability to function fully within their total environment. To this end the occupational therapist renders service to clients in all stages of health and illness, to institutions, to other professionals and colleagues, to students, and to the general public. A more recent code was adopted in 2000. This document is heavily principle-based, with references to beneficence, nonmalificence, and justice, as well as fidelity and veracity.

Preamble

The American Occupational Therapy Association's Code of Ethics is a public statement of the common set of values and principles used to promote and maintain high standards of behavior in occupational therapy. The American Occupational Therapy Association and its members are committed to furthering the ability of individuals, groups, and systems to function within their total environment. To this end, occupational therapy personnel (including all staff and personnel who work and assist in providing occupational therapy services, (e.g., aides, orderlies, secretaries, technicians) have a responsibility to provide services to recipients in any stage of health and illness who are individuals, research participants, institutions and businesses, other professionals and colleagues, students, and to the general public.

The *Occupational Therapy Code of Ethics* is a set of principles that applies to occupational therapy personnel at all levels. These principles to which occupational therapists and occupational therapy assistants aspire are part of a lifelong effort to act in an ethical manner. The various roles of practitioner (occupational therapist and occupational therapy assistant), educator, fieldwork educator, clinical supervisor, manager, administrator, consultant, fieldwork coordinator, faculty program director, researcher/scholar, private practice owner, entrepreneur, and student are assumed.

Any action in violation of the spirit and purpose of this Code shall be considered unethical. To ensure compliance with the Code, the Commission on Standards and Ethics (SEC) establishes and maintains the enforcement procedures. Acceptance of membership in the American Occupational Therapy Association commits members to adherence to the Code of Ethics and its enforcement procedures. The Code of Ethics, Core Values and Attitudes of Occupational Therapy Practice (AOTA, 1993), and the Guidelines to the Occupational Therapy Code of Ethics (AOTA, 1998) are aspirational documents designed to be used together to guide occupational therapy personnel.

Principle 1. Occupational therapy personnel shall demonstrate a concern for the well-being of the recipients of their services. (beneficence)

A. Occupational therapy personnel shall provide services in a fair and equitable manner. They shall recognize and appreciate the cultural components of economics, geography, race, ethnicity, religious and political factors, marital status, sexual orientation, and disability of all recipients of their services.

B. Occupational therapy practitioners shall strive to ensure that fees are fair and reasonable and commensurate with services performed. When occupational therapy practitioners set fees, they shall set fees considering institutional, local, state, and federal requirements, and with due regard for the service recipient's ability to pay.

C. Occupational therapy personnel shall make every effort to advocate for recipients to obtain needed services through available means.

Principle 2. Occupational therapy personnel shall take reasonable precautions to avoid imposing or inflicting harm upon the recipient of services or to his or her property. (nonmaleficence)

A. Occupational therapy personnel shall maintain relationships that do not exploit the recipient of services sexually, physically, emotionally, financially, socially, or in any other manner.

B. Occupational therapy practitioners shall avoid relationships or activities that interfere with professional judgment and objectivity.

Principle 3. Occupational therapy personnel shall respect the recipient and/or their surrogate(s) as well as the recipient's rights. (autonomy, privacy, confidentiality)

A. Occupational therapy practitioners shall collaborate with service recipients or their surrogate(s) in setting goals and priorities throughout the intervention process.

B. Occupational therapy practitioners shall fully inform the service recipients of the nature, risks, and potential outcomes of any interventions.

C. Occupational therapy practitioners shall obtain informed consent from participants involved in research activities and indicate that they have fully informed and advised the participants of potential risks and outcomes. Occupational therapy practitioners shall endeavor to ensure that the participant(s) comprehend these risks and outcomes.

D. Occupational therapy personnel shall respect the individual's right to refuse professional services or involvement in research or educational activities.

E. Occupational therapy personnel shall protect all privileged confidential forms of written, verbal, and electronic communication gained from educational, practice, research, and investigational activities unless otherwise mandated by local, state, or federal regulations.

Principle 4. Occupational therapy personnel shall achieve and continually maintain high standards of competence. (duties)

A. Occupational therapy practitioners shall hold the appropriate national and state credentials for the services they provide.

B. Occupational therapy practitioners shall use procedures that conform to the standards of practice and other appropriate AOTA documents relevant to practice.

C. Occupational therapy practitioners shall take responsibility for maintaining and documenting competence by participating in professional development and educational activities.

D. Occupational therapy practitioners shall critically examine and keep current with emerging knowledge relevant to their practice so they may perform their duties on the basis of accurate information.

E. Occupational therapy practitioners shall protect service recipients by ensuring that duties assumed by or assigned to other occupational therapy personnel match credentials, qualifications, experience, and scope of practice.

F. Occupational therapy practitioners shall provide appropriate supervision to individuals for whom the practitioners have supervisory responsibility in accordance with Association policies, local, state and federal laws, and institutional values.

G. Occupational therapy practitioners shall refer to or consult with other service providers whenever such a referral or consultation would be helpful to the care of the recipient of service. The referral or consultation process should be done in collaboration with the recipient of service.

Principle 5. Occupational therapy personnel shall comply with laws and Association policies guiding the profession of occupational therapy. (justice)

A. Occupational therapy personnel shall familiarize themselves with and seek to understand and abide by applicable Association policies; local, state, and federal laws; and institutional rules.

B. Occupational therapy practitioners shall remain abreast of revisions in those laws and Association policies that apply to the profession of occupational therapy and shall inform employers, employees, and colleagues of those changes.

C. Occupational therapy practitioners shall require those they supervise in occupational therapy-related activities to adhere to the Code of Ethics.

D. Occupational therapy practitioners shall take reasonable steps to ensure employers are aware of occupational therapy's ethical obligations, as set forth in this Code of Ethics, and of the implications of those obligations for occupational therapy practice, education, and research.

E. Occupational therapy practitioners shall record and report in an accurate and timely manner all information related to professional activities.

Principle 6. Occupational therapy personnel shall provide accurate information about occupational therapy services. (veracity)

A. Occupational therapy personnel shall accurately represent their credentials, qualifications, education, experience, training, and competence. This is of particular importance for those to whom occupational therapy personnel provide their services or with whom occupational therapy practitioners have a professional relationship.

B. Occupational therapy personnel shall disclose any professional, personal, financial, business, or volunteer affiliations that may pose a conflict of interest to those with whom they may establish a professional, contractual, or other working relationship.

C. Occupational therapy personnel shall refrain from using or participating in the use of any form of communication that contains false, fraudulent, deceptive, or unfair statements or claims.

D. Occupational therapy practitioners shall accept the responsibility for their professional actions which reduce the public's trust in occupational therapy services and those that perform those services.

Principle 7. Occupational therapy personnel shall treat colleagues and other professionals with fairness, discretion, and integrity. (fidelity)

A. Occupational therapy personnel shall preserve, respect, and safeguard confidential information about colleagues and staff, unless otherwise mandated by national, state, or local laws.

B. Occupational therapy practitioners shall accurately represent the qualifications, views, contributions, and findings of colleagues.

C. Occupational therapy personnel shall take adequate measures to discourage, prevent, expose, and correct any breaches of the Code of Ethics and report any breaches of the Code of Ethics to the appropriate authority.

D. Occupational therapy personnel shall familiarize themselves with established policies and procedures for handling concerns about this Code of Ethics, including familiarity with national, state, local, district, and territorial procedures for handling ethics complaints. These include policies and procedures created by the American Occupational Therapy Association, licensing and regulatory bodies, employers, agencies, certification boards, and other organizations who have jurisdiction over occupational therapy practice.

CODE OF ETHICS OF THE PHYSICIAN ASSISTANT PROFESSION

American Academy of Physician Assistants

1983, AMENDED 1985, REAFFIRMED 1990

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The American Academy of Physician Assistants' (AAPA) current Code of Ethics was adopted in 1983, amended in 1985, and reaffirmed in 1990. In addition to standard features, the code explicitly recognizes that: (1) It is necessarily limited and does not preclude additional, equally imperative, obligations; (2) physician assistants should use their skills "to contribute to an improved community"; and (3) physician assistants "shall place service before material gain." The AAPA also has issued Guidelines for Professional Conduct, which interpret and elaborate upon the principles found in the code of ethics.

<http://www.aapa.org/images/GECINSERTATION.pdf>

The American Academy of Physician Assistants recognizes its responsibility to aid the profession in maintaining high standards in the provision of quality and accessible health care services. The following principles delineate the standards governing the conduct of physician assistants in their professional interactions with patients, colleagues, other health professionals and the general public. Realizing that no code can encompass all ethical responsibilities of the physician assistant, this enumeration of obligations in the Code of Ethics is not comprehensive and does not constitute a denial of the existence of other obligations, equally imperative, though not specifically mentioned.

Physician assistants shall be committed to providing competent medical care, assuming as their primary responsibility the health, safety, welfare and dignity of all humans.

Physician assistants shall extend to each patient the full measure of their ability as dedicated, empathetic health care providers and shall assume responsibility for the skillful and proficient transactions of their professional duties.

Physician assistants shall deliver needed health care services to health consumers without regard to sex, age, race, creed, socioeconomic and political status.

Physician assistants shall adhere to all state and federal laws governing informed consent concerning the patient's health care.

Physician assistants shall seek consultation with their supervising physician, other health providers, or qualified professionals having special skills, knowledge or experience whenever the welfare of the patient will be safeguarded or advanced by such consultation. Supervision should include ongoing communication between the physician and the physician assistant regarding the care of all patients.

Physician assistants shall take personal responsibility for being familiar with and adhering to all federal/state laws applicable to the practice of their profession.

Physician assistants shall provide only those services for which they are qualified via education and/or experience and by pertinent legal regulatory process.

Physician assistants shall not misrepresent in any manner, either directly or indirectly, their skills, training, professional credentials, identity, or services.

Physician assistants shall uphold the doctrine of confidentiality regarding privileged patient information, unless required to release such information by law or such information becomes necessary to protect the welfare of the patient or the community.

Physician assistants shall strive to maintain and increase the quality of individual health care service through individual study and continuing education.

Physician assistants shall have the duty to respect the law, to uphold the dignity of the physician assistant profession and to accept its ethical principles. The physician assistant shall not participate in or conceal any activity that will bring discredit or dishonor to the physician assistant profession and shall expose, without fear or favor, any illegal or unethical conduct in the medical profession.

Physician assistants, ever cognizant of the needs of the community, shall use the knowledge and experience acquired as professionals to contribute to an improved community.

Physician assistants shall place service before material gain and must carefully guard against conflicts of professional interest.

Physician assistants shall strive to maintain a spirit of cooperation with their professional organizations and the general public.

ETHICAL PRINCIPLES OF PSYCHOLOGISTS AND CODE OF CONDUCT

American Psychological Association

1992, REVISED 2002

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A substantially revised version of the Ethical Principles of Psychologists and Code of Conduct was adopted by the American Psychological Association (APA) in 1992. The 1992 revision, which is still current, consists of an introduction, a preamble, six general principles, and specific ethical standards. The preamble and general principles represent "aspirational goals to guide psychologists toward the highest ideals of psychology," whereas the ethical standards establish "enforceable rules for conduct." The standards are noteworthy for the scope of the topics addressed, including sexual harassment, misuse of influence, and informed consent, that pertain to therapeutic and research relationships, as well as those that pertain to the care and use of animals in research.

The preamble, general principles, and excerpts from the ethical standards follow.

<http://www.apa.org/ethics/code2002.html>

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Preamble

Psychologists are committed to increasing scientific and professional knowledge of behavior and people's understanding of themselves and others and to the use of such knowledge to improve the condition of individuals, organizations, and society. Psychologists respect and protect civil and human rights and the central importance of freedom of inquiry and expression in research, teaching, and publication. They strive to help the public in developing informed judgments and choices concerning human behavior. In doing so, they perform many roles, such as researcher, educator, diagnostician, therapist, supervisor, consultant, administrator, social interventionist, and expert witness. This Ethics Code provides a common set of principles and standards upon which psychologists build their professional and scientific work.

This Ethics Code is intended to provide specific standards to cover most situations encountered by psychologists. It has as its goals the welfare and protection of the individuals and groups with whom psychologists work and the education of members, students, and the public regarding ethical standards of the discipline.

The development of a dynamic set of ethical standards for psychologists' work-related conduct requires a personal commitment and lifelong effort to act ethically; to encourage ethical behavior by students, supervisees, employees, and colleagues; and to consult with others concerning ethical problems.

GENERAL PRINCIPLES

This section consists of General Principles. General Principles, as opposed to Ethical Standards, are aspirational in nature. Their intent is to guide and inspire psychologists toward the very highest ethical ideals of the profession. General Principles, in contrast to Ethical Standards, do not represent obligations and should not form the basis for imposing sanctions. Relying upon General Principles for either of these reasons distorts both their meaning and purpose.

Principle A: Beneficence and Nonmaleficence

Psychologists strive to benefit those with whom they work and take care to do no harm. In their professional actions, psychologists seek to safeguard the welfare and rights of those with whom they interact professionally and other affected persons, and the welfare of animal subjects of research. When conflicts occur among psychologists' obligations or concerns, they attempt to resolve these conflicts in a responsible fashion that avoids or minimizes harm. Because psychologists' scientific and professional judgments and actions may affect the lives of others, they are alert to and guard against personal, financial, social, organizational, or political factors that might lead to misuse of their influence. Psychologists strive to be aware of the possible effect of their own physical and mental health on their ability to help those with whom they work.

Principle B: Fidelity and Responsibility

Psychologists establish relationships of trust with those with whom they work. They are aware of their professional and scientific responsibilities to society and to the specific communities in which they work. Psychologists uphold professional standards of conduct, clarify their professional roles and obligations, accept appropriate responsibility for their behavior, and seek to manage conflicts of interest that could lead to exploitation or harm. Psychologists consult with, refer to, or cooperate with other professionals and institutions to the extent needed to serve the best interests of those with whom they work. They are concerned about the ethical compliance of their colleagues' scientific and professional conduct. Psychologists strive to contribute a portion of their professional time for little or no compensation or personal advantage.

Principle C: Integrity

Psychologists seek to promote accuracy, honesty, and truthfulness in the science, teaching, and practice of psychology. In these activities psychologists do not steal, cheat, or engage in fraud, subterfuge, or intentional misrepresentation of fact. Psychologists strive to keep their promises and to avoid unwise or unclear commitments. In situations in which deception may be ethically justifiable to maximize benefits and minimize harm, psychologists have a serious obligation to consider the need for, the possible consequences of, and their responsibility to correct any resulting mistrust or other harmful effects that arise from the use of such techniques.

Principle D: Justice

Psychologists recognize that fairness and justice entitle all persons to access to and benefit from the contributions of psychology and to equal quality in the processes, procedures, and services being conducted by psychologists. Psychologists exercise reasonable judgment and take precautions to ensure that their potential biases, the boundaries of their competence, and the limitations of their expertise do not lead to or condone unjust practices.

Principle E: Respect for People's Rights and Dignity

Psychologists respect the dignity and worth of all people, and the rights of individuals to privacy, confidentiality, and self-determination. Psychologists are aware that special safeguards may be necessary to protect the rights and welfare of persons or communities whose vulnerabilities impair autonomous decision making. Psychologists are aware of and respect cultural, individual, and role differences, including those based on age, gender, gender identity, race, ethnicity, culture, national origin, religion, sexual orientation, disability, language, and socioeconomic status and consider these factors when working with members of such groups. Psychologists try to eliminate the effect on their work of biases based on those factors, and they do not knowingly participate in or condone activities of others based upon such prejudices.

ETHICAL STANDARDS

1. Resolving Ethical Issues

1.01 MISUSE OF PSYCHOLOGISTS' WORK

If psychologists learn of misuse or misrepresentation of their work, they take reasonable steps to correct or minimize the misuse or misrepresentation.

1.02 CONFLICTS BETWEEN ETHICS AND LAW, REGULATIONS, OR OTHER GOVERNING LEGAL AUTHORITY

If psychologists' ethical responsibilities conflict with law, regulations, or other governing legal authority, psychologists make known their commitment to the Ethics Code and take steps to resolve the conflict. If the conflict is unresolvable via such means, psychologists may adhere to the requirements of the law, regulations, or other governing legal authority.

1.03 CONFLICTS BETWEEN ETHICS AND ORGANIZATIONAL DEMANDS

If the demands of an organization with which psychologists are affiliated or for whom they are working conflict with this Ethics Code, psychologists clarify the nature of the conflict, make known their commitment to the Ethics Code, and to the extent feasible, resolve the conflict in a way that permits adherence to the Ethics Code.

1.04 INFORMAL RESOLUTION OF ETHICAL VIOLATIONS

When psychologists believe that there may have been an ethical violation by another psychologist, they attempt to resolve the issue by bringing it to the attention of that individual, if an informal resolution appears appropriate and the intervention does not violate any confidentiality rights that may be involved. (See also Standards 1.02, Conflicts Between Ethics and Law, Regulations, or Other Governing Legal Authority, and 1.03, Conflicts Between Ethics and Organizational Demands.)

1.05 REPORTING ETHICAL VIOLATIONS

If an apparent ethical violation has substantially harmed or is likely to substantially harm a person or organization and is not appropriate for informal resolution under Standard 1.04, Informal Resolution of Ethical Violations, or is not resolved properly in that fashion, psychologists take further action appropriate to the situation. Such action might include referral to state or national committees on professional ethics, to state licensing boards, or to the appropriate institutional authorities. This standard does not apply when an intervention would violate confidentiality rights or when psychologists have been retained to review the work of another psychologist whose professional conduct is in question. (See also Standard 1.02, Conflicts Between Ethics and Law, Regulations, or Other Governing Legal Authority.)

1.06 COOPERATING WITH ETHICS COMMITTEES

Psychologists cooperate in ethics investigations, proceedings, and resulting requirements of the APA or any affiliated state psychological association to which they belong. In doing so, they address any confidentiality issues. Failure to cooperate is itself an ethics violation. However, making a request for deferment of adjudication of an ethics complaint pending the outcome of litigation does not alone constitute noncooperation.

1.07 IMPROPER COMPLAINTS

Psychologists do not file or encourage the filing of ethics complaints that are made with reckless disregard for or willful ignorance of facts that would disprove the allegation.

1.08 UNFAIR DISCRIMINATION AGAINST COMPLAINANTS AND RESPONDENTS

Psychologists do not deny persons employment, advancement, admissions to academic or other programs, tenure, or promotion, based solely upon their having made or their being the subject of an ethics complaint. This does not preclude taking action based upon the outcome of such proceedings or considering other appropriate information.

2. Competence

2.01 BOUNDARIES OF COMPETENCE

(a) Psychologists provide services, teach, and conduct research with populations and in areas only within the boundaries of their competence, based on their education, training, supervised experience, consultation, study, or professional experience.

(b) Where scientific or professional knowledge in the discipline of psychology establishes that an understanding of factors associated with age, gender, gender identity, race, ethnicity, culture, national origin, religion, sexual orientation, disability, language, or socioeconomic status is essential for effective implementation of their services or research, psychologists have or obtain the training, experience, consultation, or supervision necessary to ensure the competence of their services, or they make appropriate referrals, except as provided in Standard 2.02, Providing Services in Emergencies.

(c) Psychologists planning to provide services, teach, or conduct research involving populations, areas, techniques, or technologies new to them undertake relevant education, training, supervised experience, consultation, or study.

(d) When psychologists are asked to provide services to individuals for whom appropriate mental health services are not available and for which psychologists have not obtained the competence necessary, psychologists with closely related prior training or experience may provide such services in order to ensure that services are not denied if they make a reasonable effort to obtain the competence required by using relevant research, training, consultation, or study.

(e) In those emerging areas in which generally recognized standards for preparatory training do not yet exist, psychologists nevertheless take reasonable steps to ensure the competence of their work and to protect clients/patients, students, supervisees, research participants, organizational clients, and others from harm.

(f) When assuming forensic roles, psychologists are or become reasonably familiar with the judicial or administrative rules governing their roles.

2.02 PROVIDING SERVICES IN EMERGENCIES

In emergencies, when psychologists provide services to individuals for whom other mental health services are not available and for which psychologists have not obtained the necessary training, psychologists may provide such services in order to ensure that services are not denied. The services are discontinued as soon as the emergency has ended or appropriate services are available.

2.03 MAINTAINING COMPETENCE

Psychologists undertake ongoing efforts to develop and maintain their competence.

2.04 BASES FOR SCIENTIFIC AND PROFESSIONAL JUDGMENTS

Psychologists' work is based upon established scientific and professional knowledge of the discipline. (See also Standards 2.01e, Boundaries of Competence, and 10.01b, Informed Consent to Therapy.)

2.05 DELEGATION OF WORK TO OTHERS

Psychologists who delegate work to employees, supervisees, or research or teaching assistants or who use the services of others, such as interpreters, take reasonable steps to (1) avoid delegating such work to persons who have a multiple relationship with those being served that would likely lead to exploitation or loss of objectivity; (2) authorize only those responsibilities that such persons can be expected to perform competently on the basis of their education, training, or experience, either independently or with the level of supervision being provided; and (3) see that such persons perform these services competently. (See also Standards 2.02, Providing Services in Emergencies; 3.05, Multiple Relationships; 4.01, Maintaining Confidentiality; 9.01, Bases for Assessments; 9.02, Use of Assessments; 9.03, Informed Consent in Assessments; and 9.07, Assessment by Unqualified Persons.)

2.06 PERSONAL PROBLEMS AND CONFLICTS

(a) Psychologists refrain from initiating an activity when they know or should know that there is a substantial likelihood that their personal problems will prevent them from performing their work-related activities in a competent manner.

(b) When psychologists become aware of personal problems that may interfere with their performing work-related duties adequately, they take appropriate measures, such as obtaining professional consultation or assistance, and determine whether they should limit, suspend, or terminate their work-related duties. (See also Standard 10.10, Terminating Therapy.)

3. Human Relations

3.01 UNFAIR DISCRIMINATION

In their work-related activities, psychologists do not engage in unfair discrimination based on age, gender, gender identity, race, ethnicity, culture, national origin, religion, sexual orientation, disability, socioeconomic status, or any basis proscribed by law.

3.02 SEXUAL HARASSMENT

Psychologists do not engage in sexual harassment. Sexual harassment is sexual solicitation, physical advances, or verbal or nonverbal conduct that is sexual in nature, that occurs in connection with the psychologist's activities or roles as a psychologist, and that either (1) is unwelcome, is offensive, or creates a hostile workplace or educational environment, and the psychologist knows or is told this or (2) is sufficiently severe or intense to be abusive to a reasonable person in the context. Sexual harassment can consist of a single intense or severe act or of multiple persistent or pervasive acts. (See also Standard 1.08, Unfair Discrimination Against Complainants and Respondents.)

3.03 OTHER HARASSMENT

Psychologists do not knowingly engage in behavior that is harassing or demeaning to persons with whom they interact in their work based on factors such as those persons' age, gender, gender identity, race, ethnicity, culture, national origin, religion, sexual orientation, disability, language, or socioeconomic status.

3.04 AVOIDING HARM

Psychologists take reasonable steps to avoid harming their clients/patients, students, supervisees, research participants, organizational clients, and others with whom they work, and to minimize harm where it is foreseeable and unavoidable.

3.05 MULTIPLE RELATIONSHIPS

(a) A multiple relationship occurs when a psychologist is in a professional role with a person and (1) at the same time is in another role with the same person, (2) at the same time is in a relationship with a person closely associated with or related to the person with whom the psychologist has the professional relationship, or (3) promises to enter into another relationship in the future with the person or a person closely associated with or related to the person.

A psychologist refrains from entering into a multiple relationship if the multiple relationship could reasonably be expected to impair the psychologist's objectivity, competence, or effectiveness in performing his or her functions as a psychologist, or otherwise risks exploitation or harm to the person with whom the professional relationship exists.

Multiple relationships that would not reasonably be expected to cause impairment or risk exploitation or harm are not unethical.

(b) If a psychologist finds that, due to unforeseen factors, a potentially harmful multiple relationship has arisen, the psychologist takes reasonable steps to resolve it with due regard for the best interests of the affected person and maximal compliance with the Ethics Code.

(c) When psychologists are required by law, institutional policy, or extraordinary circumstances to serve in more than one role in judicial or administrative proceedings, at the outset they clarify role expectations and the extent of confidentiality and thereafter as changes occur. (See also Standards 3.04, Avoiding Harm, and 3.07, Third-Party Requests for Services.)

3.06 CONFLICT OF INTEREST

Psychologists refrain from taking on a professional role when personal, scientific, professional, legal, financial, or other interests or relationships could reasonably be expected to (1) impair their objectivity, competence, or effectiveness in performing their functions as psychologists or (2) expose the person or organization with whom the professional relationship exists to harm or exploitation.

3.07 THIRD-PARTY REQUESTS FOR SERVICES

When psychologists agree to provide services to a person or entity at the request of a third party, psychologists attempt to clarify at the outset of the service the nature of the relationship with all individuals or organizations involved. This clarification includes the role of the psychologist (e.g., therapist, consultant, diagnostician, or expert witness), an identification of who is the client, the probable uses of the services provided or the information obtained, and the fact that there may be limits to confidentiality. (See also Standards 3.05, Multiple Relationships, and 4.02, Discussing the Limits of Confidentiality.)

3.08 EXPLOITATIVE RELATIONSHIPS

Psychologists do not exploit persons over whom they have supervisory, evaluative, or other authority such as clients/patients, students, supervisees, research participants, and employees. (See also Standards 3.05, Multiple Relationships; 6.04, Fees and Financial Arrangements; 6.05, Barter With Clients/Patients; 7.07, Sexual Relationships With Students and Supervisees; 10.05, Sexual Intimacies With Current Therapy Clients/Patients; 10.06, Sexual Intimacies With Relatives or Significant Others of Current Therapy Clients/Patients; 10.07, Therapy With Former Sexual Partners; and 10.08, Sexual Intimacies With Former Therapy Clients/Patients.)

3.09 COOPERATION WITH OTHER PROFESSIONALS

When indicated and professionally appropriate, psychologists cooperate with other professionals in order to serve their clients/patients effectively and appropriately. (See also Standard 4.05, Disclosures.)

3.10 INFORMED CONSENT

(a) When psychologists conduct research or provide assessment, therapy, counseling, or consulting services in person or via electronic transmission or other forms of communication, they obtain the informed consent of the individual or individuals using language that is reasonably understandable to that person or persons except when conducting such activities without consent is mandated by law or governmental regulation or as otherwise provided in this Ethics Code. (See also Standards 8.02, Informed Consent to Research; 9.03, Informed Consent in Assessments; and 10.01, Informed Consent to Therapy.)

(b) For persons who are legally incapable of giving informed consent, psychologists nevertheless (1) provide an appropriate explanation, (2) seek the individual's assent, (3) consider such persons' preferences and best interests, and (4) obtain appropriate permission from a legally authorized person, if such substitute consent is permitted or required by law. When consent by a legally authorized person is not permitted or required by law, psychologists take reasonable steps to protect the individual's rights and welfare.

(c) When psychological services are court ordered or otherwise mandated, psychologists inform the individual of the nature of the anticipated services, including whether the services are court ordered or mandated and any limits of confidentiality, before proceeding.

(d) Psychologists appropriately document written or oral consent, permission, and assent. (See also Standards 8.02, Informed Consent to Research; 9.03, Informed Consent in Assessments; and 10.01, Informed Consent to Therapy.)

3.11 PSYCHOLOGICAL SERVICES DELIVERED TO OR THROUGH ORGANIZATIONS

(a) Psychologists delivering services to or through organizations provide information beforehand to clients and when appropriate those directly affected by the services about (1) the nature and objectives of the services, (2) the intended recipients, (3) which of the individuals are clients, (4) the relationship the psychologist will have with each person and the organization, (5) the probable uses of services provided and information obtained, (6) who will have access to the information, and (7) limits of confidentiality. As soon as feasible, they provide information about the results and conclusions of such services to appropriate persons.

(b) If psychologists will be precluded by law or by organizational roles from providing such information to particular individuals or groups, they so inform those individuals or groups at the outset of the service.

3.12 INTERRUPTION OF PSYCHOLOGICAL SERVICES

Unless otherwise covered by contract, psychologists make reasonable efforts to plan for facilitating services in the event that psychological services are interrupted by factors such as the psychologist's illness, death, unavailability, relocation, or retirement or by the client's/patient's relocation or financial limitations. (See also Standard 6.02c, Maintenance, Dissemination, and Disposal of Confidential Records of Professional and Scientific Work.)

4. Privacy and Confidentiality

4.01 MAINTAINING CONFIDENTIALITY

Psychologists have a primary obligation and take reasonable precautions to protect confidential information obtained through or stored in any medium, recognizing that the extent and limits of confidentiality may be regulated by law or established by institutional rules or professional or scientific relationship. (See also Standard 2.05, Delegation of Work to Others.)

4.02 DISCUSSING THE LIMITS OF CONFIDENTIALITY

(a) Psychologists discuss with persons (including, to the extent feasible, persons who are legally incapable of giving informed consent and their legal representatives) and organizations with whom they establish a scientific or professional relationship (1) the relevant limits of confidentiality and (2) the foreseeable uses of the information generated through their psychological activities. (See also Standard 3.10, Informed Consent.)

(b) Unless it is not feasible or is contraindicated, the discussion of confidentiality occurs at the outset of the relationship and thereafter as new circumstances may warrant.

(c) Psychologists who offer services, products, or information via electronic transmission inform clients/patients of the risks to privacy and limits of confidentiality.

4.03 RECORDING

Before recording the voices or images of individuals to whom they provide services, psychologists obtain permission from all such persons or their legal representatives. (See also Standards 8.03, Informed Consent for Recording Voices and Images in Research; 8.05, Dispensing With Informed Consent for Research; and 8.07, Deception in Research.)

4.04 MINIMIZING INTRUSIONS ON PRIVACY

(a) Psychologists include in written and oral reports and consultations, only information germane to the purpose for which the communication is made.

(b) Psychologists discuss confidential information obtained in their work only for appropriate scientific or professional purposes and only with persons clearly concerned with such matters.

4.05 DISCLOSURES

(a) Psychologists may disclose confidential information with the appropriate consent of the organizational client, the individual client/patient, or another legally authorized person on behalf of the client/patient unless prohibited by law.

(b) Psychologists disclose confidential information without the consent of the individual only as mandated by law, or where permitted by law for a valid purpose such as to (1) provide needed professional services; (2) obtain appropriate professional consultations; (3) protect the client/patient, psychologist, or others from harm; or (4) obtain payment for services from a client/patient, in which instance disclosure is limited to the minimum that is necessary to achieve the purpose. (See also Standard 6.04e, Fees and Financial Arrangements.)

4.06 CONSULTATIONS

When consulting with colleagues, (1) psychologists do not disclose confidential information that reasonably could lead to the identification of a client/patient, research participant, or other person or organization with whom they have a confidential relationship unless they have obtained the prior consent of the person or organization or the disclosure cannot be avoided, and (2) they disclose information only to the extent necessary to achieve the purposes of the consultation. (See also Standard 4.01, Maintaining Confidentiality.)

4.07 USE OF CONFIDENTIAL INFORMATION FOR DIDACTIC OR OTHER PURPOSES

Psychologists do not disclose in their writings, lectures, or other public media, confidential, personally identifiable information concerning their clients/patients, students, research participants, organizational clients, or other recipients of their services that they obtained during the course of their work, unless (1) they take reasonable steps to disguise the person or organization, (2) the person or organization has consented in writing, or (3) there is legal authorization for doing so.

5. Advertising and Other Public Statements

5.01 AVOIDANCE OF FALSE OR DECEPTIVE STATEMENTS

(a) Public statements include but are not limited to paid or unpaid advertising, product endorsements, grant applications, licensing applications, other credentialing applications, brochures, printed matter, directory listings, personal resumes or curricula vitae, or comments for use in media such as print or electronic transmission, statements in legal proceedings, lectures and public oral presentations, and published materials. Psychologists do not knowingly make public statements that are false, deceptive, or fraudulent concerning their research, practice, or other work activities or those of persons or organizations with which they are affiliated.

(b) Psychologists do not make false, deceptive, or fraudulent statements concerning (1) their training, experience, or competence; (2) their academic degrees; (3) their credentials; (4) their institutional or association affiliations; (5) their services; (6) the scientific or clinical basis for, or results or degree of success of, their services; (7) their fees; or (8) their publications or research findings.

(c) Psychologists claim degrees as credentials for their health services only if those degrees (1) were earned from a regionally accredited educational institution or (2) were the basis for psychology licensure by the state in which they practice.

5.02 STATEMENTS BY OTHERS

(a) Psychologists who engage others to create or place public statements that promote their professional practice, products, or activities retain professional responsibility for such statements.

(b) Psychologists do not compensate employees of press, radio, television, or other communication media in return for publicity in a news item. (See also Standard 1.01, Misuse of Psychologists' Work.)

(c) A paid advertisement relating to psychologists' activities must be identified or clearly recognizable as such.

5.03 DESCRIPTIONS OF WORKSHOPS AND NON-DEGREE-GRANTING EDUCATIONAL PROGRAMS

To the degree to which they exercise control, psychologists responsible for announcements, catalogs, brochures, or advertisements describing workshops, seminars, or other non-degree-granting educational programs ensure that they accurately describe the audience for which the program is intended, the educational objectives, the presenters, and the fees involved.

5.04 MEDIA PRESENTATIONS

When psychologists provide public advice or comment via print, Internet, or other electronic transmission, they take precautions to ensure that statements (1) are based on their professional knowledge, training, or experience in accord with appropriate psychological literature and practice; (2) are otherwise consistent with this Ethics Code; and (3) do not indicate that a professional relationship has been established with the recipient. (See also Standard 2.04, Bases for Scientific and Professional Judgments.)

5.05 TESTIMONIALS

Psychologists do not solicit testimonials from current therapy clients/patients or other persons who because of their particular circumstances are vulnerable to undue influence.

5.06 IN-PERSON SOLICITATION

Psychologists do not engage, directly or through agents, in uninvited in-person solicitation of business from actual or potential therapy clients/patients or other persons who because of their particular circumstances are vulnerable to undue influence. However, this prohibition does not preclude (1) attempting to implement appropriate collateral contacts for the purpose of benefiting an already engaged therapy client/patient or (2) providing disaster or community outreach services.

6. Record Keeping and Fees

6.01 DOCUMENTATION OF PROFESSIONAL AND SCIENTIFIC WORK AND MAINTENANCE OF RECORDS

Psychologists create, and to the extent the records are under their control, maintain, disseminate, store, retain, and dispose of records and data relating to their professional and scientific work in order to (1) facilitate provision of services later by them or by other professionals, (2) allow for replication of research design and analyses, (3) meet institutional requirements, (4) ensure accuracy of billing and payments, and (5) ensure compliance with law. (See also Standard 4.01, Maintaining Confidentiality.)

6.02 MAINTENANCE, DISSEMINATION, AND DISPOSAL OF CONFIDENTIAL RECORDS OF PROFESSIONAL AND SCIENTIFIC WORK

(a) Psychologists maintain confidentiality in creating, storing, accessing, transferring, and disposing of records under their control, whether these are written, automated, or in any other medium. (See also Standards 4.01, Maintaining Confidentiality, and 6.01, Documentation of Professional and Scientific Work and Maintenance of Records.)

(b) If confidential information concerning recipients of psychological services is entered into databases or systems of records available to persons whose access has not been consented to by the recipient, psychologists use coding or other techniques to avoid the inclusion of personal identifiers.

(c) Psychologists make plans in advance to facilitate the appropriate transfer and to protect the confidentiality of records and data in the event of psychologists' withdrawal from positions or practice. (See also Standards 3.12, Interruption of Psychological Services, and 10.09, Interruption of Therapy.)

6.03 WITHHOLDING RECORDS FOR NONPAYMENT

Psychologists may not withhold records under their control that are requested and needed for a client's/patient's emergency treatment solely because payment has not been received.

6.04 FEES AND FINANCIAL ARRANGEMENTS

(a) As early as is feasible in a professional or scientific relationship, psychologists and recipients of psychological services reach an agreement specifying compensation and billing arrangements.

(b) Psychologists' fee practices are consistent with law.

(c) Psychologists do not misrepresent their fees.

(d) If limitations to services can be anticipated because of limitations in financing, this is discussed with the recipient of services as early as is feasible. (See also Standards 10.09, Interruption of Therapy, and 10.10, Terminating Therapy.)

(e) If the recipient of services does not pay for services as agreed, and if psychologists intend to use collection agencies or legal measures to collect the fees, psychologists first inform the person that such measures will be taken and provide that person an opportunity to make prompt payment. (See also Standards 4.05, Disclosures; 6.03, Withholding Records for Nonpayment; and 10.01, Informed Consent to Therapy.)

6.05 BARTER WITH CLIENTS/PATIENTS

Barter is the acceptance of goods, services, or other nonmonetary remuneration from clients/patients in return for psychological services. Psychologists may barter only if (1) it is not clinically contraindicated, and (2) the resulting arrangement is not exploitative. (See also Standards 3.05, Multiple Relationships, and 6.04, Fees and Financial Arrangements.)

6.06 ACCURACY IN REPORTS TO PAYORS AND FUNDING SOURCES

In their reports to payors for services or sources of research funding, psychologists take reasonable steps to ensure the accurate reporting of the nature of the service provided or research conducted, the fees, charges, or payments, and where applicable, the identity of the provider, the findings, and the diagnosis. (See also Standards 4.01, Maintaining Confidentiality; 4.04, Minimizing Intrusions on Privacy; and 4.05, Disclosures.)

6.07 REFERRALS AND FEES

When psychologists pay, receive payment from, or divide fees with another professional, other than in an employer-employee relationship, the payment to each is based on the services provided (clinical, consultative, administrative, or other) and is not based on the referral itself. (See also Standard 3.09, Cooperation With Other Professionals.)

7. Education and Training

7.01 DESIGN OF EDUCATION AND TRAINING PROGRAMS

Psychologists responsible for education and training programs take reasonable steps to ensure that the programs are designed to provide the appropriate knowledge and proper experiences, and to meet the requirements for licensure, certification, or other goals for which claims are made by the program. (See also Standard 5.03, Descriptions of Workshops and Non-Degree-Granting Educational Programs.)

7.02 DESCRIPTIONS OF EDUCATION AND TRAINING PROGRAMS

Psychologists responsible for education and training programs take reasonable steps to ensure that there is a current and accurate description of the program content (including participation in required course- or program-related counseling, psychotherapy, experiential groups, consulting projects, or community service), training goals and objectives, stipends and benefits, and requirements that must be met for satisfactory completion of the program. This information must be made readily available to all interested parties.

7.03 ACCURACY IN TEACHING

(a) Psychologists take reasonable steps to ensure that course syllabi are accurate regarding the subject matter to be covered, bases for evaluating progress, and the nature of course experiences. This standard does not preclude an instructor from modifying course content or requirements when the instructor considers it pedagogically necessary or desirable, so long as students are made aware of these modifications in a manner that enables them to fulfill course requirements. (See also Standard 5.01, Avoidance of False or Deceptive Statements.)

(b) When engaged in teaching or training, psychologists present psychological information accurately. (See also Standard 2.03, Maintaining Competence.)

7.04 STUDENT DISCLOSURE OF PERSONAL INFORMATION

Psychologists do not require students or supervisees to disclose personal information in course- or program-related activities, either orally or in writing, regarding sexual history, history of abuse and neglect, psychological treatment, and relationships with parents, peers, and spouses or significant others except if (1) the program or training facility has clearly identified this requirement in its admissions and program materials or (2) the information is necessary to evaluate or obtain assistance for students whose personal problems could reasonably be judged to be preventing them from performing their training- or professionally related activities in a competent manner or posing a threat to the students or others.

7.05 MANDATORY INDIVIDUAL OR GROUP THERAPY

(a) When individual or group therapy is a program or course requirement, psychologists responsible for that program allow students in undergraduate and graduate programs the option of selecting such therapy from practitioners unaffiliated with the program. (See also Standard 7.02, Descriptions of Education and Training Programs.)

(b) Faculty who are or are likely to be responsible for evaluating students' academic performance do not themselves provide that therapy. (See also Standard 3.05, Multiple Relationships.)

7.06 ASSESSING STUDENT AND SUPERVISEE PERFORMANCE

(a) In academic and supervisory relationships, psychologists establish a timely and specific process for providing feedback to students and supervisees. Information regarding the process is provided to the student at the beginning of supervision.

(b) Psychologists evaluate students and supervisees on the basis of their actual performance on relevant and established program requirements.

7.07 SEXUAL RELATIONSHIPS WITH STUDENTS AND SUPERVISEES

Psychologists do not engage in sexual relationships with students or supervisees who are in their department, agency, or training center or over whom psychologists have or are likely to have evaluative authority. (See also Standard 3.05, Multiple Relationships.)

8. Research and Publication

8.01 INSTITUTIONAL APPROVAL

When institutional approval is required, psychologists provide accurate information about their research proposals and obtain approval prior to conducting the research. They conduct the research in accordance with the approved research protocol.

8.02 INFORMED CONSENT TO RESEARCH

(a) When obtaining informed consent as required in Standard 3.10, Informed Consent, psychologists inform participants about (1) the purpose of the research, expected duration, and procedures; (2) their right to decline to participate and to withdraw from the research once participation has begun; (3) the foreseeable consequences of declining or withdrawing; (4) reasonably foreseeable factors that may be expected to influence their willingness to participate such as potential risks, discomfort, or adverse effects; (5) any prospective research benefits; (6) limits of confidentiality; (7) incentives for participation; and (8) whom to contact for questions about the research and research participants' rights. They provide opportunity for the prospective participants to ask questions and receive answers. (See also Standards 8.03, Informed Consent for Recording Voices and Images in Research; 8.05, Dispensing With Informed Consent for Research; and 8.07, Deception in Research.)

(b) Psychologists conducting intervention research involving the use of experimental treatments clarify to participants at the outset of the research (1) the experimental nature of the treatment; (2) the services that will or will not be available to the control group(s) if appropriate; (3) the means by which assignment to treatment and control groups will be made; (4) available treatment alternatives if an individual does not wish to participate in the research or wishes to withdraw once a study has begun; and (5) compensation for or monetary costs of participating including, if appropriate, whether reimbursement from the participant or a third-party payor will be sought. (See also Standard 8.02a, Informed Consent to Research.)

8.03 INFORMED CONSENT FOR RECORDING VOICES AND IMAGES IN RESEARCH

Psychologists obtain informed consent from research participants prior to recording their voices or images for data collection unless (1) the research consists solely of naturalistic observations in public places, and it is not anticipated that the recording will be used in a manner that could cause personal identification or harm, or (2) the research design includes deception, and consent for the use of the recording is obtained during debriefing. (See also Standard 8.07, Deception in Research.)

8.04 CLIENT/PATIENT, STUDENT, AND SUBORDINATE RESEARCH PARTICIPANTS

(a) When psychologists conduct research with clients/patients, students, or subordinates as participants, psychologists take steps to protect the prospective participants from adverse consequences of declining or withdrawing from participation.

(b) When research participation is a course requirement or an opportunity for extra credit, the prospective participant is given the choice of equitable alternative activities.

8.05 DISPENSING WITH INFORMED CONSENT FOR RESEARCH

Psychologists may dispense with informed consent only (1) where research would not reasonably be assumed to create distress or harm and involves (a) the study of normal educational practices, curricula, or classroom management methods conducted in educational settings; (b) only anonymous questionnaires, naturalistic observations, or archival research for which disclosure of responses would not place participants at risk of criminal or civil liability or damage their financial standing, employability, or reputation, and confidentiality is protected; or (c) the study of factors related to job or organization effectiveness conducted in organizational settings for which there is no risk to participants' employability, and confidentiality is protected or (2) where otherwise permitted by law or federal or institutional regulations.

8.06 OFFERING INDUCEMENTS FOR RESEARCH PARTICIPATION

(a) Psychologists make reasonable efforts to avoid offering excessive or inappropriate financial or other inducements for research participation when such inducements are likely to coerce participation.

(b) When offering professional services as an inducement for research participation, psychologists clarify the nature of the services, as well as the risks, obligations, and limitations. (See also Standard 6.05, Barter With Clients/Patients.)

8.07 DECEPTION IN RESEARCH

(a) Psychologists do not conduct a study involving deception unless they have determined that the use of deceptive techniques is justified by the study's significant prospective scientific, educational, or applied value and that effective nondeceptive alternative procedures are not feasible.

(b) Psychologists do not deceive prospective participants about research that is reasonably expected to cause physical pain or severe emotional distress.

(c) Psychologists explain any deception that is an integral feature of the design and conduct of an experiment to participants as early as is feasible, preferably at the conclusion of their participation, but no later than at the conclusion of the data collection, and permit participants to withdraw their data. (See also Standard 8.08, Debriefing.)

8.08 DEBRIEFING

(a) Psychologists provide a prompt opportunity for participants to obtain appropriate information about the nature, results, and conclusions of the research, and they take reasonable steps to correct any misconceptions that participants may have of which the psychologists are aware.

(b) If scientific or humane values justify delaying or withholding this information, psychologists take reasonable measures to reduce the risk of harm.

(c) When psychologists become aware that research procedures have harmed a participant, they take reasonable steps to minimize the harm.

8.09 HUMANE CARE AND USE OF ANIMALS IN RESEARCH

(a) Psychologists acquire, care for, use, and dispose of animals in compliance with current federal, state, and local laws and regulations, and with professional standards.

(b) Psychologists trained in research methods and experienced in the care of laboratory animals supervise all procedures involving animals and are responsible for ensuring appropriate consideration of their comfort, health, and humane treatment.

(c) Psychologists ensure that all individuals under their supervision who are using animals have received instruction in research methods and in the care, maintenance, and handling of the species being used, to the extent appropriate to their role. (See also Standard 2.05, Delegation of Work to Others.)

(d) Psychologists make reasonable efforts to minimize the discomfort, infection, illness, and pain of animal subjects.

(e) Psychologists use a procedure subjecting animals to pain, stress, or privation only when an alternative procedure is unavailable and the goal is justified by its prospective scientific, educational, or applied value.

(f) Psychologists perform surgical procedures under appropriate anesthesia and follow techniques to avoid infection and minimize pain during and after surgery.

(g) When it is appropriate that an animal's life be terminated, psychologists proceed rapidly, with an effort to minimize pain and in accordance with accepted procedures.

8.10 REPORTING RESEARCH RESULTS

(a) Psychologists do not fabricate data. (See also Standard 5.01a, Avoidance of False or Deceptive Statements.)

(b) If psychologists discover significant errors in their published data, they take reasonable steps to correct such errors in a correction, retraction, erratum, or other appropriate publication means.

8.11 PLAGIARISM

Psychologists do not present portions of another's work or data as their own, even if the other work or data source is cited occasionally.

8.12 PUBLICATION CREDIT

(a) Psychologists take responsibility and credit, including authorship credit, only for work they have actually performed or to which they have substantially contributed. (See also Standard 8.12b, Publication Credit.)

(b) Principal authorship and other publication credits accurately reflect the relative scientific or professional contributions of the individuals involved, regardless of their relative status. Mere possession of an institutional position, such as department chair, does not justify authorship credit. Minor contributions to the research or to the writing for publications are acknowledged appropriately, such as in footnotes or in an introductory statement.

(c) Except under exceptional circumstances, a student is listed as principal author on any multiple-authored article that is substantially based on the student's doctoral dissertation. Faculty advisors discuss publication credit with students as early as feasible and throughout the research and publication process as appropriate. (See also Standard 8.12b, Publication Credit.)

8.13 DUPLICATE PUBLICATION OF DATA

Psychologists do not publish, as original data, data that have been previously published. This does not preclude republishing data when they are accompanied by proper acknowledgment.

8.14 SHARING RESEARCH DATA FOR VERIFICATION

(a) After research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release. This does not preclude psychologists from requiring that such individuals or groups be responsible for costs associated with the provision of such information.

(b) Psychologists who request data from other psychologists to verify the substantive claims through reanalysis may use shared data only for the declared purpose. Requesting psychologists obtain prior written agreement for all other uses of the data.

8.15 REVIEWERS

Psychologists who review material submitted for presentation, publication, grant, or research proposal review respect the confidentiality of and the proprietary rights in such information of those who submitted it.

9. Assessment

9.01 BASES FOR ASSESSMENTS

(a) Psychologists base the opinions contained in their recommendations, reports, and diagnostic or evaluative statements, including forensic testimony, on information and techniques sufficient to substantiate their findings. (See also Standard 2.04, Bases for Scientific and Professional Judgments.)

(b) Except as noted in 9.01c, psychologists provide opinions of the psychological characteristics of individuals only after they have conducted an examination of the individuals adequate to support their statements or conclusions. When, despite reasonable efforts, such an examination is not practical, psychologists document the efforts they made and the result of those efforts, clarify the probable impact of their limited information on the reliability and validity of their opinions, and appropriately limit the nature and extent of their conclusions or recommendations. (See also Standards 2.01, Boundaries of Competence, and 9.06, Interpreting Assessment Results.)

(c) When psychologists conduct a record review or provide consultation or supervision and an individual examination is not warranted or necessary for the opinion, psychologists explain this and the sources of information on which they based their conclusions and recommendations.

9.02 USE OF ASSESSMENTS

(a) Psychologists administer, adapt, score, interpret, or use assessment techniques, interviews, tests, or instruments in a manner and for purposes that are appropriate in light of the research on or evidence of the usefulness and proper application of the techniques.

(b) Psychologists use assessment instruments whose validity and reliability have been established for use with members of the population tested. When such validity or reliability has not been established, psychologists describe the strengths and limitations of test results and interpretation.

(c) Psychologists use assessment methods that are appropriate to an individual's language preference and competence, unless the use of an alternative language is relevant to the assessment issues.

9.03 INFORMED CONSENT IN ASSESSMENTS

(a) Psychologists obtain informed consent for assessments, evaluations, or diagnostic services, as described in Standard 3.10, Informed Consent, except when (1) testing is mandated by law or governmental regulations; (2) informed consent is implied because testing is conducted as a routine educational, institutional, or organizational activity (e.g., when participants voluntarily agree to assessment when applying for a job); or (3) one purpose of the testing is to evaluate decisional capacity. Informed consent includes an explanation of the nature and purpose of the assessment, fees, involvement of third parties, and limits of confidentiality and sufficient opportunity for the client/patient to ask questions and receive answers.

(b) Psychologists inform persons with questionable capacity to consent or for whom testing is mandated by law or governmental regulations about the nature and purpose of the proposed assessment services, using language that is reasonably understandable to the person being assessed.

(c) Psychologists using the services of an interpreter obtain informed consent from the client/patient to use that interpreter, ensure that confidentiality of test results and test security are maintained, and include in their recommendations, reports, and diagnostic or evaluative statements, including forensic testimony, discussion of any limitations on the data obtained. (See also Standards 2.05, Delegation of Work to Others; 4.01, Maintaining Confidentiality; 9.01, Bases for Assessments; 9.06, Interpreting Assessment Results; and 9.07, Assessment by Unqualified Persons.)

9.04 RELEASE OF TEST DATA

(a) The term *test data* refers to raw and scaled scores, client/patient responses to test questions or stimuli, and psychologists' notes and recordings concerning client/patient statements and behavior during an examination. Those portions of test materials that include client/patient responses are included in the definition of *test data.* Pursuant to a client/patient release, psychologists provide test data to the client/patient or other persons identified in the release. Psychologists may refrain from releasing test data to protect a client/patient or others from substantial harm or misuse or misrepresentation of the data or the test, recognizing that in many instances release of confidential information under these circumstances is regulated by law. (See also Standard 9.11, Maintaining Test Security.)

(b) In the absence of a client/patient release, psychologists provide test data only as required by law or court order.

9.05 TEST CONSTRUCTION

Psychologists who develop tests and other assessment techniques use appropriate psychometric procedures and current scientific or professional knowledge for test design, standardization, validation, reduction or elimination of bias, and recommendations for use.

9.06 INTERPRETING ASSESSMENT RESULTS

When interpreting assessment results, including automated interpretations, psychologists take into account the purpose of the assessment as well as the various test factors, test-taking abilities, and other characteristics of the person being assessed, such as situational, personal, linguistic, and cultural differences, that might affect psychologists' judgments or reduce the accuracy of their interpretations. They indicate any significant limitations of their interpretations. (See also Standards 2.01b and c, Boundaries of Competence, and 3.01, Unfair Discrimination.)

9.07 ASSESSMENT BY UNQUALIFIED PERSONS

Psychologists do not promote the use of psychological assessment techniques by unqualified persons, except when such use is conducted for training purposes with appropriate supervision. (See also Standard 2.05, Delegation of Work to Others.)

9.08 OBSOLETE TESTS AND OUTDATED TEST RESULTS

(a) Psychologists do not base their assessment or intervention decisions or recommendations on data or test results that are outdated for the current purpose.

(b) Psychologists do not base such decisions or recommendations on tests and measures that are obsolete and not useful for the current purpose.

9.09 TEST SCORING AND INTERPRETATION SERVICES

(a) Psychologists who offer assessment or scoring services to other professionals accurately describe the purpose, norms, validity, reliability, and applications of the procedures and any special qualifications applicable to their use.

(b) Psychologists select scoring and interpretation services (including automated services) on the basis of evidence of the validity of the program and procedures as well as on other appropriate considerations. (See also Standard 2.01b and c, Boundaries of Competence.)

(c) Psychologists retain responsibility for the appropriate application, interpretation, and use of assessment instruments, whether they score and interpret such tests themselves or use automated or other services.

9.10 EXPLAINING ASSESSMENT RESULTS

Regardless of whether the scoring and interpretation are done by psychologists, by employees or assistants, or by automated or other outside services, psychologists take reasonable steps to ensure that explanations of results are given to the individual or designated representative unless the nature of the relationship precludes provision of an explanation of results (such as in some organizational consulting, preemployment or security screenings, and forensic evaluations), and this fact has been clearly explained to the person being assessed in advance.

9.11. MAINTAINING TEST SECURITY

The term *test materials* refers to manuals, instruments, protocols, and test questions or stimuli and does not include *test data* as defined in Standard 9.04, Release of Test Data. Psychologists make reasonable efforts to maintain the integrity and security of test materials and other assessment techniques consistent with law and contractual obligations, and in a manner that permits adherence to this Ethics Code.

10. Therapy

10.01 INFORMED CONSENT TO THERAPY

(a) When obtaining informed consent to therapy as required in Standard 3.10, Informed Consent, psychologists inform clients/patients as early as is feasible in the therapeutic relationship about the nature and anticipated course of therapy, fees, involvement of third parties, and limits of confidentiality and provide sufficient opportunity for the client/patient to ask questions and receive answers. (See also Standards 4.02, Discussing the Limits of Confidentiality, and 6.04, Fees and Financial Arrangements.)

(b) When obtaining informed consent for treatment for which generally recognized techniques and procedures have not been established, psychologists inform their clients/patients of the developing nature of the treatment, the potential risks involved, alternative treatments that may be available, and the voluntary nature of their participation. (See also Standards 2.01e, Boundaries of Competence, and 3.10, Informed Consent.)

(c) When the therapist is a trainee and the legal responsibility for the treatment provided resides with the supervisor, the client/patient, as part of the informed consent procedure, is informed that the therapist is in training and is being supervised and is given the name of the supervisor.

10.02 THERAPY INVOLVING COUPLES OR FAMILIES

(a) When psychologists agree to provide services to several persons who have a relationship (such as spouses, significant others, or parents and children), they take reasonable steps to clarify at the outset (1) which of the individuals are clients/patients and (2) the relationship the psychologist will have with each person. This clarification includes the psychologist's role and the probable uses of the services provided or the information obtained. (See also Standard 4.02, Discussing the Limits of Confidentiality.)

(b) If it becomes apparent that psychologists may be called on to perform potentially conflicting roles (such as family therapist and then witness for one party in divorce proceedings), psychologists take reasonable steps to clarify and modify, or withdraw from, roles appropriately. (See also Standard 3.05c, Multiple Relationships.)

10.03 GROUP THERAPY

When psychologists provide services to several persons in a group setting, they describe at the outset the roles and responsibilities of all parties and the limits of confidentiality.

10.04 PROVIDING THERAPY TO THOSE SERVED BY OTHERS

In deciding whether to offer or provide services to those already receiving mental health services elsewhere, psychologists carefully consider the treatment issues and the potential client's/patient's welfare. Psychologists discuss these issues with the client/patient or another legally authorized person on behalf of the client/patient in order to minimize the risk of confusion and conflict, consult with the other service providers when appropriate, and proceed with caution and sensitivity to the therapeutic issues.

10.05 SEXUAL INTIMACIES WITH CURRENT THERAPY CLIENTS/PATIENTS

Psychologists do not engage in sexual intimacies with current therapy clients/patients.

10.06 SEXUAL INTIMACIES WITH RELATIVES OR SIGNIFICANT OTHERS OF CURRENT THERAPY CLIENTS/PATIENTS

Psychologists do not engage in sexual intimacies with individuals they know to be close relatives, guardians, or significant others of current clients/patients. Psychologists do not terminate therapy to circumvent this standard.

10.07 THERAPY WITH FORMER SEXUAL PARTNERS

Psychologists do not accept as therapy clients/patients persons with whom they have engaged in sexual intimacies.

10.08 SEXUAL INTIMACIES WITH FORMER THERAPY CLIENTS/PATIENTS

(a) Psychologists do not engage in sexual intimacies with former clients/patients for at least two years after cessation or termination of therapy.

(b) Psychologists do not engage in sexual intimacies with former clients/patients even after a two-year interval except in the most unusual circumstances. Psychologists who engage in such activity after the two years following cessation or termination of therapy and of having no sexual contact with the former client/patient bear the burden of demonstrating that there has been no exploitation, in light of all relevant factors, including (1) the amount of time that has passed since therapy terminated; (2) the nature, duration, and intensity of the therapy; (3) the circumstances of termination; (4) the client's/patient's personal history; (5) the client's/patient's current mental status; (6) the likelihood of adverse impact on the client/patient; and (7) any statements or actions made by the therapist during the course of therapy suggesting or inviting the possibility of a posttermination sexual or romantic relationship with the client/patient. (See also Standard *3.05, Multiple Relationships.*)

10.09 INTERRUPTION OF THERAPY

When entering into employment or contractual relationships, psychologists make reasonable efforts to provide for orderly and appropriate resolution of responsibility for client/patient care in the event that the employment or contractual relationship ends, with paramount consideration given to the welfare of the client/patient. (See also Standard *3.12, Interruption of Psychological Services.*)

10.10 TERMINATING THERAPY

(a) Psychologists terminate therapy when it becomes reasonably clear that the client/patient no longer needs the service, is not likely to benefit, or is being harmed by continued service.

(b) Psychologists may terminate therapy when threatened or otherwise endangered by the client/patient or another person with whom the client/patient has a relationship.

(c) Except where precluded by the actions of clients/patients or third-party payors, prior to termination psychologists provide pretermination counseling and suggest alternative service providers as appropriate.

HISTORY AND EFFECTIVE DATE

This version of the APA Ethics Code was adopted by the American Psychological Association's Council of Representatives during its meeting, August 21, 2002, and is effective beginning June 1, 2003. Inquiries concerning the substance or interpretation of the APA Ethics Code should be addressed to the Director, Office of Ethics, American Psychological Association, 750 First Street, NE, Washington, DC 20002–4242. The Ethics Code and information regarding the Code can be found on the APA web site, <http://www.apa.org/ethics.> The standards in this Ethics Code will be used to adjudicate complaints brought concerning alleged conduct occurring on or after the effective date. Complaints regarding conduct occurring prior to the effective date will be adjudicated on the basis of the version of the Ethics Code that was in effect at the time the conduct occurred.

The APA has previously published its Ethics Code as follows:

American Psychological Association (1953). Ethical standards of psychologists. Washington, DC: Author.

American Psychological Association (1959). Ethical standards of psychologists. American Psychologist, 14, 279–282.

American Psychological Association (1963). Ethical standards of psychologists. American Psychologist, 18, 56–60.

American Psychological Association (1968). Ethical standards of psychologists. American Psychologist, 23, 357–361.

American Psychological Association (1977, March). Ethical standards of psychologists. APA Monitor, 22–23.

American Psychological Association (1979). Ethical standards of psychologists. Washington, DC: Author.

American Psychological Association (1981). Ethical principles of psychologists. American Psychologist, 36, 633–638.

American Psychological Association (1990). Ethical principles of psychologists (Amended June 2, 1989). American Psychologist, 45, 390–395.

American Psychological Association (1992). Ethical principles of psychologists and code of conduct. American Psychologist, 47, 1597–1611.

Request copies of the APA's Ethical Principles of Psychologists and Code of Conduct from the APA Order Department, 750 First Street, NE, Washington, DC 20002–4242, or phone (202) 336–5510.

CODE OF ETHICS

National Association of Social Workers

1979, REVISED 1990, 1996, 1999

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The current Code of Ethics of the National Association of Social Workers (NASW) was adopted by the NASW Delegate Assembly in 1979 and revised in 1990, 1996 and 1999.

The Code is based primarily on certain core values such as service, justice, dignity, competence, integrity and the importance of human relationships.

Preamble

The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty. A historic and defining feature of social work is the profession's focus on individual well-being in a social context and the well-being of society. Fundamental to social work is attention to the environmental forces that create, contribute to, and address problems in living.

Social workers promote social justice and social change with and on behalf of clients. "Clients" is used inclusively to refer to individuals, families, groups, organizations, and communities. Social workers are sensitive to cultural and ethnic diversity and strive to end discrimination, oppression, poverty, and other forms of social injustice. These activities may be in the form of direct practice, community organizing, supervision, consultation, administration, advocacy, social and political action, policy development and implementation, education, and research and evaluation. Social workers seek to enhance the capacity of people to address their own needs. Social workers also seek to promote the responsiveness of organizations, communities, and other social institutions to individuals' needs and social problems.

The mission of the social work profession is rooted in a set of core values. These core values, embraced by social workers throughout the profession's history, are the foundation of social work's unique purpose and perspective:

- service
- social justice
- dignity and worth of the person
- importance of human relationships
- integrity
- competence.

This constellation of core values reflects what is unique to the social work profession. Core values, and the principles that flow from them, must be balanced within the context and complexity of the human experience.

Purpose of the NASW Code of Ethics

Professional ethics are at the core of social work. The profession has an obligation to articulate its basic values, ethical principles, and ethical standards. The *NASW Code of Ethics* sets forth these values, principles, and standards to guide social workers' conduct. The *Code* is relevant to all social workers and social work students, regardless of their professional functions, the settings in which they work, or the populations they serve.

The *NASW Code of Ethics* serves six purposes:

1. The *Code* identifies core values on which social work's mission is based.
2. The *Code* summarizes broad ethical principles that reflect the profession's core values and establishes a set of specific ethical standards that should be used to guide social work practice.
3. The *Code* is designed to help social workers identify relevant considerations when professional obligations conflict or ethical uncertainties arise.
4. The *Code* provides ethical standards to which the general public can hold the social work profession accountable.
5. The *Code* socializes practitioners new to the field to social work's mission, values, ethical principles, and ethical standards.
6. The *Code* articulates standards that the social work profession itself can use to assess whether social workers have engaged in unethical conduct. NASW has formal procedures to adjudicate ethics complaints filed against its members.* In subscribing to this *Code*, social workers are required to cooperate in its implementation, participate in NASW adjudication proceedings, and abide by any NASW disciplinary rulings or sanctions based on it.

*For information on NASW adjudication procedures, see *NASW Procedures for the Adjudication of Grievances.*

The *Code* offers a set of values, principles, and standards to guide decision making and conduct when ethical issues arise. It does not provide a set of rules that prescribe how social workers should act in all situations. Specific applications of the *Code* must take into account the context in which it is being considered and the possibility of conflicts among the *Code*'s values, principles, and standards. Ethical responsibilities flow from all human relationships, from the personal and familial to the social and professional.

Further, the *NASW Code of Ethics* does not specify which values, principles, and standards are most important and ought to outweigh others in instances when they conflict. Reasonable differences of opinion can and do exist among social workers with respect to the ways in which values, ethical principles, and ethical standards should be rank ordered when they conflict. Ethical decision making in a given situation must apply the informed judgment of the individual social worker and should also consider how the issues would be judged in a peer review process where the ethical standards of the profession would be applied.

Ethical decision making is a process. There are many instances in social work where simple answers are not available to resolve complex ethical issues. Social workers should take into consideration all the values, principles, and standards in this *Code* that are relevant to any situation in which ethical judgment is warranted. Social workers' decisions and actions should be consistent with the spirit as well as the letter of this *Code*.

In addition to this *Code*, there are many other sources of information about ethical thinking that may be useful. Social workers should consider ethical theory and principles generally, social work theory and research, laws, regulations, agency policies, and other relevant codes of ethics, recognizing that among codes of ethics social workers should consider the *NASW Code of Ethics* as their primary source. Social workers also should be aware of the impact on ethical decision making of their clients' and their own personal values and cultural and religious beliefs and practices. They should be aware of any conflicts between personal and professional values and deal with them responsibly. For additional guidance social workers should consult the relevant literature on professional ethics and ethical decision making and seek appropriate consultation when faced with ethical dilemmas. This may involve consultation with an agency-based or social work organization's ethics committee, a regulatory body, knowledgeable colleagues, supervisors, or legal counsel.

Instances may arise when social workers' ethical obligations conflict with agency policies or relevant laws or regulations. When such conflicts occur, social workers must make a responsible effort to resolve the conflict in a manner that is consistent with the values, principles, and standards expressed in this *Code*. If a reasonable resolution of the conflict does not appear possible, social workers should seek proper consultation before making a decision.

The *NASW Code of Ethics* is to be used by NASW and by individuals, agencies, organizations, and bodies (such as licensing and regulatory boards, professional liability insurance providers, courts of law, agency boards of directors, government agencies, and other professional groups) that choose to adopt it or use it as a frame of reference. Violation of standards in this *Code* does not automatically imply legal liability or violation of the law. Such determination can only be made in the context of legal and judicial proceedings. Alleged violations of the *Code* would be subject to a peer review process. Such processes are generally separate from legal or administrative procedures and insulated from legal review or proceedings to allow the profession to counsel and discipline its own members.

A code of ethics cannot guarantee ethical behavior. Moreover, a code of ethics cannot resolve all ethical issues or disputes or capture the richness and complexity involved in striving to make responsible choices within a moral community. Rather, a code of ethics sets forth values, ethical principles, and ethical standards to which professionals aspire and by which their actions can be judged. Social workers' ethical behavior should result from their personal commitment to engage in ethical practice. The *NASW Code of Ethics* reflects the commitment of all social workers to uphold the profession's values and to act ethically. Principles and standards must be applied by individuals of good character who discern moral questions and, in good faith, seek to make reliable ethical judgments.

Ethical Principles

The following broad ethical principles are based on social work's core values of service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence. These principles set forth ideals to which all social workers should aspire.

VALUE: *Service*

ETHICAL PRINCIPLE: *Social workers' primary goal is to help people in need and to address social problems.*

Social workers elevate service to others above self-interest. Social workers draw on their knowledge, values, and skills to help people in need and to address social problems. Social workers are encouraged to volunteer some portion of their professional skills with no expectation of significant financial return (pro bono service).

VALUE: *Social Justice*

ETHICAL PRINCIPLE: *Social workers challenge social injustice.*

Social workers pursue social change, particularly with and on behalf of vulnerable and oppressed individuals and groups of people. Social workers' social change efforts are focused primarily on issues of poverty, unemployment, discrimination, and other forms of social injustice. These activities seek to promote sensitivity to and knowledge about oppression and cultural and ethnic diversity. Social workers strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people.

VALUE: *Dignity and Worth of the Person*

ETHICAL PRINCIPLE: *Social workers respect the inherent dignity and worth of the person.*

Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity. Social workers promote clients' socially responsible self-determination. Social workers seek to enhance clients' capacity and opportunity to change and to address their own needs. Social workers are cognizant of their dual responsibility to clients and to the broader society. They seek to resolve conflicts between clients' interests and the broader society's interests in a socially responsible manner consistent with the values, ethical principles, and ethical standards of the profession.

VALUE: *Importance of Human Relationships*

ETHICAL PRINCIPLE: *Social workers recognize the central importance of human relationships.*

Social workers understand that relationships between and among people are an important vehicle for change. Social workers engage people as partners in the helping process. Social workers seek to strengthen relationships among people in a purposeful effort to promote, restore, maintain, and enhance the well-being of individuals, families, social groups, organizations, and communities.

VALUE: *Integrity*

ETHICAL PRINCIPLE: *Social workers behave in a trustworthy manner.*

Social workers are continually aware of the profession's mission, values, ethical principles, and ethical standards and practice in a manner consistent with them. Social workers act honestly and responsibly and promote ethical practices on the part of the organizations with which they are affiliated.

VALUE: *Competence*

ETHICAL PRINCIPLE: *Social workers practice within their areas of competence and develop and enhance their professional expertise.*

Social workers continually strive to increase their professional knowledge and skills and to apply them in practice. Social workers should aspire to contribute to the knowledge base of the profession.

Ethical Standards

The following ethical standards are relevant to the professional activities of all social workers. These standards concern (1) social workers' ethical responsibilities to clients, (2) social workers' ethical responsibilities to colleagues, (3) social workers' ethical responsibilities in practice settings, (4) social workers' ethical responsibilities as professionals, (5) social workers' ethical responsibilities to the social work profession, and (6) social workers' ethical responsibilities to the broader society.

Some of the standards that follow are enforceable guidelines for professional conduct, and some are aspirational. The extent to which each standard is enforceable is a matter of professional judgment to be exercised by those responsible for reviewing alleged violations of ethical standards.

1. Social Workers' Ethical Responsibilities to Clients

1.01 COMMITMENT TO CLIENTS

Social workers' primary responsibility is to promote the well-being of clients. In general, clients' interests are primary. However, social workers' responsibility to the larger society or specific legal obligations may on limited occasions supersede the loyalty owed clients, and clients should be so advised. (Examples include when a social worker is required by law to report that a client has abused a child or has threatened to harm self or others.)

1.02 SELF-DETERMINATION

Social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals. Social workers may limit clients' right to self-determination when, in the social workers' professional judgment, clients' actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others.

1.03 INFORMED CONSENT

(a) Social workers should provide services to clients only in the context of a professional relationship based, when appropriate, on valid informed consent. Social workers should use clear and understandable language to inform clients of the purpose of the services, risks related to the services, limits to services because of the requirements of a third-party payer, relevant costs, reasonable alternatives, clients' right to refuse or withdraw consent, and the time frame covered by the consent. Social workers should provide clients with an opportunity to ask questions.

(b) In instances when clients are not literate or have difficulty understanding the primary language used in the practice setting, social workers should take steps to ensure clients' comprehension. This may include providing clients with a detailed verbal explanation or arranging for a qualified interpreter or translator whenever possible.

(c) In instances when clients lack the capacity to provide informed consent, social workers should protect clients' interests by seeking permission from an appropriate third party, informing clients consistent with the clients' level of understanding. In such instances social workers should seek to ensure that the third party acts in a manner consistent with clients' wishes and interests. Social workers should take reasonable steps to enhance such clients' ability to give informed consent.

(d) In instances when clients are receiving services involuntarily, social workers should provide information about the nature and extent of services and about the extent of clients' right to refuse service.

(e) Social workers who provide services via electronic media (such as computer, telephone, radio, and television) should inform recipients of the limitations and risks associated with such services.

(f) Social workers should obtain clients' informed consent before audiotaping or videotaping clients or permitting observation of services to clients by a third party.

1.04 COMPETENCE

(a) Social workers should provide services and represent themselves as competent only within the boundaries of their education, training, license, certification, consultation received, supervised experience, or other relevant professional experience.

(b) Social workers should provide services in substantive areas or use intervention techniques or approaches that are new to them only after engaging in appropriate study, training, consultation, and supervision from people who are competent in those interventions or techniques.

(c) When generally recognized standards do not exist with respect to an emerging area of practice, social workers should exercise careful judgment and take responsible steps (including appropriate education, research, training, consultation, and supervision) to ensure the competence of their work and to protect clients from harm.

1.05 CULTURAL COMPETENCE AND SOCIAL DIVERSITY

(a) Social workers should understand culture and its function in human behavior and society, recognizing the strengths that exist in all cultures.

(b) Social workers should have a knowledge base of their clients' cultures and be able to demonstrate competence in the provision of services that are sensitive to clients' cultures and to differences among people and cultural groups.

(c) Social workers should obtain education about and seek to understand the nature of social diversity and oppression with respect to race, ethnicity, national origin, color, sex, sexual orientation, age, marital status, political belief, religion, and mental or physical disability.

1.06 CONFLICTS OF INTEREST

(a) Social workers should be alert to and avoid conflicts of interest that interfere with the exercise of professional discretion and impartial judgment. Social workers should inform clients when a real or potential conflict of interest arises and take reasonable steps to resolve the issue in a manner that makes the clients' interests primary and protects clients' interests to the greatest extent possible. In some cases, protecting clients' interests may require termination of the professional relationship with proper referral of the client.

(b) Social workers should not take unfair advantage of any professional relationship or exploit others to further their personal, religious, political, or business interests.

(c) Social workers should not engage in dual or multiple relationships with clients or former clients in which there is a risk of exploitation or potential harm to the client. In instances when dual or multiple relationships are unavoidable, social workers should take steps to protect clients and are responsible for setting clear, appropriate, and culturally sensitive boundaries. (Dual or multiple relationships occur when social workers relate to clients in more than one relationship, whether professional, social, or business. Dual or multiple relationships can occur simultaneously or consecutively.)

(d) When social workers provide services to two or more people who have a relationship with each other (for example, couples, family members), social workers should clarify with all parties which individuals will be considered clients and the nature of social workers' professional obligations to the various individuals who are receiving services. Social workers who anticipate a conflict of interest among the individuals receiving services or who anticipate having to perform in potentially conflicting roles (for example, when a social worker is asked to testify in a child custody dispute or divorce proceedings involving clients) should clarify their role with the parties involved and take appropriate action to minimize any conflict of interest.

1.07 PRIVACY AND CONFIDENTIALITY

(a) Social workers should respect clients' right to privacy. Social workers should not solicit private information from clients unless it is essential to providing services or conducting social work evaluation or research. Once private information is shared, standards of confidentiality apply.

(b) Social workers may disclose confidential information when appropriate with valid consent from a client or a person legally authorized to consent on behalf of a client.

(c) Social workers should protect the confidentiality of all information obtained in the course of professional service, except for compelling professional reasons. The general expectation that social workers will keep information confidential does not apply when disclosure is necessary to prevent serious, foreseeable, and imminent harm to a client or other identifiable person. In all instances, social workers should disclose the least amount of confidential information necessary to achieve the desired purpose; only information that is directly relevant to the purpose for which the disclosure is made should be revealed.

(d) Social workers should inform clients, to the extent possible, about the disclosure of confidential information and the potential consequences, when feasible before the disclosure is made. This applies whether social workers disclose confidential information on the basis of a legal requirement or client consent.

(e) Social workers should discuss with clients and other interested parties the nature of confidentiality and limitations of clients' right to confidentiality. Social workers should review with clients circumstances where confidential information may be requested and where disclosure of confidential information may be legally required. This discussion should occur as soon as possible in the social worker–client relationship and as needed throughout the course of the relationship.

(f) When social workers provide counseling services to families, couples, or groups, social workers should seek agreement among the parties involved concerning each individual's right to confidentiality and obligation to preserve the confidentiality of information shared by others. Social workers should inform participants in family, couples, or group counseling that social workers cannot guarantee that all participants will honor such agreements.

(g) Social workers should inform clients involved in family, couples, marital, or group counseling of the social worker's, employer's, and agency's policy concerning the social worker's disclosure of confidential information among the parties involved in the counseling.

(h) Social workers should not disclose confidential information to third-party payers unless clients have authorized such disclosure.

(i) Social workers should not discuss confidential information in any setting unless privacy can be ensured. Social workers should not discuss confidential information in public or semipublic areas such as hallways, waiting rooms, elevators, and restaurants.

(j) Social workers should protect the confidentiality of clients during legal proceedings to the extent permitted by law. When a court of law or other legally authorized body orders social workers to disclose confidential or privileged information without a client's consent and such disclosure could cause harm to the client, social workers should request that the court withdraw the order or limit the order as narrowly as possible or maintain the records under seal, unavailable for public inspection.

(k) Social workers should protect the confidentiality of clients when responding to requests from members of the media.

(l) Social workers should protect the confidentiality of clients' written and electronic records and other sensitive information. Social workers should take reasonable steps to ensure that clients' records are stored in a secure location and that clients' records are not available to others who are not authorized to have access.

(m) Social workers should take precautions to ensure and maintain the confidentiality of information transmitted to other parties through the use of computers, electronic mail, facsimile machines, telephones and telephone answering machines, and other electronic or computer technology. Disclosure of identifying information should be avoided whenever possible.

(n) Social workers should transfer or dispose of clients' records in a manner that protects clients' confidentiality and is consistent with state statutes governing records and social work licensure.

(o) Social workers should take reasonable precautions to protect client confidentiality in the event of the social worker's termination of practice, incapacitation, or death.

(p) Social workers should not disclose identifying information when discussing clients for teaching or training purposes unless the client has consented to disclosure of confidential information.

(q) Social workers should not disclose identifying information when discussing clients with consultants unless the client has consented to disclosure of confidential information or there is a compelling need for such disclosure.

(r) Social workers should protect the confidentiality of deceased clients consistent with the preceding standards.

1.08 ACCESS TO RECORDS

(a) Social workers should provide clients with reasonable access to records concerning the clients. Social workers who are concerned that clients' access to their records could cause serious misunderstanding or harm to the client should provide assistance in interpreting the records and consultation with the client regarding the records. Social workers should limit clients' access to their records, or portions of their records, only in exceptional circumstances when there is compelling evidence that such access would cause serious harm to the client. Both clients' requests and the rationale for withholding some or all of the record should be documented in clients' files.

(b) When providing clients with access to their records, social workers should take steps to protect the confidentiality of other individuals identified or discussed in such records.

1.09 SEXUAL RELATIONSHIPS

(a) Social workers should under no circumstances engage in sexual activities or sexual contact with current clients, whether such contact is consensual or forced.

(b) Social workers should not engage in sexual activities or sexual contact with clients' relatives or other individuals with whom clients maintain a close personal relationship when there is a risk of exploitation or potential harm to the client. Sexual activity or sexual contact with clients' relatives or other individuals with whom clients maintain a personal relationship has the potential to be harmful to the client and may make it difficult for the social worker and client to maintain appropriate professional boundaries. Social workers—not their clients, their clients' relatives, or other individuals with whom the client maintains a personal relationship—assume the full burden for setting clear, appropriate, and culturally sensitive boundaries.

(c) Social workers should not engage in sexual activities or sexual contact with former clients because of the potential for harm to the client. If social workers engage in conduct contrary to this prohibition or claim that an exception to this prohibition is warranted because of extraordinary circumstances, it is social workers—not their clients—who assume the full burden of demonstrating that the former client has not been exploited, coerced, or manipulated, intentionally or unintentionally.

(d) Social workers should not provide clinical services to individuals with whom they have had a prior sexual relationship. Providing clinical services to a former sexual partner has the potential to be harmful to the individual and is likely to make it difficult for the social worker and individual to maintain appropriate professional boundaries.

1.10 PHYSICAL CONTACT

Social workers should not engage in physical contact with clients when there is a possibility of psychological harm to the client as a result of the contact (such as cradling or caressing clients). Social workers who engage in appropriate physical contact with clients are responsible for setting clear, appropriate, and culturally sensitive boundaries that govern such physical contact.

1.11 SEXUAL HARASSMENT

Social workers should not sexually harass clients. Sexual harassment includes sexual advances, sexual solicitation, requests for sexual favors, and other verbal or physical conduct of a sexual nature.

1.12 DEROGATORY LANGUAGE

Social workers should not use derogatory language in their written or verbal communications to or about clients. Social workers should use accurate and respectful language in all communications to and about clients.

1.13 PAYMENT FOR SERVICES

(a) When setting fees, social workers should ensure that the fees are fair, reasonable, and commensurate with the services performed. Consideration should be given to clients' ability to pay.

(b) Social workers should avoid accepting goods or services from clients as payment for professional services. Bartering arrangements, particularly involving services, create the potential for conflicts of interest, exploitation, and inappropriate boundaries in social workers' relationships with clients. Social workers should explore and may participate in bartering only in very limited circumstances when it can be demonstrated that such arrangements are an accepted practice among professionals in the local community, considered to be essential for the provision of services, negotiated without coercion, and entered into at the client's initiative and with the client's informed consent. Social workers who accept goods or services from clients as payment for professional services assume the full burden of demonstrating that this arrangement will not be detrimental to the client or the professional relationship.

(c) Social workers should not solicit a private fee or other remuneration for providing services to clients who are entitled to such available services through the social workers' employer or agency.

1.14 CLIENTS WHO LACK DECISION-MAKING CAPACITY

When social workers act on behalf of clients who lack the capacity to make informed decisions, social workers should take reasonable steps to safeguard the interests and rights of those clients.

1.15 INTERRUPTION OF SERVICES

Social workers should make reasonable efforts to ensure continuity of services in the event that services are interrupted by factors such as unavailability, relocation, illness, disability, or death.

1.16 TERMINATION OF SERVICES

(a) Social workers should terminate services to clients and professional relationships with them when such services and relationships are no longer required or no longer serve the clients' needs or interests.

(b) Social workers should take reasonable steps to avoid abandoning clients who are still in need of services. Social workers should withdraw services precipitously only under unusual circumstances, giving careful consideration to all factors in the situation and taking care to minimize possible adverse effects. Social workers should assist in making appropriate arrangements for continuation of services when necessary.

(c) Social workers in fee-for-service settings may terminate services to clients who are not paying an overdue balance if the financial contractual arrangements have been made clear to the client, if the client does not pose an imminent danger to self or others, and if the clinical and other consequences of the current nonpayment have been addressed and discussed with the client.

(d) Social workers should not terminate services to pursue a social, financial, or sexual relationship with a client.

(e) Social workers who anticipate the termination or interruption of services to clients should notify clients promptly and seek the transfer, referral, or continuation of services in relation to the clients' needs and preferences.

(f) Social workers who are leaving an employment setting should inform clients of appropriate options for the continuation of services and of the benefits and risks of the options.

2. Social Workers' Ethical Responsibilities to Colleagues

2.01 RESPECT

(a) Social workers should treat colleagues with respect and should represent accurately and fairly the qualifications, views, and obligations of colleagues.

(b) Social workers should avoid unwarranted negative criticism of colleagues in communications with clients or with other professionals. Unwarranted negative criticism may include demeaning comments that refer to colleagues' level of competence or to individuals' attributes such as race, ethnicity, national origin, color, sex, sexual orientation, age, marital status, political belief, religion, and mental or physical disability.

(c) Social workers should cooperate with social work colleagues and with colleagues of other professions when such cooperation serves the well-being of clients.

2.02 CONFIDENTIALITY

Social workers should respect confidential information shared by colleagues in the course of their professional relationships and transactions. Social workers should ensure that such colleagues understand social workers' obligation to respect confidentiality and any exceptions related to it.

2.03 INTERDISCIPLINARY COLLABORATION

(a) Social workers who are members of an interdisciplinary team should participate in and contribute to decisions that affect the well-being of clients by drawing on the perspectives, values, and experiences of the social work profession. Professional and ethical obligations of the interdisciplinary team as a whole and of its individual members should be clearly established.

(b) Social workers for whom a team decision raises ethical concerns should attempt to resolve the disagreement through appropriate channels. If the disagreement cannot be resolved, social workers should pursue other avenues to address their concerns consistent with client well-being.

2.04 DISPUTES INVOLVING COLLEAGUES

(a) Social workers should not take advantage of a dispute between a colleague and an employer to obtain a position or otherwise advance the social workers' own interests.

(b) Social workers should not exploit clients in disputes with colleagues or engage clients in any inappropriate discussion of conflicts between social workers and their colleagues.

2.05 CONSULTATION

(a) Social workers should seek the advice and counsel of colleagues whenever such consultation is in the best interests of clients.

(b) Social workers should keep themselves informed about colleagues' areas of expertise and competencies. Social workers should seek consultation only from colleagues who have demonstrated knowledge, expertise, and competence related to the subject of the consultation.

(c) When consulting with colleagues about clients, social workers should disclose the least amount of information necessary to achieve the purposes of the consultation.

2.06 REFERRAL FOR SERVICES

(a) Social workers should refer clients to other professionals when the other professionals' specialized knowledge or expertise is needed to serve clients fully or when social workers believe that they are not being effective or making reasonable progress with clients and that additional service is required.

(b) Social workers who refer clients to other professionals should take appropriate steps to facilitate an orderly transfer of responsibility. Social workers who refer clients to other professionals should disclose, with clients' consent, all pertinent information to the new service providers.

(c) Social workers are prohibited from giving or receiving payment for a referral when no professional service is provided by the referring social worker.

2.07 SEXUAL RELATIONSHIPS

(a) Social workers who function as supervisors or educators should not engage in sexual activities or contact with supervisees, students, trainees, or other colleagues over whom they exercise professional authority.

(b) Social workers should avoid engaging in sexual relationships with colleagues when there is potential for a conflict of interest. Social workers who become involved in, or anticipate becoming involved in, a sexual relationship with a colleague have a duty to transfer professional responsibilities, when necessary, to avoid a conflict of interest.

2.08 SEXUAL HARASSMENT

Social workers should not sexually harass supervisees, students, trainees, or colleagues. Sexual harassment includes sexual advances, sexual solicitation, requests for sexual favors, and other verbal or physical conduct of a sexual nature.

2.09 IMPAIRMENT OF COLLEAGUES

(a) Social workers who have direct knowledge of a social work colleague's impairment that is due to personal problems, psychosocial distress, substance abuse, or mental health difficulties and that interferes with practice effectiveness should consult with that colleague when feasible and assist the colleague in taking remedial action.

(b) Social workers who believe that a social work colleague's impairment interferes with practice effectiveness and that the colleague has not taken adequate steps to address the impairment should take action through appropriate channels established by employers, agencies, NASW, licensing and regulatory bodies, and other professional organizations.

2.10 INCOMPETENCE OF COLLEAGUES

(a) Social workers who have direct knowledge of a social work colleague's incompetence should consult with that colleague when feasible and assist the colleague in taking remedial action.

(b) Social workers who believe that a social work colleague is incompetent and has not taken adequate steps to address the incompetence should take action through appropriate channels established by employers, agencies, NASW, licensing and regulatory bodies, and other professional organizations.

2.11 UNETHICAL CONDUCT OF COLLEAGUES

(a) Social workers should take adequate measures to discourage, prevent, expose, and correct the unethical conduct of colleagues.

(b) Social workers should be knowledgeable about established policies and procedures for handling concerns about colleagues' unethical behavior. Social workers should be familiar with national, state, and local procedures for handling ethics complaints. These include policies and procedures created by NASW, licensing and regulatory bodies, employers, agencies, and other professional organizations.

(c) Social workers who believe that a colleague has acted unethically should seek resolution by discussing their concerns with the colleague when feasible and when such discussion is likely to be productive.

(d) When necessary, social workers who believe that a colleague has acted unethically should take action through appropriate formal channels (such as contacting a state licensing board or regulatory body, an NASW committee on inquiry, or other professional ethics committees).

(e) Social workers should defend and assist colleagues who are unjustly charged with unethical conduct.

3. Social Workers' Ethical Responsibilities in Practice Settings

3.01 SUPERVISION AND CONSULTATION

(a) Social workers who provide supervision or consultation should have the necessary knowledge and skill to supervise or consult appropriately and should do so only within their areas of knowledge and competence.

(b) Social workers who provide supervision or consultation are responsible for setting clear, appropriate, and culturally sensitive boundaries.

(c) Social workers should not engage in any dual or multiple relationships with supervisees in which there is a risk of exploitation of or potential harm to the supervisee.

(d) Social workers who provide supervision should evaluate supervisees' performance in a manner that is fair and respectful.

3.02 EDUCATION AND TRAINING

(a) Social workers who function as educators, field instructors for students, or trainers should provide instruction only within their areas of knowledge and competence and should provide instruction based on the most current information and knowledge available in the profession.

(b) Social workers who function as educators or field instructors for students should evaluate students' performance in a manner that is fair and respectful.

(c) Social workers who function as educators or field instructors for students should take reasonable steps to ensure that clients are routinely informed when services are being provided by students.

(d) Social workers who function as educators or field instructors for students should not engage in any dual or multiple relationships with students in which there is a risk of exploitation or potential harm to the student. Social work educators and field instructors are responsible for setting clear, appropriate, and culturally sensitive boundaries.

3.03 PERFORMANCE EVALUATION

Social workers who have responsibility for evaluating the performance of others should fulfill such responsibility in a fair and considerate manner and on the basis of clearly stated criteria.

3.04 CLIENT RECORDS

(a) Social workers should take reasonable steps to ensure that documentation in records is accurate and reflects the services provided.

(b) Social workers should include sufficient and timely documentation in records to facilitate the delivery of services and to ensure continuity of services provided to clients in the future.

(c) Social workers' documentation should protect clients' privacy to the extent that is possible and appropriate and should include only information that is directly relevant to the delivery of services.

(d) Social workers should store records following the termination of services to ensure reasonable future access. Records should be maintained for the number of years required by state statutes or relevant contracts.

3.05 BILLING

Social workers should establish and maintain billing practices that accurately reflect the nature and extent of services provided and that identify who provided the service in the practice setting.

3.06 CLIENT TRANSFER

(a) When an individual who is receiving services from another agency or colleague contacts a social worker for services, the social worker should carefully consider the client's needs before agreeing to provide services. To minimize possible confusion and conflict, social workers should discuss with potential clients the nature of the clients' current relationship with other service providers and the implications, including possible benefits or risks, of entering into a relationship with a new service provider.

(b) If a new client has been served by another agency or colleague, social workers should discuss with the client whether consultation with the previous service provider is in the client's best interest.

3.07 ADMINISTRATION

(a) Social work administrators should advocate within and outside their agencies for adequate resources to meet clients' needs.

(b) Social workers should advocate for resource allocation procedures that are open and fair. When not all clients' needs can be met, an allocation procedure should be developed that is nondiscriminatory and based on appropriate and consistently applied principles.

(c) Social workers who are administrators should take reasonable steps to ensure that adequate agency or organizational resources are available to provide appropriate staff supervision.

(d) Social work administrators should take reasonable steps to ensure that the working environment for which they are responsible is consistent with and encourages compliance with the NASW Code of Ethics. Social work administrators should take reasonable steps to eliminate any conditions in their organizations that violate, interfere with, or discourage compliance with the *Code*.

3.08 CONTINUING EDUCATION AND STAFF DEVELOPMENT

Social work administrators and supervisors should take reasonable steps to provide or arrange for continuing education and staff development for all staff for whom they are responsible. Continuing education and staff development should address current knowledge and emerging developments related to social work practice and ethics.

3.09 COMMITMENTS TO EMPLOYERS

(a) Social workers generally should adhere to commitments made to employers and employing organizations.

(b) Social workers should work to improve employing agencies' policies and procedures and the efficiency and effectiveness of their services.

(c) Social workers should take reasonable steps to ensure that employers are aware of social workers' ethical obligations as set forth in the NASW Code of Ethics and of the implications of those obligations for social work practice.

(d) Social workers should not allow an employing organization's policies, procedures, regulations, or administrative orders to interfere with their ethical practice of social work. Social workers should take reasonable steps to ensure that their employing organizations' practices are consistent with the NASW Code of Ethics.

(e) Social workers should act to prevent and eliminate discrimination in the employing organization's work assignments and in its employment policies and practices.

(f) Social workers should accept employment or arrange student field placements only in organizations that exercise fair personnel practices.

(g) Social workers should be diligent stewards of the resources of their employing organizations, wisely conserving funds where appropriate and never misappropriating funds or using them for unintended purposes.

3.10 LABOR-MANAGEMENT DISPUTES

(a) Social workers may engage in organized action, including the formation of and participation in labor unions, to improve services to clients and working conditions.

(b) The actions of social workers who are involved in labor-management disputes, job actions, or labor strikes should be guided by the profession's values, ethical principles, and ethical standards. Reasonable differences of opinion exist among social workers concerning their primary obligation as professionals during an actual or threatened labor strike or job action. Social workers should carefully examine relevant issues and their possible impact on clients before deciding on a course of action.

4. Social Workers' Ethical Responsibilities as Professionals

4.01 COMPETENCE

(a) Social workers should accept responsibility or employment only on the basis of existing competence or the intention to acquire the necessary competence.

(b) Social workers should strive to become and remain proficient in professional practice and the performance of professional functions. Social workers should critically examine and keep current with emerging knowledge relevant to social work. Social workers should routinely review the professional literature and participate in continuing education relevant to social work practice and social work ethics.

(c) Social workers should base practice on recognized knowledge, including empirically based knowledge, relevant to social work and social work ethics.

4.02 DISCRIMINATION

Social workers should not practice, condone, facilitate, or collaborate with any form of discrimination on the basis of race, ethnicity, national origin, color, sex, sexual orientation, age, marital status, political belief, religion, or mental or physical disability.

4.03 PRIVATE CONDUCT

Social workers should not permit their private conduct to interfere with their ability to fulfill their professional responsibilities.

4.04 DISHONESTY, FRAUD, AND DECEPTION

Social workers should not participate in, condone, or be associated with dishonesty, fraud, or deception.

4.05 IMPAIRMENT

(a) Social workers should not allow their own personal problems, psychosocial distress, legal problems, substance abuse, or mental health difficulties to interfere with their professional judgment and performance or to jeopardize the best interests of people for whom they have a professional responsibility.

(b) Social workers whose personal problems, psychosocial distress, legal problems, substance abuse, or mental health difficulties interfere with their professional judgment and performance should immediately seek consultation and take appropriate remedial action by seeking professional help, making adjustments in workload, terminating practice, or taking any other steps necessary to protect clients and others.

4.06 MISREPRESENTATION

(a) Social workers should make clear distinctions between statements made and actions engaged in as a private individual and as a representative of the social work profession, a professional social work organization, or the social worker's employing agency.

(b) Social workers who speak on behalf of professional social work organizations should accurately represent the official and authorized positions of the organizations.

(c) Social workers should ensure that their representations to clients, agencies, and the public of professional qualifications, credentials, education, competence, affiliations, services provided, or results to be achieved are accurate. Social workers should claim only those relevant professional credentials they actually possess and take steps to correct any inaccuracies or misrepresentations of their credentials by others.

4.07 SOLICITATIONS

(a) Social workers should not engage in uninvited solicitation of potential clients who, because of their circumstances, are vulnerable to undue influence, manipulation, or coercion.

(b) Social workers should not engage in solicitation of testimonial endorsements (including solicitation of consent to use a client's prior statement as a testimonial endorsement) from current clients or from other people who, because of their particular circumstances, are vulnerable to undue influence.

4.08 ACKNOWLEDGING CREDIT

(a) Social workers should take responsibility and credit, including authorship credit, only for work they have actually performed and to which they have contributed.

(b) Social workers should honestly acknowledge the work of and the contributions made by others.

5. Social Workers' Ethical Responsibilities to the Social Work Profession

5.01 INTEGRITY OF THE PROFESSION

(a) Social workers should work toward the maintenance and promotion of high standards of practice.

(b) Social workers should uphold and advance the values, ethics, knowledge, and mission of the profession. Social workers should protect, enhance, and improve the integrity of the profession through appropriate study and research, active discussion, and responsible criticism of the profession.

(c) Social workers should contribute time and professional expertise to activities that promote respect for the value, integrity, and competence of the social work profession. These activities may include teaching, research, consultation, service, legislative testimony, presentations in the community, and participation in their professional organizations.

(d) Social workers should contribute to the knowledge base of social work and share with colleagues their knowledge related to practice, research, and ethics. Social workers should seek to con-tribute to the profession's literature and to share their knowledge at professional meetings and conferences.

(e) Social workers should act to prevent the unauthorized and unqualified practice of social work.

5.02 EVALUATION AND RESEARCH

(a) Social workers should monitor and evaluate policies, the implementation of programs, and practice interventions.

(b) Social workers should promote and facilitate evaluation and research to contribute to the development of knowledge.

(c) Social workers should critically examine and keep current with emerging knowledge relevant to social work and fully use evaluation and research evidence in their professional practice.

(d) Social workers engaged in evaluation or research should carefully consider possible consequences and should follow guidelines developed for the protection of evaluation and research participants. Appropriate institutional review boards should be consulted.

(e) Social workers engaged in evaluation or research should obtain voluntary and written informed consent from participants, when appropriate, without any implied or actual deprivation or penalty for refusal to participate; without undue inducement to participate; and with due regard for participants' well-being, privacy, and dignity. Informed consent should include information about the nature, extent, and duration of the participation requested and disclosure of the risks and benefits of participation in the research.

(f) When evaluation or research participants are incapable of giving informed consent, social workers should provide an appropriate explanation to the participants, obtain the participants' assent to the extent they are able, and obtain written consent from an appropriate proxy.

(g) Social workers should never design or conduct evaluation or research that does not use consent procedures, such as certain forms of naturalistic observation and archival research, unless rigorous and responsible review of the research has found it to be justified because of its prospective scientific, educational, or applied value and unless equally effective alternative procedures that do not involve waiver of consent are not feasible.

(h) Social workers should inform participants of their right to withdraw from evaluation and research at any time without penalty.

(i) Social workers should take appropriate steps to ensure that participants in evaluation and research have access to appropriate supportive services.

(j) Social workers engaged in evaluation or research should protect participants from unwarranted physical or mental distress, harm, danger, or deprivation.

(k) Social workers engaged in the evaluation of services should discuss collected information only for professional purposes and only with people professionally concerned with this information.

(l) Social workers engaged in evaluation or research should ensure the anonymity or confidentiality of participants and of the data obtained from them. Social workers should inform participants of any limits of confidentiality, the measures that will be taken to ensure confidentiality, and when any records containing research data will be destroyed.

(m) Social workers who report evaluation and research results should protect participants' confidentiality by omitting identifying information unless proper consent has been obtained authorizing disclosure.

(n) Social workers should report evaluation and research findings accurately. They should not fabricate or falsify results and should take steps to correct any errors later found in published data using standard publication methods.

(o) Social workers engaged in evaluation or research should be alert to and avoid conflicts of interest and dual relationships with participants, should inform participants when a real or potential conflict of interest arises, and should take steps to resolve the issue in a manner that makes participants' interests primary.

(p) Social workers should educate themselves, their students, and their colleagues about responsible research practices.

6. Social Workers' Ethical Responsibilities to the Broader Society

6.01 SOCIAL WELFARE

Social workers should promote the general welfare of society, from local to global levels, and the development of people, their communities, and their environments. Social workers should advocate for living conditions conducive to the fulfillment of basic human needs and should promote social, economic, political, and cultural values and institutions that are compatible with the realization of social justice.

6.02 PUBLIC PARTICIPATION

Social workers should facilitate informed participation by the public in shaping social policies and institutions.

6.03 PUBLIC EMERGENCIES

Social workers should provide appropriate professional services in public emergencies to the greatest extent possible.

6.04 SOCIAL AND POLITICAL ACTION

(a) Social workers should engage in social and political action that seeks to ensure that all people have equal access to the resources, employment, services, and opportunities they require to meet their basic human needs and to develop fully. Social workers should be aware of the impact of the political arena on practice and should advocate for changes in policy and legislation to improve social conditions in order to meet basic human needs and promote social justice.

(b) Social workers should act to expand choice and opportunity for all people, with special regard for vulnerable, disadvantaged, oppressed, and exploited people and groups.

(c) Social workers should promote conditions that encourage respect for cultural and social diversity within the United States and globally. Social workers should promote policies and practices that demonstrate respect for difference, support the expansion of cultural knowledge and resources, advocate for programs and institutions that demonstrate cultural competence, and promote policies that safeguard the rights of and confirm equity and social justice for all people.

(d) Social workers should act to prevent and eliminate domination of, exploitation of, and discrimination against any person, group, or class on the basis of race, ethnicity, national origin, color, sex, sexual orientation, age, marital status, political belief, religion, or mental or physical disability.

CODE OF ETHICS

American College of Healthcare Executives

AMENDED 1990

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The American College of Healthcare Executives' Code of Ethics sets standards for the ethical behavior of health-care executives both in their professional relationships and in their personal behavior, particularly when it relates to their professional role and identity. Of particular note are statements about assuring "all people…reasonable access to healthcare services" and establishing "a resource allocation process that considers ethical ramifications," as well as a section addressing conflicts of interest and a section on responsibilities to community and society

<http://www.ache.org/ABT_ACHE/code.cfm>

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Preface

The *Code of Ethics* is administered by the Ethics Committee, which is appointed by the Board of Governors upon nomination by the Chairman. It is composed of at least nine Diplomates or Fellows of the College, each of whom serves a three-year term on a staggered basis, with three members retiring each year. *The Ethics Committee shall:*

- Review and evaluate annually the *Code of Ethics,* and make any necessary recommendations for updating the Code.
- Review and recommend action to the Board of Governors on allegations brought forth regarding breaches of the *Code of Ethics.*
- Develop ethical policy statements to serve as guidelines of ethical conduct for healthcare executives and their professional relationships.
- Prepare an annual report of observations, accomplishments, and recommendations to the Board of Governors, and such other periodic reports as required.

The Ethics Committee invokes the *Code of Ethics* under authority of the ACHE *Bylaws,* Article II, Membership, Section 6, Resignation and Termination of Membership; Transfer to Inactive Status, subsection (b), as follows:

Membership may be terminated or rendered inactive by action of the Board of Governors as a result of violation of the *Code of Ethics;* nonconformity with the Bylaws or Regulations Governing Admission, Advancement, Recertification, and Reappointment; conviction of a felony; or conviction of a crime of moral turpitude or a crime relating to the healthcare management profession. No such termination of membership or imposition of inactive status shall be effected without affording a reasonable opportunity for the member to consider the charges and to appear in his or her own defense before the Board of Governors or its designated hearing committee, as outlined in the "Grievance Procedure," Appendix I of the College's *Code of Ethics.*

Preamble

The purpose of the *Code of Ethics* of the American College of Healthcare Executives is to serve as a guide to conduct for members. It contains standards of ethical behavior for healthcare executives in their professional relationships. These relationships include members of the healthcare executive's organization and other organizations. Also included are patients or others served, colleagues, the community and society as a whole. The *Code of Ethics* also incorporates standards of ethical behavior governing personal behavior, particularly when that conduct directly relates to the role and identity of the healthcare executive.

The fundamental objectives of the healthcare management profession are to enhance overall quality of life, dignity and well-being of every individual needing healthcare services; and to create a more equitable, accessible, effective and efficient healthcare system.

Healthcare executives have an obligation to act in ways that will merit the trust, confidence and respect of healthcare professionals and the general public. Therefore, healthcare executives should lead lives that embody an exemplary system of values and ethics.

In fulfilling their commitments and obligations to patients or others served, healthcare executives function as moral advocates. Since every management decision affects the health and well-being of both individuals and communities, healthcare executives must carefully evaluate the possible outcomes of their decisions. In organizations that deliver healthcare services, they must work to safeguard and foster the rights, interests and prerogatives of patients or others served. The role of moral advocate requires that healthcare executives speak out and take actions necessary to promote such rights, interests and prerogatives if they are threatened.

I. The Healthcare Executive's Responsibilities to the Profession of Healthcare Management

The healthcare executive shall:

A. Uphold the values, ethics and mission of the healthcare management profession;
B. Conduct all personal and professional activities with honesty, integrity, respect, fairness and good faith in a manner that will reflect well upon the profession;
C. Comply with all laws pertaining to healthcare management in the jurisdictions in which the healthcare executive is located, or conducts professional activities;
D. Maintain competence and proficiency in healthcare management by implementing a personal program of assessment and continuing professional education;
E. Avoid the exploitation of professional relationships for personal gain;
F. Use this Code to further the interests of the profession and not for selfish reasons;
G. Respect professional confidences;
H. Enhance the dignity and image of the healthcare management profession through positive public information programs; and
I. Refrain from participating in any activity that demeans the credibility and dignity of the healthcare management profession.

II. The Healthcare Executive's Responsibilities to Patients or Others Served, to the Organization, and to Employees

A. RESPONSIBILITIES TO PATIENTS OR OTHERS SERVED

The healthcare executive shall, within the scope of his or her authority:

1. Work to ensure the existence of a process to evaluate the quality of care or service rendered;
2. Avoid practicing or facilitating discrimination and institute safeguards to prevent discriminatory organizational practices;
3. Work to ensure the existence of a process that will advise patients or others served of the rights, opportunities, responsibilities, and risks regarding available healthcare services;
4. Work to provide a process that ensures the autonomy and self-determination of patients or others served; and
5. Work to ensure the existence of procedures that will safeguard the confidentiality and privacy of patients or others served.

B. RESPONSIBILITIES TO THE ORGANIZATION

The healthcare executive shall, within the scope of his or her authority:

1. Provide healthcare services consistent with available resources and work to ensure the existence of a resource allocation process that considers ethical ramifications;
2. Conduct both competitive and cooperative activities in ways that improve community healthcare services;
3. Lead the organization in the use and improvement of standards of management and sound business practices;
4. Respect the customs and practices of patients or others served, consistent with the organization's philosophy; and
5. Be truthful in all forms of professional and organizational communication, and avoid disseminating information that is false, misleading, or deceptive.

C. RESPONSIBILITIES TO EMPLOYEES

Healthcare executives have an ethical and professional obligation to employees of the organizations they manage that encompass but are not limited to:

1. Working to create a working environment conducive for underscoring employee ethical conduct and behavior;
2. Working to ensure that individuals may freely express ethical concerns and providing mechanisms for discussing and addressing such concerns;
3. Working to ensure a working environment that is free from harassment, sexual and other; coercion of any kind, especially to perform illegal or unethical acts; and discrimination on the basis of race, creed, color, sex, ethnic origin, age, or disability;
4. Working to ensure a working environment that is conducive to proper utilization of employees' skills and abilities;
5. Paying particular attention to the employee's work environment and job safety; and
6. Working to establish appropriate grievance and appeals mechanisms.

III. Conflicts of Interest

A conflict of interest may be only a matter of degree, but exists when the healthcare executive:

A. Acts to benefit directly or indirectly by using authority or inside information, or allows a friend, relative or associate to benefit from such authority or information.
B. Uses authority or information to make a decision to intentionally affect the organization in an adverse manner.

The healthcare executive shall:

A. Conduct all personal and professional relationships in such a way that all those affected are assured that management decisions are made in the best interests of the organization and the individuals served by it;
B. Disclose to the appropriate authority any direct or indirect financial or personal interests that pose potential or actual conflicts of interest;
C. Accept no gifts or benefits offered with the express or implied expectation of influencing a management decision; and
D. Inform the appropriate authority and other involved parties of potential or actual conflicts of interest related to appointments or elections to boards or committees inside or outside the healthcare executive's organization.

IV. The Healthcare Executive's Responsibilities to Community and Society

The healthcare executive shall:

A. Work to identify and meet the healthcare needs of the community;
B. Work to ensure that all people have reasonable access to healthcare services;
C. Participate in public dialogue on healthcare policy issues and advocate solutions that will improve health status and promote quality healthcare;
D. Consider the short-term and long-term impact of management decisions on both the community and on society; and
E. Provide prospective consumers with adequate and accurate information, enabling them to make enlightened judgments and decisions regarding services.

V. The Healthcare Executive's Responsibility to Report Violations of the Code

A member of the College who has reasonable grounds to believe that another member has violated this Code has a duty to communicate such facts to the Ethics Committee.

Appendix I

American College of Healthcare Executives Grievance Procedure

1. In order to be processed by the College, a complaint must be filed in writing to the Ethics Committee of the College within three years of the date of discovery of the alleged violation; and the Committee has the responsibility to look into incidents brought to its attention regardless of the informality of the information, provided the information can be documented or supported or may be a matter of public record. The three-year period within which a complaint must be filed shall temporarily cease to run during intervals when the accused member is in inactive status, or when the accused member resigns from the College.
2. The Committee chairman initially will determine whether the complaint falls within the purview of the Ethics Committee and whether immediate investigation is necessary. However, all letters of complaint that are filed with the Ethics Committee will appear on the agenda of the next committee meeting. The Ethics Committee shall have the final discretion to determine whether a complaint falls within the purview of the Ethics Committee.
3. If a grievance proceeding is initiated by the Ethics Committee:
    a. Specifics of the complaint will be sent to the respondent by certified mail. In such mailing,

committee staff will inform the respondent that the grievance proceeding has been initiated, and that the respondent may respond directly to the Ethics Committee; the respondent also will be asked to cooperate with the Regent investigating the complaint.

   b. The Ethics Committee shall refer the matter to the appropriate Regent who is deemed best able to investigate the alleged infraction. The Regent shall make inquiry into the matter, and in the process the respondent shall be given an opportunity to be heard.
   c. Upon completion of the inquiry, the Regent shall present a complete report and recommended disposition of the matter in writing to the Ethics Committee. Absent unusual circumstances, the Regent is expected to complete his or her report and recommended disposition, and provide them to the Committee, within 60 days.

4. Upon the Committee's receipt of the Regent's report and recommended disposition, the Committee shall review them and make its written recommendation to the Board of Governors as to what action shall be taken and the reason or reasons therefor. A copy of the Committee's recommended decision along with the Regent's report and recommended disposition to the Board will be mailed to the respondent by certified mail. In such mailing, the respondent will be notified that within 30 days after his or her receipt of the Ethics Committee's recommended decision, the respondent may file a written appeal of the recommended decision with the Board of Governors.
5. Any written appeal submitted by the respondent must be received by the Board of Governors within 30 days after the recommended decision of the Ethics Committee is received by the respondent. The Board of Governors shall not take action on the Ethics Committee's recommended decision until the 30-day appeal period has elapsed. If no appeal to the Board of Governors is filed in a timely fashion, the Board shall review the recommended decision and determine action to be taken.
6. If an appeal to the Board of Governors is timely filed, the College Chairman shall appoint an ad hoc committee consisting of three Fellows to hear the matter. At least 30 days' notice of the formation of this committee, and of the hearing date, time and place, with an opportunity for representation, shall be mailed to the respondent. Reasonable requests for postponement shall be given consideration.
7. This ad hoc committee shall give the respondent adequate opportunity to present his or her case at the hearing, including the opportunity to submit a written statement and other documents deemed relevant by the respondent, and to be represented if so desired. Within a reasonable period of time following the hearing, the ad hoc committee shall write a detailed report with recommendations to the Board of Governors.
8. The Board of Governors shall decide what action to take after reviewing the report of the ad hoc committee. The Board shall provide the respondent with a copy of its decision. The decision of the Board of Governors shall be final. The Board of Governors shall have the authority to accept or reject any of the findings or recommended decisions of the Regent, the Ethics Committee or the ad hoc committee, and to order whatever level of discipline it feels is justified.
9. At each level of the grievance proceeding, the Board of Governors shall have the sole discretion to notify or contact the complainant relating to the grievance proceeding; provided, however, that the complainant shall be notified as to whether the complaint was reviewed by the Ethics Committee and whether the Ethics Committee or the Board of Governors has taken final action with respect to the complaint.
10. No individual shall serve on the ad hoc committee described above, or otherwise participate in these grievance proceedings on behalf of the College, if he or she is in direct economic competition with the respondent or otherwise has a financial conflict of interest in the matter, unless such conflict is disclosed to and waived in writing by the respondent.
11. All information obtained, reviewed, discussed and otherwise used or developed in a grievance proceeding that is not otherwise publicly known, publicly available, or part of the public domain is considered to be privileged and strictly confidential information of the College, and is not to be disclosed to anyone outside of the grievance proceeding except as determined by the Board of Governors or as required by law; provided, however, that an individual's membership status is not confidential and may be made available to the public upon request.

Appendix II

Ethics Committee Action

Once the grievance proceeding has been initiated, the Ethics Committee may take any of the following actions based upon its findings:

1. Determine the grievance complaint to be invalid.
2. Dismiss the grievance complaint.
3. Recommend censure.

4. Recommend transfer to inactive status for a specified minimum period of time.
5. Recommend expulsion.

Appendices I and II, entitled "American College of Healthcare Executives Grievance Procedure" and "Ethics Committee Action," respectively, are a material part of this Code of Ethics and are incorporated herein by reference.

ETHICAL CONDUCT FOR HEALTH CARE INSTITUTIONS

American Hospital Association

1992

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In 1973, the American Hospital Association (AHA) developed its Guidelines on Ethical Conduct and Relationships for Health Care Institutions, the precursor to the present document, as a complement to the preceding code of ethics for health-care executives. This AHA code of ethics for health-care institutions, which addresses the major areas affecting their ethical conduct, is different because it is written for institutions, that is, their "mission, programs, and services," rather than for people.

Points of interest include (1) responsibility for "fair and effective use" of available resources and helping to resolve the problem of providing care to medically indigent individuals; (2) respect for the spiritual needs and cultural beliefs of patients and families; (3) accommodation, to the extent possible, of "the desire of employees and medical staff to embody religious and/or moral values in their professional activities"; and (4) sensitivity to "institutional decisions that employees might interpret as compromising their ability to provide high-quality health care."

Introduction

Health care institutions, by virtue of their roles as health care providers, employers, and community health resources, have special responsibilities for ethical conduct and ethical practices that go beyond meeting minimum legal and regulatory standards. Their broad range of patient care, education, public health, social service, and business functions is essential to the health and well being of their communities. These roles and functions demand that health care organizations conduct themselves in an ethical manner that emphasizes a basic community service orientation and justifies the public trust. The health care institution's mission and values should be embodied in all its programs, services, and activities.

Because health care organizations must frequently seek a balance among the interests and values of individuals, the institution, and society, they often face ethical dilemmas in meeting the needs of their patients and their communities. This advisory is intended to assist members of the American Hospital Association to better identify and understand the ethical aspects and implications of institutional policies and practices. It is offered with the understanding that each institution's leadership in making policy and decisions must take into account the needs and values of the institution, its physicians, other caregivers, and employees and those of individual patients, their families, and the community as a whole.

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Community Role

- Health care institutions should be concerned with the overall health status of their communities while continuing to provide direct patient services. They should take a leadership role in enhancing public health and continuity of care in the community by communicating and working with other health care and social agencies to improve the availability and provision of health promotion, education, and patient care services.
- Health care institutions are responsible for fair and effective use of available health care delivery resources to promote access to comprehensive and affordable health care services of high quality. This responsibility extends beyond the resources of the given institution to include efforts to coordinate with other health care organizations and professionals and to share in community solutions for providing care for the medically indigent and others in need of specific health services.
- All health care institutions are responsible for meeting community service obligations which may include special initiatives for care for the poor and uninsured, provision of needed medical or social services, education, and various programs designed to meet the specific needs of their communities.
- Health care institutions, being dependent upon community confidence and support, are accountable to the public, and therefore their communications and disclosure of information and data related to the institution should be clear, accurate, and sufficiently complete to assure that it is not misleading. Such disclosure should be aimed primarily at better public understanding of health issues, the services available to prevent and treat illness, and patient rights and responsibilities relating to health care decisions.
- Advertising may be used to advance the health care organization's goals and objectives and should, in

all cases, support the mission of the health care organization. Advertising may be used to educate the public, to report to the community, to increase awareness of available services, to increase support for the organization, and to recruit employees. Health care advertising should be truthful, fair, accurate, complete, and sensitive to the health care needs of the public. False or misleading statements, or statements that might lead the uninformed to draw false conclusions about the health care facility, its competitors, or other health care providers are unacceptable and unethical.

- As health care institutions operate in an increasingly challenging environment, they should consider the overall welfare of their communities and their own missions in determining their activities, service mixes, and business. Health care organizations should be particularly sensitive to potential conflicts of interests involving individuals or groups associated with the medical staff, governing board, or executive management. Examples of such conflicts include ownership or other financial interests in competing provider organizations or groups contracting with the health care institution.

Patient Care

- Health care institutions are responsible for providing each patient with care that is both appropriate and necessary for the patient's condition. Development and maintenance of organized programs for utilization review and quality improvement and of procedures to verify the credentials of physicians and other health professionals are basic to this obligation.
- Health care institutions in conjunction with attending physicians are responsible for assuring reasonable continuity of care and for informing patients of patient care alternatives when acute care is no longer needed.
- Health care institutions should ensure that the health care professionals and organizations with which they are formally or informally affiliated have appropriate credentials and/or accreditation and participate in organized programs to assess and assure continuous improvement in quality of care.
- Health care institutions should have policies and practices that assure that patient transfers are medically appropriate and legally permissible. Health care institutions should inform patients of the need for and alternatives to such transfers.
- Health care institutions should have policies and practices that support informed consent for diagnostic and therapeutic procedures and use of advance directives. Policies and practices must respect and promote the patient's responsibility for decision making.
- Health care institutions are responsible for assuring confidentiality of patient-specific information. They are responsible for providing safeguards to prevent unauthorized release of information and establishing procedures for authorizing release of data.
- Health care institutions should assure that the psychological, social, spiritual, and physical needs and cultural beliefs and practices of patients and families are respected and should promote employee and medical staff sensitivity to the full range of such needs and practices. The religious and social beliefs and customs of patients should be accommodated whenever possible.
- Health care institutions should have specific mechanisms or procedures to resolve conflicting values and ethical dilemmas as well as complaints and disputes among patients their families, medical staff, employees, the institution, and the community.

Organizational Conduct

- The policies and practices of health care institutions should respect and support the professional ethical codes and responsibilities of their employees and medical staff members and be sensitive to institutional decisions that employees might interpret as compromising their ability to provide high-quality health care.
- Health care institutions should provide for fair and equitably-administered employee compensation, benefits, and other policies and practices.
- To the extent possible and consistent with the ethical commitments of the institution, health care institutions should accommodate the desires of employees and medical staff to embody religious and/or moral values in their professional activities.
- Health care institutions should have written policies on conflict of interest that apply to officers, governing board members, and medical staff, as well as others who may make or influence decisions for or on behalf of the institution, including contract employees. Particular attention should be given to potential conflicts related to referral sources, vendors, competing health care services, and investments. These policies should recognize that individuals in decision-making or administrative positions often have duality of interests that may not always present conflicts. But they should provide mechanisms for identifying and addressing dualities when they do exist.

- Health care institutions should communicate their mission, values, and priorities to their employees and volunteers, whose patient care and service activities are the most visible embodiment of the institution’s ethical commitments and values.

SECTION IV.

ETHICAL DIRECTIVES FOR HUMAN RESEARCH

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German Guidelines on Human Experimentation [1931]

Nuremberg Code [1947]

Principles for Those in Research and Experimentation, World Medical Association [1954]

Article Seven, International Covenant on Civil and Political Rights, General Assembly of the United Nations [1958]

Declaration of Helsinki, World Medical Association [1964, revised 1975, 1983, 1989, 1996, 2000]

The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research [1979]

DHHS Regulations for the Protection of Human Subjects (45 CFR 46) [June 18, 1991]

Summary Report of the International Summit Conference on Bioethics [1987]

Recommendation No. R (90) 3 of the Committee of Ministers to Member States Concerning Medical Research on Human Beings, Council of Europe [1990]

International Ethical Guidelines for Biomedical Research Involving Human Subjects, Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization [1993, revised 2000]

Directives pertaining to the ethics of research on human subjects generally fall into two categories: (1) national or international policies and/or laws and (2) policies of professional groups, e.g., medicine, nursing, epidemiology, and psychology. In addition, directives may pertain either to research in general or to specific types of research. For example, the U.S. Food and Drug Administration (FDA), the Recombinant DNA Advisory Committee of the National Institutes of Health, and the Medical Research Council of Canada all have guidelines governing gene therapy, investigational drugs, or reproductive technologies; and the Ethics Committee of the American Fertility Society has issued a comprehensive document, "Ethical Considerations of the New Reproductive Technologies.

Due to space limitations, research directives issued by professional associations and those pertaining to specific areas of research are not printed in this section; but a selection of such documents are listed in the bibliography to the Appendix. In addition, some of the professional codes included in other sections contain guidelines on research.

The documents in this section are organized chronologically except for the 1991 United States DHHS regulations, which follow The Belmont Report because of the two documents' interdependence.

GERMAN GUIDELINES ON HUMAN EXPERIMENTATION

1931

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The following guidelines for therapeutic and scientific research on human subjects, which are thought to be the first of their kind, were published originally as a Circular of the Reich Minister of the Interior dated February 28, 1931. The guidelines remained in force until 1945, but were not included in the Reich legislation validated at the end of World War II. It is interesting to note the disjunction between the guidelines and the practice of the Nazi researchers.

1. In order that medical science may continue to advance, the initiation in appropriate cases of therapy involving new and as yet insufficiently tested means and procedures cannot be avoided. Similarly, scientific experimentation involving human subjects cannot be completely excluded as such, as this would hinder or even prevent progress in the diagnosis, treatment, and prevention of diseases.

   The freedom to be granted to the physician accordingly shall be weighed against his special duty to remain aware at all times of his major responsibility for the life and health of any person on whom he undertakes innovative therapy or performs an experiment.
2. For the purposes of these Guidelines, "innovative therapy" means interventions and treatment methods that involve humans and serve a therapeutic purpose, in other words that are carried out in a particular, individual case in order to diagnose, treat, or prevent a disease or suffering or to eliminate a physical defect, although their effects and consequences cannot be sufficiently evaluated on the basis of existing experience.
3. For the purposes of these Guidelines, "scientific experimentation" means interventions and treatment methods that involve humans and are undertaken for research purposes without serving a therapeutic purpose in an individual case, and whose effects and consequences cannot be sufficiently evaluated on the basis of existing experience.
4. Any innovative therapy must be justified and performed in accordance with the principles of medical ethics and the rules of medical practice and theory.

   In all cases, the question of whether any adverse effects which may occur are proportionate to the anticipated benefits shall be examined and assessed.

   Innovative therapy may be carried out only it if has been tested in advance in animal trials (where these are possible).
5. Innovative therapy may be carried out only after the subject or his legal representative has unambiguously consented to the procedure in the light of relevant information provided in advance.

   Where consent is refused, innovative therapy may be initiated only if it constitutes an urgent procedure to preserve life or prevent serious damage to health and prior consent could not be obtained under the circumstances.
6. The question of whether to use innovative therapy must be examined with particular care where the subject is a child or a person under 18 years of age.
7. Exploitation of social hardship in order to undertake innovative therapy is incompatible with the principles of medical ethics.
8. Extreme caution shall be exercised in connection with innovative therapy involving live microorganisms, especially live pathogens. Such therapy shall be considered permissible only if the procedure can be assumed to be relatively safe and similar benefits are unlikely to be achieved under the circumstances by any other method.
9. In clinics, policlinics, hospitals, or other treatment and care establishments, innovative therapy may be carried out only by the physician in charge or by another physician acting in accordance with his express instructions and subject to his complete responsibility.
10. A report shall be made in respect of any innovative therapy, indicating the purpose of the procedure, the

justification for it, and the manner in which it is carried out. In particular, the report shall include a statement that the subject or, where appropriate, his legal representative has been provided in advance with relevant information and has given his consent.

Where therapy has been carried out without consent, under the conditions referred to in the second paragraph of Section 5, the statement shall give full details of these conditions.

11. The results of any innovative therapy may be published only in a manner whereby the patient's dignity and the dictates of humanity are fully respected.
12. Sections 4–11 of these Guidelines shall be applicable, *mutatis mutandis,* to scientific experimentation (cf. Section 3).

    The following additional requirements shall apply to such experimentation:

    (a) experimentation shall be prohibited in all cases where consent has not been given;

    (b) experimentation involving human subjects shall be avoided if it can be replaced by animal studies. Experimentation involving human subjects may be carried out only after all data that can be collected by means of those biological methods (laboratory testing and animal studies) that are available to medical science for purposes of clarification and confirmation of the validity of the experiment have been obtained. Under these circumstances, motiveless and unplanned experimentation involving human subjects shall obviously be prohibited;

    (c) experimentation involving children or young persons under 18 years of age shall be prohibited if it in any way endangers the child or young person;

    (d) experimentation involving dying subjects is incompatible with the principles of medical ethics and shall therefore be prohibited.
13. While physicians and, more particularly, those in charge of hospital establishments may thus be expected to be guided by a strong sense of responsibility towards their patients, they should at the same time not be denied the satisfying responsibility (*verantwortungsfreudigkeit*) of seeking new ways to protect or treat patients or alleviate or remedy their suffering where they are convinced, in the light of their medical experience, that known methods are likely to fail.
14. Academic training courses should take every suitable opportunity to stress the physician's special duties when carrying out a new form of therapy or a scientific experiment as well as when publishing his results.

NUREMBERG CODE

1947

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The Nuremberg Military Tribunal's decision in the case of the United States v. Karl Brandt et al. includes what is now called the Nuremberg Code, a ten-point statement delimiting permissible medical experimentation on human subjects. According to this statement, human experimentation is justified only if its results benefit society and it is carried out in accord with basic principles that "satisfy moral, ethical, and legal concepts."

1. The voluntary consent of the human subject is absolutely essential.

   This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment.

   The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.
2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.
3. The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problem under study that the anticipated results will justify the performance of the experiment.
4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.

5. No experiment should be conducted where there is an a priori reason to believe that death or disabling injury will occur; except, perhaps, in those experiments where the experimental physicians also serve as subjects.
6. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
7. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.
8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.
9. During the course of the experiment the human subject should be at liberty to bring the experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.
10. During the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the exercise of the good faith, superior skill and careful judgment required of him that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

PRINCIPLES FOR THOSE IN RESEARCH AND EXPERIMENTATION

World Medical Association

1954

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Formulated by the Committee on Medical Ethics and adopted by the Eighth General Assembly of the World Medical Association (WMA), this document is the first set of guidelines governing research issued by the WMA and is the historical predecessor of the Declaration of Helsinki.

1. Scientific and Moral Aspects of Experimentation

   The word experimentation applies not only to experimentation itself but also to the experimenter. An individual cannot and should not attempt any kind of experimentation. Scientific qualities are indisputable and must always be respected. Likewise, there must be strict adherence to the general rules of respect of the individual.

2. Prudence and Discretion in the Publication of the First Results of Experimentation

   This principle applies primarily to the medical press and we are proud to note that in the majority of cases this rule has been adhered to by the editors of our journals. Then there is the general press which does not in every instance have the same rules of prudence and discretion as the medical press. The World Medical Association draws attention to the detrimental effects of premature or unjustified statements. In the interest of the public, each national association should consider methods of avoiding this danger.

3. Experimentation on Healthy Subjects

   Every step must be taken in order to make sure that those who submit themselves to experimentation be fully informed. The paramount factor in experimentation on human beings is the responsibility of the research worker and not the willingness of the person submitting to the experiment.

4. Experimentation on Sick Subjects

   Here it may be that in the presence of individual and desperate cases one may attempt an operation or a treatment of a rather daring nature. Such exceptions will be rare and require the approval either of the person or his next of kin. In such a situation it is the doctor's conscience which will make the decision.

5. Necessity of Informing the Person Who Submits to Experimentation of the Nature of the Experimentation, the Reasons for the Experiment, and the Risks Involved

   It should be required that each person who submits to experimentation be informed of the nature of, the reason for, and the risk of the proposed experiment. If the patient is irresponsible, consent should be obtained from the individual who is legally responsible for the individual. In both instances, consent should be obtained in writing.

ARTICLE SEVEN, INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS

General Assembly of the United Nations

1958

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Prepared by the Commission on Human Rights, the draft Covenant on Civil and Political Rights was first considered by the Third (Social, *Humanitarian, and Cultural) Committee of the General Assembly of the United Nations in 1954. Article Seven of the draft covenant was adopted in 1958. Discussion of the article focused primarily on the second sentence. Some members argued that emphasis on one type of cruel and inhuman treatment weakened the article. However, it was generally agreed that that sentence was directed against criminal experimentation, such as that conducted by Nazi physician-researchers, and should be retained. The difficulty lay in prohibiting criminal experimentation without hindering legitimate research.*

The committee entertained many amendments. Two notable discussions involved the "free consent" requirement and the phrase "…involving risk, where such is not required by his state of physical or mental health," which appeared at the end of the second sentence in the original draft. The committee ultimately retained the "free consent" requirement as an important criterion for determining when experimentation amounted to "cruel, inhuman, or degrading treatment." The committee also deleted the final phrase on the grounds that the term "experimentation" did not cover medical treatment that was required in the interest of an individual's health, and inclusion of the phrase would confuse the meaning of the provision by implying that scientific or medical practices directed toward an individual's welfare came within the scope of the article.

ARTICLE 7.

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

DECLARATION OF HELSINKI

World Medical Association

1964, REVISED 1975, 1983, 1989, 1996, 2000

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The Declaration of Helsinki, which offers recommendations for conducting experiments using human subjects, was adopted in 1962 and revised by the 18th World Medical Assembly at Helsinki, Finland, in 1964. Subsequent revisions were approved in Tokyo (1975), Venice (1983), Hong Kong (1989), Somerset West, Republic of South Africa (1996), and Edinburgh (2000).

<http://www.wma.net/e/policy/17-c_e.html>

A. INTRODUCTION

1. The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principles to provide guidance to physicians and other participants in medical research involving human subjects. Medical research involving human subjects includes research on identifiable human material or identifiable data.
2. It is the duty of the physician to promote and safeguard the health of the people. The physician's knowledge and conscience are dedicated to the fulfillment of this duty.
3. The Declaration of Geneva of the World Medical Association binds the physician with the words, "The health of my patient will be my first consideration," and the International Code of Medical Ethics declares that, "A physician shall act only in the patient's interest when providing medical care which might have the effect of weakening the physical and mental condition of the patient."
4. Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects.
5. In medical research on human subjects, considerations related to the well-being of the human subject should take precedence over the interests of science and society.
6. The primary purpose of medical research involving human subjects is to improve prophylactic, diagnostic and therapeutic procedures and the understanding of the aetiology and pathogenesis of disease. Even the best proven prophylactic, diagnostic, and therapeutic methods must continuously be challenged through research for their effectiveness, efficiency, accessibility and quality.
7. In current medical practice and in medical research, most prophylactic, diagnostic and therapeutic procedures involve risks and burdens.
8. Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. Some research populations are vulnerable and need special protection. The particular needs of the economically and medically disadvantaged must be recognized. Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those for whom the research is combined with care.
9. Research Investigators should be aware of the ethical, legal and regulatory requirements for research on human subjects in their own countries as well as applicable international requirements. No national ethical, legal or regulatory requirement should be allowed to reduce or eliminate any of the protections for human subjects set forth in this Declaration.

B. BASIC PRINCIPLES FOR ALL MEDICAL RESEARCH

10. It is the duty of the physician in medical research to protect the life, health, privacy, and dignity of the human subject.
11. Medical research involving human subjects must conform to generally accepted scientific principles, be based on a thorough knowledge of the scientific literature, other relevant sources of information, and on adequate laboratory and, where appropriate, animal experimentation.
12. Appropriate caution must be exercised in the conduct of research which may affect the environment, and the welfare of animals used for research must be respected.
13. The design and performance of each experimental procedure involving human subjects should be clearly formulated in an experimental protocol. This protocol should be submitted for consideration, comment, guidance, and where appropriate, approval to a specially appointed ethical review committee, which must be independent of the investigator, the sponsor or any other kind of undue influence. This independent committee should be in conformity with the laws and regulations of the country in which the research experiment is performed. The committee has the right to monitor ongoing trials. The researcher has the obligation to provide monitoring information to the committee, especially any serious adverse events. The researcher should also submit to the committee, for review, information regarding funding, sponsors, institutional affiliations, other potential conflicts of interest and incentives for subjects.
14. The research protocol should always contain a statement of the ethical considerations involved and should indicate that there is compliance with the principles enunciated in this Declaration.
15. Medical research involving human subjects should be conducted only by scientifically qualified persons and under the supervision of a clinically competent medical person. The responsibility for the human subject must always rest with a medically qualified person and never rest on the subject of the research, even though the subject has given consent.
16. Every medical research project involving human subjects should be preceded by careful assessment of predictable risks and burdens in comparison with foreseeable benefits to the subject or to others. This does not preclude the participation of healthy volunteers in medical research. The design of all studies should be publicly available.
17. Physicians should abstain from engaging in research projects involving human subjects unless they are confident that the risks involved have been adequately assessed and can be satisfactorily managed. Physicians should cease any investigation if the risks are found to outweigh the potential benefits or if there is conclusive proof of positive and beneficial results.
18. Medical research involving human subjects should only be conducted if the importance of the objective outweighs the inherent risks and burdens to the subject. This is especially important when the human subjects are healthy volunteers.
19. Medical research is only justified if there is a reasonable likelihood that the populations in which the research is carried out stand to benefit from the results of the research.
20. The subjects must be volunteers and informed participants in the research project.
21. The right of research subjects to safeguard their integrity must always be respected. Every precaution should be taken to respect the privacy of the subject, the confidentiality of the patient's information and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject.
22. In any research on human beings, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail. The subject should be informed of the right to abstain from participation in the study or to withdraw consent to participate at any time without reprisal. After ensuring that the subject has understood the information, the physician should then obtain the subject's freely-given informed consent, preferably in writing. If the consent cannot be obtained in writing, the non-written consent must be formally documented and witnessed.
23. When obtaining informed consent for the research project the physician should be particularly cautious if the subject is in a dependent relationship with the physician or may consent under duress. In that case the informed consent should be obtained by a well-informed physician who is not engaged in the investigation and who is completely independent of this relationship.
24. For a research subject who is legally incompetent, physically or mentally incapable of giving consent or is a legally incompetent minor, the investigator must obtain informed consent from the legally authorized representative in accordance with applicable law. These groups should not be

included in research unless the research is necessary to promote the health of the population represented and this research cannot instead be performed on legally competent persons.

25. When a subject deemed legally incompetent, such as a minor child, is able to give assent to decisions about participation in research, the investigator must obtain that assent in addition to the consent of the legally authorized representative.
26. Research on individuals from whom it is not possible to obtain consent, including proxy or advance consent, should be done only if the physical/mental condition that prevents obtaining informed consent is a necessary characteristic of the research population. The specific reasons for involving research subjects with a condition that renders them unable to give informed consent should be stated in the experimental protocol for consideration and approval of the review committee. The protocol should state that consent to remain in the research should be obtained as soon as possible from the individual or a legally authorized surrogate.
27. Both authors and publishers have ethical obligations. In publication of the results of research, the investigators are obliged to preserve the accuracy of the results. Negative as well as positive results should be published or otherwise publicly available. Sources of funding, institutional affiliations and any possible conflicts of interest should be declared in the publication. Reports of experimentation not in accordance with the principles laid down in this Declaration should not be accepted for publication.

C. ADDITIONAL PRINCIPLES FOR MEDICAL RESEARCH COMBINED WITH MEDICAL CARE

28. The physician may combine medical research with medical care, only to the extent that the research is justified by its potential prophylactic, diagnostic or therapeutic value. When medical research is combined with medical care, additional standards apply to protect the patients who are research subjects.
29. The benefits, risks, burdens and effectiveness of a new method should be tested against those of the best current prophylactic, diagnostic, and therapeutic methods. This does not exclude the use of placebo, or no treatment, in studies where no proven prophylactic, diagnostic or therapeutic method exists. See footnote
30. At the conclusion of the study, every patient entered into the study should be assured of access to the best proven prophylactic, diagnostic and therapeutic methods identified by the study.
31. The physician should fully inform the patient which aspects of the care are related to the research. The refusal of a patient to participate in a study must never interfere with the patient-physician relationship.
32. In the treatment of a patient, where proven prophylactic, diagnostic and therapeutic methods do not exist or have been ineffective, the physician, with informed consent from the patient, must be free to use unproven or new prophylactic, diagnostic and therapeutic measures, if in the physician's judgement it offers hope of saving life, re-establishing health or alleviating suffering. Where possible, these measures should be made the object of research, designed to evaluate their safety and efficacy. In all cases, new information should be recorded and, where appropriate, published. The other relevant guidelines of this Declaration should be followed.

Footnote: Note of Clarification on Paragraph 29 of the WMA Declaration of Helsinki

The WMA hereby reaffirms its position that extreme care must be taken in making use of a placebo-controlled trial and that in general this methodology should only be used in the absence of existing proven therapy. However, a placebo-controlled trial may be ethically acceptable, even if proven therapy is available, under the following circumstances:

- — Where for compelling and scientifically sound methodological reasons its use is necessary to determine the efficacy or safety of a prophylactic, diagnostic or therapeutic method; or
- — Where a prophylactic, diagnostic or therapeutic method is being investigated for a minor condition and the patients who receive placebo will not be subject to any additional risk of serious or irreversible harm.

All other provisions of the Declaration of Helsinki must be adhered to, especially the need for appropriate ethical and scientific review.

The Declaration of Helsinki (Document 17.C) is an official policy document of the World Medical Association, the global representative body for physicians. It was first adopted in 1964 (Helsinki, Finland) and revised in 1975 (Tokyo, Japan), 1983 (Venice, Italy), 1989 (Hong Kong), 1996 (Somerset-West, South Africa) and 2000 (Edinburgh, Scotland). Note of clarification on Paragraph 29 added by the WMA General Assembly, Washington 2002.

THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research

1979

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The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was created when the National Research Act (P.L. 93–348) became law on July 12, 1974. One of its mandates was to identify the basic ethical principles that should underlie research involving human subjects and to develop guidelines to ensure that such research is conducted in accordance with those principles. Since the first set of federal guidelines for human experimentation applicable to all programs under the auspices of what was then the Department of Health, Education, and Welfare (DHEW) was enacted in 1971, the National Commission's task, in part, was to identify and articulate the theoretical principles upon which those already existing guidelines were based.

After nearly four years of deliberation, the commission published its findings as the Belmont Report, which is printed below. The current, 1991 revision of the 1971 federal guidelines for human experimentation are also included in this section of the Appendix. Federal regulations require that every U.S. research institution that receives federal funds for research involving human subjects adopt a statement of principles to govern the protection of human subjects of research, and virtually all such institutions have endorsed the Belmont principles. Many research institutions outside of the United States also endorse the Belmont principles; however, the majority of foreign institutions cite the Declaration of Helsinki as their core ethical standard.

Scientific research has produced substantial social benefits. It has also posed some troubling ethical questions. Public attention was drawn to these questions by reported abuses of human subjects in biomedical experiments, especially during the Second World War. During the Nuremberg War Crime Trials, the Nuremberg code was drafted as a set of standards for judging physicians and scientists who had conducted biomedical experiments on concentration camp prisoners. This code became the prototype of many later codes intended to assure that research involving human subjects would be carried out in an ethical manner.

The codes consist of rules, some general, others specific, that guide the investigators or the reviewers of research in their work. Such rules often are inadequate to cover complex situations; at times they come into conflict, and they are frequently difficult to interpret or apply. Broader ethical principles will provide a basis on which specific rules may be formulated, criticized and interpreted.

Three principles, or general prescriptive judgments, that are relevant to research involving human subjects are identified in this statement. Other principles may also be relevant. These three are comprehensive, however, and are stated at a level of generalization that should assist scientists, subjects, reviewers and interested citizens to understand the ethical issues inherent in research involving human subjects. These principles cannot always be applied so as to resolve beyond dispute particular ethical problems. The objective is to provide an analytical framework that will guide the resolution of ethical problems arising from research involving human subjects.

This statement consists of a distinction between research and practice, a discussion of the three basic ethical principles, and remarks about the application of these principles.

A. Boundaries Between Practice and Research

It is important to distinguish between biomedical and behavioral research, on the one hand, and the practice of accepted therapy on the other, in order to know what activities ought to undergo review for the protection of human subjects of research. The distinction between research and practice is blurred partly because both often occur together (as in research designed to evaluate a therapy) and partly because notable departures from standard practice are often called "experimental" when the terms "experimental" and "research" are not carefully defined.

For the most part, the term "practice" refers to interventions that are designed solely to enhance the well-being of an individual patient or client and that have a reasonable expectation of success. The purpose of medical or behavioral practice is to provide diagnosis, preventive treatment or therapy to particular individuals. By contrast, the term "research" designates an activity designed to test an hypothesis, permit conclusions to be drawn, and thereby to develop or contribute to generalizable knowledge (expressed, for example, in theories, principles, and statements of relationships). Research is usually described in a formal protocol that sets forth an objective and a set of procedures designed to reach that objective.

When a clinician departs in a significant way from standard or accepted practice, the innovation does not, in and of itself, constitute research. The fact that a procedure is "experimental," in the sense of new, untested or different, does not automatically place it in the category of research.

Radically new procedures of this description should, however, be made the object of formal research at an early stage in order to determine whether they are safe and effective. Thus, it is the responsibility of medical practice committees, for example, to insist that a major innovation be incorporated into a formal research project.

Research and practice may be carried on together when research is designed to evaluate the safety and efficacy of a therapy. This need not cause any confusion regarding whether or not the activity requires review; the general rule is that if there is any element of research in an activity, that activity should undergo review for the protection of human subjects.

B. Basic Ethical Principles

The expression "basic ethical principles" refers to those general judgments that serve as a basic justification for the many particular ethical prescriptions and evaluations of human actions. Three basic principles, among those generally accepted in our cultural tradition, are particularly relevant to the ethics of research involving human subjects: the principles of respect for persons, beneficence and justice.

1. Respect for Persons. — Respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy.

An autonomous person is an individual capable of deliberation about personal goals and of acting under the direction of such deliberation. To respect autonomy is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others. To show lack of respect for an autonomous agent is to repudiate that person's considered judgments, to deny an individual the freedom to act on those considered judgments, or to withhold information necessary to make a considered judgment, when there are no compelling reasons to do so.

However, not every human being is capable of self-determination. The capacity for self-determination matures during an individual's life, and some individuals lose this capacity wholly or in part because of illness, mental disability, or circumstances that severely restrict liberty. Respect for the immature and the incapacitated may require protecting them as they mature or while they are incapacitated.

Some persons are in need of extensive protection, even to the point of excluding them from activities which may harm them; other persons require little protection beyond making sure they undertake activities freely and with awareness of possible adverse consequences. The extent of protection afforded should depend upon the risk of harm and the likelihood of benefit. The judgment that any individual lacks autonomy should be periodically reevaluated and will vary in different situations.

In most cases of research involving human subjects, respect for persons demands that subjects enter into the research voluntarily and with adequate information. In some situations, however, application of the principle is not obvious. The involvement of prisoners as subjects of research provides an instructive example. On the one hand, it would seem that the principle of respect for persons requires that prisoners not be deprived of the opportunity to volunteer for research. On the other hand, under prison conditions they may be subtly coerced or unduly influenced to engage in research activities for which they would not otherwise volunteer. Respect for persons would then dictate that prisoners be protected. Whether to allow prisoners to "volunteer" or to "protect" them presents a dilemma. Respecting persons, in most hard cases, is often a matter of balancing competing claims urged by the principle of respect itself.

2. Beneficence. — Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being. Such treatment falls under the principle of beneficence. The term "beneficence" is often understood to cover acts of kindness or charity that go beyond strict obligation. In this document, beneficence is understood in a stronger sense, as an obligation. Two general rules have been formulated as complementary expressions of beneficent actions in this sense: (1) do not harm and (2) maximize possible benefits and minimize possible harms.

The Hippocratic maxim "do no harm" has long been a fundamental principle of medical ethics. Claude Bernard extended it to the realm of research, saying that one should not injure one person regardless of the benefits that might come to others. However, even avoiding harm requires learning what is harmful; and, in the process of obtaining this information, persons may be exposed to risk of harm. Further, the Hippocratic Oath requires physicians to benefit their patients "according to their best judgment." Learning what will in fact benefit may require exposing persons to risk. The problem posed by these imperatives is to decide when it is justifiable to seek certain benefits despite the risks involved, and when the benefits should be foregone because of the risks.

The obligations of beneficence affect both individual investigators and society at large, because they extend both to particular research projects and to the entire enterprise of research. In the case of particular projects, investigators and members of their institutions are obliged to give forethought to the maximization of benefits and the reduction of risk that might occur from the research investigation. In the case of scientific research in general, members of the larger society are obliged to recognize the longer term benefits and risks that may result from the improvement of knowledge and from the development of novel medical, psychotherapeutic, and social procedures.

The principle of beneficence often occupies a well-defined justifying role in many areas of research involving human subjects. An example is found in research involving children. Effective ways of treating childhood diseases and fostering healthy development are benefits that serve to justify research involving children—even when individual research subjects are not direct beneficiaries. Research also makes it possible to avoid the harm that may result from the application of previously accepted routine practices that on closer investigation turn out to be dangerous. But the role of the principle of beneficence is not always so unambiguous. A difficult ethical problem remains, for example, about research that presents more than minimal risk without immediate prospect of direct benefit to the children involved. Some have argued that such research is inadmissible, while others have pointed out that this limit would rule out much research promising great benefit to children in the future. Here again, as with all hard cases, the different claims covered by the principle of beneficence may come into conflict and force difficult choices.

3. Justice. — Who ought to receive the benefits of research and bear its burdens? This is a question of justice, in the sense of "fairness in distribution" or "what is deserved." An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly. Another way of conceiving the principle of justice is that equals ought to be treated equally. However, this statement requires explication. Who is equal and who is unequal? What considerations justify departure from equal distribution? Almost all commentators allow that distinctions based on experience, age, deprivation, competence, merit and position do sometimes constitute criteria justifying differential treatment for certain purposes. It is necessary, then, to explain in what respects people should be treated equally. There are several widely accepted formulations of just ways to distribute burdens and benefits. Each formulation mentions some relevant property on the basis of which burdens and benefits should be distributed. These formulations are (1) to each person an equal share, (2) to each person according to individual need, (3) to each person according to individual effort, (4) to each person according to societal contribution, and (5) to each person according to merit.

Questions of justice have long been associated with social practices such as punishment, taxation and political representation. Until recently these questions have not generally been associated with scientific research. However, they are foreshadowed even in the earliest reflections on the ethics of research involving human subjects. For example, during the 19th and early 20th centuries the burdens of serving as research subjects fell largely upon poor ward patients, while the benefits of improved medical care flowed primarily to private patients. Subsequently, the exploitation of unwilling prisoners as research subjects in Nazi concentration camps was condemned as a particularly flagrant injustice. In this country, in the 1940's, the Tuskegee syphilis study used disadvantaged, rural black men to study the untreated course of a disease that is by no means confined to that population. These subjects were deprived of demonstrably effective treatment in order not to interrupt the project, long after such treatment became generally available.

Against this historical background, it can be seen how conceptions of justice are relevant to research involving human subjects. For example, the selection of research subjects needs to be scrutinized in order to determine whether some classes (e.g., welfare patients, particularly racial and ethnic minorities, or persons confined to institutions) are being systematically selected simply because of their easy availability, their compromised position, or their manipulability, rather than for reasons directly related to the problem being studied. Finally, whenever research supported by public funds leads to the development of therapeutic devices and procedures, justice demands both that these not provide advantages only to those who can afford them and that such research should not unduly involve persons from groups unlikely to be among the beneficiaries of subsequent applications of the research.

C. Applications

Applications of the general principles to the conduct of research leads to consideration of the following requirements: informed consent, risk/benefit assessment, and the selection of subjects of research.

1. Informed Consent. — Respect for persons requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them. This opportunity is provided when adequate standards for informed consent are satisfied.

While the importance of informed consent is unquestioned, controversy prevails over the nature and possibility of an informed consent. Nonetheless, there is widespread agreement that the consent process can be analyzed as containing three elements: information, comprehension and voluntariness.

Information. Most codes of research establish specific items for disclosure intended to assure that subjects are given sufficient information. These items generally include: the research procedure, their purposes, risks and anticipated benefits, alternative procedures (where therapy is involved), and a statement offering the subject the opportunity to ask questions and to withdraw at any time from the research. Additional items have been proposed, including how subjects are selected, the person responsible for the research, etc.

However, a simple listing of items does not answer the question of what the standard should be for judging how much and what sort of information should be provided. One standard frequently invoked in medical practice, namely the information commonly provided by practitioners in the field or in the locale, is inadequate since research takes place precisely when a common understanding does not exist. Another standard, currently popular in malpractice law, requires the practitioner to reveal the information that reasonable persons would wish to know in order to make a decision regarding their care. This, too, seems insufficient since the research subject, being in essence a volunteer, may wish to know considerably more about risks gratuitously undertaken than do patients who deliver themselves into the hand of a clinician for needed care. It may be that a standard of “the reasonable volunteer” should be proposed: the extent and nature of information should be such that persons, knowing that the procedure is neither necessary for their care nor perhaps fully understood, can decide whether they wish to participate in the furthering of knowledge. Even when some direct benefit to them is anticipated, the subjects should understand clearly the range of risk and the voluntary nature of participation.

A special problem of consent arises where informing subjects of some pertinent aspect of the research is likely to impair the validity of the research. In many cases, it is sufficient to indicate to subjects that they are being invited to participate in research of which some features will not be revealed until the research is concluded. In all cases of research involving incomplete disclosure, such research is justified only if it is clear that (1) incomplete disclosure is truly necessary to accomplish the goals of the research, (2) there are no undisclosed risks to subjects that are more than minimal, and (3) there is an adequate plan for debriefing subjects, when appropriate, and for dissemination of research results to them. Information about risks should never be withheld for the purpose of eliciting the cooperation of subjects, and truthful answers should always be given to direct questions about the research. Care should be taken to distinguish cases in which disclosure would destroy or invalidate the research from cases in which disclosure would simply inconvenience the investigator.

Comprehension. The manner and context in which information is conveyed is as important as the information itself. For example, presenting information in a disorganized and rapid fashion, allowing too little time for consideration or curtailing opportunities for questioning, all may adversely affect a subject’s ability to make an informed choice.

Because the subject’s ability to understand is a function of intelligence, rationality, maturity and language, it is necessary to adapt the presentation of the information to the subject’s capacities. Investigators are responsible for ascertaining that the subject has comprehended the information. While there is always an obligation to ascertain that the information about risk to subjects is complete and adequately comprehended, when the risks are more serious, that obligation increases. On occasion, it may be suitable to give some oral or written tests of comprehension.

Special provision may need to be made when comprehension is severely limited—for example, by conditions of immaturity or mental disability. Each class of subjects that one might consider as incompetent (e.g., infants and young children, mentally disabled patients, the terminally ill and the comatose) should be considered on its own terms. Even for these persons, however, respect requires giving them the opportunity to choose to the extent they are able, whether or not to participate in research. The objections of these subjects to involvement should be honored, unless the research entails providing them a therapy unavailable elsewhere. Respect for persons also requires seeking the permission of other parties in order to protect the subjects from harm. Such persons are thus respected both by acknowledging their own wishes and by the use of third parties to protect them from harm.

The third parties chosen should be those who are most likely to understand the incompetent subject’s situation and to act in that person’s best interest. The person authorized to act on behalf of the subject should be given an opportunity to observe the research as it proceeds in order to be able to withdraw the subject from the research, if such action appears in the subject’s best interest.

Voluntariness. An agreement to participate in research constitutes a valid consent only if voluntarily given. This element of informed consent requires conditions free of coercion and undue influence. Coercion occurs when an overt threat of harm is intentionally presented by one person to another in order to obtain compliance. Undue influence, by contrast, occurs through an offer of an excessive, unwarranted, inappropriate or improper reward or other overture in order to obtain compliance. Also, inducements that would ordinarily be acceptable may become undue influences if the subject is especially vulnerable.

Unjustifiable pressures usually occur when persons in positions of authority or commanding influence—especially where possible sanctions are involved—urge a course of action for a subject. A continuum of such influencing factors exists, however, and it is impossible to state precisely where justifiable persuasion ends and undue influence begins. But undue influence would include actions such as manipulating a person's choice through the controlling influence of a close relative and threatening to withdraw health services to which an individual would otherwise be entitled.

2. Assessment of Risks and Benefits. — The assessment of risks and benefits requires a careful arrayal of relevant data, including, in some cases, alternative ways of obtaining the benefits sought in the research. Thus, the assessment presents both an opportunity and a responsibility to gather systematic and comprehensive information about proposed research. For the investigator, it is a means to examine whether the proposed research is properly designed. For a review committee, it is a method for determining whether the risks that will be presented to subjects are justified. For prospective subjects, the assessment will assist the determination whether or not to participate.

The Nature and Scope of Risks and Benefits. The requirement that research be justified on the basis of a favorable risk/benefit assessment bears a close relation to the principle of beneficence, just as the moral requirement that informed consent be obtained is derived primarily from the principle of respect for persons. The term "risk" refers to a possibility that harm may occur. However, when expressions such as "small risk" or "high risk" are used, they usually refer (often ambiguously) both to the chance (probability) of experiencing a harm and the severity (magnitude) of the envisioned harm.

The term "benefit" is used in the research context to refer to something of positive value related to health or welfare. Unlike "risk," "benefit" is not a term that expresses probabilities. Risk is properly contrasted to probability of benefits, and benefits are properly contrasted with harms rather than risks of harm. Accordingly, so-called risk benefit assessments are concerned with the probabilities and magnitudes of possible harms and anticipated benefits. Many kinds of possible harms and benefits need to be taken into account. There are, for example, risks of psychological harm, physical harm, legal harm, social harm and economic harm and the corresponding benefits. While the most likely types of harms to research subjects are those of psychological or physical pain or injury, other possible kinds should not be overlooked.

Risks and benefits of research may affect the individual subjects, the families of the individual subjects, and society at large (or special groups of subjects in society). Previous codes and Federal regulations have required that risks to subjects be outweighed by the sum of both the anticipated benefit to the subject, if any, and the anticipated benefit to society in the form of knowledge to be gained from the research. In balancing these different elements, the risks and benefits affecting the immediate research subject will normally carry special weight. On the other hand, interests other than those of the subject may on some occasions be sufficient by themselves to justify the risks involved in the research, so long as the subjects' rights have been protected. Beneficence thus requires that we protect against risk of harm to subjects and also that we be concerned about the loss of the substantial benefits that might be gained from research.

The Systematic Assessment of Risks and Benefits. It is commonly said that benefits and risks must be "balanced" and shown to be "in a favorable ratio." The metaphorical character of these terms draws attention to the difficulty of making precise judgments. Only on rare occasions will quantitative techniques be available for the scrutiny of research protocols. However, the idea of systematic, nonarbitrary analysis of risks and benefits should be emulated insofar as possible. This ideal requires those making decisions about the justifiability of research to be thorough in the accumulation and assessment of information about all aspects of the research, and to consider alternatives systematically. This procedure renders the assessment of research more rigorous and precise, while making communication between review board members and investigators less subject to misinterpretation, misinformation and conflicting judgments. Thus, there should first be a determination of the validity of the presuppositions of the research; then the nature, probability and magnitude of risk should be distinguished with as much clarity as possible. The method of ascertaining risks should be explicit, especially where there is no alternative to the use of such vague categories as small or slight risk. It should also be determined whether an investigator's estimates of the probability of harm or benefits are reasonable, as judged by known facts or other available studies.

Finally, assessment of the justifiability of research should reflect at least the following considerations: (i) Brutal or inhumane treatment of human subjects is never morally justified. (ii) Risks should be reduced to those necessary to achieve the research objective. It should be determined whether it is in fact necessary to use human subjects at all. Risk can perhaps never be entirely eliminated, but it can often be reduced by careful attention to alternative procedures. (iii) When research involves significant risk of serious impairment, review committees should be extraordinarily insistent on the justification of the risk (looking usually to the likelihood of benefit to the subject—or, in some rare cases, to the manifest voluntariness of the participation). (iv) When vulnerable populations are involved in research, the appropriateness of involving them should itself be demonstrated. A number of variables go into such judgments, including the nature and degree of risk, the condition of the particular population involved, and the nature and level of the anticipated benefits. (v) Relevant risks and benefits must be thoroughly arrayed in documents and procedures used in the informed consent process.

3. Selection of Subjects. — Just as the principle of respect for persons finds expression in the requirements for consent, and the principle of beneficence in risk benefit assessment, the principle of justice gives rise to moral requirements that there be fair procedures and outcomes in the selection of research subjects.

Justice is relevant to the selection of subjects of research at two levels: the social and the individual. Individual justice in the selection of subjects would require that researchers exhibit fairness: thus, they should not offer potentially beneficial research only to some patients who are in their favor or select only “undesirable” persons for risky research. Social justice requires that distinction be drawn between classes of subjects that ought, and ought not, to participate in any particular kind of research, based on the ability of members of that class to bear burdens and on the appropriateness of placing further burdens on already burdened persons. Thus, it can be considered a matter of social justice that there is an order of preference in the selection of classes of subjects (e.g., adults before children) and that some classes of potential subjects (e.g., the institutionalized mentally infirm or prisoners) may be involved as research subjects, if at all, only on certain conditions.

Injustice may appear in the selection of subjects, even if individual subjects are selected fairly by investigators and treated fairly in the course of research. Thus injustice arises from social, racial, sexual and cultural biases institutionalized in society. Thus, even if individual researchers are treating their research subjects fairly, and even if IRBs are taking care to assure that subjects are selected fairly within a particular institution, unjust social patterns may nevertheless appear in the overall distribution of the burdens and benefits of research. Although individual institutions or investigators may not be able to resolve a problem that is pervasive in their social setting, they can consider distributive justice in selecting research subjects.

Some populations, especially institutionalized ones, are already burdened in many ways by their infirmities and environments. When research is proposed that involves risks and does not include a therapeutic component, other less burdened classes of persons should be called upon first to accept these risks of research, except where the research is directly related to the specific conditions of the class involved. Also, even though public funds for research may often flow in the same directions as public funds for health care, it seems unfair that populations dependent on public health care constitute a pool of preferred research subjects if more advantaged populations are likely to be the recipients of the benefits.

One special instance of injustice results from the involvement of vulnerable subjects. Certain groups, such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized may continually be sought as research subjects, owing to their ready availability in settings where research is conducted. Given their dependent status and their frequently compromised capacity for free consent, they should be protected against the danger of being involved in research solely for administrative convenience, or because they are easy to manipulate as a result of their illness or socioeconomic condition.

DHHS REGULATIONS FOR THE PROTECTION OF HUMAN SUBJECTS (45 CFR 46)

JUNE 18, 1991

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Between 1953 and 1971 various agencies within the U.S. Department of Health, Education, and Welfare (DHEW), now the Department of Health and Human Services (DHHS), issued their own guidelines on human experimentation. Finally, in 1971, the first set of federal guidelines for human experimentation applicable to all DHEW programs was established. Those guidelines were revised slightly and officially published (May 30, 1974) as part of the Code of Federal Regulations (Title 45, Subtitle A, Part 46).

In 1981, the regulations underwent a major revision in light of various reports by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, which also issued the Belmont Report (see preceding document). The regulations were expanded to include guidelines for research involving fetuses, pregnant women, and human in vitro fertilization (Subpart B); children (Subpart C); and prisoners (Subpart D).

In June 1991, a revised Federal Policy for the Protection of Human Subjects (Subpart A) was adopted as "the Common Rule" by fifteen federal departments and agencies and the Office of Science and Technology Policy. Subparts B, C, and D remain directly applicable only to DHHS-supported human subjects research. The regulations were most recently revised November 13, 2001.

Subpart A—Federal Policy for the Protection of Human Subjects

(Basic DHHS Policy for Protection of Human Research Subjects)

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<http://ohrp.osophs.dhhs.gov/humansubjects/guidance/45cfr46.htm>

§46.101 To what does this policy apply?

(a) Except as provided in paragraph (b) of this section, this policy applies to all research involving human subjects conducted, supported or otherwise subject to regulation by any Federal Department or Agency which takes appropriate administrative action to make the policy applicable to such research. This includes research conducted by Federal civilian employees or military personnel, except that each Department or Agency head may adopt such procedural modifications as may be appropriate from an administrative standpoint. It also includes research conducted, supported, or otherwise subject to regulation by the Federal Government outside the United States.

  (1) Research that is conducted or supported by a Federal Department or Agency, whether or not it is regulated as defined in §46.102(e), must comply with all sections of this policy.

  (2) Research that is neither conducted nor supported by a Federal Department or Agency but is subject to regulation as defined in §46.102(e) must be reviewed and approved, in compliance with §46.101, §46.102, and §46.107 through §46.117 of this policy, by an Institutional Review Board (IRB) that operates in accordance with the pertinent requirements of this policy.

(b) Unless otherwise required by Department or Agency heads, research activities in which the only involvement of human subjects will be in one or more of the following categories are exempt from this policy:1

(1) Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

(3) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior that is not exempt under paragraph (b)(2) of this section, if:

  (i) the human subjects are elected or appointed public officials or candidates for public office; or (ii) Federal statute(s) require(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.

(4) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

(5) Research and demonstration projects which are conducted by or subject to the approval of Department or Agency heads, and which are designed to study, evaluate, or otherwise examine:

  (i) Public benefit or service programs; (ii) procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; or (iv) possible changes in methods or levels of payment for benefits or services under those programs.

(6) Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome foods

without additives are consumed or (ii) if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the Food and Drug Administration or approved by the Environmental Protection Agency or the Food Safety and Inspection Service of the U.S. Department of Agriculture.

(c) Department or Agency heads retain final judgment as to whether a particular activity is covered by this policy.

(d) Department or Agency heads may require that specific research activities or classes of research activities conducted, supported, or otherwise subject to regulation by the Department or Agency but not otherwise covered by this policy, comply with some or all of the requirements of this policy.

(e) Compliance with this policy requires compliance with pertinent Federal laws or regulations which provide additional protections for human subjects.

(f) This policy does not affect any State or local laws or regulations which may otherwise be applicable and which provide additional protections for human subjects.

(g) This policy does not affect any foreign laws or regulations which may otherwise be applicable and which provide additional protections to human subjects of research.

(h) When research covered by this policy takes place in foreign countries, procedures normally followed in the foreign countries to protect human subjects may differ from those set forth in this policy. [An example is a foreign institution which complies with guidelines consistent with the World Medical Assembly Declaration (Declaration of Helsinki amended 1989) issued either by sovereign states or by an organization whose function for the protection of human research subjects is internationally recognized.] In these circumstances, if a Department or Agency head determines that the procedures prescribed by the institution afford protections that are at least equivalent to those provided in this policy, the Department or Agency head may approve the substitution of the foreign procedures in lieu of the procedural requirements provided in this policy. Except when otherwise required by statute, Executive Order, or the Department or Agency head, notices of these actions as they occur will be published in the Federal Register or will be otherwise published as provided in Department or Agency procedures.

(i) Unless otherwise required by law, Department or Agency heads may waive the applicability of some or all of the provisions of this policy to specific research activities or classes or research activities otherwise covered by this policy. Except when otherwise required by statute or Executive Order, the Department or Agency head shall forward advance notices of these actions to the Office for Protection from Research Risks, National Institutes of Health, Department of Health and Human Services (DHHS), and shall also publish them in the Federal Register or in such other manner as provided in Department or Agency procedures.[1]

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[1] Institutions with DHHS-approved assurances on file will abide by provisions of Title 45 CFR Part 46 Subparts A-D. Some of the other departments and agencies have incorporated all provisions of Title 45 CFR Part 46 into their policies and procedures as well. However, the exemptions at 45 CFR 46.101(b) do not apply to research involving prisoners, fetuses, pregnant women, or human in vitro fertilization, Subparts B and C. The exemption at 45 CFR 46.101(b)(2), for research involving survey or interview procedures or observation of public behavior, does not apply to research with children, Subpart D, except for research involving observations of public behavior when the investigator(s) do not participate in the activities being observed.

§46.102 Definitions.

(a) *Department or Agency* head means the head of any Federal Department or Agency and any other officer or employee of any Department or Agency to whom authority has been delegated.

(b) *Institution* means any public or private entity or Agency (including Federal, State, and other agencies).

(c) *Legally authorized representative* means an individual or judicial or other body authorized under applicable law to consent on behalf of a prospective subject to the subject's participation in the procedure(s) involved in the research.

(d) *Research* means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge. Activities which meet this definition constitute research for purposes of this policy, whether or not they are conducted or supported under a program which is considered research for other purposes. For example, some demonstration and service programs may include research activities.

(e) *Research subject to regulation,* and similar terms are intended to encompass those research activities for which a Federal Department or Agency has specific responsibility for regulating as a research activity, (for example, Investigational New Drug requirements administered by the Food and Drug

Administration). It does not include research activities which are incidentally regulated by a Federal Department or Agency solely as part of the Department's or Agency's broader responsibility to regulate certain types of activities whether research or non-research in nature (for example, Wage and Hour requirements administered by the Department of Labor).

(f) *Human subject* means a living individual about whom an investigator (whether professional or student) conducting research obtains

(1) data through intervention or interaction with the individual, or

(2) identifiable private information.

Intervention includes both physical procedures by which data are gathered (for example, venipuncture) and manipulations of the subject or the subject's environment that are performed for research purposes. *Interaction* includes communication or interpersonal contact between investigator and subject. *Private information* includes information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (for example, a medical record). Private information must be individually identifiable (i.e., the identity of the subject is or may readily be ascertained by the investigator or associated with the information) in order for obtaining the information to constitute research involving human subjects.

(g) *IRB* means an Institutional Review Board established in accord with and for the purposes expressed in this policy.

(h) *IRB approval* means the determination of the IRB that the research has been reviewed and may be conducted at an institution within the constraints set forth by the IRB and by other institutional and Federal requirements.

(i) *Minimal risk* means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.

(j) *Certification* means the official notification by the institution to the supporting Department or Agency, in accordance with the requirements of this policy, that a research project or activity involving human subjects has been reviewed and approved by an IRB in accordance with an approved assurance.

§46.103 Assuring compliance with this policy—research conducted or supported by any Federal Department or Agency.

(a) Each institution engaged in research which is covered by this policy and which is conducted or supported by a Federal Department or Agency shall provide written assurance satisfactory to the Department or Agency head that it will comply with the requirements set forth in this policy. In lieu of requiring submission of an assurance, individual Department or Agency heads shall accept the existence of a current assurance, appropriate for the research in question, on file with the Office for Protection from Research Risks, National Institutes Health, DHHS, and approved for Federal-wide use by that office. When the existence of an DHHS-approved assurance is accepted in lieu of requiring submission of an assurance, reports (except certification) required by this policy to be made to Department and Agency heads shall also be made to the Office for Protection from Research Risks, National Institutes of Health, DHHS.

(b) Departments and agencies will conduct or support research covered by this policy only if the institution has an assurance approved as provided in this section, and only if the institution has certified to the Department or Agency head that the research has been reviewed and approved by an IRB provided for in the assurance, and will be subject to continuing review by the IRB. Assurances applicable to federally supported or conducted research shall at a minimum include:

(1) A statement of principles governing the institution in the discharge of its responsibilities for protecting the rights and welfare of human subjects of research conducted at or sponsored by the institution, regardless of whether the research is subject to Federal regulation. This may include an appropriate existing code, declaration, or statement of ethical principles, or a statement formulated by the institution itself. This requirement does not preempt provisions of this policy applicable to Department- or Agency-supported or regulated research and need not be applicable to any research exempted or waived under §46.101 (b) or (i).

(2) Designation of one or more IRBs established in accordance with the requirements of this policy, and for which provisions are made for meeting space and sufficient staff to support the IRB's review and recordkeeping duties.

(3) A list of IRB members identified by name; earned degrees; representative capacity; indications of experience such as board certifications,

licenses, etc., sufficient to describe each member's chief anticipated contributions to IRB deliberations; and any employment or other relationship between each member and the institution; for example: full-time employee, part-time employee, member of governing panel or board, stockholder, paid or unpaid consultant. Changes in IRB membership shall be reported to the Department or Agency head, unless in accord with §46.103(a) of this policy, the existence of a DHHS-approved assurance is accepted. In this case, change in IRB membership shall be reported to the Office for Protection from Research Risks, National Institutes of Health, DHHS.

(4) Written procedures which the IRB will follow (i) for conducting its initial and continuing review of research and for reporting its findings and actions to the investigator and the institution; (ii) for determining which projects require review more often than annually and which projects need verification from sources other than the investigators that no material changes have occurred since previous IRB review; and (iii) for ensuring prompt reporting to the IRB of proposed changes in a research activity, and for ensuring that such changes in approved research, during the period for which IRB approval has already been given, may not be initiated without IRB review and approval except when necessary to eliminate apparent immediate hazards to the subject.

(5) Written procedures for ensuring prompt reporting to the IRB, appropriate institutional officials, and the Department or Agency head of (i) any unanticipated problems involving risks to subjects or others or any serious or continuing noncompliance with this policy or the requirements or determinations of the IRB; and (ii) any suspension or termination of IRB approval.

(c) The assurance shall be executed by an individual authorized to act for the institution and to assume on behalf of the institution the obligations imposed by this policy and shall be filed in such form and manner as the Department or Agency head prescribes.

(d) The Department or Agency head will evaluate all assurances submitted in accordance with this policy through such officers and employees of the Department or Agency and such experts or consultants engaged for this purpose as the Department or Agency head determines to be appropriate. The Department or Agency head's evaluation will take into consideration the adequacy of the proposed IRB in light of the anticipated scope of the institution's research activities and the types of subject populations likely to be involved, the appropriateness of the proposed initial and continuing review procedures in light of the probable risks, and the size and complexity of the institution.

(e) On the basis of this evaluation, the Department or Agency head may approve or disapprove the assurance, or enter into negotiations to develop an approvable one. The Department or Agency head may limit the period during which any particular approved assurance or class of approved assurances shall remain effective or otherwise condition or restrict approval.

(f) Certification is required when the research is supported by a Federal Department or Agency and not otherwise exempted or waived under §46.101 (b) or (i). An institution with an approved assurance shall certify that each application or proposal for research covered by the assurance and by §46.103 of this policy has been reviewed and approved by the IRB. Such certification must be submitted with the application or proposal or by such later date as may be prescribed by the Department or Agency to which the application or proposal is submitted. Under no condition shall research covered by §46.103 of the policy be supported prior to receipt of the certification that the research has been reviewed and approved by the IRB. Institutions without an approved assurance covering the research shall certify within 30 days after receipt of a request for such a certification from the Department or Agency, that the application or proposal has been approved by the IRB. If the certification is not submitted within these time limits, the application or proposal may be returned to the institution.

(Approved by the Office of Management and Budget under Control Number 9999–0020.)

§§46.104–46.106 [Reserved]

§46.107 IRB membership.

(a) Each IRB shall have at least five members, with varying backgrounds to promote complete and adequate review of research activities commonly conducted by the institution. The IRB shall be sufficiently qualified through the experience and expertise of its members, and the diversity of the members, including consideration of race, gender, and cultural backgrounds and sensitivity to such issues as community attitudes, to promote respect for its advice and counsel in safeguarding the rights and welfare of human subjects. In addition to possessing the professional competence necessary to review specific research activities, the IRB shall be able to ascertain the acceptability of proposed research in terms of institutional commitments and regulations, applicable law, and standards of professional conduct and practice. The IRB shall therefore include persons knowledgeable in these areas. If an IRB regularly reviews research that involves a vulnerable category of subjects, such as children, prisoners, pregnant women, or handicapped or mentally disabled persons, consideration shall be given to the inclusion of one or more individuals who are knowledgeable about and experienced in working with these subjects.

(b) Every nondiscriminatory effort will be made to ensure that no IRB consists entirely of men or entirely of women, including the institution's consideration of qualified persons of both sexes, so long as no selection is made to the IRB on the basis of gender. No IRB may consist entirely of members of one profession.

(c) Each IRB shall include at least one member whose primary concerns are in scientific areas and at least one member whose primary concerns are in nonscientific areas.

(d) Each IRB shall include at least one member who is not otherwise affiliated with the institution and who is not part of the immediate family of a person who is affiliated with the institution.

(e) No IRB may have a member participate in the IRB's initial or continuing review of any project in which the member has a conflicting interest, except to provide information requested by the IRB.

(f) An IRB may, in its discretion, invite individuals with competence in special areas to assist in the review of issues which require expertise beyond or in addition to that available on the IRB. These individuals may not vote with the IRB.

§46.108 IRB functions and operations.

In order to fulfill the requirements of this policy each IRB shall:

(a) Follow written procedures in the same detail as described in §46.103(b)(4) and to the extent required by §46.103(b)(5).

(b) Except when an expedited review procedure is used (see §46.110), review proposed research at convened meetings at which a majority of the members of the IRB are present, including at least one member whose primary concerns are in nonscientific areas. In order for the research to be approved, it shall receive the approval of a majority of those members present at the meeting

§46.109 IRB review of research.

(a) An IRB shall review and have authority to approve, require modifications in (to secure approval), or disapprove all research activities covered by this policy.

(b) An IRB shall require that information given to subjects as part of informed consent is in accordance with §46.116. The IRB may require that information, in addition to that specifically mentioned in §46.116, be given to the subjects when in the IRB's judgment the information would meaningfully add to the protection of the rights and welfare of subjects.

(c) An IRB shall require documentation of informed consent or may waive documentation in accordance with §46.117.

(d) An IRB shall notify investigators and the institution in writing of its decision to approve or disapprove the proposed research activity, or of modifications required to secure IRB approval of the research activity. If the IRB decides to disapprove a research activity, it shall include in its written notification a statement of the reasons for its decision and give the investigator an opportunity to respond in person or in writing.

(e) An IRB shall conduct continuing review of research covered by this policy at intervals appropriate to the degree of risk, but not less than once per year, and shall have authority to observe or have a third party observe the consent process and the research.

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§46.110 Expedited review procedures for certain kinds of research involving no more than minimal risk, and for minor changes in approved research.

(a) The Secretary, HHS, has established, and published as a Notice in the Federal Register, a list of categories of research that may be reviewed by the IRB through an expedited review procedure. The list will be amended, as appropriate, after consultation with other departments and agencies, through periodic republication by the Secretary, HHS, in the Federal Register. A copy of the list is available from the Office for Protection from Research Risks, National Institutes of Health, DHHS, Bethesda, Maryland 20892.

(b) An IRB may use the expedited review procedure to review either or both of the following:

(1) some or all of the research appearing on the list and found by the reviewer(s) to involve no more than minimal risk,

(2) minor changes in previously approved research during the period (of one year or less) for which approval is authorized.

Under an expedited review procedure, the review may be carried out by the IRB chairperson or by one or more experienced reviewers designated by the chairperson from among members of the IRB. In reviewing the research, the reviewers may exercise all of the authorities of the IRB except that the reviewers may not disapprove the research. A research activity may be disapproved only after review in accordance with the non-expedited procedure set forth in §46.108(b).

(c) Each IRB which uses an expedited review procedure shall adopt a method for keeping all members advised of research proposals which have been approved under the procedure.

(d) The Department or Agency head may restrict, suspend, terminate, or choose not to authorize an institution's or IRB's use of the expedited review procedure.

§46.111 Criteria for IRB approval of research.

(a) In order to approve research covered by this policy the IRB shall determine that all of the following requirements are satisfied:

(1) Risks to subjects are minimized: (i) by using procedures which are consistent with sound research design and which do not unnecessarily expose subjects to risk, and (ii) whenever appropriate, by using procedures already being performed on the subjects for diagnostic or treatment purposes.

(2) Risks to subjects are reasonable in relation to anticipated benefits, if any, to subjects, and the importance of the knowledge that may reasonably be expected to result. In evaluating risks and benefits, the IRB should consider only those risks and benefits that may result from the research (as distinguished from risks and benefits of therapies subjects would receive even if not participating in the research). The IRB should not consider possible long-range effects of applying knowledge gained in the research (for example, the possible effects of the research on public policy) as among those research risks that fall within the purview of its responsibility.

(3) Selection of subjects is equitable. In making this assessment the IRB should take into account the purposes of the research and the setting in which the research will be conducted and should be particularly cognizant of the special problems of research involving vulnerable populations, such as children, prisoners, pregnant women, mentally disable persons, or economically or educationally disadvantaged persons.

(4) Informed consent will be sought from each prospective subject or the subject's legally authorized representative, in accordance with, and to the extent required by §46.116.

(5) Informed consent will be appropriately documented, in accordance with, and to the extent required by §46.117.

(6) When appropriate, the research plan makes adequate provision for monitoring the data collected to ensure the safety of subjects.

(7) When appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data.

(b) When some or all of the subjects are likely to be vulnerable to coercion or undue influence, such as children, prisoners, pregnant women, mentally disabled persons, or economically or educationally disadvantaged persons, additional safeguards have been included in the study to protect the rights and welfare of these subjects.

§46.112 Review by institution.

Research covered by this policy that has been approved by an IRB may be subject to further appropriate review and approval or disapproval by officials of the institution. However, those officials may not approve the research if it has not been approved by an IRB.

§46.113 Suspension or termination of IRB approval of research.

An IRB shall have authority to suspend or terminate approval of research that is not being conducted in accordance with the IRB's requirements or that has been associated with unexpected serious harm to subjects. Any suspension or termination or approval shall include a statement of the reasons for the IRB's action and shall be reported promptly to the investigator, appropriate institutional officials, and the Department or Agency head.

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§46.114 Cooperative research.

Cooperative research projects are those projects covered by this policy which involve more than one institution. In the conduct of cooperative research projects, each institution is responsible for safeguarding the rights and welfare of human subjects and for complying with this policy. With the approval of the Department or Agency head, an institution participating in a cooperative project may enter into a joint review arrangement, rely upon the review of another qualified IRB, or make similar arrangements for avoiding duplication of effort.

§46.115 IRB records.

(a) An institution, or when appropriate an IRB, shall prepare and maintain adequate documentation of IRB activities, including the following:
   (1) Copies of all research proposals reviewed, scientific evaluations, if any, that accompany the proposals, approved sample consent documents, progress reports submitted by investigators, and reports of injuries to subjects.
   (2) Minutes of IRB meetings which shall be in sufficient detail to show attendance at the meetings; actions taken by the IRB; the vote on these actions including the number of members voting for, against, and abstaining; the basis for requiring changes in or disapproving research; and a written summary of the discussion of controverted issues and their resolution.
   (3) Records of continuing review activities.
   (4) Copies of all correspondence between the IRB and the investigators.
   (5) A list of IRB members in the same detail as described in §46.103(b)(3).
   (6) Written procedures for the IRB in the same detail as described in §46.103(b)(4) and §46.103(b)(5).
   (7) Statements of significant new findings provided to subjects, as required by §46.116(b)(5).

(b) The records required by this policy shall be retained for at least 3 years, and records relating to research which is conducted shall be retained for at least 3 years after completion of the research. All records shall be accessible for inspection and copying by authorized representatives of the Department or Agency at reasonable times and in a reasonable manner.

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§46.116 General requirements for informed consent.

Except as provided elsewhere in this policy, no investigator may involve a human being as a subject in research covered by this policy unless the investigator has obtained the legally effective informed consent of the subject or the subject's legally authorized representative. An investigator shall seek such consent only under circumstances that provide the prospective subject or the representative sufficient opportunity to consider whether or not to participate and that minimize the possibility of coercion or undue influence. The information that is given to the subject or the representative shall be in language understandable to the subject or the representative. No informed consent, whether oral or written, may include any exculpatory language through which the subject or the representative is made to waive or appear to waive any of the subject's legal rights, or releases or appears to release the investigator, the sponsor, the institution or its agents from liability for negligence.

(a) Basic elements of informed consent. Except as provided in paragraph (c) or (d) of this section, in seeking informed consent the following information shall be provided to each subject:
   (1) a statement that the study involves research, an explanation of the purposes of the research and the expected duration of the subject's participation, a description of the procedures to be followed, and identification of any procedures which are experimental;
   (2) a description of any reasonably foreseeable risks or discomforts to the subject;
   (3) a description of any benefits to the subject or to others which may reasonably be expected from the research;
   (4) a disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the subject;
   (5) a statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained;
   (6) for research involving more than minimal risk, an explanation as to whether any compensation and an explanation as to whether any medical treatments are available if injury occurs and, if so, what they consist of, or where further information may be obtained;
   (7) an explanation of whom to contact for answers to pertinent questions about the research and research subjects' rights, and whom to contact in

the event of a research-related injury to the subject; and

(8) a statement that participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which the subject is otherwise entitled, and the subject may discontinue participation at any time without penalty or loss of benefits to which the subject is otherwise entitled.

(b) additional elements of informed consent. When appropriate, one or more of the following elements of information shall also be provided to each subject:

(1) a statement that the particular treatment or procedure may involve risks to the subject (or to the embryo or fetus, if the subject is or may become pregnant) which are currently unforeseeable;

(2) anticipated circumstances under which the subject's participation may be terminated by the investigator without regard to the subject's consent;

(3) any additional costs to the subject that may result from participation in the research;

(4) the consequences of a subject's decision to withdraw from the research and procedures for orderly termination of participation by the subject;

(5) A statement that significant new findings developed during the course of the research which may relate to the subject's willingness to continue participation will be provided to the subject; and

(6) the approximate number of subjects involved in the study.

(c) An IRB may approve a consent procedure which does not include, or which alters, some or all of the elements of informed consent set forth above, or waive the requirement to obtain informed consent provided the IRB finds and documents that:

(1) the research or demonstration project is to be conducted by or subject to the approval of state or local government officials and is designed to study, evaluate, or otherwise examine: (i) public benefit or service programs; (ii) procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; or (iv) possible changes in methods or levels of payment for benefits or services under those programs; and

(2) the research could not practicably be carried out without the waiver or alteration.

(d) An IRB may approve a consent procedure which does not include, or which alters, some or all of the elements of informed consent set forth in this section, or waive the requirements to obtain informed consent provided the IRB finds and documents that:

(1) the research involves no more than minimal risk to the subjects;

(2) the waiver or alteration will not adversely affect the rights and welfare of the subjects;

(3) the research could not practicably be carried out without the waiver or alteration; and,

(4) whenever appropriate, the subjects will be provided with additional pertinent information after participation.

(e) The informed consent requirements in this policy are not intended to preempt any applicable Federal, State, or local laws which require additional information to be disclosed in order for informed consent to be legally effective.

(f) Nothing in this policy is intended to limit the authority of a physician to provide emergency medical care, to the extent the physician is permitted to do so under applicable Federal, State, or local law.

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§46.117 Documentation of informed consent.

(a) Except as provided in paragraph (c) of this section, informed consent shall be documented by the use of a written consent form approved by the IRB and signed by the subject or the subject's legally authorized representative. A copy shall be given to the person signing the form.

(b) Except as provided in paragraph (c) of this section, the consent form may be either of the following:

(1) A written consent document that embodies the elements of informed consent required by §46.116. This form may be read to the subject or the subject's legally authorized representative, but in any event, the investigator shall give either the subject or the representative adequate opportunity to read it before it is signed; or

(2) A short form written consent document stating that the elements of informed consent required by §46.116 have been presented orally to the subject or the subject's legally authorized representative. When this method is used, there shall be a witness to the oral presentation. Also, the IRB shall approve a written summary of what is to be said to the subject or the representative.

Only the short form itself is to be signed by the subject or the representative. However, the witness shall sign both the short form and a copy of the summary, and the person actually obtaining consent shall sign a copy of the summary. A copy of the summary shall be given to the subject or the representative, in addition to a copy of the short form.

(c) An IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either:

(1) That the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject's wishes will govern; or

(2) That the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

In cases in which the documentation requirement is waived, the IRB may require the investigator to provide subjects with a written statement regarding the research.

(Approved by the Office of Management and Budget under Control Number 9999–0020.)

§46.118 Applications and proposals lacking definite plans for involvement of human subjects.

Certain types of applications for grants, cooperative agreements, or contracts are submitted to departments or agencies with the knowledge that subjects may be involved within the period of support, but definite plans would not normally be set forth in the application or proposal. These include activities such as institutional type grants when selection of specific projects is the institution's responsibility; research training grants in which the activities involving subjects remain to be selected; and projects in which human subjects' involvement will depend upon completion of instruments, prior animal studies, or purification of compounds. These applications need not be reviewed by an IRB before an award may be made. However, except for research exempted or waived under §46.101 (b) or (i), no human subjects may be involved in any project supported by these awards until the project has been reviewed and approved by the IRB, as provided in this policy, and certification submitted, by the institution, to the Department or Agency.

§46.119 Research undertaken without the intention of involving human subjects.

In the event research is undertaken without the intention of involving human subjects, but it is later proposed to involve human subjects in the research, the research shall first be reviewed and approved by an IRB, as provided in this policy, a certification submitted, by the institution, to the Department or Agency, and final approval given to the proposed change by the Department or Agency.

§46.120 Evaluation and disposition of applications and proposals for research to be conducted or supported by a Federal Department or Agency.

(a) The Department or Agency head will evaluate all applications and proposals involving human subjects submitted to the Department or Agency through such officers and employees of the Department or Agency and such experts and consultants as the Department or Agency head determines to be appropriate. This evaluation will take into consideration the risks to the subjects, the adequacy of protection against these risks, the potential benefits of the research to the subjects and others, and the importance of the knowledge gained or to be gained.

(b) On the basis of this evaluation, the Department or Agency head may approve or disapprove the application or proposal, or enter into negotiations to develop an approvable one.

§46.121 [Reserved]

§46.122 Use of Federal funds.

Federal funds administered by a Department or Agency may not be expended for research involving human subjects unless the requirements of this policy have been satisfied.

§46.123 Early termination of research support: Evaluation of applications and proposals.

(a) The Department or Agency head may require that Department or Agency support for any project be terminated or suspended in the manner prescribed in applicable program requirements, when the Department or Agency head finds an institution has materially failed to comply with the terms of this policy.

(b) In making decisions about supporting or approving applications or proposals covered by this policy the Department or Agency head may take into account, in addition to all other eligibility requirements and program criteria, factors such as whether the applicant has been subject to a termination or suspension under paragraph (a) of this section and whether the applicant or the person or persons who would direct or has/have directed the scientific and technical aspects of an activity has/have, in the judgment of the Department or Agency head, materially failed to discharge responsibility for the protection of the rights and welfare of human subjects (whether or not the research was subject to Federal regulation).

§46.124 Conditions.

With respect to any research project or any class of research projects the Department or Agency head may impose additional conditions prior to or at the time of approval when in the judgment of the Department or Agency head additional conditions are necessary for the protection of human subjects.

§46.201 To what do these regulations apply?

(a) Except as provided in paragraph (b) of this section, this subpart applies to all research involving pregnant women, human fetuses, neonates of uncertain viability, or nonviable neonates conducted or supported by the Department of Health and Human Services (DHHS). This includes all research conducted in DHHS facilities by any person and all research conducted in any facility by DHHS employees.

(b) The exemptions at Sec. 46.101(b)(1) through (6) are applicable to this subpart.

(c) The provisions of Sec. 46.101(c) through (i) are applicable to this subpart. Reference to State or local laws in this subpart and in Sec. 46.101(f) is intended to include the laws of federally recognized American Indian and Alaska Native Tribal Governments.

(d) The requirements of this subpart are in addition to those imposed under the other subparts of this part.

§46.202 Definitions.

The definitions in Sec. 46.102 shall be applicable to this subpart as well. In addition, as used in this subpart:

(a) Dead fetus means a fetus that exhibits neither heartbeat, spontaneous respiratory activity, spontaneous movement of voluntary muscles, nor pulsation of the umbilical cord.

(b) Delivery means complete separation of the fetus from the woman by expulsion or extraction or any other means.

(c) Fetus means the product of conception from implantation until delivery.

(d) Neonate means a newborn.

(e) Nonviable neonate means a neonate after delivery that, although living, is not viable.

(f) Pregnancy encompasses the period of time from implantation until delivery. A woman shall be assumed to be pregnant if she exhibits any of the pertinent presumptive signs of pregnancy, such as missed menses, until the results of a pregnancy test are negative or until delivery.

(g) Secretary means the Secretary of Health and Human Services and any other officer or employee of the Department of Health and Human Services to whom authority has been delegated.

(h) Viable, as it pertains to the neonate, means being able, after delivery, to survive (given the benefit of available medical therapy) to the point of independently maintaining heartbeat and respiration. The Secretary may from time to time, taking into account medical advances, publish in the Federal Register guidelines to assist in determining whether a neonate is viable for purposes of this subpart. If a neonate is viable then it may be included in research only to the extent permitted and in accordance with the requirements of subparts A and D of this part.

§46.203 Duties of IRBs in connection with research involving pregnant women, fetuses, and neonates.

In addition to other responsibilities assigned to IRBs under this part, each IRB shall review research covered by this subpart and approve only research which satisfies the conditions of all applicable sections of this subpart and the other subparts of this part.

§46.204 Research involving pregnant women or fetuses.

Pregnant women or fetuses may be involved in research if all of the following conditions are met:

(a) Where scientifically appropriate, preclinical studies, including studies on pregnant animals, and clinical studies, including studies on nonpregnant women, have been conducted and provide data for assessing potential risks to pregnant women and fetuses;

(b) The risk to the fetus is caused solely by interventions or procedures that hold out the prospect of direct benefit for the woman or the fetus; or, if there is no such prospect of benefit, the risk to the fetus is not greater than minimal and the purpose of the research is the development of important biomedical knowledge which cannot be obtained by any other means;

(c) Any risk is the least possible for achieving the objectives of the research;

(d) If the research holds out the prospect of direct benefit to the pregnant woman, the prospect of a direct benefit both to the pregnant woman and the fetus, or no prospect of benefit for the woman nor the fetus when risk to the fetus is not greater than minimal and the purpose of the research is the development of important biomedical knowledge that cannot be obtained by any other means, her consent is obtained in accord with the informed consent provisions of subpart A of this part;

(e) If the research holds out the prospect of direct benefit solely to the fetus then the consent of the pregnant woman and the father is obtained in accord with the informed consent provisions of subpart A of this part, except that the father's consent need not be obtained if he is unable to consent because of unavailability, incompetence, or temporary incapacity or the pregnancy resulted from rape or incest.

(f) Each individual providing consent under paragraph (d) or (e) of this section is fully informed regarding the reasonably foreseeable impact of the research on the fetus or neonate;

(g) For children as defined in Sec. 46.402(a) who are pregnant, assent and permission are obtained in accord with the provisions of subpart D of this part;

(h) No inducements, monetary or otherwise, will be offered to terminate a pregnancy;

(i) Individuals engaged in the research will have no part in any decisions as to the timing, method, or procedures used to terminate a pregnancy; and

(j) Individuals engaged in the research will have no part in determining the viability of a neonate

§46.205 Research involving neonates.

(a) Neonates of uncertain viability and nonviable neonates may be involved in research if all of the following conditions are met:

  (1) Where scientifically appropriate, preclinical and clinical studies have been conducted and provide data for assessing potential risks to neonates.

  (2) Each individual providing consent under paragraph (b)(2) or (c)(5) of this section is fully informed regarding the reasonably foreseeable impact of the research on the neonate.

  (3) Individuals engaged in the research will have no part in determining the viability of a neonate.

  (4) The requirements of paragraph (b) or (c) of this section have been met as applicable.

(b) Neonates of uncertain viability. Until it has been ascertained whether or not a neonate is viable, a neonate may not be involved in research covered by this subpart unless the following additional conditions have been met:

  (1) The IRB determines that:

    (i) The research holds out the prospect of enhancing the probability of survival of the neonate to the point of viability, and any risk is the least possible for achieving that objective, or

    (ii) The purpose of the research is the development of important biomedical knowledge which cannot be obtained by other means and there will be no added risk to the neonate resulting from the research; and

  (2) The legally effective informed consent of either parent of the neonate or, if neither parent is able to consent because of unavailability, incompetence, or temporary incapacity, the legally effective informed consent of either parent's legally authorized representative is obtained in accord with subpart A of this part, except that the consent of the father or his legally authorized representative need not be obtained if the pregnancy resulted from rape or incest.

(c) Nonviable neonates. After delivery nonviable neonate may not be involved in research covered by this subpart unless all of the following additional conditions are met:

  (1) Vital functions of the neonate will not be artificially maintained;

  (2) The research will not terminate the heartbeat or respiration of the neonate;

  (3) There will be no added risk to the neonate resulting from the research;

  (4) The purpose of the research is the development of important biomedical knowledge that cannot be obtained by other means; and

  (5) The legally effective informed consent of both parents of the neonate is obtained in accord with subpart A of this part, except that the waiver and alteration provisions of Sec. 46.116(c) and (d) do not apply. However, if either parent is unable to consent because of unavailability, incompetence, or temporary incapacity, the informed consent of one parent of a nonviable neonate will suffice to meet the requirements of this paragraph (c)(5), except that the consent of the father need not be obtained if the pregnancy resulted from rape or incest. The consent of a legally authorized representative of either or both of the parents of a nonviable neonate will not suffice to meet the requirements of this paragraph (c)(5).

(d) Viable neonates. A neonate, after delivery, that has been determined to be viable may be included in research only to the extent permitted by and in accord with the requirements of subparts A and D of this part.

§46.206 Research involving, after delivery, the placenta, the dead fetus or fetal material.

(a) Research involving, after delivery, the placenta; the dead fetus; macerated fetal material; or cells, tissue, or organs excised from a dead fetus, shall be conducted only in accord with any applicable Federal, State, or local laws and regulations regarding such activities.

(b) If information associated with material described in paragraph (a) of this section is recorded for research purposes in a manner that living individuals can be identified, directly or through identifiers linked to those individuals, those individuals are research subjects and all pertinent subparts of this part are applicable.

§46.207 Research not otherwise approvable which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of pregnant women, fetuses, or neonates.

The Secretary will conduct or fund research that the IRB does not believe meets the requirements of Sec. 46.204 or Sec. 46.205 only if:

(a) The IRB finds that the research presents a reasonable opportunity to further the understanding, prevention, or alleviation of a serious problem affecting the health or welfare of pregnant women, fetuses or neonates; and

(b) The Secretary, after consultation with a panel of experts in pertinent disciplines (for example: science, medicine, ethics, law) and following opportunity for public review and comment, including a public meeting announced in the Federal Register, has determined either:
  (1) That the research in fact satisfies the conditions of Sec. 46.204, as applicable; or
  (2) The following:
    (i) The research presents a reasonable opportunity to further the understanding, prevention, or alleviation of a serious problem affecting the health or welfare of pregnant women, fetuses or neonates;
    (ii) The research will be conducted in accord with sound ethical principles; and
    (iii) Informed consent will be obtained in accord with the informed consent provisions of subpart A and other applicable subparts of this part.

Subpart C: Additional DHHS Protections Pertaining to Biomedical and Behavioral Research Involving Prisoners as Subjects

Source: 43 FR 53655, Nov. 16, 1978.

§46.301 Applicability.

(a) The regulations in this subpart are applicable to all biomedical and behavioral research conducted or supported by the Department of Health and Human Services involving prisoners as subjects.

(b) Nothing in this subpart shall be construed as indicating that compliance with the procedures set forth herein will authorize research involving prisoners as subjects, to the extent such research is limited or barred by applicable State or local law.

(c) The requirements of this subpart are in addition to those imposed under the other subparts of this part.

§46.302 Purpose.

Inasmuch as prisoners may be under constraints because of their incarceration which could affect their ability to make a truly voluntary and uncoerced decision whether or not to participate as subjects in research, it is the purpose of this subpart to provide additional safeguards for the protection of prisoners involved in activities to which this subpart is applicable.

§46.303 Definitions.

As used in this subpart:

(a) “Secretary” means the Secretary of Health and Human Services and any other officer or employee of the Department of Health and Human Services to whom authority has been delegated.

(b) “DHHS” means the Department of Health and Human Services.

(c) “Prisoner” means any individual involuntarily confined or detained in a penal institution. The term is intended to encompass individuals sentenced to such an institution under a criminal or civil statute, individuals detained in other facilities by virtue of statutes or commitment procedures which provide alternatives to criminal prosecution or incarceration in a penal institution, and individuals detained pending arraignment, trial, or sentencing.

(d) “Minimal risk” is the probability and magnitude of physical or psychological harm that is normally encountered in the daily lives, or in the routine medical, dental, or psychological examination of healthy persons.

§46.304 Composition of Institutional Review Boards where prisoners are involved.

In addition to satisfying the requirements in §46.107 of this part, an Institutional Review Board, carrying out responsibilities under this part with respect to research covered by this subpart, shall also meet the following specific requirements:

(a) A majority of the Board (exclusive of prisoner members) shall have no association with the prison(s) involved, apart from their membership on the Board.

(b) At least one member of the Board shall be a prisoner, or a prisoner representative with appropriate background and experience to serve in that capacity, except that where a particular research project is reviewed by more than one Board only one Board need satisfy this requirement.

§46.305 Additional duties of the Institutional Review Boards where prisoners are involved.

(a) In addition to all other responsibilities prescribed for Institutional Review Boards under this part, the Board shall review research covered by this subpart and approve such research only if it finds that:

  (1) the research under review represents one of the categories of research permissible under §46.306(a)(2);

  (2) any possible advantages accruing to the prisoner through his or her participation in the research, when compared to the general living conditions, medical care, quality of food, amenities and opportunity for earnings in the prison, are not of such a magnitude that his or her ability to weigh the risks of the research against the value of such advantages in the limited choice environment of the prison is impaired;

  (3) the risks involved in the research are commensurate with risks that would be accepted by nonprisoner volunteers;

  (4) procedures for the selection of subjects within the prison are fair to all prisoners and immune from arbitrary intervention by prison authorities or prisoners. Unless the principal investigator provides to the Board justification in writing for following some other procedures, control subjects must be selected randomly from the group of available prisoners who meet the characteristics needed for that particular research project;

  (5) the information is presented in language which is understandable to the subject population;

  (6) adequate assurance exists that parole boards will not take into account a prisoner's participation in the research in making decisions regarding parole, and each prisoner is clearly informed in advance that participation in the research will have no effect on his or her parole; and

  (7) where the Board finds there may be a need for follow-up examination or care of participants after the end of their participation, adequate provision has been made for such examination or care, taking into account the varying lengths of individual prisoners' sentences, and for informing participants of this fact.

(b) The Board shall carry out such other duties as may be assigned by the Secretary.

(c) The institution shall certify to the Secretary, in such form and manner as the Secretary may require, that the duties of the Board under this section have been fulfilled.

§46.306 Permitted research involving prisoners.

(a) Biomedical or behavioral research conducted or supported by DHHS may involve prisoners as subjects only if:

  (1) the institution responsible for the conduct of the research has certified to the Secretary that the Institutional Review Board has approved the research under §46.305 of this subpart; and

  (2) in the judgment of the Secretary the proposed research involves solely the following:

    (A) study of the possible causes, effects, and processes of incarceration, and of criminal behavior, provided that the study presents no more than minimal risk and no more than inconvenience to the subjects;

    (B) study of prisons as institutional structures or of prisoners asincarcerated persons, provided that the study presents no more than minimal risk and no more than inconvenience to the subjects;

    (C) research on conditions particularly affecting prisoners as a class (for example, vaccine trials and other research on hepatitis which is much more prevalent in prisons than elsewhere; and research on social and psychological problems such as alcoholism, drug addiction, and sexual assaults) provided that the study may proceed only after the Secretary has consulted with appropriate experts including experts in penology, medicine, and ethics, and published notice, in the Federal Register, of his intent to approve such research; or

(D) research on practices, both innovative and accepted, which have the intent and reasonable probability of improving the health or well-being of the subject. In cases in which those studies require the assignment of prisoners in a manner consistent with protocols approved by the IRB to control groups which may not benefit from the research, the study may proceed only after the Secretary has consulted with appropriate experts, including experts in penology, medicine, and ethics, and published notice, in the Federal Register, of the intent to approve such research.

(b) Except as provided in paragraph (a) of this section, biomedical or behavioral research conducted or supported by DHHS shall not involve prisoners as subjects.

Subpart D: Additional DHHS Protections for Children Involved as Subjects in Research

Source: 48 FR 9818, March 8, 1983; 56 FR 28032, June 18, 1991.

§46.401 To what do these regulations apply?

(a) This subpart applies to all research involving children as subjects, conducted or supported by the Department of Health and Human Services.

(1) This includes research conducted by Department employees, except that each head of an Operating Division of the Department may adopt such nonsubstantive, procedural modifications as may be appropriate from an administrative standpoint.

(2) It also includes research conducted or supported by the Department of Health and Human Services outside the United States, but in appropriate circumstances, the Secretary may, under paragraph (i) of §46.101 of Subpart A, waive the applicability of some or all of the requirements of these regulations for research of this type.

(b) Exemptions at §46.101(b)(1) and (b)(3) through (b)(6) are applicable to this subpart. The exemption at §46.101(b)(2) regarding educational tests is also applicable to this subpart. However, the exemption at §46.101(b)(2) for research involving survey or interview procedures or observations of public behavior does not apply to research covered by this subpart, except for research involving observation of public behavior when the investigator(s) do not participate in the activities being observed.

(c) The exceptions, additions, and provisions for waiver as they appear in paragraphs (c) through (i) of §46.101 of Subpart A are applicable to this subpart.

§46.402 Definitions.

The definitions in §46.102 of Subpart A shall be applicable to this subpart as well. In addition, as used in this subpart:

(a) "Children" are persons who have not attained the legal age for consent to treatments or procedures involved in the research, under the applicable law of the jurisdiction in which the research will be conducted.

(b) "Assent" means a child's affirmative agreement to participate in research. Mere failure to object should not, absent affirmative agreement, be construed as assent.

(c) "Permission" means the agreement of parent(s) or guardian to the participation of their child or ward in research.

(d) "Parent" means a child's biological or adoptive parent.

(e) "Guardian" means an individual who is authorized under applicable State or local law to consent on behalf of a child to general medical care.

§46.403 IRB duties.

In addition to other responsibilities assigned to IRBs under this part, each IRB shall review research covered by this subpart and approve only research which satisfies the conditions of all applicable sections of this subpart.

§46.404 Research not involving greater than minimal risk.

DHHS will conduct or fund research in which the IRB finds that no greater than minimal risk to children is presented, only if the IRB finds that adequate provisions are made for soliciting the assent of the children and the permission of their parents or guardians, as set forth in §46.408.

§46.405 Research involving greater than minimal risk but presenting the prospect of direct benefit to the individual subjects.

DHHS will conduct or fund research in which the IRB finds that more than minimal risk to children is presented by an intervention or procedure that holds out the prospect of direct benefit for the individual subject, or by a monitoring procedure that is likely to contribute to the subject's well-being, only if the IRB finds that:

(a) the risk is justified by the anticipated benefit to the subjects;
(b) the relation of the anticipated benefit to the risk is at least as favorable to the subjects as that presented by available alternative approaches; and
(c) adequate provisions are made for soliciting the assent of the children and permission of their parents or guardians, as set forth in §46.408.

§46.406 Research involving greater than minimal risk and no prospect of direct benefit to individual subjects, but likely to yield generalizable knowledge about the subject's disorder or condition.

DHHS will conduct or fund research in which the IRB finds that more than minimal risk to children is presented by an intervention or procedure that does not hold out the prospect of direct benefit for the individual subject, or by a monitoring procedure which is not likely to contribute to the well-being of the subject, only if the IRB finds that:

(a) the risk represents a minor increase over minimal risk;
(b) the intervention or procedure presents experiences to subjects that are reasonably commensurate with those inherent in their actual or expected medical, dental, psychological, social, or educational situations;
(c) the intervention or procedure is likely to yield generalizable knowledge about the subjects' disorder or condition which is of vital importance for the understanding or amelioration of the subjects' disorder or condition; and
(d) adequate provisions are made for soliciting assent of the children and permission of their parents or guardians, as set forth in §46.408.

§46.407 Research not otherwise approvable which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of children.

DHHS will conduct or fund research that the IRB does not believe meets the requirements of §46.404, §46.405, or §46.406 only if:

(a) the IRB finds that the research presents a reasonable opportunity to further the understanding, prevention, or alleviation of a serious problem affecting the health or welfare of children; and
(b) the Secretary, after consultation with a panel of experts in pertinent disciplines (for example: science, medicine, education, ethics, law) and following opportunity for public review and comment, has determined either:
    (1) that the research in fact satisfies the conditions of §46.404, §46.405, or §46.406, as applicable, or
    (2) the following:
        (i) the research presents a reasonable opportunity to further the understanding, prevention, or alleviation of a serious problem affecting the health or welfare of children;
        (ii) the research will be conducted in accordance with sound ethical principles;
        (iii) adequate provisions are made for soliciting the assent of children and the permission of their parents or guardians, as set forth in §46.408.

§46.408 Requirements for permission by parents or guardians and for assent by children.

(a) In addition to the determinations required under other applicable sections of this subpart, the IRB shall determine that adequate provisions are made for soliciting the assent of the children, when in the judgment of the IRB the children are capable of providing assent. In determining whether children are capable of assenting, the IRB shall take into account the ages, maturity, and psychological state of the children involved. This judgment may be made for all children to be involved in research under a particular protocol, or for each child, as the IRB deems appropriate. If the IRB determines that the capability of some or all of the children is so limited that they cannot reasonably be consulted or that the intervention or procedure involved in the research holds out a prospect of direct benefit that is important to the health or well-being of the children and is available only in the context of the research, the assent of the children is not a necessary condition for proceeding with the research. Even where the IRB determines that the subjects are capable of assenting, the IRB may still waive the assent requirement under circumstances in which consent may be waived in accord with §46.116 of Subpart A.
(b) In addition to the determinations required under other applicable sections of this subpart, the IRB shall determine, in accordance with and to the extent that consent is required by §46.116 of Subpart A, that adequate provisions are made for soliciting the permission of each child's parents or guardian. Where parental permission is to be obtained, the IRB may find that the permission of one parent is sufficient for research to be conducted under §46.404 or §46.405. Where research is covered by §46.406 and §46.407 and permission is

to be obtained from parents, both parents must give their permission unless one parent is deceased, unknown, incompetent, or not reasonably available, or when only one parent has legal responsibility for the care and custody of the child.

(c) In addition to the provisions for waiver contained in §46.116 of Subpart A, if the IRB determines that a research protocol is designed for conditions or for a subject population for which parental or guardian permission is not a reasonable requirement to protect the subjects (for example, neglected or abused children), it may waive the consent requirements in Subpart A of this part and paragraph (b) of this section, provided an appropriate mechanism for protecting the children who will participate as subjects in the research is substituted, and provided further that the waiver is not inconsistent with Federal, State, or local law. The choice of an appropriate mechanism would depend upon the nature and purpose of the activities described in the protocol, the risk and anticipated benefit to the research subjects, and their age, maturity, status, and condition.

(d) Permission by parents or guardians shall be documented in accordance with and to the extent required by §46.117 of Subpart A.

(e) When the IRB determines that assent is required, it shall also determine whether and how assent must be documented.

§46.409 Wards.

(a) Children who are wards of the State or any other agency, institution, or entity can be included in research approved under §46.406 or §46.407 only if such research is:
    (1) related to their status as wards; or
    (2) conducted in schools, camps, hospitals, institutions, or similar settings in which the majority of children involved as subjects are not wards.

(b) If the research is approved under paragraph (a) of this section, the IRB shall require appointment of an advocate for each child who is a ward, in addition to any other individual acting on behalf of the child as guardian or in loco parentis. One individual may serve as advocate for more than one child. The advocate shall be an individual who has the background and experience to act in, and agrees to act in, the best interests of the child for the duration of the child's participation in the research and who is not associated in any way (except in the role as advocate or member of the IRB) with the research, the investigator(s), or the guardian organization.

SUMMARY REPORT OF THE INTERNATIONAL SUMMIT CONFERENCE ON BIOETHICS TOWARDS AN INTERNATIONAL ETHIC FOR RESEARCH INVOLVING HUMAN SUBJECTS

1987

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Twenty-six delegates, nominated by the heads of state of the Economic Summit nations, by the European Economic Community, and by the World Health Organization, met at the fourth Bioethics Summit Conference in Ottawa, Canada, on April 5–10, 1987. The Summary Report addresses the major areas discussed at the conference and presents both the background and the major recommendations of the delegates for improving the protection of research subjects throughout the world. The recommendations are shown in boldface within the text.

1. Introduction

Rapid progress in bioscience has created an urgent need for continuing development of national standards of ethics in research with human subjects. The growing interdependence of nations throughout the world has stimulated a need for internationally agreed upon standards and practices based on a careful continuing dialogue and reflection on values. The delegates at the fourth International Summit Conference on Bioethics worked towards these goals. They focused not only on the principles, but more specifically on the practice and procedures guaranteeing their implementation.

The fourth in a series of annual bioethics summit meetings initiated by Prime Minister Nakasone in 1984, this meeting reflected deeply on an area important to the entire practice of bioscience and medical research. It is hoped that the discussions and recommendations will benefit national practices, and contribute to improved international standards.

We, the delegates to this meeting, invite the Prime Minister of Canada, the Right Honourable Brian Mulroney, to present this report to the next Economic Summit Conference, to be held in Italy in June, 1987.

2. Underlying Principles and Practices: Development and Implementation of National Ethics Standards

The underlying principles for the ethics of research with human subjects are defined in national and international codes. These include respect for individuals, contribution to the well-being of peoples, and the equitable distribution of potential risks and benefits throughout society. Even though only very general international guidelines have been accepted, as yet, uniform practices are not widely accepted due to national and cultural differences.

Though need for societal review of research proposals is generally accepted, there are great differences in how countries and even institutions within some countries carry out this review. Only some of these variations can be ascribed to the cultural differences which are an essential background to societal standards.

As national standards are established, consideration must be given to evolving international guidelines for research involving human subjects. These will permit research jointly undertaken between nations and amongst groups of nations using common protocols, stimulate sharing of research results amongst nations and avoid unnecessary duplication and multiplication of research efforts.

The question of how common standards can best be developed and implemented considering the present diversity in practice and the complexity of the biomedical research enterprise occupied much of the discussion.

For that reason, the delegates recommend that, **in order to safeguard the rights and well-being of patients and research subjects, research ethics committees should be established in all countries. All research projects involving human subjects must be submitted for approval to a research ethics committee.**

It is further recommended that **these committees should be comprised of medical experts, and of experts outside the medical profession (e.g. theologians, moral philosophers, lawyers and lay members who represent the general public). Lawyers acting professionally for an institution, and others having a financial interest or potentially conflicting interest in the institution or the research in question should not serve on the ethics committee adjudicating that research. Furthermore, the committees should be of a size which is sufficient to allow for the inclusion of the three groups (medical experts, outside experts and lay members) and small enough to make efficient work possible.**

Delegates also considered the means of operation, freedoms and accountabilities of the research ethics committees. The decisions which they must take often reflect fine-tuning of competing values, and the scientific, technical or cultural environments within which they work may vary. Therefore, some differences of views between research ethics committees should be expected. Delegates were of the view that, while there may well be a need for nations to monitor the functioning of local research ethics committees, the highest standards can best be assured if they are given responsibility and authority for the review of research ethics in their institutions; as well, their effect will be enhanced if seen by researchers and society as working with the research process in a collegial sense rather than in an adversarial mode.

3. Sharing the Risks

Three groups in society can be identified as carrying risks and benefits. The researchers or clinicians who carry out the trials and other research carry the primary burdens of ethical responsibility for protection of the research subjects. In the context of drug testing, the risks and costs of developing a new drug or device remain with the manufacturer. Nevertheless, the human beings on whom the research is performed carry the most direct risks of research, but can gain the benefits of the higher standards. Society or mankind as a whole is the ultimate beneficiary from research towards improved health standards, and for that reason, the delegates recommend **that human research subjects be fully informed concerning the availability or the lack of availability of mechanisms of care and compensation to subjects who are injured as a result of their participation in research.** The delegates encourage member nations to establish and implement appropriate mechanisms for care and compensation in areas where they do not presently exist.

4. Public Participation

The delegates agreed that the imposition of societal standards on the sensitive areas raised by medical research demand the involvement of the general public. Public involvement is required not only in the development of consensus but also in consideration of individual research proposals to ensure full and open discussion which might otherwise be uncritical or too narrowly based. The multidisciplinary character of research ethics committees provides for both public accountability and credibility.

5. Research with Those with Restricted Ability to Give Consent

The overriding purpose of ethics review is the protection of the research subjects. An essential component of this protection, enunciated in all international codes of ethics is that each research subject must consent freely, and with full information, to participate in the research. However, those who are legally incompetent cannot, by definition, give their consent. Delegates focused their discussion of this issue on research with children, while recognizing that similar concerns arise with adults who are mentally handicapped and with other vulnerable populations.

All delegates accepted the need for therapeutic research with children. Such research would be of potentially direct benefit to the well-being of the individual subjects.

Non-therapeutic research with children poses special problems. While such research is necessary if treatment of childhood diseases is to advance, there was agreement that such research could only be considered under the following conditions: the specific project must be approved by a research ethics committee all needed knowledge must have been obtained through research with adults or animals, there must be no valid alternative to the use of children in the research; a valid proxy consent (by family, guardians, ombudsman, those with power of attorney or others) must have been obtained for each research subject; and, to the extent possible, the child should have given assent. Thus, it was the view of most delegates that needed non-therapeutic research on children, if within the limitations just mentioned and if involving minimal or no risk to such children, should not be precluded.

6. Research with Embryos

The integrity and uniqueness of human life in its earliest embryonic stages of formation must be accorded great respect. Generally, current forms of control of research procedures and manipulation of human embryos are not legislative in nature. In fact, in the almost total absence of legislation, research on the embryo is presently, for the most part, governed by the self-regulatory efforts of scientific and professional bodies, the centres themselves, and the review by ethics committees, local and national. Voluntary licensing control exists, for example in England, but there was consensus on the need to regulate the current anarchic proliferation and operation of in vitro fertilization centres in some countries as an interim measure while acquiring the experience necessary for effective legislation. Thus the delegates recommended **the need to keep in balance the professional liberty for clinical treatment and for scientific inquiry in the interest of progress in medical knowledge and skill while upholding regard for the human interest in the embryo. To this end, the delegates recommend the supervision and control of centres offering in vitro fertilization, of related treatments for infertility and of those conducting embryo research. Procedure should be regulated according to appropriate guidelines administered by a competent authority.**

All delegates recognized the preciousness of the human embryo. Nevertheless, different positions were taken with respect to the possibility of permitting research on the human embryo.

Several questions were raised with respect to the applicability of legal concepts of “ownership” (more properly discussed in terms of legitimate interest in) and control of human embryos during storage or after the death of the donors. Questions were also raised concerning penal sanction as opposed to professional regulation.

Considering the experimental nature of in vitro fertilization, its low success rate and the unknown long term effect of these procedures, which though “therapeutic” in nature for the infertile have implications for the manipulation and control of human life, **any work with embryos even as a treatment for infertility should be regarded as developmental procedures that are experimental in nature and therefore should be closely monitored.**

7. Pilot Studies and the Introduction of Novel Therapies

Delegates debated the special problem of ethics review of pilot studies or preliminary studies of medical innovations. Such studies were viewed as a phase between the initial observations on one or a few patients and the start of a full fledged protocol-based program.

Delegates recognized that it is often not easy to be sure whether an intervention by a physician should be regarded as a treatment undertaken only in the patient’s best interest, or whether it is guided also by an intent to gain scientific knowledge.

The decision on when a research intent is present in therapy is a determination to be made by the physician. It was the opinion of the delegates that, if the health professional has any doubt whether the intervention is in fact research, the issue would best be brought to the attention of the ethics committee.

In reviewing the novel therapy of research, delegates recommended that **they should be subject to the same ethical judgements that apply to all research protocols. Special consideration should be given to limiting the number of subjects entered into pilot studies and to monitoring closely and frequently.**

In ethics review of pilot studies as in that of other proposed research, the delegates agreed that provision should be made for a mechanism to re-examine a research project rejected by a research ethics committee if the investigator should request it. Such a mechanism should be of a sort which would not invite the overriding of local decisions by a higher or distant authority. It should maintain the collaborative nature of the relationship between the researcher and the ethics committee, rather than encourage an adversarial relationship. It was also agreed that there should be a greater exchange of information between research ethics committees.

8. Industrial Research

Industries are a major source of medical innovation. Also much of their research is mandated by national standards for licensing drugs or devices. This research involves both animals and human beings and is often carried out in a number of countries. For that reason, the interactions between industries, governments and sometimes universities are of great concern.

Differences in the way ethics standards are interpreted and implemented can have direct economic effects. Lack of consistency can adversely affect national and commercial interests as well as the safety of research subjects. Delegates recommended that, at the very least, **a nation should not allow or support, in other countries, research which does not conform to ethics review standards at least equivalent to those in force within the nation.** Nations and industries should develop international accords which strive for common attitudes and the exchangeability of standards and for mutual trust. Nations and industries should also identify emerging technologies to foster early discussion of the ethical concerns. Such interaction might help the equitable distribution of effort in research and development.

Delegates also discussed the ethical concerns raised by the growing pace of commercialization of biomedical products. The increasingly close links between university-based and industry-based research mean that academic physicians or institutions may have financial interests in the outcome of the research; any such potential conflicts of interest should be declared in the research ethics review process. Moreover, it was the opinion of some delegates that we should develop and implement values which integrate ethics and economic interests.

Delegates also discussed the effects of confidentiality, and of compensation of research subjects. The confidentiality of commercially sensitive material may not be consistent with the requirements for ethics review. In addition, payment can induce subjects, especially those of more limited means, to participate in research, and may lead to financial competition for research subjects. With respect to both industrial and other research, concern was expressed over whether patients will be compensated for adverse effects which may on rare occasions arise from research.

Much industrial research and other biomedical research depends on research with animals. Delegates recommended that **in all research we must continue to insist that animal research precede research on humans, while recognizing the obligation to reduce the number of animals required to a minimum wherever possible and to encourage alternative methods for assessing safety and efficacy.**

Much of the regulatory testing of new drugs still requires the use of animals. In this regard, delegates recommended that **governmental agencies continuously modernize their own regulatory requirements to ensure that they do not demand test results of safety and toxicology which are no longer relevant or which can be replaced by satisfactory alternatives requiring fewer animals.**

9. The Selection of Research Topics and Directed Research

Researchers consider many scientific, social and other factors when choosing research topics; choices are also made in the context of national policies and systems of support as well as national policies and practices in respect to ethics. In some instances, this results in an apparent imbalance between the research topics being chosen and major global needs for research in fields such as fertility regulation and tropical diseases.

International research programs can provide a successful mechanism to promote and carry out research in those areas which are neglected, sensitive and/or economically unattractive to national researchers. These programs can make extensive use of the international scientific community and can apply high standards of scientific and ethical review to carry out research in the areas of high global priority which are difficult to address on a national basis. Those nations with the means to support research have an obligation to devote some of those resources to the research needs of nations without such means.

The group recommended that **research should focus upon the development of knowledge in broad fields of science with the aim of achieving a fundamental understanding of biological processes, even those which might not appear to have direct application over the short or longer term.** It is seen as a scientific infrastructure of further advance. It was also recommended that **the results of research should be applied as rapidly and as effectively as possible.**

Large scale support for narrowly focussed research on specific diseases without the necessary foundation of scientific knowledge was seen as rarely, if ever, successful. Also the failure to implement the results of research for the benefit of mankind has, in itself, serious ethical implications.

10. Towards Improved Ethics Standards: Biomedical Research in an Interdependent World

The last decade has witnessed profound growth in improved communication and common endeavor among nations. As well, movement has begun towards international agreement on research with human subjects.

Delegates are certain that meaningful international agreement is not only possible but necessary, and urge the Heads of States to work toward ensuring that practice accords with principles in all aspects of research involving human subjects.

The delegates accept that society should make the human subject an active and educated participant in a process in which he or she contributes from a sense of basic human altruism and a desire to serve the common good, rather than as a “subject of research” as has sometimes been the case in the past.

The further refinement and expansion of national standards of research ethics with human subjects across political and cultural boundaries demand continuing investigation into the ethical problems of biomedical research. Furthermore while agreeing on the necessity for this ethical review process, the delegates recommended that **these committees themselves, their operations and their functions be studied.**

According to the delegates, research ethics should always be integrated into clinical decision making. The delegates recommended that *education in medical ethics for physicians, investigators and medical students be intensified and that the media and public be informed.*

Delegates also recommended that special attention be given to the ethical issues involved in epidemiological studies which can be as intrusive of human dignity and privacy as medical intervention. In particular, the regulation of confidentiality, which may both restrict the exchange and gathering of information and may at the same time fail adequately to protect the subject of such epidemiological studies, requires examination.

In regard to dissemination of principles, statements by way of declaration are laudable and necessary. However, if such statements are to have proper binding power, they must be known and an effort made to ensure compliance with them. To assist in this endeavor and in view of the importance of continuing dialogue, delegates recommended the **establishment of appropriate fora devoted to the issues arising in research with human subjects.**

Conclusions

This conference affirmed the growing importance of international agreement and cooperation on both the elaboration of principle and on the implementation of ethics review processes in medical research involving human subjects. To this end, the establishment of multi-disciplinary research ethics review bodies for the examination of research protocols was considered essential, as was further study and communication among nations.

Implementation of effective ethics review processes demands the enhanced education in medical ethics both of those involved in research and of the greater public.

The development of national and international standards for research with human subjects and their implementation must continue to aim at the protection of more vulnerable subjects.

The promulgation of ethics standards for research across nations and cultures should focus on areas of concern, as well as on international needs that are not being met.

RECOMMENDATION NO. R (90) 3 OF THE COMMITTEE OF MINISTERS TO MEMBER STATES CONCERNING MEDICAL RESEARCH ON HUMAN BEINGS

Council of Europe

1990

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In their recommendation concerning medical research on human beings, adopted February 6, 1990, the Committee of Ministers of the Council of Europe recommended that the governments of member states adopt legislation or take any other measures to ensure the implementation of the principles articulated as well as ensuring that the provisions adopted be brought to the knowledge of all persons concerned. When the recommendation was adopted, the representative of the Federal Republic of Germany reserved the right of his government to comply with it or not. Although delegates from other countries were not so explicit, other European countries are entitled to the same reservation.

The Committee of Ministers, under the terms of Article 15.b of the Statute of the Council of Europe,

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Being aware of the fact that the advancement of medical science and practice is dependent on knowledge and discovery which necessitate, as a last resort, experimentation on human beings;

Being convinced that medical research should never be carried out contrary to human dignity;

Considering the paramount concern to be the protection of the person undergoing medical research;

Considering that particular protection should be given to certain groups of persons;

Considering that every person has a right to accept or to refuse to undergo medical research and that no one should be forced to undergo it;

Considering that medical research on human beings should take into account ethical principles, and should also be subject to legal provisions;

Realising that in member states existing legal provisions are either divergent or insufficient in this field;

Noting the wish and the need to harmonise legislation,

Recommends the governments of member states:

a. to adopt legislation in conformity with the principles appended to this recommendation, or to take any other measures in order to ensure their implementation;

b. to ensure that the provisions so adopted are brought to the knowledge of all persons concerned.

Principles Concerning Medical Research on Human Beings

Scope and Definition

For the purpose of application of these principles, medical research means any trial and experimentation carried out on human beings, the purpose of which or one of the purposes of which is to increase medical knowledge.

Principle 1

Any medical research must be carried out within the framework of a scientific plan and in accordance with the following principles.

Principle 2

1. In medical research the interests and well-being of the person undergoing medical research must always prevail over the interests of science and society.
2. The risks incurred by a person undergoing medical research must be kept to a minimum. The risks should not be disproportionate to the benefits to that person or the importance of the aims pursued by the research.

Principle 3

1. No medical research may be carried out without the informed, free, express and specific consent of the person undergoing it. Such consent may be freely withdrawn at any phase of the research and the person undergoing the research should be informed, before being included in it, of his right to withdraw his consent.
2. The person who is to undergo medical research should be given information on the purpose of the research and the methodology of the experimentation. He should also be informed of the foreseeable risks and inconveniences to him of the proposed research. This information should be sufficiently clear and suitably adapted to enable consent to be given or refused in full knowledge of the relevant facts.
3. The provisions of this principle should apply also to a legal representative and to a legally incapacitated person having the capacity of understanding, in the situations described in Principles 4 and 5.

Principle 4

A legally incapacitated person may only undergo medical research where authorized by Principle 5 and if his legal representative, or an authority or an individual authorised or designated under his national law, consents. If the legally incapacitated person is capable of understanding, his consent is also required and no research may be undertaken if he does not give his consent.

Principle 5

1. A legally incapacitated person may not undergo medical research unless it is expected to produce a direct and significant benefit to his health.
2. However, by way of exception, national law may authorise research involving a legally incapacitated person which is not of direct benefit to his health when that person offers no objection, provided that the research is to the benefit of persons in the same

category and that the same scientific results cannot be obtained by research on persons who do not belong to this category.

Principle 6

Pregnant or nursing women may not undergo medical research where their health and/or that of the child would not benefit directly unless this research is aimed at benefiting other women and children who are in the same position and the same scientific results cannot be obtained by research on women who are not pregnant or nursing.

Principle 7

Persons deprived of liberty may not undergo medical research unless it is expected to produce a direct and significant benefit to their health.

Principle 8

In an emergency situation, notwithstanding Principle 3, where a patient is unable to give a prior consent, medical research can be carried out only when the following conditions are fulfilled:

—the research must have been planned to be carried out in the emergency in question;

—the systematic research plan must have been approved by an ethics committee;

—the research must be intended for the direct health benefit of the patient.

Principle 9

Any information of a personal nature obtained during medical research should be treated as confidential.

Principle 10

Medical research may not be carried out unless satisfactory evidence as to its safety for the person undergoing research is furnished.

Principle 11

Medical research that is not in accordance with scientific criteria in its design and cannot answer the questions posed is unacceptable even if the way it is to be carried out poses no risk to the person undergoing research.

Principle 12

1. Medical research must be carried out under the responsibility of a doctor or a person who exercises full clinical responsibility and who possesses appropriate knowledge and qualifications to meet any clinical contingency.
2. The responsible doctor or other person referred to in the preceding paragraph should enjoy full professional independence and should have the power to stop the research at any time.

Principle 13

1. Potential subjects of medical research should not be offered any inducement which compromises free consent. Persons undergoing medical research should not gain any financial benefit. However, expenses and any financial loss may be refunded and in appropriate cases a modest allowance may be given for any inconvenience inherent in the medical research.
2. If the person undergoing research is legally incapacitated, his legal representatives should not receive any form of remuneration whatever, except for the refund of their expenses.

Principle 14

1. Persons undergoing medical research and/or their dependents should be compensated for injury and loss caused by the medical research.
2. Where there is no existing system providing compensation for the persons concerned, states should ensure that sufficient guarantees for such compensation are provided.
3. Terms and conditions which exclude or limit, in advance, compensation to the victim should be considered to be null and void.

Principle 15

All proposed medical research plans should be the subject of an ethical examination by an independent and multidisciplinary committee.

Principle 16

Any medical research which is:

—unplanned, or

—contrary to any of the preceding principles, or

—in any other way contrary to ethics or law, or

—not in accordance with scientific methods in its design and cannot answer the questions posed should be prohibited or, if it has already begun, stopped or revised, even if it poses no risk to the person(s) undergoing the research.

INTERNATIONAL ETHICAL GUIDELINES FOR BIOMEDICAL RESEARCH INVOLVING HUMAN SUBJECTS

Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization

1993, 2002

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The 1993 guidelines were updated beginning in 1998. The document's acknowledgements states that "the 2002 text, which supersedes that of 1993, consists of a statement of general ethical principles, a preamble and 21 guidelines, with an introduction and a brief account of earlier declarations and guidelines. Like the 1982 and 1993 Guidelines, the present publication is designed to be of use, particularly to low-resource countries, in defining national policies on the ethics of biomedical research, applying ethical standards in local circumstances, and establishing or redefining adequate mechanisms for ethical review of research involving human subjects."

<http://www.cioms.ch/frame_guidelines_nov_2002.htm>

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Introduction

This is the third in the series of international ethical guidelines for biomedical research involving human subjects issued by the Council for International Organizations of Medical Sciences since 1982. Its scope and preparation reflect well the transformation that has occurred in the field of research ethics in the almost quarter century since CIOMS first undertook to make this contribution to medical sciences and the ethics of research. The CIOMS Guidelines, with their stated concern for the application of the Declaration of Helsinki in developing countries, necessarily reflect the conditions and the needs of biomedical research in those countries, and the implications for multinational or transnational research in which they may be partners.

An issue, mainly for those countries and perhaps less pertinent now than in the past, has been the extent to which ethical principles are considered universal or as culturally relative—the universalist versus the pluralist view. The challenge to international research ethics is to apply universal ethical principles to biomedical research in a multicultural world with a multiplicity of health-care systems and considerable variation in standards of health care. The Guidelines take the position that research involving human subjects must not violate any universally applicable ethical standards, but acknowledge that, in superficial aspects, the application of the ethical principles, e.g., in relation to individual autonomy and informed consent, needs to take account of cultural values, while respecting absolutely the ethical standards.

Related to this issue is that of the human rights of research subjects, as well as of health professionals as researchers in a variety of sociocultural contexts, and the contribution that international human rights instruments can make in the application of the general principles of ethics to research involving human subjects. The issue concerns largely, though not exclusively, two principles: respect for autonomy and protection of dependent or vulnerable persons and populations. In the preparation of the Guidelines the potential contribution in these respects of human rights instruments and norms was discussed, and the Guideline drafters have represented the views of commentators on safeguarding the corresponding rights of subjects.

Certain areas of research are not represented by specific guidelines. One such is human genetics. It is, however, considered in Guideline 18 Commentary under *Issues of confidentiality in genetics research.* The ethics of genetics research was the subject of a commissioned paper and commentary.

Another unrepresented area is research with products of conception (embryo and fetal research, and fetal tissue research). An attempt to craft a guideline on the topic proved unfeasible. At issue was the moral status of embryos and fetuses and the degree to which risks to the life or well-being of these entities are ethically permissible.

In relation to the use of comparators in controls, commentators have raised the question of standard of care to be provided to a control group. They emphasize that standard of care refers to more than the comparator drug or other intervention, and that research subjects in the poorer countries do not usually enjoy the same standard of all-round care enjoyed by subjects in richer countries. This issue is not addressed specifically in the Guidelines.

In one respect the Guidelines depart from the terminology of the Declaration of Helsinki. 'Best current intervention' is the term most commonly used to describe the active comparator that is ethically preferred in controlled clinical trials. For many indications, however, there is more than one established 'current' intervention and expert clinicians do not agree on which is superior. In other circumstances in which there are several established 'current' interventions, some expert clinicians recognize one as superior to the rest; some commonly prescribe another because the superior intervention may be locally unavailable, for example, or prohibitively expensive or unsuited to the capability of particular patients to adhere to a complex and rigorous regimen. 'Established effective intervention' is the term used in Guideline 11 to refer to all such interventions, including the best and the various alternatives to the best. In some cases an ethical review committee may determine that it is ethically acceptable to use an established effective intervention as a comparator, even in cases where such an intervention is not considered the best current intervention.

The mere formulation of ethical guidelines for biomedical research involving human subjects will hardly resolve all the moral doubts that can arise in association with much research, but the Guidelines can at least draw the attention of sponsors, investigators and ethical review committees to the need to consider carefully the ethical implications of research protocols and the conduct of research, and thus conduce to high scientific and ethical standards of biomedical research.

International Instruments and Guidelines

The first international instrument on the ethics of medical research, the Nuremberg Code, was promulgated in 1947 as a consequence of the trial of physicians (the Doctors' Trial) who had conducted atrocious experiments on unconsenting prisoners and detainees during the second world war. The Code, designed to protect the integrity of the research subject, set out conditions for the ethical conduct of research involving human subjects, emphasizing their voluntary consent to research.

The Universal Declaration of Human Rights was adopted by the General Assembly of the United Nations in 1948. To give the Declaration legal as well as moral force, the General Assembly adopted in 1966 the International Covenant on Civil and Political Rights. Article 7 of the Covenant states "*No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation*". It is through this statement that society expresses the fundamental human value that is held to govern all research involving human subjects—the protection of the rights and welfare of all human subjects of scientific experimentation.

The Declaration of Helsinki, issued by the World Medical Association in 1964, is the fundamental document in the field of ethics in biomedical research and has influenced the formulation of international, regional and national legislation and codes of conduct. The Declaration, amended several times, most recently in 2000 (Appendix 2), is a comprehensive international statement of the ethics of research involving human subjects. It sets out ethical guidelines for physicians engaged in both clinical and nonclinical biomedical research.

Since the publication of the CIOMS 1993 Guidelines, several international organizations have issued ethical guidance on clinical trials. This has included, from the World Health Organization, in 1995, *Guidelines for Good Clinical Practice for Trials on Pharmaceutical Products*; and from the International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH), in 1996, *Guideline on Good Clinical Practice,* designed to ensure that data generated from clinical trials are mutually acceptable to regulatory authorities in the European Union, Japan and the United States of America. The Joint United Nations Programme on HIV/AIDS published in 2000 the UNAIDS Guidance Document *Ethical Considerations in HIV Preventive Vaccine Research.*

In 2001 the Council of Ministers of the European Union adopted a Directive on clinical trials, which will be binding in law in the countries of the Union from 2004. The Council of Europe, with more than 40 member States, is developing a Protocol on Biomedical Research, which will be an additional protocol to the Council's 1997 Convention on Human Rights and Biomedicine.

Not specifically concerned with biomedical research involving human subjects but clearly pertinent, as noted above, are international human rights instruments. These are mainly the Universal Declaration of Human Rights, which, particularly in its science provisions, was highly influenced by the Nuremberg Code; the International Covenant on Civil and Political Rights; and the International Covenant on Economic, Social and Cultural Rights. Since the Nuremberg experience, human rights law has expanded to include the protection of women (Convention on the Elimination of All Forms of Discrimination Against Women) and children (Convention on the Rights of the Child). These and other such international instruments endorse in terms of human rights the general ethical principles that underlie the CIOMS International Ethical Guidelines.

General Ethical Principles

All research involving human subjects should be conducted in accordance with three basic ethical principles, namely respect for persons, beneficence and justice. It is generally agreed that these principles, which in the abstract have equal moral force, guide the conscientious preparation of proposals for scientific studies. In varying circumstances they may be expressed differently and given different moral weight, and their application may lead to different decisions or courses of action. The present guidelines are directed at the application of these principles to research involving human subjects.

Respect for persons incorporates at least two fundamental ethical considerations, namely:

a) respect for autonomy, which requires that those who are capable of deliberation about their personal choices should be treated with respect for their capacity for self-determination; and
b) protection of persons with impaired or diminished autonomy, which requires that those who are dependent or vulnerable be afforded security against harm or abuse.

Beneficence refers to the ethical obligation to maximize benefits and to minimize harms. This principle gives rise to norms requiring that the risks of research be reasonable in the light of the expected benefits, that the research design be sound, and that the investigators be competent both to conduct the research and to safeguard the welfare of the research subjects. Beneficence further proscribes the deliberate infliction of harm on persons; this aspect of beneficence is sometimes expressed as a separate principle, **nonmaleficence** (do no harm).

Justice refers to the ethical obligation to treat each person in accordance with what is morally right and proper, to give each person what is due to him or her. In the ethics of research involving human subjects the principle refers primarily to **distributive justice,** which requires the equitable distribution of both the burdens and the benefits of participation in research. Differences in distribution of burdens and benefits are justifiable only if they are based on morally relevant distinctions between persons; one such distinction is vulnerability. “Vulnerability” refers to a substantial incapacity to protect one’s own interests owing to such impediments as lack of capability to give informed consent, lack of alternative means of obtaining medical care or other expensive necessities, or being a junior or subordinate member of a hierarchical group. Accordingly, special provision must be made for the protection of the rights and welfare of vulnerable persons.

Sponsors of research or investigators cannot, in general, be held accountable for unjust conditions where the research is conducted, but they must refrain from practices that are likely to worsen unjust conditions or contribute to new inequities. Neither should they take advantage of the relative inability of low-resource countries or vulnerable populations to protect their own interests, by conducting research inexpensively and avoiding complex regulatory systems of industrialized countries in order to develop products for the lucrative markets of those countries.

In general, the research project should leave low-resource countries or communities better off than previously or, at least, no worse off. It should be responsive to their health needs and priorities in that any product developed is made reasonably available to them, and as far as possible leave the population in a better position to obtain effective health care and protect its own health.

Justice requires also that the research be responsive to the health conditions or needs of vulnerable subjects. The subjects selected should be the least vulnerable necessary to accomplish the purposes of the research. Risk to vulnerable subjects is most easily justified when it arises from interventions or procedures that hold out for them the prospect of direct health-related benefit. Risk that does not hold out such prospect must be justified by the anticipated benefit to the population of which the individual research subject is representative.

Preamble

The term “research” refers to a class of activity designed to develop or contribute to generalizable knowledge. Generalizable knowledge consists of theories, principles or relationships, or the accumulation of information on which they are based, that can be corroborated by accepted scientific methods of observation and inference. In the present context “research” includes both medical and behavioural studies pertaining to human health. Usually “research” is modified by the adjective “biomedical” to indicate its relation to health.

Progress in medical care and disease prevention depends upon an understanding of physiological and pathological processes or epidemiological findings, and requires at some time research involving human subjects. The collection, analysis and interpretation of information obtained from research involving human beings contribute significantly to the improvement of human health.

Research involving human subjects includes:

—studies of a physiological, biochemical or pathological process, or of the response to a specific intervention—whether physical, chemical or psychological—in healthy subjects or patients;

—controlled trials of diagnostic, preventive or therapeutic measures in larger groups of persons, designed to demonstrate a specific generalizable response to these measures against a background of individual biological variation;

—studies designed to determine the consequences for individuals and communities of specific preventive or therapeutic measures; and

—studies concerning human health-related behaviour in a variety of circumstances and environments.

Research involving human subjects may employ either observation or physical, chemical or psychological intervention; it may also either generate records or make use of existing records containing biomedical or other information about individuals who may or may not be identifiable from the records or information. The use of such records and the protection of the confidentiality of data obtained from those records are discussed in *International Guidelines for Ethical Review of Epidemiological Studies (CIOMS, 1991).*

The research may be concerned with the social environment, manipulating environmental factors in a way that could affect incidentally-exposed individuals. It is defined in broad terms in order to embrace field studies of pathogenic organisms and toxic chemicals under investigation for health-related purposes.

Biomedical research with human subjects is to be distinguished from the practice of medicine, public health and other forms of health care, which is designed to contribute directly to the health of individuals or communities. Prospective subjects may find it confusing when research and practice are to be conducted simultaneously, as when research is designed to obtain new information about the efficacy of a drug or other therapeutic, diagnostic or preventive modality.

As stated in Paragraph 32 of the Declaration of Helsinki, "In the treatment of a patient, where proven prophylactic, diagnostic and therapeutic methods do not exist or have been ineffective, the physician, with informed consent from the patient, must be free to use unproven or new prophylactic, diagnostic and therapeutic measures, if in the physician's judgement it offers hope of saving life, re-establishing health or alleviating suffering. Where possible, these measures should be made the object of research, designed to evaluate their safety and efficacy. In all cases, new information should be recorded and, where appropriate, published. The other relevant guidelines of this Declaration should be followed."

Professionals whose roles combine investigation and treatment have a special obligation to protect the rights and welfare of the patient-subjects. An investigator who agrees to act as physician-investigator undertakes some or all of the legal and ethical responsibilities of the subject's primary-care physician. In such a case, if the subject withdraws from the research owing to complications related to the research or in the exercise of the right to withdraw without loss of benefit, the physician has an obligation to continue to provide medical care, or to see that the subject receives the necessary care in the health-care system, or to offer assistance in finding another physician.

Research with human subjects should be carried out only by, or strictly supervised by, suitably qualified and experienced investigators and in accordance with a protocol that clearly states: the aim of the research; the reasons for proposing that it involve human subjects; the nature and degree of any known risks to the subjects; the sources from which it is proposed to recruit subjects; and the means proposed for ensuring that subjects' consent will be adequately informed and voluntary. The protocol should be scientifically and ethically appraised by one or more suitably constituted review bodies, independent of the investigators.

New vaccines and medicinal drugs, before being approved for general use, must be tested on human subjects in clinical trials; such trials constitute a substantial part of all research involving human subjects.

The Guidelines

GUIDELINE 1: *Ethical justification and scientific validity of biomedical research involving human beings*

The ethical justification of biomedical research involving human subjects is the prospect of discovering new ways of benefiting people's health. Such research can be ethically justifiable only if it is carried out in ways that respect and protect, and are fair to, the subjects of that research and are morally acceptable within the communities in which the research is carried out. Moreover, because scientifically invalid research is unethical in that it exposes research subjects to risks without possible benefit, investigators and sponsors must ensure that proposed studies involving human subjects conform to generally accepted scientific principles and are based on adequate knowledge of the pertinent scientific literature.

COMMENTARY ON GUIDELINE 1

Among the essential features of ethically justified research involving human subjects, including research with identifiable human tissue or data, are that the research offers a means of developing information not otherwise obtainable, that the design of the research is scientifically sound, and that the investigators and other research personnel are competent. The methods to be used should be appropriate to the objectives of the research and the field of study. Investigators and sponsors must also ensure that all who participate in the conduct of the research are qualified by virtue of their education and experience to perform competently in their roles. These considerations should be adequately reflected in the research protocol submitted for review and clearance to scientific and ethical review committees (Appendix I).

Scientific review is discussed further in the Commentaries to Guidelines 2 and 3: *Ethical review committees and Ethical review of externally sponsored research.* Other ethical aspects of research are discussed in the remaining guidelines and their commentaries. The protocol designed for submission for review and clearance to scientific and ethical review committees should include, when relevant, the items specified in Appendix I, and should be carefully followed in conducting the research.

GUIDELINE 2: *Ethical review committees*

All proposals to conduct research involving human subjects must be submitted for review of their scientific merit and ethical acceptability to one or more scientific review and ethical review committees. The review committees must be independent of the research team, and any direct financial or other material benefit they may derive from the research should not be contingent on the outcome of their review. The investigator must obtain their approval or clearance before undertaking the research. The ethical review committee should conduct further reviews as necessary in the course of the research, including monitoring of the progress of the study.

COMMENTARY ON GUIDELINE 2

Ethical review committees may function at the institutional, local, regional, or national level, and in some cases at the international level. The regulatory or other governmental authorities concerned should promote uniform standards across committees within a country, and, under all systems, sponsors of research and institutions in which the investigators are employed should allocate sufficient resources to the review process. Ethical review committees may receive money for the activity of reviewing protocols, but under no circumstances may payment be offered or accepted for a review committee's approval or clearance of a protocol.

Scientific review. According to the Declaration of Helsinki (Paragraph 11), medical research involving humans must conform to generally accepted scientific principles, and be based on a thorough knowledge of the scientific literature, other relevant sources of information, and adequate laboratory and, where indicated, animal experimentation. Scientific review must consider, inter alia, the study design, including the provisions for avoiding or minimizing risk and for monitoring safety. Committees competent to review and approve scientific aspects of research proposals must be multidisciplinary.

Ethical review. The ethical review committee is responsible for safeguarding the rights, safety, and well-being of the research subjects. Scientific review and ethical review cannot be separated: scientifically unsound research involving humans as subjects is ipso facto unethical in that it may expose them to risk or inconvenience to no purpose; even if there is no risk of injury, wasting of subjects' and researchers' time in unproductive activities represents loss of a valuable resource. Normally, therefore, an ethical review committee considers both the scientific and the ethical aspects of proposed research. It must either carry out a proper scientific review or verify that a competent expert body has determined that the research is scientifically sound. Also, it considers provisions for monitoring of data and safety.

If the ethical review committee finds a research proposal scientifically sound, or verifies that a competent expert body has found it so, it should then consider whether any known or possible risks to the subjects are justified by the expected benefits, direct or indirect, and whether the proposed research methods will minimize harm and maximize benefit. (See Guideline 8: *Benefits and risks of study participation.*) If the proposal is sound and the balance of risks to anticipated benefits is reasonable, the committee should then determine whether the procedures proposed for obtaining informed consent are satisfactory and those proposed for the selection of subjects are equitable.

Ethical review of emergency compassionate use of an investigational therapy. In some countries, drug regulatory authorities **require that the so-called compassionate or humanitarian use of an investigational treatment be reviewed by an ethical review committee as though it were research. Exceptionally, a physician may undertake the compassionate use of an investigational therapy before obtaining the approval or clearance of an ethical review committee, provided three criteria are met: a patient needs emergency treatment, there is some evidence of possible effectiveness of the investigational treatment, and there is no other treatment available that is known to be equally effective or superior. Informed consent should be obtained according to the legal requirements and cultural standards of the community in which the intervention is carried out. Within one week the physician must report to the ethical review committee the details of the case and the action taken, and an independent health-care professional must confirm in writing to the ethical review committee the treating physician's judgment that the use of the investigational intervention was justified according to the three specified criteria.** (See also Guideline 13 Commentary section: *Other vulnerable groups.*)

National (centralized) or local review. Ethical review committees may be created under the aegis of national or local health administrations, national (or centralized) medical research councils or other nationally representative bodies. In a highly centralized administration a national, or centralized, review committee may be constituted for both the scientific and the ethical review of research protocols. In countries where medical research is not centrally administered, ethical review is more effectively and conveniently undertaken at a local or regional level. The authority of a local ethical review committee may be confined to a single institution or may extend to all institutions in which biomedical research is carried out within a defined geographical area. The basic responsibilities of ethical review committees are:

- to determine that all proposed interventions, particularly the administration of drugs and vaccines or the use of medical devices or procedures under development, are acceptably safe to be undertaken in humans or to verify that another competent expert body has done so;
- to determine that the proposed research is scientifically sound or to verify that another competent expert body has done so;
- to ensure that all other ethical concerns arising from a protocol are satisfactorily resolved both in principle and in practice;
- to consider the qualifications of the investigators, including education in the principles of research practice, and the conditions of the research site with a view to ensuring the safe conduct of the trial; and
- to keep records of decisions and to take measures to follow up on the conduct of ongoing research projects.

Committee membership. National or local ethical review committees should be so composed as to be able to provide complete and adequate review of the research proposals submitted to them. It is generally presumed that their membership should include physicians, scientists and other professionals such as nurses, lawyers, ethicists and clergy, as well as lay persons qualified to represent the cultural and moral values of the community and to ensure that the rights of the research subjects will be respected. They should include both men and women. When uneducated or illiterate persons form the focus of a study they should also be considered for membership or invited to be represented and have their views expressed.

A number of members should be replaced periodically with the aim of blending the advantages of experience with those of fresh perspectives.

A national or local ethical review committee responsible for reviewing and approving proposals for externally sponsored research should have among its members or consultants persons who are thoroughly familiar with the customs and traditions of the population or community concerned and sensitive to issues of human dignity.

Committees that often review research proposals directed at specific diseases or impairments, such as HIV/AIDS or paraplegia, should invite or hear the views of individuals or bodies representing patients with such diseases or impairments. Similarly, for research involving such subjects as children, students, elderly persons or employees, committees should invite or hear the views of their representatives or advocates.

To maintain the review committee's independence from the investigators and sponsors and to avoid conflict of interest, any member with a special or particular, direct or indirect, interest in a proposal should not take part in its assessment if that interest could subvert the member's objective judgment. Members of ethical review committees should be held to the same standard of disclosure as scientific and medical research staff with regard to financial or other interests that could be construed as conflicts of interest. A practical way of avoiding such conflict of interest is for the committee to insist on a declaration of possible conflict of interest by any of its members. A member who makes such a declaration should then withdraw, if to do so is clearly the appropriate action to take, either at the member's own discretion or at the request of the other members. Before withdrawing, the member should be permitted to offer comments on the protocol or to respond to questions of other members.

Multi-centre research. Some research projects are designed to be conducted in a number of centres in different communities or countries. Generally, to ensure that the results will be valid, the study must be conducted in an identical way at each centre. Such studies include clinical trials, research designed for the evaluation of health service programmes, and various kinds of epidemiological research. For such studies, local ethical or scientific review committees are not normally authorized to change doses of drugs, to change inclusion or exclusion criteria, or to make other similar modifications. They should be fully empowered to prevent a study that they believe to be unethical. Moreover, changes that local review committees believe are necessary to protect the research subjects should be documented and reported to the research institution or sponsor responsible for the whole research programme for consideration and due action, to ensure that all other subjects can be protected and that the research will be valid across sites.

To ensure the validity of multi-centre research, any change in the protocol should be made at every collaborating centre or institution, or, failing this, explicit inter-centre comparability procedures must be introduced; changes made at some but not all will defeat the purpose of multi-centre research. For some multi-centre studies, scientific and ethical review may be facilitated by agreement among centres to accept the conclusions of a single review committee; its members could include a representative of the ethical review committee at each of the centres at which the research is to be conducted, as well as individuals competent to conduct scientific review. In other circumstances, a centralized review may be complemented by local review relating to the local participating investigators and institutions. The central committee could review the study from a scientific and ethical standpoint, and the local committees could verify the practicability of the study in their communities, including the infrastructures, the state of training, and ethical considerations of local significance.

In a large multi-centre trial, individual investigators will not have authority to act independently, with regard to data analysis or to preparation and publication of manuscripts, for instance. Such a trial usually has a set of committees which operate under the direction of a steering committee and are responsible for such functions and decisions. The function of the ethical review committee in such cases is to review the relevant plans with the aim of avoiding abuses.

Sanctions. Ethical review committees generally have no authority to impose sanctions on researchers who violate ethical standards in the conduct of research involving humans. They may, however, withdraw ethical approval of a research project if judged necessary. They should be required to monitor the implementation of an approved protocol and its progression, and to report to institutional or governmental authorities any serious or continuing non-compliance with ethical standards as they are reflected in protocols that they have approved or in the conduct of the studies. Failure to submit a protocol to the committee should be considered a clear and serious violation of ethical standards.

Sanctions imposed by governmental, institutional, professional or other authorities possessing disciplinary power should be employed as a last resort. Preferred methods of control include cultivation of an atmosphere of mutual trust, and education and support to promote in researchers and in sponsors the capacity for ethical conduct of research.

Should sanctions become necessary, they should be directed at the non-compliant researchers or sponsors. They may include fines or suspension of eligibility to receive research funding, to use investigational interventions, or to practise medicine. Unless there are persuasive reasons to do otherwise, editors should refuse to publish the results of research conducted unethically, and retract any articles that are subsequently found to contain falsified or fabricated data or to have been based on unethical research. Drug regulatory authorities should consider refusal to accept unethically obtained data submitted in support of an application for authorization to market a product. Such sanctions, however, may deprive of benefit not only the errant researcher or sponsor but also that segment of society intended to benefit from the research; such possible consequences merit careful consideration.

Potential conflicts of interest related to project support. Increasingly, biomedical studies receive funding from commercial firms. Such sponsors have good reasons to support research methods that are ethically and scientifically acceptable, but cases have arisen in which the conditions of funding could have introduced bias. It may happen that investigators have little or no input into trial design, limited access to the raw data, or limited participation in data interpretation, or that the results of a clinical trial may not be published if they are unfavourable to the sponsor's product. This risk of bias may also be associated with other sources of support, such as government or foundations. As the persons directly responsible for their work, investigators should not enter into agreements that interfere unduly with their access to the data or their ability to analyse the data independently, to prepare manuscripts, or to publish them. Investigators must also disclose potential or apparent conflicts of interest on their part to the ethical review committee or to other institutional committees designed to evaluate and manage such conflicts. Ethical review committees should therefore ensure that these conditions are met. See also *Multi-centre research,* above.

GUIDELINE 3: *Ethical review of externally sponsored research*

An external sponsoring organization and individual investigators should submit the research protocol for ethical and scientific review in the country of the sponsoring organization, and the ethical standards applied should be no less stringent than they would be for research carried out in that country. The health authorities of the host country, as well as a national or local ethical review committee, should ensure that the proposed research is responsive to the health needs and priorities of the host country and meets the requisite ethical standards.

COMMENTARY ON GUIDELINE 3

Definition. The term *externally sponsored research* refers to research undertaken in a host country but sponsored, financed, and sometimes wholly or partly carried out by an external international or national organization or pharmaceutical company with the collaboration or agreement of the appropriate authorities, institutions and personnel of the host country.

Ethical and scientific review. Committees in both the country of the sponsor and the host country have responsibility for conducting both scientific and ethical review, as well as the authority to withhold approval of research proposals that fail to meet their scientific or ethical standards. As far as possible, there must be assurance that the review is independent and that there is no conflict of interest that might affect the judgement of members of the review committees in relation to any aspect of the research. When the external sponsor is an international organization, its review of the research protocol must be in accordance with its own independent ethical-review procedures and standards.

Committees in the external sponsoring country or international organization have a special responsibility to determine whether the scientific methods are sound and suitable to the aims of the research; whether the drugs, vaccines, devices or procedures to be studied meet adequate standards of safety; whether there is sound justification for conducting the research in the host country rather than in the country of the external sponsor or in another country; and whether the proposed research is in compliance with the ethical standards of the external sponsoring country or international organization.

Committees in the host country have a special responsibility to determine whether the objectives of the research are responsive to the health needs and priorities of that country. The ability to judge the ethical acceptability of various aspects of a research proposal requires a thorough understanding of a community's customs and traditions. The ethical review committee in the host country, therefore, must have as either members or consultants persons with such understanding; it will then be in a favourable position to determine the acceptability of the proposed means of obtaining informed consent and otherwise respecting the rights of prospective subjects as well as of the means proposed to protect the welfare of the research subjects. Such persons should be able, for example, to indicate suitable members of the community to serve as intermediaries between investigators and subjects, and to advise on whether material benefits or inducements may be regarded as appropriate in the light of a community's gift-exchange and other customs and traditions.

When a sponsor or investigator in one country proposes to carry out research in another, the ethical review committees in the two countries may, by agreement, undertake to review different aspects of the research protocol. In short, in respect of host countries either with developed capacity for independent ethical review or in which external sponsors and investigators are contributing substantially to such capacity, ethical review in the external, sponsoring country may be limited to ensuring compliance with broadly stated ethical standards. The ethical review committee in the host country can be expected to have greater competence for reviewing the detailed plans for compliance, in view of its better understanding of the cultural and moral values of the population in which it is proposed to conduct the research; it is also likely to be in a better position to monitor compliance in the course of a study. However, in respect of research in host countries with inadequate capacity for independent ethical review, full review by the ethical review committee in the external sponsoring country or international agency is necessary.

GUIDELINE 4: *Individual informed consent*

For all biomedical research involving humans the investigator must obtain the voluntary informed consent of the prospective subject or, in the case of an individual who is not capable of giving informed consent, the permission of a legally authorized representative in accordance with applicable law. Waiver of informed consent is to be regarded as uncommon and exceptional, and must in all cases be approved by an ethical review committee.

COMMENTARY ON GUIDELINE 4

General considerations. Informed consent is a decision to participate in research, taken by a competent individual who has received the necessary information; who has adequately understood the information; and who, after considering the information, has arrived at a decision without having been subjected to coercion, undue influence or inducement, or intimidation.

Informed consent is based on the principle that competent individuals are entitled to choose freely whether to participate in research. Informed consent protects the individual's freedom of choice and respects the individual's autonomy. As an additional safeguard, it must always be complemented by independent ethical review of research proposals. This safeguard of independent review is particularly important as many individuals are limited in their capacity to give adequate informed consent; they include young children, adults with severe mental or behavioural disorders, and persons who are unfamiliar with medical concepts and technology (See Guidelines 13, 14, 15).

Process. Obtaining informed consent is a process that is begun when initial contact is made with a prospective subject and continues throughout the course of the study. By informing the prospective subjects, by repetition and explanation, by answering their questions as they arise, and by ensuring that each individual understands each procedure, investigators elicit their informed consent and in so doing manifest respect for their dignity and autonomy. Each individual must be given as much time as is needed to reach a decision, including time for consultation with family members or others. Adequate time and resources should be set aside for informed-consent procedures.

Language. Informing the individual subject must not be simply a ritual recitation of the contents of a written document. Rather, the investigator must convey the information, whether orally or in writing, in language that suits the individual's level of understanding. The investigator must bear in mind that the prospective subject's ability to understand the information necessary to give informed consent depends on that individual's maturity, intelligence, education and belief system. It depends also on the investigator's ability and willingness to communicate with patience and sensitivity.

Comprehension. The investigator must then ensure that the prospective subject has adequately understood the information. The investigator should give each one full opportunity to ask questions and should answer them honestly, promptly and completely. In some instances the investigator may administer an oral or a written test or otherwise determine whether the information has been adequately understood.

Documentation of consent. Consent may be indicated in a number of ways. The subject may imply consent by voluntary actions, express consent orally, or sign a consent form. As a general rule, the subject should sign a consent form, or, in the case of incompetence, a legal guardian or other duly authorized representative should do so. The ethical review committee may approve waiver of the requirement of a signed consent form if the research carries no more than minimal risk—that is, risk that is no more likely and not greater than that attached to routine medical or psychological examination—and if the procedures to be used are only those for which signed consent forms are not customarily required outside the research context. Such waivers may also be approved when existence of a signed consent form would be an unjustified threat to the subject's confidentiality. In some cases, particularly when the information is complicated, it is advisable to give subjects information sheets to retain; these may resemble consent forms in all respects except that subjects are not required to sign them. Their wording should be cleared by the ethical review committee. When consent has been obtained orally, investigators are responsible for providing documentation or proof of consent.

Waiver of the consent requirement. Investigators should never initiate research involving human subjects without obtaining each subject's informed consent, unless they have received explicit approval to do so from an ethical review committee. However, when the research design involves no more than minimal risk and a requirement of individual informed consent would make the conduct of the research impracticable (for example, where the research involves only excerpting data from subjects' records), the ethical review committee may waive some or all of the elements of informed consent.

Renewing consent. When material changes occur in the conditions or the procedures of a study, and also periodically in long-term studies, the investigator should once again seek informed consent from the subjects. For example, new information may have come to light, either from the study or from other sources, about the risks or benefits of products being tested or about alternatives to them. Subjects should be given such information promptly. In many clinical trials, results are not disclosed to subjects and investigators until the study is concluded. This is ethically acceptable if an ethical review committee has approved their non-disclosure.

Cultural considerations. In some cultures an investigator may enter a community to conduct research or approach prospective subjects for their individual consent only after obtaining permission from a community leader, a council of elders, or another designated authority. Such customs must be respected. In no case, however, may the permission of a community leader or other authority substitute for individual informed consent. In some populations the use of a number of local languages may complicate the communication of information to potential subjects and the ability of an investigator to ensure that they truly understand it. Many people in all cultures are unfamiliar with, or do not readily understand, scientific concepts such as those of placebo or randomization. Sponsors and investigators should develop culturally appropriate ways to communicate information that is necessary for adherence to the standard required in the informed consent process. Also, they should describe and justify in the research protocol the procedure they plan to use in communicating information to subjects. For collaborative research in developing countries the research project should, if necessary, include the provision of resources to ensure that informed consent can indeed be obtained legitimately within different linguistic and cultural settings.

Consent to use for research purposes biological materials (including genetic material) from subjects in clinical trials. Consent forms for the research protocol should include a separate section for clinical-trial subjects who are requested to provide their consent for the use of their biological specimens for research. Separate consent may be appropriate in some cases (e.g., if investigators are requesting permission to conduct basic research which is not a necessary part of the clinical trial), but not in others (e.g., the clinical trial requires the use of subjects' biological materials).

Use of medical records and biological specimens. Medical records and biological specimens taken in the course of clinical care may be used for research without the consent of the patients/subjects only if an ethical review committee has determined that the research poses minimal risk, that the rights or interests of the patients will not be violated, that their privacy and confidentiality or anonymity are assured, and that the research is designed to answer an important question and would be impracticable if the requirement for informed consent were to be imposed. Patients have a right to know that their records or specimens may be used for research. Refusal or reluctance of individuals to agree to participate would not be evidence of impracticability sufficient to warrant waiving informed consent. Records and specimens of individuals who have specifically rejected such uses in the past may be used only in the case of public health emergencies. (See Guideline 18 Commentary, *Confidentiality between physician and patient*)

Secondary use of research records or biological specimens. Investigators may want to use records or biological specimens that another investigator has used or collected for use, in another institution in the same or another country. This raises the issue of whether the records or specimens contain personal identifiers, or can be linked to such identifiers, and by whom. (See also Guideline 18: *Safeguarding confidentiality*) If informed consent or permission was required to authorize the original collection or use of such records or specimens for research purposes, secondary uses are generally constrained by the conditions specified in the original consent. Consequently, it is essential that the original consent process anticipate, to the extent that this is feasible, any foreseeable plans for future use of the records or specimens for research. Thus, in the original process of seeking informed consent a member of the research team should discuss with, and, when indicated, request the permission of, prospective subjects as to: i) whether there will or could be any secondary use and, if so, whether such secondary use will be limited with regard to the type of study that may be performed on such materials; ii) the conditions under which investigators will be required to contact the research subjects for additional authorization for secondary use; iii) the investigators' plans, if any, to destroy or to strip of personal identifiers the records or specimens; and iv) the rights of subjects to request destruction or anonymization of biological specimens or of records or parts of records that they might consider particularly sensitive, such as photographs, videotapes or audiotapes.

(See also Guidelines 5: *Obtaining informed consent: Essential information for prospective research subjects;* 6: *Obtaining informed consent: Obligations of sponsors and investigators;* and 7: *Inducement to participate.*)

GUIDELINE 5: *Obtaining informed consent: Essential information for prospective research subjects*

Before requesting an individual's consent to participate in research, the investigator must provide the following information, in language or another form of communication that the individual can understand:

1. that the individual is invited to participate in research, the reasons for considering the individual suitable for the research, and that participation is voluntary;
2. that the individual is free to refuse to participate and will be free to withdraw from the research at any time without penalty or loss of benefits to which he or she would otherwise be entitled;
3. the purpose of the research, the procedures to be carried out by the investigator and the subject, and an explanation of how the research differs from routine medical care;
4. for controlled trials, an explanation of features of the research design (e.g., randomization, double-blinding), and that the subject will not be told of the assigned treatment until the study has been completed and the blind has been broken;
5. the expected duration of the individual's participation (including number and duration of visits to the research centre and the total time involved) and the possibility of early termination of the trial or of the individual's participation in it;
6. whether money or other forms of material goods will be provided in return for the individual's participation and, if so, the kind and amount;
7. that, after the completion of the study, subjects will be informed of the findings of the research in general, and individual subjects will be informed of any finding that relates to their particular health status;
8. that subjects have the right of access to their data on demand, even if these data lack immediate clinical utility (unless the ethical review committee has approved temporary or permanent non-disclosure of data, in which case the subject should be informed of, and given, the reasons for such non-disclosure);
9. any foreseeable risks, pain or discomfort, or inconvenience to the individual (or others) associated with participation in the research, including

risks to the health or well-being of a subject's spouse or partner;

10. the direct benefits, if any, expected to result to subjects from participating in the research
11. the expected benefits of the research to the community or to society at large, or contributions to scientific knowledge;
12. whether, when and how any products or interventions proven by the research to be safe and effective will be made available to subjects after they have completed their participation in the research, and whether they will be expected to pay for them;
13. any currently available alternative interventions or courses of treatment;
14. the provisions that will be made to ensure respect for the privacy of subjects and for the confidentiality of records in which subjects are identified;
15. the limits, legal or other, to the investigators' ability to safeguard confidentiality, and the possible consequences of breaches of confidentiality;
16. policy with regard to the use of results of genetic tests and familial genetic information, and the precautions in place to prevent disclosure of the results of a subject's genetic tests;
17. to immediate family relatives or to others (e.g., insurance companies or employers) without the consent of the subject;
18. the sponsors of the research, the institutional affiliation of the investigators, and the nature and sources of funding for the research;
19. the possible research uses, direct or secondary, of the subject's medical records and of biological specimens taken in the course of clinical care (See also Guidelines 4 and 18 Commentaries);
20. whether it is planned that biological specimens collected in the research will be destroyed at its conclusion, and, if not, details about their storage (where, how, for how long, and final disposition) and possible future use, and that subjects have the right to decide about such future use, to refuse storage, and to have the material destroyed (See Guideline 4 Commentary);
21. whether commercial products may be developed from biological specimens, and whether the participant will receive monetary or other benefits from the development of such products;
22. whether the investigator is serving only as an investigator or as both investigator and the subject's physician;
23. the extent of the investigator's responsibility to provide medical services to the participant;
24. that treatment will be provided free of charge for specified types of research-related injury or for complications associated with the research, the nature and duration of such care, the name of the organization or individual that will provide the treatment, and whether there is any uncertainty regarding funding of such treatment;
25. in what way, and by what organization, the subject or the subject's family or dependants will be compensated for disability or death resulting from such injury (or, when indicated, that there are no plans to provide such compensation);
26. whether or not, in the country in which the prospective subject is invited to participate in research, the right to compensation is legally guaranteed;
27. that an ethical review committee has approved or cleared the research protocol.

GUIDELINE 6: *Obtaining informed consent: Obligations of sponsors and investigators*

Sponsors and investigators have a duty to:

- refrain from unjustified deception, undue influence, or intimidation;
- seek consent only after ascertaining that the prospective subject has adequate understanding of the relevant facts and of the consequences of participation and has had sufficient opportunity to consider whether to participate;
- as a general rule, obtain from each prospective subject a signed form as evidence of informed consent—investigators should justify any exceptions to this general rule and obtain the approval of the ethical review committee (See Guideline 4 Commentary, *Documentation of consent*);
- renew the informed consent of each subject if there are significant changes in the conditions or procedures of the research or if new information becomes available that could affect the willingness of subjects to continue to participate; and,
- renew the informed consent of each subject in long-term studies at pre-determined intervals, even if there are no changes in the design or objectives of the research.

COMMENTARY ON GUIDELINE 6

The investigator is responsible for ensuring the adequacy of informed consent from each subject. The person obtaining informed consent should be knowledgeable about the research and capable of answering questions from prospective subjects. Investigators in charge of the study must make themselves available to answer questions at the request of subjects. Any restrictions on the subject's opportunity to ask questions and receive answers before or during the research undermines the validity of the informed consent.

In some types of research, potential subjects should receive counselling about risks of acquiring a disease unless they take precautions. This is especially true of HIV/AIDS vaccine research (UNAIDS Guidance Document *Ethical Considerations in HIV Preventive Vaccine Research, Guidance Point 14*).

Withholding information and deception. Sometimes, to ensure the validity of research, investigators withhold certain information in the consent process. In biomedical research, this typically takes the form of withholding information about the purpose of specific procedures. For example, subjects in clinical trials are often not told the purpose of tests performed to monitor their compliance with the protocol, since if they knew their compliance was being monitored they might modify their behaviour and hence invalidate results. In most such cases, the prospective subjects are asked to consent to remain uninformed of the purpose of some procedures until the research is completed; after the conclusion of the study they are given the omitted information. In other cases, because a request for permission to withhold some information would jeopardize the validity of the research, subjects are not told that some information has been withheld until the research has been completed. Any such procedure must receive the explicit approval of the ethical review committee.

Active deception of subjects is considerably more controversial than simply withholding certain information. Lying to subjects is a tactic not commonly employed in biomedical research. Social and behavioural scientists, however, sometimes deliberately misinform subjects to study their attitudes and behaviour. For example, scientists have pretended to be patients to study the behaviour of health-care professionals and patients in their natural settings.

Some people maintain that active deception is never permissible. Others would permit it in certain circumstances. Deception is not permissible, however, in cases in which the deception itself would disguise the possibility of the subject being exposed to more than minimal risk. When deception is deemed indispensable to the methods of a study the investigators must demonstrate to an ethical review committee that no other research method would suffice; that significant advances could result from the research; and that nothing has been withheld that, if divulged, would cause a reasonable person to refuse to participate. The ethical review committee should determine the consequences for the subject of being deceived, and whether and how deceived subjects should be informed of the deception upon completion of the research. Such informing, commonly called "debriefing", ordinarily entails explaining the reasons for the deception. A subject who disapproves of having been deceived should be offered an opportunity to refuse to allow the investigator to use information thus obtained. Investigators and ethical review committees should be aware that deceiving research subjects may wrong them as well as harm them; subjects may resent not having been informed when they learn that they have participated in a study under false pretences. In some studies there may be justification for deceiving persons other than the subjects by either withholding or disguising elements of information. Such tactics are often proposed, for example, for studies of the abuse of spouses or children. An ethical review committee must review and approve all proposals to deceive persons other than the subjects. Subjects are entitled to prompt and honest answers to their questions; the ethical review committee must determine for each study whether others who are to be deceived are similarly entitled.

Intimidation and undue influence. Intimidation in any form invalidates informed consent. Prospective subjects who are patients often depend for medical care upon the physician/investigator, who consequently has a certain credibility in their eyes, and whose influence over them may be considerable, particularly if the study protocol has a therapeutic component. They may fear, for example, that refusal to participate would damage the therapeutic relationship or result in the withholding of health services. The physician/investigator must assure them that their decision on whether to participate will not affect the therapeutic relationship or other benefits to which they are entitled. In this situation the ethical review committee should consider whether a neutral third party should seek informed consent.

The prospective subject must not be exposed to undue influence. The borderline between justifiable persuasion and undue influence is imprecise, however. The researcher should give no unjustifiable assurances about the benefits, risks or inconveniences of the research, for example, or induce a close relative or a community leader to influence a prospective subject's decision. (See also Guideline 4: *Individual informed consent.*)

Risks. Investigators should be completely objective in discussing the details of the experimental intervention, the pain and discomfort that it may entail, and known risks and possible hazards. In complex research projects it may be neither feasible nor desirable to inform prospective participants fully about every possible risk. They must, however, be informed of all risks that a 'reasonable person' would consider material to making a decision about whether to participate, including risks to a spouse or partner associated with trials of, for example, psychotropic or genital-tract medicaments. (See also Guideline 8 Commentary, *Risks to groups of persons.*)

Exception to the requirement for informed consent in studies of emergency situations in which the researcher anticipates that many subjects will be unable to consent. Research protocols are sometimes designed to address conditions occurring suddenly and rendering the patients/subjects incapable of giving informed consent. Examples are head trauma, cardiopulmonary arrest and stroke. The investigation cannot be done with patients who can give informed consent in time and there may not be time to locate a person having the authority to give permission. In such circumstances it is often necessary to proceed with the research interventions very soon after the onset of the condition in order to evaluate an investigational treatment or develop the desired knowledge. As this class of emergency exception can be anticipated, the researcher must secure the review and approval of an ethical review committee before initiating the study. If possible, an attempt should be made to identify a population that is likely to develop the condition to be studied. This can be done readily, for example, if the condition is one that recurs periodically in individuals; examples include grand mal seizures and alcohol binges. In such cases, prospective subjects should be contacted while fully capable of informed consent, and invited to consent to their involvement as research subjects during future periods of incapacitation. If they are patients of an independent physician who is also the physician-researcher, the physician should likewise seek their consent while they are fully capable of informed consent. In all cases in which approved research has begun without prior consent of patients/subjects incapable of giving informed consent because of suddenly occurring conditions, they should be given all relevant information as soon as they are in a state to receive it, and their consent to continued participation should be obtained as soon as is reasonably possible.

Before proceeding without prior informed consent, the investigator must make reasonable efforts to locate an individual who has the authority to give permission on behalf of an incapacitated patient. If such a person can be located and refuses to give permission, the patient may not be enrolled as a subject. The risks of all interventions and procedures will be justified as required by Guideline 9 (*Special limitations on risks when research involves individuals who are not capable of giving consent*). The researcher and the ethical review committee should agree to a maximum time of involvement of an individual without obtaining either the individual's informed consent or authorization according to the applicable legal system if the person is not able to give consent. If by that time the researcher has not obtained either consent or permission—owing either to a failure to contact a representative or to a refusal of either the patient or the person or body authorized to give permission—the participation of the patient as a subject must be discontinued. The patient or the person or body providing authorization should be offered an opportunity to forbid the use of data derived from participation of the patient as a subject without consent or permission.

Where appropriate, plans to conduct emergency research without prior consent of the subjects should be publicized within the community in which it will be carried out. In the design and conduct of the research, the ethical review committee, the investigators and the sponsors should be responsive to the concerns of the community. If there is cause for concern about the acceptability of the research in the community, there should be a formal consultation with representatives designated by the community. The research should not be carried out if it does not have substantial support in the community concerned. (See Guideline 8 Commentary, *Risks to groups of persons.*)

Exception to the requirement of informed consent for inclusion in clinical trials of persons rendered incapable of informed consent by an acute condition. Certain patients with an acute condition that renders them incapable of giving informed consent may be eligible for inclusion in a clinical trial in which the majority of prospective subjects will be capable of informed consent. Such a trial would relate to a new treatment for an acute condition such as sepsis, stroke or myocardial infarction. The investigational treatment would hold out the prospect of direct benefit and would be justified accordingly, though the investigation might involve certain procedures or interventions that were not of direct benefit but carried no more than minimal risk; an example would be the process of randomization or the collection of additional blood for research purposes. For such cases the initial protocol submitted for approval to the ethical review committee should anticipate that some patients may be incapable of consent, and should propose for such patients a form of proxy consent, such as permission of the responsible relative. When the ethical review committee has approved or cleared such a protocol, an investigator may seek the permission of the responsible relative and enroll such a patient.

GUIDELINE 7: *Inducement to participate*

Subjects may be reimbursed for lost earnings, travel costs and other expenses incurred in taking part in a study; they may also receive free medical services. Subjects, particularly those who receive no direct benefit from research, may also be paid or otherwise compensated for inconvenience and time spent. The payments should not be so large, however, or the medical services so extensive as to induce prospective subjects to consent to participate in the research against their better judgment (“undue inducement”). All payments, reimbursements and medical services provided to research subjects must have been approved by an ethical review committee.

COMMENTARY ON GUIDELINE 7

Acceptable recompense. Research subjects may be reimbursed for their transport and other expenses, including lost earnings, associated with their participation in research. Those who receive no direct benefit from the research may also receive a small sum of money for inconvenience due to their participation in the research. All subjects may receive medical services unrelated to the research and have procedures and tests performed free of charge.

Unacceptable recompense. Payments in money or in kind to research subjects should not be so large as to persuade them to take undue risks or volunteer against their better judgment. Payments or rewards that undermine a person’s capacity to exercise free choice invalidate consent. It may be difficult to distinguish between suitable recompense and undue influence to participate in research. An unemployed person or a student may view promised recompense differently from an employed person. Someone without access to medical care may or may not be unduly influenced to participate in research simply to receive such care. A prospective subject may be induced to participate in order to obtain a better diagnosis or access to a drug not otherwise available; local ethical review committees may find such inducements acceptable. Monetary and in-kind recompense must, therefore, be evaluated in the light of the traditions of the particular culture and population in which they are offered, to determine whether they constitute undue influence. The ethical review committee will ordinarily be the best judge of what constitutes reasonable material recompense in particular circumstances. When research interventions or procedures that do not hold out the prospect of direct benefit present more than minimal risk, all parties involved in the research—sponsors, investigators and ethical review committees—in both funding and host countries should be careful to avoid undue material inducement.

Incompetent persons. Incompetent persons may be vulnerable to exploitation for financial gain by guardians. A guardian asked to give permission on behalf of an incompetent person should be offered no recompense other than a refund of travel and related expenses.

Withdrawal from a study. A subject who withdraws from research for reasons related to the study, such as unacceptable side-effects of a study drug, or who is withdrawn on health grounds, should be paid or recompensed as if full participation had taken place. A subject who withdraws for any other reason should be paid in proportion to the amount of participation. An investigator who must remove a subject from the study for willful noncompliance is entitled to withhold part or all of the payment.

GUIDELINE 8: *Benefits and risks of study participation*

For all biomedical research involving human subjects, the investigator must ensure that potential benefits and risks are reasonably balanced and risks are minimized.

- Interventions or procedures that hold out the prospect of direct diagnostic, therapeutic or preventive benefit for the individual subject must be justified by the expectation that they will be at least as advantageous to the individual subject, in the light of foreseeable risks and benefits, as any available alternative. Risks of such ‘beneficial’ interventions or procedures must be justified in relation to expected benefits to the individual subject.
- Risks of interventions that do not hold out the prospect of direct diagnostic, therapeutic or preventive benefit for the individual must be justified in relation to the expected benefits to society (generalizable knowledge). The risks presented by such interventions must be reasonable in relation to the importance of the knowledge to be gained.

COMMENTARY ON GUIDELINE 8

The Declaration of Helsinki in several paragraphs deals with the well-being of research subjects and the avoidance of risk. Thus, considerations related to the well-being of the human subject should take precedence over the interests of science and society (Paragraph 5); clinical testing must be preceded by adequate laboratory or animal experimentation to demonstrate a reasonable probability of success without undue risk (Paragraph 11); every project should be preceded by careful assessment of predictable risks and burdens in comparison with foreseeable benefits to the subject or to others (Paragraph 16); physician-researchers must be confident that the risks involved have been adequately assessed and can be satisfactorily managed (Paragraph 17); and the risks and burdens to the subject must be minimized, and reasonable in relation to the importance of the objective or the knowledge to be gained (Paragraph 18).

Biomedical research often employs a variety of interventions of which some hold out the prospect of direct therapeutic benefit (beneficial interventions) and others are administered solely to answer the research question (non-beneficial interventions). Beneficial interventions are justified as they are in medical practice by the expectation that they will be at least as advantageous to the individuals concerned, in the light of both risks and benefits, as any available alternative. Non-beneficial interventions are assessed differently; they may be justified only by appeal to the knowledge to be gained. In assessing the risks and benefits that a protocol presents to a population, it is appropriate to consider the harm that could result from forgoing the research.

Paragraphs 5 and 18 of the Declaration of Helsinki do not preclude well-informed volunteers, capable of fully appreciating risks and benefits of an investigation, from participating in research for altruistic reasons or for modest remuneration.

Minimizing risk associated with participation in a randomized controlled trial. In randomized controlled trials subjects risk being allocated to receive the treatment that proves inferior. They are allocated by chance to one of two or more intervention arms and followed to a predetermined end-point. (Interventions are understood to include new or established therapies, diagnostic tests and preventive measures.) An intervention is evaluated by comparing it with another intervention (a control), which is ordinarily the best current method, selected from the safe and effective treatments available globally, unless some other control intervention such as placebo can be justified ethically (See Guideline 11).

To minimize risk when the intervention to be tested in a randomized controlled trial is designed to prevent or postpone a lethal or disabling outcome, the investigator must not, for purposes of conducting the trial, withhold therapy that is known to be superior to the intervention being tested, unless the withholding can be justified by the standards set forth in Guideline 11. Also, the investigator must provide in the research protocol for the monitoring of research data by an independent board (Data and Safety Monitoring Board); one function of such a board is to protect the research subjects from previously unknown adverse reactions or unnecessarily prolonged exposure to an inferior therapy. Normally at the outset of a randomized controlled trial, criteria are established for its premature termination (stopping rules or guidelines).

Risks to groups of persons. Research in certain fields, such as epidemiology, genetics or sociology, may present risks to the interests of communities, societies, or racially or ethnically defined groups. Information might be published that could stigmatize a group or expose its members to discrimination. Such information, for example, could indicate, rightly or wrongly, that the group has a higher than average prevalence of alcoholism, mental illness or sexually transmitted disease, or is particularly susceptible to certain genetic disorders. Plans to conduct such research should be sensitive to such considerations, to the need to maintain confidentiality during and after the study, and to the need to publish the resulting data in a manner that is respectful of the interests of all concerned, or in certain circumstances not to publish them. The ethical review committee should ensure that the interests of all concerned are given due consideration; often it will be advisable to have individual consent supplemented by community consultation.

[The ethical basis for the justification of risk is elaborated further in Guideline 9]

GUIDELINE 9: *Special limitations on risk when research involves individuals who are not capable of giving informed consent*

When there is ethical and scientific justification to conduct research with individuals incapable of giving informed consent, the risk from research interventions that do not hold out the prospect of direct benefit for the individual subject should be no more likely and not greater than the risk attached to routine medical or psychological examination of such persons. Slight or minor increases above such risk may be permitted when there is an overriding scientific or medical rationale for such increases and when an ethical review committee has approved them.

COMMENTARY ON GUIDELINE 9

The low-risk standard: Certain individuals or groups may have limited capacity to give informed consent either because, as in the case of prisoners, their autonomy is limited, or because they have limited cognitive capacity. For research involving persons who are unable to consent, or whose capacity to make an informed choice may not fully meet the standard of informed consent, ethical review committees must distinguish between intervention risks that do not exceed those associated with routine medical or psychological examination of such persons and risks in excess of those.

When the risks of such interventions do not exceed those associated with routine medical or psychological examination of such persons, there is no requirement for special substantive or procedural protective measures apart from those generally required for all research involving members of the particular class of persons. When the risks are in excess of those, the ethical review committee must find: 1) that the research is designed to be responsive to the disease affecting the prospective subjects or to conditions to which they are particularly susceptible; 2) that the risks of the research interventions are only slightly greater than those associated with routine medical or psychological examination of such persons for the condition or set of clinical circumstances under investigation; 3) that the objective of the research is sufficiently important to justify exposure of the subjects to the increased risk; and 4) that the interventions are reasonably commensurate with the clinical interventions that the subjects have experienced or may be expected to experience in relation to the condition under investigation.

If such research subjects, including children, become capable of giving independent informed consent during the research, their consent to continued participation should be obtained.

There is no internationally agreed, precise definition of a "slight or minor increase" above the risks associated with routine medical or psychological examination of such persons. Its meaning is inferred from what various ethical review committees have reported as having met the standard. Examples include additional lumbar punctures or bone-marrow aspirations in children with conditions for which such examinations are regularly indicated in clinical practice. The requirement that the objective of the research be relevant to the disease or condition affecting the prospective subjects rules out the use of such interventions in healthy children.

The requirement that the research interventions be reasonably commensurate with clinical interventions that subjects may have experienced or are likely to experience for the condition under investigation is intended to enable them to draw on personal experience as they decide whether to accept or reject additional procedures for research purposes. Their choices will, therefore, be more informed even though they may not fully meet the standard of informed consent.

(See also Guidelines 4: *Individual informed consent;* 13: *Research involving vulnerable persons;* 14: *Research involving children;* and 15: *Research involving individuals who by reason of mental or behavioural disorders are not capable of giving adequately informed consent.*)

GUIDELINE 10: *Research in populations and communities with limited resources*

Before undertaking research in a population or community with limited resources, the sponsor and the investigator must make every effort to ensure that:

- the research is responsive to the health needs and the priorities of the population or community in which it is to be carried out; and
- any intervention or product developed, or knowledge generated, will be made reasonably available for the benefit of that population or community.

COMMENTARY ON GUIDELINE 10

This guideline is concerned with countries or communities in which resources are limited to the extent that they are, or may be, vulnerable to exploitation by sponsors and investigators from the relatively wealthy countries and communities.

Responsiveness of research to health needs and priorities. The ethical requirement that research be responsive to the health needs of the population or community in which it is carried out calls for decisions on what is needed to fulfil the requirement. It is not sufficient simply to determine that a disease is prevalent in the population and that new or further research is needed: the ethical requirement of "responsiveness" can be fulfilled only if successful interventions or other kinds of health benefit are made available to the population. This is applicable especially to research conducted in countries where governments lack the resources to make such products or benefits widely available. Even when a product to be tested in a particular country is much cheaper than the standard treatment in some other countries, the government or individuals in that country may still be unable to afford it. If the knowledge gained from the research in such a country is used primarily for the benefit of populations that can afford the tested product, the research may rightly be characterized as exploitative and, therefore, unethical.

When an investigational intervention has important potential for health care in the host country, the negotiation that the sponsor should undertake to determine the practical implications of "responsiveness", as well as "reasonable availability", should include representatives of stakeholders in the host country; these include the national government, the health ministry, local health authorities, and concerned scientific and ethics groups, as well as representatives of the communities from which subjects are drawn and non-governmental organizations such as health advocacy groups. The negotiation should cover the health-care infrastructure required for safe and rational use of the intervention, the likelihood of authorization for distribution, and decisions regarding payments, royalties, subsidies, technology and intellectual property, as well as distribution costs, when this economic information is not proprietary. In some cases, satisfactory discussion of the availability and distribution of successful products will necessarily engage international organizations, donor governments and bilateral agencies, international nongovernmental organizations, and the private sector. The development of a health-care infrastructure should be facilitated at the onset so that it can be of use during and beyond the conduct of the research.

Additionally, if an investigational drug has been shown to be beneficial, the sponsor should continue to provide it to the subjects after the conclusion of the study, and pending its approval by a drug regulatory authority. The sponsor is unlikely to be in a position to make a beneficial investigational intervention generally available to the community or population until some time after the conclusion of the study, as it may be in short supply and in any case cannot be made generally available before a drug regulatory authority has approved it.

For minor research studies and when the outcome is scientific knowledge rather than a commercial product, such complex planning or negotiation is rarely, if ever, needed. There must be assurance, however, that the scientific knowledge developed will be used for the benefit of the population.

Reasonable availability. The issue of "reasonable availability" is complex and will need to be determined on a case-by-case basis. Relevant considerations include the length of time for which the intervention or product developed, or other agreed benefit, will be made available to research subjects, or to the community or population concerned; the severity of a subject's medical condition; the effect of withdrawing the study drug (e.g., death of a subject); the cost to the subject or health service; and the question of undue inducement if an intervention is provided free of charge.

In general, if there is good reason to believe that a product developed or knowledge generated by research is unlikely to be reasonably available to, or applied to the benefit of, the population of a proposed host country or community after the conclusion of the research, it is unethical to conduct the research in that country or community. This should not be construed as precluding studies designed to evaluate novel therapeutic concepts. As a rare exception, for example, research may be designed to obtain preliminary evidence that a drug or a class of drugs has a beneficial effect in the treatment of a disease that occurs only in regions with extremely limited resources, and it could not be carried out reasonably well in more developed communities. Such research may be justified ethically even if there is no plan in place to make a product available to the population of the host country or community at the conclusion of the preliminary phase of its development. If the concept is found to be valid, subsequent phases of the research could result in a product that could be made reasonably available at its conclusion.

(See also Guidelines 3: *Ethical review of externally sponsored research;* 12, *Equitable distribution of burdens and benefits;* 20: *Strengthening capacity for ethical and scientific review and biomedical research;* and 21: *Ethical obligation of external sponsors to provide health-care services.*)

GUIDELINE 11: *Choice of control in clinical trials*

As a general rule, research subjects in the control group of a trial of a diagnostic, therapeutic, or preventive intervention should receive an established effective intervention. In some circumstances it may be ethically acceptable to use an alternative comparator, such as placebo or "no treatment".

Placebo may be used:

- when there is no established effective intervention;
- when withholding an established effective intervention would expose subjects to, at most, temporary discomfort or delay in relief of symptoms;
- when use of an established effective intervention as comparator would not yield scientifically reliable results and use of placebo would not add any risk of serious or irreversible harm to the subjects.

COMMENTARY ON GUIDELINE 11

General considerations for controlled clinical trials. The design of trials of investigational diagnostic, therapeutic or preventive interventions raises interrelated scientific and ethical issues for sponsors, investigators and ethical review committees. To obtain reliable results, investigators must compare the effects of an investigational intervention on subjects assigned to the investigational arm (or arms) of a trial with the effects that a control intervention produces in subjects drawn from the same population and assigned to its control arm. Randomization is the preferred method for assigning subjects to the various arms of the clinical trial unless another method, such as historical or literature controls, can be justified scientifically and ethically. Assignment to treatment arms by randomization, in addition to its usual scientific superiority, offers the advantage of tending to render equivalent to all subjects the foreseeable benefits and risks of participation in a trial.

A clinical trial cannot be justified ethically unless it is capable of producing scientifically reliable results. When the objective is to establish the effectiveness and safety of an investigational intervention, the use of a placebo control is often much more likely than that of an active control to produce a scientifically reliable result. In many cases the ability of a trial to distinguish effective from ineffective interventions (its assay sensitivity) cannot be assured unless the control is a placebo. If, however, an effect of using a placebo would be to deprive subjects in the control arm of an established effective intervention, and thereby to expose them to serious harm, particularly if it is irreversible, it would obviously be unethical to use a placebo.

Placebo control in the absence of a current effective alternative. The use of placebo in the control arm of a clinical trial is ethically acceptable when, as stated in the Declaration of Helsinki (Paragraph 29), "no proven prophylactic, diagnostic or therapeutic method exists." Usually, in this case, a placebo is scientifically preferable to no intervention. In certain circumstances, however, an alternative design may be both scientifically and ethically acceptable, and preferable; an example would be a clinical trial of a surgical intervention, because, for many surgical interventions, either it is not possible or it is ethically unacceptable to devise a suitable placebo; for another example, in certain vaccine trials an investigator might choose to provide for those in the 'control' arm a vaccine that is unrelated to the investigational vaccine.

Placebo-controlled trials that entail only minor risks. A placebo-controlled design may be ethically acceptable, and preferable on scientific grounds, when the condition for which patients/subjects are randomly assigned to placebo or active treatment is only a small deviation in physiological measurements, such as slightly raised blood pressure or a modest increase in serum cholesterol; and if delaying or omitting available treatment may cause only temporary discomfort (e.g., common headache) and no serious adverse consequences. The ethical review committee must be fully satisfied that the risks of withholding an established effective intervention are truly minor and short-lived.

Placebo control when active control would not yield reliable results. A related but distinct rationale for using a placebo control rather than an established effective intervention is that the documented experience with the established effective intervention is not sufficient to provide a scientifically reliable comparison with the intervention being investigated; it is then difficult, or even impossible, without using a placebo, to design a scientifically reliable study. This is not always, however, an ethically acceptable basis for depriving control subjects of an established effective intervention in clinical trials; only when doing so would not add any risk of serious harm, particularly irreversible harm, to the subjects would it be ethically acceptable to do so. In some cases, the condition at which the intervention is aimed (for example, cancer or HIV/AIDS) will be too serious to deprive control subjects of an established effective intervention.

This latter rationale (when active control would not yield reliable results) differs from the former (trials that entail only minor risks) in emphasis. In trials that entail only minor risks the investigative interventions are aimed at relatively trivial conditions, such as the common cold or hair loss; forgoing an established effective intervention for the duration of a trial deprives control subjects of only minor benefits. It is for this reason that it is not unethical to use a placebo-control design. Even if it were possible to design a so-called "non-inferiority", or "equivalency", trial using an active control, it would still not be unethical in these circumstances to use a placebo-control design. In any event, the researcher must satisfy the ethical review committee that the safety and human rights of the subjects will be fully protected, that prospective subjects will be fully informed about alternative treatments, and that the purpose and design of the study are scientifically sound. The ethical acceptability of such placebo-controlled studies increases as the period of placebo use is decreased, and when the study design permits change to active treatment ("escape treatment") if intolerable symptoms occur.

Exceptional use of a comparator other than an established effective intervention. An exception to the general rule is applicable in some studies designed to develop a therapeutic, preventive or diagnostic intervention for use in a country or community in which an established effective intervention is not available and unlikely in the foreseeable future to become available, usually for economic or logistic reasons. The purpose of such a study is to make available to the population of the country or community an effective alternative to an established effective intervention that is locally unavailable. Accordingly, the proposed investigational intervention must be responsive to the health needs of the population from which the research subjects are recruited and there must be assurance that, if it proves to be safe and effective, it will be made reasonably available to that population. Also, the scientific and ethical review committees must be satisfied that the established effective intervention cannot be used as comparator because its use would not yield scientifically reliable results that would be relevant to the health needs of the study population. In these circumstances an ethical review committee can approve a clinical trial in which the comparator is other than an established effective intervention, such as placebo or no treatment or a local remedy.

However, some people strongly object to the exceptional use of a comparator other than an established effective intervention because it could result in exploitation of poor and disadvantaged populations. The objection rests on three arguments:

- Placebo control could expose research subjects to risk of serious or irreversible harm when the use of an established effective intervention as comparator could avoid the risk.
- Not all scientific experts agree about conditions under which an established effective intervention used as a comparator would not yield scientifically reliable results.

- An economic reason for the unavailability of an established effective intervention cannot justify a placebo-controlled study in a country of limited resources when it would be unethical to conduct a study with the same design in a population with general access to the effective intervention outside the study.

Placebo control when an established effective intervention is not available in the host country. The question addressed here is: when should an exception be allowed to the general rule that subjects in the control arm of a clinical trial should receive an established effective intervention?

The usual reason for proposing the exception is that, for economic or logistic reasons, an established effective intervention is not in general use or available in the country in which the study will be conducted, whereas the investigational intervention could be made available, given the finances and infrastructure of the country.

Another reason that may be advanced for proposing a placebo-controlled trial is that using an established effective intervention as the control would not produce scientifically reliable data relevant to the country in which the trial is to be conducted. Existing data about the effectiveness and safety of the established effective intervention may have been accumulated under circumstances unlike those of the population in which it is proposed to conduct the trial; this, it may be argued, could make their use in the trial unreliable. One reason could be that the disease or condition manifests itself differently in different populations, or other uncontrolled factors could invalidate the use of existing data for comparative purposes.

The use of placebo control in these circumstances is ethically controversial, for the following reasons:

- Sponsors of research might use poor countries or communities as testing grounds for research that would be difficult or impossible in countries where there is general access to an established effective intervention, and the investigational intervention, if proven safe and effective, is likely to be marketed in countries in which an established effective intervention is already available and it is not likely to be marketed in the host country.
- The research subjects, both active-arm and control-arm, are patients who may have a serious, possibly life-threatening, illness. They do not normally have access to an established effective intervention currently available to similar patients in many other countries. According to the requirements of a scientifically reliable trial, investigators, who may be their attending physicians, would be expected to enroll some of those patients/subjects in the placebo-control arm. This would appear to be a violation of the physician's fiduciary duty of undivided loyalty to the patient, particularly in cases in which known effective therapy could be made available to the patients.

An argument for exceptional use of placebo control may be that a health authority in a country where an established effective intervention is not generally available or affordable, and unlikely to become available or affordable in the foreseeable future, seeks to develop an affordable intervention specifically for a health problem affecting its population. There may then be less reason for concern that a placebo design is exploitative, and therefore unethical, as the health authority has responsibility for the population's health, and there are valid health grounds for testing an apparently beneficial intervention. In such circumstances an ethical review committee may determine that the proposed trial is ethically acceptable, provided that the rights and safety of subjects are safeguarded.

Ethical review committees will need to engage in careful analysis of the circumstances to determine whether the use of placebo rather than an established effective intervention is ethically acceptable. They will need to be satisfied that an established effective intervention is truly unlikely to become available and implementable in that country. This may be difficult to determine, however, as it is clear that, with sufficient persistence and ingenuity, ways may be found of accessing previously unattainable medicinal products, and thus avoiding the ethical issue raised by the use of placebo control.

When the rationale of proposing a placebo-controlled trial is that the use of an established effective intervention as the control would not yield scientifically reliable data relevant to the proposed host country, the ethical review committee in that country has the option of seeking expert opinion as to whether use of an established effective intervention in the control arm would invalidate the results of the research.

An "equivalency trial" as an alternative to a placebo-controlled trial. An alternative to a placebo-control design in these circumstances would be an "equivalency trial", which would compare an investigational intervention with an established effective intervention and produce scientifically reliable data. An equivalency trial in a country in which no established effective intervention is available is not designed to determine whether the investigational intervention is superior to an established effective intervention currently used somewhere in the world; its purpose is, rather, to determine whether the investigational intervention is, in effectiveness and safety, equivalent to, or almost equivalent to, the established effective intervention. It would be hazardous to conclude, however, that an intervention demonstrated to be equivalent, or almost equivalent, to an established effective intervention is better than nothing or superior to whatever intervention is available in the country; there may be substantial differences between the results of superficially identical clinical trials carried out in different countries. If there are such differences, it would be scientifically acceptable and ethically preferable to conduct such 'equivalency' trials in countries in which an established effective intervention is already available.

If there are substantial grounds for the ethical review committee to conclude that an established effective intervention will not become available and implementable, the committee should obtain assurances from the parties concerned that plans have been agreed for making the investigational intervention reasonably available in the host country or community once its effectiveness and safety have been established. Moreover, when the study has external sponsorship, approval should usually be dependent on the sponsors and the health authorities of the host country having engaged in a process of negotiation and planning, including justifying the study in regard to local health-care needs.

Means of minimizing harm to placebo-control subjects. Even when placebo controls are justified on one of the bases set forth in the guideline, there are means of minimizing the possibly harmful effect of being in the control arm.

First, a placebo-control group need not be untreated. An add-on design may be employed when the investigational therapy and a standard treatment have different mechanisms of action. The treatment to be tested and placebo are each added to a standard treatment. Such studies have a particular place when a standard treatment is known to decrease mortality or irreversible morbidity but a trial with standard treatment as the active control cannot be carried out or would be difficult to interpret [*International Conference on Harmonisation (ICH) Guideline: Choice of Control Group and Related Issues in Clinical Trials, 2000*]. In testing for improved treatment of life-threatening diseases such as cancer, HIV/AIDS, or heart failure, add-on designs are a particularly useful means of finding improvements in interventions that are not fully effective or may cause intolerable side-effects. They have a place also in respect of treatment for epilepsy, rheumatism and osteoporosis, for example, because withholding of established effective therapy could result in progressive disability, unacceptable discomfort or both.

Second, as indicated in Guideline 8 Commentary, when the intervention to be tested in a randomized controlled trial is designed to prevent or postpone a lethal or disabling outcome, the investigator minimizes harmful effects of placebo-control studies by providing in the research protocol for the monitoring of research data by an independent Data and Safety Monitoring Board (DSMB). One function of such a board is to protect the research subjects from previously unknown adverse reactions; another is to avoid unnecessarily prolonged exposure to an inferior therapy. The board fulfils the latter function by means of interim analyses of the data pertaining to efficacy to ensure that the trial does not continue beyond the point at which an investigational therapy is demonstrated to be effective. Normally, at the outset of a randomized controlled trial, criteria are established for its premature termination (stopping rules or guidelines).

In some cases the DSMB is called upon to perform "conditional power calculations", designed to determine the probability that a particular clinical trial could ever show that the investigational therapy is effective. If that probability is very small, the DSMB is expected to recommend termination of the clinical trial, because it would be unethical to continue it beyond that point.

In most cases of research involving human subjects, it is unnecessary to appoint a DSMB. To ensure that research is carefully monitored for the early detection of adverse events, the sponsor or the principal investigator appoints an individual to be responsible for advising on the need to consider changing the system of monitoring for adverse events or the process of informed consent, or even to consider terminating the study.

GUIDELINE 12: *Equitable distribution of burdens and benefits in the selection of groups of subjects in research*

Groups or communities to be invited to be subjects of research should be selected in such a way that the burdens and benefits of the research will be equitably distributed. The exclusion of groups or communities that might benefit from study participation must be justified.

COMMENTARY ON GUIDELINE 12

General considerations: Equity requires that no group or class of persons should bear more than its fair share of the burdens of participation in research. Similarly, no group should be deprived of its fair share of the benefits of research, short-term or long-term; such benefits include the direct benefits of participation as well as the benefits of the new knowledge that the research is designed to yield. When burdens or benefits of research are to be apportioned unequally among individuals or groups of persons, the criteria for unequal distribution should be morally justifiable and not arbitrary. In other words, unequal allocation must not be inequitable. Subjects should be drawn from the qualifying population in the general geographic area of the trial without regard to race, ethnicity, economic status or gender unless there is a sound scientific reason to do otherwise.

In the past, groups of persons were excluded from participation in research for what were then considered good reasons. As a consequence of such exclusions, information about the diagnosis, prevention and treatment of diseases in such groups of persons is limited. This has resulted in a serious class injustice. If information about the management of diseases is considered a benefit that is distributed within a society, it is unjust to deprive groups of persons of that benefit. Such documents as the Declaration of Helsinki and the UNAIDS Guidance Document *Ethical Considerations in HIV Preventive Vaccine Research,* and the policies of many national governments and professional societies, recognize the need to redress these injustices by encouraging the participation of previously excluded groups in basic and applied biomedical research.

Members of vulnerable groups also have the same entitlement to access to the benefits of investigational interventions that show promise of therapeutic benefit as persons not considered vulnerable, particularly when no superior or equivalent approaches to therapy are available.

There has been a perception, sometimes correct and sometimes incorrect, that certain groups of persons have been overused as research subjects. In some cases such overuse has been based on the administrative availability of the populations. Research hospitals are often located in places where members of the lowest socioeconomic classes reside, and this has resulted in an apparent overuse of such persons. Other groups that may have been overused because they were conveniently available to researchers include students in investigators' classes, residents of long-term care facilities and subordinate members of hierarchical institutions. Impoverished groups have been overused because of their willingness to serve as subjects in exchange for relatively small stipends. Prisoners have been considered ideal subjects for Phase I drug studies because of their highly regimented lives and, in many cases, their conditions of economic deprivation.

Overuse of certain groups, such as the poor or the administratively available, is unjust for several reasons. It is unjust to selectively recruit impoverished people to serve as research subjects simply because they can be more easily induced to participate in exchange for small payments. In most cases, these people would be called upon to bear the burdens of research so that others who are better off could enjoy the benefits. However, although the burdens of research should not fall disproportionately on socioeconomically disadvantaged groups, neither should such groups be categorically excluded from research protocols. It would not be unjust to selectively recruit poor people to serve as subjects in research designed to address problems that are prevalent in their group—malnutrition, for example. Similar considerations apply to institutionalized groups or those whose availability to the investigators is for other reasons administratively convenient.

Not only may certain groups within a society be inappropriately overused as research subjects, but also entire communities or societies may be overused. This has been particularly likely to occur in countries or communities with insufficiently well-developed systems for the protection of the rights and welfare of human research subjects. Such overuse is especially questionable when the populations or communities concerned bear the burdens of participation in research but are extremely unlikely ever to enjoy the benefits of new knowledge and products developed as a result of the research. (See Guideline 10: *Research in populations and communities with limited resources.*)

GUIDELINE 13: *Research involving vulnerable persons*

Special justification is required for inviting vulnerable individuals to serve as research subjects and, if they are selected, the means of protecting their rights and welfare must be strictly applied.

COMMENTARY ON GUIDELINE 13

Vulnerable persons are those who are relatively (or absolutely) incapable of protecting their own interests. More formally, they may have insufficient power, intelligence, education, resources, strength, or other needed attributes to protect their own interests.

General considerations. The central problem presented by plans to involve vulnerable persons as research subjects is that such plans may entail an inequitable distribution of the burdens and benefits of research participation. Classes of individuals conventionally considered vulnerable are those with limited capacity or freedom to consent or to decline to consent. They are the subject of specific guidelines in this document (Guidelines 14,15) and include children, and persons who because of mental or behavioural disorders are incapable of giving informed consent. Ethical justification of their involvement usually requires that investigators satisfy ethical review committees that:

- the research could not be carried out equally well with less vulnerable subjects;

- the research is intended to obtain knowledge that will lead to improved diagnosis, prevention or treatment of diseases or other health problems characteristic of, or unique to, the vulnerable class-either the actual subjects or other similarly situated members of the vulnerable class;
- research subjects and other members of the vulnerable class from which subjects are recruited will ordinarily be assured reasonable access to any diagnostic, preventive or therapeutic products that will become available as a consequence of the research;
- the risks attached to interventions or procedures that do not hold out the prospect of direct health-related benefit will not exceed those associated with routine medical or psychological examination of such persons unless an ethical review committee authorizes a slight increase over this level of risk (Guideline 9); and,
- when the prospective subjects are either incompetent or otherwise substantially unable to give informed consent, their agreement will be supplemented by the permission of their legal guardians or other appropriate representatives.

Other vulnerable groups. The quality of the consent of prospective subjects who are junior or subordinate members of a hierarchical group requires careful consideration, as their agreement to volunteer may be unduly influenced, whether justified or not, by the expectation of preferential treatment if they agree or by fear of disapproval or retaliation if they refuse. Examples of such groups are medical and nursing students, subordinate hospital and laboratory personnel, employees of pharmaceutical companies, and members of the armed forces or police. Because they work in close proximity to investigators, they tend to be called upon more often than others to serve as research subjects, and this could result in inequitable distribution of the burdens and benefits of research.

Elderly persons are commonly regarded as vulnerable. With advancing age, people are increasingly likely to acquire attributes that define them as vulnerable. They may, for example, be institutionalized or develop varying degrees of dementia. If and when they acquire such vulnerability-defining attributes, and not before, it is appropriate to consider them vulnerable and to treat them accordingly.

Other groups or classes may also be considered vulnerable. They include residents of nursing homes, people receiving welfare benefits or social assistance and other poor people and the unemployed, patients in emergency rooms, some ethnic and racial minority groups, homeless persons, nomads, refugees or displaced persons, prisoners, patients with incurable disease, individuals who are politically powerless, and members of communities unfamiliar with modern medical concepts. To the extent that these and other classes of people have attributes resembling those of classes identified as vulnerable, the need for special protection of their rights and welfare should be reviewed and applied, where relevant.

Persons who have serious, potentially disabling or life-threatening diseases are highly vulnerable. Physicians sometimes treat such patients with drugs or other therapies not yet licensed for general availability because studies designed to establish their safety and efficacy have not been completed. This is compatible with the Declaration of Helsinki, which states in Paragraph 32: “ *In the treatment of a patient, where proven…therapeutic methods do not exist or have been ineffective, the physician, with informed consent from the patient, must be free to use unproven or new…therapeutic measures, if in the physician’s judgement it offers hope of saving life, re-establishing health or alleviating suffering*”. Such treatment, commonly called ‘compassionate use’, is not properly regarded as research, but it can contribute to ongoing research into the safety and efficacy of the interventions used.

Although, on the whole, investigators must study less vulnerable groups before involving more vulnerable groups, some exceptions are justified. In general, children are not suitable for Phase I drug trials or for Phase I or II vaccine trials, but such trials may be permissible after studies in adults have shown some therapeutic or preventive effect. For example, a Phase II vaccine trial seeking evidence of immunogenicity in infants may be justified when a vaccine has shown evidence of preventing or slowing progression of an infectious disease in adults, or Phase I research with children may be appropriate because the disease to be treated does not occur in adults or is manifested differently in children (Appendix 3: *The phases of clinical trials of vaccines and drugs*).

GUIDELINE 14: *Research involving children*

Before undertaking research involving children, the investigator must ensure that:

- the research might not equally well be carried out with adults;
- the purpose of the research is to obtain knowledge relevant to the health needs of children;
- a parent or legal representative of each child has given permission;
- the agreement (assent) of each child has been obtained to the extent of the child’s capabilities; and,

- a child's refusal to participate or continue in the research will be respected.

COMMENTARY ON GUIDELINE 14

Justification of the involvement of children in biomedical research. The participation of children is indispensable for research into diseases of childhood and conditions to which children are particularly susceptible (cf. vaccine trials), as well as for clinical trials of drugs that are designed for children as well as adults. In the past, many new products were not tested for children though they were directed towards diseases also occurring in childhood; thus children either did not benefit from these new drugs or were exposed to them though little was known about their specific effects or safety in children. Now it is widely agreed that, as a general rule, the sponsor of any new therapeutic, diagnostic or preventive product that is likely to be indicated for use in children is obliged to evaluate its safety and efficacy for children before it is released for general distribution.

Assent of the child. The willing cooperation of the child should be sought, after the child has been informed to the extent that the child's maturity and intelligence permit. The age at which a child becomes legally competent to give consent differs substantially from one jurisdiction to another; in some countries the "age of consent" established in their different provinces, states or other political subdivisions varies considerably. Often children who have not yet reached the legally established age of consent can understand the implications of informed consent and go through the necessary procedures; they can therefore knowingly agree to serve as research subjects. Such knowing agreement, sometimes referred to as assent, is insufficient to permit participation in research unless it is supplemented by the permission of a parent, a legal guardian or other duly authorized representative.

Some children who are too immature to be able to give knowing agreement, or assent, may be able to register a 'deliberate objection', an expression of disapproval or refusal of a proposed procedure. The deliberate objection of an older child, for example, is to be distinguished from the behaviour of an infant, who is likely to cry or withdraw in response to almost any stimulus. Older children, who are more capable of giving assent, should be selected before younger children or infants, unless there are valid scientific reasons related to age for involving younger children first.

A deliberate objection by a child to taking part in research should always be respected even if the parents have given permission, unless the child needs treatment that is not available outside the context of research, the investigational intervention shows promise of therapeutic benefit, and there is no acceptable alternative therapy. In such a case, particularly if the child is very young or immature, a parent or guardian may override the child's objections. If the child is older and more nearly capable of independent informed consent, the investigator should seek the specific approval or clearance of the scientific and ethical review committees for initiating or continuing with the investigational treatment. If child subjects become capable of independent informed consent during the research, their informed consent to continued participation should be sought and their decision respected.

A child with a likely fatal illness may object or refuse assent to continuation of a burdensome or distressing intervention. In such circumstances parents may press an investigator to persist with an investigational intervention against the child's wishes. The investigator may agree to do so if the intervention shows promise of preserving or prolonging life and there is no acceptable alternative treatment. In such cases, the investigator should seek the specific approval or clearance of the ethical review committee before agreeing to override the wishes of the child.

Permission of a parent or guardian. The investigator must obtain the permission of a parent or guardian in accordance with local laws or established procedures. It may be assumed that children over the age of 12 or 13 years are usually capable of understanding what is necessary to give adequately informed consent, but their consent (assent) should normally be complemented by the permission of a parent or guardian, even when local law does not require such permission. Even when the law requires parental permission, however, the assent of the child must be obtained.

In some jurisdictions, some individuals who are below the general age of consent are regarded as "emancipated" or "mature" minors and are authorized to consent without the agreement or even the awareness of their parents or guardians. They may be married or pregnant or be already parents or living independently. Some studies involve investigation of adolescents' beliefs and behaviour regarding sexuality or use of recreational drugs; other research addresses domestic violence or child abuse. For studies on these topics, ethical review committees may waive parental permission if, for example, parental knowledge of the subject matter may place the adolescents at some risk of questioning or even intimidation by their parents.

Because of the issues inherent in obtaining assent from children in institutions, such children should only exceptionally be subjects of research. In the case of institutionalized children without parents, or whose parents are not legally authorized to grant permission, the ethical review committee may require sponsors or investigators to provide it with the opinion of an independent, concerned, expert advocate for institutionalized children as to the propriety of undertaking the research with such children.

Observation of research by a parent or guardian. A parent or guardian who gives permission for a child to participate in research should be given the opportunity, to a reasonable extent, to observe the research as it proceeds, so as to be able to withdraw the child if the parent or guardian decides it is in the child's best interests to do so.

Psychological and medical support. Research involving children should be conducted in settings in which the child and the parent can obtain adequate medical and psychological support. As an additional protection for children, an investigator may, when possible, obtain the advice of a child's family physician, paediatrician or other health-care provider on matters concerning the child's participation in the research.

(See also Guideline 8: *Benefits and risks of study participation;* Guideline 9: *Special limitations on risks when subjects are not capable of giving consent;* and Guideline 13: *Research involving vulnerable persons.*)

GUIDELINE 15: *Research involving individuals who by reason of mental or behavioural disorders are not capable of giving adequately informed consent*

Before undertaking research involving individuals who by reason of mental or behavioural disorders are not capable of giving adequately informed consent, the investigator must ensure that:

- such persons will not be subjects of research that might equally well be carried out on persons whose capacity to give adequately informed consent is not impaired;
- the purpose of the research is to obtain knowledge relevant to the particular health needs of persons with mental or behavioural disorders;
- the consent of each subject has been obtained to the extent of that person's capabilities, and a prospective subject's refusal to participate in research is always respected, unless, in exceptional circumstances, there is no reasonable medical alternative and local law permits overriding the objection; and,
- in cases where prospective subjects lack capacity to consent, permission is obtained from a responsible family member or a legally authorized representative in accordance with applicable law.

COMMENTARY ON GUIDELINE 15

General considerations. Most individuals with mental or behavioural disorders are capable of giving informed consent; this Guideline is concerned only with those who are not capable or who because their condition deteriorates become temporarily incapable. They should never be subjects of research that might equally well be carried out on persons in full possession of their mental faculties, but they are clearly the only subjects suitable for a large part of research into the origins and treatment of certain severe mental or behavioural disorders.

Consent of the individual. The investigator must obtain the approval of an ethical review committee to include in research persons who by reason of mental or behavioural disorders are not capable of giving informed consent. The willing cooperation of such persons should be sought to the extent that their mental state permits, and any objection on their part to taking part in any study that has no components designed to benefit them directly should always be respected. The objection of such an individual to an investigational intervention intended to be of therapeutic benefit should be respected unless there is no reasonable medical alternative and local law permits overriding the objection. The agreement of an immediate family member or other person with a close personal relationship with the individual should be sought, but it should be recognized that these proxies may have their own interests that may call their permission into question. Some relatives may not be primarily concerned with protecting the rights and welfare of the patients. Moreover, a close family member or friend may wish to take advantage of a research study in the hope that it will succeed in "curing" the condition. Some jurisdictions do not permit third-party permission for subjects lacking capacity to consent. Legal authorization may be necessary to involve in research an individual who has been committed to an institution by a court order.

Serious illness in persons who because of mental or behavioural disorders are unable to give adequately informed consent. Persons who because of mental or behavioural disorders are unable to give adequately informed consent and who have, or are at risk of, serious illnesses such as HIV infection, cancer or hepatitis should not be deprived of the possible benefits of investigational drugs, vaccines or devices that show promise of therapeutic or preventive benefit, particularly when no superior or equivalent therapy or prevention is available. Their entitlement to access to such therapy or prevention is justified ethically on the same grounds as is such entitlement for other vulnerable groups.

Persons who are unable to give adequately informed consent by reason of mental or behavioural disorders are, in general, not suitable for participation in formal clinical trials except those trials that are designed to be responsive to their particular health needs and can be carried out only with them.

(See also Guidelines 8: *Benefits and risks of study participation;* 9: *Special limitations on risks when subjects are not capable of giving consent;* and 13: *Research involving vulnerable persons.*)

GUIDELINE 16: *Women as research subjects*

Investigators, sponsors or ethical review committees should not exclude women of reproductive age from biomedical research. The potential for becoming pregnant during a study should not, in itself, be used as a reason for precluding or limiting participation. However, a thorough discussion of risks to the pregnant woman and to her fetus is a prerequisite for the woman's ability to make a rational decision to enroll in a clinical study. In this discussion, if participation in the research might be hazardous to a fetus or a woman if she becomes pregnant, the sponsors/investigators should guarantee the prospective subject a pregnancy test and access to effective contraceptive methods before the research commences. Where such access is not possible, for legal or religious reasons, investigators should not recruit for such possibly hazardous research women who might become pregnant.

COMMENTARY ON GUIDELINE 16

Women in most societies have been discriminated against with regard to their involvement in research. Women who are biologically capable of becoming pregnant have been customarily excluded from formal clinical trials of drugs, vaccines and medical devices owing to concern about undetermined risks to the fetus. Consequently, relatively little is known about the safety and efficacy of most drugs, vaccines or devices for such women, and this lack of knowledge can be dangerous.

A general policy of excluding from such clinical trials women biologically capable of becoming pregnant is unjust in that it deprives women as a class of persons of the benefits of the new knowledge derived from the trials. Further, it is an affront to their right of self-determination. Nevertheless, although women of childbearing age should be given the opportunity to participate in research, they should be helped to understand that the research could include risks to the fetus if they become pregnant during the research.

Although this general presumption favours the inclusion of women in research, it must be acknowledged that in some parts of the world women are vulnerable to neglect or harm in research because of their social conditioning to submit to authority, to ask no questions, and to tolerate pain and suffering. When women in such situations are potential subjects in research, investigators need to exercise special care in the informed consent process to ensure that they have adequate time and a proper environment in which to take decisions on the basis of clearly given information.

Individual consent of women: In research involving women of reproductive age, whether pregnant or non-pregnant, only the informed consent of the woman herself is required for her participation. In no case should the permission of a spouse or partner replace the requirement of individual informed consent. If women wish to consult with their husbands or partners or seek voluntarily to obtain their permission before deciding to enroll in research, that is not only ethically permissible but in some contexts highly desirable. A strict requirement of authorization of spouse or partner, however, violates the substantive principle of respect for persons.

A thorough discussion of risks to the pregnant woman and to her fetus is a prerequisite for the woman's ability to make a rational decision to enroll in a clinical study. For women who are not pregnant at the outset of a study but who might become pregnant while they are still subjects, the consent discussion should include information about the alternative of voluntarily withdrawing from the study and, where legally permissible, terminating the pregnancy. Also, if the pregnancy is not terminated, they should be guaranteed a medical follow-up.

GUIDELINE 17: *Pregnant women as research participants.*

Pregnant women should be presumed to be eligible for participation in biomedical research. Investigators and ethical review committees should ensure that prospective subjects who are pregnant are adequately informed about the risks and benefits to themselves, their pregnancies, the fetus and their subsequent offspring, and to their fertility.

Research in this population should be performed only if it is relevant to the particular health needs of a pregnant woman or her fetus, or to the health needs of pregnant women in general, and, when appropriate, if it is supported by reliable evidence from animal experiments, particularly as to risks of teratogenicity and mutagenicity.

COMMENTARY ON GUIDELINE 17

The justification of research involving pregnant women is complicated by the fact that it may present risks and potential benefits to two beings—the woman and the fetus—as well as to the person the fetus is destined to become. Though the decision about acceptability of risk should be made by the mother as part of the informed consent process, it is desirable in research directed at the health of the fetus to obtain the father's opinion also, when possible. Even when evidence concerning risks is unknown or ambiguous, the decision about acceptability of risk to the fetus should be made by the woman as part of the informed consent process.

Especially in communities or societies in which cultural beliefs accord more importance to the fetus than to the woman's life or health, women may feel constrained to participate, or not to participate, in research. Special safeguards should be established to prevent undue inducement to pregnant women to participate in research in which interventions hold out the prospect of direct benefit to the fetus. Where fetal abnormality is not recognized as an indication for abortion, pregnant women should not be recruited for research in which there is a realistic basis for concern that fetal abnormality may occur as a consequence of participation as a subject in research.

Investigators should include in protocols on research on pregnant women a plan for monitoring the outcome of the pregnancy with regard to both the health of the woman and the short-term and long-term health of the child.

GUIDELINE 18: *Safeguarding confidentiality*

The investigator must establish secure safeguards of the confidentiality of subjects' research data. Subjects should be told the limits, legal or other, to the investigators' ability to safeguard confidentiality and the possible consequences of breaches of confidentiality.

COMMENTARY ON GUIDELINE 18

Confidentiality between investigator and subject. Research relating to individuals and groups may involve the collection and storage of information that, if disclosed to third parties, could cause harm or distress. Investigators should arrange to protect the confidentiality of such information by, for example, omitting information that might lead to the identification of individual subjects, limiting access to the information, anonymizing data, or other means. During the process of obtaining informed consent the investigator should inform the prospective subjects about the precautions that will be taken to protect confidentiality.

Prospective subjects should be informed of limits to the ability of investigators to ensure strict confidentiality and of the foreseeable adverse social consequences of breaches of confidentiality. Some jurisdictions require the reporting to appropriate agencies of, for instance, certain communicable diseases or evidence of child abuse or neglect. Drug regulatory authorities have the right to inspect clinical-trial records, and a sponsor's clinical-compliance audit staff may require and obtain access to confidential data. These and similar limits to the ability to maintain confidentiality should be anticipated and disclosed to prospective subjects.

Participation in HIV/AIDS drug and vaccine trials may impose upon the research subjects significant associated risks of social discrimination or harm; such risks merit consideration equal to that given to adverse medical consequences of the drugs and vaccines. Efforts must be made to reduce their likelihood and severity. For example, subjects in vaccine trials must be enabled to demonstrate that their HIV seropositivity is due to their having been vaccinated rather than to natural infection. This may be accomplished by providing them with documents attesting to their participation in vaccine trials, or by maintaining a confidential register of trial subjects, from which information can be made available to outside agencies at a subject's request.

Confidentiality between physician and patient. Patients have the right to expect that their physicians and other health-care professionals will hold all information about them in strict confidence and disclose it only to those who need, or have a legal right to, the information, such as other attending physicians, nurses, or other health-care workers who perform tasks related to the diagnosis and treatment of patients. A treating physician should not disclose any identifying information about patients to an investigator unless each patient has given consent to such disclosure and unless an ethical review committee has approved such disclosure.

Physicians and other health care professionals record the details of their observations and interventions in medical and other records. Epidemiological studies often make use of such records. For such studies it is usually impracticable to obtain the informed consent of each identifiable patient; an ethical review committee may waive the requirement for informed consent when this is consistent with the requirements of applicable law and provided that there are secure safeguards of confidentiality. (See also Guideline 4 Commentary: *Waiver of the consent requirement.*) In institutions in which records may be used for research purposes without the informed consent of patients, it is advisable to notify patients generally of such practices; notification is usually by means of a statement in patient-information brochures. For research limited to patients' medical records, access must be approved or cleared by an ethical review committee and must be supervised by a person who is fully aware of the confidentiality requirements.

Issues of confidentiality in genetic research. An investigator who proposes to perform genetic tests of known clinical or predictive value on biological samples that can be linked to an identifiable individual must obtain the informed consent of the individual or, when indicated, the permission of a legally authorized representative. Conversely, before performing a genetic test that is of known predictive value or gives reliable information about a known heritable condition, and individual consent or permission has not been obtained, investigators must see that biological samples are fully anonymized and unlinked; this ensures that no information about specific individuals can be derived from such research or passed back to them.

When biological samples are not fully anonymized and when it is anticipated that there may be valid clinical or research reasons for linking the results of genetic tests to research subjects, the investigator in seeking informed consent should assure prospective subjects that their identity will be protected by secure coding of their samples (encryption) and by restricted access to the database, and explain to them this process.

When it is clear that for medical or possibly research reasons the results of genetic tests will be reported to the subject or to the subject's physician, the subject should be informed that such disclosure will occur and that the samples to be tested will be clearly labelled.

Investigators should not disclose results of diagnostic genetic tests to relatives of subjects without the subjects' consent. In places where immediate family relatives would usually expect to be informed of such results, the research protocol, as approved or cleared by the ethical review committee, should indicate the precautions in place to prevent such disclosure of results without the subjects' consent; such plans should be clearly explained during the process of obtaining informed consent.

GUIDELINE 19: *Right of injured subjects to treatment and compensation*

Investigators should ensure that research subjects who suffer injury as a result of their participation are entitled to free medical treatment for such injury and to such financial or other assistance as would compensate them equitably for any resultant impairment, disability or handicap. In the case of death as a result of their participation, their dependants are entitled to compensation. Subjects must not be asked to waive the right to compensation.

COMMENTARY ON GUIDELINE 19

Guideline 19 is concerned with two distinct but closely related entitlements. The first is the uncontroversial entitlement to free medical treatment and compensation for accidental injury inflicted by procedures or interventions performed exclusively to accomplish the purposes of research (non-therapeutic procedures). The second is the entitlement of dependants to material compensation for death or disability occurring as a direct result of study participation. Implementing a compensation system for research-related injuries or death is likely to be complex, however.

Equitable compensation and free medical treatment. Compensation is owed to research subjects who are disabled as a consequence of injury from procedures performed solely to accomplish the purposes of research. Compensation and free medical treatment are generally not owed to research subjects who suffer expected or foreseen adverse reactions to investigational therapeutic, diagnostic or preventive interventions when such reactions are not different in kind from those known to be associated with established interventions in standard medical practice. In the early stages of drug testing (Phase I and early Phase II), it is generally unreasonable to assume that an investigational drug holds out the prospect of direct benefit for the individual subject; accordingly, compensation is usually owed to individuals who become disabled as a result of serving as subjects in such studies.

The ethical review committee should determine in advance: i) the injuries for which subjects will receive free treatment and, in case of impairment, disability or handicap resulting from such injuries, be compensated; and ii) the injuries for which they will not be compensated. Prospective subjects should be informed of the committee's decisions, as part of the process of informed consent. As an ethical review committee cannot make such advance determination in respect of unexpected or unforeseen adverse reactions, such reactions must be presumed compensable and should be reported to the committee for prompt review as they occur.

Subjects must not be asked to waive their rights to compensation or required to show negligence or lack of a reasonable degree of skill on the part of the investigator in order to claim free medical treatment or compensation. The informed consent process or form should contain no words that would absolve an investigator from responsibility in the case of accidental injury, or that would imply that subjects would waive their right to seek compensation for impairment, disability or handicap. Prospective subjects should be informed that they will not need to take legal action to secure the free medical treatment or compensation for injury to which they may be entitled. They should also be told what medical service or organization or individual will provide the medical treatment and what organization will be responsible for providing compensation.

Obligation of the sponsor with regard to compensation. Before the research begins, the sponsor, whether a pharmaceutical company or other organization or institution, or a government (where government insurance is not precluded by law), should agree to provide compensation for any physical injury for which subjects are entitled to compensation, or come to an agreement with the investigator concerning the circumstances in which the investigator must rely on his or her own insurance coverage (for example, for negligence or failure of the investigator to follow the protocol, or where government insurance coverage is limited to negligence). In certain circumstances it may be advisable to follow both courses. Sponsors should seek adequate insurance against risks to cover compensation, independent of proof of fault.

GUIDELINE 20: *Strengthening capacity for ethical and scientific review and biomedical research*

Many countries lack the capacity to assess or ensure the scientific quality or ethical acceptability of biomedical research proposed or carried out in their jurisdictions. In externally sponsored collaborative research, sponsors and investigators have an ethical obligation to ensure that biomedical research projects for which they are responsible in such countries contribute effectively to national or local capacity to design and conduct biomedical research, and to provide scientific and ethical review and monitoring of such research.

Capacity-building may include, but is not limited to, the following activities:

- establishing and strengthening independent and competent ethical review processes/ committees
- strengthening research capacity
- developing technologies appropriate to health-care and biomedical research
- training of research and health-care staff
- educating the community from which research subjects will be drawn

COMMENTARY ON GUIDELINE 20

External sponsors and investigators have an ethical obligation to contribute to a host country's sustainable capacity for independent scientific and ethical review and biomedical research. Before undertaking research in a host country with little or no such capacity, external sponsors and investigators should include in the research protocol a plan that specifies the contribution they will make. The amount of capacity building reasonably expected should be proportional to the magnitude of the research project. A brief epidemiological study involving only review of medical records, for example, would entail relatively little, if any, such development, whereas a considerable contribution is to be expected of an external sponsor of, for instance, a large-scale vaccine field-trial expected to last two or three years.

The specific capacity-building objectives should be determined and achieved through dialogue and negotiation between external sponsors and host-country authorities. External sponsors would be expected to employ and, if necessary, train local individuals to function as investigators, research assistants or data managers, for example, and to provide, as necessary, reasonable amounts of financial, educational and other assistance for capacity-building. To avoid conflict of interest and safeguard the independence of review committees, financial assistance should not be provided directly to them; rather, funds should be made available to appropriate authorities in the host-country government or to the host research institution.

(See also Guideline 10: *Research in populations and communities with limited resources*)

GUIDELINE 21: *Ethical obligation of external sponsors to provide health-care services*

External sponsors are ethically obliged to ensure the availability of:

—health-care services that are essential to the safe conduct of the research;

—treatment for subjects who suffer injury as a consequence of research interventions; and,

—services that are a necessary part of the commitment of a sponsor to make a beneficial intervention or product developed as a result of the research reasonably available to the population or community concerned.

COMMENTARY ON GUIDELINE 21

Obligations of external sponsors to provide health-care services will vary with the circumstances of particular studies and the needs of host countries. The sponsors' obligations in particular studies should be clarified before the research is begun. The research protocol should specify what health-care services will be made available, during and after the research, to the subjects themselves, to the community from which the subjects are drawn, or to the host country, and for how long. The details of these arrangements should be agreed by the sponsor, officials of the host country, other interested parties, and, when appropriate, the community from which subjects are to be drawn. The agreed arrangements should be specified in the consent process and document.

Although sponsors are, in general, not obliged to provide health-care services beyond that which is necessary for the conduct of the research, it is morally praiseworthy to do so. Such services typically include treatment for diseases contracted in the course of the study. It might, for example, be agreed to treat cases of an infectious disease contracted during a trial of a vaccine designed to provide immunity to that disease, or to provide treatment of incidental conditions unrelated to the study.

The obligation to ensure that subjects who suffer injury as a consequence of research interventions obtain medical treatment free of charge, and that compensation be provided for death or disability occurring as a consequence of such injury, is the subject of Guideline 19, on the scope and limits of such obligations.

When prospective or actual subjects are found to have diseases unrelated to the research, or cannot be enrolled in a study because they do not meet the health criteria, investigators should, as appropriate, advise them to obtain, or refer them for, medical care. In general, also, in the course of a study, sponsors should disclose to the proper health authorities information of public health concern arising from the research.

The obligation of the sponsor to make reasonably available for the benefit of the population or community concerned any intervention or product developed, or knowledge generated, as a result of the research is considered in Guideline 10: *Research in populations and communities with limited resources.*

Appendix 1

ITEMS TO BE INCLUDED IN A PROTOCOL (OR ASSOCIATED DOCUMENTS) FOR BIOMEDICAL RESEARCH INVOLVING HUMAN SUBJECTS.

(Include the items relevant to the study/project in question)

1. Title of the study;
2. A summary of the proposed research in lay/non-technical language;
3. A clear statement of the justification for the study, its significance in development and in meeting the needs of the country /population in which the research is carried out;
4. The investigators' views of the ethical issues and considerations raised by the study and, if appropriate, how it is proposed to deal with them;
5. Summary of all previous studies on the topic, including unpublished studies known to the investigators and sponsors, and information on previously published research on the topic, including the nature, extent and relevance of animal studies and other preclinical and clinical studies;
6. A statement that the principles set out in these Guidelines will be implemented;
7. An account of previous submissions of the protocol for ethical review and their outcome;
8. A brief description of the site(s) where the research is to be conducted, including information about the adequacy of facilities for the safe and appropriate conduct of the research, and relevant demographic and epidemiological information about the country or region concerned;
9. Name and address of the sponsor;
10. Names, addresses, institutional affiliations, qualifications and experience of the principal investigator and other investigators;
11. The objectives of the trial or study, its hypotheses or research questions, its assumptions, and its variables;
12. A detailed description of the design of the trial or study. In the case of controlled clinical trials the description should include, but not be limited to, whether assignment to treatment groups will be randomized (including the method of randomization), and whether the study will be blinded (single blind, double blind), or open;
13. The number of research subjects needed to achieve the study objective, and how this was statistically determined;
14. The criteria for inclusion or exclusion of potential subjects, and justification for the exclusion of any groups on the basis of age, sex, social or economic factors, or for other reasons;
15. The justification for involving as research subjects any persons with limited capacity to consent or members of vulnerable social groups, and a description of special measures to minimize risks and discomfort to such subjects;
16. The process of recruitment, e.g., advertisements, and the steps to be taken to protect privacy and confidentiality during recruitment;
17. Description and explanation of all interventions (the method of treatment administration, including route of administration, dose, dose interval and treatment period for investigational and comparator products used);
18. Plans and justification for withdrawing or withholding standard therapies in the course of the research, including any resulting risks to subjects;
19. Any other treatment that may be given or permitted, or contraindicated, during the study;
20. Clinical and laboratory tests and other tests that are to be carried out;
21. Samples of the standardized case-report forms to be used, the methods of recording therapeutic response (description and evaluation of methods and frequency of measurement), the follow-up procedures, and, if applicable, the measures proposed to

determine the extent of compliance of subjects with the treatment;

22. Rules or criteria according to which subjects may be removed from the study or clinical trial, or (in a multi-centre study) a centre may be discontinued, or the study may be terminated;
23. Methods of recording and reporting adverse events or reactions, and provisions for dealing with complications;
24. The known or foreseen risks of adverse reactions, including the risks attached to each proposed intervention and to any drug, vaccine or procedure to be tested;
25. For research carrying more than minimal risk of physical injury, details of plans, including insurance coverage, to provide treatment for such injury, including the funding of treatment, and to provide compensation for research-related disability or death;
26. Provision for continuing access of subjects to the investigational treatment after the study, indicating its modalities, the individual or organization responsible for paying for it, and for how long it will continue;
27. For research on pregnant women, a plan, if appropriate, for monitoring the outcome of the pregnancy with regard to both the health of the woman and the short-term and long-term health of the child;
28. The potential benefits of the research to subjects and to others;
29. The expected benefits of the research to the population, including new knowledge that the study might generate;
30. The means proposed to obtain individual informed consent and the procedure planned to communicate information to prospective subjects, including the name and position of the person responsible for obtaining consent;
31. When a prospective subject is not capable of informed consent, satisfactory assurance that permission will be obtained from a duly authorized person, or, in the case of a child who is sufficiently mature to understand the implications of informed consent but has not reached the legal age of consent, that knowing agreement, or assent, will be obtained, as well as the permission of a parent, or a legal guardian or other duly authorized representative;
32. An account of any economic or other inducements or incentives to prospective subjects to participate, such as offers of cash payments, gifts, or free services or facilities, and of any financial obligations assumed by the subjects, such as payment for medical services;
33. Plans and procedures, and the persons responsible, for communicating to subjects information arising from the study (on harm or benefit, for example), or from other research on the same topic, that could affect subjects' willingness to continue in the study;
34. Plans to inform subjects about the results of the study;
35. The provisions for protecting the confidentiality of personal data, and respecting the privacy of subjects, including the precautions that are in place to prevent disclosure of the results of a subject's genetic tests to immediate family relatives without the consent of the subject;
36. Information about how the code, if any, for the subjects' identity is established, where it will be kept and when, how and by whom it can be broken in the event of an emergency;
37. Any foreseen further uses of personal data or biological materials;
38. A description of the plans for statistical analysis of the study, including plans for interim analyses, if any, and criteria for prematurely terminating the study as a whole if necessary;
39. Plans for monitoring the continuing safety of drugs or other interventions administered for purposes of the study or trial and, if appropriate, the appointment for this purpose of an independent data-monitoring (data and safety monitoring) committee;
40. A list of the references cited in the protocol;
41. The source and amount of funding of the research: the organization that is sponsoring the research and a detailed account of the sponsor's financial commitments to the research institution, the investigators, the research subjects, and, when relevant, the community;
42. The arrangements for dealing with financial or other conflicts of interest that might affect the judgement of investigators or other research personnel: informing the institutional conflict-of-interest committee of such conflicts of interest; the communication by that committee of the pertinent details of the information to the ethical review committee; and the transmission by that committee to the research subjects of the parts of the information that it decides should be passed on to them;
43. The time schedule for completion of the study;
44. For research that is to be carried out in a developing country or community, the contribution that the sponsor will make to capacity-building for scientific and ethical review and for biomedical research in the host country, and an assurance that the capacity-building objectives are in keeping with the values and expectations of the subjects and their communities;

45. Particularly in the case of an industrial sponsor, a contract stipulating who possesses the right to publish the results of the study, and a mandatory obligation to prepare with, and submit to, the principal investigators the draft of the text reporting the results;
46. In the case of a negative outcome, an assurance that the results will be made available, as appropriate, through publication or by reporting to the drug registration authority;
47. Circumstances in which it might be considered inappropriate to publish findings, such as when the findings of an epidemiological, sociological or genetics study may present risks to the interests of a community or population or of a racially or ethnically defined group of people;
48. A statement that any proven evidence of falsification of data will be dealt with in accordance with the policy of the sponsor to take appropriate action against such unacceptable procedures.

Appendix 2

WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINKI

<www.wma.net>

Appendix 3

THE PHASES OF CLINICAL TRIALS OF VACCINES AND DRUGS

Vaccine development

Phase I refers to the first introduction of a candidate vaccine into a human population for initial determination of its safety and biological effects, including immunogenicity. This phase may include studies of dose and route of administration, and usually involves fewer than 100 volunteers.

Phase II refers to the initial trials examining effectiveness in a limited number of volunteers (usually between 200 and 500); the focus of this phase is immunogenicity.

Phase III trials are intended for a more complete assessment of safety and effectiveness in the prevention of disease, involving a larger number of volunteers in a multicentre adequately controlled study.

Drug development

Phase I refers to the first introduction of a drug into humans. Normal volunteer subjects are usually studied to determine levels of drugs at which toxicity is observed. Such studies are followed by dose-ranging studies in patients for safety and, in some cases, early evidence of effectiveness.

Phase II investigation consists of controlled clinical trials designed to demonstrate effectiveness and relative safety. Normally, these are performed on a limited number of closely monitored patients.

Phase III trials are performed after a reasonable probability of effectiveness of a drug has been established and are intended to gather additional evidence of effectiveness for specific indications and more precise definition of drug-related adverse effects. This phase includes both controlled and uncontrolled studies.

Phase IV trials are conducted after the national drug registration authority has approved a drug for distribution or marketing. These trials may include research designed to explore a specific pharmacological effect, to establish the incidence of adverse reactions, or to determine the effects of long-term administration of a drug. Phase IV trials may also be designed to evaluate a drug in a population not studied adequately in the pre-marketing phases (such as children or the elderly) or to establish a new clinical indication for a drug. Such research is to be distinguished from marketing research, sales promotion studies, and routine post-marketing surveillance for adverse drug reactions in that these categories ordinarily need not be reviewed by ethical review committees (see Guideline 2).

SECTION V.

ETHICAL DIRECTIVES PERTAINING TO THE WELFARE AND USE OF ANIMALS

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1. Veterinary Medicine

Veterinarian's Oath, American Veterinary Medical Association (AVMA) [1954, revised 1969, 1999]

Principles of Veterinary Medical Ethics, American Veterinary Medical Association (AVMA) [revised 1993]

2. Research Involving Animals

International Guiding Principles for Biomedical Research Involving Animals, Council for International Organizations of Medical Sciences (CIOMS), World Health Organization [1984]

Principles for the Utilization and Care of Vertebrate Animals Used in Testing, Research, and Education, U.S. Interagency Research Animal Committee [1985]

Ethics of Animal Investigation, Canadian Council on Animal Care [revised 1989]

Australian Code of Practice for the Care and Use of Animals for Scientific Purposes, National Health and Medical Research Council, Commonwealth Scientific and Industrial Research Organization, and Australian Agricultural Council [revised 1989, 1997]

World Medical Association Statement on Animal Use in Biomedical Research, World Medical Association [1989]

Guidelines for Ethical Conduct in the Care and Use of Animals, American Psychological Association [1985, revised 1992]

Principles and Guidelines for the Use of Animals in Precollege Education, Institute of Laboratory Animal Resources, National Research Council [1989]

Concern for the humane treatment of animals was expressed in the nineteenth century in both the United Kingdom and the United States through societies organized for the prevention of cruelty to animals. The Cruelty to Animals Act, enacted by the British Parliament in 1876, was among the earliest and most comprehensive laws for the protection of animals. Antivivisection proposals were made to the New York State legislature in the nineteenth century, but it was not until 1966 that the United States government enacted the Animal Welfare Act (7 U.S.C. 2131 et seq.), which, with accompanying regulations administered by the U.S. Department of Agriculture (USDA), is the most comprehensive code for the promotion of animal welfare in the United States.

I. Veterinary Medicine

Documents focusing on the ethics of veterinary medicine are similar to those pertaining to human health care except that they are concerned both with the patient (animal) and the client (owner).

VETERINARIAN'S OATH

American Veterinary Medical Association (AVMA)

1954, REVISED 1969, 1999

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Originally adopted by the AVMA House of Delegates in 1954, the Veterinarian's Oath was revised in 1969. Phrases regarding "the promotion of public health, and the advancement of medical knowledge" were added to the oath. Others were dropped, including a specific pledge to "temper pain with anesthesia where indicated" and one not to use professional knowledge "contrary to the laws of humanity." The 1969 version of the oath, printed below, is administered to the graduating classes at many veterinary colleges. The oath was amended by the Executive Board, November 1999.

<http://www.avma.org/membshp/about.asp>

Being admitted to the profession of veterinary medicine, I solemnly swear to use my scientific knowledge and skills for the benefit of society through the protection of animal health, the relief of animal suffering, the conservation of animal resources, the promotion of public health, and the advancement of medical knowledge.

I will practice my profession conscientiously, with dignity, and in keeping with the principles of veterinary medical ethics.

I accept as a lifelong obligation the continual improvement of my professional knowledge and competence.

PRINCIPLES OF VETERINARY MEDICAL ETHICS

American Veterinary Medical Association (AVMA)

REVISED 1993

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Whereas animal research guidelines focus on the treatment of animals being used primarily for human purposes, veterinary medicine is concerned with balancing the interests and welfare of the patient (animal) and those of the client (owner). As a professionally generated ethics document, the AVMA's Principles of Veterinary Medical Ethics in many ways parallels the structure, content, and function of professional documents in human health care. The following are excerpts from the principles.

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Attitude and Intent

The Principles of Veterinary Medical Ethics are purposely constructed in a general and broad manner, but veterinarians who accept the Golden Rule as a guide for general conduct and make a reasonable effort to abide by the *Principles of Veterinary Medical Ethics* in professional life will have little difficulty with ethics.

The honor and dignity of our profession rest in our obedience to a just and reasonable code of ethics set forth as a guide to the members. The object of this code, however, is more far-reaching, for exemplary professional conduct not only upholds honor and dignity, but also enlarges our sphere of usefulness, exalts our social standards, and promotes the science we cultivate. Briefly stated, our code of ethics is the foundation of our individual and collective efforts. It is the solemn duty of all members of the Association to deport themselves in accordance with the spirit of this code.

These *Principles of Veterinary Medical Ethics* are intended as aspirational goals. This code is not intended to cover the entire field of veterinary medical ethics. Professional life is too complex to classify one's duties and obligations to clients, colleagues, and fellow citizens into a set of rules.

General Concepts

The *Principles of Veterinary Medical Ethics* are intended to aid veterinarians individually and collectively in maintaining a high level of ethical conduct. They are standards by which an individual may determine the propriety of conduct in relationships with clients, colleagues, and the public. A high standard of professional behavior is expected of all members of the profession.

Veterinarians should be good citizens and participate in activities to advance community welfare. They should conduct themselves in a manner that will enhance the worthiness of their profession.

Professional associations of veterinarians should adopt the AVMA *Principles of Veterinary Medical Ethics* or a similar code, and each should establish an active committee on ethics.

State veterinary associations should include reports or discussions on professional ethics in the programs of their meetings.

Teaching of ethics and professional concepts should be intensified in the educational programs of the colleges of veterinary medicine.

The *Principles of Veterinary Medical Ethics* should be subjected to review with the object of clarification of any obscure parts and the amendment of any inadequate or inappropriate items. A determined effort should be made to encourage compliance with the *Principles* in their entirety.

Guidelines for Professional Behavior

1. In their relations with others, veterinarians should speak and act on the basis of honesty and fairness.
2. Veterinarians should consider first the welfare of the patient for the purpose of relieving suffering and disability while causing a minimum of pain or fright. Benefit to the patient should transcend personal advantage or monetary gain in decisions concerning therapy.
3. Veterinarians should not employ professional knowledge and attainments nor render services under terms and conditions which tend to interfere with the free exercise of judgment and skill or tend to cause a deterioration of the quality of veterinary service.
4. Veterinarians should seek for themselves and their profession the respect of their colleagues, their clients, and the public through courteous verbal interchange, considerate treatment, professional appearances, professionally acceptable procedures, and the utilization of current professional and scientific knowledge. Veterinarians should be concerned with the affairs and welfare of their communities, including the public health.
5. Veterinarians should respect the rights of clients, colleagues, and other health professionals. No member shall belittle or injure the professional standing of another member of the profession or unnecessarily condemn the character of that person's professional acts in such a manner as to be false or misleading.
6. Veterinarians may choose whom they will serve. Once they have undertaken care of a patient they must not neglect the patient. In an emergency, however, they should render service to the best of their ability.
7. Veterinarians should strive continually to improve veterinary knowledge and skill, making available to their colleagues the benefit of their professional attainments, and seeking, through consultation, assistance of others when it appears that the quality of veterinary service may be enhanced thereby.
8. Advertising or solicitation of clients by veterinarians should adhere to the Advertising Regulations, and should in no case be false, misleading, or deceptive.
9. The veterinary profession should safeguard the public and itself against veterinarians deficient in moral character or professional competence. Veterinarians should observe all laws, uphold the honor and dignity of the profession, and accept its self-imposed discipline.
10. The responsibilities of the veterinary profession extend not only to the patient but also to society. The health of the community as well as the patient deserves the veterinarian's interest and participation in nonprofessional activities and organizations.

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Referrals, Consultations, and Relationships with Clients

Consultations and referrals should be offered or sought whenever it appears that the quality of veterinary service will be enhanced thereby.

Consultations should be conducted in a spirit of professional cooperation between the consultant and the attending veterinarian to assure the client's confidence in and respect for veterinary medicine.

When a fellow practitioner or a diagnostic laboratory, research, academic, or regulatory veterinarian is called into consultation by an attending veterinarian, findings and discussions with the client shall be handled in such a manner as to avoid criticism of the attending veterinarian by the consultant or the client, if that criticism is false or misleading.

When in the course of authorized official duty it is necessary for a veterinarian to render service in the field of another veterinarian, it will be considered unethical to offer free or compensated service or advice other than that which comes strictly within the scope of the official duty, unless the client and attending veterinarian agree.

Consultants must not revisit the patient or communicate in person with the client without the knowledge of the attending veterinarian.

Diagnostic laboratory, research, academic, or regulatory veterinarians in the role of consultants shall deport themselves in the same manner as fellow practitioners whether they are private, commercial, or public functionaries.

In dealing with referrals, veterinarians acting as consultants should not take charge of a case or problem without the consent of the client and notification of the referring veterinarian.

The first veterinarian to handle a case has an obligation to other veterinarians that the client may choose to consult about the same case. The first veterinarian should readily withdraw from the case, indicating the circumstances on the records, and should be willing to forward copies of the medical records to other veterinarians who request them.

A veterinarian may refuse to accept a client or a patient, but should not do so solely because the client has previously contacted another veterinarian.

If for any reason a client requests referral to another veterinarian or veterinary institution, the attending veterinarian should be willing to honor the request and facilitate the necessary arrangements.

The following suggestions are offered for consideration by veterinarians in dealing with clients with whom they are not acquainted or for whom they have not previously rendered service:

1) Conduct yourself in word and action as if the person had been referred to you by a colleague. Try to determine by careful questioning whether the client has consulted another veterinarian and if so, the veterinarian's name, diagnosis, and treatment. It may be advisable to contact the previous veterinarian to ascertain the original diagnosis and treatment before telling the client how you plan to handle the case.
2) Describe your diagnosis and intended treatment carefully so that the client will be generally satisfied with the professional contact.
3) Consider the advisability of notifying the previous veterinarian(s) of your diagnosis and therapy.
4) If your colleague's actions reflect professional incompetence or neglect or abuse of the patient, call it to your colleague's attention and, if appropriate, to the attention of officers or practice committees of the local or state veterinary associations or the proper regulatory agency. Remember that a client who is abruptly changing veterinarians is often under severe stress and is likely to overstate or misstate the causes for differences with the other practitioner.

Confidentiality

The ethical ideals of the veterinary profession imply that a doctor of veterinary medicine and the veterinarian's staff will protect the personal privacy of clients, unless the veterinarian is required, by law, to reveal the confidences or unless it becomes necessary in order to protect the health and welfare of the individual, the animals, and/or others whose health and welfare may be endangered.

Emergency Service

Every practitioner has a moral and ethical responsibility to provide service when because of accidents or other emergencies involving animals it is necessary to save life or relieve suffering. Since veterinarians cannot always be available to provide this service, veterinarians should cooperate with colleagues to assure that emergency services are provided consistent with the needs of the locality.

Frauds

Members of the Association shall avoid the impropriety of employing misrepresentations to attract public attention.

When employed by the buyer to examine an animal for purchase, it is unethical to accept a fee from the seller. The acceptance of such a fee is prima facie evidence of fraud. On the other hand, it is deemed unethical to criticize unfairly an animal about to be sold. The veterinarian's duty in this connection is to be a just and honest referee.

When veterinarians know that surgery has been requested with intent to deceive a third party, they will have engaged in an unethical practice if they perform or participate in the operation.

Secret Remedies

It is unethical and unprofessional for veterinarians to promote, sell, prescribe, or use any product the ingredient formula of which has not been revealed to them.

Genetic Defects

Performance of surgical procedures in all species for the purpose of concealing genetic defects in animals to be shown, raced, bred, or sold as breeding animals is unethical. However, should the health or welfare of the individual patient require correction of such genetic defects, it is recommended that the patient be rendered incapable of reproduction.

Alliance with Unqualified Persons

No member shall willfully place professional knowledge, attainments, or services at the disposal of any lay body, organization, group, or individual by whatever name called, or however organized, for the purpose of encouraging unqualified groups and individuals to diagnose and prescribe for the ailments and diseases of animals.

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Therapy, Determination of

Determination of therapy must not be relegated to secondary consideration with remuneration of the veterinarian being the primary interest. The veterinarian's obligation to uphold the dignity and honor of the profession precludes entering into an arrangement whereby, through commission or rebates, judgment on choice of treatment would be influenced by considerations other than needs of the patient, welfare of the client, or safety to the public.

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Vaccination Clinics

Definition: The term vaccination clinics applies to either privately or publicly supported activities in which veterinarians are engaged in mass immunization of pet animals. Usually, animals are brought into points of assembly by their owners or caretakers in response to a notification that immunization services will be available. Characteristically, these clinics do not provide the opportunity for the participating veterinarians to (1) conduct a physical examination of the individual animals to be immunized, (2) obtain a history of past immunization or prior disease, or (3) advise individual owners on follow-up immunization and health care.

Scientific and Technical Considerations—Rabies vaccination for the purpose of protecting the public health may be achieved in a rabies vaccination clinic.

When the primary objective is to protect the animal patient's health, clinical examination of the patient including proper history taking, is an essential and necessary part of a professionally acceptable immunization procedure.

Such a clinical examination is expected to be provided without regard to where the vaccination procedure is performed.

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Drugs, Practitioner's Responsibility in the Choice of

Practitioners of veterinary medicine, in common with practitioners in other branches of medicine, are fully responsible for their actions with respect to a patient from the time they accept the case until it is released from their care. In the choice of drugs, biologics, or other treatments, they are expected to use their professional judgment in the interests of the patient, based upon their knowledge of the condition, the probable effects of the treatment, and the available scientific evidence which may affect these decisions. If the preponderance of professional judgement is, or seems to be, contrary to theirs, the burden upon the practitioners to sustain their judgment becomes heavier. Nevertheless, the judgment is theirs and theirs alone.

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Dispensing, Marketing, and Merchandising

Dispensing is the direct distribution of veterinary products to clients for their use on the supposition that the veterinarian has knowledge of the particular case or general conditions relating to the current health status of the animals involved and has established a veterinarian client patient relationship. A veterinarian client patient relationship is characterized by these attributes:

1) The veterinarian has assumed the responsibility for making medical judgments regarding the health of the animal(s) and the need for medical treatment, and the client (owner or other caretaker) has agreed to follow the instructions of the veterinarian; and when
2) There is sufficient knowledge of the animal(s) by the veterinarian to initiate at least a general or preliminary diagnosis of the medical condition of the animal(s). This means that the veterinarian has recently seen and is personally acquainted with the keeping and care of the animal(s) by virtue of an examination of the animal(s) and/or by medically appropriate and timely visits to the premises where the animal(s) are kept; and when
3) The practicing veterinarian is readily available for follow-up in case of adverse reactions or failure of the regimen of therapy.

In the veterinarian's office dispensing becomes the distributing of professional veterinary products by virtue of verbal information presented by the owner, as an adjunct to the knowledge gained previously by the practitioner. This is in contrast to a written prescription involving a pharmacist.

Marketing is interpreted to mean those efforts directed at stimulating and encouraging animal owners to make use of veterinary services and products for the purpose of improving animal health and welfare.

Merchandising is buying and selling of professional veterinary products without a veterinarian client patient relationship. Merchandising as defined here is unethical.

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2. Research Involving Animals

Guidelines and regulations addressing the ethical treatment of animals, especially their use in scientific research, include those developed by groups involved in animal use and those generated by nonresearch groups.

INTERNATIONAL GUIDING PRINCIPLES FOR BIOMEDICAL RESEARCH INVOLVING ANIMALS

Council for International Organizations of Medical Sciences (CIOMS), World Health Organization

1984

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The purpose of the guiding principles, approved in 1984, is to provide a conceptual and ethical framework for whatever regulations governing animal research a country chooses to adopt. The guiding principles reflect consultation with a large, representative sample of the international biomedical community as well as with representatives of animal welfare groups. They have gained general international acceptance and have served as a model for similar guidelines in specific countries, including the United States and Canada.

Basic Principles

I. The advancement of biological knowledge and the development of improved means for the protection of the health and wellbeing both of man and of animals require recourse to experimentation on intact live animals of a wide variety of species.

II. Methods such as mathematical models, computer simulation and in vitro biological systems should be used wherever appropriate.

III. Animal experiments should be undertaken only after due consideration of their relevance for human or animal health and the advancement of biological knowledge.

IV. The animals selected for an experiment should be of an appropriate species and quality, and the minimum number required, to obtain scientifically valid results.

V. Investigators and other personnel should never fail to treat animals as sentient, and should regard their proper care and use and the avoidance or minimization of discomfort, distress, or pain as ethical imperatives.

VI. Investigators should assume that procedures that would cause pain in human beings cause pain in other vertebrate species although more needs to be known about the perception of pain in animals.

VII. Procedures with animals that may cause more than momentary or minimal pain or distress should be performed with appropriate sedation, analgesia, or anaesthesia in accordance with accepted veterinary practice. Surgical or other painful procedures should not be performed on unanaesthetized animals paralysed by chemical agents.

VIII. Where waivers are required in relation to the provisions of article VII, the decisions should not rest solely with the investigators directly concerned but should be made, with due regard to the provisions of articles IV, V, and VI, by a suitably constituted review body. Such waivers should not be made solely for the purposes of teaching or demonstration.

IX. At the end of, or when appropriate during, an experiment, animals that would otherwise suffer severe or chronic pain, distress, discomfort, or disablement that cannot be relieved should be painlessly killed.

X. The best possible living conditions should be maintained for animals kept for biomedical purposes. Normally the care of animals should be under the supervision of veterinarians having experience in laboratory animal science. In any case, veterinary care should be available as required.

XI. It is the responsibility of the director of an institute or department using animals to ensure that investigators and personnel have appropriate qualifications or experience for conducting procedures on animals. Adequate opportunities shall be provided for in-service training, including the proper and humane concern for the animals under their care.

PRINCIPLES FOR THE UTILIZATION AND CARE OF VERTEBRATE ANIMALS USED IN TESTING, RESEARCH, AND EDUCATION

U.S. Interagency Research Animal Committee

1985

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Developed in 1984 by the U.S. Interagency Research Animal Committee, which serves as a focal point for the discussion by federal agencies of issues involving the use of animals in research and testing, these principles are based on the CIOMS Guiding Principles. The U.S. principles are endorsed, implemented, and supplemented by the National Institutes of Health's Public Health Service Policy on Humane Care and Use of Laboratory Animals, which was revised in 1986, and the Guide for the Care and Use of Laboratory Animals, prepared by the Institute of Laboratory Animal Resources, National Academy of Sciences, in 1985. The Public Health Service (PHS) policy applies to all PHS researchers, grantees, and contractors who use warm-blooded vertebrates in research and testing. The policy requires compliance with the Animal Welfare Act (AWA) (7 U.S.C. 2131 et seq.) and the USDA regulations that implement it (9 CFR, Subchapter A—Animal Welfare).

The AWA was originally enacted in 1966 to impose civil and criminal penalties on persons who stole household pets and sold them to biomedical research facilities. It has been amended many times to provide additional protections for warm-blooded animals used in agriculture, the food and fiber industry, circuses, pet shops, and research. In 1985, the AWA was amended by P.L. 99–198 to require, among other provisions, the establishment of Animal Care and Use Committees to oversee animal housing and care and to review proposed research. Both the USDA regulations implementing the act and the PHS policy reference the Guide for the Care and Use of Laboratory Animals as the standard according to which programs for the care and use of laboratory animals will be judged.

The AWA and its accompanying regulations and the correlative Public Health Service Act and its accompanying PHS policy together with the guide constitute the fundamental documents that govern the care and use of animals used for research, testing, and teaching in the United States. Additionally, the Food and Drug Administration's Good Laboratory Practices regulations include similar provisions for the care and use of animals in testing sites used by the industry.

The development of knowledge necessary for the improvement of the health and well-being of humans as well as other animals requires in vivo experimentation with a wide variety of animal species. Whenever U.S. Government agencies develop requirements for testing, research, or training procedures involving the use of vertebrate animals, the following principles shall be considered; and whenever these agencies actually perform or sponsor such procedures, the responsible institutional official shall ensure that these principles are adhered to:

I. The transportation, care, and use of animals should be in accordance with the Animal Welfare Act (7 U.S.C. 2131 et seq.) and other applicable Federal laws, guidelines and policies.

II. Procedures involving animals should be designed and performed with due consideration of their relevance to human or animal health, the advancement of knowledge, or the good of society.

III. The animals selected for a procedure should be of an appropriate species and quality and the minimum number required to obtain valid results. Methods such as mathematical models, computer simulation, and in vitro biological systems should be considered.

IV. Proper use of animals, including the avoidance or minimization of discomfort, distress, and pain when consistent with sound scientific practices, is imperative. Unless the contrary is established, investigators should consider that procedures that cause pain or distress in human beings may cause pain or distress in other animals.

V. Procedures with animals that may cause more than momentary or slight pain or distress should be performed with appropriate sedation, analgesia, or anesthesia. Surgical or other painful procedures should not be performed on unanesthetized animals paralyzed by chemical agents.

VI. Animals that would otherwise suffer severe or chronic pain or distress that cannot be relieved should be painlessly killed at the end of the procedure or, if appropriate, during the procedure.

VII. The living conditions of animals should be appropriate for their species and contribute to their health and comfort. Normally, the housing, feeding, and care of all animals used for biomedical purposes must be directed by a veterinarian or other scientist trained and experienced in the proper care, handling, and use of the species being maintained or studied. In any case, veterinary care shall be provided as indicated.

VIII. Investigators and other personnel shall be appropriately qualified and experienced for conducting procedures on living animals. Adequate arrangements shall be made for their in-service training, including the proper and humane care and use of laboratory animals.

IX. Where exceptions are required in relation to the provision of these Principles, the decisions should not rest with the investigators directly concerned but should be made, with due regard to Principle II, by an appropriate review group such as an institutional animal research committee. Such exceptions should not be made solely for the purposes of teaching or demonstration.

ETHICS OF ANIMAL INVESTIGATION

Canadian Council on Animal Care

REVISED 1989

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More detailed than the CIOMS and U.S. government principles, the Canadian Council on Animal Care's Ethics of Animal Investigation includes nine principles designed to be used in association with the CCAC's Guide to the Care and Use of Experimental Animals, a highly respected, two-volume document that provides detailed requirements for the humane use of animals in research, teaching, and testing.

The use of animals in research, teaching, and testing is acceptable only if it promises to contribute to understanding of fundamental biological principles, or to the development of knowledge that can reasonably be expected to benefit humans or animals.

Animals should be used only if the researcher's best efforts to find an alternative have failed. A continuing sharing of knowledge, review of the literature, and adherence to the Russell-Burch "3R" tenet of "Replacement, Reduction and Refinement" are also requisites. Those using animals should employ the most humane methods on the smallest number of appropriate animals required to obtain valid information.

The following principles incorporate suggestions from members of both the scientific and animal welfare communities, as well as the organizations represented on Council. They should be applied in conjunction with CCAC's "Guide to the Care and Use of Experimental Animals."

1. If animals must be used, they should be maintained in a manner that provides for their physical comfort and psychological well-being, according to CCAC's "Policy Statement on Social and Behavioural Requirements of Experimental Animals."
2. Animals must not be subjected to unnecessary pain or distress. The experimental design must offer them every practicable safeguard, whether in research, in teaching or in testing procedures; cost and convenience must not take precedence over the animal's physical and mental well-being.
3. Expert opinion must attest to the potential value of studies with animals. The following procedures, which are restricted, require independent, external evaluation to justify their use:
    i) burns, freezing injuries, fractures, and other types of trauma investigation in anesthetized animals, concomitant to which must be acceptable veterinary practices for the relief of pain, including adequate analgesia during the recovery period;
    ii) staged encounters between predator and prey or between conspecifics where prolonged fighting and injury are probable.
4. If pain or distress are necessary concomitants to the study, these must be minimized both in intensity and duration. Investigators, animal care committees, grant review committees and referees must be especially cautious in evaluating the proposed use of the following procedures:
    a) experiments involving withholding pre- and post-operative pain-relieving medication;
    b) paralyzing and immobilizing experiments where there is no reduction in the sensation of pain;
    c) electric shock as negative reinforcement;
    d) extreme environmental conditions such as low or high temperatures, high humidity, modified atmospheres, etc., or sudden changes therein;
    e) experiments studying stress and pain;
    f) experiments requiring withholding of food and water for periods incompatible with the species specific psychological needs; such experiments should have no detrimental effect on the health of the animal;
    g) injection of Freund's Complete Adjuvant (FCA). This must be carried out in accordance with "CCAC Guidelines on Immunization Procedures."
5. An animal observed to be experiencing severe, unrelievable pain or discomfort should immediately be humanely killed, using a method providing initial rapid unconsciousness.
6. While non-recovery procedures involving anesthetized animals, and studies involving no pain or distress are considered acceptable; the following experimental procedures inflict excessive pain and are thus unacceptable:
    a) utilization of muscle relaxants or paralytics (curare and curare-like) alone, without anesthetics, during surgical procedures;
    b) traumatizing procedures involving crushing, burning, striking or beating in unanesthetized animals.
7. Studies such as toxicological and biological testing, cancer research and infectious disease investigation may, in the past, have required continuation until

the death of the animal. However, in the face of distinct signs that such processes are causing irreversible pain or distress, alternative endpoints should be sought to satisfy both the requirements of the study and the needs of the animal.

8. Physical restraint should only be used after alternative procedures have been fully considered and found inadequate. Animals so restrained must receive exceptional care and attention, in compliance with species specific and general requirements as set forth in the "Guide."
9. Painful experiments or multiple invasive procedures on an individual animal, conducted solely for the instruction of students in the classroom, or for the demonstration of established scientific knowledge, cannot be justified. Audiovisual or other alternative techniques should be employed to convey such information.

AUSTRALIAN CODE OF PRACTICE FOR THE CARE AND USE OF ANIMALS FOR SCIENTIFIC PURPOSES

National Health and Medical Research Council, Commonwealth Scientific and Industrial Research Organization, and Australian Agricultural Council

REVISED 1989, 1997

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The first Australian code was issued in 1969 and revised in 1979, 1982, 1985, and 1989. The current code encompasses all aspects of the care and use of animals for scientific purposes in medicine, biology, agriculture, veterinary and other animal sciences, industry, and teaching. Section 1 of the code, "General Principles for the Care and Use of Animals for Scientific Purposes," which is printed below, is similar to the CIOMS principles, but is unique in its inclusion of the principle that animals must not be taken from their natural habitats if others, bred in captivity, are available. In addition to general principles for the care and use of animals, the code specifies the responsibilities of researchers and institutions and the composition and function of Animal Experimentation Ethics Committees. It also provides guidelines for the acquisition and care of animals. It was most recently revised in 1997.

<http://www.health.gov.au/nhmrc/research/awc/pca.pdf>

For the guidance of Investigators, Institutions and Animal Experimentation Ethics Committees and all involved in the care and use of animals for scientific purposes.

1.1 Experiments on animals may be performed only when they are essential to obtain and establish significant information relevant to the understanding of humans or animals, to the maintenance and improvement of human or animal health and welfare, to the improvement of animal management or production, or to the achievement of educational objectives.

1.2 People who use animals for scientific purposes have an obligation to treat the animals with respect and to consider their welfare as an essential factor when planning and conducting experiments.

1.3 Investigators have direct and ultimate responsibility for all matters relating to the welfare of the animals they use in experiments.

1.4 Techniques which replace or complement animal experiments must be used wherever possible.

1.5 Experiments using animals may be performed only after a decision has been made that they are justified, weighing the scientific or educational value of the experiment against the potential effects on the welfare of the animals.

1.6 Animals chosen must be of an appropriate species with suitable biological characteristics, including behavioural characteristics, genetic constitution and nutritional, microbiological and general health status.

1.7 Animals must not be taken from their natural habitats if animals bred in captivity are available and suitable.

1.8 Experiments must be scientifically valid, and must use no more than the minimum number of animals needed.

1.9 Experiments must use the best available scientific techniques and must be carried out only by persons competent in the procedures they perform.

1.10 Experiments must not be repeated unnecessarily.

1.11 Experiments must be as brief as possible.

1.12 Experiments must be designed to avoid pain or distress to animals. If this is not possible, pain or distress must be minimised.

1.13 Pain and distress cannot be evaluated easily in animals and therefore investigators must assume that animals experience pain in a manner similar to humans. Decisions regarding the animals' welfare must be based on this assumption unless there is evidence to the contrary.

1.14 Experiments which may cause pain or distress of a kind and degree for which anaesthesia would normally be used in medical or veterinary practice must be carried out using anaesthesia appropriate to the species and the procedure. When it is not possible to use anaesthesia, such as in certain toxicological or animal production experiments or in animal models of disease, the end-point of the experiments must be as early as possible to avoid or minimise pain or distress to the animals.

1.15 Investigators must avoid using death as an experimental end-point whenever possible.

1.16 Analgesic and tranquilliser usage must be appropriate for the species and should at least parallel usage in medical or veterinary practice.

1.17 An animal which develops signs of pain or distress of a kind and degree not predicted in the proposal, must have the pain or distress alleviated promptly. If severe pain cannot be alleviated without delay, the animal must be killed humanely forthwith. Alleviation of such pain or distress must take precedence over finishing an experiment.

1.18 Neuromuscular blocking agents must not be used without appropriate general anaesthesia, except in animals where sensory awareness has been eliminated. If such agents are used, continuous or frequent intermittent monitoring of paralysed animals is essential to ensure that the depth of anaesthesia is adequate to prevent pain or distress.

1.19 Animals must be transported, housed, fed, watered, handled and used under conditions which are appropriate to the species and which ensure a high standard of care.

1.20 Institutions using animals for scientific purposes must establish Animal Experimentation Ethics Committees (AEECs) to ensure that all animal use conforms with the standards of this Code.

1.21 Investigators must submit written proposals for all animal experimentation to an AEEC which must take into account the expected value of the knowledge to be gained, the validity of the experiments, and all ethical and animal welfare aspects.

1.22 Experiments must not commence until written approval has been obtained from the AEEC.

1.23 The care and use of animals for all scientific purposes in Australia must be in accord with this Code of Practice, and with Commonwealth, State and Territory legislation.

WORLD MEDICAL ASSOCIATION STATEMENT ON ANIMAL USE IN BIOMEDICAL RESEARCH

World Medical Association

1989

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Adopted by the Forty-first World Medical Assembly in Hong Kong, September 1989, the World Medical Association Statement on Animal Use in Biomedical Research includes principles that affirm not only the need to respect the welfare of animals used for research but also the continued use of animals in biomedical research as essential, and it condemns the harassment of scientists by animal rights activists.

Preamble

Biomedical research is essential to the health and well-being of every person in our society. Advances in biomedical research have dramatically improved the quality and prolonged the duration of life throughout the world. However, the ability of the scientific community to continue its efforts to improve personal and public health is being threatened by a movement to eliminate the use of animals in biomedical research. This movement is spearheaded by groups of radical animal rights activists whose views are far outside mainstream public attitudes and whose tactics range from sophisticated lobbying, fund raising, propaganda and misinformation campaigns to violent attacks on biomedical research facilities and individual scientists.

The magnitude of violent animal rights activities is staggering. In the United States alone, since 1980, animal rights groups have staged more than 29 raids on U.S. research facilities, stealing over 2,000 animals, causing more than 7 million dollars in physical damages and ruining years of scientific research in the process. Animal activist groups have engaged in similar activities in Great Britain, Western Europe, Canada and Australia. Various groups in these countries have claimed responsibility for the bombing of cars, institutions, stores, and the private homes of researchers.

Animal rights violence has had a chilling effect on the scientific community internationally. Scientists, research organizations, and universities have been intimidated into altering or even terminating important research efforts that depend on the use of animals. Laboratories have been forced to divert thousands of research dollars for the purchase of sophisticated security equipment. Young people who might otherwise pursue a career in biomedical research are turning their sights to alternative professions.

Despite the efforts of many groups striving to protect biomedical research from animal activism, the response to the animal rights movement has been fragmented, underfunded, and primarily defensive. Many groups within the biomedical community are hesitant to take a public stand about animal activism because of fear of reprisal. As a result, the research establishment has been backed into a defensive posture. Its motivations are questioned, and the need for using animals in research is repeatedly challenged.

While research involving animals is necessary to enhance the medical care of all persons, we recognized also that humane treatment of research animals must be ensured.

Appropriate training for all research personnel should be prescribed and adequate veterinary care should be available. Experiments must comply with any rules or regulations promulgated to govern human handling, housing, care, treatment and transportation of animals.

International medical and scientific organizations must develop a stronger and more cohesive campaign to counter the growing threat to public health posed by animal activists. Leadership and coordination must be provided.

The World Medical Association therefore affirms the following principles:

1. Animal use in biomedical research is essential for continued medical progress.
2. The WMA Declaration of Helsinki requires that biomedical research involving human subjects should be based on animal experimentation, but also requires that the welfare of animals used for research be respected.
3. Humane treatment of animals used in biomedical research is essential.
4. All research facilities should be required to comply with all guiding principles for humane treatment of animals.
5. Medical Societies should resist any attempt to deny the appropriate use of animals in biomedical research because such denial would compromise patient care.
6. Although rights to free speech should not be compromised, the anarchistic element among animal right activists should be condemned.
7. The use of threats, intimidation, violence, and personal harassment of scientists and their families should be condemned internationally.
8. A maximum coordinated effort from international law enforcement agencies should be sought to protect researchers and research facilities from activities of a terrorist nature.

GUIDELINES FOR ETHICAL CONDUCT IN THE CARE AND USE OF ANIMALS

American Psychological Association

1985, REVISED 1992

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Some professional associations, such as the American Psychological Association (APA), have developed their own guidelines governing research with animals, which reinforce and/or supplement all pertinent laws and other regulations. The APA produced one of the earliest and most complete sets of association guidelines pertaining to research on animals. Like other professional groups, the APA requires that individuals publishing research in APA journals attest to the fact that animal research was conducted in accordance with its guidelines.

I. Justification of the Research

A. Research should be undertaken with a clear scientific purpose. There should be a reasonable expectation that the research will a) increase knowledge of the processes underlying the evolution, development, maintenance, alteration, control, or biological significance of behavior; b) increase understanding of the species under study; or c) provide results that benefit the health or welfare of humans or other animals.

B. The scientific purpose of the research should be of sufficient potential significance to justify the use of animals. Psychologists should act on the assumption that procedures that would produce pain in humans will also do so in other animals.

C. The species chosen for study should be best suited to answer the question(s) posed. The psychologist should always consider the possibility of using other species, nonanimal alternatives, or procedures that minimize the number of animals in research, and should be familiar with the appropriate literature.

D. Research on animals may not be conducted until the protocol has been reviewed by the institutional animal care and use committee (IACUC) to ensure that the procedures are appropriate and humane.

E. The psychologist should monitor the research and the animals' welfare throughout the course of an investigation to ensure continued justification for the research.

II. Personnel

A. Psychologists should ensure that personnel involved in their research with animals be familiar with these guidelines.

B. Animal use procedures must conform with federal regulations regarding personnel, supervision, record keeping, and veterinary care.

C. Behavior is both the focus of study of many experiments as well as a primary source of information about an animal's health and well-being. It is therefore necessary that psychologists and their assistants be informed about the behavioral characteristics of their animal subjects, so as to be aware of normal, species-specific behaviors and unusual behaviors that could forewarn of health problems.

D. Psychologists should ensure that all individuals who use animals under their supervision receive explicit instruction in experimental methods and in the care, maintenance, and handling of the species being studied. Responsibilities and activities of all individuals dealing with animals should be consistent with their respective competencies, training, and experience in either the laboratory or the field setting.

III. Care and Housing of Animals

The concept of "psychological well-being" of animals is of current concern and debate and is included in Federal Regulations (United States Department of Agriculture [USDA], 1991). As a scientific and professional organization, APA recognizes the complexities of defining psychological well-being. Procedures appropriate for a particular species may well be inappropriate for others. Hence, APA does not presently stipulate specific guidelines regarding the maintenance of psychological well-being of research animals. Psychologists familiar with the species should be best qualified professionally to judge measures such as enrichment to maintain or improve psychological well-being of those species.

A. The facilities housing animals should meet or exceed current regulations and guidelines (USDA, 1990, 1991) and are required to be inspected twice a year (USDA, 1989).

B. All procedures carried out on animals are to be reviewed by a local IACUC to ensure that the procedures are appropriate and humane. The committee should have representation from within the institution and from the local community. In the event that it is not possible to constitute an appropriate local IACUC, psychologists are encouraged to seek advice from a corresponding committee of a cooperative institution.

C. Responsibilities for the conditions under which animals are kept, both within and outside of the context of active experimentation or teaching, rests with the psychologist under the supervision of the IACUC (where required by federal regulations) and with individuals appointed by the institution to oversee animal care. Animals are to be provided with humane care and healthful conditions during their stay in the facility. In addition to the federal requirements to provide for the psychological well-being of nonhuman primates used in research, psychologists are encouraged to consider enriching the environments of their laboratory animals and should keep abreast of literature on well-being and enrichment for the species with which they work.

IV. Acquisition of Animals

A. Animals not bred in the psychologist's facility are to be acquired lawfully. The USDA and local ordinances should be consulted for information regarding regulations and approved suppliers.

B. Psychologists should make every effort to ensure that those responsible for transporting the animals to the facility provide adequate food, water, ventilation, space, and impose no unnecessary stress on the animals.

C. Animals taken from the wild should be trapped in a humane manner and in accordance with applicable federal, state, and local regulations.

D. Endangered species or taxa should be used only with full attention to required permits and ethical concerns. Information and permit applications can be obtained from the Fish and Wildlife Service, Office of Management Authority, U.S. Dept. of the Interior, 4401 N. Fairfax Dr., Rm. 432, Arlington, VA 22043, 703–358-2104. Similar caution should be used in work with threatened species or taxa.

V. Experimental Procedures

Humane consideration for the well-being of the animal should be incorporated into the design and conduct of all procedures involving animals, while keeping in mind the primary goal of experimental procedures—the acquisition of sound, replicable data. The conduct of all procedures is governed by Guideline I.

A. Behavioral studies that involve no aversive stimulation or overt sign of distress to the animal are acceptable. This includes observational and other noninvasive forms of data collection.

B. When alternative behavioral procedures are available, those that minimize discomfort to the animal should be used. When using aversive conditions, psychologists should adjust the parameters of stimulation to levels that appear minimal, though compatible with the aims of the research. Psychologists are encouraged to test painful stimuli on themselves, whenever reasonable. Whenever consistent with the goals of research, consideration should be given to providing the animals with control of the potentially aversive stimulation.

C. Procedures in which the animal is anesthetized and insensitive to pain throughout the procedure and is euthanized before regaining consciousness are generally acceptable.

D. Procedures involving more than momentary or slight aversive stimulation, which are not relieved by medication or other acceptable methods, should be undertaken only when the objectives of research cannot be achieved by other methods.

E. Experimental procedures that require prolonged aversive conditions or produce tissue damage or metabolic disturbances require greater justification and surveillance. This includes prolonged exposure to extreme environmental conditions, experimentally induced prey killing, or infliction of physical trauma or tissue damage. An animal observed to be in a state of severe distress or chronic pain that cannot be alleviated and is not essential to the purposes of the research should be euthanized immediately.

F. Procedures that use restraint must conform to federal regulations and guidelines.

G. Procedures involving the use of paralytic agents without reduction in pain sensation require particular prudence and humane concern. Use of muscle relaxants or paralytics alone during surgery, without general anesthesia, is unacceptable and shall not be used.

H. Surgical procedures, because of their invasive nature, require close supervision and attention to humane considerations by the psychologist. Aseptic (methods that minimize risks of infection) techniques must be used on laboratory animals whenever possible.

   1. All surgical procedures and anesthetization should be conducted under the direct supervision of a person who is competent in the use of the procedures.
   2. If the surgical procedure is likely to cause greater discomfort than that attending anesthetization, and unless there is specific justification for acting otherwise, animals should be maintained under anesthesia until the procedure is ended.
   3. Sound postoperative monitoring and care, which may include the use of analgesics and antibiotics, should be provided to minimize discomfort and to prevent infection and other untoward consequences of the procedure.
   4. Animals can not be subjected to successive surgical procedures unless these are required by the nature of the research, the nature of the surgery, or for the well-being of the animal. Multiple surgeries on the same animal must receive special approval from the IACUC.

I. When the use of an animal is no longer required by an experimental protocol or procedure, in order to minimize the number of animals used in research, alternatives to euthanasia should be considered. Such uses should be compatible with the goals of research and the welfare of the animal. Care should be taken that such an action does not expose the animal to multiple surgeries.

J. The return of wild-caught animals to the field can carry substantial risks, both to the formerly captive animals and to the ecosystem. Animals reared in the laboratory should not be released because, in most cases, they cannot survive or they may survive by disrupting the natural ecology.

K. When euthanasia appears to be the appropriate alternative, either as a requirement of the research or because it constitutes the most humane form of disposition of an animal at the conclusion of the research:

   1. Euthanasia shall be accomplished in a humane manner, appropriate for the species, and in such a way as to ensure immediate death, and in accordance with procedures outlined in the latest version of the "American Veterinary Medical Association (AVMA) Panel on Euthanasia."
   2. Disposal of euthanized animals should be accomplished in a manner that is in accordance with all relevant legislation, consistent with health, environmental, and aesthetic concerns, and approved by the IACUC. No animal shall be discarded until its death is verified.

VI. Field Research

Field research, because of its potential to damage sensitive ecosystems and ethologies, should be subject to IACUC approval. Field research, if strictly observational, may not require IACUC approval (USDA, 1989, pg. 36126).

A. Psychologists conducting field research should disturb their populations as little as possible—consistent with the goals of the research. Every effort should be made to minimize potential harmful effects of the study on the population and on other plant and animal species in the area.

B. Research conducted in populated areas should be done with respect for the property and privacy of the inhabitants of the area.

C. Particular justification is required for the study of endangered species. Such research on endangered species should not be conducted unless IACUC approval has been obtained and all requisite permits are obtained (see above, III D).

VII. Educational Use of Animals

APA has adopted separate guidelines for the educational use of animals in precollege education, including the use of animals in science fairs and demonstrations. For a copy of APA's "Ethical Guidelines for the Teaching of

Psychology in the Secondary Schools," write to: High School Teacher Affiliate Program, Education Directorate, APA, 750 First St., NE, Washington, DC 20002–4242.

A. Psychologists are encouraged to include instruction and discussion of the ethics and values of animal research in all courses that involve or discuss the use of animals.
B. Animals may be used for educational purposes only after review by a committee appropriate to the institution.
C. Some procedures that can be justified for research purposes may not be justified for educational purposes. Consideration should always be given to the possibility of using nonanimal alternatives.
D. Classroom demonstrations involving live animals can be valuable as instructional aids in addition to videotapes, films, or other alternatives. Careful consideration should be given to the question of whether this type of demonstration is warranted by the anticipated instructional gains.

PRINCIPLES AND GUIDELINES FOR THE USE OF ANIMALS IN PRECOLLEGE EDUCATION

Institute of Laboratory Animal Resources (ILAR)
National Research Council

1989

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The ILAR Principles and Guidelines provide guidance for improving the scientific integrity of precollege research and encouraging more humane study of animals in precollege education. They are designed to help schools implement changes in their use of animals in teaching programs to bring them more in line with current approaches to the use of animals in higher education and research.

The humane study of animals in precollege education can provide important learning experiences in science and ethics and should be encouraged. Maintaining classroom pets in preschool and grade school can teach respect for other species, as well as proper animal husbandry practices. Introduction of secondary school students to animal studies in closely supervised settings can reinforce those early lessons and teach the principles of humane care and use of animals in scientific inquiry. The National Research Council recommends compliance with the following principles whenever animals are used in precollege education or in science fair projects.

Principle 1

Observational and natural history studies that are not intrusive (that is, do not interfere with an animal's health or well-being or cause it discomfort) are encouraged for all classes of organisms. When an intrusive study of a living organism is deemed appropriate, consideration should be given first to using plants (including lower plants such as yeast and fungi) and invertebrates with no nervous systems or with primitive ones (including protozoa, planaria, and insects). Intrusive studies of invertebrates with advanced nervous systems (such as octopi) and vertebrates should be used only when lower invertebrates are not suitable and only under the conditions stated below in Principle 10.

Principle 2

Supervision shall be provided by individuals who are knowledgeable about and experienced with the health, husbandry, care, and handling of the animal species used and who understand applicable laws, regulations, and policies.

Principle 3

Appropriate care for animals must be provided daily, including weekends, holidays, and other times when school is not in session. This care must include

a. nutritious food and clean, fresh water;
b. clean housing with space and enrichment suitable for normal species behaviors; and
c. temperature and lighting appropriate for the species.

Principle 4

Animals should be healthy and free of disease that can be transmitted to humans or to other animals. Veterinary care must be provided as needed.

Principle 5

Students and teachers should report immediately to the school health authority all scratches, bites, and other injuries; allergies; or illnesses.

Principle 6

Prior to obtaining animals for educational purposes, it is imperative that the school develop a plan for their procurement and ultimate disposition. Animals must not be captured from or released into the wild without the approval of the responsible wildlife and public health officials. When euthanasia is necessary, it should be performed in accordance with the most recent recommendations of the American Veterinary Medical Association's Panel Report on Euthanasia (Journal of the American Veterinary Medical Association, 188[3]: 252–268, 1986, et seq.). It should be performed only by someone trained in the appropriate technique.

Principle 7

Students shall not conduct experimental procedures on animals that

a. are likely to cause pain or discomfort or interfere with an animal's health or well-being;
b. induce nutritional deficiencies or toxicities; or
c. expose animals to microorganisms, ionizing radiation, cancer-producing agents, or any other harmful drugs or chemicals capable of causing disease, injury, or birth defects in humans or animals.

In general, procedures that cause pain in humans are considered to cause pain in other vertebrates.

Principle 8

Experiments on avian embryos that might result in abnormal chicks or in chicks that might experience pain or discomfort shall be terminated 72 hours prior to the expected date of hatching. The eggs shall be destroyed to prevent inadvertent hatching.

Principle 9

Behavioral conditioning studies shall not involve aversive stimuli. In studies using positive reinforcement, animals should not be deprived of water; food deprivation intervals should be appropriate for the species but should not continue longer than 24 hours.

Principle 10

A plan for conducting an experiment with living animals must be prepared in writing and approved prior to initiating the experiment or to obtaining the animals. Proper experimental design of projects and concern for animal welfare are important learning experiences and contribute to respect for and appropriate care of animals. The plan shall be reviewed by a committee composed of individuals who have the knowledge to understand and evaluate it and who have the authority to approve or disapprove it. The written plan should include the following:

a. a statement of the specific hypotheses or principles to be tested, illustrated, or taught;
b. a summary of what is known about the subject under study, including references;
c. a justification for the use of the species selected and consideration of why a lower vertebrate or invertebrate cannot be used; and
d. a detailed description of the methods and procedures to be used, including experimental design; data analysis; and all aspects of animal procurement, care, housing, use, and disposal.

Exceptions

Exceptions to Principles 7–10 may be granted under special circumstances by a panel appointed by the school principal or his or her designee. This panel should consist of at least three individuals, including a science teacher, a teacher of a nonscience subject, and a scientist or veterinarian who has expertise in the subject matter involved. At least one panel member should not be affiliated with the school or science fair, and none should be a member of the student's family.

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SECTION VI.

ETHICAL DIRECTIVES PERTAINING TO THE ENVIRONMENT

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World Charter for Nature, General Assembly of the United Nations [1982]

Rio Declaration on Environment and Development, United Nations Conference on Environment and Development [1992]

Conservation Policies of the Wildlife Society, The Wildlife Society [1988]

Code of Ethics for Members of the Society of American Foresters, Society of American Foresters [1976, amended 1986, 1992, 2000]

Code of Ethics and Standards of Practice for Environmental Professionals, National Association of Environmental Professionals [1979, revised 1994]

Code of Ethics, National Environmental Health Association [revised 1992]

Bioethics refers not only to the ethics of health care but also to the ethics of the life sciences, which include ecology and environmental sciences. Enhancing the health of plants, animals, and the entire biosphere has inherent moral value; it is also crucial for the protection and promotion of human health and well-being, which depend upon a healthy environment. Whether the environment is perceived to have intrinsic value, instrumental value, or both, society increasingly recognizes moral duties to preserve and nurture it and to foster a health-promoting relationship between humans and their environment. Many countries have laws and regulations designed to protect the environment and its resources through limitations on the emissions of industrial pollutants, hazardous waste disposal, recycling programs, and conservation policy.

The documents in this section fall into two categories: policy and professional conduct. They are issued both by professional groups and by a nonprofessional body, the United Nations. The editors have not attempted to include any of the myriad national and international laws and regulations pertaining to the environment, opting instead for more general policy statements.

WORLD CHARTER FOR NATURE

General Assembly of the United Nations

1982

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A multinational task force began drafting the World Charter for Nature in 1975. Sponsored by thirty-four developing nations, it was adopted by the General Assembly of the United Nations on October 29, 1982, by a vote of 111 to 1, with the United States casting the sole dissenting vote.

The General Assembly,

Reaffirming the fundamental purposes of the United Nations, in particular the maintenance of international peace and security, the development of friendly relations among nations and the achievement of international co-operation in solving international problems of an economic, social, cultural, technical, intellectual or humanitarian character,

Aware that:

(a) Mankind is a part of nature and life depends on the uninterrupted functioning of natural systems which ensure the supply of energy and nutrients,
(b) Civilization is rooted in nature, which has shaped human culture and influenced all artistic and scientific achievement, and living in harmony with nature gives man the best opportunities for the development of his creativity, and for rest and recreation,

Convinced that:

(a) Every form of life is unique, warranting respect regardless of its worth to man, and, to accord other organisms such recognition, man must be guided by a moral code of action,
(b) Man can alter nature and exhaust natural resources by his action or its consequences and, therefore, must fully recognize the urgency of maintaining the stability and quality of nature and of conserving natural resources,

Persuaded that:

(a) Lasting benefits from nature depend upon the maintenance of essential ecological processes and life support systems, and upon the diversity of life forms, which are jeopardized through excessive exploitation and habitat destruction by man,
(b) The degradation of natural systems owing to excessive consumption and misuse of natural resources, as well as to failure to establish an appropriate economic order among peoples and among States, leads to the breakdown of the economic, social and political framework of civilization,
(c) Competition for scarce resources creates conflicts, whereas the conservation of nature and natural resources contributes to justice and the maintenance of peace and cannot be achieved until mankind learns to live in peace and to forsake war and armaments,

Reaffirming that man must acquire the knowledge to maintain and enhance his ability to use natural resources in a manner which ensures the preservation of the species and ecosystems for the benefit of present and future generations,

Firmly convinced of the need for appropriate measures, at the national and international, individual and collective, and private and public levels, to protect nature and promote international co-operation in this field,

Adopts, to these ends, the present World Charter for Nature, which proclaims the following principles of conservation by which all human conduct affecting nature is to be guided and judged.

I. General Principles

1. Nature shall be respected and its essential processes shall not be impaired.
2. The genetic viability on the earth shall not be compromised; the population levels of all life forms, wild and domesticated, must be at least sufficient for their survival, and to this end necessary habitats shall be safeguarded.

3. All areas of the earth, both land and sea, shall be subject to these principles of conservation; special protection shall be given to unique areas, to representative samples of all the different types of ecosystems and to the habitats of rare or endangered species.
4. Ecosystems and organisms, as well as the land, marine and atmospheric resources that are utilized by man, shall be managed to achieve and maintain optimum sustainable productivity, but not in such a way as to endanger the integrity of those other ecosystems or species with which they coexist.
5. Nature shall be secured against degradation caused by warfare or other hostile activities.

I. Functions

6. In the decision-making process it shall be recognized that man's needs can be met only by ensuring the proper functioning of natural systems and by respecting the principles set forth in the present Charter.
7. In the planning and implementation of social and economic development activities, due account shall be taken of the fact that the conservation of nature is an integral part of those activities.
8. In formulating long-term plans for economic development, population growth and the improvement of standards of living, due account shall be taken of the long-term capacity of natural systems to ensure the subsistence and settlement of the populations concerned, recognizing that this capacity may be enhanced through science and technology.
9. The allocation of areas of the earth to various uses shall be planned and due account shall be taken of the physical constraints, the biological productivity and diversity and the natural beauty of the areas concerned.
10. Natural resources shall not be wasted, but used with a restraint appropriate to the principles set forth in the present Charter, in accordance with the following rules:
    (a) Living resources shall not be utilized in excess of their natural capacity for regeneration;
    (b) The productivity of soils shall be maintained or enhanced through measures which safeguard their long-term fertility and the process of organic decomposition, and prevent erosion and all other forms of degradation;
    (c) Resources, including water, which are not consumed as they are used shall be reused or recycled;
    (d) Non-renewable resources which are consumed as they are used shall be exploited with restraint, taking into account their abundance, the rational possibilities of converting them for consumption, and the compatibility of their exploitation with the functioning of natural systems.
11. Activities which might have an impact on nature shall be controlled, and the best available technologies that minimize significant risks to nature or other adverse effects shall be used; in particular:
    (a) Activities which are likely to cause irreversible damage to nature shall be avoided;
    (b) Activities which are likely to pose a significant risk to nature shall be preceded by an exhaustive examination; their proponents shall demonstrate that expected benefits outweigh potential damage to nature, and where potential adverse effects are not fully understood, the activities should not proceed;
    (c) Activities which may disturb nature shall be preceded by assessment of their consequences, and environmental impact studies of development projects shall be conducted sufficiently in advance, and if they are to be undertaken, such activities shall be planned and carried out so as to minimize potential adverse effects;
    (d) Agriculture, grazing, forestry and fisheries practices shall be adapted to the natural characteristics and constraints of given areas;
    (e) Areas degraded by human activities shall be rehabilitated for purposes in accord with their natural potential and compatible with the well-being of affected populations.
12. Discharge of pollutants into natural systems shall be avoided and:
    (a) Where this is not feasible, such pollutants shall be treated at the source, using the best practicable means available;
    (b) Special precautions shall be taken to prevent discharge of radioactive or toxic wastes.
13. Measures intended to prevent, control or limit natural disasters, infestations and diseases shall be specifically directed to the causes of these scourges and shall avoid adverse side-effects on nature.

III. Implementation

14. The principles set forth in the present Charter shall be reflected in the law and practice of each State, as well as at the international level.
15. Knowledge of nature shall be broadly disseminated by all possible means, particularly by ecological education as an integral part of general education.
16. All planning shall include, among its essential elements, the formulation of strategies for the

conservation of nature, the establishment of inventories of ecosystems and assessments of the effects on nature of proposed policies and activities; all of these elements shall be disclosed to the public by appropriate means in time to permit effective consultation and participation.

17. Funds, programmes and administrative structures necessary to achieve the objective of the conservation of nature shall be provided.
18. Constant efforts shall be made to increase knowledge of nature by scientific research and to disseminate such knowledge unimpeded by restrictions of any kind.
19. The status of natural processes, ecosystems and species shall be closely monitored to enable early detection of degradation or threat, ensure timely intervention and facilitate the evaluation of conservation policies and methods.
20. Military activities damaging to nature shall be avoided.
21. States and, to the extent they are able, other public authorities, international organizations, individuals, groups and corporations shall:
    - (a) Co-operate in the task of conserving nature through common activities and other relevant actions, including information exchange and consultations;
    - (b) Establish standards for products and manufacturing processes that may have adverse effects on nature, as well as agreed methodologies for assessing these effects;
    - (c) Implement the applicable international legal provisions for the conservation of nature and the protection of the environment;
    - (d) Ensure that activities within their jurisdictions or control do not cause damage to the natural systems located within other States or in the areas beyond the limits of national jurisdiction;
    - (e) Safeguard and conserve nature in areas beyond national jurisdiction.
22. Taking fully into account the sovereignty of States over their natural resources, each State shall give effect to the provisions of the present Charter through its competent organs and in co-operation with other States.
23. All persons, in accordance with their national legislation, shall have the opportunity to participate, individually or with others, in the formulation of decisions of direct concern to their environment, and shall have access to means of redress when their environment has suffered damage or degradation.
24. Each person has a duty to act in accordance with the provisions of the present Charter; acting individually, in association with others or through participation in the political process, each person shall strive to ensure that the objectives and requirements of the present Charter are met.

RIO DECLARATION ON ENVIRONMENT AND DEVELOPMENT

United Nations Conference on Environment and Development

1992

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The Rio Declaration on Environment and Development consists of twenty-seven principles for governing the economic and environmental behavior of individuals and states in the quest for global sustainability. The preamble to the declaration affirms the goal "of establishing a new and equitable global partnership" in the effort to develop international agreements that "respect the interests of all and protect the integrity of the global environmental and developmental system." It also recognizes "the integral and interdependent nature of the Earth, our home." The declaration was adopted by the United Nations Conference on Environment and Development at its meeting in Rio de Janeiro, June 3–14, 1992. The United States subscribes to the document. The text of the twenty-seven principles follows.

1. Human beings are at the centre of concerns for sustainable development. They are entitled to a healthy and productive life in harmony with nature.
2. States have, in accordance with the Charter of the United Nations and the principles of international law, the sovereign right to exploit their own resources pursuant to their own environmental and developmental policies, and the responsibility to ensure that activities within their jurisdiction or control do not cause damage to the environment of other States or of areas beyond the limits of national jurisdiction.
3. The right to development must be fulfilled so as to equitably meet developmental and environmental needs of present and future generations.
4. In order to achieve sustainable development, environmental protection shall constitute an integral part of the development process and cannot be considered in isolation from it.
5. All States and all people shall cooperate in the essential task of eradicating poverty as an indispensable requirement for sustainable development, in order to decrease the disparities in standards of

living and better meet the needs of the majority of the people of the world.

6. The special situation and needs of developing countries, particularly the least developed and those most environmentally vulnerable, shall be given special priority. International actions in the field of environment and development should also address the interests and needs of all countries.
7. States shall cooperate in a spirit of global partnership to conserve, protect and restore the health and integrity of the Earth's ecosystem. In view of the different contributions to global environmental degradation, States have common but differentiated responsibilities. The developed countries acknowledge the responsibility that they bear in the international pursuit of sustainable development in view of the pressures their societies place on the global environment and of the technologies and financial resources they command.
8. To achieve sustainable development and a higher quality of life for all people, States should reduce and eliminate unsustainable patterns of production and consumption and promote appropriate demographic policies.
9. States should cooperate to strengthen endogenous capacity-building for sustainable development by improving scientific understanding through exchanges of scientific and technological knowledge, and by enhancing the development, adaptation, diffusion and transfer of technologies, including new and innovative technologies.
10. Environmental issues are best handled with the participation of all concerned citizens, at the relevant level. At the national level, each individual shall have appropriate access to information concerning the environment that is held by public authorities, including information on hazardous materials and activities in their communities, and the opportunity to participate in decision-making processes. States shall facilitate and encourage public awareness and participation by making information widely available. Effective access to judicial and administrative proceedings, including redress and remedy, shall be provided.
11. States shall enact effective environmental legislation. Environmental standards, management objectives and priorities should reflect the environmental and developmental context to which they apply. Standards applied by some countries may be inappropriate and of unwarranted economic and social cost to other countries, in particular developing countries.
12. States should cooperate to promote a supportive and open international economic system that would lead to economic growth and sustainable development in all countries, to better address the problems of environmental degradation. Trade policy measures for environmental purposes should not constitute a means of arbitrary or unjustifiable discrimination or a disguised restriction on international trade. Unilateral actions to deal with environmental challenges outside the jurisdiction of the importing country should be avoided. Environmental measures addressing transboundary or global environmental problems should, as far as possible, be based on an international consensus.
13. States shall develop national law regarding liability and compensation for the victims of pollution and other environmental damage. States shall also cooperate in an expeditious and more determined manner to develop further international law regarding liability and compensation for adverse effects of environmental damage caused by activities within their jurisdiction or control to areas beyond their jurisdiction.
14. States should effectively cooperate to discourage or prevent the relocation and transfer to other States of any activities and substances that cause severe environmental degradation or are found to be harmful to human health.
15. In order to protect the environment, the precautionary approach shall be widely applied by States according to their capabilities. Where there are threats of serious or irreversible damage, lack of full scientific certainty shall not be used as a reason for postponing cost-effective measures to prevent environmental degradation.
16. National authorities should endeavour to promote the internalization of environmental costs and the use of economic instruments, taking into account the approach that the polluter should, in principle, bear the cost of pollution, with due regard to the public interest and without distorting international trade and investment.
17. Environmental impact assessment, as a national instrument, shall be undertaken for proposed activities that are likely to have a significant adverse impact on the environment and are subject to a decision of a competent national authority.
18. States shall immediately notify other States of any natural disasters or other emergencies that are likely to produce sudden harmful effects on the environment of those States. Every effort shall be made by the international community to help States so afflicted.
19. States shall provide prior and timely notification and relevant information to potentially affected States on

activities that may have a significant adverse transboundary environmental effect and shall consult with those States at an early stage and in good faith.

20. Women have a vital role in environmental management and development. Their full participation is therefore essential to achieve sustainable development.
21. The creativity, ideals, and courage of the youth of the world should be mobilized to forge a global partnership in order to achieve sustainable development and ensure a better future for all.
22. Indigenous people and their communities and other local communities have a vital role in environmental management and development because of their knowledge and traditional practices. States should recognize and duly support their identity, culture and interests and enable their effective participation in the achievement of sustainable development.
23. The environment and natural resources of people under oppression, domination and occupation shall be protected.
24. Warfare is inherently destructive of sustainable development. States shall therefore respect international law providing protection for the environment in times of armed conflict and cooperate in its further development, as necessary.
25. Peace, development and environmental protection are interdependent and indivisible.
26. States shall resolve all their environmental disputes peacefully and by appropriate means in accordance with the Charter of the United Nations.
27. States and people shall cooperate in good faith and in a spirit of partnership in the fulfillment of the principles embodied in this Declaration and in the further development of international law in the field of sustainable development.

CONSERVATION POLICIES OF THE WILDLIFE SOCIETY

The Wildlife Society

1988

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In addition to national and international bodies, professional organizations, such as the Wildlife Society, also issue environmental policies. Founded in 1937, the Wildlife Society is dedicated to the wise management and conservation of the world's wildlife resources. Excerpts from the society's Conservation Policies are printed below.

Human Populations

Burgeoning human populations continue to place an overwhelming and detrimental demand on many of the world's limited natural resources. Human degradation of terrestrial and aquatic communities is biologically unadvisable. Certain of these resources are irreplaceable, and others must be either preserved intact or managed carefully to ensure the integrity of the ecosystem and humanity. These resources will continue to decline or to sustain irreparable damage, despite scientific and technological advances, if the growth of the human population is not restrained.

The policy of The Wildlife Society, in regard to human populations is to:

1. Actively support an enlightened policy of population stabilization that will encourage the conservation of natural resources and enhance the quality of human existence.
2. Promote a better understanding of mankind's role in the world's ecosystems so as to minimize the contamination and harmful alteration of the global environment.

Environmental Quality

The demands that human societies make upon the earth and its biota inevitably result in environmental change. Many ecosystems have been exploited for immediate monetary profit rather than managed for sustained biotic yields. Careless or excessive exploitation often leads to unnecessary degradation of the environment. The common aim of mankind should be to perfect processes for deriving support from the environment without destroying its stability, diversity, productivity, or aesthetic values.

The policy of The Wildlife Society, in regard to environmental quality, is to:

1. Stimulate and support educational programs that emphasize mankind's dependence on functional ecosystems, and, consequently, the necessity for living in harmony with the environment.
2. Foster research designed to elucidate the complex biotic relationships of ecosystems.
3. Encourage the development and use of methods designed to reduce environmental degradation and to reclaim and reconstitute degraded ecosystems.
4. Contribute to the development of technologies, social systems, and individual behaviors that will

maintain the diversity and beauty of the environment.

The Management of Living Natural Resources

Human population growth jeopardizes mankind's existence. The continued well-being of mankind, and earth's other living natural resources, is dependent upon a healthy environment maintained through the skilled management of resources. As human populations increase, wild plant and animal habitats usually decrease. Many people presume that all wild habitats are untouched by humanity. Actually, few natural areas have escaped the influence of mankind. Often these influences have disrupted natural areas, thus requiring the need for scientific management of these areas and their associated living resources.

A "hands-off," non-manipulative policy for plant and animal resources eventually could result in reestablishing naturally-functioning plant and animal communities as wild areas, if mankind's ever-present impacts could be eliminated. In such areas the actions of nature would dominate and low-priority would be given to material human wants. Such areas have been and are being established where practicable.

Only limited amounts of land can be devoted to wild areas because of the demands of our growing human population. Land is required for housing, crops, mineral and timber production, manufacture and sale of goods, intensive recreation, and other necessary and desirable purposes. Plant and animal communities associated with these more intensive land uses, although often highly productive, are usually unnatural in that they lack the diversity and stability of unaltered communities. Applying sound land and water management practices to these altered lands can assist natural processes in providing habitat suitable for plants and animals which are forced to live in close association with human activities. Plant and animal populations also may be enhanced and optimized at levels within the land's ability to support them through proven professional resource management practices.

The Wildlife Society recognizes the serious implications of mankind's ever-increasing worldwide demands for living space, food, shelter and other products. It also recognizes a need for a policy of continued, intensified and improved management for earth's living resources.

The policy of The Wildlife Society, in regard to management of living natural resources, is to:

1. Support and strengthen scientific management as the rational instrument for maintaining, restoring, and enhancing plant and animal resources for the continued use and appreciation by humanity.
2. Encourage the development and dissemination of information to improve public understanding of the need for, and the positive benefits from, scientific management.
3. Encourage the retention or enhancement of habitat for native plants and animals on public and private lands.
4. Seek support for ethical restraints in the use of living natural resources.
5. Reaffirm our view that scientific management includes both the regulated harvest of the surplus of those species in plentiful supply, as well as the protection of those plant or animal species which are rare, threatened, or in danger of extinction.

Conservation Education

Worldwide growth of human populations is placing unprecedented demands and stresses on the world's finite natural resources. Satisfying human needs for energy, food, fibers, minerals, and wood products has the potential for further destruction of wildlife habitat and aesthetic resources. If these natural resources are to be given adequate consideration in the context of human needs, a sound program of conservation education is of paramount importance.

The educational process must contain four key elements if it is to be effective in enabling people to cope with resource problems. First, it must provide basic understanding of the properties and distribution of natural resources. Second, it must provide and encourage alternatives to current degrading resource uses and promote changes in life styles that can be accommodated by the existing resources base. Third, it must provide people with an understanding of the political, economic, and social processes by which changes in resource use can be effected. And last, it must lead to positive action in behalf of resource conservation.

The policy of The Wildlife Society, in regard to conservation education, is to:

1. Assist in the development and promotion of educational programs that will disseminate ecologically sound knowledge to advance wise management of wildlife and other natural resources.
2. Promote increased cooperation and communication among all agencies and groups concerned with conservation education and resource management.

3. Encourage members of the wildlife profession (a) to interpret and make readily available those results of wildlife research that citizens require for decision-making, and (b) to actively participate in the implementation of sound, publicly oriented programs in conservation education.

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CODE OF ETHICS FOR MEMBERS OF THE SOCIETY OF AMERICAN FORESTERS

Society of American Foresters

1976, AMENDED 1986, 1992, 2000

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In 1992 the Society of American Foresters adopted a new "land ethic canon" espousing "stewardship of" and "respect for the land." The 2000 version's preamble exhorts "foresters [to] seek to sustain and protect a variety of forest uses and attributes, such as aesthetic values, air and water quality, biodiversity, recreation, timber production, and wildlife habitat."

<http://www.safnet.org/who/codeofethics.cfm>

Preamble

Service to society is the cornerstone of any profession. The profession of forestry serves society by fostering stewardship of the world's forests. Because forests provide valuable resources and perform critical ecological functions, they are vital to the wellbeing of both society and the biosphere.

Members of the Society of American Foresters have a deep and enduring love for the land, and are inspired by the profession's historic traditions, such as Gifford Pinchot's utilitarianism and Aldo Leopold's ecological conscience. In their various roles as practitioners, teachers, researchers, advisers, and administrators, foresters seek to sustain and protect a variety of forest uses and attributes, such as aesthetic values, air and water quality, biodiversity, recreation, timber production, and wildlife habitat.

The purpose of this Code of Ethics is to protect and serve society by inspiring, guiding, and governing members in the conduct of their professional lives. Compliance with the code demonstrates members' respect for the land and their commitment to the long-term management of ecosystems, and ensures just and honorable professional and human relationships, mutual confidence and respect, and competent service to society.

On joining the Society of American Foresters, members assume a special responsibility to the profession and to society by promising to uphold and abide by the following:

Principles and Pledges

1. Foresters have a responsibility to manage land for both current and future generations. We pledge to practice and advocate management that will maintain the long-term capacity of the land to provide the variety of materials, uses, and values desired by landowners and society.
2. Society must respect forest landowners' rights and correspondingly, landowners have a land stewardship responsibility to society. We pledge to practice and advocate forest management in accordance with landowner objectives and professional standards, and to advise landowners of the consequences of deviating from such standards.
3. Sound science is the foundation of the forestry profession. We pledge to strive for continuous improvement of our methods and our personal knowledge and skills; to perform only those services for which we are qualified; and in the biological, physical, and social sciences to use the most appropriate data, methods, and technology.
4. Public policy related to forests must be based on both scientific principles and societal values. We pledge to use our knowledge and skills to help formulate sound forest policies and laws; to challenge and correct untrue statements about forestry; and to foster dialogue among foresters, other professionals, landowners, and the public regarding forest policies.
5. Honest and open communication, coupled with respect for information given in confidence, is essential to good service. We pledge to always present, to the best of our ability, accurate and complete information; to indicate on whose behalf any public statements are made; to fully disclose and resolve any existing or potential conflicts of interest; and to keep proprietary information confidential unless the appropriate person authorizes its disclosure.
6. Professional and civic behavior must be based on honesty, fairness, good will, and respect for the law. We pledge to conduct ourselves in a civil and dignified manner; to respect the needs, contributions, and viewpoints of others; and to give due credit to others for their methods, ideas, or assistance.

CODE OF ETHICS AND STANDARDS OF PRACTICE FOR ENVIRONMENTAL PROFESSIONALS

National Association of Environmental Professionals

1979, REVISED 1994

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The Code of the National Association of Environmental Professionals (NAEP) takes a broad view of environment, which includes physical, natural, and cultural systems. It is noteworthy that a New Jersey court ruled that the NAEP code of ethics be considered public policy in the state (Bowman v. Mobil Oil Corp., Civil Action No. 87–4093); as such, employees who abide by it cannot be fired for refusing to perform actions that directly contravene the code.

The objectives of Environmental Professionals are to conduct their personal and professional lives and activities in an ethical manner. Honesty, justice and courtesy form moral philosophy which, associated with a mutual interest among people, constitute the foundation of ethics. Environmental Professionals should recognize such a standard, not in passive observance, but as a set of dynamic principles guiding their conduct and way of life. It is their duty to practice their profession according to this Code of Ethics.

As the keystone of professional conduct is integrity, Environmental Professionals will discharge their duties with fidelity to the public, their employers, clients, and with fairness and impartiality to all. It is their duty to interest themselves in public welfare, and to be ready to apply their special knowledge for the benefit of mankind and their environment.

Creed

The objectives of an Environmental Professional are:

1. to recognize and attempt to reconcile societal and individual human needs with responsibility for physical, natural, and cultural systems.
2. to promote and develop policies, plans, activities and projects that achieve complementary and mutual support between natural and man-made, and present and future components of the physical, natural and cultural environment.

Ethics

As an Environmental Professional I will:

1. be personally responsible for the validity of all data collected, analyses performed, or plans developed by me or under my direction. I will be responsible and ethical in my professional activities.
2. encourage reason, planning, design, management and review of activities in a scientifically and technically objective manner. I will incorporate the best principles of the environmental sciences for the mitigation of environmental harm and enhancement of environmental quality.
3. not condone misrepresentation of work I have performed or that was performed under my direction.
4. examine all of my relationships or actions which could be legitimately interpreted as a conflict of interest by clients, officials, the public or peers. In any instance where I have a financial or personal interest in the activities with which they are directly or indirectly involved, I will make a full disclosure of that interest to my employer, client, or other affected parties.
5. not engage in conduct involving dishonesty, fraud, deceit, or misrepresentation or discrimination.
6. not accept fees wholly or partially contingent on the client's desired result where that desired result conflicts with my professional judgement.

Guidance for Practice as an Environmental Professional

As an Environmental Professional I will:

1. encourage environmental planning to begin in the earliest stages of project conceptualization.
2. recognize that total environmental management involves the consideration of all environmental factors including: technical, economic, ecological, and sociopolitical and their relationships.
3. incorporate the best principle of design and environmental planning when recommending measures to reduce environmental harm and enhance environmental quality.
4. conduct my analysis, planning, design and review my activities primarily in subject areas for which I am qualified, and shall encourage and recognize the participation of other professionals in subject areas where I am less experienced. I shall utilize and participate in interdisciplinary teams wherever practical to determine impacts, define and evaluate all reasonable alternatives to proposed actions, and assess short-term versus long-term productivity with and without the project or action.
5. seek common, adequate, and sound technical grounds for communication with and respect for the

contributions of other professionals in developing and reviewing policies, plans, activities, and projects.

6. determine that the policies, plans, activities, or projects in which I am involved are consistent with all governing laws, ordinances, guidelines, plans, and policies, to the best of my knowledge and ability.
7. encourage public participation at the earliest feasible time in an open and productive atmosphere.
8. conduct my professional activities in a manner that ensures consideration of technically and economically feasible alternatives.

Encourage Development of the Profession

As an Environmental Professional I will:

1. assist in maintaining the integrity and competence of my profession.
2. encourage education and research, and the development of useful technical information relating to the environmental field.
3. advertise and present my services in a manner that avoids the use of material and methods that may bring discredit to the profession.

CODE OF ETHICS

National Environmental Health Association

REVISED 1992

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The National Environmental Health Association's Code of Ethics explicitly states that the environment is not restricted by political boundaries; it must be viewed as a single entity. Health is recognized to be one of the fundamental rights of every human being, and those to whom the code applies have an obligation to work to provide a healthful environment for all. It is noteworthy that the code has a line for the member's signature, making it a personal pledge by the professional.

As a member of the National Environmental Health Association, I acknowledge:

That I have an obligation to work to provide a healthful environment for all. I will uphold the standards of my profession, continually search for truths, and disseminate my findings. I will continually strive to keep myself fully informed on developments in the fields of public and environmental health and protection:

That I have an obligation to the public whose trust I hold and because of this, I will endeavor to the best of my ability to safeguard the public's health. I will be loyal to this trust in whatever governmental division, industry, or institution by which I am retained:

That the environment is not restricted by man-made political boundaries and therefore must be considered as a single entity;

That the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, cultural background, economic or social condition; and

That I will uphold the constitution and bylaws of the National Environmental Health Association and will at all times conduct myself in a manner worthy of my profession.

By my signature hereon, I acknowledge and affirm a realization of my personal responsibility to actively discharge these obligations.

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APPENDIX II

ADDITIONAL RESOURCES IN BIOETHICS

In the intervening years since the revised edition of this Encyclopedia was published in 1995, the diversity and wealth of bioethics resources has once again increased enormously. The explosion of interest in this field continues to be demonstrated by the appearance of new periodicals devoted exclusively to bioethics along with increasing attention to bioethical issues by both general journals and specialty journals covering related disciplines, as well as the development of various organizational entities in bioethics.

The widespread availability of the Internet has had a great impact on the publication and accessibility of information. The preponderance of peer-reviewed bioethics literature continues to be published in print format, and is often now simultaneously offered via the Internet free or through subscriptions. These important sources of bioethics research are listed below, and the Web sites of most journals have been added to the list.

Another equally important development in the last decade is the institutionalization of bioethics concern by governments and professional groups around the world. In this update, the focus is restricted to national, international, regional and professional entities, most of which have Web sites. These groups supplement the peer-reviewed literature with what is called "gray literature." They are an important new entity involved in the exchange of ideas about contemporary ethical, legal, and public policy questions.

For the 1995 edition of this Encyclopedia, bioethics organizations, primarily those located in and fostered by academic institutions, that were developing library collections to support delineated courses of study, were highlighted. Many of those continue. Those academic programs that do not house special libraries of their own rely on bioethics collections in their respective universities, so those libraries can be useful sites for bioethics research. Long lists of academic programs in bioethics can be found at many Web sites, including the Educational Opportunities page at <http://bioethics.georgetown.edu>.

This update provides a detailed look at the information services at the Kennedy Institute of Ethics at Georgetown University, as the first and most comprehensive library of its kind supporting bioethics research. Then, sources of periodical literature important to the field will be listed in two parts: A) Bioethics and Health Law Journals and B) General Philosophical, Scientific, and Medical Journals. Finally, the organization of bioethics endeavors in government and professional groups are shown, most with a Web address, arranged in the following categories: A) National Libraries of Bioethics, B) National Deliberative Bodies on Bioethics, C) Regional and International Bioethics Organizations, and D) Professional Groups.

I. Information Services of the Kennedy Institute of Ethics

Since the early 1970s the Kennedy Institute of Ethics has made a sustained effort to foster research and education in bioethics by collecting, analyzing, and disseminating bioethics information through various means. Its information services programs have grown significantly since the revised edition of this work was published in 1995, particularly with regard to free information services via the Internet.

Two long-standing information projects are: (1) the operation of a comprehensive bioethics library, the National Reference Center for Bioethics Literature (NRCBL), established in 1985 with support from the U.S. National Library of Medicine (NLM); and (2) the ongoing creation of bibliographic database records for the NLM, a project initiated in 1973. A third project joined these two in 1994 with support from what is now the U.S. National Human Genome Research Institute: the National Information Resource on Ethics and Human Genetics (NIREHG), which specifically tracks literature on the ethical, legal, and social implications of advances in genetics research and its applications. NIREHG hosts the Genetics and Ethics database at: http://bioethics.georgetown.edu/nirehg/index.html.

Originating from the Institute's ethics library, established in 1973 with funding from the Joseph P. Kennedy, Jr., Foundation, NRCBL now comprises more than 500 ongoing periodical subscriptions; 28,000 books; 200,000 cataloged, article-length documents; extensive archival materials pertaining to government organizations; 400 audiovisuals; and 500 course syllabi. Open to the public, it serves both on-site researchers and remote users through its reference desk service, through its toll-free number (1–888- BIOETHX, in the United States and Canada) and via email (bioethics@georgetown.edu). Services include the online database *ETHX on the Web,* reference service, custom database searches, a multifaceted publications program, document delivery, and a syllabus exchange clearinghouse for educators.

The Bioethics Information Retrieval Project, begun in 1975 and now operating under contract with the U.S. National Library of Medicine, contributes to making English-language literature accessible via two very large databases operated by the NLM: PubMed for journal articles and LOCATOR*plus* for books and chapters in books. The records in the predecessor BIOETHICSLINE® database (which was developed and augmented by the Project from 1975 through 2000), have been merged into one or the other of the aforementioned large databases. The closed BIOETHICSLINE database (1973–2000) continues to be distributed by Ovid and is archived at the NRCBL.

One of the early, major reasons for developing a bibliographic retrieval system for bioethics was to pull together the literature of a highly interdisciplinary field of study. In spite of the fact that specialty journals now exist, and that the major weeklies, such as *The Lancet* and *Science,* cover bioethical issues routinely, the literature is still widely dispersed.

Access to bioethics citations is available directly from the U.S. National Library of Medicine. Within PubMed, limiting searching to the "bioethics subset" serves to collect relevant materials, and in LOCATOR*plus* limiting searching to "ethics kie" similarly aggregates ethical works. Further instructions for searching these databases is at: http://bioethics.georgetown.edu/ir/bioline.htm.

An annual *Bibliography of Bioethics,* compiled from that portion of the literature selected for inclusion in NLM databases, has been published by the Kennedy Institute for almost three decades. Volume 29 for 2003 is estimated to include more than 5,000 citations. It will comprise two major sections: the first for journal articles, essays in books, and other similar materials; and the second for books.

NIREHG delivers many specialized services on its Web page, including updated Scope Notes on selected topics (eugenics, gene mapping, genetic counseling and screening, among others), and a bibliographic database of more than 19,000 entries called *Genetics and Ethics.*

II. Periodical Literature

Given the growth of interest in the field, it is not surprising that specialty journals have emerged that are devoted primarily to bioethical issues. A few have been published for decades, while others first appeared more recently. Some are affiliated with research organizations or professional societies. Publication information for several such periodicals is provided below in the section on Bioethics and Health Law Journals. This is not a comprehensive list, but it is representative of English-language sources. For information regarding foreign-language sources, readers may wish to contact the documentation centers mentioned below who are analyzing bioethics literature in other languages.

Since bioethical topics continue to receive a great deal of attention, the periodicals of contributing disciplines likewise continue to devote considerable space to pertinent issues. Medical, scientific, and philosophical journals that have consistently covered bioethics are also listed under General Philosophical, Scientific, and Medical Journals, below. Please note that U.S. offices are listed when available.

A. BIOETHICS AND HEALTH LAW JOURNALS

Accountability in Research, quarterly, published by: Gordon and Breach Publishing Group, c/o International Publishers Distributor, P.O. Box 32160, Newark, NJ 07102; <http://www.tandf.co.uk/journals/titles/08989621.html>; ISSN: 0898–9621.

American Journal of Bioethics (AJOB), quarterly, published by: MIT Press Journals, Five Cambridge Center, Cambridge, MA 02142; <http://mitpress.mit.edu>; ISSN: 1526–5161.

American Journal of Law and Medicine, quarterly, published by: American Society of Law, Medicine & Ethics, 765 Commonwealth Ave., 16th Floor, Boston, MA 02215; <http://www.aslme.org/>; ISSN: 0098–8588.

Bioethics (official journal of the International Association of Bioethics), five issues per year, published by: Blackwell Publishers Journals, Customer Services, P.O. Box 805, Oxford OX4 1FH, England; <http://www.bioethics-international.org/bioethics.html>; ISSN: 0269–9702.

Bioethics Forum, quarterly, published by: Midwest Bioethics Center, 1021–1025 Jefferson Street, Kansas City, MO 64105–1329; <http://www.midbio.org>;ISSN: 1065–7274.

Christian Bioethics, 3/year, published by: Swets & Zeitlinger, 440 Creamery Way, Suite A, Exton, PA 19341; <http://www.swets.nl/sps/journals/jhome.html>; ISSN: 1380–3603.

CQ: Cambridge Quarterly of Healthcare Ethics, quarterly, published by: Cambridge University Press, 110 Midland Ave., Port Chester, NY 10573- 4930; <http://journals.cambridge.org>; ISSN: 0963–1801.

Developing World Bioethics, semiannual, published by: Blackwell Publishers, 350 Main Street, Malden, MA 02148; <http://www.blackwellpublishers.co.uk>; ISSN: 1471–8731.

Ethics & Behavior, quarterly, published by: Lawrence Erlbaum Associates, Inc., Attn: Journals, 10 Industrial Avenue, Mahwah, NJ 07430–2262; <http://www.catchword.co.uk>; ISSN: 1050–8422.

Hastings Center Report, bimonthly, published by: The Hastings Center, 21 Malcolm Gordon Road, Garrison, NY 10524–5555; <http://www.thehastingscenter.org/;> ISSN: 0093–0334.

Health Care Analysis: An International Journal of Health Philosophy and Policy, quarterly, published by: John Wiley & Sons, Baffins Lane, Chichester, West Sussex, PO19 1UD England; <http://www.wiley.com/>; ISSN: 1065–3058.

Health Matrix: The Journal of Law-Medicine, biannual, Case Western Reserve University, School of Law, 11075 East Boulevard, Cleveland, OH 44106; <http://lawwww.cwru.edu/academic/healthMatrix/>; ISSN: 0748–383X.

HEC Forum (Healthcare Ethics Committee Forum), quarterly, published by: Kluwer Academic Publishers Group, P.O. Box 322,3300 AH Dordrecht, The Netherlands, or P.O. Box 358, Accord Station, Hingham, MA 02018–0358, <http://journals.kluweronline.com>; ISSN: 0956–2737.

International Journal of Bioethics/Journal International de Bioéthique, quarterly, published by: Editions Alexandre Lacassagne, 162, avenue Lacassagne, 69003 Lyon, France, <http://www.info-presse.fr/>; ISSN: 1287–7352.

IRB: Ethics & Human Research, bimonthly, published by: The Hastings Center, 21 Malcolm Gordon Rd., Garrison, NY 10524–5555, <http://www.thehastingscenter.org/;> ISSN: 0193–7758.

JONA's Healthcare Law, Ethics, and Regulation, quarterly, published by: Lippincott Williams & Wilkins, 16522 Hunters Green Parkway, Hagerstown, MD 21740–2116; <http://www.lww.com/>; ISSN: 1520–9229.

Journal of Clinical Ethics, quarterly, published by: Journal of Clinical Ethics, 12 South Market Street, Suite 300, Frederick, MD 21701; <http://www.clinicalethics.com/>; ISSN: 1046–7890.

Journal of Health Politics, Policy and Law, bimonthly, published by: Duke University Press, Journals Dept., P.O. Box 90660, Durham, NC 27708–0660, <http://www.jhppl.org/>; ISSN: 0361–6878.

The Journal of Law, Medicine & Ethics, quarterly, published by: American Society of Law, Medicine & Ethics, 765 Commonwealth Avenue, 16th Floor, Boston, MA 02215, <http://www.aslme.org/>; ISSN: 0277–8459.

Journal of Medical Ethics, includes *Medical Humanities* [ISSN: 1468–215X] in June and September as supplements; bimonthly, published by: St. Chloe House, The Avenue, Old Bussage, Glos GL6 8AT, United Kingdom; <http://jme.bmjjournals.com/>; ISSN: 0306–6800.

Journal of Medical Humanities, quarterly, published by: Kluwer, <http://www.kluweronline.com/>; ISSN: 1041–3545.

The Journal of Medicine and Philosophy, bimonthly, published by: Swets & Zeitlinger BV Publishers, P.O. Box 4508, Church Street Station, New York, NY 10261–4508, <http://www.swets.nl/swets/show>; ISSN: 0360–5310.

Kennedy Institute of Ethics Journal, quarterly, published by: Johns Hopkins University Press, 2715 North Charles Street, Baltimore, MD 21218–4319, <http://www.press.jhu.edu/press/index.htm>; ISSN: 1054–6863.

Medical Humanities, biannual (see *Journal of Medical Ethics* above), published by: BMJ Publishing Group, P.O. Box 590A, Kennebunkport, ME 04046; <http://mh.bmjjournals.com/>; ISSN: 1468–215X.

Medicine and Law, quarterly, published by: International Center for Health, Law and Ethics, University of Haifa, Law Faculty, P.O. Box 6451, Haifa 31063, Israel; <http://research.haifa.ac.il/~medlaw/publications/hindex.htm>; ISSN: 0723–1393.

Medicine, Health Care and Philosophy, three issues per year, Kluwer Academic, 101 Philip Drive, Norwell, MA 02061; <http://journals.kluweronline.com;> ISSN: 1386–7423.

Milbank Quarterly, quarterly, published by: Blackwell Publishers, 238 Main Street, Cambridge, MA 02142; <http://www.blackwellpublishing.com/>; ISSN: 0887–378X.

National Catholic Bioethics Quarterly, quarterly, published by: The National Catholic Bioethics Center, 159 Washington Street, Boston, MA 02135; <http://www.ncbq.com/>; ISSN: 1532–5490.

New Zealand Bioethics Journal, three issues per year, Bioethics Centre, University of Otago, P.O. Box 913, Dunedin, New Zealand; <http://healthsci.otago.ac.nz/dsm/nzbj/NzBioethicsJournal.html>; ISSN: 1175–3455.

Nursing Ethics, bimonthly, published by: Arnold, c/o Turpin Distribution Services Ltd., Blackhorse Road, Letchworth, Hertfordshire SG6 1HN, England; <http://www.arnoldpublishers.com/journals/pages/nur_eth/aut.htm>; ISSN: 0969–7330.

Second Opinion, quarterly, published by: Park Ridge Center, 221 E. Ontario, Suite 800, Chicago, IL 60611–3215, ISSN: 0890–1570.

Theoretical Medicine and Bioethics, bimonthly, published by: Kluwer Academic Publishers, Drs A.M. Ultee, Van Godewijckstraat 30, P.O. Box 17, 3300 AA Dordrecht, The Netherlands, <http://www.kluweronline.com>; ISSN: 1386–7415.

Yale Journal of Health Policy, Law, and Ethics, biannual, published by: Yale Law School, P.O. Box 208215, New Haven, CT 06520–8215; <http://www.yale.edu/yjhple/>; ISSN: 1535–3532.

B. GENERAL PHILOSOPHICAL, SCIENTIFIC, AND MEDICAL JOURNALS

American Journal of Public Health, monthly, published by: American Public Health Association, 1015 15th St., NW, Washington, DC 20005; <http://www.ajph.org>; ISSN: 0090–0036.

Annals of Internal Medicine, twice per month, published by: Annals of Internal Medicine (on behalf of the American College of Physicians), P.O. Box 7777-R-0320, Philadelphia, PA 19175; <http://www.annals.org>; ISSN: 0003–4819.

Archives of Internal Medicine, monthly, published by: American Medical Association, Subscription Department, P.O. Box 5201, Chicago, IL 60680–5201; <http://archinte.ama-assn.org/>; ISSN: 0003–9926.

BMJ (British Medical Journal), weekly, published by: British Medical Journal, P.O. Box 560B, Kennebunkport, ME 04046; <http://bmj.com>; ISSN: 0959–8146.

Ethics, quarterly, published by: University of Chicago Press, P.O. Box 37005, Chicago, IL 60637; <http://www.journals.uchicago.edu>; ISSN: 0014–1704.

JAMA: The Journal of the American Medical Association, weekly, published by: American Medical Association, Subscription Department, P.O. Box 5201, Chicago, IL 60680–5201, <http://jama.ama-assn.org>; ISSN: 0098–7484.

Journal of Applied Philosophy, three issues per year, published by: Blackwell Publishers, 108 Cowley Road, Oxford OX4 1JF United Kingdom; <http://www.blackwellpublishers.co.uk>; ISSN: 0264–3758.

The Lancet, weekly, published by: Williams & Wilkins, 428 East Preston Street, Baltimore, MD 21202; <http://www.thelancet.com/journal>; ISSN: 0099–5355.

Milbank Quarterly, quarterly, published by: Blackwell Publishers, 238 Main Street, Cambridge, MA 02142; <http://www.blackwellpublishing.com/>; ISSN: 0887–378X.

Nature, weekly, published by: Nature, P.O. Box 5055, Brentwood, TN 37024–9743; <http://www.nature.com/>; ISSN: 0028–0836.

New England Journal of Medicine, weekly, published by: New England Journal of Medicine, 1440 Main Street, Waltham, MA 02154–1649, <http://content.nejm.org>; ISSN: 0028–4793.

Philosophy & Public Affairs, quarterly, published by: Johns Hopkins University Press, 701 W. 40th Street, Baltimore, MD 21211–2190; <http://www.press.jhu.edu/press/index.htm>; ISSN: 0048–3915.

Science, weekly, published by: American Association for the Advancement of Science, P.O. Box 2032, Marion, OH 43305–0001; <http://www.sciencemag.com>; ISSN: 0036–8075.

Women's Health Issues, bimonthly, Elsevier Science Publishing Co., Regional Sales Office, P.O. Box 945, New York, NY 10159–0945; <http://www.elsevier.com/>; ISSN: 1049–3867.

III. Governmental and Professional Bioethics Organizations

The ORGS database maintained by NRCBL now has more than one thousand entries. Only a selected subset can be listed here. Four categories have been selected because each represents in some way a group approach to the deliberation of bioethical problems. The first two groups are supported by their respective governments; the third benefits from international and regional support; and the final type of organization has the support of groups of professionals with common interests. The four categories are: A. National Libraries of Bioethics; B. National Deliberative Bodies on Bioethics; C. Regional and International Bioethics Organizations; and D. Professional Groups. Either a Web or postal address was required for candidate organizations to be included in this section. If the Web site offers an alternative English version, that is listed.

A. NATIONAL LIBRARIES OF BIOETHICS

With federal support, the following reference centers provide bioethics information to the public. Each contains resources unique to the language of its country.

FRANCE
Documentation center on ethics of life sciences and health (CDEI), (Centre de Documentation et d'Information en Éthique des Sciences de la Vie et de la Santé)
Institut National de la Santé et de la Recherche Médicale (INSERM)
71 rue Saint-Dominique
75007 Paris
<http://www.inserm.fr/servcom/servcom.nsf/(Web+Startup+P age)?ReadForm&english>

GERMANY
Deutsches Referenzzentrum für Ethik in den Biowissenschaften
Niebuhrstr. 53
D-53113 Bonn
<http://www.drze.de>

UNITED STATES
National Reference Center for Bioethics Literature
Joseph and Rose Kennedy Institute of Ethics
Georgetown University
Washington, DC 20057–1212
<http://bioethics.georgetown.edu>

B. NATIONAL DELIBERATIVE BODIES ON BIOETHICS

AUSTRALIA
Australian Health Ethics Committee
National Health and Medical Research Council; and Health Ethics Section
Centre for Health Advice Policy & Ethics (CHAPE)
GPO Box 9848
Canberra ACT 2601
<http://www.health.gov.au/nhmrc>

AUSTRIA
Austrian Commission on Bioethics
Bundeskanzleramt
Hohenstaufengasse 3
1010 Vienna
<www.bka.gv.at/bka/bioethik/>

BELGIUM
Comité consultatif de Bioéthique de Belgique
C.A.E. Quartier Vésale—V416
Mme. Boxxon
19 bte 5 Bd. Pachéco
1010 Bruxelles
<http://www.health.fgov.be/bioeth/>

CANADA
National Council on Ethics in Human Research (NCEHR)
774 Echo Drive
Ottawa, Ontario K1S 5N8
<http://www.ncehr-cnerh.org>

DENMARK (Copenhagen)
Danish Council on Ethics
Ravnsborggade, 2–4
DK-2200 Copenhagen N
<http://www.etiskraad.dk>

FINLAND
National Advisory Board on Health Care Ethics
P.O. Box 33
(Kirkkokatu 14, Helsinki)
00023 Valtioneuvosto
<http://www.etene.org/>

National Advisory Board on Research Ethics
Mariankatu 5
FIN 00170 Helsinki
<http://pro.tsv.fi/tenk>

FRANCE
National Consultative Bioethics Committee
Le Comité Consultatif National d'Ethique pour les Sciences de la Vie et de la Santé
71, rue Saint-Dominique
75007 Paris
<http://www.ccne-ethique.org>

GERMANY
Der Nationale Ethikrat Berlin-Brandeburgische Akademie der Wissenchaft
Jägerstrasse 22/23
10117 Berlin
<http://www.ethikrat.org>

GREECE
Hellenic National Bioethics Commission
Evelpidon 47
113 62 Athens
<http://www.bioethics.gr>

INDIA
Indian Council of Medical Research
V. Ramalingaswami Bhawan
Ansari Nagar
New Delhi–110029
<http://icmr.nic.in/>

IRELAND
Irish Council for Bioethics
Comhairle Bitheitice na h&#201;ireann
Academy House
19 Dawson Street
Dublin 2
<http://www.bioethics.ie>

ISRAEL
Israel Academy of Sciences and Humanities
Bioethics Advisory Committee
c/o Department of Science Teaching
The Weizmann Institute of Science
Rehovot 76100
<http://stwww.weizmann.ac.il/bioethics/index-e.html>

ITALY
Comitato Naztionale Italiano di Bioetica
Via Veneto, 56
00187 Roma
<http://www.governo.it/bioetica/eng/index.html>

LITHUANIA
Lithuanian Bioethics Committee
(Lietuvos bioetikos komitetas)
Vilniaus g. 33–230
LT-2001 Vilnius
<http://www.sam.lt/bioetika>

MALTA
The Bioethics Consultative Committee
c/o Department of Health
15, Merchants Street
Valletta
<http://www.synapse.net.mt/bioethics>

THE NETHERLANDS
Health Council
Standing Committee on Medical Ethics and Health Law
P.O. Box 16052
2500 BB The Hague
<http://www.gr.nl>

NEW ZEALAND
National Ethics Committee on Assisted Human Reproduction
Ministry of Health
133 Molesworth St
P.O. Box 5013, Wellington
<http://www.newhealth.govt.nz/>

Royal Commission on Genetic Modification
Ministry for the Environment
84 Boulcott Street
P.O. Box 10 362, Wellington
<http://www.gmcommission.govt.nz/>

NORWAY
The National Biotechnology Advisory Board
Prinsens gt. 18, Boks 522 Sentrum
0105 Oslo
<http://www.bion.no>

The National Committees for Research Ethics (Norway):
The National Committee for Medical Research Ethics, NEM
The National Committee for Research Ethics in Science and Technology, NENT
The National Committee for Research Ethics in the Social Sciences and the Humanities, NESH
Street address: Prinsensgate 18
Postal address: P.O. Box 522, Sentrum, N-0105 Oslo
<http://www.etikkom.no/Etikkom/Engelsk>

Department of Science and Technology
Philippine Council for Health Research and Development
3F DOST Main Bldg., DOST Compound
Gen. Santos Ave., Bicutan, Tagig, Metro Manila
<http://www.pchrd.dost.gov.ph/PCHRD/ethics/NEC.htm >

PORTUGAL
National Council on Ethics of Life Sciences
Conselho Nacional de Ética para as Ciências da Vida
Rue Prof. Gomes Teixeira
Edif PCM, 8
1399–022 Lisbon
<http://www.cnecv.gov.pt>

RUSSIA
National Committee on Bioethics
Volkhonka 14/1
119992 Moscow

SINGAPORE
Bioethics Advisory Committee
250 North Bridge Road
#15–01/02
Raffles City Tower
Singapore 179101
<http://www.bioethics-singapore.org/bac/index.jsp>

National Medical Ethics Committee (NMEC)
Ministry of Health
College of Medicine Building 16 College Road
Singapore 169854
<http://www.moh.gov.sg/nmec/nmec.html>

SOUTH AFRICA
Medical Research Council of South Africa, 2001
P.O. Box 19070
7505 Tygerberg
<http://www.mrc.ac.za/ethics/ethicshuman.htm>

SWEDEN
Swedish Gene Technology Board
<http://www.genteknik.se/>

Swedish National Council on Medical Ethics
Statens Medicinsk-etiska Rad
The Department of Justice
SE-103 33 Stockholm
<http://www.smer.gov.se/>

SWITZERLAND
Swiss National Advisory Commission on Biomedical Ethics
Nationale Ethikkommission im Bereich der Humanmedizin (NEK-CNE)
Bern
<http://www.nek-cne.ch/>

TURKEY
Bioethics Ad Hoc Committee for the Turkish National Commission for UNESCO
(Biyoetik _htisas Komitesi)
<http://www.unesco.org.tr>

UNITED KINGDOM
Advisory Committee on Genetic Testing
Department of Health
HGC Secretariat
Area 652C, Skipton House
80 London Road
London SE1 6LH
<http://www.doh.gov.uk/genetics/acgt/publications.htm >

Central Office for Research Ethics Committees (COREC)
Room 76, B Block
40 Eastbourne Terrace
London W2 3QR
<http://www.corec.org.uk>

Human Fertilisation and Embryology Authority
Paxton House
30 Artillery Lane
London E1 7LS
<http://www.hfea.gov.uk/>

Human Genetics Commission
Department of Health
Area 652C, Skipton House
80 London Road
London SE1 6LH
<http://www.hgc.gov.uk>

Nuffield Council on Bioethics
28 Bedford Square
London, WC1B 3EG
<http://www.nuffield.org/bioethics/>

Xenotransplantation Interim Regulatory Authority (UKXIRA)
UKXIRA Secretariat
Department of Health
Room 339, Wellington House
133–155 Waterloo Road
London SE1 8UG
<http://www.doh.gov.uk/ukxira/index.htm>

UNITED STATES
Department of Clinical Bioethics
National Institutes of Health
10 Center Drive Building 10, Room 1C118
Bethesda, MD 20892–1156
<http://www.bioethics.nih.gov/>

Department of Energy
Ethical, Legal, and Social Issues Program
Office of Science
U.S. Department of Energy
1000 Independence Avenue, SW
Washington, DC 20585
<http://www.ornl.gov/TechResources/Human_Genome/elsi/elsi.html >

National Human Genome Research Institute (NHGRI)
Ethical, Legal and Social Implications (ELSI) Program
National Institutes of Health
Building 31, Room B2B07
31 Center Drive, MSC 2033
Bethesda, MD 20892–2033
<http://www.genome.gov/page.cfm?pageID=10001618 >

The President's Council on Bioethics
1801 Pennsylvania Avenue, NW
Suite 600
Washington, DC 20006
<http://www.bioethics.gov>

C. REGIONAL AND INTERNATIONAL BIOETHICS ORGANIZATIONS

CENTRE FOR ASIAN AND INTERNATIONAL BIOETHICS
Faculty of Health Sciences
Ben Gurion University of the Negev
Beer-Sheva
Israel
<http://fohs.bgu.ac.il/toplevel/default.asp?DivType=CNT >

COUNCIL FOR INTERNATIONAL ORGANIZATIONS OF MEDICAL SCIENCES
World Health Organization
CH–1211 Geneva 27
Switzerland
<http://www.cioms.ch>

COUNCIL OF EUROPE
Bioethics Program, Legal Affairs
Council of Europe
F–67075 Strasbourg Cedex
France
<http://www.coe.int/T/E/Legal_affairs/Legal_co-operation/Bioethics/>

Steering Committee for Bioethics (CDBI, formerly CAHBI)
Council of Europe
Pièce 2004
67006 Strasbourg
France
<http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/CDBI/<

EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS (EACME)
c/o Mrs. A. Heijnen, Instituut voor Gezondheidsethiek
P.O. Box 616
6200 MD Maastricht
The Netherlands
<http://www.eacmeweb.com/en/>

EUROPEAN GROUP ON ETHICS IN SCIENCE AND NEW TECHNOLOGIES
c/o European Commission
B–1049 Brussels
Belgium
<http://europa.eu.int/comm/european_group_ethics/index_en.htm >

NORDIC COMMITTEE ON BIOETHICS
Rikhard Nymansväg 9 B
00370 Helsingfors
Finland
<http://www.ncbio.org/Html/eng_index.htm>

UNESCO
International Bioethics Committee
7, Place de Fontenoy
75700 Paris
France
(Includes a database of bioethics organizations.)
<http://www.unesco.org/ibc/>

D. PROFESSIONAL GROUPS

ALL INDIA ASSOCIATION OF BIOETHICS (AIBA)
c/o Dr.Jayapaul Azariah
No. 3, 8th Lane, 5th Cross Street, Indira Nagar,
Chennai 600 020
India
<http://www.biol.tsukuba.ac.jp/~macer/aiba.html#6>

AMERICAN SOCIETY FOR BIOETHICS AND HUMANITIES
4700 W. Lake
Glenview, IL 60025–1485
<http://www.asbh.org/>

ASIAN BIOETHICS ASSOCIATION
c/o Hyakudai Sakamoto, Ph.D., President
University Research Center, Nihon University
4–8-24 Kudan-Minami, Chiyoda-ku, Tokyo 102
Japan
<http://web.kssp.upd.edu.ph/philo/fora_BioethicsAsia.htm >

AUSTRALASIAN BIOETHICS ASSOCIATION
c/o School of Public Health and Community Medicine
University of NSW
NSW 2052
Australia
<http://www.australasian-bioethics.org.au/>

CANADIAN BIOETHICS SOCIETY
c/o Ms. Lydia Riddell
561 Rocky Ridge Bay NW
Calgary, Alberta T3G 4E7
Canada
<http://www.bioethics.ca/english/index.html>

FORUM FOR ETHICAL REVIEW COMMITTEES IN THE ASIAN AND WESTERN PACIFIC REGION (FERCAP)
c/o Dr. (Mrs.) N.A. Kshirsagar, Dean
Professor & Head, Dept. Clinical Pharmacology
'A' Bldg 4th Floor
TN Medical College & BYL Nair Ch. Hospital
Mumbai 400 008
India
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Division of Health and Human Development
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WORLD HEALTH ORGANIZATION
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This resource is, to be sure, incomplete; any omissions are the responsibility of the author. To recommend additions, please email: goldstdo@georgetown.edu or fax: +202-687–6770.

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APPENDIX III

KEY LEGAL CASES IN BIOETHICS

Jacobson v. Massachusetts

197 U.S. 11 (1905)

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The State of Massachusetts imposed a law mandating that all inhabitants either submit to a smallpox vaccination or pay a fine. Jacobson claimed that his liberty interest in caring for his own body and health was invaded when he was subjected to a fine for refusing to submit to the vaccination. The U.S. Supreme Court held that liberty rights were not absolute, but rather, could be limited to ensure equal enjoyment of rights by others. The Court cautioned, however, that their interpretation of the law did not give states the power to regulate in an arbitrary, oppressive, or unjust manner.

Schloendorff v. Society of the New York Hospital

105 N.E. 192 (N.Y. 1914)

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Ms. Schloendorff, an inpatient at the Society of the New York Hospital, had a fibroid tumor removed. Following her operation Ms. Schloendorff developed gangrene in her arm, which necessitated the amputation of some of her fingers. Claming that she consented only to an examination and not to the actual surgery (the patient was under general anesthesia for both the exam and the surgery), Ms. Schloendorff sued the Hospital for her injuries. The highest court in the State of New York held that the Hospital was not liable. Despite this ruling, Justice Cardozo wrote that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body" (*Id.* at 129), marking the beginning of the development of the doctrine of informed consent.

Buck v. Bell

274 U.S. 200 (1927)

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The State of Virginia enacted a law claiming that the welfare of society could legally be promoted by the careful sterilization of certain mentally defective individuals. Carrie Buck was described as "the daughter of a feeble-minded mother in the same institution, and the mother of an illegitimate feeble-minded child" (*Id.* at 205), and was targeted for sterilization by the state institution in which she lived. Since the sterilization was not deemed to be detrimental to Ms. Buck's general health, and since it was seen as a way to promote the general welfare of society by "prevent[ing] those who are manifestly unfit from continuing their kind" (*Id.* at 207), the U.S. Supreme Court upheld the forced sterilization. The Court explained, "[t]hree generations of imbeciles are enough" (*Id.*).

Skinner v. Oklahoma

316 U.S. 535 (1942)

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Mr. Skinner was convicted of stealing chickens and subsequently convicted on two separate occasions of robbery with firearms. According to the terms of the Oklahoma Habitual Criminal Sterilization Act, Mr. Skinner could be sterilized for his acts as a repeated felon as long as the sterilization would not be detrimental to his general health. The U.S. Supreme Court held that state sterilization laws were subject to strict scrutiny to ensure that they did not violate the constitutional guarantee of equal protection. The Court based this holding on the notion that, "[m]arriage and procreation are fundamental to the very existence and survival of the race" (*Id.* at 541) and that the power to sterilize, if misused, "may have subtle, far reaching and devastating effects" (*Id.*). The Court ultimately found the Act unconstitutional because it called for the sterilization of only certain offenders and not others who committed equally reprehensible acts.

Prince v. Massachusetts

321 U.S. 158 (1944)

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Betty Prince was accused of violating a statute prohibiting her from allowing her nine-year-old niece (over whom she had custody) to sell religious pamphlets from the street corner. Prince responded that her actions were protected by the First Amendment as well as by her rights as a parent. The U.S. Supreme Court upheld the statute, and explained that the "state has a wide range of power for limiting parental freedom and authority in things affecting the child's welfare; and that this includes, to some extent, matters of conscience and religious conviction" (*Id.* at 167). Courts restricting parental rights to make decisions about withholding medical care for minor children routinely cite this case.

Griswold v. Connecticut

381 U.S. 479 (1965)

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Griswold, the Executive Director of the Planned Parenthood League of Connecticut, gave information and medical advice about contraception to married couples. Griswold and others were found guilty of violating Connecticut law forbidding the use of, or counseling about, contraceptives. Although not mentioned specifically in the United States Constitution, the U.S. Supreme Court extrapolated a zone of privacy from fundamental constitutional guarantees. The Court held that the Connecticut law forbidding contraceptive use violated the privacy of the marital relationship and was therefore unconstitutional. In a subsequent opinion, the U.S. Supreme Court stated, "[i]f the right of privacy means anything, it is the right of the individual, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child" (*Eisenstadt v. Baird,* 405 U.S. 438, 453 (1972)) (declaring unconstitutional a Massachusetts statute prohibiting the distribution of contraceptives to single persons but allowing distribution to married persons).

Strunk v. Strunk

445 S.W.2D 145 (KY. 1967)

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Tom Strunk was 28 years old and suffered from a fatal kidney disease. After exhaustive testing, it was determined that the only available kidney donor was Jerry Strunk, Tom's 27-year-old brother. Jerry Strunk was an incompetent, state-institutionalized individual with the approximate mental capacity of a six-year-old child. The Strunk parents petitioned the court for permission to proceed with the operation to transplant one of Jerry's kidneys to Tom. The highest court in Kentucky affirmed the lower court's authorization of the procedure. They based their decision on the conclusion that because of the close relationship between the brothers—noting in particular Jerry's family ties through Tom and the necessity of Tom's presence to Jerry's improvement—it would be in Jerry's best interest to have Tom alive.

Canterbury v. Spence

464 F.2D 762 (D.C. CIR. 1972)

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Canterbury was a patient who suffered from back pain who sought surgical intervention after medical treatments failed to alleviate his pain. The physician did not inform Canterbury that there was a minor risk of paralysis associated with the surgery. Canterbury was recovering normally after the surgery when he suffered a fall that led to minor paralysis of his legs and urinary incontinence. Although Canterbury (via his mother) had given consent to the surgery, the consent it was not "informed." The physician protested that he had acted according to the custom of the profession (a professional standard of disclosure), but the Appellate Court held that the patient's right to make decisions about his or her own care affects the nature of what a physician must reveal—applying a "patient-oriented" standard of disclosure. They stated that the physician must provide the patient with "material" information to enable him/her to make an "intelligent choice." The standard of disclosure for informed consent continues to be debated today.

Roe v. Wade

410 U.S. 113 (1973)

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The case arose from a challenge to a Texas statute declaring the attempt or actual procurement of an abortion, other than to save the life of the pregnant woman, a crime. The U.S. Supreme Court declared the statute unconstitutional, but made a series of findings that continue to affect reproductive law and policy. The Court, listing a variety of potential harms that might befall a woman with no choice of abortion, held that the right of privacy "is broad enough to encompass a woman's decision whether or not to terminate her pregnancy" (*Id.* at 153). Freedom to obtain an abortion is not absolute, since the Court noted that the state has an interest in protecting both potential human life and the health of the mother. Using the trimester framework as guideposts, the Court held that at different times in the pregnancy the interests of the State might become sufficiently compelling to sustain regulation of the interest of the pregnant woman in having an abortion. Finally, the Court explained that a fetus is not a "person" entitled to legal protection under the Fourteenth Amendment's Due Process and Equal Protection clauses.

The Supreme Court reexamined these issues in *Planned Parenthood of Southeastern Pennsylvania v. Casey,* 505 U.S. 833 (1992). The facts of the case revolved around specific provisions of a Pennsylvania abortion statute regulating consent, waiting periods, parental consent for minors, spousal notification, definitions of "medical emergency" and reporting requirements. The U.S. Supreme Court reaffirmed the holding in *Roe v. Wade* that a woman had a right to choose an abortion, but rejected *Roe's* trimester framework to favor a fetal viability notion for measuring state and individual interests. The Court stated that prior to fetal viability, the state could not impose an undue burden (described as a substantial obstacle) on the woman's right to choose to have an abortion. Specifically, the Court held that only Pennsylvania's spousal notification requirement imposed an undue burden and therefore invalidated only that provision.

O'Connor v. Donaldson

422 U.S. 563 (1975)

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Kenneth Donaldson was committed as a mental patient to a Florida state hospital and kept confined there against his will for approximately 15 years; he subsequently sued the hospital claiming that his right to liberty had been violated. Donaldson was never accused of being a danger to society or incapable of taking care of himself. The U.S. Supreme Court held that finding a person to be mentally ill is not *per se* sufficient to justify the State's involuntarily confinement of that person. Further, the Court stated, "mere public intolerance or animosity cannot constitutionally justify the deprivation of a person's physical liberty" (*Id.* at 575).

Tarasoff v. Regents of the University of California

51 P.2D 334 (CAL. 1976)

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A patient seeking psychotherapy confided to his therapist that he intended to kill Tatiana Tarasoff. The therapist did not warn the intended victim, nor did he notify persons likely to inform Ms. Tarasoff of her imminent peril. After Ms. Tarasoff was murdered, her parents sued the university, the psychotherapists involved in the case, and the campus police. The Supreme Court of California noted that "[w]hen a therapist determines, or pursuant to the standards of his profession should determine, that his patient presents a serious danger of violence to another, he incurs an obligation to use reasonable care to protect the intended victim against such danger. . .[which] may call for him to warn the intended victim or others likely to apprise the victim of the danger, to notify the police, or to take whatever other steps are reasonably necessary under the circumstances" (*Id.* at 340). The Court explained that at times of imminent and specific danger, the duty to warn outweighs the right of confidentiality.

In re Quinlan

355 A.2D 647 (N.J. 1976)

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Karen Quinlan was characterized as existing in a persistent vegetative state, in which she retained some homeostatic function but would never regain cognitive function. Mr. Quinlan, Karen's father, sought the Court's permission to withdraw the life-sustaining mechanisms prolonging her eventual death. The Supreme Court of New Jersey held that the right of privacy was broad enough to encompass patients' decisions to decline medical care. The Court explained that the State's interest in preserving the sanctity of human life could ultimately be overcome by the rights of the individual. The Court cautioned that the right of choice was for Karen to exercise, but since she was incompetent, allowed the guardian and family to determine whether Karen would have wanted to remove support in these circumstances.

Superintendent of Belchertown State School v. Saikewicz

370 N.E.2D 417 (MASS. 1977)

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Mr. Saikewicz was a mentally incompetent resident of a state facility who suffered from acute myeloblastic monocytic leukemia. Since he was unable to give informed consent for his treatment, the superintendent of the facility petitioned the court for appointment of a guardian to make decisions concerning Mr. Saikewicz's care. The appointed guardian noted that the illness was incurable, but could be managed with chemotherapy. The guardian explained that it would not be in Mr. Saikewicz's best interest to be treated, since the benefit of some uncertain extension of life would not outweigh the fear and pain caused by a treatment he had no ability to understand. The Supreme Court of Massachusetts recognized an individual's right to be free from unwanted medical intervention for an incurable illness. The Court ultimately applied the doctrine of substituted judgment, in which "the decision … [is] that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person" (*Id.* at 752–53). The Court concluded that the decision to withhold treatment was made with regard to Mr. Saikewicz's actual interests.

In re Conroy

486 A.2D 1209 (N.J. 1985)

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The nephew and guardian of incompetent nursing home resident, Ms. Conroy, petitioned the Court to remove her nasogastric feeding tube. Ms. Conroy suffered from myriad conditions, and her physician felt that removal of the tube would hasten Ms. Conroy's eventual death. Ms. Conroy died, with the feeding tube intact, as the litigation was pending. The Supreme Court of New Jersey stated that if Ms. Conroy would have been competent to decline treatment, "[h]er interest in freedom from nonconsensual invasion of her bodily integrity would outweigh any state interest in preserving life or in safeguarding the integrity of the medical profession" (*Id.* at 1226). The Court noted that for incompetent patients, a subjective standard considering what the patient (if competent) would have wanted is the appropriate manner in which to make such decisions. The Court explained that when the formerly competent patient's wishes cannot be reliably determined, in rare circumstances it would be appropriate to withhold or withdraw life sustaining treatment if the benefits of removal outweigh the burdens.

In re Baby M

537 A.2D. 1227 (N.J. 1988)

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Mr. Stern and Ms. Whitehead entered into a surrogacy contract in which Mr. Stern's sperm would be used to impregnate Ms. Whitehead. Upon delivering the child, Ms. Whitehead agreed to terminate any parental rights so that Ms. Stern (Mr. Stern's wife) could adopt the child. Mr. Whitehead (Ms. Whitehead's husband) agreed to rebut all presumptions of fatherhood. After delivering, Ms. Whitehead gave the baby to the Stern's temporarily, but then absconded with the child. The Supreme Court of New Jersey held that surrogacy contracts involving payment (such as this) were a violation of public policy. Further, the Court stated that Ms. Whitehead's parental rights would not be terminated as a result of the contract because surrogates had the right to change their minds and assert parental rights over the child in question. The Court noted that in this case the best interests of the child had to be considered, and awarded custody to Mr. Stern with visitation rights to Ms. Whitehead.

Cruzan v. Director, Missouri Department of Health

497 U.S. 261 (1990)

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Nancy Cruzan entered a persistent vegetative state after sustaining injuries in an automobile accident and was supported by artificial nutrition and hydration. With the understanding that their daughter would never regain cognitive function, Nancy's parents petitioned the courts in Missouri to withdraw her artificial support. The Supreme Court of Missouri denied the Cruzan's request since they could not prove with clear and convincing evidence that Nancy would have wanted support withdrawn in such a circumstance. The U.S. Supreme Court reiterated the right of competent individuals to refuse medical treatment; however, the Court upheld Missouri's procedural requirement of meeting high evidentiary standards when incompetent's wishes are in question, based on the state's unqualified interest in preserving human life.

Davis v. Davis

842 S.W.2D 588 (TENN. 1992)

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The case involved the disposition of seven cryogenically-preserved embryos subsequent to the divorce of Junior Lewis Davis and Mary Sue Davis. The embryos were stored at a fertility clinic, and were the combination of Mr. Davis' sperm and Mrs. Davis' ova. The only complication in the divorce proceeding was the disposition of the embryos: Mary Sue wanted to donate the embryos to a childless couple, Junior wanted to have the embryos destroyed. The Supreme Court of Tennessee concluded that embryos were neither "property" nor were they "persons," but instead occupied an interim category entitled to respect based on their potential for human life. The Court explained that if a prior contract concerning the embryo's disposition had been made, that it would have been valid in this situation. Absent a contract, the Court held that Tennessee's "interest in potential human life is insufficient to justify an infringement on the gamete-providers' procreational autonomy" (*Id.* at 602). In a dispute between the procreational rights of two parties the Court stated that, in general, the party wishing to avoid procreation should prevail.

Johnson v. Calvert

851 P.2D 776 (CAL. 1993)

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The Calverts entered into a surrogacy contract in which an embryo derived from their gametes was gestated by Ms. Johnson. Relations between the parties deteriorated, and Ms. Johnson demanded custody of the resulting child. The Supreme Court of California noted that under California law each child can only have one "natural" mother. Since there was no legislation specific to the issue, the Court ruled that the "natural" mother is the woman who "intended to procreate the child—that is, she who intended to bring about the birth of a child that she intended to raise as her own" (*Id.* at 500). Since the child would not have been born but for the Calverts' intention to have a child to raise as their own, Ms. Calvert was declared the "natural" mother.

Washington v. Glucksberg

521 U.S. 702 (1997)

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The State of Washington prohibited assisted suicide, but specifically noted that withholding or withdrawing life-sustaining treatment was not suicide. Physicians, a non-profit organization, and terminally ill patients petitioned in federal court to have the statute declared an unconstitutional violation of their liberty interests protected by the Due Process clause of the Fourteenth Amendment. The U.S. Supreme Court held, "the 'right' to assistance in committing suicide is not a fundamental liberty interest protected by the Due Process Clause" (*Id.* at 727). The Court upheld the prohibition, because it was rationally related to Washington's interests in the preservation of human life, the public health problem of suicide prevention, protecting the integrity of the medical profession, protecting vulnerable populations, and avoiding a slippery slope toward euthanasia.

On the same day, the U.S. Supreme Court upheld New York's prohibition against assisted suicide in *Vacco v. Quill,* 521 U.S. 793 (1997). Physicians claimed that because New York permits refusal of life-sustaining treatment (which they saw as similar to physician-assisted suicide) the New York statute violated the Equal Protection clause of the Fourteenth Amendment. The U.S. Supreme Court maintained that there is a distinction between “letting a patient die and making that patient die” (*Id.* at 807); therefore it is consistent with the U.S. Constitution to treat the procedures differently.

COMPILED BY EMILY A. PETERSON

APPENDIX IV

ANNOTATED BIBLIOGRAPHY OF LITERATURE AND MEDICINE

This annotated bibliography focuses on literary works recognized for their portrayal of values issues in health care. It is not a bibliography of bioethics; the other essays in this encyclopedia provide bibliographies in those areas. Instead, this bibliography concentrates on stories, poems, plays, and essays that reveal conflicting values and differing perspectives in human interactions, especially under the pressure of illness and disability. Because literary works convey patients' stories as well as those of health care professionals and family members, they provide important resources for addressing issues in bioethics. This small selection makes no claim to being exhaustive; it is rather a sampling of significant works in literature and medicine. For a continuously growing online annotated bibliography of literature and medicine, see the Literature, Arts, and Medicine Database at <http://endeavor.med.nyu.edu/lit-med>.

General Essays, Memoirs, Stories of Cases

Broyard, Anatole. 1992. *Intoxicated by My Illness.* New York: Clarkson Potter 1992.

A literary critic and essayist thoughtfully observes his own experiences and feelings as he is dying. Several brilliant pieces comprise this work. Broyard writes about giving up his taste for irony. "Cancer cures you of irony. Perhaps my irony was all in my prostate." The work contains powerful and personal descriptions of his illness. He also portrays his personal physician and ponders what he would hope for in an ideal doctor. He closes with an abstract exploration of the meaning of death.

Coles, Robert. 1989. *The Call of Stories.* Boston: Houghton Mifflin Company.

This major work in literature and medicine contains clear arguments for the importance of stories in people's lives and in their health care. Coles sees patients as people who have stories and whose illnesses must be understood as parts of their life narratives. Learning from the great physician–writer William Carlos Williams, Coles understands that we need to respect each other's stories and learn from them.

Cousins, Norman. 1979. *Anatomy of an Illness.* New York: Norton.

This well-known autobiographical case history records how Cousins used humor and laughter to help cure his illness. Cousins checked himself out of the hospital and into a hotel room, where he ate better food, watched comedies, read jokes, and gave himself large doses of vitamin C. He attributes his returning health to the therapy of laughter, and to the capacity of the human mind and body to regenerate.

Davis, Cortney. 2001. *I Knew a Woman.* New York: Random House.

A nurse practitioner in an inner city Obstetrics & Gynecology clinic describes four of her women patients, from a fifteen-year-old homeless pregnant child to a mature woman struggling with cancer. Another of her patients is pregnant and drug addicted; a fourth suffers from pains that come from buried memories of sexual abuse. The stories of all four patients weave in and out of the narrator's own stories about herself, her own health and illness experiences, her own respectful appreciation of the female body.

Frank, Arthur. 1995. *The Wounded Storyteller.* Chicago: University of Chicago Press.

Frank argues that sick people are colonized by the health care profession, that takes over their bodies and their life stories. In order to heal, patients need to construct new narratives from the "narrative wreckage" of serious illness or injury. Frank describes three kinds of illness stories: (a) restitution narratives, where the patient returns to a previous state of health; (b) chaos narratives, where neither the patient (nor the health care professional) is in control; and (c) quest narratives, in which the patient understands his or her illness as a spiritual journey.

Gawande, Atul. 2002. *Complications: A Surgeon's Notes on an Imperfect Science.* New York: Henry Holt.

Written while Gawande was a resident in surgery, these essays explore many contemporary concerns about child abuse, informed consent, medical mistakes, chronic pain management—all grounded in stories about particular patients who are real people, not just reifications of disease and trauma. Gawande writes with wit and energy, gracing his penetrating insights with a tender humor.

Groopman, Jerome. 1997. *The Measure of our Days: New Beginnings at Life's End.* New York: Viking Press.

Groopman describes eight patients as they struggle with life-threatening illnesses and discover new understandings about themselves. More than medical cases, these narratives portray spiritual quests and new recognitions of what the patients have valued in their lives, sometimes bringing a dismayed awareness of mistakes and wrong turns, sometimes bringing peace and reconciliation. This articulate work also portrays a sensitive and caring physician.

Hilfiker, David. 1994. *Not All of Us Are Saints.* New York: Farrar, Straus & Giroux.

In the inner city of Washington, D.C., Dr. Hilfiker practices what he calls "poverty medicine." He devotes his time and skill to working with homeless men dying of AIDS. Most are African-American; many are addicted to drugs and alcohol as well as being sick with AIDS. Hilfiker encounters many uncomfortable differences between his white middle-class life and the poverty of the homeless dying men. His service to them goes beyond medical treatment.

Klass, Perri. 1987. *A Not Entirely Benign Procedure.* New York: G. P. Putnam.

This collection of autobiographical essays examines the experiences of a young woman in Harvard Medical School as she confronts the macho world of medicine. Originally published in *The New York Times* and other journals, these essays are often funny, always insightful, and sometimes troubling. Klass, who had a baby while she was at Harvard, records surprising discrepancies between what she was learning as a medical student and what she was experiencing as a pregnant woman. She is especially aware of the power of language to label, dismiss, and silence people.

Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing and the Human Condition.* New York: Basic Books.

Kleinman explores the meanings of illness in a medical world that concentrates on the biological mechanisms of disease. The technical quest for control of symptoms overshadows and even prevents inquiry into multivocal meanings of the illness, to which powerful emotions and interests often are attached. Those meanings are bound up with the relationships of the patient with spouse, children, friends, caregivers, even the patient himself. Kleinman asserts that the multiple voices must be heard if the doctors are to deliver more effective and humane care.

Lorde, Audre. 1980. *The Cancer Journals.* Argyle, NY: Spinsters.

In this collection of journal entries, prose, and poetry, Audre Lorde ponders her breast cancer and mastectomy. As a lesbian and feminist, she is not interested in making her appearance attractive or even socially-acceptable to men, so she refuses reconstructive surgery or even wearing a prosthesis. She resists the culture that tries to hide the fact that a woman has had a mastectomy. She encourages women who have undergone that surgery to see themselves like Spartan warriors and to be proud of their scars. Her greatest comfort comes from supporting network of other women.

Lynch, Thomas. 1998. *The Undertaking: Life Studies from the Dismal Trade.* New York: Penguin.

This award-winning collection of essays describes Lynch's experiences and reflections on his career as an undertaker. Often finding humor and compassion in the funeral home environment, Lynch portrays the survivors as they try to deal with the death of friends and family. He recognizes the importance of rituals and community around the passage of death, and treats his subjects with a tenderness and wit that makes his writing thoroughly engaging.

Nuland, Sherwin. 1994. *How We Die: Reflections on Life's Final Chapter.* New York: Knopf .

Nuland believes that death is a normal biologic process, but Americans treat it as if it were an enemy to be fought off. Because so many deaths occur in hospitals, they are hidden from view and from public understanding, adding to fear of dying. Nuland writes that very few will "die with dignity." Physicians, patients, and families should allow nature to take its course instead of trying to do everything to keep someone alive. The “best” possible death reflects the hospice philosophy-it occurs in relative comfort, in the company of loved ones.

Remen, Rachel Naomi. 2000. *My Grandfather’s Blessings.* New York: Riverhead Books.

Pediatrician and psychiatrist, Remen has a lifetime’s experience working with cancer patients, others who are chronically or terminally ill and with those who are recovering from life-threatening illnesses. She discovers that many people, when forced deeply into their own vulnerability, transform their suffering into wisdom and appreciate their connections. They learn to serve and belong to one another, valuing authentic relationships.

Sacks, Oliver. 1984. *A Leg to Stand On.* New York: Harper Collins.

This is one of many books Sacks has written about his medical practice. In this work, Sacks recounts his own injury, hospitalization and long recovery, including a bout with depression. As a physician, he has a kind of double perspective (patient, doctor). As a patient, he feels alienated and alone, and he comes to realize how important caring relationships are between health care professionals and their patients. As a physician, he comes to understand the suffering of his patients.

Sontag, Susan. 1978. *Illness as Metaphor.* New York: Farrar, Straus & Giroux.

This classic argument says that using metaphorical thinking to describe illness is wrong because it is untruthful and misleading. Metaphors deny the direct approach, Sontag argues, and often lead to blaming the patient for contracting the disease. Cancer patients may be seen as life’s losers with character flaws that cause the disease. Cancer invades and destroys, requiring an arsenal of weapons to fight it; military metaphors take over and the patient becomes the battleground.

Verghese, Abraham. 1994. *My Own Country: A Doctor’s Story of a Town and Its People in the Age of AIDS.* Simon and Schuster.

Verghese is an Indian physician, born in Ethiopia and now practicing in America. In this collection, he describes caring for men and women with HIV/AIDS who have come home to their Tennessee families to die. He comes to understand rural people as they grapple with the realization that their sons are gay and are dying. He treats a woman infected by her husband (whose sister has also been infected by him) as they struggle to keep their condition private. He tries to explain to his wife and his colleagues why he is caring for these AIDS patients.

Novels

Barker, Pat. 1991. *Regeneration.* London: Penguin.

During World War I, The English poets Sigfried Sassoon and Wilfred Owen met when both were patients in Craiglockhart War Hospital where they were under the care of Dr. W. Rivers. This powerful anti-war novel describes their resistance to the war, the “shell shocked” soldiers exposed to too many horrors, the efforts of Dr. Rivers to give them genuine healing through conversation about the origins of their ailments. Wilfred Owen wrote deeply moving poetry about the experiences of the common soldier [see entry in this bibliography]. He was killed a week before Armistice.

Bronte, Charlotte. 1983 (1847). *Jane Eyre.* New York: Bantum.

In this famous nineteenth century Gothic novel, Jane Eyre survives a typhus epidemic to be a governess for Rochester’s illegitimate daughter. Jane sometimes hears weird laughter and odd noises. One night she finds Rochester unconscious in his bed that had been set on fire. Jane agrees to marry him, but at the wedding a man claims that Rochester is already married. His insane Creole wife is imprisoned on the third floor of the house. In her madness she finally burns down the house, blinding Rochester as he tries unsuccessfully to save her.

Camus, Albert. 1947. *The Plague.* Paris: Gallimard.

This great novel compares the bubonic plague and subsequent quarantine in Oran, Algeria, to other forms of occupation by war and colonization. Dr. Rieux, having just sent his wife to a sanitarium for her health, discovers dying rats as the city begins its nearly year-long struggle with plague. The novel explores many issues of isolation, of religious faith in times of great suffering, of the physician’s commitment to providing health care at the continuing risk to his own life, of the public health efforts to defend against the invader.

Dickens, Charles. 1998 (1851). *The Old Curiosity Shop.* New York: Oxford.

Dickens’s fourth novel mixes social realism and romance. Little Nell is forced to grow up quickly as she tries to manage her mentally ill grandfather's manipulative and destructive behavior. Characters often are physically distorted—a condition resulting from the industrial revolution. Through these characters, Dickens connects physical deformity and moral deformity. Little Nell is a golden haired beauty, as good as she is lovely. Quilp's misshapen body mirrors his depraved moral state, and Nell's physical wasting results from the moral disease of Victorian society.

Dostoevsky, Fyodor. 1960 (1864). *Notes from Underground.* New York: E. P. Dutton.

Exploiting the tensions between individual freedom and determinism, between atheism and belief in God, between faith in progress and human limitations, Dostoevsky portrays the contradictions that besiege modern humanity. As a religious philosopher, he sees man as fallen but free to choose; as a political historian he sees the West as fallen and in need of redemption; as a psychologist, he explores the problems of isolated and alienated people, driven by passions and capable of inspiration yet critical of utopian optimism. His protagonists can be vile and willfully disgusting, but they assert their freedom to be that way in the face of biological and social determinism.

Ellison, Ralph. 1972 (1952). *Invisible Man.* New York: Random House.

Combining brutal realism of a racist society with a surreal dreamy interior consciousness of his protagonist, Ellison portrays the invisibility of those who are seen only as stereotypes, never as real individuals. Trying to find his identity in this context, the unnamed protagonist naively expects to make it, but is continually expelled and rejected, confused and disillusioned. Mental hospital staff submit him to shock treatments and decide he is cured when he (they mistakenly believe) can no longer remember his name. He ends up living under a New York City manhole. The novel won the National Book Award in 1953.

Faulkner, William. 1987 (1930). *As I Lay Dying.* New York: Vintage.

This novel of grotesque humor follows a poor white family as it carries the mother's casket through hell and high water (literally) trying to keep the promise to bury her in her native town. This archetypal journey takes several days, so the decomposing body stinks. Trying to save the casket from being swept away in a flooded river, Cash, the eldest son, breaks a leg and so is forced to lie on top of the casket as the rickety wagon slowly lumbers along. Old Doc Peabody eventually has to chip off the concrete the family poured on Cash's leg, so the leg can be set and cast. The profoundly dysfunctional family buries the mother and then picks up a new one on the way out of town.

Flaubert, Gustave. 1965 (1857). *Madame Bovary.* New York: W. W. Norton 1965.

In this great realist novel, the peasant Emma marries an elderly, bumbling doctor, Charles Bovary, who soon bores her. Neither of her inevitable love affairs work out, and since she cannot pay her debts or get anyone to help her, she commits suicide by swallowing arsenic. Flaubert tells this story in a detached, objective voice that makes no judgments but allows for a sense of inexorable determinism that will defeat anyone trying to escape the base and tedious everyday life.

Gaines, Ernest. 1993. *A Lesson Before Dying.* New York: Random House.

An inarticulate young black man, witness to his friends' murder of a white man, is convicted of murder himself and sentenced to death by an all white jury and judge. The narrator of this sensitive novel, a frustrated white school teacher, provides the condemned man with a way to express his feelings and thoughts about his confrontation with death. Both men grow as their relationship develops into empathy and caring, overcoming racial barriers, at least between the two of them.

Garcia Marquez, Gabriel. 1988. *Love in the Time of Cholera.* New York: Penguin.

Winner of the Nobel Prize for literature, Garcia Marquez is known for his "magic realism," in which brutally realistic events are interspersed with the fantastic and surrealistic, angels fall into pigsties, dead men live in their caskets for years, giant bodies wash up on the beach without showing any signs of decay. His stories reveal Latin American sociopolitical history while they express the symbolism and archetypes of folktale. In this novel, a complicated marriage between a woman and doctor lasts over fifty years, through cholera epidemics and political and personal turmoil. When the doctor dies, his wife reunites with an aged friend who has loved her since before she met the doctor.

Hurston, Zora Neal. 1990 (1937). *Their Eyes Were Watching God.* New York: Harper & Row.

Anthropologist Hurston creates a strong, determined African-American heroine who survives poverty and loveless marriages in which her husbands treated her like property. Finally free of them, she falls in love with a man who treats her as an equal partner; they work together on truck farms until he is bitten by a rabid dog. She cares for him, even though he becomes antagonistic, until he dies of rabies. She is at peace with herself at the end, having come to terms with life.

Huxley, Aldous. 1989 (1932). *Brave New World.* New York: Harper.

In this early version of genetic engineering, people are created in test tubes and chemically manipulated and conditioned to fill certain classes and roles. Henry Ford, the lord of mass production, has replaced God. Drugs keep the population happy, free sex replaces marriage and the family, everyone buys stuff whether they need it or not. The World Controller explains why keeping people contented is better than allowing them to think for themselves.

James, William. 1992 (1898). *The Turn of the Screw.* New York: Oxford University Press.

This ghost story can also be read as the hysterical writing of a mentally ill governess who "experiences" evil spirits haunting the two children she cares for. One spirit comes from a former governess who probably was pregnant and who died mysteriously (from suicide or from trying to abort the pregnancy?). The other spirit belongs to a valet who was killed in a fall. Suggestions of child abuse and other horrors come through the obsessions of the narrator.

Joyce, James. 1964 (1916). *Portrait of the Artist as a Young Man.* New York: Viking Press.

This famous pedagogical novel follows Stephen Dedalus from his infancy to young adulthood, from his father's storytelling to Aquinas' aesthetics. It also portrays the development of an artist growing up with an alcoholic father in an Ireland depressed both by English colonization and Catholic domination. The young man Stephen refuses to serve his home, his country or his church, determined to escape those nets by going into exile.

Kafka, Franz. 1972 (1915). *Metamorphosis,* trans. Stanley Corngold.

Mixing the ordinary and the surreal, Kafka takes everyday people and events and converts them to nightmare. Feeling trapped in a boring, mechanical job he had to support his family, Gregor Samsa wakes up one morning to find himself transformed into a giant cockroach. His sense of being metaphorically stepped on turns into fact. His family reacts with shock that evolves into shame and resentment; as his beetle self dries up and dies, they actively start supporting themselves. As his carcass gets dumped in the trash, they go off on a family vacation.

Lewis, Sinclair. 1925. *Arrowsmith.* New York: Harcourt Brace.

Martin Arrowsmith confronts the temptations and complexities typical of the medical professional: pure research vs. research for profit; public health vs. business interests; care for patients vs. laboratory research; individual standards vs. institutional demands; service to others vs. greed and power grabbing. Lewis satirizes many aspects of medicine, from the training in medical schools to the practice both in small towns and big cities. In the end, after being entangled in most of these conflicts, Arrowsmith decides to devote his life to research, where he can meet his standards of intellectual honesty.

Mann, Thomas. 1927 (1924). *The Magic Mountain.* New York: Knopf.

The protagonist, Hans, goes to visit a cousin in a tuberculosis sanitarium and remains there for seven years, struggling with his own critical illness and near death experiences while learning gradually through that suffering what is worth valuing. In addition to falling in love with a married woman who is also a patient in the TB sanitarium, Hans engages in challenging intellectual discussions with other patients about life and death, religion and politics. The beginning of the First World War brings an end to this retreat from the real world.

Maugham, Somerset. 1992 (1915). *Of Human Bondage.* New York: Penguin.

The orphaned Philip, who has a club foot, is sent away to boarding school where he struggles to grow up with children who are not crippled and who have parents to care for them. As he grows up, he tries awkwardly and often unsuccessfully to find fulfilling relationships with other people, especially women. After seeking possible careers in languages and art, Philip decides to take medical training to become a physician like his father.

Morrison, Toni. 1974. *Sula.* New York: Alfred A. Knopf.

This novel explores friendship between two African-American women—conventional nurturer (Nel) and a free spirit (Sula)—as they adjust to and rebel against their community and their families. Characters in this black rural town include the mentally-ill Shadrack, who creates National Suicide Day; drug-addicted Plum, whose mother burns him to death; Eva, Sula's grandmother, who lets a train run over her leg so she can collect insurance money and support her family. Sula and Nel, as young girls, accidentally cause Chicken Little's death, but they keep that dreadful secret to themselves.

Ondaatje, Michael. 1992. *The English Patient.* New York: Random House.

Near the end of World War II, four people retreat to an abandoned villa north of Florence: nurse Hana cares for the severely burned, dying English patient whose identity is unknown; Kip, a Sikh bomb-disposal expert, becomes Hana's lover; Caravaggio, a drug addicted friend of Hana's family, steals from her supply of morphine she uses to help the English patient. This award-winning novel explores the need for reaching across barriers of religion, race and nationality; both Caravaggio and the English patient have crossed boundaries as spies. The lyrical narrative moves in and out of the characters' memories as well as through chronological time.

Ozick, Cynthia. 1990. *The Shawl.* New York: Random House.

Holocaust survivor, Rosa, lives in a squalid one-room apartment in Miami, trying to endure day-to-day as she lives with her nightmare memories of the concentration camp. Rosa hid her baby daughter in a shawl, but her niece, Stella, took the shawl for herself. Rosa helplessly watched as a German camp guard threw her daughter against the electric barbed-wire fence. Now, decades later, Rosa talks to her dead child. An acquaintance she meets in a laundry tries to connect her to living in the present and caring about her own future.

Pasternak, Boris. 1958. *Doctor Zhivago.* New York: Pantheon.

This sprawling novel follows Dr. Zhivago as the Russian revolution spreads over the country. In his medical practice and in his poetry writing, the doctor is devoted to the imagination and intuition, so he earns the distrust of the Bolshevik dogmatists, and escapes with his family to a Ural mountain farm. His sensory appreciation of beauty attracts him to his lover, Lara, and to the mountains; his sense of justice makes him sympathetic with the peasants and those hurt by the war. His values are much larger and more humane than those driving the revolution.

Percy, Walker. 1980. *The Second Coming.* New York: Farrar Straus & Giroux.

A disillusioned retired lawyer, Will Barrett, struggles with his memories of his father's attempt to kill him and his father's suicide. Will finds everyone in his present world to be inauthentic and shallow; his depression is deepened by the materialistic values of his affluent society and by the false, superficial faith of the organized church. Meanwhile a mentally ill young woman, Allison, has escaped from a mental hospital and is living in a greenhouse when Will meets her. Allison loves the natural world and growing things. Her freshness and love of life heal Will; and she is healed by his love. The Second Coming refers to God's coming into their love.

Plath, Sylvia. 1981 (1963). *The Bell Jar.* New York: Bantam.

The novel draws on Plath's own experience with mental illness, with a suicide attempt and the following institutionalization in McLean psychiatric hospital. The protagonist, Esther, goes through shock therapy and develops a special relationship with her doctor. The Bell Jar refers metaphorically to being trapped inside a glass jar of depression. Esther gradually improves and is ready to leave McLean by the end of the novel. Plath herself, however, committed suicide the same year this book was published.

Shelley, Mary. 1992 (1918). *Frankenstein.* London: Penguin.

This classic novel examines what happens when a proud scientist steps over a line between the mortal and the divine and tries to create life himself. Dr. Frankenstein's creation is an ugly monster, yet one who wants to be loved and accepted. Finding only rejection, the creature turns malicious and murderous. He has no chance to learn civilized values or moral sensibility. Trying perhaps to take responsibility for his creation, Dr. Frankenstein pursues the monster at the cost of his own life.

Shem, Samuel [Stephen Bergman]. 1995 (1978). *House of God.* New York: Dell.

This irreverent and very popular novel satirizes the education and training of medical students and residents. The "House of God" refers to Beth Israel Hospital in Boston. The residents learn cynical definitions (GOMERS are elderly people who should Get Out of My Emergency Room) and laws (turf unpleasant patients to someone else's responsibility). Exhaustion and cynicism erode the ideal of the "caring" physician. Powerful physicians abuse those lower on the scale; patients get ignored. Still the comic perspective of the novel helps the medicine go down.

Solzhenitsyn, Alexander. 1968. *Cancer Ward.* New York: Dial.

The world of the dying is portrayed through the differing perspectives of thirteen patients brought together in the cancer ward where they suffer both their illnesses and the inflexible medical system. Most undergo radiation therapy though not many benefit from it. The ward becomes a metaphor for the totalitarian Soviet state afflicted by symbolic cancer that eats away at it vitality. The novel also explores the value of individual life in a culture that insists on the collective.

Tolstoy, Leo. 1935 (1886). *The Death of Ivan Ilyich.* London: Oxford University Press

This short novel is probably *the* most frequently taught work in the literature and medicine "canon." The work satirizes the tedium of everyday life, the chasing after trivial acquisitions, the hypocrisy of doctors and family, while their unexamined lives plod along. At the same time, Ilyich starts questioning his way of life when he confronts his own dying, and in that confrontation he resembles all humanity. The only honest person around him is the peasant servant, Gerasim, who helps Ilyich face the reality of death.

Drama

Albee, Edward. 1994. *Three Tall Women.* New York: Dutton.

Three women meet in a sick room. A frail, cranky old woman is in bed, her compassionate caregiver is middle-aged, and an impatient young woman comes to solve some financial problems. They discuss A's aging and the highlights of her life. At the end of the first act, the old woman has a stroke. In the second act, she is replaced by a dummy in the bed, and the three, all of whom turn out to be the same person at different times in her life, discuss with some humor and forgiveness how the young one evolved into the middle aged one and then into the elderly woman.

Beckett, Samuel. 1959. *Krapp's Last Tape.* London: Faber and Faber.

Nobel Laureate Beckett created several great tragicomedies, adapting music hall slapstick to tragedy in order to help his audiences laugh at our human condition. In this play, the clown-like Krapp is an old man, alone with his tape recorded commentaries made at earlier times in his life. As he listens to various earlier "selves" describing work or love or belief, he realizes he is not the same person he used to be. The dialogue between his past (on tape) and his present self helps him recognize that death is near, that he is through with former goals as he experiences a sense of loss and an uncertainty about his identity.

Chekhov, Anton. 1988 (1899). *Uncle Vanya.* London: Metheun.

Uncle Vanya is caretaker of an estate where his brother-in-law comes to live with his young wife, Yelena. The local doctor, Astrov, comes to treat the brother-in-law's gout and falls in love with Yelena. He is a good physician, but his love for Yelena is hopeless, and he consoles himself with alcohol. Like many of Chekhov's doctors, he has become disillusioned and alienated.

Coburn, D.L. 1977. *The Gin Game.* New York: French.

This prize winning tragicomedy takes place on the back porch of a charity nursing home where two patients, Fonsia and Weller, play gin rummy and talk about their lives. Both comment on the problems of trying to live in such a place, where the staff steal things, the food makes people sick, most patients are drugged and strapped in their wheelchairs. Both deny some truths about themselves that gradually emerge and the gin game gets more and more serious, Fonsia keeps winning without trying, and Weller gets furious.

Edson, Margaret. 1999. *Wit.* New York: Faber and Faber.

Winner of the Pulitzer Prize, this play opens with Vivian Bearing, a scholar of Donne's Holy Sonnets, being diagnosed with terminal ovarian cancer. She agrees to become a research subject, and tackles her full-dose chemotherapy with the same toughness and discipline she brought to her scholarship. Her doctors see her as research subject rather than a vulnerable patient; they have a very remote bedside manner. Vivian learns that she does want some compassion, some human sympathy, which Susie, her nurse, does give her. The play raises important issues about death and dying and about the complex mix of research and patient care.

Ibsen, Henrik. 1951 (1882). *An Enemy of the People.* New York: Viking Press.

When a scientist becomes a "whistle blower," warning of serious danger to public health in contaminated water supply, he discovers he is detested rather than thanked. Several vested interests make money on the system the way it is. They have the power to make him an outcast by turning the majority against him. The dynamic tension lies between an individual who knows he has the truth and the great majority that is wrong. In a democratic society, should the majority always rule?

Kopit, Arthur. 1978. *Wings.* New York: Hill and Wang.

This play opens inside the mind of a woman suffering a stroke, with confusions, disconnections, fragmented pieces of language and gibberish. At the same time, the caregivers are speaking normal language, though it sounds like nonsense to her. Later, in therapy, she hears a recording of herself and realizes she is speaking nonsense (though in her head she makes sense to herself). As she gradually improves through therapy, she connects again to her history, her identity.

Kushner, Tony. 1993 and 1994. *Angels in America. Part One: Millennium Approaches; Part Two: Perestroika.* New York: Theater Communication Group.

These plays both won Pulitzer Prizes. Grounded in American politics and its struggles with racism, anti-Semitism, homophobia, sexism, the play follows two men suffering with AIDS. One, a fictional version of the McCarthy lawyer Roy Cohn, denies he has the disease because he has power and influence (which, he says, gay men cannot have). The second sick man, Prior, has been selected by an Angel to be the next Prophet. Angel crashes through the ceiling at the end of Part One, and the audience has no choice but to accept this magical intrusion in a realistic play. Characters have to let go of their past and keep going even when they are suffering.

Marlowe, Christopher. 1959 (1588). *Doctor Faustus.* New York: Washington Square Press.

This classic play explores the timeless theme of a scholar wanting to know everything, to go beyond human boundaries, to have unlimited power because of that knowledge. So ambitious and prideful is Faustus that he is willing to sell his soul to the devil to gain that knowledge. Not only can he understand how the universe works; he can also call up Helen of Troy for his intellectual and sensual delight. The cost of this unlimited knowledge: Faustus is forever damned. A chorus warns at the end of the play that wise people will not try to "practice more than heavenly power permits."

McPherson, Scott. 1992. *Marvin's Room.* New York: Penguin: Plume.

Bessie, who has been caring for her invalid aunt and her father who is helpless after suffering a stroke, discovers she has leukemia. Bessie's sister, Lee, who has been out-of-touch for years, arrives with her two sons in the hopes that one of them might be a bone-marrow match for Bessie. Lee cannot stand the idea of devoting her life to caring for helpless aging relatives. She has plenty of trouble already trying to be a mother to her two sons, particularly Hank who has been committed to a mental hospital because he burned down the family home. While Bessie will die of leukemia, both Hank and Lee learn to care for each other and for the family.

Miller, Arthur. 1949. *Death of a Salesman.* New York: Viking Penguin.

Willy Loman, who used to have a somewhat successful career as a salesman, now finds himself depressed, without prospects, getting older and out-of-step with his contemporaries. He has lived on his dreams of making it, and has instilled the same kind of inflated assumptions in his son, Biff, who was once a high school football hero but is now a failure. Biff recognizes that his father has blown him full of hot air and that he's not a leader. Willy cannot take the deflation and commits suicide.

Molière, 1959 (c. 1666). *The Doctor in Spite of Himself.* New York: Viking.

This seventeenth century satire explains that even a woodcutter can set himself up as a physician and can practice medicine as effectively (or more so) than the trained professionals. The fake Latin jargon that the woodcutter spouts persuades the gullible patients that he knows what he is doing, and through a series of fortuitous events, he does manage to find out why the master's daughter has stopped talking. He then concludes that he likes this doctoring profession more than woodcutting and will probably make a career of it.

Nichols, Peter. 1967. *Joe Egg.* New York: Grove Press.

Joe Egg is a severely handicapped child, unable to talk or do anything for herself. Her parents, Bri and Sheila, make up personalities for her and invent little plays about all the reasons why their only child is a vegetable. The constant attention they must give Joe Egg means they cannot tend to each other's needs. Bri gets so desperate he actually tries to kill his child. In the end, the marriage cannot survive the relentless pressure of caregiving.

Pomerance, Bernard. 1979. *Elephant Man.* New York: Grove Press.

Severely deformed John Merrick is saved from being exhibited in a freak show by Dr. Treves, who admits him to his London hospital as a permanent patient. There Merrick becomes a favorite of the aristocracy, still on exhibit but to a different class. Based on the life of the real John Merrick, this play shows how the severely deformed can never be "normalized" even by those working hard to see past the deformity to the real person inside.

O' Neill, Eugene. 1956. *Long Day's Journey Into Night.* New Haven: Yale University Press.

This autobiographical play was written in 1941 but never produced until after O'Neill's death. The mother, Mary Tyrone, is a drug addict; the actor/father, James, is an alcoholic; the youngest brother, Edmund, is sick with tuberculosis; older brother, Jamie, who represents O'Neill, shows the marks of his own dissipation and cynicism. They struggle together with Mary's relapse into drugs, with the diagnosis of Edmund's TB, and James' refusal to spend money to send him to a private sanitarium.

Shaffer, Peter. 1975. *Equus.* New York: Avon Books.

A teenage boy has blinded several horses with a hoof pick. He comes under the care of the psychiatrist, Dysart, who gradually discovers that boy has mixed religion, sex, and horses into an orgiastic worship of his personal god, Equus. While Dysart knows he can help the boy, he envies the passion in the boy's worship and is reluctant to make him "normal," because that means taking away his worship. Without worship you shrink.

Shaw, George Bernard. 1946 (1908). *The Doctor's Dilemma.* New York: Penguin.

Four doctors gather in honor of their friend, Ridgeon, a research doctor who has his own theory of disease. A young Mrs. Dubechat asks Ridgeon to cure her husband of consumption. Ridgeon has only a limited amount of his special medicine, so he cannot treat all who come to him. Instead of curing the dishonest Mr. Dubechat, Ridgeon treats one of the doctors who also has consumption. Dubechat dies, which is convenient, since Ridgeon has fallen in love with Mrs. Dubechat. Shaw prefaced this play with an 88 page essay about medicine in England.

Shakespeare, William. 1948 (1606). *King Lear.* New York: Harcourt Brace Jovanovich.

The greatest of Shakespeare's tragedies, this play opens with the aged king giving up his kingdom, dividing it among his three daughters. Foolishly and willfully, he makes this a test of his daughters' love for him—whoever says she loves him the most will get the most land. Two older daughters lie but the youngest is honest. Lear reacts furiously, driving her out of the country. The demented old man finds himself unwanted and cast out by his older daughters. In the end the youngest daughter is murdered; Lear carries her in his arms in a heartbreaking final scene.

Sophocles. Oedipus at Colonus. 1982 (401 B.C.E.). New York: Viking Press.

The third play in the Theban trilogy (*Antigone* and *Oedipus the King* being the first two), the blind Oedipus, exiled from Thebes, goes to his birthplace near Athens. He is filthy, old, withered, his wild white hair flying in the wind. The prophesy many years before not only said Oedipus would kill his father and marry his mother; it also said he would die at Colonus and be a blessing to the Athenians who let him live among them. He manages to thwart Creon, who tries to trick him back to Thebes; he is reunited with his daughters/sisters; and dies/disappears at the prophesied secret spot.

Steinbeck, John. 1937. *Of Mice and Men.* New York: Viking Press.

Lennie, a large, very strong mentally retarded man, is buddies with George, who watches over Lennie as they move from one farm job to another during the depression. Both men long for a home—a little place where they could live off the fat of the land—but they have no money and have to move with the work. Lennie does not realize his own strength and often gets into trouble by misusing it. He accidentally kills a mouse and then a puppy and finally the wife of one of the farm bosses. To keep him from a life in prison, George shoots him in the head.

Vonnegut, Kurt. 1974. "Fortitude" in *Wampeters, Foma and Granfalloons.* New York: Dell.

Dr. Frankenstein has one patient: Sylvia Lovejoy. He has gradually replaced all her organs and limbs with mechanical devices that he runs from a large console. She is now just a head on top of a box, with lots of wires and tubes connecting her to the console. He also controls her moods, wakes her up, puts her to sleep. Sylvia raises questions about the quality of her life, and even tries to shoot herself, but her prosthetic arms have been constructed so as to prevent her from doing that. So she shoots Dr. Frankenstein instead. In the last scene both his head and hers are together, and they share all the artificial organs.

Williams, Tennessee. 1955. *Cat on a Hot Tin Roof.* New York: New Directions.

This tense drama opens with Big Daddy being brought back home from a hospital where he was diagnosed with terminal cancer. The doctor tells the family, but not Big Daddy. The two sons and their wives begin competing for his attention (and inheritance). Maggie tries to seduce her alcoholic husband Brick, who drowns his guilt about the death of his homosexual friend. Brick and Big Daddy drink and argue, each claiming the other isn't facing the truth ("a powerful odor of mendacity"). In the end Big Daddy makes Brick face his responsibility in his friend's death, Brick tells Big Daddy he's dying, and Maggie continues her seduction.

Short Stories

Borges, Jorge Luis. 1969. "The Immortals" in *The Aleph and Other Stories.* New York: Dutton.

The protagonist visits his gerontologist and learns that his doctor has a method of making people immortal. The doctor shows him a room where several heads are sitting on boxes with the rest of their bodies replaced by machinery. The narrator is terrified, changes his name, and moves away. This story stimulates interesting discussions about immortality research.

Canin, Ethan. 1988. "We Are Nighttime Travelers" in *The Emperor of the Air and Other Stories.* Boston: Houghton Mifflin.

An elderly, ill couple have been living with each other for a long time without any real physical or emotional contact. Frank, who spends most of his days at the aquarium reading poetry, knows he is near death. Francine finds scraps of romantic poems on the windowsills and fears an intruder. One night Frank, who has been leaving the romantic notes for his wife, takes Francine on a walk in the crystal snow and then kisses her in a rekindling of their love.

Doyle, Arthur Conan. 1893. *Round the Red Lamp.* New York: Doubleday.

This collection contains seventeen stories all dealing with physicians. Both Holmes and Dr. Watson use medical methods of diagnosis to help them do their detective work. "The Doctors of Hoyland" is especially interesting in its dealing with sexism: a famous Dr. Smith, who moves into a town where Dr. Ripley has an established practice, turns out to be a woman. Dr. Ripley believes women cannot be doctors, that it is a biological and cultural impossibility. His belief changes when she treats his broken leg.

Forster, E.M. 1947. "Road to Colonus" in *Collected Tale of E.M. Forster.* New York: Knopf .

An aging Mr. Lucas and his unmarried daughter Ethel take a trip to Greece. At one place, he climbs into the hollow of a giant tree that has a spring bubbling out of it. In there he undergoes a kind of magical transformation and decides he will stay there the rest of his life. The family treats this behavior as demented, and forces him to go back to England. Later they learn that the old tree fell over the night they left, killing the people in the nearby inn. The story parallels Oedipus at Colonus, except that Mr. Lucas did not get to die in his sacred place.

Gaines, Ernest. 1963. "The Sky is Gray" in *Bloodline.* New York: Doubleday.

A child in rural Louisiana develops a toothache; he goes with his mother into Baton Rouge to find a dentist. The family is scrambling to survive, partly because the father is away in the army. The boy endures several racist experiences, from where he can sit on the bus to where he can eat in town, even to where he can get out of the freezing wind. His mother keeps urging him to be a man, well before most boys could consider such responsibility. The mother and son get some food and shelter from an unusual white couple who make arrangements for a different dentist to remove the boy's tooth.

Gilman, Charlotte Perkins. 1989 (1892). *The Yellow Wallpaper and Other Writings.* New York: Bantam.

This classic story in the literature and medicine canon is narrated by a young mother with a post-partum depression. Her patronizing physician–husband treats her like a child and forces her to take the Weir Mitchell "rest cure" and avoid all stimulation, even from books and writing. The narrator cannot stand the wallpaper in the room where she is kept, and gradually goes insane as she rips it off the wall. By the end she is crawling around the room through wallpaper scraps.

Hawthorne, Nathaniel. 1987. "Dr. Heidegger's Experiment" (1837); "The Birthmark" (1844); Rappaccini's Daughter" (1844) in *Selected Tales and Sketches.* New York: Penguin.

These three famous stories are cautionary tales, warning about scientist-researchers crossing ethical lines in their experiments on people. "The Birthmark," used by Leon Kass to open the deliberations of the President's Council on Bioethics, portrays a husband obsessed with removing a tiny birthmark on his wife's face. In his effort to make her perfect, to remove her flaw, he kills her. In Dr. Heidegger's experiment, he gives a "fountain of youth" elixir to four elderly friends who regress into their romantic youth, just for a few minutes. Then they age again, and feel worse for the contrasting experience.

Hemingway, Ernest. 1998. "Indian Camp" (1925); "Hills Like White Elephants" (1927); "God Rest You Merry, Gentlemen" (1925); "A Clean, Well-Lighted Place" (1926). *The Complete Short Stories of Ernest Hemingway.* New York: Charles Scribner.

"Indian Camp" is narrated by a boy who goes with his physician-father to an Indian camp where a woman is having trouble delivering her baby. The hubristic father performs a Caesarian with a jack-knife and fishing line without anesthesia; his pride get deflated when he realizes the woman's husband has slit his own throat in his anguish for her—all this in front of the doctor's young son. In "Hills Like White Elephants" a young couple argues over whether or not she should get an abortion. She wants the baby; he wants his freedom. "God Rest You Merry, Gentlemen" is a horrifying story of a teenager, terrified by his sexual awakening and believing sex was sinful, who requests a castration and tries to amputate his penis. The doctors are callous and incompetent. In "A Clean, Well-Lighted Place," depressed old men face the nothingness of darkness, the meaninglessness of life, the sense that there is no God ("our nada who art in nada, nada be thy name"). They want to stay up all night in a clean, well-lighted place so the nothingness is not so threatening.

Joyce, James. 1947 (1914). *Dubliners.* New York: Viking Press.

The first three of these stories are narrated by children, exposed to death, pederasty, and their own emotional turbulence. Young adults in the next few stories are trapped by the paralysis of Ireland, itself still dominated by England and the Catholic Church. In "Eveline," although the sailor promises her love and freedom, she is unable psychologically to break free from caring for her dominating father. In "Counterparts" an alcoholic father blunders at work, uses up his money drinking, and comes home to beat his son. In the most famous of this collection, "The Dead," Gabriel moves from being full of himself to understanding that he really does not know his wife very well nor has he ever really been in love. He also realizes that his maiden aunts will die soon, and, like the snow falling all over Ireland, he is connected to all humanity, the living and the dead.

Lawrence, D. H. "Rocking Horse Winner"; "The Blind Man"; "The Prussian Officer" in *Selected Short Stories.* Cambridge, England: Cambridge University Press 1999.

Lawrence is best known for his penetrating psychological studies. In "Rocking Horse Winner," a boy is convinced that his mother would be happy if she had more money, so he frantically rides his rocking horse until he has a vision of the horse that will win the race. Then the gardener places the bet for him, and he wins every time; but his mother is never satisfied. The boy obsessively rocks himself to death. In "The Prussian Officer," a young peasant soldier engaged to be married becomes the unwilling victim of his officer's homosexual advances and kills him, with repercussions that lead to his own death.

Malamud, Bernard. 1997. "The Jewbird"; "Idiots First"; "In Retirement" in *Complete Stories.* New York: Robert Giroux.

Malamud treats difficult human problems with sensitivity and, sometimes, a little magic realism. In "Idiot's First," a desperate dying father tries to get his mentally retarded son on to a train. A devilish character, Ginzburg, appears in numerous locations trying to bring death before the father can get his son safely on his way. In "The Jewbird" an old, smelly talking crow arrives at a New York family's apartment and stays for a year, to the fury of the father and the benefit of the son. This fable-like story suggests problems aging relatives and their families have trying to live together. "In Retirement" describes a retired, widowed physician who develops a crush on a young woman in his apartment building and talks himself into believing they might have a relationship. She rejects him by throwing his torn up letter at him.

O'Connor, Flannery. 1971. *The Complete Stories.* New York: Farrar, Straus & Giroux.

Most of O'Connor's stories deal with "grotesques"—people who are physically and/or psychologically distorted—as they search for some kind of meaning in their lives. In "Good Country People," for instance, a large one-legged woman named Hulga thinks she is seducing an innocent Bible salesman, but he turns out to have pornographic cards and condoms in his hollow Bible, and he gleefully steals her glasses and her wooden leg. In "Revelation," Mrs. Turpin sits in a doctor's waiting room talking in a prejudiced, self-righteous way about "poor white trash, niggers," and others. A young woman with acne throws a book at her, tries to strangle her, and tells her to "go back to hell where you belong, you old warthog." When Mrs. Turpin demands of God what he means, she has a vision of poor white trash and blacks marching into heaven ahead of her.

Olsen, Tillie. 1961. "Tell Me a Riddle" in *Tell Me a Riddle.* New York: Dell.

An elderly woman develops cancer just at the time that she finally has raised all her children and has her house to herself. Her husband wants to move into a retirement village, but his wife just wants the peace and rhythm of home. They fight furiously. No one tells her she has cancer; instead they take her on one trip after another to see her children and grandchildren. She gets much sicker and is cared for in an apartment far from home by a grandchild who brings compassion and some real communication. The old couple holds hands in their sleep—a suggestion of reconciliation as she dies.

Ovid. 1955 (c. 15 b.c.e.). *Metamorphoses.* New York: Penguin.

Ovid's retelling of Greek and Roman myths combines such compelling narrative with beautiful writing that it has become a source for writers ever since. Beginning with the creation of the world and continuing to his own time, Ovid's stories tell of changes and transformations, often with great psychological suggestiveness. For instance, when the sculptor Pygmalion falls in love with his own statue, the goddess Venus changes it into a real woman. When Narcissus falls in love with his own reflection in the pool, he falls into it and drowns, transforming into the flower; and the poor nymph Echo, who loved Narcissus, fades away until nothing is left of her but her voice.

Poe, Edgar A. 1978.*Collected Works of Edgar Allen Poe.* Cambridge, MA: Harvard University Press.

Famous for his nightmare stories in gothic settings, Poe presents distorted characters in desperate situations. One of his most famous works, "The Tell Tale Heart," portrays a man so obsessed with the blind "evil" eye of his old neighbor that he kills him and buries him beneath the floorboards. When the police arrive to question him, the narrator hallucinates that he is hearing the old man's heart beating beneath the floor. Finally it gets so loud, he cannot stand it, and confesses. In "Hop-Frog," the dwarf kept as a slave to entertain the king becomes so outraged at the king's brutal behavior that he concocts a way to burn him alive.

Selzer, Richard. 1998. *The Doctor Stories.* New York: Picador USA.

Selzer is one of the major physician–writers of the twentieth century. This collection brings together twenty-five of his stories, which have become part of the canon of literature and medicine. They include such classics as "Brute," "Imelda," "Mercy," and "Tube Feeding." Often the physician makes some kind of misjudgment or acts in a way he later regrets. In "Brute" an exhausted doctor, trying to control a drunk, unruly patient, sutures his earlobes to the bed so he has to hold still for stitches. Selzer's stories teach humility as well as respect for humanity.

Stevenson, Robert Louis. 1993 (1886). "The Strange Case of Dr. Jekyll and Mr. Hyde," in *Complete Stories,* Vol. 2. Edinburgh: Mainstream.

The classic story of the split personality or double presents Dr. Jekyll, who gives up medical practice for experimental research, and his alter-ego, Mr. Hyde, who is an evil man released from Dr. Jekyll when he has taken one of the research potions. Hyde kills a man, and Jekyll realizes that the only way he can prevent Hyde from killing others is to commit suicide, killing both personalities at the same time.

Walker, Alice. 1967. *In Love and Trouble.* Orlando, FL: Harcourt Brace Jovanovich.

This collection contains several powerful African-American tales, among them three stories often used in medical humanities: "To Hell with Dying," "Everyday Use," and "Strong Horse Tea." They present a view of health care that has nothing to do with hospitals or conventional medicine. Access to white people's doctors is not an option in "Strong Horse Tea." A wise old black woman knows the baby is dying, and sends the mother out to collect horse urine (not really for the baby, but to keep the mother occupied while the baby dies).

Williams, William Carlos. 1984. *The Doctor Stories.* New York: New Directions.

This is the most used collection of stories in the literature and medicine canon. Williams touches on many important themes: the addicted doctor in "Old Doc Rivers"; the physician who loses his temper and manhandles a terrified child in "The Use of Force"; the fatal misdiagnosis of a beloved child's infection in "Jean Beicke"; the simple reward of a sniff of snuff in "Ancient Gentility"; a close and respectful relationship with a mother in labor in "A Night in June"; a delight in helping an independent teenager clear up her acne in "The Girl with a Pimply Face." Williams' sensitivity to language and his great compassion for and interest in his fellow human beings enriches all his work.

Selected Books of Poetry

Selected individual poems of many major poets appear in the anthologies listed under Selected Anthologies of Literature and Medicine.

Abse, Dannie. 1977. *Collected Poems: 1948–1976.* London: Hutchinson.

Welsh physician–poet Dannie Abse's work often explores the world of medicine with the acute sensibility of one trained to observe in detail. Among his poems often used in medical humanities classes are "X-Ray," "Pathology of Colors," "Case History," "Carnal Knowledge."

Campo, Raphael. 1996. *What the Body Told.* Durham, NC: Duke University Press.

Physician-poet Campo devotes a section of this collection to poems about his clinical practice, often the horrors he faces: a twelve-year-old pregnant by her father; a three-year-old who has swallowed cocaine; a homeless man whose eyelids have frozen shut. Yet he meets these cases with compassion and a recognition of the common humanity he shares with them.

Coulehan, Jack. *The Knitted Glove,* 1991; *First Photographs of Heaven,*1994; *Medicine Stone: Poems,* 2002. Troy, ME: Nightshade Press.

Physician–poet Jack Coulehan writes sensitively and compassionately about his patients and their cultural contexts, whether he is treating Appalachian children for worms or seeking healing in a Native American dance. Coulehan also has several poems about Chekhov, the master physician-writer who set the standard for stories and drama.

Davis, Cortney. 1994. *The Body Flute.* East Hampton, MA: Adastra. 1997. *Details of Flesh.* Corvallis, OR: Calyx.

Nurse and writer Cortney Davis is talented both in poetry and prose. In these two collections of poems, she gives vivid, sensual descriptions of nursing experiences, often identifying with her patients while enduring the mechanized hospital system. She has a special sensitivity to women and their illnesses.

Getsi, Lucia Cordell. 1992. *Intensive Care.* Minneapolis, MN: New Rivers Press.

As the poet's daughter, suffering from Guillain-Barre Syndrome, fights for her life, the mother suffers with her and surrounds her with love and support. These tough poems assert control over the chaos of illness. Getsi also notices the conditions of other patients. Many of the children with her daughter in the rehabilitation institute never see their mothers (who are dead, or abusive, or indifferent).

Gunn, Thom. 1992. *The Man with Night Sweats.* New York: Farrar Straus & Giroux.

These poems detail the many deaths from AIDS and the struggles of caregivers to try to be there through the dying process. Through the ravages of the plague, Gunn finds affirmation in love and compassion.

Hacker, Marilyn. 1994. *Winter Numbers.* New York: Norton.

A masterful sonnet sequence entitled "Cancer Winter" describes the author's experience with breast cancer, mastectomy, and return to health, but with concerns about disfigurement and its effect on her lover. She also compares her personal experience with universal tendencies: "My self-betraying body needs to grieve / at how hatreds metastasize."

Hall, Donald. 1998. *Without.* Boston: Houghton Mifflin.

The first half of this beautiful collection of poems traces the dying of Jane Kenyon, Hall's wife, from leukemia. At the center of the book, "Without" expresses his great loss at her death. The last half finds him struggling to deal with his grief, writing poem-letters to her with "news" about the family dog, Gus, and their friends' lives.

Lynch, Thomas. 1998. *Still Life in Milford.* New York: Norton.

Undertaker-poet Thomas Lynch has an Irishman's gift for storytelling and a tight control over his poetry. These poems range from laments to love poems. The are portraits of his home town, small enough that people know each other and suffer as a community when someone dies. As the funeral director in town, Lynch tends to the grieving survivors and keeps secrets the dead would probably not want revealed.

Olds, Sharon. 1992. *The Father.* New York: Alfred A. Knopf

These tough poems describe the poet sitting at her father's bedside as he is dying of cancer, dealing with disgusting smells, sounds and sights as his body disintegrates. But the poet's main struggle is with her own negative feelings about him: an alcoholic, divorced from her mother, not a warm or caring father.

Owen, Wilfred. 1986. *The Poems of Wilfred Owen,* ed. Jon Stallworthy. W. W. Norton.

The most important English poet of the First World War, Owen told the truth about the horror of war and its toll on the bodies and minds of young men. Many of his poems are classics, including "Arms and the Boy," "Dulce et Decorum Est," "Disabled," "Futility," "Mental Cases." Benjamin Britten selected Owen's poetry for his "War Requiem."

Shafer, Audrey. 2001. *Sleep Talker: Poems by a Doctor/Mother.* Philadelphia, PA: Xlibris Corporation.

Physician and mother and poet, Audrey Shafer writes about how she balances and interweaves her medical career, her marriage and family, her writing. She explores the emotional experiences in all her contexts, sees her home life through the perspective of medicine and her medical career through the perspective of motherhood.

Stone, John. 1972. *The Smell of Matches.* Baton Rouge: Louisiana State University Press. 1980. *In All This Rain.* Baton Rouge: Louisiana State University Press. 1985. *Renaming the Streets.* Baton Rouge: Louisiana State University Press. 1998. *Where Water Begins: New Poems and Prose.* Baton Rouge: Louisiana State University Press.

Cardiologist and poet, John Stone set the standard for excellent poetry by doctor–poets. Many of his poems in these collections portray his experiences with patients, from his first heart surgery patient to a young teenager in labor. One of his most touching poems treat the difficult situation of having to tell family members a loved one has died. In his later work, he examines his own grieving process over the untimely death of his wife, including his sleep disorder.

Selected Anthologies of Literature and Medicine

Belli, Angela, and Coulehan, Jack, eds. 1998. *Blood and Bone: Poems by Physicians.* Iowa City: University of Iowa Press.

This anthology collects one hundred poems of contemporary physician–writers about their work in medicine. Many of today's most notable authors are included: John Stone, Jack Coulehan, Raphael Campo, Audrey Shafer, Marc Straus. The editors introduce the collection by discussing the connections between medicine and poetry: both require the ability to see and pay attention; the medical encounter is "the poetic act of…standing in the presence of suffering."

Chekhov, Anton. 2003. *Chekhov's Doctors,* ed. Jack Coulehan. Kent, OH: Kent State University Press.

Chekhov was a physician who made most of his living by writing. Of his hundreds of short stories, many focus on physicians. This collection gathers several excellent works, among them: "A Doctor's Visit," where a young doctor learns to empathize with his patient; "The Grasshopper," in which a doctor's devotion to science and his practice makes him a dull husband for his romantic wife who finds a lover; "Enemies," in which a doctor's own son has just died but he is called out on a medical emergency that turns out to be a hoax.

Davis, Cortney, and Schaefer, Judy, eds. 1995. *Between the Heartbeats: Poetry and Prose by Nurses.* Iowa City: University of Iowa Press.

This is the first major anthology devoted to the works of nurses who are also writers. The registered nurses in this anthology write honestly and thoughtfully about their experiences caring for patients. The collection helps to show that nurses' perspectives and understandings about health care are different from the physicians' and that those differences ought to be heard. Most, but not all, the nurses are women.

Donley, Carol, and Buckley, Sheryl, eds. 1996. *The Tyranny of the Normal: An Anthology.* Kent, OH: Kent State University Press.

This anthology collects stories and poems about physical disability. It opens with several critical essays that provide some theoretical approaches. The title comes from an essay by the literary critic, Leslie Fiedler, who finds people either rejecting disfigured "others" or trying to normalize them. "The Quasimodo Complex" is defined as a disfigured person's sense of his "otherness" through the reactions of people to him. The fictional sections of this collection focus on dwarfism, eating disorders, and physical disabilities caused by birth defects and accidents.

Donley, Carol, and Kohn, Martin, eds. 2002. *Recognitions: Doctors and Their Stories.* Kent, OH: Kent State University Press.

This anthology collects new works by physician–writers who have come to realize the struggle—sometimes tragic, sometimes triumphant, sometimes seemingly trivial—that is part of the calling to heal. Most of the essays and stories portray rewarding or educational experiences in the physician's life and work. The last piece in the collection is a parable by Richard Selzer. In it a dying patient lays hands on the physician in order to ease the doctor's suffering.

Haddad, Amy and Brown, K. H., eds. 1999. *The Arduous Touch: Women's Voices in Health Care.* West Lafayette, IN: Purdue University Press.

Contributors to this anthology are nurses, physicians, therapists, emergency room technologists, and many other women whose careers are in health care. Their essays, short stories, and poems are grouped into three categories: Power and Powerlessness, Vulnerability and Voice, Connection and Disconnection. Many also focus on issues in health care training when the women encounter experiences for the first time.

Kohn, Martin, Donley, Carol and Wear, Delese, eds. 1992. *Literature and Aging: An Anthology.* Kent, OH: Kent State University Press.

The editors have collected from well-known writers many poems, plays, and stories about aging, and have arranged them into four groups: aging and identity, aging and love, aging and the family, and aging and the community. The short plays include works by Edward Albee, Kurt Vonnegut, Harold Pinter, and Lady Gregory. Many major short story writers are included, such as Ernest Hemingway, Saul Bellow, Flannery O'Connor, Eudora Welty. Poets include Robert Frost, W.B. Yeats, Alice Walker, Anne Sexton.

Mukand, Jon, ed. 1994. *Articulations: The Body and Illness in Poetry.* Iowa City, IA: University of Iowa Press. [New edition of the original collection entitled *Sutured Words.*]

This seminal collection of twentieth-century American poetry gathers hundreds of poems on health care subjects, ranging from hospital experiences, death and dying experiences, views of physicians and nurses, views of families of ill patients, women's experiences, views of those with disabilities or mental illnesses, and social issues that impact health care. The anthology includes major writers, such as Anne Sexton, Sharon Olds, James Dickey, Langston Hughes, Lucille Clifton, Denise Levertov.

Reynolds, Richard, and Stone, John, eds. 2001. *On Doctoring: Stories, Poems and Essays,* 3rd edition. New York: Simon and Schuster.

This well-respected anthology is given to medical school students all across the country. It contains many of the "classic" stories and poems of the literature and medicine canon: poems from John Donne and John Keats to Raphael Campo and Jane Kenyon, stories from Anton Chekhov and William Carlos Williams to David Hilfiker and Ethan Canin. Each author is given a brief introduction.

Secundy, Marian Gray, ed. 1992. *Trials, Tribulations, and Celebrations: African-American Perspectives of Health, Aging and Loss.* Yarmouth, ME: Intercultural Press.

This anthology collects African-American poems, stories, and essays that describe the health care problems and experiences of black people, whose voices often are unheard or silenced. Included is Zora Neale Hurston's account of being forced into a utility closet in a white doctor's office so she would not be seen by white patients. The collection contains works by such well-known writers as Maya Angelou, Toni Cade Bambara, Gwendolyn Brooks, Langston Hughes, and Alice Walker.

Walker, Sue B., and Roffman, Rosaly D., eds. 1992. *Life on the Line: Selections on Words and Healing.* Mobile, AL: Negative Capability Press.

This huge collection of poems, stories, and essays is divided into sections that deal with Abuse, Death and Dying, Illness, Relationship, Memory, Ritual and Remedies, and an especially interesting group called "White Flags from the Silent Camp," a title taken from a Rita Dove poem.

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See the Literature, Arts, and Medicine Database at <http://endeavor.med.nyu.edu/lit-med/>.

FILM/VIDEO

DOCUMENTARIES

***Best Boy.* 1979. Ifex Films.**

Mentally retarded man learns to make adjustments and move from his elderly parents' care to a sheltered home.

***Complaints of a Dutiful Daughter.* 1994. Women Make Movies.**

Funny and compassionate story of Deborah Hoffman's mother suffering from Alzheimer's and eventually moving into a nursing home.

***Dax's Case.* 1985. Concern for Dying.**

Severely burned man, who is blind and has lost most of his hands, asks to be allowed to die but his request is not granted. A classic conflict between patient autonomy and physician beneficence.

***Death on Request.* 1994. Fanlight Productions.**

Euthanasia in the Netherlands. Man dying of ALS asks for euthanasia; his doctor comes to his home and complies with his wish.

***On Our Own Terms.* 2000. Public Affairs Television, Inc.**

"Moyers on Dying in America"; four 90-minute parts. Efforts of patients and families to control pain and make end-of-life experiences better for all involved.

***Strangers in Good Company.* 1990. Touchstone.**

Six elderly women have to find ways to survive when their bus breaks down in the wilderness. They learn from each other and help each other doing everything from catching frogs to making fish nets out of panty hose.

***When Billy Broke His Head.* 1994. Independent Television Service.**

Brain damaged Billy tries hard to support himself, but like many others with disabilities, he finds himself discriminated against by the government and by institutions of culture. Good portraits of several politically active disabled people.

DRAMAS

***Awakenings.* 1990. Columbia Pictures.**

Based on a story by Oliver Sacks, this film portrays a doctor using L-Dopa to awaken catatonic patients who were victims of encephalitis lethargica. Unfortunately his successes could not be permanent.

***A Beautiful Mind.* 2001. Universal Pictures.**

A biography of Nobel Prize winning genius mathematician and his battle with schizophrenia, medication seeming both to control his illness and dilute his brilliance.

***Born on the Fourth of July.* 1989. MCA Universal.**

The second of the Oliver Stone's Vietnam trilogy, this film follows an idealistic young soldier who comes home a paraplegic and depressed over his accidental killing of a fellow soldier.

***Coming Home.* 1978. MGM United Artists.**

Marine sergeant comes back from Vietnam a paraplegic and tried to find ways to reconstruct his life. Inside the VA hospital he meets an old high school friend whose husband is serving overseas.

***The Doctor.* 1991. Touchstone Pictures.**

Aggressive and remote surgeon becomes a patient himself, learning the hard way how a patient deserves some compassion and understanding.

***The English Patient.* 1996. Miramax.**

A good film of the award-winning novel (see annotation under Ondaatje, Michael—Novels).

***The Gin Game.* 1984. Nederlander.**

Jessica Tandy and Hume Cronyn play two combative residents of a nursing home (see annotation under Coburn, D.L.—Dramas).

***Girl, Interrupted.* 1999. Columbia Pictures.**

An autobiographical story about a suicidal teenage girl admitted to McLean Hospital for the mentally ill in Boston. Also graphic portraits of other patients with eating disorders, depressions, and psychoses.

Lorenzo's Oil. **1992. MCA Home Video.**

Parents take over the care of their child afflicted with a rare illness, dismissing conventional medical treatments and creating one of their own. The strains of caring for a critically ill child take their toll on the marriage.

Marvin's Room. **1996. Buena Vista Pictures.**

(See annotations under McPherson, Scott—Dramas).

'Night, Mother. **1987. MCA Home Video.**

A debate between a suicidal woman tired of her battle with chronic illness and her mother who tries unsuccessfully to persuade her to live.

One Flew Over the Cuckoo's Nest. **1997 (1975). 1997 Pioneer Entertainment.**

A satirical film protesting coercive psychiatric treatment, shock therapy, and lobotomy, this film portrays sick and well patients, the later in the mental ward as an escape from the law or responsibilities.

Ordinary People. **1998 (1980). Paramount Home Video.**

Family trying to deal with drowning death of one son, while his brother feels guilty about not being able to save him.

Rain Man. **1998 (1988). MGM Home Video.**

A man expecting a big inheritance finds it is left to a brother he did not know existed. He discovers his brother is an autistic savant. The two travel together in a journey that undoes many of the prejudices and self-centeredness of the healthy one.

Regeneration (Behind the Lines). **1998. Artisan Entertainment.**

A fine film of Pat Barker's historical fiction (see Barker, Pat—Novels).

What's Eating Gilbert Grape? **1993. Paramount Pictures.**

A six hundred pound mother relies on her teenage son to take care of the family, including his brother who is mentally handicapped.

Whose Life Is It, Anyway? **1981. United Artists.**

A sculptor becomes a quadriplegic because of an automobile accident. No longer able to use his hands creatively or to do anything for himself, he fights to be released from the hospital and taken off kidney dialysis so he can die.

Wit. **2001. HBO Home Video.**

(See annotation under Edson, Margaret—Drama).

CAROL DONLEY

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APPENDIX V

ACKNOWLEDGMENTS

Aging and the Aged: VI: Anti-Aging Interventions: Ethical and Social Issues

Support for the research reported in this entry comes from a research grant (1R01AGHG20916–01) from the National Institute on Aging and the National Human Genome Research Institute.

Biomedical Engineering

The author thanks Gerald M. Saidel of Case Western Reserve University's Biomedical Engineering Department for his contributions and comments on this article.

Death: I. Cultural Perspectives

Sections of this essay are based on Koenig and Davies (2003), by permission of the Institute of Medicine.

Deep Brain Stimulation

The author is indebted to my predecessor John C. Oakley who wrote "Electrical Stimulation of the Brain" for the 2nd edition of the *Encyclopedia of Bioethics.*

Embryo and Fetus: III. Embryonic Stem Cell Research

Work on this paper is roughly divided in two with John Harris taking responsibility for the section on ethical issues and Derek Morgan and Mary Ford for the one on legal and regulatory issues. Note that this paper draws on a number of previously published works, particularly Harris's "The Use of Human Embryonic Stem Cells in Research and Therapy" (a chapter in *A Companion to Genethics: Philosophy and the Genetic Revolution,* edited by Justine Burley and John Harris [Oxford: Basil Blackwell, 2002]) and Harris's "Stem Cells, Sex, and Procreation," an article to be published in *Cambridge Quarterly of Ethics.* Work on this paper was supported by a project grant from the European Commission for EUROSTEM under its "Quality of Life and Management of Living Resources" Programme, 2002.

Emotions

The author would like to thank Elisa Hurley for all her help in updating this article.

Fertility Control: II. Social and Ethical Issues

The author gratefully acknowledges contributions to an earlier edition of the *Encyclopedia* by Carole Joffe and Charles E. Curran.

Genetics and Human Behavior: I. Scientific and Research Issues

The author gratefully acknowledges the assistance of the National Science Foundation and NIH ELSI via a grant to AAAS-Hastings Center for support for his work in behavioral genetics.

Medical Ethics, History of Europe: Contemporary: IV. United Kingdom

With gratefully acknowledged advice from Richard Ashcroft and Kenneth Boyd.

Psychopharmacology

This work was supported, in part, by the National Institute of Mental Health grants MH49671, MH 43693, MH59101 and by the Department of Veterans Affairs.

Reproductive Technologies: III. Fertility Drugs

Table entitled "Summary of Drugs Used to Stimulate Ovulation" used with permission of the New York State Task Force on Life and the Law. Published originally in the report, *Assisted Reproductive Technologies, Analysis and Recommendations for Public Policy* (1998).

Smoking

Research assistance by Rana Khalil.

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